



Leicester
City Council

**MEETING OF THE PUBLIC HEALTH AND HEALTH INTEGRATION
SCRUTINY COMMISSION**

DATE: TUESDAY, 28 APRIL 2026

TIME: 5:30 pm

**PLACE: Meeting Room G.01, Ground Floor, City Hall, 115 Charles
Street, Leicester, LE1 1FZ**

Members of the Committee

Councillor Pickering (Chair)

Councillor Agath (Vice-Chair)

Councillors Clarke, Haq, March, Sahu, Singh Johal and Westley

Youth Council Representatives

To be advised

Members of the Committee are invited to attend the above meeting to consider the items of business listed overleaf.

For Monitoring Officer

Officer contacts:

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Leicester City Council, City Hall, 115 Charles Street, Leicester, LE1 1FZ

Information for members of the public

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Further information

If you have any queries about any of the above or the business to be discussed, please contact: Georgia.Humby@leiceser.gov.uk and Kirsty.Wootton@leicester.gov.uk of Governance Services. Alternatively, email committees@leicester.gov.uk, or call in at City Hall.

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**USEFUL ACRONYMS RELATING TO PUBLIC HEALTH AND HEALTH
INTEGRATION SCRUTINY COMMISSION**

Acronym	Meaning
AEDB	Accident and Emergency Delivery Board
BCF	Better Care Fund
CAMHS	Children and Adolescents Mental Health Service
CHD	Coronary Heart Disease
CVD	Cardiovascular Disease
COPD	Chronic Obstructive Pulmonary Disease
CQC	Care Quality Commission
CQUIN	Commissioning for Quality and Innovation
DES	Directly Enhanced Service
DoSA	Diabetes for South Asians
DTOC	Delayed Transfers of Care
ED	Emergency Department
EDEN	Effective Diabetes Education Now!
EHC	Emergency Hormonal Contraception
ECMO	Extra Corporeal Membrane Oxygenation
EMAS	East Midlands Ambulance Service
FBC	Full Business Case
FIT	Faecal Immunochemical Test
GPAU	General Practitioner Assessment Unit
GPFV	General Practice Forward View
HALO	Hospital Ambulance Liaison Officer
HCSW	Health Care Support Workers
HEEM	Health Education East Midlands
HWB	Health & Wellbeing Board
HWLL	Healthwatch Leicester and Leicestershire
ICB	Integrated Care Board
ICS	Integrated Care System
IDT	Improved discharge pathways
ISHS	Integrated Sexual Health Service

JSNA	Joint Strategic Needs Assessment
LLR	Leicester, Leicestershire and Rutland
LTP	Long Term Plan
MECC	Making Every Contact Count
MDT	Multi-Disciplinary Team
NDPP	National Diabetes Prevention Pathway
NEPTS	Non-Emergency Patient Transport Service
NICE	National Institute for Health and Care Excellence
NHSE	NHS England
NQB	National Quality Board
OBC	Outline Business Case
OPEL	Operational Pressures Escalation Levels
PCN	Primary Care Network
PICU	Paediatric Intensive Care Unit
PHOF	Public Health Outcomes Framework
PPG	Patient Participation Group
QNIC	Quality Network for Inpatient CAMHS
RCR	Royal College of Radiologists
RN	Registered Nurses
RSE	Relationship and Sex Education
STI	Sexually Transmitted Infection
STP	Sustainability Transformation Plan
TasP	Treatment as Prevention
UHL	University Hospitals of Leicester

PUBLIC SESSION

AGENDA

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<http://www.leicester.public-i.tv>

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<http://www.leicester.public-i.tv/core/portal/webcasts>

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1. WELCOME AND APOLOGIES FOR ABSENCE

To issue a welcome to those present, and to confirm if there are any apologies for absence.

2. DECLARATIONS OF INTERESTS

Members will be asked to declare any interests they may have in the business to be discussed.

3. MINUTES OF THE PREVIOUS MEETING

Appendix A

The minutes of the meeting of the Public Health and Health Integration Scrutiny Commission held on 24th March 2026 have been circulated, and Members will be asked to confirm them as a correct record.

4. CHAIRS ANNOUNCEMENTS

The Chair is invited to make any announcements as they see fit.

5. QUESTIONS, REPRESENTATIONS AND STATEMENTS OF CASE

Any questions, representations and statements of case submitted in accordance with the Council's procedures will be reported.

6. PETITIONS

Any petitions received in accordance with Council procedures will be reported.

7. HEALTH PROTECTION

The Director of Public Health will provide the Commission with a verbal update.

8. RHEUMATOLOGY

The University Hospitals Leicester (UHL) to give an update on Rheumatology Services in Leicester.

9. LLR CHILD DEATH OVERVIEW PANEL ANNUAL REPORT 2024/25 [Appendix B](#)

The Director of Public Health, Leicester City Council and Dr Suzi Armitage, LLR Designated Doctor for Child Deaths, Leicestershire Partnership Trust will outline the work of the Child Death Overview Panel (CDOP) and present the findings of the CDOP annual report to the Commission.

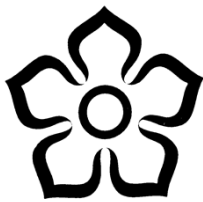
10. REDUCING INFANT MORTALITY IN LEICESTER [Appendix C](#)

The Acting Consultant in Public Health submits a report to update the Commission on the Infant Mortality Rate in Leicester.

11. WORK PROGRAMME [Appendix D](#)

Members of the Commission will be asked to consider the work programme and make suggestions for additional items as it considers necessary.

12. ANY OTHER URGENT BUSINESS



Leicester
City Council

Minutes of the Meeting of the
PUBLIC HEALTH AND HEALTH INTEGRATION SCRUTINY COMMISSION

Held: TUESDAY, 24 MARCH 2026 at 5:30 pm

P R E S E N T:

Councillor Pickering – Chair
Councillor Agath – Vice Chair

Councillor Haq
Councillor Sahu

Councillor March
Councillor Singh Johal

Assistant City Mayor – Councillor Dempster

* * * * *

15. WELCOME AND APOLOGIES FOR ABSENCE

The Chair welcomed those present to the meeting.

Apologies were received from Cllr Clarke.

16. DECLARATIONS OF INTERESTS

Members were asked to declare any interests they may have had in the business to be discussed.

There were no declarations of interest.

17. MINUTES OF THE PREVIOUS MEETING

It was noted that ICBs had been written to regarding Neighbourhood 2 and a reply was being awaited.

AGREED:

That the minutes of the meeting of the Public Health and Health Integration Scrutiny Commissions held on 19th January and 27th January be confirmed as a correct record.

18. CHAIRS ANNOUNCEMENTS

Regarding Loros Hospice, in November, government funding along with the support of community donations had enabled four beds to reopen on a temporary basis. These beds plus two more had been confirmed as permanent, after the hospice was awarded a £1.2m funding increase.

Dr Nil Sanganee, Chief Medical Officer at Leicester, Leicestershire and Rutland and Northamptonshire Integrated Care Boards, had said:

“We are really pleased to be able to provide additional funding to support the reopening of more inpatient beds at LOROS. The hospice provides exceptional care for people and their families across Leicester, Leicestershire and Rutland and plays a vital role in ensuring people receive compassionate, specialist support at the end of life.”

19. QUESTIONS, REPRESENTATIONS AND STATEMENTS OF CASE

The Monitoring Officer reported that none had been received.

20. PETITIONS

The Monitoring Officer reported that none had been received.

21. HEALTH PROTECTION

The Director of Public Health provided the Commission with a verbal update. Key points to note were as follows:

- There had been an increase in MMR 2 uptake meaning that Leicester City was now higher than many comparator areas.
- There had been an increased uptake for Flu and Covid vaccinations, detailed figures were not yet available.
- The HPV school vaccination programme had commenced in January; a new consent form appeared to have increased uptake.
- Long-term organisational changes within ICB and future structure of team responsible for immunisation and screening not yet determined.
- The TB action plan had been refreshed with a new plan and risk register.
- Regarding the Meningitis outbreak in Kent the following was noted:
 - It was an unusually large outbreak, there were now 23 confirmed and probable cases. New cases were not evident, and the outbreak seemed to be well contained. Suspected cases in Leicester had not actually been Meningitis.
 - The outbreak seemed to have centred around a nightclub due to close contact as possibly sharing of drinks and vapes.
 - Around 10% of the population were likely to carry the Meningococcal bacteria, but this was mostly harmless and did not become invasive.
 - This outbreak was Meningitis B, the vaccination was currently

only given to babies, offering good protection for the first few years and then beginning to wane. For the other strain (ACWY), vaccinations were offered to school children aged 13 and 14.

- The UK Health Security Agency and the Joint Committee on Vaccination and Immunisation will be considering whether including the MenB vaccine in the school aged schedule is now cost effective.
- Within Leicester, vaccine uptake was being encouraged via promotional materials and campaigns were being run directly with young people.
- Leicester vaccination rates for Meningitis B were at around a 90% uptake for one-year-olds and 86% for two-year-olds. The school age uptake for the ACWY vaccine was just less than 50%. It was hoped that the new consent forms would improve uptake.
- The UK Health Security campaigns were being utilised and Community Wellbeing Champions and radio publicity were raising awareness.
- The publicity information and details on signs and symptoms could be circulated to councillors.

In response to member and Young People's Council (YPC) member questions and discussions, the following was noted:

- A team from the Leicestershire Partnership NHS Trust (LPT) go into schools to carry out the vaccinations.
- Early indications are that the new process for vaccine consent had led to a 10% point increase across school vaccinations.
- Meningitis vaccine supply was sufficient.
- Teams in Public Health were working closely with ICB colleagues and at LPT to continue to promote the vaccine message. Messages had been sent to teachers via the intranet.
- The UK Health Security Agency carried out contact tracing for those in close contact with Meningitis cases. GP Practices within Leicester would be able to supply the necessary antibiotics should they be required.
- Meningitis symptoms could be confused with many other illnesses, so the advice focussed on understanding when to raise concerns and call 999. .
- Members recommended that the Commission write to the Secretary of State for Health and Social Care for more funding for the vaccination programme for the city.
- The House of Lords were setting up a committee to look at childhood vaccination rates; it was hoped that they would come to Leicester to understand the unique challenges for the city.
- Children from abroad coming to live in Leicester would have access to a catch-up vaccination programme through schools and GPs.

AGREED:

- 1) That the report be noted.
- 2) That comments made by members of this commission to be taken

- into account.
- 3) Slides on Meningitis signs and symptoms could be circulated to the commission.
 - 4) The presentation which includes data on the rate of Meningitis vaccine uptake for 14/15 year-olds would be supplied to the commission.
 - 5) That the Commission write to the Secretary of State for Health and Social Care to request increased funding to promote vaccine coverage in the city.

22. PUBLIC HEALTH AND RESEARCH

The Director of Public Health in conjunction with De Montfort University submitted a report to outline the first stages of work which includes a public health workforce research capacity audit, the appointment of a Local Authority Research Practitioner (LARP), a new research clinic, the creation of a Public Health Research Working Group, the development of a forward-looking research strategy, strengthened university partnerships, new research governance infrastructure, and a research repository.

The Acting Consultant for Public Health gave a slide presentation, key points to note were as follows:

- Leicester was unique in its demographics and applying national research evidence could be problematical. It was vital for Leicester to build strong research resources and evidence.
- Working with communities was key.
- A new Local Authority Research Practitioner post had been taken up, partly funded by the National Institute for Health Research (NIHR) and partly with De Montfort University.
- A workforce skills audit had been completed to map current capabilities and inform development.
- A research clinic had been established to support staff undertaking research.
- A cross-team working group was developing a research strategy.
- Work was ongoing to strengthen governance and ethics.
- For the workforce audit, the response rate had been 43%. A diverse skill-set was found to be in place. Most people had a lot of experience in data collection but there were other areas which could be improved upon via the ongoing workforce plan.
- There was a focus on relationship building, including with the universities. A summer research showcase was planned to promote local work.
- The research governance and ethics work focused on developing an ethical framework with the communities.
- It was hoped that a research repository would create a systematic record of all external collaborations.

- There were also examples of individual projects being worked on.
- There were 6 recommendations to Scrutiny:
 - To note the strategic direction
 - To endorse the principal of community partnerships
 - To gather views on expanding the current work
 - To note the research repository and endorse its mechanism for oversight and accountability with partners
 - To support with the progress made on governance and ethics
 - To request a further update on the implementation of the Public Health Research Strategy at a future meeting

In response to member questions and comments, the following was noted:

- Members welcomed community partnerships.
- Total annual costs for the local authority research package were £14.5k from DMU, £14.5k from the City Council, and £29k from HR contractors. The Local Authority Research Practitioner post was funded from this money.
- The funds from the Public Health budget would provide a starting point to build skills and capacity for ethical and effective research. Work had been carried out on running research clinics and best evaluation methods. There had been a large uptake from Public Health.
- Officers were satisfied with the workforce survey uptake whilst some members felt that it was low.
- Learning from COVID-19 highlighted that Leicester's communities required communication approaches that differed from national messaging.
- Programmes would include young people to gain an oversight of service users.
- The team was six months into the two-year funding period.

AGREED:

- 1) That the report be noted and the recommendations to Scrutiny be supported.
- 2) That comments made by members of this commission to be taken into account.

23. MENTAL HEALTH AND SUICIDE PREVENTION

The Director of Public Health submitted a report to update the Public Health and Health Integration Scrutiny Commission about the latest work on Suicide Prevention and to promote mental wellbeing in Leicester.

The Suicide Prevention Officer gave a presentation and made the following points:

- The focus was on reaching people that are at higher risk of suicide and providing early intervention.

- The data showed that people who took their own life were often not known through statutory services, so it was necessary to take the work the service did out to people.
- Real time real-time suicide surveillance data was collected and the service worked very closely with Leicestershire Police, Leicester Fire Service and Network Rail.
- Weekly meetings took place with Leicestershire Police to look at the data from the previous week of any suspected suicide. This acted as an immediate response in place to communities.
- Multi-agency work looked at high-risk locations and our high-risk groups.
- In the past year there were 26 suspected deaths by suicide in the city. This was similar to the national average.
- The Mental Health Regulator acted as accredited mental health and suicide prevention training through public facing and business leaders, organisations and community groups. Organisations were trained to recognise signs and symptoms of poor mental health. This helped to break down the stigma associated with mental health and helped organisations know where to signpost people for support.
- 103 organisations were 'Mental Health Friendly', including sports clubs which allowed people to have conversations.
- Resource packs were provided and could be passed over discreetly.
- The key focus was on men aged 35-54 as they were the highest risk group, consisting of 75% of suicides.
- A men's mental health conference had been put on, to try and increase awareness of what was on offer. A video was shown on this. Link to video: <https://www.canva.com/design/DAG6phFNfoo/BtgE8jZWTUEPqmxdeSAPow/edit>
- Specific men's mental health was being co-produced, this included a booklet which could be given to people, for example, if they were discharged from hospital following a suicide attempt.

In response to member and Young People's Council (YPC) member questions and discussions, the following was noted:

- Leicestershire and Rutland Football Association had been worked with, and clubs had trained welfare officers who delivered sessions known as 'my space, my game', whereby anybody could attend to play and then were invited to the clubhouse to talk to trained staff.
- It was noted that some people in the focus group had not realised that the issues they were experiencing were mental health issues.
- It was suggested that questions on low mood and suicide could be included in the NHS Health Checks. The possibility of this could be considered, although it was noted that the NHS Health Checks were commissioned on strict criteria, and it was necessary to avoid 'mission creep', making the survey too wide-ranging.
- In response to comments about the need for places for people to talk and the emergence of some faith-based groups, it was noted that the Business Intelligence Team had been consulted regarding the demographics of suicide victims. Local groups had been useful as it had been noticed that men

responded to peer-support, and the more groups that were encouraged, the better the chance of reaching men.

- In terms of health inequalities, mental health and social isolation were being considered.
- The numbers of child suicides were small, but would be covered in the CDOP Annual Report coming to the Commission.
- The way the team approached the issue was very effective, but more could always be done.
- In terms of locality friendly spaces for men, it was noted that there were many spaces specifically for men, and the existing organisations were looking at adding resources for men.
- Regarding specific mental health training, it was important to get people feeling more confident about gender differences and internal stigma for men.
- With regard to queries about where people could go in a crisis, it was noted that it was necessary to reach people where they were to avoid them reaching a crisis. It was aimed to make a safety-plan so that if people were struggling, there was a plan that they had written with someone including safety factors, including what support there was and how they could distract themselves.
- With regard to a query about targeting younger people to avoid them thinking that they couldn't reach out, it was noted that the mentality appeared to be different for younger people compared to those in the 35-54 age-group. Young people had been written into the strategy as a high-risk group and more would be coming. It was further noted that key messaging was important, and being open in lessons at school could play a part.
- With regard to a point made about targeting areas where more people were at risk of suicide, it was explained that areas with higher rates were cross-referenced and the service were doing well at getting mental health friendly places into those areas.
- Issues surrounding care-leavers could be referred to the Corporate Parenting Board.
- With regard to the booklet, organisations could distribute it. Focus groups had been asked where they thought it should be, suggestions had included GP surgeries, local gazettes, social media and making it available through QR codes.

AGREED:

- 1) That the report be noted.
- 2) That comments made by members of this commission to be taken into account.
- 3) That consideration be given to looking into including questions on low mood and suicide in the NHS Health Checks

24. WORK PROGRAMME

NHS Dentistry could be considered at the next meeting.

A report on palliative care, including information on Loros could come to the

Commission.

A Winter Plan Debrief could come to the Commission.

The work programme was noted.

25. ANY OTHER URGENT BUSINESS

There being no further business, the meeting ended at 19:20

Leicester, Leicestershire & Rutland Child Death Overview Panel (CDOP) Annual Report 2024-2025



Authors

Dr Suzi Armitage, LLR Designated Doctor for Child Deaths

Rob Howard, LLR CDOP Chair, Director of Public Health, Leicester City Council

Helen Reeve, Senior Intelligence Manager, Public Health, Leicester City Council

Acknowledgement to CDOP members 2024-2025:

Rob Howard, Consultant in Public Health, Leicester City Council, CDOP Chair

Claire Turnbull, Designated Nurse Safeguarding, LLR ICB, CDOP Vice Chair

Dr Suzi Armitage, Designated Doctor for Child Deaths (DDCD)

Kat Blake-Smith, Head of Children and Young People's Integration in Public Health, Leicestershire County Council

Rebecca Broughton, Head of Outcomes & Effectiveness, UHL

Joanne Dickens, Perinatal Safety & Mortality Review Coordinator Midwife, UHL

DI Ross Dimmock, Detective Inspector CAIU & Force Lead for Child Death, Leicestershire Police

Emma Wilson, Named Professional for Safeguarding Children & Young People, East Midlands Ambulance Service

Louise Evans, Head of Nursing for Children's Hospital, UHL

Kay Fletcher, Head of Service for Safeguarding & Quality Assurance, Leicestershire County Council

Dr Lina Gatsou, CAMHS Named Doctor for Safeguarding Children, Leicestershire Partnership NHS Trust

Darrell Griffin, Service Manager, Rutland County Council

Julia Khoosal, Head of Service, Children's Safeguarding & Quality Assurance, Leicester City Council

DI Dominic Markham, Detective Inspector CAIU & Force Lead for Child Death, Leicestershire Police

Dr Penelope McParland, Consultant Obstetrician UHL

Dr Robin Miralles, Consultant Neonatologist, UHL

Siouxie Nelson, Clinical Lead for LeDeR Programme, LPT

Dr Anand Patil, Consultant Paediatric Intensivist, UHL

Dr Joanna Preece, Consultant Neonatologist, UHL

Dr Amit Rastogi, Named GP Safeguarding Adults & Children, LLR ICB

Dr Rachel Rowlands, Paediatric Emergency Medicine Consultant, UHL

Dr Kamini Yadav, Consultant Neonatologist, UHL

Catherine Yeomanson, Family Services Manager, Leicestershire Partnership NHS Trust

LLR Child Death Review Service

Sue Stephenson, Child Death Review Nurse

Jo Lane, Child Death Review Nurse

Kerry Wale, Child Death Review Nurse

Melvinna West, Child Death Overview Panel Administrator

A tribute to our colleague and friend, Kerry Wale

Kerry worked as a Child Death Review Nurse (having previously been a Health Visitor) since 2023 and was a key part of our small team, until her sudden death in 2025. She worked closely with families and professionals from many different backgrounds and agencies. She was a passionate advocate for bereaved families, a highly respected colleague, and is remembered with much fondness.

