

# STANDARD OPERATING PROCEDURE

## CONI - THE MANAGEMENT AND DELIVERY OF THE CARE OF THE NEXT INFANT PROGRAMME FOR THE 0-19 IPHN SERVICE

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<b>Name of Trust Strategy / Policy / Guidelines this SOP refers to:</b>	

**VALIDITY – All local SOPS should be accessed via the Trust intranet**

### CHANGE RECORD

Version	Date	Change details
1.0	09/08/23	<i>New SOP. Adapted from older document, following transfer of Hull 0-19 IPHN service from CHCP. Approved at Physical Health and Medical Devices Group (9 August 2023).</i>

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## 1. INTRODUCTION

Families who have experienced the sudden and unexpected death of a baby or very young child are often very anxious when they have another baby. The aim of CONI is to provide emotional and practical support to bereaved families during the last few months of pregnancy and through the early months of their new baby's life, enabling them to enjoy this special time.

CONI was developed from the model of care offered to families in a randomised control study conducted with families in the 1980s, and is available in England, Wales, and Northern Ireland. Where it has been commissioned, it is usually part of the local health visiting service.

CONI is offered to parents expecting a new baby where either parent has previously experienced the sudden unexpected death of a child under 2 years of age. The programme may also be offered to support families with a surviving child(ren) from a multiple birth where one baby has died unexpectedly.

## 2. SCOPE

The purpose of this standard operating procedure (SOP) is to provide instruction around the management and delivery of the CONI programme for the Hull 0-19 service. This SOP is applicable to all Humber Teaching NHS Foundation Trust Specialist Public Health Nurses, bank and student Specialist Public Health Nurses, Public Health Nurses and Health & Development Practitioners, and Nursing Associates working within the Hull 0-19 Integrated Public Health Team who are responsible for the delivery the CONI Programme.

## 3. DUTIES AND RESPONSIBILITIES

### 3.1. Role of the Local CONI Coordinator

The local CONI coordinator will liaise with the Lullaby Trust CONI Team and is responsible for the local administration of CONI, supported by the CONI Champions. Whilst the care of the family remains with the named health visitor, the coordinator is available for advice and support.

The local co-ordinator may be a health visitor or any other person with the appropriate knowledge and skills, who is employed by and practices within the Hull 0-19 IPHN Service. The role will vary according to our local needs. The following responsibilities within the CONI co-ordinator role are only a guide. They will include all or part of the following: -

### 3.2. Identification of families

Ensuring a system remains in place to identify mothers booking for antenatal care with a previous history of sudden infant death. Most mothers are referred to the local co-ordinator by their hospital or community midwife during their initial booking in appointment, however the referral procedure should also be known to obstetricians, GPs and health visitors. It is recommended that all mothers with a history of SIDS/SUDI are referred to the local co-ordinator to be offered the opportunity to learn about the CONI programme. Please see Appendix A (Coni Process) for the referral identification and referral process.

