



Project Report  
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World of Difference Project Officer for the  
Scottish Cot Death Trust  
March – May 2011



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## **Executive Summary**

Approximately 500 surveys were sent directly to bereaved family members either by email or by post. The survey link was also posted to the Trust website. 111 surveys were completed in total. Of these 111 surveys, 2 were void as they contained completely blank responses so these were removed.

Therefore 109 valid responses were received from 487 surveys. This is an overall response rate of 22.4% from the known recipients.

### Key Findings

The general key findings of this survey are

- Inconsistency of care
- Impact of communication
- Issue of abandonment expressed by bereaved families
- Importance of professionals actively listening to families
- Not to make families feel any more guilty than they already feel themselves
- Families value honesty, empathy and open communication when dealing with tragedy.

The specific key findings particular to individual professional groups are

- Families respect the role the police have to play and the comments received demonstrate the positive impact police officers and CID can make and have made in what is inevitably an extremely tough role
- The most important action that Health Visitors and GPs can take to support families is to listen to them and not abandon them
- Funeral Directors provide an invaluable service and were by far the most helpful professional involved with the group of respondents
- Paediatricians have some work to do to ensure families are aware of who they are and what their role is

### Key Recommendations

- Further more detailed analysis is required in order to do justice to the depth and quality of information provided by families.
- Make contact with the governing bodies of the health professionals evaluated within this survey and make them aware of the impact they have on bereaved families so that they can become aware of the things that have helped bereaved families and learn where they have room for improvement.
- Further evaluate the information provided by families regarding the Trust and make decisions based on this evaluation.

## **Dedication**

This project is dedicated to the babies and children and their incredible families who have given their time and energy to make it possible... "Thank you each and every one of you"

## **Aims and Objectives**

- To design, implement and report findings of an online survey for bereaved families to provide information to the Scottish Cot Death Trust about families' experiences of the professionals involved throughout their bereavement
- To raise as much awareness as possible of the Scottish Cot Death Trust
- To maintain an online blog for the duration of my project

## **Scope**

Project duration was 8 weeks between March and May 2011

## **Background Information**

The Trust attended a conference in Australia in 2010 where results from a survey conducted by SIDS&KIDS were presented. The Executive Director of the Trust had an objective to replicate a similar survey within those families supported by the Trust.

An application was successfully submitted to the Vodafone Foundation's World of Difference programme in November 2010 for Linda Sterry to work with the Trust and manage this project.

This report details the work undertaken, the survey findings and also details recommendations for further work.

## **High Level Project Plan**

- Agreed project objective and scope
- Designed Survey
- Implemented Survey
- Reported on Survey findings

## **Project Implementation**

The following tasks were carried out as part of this project:

- Research background information (SIDS&KIDS survey, 2004 Kennedy report, etc.)
- Learn how to use Surveymonkey
- Consider what information from respondents would be useful for the Trust in order to create a list of questions
- Consider what would encourage families to respond (eg. wording of letter, awareness of why what we're doing, 1-1 email contact, etc)
- Gather as many email addresses as possible
- Design questions for survey
- Design letter to accompany survey (see appendix 1)
- Develop three sections within the survey
  - Personal Information
  - Your Experience of the Professionals
  - What the Trust can do for you and others
- Input email addresses to surveymonkey
- Produce paper version of survey for sending to those without email (see appendix 2)
- Send 1-1 surveymonkey link to those with email
- Print and post paper copies of survey to those without email
- Use my blog and social media to create as much awareness for this survey and the Trust as possible
- Send reminders via surveymonkey to encourage the number of survey responses
- Evaluate survey responses
- Write report based on survey evaluations
- Export completed survey information from Surveymonkey to Excel for future use
- Write guidelines for the Excel information
- Provide recommendations for future work
- Handover documentation

## Detailed Survey Evaluation

Approximately 500 surveys were sent directly to bereaved family members either by email or by post. The survey link was also posted to the Trust website. 111 surveys were completed in total. Of these 111 surveys, 2 were void as they contained completely blank responses so these were removed.

This is only an approximate number as some participants may have picked up the link from the Trust website

Therefore 109 valid responses were received from 487 surveys. This is an overall response rate of 22.4% from the known recipients.

140 surveys were sent directly to email addresses and of these 79 surveys were completed (65 fully and 14 partially). One recipient opted out of the survey and 12 email addresses returned the email as undeliverable. The response rate from the email recipients was 64%.

360 paper copies of surveys were posted and of these there were 32 completed responses. The responses received on the paper surveys were manually added to survey monkey so all information was collated in electronic format in one location. The response rate from the paper recipients was 9%.

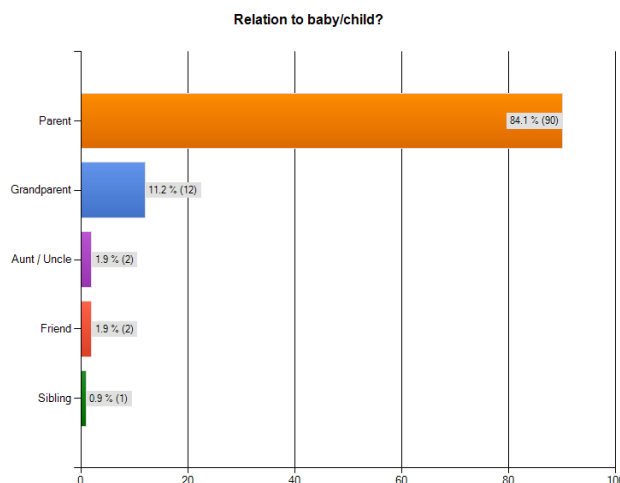
When reading this report it is very important to remember that this is not an average population sample as each of these respondents have chosen to share their information and experiences with the Scottish Cot Death Trust and have already had some form of contact with the Trust.

All 109 of the valid respondents confirmed the details they submitted could be added to the Trust's database.

### ***Personal Information***

The personal information was completed by almost all respondents and is of great importance as it enables the Trust to put the experiences in context of date and location.

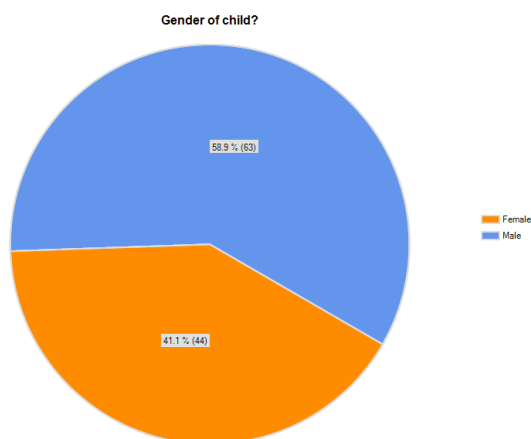
Of the 109 respondents there were 90 parents, 12 grandparents, 1 sibling, 2 aunt/uncle and 2 friends. 2 respondents did not specify their relation to the baby/child. This is shown in the chart below.