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Glossary of abbreviations used

CAIU	Child Abuse Investigation Unit
CDOP	Child Death Overview Panel
CDIM	Child Death Initial Meeting
CDRM	Child Death Review Meeting
CSPR	Child Safeguarding Practice Review
EMAS	East Midlands Ambulance Service
ICB	Integrated Care Board
IMD	Index of Multiple Deprivation Official measure of relative deprivation for small areas (population 1500) in England. IMD 1 refers to an area which is in the 10% most deprived small areas in the country, IMD 10 an area in the 10% least deprived.
JAR	Joint Agency Response A coordinated multiagency response to a death occurring in any of the following circumstances: <ul style="list-style-type: none"> - Death due to external causes - Death occurring in suspicious circumstances. - Death that is sudden (not anticipated in preceding 24 hours) and for which no medical explanation is evident – a sudden unexpected death in infancy/childhood. - Death of a child or young person detained under the mental health act or in custody. - A stillbirth occurring without in the absence of a registered health professional.
LeDeR	Learning Disability Mortality Review
LLR	Leicester, Leicestershire & Rutland
LPT	Leicestershire Partnership NHS Trust
MBRRACE-UK	Mothers & Babies: Reducing Risk through Audit & Confidential Enquiries across the UK
MNSI	Maternity & Neonatal Safety Investigation
NCMD	National Child Mortality Database
NNU	Neonatal Unit
PMRT	Perinatal Mortality Review Tool
SUDI/C	Sudden Unexplained Death in Infancy/Childhood Descriptive term, used at presentation - the death of an infant/child which was not reasonably expected to occur 24 hours previously, and in whom no pre-existing medical cause of death is apparent. Following detailed investigation, a cause of death may be found.
SIDS	Sudden Infant Death Syndrome An unexpected death of an infant occurring during normal sleep, which remains unexplained after a thorough investigation and review of the circumstances.
UHL	University Hospitals of Leicester NHS Trust

LLR CDOP 2024/2025

1

LLR Genetic Pathway for unexplained child deaths launched

4

Presentations & briefings for Safer Sleeping Risk Assessment

64

Attendees at Joint Agency Response training (↑9)

8

Child Death Overview Panels held (↓2)

81

Case reviews completed (↓8)

424

Contributory factors identified (↑11)

119

Modifiable factors identified (↑16)

92

notifications received (↑10)

19

Joint Agency Responses undertaken (↓8)

33

Child Death Initial Meetings held (↓16)

49

Cases where CDOP raised actions (↑5)

1

National Alert raised to NCMD (↓1)

Top **6** contributory factors that could be **modified** to reduce future child deaths in our area



Smoking in pregnancy



Unhealthy weight in pregnancy



Household exposure to cigarette smoke



Poor communication between agencies



Guidelines or policies not being followed



Missed signs of deterioration



Introduction

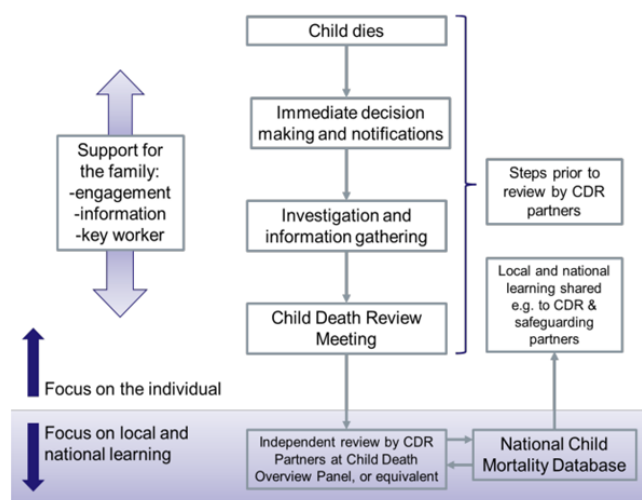
The national process of reviewing child deaths was established in April 2008 and updated in Chapter 6 of Working Together to Safeguard Children 2023. It is the responsibility of the Child Death Review Partners to ensure that a review of every death of a child normally resident in their area is undertaken by a CDOP. Across LLR, the Child Death Review Partners are the three Local Authorities and the LLR Integrated Care Board.

The overall purpose of the LLR CDOP is to undertake a comprehensive and multi-agency review of all child deaths, to better understand how and why children across LLR die, with a view to detecting trends and/or specific areas which would benefit from further consideration^{1,2}. The LLR CDOP has been gathering data since 2009 and been producing annual reports which summarise the data collected in each year.

The process for reviewing child deaths commences with Notification to the Child Death Review team and culminates in final scrutiny at the Child Death Overview Panel (please see fig 1). The Child Death Review process integrates with the Perinatal Mortality Review Programme and shares learning by collaborative working with the Learning Disability Mortality Review Programme (LeDeR). All data from LLR Child Death Reviews is submitted to the National Child Mortality Database (NCMD) for the purposes of data analysis and learning at a national level.

Hearing the experiences of families is an important part of the Child Death Review process, particularly in learning about what went well, and what needs to be improved in terms of care and service provision. All families will have contact either via the Perinatal Mortality Review process, their Key Worker or Child Death Review Nurse, to ensure they are offered support, and the opportunity to ask questions about their child’s care. Families are also offered the opportunity to have feedback after their child’s review meeting. Whether or not families have been asked for feedback is noted in every case, as are any questions or feedback raised, along with the assurance that their questions and any concerns have been sensitively dealt with and addressed.

Figure 1: The Child Death Review process as set out in Working Together to Safeguard Children 2018, Chapter 5³.





Family Support: Child Death Review Nurse update

- The Child Death Review Nurses continued joint home visits with police under the Joint Agency Response, providing support for families, acting as Child Death Review Key Workers, and representing families' voices at professional meetings.
- Building on their involvement in the Birmingham University study which led to the development of the *NCMD Key Worker Toolkit*, the team have worked on the implementation of the Toolkit across LLR.
- The team developed a local information booklet for families with clear signposting to local support services, complementing the national 'When a child dies' booklet.

Genetics pathway development

- In 2023, the R441 Whole Genome Sequencing (WGS) gene panel became available for unexplained child deaths (those where a medical cause of death could not be found following post-mortem examination).
- Working with HM Coroner, the local Clinical Genetics service, and Paediatric staff from UHL, a local pathway has been developed for integrating WGS into the Joint Agency Response.
- As one of the first areas in England to have a pathway in place, the LLR pathway has been shared nationally at the Association of Child Death Review Professionals National Conference 2024. Learning from the pathway development was also included in the 'SIDS Masterclass' at the Royal College of Paediatrics & Child Health Annual Conference 2025.
- We are immensely grateful for feedback from families which has enabled us to further improve and develop the pathway, ensuring rapid access to testing, and better communication and coordination of care.

Training delivery

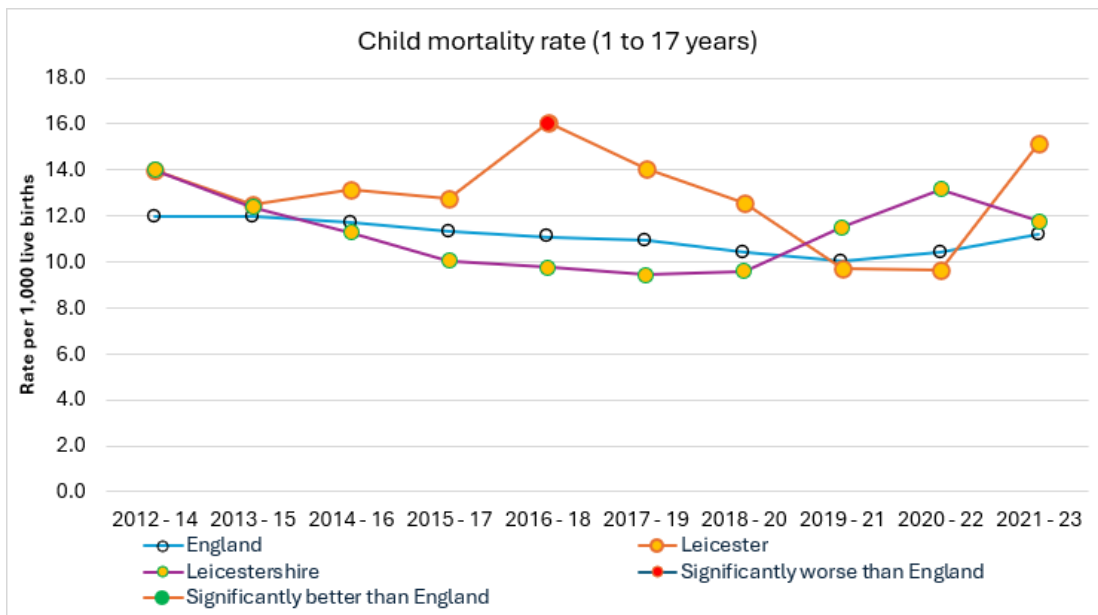
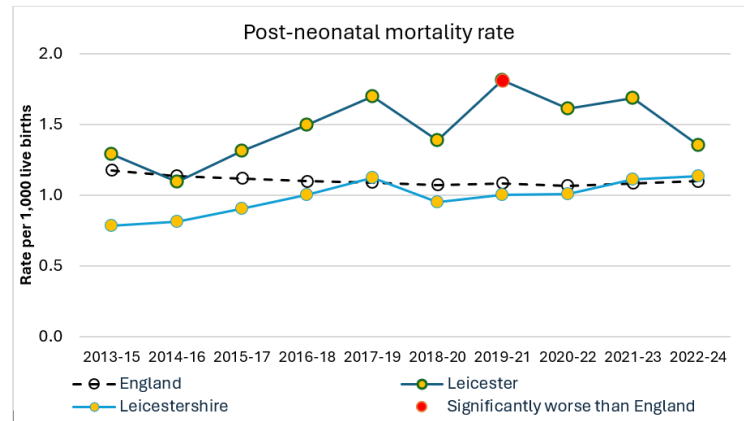
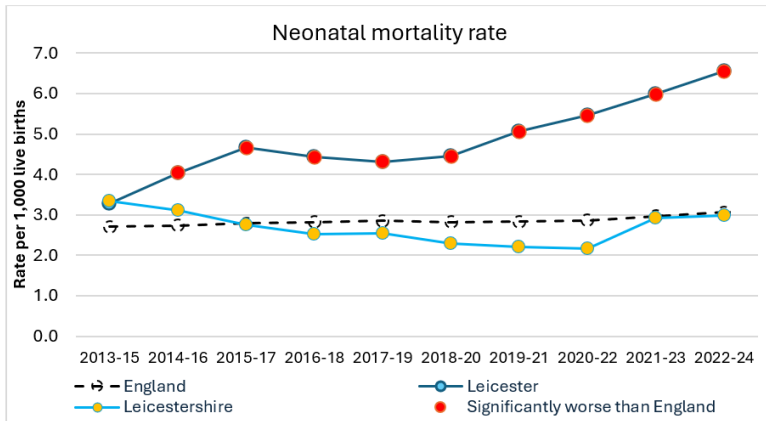
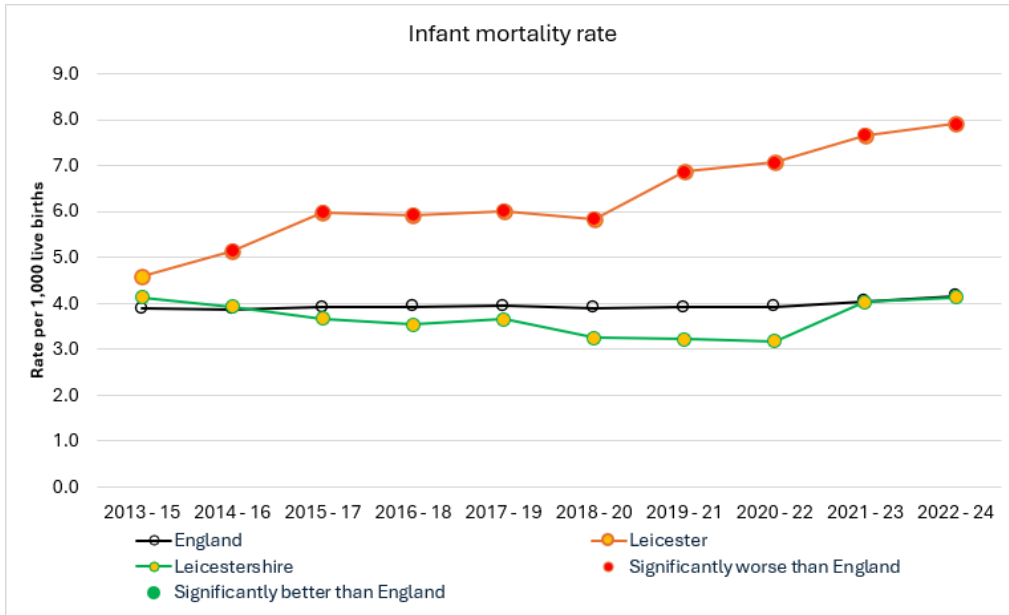
- The LLR Child Death Review service deliver local Joint Agency Response training for health professionals and police.
- In 2024/25 both face-to-face and online training were offered for the first time since the pandemic; 64 professionals attended, 100% of feedback respondents said they would recommend the course to colleagues.
- Annual training will now continue in both formats.

Gathering information for reviews

- Each child death review requires comprehensive data collection via statutory Reporting Forms, completed by front-line professionals, covering information about the child, family, social and physical environments, and the services provided. Additional reports and any governance reviews are also collated. During 2024/25 updates to information gathered included:
 - GPs completing Reporting Forms for all neonatal cases.
 - Collecting information from smoking cessation services on engagement after referral.
- LLR CDOP (together with maternity & neonatal staff at UHL) participated in Phase 1 of the integrated MBRRACE-NCMD system roll-out to streamline neonatal notification and reviews.

Notification & Child Death Initial Meeting Audit

- A three-month audit of cases notified to LLR CDOP assessed compliance with Child Death Review Statutory & Operational Guidance.
- Whilst some aspects of the Joint Agency Response require refinement, it is well-recognised that there are limitations to the current Kennedy Guidance, with a need for a more situation-specific guidance, which remains proportionate to the individual case context. An update to the 2016 Kennedy Guidance remains awaited.
- Areas of good practice included universal Key Worker allocation, timely notifications, and good multiagency representation at Child Death Initial Meetings, including primary care and community services.
- Actions have been taken to improve post-mortem sampling in the Emergency Department, enhance support and information for Initial Meeting attendees, and clarify how family feedback is shared with other agencies.



Data: <https://fingertips.phe.org/profile/child-health-profiles>



Key information: Notifications

LLR CDOP received 92 notifications of deaths of LLR residents under the age of 18 years (an increase from 2023/24).

27 (29%) of cases met the criteria for a Joint Agency Response. 'Neonatal' response cases (babies who die after birth but before discharge from hospital) continue to make up the largest proportion of notifications received (55% of the total; 37% of whom were babies born under 23 weeks gestation). CDOP has only reviewed deaths of babies under 23 weeks since 2020, however these children have always been included in ONS data (p8). This cohort of babies contribute to the increasing trend seen in the infant mortality & neonatal mortality rates.

Local Authority:

Leicester City: 48 cases (52%)

Leicestershire & Rutland: 44 cases (48%)

Place of death:

77% of children died in hospital.

- 56% in Neonatal Unit/Delivery Suite
- 9% in Paediatric Intensive Care

20% of children died at home.

1% of children died in a hospice setting.

1% of children died abroad.

Chart 1. Death notifications by LA of residence 2017/18 to 2024/25

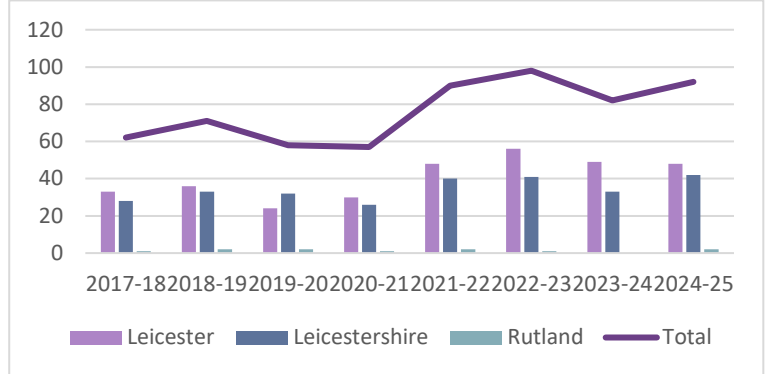


Chart 2. 5-year mean notifications by age group 2017/18 – 2024/25

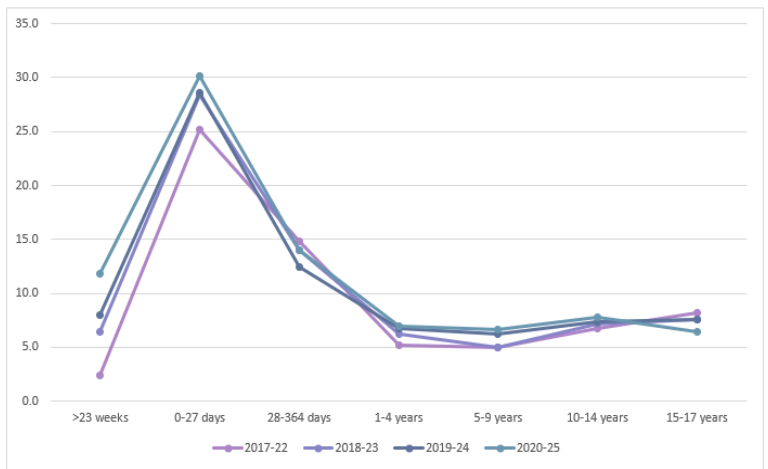


Chart 3. Notifications by category of response 2017/18 to 2024/25

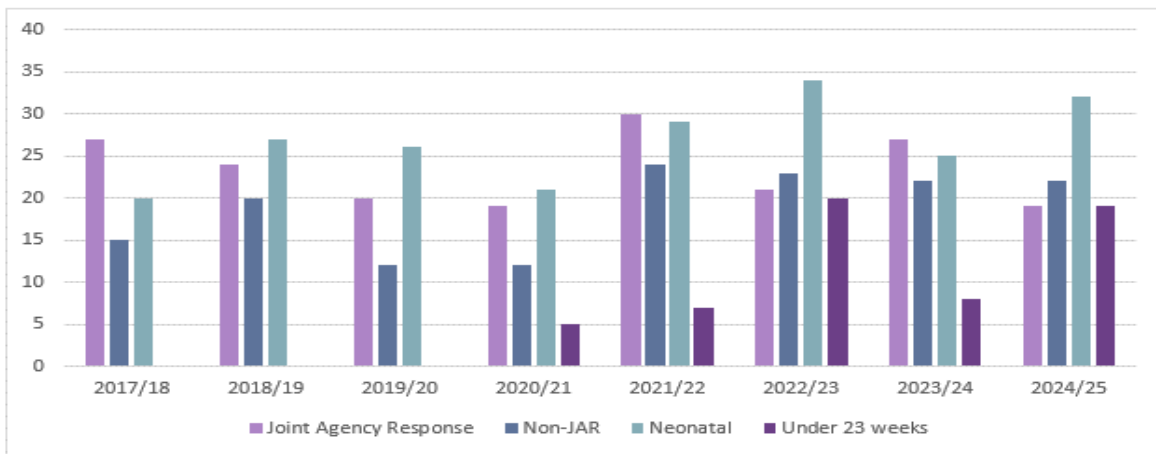


Table 1. Notifications by age & ethnicity 2024/25

Ethnic Group	28-346		1-4 years	5-9 years	10-14 years	15-17 years	Total
	0-27 days	days					
White	21	5	2	4	7	1	40
Other	2	1	0	0	0	0	3
Mixed	5	1	1	0	1	0	8
Black or Black British	2	1	0	0	1	0	4
Asian or Asian British	22	6	3	4	0	2	37
Total	52	14	6	8	9	3	92



