



Case Review of Sudden Unexpected Deaths in Infancy(SUDI) in Scotland
Final Report





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Joint Grantholders: Hazel Brooke, MBE MA
Member and Past Chairman of Executive Committee, SIDS
International
Executive Director, Scottish Cot Death Trust
Royal Hospital for Sick Children
Yorkhill
Glasgow G3 8SJ

Dr John P McClure, MBChB, FRCP (Glas & Edin),
FRCPCH,DCH, D(Obs) RCOGConsultant Paediatrician
Crosshouse Hospital
Kilmarnock KA2 0BE
Telephone: 01563 521133
Fax: 01563 577976
Email:john.mcclure@aaaht.scot.nhs.uk

Contact Person: Dr John McClure

Project Co-ordinator Doris Smith

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EXECUTIVE SUMMARY

INTRODUCTION

Despite the decline in the incidence of Sudden Unexpected Death in Infancy (SUDI) over the past 15 years it remains the largest single cause of Post Perinatal Infant Mortality in Scotland. A much higher proportion of the remaining SUDI cases now occur within the most vulnerable families in the community, while the incidence in the more affluent sections of society has decreased substantially. After many paediatricians and pathologists expressed the opinion that all SUDI should be subject to a standardised form of local multidisciplinary review, the Scottish Cot Death Trust (SCDT) sought funding in 2000 from NHS Quality Improvement Scotland to design and implement a pilot study. The project required participation from all Health Boards and Local Authorities in Scotland and co-operation from the Crown Office and the Procurator Fiscal Service. The data were collected between September 2001 and September 2004.

AIMS AND OBJECTIVES

- to trial the concept of multidisciplinary case review
- to audit consistency of approach by police and Procurators Fiscal
- to audit consistency of diagnosis by pathologists
- to identify family support needs and to provide feedback to appropriate professionals
- to secure interagency working
- to look at epidemiological trends
- to identify antecedent factors

METHODS

The Crown Office would issue a Circular to Procurators Fiscal (PF) instructing them, on receipt of the gross pathology report from the Pathologist, to inform the bereaved parents that their infant's death would be the subject of case review and to offer to pass their details, unless they objected, to SCDT for support purposes. On receipt of the final autopsy report the PF would authorise the Pathologist to contribute relevant information from the Police Enquiry Form and autopsy report to the case review meeting. The Pilot Co-ordinator would send the details to a link consultant paediatrician in the relevant Health Board Area who would organise the multidisciplinary review meeting in the GP surgery and complete all report forms, returning them to the Co-ordinator. For cases where review was not possible pathologists would retrieve as much data as possible from the Police Report. SCDT would co-ordinate the process.

The *Study Population* consisted of all sudden unexpected deaths in infants under 2 years, occurring in Scotland between 1st September 2001 and 31st August 2004 where the Procurator Fiscal did not intend to pursue further investigation with a view to either criminal proceedings or an FAI. One hundred and thirty eight SUDI cases fell into this category, of which 80 were the subject of multidisciplinary case review.

RESULTS

Problems were encountered in all groups of participants in the process:

- The Crown Office did not issue the Circular until the end of Year 1 of the Pilot, thus
- preventing review of all cases for that year.
- Procurators Fiscal frequently failed to follow the instructions from the Crown Office unless reminded by the Pilot Co-ordinator. This significantly increased the workload of the Co-ordinator and resulted in delays in offer of support to bereaved families.
- 77% of link paediatricians had not arranged any review meetings 18 months into the pilot. At this point SCDT assumed responsibility for arranging all meetings but the delay meant that many cases were not reviewed for at least 18 months after death had occurred. This had an effect on engagement with the GPs who often did not appreciate the purpose of a review at this late stage.
- By Year 3 of the Pilot some paediatricians were unwilling to participate in the project and one pathologist had retired, necessitating the use of reviewers from outwith the Health Board Area where the death had occurred.

However, the data collected demonstrated:

- the value of review for the sharing of information, particularly in sensitive areas such as drug and alcohol abuse where the police report was often deficient. We failed to secure a standardised police enquiry form prior to the launch of the pilot and this resulted in missing information, particularly for the unreviewed cases
- that SUDI cases frequently occurred in deprived families where lifestyle was complicated by poverty, smoking, alcohol, methadone and illegal drug use and where Primary Care and Social Work had concerns about the family
- that there was almost no evidence of concerns by the review team about professional input to the family or response of healthcare professionals that the delays in reviewing most of the cases prevented the review team from taking agreed actions to support the family in the aftermath of the death and with the next child. Had review taken place 3-4 months after the death, as planned, this would have been an important part of the process.

CONCLUSIONS

- Case review is possible and multidisciplinary input provides considerably more information than that provided by individual disciplines
- Paediatric pathology in every case was invaluable
- The personnel involved in the multidisciplinary process were appropriate and the process, particularly the location of the review meeting in the Primary Care setting, was effective when implemented
- The process by which Primary Care records were retrieved worked well
- Hospital records, if they exist, should be part of the review
- The delay in carrying out review had a negative effect on co-operation and reduced the potential for support for the bereaved family
- Absence of Social Work representation at some review meetings was

disappointing but the lack of consultation about meeting dates was a contributory factor

- Attempts to carry out a full audit of consistency of pathology final diagnosis proved difficult but data has been gathered for future analysis
- The Police Report is vital to the process and lack of standardisation adversely affected the amount of information available
- Considerable organisation locally and centrally is required, is time-consuming and needs to be recognised and resourced

RECOMMENDATIONS

- Case review should be a mandatory component of the investigation of SUDI and the care of the bereaved families
- There should be a standing Steering Committee and central co-ordinating point for Case Review until it is firmly established
- Paediatric pathology input, with a full range of investigations, must continue in all SUDI cases
- The role of the link paediatrician and the paediatric pathologist should be clarified and recognition provided in job plans
- The Police Inquiry Form should be standardised for Scotland, through negotiation and joint working with the Association of Chief Police Officers in Scotland.

INTRODUCTION

Cases of sudden infant death have been recorded through the ages. One of the earliest references is in the Book of Kings in the Bible, “...and this woman’s child died during the night because she overlaid it”. Overlaying continued to be accepted for centuries as the cause of such deaths, with Templeman¹ in Dundee in 1890 claiming that, “The principal causes producing this great mortality from overlaying are:

- Ignorance and carelessness of mothers
- Drunkenness
- Overcrowding

In 1969 the following definition of Sudden Infant Death Syndrome (SIDS) was proposed: “The sudden death of an infant or young child which is unexpected by history and in which a thorough post mortem examination fails to demonstrate an adequate cause for death”. This definition was widely used on death certificates throughout the next three decades. During the seventies and eighties many developed countries experienced an increase in the rate of SIDS, with an average incidence of 2.4 per 1,000 livebirths. Research suggests that this epidemic was due to the advice given to parents to place their babies prone for sleep. A public health campaign was launched by the Scottish Home and Health Department in 1991 advising against this practice and advocating the supine position. Over the next decade there was a dramatic decrease in SIDS incidence in Scotland, to around 35 per annum (a rate of 0.6 per 1,000 livebirths).

In recent years pathologists in Scotland have moved away from the use of the term “SIDS” on the death certificate that is written following the initial post mortem examination. They believe it is premature to use it at this stage in the investigation of the death when post mortem test results, which may eventually provide either some evidence that the infant was not completely well or possibly a full explanation of the death, are not yet available. In Scotland by far the most common term currently used for sudden unexpected infant deaths on gross pathology is Sudden Unexpected Death in Infancy (SUDI) and we have therefore used this term throughout this report.

Following the decline in the number of deaths in the 1990’s, a much higher proportion of deaths than previously now occurred in the most vulnerable families in the community, highlighting the already known link with deprivation². Paediatricians and pathologists increasingly expressed their opinion that all SUDI should be subject to a standardised form of local multidisciplinary review and in 2000 the Scottish Cot Death Trust (SCDT) formed a Steering Group (**Appendix 1**) to design a pilot study.

AIMS AND OBJECTIVES

- to trial the concept of multidisciplinary case review
- to audit consistency of approach by police and Procurators Fiscal (PF)
- to audit consistency of diagnosis by pathologists
- to identify family support needs and to provide feedback to appropriate professionals
- to secure interagency working
- to look at epidemiological trends
- to identify antecedent factors

FUNDING

A Review Protocol was submitted to NHS Quality Improvement Scotland (NHS QIS) with a request for three years funding which was formally granted in March 2001. An additional nine months' funding was granted in July 2005 in recognition of the unforeseen problems encountered in conducting the pilot study. The project came under the umbrella of the Scottish Perinatal Mortality and Morbidity Review Advisory Group (SPMMRAG) of NHS QIS to which interim reports were made. SCDT co-ordinated the pilot.

METHODS

Setting

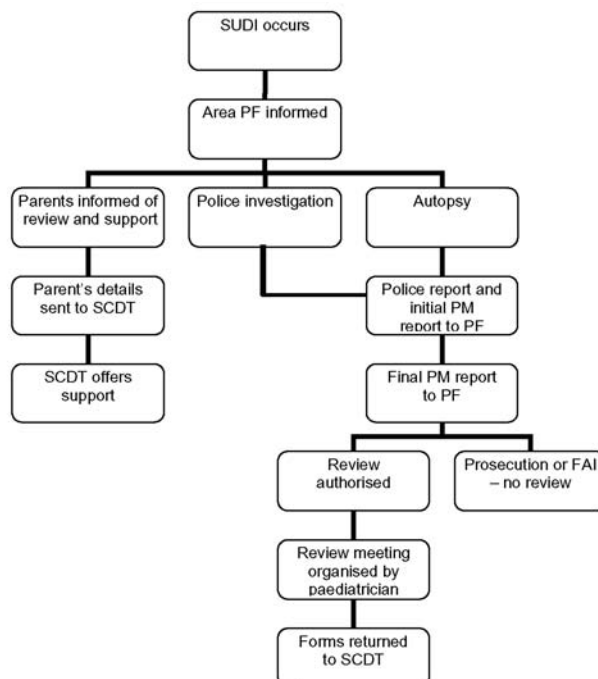
The project required participation from all Health Boards and Local Authorities in Scotland and co-operation from the Crown Office and the Procurator Fiscal Service. A letter explaining the pilot and requesting co-operation was sent in May 2001 to:

- The Medical Director of each NHS Trust in Scotland
- The Director of Public Health for each Health Board Area
- The Commissioner for Child Health for each Health Board Area
- The Director of Social Work for each Local Authority

Study Population

The study population consisted of all sudden unexpected deaths in infants under two years of age, occurring in Scotland between 1st September 2001 and 31st August 2004 where the Procurators Fiscal did not intend to pursue further investigation with a view to either criminal proceedings or a Fatal Accident Inquiry (FAI).

