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ISPOR Report

Primer on Health Equity Research in Health Economics and Outcomes Research: An ISPOR Special Interest Group Report

Matthew J.S. Griffiths, MSc, Richard Cookson, PhD, Anton L.V. Avanceña, PhD, Manuel A. Espinoza, PhD, Caroline M. Jacobsen, MPhil, Jesse Sussell, PhD, Stacey Kowal, MSc

ABSTRACT

Objectives: Disparities in health and healthcare between more and less socially advantaged groups are pervasive, multidimensional, and far-reaching. The material and social conditions in which people are born, grow, work, live, and age are systematically associated with their health and with the volume, quality, and outcomes of care received by the vast majority of the general population, as well as by specific marginalized populations. The field of health economics and outcomes research (HEOR) has an important role in supporting health equity goals. This publication aimed to act as a "primer" for conducting health equity research within the field of HEOR, establishing foundational understanding of key concepts.

Methods: The ISPOR Special Interest Group on Health Equity Research was established in 2021 to advance equity-informative methods and data to better enable researchers to empirically investigate—and ultimately reduce—unfair social differences in health. This publication was developed by the ISPOR Special Interest Group leadership team with input from the group membership.

Results: The resultant publication provides an overview of health equity research methods and data considerations as they relate to HEOR-relevant topics including clinical trials, real-world evidence and economic evaluation. Reflecting the current body of research on health equity in HEOR, particular focus is given to the latter. It also brings together a list of core reference material to support future learning.

Conclusions: This report provides the HEOR community with a tailored "state of play" overview of health equity, to support development of foundational understanding and inspire increased engagement.

Keywords: DCEA, disparity, diversity, equality, equity.

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Highlights

- Campaigns such as those led by the World Health Organization, as well as recent events and social movements, have helped illuminate prevailing disparity and inequity in health and healthcare worldwide. However, although there has been methodological research and increasing calls for greater inclusion of equity considerations in health economics and outcomes research (HEOR), application of research to practice has been limited and awareness and understanding of equity-focused methods among the HEOR field are inconsistent.
- This "primer" provides an important overview of health equity considerations as they relate to multiple domains of HEOR, including clinical trial research, real-world evidence and economic evaluation. By providing a "state of play" of these different areas of health equity research in one publication, it aims to improve baseline understanding and awareness of equity methods, data requirements, and immediate challenges. It also provides the HEOR community with a core reference point for foundational resources.
- By increasing engagement with, and understanding of, the field of equity-focused HEOR, this publication hopes to inspire a future generation of HEOR researchers to contribute to advancing methods, improving data quality, and influencing adoption in practice of equity-focused methods to ultimately drive improvements in equity in health and healthcare.

Introduction

According to the World Health Organization, "Three distinguishing features, when combined, turn mere variations or differences in health into a social inequity in health. They are systematic, socially produced (and therefore modifiable) and unfair."[1] Health equity research aims to measure and understand these differences in health and healthcare, variously known as "disparities," "inequalities," or "inequities" (which will be used interchangeably henceforth). This involves differences in health and healthcare that are associated with numerous aspects of social disadvantage, including socioeconomic status, race and ethnicity, gender, geographic location, disability, and others.[2] The causal pathways are complicated, but the unifying feature is a sense that differences are unwarranted: social status should not cause ill health, ill health should not affect social status, and other factors, such as disability, should not determine either. The "social determinants of health" framework provides an important tool for understanding the many nonmedical factors that influence health outcomes and contribute to health inequities.[3,4]

Although the World Health Organization has campaigned for health equity for decades, there has been a lack of progress in reducing health disparities.[5,6] The COVID-19 pandemic and recent social movements have placed a further spotlight on the magnitude of prevailing disparity and inequity worldwide.[7] In the health economics and outcomes research (HEOR) field, although there has been methodological research and increasing calls for greater inclusion of equity considerations, until recently the application of HEOR has traditionally focused more on questions of efficiency rather than distributional concerns. The HEOR field also recognizes the importance of other considerations that can be captured using priority-setting approaches, which include not only health equity but also severity, rarity, and other considerations.[8]

The ISPOR Special Interest Group on Health Equity Research aims to advance equity-informative methods and data to better enable HEOR to reduce unfair social differences in health.[9] This "primer" aims to provide an overview of the state of health equity as it relates to the HEOR field, with an emphasis on health technology assessment (HTA) and cost-effectiveness analysis (CEA). It also establishes key concepts and provides a gateway to further reading (see Supplemental Materials found at https://doi.org/10.1016/j.jval.2024.09.012) on various equity-related topics. Finally, it intends to inspire further research among the ISPOR HEOR community and beyond.

Equity Considerations in HEOR: Where Are We?

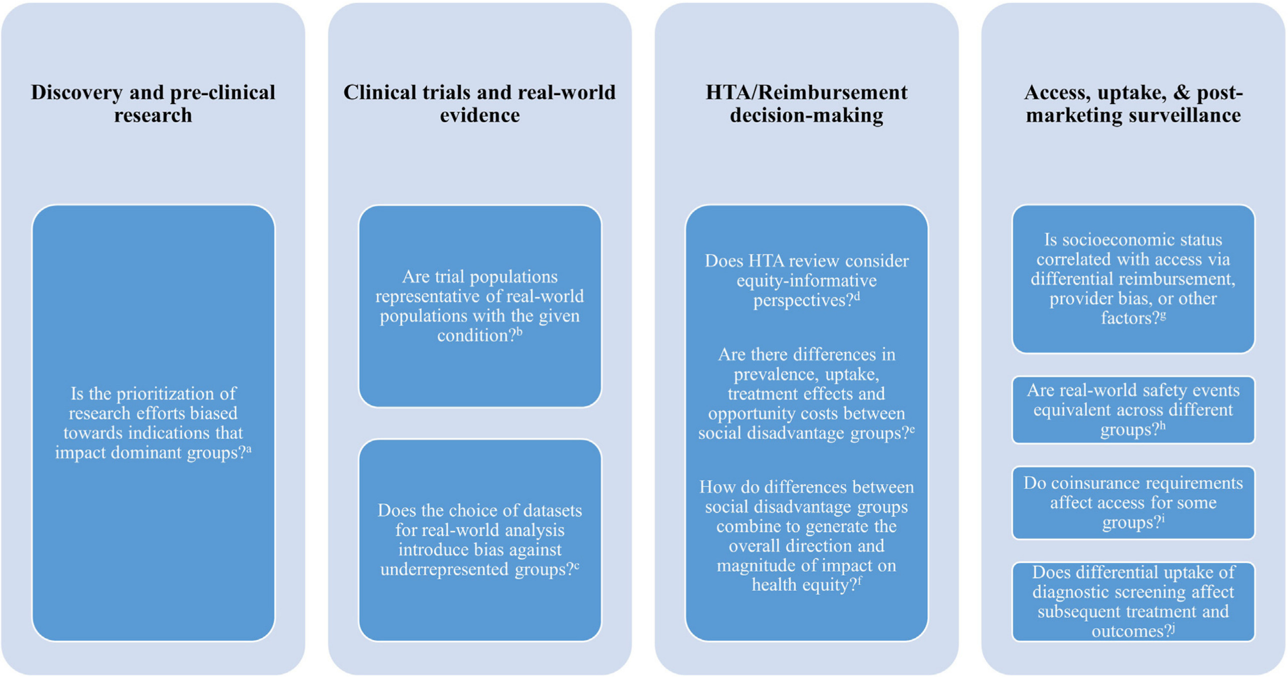
Health equity considerations are relevant across HEOR disciplines, from clinical research to reimbursement decision making and postmarket access activities (Fig. 1).[10-18]

