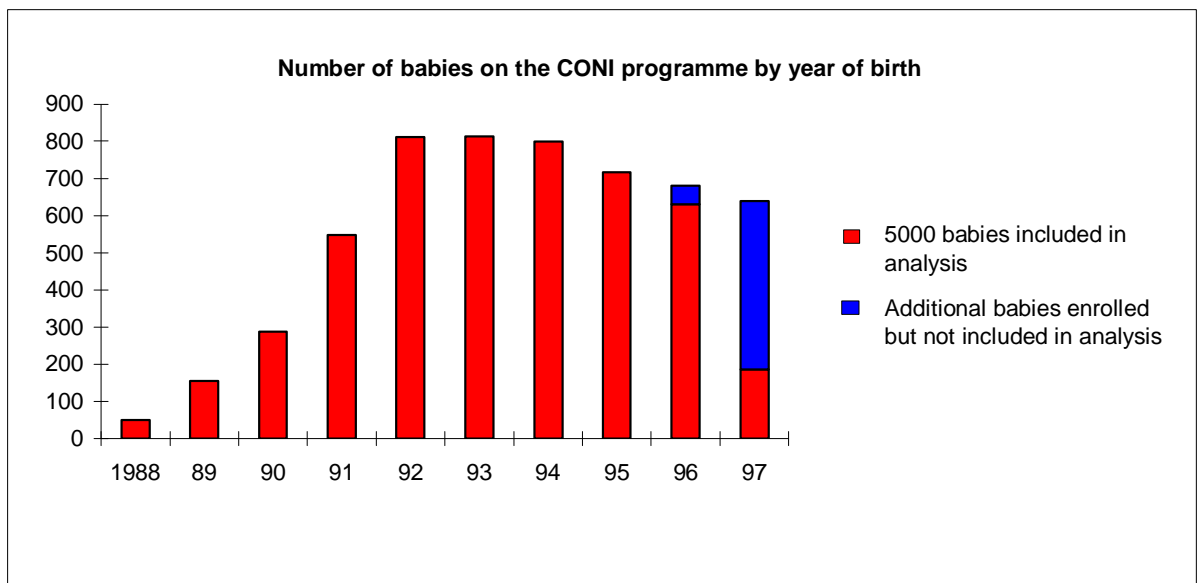


REPORT ON 5000 BABIES

USING THE

CONI (Care Of Next Infant)

PROGRAMME



CONI National Organiser
Statistician

Mrs Alison Waite
Mrs Angela McKenzie

Steering committee

Dr Robert Carpenter
Dr Robert Coombs
Dr Charlotte Daman-Willems
Professor John Emery

Administrative support

Mrs Anne Hudson
Mrs Jackie Fletcher

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Introduction

Cot death is a tragedy that has long-lasting effects on the family. Any child death can leave parents feeling apprehensive about subsequent children but when the death was both sudden and unexplained parents are usually very concerned. They fear for the safety of the next child and they wonder how they will be able to cope with their anxieties during the child's infancy.

During the 1970s, apnoea monitors were being promoted as a possible means of preventing cot deaths in babies deemed to be at high risk and as means of reducing parental anxiety. Between 1981-1987 a multi-centre controlled study was undertaken, funded by the Foundation for the Study of Infant Deaths (FSID), involving 625 children born subsequent to a cot death to see if it would be possible to test the effect of apnoea monitors on the prevention of repeat cot deaths. Deaths occurred in both the monitored and unmonitored groups and it became clear that to measure the effects of monitors on mortality would require an impracticably large number of children. However the study did indicate that parents could be greatly helped by an organised system of care and that professionals found this helpful too.

The Care of Next Infant (CONI) programme has been developed by FSID to help Health Trusts to provide organised support to families with children born after a cot death. The system of care offered to families is based on experience gained in the controlled study and in consultation with other groups running established care programmes for families following a cot death.

The programme requires the involvement of the health visitors, paediatricians, midwives and general practitioners in each locality. Each centre has a local co-ordinator to administer the programme, who is usually a health visitor. Each centre also develops a system to identify mothers presenting for ante-natal care who have a history of cot death. The parents are invited to meet with the local co-ordinator and/or paediatrician to discuss the care that can be offered and to choose the surveillance methods they would like to use. These include weekly health visitor visits, a symptom diary for daily completion, an apnoea monitor, weighing scales for daily weighing, a specially designed weight chart for plotting weights and a room thermometer. The programme is offered for six months or two months past the age at death of the cot death sibling, whichever is the longer.

Data collected from each centre is collated in the CONI office sited in the Division of Child Health at the University of Sheffield. This provides a unique opportunity to combine information from over 170 centres in this population of families who will be seen only rarely in each centre. We report on the national data and individually to centres when sufficient families have been enrolled.

The central organisation of the CONI programme is funded by FSID and is essential for the continuity of the programme. Mrs Alison Waite, National CONI Organiser is available to advise on setting up and running the programme and provide ongoing support. Mrs. Angela McKenzie is responsible for data processing and statistical analysis. They are advised by a Steering Committee: Dr Robert Carpenter, Dr Robert Coombs, Dr Charlotte Daman-Willems and Professor John Emery.

Regular contact is maintained with local CONI co-ordinators and paediatricians by letter, telephone and a programme of regional meetings. The meetings provide an opportunity to discuss recent developments in cot death research, data from the CONI programme

and problems encountered in running the programme. They also give the co-ordinators the opportunity to identify improvements or developments to the programme. For

example, the extension of CONI to other groups of parents under the CONI PLUS programme originated from discussions at these meetings.

CONI PLUS is an optional extension of the CONI programme to include parents who have had a close relative die from cot death; parents whose babies have died from causes other than cot death and parents whose child has suffered an apparently life threatening event.

This report presents data from the CONI programme only, ie concerning families in which one or both parents have previously experienced a cot death.

a) Source of Families and data collected

5000 babies have now completed their period of surveillance on the CONI programme. This report relates to these 5000 babies who are termed 'index' babies and looks at trends[⊗] over the 10 years that the programme has been running.

Data is collected from families when they initially enroll on the programme and from confidential questionnaires which are sent to all parents when the planned period of surveillance is completed. For the first 25 babies in each NHS Trust, confidential questionnaires are also sent to the health visitor and GP. The health visitor's record detailing family contacts with herself, the baby clinic, the GP, the hospital etc and the daily diary from the parents are also studied and the information noted.

There have been changes made to the confidential questionnaires sent out over this 10 year period, therefore the results for some questions are not known for the earlier years.

The 5000 babies came from 169 different NHS Trusts (appendix 1). Centres were set up from 1988, with the greatest number starting between 1990 and 1994.

In addition to the 5000 babies a further 200 were originally enrolled but could not be followed up for various reasons. For example the family withdrew the baby when it was a few days old, the baby was placed for fostering or adoption, the Trusts returned the details of the birth when the baby was over a year old or the family moved away and could not be traced. There is considerable variation between the Trusts in the number of families enrolled. This reflects the varying population sizes, birth rates and also the length of time that the programme has been available in the Trusts. In no area are we or the local personnel sure of the number of subsequent pregnancies following a cot death and it is certain that the families enrolled on CONI are not a complete population. Although we cannot be confident that the scheme was offered to all families where there had been a previous cot death, we know of only 165 families eligible to be on the programme who refused participation at the initial interview.