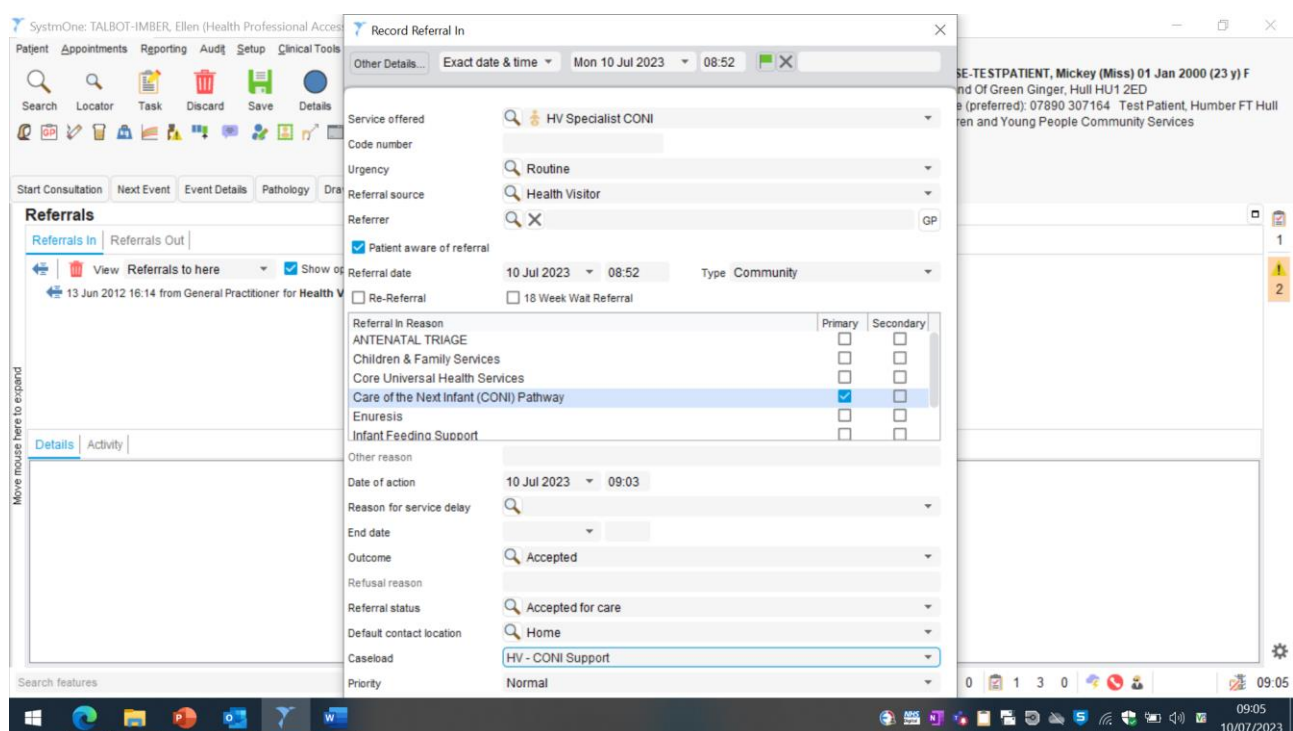
Within the Hull 0-19 IPHN Team, there are two Health Visitors, who are responsible for screening antenatal booking forms, and allocating women to a health visitor. Both professionals are aware of the CONI programme and will ensure that any women identified as being eligible for the programme who have not yet been referred are discussed with the CONI co-ordinator so that an initial contact can be made to discuss available resources and offer support.

### 3.3. Visiting/contacting the parents

The CONI co-ordinator should make initial contact with the family to organise a visit approximately 2 months before the estimated delivery date of their baby. Ideally, this takes place in the parents'

home, with their own health visitor/nurse present. The purpose is to explain the various elements of support in detail and to help the parents to select the support elements that they are going to use. The functions (and limitations) of the equipment, Symptom Diary and other resources are also explained. The CONI co-ordinator completes the online electronic Enrolment Form on the Lullaby Trust CONI webpage, and gains consent for the information to be shared with CONI Team and the Lullaby Trust. If consent to share is declined, or the parents do not wish to receive support from CONI, then the co-ordinator completes the Notification of Non-Participation Form (Please see Appendix C) which is sent to the Lullaby Trust CONI team via email. Person-identifiable information is not captured on this form. The option to decline consent will not affect the care they receive. The co-ordinator should also explain that parents who give consent to participate, will be invited to complete an online Feedback Form at the end of the programme. Ideally, the co-ordinator will visit/contact them again to complete this. The electronic online Enrolment and Feedback Forms are automatically received by the CONI Team when 'submit' is clicked. The introductory visit and any subsequent visits or contacts with the family should be recorded using SystmOne, in line with local policy.

Once a family have consented to enrolment on the programme, the CONI co-ordinator will complete a referral on SystmOne. This can be done by completing a referral in template via the clinical tree within the clients record. Please see below for screen shot as to how the referral should be completed, this referral should remain in place until completion of the CONI programme at which point the Co-ordinator will complete a final visit, collect the Nanny Baby Monitor from the family, and will then end the referral on completion of the record of the visit. This referral is in addition to the Health Visitor referral which will be placed in the Specialist caseload of the allocated Health visitor.



### 3.4. Arrange antenatal contact with the paediatrician

Where the paediatrician is prepared to see families antenatally, the co-ordinator liaises with the paediatrician on behalf of parents as appropriate. Currently we do not have a paediatrician allocated to the CONI programme, however this is an ongoing task and the SOP will be updated accordingly.

