Building a case for investment in involving young people in health research

Questions and answers

1. Involving young people in this proposal

- We’d like to involve young people with experience of being involved in health research in the rapid evidence review process. Is this something that Wellcome would be open to?
- What are your expectations in terms of engaging with youth in this work BEFORE the submission of the full proposal on June 8th?
- To what degree, would Wellcome expect the project itself to show working with young people, given the timeframe constraints? For example, which stage of Arnstein’s or Hart’s ladders of participation would Wellcome consider appropriate to the project methodology?

We are open to suppliers choosing to involve young people in all stages of this project, from having an input into the proposal to involving them in the delivery of the rapid evidence review and/or the stakeholder consultation. We acknowledge that involving young people in a meaningful way, such that they can contribute to a project/research takes time and requires a particular skillset i.e. researchers/consultants that have experience and expertise in this area.

It is up to the researcher/consultant to decide whether this is an appropriate and realistic approach given the timeline constraints. For example, researchers/consultants who may already have established networks/relationships with young people may find it easier to involve them in this piece of work. Similarly, it is up to the consultant to suggest which stage of Arnstein’s or Hart’s ladders of participation is appropriate. What is important is to justify sufficiently the approach suggested.

2. Scope

- Could you please clarify the scope of the term ‘research’ in the statement “young people’s involvement in research...”? i.e. Does young people’s participation in research refer to participation in third-party life sciences and medical research funded by Wellcome or does it refer to research carried out or commissioned by Wellcome in order to inform Wellcome’s own strategy and activities?
- Will the work done in this proposal immediately look to inform an update of Wellcome’s funding guidelines https://wellcome.ac.uk/grant-funding? If so, would Wellcome be open to including new criteria in its funding assessments?

Wellcome takes a broad view of research – both that carried out independently by third parties (e.g., via grant funding in universities) and that which is carried out and/or commissioned by Wellcome. Similarly, we are interested in all elements of the research process, from identifying and shaping research questions, to carrying out research, to disseminating and implementing research. Within this scope, we are specifically interested in how young people can contribute to research focused on mental health, infectious disease and the health effects of global heating.
This project is intended to be exploratory to examine the potential role of young people. It is not yet determined how this work would be included in Wellcome’s future strategic direction. As such, it is premature to speculate on the impact of Wellcome’s funding guidelines.

3. Framing

- Problem-based framing often invokes the same modes of thinking that produced the problems in the first place. Is Wellcome open to reframing their goals in terms of potential in addition to their framing of them as challenges?

We recognise that three global challenges today threaten to undermine our efforts to improve health in the future. The effects of climate change, infectious diseases and mental health problems limit life for people of all ages, across the world and can impact communities for generations. With our work we will be bringing people together across research, innovation and society to generate vital new knowledge in these areas, to inform and inspire new ideas for solutions. We accept that the three Health Challenges provide opportunities where we are placed to act. Each challenge needs effective and equitable science-based solutions, integrated with innovation and cultural engagement.

This work will not shape our overall strategy but it is a specific aspect of it - how we incorporate youth voice. So, there might be some potential in terms of how we engage with youth, but ultimately, the overall goals will continue to be framed as challenges.

4. Methodological issues

- Relative emphasis of efforts across phases: Do we understand correctly that the emphasis of the effort should be on the second phase (i.e., with a shorter first phase, and a relatively longer and more in-depth second phase)?

- Infectious diseases, climate and health and mental health are specific patterns of phenomena emerging from complex living systems and therefore require a living systems approach in order to deeply address them; is Wellcome open to a living systems-based methodology?

The emphasis of the effort should be the same between the first and second phases. The timeframe is determined by internal needs to develop our future strategic activities. We understand that this creates limitations as to what can be achieved within this limited time. It is important that the rapid evidence review is finished by the specified timeframe so that it informs our team’s strategic thinking.

Section 3 of the RFP explains the requirements that we expect the supplier to consider when they develop their proposal. We are open to prospective suppliers suggesting a methodology that is appropriate to adopt for this piece of work, provided it is sufficiently justified.

