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Chapter 16. Future challenges

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Contents

Abstract

In this chapter we discuss some of the challenges facing the field of distributional cost-effectiveness analysis (DCEA). We cover four methodological challenges for researchers: (i) modelling complexities such as economies of scale, spillovers and behavioural responses, (ii) *ex post* DCEA based on distributions of realised outcomes rather than expected outcomes, (iii) cross-sectoral DCEA combining information about health and non-health dimensions of well-being, and (iv) fair shares DCEA based on distributing in proportion to strength of claim rather than maximising value. We also discuss the practical challenge of making DCEA more useful to decision makers.

Keywords: Complexity, cross-sectoral programmes, distributional cost-effectiveness analysis, *ex post* inequality, fair shares, value maximizing.

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1. Introduction

In this chapter we discuss some of the challenges facing the field of distributional cost-effectiveness analysis (DCEA). Some are scientific challenges to do with simulating distributions in more detailed and credible ways, some are ethics-related challenges to do with evaluating distributions in ways that address a broader range of equity concerns, and others are practical challenges to do with facilitating more widespread and systematic use of DCEA in decision making and then learning from this experience where future methods and empirical work may best be done. We focus on describing the challenges rather than trying to address them – that task we leave to the reader.

DCEA is more data demanding than standard CEA. In particular, there are usually too few data to populate the various steps on the "staircase of inequality" (see chapter 8) and to estimate the distribution of health opportunity costs (see chapter 9). However, the routine data challenges facing DCEA analysts have already been extensively discussed in the relevant methods chapters, so this chapter focuses on special challenges relating to the development of new methods.

We cover four methodological challenges for ongoing research: (i) complex modelling, (ii) *ex post* DCEA, (iii) cross-sectoral DCEA, and (iv) fair shares. The first of these challenges is primarily scientific, the fourth is primarily ethics-related, and the middle two involve a mix of scientific and ethics-related issues. We also discuss the practical challenge of making DCEA more useful to decision makers. We first summarise the challenges in broad terms below, before describing them in more detail in the rest of the chapter together with references to further readings.

Complex modelling

Some health technologies and programmes are complex by virtue of their many components, which can interact differently in different contexts and so generate different distributional consequences. Inadequacies in the available data, together with shortages of research skills and time, mean that important complexities currently often have to be left out – for example, economies of scale and scope, spillovers, behavioural responses, multiple morbidity and disadvantage, and general equilibrium effects.

We discuss the challenges of complex modelling under three broad health policy topic headings, each of which raises a distinctive set of complexities: system-level health policies (e.g. economies of scale), infectious disease control (e.g. infection spillover effects) and non-communicable disease prevention (e.g. behavioural responses). These are all important challenges for health economic evaluation in general, as well as DCEA in particular, and addressing them will facilitate the more detailed and accurate modelling of distributional consequences needed to tackle some of the more specific DCEA challenges listed below.

Ex post DCEA

The realized lifetime health of an individual or group – i.e. the number of HALYs they will actually experience from birth until death – is uncertain. Various lifetime health outcomes are possible *ex ante* (i.e. before death), only one of which is ultimately realized *ex post* (i.e. after death). Currently, the usual approach to equity analysis in DCEA and the wider health services research literature is to focus on expected lifetime health – i.e. the probability weighted mean of all the possible outcomes. This is also the approach adopted in this handbook and is known as the *ex ante* approach to evaluating distributions. Another approach, however, would be to look at the *ex post* lifetime health outcomes. Rather than focusing on a single distribution of expected health outcomes, one could instead simulate and evaluate various possible distributions of *ex post* lifetime health and their probabilities of

occurring. The *ex ante* and *ex post* approaches to evaluating distributions can yield different conclusions about equity, as we illustrate later with a simple example.

Many distinguished experts in economics and ethics have examined this issue from a theoretical perspective and concluded that *ex post* evaluation of distributions is more coherent than *ex ante* evaluation. Addressing this disconnect between theory and practice by developing practical ways of conducting *ex post* DCEA is an important future methodological challenge, raising technical and data availability challenges as well as ethical challenges.

Cross-sectoral DCEA

As we have seen, DCEA currently focuses on (expected) distributions of health-related outcomes, including distributions of health itself, health service delivery and financial protection from the cost of health services. It can evaluate distributions of these three outcomes separately but cannot integrate this into an overall assessment of distributional equity. Nor can it handle distributions of other non-health outcomes – for example, consumption, education, employment, adverse experiences, stigma, life satisfaction. These limitations are usually unimportant when the aim is to inform health sector decision making designed from a health sector perspective. They are more problematic, however, if the aim is to inform decision-making about cross-sectoral programmes which are designed to improve both health and non-health outcomes and have opportunity costs that fall on both health and non-health budgets, or if there are concerns about the consequences of health sector decisions for non-health outcomes.

