On the unfairness of the "fair-share principle" for health research

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Abstract

How ought scarce health research resources be allocated, where health research spans "basic", translational, clinical, health systems and public health research? In this paper I first outline a previously suggested answer to this question: the "fair-share principle" stipulates that total health research funding ought to be allocated in direct proportion with suffering caused by each disease. Second, I highlight a variety of problems the fair-share principle faces. The principle is inattentive to problems of aggregation and distribution of harms incurred from disease and benefits accrued from research, and neglects considerations of cost-effectiveness. Moreover, the principle fails to recognise that using Global Burden of Disease Study estimates as proxies for "suffering" underdetermines health research resource allocation. Importantly, in drawing on these estimates, which are disease-centric and only take "proximal" causes of health loss into account, the fair-share principle disregards the social determinants of health. Along with them, the principle ignores public health research, which often focusses on "distal" causes of health loss to improve population health and reduce health inequalities. Following the principle therefore leads to inequitable priority-setting. I conclude that despite relatively widespread appeals to it, the fair-share principle is not an ideal to aim for during priority-setting.

Key words

Global Burden of Disease Studies, Health Equity, Health Research, Philip Kitcher, Priority-setting, Public Health

Introduction

The questions of how societies ought to prioritise health research and how to allocate and ration scarce health research resources are urgent and receive relatively little attention. Health research is here understood broadly, following the World Health Organization (WHO), which defines health research as "the development of knowledge with the aim of understanding health challenges and mounting an improved response to them" (2012, 5). This development of knowledge spans "basic", translational, clinical, health systems and public health research (for this taxonomy, see Pratt and Hyder 2017). Accordingly, the health research resources in question include funding for different research programmes and research areas, scientists and technicians, computing power, laboratory space, research animals, clinical trial resources, experimental public health intervention resources etc.[1]

Calls from within academia to provide ethical analyses of research priority-setting (e.g. Pratt and Hyder 2017; Pratt et al. 2018) as well as global health and political events are beginning to raise the profile of these questions. For example, discussions concerning health research prioritisation came to the fore during the COVID-19 pandemic. Various funding bodies, including the US and UK governments, provided extra funding for laboratory-based biomedical/translational research on the virus and clinical research on therapies and vaccines, awarding these grants at extraordinary speed (Chinnery et al. 2021). This re-prioritisation and the "pivoting" of researchers from their areas of expertise to COVID-19 research was seen by some as "covidization", risking loss of expertise to study other infectious diseases (Pai 2020; Prudêncio and Costa 2020) and non-communicable diseases, in part because of loss of funding (BBC News 2020).[2] As a public health emergency, the pandemic also boosted investment into epidemiological, social science, and public health research (Bucher et al. 2023). Due to its global impact and the urgency to act in response, the pandemic highlighted the complexity of health research priority-setting. However, priority-setting is an ongoing and constitutive feature of health policy. And yet, with a few exceptions, philosophers have largely

not contributed to giving a substantive answer to the pressing question of how health research priorities ought to be set.

It is perhaps unsurprising that an infectious disease pandemic led to an uptick in research funding for epidemiological and public health research related to SARS-CoV-2. But as we know from decades of research in epidemiology, most adverse health outcomes, including non-communicable diseases, fall to some extent within the remit of public health. Since the mid-twentieth century different theoretical approaches to epidemiology have carved up the landscape of disease causation in a number of ways—ranging from the earlier "web" of disease causation to later social epidemiological theories (cf. Krieger 2024). No matter the precise approach favoured, however, the frameworks all agree that disease causation is complex; adverse health outcomes are never the result of a single cause.

In parallel with these developments in epidemiological and public health theory, there has been much progress as well as philosophical debate about how to measure disease burden and health outcomes (e.g. Lenard and Straehle 2012; Eyal et al. 2013; 2020b). For example, there have been extensive discussions covering the development of the disability-adjusted life year (DALY) as a combined index of health loss that takes both morbidity and mortality into account, the various ethical values embedded within the DALY and how they affect the use of the index in health policy (e.g. Voigt 2012; Schroeder 2017; Solberg et al. 2020).

In what follows I latch onto these debates, which have often proceeded in isolation from one another, by considering health research priority-setting. Overall, I show that questions about the validity of the DALY metric for health policy depends in important and often overlooked ways on how causes of health loss are represented in epidemiological studies. To do this I discuss the architecture of the most commonly used study of global health loss, the Global Burden of Disease (GBD) Study. Moreover, I demonstrate how the GBD interacts with a particular view of how health research ought to be prioritised, which leads to the sidelining of issues of concern for public health and inequitable health research funding allocation.

I first outline this particular way of tackling the question how health research resources ought to be allocated: the "fair-share principle" stipulates that health research funding ought to be allocated in direct proportion with suffering caused by each disease. Second, I highlight a variety of ethical and epistemic problems the fair-share principle faces. I divide these problems into "internal" and "external" problems. Internal problems refer to those problems that occur even when the framework within which the principle operates—namely one in which health research is construed narrowly and in biomedical terms—is accepted. External problems, on the other hand, refer to those that arise when this narrow framework itself is challenged. Internally, the principle is inattentive to problems of aggregation and distribution of harms incurred from disease and benefits accrued from research, and neglects considerations of cost-effectiveness. External problems arise when decades of work in epidemiology and public health is taken seriously: using GBD Study estimates of disease burden (Eyal et al. 2020a; Tichenor and Sridhar 2020) for the principle's implementation underdetermines health research resource allocation. My argument hinges on the premise that these DALY disease burden estimates are disease-centric and only measure or represent "proximal" causes of health loss. As such they disregard population and public health research that has long stressed the role of the social determinants of health. Therefore, the fair-share principle not only risks overlooking important lessons coming from population and public health research, but also ultimately fails to meet the standards of fairness in the allocation of funding it was striving to achieve. Building on these critiques I conclude that the fair-share principle is not an ideal to aim for when setting the health research agenda.