Of the 109 respondents 50 (47%) remain living at the same address and 56 (53%) live at another address than the one they lived at when the baby/child died.

The age of the mother at the time of the child's death ranged from 17 to 40 and the age of the father at the time of the child's death ranged from 18 to 44. The mean age of the mothers was 27.8 years. The mean age of the fathers was 29.9 years.

Of the babies and children discussed in this survey 59 (60%) were male and 39 (40%) were female.



Respondents were asked the dates of birth and the dates of deaths of their babies/children. There were 105 responses to these questions and 4 respondents skipped this question. The deaths of these children ranged from 1966 to 2011 and are shown in the table below.

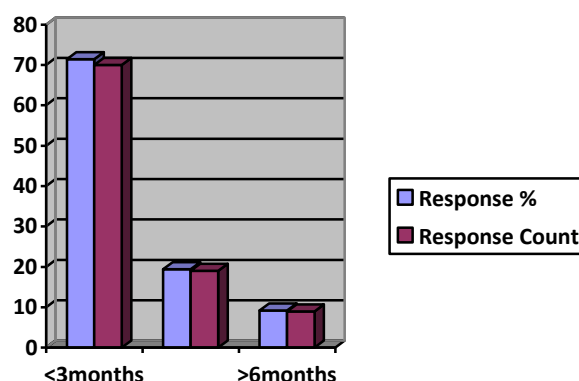
Year	Number of Respondents	Number of Babies/Children
1966	1	1
1973	2	2
1977	1	1
1979	1	1
1981	1	1
1982	2	2
1984	1	1
1985	3	3
1986	1	1
1987	1	1
1988	2	2
1989	3	3
1990	4	4
1991	2	2
1992	1	1
1994	4	4
1997	4	4
1998	2	2
1999	3	2
2000	4	3
2001	1	1
2002	3	3
2003	5	5

2004	4	4
2005	5	5
2006	7	5
2007	3	3
2008	9	8
2009	10	7
2010	9	9
2011	4	4

The ages of the children at the time of their deaths was an original requirement of this report and is useful information to the Trust. However this has not been straightforward to extract from the survey data and requires further work. The required information is shown in a table in the recommendations for further work section.

The time taken for final post-mortem results to be known for the respondents is shown in the table below. This shows that over 90% of families received their post-mortem results within 6 months and 70% received them within 3 months.

Time taken	Response %	Response Count
3 months or less	71.4%	70
4-6 months	19.4%	19
Over 6 months	9.2%	9



It would be of further interest to split this down over time e.g. in the last 10 years versus 10/20/30/40 years ago. Again this has been added as a suggestion for further work.

There were 44 comments left within this section which included the following quotes from respondents:

- *“The way the parents discovered the results of the postmortem was rather shocking. The people concerned obviously were not working together as a proper team.”*
- *“In general PF office were quite considerate and helpful”*
- *“Currently we are still waiting for the final results. It has now been over 7 months”*
- *“I've never been told the final results”*



## ***Your Experience of the Professionals***

Within this section respondents were asked to rate the helpfulness of the professionals who were involved around the time of and following their child's death. They were also asked to explain what these professionals did that made them helpful/unhelpful and what they could have done better.

<b>Professional</b>	<b>Very Unhelpful</b>	<b>Quite Unhelpful</b>	<b>Neither Helpful or Unhelpful</b>	<b>Quite Helpful</b>	<b>Very Helpful</b>	<b>N/A</b>	<b>Response Count</b>
<b>Ambulance Service</b>	14.7%	6.3%	11.6%	11.6%	38.9%	16.8%	
	(14)	(6)	(11)	(11)	(37)	(16)	(95)
<b>Health Visitor</b>	18.6%	7.2%	13.4%	14.4%	27.8%	18.6%	
	(18)	(7)	(13)	(14)	(27)	(18)	(97)
<b>GP</b>	18.4%	9.2%	14.3%	11.2%	39.8%	7.1%	
	(18)	(9)	(14)	(11)	(39)	(7)	(98)
<b>Paediatrician</b>	7.5%	6.5%	12.9%	11.8%	22.6%	38.7%	
	(7)	(6)	(12)	(11)	(21)	(36)	(93)
<b>Police</b>	21.6%	8.2%	16.5%	20.6%	27.8%	5.2%	
	(21)	(8)	(16)	(20)	(27)	(5)	(97)
<b>Pathologist</b>	10.4%	7.3%	15.6%	17.7%	28.1%	20.8%	
	(10)	(7)	(15)	(17)	(27)	(20)	(96)
<b>Funeral Director</b>	10.3%	3.1%	1.0%	10.3%	70.1%	5.2%	
	(10)	(3)	(1)	(10)	(68)	(5)	(97)
<b>Religious Leader</b>	11.2%	2.0%	10.2%	14.3%	41.8%	20.4%	
	(11)	(2)	(10)	(14)	(41)	(20)	(98)
<b>Procurator Fiscal</b>	8.8%	9.9%	22.0%	13.2%	19.8%	26.4%	
	(8)	(9)	(20)	(12)	(18)	(24)	(91)
<b>Other</b>	18.9%	2.7%	2.7%	0%	40.5%	35.1%	
	(7)	(1)	(1)	(0)	(15)	(13)	(37)

The key themes from the respondent's experiences for each of the professionals have been summarised below along with actual anonymous quotes from the responses.

### **Ambulance Service**

50% of respondents had a helpful experience and 21% had an unhelpful experience with 12% having a neutral experience.

#### **Most helpful themes were:**

- They did all they could, Tried their best,
- Kind, Sympathetic, helpful and understanding, looked after us, comforting, kept us calm, sat with me until my husband and family arrived
- Explained what to do and what would happen next in a reassuring way (Kept us informed)
- Speed of Response

#### **Most unhelpful themes were:**

- Slow ambulance response
- They appeared shocked, panicky and came with inaccurate info
- They didn't keep us informed
- They gave us false hope
- No one was unhelpful
- Ambulance service not equipped for babies
- They would not let us be with her

#### **Quotes from respondents regarding the Ambulance Service:**

- *"did all they could in a kind and sympathetic way"*
- *"responded very quickly indeed and although we knew it was too late and we could see it on their faces too, they did try to resuscitate our child. They were very sympathetic with regard to our loss and explained to us what was to happen next"*
- *"The ambulance services were most unhelpful as when they came to the house after dialling 999, they would not allow me to travel in the ambulance with my son and did not ask if I could get to the hospital ok especially since I live 11 miles away and it was rush hour traffic. I therefore had to drive myself to the hospital"*
- *"they were shocked and pretty helpless, panicked and accused us as soon as they arrived"*

### **Health Visitor**

42% of respondents had a helpful experience and 26% had an unhelpful experience with 13% having a neutral experience.

