# Pan Sussex Statutory Child Death Review Process

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# Why do we review every Child Death?

In November 1999, Sally Clark became the victim of a miscarriage of justice when she was found guilty of the murder of her two infant sons. Her first son died in 1996 within a few weeks of his birth, and her second son died in similar circumstances in 1998.

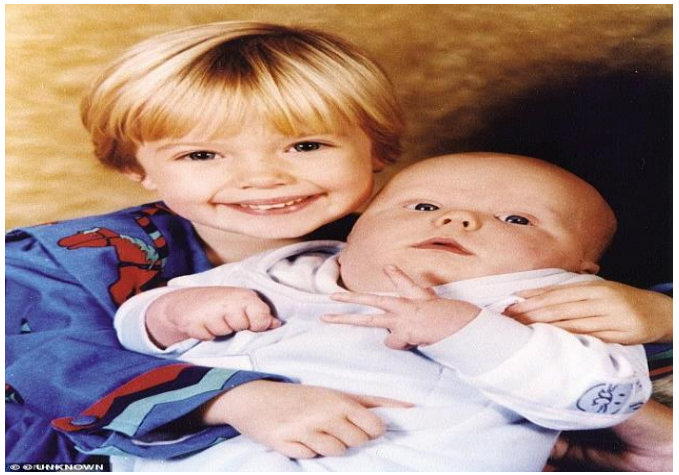



The convictions were overturned in a second appeal in 2003, Other cases were then reviewed leading to overturning the convictions of Angela Cannings, Donna Anthony and Trupti Patel.

# Why do we review every child death?

- Identified that all the information needed to explain what had happened was obtained within 3 months of the deaths, however, the information was collected and held by individual agencies and could not be reviewed and understood in full.

- The intention is to understand why children die and put in place interventions to protect other children and prevent future deaths from occurring.



# The Child Death Review (CDR) process

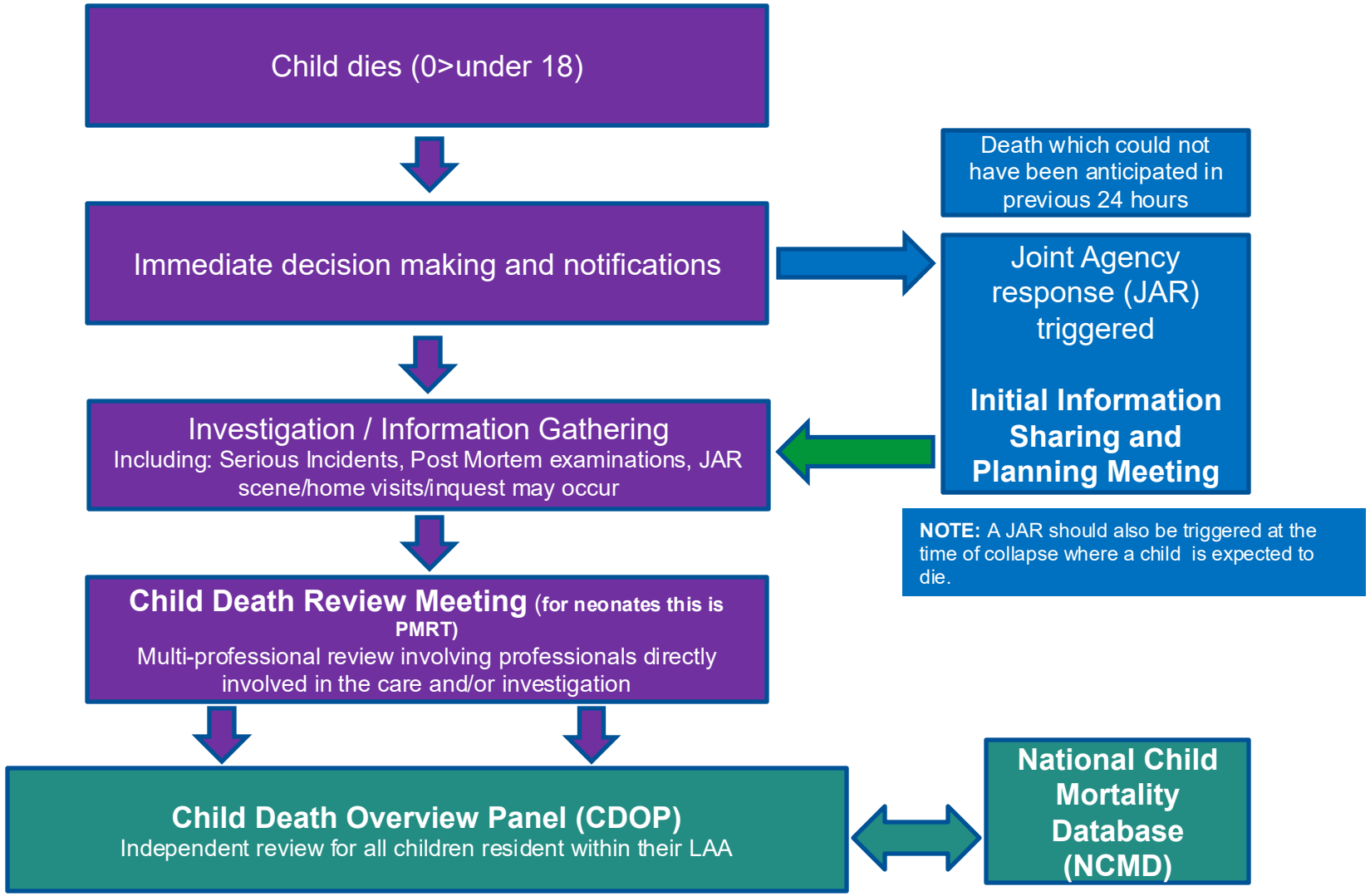
Child Death Review partners (Local Authorities & NHS Sussex) hold legal responsibility for reviewing child deaths as set out in the Children Act 2004, as amended by the Children & Social Work Act 2017.

All child deaths (up to their 18th birthday) from any cause. Includes live born babies of any gestations. Does not cover still-births, late foetal loss or termination of pregnancies carried out within the law

Purpose is to gather data and analysis to ensure lessons are learnt and where possible recommendations made to reduce the risk of future deaths.

Child Death Overview Panel (CDOP) works on behalf of CDR partners – conduct independent reviews & provide multi agency scrutiny for all child deaths in their area.

# Overview of the Child Death Review Process

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# All Deaths eCDOP Notification

- Statutory requirement to notify the CDOP within 24 hours of death occurring.
- Completed on eCDOP portal (24-hour access – no passwords needed)
- **Notification form:** **www.eCDOP.co.uk/PANsussex/live/public**
- As soon as ANY professional ie health/police/ambulance/education are aware of a child death they must makes a notification OR make a collective decision as to which professional is going to do it.
- Information submitted is vital for supporting the administration of CDR Process. Give as much detail as possible – including details of relevant key professionals
- NCMD real-time surveillance at a national scale. Immediate actions.
- For assistance, contact CDOP team - **sxicb.cdop@nhs.net** Tel: 07768 555701 / 07385 930103

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# Joint Agency Response (JAR)

A co-ordinated, multi-agency response with Leads from Health, Police & Social Work. Aims are to establish the cause of death and ensure the family are supported. Part of this process also considers any safeguarding issues including community safety.

**Triggered if a neonate/child's death would not have been expected to occur in the previous 24 hours or collapse leading to likely death**:

- Due to external causes.
- Sudden & no immediate apparent cause.
- Occurs in custody or where a child was detained under Mental Health Act.
- Initial circumstances raise any suspicions that the death may not be natural.
- **Still birth where no healthcare professional was in attendance**.

**Coroner must be informed**

# The Coroner Service

- Coroner in charge of deceased child's body
- Coroners Officer – liaises with family and professionals on behalf of coroner
- Postmortem usually requested – Coroners decision
- Postmortem usually carried out in London – can take many months to get full results
- Usually an Inquest unless natural cause of death identified - Who, where, when & how they came about their death
- After an Inquest, a death certificate can be issued (interim death certificate issued after actual PM so funeral can take place)

# Sussex agreement

- Medical equipment, specifically ET tubes, can be removed from the child UNLESS there is a concern that the ET tube/intubation may have caused or contributed to the death, in which case the tube must remain in situ and an immediate discussion with the coroner. To take place

- Any equipment removed should be kept until the coroner agrees for disposal; it is hoped this will be more sensitive and less traumatic for the parents when being with their child.

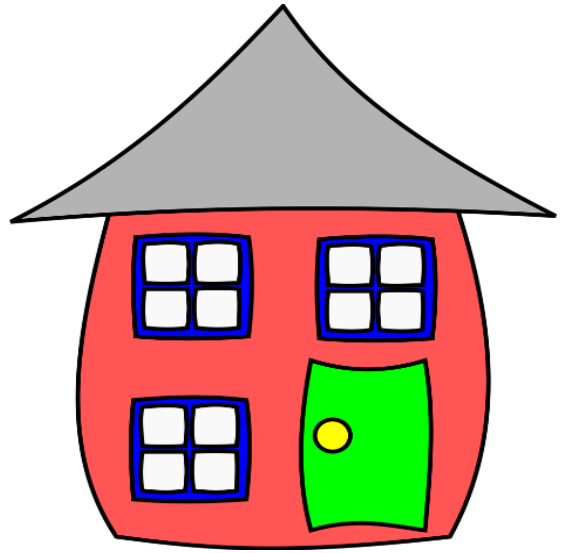
- If the child already had inserted feeding tubes, central lines etc then these should also remain in situ as potentially they may need analysis as part of the PM/coronial/police investigation.

# JAR - Initial Information Sharing and Planning Meeting (IISPM)

- Convened, chaired and minutes by Children's Services (ideally within 24 hrs of the death).
- Lead health professional, lead police investigator, child death review (CDR) specialist nurse, primary care & any other professionals who knew the child or family.
- Review all information & identify further investigations/actions required. Consider safeguarding.
- Planning support for family & wider community i.e. school.
- Allocation of keyworker
- Ensure Coroner and CDOP informed.
- Consider follow up meeting & referral for Safeguarding Practice Review.

# JAR - Joint Home Visit

- Senior Police Officer & CDR Specialist Nurse and/or appropriate professionals
- Scene of death/collection of evidence, photographs, if required
- Additional history taking/answer parents' questions
- Consider safeguarding
- Support around the family, children, schools
- Signposting
- Introduce the CDR process and provide “When a Child Dies” booklet



# Case Study - Hazel

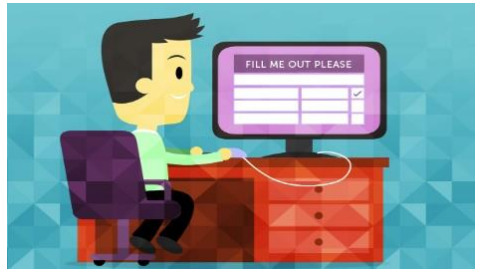
Hazel, 4 months old, found unresponsive by mother – both been asleep on sofa. Declared deceased at scene by ambulance.

JAR Triggered. CDR Nurse informed by Police, work begins to ascertain which services child known to. IISPM convened for later that day. Other safeguarding concerns identified so STRAT convened for siblings – Section 47 agreed.

Home visit from Police and CDR Nurse. Clarified events & looked at where baby was sleeping. Cot in upstairs bedroom but filled with equipment and toys. Discussed with family how to tell siblings what had happened – given links to Winston's Wish. Touched on CDR process.

# eCDOP Reporting Forms

- **Purpose -** gather detailed information from all agencies & professionals.
- Four domains (child, social environment, physical environment and service provision)
- About your service & input to that child/family. How well you knew them? Did they engage with services?
- What went well? What could have been improved?




**Guidelines on how to complete a form will be emailed with the form via CDOP.**

Please contact the CDOP team if you require any assistance (contact details at end of slides).

