The Neurological Voice Project

Information sheet

We would like to tell you about a research study but, before you decide if you would like to take part, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information and feel free to discuss this with family, friends and your general practitioner if you wish. Please ask if there is anything that is not clear or if there is an area that you would like more information.

What is the purpose of the study?

This study aims to generate a personalised voice, for use in a communication aid, for individuals who due to disease, are losing the ability to speak. This is achieved in one of two ways; firstly, by taking a recording of your voice early on in the disease and storing this for your use if required at a later date when speech may become affected; secondly, for people unable to record their own voice we hope to be able to combine anonymised "clips" of individual recordings (with permission from the recording donors) to synthesise a computer generated voice that retains accent, age and gender qualities but cannot be identified to an individual donor. Either of these goals would represent a major advance on current voice provision that is restricted to impersonal and robotic voice products that are not matched even to age or accent. Multiple feedback from patients, carers and patient societies has indicated that this is a major unmet clinical need and provision of personalized speech is associated with greater dignity and improved self-identity for the individual and their carers / family.

Why have I been approached?

As someone who has been diagnosed with a neurological disease which may later involve speech deterioration, we are inviting you to contribute to this project irrespective of whether you have any speech involvement at present or not.

Or

As someone who has intact speech your recording could be used, if you agree to share your recording, along with recording clips from others in order to recreate a wholly synthesised amalgam voice for individuals who due to advanced disease have been unable to record their own voice. This final voice will not be identifiable to any individual as it will be a fusion of fragments or clips from many volunteers.

Do I have to take part?

No, and if you choose not to take part this will not affect your clinical care. You are also free to withdraw from the study at any time without providing a reason and this will not affect your care.

Neither taking part in the study, or not, will have any influence on your clinical management.

What do I have to do?

You need to read this information sheet carefully and ask any questions that you feel you need to (our contact details are below) and then return the slip in the envelope provided to indicate whether you are interested or not in the project. If you are interested, the research nurse will contact you to arrange a suitable time for you to come and discuss the project further, take consent and record your voice. The recording could be done at the next clinic visit or at any other time that is convenient to you. Recordings can typically take up to 1 – 2 hrs.

It may be necessary to have more than one recording of your voice to allow further acoustic analysis of the recordings.

Are there any risks or disadvantages of taking part?

There are no discernable risks or disadvantages to taking part.

(Please note that this is a research project and, as it is in the early stages, we cannot guarantee the end product being available for individuals who participate at this early stage of the project).

What are the possible benefits of taking part?
The possible benefits to you are the use of your own voice in a communication aid if your speech substantially deteriorates.

The benefits to others who have been unable to record their own voice, should you agree to share your recording, is the use of multiple clips to synthesise a computer generated voice that is as close to their original voice as possible.

Participation in this study does not involve a financial cost or payment to the participant.

Will my taking part in the study be kept confidential?
Your personal information and voice recording will be kept securely on an NHS approved system, in Edinburgh University. Only the core members of the research team will be able to link your identifiable data with the unidentifiable data stored via a unique study number.

If you agree, your GP would be informed of your participation in this study.

What happens to the results of the study?
The results will be presented at academic meetings and published in academic journals. You will not be identified in any presentation or publication. If you would like to receive a summary of the results please contact the national co-ordinating office (address supplied below).

Who is organising the research?
The study is organised by a team of researchers based in Edinburgh University and working in the field of Neurosciences and Informatics. The researchers are not paid to recruit patients into the study.

Who has reviewed the study?
The study has been reviewed by South East of Scotland Research Ethics Committee 2.

What if there is a problem?
All core research staff are covered by NHS/University of Edinburgh contracts and the NHS/ university public liability insurance. We do not anticipate any problems with this study but if you do have a complaint, please report this using the standard NHS Lothian Complaints Procedure (0131 558 3681).

Is there anyone I can speak to about this study who can offer me independent advice?
If you have any questions needing independent advice, please contact: Dr Richard Davenport, Consultant Neurologist, Western General Hospital, Edinburgh EH4 2XU. Email: rjd@skull.dcn.ed.ac.uk

Contact for further Information:

Shuna Colville
Research Nurse
The Euan MacDonald Centre
Chancellor's Building
49 Little France Crescent
Edinburgh Tel: 0131-242-7985
EH16 4SB E-mail: info@smart-mnd.org

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