Table 2. Completed reviews by year 2020/21 – 2024/25

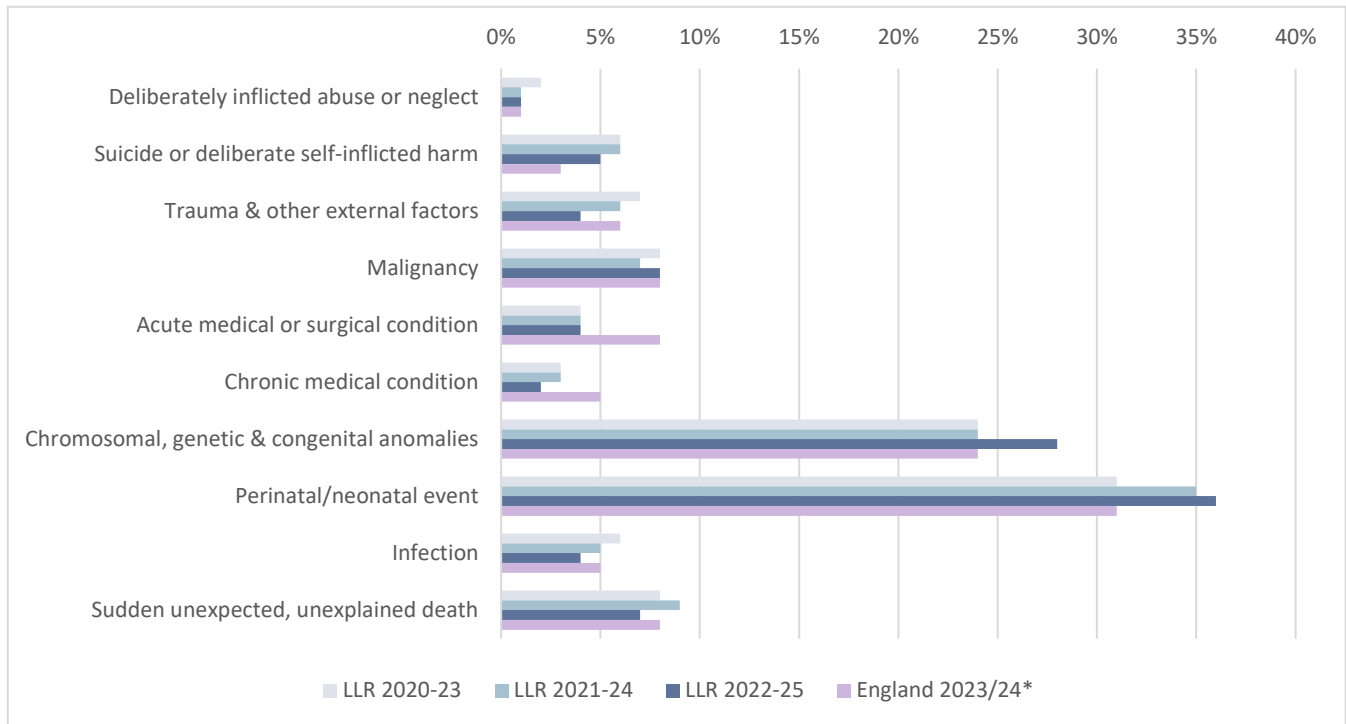
	2020/21	2021/22	2022/23	2023/24	2024/25
Leicester City	32	35	45	53	46
Leicestershire & Rutland	32	36	41	36	35
Total LLR	64	71	86	89	81

Table 3. Completed reviews by year of death 2024/25

Year of death	Cases
2017-18	1
2021-22	4
2021-22	24
2022-23	47
2023-24	5
Total	81

Chart 4. Category of death for completed reviews – 3 year merged data 2020 – 2025

*Data from NCMD Data Release Child Death Reviews Data: year ending 31 March 2024, published November 2024



Key information: Completed reviews

- Cases are only brought to panel once all other investigations (including Inquests, Police investigations, Serious Incident Investigations and Child Safeguarding Practice Reviews) are concluded and reports available to CDOP, hence there is a time lag between the year of death and completion of the review.
- In 2024/25 LLR CDOP held 8 panels and completed reviews for 81 cases.
- CDOPs are asked to categorise each case by cause of death (see Appendix A). In 2024/25 in LLR, the percentage of deaths due to congenital anomalies equalled perinatal/neonatal events as the most frequently recorded category of death.
 - Deaths due to a perinatal or neonatal event (33% in LLR vs 35% in England*).
 - Includes complications of prematurity/immaturity, perinatal asphyxia and perinatal infection.
 - Deaths due to a chromosomal, genetic, or congenital anomaly (33% in LLR vs 24% in England*).
 - Sudden unexpected, unexplained deaths (6% in LLR vs 4% in England*).
 - Deaths occurring at any age, which, following a thorough investigation and post-mortem, no clear medical cause has been identified.
 - Deaths due to malignancy (6% in LLR vs 9% in England*).
 - Deaths due to infection (5% in LLR vs 4% in England*).
 - Deaths due to acute medical or surgical condition (5% in LLR vs 6% in England*).



Contributory factors: definition

A factor is deemed to be 'contributory' if it was known to be present and may have contributed to the vulnerability or death of the child. Had that factor been absent, it would have created the prospect of a different outcome.

Contributory factors are classified by Domain, then by Group, and finally by Sub-group to provide both a thematic overview, and a more in-depth, nuanced analysis of those features known to be present which may have shaped the outcome in each case. For a full list of Contributory Factor Domains, Groups & Subgroups, please see Appendix B.

Table 4. Domain A: Factors intrinsic to the child 2024/25

Noted in 80 cases (99%).

Factor by group	No of cases	% of cases
Child health history/medical condition	77	95
Risk factor in mother during pregnancy	32	40
Child's developmental condition/disability	11	14
Emotional/behavioural factors	3	4
Other	2	2
Smoking/alcohol/substance use/misuse by child	2	2

Table 6. Domain C: Factors in the physical environment 2024/25

Noted in 5 cases (6%).

Factor by group	No of cases	% of cases
Sleep environment	4	5
Home safety/conditions	1	1
Public Safety	1	1
Vehicle collision	0	0

Key information: Contributory Factors

- Domains, Groups and Subgroup categories are determined nationally by the National Child Mortality Database, to enable standardised case analysis across England.
- In 99 % of cases, factors intrinsic to the child were identified as contributing to vulnerability or death.
 - Sole domain in which factors were identified for deaths due to malignancy and infection.
- In 39% of cases, factors in the family or social environment contributed to vulnerability or death.
 - Noted in 100% of deaths due to deliberately inflicted injury, abuse or neglect and suicide/self-inflicted harm, 50% of deaths due to trauma, chronic or acute medical conditions, 41% of deaths due to genetic or congenital anomalies, 40% of sudden unexpected unexplained deaths & 37% of deaths due to perinatal or neonatal events.
- In 6% of cases, factors in the physical environment contributed to vulnerability or death.
 - Noted in 80% of sudden unexpected unexplained deaths, and 4% of deaths due to perinatal or neonatal events.
- In 30% of cases, factors in service provision contributed to vulnerability or death.
 - Noted in 100% of deaths due to suicide/self-inflicted harm, that were sudden unexpected unexplained, 41% of deaths due to neonatal or perinatal events & 22% of deaths due to congenital or genetic anomalies.

Table 5. Domain B: Factors in the family/social environment 2024/25

Noted in 31 cases (39%).

Factor by group	No of cases	% of cases
Parent/carer's health	12	15
Cultural factors	10	12
Smoking/alcohol/substance misuse/use by parent/carer	10	12
Challenges for parents with access to services	9	11
Household functioning, parenting/supervision	8	10
Domestic or child abuse/neglect	7	9
Social Care	3	4
Poverty & deprivation	2	2
Other	1	1
School/peer groups	1	1

Table 7. Domain D: Factors in service provision 2023/24

Noted in 24 cases (30%).

Factor by group	No of cases	% of cases
Following guidelines/pathway/policy	13	16
Initiation of treatment/identification of illness	8	10
Communication within or between agencies	6	7
Access to appropriate services	5	6
Communication with family	5	6
Staffing/bed capacity/equipment	5	6
Other	1	1



Modifiable factors: definition

A factor is deemed to be ‘modifiable’ if it may have contributed to the vulnerability or death of a child (i.e., has been identified as a Contributory Factor), and through means of a locally or nationally achievable intervention, could be modified to reduce the risk of future deaths.

Table 8. Number of cases where modifiable factors identified by category of death 2024/25

	Completed reviews	Modifiable factors identified	% of cases where MF identified
Deliberately inflicted injury, abuse, or neglect	2	1	50
Suicide or deliberate self-inflicted harm	3	3	100
Trauma and other external factors	2	1	50
Malignancy	5	0	0
Acute medical or surgical condition	4	2	50
Chronic medical condition	2	1	50
Chromosomal, genetic, or congenital anomaly	27	10	37
Perinatal/neonatal event	27	14	52
Infection	4	1	25
Sudden unexpected, unexplained death	5	4	80
Overall	81		46

Key information: Modifiable factors

- Modifiable factors were identified in 46% of LLR cases (n=37) compared to 43% across England⁴.
- Across the 37 cases where modifiable factors were identified, 119 individual factors were recorded (1-11 per case).
 - 49% of these cases were in children who died in the first 28 days of life.
- Modifiable factors were found in 60% of cases for those living in the most deprived areas (IMD 1&2) compared to 25% for those in the least deprived areas (IMD 9&10).
- The top six modifiable factors identified in 2024/25 (by sub-group) were:
 - Smoking in pregnancy.
 - Leads to adverse pregnancy outcomes including placental abruption, prematurity and low birth weight.
 - Exposure to nicotine during pregnancy increases SIDS risk, through affecting development of the parts of the nervous system which enable the body to respond to changes in oxygen and carbon dioxide levels⁵.
 - High maternal Body Mass Index.
 - Healthy pre-pregnancy weight reduces the risk of pregnancy complications including gestational diabetes & pre-eclampsia, and the risk of congenital malformations⁶.
 - Household smoking/e-cigarette use by parent/carer.
 - Poor communication/information-sharing between agencies.
 - Guidelines/policy/pathways not being followed.
 - Failure to recognise signs of deterioration in a child.
- Sleep environment was the 7th most frequently recorded modifiable factor in 2024/25, having been 4th in 22/23 and 5th in 23/24.

Table 9: Most frequently recorded modifiable factors by Domain Group 2024/25

Most frequently recorded modifiable factors by domain Group:	No of cases 23/24	No of cases 24/25
Risk factors in mother during pregnancy/ delivery	14	14
Following guidelines/pathway/policy	7	13
Smoking/alcohol/substance misuse/use by a parent/carer	8	9
Initiation of treatment/identification of illness	5	7
Communication within/between agencies	3	6
Staffing/bed capacity/equipment	4	5



Key information: Modifiable factors in Service Provision

25% of completed case reviews in 2024/25 were found to have modifiable factors in Service Provision. In 80% of these cases, learning and actions had already been identified via internal or external governance reviews, Prevention of Future Death Report, Child Safeguarding Practice Review or Rapid Reviews. In 20% of cases learning was identified for the first time in the Child Death Review Meeting (15%) or at Panel (5%).

In England in the 21st century, the death of any child is a high-harm, but low-frequency event. Safety systems exist within all agencies to identify and stratify risk, with the aim of reducing chances of harm, but cannot prevent every adverse event.

Models such as SIEPS, FRAM and Accimap are used in healthcare to analyse incidents (system failures), mapping the interplay of technical and human factors. Child Death Review identifies factors which may have contributed to a child's vulnerability, ill-health or death, incorporating learning from incident analysis and the family perspective. This leads to a broader consideration of factors at play, including around interagency working, where different organisational systems may intersect.

Nathan et al⁷ describe a model for risk assessment to reduce such high-harm, low-frequency events, which describes the recognition and response to risk as fundamentally embedded in interpersonal interaction. This in turn takes place in the context of wider organisational and system pressures and processes. Mapping out modifiable factors in service provision using this model, reveals some common, cross-cutting themes which are relevant to all agencies, contexts and categories of death.

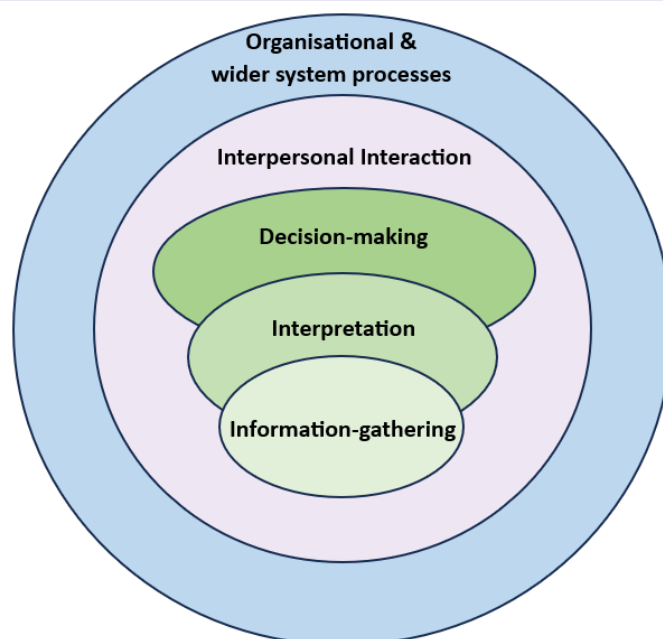


Fig 2. Risk assessment framework for reducing high-harm low-frequency events, adapted from Nathan et al⁷.

Available under CC BY License.

1. Recognising risks: Information-gathering, interpretation & decision-making

A. Subject-matter expertise

- Knowledge & experience, supported by risk identification tools, are necessary to accurately identify and interpret risk factors in context.
- Practitioners need easy access to senior or expert support, advice and review, and the ability to escalate concerns quickly. This includes access to senior oversight and support for less experienced staff to deliver high-quality care.
- Practitioners need to be able to easily escalate when demand (acuity) threatens to exceed capacity for safe care.

- **Issues with initiation of treatment or identification of illness** were seen in 7 cases, including:
 - In diagnosis (2 cases)
 - With availability of information (1 case)
 - With treatment, including delays (1 case)
 - Lack of recognition of a deteriorating child (6 cases)
 - Recognising & interpreting abnormal clinical observations and investigations (4 cases)
 - Recognising vulnerability and risk in young people with neurodiversity, emotional distress & high-risk behaviours (1 case)
- **Equipment related issues** were noted in 2 cases.
- **Issues impacting on the quality of referral, assessment or review** were seen in 5 cases, including:
 - Referrals for smoking cessation
 - Assessment of risk for neonatal sepsis
 - Assessment of risk for preterm labour
 - Inclusion of fathers in multiagency assessment



B. Clear evidence-based guidance, policies and pathways are essential to support information-gathering, interpretation & decision-making.

Issues with guidelines, pathway or policy were seen in 9 cases, including:

- Pathways/guidance available but not followed (6 cases)
 - Out-of-hospital resuscitation of newborns
 - Antenatal referrals for smoking cessation or toxicology screening
 - Mental health support pathways
- Pathways/guidance unclear or unavailable (4 cases)
 - Recognition of risk in children with a Learning Disability
 - Guidance about stepping down observations.
 - Unclear referral pathways.

C. Information-sharing to build, revisit & revise emerging pictures of risk.

- Practitioners need time, resources, and access to information, so that they can communicate, share, and build an up-to-date picture of cumulative and emerging risks.
- Timely sharing of the right information with the right agency is essential.
- Clear, consistent language, free of intra-agency jargon, supports situational awareness between agencies, and enables safe decision-making.

Issues in communication within or between agencies were seen in 6 cases:

- Between clinical teams:
 - Obstetric & neonatal teams
 - Referring location & critical care transport teams
 - Handover between day & night shifts
 - Referring team and investigation team
- Between hospital and Social Care
 - Complex discharge-planning following prolonged hospitalisation.
- Between school, family, and primary care
 - Mental health and emotional wellbeing concerns.
- Between NHS & private care providers delivering mental health services.
- Between health and Social Care services supporting families after the birth of a new baby.

2. The role of interpersonal interactions

Risk assessment relies on experience, clear pathways, and inter-agency communication. However, all risk assessment (information-gathering, interpretation & decision-making) occurs in, and is shaped by, interactions between a practitioner and the child or family. Children, young people & their families are critical partners in this process, and the quality of this interaction is critical in recognising & responding to risk.

Communication with families was noted as modifiable in 4 cases.

- Interpreters need to be available & appropriate – different dialects within a language can add an additional barrier and lead to misunderstanding.
- An empathetic, collaborative approach fosters shared understanding and better outcomes. When parents raise concerns about their child, or about their care, it is safety-critical that these concerns are heard and addressed.

Theme: Infant Mortality



Key information: Infant deaths in LLR

Definition - Infant: liveborn child (of any gestation), up to 364 days of age.

- Notifications received: 66 cases (72% of all case notifications) – marked increase from 55% in 2023-24.
- Births at previsible gestation: 18 cases (27% of all infant case notifications).
- Reviews completed: 55 cases (68% of all completed reviews).
- Modifiable factors identified in 25 cases (45% of infant deaths reviewed).
- Most common modifiable factors by Domain Group (as percentage of infant cases reviewed):
 - Risk factors in mother during pregnancy/delivery (including smoking in pregnancy): 14 cases (25%)
 - Not following guidelines, pathways or policies: 9 cases (16%)
 - Smoking/vaping/alcohol/substance misuse/use by parent/carer: 4 cases (7%)
 - Sleep environment: 4 cases (7%)
 - Issues with staffing/bed capacity/equipment: 4 cases (7%)
 - Issues with initiation of treatment or identification of illness: 4 cases (7%)

Table 12. Age at death for notifications of deaths occurring under 1 year of age 2024/25

Age at death	No of cases			
	21/22	22/23	23/24	24/25
Born under 23 weeks gestation & died <1 day	7	20	8	18
0-27 days	34	34	26	34
28-364 days	19	17	11	14
Total	60	71	45	66

Chart 5. Percentage of infant deaths reviewed by Index of Multiple Deprivation 2022/23 – 2024/25

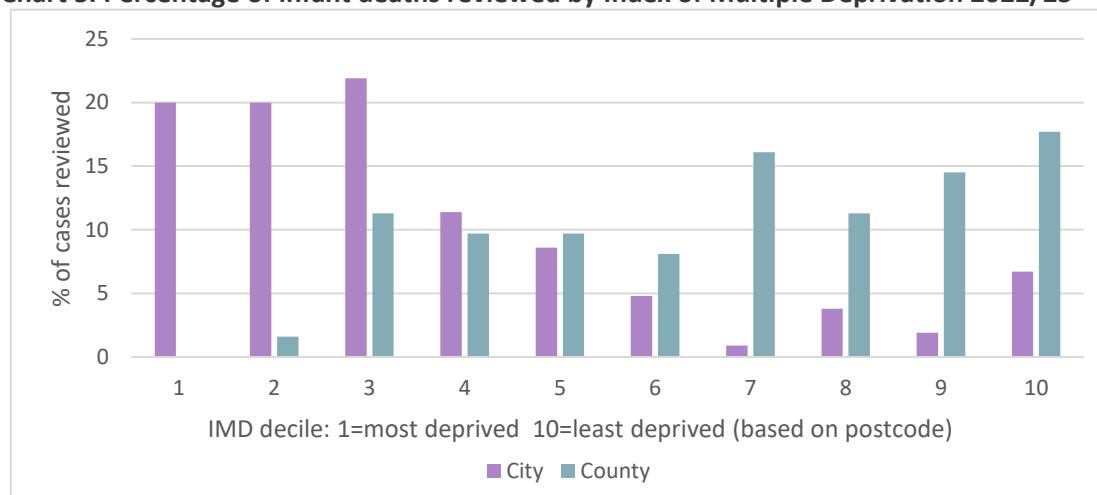


Table 13. Categories of death for children under 1 year – completed reviews 2024/25

Category of death	% of cases under 1 yr of age			% of cases under 1 yr of age where modifiable factors identified by category		
	22/23	23/24	24/25	22/23	23/24	24/25
Perinatal/neonatal event	52%	64%	49%	54%	35%	52%
Chromosomal, genetic or congenital anomaly	28%	18%	38%	14%	0	29%
Sudden unexpected, unexplained death	10%	11%	7%	100%	71%	100%
Infection	2%	2%	2%	100%	100%	0
Malignancy	4%	2%	2%	50%	0	0
Deliberately inflicted injury, abuse or neglect	0	0	2%	0	0	100%
Trauma or other external factors	2%	2%	0	100%	100%	0
Acute medical condition	2%	2%	0	0	0	0
Chronic medical condition	0	2%	0	0	0	0

Theme: Sudden unexplained infant deaths



Key information: Sudden unexpected unexplained deaths of infants

In the period between 1st April 2018 and 31st March 2024, CDOP reviewed the deaths of 26 children who died under 1 year of age, and whose deaths were categorised by the panel as Sudden Unexpected Unexplained Deaths.

This categorisation is based on the medical cause of death at post-mortem and review of the circumstances of death & will include all deaths attributed to Sudden Infant Death Syndrome (SIDS) or with an 'unascertained' medical cause (where it was not possible to determine the most likely medical cause of death), but not those as a result of external causes such as overlay or mechanical airways obstruction.

- 62% of infants who died suddenly & unexpectedly over the past 5 years were bottle-fed.
 - Breast-feeding is known to reduce the risk of SIDS, and this is likely to be through a variety of physiological mechanisms which may be protective for babies. It is important that safer sleeping messages are accessible to all caregivers, regardless of feeding methods.
- Half of babies were not first-born infants, highlighting the importance of reiterating safer sleeping advice to families with each baby that is born.
- 35% of babies were born premature.
 - The proportion of babies born preterm and dying suddenly & without explanation has fallen from around two thirds in 2015-16 to 2020/21, however this group is still over-represented. There is an association between maternal smoking and prematurity, and both these factors increase the risk of SIDS.
- Unsafe sleeping practices were identified in 56% of cases – this has remained relatively unchanged over time.
- Parental smoking was noted in around three quarters of cases.
- Over two thirds of cases had multiple modifiable factors, highlighting both the many vulnerabilities that are often present, and the need to consider safer sleeping alongside support for wider contextual issues in reducing risk.