Various approaches to evaluating multidimensional outcome distributions are being developed. These include disaggregate approaches that keep health and non-health outcomes separate – such as the presentation of separate quantitative and qualitative information about wider equity impacts on non-health dimensions of wellbeing, and the use of multidimensional

inequality and welfare indices – as well as aggregate approaches which combine health and non-health outcomes into a general composite outcome.

Fair shares

DCEA currently evaluates distributions by seeking an optimal trade-off between efficiency and equity objectives – the "value maximizing" way of thinking. However, another way of evaluating distributions is the "fair shares" or "proportionality" way of thinking. This seeks to distribute resources in proportion to strength of claim, rather than to maximise social welfare or equity-weighted net benefit. As explained in chapter 2, the logic of proportionality differs from the logic of maximizing. Maximising implies that the needs of individuals with relatively weak claims – for instance, those who need cost-ineffective care – should be completely over-ridden in the pursuit of maximum value. By contrast, proportionality implies that the needs of individuals with relatively weak claims should still be met to some extent – if only partially – even if this means failing to maximise value. Fair shares concerns which do not fit comfortably within the existing DCEA framework and which we discuss later include:

- the "fair chances" argument for health care lotteries
- the "realisation of potential" argument
- the "negligible claims" problem.

These concerns can be addressed through a deliberative process and considered alongside, without being integrated into, a DCEA. A future challenge, however, is finding analytical approaches to inform deliberations about these non-maximising concerns.

Making DCEA more useful in practice

Key practical challenges for DCEA research commissioners and users include:

- identifying and involving stakeholders

- institutionalising the use of DCEA
- improving underpinning data sources (e.g. surveys, administrative data linkage)
- improving evidence synthesis (e.g. for simulating distributions of opportunity costs and for parameterizing steps on the staircase of inequality)
- improving simple low-cost approaches.

Our list of DCEA management challenges is by no means exhaustive. There are many other challenges facing the wider community of people interested in helping decision makers to make fairer decisions with better health outcomes – not least the challenge of developing deliberative decision-making processes that address equity concerns and that both use and supplement the fruits of DCEAs.

2. Complexity

2.1 System-level health policies

The focus of the current volume has mostly been on decisions about specific health services for specific population groups. There are also, however, important equity concerns about system-level health policies – the general infrastructure "platforms" supporting the delivery of many different health services. For equity to be possible, health workers, clinical facilities and medical equipment have to be distributed to match local population need; information systems have to be sufficiently widely available that there are no "invisible" populations, whose ill-health goes unrecognised by planners; and there has to be a robust system for ensuring that financial resources are distributed equitably among geographical areas.

The WHO has produced guidance on health system strengthening which describes six "health systems building blocks": services, workforce, information, technologies, financing and leadership and governance (World Health Organization, 2007). This provides a useful map of the terrain but falls short of providing a clear analytical framework for decision makers

wanting to turn general aspirations into specific expenditure priorities. In principle, health economic evaluation can help to set specific priorities for health system strengthening. However, health system dynamics are complex and raise substantial modelling challenges that are often assumed away in conventional modeling exercises. For example, analysing health systems strengthening almost always necessitates examining economies of scale and scope and geographical and social differences in delivery cost (Morton et al., 2016; Hauck et al., 2019). There are also likely to be important behavioural response feedbacks in terms of how providers, such as individuals like doctors or institutions like hospitals, respond to changes in prices and incentives.

System-level policies intended to benefit disadvantaged groups can have unintended consequences for other – perhaps hitherto unrecognised – disadvantaged groups. For example, e-health technologies designed to reach geographically remote communities will probably exclude the less computer-literate; when bednets are distributed in the most high-risk parts of a village, the mosquitos shift their attention to the moderate-risk areas; funding uplifts for the most deprived territorial health authorities can disproportionately benefit affluent enclaves within these generally deprived regions. The idiosyncrasies, the coarseness of institutional mechanisms for service delivery and the vagaries of human behaviour and biology, mean that well-intentioned policies can sometimes have unintended consequences that harm equity.

2.2 Infectious disease modelling

The modelling of indirect spillovers to the wider population from infectious disease prevention, as well as direct impacts on programme recipients, raises important challenges for DCEA. A changed risk of infection and disease for one person at one time will influence risk of transmission to others for many years to come, including transmission to future generations (Vynnycky & White, 2010). Allowing for these dynamic spillover effects and further

opportunity costs in the wider population substantially complicates DCEA. Some equity-relevant groups are more likely to be infected, and hence to infect others, due to adverse environments (e.g. poverty-related under-nourishment, crowded living spaces, poor sanitary conditions) and exposure to behavioural risks (e.g. unprotected sex). Progression from infection to various stages of disease may also vary by equity-relevant group due to co-morbidities (e.g. influenza may exacerbate chronic obstructive pulmonary disease) and physiological characteristics that influence disease incubation and progression. Counter-intuitive things can happen when programme recipients are not the only beneficiaries and health opportunity costs are not distributed uniformly across non-recipients – for example, some groups can suffer an increased risk of disease even if the total community infection rate is reduced (Panagiotopoulos et al., 1999). Models of infectious disease transmission dynamics capable of handling these issues have been developed but have only recently started to be used to conduct distributional analysis by equity-relevant group (Verguet et al., 2017; Chang et al., 2018).

2.3 Non-communicable disease modelling

Modelling distributions in the context of non-communicable disease prevention raises further complexity challenges, including:

- behavioural responses of individuals (e.g. in relation to diet, physical activity and the consumption of tobacco, alcohol and narcotics)
- behavioural responses of producers (e.g. food and drinks industry, tobacco industry)
- multimorbidity and multiple disadvantage (e.g. understanding the individual-level clustering, compounding and interaction of multiple mental and physical illnesses alongside multiple developmental, educational, financial and social risk factors)
- long-term change over the lifecourse and between generations in equity-relevant variables (e.g. income, neighbourhood deprivation, education)

- disentangling the influence of neighbourhood-level environmental factors (e.g. air and noise pollution, crime, obesogenic environment) from individual and household factors (e.g. education, household income).

Addressing these complexity challenges will require the development and validation of scientifically credible lifecourse microsimulation models for economic evaluation, which synthesise a large body of inter-disciplinary theory and evidence about the long-term social determinants of health and wellbeing over the lifecourse. Such models will also be useful in providing the detailed information on distributional consequences needed to handle further challenges outlined below – including both *ex post* DCEA and cross-sectoral DCEA.

3. *Ex post* DCEA

In this book, we have adopted an *ex ante* perspective focusing on expected outcomes. We have quantified efficiency impacts in terms of expected net benefit and equity impacts in terms of inequality in the distribution of expected lifetime health by equity-relevant variables. However, prominent economists and philosophers have argued that it may also be useful to evaluate equity from an *ex post* perspective that focuses on realized outcomes (Diamond, 1967; Fleurbaey, 2010; Adler, 2012; Fleurbaey & Voorhoeve, 2013). The analyst may have some information about the probable distributional pattern of *ex post* outcomes, even if it is not known who will benefit.

3.1 A simple example

Consider the following simple example, with just two individuals to make things easy. Person 1 has a life expectancy of 70 and person 2 of 65. A decision maker is comparing two health programmes, both remarkably effective (table 16.1).

		Life Expectancy
Programme U	Person 1	76
	Person 2	76
Programme E	Person 1	75
	Person 2	75

Table 16.1 Level and distribution with limited information

Programme U will equalise expected lifetime health at 76; programme E will equalise expected lifetime health at 75. A decision maker concerned with both the level and distribution of health may find this choice easy: programme U is as egalitarian as programme E but will improve health even more. Programme U is better, all things considered. That is, if we adopt the *ex ante* perspective.

However, the decision maker is curious, she has heard about the *ex post* perspective, and asks for more information. As it happens, both programmes have been rigorously evaluated and the possible *ex post* outcomes are shown in table 16.2.

		Life Expectancy	State of the world (equiprobable)	
			State α	State β
Programme U	Person 1	76	100	52
	Person 2	76	52	100
Programme E	Person 1	75	75	75
	Person 2	75	75	75

Table 16.2 Level and distributions with more information

In programme U, there is a 50 percent chance of person 1 benefiting a lot and a 50 percent chance of person 2 benefiting a lot. In programme E, by contrast, both will experience 75 life years for certain. The possible *ex post* distributional patterns and their probabilities of occurring are known, even though it is unknown who will benefit under programme U.

A key principle for *ex post* egalitarians is that "when one lacks information, but can infer that there is a particular alternative one would invariably regard as best if one had full information, then one should choose this alternative" (Fleurbaey & Voorhoeve, 2013). In our example, we can infer that the distributional pattern under programme E is more equal than that under programme U, whatever the state of the world. From the *ex post* perspective, programme U would be more effective, but also more unequal in terms of realised outcomes. The decision makers may therefore want, with the help of the analyst, to explore a trade-off between improving health and reducing unequal *ex post* outcomes. If the decision maker has strong aversion to *ex post* inequality, she may even rank programme E over U.