Plan of Case Review



The Crown Office would issue a Circular to all Procurators Fiscal instructing them, on receipt of the gross pathology report from the Pathologist, to send a letter to the bereaved parents informing them:

- that their infant's death would be the subject of case review (parental permission for the review was not required but the Crown Office stipulated that parents must be made aware of the review)
- that, unless they objected within 14 days of the date of writing, their contact details would be passed to SCDT for support purposes.

If no objection was received, Procurators Fiscal would forward these details in writing to SCDT.

The General Register Office (GRO) would also notify SCDT of all deaths in infants aged 0-2 years which had been reported to the PF to ensure that no cases were missed.

On receipt of the final autopsy report the PF would authorise the Pathologist to contribute relevant information from the Police Inquiry Form and autopsy report to the case review meeting. The PF was also requested early on in the pilot to copy this authorisation to SCDT. On receipt of this the Co-ordinator would give the case an identification number and pass the details, by means of a referral form (**Appendix 2**), to a link consultant paediatrician in the relevant Health Board Area who would organise the case review meeting in the GP Surgery, complete the Abstraction and Case Review Summary Forms (**Appendix 3**) and return them, with all identifiers removed, to the Co-ordinator. In designing the Abstraction form it was anticipated that the contents would reflect a new national Police Inquiry Form. For cases where review was not possible, pathologists would retrieve core data from the Police Report.

SCDT would co-ordinate the process and submit a final report on the project to NHS Quality Improvement Scotland.

Composition of Local Review Team

- Pathologist who carried out the autopsy
- Link Paediatrician
- Infant's general practitioner (GP)
- Infant's Health Visitor
- Representative of Social Work

RESULTS

Process

Procurators Fiscal

Table 1 SUDI cases reviewed

	Year 1		Year 2		Year 3	
	no.	%	no.	%	no.	%
Reviewed	0	0	45	96	35	85
Not reviewed	50	100	2	4	6	15
Total	50	100	47	100	41	100

Note: Reasons for non-review of a total of 58 cases were: 50 occurred in Year 1, prior to issue of Crown Office Circular, 1 was a possible FAI, 5 were due to GP reluctance to participate, and in 2 cases it proved impossible to negotiate mutually acceptable dates for the GP and the pathologist/paediatrician to meet.

Table 2 Source of referral of death

	Year 1		Year 2		Year 3	
	no.	%	no.	%	no.	%
PF referred parents to SCDT without reminder	*0	0	**16	35	9	22
Self referrals	9	18	6	13	7	17
Total (notified to SCDT by GRO)	50	100	47	100	41	100

* Because Crown Office Circular had not been issued

** 1 case for Year 2 was first thought to be a possible FAI and therefore not eligible for referral. However, on the exclusion of FAI, it was included in the review population.

Four months into Year 2 of the pilot, 8 SUDI cases had occurred but only one had been referred by a PF to SCDT for support. There were 50 cases in Years 2–3 where SCDT first learned of the death from GRO (Table 2) and this notification was on average 4 weeks after death. When the Co-ordinator followed these up with the PF it was found that the initial letter had been sent to the parents in only 3/25 of these cases in Year 1 and 15/25 in Year 2.

Table 3 Telephone calls required to remind PF to comply with Circular

	Year 1	Year 2	Year 3
Regarding support	*0	83	52
Regarding review authorisation	*0	112	58

*Because Crown Office Circular had not been issued

The copy of the letter from the PF to the pathologist authorising sharing of information from the Police and autopsy reports with the review team was sent to SCDT in only 9 cases in Year 2 and 29 in Year 3. This resulted in many additional phone calls to ascertain when review could proceed. (Table 3)

PARTICIPATION OF THE REVIEW TEAM

Link Paediatricians (for list see Appendix 4)

Since the delay in issue of the Crown Office Circular until August 2002 had prevented review of cases for Year 1, the link paediatricians were asked to organise review meetings from the beginning of the second year (September 2002). By March 2004 (halfway through Year 3) only five cases had been reviewed and this delay resulted in some reviews taking place more than 18 months after the infant's death. SCDT at this point assumed responsibility for organisation of all review meetings

Table 4 Paediatric input to case reviews

Input by	Year 1		Year 2		Year 3	
	no.	%	no.	%	no.	%
Designated link paediatrician	n/a		40	89	22	63
External paediatrician	n/a		5	11	12	34
No paediatrician	n/a		0	0	1	3
Total cases reviewed	n/a		45	100	35	100

In Year 2 cases the designated link paediatrician participated in most local review meetings (Table 4) but in Year 3 cases an external paediatrician was more frequently involved because some link paediatricians were unwilling to continue their co-operation with the pilot. On taking over responsibility for meeting organisation SCDT introduced a meeting attendance record form (**Appendix 5**) and this was completed by the link paediatrician for 37 cases. In only one reviewed case did the paediatrician fail to attend (because of an unexpected emergency).

General Practitioners/Health Visitors

General Practitioners participated in 78/80 case reviews. In the remaining two cases the review took place without the GP but information from the infant's case notes was available and the Health Visitor supplied additional background on the infant and family circumstances. Where we had completed attendance forms for the review meeting the Health Visitor had attended in all but two cases, one of which was a two-day old infant with whom the Health Visitor had had no contact. In Years 2 and 3 eight cases were not reviewed (see Table 1). Of the five cases in which the GP was reluctant to participate three of the infants had not been registered with the practice, in one the GP had retired and no-one else in the practice was willing to participate and in the final case the GP refused, initially, to participate unless locum funding was provided. Although he later agreed to participate without funding, the pilot had run out of time.

Although in most areas the pathologist, when informing the GP of the initial autopsy result, had attached a proforma request from SCDT that the infant's casenotes be retained in the surgery pending a case review, these had almost invariably been returned to the Primary Care Trust.

Pathologists (for list see Appendix 6)

Nine out of the ten paediatric pathologists involved in the autopsy of SUDI cases in Scotland participated in the reviews.

Table 5 Pathology input to case reviews

Input by	Year 1		Year 2		Year 3	
	no.	%	no.	%	no.	%
Pathologist from Dept. where autopsy performed	n/a		41	91	27	77
External pathologist	n/a		0	0	5	14
No pathologist	n/a		4	9	3	9
Total cases reviewed	n/a		45	100	35	100

The retiral of one pathologist during the period of the pilot created a potential lack of pathology input in eight cases. In five of these a pathologist from another department

participated in the review and in three there was no pathologist at the review meeting (Table 5) but the paediatrician had prior access to information extracted from the autopsy and police reports. The reviews of two deaths which occurred in remote areas were carried out by the GP and an external paediatrician, again with prior access to information from the autopsy and police reports. In cases for which we received a record of attendance, the pathologist was unable to attend in a further four cases but provided information in advance of the meeting for three of these. In the final case the pathologist was unable to find the GP surgery.

Pathologists also provided core and event scene data on 57/58 unreviewed cases from the Police Report as agreed with the Crown Office.

During the final year of the project the Steering Group developed an expanded Summary of Post Mortem form (**Appendix 7**) to provide more detailed information about the various tests carried out in SUDI cases. Departments of Pathology were asked to complete these forms retrospectively and this was done in 135/138 cases.

One of the aims of the Pilot had been to audit consistency of diagnosis by pathologists. This proved difficult logistically but data was gathered regarding the degree of significance of various investigations in informing the final cause of death, with a view to analysing these in the future.

Social Work

In 39/80 reviewed cases Social Work had been involved with the infant's family. We had information on attendance at review meetings for 19 of these cases and Social Work sent a representative to 10/19. In cases where we knew there had been no previous connection with the bereaved family (40) we had attendance information on 17 cases and Social Work was represented at the review in only six.

Police

Anecdotal feedback from the local review teams revealed a wide disparity in focus and completeness in the police report. This was also evident from the paucity of data available for the non-reviewed cases. However, some reports were excellent and closely mirrored the sequence of information required for the Abstraction form.

DATA

Table 6 Age of SUDI infants at death

Age at Death (weeks)	SUDI cases n=138	%
<1	5	4
1-4	19	14
5-8	25	18
9-12	22	16
13-16	26	19
17-26	20	14
27-52	15	11
>52	6	4

Twenty-four of the SUDI cases died in the neonatal period, 49 died pre-immunisation and 117 pre-weaning. Eighty-five died before the age of 6 months, confirming the findings of other SUDI studies.

