Burden of Disease and NIH Funding Priorities

Posted on June 19, 2015 by Sally Rockey and Carrie Wolinetz

Dr. Carrie Wolinetz is NIH’s Associate Director for Science Policy, and writes about biomedical research policy issues on her new blog, Under the Poliscope.

Recently, many voices have asked how NIH considers public health needs when setting funding priorities. The quick answer is that public health needs are a critical factor in our decision making—in addition to scientific merit, portfolio balance, and budgetary considerations. But the question of how one measures public health need, as it turns out, isn’t as simple as you might think.

Public health needs are not only reflected by how many people have a particular disease, but also by the burden of disease – the impact of a health condition as measured by mortality, morbidity, financial cost, and other indicators. Different diseases can impose vastly different kinds of burdens. Some diseases may cause premature death, while other chronic conditions may cause long-term disability and impose a great emotional and monetary toll for patients, family members, and society. Many diseases vary widely in the severity of symptoms, the acute vs. chronic nature of the disorder, treatment strategies, and health outcomes. A thousand people with influenza, for example, is not equivalent to a thousand people with headaches. To further complicate matters, identifying affected individuals can be challenging;
diagnosing certain psychiatric disorders is far different than diagnosing diabetes. Current disease burden may not necessarily predict future disease burden. Consider the potential burden that the recent Ebola epidemic may have created had it not been contained. And finally, NIH will invest in research on certain diseases that are close to a cure, to propel us towards the ultimate goal of eradication.

Clearly, there can be no "one size fits all" approach to measuring and comparing the burden across different diseases. Nevertheless, we wanted to look at a few possibilities for depicting the relationship between disease burden and NIH funding. Thus, NIH’s Office of Extramural Research and Office of Science Policy collaborated on an exploratory analysis, which you can see on our new burden of disease page on RePORT. This page illustrates how NIH funding levels relate to U.S. and global deaths and disability-adjusted life years (DALYs)—a measure that quantifies the number of healthy years of life lost due to morbidity or premature mortality caused by disease. This analysis comes with several caveats, however, and more information can be found via the methodology link on the disease burden page.

We think you'll find these data interesting, and we hope this analysis contributes to the conversation of advancing public health through scientific research. That being said, disease burden can't be the only factor in setting funding priorities. NIH is also committed to funding research into rare diseases, which affect a smaller component of the population, thus skewing burden measures. Much of the NIH portfolio involves basic research, which seeks to understand the basic biological processes involved in both health and disease. Basic research doesn't neatly map onto the burden of a single disease or condition, especially for areas such as genetics or pediatrics. Many of the projects from NIH’s basic research portfolio produce findings that can have implications for the cause and treatment of a variety of diseases, and can be applied across several fields.

As NIH sets its priorities, it’s important that we monitor the public health landscape for unmet needs and emerging challenges, so that the research we support translates into meaningful health benefits. Scientific disciplines mature at different rates, and not all areas are equally ripe for major scientific progress. For example, advances in imaging technologies and tools for mapping connections between neurons now allow us to study the brain and the diseases that affect it in a way that would not have been possible a decade ago. Investing the same amount of money into two different areas can generate very different returns for increasing scientific knowledge and advancing human health. Getting the most out of NIH’s research investment means making smart
investments, which come from a deep understanding of the scientific landscape. So while we’re looking forward to using these analyses as a jumping off point for a larger conversation about priority setting, NIH believes that a process that includes multiple measurements of public health needs, but is also informed by scientific opportunity, allows us to fund the best science.

This entry was posted in blog, Rock Talk and tagged disease burden, Funding data, RCDC, RePORT, Science policy by Sally Rockey and Carrie Wolinetz. Bookmark the permalink [https://nexus.od.nih.gov/all/2015/06/19/burden-of-disease-and-nih-funding-priorities/].

16 THOUGHTS ON “BURDEN OF DISEASE AND NIH FUNDING PRIORITIES”

Angie Johnston on June 24, 2015 at 5:10 am said:

I have always wondered how you prioritized, as well, and I want to sincerely thank you for the answer. It’s nice to see that the NIH is this well-rounded.
I have a friend in medical research, and she says that everyone she knows does it out of pure interest in the research.