Questionnaires were sent to over 97% of the parents. Some parents had moved without leaving a forwarding address before the confidential questionnaire could be sent, some parents were known to be illiterate and some spoke no English. Repeat questionnaires have been sent to parents who have not responded within about 2 months but despite this the response rate from parents, while acceptable for a postal survey, is lower than for the health visitors and GPs (table 1).

[⊗] Values of $p < 0.05$ implies the observation is unlikely to be due to chance and $p < 0.01$ implies that it is very unlikely that the observation is due to chance.

Table 1 Response rates for confidential questionnaires

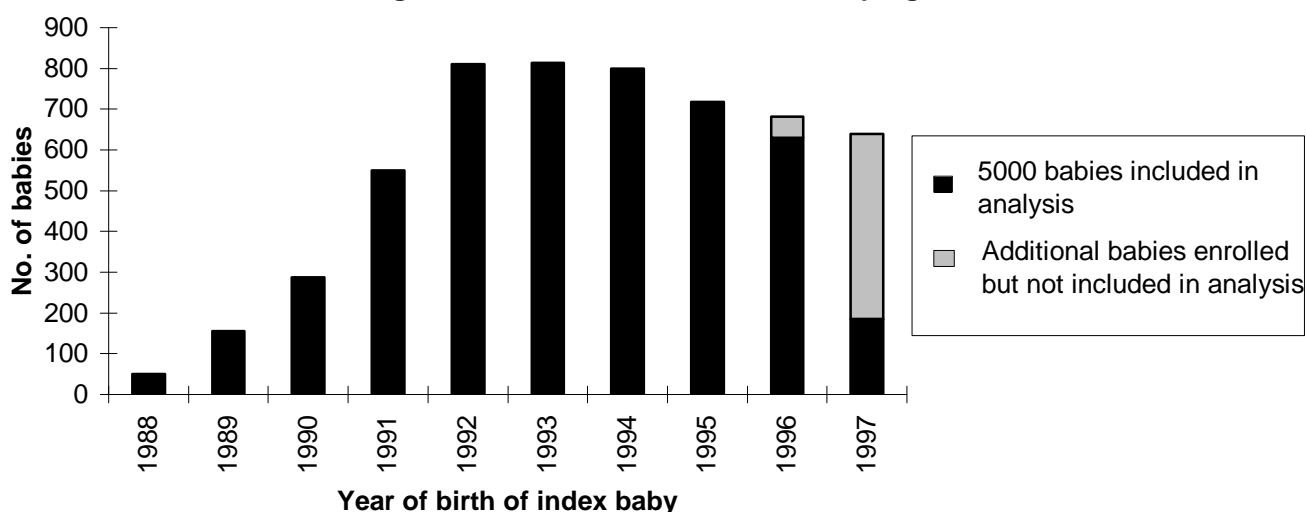
	Parents	HVs*	GPs*
Number of questionnaires sent	4806	3285	3259
Completed questionnaires returned	2768	2778	2442
Response rate	58%	85%	75%

*Questionnaires sent to first 25 in each centre

The health visitors' records of contacts by the family with health professionals, are only returned to the CONI office for the first 25 families in each area. Thus this information is only available for 2711 of the 5000 babies.

The greatest enrolment in the programme occurred amongst babies born between 1992 and 1994 (fig 1). Since early 1998, more babies born in 1996 and 1997 have now completed their period of surveillance on the programme. However, they were not amongst the first 5000 babies to complete the period of surveillance and so are not included in this analysis.

Fig 1 Number of babies on the CONI programme



Over the 10 year period many families have been on the programme with at least 2 babies born at different times and subsequent to the cot death (table 2). If a mother has twins or triplets these are each counted as separate index babies, however being on the programme with these babies is only counted as once on the programme. A total of 4182 different families have been on the programme. A family is considered to have been on the programme previously if either or both of the parents of the index baby have used the programme with a previous baby.

Table 2 Number of times each family was on the CONI programme

	Number of families	Number of babies (singleton and multiple births)
On programme once	3531	3610
Twice	583	1175
Three times	57	171
Four times	11	44
Total	4182	5000

b) Deaths of index babies

44 of the 5000 babies died either whilst on the programme or after completion. 9 of these deaths were expected, (ie severe congenital anomalies, extreme prematurity etc) and the remaining 35 were unexpected. Of the 44 deaths, 2 occurred under 1 week and 2 occurred over 1 year. The 40 post perinatal (8 days to under 1 year) deaths may be compared with national figures. The post perinatal death rates for England and Wales for all causes of death fell from 5.15 in 1988 to 2.80 in 1996 (1). The post perinatal death rate for the babies who were enrolled on the CONI programme is 8.0 deaths/1000 live births. Further details are supplied in appendix 2.

c) Previous post perinatal deaths of siblings to index baby

104 of the parents of the index babies had experienced 2 previous baby deaths and 4 had experienced 3 previous deaths (table 3) making in total an additional 112 (104 + 4x2) deaths in these families. In some the cause of death was not stated; however because they were enrolled on to the CONI programme, it is assumed that all families had lost at least 1 baby as a cot death.

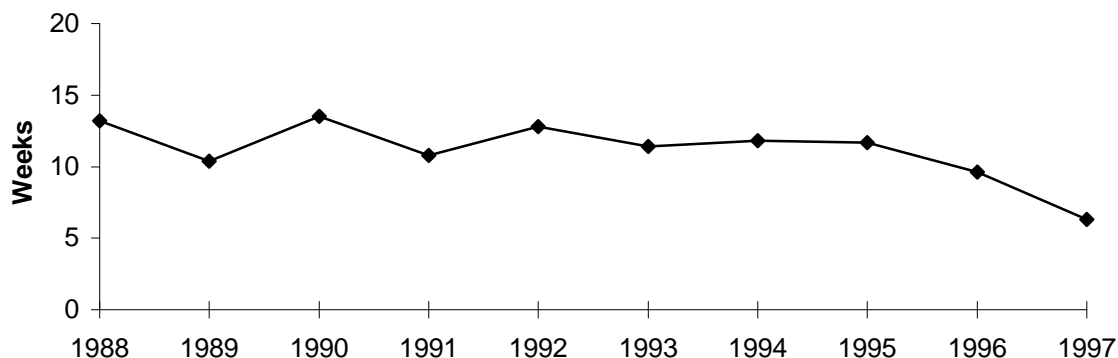
Table 3 Number of deaths experienced by the parents of the 4182 families who were on CONI for the first time

One death		4074
Two deaths		
Both SIDS	62	
1 SIDS, 1 other cause	20	
1 SIDS, 1 cause not recorded	8	
Both other causes	5	
Both cause not recorded	9	104
Three deaths		
3 SIDS	1	
2 SIDS, 1 other cause	1	
1 SIDS, 2 other causes	1	
3 other causes	1	4
		<hr/>
		4182

d) Age of previous cot death

The median age at death of the cot death baby, in families with only one previous death, has decreased by about 4 weeks over the years ($p < 0.01$) (fig 2).