Table 7 Risk factors for SUDI cf. Scottish births for 2004*

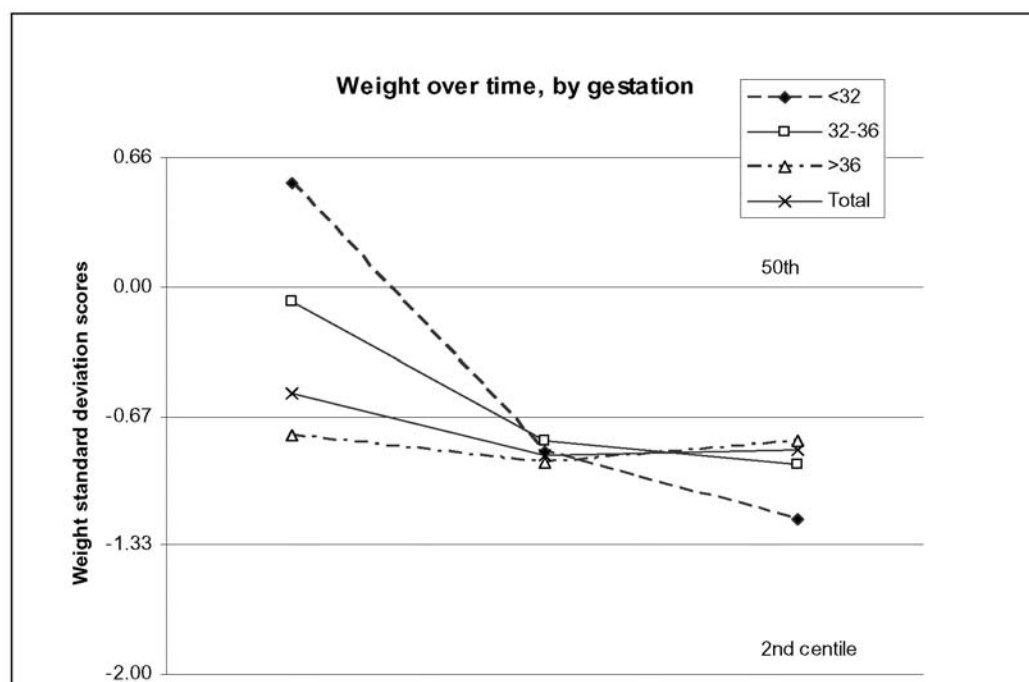
Factor	SUDI cases n=138	%	Scottish Livebirths %
SIMD**			
1	10/138	7	19
2	20/138	14	19
3	18/138	13	19
4	36/138	26	20
5	54/138	39	24
Male gender	93/138	67	51
Multiple Birth	7/134	5	3
Birth Wt <2499g	31/120	26	8
Gestation <37/52 weeks	31/121	26	8
Maternal parity			
0	45/133	34	45
1	50/133	37	35
2	21/133	16	14
3	9/133	7	4
>3	8/133	6	3
Maternal Age, years			
<20	14/122	11	8
20-24	39/122	32	18
25-29	35/122	29	24
30-34	25/122	21	30
35-39	8/122	6	17
>40	1/122	1	3

* Figures supplied by Information Services Division of NHS National Services Scotland

** The Scottish Index of Multiple Deprivation (SIMD). 1=least deprived quintile, 5=most deprived quintile

Table 7 compares the SUDI cases with Scottish livebirth data for 2004 in terms of some well-established risk factors for SUDI. Sixty-five percent of cases occurred in deprivation (SIMD) categories 4 and 5 and male infants were more vulnerable than females. Multiple birth did not appear to be a risk factor in this study. The incidence of low birthweight and preterm infants was considerably higher than the comparable incidence for Scottish livebirths in 2004 and 43% of the SUDI mothers were aged <25 compared with 26% of Scottish mothers in 2004.

Figure 1 Weight Standard Deviation Score over time, by gestation



Having confirmed (Table 7) that low birthweight was a risk factor for SUDI, Figure 1 illustrates the weight pattern of SUDI infants by gestational age group. The term infants were relatively short and light at birth, on average below the 25th centile; a total of 38% were below the 9th centile and 20% were below the 2nd centile.

From this point on in the analysis we divided the data into two groups - reviewed and unreviewed deaths - to highlight the absence of information in the unreviewed group where the sole source of data was the police report. In tables 8-15 the numbers in the columns headed "Information available" indicate the number and percentage of cases in each group for which we had data. Where the percentage was less than 70% it would be inadvisable to regard the sample as representative of the whole.

Previous health of SUDI cases	Reviewed n=80		Unreviewed n=58	
		Information available		Information available
Neonatal Intensive Care	5/79(6%)	79/80(99%)	10/55(18%)	55/58(95%)
Neonatal Special Care	18/79(23%)	79/80(99%)	3/55(5%)	55/58(95%)
Outpatient appointments	8/79(10%)	79/80(99%)	5/56(9%)	56/58(97%)
Inpatient episodes	11/79(14%)	79/80(99%)	2/56(4%)	56/58(97%)
Non-routine GP visits	26/78(33%)	78/80(98%)	17/53(32%)	53/58(91%)
Interval since baby was last seen by GP or HV				
0-1 days	14/77(18%)	77/80(96%)	5/38(13%)	38/58(66%)
2-7 days	29/77(38%)	77/80(96%)	12/38(32%)	38/58(66%)
8-13 days	15/77(20%)	77/80(96%)	12/36(33%)	36/58(62%)
> 13 days	19/77(26%)	77/80(96%)	9/38(24%)	38/58(66%)
Health of baby in the week prior to death				
Good	54/74(77%)	74/80(93%)	34/53(64%)	53/58(91%)
Fair	14/74(17%)	74/80(93%)	15/53(28%)	53/58(91%)
Poor	3/74(4%)	74/80(93%)	4/53(8%)	53/58(91%)
Health of baby 24 hours prior to death				
Good	54/75(72%)	75/80(94%)	34/54(63%)	54/58(93%)
Fair	15/75(18%)	75/80(94%)	16/54(30%)	54/58(93%)
Poor	6/75(7%)	75/80(94%)	4/54(7%)	54/58(93%)
Infant immunised in the previous 14 days				
	24/79(30%)	79/80(99%)	11/43(26%)	43/58(74%)

Table 8 Information available on previous health of SUDI case

Whilst abstracting data from the Police Report can provide a certain degree of accuracy and reliability on an infant's previous health, a third of unreviewed cases had no information on when the infant was last seen by Primary Care. (Table 8)

Table 9 Potential parental risk factors

Risk Factor	Reviewed n=80		Unreviewed n=58	
		Information available		Information available
Mother on methadone	16/78 (21%)	78/80(98%)	5/28 (18%)	28/58(48%)
Father on methadone	12/59 (20%)	59/80(74%)	2/19 (11%)	19/58 (33%)
Maternal smoking	59/79 (75%)	79/80(99%)	27/30 (90%)	30/58(52%)
Paternal smoking	46/58 (79%)	58/80(73%)	19/21 (90%)	21/58(36%)
Maternal alcohol habit	7/71 (10%)	71/80(89%)	2/7 (29%)	7/58(12%)
Paternal alcohol habit	9/49 (18%)	49/80(61%)	4/9 (44%)	9/58(16%)
Mother illegal substances	23/71 (32%)	71/80(89%)	7/19 (37%)	19/58(32%)
Father illegal substances	20/54 (37%)	54/80(69%)	5/15 (33%)	15/58(26%)
Mother on tranquillisers	8/74 (11%)	74/80(93%)	2/12 (17%)	12/58(21%)
Mother on antidepressants	13/74 (18%)	74/80(93%)	1/12 (8%)	12/58(21%)
Mother - previous case SUDI	2/56 (4%)	56/80(70%)	1/29 (3%)	29/58(50%)
Father - previous case SUDI	3/43 (7%)	43/80(54%)	0/16 (0%)	16/58(28%)

Table 9 shows the incidence of use of tobacco and addictive substances by parents and the history of a previous sudden death in the infant of either parent. We had good information for the reviewed cases about mother's use of methadone, alcohol and illegal substances but less information about father's use of these substances. Thirty-two percent of reviewed deaths occurred where the mother was recognised as having a drug habit, 75% of SUDI families smoked and 29% of mothers were on prescribed tranquillisers or antidepressants. There was little evidence of past history of sudden infant deaths occurring with either parent. There was poor information about these important factors in the unreviewed cases.

Table 10 Death scene circumstances

Circumstance	Reviewed n=80		Unreviewed n=58	
		Information available		Information available
Day Death	7/78 (9%)	78/80(98%)	5/55 (9%)	55/58(95%)
Night Death	71/78 (91%)	78/80(98%)	50/55 (91%)	55/58(95%)
Place of Death				
Home	71/80 (89%)	80/80(100%)	50/57 (88%)	57/58(98%)
Hospital	4/80 (5%)	80/80(100%)	5/57 (9%)	57/58(98%)
Other	5/80 (6%)	80/80(100%)	2/57 (4%)	57/80(98%)
Carer at Death				
Mother	28/80 (35%)	80/80(100%)	18/57 (32%)	57/58(98%)
Father	4/80 (5%)	80/80(100%)	6/57 (11%)	57/58(98%)
Both	42/80 (53%)	80/80(100%)	30/57 (53%)	57/58(98%)
Other	6/80 (7%)	80/80(100%)	3/57 (5%)	57/58(98%)
Breastfed at death	18/80 (23%)	80/80(100%)	10/51 (20%)	51/58(88%)
Position put down				
Supine	48/59 (81%)	59/80(74%)	28/36 (78%)	36/58(62%)
Prone	7/59 (12%)	59/80(74%)	6/36 (17%)	36/58(62%)
Side	4/59 (7%)	59/80(74%)	2/36 (6%)	36/58(62%)
Position found				
Supine	42/60 (70%)	60/80(75%)	24/40 (60%)	40/58(69%)
Prone	13/60 (22%)	60/80(75%)	12/40 (30%)	40/58(69%)
Side	5/60 (8%)	60/80(75%)	4/40 (10%)	40/58(69%)
Room at death				
On own	10/77 (13%)	77/80(96%)	15/56 (27%)	56/58 (97%)
Parents' room	65/77 (84%)	77/80(96%)	34/56 (61%)	56/58 (97%)
Other	2/77 (3%)	77/80(96%)	7/56 (13%)	56/58 (97%)
Co-sleeping	52/76 (68%)	76/80(95%)	26/55 (47%)	55/58(95%)

We designated as “day deaths” infants found dead between 9:30 am and 6:30 pm, the rest being “night deaths”. Most infants were in the care of either the mother or both parents. Twenty-one percent of SUDI cases for whom we had information about method of feeding at death were breastfeeding. When stratified for deprivation category 43% of infants in deprivation categories 1-3 were breastfeeding but only 9% in deprivation categories 4-5. Almost a fifth of the reviewed cases were placed non-supine for sleep. Ninety-three percent of infants <6 weeks of age were sleeping in the parents’ room. For the SUDI cases in which we knew routine sleep circumstances 87% were normally put down in a cot or crib and only 36% normally shared with an adult at some point during the night. However, on the day/night of death, 68% of all reviewed cases were sharing a sleep surface with an adult (Table 10).