Richard Weinberg on July 1, 2015 at 8:45 pm said:

Yes, it’s nice to see that NIH thinks about these things. However, as hinted on the RePORT page, it’s not clear how to measure “burden” fairly.

Death has the advantage of being readily measurable, but certainly doesn’t tell the whole story, nor does DALY, though at least it tries.

NMS on July 1, 2015 at 8:47 pm said:

By monitoring “the public health landscape for unmet needs and emerging challenges” you probably could not miss the fact that cardiovascular diseases are still the major killer of americans and cost us trillions, yes, “T” of dollars. Yet no new perspective medication has emerged in the last 20 years after the memorable discovery of statins. How comes? The answer is known: NIH still operates for process rather than results, it does not encompass the entire creative process from the initial investment to the conclusive result that was supported by finding authorization. Instead, NIH officials continue to congratulate each other on job well done immediately following the distribution of the allocated money, year after year, probably assuming that
the job indeed is done. Well, the most important task today is to make the governmental programs productive. It will be one of the major issues of the forthcoming presidential election campaign. Above all, this should include the NIH. Tomorrow will not be as today, but more for the NIH, – this time has gone for good. NIH should educate itself how to become a leader in knowledge work management, to be able to present public the results not in new imaging technologies, but in bioeconomy, in health care.

Margalit on July 6, 2015 at 12:34 pm said:

Why is NIH still treat AIDS grants differently? For every NIH PA or PAF, there are AIDS and non-AIDS considerations. AIDS is not the biggest health issue and shouldn’t get special treatment. Right now, it has set asides and preference without any reason

James Mugisha on February 12, 2016 at 7:34 am said:

I think I differ in opinion with Margalit. HIV still needs focused and enhanced funding as long as the specific cure is not yet found. HIV should remain high on nations agenda considering the economic, cultural, social dimensions of the disease. treating like any other diseases may cause laxity and the gains so far achieved can begin to regress.
Hello, Dr. Wolinetz. I think it’s important to note that this commentary is about the public’s health—but it is NOT about public health, so I’d recommend some editing. If it were about public health, the assessments would have examined funding/programs in relation to the preventable risk factors (i.e., “upstream causes”, such as smoking, bad nutrition, malaria, HIV, environmental contaminants, etc.) that are known to cause the global burden of disease, rather simply the global burden of disease itself. This would lead to a very different analysis and, I would venture, demonstrate that NIH’s focus is mainly on therapeutics/treatment (as well as basic research, as you outlined) rather than prevention, which is the cornerstone of public health. BTW, the global burden of disease project does also extend to a broad analysis of risk factors (see, for example, Lim et al., A comparative risk assessment of burden of disease and injury attributable to 67 risk factors and risk factor clusters in 21 regions, 1990-2010: a systematic analysis for the Global Burden of Disease Study 2010. Lancet. 2012 Dec 15;380(9859):2224-60. doi: 10.1016/S0140-6736(12)61766-8. PubMed PMID: 23245609.) Best wishes–Howard Hu MD MPH ScD, University of Toronto

Perfectly stated.
Descriptive epidemiology is part of public health just like risk factor analysis.

I hear you loud and clear and share your opinion. This is the eternal frustration when applying for NIH funding for any Social Epidemiologist/Scientist. Preventing disease by looking upstream is not sexy enough, I suppose(?)

I was interested to see how funding for back pain, neck pain, and other musculoskeletal disorders came out, so looked to the methodology link provided above. Although these conditions are ranked #6, #21, and #24 in global DALYs and #3, #11, and #6 in US DALYs, they were not included in the list of conditions on the NIH burden of disease site. I am guessing these conditions were excluded because they were not able to be matched with current NIH research, condition, and disease categories. Leaving these common and burdensome conditions out seems to have potentially important implications for both NIH priority setting and the public health. Certainly the figures would look different if they were included. Is it time to step back and examine
what is and is not included in the NIH research, condition, and disease categories?

