



## Involving parents and staff in learning from child deaths Parents Information Leaflet

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**This study is about how bereaved parents can be involved in learning from child deaths.** 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?

- Some weeks after any child dies, the doctors, nurses and other staff looking after them have a meeting to discuss what happened to try and learn from deaths to improve care and help families in the future. Information from parents is very important for this meeting, as they knew their child best, and will have been involved in all their treatment and care throughout their life. Parents may also have questions they want answered about their child's illness, treatment, or death.
- This study wants to find out about the most helpful and supportive ways of involving parents in learning from child deaths and sharing information with them about the process.
- We are also asking the healthcare professionals involved in death reviews their experiences. We will bring all this information to two workshops where parents and professionals will work together to develop a range of materials to support parents' involvement in child death review. These workshops will be attended by bereaved parents, healthcare professionals and representatives from bereavement support organisations.

## 2. Why have I been invited?

- We are inviting parents of children, aged between one month and 18 years, who died after a stay in hospital, hospice or at home with palliative care, anywhere in England, during 2021 to take part.
- We are only inviting parents whose children died during 2021 to make sure we learn of the impact of recent changes in the way we learn from child deaths.
- It is up to you to decide whether or not to take part in this study. Your treatment and your family's care will not be affected now or in the future if you decide not to take part and you are free to leave the study at any time.

## 3. What will happen if I take part?

- If you are interested in taking part in this study, please let the researcher know by email, phone or using the reply slip, and they will contact you to discuss the study further. They will ask for a little more information about you and your child to make sure the study is right for you.
- The researcher will discuss with you what the study is about, 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.
- You may be offered a choice of having an interview on your own or with a partner, friend or other relative, or joining a focus group – a group interview with other bereaved parents.
- If you decide to take part the researcher will ask you to complete a consent form.
- You can return this to the researcher by email, or we can record consent before the interview or focus group starts. If needed we will email you a copy of the form, for your records.

- The researcher will ask for detail of your family doctor (GP) at the start of the interview, this is in case they are worried about you and to help you access support.
- We hope to interview around 30 families making sure we interview a range of people with different experiences and from different backgrounds; so we may not be able to interview everyone who volunteers.
- If you are not able to have an interview, we still value your contribution and you will be invited to complete a brief survey of your experiences.
- To say 'Thank You' for taking part, everyone who we interview will receive a £20 Voucher from Amazon or Love2Shop. We will pay travel expenses for those who travel for an interview or focus group, and childcare costs where needed.

### 3a. What will happen if I have an interview?

- If you agree to take part, a researcher will interview you about your experiences of talking with doctors, nurses and other staff after your child died. They will ask about what type of information you might have been given, and what type of information would have been helpful. The researcher can meet you at your home, another place you both agree (eg a clinic) or arrange an online interview at a time which suits you both.
- You can be interviewed by yourself or with your partner, a friend or another relative present. If another person takes part in the interview with you, they will need to sign a consent form too.
- With your permission the researcher will audio-record the interview and it will then be typed up (transcribed). The audio-recording will be destroyed after analysis. The interview will take up to 1 hour.
- The transcriptions will be anonymised (any names and details that could be used to identify you personally will be removed) and any quotes we use will not be identifiable.
- The researcher will not be able to provide any further information for you about your child and family's experience that you do not already have; they do not have access to any clinical information. If needed, we can suggest where you can get further information or advice.

### 3b. What will happen if I join a parent focus group?

- If you agree to take part you will join up to 6 other bereaved parents for a group discussion about your experiences of talking with doctors, nurses and other staff after your child died. The discussion will include what type of information you might have been given, and what type of information would have been helpful.
- The focus group will take place in a city centre in a private meeting room, such as at a hotel. There will be drinks and snacks provided.
- You can come by yourself or with your partner, a friend or another adult relative. If another person is with you, they will need to sign a consent form as well if they join in the discussion.

- With your permission the researchers will audio-record the focus group and it will then be typed up (transcribed). The audio-recording will be destroyed after analysis. The focus group will take up 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 we use will not be identifiable.
- The researcher will not be able to provide any further information for you about your child and family's experience that you do not already have; they do not have access to any clinical information. If needed, we can suggest where you can get further information or advice.
- As this is a group discussion, people who take part will be aware of what other people have said. We therefore ask all participants to maintain the confidentiality of others in the group by ensuring they do not disclose what someone else has said.

### **3c. Can I join the workshops?**

- After the interviews and focus groups, we will hold two workshops for bereaved parents, healthcare professionals and representatives from bereavement support organisations where we will share the study findings. Parents and professionals will work together to develop a range of materials to support parents' involvement in child death review.
- At the end of the interview/ focus group discussion you will be asked if you might be interested in being part of the workshops. If you are, we will contact you nearer to time with more details and you can decide then if you do want to attend. We want to make sure we invite a range of bereaved families from different backgrounds and with different experiences, so it may not be possible to invite everyone who wishes to attend.