The fair-share principle for health research

Together with collaborators, the philosopher Philip Kitcher has advanced the so-called fair-share principle as a regulative principle to guide decision-making about the distribution of finite resources (i.e. funding) to health research. As will become clear, Kitcher and many others

conceive of health research narrowly—focussing on biomedical, translational and clinical research—to the detriment of certain considerations of fairness.

Kitcher's main concern in articulating this principle is the mismatch that has been characterised as the 10/90 gap in health research—"less than 10% of this [global spending on health research] is devoted to diseases or conditions that account for 90% of the global disease burden" (Global Forum for Health Research 2000, 1)—which continues to persist (Adam et al. 2023). Although other philosophers have also pointed out the "disparities" (Resnik 2004) and "distortions" (De Winter 2012) of the health research landscape, the focus is on Kitcher's analysis for three reasons. First, Kitcher sustains a discussion of the subject in multiple publications (Flory and Kitcher 2004; Kitcher 2004; 2011; Reiss and Kitcher 2009). Second, he proposes a clear principle to rectify the mismatch. Third, this principle represents the view of other scholars, including in global and public health, bioethics, health systems analysis, health policy and the health sciences (e.g. Murray 1994; Stuckler et al. 2008; Gillum et al. 2011; Evans, Shim, and Ioannidis 2014; Kinge et al. 2014; Hanna 2015; Yao et al. 2015; Millum 2023; C. B. Oliveira et al. 2023; Pandey and Adhikari 2023; Madsen and Andersen 2024).

In its most recent iteration, the fair-share principle states that:

> Waiving considerations of tractability, each disease should be investigated according to its contribution to the total suffering caused by disease. … However the contributions [to suffering] are assessed, if the principle is applied directly to the statistics on disease incidence, it is evident that actual research into diseases is skewed toward conditions affecting affluent people. Many diseases that kill or incapacitate poor people receive support on the order of one-hundredth of their fair share. (Kitcher 2011, 122)

How should this principle be interpreted? In particular, how should "total suffering" be understood, measured and operationalised? Flory and Kitcher "measure the alignment between disease burden" and the "directions of biomedical research" (2004, 39) by comparing

the share of the total global budget for health research[3] that goes towards researching malaria and tuberculosis with the share of the total number of deaths attributed to these diseases. They conclude that malaria and tuberculosis are not receiving their fair share of research investment. Since many people die of these diseases prematurely, and both those who do and don't die suffer from the diseases in other ways, Flory and Kitcher also use the DALY as a proxy for "total suffering". For a given condition, DALYs are calculated by adding the years of life lost to premature mortality (YLLs), calculated against a reference life expectancy, to the years of life lived with disability (YLDs). The larger the DALY, the larger the health loss. Based on DALY estimates gathered for the 2000 GBD study (World Health Organization 2000), Flory and Kitcher conclude that for malaria and tuberculosis using the total number of deaths or DALYs yields comparable results. This is unsurprising given that tuberculosis and malaria kill large numbers of young people; the YLLs thus contribute a larger share to the DALY than the YLDs.[4]

The authors also make the further point that individual biomedical researchers have a responsibility to address the 10/90 gap in health research by, for example, switching their research focus from arthritis to infectious disease research (Flory and Kitcher 2004, 60–61). Moreover, they suggest that "the biomedical research community in the affluent world has the obligation to modify the current research agenda so as to give much greater weight to investigations into the diseases that produce extraordinary suffering among the poor" (Flory and Kitcher 2004, 56). Note the emphasis on biomedical research.

The fair-share principle thus establishes a direct and proportional link between disease burden and health research investment. Various other authors also assume that measuring disease burden should guide or even determine research priority-setting, often implicitly and sometimes explicitly stating that funding ought to be distributed in direct proportion with disease burden. For example, work by Stuckler *et al*. found that the WHO budget 1994-2007 was "heavily skewed toward infectious diseases" (2008, 1563), awarding 87% of its total budget to infectious diseases despite the fact that they accounted for less than 15% of global mortality and DALY burden. The authors conclude that the WHO's budget was misaligned with

disease burden. Similarly, in their analysis of National Institutes of Health (NIH) funding, Gillum *et al*. conclude that "NIH funding is not better aligned with US disease burden [as measured in DALYs]" (2011, e16840) in 2006 than in 1999. Finally, Yao *et al.*, in designing an index for assessing this "misalignment" of health research funding and disease burden, assume "that to achieve maximal societal benefit, [research] resources should be allocated across the full distribution of illness proportional to the costs those illnesses impose on society" (2015, 809), where costs are operationalised in terms of DALYs. These examples illustrate that versions of the fair-share principle abound in the literature.[5]

Internal problems for the fair-share principle

Having explicated the fair-share principle I now turn to some of the problems it faces. Following the terminology proposed in the introduction, I start with the internal problems, i.e. those problems that arise when we take its tacit assumption—that the proper purview of health research should privilege biomedical, translational and clinical research—at face value.

Aggregation and distribution

The fair-share principle falls short of being action-guiding because it is widely recognised among scholars and policy-makers that resource allocation should take into account not only the amount of benefit a given research programme could contribute (i.e. how much suffering from disease could be reduced). Priority-setting should also consider the fair distribution of benefits among intended recipients as well as research programmes' cost-effectiveness (cf. Ottersen and Norheim 2020). Focussing first on the ethical issue concerning the distribution of benefits: maximising health at the aggregate level is not the only thing we care about. This is reflected in actual people's preferences to trade off maximal health gains against prioritising those with more severe symptoms/diseases. At least in the case of health *care* resource allocation, empirical studies suggest that people care about the equitable distribution of health benefits (e.g. Shah 2009; Nord and Johansen 2014; Gu et al. 2015). It is not unreasonable to

suppose that similar preferences apply to the allocation of health *research* resources. People might prefer investing in research for a relatively rare but severe disease rather than for a very mild but widespread adverse health outcome, even if the aggregate benefit of e.g. curing ingrown toenails would have been larger in terms of DALY reduction.

