

How should I involve people with lived experience in my research?

The involvement of lived experience experts in the design and delivery of stratification research projects will be crucial to ensure they are of maximum benefit to end users and to optimise the experience of research participants.

We appreciate that research teams may have different levels of experience of involving and collaborating with lived experience experts in their research. Below we have provided a list of principles of involving lived experience experts in your project, and some examples gathered from teams we have previously funded of what this could look like at each stage of the research project.

Do:

- Make sure lived experience is central to guiding how the research project is designed, implemented, monitored, and disseminated.
- Seek appropriate lived experience input to mitigate against risks and ethical considerations in your study design
- Where possible, involve people with lived experience in writing your preliminary and full application (if shortlisted) to Wellcome for this funding call.
- Recognise lived experience experts as colleagues, valuing their expertise as you would with any other member of the project team.
- Involve a diverse group of people with lived experience, as one person is not able to speak on behalf of multiple communities and contexts.
- Compensate or pay lived experience contributors for their involvement and build these costs into your proposal.
- Acknowledge the contribution of lived experience experts to your project, by naming them on your applications and research outputs or papers (if they wish).

Don't:

- Treat people with lived experience as research participants. They should be involved as experts and inform the design, governance, and delivery of the research as, for example, co-applicants or co-researchers, collaborators, embedded colleagues, through advisory groups, or by gathering their perspectives through workshops or online discussions.
- Ask people with lived experience to tell their personal stories or background of mental illness – they may share this but only if they would like to. Instead, ask for their opinion and expertise on various elements of your research.
- Involve lived experience in small or inconsequential ways, such as only asking for their opinions after the major decisions about the project have been made or involving them only at the end of the project where their ideas cannot be incorporated.
- Be too rigid on involvement. Many individuals can contribute in different ways (e.g. in workshops, over email).

Examples of involvement at different stages of a research project

Please note: These examples are here for guidance and are not an exhaustive list of ways to involve people with lived experience throughout your research. We recognise that teams will have different methods of involving people with lived experience, depending on their project, and we are open to any method of involvement, so long as you justify this in your application. We also suggest teams consider multiple methods of involvement across all stages of the project, not just one example at each stage. Involvement (or exclusion) of people with lived experience at each stage of the project must be justified.

Lived Experience Roles

- As a co-applicant embedded within the research team (check that they meet the eligibility criteria as listed on the webpage).
- A co-researcher or a collaborator.
- As advisors or members of an advisory or steering group – this could be a group specifically for lived experience experts as part of a larger advisory group of experts. This group can provide advice and accountability for the project.
- By collaborating through workshops or online discussions.

Project design

- Helping to develop the preliminary and full application (if shortlisted) submitted to Wellcome
- Reviewing and inputting into the study scope and design, For example advising on risks, mitigations and end user priorities
- Identifying and advising on ethical considerations around stratification, such as those identified by [Fusar-Poli et al.](#)

- Refining and designing the research methodologies
- Reviewing and defining the opportunities that the proposed research has for impact, including applicability and acceptability in different contexts

Data collection

- Designing the methods for data collection, for example to advise on acceptability to research participants, identify and mitigate risks and minimise drop off.
- Reviewing and/or designing any data collection approaches and tools, such as a participant recruitment plan (if applicable) and data management proposal.

Analysis

- Exploring the preliminary findings from the research and engagement with other people with lived experience and professionals to contextualise and inform the interpretation of results and next steps/follow on experiments
- Discussing the impact of the findings with the project team
- Identifying potential risks around implementation, for example bias in algorithmic profiling.

Reporting and dissemination

- Contributing to/co-authoring publications/research papers including a sensitivity and accessibility check on language and terminology
- Co-developing outputs – including papers, presentations, blogs
- Identifying the best knowledge dissemination routes and methods
- Writing reflective pieces about the project and/or their involvement in the project.

Frequently Asked Questions (FAQs)

Lived experience involvement

What do you mean by people with lived experience?

We understand lived experience as a unique form of knowledge, insight, and expertise, that comes from having experience of mental health challenges. When we refer to 'lived experience experts' or 'people with lived experience' we are referring to people who identify as having experienced psychosis broadly defined, either in the past or currently. People with lived experience do not need to have been diagnosed by professionals or have accessed formal mental health services.

Should people with lived experience be involved in developing our application?