Robert E. Shapiro, MD, PhD
on July 2, 2015 at 5:43 pm said:

Dr. Wolinetz’s comments bring welcome attention by the NIH Office of Science Policy to the enduring problem of disparities between NIH research funding and public health needs as measured by disease burden.

This is not a new problem or a new discussion. In 1999, in response to Congressional concerns, former NIH Director Harold Varmus testified to a similar set of priorities guiding NIH funding policies as currently outlined by Dr. Wolinetz ([http://www.hhs.gov/ash/testify/t990506a.html](http://www.hhs.gov/ash/testify/t990506a.html)).

Regarding NIH and disease burden, Dr. Varmus stated that “To further explore the potential utility and strengths and limitations of disease-specific burden of illness, this summer we are convening a small group of experts to identify data sources, review models for the use of burden/cost of disease data, and explore how NIH might more effectively use this data.” Skip forward across a slow-walk of 16 years later, and NIH now states (page 13, [http://1.usa.gov/16brxB](http://1.usa.gov/16brxB)) that: “…funding is not directed to any specific disease research area”, but that “Peer review, scientific opportunity, and public health needs are key factors in the National Institutes of Health’s (NIH’s) priority-setting and resource allocation processes.”

Of course, it is definitely not the case that NIH “…funding is not directed to any specific
disease research area”. NIH RFAs, PAs with set-aside funds, special programs, and broader initiatives have always been issued to focus funding (currently Precision Medicine, BRAIN initiative, ADNI, etc). Dr. Wolinetz acknowledges as much when she states that “NIH will invest in research on certain diseases that are close to a cure” and that “NIH is also committed to funding research into rare diseases”, etc. Moreover, NIH itself is grossly structured to direct funds towards some disease areas rather than others. That is, Institute budgets are limited to particular spheres of disease that remain stable through the protected guardianship of the NIH Institute Directors. For example, cancer research might be enhanced by the successful promotion of an increase in the NCI budget by the NCI Director.

NIH administrators have often cited a guiding policy of funding only the best research proposals submitted by independent scientists, as reviewed and determined by their research peers. This is laudable in that it serves to fund the best grant proposals submitted. But it makes no concession to the fact that some diseases are either stigmatized by society or are unfashionable (or unknown) to scientists and therefore an insufficient number of meritorious grant proposals may be submitted. As a result, some Americans have the double misfortune of both being disabled by a disease, but also enduring the fact that their disease is not interesting enough to research scientists to bother to search for its causes or cures. Too bad for them.

There are numerous egregious examples. Dr. Wolinetz cites headaches relative to influenza (“A thousand people with influenza, for example, is not equivalent to a thousand
people with headaches”). Perhaps this is because both NIH’s analyses and those recently cited in JAMA (eFigure 4,) point to migraine as among the most conspicuously underfunded diseases relative to DALYs. Migraine and schizophrenia have approximately equal US DALYs (805K vs 835K in GBD 2010) and schizophrenia sits directly on the regression line for “Predicted Funding” (eFigure 4), but in 2014, schizophrenia received >12 times more NIH research funds than migraine ($253M vs $20M, http://report.nih.gov/categorical_spending.aspx).

NIH has issued only one RFA for migraine research in its history and it funded just four grants in 2007. An even more extreme case of neglect is that of cluster headache, widely regarded as the most severe pain that can be experienced. Cluster headache is more prevalent than MS and likely causes as many DALYs (though these haven’t been calculated by GBD). Yet, MS received $102M in NIH funding in 2014, while cluster headache has received < $4M in attributed funding over the past 25 years (RePORTER data). Cluster headache is invisible to NIH.

So while Dr. Wolinetz notes that NIH monitors “the public health landscape for unmet needs” and responds promptly to some of these needs with funding initiatives, other disorders remain persistently neglected. The disorders that fall through the cracks seem mostly to be chronic disabling (but not fatal) illnesses that are not represented by well-funded and politically connected patient advocacy groups.

