UNIVERSITY OF SOUTHAMPTON

FACULTY OF MEDICINE

AN EVALUATION OF A RISK RELATED INTERVENTION PROGRAMME TO REDUCE THE RATE OF POSSIBLY PREVENTABLE POSTPERINATAL DEATHS (INCLUDING SUDDEN INFANT DEATHS) IN PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT

by

JEAN POWELL

This Thesis is Dedicated to

RAMON POWELL, my husband

and

MAGGIE BOYDELL, my mother

who have given unstintingly of
their time and their love over many years
to allow me, by the Grace of God,
to undertake this study

TABLE OF CONTENTS

Page number

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF MEDICINE

COMMUNITY MEDICINE, MEDICAL STATISTICS AND COMPUTING

Doctor of Philosophy

AN EVALUATION OF A RISK RELATED INTERVENTION PROGRAMME TO REDUCE THE RATE OF POSSIBLY PREVENTABLE POSTPERINATAL DEATHS (INCLUDING SUDDEN INFANTS DEATHS) IN PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT

by Jean Powell

The programme of risk related intervention (RRI) was prompted by a sharp and sustained rise in the rate of possibly preventable postperinatal deaths (PPPD) in Gosport from 1977-81. A preliminary study which included the dead infants indicated that the 'Sheffield' Scoring System identified those at risk of sudden death.

The Portsmouth Study comprised an initial phase in Gosport 1.1.82-31.3.83, then it was extended to include all infants born 1.4.83-31.3.85 to women resident in Portsmouth and South East Hampshire Health District. The 'Sheffield' system was used in Gosport to identify infants at high risk (HR), then was modified to include local factors and select a very high risk (VHR) group. Two other risk groups were identified: non accidental injury; families with previous experience of child death.

All infants were 'scored' by computer then the risk factors were notified to health visitors and general practitioners. RRI by health visitors included: a programme of home visiting in the infants' first year - 5 visits for low risk, 11 for HR (9% of total), 21 for VHR (1%); provision of room thermometers for HR and VHR; leaflets and advice to all parents regarding hyperthermia; naked weighing of all infants and plotting weights on percentile charts.

RRI appears to have been effective as during the study period there was a significant reduction in PPPD in the groups receiving extra care. Also the mean rate of PPPD 1983-87 when compared to the five years before intervention showed: a reduction of 60.6% in Gosport; 32.2% in Portsmouth (including Gosport); against 12.2% in England and Wales; and only 5.4% in Wessex Region (not including Portsmouth).

The study validated findings that patterns of age, sex, season, time, illnesses, overheating, smoking and infant feeding in PPPD are similar to typical patterns found in studies of SIDs only.

The computerised scoring system, patterns of intervention and changes in practice of health care, have been acceptable not only to professionals but also to parents, who have generally welcomed the extra support given to them and the extra attention given to their infants.

LIST OF TABLES

Page number

Page number

Page number

Page Number

LIST OF FIGURES

GLOSSARY AND ABBREVIATIONS

Apnoea - cessation of breathing

Cot death - sudden unexpected infant death, English terminology

Crib death - sudden unexpected infant death, American terminology

EDD - expected date of delivery

GIS - Gosport Infant Surveillance

HR Infants - child under the age of one year estimated to be at High Risk of possibly preventable postperinatal death or child abuse, according to the Portsmouth Infant Surveillance Scoring System

Inevitable Postperinatal Deaths - infants dying between the ages of one week and one year from conditions considered to be incompatible with life, for example:- severe heart lesions or neural tube defects; complications of gross prematurity when infants never leave hospital; malignant neoplasms; degenerative conditions (Carpenter and Emery, 1974)

Infant - child from birth to one year (OPCS)

Infant Death - death occurring under one year of age (OPCS)

Infant Mortality Rate - number of deaths under one year of age per 1000 live births

LR Infant - child under the age of one year estimated to be at Low Risk of possibly preventable postperinatal death or child abuse according to the Portsmouth Infant Surveillance Scoring System

NAI - non accidental injury

Neonatal Death - death occurring within the first four weeks of life

ORLS - Oxford Record Linkage System

OPCS - Office of Population Censuses and Surveys

Parity - the number of pregnancies resulting in either a live birth or stillbirth

PCD - previous child death

Perinatal Death - stillbirth or death within 7 days of birth

PPPD - possibly preventable postperinatal deaths, these include deaths from SIDs, infections, accidents and non accidents (Carpenter and Emery, 1974)

Postperinatal Death - death between 7 days and one year

Postneonatal Death - death between 4 weeks and one year

Registerable births - all live births irrespective of weight or gestation

Sibling - a brother or sister

Statistical Significance - a method of determining whether a result could have occurred by chance, thus 0.05 or 5% probability means that the odds are at least 1 in 20 against the finding occurring at random.

Stillbirths - infants born dead after 28 completed weeks of gestation

SID - sudden infant death

SIDS - Sudden Infant Death Syndrome - 'The sudden death of an infant or young child which is unexpected by history and in which a thorough postmortem examination fails to demonstrate an adequate cause of death' (Beckwith 1970).

VHR Infant - a child under the age of one year estimated to be at very high risk of possibly preventable postperinatal deaths according to the Portsmouth Infant Surveillance Scoring System

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My grateful thanks go first and foremost to the health visitors of Gosport and then to all health visitors who have worked in Portsmouth and South East Hampshire Health District since 1983. This study would not have been possible without their co-operation and the dedicated care they have given to thousands of infants.

My sincere thanks go to:

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* The nurse managers and general managers who allowed time and resources to be used.

* The typists who have typed and retyped questionnaires and forms with skill and patience.

* Mike Davies, the 'computer expert', who dedicated a lot of his personal time and effort to designing some of the original computer programmes and printouts.

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* The general practitioners working in the Health District who co-operated with the system and supported parents.

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I am grateful to the thousands of parents who were involved in this study simply because their baby happened to be born in Portsmouth Health District: they answered questions asked by midwives and health visitors; they allowed their babies to be dressed and undressed, to be weighed and measured; they were generally most co-operative and even appreciative of the extra attention their infants received.

My final thanks are to my husband, my mother, our daughter Catherine, our son Geoffrey, to Dorothy and other friends, who have all sacrificed time to allow me to complete this study and encouraged me when I needed it.

CHAPTER 1

INTRODUCTION

The cause of sudden infant death has been investigated in depth in many countries throughout the world for the past two decades and in spite of large amounts of time and money being invested into why these deaths occur, the cause or causes remains uncertain.

It has been suggested that some postperinatal deaths, including some sudden infant deaths, are possibly preventable (Carpenter and Emery, 1974, Taylor and Emery, 1983, Knowelden et al, 1984). If therefore scarce resources are targeted at the infants who are estimated to be most at risk and if the overall care to all infants is improved, then there should be a reduction in possibly preventable postperinatal deaths (PPPD), which would include a reduction in sudden infant deaths.

The higher than National rate of PPPD in Portsmouth and South East Hampshire Health Authority, but particularly the exceptionally high rates in Gosport from 1979-1981, led to this Portsmouth Study.

The aim of this Portsmouth Study is to attempt to reduce the numbers of PPPD occurring in the Health District. The author decided after deliberation on the research studies available and discussions with various people that it would be necessary to introduce several changes in the delivery of care to infants and to their parents to achieve this aim. These changes would include:-

First - To establish risk related intervention.

It would be preferable to implement a modified 'Sheffield Scoring System' (Carpenter and Emery, 1977) to select out infants at high risk of unexpected death thereby enabling the health professionals involved with infants to intervene according to the estimated risk.

Second - **To improve the health care offered to infants**.

There would be no reduction in the services offered to any infants but some categories of infants would receive more services than others.

Infants at Risk would receive:

- a recommended pattern of home visiting related to risk of either sudden infant death based on the system used in Sheffield or of non accidental injury as indicated in various research studies;
- a room thermometer to enable parents to keep the temperature of their infants' environment at a recommended level, as part of the plan to prevent infants suffering hyperthermia and hypothermia;
- a respiration monitors/apnoea alarm, plus extra professional help, to relieve stress and to support parents whose infants were estimated to be prone to apnoeic attacks, although various articles suggested monitors could be detrimental as well as a advantageous to parents.

All Infants would receive:

- regular and more frequent naked weighing, but particularly those infants estimated to be at high risk. This decision was taken by the author as weight gain had been shown in various studies to be a good indicator of infants' well-being and the previous practice of weighing infants with their clothes on was inaccurate and therefore unacceptable;
- Sheffield type weight percentile charts where naked weights would be accurately plotted. These would clearly indicate infants who were failing to thrive to both professionals and to parents.

Parents of All Infants would receive:

- advice on how to keep their infant's body temperature normal, as research indicated infants died from hyperthermia as well as from hypothermia;

- information regarding the detrimental effects of maternal smoking to the foetus during pregnancy and also the adverse effects to infants when they are exposed to passive smoking, as these disadvantages have been shown in many studies.

To accomplish the above changes in the health care services offered to infants and their parents it would be necessary to standardise some health visiting practices and procedures, and also to provide more inservice training for health visiting staff.

Third - Development of the use of computers:

- to ensure data are checked for consistency and completeness;
- to improve communications to various disciplines involved in the care of infants by generating information in a format which is understandable and will fit into existing filing systems;
- to produce statistics and data on health visitors' case loads for use by managers to enable a more even distribution of work;
- to store data for subsequent evaluation and analysis.

THIS THESIS will evaluate the effectiveness of risk related intervention and other health care services, given to the cohort of infants born to mothers resident in Gosport from 1.1.82 and mothers resident in the whole health district from 1.4.83 until 31.12.85., on the rates of possibly preventable postperinatal deaths in Portsmouth and South East Hampshire Health Authority. The trends in infant death rates in Gosport and Portsmouth Health District will also be compared to those in Wessex and in England and Wales 1965-1988.

CHAPTER 2

BACKGROUND INFORMATION

2.A REASON FOR THE STUDY

In 1979 it was noted by the author and Health Visitors in Gosport, Hampshire, that there appeared to be an increase in the incidence of sudden infant deaths in the Borough so they instigated a confidential enquiry.

Two meetings were held which were attended by many interested professionals including General Practitioners, Clinical Medical Officers, Paediatricians, Pathologists, Health Visitors and Nurse Managers. Many of the people attending the meetings had known some of the infants who had recently died, and were able to give detailed information regarding the infants and their families. This led to a recommendation for a detailed retrospective and ongoing study to be carried out, to investigate the incidence of sudden infant deaths in Gosport, and the possibility of local contributory factors.

The Sheffield risk related intervention project (Carpenter and Emery 1974, Carpenter et al 1977) were the only studies known to the author at that time laying any claim to reducing post perinatal mortality so the author and others (Powell et al, 1981) carried out a study using the Sheffield criteria. The results of the retrospective and ongoing study prompted an intervention study in Gosport, which developed after a year to encompass the whole of Portsmouth Health District.

2.B. GOSPORT, HAMPSHIRE

Portsmouth and South East Hampshire Health Authority covers an area of 45,000 hectares and has a total population of 520,100 persons. The Health District is divided into three Sectors; North, South and West; Gosport Borough is half of the West Sector (Figure 2.1.).

Gosport is a peninsula covering 2,500 hectares, and since the 17th Century has been involved with the Royal Navy. There are currently a number of important Naval establishments in the Borough: the Submarine headquarters; the Marine Engineering Service; the pay, drafting and records establishment; the armament depot; the headquarters of the supply and transport services; the headquarters of the Fleet Air Arm; and Haslar Hospital, the largest service hospital in Britain. Many of Her Majesty's ships are also Portsmouth based, and the combination of these factors has necessitated the provision of accommodation in the area for wives and children of serving personnel. Over 4,000 married quarters are provided in Gosport; 3,000 of these in Rowner, one of the largest housing estates in the country for service families.

The service accommodation has helped to produce unique problems within the Gosport area:- the population is young and very mobile; there is a high concentration of children 0-4 years (Figure 2.2.); the average number of births each year is 1,250 and 45% of these babies are born into service families; there is a high concentration of young wives separated from their naval husbands, who may be away at sea for long periods of time; the young nuclear families are unsupported by their extended families, as the wives have left their 'home town' to be with their husbands; the average duration of tenancy is less than 18 months, so it is very difficult to form lasting, meaningful relationships. A high incidence of child maltreatment was reported in the area in the Mid 1970's (Bennett and Pethybridge, 1979). They estimated that child abuse occurred in Service families with approximately the same frequency as in

Figure 2.1.

Portsmouth and South East Hampshire Health District, Identifying the North, West and South Sectors Boundaries and Gosport Borough.

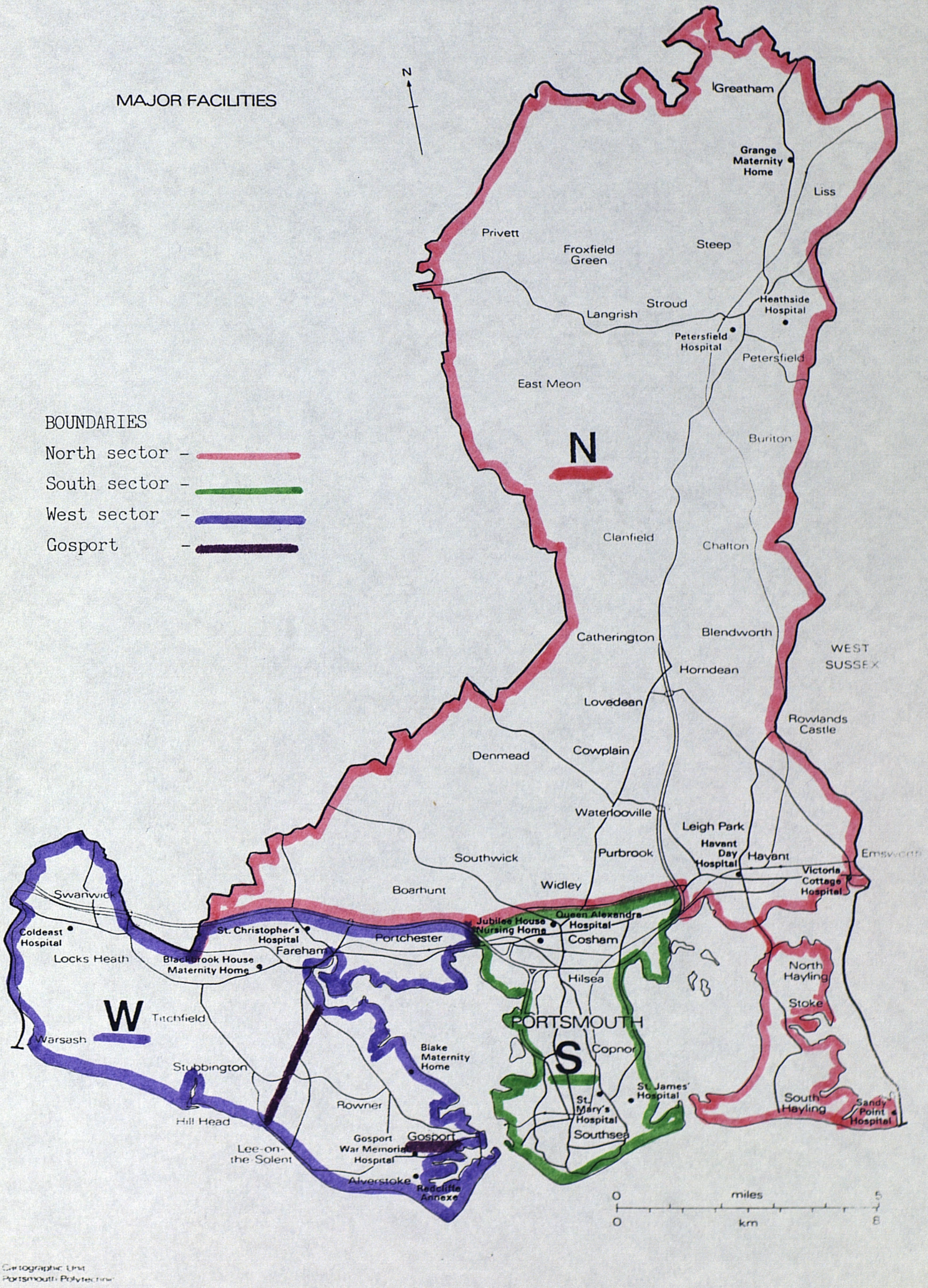
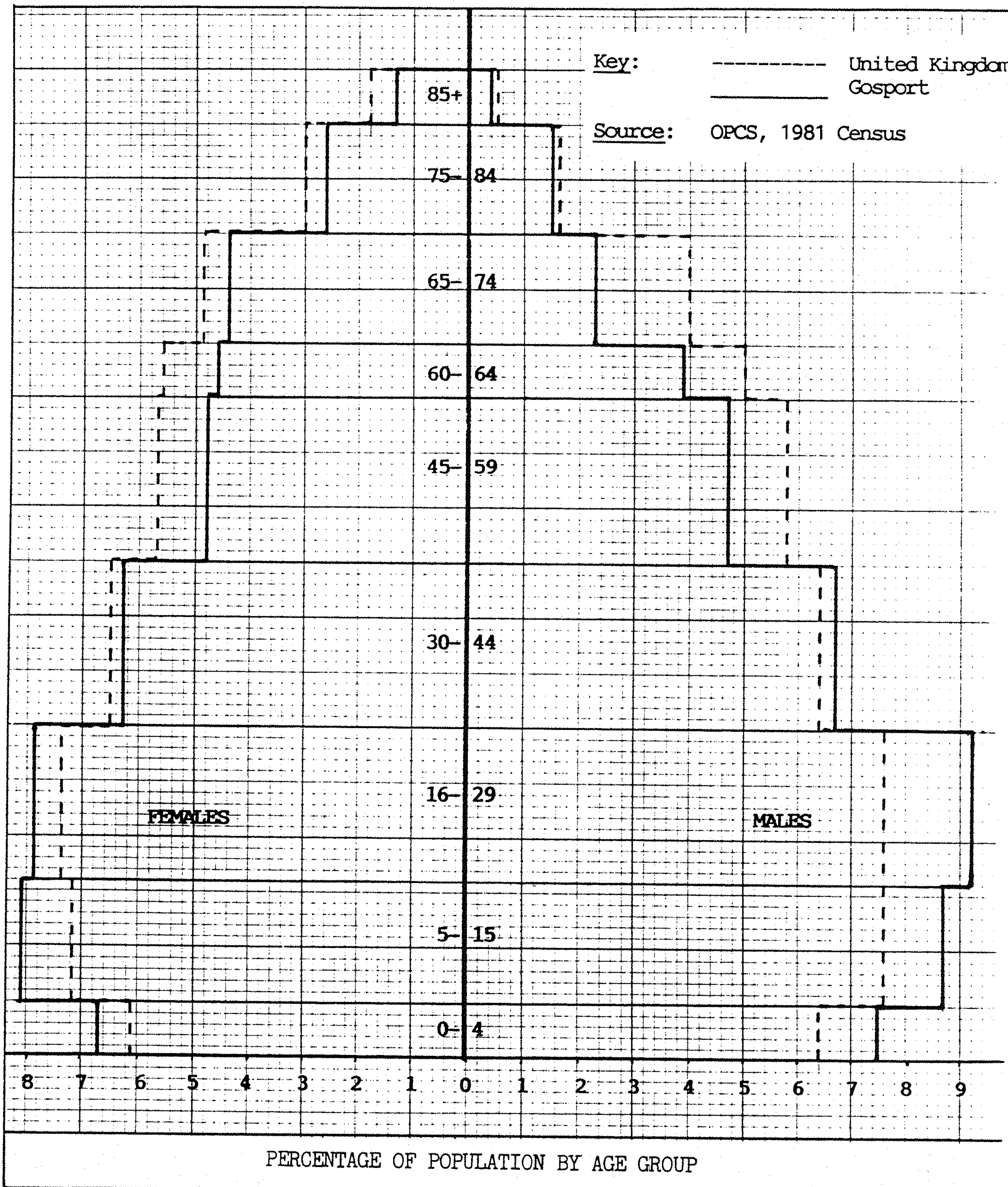


Figure 2.2.

The Structure of Population by Age and Sex in the United Kingdom and Gosport Borough in 1981.



Social Class V civilian families, which was similar to the findings in Service Families in Oxford (Fedrick, 1974).

A study in Hawaii, investigating abuse within military families, also found they were subject to family discord, interrupted child care, problems of relocation and isolation (Dubanoski and McIntosh, 1984); identifying similar problems occurring on the opposite side of the world and in a different culture.

These typical factors of service families make heavy demands on health and social services.

2.C SUDDEN INFANT DEATH

To experience the death of a baby is usually a very traumatic experience for everyone concerned, but when the death is sudden and unexpected it can be devastating for parents and relatives, and very distressing for any professionals involved. Sudden infant death is the major cause of mortality in the post perinatal period in developed countries. It continues to be the subject of innumerable papers, articles, books and conferences.

2.C.1. HISTORY OF SUDDEN INFANT DEATH

It is difficult to record the history of sudden infant death as terminology, expectations and recording has varied over the centuries.

The first reference to what was probably sudden infant death is in the Holy Bible, in 1 Kings 3:19. King Solomon had to judge a difficult case of two women who both claimed to be the mother of a live child, whilst one was actually the mother of a dead child "one night she accidentally rolled over on her baby and smothered it".

Suffocation was mainly suspected until the late 19th century to be the cause of infants dying, either by being overlain or being smothered by bedclothes.

Russel-Jones (1985) gave a summary of sudden infant death in history and literature. He mentioned that they were recorded in Egypt in the 1st century BC and also in Greek and Latin literature. The next recorded occurrence was in the 12th century in Welsh literature; and in 1291 a German placard stated - mothers were forbidden to take children under 3 years into their beds. In 1632 'overlaid and starved at nurse' were stated as causes of death categories, although at this time deliberate infanticide appeared to be tolerated. Curgenven (1871), in a paper entitled 'The Waste of Infant Life', said suffocation at the mother's breast, frequently on a Saturday night after she had been drinking, was the most common cause, and in Winter when drawing up the bedclothes. He also described the sudden death of twins. McCarthy (1871) presented a paper suggesting tight bandages and bedclothes were the causes of death.

Templeman (1892) in a study on 399 infants in Dundee from 1882-1891 agreed with Curgenven (1871), that a disproportionate number of deaths (46%) occurred on Saturday night, which he concluded was due to alcoholic intoxification of the parents. The infants were found in bed, or on a pile of jute sacks, with their parents and as many as seven other siblings, so overlaying due to overcrowding could have been the cause of death. 54% of the infants died under the age of five months and 62% died between October and March, which suggests many of them were SIDs. Templeman recommended infants should be placed to sleep in a separate cot and also a law should be passed, as in Germany, that no child under 2 years should share a bed with others.

In England it was not until the 17th and 18th Centuries that sudden unexpected deaths in infants became the concern of the police and the secular courts. By the early 19th Century, civil and Coroners' courts were investigating cases of overlaying and smothering to try to determine specific causes of death, although at that time post-mortems were not routinely carried out.

In the late 19th Century when post-mortems were becoming more frequent the theory of enlarged thymus emerged. Paultouf (1889) stated that victims of sudden infant death were often found to have a large thymus, which might have a causal relation. Hamer (1906), however, stated that this concept was false and an enlarged thymus was in fact normal in children of that age group.

In the early 20th Century the numbers of infants dying from being overlain was very high; 1,348 such infant deaths in Edinburgh district alone were recorded in 1912, although these had reduced to 704 in 1917, due mainly to the changes in the licensing law according to Saleby (1917). Social conditions improved during the 20th Century and infants were placed in a cot by themselves; the cause of infants dying was then blamed on soft pillows and bedclothes.

In 1926 there was a change in the Coroner's Act of 1887, which made post-mortems on infants dying suddenly almost mandatory, and after that date it became unacceptable to state 'Cause unknown' on a death certificate. Professor B. Knight (1983), forensic pathologist, states that in the 20's and 30's pathologists were convinced that the sudden infant deaths were due to natural causes, but were unsure of the disease, and the practice grew of calling the death a result of a respiratory infection. Such terms as acute bronchiolitis, acute tracheobronchitis, or acute capillary bronchitis, were frequently used where no specific abnormalities could be found. This 'false recording' on death certificates created problems when statistics regarding causes of infant deaths were needed and led researchers to think that infection of some kind was the usual cause of death, which remained unchallenged until the 1940's when post-mortems were performed with greater expertise.

In the 1950's and 60's there was an increased interest in research and various theories were suggested as to the cause of sudden infant death. Infection, hypersensitivity and suffocation were all proposed in the Ministry of Health Enquiry into Sudden Death in Infancy in England, chaired by Professor Banks (Banks, 1965).

In 1963 the first major international conference on sudden infant death was held in Seattle, USA, and the confusing terminology relating to sudden infant deaths was highlighted (Landing, 1963). In 1967 Valdes-Dapena wrote, "At the present time, after autopsy has been completed and no cause of death determined, the pathologist usually feels constrained to, or is required by law to, enter some definitive cause of death on death certificates. Thus 'bronchopneumonia' or 'suffocation' may appear there when actually no cause for death is known" (Valdes-Dapena, 1967). At the second international conference in 1969 Dr. Bruce Beckwith, to avoid further confusion, put forward a specific definition of Sudden Infant Death Syndrome.

> "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 of death" (SIDS) (Beckwith, 1970).

This definition was accepted by other people attending the conference. It was subsequently included in the International Classification of Diseases in the 9th revision in 1979, coding number 790, and since then it has been an accepted cause of death internationally (WHO, Geneva, 1979).

Although SIDS is probably the most widely accepted terminology, many people do not agree with it. It is felt to be a process of elimination rather than the identification of positive criteria (Keeling et al, 1985). In particular, Professor John Emery the former Professor of Paediatric Pathology at the University of Sheffield, stated at a symposium of the Institute of Medical Ethics London Medical Group, that he found the statement too ambiguous and questioned "What is sudden, what is unexpected by history and what is a thorough post-mortem?" (Emery, 1985). Perrot and Nawojczyk (1988) also asked 'How thorough is thorough?'.

A Multicentre Study of Post Neonatal Mortality felt 'SIDS' encouraged the view that the sudden unexpected death is a single entity or a common final pathway (Knowelden et al, 1984). Although it has been stated by paediatricians and pathologists that there is some critical combination of intrinsic and extrinsic factors which prove lethal, what is in doubt is the mechanism or 'final common pathway' of death (Froggatt, 1970; Valman, 1977; Arneil et al, 1985; Emery, 1985).

Perhaps as quoted by Lady Limerick at the 1974 International Symposium on Sudden Infant Death in Canada, in appropriate metre:-

> "When theories compete in profusion
> Then the experts conclude, in confusion
> 'There'll be flaws in all laws
> Of this unexplained cause
> Till the problem is solved by exclusion" (Limerick, 1974)

The deaths are still also referred to as: Sudden Unexpected Death in Infancy (SUDI), Sudden Unexpected Infant Death (SUID), Unexpected Sudden Infant Death (USID) and various other combinations of the words. In Britain they are popularly known as 'cot' deaths and in North America as 'crib' deaths. Published reports on sudden infant death therefore are still confused by variations in the terminology (Sunderland, 1985).

The term Sudden Infant Death (SID) will be used throughout this thesis, unless quoting other workers when their terms are used.

2.C.2 CORONER'S INVESTIGATION, PATHOLOGY AND REGISTRATION OF SUDDEN INFANT DEATHS IN ENGLAND AND WALES

2.C.2.a THE CORONER'S INVESTIGATION

The Coroner is obliged under English law (The Coroner's Act, 1887, as amended) to inquire into any sudden death of unknown cause, as well as any deaths which appear to be unnatural or violent, and disposes of the inquiry in a way which best serves the public interest. The Coroner is authorised to select and pay a suitably qualified pathologist to carry out a post-mortem examination and produce a report as to the cause of death, which becomes the property of the Coroner. When the Coroner is satisfied with the result of the necropsy and the inquiries, he is then able to supply the Registrar with a certified cause of death.

2.C.2.b. PATHOLOGY

The benefits of post-mortem examination and standardised pathology in SID according to Morales and co-workers (1984) fall into three categories:-

1) to law and society;

2) to academic medicine;

3) to the family of the infant, who may be able to accept and adjust to their tragic loss if there is a reason for it.

The standards of necropsy, interpreting the results of the post-mortem examination and investigations, then stating the cause of death, rely on the techniques, experience and personality of the pathologist involved. Interpretations of pathology observations can cause problems when comparing series with one another, for example some pathologists would attribute a large percentage of deaths to so-called 'interstitial pneumonia' whilst others would interpret the same histological sections as normal lung (Valdes-Dapena, 1967).

'SIDS is death without sufficient pathology' is a statement of Shannon and Kelly (1982), although their two part series on SIDS and Near SIDS in the New England Journal of Medicine describes intensive pathological investigations from cardiovascular to toxicology and chemistry. It is recognised, however, that some pathologists perform only a cursory post-mortem examination, or through lack of experience carry out inappropriate tests, and then state 'Sudden Infant Death Syndrome' on the post mortem report (Barson, 1985). Emery (1983) commented "The diagnosis of 'Sudden Infant Death Syndrome' has become too easy and it has become easy to find nothing at necropsy" he also stated (1986) "Until infants' deaths are examined more critically than they have been in the past it is unlikely that the many probable causal pathologies of these clinically tragic infants' deaths will be identified".

A protocol for pathological investigations in cases of sudden infant death has been drawn up by a working party of the British Paediatric Association to provide a basic standard (Wigglesworth et al, 1987).

which should prove to be beneficial for comparative studies if all pathologists follow the recommendations.

Much tighter criteria were recommended by the speakers at the XIX International Congress of Paediatrics in Paris in 1989 who concluded, "that all postperinatal deaths should be examined in very great depth in a few centres that have the time and skill to do so; epidemiological studies should be based only on data from these centres; and journals should be encouraged to accept only those studies on the sudden infant death syndrome in which every child had been examined by a paediatric pathologist and been subject to a neutral confidential enquiry".

2.C.2.c. REGISTRATION OF DEATH

The Births and Deaths Registration Act, 1933, states that the death, and cause of death, of every person dying in England and Wales must be registered by the Registrar of Births and Deaths for the sub-district in which the death occurs.

A registered medical practitioner who attended a patient during his last illness is required to sign a Medical Certificate of the Cause of Death. However, when death has occurred suddenly and unexpectedly for no obvious reason, or if a doctor has not attended the person during their last illness, or if he has not seen the patient within 14 days prior to death, the doctor or the registrar should refer the death to the Coroner.

The interpretation amongst Coroners of what constitutes a SID appears to vary considerably. A study looking at the proportion of postneonatal deaths certified by coroners showed wide Regional variation, ranging from 5.8% in Sheffield to 39.7% in the North West Metropolitan District (Weatherall and White, 1976).

The registered cause of sudden infant death is inconsistent, as shown in a survey by the Foundation for the Study of Infant Deaths, where the unexpected deaths of 713 babies were registered on their death certificates in 35 different ways (Golding et al, 1985). The 713 causes of death were divided in this particular study into five categories:-

1. SIDS as the main cause of death (66%)
2. A recognised condition plus SIDS, for example Bronchial pneumonia/SIDS; Asphyxia due to regurgitated vomit/SIDS (7.3%)
3. A recognised condition only, e.g. Tracheobronchitis; Bronchopneumonia (15%)
4. A vague condition, e.g. Respiratory failure; Natural causes (8-7%)
5. Accidental causes, e.g. Misadventure; Asphyxia; Choking on vomit or inhalation of vomit (3%)

The Office of Population Censuses and Surveys (OPCS) regularly publish information regarding SIDS. Their figures relate to infants in the first year of life, for whom the death certificates contained the words, sudden unexpected death, cot death or similar term, regardless of whether any other specific cause was given. It is stressed that despite a death being sudden or unexpected, a possible mechanism of death is identified in up to 10% of SIDS (Table 2.1.).

In a recent study of 988 children aged 1 week to 2 years dying from all causes in eight urban centres in England, it was stated that in up to 25 per cent of the deaths certified as Sudden Unexpected Death the label 'cause unknown' was not appropriate, and some death certificate entries were frequently in conflict with the clinical and pathological evidence (Knowelden et al, 1984).

Table 2.1.

Listing of the Underlying Causes of Death where Sudden Infant Death Syndrome is also mentioned on the Death Certificate 1983 and 1984, England and Wales

ICD Code	Description	1983	1984
001-009	Intestinal infections	2	5
030-041 050-057, 070-079, 130-136	Other infections and parasitic diseases	4	4
240-259, 280-289	Disorders of endocrine glands and of blood and blood forming organs	1	3
320-359. 380-389	Diseases of the nervous system and of the ear and mastoid process	11	5
415-438	Heart and cerebrovascular disease	5	3
462	Acute pharyngitis	-	3
464	Acute laryngitis and tracheitis	4	4
465	Acute upper respiratory infections of multiple or unspecified site	21	10
466	Acute bronchitis and bronchiolitis	41	41
470-478	Other diseases of upper respiratory tract	-	3
480-487	Pneumonia and influenza	44	19
490	Bronchitis not specified as acute or chronic	4	5
491	Chronic bronchitis	1	1
507	Pneumonitis due to solids and liquids	-	1
510-519	Other diseases of respiratory system	13	10
520-579	Diseases of the digestive system	1	-
580-599	Diseases of the urinary system	1	1
740-759	Congenital anomalies	14	11

Table 2.1. Continued

Listing of the Underlying Causes of Death where Sudden Infant Death Syndrome is also mentioned on the Death Certificate 1983 and 1984, England and Wales

ICD Code	Description	1983	1984
761	Foetus or newborn affected by maternal complications of pregnancy	5	-
764-765	Slow Foetal growth, foetal malnutrition and immaturity	2	2
767	Birth Trauma	1	2
768	Intrauterine hypoxia and birth asphyxia	2	1
770	Other respiratory conditions of foetus and newborn	1	1
776	Haematological disorders of foetus and newborn	1	-
779	Other conditions arising in the perinatal period	3	3
799	Other ill-defined and unknown causes of morbidity and mortality	24	18
800-899	Injury and poisoning	12	11
Total		**218**	**167**

Source - OPCS Monitor, DH3, 85/4

2.C.3. RATES AND TRENDS OF SUDDEN INFANT DEATHS

2.C.3.a. THE RATES OF SUDDEN INFANT DEATHS

The Sudden Infant Death rate, that is the number of SIDs per 1000 live births, varies considerably throughout the world. A table in 'Sudden Infant Death - Patterns, Puzzles and Problems', (Golding et al, 1985) lists the incidence of SID in various populations, and the rate per 1,000 live births varies from 0.3 in Jewish children in Israel and 0.5 in Gothenburg, Sweden, to 5.2 in Trier, West Germany. The methodology in the 45 studies was not standard and the figures were all accumulated prior to 1979, many of them in the 1960's, so it was difficult and meaningless to attempt to directly compare areas.

Recent studies, however, show the rate of SIDs per 1,000 live births in Australia, America and Western Europe are fairly consistent:-

Australia - New South Wales - 1.35, Tasmania - 2.94, Brisbane - 1.50, (Tudehope and Cleghorn, 1984); .

America - approximately 2.0, affecting 8,000-10,000 infants each year (Brady and Gould, 1984);

Scotland - 2.7, (Arneil et al, 1985);

England and Wales - 1.94 in 1985, 2.28 in 1986, 2.24 in 1987 (OPCS, 1988).

2.C.3.b. THE TRENDS IN SUDDEN INFANT DEATH

In the Sudden Infant Death Syndrome Monitor DH3 85/4 (OPCS, 1985) it was stated that from 1969 to 1982 the mortality rates in England and Wales attributed to SID (as judged by mention anywhere on the death certificate of sudden or cot deaths) rose uninterruptedly from 0 in 1969, reaching a maximum figure in 1982 of 2.13 per 1,000 live births. It was suggested in four publications (OPCS 1980, 1982, 1984, 1988) that the SID rate has almost certainly risen since 1969, due at least partly to increasing interest and recognition of SIDS, but the rise in mortality rate for sudden infant deaths took place against a fall in mortality rates attributed to respiratory disease. The combined rate, however, for SIDs and respiratory disease remained virtually constant. This opinion of the OPCS is supported by Gordon (1986) and by Murphy and co-workers (1982) who completed a study in Cardiff from 1965-77 and stated "in the early years of the study non-specific diagnosis such as 'mild bronchitis' had been used, latterly the expression SIDS was used by all pathologists".

The upward trend in the SID rate per 1,000 live births in England and Wales was reversed in 1983 and 1984 to 2.09 and 1.95 respectively and it would appear SIDs were not being attributed to other causes, as all categories of neonatal deaths were reduced in this two year period (Figure 2.3.). There was little change in 1985 but the rates for 1986 and 1987 rose again to 2.28 and 2.24 per thousand live births respectively, which fluctuated in line with the cumulative postneonatal deaths by selected causes in England and Wales 1963-1987.

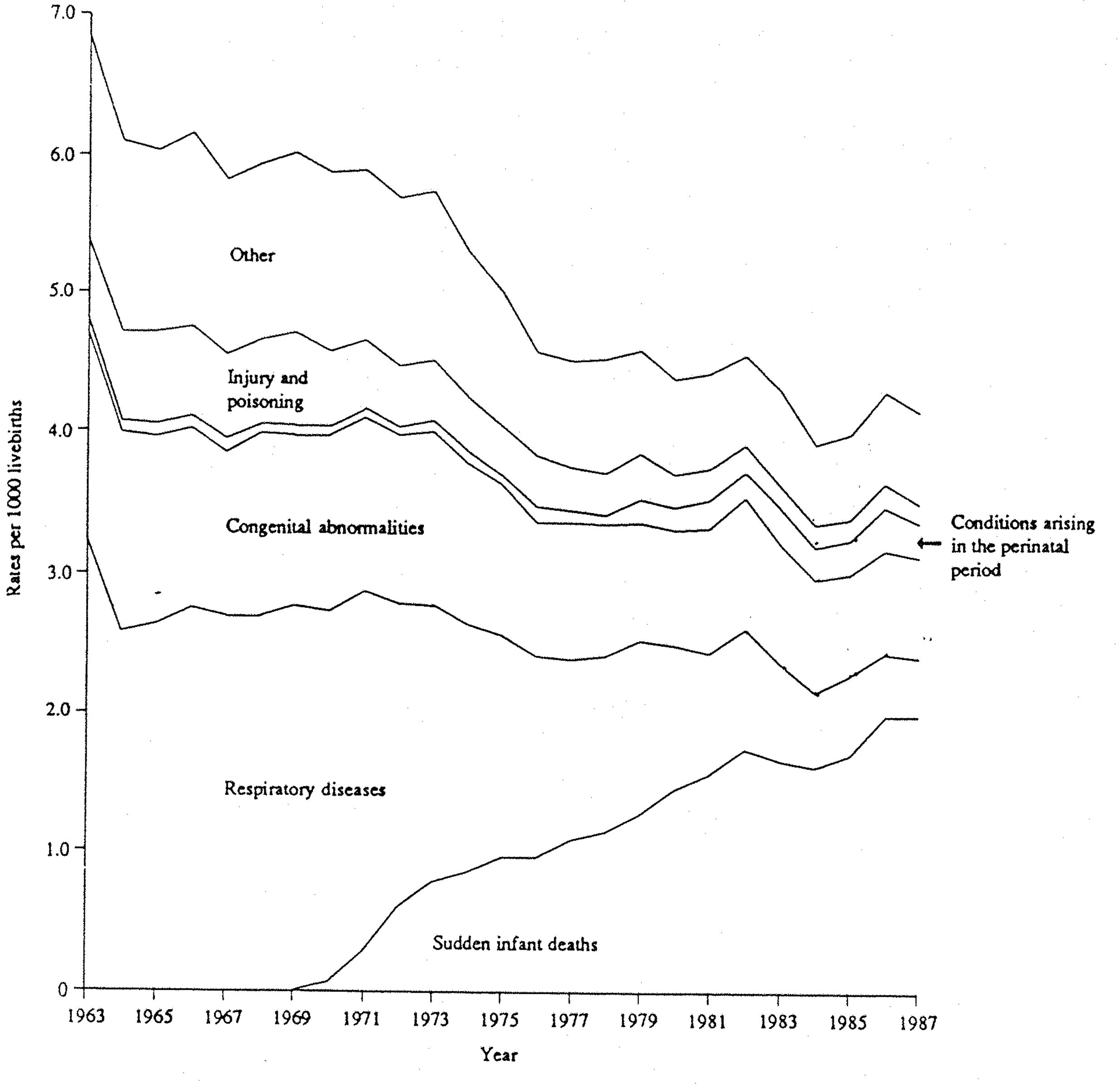
2.C.4. SUDDEN INFANT DEATHS - AGES

2.C.4.a. AGE RANGE

It is very difficult to compare studies of SID as different age ranges are often used. Some studies include all infants who die suddenly and unexpectedly from birth onwards (Spiers and Wang, 1976), whilst some do not include infants who died in their first week of life (Bain and Bartholomew, 1985), and others do not consider infants who die in their first month of life (Brady and Gould, 1984). Most studies only consider

Figure 2.3.

