

**INFORMATION LETTER**  
for participation in scientific research  
**Investigating the genetic basis of synaesthesia**

**1a. Introduction/Aim of the research**

This study will investigate the genetic basis of synaesthesia, a perceptual phenomenon in which stimuli give rise to experiences in other sensory modalities. An example would be the experience of colours associated with numbers and letters. The aim of the study is to identify the genes associated with synaesthesia by connecting test scores on an on-line synaesthesia test with genetic information. The study is being organized 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. The expected end date of the study is 01-06-2026.

**1b. The research**

The research includes an online quiz in which you are asked to match colours to letters, numbers, days and months. All aspects of the research can be completed from home. There is no need to travel to participate in the study. There are no known risks from participating in the research. The research includes the following steps:

1. **REGISTRATION:** Firstly we would like you to register on the MPI web site [www.mpi.nl/synaesthesia](http://www.mpi.nl/synaesthesia).
2. **SYNAESTHESIA TEST:** Next, take the synaesthesia test. Please make sure that you have 20-30 minutes available to complete the test. You can use one of these three options to reach our test:
  - a. Online, using the link on the MPI website. Your results will be shared with the researchers once you click "Submit My Results".
  - b. In the SynQuiz App. The app can be downloaded from the Google Play Store or Apple App Store. Share your results by entering 'synaesthesia@mpi.nl' in the "share your results with a researcher" box.
  - c. Have you taken The Synesthesia Battery at [www.synesthete.org](http://www.synesthete.org) at some point in the past? You can use those results to join our study. Log on to synesthete.org and enter synaesthesia@mpi.nl in the "share your results with a researcher" email field.
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.

4. **ADDITIONAL SURVEYS:** If you indicated in the online test on the MPI website that you experience synaesthesia relating to your sense of touch, we may also send you additional surveys to help us better understand the extent of your synaesthesia and whether your family members also experience synaesthesia.

The study has been reviewed independently by the Ethics Committee Social Sciences (ECSS) of the Radboud University and there is no formal objection to this study

### **2a. Use of your personal data**

To conduct the research it is necessary that your personal data are collected, used and stored. It concerns the following data: 1) Personally identifiable information, including name, address, age, gender and ethnicity. 2) experimental data including your genetic information. All personal data will be stored securely and kept confidential within the Max Planck Institute for Psycholinguistics. Only authorized 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. The experimental data will be stored securely and kept confidential within the Max Planck Institute for Psycholinguistics. To ensure your anonymity, 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. Only authorized 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.

The use and storage of your personal data is necessary for connecting your test scores on the synaesthesia test to your genetic information. 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 trait. Personal data will be stored because we have a legal obligation to register your permission to participate in this study and because we are obliged to inform you in case of clinically relevant findings.

For the current research it is also necessary to collect specific personal data in order to answer the scientific research question and to publish the results. These specific personal data are country of birth, and country of birth of your parents. We also collect information on ethnicity. Human genetic variability stemming from ethnical diversity makes some genetic studies more challenging. We therefore collect information on country of birth and ethnicity to include in the genetic analysis in our research.

### **2b. Confidentiality of your data and data processing**

The information you provide for the current research purposes is treated with the utmost care and is accessible to authorized staff only. Personal data collected by the researcher about you will remain confidential throughout the research. In order to safeguard your privacy, the researcher saves your personal data using a process of encryption/pseudonymisation. This means that your name and any other particulars that can identify you directly, are kept separate from the research data. It is only possible to find out which research data belongs to which person by means of a code or subject

number. The link between data that can identify you directly and all other research data is stored in a key file. This key file is password protected. Only authorized members of the research team have access to this information. No other parties involved in the research shall receive any data that can be traced back to you. In order to disguise your identity, only anonymized research data are to be used in reports and publications regarding the research.

Your saliva sample, DNA and genetic information we collect will be identified only by a code number, and will not be linked to your personal details. This anonymized 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. All data will be stored securely and will only be used for the purposes of scientific research

### **2c. Retention period of your data**

The consent form signed by you will be kept for 10 years upon completion of the research. Your (anonymized) research data including your synaesthesia test results, DNA and genetic information will be stored for at least 10 years after the research has been completed. The link between your personal data and your research data will be kept for a maximum of 1 month following completion of the research. This means that you can request to have your research data deleted (by sending an email to [synaesthesia@mpi.nl](mailto:synaesthesia@mpi.nl)) no later than 1 month after the completion of the research. After that, your research data can no longer be deleted, as they are stored anonymously only. This means we no longer know which research data belong to you personally.