3.2 Ethical and technical challenges

The *ex post* perspective raises interesting ethical challenges. For example, it violates the principle of *ex ante* Pareto (for good discussions, see (Fleurbaey, 2010; Adler, 2012)). *Ex ante* Pareto says that "if an alternative has higher expected utility for every person than every other alternative, then this alternative should be chosen" (Fleurbaey & Voorhoeve, 2013). Consider again table 16.2. Expected lifetime health is 76 in programme U compared to 75 with programme E, for both individuals. Both have higher expected lifetime health under programme U. The *ex ante* Pareto principle therefore recommends choosing programme U – even though it will ultimately involve much worse outcomes for one of the individuals.

The *ex post* perspective also raises important technical and data availability challenges for DCEA. *Ex ante* DCEA requires information about the likely mean health outcome of a programme and how this depends upon equity-relevant characteristics. By contrast, *ex post* DCEA requires information about likely variability in the health outcomes of a programme and how this depends on equity-relevant characteristics. In some cases, standard probabilistic decision models may provide enough information for simple *ex post* analysis (Samson et al., 2018). More generally, however, the information demands are considerably stronger. For

example, in the NRT example used in our spreadsheet training exercises, there is substantial and right-skewed individual-level variability in effectiveness, whereby some individuals gain many HALYs but most gain little or nothing (see chapter 8). To simulate the *ex post* distributional pattern we would need to know how this variability in health effects depends upon baseline health – i.e. are worse-off individuals with poor baseline health more or less likely than others to lie in the right tail of the distribution of programme effects with large HALY gains? To analyse "unfair" *ex post* inequality relating to deprivation and region, as well as "pure" *ex post* inequality, we would also need to know how the variability of health effects depends upon deprivation and region.

Addressing these issues requires further research into methods of causal inference for looking at programme effects on the variance and skewness of outcomes, as well as effects on the mean outcome (Chernozhukov et al., 2013). It also requires careful conceptual analysis of different kinds of uncertainty in outcomes and how far these sources of uncertainty may be "fair" or "unfair" (Asada et al., 2015; van der Bles et al., 2019). Evaluation of distributional consequences from an *ex post* perspective is thus a fascinating and important challenge for DCEA and for health services and public health research more generally.

4. Cross-sectoral DCEA

We saw in chapter 10 how to simulate distributional impacts on financial protection from health care costs, alongside distributional impacts on health. Decision makers may also be interested in distributional impacts on other non-health outcomes. Difficult challenges arise, however, when seeking to evaluate multidimensional outcome distributions. Analytical methods are starting to be developed for evaluating programmes with distributional impacts on both health and non-health outcomes, but they are diverse and embryonic in form. We sketch out some of the promising lines of enquiry and the challenges faced in developing these into routinely applicable approaches in the coming years.

We label this section "cross-sectoral DCEA", since the most obvious application of these methods is to programmes that cut across multiple policy sectors. Education and social protection policies, for example, will often influence distributions of income as well as distributions of health. Cross-sectoral issues also arise in relation to expenditure on health care and public health. One obvious question, for example, is how much health care should be financed through the government budget, i.e. through taxes or social security contributions. An increase in the government budget might lead to a decrease in private consumption of health care and other goods. This trade-off raises important questions of distributive justice in terms of who gains and who loses. This issue cannot be addressed merely by looking at health impacts – it requires analysis of the distribution of both health and non-health outcomes. Furthermore, priority setting within the public health care budget can have distributional consequences for household finances, which in turn has consequences for wellbeing beyond health. Treatments that are not covered in the collective system have to be funded privately or forgone. Co-payments and deductibles for publicly funded care have been introduced in many countries, and so the health effects of reimbursement decisions have to be weighed against the consumption effects of co-payments.

4.1 Disaggregate approaches

One approach is to present decision makers with separate information about wider equity impacts concerning the distribution of non-health outcomes, without aggregating health and non-health outcomes into a general composite outcome measure. For example, this is the approach currently taken in extended cost-effectiveness studies, which look separately at distributions of health and financial protection (Verguet et al., 2016). Disaggregate approaches can go some way towards formal evaluation through use of multidimensional dominance criteria (Atkinson & Bourguignon, 1982) and systematic approaches to designing dashboards of distributional consequences (McKnight et al., 2019). However, they stop short

of constructing general composite indices and analyzing potential trade-offs and compensation between health and non-health outcomes – for example, the possibility that increased inequality in non-health effects (e.g. tobacco tax contributions as a proportion of income) may be offset by reduced inequality in health effects (e.g. smoking-related deaths) to yield an overall improvement in equity.

