

The CAPVA Study Participant Information Sheet for Parents & Carers (full version)

Full title of study: Randomised Controlled Trial (RCT) of the Child and Adolescent to Parent Violence and Abuse (CAPVA) programme run by RISE Mutual CIC.

Introduction

You are being invited to take part in a study about child to parent violence and abuse (CAPVA). This study will involve comparing different types of support that are provided to families experiencing CAPVA. You are receiving this invitation as a practitioner has spoken to you about the study and a referral has been made about your child or the child in your care. This study is designed to understand what does and doesn't work, to help your family and other families in the future.

The study is funded by the Youth Endowment Fund and is comparing support provided by RISE Mutual CIC (RISE) with different types of support offered by your local authority. The research is led by the University of Hertfordshire (UH).

Before you decide whether you want to take part in this study, it is important that you understand what the study is about and what to expect if you join it. Please take the time to read the following information carefully and discuss it with others if you wish. We know this document is quite long. It is important that you have all the information you need before deciding to take part.

Questions 1-14 explain what is involved in taking part in the study. Questions 15-22 focus on confidentiality, what happens to your data, how it will be protected and how to contact the research team. Our contact details are on the last page, and we will be happy to answer your questions.

If you wish to view video and summary versions of this information beforehand, please visit: www.go.herts.ac.uk/RISE-CAPVA-efficacy-study or scan the QR code below:



Thank you for taking time to read this information. Please keep it for your record.

1. Why am I invited to take part in this study?

You are invited to take part because you are a parent or carer of a child aged between nine and 17 who is struggling with their feelings and behaviours. We want to know how best to support families whose children are being violent or abusive. A practitioner within your local authority has spoken with you and referred you to the study, as you may be eligible to take part.

2. Who is funding this study?

The study is funded by the Youth Endowment Fund (YEF), a charity established in March 2019 with a purpose to prevent children and young people becoming involved in violence. To fulfil this purpose, YEF fund projects and evaluations to find out what works in supporting children, young people, and their families, who are impacted by violence. Please visit <https://youthendowmentfund.org.uk/> to read more.

3. What is the purpose of this study?

The main purpose of this study is to evaluate the CAPVA programme developed by RISE by comparing it with the support that is usually available where you live. The CAPVA programme run by RISE works differently than some of the other types of support offered. Before the RISE programme is used more widely, it is important to understand whether it is helpful and what it is like for families who engage with it. So, this study will test whether the CAPVA programme leads to reductions in challenging behaviours from young people.

It will also be important to understand whether support from RISE is more effective than other kinds of support that are offered. So, we need to compare the RISE programme to the other types of support available through your local authority. For the study, we refer to the other types of support as 'business as usual' or BAU.

Half the eligible families who agree to take part in the study will be randomly allocated to the usual support, the BAU group. In the BAU group, families will receive the support normally available in their area. The other half will be randomly allocated to receive the CAPVA programme. Following up with families from both groups, for around a year after initial referral, will let us find out if the support they receive makes any difference.

4. Why will only half of those taking part receive the RISE CAPVA programme?

Some previous research shows that the RISE CAPVA programme is promising. However, there has been no research that compares it to existing practice. It is important not to invest money in any programme without understanding whether it is going to make a real difference and without being sure that differences are for the good. By having two groups, with each group randomly selected to either attend the CAPVA programme or to receive the usual support, we will be able to see whether the CAPVA programme makes a difference to families.

We know it can feel disappointing to sign up for a study like this and then find out that you are in the group that will not be offered a new form of support. It is important to remember that you will be offered the support that other families in your area would normally be getting. Also, by taking part in this study, you will be helping all of us to learn what helps to reduce CAPVA the most.

5. Do I have to take part in this study?

No, you don't. It is completely up to you whether you would like to take part in this study. If you do not want to take part in the study, you don't have to. Although we would like as many people as possible to take part, your participation in the study is completely voluntary. Even if you do decide to take part, you can still choose to withdraw from the study or from the support that you're receiving, at any point.

6. What will happen if I do not take part?

If you decide that you don't want to take part, then the lead professional working with your family will still work with you as they would normally. You will not be screened for potential suitability for the study and your experience of usual support will not be included in the research.