Fig 2 Median age at death of baby who died (for families who had lost only 1 baby) by year of birth of index baby



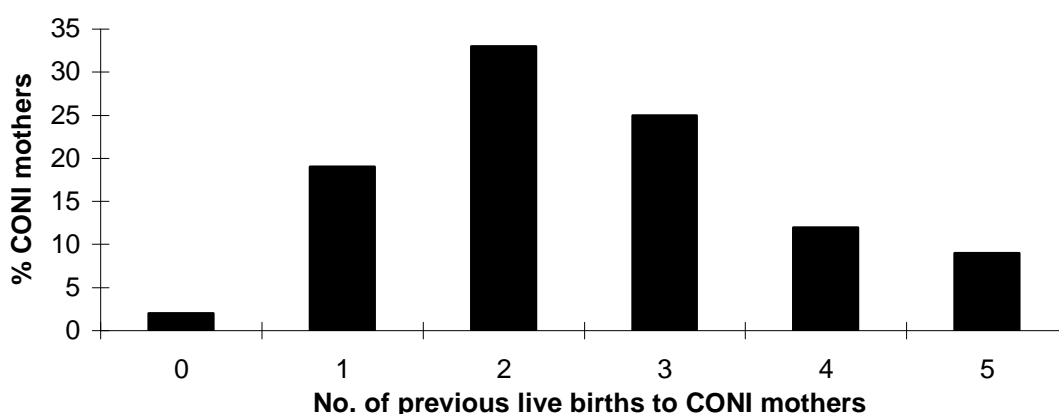
e) Sex of previous cot death

The sex of the baby who died, has remained constant at about 65% male.

f) Obstetric history and birth of the index baby

Figure 3 shows the number of previous live births to the mothers prior to the birth of the first index baby for each family. Previous analyses have shown that families on for a second, third and fourth time had on average 1, 2 or 3 more live births respectively. About 2% of the mothers had had no previous live births because families were accepted onto the CONI programme when either parent had lost a previous baby as a cot death.

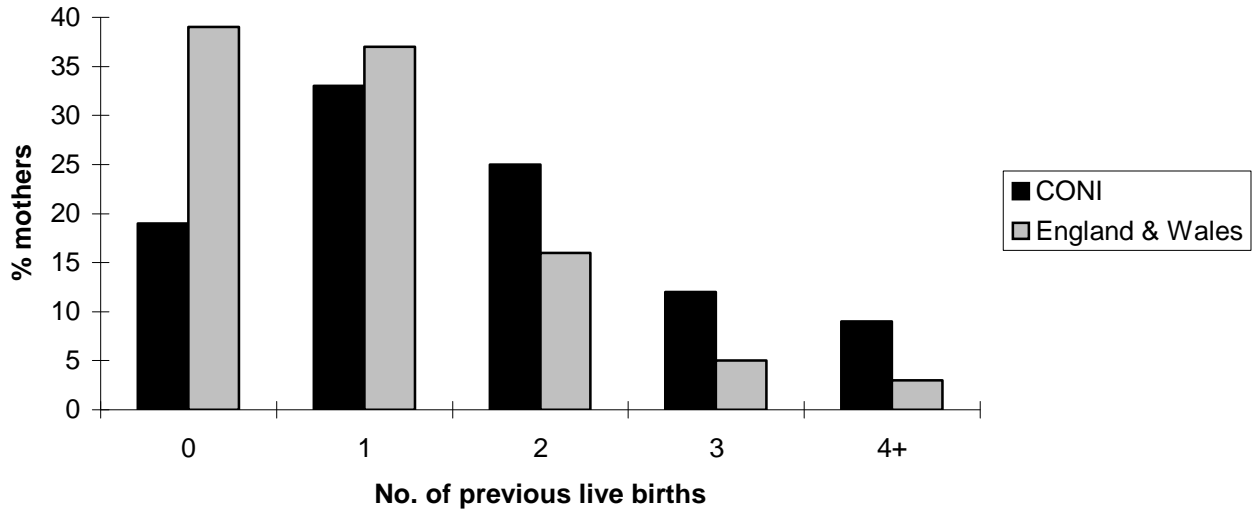
Fig 3 No. of mothers' previous live births (for those families for whom this is the first time on CONI)



The Office for National Statistics publish data on previous live births with regard to births within marriage only (1). Figure 4 shows that even if one birth is subtracted from the CONI data to allow for every mother having given birth to a previous baby that has died,

the CONI mothers have significantly more previous live births. However, we do not know the proportion of CONI babies that are born within marriage and the two groups may differ in their social characteristics.

Fig 4 No. of previous live births for CONI mothers (reduced by one) compared with 1995 figures for England & Wales for births within marriage



About 4% of the deliveries were multiple births compared with 3% nationally (1), and 50% of the babies were male compared with 51% nationally (1).

g) Birth weight of index baby

The mean birth weight of the index babies declined over the years ($p < 0.01$) (fig 5) and correspondingly the proportion of low birth weight babies (< 2500 gm) increased ($p < 0.05$) (fig 6). However gestational age less than 37 weeks remained constant at a mean of 11% so that the reduction in weight cannot be explained by gestational age.

Fig 5 Mean birth weight in gm by year of birth of index baby

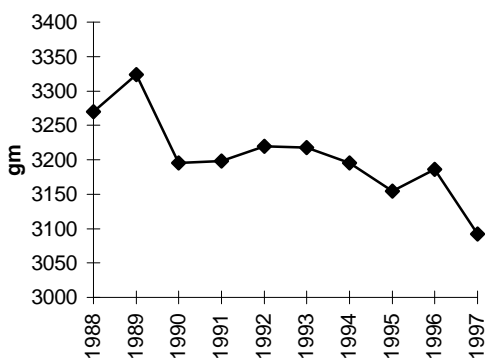
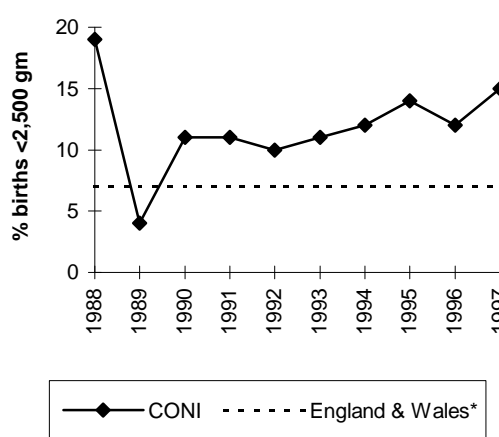


Fig 6 Birth weight less than 2,500 gm by year of birth of index baby



*Office for National Statistics. Infant & perinatal mortality Monitor DH3 series

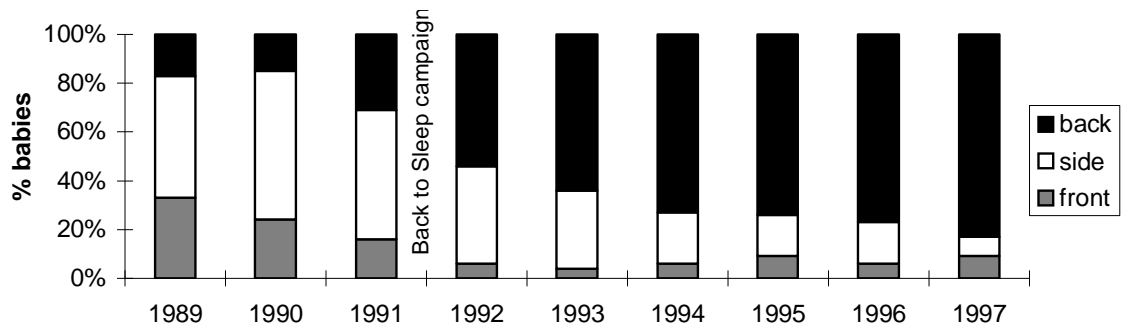
h) Breast feeding

There has been a slight decrease in mothers initially breast feeding their babies from 51% in 1989 to 42% in 1997 ($p < 0.05$).

i) Sleeping positions of babies in the first 3 months

The usual sleeping position for babies has changed during the 10 years (fig 7). Prior to the 'Back to Sleep' campaign in late 1991, 55% of babies on CONI slept on their sides, 24% on their backs and 21% on their fronts. Since the campaign the proportion sleeping on their backs has steadily increased to 83% in 1997 and side sleeping has proportionately decreased, with the number sleeping prone remaining consistent at about 6%.

