Matching Taxpayer Funding to Population Health Needs

Michael Hanna

The most recently available data suggest that the situation has not changed much since. There are 29 diseases/conditions that have a clear match of terminological categories between the landmark Global Burden of Disease 2010 (GBD-2010) study and NIH’s recent reports (methodological details are available in the Appendix). Visualization of the data appears to suggest a reasonable correlation between funding and burden-of-illness for the diseases/conditions with matching data, while revealing 2 gross exceptions: ischemic heart disease and HIV/AIDS (Figure). However, a closer look at the exact ratios of research funding to burden-of-illness shows a very wide spread of over-funding and under-funding, with several extreme values at both ends of the scale (Table). Although these 29 diseases/conditions account for only about 44% of all NIH funding and nearly 54% of all burden-of-illness in high-income North America, the results presented in the Table and Figure are completely robust against issues of incomplete data. If complete data were available for NIH funding and burden-of-disease, the Figure and Table would have many more entries, but the entries already shown would not change one bit. Some of the “missing data” are due simply to NIH and GBD using different terms for categorization. To facilitate future analysis and better policy setting, NIH should begin reporting the amount of funding for all diseases and conditions used in the GBD study, using the same terms. Diseases/conditions that account for more than 1% each of the burden-of-illness in North America yet for which specific data on NIH funding are not available include: low back pain, other musculoskeletal disorders, neck pain, anxiety disorders, self-harm, falls, lower respiratory infections, preterm birth complications, and other cardiovascular and circulatory diseases.

NIH’s mission is “to seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.” In order to lengthen life and reduce disability, research funding would have to be directed toward those diseases and conditions that actually shorten life and cause disability. Thus, the Institute of Medicine and the Progressive Policy Institute have recommended that funding allocation be guided by the burden-of-illness. Previous studies have raised doubts about how well this is being achieved. Their analyses were slightly flawed though, because they performed statistical analysis (correlation coefficients and regression analysis) requiring little or no missing data and they discussed their results as if they did have complete data, but in fact the data they analyzed did not cover anywhere near 100% of NIH funding or US burden-of-illness.

In the present analysis of the most recently available public data, infectious diseases—specifically malaria, HIV/AIDS, and tuberculosis—appear to be grossly overfunded, relative to their burden-of-illness in the North American population. In particular, it is striking that HIV/AIDS still consumes nearly 10% of the entire NIH budget while accounting for less than 1% of the population’s total burden-of-illness. To this list of
infectious diseases, one may also add smallpox, which presumably has caused zero disability-adjusted life years worldwide since its eradication in 1977, yet which still receives $40 million per year in research funding from NIH,7 roughly the equivalent of 160 “R01” grants. Meanwhile, several other major health conditions—all of them noncommunicable—appear substantially underfunded. Ischemic heart disease, stroke, road injuries, violence, depression, lung cancer, chronic obstructive pulmonary diseases, and migraines each account for more than 1% of all burden-of-illness in America yet receive less than half the funding one would expect based on their burden to Americans’ health. Overall, this suggests that NIH funding patterns have not yet fully caught up with the broad epidemiological shift from the infectious diseases of the past to the lifestyle/environment health conditions of the present and future.10,11 And although the present results for these 29 diseases/conditions are entirely reliable and would not change if more data were available, we remain in the dark about all the other diseases and conditions that account for 46% of US burden-of-illness and up to 56% of NIH funding.