Defining Health Disparities

It is important to have a clear understanding of what does and does not count as a health disparity. Within the ISPOR Health Equity Research Special Interest Group, health disparities are defined as unfair differences in health between more and less socially advantaged groups.[19] Social advantage groups can be classified not only using conventional indicators of socioeconomic status (eg, income, wealth, occupational class, neighborhood deprivation, education) but also using ethnicity, regional deprivation, gender, disability, social exclusion, and other indicators of social disadvantage that are closely linked with economic disadvantage and social discrimination.[20]

Concern for reducing health disparities is just one important ethical concern that health decision makers should consider.

Figure 1. Examples of equity considerations throughout the development of a new health intervention. [a]A lack of research on interventions for sickle cell anemia, a condition that predominately occurs in patients of African origin.[11] [b]Black Americans represent approximately 10% to 12% of the US population, but only 1% to 2% of typical clinical trial populations.[12] [c]Healthcare claims databases that aggregate claims from commercial insurers represent a nonrandom sample of the population: they are necessarily biased toward employed populations and may disproportionately represent wealthier and more educated individuals.[13] [d]The National Institute for Health and Care Excellence (NICE) 2022 Methods and Process Updates noted the importance of considering health inequalities to NICE's 2021-2016 Strategy, but that further work is required before any formalized equity modifier could be introduced.[14] [e]Analysis of the UK Bowel Cancer Screening Pilot found variation in uptake of fecal occult blood screening by gender, age, and level of deprivation.[15] [f]Access to inpatient COVID-19 medicines for all US patients reduced existing health disparities in the United States by 0.234%, given that more vulnerable subgroups were more likely to use these medicines and, on average, gained 35% more health benefit given higher baseline mortality risks.[10] [g]A large-scale field experiment requesting an appointment at more than 1200 physicians in Austria for 3 fictitious female patients differing with respect to level of educational attainment found that physicians provided significantly shorter response times and marginally significantly shorter waiting times for patients with a university degree than without.[16] [h]For example, patient groups with cognitive impairment may experience increased risk of adverse drug events.[17] [i]Financial barriers to healthcare, including difficulties covering premiums, copays, and other out-of-pocket expenses, were reported in a study of a low-income, insured population in New York City.[18]



Discovery and pre-clinical research

Is the prioritization of research efforts biased towards indications that impact dominant groups?[a]

Clinical trials and real-world evidence

Are trial populations representative of real-world populations with the given condition?[b]

Does the choice of datasets for real-world analysis introduce bias against underrepresented groups?[c]

HTA/Reimbursement decision-making

Does HTA review consider equity-informative perspectives?[d]

Are there differences in prevalence, uptake, treatment effects and opportunity costs between social disadvantage groups?[e]

How do differences between social disadvantage groups combine to generate the overall direction and magnitude of impact on health equity?[f]

Access, uptake, & post-marketing surveillance

Is socioeconomic status correlated with access via differential reimbursement, provider bias, or other factors?[g]

Are real-world safety events equivalent across different groups?[h]

Do coinsurance requirements affect access for some groups?[i]

Does differential uptake of diagnostic screening affect subsequent treatment and outcomes?[j]

Concern for health disparity can be distinguished from other ethical concerns about the distribution of health resources, such as concern for efficiency in increasing total health, concern to prioritize severely ill patients, and concern for ensuring appropriate procedures of decision making.[19] Furthermore, health disparities among social advantage groups are only a subset of all unwarranted variations in health among individuals.[21] For example, rather than prioritizing the consideration of social disadvantage, decision makers may wish to give priority to severely ill patients based on differences in health among disease groups or may independently be concerned with reducing unwarranted variations in health outcomes among patients treated by different providers or living in different areas. Therefore, measuring and addressing health disparities is challenging given the interplay among many complex factors that shape health outcomes and can give rise to diverse ethical concerns.