#### **Most helpful themes were:**

- Made contact and was someone I could talk to
- Follow up visits after initial shock / Didn't abandon me
- Also supported my family, other children and friends
- Showed empathy, compassion, respect, listened
- Helped with practicalities e.g. sickness, medication from GP, contacting child benefit/tax credits

- Supported me during next pregnancy

**Most unhelpful themes were:**

- No contact / wasn't there when I needed her
- No follow up afterwards
- Not equipped to support us
- Tactless
- Blamed incompetence on inexperience/ignorance
- Seemed uncomfortable around us

**Quotes from parents regarding Health Visitors:**

- *"health visitor made sure that she visited me to look after my health. She gave me full support when I fell pregnant again ensured that I was looked after more. Although the health visitor had never experienced a cot death on her case load, she found out relevant information and contacted the SCDT."*
- *"continued to visit on a few occasions in the following months which was nice to not feel completely abandoned after I didn't have a baby to visit"*
- *"GP and the Health visitor could have dealt with me differently. They blamed their inexperience on the fact that they hadn't had a cot death at the surgery and didn't know how to deal with someone like me"*
- *"one health visitor I do still remember said 'oh well you are young enough to have another' Needless to say she was asked to leave. Not something you want to hear from anyone"*
- *"wasn't available to talk too when I needed her, she told me that I shouldn't be depressed and that I should move on. It took me along time to trust health visitors after that"*
- *"HV could have let me talk and speak my worries about what i should have done"*

**GP**

51% of respondents had a helpful experience and 28% had an unhelpful experience with 14% having a neutral experience.

**Most helpful themes were:**

- Visited us at home
- Extremely attentive, Compassionate, respectful, understanding, supportive, kind
- Gave me medication
- Support with next baby
- Paced further visits depending on my needs
- Listened to me

**Most unhelpful themes were:**

- Was out of his depth / not equipped to deal with cot death
- Offered me drugs that I didn't want/need
- Made me feel like I was a paranoid parent
- Didn't visit us / didn't follow us up

- Provided no support or information
- Wouldn't give me drugs
- Didn't feel he was interested / he didn't know what to say to us / seemed uncomfortable in my presence

#### **Quotes from respondents regarding GPs:**

- "Our GP just turned up on our door step every so often to check we were still alive"
- "The GP help us with medication to get through the funeral and advice."
- "came to visit me at the house as initially I couldn't face going to the surgery"
- "GP offered me sleeping tablets which I declined. He quite clearly had no idea what to say"
- "I had one phone call from my GP a few weeks after my baby died. He asked me how I was. I answered I was fine because I did not feel he was that interested in what had happened"
- "Both my GP & Health Visitor at the time did not seem to know how to deal with cot death and I feel that they were uncomfortable coming to visit us,"
- "As for the GP he came round to sedate me however, I did not want to be sedated but he left the drugs with me anyway"

#### **Paediatrician**

34% of respondents had a helpful experience and 14% had an unhelpful experience with 13% having a neutral experience. 40% of respondents responded with N/A. 40% of respondents responding with N/A is very high considering the role of a Paediatrician. This is also reinforced by the lack of comments within the helpful and unhelpful section.

#### **Most helpful themes were:**

- Sympathetic
- Supported next pregnancy
- Offered ongoing support
- Informed us of the Trust
- Spoke to us honestly

#### **Most unhelpful themes were:**

- Never saw Paediatrician
- No follow up from Paediatrician
- Discharged too early from hospital to free up a bed
- Felt abandoned

#### **Quotes from respondents regarding Paediatricians:**

- *"one of them came to us after, told us about the trust and said to get in touch with her also later on"*
- *"The paediatrician who followed my next pregnancy was a great support and knowing that he was one of the best paediatricians I could have, helped me being more positive"*
- *"Paediatrician - no follow up from the Sick Kids Hospital"*
- *"The paediatrician was helpful when we finally got to meet with him but it was very distressing to wait for months following many phone calls to the hospital to finally"*

*arrange an appointment. My general feeling was of complete abandonment from the Health Care Professionals after the death of my daughter”*

## **Police**

48% of respondents had a helpful experience and 30% had an unhelpful experience with 16% having a neutral experience. Of all the professionals there were probably the most comments received concerning the police. Families truly do respect the role the police have to play and although at the time it has been a shocking and traumatic experience to have the police in their houses the comments received in the helpful section of this survey demonstrate the positive impact police officers and CID can make and have made in what is inevitably an extremely tough role.

### **Most helpful themes were:**

- Very thorough, efficient, comforting, considerate, showed empathy, extremely compassionate, exceptional, caring throughout, professional but in a caring manner, respectful
- Patient, understanding, supportive, kind, polite, sympathetic, pleasant, friendly, explained things well, visibly moved by events
- Understanding police ‘have a job to do’
- Didn’t make us feel it was our fault, were not judgemental,
- Helped with practicalities
- Kept us informed, phoned often, kept us updated about what was happening where and when
- Allowed me time with my child

### **Most unhelpful themes were:**

- Treated us as guilty or under suspicion, blamed us, made us feel like criminals, used words like ‘crime scene’, or ‘crime zone’
- Showed no respect, insensitive, tactless, cold, arrogant, clinical, unsympathetic, detached from our distress, lacking compassion, abrupt, did not listen, could have done more,
- Took items as evidence, issues around returning/not returning these items in a professional, respectful manner
- Didn’t seem equipped to deal with the situation, seemed uncomfortable and awkward with distressed parents
- Parents separated at such a tragic time, not allowed to say goodbye
- Told us too much detail about the post mortem
- Didn’t inform us about the SCDT

### **Quotes from respondents regarding Police:**

- *“Police that arrived at the scene were very helpful and supportive. I never felt that they were pointing the finger at me, especially when they had to take the cot away to be analysed”*
- *“Police family liaison were extremely compassionate and understanding, we were driven to Yorkhill by them on various occasions and they could not do enough to help”*
- *“the police worked hard at not making us feel like we were under suspicion although i still felt like i was but that was more in my mind”*