Table 14. LLR Sudden Unexpected Unexplained Deaths in Infancy –5-year pooled data 2016/17 to 2024/25

	2016/17 to 2021/22 (n=15)		2017/18 to 2022/23 (n=20)		2018/19 to 2023/24 (n=24)		2019/20 to 2024/25 (n=26)	
	N	%	N	%	N	%	N	%
Bottle fed	11	73%	15	75%	16	67%	16	62%
First born	6	40%	8	40%	12	50%	13	50%
Preterm	9	60%	10	50%	9	38%	9	35%
IMD 1&2	6	40%	7	35%	7	29%	7	27%
Birthweight <2.5kg	9	60%	10	50%	9	38%	10	38%
Mean maternal age	28.73 yrs (20-36 yrs)		27.4 yrs (20-36 yrs)		25.7 yrs (17-36 yrs)		27.1yrs (17-36yrs)	
Known to Social Care	8	53%	10	50%	10	42%	10	38%
Housing issues	6	40%	7	35%	9	38%	8	31%
Domestic Abuse	7	47%	8	40%	7	29%	6	23%
Parental drugs/alcohol	5	33%	7	35%	7	29%	7	27%
Medical cause of death:								
'Unascertained'	11	73%	16	80%	20	83%	21	81%
'SIDS'	4	27%	4	20%	4	17%	4	15%
Other (inc 'SUDI')	0	0	0	0	0	0	2	8%
Modifiable Factors								
Unsafe sleeping	9	60%	12	60%	15	63%	17	56%
Parental smoking	9	60%	14	70%	18	75%	19	73%
One or more MF	13	87%	18	90%	20	83%	22	85%
More than one MF	11	73%	15	75%	17	71%	17	65%



Table 15. Key learning themes identified during the 2024/25 LD Thematic Review

	Children & young people with a Learning Disability and their families often describe challenges with navigating and accessing health and care systems, often having to repeat their stories. Care Passports can provide a single summary of a child's health and care needs, and reasonable adjustments to enable them to access the care and support they require.
	When Children & young people with a Learning Disability are included on the GP Practice Learning Disability Register, this enables reasonable adjustments to be provided, and delivers enhanced support for their long-term health & wellbeing, and for their family.
	Children & young people with a Learning Disability are vulnerable to the impact of second-hand cigarette smoke inhalation, which can exacerbate existing health issues.
	Aspiration pneumonia is a significant cause of ill-health and death for children, young people & adults with a Learning Disability; identification of those at risk and appropriate management can reduce the impact of aspiration pneumonia on long-term health & outcomes.
	For those with a life-limiting condition, children, young people & their families benefit significantly from timely and clear advanced care planning, including being offered choice around their preferred place of death, and information about practical considerations, before and after bereavement.
	Having an allocated lead medical consultant enables delivery of high-quality coordinated care across different teams and agencies, even in highly medically and socially complex cases. In line with national guidance & the recommendations of the Francis Report, every child and young person with complex healthcare needs should have an allocated lead medical consultant.

Recommendations & actions for 2025/26

7. For collaboration between UHL, LPT & the ICB LDA Collaborative to develop an LLR-wide Care Passport for children & young people with a Learning Disability.
8. For continuation of the ongoing work across LLR, led by the Learning Disability Primary Care Liaison Nurse team, to identify children & young people with a Learning Disability, to ensure they are included on the GP Practice Learning Disability Register, and for all agencies to promote participation in the Annual Learning Disability Health Check for young people (aged 14yrs onwards) and their families, as a key part of transition to adulthood.
9. For Public Health in Leicester City & Leicestershire to explore expanding smoking cessation in-reach services to parents and carers of children and young people with a Learning Disability.
10. For the LDA Collaborative to evaluate whether the Aspiration Pneumonia tool used for adults with a Learning Disability would be clinically appropriate for use in the paediatric population across LLR.
11. For paediatric services across UHL and LPT to continue to ensure that all children and young people with a life-limiting condition are considered for a Children & Young People's Advanced Care Plan (CYPACP), that discussions around advanced care planning with families are informed, timely, sensitive and clear, and that (wherever possible) the wishes of children, young people & their families are accommodated in end-of-life care planning.
12. In line with the recommendations of the NCMD Report Learning from deaths: Children with a learning disability and autistic children aged 4-17yrs (based on the Francis Report findings & Paediatric Critical Care Society 2021 Standards), paediatric services across LPT & UHL to ensure that every child & young person with a Learning Disability & medical complexity has an allocated lead medical consultant.



Key information: National Child Mortality Database

In line with statutory guidance, all data collected by every CDOP across England is submitted to the National Child Mortality Database (NCMD). This is the only such database in the world, collecting a unique standardised dataset about every child who dies (including the facts of the case & case analysis), regardless of the circumstances of their death. As such, it is a very powerful tool to identify themes and trends which may be contributing to child mortality in England.

The NCMD are commissioned by NHS England to publish two thematic reports each year, looking at specific themes and making recommendations for action to national & local bodies (both commissioners and providers) to improve quality of care, address safety issues, share learning and reduce child mortality.

All NCMD Thematic Reports are published and available online: www.ncmd.info/publications/

NCMD Report: Learning from Deaths: Children with a learning disability & autistic children aged 4-17 years ⁹

Key points:

- 818 deaths occurring between April 2019 – March 2022, with completed reviews by November 2023.
- 669 deaths of a child with a learning disability, 77 deaths of autistic children, 87 deaths of autistic children with a learning disability.
- Children with a learning disability made up 31% of total number of deaths of children aged 4-17yrs.
- Autistic children made up 3% of the total number of deaths of children aged 4-17yrs.
- Recommendations included:
 - Provision of reasonable adjustments, with use of digital flags in electronic records.
 - Ensuring recognition that children with a learning disability are at higher risk of death from infection – guidance and training needed to support this.
 - Ensure autistic children and young people or those with learning disability who have multiple co-morbidities or complex health care needs, have a named lead healthcare professional.
 - Ensuring timely access to appropriate support for those waiting for an autism assessment.
 - Ensuring ‘was not brought’ policies recognise and meet the needs of the complex lives of children with a learning disability, autistic children, and their families, and that they support effective attendance with suitable safeguarding and escalation in place where needed.

NCMD Programme Thematic Report: Child Deaths due to Asthma or Anaphylaxis, Dec 2024 ¹⁰

Key points:

- 54 child deaths due to asthma, and 19 due to anaphylaxis, between April 2019 – March 2023.
- Death rate from asthma 4 times higher for children from most deprived areas.
- 15-17 year olds were the age group with the highest death rate due to asthma and anaphylaxis.
- 87% had 3 or more reliever inhalers dispensed in the year before death.
- 65% had attended an emergency department or had an emergency admission in the year before death.
- 87% of cardiac arrests due to asthma occurred outside of hospital.
- Recommendations included:
 - Recognising asthma as an important and significant public health issue.
 - Ensuring a government plan to reduce air pollution levels to meet the World Health Organisation guidelines.
 - Adoption of the ‘Asthma Friendly Homes’ initiative to tackle mould, damp and reducing household smoking.



Key information: CDOP Actions 2024/25

- The role of LLR CDOP is to review and analyse information about the death of any child normally resident in our area.
- Where it is considered that it would be appropriate for a person to take action, there is a statutory duty (as set out in the Children Act 2004) to inform that person.
- Out of 81 completed case reviews, actions were raised in relation to 49 cases.
- In the 32 cases where no additional CDOP actions were raised, this includes all cases where actions had been raised and completed prior to the case coming to panel.
- ‘Data to learning to action’: LLR CDOP has engaged widely across the system, using the data gathered to inform learning, and sharing this to shape actions taken to reduce child mortality and enhance the welfare of children, young people and their families across Leicester, Leicestershire & Rutland. Examples of this are shown in Fig 6 (also see Appendix A).

Table 16. Cases where actions undertaken by LLR CDOP in 2024/25

Action undertaken	Number of cases
Clarification of information	16
Escalation of response (including via NCMD Alert)	5
Sharing of information/learning	6
- includes with:	
o Bereaved family	
o Another locality Child Death Overview Panel	
o Primary care	
o Healthy Together team	
o Midwifery service	
Seeking assurance	32
Other	4
No Panel actions identified	32

Fig 6. LLR CDOP System map to illustrate the process of data collection, learning, collaboration and action.





1 Infant Mortality in LLR

- For all agencies in LLR to promote and protect breastfeeding for all families as a golden thread running throughout all other work, as this is a key means of both reducing risk of sudden unexplained infant deaths and improving short and long-term health outcomes for women & children.
- For all agencies in LLR to continue to promote and audit the use of the LLR Safer Sleeping Risk Assessment Tool.
- For commissioners & providers to increase resources to tackle rates of smoking in pregnancy and to increase the number of smoke-free homes in LLR.
- For an increase in work to promote healthy weight both pre-pregnancy and in pregnancy, linking with the Leicester City Whole Systems Approach to Healthy Weight and NHS #Readyforpregnancy campaign.

2 Service Provision

- For agencies to fully explore, as part of internal governance reviews, the barriers or drivers behind decision-making when guidance or policy is not followed by front-line practitioners.
- For all staff working within health (primary and secondary care, physical and mental health, perinatal and paediatric services) to be able to assess and recognise risk (within expected levels of competence), and to respond appropriately, with all staff being empowered to escalate any concerns as soon as they arise.
- For a restorative culture of openness and learning throughout all agencies, which welcomes the voices and experiences of children, families, and front-line staff as an opportunity for learning, and fully considers the wider contextual, human and system factors which may have contributed to outcomes.

3 Learning from excellence: End-of-life care

- For sharing of best practice in end-of-life care, so that all senior clinical staff caring for infants, children and young people are aware of what good care, good communication, and advanced care planning looks like.
- For both UHL and LPT to ensure appropriate training is delivered to medical staff to support timely conversations, delivery of high-quality child-centred advanced care planning, (including robust anticipatory care planning and parallel planning), and family awareness of post-bereavement care & processes.

4 Children & Young People with a Learning Disability

- For a multiagency approach to develop, promote & embed the use of 'Care Passports' for children and young people with a Learning Disability.
- For health services across LLR to ensure all children & young people with a Learning Disability are identified for inclusion on the GP Practice Learning Disability Register to support optimisation of health outcomes.
- For all children and young people with a Learning Disability & medical complexity to have an allocated lead medical consultant.

5 Healthy lungs for babies, children, young people & their families

- For increasing promotion of smoke-free homes across Leicester City, Leicestershire & Rutland.
- For ongoing work to ensure accessible smoking cessation services are offered to households as part of standard antenatal care.
- For ongoing work to address childhood exposure to poor outdoor air quality through work including transport plans, promotion of active travel, and anti-idling campaigns outside schools.
- For the development of smoking cessation in-reach services via Paediatric Respiratory Clinics, ensuring particularly that those children and young people with both a Learning Disability and complex respiratory needs, are afforded the opportunity to live in a smoke-free home.
- For consideration by the ICB, Public Health and Housing across LLR, of adopting the 'Asthma-friendly homes' initiative, as recommended in the NCMD Asthma Report, to tackle mould, damp and household smoke exposure.



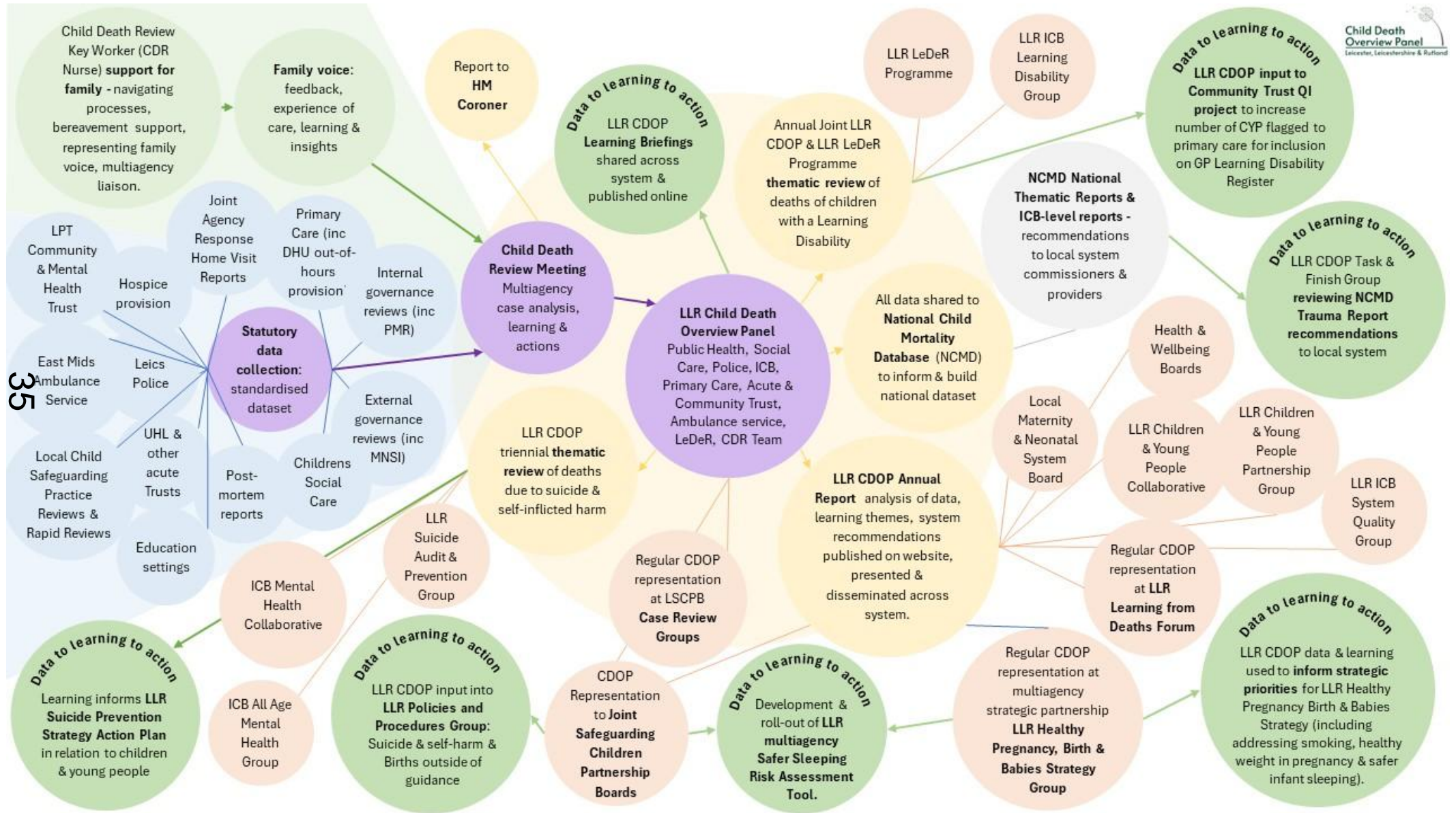
1. Oversight of the 2024/25 Annual Report recommendations as a standing item on the Panel Agenda, and development of an Action Plan with allocated leads for progression of the recommendations.
2. Regular Child Death Overview Panels every 6-8 weeks, with additional themed Neonatal Panels.
3. LLR CDOP triennial thematic review of deaths due to suicide & self-inflicted harm, with development and publication of an LLR Joint Agency Response Pathway following a suspected suicide of a child or young person.
4. Multiagency stakeholder review of the NCMD Deaths due to Traumatic Incidents report recommendations, to establish whether additional actions are indicated within LLR.
5. Ongoing participation in East Midlands Regional CDOP Network.
6. Delivery of Joint Agency Response multiagency training sessions, including an in-person training day, and development of an online e-learning offer.
7. Continued close working with the LLR LeDeR programme, with annual themed panels for children & young people with a Learning Disability and sharing of learning between LeDeR and CDOP.
8. Engagement with LLR Learning from Deaths Forum to share learning themes with the wider system.
9. Sharing of learning via the LLR CDOP Annual Report across the Integrated Care System.
10. Ongoing implementation of the NCMD Key Worker Toolkit, in close collaboration with agencies supporting bereaved families, to ensure equity of access to bereavement support and to the opportunity for families to participate in the Child Death Review process.



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8. Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) policy 2021. London: NHS England & NHS Improvement; 2021. 62. Available at: <https://www.england.nhs.uk/wp-content/uploads/2021/03/B0428-LeDeR-policy-2021.pdf>
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Appendix A. LLR CDOP System Map 2026.



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- Key:
- Data source: professionals
 - Data source: families
 - Child death review process.
 - Regular CDOP data & learning outputs.
 - System-level groups and multiagency partnerships.
 - Example of translating CDR data into learning, & then into action.

Appendix B. NCMD Cause of death categorisation.

The CDOP should categorise the likely cause of death using the following schema.

This classification is hierarchical: where more than one category could reasonably be applied, the highest up the list should be marked.

Category	Name & description of category	Tick box below
1	Deliberately inflicted injury, abuse or neglect This includes suffocation, shaking injury, knifing, shooting, poisoning & other means of probable or definite homicide; also deaths from war, terrorism or other mass violence; includes severe neglect leading to death.	
2	Suicide or deliberate self-inflicted harm This includes hanging, shooting, self-poisoning with paracetamol, death by self-asphyxia, from solvent inhalation, alcohol or drug abuse, or other form of self-harm. It will usually apply to adolescents rather than younger children.	
3	Trauma and other external factors This includes isolated head injury, other or multiple trauma, burn injury, drowning, unintentional self-poisoning in pre-school children, anaphylaxis & other extrinsic factors. Excludes Deliberately inflicted injury, abuse or neglect (category 1).	
4	Malignancy Solid tumours, leukaemia's & lymphomas, and malignant proliferative conditions such as histiocytosis, even if the final event leading to death was infection, haemorrhage etc.	
5	Acute medical or surgical condition For example, Kawasaki disease, acute nephritis, intestinal volvulus, diabetic ketoacidosis, acute asthma, intussusception, appendicitis; sudden unexpected deaths with epilepsy.	
6	Chronic medical condition For example, Crohn's disease, liver disease, immune deficiencies, even if the final event leading to death was infection, haemorrhage etc. Includes cerebral palsy with clear post-perinatal cause.	
7	Chromosomal, genetic and congenital anomalies Trisomies, other chromosomal disorders, single gene defects, neurodegenerative disease, cystic fibrosis, and other congenital anomalies including cardiac.	
8	Perinatal/neonatal event Death ultimately related to perinatal events, e.g., sequelae of prematurity, antepartum and intrapartum anoxia, bronchopulmonary dysplasia, post-haemorrhagic hydrocephalus, irrespective of age at death. It includes cerebral palsy without evidence of cause and includes congenital or early-onset bacterial infection (onset in the first postnatal week).	
9	Infection Any primary infection (i.e., not a complication of one of the above categories), arising after the first postnatal week, or after discharge of a preterm baby. This would include septicaemia, pneumonia, meningitis, HIV infection etc.	
10	Sudden unexpected, unexplained death Where the pathological diagnosis is either 'SIDS' or 'unascertained', at any age. Excludes Sudden Unexpected Death in Epilepsy (category 5).	