### 3.5. Organisation of Basic Life Support (BLS) instruction

Basic Life support instruction will be offered ideally before the birth of the baby and should allow the opportunity for parents and close relatives or carers to be well informed and feel confident in Basic Life Support. If the family choose to receive Basic Life Support Training, the CONI Co-

ordinator will make a referral to the Humber Teaching NHS Foundation Trust Resuscitation Team by emailing John Sands ([john.sands@nhs.net](mailto:john.sands@nhs.net)), if John is unavailable, the referral should be emailed to the Learning Centre (HNF-TR.Learningcentre@nhs.net). The team will then contact the family to offer 1:1 BLS training in the family home. Should the family not wish to receive the training at home, this can be offered at an NHS premises, however there may be a slightly longer wait. Parents may offer for wider family members to attend the training with them and should advise the Resuscitation Team of how many people will be present at their time of contact.

If the family choose not to receive face to face training, the CONI co-ordinator can advise on suitable online instruction videos e.g. St. Johns Ambulance  
How to do CPR on a baby (under one year old) - Baby First Aid | St John Ambulance ([sja.org.uk](http://sja.org.uk))  
How to do a baby primary survey | St John Ambulance ([sja.org.uk](http://sja.org.uk)) March 2021

### 3.6. Distribution and care of equipment

The Humber Teaching Foundation Trust Hull 0-19 IPHN Service have chosen to distribute Nanny Baby Breathing Monitors (BM-02). These have been purchased by the trust and will be loaned to the family. The Lullaby Trust has stipulated that each pad for the monitors be single use, and it is the responsibility of the CONI co-ordinator to request a new pad for each family. This will be distributed by the Lullaby Trust directly to the family on completion of the enrolment form following the initial visit with the family. Where possible, families should be given the monitor and resources/elements that they will be using at, or soon after the first home visit. This allows the parents to familiarise themselves with the workings of the monitor before the baby is born. It also avoids the problem of supplying equipment during the short period the mother and baby are in hospital. There is a system online, managed by the 0-19 IPHN Administration manager, for logging the placement of all equipment to enable re-call at the end of the programme. The CAFM Manager has stipulated that there are no specific manufacturer requirements with regards to the upkeep of the monitors. The pad will be disconnected and left with the family following use, and the monitor will be collected and decontaminated by the CONI co-ordinator. Parents will have a copy of the instruction manual in order to ensure correct use. Should there be any concerns that there is a fault with the equipment, the families are aware to report this to the CONI co-ordinator via the Hull IPHNs single point of contact telephone number 01482259600. The CONI co-ordinator will then liaise with the manufacturer and the lullaby trust on their behalf.

### 3.7. Distribution of CONI support elements

The following resources will be discussed and made available to all families at the initial visit with the CONI co-ordinator, who is also responsible for ensuring stocks are monitored and replenished. Resources must be ordered via the Lullaby Trust Website and do incur a cost.

- Symptom Diary
- Baby Check A5 demo card A 2-sided card explaining how to use the Baby Check App.
- Sheffield Weight Chart
- Alarm Record (optional) - If parents are troubled because an alarm sounds for no apparent reason, they can record the details of each alarm on the Alarm Record to help identify possible causes. This can then be discussed with the health visitor/nurse.
- Information for GP Records An information sheet to be inserted into the baby's GP electronic and/or paper records to act as a reminder that the baby is enrolled on the CONI programme. Organised by the CONI Coordinator. If a paper sheet is not available, telephone contact should be made with the Family's allocated GP to inform them of the family's participation on the scheme, and request a marker is placed on the homescreen of the mother and child's records, to ensure sensitive and if possible prioritised care can be made available should the child become unwell.
- Paediatric Healthcare Passport - An A5 sheet to be inserted into the baby's Personal Child Health Record (Red Book) by the health visitor to alert A&E staff that the baby is enrolled on the CONI programme and facilitate easier access to an assessment by a senior paediatric doctor or nurse. Organised by the CONI Coordinator. A local card may be available to use instead.
- Safer sleep easy read card

The risk of sudden infant death is reduced when parents follow current evidence-based advice. All parents are provided with the Lullaby Trust 2-sided 'Safer sleep easy read card' giving key advice

for reducing the risk of sudden infant death. Foreign language versions are available to download at: [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk) It is important for health professionals to establish that parents have understood and remember this information at least until the baby is six months old. Parents need to be given all possible assistance to adopt the advice.

- Product Guide There are many sleeping products on the market. This guide helps parents make an informed choice. This can be sent to the family earlier in pregnancy i.e. to acknowledge CONI referral received and when the first home visit is expected.
- Bereavement support leaflet Advice and information for bereaved families, including The Lullaby Trust services and other sources of support.
- Room Thermometer -a strip thermometer, where the temperature is indicated by the brightest green square.
- CONI Leaflet - an introductory leaflet to the CONI. This can be issued by the midwife at booking or at first contact between local the co-ordinator and parents. Some resources are free of charge and should be downloaded from the CONI webpages on the Lullaby Trust website.
- Resuscitation Council child and baby CPR Booklet "Aaron's Heart".

