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Involving parents and staff in learning from child deaths

Submission date
30/06/2023

Recruitment status
No longer recruiting

Registration date
25/09/2023

Overall study status
Completed

Last Edited
12/11/2024

Condition category
Other

[ ] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] 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

Contact information

Type(s)
Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

Integrated Research Application System (IRAS)
316560

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
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

Study type(s)
Other

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(s)
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

Key secondary outcome(s))
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

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

Healthy volunteers allowed
No

Age group
Adult

Sex
All

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
United Kingdom

England

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

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, Research for Patient Benefit (RfPB), The NIHR Research for Patient Benefit (RfPB), RfPB

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Results and Publications

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

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes