Supplementary Participant Information Sheet for COVID-19 (coronavirus) questions in PROTECT.

Version 1.0, Date: 03/04/2020

As part of your participation in the PROTECT study we would like to invite you to complete a series of supplementary questionnaires about the COVID-19 (coronavirus) pandemic.

Time commitment: The questionnaires will take around 15 - 25 minutes every two weeks to complete but you can save your responses and return to them within 48 hours after starting.

Why are we asking these additional questions?

We want to find out how the COVID-19 (coronavirus) pandemic is affecting people's mental health and lifestyle. We are especially interested in understanding how self-isolation measures are impacting people.

Why have I been invited?

You have been invited because you are enrolled in the Platform for Research Online to investigate Cognition and Genetics in Ageing (PROTECT).

What will I have to do?

We are asking you to do a series of questionnaires about your experiences during the COVID-19 (coronavirus) pandemic. These include questions about your physical and mental health as well as your lifestyle during periods of self-isolation. If you complete the questionnaire in the first week we will ask you to complete a shorter version of the questionnaire every two weeks for six months. The first week questionnaire will take about 25 minutes to complete. Questionnaires in later weeks are shorter and should take 15 minutes or less to complete. Once you begin a questionnaire, it will remain available for 48 hours to complete if you need to exit it for any reason after starting.

Do I have to complete the new questionnaires?

No they are optional. If you don't want to complete them your participation in the PROTECT will not be affected and you don't need to take any further action. You can do as many or as few of the questionnaires as you want over the next six months.

What are the possible benefits and risks of completing the new questionnaires?

There are no direct benefits to taking part in this study but you will be helping us learn more about how people in the UK are responding to public health measures like self-isolation during this pandemic. There is a small risk that some people may find certain questions difficult to answer or distressing. For example, some of the questions about mental health may be distressing for some participants. In these cases there is clear information on where to go for support.

Can I withdraw?

These questionnaires are part of your PROTECT study participation and are optional. If you start a questionnaire and then decide that you do not want to participate you can close the questionnaire without submitting it and your answers will not be saved.

You can withdraw from the PROTECT study at any time without giving a reason. You can do this through the 'Withdraw from Study' link on the website or by contacting us on the PROTECT helpdesk.

Data governance

Your data will be handled in accordance with existing procedures of the PROTECT study. That means all study data will be stored securely according to Data Protection Laws* and the security procedures in place at the University of Exeter, King's College London, South London and Maudsley NHS Foundation Trust. For further information on how your personal information will be processed please visit our privacy policy on the study website.

**Data Protection Laws means (a) any law, statute, declaration, decree, directive, legislative enactment, order, ordinance, regulation, rule or other binding restriction (as amended, consolidated or re-enacted from time to time) which relates to the protection of individuals with regards to the Processing of Personal Data to which a Party is subject, including the Data Protection Act 1998 ("DPA") and EC Directive 95/46/EC (the "DP Directive") (up to and including 24 May 2018) and on and from 25 May 2018, the GDPR and all legislation enacted in the UK in respect of the protection of personal data; and (b) any code of practice or guidance published by the ICO (or equivalent regulatory body) from time to time.*

Further Information

If you would like more information about these questionnaires before you decide whether or not to take part, you can contact a member of the study team by emailing support.protect@exeter.ac.uk.

The full PROTECT Study Participant Information Sheet is available to download from the PROTECT Study webpage: https://www.protectstudy.org.uk/Home/Faq#section-eight

The London Bridge NHS Research Ethics Committee has approved the addition of these questionnaires to the PROTECT study (Ref: 13/LO/1578)

Consent to Take Part

- I confirm that I have read and understand the Supplementary Information Sheet for Participants for COVID-19 (coronavirus) questions in PROTECT dated 03/04/2020 (v1). I have had the opportunity to consider the information, seek clarification and understand my involvement in the study.