NCMD
National Child Mortality Database

Guidelines for determining modifiability in CDRM and CDOP reviews

Version 1

Contents

Acknowledgements:

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- Dr James Fraser, Chair, NCMD Professional Advisory Group
- Association of child death review professionals CDOP Chairs Sub-group
- Association of child death review professionals Public Health Sub-group
- Child death overview panel administrators, co-ordinators and managers

Purpose:

There continues to be variability in how CDOPs decide if certain factors are modifiable or not. The purpose of this document is to provide a set of guiding principles which CDRMs and CDOPs can use to determine whether any factor is modifiable or not during their review.

Background:

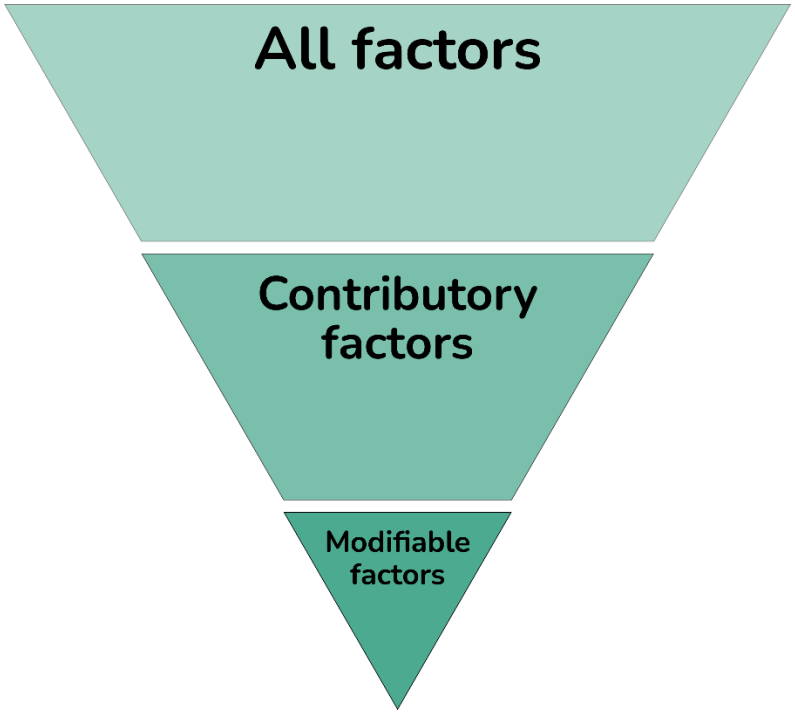
The purpose of the CDR / CDOP process is to identify learning that can inform actions to help reduce child deaths. The analysis form requires that all contributory factors in a child's death are scored 0-2 based on the extent to which they may have contributed.

- A score 0 indicates that information is not available.
- A score 1 indicates that factors identified but unlikely to contribute to death.
- A score 2 indicates that a factor was identified that may have contributed to vulnerability, ill-health or death.

In addition to scoring individual factors, professionals at CDRMs and CDOPs are required to identify whether they have identified one or more factors across any domain[1] which **may** have contributed to the death of the child **and** which **might**, be modified by any action to reduce the risk of future child deaths either at a local, regional or national level. These are called modifiable factors. See also Figure 1. While factors scored 1 may generate useful discussion regarding local system improvements, CDRM and CDOP chairs should focus on those factors scored 2 that are deemed to be modifiable. The analysis form provides a framework whereby system improvements may be recorded; for example, by, CDRM chairs at a local level and CDOP chairs at a local, regional or national level. Bereavement care or other post-death issues should **not** be recorded as modifiable, even though important learning may still be noted separately.

[1] Domain A: Factors intrinsic to the child
Domain B: Factors in the social environment including family and parenting capacity
Domain C: Factors in the physical environment
Domain D: Factors in service provision
For more information on how to classify and record factors, see NCMD guidance here

Figure 1: Relationship between different types of factors relating to child deaths



NCMD Model for determining modifiability:

NCMD developed the following model to help CDOPs determine whether a factor is modifiable.

Step 1: Ensure all factors are recorded and graded from 0-2 on the analysis form
Step 2: Concentrate on those factors that have been graded as a 2
Step 3: For each factor, ask if this factor were absent, might the outcome for future children in similar circumstances have been different? This question should be considered in terms of prevention of future deaths, rather than certainty about causation in the individual case.