4.1 Rapid evidence review

- Could the literature review consider evidence from the ‘grey’ literature as well as from peer-reviewed publications?

- In terms of the Rapid Evidence Review (RER), there is a clear focus on academic literature, rightly so, but is there any interest in grey literature within this space?
Is there a preference for the RER to be carried out in collaboration with an academic institution, or do you welcome reviews from any organisation who is a suitable fit (e.g. other NGO’s or institutions with technical expertise)?

Is there any flexibility on the sequencing of the rapid evidence review and the stakeholder consultation? At the moment, the latter is envisaged to take place after the former and be subject to a potential break clause in the contract. However, we feel that the consultation and co-creation by young people throughout the entire process may add value beyond simply acting as a sounding board for the findings. For example, through helping to suggest sources of grey literature for the rapid evidence review, helping to shape and frame the review questions, introducing alternative perspectives on ‘whose evidence counts’ etc. (We think this could feasibly move beyond a consultation once the output has been developed by experts, to instead invoke more ownership of the report findings from the outset).

We acknowledge that good practice and relevant examples of involving young people in health research are included in grey literature. However, the rapid evidence review will consider evidence from peer reviewed studies only and not the ‘grey’ literature. Also, importantly, ‘depending on the number of publications on young people’s involvement in health research, it may be decided to widen the scope of the review to include studies on youth involvement in research in general.’

We welcome proposals from all types of organisations. What is important is that the prospective supplier thoroughly justifies the suggested methodology’s robustness and appropriateness to sufficiently answer the research questions and demonstrates the relevant experience of the organisation/individual(s) in conducting rapid evidence reviews.

There is no flexibility in sequencing the rapid evidence review and the stakeholder consultation; these phases have been designed based on our strategic needs and timeframes. As mentioned in the answer to question 1, if young people are involved in this piece of work, we expect it to be appropriate and meaningful based on the time restrictions.

4.2 Stakeholder consultation

- Will Wellcome suggest criteria for, and/or specific stakeholders to be included within the consultation?
- Will a full proposal need to identify specific stakeholder or mainly types of stakeholder?
- Is there an expectation of the number of stakeholders to be consulted or is that left to the consultants to decide?
- In order to size the effort required, do you have any specific (min.) expectations as to how many stakeholders/stakeholder groups we should engage with over the course of Phase 2 through:
  - high-level consultation methods (i.e., online surveys); and
  - more in-depth approaches (i.e., 1on1 interviews, focus groups)?
- Geographic scope for the consultation: Is there an explicit preference by Wellcome Trust for either a more focused, in-depth analysis of three specific countries (and if so a preference as to which countries), or for a more global approach? [cf. “In Africa and Asia the supplier may choose to conduct a deep dive consultation in a maximum of three countries in each continent or have a cross continent approach to cover as many LMIC countries as possible”]
- Are there any particular regions or countries Wellcome would like prioritised for the stakeholder consultation?
- How much of the relative focus of research is expected to be on the UK versus LMICs?
- In considering LMICs, is the primary scope of this work focused on sub-Saharan Africa and South East Asia or is there the potential to include Central and South American countries?

At this stage, we expect the supplier to justify why they are suggesting the inclusion of particular stakeholders/groups. After we commission this work we will collaborate with the supplier to further refine the criteria for identifying the specific stakeholders to be included within the consultation.

A full proposal should mainly identify types of stakeholders, rather than specific stakeholders. Identifying some of the specific stakeholders that need to be consulted may strengthen the proposal as it will indicate the expertise of the prospective supplier in engaging stakeholders in the areas this work will focus on.

It is up to the prospective supplier to suggest the number of stakeholders and consultation methods, based on their experience and expertise and what can be achieved realistically within the available time and resources. A more detailed consultation plan, which listed in the RFP’s deliverables, is expected to be submitted in September and will be informed by the results of the rapid evidence review. There will be flexibility in terms of the suggestions included in the proposal and what will be included in the detailed consultation plan.

Currently, there is no explicit preference by Wellcome for the in-depth analysis of three specific countries or a more global approach at this stage. This decision will be further informed by the results of the rapid evidence review and current work being done internally scoping our work in LMIC in Africa and Asia.

