

Hi, we're Caitlin Dunn, Deborah McFarland and Kelly Callahan, and we published a study in PLOS NTDs about how onchocerciasis (river blindness) programs helped achieve the aims of certain Millennium Development Goals (MDGs) — Ask Us Anything!

PLOSScienceWednesday ¹ and r/Science AMAs¹

¹Affiliation not available

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ABSTRACT

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Thanks for doing this AMA! I was wondering if you could speak a bit about the millennium development goals (MDGS), NTDS, and how looking at health in cultural & environmental contexts impacts them. In anthropology (my field of study) we've long argued that if you can improve underlying conditions such as health, education, and clean water there is a powerful ripple effect that improves a huge range of the MDGS. But that these approaches need to be culturally sensitive and contextual - i.e. a copy paste approach will likely fail. Malaria, TB, and HIV are very serious diseases but as your articles point out they may not be the most or only pressing concern for local health. The CDC estimates that 123 million people live in areas that put them at risk for river blindness, 25 million are infected, and 300,000 have gone blind due to it - that's pretty significant! The reasons for poverty are complex and multivariate and that is true with regards to the ways that health impacts poverty. Even if we eliminated HIV, TB, and malaria in a region if huge numbers of people are going blind due to a preventable disease that's clearly an issue that needs to be addressed.

It seems obvious that while the big three are important, in order to meaningfully address the MDGS list we need to 1) also address local issues that negatively impact health such as NTDs and 2) develop locally specific approaches that are culturally sensitive so they will be successful. So question #1: Why has that been such a debate and a fight?

My second question is about how other factors may impact the successful approach to treating NTDs and related health issues. Robert Levine argues that women's education makes a huge impact on child health and survival rates. In four very different cultures he found that the better a mother's literacy the better she was able to understand health directives *even when they were given over the radio or in conversation* and the better she was at navigating and attaining health services. In their Lancet article, the Levines show that for every additional year a mother attends primary school, her child's mortality rate decreases by 10 percent up to age five. So question #2: in your proposed solutions for tackling NTDs do you also look at factors such as mother's literacy that are not directly related to the disease but may deeply impact how

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successful public health initiatives addressing that disease will be?

[firedrops](#)

Kelly: The Millennium Development Goals (MDGs) were created to address the poverty gap and remove the “debate and the fight” from focusing on specific issues that trap populations in cycles of poverty such as provision of sanitation, water and the NTDs. The MDGs were created to help end the fight and change the focus to include local issues that impact health such as the NTDs and to garner more support in the local context. Despite the MDG focus on other issues, such as local sanitation and provision of water and the specific diseases that affect the population, MDG 6, as stated in our paper did not name the NTDs. MDG 6.C simply stated “other major diseases”. So, despite the focus – there is SO much more to be done and it is still a fight to keep the NTDs on the global health agenda. Despite the numbers, the NTDs are not cited as “killers” and often times they are relegated to the back of the list – when in fact, as shown in our review, should be at the top of the list. It is still a fight to ensure the NTDs are on the agenda for the next set of goals, the Sustainable Development Goals (SDGs) which are currently under review.

Could you please explain more about your approach, ie your literature and data review? How did you determine which studies were relevant? What did you find difficult to include or exclude? Did the original researchers give you access to data for meta-analysis? A lot of health and development literature comes under criticism due to non-replicability, limited applicability of the experimental conditions, or simply findings which can over-reach the analysis.

I guess I'm asking: how does John Snow Inc ensure rigor and quality control in terms of its process and epistemology.

Edit: per mod request.

[twaggg](#)

Thanks for your question. This literature and data review was conducted while I was a Graduate Assistant for The Carter Center and, as such, I was given full access to all Carter Center data, as well as Emory University resources. The literature reviewed was from peer-reviewed journals, and when possible, we went back to review any primary study referenced. The majority of the literature includes field data which is wholly different than clinical data. Other sources came from reputable international organizations including the World Bank and UN Statistics Division.

