Rotherham Safeguarding Children Board

Rotherham Child Death Overview Panel

Annual Report 2018-2019

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Introduction

Child death reviews

The death of a child is a devastating loss with profound impacts on any and all involved in caring for the child in any capacity. Families in such circumstances deserve empathy and compassion and clear and sensitive communication. They also need to understand what happened to their child and know that people will learn from what happened.

The process of expertly reviewing all children's deaths is grounded in deep respect for the rights of children and their families, with the intention of preventing future child deaths. In view of this, in England every child death must have a review carried out regardless of the cause of death. A child is deemed to have been live-born when any sign of life is noted following birth, which can include a movement, breath, cry or heartbeat (as clarified by the Chief Coroner, following a challenge by Kingston's Child Death Overview Panel).

Child Death Overview Panels

The Child Death Overview Panel (CDOP) is a multi-agency panel with a specific geographical footprint, which reviews the death of any child aged from 0-18 years who is normally resident within that area, irrespective of where the child died.

CDOPs were established in England on 1st April 2008, since when all child deaths have been reviewed by such panels, which comprise representatives from a range of organisations and professional disciplines, both within and outside healthcare.

CDOPs are required to review child deaths in order to identify whether there is any learning that could influence better outcomes for children at both a local and national level. CDOPs promote the sharing of information and learning to all organisations, in both the statutory and voluntary sector, about how to reduce the likelihood and impact of modifiable risks which might lead to the death of a child.

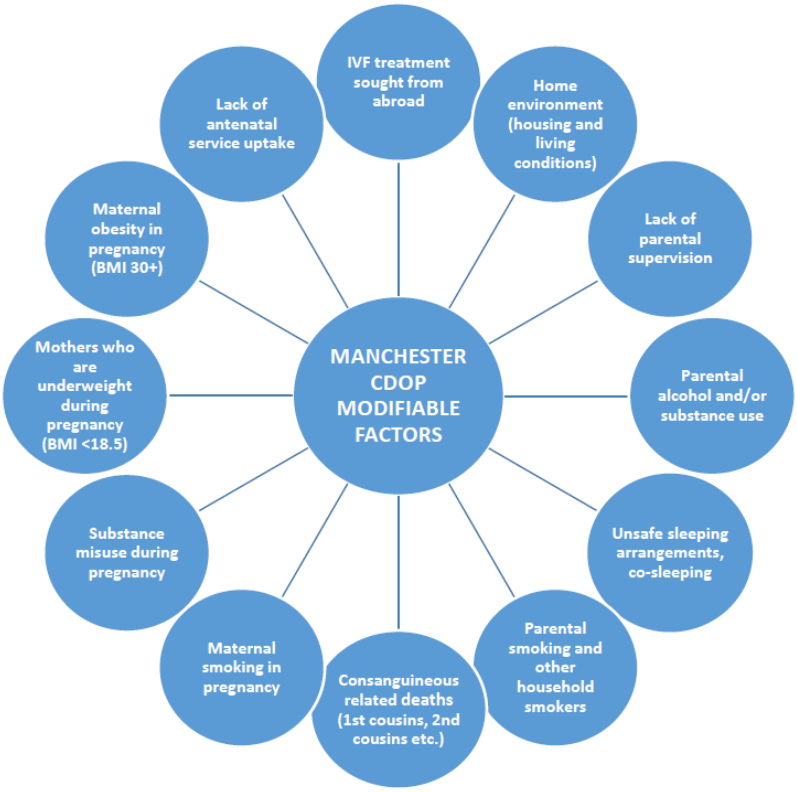
Modifiable factors

In reviewing the death of each child, the CDOP should consider modifiable factors in relation to the individual child, the environment, parenting capacity or service provision, and consider what action, if any, could be taken locally and what action could be taken at a regional or national level.

According to The Lancet, modifiable factors can be identified in 20% of child deaths nationally (Dr Sidebotham, Fraser, Fleming, Ward-Platt, & Hain, 2014). These can include factors in service delivery, factors relating to parental behaviour, including maternal smoking in pregnancy, maternal obesity in pregnancy, and smoking within the household, and factors relating to parenting skills and levels of care, including unsafe sleeping practices. As all cases are unique, there is no definitive list of modifiable factors.

However, the four CDOP panels within the Greater Manchester CDOP network have taken the step of developing a standard for identifying particular modifiable factors in relation to different categories of death, in order that there is a locally consistent approach. It remains to be seen whether the implementation of the new national child mortality database might lead to a more general standardisation of modifiable factors. In the meantime, this could be something for the four South Yorkshire CDOPs to consider as they begin to work to respond to sub-regional trends in child deaths.

The Manchester CDOP report for 2017-18 also includes a helpful graphic, summarising all modifiable factors identified by their reviews of children of all ages.



Modifiable factors identified in Manchester CDOP Annual Report 2017-2018 (page 9). Reproduced with kind permission of Manchester Child Death Overview Panel.

The Rotherham panel

Rotherham's CDOP panel meetings are generally half-day meetings, with representation from a range of agencies, including the local authority's Public Health team, Children's social care, The Rotherham NHS Foundation Trust (designated doctor and nursing and midwifery representatives), Rotherham Doncaster and South Humber NHS Foundation Trust, the Rotherham Clinical Commissioning Group, Bluebell Children's Hospice, and South Yorkshire Police. The main business of the meetings is to present and review child deaths for which sufficient data has been collated from relevant agencies. The meetings also follow up agreed actions from previous meetings, and discuss other related business as it arises.

CDOPs as an arm of prevention

The multi-agency viewpoint that CDOPs adopt means they aim to influence a range of factors within health services, within the home, the school, the local environment, and in relation to parenting capacity and early childhood experiences. In other words, they have an important role to play to reduce risks and improve protective factors within the wider system. This means that the principal objective of reducing infant mortality should not be the only benefit from the efforts of CDOPs. There should also be a wider positive health and wellbeing impact for our children.

The work of the CDOP should be seen alongside a very welcome shift within the policy context for our health services towards preventing ill-health and tackling health inequalities, in preference to simply treating. The NHS Long Term Plan is the latest expression of this shift, which acknowledges that "the health of children and young people is determined by far more than healthcare" and that "income, education, housing, stable and loving family life and a healthy environment all significantly influence young people's health and life chances" (paragraph 3.6), but which nevertheless sets out to use the resources of the NHS to "accelerate action to achieve 50% reductions in stillbirth, maternal mortality, neonatal mortality and serious brain injury by 2025" (paragraph 3.9).