Since the fair-share principle relies on the aggregation of total suffering caused by each disease, it fails to address questions of distributional fairness when it comes to the disease burden experienced by individuals. For example, it turns out that in 2019—by the reckoning of the GBD Study—back and neck pain jointly contributed 3.37%, while malaria and tuberculosis jointly contributed 3.8% of global DALYs (Vos et al. 2020). Back and neck pain affect many more people than malaria and tuberculosis; but back and neck pain do not directly cause death. Although the aggregated DALYs are comparable, at the individual level the health loss of someone suffering from an average case of back pain is much smaller than the health loss suffered by someone with an average case of malaria. Assuming that the problems are "comparably tractable", the fair-share principle would recommend, counterintuitively, that health research into back and neck pain should receive almost equal amounts of funding as malaria and tuberculosis research.

To avoid this conclusion, Joseph Millum (2023) develops a revised version of the fair-share principle (or the "proportional view" in his terminology). The basic proportional view states that, "*[i]nsofar as the scientific opportunities are equal*, each patient merits research into their condition proportional to the burden of disease for which that condition is responsible" (Millum 2023, 77). This formulation allows judgements and claims at the level of individuals. Millum then assumes a moderate prioritarianism according to which there are reasons to benefit the worst off—with respect to health—even when doing so does not yield the maximal amount of health benefits overall. To incorporate this ethical stance, he proposes a severity-weighted proportional view according to which "each person has a claim to health research resources proportional to their *priority-weighted* burden of disease" (Millum 2023, 89). By evaluating health research resource allocations against a standard of moderate prioritarianism Millum captures the important insight that the distribution of benefits matters when it comes to

health research priority-setting, thus improving on the unmodified fair-share principle in this respect.[6] This, however, introduces the problem of just how much more weight should be given to diseases that make individuals worse off. Millum leaves this question open. Once an ill-defined priority-weighting is incorporated into the fair-share principle, this raises the more general problem of how the principle can be directly action-guiding.

Cost-effectiveness and tractability

Now consider whether the fair-share principle accommodates the idea that investment in health research needs to be cost-effective. Roughly, a research programme is more cost-effective than another if it is cheaper to implement to achieve a pre-defined target. Cost-effectiveness therefore incorporates two variables, the economic cost of a research programme and its expected benefit should it succeed. The benefit can be conceptualised as a reduction in DALYs. Although Kitcher and Millum include clauses on "tractability" and "scientific opportunity", respectively, these are not the same criteria as cost-effectiveness. Certain projects might be currently intractable and "however valuable it might seem to gain an answer to a particular question, it would be quixotic to undertake projects for which the existing conceptual and material resources are plainly inadequate" (Kitcher 2011, 32). There might, however, be tractable research programmes, for which conceptual and material resources *are* adequate, but whose implementation would be extremely expensive. This might be the case, for example, for pre-clinical cancer research using radiopharmaceuticals, where the radioactive raw materials are very expensive even though there are clear avenues for further research. Some research may seem so promising, i.e. the health benefits to be gained so large, that the high cost can be justified, but this is a separate consideration from research tractability. Given limited resources, weighing in on whether the cost of research can be justified is an ethical consideration that should not be sidestepped by "simply" applying the fair-share principle.[7]

Considerations of tractability and cost/cost-effectiveness thus make the evaluation of actual distributions of health research funding incredibly difficult, as both Kitcher[8] and Millum[9]

acknowledge. Even from within the narrow biomedical framework of the fair-share principle there are now three good reasons—giving priority to the worst off, factoring in tractability, and considering cost-effectiveness—for health research resources to be distributed out of proportion with disease burden, raising the question of the usefulness and applicability of the principle.

External problems: how the fair-share principle sidelines health inequalities

In addition to these three considerations there is another set of problems for the fair-share principle and related proposals that arises from its narrow focus on health research as biomedical research. These "external" problems become evident when work in epidemiology and public health is taken seriously, and they appear in the processes of specifying a research budget and drawing on real-world disease burden estimates. I will argue that these estimates underdetermine health research budget allocation in the sense that even comprehensive estimates are incomplete in a variety of ways, and that these estimates reinforce, and seem to justify, the fair-share principle's focus on biomedical research while neglecting the complex causal factors that are pivotal to public health.

To distribute health research resources according to the fair-share principle is to suggest that, waiving considerations of tractability, Disease X, which causes 10% of total suffering from all diseases, ought to receive 10% of the health research budget; Disease Y, which causes 5% of total suffering, ought to receive 5% of the health research budget, and so on. This simple allocation mechanism assumes that the collection of all diseases and the total health research budget can be represented as two sets, each containing the same number of elements (each disease is one element in the "disease set" and the budget is subdivided into portions to match the number of diseases) so that there is a one-to-one mapping between the elements of the sets. Does this simple mapping work? In what form is the "disease set" available? What does the health research budget consist of?

Specifying the health research budget

Starting with the latter question first, recall that in their assessment of malaria and tuberculosis research funding, Flory and Kitcher use estimates for the global health research budget to conclude that research into these diseases is underfunded when considering global disease burden (see endnote 3). Later they argue that funding levels should not be thought of as fixed to current levels. Instead, "affluent nations (in particular the United States) could afford to increase the [NIH] research budget so that such diseases as cancer were still funded at approximately their current levels … and the entire research budget were constructed by indexing to these amounts by applying the fair share principle" (Flory and Kitcher 2004, 63). Gillum *et al.* (2011) also scrutinise the NIH budget and Stuckler *et al.* (2008) analyse the WHO budget.