7. Are there any other restrictions that might prevent me from participating in this study?

The CAPVA programme is designed for families of children and young people aged nine-17 who display verbal, financial, physical and/or emotional means to exert power and control over a parent/carer. When a family is referred to the study, they will usually work with a RISE practitioner across two preliminary sessions to find out if they are suitable to take part in the study. Sometimes, families are not in a good place to take part in the study and may need different support. For example, the RISE practitioner will talk to you about whether there are other violent and abusive behaviours within the home (such as between parents). Also, parents or carers who do not have time or interest in engaging with the CAPVA programme, and therefore this study, will not be able to continue to the next stage.

8. Will you tell me more about the RISE CAPVA programme?

The RISE CAPVA programme seeks to change behaviours of adolescents and young people who are violent or abusive towards their parents and carers. It does this first by seeking to change the ways in which parents and carers respond to the young people's behaviours. The Programme runs for up to 18 sessions and engages parents or carers for a minimum of 12 sessions. It also aims to engage with the young people for six separate sessions. The sessions with parents and carers will teach Non-Violent Resistance (NVR) techniques to help change young people's behaviour in a respectful and calm way, avoiding punishments. RISE practitioners work with parents and carers to help them develop the skills and confidence to use the NVR de-escalation and resistance techniques, refuse demands made by children and young people, and reset boundaries. These skills are developed gradually with practitioner support so that parents or carers will eventually be able to use them without the practitioner. If young people also join the programme, then work with them adopts a flexible skills-based approach using trauma informed care alongside cognitive behavioural training and mindfulness. The practitioner will also work together with a family to build their community support networks. Later sessions focus on reconciliation, ensuring the family is equipped to sustain positive change going forward.

9. How long will my part in the study take?

If you decide to take part in this study, you will be contacted a few times across about 12 months from when you were first referred by a practitioner in your borough. This is because we want to see how you and the young person are getting on and whether the support you will receive makes any difference over time.

10. What should I do if I am interested in taking part?

Before receiving this information sheet, you may have already spoken to a practitioner from your borough. You might also have already spoken to a RISE practitioner to check whether you are eligible to join the study. When we know if someone is eligible to take part in the study, then we send out this sheet again, with a link to click on, if you want to take part. That link will take you to a consent form.

11. What will happen to me if I take part?

If you consent to take part in the study, we'll ask you to complete a survey that is based on questions about your child (or the child in your care), their behaviour, difficulties and relationships in the family. We will also collect some information about your family background. We will ask you to fill out a survey at the start and end of the study (around nine months from now). At both times, we'll ask about the child's violent or abusive behaviour and their difficulties. At the beginning, we will also ask you to tell us about some other difficulties that the young person might have, when they are asked to do things and in how they interact with the world around them. The surveys can be completed online on most devices that have access to the internet. The research team can also help you to fill them in, or you can ask for help from the practitioner working with you. Each survey will normally take about 40 minutes.