The Role of Health Equity in Clinical Trials and Real-World Evidence

Clinical trials

Increasing diversity and inclusiveness in clinical trials is necessary for improving the evidence to advance health equity in the wider population. Regulatory and funding agencies have issued guidelines that encourage the inclusion of diverse populations in randomized controlled trials (RCTs), and examples of inclusive RCTs are growing in number.[22-25] However, as gaps in adequate inclusivity continue to exist across global trials, an increased emphasis on designing and implementing inclusive trials is needed.[26,27] Representation in RCTs helps to (1) understand the effectiveness of technologies on populations with different characteristics and lived experiences, (2) ensure that populations disproportionately affected by certain conditions are involved in studies of interventions that aim to benefit them, and (3) allow equitable access to innovations and potentially improved routine care.[28,29] Improving diversity and inclusiveness of clinical trials will require overcoming numerous challenges, such as the traditional geographic location of clinical trial centers, the impact of clinical trial participation on time away from work and family responsibilities, and historic mistrust in science and medicine among some groups of society.[30]

Real-world evidence

There is a growing emphasis on enhancing the role of real-world evidence (RWE)—or observational data generated by health systems, providers, payers, and other stakeholders—in supporting health equity research.[31]

The application of RWE to equity research brings great promise given the wealth of data available but it also presents important new challenges. Many countries routinely collect nationally representative population data with rich information on demographics and broader social determinant of health variables at granular geographic levels that can be used to measure existing disparities. However, there may be limits to the availability of longitudinal data, as well as a lack of collection of important variables for HEOR research questions, such as those needed to determine quality-adjusted life expectancy for the general population.[10] Next, HEOR has long leveraged RWE sources with rich clinical detail such as electronic health records or claims, but these data commonly lack important information on broader patient, geographic, and health system factors needed to understand equity drivers and consequences. Furthermore, many data sets are based on payments and claims for populations that are not nationally representative, which can give rise to biased samples that exclude the most vulnerable groups (ie, the uninsured and the homeless).[32]

In recent years, “enrichment” efforts have allowed analysts to link electronic health record or claims data sets with external data sources to add additional data variables for more robust equity research, such as race and ethnicity or geographic vulnerability measures. Other data sets leverage approaches such as natural language processing of unstructured text to gain a deeper understanding of patients, including their experiences with broader material and social conditions affecting health such as housing, food, and economic security.[33,34] Although these efforts can help to embed equity elements, they commonly rely on geographic data on broader social and environmental factors that are not tied to individual behaviors and outcomes, and included variables usually fail to capture the root causes of health inequities, such as place-based drivers of health (ie, density of providers) or provider behaviors that affect bias and discrimination.[35,36] Even when information on equity-relevant concepts is included in data sets, there can be biases in the reporting of data, a lack of standardization, and challenges with interoperability.[37]

New tools and resources are needed to best harness the potential of RWE in equity research, including (1) the development of best practices guidance to inform selection of optimal data sources and to more clearly document the strengths/limitations of RWE for exploring equity research questions to ensure findings are appropriately interpreted and (2) alignment of key stakeholders around the definition of equity-relevant variables and populations of interest to support more efficient prioritization of data collection and enrichment efforts.[38]

The Role of Health Equity in Assessment of Health Technologies

Current processes and methods for HTA need to better consider equity effects across all aspects of the assessment.[39,40] The clinical and economic modeling data used to inform HTA commonly fail to provide evidence on factors that drive health disparities across a population, including[41]:

- RWE on inequality in disease prevalence, which is often the main factor driving the impact of a new technology on health disparities within the general population
- trial evidence or RWE on inequality in utilization of new technologies and the current comparator standard of care
- the distribution of the health opportunity costs of cost-increasing programs (ie, the distribution of the health foregone as a result of displaced healthcare activities)
- size of health disparity impacts compared with other programs
- trade-offs between equity and efficiency objectives

Recognizing the need to address these types of questions, a range of new methods and guidance documents are becoming available to allow researchers to integrate health equity considerations into effectiveness and/or CEA.[42] For example, the Consolidated Standards of Reporting Trials, the reporting standards for RCTs, was updated in 2017 to include best practices for reporting health equity-relevant data.[43] Similarly, information on distributional effects and consideration of priority populations was added as a checklist item in the 2022 Consolidated Health Economic Evaluation Reporting Standards statement.[44] More recently, some funding bodies are starting to issue guidance on improving both the collection and reporting of data on health disparities.[45] However, the impact of the implementation of these standards is not yet visible.

Table 1. Examples of published equity-informative economic evaluation studies.

Setting	Example published equity-informative study				
	Type of study and citation	Interventions/ programs compared	Equity variable(s) considered	Main results, including baseline cost-effectiveness results	Equity impact
United Kingdom	DCEA by Collins et al[56] (2020)	Three cardiovascular screening strategies vs no intervention	Socioeconomic status (Index of Multiple Deprivation quintile)	"Current," "increased," and "universal plus targeted top-up" screening scenarios were cost-effective; under specific conditions, net health benefits of all 3 scenarios were negative due to opportunity costs.	Targeted scenario reduced health inequality between most and least deprived populations; results were sensitive to opportunity cost assumptions.
Mexico	ECEA by Saenz-de-Miera et al[57] (2021)	One-time, one-peso tobacco excise tax increase vs status quo	Income quintiles	Tobacco tax increase was cost-saving.	Bottom income quintile gained 3 times more life-years from intervention than top quintile; approximately 276 000 poverty cases (21 000 in the 2 lowest income quintiles) and 568 000 cases of catastrophic health expenditure (136 000 in the lowest income quintile) averted.
United States of America	DCEA by Quan et al[58] (2021)	16 HIV diagnostic, treatment, and prevention interventions and 2 scale-up approaches vs status quo	Race/ethnicity	Optimal combinations of interventions in 6 United States cities were cost-saving or cost-effective.	Equity approach that scaled up interventions based on a community's share of new infections was more cost-effective and reduced racial/ ethnic disparities.
Malawi	DCEA by Arnold et al[59] (2020)	73 interventions to be included in Malawi Essential Health Package	Household wealth and residence (urban vs rural)	50 interventions have positive population health benefits and 23 interventions have negative population health benefits after consideration of opportunity costs.	The Essential Health Package averts 0.85 DALYs among individuals in poorest quintile and 0.10 in richest quintile; the Essential Health Package reduces inequality between wealth quintiles.
Vietnam	ECEA by Essue et al[60] (2020)	Elimination of medical and nonmedical OOP costs for small-incision cataract surgery vs status quo	Income and gender	Elimination of medical OOP costs has ICERs between 2494 and 4149 per DALY averted (2016 Int$); elimination of all OOP costs has ICERs between 3479 and 8444 per DALY averted.	More DALYs averted among richest quintiles than poorest quintiles; more catastrophic health expenditures averted, solely among poorest quintile, by eliminating all OOP costs. Females would have a greater share of benefits.

DALY indicates disability-adjusted life-year; DCEA, distributional cost-effectiveness analysis; ECEA, extended cost-effectiveness analysis; HIV, human immunodeficiency virus; ICER, incremental cost-effectiveness ratio; Int$, international dollars; OOP, out-of-pocket.