Step 4: If the answer to Step 3 is Yes, reviews should be able to identify a realistic and achievable at any level action to reduce the risk of future child deaths.

In order for something to be modifiable CDOP must be able to answer Yes to Step 3 AND be able to identify an achievable action at any level (Step 4). Note: It does not have to be CDOP that carries out the action identified. If an achievable action cannot be identified, the factor is not modifiable. If the action identified is already in place, this should only be marked as modifiable if it wasn't in place or it wasn't appropriately commissioned or accessible at the time the child died. It is important to note that one of the statutory requirements in the Children Act 2004 Section 16M, is for child death review partners to inform an organisation where they feel action should be taken. Working Together to Safeguard Children 2026 states that CDOPs are the vehicle through which the child death review process is conducted on behalf of the CDR partners. Therefore, the responsibility to inform an organisation when action must be taken is within the remit of CDOPs.

Any action described should clearly identify the responsible agency. While responsibility for carrying out the action lies with the identified agency, the CDOP has responsibility for maintaining a record, such as an 'Action Log', that demonstrates evidential completion. Such records would be expected to be an integral part of CDOP reports. Any national actions described should be highlighted to NCMD for collation or escalation where appropriate. Where no action can be articulated, the factor should not be marked as modifiable, even if this is theoretically undesirable.

See Flowchart in Appendix A of this guidance for further information.

Consistency in determining modifiability:

Some variability in determining whether any individual factor is modifiable is to be expected given that the same modifiable factor may be relevant in one case and not in another and given the different populations that each CDOP covers. For example, while parental smoking may be modifiable, and relevant in the case of a child that dies of asthma, it would not be in a child that dies in a road traffic collision. Best practice might be that CDOPs consider periodically auditing their decisions on modifiability e.g. through regional peer review.

The following further set of principles are designed to assist CDOPs to judge whether an action might be recognised and achievable.

Is there:

- Existing Government legislation (e.g. driving and drug/alcohol consumption, or smoke alarms and public buildings)
- NICE guidance regarding evidence-based health and social care practice (often relevant in children who die from medical illness)
- Other relevant published evidence in highly citated journal (e.g. smoking and prematurity, high maternal BMI and pre-eclampsia)
- Other published best practice documents/ national standards/ service specifications (e.g. nurse: patient ratios in critical care, local authority standards around children in need)

Examples to help CDOPs think about what appropriate actions at different levels (contributory factor 2, deemed modifiable) might be

Local actions: Can be implemented by a single hospital, service, department or team e.g. staff training, updating team protocols and guidance, improving communication by staff

Regional actions: Involving co-ordination across multiple organisations or local areas (e.g. via ICS or ODN) e.g. commissioning of services, clinical network pathways, campaigns / awareness raising

National actions: Requiring a change in policy, legislation or action from a national body (e.g. NHS England, DHSC) e.g. improving national guidelines, public health campaigns or regulatory action

Factors Intrinsic to the Child			
Factor	**Local Action**	**Regional Action**	**National Action**
Smoking in pregnancy impacting on low birth weight/ extreme prematurity	• Easy to access smoking cessation service, including consideration of language and accessibility needs	• CDOP to ask OHID to scrutinise opt out and quit rates for pregnant smokers	• Implementation of national financial incentive scheme for pregnant smokers

High maternal BMI along with gestational diabetes (macrosomia, perinatal asphyxia, hypoglycaemia)	• Preconception care - include risks of obesity in pregnancy as part of tier 2 work • Work with communities at higher risk including through community champions to raise awareness of risks • Local authority/Public Health team commissioning weight management services for pregnancy and/or gestational diabetes weight nutrition programmes. • Ensure Teenage Pregnancy Prevention Framework is in use. This provides evidence -based guidance for local authorities, including the important role of RSHE and links to local sexual health services.	• Consider commissioning and equipment requirements for extreme obesity • Consider regional units or specialist input options • Consider the Department of Health and Social Care's Framework for Sexual Health Improvement in England which supports the prevention of early, unplanned pregnancy.	• Ensure preconception care is included in RHSE in schools, to also cover alcohol, smoking, folate, nutrition as well as risks of obesity as required in current guidance • Midwifery training around monitoring requirements and overcoming challenges of extreme obesity in monitoring and scanning e.g. via NHS England Workforce Training & Education
Drowning	• Work with schools to encourage training in swimming and recovery /water safety e.g. via RLSS-UK resources	• Recommend safety improvements to regional waterway associations e.g. Canal & River Trust	• Swimming lessons to be mandated as part of the national curriculum • Regular evidence-based messaging about safety in the home and safe swimming.