Postneonatal Mortality Rates in England and Wales 1963-1987 categorised into various Causes of Death.



Sudden infant death relates to only those deaths where the underlying cause of death was assigned as sudden infant death (ICD 795 and 798) and thus does not include those deaths where sudden infant death was mentioned on the death certificate but where another cause was assigned as underlying cause. Coding rules ensure that a more specific cause is selected in preference to a less specific one for example pneumonia rather than sudden infant death therefore sudden infant death is selected, with rare exceptions, when it is the only cause mentioned on the death certificate.

Graph compiled from OPCS data by A. Gardner (1988), London School of Hygiene and Tropical Medicine.

infant death as occurring up to one year of age (OPCS, 1985), but some studies include children up to the age of two years (Knowelden et al, 1984) and occasionally all sudden deaths up to five years of age are considered and recorded (Fedrick, 1973). The 'conventional' age group according to Froggatt and co-workers (1971) is 2-103 weeks, although generally infants are regarded as being up to one year old.

To overcome problems such as different age ranges, it has been suggested that core data regarding infants are collected in a comparable way (Macfarlane, 1984). If everyone accepted Infant Death as "deaths at ages under one year" (OPCS, 1985) it would at least encourage standardisation and allow comparisons.

2.C.4.b. DISTRIBUTION OF AGE AND POSSIBLE CAUSES OF DEATHS

The majority of SIDs occur between 4 to 20 weeks, and the peak incidence in England and Wales 1971-84, was 9 to 12 weeks or 2 months old (Table 2.2.).

The Multicentre Study of Post Neonatal Mortality investigated 988 infant deaths and found unexpected deaths occurred mainly at ages 4-19 weeks, whilst deaths due to recognised infections often occurred after the 19th week (Knowelden et al, 1984).

The Oxford Record Linkage Study (ORLS, 1966-75) noted that 53.5% of the SID males had died by 13 weeks compared with only 39.6% of the SID females (Golding et al, 1985).

A baby receives in utero protective immunoglobulin G from it's mother, the level of which begins to decrease after birth and is gradually replaced by endogenous immunoglobulin. The trough in protection is estimated at about eleven to twelve weeks, which is almost coterminous with the age peak of SIDs (Froggatt, 1970).

Table 2.2.

Tabulation of the Age when Infants Died, 1971-1984 in England and Wales where the term 'Sudden Unexpected Death in Infancy', or similar, was mentioned on the Death Certificate as the Primary or Underlying Cause.

Year of Deaths	All	Age at Death: Under 1 month	1-month	2-month	3-month	4-month	5-month	6 months up to 1 year
1971	489	39	91	127	91	46	40	55
1972	771	133	133	201	144	95	54	104
1973	922	56	186	235	165	119	49	112
1974	932	54	195	225	187	89	61	121
1975	912	48	186	233	173	102	68	102
1976	879	59	168	204	182	97	58	111
1977	911	69	154	201	153	128	58	148
1978	971	60	178	245	156	118	87	127
1979	1079	55	206	226	190	145	92	165
1980	1222	92	225	253	215	135	100	202
1981	1265	86	256	260	227	150	99	187
1982	1332	65	228	303	260	163	88	225
1983	1315	73	251	274	241	175	100	201
1984	1242	77	237	268	204	157	95	204
1971-1984	**14242**	**873**	**2694**	**3255**	**2588**	**1719**	**1049**	**2064**
% of Total SIDS		**6.1%**	**18.9%**	**22.9%**	**18.2%**	**12.1%**	**7.3%**	**14.5%**

Source - OPCS Monitors DH3, 1980 - 80/3; 1982 - 82/1; 1984 - 84/1; 1985 - 85/4.

A variety of physiological changes are taking place in all infants about this time. Morley during a lecture in Cambridge in 1985 suggested that males are particularly vulnerable at this stage in their lives due to the possible influence of the surge of testosterone. Gunther (1975) had previously suggested that the effect of the testosterone was to lessen the size of the thymus (Castro, 1974) thereby decreasing the male infant's immune defence systems.

A study in Illinois (Goldberg et al, 1986) reached the conclusion that the age pattern of SIDs observed throughout the world, with its peak at 2-4 months, suggested SID is associated with growth and development. The authors unfortunately could only guess at the causes, which showed no advancement on the opinions of Froggatt, Lynas and Marshall (1971) as stated in their study in Northern Ireland "The characteristic age range is an important factor and there seems little doubt these infants die during a period of increased physiological vulnerability because some critical combination of intrinsic and extrinsic factors proves lethal".

2.C.5. THE SEX OF SUDDEN INFANT DEATHS

A review of the world literature by Valdes-Dapena in 1967 stated that 25 out of 29 series which included data on SID, indicated a preponderance of males of between 55% to 83% of deaths, and in the remaining four studies the proportions of males were 46%, 49%, 49%, and 50% (Valdes-Dapena, 1967).

Shannon and Kelly (1982) commented that seven studies throughout the world agreed that boys have a greater risk of SID, but the increased proportion of boys is associated with infection when this is looked for. Carpenter and Gardner (1982) in their study into all sudden respiratory infant deaths in England and Wales from 1965 to 1976 found that the male/female sex ratio started high at 1.57 at birth, fell suddenly to 1.21 at 2 weeks, built up to 1.54 at age two-three months and finally declined to reach 1.22 by 10-12 months. This corresponds with the sharper peaking of age for male deaths than female deaths at 3 months, which relates to the rise in testosterone and reduction in immunity in males at approximately three months of age described in the previous section.

A Scottish study investigating 283 SIDs aged one week to 2 years found there the proportion of males was 63% slightly above the average for England and Wales (Bain and Bartholomew, 1985).

Figures are regularly published for SIDs in England and Wales (OPCS, 1980, 1982, 1984, 1985) and the collation of deaths over a thirteen year period from 1971-84 showed an excess of male deaths at 60% (Table 2.3.).

Although a majority of countries experience a male preponderance of sudden infant deaths, in China the reverse is experienced. Emery (1985) suggests this anomaly is possibly influenced by the limited number of children allowed per family and the desire of the family to have a male child to continue their lineage and to work their farms.

2.C.6. <u>SEASONAL VARIATION OF SUDDEN INFANT DEATHS</u>

2.C.6.a. <u>WINTER PEAK - INFECTIONS</u>

In many studies SIDs have been found to occur in the winter more than in the Summer (Froggatt et al, 1971; Knowelden et al, 1984; Tonkin, 1986). Valdes-Dapena (1967) reported on 23 studies throughout the world from Australia to Denmark and all studies revealed a distinctly higher incidence, as great as twice the number of cases, during the colder

Table 2.3.

Tabulation of the Numbers, Sex and Rate per 1000 Live Births of Infants who died in England and Wales 1971-1984, where the Term 'Sudden Unexpected Death in Infancy', or similar, was mentioned on the Death Certificate as the Primary or Underlying Cause.

	MALE		FEMALE		PERSONS	
	Number	Rate	Number	Rate	Number	Rate
1971	297	0.74	192	0.51	489	0.62
1972	482	1.29	289	0.82	771	1.06
1973	527	1.51	395	1.21	922	1.36
1974	564	1.81	360	1.16	932	1.46
1975	564	1.81	348	1.19	912	1.51
1976	517	1.72	362	1.27	879	1.50
1977	535	1.83	376	1.36	911	1.60
1978	600	1.95	371	1.28	971	1.63
1979	637	1.94	442	1.43	1079	1.69
1980	740	2.20	482	1.50	1222	1.86
1981	755	2.32	510	1.65	1265	1.99
1982	822	2.56	510	1.67	1332	2.13
1983	827	2.56	488	1.60	1315	2.09
1984	716	2.20	526	1.69	1242	1.95
1971-1984	8591		5651		14242	
Percentage of Total SIDS	60%		40%		100%	

Source - OPCS Monitors DH3, 1980 - 80/3; 1982 - 82/1; 1984 - 84/1 months of the year.

Respiratory viruses are more prevalent in the winter or colder months and are probably responsible for a substantial proportion of SIDs (Ferris et al, 1973). In Melbourne, Australia, an association was shown between the peak seasonal incidence of SID and respiratory syncytial virus infections in infants (Williams et al, 1984). 763 cases of SID were studied and viruses were present in the respiratory tract of 200 (26%) of the dead infants. The study showed a detection of infection in 14% of the 385 babies aged 3 months or younger, but in 39% of the 378 babies over 3 months. In a statistical study comparing findings in Melbourne and Brisbane of the peak incidence of SID and peak isolation of respiratory syncytial virus, both peaks occurred six weeks earlier in Brisbane, suggesting infection may be a precipitating factor.

Fedrick (1973) investigated seasonal differences in Oxfordshire and found over a five year period that 130 SIDs (63%) occurred from November-April, compared to 76 (37%) in May-October. She also found that male infants over the age of 12 weeks predominated in Winter deaths, she suggested that the findings related to acute infection.

Macfarlane (1982) considered the seasonal aspects of post neonatal mortality from 1965-73 in England and countries in the Northern Hemisphere from data in the WHO Demographic Year-book. She suggested the excessive deaths are not associated with seasonal variation, but with infection, for example numbers are inflated when there is a flu epidemic. This conclusion is rather confusing as often epidemics, particularly respiratory ones, are seasonal.

2.C.6.b. <u>WINTER PEAK - WEATHER</u>

Early work by Steele and co-workers (1967) failed to establish an association between specific weather patterns and the occurrence of SIDS.

Fedrick (1973) correlated the monthly rate of SIDs with monthly measurements of mean maximum temperature during the day and night, mean rainfall, mean wind, mean daily hours of sunshine, days with snow, pressure at 2 a.m. and relative humidity. Findings revealed little of interest apart from an association with lack of sunshine and the lowest night temperatures from November-March, which was hardly unexpected information regarding the Winter period in the Northern Hemisphere.

A study by Greenberg and co-workers (1973), investigated 942 SIDs in Chicago over a four year period from 1966-1969, and planned the study to consider environmental factors relating to SIDS. They investigated meteorologic data produced by the United States Weather Bureau for each day of the study period. The variables looked at were: maximum, minimum and average temperature; rainfall, snow and sleet; wind direction and wind speed; and maximum and minimum relative humidity. They were unable to confirm that sudden decreases in temperature, increase in wind speed or any other meteorological variable were significantly associated with SIDs.

A study on 6,226 deaths ascribed to SIDs by OPCS has shown that there appears to be a significant number of deaths between four and six days after particularly cold night temperatures irrespective of age at death (Murphy and Campbell, 1987) and a similar pattern was noted in Australia (Campbell, 1989). There appeared to be no apparent increase in the general level of viral disease when the 'epidemics' of SIDS occurred, which does not support the hypothesis that epidemic viral infection is associated with marked seasonal fluctuations of SIDS. The final comment in the article by Murphy and Campbell (1987) was to remind parents to avoid whenever possible both chilling and/or paradoxically overheating their infants.

2.C.6.c. WINTER PEAK - POLLUTION

Hoppenbrouwers and co-workers (1981) carried out a highly sophisticated study, which investigated the occurrence of SIDs and pollution in Los Angeles County. The mean daily levels of temperature, carbon monoxide, sulphur dioxide, nitrogen dioxide and hydrocarbons were all measured over a 3 year period, 1974-77. They found the effects of temperature and pollution were confounded about 6-7 weeks before the peak incidence of SIDs and concluded that pollution levels may be a predisposing factor for risk of SIDs.

The World Health Organisation (1986), however, using U.K. data found no evidence of direct or indirect relationship between sudden respiratory death and pollution. High SIDs rates were found along the south coast of England where pollution was minimal and low SID rates in London and Sheffield where pollution was high, which suggests an inverse relationship between SID and pollution.

2.C.7. DAY OF THE WEEK WHEN SUDDEN INFANT DEATHS OCCUR

It was noted in a study in South East Scotland that 47% of SIDs occurred on Friday, Saturday or Sunday (Bain and Bartholomew, 1985) and in Newcastle 16 (55%) of 29 SIDs occurred on Saturday, Sunday and on Bank Holidays (Downham et al, 1977). Macfarlane and Gardner (1982) who completed a very large study from OPCS data on 59026 neonatal deaths from all causes April 1969 - November 1979 found that unexpected deaths were more common on Sunday and Saturday than on weekdays and suggested that medical care may be less adequate or available at the weekends. An assumption is that some parents are more reluctant to seek, or find it difficult to obtain, medical assistance at weekends or during Bank Holidays (Golding et al, 1985).

A large study by Murphy and co-workers (1986) investigated the day and age at death of 6,226 infants. The data was supplied by the OPCS and the infants had the phrase Sudden Infant Death or equivalent written on the death certificate. Deaths of infants under three months of age showed no association with day of the week but for all deaths up to one year there was an excess at weekends, as deaths increased steadily from Monday to Sunday, due largely to the deaths of infants from 3 months to one year. The suggestion of the authors was the changed parental behaviour as their infants got older, they hesitate and are perhaps diffident about calling out a doctor at weekends for what sometimes appears to be a minor illness.

Fedrick (1973) found that Thursday had a peak incidence of SIDs, as 37 (18%) of the 206 total in the Oxford study died on that day, but the author did not give an opinion as to why Thursday should be different and the numbers in this study were small.

The two large studies cited in this chapter which are capable of detecting small variations in incidence in the course of the week both show a slight excess of mortality at weekends, however, many other studies of different sizes have failed to demonstrate any consistent association between a particular day of the week when infants were dying suddenly and unexpectedly (Valdes-Dapena, 1967; Froggatt et al, 1971; Golding et al, 1985; Knowelden et al, 1984), so for practical prediction it is equally likely for SIDs to occur on any day of the week.

2.C.8. THE TIME OF DAY WHEN SUDDEN INFANT DEATHS OCCUR

The typical pattern of a 'cot death' was considered to be one of an apparently well infant being placed into a cot in the evening, being found dead by parents the next morning and to have died during 'the night'. The exact time however when SIDs occur is frequently unknown, as the deaths are unexpected and the infants are usually alone.

An early study by Steele and co-workers (1967) in Ontario revealed 51.6% of infants were found dead or moribund between 0600-1200, and almost two decades later the pattern had not changed as a study on 308 SIDs in Southern England revealed that half of the deaths were discovered between 0600-1200 (Watson et al, 1981). Data analysed by Limerick on 655 infants also showed the same time pattern of the discovery of dead infants (Golding et al, 1985).

The longest period of inactivity for many infants aged 2-4 months old, when most SIDs occur, is the twelve hours from 1800-0600, although younger infants would not have such a long undisturbed period as most of them would require feeding at least once during that period of time. Most parents start their day after 0600, therefore it would appear to be logical that a majority of the SIDs are found between 0600- 1200 although they may have been dead, but undiscovered, for several hours.

As far as is known to the author no studies have been undertaken to look at the factors associated with the apparent excess of deaths occurring before 0600, for example: when was the infant last seen, any differences in family circumstances, what was the room temperature, feeding pattern, etc?

2.C.9. THE PLACES AND POSITIONS OF SUDDEN INFANT DEATHS

2.C.9.a. PLACES WHERE SUDDEN INFANT DEATHS OCCUR

The majority of SIDs occur in cots - hence the accepted term 'cot death' in the United Kingdom, and 'crib death' in America and Canada - and they are usually associated with death at home, but infants have also died unexpectedly in their cots in hospitals and in nurseries in maternity units.

SIDS have also occurred:-

in PRAMS - indoors at home; whilst visiting friends and relations; whilst shopping; in the park; returning home from the child health clinic; in church; or in the garden.

in CARS - whilst travelling or left alone whilst carers are carrying out other activities.

in BEDS - with their parents.

in the ARMS - of parents, doctors, and nurses.

in AMBULANCES - which have been summoned when babies have been found almost dead.

in ACCIDENT AND EMERGENCY DEPARTMENTS - when they have arrived too late to be resuscitated.

SIDS have in fact occurred wherever a baby might be expected to be found and occasionally where they would not be expected to be, for example, wedged between a mattress (Tyrrell, 1982) or on the floor by their cot. These deaths would be registered in some Districts as 'SID' and in others as 'Accidental Death' creating once again the problems of comparisons.

There appears to be no special 'at risk' place for babies to die, except in a bed with adults, as it has been shown in some circumstances that infants have died through being overlain.

2.C.9.b. <u>THE POSITION OF SUDDEN INFANT DEATHS</u>

There has been speculation for over three decades about the safest position in which to place infants to sleep.

Emery (1959) found no convincing increase in children lying face down as distinct from face up when found dead in their cots as compared with the proportion of children who normally sleep prone or supine.

Carpenter and Shaddick (1965) investigated the circumstances in which 110 cases of 'cot death' normally slept and the position in which they died compared with 191 controls. Significantly more cases than controls were found face downwards, but they found pillows were more often used for cases than controls, and also that the pillows and mattresses used for the cases were softer.

Emery and Thornton (1968) completed a complex study on the effects of obstruction to respiration in infants with particular reference to mattresses, pillows and their coverings, and were forced to conclude that external obstruction to respiration could be a contributory factor in some cases.

Camps (1972) suggested: 'If infants are placed on their back, if they vomit and regurgitate they may suffocate; however, they could suffocate on the bedding if placed face down'.

Debate was stimulated in the correspondence columns of the Lancet regarding the safest sleeping position in which to place infants after an article by Lee and co-workers (1988), and also in the British Medical Journal after an Editorial (Milner and Ruggins, 1989) and two articles on the same topic (Lee et al, 1989; Jonge et al, 1989).

Lee and co-workers (1989) reported the very low incidence of SIDs

(0.3 per 1000 live births) in Hong Kong. They suggested that a tradition of using a supine sleeping position for infants to avoid suffocation might, at a time when the mechanism of control of breathing is changing, influence respiratory patterns, and reduce vulnerability to SID from apnoea. They did however comment that infants were always in a stimulating living environment. Davies (1985) and Emery (1988) had already commented on the fact that infants in Hong Kong are hardly ever left alone, and observed if they are placed on their backs they can be more easily observed.

Jonge and co-workers (1989) suggested the increased SID rate in Holland from 0.46 per 1000 live births in 1969-71 to 1.31 since 1978, was perhaps due to the medical and popular press advice since 1971 of advocating a prone sleeping position for infants rather then the traditional lateral or supine position. A retrospective investigations of the usual sleeping position of 142 SIDs who died in 1980 and 1981, and of 254 matched and 320 unmatched controls who were asked the sleeping position of their child at 2-4 and 5-7 months was completed. 88% of the SIDs were found prone compared with 60% of the controls. They concluded a lateral or supine sleeping position for infants was advisable unless medical conditions dictate otherwise, although the methodology of the study and the foundation for this advice did not appear to be very strong.

Subsequent letters in the medical journals held diverse opinions regarding the sleeping position in which infants should be placed :

- Jones (1989) supported the prone position mainly for orthopaedic reasons, although the value of this was challenged by Conner (1989);
- Nicholl and Cathain (1988) had completed secondary analysis of

data from the National study on post neonatal mortality (Knowelden et al, 1984) which showed 42% of the 265 SIDs normally slept in the prone position compared to only 25% of the 273 controls. Nicholl (1989) also stated the association between prone sleeping and cot death is indisputable, but questioned whether there is a cause for infants to be placed prone, predisposing SIDs rather than the position itself. He cited as an example experiences with his own infant who on three occasions when he had a chest infection would only settle comfortably when he was placed prone;

- Harrison (1989) suggested whether infants were placed prone or supine they should not be left for too long;
- Barrie (1989) stated it would be preferable to place infants in the lateral position with the head of the cots raised by 15-20% to allow the larynx to be higher than the stomach and reduce gastro-oespohageal reflux;
- Semple (1989) suggested raising the foot of the cot 2-3 inches to encourage venous return to the heart;
- Beal (1988) stated that as far as she was aware no study on SIDs and controls has found prone sleeping to be more common in control infants than SIDs cases, nor supine sleeping to be less common in controls than in SIDs.

Theories abound but agreed conclusions are not yet available.

2.D. PROBABLY INEVITABLE AND POSSIBLY PREVENTABLE POSTPERINATAL DEATHS (PPPD)

Postperinatal deaths have been classified in several studies as 'Inevitable' or 'Probably Inevitable' and 'Preventable' or 'Possibly

Preventable' (Carpenter and Emery 1974; Taylor and Emery 1982; Knowelden et al, 1984; Sunderland et al, 1986).

2.D.1. INEVITABLE OR PROBABLY INEVITABLE DEATHS

The category of inevitable deaths includes infants with:- **congenital abnormalities**, for example severe heart lesions or neural tube defects; **complications of gross prematurity** when often infants never leave hospital; **malignant neoplasms**; and **degenerative conditions** (Carpenter and Emery, 1974 and 1983; Knowelden et al, 1984). These comprised 46% of total post perinatal mortality in England and Wales in 1981 (Gardner, 1987).

Some inevitable deaths may be prevented by prenatal services, for example, scanning and amniocentesis detect gross abnormalities, which are increasingly terminated.

2.D.2. PREVENTABLE OR POSSIBLY PREVENTABLE DEATHS

Preventable or possibly preventable deaths were defined by Carpenter and Emery because of the findings in the retrospective study in which they had been involved (Protestos et al, 1973) and the subsequent prospective study (Carpenter and Emery 1974). Unexpected explained and unexplained deaths were defined as 'possibly preventable' as the identifying characteristics of both were found to differ very little.

The total postperinatal mortality in England and Wales in 1981 showed 64% were possibly preventable deaths (Gardner, 1987). These deaths were attributed to:

- **unexpected deaths**, including SIDs (64%),
- **infections** (32%),
- **accidental and non accidental injury** (4%)

Similar percentages were found in the Multicentre Study Report (Knowelden et al, 1984). The study was explicitly evaluated by Lady Limerick in the Foundation for the Study of Infant Deaths, March 1985 Newsletter, and the percentages of possibly preventable deaths were clearly shown in the pie-charts.

The classification of deaths between SIDs and infection is arbitrary, as shown in Section 2.C.2 of this study, and all of these deaths have been classified as preventable by various groups (Carpenter and Emery, 1974, Carpenter et al, 1983 and Knowelden et al, 1984).

Emery stated at the 3rd International Symposium on SID "some mothers are insensitive to illness in their child, particularly if the illness is not associated with dramatic symptoms, and lack of critical observation by the parent may account for some cot deaths in which all abnormal symptoms have been actively denied" (Emery and Carpenter, 1974).

Cot deaths studied in North London revealed that a majority of the babies had a clinical history of illness, and in many cases the quality of health care could have been improved by parents and by the medical attendant (Cameron and Watson, 1975).

Lack of awareness of illness and inappropriate care was also found in the Multicentre Study of Post Neonatal Mortality (Knowelden et al, 1984). In 71 (24%) infants out of 297 who died at home from terminal illness, the families were thought to have acted inappropriately, as they appeared unaware of the severity of the child's illness. Terminal illness in this report was defined as - 'clinically apparent illness in apparently normally-formed children in the days immediately prior to and leading to death, comprising of infections of the upper respiratory tract, the lower respiratory tract, gastrointestinal tract and central nervous system'. One of the recommendations of the study was for the education of parents in child care, so that they would be aware when their babies were unwell, and to know when to summon professional help. The study also recommended improvements in the training of general practitioners in the management of sick children as it had been found out of a total of 131 infants in contact with their general practitioners during a terminal illness, 84 infants (64%) were deemed to have been subjected to inappropriate action by them. Of these:

9% - slow response to urgent call

7% - poor communication with parents

17% - failure to follow up

25% - inappropriate treatment

11% - prescribed without seeing infant

20% - failure to admit to hospital

The percentages do not total to 64% as there was more than one entry for some infants.

General practitioners should have already been aware of their preventive role as a report had been produced by the Royal College of General Practitioners, 'Healthier Children, Thinking Prevention' (Donovan and Pereira Gray, 1982) which stated "The main factors affecting the health and deaths of children are to be found in the child's environment. The opportunities for prevention are many and depend on the provision of local, accessible and technically competent primary health care teams".

The factors which determine whether a child with a potentially treatable illness receives successful health care are complex (Wright et al, 1985) and these factors are not immediately susceptible to purely economic intervention nor necessarily to an unselective increase in primary health care (Taylor and Emery, 1983).

The Multicentre study (Knowelden et al, 1984) also identified that, of the 69 deaths in hospital 18 (26%) had been either inappropriately treated or there had been delay in starting treatment. All of these 18 infants had infections:

8 of the central nervous system;

3 of the gastrointestinal system;

5 of the lower respiratory tract;

2 had non specific infections.

Table 62 in the DHSS Multicentre report (Knowelden et al, 1984) indicates that only a comparatively small fraction (5%) of the 519 unexpected deaths show no clinical or pathological evidence of terminal illness.

Subsequent subsections 2.D.3 - 2.D.7. discuss aspects of infant care which might reduce the numbers of PPPDs.

2.D.3. MONITORING INFANTS WEIGHT GAIN OR LOSS

2.D.3.a WEIGHING INFANTS

Personal observations in the early and mid seventies indicated it had become unfashionable to weigh babies and the regular use of scales in some child health clinics was not considered necessary. Student health visitors at Southampton University in the 1970's were informed by some lecturers that the most valuable aspect of parents attending clinics was the social contact they had there with other parents. Many health visitors were encouraged by doctors and their managers to let mothers weigh their infants themselves at the child health clinics if they wanted to, but it even became policy in some practices, for example in Oxfordshire, not to weigh healthy infants (Ounsted et al, 1982).

Infants and children who were brought to child health clinics were usually weighed with their clothes on, as conditions were often unsuitable to weigh infants naked and it was not considered to be important. To weigh infants wearing their clothes then to deduct a 'guessed weight' for the clothing makes a nonsense of the procedure of weighing, as was shown in The Purple Line (Television South Documentary 1984).

A study in Scotland by two health visitors also indicated how pointless it was to delegate the task of weighing infants with their clothes on. They weighed 30 infants naked at home every Tuesday morning and then plotted the infants' weights on their individual weights percentile charts. The plotted weights all stayed within the expected channels on their Sheffield type weight percentile charts (Carpenter and Gardner, 1989). The same babies were also weighed dressed at the child health clinic each Tuesday afternoon, and the weights were marked on the same charts in a different colour. The dressed weights were found to fluctuate by as much as three channels either up or down (Weston, 1985). The differences in the clinic weights could have been due to either extreme changes in the baby's clothing each week, unreliable clinic scales, or incompetent people weighing the babies. These results emphasised that weighing infants is a skill which needs to be carried out by competent persons, on reliable equipment and the infants need to be naked to obtain reliable results.

More recently it has been suggested by some doctors and shown by health visitors that naked weight gain is a fairly accurate indicator of infant well-being and it is important for infants to be regularly weighed naked (Davies and Williams, 1983; Powell, 1985). Low birthweight infants, who are at risk on several counts, should be weighed frequently especially in their first six months of life, and if they are non-clinic attenders this service should be offered at home (Davies, 1984; Watkins et al, 1984). Health visitors were seldom provided with portable baby scales as part of their necessary equipment in the early 1980s, so the recommendation to weigh babies at home was not always easily carried out (Personal communication with nurse managers and health visitors, 1984-86). This situation appears to have been rectified by the late 1980s in many Health Districts (Personal communication with nurse managers and health visitors, 1985-1988).

2.D.3.b. MONITORING WEIGHTS ON PERCENTILE CHARTS

The weight of all babies should be monitored closely as the rate of weight gain is the most sensitive growth indicator of disturbed development (Kristiansson, 1980; Spencer, 1985).

The cause of failure to thrive may be organic or non-organic, and all infants who fail to thrive should be referred for investigation (Barnes, 1986).

Non-organic failure to thrive can be a very complex problem, requiring extensive exploration (Kershaw, 1986). Non-organic growth retardation can indicate that:

- the mother is failing in some aspect of her care giving functions (Haynes et al, 1983);
- there is family or marital disorganisation (Gagan et al, 1984);
- there are social problems and possible child abuse (Stanton and Oakley, 1983);
- there may simply be inadequacy of nutrition caused by both a

failure of the provision of food and/or by inadequate intake (Skuse, 1985).

Percentile charts allow growth to be supervised, but in some health districts considerable problems are experienced, as all infants do not have their own charts, and some professional staff are unable or unwilling to record infants' weights accurately even if a chart is available (Blom-Cooper et al, 1985).

It has been noted that SIDs exhibit growth impairment (Froggatt et al, 1971; Peterson et al, 1974;). Further work by Peterson (1981) on 155 SIDs and 270 controls confirmed that postnatally the cases were significantly lighter for their length than were the live controls. The autopsy weights of the cases showed mean differences of 500-1000 grams lighter than the live controls, which he suggested was unlikely to have been produced purely by the agonal bowel and bladder evacuation and post-mortem dehydration, indicating perhaps these infants had been ill for at least some hours. It is probable that some of these weight losses would have been apparent if percentile charts had been routinely kept and intervention may have been possible, with the result of fewer deaths.

2.D.4. OVERHEATING OF INFANTS

New born babies lose heat rapidly, but babies more than one month old are better at generating and conserving heat than they are at losing it. Babies may be particularly susceptible to overheating because they have a high metabolic rate and labile temperatures. Therefore the dangers of becoming too cold are much less than those of overheating (Downham and Stanton, 1981; Murphy and Campbell, 1987).

Some parents normally tend to overdress their babies, to swaddle them too much and to keep the room temperatures too high, but they do all of these to an even greater extent when the babies are unwell (Stanton et al, 1980). These conditions could lead to hyperpyrexia and heatstroke, causing profound disturbances such as convulsions or coma, or death (Shibolet et al, 1967).

It is strongly suggested therefore that overheating may be a cause of some SIDs (Bacon et al, 1979; Bacon, 1983; Bacon, 1986; Stanton, 1984; Nelson et al, 1989; Fleming et al, 1990).

2.D.5. RESPIRATION MONITORS/APNOEA ALARMS (MONITORS)

A considerable number of articles have been written regarding the advantages and disadvantages of providing monitors to infants at risk of SID.

The main purposes of providing a monitor would appear to be:

- to inform parents that their infant is breathing;
- to alarm parents when their infant has stopped breathing;
- to give parents the opportunity to resuscitate their infant.

2.D.5.a. SELECTION OF INFANTS TO BE MONITORED

It has been suggested that infants most at risk of SID are:

- a surviving twin (Brown, 1984);
- infants who have experienced a significant apnoea attack, often termed 'Near Miss for SIDs' (Duffty and Bryan, 1982);
- extremely premature infants who experience prolonged neonatal apnoea (Tudehope and Cleghorn, 1984);
- siblings of SIDs, (Peterson et al, 1980) and although Peterson and co-workers (1986) have amended their previous opinion other

authors have found SIDs occurring more than once in some families (Diamond, 1986; Emery, 1986).

2.D.5.b. MONITORS NOW AVAILABLE

Ideally when an infant is monitored, according to Southall (1983) and to Rahilly and Symonds (1984): breathing movement detectors should not be used without an accompanying heart rate alarm; the home monitors should record data on the heart rate and breathing activity before and during every alarm; the alarm signal should be recorded. Accumulated data could then possibly lead to the identification of mechanisms behind SID. These recommendations are commendable, but unfortunately complex monitoring equipment is very costly as are assessment facilities which would have to be provided to analyse all the data which would be generated as these are currently available only in a few specialist centres.

The apnoea monitors currently available in the United Kingdom for home monitoring detect cessation of chest or abdominal movement, or both, but are not designed to detect obstructive apnoea. Milner (1985) described in detail the four types of monitors available in 1985 (Appendix 20.A.), but several additional models by Densa Limited have since been introduced.

2.D.5.c. ADVANTAGES AND DISADVANTAGES OF USING MONITORS

Many paediatricians agree that monitors are useful and some even extol the virtue of their use (Simpson, 1984; Edmunds, 1986; Swift, 1987; Tonkin and Hutton, 1988) whilst others are sceptical or even condemn the use of monitors currently available for home use (Stanton, 1982; Southall, 1983). Professor J. L. Emery and Professor C. G. Arneil, presented opposing opinions as to the value of respiration monitors during an open discussion at a Community Paediatric Course in Sheffield in October 1985.

Some early American studies found that using monitors with their baby were detrimental to parents in the emotional, personal and social aspects of their lives (Nelson, 1978; Black, 1978). Many of the problems experienced with monitors in the seventies, for example, lack of portability, the need of an electricity supply and considerable cost, have been partly alleviated as monitors are now small, portable and relatively cheap to buy and run. The main problems encountered when using monitors are false alarms, monitor malfunction, and skin irritation from electrodes (Spitzer and Fox, 1984). Stress is also mentioned frequently in various studies but 75% of the parents in a study by Kelly and Shannon (1982) stated home monitoring had relieved their anxiety. It has been stated parents who have had a previous infant death would be under considerable stress whether their next infant was on a monitor or not on one (Simpson, 1984).

Studies have shown that objective benefits of using monitors to infants remain unproven (Mackay et al, 1984; Davidson Ward et al, 1986) and indisputable evidence is not yet available that the use of monitors is a preventive measure to be used against SID. Some parents in recent Scottish studies however are adamant that their infants' lives have been saved by the use of monitors, and it has been claimed that the mental health and well being of these families have been maintained by their use (Edmunds, 1986; Marshall, 1986). Other studies have claimed that some parents easily adapted to using monitors as they were able to sleep better, their lives were not inhibited and they were able to feel more comfortable with their infant (Cain et al, 1980; Hammond, 1983). It has been suggested that monitors have a place in highly selected situations, if only to give reassurance to parents (Simpson, 1983; Milner, 1985; Dunn and Mathews, 1987) although Swift (1989) stated 'Lack of scientific proof should never deny anxious parents an alarm for their sake as much as their child's.

Shannon and Kelly (1982) stated, after a very complex study on apnoea and respiratory control in Boston "If the use of devices is controlled and recommended by trained medical personnel who offer a 24 hour a day support programme, the parents' level of stress is tolerable, the outcome is usually excellent, and the costs are acceptable". This would appear to justify the use of monitors.

A study by Emery and co-workers (1985) compared the support of monitors with that of weighing scales for siblings after a SID. The monitors or scales were randomly allocated to the two groups of 50 parents and general support measures were given to both groups. It was found that parents readily accepted a monitor and it gave confidence, but it was suggested they became over-reliant on it as only 40% were willing to give up the monitor at six months. This is understandable as parents are aware that infants die over the age of six months and they do not want to find a second infant dead. The study showed by comparison that weighing their infants daily did not give immediate satisfaction to parents, but scales were found to be supportive over a six month period and 74% were happy to stop using them. One infant in the study unfortunately died at 32 weeks, after the monitor had been withdrawn at 29 weeks, but when weighed at post-mortem the infant's weight was equal to his weight at thirteen weeks. It was discovered although the infant had been taken to the child health clinic and weighed regularly, the weights had never been plotted on a percentile chart and no-one had been alerted to any possible problems. This incident would suggest that infants who have a monitor also need to have their weight regularly checked and plotted on a percentile chart.

2.D.6. MATERNAL AND PASSIVE SMOKING

For many years it has been recognised that maternal smoking has an undesirable effect on the foetus. Butler and Alberman (1969) demonstrated that a mother smoking 10 or more cigarettes per day during pregnancy increased the foetal plus neonatal mortality rate by 28%. The subsequent health and development of the child are affected as shown by Fogelman (1980) in the National Child Development Study when 16 year old children whose mothers smoked more than 10 cigarettes per day after the fourth month of pregnancy showed a lower average reading and mathematics test score, the boys were shorter but the girls were not, and more of them had suffered from asthma or wheezy bronchitis, than children of mothers who had not smoked.

The detrimental effects of cigarette smoke are known to extend beyond the smoker, as other individuals present inhale smoke and are passively smoking. Infants of parents who smoke seem to be particularly vulnerable in their respiratory tract, as they are more susceptible to wheezy bronchitis, which was evident in studies ranging geographically as far apart as France (Liard et al, 1982), in England (Morgan, 1985; Southall and Samuels, 1989) and Shanghai (Yue Chen et al, 1986). The infants are also affected in their digestive system as they appear to be more prone to infantile colic (Said et al, 1984). They are also more retarded in their growth (Peterson, 1981).

Exposure to cigarette smoke also appears to enhance the risk of SID

(Steele and Langworth, 1966; Bergman and Wiesner, 1976; Naeye et al, 1976; Brady and Gould, 1984; Spitzer and Fox, 1984; Knowelden et al, 1984). Peterson (1981) stated "The hypothesis that emerges is that maternal smoking may also affect other developing and maturing physiologic processes such as neuroregulation of breathing, which could result in apnoeic spells and observable tissue changes indicative of antemortem hypoxia in SID victims".

Very extensive and detailed studies would be needed to determine the separate effects of maternal smoking in pregnancy and of postnatal passive smoking.

2.D.7. NON ACCIDENTAL INJURY

'Should Child Abuse and Neglect be considered when a Child Dies Unexpectedly?' is the provocative title of an article by Christoffel and others (1985) and it is suggested by Emery and colleagues (1988) that 'The possibility of infanticide must be considered in all unexpected child deaths'. Perrot and Nawojczyk (1988) even suggest the Beckwith definition of Sudden Infant Death Syndrome (1970) should have an extra phrase 'and a thorough investigation of the circumstances fails to demonstrate suspicion of a nonnatural manner of death',

The estimation of deliberate or accidental killings vary considerably:

- Dr. Donald Wayte, pathologist, asserted that "most of Britain's 1,500 a year cot deaths were caused by unintentional smothering" (Dineen et al, 1984);
- filicide is the probable mechanism in death of 10% of unexplained, unexpected deaths (Taylor and Emery, 1982);
- there is an association between child abuse and about 10% of

children diagnosed as 'SIDS' (Newlands and Emery, 1989);

- between 2-10% of infants labelled as dying from SIDS have probably been smothered by their mother (Meadows, 1989);
- total infanticides were probably 24, less than 2.5% of the postperinatal deaths considered in the Multicentre Study on Post Neonatal Mortality (Knowelden et al, 1984) but these accounted for 7% of the unexpected deaths.

2.D.7.a. GENTLE BATTERING

Suggestions have been made that some SIDs are due to smothering or 'gentle battering', although Southall and colleagues (1987) reject this latter phrase as video and physiological recordings on two infants showed they struggled violently until they lost consciousness.

2.D.7.b. PREDICTION AND POSSIBLE PREVENTION OF DEATH FROM CHILD ABUSE

Child abuse is a most distressing condition and prevention is clearly important. Attempts have been made to predict children at risk of abuse, as it might form a basis of intervention programmes aimed at reducing abuse and some infant mortality. Various researchers have found different predictive factors, but all have pointed out the value of early recognition of indicators, prompt notification of concern to all health care personnel and action by the appropriate people (Beswick et al, 1976; Hyman, 1978; Schmitt, 1980; Murphy et al, 1981; Diamond and Jaudes, 1983).

A letter was circulated by the Department of Health and Social Security, written by the Chief Nursing Officer to all Senior Nursing Officers, encouraging health visitors and midwives to become aware of problems of child abuse and of predictive studies (Friend, 1978).

Midwives are the professionals who are ideally suited in the first two weeks of a infant's life to notice signs of bonding failure, which may indicate risk of abuse (Lynch and Roberts, 1977). The study stressed that early recognition of potential child abuse is only the beginning, there then needs to be a co-ordinated effort both in hospital and the community to provide preventive help for parents.

