

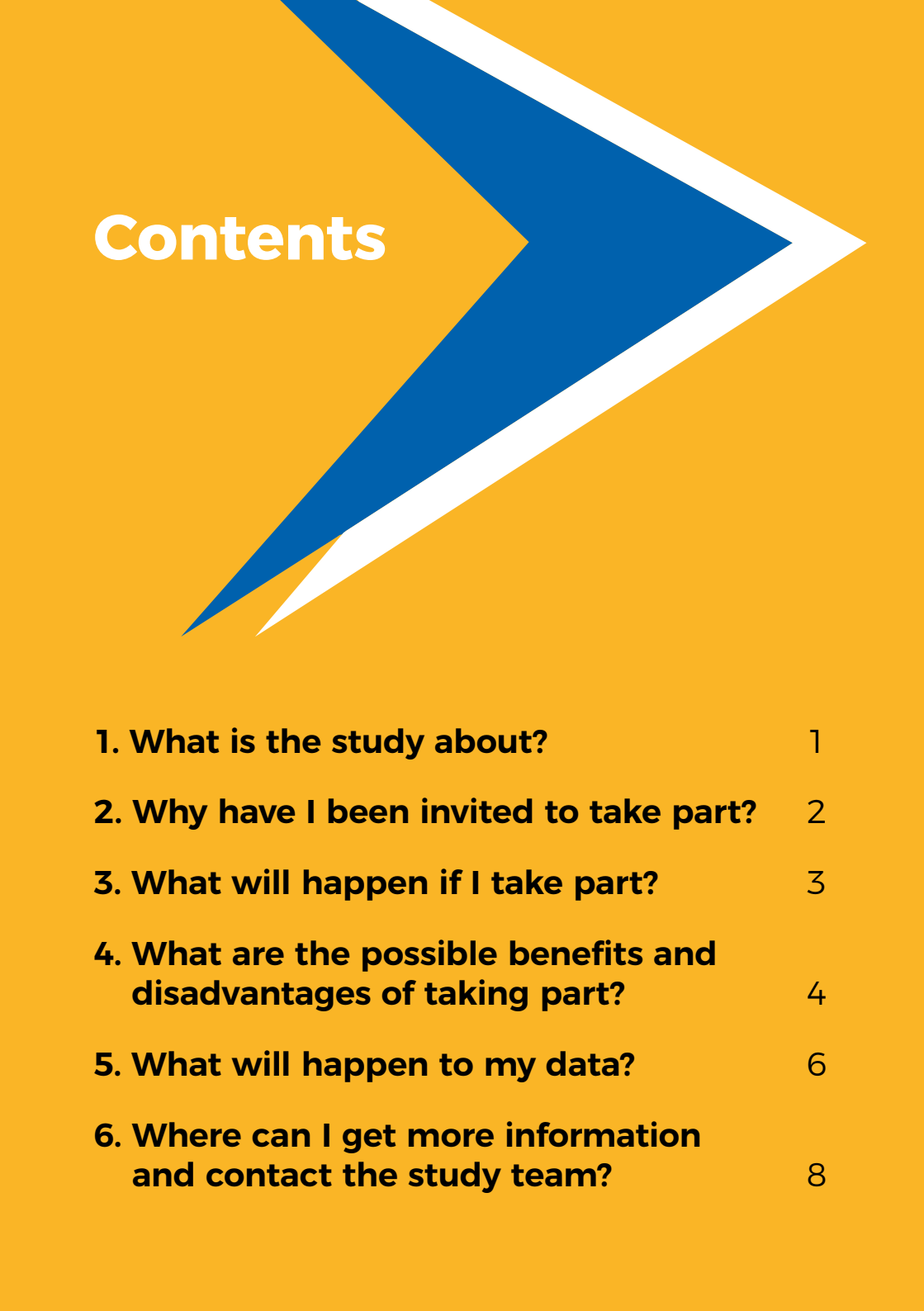


Family Interviews Information Booklet

The Pioneer Study aims to find out more about why some children die suddenly and unexpectedly.

We would like to invite you to join our study, but we want to be sure you know what is involved.

Please read this leaflet carefully, take your time to decide and talk to others if you wish.



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1. What is the study about?

The Pioneer Study is a research project led by a team at the University of Bristol. The first part of the study is looking at all sudden and unexplained deaths of children aged 1 to 17, using National Child Mortality Database data. The aim is to find patterns and clues to what the underlying causes might be.

The second part, this part, involves **family interviews** to ask bereaved parents themselves about what they think happened, or anything they think might have contributed to the death of their child. We know that parents know their children best, and they may have information that was not collected, or not thought to be important at the time. This has never been collected as part of a research project before, so this would be new and valuable information. It may lead to changes in the information that is collected for all sudden and unexpected child deaths.

It's important to know that the **interview will not be able to provide you with answers about why your child died.** The study hopes to include parent perspectives, that may help to identify patterns to guide research to look in the right place, which may help families in the future.

The study is funded by:



2. Why have I been invited to take part?

- We are inviting up to 25 families who have been supported by the charity SUDC UK to take part in an interview.
- It is up to you to decide whether or not to take part in this study. You are free to leave the study at any time.
- To be eligible to take part, you need to be a parent or primary caregiver, aged 16 or over, of a child aged 1-17 years who:
 - Died suddenly and unexpectedly with no immediately apparent cause
 - The death occurred within England
 - You have received the death certificate and registered the death
- We expect that more people may be interested than we are able to include. Because this is a qualitative study, we are only able to conduct up to 25 interviews.
- If more than 25 parents' express interest, we will select participants to ensure we include a broad and diverse range of experiences and perspectives (reflecting different circumstances, backgrounds, and experiences).
- Unfortunately, this means that not everyone who expresses interest will be invited to take part in an interview. We recognise that this may be disappointing, and we want to reassure you that this decision is not based on the importance or value of your experience.