Reporting of data required to analyze equity impacts remains inconsistent and highly heterogeneous, hampering efforts to curate and synthesize equity information from different studies and to compare the direction and magnitude of equity impacts across diseases. Reporting of such data is important given that it allows researchers to understand heterogeneous treatment effects across equity-relevant variables, through subgroup analysis and estimation of quantile and conditional average treatment effects.[46-50] These methods are being used more frequently to understand heterogeneous treatment effects that are masked by a focus on average outcomes. Indeed, policies by the National Institutes of Health and the Food and Drug Administration in the

United States now require evaluation of heterogeneity in treatment effects for appropriate trials.[48] Clinical studies (eg, RCTs) are frequently insufficiently powered to detect differences among subgroups, including equity-relevant subgroups. However, given the availability of meta-analytic techniques to pool study results, analysis and reporting of equity-relevant subgroups should be encouraged to increase information available to future researchers.

Some countries have integrated equity discussions in their HTA process and qualitative approaches to systematically include equity concerns in the evaluation of health technologies exist. These have been presented as checklists that serve deliberative processes in HTA.[51,52] Recently, US HTA organizations laid out recommendations for improving consideration of health equity, with an emphasis on representative patient engagement.[39,53] However, analytic methods that more formally incorporate equity concerns into HTA are needed. Arguably, it is in the arena of economic evaluations where the integration of health equity in HEOR has been most prominent. Equity-informative CEA methods, such as distributional CEA (DCEA) and extended CEA, have been applied to many public health and healthcare contexts worldwide, encouraged and made possible by improvements in the collection and reporting of equity-relevant economic model input data from RCTs and observational studies.[42,54,55] Published equity-informative CEAs are growing in number worldwide, providing important insight into the available data sources and equity-relevant subgroups that could be leveraged in future work.[42,54,55] A summary of 5 example equity-informative CEAs is presented in Table 1.[56-60]

Using Economic Evaluation to Assess Impacts on Health Disparity

DCEA is an umbrella term for studies that provide information about equity in the distribution of costs and effects as well as more traditional information about efficiency in terms of aggregate costs and effects.[19] DCEA can solely explore the implications of giving special priority or “equity weight” to improving the health of 2 groups: program recipients versus nonrecipients.[61,62] It can also involve a more detailed analysis of the distribution of health benefits and burdens within the general population between several groups defined by equity-relevant social variables (eg, socioeconomic status, geographic location, ethnicity), disease variables (eg, severity of illness, rarity), or risk factors. DCEA is not restricted to the analysis of health outcomes and can be used to analyze distributional consequences for nonhealth outcomes, such as income or financial protection from out-of-pocket healthcare costs. In cases where a study considers health and financial protection together, the term extended CEA is used.[63] Finally, one can also conduct simple or “aggregate” DCEA, which involves modeling of distributions on top of pre-existing basic cost-effectiveness results rather than going “under-the-bonnet” of the cost-effectiveness decision model and doing more complicated modeling of distributions that may also change conventional cost-effectiveness findings.[64]

The output of a DCEA is an assessment of the impact of an intervention on the distribution of a health and/or nonhealth outcome among various defined equity-relevant groups (eg, racial, socioeconomic). Both the equity-relevant groups and the units in which equity impact is measured are dependent on decision-maker needs. For example, in one policy context, distributional impacts on quality-adjusted life expectancy might be of most interest, whereas in another the distributional impacts on infant mortality might be more relevant. A decision-making organization may wish to specify a standard base case health disparity metric suited to their own context. This metric can be based on a generic social disadvantage classification system and a generic health outcome measure to facilitate comparisons of the direction and magnitude of health disparity impact among different interventions in different disease areas.[38,65]

The overall impact of an intervention on health disparity will depend on the direction and magnitude of social differences at various stages in the patient pathway, including social differences in:

- disease prevalence or need for the intervention
- screening, referral, and diagnosis rates
- uptake of the intervention
- effects of the intervention
- opportunity costs of the intervention

The direction of impact may vary from one stage to another. For example, among more socially disadvantaged groups, smoking *prevalence* may be higher whereas *uptake* of smoking cessation services may be lower. Where impacts work in opposite directions, it is challenging to assess the overall impact on reducing health disparities without doing detailed calculations. These stages can be visualized as a “staircase of inequality impact” (Fig. 2). It is important to consider the impact of an intervention at each step and how these impacts combine to determine the overall distributional impact—especially when impacts may work in opposite directions at different steps.

Opportunity costs are similarly important in DCEA as they are in standard CEA. DCEA also takes into account not only who gains health from the new intervention but also who loses health due to the foregone activities that would otherwise have been funded. By considering the data across equity-relevant subgroups for each step of the equity staircase, DCEA determines the overall equity impact of adoption of the intervention.

This assessment of equity impact can then be considered against the overall impact on health (ie, net health benefit) or the output of conventional CEA. The resulting equity and efficiency impacts of a new intervention can be plotted on the equity-efficiency impact plane (Fig. 3).

