

Participant Information Sheet

Gathering Experiences

STUDY TITLE

Optimising cultural expeRIences for mental health in underrepresented younG people onlINe (ORIGIN)

GET INVOLVED!

We'd like to invite you to take part in our research study. Before you decide, it is important that you understand why the research is being done and what it would involve for you. Please take time to read this information and discuss it with others if you wish. If there is anything that is not clear, or if you would like more information, please ask us.

BACKGROUND

Three quarters of mental health problems start before the age of 25. However, people in this age range are the least likely to access and receive mental health care. People from underrepresented backgrounds are even less likely to receive help. For example, people who feel they are not listened to, understood, valued, or miss out on opportunities that others have access to.

There are lots of long-term consequences if poor mental health goes untreated. Online tools may be a more accessible way of helping people to cope with mental health challenges.

In this work, we are looking to develop an online arts and culture experience, to support mental health in diverse people aged 16-24. This would be like an online museum where you could engage with diverse people's art and artifacts and the stories and lifestyles behind them.

At this stage, we would like to learn more about the people whose voices are not well represented in healthcare research to help with this work.

We will be interviewing people aged 16-24 years with current or recent (over the past year) personal experience of mental health problems.

Optimising cultural
expeRIences
for
mental health
in
under-represented
younG people
onlINe

We are interested in speaking to people from a range of backgrounds and identities including different:

- Ethnicities
- Educational and employment experiences (including those who are not currently in education, training or employment)
- Gender and sexual identities
- Neurodiversity (including ADHD and autism)
- From different regions of the UK (including rural and coastal areas)
- And more.

We will be exploring different people’s experiences of mental health problems (these do not need to have been diagnosed), coping, what has helped and how things might be improved.

YOU MAY BE ELIGIBLE TO PARTICIPATE IN THIS STUDY IF YOU ARE:




- Aged 16-24 years
- Living in England
- Currently experiencing or have experienced (over the past year) a mental health problem (for example, feeling very sad or anxious a lot of the time).

WHAT WILL HAPPEN IF I DECIDE TO TAKE PART IN THIS STUDY?

Stage 1. Eligibility and Consent

If you decide that you would like to participate, you will be asked to confirm that you are eligible and provide informed consent. This would be done online after reading this information and completing the consent form. We are happy to help over the phone if needed.



Stage 2. Questionnaire

You will then be given the opportunity to fill in a form (online, by phone or in person) where you can answer questions about your age, ethnicity, current mental health, other background information and contact details (email address or telephone number). You may also wish to consider this information and whether you wish to take part, with a supportive adult who you trust. You may also have this person with you when taking part in the study. It should take approximately 10 minutes to complete the questions. If you feel you would like assistance filling in the online form, please contact the ORIGIN email (origin@psych.ox.ac.uk), with the subject heading “WP1 – Form”.



Stage 3. Selection

We will select a range of people from different backgrounds, identities and locations for an interview. We will contact you in due course if you are selected for an interview. At this stage, we would go over the consent form with you again to make sure you are happy to proceed. We would do this in person, online, or by phone, based on your preferences.



We may not be able to contact everyone who expresses an interest. If you do not hear from us, it is important for you to understand that this is not a reflection on you but on the need for this research to include a range of different people from different places. Through the online questionnaire (Stage 1.) you will have the opportunity to select whether you would like to be contacted for participation in other ORIGIN studies and other studies beyond the lifespan of this project, if you wish.

Stage 4. If selected for interview

If selected to take part in the interview a researcher will contact you on the telephone number or email address you provided and will invite you to an interview so you can tell us your experiences of mental health and ideas about what might help best. The interviews will take place at a time convenient to you and can be done online through Microsoft Teams, by phone, or in person. We will discuss the time, duration, and format of the conversation with you to ensure that you are comfortable and have the time and space to share your story as you choose. You will be able to take breaks, and we can meet you more than once if you prefer, over several occasions, or within the same day. We are also able to consider other ways of communication if you prefer, as you may have other ways in which you would like to share your experiences.



Stage 4. Continued.