Any application of the fair-share principle needs to specify a budget. This is epistemically important because obtaining estimates for health research funding is non-trivial. Data gaps exist especially for national health research investments in low-income countries, and detailed breakdown of industry-funded research is often unavailable publicly (cf. Global Forum for Health Research 2001; Røttingen et al. 2013).[10] Thus, being clear about which research budget is being invoked in an application of the fair-share principle is important both because it clarifies the size of the research budget to be parcelled out, and it can alert researchers to the need for gathering more data on health research resources. What is often overlooked by proponents of the fair-share principle and similar proposals, however, is that budgets like that of the NIH and WHO are not designed in purely disease-centric terms. Advocating for total funding to be parcelled out proportionally to disease burden necessarily reappropriates parts of those budgets that were reserved for other purposes, such as research capacity strengthening and personnel training.

Specifying the budget is also ethically important because different funders have different responsibilities towards a variety of stakeholders (cf. Pratt and Hyder 2017; Pierson and Millum 2018). It would be odd, for example, to charge a charity like Breast Cancer Now with not "aligning" its research funding with UK disease burden more generally, given its mission.

What a given funder's responsibilities ought to be—whether a health charity should aim at disease burden alleviation beyond its mission; whether a publicly-funded national research body ought to take global rather than national disease burden into account—is an ethical question that the fair-share principle presupposes an answer to.[11] However, even when a clearer context is set for applying the fair-share principle—e.g. divvying up the NIH budget in proportion to global disease burden—the underdetermination problem I describe in the following sections persists.

Global Burden of Disease estimates underdetermine research priority-setting

Turning now to the question of which diseases constitute the elements of the "disease set", let's take a closer look at the GBD Study, given how widely used and easily invoked it is. I will show that the studies' disease burden estimates reinforce, and seem to justify, the fair-share principle's focus on biomedical research, rather than taking into consideration a larger array of health determinants and approaches to health research.

The GBD Study was developed in the 1990s (cf. Murray, Lopez, and Jamison 1994) and the most recent study presents estimates for 2021 (Ferrari et al. 2024). Originally, the study was run by researchers at Harvard University, then moved to the WHO and is now overseen by the Institute for Health Metrics and Evaluation with funding from the Bill and Melinda Gates Foundation (Eyal et al. 2020a; Tichenor and Sridhar 2020). The overarching aim of these global studies has been to provide a comprehensive measure of the global burden of diseases, injuries and risk factors, with the derivative aim of using these estimates for policy-making. One of the intended uses of the DALY as an indicator of disease burden was to "aid in setting health research priorities" (Murray 1994, 429).

The health outcomes of the GBD are grouped at four levels of hierarchical categories, which are "mutually exclusive, collectively exhaustive of the mortality and morbidity burden, and relevant to global health policymaking" (Vos 2020, 16). Importantly, each health outcome is attributed to exactly one cause (categorical attribution). This simplification means, first, that the total number of deaths, attributed by cause, will add up to the actual number of total deaths;

second, that each death/DALY is attributed to only a single cause so that the numbers cannot be artificially "inflated". For example, if one hundred people die with/from HIV and TB, their deaths are all attributed to HIV and it would not be possible to say that one hundred people died of HIV *and* one hundred people died of TB. These features make the resulting estimates intuitive, but the drawback of categorical attribution is that it does not capture the actual causal complexity of health loss (cf. Murray and Schroeder 2020), a point to which I return below.

At the highest level, "Level 1 consisted of other COVID-19 pandemic-related outcomes and three broad aggregate categories: CMNN [communicable, maternal, neonatal, and nutritional] diseases; non-communicable diseases; and injuries" (Ferrari et al. 2024, 2136). Level 2 includes e.g. "neoplasms" and "musculoskeletal disorders" nested under non-communicable diseases; "maternal and neonatal disorders" and "respiratory infections and tuberculosis" under CMNN diseases; "transport injuries" and "self-harm and interpersonal violence" nested under injuries. Level 3 becomes more specific: "musculoskeletal disorders" are broken down into "low back pain" and "neck pain" etc.; "tuberculosis" is separated from "lower respiratory infections"; "self-harm" is separated from "interpersonal violence". At Level 4 there are even more fine-grained distinctions. For example, Level 3 "gynaecological diseases" are disaggregated at Level 4 into "endometriosis", "uterine fibroids", "premenstrual syndrome", "other gynaecological diseases" etc.[12] This is indeed a comprehensive attempt at capturing global health loss.[13]

This brief introduction to the GBD will hopefully begin to make clear that stating that e.g. malaria contributes 1.9% of total global DALYs and that a proportional amount of health research funding (e.g. from the WHO or NIH) should be invested in malarial research, implies that the remaining 98.1% of that health research budget should (proportionally) be invested in research on the other elements of the "disease set" as the GBD aggregates them, namely, "road injuries", "neck pain", "premenstrual syndrome" etc. However, as this list of diseases and injuries makes clear, there are some elements in that list that are not suitably addressed by research funded by the health research budget. Following the fair-share principle would involve investing 2-3% of the (global) health research budget into research addressing health

loss from road injuries, and about 1% into research on reducing health loss from interpersonal violence. Reducing health loss from some of these causes can and should be achieved through very different means.

What are the grounds of this "should"? In what sense is the health research budget "unsuited" to addressing certain elements in the "disease set"? There are several reasons why the GBD "disease set" is inappropriate for furnishing the fair-share principle, which I lay out in this and the following three sections. First, there are "diseases" among the GBD estimates that are in some sense intuitively unsuitable to the health research budget, such as road injuries, even when that budget is construed broadly to encompass research beyond biomedical and clinical research.[14] One way of dealing with this problem when using the GBD estimates is to screen off those causes—such as potentially the entire Level 1 injuries category—whose associated health losses are not (or should not be) within the remit of the health research budget. One advantage of this is that the percentage of DALYs lost due to e.g. malaria and tuberculosis would inflate, so one could make an even stronger case for the unjust underfunding of these diseases.[15]

In the case of road injuries, investments into better roads, enforcement of helmet and seat belt regulations, and lower speed limits—funded e.g. by the Department of Transport—may be more appropriate interventions for two reasons. Unlike much health research funding, embodied by NIH or UK Research and Innovation budgets, investing in safer roads intervenes in the complex causal landscape of health loss at an earlier, preventive stage.[16] And this is related to the second reason, which is that in the case of avertable road injuries, it would be better, morally speaking, to prevent health loss in the first place than to treat road injuries, even when this is not the most cost-effective option. This is thus an ethical reason for suggesting that the limited health research budget ought not be allocated proportionally to a cause of health loss for which other, more appropriate strategies exist.[17]

Unlike the element "road injuries", there are elements of the GBD "disease set", such as malaria and tuberculosis, about which there is widespread agreement that the health loss they cause could and should be reduced, at least in part, with further insights from health research.

