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Participant Information Sheet Interviews

For young people aged under 16

*The Growth Hormone Deficiency Reversal Trial – Qualitative Study*

This study is part of a bigger project that is looking at the best ways to treat young people who have been previously diagnosed with Growth Hormone Deficiency. It is called The Growth Hormone Deficiency Reversal Trial. We call it the GHD trial, for short.

**Why are we doing it?**

We want the GHD trial to work really well. Our team is therefore finding out what makes families want to be involved or not. This information will help the GHD trial to improve the way they do their research. This will ensure that the results are really useful.

**Why are we asking you?**

The GHD trial is taking place in your hospital. We think that you and your parents/carers have been invited to take part (by your usual care team). You may have decided to take part or chosen not to. Or, you may have started the GHD trial and left it. Whatever your decisions, we would be really interested to hear what you think about it.

**What will the study involve?**

It will involve taking part in an interview with a researcher. This is a conversation where one of our research team will ask you some questions about being invited to take part in the GHD trial and your thoughts about being involved (or not). We are interested in what you think and happy to hear positive and negative things. If you are taking part in the GHD trial we will also ask if it is ok to speak to you again in about 6 months to see how things are going. We would also like to interview one or both of your parents / carers. We will do this separately unless you wish to talk to us whilst your parents are present. We think the interviews will last between 30 and 45 minutes each.

**Before the interview:**

1. Our research team will contact you to arrange a good time to do the interview.
2. The interview might be face to face (at your house or another suitable place that you choose) or it might be done by telephone, Skype, FaceTime or something similar. This will depend on where you live and what you prefer.
3. Before the interview, we will talk to you about the study and answer any questions that you have to make sure you understand why you are being asked to take part. You can then decide if you want to take part.
4. If you want to take part, you will be asked to agree to some statements that show you are happy to take part.

**During the interview:**

1. You can talk on your own or with your parents/carers (or someone else that you trust).
2. We will ask you a few simple questions about the GHD trial. For example, could we make the experience of the trial better for people your age?
3. You don’t have to tell us anything that you don’t want to and there are no right or wrong answers.
4. The interview should feel like a conversation. You can stop at any time. You do not have to
answer any questions you do not want to and can take a break at any time.
5. The interview will be audio-recorded so we don’t forget anything that was said.

**After the interview:**

1. When the interview is finished we will check that you are still happy for us to use the conversation about the trial and we will answer any questions that you have.
2. The interview will then be typed up by a professional company. This will not include your name or any other information that could identify you.
3. The finding from all of the interviews we conduct with young people will be written-up by the researchers and used to help the GHD trial team improve their research. It may also be used to educate other people who do research. We might include small parts of your interview in our reports, but we won’t include any names, so that no one will know that it was you who said it.

**Do I have to take part?**

No - it is your choice whether you want to take part and you can change your mind at any time.

**What do I do if I don’t want to take part in the study anymore?**

It’s ok to change your mind. Just tell your parents/carers or the researchers that you don’t want to take part anymore. You don’t have to give us a reason.

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

**What are the pros and cons of taking part?**

* Pros: Some people who take part in research say it is interesting. However, there is no other benefit for you. The information may help improve care for other young people in the future.

 Cons: We hope that taking part will be a good experience, and we don’t expect that taking part will harm you. However, we know that sharing experiences can sometimes be emotional. You can pause or stop the interview at any time. We can also give you information about people who can support you with your feelings.

**Will my information be kept private?**

All of your information will be kept private. No one will know you have taken part in the study unless you decide to tell them. We might use some of your words in our reports, but these will not include your name or anything else that could identify you.

All of your information will be kept electronically on secure computer servers at the University of Birmingham. Only the researchers involved in this study will have access to your information and access will be password protected. The only other person who will see your information is the professional who writes up your information from the recording of our interview, and takes your name out. They have agreed to keep your information private, not share it with anyone except the researchers and delete their copy of the recording once they have finished writing it up.

The only times when we cannot keep information private is if we think you or someone else may be in danger. This might mean telling other people who are responsible for keeping children and families safe.

Once we have finished the study, we will keep some of the information so we can check the results. This information will be kept safe at the University of Birmingham for 10 years.

You can find out more about how we use your information:

* at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
* at https://understandingpatientdata.org.uk/introducing-patient-data
* by asking one of the research team
* by contacting the Sponsor’s (University College London) Data Protection Officer: data-protection@ucl.ac.uk

**How will we use information about you?**

We will need to use information from you for this research project.

This information will include your and name contact details. Qualified people will use this information to do the research or to check your records to make sure that the research is being done properly.

We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**What will you do with the information?**

The information will be written up and fed back to the GHD trial team improve their research. We may also talk about the findings at meetings or publish them in medical journals. They may also be shared on social media or in newspapers. We will make sure that no one can be identified from these.

**Who has reviewed the study?**

The study has been checked by a Research Ethics Committee. This is a group of people who examine research to make sure it is safe for the people who take part.

**Who is organising and funding the study?**

The study is sponsored by University College London (UCL) and organised by the University of Birmingham. It is being paid for by the National Institute for Health Research Health Technology Assessment Programme.

**What if there is a problem or I want to complain?**

If there is a problem you should talk to your parents/carers or any of the researchers.

You can also make complaints to Dr Birgit Whitman, Head of Research Governance & Integrity, Research support Group, Aston Webb Building, University of Birmingham, B15 2TT (researchgovernance@contacts.bham.ac.uk; 0121 4158011).

General advice about taking part in research can also be discussed with the hospital PALS Office (Patient Advice and Liaison Service – [insert PALS contact details]). They can offer independent and confidential advice and help resolve problems.

1. Please have a think about the study and discuss it with people that you trust.
2. Please let us know if you are:
* Interested in taking part
* Need more information
* Have any questions
1. You can also ask your parents/carers to contact us for you.

**If you want to ask us anything:**

You can contact me, [insert name or team]. This is my picture above. I am [insert role] and will reply as soon as possible.

**Email:** XXXXXXXXX

**Phone:** XXXXXX

**Text:** XXXXX

**FaceTime:** XXXXX

Thank you for reading this leaflet