	• Enhanced work with minority communities who may not access water • Include water safety messaging with health visiting and children's centres and hubs and post-natal wards.		• Regulation about bath seats and messaging about harm. • Stronger national guidance and expectations about life saving equipment (life buoy rings) around reservoirs and other open water.
Factors in the social environment			
Factor	**Local action**	**Regional action**	**National action**
Poverty / deprivation	• Work with marginalised community groups and hospitals to improve health literacy and access, and decrease discrimination and perception of discrimination	• Promote schemes such as Healthy Start to improve uptake within region Get help to buy food and milk (Healthy Start)	• Increase child benefit • Expand free school meals • Increase child maintenance payments for lone parents • Raise the minimum wage
Advice given, not followed[2]	• Check / confirm that relevant local service provision is appropriately commissioned / delivered		• NCMD thematic analysis to identify whether further research is needed on what drives people's choices
Factors in the physical environment			
Factor	**Local actions**	**Regional actions**	**National actions**
Choking on food	• Awareness raising for families to cut grapes / sausages length wise	• Regional health promotion of safe eating and weaning guidance from regional Public Health team or ICB (e.g. Best Start in Life health advice - NHS)	• Production of national assets to be used in local campaigns by charities or other relevant organisations

[2] This would be in an instance where CDOP is certain that the service is commissioned appropriately and has been offered in a way that supports uptake of the service.

Unsafe sleeping environment in sudden unexplained deaths in infancy	• Use of baby sleep planning app by local professionals • Ensure fathers/primary care givers and extended family members inclusion and active awareness raising if involved in supporting a new mother. • Staff audit of local health visiting service on provision of safe sleep guidance, could use tool like UNICEF BFI standards	• Regional health promotion of safe sleeping guidance from The Lullaby Trust	• Legislation to outlaw smoking in homes with children under 18 (similar to current law in vehicles)
Broken window on upper floor / block of flats leading to a fall from height	• Landlords (including local authority and housing associations) to prioritise fixing windows when reported by residents with young children. • Use Child Accident Prevention Trust resources including posters and leaflets to raise awareness among tenants of how to keep young children safe from falls. These are available in a number of different languages		• National campaign to include window restrictors within the Decent Home Standards requirements • Regulation to require broken windows in rented properties to be fixed within a mandated timeframe if young children live within the property