In the case of malaria, some research programmes try to better understand the *Plasmodium* parasite with the aim of designing new drugs to interfere with its life cycle. Another approach is to develop more effective vaccines that do not need to be transported and stored at low temperatures. However, even in the case of malaria, other effective approaches may not be biomedical, such as investigating how best to distribute bed nets.

Back and neck pain are also good examples of elements of the disease set that are the purview of both health research, broadly construed, and non-health research budgets. Many cases of back pain are caused by strains sustained while lifting something heavy, and many cases of neck pain are caused by poor posture. One approach to reducing health loss from such pain is by investing in research programmes that aim at developing new or more effective pain medicines.[18] Another approach—funded by e.g. the Department for Work and Pensions in the UK—may look into "occupational health" more generally, for example by designing, testing and implementing new guidelines for ways of working at a desk that reduce the risk of neck injuries. A "socially responsible" epidemiological approach (cf. Valles 2021) will also investigate how the burden of back and neck pain differentially affects sub-populations and what might be done to reduce inequalities in health outcomes. These examples suggest that most, if not all, elements of the disease set ought to be tackled by some combination of health research and non-health resources. No element in the disease set is plausibly addressed *only* with the resources of a narrowly-construed health research budget.

Categorical attribution of causes obscures the roles of social determinants of health

Recall that the GBD studies use the convention of categorical attribution of causes, assigning a single "proximal" cause and thereby obscuring the complex causal landscape of actual health losses. When applying the fair-share principle to the "disease set" construed in this way there is thus a discrepancy between these narrowly-defined "proximal" causes, on the one hand, and the variety of ways in which the health losses could have been prevented or ameliorated, on the other.[19]

This discrepancy presents epistemic problems and ethical risks. On the epistemic side, James Woodward (2020) discusses how knowledge of "proximal" causes is not enough for prioritising disease research interventions for two reasons.[20] First, "proximal" causes are often not independent of one another. For example, recall that HIV/TB deaths are attributed by convention to HIV; the fair-share principle only "sees" the HIV burden and recommends more research accordingly, which, in this case, may well be an effective way of reducing health loss due to HIV/TB. But does that mean an HIV/TB death lends no support to the idea of investigating more effective antibiotics? Even in cases where the causes are not so clearly linked, e.g. in older adults who have type 2 diabetes and are also at risk of falls, completely eradicating type 2 diabetes using a new drug might not prevent a patient's injury or death from a fall in a given time frame. Thus, "excising" or intervening on a "proximal" cause may, under some circumstances, have no effect on health loss (injury or mortality in this case).

The second, related epistemic reason Woodward highlights is that we cannot predict the outcomes of prioritising certain diseases over others unless we know much more about the proposed disease interventions that result from the research. For example, reducing health loss from lung cancer could be brought about by a new drug that is highly effective against smoking-induced lung cancer, or by an effective anti-smoking campaign, or by increasing tax on tobacco. However, the latter two approaches will also reduce health loss from a number of other cancers as well as smoking-related heart disease. So, stating that lung cancer ought to be investigated in proportion to the disease burden attributed to it is insufficient for specifying the kinds of research or disease interventions that ought to be prioritised.

These epistemic considerations are related to the ethical risk of applying the fair-share principle to this narrow set of "proximal" causes. In addition to increasing overall population health, health policy also aims at reducing health inequalities. Insofar as health research priority-setting is part of health policy, health research priority-setting ought to take on these aims. In light of this second aim, we can see how applying the fair-share principle to GBD estimates also creates an ethical problem: by concentrating on "proximal" causes the principle risks entrenching a focus on these causes at the expense of more "distal" causes.[21] This is

problematic because although the exact mechanisms by which “distal” causes, including the social determinants of health, contribute to health loss are a matter of much research, it is near-universally accepted that these determinants do contribute to health loss. Importantly, they do so in ways that affect different (sub)populations differentially, with more disadvantaged (sub)populations more adversely affected.

As indicated above, in the case of smoking-related lung cancer there are many possible interventions to reduce health loss, ranging from biomedical research on immunotherapies to smoking cessation programmes to tobacco taxation to tackling poverty. These different interventions will have different effects both on the amount of health loss that can be averted and who will benefit most from them. For example, in high-income countries smoking cessation programmes are more likely to benefit people of higher socioeconomic status (Hiscock et al. 2012), who are also more likely to enrol in clinical trials and thus benefit from new pharmaceuticals (Donzo et al. 2024).[22]

When the fair-share principle draws on GBD estimates, its prescription for health research is tied to an oversimplified representation of health loss, which highlights “proximal” causes at the expense of the social determinants of health. The principle fails to be fair because attention to “proximal” causes narrows the focus on, and seems to justify, biomedical interventions, thereby sidelining population and public health research on the social determinants of health and perpetuating health injustices (cf. Goldberg 2014; Valles 2021). It seems only incidental—given the current health research agenda and disease distributions—that the fair-share principle recommends increasing health research on diseases like malaria and tuberculosis, which disproportionally affect disadvantaged populations. Although it is no accident that these diseases continue to affect mainly populations in the Global South, the principle itself does not take considerations of health inequalities and how they arose into account.