Disaggregate information may take the form of a quantitative distributional breakdown – for example, a distribution of financial protection outcomes alongside a distribution of health outcomes. It may also take the form of qualitative data about the lived experiences of programme recipients, which can be translated into an overall subjective rating of wider equity impact. For example, treatment regimens requiring frequent clinical visits may generate social stigma and disrupt family life in ways that are particularly burdensome for people already suffering multiple disadvantages. A new treatment that reduces the frequency of clinical visits may then have a beneficial wider equity impact (Zwerling et al., 2017). Qualitative data may help decision makers to consider the nature and importance of this wider equity impact and weigh it up informally against impacts on total health and equity in the distribution of health. Selecting the relevant non-health outcomes and placing qualitative information about those outcomes into "level of importance" categories requires explicit value judgments by decision makers and stakeholders, and the resulting disaggregate information provides some, albeit limited, guidance for decision makers.

4.2 Aggregate approaches

There are three main approaches to constructing a general composite outcome measure for economic evaluation that combines and values both health and non-health outcomes:

- full income (i.e. income plus the monetary value of health and non-health outcomes)
- equivalent income (i.e. income adjusted for health and non-health outcomes)

- wellbeing QALYs (i.e. life-years adjusted for health- and non-health-related quality).

Each of these measures can then be used in distributional analysis, both to simulate distributions and to evaluate them using the methods described in part three of this handbook (i.e. dominance analysis, rank- and level-dependent equity weights based on social welfare functions and direct equity weights).

Full income is perhaps the simplest approach: one takes a standard measure of income and then adds to this the monetary value of health and other outcomes. A drawback of this approach is that it assumes a common constant exchange rate between income and health – i.e. the monetary value of health. Equivalent income refines this approach by allowing more carefully for heterogeneity in individual preferences between income, health and other outcomes within an explicit welfare theoretical framework. An individual's equivalent income is the hypothetical level of income that, if combined with reference levels of health and other outcomes, would place the individual in a situation that they consider as good as their current actual situation. The reference level is a normative choice for the decision maker, but a convenient choice is often a maximal value such as full health.

If reference levels are set at maximal values, then equivalent income is always lower than actual money income unless the individual reaches the maximal reference values for all other outcomes. In a two-dimensional case focusing on income and health only, the difference between equivalent and actual income reflects the decrease in well-being that results from not reaching full health. This decrease is measured as the willingness-to-pay of the individual for full health. Equivalent income can be measured using information on individual preferences from stated preferences techniques such as contingent valuation or discrete choice modelling, or using derivation of marginal rates of substitution from life satisfaction data (Decancq et al., 2015).

Both full income and equivalent income can then be equity weighted to allow for distributional concerns. Fleurbaey and colleagues provide an illustration of how to derive distributional weights in a framework with equivalent incomes (Fleurbaey et al., 2013), and Samson and colleagues illustrate the use of equity-weighted equivalent income as a metric for distributional cost-benefit analysis (Samson et al., 2018).

Another approach is the wellbeing QALY (Brazier & Tsuchiya, 2015) (Cookson, forthcoming) [note to typesetter: update Cookson reference with published version when available], which is also known as the equivalent health approach (Canning, 2013). The basic idea is to measure policy outcomes in terms of years of good life, rather than years of healthy life. Rather than adjusting only for health-related quality of life, a broader adjustment is made for all relevant dimensions of quality of life. Years of good life capture both health and non-health benefits, whereas years of healthy life only capture health benefits.

Like the equivalent income approach, the wellbeing QALY approach requires individual-level information on multiple health and non-health outcomes. Producing this detailed underpinning information itself raises substantial microsimulation modelling challenges, as explained above in the section on complex modelling. Once this detailed information is available, however, the challenge is then how to convert individual-level measures of income, health and other specific outcomes into a general composite outcome. We can distinguish three broad ways of doing this:

- a wellbeing index that combines and weighs multiple specific outcomes using various sources of evidence and value judgement – the "mash-up" approach
- questionnaire data on life satisfaction (or some other one-dimensional quality of life questionnaire score) – the "life satisfaction" approach

- questionnaire data on multi-dimensional quality of life – the "multi-dimensional questionnaire" approach.

The latter two approaches do not necessarily require programme effects to be measured directly using questionnaire data on life satisfaction or multi-dimensional quality of life. Instead, the available programme-specific outcome measures can be valued indirectly by mapping them onto life-satisfaction or quality of life outcomes.[1] For example, one can define a "WELLBY" as a one-point improvement in life satisfaction for one person for one year [note to typesetter: add reference to Frijters wellbeing report here once published]. Any policy outcome can then in principle be valued indirectly in terms of its expected effect on life satisfaction – for example, the effect of changes in employment, income and morbidity can all be estimated by applying robust causal inference methods to life satisfaction data from longitudinal surveys or (preferably) well designed quasi-experiments relevant to the decision-making context. When the questionnaire approaches are used indirectly in this way, they move a step closer to the mash-up approach insofar as they do not rely exclusively on questionnaire data but combine outcomes data of various different kinds. However, the remaining difference is that the "conversion rate" between each outcome measure and wellbeing is based exclusively on questionnaire data, rather than a wellbeing function that combines different kinds of data and social value judgement. Combining different kinds of data has advantages, insofar as it makes use of a wider range of information. It also has disadvantages, of course, insofar as it runs the risk of incoherence if diverse forms of data are mashed together in an unstructured and inconsistent manner. To guard against this, care is