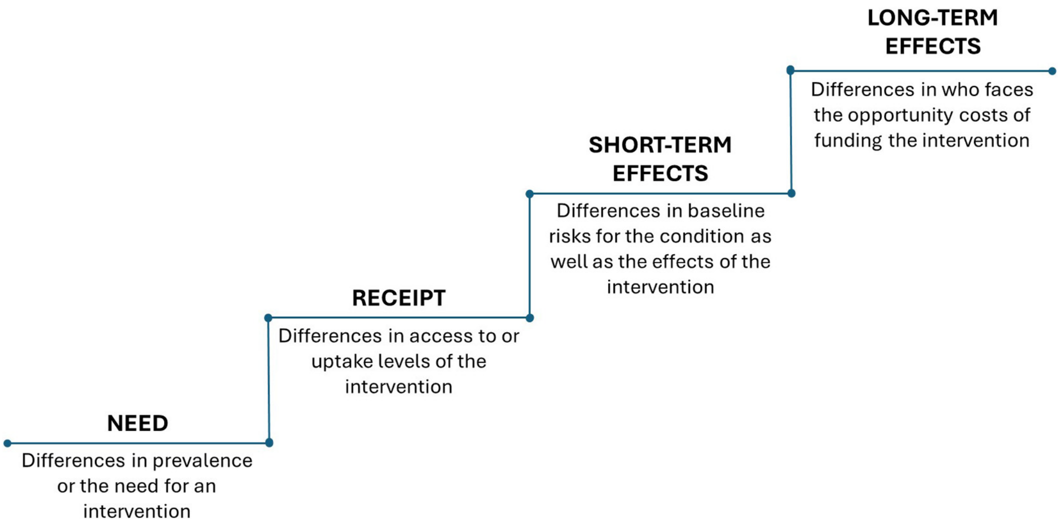
By assessing the equity impact alongside information on efficiency, DCEA makes any trade-off between the two transparent and explicit. Where such trade-off exists, it becomes the role of the decision maker to determine what to do with this information.[42] DCEA aims to provide equity information as an input into context-specific deliberation on the trade-off between equity and efficiency; it is not intended to represent an algorithmic approach to determining what decision should be taken based on a universal equity formula. Decision making on a new healthcare intervention that involves a trade-off between equity and efficiency can be done informally based on intuitive judgments or can be done formally using a range of methods outlined in the DCEA handbook by Cookson and colleagues.[19]

What Are the Data Requirements for Consideration of Equity Effects in Economic Evaluation?

To support a more routine application of DCEA, representative data on existing health disparities are needed to assess the equity impacts of healthcare decisions. Each country needs nationally representative estimates for several data elements, including:

- baseline health inequalities
- distributional relative treatment effects

Figure 2. Staircase of inequality.

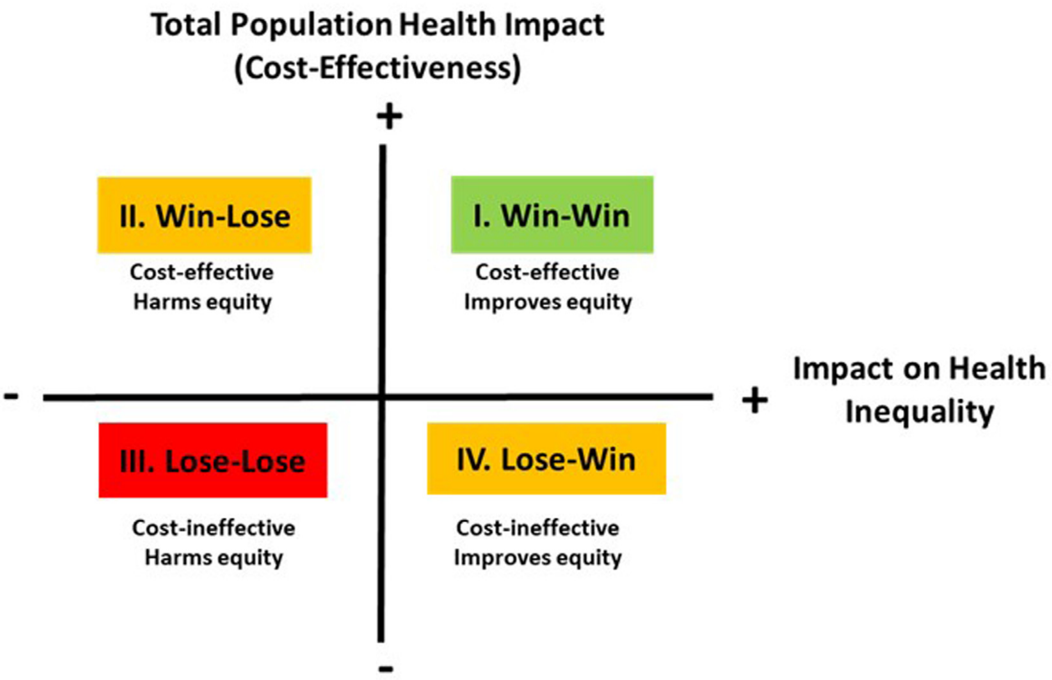


- the distribution of opportunity costs
- population inequality aversion

Evidence on current health disparities that can be routinely updated characterizes the current population burden of health disparity and provides information on the capacity to benefit from health interventions across equity-relevant subgroups.[19] Equity-relevant subgroups will need to reflect stakeholder-endorsed, defined subgroups within a population that align with the country's key equity objectives. Given that population demographics and equity priorities will vary across settings, each country will need to generate their own baseline information on differences in health by socioeconomic status, race and ethnicity, location, and other aspects of social disadvantage.[65,66] These baseline data are essential to understanding preintervention health disparities.

Information will also be needed on distributional effects of a disease or treatment. Ongoing efforts to improve clinical trial

Figure 3. Equity-efficiency impact plane. *Note.* Interventions in the northeast quadrant are both cost-effective and have a positive impact on reducing health disparity and therefore represent a win-win. Interventions in the southwest quadrant are the opposite. For interventions in the northwest and southeast quadrants, there is a trade-off between cost-effectiveness and the impact on health disparity.



representativeness will help increase information on distributional effects.[67] However, collecting this type of information routinely from clinical trials may not be feasible given that equity-relevant subgroups may vary across geographies and due to the challenges of securing sufficient sample size to examine effects across groups. Therefore, retrospective data will play an increasingly important role in measuring existing differences in disease burden and treatment access across subgroups. In the absence of such data, researchers may wish to conduct scenario analyses to explore the impact of a range of different assumed distributional effects, or assume the same treatment effect across subgroups.

Information on the distribution of opportunity costs can be estimated by measuring the changes in health expenditure by key equity-relevant subgroups.[68-70] However, many geographies lack representative data on patient outcomes, aspects of social disadvantage, and resource/expenditure patterns for the entire population. Collection of such data can be particularly challenging in low- and middle-income countries for reasons including resource constraints, system and technology limitations, and challenges accessing certain population groups.[71] Therefore, work will be needed to improve existing data sources through enrichment, linkage, and use of statistical methods to address suppression of data for privacy or data missingness. Although generation of these data may require notable effort, its value extends beyond use in DCEA. With these new data, decision makers can (1) understand and identify patients who will benefit the most from interventions, (2) use data-driven insights to inform the design of inclusive clinical trials, and (3) better elucidate health equity issues to drive policy and public health intervention planning. In the absence of these data, researchers conducting DCEA will need to make assumptions, for example, assuming the same distribution of opportunity costs as observed in other countries or assuming that opportunity costs are distributed equally across equity-relevant subgroups.