GBD Study lacks health loss estimates for most rare diseases

The GBD studies lack disease burden estimates for most rare diseases and this presents another issue, both epistemic and ethical, when the GBD is used as input into the fair-share principle. With a few exceptions, such as sickle cell disease, rare diseases are not captured in the GBD studies with enough granularity to be useful for the fair-share principle. For example, Huntington's disease is lumped under the level 3 category "other neurological disorders"; cystic fibrosis under the level 4 category "other endocrine, metabolic, blood, and immune disorders excluding thyroid disorders". There is thus no way to directly tease out disease burden estimates from the GBD studies for most rare diseases, making recommendations for proportional allocation of health research resources into rare disease research impossible. However, even if this problem could be overcome and more fine-grained data on rare diseases were available[23], the research resources the fair-share principle would prescribe investing in individual rare disease research would, by definition, always be at the low end. If the current NIH cancer research budget were kept at its current level, for example, and the rest of the research budget indexed to that (by increasing the NIH budget), the funding for research into malaria and tuberculosis would increase, assuming the budget is being allocated with reference to global disease burden. But this would still yield such low funding for individual rare diseases as to be practically meaningless.

There are two ways to solve this "internal" problem while sticking to the fair-share principle and its narrow biomedical scope. First, a health research budget could allocate more funding to the tractable rare diseases and the rest of the budget could then be calculated by indexing to the new rare disease budgets using the fair-share principle. This solution, however, would have to see a huge increase in the total health research budget, and it is not clear how this could be achieved. Second, more resources for rare disease research could be justified on the basis that this research is especially likely to yield insights that might also decrease the disease burden of common diseases. Since most rare diseases are caused by single genetic mutations, they are sometimes viewed as particularly tractable (cf. Lauer, Gordon, and Olive 2015). This reasoning, however, takes an entirely consequentialist approach to health

maximisation, leaving no room to justify adequate rare diseases research budgets to patients suffering from rare diseases.

Alternatively, if the narrow reading of the fair-share principle is challenged, as I have been recommending, then a different question arises for these monogenic rare diseases. To what extent is the incidence of each rare disease associated with the social determinants of health? If the incidence of a certain rare disease is not so associated (an open empirical question), i.e. if those determinants are not a viable point of intervention on the incidence of this disease, then there would be good reason to pursue more biomedical research into that disease specifically.[24] This mirrors a point made above: unlike in the case of road injuries, where there are lots of interventions that do not require health research, some rare diseases may mainly be tractable with more biomedical research. If so, this provides a reason to fund rare disease research beyond its "fair share".

"Basic" research, health systems and public health research

An important result of the examination of the "external" problems for the fair-share principle is that the "disease set" provided by the GBD studies underdetermines allocation of health research resources because it omits at least three crucial elements that are and should be part of health research, namely "basic" research, health systems and public health research (cf. Pratt and Hyder 2017).

A large portion of actual health research budgets goes towards funding "basic biological research" or "disease-neutral" research, like assembling biobanks, building digital databases for storing and annotating genomic data, or understanding yeast metabolism. For example, in a comparison of UK health research investment with UK disease burden (in DALYs via the GBD studies) only three quarters of the funding could be matched to "health categories", because "two health [funding] categories, *Generic Health Relevance* and *Disputed Aetiology and Other* have no equivalent GHE [WHO Global Health Estimates] codes" (UK Clinical Research Collaboration 2024, 36).[25] "Generic health relevance" is the largest area of funding, comprising almost a quarter of total health research funding.[26] The fair-share principle gives

no guidance about how much of the health research budget should be reserved for these kinds of research. How much less funding would malaria and tuberculosis research get once basic research is added as an element to the "disease set"?

In addition to assessing the UK health research budget in terms of "health categories", it can also be assessed by "research activities", which encompass underpinning research, aetiology, prevention, detection and diagnosis, treatment development, treatment evaluation, disease management, and health services research. Although there is no clear mapping between these types of activities and public health research, I estimate that approximately 10% of the UK's health research budget (parts of "aetiology" and "prevention") could be classified as public health research. It is noteworthy, for example, how much more is spent on research to understand "biological and endogenous" aetiological factors (17%), which is primarily undertaken in laboratories and does not form part of public health research, compared to "psychological, social and economic" aetiological factors (1%) (UK Clinical Research Collaboration 2024, appendix 6). Whether 10% is adequate for public health research is an open question, which the fair-share principle cannot address. The necessity of funding public health research, which often does not focus on single diseases in isolation and generally does not study the "proximal" causes of health loss, emphasises the inadequacy of the GBD studies' "disease set" as a guide for health research resource allocation.

In summary, there are both "internal" reasons—giving priority to the worst off, factoring in tractability, and considering cost-effectiveness—as well as "external" reasons—recognising a broader range of types of research and research funding, and going beyond "proximal" causes for health loss—for actual health research resources to be distributed out of proportion with disease burden and across a much wider range of research activities than the fair-share principle suggests.

Should the fair-share principle be rescued?

Given this extensive critique, should we nonetheless cling to the fair-share principle? To answer this question, I distinguish between two roles the principle could be playing. Either its prescriptions could be the ideal outcome to aim for and against which actual practices are to be judged, or it could be a starting point for setting the health research agenda. I will conclude that the fair-share principle is neither the right ideal to aim for nor a particularly helpful guide.

