



# **Mental Health Award: Looking Backwards, Moving Forward**

**Understanding how  
interventions for anxiety,  
depression, and psychosis work**

**Supplementary material**

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# Supplementary material to guide you through applying to this Mental Health Award

## Glossary of terms

### Active ingredient

The aspect of an intervention (whether biological, cognitive, behavioural, relational, societal, or a mix) that drives resolution or reduction of symptoms, is conceptually well defined, and links to specific hypothesised mechanisms of action.

### Anxiety, depression, and psychosis

We take anxiety, depression, and psychotic disorders as broadly defined categorisations to include all types of anxiety and depressive disorders (including obsessive compulsive disorder and post-traumatic stress disorder) and all forms of psychotic disorders (including schizophrenia, postpartum psychosis, and bipolar disorder).

We recognise that the current diagnostic categories are imperfect but removing all categories or creating new ones also presents difficulties. Therefore, we propose to keep using these as broadly defined constellations of features or symptoms. We take anxiety, depression, and psychosis to refer to constellations of thoughts, feelings, and behaviours that have historically been classified as discrete conditions. Active ingredients of particular interventions are in scope if they are aimed either at the level of the diagnostic category, or if they address specific distressing and impairing symptoms, thoughts, feelings, or behaviours broadly defined as part of anxiety, depression, and/or psychosis. Please see the FAQs for further details on foci we consider in scope. Whilst we do not specify any particular diagnostic or classificatory system, we expect applicants to utilise a framework and measurement approach that fits the aim of their study, and to provide a clear rationale for doing so.

### Back (or reverse) translation

A bedside-to-bench approach where teams start from real world clinical data, clinical trial data, and/or large-scale datasets/cohort data, to develop novel hypotheses that explain why/how a given intervention works (including why it works for some but not others). These hypothesized mechanisms are then tested experimentally.

### Co-applicants

Co-applicants must have expertise that is essential for the delivery of the project and must add value to the team, for example, by designing or leading a specific work-package or research aim. Their contribution to the project must be clearly justified and they must have the appropriate time and necessary resources to deliver the project.

### Collaborators

Collaborators are distinct from co-applicants in that they will support the delivery of the project (e.g., providing technical or knowledge area expertise, access to tools or resources) but are not leading on a specific work-package or research aim of the project.

### Contexts

This can refer to geographical contexts like a location (e.g., country, region) or setting (e.g., school, clinic), individual contexts (e.g., age, developmental stage, sex, ethnicity), socio-economic or environmental contexts (e.g., family support structures, loneliness, poverty), and/or biological contexts (e.g., presence of specific biomarkers).

### Early intervention

An intervention that can be used as early as possible in the trajectory of mental health problems, in a way that reflects the priorities and needs of those who experience these problems. Universal (i.e., population-level) preventative interventions and/or interventions focused on managing chronic mental health problems are out of scope.

### As early as possible

This will be project specific as in some contexts, especially in lower resource settings, people may not seek help for symptoms until later on in the development of their condition. There may also be cases where research with an older population could have implications for early intervention (e.g., research that would enable better targeting of interventions at an early stage), and so there is no age cut-off. However, teams would need to justify their approach in terms of implications for early intervention.

### Effective

Successful in producing a significant positive change on a validated measure for anxiety, depression, or psychosis in a defined population, ideally in at least one peer-reviewed (and preferably pre-registered) randomised control trial.

### Effectiveness

How well an intervention works under real world conditions.

### Efficacy

The ability of a therapeutic approach to produce a beneficial result at the dose tested (e.g., concentration of drug, frequency, or duration of therapy), in the desired population, and under ideal conditions.

**Intervention**

Any therapeutic approach that has proven to be effective in preventing, resolving, or reducing the symptoms of anxiety, depression, and/or psychosis. An intervention may be something that an individual can do themselves (e.g., physical activity), something provided by a healthcare professional (e.g., selective serotonin reuptake inhibitors), or by communities and wider civil society (e.g., access to green space). The focus must, however, be on early interventions – interventions that can be used as early as possible in the trajectory of mental health problems.

**Level of explanation**

By level of explanation, we mean all levels at which you could approach the problem and explain the underpinning mechanism of action, from the molecular and cellular (e.g., role of neurotransmitters), to the systems (e.g., role of specific neuronal networks), cognitive (e.g., role of decision-making processes), behavioural (e.g., role of new routines), social (e.g., role of engagement with one's community), and societal (e.g., role of financial policy) level.

**Mechanism**

The means by which a therapy exerts its effects, at any level of explanation, or across levels.

**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 'people with lived experience' or 'lived experience experts', we are referring to people who identify as having experienced anxiety, depression and/or psychosis broadly defined, either in the past or currently.

**Research output**

Any output from a research project, which could include (but is not limited to) a peer-reviewed primary research publication, preprint, dataset, code, software, commercial or interventional product or tool, clinical practice development, policy publication, or patent.

**Resolution**

This could range from complete recovery to remission.

**Symptoms**

Those features of anxiety, depression, and/or psychosis that hold people back. This may include any distressing and impairing thoughts, feelings, and behaviours (e.g., anhedonia, suicidal ideation).

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

We appreciate that research teams may have different levels of experience of involving people with lived experience in their research.

Below we have provided a list of principles of involving lived experience experts in your project, and some examples gathered from previous teams we have 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.
- 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 (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 right at the end of the project when 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).
- As a co-researcher or collaborator.
- As advisors or members of an advisory group – this could be a group specifically for lived experience experts as part of a larger advisory group of experts.
- 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.
- 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.
- Reviewing and/or designing any data collection approaches and tools, such as a participant recruitment plan (if applicable).

## Analysis

- Exploring the preliminary findings from the research and engaging with other people with lived experience and/or professionals to inform the interpretation of results and next steps/follow-up experiments.
- Discussing the impact of the findings with the project team.

## Reporting and dissemination

- Contributing to/co-authoring publications/research papers, including a sensitivity and accessibility check on language and terminology.
- Co-developing research 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.

## Responses to Frequently Asked Questions (FAQs)

### **What do we mean by lived experience?**

#### **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 anxiety, depression and/or 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.

### **Role of people with lived experience in developing applications**

#### **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.

### **Ways of involving people with lived experience in research**

Note: for more information on how to involve people with lived experience in your research, please see the supplementary material available on the webpage for 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 for this funding call.

#### **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, co-applicants, collaborators, expert advisors, or advisory group members. We are open to any methods and roles the 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 that the approaches and roles are appropriate for the research aims and the stages of the project.

#### **Do all projects need to involve people with lived experience?**

We expect lived experience experts to be involved in most research projects that we fund. For example, all projects involving developing, testing, or understanding interventions for people with or at risk of anxiety, depression and/or psychosis must have lived experience involvement. However, we understand that in some limited circumstances, involvement may not be appropriate. In these cases, we require a clear justification of why there is no lived experience involvement, 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.

#### **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.

### **Payment and compensation**

#### **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 lived experience experts on the project
- Travel costs
- Salary costs for lived experience researchers embedded in the 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.

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