First off, I would like to thank you all for doing this AMA and raising awareness of one of the most debilitating yet preventable/treatable NTDs.

I am an MD/MPH student (third year) who wants to specialize in Infectious Disease - Tropical Medicine. NTDs specifically are a personal passion of mine; there's so little awareness, funding, and programs for them even though they create such a poor quality-of-life for millions worldwide. Most of my research has been on Chagas, Dengue, and Chikungunya, but River Blindness is something I'd love to work with in the future.

My questions are:

- 1) How did you all get started in public health, and how did you end up working with NTDs and/or specifically onchocerciasis?**
- 2) What personally was the most surprising finding you discovered in your study?**
- 2) What has been the most rewarding and most difficult aspect of your work(s) thus far?**

3) Favorite NTD or microbe besides onchocerciasis?

4) Do you have any advice for a fellow female wanting to work in this field?

5) Mrs. Callahan, do you coordinate your efforts against trachoma and onchocerciasis to try to eliminate/control them simultaneously in areas plagued with both organisms? Also, I would love to get involved with your efforts of NTD eradication and control. What are some steps I can take to make myself a strong candidate for your program(s)?

Sorry for so many questions, you all are just very inspirational and great examples of what I want to become. Thank you again for the AMA, I hope you have a great day and great success with your study!

[mightymushroom45](#)

This is Kelly, Congratulations on working towards a career you will LOVE!! You asked some great questions, so in response:

- 1) How did you all get started in public health, and how did you end up working with NTDs and/or specifically onchocerciasis? I was a United States Peace Corps Volunteer. I was among the first Volunteers placed in a location/position under a partnership agreement with the World Health Organization Collaborating Center for Research, Training and Eradication of Dracunculiasis, The U.S. Centers for Disease Control and Prevention and the U.S. Peace Corps. The partnership agreement focused on placing Peace Corps Volunteers in highly endemic Guinea worm disease areas. It was through my work in the Ivory Coast that I fell in love with the great worm and the NTDs. I was asked to join The Carter Center in South Sudan efforts against the worm and I have been working with the Center for 17 years – learning more and more and loving it!!
- 2) What personally was the most surprising finding you discovered in your study? There is so much more to gain by focusing on the NTDs than I had imagined!!
- 3) What has been the most rewarding and most difficult aspect of your work(s) thus far? Behavioral change is both the most rewarding and the most difficult. The effort is enormous and it takes great focus however, the rewards are beyond measure.
- 4) Favorite NTD or microbe besides onchocerciasis? Guinea worm disease. It is fascinating... The Carter Center website has a great overview:
http://www.cartercenter.org/health/guinea_worm/index.html
- 5) Do you have any advice for a fellow female wanting to work in this field? Find a mentor. Find someone that has what you want, male or female and ask that person to mentor you, Use that mentor. I have two. I found two men I deeply respect for their character and morality. I use one on a day to day basis and the other when a major issue comes up and I need a 30,000 foot perspective. Take a class in negotiation. Life is a constant conversation and negotiation. Be a U.S. Peace Corps Volunteer or any type of volunteer for a sustained period. Learn what you don't like – it is as important as what you do like...
- 6) Mrs. Callahan, do you coordinate your efforts against trachoma and onchocerciasis to try to eliminate/control them simultaneously in areas plagued with both organisms? Also, I would love to get involved with your efforts of NTD eradication and control. What are some steps I can take to make myself a strong candidate for your program(s)?

Yes - in certain countries and certain areas the Trachoma Control Program and the Onchocerciasis Elimination Programs are coordinated at the country level. At The Carter Center each Program has a separate director and a separate team – but we all work together when and if possible.

The Carter Center health programs are community based – so any experience within community work is highly valued!! The Center also looks for specific degrees, like Master of Public Health, Global Health, Epidemiology and Anthropology. You are well on your way to that!! We periodically post positions using the Emory University career website. Keep a look out there!!