A collaborative study was set up in Oxford in 1978 (Ounsted et al, 1982) between midwives, the maternity hospital social work department and the medical staff, supporting the notion that bonding failure leading to neglect and abuse is preventable (Kempe, 1978). Midwives were encouraged to refer to the paediatrician and senior social worker any patient who caused them concern, particularly regarding the mothers' interaction with their babies. 110 (2%) of the total 5,356 infants were referred in the first year, one third of these were seen by the Consultant who encouraged bonding by emphasising the uniqueness of each infant, attempted to build up self confidence and self respect and offered the services of the hospital should these be needed at any time after discharge. The primary health care teams were frequently contacted regarding individual patients and the concerns of staff were discussed. After three years the study seemed highly successful considering 7108 infants were involved fifteen families received extensive help. In the first 18 months of the study only one infant had been seriously abused compared to six seriously abused in the eighteen months prior to the study, there had however been more referrals for failure to thrive and the number of minor injuries had increased indicating families had benefited from help being given much earlier.

Health visitors are the professionals in the best position to observe infants and children over an extended period as they have access to almost all children from 0-5 years, either in their own homes, attending child health clinics, in playgroups or in nursery schools. They are especially trained in growth and development from birth onwards and are responsible for regularly screening each child for developmental attainment, in addition to monitoring their growth, and for referring a child to the appropriate specialist if there is any deviation from the expected norms (Scott, 1977). Every health visitor should be aware of the prenatal and birth history of each child on her caseload, in addition to all the information since its birth. They should also be aware of any family problems, particularly noting a previous history of child abuse or neglect, as it was observed in studies in Oxford (Roberts et al, 1980) and in Wiltshire (Oliver, 1985) that children from abusing families were at greater risk of death in infancy.

Unfortunately, due to a variety of reasons, some health visitors do not achieve these expectations, as shown by the following comments:

- 'in a study of eleven reports of child deaths from Non-Accidental Injury, a criticism was that height and weight profiles on the children, particularly relevant in cases of neglect, were not kept' (Sharman, 1982);
- 'A significant proportion of battered children were found to have failure to thrive' (Smith and Hanson, 1974);
- 'The fact of failure to thrive was overlooked if not ignored and development barely gets a mention in the records' from A Report Surrounding the Death of Jasmine Beckford' (Blom-Cooper et al, 1985).

In a retrospective case-control study by Lynch and Roberts (1977) there were five specific factors which were significantly more common in 50 abused children when compared with 50 controls born at the same hospital. The factors were:

- mother under 20 when the first child was born;
- evidence of maternal emotional disturbance;
- baby's admission to special care baby unit;
- referral of the family to the hospital social worker;
- the midwives' concern regarding the mother's ability to care for her infant.

Research was attempted in Oxford to consider a link between the five factors identified for child abuse and possible prediction of sudden infant death. It was found that only one of the five factors discriminated between the infants who died suddenly and their matched controls which was, 'concern regarding maternal ability to care for their infant' (Roberts et al, 1984). The conclusion of the study was the factors predictive of child abuse did not predict sudden infant death.

A study by Murphy and co-workers (1981) in Cardiff attempted to establish if one set of predictors could identify infants at risk of SID and child abuse. Nineteen factors available on the local Birth Survey records were considered for 99 SIDs and 80 children who had suffered non accidental injury. Only eight of the nineteen factors were common to both groups, and these were: maternal age, social class, city ward, maternal smoking, poor use of ante-natal care, lack of employment during pregnancy, artificial feeding, and admission to special care baby unit. It was decided that the same groups of predictors do not select children at risk of child abuse and SID, even though they were in close agreement, and the predictive powers were relatively weak for either child abuse or SID.

A study by Golding and Peters (1985) investigated prediction of SID by the Sheffield Score (Carpenter et al, 1977) and the ORLS 'New Score' (Golding et al, 1985) with regard to social and medical factors, in 12,743 children of the 16,771 in the National Birth Cohort born in 1970, who were examined at the age of five years. The 'New Score' looked at social class, mother's marital status, age and parity, interval from preceding delivery to present conception, whether the mother knew the date of her last menstrual period, the amount she smoked during pregnancy, the sex, gestation and birth of the infant, whether a congenital defect was noted, and whether the child was a singleton or a twin. The researchers compared the morbidity of children who had scored high risk on both scoring systems, but who had not yet died. The 'Sheffield' and 'New Score' showed very close relationships in their predictions of risk. The children who scored high risk in both were more likely at five to have poor intellectual development, to have a handicap which would interfere with school life, to have been hospitalised for a respiratory infection, and were less likely to have had a full course of immunisations. The high SIDs risk scores also predicted marital changes, poor home circumstances, and the children being taken into care, which, as far as the author is aware, is the first time a long term result has been given of children who have scored High Risk on the Sheffield Scoring System.

Emery (1985) stated "If indeed one in ten cot deaths are associated with filicide, this becomes an important aspect of prevention". An alerting system to encourage health visiting intervention according to risk to prevent deaths or injuries from child abuse would appear to be a most desirable development in the care of children.

2.E. THE SHEFFIELD SCORING SYSTEM, RISK RELATED INTERVENTION AND EVALUATION OF THE SHEFFIELD SCORING SYSTEM

2.E.1. THE SCORING SYSTEM

A system of scoring developed to predict the risk of unexpected infant death has been used in Sheffield since 1973.

A retrospective study was carried out in Sheffield in 1972 (Protestos et al, 1973). The obstetric, perinatal and postnatal records were studied of 135 infants who had died unexpectedly and 135 live controls who were listed in the hospitals' birth registers next to the dead infants, so were only matched by date of birth.

Extensive information was extracted from the hospital records regarding the social, physical and medical state of all the 270 mothers and 270 infants, and included both quantitative and qualitative data.

Necropsy was carried out by the same paediatric pathologist who divided the cases into four groups:

Group A - An unexpected death in a child with a disease of long standing, e.g. heart deformity, hydrocephalus.

Group B - Necropsy revealed a well accepted cause of severe disease, e.g. acute adrenal insufficiency, meningitis.

Group C - A lesion found that would be expected to cause minor, but recoverable illness, e.g. tracheitis, small areas of pneumonia.

Group D1 - No evidence of definable disease, but tissue changes indicating general disturbance, such as thymus reaction or rib growth arrest.

Group D2 - No abnormalities found at all.

The pathological findings on the 135 infants showed:

Group A	-	16 infants (11.9%)		- **INEVITABLE**
Group B	-	25 infants (18.5%)		) **POSSIBLY**
Group C	-	50 infants (37.0%) -	) includes	) **PREVENTABLE**
Group D	-	44 infants (32.6%) -	) SIDS	)

For the purpose of the study the 94 infants in groups C and D were combined, as the identifying characteristics in both groups were found to have little difference.

A comparison of over 200 variables from cases and controls showed 40 characteristics which were statistically significant, and could be used to identify at birth, or soon after birth, babies who may be at increased risk of unexpected death.

A stepwise discrimination analysis was used to identify the minimum subset of variables. The magnitude of the coefficients indicated the relative importance of the various factors which, when combined, would best distinguish between cases and controls, and a scoring system was developed using eight variables, listed in order of importance - mother's age; birth order; blood group; breast feeding; duration of second stage of labour; urinary infection during pregnancy; polyhydramnios; premature (that is <37 weeks and/or <2500g). The High Risk Infants were not identified by single factors, but by the weighted combination of all observations. The high risk group, that is those with scores larger than the 85 per cent quantile, were found to include 60% of SIDs (Protestos et al, 1973).

A two year prospective study commenced in Sheffield in 1973 (Carpenter and Emery, 1977). 11424 infants were scored at birth, and after excluding 35 infants with gross congenital anomalies, 1759 infants

(15.4%) were identified as being at high risk of SID. 837 parents of high risk infants, selected at random, were invited to participate in the study and 922 infants were used as controls. 210 parents who were invited to participate refused, leaving a total of 627 high risk infants who completed the study - 'the observation group'.

The observation group had a clinical examination within 48 hours of birth and at five weeks by a paediatrician and in their first 20 weeks they had ten home visits by one of the four research health visitors. The control group had the standard three home visits as specified by the Sheffield Health Authority.

In the two year study period 59 deaths occurred in the cohort, of which 29 were inevitable. The 30 unexpected deaths occurred in the following categories:

15 (1.6%) in the low risk group;

2 (3.2%) in the observation group;

9 (9.8%) in the high risk control group;

3 (14.3%) in the high risk group who refused to participate.

The study conclusions were that infants at increased risk of unexpected postperinatal death could be identified at birth and the data suggested that these deaths may be prevented by alerting the primary health care nurses to the surveillance of this group.

Data had been assembled on 115 cases of unexpected infant deaths which had occurred since the previous study by Protestos and others in 1973, and on 115 controls (Carpenter et al, 1977). 39 of the new cases were excluded, because deaths were associated with congenital abnormalities and were placed in Groups A and B as previously described. This left 76 comparable new cases, the parents of which were interviewed at home after the death of their baby. All hospital, GP and Community Health Service records relating to them were abstracted, as were identical data on 115 controls selected as in the previous study. Thus the data studied was from 250 unexpected deaths and 250 controls, as the original 135 deaths and controls from the study by Protestos and others was included and, after re-analysis of the total data, two of the factors in the original score were adjusted - 'polyhydramnios' was replaced by 'twin' and 'prematurity' by 'birthweight' (Table 2.4.).

Birth score, interview data and hospital admissions were used in a further stepwise discriminant analysis, and a second stage scoring system was produced. The relevant variables to be scored at four weeks were:

- cyanotic attack;
- feeding difficulties (infant not established in a pattern acceptable to the mother nor to the health visitor);
- interval in months to the previous live birth;
- inpatient admission of the baby;
- state of repair of house, furnishings and equipment (according to the health visitor's professional assessment)

These additional factors were incorporated into a second stage of the scoring system (Table 2.5.).

The effectiveness of the revised scoring systems was evaluated on the 76 additional cases of SID and 115 controls. The birth score identified 57% of unexpected deaths and emerged as the best single predictor; the multistage scoring system identified 75% of the unexpected deaths.

Whilst the scoring system was being constructed, data on 24 extra cases and 48 controls became available, which was used to validate the new system. Both systems did less well than originally predicted, which

Table 2.4.

Sheffield Birth Score
Factors Predicting Infants at Risk of Sudden Infant Death

Item		Score
Mother's age	10x(50 - age in years)	
Previous pregnancies	0	0
	1	21
	2	43
	3	64
	4	85
	5	107
	6	128
	7	149
	8	171
	9 or more	192
Duration of 2nd stage of labour	<5 mins	127
	5-14 mins	100
	15-29 mins	72
	30 mins-2 hrs	45
	2 hrs and more	18
	NA	76
	Unknown	76
Mother's blood group	0, B, AB	44
	A	0
	Unknown	22
Birthweight	<2000 g	93
	2000-2499 g	78
	2500-2999 g	62
	3000-3499 g	47
	3500-3999 g	31
	4000-4499 g	16
	4500-5500 g	0
Twin	Yes	103
	No	0
Feeding Intention	Breast only	0
	Bottle or both	38
Urinary infection during pregnancy	Yes	54
	No	0
	Unknown	5
Cut point for total birth score		500

High-risk 500 and over, low-risk 499 and under (Carpenter et al, 1977).

Table 2.5.

Sheffield Month Score
Factors Predicting Infants at Risk of Sudden Infant Death

Item		Score
Birth score	Brought forward	
Cyanotic or apnoeic attacks in hospital before initial discharge	Yes	237
	No	0
Difficulty establishing feeds	Yes	83
	No	0
	Not known	36
State of repair of home	Excellent	9
	Good	43
	Average	78
	Fair	112
	Poor	147
	Not seen	73
Interval to last live birth	2x(100 - number of months)	
	1st live birth	128
	100 months or more	0
Inpatient admission	Yes	154
	No	0
Cut point for total month score	**High-risk**	**754 and over**
	Medium-risk	**600-753**
	Low-risk	**599 or less**

Source - Carpenter and Emery, 1974.

was thought to be due to efforts being made in Sheffield to prevent deaths in high risk infants (Carpenter et al, 1977).

2.E.2. RISK RELATED INTERVENTION

Recommendations to reduce the chances of an infant dying suddenly and unexpectedly were made to the Sheffield Health Authority, which were: the total infant population in Sheffield should be given a birth score; at four weeks they should be visited at home by a health visitor who would complete a questionnaire from which a month score would be calculated; at six weeks a routine medical examination should be done at the child health clinic; attention should then be focused on the high risk group of infants, at least until the age of six months and possibly longer, so that by resolving difficulties associated with their nurture, it would improve their chance of survival through infancy (Carpenter et al, 1977). It was stated, however, that the present stage of knowledge did not justify telling any parent that their child was at risk of cot death.

Sheffield Health Authority gradually accepted all the recommendations of the research team. The research health visitors no longer visited some of the high risk infants, the care of all infants again became the responsibility of the Primary Health Care Teams.

In September 1975 all Sheffield health visitors began making a routine 'one month' visit between 25-31 days after birth. All infants were rated as high or low risk and the health visitor was informed of any high risk infant on her caseload. The modified scoring system (Carpenter et al, 1977) designated about 15% of infants in Sheffield as 'high risk' of sudden infant death.

In 1976 a protocol for home visiting was agreed with the health visitors, which stated: all infants would have a primary birth visit and a visit at four weeks by the health visitor; low risk infants would be visited at home in their first year at three months and at nine months; high risk infants would be visited at home every two weeks up to three months and every month up to six months, then nine months and one year. Additional visits would also be made if the health visitor assessed them to be necessary (Battye and Deakin, 1979).

There has been a reduction in the total infant mortality in Sheffield since 1973, particularly in the category of possibly preventable deaths, which have fallen from 5.2 to 1.9 per 1,000 live births. The lower infant death rate is estimated to be due to:- less infants at risk as the mean score of all infants has reduced because of changes in family structure, longer duration of the second stage of labour and an increase in the number of women breast feeding their infants; risk related intervention has resulted in special care of high risk infants, which includes the extra visiting; the effect of case conferences; increased vigilance that the programme has generated from all professionals dealing with infants (Carpenter et al, 1983).

Health visitors in Sheffield have appreciated the use of having a scoring system and a pattern of risk related intervention. The four week visit and the use of a questionnaire gave the opportunity to discuss many different aspects of child care with mothers, who saw the health visitors more positively and understood their role better. New health visitors appreciate the structured pattern of visiting and the co-operation from general practitioners and paediatricians has been very much improved since 1973 (Battye and Deakin, 1979).

Other studies have also commented on the value of home visiting by health visitors. Stacey (1980) stated, "It allows observation of family dynamics as well as recognition of skills used by the mother and encouragement of these". Norman (1983) assessed that routine visiting by the health visitor establishes regular contact with parents, which is more effective than spasmodic visiting, as it encourages improved relationships and mutual understanding of both health visitor and client.

Risk related intervention was instigated in Nottingham from January 1978, using a scoring system specifically designed for use in that city after a 3 year study into the post neonatal deaths (Madeley and Latham, 1979). The scoring system was subsequently modified in January 1980 after consideration of user comments (Madeley, 1982). The scoring system was thought to have been a useful exercise: it made health visitors aware of important risk factors and it helped them to decide their priorities; it provided data to increase the number of health visitors in areas of high need; the post neonatal mortality rate fell from 8.7 per 1000 live births in 1974 to 3.6 per 1000 in 1981, and the first time for decades the rate was no higher than the national average; contact with low risk infants had increased as well as extra visits to the high risk infants.

It was thought, however, that a formal scoring system had become redundant as health visitors 'no longer needed to be told which infants were at risk and time could be saved by a reduction in paperwork' (Madeley et al, 1986). The birth scoring system was abandoned in March 1985, although health visitors were encouraged to pay more attention to their high risk cases as part of their normal clinical practice.

Madeley (1988) stated although he had originally been a supporter of scoring systems he had become increasingly sceptical about their effect on mortality figures as he felt the reduction of deaths in Nottingham was part of an improvement already taking place. He felt an antipoverty drive was necessary by professionals to improve standards of care to all families, but particularly those in poor circumstances, and this would be effective in reducing post neonatal mortality.

The author found the recommendation by Madeley and co-workers (1986) and Madeley (1988) that other District Health Authorities should not set up birth scoring systems to be very negative and possibly quite damaging to potential developments in child care and awareness. The primary health care staff in Nottingham since 1978 have had a high level of teaching input and other interactions from Madeley and other specialists which has probably raised their levels of knowledge, enthusiasm and child care. It is highly likely staff in many other districts do not have these Nottingham advantages and if they take Madeley's advice they will also be denied the use of a scoring system and all the benefits which accompany it.

2.E.3. COMMENTS ON THE 'SHEFFIELD' SCORING SYSTEM

The Sheffield scoring system has been evaluated in several health districts with varying results and recommendations.

Nine Areas in Southern England took part in an epidemiological survey of unexpected deaths (Carpenter et al, 1981). The nine areas were divided into three groups - Area I comprised 4 districts in North East Thames Region (Hackney, Islington, South Camden and Tower Hamlets); Group II was Cheltenham and Gloucester Area Health Authority; Group III comprised 7 Health Districts (Northants; Brent and Harrow; Basingstoke and North Hampshire; Brighton; Enfield and Haringey; Kensington, Chelsea and Westminster; South West and East Hertforshire). A birth and multistage Sheffield score were calculated for 308 SIDS and for only 236 live controls, as data for controls was not allowed to be collected in some areas. The percentage of high risk cases and controls predicted by the multistage Sheffield score showed that in the three groups the scoring did not predict nearly as well as it had in Sheffield.

Area	% Predicted as High Risk		
	Cases	Controls	Difference
I	46	24	22
II	29	20	9
III	28	6	22
Sheffield	70	14	55

Results in Group II appear to be particularly disappointing as the difference between the cases and controls was only 9%. It was suggested scoring to identify infants at risk could be improved by modifications specific to the areas, but to achieve this would require a considerable amount of time and resources.

A Southampton study reviewed 49 deaths and 98 controls with respect to the eight risk factors scored at birth. It was suggested the Sheffield at birth scoring system might be usefully used prospectively in Southampton with a possible minor modification relating to mother's blood group (Harris et al, 1982). A prospective study was commenced there in 1981 but the results have not yet been made available.

The Multicentre Study of Post Neonatal Mortality was the report of a confidential inquiry into all 988 deaths of infants aged one week to two years, in eight large urban centres, during the years 1976-79

(Knowelden et al, 1984).

The Sheffield birth score was calculated on 846 index cases (deaths) and 745 controls, but as it was intended to discriminate between preventable deaths and survivors attention was confined mainly to the six clinically assessed categories of terminal disease and unexpected deaths. Clinical assessments were used as these were known in almost all cases whilst only 519 cases (53%) had full necropsy. The six selected categories were deaths from central nervous system infections, gastro-intestinal infections, upper and lower respiratory tract infections, non-specific infections and unexpected deaths. 457 infants, 54% of the deaths which were given a Sheffield score, were in the one of the six categories. The hypothesis was established that the cases dying unexpectedly were in the same distribution of characteristics (when pregnancy, birth and infants' details were considered) as were cases in the other five categories. The score did not discriminate between cases of sudden unexpected death and cases in the other five categories, findings which agree with those of Carpenter and Emery (1974) who regarded them as being possibly preventable.

There was close similarity between the scores of infants dying from congenital anomalies and controls.

The score discriminated clearly as a whole because 36% of the deaths had a score of 500 or more compared to only 18% of the controls, but the level of discrimination varied between centres.

It was suggested lowering the cut off point to 450 and above would increase the yield to about 60% of the deaths, but at the cost of scoring 40% of the controls at risk. It would be extremely expensive to attempt to implement a risk related programme to 51% of the infant population.

It was also recommended it would be necessary to use a different threshold in each centre to identifying children at high risk, or a Sheffield scoring system would have to be prepared and evaluated separately for each centre and modified to meet changing circumstances. Changes to the Sheffield score appropriate to each District appears to be a regular recommendation when the score is tested in places other than Sheffield.

Leeds was one of the centres in the Multicentre Study, and it was found there that the scoring system discriminated well. 52% of the clinical unexpected deaths were identified as high risk, which was almost as good as the 55% initially found in Sheffield. It would be interesting to know if multistage scoring on these infants would have further improved effectiveness to 75%, as happened in Sheffield.

In Mansfield, Nottingham, between 1970-77 the possibly preventable infant death rate as defined by Carpenter and Emery (1974) was on average 10% above the rate of England and Wales. Since March 1978 a Sheffield birth and one month score has been calculated for all infants born in Mansfield. Initially health visitors were notified of infants at high risk of SID and although specific guidelines regarding intervention had not been produced for health visitors, the number of preventable deaths were reduced in 1978-79 to 2.4 per 1000 live births compared to the national rate of 3.4 per thousand. From 1st January 1980 health visitors were notified only of the high risk infants born on odd days and the limited notification was associated with a slight increase in the possibly preventable death rate to 2.6% (Carpenter and Gardner, 1982). These fluctuations in the infant death rate could be due to the small numbers of deaths involved and further results of the study are awaited.

In <u>Exeter</u>, inquiries into stillbirths and deaths up to the age of 2 years, revealed that in a one-year period from 1st October 1980 to 31st September 1981 there had been a total of 62 deaths. These 62 deaths included 30 stillbirths, 15 neonatal deaths, and 17 deaths between the ages of 29 days and 2 years. All 62 cases had matched controls selected for area of residence, parity, date of conception and sex. There were 9 SIDs, although a further two infants could have been included as possibly preventable deaths - one who died from an acute infection, and another who had inhaled vomit and been certified as an accident. Only one of the 9 SIDs and none of the controls showed a high risk prediction when using the Sheffield birth score (Brimblecombe et al, 1984). The authors stated the numbers involved were too small to permit significant conclusions to be drawn. It might be observed that the effectiveness of the scoring system for selecting infants at risk can only be judged for comparison by using random controls, as matching substantially diminishes the effectiveness of the prediction.

In <u>Dublin</u> 18,801 infants were born between January 1979 and December 1981, of which 48 were subsequently SID victims. The 48 infants who died and five controls for each dead infant were scored at birth and six weeks according to the Sheffield scoring system (O'Brien and Mathews, 1985). It was found that the scoring system had some predictive value but it was neither very sensitive nor very specific, perhaps selecting all of the controls from the same hospital as the cases may have diminished the effectiveness of the analysis. It was suggested a modified score might be more suitable, as despite the apparent ineffectiveness of the risk score to identify infants at high risk, consideration of potential benefits of optimal allocation of resources as presented by Carpenter (1983) suggests it would be possible to mount an intervention programme that would be expected to reduce mortality. This study unfortunately was only written up in a limited way in the correspondence section of the 'Lancet'. It would have been interesting to know how many of the 18,801 infants died of preventable causes, and if the results would have been substantially different if these had been included.

An evaluation of the Sheffield Birth Scoring System was attempted in a joint study in Birmingham and Nottingham (Oakley et al, 1978). A total of 139 infants who had died unexpectedly between 1 week and 2 years were included, none of which had congenital heart defects, neoplasia nor deaths from accident or trauma as these were excluded. An equal number of living controls were selected by taking the next birth in the maternity hospital index and who lived within the same cities boundaries as the index infants. Each birth was scored according to the Sheffield factors and in addition 200 variables were subjected to case/control comparisons. There was no significant difference between the cases and controls when 6 of the 8 Sheffield Factors were considered. Low birthweight was relevant only in Birmingham, and the only factor which was significant in both cities was low maternal age. The variables in the study, however, were not compared exactly to those in Sheffield as the following criteria were used in Birmingham and Nottingham: maternal age <24 years at delivery; birthweight <3000g; primiparous; 2nd stage of labour less than 10 minutes; maternal blood group A. These differences probably had some influence on the final results. The authors stated the 'Sheffield birth scoring system', which they had not actually tested, would not be of use in a prospective prevention programme as the sensitivity and specificity were low, particularly in Birmingham where fewer than half of the cases but as many as one third of the control population were labelled 'at risk'. They suggested that if a scoring system is needed to improve national infant mortality rates, one should be devised which could apply to any community. Carpenter and colleagues (1978) commented on the paper in the Correspondence Section of the Archives of Disease in Childhood. The data from the study had been re-analysed by Carpenter who suggested the original analysis by Oakley and colleagues was at variance with their conclusions.

Two studies were written from the Oxford Record Linkage Study (ORLS) data before publication of the Sheffield scoring system, and it is interesting to note that 8 of the 13 multistage factors were independently considered regarding SIDs in Oxford in two papers 'The Mother' (Fedrick, 1974a) and 'Details of pregnancy, delivery and abnormality in the infant' (Fedrick, 1974b). 170 SIDs were compared with the general population of infants and significant differences were found with low birthweight, twin delivery, subsequent hospital admission, low maternal age, high parity, and short pregnancy interval. The 170 SIDs were then compared with 510 live controls, matched for maternal age, parity, social class, hospital and year of delivery. There did not appear to be an association between blood group, duration of labour or breast feeding. The four remaining Sheffield multistage factors which were not considered were - urinary tract infection, feeding difficulties, cyanotic attack, and state of repair of house, furnishings and equipment.

A paper by Golding and Peters (1985) compared a system based on both data from <u>ORLS and general observations from the literature</u> with the scoring systems of:

- Sheffield at birth only (Carpenter et al, 1977);
- Cardiff (Murphy et al, 1982);
- California (Lewak et al, 1979).

The four scoring systems were assessed using information from a survey of 17196 infants all born in the United Kingdom 5-11th April 1970 (Chamberlain et al, 1975). Some scoring data had not been collected in the Birth Survey so a mean or median score were substituted, which was effectively neutral for all four scores. The cases from the cohort were 34 SIDs and 48 infants who died from an explained/possibly preventable cause, compared to 318 controls who were systematically selected by taking every 50th name on the file - 400 infants in total. The findings showed the Cardiff score did not predict well when compared with the other three.

The results also indicated that these particular systems are not as reliable for predicting explained deaths as they are for SIDS, but if they predict morbidity with reasonable accuracy then insight into the mechanism of SIDs may be gained by focusing attention on those at high risk. It is unfortunate the Sheffield birth score only was used, as inclusion of the five postnatal factors would very likely have shown a more positive predictor.

All of the comparative studies reviewed which have considered the effectiveness of the Sheffield Scoring System and risk related intervention have been retrospective and the results of the prospective studies in Mansfield and Southampton are still awaited. All of these studies have varied in size, methodology, evaluation and sometimes there have even been variations from the original factors considered in Sheffield, consequently the results are bound to be different and sometimes their validity suspect. It has been recommended in almost all of the studies that local factors should be taken into consideration when a scoring system is used, however this would demand a considerable amount of time and manpower to establish local relevant criteria.

Letters in the correspondence section of the 'Lancet' (Gadella, 1983; Southall, 1983) and comments from audiences at seminars (DHSS, 1983; Grand Round, 1983) have suggested the evidence by Carpenter for the value of scoring and the effects of risk related intervention is based on a very small number of deaths. Carpenter (1989), therefore, is collaborating with the organisers of several risk related intervention studies in this Country and one in America based on the Sheffield scoring system to:

- allow more data to be obtained from different areas;
- control modifications to the original Sheffield scoring system to account for local conditions;
- analyse how effective risk related intervention is in reducing the numbers of postperinatal deaths when greater numbers and different areas are taken into consideration.

Taylor and co-workers (1983) regard the use of a scoring and risk related intervention system very positively as it has been beneficial in Sheffield to improve the care given to infants and has reduced the numbers of post perinatal deaths. It has become the vehicle through which health visitors are aware of the possibility of increased risk and the benefits of home visiting.

Hamilton (1986) suggested that if the Sheffield scoring system and intervention could be extended throughout England and Wales it might be possible to save 800-1000 lives per year. He also suggested that a centralised co-ordinated system could prove beneficial, but to become a viable proposition the management of such a system would require commitment and enthusiasm from a team of dedicated workers, with adequate financial backing.

2.F. GOSPORT RETROSPECTIVE STUDY 1977-1981

Over a 5 year period from 1977-1981 there were 49 SIDs in Gosport, a mean rate of 7.3 per 1000 live births compared to a rate of 2.3 per 1000 for England and Wales (OPCS, 1980). These individual deaths and the very high post perinatal rate evoked considerable concern amongst some of the health care professionals.

A retrospective study was designed (Powell et al, 1983):

- to ascertain if the Sheffield birth scoring system could identify infants in Gosport who were 'at risk' of SID;
- to test if local socio-economic and child care variables could be used to modify the Sheffield score for use in Gosport;
- to ascertain whether infants of service families were at higher risk of SID than infants of civilian families.

Two controls were chosen for each case of SID by taking the infants listed before and after the dead infant in the health visitor's birth record book, therefore they were matched by date of birth, locality, and the same medical and health visiting care. Information on all of the infants was obtained from obstetric and health visitors' records, and for the cases from death notifications and coroners' reports. Two of the 49 SIDs had insufficient data entered on the health visiting records for them to be included in the study, so only 47 cases and 94 controls were studied. Sheffield birth scores were calculated for the 141 infants in the standard way (Appendix 3.A.). Maternal blood group results and urinary tract infection details were not generally available so 27 points were included in the score for most infants, to take into account the unknown values of 5 for maternal urinary tract infection during pregnancy, and 22 for blood group. The mean Sheffield score for the cases was 464, compared to 436 for the controls; 26% of cases scored in excess of 500, indicating they were at high risk, compared with 12% of the controls. A formal test of significance incorporating the test for trend described by Armitage (1971) was significant (x = 9.63, d.f. = 1, P <0.001) suggesting an increasing proportion of cases with an increasing Sheffield score.

Gosport health visitors suggested 21 social, economic and child care variables they considered to be relevant factors in SIDs and all of these were included in the study. Infant nutrition and maternal smoking, however, were the only factors found to be relevant. Father's occupation appeared to exert only a minor additional influence when compared with other social factors and gave no significant improvement to the scoring system.

There were 29 SIDs in civilian families, 8.7 per 1000 live births, compared with 20 in service families, 6.6 per 1000. These results indicated infants in service families appeared to be at less risk than infants in civilian families.

The numbers of deaths occurring in the electoral wards in the Borough showed considerable variation. The most affluent ward had 350 births but no deaths during the study period, in contrast to one of the least affluent wards which had 360 births and 6 deaths, a rate of 16.7 per 1000 live births.

There was an excess of SIDs in the months November to March inclusive. There were 34 male deaths compared to 15 female deaths.

The authors had some reservations about the conclusions of the study in view of: the relatively small numbers involved; two of the Sheffield factors were mainly allocated an 'unknown score'; there were only small differences in the percentages between index cases and controls.

Nevertheless, it was decided after considering various options that to use a combination of the Sheffield scoring system and risk related intervention seemed to be the best approach of directing scarce child health resources against the problem of a very high rate of possibly preventable postperinatal deaths in Gosport.

CHAPTER 3

METHOD AND MATERIALS

3.A. GOSPORT INFANT SURVEILLANCE

3.A.1. INTRODUCTION

The Gosport Infant Surveillance Study of risk related intervention was initially planned for one year and commenced on the 1st January 1982. Every infant born to a Gosport mother was to be included in the study.

A questionnaire was to be completed at birth by the midwife who delivered each infant and a second questionnaire was to be completed between 25-31 days by the health visitor responsible for the family. A score was to be calculated from the two questionnaires, and the scoring factor - high risk (HR) or low risk (LR) - was to be notified to the general practitioner and health visitor responsible for each infant. If an infant scored HR the general practitioner would identify the infant's records, and the health visitor would visit the infant at home on at least eleven occasions during the first year, instead of five times as has had been recommended for all infants in the Portsmouth Health District's guidelines for home visiting since 1978 (Powell, 1984).

Portable weighing scales were to be provided for each health visitor as all infants were to be weighed when the questionnaire was completed at four weeks and the HR infants were also to be weighed on every home visit during their first six months. The routine for LR infants was to remain unchanged, except they were to be weighed at home at four weeks, as well as when they attended clinics, unless the health visitor was concerned about them when they would be weighed more frequently at home.

A weight percentile chart was supplied only for each HR infant and these were to be completed according to the guidelines. These guidelines included specific instructions for infants to be referred for medical assessment if the weight moved one channel width, that is one standard deviation, in any subsequent 2 week period or two channel widths in a period of eight weeks. The general practitioners and paediatricians had agreed to see any infants whose weights were causing the health visitors any concern. LR infants would have their weight recorded numerically, unless concern demanded the use of a weight percentile chart.

A typed leaflet entitled 'Do not overheat your baby' (Appendix 8A) was to be given to parents of every infant, and a wall thermometer was to be loaned for a year to parents of all HR infants.

Health visitors were asked to keep a monitoring chart of all contacts they had with each HR infant and also a chart of contacts with one LR control infant. The controls were selected by taking the next LR infant available after the HR infant in the health visitor's birth record book, regardless of congenital abnormality or any other factor.

A research proposal for the Gosport Infant Surveillance Study was submitted to the Health District's Ethical Research Committee, who gave their approval.

3.A.2. GOSPORT SCORING SYSTEM

Provisional findings from the Gosport retrospective study suggested that the Sheffield Birth and Month Scoring Systems (Appendices 3.A.i and 3.A.ii.) would select out some infants who were at risk of SID.

The birth questionnaire, GIS/1 (Appendix 1.A.) was designed with the co-operation of the midwifery staff working in Portsmouth Health

District, after a pilot study by midwives in St. Richard's Maternity Hospital, Chichester. Initially the pilot questionnaire was very simple and contained only the eight Sheffield scoring factors plus essential details of name and address of the mother. The midwives, however, decided all the information contained on the midwifery discharge sheet should be included in the birth questionnaire. This was offered because they had received complaints from the health visitors that the forth carbon copy of the discharge form they received on the 10-14th day after delivery was often indecipherable. This offer by the midwives to complete a comprehensive questionnaire, which would be forwarded to the health visitor immediately after scoring, was very much appreciated.

The five multistage Sheffield scoring factors were included in the four week questionnaire GIS/2 (Appendices 2.A.i. and 2.A.ii), which were designed after an appraisal of the forms used in Sheffield, Stevenage and Southampton. Gosport health visitors were consulted about the design of the questionnaires: if there were any additional factors they thought might be relevant; if they were too lengthy considering the limited time they had available; would they be acceptable to parents with regard to their sensitivity. The health visitors contributed suggestions which were added to the forms; they decided the length of the questionnaires was acceptable as they took only a few minutes to complete; although the first page could be completed with parents, the second page which contained several professional subjective assessments was to be completed by the health visitor immediately after the home visit.

Nurse managers in Sheffield had advised the author that parents should not be told the questionnaires and scoring system had any connection with cot deaths. It was decided therefore that parents would be asked to complete the questionnaire 'To help to improve services for infants in Gosport'. Parents constantly asked 'Is it because of all the cot deaths?', so it was decided after only one month that parents would be told the exact reasons for the study.

3.A.3. PERSONNEL INVOLVED

3.A.3.a. MIDWIVES, MIDWIFERY MANAGERS AND WARD CLERKS

Approximately 1,250 infants are born each year to Gosport mothers. Between 81-89% of these infants are born in St. Mary's Maternity Unit, Portsmouth, the remainder are born mainly in Blake Maternity Home, Gosport, and occasionally an infant is delivered at home.

About two hundred different midwives might be involved with the deliveries of infants to Gosport mothers, so it was necessary for the author to hold several 'teaching sessions' on day and night duty with midwives and their managers: to discuss the very high rate of postperinatal deaths experienced in Gosport; to inform them of the retrospective study that had been undertaken; and to ask for their assistance in the study we were about to start.

A meeting was also arranged between the author and the ward clerks to give them information about the study, as they would be contacted if any details were missing from the questionnaires. They were pleased to be involved in the study.

3.A.3.b. HEALTH VISITORS AND SENIOR NURSE MANAGERS

There were 21 health visitors in Gosport, and all except two had experienced at least one SID in the previous five years. All of the health visitors had been involved in the retrospective study and they had been consulted regarding the construction of the four week questionnaire.

The health visitors' involvement in the study was to be very time consuming as in addition to maintaining the usual amount of care to all low risk infants extra effort would be needed to achieve the recommended intervention:

- considerably more home visiting;
- extra weighing of infants;
- adaptation to using new percentile charts;
- completion of a percentile chart each time an HR baby was weighed;
- monitoring charts to be kept regarding all contacts with HR infants and controls.

The proposed study, however, had the health visitors' full commitment.

The senior nursing officer, the divisional nursing officer and the chief nurse were all kept fully informed of the proposals and their approval was given for all aspects of the study.

3.A.3.c. GENERAL PRACTITIONERS

A meeting of the Gosport Committee of General Practitioners was attended by the author to inform them of the results of the retrospective study, to tell them of the proposed study and to ask for their help and commitment.

All of the 39 general practitioners in Gosport agreed to be involved in 'Infant Surveillance', as the study was known locally. Each doctor was sent a letter explaining the study, a copy of the 'Sheffield-Scoring Factors' (Appendices 3.A.i. and 3.A.ii.), the 'Sheffield Percentile Charts' (Appendix 4.A.) and guidelines for their use

(Appendix (5.); and also a copy of the notification slip they would receive regarding each infants' 'Risk Status' (Appendix 6.A.).

The doctors in four out of the seven group practices in Gosport decided that when they were notified an infant was HR the front of the infant's records would be identified to enable all partners and reception staff to be aware that this child needed extra attention. This was illustrated in the TVS documentary 'The Purple Line' (1984).

3.A.3.d. <u>PAEDIATRICIANS</u>

The paediatricians were personally informed of the aims of the study and they gave their assurance to see promptly any infant about whom there was concern.

3.A.3.e. <u>CLINICAL MEDICAL OFFICERS</u>

A meeting was held between the Infant Surveillance Co-ordinator (the author) and the six clinical medical officers in Gosport to inform them of the Infant Surveillance system. Interest and support was expressed by all of them.

3.A.3.f. <u>ADMINISTRATORS, TYPISTS AND CLERKS</u>

The author needed administrative support and help with the study which included: typing; duplicating; scoring the questionnaires; sending out the risk factor notification memoranda to general practitioners and health visitors; filing and record keeping. The sector administrator expressed a commitment to the Infant Surveillance system and gave permission for staff already in post to undertake all the necessary tasks.

3.A.4. MATERIALS FOR GOSPORT INFANT SURVEILLANCE SYSTEM

It was estimated that the following items would be necessary for the Gosport Infant Surveillance system:

- Birth Questionnaires x 1300 (Appendix 1.A.)
- Month Questionnaires x 1300 (Appendices 2.A.i. and 2.A.ii.)
- 'Do not overheat baby' leaflet x 1300 (Appendix 8.A.)
- Portable weighing scales x 18
- Room thermometers x 100

Extra stationery was provided by the sector administrator.

The district community physician contributed £1,000 to buy seven portable weighing scales and 100 wall thermometers.

Donations were received from local firms and voluntary groups in the area as a result of appeals, which enabled the remaining eleven portable scales to be purchased.

3.B. PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT INFANT SURVEILLANCE SYSTEM

3.B.1. PILOT STUDY

The Infant Surveillance system proved to be very acceptable to health visitors working in Gosport. Nurse managers in other parts of the district asked if their staff could also participate in risk related intervention as SIDs were occurring in their sectors and health visitors had expressed an interest to be involved.

The Gosport study had been a useful pilot exercise for allowing the Infant Surveillance system to be thoroughly tested and it allowed adjustments to be made before extending it to the remainder of the Portsmouth and South East Hampshire Health District.

3.B.2. SCORING SYSTEM CHANGES

Dr. R. G. Carpenter was consulted and gave advice regarding the proposed changes in the scoring system for use in Portsmouth.

3.B.2.a. SUDDEN INFANT DEATH SCORING FACTORS

In Gosport only twelve of the thirteen Sheffield factors had been available for scoring in most instances. Maternal blood group is not routinely assessed antenatally so a score of 22, for 'blood group unknown', had been allotted to a majority of the scores in Gosport. Maternal smoking had been shown to be relevant in the Gosport retrospective study (Powell et al, 1983) so maternal blood group was replaced by a numerical score for maternal smoking. The smoking score was:

- non-smoker = 0
- 1-10 cigarettes per day = 20
- 11+ cigarettes per day = 40 (Appendix 3.B.i.)

During the pilot study 3 of the 8 infants who died had risk scores of over 1000, so it was decided that a new category of Very High Risk (VHR) was to be introduced for babies who scored 1000 or more (Appendix 3.B.ii.).

3.B.2.b. CHILD ABUSE FACTORS

The two questionnaires completed for each child contained 88 variables, including some factors estimated to be useful in predicting child abuse.

The factors selected for scoring infants at risk of child abuse in Gosport included five similar to those used by Lynch and Roberts (1977):

- baby admitted to special care baby unit;
- maternal history of emotional/psychiatric illness;

- midwife/health visitor's concern regarding handling of the baby;
- family known to social services department;
- mother under 20 years when her first child was born;
- and in addition marital instability (Murphy et al, 1981)

according to the health visitor's current knowledge of the family.