It is sometimes objected that research funding should not be matched to the burden-of-illness because many research studies, such as the Human Genome Project, cannot be attributed to any one specific illness. But this objection is entirely beside the point for several reasons. First, the data presented here only refer to research funding that the NIH itself was in fact able to attribute to a specific illness. That portion of research funding that can be attributed to specific illnesses should be allocated according to four other criteria in addition to public health needs: quality of the research, scientific opportunity, portfolio diversification, and infrastructure support.3 The latter two criteria seem difficult to measure objectively and may serve merely to misallocate research funding away from Americans’ real health needs. The former two criteria (scientific opportunity and research quality) seem quite reasonable on the surface, but upon deeper reflection, they seem more like a superficial cover for lack of proper long-term priority setting.9,12 For over time, the research community will “follow the yellow brick road” (ie, they will “go where the money leads”), thus creating a self-reinforcing feedback loop about where the NIH leads,5 which in the end means the NIH will “follow the yellow brick road” (ie, they will “go where the money leads”), thus creating a self-reinforcing feedback loop about where the NIH leads, so they do not seem relevant in explaining why research funding is not allocated proportional to public health needs. The former two criteria (scientific opportunity and research quality) seem quite reasonable on the surface, but upon deeper reflection, they seem more like a superficial cover for lack of proper long-term priority setting.9,12 For over time, the research community will “follow the yellow brick road” (ie, they will “go where the money leads”), thus creating a self-reinforcing feedback loop about which diseases/conditions are well researched versus which ones are abandoned as professional dead-ends. So, instead of passively following scientific trends and inertia, NIH and with reasonable certainty to a general field, such as cardiology, mental health, or dermatology. Such research funding could and should be dealt with in an analogous way, allocating it proportional to the sum of the burden-of-illness of all single illnesses within a broader field. Third, one might also argue that the NIH and/or the public should first decide how much research funding to dedicate to the different genres of research: basic versus translational versus clinical versus public health versus social science. Because although they are all important, each of these genres of research represents a rather different strategy toward reducing the burden-of-illness in the population, and each of them has different time horizons for impact and different ratios of risk to potential benefit. So, deciding how much of the federal budget to invest in each genre of research is really more a matter of public policy. But this is a separate issue worthy of its own discussion; here we are concerned only with research funding that is indeed attributable to a specific illness.

In the late 1990s, the NIH stated that research funding is allocated according to four other criteria in addition to public health needs: quality of the research, scientific opportunity, portfolio diversification, and infrastructure support.3 But these criteria seem difficult to measure objectively and may serve merely to misallocate research funding away from Americans’ real health needs. The latter two criteria (portfolio diversification and infrastructure building) could both be fulfilled just as well even if NIH funding was matched to burden-of-illness, so they do not seem relevant in explaining why research funding is not allocated proportional to public health needs. The former two criteria (scientific opportunity and research quality) seem quite reasonable on the surface, but upon deeper reflection, they seem more like a superficial cover for lack of proper long-term priority setting.9,12 For over time, the research community will “follow the yellow brick road” (ie, they will “go where the money leads”), thus creating a self-reinforcing feedback loop about which diseases/conditions are well researched versus which ones are abandoned as professional dead-ends. So, instead of passively following scientific trends and inertia, NIH and

Nonstandard Abbreviations and Acronyms

GBD-2010 Global Burden of Disease 2010 study
NIH National Institutes of Health

Symbol Key
5 malaria
6 tuberculosis
a breast cancer
b cardiomyopathy
c drug abuse
d depression
e lung cancer
f diabetes
g prostate cancer
h hypertension
i schizophrenia
j Alzheimer’s
k colo-rectal cancer
l arthritis
m chronic liver disorders
n asthma
o liver cancer
p pancreatic cancer
q road injury
r violence
s depression
t sickle cell disease
u stroke
v lung cancer
w COPD
x COPD
y migraines
Congress should proactively drive up the scientific opportunities and research quality precisely in the areas where it is needed most, by rationally allocating research funding proportional to American taxpayers’ current health needs. Put another way, it makes very little sense to continue spending US taxpayer dollars on malaria research simply because someone has written yet another clever grant proposal using the latest techniques, while Americans continue suffering from migraines, only because there is too little funding there to ever generate much progress.

Yet a large part of this problem of the distribution of research funding seems to arise (unintentionally and probably unawares) from the fact that Congress allocates the overall NIH budget directly to the 27 different institutes and centers of the NIH, each of which has its own limited domain of diseases/conditions to address. The amount of funding allocated to the various institutes is sometimes quite disproportionate to the burden-of-illness of that institute’s area, and many institutes do not have a dedicated institute at all. Thus, for example, in 2012, the National Cancer Institute received $5.072 billion (16.4% of the total NIH budget); the National Institute of Allergy and Infectious Diseases received $4.491 billion (14.6%); the National Heart, Lung, and Blood Institute received $3.079 billion (10.0%); the National Institute of Diabetes and Digestive and Kidney Diseases received $1.947 billion (6.3%); the National Institute of Neurological Disorders and Stroke received $1.626 billion (5.3%); the National Institute of Mental Health received $1.480 billion (4.8%); the National Institute

