

Employing social care Personal Assistants during the Covid-19 pandemic

Information Sheet for Personal Assistant Employers

We would like you to help us by taking part in a research study. This sheet provides you with information about this research to help you decide if you would like to take part. Before you decide, please take a few moments to read this information to understand why the research is being done and what it will involve.

Why are we doing this study?

We want to learn about the experiences of people employing their own social care workers (Personal Assistants) during and after the COVID-19 pandemic.

Why is this research important?

The COVID-19 pandemic has created multiple challenges for people using social care. Learning about what happened to people employing Personal Assistants during this time will help to understand what support people had and how they made decisions, so we can try to improve social care now and in the future.

Why have I been invited to participate?

You are being invited to take part in this study because you are an employer of a Personal Assistant or direct care worker (although you may have temporarily stopped your social care support due to COVID-19).

What will happen if I decide to take part?

Deciding to take part in the study will mean that we will contact you to arrange a suitable date and time for an interview. This would be done by telephone or video call if you tell us you would be interested in taking part. We would talk to you about your experiences as an employer of a Personal Assistant during the COVID-19 pandemic. The interview would last for about 45 minutes. The researcher will ask if they can record your interview but if you don't want your answers to be recorded this way, then the researcher will note down your responses. All your information will be kept confidential.

Do I have to take part?

It is entirely up to you whether to take part. If you decide that you do not want to take part that is fine and will not affect any care or services you receive. If you decide that you would like to help with this study, you will be asked to keep this information sheet and to sign a consent form, giving verbal agreement to say that you agree to take part. If you change your mind, you can withdraw up to one week after the interview, before the information we collect is analysed. You will not be asked to give a reason to withdraw.

What are the potential risks of taking part be?

There is a very small risk that some of the questions we ask you might be unsettling or upsetting, but if you want to take a break or stop the interview at any time you can do so. You also do not have to answer any questions you do not wish to. We will be able to signpost you to sources of support if you feel upset or distressed by the topics discussed during the interview.

What are the potential benefits of taking part?

Findings from this study will help us to understand better about the experiences of Personal Assistant employers during the COVID-19 pandemic. Some people enjoy taking part in research because they feel they are contributing to something worthwhile. You may also find it helpful to talk about the situation and your experience. We will send you a £20 voucher to thank you for your contribution to this study. You will be provided with a summary of the study's main findings and recommendations unless you say you would prefer not to receive them.

Will my information be kept confidential?

Yes, we will treat all information carefully and confidentially. Your data will be processed in accordance with the General Data Protection Regulation 2018 (GDPR). Data will be treated as strictly confidential and you will not be identifiable in the reports we write. The only exception to this would be if you disclose that you have, or might, seriously harm someone needing care and support, or that someone might, or may have seriously harmed you, or if someone else is at serious risk of, or is, being harmed; we would be obliged to report this to an appropriate organisation, such as the local Adult Social Care Department. We would normally discuss this with you before speaking to anyone else.

What will happen with my information?

Information collected from the research interviews will remain confidential to the small research team involved in the study. It will be stored on password protected files on password protected computers of the research team only. Interview transcripts will be anonymised and stored separately from your contact information. We would like to record our interview conversation, and these recordings will be transcribed using a third-party service, but anyone undertaking this work will have signed a confidentiality agreement. Once the study is completed, anonymised data will be kept for seven years, and then destroyed. Data may be used by the research team for future research. Any such use of identifiable data would be reviewed and approved by a research ethics committee.

If you would like more information about how your data will be processed in accordance with GDPR please visit the link below:

<https://www.kcl.ac.uk/research/support/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>

Who is doing and funding this research?

This study is being carried out by researchers at the Health and Social Care Workforce Research Unit (HSCWRU) at King's College London. The study is funded by the National Institute of Health Research (NIHR) School for Social Care Research.

Who has reviewed this research study?

The study has been reviewed and approved by King's College Research Ethics Committee [Ref: MRA-20/21-21647] and the Health Research Authority (HRA) [21/IEC08/0010]. This means that independent reviewers who protect the dignity, rights, safety and wellbeing of participants and researchers, have deemed the study favourable.

What will happen to the results of this study?

We will use your answers to prepare a report for the NIHR School for Social Care Research, and to write other papers which we will publish. No-one will be identified in this report, or in any of the other ways we use what people tell us such as conference presentations. We plan to create a YouTube presentation and webinar and present the results at conferences and workshops. Findings may be relevant to those who support Personal Assistant employers such as social workers and care managers, in addition to Personal Assistant employers themselves.

What if there is a problem?

If you have any comments or queries about the research, you can contact Dr Kritika Samsi who is the Principal Investigator on this study, at kritika.1.samsi@kcl.ac.uk.

If this study has harmed you in any way, or if you wish to make a complaint about the conduct of this study, you can contact Professor Reza Razavi, at reza.razavi@kcl.ac.uk or 0207 848 3224

Thank you for reading this information sheet and considering taking part in this research. If you have any questions or wish to express interest in taking part in the study, please contact Monica Leverton who is a Research Associate at King's College London, by email at monica.leverton@kcl.ac.uk or by telephone on 0207 848 1782.