If three or more of the child abuse factors were indicated, the infant was scored 'High Risk'.

General practitioners and health visitors were initially informed of the infant's high risk of child abuse by a # sign on the notification slip (Appendix 6.B.) but this was later superseded by the scoring factors actually being listed (Appendix 6.C.).

3.B.2.c. SPECIAL FACTOR - PREVIOUS CHILD DEATH IN THE FAMILY

The Sheffield scoring system does not take into account the risk factor of a previous SID so it is possible for subsequent infants to score LR. It was decided that any previous child death could be categorised separately as a 'special factor' to indicate that an infant was at HR. It was decided to score all subsequent siblings of previous child deaths as HR to ensure regular health visiting care, as well as general practitioner sensitivity and support.

3.B.2.d. SUMMARY - SCORING SYSTEM CHANGES

* **BIRTH SCORE** - Sheffield factors x 7

Maternal blood group - **OUT**; maternal smoking - **IN**

* **MONTH SCORE** - Birth score + Sheffield factors x 5

LR - 753 or less; **HR 754-999**, **VHR - 1000 or more**

* **NON-ACCIDENTAL INJURY** - 6 factors, **HR if 3 or more factors scored**

* **PREVIOUS CHILD DEATH** - A special factor scoring **HR** to ensure siblings of previous child deaths received extra care (Appendix 3.B.ii.)

3.B.3. PERSONNEL AND TRAINING

3.B.3.a. COMMUNICATION AND INFORMATION

Implementing a District wide system involved several hundred people of various disciplines, and it was important for all personnel to fully understand the aims of the Infant Surveillance system and the value of risk related intervention.

'Infant Surveillance Packages' were assembled, which contained: a contents sheet; a birth to one year procedure sheet; guidelines for home visiting; guidelines regarding weight percentile charts; Portsmouth scoring factors; heating/overheating leaflet; plus a sample copy of all forms which should be used (Appendix 9.A.).

The Infant Surveillance packages were given to relevant personnel during training sessions and have subsequently been updated as the system has been modified and new forms have been developed (Appendix 9.B.).

3.B.3.b. MIDWIVES, MIDWIFERY MANAGERS AND WARD CLERKS

There were 280 midwives in the Health District, based either at St. Mary's Maternity Unit or at four small maternity units. The author held training sessions for hospital and community staff in their own units, on day and night duty. These sessions were appreciated by staff who were hearing about Infant Surveillance for the first time and also by staff who were already involved as they wanted to know of any results.

The midwifery nurse managers were kept fully informed of the system, consequently they were very co-operative and supportive.

Meetings were again held with the maternity ward clerks, who were glad to be recognised as part of the team working towards the possible prevention of infant deaths.

The author supplied Infant Surveillance packages to each unit, to the maternity wards and to the school of midwifery.

3.B.3.c. HEALTH VISITORS AND THEIR SENIOR MANAGERS

The chief nurse in Portsmouth commended the proposal of an extension of the Gosport Infant Surveillance system to the remainder of the Health District but could not finance any extra staff. Two directors of Community nursing services and three nursing officers also gave the extension of the system their total commitment, but one director and two nursing officers in the North Sector, although they gave it their approval, had some reservations.

The study of risk related intervention was discussed with 100 health visitors, all working outside Gosport. The author held small group meetings of not more than ten health visitors which allowed considerable interaction and were very valuable. All staff agreed to participate in the Infant Surveillance system although some health visitors, who had not experienced a SID, did not feel as committed to the considerable amount of extra work as health visitors who had been involved with families whose infants had died. Each health visitor in the District was given an Infant Surveillance package and these have been supplied routinely to all new staff (Appendix 9.A).

3.B.3.d. GENERAL PRACTITIONERS

The author was invited to a meeting of Portsmouth District Committee of General Practitioners to explain about the proposed extension of the Gosport Infant Surveillance system and to ask for the participation of all general practitioners. 'Infant Surveillance' was recommended by several Gosport general practitioners who were in attendance at the District Meeting and consequently full approval for District implementation was given by the Committee.

A letter and enclosures were sent to each of the 300 general practitioners in the District (Appendix 18.). Several of the doctors requested information about previous research and further details of the study so meetings between them and the author were arranged in some surgeries and health centres. None of the general practitioners refused to participate in the study.

3.B.3.e. PAEDIATRICIANS

The six paediatricians in Portsmouth had been regularly informed about the intervention in Gosport as the author had attended meetings of the Paediatric Division and also the Health Care Planning Team for Children. They again committed their support of the Infant Surveillance system by promising prompt investigation of infants about whom there were any concerns.

3.B.3.f. CLINICAL MEDICAL OFFICERS

The District Community Physician and the clinical medical officers throughout Portsmouth Health District were enthusiastic to hear of the proposed extension of the Gosport Infant Surveillance system. They requested information to be made available to them in the child health clinics regarding details of each infant's birth and of the infants' scoring factors. The information requested was supplied to them by a computer memo (Appendix 16.) which enabled them to have background knowledge to counsel parents more effectively and to select out infants who required closer monitoring.

3.B.3.g. ADMINISTRATORS AND CLERKS

The community unit administrator was very interested in the proposed Portsmouth Infant Surveillance system and was able to provided considerable clerical help and stationery from within existing resources. He also agreed to have a computer and computer clerk based within the Preschool Child Health Computer Department. This site was chosen by the author as most preferable because all information regarding the movements of children in, or out, or within the District are known to staff in this particular department.

3.B.3.h. COMPUTER CLERK

A computer clerk was employed for the two year project who was funded by the Foundation for the Study of Infant Deaths. He subsequently proved to be a vital link in the administration of the Infant Surveillance system because of his diligence, co-operation, receptiveness of ideas and his ability to adapt the original computer programs to the specific developments of the Portsmouth System.

3.B.3.i. HEALTH EDUCATION STAFF

A meeting was held between the author, the District Director of Health Education, Health Education Officers and technicians, who gave their support and commitment to Infant Surveillance. They developed ideas and produced a leaflet to be made available to parents of all new infants (Appendix 8.B.).

3.B.3.j. PATHOLOGISTS AND VIROLOGISTS

A meeting was held between the author and medical practitioners from various disciplines, including pathologists and virologists, in an attempt to standardise District procedures regarding postmortems and specific investigations on SIDs.

3.B.3.k. CORONERS, POLICE AND AMBULANCE STAFF

The local coroners, representatives from the police and ambulance services, were invited by a paediatrician and the author to a meeting to enable all personnel involved with SIDS to discuss their roles. This meeting resulted in guidelines on 'What to do when a infant infant dies suddenly and unexpectedly', which was widely used by all disciplines (Appendix 19.).

3.B.3.1. RESEARCHERS AND STATISTICIANS

Gosport Infant Surveillance, and then Portsmouth, became part of the Multicentre Collaborative Study which was financially supported by the Foundation for the Study of Sudden Infant Deaths. Advice and support was necessary from Dr. R. G. Carpenter and the research team who organised the Multicentre Study: to organise computerisation of the Portsmouth system; to analyse statistical data; to interpret the results of risk related intervention,

3.B.4. MATERIALS FOR THE PORTSMOUTH INFANT SURVEILLANCE SYSTEM

3.B.4.a. EQUIPMENT

Implementation of the Portsmouth Infant Surveillance system would require a considerable amount of equipment which included:-

- Birth questionnaires x 7000 per annum (Appendix 1.B.)
- Month questionnaires x 7000 x 2 per annum (Appendices 2.B.i and B.ii.)
- Weight percentile charts x 2000 for one year; x 8000 for subsequent years (Appendix 4.A.)

All of the necessary stationary was provided from the Community Unit's administration budget.

- Wall thermometers x 1000
- Portable baby scales x 80

These were purchased from joint funding monies and from donations from local firms and voluntary groups.

- Leaflets 'Keep Baby Warm in Winter/Cool in Summer' x 8000 per annum (Appendix 8.B.)

Generously provided by the District Health Education Department.

- A microcomputer, programs and paper

These were initially provided by the Foundation for the Study of Sudden Infant Death.

- Apnoea Monitors x 75
- Sensors to be used with the monitors x 300 annually
- Scales for use by parents x 10

This equipment was purchased with money from voluntary contributions.

3.B.4.b. STAFFING

The only additional staff required when the study was expanded to a District wide system was a computer clerk on a salary of £6,500-7,950 per annum, which was funded by the Foundation for the Study of Sudden Infant Death for two years. then the post was absorbed into the Community Unit's manpower establishment.

The extra work which was generated by the Infant Surveillance system was absorbed and contained by clerks within their existing staffing capacity.

No extra finances were available for health visitors but most of them managed to achieve the visiting patterns recommended for risk related intervention.

The author, as well as co-ordinating the study, was a nursing officer managing 36 members of staff including health visitors, community health nurses, school nurses and nursery nurses.

The combined Gosport and Portsmouth Infant Surveillance systems are known as the Portsmouth Study.

3.C. <u>RISK RELATED INTERVENTION</u>

3.C.1. <u>HOME VISITING BY HEALTH VISITORS</u>

Home visiting by health visitors was reviewed, and recommendations were made for a routine and minimum number of visits to be made during each infant's first year (Appendices 10.i., 10.ii., and 11. Table 3.1.). The home visiting programme allowed flexibility by the health visitors to visit more frequently if their professional assessment deemed it necessary.

<u>LR Infants</u> would be visited according to the District's already established home visiting guidelines = **5 visits in the infant's first year (level 0).**

<u>HR Infants</u> would be visited according to the Sheffield recommendations - every two weeks for 3 months, every month for 3 months, then routine visiting = **11 visits in the first year (level I).**

<u>VHR Infants</u> were to be visited each week for 3 months, every two weeks for a further 3 months, then every month until baby was a year old = **21 visits (level II).**

No additional health visiting staff were allocated to cover the extra work involved in the study and health visitors expressed their

Table 3.1.

Portsmouth and South East Hampshire Health District's Risk Related Intervention Programme the Recommended Minimum Number and Timing of Home Visits to be done by Health Visitors in each Infant's First Year

	Low Risk (Level 0)	High Risk (Level I)	Very High Risk (Level II)
	10-14 days	10-14 days	10-14 days
	4 weeks	4 weeks	4 weeks
		6 weeks	6 weeks
			7 weeks
		8 weeks	8 weeks
			9 weeks
		10 weeks	10 weeks
			11 weeks
		12 weeks	12 weeks
			14 weeks
		4 months	16 weeks
	4-5 months		18 weeks
		5 months	20 weeks
			22 weeks
		6 months	6 months
			7 months
	7-9 months	7-9 months	8 months
			9 months
			10 months
			11 months
	1 year	1 year	1 year
Total visits in 1st year	**5 visits**	**11 visits**	**21 visits**

concern, if a large percentage of time was to be spent visiting HR and VHR infants then the LR infants may not receive adequate attention. It was decided contacts with HR and VHR infants, plus a control for each, would be monitored for one year only (1983) in the South and West Sectors; the North Sector were not prepared to spare any time for the extra paperwork (Appendix 14.A.). Samples of one HR and one LR infant were selected retrospectively from each health visitor's case load to assess the number of contacts in 1984/85 (Appendix 14.B.).

3.C.2. WEIGHING INFANTS

A District policy stated as from the 1st April 1983 all infants were to be weighed naked at approximately four weeks old, when the second questionnaire was completed. If infants scored HR or VHR they were to be weighed naked at each recommended home visit but infants would be weighed whenever a health visitor was concerned about them.

The health visitors were encouraged to weigh all infants naked at the child health clinics and well baby clinics. Conditions at a few clinics were unsuitable for infants to be undressed, so parents would be asked to either weigh the infant's clothes before dressing him/her on the morning when the clinic was to be visited, or to bring a duplicate set of clothes to the clinic to be weighed there. This strategy would allow the weight of the clothes to be deducted from the infant's actual clinic weight.

3.C.3. MONITORING OF INFANTS' WEIGHTS

Only HR and VHR babies had weight percentile charts issued for them in 1982 and 1983, but on 1st April 1984 it became policy for the health visitors to receive a weight chart (Appendix 4.A.) with the records of every infant for whom they were responsible.

The guidelines for the weight percentile chart (Appendix 5.) state how the charts should be completed and stress that medical help should be sought if the infant's weight passes through one channel/standard deviation in 2 weeks or through two channels in 8 weeks.

The health visitors were encouraged to indicate on the weight percentile charts in green ink when any changes in feeding routines occur, and in red ink when there were any crisis situations or illnesses.

3.C.4. MONITORING TEMPERATURE

The Health Education Department were most helpful in designing and producing a leaflet to give advice to parents on keeping their infant's temperature adequate (Appendix 8.B.). Draft copies of the leaflet were produced initially in black and white and these were then distributed and discussed with groups of parents and health visitors. The suggestions and comments from the groups were incorporated into the leaflet before final printing.

Parents of all infants born after 31st March 1983 have received a copy of the leaflet 'Keeping your baby warm in Winter/cool in Summer' from the health visitors when they have visited at home for the first time.

Wall thermometers have been loaned for one year to the parents of all HR and VHR infants since 1st April 1983. Parents are instructed to attempt to keep the room temperature where the infant is, between 65-70oF at all times.

3.C.5. RESPIRATION MONITORS/APNOEA ALARMS

The use of respiration monitors/apnoea alarms was considered by a working party consisting of a paediatrician, a general practitioner, a midwife, an administrator and the author.

The working party considered:

- the objectives of using monitors;
- the eligibility criteria;
- an allocation system;
- teaching of emergency responses;
- funding and maintenance of equipment.

A draft policy on monitors was submitted to the District Committee of General Practitioners, the Paediatric Division, paediatric nurses, midwives and health visitors. Suggestions were received from various professionals and these were incorporated into a final document which was accepted in 1985 as 'A Policy on the Use of Respiration Monitors/Apnoea Alarms for Portsmouth and South East Hampshire Health District' (Appendices 20.B.i. and 20.B.ii.).

Parents have usually been allocated monitors when they arrived home where health visitors or midwives have demonstrated how to use them and general practitioners have instructed parents on resuscitation techniques. When monitors have been issued in hospital, instructions to parents regarding the use of equipment and resuscitation technique have been demonstrated by paediatricians and ward staff but the primary health care team have taken on responsibilities when the infants have returned home. Parents have also received printed instruction hand-outs when they have been loaned a monitor. (Appendices 21.A., 21.B., 21.C. and 21.D.).

Brief questionnaires were completed by the health visitors and nurses when monitors were issued (Appendix 22.), and parents completed a questionnaire when the monitors were collected (Appendix 23.).

3.D. COMPUTER USAGE WITH PORTSMOUTH INFANT SURVEILLANCE SYSTEM

It was decided to record on the computer not only the necessary items to produce a risk score but all of the details from the birth and four week questionnaires - a total of 88 variables.

3.D.1. COMMUNICATIONS TO CLINICIANS

Information about all infants born in the Health District was supplied from the computer to various professional staff (Table 3.2., Figure 3.1.).

Health visitors received a computer printout for each infant for whom they were responsible, which gave full details of the pregnancy and birth (PCH/1B - Appendix 1.D.) and a notification of the risk factors regarding SID, NAI and Previous Child Deaths (PCH/5a - Appendix 6.C.).

General practitioners received two separate printouts concerning each infant registered with them. A PCH/24 form, especially designed to fit into their records, which gave details of the infant and it's birth (Appendix 17.). A second printout informed the doctor of each infant's risk status (PCH/5b - Appendix 6.C.).

Clinical medical officers received a printout for infants who attended their child health clinics giving details of the infant and relevant facts about it's birth. The health visitors discussed the PCH/22 forms (Appendix 16.) with parents when they visited them at home for the first time. If parents were happy for the forms to be filed in their infant's records at the child health clinic, they were asked to sign and date them to that effect.

A senior clinical medical officer received information from the

Table 3.2.

Portsmouth Child Health Computer System - Infant Surveillance

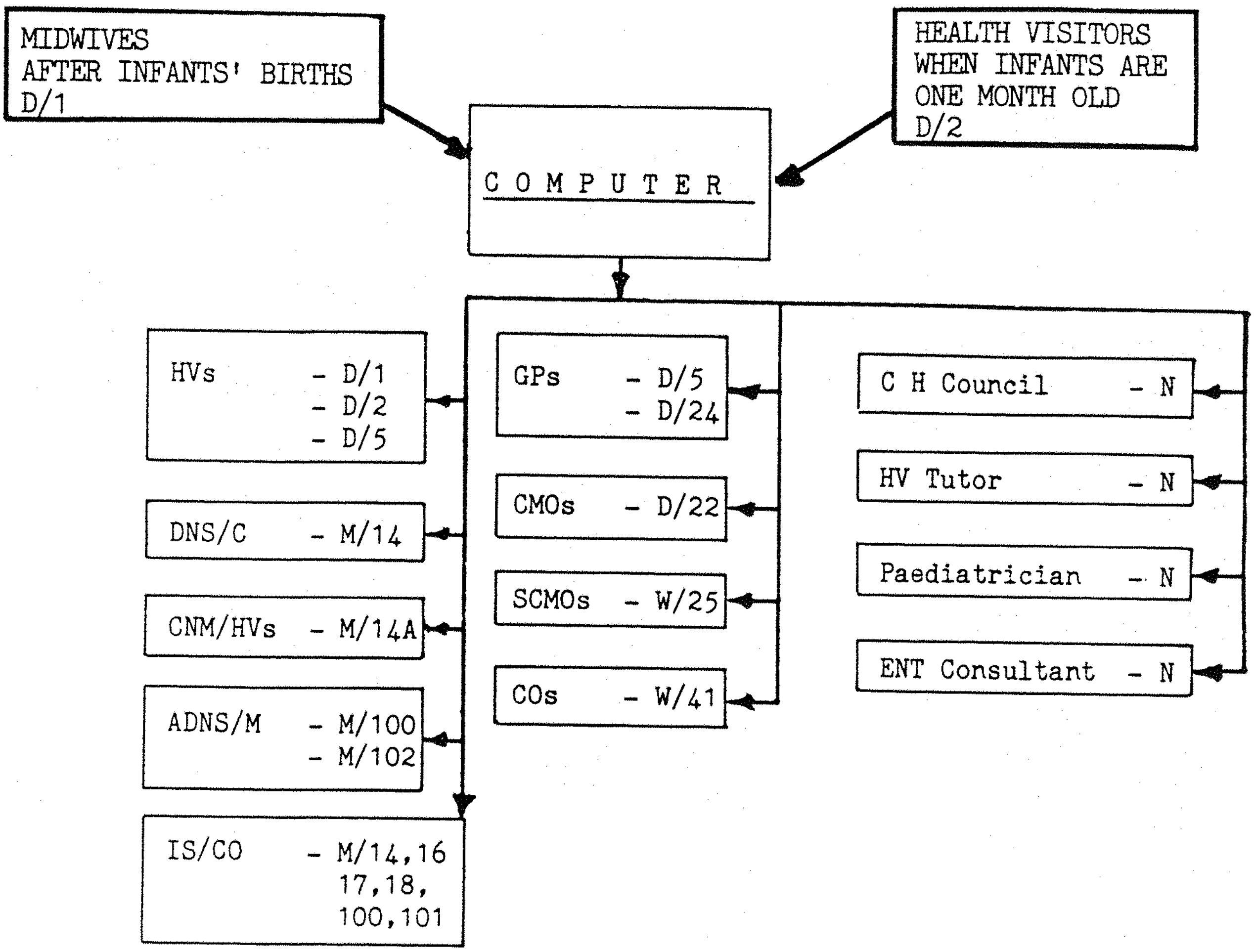
Data received on questionnaires PCH/1a from midwives and PCH/2a and 2b from health visitors is computerised and communications are generated for use by various disciplines

Form:	Sent to:	Description of Form
PCH/1B	HVs	Birth data
PCH/5a	HVs	Memo regarding infant's risk factor and score
PCH/5b	GPs	Memo regarding infant's risk factor and score
PCH/8	HVs	Request to return IS/2 if not received for computing by 6 weeks
IS/14d	DNS/C	Summary of the total infants born in each of the three localities and the percentage of the infants scoring low, high or very high risk
IS/14x	CNM/HVs	Listing of each health visitor and the number of low, high and very high risk infants allocated to each one
IS/16	IS/CO	Listing of children with abnormalites noted at birth
PCH/22	CMOs	Details of maternal history, pregnancy and infant's birth to be filed in child health clinics
PCH/24	GPs	Details of birth and of the infant especially designed to fit in GP's records
IS/25	SCMOs	Details of maternal history, pregnancy and infant's birth to allow selection of infants to be placed on an observation register
IS/40	CNM/HVs	Listing of all high risk infants in a locality and the HV responsible for each infant
IS/41	CAS/CO	Listing of all high risk infants and appropriate GP
IS/100	ADNS/M	Collation of birth data
IS/101	IS/CO	Collation of data collected at one month

Abbreviations: HV - Health Visitor; GP - General Practitioner; DNS/C - Director Nursing Services/Community; CAS/CO - Casualty Officer; CNM/HV - Clinical Nurse Manager/Health Visiting; CMO - Clinical Medical Officer; ADNS/M - Assistant Director of Nursing Services/Midwifery; SCMO - Senior Clinical Medical Officer; IS/CO - Infant Surveillance Co-ordinator;

Figure 3.1.

Portsmouth Infant Surveillance
Questionnaires have been Completed for all Infants
at Birth and at One Month since 1.4.83,
Data is Computerised and Communications produced which are sent to
Health Professionals either Daily, Weekly, Monthly or Whenever Requested



Key:
D - Daily
W - Weekly
M - Monthly
N - Whenever requested
1, 2, etc - Number of the computer form
HVs - Health Visitors
DNS/C - Director of Nursing Services/Community
CNM/HV - Clinical Nurse Managers/Health Visiting
ADNS/M - Assistant Director of Nursing Services/Midwifery
GPs - General Practitioners
CMOs - Clinical Medical Officers
COs - Casualty Officers
IS/CO - Infant Surveillance Co-ordinator

Example: D/1 - is Daily/Form 1 submitted to the Computer Department birth and four week forms which enabled her to compile a register of children she considered to be at risk of developmental delay (IS/25 - Appendix 24.) .

A casualty consultant requested, and received each week, a list of infants calculated to be at high risk of SID (IS/41 - Appendix 25.).

3.D.2. INFORMATION FOR MANAGERS

Clinical nurse managers received each week a list of infants who were at VHR or HR of SID, of NAI, or if the family had experienced a previous child death, plus the name of the health visitor responsible for each infant who is listed (IS/40 - Appendix 26.). They also received each month a list containing all health visitors and the numbers of infants of high and low risk status who had been allocated to each of them (IS/14'x' - Appendix 27.).

Three directors of community nursing services each received a list each month of the total number of births in the district and the figures for specific areas (IS/14d - Appendix 28.).

The assistant director of midwifery nursing services was sent each month a collation of all the information given on the birth forms (IS/100 - Appendix 29.) and the month forms (IS/101 - Appendix 30.). A tabulation of the dates and times of all births each month and the units in which they occurred was also sent to her (IS/102 - Appendix 31.).

3.D.3. DATA AVAILABLE

A micro computer was initially used for the study and all details from the questionnaires were stored on floppy discs. A mini computer system has since been installed and all processed data is readily available for analysis.

3.E. COLLECTION OF DATA ON INFANTS WHO DIED WHO WERE NORMALLY RESIDENT IN PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT

When an infant who is resident in the health district dies the staff in the Preschool Child Health Computer Department are informed of the fact by either the health visitor, and/or the hospitals in the District, and they also receive details of all deaths in the District from the Registrar.

Since January 1982 the author has been notified of all the infant deaths occurring in the District by staff in the Preschool Child Health Computer Department. Health visiting records of dead infants have been made available to the author. Since January 1982 in Gosport, and in the whole of the Health District since April 1983, health visitors have completed a questionnaire (Appendices 15.A. and 15.B.) after a bereavement visit to parents, regarding the infant's condition prior to death and also any illnesses experienced by the infant or by members of their immediate family.

At the beginning of the Study weight percentile charts were not always available for every infant so the author compiled charts from information recorded on the health visitors' records. If a percentile chart was in the records a photocopy was taken, which was then checked for accuracy of recording and adjustments made on the copy if necessary.

Details of the dead infants were also available from pathology reports, and sometimes from police investigation reports.

Information, therefore, has been available to the author of all health visitor contacts with the dead infants when they were alive, of details prior to their deaths and investigations after their deaths.

The completeness of assembled data has been ensured by cross checking it against special tabulations prepared from data tapes made available from OPCS. These data tapes have also made it possible to examine trends in birth and various categories of infant deaths (Tables 5.1. - 5.5.).

3.F. EVALUATION OF PORTSMOUTH INFANT SURVEILLANCE

3.F.1. PROFESSIONAL ASSESSMENT

Assessments, as to the value to Infant Surveillance, were sought from the professionals involved and responsible for risk related intervention.

Twenty questionnaires (Appendix 32.) were circulated and completed by **health visitors**, a sixth of the total health visitors in the health district. 40 **general practitioners**, an eighth of the district total, were sent a questionnaire (Appendix 33.) and 30 replies were received. One **paediatrician**, out of the six in the health district, was sent the same questionnaire as the general practitioners, and he replied.

3.F.2. PARENTAL ASSESSMENT

Twenty four families in Gosport all agreed to be interviewed in their homes in October 1985 regarding their opinion of Infant Surveillance. A semi-structured questionnaire was completed with each of the families (Appendices 34.i. and 34.ii.).

Initially it was decided to interview 12 primiparous and 12 multiparous women, as their current experiences could then be compared with services received with previous children in this District and possibly in other Health Districts.

An attempt was made to select 24 infants born in April 1985, six from each of the following risk categories: very low risk (VLR - infants with a month score of less than 500), LR, HR, and VHR. There was only one VHR baby born in April 1985, so the remaining five infants needed for this category were taken from the previous months, four of whom were second or third children in the family. 21 of the infants therefore were six months old, and the remaining five were between seven and eleven months old when their parents were interviewed. Nine of the mothers were primiparous and 15 multiparous.

3.G. STATISTICAL ANALYSIS

Tabulations and analysis of the smaller data sets were done manually. Larger data was processed by computer using standard statistical packages, for example SPSS (Statistical Package Social Sciences) and SAS (Statistical Analysis Software).

Logistic regression was used to evaluate the effect of intervention and the trends in mortality. These analyses were carried out using the GLIM (Generalised Linear Interactive Modelling) statistical software, the results of which are described in Chapters 4 and 5.

A detailed description of the analyses is given in Appendix 40. by Dr. R. G. Carpenter.

CHAPTER 4

RESULTS

The pilot study in Gosport on infants born between 1.1.82.-31.3.82 tested the feasibility of the methodology of the project and therefore the results were not totally available before the main study of risk related intervention was started for all infants born in Portsmouth Health District between 1.4.83 and 31.3.85. The results of the pilot study are therefore presented alongside those of the main study and where appropriate have been combined with them. The two studies combined will be known as the Portsmouth Study.

The results are presented under a series of headings.

4.A. STATISTICS REGARDING THE NUMBERS OF BIRTHS AND THE RISK SCORES OF INFANTS IN THE PORTSMOUTH STUDY 1.1.82-31.3.85.

4.A.1. ANALYSIS OF DATA

The data from 1.1.82-31.3.83 had been scored manually, and when subsequently it was entered onto a computer for analysis some errors were found in the calculated scores, but in only 8 of the 1,489 infants (0.5%) was the risk status affected. Analysis of data for the total study is based on the correct score and not on the original scores.

There were 15,060 birth questionnaires scored in the Portsmouth study and 13,864 four week questionnaires, of which:

- 12,529 (90.36%) **scored low risk**
- 1,336 (9.64%) **scored high or very high risk** (Table 4.1.).

195 infants (1.41%) were scored as being at risk of more than one factor, for example SID, NAI or the family had experienced a previous child death (Table 4.2.).

Table 4.1.

The Total Number of Infants born 1.1.82 - 31.3.85 in Portsmouth and South East Hampshire Health District, who at one month scored Low, High or Very High Risk of Sudden Infant Death

Total Infants scored at Birth 15060

	Infants N	Percentage of Total Infants Scored at One Month	
Low Risk (LR)	12529	90.36	
High Risk (HR)	1165	8.41	9.64
Very High Risk (VHR)	170	1.23	
Total Infants scored at 1 month	**13864**	**100**	

The number of infants not scored at 1 month was 1196, 7.9% of the total, which included infants who:-

were stillborn or had died;
had transferred out of the District;
were not residents in the District;
were still in special care baby unit;
the health visitor was too busy;
or the parent refused (0.5%)

Table 4.2.

The Total and Percentage of Infants born 1.1.82 - 31.3.85 in Portsmouth and South East Hampshire Health District, when Scored at One Month were estimated to be at Risk of Sudden Infant Death, or of Non Accidental Injury, or the Family had Experienced a Previous Child Death, or a combination of the Risk Factors

Total Infants scored 1.1.82-31.3.85	15060
Total Infants Scored at One Month	13864

Infants scored 'At Risk'	N	Percentage of Infants Scored at One Month	
HR or VHR of Sudden Infant Death only	1159	8.36	
Non Accidental Injury (NAI) only	129	0.93	
Previous Child Death (PCD) only	234	1.69	
HR/VHR + NAI	107	0.77)	1.32
HR/VHR + PCD	58	0.42)	
NAI + PCD	7	0.05)	
HR/VHR + NAI + PCD	11	0.08)	
TOTAL INFANTS AT RISK BY SCORE, NAI OR PCD	**1705**	**12.30**	

In the pilot study in Gosport 39 infants with NAI or PCD only did not receive extra care. These 39 infants are included in the appropriate groups in this table to show the correct proportions of high risk infants in the study.

4.A.2. COMPLETENESS OF COVERAGE

The completeness of coverage of the scheme may be estimated for the calendar year 1984, as that was the only complete year in the study for the whole of the Health District.

In 1984 there were 6,740 infants born to mothers normally resident in the Health District, but only 95.8% were scored at birth, as the remainder of the infants were born out of the District and the relevant information to complete a birth score was unavailable. One month questionnaires were completed for 6,157 infants, 91.3% of the total births. The remaining 8.7% comprised:

- 283 infants (4.1%) who were born out of the District and scoring details were unavailable;
- 115 infants (1.9%) had moved out of the district, or had died;
- 159 infants (2.3%) were still in special care baby unit, or the family were away on holiday, or the health visitor was too busy to complete the form;
- 31 parents (0.5%) did not wish to be involved in the Infant Surveillance system.

4.B. HEALTH VISITOR CONTACTS WITH INFANTS

4.B.1. HEALTH VISITOR CONTACTS AT HOME AND AT CHILD HEALTH CLINICS

There were 1324 births in Gosport in 1982 and 10% were identified as HR. Monitoring Forms of all health visitor contacts (Appendix 14.A.) were kept for the HR infants and also for a LR control but for only the first six months of the infants' lives as initially this was the period to which the intervention was particularly directed (Table 4.3.). Analysis was completed on the first 61 HR monitoring forms

Table 4.3.

Gosport Infant Surveillance
Recommended Home Visiting Schedule for Health Visitors in 1982

Low Risk Infants (Level 0)		High Risk Infants (Level I)
10-14 days		10-14 days
25-31 days		25-31 days
		6 weeks
		8 weeks
		10 weeks
		12 weeks
4-5 months		4 months
		5 months
		6 months
7-9 months		7-9 months
1 year		1 year
5 visits	**TOTAL**	**11 visits**

Mothers and infants are usually visited at home by domiciliary midwives until the 10-14th day after delivery, health visitors then take responsibility for infants.

returned and for the matching controls (Powell, 1986). Data regarding **home visiting** showed:

- the average number of home visits received by HR infants up to the age of six months was 5.2 more than the controls;
- 85% of the HR received between 1-15 more home visits than their controls;
- 4 controls received more home visits than the HR infants including one who actually had 5 more.

The **attendance at child health clinics** showed the opposite trend:

- the HR infants had on average 3.7 fewer visits to the clinic than the LR controls;
- 79% of LR controls had an equal number or more visits to clinic;
- one HR infant had been to clinic 18 times whilst the control had been only three times.

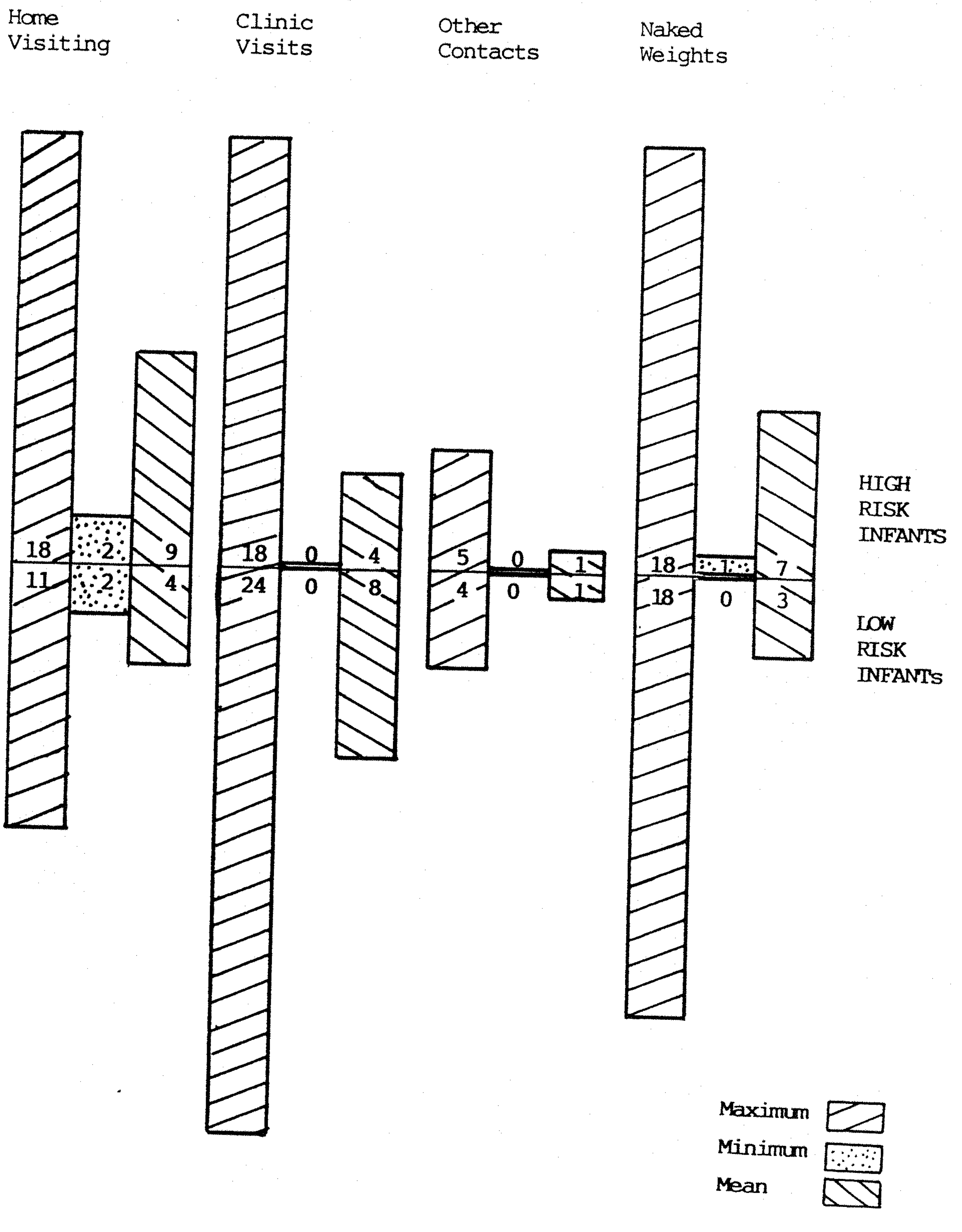
The average number of **total health visitor contacts** with HR infants was 14, 9 of which were at home; compared to 13 total health visitor contact with LR infants, 8 of which were at child health clinics (Figure 4.1.).

4.B.2. HOME VISITING OF LR, HR AND VHR INFANTS

From April 1983 until July 1984 health visitors in two sectors of the Health District completed monitoring charts on some HR infants, and LR controls. Data regarding the number of home visits was collected on 221 completed monitoring forms for HR infants and 210 LR controls as the remaining 11 controls had moved out of the District. The median number of home visits to infants <1 year for the LR, HR and VHR groups were 4, 10 and 16, respectively which corresponds very closely to the recommended visiting schedule (Table 3.1.). The distribution of the

Figure 4.1.

Gosport Infant Surveillance 1982
the Maximum, Minimum and Mean Health Visitor Contacts
with High Risk and Low Risk (Control) Infants in Their First Six Months
of Life where Maximum Intervention was Directed.



percentage of infants who received home visits were: LR = 1-9 visits (98.6%) ; HR = 5-14 visits (77.2%); VHR = 15+ visits (52.5%) (Table 4.4.).

As a further check on home visiting patterns all health visitors were asked to summarise retrospectively the number of visits to the first HR and the next LR notified to them in 1984 (Appendix 14.B.). Analysis of the 45 returns from health visitors gave results similar to the previous findings on home visiting, although it was also noted that LR controls were normally visited at home four times in the first three months which is extra to the minimum recommendations, but they were not weighed.

4.B.3. PARENTS' EVALUATION OF HEALTH VISITOR CONTACT

Twenty four mothers were interviewed using a semi-structured questionnaire (Appendices 34.i. and 34.ii.). When asked if they preferred to be visited at home by their health visitor, or to see her at a child health clinic, 12 mothers (50%) preferred to be visited at home, of which 75% were mothers of HR and VHR infants compared to only 25% mothers of LR and VLR (with a month score of <500) infants. The remaining 12 mothers (50%) stated either home or clinic. None of the mothers stated they preferred the child health clinic, nor did any of them state neither home nor clinic (Table 4.5.).

4.B.4. HEALTH VISITORS' EVALUATION OF CONTACTS WITH INFANTS

Thirty five health visitors, 29% of the total health visitors in the District, were asked to complete a questionnaire which included the question 'In your opinion which is more effective a home visit or a clinic visit, and why do you have his opinion?' (Appendix 35.).

There was unanimous agreement that a home visit was preferable to a

Table 4.4.

Portsmouth Infant Surveillance System April 1983–July 84
the Number of Home Visits by Health Visitors in Infants' First Year
by the Percentage of Infants in Low, High or Very High Risk Groups

Number of Home Visits in Infants' 1st Year	Low Risk Controls %	High Risk Infants %	Very High Risk Infants %
0	1.0	–	–
1–4	58.1	6.4	5.3
5–9	39.4	43.1	21.1
10–14	1.0	34.1	21.1
15–19	–	9.4	10.7
20–24	–	4.5	36.8
25+	0.5	2.5	5.3
Total	**100**	**100**	**100**
Number of Infants	**210**	**202**	**19**
Median Number of Visits:-			
<6months	**3**	**8**	**13**
<1yr	**4**	**10**	**16**
Control Records unavailable	**11**	—	—

Table 4.5.

Portsmouth Infant Surveillance 1.4.83-31.3.85
Answers from 24 Mothers who were asked during a Semi-structured Interview whether they preferred to see their Health Visitor - at Home, at Clinic, Either or Neither

Preferred to be seen by Health Visitor	Risk Category of the Infants (Month Score)			
	Very low risk (<500)	Low risk (500-753)	High risk (754-999)	Very High Risk (>1000)
At Home	1	2	6	3
At Clinic	-	-	-	-
Either Home or Clinic	5	4	-	3
Neither Home nor Clinic	-	-	-	-
TOTALS	6	6	6	6

clinic visit. Some health visitors gave two or three answers as to the benefit of home visiting, resulting in the most common opinion 'they give a better understanding of the clients in their own environment' This was followed closely by:

- the mother appreciates being in her own home;
- she is more relaxed;
- she is more in control;
- she feels more of an equal (Table 4.6.).

Health visitors were also asked for any other comments and all of these were connected with child health clinics:

- 3 suggested extra facilities should be available;
- well baby clinics were preferable;
- clinics have a social benefit.

Comments regarding clinics, however, were probably limited due to the construction of the questionnaire.

