



The FACT Study:

Facilitating Bystander Cardiopulmonary Resuscitation Training in high-risk areas

Details about my Data

What will you do with my data?

What do you mean by data?

Data is the word we use to describe any information we get from you as part of the study – this includes your contact details, things like your age and gender, your answers in the workshop questionnaire, the things you talk about in your interview (if you were asked to do one), and any field notes the researcher makes about the study. Everyone in the study is taking part in the workshop and completing a questionnaire. A few people are also doing an interview.

Why do you need my data?

We want to find out what you think about our Community CPR Awareness and Training Workshop, to see if there are ways that you think we can make this better.

We want to be able to improve things concerning bystander CPR in local communities across the country, and it is important that we make sure that we get your thoughts on how we can do this in the best way possible.

How will you look after my data?

- Any data you give us will be kept safe and confidential.
- Data you give us on the questionnaires or in the interviews won't have your name on it. Instead this will be organised with a unique Study ID number. This means we can keep it separate from your contact details.
- Only people who need to see your data for the study will have access to it.
 - This might include individuals from the study team, King's College London, The University of Warwick, Lancaster University, or from relevant regulatory authorities.
- The recordings from your interview (if you have one) will be typed up and any information in them like your name will be removed.
- Your data will be stored at the University of Warwick.

More Information:

Can you tell me more?

- The things you write down in your questionnaire or . in your interview (if you do one) are known as data.
- The information about you like your name and contact details are known as 'personally identifiable data'. There are extra safeguards in place to look after this data.
- Other information you may choose to give us, such as your race or ethnicity, are known as 'special categories of personal data'.

Is there anything legal I need to know?

- There are laws and regulations and University policies and procedures that mean that your data is kept safe, that it is accurate and reliable and that it is only used for the study purposes that you agree to.
- All information you give us will be always kept confidential and held in line with the UK General Data Protection Regulation (UK GDPR).
- The joint Data Controllers for the study are King's College London and the University of Warwick.
- Your questionnaire answers will be entered and kept online with Qualtrics, which is a third-party company. They have legal agreements in place with the University of Warwick and have been through strict information security assessment.
- If you take part in an interview, we will use a transcription company to type up the recordings of your interviews. The company will have a contract with us, and they will have to keep your information safe and confidential too. They will destroy your information after it has been typed up and sent back to the research team.

Will people know what I've said during the study?

- Your questionnaire will have your study participant number on it, but not your name. The researchers will see answers to the questionnaires when putting the answers into the Qualtrics software and analysing the data from all the questionnaires, but they won't know whose answers they are as they will only see the study participant number.
- If you did an interview, a paid typist from the transcription company will type out what you have said in your interview.
- Names and places and anything else that might identify you will be taken out of the typed up interview.
- If you do an interview, we may use things you have as examples in outputs such as presentations or reports for the study, but without giving your name or anything else that can identify you. This means that no one else should know that they were your words.

We need to let you know that if there was a worry about a major risk of serious harm to you or others that came up in the workshop, the study team might need to share that information, but we don't think this is likely to happen.

Will my data be safe?

The University of Warwick has in place policies and procedures to keep your data safe. You can read more about what the University does to protect your data and your rights here:

<https://warwick.ac.uk/services/legalandcomplianceservices/dataprotection/privacynotices/research/>We need to manage your information in specific ways in order for the research to be reliable and accurate. This means that we won't be able to let you see or change the data we hold about you.

Your questionnaire will be entered into Qualtrics. They have in place policies and procedures to keep your data safe. You can read more about what Qualtrics does to protect your data and your rights here:

<https://www.qualtrics.com/privacy-statement/>

<https://www.qualtrics.com/support/survey-platform/getting-started/data-protection-privacy/>

Who will have access to my data?

- Only members of the study team who need to talk to you about taking part the workshop will have access to contact information about you. It will not be shared with anyone else.
- All those connected with the study who get to see your information have to have a good reason, e.g. the typist or the research team to look at it and have to keep specific things about you and others involved in the study to themselves. This is known as treating the information about you and other study participants confidentially.

How long will you keep my data for?

All information that we collect will be stored securely in either lockable filing cabinets or password-protected computers or on the secure university computer servers. Research data (questionnaire answers and interview recordings or transcripts) will be kept separate from the contact details as soon as is practical.

We will keep the following data until the end of the study, which is currently planned to be end of **October 2024**:

- Contact details, interview recordings (if you have one).

Once the study has finished and we have let you and other people know about the results, we will destroy your contact details.

Once the interview recordings have been transcribed with identifying information removed and the accuracy checked we will destroy the recordings. At the latest this will be at the end of the study.

We will keep the following data until 10 years after the end of the study, which is currently planned to be **end of October 2034**:

- Questionnaires, interview transcripts (if you have one), consent forms (or recordings of verbal consent), anonymous researcher field notes;

Your name will remain with your consent information (on the form or in the recording), and will be stored with the pseudonymised study data.

Will you use my data again in the future?

If you agree to take part, we may use anonymous information collected from the questionnaires for future research. Any future research will only take place if approved by an independent Research Ethics Committee, where needed. The interview transcripts will not be available to other researchers to use in future research.

How do you know I've given you permission to use my data?

If you decide to take part we will ask you give your permission by answering some consent questions. This will either be done in a telephone or online call before you come to the workshop, or we will fill in a consent form with you when you arrive. This will let us have a clear record for you and the study team about what you are agreeing to. We need a separate record of consent if you take part in an interview, so we will follow the same process of gaining your permission before the interview either by telephone or online or in person at the interview.

What if I change my mind?

You might want to stop taking part in the study – if so, you don't have to give a reason. This would not affect you in any way. Please do let us know by telephone/email.

Before the workshop:

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

During the workshop:

If you change your mind during the workshop, you are free to leave at any point - just tell the researcher leading the discussion before you go.

After the workshop:

If you change your mind after you have been to the workshop and completed your questionnaire, you are able to let us know that you want to stop taking part within 4 weeks from that point. This is because after 4 weeks we will combine your questionnaire answers with other people's answers in our analysis and we will not be able to remove it after that.

Before the interview, if you do one:

If change your mind about doing an interview after it has been arranged, just let the researcher or the study manager know using the contact information on this sheet.

At the interview, if you do one:

If you change your mind at the interview, just let the researcher know you want to stop. The researcher will ask you if you want everything you have said up to that point taken out of the study or if you are happy for it to still be included.

After the interview, if you do one:

If you change your mind after the interview, please let us know within 2 weeks of the interview. This is because after that we will be grouping information from different interviews together in our analysis and it won't be possible to separate out your information from other people's.

Future contact:

If you change your mind about being happy for us to contact you in the future, that is not a problem. Please just contact the study team to let us know.

How can I contact the study team?

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

FACT Study Manager, Warwick Clinical Trials Unit

Tel No: 02476 151712

Email: facts@warwick.ac.uk