

Involving parents and staff in learning from child deaths

Submission date 30/06/2023	Recruitment status No longer recruiting	<input type="checkbox"/> Prospectively registered <input type="checkbox"/> Protocol
Registration date 25/09/2023	Overall study status Completed	<input type="checkbox"/> Statistical analysis plan <input type="checkbox"/> Results
Last Edited 12/11/2024	Condition category Other	<input type="checkbox"/> Individual participant data <input checked="" type="checkbox"/> Record updated in last year

Plain English summary of protocol

Background and study aims

This study aims to improve how bereaved parents/carers and professionals work together to learn from child deaths. Each year in England and Wales around 2800 children aged between 1 month and 18 years die. Most parents/carers want to know why their child died and this can be an important part of grieving.

Child Death Review (CDR) is when health professionals study deaths in detail, to understand why children die and help stop other children from dying in the future. Although parents/carers do not attend review meetings their knowledge of their child's life, illness, and treatment is important to guide the review. Parents/carers should be informed of CDR meetings and asked if they have questions or information to share but this rarely happens in practice.

Who can participate?

Parents/carers of children, aged between 1 month and 18 years, who died after a stay in hospital, hospice or at home with palliative care, anywhere in England, from the start of 2021 onwards. The researchers are only inviting parents/carers whose children died since the start of 2021 to make sure they learn of the impact of recent changes in the way we learn from child deaths. They are also inviting professionals involved in Child Death Review Meetings from hospitals, hospices or community palliative care teams to be interviewed.

What does the study involve?

The researchers will ask all children's intensive care units in England and palliative care services to complete a short questionnaire. They will find out what they are doing to support bereaved parents to involve them in death reviews. This will help them to choose five sites to focus on for professional interviews.

The researchers will interview professionals from intensive and palliative care to find out how they involve parents, things that work well, what the challenges are and how they overcome these. They will interview around 25 professionals from 5 different sites, using Microsoft Teams. The researchers will also interview bereaved parents/carers about their experiences when their child died and what happened afterwards. They will be asking hospital bereavement teams and bereavement charities to tell parents about the project. The researchers will interview around 20 parents and also offer group sessions. Interviews will be either in person or remote via the phone or a video call like Zoom or MS Teams.

After the research is finished the researchers will arrange a meeting for bereaved families and professionals to share the results and discuss ideas for improvement. They will work together to co-design tools to help involve parents in the Child Death Review process including professional guidelines, family information, videos, podcasts and training materials.

What are the possible benefits and risks of participating?

Although there will not be any direct benefit, taking part will help 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.

People taking part may find it upsetting to talk about children dying and what happens afterwards. There should be no other risks or problems and taking part in this study will not affect, in any way, a family's medical care now or in the future or employment if they are a healthcare professional. The researchers may get in touch the day after people take part to check how they are and if they have any questions. They will provide everyone with a list of agencies and services that support bereaved families.

Where is the study run from?

University of Birmingham and Birmingham Community Healthcare NHS Trust (UK)

When is the study starting and how long is it expected to run for?

November 2021 to October 2023

Who is funding the study?

The National Institute for Health and Care Research (NIHR) (UK)

Who is the main contact?

Jenna Spry, j.l.spry@bham.ac.uk

Study website

<https://research.bhamcommunity.nhs.uk/study/involving-parents-and-staff-in-learning-from-child-deaths/>

Contact information

Type(s)

Principal Investigator

Contact name

Dr Joanna Garstang

ORCID ID

<http://orcid.org/0000-0001-9268-0581>

Contact details

School of Nursing
University of Birmingham
Edgbaston
Birmingham
United Kingdom
B15 2TT

+44 (0)7710 447278
j.garstang@bham.ac.uk

Additional identifiers

EudraCT/CTIS number

Nil known

IRAS number

316560

ClinicalTrials.gov number

Nil known

Secondary identifying numbers

IRAS 316560, CPMS 53636

Study information

Scientific Title

Improving parental engagement in child death review

Study objectives

1. To understand existing practice, and explore the views of parents and health professionals involved in Child Death Review.
2. To develop, using co-design with clinicians and parents, a best-practice toolkit for parental involvement in post-neonatal Child Death Review.

Ethics approval required

Ethics approval required

Ethics approval(s)

Approved 27/09/2022, West Midlands - South Birmingham Research Ethics Committee (Equinox House, City Link, Nottingham, NG2 4LA, United Kingdom; +44 (0)207 104 8345; southbirmingham.rec@hra.nhs.uk), ref: 22/WM/0172

Study design

Multicentre mixed methods study using a sequential explanatory design with in-depth interviews conducted alongside a survey

Primary study design

Observational

Secondary study design

Cross sectional study

Study setting(s)

Charity/Voluntary sector, Community, Home, Hospice, Hospital, Telephone, Workplace, Other

Study type(s)

Other

Participant information sheet

Not available in web format, please use contact details to request a participant information sheet

Health condition(s) or problem(s) studied

Reviewing the involvement of bereaved parents/carers in the review of their child's death

Interventions

The project will use a sequential explanatory design, with in-depth interviews conducted alongside a survey. The quantitative survey data will inform sampling strategies for interviews and guide qualitative analysis. Qualitative data will take priority as the aim is to understand and explain experiences, barriers, and facilitators. The co-design workshop is not research in itself, but a method for utilizing and developing the research findings.