Table 11 Further information about co-sleeping cases

Further co-sleeping information	Reviewed n=80		Unreviewed n=58	
		Information available		Information available
In adult bed	40/76 (53%)	76/80(95%)	17/55 (31%)	55/58(95%)
On sofa	12/76 (16%)	76/80(95%)	9/55 (16%)	55/58(95%)
With smoker	43/74 (58%)	74/80(93%)	14/44 (32%)	44/58(76%)
With mother alone	24/76 (32%)	76/80(95%)	10/55 (18%)	55/58(95%)
With father alone	7/76 (9%)	76/80(95%)	7/55 (13%)	55/58(95%)
With both parents	19/76 (25%)	76/80(95%)	7/55 (13%)	55/58(95%)
With other	2/76 (3%)	76/80(95%)	2/55 (4%)	55/58(95%)

More detailed analysis of co-sleeping (Table 11) indicated that the majority of co-sleepers were in an adult bed with the remainder on a sofa. Of the 24 mothers of reviewed cases who slept alone with their baby seven were methadone users, 11 were users of illegal substances, two had a known alcohol habit, four had used alcohol in the previous 12 hours and five had used illegal substances in the previous 24 hours. In 4/7 reviewed cases where the infant was co-sleeping with the father alone, the father had consumed alcohol in the previous 12 hours. In 7/19 cases where both parents were co-sleeping with the infant both had consumed alcohol in the previous 12 hours.

Table 12 Home/parenting concerns

Home/parenting concerns	Reviewed n=80		Unreviewed n=58	
		Information available		Information available
Heating in home	18/75 (24%)	75/80(94%)	3/45 (7%)	45/58(78%)
Hygiene in home	24/75 (32%)	75/80(94%)	7/42 (17%)	42/58(72%)
Neglect of child(ren)	12/72 (17%)	72/80(90%)	5/46 (11%)	46/58(79%)
CAR* checked	40/71 (56%)	71/80(89%)	24/27 (89%)	27/58(46%)
Findings on CAR	9/37 (24%)	37/40(93%)	3/18 (17%)	18/58(75%)
Social Work Involvement	39/75 (52%)	75/80(94%)	11/24 (46%)	24/58(41%)
History of Domestic Violence	18/74 (25%)	74/80(93%)	4/12 (33%)	12/58(21%)
Parent(s) known to police	30/70 (43%)	70/80(83%)	5/17 (29%)	17/58(29%)

*Child Abuse Register

There was evidence of the Child Abuse Register being checked in only 56% of reviewed cases. While the comparable figure for the unreviewed cases appears better, the low number of cases for which we had information means that the CAR was checked for <50% of unreviewed cases. (Table 12)

Table 13 Concerns highlighted at Review Meeting

Concerns at review meeting	Reviewed n=80	Information available
Social	41/78 (53%)	78/80 (98%)
Family	41/79 (52%)	79/80 (99%)
Other	19/78 (24%)	78/80 (98%)
Provision of professional support	6/78 (8%)	78/80 (98%)
Response of healthcare professionals	5/78 (6%)	78/80 (98%)

Of the six cases where there were concerns about provision of professional support (Table 13), five involved difficulty of access to the family and one communication between Social Work and Primary Care. Of the five cases with concerns about the response of healthcare professionals, two reflected failure of communication between health care professionals, two difficulty of access to the family and one some criticism of hospital supervision. Where there were “Other” concerns, seven related to maternal competence or co-operation with Primary Care/Social Work, six to the infant’s overall circumstances, four to the infant’s sleep position/location and one to the history of an apnoeic episode in an older sibling.

Table 14 Initial and final death certification

Certification	Reviewed n=80		Unreviewed n=58	
	Original	Final	Original	Final
Explained	5/80 (6%)	17/80 (21%)	3/58 (5%)	11/58 (19%)
SIDS	1/80 (1%)	10/80 (13%)	1/58 (2%)	9/58 (15%)
SUDI	67/80 (84%)	0/80 (0%)	44/58 (76%)	1/58 (2%)
SUDI (Pathology Findings)	0/80 (0%)	9/80 (11%)	0/58 (0%)	12/58 (21%)
SUDI (Social/Parenting issues)	0/80 (0%)	17/80 (21%)	0/58 (0%)	9/58 (15%)
SUDI (both pathology and social/parenting)	0/80 (0%)	27/80 (34%)	0/58 (0%)	15/58 (26%)
Unascertained	6/80 (8%)	0/80 (0%)	10/58 (17%)	1/58 (2%)
Possible asphyxia	1/80 (1%)	0/80 (0%)	0/58 (0%)	0/58 (0%)

The percentage of explained deaths in both reviewed and unreviewed cases increased substantially following histology results. The cases termed “SUDI” on initial post mortem were subsequently divided into sub-categories to reflect a variety of concerns (Table 14).

Table 15 Pathological investigations known to have been carried out on SUDI cases

Investigation	Reviewed n=138	Information available
Interval between death and post mortem examination		
<12 hours	5/85 (6%)	85/138 (62%)
24 hours	7/85 (8%)	85/138 (62%)
48 hours	25/85 (29%)	85/138 (62%)
>48 hours	48/85 (56%)	85/138 (62%)
Histology		
CNS	132/135 (98%)	135/138 (98%)
Cardiovascular	134/135 (99%)	135/138 (98%)
Respiratory	134/135 (99%)	135/138 (98%)
Alimentary system	133/135 (99%)	135/138 (98%)
Endocrine system	134/135 (99%)	135/138 (98%)
Genito-urinary system	134/135 (99%)	135/138 (98%)
Microbiology	134/135 (99%)	135/138 (98%)
Virology	132/135 (98%)	135/138 (98%)
Biochemistry		
Electrolytes	109/124 (88%)	124/138 (90%)
Urea	112/124 (90%)	124/138 (90%)
Glucose	54/124 (44%)	124/138 (90%)
Metabolic Studies		
Whole blood	4/125 (3%)	125/138 (91%)
Blood spots	47/124 (38%)	124/138 (90%)
Urine	17/126 (13%)	126/138 (91%)
Bladder washout	8/125 (6%)	125/138 (91%)
Fibroblast culture	34/125 (26%)	125/138 (91%)
Toxicology	60/126 (48%)	126/138 (91%)

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DISCUSSION

Process

The principle of case review was strongly supported in the planning stage, particularly by all the health care professionals involved. Implementation, however, identified a range of difficulties within different areas and within the professional groups involved and is reflected in the timescales.

Crown Office

The question of case review and access to material from the autopsy report was first raised by the Pilot Steering Group with the Policy Group at the Crown Office in August 2000. However, a meeting was not secured with the Head of Policy Group until November 2001. Professor Greer, Chairman of SPMMRAG, wrote to the Solicitor General in April 2002, highlighting the considerable delay in negotiations. In response the Crown Agent Designate explained that the delay in arranging the meeting was due to an unfortunate combination of events including changes in personnel and maternity leave over the summer of 2001. He indicated that subsequent delays were the result of the need to observe the requirements of the Data Protection Act but stated that the matter was now “not far from resolution”. It was, nevertheless, another 5 months before the Circular was issued to Procurators Fiscal. Unfortunately, this delay meant that parents of cases occurring during Year 1 of the pilot (September 2001-September 2002) had not been informed that a review of their baby’s death would take place and, since this was a requirement from the Crown Office, these cases could not be reviewed. While appreciating the delicate issues surrounding data protection the delays in issuing of the Circular to Procurator Fiscals from the Crown Office seemed excessive.

Procurators Fiscal

The problems of PF non-compliance with the Circular appeared to stem from a lack of awareness of its existence and/or contents, particularly in areas of low SUDI incidence. Frequent staff changes exacerbated this problem, with incoming PFs stating that they had not had time to look at existing procedures since taking up post.

A reminder about the Circular and the need for SCDT to be informed when review was authorised was issued by the Chairman of the Scottish Cot Death Trust in December 2002 and by the Policy Group itself in January 2003. In September 2003 (beginning of Year 3 of the pilot), with compliance still disappointing, Professor Greer requested that the Policy Group send another reminder. We do not know if this happened. If it did, it made no appreciable difference to the level of compliance.

There was evidence of a failure on the part of PFs to appreciate that the review population included **all** sudden unexpected infant deaths, not just those registered as “SIDS” or “SUDI”. For example, some PFs assumed that a death certified as “Undetermined pending further investigation” was excluded, as were deaths explained on gross pathology, even if those were unexpected.