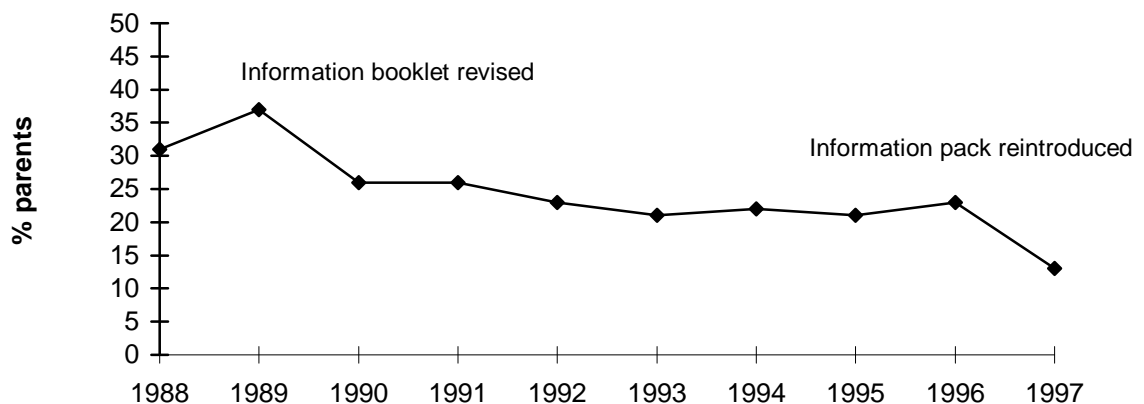
Fig 7 Usual sleeping position in first 3 months by year of birth of index baby reported by parents at 6 months



j) Opinions of parents about initial CONI interview and written information

Parents have been consistently satisfied with the explanation of the programme, given at the initial interview. 93% reported the detail given was appropriate, 5% found they were given too little detail and 2% felt they were given too much detail. About a quarter of the parents would have liked more written information, however the proportion of parents wanting this decreased over time ($p < 0.01$) (fig 8). The information booklet was revised and simplified for parents in 1989 and from October 1996 an FSID Information Pack was re-introduced. Parents' comments show a wide variation in the type of extra information required. While some parents want more detail about specific aspects of the programme others want more information about cot death, especially recent research, indicating a continuing search for explanations about the death of their child.

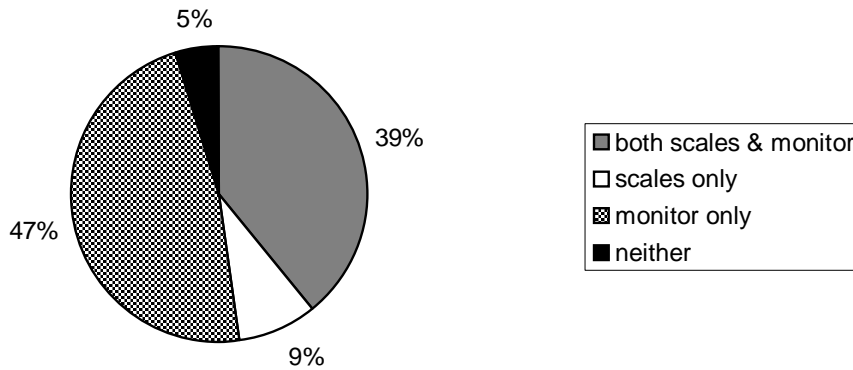
Fig 8 Parents would have liked more written information by year of birth of index baby



k) Type of surveillance used by the families of the index babies

All the parents were offered the choice of weekly home visits by the family's health visitor, a symptom diary for daily completion, an apnoea monitor, accurate weighing scales for daily weighing at home by the parents, a specially designed weight chart for plotting weights and a room thermometer. The choice of equipment has remained consistent over the 10 years.

Fig 9 Type of equipment chosen by families



Scales

In total 48% chose scales at home for weighing, 39% wanting both scales and apnoea monitor (fig 9). Babies were also weighed regularly by the health visitor at her visits or at clinic and 86% of parents were issued with a Sheffield weight chart. Most parents were always helped by seeing the plot of their babies' weight on the chart (fig 10), but many were sometimes made anxious by this (fig 11). Parents can be both sometimes anxious and yet always helped (table 4).

Fig 10 Parents helped by seeing plot

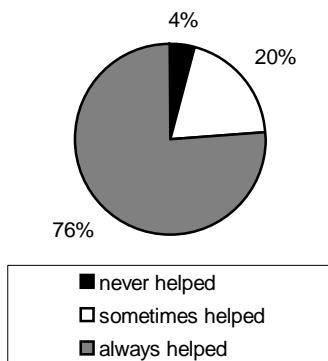


Fig 11 Parents made anxious by seeing plot

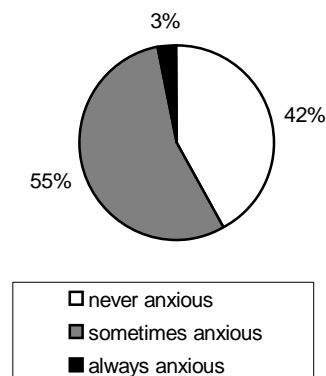


Table 4 Parents' reactions to seeing their baby's weight plotted on the chart

Parents' reactions	Never anxious	Sometimes anxious	Always anxious	Total
Never helped	2%	0%	2%	4%
Sometimes helped	6%	13%	1%	20%
Always helped	28%	42%	6%	76%
Total	36%	55%	9%	100%

Apnoea monitors

Apnoea monitors were used by 86% (47%+39%) of families (fig 9). The types of monitor used varied over the years. Of the 4322 babies issued with monitors, 52% have used Graseby MR10 monitors, however this has declined from 75% at the commencement of the programme to 49% in 1997. Densa monitors have been used for 36% of the babies, their use has increased from 15% to 39% in 1997. Eastwood mattress monitors have been used for 6% babies and Eastwood sensor monitors for 3%. Ten other makes of apnoea monitors were used by 68 babies. These are:

Vickers	21
Axminster	19
RM25 Greenwich	10
Huntleigh	5
Draeger	4
Cooknell mini-minder	4
Breathguard	2
Baby watch	1
Hi-sense mattress	1
Baby sense	1

Transcutaneous oxygen monitors were used for 72 babies in two centres.

Of the families using an apnoea monitor, 7% used more than one make, but the percentage changing monitors has declined steadily from 13% in 1990 to 4% in 1997 ($p < 0.001$). The majority of the families (79%) were always given confidence by using the apnoea monitor, 11% were given confidence sometimes but 10% were only rarely given confidence. However, over the 10 years, the proportion of parents always given confidence by the monitor has gradually declined from 84% to 75% ($p < 0.05$).

Symptom diaries

The uptake of symptom diaries for daily completion has fallen over the years ($p < 0.0001$), but remains high at about 80%. Of those parents who had a diary, half were always helped by using it (fig 12). 62% of the parents sometimes found the diary a nuisance to complete (fig 13), but a quarter both sometimes found it a nuisance, yet always found it helpful (table 5).

