Neurological Voice Bank Project: Donor Information Sheet

We would like to invite you to participate in a research project that aims to bank “donor” voices. Before you decide to participate it is important that you understand the research that is being done and what it will involve. Please take time to read the following information and feel free to discuss this with family and friends 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?
The study aims to use recorded donor voices to reconstruct patient voices that have been damaged through disease, such as Motor Neurone Disease. Using the donor voices researchers at Edinburgh University Informatics Department can reconstruct the patient’s voice, as near to their original voice as possible, for use in a communication aid.

Do I have to take part?
No, it is up to you to decide whether or not to take part. You are free to withdraw from the study at any time and without giving reason.

Who can donate their voice?
To be able to donate, you should:
be aged over 16 years of age
be a native speaker of English
have no difficulties reading or understanding printed materials
have no difficulties or problems with your speech.

What will I have to do?
Please read this information sheet carefully. If you agree to participate in the study, we will make an appointment for you to come to the recording studio at the Anne Rowling Regenerative Neurology Clinic, Royal Infirmary of Edinburgh, Little France, Edinburgh at a date and time that is convenient for you. When you arrive, you will be able to get the research team to answer any questions you may have about the project. The researcher will then go through the consent form and speaker release form with you. If you feel you have had all your questions answered, and you have signed the forms, we will ask you to complete a short questionnaire about you to tell us about your age, occupation and your accent. The recording session then follows; it should take about 1 hour. For the recording, we will ask you to read aloud several hundred sentences. These will be displayed on a computer screen in the recording studio. We will give you frequent breaks during the recording session to avoid your voice getting tired.

Will my personal information be kept confidential?
Any personal details are kept separately to the recordings. Only people from the immediate research team have access to your personal details. Your recording, stored in digital format, is allocated a unique study number which will be used in place of your name when processing the speech or on our computers or distributing the recordings. This means your voice is stored anonymously. No personal data is ever used in publications. The voice recordings are stored in strictest confidence on a secure computer server within the Department of Clinical Neurosciences, Western General Hospital, Edinburgh.

What are the possible disadvantages/ risks of taking part?
There are no discernible risks or disadvantages to taking part.

**What are the possible benefits of taking part?**
You will not benefit directly from this study, but people whose voices have become damaged through disease progression will benefit from your contribution. Your donor voice can be used, along with other donor voices, to help reconstruct a voice as near to the recipient’s original voice as possible for use in a communication aid. This is of great benefit to the patient, their family and friends.

**How will the recordings be used?**
The recordings are used not only as a bank of voices to aid the reconstruction of a “damaged voice”, but they will assist us in our research to improve assistive technologies for people with vocal problems. Your recording may help us to provide a wider range of choices to people with vocal problems. Your recording could also be used in connection with other research activities and potentially commercial companies. Improved speech generation devices may be licensed to the NHS or other third parties. Any income generated in this way may be used by the University of Edinburgh to advance our research on assistive technology and voice banking.

**What happens to the results of the study?**
The results will be presented at academic meetings and published in academic journals. Presentations may be made at conferences or more informal talks and in all cases any data presented is anonymised.

**Who is organising the research?**
The research is organised by a team from the University of Edinburgh in a joint project between the Department of Informatics (Dr Junichi Yamagishi and Prof Simon King) and the Euan MacDonald Centre for Motor Neurone Disease Research (Prof Siddharthan Chandran).

**Who has reviewed the study?**
The study has been granted ethical approval by the University of Edinburgh Informatics Research Ethics Committee.

**Contact for further information**
If you wish any further information please contact:

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Thank you for taking the time to read this information sheet. This is your copy to keep.

07/11/2013  Neurological Voice Bank Project  Donor Information Sheet Version 5