Melbourne School of Psychological Sciences

Plain Language Statement

PROJECT TITLE: **Investigating the genetic basis of singing and music abilities in large multiplex families**

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Introduction

We would like to invite you to participate in our study: ***Investigating the genetic basis of singing and music abilities in large multiplex families***. This research aims to investigate the genetic basis of singing and music abilities by looking for genes in large families where clustering of above-average or below-average music and singing abilities have occurred. The project is supported by the Australian Government through the Australian Research Council's Discovery Projects funding scheme (Project DP170102479).

What is the purpose of the study?

"Why are human beings musical? Why does music evoke powerful and pleasurable feelings in us? Why do so many people find music such an important part of their lives?"

For centuries, many have been intrigued by the expression of musical abilities. Much remains unknown about why and how humans have the capacity to process and produce music. Investigating the genetic and environmental influences on various types of music behaviour can help piece together the puzzle of human musicality. Anecdotally, singing and music abilities seem to run in some families (e.g., Jackson 5, the Beach Boys and the Bach family, just to name a few).

Moreover, engaging in music and singing activities has been shown to provide numerous benefits to one's mind and body. To help everyone maximise their music potential, increase their music engagement and reap these benefits, a thorough understanding of the genetic and environmental influences on the development of music and singing abilities is necessary.

Who are eligible?

Families reporting to have six or more immediate and extended family members (aged 15 and above) with i) above-average singing ability; or ii) below-average singing ability; or iii) above-average music ability; or iv) below-average music ability, will be eligible to take part in the first part of the study to assess their singing and music abilities online. Families whose assessed music and singing abilities match those initially reported will be eligible to take part in the second part of the study, where DNA samples will be requested from the family members to look for genes that are associated with singing and music abilities.

What would I be asked to do?

Part I: Online assessments of singing and music abilities

After you have consented to participate in the first part of the study, we will send you an email containing the web links to our online singing and music assessments which you can access on your computer anywhere you like. **Please ensure you complete the study in a quiet location by yourself, without your family being present.**

If you have consented to forward information about our study to your immediate and extended family members, you will also receive another email containing details of the study, so that they can read about the study and decide whether they would like to participate.

The online study includes **three** separate assessments:

i) Singing assessment

(Note: Previous participants of our twin study on singing ability are not required to complete this assessment.)

1) Answer some background questions about you: your name, sex, birthdate, email address, languages spoken and education level.
2) Do some music and singing activities:
    a. Sing a familiar song three times*
    b. Hear and match pitches by moving a pitch slider
    c. Hear and sing some pitches*
    d. Hear and sing some short melodies*
    e. Hear 2 versions of a familiar song and judge whether they sound right
3) Answer some questions about your music and singing experience (e.g., your childhood engagement with singing and music, any musical training undertaken, interest in singing and music, and self-assessment of music and singing abilities)

**You will be audio-recorded during these activities.*

It will take you **20-30 minutes** to complete this assessment. You also have the option to save your progress and resume later using a unique link that will be emailed to you if you cannot finish the study in one go.

ii) Congenital amusia assessment

1) Hear pairs of short melodies to judge whether each pair is the same or different
2) Hear some melodies and judge whether there is a time delay within the melody
3) Hear some melodies and judge whether there is an out-of-key note within the melody

It will take you **20-30 minutes** to complete this assessment.

iii) Music aptitude assessment

1) Hear pairs of short melodies to judge whether each pair is the same or different
2) Hear pairs of rhythm sequences to judge whether each pair is the same or different

It will take you around **20 minutes** to complete this assessment.

Note: You do not have to complete all three assessments in one sitting.

Part II: DNA sample collection

Based on the outcome of the assessments in Part I, if your family is eligible to take part in the second part of the study, you will be contacted to arrange for DNA sample collection, subjecting to your informed consent. Your DNA sample will be used to investigate changes in genes that may be causing differences in singing and music abilities. This may involve looking for changes in specific genes, or it may involve looking at a large number of genes and comparing the information in your genes with other people in your family or other people with singing or music abilities similar to yours.

Depending on your age, blood samples of no more than 30 mls or 1 ½ tablespoons will be taken. This blood sample will be taken by needle from the participant's arm. If you are a twin with same-sex co-twin, some of the blood will be used to test whether or not you are identical. This sample is separate from any routine blood tests requested by your doctor and it can be collected at a time and location convenient for you. It can be collected when you visit the hospital for a clinic appointment or we can arrange for it to be taken at a local pathology collection centre by a qualified health practitioner. In some cases, a repeat sample may be requested for additional tests. Samples will be used to obtain genetic material called DNA and RNA. A blood sample is preferred as it provides a greater quality and quantity of genetic material.

If it is not possible to collect a blood sample from you, we may request a sample of saliva instead. This is collected by spitting into a tube that we will provide. There are some tests that can only be performed from a blood sample so a saliva sample is not suitable in all situations. In rare cases a scraping of cheek cells may be used, particularly in cases where collecting saliva or blood may be difficult.

