



# Funding for tuberculosis research—an urgent crisis of political will, human rights, and global solidarity



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Tuberculosis (TB) killed more people in 2015 than any other single infectious agent, but funding for research to develop better prevention, diagnosis, and treatment methods for TB declined to its lowest level in 7 years. TB research and development (R&D) is woefully underfunded, a situation best viewed as a crisis of political will and a failure on the part of governments to see unmet innovation needs in the TB response as a human rights issue requiring immediate action. Over 60% of available money for TB R&D comes from public sources, and 67% of public money comes from a single country: the USA. The election of Donald Trump to the US presidency in November 2016 has introduced great uncertainty into the support that science generally, and TB research in particular, will receive in the coming years. Advocacy on the part of all actors—from civil society to TB-affected communities to scientists themselves—is urgently needed to increase US government support for TB research moving forward.

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## 1. Introduction

In 2015, tuberculosis (TB) killed 1.8 million people and caused 10.4 million to fall ill, yet funding for TB research and development (R&D) fell by US\$53.4 million from 2014.<sup>1</sup> This decline, reported by the Treatment Action Group (TAG) in its 11<sup>th</sup> annual report on TB research funding trends, caused global spending on TB R&D to fall to \$620.6 million, its lowest level since 2008.<sup>2</sup> TB is preventable and curable with available technologies, but the ascendancy of TB to the world's leading cause of death from a single infectious agent makes it clear that eliminating TB will depend on accelerating research and innovation to develop better prevention, diagnosis, and treatment methods.

The juxtaposition of rising estimates of TB mortality and morbidity and diminishing investments in TB research indicates that governments have yet to mobilize behind the World Health Organization (WHO) End TB Strategy, which has set targets of reducing TB deaths by 95% and TB incidence by 90% by 2035.<sup>3</sup> The End TB Strategy warns that new tools to fight TB must be introduced no later than 2025 in order to meet these targets, yet research by TAG shows that funding for TB R&D is flagging. TAG has conducted a global survey of TB R&D funding each year since 2005, the methodology for which is described in detail in its 2016 report

(2016 report on tuberculosis research funding trends, 2005–2015: no time to lose).<sup>2</sup> Total funding for TB R&D has never exceeded \$700 million per year since 2005 and has stagnated since 2009, declining in three of the last five years—by \$36.5 million in 2012, \$12.3 million in 2014, and \$53.4 million in 2015 (see Figure 1).<sup>2</sup> These numbers point to an acute absence of political will setting back the TB response; in the words of one TB activist, Lynette Mabote, “there can be no end to TB without an end to political indifference in [its] R&D agenda”.<sup>4</sup>

## 2. Funding for TB research and human rights

The divergence between the size of the TB epidemic and funding for the R&D required to overcome TB also points to the failure of governments to see unmet innovation needs in the TB response as a human rights crisis requiring immediate action. Under international human rights law, governments are obligated to uphold the human right of everyone to enjoy the benefits of scientific progress and its applications (hereafter the ‘right to science’). This right first appeared in Article 27 of the Universal Declaration of Human Rights and is set forth in detail in Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>5,6</sup> Although the right to science remains less well defined than other related human rights (e.g., the right to health), a growing normative consensus on its meaning points toward the obligation of governments to fulfill the right by directing public funding in a ‘purposive development’ of science and technology,

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### Total TB R&D Funding, 2005–2015

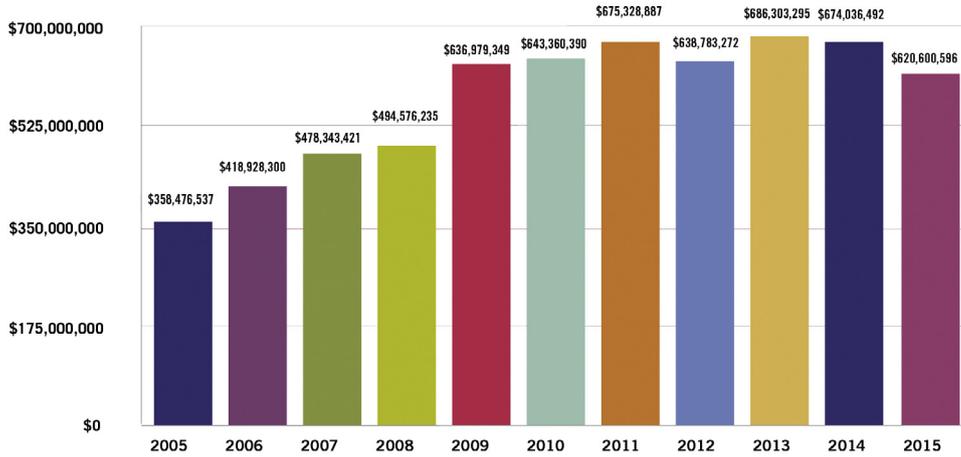


Figure 1. Total TB R&D Funding, 2005–2015.

