



UNIVERSITY OF
BIRMINGHAM



Involving parents
and staff in learning
from child death

NHS

Birmingham
Community Healthcare
NHS Foundation Trust

Involving parents and staff in learning from child deaths

Staff 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?

- After any child dies, the healthcare organisation caring for them should arrange a Child Death Review Meeting (CDRM) to consider in detail the full causes and risk factors, support for the family and learning arising from the death. Although parents do not attend CDRMs they should be informed of these, asked if they have questions to be answered or other information they wish to share. Following the CDRM, the conclusions should be shared with parents.
- The best way of involving parents in CDRM is unknown. 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.
- This study is focusing on CDRMs for children who die in hospital, hospice or at home supported by palliative care teams. We are excluding infants whose deaths are reviewed using the Perinatal Mortality Review Tool or children whose deaths are investigated by a Joint Agency Response as there are already guidelines for involving parents in these processes.
- We are also asking bereaved parents 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 professionals involved in CDRMs from hospitals, hospices or community palliative care teams to be interviewed.
- 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.

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 by telephone or via Microsoft Teams or Zoom.
- 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.
- If you decide to take part the researcher will ask you to complete a consent form and return it to them by email, post or what's app.
- If you agree to take part, a researcher will interview you about your experiences of involving parents in Child Death Review meetings. They will ask about what information you might share with them, any difficulties you have had with the process and what has helped establish these.

- With your permission the researchers will audio-record the interview and it will then be 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.
- We will ask you to share details of the study with other colleagues, so that we can interview several staff members from the same trust or team.
- To say 'Thank You' for taking part, everyone who we interview will receive a £20 Voucher from Amazon or Love2Shop.

3b. 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 professionals 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.
- After the study we will send you an email to thank you for your participation.

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

- You may find it upsetting to talk about managing child deaths, however some staff have reported that they find taking part in research projects and talking about their work helpful. We may get in touch the day after you take part to check how you are and if you have any questions.
- There should be no other risks or problems and taking part in this study will not affect, in any way, your employment or healthcare.
- If during the study, we become concerned about your safety we will seek support for you from the appropriate services.

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.
- If there are any concerns around professional conduct or you or someone else may be at risk of harm then this may lead to confidentiality be broken.

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 participants 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
 - by reading the study data privacy notice, here: **WEBSITE**
 - Visiting <https://www.bhamcommunity.nhs.uk/about-us/corporate-information/privacy-notices-and-data-protection/>
 - by contacting Michael Morgan-Bullock who is the Trust's Data Protection Officer: 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

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

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) 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 our stakeholder group which includes bereaved parents.

More information about the study is available here:

WEBSITE ADDRESS

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

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

Support Organisations

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/>