4.C. INFANT FEEDING, WEIGHING AND MONITORING

4.C.1. AVERAGE WEIGHT GAIN PER DAY (AWGPD)

Birth and one month data was collected from forms completed by midwives and health visitors respectively on 6680 infants born 1.4.83-31.3.84. Infants' weights were recorded on both occasions, so all birth weights were used but on the one month form only weights which were taken between 20 and 40 days were included in the analysis (Chadwick, 1985). The weight changes between birth and one month were then obtained and the AWGPD was calculated from these figures.

11 boys and 22 girls apparently lost weight by up to 330 grams between birth and one month visits, similarly 11 boys and 9 girls gained

Table 4.6.

Portsmouth Infant Surveillance
Replies of 35 Health Visitors who answered the Question 'In Your Opinion which is more effective, a home visit or a clinic visit and please state why you have this opinion?' (Appendix 35).

35 health visitors expressed the opinion that a home visit was more effective than a clinic visit

Number of Comments	Comments by Health Visitors regarding why Home Visits are more effective than Clinic Visits
20	Very valuable, gives a better understanding of the client in their own environment, regarding standards, etc.
19	Client appreciates being in her own home, more relaxed, more in control, more of an equal
16	Time factor appears less crucial, as no one else is waiting
15	Health visitor/client relationships improved
9	Privacy
8	Interaction between family members observed
6	Confidentiality
5	Less interruptions
5	Teaching more relevant when all needs assessed
1	More job satisfaction for health visitor
1	Only overt problems discussed at clinic
105 Total	**- some health visitors gave several comments**
	Comments regarding Child Health Clinics:-
1	All clinics should be warm enough for naked weighing
1	Privacy should be ensured for interviews
1	Every mother attending should see the Health Visitor
1	Social interaction is valuable for mothers
1	A well baby clinic is preferable to a child health clinic.
5 Total	**- many health visitors did not comment on clinics**

more than 2400 grams in the same period. Some of these observations may be genuine, but as they represent a rate of weight gain or loss more than 3 standard deviations from the mean they were excluded as probably due to measuring errors. After excluding infants who were not followed up in the specified period, who were not weighed at one month and the 53 infants with improbable weight gain, there remained 5173 records (77% of the total) of which 2732 were males and 2441 females.

The male infants weighed on average 132 grams more than the females at birth, and gained 3.6 grams per day more than the females, so consequently at thirty days the males averaged 240 grams more than the females (Table 4.7.).

It would appear that children with lower or higher birth weights gain less weight during the first month of life than do children of average birth weights. The largest group of infants of both sexes have a birth weight between 3000 and 3499 grams, and these babies produce the largest AWGPD for the male infants, but the female infants largest AWGPD is in the 2500-2999 gram group (Table 4.8.).

The variation of weight gain with sex and birth weight implies it is essential to use accurately constructed weight charts when monitoring infants' weight gain.

4.C.2. <u>THE EFFECT OF MATERNAL SMOKING ON BABY'S WEIGHT</u>

Data regarding smoking was not available on 49 of the 6880 birth questionnaires, nor on 16 of the 5173 questionnaires completed at one month, which were included in the remaining analysis on AWGPD data.

The effect that maternal smoking had on infant's weight at birth and subsequent weight gain was analysed. The mean birth weight and AWGPD was obtained for both sexes and for smoking and non-smoking mothers. The

Table 4.7.

Portsmouth Infant Surveillance The Mean Birth Weight, Month Weight and Average Weight Gain per Day (AWGPD) on 2732 Males and 2441 Females out of the Total Birth Cohort of 6680 Infants born in the Health District 1.4.83-31.3.84.

Variable	Sex	Mean (Grams)	S.e.
Birth Weight	M	3378	9.8
	F	3246	10.1
Month Weight	M	4296	12.2
	F	4056	11.7
AWGPD (Grams/Day)	M	29.4	0.2
	F	25.8	0.2

One month weight measurements recorded between 20-40 days were taken into account and weight change limits were set between 0-60 grams.

Table 4.8.

Portsmouth Infant Surveillance Birth Weights and Average Weight Gain per Day (AWGPD) in a One Month Period on 2732 Males and 2441 Females out of the Total Birth Cohort of 6680 Infants born in the Health District 1.4.83 - 31.3.84.

Sex	Birth Weight (Grams)	N	AWGPD (Grams/Day)			
			Mean	S.e.	Minimum	Maximum
Male	500-1499	5	16.64	3.18	9.38	28.50
	1500-1999	20	17.85	1.73	7.88	36.00
	2000-2499	124	27.32	1.03	3.46	59.06
	2500-2999	440	30.27	0.49	0.00	60.00
	3000-3499	1027	30.30	0.33	0.00	59.66
	3500-3999	841	29.17	0.38	1.03	59.33
	4000-4499	242	27.50	0.66	1.67	59.64
	4500-	33	24.32	1.93	5.00	49.67
Female	500-1499	7	13.09	2.00	7.14	18.07
	1500-1999	21	23.30	2.19	6.81	45.93
	2000-2499	140	27.07	0.87	0.30	60.00
	2500-2999	559	27.29	0.39	2.57	57.42
	3000-3499	992	26.65	0.31	0.00	56.97
	3500-3999	580	23.90	0.39	0.00	56.00
	4000-4499	127	22.78	0.87	2.81	56.54
	4500-	15	14.68	2.43	0.00	34.48

One month weight measurements recorded between 20-40 days only were taken into account and weight change limits were set between 0-60 grams. AWGPD, therefore, could not be calculated for 749 males and 758 females, as they contained missing values, incorrect dates or weight changes outside the set limits.

results showed:

- on average infants whose mothers smoked weigh considerably less at birth than infants of non-smoking mothers;
- male infants of non-smoking mothers weigh about six per cent more and female infants seven per cent more at birth than do infants of smoking mothers;
- the AWGPD of infants of smoking mothers was slightly more than infants of non-smoking mothers in females only (Table 4.9.).

4.C.3. WEIGHT GAIN OF BREAST FEEDING INFANTS COMPARED TO BOTTLE FEEDING INFANTS

Mothers' feeding intention was recorded by midwives on the birth forms and the actual feeding of infants was noted by health visitors on the month forms.

Types of feeding were considered regarding weight gain and it was found that breast fed male infants gained more weight than bottle fed males and males who had been fed both breast and bottle. Results on female infants showed there was less difference between breast fed and bottle fed infants, although when breast fed was compared with breast plus bottle the findings are similar to the male results (Table 4.10.).

The types of feeding from birth to one month showed considerable changes, and as the results for male and female infants were similar they are combined (Figure 4.2.):

- 73% of mothers intended to breast feed their infants, but by one month only 45% were actually doing so;
- 25% to 50% increase of totally bottle fed infants;
- 4% were being fed both breast and bottle;
- 1% the pattern of feeding was unknown.

Table 4.9.

Portsmouth Infant Surveillance - Birth Weight and Average Weight Gain per Day (AWGPD) of Infants whose Mothers Smoked and Infants whose Mothers Did Not Smoke in the Birth Cohort of 6680 Infants born in the Health District 1.4.83 - 31.3.84.

Sex	Variable	Smoking	N	Mean	S.e.
Male	Birth Weight (Grams)	Yes	1100	3215	16.5
		No	2350	3404	11.9
	AWGPD (Grams/Day)	Yes	865	29.35	0.37
		No	1855	29.40	0.25
Female	Birth Weight (Grams)	Yes	984	3074	17.4
		No	2197	3292	11.4
	AWGPD (Grams/Day)	Yes	754	26.29	0.35
		No	1683	25.65	0.24

Data regarding smoking was not available on 49 of the 6880 birth questionnaires, nor on 16 of the 5173 questionnaires completed at one month, which were included in the remaining analysis on AWGPD data.

Table 4.10.

Portsmouth Infant Surveillance
Comparison of Average Weight Gain per Day (AWGPD)
on 2732 Males and 2441 Females who were fed Breast, or Bottle,
or Breast and Bottle, out of the Total Cohort of 6680 Infants
who were born in the Health District 1.4.83 - 31.3.84.

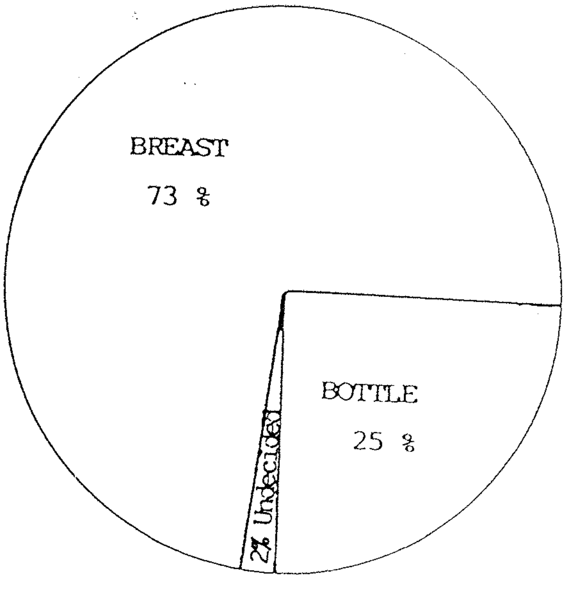
Type of Feeding at one month	Sex	AWGPD (Grams/Day)		
		N *	Mean	S.e.
Breast	M	1194	30.77	0.33
	F	1092	26.70	0.31
Bottle	M	1360	28.63	0.28
	F	1230	25.47	0.27
Breast and Bottle	M	136	25.12	0.91
	F	99	21.52	0.97

* Excluding 42 males and 20 females with unknown feeding pattern at one month

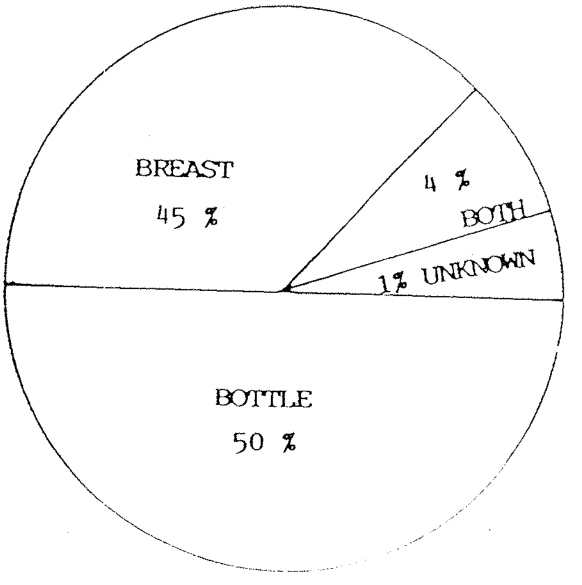
Figure 4.2.

Comparisons between the Feeding Intention of 5173 Mothers when their Infants were born in Portsmouth Health District from 1.4.83 - 31.3.84 and their actual Feeding Practice when the Infants were one month old.

A) Mother's Feeding Intention at Infant's Birth.



B) Actual Feeding Method when Infant was One Month Old.



4.C.4. MONITORING OF INFANTS' WEIGHTS USING SHEFFIELD WEIGHT PERCENTILE CHARTS

'Sheffield' weight percentile charts were kept by health visitors on all HR infants born in Gosport only in 1982 and these were recalled for analysis when the infants were one year old. The channels on the charts were numbered 0-11 and the babies who were born premature were given an estimated birth channel, by continuing the dotted line down into the pre-term period (Appendix 4.B.).

Initially 71 weight charts were analysed and it was indicated that 75% of the babies had a birthweight below the 50th percentile defined for Sheffield infants, but this was expected as only HR infants were being analysed and lower birthweight is a high scoring factor (Table 4.11.). Distribution of Gosport birth weights, adjusted to the expected date of delivery, were compared to the distribution of birth weights of all infants born in Sheffield in 1975 (Figure 4.3.).

At 6 weeks 84% of Gosport infants were within one channel of their birth weight, at 12 weeks 64% were within one channel, and by 26 weeks 60%; therefore these data suggested the Sheffield charts were appropriate for Gosport infants.

The recorded weights on 71 children over the first six months of life gave rise to 549 independent assessments of weight gain over 2 weeks, and 212 assessments over 8 weeks. On 13 occasions there was a drop of at least one channel over a 2 week interval, representing 2.4% of the total, which corresponds very closely to the 2.5% intended by Carpenter when constructing the charts, in that a drop in channel corresponds to a weight change of two standard deviations over a 2 weeks period (Carpenter, 1985). Table 4.12. shows that only 5% of the infants

Table 4.11.

Weight Percentile Charts
Frequency of Distribution of the Estimated Birth Weight, allowing for Prematurity, of 71 High Risk Infants born to Gosport Mothers in 1982.

Channel No.	Frequency	%	Cumulative %
0	3	4.2	4.2
1	1	1.4	5.6
2	10	14.1	19.7
3	3	4.2	23.9
4	14	19.7	43.7
5	22	31.0	74.6
6	11	15.5	90.1
7	4	5.6	95.6
8	2	2.8	98.6
9-11	1	1.4	100.0
	Cases - 71	Mean - 4.4648	S.D. - 1.9554

If an infant was born prematurely the birth weight was estimated at 40 weeks gestation and the chart plotted in the appropriate Birth Channel.

If weights are normal, the cumulative distribution at Channel 5 = 50%, but the observed 75% show low birth weight in the selected high risk cases.

Figure 4.3

Distribution of Birth Weights
of 71 High Risk Infants in Gosport in 1982
adjusted to Expected Date of Delivery (EDD), compared to Distribution
of Birth Weights of Full Term Infants in Sheffield in 1975

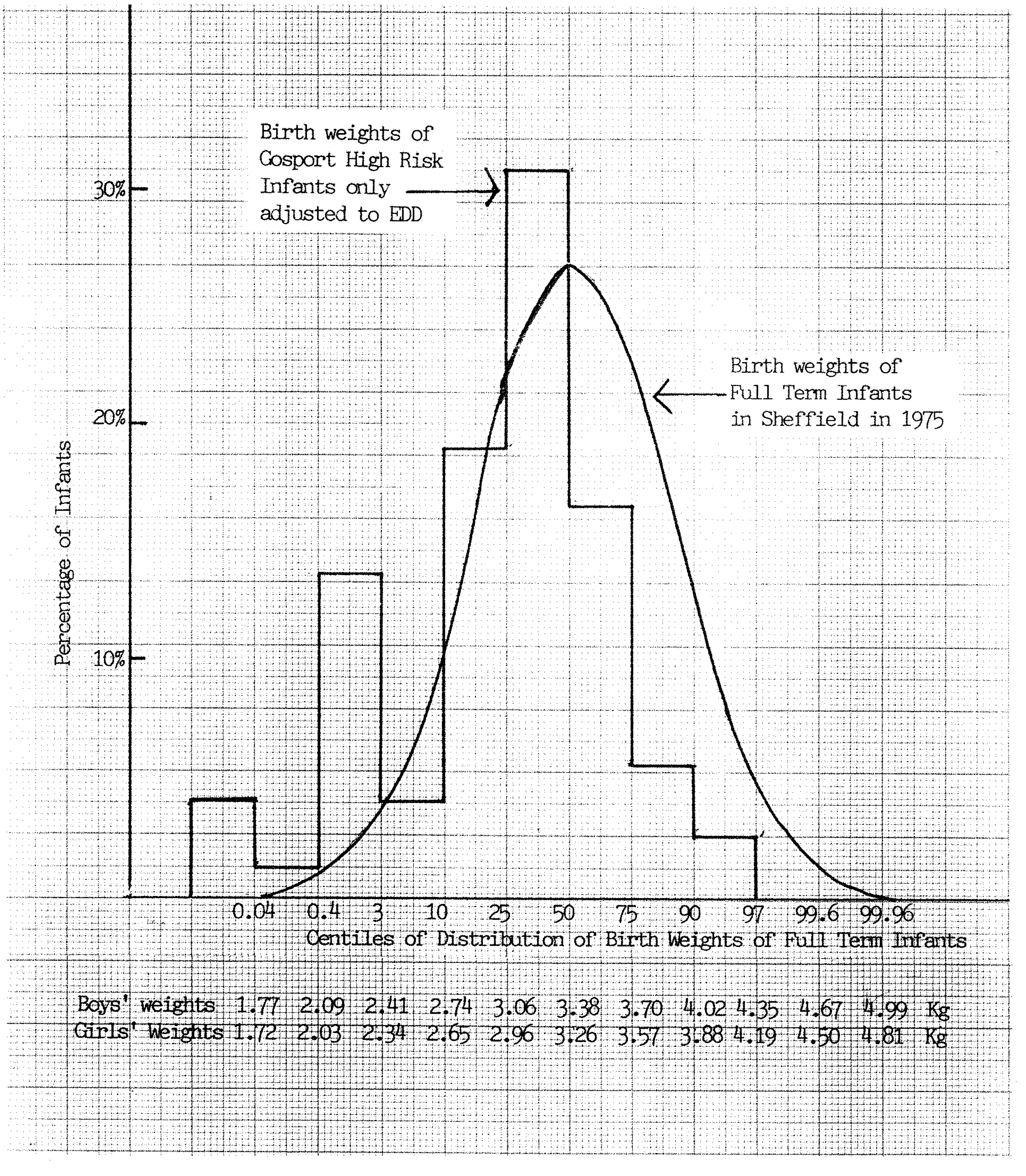


Table 4.12.

Weight Percentile Charts,
Analysis of a Test for Association of Channel Change and Illness
from Birth to Six Months on 71 High Risk Infants in Gosport in 1982

1 Channel Change in 2 weeks

	Illness		Totals	
Channel Drop	Yes	No	N	%
No	29 (5%)	507	536	97.6
Yes	10 (77%)	3	13	2.4
Total	39	510	549	100

Chi squared = 87.8 P < 0.0001
Sensitivity = 25.6% Specificity = 99.4%
( ) indicated % of line total

2 Channels Changes in 8 Weeks

	Illness		Total	
Channel	Yes	No	N	%
No	27 (13%)	178	205	96.5
Yes	5 (71%)	2	7	8.5
Total	32	180	212	100

Chi squared = 13.67 P < 0.01
Sensitivity = 16% Specificity = 98.9%
( ) indicates % of line total

whose weight gain did not drop significantly were ill, whereas 77% showing a significant failure of weight gain were ill. Of the 39 recorded illnesses 25% were associated with significant failure of weight gain and of the 510 occasions when the infant was seen not to be ill, on only three was there a significant failure of weight gain (Table 4.12.). These figures imply that when an infant is ill there is a 1:4 chance there will be a failure of weight gain, but if the infant's weight does fall off then the infant is almost certainly ill.

4.D. TEMPERATURE CONTROL

4.D.1. OVERHEATING

All parents were to be advised to keep their infants' room temperatures between 65-70oF (18-20oC). The health visitors discovered when they were actually giving out thermometers and checking room temperatures, that they were frequently in the 80's and sometimes over 90oF. When the high temperatures were discussed with parents, they often stated "I was trying to keep it as warm as the maternity ward".

4.D.2. INADEQUATE HEATING

It is highly likely health visitors have had to advice parents to increase the heating in their homes because temperatures were too low but in the three year study period only one family has actually been discussed with the author. A young mother and her baby were living in dreadful housing conditions and the temperature recorded in the home was very low. The health visitor was advised to contact the council's housing department informing them of the situation and of the baby's high risk status. The family were dealt with very sympathetically and were rehoused within the week.

4.D.3. HYPERPYREXIA

Thirty five of the 51 Possibly Preventable Postperinatal Deaths (PPPD) included in the Portsmouth Study had rectal temperatures recorded when they were brought into the Accident and Emergency Unit. Three of these 35 infants had very high temperatures of 40oC, 41oC and 41.5oC, and several others had temperatures which were normal or slightly raised even though they had been dead for several hours.

4.E. MONITORS AND WEIGHING SCALES

4.E.1. ALLOCATION OF MONITORS

A few monitors became available during the course of the Portsmouth study. In an eighteen month period from September 1983 to March 1985 only 45 parents were loaned a monitor.

Initially monitors were requested mainly by parents when they had a subsequent baby after experiencing an SID - 'Sibs of SIDs'. Gradually the demand for monitors changed from requests from parents, to requests from doctors for parental use with infants who have had severe apnoea attacks and for those with various medical conditions (Table 4.13.). Requests for monitors needed for medical reasons include: six infants 27-29 weeks gestation who had all experienced prolonged apnoea attacks and other problems, for example, Fallot's tetralogy plus kidney problems and three infants with cardiac abnormalities.

The risk score of each infant who was loaned a monitor was noted and except for the Sibs of SIDs in groups 2 and 3 who would all be at HR because of the Previous Child Death category, the mean scores of all the infants were in the HR or VHR range (Table 4.14.).

Monitors were loaned to parents when the age of their infants

Table 4.13.

Portsmouth Infant Surveillance Study
the Reasons why Respiration Monitors/Apnoea Alarms (Monitors)
were loaned to the first 45 Parents for use with their Infants at Home
Grouped in Allocation Order

Group Allocation Order	Reasons for allocation of a Monitor				Total Infants
	Siblings of SIDS	Siblings of SIDs + Significant Apnoea Attack	Significant Apnoea Attack	Medical Reasons	
Group 1 1-15 Infants	10	0	4	1	15
Group 2 16-30 Infants	5	3	4	3	15
Group 3 31-45 Infants	4	0	5	6	15
Total	**19**	**3**	**13**	**10**	**45**

Table 4.14.

Respiration Monitors/Apnoea Alarms (Monitors)
The Range and Mean Risk Score of the first 45 Infants in Portsmouth Health District who were allocated Monitors for use at Home

Groups of Infants	Reasons for Allocation of Monitors			
	Siblings of SIDs	Siblings of SIDs + Significant Apnoea Attacks	Significant Apnoea Attack	Medical Reasons
	Sudden Infant Death Risk Scores			
Group 1 **1-15 infants**				
- range	390-1217	-	791-816	997
- mean	780	-	800	997
Group 2 **16-30 infants**				
-range	630-772	1115-1228	684-879	571-1235
- mean	672	1172	818	1013
Group 3 **31-45 infants**				
- range	620-753	-	605-988	707-1248
- mean	678	-	858	1050

Portsmouth Infant Surveillance Scoring System

< 754 - Low Risk
754-999 - High Risk
1000 or more - Very High Risk (Powell, 1985)

ranged from 7 days to 1 month old, with a median age of 2 weeks. The monitors were loaned on average for a period of six months, although the range was from one month to twelve months. The number of sensors used by individual families varied from 2 to 43, with an average use of 8 sensors per infant.

Although all of the parents who had been loaned a monitor had been taught resuscitation techniques by a medical practitioner none of them have needed to actively attempt to resuscitate their infant.

4.E.2. PARENTAL EVALUATION OF MONITORS

Parents' opinions regarding the use of monitors were collected by health visitors completing a small questionnaire with parents, when they collected the monitors after use.

Forty three of the 45 parents would have preferred the monitor to have been issued in hospital and a majority felt the time to discontinue using a monitor was when infants were about six months old or when they felt confident there was no longer a risk of SID.

Parental responses as to the value of having a monitor included:

- reassurance, which was the most common statement;
- we were able to sleep;
- we felt more confident;
- we were less nervous;
- the clicking/ticking lets you know that baby is alright;
- even if something happens (baby dies) you know you have tried everything.

When parents were asked the disadvantages of using a monitor:

- 15 stated 'None';
- the remaining 30 mainly commented on 'false alarms'.

The alarms averaged once a week, with the range from none to several per night. One mother who had experienced a lot of 'false alarms' was questioned further and replied, 'Actually he had stopped breathing, and the sound of the alarm started him again. I have watched that happen several times and I am sure, but for the alarm, my baby would have died'.

Other comments from parents included:

- monitors should be available for any parent who wants one;
- we would like the loan of one with our next baby;
- batteries were rather expensive - rechargeable ones would be better;
- without the monitor I am sure I would have had a breakdown;
- it was a lifesaver for all of us;
- it was my eyes and ears when I wasn't actually with the baby;
- it gave us such security, we could not have managed without it.

4.E.3. WEIGHING SCALES AS AN ALTERNATIVE TO A MONITOR

Five parents have used scales to weigh their infant every day to enable them to monitor their baby's progress. One mother had a psychiatric history and her GP thought scales were the preferred method of monitoring, one infant had a kidney abnormality and was awaiting surgery, and three parents preferred scales.

Five families had scales and a monitor for a short period, as their infants had had to be resuscitated after severe apnoeic attacks. The parents who had both types of equipment were asked after a month to return one item, and without exception they returned the scales.

4.F. NON ACCIDENTAL INJURY (NAI)

4.F.1. NUMBERS OF CHILDREN PREDICTED AT RISK OF NAI

Infants were scored at risk of NAI from 1.4.83 only and in the subsequent two year period there were 12,375 infants who were scored at one month, of which 232 (1.87%) infants scored 3 or more risk factors. Of the 232 infants who scored at risk of NAI, 117 (50%) were at risk of NAI only, 98 (42%) were also scored at risk of SID, 6 (3%) of the families had experienced a previous child death (PCD), and 11 (5%) were at risk on all three factors (Table 4.15.). Two of the 11 infants who were at risk on all three factors subsequently died.

4.F.2. CHILDREN ON THE HAMPSHIRE SOCIAL SERVICES NAI REGISTER AUGUST 1985

The Hampshire NAI register was interrogated in August 1985 and identified 30 infants, 2.5% of the cohort of 12126 infants. 249 infants from families who had experienced a previous child death were not included in the analysis, including one infant on the register.

The month score of the cohort was compared to the number of infants on the register and it was found: the rate per thousand increased as the month score went higher; the risk of abuse roughly doubles with every 100 points of score; 24% of cases had scores of 850 or more, which were in 3.3% of the population; 45% of cases scored high risk by the month score in 9.2% of the population (Table 4.16.). The rate of increase is significantly greater than 1 ($p < 0.001$).

The number of social risk factors scored by children on the NAI register were compared with the number of infants in the same category and the risk per 1000 (Table 4.17.). The risk of abuse roughly doubles with every 100 points of score, and when 4/5 factors are present it is

Table 4.15.

Infants born in Portsmouth and South East Hampshire Health District 1.4.83 - 31.3.85 who scored High Risk of Non Accidental Injury (NAI) and/or Other Factors

Total Infants born 1.4.83-31.3.85	- 13522	
Total Infants Scored at one month	- 12375	
Total Infants who scored 3 or more risk factors	- 232	(1.87%)

Infants at High Risk of Non Accidental Injury	N	%
NAI only	117	50
NAI + Sudden Infant Death (SID)	98	42
NAI + Previous Child Death (PCD)	6	3
NAI + SID + PCD	11	5
Totals	232	100

Table 4.16.

Portsmouth Infant Surveillance
Comparison of the Month Scores of Infants born in the Health District between 1.4.83 - 31.3.85 who were listed in August 1985 on Hampshire Social Services Non Accidental Injury (NAI) Register and those who were not listed on the NAI Register

Month Score	Infant Population N	Infant Population % population	Cases on NAI Register N	Cases on NAI Register % cases	Case per 1000 Infant Population
<450	710	5.9	0	0	0
450-	3178	26.2	1	3.4	0.3
550-	4516	37.2	7	24.2	1.6
650-	2611	21.5	8	27.6	3.1
754-	714	5.9	6	20.7	8.4
850-	262	2.2	4	13.8	15.3
1000-	135	1.1	3	10.3	22.2
Totals	12126	100	29	100	2.4

Infants whose families had experienced a previous child death were not included in this anaylsis.

The risk of abuse roughly doubles with every 100 points of score.

95% Confidence Interval (1.7 : 2.8)

Table 4.17.

Portsmouth Infant Surveillance
Comparison of the Social Risk Factors scored by Infants
born in the Health District 1.4.83 - 31.3.85 who were listed on
Hampshire Social Services Non Accidental Injury (NAI) Register
in August 1985 and those Infants who were not listed on the Register

Number of Social Risk Factors	Infant Population		Cases on NAI Register		Cases per 1000 Infant Population
	N	%	N	%	
0	8407	69.3	5	17.2	0.6
1	2873	23.7	5	17.2	1.7
2	628	5.2	8	27.6	12.7
3	167	1.4	5	17.2	29.9
4/5	51	0.4	6	20.8	117.6
Totals	**12126**	**100**	**29**	**100**	**2.4**

Infants whose families had experienced a previous child death were not included in this analysis

Logistic Regression - risk increases 3.8 fold per risk factor.

95% Confidence Interval (2.95 : 4.95)

196 times greater than when none are present.

When SID and NAI risk factors are considered together it appears that only the increase of risk with social risk score is significant. Given the number of social risk factors, the risk does not increase significantly as the month score increases ($p>0.05$), but given the month score the risk increases sharply as the risk factor increases ($p<0.01$) (Table 4.18.A.).

Table 4.18.B shows no discontinuity of risk associated with intervention, for example when two risk factors were present the rate of risk for those scoring 650-753 was 7.9 per 1000, the corresponding risk when 3 or more factors were present was 23.3 and when 2 risk factors were present and the score exceeded 754 the risk was 28.8. despite the fact that both of these groups had intensive surveillance. It is possible that some cases of mild abuse were not known and increased surveillance could have identified more cases. If so this factor might mask the benefits of intervention.

These results however are from only a preliminary study and further investigation needs to be carried out.

In the 249 families who had experienced a previous child death there was only one family with an infant on the child abuse register in August 1985, which does not suggest a previous child death is a useful indicator of child abuse.

4.F.3. HEALTH VISITORS PREDICTORS OF NAI

The 4 week form completed by health visitors contains a question: "Would you consider this baby to be at High Risk of NAI? -Yes/No".

Analysis on 6680 children born 1.4.83-31.3.84 and scored for NAI indicated that 160 infants were at risk, 88 males and 72 females. Health

Table 4.18.

Portsmouth Infant Surveillance -
Comparison of Cases listed on the Hampshire Social Services Non Accidental Injury (NAI) Register in August 1985 with Infants who were not listed on the Register, who were all born in the Health District between 1.4.83 and 31.3.85. by A) Month Score and the Number of NAI Risk Factors plus B) Rate of Cases of Abuse per 1000 population

A) Month Score and the Number of NAI Risk Factors

	Month Score	Number of NAI Risk Factors 0	1	2	High Risk Group 3	4/5	Total
	<550	3489(1)	359(0)	36(0)	3(0)	1(0)	3888(1)
	550-	3467(2)	892(2)	130(0)	23(2)	4(1)	4516(7)
	650-	1168(2)	1103(2)	254(2)	69(0)	17(2)	2611(8)
High Risk Group	754-	195(0)	336(1)	127(3)	41(0)	15(2)	714(6)
High Risk Group	850-	71(0)	119(0)	51(2)	14(2)	7(0)	262(4)
High Risk Group	1000+	17(0)	64(0)	30(1)	17(1)	7(1)	135(3)
	Totals	**8407(5)**	**2873(5)**	**628(8)**	**167(5)**	**51(6)**	**12126(29)**

Infants whose families had experienced a previous child death were not included in this analysis.

Cases on the register are noted in brackets.

18 of the 29 cases of abuse (62.1%) are in the high risk groups comprising 10.1% of the population. Conversely only 11 of the 29 cases (37.9%) are in 89.9% of the population that are low risk.

Rate of increase per factor when the month score is constant is 3.45.

95% Confidence Interval (2.51 : 4.64)

Table 4.18. continued

B) Rate of Cases of Abuse per 1000 Infant Population

Month Score	0	1	2	High Risk Group Scoring 3+ Factors
< 550	3489(0.3)	359(0)	36(0)	4(0)
550-	3467(0.6)	892(2.2)	130(0)	27(111.1)
650-	1168(1.7)	1103(1.8)	254(7.9)	86(23.3)
High Risk Group Scoring 754 or more				
754+	283(0)	519(1.9)	208(28.8)	101(59.4)

Rate of cases per 1000 infant population is identified in brackets visitors' estimation of risk on the 6,680 children was 79 infants, 43 males and 36 females (Table 4.19.A.). It would appear that the health visitors think that the scoring system is overestimating the number of children at risk, although in 742 cases their assessment of risk was unknown as the question was not answered. The health visitors justified not answering this question because of their fears of litigation, for example, if a particular child came under investigation they thought questions might be asked why they had made a decision regarding risk and then not acted accordingly. This fear seems unjustified considering 85% of infants who were not assessed had no risk factors.

There was 97.5% agreement on whether infants were at risk or not between health visitors' opinions and the scoring factors predicting NAI (Table 4.19.B.). However, although all of the health visitors were aware of the scoring factors, some appeared to disregard them and rely on their subjective judgement, as they indicated 106 infants with three or more NAI factors were definitely not at risk, and 23 infants with none or only one factor were estimated to be at risk (Table 4.19.A.).

It was decided as a result of the analysis of health visitors' opinions regarding NAI risk to investigate their criteria for arriving at that opinion. Thirty five health visitors (29% of the total health visitors in the District) were asked to complete a questionnaire listing five factors in order of importance to predict infants at risk of NAI (Appendix 35.). The responses to the questionnaire included 13 different types of answers which were scored so that the most important factor listed first scored five and the least important factor scored one.

'Social factor' although only once listed first, was listed by 80% of health visitors and it scored the highest number of points. Social

Table 4.19.

Health Visitors' Assessments as to whether Infants were At Risk of Non Accidental Injury compared with the Number of Predicting Factors scored on the Infant Surveillance System, on 6680 Infants born 1.4.83 - 31.3.84 in Portsmouth and South East Hampshire Health District

A) Comparison of Health Visitors' Assessments and Predicting Factors

HV's Assessment ofInfants at risk of NAI	Sex	Number of Factors Predicting NAI							Total
		0	1	2	3	4	5	6	
Yes	M	1	6	14	13	9	0	0	43
	F	5	11	7	7	5	1	0	36
No	M	2124	715	160	46	11	0	0	3056
	F	1974	638	142	39	10	0	0	2803
Unknown	M	321	32	18	6	3	0	0	380
	F	307	32	13	6	4	0	0	362
Total	M	2446	753	192	65	23	0	0	3479
	F	2286	681	162	52	19	1	0	3201

B) Summary of aggreement of Health Visitors Assessment and Predicting Factors

HV's Assessment of Infants at Risk of NAI	Number of Factors Predicting NAI		Total
	<3	3+	
Yes	44	35	79
No	5753	106	5859
Total	5797	141	5938

Health visitors were aware of the scoring factors and of the information on the birth forms when they made their assessments. 5788 (97.5%) of the health visitors' assessments and predicting scores were in agreement. The 742 unknown assessments were excluded from this analysis factor was closely followed by parental state, parental background, young parents, previous child abuse, etc., (Table 4.20.).

A history of previous child abuse was most frequently stated by health visitors as the most important factor in predicting NAI, followed by unwanted baby for various reasons, parental attitude, parents themselves were victims of child abuse, parental emotional state, young parents, single parents, etc. (Table 4.21.).

4.G. DATA RELATING TO THE 51 POSSIBLY PREVENTABLE POSTPERINATAL DEATHS (PPPD) IN THE PORTSMOUTH STUDY WHO WERE BORN 1.1.82-31.3.85.

The pilot study in Gosport was too small to assess the impact of the intervention programme on mortality beyond noting that postperinatal mortality was less than it had been for several years, so details of all of the 51 PPPD in the The Portsmouth Study are considered together in this section.

4.G.1. TRENDS IN PPPD

PPPD included in this analysis include deaths occurring between one week and one year which were due to SID, infections, accidents and NAI. Details regarding the dead infants have been acquired from local sources, which were cross checked for completeness against special tabulations prepared from data tapes (made available by the OPCS) relating to all infant deaths.

These data tapes have also made it possible to examine trends in births and various categories of infant deaths in Gosport Borough and in Portsmouth Health District from 1965-1987 and in Wessex Region from 1974-1987 (Wessex as it is currently recognised was only established in

Table 4.20.

Health Visitors' Perception of Factors Predicting Infants at Risk of Non Accidental Injury (NAI)

Ranking	Health Visitors' Factors for Predicting Infants at Risk of NAI	Total Point Scores
1	Social - home environment, unemployment	80
2	Parental 'State' - violence, stress, unity	72
3	Parental background - victims of abuse	53
4	Parents - young, immature, unrealistic expectations	43
5	Siblings - victims of child abuse	43
6	Baby - unwanted, wrong sex, handicapped, premature	43
7	Baby - difficult, crying, sick, hyperactive	34
8	Mother - attitude, bonding, ability, depression	34
9	Parent - single, lonely, no support	22
10	Siblings - several, particularly under 5's	14
11	Health visitor training and intuition	8
12	Marital state - co-habitee, lodger, stepfather	7
13	Alcohol, drugs	2

35 Health visitors completed a questionnaire (Appendix 35) which asked them to 'State Five Factors, in order of Importance, which you consider predict children at risk of NAI'. The responses were scored by giving the factor listed first five points, second four points, down to the factor given last one point. Total points given to each factor is shown above

Table 4.21.

Health Visitors' Perception of the Most Important Factor Predicting Infants at Risk of Non Accidental Injury (NAI)

Rank	Health Visitors' Stated Most Important Predicting Factor	Number of times factor listed first by HVs
1	Previous child abuse	7
2	Unwanted baby - Wrong sex, handicapped, premature	6
3	Parental attitude to baby - bonding, post natal depression	5
4	Parents background - victims of childhood abuse	5
5	Parental 'state' - violence, stress, unity	4
6	Parents young, immature, unrealistic	2
7	Parent - single, lonely, no support	2
8	Social - home environment, unemployment	1
9	Baby - difficult, crying, sick, hyperactive	1
10	Siblings - several, particularly under 5's	1
11	Alcohol, drugs	1
	Total 1st Responses	35

35 health visitors completed a questionnaire (Appendix 35) which asked if they would state five factors in order of importance which they considered predicted infants at risk of non accidental injury.

1974 during the National Health Service reorganisation), allowing comparison with the rates of England and Wales (E&W). These will be discussed more fully in Chapter 5.

4.G.2. THE NUMBERS AND RATE OF PPPD

There were 51 unexpected deaths amongst infants in the study cohort of 15,060 infants a rate of 3.39 per 1000 live births.

4.G.3. THE AGES OF THE PPPD

Thirty six (70%) of the infants died in the period 2-5 months (Table 4.22., Figure 4.4.), which correspond to findings in studies considering only SIDs.

4.G.4. THE SEX OF PPPD

In the Portsmouth study 28 males died compared to 23 females. There was an extreme ratio of male/female deaths 10:1 in 1983; in 1985 there were equal numbers; but most exceptional in 1984 was a female majority of 11:6 (Table 4.23.). The variation in sex ratio is significant, $P < 0.05$, but this seems to be a chance observation.

4.G.5. THE MONTHS WHEN PPPD OCCURRED

In the Portsmouth study 76% of the infants died in the five months from December up to and including April, with the peak of nine deaths in February and March (Table 4.24.). If deaths had continued at the Summer level then 24 deaths would be expected not 51 as actually occurred

4.G.6. THE DAYS OF THE WEEK WHEN PPPD OCCURRED

Deaths were fairly evenly distributed throughout days of the week, although numbers were slightly lower on Saturday and Sunday (Table 4.25.).

Table 4.22.

Comparison of the Ages of the Possibly Preventable Postperinatal Deaths (PPPD) in the Portsmouth Study Cohort with the Percentages of Sudden Infant Deaths (SID) in England and Wales (E&W) 1983-1984

Age at Deaths (months)	Numbers of of PPPDs	% of total PPPDs	% of SIDs in E&W 1983-4 *
Under 1	3	5.9	5.9
1-2	5	9.8	19.1
2-3	14	27.5	21.2
3-4	12	23.4	17.4
4-5	10	19.6	13.0
5-6	2	3.9	7.6
6-7	2	9.9	15.8
7-8	-		
8-9	1		
9-10	1		
10-11	-		
11-1 year	1		
Total	**51**	**100**	**100**

* Figures and percentages taken from Table 2.2.

Figure 4.4.

Distribution of the Ages
of 51 Possibly Preventable Postperinatal Deaths
in the Portsmouth Study of Infants born 1.1.82. - 31.3.85.