An optional interview

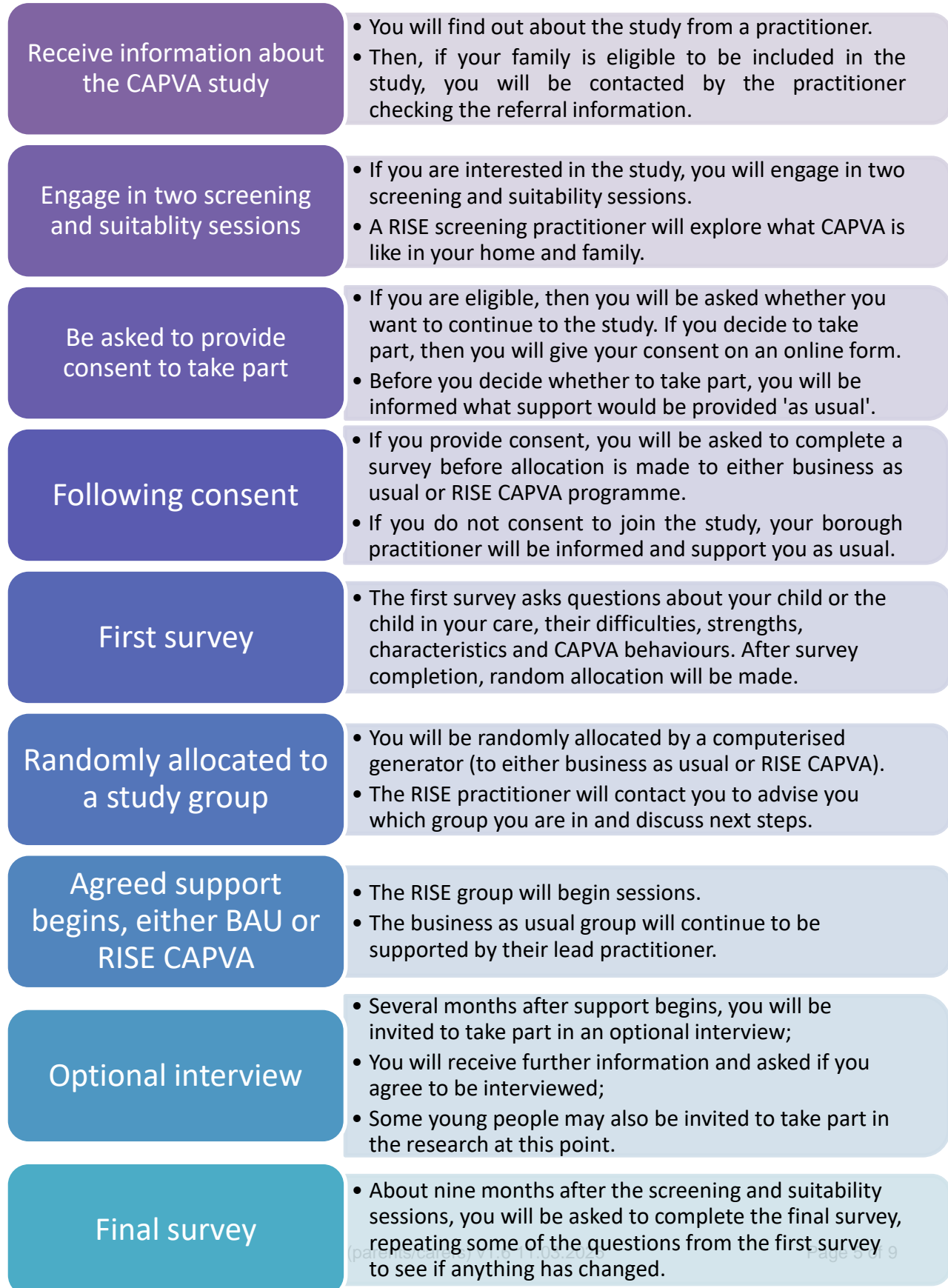
If you decide to take part in this study, then you will also be invited to take part in an optional interview around the time you complete your final survey. The interviews will help us understand families' views on the support received and whether that support has helped relationships between parents, carers and young people. Each interview should take no longer than an hour and will be audio-recorded. The recordings will be professionally transcribed, then analysed. Your name will not be used in the transcriptions, and we will remove references to specific people or places.

Child and young person involvement

If your family is randomly allocated to the CAPVA programme, then we may also approach you to let us invite the child or young person themselves, to take part in the research directly.

Diagram 1 summarises what will happen to families who take part in the study.

Diagram 1 – what will happen during the study?



12. What will happen if I no longer want to be part of the study?

If you do agree to join the study, but change your mind, you are free to withdraw from the study at any time without giving a reason. If you have been allocated to the RISE CAPVA programme group, and have already started sessions, then both you and the young person will still be able to take part in it. However, if you have been allocated to the RISE CAPVA group and have not begun the programme itself, then you will not receive that programme. Instead, you will continue to be supported by your local authority.

13. What are the possible disadvantages or risk of taking part?

We do not anticipate that taking part in the study will expose you to additional direct risks. However, we realise that reflecting on your experiences of violence and abuse may bring up troubling emotions. Your RISE or the lead practitioner from your local authority will be your main support during the time that you are participating in the study. The arrangements you have in place with them for support, should not change.

