



Max Planck Institute
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Investigating the genetic basis of synaesthesia

Information Sheet for Participants (version February, 2014)

You are being invited to participate in a research project by the Max Planck Institute for Psycholinguistics. This information sheet will explain why this research is being carried out and describe what your participation would involve. Participation in this study is voluntary; please take the time to read the following information carefully so that you can decide if you would like to participate.

Why have I been contacted?

We have contacted you because you or a member of your family has previously provided information about your synaesthesia to our researchers, or network of scientific partners. We would like to invite you to participate in a new study.

What is the purpose of this study?

This study will investigate the genetic basis of synaesthesia. Previous research has shown that synaesthesia runs in families, but very little is known about which genes are responsible for this. Finding the genes associated with synaesthesia would be a major breakthrough in our understanding of this interesting trait. In addition, because synaesthesia involves the brain making connections between different kinds of information (such as letters and colours), understanding its genetic basis may also tell us more about how the brain processes and makes connections between different kinds of information even in people who do not experience synaesthesia.

Who is organising and funding the study?

The study is being organised and funded by the Language & Genetics Department, Max Planck Institute for Psycholinguistics in Nijmegen, The Netherlands (Director Simon E. Fisher). The Max Planck Institute for Psycholinguistics is a non-profit, academic research institute which is part of the Max Planck Society, an association of research institutes publicly funded by the German government.

How can I take part?

All parts of this study can be completed from home. There is no need to travel to participate in the study.

1. **REGISTRATION:** Firstly we would like you to register on the MPI web site <http://www.mpi.nl/synaesthesia>. To protect your personal data you will be assigned an alias email address e.g. 123456@mpi.nl.
2. **SYNAESTHESIA TEST:** To complete the test, go to www.synesthete.org and register there by entering your alias email address and choosing a password. Note that the www.synesthete.org website is hosted at Baylor College of Medicine, Houston, Texas, USA. Read all information on the web site carefully. It is not necessary to provide your name or other personally identifiable information to take the assessment test. In addition, you will need to make your test results available to our research team at the MPI by entering our research email address synaesthesia@mpi.nl when prompted. If you don't do this, we will not receive your results. You don't have to do the whole test in one go – once you have registered you can log in again later to finish the tests or view your results.
3. **GENETICS:** Depending on the results of your synaesthesia test, we may invite you to provide a small sample of saliva, from which we can obtain your DNA. We will post you a saliva collection kit with full instructions, and a prepaid envelope in which you can return the sample to us. We will also send you a consent form to sign and return, to confirm that you have read this information and understand what participating in the genetics research entails. If you are under 18 years old your parent or legal guardian will be required to sign with you.

What will happen to my genetic material (DNA)?

To preserve your anonymity, your saliva sample will be assigned a code so that staff working with your DNA data will not be able to find out your personal details. Your genetic material will be stored and analysed under the supervision of Dr Fisher's research group. Your anonymously coded DNA may be sent to specialist genomics companies and research institutes to carry out services such as DNA sequencing or genotyping, but the resulting data will be returned

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only to researchers at the Max Planck Institute for Psycholinguistics. Your DNA sample will be retained since it may be useful in future research on synaesthesia and language. Your DNA, and data arising from it, may be used in other ethically approved studies of the Language & Genetics research programme at the Max Planck Institute for Psycholinguistics (<http://www.mpi.nl/departments/language-and-genetics/projects>), but not for any other purposes without re-contacting you and asking for specific permission. Samples or data, again excluding personal information, may be shared with additional researchers at other institutions under strict terms of collaboration and limited duration, for example for the purposes of meta-analysis with other cohorts.

What are the possible risks of taking part?

There are no known risks from participating in this study.

What are the possible benefits of taking part?

Your participation will help us to identify genes associated with synaesthetic experiences, which will greatly enhance our understanding of them, and may also tell us more about how the brain works in general. We are not able to provide personalised genetic counselling, or advice related to findings that we make with your sample. The focus of our research is on genes involved in synaesthetic experiences, but there is a very small chance that we will happen to observe other variations in your genome that could be medically relevant. In this case, we would refer the anonymised information to an independent expert panel at the Department of Human Genetics, University Medical Center, Nijmegen, who will assess whether and how it would be helpful for you to be informed.

What information will be held about me? Who will have access to my data?

All personally identifiable information that our research team collects from you (such as your name and address) will be stored securely and kept confidential within the Max Planck Institute for Psycholinguistics. Only authorised persons who are directly involved in this study will be able to access this information, and it will not be disclosed to anyone outside the research group without your permission. As noted above, the synaesthesia assessment web site www.synesthete.org is hosted at Baylor College of Medicine. The data that you provide on www.synesthete.org will be securely stored there and accessible to our team if you have made them available to us. The experimental data we collect from you (including genetic information) will be identified only by a code number, and will not be linked to your personal details. This anonymised data will be available to the research team and regulatory authorities, and may also be made available for use in other ethically approved studies by the Max Planck Institute for Psycholinguistics and scientific partners in the future. Any data that you have previously provided to researchers in the Max Planck Institute for Psycholinguistics or collaborators may be used in this study. All data will be stored securely and will only be used for the purposes of scientific research.

What will happen to the results of the study?

The results from this study will be published in scientific journals. All data in publications will be anonymous to preserve confidentiality.

Can I withdraw from this study later on?

You can withdraw from the study at any time.

Who has reviewed and approved this study?

This study was reviewed and approved by the *Ethische Commissie Gedragswetenschappelijk Onderzoek* (Ethics Committee, Faculty of Social Sciences) at the Radboud University Nijmegen, The Netherlands. This is an independent group of people who ensure that the dignity, rights and safety of participants and researchers are protected.

Who do I contact for more information or if there is a problem?

If you have any enquiries relating to this study, please feel free to contact the Project Leader, Katerina Kucera, using the following contact details:

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