Appendix C. Updated NCMD Contributory Factors – Oct 2024

Domain A. Factors intrinsic to the child

Domain Group	Domain Sub-group
Child health history/medical conditions	Prematurity. Low birth weight. Bottle-fed. Breast-fed. Acute/sudden onset illness. Chronic health condition. Malignancy/cancer Congenital/genetic/chromosomal condition. Child not fully immunised (regardless of reason).
Risk factors in mother during pregnancy/delivery	Twin/multiple pregnancy. Assisted conception. High maternal BMI. Low maternal BMI. Smoking cigarettes/tobacco in pregnancy. E-cigarette use (including vaping devices) in pregnancy. Substance misuse in pregnancy. Alcohol misuse in pregnancy. Perinatal mental health condition. Maternal diabetes/gestational diabetes. Maternal age. Maternal infection. Late booking/concealed pregnancy. Other obstetric complications. Delivery complications.
Child's developmental conditions/disabilities	Learning disability. Sensory impairment. Motor impairment. Other developmental impairment or disability. Neurodevelopmental conditions.
Emotional/behavioural factors	Mental health condition. Behaviour that put the child at risk. Suicidal or self-harm ideation. Poor or non-compliance with medication. Sexual orientation or gender identity issues. Loss of key relationships. Isolation from friends/family/support. Child was victim of bullying. Social media/internet use.
Smoking/vaping/alcohol/substance use/misuse by the child	Child consumed alcohol on day of death. Child consumed alcohol regularly/known to binge-drink. Child consumed drugs on day of death. Child was known to be a regular drug user. Child smoked tobacco/ used e-cigarettes (including vaping devices).
Other	

Domain B. Family & Social Environment

Domain Group	Domain Sub-group
Smoking/vaping/alcohol/substance misuse/use by a parent/carer	<p>Parent/carer had consumed alcohol around the time of child's death.</p> <p>Parent/carer known for alcohol misuse.</p> <p>Parent/carer had consumed drugs around the time of child's death.</p> <p>Parent/carer known for substance misuse.</p> <p>Parent/carer smoked cigarettes/tobacco in the household.</p> <p>Parent/carer used e-cigarettes (including vaping devices).</p>
Challenges for parents with access to services	<p>Parental non-engagement with any service.</p> <p>Child was not brought to appointment(s)/did not attend.</p> <p>Evidence of disguised compliance by parents in any service.</p> <p>Delay in seeking/failure to seek medical support.</p>
Domestic or child abuse/neglect	<p>Child was subject to physical abuse by an adult.</p> <p>Child was subject to sexual abuse by an adult.</p> <p>Child was subject to emotional abuse by an adult.</p> <p>Child was subject to neglect by an adult.</p> <p>Other known domestic violence/abuse in the household.</p>
Household functioning, parenting/supervision	<p>Complex home circumstances.</p> <p>Lack of appropriate supervision.</p>
Poverty & deprivation	<p>Income deprivation.</p> <p>Employment deprivation/unemployment.</p> <p>Health deprivation & disability.</p> <p>Barriers to services.</p>
Social Care	<p>Child on child protection plan at time of death.</p> <p>Child on Child in need plan at time of death.</p> <p>Child was a looked after child at time of death.</p> <p>Child was previously known, but not an open case.</p> <p>Child was a refugee/asylum seeker.</p> <p>Parent/carer was a care leaver.</p>
Cultural factors	<p>English not parents' first language.</p> <p>Parents are/were asylum seekers/refugees.</p> <p>Close relative marriage (consanguineous).</p>
Parent/Carer's health	<p>Physical health condition in parent/carer.</p> <p>Mental health condition in parent/carer.</p> <p>Disability in parent/carer.</p> <p>Learning disability in parent/carer.</p>
School/peer groups	<p>Exclusion/suspension from school.</p> <p>Truancy/poor attendance record.</p> <p>Gang/knife crime.</p> <p>Drug use in peer group.</p>
Other	

Domain C. Physical environment

Domain Group	Domain Sub-group
Sleep environment	<p>Unsafe sleeping arrangements.</p> <p>Co-sleeping. (<i>Co-sleeping alone does not constitute an unsafe sleep environment. IT is only a risk when combined with other factors e.g. smoking or drug/alcohol use.</i>)</p>
Home safety/conditions	<p>Overcrowded living conditions.</p> <p>Dirty, mouldy or property in poor repair.</p> <p>Unsafe appliances/environment.</p> <p>Attack by pets/animal.</p> <p>Living environment deprivation/homelessness.</p>
Vehicle collision	<p>Speeding vehicle/recklessness.</p> <p>Young child not appropriately restrained in car seat/booster seat.</p> <p>Child not using other appropriate safety equipment.</p> <p>Unsafe road conditions.</p>
Public safety	<p>Absent/non-visible warning signs.</p> <p>Unsafe street furniture/public equipment.</p> <p>Availability of safety equipment.</p> <p>Accessible railway tracks/other infrastructure.</p> <p>Accessible water.</p> <p>Poor compliance with health & safety regulations.</p>
Other	

Domain D. Service Provision

Domain Group	Domain Sub-group
Initiation of treatment/identification of illness	Issue in diagnosis. Issue with availability of information. Issue with treatment, including delays. Lack of recognition of deteriorating child/clinical symptoms/signs. Lack of escalation for senior review.
Following guidelines/pathway/policy	Guideline/policy/pathway available but not followed. Guideline/policy pathway unclear or unavailable No referral/assessment/review undertaken. Poor quality referral/assessment/review. Delayed referral/assessment/review.
Access to appropriate services	Issue with or lack of transfer of child. Child not born in appropriate setting. Service uncommissioned/unfunded/unavailable. Availability/accessibility of medication. Transition between paediatric and adult services.
Staffing/bed capacity/equipment	Staffing capacity or inappropriate skill mix. Bed/cot capacity. Equipment related issues.
Communication within or between agencies	Poor communication/information sharing within an agency. Poor communication/information-sharing between agencies. Poor documentation/record keeping.
Communication with family	Poor communication between professionals and family. Poor information sharing with family. Information provided to parents was inappropriate. Lack of interpreter availability/use/suitability.
Other	



LLR Child Death Overview Panel Annual Report 2024/25

Rob Howard, LLR CDOP Chair, Director of Public Health, Leicester City Council

Dr Suzi Armitage, LLR Designated Doctor for Child Deaths

Helen Reeve, Senior Data Analyst, Leicester City Council

Headline findings



Top **6** contributory factors that could be **modified** to reduce future child deaths in our area



Smoking in pregnancy



Unhealthy weight in pregnancy



Household exposure to cigarette smoke



Poor communication between agencies



Guidelines or policies not being followed

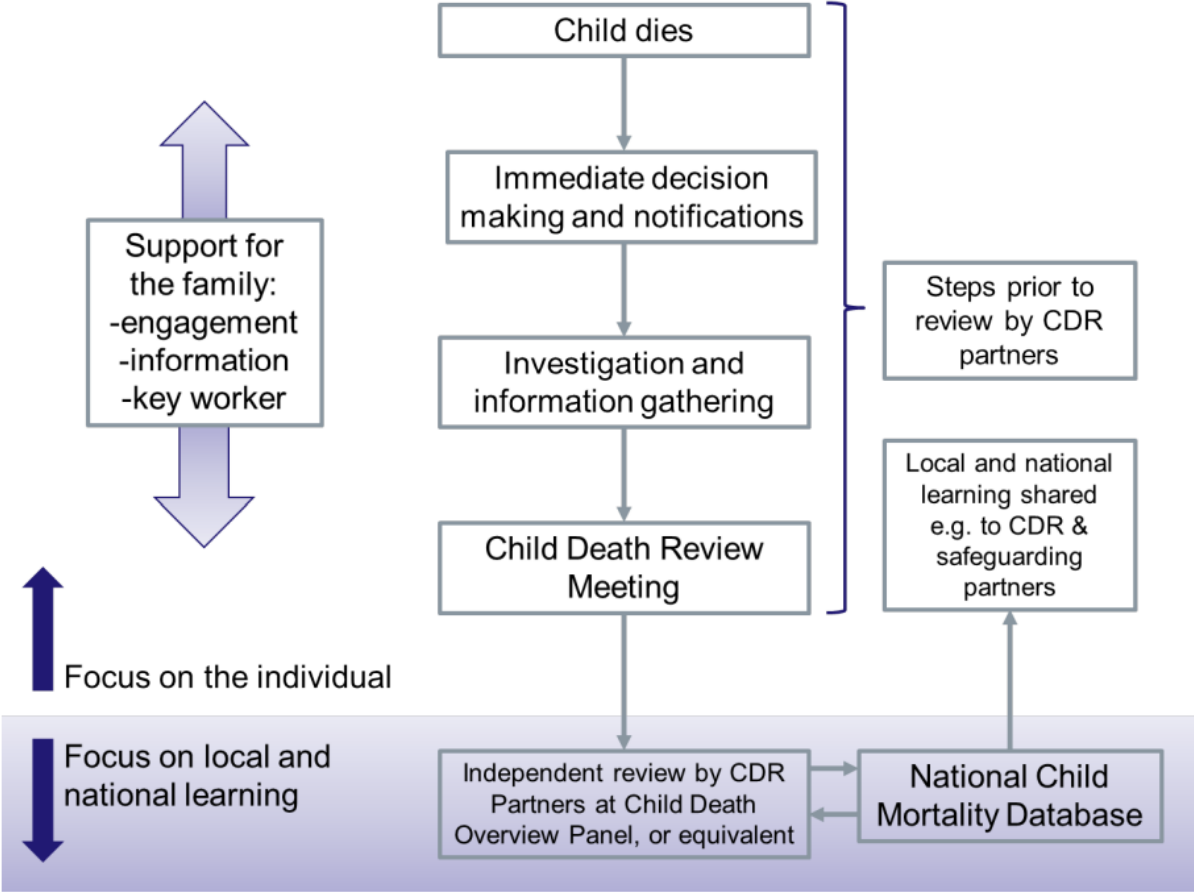


Missed signs of deterioration



Child Death Review Process

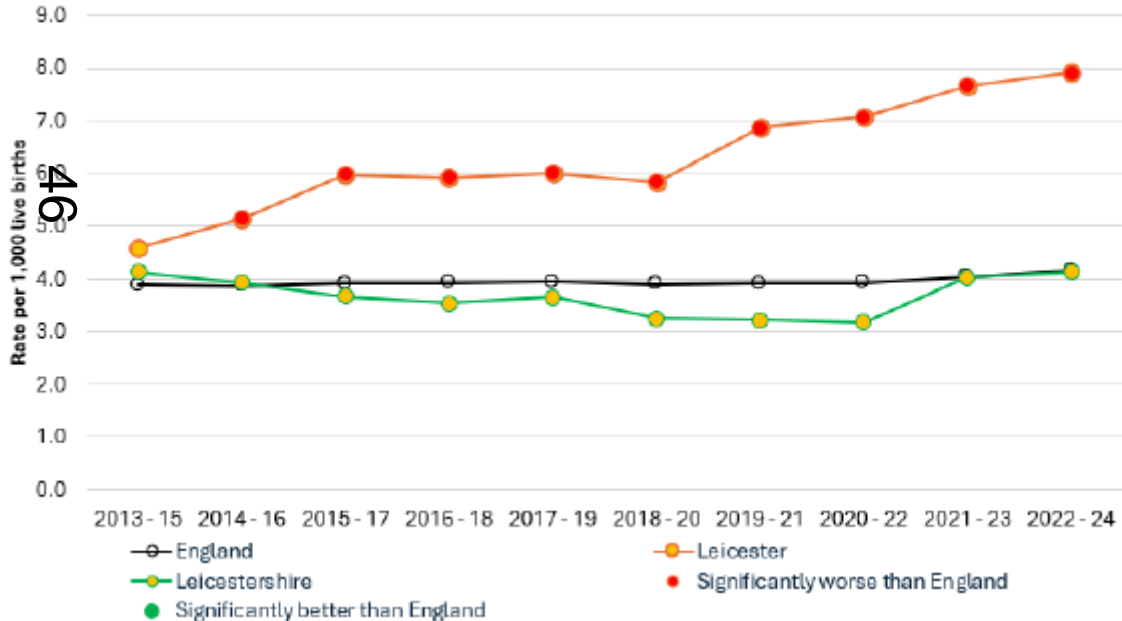
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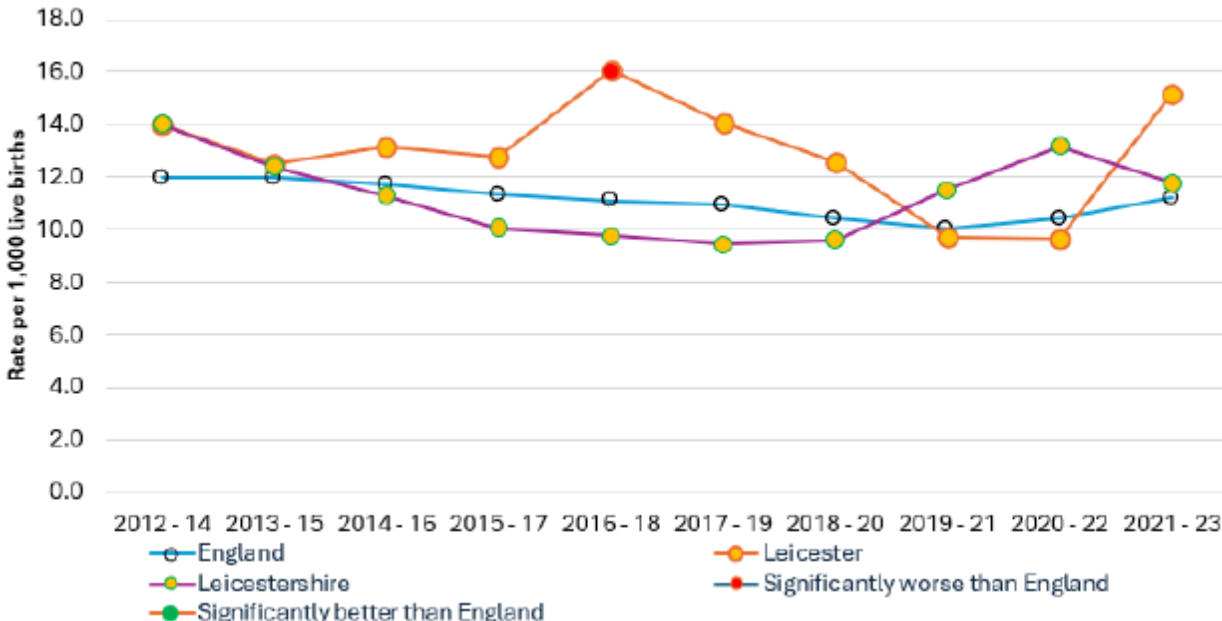


Summary Statistics

Infant mortality rate



Child mortality rate (1 to 17 years)



Wider context



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ICB: NHS Leicester, Leicestershire and Rutland Data source: NCMD, ONS mid-year population estimates

	Your ICB		England
	Infant deaths	Rate per 1,000 infants	Rate per 1,000 infants
1 (Most deprived)	126	7.7	5.3
2	48	4.1	3.8
3	45	3.9	3.0
4	51	3.2	2.6
5 (Least deprived)	40	3.1	2.2

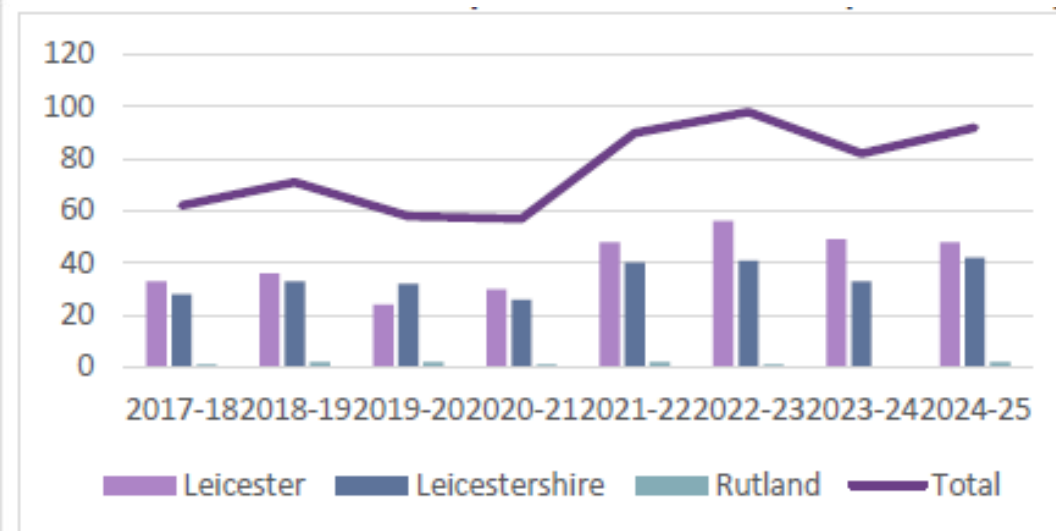
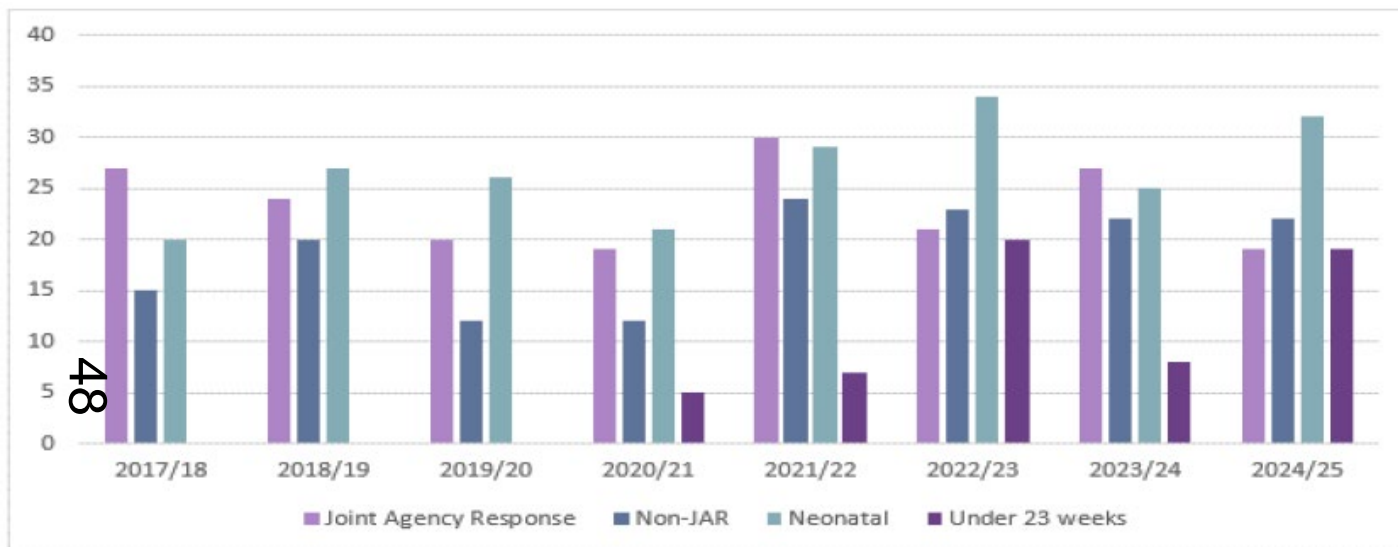
ICB: NHS Leicester, Leicestershire and Rutland Data source: NCMD, ONS mid-year population estimates

	Your ICB		England
	Deaths of 1 - 17 year olds	Rate per 100,000 population	Rate per 100,000 population
1 (Most deprived)	41	13.0	15.4
2	36	17.4	12.4
3	33	14.5	11.5
4	36	10.9	10.0
5 (Least deprived)	23	8.3	8.3

Notifications 2024/25



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Location of death:

- 77% In hospital
 - 56% on delivery suite or neonatal unit
 - 9% in Paediatric Intensive Care
- 20% Child's home
- 1% Hospice
- 1% Abroad

- 92 notifications in total.
- 29% of cases – Joint Agency Response
- 55% of cases – babies who died after birth on delivery suite or NNU
 - 37% of these born at <23/40 gestation.