We would welcome you to collaborate with people with lived experience on your preliminary and full application (if shortlisted). However, we recognise that this may not be possible for all research teams.

If we are involving people at the application design stage, can we include that consultation charge for the work done prior to being awarded funding?

No, this is not possible. Wellcome will not be held responsible for any costs associated with the production of a response to this funding call.

Can people with lived experience be included as team members for this funding call?

Yes, this is encouraged. We are looking for people with lived experience to be involved throughout the research and would welcome them being named as co-applicants on applications, so long as they meet the eligibility requirements. For more information on these requirements please refer to the main webpage.

How should people with lived experience be involved in the research project?

We recognise that there are a range of different ways that research teams can involve and collaborate with people with lived experience. For example, this may include, but not be limited to, expert advisors, co-researchers, advisory group members, or co-applicants. We are open to any methods and roles team choose, but we are expecting lived experience experts to be involved in the most appropriate ways to inform multiple aspects and stages of the research project. Key for us is that this is not tokenistic, or a tick box exercise and the approaches and roles are appropriate for the research aims and stage of the research.

Do all projects need to involve people with lived experience?

We require all stratification projects to seek input from people with lived experience ensure that the potential for impact for end users is prioritised in the study design and analysis. However, we understand that in some limited circumstances, involvement may not be appropriate across every stage of the research. In these cases, we require a clear justification of why there is no lived experience involvement included at certain stages, and this will be assessed during the review process.

How many lived experience advisors would you like to see on the project?

This is entirely up to the research team and will depend on how you plan on involving people with lived experience. We will be reviewing the justification you provide for the chosen approach, to ensure that people with lived experience are meaningfully involved throughout the project. The research team should seek input from people with lived experience that is sufficiently representative given the specific context of your study.

To what degree of detail do we need to indicate who we involve as people with lived experience? At the application stage (preliminary or full), do we need to have identified individuals already, or is the identification strategy sufficient?

We recognise that teams may be at different stages in developing their plans and some teams may have already identified individuals, whereas others may not yet have identified those they are going to work with. When reviewing applications, we will be considering the strength of your proposed plans for involving people with lived experience. As part of this we will review how you plan to identify people who have relevant knowledge, skills and experience to inform your specific proposal.

Will we need ethical approval to involve lived experience advisors in our project?

We are expecting people with lived experience to be involved in informing the design, governance, and delivery of the projects. This is distinct from any research you will be conducting with participants. Therefore, their roles would be in contributing advice, knowledge and expertise to the design, governance, and delivery of the project. This will likely mean that you do not need ethical approval to work with people in this way and that you can incorporate their contributions as you would with any other advisor, collaborator, or co-researcher. However, some institutions do vary with their requirements for ethical approval so we would encourage you to check with your institution.

How can we ensure that lived experience experts are properly supported in their roles?

We encourage research teams to build a positive and supportive work environment in their project team and for collaborating with lived experience experts. There are proactive steps teams could take to support lived experience experts to feel more embedded in a project, such as jointly agreeing best ways of collaborative working, providing technical training if required, and encouraging team members to clarify acronyms and jargon regularly. Regular team check-ins where team members (including lived experience experts) feel able to raise any issues and how to address them could help to mitigate future issues around lack of support arising. The Wellcome lived experience team will also be running workshops with funded teams on lived experience involvement to enable teams to share and develop their practice and gain support.

Should people with lived experience be paid for their involvement?

Yes, we expect people with lived experience to be appropriately compensated or paid for their time. The budget that must be completed during the application process should include appropriate remuneration for lived experience experts and costs for involvement.

We cannot advise on ways to appropriately compensate or pay people with lived experience, as approaches differ between organisations and contexts. However, when thinking about appropriate compensation or payment, we would encourage you to think about the experience, knowledge, and skills that someone will be bringing to the project, as well as their responsibility within the process. Please make sure you are appropriately budgeting for the costs needed to support meaningful involvement, as set out in your proposals. For example, this could include (but not be limited to):

- Consultant fees for LE experts on the project
- Travel costs
- Salary costs for LE researchers embedded in a team
- Expenses to support meetings or workshops

Is there any advice if those involved with lived experience are in receipt of social security, in terms of the implications of being paid for their involvement?

It is not possible for us to advise on social security, as the arrangements will be different in different countries. It is the responsibility of the research team to ensure that they are abiding by any relevant regulations in their context, and we would encourage you to seek advice from relevant local organisations if needed.