### Table: Ratio of the Portion of Research Funding to the Portion of Burden-of-Illness

<table>
<thead>
<tr>
<th>GBD-2010</th>
<th>DALY %</th>
<th>Ratio %</th>
<th>Fund %</th>
<th>NIH</th>
</tr>
</thead>
<tbody>
<tr>
<td>Malaria</td>
<td>0.001</td>
<td>49000%</td>
<td>0.49</td>
<td>Malaria</td>
</tr>
<tr>
<td>HIV/AIDS</td>
<td>0.69</td>
<td>1442%</td>
<td>9.95</td>
<td>HIV/AIDS</td>
</tr>
<tr>
<td>Tuberculosis</td>
<td>0.06</td>
<td>1183%</td>
<td>0.71</td>
<td>Tuberculosis</td>
</tr>
<tr>
<td>Breast cancer</td>
<td>1.31</td>
<td>198%</td>
<td>2.59</td>
<td>Breast Cancer</td>
</tr>
<tr>
<td>Cardiomyopathy and myocarditis</td>
<td>0.82</td>
<td>184%</td>
<td>1.51</td>
<td>Heart Disease - Coronary Heart Disease</td>
</tr>
<tr>
<td>Drug use disorders</td>
<td>2.55</td>
<td>133%</td>
<td>3.40</td>
<td>Drug Abuse (NIDA Only)</td>
</tr>
<tr>
<td>Chronic kidney diseases</td>
<td>1.43</td>
<td>126%</td>
<td>1.80</td>
<td>Kidney Disease</td>
</tr>
<tr>
<td>Epilepsy</td>
<td>0.40</td>
<td>125%</td>
<td>0.50</td>
<td>Epilepsy</td>
</tr>
<tr>
<td>Prostate cancer</td>
<td>0.74</td>
<td>112%</td>
<td>0.83</td>
<td>Prostate Cancer</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>3.13</td>
<td>110%</td>
<td>3.43</td>
<td>Diabetes</td>
</tr>
<tr>
<td>Alcohol use disorders</td>
<td>1.38</td>
<td>107%</td>
<td>1.47</td>
<td>Alcoholism</td>
</tr>
<tr>
<td>Hypertensive heart disease</td>
<td>0.76</td>
<td>92%</td>
<td>0.70</td>
<td>Hypertension</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>1.04</td>
<td>84%</td>
<td>0.87</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>Alzheimer’s disease and other dementias</td>
<td>2.50</td>
<td>68%</td>
<td>1.71</td>
<td>Alzheimer’s Disease + Frontotemporal Dementia</td>
</tr>
<tr>
<td>Colon and rectum cancers</td>
<td>1.44</td>
<td>68%</td>
<td>0.98</td>
<td>Colo-Rectal Cancer</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>1.24</td>
<td>67%</td>
<td>0.83</td>
<td>Arthritis</td>
</tr>
<tr>
<td>Cirrhosis of the liver</td>
<td>1.47</td>
<td>63%</td>
<td>0.93</td>
<td>Chronic Liver Disease and Cirrhosis</td>
</tr>
<tr>
<td>Asthma</td>
<td>1.29</td>
<td>57%</td>
<td>0.74</td>
<td>Asthma</td>
</tr>
<tr>
<td>Liver cancer</td>
<td>0.48</td>
<td>50%</td>
<td>0.24</td>
<td>Liver Cancer</td>
</tr>
<tr>
<td>Pancreatic cancer</td>
<td>0.84</td>
<td>49%</td>
<td>0.41</td>
<td>Pancreatic Cancer</td>
</tr>
<tr>
<td>Road injury</td>
<td>2.68</td>
<td>44%</td>
<td>1.18</td>
<td>Injury (total) Accidents/Adverse Effects</td>
</tr>
<tr>
<td>Ischemic heart disease</td>
<td>9.51</td>
<td>44%</td>
<td>4.14</td>
<td>Heart Disease</td>
</tr>
<tr>
<td>Interpersonal violence</td>
<td>1.21</td>
<td>41%</td>
<td>0.50</td>
<td>Violence Research</td>
</tr>
<tr>
<td>Major depressive disorder</td>
<td>3.75</td>
<td>37%</td>
<td>1.39</td>
<td>Depression</td>
</tr>
<tr>
<td>Sickle cell disorders</td>
<td>0.57</td>
<td>37%</td>
<td>0.21</td>
<td>Sickle Cell Disease</td>
</tr>
<tr>
<td>Cerebrovascular disease</td>
<td>3.16</td>
<td>32%</td>
<td>1.00</td>
<td>Stroke</td>
</tr>
<tr>
<td>Trachea, bronchus, and lung cancers</td>
<td>3.76</td>
<td>20%</td>
<td>0.75</td>
<td>Lung Cancer</td>
</tr>
<tr>
<td>Chronic obstructive pulmonary disease</td>
<td>4.36</td>
<td>8%</td>
<td>0.33</td>
<td>Chronic Obstructive Pulmonary Disease</td>
</tr>
<tr>
<td>Migraine</td>
<td>1.03</td>
<td>6%</td>
<td>0.06</td>
<td>Migraines</td>
</tr>
</tbody>
</table>

