

Access to primary care – participant information sheet

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You are being invited to take part in a research project and it is important you understand why the research is being done and what participation will involve. Please take your time to read the following information, discuss with others if you wish, and ask us if anything is unclear. Thank you for reading this.

Who are we?

We are a team of researchers based at UCL's Children's Policy Research Unit (CPRU) and we're interested in understanding why some young people don't go to their GP, even when they need to. The project leads are Professor Ruth Gilbert. The researcher at the workshops will be Dr Lauren Herlitz and the creative facilitator will be James Baldwin.

What are we doing?

We are running creative podcast workshops with groups of young people to understand why it can be difficult to go to the GP and how services can be changed to make them more accessible. We thought making a podcast would be more interesting than just a focus group. We run other health research projects related to young people so we may use what we find out from these workshops for these projects too.

What is a podcast?

A podcast is a piece of audio – a bit like a radio programme – that can be found online that people can choose to listen to.

Why have I been chosen?

You have been chosen because you are involved in one of our partner organisations who have agreed to support this project, we are interested in getting a range of different views and experiences, and the leader from our partner organisation believes you would find the workshop interesting and would be comfortable sharing your experiences with other people at the workshop.

Do I have to take part?

No, it's totally up to you whether you take part. If you don't take part, it won't in any way affect your relationship with your workers.

What will happen if I take part?

You will be given a consent form to read and answer with your parent or carer. (If you're under 18, your parent or carer will also need to complete a consent form).

We're inviting around 6 to 8 people from your organisation to meet up together to create a podcast and it will take about three hours with two short breaks.

We'll introduce the study and explain what will happen on the day, then the workshop will start. James, the creative lead, will get you talking about music and things you know and feel comfortable chatting about and help you to become familiar with the podcasting process (e.g. using a microphone, adding music). You'll be given the chance to say whether you would like your voice to be heard on the podcast, or whether you'd prefer someone else to read out your words or paraphrase them. Then we'll start to think and talk about

going to the doctor or pharmacist and James will support you to create a podcast from your views.

The podcast won't be finished at the end of the workshop. James and Lauren will have to spend time editing the discussion so that the podcast lasts around 15 mins. James will also have to tidy up the sound.

The leader from your organisation will share the final podcast with you and invite you to give your feedback, which they will share with the research team. If you would like to give more personal feedback, you will have the option to record a voicenote(s) on Whatsapp to share your views directly with the research team.

The final podcast will be shared online on the research team's website <https://www.ucl.ac.uk/children-policy-research/>

Will I be recorded?

We will audio record all the group discussions from the workshop for the research study as we want everyone's views to be included. A separate recording will also take place to create the podcast.

What are the possible disadvantages and risks of taking part?

We're hoping the workshop will be fun and that it will be helpful to share experiences with other people. However, it might be a bit stressful remembering difficult times at the GP. You might be nervous at the start about taking part in the workshop because it is a new experience. The lead person from your organisation who invited you to attend the workshop will be there on the day and available to speak to at any time. There will be plenty of people around if you need to take a break or to talk to someone. You're also welcome to email us afterwards if you have any feedback.

We hope that you will think that the final podcast is a good representation of the workshop discussion. However, if you are unhappy with the final podcast, you can ask the leader from your

organisation to tell the research team, or you can tell us directly by emailing Lauren at l.herlitz@ucl.ac.uk.

What are the possible benefits of taking part?

Hopefully it will be a fun afternoon and you'll create something you'll be pleased about. We're hoping that the podcast will be helpful for health professionals to understand your views and start changing their practice. And perhaps other young people might find it helpful to listen to as well.

Are there any incentives for taking part?

We are offering a £50 shopping voucher to participants who complete the workshop as a thank you for the time you are giving.

What if something goes wrong?

If you'd like to make a complaint, please email Professor Ruth Gilbert r.gilbert@ucl.ac.uk who leads this study. If you feel your complaint is not handled to your satisfaction, please contact the Chair of the UCL Research Ethics Committee ethics@ucl.ac.uk

What about confidentiality?

You will be taking part in group discussions during the workshop and while we will ask participants to respect the privacy of fellow participants, confidentiality cannot be guaranteed. You will need to decide for yourself how much of your feelings, thoughts, views and experiences you are comfortable sharing.

The podcast recording will be public so your voice will be heard by people if you choose to have your voice included. If people that know you listen to the podcast, they may recognise your voice. We'd like you to choose a pseudonym/fake name or you can be 'anonymous' in research reports and in the podcast. This is to make sure you can't be identified. The creative facilitator and the researcher will make sure that any personally identifiable

information or personal health and social care data is not included in the final podcast. The audio recordings will be transcribed by a typist who has signed a confidentiality agreement and all the recordings are sent by secure, encrypted links.

What will happen to the results of the research project?

The podcasts will be shared with you and made available on our website as soon as they're ready. We will play them to healthcare professionals and ask them for their views. We will then publish a summary of the overall study which will be available on the website by the end of 2023. A full report will be published in a peer-reviewed journal.

Who is funding the research?

The National Institute of Health Research has funded this study.

Who is sponsoring the research?

The UCL Great Ormond Street Institute of Child Health (ICH) has sponsored this study

Local Data Protection Privacy Notice

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at data-protection@ucl.ac.uk. This 'local' privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our 'general' privacy notice: click [here](#)

The categories of personal data used will be as follows: Name, age, ethnicity. The lawful basis that would be used to process your *personal data* will be performance of a task in the public interest and research purposes will be the lawful basis for processing *special category personal data*. *Your personal data will be processed so long as it is required for the research project*. We will endeavour to

minimise the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, or if you would like to contact us about your rights, please contact UCL in the first instance at data-protection@ucl.ac.uk.

Study contact

If you require any further information, please contact Dr Lauren Herlitz l.herlitz@ucl.ac.uk

Thank you for reading this information and for considering taking part in this study