We expect the focus of the research to be predominantly on LMICs in Asia and Africa rather than on the UK, especially regarding the stakeholder consultation, as these are the areas we would like to expand in terms of involving young people in health research.

The rapid evidence review may include examples/published research from LMIC in Central and South American countries but the stakeholder consultation will not include these countries.

5. Ethics

- What is Wellcome’s position on the expectations for securing in-country ethical approval in LMICs (should this be required) when ethics committees in many settings are not functioning during this period?
- If site in-country ethics committees are non-operational, would Wellcome accept UK University ethics committee approvals that work with the Global Code of Conduct for Research in Resource-Poor Settings (GCC)?

National Research Ethics Committees, during emergencies, may face issues of capacity and procedural challenges. As per the Nuffield Council on Bioethics’ report, in those cases, it is recommended to seek input from local advisory groups, local academics or local NGOs with the necessary experience, that may be able to provide a complementary review.

A UK University Ethics Committee’s approval that works with the Global Code of Conduct for Research in Resource-Poor Settings (GCC) is a sound process for ensuring ethical considerations in this work. In addition to this we would expect where feasible the researcher/consultant to be able to obtain local approval where possible.
6. Contractual considerations

- Would Wellcome be able to help connect potential suppliers expressing interest in the opportunity if they are also looking to collaborate with other organisations to bring together different areas of expertise and share existing resources?
- In working in partnership on this work programme, are there any expectations from Wellcome on the relative representation of UK and LMICs i.e. is the balance of work addressed equally towards the UK and LMICs, or is there more of an emphasis on LMICs?
- We foresee that to be able to undertake the stakeholder consultation, we will need to have a number of sub-collaborations e.g. with local NGOs in UK and LMICs. These relationships may only become apparent through the rapid evidence review or may take time to secure even with existing contacts due to COVID, so we may not be able to name them in the application.
  - Is it OK to involve additional organisations in the implementation of the research that have not been included in the proposal?
  - Are we able to sub-contract and devolve budget to these organisations if we see fit?
- If applying as a Consortium, would one financial beneficiary be preferred, or is there scope to award directly to two main organisations?
- We have currently formed a partnership of several universities and institutions, including a UN Agency and we are also collaborating with companies, non-profits and associations that represent youth networks and health-related research. To complete the work described according to the timeline in the RFP, we anticipate the need to subcontract parts of the work to some of these partners. Are there any limitations for Wellcome Trust to how charges can be disbursed to such third parties, that we should be aware of?
- Does Wellcome have a preferred type of organisation to lead on the project e.g. NGO, academic institution, NHS supplier, freelancer, SME or other organisation?
- The costing description in the call document implies that the supplier will either be a registered company, a sole trader (not registered) or Individuals submitting proposals through their own personal services company. Is Wellcome open to applications from academic research institutions for this call?
- Would it be possible for you to consider our status as an international organization and see whether there are alternative contractual arrangements possible to that of being a formal supplier through a grant mechanism? For example, through a partnership cooperation agreement?

We acknowledge, that a range of skills, experiences and tools/structures are required for this work, which could be achieved through a consortium of organisations/partnership approach.

It is up to the prospective suppliers to find potential partners/other organisations or professionals to ensure that they can deliver all the necessary activities and answer the research questions specified in this RFP.

Wellcome has already established support and presence in LMICs in Africa and Asia. The Education and Learning team’s work until now has focused in the UK and this research will inform how it expands beyond the UK. Therefore, it is important for the prospective suppliers to demonstrate that they understand the context and are able to reach out to stakeholders in Africa and Asia, as much as in the UK.

It is advisable that any partners that will support the delivery of the activities are named. However, it is fine to include further organisations later on if they are suitably qualified to
facilitate the delivery of the project. It will be up to the chosen supplier to manage this relationship, including with respect to sub-contracting and managing the budget as specified by Wellcome. The chosen supplier will be required to declare to Wellcome if they intend to engage individuals via a personal services company as part of any onward sub-contracting arrangement.