Finally, DCEA includes an evaluation of trade-offs between total health and health inequality using social welfare indices that incorporate health inequality aversion parameters.[72,73] These parameters describe the amount of total health that a decision maker would be willing to sacrifice to achieve a more equal health distribution. Inequality aversion parameters have only been studied in some countries and evidence informing them is limited.[73,74] In DCEA, these indices are used to evaluate the trade-off associated with the different interventions under comparison. Although inequality aversion parameters allow quantitative trade-off between equity and efficiency, without such data DCEA is still a valuable tool in allowing decision makers to understand equity impacts and balance these against efficiency objectives in a more qualitative or deliberative manner.

Conclusion

Several challenges to addressing health equity with HEOR persist. First, evidence produced through equity-informative methods is only useful if health equity is understood by those determining the allocation and distribution of healthcare resources to be an important decision-making criterion, alongside effectiveness and efficiency considerations that have historically taken primacy in applied HEOR. Second, equity-informative methods are data intensive and require additional technical and computational capacity. We believe that professional societies such as ISPOR, International Health Economics Association, and Health Technology Assessment International, which have dedicated interest groups on health equity research, play an important role in building capacity for equity-informative methods. Finally, although innovations in health equity and HEOR are valuable and welcome, it is important to note that health equity is only one dimension of value often overlooked in HTA.[75]

Encouragingly, HEOR as a field is adept at using new methods, data sources, and long-standing best practices to inform important decisions in the face of data gaps and uncertainty. Therefore, although addressing the challenges outlined in this primer should remain a paramount goal for all stakeholders, improved and enriched data and methods for DCEA can be used today to better embed health equity into the field of HEOR.

Author Disclosures

Author disclosure forms can be accessed below in the Supplemental Material section.

Supplemental Material

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Author Affiliations: Costello Medical, London, England, UK (Griffiths); Centre for Health Economics, University of York, York, England, UK (Cookson); Health Outcomes Division, College of Pharmacy, The University of Texas at Austin, Austin, TX, USA (Avanceña); Department of Internal Medicine, Dell Medical School, The University of Texas at Austin, Austin, TX, USA (Avanceña); Departamento de Salud Pública, Pontificia Universidad Catolica de Chile, Santiago, Chile (Espinoza); Centro para la Prevención y Control del Cancer, Santiago, Chile (Espinoza); Health Economics Center of Excellence, Boston Scientific, Marlborough, MA, USA (Jacobsen); Genentech, Inc, South San Francisco, CA, USA (Sussell); Genentech, Inc, Alameda, CA, USA (Kowal).

Correspondence: Matthew J.S. Griffiths, MSc, Costello Medical, 135 Park Street, London SE1 9EA, United Kingdom. Email: matt.griffiths@costellomedical.com

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REFERENCES

1. Whitehead M, Dahlgren G, WHO Regional Office for Europe. Levelling up (part 1): a discussion paper on concepts and principles for tackling social inequities in health. https://apps.who.int/iris/handle/10665/107790; Published 2006. Accessed February 14, 2024.
2. Brender JD, Maantay JA, Chakraborty J. Residential proximity to environmental hazards and adverse health outcomes. *Am J Public Health*. 2011;101(Suppl 1):S37–S52.

