

Participant Information Sheet

Version : 3 (20th February 2025)

Study Title: An exploration of professionals perceptions of Klinefelter's Syndrome in the context of the criminal justice system

Principal investigator: Harry Evans (100582634@unimail.derby.ac.uk)

I would like to invite you to take part in my research study, which considers professionals/practitioners/volunteers experiences and perceptions relating to individuals with Klinefelter's syndrome (KS), and how these relate to the criminal justice contexts. It is critical that you understand the importance of this research, as well as what would be expected of you as a participant. I would be happy to discuss the study or answer any questions you may have In relation to the research.

What is the purpose of the research?

This piece of research will consider professionals/practitioners/volunteers experiences and perceptions relating to individuals with KS. The research considering KS, especially that within in the context of offending behaviour/the criminal justice system, is relatively under-researched. Additionally, research considering the people that work with individuals with KS (i.e., volunteers) is limited, emphasising the need for this research to take place. From this, this research aims to provide insight into this population, informing our understandings/practices relating to KS. These insights will aid in developing best practice in supporting individuals with KS, in addition to contributing to further understanding of this population.

Why have I been invited to participate?

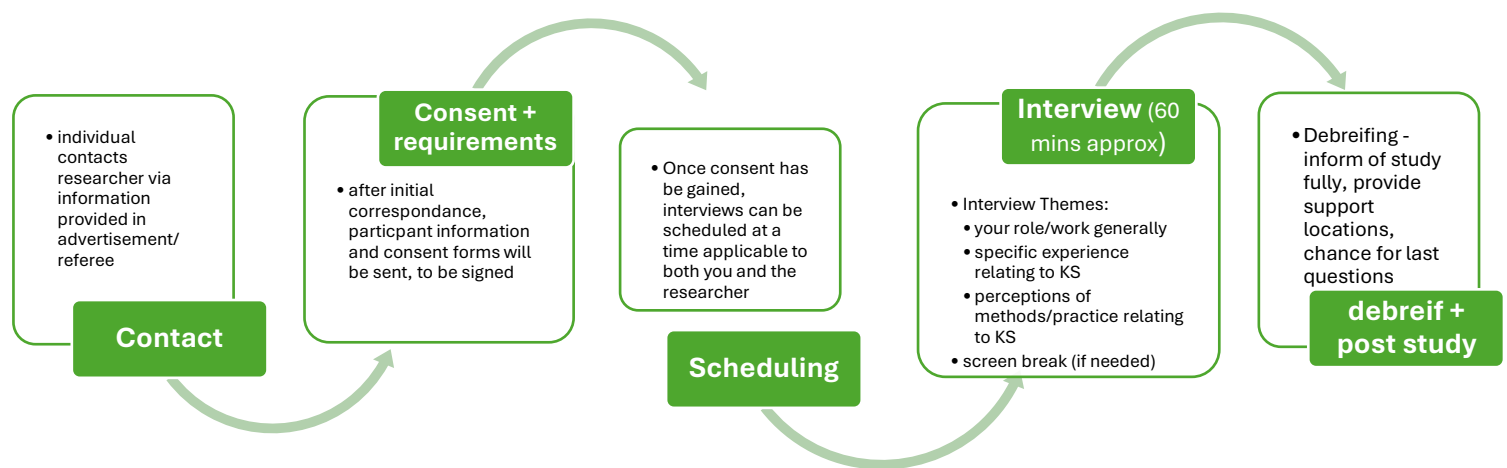
You have been invited to participate in the research due to your experiences/insights working (e.g., volunteering, practitioner work, legal work) with individuals with KS. I have chosen to research this group of individuals based on the reasons stated above (i.e., little/no previous work in this area). Considering specifically who is eligible to participate, the eligibility criteria is stated as: (i) aged 18 years or older, (ii) has some form of professional/practitioner/volunteering experience with individuals with KS, (iii) has no personal experiences of KS (e.g., personal diagnosis or familial diagnosis), (iv) not currently employed by the NHS or HMPPS. If you meet all of these criteria and fully understand what's expected of you as a participant (distinguished through signing of the consent form), participation is permitted.

Do I have to take part?

Participation for this study is completely voluntary, meaning if you decide that you don't want to participate, this is permitted. Participation will be fitted around other events/obligations you may have, which will be decided upon once selection has occurred. There will be several points during the research process where you can leave if you wish, without a reason. However, after participation (defined as completing the interview), you will have up to 2 weeks to withdraw.

What will happen to me if I take part?

Participation in this research will take the following steps:



Further information on participation:

- ✓ Participation in the study ends after the interview is completed (once the two week withdrawal acceptance period has passed)
- ✓ Interview questions will orientate around the topic of KS, aiming to investigate your experiences/insights/perceptions relating to practice/support
- ✓ Interview discussion will not specifically reference the NHS/HMPPS

Expenses and payments?