If you experience difficult, unexpected situations during the study, that go beyond the CAPVA you are already experiencing, then please let the study team know. A form will be available to complete online so that you can tell the study trial manager and safeguarding lead about issues you are experiencing. These issues will be recorded, and we will advise you and your practitioner on any necessary response to potential risks of harm raised.

14. What are the possible benefits of taking part?

By taking part in this study, you will contribute to much-needed research on how best to support families experiencing CAPVA. The information from this study will help improve services to other families in the future. By taking part, you will be helping to shape how support services are offered. Whichever group you are allocated to, you can positively impact other families.

15. Will taking part in this study be kept confidential?

We will treat the information shared with us securely and confidentiality will be respected, in accordance with the legal constraints and professional guidelines. The research team has received safeguarding training and we are aware that there are circumstances in which confidentiality has to be broken. For example, if you tell us something that makes us concerned about your or another individual's welfare or there is a pressing risk of harm, then we will need to follow safeguarding procedures. If that happens, then researchers will also contact the practitioner that supports you and a designated safeguarding officer from your local authority, to agree on appropriate action. If it is a serious incident, then it may also need to be reported to the Youth Endowment Fund.

- You can see more about serious incident reporting here:
<https://youthendowmentfund.org.uk/wp-content/uploads/2021/08/2103-YEF-Serious-Incident-Policy.pdf>
- You can see also more about the ways in which YEF funded research approaches safeguarding here <https://youthendowmentfund.org.uk/wp-content/uploads/2024/03/YEF-Safeguarding-Policy.pdf>

16. How will you use the data you collect?

To carry out the CAPVA study, we need to collect some personal data from you, including sensitive personal information which is classed as special category data. Personal data allows a person to be identified, such as your child's name and date of birth. Special category data is information which may be considered sensitive, like information relating to your ethnicity.

UH will be using information from you to complete this study and will act as data controllers. This means that UH are responsible for looking after your information and using it properly. RISE will process data coming from referrers and work with you during screening, when they will be data controllers. They will then transfer the information to UH where it will be stored on the secure study database.

Data protection laws require us to have valid reason to use your personal information. This is referred to as the 'lawful basis for processing' data. For the research data collected for the CAPVA study, the lawful basis for processing is as follows:

- a) processing your personal data is necessary for the performance of a task carried out in the public interest (Article 6(1)(e) of the UK GDPR); and
- b) processing special categories of your personal data (which is personal data about your gender, ethnicity, etc.) is necessary for archiving, research or statistical purposes (Article 9(2)(j) of the UK GDPR)

Individuals have certain rights under data protection laws. There are exemptions from some of these rights where personal data is used for the purposes of research. Your rights to access, change or move your information are limited as your information needs to be managed in specific ways for the research to be reliable and accurate. If you withdraw from the study, information about you that we have already collected will still be kept for the purposes of the study. To safeguard your rights, the minimum personally identifiable information possible will be used. If you have any queries about the data we collect on you, please contact the trial manager using the contact details at the end of this message.

17. How will you keep any information you collect safe?

The confidentiality of people who participate in this study will be maintained. Your answers to the surveys will be stored anonymously and information provided in interviews will be anonymised prior to storage. Your contact details will be kept securely, confidentially and separately from the survey and interview information. You will be allocated a unique study identification number, so your name will not be linked to the research data. All information collected will be used for the purposes of the study and will be stored in accordance with the Data Protection Act 2018 and UK GDPR. You will not be identifiable in any reports or publications coming from this study. It is intended that all information for this study will be collected and stored electronically. However, in some situations, there may be paper copies of information provided. Any data in a physical format, will be stored in a locked cabinet at the university, this includes any paper consent forms, interview notes or survey responses.

18. What will happen to the results of this study?

We rely on the public task, lawful basis to use your data. We will only use more sensitive information if it is necessary for research purposes or statistical purposes which are in the public interest. We will use the information you give us to evaluate how well the RISE CAPVA programme works, in comparison to other forms of support available. We will write a report about our findings based on all the surveys and interviews completed. The final report will not contain any personal information about the people who took part in the study, and it will not be possible to identify individuals from the report. The report will be published on the UH and YEF websites and we might also use the report for academic articles, and in presentations to academic, policy, local authority, governmental or charity audiences. Any personal information that you give us will be stored securely and kept confidential. If you would like a copy of the published research, please let one of the researchers know and we will be happy to help you access it.