We would like to audio record the discussion as it can be difficult to capture all the information you share with us in written notes. If this would stop you from participating, we would be happy to discuss an alternative with you. You are welcome to ask any questions before deciding to take part in the study, or if you have any concerns, by contacting Dr Rebecca Syed Sheriff (rebecca.sheriff@psych.ox.ac.uk).



To read a simplified version of this process, please visit:
https://go.glam.ox.ac.uk/WP1_interview_process

DO I HAVE TO TAKE PART?

No. It is completely up to you if you want to take part. If you decide to participate and change your mind later, that's OK too. You can stop at any time by letting a member of the research team know or by e-mailing a member of the research team. You do not have to tell us why, if you no longer wish to take part. It will be your choice as to whether you would like us to still use the information you have shared with us up until that point. If not, all of the information recorded up until the point you leave the study will be immediately destroyed if it has not already been used in analysis.

We expect that we will have de-identified your data and started to analyse it two weeks after your interview. After this point it will not be possible to remove your data. However, your data will be de-identified.

IS THERE ANYTHING I SHOULD BE CONCERNED ABOUT IF I TAKE PART?

Sometimes, answering questions and sharing experiences, particularly about mental health difficulties, can be upsetting. You may choose to have somebody you know with you at the interview. There is a possibility that during the interview you may experience discomfort due to the experiences you are sharing. If you feel upset at any point during the interview, we will pause and allow you time to decide if you would like to continue, have a break or discontinue altogether. We have a research team who are experienced in working with people with mental health difficulties. If required, we can signpost you to appropriate support.

We would like to audio record the discussion as it can be difficult to capture all the information you share with us in written notes. If this would stop you from participating, we would be happy to discuss an alternative with you. You can contact the study team via origin@psych.ox.ac.uk.

WHAT ARE THE BENEFITS OF TAKING PART?



Taking part in the study allows you to share your experiences about your mental health and coping. What you share might help us improve future mental health support and has the potential to have a positive impact on many other 16-24 year olds' mental health.

WHAT IF THERE IS A PROBLEM?

If there is a problem or if you have any questions or concerns about the study, you can contact the study team via origin@psych.ox.ac.uk.

Additionally, there may be someone who is responsible for safeguarding more locally on behalf of the study team. This person is known as the local principal investigator. We can put you in touch with them if this is the case.



If you have concerns or wish to complain about any aspects of the way in which you have been approached or treated, or how your information is handled during the course of this study, you should contact Dr Rebecca Syed Sheriff (rebecca.sheriff@psych.ox.ac.uk) or you may contact the University of Oxford Research Governance, Ethics & Assurance (RGEA) office on 01865 616480, or the Director of RGEA, email rgea.complaints@admin.ox.ac.uk.

The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this study.

The Patient Advisory Liaison Service (PALS) is a confidential NHS service that can provide you with support for any complaints or queries you may have regarding the care you receive as an NHS patient. PALS is unable to provide information about this research study.

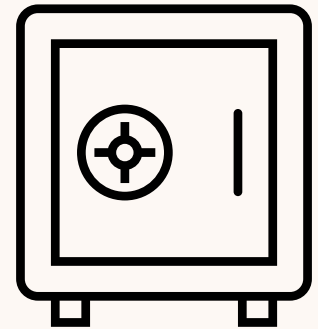


WILL I BE REIMBURSED FOR TAKING PART?

Those who are interviewed will be offered £40.00, in the form of a Love2Shop voucher. If preferred we will facilitate a bank transfer instead.

WILL MY TAKING PART IN THE STUDY BE KEPT CONFIDENTIAL?

Yes. All study records, including audio recordings and transcripts will be labelled with a code instead of your name. We will only use your name and contact details to contact you. These details will be held securely and only used when necessary for the study.



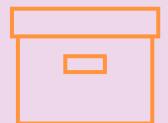
During the interview, all discussions will be confidential. However, confidentiality may have to be broken if you provide information that leads the team to believe that there is a risk of harm to you or someone else. In this case, we would have to inform the relevant agencies (such as social work or the police). We would always let you know about this first.