- If you are eligible but not selected for an interview, we will invite you to take part in a national online survey. This survey will provide another opportunity for you to share your views and contribute to the research.
- We are only able to hold one interview per child, but we can interview two people together, or one after another in the same interview.

3. What will happen if I take part?

- If you are interested in taking part in this study, let the researcher know and they will arrange a time to speak with you, either online, or on the phone.
- The researcher will discuss with you what the study is about, check you are eligible to take part, and you may ask any questions you wish.
- You will have further time to think about whether you would like to take part or not.
- If you decide to take part the researcher will ask you to complete a consent form. You can do this online, or we can record consent before the interview starts. We will email you a copy of the form, for your records.
- If you agree to take part, the interview will be about your child, your understanding of the events leading up to their death, factors you think may have contributed, any unanswered questions you have and any suggestions for

future research you would like to see. The researcher will arrange an online chat or call you on the phone at a time which suits you both.

- With your permission the researchers will audio-record the interview and then transcribe it. The audio-recording will be destroyed after analysis. The interview will take up to 1 to 2 hours.
- The transcriptions will be anonymised (any names and details that could be used to identify you personally will be removed) and any quotes used to describe the findings will not be identifiable.

4. What are the possible benefits and disadvantages of taking part?

- It's important to note that taking part in this research will not provide you with answers about why your child died. The study hopes to identify patterns to guide research to look in the right place, which may help families in the future.
- Taking part will help us to decide what data should be collected nationally, so that we can look for patterns in subsequent child deaths. We will also be able to make recommendations about where families would like research to focus.
- The interview will take about an hour, but maybe more if there is a lot to talk about.
- Talking about your child's death can be upsetting, and we want to support you to do this in a way that does not cause

you any more harm. We will let you guide the conversation, and go at your pace. You can take breaks, or stop the interview at any time. We will ask you to have someone you can contact when the interview is over, and someone from SUDC UK will be in touch to offer you further support.

- In all research interviews, it is possible that we may hear things that give us cause for concern, if there are any issues raised which you or we are not happy about we will discuss together what, if anything, we should do.
- There should be no other risks or problems and taking part in this study will not affect, in any way, your families' medical care now or in the future.
- If during the course of the study we become concerned about you or anyone's safety we will talk together with you about what to do , and we may seek support for you and your family from the appropriate services.
- To honour your time, everyone who we interview will receive a £25 voucher.



5. What will happen to my data?

We understand that the information you share in this interview is personal and may be very sensitive. We take your privacy seriously.

If you take part:

- The interview will be audiorecorded (with your permission) and then written out as a transcript
- The recording will be stored securely and deleted after analysis
- The transcript will be anonymised, meaning names and identifying details are removed
- Anonymised data will be kept indefinitely by the study team

Any contact details you give us (such as your email address or phone number) will be used only to arrange the interview or send you study information. These details are kept separately from the interview data and deleted when no longer needed.

Only the Pioneer research team at the University of Bristol will have access to identifiable information. Quotes from interviews may be used in reports or publications, but they will be carefully chosen so that no individual can be identified.

All information is stored securely and handled in line with UK data protection laws.

You are free to stop the interview or withdraw from the study at any time. If you withdraw before the interview data have been analysed (about January 2027), we can delete your interview data. To withdraw from the study, please email [**pioneer@bristol.ac.uk**](mailto:pioneer@bristol.ac.uk) and we will confirm whether deleting your interview data is possible.

If you have any questions about how your information is used, you can contact:

- The study team: [**pioneer@bristol.ac.uk**](mailto:pioneer@bristol.ac.uk)
- The Research Governance Team:
[**research-governance@bristol.ac.uk**](mailto:research-governance@bristol.ac.uk) –
as an independent contact if you wish to make a complaint or raise any concerns with this research.
- University of Bristol Data Protection Officer:
[**data-protection@bristol.ac.uk**](mailto:data-protection@bristol.ac.uk)

You can find more information about data protection at the University of Bristol here: [**bristol.ac.uk/secretary/data-protection/privacy-notices/research-participant-privacy-notice**](https://bristol.ac.uk/secretary/data-protection/privacy-notices/research-participant-privacy-notice)

6. Where can I get more information and contact the study team?

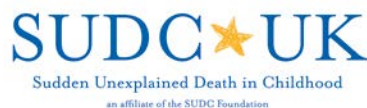
The study is being run by researchers at the University of Bristol, funded by SUDC UK.



If there is anything you do not understand or if you would like more information, please email:

Anna Pease (Researcher):

pioneer@bristol.ac.uk



Registered charity (England & Wales) No. 1175413

This study and the research team are:

- Dr Anna Pease, Bristol Medical School, University of Bristol
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- Dr James Fraser, University Hospitals Bristol and Weston NHS Foundation Trust
- Sylvia Stoianova, National Child Mortality Database
- Dr Rohini Rattihalli, Oxford Children's Hospital
- Dr Mary Sheppard, City St. George's University of London.

Thank you very much for taking the time to read this information leaflet.