The NHS Long Term Plan contains much to be welcomed in respect of intended improvements in maternity and neonatal care, and the expansion of community based mental health services for children and young people. However, although making a fleeting reference to "the cross-government ambition for women and children focusing on the first 1001 critical days of a child's life" (paragraph 3.16), this is one area in which the long term plan is disappointingly light. The first 1001 days (from conception to age 2) can set the pattern for the rest of a person's life and therefore represent our best opportunity to prevent health inequalities. Furthermore, it is a period of crucial interest to CDOPs – 26% of babies in the UK are estimated to be living in complex family situations, and babies in England are said to be seven times more likely to be killed than older children (Building Great Britons. All Party Parliamentary Group for Conception to Age 2).

Work done by or on behalf of Rotherham CDOP this year

Some key strands of work are highlighted below, ranging from work done by the panel itself and its administrative support function to make direct quality improvements to the panel's processes for collating and presenting information, to work done in partner agencies and services on behalf of CDOP, which should lead to a reduction in risk and an improvement in the prospects of Rotherham children.

New guidance for child death reviews

The recent national review of 'Working Together' guidance for safeguarding arrangements has meant that much of the work by Rotherham's CDOP members outside of its core business of reviewing cases has been to prepare for the implementation of these new arrangements (the main changes to guidance are outlined later in this report).

A Rapid Response Task and Finish Group has been established, which has met three times since March 2018. Its purpose is to consider the expected impacts of the new guidance on aspects of the child death review process, including: child death notifications; the process for rapid response to unexpected child deaths; and how bereavement support is provided to families. Some of the changes are also being progressed at a sub-regional level, through joint work by the four South Yorkshire CDOP panels.

With respect to the changes to child death notification, partly to prepare for the launch of the new National Child Mortality Database (NCMD) in April 2019, all four South Yorkshire CDOPs decided to move to the use of the eCDOP system. Not only will this enable automatic data transfer to the NCMD, but it should also result in better data quality, security and ability to draw out trends both locally and sub-regionally.

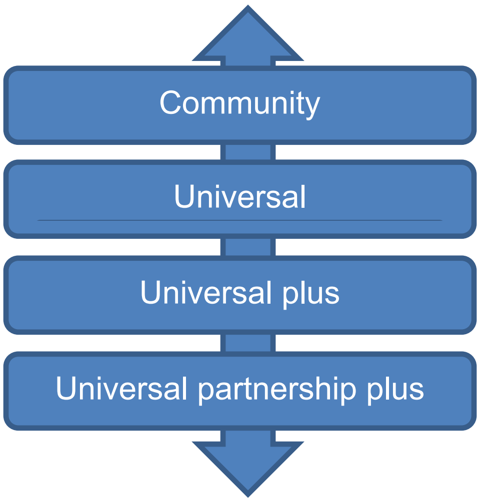
Local quality improvements

Amongst the many learning points that emerged during the year, the need for better communication both within and between agencies was clearly identified. This includes the issue of the quality of the written reports within the wider child death review process, some of which were thought to be overly descriptive in nature.

Training has continued to be offered to a range of professionals (since it commenced in April 2017), with a focus on improving the quality of CDOP processes, and information collation and submission. There is evidence that this has led to an improvement in the quality of information received by the panel.

Healthy Child Programme Pathways

Following a particular issue identified by CDOP in relation to an individual case who appeared not to be receiving the appropriate level of intervention from the 0-19s service, an assurance process has been instigated in the service. Improved service quality in this respect is now assured by the 0-19s service, through a quarterly review of caseloads to ensure that children and young people are assigned the correct pathway commensurate with their level of need. The pathways range between community, universal, universal plus and universal partnership plus.



Range of community services for children

Healthy Child Programme delivered to give every child best start in life

Timely additional support provided for a specific issue or need

Ongoing support for more complex needs

Safer Sleeping

During 2018 – 19, CDOP further embedded the Safe Sleep guidance, which was originally developed in partnership with TRFT, led by Public Health. This was adopted by the Learning and Improvement Sub Group of the Rotherham Local Safeguarding Children Board (RLSCB) in 2017-18. The guidance was added to the RLSCB procedures portal in June 2017, which professionals have access to. Its purpose is to:

- Provide the multi-disciplinary workforce in Rotherham with clear and consistent evidence-based information;
- Provide workers with the confidence and knowledge to facilitate an open and honest discussion to support baby's carers to make informed safer sleeping choices for their babies;
- Ensure consistent advice about safer sleeping arrangements is given across Rotherham by all workers.

Each agency is responsible for reviewing the guidelines and embedding it as part of their own processes and protocols, in a way that is meaningful to staff.

Safe sleep audits

Progress is being measured through regular audit. An audit in 2017 revealed that the use of the safe sleep questionnaire included on SystmOne had successfully been embedded within midwifery, but not yet within the 0-19s service. In the most recent audits, midwifery and 0-19s have reported separately.

The maternity safe sleep audit from January 2019 showed 100% compliance – i.e. every new born baby in Rotherham had an initial safe sleep assessment performed by community midwifery.

A similar audit of SystmOne records carried out in the 0-19s service for the month of January 2019 showed 140 safe sleep assessments carried out by the 0-19s service, representing 72% of new births. Whilst this shows an ongoing need for improvement, this already represents a very large improvement on the previous year, when only 24% of new births had a safe sleep assessment. The audits did not simply look at quantity considerations, but also looked for identification of risk factors arising from safe sleep assessments and whether these had been appropriately escalated and followed up.

Dip sampling of child health records is being conducted at intervals in order not to lose a focus on maintaining and improving performance, in the interests of making sure all Rotherham children have the best start.

Ongoing care

There is now an increased and increasing level of understanding across all services to support families that safe sleeping is an ongoing concern throughout a child's early life, especially the first twelve months. A single assessment or advice pack cannot be sufficient to be assured that safe sleep practices continue.

This continuum starts in the hospital, before the pre-discharge assessments and the discharge information package issued to new parents. Any unsafe sleeping practices identified prior to discharge from the hospital and the community midwifery service will lead to an intervention to rectify the issue, to give advice to families and to ensure that information is handed on to the 0-19s service for follow-up in the community, including for the first safe sleep assessment carried out in the family home.

Multi-agency training

The responsibility for being alert to unsafe sleeping should lie with all frontline staff (including non-healthcare staff) who engage with families, and training is now being rolled out for this purpose. Two training sessions were first delivered in March 2019, with a further two to be delivered in September. It is anticipated that this pattern of two training days per year (four sessions) will then continue on an annual basis. The training is advertised via the Safeguarding Board's prospectus for multi-agency training, and is therefore open to anyone who accesses that facility. The first training sessions evaluated very well.

Safer Sleep Champions

Momentum for the importance of safe sleep is also maintained through identifying safe sleep champions across related services, and the model appears to be growing. There is now a safer sleep champion for each of the 0-19s area teams; and there are three safer sleep champions in midwifery; two within the hospital; safer sleep champions are being recruited within Early Help; and enquiries have recently also been received for establishing two champions within childminding.

