



MRC SGDP CENTRE

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Information Sheet

Title of Project: Wellbeing in Grandparents of Children with Autism Spectrum Disorder (ASD)

Ethical Approval References: PNM/13/14-56 (Psychiatry, Nursing and Midwifery (PNM) Research Ethics Subcommittee (RESC) at King's College London)

Researchers: Miss Esra Zivrali (MRC SGDP Centre)

Supervisors: Professor Francesca Happé (MRC SGDP, Institute of Psychiatry); Professor Patricia Howlin (Department of Psychology, Institute of Psychiatry)

Information about the Research

Participant Information Leaflet, Version 1.0.4, date 30 July 2014

Introduction

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

What is the purpose of the study?

Autism Spectrum Disorder (ASD) is a life-long condition, and therefore it is important to understand how the process of ageing affects individuals with autism. ASD has a large genetic component, and sometimes relatives of those with ASD recognise similar but much subtler features in themselves. These ASD-related traits can be assets (e.g. eye for detail) or challenges (e.g. social difficulties). This research project will explore wellbeing in the older relatives of children with ASD. For example, this research will look at the changes in mental health, physical wellbeing and cognitive skills affected in ageing. The study will also explore how social functioning such as relationships affects quality of life.

The aim of this research is to obtain information that will help us to understand the possible changes that occur with age and how this affects the quality of life for individuals who may share more or less of the traits associated with ASD. In this way, the study will enable us to identify ways in which support services can be improved to help older adults with autism to lead healthy and fulfilling lives.

Why have I been invited?

We are inviting biologically related grandparents (aged 50+) of young people with ASD to participate in this study.

Do I have to take part?

No. It is entirely up to you whether or not you decide to take part. If you do decide to take part, you are still free to withdraw from the study at any time before 30.09.2016 without giving a reason and without penalty. We will destroy the information we have about you, if you wish.

What will happen to me if I take part?

If you are recruited into the study, you will be sent a booklet of questionnaires about your lifestyle, preferences, and wellbeing. There are also photo and cartoon puzzles developed by us for you to complete. Completion of the set of questionnaires will take approximately 60-90 minutes in total. After you have completed all of the questionnaires, we would like you to send all the materials back to us by using the enclosed envelope in the package sent to you.

Will I be compensated for my time?

To thank you for your time and involvement we will put you in a £50 Amazon voucher prize draw at the end of the year.

What are the possible benefits of taking part?

Taking part in research projects is often a rewarding and interesting experience. For this research project, in particular, you will contribute to research that aims to create an awareness of how ageing affects individuals with autism, in order to support people such as your grandchildren throughout the life-span. We cannot promise any direct benefits to you but hope our research will make a difference in the longer term.

What are the possible disadvantages of taking part?

There are no likely risks in taking part in the study, however we appreciate the demands on your time required for the duration of the questionnaires.

If at any time you feel any discomfort or anxiety, you can stop answering the questions. If you have any concerns at any time before, during or after the research session, you are welcome to contact the research supervisors at any time, at the MRC SGDP at the Institute of Psychiatry.

Will my taking part in the study be kept confidential? / Will my information be kept confidential?

Yes. We will follow ethical and legal practice. All personal information is regarded as strictly confidential and will be held securely until the research is completed. All data for analysis will be anonymised, in other words it will contain only information about the scores and results from questionnaires and other tests, but will not contain any personal information to identify you. We will keep any information we have about you in a safe and secure place.

Will you tell my GP that I am taking part in this study?

GP's will not be routinely informed about the study, but we will be happy to let your GP know if you wish us to. This would not be done without your knowledge.

Consent

Your submission of the questionnaires will also be considered as your consent to participate into the study. In terms of the Mental Capacity Act Code of Practice (2005), "Every adult has the right to make his or her own decisions and must be assumed to have capacity to make them unless it is proved otherwise". In the unlikely event that you were to lose capacity to act independently and make informed decisions, once the study had begun, the researcher(s) would exclude your further participation. Furthermore, any identifiable data that relates to you would be either anonymised or disposed of. The researchers would also be required to seek further assistance and refer you for further care to a clinical practitioner at the Institute of Psychiatry, and may also advise your carer and/or GP.

What will happen after this research study?

This study is a part of a larger research project that aims to understand the effects of the ageing process on psychological, social and physical wellbeing in people with autism spectrum disorder, and how this relates to overall quality of life. We will also ask for your permission to contact you in the future about additional research sessions related to this project, as well as whether you would be interested in being involved in other research studies. It is entirely up to you if you would like to give permission for us to contact you in the future, and will not affect your participation in this research study. Consent to be contacted again about new projects does not in any way affect you taking part in any future studies.

What will happen to the results of the research study?

We will aim to publish the study findings in scientific journals, and present them at academic conferences and other public seminars related to autism spectrum disorder. The researcher will also include the findings in her PhD thesis. Furthermore, key highlights from the research findings will be made available for public access through the National Autistic Society. All publications will contain anonymous data from the tests and questionnaires used in the study, so that no one else will be able to identify you or know that you have taken part in this study, unless you tell them. We may ask for your permission to use anonymous quotes in any publications. If you would like to be sent a summary of the overall study findings, once the research has been completed, it will be provided for you.

Who is organising and funding the research?

This research study is being organised by researchers working at King's College London. The study has been funded by the Republic of Turkey Ministry of Education.

Who has reviewed this study?

This research study has been reviewed and approved by the King's College London (KCL) College Research Ethics Committee (CREC)-Psychiatry, Nursing, & Midwifery Review Subcommittee/Panel (PNM RESC).

If this study has harmed you in any way, please contact the research supervisors whose contact details are provided below.

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If you would like any further information about this study and for general queries, please contact:

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Thank you for reading this information sheet.

Please keep this in a safe place, in case you need to refer to it at a later time.