### **3.8. Submission of completed forms**

Other than the Enrolment and Feedback Forms, all CONI paperwork is kept by the parents. They are advised to retain these in the red book.

### **3.9. Liaise with and support other personnel**

The local co-ordinator should ensure the paediatrician, GP, health visitor/nurse and midwife are fully informed about the family's involvement on the CONI programme. They need to provide the baby's GP practice with the Information for GP Records sheet. This can be stored in paper records or scanned to electronic records or replaced with an appropriate electronic alert/bookmark to prompt the GP/other professionals about the baby's previous or family history. This will allow for the GP surgery to be aware of the family's involvement on the programme, in order to provide sensitive care, and where possible, prioritise the family when appointments are needed in order to reduce anxiety when their baby is unwell.

After the baby is born the care of the baby and family usually lies with the commissioned public health team, with the family's health visitor/nurse as key worker. The local co-ordinator is not required to visit the family again until the programme is ending, but their knowledge and experience should be available to the health visitor. Some co-ordinators do make a subsequent visit to check that there are no problems or make contact by telephone. However, care needs to be taken not to undermine the role of the family health visitor/nurse. It is recommended that once a family is registered on the CONI programme that they be offered an enhanced service of visits, tailored to how many the family feel they need. These visit may be completed solely by the health visitor depending on capacity, but may also be a combination of Health visitor contacts, referral to a Health and Development Practitioner or clinic contacts. It is important to find out what the family would prefer.

### **3.10. Completion of the programme - Visit at 6-7 months**

This visit provides the co-ordinator with the opportunity to discuss drawing the programme to a close and assessing whether the parent(s) have any continuing worries, concerns, or continuing needs. The co-ordinator can explore with them what might be helpful, such as the availability of any local support services, and also specific support available from the Lullaby Trust e.g. bereavement support. Any Loaned equipment can also be retrieved by the co-ordinator at this time. Ongoing evaluation of CONI is very important; thus, the family will be invited to complete an online Feedback Form at this visit with the co-ordinator. Following the final visit for CONI, the co-ordinator is responsible for documenting the visit on SystemOne, then ending the referral to the CONI programme marking it as care complete. Care will then continue to be provided by the families allocated Health Visitor as needed or in line with the Universal Healthy Child Programme.

### **3.11. Maintain local awareness of the CONI programme**

Health professionals may only meet a family who are eligible for the CONI programme infrequently and it can be difficult to retain detailed knowledge of the programme. Co-ordinators are

encouraged to maintain local awareness of CONI through informal and formal staff meetings or training sessions, where possible. Colleagues can be signposted to the CONI bite-size presentations on the Lullaby Trust's CONI webpage [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk) CONI updates will also be made available via the Hull 0-19 IPHN staff newsletter, and via safer sleep updates completed every 3 years by staff.

### **3.12. Notification of the death of a baby on the programme**

It is essential that the CONI Team be immediately notified of the death of a baby enrolled on the programme. The co-ordinator needs to complete the Notification of Baby Death Form (Appendix D) and send it to the CONI Team via email. This form does not ask for person-identifiable information.

## **4. Training Requirements**

Prior to undertaking any of the tasks outlined within this SOP, any 0-19 staff member with an identified role or responsibility must:

- Access, read and sign up to the SOP via MyCompliance
- Undertake the CONI training/update delivered by the CONI coordinator and champions. This will be reviewed regularly to account for new staff entering the service.

## **5. REFERENCES**

Care of Next Infant (CONI) - The Lullaby Trust - [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

## **6. ABBREVIATIONS & DEFINITIONS**

BLS – Basic Life Support  
CONI – Care of the Next Infant  
SIDS – Sudden Infant Death Syndrome  
SUDI – Sudden and Unexpected Death of an Infant  
SOP – Standard Operating Procedure

