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Information Sheet – Participant

Title of Project: Age-related Effects on Cognition and Quality of Life in Adults with Autism Spectrum Disorder

Ethical Approval References: PNM/13/14-26 (Psychiatry, Nursing and Midwifery (PNM) Research Ethics Subcommittee (RESC) at King's College London)

PSYETH(UPTD) 13/14 28 (City University London School of Arts & School of Social Sciences Research Ethics Committee)

Researcher: Miss Esra Zivrali (MRC SGDP Centre, Institute of Psychiatry, Psychology & Neuroscience)

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

Collaborators: Professor Dermot Bowler (City University London), Ms Amanda Roestorf (City University London)

Information about the Research

Participant Information Leaflet, Version 2.0.0b, date 26 November 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. This research project will explore how the symptoms associated with autism change over the lifespan. For example, this research will look at the changes in mental health and physical well-being and cognitive skills such as language and memory are affected in ageing. The study will also explore how social functioning such as independent living, relationships and social communication affect 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 with autism. 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 adults (aged 18+) who have an autism spectrum disorder (i.e. autism or Asperger syndrome) to participate in this study. Whether you received a childhood diagnosis, or one in later-life, we welcome your involvement in this research project.

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 at any time without giving a reason and without penalty. We will destroy the information we have about you, if you so wish.

What will happen to me if I take part?

If you are recruited into the study, you will be invited to attend two research sessions, held on separate days. These will take place at either the MRC Social Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience or at the Autism Research Group at City University London and will be a time that fits in best with your other commitments. The research sessions will usually involve you meeting with just one researcher. You are welcome to bring someone you know with you.

First research session will take about 4-5 hours, and the second one will take about 2-3 hours. During the research sessions you will be asked to fill in some questionnaires. Questions will be about your preferences, emotions, wellbeing, and health. There will also be other computer-tests and puzzles testing your memory, language and social functioning. In addition, if you received your autism diagnosis more than 5 years ago, or you do not have any details about your diagnosis, we may need to confirm your diagnosis via the Autism Diagnostic Observation Schedule (ADOS). This will be done by trained practitioners at the MRC Social Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience or at the Autism Research Group at City University London. No additional time is needed, as this has been planned into the overall time for the research sessions. During the research sessions lunch and/or refreshments will be provided in comfort breaks.

We may also require some additional information from a person who has known you for 5 years or longer, and is in regular contact with you. This person may be a spouse or partner, friend, carer, parent or brother or sister. If you agree to us contacting them, please provide their name and contact details to the researcher.

What will happen to the audio or videotape if my interview is recorded?

We will ask for your permission to participate in audio and video recording for some parts of the research. You have the choice to refuse permission for both audio and video, or you may choose to allow either audio or video recordings. The recordings will be reviewed only by researchers in the MRC Social, Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience and the Autism Research Group at City University London. All tapes will be labelled with an ID number, rather than your name and no other personal information about you will be included with the tapes. Once the tapes have been transcribed and analysed, they will be destroyed.

Will I be compensated for my time?

To thank you for your time and involvement we will offer you £25 per research session. If you choose to participate in both research sessions, you will therefore be paid £50 in total for your time. We will also provide lunch and/or refreshments during each session and pay for any reasonable travel costs. This will be paid to you directly at the end of each session.

You may be asked to participate in additional research sessions, which will be held at on a separate day and time, at your convenience. You will be remunerated for each session that you attend at the pro-rated rate of £8/hour.

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 yourself long into later-life.

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 testing sessions. If at any time you feel any discomfort or anxiety, please let the researcher know and the research session will end immediately.

What if something goes wrong?

In the unlikely event of you suffering any adverse effects as a result of your participation in this research, compensation will be made available through the 'No Fault' Compensation Scheme available from either King's College London (for the MRC Social Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience), or through City University London (for the Autism Research Group), depending on where you attended your research session. This scheme includes payment of damages or compensations in respect of any claim made by research participants for bodily injury arising out of participation in any human volunteer study. In the unlikely event that you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for legal action but you may have to pay legal costs.

What if I have any concerns or would like to make a complaint?

If you have a concern about any aspect of this study, please ask to speak to the researchers, or the research supervisors, who will do their best to answer your questions. If you remain unhappy and wish to complain formally, you may do so by contacting the individuals listed below.

For the MRC Social Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience:

Dean's office at King's College London

Tel: +44 (0)20 7848 0154

For the Autism Research Group at City University London:

Ms Anna Ramberg, Secretary to Senate Research Ethics Committee

Tel: +44 (0)20 7040 3040 / Email: anna.ramberg.1@city.ac.uk

Will my taking part in the study and 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. We will erase audio and video tapes once we have transcribed and analysed the data.

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

GPs 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

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 end the session immediately and 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 either at the Institute of Psychiatry, Psychology and Neuroscience or City University London and may also advise your carer and/or GP.

What will happen after this research study?

This study is the first stage of a larger research project that aims to understand the effects of the ageing process on psychological, social and physical well-being 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 researchers will also include the findings in their Master's and PhD theses. 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, we will ask you to provide your contact details, which will be stored securely in the research offices of the Social, Genetic and Developmental Psychiatry Centre at the Institute of Psychiatry, Psychology and Neuroscience and the Autism Research Group at City University London.

Who is organising and funding the research?

This research study is being organised by researchers working at King's College London and City University London. The study has been funded by the Republic of Turkey Ministry of Education for King's College London and the Medical Research Council (MRC UK) for City University London in collaboration with the National Autistic Society.

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) (PNM/13/14-26) and City University London School of Arts and School of Social Sciences Research Ethics Committee (project reference: PSYETH(UPTD) 13/14 28).

If you would like any further information about this study please contact:

Miss Esra Zivrali, email: esra.zivrali@kcl.ac.uk; Tel: +44 (0)20 7848 5401; Mobile: +44 (0)79 3365 9264

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.