particularly to benefit marginalized or vulnerable groups.<sup>7</sup> In addition to spurring the development of science and technology through public investment, governments must ensure that all people can enjoy the benefits of scientific progress, without discrimination, including tangible applications of innovation (e.g., new tools to fight disease).<sup>8</sup> These activities have been summarized as a dual obligation to both develop and diffuse science.<sup>9,10</sup>

As the slow scale-up of treatment for drug-resistant TB (DR-TB) has illustrated, the diffusion component of the right to science has been imperfectly honored. An estimated 80% of people with DR-TB receive no treatment, and new TB drugs bedaquiline and delamanid have reached only a fraction of the people who are eligible to receive them under WHO guidance.<sup>1,11</sup> The struggle to secure treatment for all people with DR-TB shows how scientific advancement and access to its benefits is a prerequisite for the realization of other rights, such as the right to health (e.g., ICESCR Article 12) and the right to life (e.g., Article 6 of the International Covenant on Civil and Political Rights).

The challenges to diffusion, however, begin with development and cannot be separated from the grave underfunding of TB research.<sup>9</sup> In addition to the low level of funding, TB research sits in the precarious position of relying on a handful of donors for the majority of its support. From 2011 to 2015, two institutions—the US National Institutes of Health (NIH) and the Bill & Melinda Gates Foundation (BMGF)—contributed 57% of all money spent on TB research globally.<sup>2</sup> With the notable exception of the BMGF, government financing underwrites the bulk of TB R&D. Pharmaceutical industry investments in TB R&D declined by 40% over the last 5 years, dropping from \$145 million in 2011 to \$87 million in 2015 (see Figure 2).<sup>2</sup> In 2015, public institutions contributed 63% of money for TB research, and 67% of public funding came from the government of the USA. Total US government investment of \$265 million in TB R&D in 2015 was seven times greater than the \$37 million spent by the UK, the second-largest contributor. A similar degree of concentration applies within different categories of TB research.<sup>2</sup> Awards from the NIH comprised 68% of TB basic science funding in 2015, and the NIH and the BMGF together accounted for

### Total TB R&D Funding by Funder Category, 2005–2015 (in Millions)

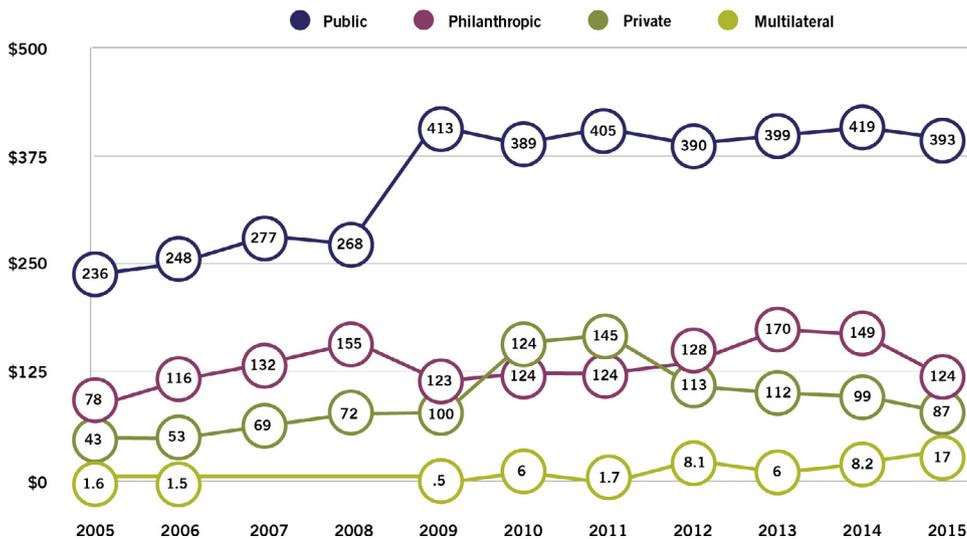


Figure 2. Total TB R&D Funding by Funder Category, 2005–2015 (in Millions).

at least 40% of funding for TB diagnostic, drug, vaccine, and operational research in the same year.<sup>2</sup>

### 3. Funding for TB research and political will

This degree of concentration leaves the TB research field vulnerable to sudden shifts in political will in leading donor nations. Political upheavals over the last year have heightened this potential vulnerability. In June, voters in the UK approved a referendum to leave the European Union, a move widely interpreted as a blow to research on both sides of the English Channel.<sup>12</sup> Priti Patel, the new director of the UK Department for International Development (DFID), the sixth largest contributor to TB research with \$23 million in spending in 2015, formerly called for the agency to be closed and has signaled that DFID will adopt a more trade-focused agenda under her tenure.<sup>13,14</sup> But the biggest political threat to maintaining funding for TB research came in November 2016 when US presidential candidate Donald Trump won a majority of votes in the Electoral College, becoming president-elect.