Smoking in pregnancy

One of the biggest risk factors for sudden infant death syndrome (SIDS) is smoking. This risk arises not just from smoking within the household where an infant is sleeping, but arises as a result of smoking during pregnancy. Smoking during pregnancy also increases the risk of complications such as miscarriage, premature birth, a low birth weight baby and stillbirth, and is therefore a key modifiable factor concern for CDOP.

Smoking at time of delivery

Rotherham has a high proportion of mothers who are smokers at the time of delivery – 19.9% in 2017/18 – the highest of the South Yorkshire local authority areas and considerably worse than the England position - 10.8% in 2017/18 *(Proportions calculated by PHE from the NHS Digital return on Smoking Status At Time of delivery, for Public Health Outcomes Framework indicator 2.03).*

The Rotherham Stop Smoking Service has a specialist service for women and their families comprising specially trained Midwives and Stop Smoking personnel. All women are offered carbon monoxide monitoring at every appointment. The service has a 100% target for CO monitoring at booking, and is currently achieving well above 80%. Pregnant women who are smokers are immediately referred for smoking cessation support – this is provided as an opt-out service, and women will always be advised of the risks of smoking in pregnancy even if they do wish to opt out of the service. The service provides ‘one to one’ appointments including at outreach locations, offering support throughout pregnancy and after the birth.

The team has an aim to reduce the percentage of women smoking at time of delivery by 0.5% by 2020, and they successfully achieved a 0.5% reduction for 2018/19.

This work is now being overseen by the Better Births Group – a multi-agency group including representation from the CCG, Public Health, the Local Maternity System, the Maternity Voices Partnership, clinicians and others. The group meets on a monthly basis to progress action against its action plan. Some examples of related ongoing and planned activities are given below.

1. Capacity for achieving the smoking at time of delivery targets has been increased through a one-year secondment into the team of a Band 6 midwife.

2. In order to help engage harder to reach mothers in the service, the team has secured funding to procure two placenta demonstration models to assist the smoking cessation midwives in better communicating risk and impact of smoking in pregnancy.
3. Funding has also been secured for a future money box incentive scheme.
4. A YouTube video to promote the service is planned, and a script has been devised for this purpose.
5. The Maternity Voices Partnership has engaged supportively with the service, and has carried out an audit.
6. Invoicing for the nicotine replacement therapy (NRT) voucher scheme for community pharmacies has been improved by deploying the PharmOutcomes system for this purpose since the beginning of January 2019.
7. The standard operating procedure for the NRT voucher has been reviewed and made electronically available.
8. A flowchart for prescribing NRT for inpatients has been developed and distributed to clinical areas.
9. A service level agreement (SLA) for community pharmacies has been implemented, which includes the Patient Group Directions (PGD) protocol for dispensing treatments, as of April 2019.
10. Smoking in pregnancy team leaders have been upskilled to lead Very Brief Advice (VBA) training. A number of staff have now received VBA training and have given very positive evaluation feedback.

Child safety

CDOP has had specific cause for concern in respect of choking hazards for babies and infants, and planned to use Child Safety Awareness week (June 2019) as an opportunity to raise parental awareness of this. The Paediatric Liaison Service worked in conjunction with the 0-19 service and with hospital departments (Urgent and Emergency Care Centre and the children's ward) to set up a public stand in the hospital foyer, displaying resources from the Child Accident and Prevention Trust (CAPT) and the Royal Society for the Prevention of Accidents (RoSPA) .There was a particular focus on small babies choking on small things, with the message "put them out of my sight and reach".

For children's safety awareness, Rotherham benefits from the unique facility of the Lifewise Centre, which uses film-set style realistic scenarios to provide safety training to Year 6 pupils in Rotherham and across the whole of South Yorkshire.

Consanguinity

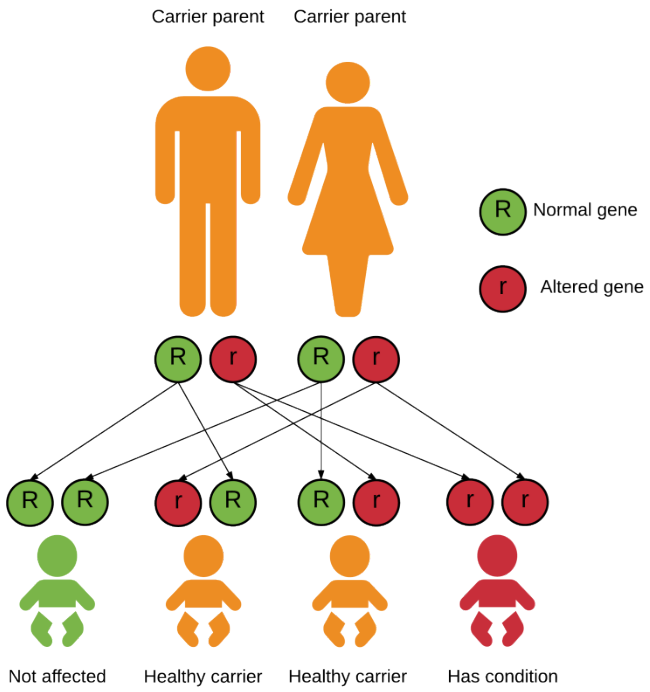
The Panel highlighted a concern with respect to the increased risk arising of genetic conditions associated with marriage between cousins. This is considered in greater depth in the following chapter. CDOP has arranged for a workshop to explore this issue to take place as part of the Safeguarding Awareness Week events in July 2019.

Consanguinity (or close relative marriage)

Consanguinity refers to a relationship in which the couple share a close common ancestor - in general, where the couple are related as second cousins or closer. In fact, where consanguineous marriage is customary it is most often between first cousins, i.e. where the couple shares a set of grandparents. It is a matter of concern to CDOP because marrying a close relative increases the likelihood that partners will share a genetic mutation, and thereby increase the risk of giving birth to children with rare but life-threatening genetic diseases.

Consanguinity is a customary practice in many parts of the world – around 1 billion people live in countries where it is common, and at least 8.5% of children globally are estimated to have consanguineous parents. Within regions of the UK, the prevalence of consanguinity varies according to the prevalence of certain minority ethnic groups, including those originating from Pakistan, Bangladesh and the Middle East, as well as some groups with an Indian heritage and some Irish Travellers. Consanguinity in the UK is most prevalent amongst the British Pakistani community, where 55% of marriages are estimated to be consanguineous. Where such populations are very substantial, such as in Bradford, for example, the impact on rates of congenital anomalies is detectable – the Born in Bradford study found that consanguineous marriages accounted for nearly a third of abnormalities amongst 11,300 babies.

