

INFORMATION SHEET FOR PARTICIPANTS < 16yo

Ethical Clearance Reference Number: LRS-20/21-20985



Title of study – Echoes, a collective database of heart sounds to help cardiology research

Invitation Paragraph

Hello! I am Pablo, and I am a researcher at King's College London, working to develop computer solutions to improve how we cure heart disease. I would like to invite you to participate in this research project, and here I explain you what you need to know about it. Please read carefully. In case you had any doubt, or if you are interested and wanted to know more, I'll be glad to answer any question, so ask your parents about getting in touch with me on your behalf!

You can look at our research activities led by my team, the Cardiac Modelling and Imaging Biomarkers (<http://cmib.website/>), and by our collaborators in the Netherlands (<https://www.carimmaastricht.nl/>) and in Cellule Studio (<https://www.cellule.co.uk/>).

What is the purpose of the study?

The purpose of the study is to check if the microphone of a mobile phone provides enough sound quality to record the sounds of the heart beat. If good enough, we will share the sounds recorded to other researchers, and see if joining forces we can build tools to improve cardiac health. But attention! The Echoes app does not tell you anything about the health of your heart.

Besides, we want you to use the Echoes app to have fun and learn about how the heart works (look at <https://www.echoesapp.org/>), about the research we are doing, and to know your opinion and your impressions about all this! Would you like to have computers to help to take care of your health? This is our biggest question, you can read more about it here: <http://cmib.website/public-engagement/>.

Why have I been invited to take part?

You are being invited to participate in this study because we simply want as many people as possible to enrich the database of heart sounds. Please also encourage your friends and relatives to use it!

What will happen if I take part?

If you agree to take part you will (1) get the Echoes app, (2) tell us a bit about you (age, gender, weight, height and cardiac condition, if any) by entering this data in the app, and (3) have fun while recording and re-play your heart sounds with the mobile. The challenge is for you to get the cleanest and loudest heart sound! And there will be some instructions to guide you.

Every time you record your sound, a copy will reach us, and we will check the clarity of the sound. Later on we will publish all the collection of sounds from all over the world to allow other researchers to work with them when designing better solutions to take care of the health of our hearts.

Do I have to take part?

Only if you want to! The condition to be part of the study is that you give us permission to use your heart sounds for our research. If you change your mind, you simply tell me – but only before I send copies of your sounds to other researchers, planned to be during Fall 2022.

What are the possible risks of taking part?

You might feel the contact of the mobile against your chest cold, but that'll be all!

In case that you have had a cardiac surgery to have a device implanted in you to help your heart work well, there may be some interferences between the mobile and your device. There are no actual risk known from these interferences, but it is better that you make sure you tell your parents first and you use the mobile in flight mode.

What are the possible benefits of taking part?

You will learn about how your heart works and sounds, and about our research. Most of all, I hope you have fun, and you discover a bit more about how your body works! Another thing will be that you could also feel good because you will be helping to our research. We are trying to design better tools to keep our heart in good health and sharing with us your heart sounds you will be helping with your two cents. If you want to know more, you always have the possibility to ask your parents contact us on your behalf about any matter related to this research.

And remember, Echoes app is not a tool that tells anything about the health of your heart - do not worry if you don't manage to record your heart sounds, or if they sound poorly or weakly, we expect this will be the case in a lot of the people trying!

Data handling and confidentiality

Your data will be processed in accordance with the law called "General Data Protection Regulation 2016". Nobody, including the researchers, will be aware of your identity. The mobile phone you used will generate a code (a strange number in the screen on the app) that will be associated to all the information you give us, so that we will be able to delete your data if you ask us, or to use the Echoes app in more studies in the future.

Your answers will be treated confidentially, and we will never publish anything that can be linked to you. Your data will be held securely for ten years hoping that many more researchers and companies could use it to design better solutions to care for our cardiac health!

How is the project being funded?

This study is being funded by the Wellcome Trust (g.a. 209450/Z/17/Z), and by the European Commission (g.a. 764738, <https://picnet.eu/>)

What will happen to the results of the study?

We will tell other researchers if we find enough sound quality recorded from mobiles like yours. We are hoping so, and we expect that then many other researchers will then try to look for the sound characteristics that will help to improve the care of heart health – to make this task easier we will give them access to all the data and the Echoes app.

Who should I contact for further information?

If you have any questions or require more information about this study, please contact us on echoes@kcl.ac.uk, or me personally on pablo.lamata@kcl.ac.uk

What if I have further questions, or if something goes wrong?

If this study has harmed you in any way or if you wish to make a complaint about the conduct of the study you can contact King's College London using the details below for further advice and information:

The Chair, Ms Gemma Singleton, rec@kcl.ac.uk

Thank you for reading this information sheet and for considering taking part in this research.