[1] A limitation of indirect mapping is that it only captures programme effects on the general outcome (e.g. life-satisfaction) via effects on the set of specific outcomes (e.g. income and health) and so may not capture the full effect.

needed to make all value judgements explicit and to provide a coherent structure for any mash-up approach.

The development of general composite measures of benefit for cross-sectoral evaluation is thus a lively ongoing research endeavour, where the key challenge as ever is to find methods that are credible and useful to decision makers rather than merely being intellectually appealing to researchers.

5. Analysing fair shares

Chapter 2 distinguished three different ways of thinking about equity with importantly different logical structures:

- value maximization (e.g. maximise health, reduce health inequality)
- moral rights (e.g. right to non-discrimination)
- fair shares (e.g. distribution in proportion to need).

Part three of this handbook focused on evaluating distributions based on the "value maximisation" approach. Economic analysis can also play a role in examining moral rights, for example by examining the health opportunity cost of respecting a moral right for one group of people in terms of the foregone health benefits for other groups. However, an unresolved future challenge is how to analyse the third kind of principle: fair shares. In this section we discuss three different ethical arguments about health equity claims and how they might be analysed using DCEA methods – the fair chances argument, the realization of potential argument, and the aggregation of small benefits argument.

5.1 Lotteries and the "fair chances" argument

According to the fair chances argument, everyone should have a fair chance of accessing needed health care – not a guarantee, just a fair chance – including people who need care that is cost-ineffective, and including people who are relatively well-off in terms of baseline health

or other equity-relevant characteristics (Broome, 1994; Brock, 2003). If this proposition is accepted, a practical implication is that scarce health care resources should sometimes be allocated using lottery mechanisms that provide fair chances. Explicit lottery mechanisms are indeed sometimes used to help allocate rare and indivisible healthcare resources, such as organs for transplantation. And some authors argue for more widespread use of health care lotteries, for example co-payment lotteries to ensure that low-income families have a fair chance of accessing high-cost specialized hospital services (Wagstaff, 2013).

If decision makers are convinced by the fair chances argument, the question then arises: how could DCEA methods be used to help design and evaluate health care lottery mechanisms? Existing DCEA methods could be used to examine the impact of different lottery designs on unfair inequalities in the distribution of health, health care delivery and financial protection. Plausibly, analysis of this kind and formal evaluation based on maximizing equity-weighted net health benefit would find in favour of spending the lion's share of the public health care budget on care that is cost-effective and/or disproportionately benefits disadvantaged groups. It would not fundamentally get to grips with the logic of proportionality and the argument that people who need care that is cost-ineffective should still receive a fair chance of treatment. Nor would it help to clarify the potential conflicts and trade-offs between maximizing and proportionality ways of thinking. A future challenge, therefore, is to develop quantitative approaches to defining and measuring the strength of need claims and the appropriate lottery weights for different kinds of people with different strengths of claim. A judgement would then be required as to which objective is more important – increasing total health, reducing unfair inequality in health, or delivering fair chances – and a further challenge would arise about how to analyse trade-offs between these three different objectives.

5.2 Realisation of potential

According to the "realization of potential" argument, each individual has a claim to the health care resources that will allow them to achieve their full potential to benefit. This "fair shares" way of thinking yields different recommendations to the "value maximizing" way of thinking. For example, imagine patient A gains 50 expected discounted HALYs from a treatment that costs the same as treating 10 patients B-L who each gain 2.5 expected discounted HALYs. Assume they are the same in all other potentially equity-relevant respects, including age, severity of illness, socioeconomic status and so on. Maximising net health benefit would recommend treating patient A, since this delivers twice as many HALYs – 50 rather than just 25. However, the "realization of potential" argument is that the claim of patient B should not be completely over-ridden by the claim of patient A, merely because their capacity to benefit is 20 times smaller. Collectively, the 10 patients B-L may have a greater claim on public resources than patient A alone, and so it may be fairer to treat them, or divide the resources 11 ways in proportion to strength of claim, or hold a lottery as per the fair chances argument described above.