Completed Reviews 2024/25

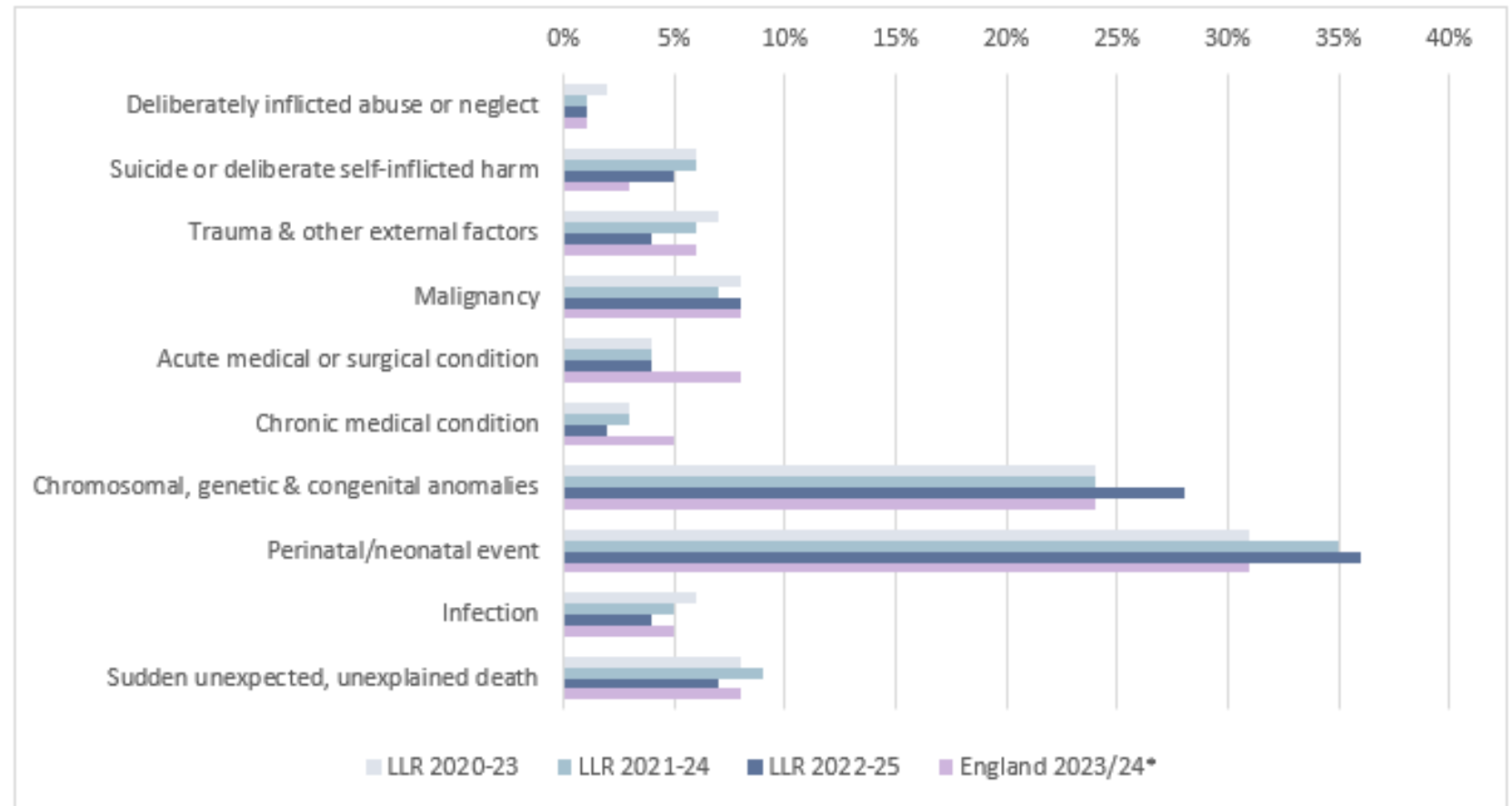
Category of death for completed reviews – 3 year merged data 2020 – 2025

*Data from NCMC Data Release Child Death Reviews Data: year ending 31 March 2024, published November 2024

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Completed reviews by year of death 2024/25

Year of death	Cases
2017-18	1
2021-22	4
2022-23	24
2023-24	47
2024-25	5
Total	81



Analysing the death of a child

- Health history/medical conditions
- Risk factors in mother during pregnancy
- Developmental conditions/disability
- Emotional/behavioural factors
- Smoking/substance misuse by child
- Other

- Initiation of treatment/identification of illness
- Following guidelines/pathway/policy
- Access to appropriate services
- Staffing/bed capacity/equipment
- Communication within or between agencies
- Communication with family
- Other

Child Factors



Family & Social Environment

Service Provision

Physical Environment

- Smoking/alcohol/substance misuse by parent/carer
 - Challenges with access to services
 - Domestic or child abuse/neglect
 - Household functioning
 - Poverty & Deprivation
 - Social Care
 - Cultural factors
 - Parent/Carer's health
 - School/peer groups
 - Other
- Sleep environment
 - Home safety/conditions
 - Vehicle Collision
 - Public Safety
 - Other

Definitions

Contributory Factor = Factor present & contributed to the death or vulnerability of the child.

Modifiable Factor = Factor could be modified by means of a locally or nationally achievable intervention to reduce risk of future deaths.



Local learning: contributory factors (1)

Domain A: Factors intrinsic to the child 2024/25

Noted in 80 cases (99%).

51

Factor by group	No of cases	% of cases
Child health history/medical condition	77	95
Risk factor in mother during pregnancy	32	40
Child's developmental condition/disability	11	14
Emotional/behavioural factors	3	4
Other	2	2
Smoking/alcohol/substance use/misuse by child	2	2

Domain B: Factors in the family/social environment 2024/25

Noted in 31 cases (39%).

Factor by group	No of cases	% of cases
Parent/carer's health	12	15
Cultural factors	10	12
Smoking/alcohol/substance misuse/use by parent/carer	10	12
Challenges for parents with access to services	9	11
Household functioning, parenting/supervision	8	10
Domestic or child abuse/neglect	7	9
Social Care	3	4
Poverty & deprivation	2	2
Other	1	1
School/peer groups	1	1

Local learning: contributory factors (2)



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Domain C: Factors in the physical environment 2024/25

Noted in 5 cases (6%).

Factor by group	No of cases	% of cases
Sleep environment	4	5
Home safety/conditions	1	1
Public Safety	1	1
Vehicle collision	0	0

Domain D: Factors in service provision 2023/24

Noted in 24 cases (30%).

Factor by group	No of cases	% of cases
Following guidelines/pathway/policy	13	16
Initiation of treatment/identification of illness	8	10
Communication within or between agencies	6	7
Access to appropriate services	5	6
Communication with family	5	6
Staffing/bed capacity/equipment	5	6
Other	1	1



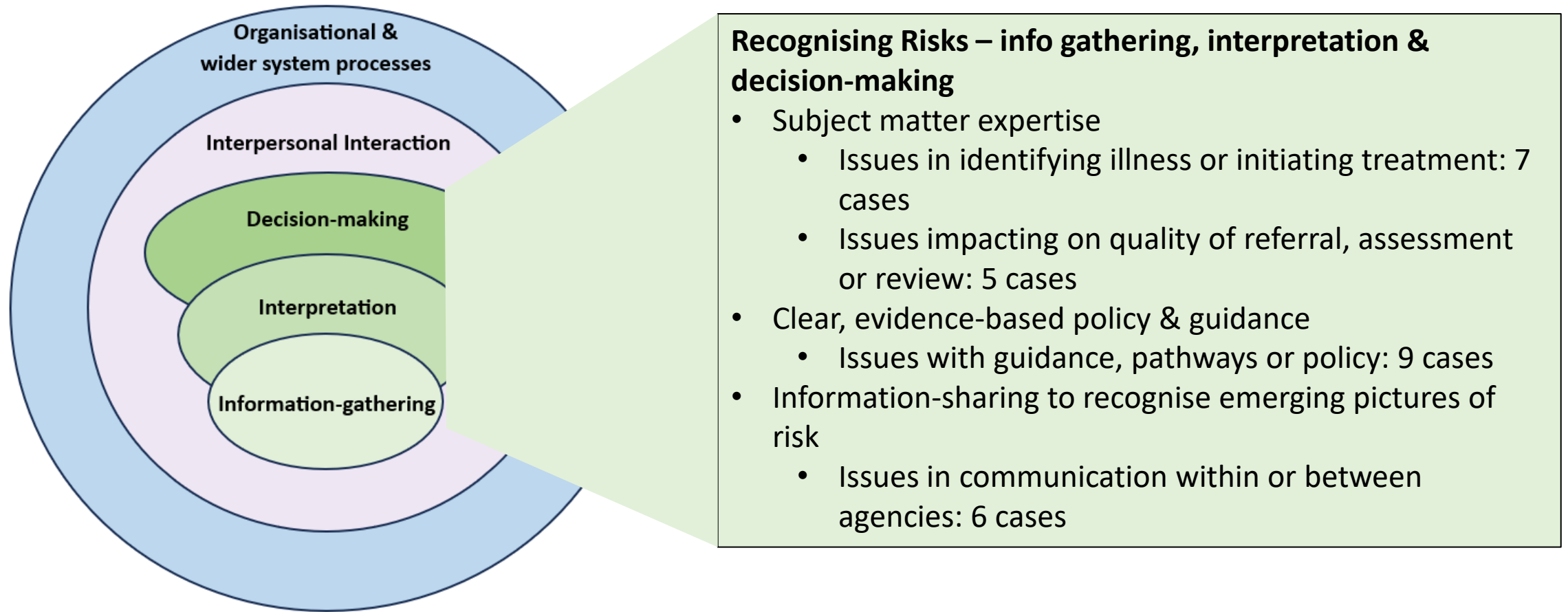
Local learning: modifiable factors

- Modifiable factors in 46% of LLR cases (43% England)
- 49% of these cases were children who died <28 days of age
- Most deprived quintile – MF in 60% of cases, least deprived quintile MF in 25%
- Most frequent by domain sub-group:
 - Smoking in pregnancy
 - High maternal BMI
 - Household smoking by parent/carer
 - Poor communication/information-sharing between agencies
 - Guidelines/policy/pathways not being followed.

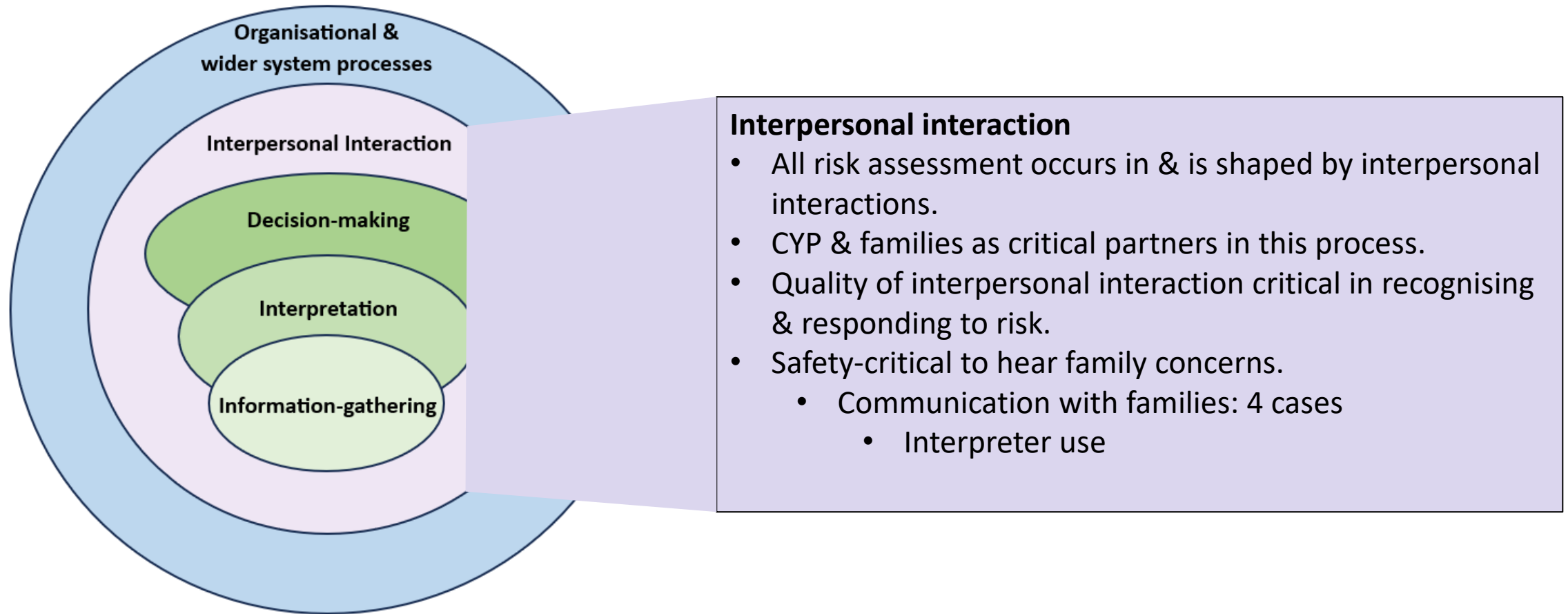


Local learning: Service provision

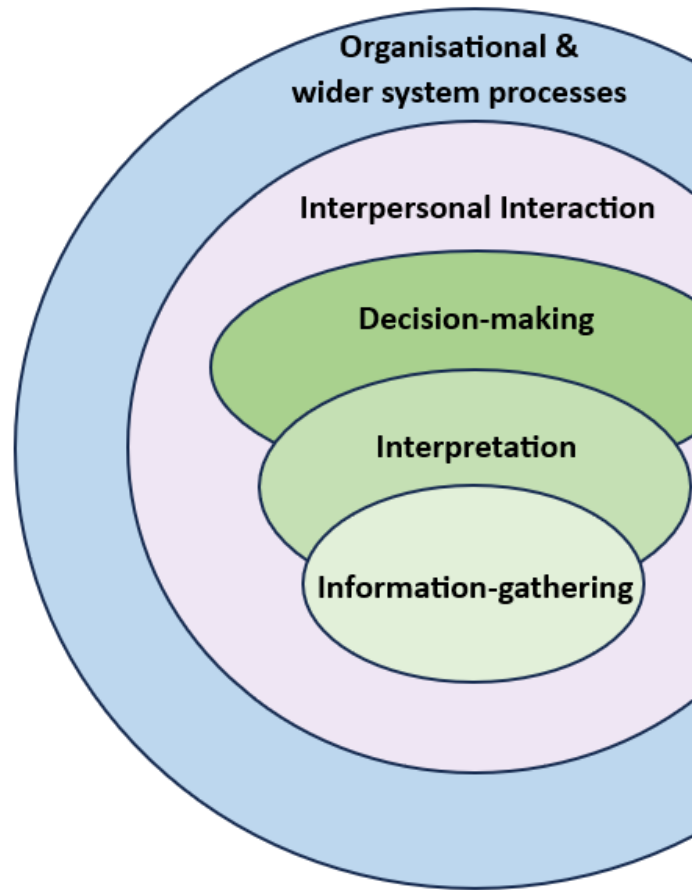
- 25% of completed reviews had modifiable factors relating to service provision.
 - 80% - learning already identified
 - 20% - learning identified at CDR Meeting (15%) or CDOP (5%).
- Low frequency, high-harm events
- Risk identification & mitigation
- Interagency working – different systems interacting



Risk assessment framework for reducing high-harm low-frequency events, adapted from Nathan et al⁷. Available under CC BY License.



Risk assessment framework for reducing high-harm low-frequency events, adapted from Nathan et al⁷. Available under CC BY License.



Risk assessment framework for reducing high-harm frequency events, adapted from Nathan et al⁷. Available under CC BY License.

Organisational & wider system processes

- Risk assessment & interpersonal interaction occurs within broader organisational & system processes & pressures
- To mitigate risks, need available & effective resources:
 - Provision of MHST
 - Organisational level processes which support care planning & risk assessment
 - Organisational level support to meet training needs
 - Clear & frictionless referral pathways
- Issues with access to appropriate services: 2 cases
- Issues with staffing capacity/skill mix: 3 cases







Addressing inequalities

- **Consider how diversity & difference may alter how risk factors present, interact & impact on CYP & families**
 - EAAL
 - Neurodiversity/Sensory impairments
 - LD
 - Black & minority ethnic groups
 - Trauma-experienced
 - Deprivation



Thematic learning – Learning Disability

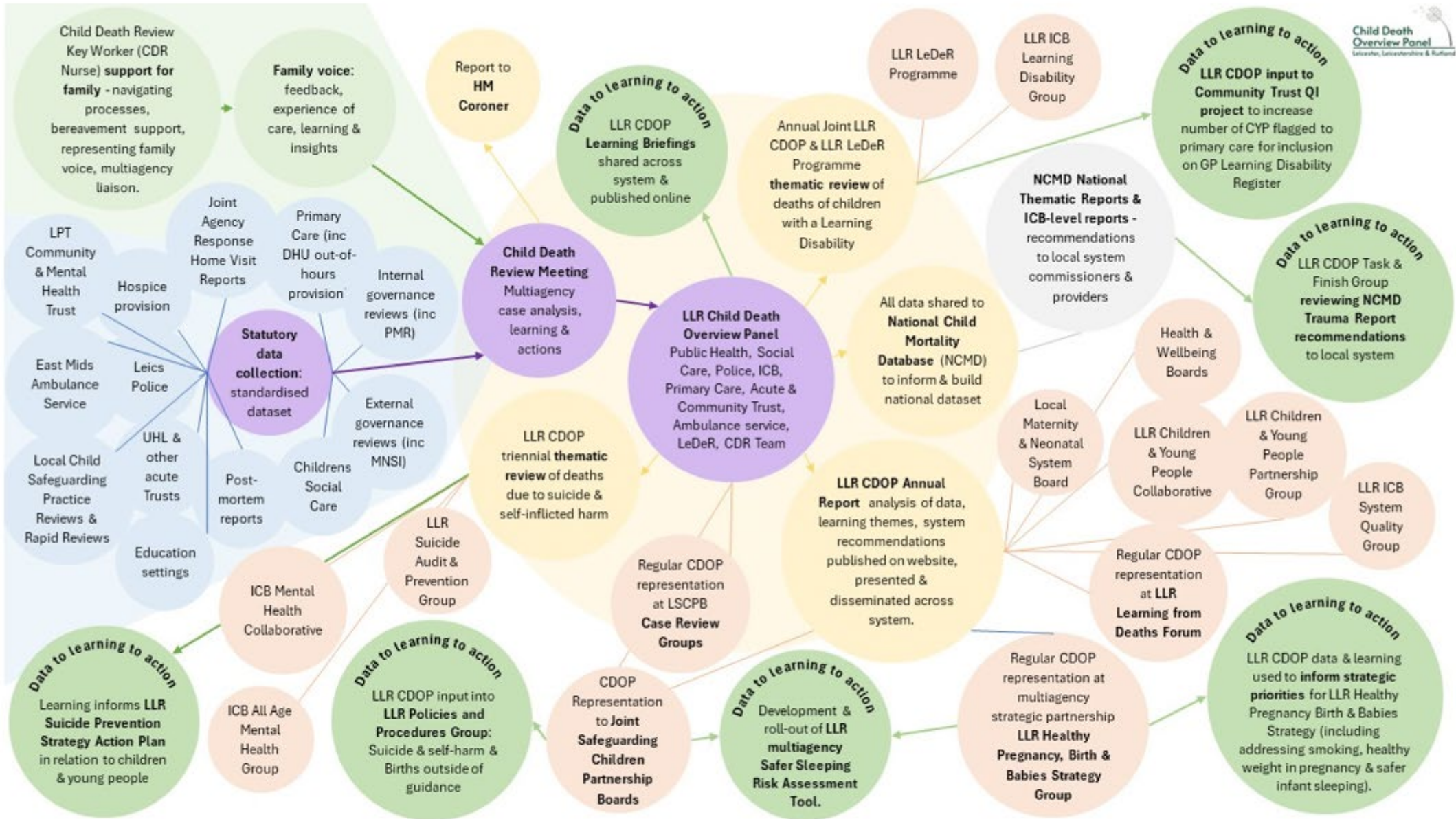
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	Care Passports to support information-sharing & accessible care for all
	Inclusion of CYP with LD on the GP LD Register & participation in good quality annual health checks.
	CYP with LD are vulnerable to impact of environmental smoke exposure when household members smoke.
	Identification & management for those at risk of aspiration pneumonia
	Timely & clear advanced care planning with choice about location for end-of-life care and information about pre & post bereavement care.
	Importance of an allocated medical lead for every child & young person with complex health needs.



National learning: NCMD Reports

- Available online: www.ncmd.info
- Learning from deaths: Children with LDA aged 4-17yrs
 - Provision of reasonable adjustments – digital flags
 - Awareness of risk of infection
 - Named healthcare professionals
 - Timely access to support for those on NDC assessment waiting lists
- Child deaths due to Asthma / Anaphylaxis
 - Asthma as important & significant public health issue
 - Adoption of asthma friendly homes
 - 87% of deaths – 3+ reliever inhalers prescribed in 12 months before death
 - 50% of deaths – 12+ reliever inhalers prescribed in 12 months before death



Key:

- Data source: professionals
- Data source: families
- Child death review process.
- Regular CDOP data & learning outputs.
- System-level groups and multiagency partnerships.
- Example of translating CDR data into learning, & then into action.



CDOP Recommendations

1. Infant Mortality

- Promote & protect breastfeeding for all
- Safer Sleeping Risk Assessment Tool
- Reduce rates of smoking in pregnancy, increase number of smoke-free homes
- Promotion of healthy weight before & in pregnancy

62

2. Service provision

- Curiosity in governance reviews – barriers & drivers to following guidance/policy
- Support staff to be able to recognise & respond to risk & empower to escalate concerns
- Restorative culture of openness & learning, welcome the voice of CYP & front-line professionals & fully consider wider system context.

3. Learning from excellence

- Sharing of best practice so all can see what good care, communication & advanced care planning looks like
- UHL & LPT to ensure appropriate training for medical staff around communication, advanced care planning & supporting families with post-bereavement care & processes.