# CDRM – Child Death Review Meeting

- In most cases, CDRM is chaired & owned by the hospital where the child died.
- Aim to hold within 3 months of the death (once investigations and key reports have been completed).
- Review history, treatment, and outcomes to **determine cause of death**
- Ascertain **contributory and modifiable factors** specific to child, social & physical environment & service delivery.
- Identify **local learning and actions.**
- **Voice of the family** represented & then feedback given to family after meeting.
- **Review support** provided to family and staff, involved in the care of the child.
- Ensure that CDOP and coroner are informed of the outcomes of the meeting (minutes/analysis form).
- Perinatal Mortality Review Tool meeting (PMRT) – for babies who die up to 28 days.

# Hazel – Voice of family

- Mother was laying at opposite end of sofa to Hazel – she felt there was no way she could have laid on her.
- Other children did not feel safe, sleeping in new bedroom due to noisy neighbours so they all slept downstairs.
- Had only recently moved due to risk of domestic violence – property not in habitable state.
- Remembers being given safer sleep advice but did not realise the seriousness of this.

# Hazel – Learning from CDRM

- Risks of sleeping on sofa not specifically discussed
- Regular sleeping arrangements not seen by health professionals
- No discussion about co-sleeping risks eg smoking, drinking, extreme tiredness

# Child Death Overview Panel (CDOP)

The panel independently and anonymously reviews all child deaths who reside in their local authority area - regardless where they die.

- Held monthly and include specialist panels; neonates, suicide, oncology.
- Independent Chair and Lay Person
- Senior representatives from agencies across Sussex providing final multi agency scrutiny (after all review processes have concluded)

Functions: to gather and collate data to analyse all information to;

- Clarify cause of death, identify contributory factors and learning that may prevent future deaths
- Make recommendations where actions have been identified
- Provide data to national child mortality database (NCMD)
- Contribute to local, regional and national initiatives to improve learning

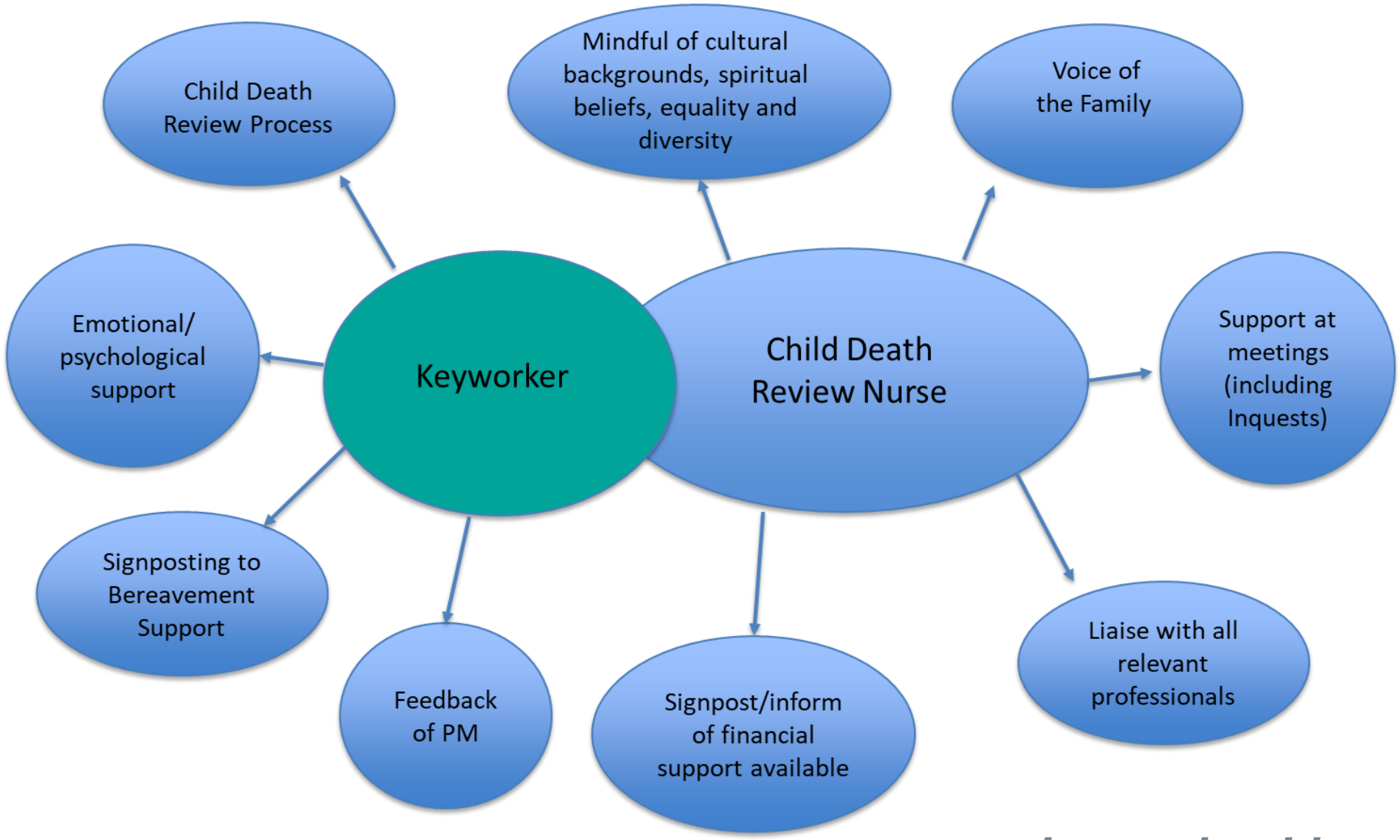
# Hazel – Learning from CDOP

Number of babies have died in Sussex due to unsafe sleep. Multi-professional training program to update on latest recommendations, for example – 2023 survey of 3400 new parents – 9 out of 10 families co-sleep at some point but less than half given professional advice on how to reduce risk of SIDS if co-sleeping. Or when NEVER to co-sleep (smoking in pregnancy, someone in bed smokes, taken medication that makes them sleepy, alcohol or drugs, premature babies)

# Role of the keyworker (statutory guidance)

- Be a reliable and readily accessible point of contact for the family after the death;
- help co-ordinate meetings between the family and professionals as required.
- Be able to provide information on the child death review process and the course of any investigations pertaining to the child, including liaising with the coroner's officer and any police family liaison officer;
- Represent the 'voice' of the parents at professionals' meetings, ensure that their questions are effectively addressed, and to provide feedback to the family afterwards; and
- Signpost to expert bereavement support if required.

