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Nottingham
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Faculty of Medicine & Health Sciences
School of Health Science
Institute of Mental Health
Room D19 Floor D
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Study Title: Citizen Science To Achieve Co-production at Scale (C-STACS) Expert consultation

PARTICIPANT INFORMATION SHEET

Research Ethics Reference: [FMHS 36-0722]

Version 1.2 Date: 22/08/2022

You are invited to participate in this research project seeking to learn about the views of key stakeholders about citizen science in mental health. The study is being conducted as part of the UKRI-funded Citizen Science To Achieve Coproduction at Scale (C-STACS) study, and we hope that the findings from C-STACS will improve the lives of people with mental health issues. The study is being conducted by Dr Olamide Todowede and Prof Mike Slade. Please take your time to read this carefully and ask any questions if not clear.

What is the purpose of the research?

Mental health has a long tradition of leading other areas of health in relation to public involvement and engagement. The use of experts by experience, co-production and shared decision-making are common means of driving mental health transformation within mental health systems internationally. This established tradition of individual and small group participation means that the time is now right to develop new knowledge through mass participation by experts by experience such as using the citizen science approach. Citizen science is any activity that involves the public in scientific research. This has the potential to bring together science, policymakers, and society in an impactful way. This study aims to incorporate mental health constructs and citizen science constructs, to generate new knowledge for mental health studies. The aim of this study is to capture the perspectives of key stakeholder groups about the use of citizen science focusing on the ethical, legal, and societal issues, implications, and prospective solutions in using the citizen science approach in mental health.

Why have I been invited to take part?

You have been invited to take part in this study because you have shown an interest in this research. To participate in the study, you must be an adult of 18 years or older, willing to have your interview audio or video-recorded and meet one of the following criteria to participate.

- a. **The citizen science academic experts:** Principal investigators or coordinators for externally funded citizen science study, these individuals might be from either multidisciplinary or interdisciplinary backgrounds different from public health or mental health.
- b. **The citizen science project contributors:** Non-scientist who has participated or is currently participating in a citizen science study of any topic (preferably health research).
- c. **Experts by experience (EBE):** People with lived experience of mental health; people currently experiencing or have experienced in the last 5 years of mental health problems and



able to give informed consent. The EBEs will include people that have not or have used mental health services.

- d. **Informal carers:** A person who is currently or has a recent experience of being an informal carer for someone with mental health problems, this person could be a family and/or friend of someone with mental health problems.
- e. **Mental health workers:** Individual in a recognised profession that cares for people with mental health problems; this includes but is not limited to psychiatry, clinical psychology, occupational therapy, social work, mental health nursing and peer support work; this person must have at least one-year post-qualification; currently working in mental health services.

A total of 100 people will be invited to take part in this study.

Do I have to take part?

No, it is up to you to decide if you want to take part in this research. If you agree to participate, we will ask you to sign a consent form (if in person, in which case we will give you a copy to keep) or give verbal consent (if online). However, you would still be free to withdraw from the study at any time, without giving a reason, simply let the research team know.

What will happen to me if I take part?

A researcher will contact you to schedule an initial meeting to discuss taking part, this should not take more than 15 minutes. This initial meeting will be online (via MS Team) or face-to-face meeting (depending on logistics and preferences) and we will send the Participant Information Sheet and Consent Form by email or post (depending on preference) to you in advance of the meeting. At the initial meeting, the researcher will check your eligibility to participate in the study and will discuss all aspects of participation including going over the information sheet, informing you that entry into the study is entirely voluntary and that your legal rights and employment (for academic experts) and treatment and care (for service users) will not be affected by your decision to participate, and you can withdraw at any time without needing to give reasons.

If you are eligible and agree to take part in the study, you will be asked to attend one 60-minute interview meeting online (via MS Teams) or face-to-face meeting, depending on logistics and preferences. The interview will involve asking you some reflective questions about the citizen science project that you may have conducted or currently doing, or your views about citizen science and mental health, including the ethical and legal issues that need to be considered in using citizen science. Interviews will be audio-recorded, and online meetings will be video recorded with MS Teams transcription activated to transcribe the interview.

If you are still happy to take part, then you will then be asked to sign a consent form and verbal consent will be taken before the commencement of the interview. In the event of your withdrawal, you may withdraw any study data collected from you to that point or choose to have it included and used



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in the final analysis. During the initial meeting and throughout the interview session, we will talk you through the study procedures and give you chance to ask any questions.

Expenses and Payments

All participants except citizen science academic experts and mental health workers will be remunerated £20 for their time.

What are the possible disadvantages and risks of taking part in the study?