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[mightymushroom45](#)

Caitlin here: 1) I also got my start in public health in the U.S. Peace Corps, though I was an education volunteer in Zambia. Living with the community there I saw firsthand how interconnected poverty is with poor health (and how that impacted kid's educational opportunities). Since then I have wanted to work to help provide people with more opportunities and resources to live dignified and healthy lives. The Carter Center does just that so I was honored to work with them while studying at Emory. I ended up working with onchocerciasis by chance. Kelly had worked on two prior papers on Trachoma & Guinea Worm and asked me to research and write about this NTD. 2) While not necessarily surprising, I was most impressed with just how much has been done to combat NTDs with relatively little resources. The hard work and tenacity of those involved is laudable and I think the substantial involvement of communities in deciding how and when to distribute drugs is a great model for other programs.

Hi guys, I'm a journalist - I have a couple of questions:

- 1. How did the programmes target those who had the disease and was there any effort to**

tackle those in particular with low status and in low socio-economic groups?

2. Given that the Sustainable Development Goals (SDGs) due to be agreed by the UN at the end of this month, can you tell us whether your call in the PLOS paper for NTDs to be included has been heeded? If so, will this have any impact on the spread of Onchocerciasis control programmes? Why or why not?

Thanks!

[joe-turner](#)

Hi Joe!!

This is Kelly. Thanks for your questions. In response:

How did the programmes target those who had the disease and was there any effort to tackle those in particular with low status and in low socio-economic groups?

The NTDs affect the 1.2 billion of the most impoverished persons in the world – they are disease of poverty. So, the programs are specifically targeted towards the most impoverished persons in the world. The Onchocerciasis Elimination Program, Guinea Worm Eradication Program, Trachoma Control and other NTD Programs are specifically targeting those populations.

The Programs use data to target and management the interventions and ensure impact. The Guinea Worm Eradication program has used data since 1983 to drive cases down from an estimated 3.6 million to less than 14 cases end August 2015:

http://www.cartercenter.org/news/publications/health/guinea_worm_wrapup_english.html

The Programs use data to target where the diseases are worst – often times mapping the disease through surveys. The Global Trachoma Mapping Project has just finished mapping most of the world for trachoma infection: <http://www.sightsavers.org/update-worlds-largest-infectious-disease-mapping-project/>

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We remain hopeful the SDGs will specifically name the NTDs ensuring a measureable, greater focus on Onchocerciasis, Trachoma and other NTDs. We need to continue advocating for their inclusion with measureable performance indicators for impact!!

Thanks for doing this AMA! I'm curious about the process of categorizing the neglected tropical diseases. How does a disease make it onto the "neglected" list? Clearly there are initiatives that focus on them. Are they classified as neglected because the initiatives are smaller than those of "the big three"? Does the classification change much or at all over time? What about something like guinea worm disease that is nearly gone? What distinguishes the NTDs from other tropical diseases that aren't on the official list? Or is the list comprehensive?

[Nyota_Vumbi](#)

Caitlin: Neglected Tropical Diseases (NTDs) are a group of parasitic and bacterial infections that are classified together because of their geographic affinity, historically low research priority, and the negative impact they have on the health and economic prospects of the populations they affect. They result from four different causative pathogens: protozoa, bacteria, heminith, and viruses. The classification of NTDs is somewhat disputed so the number of NTDs can vary between sources, however, the World Health Organization lists 17 priority NTDs. In recent years there has been more attention and resources brought to NTDs. One of the most significant events being the signing of the London Declaration on Neglected Tropical Diseases in which partners committed their resources to

sustain and expand NTD programs. Specifically, the declaration outlines targets for 10 NTDs by 2020: the control of schistosomiasis, Chagas disease, visceral leishmaniasis, soil transmitted helminths (STHs), and onchocerciasis; the elimination of lymphatic filariasis, leprosy, trypanosomiasis and blinding trachoma; and the eradication of guinea worm. These NTDs were selected because they cause the greatest disease burden and/or can be controlled with existing strategies.