# Role of the Keyworker

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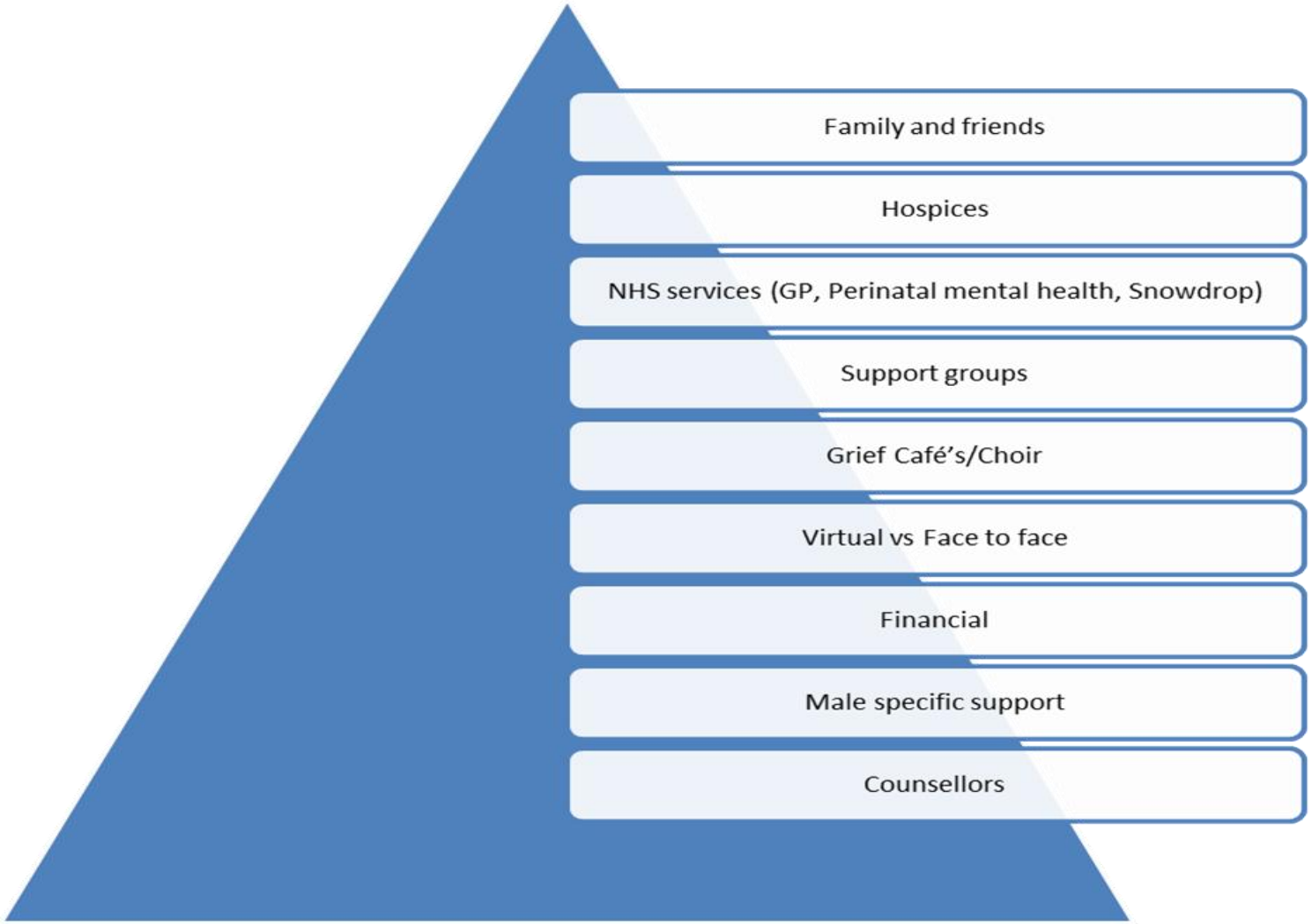
# Support for Hazel's family

- Regular contacts (phone, text, face to face, emails with links to resources) – discussed coping strategies, 'hope box'.
- Siblings given resources/workbooks; parents signposted to Winston's Wish website for advice.
- Referred to Lullaby Trust and allocated a 'befriender'.
- Communication with social worker.
- Chased PM and organised/facilitated meeting with Paediatrician and parents to feedback PM findings. TIC approach – home visit instead of parents having to go back into hospital.
- Talked over what would happen at Inquest, attended to support parents.
- Informed parents about bereavement benefits resulting in a further 2 weeks off work at time of PM results.
- Mental health deteriorated so Mother referred for trauma-based support.
- Parents separated so support also offered to father but declined.

# Identifying appropriate sources of support




https://nationalbereavementalliance.org.uk/wp-content/uploads/2023/11/Grief-Support-Guide_Eng3-Nov-23.pdf

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# Feedback on CDR service

- “She knew when to and not to contact and recommended services that we could benefit from”
- “Nurse came and phoned was a big help for me”
- “We were provided with so much support in ways “
- “CDR nurse intervention and advice was instrumental in allowing me to deal with it all “
- “Very grateful for CDR Nurses help and could not have got it through it without her. Some of my family had not been supportive and did not understand what I was going through. CDR nurse intervention and advice was instrumental in allowing me to deal with it all and helping the children to understand too. I want to sing her praises”.
- I want you to know how grateful I am to have your support. Please know that without you I don’t know if I’d be putting one foot in front of the other in the same way”

# CDOP Team Role

- The CDOP Manager and CDOP Business Support Officer work on behalf of the CDR partners.
- Manage and coordinate the Child Death Reviews and successful running of the CDOP
- Ensure effective management of all data collection (Notification, Reporting Forms) and storage (eCDOP)
- Establish agencies that have been involved (with the child or family before and after death)
- Receive relevant information i.e Reporting Forms and other information/reports
- Liaise with the Chair of the child death review meetings to receive meeting summary notes (draft Analysis Form)
- Record CDOP's conclusions (final Analysis Form) and submit data to the National Child Mortality Database

# How does learning affect our practice?

# Sharing Learning from Child Death Reviews

**Child Death Review Meeting learning**:

- Agencies (e.g. hospital and community trusts, police, social care) responsible for actioning their own learning and disseminating.
- Training sessions

**Child Death Overview Panel Learning**

- Discussed at Commissioners meeting and taken forward
- to contribute to local, **regional and national initiatives** to improve learning from child death reviews, including, where appropriate, approved research (ICON)

- Quarterly Child Death Review Partnership **Newsletter** – available for distribution
- **Annual report**
- Make **recommendations** to all relevant organisations where actions have been identified which may prevent future child deaths or promote the health, safety and wellbeing of children
- Child Death Review Partnership Annual **Conference**
- NCMD | The National Child Mortality Database Webinars, thematic review and reports

# CDOP Annual Report 2023 - 2024

- Notified of 78 deaths.
- JAR required for just over third.