One reason offered by PFs for delay in authorising SCDT to offer support was their wish to secure toxicology results before doing this. Given that there were no cases of positive toxicology during the three years of the study this approach was perhaps over-cautious and deprived the most needy parents of support. The Circular advised that even where the enquiries were ongoing PFs should consider referral to the SCDT unless there was concern that doing so might prejudice the ongoing enquiry. It suggested that the risk of such prejudice was unlikely but that cases of doubt or difficulty could be referred to the Policy Group for further advice. The Circular emphasised that **“every effort should be made to avoid any delay in providing notification to the Scottish Cot Death Trust”**. Fiscal failure to issue the initial letter to parents resulted in many families waiting substantial amounts of time for an offer of support from SCDT. Even after a reminder from the Co-ordinator it was often another week or more before the letter was sent and this increased the likely delay in offering support to at least 7 weeks. In fact, of the parents who did not self-refer to SCDT, in Year 2 of the pilot 32 waited more than eight weeks (maximum wait 17 weeks) before their details reached SCDT. In Year 3 the figure was 21(maximum wait 13 weeks). In a few cases the amount of time which had elapsed between the death and the Trust being authorised to offer support was so great that it was felt inappropriate to contact the family.

An additional concern was that, where bereaved parents contacted SCDT themselves, the Co-ordinator had no reason to pursue the PF to make sure that the initial letter had been sent. Since the first purpose of this letter was to inform the parents that a case review would take place, we cannot be certain that all parents were made aware of this. In 7 out of the 13 cases of self-referral SCDT did eventually receive a letter of authorisation for support to be offered but absence of such letters for the remaining 6 cases suggests that review may have taken place without parental knowledge. One Pathology Department developed a system of early notification to SCDT of the SUDI cases to facilitate interaction if parents self-referred. It may be worth considering extending this valuable practice in the future.

When the Co-ordinator contacted Pathology Departments to find out if they had received

authorisation to share information from the Police and autopsy reports at the case review, very few had. PFs also generally failed spontaneously to notify SCDT when review could proceed and this placed an extra, unnecessary, workload on the Co-ordinator.

It is important to recognise that some PFs were exceedingly helpful, pleasant and punctilious in implementing the Circular and that the situation, particularly in terms of authorisation for case review, did improve as the Pilot proceeded, with Fiscals acting more frequently without reminders and not requiring so much explanation of the pilot when they were reminded. However, the failures to implement the Circular resulted in a substantial amount of time being spent by the Co-ordinator in trying to make contact with the various PFs to remind them of the Circular.

The performance of the General Register Office in informing SCDT of all SUDI deaths was exemplary, with notification timely and complete.

Paediatricians

The initial inability of most of the link paediatricians to fulfil their agreed role was a major impediment to the pilot. The Steering Committee (which included three of the link paediatricians) had consulted thoroughly with them both by letter and in person from early on in the planning stage of the pilot and no objections were registered at that point although one did express some concern about workload. It is, however, difficult to quantify the effect of discussions surrounding job plans during this time. Greater Glasgow did not have a nominated paediatrician as the Pathology Department at Yorkhill had traditionally provided a support service for bereaved parents. However, a senior paediatrician agreed to assume the link role for Greater Glasgow.

In four of the areas the link paediatricians were very pro-active from the beginning of the pilot in taking responsibility for organisation and chairing review of local cases, a total of 9/80 over Years 2 and 3. At the end of Year 2 various steps were taken to try and make the task easier for the paediatricians, including identification by SCDT of a Social Work contact in each local authority who would arrange representation at the meeting, provision of proforma letters by SCDT for the GP and Social Work to avoid the need for any lengthy explanation of the pilot and retrieval of GP notes by SCDT where necessary. These steps did not resolve the situation and by June 2004 (towards the end of Year 3 of the pilot) the total number of completed reviews was five.

In February 2004, Dr John McClure, the Chairman of the Pilot Steering Committee, was released from his clinical duties by Ayrshire and Arran Acute NHS Trust to try to facilitate the review process. Visits to the various review centres revealed that paediatricians and pathologists alike considered that neither they nor their administrative staff had time to arrange the review meetings and SCDT therefore agreed to assume responsibility for this task. Dr McClure also offered to support the local review teams by assisting with the first meeting. Unfortunately by this time there was a substantial backlog of meetings which increased the workload for the clinicians. In one area the link paediatrician indicated that he was not prepared to travel outwith his hospital to GP surgeries and GPs were then asked to come to the hospital concerned for the review meetings, raising issues of GP locum cover in one case. In two areas the link paediatrician did not participate in any reviews over the whole period of the pilot.

In view of the problems encountered with the pilot, NHS Quality Improvement Scotland had indicated its willingness to accept the data for Year 2 alone (September 2002 -August 2003), rather than the three years originally expected. However, the Steering Committee felt a responsibility to review the cases for Year 3 despite the increasing reluctance of some paediatricians to participate and the retirement of one pathologist. At this point Dr Tom Turner, Queen Mother's Hospital, Glasgow, Dr Allan Howatson, Royal Hospital for Sick Children, Glasgow and Dr John McClure, Chairman of the Steering Committee, reinforced their exceptional commitment to the pilot by offering to provide pathology and paediatric input to any meetings lacking a pathologist or paediatrician. In the remaining areas, even after SCDT took over the arrangement of meetings, the clinical pressures on paediatricians often resulted in increasing reluctance when approached for dates for review meetings and this made the task of the Co-ordinator more difficult.

GPs and Health Visitors

GP attendance at 79/81 review meetings suggests that locating the meetings in the GP surgery was very advantageous. However, the substantial delays (anything up to two years) between the death of the infant and the review meeting made negotiating GP attendance very difficult. The time lapse meant that the case notes had been sent back to the Primary Care Trust, the family had not infrequently moved out of the area, the GP or HV had sometimes retired or moved on and the mother might already have had another baby. This resulted in questioning as to the relevance of the review. Although GPs received an explanatory letter, including a copy of the Pilot Protocol, from the Co-ordinator prior to being telephoned to arrange the meeting many still failed to appreciate the value of the meeting for future care of the family. Another complication in the Lothian Area was the fact that another death survey was taking place under the auspices of the Child Protection Reform Programme and GPs there could not understand why they were being asked to discuss a case twice.

Some GPs were receptive to the idea of review but others were resentful that a death which they regarded as "in the past" was now being scrutinised again. It may be that some of the reactions stemmed from concern that their patient care was in some way being questioned. However, once GPs had agreed to participate, they did arrange for attendance from Health Visitors at the review meetings and both they and the Health Visitors frequently commented, after the meeting, that it had been extremely useful.

Pathologists

Most pathologists participated willingly in the reviews despite pressure of other commitments and the considerable amount of travel involved, particularly for pathologists from Glasgow and Aberdeen. An important extra contribution by all the Departments of Pathology (with the permission of the Policy Group) was the extraction of core data from the Police report for unreviewed cases and the completion of the expanded Pathology Summary Form. On the subject of audit of diagnosis, we suggest that as policy there should be a routine audit process in the future conducted by paediatric pathologists.

Social Work

The absence of Social Work representation from case reviews where the Department had previously been involved with the family was disappointing. The most common reason given for non-attendance was insufficient notice of the meeting and manpower shortages. While it was very helpful to have identified a contact in Social Work in each local authority area who took responsibility for notifying appropriate colleagues about the date of the review meeting, ideally we would have consulted Social Work on the suitability of the date

before confirming it. The Pilot Protocol had proposed that, even in cases where the family did not have a Social Worker, there should still be representation from Family Services at the case review meeting but in practice this was reported, both through the attendance monitoring and anecdotal feedback from the link paediatricians, as rarely occurring.

Police

During the planning stage of the pilot very positive discussions had been held with the Chairman of the Investigative Sub-Committee ACPO(S) on the preparation of a standard Police Inquiry Form for Scotland. However, ACPO Crime Committee was at that time working on the development of a standard form for England and Wales and ACPO(S) chose to delay further work on a standard Scottish form while the English form was progressed. As a result the pilot was unable to audit consistency of approach by the Police and some of the information we had hoped would be available from the Police Report at the case review meeting was missing. For example, information on parental alcohol or drug use in the hours prior to the infant's death was available in only 54% of reviewed cases – was this question not asked or was no record made because the answer had been negative? Often no mention was made of whether the Child Abuse Register had been checked and we could not be certain whether it *had* been checked, with no significant findings, or whether no such check had been made. We accept that the primary focus of the Police report has to be the exclusion of criminality but the amount of background information on family circumstances and antecedent factors which was missing was disappointing from the point of view of case review.

DATA

Table 7 confirms the association between deprivation and SUDI which has become more marked since the decrease in the incidence over the past 15 years. Sixty-five percent of the deaths were in categories 4 and 5, compared with the figure of 44% in these categories for Scottish livebirths in 2004. In the past it was considered that first babies were less likely to be victims of SUDI than infants born later in the family but this was not borne out by our data. The New Zealand Cot Death Group examined the risk factors for SUDI for preterm and term infants and found that increasing parity was a risk factor for SUDI in term infants but not in preterm infants³. It may be that the high percentage of preterm infants in our population accounts for the high percentage of first babies who died.

The percentage of low birthweight and preterm infants is strikingly at odds with the general population and the percentage of term infants (20%) below the 2nd centile contrasted with an expected 2%. The pre-term infants were an appropriate size at birth for their gestation and the degree of weight loss after birth was no more than would be expected in view of their prematurity (Figure 1). In contrast, the term infants as a group were relatively small at birth, most being clustered around the 25th centile, and showed no tendency to weight loss up to the time of death. Thus neither group showed any evidence of poorer post-natal growth than would be expected, but as a whole most were small at birth.

The relatively high incidence of babies admitted to Neonatal Intensive Care (Table 8) probably reflects the high proportion of low birthweight and preterm infants in the SUDI population. The limited information about when the infant was last seen by Primary Care in the unreviewed group emphasises the need, if review does not take place, for a standardised Police Inquiry Form. Of the 24 infants immunised in the 2 weeks prior to death 18 had had a component of the Primary, 5 had HepB and one was not known.