- *“Police Liaison officer kept me informed as to what would happen at every step. Where he was, when his PM would be, what would happen next. Until she arrived on the evening of the day he died the police were a shambles. She and her CID colleagues came to his funeral which I thought was a nice gesture on their part”*
- *“Police arrived within 15 minutes of the 999 call. They were firm but kind, they sealed off the room where she died and called it a 'Crime Zone'... We know that the police were only doing their job”*
- *“CID were harsh but understandable in the world we live in today, but caring and professional, police officers were professional even when removing sensitive items from our home”*
- *“Police were respectful enough but having to deal with the questioning, taking pictures, raiding the bins in your house and emptying you of all your Childs possessions (crib, blankets, clothing, bottles etc) just hours after her death was awful. Wish something could be done about that.”*
- *“The Police came in and out as fast as possible and all questions were asked with sensitivity”*
- *“two police officers entered my house and were most arrogant and showed no respect to firstly myself and secondly my (older) son”*
- *“The police and hospital staff at yorkhill were fantastic as they didn't know myself or my family and were really caring throughout it all”*
- *“Police had taken items from our home as evidence, marked them with permanent pen, and were not returned to us until we requested them back. some weeks later we had baby bottles returned to us still with the milk (now a solid form) inside”*
- *“Police did not seem to know how to deal with the situation. Felt we were under suspicion. We were not allowed to be alone with him after he died. We did not get his belongings back until 6 months after his death”*
- *“The police were the most unhelpful. This was primarily because they were treating the house as a potential crime scene and not wanting things moved etc. I was upset as I knew something terrible had happened to my friend's son and they remained very detached from our distress. I don't remember them saying anything in particular to upset me, however i remember feeling hurt that they may think that a crime had been committed. I felt they didn't know what to say to us and i was glad to be away from them.”*
- *“The police didn't meet us at the hospital as they should have and nobody told us there would be police at our house when we returned home. We arrived home from the hospital to a policeman 'guarding' our front door and telling us we couldn't come in as it was a 'crime scene'. Those words have stuck with me and were deeply hurtful. We had to give statements and it felt like we were under suspicion of harming him for a while. At one point we had no idea whether we would be allowed back into our*

*house that evening but that was sorted out once the CID folks arrived. The police officers from apparently were sat in the carpark at the hospital and didn't meet us as they should have done"*

- *"were as kind as the law allowed"*

### **Pathologist**

46% of respondents had a helpful experience and 18% had an unhelpful experience with 16% having a neutral experience. Generally there were not a lot of comments regarding the pathologists and of those most of them were helpful comments. There were a few isolated unhelpful experiences shared but general theme was that if the families were offered or able to meet the pathologists then it was a helpful experience.

#### **Most helpful themes were:**

- Very kind, excellent, sympathetic, caring, attentive manner, was amazing, direct
- Took time to explain things to us, used laymans terms, were informative
- Made us realise that it wasn't our fault, reaffirmed that there was nothing we could have done to prevent it, set my mind at rest, reassured me
- Answered any questions as best as he could

#### **Most unhelpful themes were:**

- Never saw a pathologist
- Felt as though it was our fault
- Lack of information, no expectations of what we would see, what our child would look like
- Were shown the wrong child

#### **Quotes from respondents regarding Pathologists:**

- *"the pathologist was very kind to us, explaining everything in laymans terms"*
- *"Pathologist excellent once we finally got to meet him(several months later)"*
- *"the Pathologist had commented on her being a well looked after and loved baby. About a year later when I was pregnant again I felt i wanted to speak to him directly. The trust helped me get in touch and he asked if I would like to see him in person. As I was heavily pregnant I asked if we could just talk on the phone. He spoke to me for a long time and answered all my questions. It was a relief to know that I was definately not to blame for my daughter's death."*
- *"Pathologist explained the situation and answered any questions we had. He did not rush us and took plenty of time with his explanation of tests that had to be completed and those which had been finished."*
- *"on reflection we found the pathologist very unhelpful as the only words he said to us was after the post mortum and his exact words were - we found nothing. I didnt really understand what he meant so I said there must be a reason why she died and he said one word- nothing -and just walked away. We sat there stunned and didnt know what to do until an assistant came out and gave us the form needed to get the death cert and that said cause of death SIDS. We found the whole experience horrific as because our daughter had been moved from our local hosp to Yorkhill for the pm we*

*had to go to yorkhill and identify her body before the post mortum. We also had to ask my brother to identify her as they wouldnt let only parents id her. this made us feel as though they blamed us for her death.”*

### **Funeral Director**

80% of respondents had a helpful experience and 13% had an unhelpful experience with 1% having a neutral experience.

#### **Most helpful themes were:**

- True professionals, very supportive, calming influence, amazing, wonderful, brilliant, particularly nice and caring, showed great compassion, showed empathy, respectful, understanding, patient, comforting and showed sensitivity
- Guided us through a very traumatic time, helped take the strain, did everything for us, didn't rush us, gave advice, made this awful experience a little more bearable, understood our immense grief
- Didn't try to hide his feelings, was clearly moved
- Allowed us to spend time with our child
- Treated our child with respect, like one of the family, always referred to her by her name

There were no unhelpful themes for the Funeral Directors which shows what an incredible role they perform. There were a couple of instances where a health professional had 'forgot' to take hand and footprints and the funeral directors have tried to assist.

#### **Quotes from respondents regarding Funeral Directors:**

- *“We found the funeral director a great help as neither my husband or I had ever organised a funeral before and we didn't know where to start. the funeral director explained the process to us. He gave us time to plan things and never tried to hurry us into making decisions”*
- *“The funeral director was also very helpful and didn't even try and hide his feelings and difficulties he experienced while handling our case, but still was very professional in every way”*
- *“the funeral director ...treated her like one of the family, she was talked to daily while in his care and i will never forget him for this”*
- *“Funeral Director was incredible. He was calm, caring, clearly moved by our family's loss, helpful, knowledgeable, never told us what we should do but presented us with many options. Of all the people who were involved his calming influence got me through the very difficult days from the date of death to the funeral and afterwards. Every day he just gave me a list of things to do for that day - nothing was too much trouble”*
- *“The funeral directors where completely and utterly amazing, nothing was too much trouble, I found them to be a pillar of support”*
- *“Funeral Director was brilliant in his dealing with us in every manner”*



## **Religious Leader**

56% of respondents had a helpful experience and 13% had an unhelpful experience with 10% having a neutral experience.

### **Most helpful themes were:**

- Was understanding, compassionate, extremely supportive and showed sensitivity
- Respected my wishes
- Understanding and non-judgemental
- Chaplain on duty baptised our child
- Helped us cope
- Helped us plan funeral, made it special to us
- Showed total love and affection
- Visited us at home
- Listened to us
- Allowing us to be very sad
- Made time for us

### **Most unhelpful themes were:**

- Lack of compassion and empathy
- Unprofessional
- Inappropriate comments

### **Quotes from respondents regarding Religious Leaders:**

- *"He helped the whole family cope with our great loss"*
- *"they were amazing and showed total love and affection for us and our child"*
- *"were really understanding for what I wanted for my son and the way I wished my son to be laid to rest"*
- *"Minister visited us at home and talked to us about it all where everyone else acted like our child was never here."*
- *"Minister was very understanding, gave us as much advice as he could, and discussed at length what the family wanted for the funeral service and gave a service we could look back on with pride."*
- *"Our parish priest was really helpful. Allowing us to be very sad and not telling us it was all part of a great plan but just being there for us and helping us plan the service for the funeral. He told us what service is usual for a baby or small child and after that there didn't seem to be anything that he wouldn't let us include."*
- *"Priest at hospital was laughing in corridor as we left"*
- *"Local village minister was very unhelpful as could not empathise with situation and was unprofessional in approach. However, our own church minister was very caring and professional."*
- *"religious leader's comments were shockingly inappropriate. For example, he commented on the fact that our child had not been baptised and proceeded to talk about the damned. My mother, a very gentle lady with a deep faith told him to leave."*

## **Procurator Fiscal**

33% of respondents had a helpful experience and 19% had an unhelpful experience with 22% having a neutral experience.