Funding for TB research, for global health, and for science in general did not feature prominently in the US presidential election, but the nativist and anti-globalist rhetoric of Trump's campaign leave little doubt: the TB research field can no longer afford to retain its reliance on the US government in this new political landscape. The final composition of Trump's political appointees and White House staff were unknown at the time of writing, but TB scientists and their advocates should not assume that the individuals directing science policy in the USA will be scientists themselves or even have scientific training. There is a strong possibility that science policy advisors in Trump's administration will hold open animosity toward science and the democratic values that animate it (e.g., freedom of expression and assembly, universal education, the right to seek and impart information, among others). Another possibility is that political staffers in the new administration may exalt science as a concept while impugning the scientific method and advancing policies that weaken its essential elements (e.g., academic freedom, the university tenure system, independent peer review, stringent standards for new drug and device regulation, etc.).

For several reasons, funding for TB research may be particularly vulnerable within this system. First, TB already ranks low on the global health R&D agenda compared to other pandemics (e.g., HIV) and emerging infectious diseases (e.g., Ebola virus and Zika virus) that command headlines and Congressional attention. Second, the low incidence of TB in the USA means that TB research is primarily seen as an issue of international development and foreign aid. If the new administration chooses to focus on a domestic policy agenda, investments in TB research may be viewed as a luxury the US cannot afford (particularly if Trump carries through on his plan to further cut taxes). Third, although TB did not feature prominently in Trump's campaign, it has not escaped the attention of those close to him. Shortly after Election Day, Trump named Stephen Bannon, the former executive chairman of Breitbart News, a right-wing website, as his chief strategist and personal advisor. The site has published more than 50 articles since 2015 that seize on the higher rates of TB in foreign-born persons in the USA to advance an anti-immigrant, anti-refugee agenda. The policy proposal that results from this line of xenophobic thinking is to control TB by limiting immigration, rather than to approach TB as an issue warranting a public health response grounded in respect for human rights and the need for scientific advancement.

### 4. Future directions for TB R&D advocacy

What will advocacy for TB R&D look like in this climate? There will likely be a push to sell science to policymakers based on a

narrow reading of its instrumental value—for example, emphasizing global health research as a matter of national security or positioning biomedical R&D as a way to acquire competitive advantage over other countries. It will be important to resist this reductive impulse and continue to advocate for science in terms of both its instrumental *and* intrinsic value. In an instrumental sense, advances in medical science can save lives, improve health, and contribute to robust economies; these are positive outcomes that advocates for TB R&D should stress. Equally important is the intrinsic value of science, which draws from something deeper: science's identity as one of the most complex forms of human culture, a system of meaning making and exploration grounded in individual and collective creativity whose potential to improve human welfare stems from a respect for persons.<sup>15</sup> It is this same fundamental respect for persons that gives rise to the core pillars of human rights—their universal, inalienable, indivisible, and timeless character.

In June 2016, before the outcome of the US presidential election became clear, TAG and other US-based advocacy groups published an ambitious set of targets seeking to increase US government funding for TB research to \$300 million by 2017 and \$400 million by 2020.<sup>16</sup> Reaching \$300 million by 2017 would return funding to a level equal to 2009 purchasing power when adjusted for inflation and the rising costs of biomedical research. An additional increase of \$100 million by 2020 would allow US government funding to outpace inflation and exceed 2009 purchasing power by \$72 million.<sup>16</sup> The task of increasing US government support for TB R&D has become exponentially more difficult given the new political landscape. However, adopting a defensive posture that seeks to maintain the status quo or minimize cuts to funding will foreclose on the End TB Strategy vision of TB elimination.

Advocacy for TB research is needed now more than ever, and it will need to come from all corners—civil society, TB-affected communities, and scientists themselves. The voices of TB scientists speaking up for the instrumental and intrinsic value of their research and defending the integrity of the scientific enterprise at large will become especially important. Adopting a more activist stance may require engaging the public in ways that at first feel uncomfortable to many scientists, but it will be required to do more than minimize losses to the inadequate amount of funding currently available. We owe it the tens of millions of people who will fall ill with TB in the coming years to demand more.

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