How should we raise awareness of NTDs? Are there specific strategies that you recommend?

Linking NTDs to achieving MDGs seems like an interesting option.

NTDs are truly "neglected" by the news media, and deserve more coverage given their impact on quality of life. I edit Global Health NOW (<http://www.globalhealthnow.org/>) and am always amazed how infrequently news articles on NTDs appear--aside from dengue and chikungunya, which may need to be lifted out of WHO's neglected status given their increasing prevalence.

[globalhealtheditor](#)

This is Deb. You're right, that NTDs are still neglected in terms of news media coverage. Guess it's not too surprising that the coverage is neglected for neglected diseases of often neglected people. Thanks for your work at Global Health NOW. We would be glad to help you write articles on NTDs and showcase the hard work that happens every day in these neglected communities. There are global advocacy groups, including the Global Network for NTDs (GNNTDC), which have excellent resources and media feeds that anyone can use. Linking NTDs to the MDGs, which are about to be history, and now into the SDGs is critical to elevating the NTDs to the global agenda. Stories of people who are doing the work around the world and stories from the affected communities are compelling and when people see the achievements over the last 20 years, there is hope. The work of The Carter Center in Guinea worm eradication and in oncho control has been well documented and there are some superb films and videos. Use them in your classrooms, religious institutions, civic groups. The more who know of the work, the better.

Afternoon,

Many people are likely unfamiliar with the MDGs -- would you break that down into something management and help everyone understand why they were created?

Thank you!

[adenovato](#)

Caitlin: Sure! In 2000, 189 member states of the United Nations came together, in what was then the largest gathering of world leaders, for a summit that resulted in the adoption of the United Nations Millennium Declaration. In signing this declaration, the global community committed to uphold the dignity, equality and human rights of all people while working together for peace and development. Eight goals were set to reduce extreme poverty and ensure the rights of all people to education, gender equity, health, and environmental sustainability. In order to reach these goals by 2015 and measure progress, 18 time-bound targets and 48 indicators were developed using data from 1990 as a baseline.

The MDGs are useful for many reasons including holding governments accountable. Annual progress reports, published by the Statistics Division of the UN Department of Economic and Social Affairs, measure change over time and compare countries' progress toward each goal. Included in these reports are model trajectories that illustrate which targets countries are on track to meet, and in which areas they are lagging behind. This visual presentation of data is useful to government officials so they can make sure policies and budgets line up with priority development areas. The role developed countries play in reaching these goals is emphasized by including targets for international assistance and debt relief, fair trade, partnerships and access to medicine and technologies.

The MDGs have also brought greater attention to the relationship between poor health and poverty. Since many of the indicators (48) relate to health there is no way that they can be accomplished without focusing on improving health. Consequently, the MDGs have provided a blueprint for global health policy and programming for the past decade.

Hi Ms. Dunn, Ms. Callahan, and Dr. McFarland. Thank you so much for participating in this AMA and for all the work you do to alleviate the burden of these diseases of poverty. I have a few questions for you regarding your river blindness research:

Merck's donation of ivermectin to fight onchocerciasis indefinitely is an impressive example of a strong public-private partnership (PPP), and seems to have ensured a sustainable supply of medication, which is no doubt crucial to control and elimination efforts. To my knowledge, we've seen the similar success with controlling trachoma through donations of azithromycin from Pfizer.

- 1. Do you think building a partnership between a pharmaceutical company, like Pfizer or Merck, and a public health commitment, like addressing trachoma or river blindness, is critical for the control and eventual elimination of eligible NTDs? And do you feel these PPPs between pharma and public health are sustainable models for control and elimination efforts of NTDs?**
- 2. Also, with a reliable supply chain in tact, what are some of the other barriers to medication delivery in settings with elevated burden of onchocerciasis?**

Thank you!