Intervention Type

Other

Primary outcome measure

1. Current CDR implementation and factors shaping this, assessed using a professional survey at a single timepoint
2. The processes of implementing, embedding and normalising parental CDR involvement, assessed using qualitative, semi-structured interviews with healthcare professionals at a single timepoint
3. Idiographic/personal meanings of the CDR process, assessed using qualitative, semi-structured interviews/focus groups with bereaved parents/carers at a single timepoint

Secondary outcome measures

The creation of a best-practice toolkit for parental involvement in the child death review process, through two sequential co-design workshops with bereaved parents and professionals at two timepoints approx. 6 weeks apart at months 11 and 14 of the study

Overall study start date

01/11/2021

Completion date

31/10/2023

Eligibility

Key inclusion criteria

Healthcare professionals:

1. The healthcare professionals (HCPs) (doctors and nurses) based in hospitals, hospices or community palliative care teams involved in Child Death Review (CDR) for children aged between 1 month and 18 years (post-neonatal child deaths)
2. HCPs able to be complete a survey or be interviewed in English
3. Able to give consent

Bereaved parents:

1. The parents of children who died aged between one month and eighteen years (post-neonatal child deaths) since the start of 2021 (but not within the last 6 months), in hospital, hospice or at home with palliative care from any cause
2. Parents of children who died a minimum time period of 6 months ago, to ensure that hospitals /palliative care teams have had time to contact parents about CDR and to allow completion of CDR processes with parents offered feedback
3. Parents may still take part if they are taking legal action against healthcare trusts as the research project will not be seeking clinical information from healthcare organisations so participation will not prejudice any legal proceedings
4. Parents able to be interviewed in English or through an interpreter
5. Able to give consent

Participant type(s)

Health professional, Other

Age group

Adult

Sex

Both

Target number of participants

45

Key exclusion criteria

Healthcare professionals:

1. HCPs not involved in Child Death Review in their hospital, hospice or palliative care team
2. Refusal or unable to give consent

Bereaved parents:

1. Parents of children who die suddenly in the community or hospital Emergency Department (e.g. Sudden Unexpected Death in Childhood [SUDIC], trauma, suicide)
2. Parents of children who have died prior to 2021 and less than 6 months ago
3. Refusal or unable to give consent
4. Parents of babies aged under 1 month

Date of first enrolment

03/04/2023

Date of final enrolment

31/08/2023

Locations**Countries of recruitment**

England

United Kingdom

Study participating centre

Birmingham Community Healthcare NHS Foundation Trust

3 Priestley Wharf

Holt Street

Birmingham Science Park, Aston

Birmingham

United Kingdom

B7 4BN

Sponsor information

Organisation

Birmingham Community Healthcare NHS Trust

Sponsor details

Research and Innovation

Trust Headquarters

3 Priestley Wharf

20 Holt Street

Birmingham

England

United Kingdom

B7 4BN

+44 (0)1214667038

bchc.ri-info@nhs.net

Sponsor type

Hospital/treatment centre

Website

<http://www.bhamcommunity.nhs.uk/>

ROR

<https://ror.org/04r10g051>

Funder(s)

Funder type

Government

Funder Name

Research for Patient Benefit Programme

Alternative Name(s)

NIHR Research for Patient Benefit Programme, RfPB

Funding Body Type

Government organisation

Funding Body Subtype

National government

Location

United Kingdom

Results and Publications

Publication and dissemination plan

The final result of the project will be peer-reviewed papers, conference presentations and a best-practice toolkit to support parental engagement in CDR. The exact nature of the toolkit will be dependent on the study findings, but we anticipate that it will include diverse materials aimed at (i) professionals such as practice-based guidelines, template letters, training materials, methods to support organisational improvement and appraise progress, and (ii) parents, such as information leaflets, web-based interactive guides, infographics, directories of useful organisations/contacts.

(added 12/11/2024)

The main results relating to the co-design element of the project have been accepted for publication in Archives of Disease in Childhood and should be available before the end of 2024. Two further papers on parents and professionals experiences will be submitted for publication by 31/1/25.

The Child Death Review toolkit, that was co-designed in this project is freely available on the National Child Mortality Database website www.ncmd.info

Intention to publish date

01/12/2024

Individual participant data (IPD) sharing plan

The data-sharing plans for the current study are unknown and will be made available at a later date.

IPD sharing plan summary

Data sharing statement to be made available at a later date