Fig 12 Parents helped by completing diary

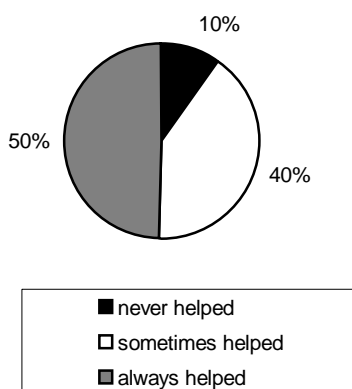


Fig 13 Parents found completing diary was a nuisance

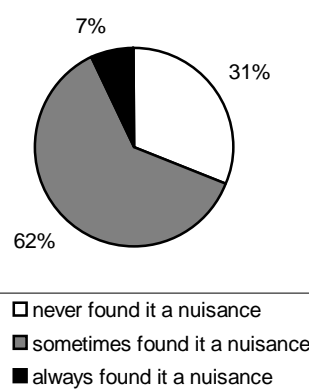


Table 5 Parents' reactions to keeping the daily symptom diary

Parents' reactions	Always a nuisance	Sometimes a nuisance	Never a nuisance	Total
Never helped	3%	6%	1%	10%
Sometimes helped	3%	30%	7%	40%
Always helped	1%	26%	23%	50%
Total	7%	62%	31%	100%

The use of the diaries varies from meticulous 26 week detailed records, to sketchy completion. It is quite common for diaries to be detailed initially and then less complete as the surveillance period draws to a close.

Room thermometers

Room thermometers were only made available during 1989. Since then there has been a steady increase in uptake and now nearly 90% of families choose to have one.

l) Record keeping during surveillance

The information obtained from the health visitor record card and the daily diary is only available for the first 25 babies in each Health Trust. It is planned that babies stay on the programme and records are kept up to the age of 6 months or 2 months after the age at which the earlier sibling died; whichever is longer. In this report a cut-off point was taken at 26 weeks and information relating to health visitor or GP contacts etc after 26 weeks was disregarded. The average age of the babies at the time of the last records was 23.8 weeks. There is a correlation between the age of the babies at date of the last record and the age of death of the previous baby ($p < 0.001$).

m) Contact with health professionals

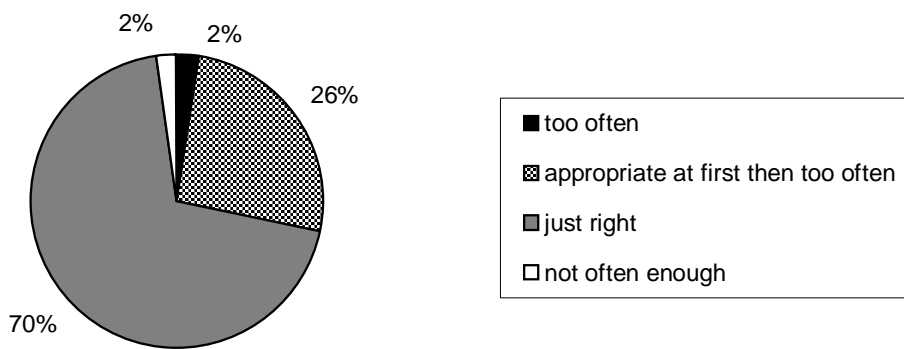
The number of contacts the families have with professionals is assessed from the health visitor record card and daily diaries; parents' views are taken from the confidential questionnaire.

Health visitor

An average 95% of the families chose weekly health visitor visits. The proportion has decreased over the years from 100% to 93% ($p < 0.0001$), but it remains the most requested element of the programme.

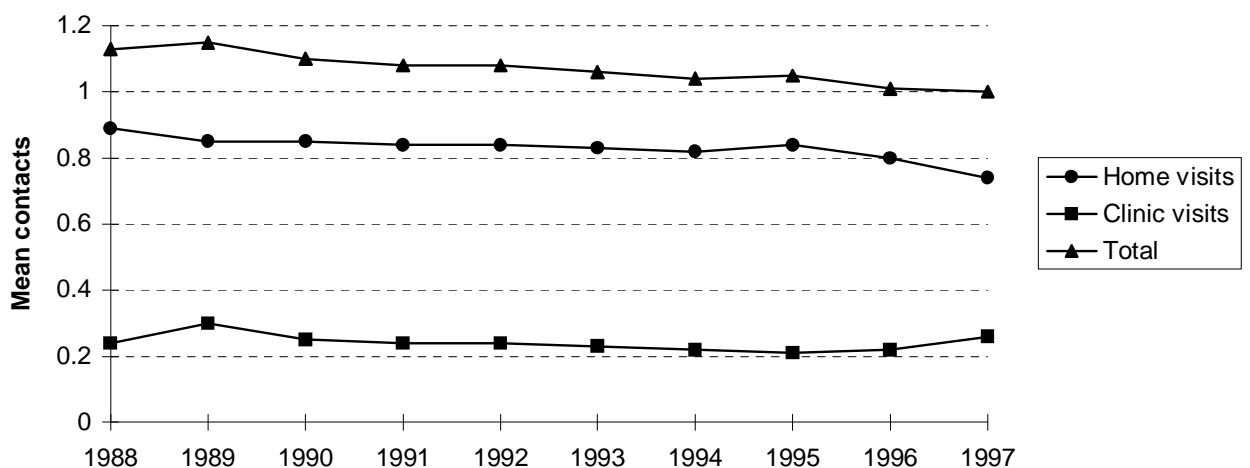
A weekly home visit from the health visitor throughout the 26 weeks was considered just right by 70% of the families and 26% thought it appropriate at first but more frequent than was needed later on (fig 14).

Fig 14 Parents' views on weekly home visits by health visitor



There was only a very slight decline in the number of home visits by the health visitor per week to the families over the period of the study ($p < 0.05$) (fig 15). Clinic visits also decreased over the 10 years ($p < 0.01$) and thus the total contacts with the health visitor at home or at clinic declined ($p < 0.001$) but still averages one contact per week.

Fig 15 Contacts with health visitor per week



There was no difference in contacts with the health visitor between families using the programme for the first time and those on for subsequent occasions. The health visitors record visits made to the home when no access is gained to the family. Overall, 58% of families never had a 'no access' visit but 18% had three or more.