One way of addressing the realization of potential argument is a system of direct equity weights with diminishing marginal returns to capacity to benefit (Nord, 2018). In this system, social value is not a simple linear function of capacity to benefit but is instead a concave function. However, this approach is still based on a "value maximising" way of thinking according to which the aim is to maximise equity-weighted net health benefit, and it does not address the question of how to ensure that no legitimate claims are completely over-ridden. A future challenge is to develop approaches that explicitly adopt a "fair shares" way of thinking by defining how individual fair shares are to be defined and measured, rather than seeking to maximise equity-weighted net health benefit.

5.3 Negligible claims

It might be argued that people with small health benefits have a negligible claim on public resources if this means forgoing large health benefits for others (Kamm, 2005). In the Netherlands, for example, decision makers have proposed withdrawing public funding for treating minor ailments to ensure funding is available for treatments with larger benefits (Voorhoeve, 2018; Voorhoeve, 2020). This is a variant of "fair shares" thinking – it implies that some people's strength of claim is so negligibly weak that their "fair share" of health care for the ailment in question is zero.

This differs from the argument that priority should be given to worse-off patients with poor baseline health. The negligible claims argument focuses not on baseline health but on capacity to benefit. Someone in good health may have substantial capacity to benefit from preventive care, whereas someone in poor health may have low capacity to benefit. It also differs from the financial protection argument that priority should be given to covering high cost treatments, since those who need low cost treatment can pay privately out of pocket without suffering hardship (Smith, 2013). The negligible claims argument is about the size of the health benefit, not the size of the financial protection benefit.

A future challenge is developing analytical methods that operationalize the concept of a negligible claim and draw out the implications of adopting a "fair shares" principle alongside health maximization and health inequality reduction objectives.[2]

6. Making DCEA more useful in practice

The fundamental aim of DCEA is to provide decision makers and stakeholders with useful information that helps them make better decisions with fairer outcomes. The most important

[2] This challenge interacts with the challenge of *ex post* DCEA, insofar as it is often uncertain whether an individual's realized health benefit will be large or negligibly small.

challenge facing this embryonic field is thus a practical one: how can DCEA become more useful to decision makers and stakeholders? It took standard CEA four decades to develop from the stage of invention in the 1960s and 1970s through to early application in the 1980s and methodological standardization in the 1990s, before moving on to widespread use in health decision-making around the world from the 2000s onwards (Williams & Cookson, 2006). How can DCEA emulate this success and become a routine part of decision-making in health care and public health?

We expand on this challenge below under five principal headings:

- identifying and involving stakeholders
- institutionalizing the use of DCEA
- optimizing data sources and evidence synthesis
- removing barriers and facilitating implementation
- research into better DCEA theory, methods and practice.

While these categories matter in all forms of CEA, we concentrate on those we conjecture to be most important in its distributional aspects.

6.1 Stakeholders

How can analysts work together effectively with decision makers and stakeholders to co-produce useful information? Who else, besides the analysts, ought to be involved in the analysis and its application in any specific case; who else might have a useful role in the implementation of the decision and the management of its roll out; and who else might have a useful role in learning from the process from start through to implementation in ways that enable suitable future revisions to be made in the light both of experience and any changes in the evidential or value foundations of the analysis?

Decision makers obviously need to be involved because they are the key customers for DCEA information. But without the appropriate involvement of a broader range of stakeholders, decisions, no matter how well-informed by evidence and how explicit about the value content, may lack public, professional or political credibility and may be impossible to implement (Culyer, 2006; Li et al., 2017). CEA and DCEA can appear to be mechanistic and "hard" technologies that are insensitive to individual and social nuances. This may be far from the truth in many applications. However, the perception of insensitivity, particularly with relatively nontransparent systems of decision making, may be sufficient to bring the principles of DCEA into disrepute (Culyer, 2005). Involving "real" people appropriately in the decision-making process is therefore a form of direct democracy that lends credence to the process. Stakeholder participation is also an important source of information about social values and about the lived experiences of those most affected by decisions. Identifying and involving stakeholders is thus fundamental to the successful application and use of DCEA in decision-making.

Box 16.1 contains a list of possible stakeholders (which are relevant in any application is, of course, context dependent) and some roles they might play at various stages of a DCEA. The relevance of each will, of course, depend on social and political factors, local appraisal of what is possible and the aims of the exercise. All of these groups might be invited to observe, comment on or participate in particular stages of the process. As well as contributing useful information from various different perspectives, each group of course has its own set of vested interests and tendencies towards special pleading and bias.

Box 16.1 Potential stakeholders and the roles they can play

Decision makers
Source of social value judgements, topic selection, process design and development.

Technical advisors
Supporting decision makers in their roles.

Patients and the public
Validation of equity outcome measures, information about how decisions would affect their lives, knowledge brokers.