The very high number of SUDI parents smoking (Table 9) confirms that this is a high risk activity for SUDI. The high incidence of use of methadone and illegal substances suggests that these may similarly be high risk activities. Despite the poor amount of information available, the number of co-sleeping parents in the reviewed group admitting to alcohol use in the 12 hours prior to death is indeed noteworthy and concerning. The figure for mothers on antidepressants at the time of their baby's death (18%) compares with an estimated 10-15% of mothers suffering from post-natal depression⁴ although how many of these are on medication is unclear.

The high incidence of infants <6 weeks of age sharing the parental room (Table 10) showed compliance with the current Health Department advice but 73% of roomsharing infants in this age group were also bedsharing. It is interesting to note the difference in incidence of co-sleeping for the two groups. The figure of 47% for unreviewed cases (50/58 of which occurred during Year 1 of the Pilot) is much closer to the figure of 52% in the most recent Scottish case-control study⁵. The figure of 68% for the reviewed cases, which occurred during Years 2 and 3 of the study, may reflect the change in feeding practices which has taken place since then.

Table 11 examines in more detail the circumstances of co-sleeping. The high percentage sofa sharing (16% of reviewed cases) compares with a figure of 11% on the night of death in the Scottish case-control study.⁵ The information on co-sleeping linked to alcohol and

drug use may underestimate the frequency of these practices as we had variable amounts of information on this. While there was good information in the reviewed cases, facilitated by the Primary Health Care team, regarding the mother's drug habit or participation in a methadone programme, there was much less information about whether she had used either substance in the period prior to the baby's death. This was important data which did not appear to be available even from the Police Report.

The concerns about heating/hygiene in the home (Table 12) in the unreviewed cases can only reflect the opinion of the attending police at the time of death, whereas in the reviewed cases the combined opinion of police, Primary Care and Social Work may be a truer reflection of the circumstances. The lack of information about whether the Child Abuse Register had been checked was of concern and this action should be clearly recorded in the Police Report. The high level of Social Work involvement presumably reflects the weighting towards deprivation in the SUDI population.

Although there was a high incidence of prior concern about these families it was clear at the review meeting that health care professionals and social work staff had made strenuous and continuous attempts to support them. In a very few cases it was considered that lessons could be learned from the review (Table 13) but there was no evidence that any aspect of provision of support by, or response of, health care professionals or Social Work contributed directly to the death of any infant. While each of these 80 deaths was a tragedy, we briefly describe five particularly concerning cases in **Appendix 8**.

The quality of post mortem examinations was high and validity of the thorough investigations was confirmed by the changes between initial and final diagnoses (Table 14) namely the increased numbers of explained deaths and of true SIDS cases. Even where pathology eventually proved negative there was often a reluctance on the part of the review team to give a diagnosis of "SIDS" because of concerns about the death circumstances or parenting skills. It is noteworthy that social/parenting concerns were identified more often in the reviewed group (55% vs. 41% in the unreviewed group).

Table 15 indicates the investigations carried out on the SUDI infants at autopsy. Overall there were good histology, microbiology and basic biochemistry standards, reflecting the ease of obtaining samples and the fact that these are most likely to provide diagnostically relevant information. Toxicology was not always done as this is separately authorised by the PF at his/her discretion.

CONCLUSIONS

- Case review is possible and the multidisciplinary input provides considerably more information than that provided by individual disciplines
- Paediatric pathology in every case was invaluable
- The personnel involved in the multidisciplinary process were appropriate and the process, particularly the location of the review meeting in the Primary Care setting, was effective when implemented
- The process by which Primary Care records were retrieved worked well
- Hospital records, if they exist, should be part of the review
- The delay in carrying out review had a negative effect on co-operation and reduced the potential for support for the bereaved family
- Absence of Social Work representation at some review meetings was disappointing but the lack of consultation about meeting dates was a contributory factor
- Attempts to carry out a full audit of consistency of pathology final diagnosis proved logistically difficult but data has been gathered for future analysis
- The Police Report is vital to the process and lack of standardisation adversely affected the amount of information available
- Considerable organisation locally and centrally is required, is time-consuming and needs to be recognised and resourced.

RECOMMENDATIONS

- Timely case review should be a mandatory component of the investigation of SUDI and the care of the bereaved families
- There should be a standing Steering Committee and central co-ordination point for Case Review until it is firmly established
- Paediatric pathology input, with a full range of investigations, must continue in all cases of SUDI
- The role of the link paediatrician and the paediatric pathologist should be clarified and recognition provided in job plans
- The Police Inquiry Form should be standardised for Scotland, through negotiation and joint working with the Association of Chief Police Officers in Scotland.

ACTION FOR THE FUTURE

Early in 2004 SCDT became aware that Baroness Kennedy was chairing a committee set up by the Royal College of Paediatrics and Child Health and the Royal College of Pathologists to prepare a protocol for the investigation of SUDI in England and Wales. In April of the same year a representative of SCDT was invited to a stakeholders' meeting to discuss the draft protocol. It was clear that it would not apply to Scotland because of the different legal system. Members of the Case Review Pilot Steering Committee formed the nucleus of a SUDI Protocol Steering Group (**Appendix 9**) to prepare a protocol for Scotland. Work on this has been progressing over the past year. We now have:

- a revised standardised autopsy protocol
- a draft A& E Protocol which includes a list of Key Tasks which should be carried out in every case of SUDI
- a process for multidisciplinary case review which has been successfully piloted

Agreement is nearing completion with all the medical staff concerned. We are now in consultation with the Association of Chief Police Officers in Scotland on the preparation of a standardised Police Inquiry Form and with Crown Office to ensure its approval of the protocol.

Without the support and commitment of SCDT the pilot of case review would not have been completed. It is essential that, if review becomes a requirement, there is a co-ordinating body such as SCDT involved, with the ability to draw together senior personnel to support the multidisciplinary nature of case review.

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Dr Allan Howatson, Consultant Pathologist, Royal Hospital for Sick Children, Glasgow

Dr Tom Turner, Consultant Paediatrician, Queen Mother's Hospital, Glasgow

APPENDICES

Appendix 1

Pilot Steering Committee

Dr Angus Gibson (Committee Chairman 2000-2002), Scottish Cot Death Trust, Royal Hospital for Sick Children, Glasgow

Dr John McClure (Committee Chairman 2002-2006), Consultant Paediatrician, Crosshouse Hospital, Kilmarnock

Dr Jean Keeling, Consultant Paediatric Pathologist, Royal Hospital for Sick Children, Edinburgh

Dr Allan Howatson, Consultant Paediatric Pathologist, Royal Hospital for Sick Children, Glasgow

Dr Elizabeth Gray, Consultant Paediatric Pathologist, Aberdeen Royal Infirmary, Aberdeen

Professor Robert Hume, Professor of Developmental Medicine, University of Dundee, Dundee

Dr Tom Turner (from 2003), Consultant Paediatrician, Queen Mother's Hospital, Glasgow

Dr Una McFadyen, Consultant Paediatrician, Stirling Royal Infirmary, Stirling

Mrs Hazel Brooke, Executive Director, Scottish Cot Death Trust, Royal Hospital for Sick Children, Glasgow

Mrs Helen Cormack (lay representative), c/o Scottish Cot Death Trust, Royal Hospital for Sick Children, Glasgow

SUDI CASE REVIEW – REFERRAL	
Study Number:	
Name of Child:	
Date of Birth:	
Date of Death:	
Name of Mother:	
Address:	
G.P:	
Social Work Contact:	
Death Certified by:	
Date Passed:	

Abstraction Form : SUDI Case Review

1. Study No:

2. Sex: M ☐ F ☐ indeterminate ☐

3. Birth Weight: gms

4. Estimated Gestation: By dates: wks
 By first ultrasound: wks
 By neonatal assessment: wks

5. Was infant: Singleton ☐ Twin ☐ Triplet ☐ Other ☐

6. How many previous livebirths for mother:

7. Mother's age at time of infant's death:

8. Infant's ethnic background:
 (Parent's assessment)

Indian ☐
 Pakistani ☐
 Bangladeshi ☐
 White ☐
 Black Caribbean ☐
 Black African ☐
 Chinese ☐
 Mixed (specify)
 Other (specify)
 Not Known ☐

9. Place of Death:

Infant's home ☐
 Hospital ☐
 Other (specify)
 Not Known ☐

10. Time last known to be alive: hrs
 (use 24 hour clock)

11. Place last known to be alive:

Cot, carrycot, crib, pram, moses basket ☐
 Baby chair, car seat ☐
 Parent's bed ☐
 Sofa/Chair ☐
 Carer's arms ☐
 Other (specify)
 Not Known ☐

12. State of infant at that time:

Quiet ☐
 Burbling ☐
 Crying ☐
 Not Known ☐

13. Observed by:

Mother ☐
 Father (Mother's current partner) ☐
 Other (specify)
 Not Known ☐

14. **Carer(s) at time of death:**
- | | |
|-----------------------|--------------------------|
| Mother | <input type="checkbox"/> |
| Father | <input type="checkbox"/> |
| Both | <input type="checkbox"/> |
| Other (specify) | |
| Not Known | <input type="checkbox"/> |
15. **Infant's previous state of health:**
 précis of medical history e.g. preterm delivery, neonatal intensive care, hospital admissions, non-routine GP visits, diagnosis of any illness (using ICD code)