Parents were asked to indicate from a list, the ways in which the health visitor helped them. The percentage of parents ticking each item are as shown:

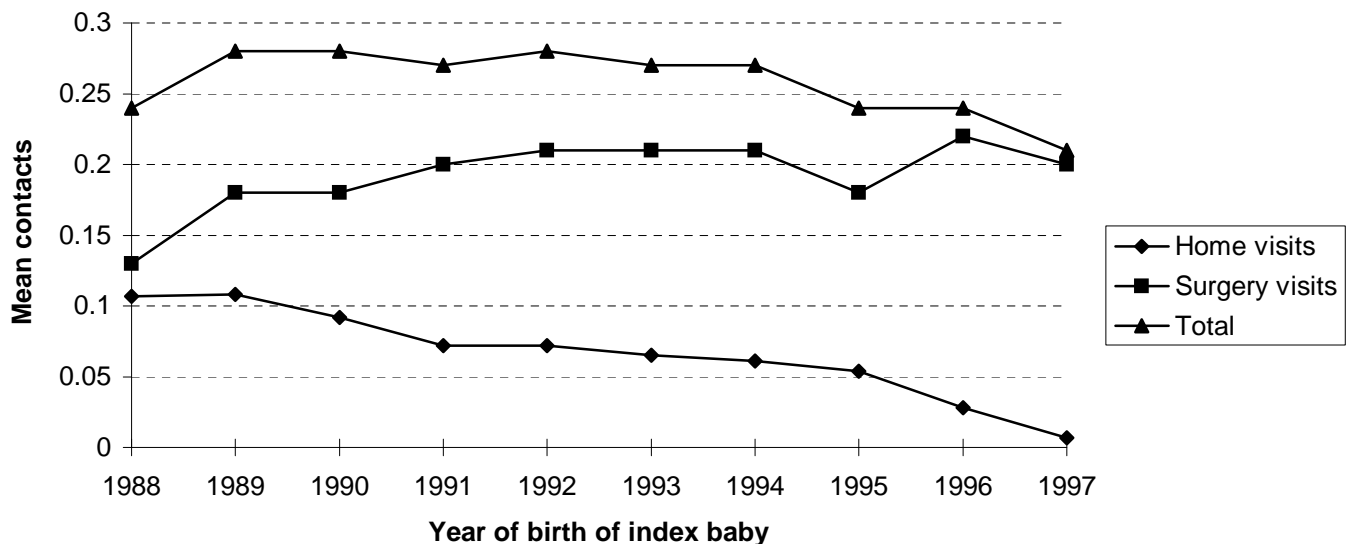
By listening to you	88%
By going through the symptom diary with you	59%
Giving advice about child care	49%
By contacting your GP	37%
Giving advice about cot death	34%
Giving advice about the monitor	33%
By contacting a paediatrician	18%
She did not help me	4%

Over 90% of the parents with whom the health visitor discussed clothing and bedding found it helpful.

General Practitioner

Over the study period, GPs made a decreasing number of home visits ($p < 0.0001$), but there was a slight increase in visits to the surgery ($p < 0.05$) and therefore the overall contacts with the GP were only slightly reduced ($p < 0.05$) (fig 16).

Fig 16 Contacts with GP per week



The mean GP contacts for the 10 year period were 0.27 and this is equivalent to one contact approximately every 4 weeks or 7.0 contacts in 26 weeks. Fleming and Charlton (2) reported a mean number of contacts for babies under one year, in one parent households, of 6.17 for boys and 5.89 for girls. The CONI data may be inflated by attendances at the GP surgery for immunisations, recorded as GP contacts when in reality the baby was seen by the practice nurse. It is also likely that contacts in the first year are not evenly distributed throughout the year but are heavier in the first 6 months. Thus the differences may not be as great as the figures suggest.

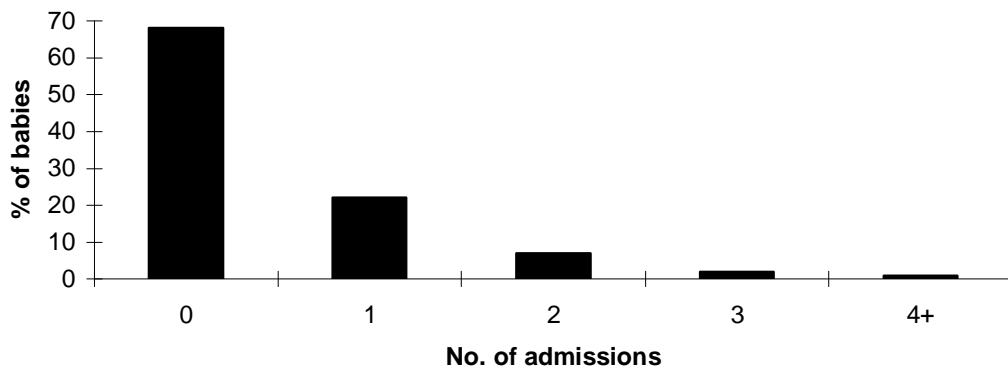
Paediatrician

In the early phase of the CONI programme about 65% of babies were seen by the paediatrician after discharge from the post-natal ward but this has declined to 47% of babies in recent years ($p < 0.01$). Those babies who were seen by the paediatrician, attended paediatric clinic, on average, once every 8 weeks. The parents who were able to see the paediatrician after discharge much appreciated the opportunity and over 80% of them found it helpful.

Hospital admissions

In-patient admissions did not alter over time, 68% were never admitted to hospital and 10% had more than one admission in 6 months (fig 17).

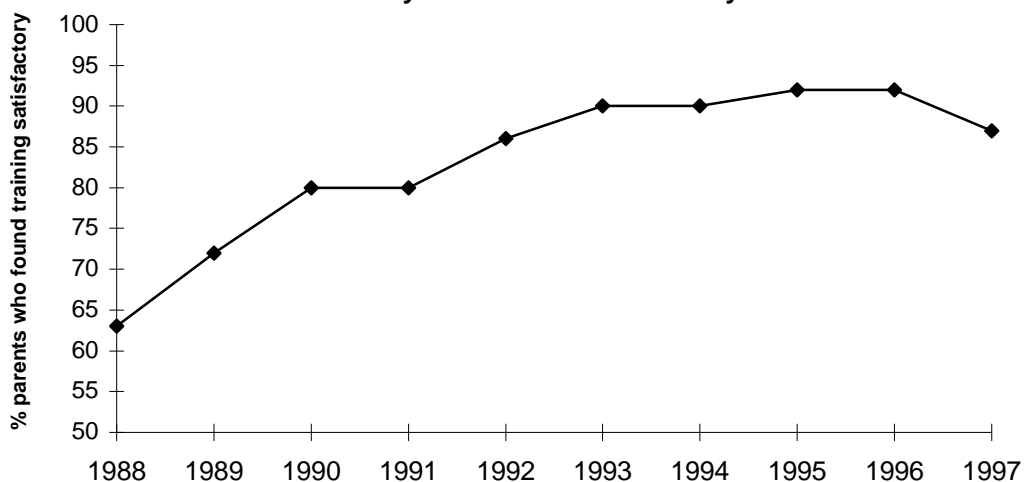
Fig 17 Hospital admissions for index baby 0-26 weeks



n) Resuscitation training

An earlier analysis in 1991 of parents' comments about resuscitation training led to our current recommendations that parents are trained using a resuscitation doll and preferably in the ante-natal period. Satisfaction with training has since improved (fig 18), overall 87% have been satisfied, 2% found it too complicated and 11% found it inadequate.

Fig 18 Parents' satisfaction with training in resuscitation by year of birth of index baby



o) Value of programme to parents

The parents were asked to number 9 different components available during the surveillance, in number order (1 = most helpful and 9 = least helpful), to indicate the ways in which they were most helped. Some of the parents had difficulty following these instructions and their answers had to be discarded. The answers were then divided into those who just had scales at home for daily weighing, those who just had an apnoea monitor, those who had both scales and a monitor and those who had neither (table 6). For the families with scales only, the parents indicated that the scales and weight chart were the most helpful component of the survey, followed by the health visitor's visit and then the symptom diary. If the parents had scales and an apnoea monitor, the order was the same but displaced one place down by the apnoea monitor. The parents who had an apnoea monitor only, still tended to include weighing in their ranking, presumably referring to a weekly weigh by the health visitor at home or weighing at the clinic and they interchanged the ranking of the health visitor's visit and the use of scales and weight chart. For those having neither scales nor an apnoea monitor, the health visitor's weekly visit was the most important component to them. Thus the health visitor's weekly visit was only surpassed in popularity by the scales at home for daily weighing or the apnoea monitor, if either of these were used.