There should be no loss in terms of expenses for participation within this study. As interviews take place online (Via Microsoft Teams), individuals will avoid any potential travel costs. Additionally, interviews will be scheduled around any work commitments. Therefore, no financial compensation payments will be offered to participants.

What are the possible disadvantages and risks of taking part?

Participation will require a longer period of engagement compared to other research studies, due to the use of interviews, which are expected to last around 60 minutes. Due to this length of time, a short screen break can be offered if needed.

What are the possible benefits of taking part?

Although there is no financial gain to participation, taking part in this study provides an opportunity to contribute to the development of knowledge in an under researched area. In doing so, the understandings developed from this piece of research may inform future practice/research considering KS and associated support offered, generally and in the criminal justice system. In addition to research benefits, this study will contribute to increasing awareness and developing best practice for professionals working with individuals with KS

Use of your data and your rights

Privacy Notice

Thank you for agreeing to take part in this research project. The information that you supply will be recorded and processed in line with the UK GDPR / Data Protection Act 2018 / EU GDPR.

Data collected will be used by the student researcher to investigate the experiences/insights of individuals who have worked with individuals with KS. This is part of an independent research project that contributes to the Master of Forensic Psychology. The University of Derby is the data controller.

Pseudonymised data from this project may be used in future publications.

We retain the data for a minimum period of 10 years after such time it will be securely destroyed. Data will not be retained for longer than is necessary. Personal information (e.g., participant characteristics/names) will be deleted/destroyed on completion of this module.

Our lawful basis for processing this data is your explicit consent.

As a data subject you can request withdrawal of consent up to two weeks after the data has individually been collected (interview) by contacting Harry Evans (100582634@unimail.derby.ac.uk) or Henriette Bergstrøm (research supervisor) (h.bergstrom@derby.ac.uk). After this period, data are pseudonymised and we will be unable to extract your individual data.

Our Data Protection Officer (DPO) is James Fussell on 01332 591954. Alternatively you can email gdpr@derby.ac.uk.

Further information on how we handle your information and details of our DPO can be found on our website: <https://www.derby.ac.uk/its/datagov/privnotice>

Additional Information

The supervisor of this project, who also has access to the data, is highly qualified and experienced and has been very careful to discuss with the student processes to ensure the security of your data. An Ethics review has been completed on behalf of the College of Health, Psychology and Social Care Research Ethics Committee by the supervisor and an independent reviewer (ETH2425-2501)

We are obliged to:

- Not seek more information from you than what is essential and necessary for this research;
- Minimise identification through the use of pseudonyms
- Use your anonymised / pseudonymised data for the purposes of this study and for any relevant publications that arise from it;
- Store data safely in password-protected databases to which only the named researchers have access.

Further information about the project can be obtained from the research student (Harry Evans – 100582634@unimail.derby.ac.uk) or their research supervisor (Dr. Henriette Bergstrøm – h.bergstrom@derby.ac.uk), University of Derby, Kedleston Road, Derby, DE22 1GB.

Further information

- Information shared in the interview will be treated confidentially. However, in the event that information is disclosed relating to unsafe practice or harm to yourself or others, such information will be communicated to the relevant authorities/organisations.
- Recording of these interviews is necessary for the method of data analysis used in this study, however, this will only be accessed by the researcher, as well as the research supervisor, aiming to keep anonymity to its highest level

What will happen to the results of the research?

Once this research is complete, there is the intention for publishing. However, irrespective of this, all personal/participant data within the project, e.g., quotes obtained from interview transcripts will be pseudonymised, in order to protect participants, removing the possibility of identification. Participants names will be pseudonymised (via a method chosen by the researcher), which the data obtained from them will be stored under. Raw data will only be visible to the researcher as well as the research supervisor (Dr. Henriette Bergstrøm).

Further information and contact details:

For Further information regarding participation or the study itself, you can contact:

Harry Evans (Researcher) – 100582634@unimail.derby.ac.uk

Or

Dr. Henriette Bergstrøm (Research supervisor) - h.bergstrom@derby.ac.uk

Thank you

Thank you for taking the time to read my participant information sheet, if you have any questions regarding the study or participation, please don't hesitate to contact me (Harry Evans, 100582634@unimail.derby.ac.uk).

What to do next

The next step is to contact the researcher (Harry Evans, 100582634@unimail.derby.ac.uk) so the following steps can be taken:

- Obtaining your informed consent for participation
- Chance to obtain further information about the study or ask any questions regarding participation
- Scheduling a date and time for the interview to take place