- 42% babies less than 28 days old
- 12% babies 28 – 364 days old
- 17% Children aged 1-9years old
- 29% 10-17years old.

- Brighton 9
- East Sussex 22
- West Sussex 41

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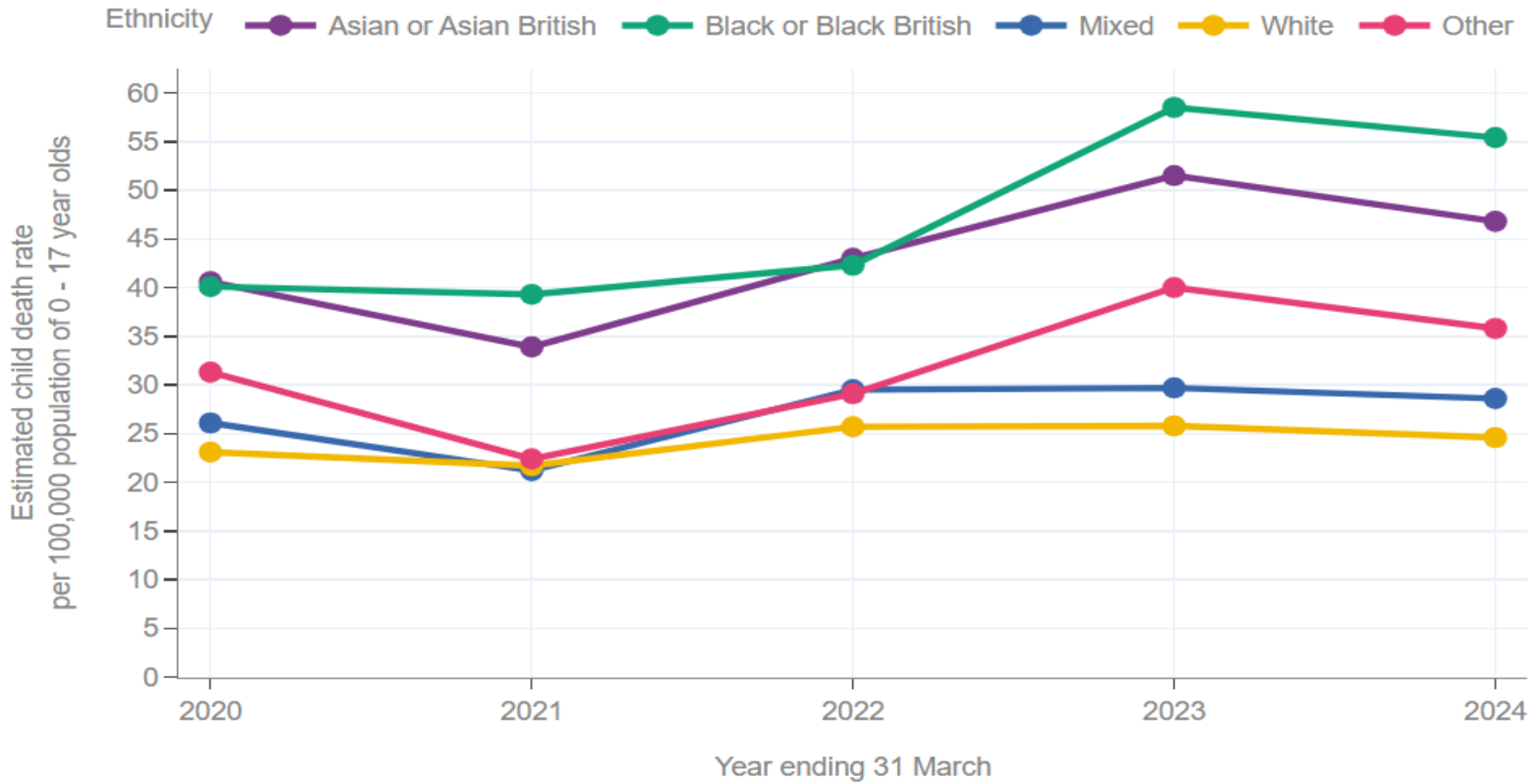
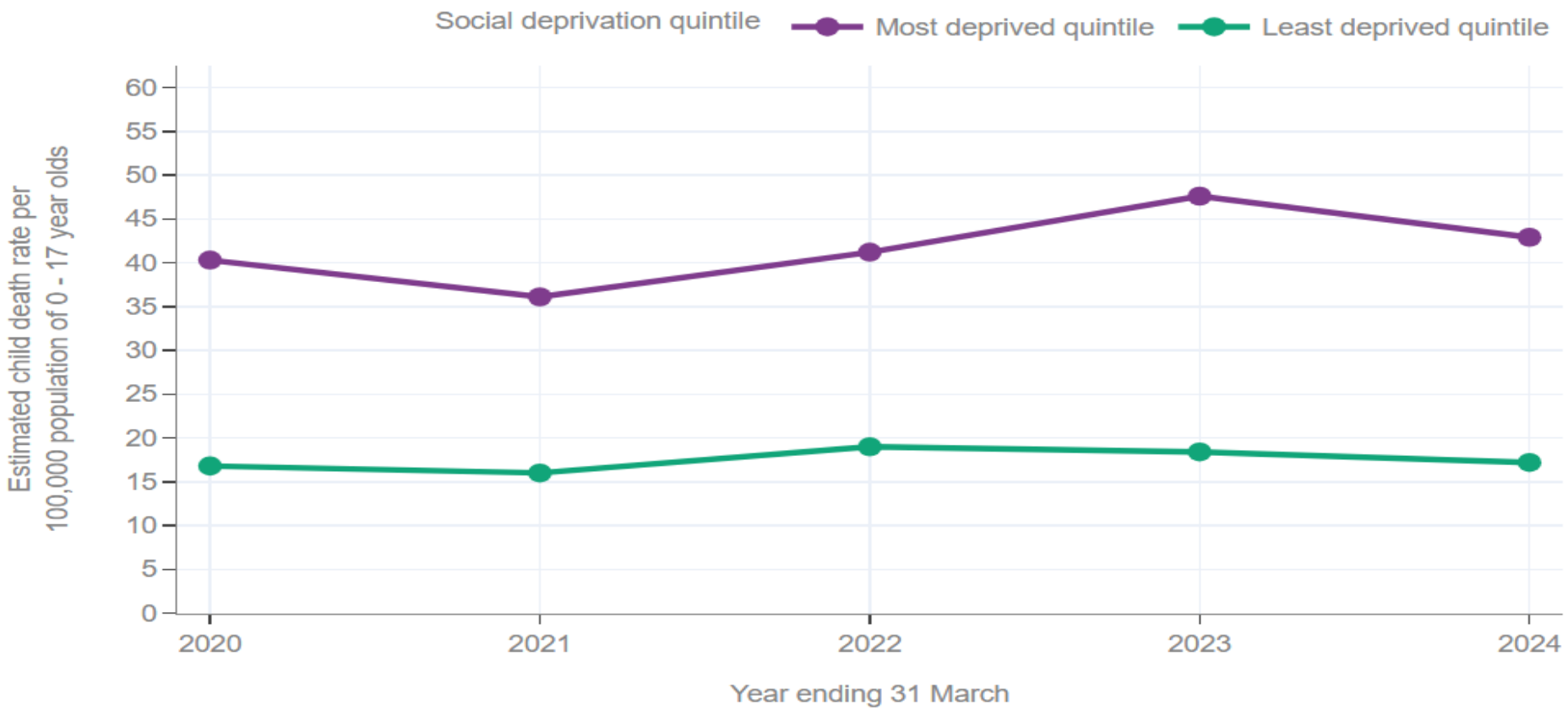
# National Data NCMD