Table 6 Parents' rankings of the various aspects of the programme

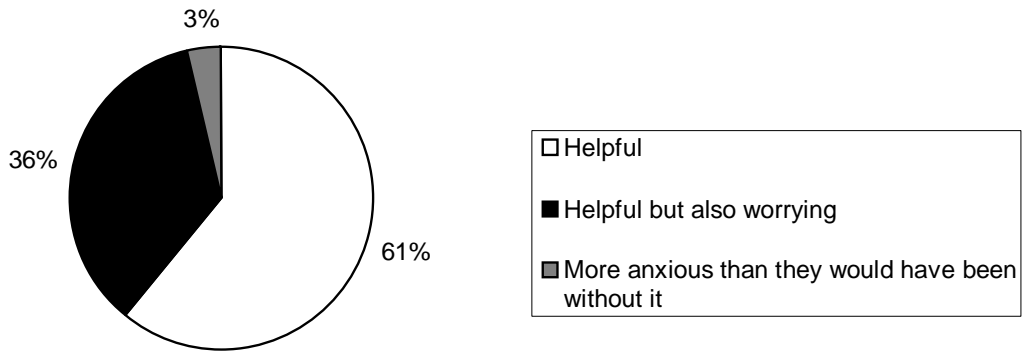
	Scales only	Monitor only	Scales and monitor	Neither
	Rank	Rank	Rank	Rank
Apnoea monitor	—	1	1	—
Scales and weight chart	1	3	2	2
Health visitor's visit	2	2	3	1
Symptom diary	3	4	4	3
Taking part in programme	4	5	5	4
Room thermometer	5	6	6	5
Contacts with GP	6	8	7	6
Contacts with Paediatrician	7	7	8	7

p) Overall view of the programme

Views of the parents

The overall parents' impression of the CONI programme showed that 97% found it helpful, though a third of these also found it worrying at times (fig 19).

Fig 19 Parents' views on CONI programme

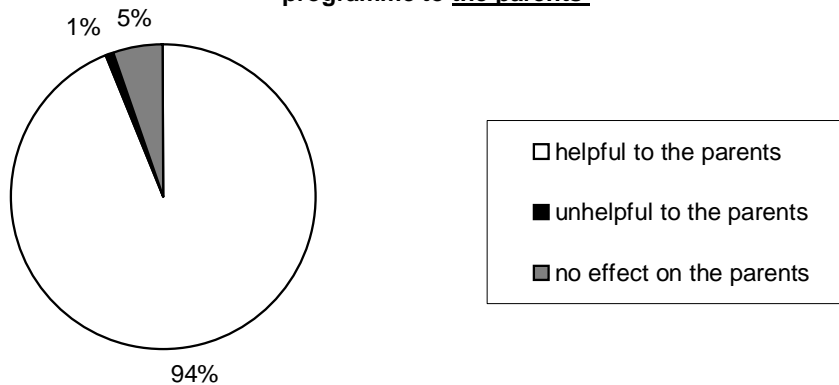


99% of the parents would recommend the programme to other parents who have had a cot death and 99% of the parents thought that all parents who have had a baby death from any cause should be offered appropriate support in a similar way to this programme.

Views of the health visitors about the programme

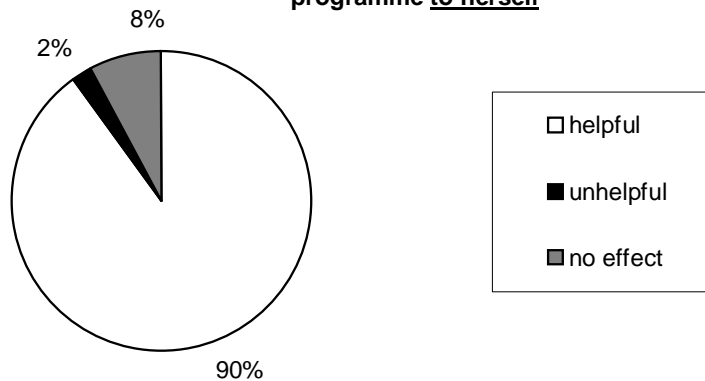
Almost all the health visitors thought that the programme had been helpful to the parents (fig 20).

Fig 20 How helpful the health visitor considered the programme to the parents



90% of the health visitors thought that the programme had been helpful to them themselves and only 2% found it unhelpful (fig 21).

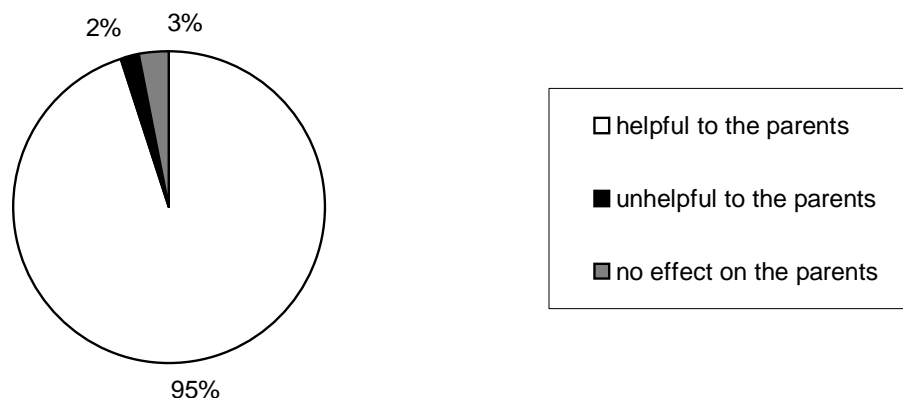
Fig 21 How helpful the health visitor considered the programme to herself



Views of the GPs about the programme

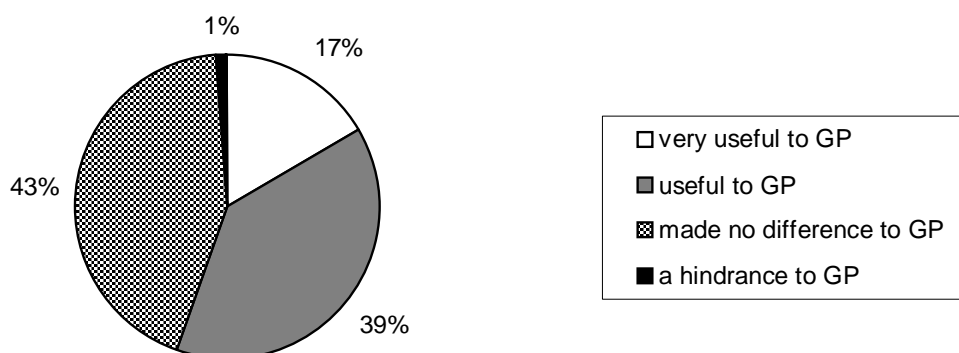
Almost all the GPs thought that the programme had been helpful to the parents (fig 22). A few thought that it had had no effect on helping the parents and 2% felt it had been unhelpful. This was mainly due to raising anxiety levels.

Fig 22 How helpful the GP considered the programme to the parents



56% of the GPs thought that the programme had been helpful to them themselves and only 1% thought it was a hindrance to themselves (fig 23).