Only the research team will have access to the research data. Responsible members of the University of Oxford and NHS Trust, if relevant, may be given access to data for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

We may use anonymised data to support future research, use direct quotes in research outputs, and share data with other researchers. All personal information that could identify you will be removed or changed before information is shared with other researchers or results are made public.

WHAT WILL HAPPEN TO MY DATA?

We will be using information provided by you and from NHS waitlists in order to undertake this study and will use the minimum of personally-identifiable information possible. We will store any research documents with personal information, such as consent forms, securely at the University of Oxford for 10 years after the end of the study, as part of the research record. This will include audio recordings of the interviews. These recordings will not be shared beyond the immediate research team and sponsor. Audio recordings will be transcribed by the research team, and transcripts stored digitally in password protected files.



If you share your bank details with us to enable us to pay you for your time, these details will be stored for 7 years in accordance with University of Oxford financial policy.

If you agree to your details being held to be contacted regarding future research, we will retain a copy of your consent form until such time as your details are removed from our database but will keep the consent form and your details separately. We will keep any contact details for 12 months after the study has finished in case we need to contact you for clarification whilst we publish our results. If you decide that you no longer want your data to be stored, all of the information recorded up until the point you leave the study will be immediately destroyed if it has not already been used in analysis.



If you are approached for this research because you are on an NHS waiting list, the local NHS Trust will use your list details, e.g. name, NHS number, home address, and contact details, to contact you about the research study, and ascertain eligibility.

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data is available at <https://compliance.web.ox.ac.uk/individual-rights>.

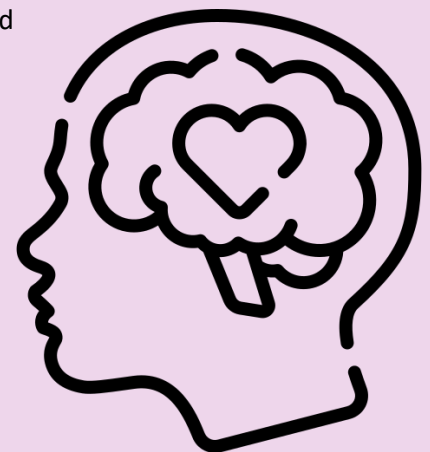
You can find out more about how we store and use your information by contacting rebecca.sheriff@psych.ox.ac.uk.

WHO IS ORGANISING AND FUNDING THE STUDY?

This study is sponsored by the University of Oxford, and funded by the National Institute for Health Research, Programme of Applied Research. This means that the results of this research will inform developments in mental health interventions.

This study is the result of some initial work that was conducted by Dr Rebecca Syed Sheriff developing and testing an online cultural experience called 'Ways of Being' which was co- designed by people aged 16-24 to support mental health in people aged 16-24. Mental health symptoms reduced more in people randomly allocated to Ways of Being than those allocated to a traditional museum website. Diverse young people of different ethnicities and identities (eg.: LGBTQIA+) found it particularly helpful. People aged 16-24 with lived experience of mental health difficulties asked for it to be further developed.

You can read more about this here: <https://www.glam.ox.ac.uk/oace-project>.



WHO HAS REVIEWED THE STUDY?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect participants' interests. This study has been reviewed and given favourable opinion by the South Central - Berkshire Research Ethics Committee. REC Reference number: <24/SC/0083>.

WHO CAN I CONTACT FOR FURTHER INFORMATION?

If you have any questions at all, you can contact Dr Rebecca Syed Sheriff (rebecca.sheriff@psych.ox.ac.uk) or the research team (origin@psych.ox.ac.uk).

Thank you very much for taking the time to read this. Please ask any questions you have or continue to the consent form here: <https://rb.gy/rwq2ia>.

WP1 Participant Information Sheet

Version 2. Date 03.04.2024.

Optimising cultural expeRiences for mental health in underrepresented younG people onlINe (ORIGIN)

Dr Rebecca Syed Sheriff

IRAS Project Number: 340259

REC Reference number: <24/SC/0083>