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Exploring the Experience of Young People Who Have Provided Cardiopulmonary Resuscitation and the Impact of CPR Training

Invitation to take part in an interview

- We would like to invite you to take part in an interview for a research study.
- We want to hear from people who have performed cardiopulmonary resuscitation (CPR) whilst aged 11-18.
- We want to learn about how young people are impacted by being involved in a situation where CPR is required.
- We also want to know how CPR training sessions prepare people for performing CPR in the real world.
- We want to speak to a range of people about their thoughts and experiences

Important things that you need to know

- We will keep your data safe and confidential
- You can choose to stop taking part at any time

If you have any questions, please let us know

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How can I ask more questions about the study?

If you have any questions about the study, now or in the future, then please ask your parent/guardian to contact the study team:

Child CPR Study Researcher, Kings College London

Email: childcprstudy@kcl.ac.uk or scan QR

Tel No: 020 7848 2303

What is this study about?

Why is this important?

We don't know much about what it is like for young people who are involved helping someone who has a cardiac arrest by doing CPR or getting and even using a heart-restarter machine. It is a very difficult thing to have to face and we want to know more about what it is like at the time and afterwards.

The information will be useful to help work out whether CPR training should be changed and if more support is needed for young people and their families afterwards. It will be useful for schools and their support services, for health services and for CPR training and campaigning organisations.

What do we want to do?

We want to talk to young people who were involved in a resuscitation attempt when they were between the ages of 11 and 18.

How can I help?

If you helped at a cardiac arrest in the last 5 years and were aged 18 or under at the time, we would like to interview you.

Key Words:

CPR:

Cardiopulmonary resuscitation – pressing up and down on the chest of someone who has had a cardiac arrest. It helps to pump blood around the person's body when their heart can't.

Cardiac arrest:

When someone collapses because their heart stops beating and they stop breathing.

Bystander:

People who are nearby when someone else is having a cardiac arrest.

Heart-restarter machine:

A machine which can give an electrical shock to the heart of someone who is in cardiac arrest.

Also called: Defib, AED (Automated External Defibrillator), PAD (Public Access Defibrillator)

What does taking part involve?

What are you asking me to do?

We would like to have a conversation with you about your experience. The interview will take approximately one hour and will be run by one of the study team members. You won't need to prepare anything in advance, simply turn up. The researcher will contact you to arrange a place to meet for the interview. It will need to be somewhere where you can have a private conversation and that is acceptable to you both.

Prior to the interview we will ask you to sign a form agreeing to take part – this is called your consent. At the time of the interview, we will also check in that you are still happy to go ahead.

The interview will be recorded (audio only) and the researcher may make some paper notes too. We need to have a record of our discussions to make sure we remember the most important and useful things that were discussed by you and other people we interview. We will also ask you some personal information, such as your religion, gender, age, education and where you live. This is so we can do our best to make sure we include a broad range of people from different backgrounds in the study. You don't have to share this information if you don't want to.

If you agree, we will contact you with the results of the study, so you can understand how your experiences may affect future CPR training and the support that may be available in the future.

What would you ask me?

If you take part, the researcher will ask you about your experience of helping someone who was having a cardiac arrest. For example, she will ask you what happened and what you were feeling during and after this event. She will also ask you who you have talked to about it and if anything has helped you to deal with what happened. In addition, you may be able to tell her about any CPR training you have had and how well you think it prepared you for doing CPR. It will be up to you whether you want to answer the questions and how much you want to say. You will be able to tell the researcher anything you think is relevant and might help us understand more about what it was like.

Do I have to take part?

Not at all. Taking part in the interview is completely voluntary. You can stop taking part in the interview at any point, and don't have to give a reason.

What are the possible benefits for me?

There is unlikely to be a direct benefit to you. However, taking part will help us learn about how young people are affected by helping in a cardiac arrest. This will help us adapt training and develop effective support if required.

What are the possible disadvantages for me?

Talking about cardiac arrest and performing CPR can be hard and may be upsetting. The researcher will check to see if you are OK during the session and stop if the conversation is upsetting you. You will be able to take a break at any time. If you are not able to complete the interview due to being upset, then we will use any partial data unless you request that we remove your data from the study. If the interviewer stops the interview because they are concerned about you, then we will ask for consent to keep the partial data. If it is not possible to ask for this consent for any reason, then we will assume that the data should not be included in the study.

As we will be discussing an upsetting topic, there is a small possibility that, during the interview, we will discover significant mental health issues. If this occurs, then we will ensure that you are directed to the necessary support, including urgent healthcare input if needed.

If you agree, we'd like to get in touch with you about 2 weeks after the interview just to check on how you're doing and remind you where you can get support from.

Expenses and payments

You will be given a £25 voucher for your attendance at the interview to say "Thank you".

What will happen if I don't want to carry on being part of the study?

You might want to stop taking part in the study – if so, you don't have to give a reason. Just let the research team know. This would not affect you in any way.

Before the interview:

If you change your mind before attending the interview, please let us know by telephone/email and we will remove your information from the participant list.

During the interview:

If you change your mind during the interview, you are free to leave at any point – just let the researcher know. Before you leave, you will be asked if you are happy for your answers to the questions you have given so far to be used in our study. If you do not wish for these answers to be used, then we will destroy all data that we hold relating to you and your participation in the study.