Fig 23 How useful the programme was to the work of the GP



DISCUSSION

1. Overall satisfaction

The CONI programme had been consistently valued by parents. Almost all of the parents found the programme helpful, although a third also found it worrying at times. This latter valuation illustrates the difficult situation for the parents who want help, but also find that it can be a reminder of what they have lost and stand to lose. These two quotes from parents are typical examples of explanations offered with this assessment. 'This scheme is great, but worrying, but having another baby is worrying anyway. It is nice to have the support.' and 'It was worrying at times, but this is good as it kept us aware.' The individual elements of the programme each have the capacity to reassure and to cause anxiety. It is necessary to recognise that a degree of appropriate anxiety is needed for a parent to properly fulfill their caring role, to be alert to the needs of their infant and seek help when required.

2. Apnoea monitors

It is interesting to note that while most of parents were given confidence by using a monitor there has been a gradual decline in those stating that this was always the case. We suspect this reflects improving education of both parents and professionals in the limitations of the apnoea monitors. However, monitors remain highly valued by parents, 'For me it was an absolute necessity, my "life-line".'

3. Symptom diaries

There has been a significant decline between 1988 and 1995 in the number of parents opting to use the symptom diaries. We have noted parents' comments that they would like to be able to write in more detail about symptoms or concerns and in 1996 produced a new version that gave more space than the original tick chart. Both versions are currently available and there has been a slight upward trend in the take-up of the diary again. The assessment of usefulness of the diaries by parents is very consistent with most being always or sometimes helped. We are currently consulting with local co-ordinators about how they would like to see the diary developed. Their appearance could certainly be more attractive and perhaps some illustrations would make them more useful to parents with poor literacy skills. Unfortunately we have no data on the educational background of the parents and it is most likely that the use of diaries is closely related to the parents' skills in reading and writing.

4. Resuscitation training

The percentage of parents who found the resuscitation training satisfactory has been consistently high since 1992. Previous analyses of the parents' questionnaire identified that parents needed to practice resuscitation on a doll. Dissemination of this information in early 1990s has improved the quality of the training received by parents.

5. General information

Also as a result of a previous analysis there have been changes made to the information booklet given to parents and the administration of stationery to parents to try and ensure that all parents receive all the appropriate stationery. They are now more satisfied with the written material they receive although there is still room for further improvement. Parents have been highly satisfied with the initial verbal explanation of the programme from the CONI co-ordinator and/or paediatrician.

6. Health visitor home visits

Contacts with the health visitor remain high at one per week per family. Some families receive more than one visit per week particularly in the early weeks with the new baby. It is remarkable that this level of visiting has been sustained over a 10 year period which has seen the health visiting service in general move away from home visiting. It is important to note that the parents value the visit second only to the equipment issued and these rankings are consistent with previous analyses. We have a vast number of comments which show that many parents feel the health visitor could have done no more than she did to help them and praising her for her understanding and friendship. 'She was always there for me and never seemed too busy or tried to get away when times were harder than usual.' 'Re-assured me and didn't mind if each week I repeated the same fears and asked the same questions.' Thus it is apparent that a large part of the success of the programme can be attributed to the commitment and professionalism of the health visitors. It is pleasing then, to note that almost all the health visitors also

found the programme helpful. Many health visitors have commented on the satisfaction that they felt when working with families on the programme and with the organisation of the scheme. 'I was grateful to be a part of what I see to be an extremely valuable project that is so supportive to those families concerned.'

It is imperative that health visitors are able to continue to offer the CONI families weekly home visits.

7. Numbers enrolled

The enrolment of families on CONI has remained higher than anticipated after the drop in cot deaths following the 'Back to Sleep' campaign. This can be partially, but not totally explained by families using the programme more than once. There are also families where the next infant after the cot death is born after an interval of 5 -10 years. We also have families where the parents of the cot death baby both have subsequent children with new partners.

8. Sleeping position

It is interesting that in the years prior to the 'Back to Sleep' campaign over half the index babies were placed on their sides to sleep and about a fifth prone. Subsequent to the campaign there has been a decline in both prone and side sleeping in favour of the supine position. It is surprising that 6% of the index babies continue to be placed prone to sleep, given that the families have experienced a previous cot death and receive close supervision and literature advising against this practice.

9. The mortality on the programme and the possibility that deaths are prevented

44 babies who were or had been on the CONI programme died (8.8 per 1000 live births), of whom 35 were unexpected child deaths. Of the 44 deaths, 40 were in the post perinatal period giving a post perinatal death rate of 8.0 deaths per 1000 live births which is considerably higher than the national rates. However, we are certainly not dealing with a normal birth population. Of the 35 children dying unexpectedly on the scheme 8 (1.6 per 1000 live births) were finally categorised as true cot deaths, after confidential enquiry.

Table 2 shows that the 5000 children on CONI came from 4182 families. Excluding children on CONI and baby deaths which led to the family enrolling on CONI, these families also had a total of 6406 previous live born infants of whom 112 (17.5/1000 live births) had died. So prior to the death that led to enrolment, these families had lost 17.5 infants per 1000 live births. After enrolling on the CONI programme they lost 8.8 infants per 1000 live births. The significance of the difference between the earlier mortality in the families and the deaths on the programme is difficult to interpret and will be explored critically elsewhere, but it does not appear to be explicable alone on the basis of falling infant mortality over the period because, for example, mortality has been shown to increase with birth order.³ Without question we are dealing with families where there is increased risk of multiple deaths and this has to be critically assessed. It is possible that the activities of health professionals has led to a lower rate of death in the group as a whole, but the continuing relatively high rate of death does highlight the need for alertness to the vulnerability of at least some of the infants.

FINAL COMMENTS

1. The CONI programme is widely available and overall there is a high uptake by parents of the programme.
2. Whilst there have been several trends in usage of the elements of the programme, there is wide acceptance of all aspects of the programme and all the elements are found to be useful by a convincing majority of the parents responding to the questionnaires.
3. Doctors and health visitors value the programme especially because it gives them a framework in which to work to help the parents.
4. In the opinion of the Steering Committee, the continuation of the programme at its current level of operation within the health service depends on the maintenance of the central organisation at least at existing levels.
5. The CONI programme provides a system of care targeted at parents who have suffered a child death, particularly those where the death has been unexpected. It provides a basic framework of help for these families which is understood by parents and the health professionals. This basic framework can be modified to suit the individual needs of each of the families.
6. We have shown the following:
 - i) The programme helps the health visitors in their work by providing practical help and by the knowledge that they are part of a national scheme.
 - ii) The programme is really valued by parents and they particularly appreciate the involvement of their health visitor.
 - iii) There is some evidence to suggest the scheme may be preventing further deaths.

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1. Office for National Statistics (1997) '1995 Birth Statistics' Series FM No. 24.
2. Fleming DM, Charlton JRH. Morbidity and healthcare utilisation of children in households with one adult: comparative observational study. *BMJ* 1998;316:1572-6.
3. FSID (1997) Factfile 1: Cot Death - facts, figures and definitions.

Acknowledgements

We would like to thank the parents for taking the time and trouble to complete our records. We would also like to thank the local co-ordinators, paediatricians, health visitors, GPs and midwives for their commitment to the parents and the programme and without whose help the CONI programme could not operate. We are grateful for the funding provided by the Foundation for the Study of Infant Deaths and for the encouragement and counsel of the members of the Information and Support Committee.

The Foundation for the Study of Infant Deaths,
14 Halkin Street,
London
SW1X 7DP

ISBN 0 9510753 7 3

