Study Information Sheet

The lived experience of people with Kallmann syndrome /Congenital Hypogonadotropic Hypogonadism (CHH).

Thank you for considering participating in this research project. The purpose of this document is to explain to you what the work is about and what your participation would involve and enable you to make an informed choice.

What is the purpose of the study?

The purpose of this study is to gain knowledge and insight from people who have lived experience of people with Kallmann syndrome/Congenital Hypogonadotropic Hypogonadism (CHH). The findings of the study will be used to provide a record of what it might be like to have Kallmann syndrome/Congenital Hypogonadotropic Hypogonadism (CHH).

What will the study involve?

You will be asked to complete an interview on MS teams - online. The interview will include questions related to your experiences of having Kallmann syndrome/Congenital Hypogonadotropic Hypogonadism (CHH), and how it has or does affect your experiences, or how you think about yourself. The interview will take about 30-40 mins to complete and will be conducted by a member of our research team.

Why have you been asked to take part?

You have been asked to participate as you have Kallmann syndrome/Congenital Hypogonadotropic Hypogonadism (CHH) and responded to our call for participants.

Do you have to take part?

Participation is completely voluntary. You are under no obligation to take part in the research, and you have the right to refuse to participate, and/or refuse to answer specific questions and/or to withdraw from involvement in the research at any time during the data collection, up to the point of data submission, without any consequences. This information sheet will be shown before you answer any questions in the interview. You can contact Dr Samantha Dockray if you have questions before you decide to participate.

Will your participation in the study be kept confidential?

All information you provide will be confidential and anonymised. Interview recordings will not be shared with the research collaborators, Mr Neil Smith (Kallmann syndrome patient advocate) or Dr Andrew Dwyer (Boston College). Written transcripts of some sections of interviews may be shared with Mr Neil Smith and Dr Andrew Dwyer after removal of any possible identifying details.

What will happen to the information which you give?

Data will be securely stored in a password protected file. The file will be accessible to Dr Samantha Dockray and her research team. Members of the research team and supervised by Dr Samantha Dockray. After ten years, the data will be destroyed. Summary data will be available upon request.

What will happen to the results?

The results will be analysed and only accessed by members of the research team (Dr. Samantha Dockray and her team, Mr Neil Smith, Dr Andrew Dwyer). The study may be published, for example in a peer-reviewed journal, professional journal, teaching award submission and/or presented at conferences. The findings will also be shared with members of the Kallmann syndrome networks in knowledge exchange events and an e-booklet.

What are the possible disadvantages of taking part?

No negative outcomes are anticipated from participating in this study. However, on enrolment you will be provided with a list of free, confidential publicly available support services. The list includes services provided in most regions of the world.

Who has reviewed this study?

Ethical approval for this study has been granted by the School of Applied Psychology, UCC.

Have questions?

If you need any further information, please contact Dr. Samantha Dockray (s.dockray@ucc.ie)