### **2d Sharing your data**

Due to the importance of control, reuse and/or replication of research results, research data (including any anonymous personal data) are increasingly shared with or made available to other researchers. Your data will be anonymized prior to this form of sharing. This means that you can no longer be identified on the basis of these data. 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 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 Department of the Max Planck Institute for Psycholinguistics, 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. If you do not want your anonymized data to be shared, you can request to have your data deleted up to a maximum of 1 month after completion of the research.

### **2e Right of access by supervisory authorities to inspect the research's compliance with ruling guidelines**

Some persons and organizations must have access to your personal and research data. This is necessary in order to test whether the research has been carried out properly and reliably. These persons and supervisory authorities inspecting your data for verification include: authorized persons within the Language & Genetics Department of the Max Planck Institute for Psycholinguistics, the

Max Planck Society or Radboud University (for example a dean, director or data officer) and (inter) national supervisory authorities (for example the Dutch Data Protection Authority and the Netherlands Board on Research Integrity). They are held to inspecting your data on a strictly confidential basis. You will be asked to grant permission for this access. If you refuse to do so, you cannot participate in the study.

## **2f. Additional information on your rights regarding the processing of your personal data**

The Max Planck Institute for Psycholinguistics (specifically, the Max-Planck-Gesellschaft zur Förderung der Wissenschaften e.V., Hofgartenstraße 8, 80539 Munich) is responsible for compliance with the General Data Protection Regulation (GDPR) when processing your personal data. The researcher ensures that your privacy and the conditions attached to it are safeguarded and he/she adheres to the Dutch code of conduct for scientific integrity and MPI policy regarding the storage and management of personal and research data when conducting this research. The scientific basis for personal data processing is your consent according to article 6, section 1 under a) or article 9, section 2 under a) GDPR. You have the right to withdraw your consent for the processing of your personal data at any time. Your personal data will then be deleted. Please see the MPI Privacy Policy for more information about your rights regarding the processing of your data:

<https://www.mpi.nl/page/privacy-information-participants>.

If you have any questions about your privacy, please contact the Privacy Officer of the MPI ([privacy@mpi.nl](mailto:privacy@mpi.nl)) or the Data Protection Officer of the Max Planck Society (Heidi Schuster, Hofgartenstraße 8, D-80539 Munich via [datenschutz@mpg.de](mailto:datenschutz@mpg.de) or by calling +49 89 2108 1554; Heidi Schuster speaks English or German). Further information about your rights regarding the processing of your personal data can be found on the website of the Dutch Data Protection Authority (<https://autoriteitpersoonsgegevens.nl/en>).

## **3. Findings that may be of personal clinical interest**

The obtained research data will not be viewed from a medical and/or clinical perspective. Therefore, your participation in the study cannot be considered a medical/clinical test. In exceptional cases, new data can be obtained regarding your health such as results that are viewed as worrying and/or that may be of personal clinical importance. In such cases, you will be informed accordingly by the researcher/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, up to a maximum of 1 month after the end of the study, once your personal details are removed. If you do not wish to be informed on these findings, you cannot participate in the study.

## **4. Future research**

Following your participation in the current study, we would like to approach you for future research. Please indicate on the consent form whether you agree to being contacted by us again. Should you agree, your personal information will be saved for 2 years after completion of the study. As always, participation would be on a voluntary basis and you may expect a new request to consent to participate in any future study. It is within your rights to have your contact details removed at any time and/or withdraw your consent to be approached for future research.

## **5. Voluntary participation**

Your participation in this study is entirely voluntary. If you decide not to participate, there will be no consequences. If, during the course of the research, you wish to withdraw your consent and terminate your participation, you have every right to do so at all times. Again, there will be no adverse consequences for you.

#### **6. Compensation or remuneration**

Not applicable

#### **7. Contact information**

If you have any questions, comments, complaints or concerns about this study, or would like to receive additional information regarding your test scores, please contact the researcher responsible via our study email address: [synaesthesia@mpi.nl](mailto:synaesthesia@mpi.nl). The name and further contact details of the current project leader can be found on [www.mpi.nl/synaesthesia](http://www.mpi.nl/synaesthesia).