**Figure 3. Estimated child death rate per 100,000 population, by ethnicity**



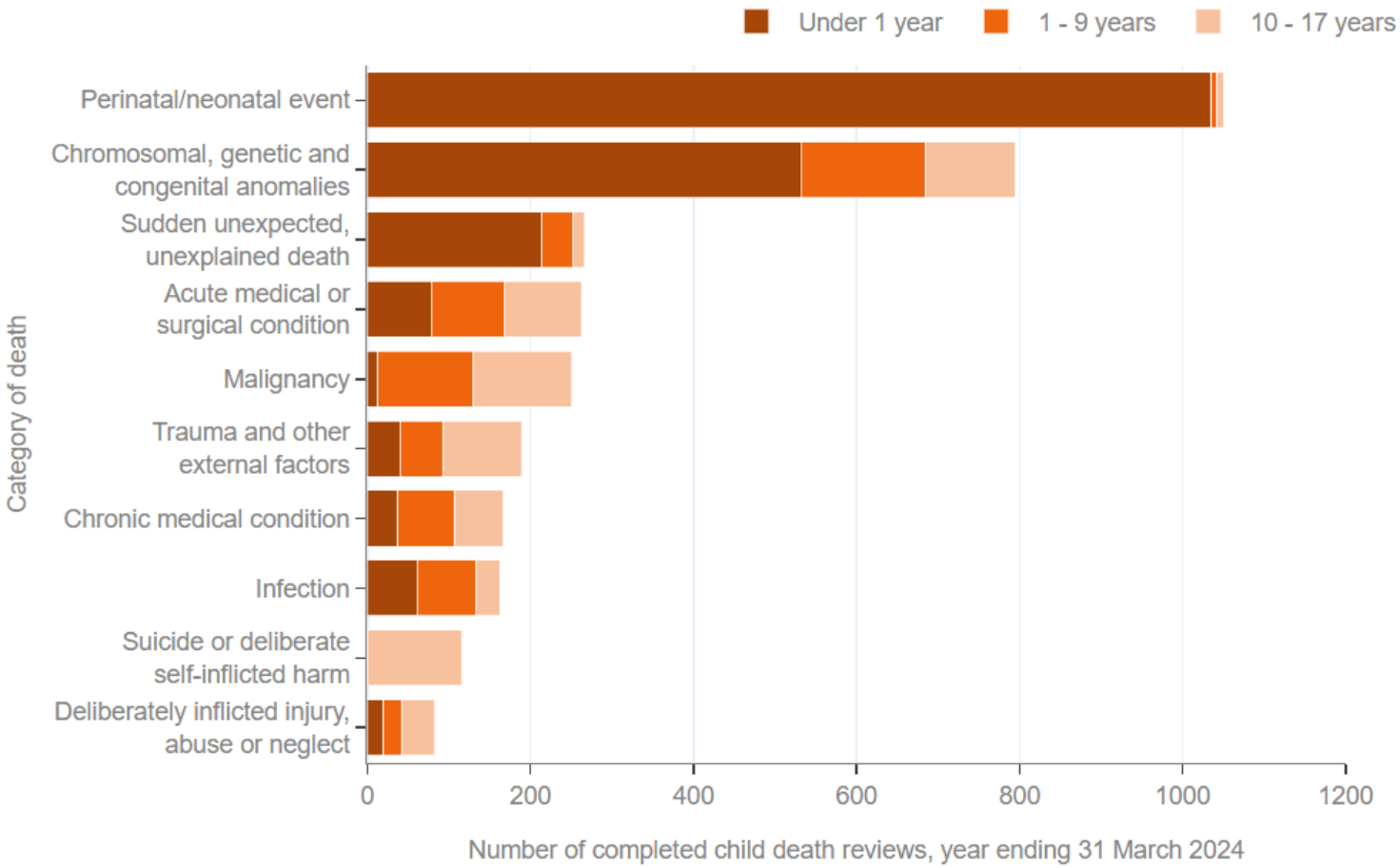

Data Source: NCMD, ONS Census (2021)
www.ncmd.info/cdr24/

**Figure 5. Estimated child death rate per 100,000 population, by most/least deprived quintiles**



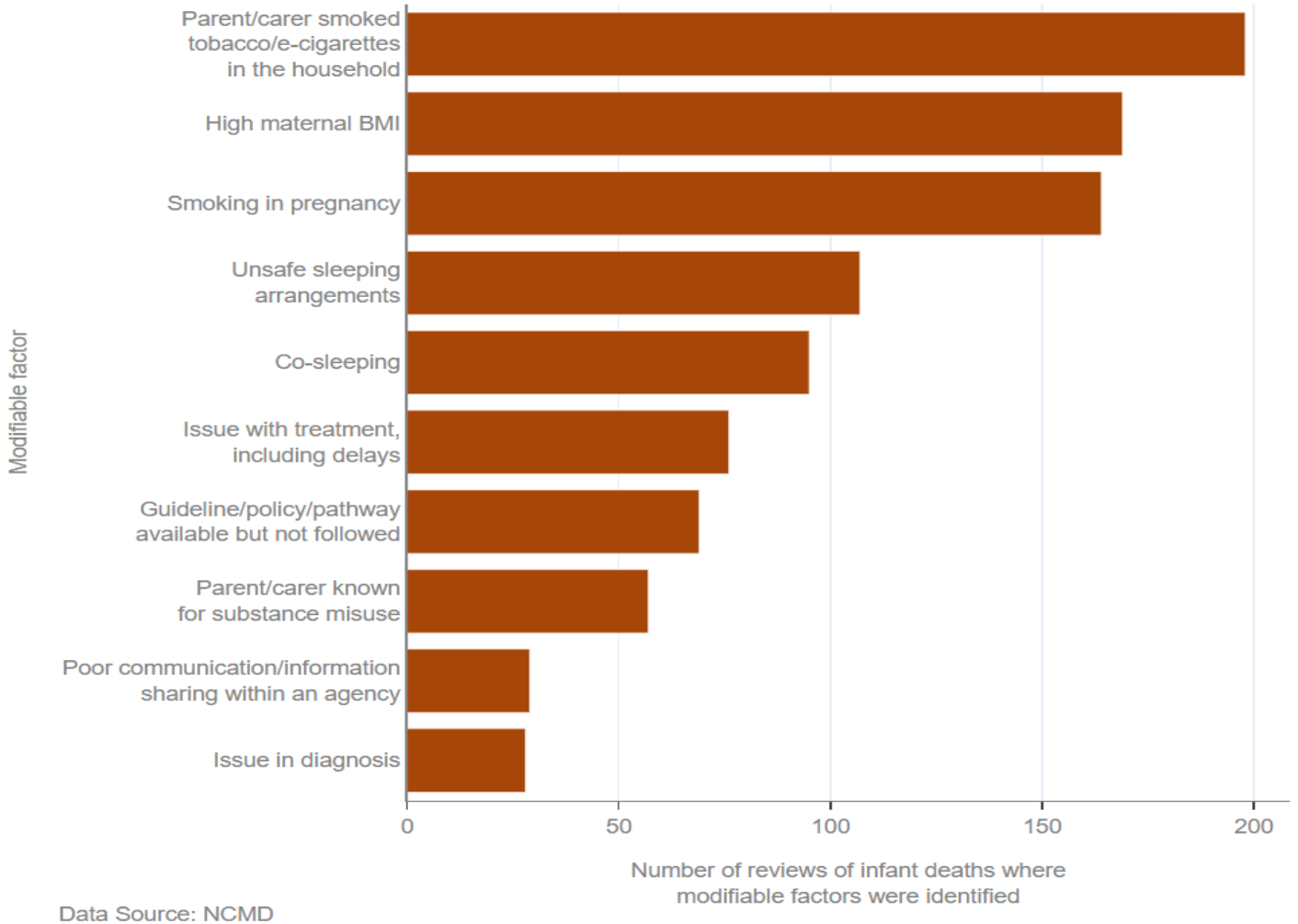

Data Source: NCMD, ONS mid-year population estimates, Index of Multiple Deprivation (2019)
Please note population for year ending 31 March 2023 is used for year ending 31 March 2024.
www.ncmd.info/cdr24/

**Figure 16. Number of child death reviews by CDOPs by primary category of death and age group, year ending 31 March 2024**