[sarark](#)

1. The partnership with the pharmaceutical companies who donate the drugs for NTDs has been essential since the first donation from Merck for the control of onchocerciasis. The pharma companies that followed Merck's lead, e.g. GlaxoSmithKline donation of albendazole for LF, are necessary, although not sufficient, for reaching the 2020 NTD Roadmap targets. The estimated value of the drug donations for the PCT (preventive chemotherapy diseases, e.g. oncho) was \$1,425,211,300 in 2014 and is forecast to be \$2,305,138,691 in 2020. Resources available from domestic resources in the endemic countries are equally essential as are the resources from the donor community that are non-drug donations. And perhaps most importantly, the contributions from affected communities are the foundation for many of the drug distribution interventions. Partnership is a word that easily rolls off the tongue and can be a promise more than reality but the NTD Partnership is real, essential and a model of cooperation not often seen in the global health world. Are the gains to date sustainable? It depends what you mean by sustainable. Merck, for example, is committed to donating the drugs as long as necessary to eliminate onchocerciasis. That's a tangible, sustainable commitment. Communities are committed to delivering the drugs in endemic communities. That's a sustainable commitment.
2. There are often supply chain issues that arise even in the case of donated drugs. The drugs may not arrive on time or in accord with the MOH and/or community time frame. There may be issues at the port of entry that delay the supply of drugs to the health facilities and to the communities. Many of the communities where oncho is endemic have taken Mectizan for 10 or more years and the oncho nodules and cases of blindness brought about by massive worm infestation are no longer seen in communities. People are wondering why they need to take the drug any longer. There is a certain tiredness on the part of the communities, the distributors and perhaps the local health systems.

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- 2. Also, with a reliable supply chain in tact, what are some of the other barriers to medication delivery in settings with elevated burden of onchocerciasis?**

Thank you!

[sarark](#)

Caitlin: I'll chime in here too, Deb. As you can imagine, there are many other challenges outside supply chain issues. Moving towards the goal of elimination, it means expanding coverage to include hypoendemic regions, in addition to those being treated now. This scale-up will require more financial and human resources as well as the political will to commit to the task. While the CDTI platform has been incredibly effective, it is important that the volunteers are not over-burdened with more add-ons. Integration with other public health interventions must be critically considered and rely on data to measure if and when add-ons are conducive. More specifically, it will be necessary to address the technical challenges of MDA in areas co-endemic with loiasis (also known as Loa-Loa), a filarial disease endemic to Cameroon, the Central African Republic, the Congo, Democratic Republic of the Congo, Nigeria and South Sudan; its presence limits the expansion of MDA as ivermectin can cause encephalopathy in individuals who are co-infected. It has also proven difficult to reach therapeutic coverage levels in regions with ongoing conflicts as community distributors are cut off from target populations. The black fly is a highly efficient vector that can cover vast expanses (in the Western Savannah the flies have been known to ride along the winds, reaching as far as 600km) which means control and elimination programs must be vigilant in order to prevent recrudescence. While ivermectin is an effective and safe drug that kills 95% of the microfilaria with just one dose, more research is urgently needed to develop a safe and effective macrofilaricide to kill adult worms, as well as develop better diagnostic tests.

[Google is being rumored](#) to getting involved in using CRISPR/Cas9-mediated editing for gene drives in order to eliminate fly born diseases such as malaria, dengue, and others. What do you think of the potential of gene drives in these contexts?

[e_swartz](#)

This is Kelly:

Unfortunately, none of us are experts in gene drives and cannot answer this specific question. However, eliminating or reducing fly populations as they relate to disease transmission is certainly warranted. There are many instances of NTD Programs looking towards reducing or eliminating the vector: the Trachoma Control Program works to reduce the eye-seeking fly, *Musca sorbens*, which transmits trachoma infection from person to person. It is imperative to reduce the fly population especially in hyper-endemic areas.