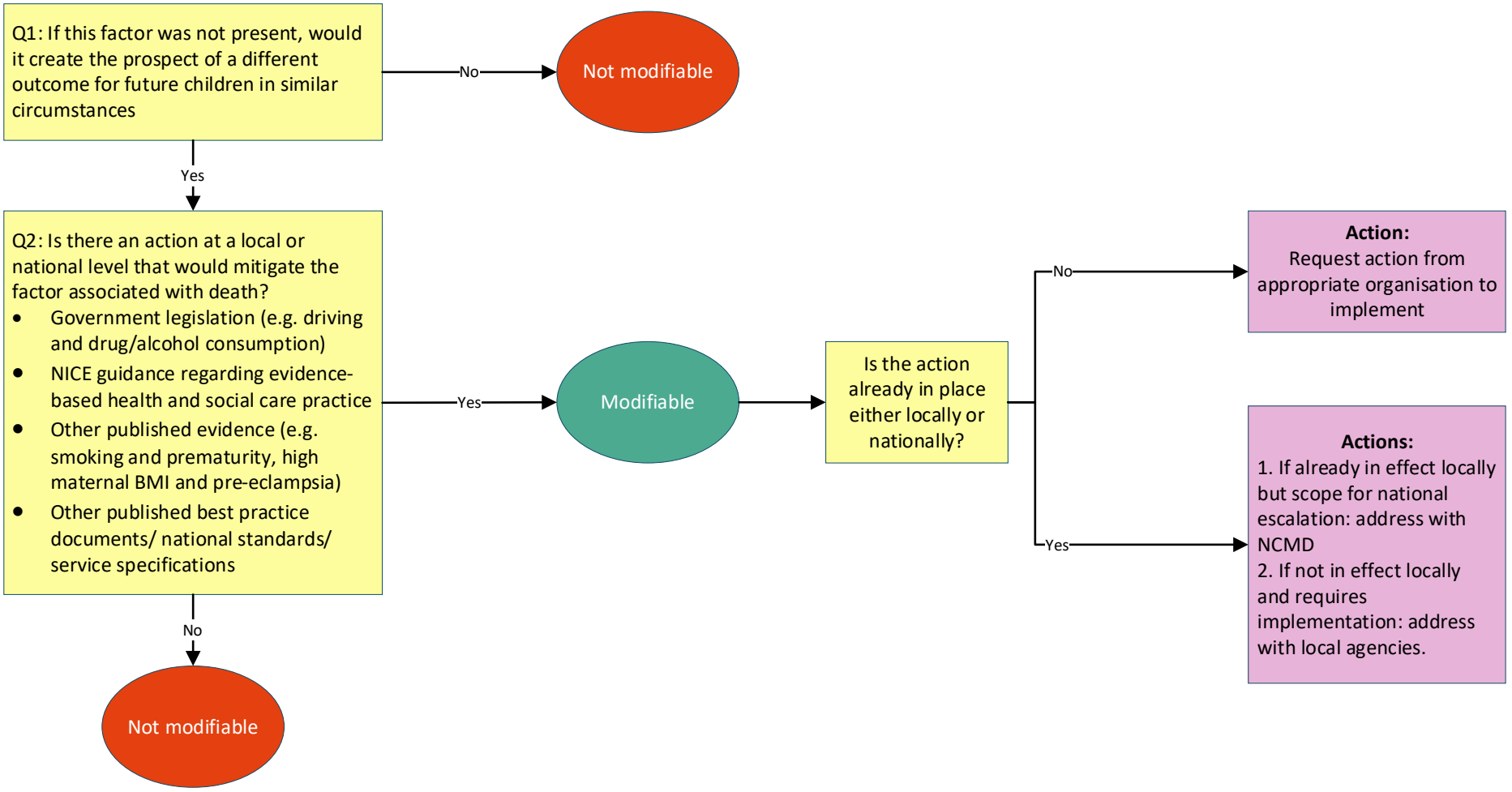
Factors in service provision			
Factor	**Local actions**	**Regional actions**	**National actions**
Delay in giving antibiotics	• Work with Urgent Treatment Centres to include N-EWS and P-EWS or similar evidence-based assessment tools • Training for GPs and other primary health professionals in recognition of sepsis • Encourage acute trusts to provide guidance for parents and carers	Adherence to NICE Sepsis guidance	
Delay in transport to tertiary centre in child with traumatic head injury	• Checks on prioritisation processes by providers. • Clarify local pathways and expected time scales.	• ODN level action (neurotrauma/ Transport service)- review of guidance around time-sensitive transfers • Ensure local and regional commissioning is fit for purpose and meets need or is flagged as a risk.	
Access to genetic counselling services for consanguineous families	• Ensure that a process is in place for families to receive a culturally competent, informed referral to genetic services • Seek assurance that families are appropriately referred when risks are identified. e.g. where there	• Ensure families referred to genetic services have access to high-quality, culturally sensitive, non-directive and non-stigmatising counselling, with clear information on genetic risks and reproductive options to support informed decision-making	

	is a recessive condition in a consanguineous family		

Appendix A

The following flowchart is for use after all factors have been identified and scored from 0-2. It should be used for factors that have been scored as a 2.

Flow chart for considering modifiability in CDRM/CDOP reviews for factors graded as 2



Appendix B – Glossary of Terms

Acronym	Definition
BMI	Body mass index
CDOP	Child death overview panel
CDR	Child death review
CDRM	Child death review meeting
DHSC	Department of health & social care
ETOH	Medical abbreviation for alcohol
ICB	Integrated care board
ICS	Integrated care system
NCMD	National child mortality database
N-EWS	Neonatal early warning score
NHSE	NHS England
NICE	National institute for health and care excellence
ODN	Operational delivery network
OHID	Office for health improvement and disparities
P-EWS	Paediatric early warning score
RHSE	Relationships, sex and health education
RLSS-UK	Royal lifesaving society UK
UNICEF BFI standards	United nation’s children’s fund baby friendly initiative standards