

Carers: Young Adult and Ethnically Diverse (CARED)

Phase 1: Survey

(CARED-S)

CARED-S Participant Information Sheet

Version 1, dated 23.01.2023

Thank you for your interest in our research study. Before you decide if you would like to take part, it is important that you understand why the study is being carried out and what your participation would involve.

Please take some time to read this information sheet and feel free to ask and talk to trusted individuals about it if you wish to do so. You can also contact the lead researcher Chandini Subramanyam on cs863@leicester.ac.uk for more information.

It is completely your choice to take part in this study.

What is this study about?

This study is being carried out by Chandini Subramanyam as part of her PhD at the University of Leicester. This study is about the emotional and mental health of young adult carers from ethnically diverse communities. We are inviting young adults (ages 18-29) from ethnically diverse backgrounds to take part. We would like to hear from people who DO and DO NOT have a caring role. We would like to understand your thoughts and experiences around:

- Your mental and emotional health
- Your experiences of formal support services
- And if you care for someone, your experiences of being a carer or supporting someone with a serious illness or disability

Why is this study important?

We would like to know more about the mental and emotional health of ethnically diverse, young adult carers and how to better help them.

However, we would still like you to take part if you are a young adult from an ethnically diverse community **but you are not** a carer. This is because it is important for us to understand how the health, wellbeing and needs of young adult carers differ from those of similar people who do not have a caring role.

The findings from this study will help us to design and implement future support services and resources for ethnically diverse, young adult carers. This will be to better assist them with caring and maintaining or improving their mental and emotional health.

Who can take part in this study?

To take part you must be:

- A young adult (18-29 years old)
- Not White British
- Living in the UK

Who is funding and organising this study?

This study is being run and organised by the University of Leicester and funded by LOROS hospice.

What do I do have to?

The CARED study has two phases, CARED-S (survey) and CARED-I (interview).

At the moment we are only inviting you to take part in the CARED-S survey.

However, at the end of the survey, there will be an option for you to provide your preferred contact details so that the researcher can get in touch to tell you more about the second phase of the project (CARED-I). We will be inviting some people to talk to a researcher in more depth about their experiences as a young adult carer. This is completely optional. The survey will ask if you would like more information about CARED-I, but you can decide later whether you want to take part or not.

This information sheet is for the CARED-S survey.

If you decide to take part in the online survey, please follow the link provided here : [LINK]

The survey webpage provides a brief explanation about the survey and then asks two simple questions to make sure you are eligible to take part. If you are, then you will be taken to the main survey questions.

The survey consists of a number of questions about:

- Yourself
- Your caring/supporting role (if you have one)
- Your general health and wellbeing
- Your depression, anxiety and stress levels

If you are a carer for someone with a serious illness or disability, you will also be asked some questions about:

- How your caring role affects you (both positive and negative aspects)
- How you manage your caring role and your own wellbeing

There is also space for you to write more detail about any of the questions asked if you wish to do so.

Although there may seem to be a lot of questions, they are very quick to answer and most of them only require you to tick a box. The whole survey will take between 20-30 minutes to fill in. You can miss out any of the questions if you prefer not to answer them.

Finally, at the end of the survey form there is a “Submit” button to tick which will send your survey responses to the research team. By clicking the Submit button, you agree to us using your responses anonymously for the research.

Are there any risks to taking part?

The risk of taking part in this study are minor however, we understand that answering questions about your caring experience might be upsetting. As a result, at the end of the survey we will provide signposting for services that can offer advice and help. You can miss out any questions you feel are distressing or you would prefer not to answer. You can also withdraw from the study at any point before you submit your answers without giving any reason just by closing the browser.

Are there any benefits to taking part?

There are no direct benefits to taking part. However, your survey responses will be used to drive further research to better develop support resources for young adult carers from ethnically diverse communities.

How will you use the information I provide?

- We will keep all the study information safe and secure on password-protected computers and secure files.
- Any of your survey responses used will be entirely anonymous and no one will be able to tell that you contributed to the study.
- We will keep all anonymous data for 7 years from the date of the end of the study. The research team might refer to or use this data for future projects. Your data will be completely anonymised and you will not be identifiable.
- If you provide your contact details to participate in Phase 2 (an interview), this will be kept in a secure file and you will be contacted through a secure university email.
- We will give your information a code so that only the research team know your personal information.
- At all times, this research study will comply with General Data Protection Regulations (GDPR, 2018)

Who has reviewed this study?

Ethical approval has been provided by the University of Leicester Research Ethics Committee. This means that the study has been reviewed as meeting your rights, all possible risks have been reduced, and we have given you enough information so that you can decide to take part.

What will happen to the results of this project?

The results of the study will be used to help the research team to develop a better understanding of the mental and emotional health of ethnically diverse, young adult carers and how to better help them. Information collected during this study will inform the next phase of the project (interviews). Results (survey and interviews) will be written up into a PhD thesis.

The results will also be presented at conferences and in journal articles, and shared via newsletters and social media platforms. We aim to also use the results to create and develop support resources and services.

We are happy to send you a summary of the findings once the project is complete. If you would like us to do so, please email cs863@leicester.ac.uk. We will only use the contact details to send you a summary of the findings and what the results will lead to. Once we have sent this, we will delete your contact details.

Please share this survey with others!

[LINK] <https://leicester.onlinesurveys.ac.uk/cared-c-survey>

Contact information:

If you would like more information about the study please do not hesitate to contact Chandini Subramanyam (details below). Alternatively, if you have any concerns about this study you can contact Lead-Supervisor Zoebia Islam (details also below)

Primary Researcher:

Chandini Subramanyam

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Version 2, Dated 23.01.23

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