16. **Interval between last GP/HV visit and death:** days
17. **Any concerns at that visit:**
- | | |
|-----------------------|--------------------------|
| Medical | <input type="checkbox"/> |
| Parenting | <input type="checkbox"/> |
| Social | <input type="checkbox"/> |
| Other (specify) | <input type="checkbox"/> |
18. **Health in last week:** Good ☐ Fair ☐ Poor ☐ Not Known ☐
19. **Health in last 24 hrs:** Good ☐ Fair ☐ Poor ☐ Not Known ☐
20. **Was infant immunised in last 2 weeks?** Yes ☐ No ☐ Not Known ☐
 If yes, indicate type and date:
Type: Primary ☐ MMR ☐ HepB ☐ BCG ☐
Date:
21. **Has a previous infant of mother or father collapsed or died suddenly?**
- | | | | |
|--------|--------------------------|--------------------------|--------------------------|
| | Collapse | Sudden Death | Not Known |
| Mother | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Father | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
22. **Was infant on medication at death?** Yes ☐ No ☐ Not Known ☐
 (if Yes specify)
23. **Was this prescribed by GP?** Yes ☐ No ☐ Not Known ☐
24. **Was mother on any medication at time of infant's death?** Yes ☐ No ☐ Not Known ☐
 (if Yes specify)
25. **Was father on any medication at time of infant's death?** Yes ☐ No ☐ Not Known ☐
 (if Yes specify)
26. **Was infant breastfed on discharge from maternity unit?** Yes ☐ No ☐ Not Known ☐
 If Yes, for how many weeks?
27. **At death, how was infant fed?**
- | | | |
|------------|--------------------------|--------------------------|
| | Yes | No |
| Breast | <input type="checkbox"/> | <input type="checkbox"/> |
| Formula | <input type="checkbox"/> | <input type="checkbox"/> |
| Cow's milk | <input type="checkbox"/> | <input type="checkbox"/> |
| Other milk | <input type="checkbox"/> | <input type="checkbox"/> |
| Solids | <input type="checkbox"/> | <input type="checkbox"/> |
| Not Known | <input type="checkbox"/> | <input type="checkbox"/> |

28. Any change in feeding in previous week? Yes ☐ No ☐ Not Known ☐

(if Yes, specify)
.....

29. Time infant found dead: hrs
(use 24 hour clock)

30. Found by: Mother ☐
Father ☐
Other (specify) ☐
.....
Not Known ☐

31. At time of death was infant: In room alone ☐
In room with parent(s) ☐
In room with sibling ☐
Other (specify) ☐
.....
Not Known ☐

32. Was anyone sharing sleep place with infant at time of death? Yes ☐ No ☐ Not Known ☐
If Yes, was it? Adult's bed ☐
Sofa/chair ☐
Not appl. ☐
Not Known ☐

33. If Yes, who shared with infant? Mother ☐
Father ☐
Other (specify) ☐
.....
Not appl. ☐
Not Known ☐

34. How close was infant to sharer(s) Direct contact ☐
Close but not touching ☐
At arm's length ☐
Not appl. ☐
Not Known ☐

35. Describe positional relationship of infant to adults in bed/sofa/chair:

beside 1 person and edge of bed/sofa ☐ beside 2 persons and edge of bed/sofa ☐
between 2 persons ☐ between person and wall ☐
between person and back of sofa/chair ☐ infant lying on parent's chest ☐
other (specify)
Not appl. ☐ Not known ☐

36. Were there any concerns about the position of the infant at death? Yes ☐
No ☐
Not Known ☐
(if Yes, specify)
.....

37. Did infant normally sleep in parent's bed for any period during the night? Yes ☐
No ☐
Not Known ☐

38. **Normal place infant put down to sleep at night:** Cot, carrycot, crib, pram, Moses basket ☐
 Baby chair, car seat ☐
 Parent's bed ☐
 Sofa/Chair ☐
 Carer's arms ☐
 Other, please specify _____
 Not Known ☐

39. **Normal position infant put down to sleep:** On back ☐
 On side ☐
 On front ☐
 Variable ☐
 Not Known ☐

40. **Position infant put down for last sleep:** On back ☐
 On side ☐
 On front ☐
 Not appl. ☐
 Not Known ☐

If different from normal position, specify reason

41. **Position found:** On back ☐
 On side ☐
 On front face to side ☐
 On front face into mattress ☐
 Not appl. ☐
 Not Known ☐

42. **Presence of body fluids when infant found by carer:**
 Frothy fluid (clear or lightly blood-stained) at nose/mouth ☐
 Bloody fluid (heavily blood-stained) at nose/mouth ☐
 Nil at nose/mouth ☐
 Not Known ☐

43. **Fluids also seen by attending person:**
 Ambulance/Police Yes ☐ No ☐ Not Known ☐
 Medical staff Yes ☐ No ☐ Not Known ☐

44. **Presence of injuries:** Yes ☐ No ☐ Not Known ☐
 (if Yes, specify) _____

45. **Type of mattress infant found on** Totally covered with plastic ☐
 Partially covered with plastic ☐
 Removable plastic cover ☐
 Cloth cover ☐
 Not appl. ☐
 Not Known ☐

46. **Was infant's face/head covered with bedding?** Yes ☐ No ☐ Not Known ☐

47. **Dummy use:** Routinely: Yes ☐ No ☐ Not Known ☐
 On the day or night of death: Yes ☐ No ☐ Not Known ☐

48. Home conditions:

Were there concerns about condition of house?

Adequacy of heating Yes ☐ No ☐ Not Known ☐

Hygiene Yes ☐ No ☐ Not Known ☐

Is there any evidence of neglect of any children? Yes ☐ No ☐ Not Known ☐
(if Yes, specify)

.....

.....

Is "father" (as hitherto used in this form) the natural father of the infant?

Yes ☐ No ☐ Not Known ☐

Number of adults in household

Number of school age children in household

Number of children under school age in household

49. Tobacco Smoking:

Mother Yes ☐ No ☐ Not Known ☐

Father Yes ☐ No ☐ Not Known ☐

Other household member Yes ☐ No ☐ Not Known ☐

Was infant co-sleeping with a smoker at time of death? Yes ☐ No ☐ Not Known ☐

50. Alcohol:

Was mother a habitual abuser of alcohol? Yes ☐ No ☐ Not Known ☐

Was father a habitual abuser of alcohol? Yes ☐ No ☐ Not Known ☐

Was other carer a habitual abuser of alcohol? Yes ☐ No ☐ Not Known ☐

Had mother consumed alcohol in the 12 hours prior to the infant's death? Yes ☐ No ☐ Not Known ☐

Had father consumed alcohol in the 12 hours prior to the infant's death? Yes ☐ No ☐ Not Known ☐

Had other carer consumed alcohol in the 12 hours prior to the infant's death? Yes ☐ No ☐ Not Known ☐

(if Yes, specify: e.g. quantity and timing of consumption of any of the above)

.....

.....

51. Illegal Substances:

Was mother a habitual user of illegal substances? Yes ☐ No ☐ Not Known ☐

Was father a habitual user of illegal substances? Yes ☐ No ☐ Not Known ☐

Was other carer a habitual user of illegal substances? Yes ☐ No ☐ Not Known ☐

Was mother on a methadone programme? Yes ☐ No ☐ Not Known ☐

Was father on a methadone programme? Yes ☐ No ☐ Not Known ☐

Was other carer on a methadone programme? Yes ☐ No ☐ Not Known ☐

Had mother used illegal substances in the 24 hours before infant's death? Yes ☐ No ☐ Not Known ☐

Had father used illegal substances in the 24 hours before infant's death? Yes ☐ No ☐ Not Known ☐

Had other carer used illegal substances in the 24 hours before infant's death? Yes ☐ No ☐ Not Known ☐

(if Yes, specify)

.....

52.	Child Abuse Register checked?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Known <input type="checkbox"/>
	(if Yes, specify findings)			
53.	Any social work involvement?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Known <input type="checkbox"/>
	(if Yes, specify)			
54.	Any history of domestic violence?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Known <input type="checkbox"/>
	(if Yes, specify)			
55.	Was either parent or carer known to the Police?	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Not Known <input type="checkbox"/>
	(if Yes, specify findings)			

SUMMARY OF LOCAL CASE REVIEW

Study No.

Growth (Please use the UK 1990 growth reference charts)

At birth	Centile	Last live wt.	Centile	At death	Centile
Wt g		Wt g		Wt g	
L cm				L cm	
HC cm				HC cm	

Growth velocity: Satisfactory ☐ Unsatisfactory ☐

Any evidence of recent weight loss: Yes ☐ No ☐

Significant concerns identified:

1. **Social** Yes ☐ No ☐

Specify:

.....

.....

.....

2. **Family** (including details of significant physical and/or mental illness)

Yes ☐ No ☐

Specify:

.....

.....

.....

3. **Provision of Healthcare/Social support**

Yes ☐ No ☐

Specify:

.....

.....

.....

4. **Response by Healthcare Professionals**

Yes ☐ No ☐

Specify:

.....

.....

.....

5. **Other**

Yes ☐ No ☐

Specify:

.....

.....

.....

6. **Additional information which became available at local enquiry meeting**
(not previously available from notes)

.....

.....

.....

7. **Final categorisation of case:**

- Specific cause of death identified ☐
- Sudden Infant Death Syndrome ☐
- SUDI (pathology findings) ☐
- SUDI (social/parenting concerns) ☐
- SUDI (both pathology findings and social/parenting concerns) ☐
- Unascertained (doubts of criminality remain, although no prosecution) ☐
- Prosecution pending ☐

8. **Action, if any, taken by review team**

Appendix 4

Link Paediatricians

In the early 1980s the British Paediatric Association identified a senior paediatrician for each Health Board Region/Area in the UK with responsibility for counselling families affected by a sudden unexpected infant death and providing support and advice to them with subsequent infants. In Scotland this system had prevailed over the years, with those paediatricians or their successors participating in the 1981-82 Study of Post Perinatal Infant Mortality⁶ and maintaining close links with SCDT, their names appearing on the SCDT's Information Leaflet for Bereaved Parents. They agreed to act as the "link" for their Health Board Area, organising and reporting on the case review meeting.