Rotherham's demographic profile means that the effect at a population level is likely to be much less evident than in Bradford, but at the level of each consanguineous couple, the risk for each of their children is likely to be the same. In fact, the level of risk is not dissimilar to that of babies born to older women, and our approach to the problem ought to follow a similar pattern – raising awareness of risks, and of testing available to enable an informed choice.



In effect, when both parents carry the same recessive gene, the risks for their offspring are always the same (irrespective of whether they are related): a 1 in 4 chance of being completely unaffected (receiving two normal copies of the gene) a 1 in 2 chance of being a healthy carrier (receiving one normal and one altered copy); a 1 in 4 chance of inheriting the genetic condition (receiving two altered copies of the gene).

In the general population, the chances of both parents being carriers of a particular gene are low. The chances are greater where the parents are cousins, known within the extended family.

The risk of a birth defect occurring amongst the general population is about 3%, but this doubles to about 6% amongst consanguineous couples. However, it is important to note that the absolute risk remains low, and the vast majority of babies born to couples who are blood relatives are unaffected.

Consanguinity in Rotherham

Estimating the number of consanguineous couples living in Rotherham is not straightforward. In general, rates are higher among non-White groups, and highest amongst the Pakistani population. Rotherham's BME population is not particularly substantial for an urban area (about 8% of the overall population), but the largest group is the Pakistani community, which comprises about 3% of the Rotherham population. National modelled estimates (Bernadette Modell) produced for the old PCT areas, using 2010 population estimates, suggest there might be in the region of 200 new consanguineous couples per year in Rotherham. Such estimates are likely to have very wide margins of error, but may be broadly indicative. For comparison purposes, the same model suggests that the former Bradford and Airedale PCT would have around 1600 new consanguineous couples annually.

Consanguinity and child deaths

There are a great number of autosomal recessive conditions, and many will have a severe effect on the life of a child, including resulting in life-limiting physical or intellectual impairment, and some are effectively incompatible with life or may ultimately result in death in early or late childhood.

Rotherham's CDOP always attempts to record the consanguinity status of parents for each child death it reviews. From the records of 193 cases considered by the panel, consanguinity is recorded on ten occasions.

The fact that consanguinity is present is not itself evidence that it was a material factor in the child death – five of the ten cases where consanguinity is definitely recorded also have chromosomal, genetic and congenital anomalies as the category of cause of death, which would be consistent with a recessive condition as the primary cause. However, only one of these cases has been identified by the panel as having a modifiable cause of death, one other death is also recorded as modifiable, but in this case the cause of death was malignancy, which seems unlikely to be related to consanguinity.

The number of child deaths coming to panel that might be related to a recessive condition associated with consanguineous parents seems encouragingly low. A maximum of 10 out of 193 cases is just over 5%, whereas the modelled data referred to above (Bernadette Modell) predicts an increase in under-5 mortality in Rotherham of close to 18%.

Addressing the issue – a family-centred approach

The World Health Organisation has acknowledged that attempts to discourage the practice of consanguineous marriage at the population level are “undesirable and inappropriate”, and has instead advocated a family-centred approach, based on identifying those families at risk and enabling properly informed choice, backed up by supportive services.

For CDOP the extent to which a death can be seen as modifiable is therefore likely to relate to the perceived level of informed choice that is at the disposal of the local population. Informed choice is likely to include a good understanding of genetic risk associated with close relative marriage, information within extended families and kinship groups relating to risk of specific conditions within that family group, provision of informed and supportive information from healthcare workers, and access to genetic testing (including carrier testing and prenatal testing) and advice from specialist genetics services.

Recommendations for further action

Rotherham CDOP has contacted Sarah Salway, Professor of Public Health at the University of Sheffield. Sarah has undertaken research and service development relating to consanguinity at both local and national levels over the past 8 years, and currently co-chairs the national steering group on Close Relative Marriage and Genetic Risk (with Naz Khan, Manchester Genomics Centre).

As the next step for this work, Professor Sarah Salway has agreed to facilitate a workshop in Rotherham on close relative marriage and genetic risk as part of Rotherham’s Safeguarding Awareness Week (July 2019). She will be joined for this purpose by Saima Ahmed, who works as a community outreach worker for this topic providing genetic literacy input to neighbourhoods in Sheffield, and also Julia Thompson, from Sheffield City Council’s Children and Young People’s Public Health Team.

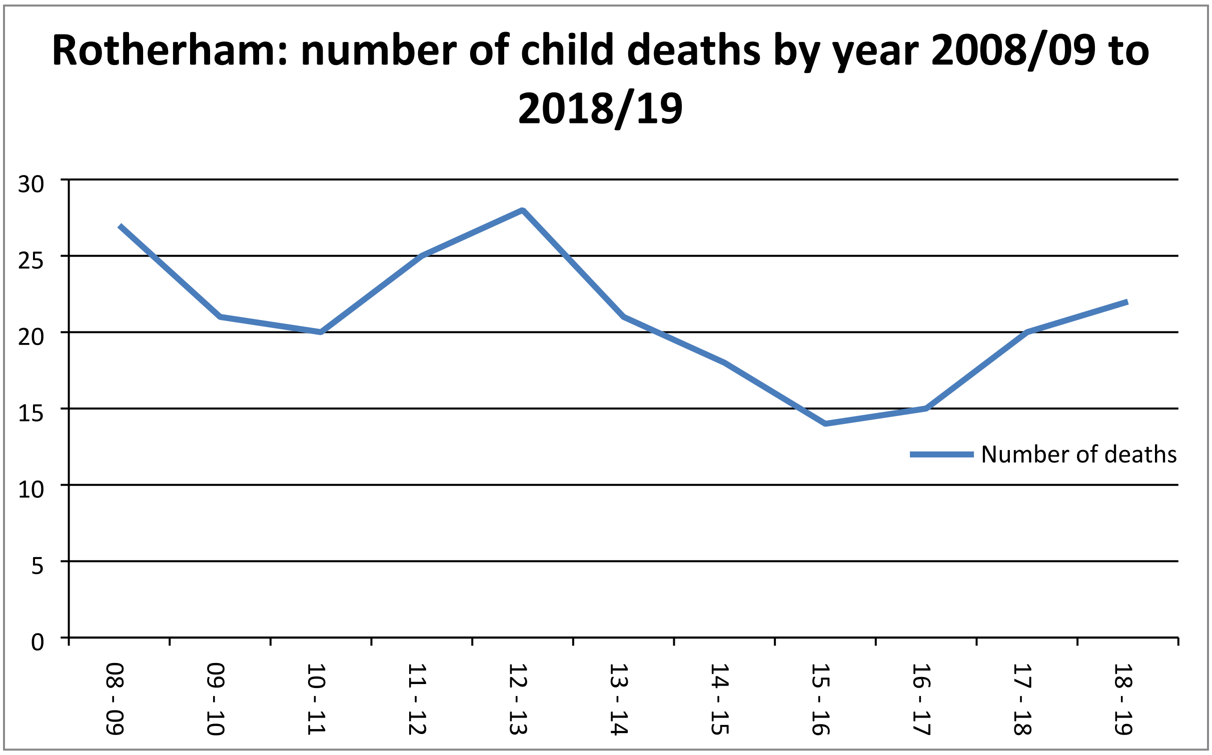
Sarah Salway is keen to develop some standards for sustainable approaches locally that avoid some of the short-lived interventions of the past, and help to engender a culture of informed choice. In addition, she has shared some resources with Rotherham, developed by Sheffield, which Rotherham CDOP may wish to adapt for use in Rotherham. They include public information leaflets and a YouTube video and associated guide developed for training purposes.