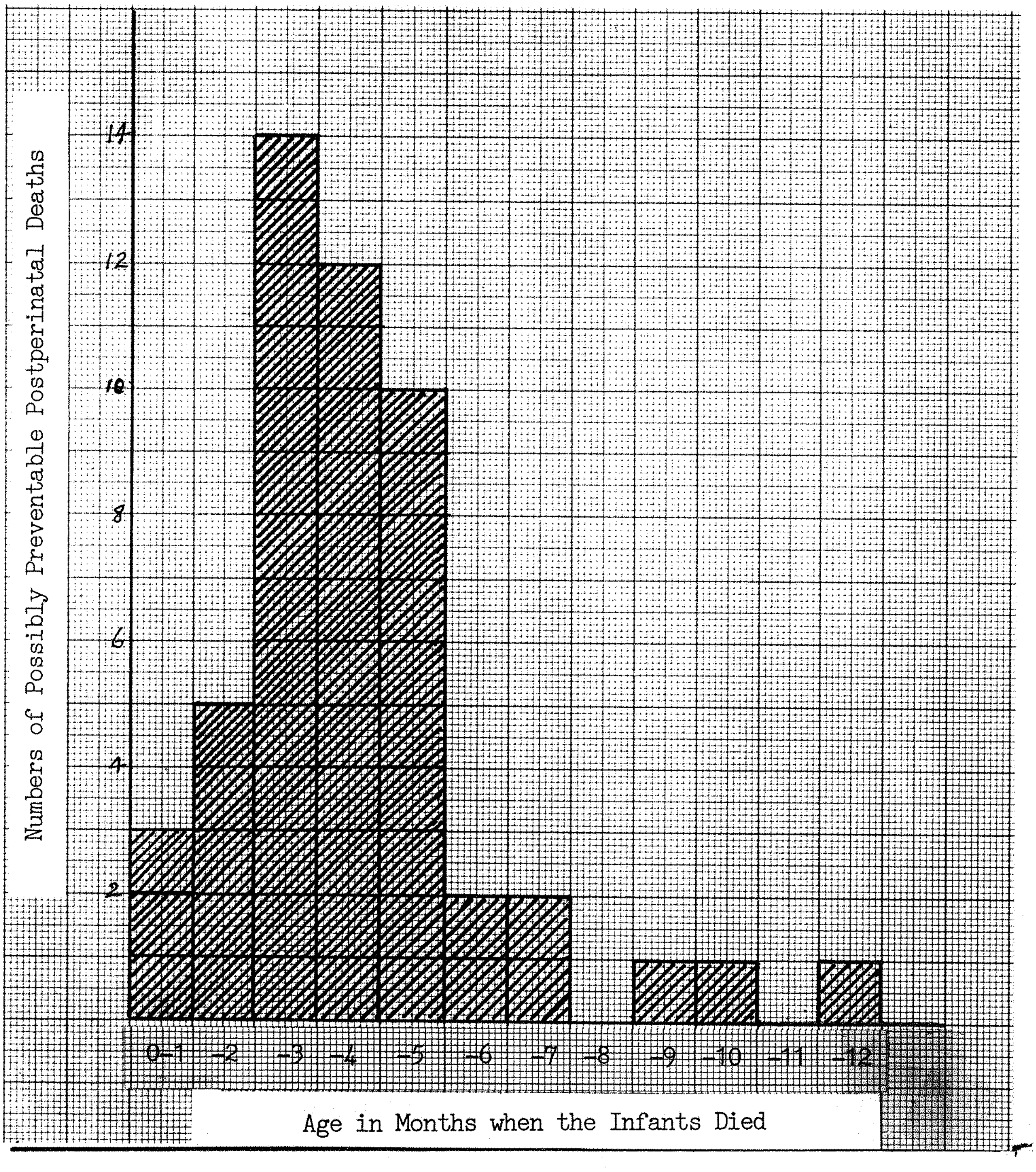


Table 4.23.

The Sex of the 51 Possibly Preventable Postperinatal Deaths in the Portsmouth Study who were born 1.1.82 - 31.3.85

Year of Death	Possibly Preventable Postperinatal Deaths		
	Male	Female	Total
1982	3	2	5
1983	10	1	11
1984	6	11	17
1985	9	9	18
1.1.86-31.3.86	-	-	-
Totals and Percentages	28(55%)	23(45%)	51(100%)

Table 4.24.

The Month when the 51 Possibly Preventable Postperinatal Deaths (PPPD) occurred in the Portsmouth Study of Infants born 1.1.82 - 31.1.85.

Month of Death	Numbers of PPPD	% of cases	
January	6	11.8	
February	9	17.6	
March	9	17.6	
April	7	13.7	
May	-	-)	
June	3	5.9)	
July	2	3.9)	
August	2	3.9)	
September	3	5.9)	23.6%
October	1	2.0)	
November	1	2.0)	
December	8	15.7	
Total and Percentage	51	100	

5 months December-April = 76.4% of the PPPDs

7 months May-November = 23.6% of the PPPDs

Table 4.25.

The Days of the Week when the
51 Possibly Preventable Postperinatal Deaths (PPPD) occurred in the
Portsmouth Study of Infants born 1.1.82. - 31.3.85.

Day of the Week	Possibly Preventable Postperinatal Deaths	
	N	% of total cases
Sunday	5	9.5
Monday	9	17.6
Tuesday	7	13.7
Wednesday	9	17.6
Thursday	8	15.8
Friday	7	13.7
Saturday	6	11.8
Totals	**51**	**100**

Mean % of Deaths per day = 14.3%

Weekend deaths (Saturday and Sunday) = 21.6%

4.G.7. THE TIME OF DAY WHEN PPPD WERE FOUND

The majority of infants (56.9%) were found dead in the quarter period of the day from 0600-1159 hours (Table 4.26.). This corresponds with the traditional grouping pattern of most studies of SIDs.

4.G.8 THE SITUATION WHERE PPPD WERE FOUND

Forty two (82.4%) of the 51 infants, were found dead in their cots, 7 (13.7%) were in their prams, and 2 (3.9%) were in their parents' bed.

A majority of the infants (72%) died in a bedroom either with their parents, with siblings or on their own, although the lounge, the hall, the car, a tent and the garden were all stated as places where they had died (Table 4.27.).

4.G.9. FEEDING PATTERNS OF PPPD

Investigation of the feeding pattern of the dead infants revealed that only 7 (13.7%) of them were reported to be wholly breast fed when they died (Table 4.28.). Nineteen (37.2%) of the dead infants were breast fed from birth compared with 73% in the total cohort whose mothers intended to breast feed them ($P < 0.001$) (Figure 4.2.A.). Three of the infants had died by one month and of the 48 surviving only 16 (33%) were being breast fed, compared with 45% of breast fed infants in the total population at one month (Figure 4.2.B.). The numbers suggest that bottle feeding may be a risk factor but they are too small for the difference to be statistically significant ($P < 0.2$).

Parents had started mixed feeding with 17 of the infants who died, three as early as 5-8 weeks, and six between 9-12 weeks; so 9 infants had actually received mixed feeding earlier than the DHSS recommendations (DHSS Report, 1984).

Table 4.26.

The Time of Day when the 51 Possibly Preventable Postperinatal Deaths in the Portsmouth Study of Infants born 1.1.82. - 31.3.85. were actually found to be dead

Time when the Infants were found Dead	Possibly Preventable Postperinatal Deaths	
	N	% of cases
0000-0559	4	7.8
0600-1159	29	56.9
1200-1759	11	21.6
1800-2359	7	13.7
Totals	**51**	**100**

Table 4.27.

The Situation and Environment in which the 51 Possibly Preventable Postperinatal Deaths occurred in the Portsmouth Study of Infants born 1.1.82. - 31.3.85.

Situation where Infants were Found	Possibly Preventable Postperinatal Deaths	
	N	%
Cot or Carry Cot	42	82.4
Pram	7	13.7
Parents' Bed	2	3.9
Totals	**51**	**100**

Carry Cot/Cot Situated in	N	%
Baby's Own Bedroom	17	40.5
Parents' Bedroom	8	19.0
'Bedroom'?	6	14.3
Siblings Bedroom	4	9.5
Lounge	4	9.5
Hall	1	2.4
Car	1	2.4
Camping Site	1	2.4
Totals	**42**	**100**

Prams Situated	N	%
Indoors	6	86
Outdoors	1	14
Totals	**7**	**100**

Table 4.28.

The Feeding Pattern of the 51 Possibly Preventable Postperinatal Deaths in the Portsmouth Study of Infants born between 1.1.82 - 31.3.85.

A)	Feeding Pattern	Possibly Preventable Postperinatal Deaths	
		N	%
	Breast fed only	7	13.7
	Bottle fed	44	86.3
	Totals	**51**	**100**

B)	Age Bottle Feeding Commenced	N	%
	At Birth	25	56.9
	0-1 Week	1	2.3
	1-2 Weeks	2	4.5
	2-3 Weeks	2	4.5
	3-4 Weeks	3	6.8
	4-5 Weeks	5	11.4
	5-6 Weeks	3	6.8
	6-7 Weeks	0	-
	7-8 Weeks	0	-
	8-9 Weeks	1	2.3
	9+ Weeks	2	4.5
	Totals	**44**	**100**

C)	Mixed Feeding Commenced	N	%
	0-5 Weeks	0	-
	5-8 Weeks	3	17.6
	9-12 Weeks	6	35.3
	13-16 Weeks	7	41.2
	16 Weeks	1	5.9
	Totals	**17**	**100**

4.G.10. WEIGHT RECORDINGS ON ALL THE PPPD FROM BIRTH TO DEATH

Forty three infants (84%) had not changed more than two channels on their weight percentile charts from their birth weight to their last recorded weight, but 8 infants (16%) had lost weight indicated by decreases of between three and six channels (Table 4.29.). Of the eight infants who had severe weight losses:

- five were known to the paediatricians for various family or individual problems;
- one was under the care of the general practitioner for severe diarrhoea;
- one had three healing fractured ribs, which were found on postmortem;
- the remaining infant was adopted and in the care of young, inexperienced parents.

The infants' weights after death were available for only 40 of the 51 PPPD as in the initial stages of the study it was not routine procedure for the pathologists to record weights, and one infant had died in another Health District. The author was informed by two pathologists that the weight loss when an infant died would normally be no more than 100 grams, but some infants in the study had lost considerably more than that: four infants' weights had moved through two channels on the weight charts in less than five days, and one through three channels (>1 Kg) in three days (Table 4.30.). Four infants' weights had actually increased by one or two channels (.75-1Kg) from when they had been weighed one or two weeks prior to death, to when they were weighed after death.

Table 4.29.

Channel Changes from Birth Weight to the Last Recorded Live Weight on the Weight Percentile Charts of the 51 Possibly Preventable Postperinatal Deaths in the Portsmouth Study of Infants who were born between 1.1.82. - 31.3.85.

Channel Changes	Possibly Preventable Postperinatal Deaths			
	N	%	Comments on Individual infants	
+2	4	7.8		
+1	8	15.7	B.W. - 1160g, 29 weeks gestation	*
0	15	29.4	B.W. - 1100g, 28 weeks gestation	*
-1	9	17.6	B.W. - 1250g, 30 weeks gestation	*
-2	7	13.7		
-3	3	5.9	Fractured Ribs x 3 (healing) Family H/O Cystic Fibrosis Eye Infs x 3, 2 hospital admits	 * *
-4	1	2	Severe diarrhoea c/o G.P. (Weight loss 3 channels in 2 days)	
-5	1	2	Heart murmur and anaemia	*
-6	3	6	Cows' milk allergy Down's Baby, Acute pyelitis Adopted Baby with untreated pneumonia	* *
Totals	**51**	**100**		

* Indicates that these infants had been seen by a paediatrician prior to death, in addition to the routine examination after birth.

Channel Changes from the Last Recorded Live Weight
to the Post Mortem Weight on the Weight Percentile Charts of
40 of the Possibly Preventable Postperinatal Deaths
in the Portsmouth Study on Infants born between 1.1.82.- 31.3.85.

Channel Change	Number of Charts	Time Interval in Channel Changes
+2	1	1 (1 wk)
+1	3	2 (1 wk): 1 (2 wks)
0	11	
-1	10	2 (4d): 1 (1 wk): 4 (2 wks): 1 (3 wks): 1 (7 wks): 1 (8 wks)
-2	11	1 (2d): 1 (3d): 1 (4d): 1 (5d) 2 (2wks): 2 (4wks): 1 (6 wks): 1 (7 wks): 1 (9m)
-3	3	1 (3d): 2 (3 wks)
-4	1	1 (7 wks)
TOTAL	40	

The information in brackets is the number of days (d) or weeks (wks) in which the channel changes occurred

The cases underlined were also mentioned in the comments column in Table 4.29.

4.G.11. ILLNESSES IN THE PPPD AND IN THEIR IMMEDIATE FAMILIES

Of the 51 infants who died, only twelve of them (23.5%) had no illnesses recorded in the 3 weeks prior to death either on the health visitors' records or noted on the questionnaires completed by them. 33 infants (64.7%) had had respiratory tract infections, including four who were on antibiotics, and one infant who was prescribed Actifed and Panadol by the general practitioner. 39 (76.5%) of the dead infants had various symptoms recorded for them including gastroenteritis, excessive crying, rashes, excessive posseting, unusual restlessness, anaemia, and one infant was in a splint for treatment of congenital dislocation of her hip (Table 4.31.).

Fourteen of the 51 infants (27.5%) had been seen by a paediatrician since their birth (Table 4.32.):

- 6 had previously been admitted to hospital on one or more occasions;
- 1 had been seen for investigations as an out patient;
- 3 were very premature so had attended neonatal clinics;
- 4 had non life-threatening congenital abnormalities.

4.G.12. PATHOLOGISTS' CONCLUSIONS ON THE PPPD

The pathologists' decisions on the 51 PPPD were (Table 4.33.):

- **37 Sudden Infant Deaths** (72.4%) although these included: one infant with a very peculiar infarcted liver whose mother had taken heroin during the pregnancy; one infant who had three fractured ribs which had begun to heal; one infant who had a rectal temperature of 40c on admission even though it had already been dead for several hours; one had died whilst in bed with his mother

Table 4.31.

Illnesses experienced by
the 51 Possibly Preventable Postperinatal Deaths
in the 3 Weeks prior to Death and Illnesses in their Immediate Families
in the Portsmouth Study of Infants born 1.1.82. - 31.3.85.

Illnesses/Symptoms	Number of Infants	% of 51 Infants	Number of Families	% of Families
Nil	12	23.5	27	52.9
Respiratory Tract Infection	33	64.7	21	41.1
Gastro Intestinal Symptoms	16	31.4	1	2
Unusual Restlessness	5	9.8	-	-
Excessive Crying	3	5.9	-	-
Nappy and Other Rashes	4	7.8	1 (Measles)	2
Other comments:				
Heart Murmur/Anaemia	1	2		
Excessive posseting	1	2	1 Cystic Fibrosis	2
Congenital Dislocation of Hip (baby in a splint)	1	2		
TOTALS	**76**	**149.02**	**51**	**100**

The numbers and percentages of infants total more than 51 as some infants had several symptoms

Table 4.32.

Reasons why 14 of the 51 Possibly Preventable Postperinatal Deaths (PPPD) were known to the Paediatricians in the Portsmouth Study of Infants born between 1.1.82. - 31.3.85.

Category of Contacts	Numbers of Infants	% of 51 PPPD	Reasons why Infants were known to Paediatricians
In Patient Admission x 1	2	3.9	a) Respiratory Tract infection + fractured femur b) Vomiting + Anaemia + heart murmur
In Patient Admission x 2	2	3.9	a) [1] Diarrhoea + vomiting [2] Respiratory Tract Infection b) [1] Vomiting [2] Persistent Vomiting
In Patient Admission x 3	2	3.9	a) (B.W. - 1100g) [1] Bronchiolitis [2] Pneumonia [3] Cough + Vomiting b) [1] Eye Infection [2] Eye Infection [3] Respiratory Tract Infection
Out Patient Attendances	1	2	Posseting ++, family history of Cystic Fibrosis
Special Care Baby Clinics	3	5.9	a) B.W. - 1160g b) B.W. - 1250g c) B.W. - 2170g - Prolonged Jaundice
Congenital Abnormalities	4	7.8	a) Down's Syndrome b) Accessory Auricles c) Dislocated Hip d) Talipes
TOTALS	**14**	**27.5**	

Table 4.33.

Pathologists' Conclusions and some Comments on the 51 Possibly Preventable Postperinatal Deaths (PPPD) in the Portsmouth Study of Infants born between 1.1.82. - 31.3.85.

Pathologists' Conclusions	Number of PPPD	% of PPPD	Comments on Individual PPPD
Sudden Infant Death	37	72.4	1 - a very infarcted liver
			1 - 3 fractured ribs
			1 - rectal temp of 40oC
			1 - overlain by mother
SID with Infection	7	13.7	1 - rectal temp was 41.5oC
Pneumonia	3	5.9	1 - rectal temp was 41oC
Bronchiolitis	1	2	
Acute Pyelitis	1	2	Down's Syndrome
Open Verdict	1	2	Overlain by father
Infanticide	1	2	Mother c/o psychiatrist
TOTALS	**51**	**100**	

and was probably overlain;

- 7 **Sudden Infant Death with Infection**, after results were received from the histology and virology investigations;
- 3 infants with **pneumonia**;
- 1 with **bronchiolitis**;
- 1 with **acute pyelitis**;
- 1 **overlain** and recorded as 'open verdict';
- 1 **infanticide** as she was smothered by her mother.

4.G.13. ANALYSIS OF THE SCORES OF PPPD AND OF RISK RELATED INTERVENTION

Intervention is targeted on infants identified as being at increased risk by the score system and is aimed at reducing PPPD. It's effect should therefore be seen primarily in a reduction in mortality in HR infants, although increased general awareness by parents and professionals which the programme generates may also reduce the total number of PPPD.

When attempting to assess whether intervention reduced the mortality of HR infants, it is not possible simply to compare the ratio of HR to LR deaths before and after intervention because the relation of mortality to the risk predictor is not known before the study began and the month score system could not be completed on infants in the retrospective Gosport Study (Powell et al, 1983). So the method of regression discontinuity analysis is used, as described by Judd and Kenny (1981) and Carpenter (1983). The method may be described briefly as follows.

The Sheffield data used to construct the month score system shows that when plotted on a log scale, risk increases linearly with score over the whole range of scores. If HR infants receive extra care which reduces mortality one would expect a break in this relationship at the point when the extra care is applied. If the reduction in mortality is a proportional one, it would result in the straight line relationship being displaced downwards because on a log scale a proportional reduction is represented by a constant. Finally when two levels of intervention are used, as in the Portsmouth Study between April 1983 and March 1985, two breaks in the relationship between risk score and the death rate might be expected, one at a score of 754 and the second at 1000. The following analysis, described in detail in Appendix 40, examines the data for evidence of such breaks.

4.G.13.a. PPPD NOT SCORED.

Of the 51 PPPD in the study 45 infants had been scored at birth and one month but six had not been fully scored. The six infants not scored included:

- Three who died aged less than one month, this number would be expected from the age distribution of sudden infant deaths in England and Wales (Table 4.22.).
- Three infants who were born outside the District. From 1984 data it is estimated that by the median age of death, three and a half months, the corresponding population of infants born outside the area but resident in the area was 1116. Therefore, the PPPD rate of resident infants born out of the Health District was 2.7 per thousand, which is the same as the District PPPD rate for 1983-84.

The proportion of deaths not covered by the intervention programme is almost exactly as expected. In particular, it may be noted that no small high risk group of infants has been excluded from the analysis of mortality to score.

4.G.13.b. RELATION OF MORTALITY TO RISK PREDICTORS.

The crude mortality rates are tabulated in relation to each of the risk predictors; by month score (Table 4.34.A.), by the number of social risk factors (Table 4.34.B.) and in relation to a previous child death in the family (Table 4.34.C.). No account is taken of intervention nor of the inter-relationship between the risk predictors in these tabulations, they do however strongly suggest that month score, social risk score and history of previous child death are all predictors of risk.

4.G.13.c. EFFECT OF INTERVENTION.

Inspection of Table 4.34.A. shows a 66% reduction in the mortality rate between those scoring 650-753 and those scoring 754-849, although the latter group are at higher risk than the former. This is the sort of effect that would be expected if the intervention reduces mortality in the HR group. Figure 4.5. shows the death rates tabulated in Table 4.34.A. plotted on a log scale against score, together with 95% confidence intervals for the individual rates. Also shown is a logistic regression model fitted to these data. The slope of the regression line corresponds to a proportional increase in risk of 2.26 per hundred points of score with a 95% confidence interval of 1.59 to 3.21. As the score increases from 700 to 800, across the point of intervention, the risk would expect to increase from 7.1 to at least 7.1 x 1.59 = 11.3 per thousand. The observed risk in this group is 2.4 per 1000, 69% less than predicted. Thus logistic regression analysis shows a significant discontinuity occurs at the point of intervention, $p = 0.002$,

Table 4.34.

Comparison of the Risk Predictor Rate scored at one month by the 45 Possibly Preventable Postperinatal Deaths (PPPD) with those infants in the live population also scored at one month in the Portsmouth Study of Infants 1.1.82. - 31.3.85.

A) RATE ‰ BY MONTH SCORE

Month Score	Number of Infants	PPPD	Rate ‰
up to 450	774	1	1.3
450-	3479	4	1.1
550-	5168	11	2.1
650-	3108	22	7.1
754-	841	2	2.4
850-	323	2	6.2
1000+	171	3	17.5
TOTAL	13864	45	3.2

B) RATE ‰ BY THE NUMBER OF NON ACCIDENTAL INJURY (NAI) RISK FACTORS

Number of NAI Factors	Number of Infants	PPPD	Rate ‰
0	9556	20	2.1
1	3321	14	4.2
2	733	5	6.8
3	192	4	20.8
4/5	62	2	32.2
TOTAL	13864	45	3.2

C) RATE ‰ IN RELATION TO A HISTORY OF PREVIOUS CHILD DEATH

Previous Child Deaths	Number of Infants	PPPD	Rate ‰
NO	13554	42	3.1
YES	310	3	9.7
TOTAL	13864	45	3.2

corresponding to an 86% reduction in mortality in the group receiving extra care. The 95% confidence limits for the reduction in mortality are 39.3%, 96.7%

To validate the effects of intervention the 13 risk predictors which make up the month score were compared on 3325 infants in the cohort who were born 1.4.83-31.3.85 and who scored either just above or just below the cut off point of intervention. Group B comprised 714 infants who scored 754-849 and Group A comprised 2611 infants who scored 650-853. The comparison between Group B and Group A show the mother's age is significant ($p < 0.05$) and the differences in the remaining 12 risk factors are all very highly significant (Table 4.35.). The infants scoring 754-849 were therefore at significantly increased risk with respect to every risk factor compared with those scoring 650-753, so there is no reason to suppose that the discontinuity shown in Figure 4.5. is due to anything other than the effect of intervention.

Statistical analysis given in Appendix 40 shows that when all the data are analysed each of the risk predictors is statistically significant and that mortality is significantly reduced by both levels of intervention $p < 0.01$. The effect of level II intervention is almost exactly double that of level I intervention. The data cannot be adequately described by the assumption that both level I and level II intervention produce the same effects.

4.H. INFANT SURVEILLANCE - THE EVALUATION OF PARENTS AND OF PROFESSIONALS

4.H.1. PARENTAL EVALUATION

Twenty four families were visited and answered questions from a

Comparison of 2611 Infants scoring 650-753 (group a) with 714 Infants scoring 754-849 (group b) between 1.4.83 - 31.3.85, for each Risk Factor included in the Month Risk Score, Infants scoring positive to Previous Child Death excluded.

A) CONTINUOUS VARIABLE

Variable	Average Difference b - a	Standard Error	Z	p
Mothers'Age	-0.37years	0.170	2.17	<0.05
Birth Weight	-159g	22.1	7.17	<0.001
Interval Previous Live Birth	-3.7months	0.76	4.90	<0.001
Number of Previous Pregnancies	0.33	0.054	6.13	<0.001

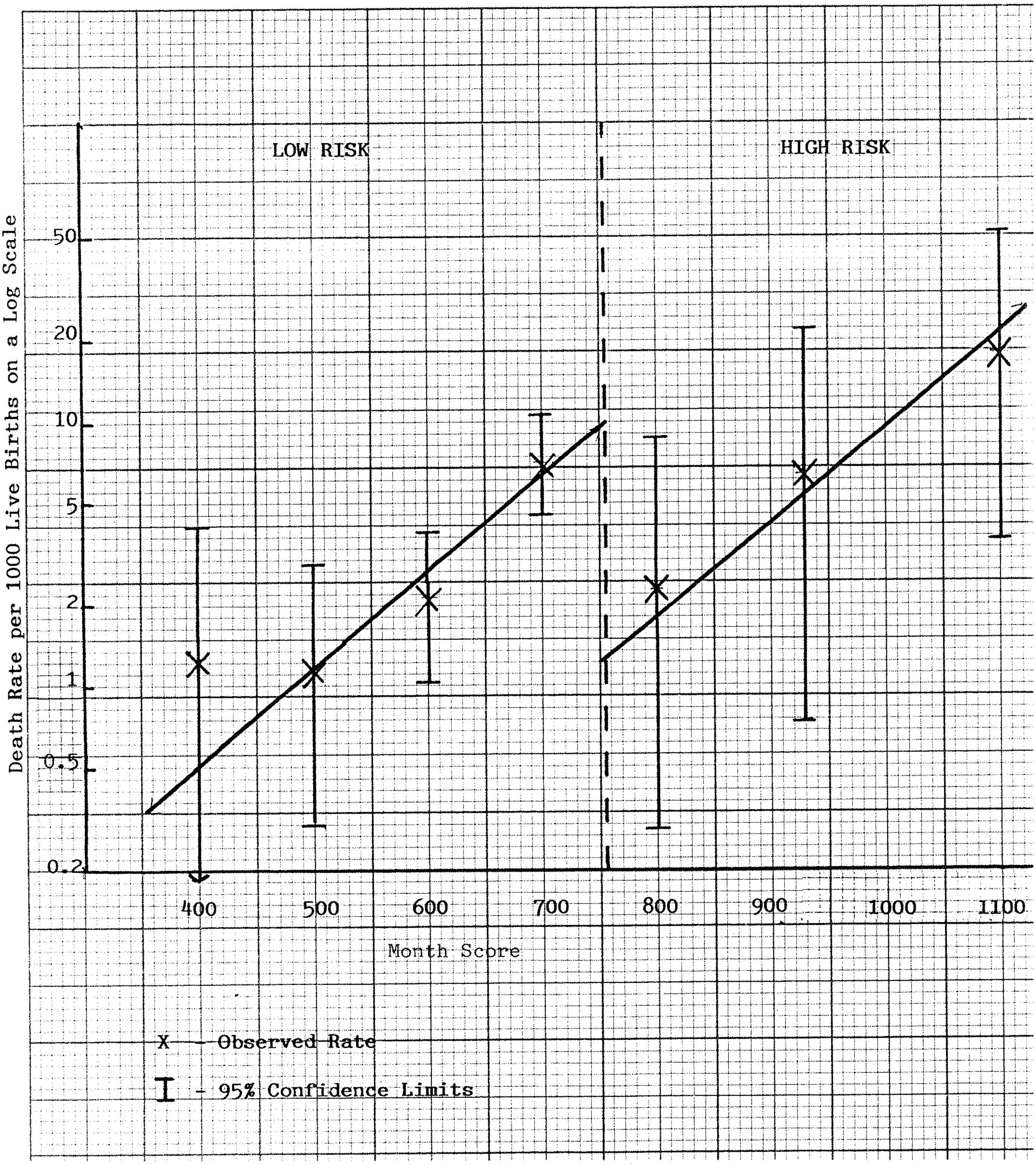
B) PERCENTAGE DIFFERENCES

Variable	Difference %b - %a	Chi squared with 1 df
Urinary Tract Infection	9.7	47.2
Bottle Fed	7.5	12.2
Labour II < 15 minutes	13.2	34.7
Mother smoking	13.7	41.3
Twin	4.0	21.1
Cyanotic Attack	7.5	113.4
Inpatient admission	10.7	126.7
Difficulty Breastfeeding	11.3	49.7
State of Repair of House etc, below average	19.8	132.1

p <0.001 for each variable.

Figure 4.5.

Death Rates per 1000 Live Births of the 45 Possibly Preventable Postperinatal Deaths scored at One Month, who were born 1.1.82-31.3.85. in the Portsmouth Study, plotted on a Log Scale against Score, Together with 95% Confidence Intervals for the Rates showing fitted Logistic Regression for Low and High Risk Groups and the significant discontinuity (p = 0.002) at the dividing line between them.



semi-structured questionnaire (Tables 4.36. i-xiv). All of the mothers knew the name of their health visitor, many referred to her by her first name and five even knew the name of the relief health visitor.

The parental responses were very positive, ten mentioned particularly the doctors and health visitors being very good, and two stated they were glad they were living in Gosport.

The HR and VHR mothers were aware that they had been visited weekly, which was generally more often than they had experienced with previous infants, and all of them except one had visited a child health clinic at least once. When asked why they were visited so frequently, five replied "He/She was a High Risk/Purple Line Baby"; and when it was queried what that meant, they were all aware of the risk of cot deaths, but they were reassured "as the doctors and health visitors are doing something about it". Other replies regarding frequent visiting were, "To weigh baby; Premature Baby; Apnoea Attacks; and Postnatal Depression".

38 comments were received about why they liked being visited at home (Table 4.36.xi.), which included 17 who stated - it was more convenient or more time was available, whilst only 2 mothers stated they did not like to be visited without warning. 75% of the HR/VHR mothers preferred to be visited at home instead of attending a clinic, compared with only 25% of the LR/VLR mothers (Table 4.5.).

When asked what type of problems they discussed with health visitors, the HR/VHR mothers generally gave multiple answers of, "Anything/everything; the children; us;" whilst the LR/VLR mothers gave more simple answers and were very much more child orientated.

Table 4.36.

The Collated Replies of 24 Parents of Infants in the Portsmouth Study who were visited at Home and asked Questions regarding Health Visitors, Home Visiting, Child Health Clinics and Services for Children from a Semi Structured Questionnaire - Appendix 34.(i) and 34.(ii)

Key
VHR - Very High Risk; month score 1000 or more
HR - High Risk; month score 754-999
LR - Low Risk; month score 500-753
VLR - Very Low Risk; month score less than 500
Y = Yes N = No

i) Question - How many children do you have?

Answers	n
1 child	9
More than 1 child	15
TOTAL	24

ii) Question - Who is your health visitor?

Results	n
Mothers who knew the name of their health visitor	24
Mothers who also knew the name of the relief health visitor	5

iii) Question - How often does your health visitor visit?

Risk Category	n	Frequency of visits
Very High Risk Infant	5	Every Week
	1	Whenever Needed
High Risk Infants	3	Every Week
	3	Twice Each Week
Low Risk Infants	1	Daily Initially
	4	2-3 Times Since Birth
	1	1 Since Birth
Very Low Risk Infants	2	1-2 Since Birth
	2	2-3 Since Birth
	2	4 Since Birth
TOTAL	24	

Table 4.36. continued

Parental Replies to Questions about Services for Children

v) **Question - Do you attend a baby clinic?**

Mothers of:	Y	N	Comments
Very High Risk Infants	5	1	premature twins
High Risk Infants	6	-	
Low Risk Infants	5	1	postnatal depression
Very Low Risk Infants	6	-	
TOTAL	**22**	**2**	

vi) **Question - Which clinic do you attend?** - appropriate answers

vii) **Question - What do you like about the clinic?**

Replies	n
It's friendly	7
Health visitors are helpful	6
To meet other mothers	3
Leaflets/toys available	3
To weigh baby	3
To get baby's milk	3
It's a clinic	1
It's alright	1
TOTAL	**27**

Some mothers gave more than one answer giving a total of more than 24.

viii) **Question - What do you dislike about the clinic?**

Comments	n
Nil	12
It's a clinic	3
Lack of Safety	3
Feels Impersonal	1
Too far away	1
Waiting	1
Overcrowded	1
Rowdy	1
People look at you	1
TOTAL	**24**

Parental replies to questions about services for children

ix) Question - Why does the health visitor call as often as she does?

Replies	n
He was a High Risk/Purple Line Baby	5
To weigh baby	3
Baby premature	2
Had an apnoea attack	2
Twins	1
Post Natal Depression	1
Don't know	1
Not applicable to ask	9
TOTAL	**24**

x) Question - What do you like about being visited at home?

Replies	n
It's convenient	10
More time/relaxed	7
Reassuring/useful	3
It's nice	3
She cares	3
She comes whenever I need her	3
She gave me her home number	3
It's private	2
Here is where the problems are	1
It's alright/nil	3
TOTAL	**38**

Some mothers gave more than one answer which resulted in a total of >24.

xi) Question - What do you dislike about being visited at home?

Replies	n
Nil	22
Surprise visits	2
TOTAL	**24**

Parental Replies to Questions about Services for Children

xii) Question- What type of problems do you discuss with your health visitor?

Comments	n
Anything/everything	14
Children	20
Parents	9
Extended family	1
Housing	1
TOTAL	45

Some mothers gave more than one answer giving a total greater than 24.

Category of Mothers	Multiple Answer	Simple Answer Children Orientated
Very High Risk Infants	6	-
High Risk Infants	5	1
Low Risk Infants	3	3
Very Low Risk Infants	2	4
TOTAL	16	8

xiii) Question - Who would you contact in a medical emergency?

Replies	n
General Practitioners	18
Health Visitor	4
Hospital	1
My friend	1
Total	24

xiv) Question - Would you like to make any comments or suggestions about the services for children?

Comments	n
Doctors and health visitors are very good	10
Need more playgroups/mum and toddler groups	6
Everything is alright	4
I'm glad we live in Gosport	2
More information on what is available	1
Nil	1
TOTAL	24

4.H.2. HEALTH VISITORS' EVALUATION

The introduction of risk related intervention has changed the pattern of the health visitor's work more than that of any other professional.

Twenty health visitors, one sixth of the district total, completed anonymous questionnaires asking for three advantages, three disadvantages and their overall opinion of the Infant Surveillance System (Appendix 32.).

The replies to the questions were given a numerical score of 3 for the first answer, 2 for the second and 1 for the third. The replies regarding the advantages were, in descending order:

- improved monitoring of all babies;
- improved relationships with parents;
- increased parental awareness of their children;
- improved liaison within Primary Health Care Teams;
- to the lowest response - valuable to research (Table 4.37.A.).

The replies regarding the disadvantages of Infant Surveillance were also given a numerical score, and 'Nil' had a resounding lead of 45 points. The health visitors were very concerned, however, about:

- the extra anxiety it could create for parents;
- other age groups were given less time and attention because of the extra demands;
- extra paperwork was created;
- professional judgement could be undermined;
- a reduction in clinic attendances (Table 4.37.B.).

The health visitors' overall opinions of the Infant Surveillance system were very positive, and many commented **their health visiting practice had improved** because of the use of clear objectives, a

Table 4.37.

Portsmouth Infant Surveillance System -
The Collated Replies of 20 Health Visitors who were asked to state their opinions as to its Advantages and Disadvantages (Appendix 32)

A) ADVANTAGES	POINT SCORE
Improved monitoring of infants, weighing, charts, etc.	34
Improved relationships with parents	28
Increased parental awareness of their children and their improved readiness to ask for help	16
Reduction in the numbers of S.I.D.s	10
Improved liaison within the Primary Health Care Team	10
Highlighting of Children at Risk	10
Reassuring to Parents	5
Improves health visiting	4
Better facilities for staff, eg. scales and percentile charts	2
Valuable to research	1
Total	**120**

B) DISADVANTAGES	POINT SCORE
Nil	45
Anxiety for parents	28
Time consuming, other groups suffer	20
Extra paperwork involved	11
Stress for professionals	6
Could reduce professional judgement	5
Parents feel overprotected	3
Reduction in clinic attendances	2
Total	**120**

Key:- The first answer was given a score of 3 points, the second 2 points and the third 1 point, allowing an overall score to be given.

C) HEALTH VISITORS' OVERALL OPINIONS OF INFANT SURVEILLANCE	n
Beneficial to Portsmouth, excellent system, useful tool	8
Improves health visiting, clear objectives, staff feel effective	6
Improved care, helpful, constructive	3
Worth doing, would not like it to stop	1
I would do it wherever I worked	1
Very good - it's better for babies	1
Total	**20**

constructive approach, the availability of extra facilities for example scales and percentile charts, and it helped them to feel more effective (Table 4.37.C.). Some health visitors also stated:

- it was a useful tool;
- it improved care to the families who needed it;
- it contributed to research;
- it was an excellent system very well worth doing;
- would not like it to be stopped;
- would use the system wherever I am health visiting.

4.H.3. <u>GENERAL PRACTITIONERS' EVALUATION</u>

All of the forty general practitioners in Gosport were sent a questionnaire (Appendix 33.) to establish their opinion of the Infant Surveillance System and replies were received from 30 of them within two weeks (10% of the total general practitioners in the Health District). A majority of the replies were very positive.

The general practitioners stated the Infant Surveillance System was beneficial because:

- it is an alerting system allowing special care of infants most at risk and therefore making the best use of limited resources.
- it involves parents, which allows greater co-operation, and education;
- it encourages closer liaison and co-operation between the members of the Primary Health Care Team (Table 4.38.A.).

The disadvantages of Infant Surveillance were concern about increasing parental anxiety and the greater demand of GP time, although several general practitioners stated that this was acceptable. It was very encouraging to find eleven general practitioners (37%) stated

Table 4.38.

Portsmouth Infant Surveillance System - The Collated Replies of 30 General Practitioners who completed questionnaires stating their Opinions as to its Advantages and Disadvantages (Appendix 33)

A) ADVANTAGES	POINT SCORE
Alerting System	32
Special care of those in need, allocation of scarce resources	25
Reduction in SIDs	25
Parents reassured, involved, educated	18
Increased primary health care team relationships, morale, motivation, job satisfaction	18
Improved resources - percentile charts, policies, communication, information	13
Improved care of all infants	3
Total	134

B) DISADVANTAGES	POINT SCORE
None	78
Anxiety of parents	30
Time consuming, more work	9
Concern re low risk care	5
Computer print out - layout, size	5
Total	127

Key:- The first answers were given a score of 3 points, the second 2 and the third 1 point, allowing an overall score to be given. Some general practitioners did not give three items in each section.

C) GENERAL PRACTITIONERS' OPINIONS OF INFANT SURVEILLANCE	N
Very worthwhile, useful, excellent, works well, must continue	24
Theoretically good - we would probably have assessed risk anyway	1
I treat all paediatric problems with the same amount of care, regardless of score factor	1
Reservations re long term over reliance on doctors, when parents should be more self reliant	1
You have even got the doctors interested	1
Not relevant in small practice, where all patients and conditions are well known	1
No room for complacency	1
Total	30

'None' to the question of "Disadvantages of the Infant Surveillance System?" (Table 4.38.B.).

The general practitioners also gave 30 general opinions 24 of which were very positive and encouraging (Table 4.38.C).

4.H.4. PAEDIATRICIAN'S EVALUATION

Only one Paediatrician out of five in the Portsmouth Health District was selected at random and asked to complete a questionnaire regarding Infant Surveillance. He stated there did not appear to be any significant adverse effects on infants or families. His comments regarding advantages were:

"There is an improvement in attitude of parents to child care and hospitalisation;

resulting from expectations that growth and standard of care receive high priority, monitoring and assessment in the child's 1st year of life;

resulting from a concerted team approach, co-ordinated so that care delivery is proportional to need wherever this can be measured and predicted."

"A timely intervention in child care management", was his overall opinion.

CHAPTER 5

COMPARISON BETWEEN THE TRENDS IN INFANT DEATH RATES 1965-1988 IN ENGLAND AND WALES, WESSEX REGIONAL HEALTH AUTHORITY, PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY AND GOSPORT BOROUGH

The Portsmouth Study of Risk Related Intervention was originally designed to finish on the 31st March 1985, but the evaluation of the Study could not be completed until after the 31st March 1986 as all infants in the cohort would not have achieved the age of one year until that date.

The results of risk related intervention in March 1985 appeared to be effective, as the death rates in Gosport and in Portsmouth and South East Hampshire Health District (Portsmouth District) were less than in the years prior to intervention, so it was recommended to the District Health Authority that the Infant Surveillance System became part of the child health care programme. This proposal was accepted and continuation of the system has allowed ongoing appraisal of risk related intervention and the monitoring of trends in infant mortality.

Data tapes made available by the OPCS have allowed tables to be produced for comparisons between the rates of births and various categories of infant deaths in Gosport Borough, Portsmouth District, Wessex Regional Health Authority (Wessex) and England and Wales (E&W).