### **Most helpful themes were:**

- Very sympathetic
- Open to further questions
- Gave enough information, facts and clear explanations
- Helped explain things in direct and informative letters

### **Most unhelpful themes were:**

- Shambles, not sympathetic, poor communication skills, unaccommodating, lacking respect
- Treated us like criminals
- Didn't allow us to hold/touch our child
- Inappropriate / insensitive / tactless phone calls from PF office

### **Quotes from respondents regarding Procurator Fiscals:**

- *"The Procurator Fiscal gave us sufficient information"*
- *"My husband dealt with the Funeral Director, pathologist and procurator fiscal, however I do remember him saying that he was treated extremely well and that they always explained things clearly to him."*
- *"always stressed that they were there to help us understand what had happened not to make us feel like they were investigating us"*
- *"The PF involvement following the PM was a shambles - there was a change in cause of death ...She sent letters to my GP and to us a week apart re this but made out to my GP that I had already been informed. I found out this information at a routine GP appt and my GP thought I was already aware. The communication involved was terrible and when I emailed her to tell her so she blamed it on her office manager being on holiday! It then took 10 days to arrange a meeting with the Paediatrician, my GP and health visitor - those 10 days were the worst days I experienced with the exception of the day my son died."*
- *"Procurator Fiscal - lack of communication about the progress of the final report, sending information to the wrong address, disorganised, no clear procedures on communicating with parents, poor communication skills when you phone the office for update reports, receptionist at the fiscal's office using inappropriate language - such as SOON, not sure, maybe."*

## **Other Professionals**

There are examples in this section of Trust staff being helpful. Other examples of specific hospital staff also being particularly helpful and memorable. Further analysis of this information should form part of future work.

## Key Professional

Respondents were asked if there was one key professional who was important for them and the most common answer was Health Visitors and GPs, closely followed by the Police. The breakdown of these responses are shown in the table below

Key Professional	No Respondents
Health Visitor	12
GP	12
Police	11
Funeral Director	9
Pathologist	7
Paediatrician	3
Religious Leader	3
Scottish Cot Death Trust	2
Midwife	2
Defence Lawyer	1

This table shows just how important each of these professional groups was to the respondents. It is interesting to note that the Paediatricians are 6<sup>th</sup> on this list. It is clear that whilst many strong views – both positive and negative - have been expressed about the experiences of Health Visitors, GPs and Police their input is vital to this group of respondents.

## What could these Professionals have done better?

Respondents were then asked what these professionals could have done better. This section also requires further analysis as time has prevented any detailed analysis of this section.

The high level themes are:

- Communication
- Education/training of staff
- Common sense and Compassion
- Support for surviving siblings
- Ongoing regular support from health visitors and GPs rather than just one checkup
- Someone to actively listen and just be there for families
- Not make families feel any more guilty than they already feel themselves
- Use of appropriate language by procurator fiscal staff
- Treat families with more respect and keep them informed of what to expect
- Be mindful of older siblings at the time of a sudden and unexplained death

## Help for newly bereaved families?

There are many responses in this section which require more detailed analysis but a selection of quotes are included below:-

- *“Nothing can prepare you for this. So i believe no matter what information you have before bereavement a parent is still very much in shock and confusion.i do not wish i had known anything. it would not have helped at the time. Although I believe pre natal care now does include some leaflets and advice which i did not have 25 years ago. This is a good thing. I dont know how it would be possible to convey to*

*grieving parents that life does go on despite their grief and one day they may find the courage to have more family never to replace their lost little one. Thankfully i am proud to be the mum of 2 fine lads and a daughter!"*

- *"that there not alone there is services out there that can help you through the grieving process and also that there is 1 child every 9 days that dies of a cot death. Which i would have never known if i had never seen your website"*
- *"Your experience will change your life. It will not always feel as raw as it does in the early weeks... The edges of your grief will soften with time. You will learn to find a way to live amongst your grief. Your life will never be the same but you will find a way to feel again, to smile and to find joy."*
- *"If ALL police personnel were given more training in bereavement I feel it would benefit all parents"*
- *"The length of time the final results of a post mortem can take."*
- *"I don't think anything could prepare folk for this experience, but I think if we knew that the house or wherever the death occurs is treated as a crime scene as a matter of course it would have been helpful. It would not make anyone feel better about the death but might make them feel less criminalised when they know they have done nothing wrong."*
- *"To be informed that you could speak to the pathologist prior to post mortem and before PM results fully available."*

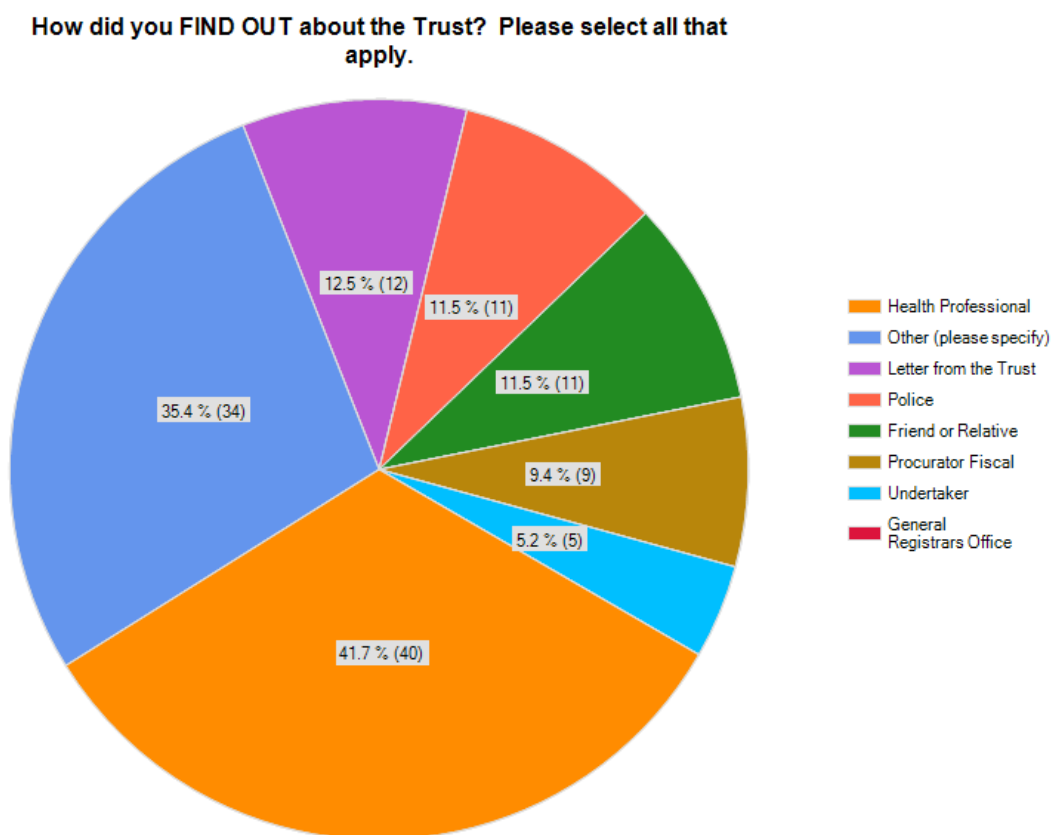
## *What the Trust can do for you and others?*