The fair-share principle as an ideal

Kitcher arrives at the fair-share principle via a thought experiment that is meant to clarify how democratic societies ought to organise their scientific activities. For Kitcher, the distribution of resources the fair-share principle prescribes is the one an ideal democratic society would and should endorse and implement (cf. Reiss and Kitcher 2009; Kitcher 2011). However, the preceding discussion shows in detail why the fair-share principle is not such an ideal: several factors justifiably lead away from the directly proportional allocation of research resources to disease burden.[27] Knowledge of these factors would be brought to the table by some of the ideal democratic deliberators in Kitcher's thought experiment. Ideal deliberators' preferences can and ought to change during deliberation to take into account expert knowledge and other deliberators' preferences. In particular, many deliberators would overcome their "ignorance about the plight of people whom inquiry often neglects [which] should be the prelude to sympathetic identification with them" (Kitcher 2011, 129–30). But it is not just increased sympathetic identification, however important, that would figure in these ideal deliberations. The considerations of tractability and cost/cost-effectiveness, a deeper understanding of the ways in which disease burden is measured and recorded, and an appreciation of how the fair-share principle obscures all but the "proximal" causes of health loss would also have to enter into ideal deliberation.[28] Although it is plausible that ideal deliberation would recommend increasing the amount and/or the share of health research resources for diseases such as malaria and tuberculosis from current levels, it is not clear that

ideal deliberators would come up with the fair-share principle. Ideal deliberation—especially if swayed greatly by increased sympathy and knowledge of historical neglect—may well yield the recommendation that malaria and tuberculosis research be allocated health research resources beyond their "fair share". Such deliberation could go further and recommend that research address not only "biological and endogenous" factors but also social and political determinants of health, which will affect a wide variety of health outcomes.

The above critique of the fair-share principle shows that it fails to reflect the crucial process of giving and taking reasons for justifying priority-setting. The principle obscures the reasons Kitcher has for advocating an increase in funding for tuberculosis and malaria research. He is particularly concerned with these diseases not only because they cause high health losses but because they affect and kill children and "produce extraordinary suffering among the poor" (Flory and Kitcher 2004, 56). This wording suggests an interest in more than mere proportionality, an interest in wanting to give reasons for redirecting research funding that appeal to considerations other than health (e.g. socioeconomic status, historical neglect). These ethical reasons could, should and do bear on actual health research priority-setting.

The fair-share principle as a means

If the fair-share principle is ruled out as an ideal, could it serve as a means? Could it be a useful starting point for guiding research priority-setting? This seems a more promising use of the fair-share principle. How could the foregoing critique stimulate "actual conversation, even if among non-ideal conversationalists" (Douglas 2013, 903) about health research agenda-setting? One approach in a practical health research priority-setting exercise might be to use the fair-share principle as a guiding framework to get a rough idea of how resources could be allocated. Then, in further deliberative steps, the proportions could be adjusted to take into account the severity of individual diseases, the cost-effectiveness and tractability of research programmes, and the various ways in which disease burden data underdetermine health research budget allocation.

The fair-share principle could also be a starting point for further research. In particular, the above critique highlights the need for more empirical research along a number of avenues. For example, in the absence of the possibility of conducting actual deliberations in which all viewpoints are represented, there is still space to conduct e.g. surveys of diverse groups of people to ascertain preferences regarding how to allocate health *research* resources (as opposed to health *care* resources) to diseases of varying severity. The discussion may also prompt research on whether and how to incorporate data on rare diseases in the GBD studies, and to what extent social determinants of health contribute to the incidence of rare diseases. With respect to the political processes of setting research priorities, there is a need to better understand how public funds are allocated to different programmes so that actual democratic deliberators can take this into account.[29] In addition to these possible avenues for future research, actual deliberation—potentially with the fair-share principle as an input—would no doubt suggest additional lines of inquiry.

The fair-share principle as a thought-terminating heuristic

However, even as a starting point for deliberation, a potential worry with such a seemingly simple principle is what the philosopher C. Thi Nguyen (2021) has called the seduction of clarity. Nguyen argues that we, as cognitively limited agents, have to prioritise our intellectual inquiries; we cannot investigate all epistemic problems and questions all the way to "the end". Instead, we are partly guided by phenomenal states that accompany epistemic achievements in deciding how to apportion our limited cognitive resources. In particular, "understanding is our successful grasp of parts of the world and their relationships, and the sense of clarity is the phenomenal state associated with understanding" (Nguyen 2021, 232). This sense of clarity—a sense of cognitive ease and fluency, the subjective sense that it is easy to process and integrate new information in a given domain—often correctly indicates to us that we have understood the issue at hand well enough, allowing us to move on to other issues. Conversely, a sense of confusion can prompt us to continue our investigation. Nguyen suggests that certain aspects of our epistemic environments, unwittingly

or deliberately, make use of this sense of clarity as a thought-terminating heuristic. Nguyen shows that a variety of "quantified systems" can evoke this sense because they are "by design, highly usable and easily manipulable. They provide a powerful experience of cognitive facility. It is much easier to *do things* with grades and rubrics than it is with qualitative descriptions" (Nguyen 2021, 245).

Similarly, I suggest it is much easier to *do things*—like using them in the fair-share principle—with DALYs as percentages of "total suffering" than with qualitative descriptions or even multi-dimensional measures of health loss. The fair-share principle's simplicity—in part produced by its appeal to metrics, and specifically by its appeal to the notion of "total suffering" that can be subdivided into parcels adding up to 100%, which, in turn, can be neatly mapped to the "total health budget"—may seduce us and act as a thought-terminating heuristic. Deliberators in a priority-setting exercise may find the principle so intuitive that it might be tempting to skip further steps that go into defending a genuinely fair allocation of health research resources that can do justice to the complex, multi-level phenomenon of a population's distribution of ill health (cf. Krieger 2024). Since the fair-share principle obscures such a large range of epistemic and ethical considerations, and because it could act as a thought-terminating heuristic, I suggest we abandon it all together.

[1] The questions being addressed here are therefore distinct from questions regarding the allocation and rationing of scarce clinical and health *care* resources, such as hospital beds, ventilators, vaccines, and medical staff. These questions receive ample attention in bioethics (e.g. Bognar and Hirose 2022).

[2] There were, of course, parallel debates about reduced provision of non-emergency medical *care* due to the rise of COVID-19-related health care needs.