It is mandatory that Wellcome contracts with one lead party only. It will be up to the consortium to nominate a lead party. There is no preference regarding what type of organisation can be the lead contact. In addition, academic institutions are welcome to apply for this work similarly to other types of organisations/individual professionals.

There are no specific limitations for Wellcome Trust regarding how charges can be distributed to third parties, as long as this is done in line with the budget specifications agreed with Wellcome.

Wellcome can contract with international organisations and this should not be a problem. If the organisation has entities in multiple jurisdictions our preference is usually to contract with the UK entity if possible. Please note the contract will be under English jurisdiction and governing law and this is non-negotiable.

As this is a contract for services, from a tax perspective we are not able accommodate an alternative form of contractual arrangement such as a grant agreement.

### 7. Budget allocation

- In light of lock downs and travel restrictions related to COVID-19, are we correct to assume that there is no travel involved in this proposal?
- Since it seems that the engagement with partners, particularly youth, would be long distance, can we allocate part of the budget for social media advertising, website or app development to engage with possible participants in the stakeholder phase?
- The call also mentions payments to participants, has Wellcome had similar experiences where participants were paid for participating and how was this experience? In my experience, research participants are sometimes paid and sometimes provided an incentive, but it all depends on the countries of origin of participants. If you as a foundation have a standard or best practice for this, it would be helpful to have it. If not, we can develop one.
- To involve youth in this project, we would like to offer awards for participation, which may take the form of small individual monetary or in-kind prizes awarded to student teams or individuals. Would this use of funds allocated by Wellcome Trust be acceptable?
- Same wise, can we allocate budget to pay for access to journal articles and software to conduct systematic reviews (Covidence https://www.covidence.org/home)?
- Can the budget cover full salary costs and associated organisational overheads?

We expect the design and implementation of this study to take into consideration restrictions and limitations posed by COVID-19 now and until its completion. This also applies to any travel arrangements. Having said that, we will have a flexible approach in relation to the budget allocation considering that the situation and lockdown restrictions may vary from country to country. For example, the stakeholder consultation will take place between September and December 2020. The detailed plan for conducting the stakeholder consultation needs to be submitted on the 15 of September. By then if any situation changes in a particular context, we will be open to travel and other expenses being allocated for face
to face meetings. Careful consideration will be given to ensure the safety of the participants. Any activity planned should adhere to relevant ethical considerations and approvals.

It is up to the prospective suppliers to decide the best allocation of the budget to ensure timely and efficient delivery of the activities. Any budget allocation e.g. social media advertising, website or app development etc. should be justified in the proposal.

Payments/rewards and other incentives is a method we have tried successfully in some of our funded projects in the UK to ensure higher participation rates. We acknowledge that this method has pros and cons (see for example Head, 2009). We can gather intelligence from Wellcome’s funding in LMICs in relation to paying/rewards to research participants in social sciences and inform decisions made for this work after the commission to the successful supplier. At this stage we are looking for the prospective suppliers to justify which method/approach would be best for this study, based on their experience and expertise. Individual monetary or in-kind prizes awarded to participants can be included in the budget.

Budget can be allocated to pay for access to journal articles and software to conduct systematic reviews as long as the total project costs are within the available budget i.e. £200,000 including VAT.

This piece of work will be a contract and not a project within a funding programme. We expect all the expenses to be allocated to the delivery of the activities. Associated overheads e.g. related to admin support should be explicitly included and justified in the budget.

8. Timeline

- The only question we have is regarding the timeline flexibility in view of the current COVID-19, some of the activities may be slightly more difficult to organise than during normal times - e.g. focus group discussions, due to various factors including connectivity issues.

- The timeframe for completion of this work is extremely tight and we have some concerns about its feasibility, especially given the fact this falls over the summer period when many key stakeholders including young people are likely to be unavailable. Is there any chance at all of a slightly extended timeframe to allow for more time to undertake a more rigorous process, or is September a hard stop due to ongoing strategy development consultations within Wellcome? (A slippage by a couple of months into early next year, may allow for more inclusive stakeholder consultations which take place at least partially face to face. An online consultation process which will be the necessary default option given the current pandemic may make equity issues and participation/engagement by marginalized groups of young people harder to incorporate)

The timeframe is determined by internal needs to inform our future strategic activities. We understand that this creates limitations to what can be achieved.