After the interview:

If you change your mind about taking part in the study, that is not a problem. We will hold your data separately, linked to you by a participant number, so it is important that you keep a record of this number – it will be on your consent form. We will keep your data separately for one month after your interview. During this month you can contact us and request withdrawal from the study and we will destroy all data that we hold relating to you and your participation in the study. After this one-month period, we will be analysing your data alongside data from other interviews. Therefore, after this point, you will no longer be able to withdraw from the study. On the day of your interview, you will be given a sheet with more information about withdrawal from the study which will include a confirmation of the final withdrawal date.

Have people like me helped design this study?

Running the study:

- Several members of our research team are members of the public who have been involved in cardiac arrest situations and have experience of the effects it can have.

- We are setting up a Young Person Advisory Group with members aged 11-18. This group will give researchers advice about the best ways to carry out the research. They will also help us tell young people about what we learn from the study in interesting and understandable ways.

Designing the project:

- Members of the research team, including those members of the public with out-of-hospital cardiac arrest experience helped us design the project.

Setting up the study:

- We have been working with Sudden Cardiac Arrest UK (A support group for survivors of cardiac arrest) and Chain of Survival UK (A support group for providers of CPR in out of hospital cardiac arrest) to ensure we are sensitive to the needs of those involved in a cardiac arrest.

Overseeing the project:

- The independent committee who make sure the study is run properly and give the team advice includes members of the public to make sure your voices are heard.

What will you do with my data?

Data is the word we use to describe any information we get from you as part of the study – this includes your personal data (your contact details) as well as our notes on your thoughts and opinions.

Why do you need my data?

We want to understand your experience of performing CPR. Specifically, we want to know what support you received and what was helpful. We also want to understand whether any CPR training you previously received was helpful in preparing you for performing CPR in the real world. The answers you give us will be audio-recorded, and sent to a third-party transcription company (who have signed a confidentiality agreement), so we can obtain a written record of what you said. Transcriptions will be pseudonymised, which means that anything that identifies you, including your name, will be removed from the transcript, so people will not be able to link it to you.

We are going to combine and analyse this pseudonymised data with data from other people in this study. We will share our findings with relevant people and organisations, including producing a study report for the funder and publishing articles for academic journals.

We will consider our findings alongside other research looking at supporting adults or young people through emotionally difficult events. This will help us come up with ideas on how to improve the training and support available.

We hope to discuss these ideas with young people, teachers and experts in CPR training to ensure that the ideas that we have will be effective, realistic and can be implemented. We may try out some of these ideas in further research studies.

How will you look after my data?

Any data you give us will be kept confidential, and stored securely (as electronic documents) on the Kings College London study-specific SharePoint site. Any paper data will be stored in a locked cabinet in a locked office at King's College London.

The recording from your interview will be typed up (this is called a transcript) and your details will be removed so you cannot be identified from the transcript. The transcript will be identified by your study ID number instead (pseudonymised).

Only people who need to see your data for the study will have access to it. Members of our research team from King's College London will be able to access all the information you give us, including data that identifies you (such as contact details and your signed consent form). Other members of the research team, based at University of Oxford and University of Warwick, will have access to your pseudonymised interview transcripts.

This pseudonymised data and your signed consent form will be kept in an electronic archive (KCL Digital Records Management Service) for 10 years after the end of the study. During those 10 years, the pseudonymised data might be used in future research by the research team, but only if it has the proper approvals in place and you agree.

The audio recordings will be destroyed once the interviews have been transcribed and checked for accuracy and the team are confident that they will no longer be needed to check transcripts. Data that identifies you, such as contact details, will also be destroyed. At the latest this will be at the end of the study.

If you share something with us that makes us concerned about your (or another person's) safety, we must tell someone else. If this happens, we will talk to you about it in private, and we will only tell people who can help you to stay safe.

What else do I need to know?

Who is organising and funding the study?

King's College London is responsible for organising and running the study.

Our lead researchers are Dr Claire Hawkes and Dr Michael Smith at King's College London .

This study is funded by the National Institute for Health Research (NIHR) Health and Social Care Delivery Programme (Reference: NIHR204360). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.
More details about the NIHR's work can be found here: (https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm).

Who has checked the study to make sure it will be done properly?

This study has been checked and approved by the King's College London Health Faculties Research Ethics Sub-Committee, who are in charge of making sure that studies like this are run properly. They will check and approve any changes that may need to be made as well.

Reference number: HR/DP-23/24-34646

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Will I find out the results of the study?

Yes. We will let all the people involved in the study know what we learn, if they agree to this.

We will speak to organisations involved in training and support to spread the word about our results.

What if I’m not happy?

If you are unhappy about any part of this study then please contact the study team, who will do their best to answer your questions.

If you are still not happy or don’t feel comfortable talking to the study team, you can contact an independent senior Kings College London official using the contact details below:

The Chair
Health Faculties Research Ethics Subcommittee
rec@kcl.ac.uk

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner’s Office (ICO).

What do I do next?

I don’t think this is for me

That’s not a problem at all. We really appreciate you taking the time to read this leaflet.

I want to learn more

If you would be interested in taking part, then we would love to hear from you. Get in touch with the study team using the following details:

Study Researcher
Kings College London
Tel No: 020 7848 2303
Email: childcprstudy@kcl.ac.uk or scan QR

I think my friend might be interested too

We would be happy to hear from them. Please ask them to get in touch with the study team.

Thank you for taking the time to read this leaflet