The tables comprised:

- figures from 1965-1988 inclusive for E&W and also for Gosport;
- figures for Portsmouth District from 1982-1988, whilst the figures from 1965-1981 relate to four administrative districts - Portsmouth, Havant, Fareham and Gosport which together include 93%

of births in the Portsmouth District;

- Wessex figures are only available from 1974-1988 as the Regional Health Authority was established in 1974 during the National Health Service reorganisation and previously Wessex Regional Hospital Board had slightly different boundaries.

Wessex figures in the tables exclude data from Portsmouth District to enable a clearer picture to be given. The data for Gosport is shown, but numbers of deaths in all categories are small so rates are very variable. The Gosport data is, therefore, included in the Portsmouth District data and figures for the whole Health District are presented in this analysis.

The infant death rate, that is all deaths under one year per 1000 live births, (Table 5.1. and Figure 5.1.) showed:

- the Wessex rates were HIGHER than E&W for 7:15 years;
- Portsmouth rates were HIGHER than E&W for only 7:24 years;
- but Gosport rates were HIGHER for 10:24 years.

The perinatal death rate, that is the combined numbers of stillbirths and deaths under one week per 1000 total live and stillbirths, (Tables 5.2. and Figure 5.2.) revealed:

- the Wessex rates had been consistently good until 1988, as they were LOWER than E&W on each of the 14 other accountable years;
- Portsmouth rates were LOWER than E&W for 20:24 years, although 1985 and 1987 since intervention were HIGHER;
- Gosport rates were also LOWER for 20:24 years, these are however to be considered with caution as the rate can depend on the obstetric and maternity care available and only 11-19% of Gosport infants are actually delivered in the local maternity unit, leaving

Table 5.1

Infant Death Rates 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough

Year	England and Wales	Wessex RHA excluding Portsmouth	Portsmouth & S E Hants Health Authority	Gosport Borough
1965	19.00	.	18.07	22.30
1966	19.00	.	20.42	20.65
1967	18.30	.	16.64	16.51
1968	18.30	.	19.21	16.82
1969	18.00	.	16.54	16.37
1970	18.20	.	13.90	14.28
1971	17.50	.	15.13	15.32
1972	17.20	.	14.06	11.92
1973	16.90	.	12.90	11.90
1974	16.30	15.21	13.71	12.42
1975	15.70	15.56	14.81	15.75
1976	14.30	12.89	11.91	11.83
1977	13.80	13.41	11.61	19.74
1978	13.20	12.45	11.68	11.60
1979	12.80	12.81	12.97	15.50
1980	12.00	12.48	9.78	16.22
1981	11.10	11.84	12.58	24.17
1982	10.80	10.23	10.43	11.86
1983	10.10	10.60	8.34	9.47
1984	9.50	10.01	8.61	5.55
1985	9.40	8.89	9.63	9.74
1986	9.60	8.90	9.95	9.24
1987	9.20	9.31	10.11	12.22
1988	9.00	9.09	8.43	8.86

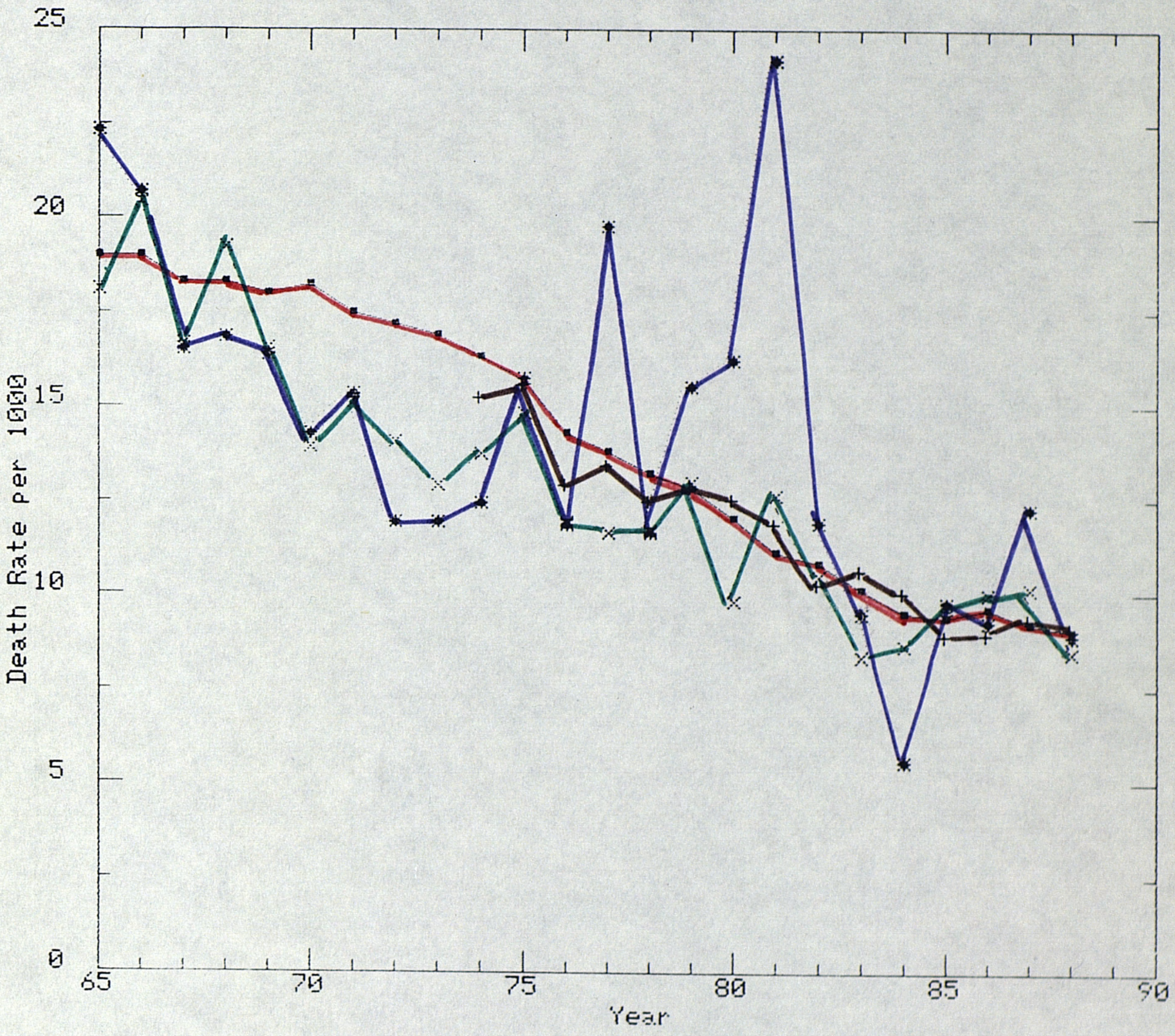
Definition: Infant Deaths - deaths at ages under one year (OPCS; DH3: 89/1)

Key: * = Risk Related Intervention

Source: OPCS

Figure 5.1.

Infant Death Rates per 1000 live births 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough.



Definition: Infant Deaths - deaths at ages under one year (OPCS; DH3: 89/1)

Key:
- = England and Wales
- = Wessex Region excluding Portsmouth
- x = Portsmouth Health District including Gosport
- * = Gosport Borough

Source: OPCS

Table 5.2

Perinatal Death Rates 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough

Year	England and Wales	Wessex RHA excluding Portsmouth	Portsmouth & S E Hants Health Authority	Gosport Borough
1965	26.90	.	24.52	18.73
1966	26.30	.	24.68	20.37
1967	25.40	.	25.34	22.76
1968	24.70	.	23.87	23.58
1969	23.40	.	19.99	14.99
1970	23.50	.	20.17	15.40
1971	22.20	.	19.45	20.19
1972	21.70	.	15.87	9.37
1973	21.00	.	18.24	14.88
1974	20.30	18.28	16.60	20.22
1975	19.30	16.68	18.84	18.88
1976	17.70	14.65	17.25	11.76
1977	17.00	14.95	17.69	17.06
1978	15.50	13.50	11.97	12.35
1979	14.70	13.13	11.38	8.49
1980	13.30	12.16	9.56	11.51
1981	11.80	9.45	10.56	11.28
1982	11.30	9.68	11.44	10.21
1983	10.40	9.37	9.48	10.98
1984	10.10	8.64	8.57	4.74
1985	9.80	8.77	10.83	14.47
1986	9.60	8.82	8.80	4.61
1987	8.90	8.06	12.05	12.96
1988	8.70	8.82	8.13	8.03

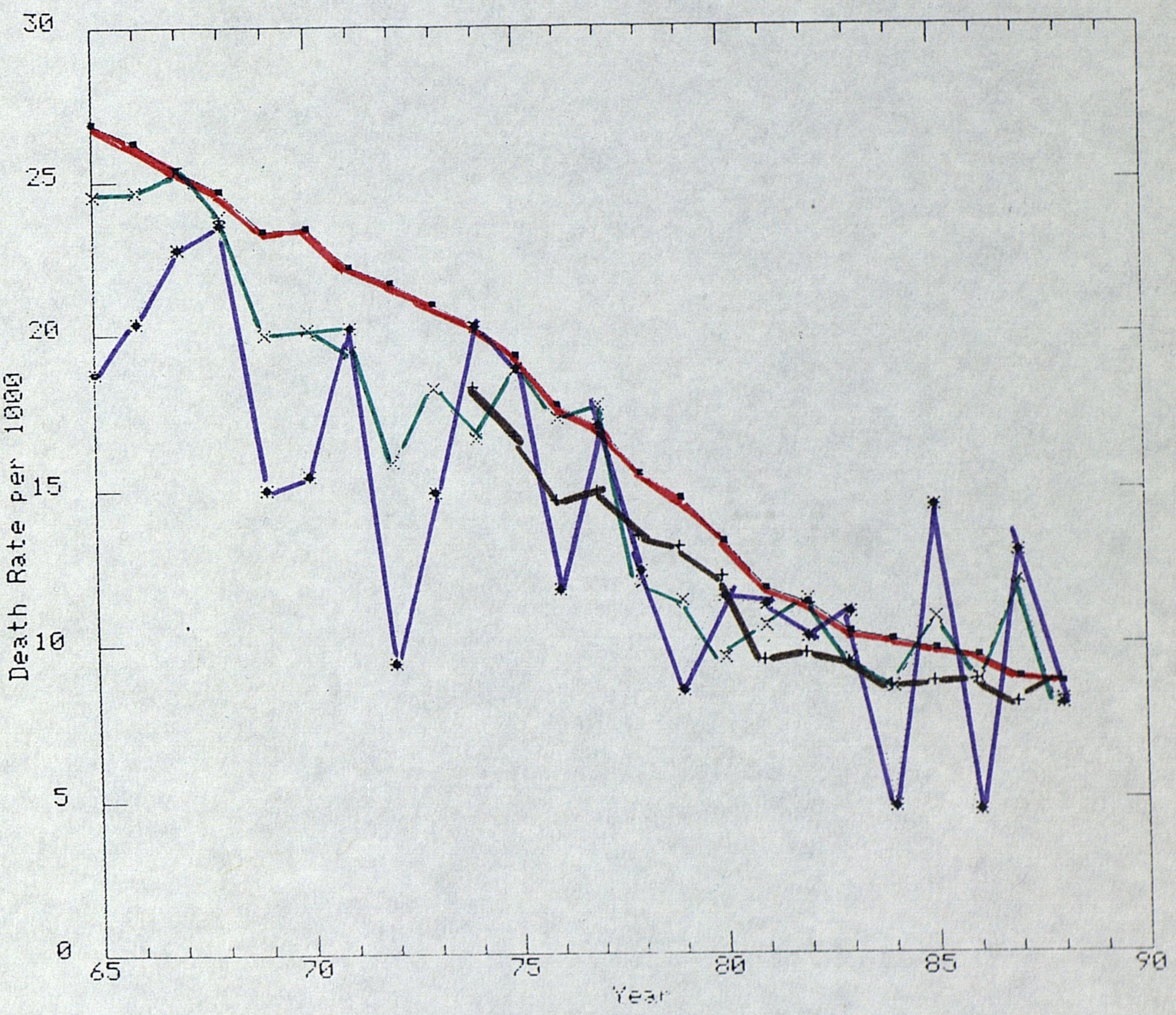
Definition: Perinatal Deaths - Stillbirths and deaths in the first week of life (OPCS; DH3; 89/1)

Key: * = Risk Related Intervention

Source: OPCS

Figure 5.2.

Perinatal Death Rates per 1000 live and stillbirths 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough



Definition: Perinatal Deaths - stillbirths and deaths in the first week of life (OPCS; DH3: 89/1)

Key:
- = England and Wales
- = Wessex Region excluding Portsmouth
- = Portsmouth Health District including Gosport
- = Gosport

Source: OPCS

a very large majority to be delivered in Saint Mary's Maternity Unit in Portsmouth.

The postperinatal death rate, that is all deaths between one week and one year per 1000 live births, (Table 5.3. and Figure 5.3.) showed:

- the Wessex rates were HIGHER than E&W for 12:15 years, and were consistently high from 1979-1987;
- Portsmouth rates were HIGHER in only 9:24 years, although 2 of these have been in the 6 years since intervention;
- Gosport rates were higher in 13:24 years including 3 in the last 7 years since intervention. Figure 5.3 shows the extraordinary high peaks of Gosport's postperinatal death rate.

A comparison of the mean postperinatal rates in the five years before intervention and the five years since intervention showed there were decreases in all areas studied. The decreases were far less in E&W (5.90 to 5.18) and Wessex (6.40 to 5.67), where sporadic intervention has occurred, compared to Portsmouth (6.61 to 5.10) and Gosport (10.54 to 5.40) who appear to have benefited from risk related intervention.

The inevitable postperinatal death rate, includes deaths occurring in the period one week to one year per 1000 live births where the infants have a condition which is incompatible with life, for example: severe congenital anomalies; respiratory distress syndrome when the infant never leaves hospital; malignant neoplasms and degenerative conditions. Table 5.4. and Figure 5.4. show:

- Wessex rates were consistently LOWER than E&W for 13:15 years;
- Portsmouth rates were LOWER than E&W for 18:24 years;
- Gosport rates were LOWER than E&W for 17:24 years, including 5 of the 7 years since intervention. This would indicate there has not been a shift in certification of the causes of death.

Table 5.3

Postperinatal Death Rates 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough

Year	England and Wales	Mean Rate	Wessex RHA excluding Portsmouth	Mean Rate	Portsmouth & S E Hants Health Authority	Mean Rate	Gosport Borough	Mean Rate
1965	7.70		.		8.57		13.51	
1966	7.90		.		9.44		13.76	
1967	7.60		.		7.41		9.25	
1968	7.70		.		8.63		7.76	
1969	7.70		.		7.07		9.45	
1970	7.60		.		4.97		6.21	
1971	7.60		.		6.56		6.81	
1972	7.40		.		7.10		6.90	
1973	7.40		.		5.70		6.89	
1974	6.90		7.48		5.26		3.65	
1975	6.60		6.80		6.52		6.63	
1976	6.20		6.23		5.18		5.52	
1977	6.20		5.99		4.42		8.58	
1978	6.10)		5.93)		5.93)		5.80)	
1979	6.00)		6.18)		7.75)		10.85)	
1980	5.80)	5.90	6.62)	6.40	5.93)	6.61	10.81)	10.54
1981	5.80)		7.27)		7.51)		17.37)	
1982	5.80)		5.98)		5.92)		7.91)	
1983	5.40]		6.27]		4.47]		4.74]	
1984	5.10]		5.98]		4.60]		4.76]	
1985	5.10]	5.18	5.20]	5.67	5.38]	5.10	4.87]	5.40
1986	5.30]		5.33]		6.08]		6.93]	
1987	5.00]		5.58]		4.99]		5.70]	
1988	5.10		4.99		5.09		4.83	

Definition: Post Perinatal Deaths - deaths over one week and under one year (OPCS; DH3: 89/1)

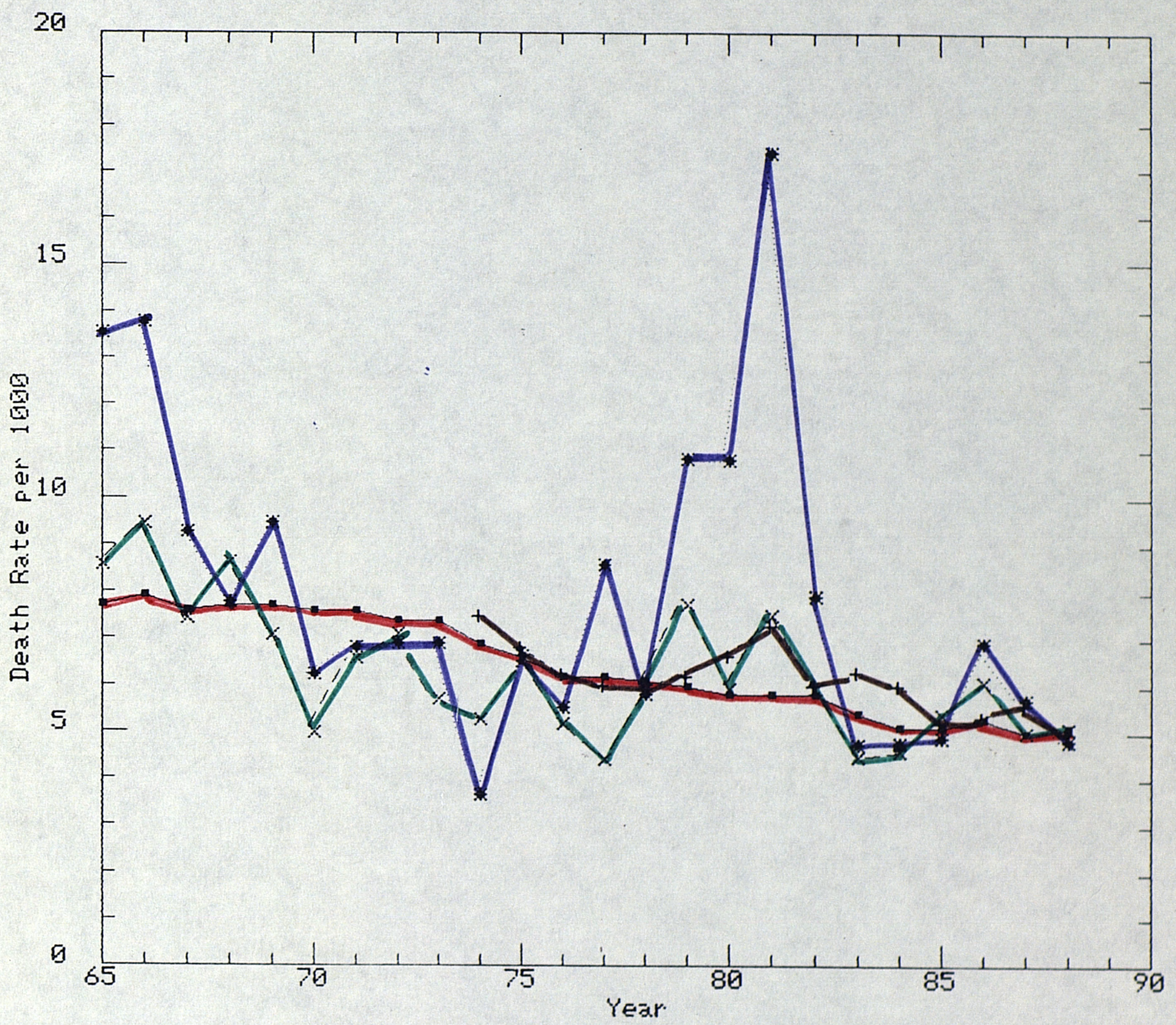
Five year periods were chosen for means as being reasonable to compare and evaluate intervention, as beyond that other factors are likely to occur.

Key: * = Risk Related Intervention

Source: OPCS

Figure 5.3.

Postperinatal Death Rates per 1000 live births 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough.



Definition: Postperinatal Deaths - deaths over one week and under one year (OPCS; DH3: 89/1)

Key:
- ■ = England and Wales
- + = Wessex Region excluding Portsmouth
- x = Portsmouth Health District including Gosport
- * = Gosport Borough

Source: OPCS

Table 5.4

Inevitable Postperinatal Death Rates 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough

Year	England and Wales	Wessex RHA excluding Portsmouth	Portsmouth & S E Hants Health Authority	Gosport Borough
1965	3.51	.	3.94	6.08
1966	3.59	.	3.42	3.44
1967	3.38	.	3.04	2.64
1968	3.37	.	3.77	3.23
1969	3.16	.	2.78	3.15
1970	3.28	.	1.40	2.48
1971	3.17	.	3.03	3.41
1972	3.19	.	2.37	1.25
1973	3.21	.	2.10	2.50
1974	3.01	3.01	1.91	0.73
1975	2.88	2.57	3.17	4.15
1976	2.73	2.16	1.38	0.79
1977	2.84	2.23	1.84	2.58
1978	2.67	2.25	2.88	1.66
1979	2.64	2.18	2.53	2.33
1980	2.58	2.36	1.76	3.09
1981	2.66	3.34	1.96	4.53
1982	2.61	2.39	1.71	0.79
1983	2.49	1.90	1.79	0.79
1984	2.42	2.66	1.93	0.79
1985	2.34	2.01	1.56	1.62
1986	2.18	1.86	3.04	4.62
1987	2.10	1.88	2.16	3.26
1988	2.20	1.64	1.34	0.81

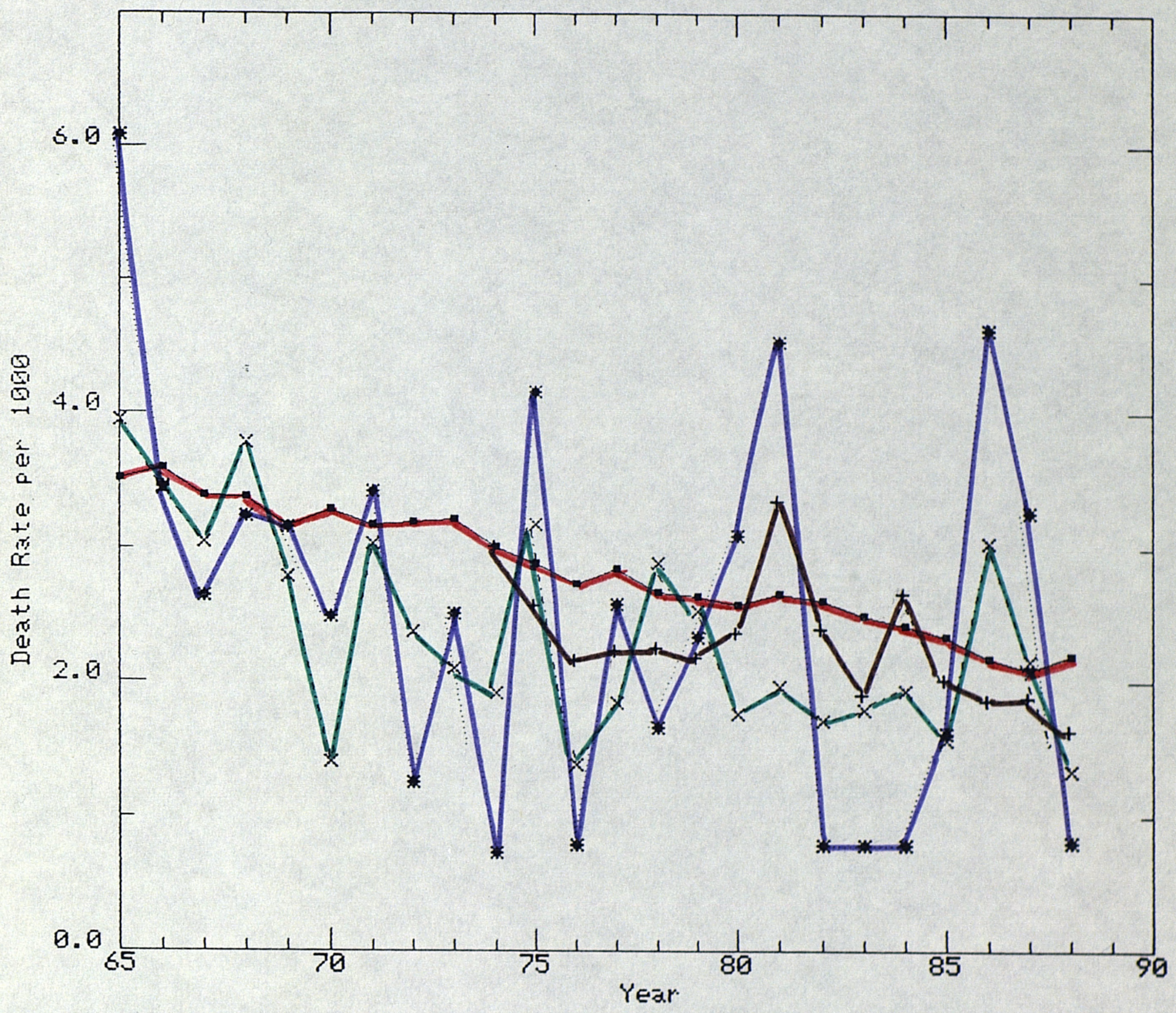
Definition: Inevitable Postperinatal Deaths - Deaths over 1 week and under 1 year from congenital abnormalities (for example severe heart lesions or neural tube defects; complications of gross prematurity; malignant neoplasms; degenerative conditions (Carpenter and Emery, 1974, 1983; Knowelden et al, 1984). (OPCS; DH3: 89/1)

Key: * = Risk Related Intervention

Source: OPCS

Figure 5.4.

Inevitable Postperinatal Death Rates per 1000 live births 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough



Definition: Inevitable Postperinatal Deaths - deaths over one week and under one year from congenital abnormalities, for example: severe heart lesions or neural tube defects; complications of gross prematurity; malignant neoplasms; degenerative conditions (Carpenter and Emery, 1974, 1983; Knowelden et al, 1984).

Key:
- England and Wales
- Wessex Region excluding Portsmouth
- Portsmouth District including Gosport
- Gosport Borough

Source: OPCS

The inevitable postperinatal death rates in the three areas studied were generally below the rate for E&W, except for peaks in Gosport, which is demonstrated in the fitted rates for Portsmouth including Gosport in Figure 5.5.

The possibly preventable postperinatal death (PPPD) rate, includes deaths per 1000 live births occurring in the period one week to one year from SIDs, infections, accidents and trauma. Table 5.5. shows:

- the Wessex rates were HIGHER than E&W in each of the 15 years which were monitored;
- Portsmouth rates were HIGHER than E&W in 12:24 years;
- Gosport rates were HIGHER than E&W in 18:24 years.

Figure 5.6. shows the abnormally high rate of PPPD in Gosport prior to intervention and although it is disappointing not all of the points after 1982 are below the ones for E&W, it is encouraging to see they are remaining consistently lower.

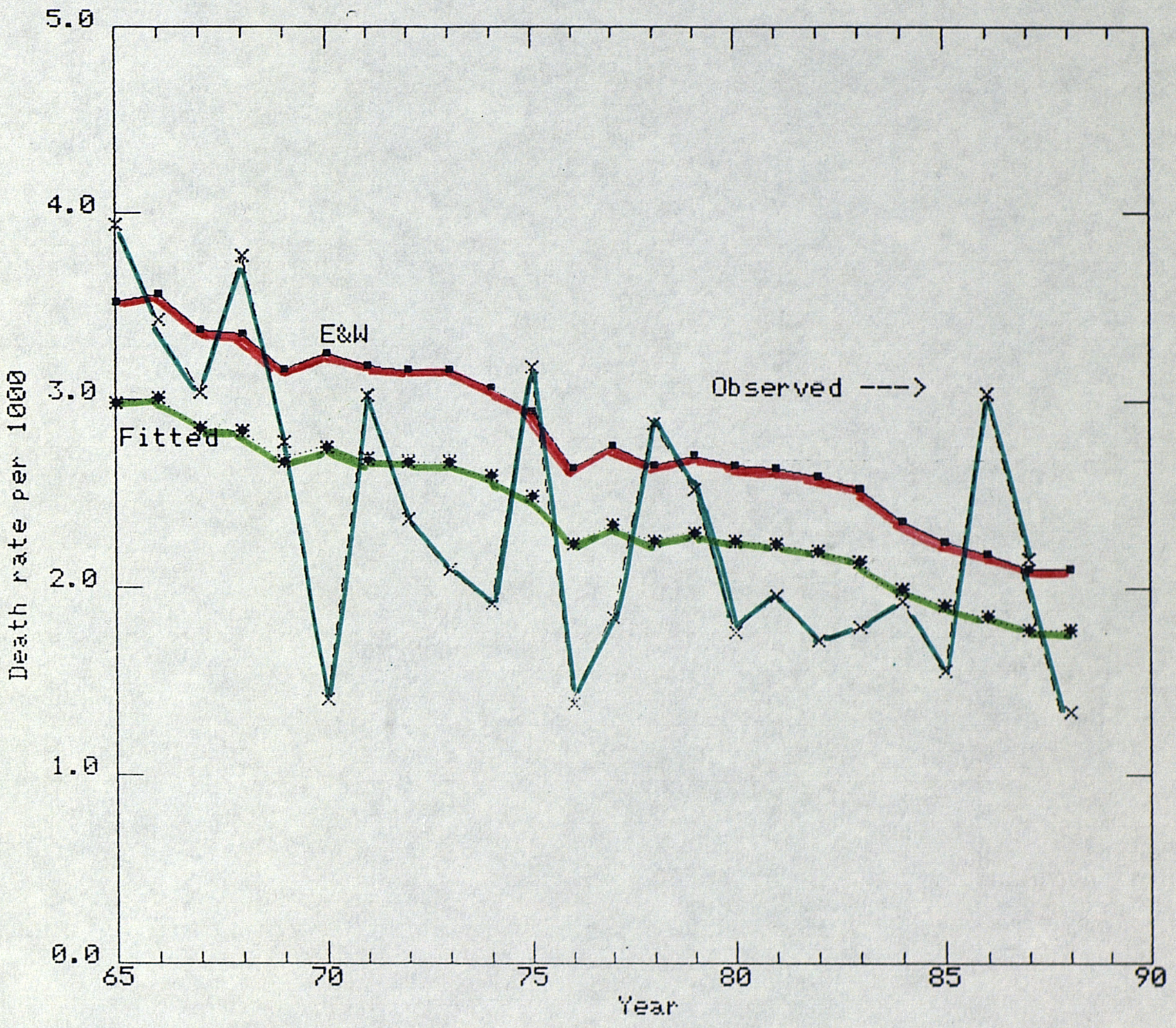
There has been a reduction in the mean rates of PPPD in all observed areas in the five year period 1983-87 when compared to 1978-82, but the reduction has been considerably greater in Gosport (60.6%) and Portsmouth (32.2%), than experienced in E&W (12.2%) and Wessex (5.4%).

It is interesting to note the PPPD rates for Wessex, without Portsmouth, have stayed consistently higher than the rates for E&W (Figure 5.7.) although this has not been shown in Portsmouth, including Gosport, where the rates have only been above E&W twice since the risk related intervention programme commenced (Table 5.5.).

A full statistical evaluation of the study is given in Appendix 40.

Figure 5.5.

Observed and Fitted Inevitable Postperinatal Death Rates per 1000 live births 1965-1988 in Portsmouth compared to the Observed Rate in England and Wales



Definition: Inevitable Postperinatal Deaths - deaths over one week and under one year from congenital abnormalities, for example: severe heart disease or neural tube defects; complications of gross prematurity; malignant neoplasms; degenerative conditions (Carpenter and Emery, 1974, 1983; Knowelden et al, 1984).

Key
= England and Wales observed rate
= Portsmouth, including Gosport, observed rate
= Portsmouth, including Gosport, fitted rate

Source: OPCS

Table 5.5

Possibly Preventable Postperinatal Death Rates 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough

Year	England and Wales	Mean Rate	Wessex RHA excluding Portsmouth	Mean Rate	Portsmouth & S E Hants Health Authority	Mean Rate	Gosport Borough	Mean Rate
1965	4.19		.		4.63		7.43	
1966	4.31		.		6.02		10.32	
1967	4.22		.		4.37		6.61	
1968	4.33		.		4.86		4.53	
1969	4.54		.		4.29		6.30	
1970	4.32		.		3.57		3.72	
1971	4.43		.		3.53		3.41	
1972	4.21		.		4.73		5.65	
1973	4.19		.		3.60		4.38	
1974	3.89		4.47		3.35		2.92	
1975	3.72		4.23		3.35		2.49	
1976	3.47		4.07		3.80		4.73	
1977	3.36		3.76		2.58		6.01	
1978	3.43)		3.67)		3.06)		4.14)	
1979	3.36)		4.00)		5.22)		8.53)	
1980	3.22)	3.27	4.26)	3.89	4.17)	4.44	7.72)	8.07
1981	3.14)		3.93)		5.55)		12.84)	
1982	3.19)		3.60)		4.20)		7.11)	
1983	2.91]		4.37]		2.68]		3.95]	
1984	2.68]		3.32]		2.67]		3.97]	
1985	2.76]	2.87	3.19]	3.68	3.82]	3.01	3.25]	3.18
1986	3.12]		3.47]		3.04]		2.31]	
1987	2.90]		3.70]		2.83]		2.44]	
1988	2.90		3.35		3.75		4.03	
Reduction in mean rate 1978-82 : 1983-87		12.2%		5.4%		32.2%		60.59%

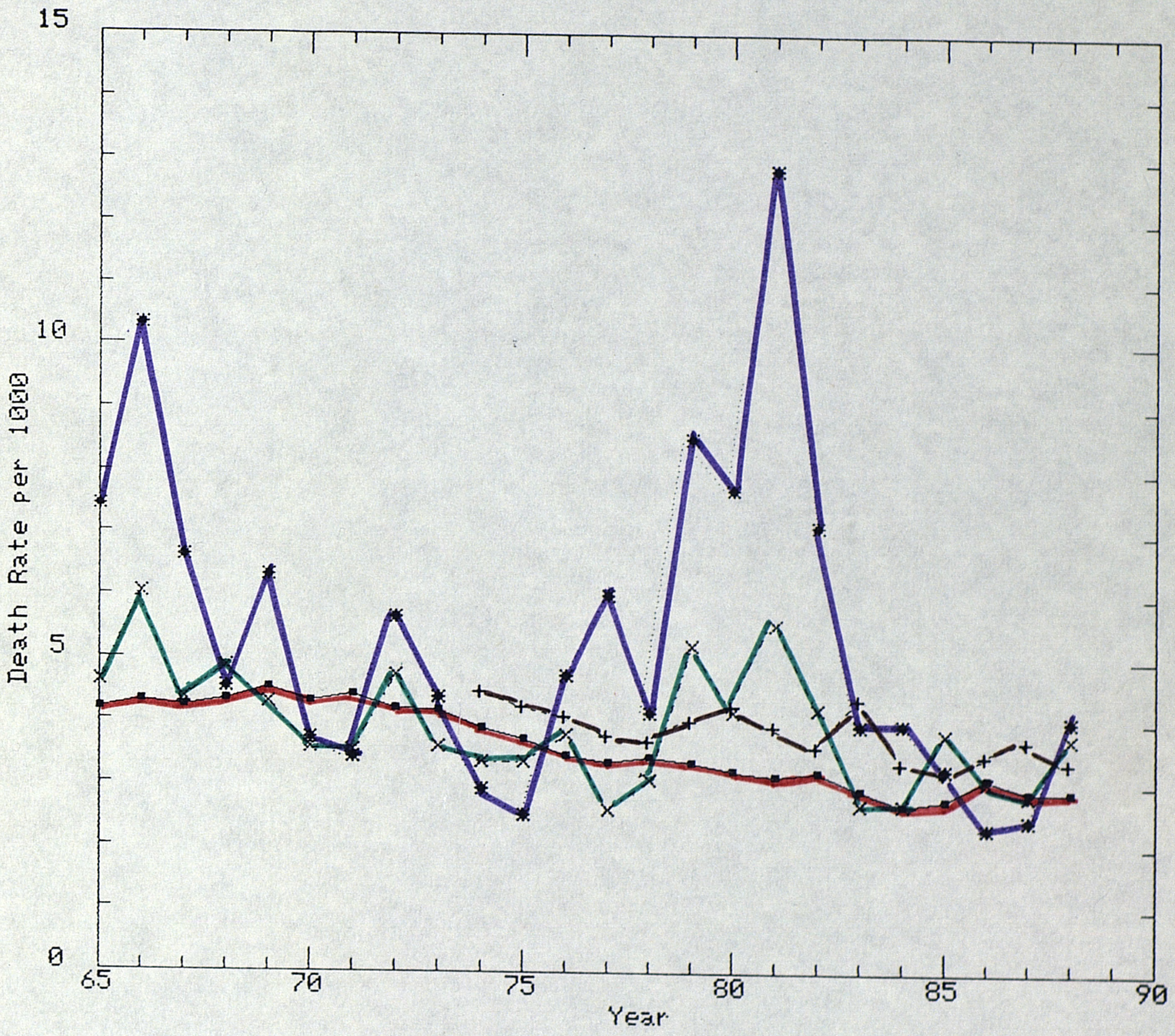
Definition: Possibly Preventable Postperinatal Deaths - Deaths between 1 week and 1 year including sudden infant deaths (SIDS) infections, accidents and non accidents (Carpenter and Emery, 1974; Gardner, 1987). (OPCS; DH3: 89/1)

Key: * = Risk Related Intervention

Source: OPCS

Figure 5.6.

Possibly Preventable Postperinatal Death Rates per 1000 live births 1965-1988 in England and Wales, Wessex Regional Health Authority, Portsmouth and South East Hampshire Health Authority and Gosport Borough



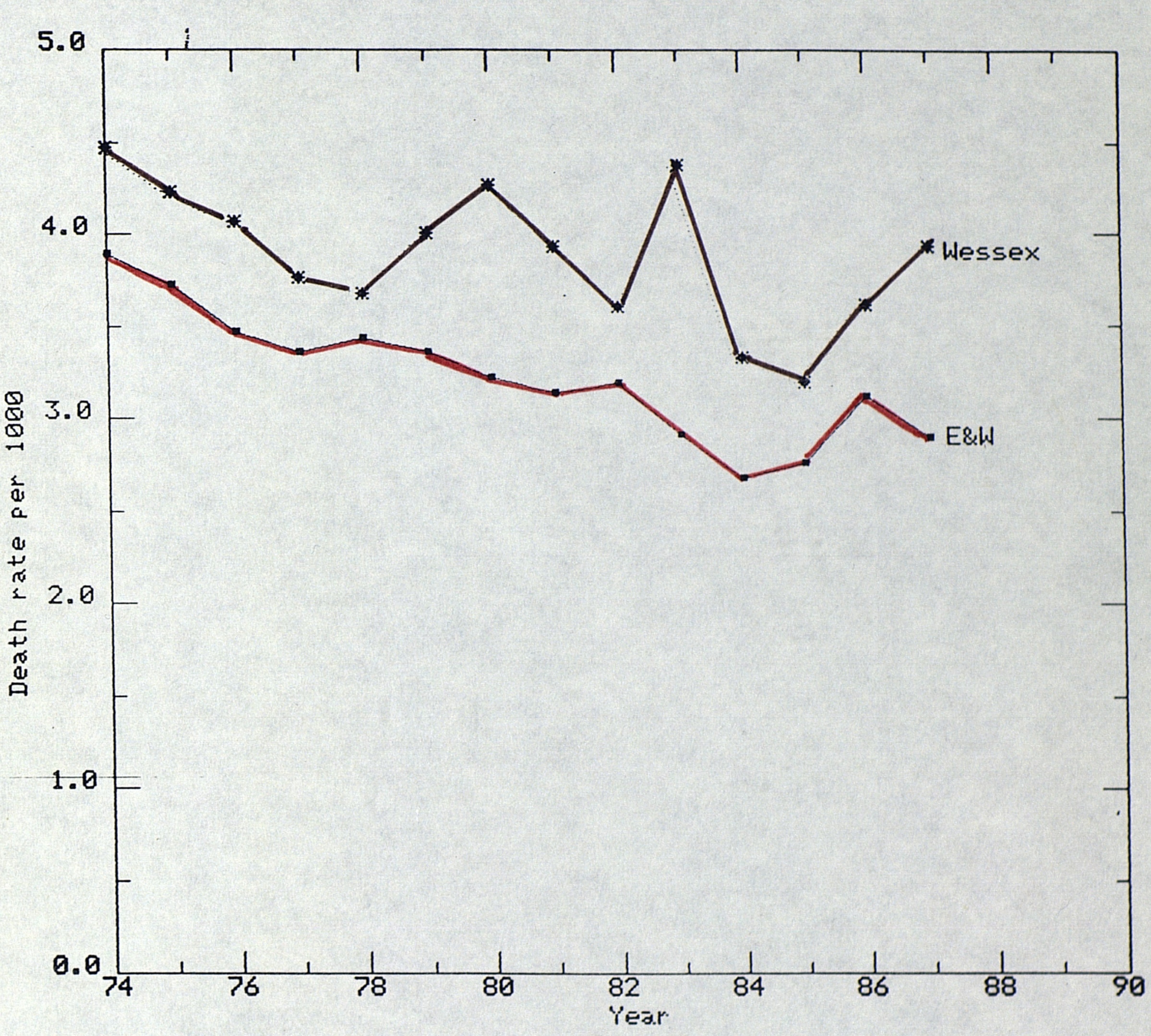
Definition: Possibly Preventable Postperinatal Deaths - deaths between one week and one year including sudden infant deaths (SIDS), infections, accidents and non accidents (Carpenter and Emery, 1974; Gardner, 1987).