We also recognize that the timeframe places restrictions on the stakeholder consultation and are realistic with what could be achieved within this timeframe. However, we believe that if the right partners are brought together for this project, who have already built networks and relationships to the areas we are looking for, we can get reasonable consultation results.

It is essential that the rapid evidence review is completed by the indicated timeline. There is some flexibility with the stakeholder consultation’s timeline. The available budget for this piece of work has been decided to allow additional staff resources to ensure timely delivery of the project.
9. Proposal page limit

- Does the 10-page application form limit include the budget, or could the table provided be an appendix?
- In addition to our qualifications, are we correct in assuming that the cover letter and team bios are not included in the 10-page limit? Are there any other sections that may not be included within the 10-page limit?

A proposal for undertaking the work should be maximum 10 pages. Submitting a proposal more than 10 pages will automatically result in the rejection of the proposal.

The contents that we expect to be included in a proposal are outlined on p.8 of the RFP.

The budget and short description of experience and expertise of the researchers/consultants should be included within the 10 page limit. There is no need for a cover letter. The only acceptable information that could be included in an appendix are examples of similar types of work. These could be included using links to websites/webpages.

10. Deliverables' format

- Is there a preference by the Wellcome Trust for format of reports (e.g., Word, PowerPoint), and format/length of presentations to Wellcome staff and others?

There is no preference in terms of format of the deliverables/reports. We are open about the format of the deliverables, though we would expect the reports to answer the key questions and have the following characteristics: compelling, actionable and shareable. In the Deliverables table we have indicated max number of pages for the reports.

The contents and structure of the reports will be agreed after the commission of this work in collaboration with the appointed researcher(s)/consultants. The same applies to the format/length of presentations.

As an indication, the format of the presentations could be oral, combined with PowerPoint/Prezi slides. Considering the COVID 19 restrictions it is likely that the presentations will be delivered online rather than face to face unless a significant change happens to the current situation. We would not expect the presentation and discussion to last more than 1 hour each time.

11. Intellectual property and publishing the reports/outputs

- We presume that the consultants will be able to publish the literature review in addition to submitting it to the Trust?
- Could the project findings and methodology be submitted for peer-review publication once all requirements for disseminating the work within Wellcome were complete?
- We appreciate that the Trust will own the IP for the report but nonetheless will it available to the public in case one wants to refer to it?
- Where would Wellcome see the intellectual property for the work sitting?
- Is there any flexibility in the intellectual property clauses, such that the supplier could have a licence for the foreground IP outside of delivering these services?
- The terms and conditions state that intellectual property of any outputs would remain with Wellcome. Would it be possible for an academic institution to retain
ownership of IP so that they could develop or share learning with others, with Wellcome having a licence to use it indefinitely; or alternatively for an academic institution be given a perpetual licence to use it for teaching and research purposes?

Reports will be made available on Wellcome’s website and disseminated through various channels to maximise reach and influence. The intellectual property of the deliverables will remain with Wellcome. If the supplier wishes to publish or use the work e.g. for further publication, share learning with others etc. they will need to obtain approval from Wellcome. We expect the outputs of this work to be publishable e.g. to be submitted for peer-review publication, provided it is going to be open access and permission from Wellcome should be sought.

The obligation will be on the chosen supplier to ensure that the relevant permissions and copyright clearances have been obtained from any third parties contributing to the deliverables in order that the intellectual property can be assigned to Wellcome free of any encumbrances.

12. Contract negotiations

- What sort of flexibility would there be for the successful bidder in negotiating the contract, i.e. are there any areas of the contract that are absolutely not open to discussion?

Participants in the RFP process are asked to highlight which elements of the Terms and Conditions they wish to negotiate. We feel the terms which have been supplied are fair for the exercise in hand and would not expect a large number of changes accepted to them.