Informal carers
Same roles as patients and the public and can also represent patients.

Managers
Topic selection, implementation planning, local financing issues, local inequities.

Clinical professionals
Clinical experience, research expertise, expertise in minorities and multiple disadvantages.

Research and researchers
Research funding, research production, topic selection, data development, methods, systematic reviews and meta-analysis, generalization of evidence, quality assurance.

Manufacturers
Information about products being evaluated and comparators, views on reasonableness of criteria, speed and rigour of process, design and support for research.

Insurers
Information about the design of insured packages, issues of coverage, comprehensiveness and copayments, liaison with researchers.

NGOs, donors, development partners
Multilateral and bilateral relationships, international standard setting, coverage issues, financing, consultancy and advice.

Politicians, including opposition politicians
Democratic accountability, representation of opposition views and minority interests.

Courts and the judiciary
Consistency with rights to health, constitutional issues, legality of process, judicial review.

Knowledge brokers and the media
Communication skills, public and professional education.

6.2 Institutionalization

The next set of challenges are to do with the institutional and political contexts of decision making and how these might be best designed to support the fundamental purpose of DCEA i.e. better-informed decisions. Institutionalization has many advantages in CEA: achieving a critical mass of evaluative skills, economies of scale and scope, a single centre of excellence and communication (or a few), and close relationships and partnerships with other relevant institutions. These apply with equal force in DCEA. Institutionalization in DCEA also enables the creation of consensus and continuity in the value framework for DCEA, which comprises many inter-linked elements including those listed in box 16.2

Box 16.2 Institutional context for DCEA

Social value judgments (e.g. use of QALY/DALY, cost-effectiveness thresholds, focus on future or lifetime health for equity analysis, inequality aversion parameter values).

General cultural conditions (e.g. religious taboos, prevalence and belief in the role of traditional medicine).

General political conditions (e.g. stability of regime, acquiescence of formal opposition parties).

Professional politics of health care (e.g. past and current medical attitudes, managerial attitudes, organised labour attitudes).

History of health care and public health (e.g. memories of what seems to have previously worked and what not, continuity of movement towards universal healthcare coverage and healthy public policy).

6.3 Strengthening the evidence base

There are several limitations in data sources and evidence available to support DCEA, as noted in each of the methods chapters. Institutionalization and networked research afford an opportunity for coherent programmes to prioritize and address research into DCEA methods and usage and, in connection with universities and independent research institutions, the development of both theoretical and empirical research to support future applications of DCEA. Having several linked centres of expertise in evaluating the quality of evidence submitted to the national or regional HTA agency (if one exists), and in conducting systematic reviews and in performing primary empirical research in DCEA, builds a powerful foundation for evidence-informed decision making in distributional matters and also helps to build a wider culture of evidence-informed critical appraisal.

6.4 Political economy

A major absence in current DCEA research activity lies in what one might call "political economy": research to investigate the cultural, historical, economic and political environment in which policy is made and to understand why decisions are taken that seem irrational. In many cases, wise investment opportunities are missed not because they cannot be identified but because they are difficult to implement – for a range of reasons, from corruption and dishonesty in the political culture to rigidity in planning and managerial hierarchies. Locating and understanding barriers, removing them or mitigating their effects, and designing incentive-compatible systems of decision making at all levels are three major possible research themes.

6.5 Methodological standardisation

At present, the state of DCEA methods is rather like the state of computing in the 1960s:

powerful tools exist but can only be deployed effectively by highly specialized research teams. Further research is needed to reduce the cost and increase the power and accessibility of DCEA in ways that make it suitable for widespread production and use.

At least five different kinds of research are needed to take the theory and methods of DCEA to the next level of mass production and routine use in decision making:

- fundamental research – policy-oriented rather than entirely curiosity-driven – to address methodological challenges, including the four outlined in this chapter
- comparative research into the values informing different systems and the various ways in which they have influenced decisions and decision-making processes
- primary research (short term) on topics of immediate policy relevance in the jurisdiction
- primary research (long term) on developing general data infrastructure (for example cohort studies and improved reporting of equity-relevant distributional breakdowns in intervention studies) and general evidential building blocks (for example, estimates of the distribution of opportunity costs by equity-relevant group)
- secondary research in the form of equity-related literature reviews and, where feasible, meta-analysis.

Training and capacity building are also key future challenges for the field of DCEA – both to develop the capacity of analysts to produce useful distributional analyses and to develop the capacity of decision makers and their technical advisers to understand, critically appraise and use evidence and analysis to make fairer decisions with better health outcomes. Coordinated programmes of research and capacity building, for example by a consortium led by a ministry of health and local universities together with funding sources, would help to glue together these different strands of work and ensure continuing relevance to decision making.

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