**Total** | **53.60** | **81%** | **43.65** | **Total**

The table shows the portion of burden-of-illness, the portion of research funding, and their ratio for the 29 diseases/conditions for which there was a close match of terminology between the two data sources. The far left column shows the categories used in the GBD-2010 study; the far right column shows the categories used by NIH. The inner left column is the percent of all DALYs from the GBD-2010, and the inner right column is the percent of the total NIH budget, both as described in the Appendix. The middle column is the percent of funding divided by the percent of burden-of-illness, expressed as a percentage. Thus, in principle, 100% would mean an exact matching of funding level to burden-of-illness. As can be seen at the bottom though, the total shows that the overall midpoint lies at 81%. Logically, this does not mean that NIH is 19% underfunded. Most of this missing 19% probably only reflects the incompleteness of this list of diseases/conditions and the fact that some research funding cannot be attributed to a specific disease or condition. Some slight portion of it may also represent allocation of funding to research on diseases that do not cause any burden-of-illness in the North American population (eg, smallpox). Some of it also reflects the fact that a portion of the total NIH budget is directed to activities and costs other than research, such as administration, training, and infrastructure at the NIH. But however the explanations may be, the point to keep in mind is that 81% (not 100%) is the midpoint for the data available here. DALYs indicates Disability-Adjusted Life Years; GBD-2010, Global Burden of Disease 2010 study; NIDA, National Institute on Drug Abuse; and NIH, National Institutes of Health.
of Environmental Health Sciences received $0.764 billion (2.5%); the National Institute of Arthritis and Musculoskeletal and Skin Diseases received $0.536 billion (1.7%); the National Institute of Child Health and Human Development received $0.416 billion (1.3%); and the NIH overall received $3.075 billion (10.0%) earmarked specifically for research on HIV/AIDS. After funding has been allocated to the different institutes in this way, it is probably rather difficult to ensure that every illness receives a slice of the overall NIH budget proportional to its actual burden-of-illness on the population.

The financial allocations by Congress to the various NIH institutes may be influenced by outside lobbying from special interest groups (either patient/illness groups, industry, or occupational representatives), whose interests are not identical with the best interests of the nation as a whole, as seen in previous research funded by the NIH itself. A sophisticated study using multiple sources of quantitative and qualitative data on 15 diseases over 19 years found that single-disease advocacy had a strong relationship with funding changes: every $1000 spent on lobbying for a disease yielded an increase of $250,000 in NIH/Department of Defense research funds for that disease the following year, even without including the outliers of HIV/AIDS and breast cancer. The media surely also shapes the perceptions of Congress and the public about the importance of some illnesses, in ways that do not correspond scientifically with their actual burden-of-illness on the population. Mechanisms should be put in place to ensure that taxpayer funding for medical and scientific research reflects the epidemiologically objective health needs of the entire nation as a whole, without being distorted by any lobbying efforts or media campaigns driven by specific subgroups of patients, much less other business or occupational parties. But regardless of how much influence lobbying and media attention have on the distribution of funding or not, there seems to be a fundamental problem of allocating the overall budget for medical research to a variety of institutes rather than to the NIH as a whole because these institutes do not map well to the entire spectrum of all illnesses and because they are receiving different levels of funding that seem vastly disproportionate to the relative burden-of-illness for the diseases and conditions each institute is charged with addressing. Some effort should be made at the Congressional level to at least rebalance the funding levels of the various NIH institutes relative to the burden-of-illness in their respective areas, or even to restructure NIH altogether, ideally into a single entity with a unified budget.