Evaluation feedback from the workshop will be discussed at a future meeting of CDOP, along with the potential use of these resources, and opportunities for taking the work forward within Rotherham, and potentially at a South Yorkshire level, by means of a themed sub-regional panel discussion, for example.

Child death data analysis.

Number of deaths

The number of child deaths in Rotherham in 2018-19 was 22, which is similar to the average number of deaths in each panel year (April – March) since its inception in 2008, during which period there have been 231 deaths at an average of 21 per year. Whilst the number of deaths in an individual year has been as high as 28 in 2012-13 and as low as 14 in 2016-17, in general the annual variation seems to be explained by random variation, and there is no discernible trend in numbers of deaths.



A large proportion of child deaths occur in the neonatal period (the first 28 days of life). Of the 231 child deaths in Rotherham since CDOP began in 2008, 105 have been aged 28 days or less at death, of which 72 were perinatal deaths (i.e. they died in the first week of life). 52 non-neonatal deaths were within the first year of life; 18 were aged between 1 and 5 years; 56 were aged 5 and over.

A large proportion of child deaths occurred to children with postcodes within the most deprived lower super output areas (LSOAs). 44% of 223 matched postcodes were within the most deprived quintile of LSOAs in England. Just under a third of the general Rotherham population live within such deprived locations, so 44% of child deaths looks like a large proportion, suggesting that living in high levels of deprivation in Rotherham confers a greater risk of infant mortality. This is an example of health inequality that has been observed more generally across the UK (Weightman, Morgan, Shepherd, Kitcher, Roberts, & Dunstan, 2012)

Deaths reviewed by the Panel

Child Death Reviews 2018-19

During 2018-19 CDOP met on two occasions, with a total of 10 deaths being reviewed to completion (other cases came to panel, but with actions or information still outstanding at the end of the year).

CDOP would normally expect to meet more frequently than this, but sets the number of meetings to match the number of cases in the pipeline that are ready to come to panel (i.e. there is sufficient information for a well-informed review and there are no essential outstanding items).

Reviews since 2008

Over the life of the panel, on average about 18 cases are reviewed per year. Since 2008, the Panel has reviewed a total of 194 cases, with each case taking an average of just over 12 months to come to panel. This should be considered alongside the new guidance for child death reviews, which, whilst not stipulating a required review timeframe, does envisage the majority of cases being reviewed by CDOP within six weeks of receiving the report from the child death review meeting, which itself should ideally happen within three months of a child death occurring.

Modifiability

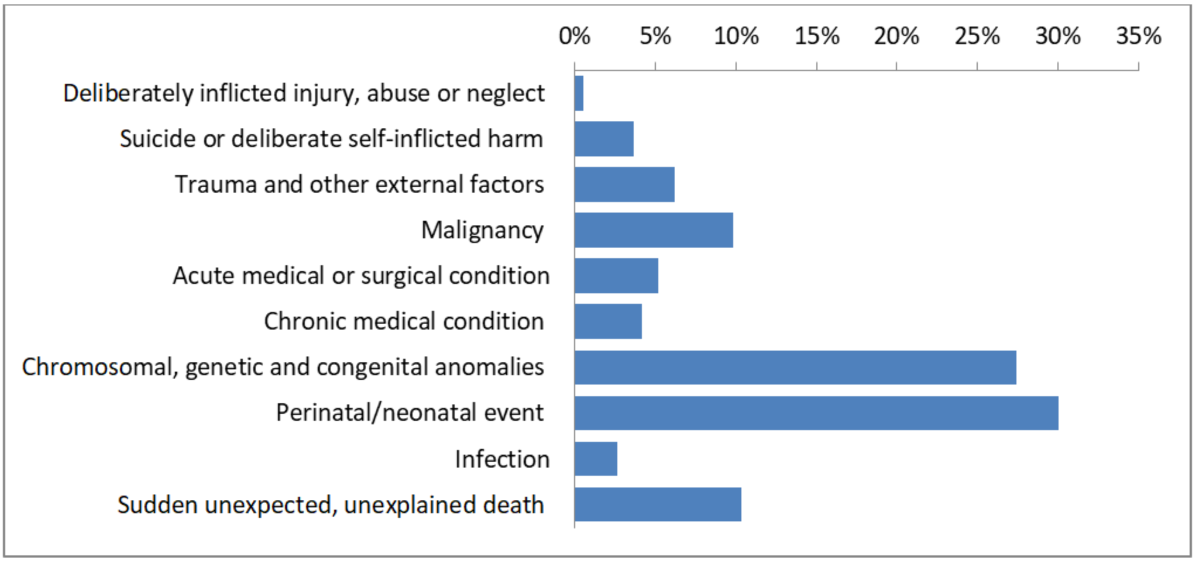
Of the ten cases reviewed during the year 2018-19, two were regarded by the panel as being modifiable - i.e. there were factors that may have contributed to the death or increased the risk of death, which could potentially have been altered in a way that might have reduced the risk or even led to a different outcome.

It is rarely straightforward for the panel to make a decision about modifiability, and there is some variability evident over the years in the propensity to view a death as modifiable. Over the life of the panel, out of 194 cases reviewed, 35 were regarded as modifiable deaths by the panel. The proportions for each year are shown below.

Year	Number of cases reviewed	Number regarded as modifiable	Porportion modifiable
08 - 09	12	4	33%
09 - 10	21	3	14%
10 - 11	21	7	33%
11 - 12	18	2	11%
12 - 13	22	4	18%
13 - 14	19	1	5%
14 - 15	29	2	7%
15 - 16	7	1	14%
16 - 17	24	8	33%
17 - 18	11	1	9%
18 - 19	10	2	20%
Grand Total	**194**	**35**	**18%**

Category of death

The panel assigns a category to each death that it thinks most usefully summarises the main cause. There are ten such categories, with “chromosomal, genetic and congenital anomalies” and “perinatal/neonatal event” being the most frequently chosen. The categories are shown below, along with the proportions assigned by the panel over its eleven years of reviewing cases:



Other summary tables

Tables below summarise all cases reviewed since 2008 by age range, expected vs unexpected death, ethnicity and gender.