### When did you hear about the Trust?

When did you hear about the Trust?	No of Respondents	% of Respondents
Already knew about the Trust	6	6.5%
During the first week	35	37.6%
Weeks 2-4	26	28%
Months 2-3	11	11.8%
Months 4-6	2	2.2%
Later than 6 months	13	14%

The above table shows that in the first week 44% of respondents had heard of the Trust and by the end of the first month 82% of respondents had heard of the Trust.

### How did you find out about the Trust?



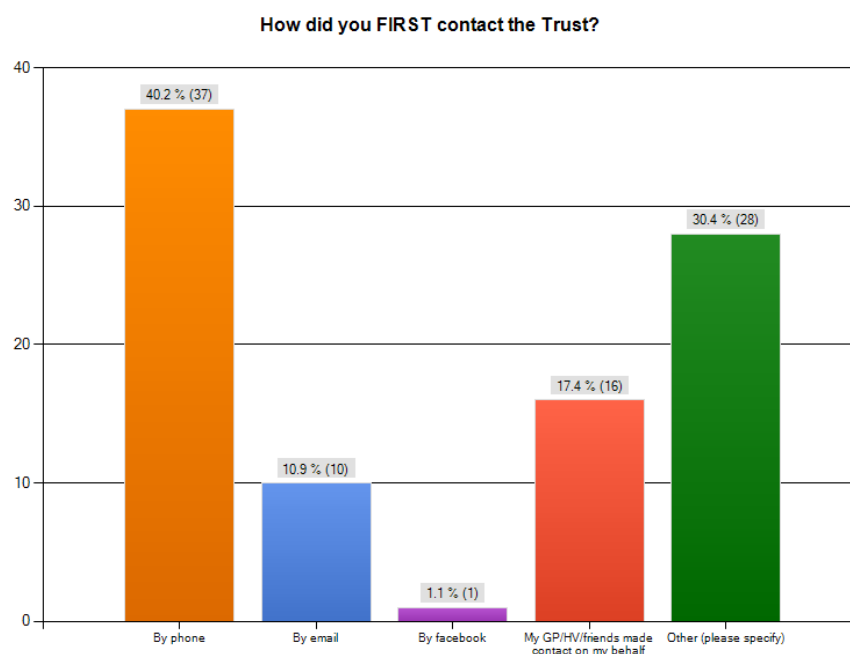
Common themes within the large 'other' section included 'was given a leaflet,' 'Can't remember' and 'the internet.'

## How soon did you have contact?



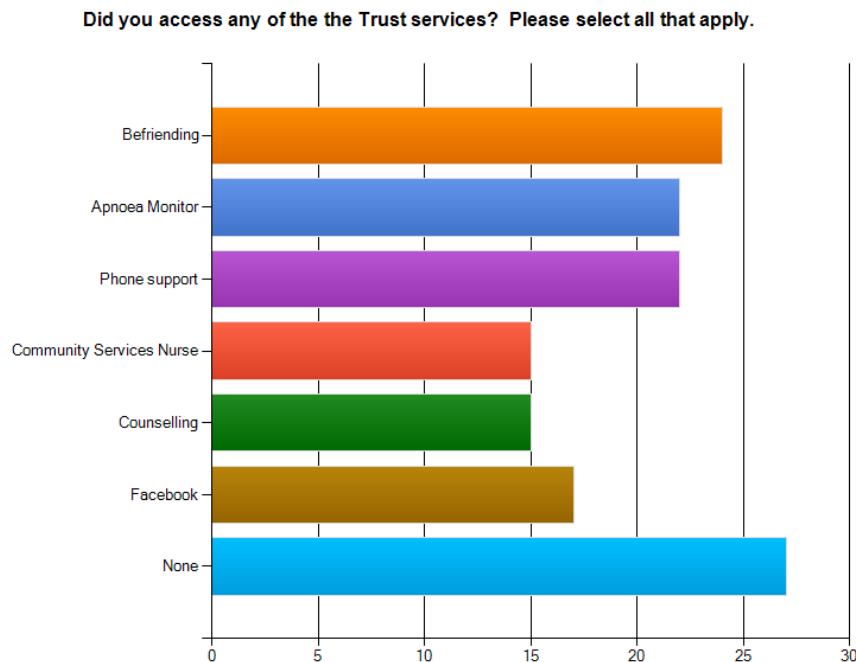
It is interesting to note that almost 50% of respondents had contact within the first month of their bereavement.

## How did you FIRST contact the Trust?



Themes within the 'other' responses included 'Letter from the Trust', 'Procurator Fiscal' and 'Can't remember'.

## What services have you used?



The above chart shows that all of the services provided by the Trust are used and also that sometimes families do not necessarily need or want them.

Questions were asked about the following with space for respondents to openly respond:

- Improve Trust services / help other bereaved families
- Good things Trust do
- What could Trust do better
- Other services / info you'd like Trust to provide

The responses for these have been imported into Excel and can be evaluated as part of future work by the Trust.

Respondents were asked if they would be interested in helping others in the same situation as themselves. Of the 88 respondents who answered this question, 66 said yes and 22 answered no.

The respondents were then asked to select any / all of the ways they may be interested in helping and these responses are shown in the table below

Ways to help others?	Number of respondents
Helping others cope	44
Volunteering	40
Fundraising	41
Support Groups	32
Other	17

Of the comments in the 'other' section many said they would like to help but they are not ready or too early in their grief or too raw or not over it. Some said they do these things already.

The respondents within this section have been identified and supplied to the Trust.

# Conclusions

## General conclusions

- The survey attained a response rate of 22%.
- 109 survey responses were gathered 84% of these from bereaved parents and 11% from bereaved grandparents thus highlighting the role the Trust plays not just in supporting parents but also supporting grandparents.
- Communication, respect and feelings of abandonment seem to be the key themes from many of the respondents.
- One thing that is particularly striking when reading all these experiences is the inconsistency of care/experiences.
- Some respondents found none of the professionals helpful, some found none of the professionals unhelpful.
- There is such a vast range of experiences expressed in response to this survey.
- There are some situations handled in an amazingly inspiring and humane manner and equally some incredibly awful experiences.
- Some of these awful experiences appear to be preventable through improved awareness and training and some seem to be circumstantial.
- Families shared many more helpful memories than unhelpful memories.
- Further more detailed analysis is required in order to do justice to the depth and quality of information provided by families.
- Resounding feeling I had whilst reading and analysing the responses was that it is clear that families have had similar experiences and how much stronger they would be as a group.