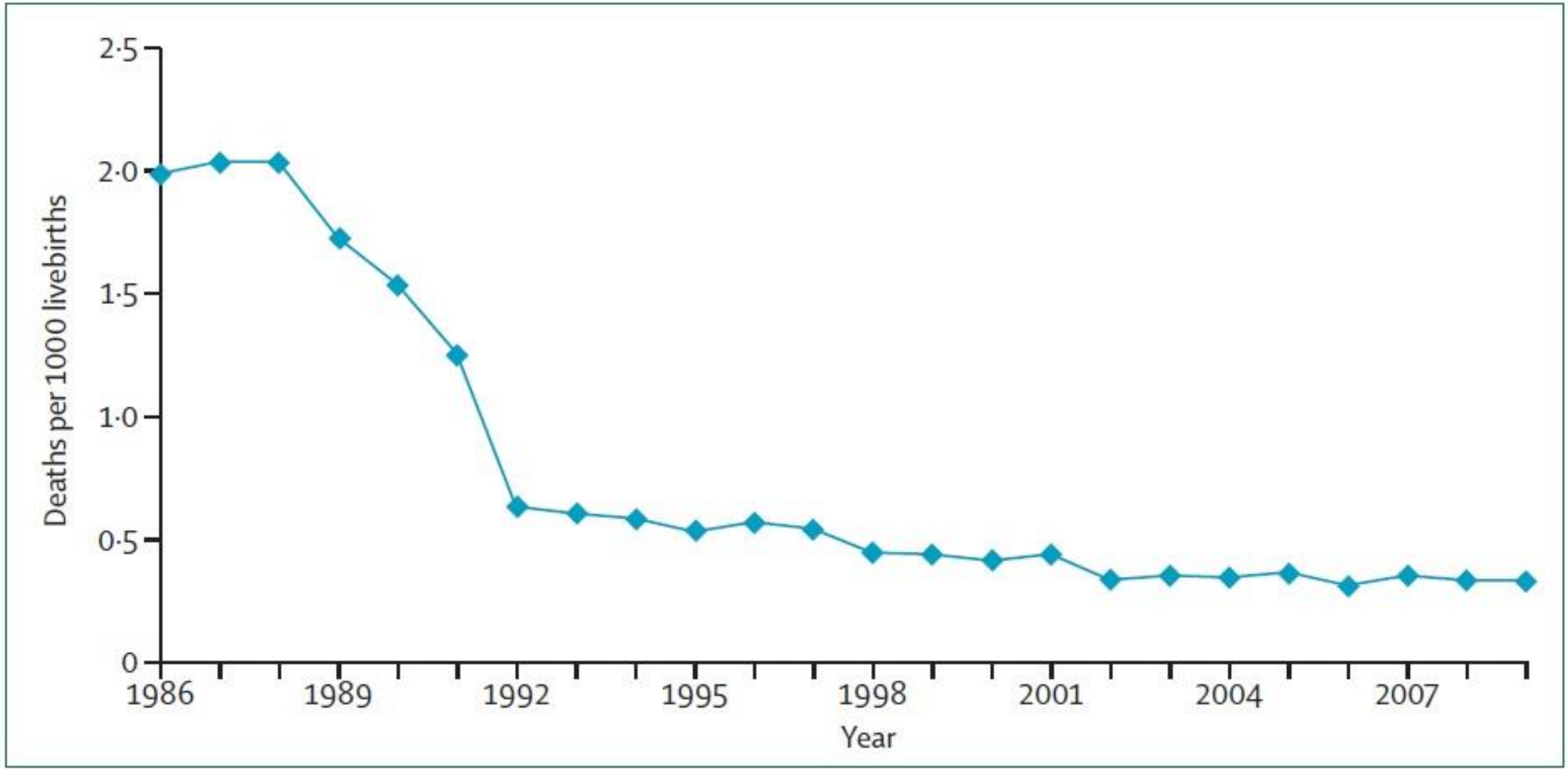

Data Source: NCMD
www.ncmd.info/cdr24/

**Figure 18. Most common modifiable factors identified by CDOPs in reviews for children aged under 1 year, year ending 31 March 2024**




Data Source: NCMD
www.ncmd.info/cdr24/

# Significant reduction in infant deaths – WHY?

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# Sudden Infant Death Syndrome

- 4 babies die suddenly & unexpectedly every week in UK, no cause found.
- The rate of SIDS has reduced by more than 81% since back to sleep message in 1991. Saving the lives of around 20,000 babies
- 2019 SIDS rates in England & Wales 0.27 deaths per 1000 live births.
- 2019 South East 0.29 deaths per 1000 live births (increased from 0.28 in **2018**)
- Survey – only 32% of father's been given safer sleep advice
- Lullaby Trust support research into SIDS, promote safer sleep advice, support bereaved parents and care of next infant programme, training for professionals
- Out of Routine Report July 2020 Child and Safeguarding Practice Review Panel (Lullaby Trust 2022)


- Out of Routine Report July 2020 Child and Safeguarding Practice Review Panel (Lullaby Trust 2022)

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# When crying gets too much...

I nfant crying is normal, it will stop!

C omfort methods can soothe the baby and the crying will stop.

It's okay to walk away if you have checked the baby is safe and the crying is getting to you.

N ever, ever shake or hurt a baby.

**Speak to someone if you need support such as family, friends, Midwife, GP or Health Visitor**

# Working with families when a child has died

# What to say?

- “I don’t know what to say but I am here to listen”
- Use a calm voice
- Use the child’s name
- Use simple language
- Important to use the word ‘died’

- You are unlikely to make the situation worse by what you say
- It’s ok to show your emotion – it shows you care
- Normalise how they are feeling
- No set way how to grieve and everyone will do this differently

# What not to say

- “I know exactly how you feel”
- “You’ll get through it, just be strong”
- “Everything happens for a reason, life goes on”
- “At least…”
- “Stop feeling that way, feel this way”
- “It’s been a while since they died, aren’t you over them yet?”
- “They’re in a better place”
- “It must have been their time to go”
- “Oh well, it’s a part of life”
- “Just give it time, it’ll get better/time heals”

(Winston’s Wish 2023)

# Physical Symptoms of Grief

## Conversations with families


- Try to eat little and often
- Ensure drinking enough water
- Get some exercise and fresh air
- Reduce caffeine and alcohol
- Structure to the day can help
- Allow yourself to express your emotions

# Supporting children

- Be honest with children (ensuring this is age appropriate).
- Use the word ‘died’ – saying ‘gone to sleep’ can leave children feeling scared & worried the same thing will happen to them.
- Why?  Body has stopped working.
- Children need to see others grieving – it gives them permission to be upset too.
- Include children in saying goodbye – they may want to be involved in the funeral planning and to attend the funeral.  It should be their choice, ensuring they are fully prepared.
- Reassure they are not to blame.
- Puddle jumping.
- Memory boxes and bags for siblings.

# Our Own Feelings

- Being alongside someone experiencing loss can be emotionally draining and it can be hard if it brings up personal experiences – the need for support is perfectly normal.
- Prepare to be emotionally affected.  It is normal to feel overwhelmed, drained or exhausted.
- We need to acknowledge to ourselves and our own supporters how we're feeling – our own losses may resurface, and it may be that we do not currently have the emotional capacity to support someone.  It is important to know our own limits.
- Equally we don't need to be a bereavement specialist to help a child who has been bereaved.  The key person with a relationship with the family can help them to feel listened to.
- It is important to share feelings. Talk to friends/colleagues and share experiences.
- Anticipate where you may experience an emotional reaction.
- It is important that we listen to ourselves.


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# Any questions?