Note: Even if you are eligible for the second part of the study, you do not have to agree to a blood or saliva sample being collected. Participation is completely voluntary.

What are the risks?

In Part I of the study, it is unlikely you will experience harm. While the risks to you are likely to be minimal, there is a chance that you might experience some fatigue due to the length of the study. To mitigate this possible risk, the three assessments are independent of one another and do not need to be completed in one sitting. Furthermore, the online singing study allows you to save your progress in the study and resume later if you cannot finish the study in one go.

In Part II of the study, possible risks, side effects and discomforts include:

- There are no major risks associated with a blood test. It is possible the participant may feel some discomfort during the blood test. The participant may feel a sting when the needle is put in their arm to take the blood. It is possible there may be some bruising, swelling or bleeding where the needle enters the skin. Some people can feel a little light-headed when blood is taken.
- There may be additional risks that the researchers do not expect or do not know about.

If you suffer any injury as a result of participating in Part II of the study, hospital care and treatment will be provided by the public health service at no extra cost to you if you elect to be treated as a public patient.

If you would like to discuss any personal issues or require independent genetic counselling before deciding whether to participate in Part II of the study, or as a result of your participation in Part II of the study, this can be arranged by contacting Dr. Yi Ting Tan. The independent counselling would be free of charge and is provided by specially trained staff from the Genetic Health Services Victoria or the equivalent service interstate.

What are the benefits?

For Part I of the study, you can choose to receive a personalised feedback report (via email) about your singing ability based on the singing activities you have completed. You will also receive feedback on how you did at the end of the congenital amusia assessment and the music aptitude assessment.

For Part II of the study, we cannot guarantee or promise that you will receive any benefits from the genetic analyses. As our research is in its early phase, it may take many years before we can find meaning or reliable results. Furthermore, it is unlikely that our genetic analyses on music and singing ability will uncover information that has major health implications to you. As such, we will not be providing you with individual genetic results from the analyses.

All participants who opt to receive newsletters from us will occasionally receive newsletters which will highlight any interesting findings, as they become available, or future plans for the study. Once the study is fully completed, a summary of the findings will also be made available to you. In instances where large numbers of genes are studied simultaneously, you will not be given the names of all the individual genes studied. The findings may also be disseminated through conference presentations, journal publications or mass media.

How would my confidentiality be protected?

Data collected in Part I of the study will remain confidential. It will be used for the purposes of investigating singing ability in multiplex families. It will be stored digitally on a secure, password-protected server and subsequently in a password-protected computer folder, with access limited to members of the research team. The information you provide to the study will not be made available to anyone outside of the research team without your consent, except when required by law. We will not share personal information among your family members without your consent. Your confidentiality would be protected subject to legal limitations. The results of the research will be published in a form that will not allow individuals to be identified. Your data will be retained for a minimum of five years after the last publication or public release of the work of research. After this period, all digital files will be deleted and hard copy documents will be appropriately destroyed. Your data may be used again for future ethically approved research.

As for DNA samples collected in Part II of the study, your DNA sample, labelled with your name, date of birth and diagnosis will be sent to the translational neurogenetics laboratory at Melbourne Brain Centre (Heidelberg) and the DNA (genetic material) extracted. The DNA sample will be stored in a coded form with the key to the code kept on a password-protected database that is only accessible to members of the research team.

As this is an ongoing research study, we would like to store your DNA sample for the duration of the study so we can test it when new genes for singing and music abilities are identified. However, if this project ceases your DNA sample will be destroyed. Also, you can request that your DNA sample be destroyed at any time by contacting us.

Your DNA will not be used for any purpose other than for the study of genes thought to be relevant to singing and music abilities and to determine the zygosity of same sex twins (whether the twins came from the same or different eggs) and your sample will not be released for other uses, except as described above, without your specific written consent.

In any publication and/or presentation, information will be provided without any identifying details such as names or dates of birth. However, when our research findings are published in scientific journals we may include family trees and music-related information about your family. Such information may make it possible for someone who knows you well to identify you and your family. This is unlikely but the possibility needs to be acknowledged.

What if I want to withdraw from the Research?

Participation in this research is completely voluntary. You are free to withdraw at any time and to withdraw any data previously supplied. This would have no effect on your relationship with any member of the School of Psychological Sciences, or the University of Melbourne.

Where can I get further information?

If you have not understood any of this information please contact any of the researchers listed above. This research project has been approved by the Human Research Ethics Committee of The University of Melbourne. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the research team, you should contact the Manager, Human Research Ethics, Office for Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 2073 or Fax: +61 3 9347 6739 or Email: HumanEthicscomplaints@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence please provide the name of the research team or the name or the project's ethics ID number.

How do I agree to participate?

Please indicate your consent to take part in the study by clicking on the consent form web link in the invitation email you have received.

Thank you for taking the time to consider this study.