## Personal Information Conclusions

- The gender split of the babies/children discussed in this survey was 60% boys and 40% girls.
- The age of the mother at the time of the child's death ranged from 17 to 40 and the age of the father at the time of the child's death ranged from 18 to 44.
- The mean age of the mothers was 27.8 years. The mean age of the fathers was 29.9 years.
- Over 90% of families received their post-mortem results within 6 months and 70% received them within 3 months.
- There was doubt in the early stages of this project as to whether it was appropriate from a respectful perspective to send this survey to families who are in the earliest stages of their loss.
- This has absolutely been confirmed as being an appropriate course of action as there were 4 responses from families whose babies have died this year.

## Experience of the Professionals Conclusions

- It is important to note that the professionals who are perhaps not highlighted as having been really helpful or not so helpful may just be doing a really good job and therefore don't stand out in either a positive or negative way.
- Families value honesty and open communication when dealing with tragedy.
- Empathy and honesty are what families have described as being helpful.
- Feeling judged as being guilty before proven innocent is a common theme.
- Families seem to look back on experiences with a positive light when they were given factual information and truthful explanations.
- Families respect the fact that the police have a job to do.
- Many siblings present at the time are not considered by the professionals.



- Families respect the role the police have to play and although at the time it has been a shocking and traumatic experience to have the police in their houses the comments received in the helpful section of this survey demonstrate the positive impact police officers and CID can make and have made in what is inevitably an extremely tough role.
- The most important action that Health Visitors and GPs can take to support families is to listen to them and not abandon them.
- Funeral Directors provide a vital service for these families. Amongst the vast quantity of experiences there was not a single unhelpful experience of funeral directors.
- Generally if families were able to meet the pathologists it was a helpful experience.
- There was mixed feedback regarding the procurator fiscals staff – Some really poor feedback regarding use of inappropriate language with bereaved families and apparent lack of communications procedures balanced with some who gave clear explanations and were sympathetic towards families.
- There were mixed experiences of the Ambulance Service – some respondents praised their speed of response, some said they were really slow; many said they did all they could; others said they didn't keep them informed.
- Religious Leaders generally were compassionate, extremely supportive and helpful when planning funerals and helping families cope. There were some instances of unprofessionalism mainly around inappropriate remarks.
- The overwhelming sense from reading the responses is that the Paediatrician has not had an impact on the family or is it perhaps families are unaware of who their paediatrician was? Paediatricians have some work to do to ensure families are aware of who they are and what their role is.

#### Scottish Cot Death Trust Conclusions

- In the first week 44% of respondents had heard of the Trust and by the end of the first month 82% of respondents had heard of the Trust.
- Almost 50% of respondents had contact within the first month of their bereavement.
- 66 individuals want to help the Trust help other families in some way.
- Many families appreciate the Trust even if they do not actually access their services.
- Families have a need to better support bereaved siblings from the responses to what the professionals could have done better question.

## **Lessons Learnt**

- Restrict the date format entry criteria in any future survey e.g. 01/12/11
- Email is by far the most effective manner to send survey links.
- Give more time to the survey evaluation.
- An incredible quantity and quality of work can be achieved in a short timescale with a good objective driven scope.

## Recommendations for Further Work

- Further more detailed analysis is required in order to do justice to the depth and quality of information provided by families.
- Extract information regarding age ranges of children as per the table below:

Age of child	Response %	Response Count
<3 months		
3-6 months		
6-12 months		
12-24 months		
>24 months		

- Further detailed analysis of the responses of some questions in time (perhaps decades) to show whether there is a consensus of if and how experiences (such as length of time to receive the final post-mortem results) have changed over time.
- It would be of further interest to map experiences by geographic area.
- More detailed analysis of what the professionals could have done better
- Analysis of the information provided regarding Trust services
  - Improve Trust services / help other bereaved families
  - Good things Trust do
  - What could Trust do better
  - Other services / info you'd like Trust to provide
- Make contact with those who have indicated an interest in helping the Trust
  - Potential Befrienders
  - Look geographically and see if support groups could be established
  - Look geographically at potential fundraisers and see if this could be combined with area support groups
  - Potential volunteer speakers
- Identify who within the Trust could be responsible for managing this
- Update the Trust's database with information received as part of the survey
  - Add any new personal and contact details received
  - Add respondent experience details
  - Identification of anyone who answered 'not at all' to question 29 and write to them to clarify their wishes
  - Ensure the individual who opted out of the survey's details are amended accordingly
- Ensure the linda.sterry@scottishcotdeathtrust.org email address is checked for a period of time.
- Make contact with the governing bodies of the health professionals evaluated within this survey and make them aware of the impact they have on bereaved families so that they can acknowledge the things they and others do well and learn where they have room for improvement.
- If / when the GRO data is evaluated it would be interesting to contrast the information from that analysis with the information provided in this survey.
- Set up some statistical monitoring which could routinely provide a report regarding some of the demographics of bereaved families.
- Continue to gather and update email addresses from families as frequently as possible.

## **Appendix 1 – Copy of letter that accompanied paper survey**

April 2011

Dear ,

From one bereaved family to another I am asking for your help - I am looking for fifteen minutes of your time to complete this survey. I am being funded by the Vodafone World of Difference Programme to work with the Trust for two months. During my time I hope to work on a number of projects which will improve the way in which professionals deal with newly bereaved families. The information gathered from this survey will be used by the Trust to improve its own support services and to inform the various professionals involved in a cot death.

A little bit about me - my son Gregor died suddenly and unexpectedly in March 2009 aged two. For 5 months we believed he had died from Cot Death but the final post mortem results showed the cause of his death was an overwhelming virus. Although I have a cause of death I still have more questions than answers and was subjected to a similar process as many of you have been through. There were many aspects of how my family were treated on the day of Gregor's death and the aftermath that I want to try and ensure do not happen to others and conversely there were also some professionals who were amazing.

With regard to the confidentiality of the information you provide please be assured that your personal details will NEVER be released to anyone and will be treated as strictly confidential. The information regarding your experience of the professionals may be used but AT ALL TIMES your identity would remain anonymous.

You may have completed a survey in 2009, if you took the time to do this then on behalf of the Trust thank you. As a direct result of that survey the Trust implemented a counselling service for bereaved families, started a Facebook page, expanded their Befriender programme and have also been working with Quality Improvement Scotland to assist with their plans for SUDI (Sudden Unexplained Death of Infants) reviews.

The closing date for completed responses is Sunday 1st May. If there are other members of your family who are willing to complete this from their perspective please do get in touch with me at [linda.sterry@scottishcotdeathtrust.org](mailto:linda.sterry@scottishcotdeathtrust.org) and I will arrange to send them a personal survey link to capture their responses.