Dr Paul Duffty, Aberdeen Maternity Hospital, Aberdeen

Dr Greg Hunt, Royal Alexandra Hospital, Paisley

Dr Andrew Duncan, Borders General Hospital, Melrose

Dr Catherine Lees, Wishaw General Hospital, Wishaw

Dr Una McFadyen, Stirling Royal Infirmary, Stirling

Dr Stephen Cunningham, Royal Hospital for Sick Children, Edinburgh

Dr Tom Turner, Royal Hospital for Sick Children, Glasgow

Dr T Reddy, Raigmore Hospital, Inverness

Dr Chris Steer, Victoria Hospital, Kirkcaldy

Dr John P McClure, Crosshouse Hospital, Kilmarnock

Dr Ruth Thomson, Dumfries and Galloway Royal Infirmary, Dumfries

Dr Ruth McKay, Drumquhar Medical Centre, Perth

Professor Robert Hume, University of Dundee, Dundee

CASE REVIEW MEETING - ATTENDANCE RECORD

CASE NO.

DATE
& TIME

Please tick as appropriate	Attended	Did not Attend	Reason for Non-attendance
Paediatrician			
Pathologist			
GP			
Health Visitor			
Social Work Representative			

Appendix 6

Pathologists involved in autopsy and/or review of SUDI Cases

Dr Allan Howatson, Department of Pathology, Royal Hospital for Sick Children, Glasgow

Dr Patricia McKeever, Department of Pathology, Royal Hospital for Sick Children, Glasgow

Dr Janette McFarlane, Department of Pathology, Royal Hospital for Sick Children, Glasgow

Dr Jean Keeling, Department of Pathology, Royal Hospital for Sick Children, Edinburgh

Dr Margaret Evans, Department of Pathology, Royal Hospital for Sick Children, Edinburgh

Dr Kathryn Mackenzie, Department of Pathology, Royal Hospital for Sick Children, Edinburgh

Dr James H K Grieve, School of Medicine, University of Aberdeen, Aberdeen

Dr Elizabeth Gray, Department of Pathology, Aberdeen Royal Infirmary, Aberdeen

Dr Robert Nairn, Department of Pathology, Crosshouse Hospital, Kilmarnock

SUMMARY OF POST MORTEMStudy No.

--	--	--

Gross Pathology**(tick as appropriate)**

	Normal	Not Sig.	Minor Sig.	Major Sig
CNS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cardiovascular	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alimentary system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genito-urinary system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin (including petechiae)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Any Therapeutic Injuries*		Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Any Incidental Injuries*		Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Any Non-incidental Injuries *		Yes <input type="checkbox"/>	No <input type="checkbox"/>	

Additional Info - free text

.....

Histology **(tick as appropriate)**

	Normal	Not Sig.	Minor Sig.	Major Sig
CNS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Cardiovascular	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Respiratory	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Alimentary system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Endocrine system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Genito-urinary system	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Skin (including petechiae)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Additional Info - free text

Microbiology – (tick as appropriate (one answer only))

- Cause of death ☐
- Probable cause of death ☐
- Possible cause of death ☐
- Contamination ☐
- PM overgrowth ☐
- Incidental findings ☐
- Wholly negative ☐

Virology – (tick as appropriate)

- Cause of death ☐
- Probable cause of death ☐
- Possible cause of death ☐
- Incidental findings ☐
- Wholly negative ☐

Biochemistry (tick as appropriate)

(E = Electrolytes, U = Urea, G = Glucose)

	Normal	Abnormal	If abnormal, PM change?	
E Vitreous	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
E Blood	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
U Vitreous	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
U Blood	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
G Vitreous	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
G Blood	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
G CSF	<input type="checkbox"/>	<input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>

Interval between death/pm (only if any of the above abnormal)hours

Metabolic Studies (tick as appropriate)

	Done	Not done	If done were results	Normal	Abnormal
Whole blood	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Blood spots	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Whole urine	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Bladder washout	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Fibroblast culture	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>
Other	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>	<input type="checkbox"/>

Free text

.....

.....

Toxicology (tick as appropriate)

Done ☐ Not done ☐

If done, were results Positive ☐ Negative ☐

If positive, state what these were

.....

.....

Final categorisation of case (tick as appropriate)

Specific cause identified	<input type="checkbox"/>
Sudden Infant Death Syndrome	<input type="checkbox"/>
SUDI (pathology findings)	<input type="checkbox"/>
SUDI (social/parenting concerns)	<input type="checkbox"/>
SUDI (both pathology findings and social/parenting concerns)	<input type="checkbox"/>
Unascertained (doubts of criminality remain, although no prosecution)	<input type="checkbox"/>
Prosecution pending	<input type="checkbox"/>

Appendix 8

Case Studies of five SUDI infants

Case A

Male infant. Breastfed initially – length of time unknown. Age at death 12 weeks. Mother was in prison at the time of death, her older children were in care and the baby, who was in the care of the father, was on the At Risk Register. Both parents smokers, users of illegal substances, on a methadone programme and there was a history of domestic violence. There was intense input from Social Work, with 3 home helps involved and the baby was seen frequently by the Health Visitor, Community Paediatrician and GP. There had been a case conference prenatally, after the birth and 6 weeks before the death.

In the week prior to death the baby had been well and was seen by Primary Care the previous day. On the night of death baby was sharing an adult bed with father, lying supine on a pillow. He had previously slept in a crib but there had been no crib in the house for the past two weeks. He was found dead at 9:30 am by a home help – father had not realised the baby was dead. Father had used illegal substances in the previous 24 hours. Toxicology on the baby was negative and there were no significant pathological findings.

Case B

Male infant. Bottle-fed. Age at death 11 weeks. Father had prison record, with alcohol a contributory factor, and history of depression. Mother known to Social Work because of destitution. Poor housing, concerns about heating and hygiene. Baby was under stimulated, lacked adequate clean clothing and was fed inappropriately. Health Visitor found it difficult to get access to home. Grandmother brought infant to Primary Care when mother ignored advice. Both parents were smokers, alcohol abusers and used cannabis. GP saw baby 2 days before death and diagnosed asthma and upper respiratory tract infection. He prescribed Ventolin and **?Amoxil**.

On night of death baby was sleeping between the parents on a mattress on the floor of the living room as there was no heating in the bedroom. An older sibling was sleeping at the bottom of the mattress but when mother found the baby the older sibling had moved to lie between the baby and the father. Toxicology was negative and pathology did not give an explanation.

Case C

Male infant. Breastfed until death at age 11 weeks. Biological father not involved. Mother had another partner. Poor hygiene, cold home. Mother smoked and had drug habit but had not used drugs in the 24 hours before the death. She had history of depression and was taking Amitriptyline. She avoided contact with the Health Visitor. Social Work was unaware that other agencies were involved with the mother although at the review meeting the representative said that a “case discussion would have eventually been held”. Baby seen by Primary Care 16 days before death when there were concerns about parenting and social circumstances.

Baby's health was good in the week and 24 hours prior to death. On the night of death the baby was sharing a sofa with mother, lying at the opposite end from her on a beanbag.

Baby usually slept there as mother did not have a bed. Final diagnosis was SUDI with pathology and social/parenting concerns.

Case D

Female infant. Age at death 98 weeks. Young mother, no contact with father. History of sexual abuse, drug problems and recently recorded as being depressed. Receiving counselling. Baby put in foster care at 1 year for 9 months because of attachment/bonding difficulties. Back with mother at time of death. Mother was a smoker and cannabis was found in the house by the police. Intensive input from health and social services. In hospital for 3 days with impetigo 3/52 before death. Had viral illness week before death, prescribed paracetamol. Found dead at 12:00 in cot. Cause of death viral infection.

Case E

Male infant. Age at death 7 weeks. Both parents smoked and used illegal substances, mother was depressed and suffered from Post Traumatic Stress Disorder. Father also on methadone programme. Older sibling in care because of possible emotional deprivation. Baby on At Risk Register. Social Work very involved, intensive family support. Last seen by Primary Care 4 days before death when baby had oral thrush. Noted that mother was "distant". Well in 24 hours prior to death. Baby sharing bed with both parents. Father had taken drugs in previous 24 hours. Found dead at 06.00. Final diagnosis was SUDI with pathology and social/parenting concerns.

Appendix 9

Membership of SUDI Protocol Steering Group

Dr John McClure, Chairman, Scottish Cot Death Trust, Yorkhill, Glasgow

Dr K Aniruddhan, Consultant Paediatrician, Victoria Hospital, Kirkcaldy

Dr Ian Bashford, Senior Medical Officer, Scottish Executive Health Department, Edinburgh

Professor Jeanne Bell, Consultant Neuropathologist, University of Edinburgh

Mrs Hazel Brooke, Scottish Cot Death Trust, Yorkhill, Glasgow

Dr Paul Brown, Consultant Pathologist, Forensic Medicine Unit, School of Medicine, Aberdeen

Dr Paul Duffty, Consultant Paediatrician, Aberdeen Maternity Hospital

Dr Meg Evans, Consultant Pathologist, Royal Hospital for Sick Children, Edinburgh

Dr Elizabeth Gray, Consultant Pathologist, Aberdeen Royal Infirmary, Aberdeen

Dr J K Grieve, Consultant Pathologist, Forensic Medicine Unit, School of Medicine, University of Aberdeen

Mr David Green, Assistant Procurator Fiscal, Procurator Fiscal's Office, Glasgow

Dr Allan Howatson, Consultant Paediatric Pathologist, Royal Hospital for Sick Children, Glasgow

Dr Catherine Lees, Consultant Paediatrician, Wishaw General Hospital, Wishaw

Dr Una McFadyen, Consultant Paediatrician, Stirling Royal Infirmary, Stirling

DCI Kevin Quinn, Strathclyde Police, Family Protection Policy Unit, 'H' CID (Operations), Glasgow

Mr Will Scott, Head of Branch, Scottish Executive Health Department, Edinburgh

Dr Colin Smith, Senior Lecturer, Pathology (Neuropathology), University of Edinburgh

Dr Tom Turner, Consultant Paediatrician, Queen Mother's Hospital, Glasgow