## **7. KEEPING UP TO DATE**

- The CONI Team is available for advice by e-mail: [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk) and they can ring back enquirers, if required. For sensitive or confidential information [bchnt.conilullabytrust@nhs.net](mailto:bchnt.conilullabytrust@nhs.net)
- Information about CONI, including resources and forms, can be found on the CONI webpages: [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)
- A programme of online virtual Question and Answer (Q&A) sessions offers all local co-ordinators the opportunity to receive an update on latest SIDS research, bereavement support and developments about CONI. Co-ordinators are also able to submit questions to the CONI Team in advance. Dates for the Q&A sessions can be found in the Upcoming Meetings section on the CONI webpages: [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)
- Coordinators also receive regular e-newsletters containing key information.
- Information is posted or emailed to the local co-ordinator by both the CONI Team and the Lullaby Trust.
- Co-ordinators are encouraged to sign up to receive the Lullaby Trust Professional Newsletter at Lullaby Trust website: [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

## **8. TRAINING FOR NEW AND EXISTING CONI CO-ORDINATORS**

Training is available for all new local co-ordinators by arrangement with the Lullaby Trust CONI Team. Existing co-ordinators are required to undertake refresher training every 3 years, the lullaby

trust will not notify co-ordinators of impending lapses to their training, so it is the responsibility of the co-ordinator to monitor this and arrange training as needed via the lullaby trust. Training is by Distance Learning Course. There is a charge of £55 for initial and £25 for update training which includes co-ordinator resources. Dates for the training are in the Upcoming Meetings section on the CONI webpages: [www.lullabytrust.org.uk](http://www.lullabytrust.org.uk) Following completion of training a CONI ID number is allocated to each new co-ordinator.

## **9. CONI CHAMPIONS**

In addition to the local CONI co-ordinator, some CONI teams may also have CONI Champions. These are professionals who enthusiastically support and represent the local CONI programme. They should have received full CONI training and should attend the CONI Q&A updates. They can be the initial contact for parents and professionals. Champions can explain the elements of CONI support to parents and professionals and are aware of the local CONI criteria and referral pathway. They can have a particular role in the local CONI team e.g. manage the equipment and resources. They also should have the skills and confidence to talk with bereaved parents. They are not expected to undertake initial or enrolment visits. They should have knowledge of the Lullaby Trust website, specifically the CONI webpages.

Any documentation to be inserted into client records must be in the approved Trust format and accessed via the Trust's intranet.

## **10. REVIEW**

This SOP will be reviewed every 3 years or sooner if prompted by changes in legislation or best practice requirements.



## Appendix A: CONI Process

1. Parents identified as suitable for the CONI programme (families who have suffered a previous SIDS/SUDI) – either via the Health Visitor, Midwife, Lullaby Trust or family themselves by either a telephone call to the service or via email.
2. Discussions between the CONI coordinator and the named Health Visitor to arrange a joint home visit to the parents. Telephone liaison by named health visitor with parents to arrange a home visit around 8 weeks before the baby's due date.
3. Parents visited, and all aspects of the CONI programme discussed – Parents then decide which aspects of the programme they wish to use and enrollment onto the programme
4. Date for equipment to be delivered arranged between the CONI coordinator and the parents via telephone
5. Mother allocated onto the CONI caseload held by the CONI coordinator. This referral will be held in a specialist caseload on system one.
6. When born, the baby is allocated onto the health visitors specialist caseload (to reflect the additional visits) – health visitors can contact the CONI coordinator if they need any other visits reallocating due to the increased workload. Named health visitor will re assign caseload on system one.
7. On completion of the programme the CONI coordinator will arrange to visit the family to collect any equipment and complete the evaluation forms found on the Lullaby Trust website.

## Appendix B: Equality Impact Assessment

### For strategies, policies, procedures, processes, guidelines, protocols, tenders, services

1. Document or Process or Service Name: CONI - the Management and Delivery of the Care of the Next Infant Programme (0-19 IPHN Service).
2. EIA Reviewer: Ellie Talbot-Imber - HV CONI Co-ordinator.
3. Is it a Policy, Strategy, Procedure, Process, Tender, Service or Other? SOP

Main Aims of the Document, Process or Service	
Please indicate in the table that follows whether the document or process has the potential to impact adversely, intentionally or unwittingly on the equality target groups contained in the pro forma	

Equality Target Group	Is the document or process likely to have a potential or actual differential impact with regards to the equality target groups listed?	How have you arrived at the equality impact score?
1. Age 2. Disability 3. Sex 4. Marriage/Civil Partnership 5. Pregnancy/Maternity 6. Race 7. Religion/Belief 8. Sexual Orientation 9. Gender re-assignment	Equality Impact Score <b>Low = Little or No evidence or concern (Green)</b> <b>Medium = some evidence or concern (Amber)</b> <b>High = significant evidence or concern (Red)</b>	a) who have you consulted with b) what have they said c) what information or data have you used d) where are the gaps in your analysis e) how will your document/process or service promote equality and diversity good practice

Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
<b>Age</b>	Including specific ages and age groups:  Older people Young people Children Early years	Low	This document applies to all ages
<b>Disability</b>	Where the impairment has a substantial and long term adverse effect on the ability of the person to carry out their day to day activities:  Sensory Physical Learning Mental health  (including cancer, HIV, multiple sclerosis)	Low	This document applies to all regardless of abilities. Where needed additional support can be given
<b>Sex</b>	Men/Male Women/Female	Low	This document applies to all regardless of sex
<b>Marriage/Civil Partnership</b>		Low	This document applies to all regardless of marital status
<b>Pregnancy/Maternity</b>		Low	This document applies to both pregnant women / persons and new parents
<b>Race</b>	Colour Nationality Ethnic/national origins	Low	This document applies to all regardless of race
<b>Religion or Belief</b>	All religions Including lack of religion or belief and where belief includes any religious or philosophical belief	Low	This document applies to all regardless of religion or belief
<b>Sexual Orientation</b>	Lesbian Gay men Bisexual	Low	This document applies to all regardless of sexual orientation

Equality Target Group	Definitions	Equality Impact Score	Evidence to support Equality Impact Score
<b>Gender Reassignment</b>	Where people are proposing to undergo, or have undergone a process (or part of a process) for the purpose of reassigning the person's sex by changing physiological or other attribute of sex	Low	This document applies to all

**Summary**

Please describe the main points/actions arising from your assessment that supports your decision.
EIA Reviewer: Ellie Talbot-Imber
Date completed: 10/08/2023   Signature: Ellie Talbot-Imber

## Appendix C – Co-ordinator Notification of Non Participation Form



### CO-ORDINATOR NOTIFICATION OF NON-PARTICIPATION

It is important for us to record as accurately as possible the number of families who decline CONI, or who use CONI but do not wish their details to be sent to the CONI Team. Please use this form to notify us of any families known to you who are eligible to participate on CONI and decide against using the programme or who enrol on CONI but decline consent for details to be sent to the CONI Team.

**Local Co-ordinator ID\***

If you don't remember your ID you can email the CONI team at [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk)

**Employer:**

### Baby's/Parent's details

**Year baby due/born \***

**What is the mother's postcode? (first part and first number e.g. EX39 3; HD1 4; W9 3; SG5 3)\***

0 of 5 max characters

**Reason for enrolment on CONI:**

- Previous sudden unexpected infant death of child of the: mother / father / both parents
- Close relative died of SIDS
- 'Other' baby death
- Apparent Life-threatening Event (ALTE)

Other, please specify:

**Family are enrolled but do not wish information to be shared with the Lullaby Trust\***

Yes

**Parents have decided against using CONI\***

Yes

**For following reason:**

**Date\***

Please send by email to: [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk) or post to the CONI Team, The Lullaby Trust, CAN Mezzanine – Borough, 7-14 Great Dover St, London SE1 4YR

You can change the way you hear from The Lullaby Trust at any time by emailing: [office@lullabytrust.org.uk](mailto:office@lullabytrust.org.uk) or calling 020 7802 3200. Please also see our privacy policy on our website for how we collect, use and look after your information.

## Appendix D – Co-ordinator notification of baby death form



### CO-ORDINATOR NOTIFICATION OF BABY DEATH

It is **essential** that the CONI Team is notified immediately of the death of a baby enrolled on the programme. Please use this form to notify us of a baby death and send by email to:

[coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk)

If anyone involved with this baby's death would like bereavement support please contact: 0808 080 26868.

Where the death presents suddenly the CONI Steering Group will normally offer expert advice to the local professionals involved. Please contact: [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk)

**Local Co-ordinator ID\*** (If you don't remember your ID you can email the CONI Team at: [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk))

**Employer:**

### Baby's/Parent's details

**Baby's date of birth \***

**Baby's date of death \***

**Where does the mother live?\***

**County:**

**Mother's postcode (first part and first number e.g. EX39 3; HD1 4; W9 3; SG5 3)\***

0 of 5 max characters

**Date\***

Please send by email to: [coni@lullabytrust.org.uk](mailto:coni@lullabytrust.org.uk)

You can change the way you hear from The Lullaby Trust at any time by emailing: [office@lullabytrust.org.uk](mailto:office@lullabytrust.org.uk) or calling 020 7802 3200. Please also see our privacy policy on our website for how we collect, use and look after your information.