Your participation is very much appreciated not only by the Trust but also by the families who will sadly be walking in our shoes in the future. If there is something you want to say that doesn't fit the survey questions then please do send it separately by email or by letter to the Trust as that may just be important information that could help make someone else's experience less painful. If you want to get any further information or discuss anything contained in this letter then please give the Trust a call on 0141 357 3946.

I hope you will support me in my endeavours - Every single one of us and our respective families has a different story to tell and with your help I want to make a huge difference.

With love,

**Linda Sterry**

**Parent**

## Appendix 2 – Copy of paper survey

### What the Trust can do for you and others?

26. Please tell us about any other services or information you would like the Trust to provide?

27. Would you be interested in helping others in the same situation as yourself?

Yes ☐ No ☐

28. Please select any/all of the ways you may be interested in helping?

Helping other parents cope ☐ Fundraising ☐

Volunteering ☐ Support Groups ☐

Other, please specify

29. How would you like the Trust to contact you in the future? Please complete all acceptable contact means:

Email

Phone

Post

Not at all ☐

30. Are you happy for the Trust to add your details to our database?

Yes ☐ No ☐

*Thank you for taking the time to help me 'Make a Difference'*



Survey for bereaved families to influence the future work of the Scottish Cot Death Trust  
By Linda Sterry (Parent)

### If at all possible, we would prefer you to complete this survey online

To get access to the online version, please enter the following link into your internet browser:

<https://www.surveymonkey.com/s/scdtsurvey>

Every family member has their own unique experience, so please do pass the above link onto others in your family and ask them to complete it

If you have any questions or need assistance with the survey, please email [Linda.Sterry@scottishcotdeathtrust.org](mailto:Linda.Sterry@scottishcotdeathtrust.org) or call the Trust office on 0141 357 3946

Scottish Cot Death Trust  
Royal Hospital for Sick Children, Yorkhill, Glasgow, G3 8SJ  
The Scottish Cot Death Trust, a registered Scottish Charity (SC003458)

[www.scottishcotdeathtrust.org](http://www.scottishcotdeathtrust.org)

### Personal Information

The benefit of including your personal information makes your input much more useful and valuable to the Trust as we can use it in context (eg where and when) to identify to what degree the system is failing newly bereaved families and how we can best work at ensuring families are treated with the respect and sensitivity they deserve.

I fully acknowledge this survey may coincide with special dates for some of you and if this causes distress then I am truly sorry. Equally I appreciate you are all at different points in time with respect to your bereavements. If you are not the parents of the child discussed in this survey please be aware that some of the questions may not be appropriate for you but I do value your input as we know and understand there are so many perspectives of those affected by the sudden and unexpected death of a child.

It is important for me to clarify that when I use the word baby/child I am asking about the baby/child who has died as I know that some of you will not be the parents and that is why I have not asked about 'your' child.

Please provide us with as much information as you can.

1. Please tell us the baby/child's name?

2. Please enter details of where you lived when the baby/child died?

Postcode

Town

3. Do you still live there?

Yes ☐ No ☐

4. What is your current home address?

5. Relation to baby/child?

Parent ☐ Grandparent ☐ Sibling ☐

Aunt/Uncle ☐ Friend ☐ Other, Please specify

### What the Trust can do for you and others?

22. Did you access any of the Trust services? Please select all that apply.

Befriending ☐ Apnoea Monitor ☐

Phone Support ☐ Community Services Nurse ☐

Counselling ☐ Facebook ☐

None ☐

Other, please specify

23. Is there anything else you'd like to tell the Trust that would help improve our service or help other bereaved families?

24. Tell us about what you think are the good things that the Trust do?

25. What could the Trust do to improve their service for bereaved families?

### What the Trust can do for you and others?

The next few questions relate to you and the Trust. We are currently evaluating how best to make and maintain contact with families, so we would like to find out more about your experiences and preferences.

#### 18. Relative to your bereavement, when did you HEAR ABOUT the Trust?

Already knew about the Trust	<input type="checkbox"/>	During the first week	<input type="checkbox"/>
Weeks 2–4	<input type="checkbox"/>	Months 2–3	<input type="checkbox"/>
Months 4–6	<input type="checkbox"/>	Later than 6 months	<input type="checkbox"/>

#### 19. How did you FIND ABOUT the Trust? Please select all that apply:

Police	<input type="checkbox"/>	Undertaker	<input type="checkbox"/>
Health Professional	<input type="checkbox"/>	General Registrars Office	<input type="checkbox"/>
Letter from the Trust	<input type="checkbox"/>	Friend or Relative	<input type="checkbox"/>
Procurator Fiscal	<input type="checkbox"/>	Other	<input type="checkbox"/>

If other, please specify

#### 20. How soon after your bereavement did you HAVE CONTACT with the Trust?

During the first week	<input type="checkbox"/>	Weeks 2–4	<input type="checkbox"/>
Months 2–3	<input type="checkbox"/>	Months 4–6	<input type="checkbox"/>
Later than 6 months	<input type="checkbox"/>		

#### 21. How did you FIRST contact the Trust?

Phone	<input type="checkbox"/>	Email	<input type="checkbox"/>
Facebook	<input type="checkbox"/>	Referral (Friends/GP/HV)	<input type="checkbox"/>

Other, please specify

### Personal Information

#### 6. Mother's age at the time of child's death?

#### 7. Father's age at the time of child's death?

#### 8. The baby/child's date of birth?

#### 9. Gender of child?

Male ☐ Female ☐

#### 10. The baby/child's date of death?

#### 11. How long did it take until final postmortem results were known?

3 months or less ☐ 4–6 months ☐ Over 6 months ☐

Any other relevant comments:

### Your experience of the Professionals

This section is looking for information about your experience of the professionals. There are some questions in this section which have been set as mandatory—these questions have been marked with a \*. This is because they form the basis of what we really want/need to know about your experience, so we can add it to the experience of others and ultimately look for common themes which we intend to feedback to the professionals, so your input really can make a difference.

#### 12. How would you rate the helpfulness of the professionals listed below:

	Very Unhelpful	Quite Unhelpful	Neither Helpful or Unhelpful	Quite Helpful	Very Helpful	N/A
Ambulance Service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health visitor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
GP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Paediatrician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Police	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Pathologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Funeral Director	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Religious Leader	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Procurator Fiscal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Other (please specify)

#### 13. Thinking about the Professionals who were most helpful, can you explain what they did that made you feel like they were helpful to you? Please tell us about as many of the Professionals as you can:

### Your experience of the Professionals

#### 14. Thinking about the Professionals who were unhelpful, can you explain what they did that made you feel like they were being unhelpful? Please tell us about as many of the Professionals as you can:

#### 15. What could these Professionals have done better?

#### 16. Was there one key Professional who was important for you?

#### 17. Reflecting on your personal experience (and not the process), what information do you wish you had known then that you think may be helpful to a newly bereaved family now?