No specific risks are anticipated for taking part in this study. However, people with lived experience of mental health and their carers might find talking about some aspects distressing, particularly those which might be sensitive and personal and might come up during the interview. It is up to you to share how much you feel comfortable sharing and you can stop at any time.

What are the possible benefits of participating in the study?

The information you provide from participation in this study will contribute towards gaining a better understanding of how to conduct ethical citizen science activities and projects and how this can be integrated into mental health research. This is an area in which there is still little understanding and your contribution to this research project could help to develop new knowledge about integrating citizen science construct into mental health construct which may transform mental health practice in the future.

What happens after the interview?

You will only be asked to attend one interview. The interview will be transcribed and analysed. The findings from all the interviews will inform the use of citizen science in mental health research. We will also use the finding of these interviews to inform the conduct of a larger citizen science project that will be looking at mental health self-management and recovery. Any published data will be thoroughly anonymised, i.e., details will be changed to ensure you cannot be identified through it.

What if there is a problem?

If you have a concern about any aspect of this study, please speak to the principal researcher, Olamide Todowede who will do her best to answer any questions or concerns you may have. The researcher's contact details are given at the end of this information sheet. If you remain unhappy or have a complaint about your treatment by the researcher or anything to do with the study, you can approach the principal investigator, Mike Slade (contact details below). If you wish to make a formal complaint you can do this by contacting the FMHS Research Ethics Committee Administrator, Faculty Hub, Medicine and Health Sciences, E41, E Floor, Medical School, Queen's Medical Centre Campus, Nottingham University Hospitals, Nottingham, NG7 2UH or via E-mail: FMHS-ResearchEthics@nottingham.ac.uk. Please quote ref no: FMHS 36-0722"

Will my taking part in this study be kept confidential?

If you join the study, all identifiable information collected from you will be held and stored strictly confidentially following an ethical and legal practices. Transcripts will be stored on a password-



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protected University of Nottingham computer and secure server. Any written notes which are made during an interview will be stored in a locked cabinet at the Institute of Mental Health and if typed up by the researcher will be stored in a password-protected University computer. Interview recordings, transcripts and field notes will be filed under pseudonyms and codes assigned to participants on a password-protected University computer. The file linking participants' names to their pseudonyms and study codes will be encrypted and stored on a password-protected computer.

The data collected for the study will be looked at and stored by authorised persons from the University of Nottingham who are organising the research. They may also be looked at by authorised people from regulatory organisations to check that the study is being carried out correctly. All will have a duty of confidentiality to you as a research participant.

Your contact information will be kept by the University for 12 months after the end of the study so that you can be contacted about any potential outcomes of the study (unless you advise that you do not wish to be contacted). This information will be kept separately from the research data collected and only those who need to will have access to it. All other data (your interview transcript) will be kept securely for 7 years. After this time, your data will be disposed of securely. During this time, all precautions will be taken by all those involved to maintain your confidentiality and only members of the research team will have access to your personal data.

In accordance with the University of Nottingham's, the Government's, and our funders' policies, with your permission, we may share our research data with researchers in other universities and organisations, including those in other countries, for research in health and social care. Sharing research data is important to allow peer scrutiny, re-use (and therefore avoid duplication of research) and to understand the bigger picture in particular areas of research. It is your choice however if you are happy for us to do this and you can let us know on the consent form. Data sharing in this way is anonymised (so that you could not be identified).

Although what you share with us is confidential, should you disclose to us anything which indicates that you or others may be at risk, the researcher will discuss with you whether there is a need to involve and/or to inform appropriate others.

Also, Under United Kingdom Data Protection laws the University is the Data Controller (legally responsible for the data security), and the Principal Investigator of this study (Prof Mike Slade) is the Data Custodian (manages access to the data). You can find out more about how we use your personal information and read our privacy notice at:
<https://www.nottingham.ac.uk/utilities/privacy.aspx/>

What will happen if I do not want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights, or if relevant your medical treatment or employment, being affected. To withdraw from the study please contact the principal researcher (contact details provided at the end of this information sheet) providing your name and stating that you wish to withdraw from the study. Also, you can withdraw from participating during the interview.

Who is organising and funding the research?



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This research is being carried out by Dr Olamide Todowede under the supervision of Professor Mike Slade within the Faculty of Medicine and Health Sciences, University of Nottingham. It is funded by the UK Research and Innovation (UKRI).

Who has reviewed the project?

All research at the University of Nottingham is reviewed by an independent group of people called a Research Ethics Board to protect your interests as a research participant. This study is reviewed by the Faculty of Medicine and Health Sciences Research Ethics Committee at the University of Nottingham.

Further information and contact details

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