

R&D for the Overlooked: Restoring Hope, One Research Question at a Time

Frequently asked questions

Who is being asked to contribute to this work?

We are asking for the help of people who have insight into one or more of the diseases and disease groups on the WHO NTD list. That insight may be drawn from having been affected by an NTD; by managing patients affected by NTDs; through undertaking research; by delivering control, elimination or eradication programmes; or by considering applications for funding of R&D work on NTDs.

How many people will contribute to this work?

We plan to involve hundreds of people who have these insights. If you have suggestions of other people who could potentially contribute, please send them the link to the project website (<https://bit.ly/RDBPNTD>) and encourage them to volunteer.

If I volunteer to be a contributor, what will WHO ask me to do?

We will ask you questions about yourself and your expertise. We will also ask you to complete a standard WHO Declaration of Interests form.

The R&D prioritization process will be done in themes: 21 disease- and disease-group-specific themes, and four cross-cutting themes: (1) integration among NTDs - joint planning, implementation, monitoring and evaluation; (2) mainstreaming into national health systems; (3) coordination across sectors within and beyond health; and (4) delivery through strong country health systems with robust regional and global support.

For each theme for which you have expertise, we will ask you to help determine R&D priorities in three stages. In stage one, we will ask you to propose (and possibly refine) research ideas. In stage two, which will happen a month or two after stage one, we will ask you to score research questions which have been curated (by the WHO secretariat and a team of collaborating scientists) to remove duplicates and express the essence of the submitted research ideas in a standardized, clear way. In stage three, we will ask you to allocate hypothetical resources (funding, time or effort) on a competitive basis to different NTD R&D research questions.

We anticipate that nearly all of these processes will be completed via online forms; it is also possible that we will contact you by email for clarification of a research idea that you submit, or ask you to join an online discussion. You will not have to respond to any questions which you do not want to answer. Your contributions can be made at a time of your own choosing, generally within response windows of several weeks' duration.

The full protocol will be provided online as soon as it is finalized.

How much time will I need to spend on this as a contributor?

Being a contributor is likely to require (for each theme to which you contribute) 2-3 hours of your time, spread over several months in late 2024 and early 2025.

Can I choose the themes to which I contribute?

Yes.

What benefits are there in being a contributor?

You will help to determine the priorities for global R&D work on NTDs over the next five years and beyond. You will not be offered payment or per diems for participating in this work.

Are there any costs incurred or risks or discomforts caused by being a contributor?

You will not be charged for participating in this work. There is minimal risk in participating.

What will happen to the information that I provide?

All the Personal Data that WHO collects as part of this work will be kept confidential. The data will be kept securely and only the people involved in running or supervising the work (who are staff of and consultants to WHO) will have access. Whenever possible, a record number rather than your name will be used on the data that we handle. Neither your name nor other facts that might identify you will appear when we present this work or publish its results. No information from this work will be placed in or associated with your medical records.

Rather than us contributing separately, would it be better for me or one of my colleagues to coordinate responses from all the members of my lab / group / department / division / institution / country?

For four reasons, we think it is better that each individual with relevant expertise volunteers as a separate contributor.

First, we are hopeful that we will uncover novel R&D ideas in this process. The likelihood of that happening is probably higher the greater the number of people who contribute individually and think independently.

Second, after research questions are scored in stage two, and after the resource allocation exercise is undertaken in stage three, we will generate summary statistics relating to the mean scores given and mean resources allocated to different research questions. In these stages, a consensus view offered by a group of 10 people would only carry the same weight as a single individual completing the same stages of the process alone.

Third, we are interested to see the number of people with relevant expertise that we can reach and are willing to contribute to each theme, from each country. This will help us gauge the size of the community of practice for NTD R&D.

Fourth, WHO needs to be aware of and manage all possible conflicts of interest, which can only be done if potential contributors fill in the Declaration of Interests form individually.

Will contributing ideas mean that I will have a direct influence on the Global NTD Programme at WHO?

Your contributions will be combined with those from hundreds of other people, and used to develop R&D priorities for NTDs for use by the whole NTD ecosystem. The provision of contributions should not give you the expectation that they will be positively considered by WHO, but they may indirectly inform WHO's work in the technical area concerned.

Who is responsible for this work?

The work will be coordinated by Dr Anthony Solomon (Chief Scientist to the Global NTD Programme, WHO), Dr Whitney Blanco, (Consultant to the Global NTD Programme, WHO) and Dr Fatima Serhan, (Executive Officer, Science Division, WHO), under the guidance of Dr Ibrahima Socé Fall (Director, Global NTD Programme, WHO) and Sir Jeremy Farrar (Chief Scientist to WHO).

Who has reviewed this work from an ethics standpoint?

This work was reviewed by the WHO Ethics Review Board, which determined it to be non-research activity.

Do I have to contribute?

No. You do not have to volunteer as a contributor. If you have relevant expertise, though, we would love it if you did.

I heard about all of this too late! Stage one has already been completed! Can I still volunteer for stages two and three?

Yes, please do. Your contributions will still be very helpful.

What if I have more questions? What if there is a problem?

If you have any questions about this work or your part in it, if you wish to ask about your rights as a contributor, or if you have concerns or complaints about the work, please ask one of its coordinators in the first instance:

Dr Anthony Solomon (solomona@who.int)

Dr Whitney Blanco (blancow@who.int)

If you prefer, you can also contact the Global NTD Programme using the generic WHO/NTD email address (neglected.diseases@who.int) or contact the World Health Organization Data Protection and Privacy Officer (dataprotection@who.int).