One of the main reasons why research funding should be closely proportional to the burden-of-illness is because it would be difficult to justify any other arrangement to the citizenry. America is a country that prides itself as being based on principles of equality, fairness, and justice. So most Americans would probably expect that the total pool of taxes for research funding be distributed more or less equitably among the illnesses that are affecting the health of the American people. Among the research community, it might sometimes seem like there are other scientific or practical reasons for distributing the available research funding according to some other set of criteria, and that as scientists we know best anyway. But there is a deeper unaddressed question here about the ethics and policy of a society that collects taxes from the entire nation but then substantially concentrates its research on some patient populations while leaving other patient populations semi-neglected. Put in more human terms, imagine that we are sitting face-to-face with a patient with severe migraines. How would we explain to her why such a low portion of medical research funding is directed toward research on migraines? Would she accept our explanation as ethical and just? No matter what the scientific or administrative explanations might be, the current distribution of research funding seems to be fundamentally unfair toward patients suffering from diseases or conditions that are substantially underfunded relative to their burden-of-illness on the population. So most taxpayers would probably not support such imbalances, if they were aware of them. But if Americans’ taxes for medical research were being fairly distributed on all the illnesses that currently burden their health, then most Americans would probably support an overall increase in funding levels for medical research across the board.

Overall, the NIH surely does a good job of managing a complex set of decisions about awarding research funding. Nonetheless, the resulting distribution of taxpayer dollars does not always match up well with America’s actual distribution of burden-of-illness. Fifteen years ago, the Institute of Medicine gently pointed out this problem to the NIH, while simultaneously shielding them from outside interference. Unfortunately, current data (as shown in the Table here) imply that not much has changed since then, probably because NIH cannot really implement such a change. NIH relies mainly on peer review of investigator-initiated proposals to make funding decisions from the bottom up, mostly within specific fields of illness represented by a single NIH institute. But if the American people want their tax dollars to be shifted away from HIV/AIDS and toward heart disease, for example, then this decision needs to be made top-down at the level of Congressional appropriations. Such a decision is not a question of scientific opportunities or research quality but instead is a question of health priorities and public values. Although the expertise of NIH and its peer reviewers is essential in choosing among specific research proposals for any one illness, the larger policy question of how to allocate taxpayer funding among various medical areas should not be abdicated by the public to technocratic evaluations of the specific grant proposals nor to historical inertia of the Congressional allocations. The general public (including the broader healthcare community) should become more actively involved in this policy making because all NIH funding is really the public’s hard-earned tax money and should have the overriding goal of improving their health. Similarly, “Congress has a constitutional duty to ensure that tax dollars are spent properly and to set policy,” so they should readjust their appropriations to the various NIH institutes, to be consistent with the current distribution of burden-of-illness in the American population.

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Disclosures

None.
Appendix: Methods

The Table and Figure are based on publicly available cross-sectional data. The burden-of-illness was represented by disability-adjusted life years (DALYs) data from the Global Burden of Disease Study 2010 (GBD-2010). DALYs are a way to measure the burden of a disease or other health condition on the population. DALYs are the sum of years of life lost (because of early death, relative to normative life expectancy at each age) and years lived with disability (weighted by the percent severity of the health loss and allocated among all comorbidities). DALYs have become the standard way to measure burden-of-illness, and two previous studies have determined that DALYs are the only independent predictor of how much research funding the National Institutes of Health (NIH) allocates to various diseases and conditions. To facilitate future comparisons across countries or years, absolute data were converted here to percentages of the total. The DALYs for each disease/condition for high-income North America were divided by the total number of DALYs for all causes for high-income North America (90,160,242; personal communication) to arrive at a percentage of all burden-of-illness for each disease/condition. Similarly, the percentage of NIH research funding for each disease/condition was calculated by dividing NIH’s “Estimates of Funding” in Fiscal Year 2012 by the total NIH discretionary budget for Fiscal Year 2012 ($30.9 billion). Disease/condition categories were eliminated if and only if there was no clear match between a GBD-2010 category and an NIH category. The magnitude of overfunding/underfunding was then calculated for each disease/condition by dividing its percentage of NIH funding by its percentage of burden-of-illness. Because the available data covered far less than say 80% of all NIH funding and burden-of-disease and because the available data cannot be assumed to be a representative sample of all the diseases/conditions, it was considered inappropriate to calculate a correlation coefficient or perform regression, as past research had done. If complete funding and burden-of-disease data were available, the results of any correlation or regression analysis would surely be different than what would be obtained with the present dataset. By contrast, the results presented in the Figure and Table would not change at all if more complete data were available. If more complete data were available, there would simply be more entries in the Figure and Table.

References

tachment/2017336178/2037711222/mmc1.pdf.

Key Words: burden-of-illness • NIH • research funding
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