Certainly, many factors should influence NIH funding policies, including promoting acceleration of research to counter imminent public health threats or to capitalize on opportunities from research breakthroughs. But
if NIH has a means to do so, there is no reason that it should not also aggressively recruit investigators to study a major disease in which insufficient investigator interest has been shown. When this problem has been raised with NIH administrators, they have indicated that it is the responsibility of the few research scientists that are interested in a neglected disease to submit more outstanding research proposals… and then they will fund them. They shrug: it’s not NIH’s responsibility to build the field and thereby risk funding mediocre research. Is this realistic, or fair? Surely in the case of migraine, a sustained RFA with set-aside funds could be promoted sufficiently to the 40,000 or so US neuroscientists (hungry for an RO1) to draw enough worthy grant proposals from talented investigators. How much would an RFA for migraine lower the funding line and diminish research quality? Really? Moreover, the 50 million or so Americans with disabling migraine this year should have a say in this matter too. How many of them would quibble about a marked increase in migraine research that was scored by study sections as only truly “excellent” rather than “outstanding”, particularly if the alternative was a continuation for several more decades of the current meager funding levels. A sustained RFA could jump-start and transform the field.

NIH remains conspicuously silent about whether they will apply the data that they have just posted on funding vs. disease burden to any change in their funding policies. They need to do so, and urgently. If NIH administrators are unwilling or unable to decide which disease burden measures (i.e. DALYs, costs, etc.) are currently the most suitable to guide their funding policies and how best to apply them to ensure reasonable equity in funding, then they
should empanel a committee of appropriate public and private stakeholders to collectively, and by consensus, make these decisions for them.

All Americans are entitled to equal access to the promise and benefits provided by publicaly funded research. NIH policy needs a funding safety net to ensure that everyone is equitably included.

Robert E. Shapiro, MD, PhD on July 6, 2015 at 3:54 pm said:

The citation for "eFigure 4" is Moses et al JAMA. 2015;313(2):174-189

stacy nicotra on November 6, 2016 at 10:55 pm said:

THANK YOU!! I suffer from migraines and I feel left out. My doctors cant do anything for me and the meds dont work. I also suffer from PLC and im just about to give up! Every doctor I have seen has no idea how to treat this, how I got it, or how it will affect me long term. There NEEDS to be research for this ASAP! I belong to a pleva group on facebook, we have about 1000 members suffering from this but NOBODY can help us! Any ideas what we can do to get some answers? Thank you.

ColumbuM on November 8, 2016 at 11:11 am said:
Hi Staccy. Try

Gayle Gordillo
on July 3, 2015 at 12:23 pm said:

The prevalence of chronic wounds is 2% of the US and global populations and these conditions are associated with significant disability, but are not captured anywhere on these dot plots. There needs to be a paradigm shift as how wounds are perceived as a health care problem. They are categorized as a complication incidental to an underlying condition. A diabetic foot ulcer may be a complication of diabetes, but an endocrinologist is not well trained to manage this condition. The same is true with pressure ulcers in people with spinal cord injuries, as physiatrists, neurosurgeons, ets are not well trained to manage this condition. Wounds deserve to be classified as a separate entity with its own distinct support. This is a significant public health issue that needs to be on the NIH and CDC radar.

MARK CAMENZIND
on August 26, 2016 at 2:08 am said:

The NIH totally misses some diseases, esp M.E., Myalgic Encephalomyelitis, aka CFS, Chronic Fatigue Syndrome, that affects 2-1 million in US yet gets $6M/year in 2105 for NIH R&D vs $3B per year for HIV AIDS that is less
common and a less severe disease. Since
AIDS is 75% males disease and ME/CFS is
75% female disease, and worse, yet less
funding by orders of magnitude, this represents
gross discrimination by HHS/NIH against
women, and against ME, and must end NOW.
Top researchers are try to solve this horrid
disease, but need philanthropic funding to
make up for 3 decades of federal
discrimination against ME.