### **4. What are the possible benefits of taking part?**

- Although you will not benefit directly, taking part will help us to better support parents to be involved in learning from children's deaths. This may help improve care and treatment for future children, as well as support for bereaved families. Some bereaved parents find taking part in research projects and talking about their child helpful.

### **5. What are the possible disadvantages and risks of taking part?**

- You may find it upsetting to talk about what happened after your child died.
- There should be no other risks or problems and taking part in this study will not affect, in any way, your family's medical care now or in the future. We may get in touch the day after you take part to check how you are and if you have any questions.
- If during the study, we become concerned about you or your family's safety we will seek support for you and your family from the appropriate services. We will

provide everyone with a list of agencies and services that support bereaved families.

## 6. How will we use information about you?

- We will need to use information from you for this research project.
- This information will include your name, initials and contact details. People will use this information to do the research or to check your records to make sure that the research is being done properly.
- People who do not need to know who you are will not be able to see your name, initials or contact details. Your data will have a code number instead.
- We will keep all information about you safe and secure.
- Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

## 7. What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason. We will keep information about you that we already have unless you let us know that you would like it removed within 7 days of the interview you took part in. It will not be possible to remove individuals' information from the focus group.
- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.
- We will be using quotes from the interviews and focus groups to highlight key findings in research publications and the workshops but these will not be identifiable.
- We can send you the results from the study if you would like to see them, the researcher will need an email address to do this, but this will be kept separately to any of the other data we collect and deleted after we've sent you the results.
- After the study finishes, we may make anonymised transcripts available for future research via the University of Birmingham BEAR archive <https://intranet.birmingham.ac.uk/it/teams/infrastructure/research/bear/research-data-service/bear-archive/index.aspx>. Access will only be granted to researchers with appropriate ethical approval.

## 8. Where can you find out more about how your information is used?

- You can find out more about how we use your information:
  - by asking one of the research team
  - at [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
  - by reading the study data privacy notice, here: **WEBSITE**
  - Visiting <https://www.bhamcommunity.nhs.uk/about-us/corporate-information/privacy-notice-and-data-protection/>

- by contacting Michael Morgan-Bullock who is the Trust's Data Protection Officer: [bchc.dpo@nhs.net](mailto:bchc.dpo@nhs.net)  
Data Protection Officer Information Governance Birmingham Community Healthcare NHS Foundation Trust 3 Priestley Wharf Holt St Birmingham B7 4BN

### 9. Where can I get more information and contact the research team?

The study is being run by researchers at the University of Birmingham and Birmingham Community Healthcare NHS Trust, funded by the National Institute for Health Research.

If there is anything you do not understand or if you would like more information, please email Jenna Spry [j.i.spry@bham.ac.uk](mailto:j.i.spry@bham.ac.uk)

### 10. What if there is a problem?

If you have any concerns related to your participation in this study, please contact:

The Research and Innovation team  
Birmingham Community Healthcare NHS Trust  
3 Priestley Wharf, Holt Street,  
Birmingham Science Park, Aston, Birmingham. B7 4BN  
[bchnt.researchinnovation@nhs.net](mailto:bchnt.researchinnovation@nhs.net)

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against Birmingham Community Healthcare NHS Trust but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you.

If you want to give Birmingham Community Healthcare NHS Trust feedback or have concerns then please email the PALS Services Team ([contact.bchc@nhs.net](mailto:contact.bchc@nhs.net)) or call 0800 917 2855. Opening hours are 9.30am to 4.30pm Monday to Friday, excluding Bank Holiday.

This study and the research team are under the supervision of Dr Joanna Garstang, Dr Karen Shaw, and Professor Sara Kenyon, University of Birmingham, Dr Anna Pease, University of Bristol, and Mrs Gayle Routledge, Child of Mine.

This information leaflet has been developed with the support of Child of Mine, Together for Short Lives, Sudden Unexplained Death in Childhood UK, Edwards Trust, Child Bereavement UK.

More information about the study is available here:

**[WEBSITE ADDRESS](#)**

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

**Support Organisations**

**We know that for some, reading this information leaflet may have been upsetting.**

You may find it helpful to contact your GP. You may also be able to find support from:

**National support organisations**

Child Bereavement UK

<https://www.childbereavementuk.org/>

Together for Short Lives

<https://www.togetherforshortlives.org.uk/get-support/your-childs-care/bereavement-support/>

Good grief trust

<https://www.thegoodgrieftrust.org/>

Young Lives vs Cancer

<https://www.younglivesvscancer.org.uk/what-we-do/bereavement-support/>

Cruse Bereavement Support

<https://www.cruse.org.uk/>

**Midlands support organisations** (this will be revised for other areas as needed)

Child of Mine

<https://achildofmine.org.uk/>

Edwards Trust

<https://edwardstrust.org.uk/>