Age range	Expected	Unexpected	Total
<28 days	76	10	86
28-364 days	23	22	45
1-4 yrs	<5	8	12
5-9 yrs	8	<5	12
10-14 yrs	11	5	16
15-17 yrs	<5	19	23
Grand total	**126**	**68**	**194**

Ethnic group	Female	Male	Total
Asian/Asian British	13	7	20
Black / African / Caribbean / Black British	<5	<5	<5
Mixed / Multiple ethnic groups	<5	<5	6
Other or Not known	8	13	21
White British	54	83	137
White Other	<5	<5	8
Grand total	**83**	**111**	**194**

Changes to national guidance for Child Death Reviews

Background to child death reviews

The Children Act 2004 introduced a requirement for local authorities in England to review the death of every child residing in their area, to determine whether there were any modifiable factors that could lead to system improvements. Local Child Death Review partners were established to take ownership of the process, who in turn established local Child Death Overview Panels (CDOPs) that were charged with the role of investigating the circumstances and contexts for the death of every child in their region. From 1 April 2008 child death review (CDR) processes were made mandatory for Local Safeguarding Children Boards in England for all child deaths up to the age of 18 years.

As arrangements were agreed locally, the child death review processes have been variable across England. For example, there has been no minimum caseload requirement; large variation in governance arrangements; limited standardisation of administration and data collection; and varying levels of engagement outside the medical sphere with wider stakeholders to achieve a breadth of learning through the reviews.

Recent Changes

In 2016 Sir Alan Wood was appointed to undertake a fundamental review of Local Children Safeguarding Boards (LSCBs) including Serious Case Reviews (SCRs) and Child Death Overview Panels (CDOPs). Subsequently, the legal framework covering these areas has been amended by The Children and Social Work Act (2017), implementing his recommendations. Key recommendations of the review included the replacement of existing statutory arrangements for LSCBs with a new framework for multi-agency arrangements for child protection, and the discontinuation of SCRs in favour of new national and local arrangements.

With respect to CDOPs, Sir Alan was asked to identify what makes an effective Child Death Overview Panel and explore which body is best placed to review child deaths to ensure that CDOPs are managed and held to account effectively. His recommendations included moving the national sponsor from CDOPs from the Department for Education to the Department of Health, and considering how best to organise CDOPs regionally and sub-regionally to promote learning and dissemination.

Following the Children and Social Work Act (2017), new statutory guidance was published in 2018 - Working together to safeguard children 2018 (replacing the 2015 guidance) – along with more specific further statutory and operational guidance for Child Death Reviews.

Some of the key changes to the child death review processes arising from this new guidance are set out below:

1. Governance

Change in responsibility for the child death review process from Local Safeguarding Children Boards to local CDR partners, which are the local authorities and clinical commissioning groups (CCGs) within the relevant geographical footprint. *From Rotherham's point of view, however, governance is likely still to fall within the remit of the new child safeguarding arrangements.*

2. Minimum footprint

Possible need for merger of existing Child Death Overview Panels, given that CDR partners should represent a geographical footprint that will enable the review a minimum of 60 deaths each year. *Whilst Rotherham's CDOP only reviews around 20-30 child deaths each year, the footprint will remain unchanged, as it mirrors the local patient flows and agency responsibilities that best enable data collection and review. In order for thematic learning to take place across a larger footprint, a sub-regional thematic panel will meet on a less frequent basis to consider review findings from the four South Yorkshire CDOPs.*

3. Joint Agency Response

Requirement to perform a Joint Agency Response – Resource will need to be identified to coordinate a new multi-agency response (on-call health professional, police investigator, duty social worker), if a child's death: is or could be due to external causes; is sudden and there is no immediately apparent cause (including SUDI/C); occurs in custody, or where the child was detained under the Mental Health Act; where the initial circumstances raise any suspicions that the death may not have been natural; or in the case of a stillbirth where no healthcare professional was in attendance.

4. Child Death Review Meetings

Establishment of local multi-agency Child Death Review Meetings (CDRM). A resource will need to be identified to co-ordinate new local multi-agency meetings, and relevant professionals may need additional time in order to attend or feed into CDRMs.

5. Role and responsibilities

A number of new or enhances roles in the CDR process are identified, including:

a. Establishment of a '**key worker**' role to act as a single point of contact with the bereaved family for the duration of the death review process. Some additional resource is likely to be needed to be identified to fulfil this function – it may need to be included in relevant job plans. In addition to the key worker, an appropriate ‘medical lead’ (i.e. consultant neonatologist or paediatrician) should also be identified after every child’s death to support the family, and to liaise with the key worker.

b. In the case that a Joint Agency Response is needed, a **lead health professional** should be assigned, in order to co-ordinate health responses and liaise with police and other agencies. The lead health professional will be also be responsible for organising and chairing the CDRM.
c. Child Death Review partners should appoint a **Designated doctor for child deaths** to be responsible for the child death review process, to work closely in an advisory and co-ordinating capacity with the CDOP Administrator and the Chair of CDOP, and to work with the Chair in preparing an annual report of CDOP acitivities.

6. Child Death Overview Panels

a. CDOP panels are expected to include representation from: public health; the Designated doctor for child deaths (and a hospital clinician if the Designated doctor is a community doctor or vice versa); social services; police; safeguarding; primary care; nursing and/or midwifery; lay representation; other professionals on the merits of the cases being considered.
b. The Chair should be independent of the key providers.
c. Panel members should not lead discussions if they are the named professional with responsibility for the care of the child.
d. Panels should aim to review all children’s deaths within six weeks of receiving the report from the CDRM or the result of the coroner’s inquest (except where a themed panel is planned).
e. They may (for pragmatic reasons) choose to review the death of a child who died in their area, but who is not normally resident there.
f. May choose to review some cases within a themed panel discussion. *In Rotherham, it is likely that such themed panels would take place at the South Yorkshire level.*
g. Reporting – CDOP should continue to prepare an annual report for CDR partners. The guidance also refers to the requirement for CDR partners to publish a report “at such intervals as they consider appropriate”, to cover what they have done through CDOP arrangements and how effective this has been.
h. They should submit data on each child death to the National Child Mortality Database (NCMD) from 1st April 2019 - CDRMs will need to ensure data is captured systematically in order to enable efficient and consistent flow of data to NCMD.

Timeline for implementation of changes

The key dates for the new requirements are:

1st April 2019 – The National Child Mortality Database goes live. Department of Health & Social Care transitional arrangements outline that from 1st April 2019, all new child deaths and any open cases (those not yet reviewed by a child death overview panel) of children who died before that date should be added to the NCMD. The data collection requirements to support the review of each child's death also change on this date.