3. World Health Organization (WHO). Social determinants of health. https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1. Accessed February 14, 2024.
4. Marmot M, Friel S, Bell R, Houweling TAJ, Taylor S, Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. *Lancet*. 2008;372(9650):1661–1669.
5. *National Healthcare Quality and Disparities Report*. Agency for Healthcare Research and Quality; 2022. https://www.ahrq.gov/research/findings/nhqrdr/nhqdr22/index.html. Accessed July 23, 2024.
6. National Academies of Sciences, Engineering, and Medicine. *Ending Unequal Treatment: Strategies to Achieve Equitable Health Care and Optimal Health for All*. Washington, DC: National Academies Press; 2024.
7. Vasquez Reyes M. The disproportional impact of COVID-19 on African Americans. *Health Hum Rights*. 2020;22(2):299–307.
8. Baltussen R, Niessen L. Priority setting of health interventions: the need for multi-criteria decision analysis. *Cost Eff Resour Alloc*. 2006;4(1):14.
9. International Society for pharmacoeconomics and outcomes research. Health Equity Research Special Interest Group. https://www.ispor.org/member-groups/special-interest-groups/health-equity-research. Accessed February 14, 2024.
10. Kowal S, Ng CD, Schuldt R, Sheinson D, Cookson R. The impact of funding inpatient treatments for COVID-19 on health equity in the United States: a distributional cost-effectiveness analysis. *Value Health*. 2023;26(2):216–225.
11. Farooq F, Mogayzel PJ, Lanzkron S, Haywood C, Strouse JJ. Comparison of US federal and foundation funding of research for sickle cell disease and cystic fibrosis and factors associated with research productivity. *JAMA Netw Open*. 2020;3(3):e201737.
12. Ma MA, Gutiérrez DE, Frausto JM, Al-Delaimy WK. Minority Representation in Clinical Trials in the United States: Trends Over the Past 25 Years. *Mayo Clin Proc*. 2021;96(1):264–266.
13. Dahlen A, Charu V. Analysis of sampling bias in large health care claims databases. *JAMA Netw Open*. 2023;6(1):e2249804.
14. National Institute for Health and Care Excellence. Review of methods, processes and topic selection for health technology evaluation programmes: conclusions and final update. Appendix: further discussion and rationale for conclusions - methods. https://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-technology-appraisal-guidance/changes-to-health-technology-evaluation. Accessed July 3, 2022.
15. Weller D, Coleman D, Robertson R, et al. The UK colorectal cancer screening pilot: results of the second round of screening in England. *Br J Cancer*. 2007;97(12):1601–1605.
16. Angerer S, Waibel C, Stummer H. Discrimination in health care: A field experiment on the impact of patients' socioeconomic status on access to care. *Am J Health Econ*. 2019;5(4):407–427.
17. Grimes T, Marcilly R, Bonnici West L, Cordina M. Medication-related outcomes and health equity: evidence for pharmaceutical care. *Pharmacol (Basel)*. 2023;11(2):60.
18. Frazier TL, Lopez PM, Islam N, et al. Addressing financial barriers to health care among people who are low-income and insured in New York City, 2014-2017. *J Community Health*. 2023;48(2):353–366.
19. Cookson R, Griffin S, Norheim OF, Culyer AJ. *Distributional Cost-Effectiveness Analysis: Quantifying Health Equity Impacts and Trade-Offs*. Oxford, England: Oxford University Press; 2020.
20. Anand SS, Razak F, Davis A, et al. Social disadvantage and cardiovascular disease: development of an index and analysis of age, sex, and ethnicity effects. *Int J Epidemiol*. 2006;35(5):1239–1245.
21. Braveman PA, Kumanyika S, Fielding J, et al. Health disparities and health equity: the issue is justice. *Am J Public Health*. 2011;101(Suppl 1):S149–S155.
22. Center for Drug Evaluation and Research, Center for Biologics Evaluation and Research. Enhancing the diversity of clinical trial populations - eligibility criteria, enrollment practices, and trial designs guidance for industry. https://www.fda.gov/media/127712/download; Published 2020. Accessed February 14, 2024.
23. National Institutes of Health. NIH policy and guidelines on the inclusion of women and minorities as subjects in clinical research. https://grants.nih.gov/policy/inclusion/women-and-minorities/guidelines.htm; Published 2017. Accessed February 14, 2024.
24. Winter H, Willis J, Lang S, et al. Building capacity and ensuring equity in clinical trials during the COVID-19 pandemic. *J Clin Oncol*. 2021;39(15):13598.
25. Bodicoat DH, Routen AC, Willis A, et al. Promoting inclusion in clinical trials—a rapid review of the literature and recommendations for action. *Trials*. 2021;22(1):880.
26. Varma T, Mello M, Ross JS, Gross C, Miller J. Metrics, baseline scores, and a tool to improve sponsor performance on clinical trial diversity: retrospective cross sectional study. *BMJ Medicine*. 2023;2(1):e000395.
27. Kozlov M. FDA to require diversity plan for clinical trials. *Nature*; Published 2023. https://www.nature.com/articles/d41586-023-00469-4. Accessed February 14, 2024.
28. National Institute on Minority Health and Health Disparities. Diversity and inclusion in clinical trials. https://nimhd.nih.gov/resources/understanding-health-disparities/diversity-and-inclusion-in-clinical-trials.html; Published 2022. Accessed February 14, 2024.
29. Kahn JM, Gray 2nd DM, Oliveri JM, Washington CM, DeGraffinreid CR, Paskett ED. Strategies to improve diversity, equity, and inclusion in clinical trials. *Cancer*. 2022;128(2):216–221.
30. Scharff DP, Mathews KJ, Jackson P, Hoffsuemmer J, Martin E, Edwards D. More than Tuskegee: understanding mistrust about research participation. *J Health Care Poor Underserved*. 2010;21(3):879–897.
31. Rudrapatna VA, Butte AJ. Opportunities and challenges in using real-world data for health care. *J Clin Invest*. 2020;130(2):565–574.
32. Johnson CE, Whiteside YO. Real-world evidence for equality. *Health Equity*. 2021;5(1):724–726.
33. Cook LA, Sachs J, Weiskopf NG. The quality of social determinants data in the electronic health record: a systematic review. *J Am Med Inform Assoc*. 2021;29(1):187–196.
34. Patra BG, Sharma MM, Vekaria V, et al. Extracting social determinants of health from electronic health records using natural language processing: a systematic review. *J Am Med Inform Assoc*. 2021;28(12):2716–2727.
35. Remington PL, Catlin BB, Gennuso KP. The County Health Rankings: rationale and methods. *Popul Health Metr*. 2015;13:11.
36. McRae J, Onukwugha E. Why the gap in evaluating the social constructs and the value of medicines? *Pharmacoeconomics*. 2021;39(12):1365–1372.
37. Jarrín OF, Nyandege AN, Grafova IB, Dong X, Lin H. Validity of race and ethnicity codes in Medicare administrative data compared with gold-standard self-reported race collected during routine home health care visits. *Med Care*. 2020;58(1):e1–e8.
38. Meunier A, Longworth L, Kowal S, Ramagopalan S, Love-Koh J, Griffin S. Distributional cost-effectiveness analysis of health technologies: data requirements and challenges. *Value Health*. 2023;26(1):60–63.
39. Agboola F, Whittington MD, Pearson SD, Institute for clinical and economic review (ICER). Advancing health technology assessment methods that support health equity. https://icer.org/wp-content/uploads/2022/07/ICER_Advancing-Health-Technology-Assessment-Methods-that-Support-Health-Equity_040523.pdf; Published 2023. Accessed February 14, 2024.
40. Culyer A, Lomas J. Deliberative processes and evidence-informed decision making in health care—do they work and how might we know. *Evid Policy J Res Debate Pract*. 2006;2(3):357–371.
41. Cookson R, Griffin S, Norheim OF, Culyer AJ, Chalkidou K. Distributional cost-effectiveness analysis comes of age. *Value Health*. 2021;24(1):118–120.
42. Ward T, Mujica-Mota RE, Spencer AE, Medina-Lara A. Incorporating equity concerns in cost-effectiveness analyses: a systematic literature review. *Pharmacoeconomics*. 2022;40(1):45–64.
43. Welch VA, Norheim OF, Jull J, et al. CONSORT-Equity 2017 extension and elaboration for better reporting of health equity in randomised trials. *BMJ*. 2017;359:j5085.
44. Husereau D, Drummond M, Augustovski F, et al. Consolidated health economic evaluation reporting standards 2022 (CHEERS 2022) statement: updated reporting guidance for health economic evaluations. *Value Health*. 2022;25(1):3–9.
45. National Institute for Health and Care Research. Policy research programme - health inequalities. https://www.nihr.ac.uk/documents/policy-research-programme-health-inequalities/31336; Published 2022. Accessed February 14, 2024.
46. Lipkovich I, Dmitrienko A, B R D'Agostino Sr. Tutorial in biostatistics: data-driven subgroup identification and analysis in clinical trials. *Stat Med*. 2017;36(1):136–196.
47. Cookson R, Robson M, Skarda I, Doran T. Equity-informative methods of health services research. *J Health Organ Manag*. Published Online July 2, 2021. https://doi.org/10.1108/jhom-07-2020-0275.
48. Starks MA, Sanders GD, Coeytaux RR, et al. Assessing heterogeneity of treatment effect analyses in health-related cluster randomized trials: a systematic review. *PLoS One*. 2019;14(8):e0219894.
49. Cintron DW, Adler NE, Gottlieb LM, et al. Heterogeneous treatment effects in social policy studies: an assessment of contemporary articles in the health and social sciences. *Ann Epidemiol*. 2022;70:79–88.
50. Angus DC, Chang CH. Heterogeneity of treatment effect: estimating how the effects of interventions vary across individuals. *JAMA*. 2021;326(22):2312–2313.
51. Culyer AJ, Bombard Y. An equity framework for health technology assessments. *Med Decis Mak*. 2012;32(3):428–441.
52. Benkhalti M, Espinoza M, Cookson R, Welch V, Tugwell P, Dagenais P. Development of a checklist to guide equity considerations in health technology assessment. *Int J Technol Assess Health Care*. 2021;37:e17.
53. Innovation and value initiative - health equity initiative. No value without equity: transforming practice and accountability for equity in health technology assessment. https://thevalueinitiative.org/wp-content/uploads/2023/03/No-Value-Without-Equity_Synthesis-Insight.pdf; Published 2023. Accessed February 14, 2024.
54. Avanceña ALV, Prosser LA. Examining equity effects of health interventions in cost-effectiveness analysis: a systematic review. *Value Health*. 2021;24(1):136–143.
55. Yang F, Katumba KR, Griffin S. Incorporating health inequality impact into economic evaluation in low- and middle-income countries: a systematic review. *Expert Rev Pharmacoecon Outcomes Res*. 2022;22(1):17–25.

