Appendix B

**Study Title**: Parosmia Questionnaire

University of Reading Study Number UREC 20/tbc

Participant Information Sheet

**Why are we doing this study?**

We would like to understand more about the distortions experienced during parosmia, and whether they are similar worldwide. We are interested to find out if those who experience smell distortions after CoVid-19 have similar distortions to others with parosmia.

**What is the purpose of the study?**

Much of the information on parosmia gathered so far is anecdotal. We are looking to gather information on a large scale so that we can confirm the trends we have seen in preliminary studies. We will use this information to identify molecular triggers and key odour receptors. This should help us understand more about parosmia and develop strategies to minimise it.

**Who would be eligible to participate in the study?**

We are inviting adults 18 years old and over who are currently experiencing post-viral parosmia to participate. This applies to those who may have developed it from infections such as colds, flu and upper respiratory tract infections as well as those who developed parosmia as a result of CoVid-19.

**How can you be involved?**

The questionnaire is entirely on-line, so it takes place in the comfort of your own home. You just need to be able to complete an on-line survey which will take no more than 20 mins.

**Do I have to take part?**

Not at all, participation is entirely voluntary, and you are free to withdraw (stop participating) at any time without giving any reason.

**What will be involved if I take part?**

We will ask you to complete a detailed questionnaire about your smell loss, development of parosmia and key triggers. We will also ask about whether you have had Covid-19 and whether you have been tested. We estimate that this should take no longer than 15 minutes of your time.

**Confidentiality, storage and disposal of information**

Your records and personal data will remain fully anonymous and confidential. You will be assigned a random code at the beginning of the survey and this will not be linked with the information provided on the consent form. Data collected in this study will be preserved and made available in a fully anonymized un-linked form, so that it can be consulted and re-used by others.

**Are there any benefits/risks to taking part [e.g. health]?**

There are no risks to taking part. There is no individual benefit in taking part, although we hope you will enjoy taking part and finding out more about what triggers parosmia.

**What will your data be used for?**

The results will be used to try and understand why parosmia happens. We will discuss your results anonymously with our collaborators who are experts in universities or hospitals and ENT clinics.

**Who has reviewed the study?**

This project has been reviewed by the School of Chemistry, Food and Pharmacy Research Ethics Committee and has been given a favourable opinion for conduct.

**Who has funded the study?**

The study is not funded, however the study is supported by the charity AbScent and more details can be found at <https://abscent.org>

**Where can I find out more about smell disorders?**

AbScent <https://abscent.org> supports those who are experiencing loss of smell and parosmia, and their website provides well-sourced links to useful information. In particular there is advice on how to start smell-training which is a technique developed in Germany that has been proven to enhance smell recovery in some post-viral parosmics.

**Data Protection**

The organisation responsible for protection of your personal information is the University of Reading (the Data Controller). Queries regarding data protection and your rights should be directed to the University Data Protection Officer at imps@reading.ac.uk, or in writing to: Information Management & Policy Services, University of Reading, Whiteknights, P O Box 217, Reading, RG6 6AH.

**Use of Personal Data**

The University of Reading collects, analyses, uses, shares and retains personal data for the purposes of research in the public interest. Under data protection law we are required to inform you that this use of the personal data we may hold about you is on the lawful basis of being a public task in the public interest and where it is necessary for scientific or historical research purposes. If you withdraw from a research study, which processes your personal data, dependant on the stage of withdrawal, we may still rely on this lawful basis to continue using your data if your withdrawal would be of significant detriment to the research study aims. We will always have in place appropriate safeguards to protect your personal data.

**You have certain rights under data protection law which are to:**

* rectify inaccuracies in personal data that we hold about you
* be forgotten, that is your details to be removed from systems that we use to process your personal data

Some restrictions apply to the above rights where data is collected and used for research purposes. You can find out more about your rights on the website of the Information Commissioners Office (ICO) at <https://ico.org.uk>

You also have a right to complain to the ICO if you are unhappy with how your data has been handled. Please contact the University Data Protection Officer in the first instance.

Please feel free to contact me j.k.parker@reading.ac.uk if you have any questions or if you require any further information.

Thank you very much for your help.



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