29th June 2019 – All Child Death Review Partners in England must publish their plans to meet the new requirements and send these plans to NHS England at England.cypalignment@nhs.net.

29th September 2019 – All Child Death Review Partners in England must complete the transition to the new arrangements. After this date they must be compliant with the new statutory requirements.

Looking ahead

Preparations for the implementation of new guidance have been a key concern of the panel in the past year, and will continue to be so in the coming year, as the proposed local implementation of the national guidance on child death reviews is due to commence in September 2019.

With this in mind, the Rotherham panel will continue to operate locally, but cognisant of the proposed two-tier approach across South Yorkshire, it will keep its current terms of reference under review (see appendix), whilst continuing to work to develop the purpose and role of the South Yorkshire group (initial terms of reference appended).

Rotherham CDOP does not currently have lay representation within its core membership. A lay member is a recommendation within the new guidance – this will be explored during the coming year.

Rotherham will continue to build on the excellent progress made so far with embedding safe sleep assessment and advice within community midwifery and the integrated public health nursing service, and to extend awareness and skills through other frontline professions through training programmes and the further recruitment and deployment of safe sleep champions.

As special interest topics arise, whether in response to local, regional or national concerns, CDOP will seek to engage positively as far as the resources at its disposal make this possible. It has achieved this this year with respect to the issue of consanguinity, and there is further work to do on this, arising from the workshop organised for Safeguarding Awareness Week, including strengthening the local connections with the regional genetics service, and also seeking to take this issue forward at the South Yorkshire level, and to maintain our connection to the national work on this topic being driven by Sheffield University.

Appendix 1 – Rotherham CDOP current terms of reference

Rotherham

Child Death Overview Panel

TERMS OF REFERENCE

(under review pending implementation of the new Child Death Review Arrangements from September 2019)

1. Purpose

1.1 This paper sets out terms of reference for the Rotherham Local Safeguarding Children Board, Child Death Overview Panel. It replaces previous documents titled Terms of Reference.

2. Responsibilities

2.1 Core responsibilities of the Child Death Overview Panel are:

2.1.1 Review the information available on all child deaths of children up to 18 years to determine whether the death was preventable.

2.1.2 Implement, in consultation with the coroner local procedures and protocols that are in line with Working Together on enquiring into unexpected deaths, and evaluating these as part of the information set held on all deaths in childhood.

2.1.3 Collect and collate an agreed minimum dataset on each child who has died, seeking relevant information from professionals.

2.1.4 Hold meetings at regular intervals to review and evaluate the routinely collected data on the deaths of all children, and thereby identifying lessons to be learnt or issues or concerns, with a particular focus on interagency working to safeguard and promote the welfare of children.

2.1.5 Monitor the appropriateness of the response of professionals to an unexpected death of a child, reviewing the reports produced by the rapid response team in each unexpected death of a child.

2.1.6 Refer to the chair of RLSCB any deaths where, on evaluation the available information, the Panel considers there may be grounds to undertake further enquiries, investigations or a Serious Case Review.

2.1.7 Monitor the support and assessment services offered to families of children who have died.

2.1.8 Monitoring and advising the RLSCB on the resources and training required locally to ensure an effective interagency response to child deaths.

2.1.9 Organise and monitor the collection of data for the nationally agreed minimum data set.

2.2 The Child Death Overview Panel roles:

2.2.1 The Chair and Vice Chair will ensure that membership comprises of representatives from all statutory and voluntary agencies involved in working directly or indirectly with children. Attendance will be monitored and reported upon regularly.

2.2.2 Chair and Vice Chair to be agreed by RLSCB on a 2 year agreement.

2.2.3 The Panel will maintain a current work plan and provide information as requested to Rotherham Local Safeguarding Children Board Annual Report and Business Plan.

2.2.4 The Chair and Vice Chair will ensure that membership comprises of representatives from all statutory and voluntary agencies involved in working directly or indirectly with children. Attendance will be monitored and reported upon regularly.

2.2.5 The Panel will produce an annual report, relevant aspects of which will be included in the RLSCB Annual Report, describing the activities and outcomes of the Child Death Overview Panel.

2.2.6 Terms of Reference to be agreed with Rotherham Local Safeguarding Children Board on an annual basis.

2.2.7 Establish where necessary task and finish groups that will report back to the Panel. It is the responsibility of the Panel to monitor and support task and finish groups.

3. Membership

3.1 The Panel will have a partner member of RLSCB as Chair. The Chairing arrangements will be agreed by RLSCB. A Vice Chair, who will be a member or advisor to the Board, will be elected by Panel members on an annual basis.

3.2 The Panel will receive expert advice from an appropriate member of the Safeguarding Children Operational and/or Strategic Unit.

3.3 Agencies attendance required from:

3.3.1 Public Health
3.3.2 The Rotherham NHS Foundation Trust – Designated Doctor, Midwifery and 0-19 Services
3.3.3 South Yorkshire Police
3.3.4 CYPS - Social Care / Safeguarding
3.3.5 Rotherham, Doncaster and Humber Mental Health Foundation Trust
3.3.6 Coroner's Office (where needed)
3.3.7 Yorkshire Ambulance Service
3.3.9 RMBC Legal Services (where needed)
3.3.10 NHS Rotherham Clinical Commissioning Group
3.3.11 Bluebell Wood Children's Hospice

3.4 The Child Death Overview Panel reserves the right to co-opt other members for time limited pieces of work. The Child Death Overview Panel will be administered (by way of agenda preparation, production and circulation of action notes) by support supplied from the Board's joint funding.

3.5 At the start of each meeting, attendees will be asked to sign an attendance sheet. A record of attendance for each member will be reported as part of the annual report to the Rotherham Local Safeguarding Children Board. Members will be expected to attend no less than 75% of meetings. Any member not attending 3 consecutive meetings will be invited to consider their membership position and this will be reported to the Rotherham Local Safeguarding Children Board and the Board Member of their agency.

3.6 Deputies should attend if a member of the Child Death Overview Panel is not available, but it is incumbent upon members to accept their responsibility for routine attendance and to complete any actions required of them, irrespective of whether they are in attendance or not.

3.7 For the Child Death Overview Panel to be considered quorate, at least 3 partner agencies must be represented.

3.8 **Escalation –** if any case discussed gives rise to safeguarding concerns relating to the safety or welfare of any child (eg sibling) then either (i) assurance will be sought from the relevant organisation; and or (ii) a safeguarding referral will be made to the MASH.

4. <u>Agenda etc</u>

4.1 Meetings will be held a minimum of every 2 months and unless there are exceptional circumstances, will last for no longer than three hours.