[3] Notably, the figure Flory and Kitcher cite for the total global health research budget (approx. $70 billion USD in 1998) is derived from a Global Forum for Health Research report, which explicitly states that this estimated total budget includes funding for the "medical and natural sciences as well as social sciences including economics and behavioural science" (2001, 3). A central aim of the report was to create a classification system for health research funding that would go beyond biomedical research and include health systems research and research on "health determinants" (annex 2).

[4] It is a separate question, beyond the scope of this paper, whether DALYs are good measures of "total suffering" due to disease. Although the DALY is a plausible index of health loss, it is a highly value-laden measure. See, for example, Schroeder (2017) and Solberg et al. (2020) for critical discussions.

[5] Focussing on the allocation of development assistance and health aid rather than health research, Voigt & King (2017) similarly point out that studies evaluating this aid often assume that the aid/assistance should be provided in proportion to disease burden, but that disease burden and need are not necessarily the same thing.

[6] There are, of course, alternatives to prioritarianism for ensuring that the health needs of the worst off are given special concern.

[7] While considerations of cost-effectiveness seem straightforwardly ethical, considerations of tractability seem primarily epistemic: do we know where to go next with this research? Can we predict how useful (i.e. disease burden-reducing) a research programme will be? These questions themselves are non-trivial, but the question of tractability bleeds into ethical considerations of cost-effectiveness when deciding whether or not to invest in a research programme to make it more tractable so that there might be future benefits.

[8] "Mechanical application of the fair-share principle would be foolish, since considerations about profitable [sic?] inquiry should attend to considerations of research promise. Hence, the formulation given introduced the proviso that issues of relative tractability were waived. Consequently, the actual distribution of research effort might be defended by proposing that the affluent diseases actually investigated—possibly even overstudied—are especially likely to yield important insights." (Kitcher 2011, 122)

[9] Any attempt to criticise a particular health research resource distribution "face[s] the challenge of distinguishing a justified deviation [from proportionality] from a problematic mismatch" (Millum 2023, 90).

[10] In 2017 the WHO set up a Global Observatory on Health Research and Development with the aim of filling some of these gaps.

[11] In his arguments, Kitcher presupposes a cosmopolitan stance on global justice, whereby individual states have strong reasons to be concerned with addressing disease burden beyond their national jurisdictions.

[12] See https://vizhub.healthdata.org/gbd-compare/ for an interactive version of the data.

[13] Although see below for a discussion of the GBD's omission of most rare diseases.

[14] Schroeder (2017; 2019) discusses how different values embedded within the DALY make the index suitable or not for certain applications. Here I am concerned with an analogous problem: value-laden decisions about the way causes are represented in the GBD make it suitable (or not) for certain applications, such as health research priority-setting.

[15] Such an approach has been taken by Madsen and Andersen who compared the disease burden in Denmark – as estimated by the GBD Study – to the Danish research funding landscape (thus implicitly taking a statist approach). Importantly, they state, "[a]s our focus is on disease research, we exclude the injuries category" (2024, 5). They go on to show that certain conditions, including dysthymia, stroke and alcohol use disorders are "underfunded" compared to the share of total disease burden they cause in Denmark.

[16] An analysis of health research funding in the UK shows that government bodies and health charities spend approximately 7% of their budgets on "prevention", almost half of that is research on vaccines (UK Clinical Research Collaboration 2024).

[17] This approach of screening off categories has a disadvantage. Just because health losses associated with certain elements in the disease set should mainly be addressed by non-health budgets, surely some of the health research budget should go towards research into improved surgical techniques, for example, which may improve health outcomes following those inevitable road injuries that have not been prevented.

[18] Although his focus is on health law and policy, rather than health research priority-setting specifically, Goldberg argues that concentrating on access to pharmacotherapeutics for pain overlooks the "long

causal pathway between upstream, macrosocial factors and onset of disease/disease outcomes" (2013, 213).

[19] This point echoes early criticisms of those who wanted to use burden of disease measurements to directly (and in some cases proportionally) set health research budget allocations (Williams 1999; Mooney and Wiseman 2000). As Ottersen and Norheim put it, "[t]he fundamental point was that measures of disease burden focus on the *problem*, while priority setting is—or at least should be—primarily concerned with the *solutions*" (2020, 294–95).

[20] Although there is not enough space here to explore the nature of disease causation, others have also made a similar point about the non-independence of causes outside the framework of Woodward's "interventionism" (e.g. Hall 2020).

[21] For an interesting proposal to drop the proximal/distal terminology, see Krieger (2008). Due to space constraints I cannot consider this proposal here.

[22] Similarly, back pain is not distributed equally within populations; different interventions, from pharmaceutical intervention to better working conditions for manual labourers, will affect different subpopulations differentially, with implications for health-related inequalities (cf. Goldberg 2013).

[23] There are individual efforts to measure health loss in DALYs due to rare diseases (e.g. C. C. Oliveira et al. 2024), but so far they are not integrated into the GBD Studies.

[24] Even if social determinants of health are not associated with the incidence of certain rare diseases, they are still likely to make a difference when it comes to accessing healthcare and getting a diagnosis.

[25] Note that by comparing UK disease burden with UK health research funding, the authors of this report tacitly assume a statist approach, i.e. an approach that does not see strong reasons for a nation to consider disease burden beyond its jurisdiction.

[26] Unlike these two "disease-neutral" categories, the other health categories are more specific and divided, roughly, by organ system, e.g. "blood", "skin", "musculosketal", although "cancer and neoplasms" are separate. See the Health Research Classification System for further details: https://hrcsonline.net/

[27] See also Larroulet Philippi (2020) for a related critique of Kitcher's ideal theory approach.

[28] And, of course, there will be more considerations to take into account that I have not addressed or predicted here.

[29] Cubi-Molla et al. (2023) have found, for example, that different government departments in a number of Global North countries assign different (monetary) values to a quality-adjusted life year, such that departments of transport and environment tend to value such a year significantly more highly than departments of health. This affects how these departments make their rationing decisions, but these decisions are understudied and not transparent to potential deliberators.

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