CDOP Recommendations (2)

63

4. CYP with Learning Disability

- Develop, promote & embed Care Passports
- Ensure all CYP with a Learning Disability are on the GP Practice LD Register
- Allocated lead medical consultant for all CYP with LD & medical complexity

5. Healthy lungs for babies, children, young people & families

- Promote smoke-free homes across LLR
- Accessible smoking cessation services for households as part of antenatal care
- Public health work to address poor outdoor air quality across LLR
- Smoking cessation in-reach services via Paediatric Respiratory Clinics
- Consider adopting 'Asthma-friendly homes' initiative



Further information

- LLR CDOP information & resources including supporting bereaved families, Annual Reports, 7 Minute Briefings & STAR Briefings:

<https://lrsb.org.uk/child-death-overview-panel-cdop>

- National Child Mortality Database: www.ncmd.info

- Child Death Reviews: Statutory & Operational Guidance

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1120062/child-death-review-statutory-and-operational-guidance-england.pdf



Reducing Infant Mortality in Leicester

Public Health and Health Integration Scrutiny Commission

Date of meeting: 28/04/2026

Lead director/officer: Clare Mills

Useful information

- Ward(s) affected: All
- Report author: Clare Mills, Acting Consultant in Public Health
- Author contact details: clare.mills@Leicester.gov.uk
- Report version number: 51

1. Summary

This report provides an update on Infant Mortality in Leicester. The report covers:

Context:

Leicester City has the 2nd highest Infant Mortality rate in England behind Birmingham. Between 2022-2024, there were 105 infant deaths in Leicester giving a rate of 7.9 per 1,000 live births, the England rate is 4.2 per 1,000 live births.

The infant mortality rate in Leicester is significantly higher than Leicestershire and England and showing an increasing trend.

Future Plans for work with partners to reduce Infant Mortality in Leicester:

To help reduce Infant Mortality rates in Leicester, the Public Health team worked with colleagues from the ICB, Leicestershire Public Health team, NHS England and Office for Health Improvements and Disparities (OHID) to help identify the areas we can improve on. Local insight was gained from 12 twelve focus groups and 5 interviews with key stakeholders in Leicester, and from this actions were explored by 40 partners on 9th March. The key themes that were identified and explored were:

- Theme 1: Targeting Risk and Reducing Inequalities
- Theme 2: Consistent, High-Quality and Accessible Support
- Theme 3: Trusted Relationships and Community-Led Support
- Theme 4: Joined-Up Systems, Information and Intelligence

Actions Plans are currently being developed, a Steering Group established and prioritises set. Delivery against the top priorities is due to begin in the summer.

Healthy Pregnancy, Birth and Babies Group – good work that’s already happening:

- **CDOP(child death review panel) recommendation: Promote & protect breastfeeding for all:** Bumps to Babies delivery continues and is well evaluated by participants. Training and discussion on colostrum harvesting has been introduced with positive feedback from parents.
- **CDOP recommendation: Safer Sleeping Risk Assessment Tool:** Tool being used. Baby Basics providing safe sleep spaces for all babies referred to them, no wait for safe sleep spaces.
- **CDOP recommendation: Reduce rates of smoking in pregnancy, increase number of smoke-free homes:** Excellent quit rate for “Smoking at Time of Delivery” and Step Outside successfully relaunched.
- **CDOP recommendation: Promotion of healthy weight before & in pregnancy:** Maternal Weight Health Needs Assessment completed and delivery on actions begun. Healthy weight focus groups underway.

2. Recommendation(s) to scrutiny:

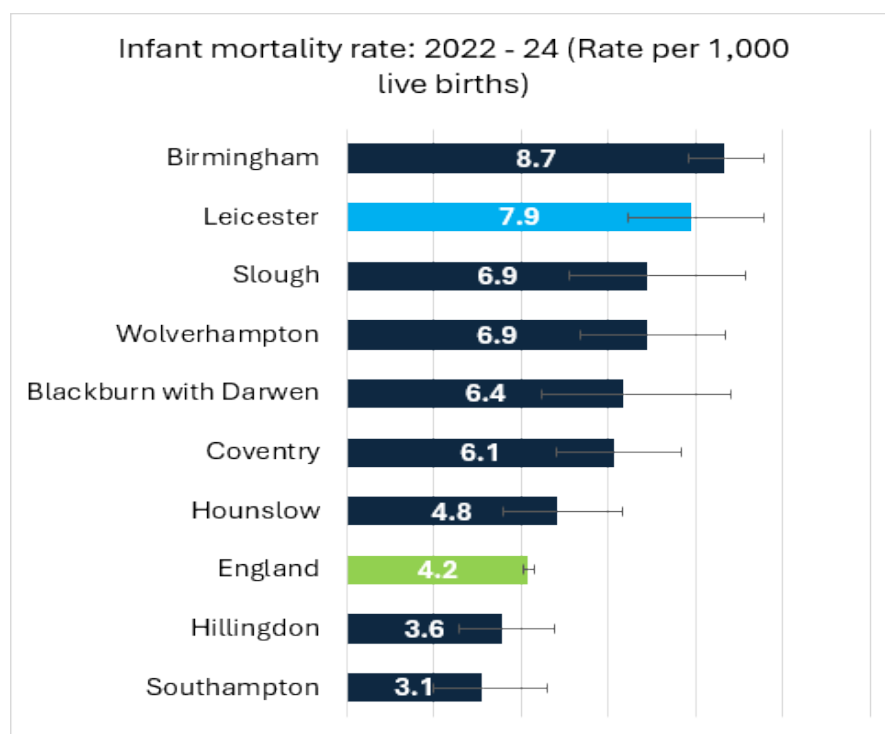
The Scrutiny Commission are invited to:

- Recognise the gravity of the current situation in Leicester.
- Support and endorse the work being developed to address Infant Mortality
- Recognise, support and champion the good work currently happening.

3. Detailed report

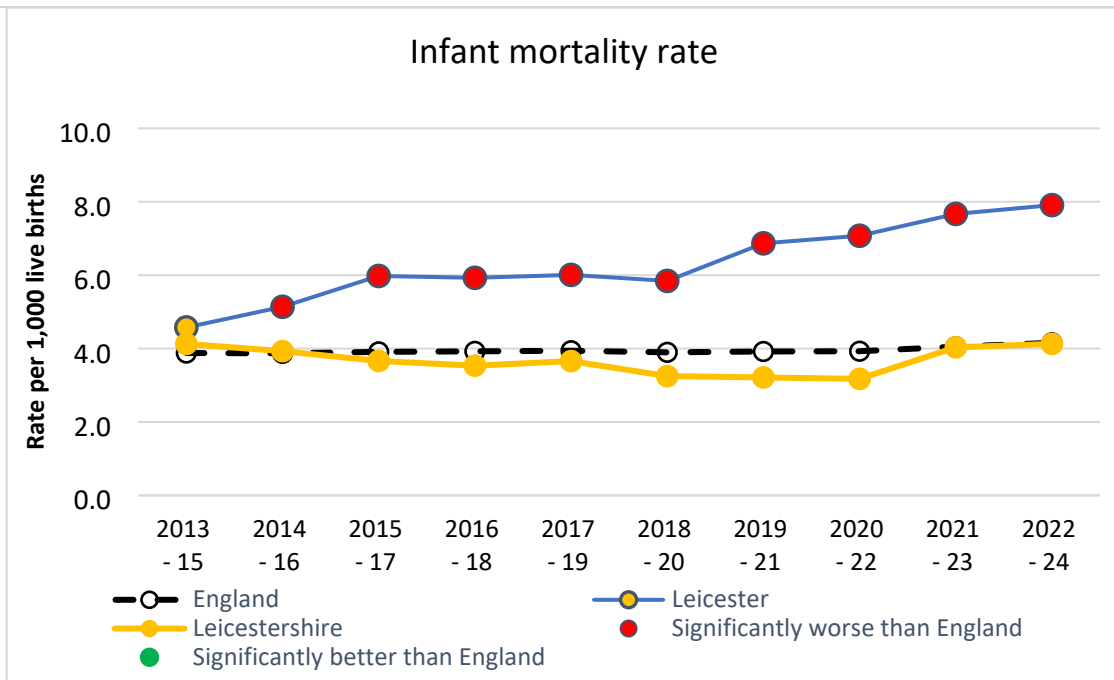
Context:

Leicester City has the 2nd highest Infant Mortality rate in England. Between 2022-2024, there were 105 infant deaths in Leicester giving a rate of 7.9 per 1,000 live births, the England rate is 4.2 per 1,000 live births.

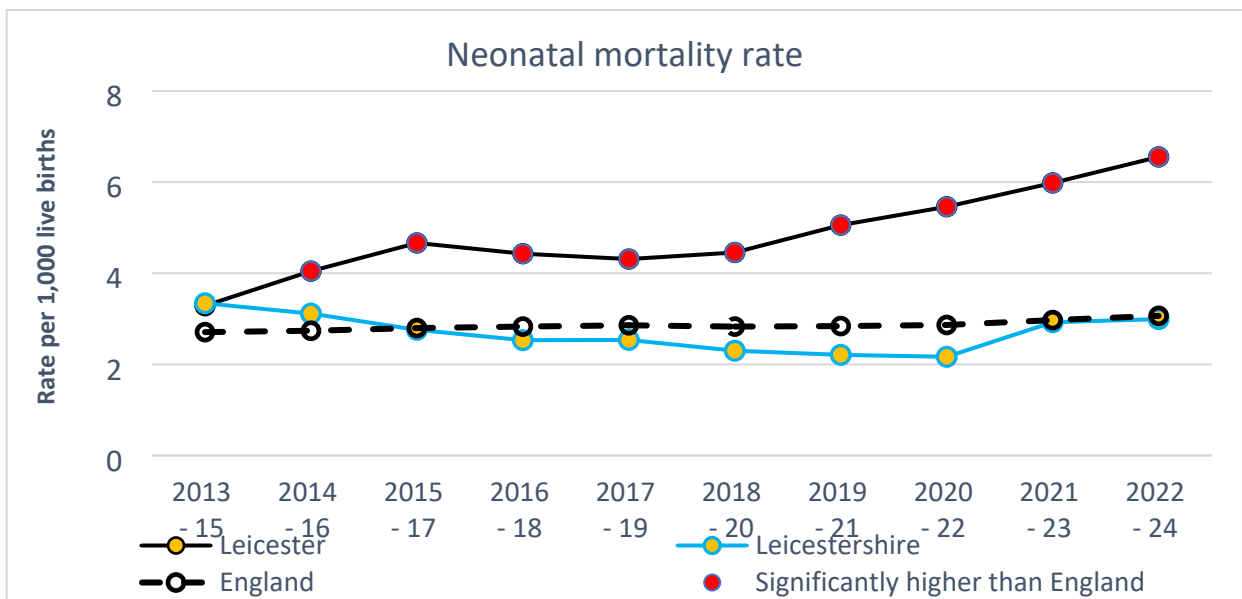


2026 <https://fingertips.phe.org.uk/> © Crown copyright 2026 (13th January 2026.)

The infant mortality rate in Leicester is significantly higher than Leicestershire and England and showing an increasing trend.



The Neonatal death rate (under 28 days) is significantly higher in Leicester than both Leicestershire and England. Neonatal deaths account for 70-80% of all infant deaths in Leicester.



Data: <https://fingertips.phe.org.uk/profile/child-health-profiles>

The top 6 contributory factors that could be modified to reduce the risk of future child deaths in Leicester are:

- Smoking in pregnancy
- Unhealthy weight in pregnancy
- Household exposure to cigarette smoke
- Poor communication between agencies
- Guidelines or policies not being followed
- Missed signs of deterioration.

Data shows national infant death rate in 2025 in Leicester, Leicestershire and Rutland is highest for infants of black or black British ethnicity (7.0 per 1,000 live births); more than double the rate of infants of white ethnicity (3.0 per 1,000 live births). The death rate of infants of Asian or Asian British ethnicity (5.2 per 1,000 live births) is also higher than for white infants.

Data: <https://www.ncmd.info/publications/child-death-review-data-release-2025/>

Future Plans for work with partners to reduce Infant Mortality in Leicester:

Leicester is fortunate to have to have so many people who understand the complexities and interdependence of the factors that influence infant mortality and in the face of this challenge, continue to passionately work towards improving outcomes for our babies; across all parts of the system fantastic work is taking place. However, despite all of our best efforts, Leicester has the second highest infant mortality rates in England.

The causes of infant mortality are complex and no one organisation can address this alone. To help reduce Infant Mortality rates in Leicester, the Public Health team worked with colleagues from the ICB, Leicestershire Public health team, NHS England and Office for Health Improvements and Disparities (OHID) to help identify the areas we can improve on. The work involves 3 phases:

- Insights
- Conference
- Action Plans and Delivery

Insights:

The team carried on 12 twelve focus groups and 5 interviews with a wide range of partners across health, local government, VCSE/community organisations about what is contributing to infant mortality in the Leicester, their knowledge and experience was vital in helping the team map work that is happening across the system, and in identifying gaps. The team explored four questions:

- (1) what is contributing to infant mortality locally
- (2) what are the key challenges
- (3) what has been successfully implemented
- (4) what more could be done.

Participants were encouraged to draw on operational experience and observed impacts on families, services and outcomes.

Thematic analysis of the discussion identified 4 key headlines:

1. Infant mortality is complex and is shaped by intersecting factors: deprivation and poverty, unstable/unsafe housing, social isolation, and higher clinical and social complexity.
2. Equity is central: stakeholders described unequal outcomes and unmet need affecting some ethnic minority and disadvantaged groups, and emphasised that translation alone is not enough; services and information must be culturally secure and accessible.
3. Variation and fragility in provision can widen gaps: workforce capacity, time in appointments, and consistency of evidence-based practice were repeatedly listed as impact on provision.

4. Whole-system coordination is key: partners highlighted the need for stronger integration across primary care, maternity, neonatal, health visiting, early help/family hubs and VCSE-supported by better data sharing and sustained implementation.

For the full report please contact Clare.mills@leicester.gov.uk

Conference:

On the 9th March 2026 an Infant Mortality Call to Action workshop was held, and over 40 participants from across health, local government, VCSE/community organisations attended. Building on the insights work the event was solution focused and participants work together, using logic models, to create actions across 4 themes:

Theme 1: Targeting Risk and Reducing Inequalities

- We have a shared understanding where and why babies are most at risk, so support is focused on the neighbourhoods and families who need it most.
- Families facing housing problems, poverty or domestic abuse get help earlier and more easily, with health services linked clearly to wider practical support.
- We understand the reasons why people are reluctant to engage with services and are using these insights to tailor support.

Theme 2: Consistent, High-Quality and Accessible Support

- Families receive the same high-quality care wherever they are seen, because a small number of proven practices are used consistently across services.
- Families can access services more easily, with flexible appointments, simpler referrals and fewer barriers to getting help.
- From preconception through to a child's first birthday, care will be provided at the right time and in the right place.

Theme 3: Trusted Relationships and Community-Led Support

- Families feel less isolated and more supported because they are connected to trusted people, groups and community networks that can help them during pregnancy and early parenthood.
- Families receive information and support in a way that feels relevant, respectful and trustworthy, because it is shaped with communities and reflects their cultures and lived experience.
- Families at highest risk have ongoing trusted relationships with our teams.
- Families benefit from strong community and voluntary sector support, because services work closely with VCSE partners and funding is more stable where impact is shown.

Theme 4: Joined-Up Systems, Information and Intelligence

- Families hear the same clear supportive messages wherever they go, so they know how to keep themselves and their babies healthy during pregnancy and early parenthood.
- Families know where to get help and are signposted quickly, because every professional knows what other help is available.
- Families will transition smoothly across services along with their information, so that professionals can tailor support to them.
- We have strong intelligence sharing processes in place and are using data to make sure we are collectively understanding and responding to the right drivers of infant mortality and the needs of communities.

Action Plans and Delivery:

The results of the workshop are currently being analysed and action plans are being developed. Next steps include:

- Confirming the content of the action plans
- Establishing a Steering Group
- Agreeing the Action Plan priorities
- Establishing working groups

Healthy Pregnancy, Birth and Babies Group – good work that’s already happening: Addressing CDOP Recommendations:

- **CDOP(child death review panel) recommendation: Promote & protect breastfeeding for all:** Bumps to Babies delivery continues and is well evaluated by participants. Training and discussion on colostrum harvesting has been introduced with positive feedback from parents.
- **CDOP recommendation: Safer Sleeping Risk Assessment Tool:** Tool being used. Baby Basics providing safe sleep spaces for all babies referred to them, no wait for safe sleep spaces.
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- **CDOP recommendation: Promotion of healthy weight before & in pregnancy:** Maternal Weight Health Needs Assessment completed and delivery on actions begun. Healthy weight focus groups underway.

Additional work:

IVF Overseas conceptions:

- CDOP has identified an emerging theme of early labour leading to babies dying who were conceived via IVF overseas.
- Overseas IVF pregnancy Task and Finish Group established.
- Public Health are commissioning Insights Work into what informs decision making around seeking IVF overseas.

“Late bookings” (after 10 weeks of conception):

- University Hospitals of Leicester have increased booked within 70 days of conception (10 weeks) from 70% to 78% of women. Above national average (64%).

- Black women and birthing people 1.7 times more likely to book late.
- Public Health have commissioned DeMontfort University to research “**Understanding health care-seeking behaviour in early pregnancy among diverse women**”

4. Financial, legal, equalities, climate emergency and other implications

4.1 Financial Implications

None

Signed:

Dated:

4.2 Legal Implications

No adverse legal implications arising but general comments are any collaborative working and information sharing should be in accordance with data protection legislation and appropriate advice and help sought.

Signed: Mannah Begum, Principal Solicitor, Commercial Legal Team

Dated: 20 April 2026

4.3 Equalities Implications

The Council must comply with the public sector equality duty (PSED) (Equality Act 2010) by paying due regard, when carrying out their functions, to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations between people who share a ‘protected characteristic’ and those who do not.

We need to be clear about any equalities implications of the course of action proposed. In doing so, we must consider the likely impact on those likely to be affected by the options in the report and, in particular, the proposed option; their protected characteristics; and (where negative impacts are anticipated) mitigating actions that can be taken to reduce or remove that negative impact.

Protected characteristics under the public sector equality duty are age, disability, gender re-assignment, pregnancy and maternity, marriage and civil partnership, race, religion or belief, sex and sexual orientation.

This report sets out actions to address infant mortality in Leicester, which is closely linked to inequality and health outcomes that vary significantly across different communities. The data shows higher rates of infant mortality among babies from Black and Asian ethnic backgrounds and in families affected by deprivation, poor housing, and other wider determinants of health.

The proposals in this report should lead to positive impacts targeting support at those most at risk, improving access to services, and strengthening culturally appropriate and community-led approaches. It will be important that delivery of the action plan is informed by data, community insight and ongoing equality monitoring to ensure that services are accessible, proportionate and effective for all groups.

An Equality Impact Assessment should be completed as the action plan is developed and implemented to ensure that any potential adverse impacts are identified and mitigated.

Signed: Equalities Officer, Surinder Singh, Ext 37 4148

Dated: 20 April 2026

4.4 Climate Emergency Implications

None

Signed:

Dated:

4.5 Other Implications

None

Signed:

Dated:

5. Background information and other papers:

6. Summary of appendices:

Appendix A, B and C – National Energy Action Internal Evaluation of the Leicester Energy Action Project.