56. Collins B, Kypridemos C, Cookson R, et al. Universal or targeted cardiovascular screening? Modelling study using a sector-specific distributional cost effectiveness analysis. *Prev Med*. 2020;130:105879.
57. Saenz-de-Miera B, Wu DC, Essue BM, Maldonado N, Jha P, Reynales-Shigematsu LM. The distributional effects of tobacco tax increases across regions in Mexico: an extended cost-effectiveness analysis. *Int J Equity Health*. 2022;21(1):8.
58. Quan AML, Mah C, Krebs E, et al. Improving health equity and ending the HIV epidemic in the USA: a distributional cost-effectiveness analysis in six cities. *Lancet HIV*. 2021;8(9):e581–e590.
59. Arnold M, Nkhoma D, Griffin S. Distributional impact of the Malawian Essential Health Package. *Health Policy Plan*. 2020;35(6):646–656.
60. Essue BM, Jan S, Phuc HT, Dodson S, Armstrong K, Laba TL. Who benefits most from extending financial protection for cataract surgery in Vietnam? An extended cost-effectiveness analysis of small incision surgery. *Health Policy Plan*. 2020;35(4):399–407.
61. Goshua G, Calhoun C, Ito S, et al. Distributional cost-effectiveness of equity-enhancing gene therapy in sickle cell disease in the United States. *Ann Intern Med*. 2023;176(6):779–787.
62. Cookson R. Distributional cost-effectiveness: putting money where your mouth is on health equity. *Ann Intern Med*. 2023;176(6):866–867.
63. Verguet S, Kim JJ, Jamison DT. Extended cost-effectiveness analysis for health policy assessment: a tutorial. *Pharmacoeconomics*. 2016;34(9):913–923.
64. Love-Koh J, Cookson R, Gutacker N, Patton T, Griffin S. Aggregate distributional cost-effectiveness analysis of health technologies. *Value Health*. 2019;22(5):518–526.
65. Phillips RL, Liaw W, Crampton P, et al. How other countries use deprivation indices—and why the United States desperately needs one. *Health Aff*. 2016;35(11):1991–1998.
66. Abel GA, Barclay ME, Payne RA. Adjusted indices of multiple deprivation to enable comparisons within and between constituent countries of the UK including an illustration using mortality rates. *BMJ Open*. 2016;6(11):e012750.
67. United States Food and Drug Administration. Collection of race and ethnicity data in clinical trials. Guidance for industry and Food and Drug Administration staff. https://www.fda.gov/media/75453/download; Published 2016. Accessed February 14, 2024.
68. Love-Koh J, Cookson R, Claxton K, Griffin S. Estimating social variation in the health effects of changes in health care expenditure. *Med Decis Mak*. 2020;40(2):170–182.
69. Dieleman JL, Chen C, Crosby SW, et al. US health care spending by race and ethnicity, 2002-2016. *JAMA*. 2021;326(7):649–659.
70. Centers for Medicare and Medicaid Services Office of Minority Health in Collaboration with the RAND Corporation. Disparities in health care in Medicare advantage by race, ethnicity, and sex. https://www.cms.gov/sites/default/files/2022-04/PR-A1902-1_final_508.pdf. Accessed February 14, 2024.
71. O'Neil S, Taylor S, Sivasankaran A. Data equity to advance health and health equity in low- and middle-income countries: a scoping review. *Digit Health*. 2021;7:20552076211061922.
72. Asaria M, Griffin S, Cookson R. Distributional cost-effectiveness analysis: A tutorial. *Med Decis Mak*. 2016;36(1):8–19.
73. Robson M, Asaria M, Cookson R, Tsuchiya A, Ali S. Eliciting the level of health inequality aversion in England. *Health Econ*. 2017;26(10):1328–1334.
74. Abasolo I, Tsuchiya A. Exploring social welfare functions and violation of monotonicity: an example from inequalities in health. *J Health Econ*. 2004;23(2):313–329.
75. Lakdawalla DN, Doshi JA, Garrison Jr LP, Phelps CE, Basu A, Danzon PM. Defining elements of value in health care-a health economics approach: an ISPOR special task force [Report]. *Value Health*. 2018;21(2):131–139.