4.2 The agenda for each meeting will be agreed with the Chair prior to publication. Any member of the Child Death Overview Panel is entitled to put an item forward for the agenda. Agendas should be issued at least 5 working days before the meeting and all paperwork should be subject to Chair/Vice Chair control. Minutes from meetings will usually be issued within 10 working days of the meeting.

4.3 At the end of each meeting, any key messages for the Rotherham Local Safeguarding Children Board will be agreed. The Child Death Overview Panel will identify a person at the end of each meeting if appropriate to work with the editor of the Rotherham Local Safeguarding Children Board Newsletter to communicate the key messages.

5. Linkage to other groups

5.1 The Child Death Overview Panel work will be undertaken on behalf of Rotherham Local Safeguarding Children Board. An annual report, work plan and reporting on an exceptional basis will therefore be an expected outcome from the Panel.

6. Declaration of interest

6.1 It is the responsibility of each member to declare any conflict of interest with an agenda item either at the start of the meeting or as the discussion unfolds.

7. Business Conduct

7.1 All meetings will:

7.1.1 Start and end on time as agreed

7.1.2 Show respect for, and value the contribution of each member

7.1.3 Encourage all members to participate

7.1.4 Ensure that the agreed work plan is developed and progressed at each meeting

8. Monitoring

8.1 The effectiveness of the Child Death Overview Panel will be monitored against:

    8.1.1 Number of times the meeting is held in accordance with its Terms of Reference

    8.1.2 Number of times the meeting is quorate

    8.1.3 Level and spread of attendance at meetings

    8.1.4 Delivery of the work plan

    8.1.5 Feedback from participants by way of the annual report

9. Governance Arrangements

9.1 The Terms of Reference will be agreed by the Chair and Panel Members.

9.2 Once agreed, the Terms of Reference will be ratified by Rotherham Local Safeguarding Children Board

9.3 Terms of Reference will be reviewed annually

9.4 Minutes of meetings, works plans and exceptional reporting is open for scrutiny by Rotherham Local Safeguarding Children Board.

Panel Chair……………………………………..Designation…………………………

Signature……………………………………… Date……………………

To RLSCB Date……………..……………Ratified……………………………....

Review Date…………………………………………..

Appendix 2 – Terms of reference for new South Yorkshire CDOP

SOUTH YORKSHIRE (BARNSLEY, DONCASTER, ROTHERHAM & SHEFFIELD) CHILD DEATH REVIEW PARTNERSHIP

TERMS OF REFERENCE

1. Purpose

1.1 The responsibility for ensuring child death reviews are carried out is held by ‘child death review partners’ who in relation to a local authority area are defined as the local authority for that area and any clinical commissioning group in that area.

1.2 Child death review partners must make arrangements to review all deaths of children normally resident in the local area, and for any non-resident child who has died in their area if appropriate.

2. Principles

2.1 The process of expertly reviewing all children’s deaths is grounded in deep respect for the rights of children and their families, with the intention of preventing future child deaths.

2.2 To improve the experience of bereaved families, as well as professionals, after the death of a child.

2.3 To ensure that information from the child death review process is systematically captured to enable local learning and, through the planned National Child Mortality Database, to identify learning at the national level, and inform changes in policy and practice.

3. Responsibilities

3.1 Review and analyse data and information about all deaths (across the South Yorkshire footprint) that have had a local review undertaken to enable further analysis, trends and learning to be gained, in order to prevent future child deaths.

3.2 To hold themed discussions on a quarterly basis to review deaths from a particular cause or group of causes. This should provide an opportunity for greater understanding and shared learning. Additionally, any required actions can be developed as a region and resources and ideas pooled. Such arrangements will facilitate appropriate professional experts being present to inform discussions, and allow easier identification of themes when the number of deaths from a particular cause is small. By necessity themed panels will need to have access to more detailed case information. In order to ensure the effectiveness of these discussions the level of information sharing should be proportionate but allow for meaningful analysis to take place. The cases presented, however, will always be anonymised.

3.3 Provide a forum where practice issues that have a regional impact can be discussed and taken forward collectively by the South Yorkshire Panel.

3.4 Where appropriate develop strategies, in conjunction with local CDOPs, with the aim of preventing future child deaths; this may include communicating with national bodies or those outside of the South Yorkshire area.

3.5 To make recommendations to all relevant organisations where actions have been identified which may help to prevent future child deaths or promote the health, safety and wellbeing of children.

4. Chairing

4.1 Chairing will take place on a rotational basis, drawn from the 4 local CDR Chairs for the period of one year.

4.2 Where necessary, a Deputy Chair will be arranged by the local area, who are currently hosting.

5. Meeting Frequency

5.1 The panel will meet for 3 hours on a quarterly basis, and be held in the area where the chair and business administration is being provided for that year.

5.2 Provision will be made for ad hoc or extraordinary meetings as required.

6. Membership

6.1 The CDOP is a multi-professional panel whose core membership may include senior representatives from the following agencies or roles:

- Public health
- Designated Doctor for child deaths
- Children's Social Services
- Police
- Bluebell Wood Children's Hospice
- Safeguarding Health Practitioner
- Primary Care (GP or health visitor)
- Nursing and/or midwifery

- Lay representation
- Additional professionals should be considered in relation to specific themes or specialist role, for example; coroner’s office, ambulance service or hospices.

6.2 In order for the meeting to be quorate, there must be at least one representative from each local authority, with a maximum of 4.

7. Meeting Administration

7.1 Administration for the South Yorkshire CDR will be provided from the same area as the incumbent chair.

7.2 This will require input and support from the other CDOP administrators.

7.3 Draft minutes from the South Yorkshire CDR should be distributed to all members within 2 weeks of the meeting, for ratification at the next meeting.

7.4 Agenda items for the forthcoming meeting are required to be submitted 2 weeks before the meeting.

7.5 The eCDOP system will be the central point for data on which the South Yorkshire CDR will base its business.

8. Conflict and Declaration of interest

8.1 At the beginning of each meeting the Chair should inquire as to conflicts of interest among the attendees. The chair and panel will then need to consider how this is taken into account for the purpose of the meeting.

9. Business Conduct

9.1 Panel members should be familiar with their responsibilities and ensure that they have read all relevant material in advance of the panel meetings.

9.2 All meetings will:

- Start and end on time as agreed
- Panel members will show respect for, and value the contribution of each member
- Ensure that members are encouraged to participate
- Hold members to account for any actions that have been agreed

9.3 All members of the CDOP are required to maintain confidentiality in respect of the children and families subject of their consideration.

10. Governance Arrangements

10.1 The terms of reference will be ratified by the respective Child Death Review Partners (CCG and Local Authority).

10.2 The Terms of reference will be reviewed annually.

10.3 A memorandum of understanding will be implemented between the Child Death Review Partners, which sets out how they will work together.