Infant Mortality in Leicester

(death of a child before their first birthday)

Clare Mills, Acting Consultant in Public Health

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Presentation will cover:

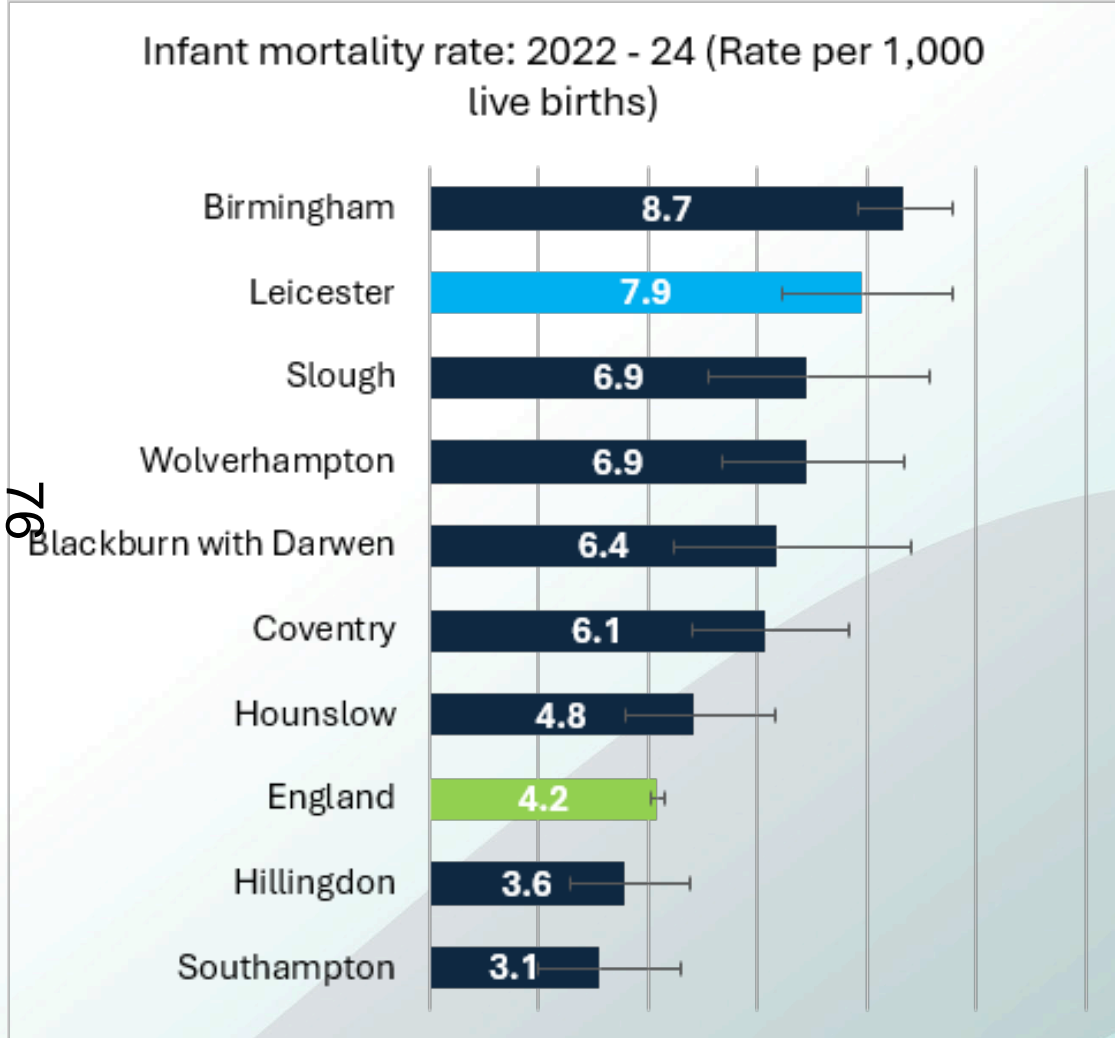
- Context, Infant Mortality in Leicester
- Future Plans for work with partners to reduce Infant Mortality in Leicester
- Healthy Pregnancy, Birth and Babies Group – good work that's already happening



Leicester
City Council

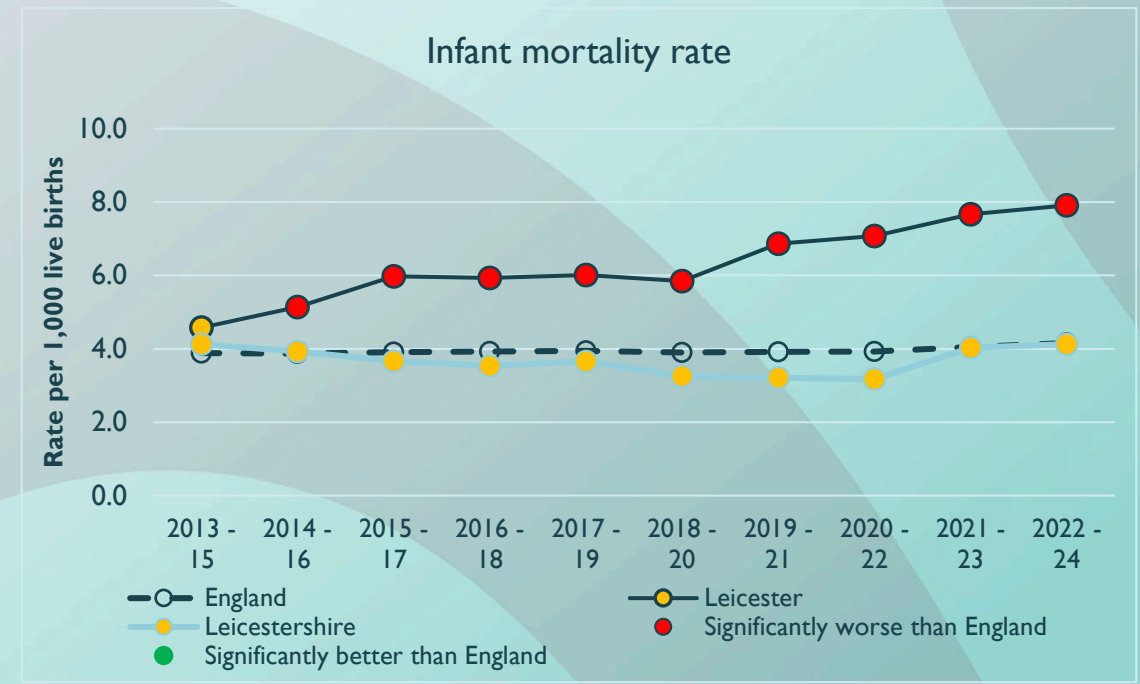
Infant Mortality

76



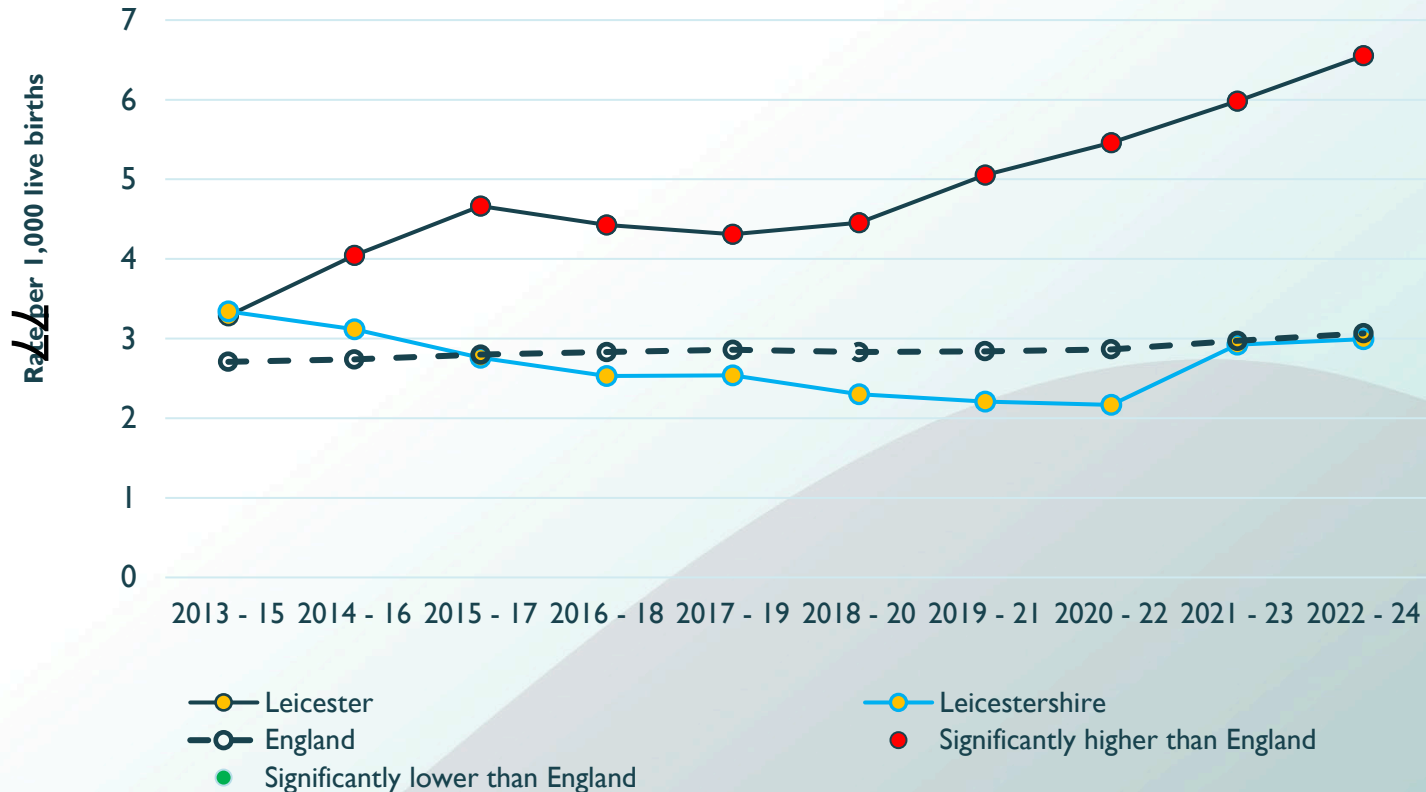
Leicester City has the 2nd highest IM rate in England. Between 2022-2024, there were 105 infant deaths in Leicester giving a rate of 7.9 per 1,000 live births (2nd highest in England (rate 4.2))

The infant mortality rate in Leicester is significantly higher than Leicestershire and England and showing an increasing trend.



Neonatal Mortality

Neonatal mortality rate



The Neonatal death rate (under 28 days) is significantly higher in Leicester than both Leicestershire and England

Neonatal deaths account for 70-80% of all infant deaths in Leicester

Infant Mortality and Ethnicity

NCMD shows national infant death rate in 2025 in Leicester, Leicestershire and Rutland is highest for infants of black or black British ethnicity (7.0 per 1,000 live births); more than double the rate of infants of white ethnicity (3.0 per 1,000 live births).

The death rate of infants of Asian or Asian British ethnicity (5.2 per 1,000 live births) is also higher than for white infants.

What causes infant deaths in Leicester?

79

Top **6** contributory factors that could be **modified** to reduce future child deaths in our area



Smoking in pregnancy



Unhealthy weight in pregnancy



Household exposure to cigarette smoke



Poor communication between agencies



Guidelines or policies not being followed



Missed signs of deterioration

Future Plans to reduce Infant Mortality in Leicester

Public Health (Leicester) ICB, Public Health (Leicestershire), NHS England and Office for Health Improvements and Disparities (OHID) lead work to help identify the areas we can improve on.

The work involves 3 phases:

- Insights
- Conference
- Action Plans and Delivery

LiveWell
Little Ones



#SaferSleepWeek



Theme 1: Targeting Risk and Reducing Inequalities

- We have a shared understanding where and why babies are most at risk, so support is focused on the neighbourhoods and families who need it most.
- Families facing housing problems, poverty or domestic abuse get help earlier and more easily, with health services linked clearly to wider practical support.
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- Families will transition smoothly across services along with their information, so that professionals can tailor support to them.
- We have strong intelligence sharing processes in place and are using data to make sure we are collectively understanding and responding to the right drivers of infant mortality and the needs of communities.

CDOP Recommendations: Infant Mortality

- Promote & protect breastfeeding for all
- Safer Sleeping Risk Assessment Tool
- Reduce rates of smoking in pregnancy, increase number of smoke-free homes
- Promotion of healthy weight before & in pregnancy

85

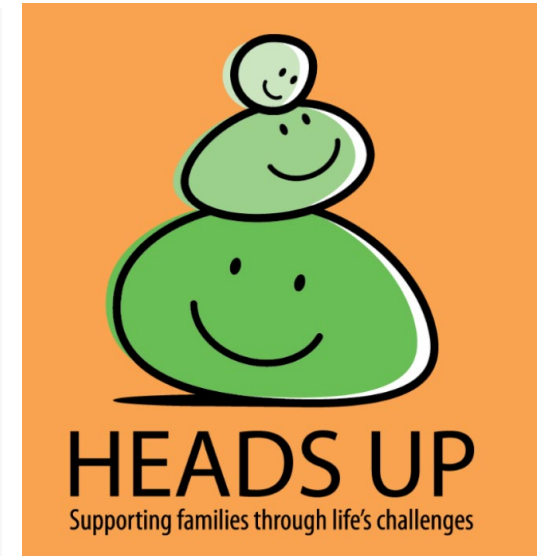
Healthy Pregnancy, Birth and Babies Group

- Organisations across Leicester, Leicestershire and Rutland meet quarterly to share best practice and progress work.
- Previously had Strategy and Action plan, superseded by the (soon to be established) Steering Group

CDOP

Recommendation:

Promote & protect breastfeeding for all



Type of antenatal education	Number of unique attendees in period	Outcome data (if available)
Bumps to Babies	161	Average percentage increase in understanding and confidence following a series of sessions – 94.58%
Teen Bumps to Babies	20	Average percentage increase in understanding and confidence following a series of sessions – 94.74%



LiveWell
Little Ones

Plan for safer sleep when drinking alcohol



#SaferSleepWeek



Leicester
City Council

CDOP Recommendation: Safer Sleeping Risk Assessment Tool

- Ongoing roll-out & embedding of the Leicester, Leicestershire and Rutland Safer Sleeping Risk Assessment Toolkit
- Designed to support practitioners from any agency to be equipped to have safer sleeping conversation with families, and recognise & respond to emerging vulnerabilities



Baby Basics Leicester

12 Jan · 🌐

Our stats are now in for 2025! We have had a 13% increase in referrals si... more

In 2025 we helped
1267 children which included:

314 Moses basket starter packs

314 Baby Baths

622 Toiletry bundles

162 Bouncy chairs

890 Clothing bundles

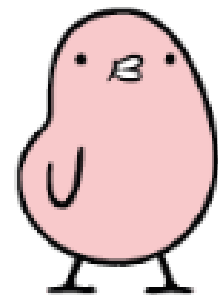
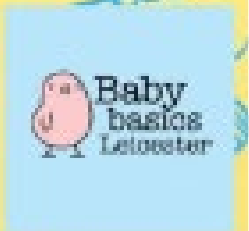
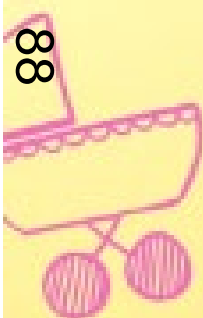
303 Cots

195 Highchairs

599 Packs of nappies

597 Book and toy bundles

And much much more....



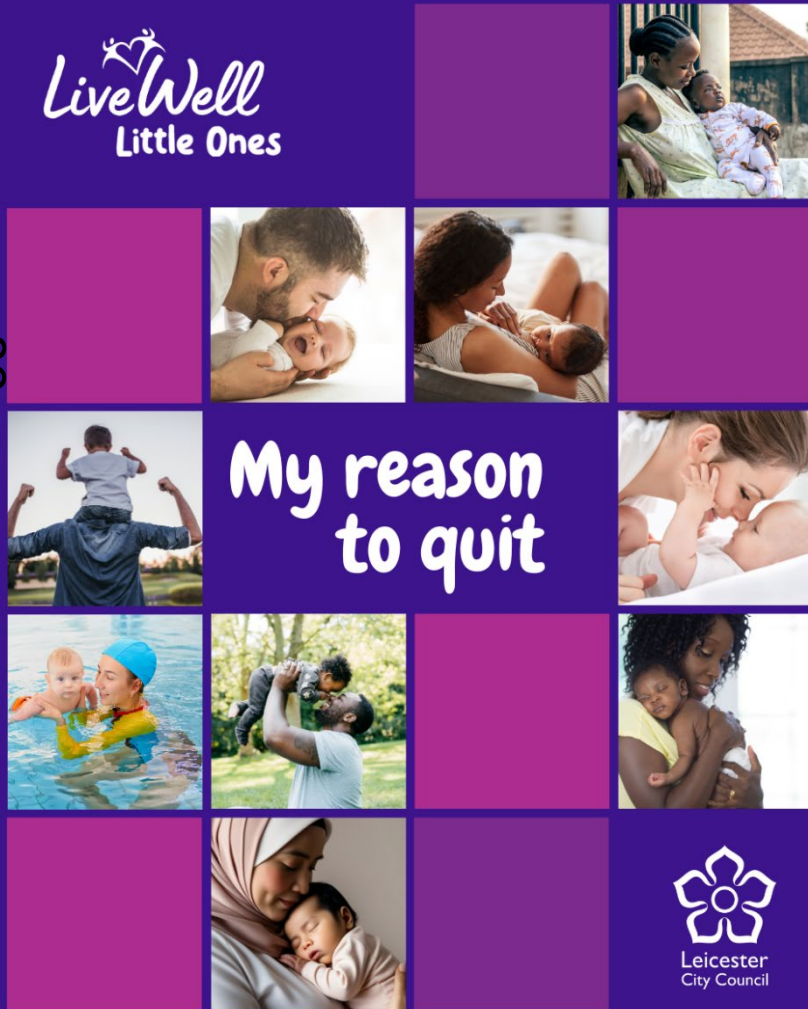

Baby basics

One of our midwives collecting three referrals at once for her team.... getting it all in the car is like playing Tetris! 🧱




CDOP Recommendation: Reduce rates of smoking in pregnancy, increase number of smoke-free homes

89



My reason to quit



Leicester City Council

Currently 6th place out of 112 maternity services in UK for having a successful quit attempt. Currently 50% of SATOB* referred have successfully quit with the CURE service.

*Smoking at time of booking

Referral rates to stop smoking services differ by ethnicity, with only 33% of Asian women and 50% of black women being referred to service when SATOB* identified compared with 80% of white women in Leicester.



CDOP recommendation: Promotion of healthy weight before & in pregnancy

Maternal Weight

Health Needs Assessment

06

A Joint Strategic Needs Assessment (JSNA) is a statutory process by which local authorities and commissioning groups assess the current and future health, care and wellbeing needs of the local community to inform decision making.

The JSNA:

Is concerned with wider social factors that have an impact on people's health and wellbeing such as poverty and employment.

Provides a view of health and care needs in the local community

Identifies health inequalities

Indicates current service provision

Identifies gaps in health and care services, documenting unmet needs



Healthy weight focus groups

October to December 2025

Other Work

Overseas IVF conceptions:

- CDOP has identified and emerging theme of early labour and infant death for pregnancies conceived via IVF overseas.
- Overseas IVF pregnancy Task and Finish Group established.
- Public Health are commissioning Insights Work into what informs decision making round seeking IVF overseas.

16

“Late bookings” (after 10 weeks of conception):

- University Hospitals of Leicester have increased booked within 70 days of conception (10 weeks) from 70% to 78% of women. Above national average (64%).
- Black women and birthing people 1.7 times more likely to book late.
- Public Health have commissioned DeMontfort University to research “**Understanding health care-seeking behaviour in early pregnancy among diverse women**”



Public Health & Health Integration Scrutiny Committee

Work Programme 2025-2026

Meeting Date	Item	Recommendations / Actions	Progress
8 July 2025	Brief introduction to PHHI Health Protection ICB funding changes – briefing paper Oral Health - PH Same day access – ICB Community Engagement and Wellbeing Champions round-up	Bowel Cancer to be added to work programme ICB to share work on bowel cancer More details to be provided at September meeting. NHS Dentistry to be added to work programme. Further information to be shared on Figures to be shared for uptake of Pharmacy First, 8 hubs and the comms campaign.	

Meeting Date	Item	Recommendations / Actions	Progress
9 September 2025	<p>Restructuring updates – ICB & NHS England</p> <p>Winter protection</p> <p>GP Access</p> <p>NHS App</p>	<p>The structure of the LNR will be brought to a future meeting</p> <p>Chief Executive and Chair to come to next meeting</p> <p>Performance data to be shared with the commission when available.</p> <p>Uptake of vaccines data for school age children to be shared with members</p> <p>Vaccine commission to attend a future scrutiny meeting</p> <p>Number data on vaccine website to be shared with commission via website</p> <p>Motion to full council to write to SOS for Health on Leicester Cities Vaccine data to be separate from the County.</p> <p>Motion to full council to write to SOS for Health on Leicester Cities Vaccine data to be separate from the County.</p> <p>An update to be brought to a future meeting.</p>	

Meeting Date	Item	Recommendations / Actions	Progress
4 November 2025	DPH Annual Report Whole systems healthy weight Smoke free generation Update on sexual health service		
19th January 2026 (SPECIAL MEETING)	Deeper look into winter pressures and ambulance wait times at UHL. GP access, PCNs. Loros update		
27 January 2026	General Fund Budget Proposals 2026/27 Health Protection Annual review of prevention and health inequalities programme Cost of living, food poverty and fuel poverty update Drugs and alcohol strategy Leicester Neighbourhoods		

Meeting Date	Item	Recommendations / Actions	Progress
24 March 2026	Public mental health and suicide prevention Research – building skills		
28 April 2026	Health Protection Update Rheumatology CDOP annual report Reducing Infant Mortality in Leicester		

Forward plan suggestions 2025/26:

NHS dentistry	A report was requested 8 July for 9 September, the report has been delayed to the next meeting. To come to first meeting of 2026/27 municipal year.	
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NHS Dentistry Access	A report had been requested for the September meeting but could not be completed. This will be considered at the next agenda setting meeting to agree a new date.	
Prevention and Health Inequalities	To include work done on Bowel Cancer.	
Palliative Care	To include information on Loros.	
Winter Plan Debrief		
Structure of the LNR	A report had been requested for the full structure of the LNR to come to scrutiny once available.	

