

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

Invitation to take part in an interview

- We would like to invite a young person who you have parental responsibility for 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, and your child's data safe and confidential.

If you, or your child share something with us that makes us concerned about your child's (or another person's) safety, we must tell someone else. If this happens, we will only talk to the necessary people to keep your child safe.

You (or your child) can decide that your child will stop taking part at any time.

If you have any questions, please let us know.

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How can I contact the study team?

If you have any questions about the study, now or in the future, then please contact the study team:

Child CPR Study Researcher, King's 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 in helping someone who has a cardiac arrest by doing CPR or getting and even using a heart-restarter machine (defibrillator). 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 your child helped at a cardiac arrest in the last 5 years, and were aged between 11-18 years-old at the time, we would like to interview them. Please read this information leaflet about the research study and, if think it is appropriate, discuss with

your child. If you and your child are interested, please contact the research team for more information about taking part.

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 the young people to do?

We would like to have a conversation with young people about their experience. The interview will take approximately one hour and will be run by one of the study team members. Nothing needs to be prepared in advance, the person being interviewed just needs to turn up. For those still attending school, we would like the interview to take place at their school if possible. However, if you or your child do not want the interview to take place in school, or your child no longer attends school, we will arrange another suitable place to meet with you both.

Prior to the interview, the researcher will arrange to speak with you and your child together (by phone or MS Teams), so you can ask any questions you have. If you and your child want to go ahead, we will ask you to sign a form agreeing that your child, or the child you have parental responsibility for, can take part – this is called your consent. We encourage you to discuss this with the young person you are consenting for before you sign it.

We want to be sure that the young person voluntarily agrees to take part too. Therefore, at the time of the interview, we will check that they are happy to go ahead. This will involve the researcher reading out statements which the young person can agree or disagree with, and will be audio recorded. The statements will be sent to you and your child in advance to allow them time to ask questions if there is anything they do not understand.

The interview will be recorded (audio only) and the researcher may make some paper notes too.

We need to have a record of the discussions to make sure we remember the most important and useful things that were discussed by the people we interview. We will also ask some personal information, such as religion, gender, age, education and where they 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. The young people don't have to share this if they don't want to.

If you agree, we will contact you with the results of the study, so you and your child, or the child you have parental responsibility for, can understand how the information they shared may affect future CPR training and the support that may be available in the future.

Do they have to take part?

Not at all. Taking part in the interview is completely voluntary. They can stop taking part in the interview at any point, and don't have to give a reason. Not taking part will have no impact on the young person's education or on future opportunities within their educational institution.

What would you ask the young person?

If your child, or the child you have parental responsibility for, does take part, the researcher will ask them about their experience of helping someone who was having a cardiac arrest. For example, she will ask them what happened and what they were feeling during and after this event. She will also ask them who they have talked to about it, and if anything has helped

them to deal with what happened. In addition, they may be able to tell her about any CPR training they have had and how well they think it prepared them for doing CPR. It will be up to them whether they want to answer the questions and how much they want to say. They will be able to tell the researcher anything they think is relevant and might help us understand more about what it was like.

What are the possible benefits?

There is unlikely to be a direct benefit to the people being interviewed. 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?

Talking about cardiac arrest and performing CPR can be hard and may be upsetting. The researcher will check to see if the young person is OK during the session and stop if the conversation is upsetting them. They will be able to take a break at any time. If the young person is not able to complete the interview due to being upset, then we will use any partial data unless you or your child request that we withdraw them completely from the study. If the interviewer stops the interview because they are concerned about the young person, 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 urgent mental health issues. If this occurs then we will ensure that you and your child 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 the young person is doing and remind you where you can get support from.

Expenses and payments

The young person will be given a £25 voucher for their attendance at the interview, which we expect to take approximately one hour.

What will happen if I want to withdraw my consent, or the young person doesn't want to carry on being part of the study?

Your child, or the child you have parental responsibility for, might want to stop taking part in the study. You may also want to withdraw your consent for them to take part. If so, neither of you have to give a reason. Just let the research team know. This decision would not affect your child or their education in any way.

Before the interview:

If you or the young person 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 the young person changes their mind during the interview, they are free to leave at any point

– they just need to let the researcher know. Before they leave, they will be asked if they are happy for the answers to the questions they have given to be used in our study. If you or they do not wish for these answers to be used, then we will destroy all data that we hold relating to their participation in the study.

After the interview:

If you or the young person change your mind about taking part in the study, that is not a problem. We will hold the 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 the data separately for one month after the 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 the young person and their participation in the study. After this one-month period, we will be analysing your child's data alongside data from other interviews. Therefore, after this point your child will no longer be able to withdraw from the study. On the day of their interview your child will be given a sheet with more information about withdrawal from the study which will include a confirmation of the final withdrawal date.

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.

Who has helped design this study?

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 the data?

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

Why do you need my data?

We want to understand the young person's experience of performing CPR. Specifically, we want to know what support they received and what was helpful. We also want to understand whether any CPR training they received was helpful in preparing them for performing CPR in the real world. The answers given 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 (transcription) of what was said. Transcriptions will be pseudonymised, which means that anything that identifies you or your child, including names, will be removed from the transcript, so you/your child cannot be identified.

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 our data?

Any data you or your child give us will be kept confidential, and stored securely (as electronic documents) on the King's 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 the interview will be typed up (transcribed) and your, and your child's details will be removed so that you cannot be identified from the transcript.

Only people who need to see the 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 and your child give us, including data that identifies both of 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 the 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. At the latest, this will be at the end of the study.

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

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 King's 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 or the young person I care for

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

King's College London

Tel No: 020 7848 2303

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



I know someone else who 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