19. Will the data be required for further use?

Personal data collected as part of this study will be held by UH for as long as is necessary to allow for collection and analysis of the data to take place. If you participate in interviews, then your identifiable data will be removed as soon as possible. The audio recordings will be stored on secure servers belonging to UH, that only a limited number of researchers will be able to access. After transcription and anonymisation is finished, the original recordings will be destroyed. After completion of the study, and reporting of the findings, the study database and associated, anonymised data, will be held for 10 years at UH. This is in line with the UH clinical trial support network guidelines. The data held at UH will then be securely disposed of (permanently deleted). To find out more about how UH will use your information, please contact our Data Protection Officer and/or access the privacy policy:

Abi Tomlinson

University of Hertfordshire, College Lane, Hatfield, Hertfordshire, AL10 9AB

✉ dataprotection@herts.ac.uk

The University of Hertfordshire Privacy Policy is available from this link:

https://www.herts.ac.uk/__data/assets/pdf_file/0017/233090/IM08-Data-Protection.pdf

It is important to note that the study database will also be archived by the Office for National Statistics (the ONS). Once we have finished the study, other approved researchers will need to be able to explore whether the RISE CAPVA programme, and other programmes funded by the Youth Endowment Fund (YEF), had an impact over a longer period of time, including whether they reduced young people's involvement in crime and violence. This is why YEF archive data within the ONS. Once we have finished our study, we will share the information we have gathered about each family with the ONS to add to the YEF archive. Any personally identifying data you shared with us, like your name and address will be removed. Any directly identifying data about your child (e.g. name, date of birth, home address) will be safely passed to the DfE and then replaced with a unique Pupil Matching Reference number (a process called pseudonymisation) from the DfE's National Pupil Database. It will be possible to link child data

with public datasets (e.g. within education), however, this will only happen within the ONS secure data storage environment.

Once your data has been transferred to the ONS, UH will hand over control to the YEF for protecting your personal information. Your de-identified data will be held in the YEF archive indefinitely, in the ONS Secure Research Service, along with all the other data collected during the evaluation. The YEF is the data controller of the information in the YEF archive. By maintaining the archive and allowing approved researchers to access the information in the archive, the YEF is performing a task in the public interest, and this gives the YEF a lawful basis to use personal information.

The YEF have put in place strong measures to protect the information in the archive. As well as the pseudonymisation process described, the YEF archive is protected by the ONS 'Five Safes' framework. The information can only be accessed by approved researchers in secure settings and there are strict restrictions about how the information can be used. You can find more information about the YEF archive and the Five Safes at <https://youthendowmentfund.org.uk/evaluation-data-archive/faqs-the-youth-endowment-fund-data-archive/>

20. Who has reviewed this study?

Most university research in the UK is reviewed by an independent group of people, called a Research Ethics Committee. This committee is here to protect your interests. The CAPVA study has received ethical approval from the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee. The UH ethics protocol number is 0233-2025-Mar-HSET.

21. Who can I contact if I have any questions?

If you would like further information or have any questions, please email CAPVAstudy@herts.ac.uk. If, however, you would like to discuss any details personally, please contact Dr Caroline Cresswell, the trial manager, in writing, by phone or by email:

Dr Caroline Cresswell

Department of Psychology, Sport and Geography, University of Hertfordshire, College Lane, Hatfield, AL10 9AB

☎ 01707 286466

✉ CAPVAstudy@herts.ac.uk or c.cresswell@herts.ac.uk

22. What if there is anything I am not happy about with this study?

If you are unhappy about any aspect of the research study or would like to raise a complaint about your participation in the study, please contact Professor Joanna R Adler (Email: j.r.adler@herts.ac.uk) the principal investigator of this study. If you still feel that your complaint has not been handled to your satisfaction, you can then contact the Chair of the UH Research Ethics Committee, at the following email address: hsetecda@herts.ac.uk or Professor Wendy Wills, Pro Vice-Chancellor (Research and Enterprise), University of Hertfordshire, College Lane, Hatfield, AL10 9AB. w.j.wills@herts.ac.uk

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