Key:
- ■ = England and Wales
- + = Wessex Region excluding Portsmouth
- x = Portsmouth Health District including Gosport
- * = Gosport Borough

Source: OPCS

Figure 5.7.

Possibly Preventable Postperinatal Death Rates per 1000 live births 1974-1988 in Wessex Regional Health Authority, excluding Portsmouth, compared to England and Wales.



Definition: Possibly Preventable Postperinatal Deaths - deaths between one week and one year including sudden infant deaths (SIDS), infections, accidents and non accidents (Carpenter and Emery, 1974; Gardner, 1987).

Key: —■— = England and Wales
—*— = Wessex excluding Portsmouth

Source: OPCS

CHAPTER 6

DISCUSSION

The concept of risk classification provides a framework of reference for better planning, programming and administration of services. This was shown in a theoretical study by Alberman and Goldstein (1970) who demonstrated the formal construction and evaluation of a risk register for the detection of handicap and stated in economic terms alone it was worth categorising children into high or low risk groups and allocating resources according to need.

The principle of risk related intervention is that those at increased risk should receive more preventive care than those at lower risk. Optimal allocation of preventive resources is achieved when, as a result of redistribution of resources, the risk is the same for everyone (Carpenter, 1983).

The Portsmouth Study enabled the selection of infants at risk of PPPD, and/or of NAI, and thereby allowed limited health visiting resources to be directed to those infants indicated to be at greatest risk.

Scoring systems predicting infants at risk of PPPD, as categorised by Carpenter (1983), have been considered unacceptable by some individuals. The reasons given and counter arguments are given below:

* Risk factors and their weights are not universally acceptable so local investigations have to be completed and scores adjusted to compensate for the differences.

- The Gosport retrospective study and pilot study were advantageous as additional factors were highlighted which allowed adjustments of the Sheffield system, for example: smoking was a relevant factor; infants were indicated HR when the family had experienced a previous child death; infants who scored over 1000 were indicated VHR and were able to receive additional care which proved beneficial. Local investigations were valuable to health visitors as they were involved with the studies which heightened their awareness to research and they were also able to raise professional issues.

* It is clinically and ethically unsatisfactory to divert care from any infant by a mathematical formula with the possibility that an infant who may need treatment will not receive it.

- Low risk infants in the Portsmouth Health District have received as many home visits as were designated for all infants in the Home Visiting Policy prior to the study. However very many infants who were scored HR and VHR have received far more attention than they would have done under the previous regime.

* Experienced health visitors may resent being told when and how to visit as, in their professional opinion, it might seem inappropriate.

- Health visitors in Portsmouth have always understood that they were professionally responsible to give appropriate care and would visit more than was recommended if they considered it was necessary. Sometimes they have questioned a particular score if they thought it was inappropriate, but this was always regarded as very positive and indicated they are aware of individual infants and of the scoring system. Newly trained health visitors have been very appreciative of certain infants being selected from their case load who warranted special attention whilst they developed the professional experience necessary to allow them to select infants requiring extra care.

* Infants at risk of NAI should be recognised early then there should be prompt notification to and action by the appropriate people.

- Health visitors and general practitioners have been informed of each infant's risk factor 5-6 weeks after it's birth, which allowed appropriate health visiting contacts to be made and for general practitioners to identify their records to ensure the infant was given special attention.

I would suggest therefore the criticisms of a formal scoring system have not been justified in Portsmouth.

Instead of a formal scoring system **other options** were available:-

* We could have done nothing hoping there would be a reduction in the numbers of PPPD and that the previous high rates had occurred purely by chance.

- The very high incidence of postperinatal deaths in Gosport in 1981 made this option totally unacceptable to all of the caring professionals.

* Health visitors are constantly assessing children and families whom they meet so it should have been possible for them to select out infants at risk of PPPD or child abuse, as advocated by Madeley (1988), and for them to give extra care according to their professional decision.

- This proposal would have demanded an elaborate initial training programme by a well informed individual to enable health visitors to be made aware of current research into SIDs and recommendations of various studies, which would have necessitated considerable time away from their caseloads, so was again unacceptable. Another issue which had to be taken into consideration was the low morale of the Gosport health visitors, as one of them publicly stated 'We were all grieving' (Television South, 1984), so it would have been inappropriate to ask them to take on any additional responsibilities.

* Regular changes in child care could have been introduced, presuming that by the Hawthorne effect (Mayo, 1949), the situation would improve.

This had several disadvantages :

- a considerable amount of teaching time would have been required to constantly introduce changes;
- it would have been very difficult for managers to monitor and to assess if staff were actually carrying out the recommended changes;
- several changes might need to take place over a very long period of time before there were noticeable changes in the death rate;
- it would be difficult to identify which changes had been effective in producing a fall in the PPPD rates, or if the PPPD rates rose to assess which parts of the care given by health visitors was not being effective.

After deliberations on the various options it was decided it was necessary to use a **structured scoring system** to involve several hundred people in Portsmouth Health District, including health visitors, general practitioners, midwives and paediatricians, in a concerted effort to improve the care to infants at risk and to monitor the effects of the changes. All of the professionals involved with the Portsmouth Study have fully supported the structured scoring system.

Health visitors particularly welcomed a system which:

- included an objective tool to select out high risk infants, which had already been tried and tested in another Health District;
- involved them in very little extra paperwork;
- required a minimal amount of training as nothing exceptional was being introduced, they were mainly being encouraged to develop good health visiting practices.

The dedication of the **midwives** has been crucial to the accuracy and effectiveness of the scoring system. They completed birth questionnaires on 15,060 infants who were delivered in the Health District, giving 100% coverage during the three and a half year study period which allowed development of the computer programmes. The birth questionnaire has now been combined with the notification of birth form, which has reduced the number of forms the midwives have to complete for each infant. A very important benefit of the scoring system is the improved communications between midwives and health visitors.

The contribution of the **ward clerks** in the midwifery unit has also been valuable to the study as they have supplied information, inadvertently missed off some birth forms, allowing completeness of data.

A very definite advantage to using a **scoring system** has been to involve **parents** whose infants have been delivered in Portsmouth Health District since March 1983 in data collection on their infants, which has ensured they have all received special attention from midwives and health visitors. WHO (1978) stated 'The need to observe, to measure and to decide on action will increase awareness, involvement and efficiency of the health worker.' In addition to increasing the professionals' responses the collection of information has also allowed a considerable data base to be accumulated, which will be useful for future planning and research.

The **health visitors**, with **parents**, were able to complete 13,864 four week questionnaires representing 92.1% coverage. 1196 questionnaires were not completed due to several factors but only 75 (0.5%) were due to parents not wanting to participate in the study. The Portsmouth scoring system allocated a risk factor to the 13,864 infants, of which 12,529 (90.36%) scored LR and 1,335 (9.64%) scored HR or VHR of SID at one month. Following changes in the scoring system in April 1983, when three extra categories of risk were introduced, of the 1,750 (12.30%) 'at risk' infants in the following categories were identified:

- 170 (1.23%) were assessed VHR;
- 310 (2.24%) had experienced a previous child death;
- 254 (1.83%) were predicted HR of non-accidental injury;
- 172 (1.24%) were at risk by two or more predictors;
- 11 (0.08%) were at risk on all three counts.

NAI risk factors were known to the health visitors although they appeared to regard criteria other than the Surveillance NAI factors when they estimated an infant to be at risk of abuse. Considerable disagreements were shown between the health visitors and the NAI factors over the small proportion of children (2.5%) who appeared to be at risk of NAI, although there was agreement on the assessment of 5859 infants

(97.5%). Health visitors may be identifying infants the scoring system is missing, or they may be making fewer false positive identifications, so these questions are to be investigated.

The **scoring system** has provided useful impetus in Portsmouth Health District for **developing the use of computers** to assist in communication between professionals involved in child care. The original basic scoring system was designed for a micro computer with data held on floppy discs. As a consequence of this study a total Portsmouth Child Health Care System has now been commercially developed for use on mini computers (Appendix 41). Interrelated modules are available to handle the maternal and obstetric details, birth data, the scoring system, immunisation and vaccination, and a developmental examination record and recall programme. A unique aspect of this computer system is the linking together of mothers and their children, regardless of changes in their surname, as these sometimes change many times in the preschool period. This facility allows better contact with individual children and increases the potential for maintaining positive health care.

The **scoring system** is now part of an effective health information system which ensures that:

- infants are selected out where the risk is greatest so that attention and care can be given where it is most appropriate;
- communications about infants to the primary health care teams are regular and serve as a reminder of the need for vigilance;
- a sound, comprehensive data base is accessible;
- routine statistics relating to caseloads are available to be produced for use by nurse managers, planners and epidemiologists;

- information is available for evaluation by researchers.

The **scoring system** has been useful to nurse managers as it highlighted the uneven distribution of health visitors' workloads, for example, some health visitors were responsible for up to fifteen infants categorised as HR whilst others had none. **Managers** were able to use the information available to make changes to health visitors' caseloads allowing a more equal distribution of work.

WHO, (1978) developed the **concept of risk strategy** stating 'the aim is to give special attention to those considered at greatest risk within a framework of health for all'. **Risk related intervention in Portsmouth Health District** endeavoured to emulate the WHO concept which involved structured changes in the patterns of infant care and health visiting procedures.

During the pilot project in Gosport the recommended pattern of <u>home visiting</u> in the first year of a child's life was:

- 5 visits for LR infants and 11 visits for HR infants.

Some health visitors expressed their anxiety about LR infants not receiving enough attention but monitoring charts completed in Gosport in 1982 showed HR infants received, on average, 14 contacts in their first six months (9 of which were at home) whilst LR infants received 13 contacts (9 of which were at clinic). These figures were very reassuring as they showed health visitors were taking their services to the HR infants who were defined as having the greatest need, whilst the LR infants, far from being neglected, were receiving almost the same number of contacts.

In April 1983 a recommendation of 21 home visits was introduced for VHR infants in their first year. In 1984 and 1985 221 completed monitoring charts were collected retrospectively from health visitors throughout the Health District to ascertain the number of home visits to various categories of infants. These charts showed that the median number of home visits corresponded almost exactly to the recommended visiting schedule although there were variations in the minimum and maximum numbers of visits by individual health visitors. These results again indicated health visitors were still supporting the Infant Surveillance Programme.

In August 1989 all health visitors in the Health District completed two monitoring charts for one randomly selected HR/VHR infant and one LR infant born between 1986-1988 and they also returned a copy of the weight percentile charts they had kept for the two infants. Initial observation reveals that they do not appear to be following the recommended guidelines as closely as they did when the original study was taking place, which may explain the rise in the PPPD rates since 1985.

Health visitors were initially expected to accomplish the recommended pattern of home visiting in addition to maintaining their usual role of health promotion, disease prevention and group work to all age groups, whilst searching out needs in their neighbourhoods and developing appropriate innovative practices. There were no additional health visitors employed but from 1982 extra community health nurses were gradually made available to help the health visitors. These registered general nurses, without any specialist community training, assisted health visitors with developmental assessments of children and also with screening for vision and hearing defects. These tasks have now been allocated to care assistants, after they have received appropriate training, which is making the best use of available financial resources.

Health visitors were directed to concentrated on the care of children and nuclear families to the detriment of their time being available to care to the elderly. The community health nurses were therefore seconded on courses and attended study days on care of the elderly. When they were considered competent they were allowed to visit elderly clients and participated in screening programmes. The community health nurses eventually provided a very good caring service.

Clerical help has also been gradually increased to assist health visitors with filing and other office duties.

The health visiting staffing levels and skill mix proportions of trained/untrained staff in Portsmouth Health District are in accordance with Wessex Region Health Authority recommendations, although none of the other Health Districts in the Region are currently involved in a structured risk related intervention programme.

Health visitors unanimously stated that home visits were preferable to clinic visits because:

- they gave a better understanding of the families, and allowed the relationships between professional and client to develop;
- they allowed observation of the family's environment and standards which enabled health promotion and teaching to be approached differently, and consequently to become more meaningful and effective;
- discussions could be more private, confidential and less hurried.

Interviews with 24 mothers supported the health visitors opinions. The HR mothers who had routinely received more home visits appeared to have a better relationship with their health visitors. This was evident as when they were asked what they discussed with her, they mainly stated 'Anything/everything', giving many examples when questioned further. The mothers of LR infants, whilst they still referred to their health visitors in a relaxed friendly way and called them by their first names, saw them mainly dealing with children and with problems relating to children.

It was suggested to the author by Professor Emery (1986) 'If perhaps parents observe health visitors, midwives and doctors giving extra care and attention to their infants, it is likely they will be influenced to regard their infant as important and to be more caring'. This opinion appeared to be validated during the interviews with the HR and VHR parents as they certainly held the view that their infant was very special.

One of the most positive developments to have taken place during the Portsmouth Study is the regular weighing of naked infants by health visitors. Prior to the study there were only 20 sets of portable baby scales for use by 120 health visitors which discouraged the weighing of infants at home, but now all health visitors have their own scales and use them effectively. Infants attending child health clinics used to be weighed dressed and a calculated guess was made as to the weight of the clothes they were wearing, this practice has now stopped.

Routine weighing of naked infants allows the health visitor to observe how a mother handles her infant and the interaction between them. She can also observe the whole infant for signs of growth and development, for failure to thrive, for neglect or abuse. Weighing at home ensures the infant is the focus of the visit, and regular expected visits avoid excuses 'not to disturb the baby', statements which are often noted in child abuse enquiries.

Written and verbal enquiries have been received by the author from nurse managers in many health districts, asking which scales are recommended. They are advised to purchase a selection of scales currently available, to allow each member of staff to choose whichever she prefers and then purchase exactly those requested by the individual members of staff. It has been observed if staff are given the scales they want they will use them correctly and often. It has been noted in other Health Districts when equipment has been bought without prior discussion with the health visitors they have not been used effectively, in fact sometimes they have never been used at all.

Monitoring growth by <u>regularly plotting weight percentile charts</u> for all infants has been another positive development during the Portsmouth Study. Health visitors have often referred infants whose weight was causing concern to general practitioners who have identified infections, particularly of the upper and lower respiratory tract and of the middle ear. These infections have not always been apparent to the health visitor nor to the parents who have often commented after commencement of treatment, "I didn't realise he was ill, but I can see the difference now". The infant's weight gain also improves after treatment has started, giving a positive sign to parents and to professionals.

Regular use of weight percentile charts have allowed health visitors to identify many infants with failure to thrive who were referred to paediatricians for investigations. Some of these infants were subsequently diagnosed as having various conditions which included:

cow's milk intolerance; coeliac disease; congenital heart disease (transposition of great vessels in two instances); cystic fibrosis when baby was only three weeks old; progeria dwarfism syndrome and gardia lamblia infection. It would appear highly likely that the lives of some postperinatal infants have been saved, or at least improved, because health visitors were vigilant, monitored infants' weights and effectively used weight percentile charts.

Two instances of non-organic failure to thrive proved interesting:
- one infant had had many investigations which were all negative, however, when the parents' relationships improved the infant started to gain weight;
- thorough investigations in another infant all proved negative but she gained weight very quickly when placed in the care of foster parents. When she was returned home again her weight dropped quite dramatically. The health visitor's percentile chart was used in court to demonstrate neglect of the infant, who was subsequently taken into the care of the social services department.

All parents are now given a copy of their infant's percentile chart at the health visitor's first visit to their home. They are taught by the health visitor to understand the importance of monitoring, and they are also given the responsibility to have their infant weighed regularly. Parents who might not understand a list of numbers and the significance of poor weight gain, can understand the weights plotted on the charts and the importance of 'staying between the black lines' as it was succinctly termed by a mother of very low intellectual ability.

The concept of being responsible for their infant's percentile charts has been readily accepted, as women in Portsmouth have carried their own ante-natal records for several years and the midwifery staff say only about ten sets of records out of 60,000 have ever been completely lost. Perhaps before too long, parents in Portsmouth can be made responsible for carrying all of their infant's documents in an endeavour to encourage parents to be more responsible for the care of their infants and to improve communications between professionals.

Surveillance without a percentile chart becomes subjective and errors can occur, as was shown in the Jasmine Beckford case of child abuse (Blom Cooper et al, 1985). This also became apparent when all of the available weights of the 51 dead infants in this study were plotted on percentile charts, as some of them should have been referred for medical opinion regarding their weight losses. Correspondence with Dr Myerberg (1989) in West Virginia also showed his investigations into the growth of infants prior to death followed a similar pattern to the PPPD in Portsmouth.

An accurately completed weight percentile chart is an indicator of growth and well-being, a valuable background picture to aid diagnosis and an essential communication link between professionals. All health visitors in the country should be taught the value of the systematic use of weight percentile charts and they should insist one is available for each infant. It should not be assumed however, as the author did, that all health visitors would know how to plot percentile charts. A 'weight percentile workshop' is now organised regularly for health visitors in Portsmouth Health District.

Health visitors have to be aware, however, that percentile charts are tools they have at their disposal whilst their professional expertise is constantly alert to total observations of each infant.

Work by Kinmouth (1990) relating SID to a raised environmental temperature and a raised body temperature, implies some infants may be unable to control their febrile responses or to regulate effectively when well wrapped and heated. Fleming and coworkers (1990) also warned of the dangers of parents overheating their infants and stated few professionals emphasise to parents the risk of overheating. Health visitors in Portsmouth have been aware of the dangers of overheating infants for many years and all of them carry room thermometers and clinical thermometers as part of their standard equipment.

They have found when home visiting that the temperatures in many of the rooms where infants were being cared for were kept far too high. The loan of a **room thermometer** to parents, or encouraging them to buy one, is crucial when attempting to keep the temperature adequate in an infant's environment as it can then be measured objectively.

Health visitors also routinely give out information **leaflets on temperature regulation** which are supplied by the Health Promotion Unit. These leaflets contain valuable information for parents and have been appreciated, but an amended leaflet is planned which will give additional information on how to reduce high body temperatures and how to administer first aid, including resuscitation techniques.

The use of a respiration monitor/apnoea alarm (monitor) cannot guarantee to prevent an infant from dying, but it can help to reassure parents their infant is still breathing or to give them immediate warning of an apnoeic attack so they can take immediate action.

The first 45 parents in the Portsmouth Study who were allocated a monitor stated in their own terminology that it had been appreciated. One third of the families stated there were no disadvantages at all to having a monitor, whilst the remaining 30 parents commented mainly on the stress of the false alarms, which averaged one per week. Whenever a monitor has been issued parents have been taught resuscitation techniques by a medical practitioner. Only two of the 400 parents who have used monitors over a seven year period have had to actively attempt resuscitation and to date no infants have died on a monitor.

All of the families who have had a monitor appreciate the regular visit each week from the health visitor and also the 24 hour available support of the general practitioners. 'CONI - Care of the Next Infant Project - A protocol for Support' (Emery et al, 1990) outlines the support to be offered to parents and except for the use of a Symptom Diary all of the recommendations, including monitors, have been part of the Portsmouth Infant Surveillance System for many years.

Most parents are given a choice of scales or a monitor, but only a very small minority have chosen scales. Occasionally after infants had experienced a severe apnoeic attack, parents were loaned scales and a monitor until they had regained their confidence. After about a month they were asked to return one piece of equipment and without exception they have returned the scales.

It is recognised that an ideal monitor for home use is not yet available, but technical advances, especially in electronics, have resulted in new devices which are seemingly more accurate, they can be worn over the infant's clothing and can be fitted to recording equipment. A report from the Foundation for the Study of Infant Deaths and the British Paediatric Respiratory Group (Milner et al, 1990) suggests conductance pad monitors are suitable for use. These are ideal in the Neonatal Unit, but their use in the Community is restricted because they cannot be used effectively in a pram or in a car as the vehicle's movements could cause a dead baby to bounce on the pad giving a false indication that it is breathing. The 70 monitors now available in Portsmouth are checked and serviced by the District Health Authority's electronics department after each loan and before they are reissued to other parents for use with their infant.

The Portsmouth Cot Death Research Fund has been supported by voluntary groups, firms and individuals to provide monitors and scales. Local people are very happy to know their monetary contributions are helping parents to live 'normal lives' with their vulnerable infants.

The main objectives of providing monitors as part of a comprehensive support service to parents was: to give assurance their infants were breathing and to give them immediate warning of an apnoeic attack so that emergency action could be taken. These objectives would appear to have been achieved. It has been estimated the support given by professionals to families who have used monitors is probably equal to, or even less than, what would have been necessary if monitors had not been available.

Possibly Preventable Postperinatal Deaths (PPPD)

This small study looked in depth at **the 51 PPPD** which occurred during the three year study period and allowed various aspects to be compared to typical patterns established in many large studies considering SIDs only, which have been referred to in earlier chapters of this thesis. The factors considered were age; sex; season; day of the week; time of day; place of death; illnesses; overheating; pathological findings; maternal smoking and infant feeding.

The age when the majority of SIDs has been shown to occur in many large studies is between 2-4 months, and 36 (72%) of the 51 PPPD died during this period of time. The previously recommended intensive home visiting pattern in Portsmouth District for HR infants has recently been extended from 3 to 4 months to cover this vulnerable period.

The sex of the PPPD was predominantly male, as had been shown in various large studies of SIDs throughout the world. The overall ratio of 28 males (54.9%) to 23 females (45.1%), however, is very similar to the ratio of 7,826 (52.0%) male births to 7,234 (48.0%) female births in the cohort of 15,060 infants considered in the study. There were two exceptional years for which the author is unable to offer an explanation: in 1983 there were 10 male deaths compared to only one female death; in 1984 there was the opposite extreme of 11 female deaths to 6 male deaths, which was very unusual.

The 'Winter Season' is often stated as being when most SIDs are likely to occur, although there does not appear to be an accepted standardised period or stated months of the 'Winter Season'. Thirty nine (76.47%) of the 51 deaths occurred in the five months of December, January, February, March and April. Three deaths occurred in Gosport in the second phase of the study from 1.1.82-31.3.83, one in January and two in February, the remainder of the two phases were taken over complete years. Only two (4.9%) deaths occurred in the months October and November, and yet seven (14.7%) deaths occurred in April.

The weather did not appear to be particularly cold during these periods when the 51 deaths occurred, but weather has not been shown to be a major factor in SIDs otherwise the rates would be very high in the Scandinavian Countries instead of very low as consistently experienced by some of them.

Respiratory infections, however, were noted in 22 (43.1%) infants prior to their deaths. The paediatric department staff at St. Mary's Hospital have often stated "If you get one cot death, you get three." This observation has been borne out as there were clustering of four deaths or more in periods of one week, on six occasions during the three year study which accounted for 27 (53.9%) of the total deaths, suggesting widespread infections could be a cause of death in some infants. These findings would also suggest, as has been found in many larger studies, that deaths are due to respiratory tract infections, which are more prevalent in the Winter months, rather than due to the effects of weather conditions.

Obstetricians and midwives might not agree with the author's suggestion to advice potential parents to plan their infants' births from April to June, but this would allow infants to reach the 'Winter Season' when they are five to seven months old and more able to cope with infections. Recommendations by Southall (1988) to reduce the infection risk to young infants by minimising contacts with older children are commendable.

Deaths happened on each day of the week and occurred without any special trend although there were less deaths at the weekend:- 5 were on Sunday, one of which was Christmas day; 6 on Saturday; 7 on Tuesday and Friday; 8 on Thursday; 9 on Wednesday and Monday, one of which was a Bank Holiday. Many large studies have failed to demonstrate any consistent association between a particular day of the week when SIDs occur so parents should be encouraged to call for medical help whenever they are concerned about their infants regardless of whether it is a weekday, a weekend or a bank holiday.

The exact <u>time of death</u> of infants in the study is unknown. However, 29 (56.9%) of the infants were found in the six hour period from 0600-1159, which is comparable with findings from other studies on SIDs only. Eleven infants (21.6%) were found between 1200-1759, and 7 (13.7%) between 1800-2239. Only 4 infants (7.8%) were found between 0000-0559, which is hardly surprising as very few adults are awake in this quarter of any 24 hour period. It might be advisable to suggest to parents not to leave their infants unchecked for exceptionally long periods, although it is unrealistic to expect very tired parents to check their babies frequently at night.

Forty one of the 51 PPPD (80.3%) <u>died in their cots</u>, which emphasises the reason SIDs are popularly called 'Cot Deaths'. Most of the cots were indoors although two cots were unusually placed, one in a car and the other in a tent. Seven infants (13.7%) were found in their prams, six indoors and the seventh one was outside on a very hot July day. One infant was smothered by her mother. Two infants were probably overlain by their parent. Jackson (1989) advocates infants sleeping in their parents' bed and although she lists a few important rules when this should not happen, it is highly unlikely many parents are aware of these rules and consequently could place their infants at considerable risk if they take them into their beds.

<u>Overheating</u> may have contributed towards some of the PPPD as temperatures of over 40oC were recorded in 3 (11.4%) of the 35 infants who had rectal temperatures taken and several of the remaining 31 infants had temperatures registering normal and slightly above normal

several hours after death had occurred. Hyperpyrexia as a cause of infant death could be more thoroughly investigated than it has in the past and the results widely publicised. An article by Fleming and coworkers (1990) received extensive media coverage and although the results were not always interpreted correctly very many parents heard the message not to overheat their infants nor to lie them in the prone position. Some Health Authorities are already giving out leaflets to all parents of new infants with information on how to keep the temperature of their infant and the infant's environment adequate. It would appear to be a serious omission not to give parents objective instructions and information on how to protect their infants from becoming too hot.

Data on maternal smoking was available on only 48 of the 51 PPPD as three infants were born in other Health Districts and the appropriate forms were not completed. Twenty eight (58.3%) of the 48 mothers smoked, compared to a district figure of 4,520 mothers (30.0%) who smoked out of a total 15,060 mothers who had a birth form completed. Two of the mothers of the dead infants actually smoked 30 cigarettes per day. Monthly forms, which gave information about **paternal smoking**, were available on only 45 infants as 3 of the 48 infants had died before forms were completed. Twenty one (46.6%) of the 45 fathers smoked, which was a smaller percentage than the mothers who were smoking but greater than the national figure of 33.0% (ASH, 1990). There were ten families where the mother smoked and the father did not, but in only five families did the father smoke and the mother did not. One father smoked 80 cigarettes per day and his wife 20, which suggests their infant, who was very premature, was probably affected by cigarette smoke most of the time he was at home with his parents. In only 12 (25.0%) of the 48 families were neither parents smoking.

Although the numbers of deaths in this study are very small they would indicate parental smoking has an adverse effect on infants and analysis of the birth weights of the cohort of infants in this study also showed that the babies whose mothers smoked were growth retarded in utero. The deleterious effect of smoking on the foetus and young child have been well documented in many studies as indicated in Chapter 2 of this thesis.

A study of 3546 women in Portsmouth whose infants were born in 1988 revealed that 30% of them were smoking, as was also shown on 4900 mothers whose infants were born in 1990. The percentage has not altered since the beginning of the study and they correspond with the National figure of 30.0% of all females who smoke (Ash, 1990).

Haglund and Cnattingius (1990) estimate smoking may be the single most important preventable risk factor in Scandinavian Countries. Health professionals in this country should actively participate in anti-smoking campaigns to improve the health of future infants, perhaps targeting women in the age group 20-24 who comprise the highest percentage who smoke (37.0%) closely followed by the age group 25-49 (35.0%) (ASH, 1990). However, perhaps campaigns should commence in the junior and middle schools to discourage children from starting to smoke, as it appears to be so difficult to stop once the habit has begun.

The <u>feeding pattern</u> of the 51 PPPD revealed:

- only 7 infants (13.7%) were totally breast fed until they died;
- 25 (49.0%) were totally bottle fed from birth, compared to 25% of the total infants in the District who were bottle fed from birth;
- 41 (80.6%) were being bottle fed by six weeks of age, two in a

very bizarre pattern according to the health visitors' records;

- only 12 (23.5%) infants did not have any infections recorded during the 3 weeks prior to death and 5 of these were breast fed.

These findings would suggest that totally bottle fed infants appear to be more vulnerable than totally breast fed infants.

Analysis on infant feeding was completed for 5,173 infants born between 1.4.83-31.3.84. and showed 73% of the mothers intended to breast feed their infants, which is greater than the national figures of 51% in 1975, 67% in 1980 and 64% in 1985 (Martin and Monk, 1982 and 1985). When the questionnaires were completed at one month, however, it was discovered that only 45% of the mothers were still breast feeding although a further 4% were feeding both breast and bottle. It is not actually known why 24% of the breast feeding mothers had decided to commence bottle feeding by four weeks, but it is highly likely more education and encouragement from midwives and health visitors would prove effective in prolonging the period of breast feeding. The Department of Health also considered this to be important as a National Breastfeeding Initiative (1990) was launched to increase the incidence of breastfeeding and to extend the duration of it. It is desirable to breast feed infants for at least six months, but longer if possible, because:

- it is the most natural food for babies;
- it needs no preparation and reduces the risk of hypernatraemia through overstrength feeds;
- it is sterile and reduces risks of gasto-intestinal infections;
- the mother/infant relationship is reputed to be improved;
- it reduces the opportunities of an infant being sensitised to cow's milk;

- the longer an infant is breast fed the more maternal antibodies it receives.

Many infants were ill prior to their death as revealed by either postmortem reports, health visitors' records or questionnaires filled in by health visitors. Fourteen infants (17.4%) were previously known to the paediatricians and four of these had been admitted to hospital on more than one occasion before their deaths for persistent infections and/or investigations.

Examination of the weight percentile charts, which were constructed from information in health visitors' and clinic records and postmortem reports, revealed some infants had **severe weight losses**, including three whose weight had passed through six channels (standard deviations) from their birth to their last recorded live weight. The percentile charts showed 13 of the 40 infants had weight losses from the last recorded weights to their weights at post-mortem (although post-mortem weights are to be regarded with caution), and identified 7 of these who should have been a cause for serious concern before their deaths. These weight losses indicate some infants were very sick and their deaths might have been prevented if medical advice had been sought, or they had been referred for specialist advice earlier. The lack of recognition of illness by some parents and the failure of the professionals, including health visitors and doctors, to recognise and treat according to the degree of illness would support the recommendations of Knowelden and co-workers (1984) regarding the education of parents in child care and in the training of professionals in the management of sick children.

According to parents who were seen by health visitors after the death of their babies only 12 of the 51 PPPD had no **signs or symptoms** of

illness in the three weeks prior to their death. Of the 12 infants who appeared to be well:

- 3 were found at postmortem to have respiratory tract infections;
- 2 were overlain;
- 1 was deliberately smothered by her mother who was being treated by a psychiatrist for postnatal depression;
- 3 had weight losses through two or more channels on their weight percentile charts in 2, 4 and 6 weeks respectively indicating these infants was probably unwell.

There were, therefore, only 3 of the 51 PPPD who had 'no history of disease and nothing was found at post-mortem' (Beckwith, 1970). Three SIDS in 15,060 births, a death rate of 0.2 per 1000 live births, which would compare with the completely unexplained death rate of 0.34 per 1000 in Sheffield (Taylor and Emery, 1990), although the parameters for the two studies were very different.

The **definition of Sudden Infant Death Syndrome**, (Beckwith, 1970) was originated to give a uniform terminology and a standard definition but it has caused considerable confusion and has been agreed with, or argued over, for almost two decades. As Golding (1988) stated 'This is not strictly a syndrome at all, but rather a definition derived by elimination'. The similarity of the findings in this study when comparing 51 PPPD with studies of SIDS only, would indicate that the patterns of both categories are very similar. These results support the findings by Carpenter and Emery (1974), and also Knowelden and co-workers (1984), that identifying characteristics in unexpected explained deaths were found to differ little from those of unexplained deaths.

The various anomalies regarding patterns of illness, pathology and death certificate reports even in this small study would support proposals for a national or even international standardised pattern of history taking, of pathology and of classification of deaths to enable epidemiological studies to become more comparable.

Evaluation of Risk Related Intervention

The **cause of the increase in PPPD in Gosport from 1977-81** is still unknown, although various factors have been considered:

- Studies of **service families** in Germany (Miller, 1987) and Essex (Rao and Hoinville, 1988) both indicated a higher incidence of SIDs in service families. The Gosport PPPD rates were higher than the E&W rates in 8 of the 12 years prior to 1977, but inadequate records prevented investigation of the causes of these deaths some of which may have been partly due to the presence of service families. Powell and coworkers (1983), however, showed that infants born into service families in Gosport from 1977-1981 were at no greater risk of SIDs than those born into civilian families.

- The pathological investigations of infants who died prior to 1982 were quite limited, particularly in respect of virology, so it is not possible to know if the high incidence of deaths in the years 1977-1981 were caused by any specific **infections**. In 1981 the paediatric wards in Haslar Hospital, Gosport, admitted several children who were very ill with Echo Virus, so it is possible some of the infants who died were also infected with the same virus.

- During confidential enquires (Taylor, 1986) **infanticide** sometimes emerges as a possible explanation for deaths. Only very occasionally was infanticide suspected due to observed parental behaviour and/or attitudes, or because of post-mortem findings, so this would appear not to be the explanation for the exceptional rise of PPPD in Gosport from 1979-1981.

Comparisons were made between **the infant, perinatal, postperinatal, inevitable and possibly preventable death rates**:- in Gosport; in Portsmouth and South East Hampshire Health District, including Gosport, (Portsmouth District); in England and Wales (E&W) for 24 years 1965-1988 inclusive; in Wessex Regional Health Authority, excluding Portsmouth, (Wessex Region) for 15 years 1974-1988 inclusive.

The **infant death** rates in Gosport were higher than the rates in E&W in 10:24 years studied, although Portsmouth District rates have been higher on only 7 occasions. The suggestions for these higher rates have already been indicated although not substantiated in the previous paragraphs.

The **perinatal death** rates for both Gosport and for Portsmouth District have only been higher than E&W on 4 of the 24 years studied, although the postperinatal rates have been higher on 13 and 9 years respectively, which could suggest that infants are surviving their first week of life only to succumb in the period 1 week to 1 year. The low perinatal deaths rates in Wessex Region and in Portsmouth District would indicate that obstetric and perinatal care is good. Wessex Regional Health Authority monitor all stillbirths and neonatal deaths which could be partly responsible for high standards of care throughout the Region. The number of low birth weight infants who survive is increasing, which again would indicate good neonatal care. Discussion with maternity staff in Portsmouth has revealed that occasionally a fresh stillbirth will be termed a live infant by the delivery attendant. This allows the parents to have the opportunity to name their infant and hold him whilst he 'dies', to have an individual funeral and grave for him if they wish, and to have the opportunity to fully grieve and mourn. There have also been reports of infants of 23 and 24 weeks gestation who have lived for only a few minutes and subsequently have been counted as perinatal deaths. If these low gestation infants had been macerated at birth they would not even have counted as a stillbirth as they were less than 28 weeks gestation, the age of registration. It is likely, therefore, the perinatal death rates might have been even lower than recorded if staff had dealt with the delivery room situation in a less sensitive way.

The **inevitable postperinatal death rates** in the three areas studied were usually lower than the rates for E&W, in fact in Wessex Region they have only been higher on two occasions in 15 years; in Portsmouth in 6:24 years and in Gosport in 7:24 year. The author can offer no explanation why these rates are consistently good and they partly negate the hypothesis that infants, with gross prematurity for example, are surviving their first week only to succumb later.

The PPPD rates when compared to E&W are of greatest concern. Wessex Region rates have been consistently higher than E&W for all of the 15 years studied, for which the author can offer no explanation, whilst Portsmouth and Gosport rates have been higher on 12:24 and 18:24 years respectively. However, when the mean rates of PPPD in the five years 1978-1982 inclusive, prior to Portsmouth District intervention in 1983, is compared to the five years from 1983-1987:

- Gosport mean rates have decreased from 8.07 to 3.18 an improvement of **60.59%**;
- Portsmouth District mean rates have decreased from 4.44 to 3.01 an improvement of **32.20%**;
- E&W rates decreased from 3.27 to 2.87, an improvement of **12.23%**;
- Wessex Region mean rates has decreased from 3.89 to 3.68 showing an improvement of only **5.39%**.

These improvements in the mean PPPD rates in Gosport and Portsmouth District are encouraging particularly when the annual rates, due to the small numbers involved, show considerable fluctuations. These reductions in the PPPD rates without a corresponding reduction in the Wessex rates are consistent with the view that the risk related intervention was effective.

Intervention reduced mortality by 86% in the group receiving extra care which was associated with an overall mortality reduction. It would be interesting to establish a risk related intervention programme in other Districts in Wessex, where there are high PPPD rates, and to monitor the effectiveness.

Statistical Evaluation of the study confirms that the reduction in PPPD in the District is not a chance effect and also presents the findings of a logistic regression discontinuity analysis of mortality in relation to the risk predictors. This procedure compares the mortality observed among infants with scores just below the point of intervention with that observed among infants with scores just above the point, after making some adjustment to allow for the linear increase of log (risk) with score. In this way the LR groups provide an 'untreated control' for the treated HR groups. This comparison was considered more ethical than involving only part of the District in the study, as some infants might then have been deprived of extra care which might have prevented their deaths.

The relationship of mortality from PPPD to the Portsmouth score has been examined using similar data sets from two other areas. In neither area had HR infants received extra home visits and in neither was there a step down in the relationship of mortality to score at the point of intended intervention (Carpenter et al, 1988).

There are several components to the intervention, including the notification of risk to general practitioners, the provision of room thermometers and the extra care given by the health visitors. The finding that, on a logistic scale, the effect of Level II intervention was more than double the effect of level I, suggests that the increased home visiting by health visitors, which included naked weighing of infants and charting their weights, was the crucial factor in reducing mortality (Carpenter et al, 1988). If the notification of general practitioners or the thermometers was the crucial component of intervention then the effect would be the same in HR and VHR groups, however these data are not compatible with this hypothesis.

Eleven (37.9%) of the 29 cases on the Hampshire Non Accidental Injury register in August 1985 scored 3 or more factors; however, 44% of the cases on the register were identified by the SID month score. When the month score and the NAI factors were used together, 18 (62.1%) of the infants were identified in only 10.1% of the total infant population. Conversely 11 (37.9%) infants not identified as high risk were in 89.9% of the population.

Roberts and coworkers (1984) in Oxford, retrospectively investigated whether or not a social risk score predicative of child abuse would also predict cot death, and concluded it did not. Five of the six Portsmouth NAI risk factors are similar but not identical to the Oxford social risk factors. It was found in the Portsmouth Study that 24% of the deaths had 2 or more NAI factors, compared with only 7% of all other infants who had 2 or more factors. If these findings are substantiated elsewhere, they imply that the prediction of unexpected death may be enhanced by including data relating to social risk factors.

Cost of Risk Related Intervention

The recommended pattern of home visiting by health visitors for HR and VHR infants obviously increased their work loads considerably. In the two year period 1.4.83-31.3.85. if all of the 12,126 infants had received only the minimum number of 5 home visits, the total number of visits would have been 60,630. The home visiting guidelines probably increased the number of home visits by an extra 8,718 visits. The extra visits when divided by 110 whole time equivalent health visitors equals 79 extra visits required over the 90 working weeks of a two year period, which results in only 0.88 extra visits per health visitor per week.

Many of the VHR infants, however, were in Special Care Baby Unit for several weeks so the actual number of home visits was probably less than the estimated visits.

This estimated extra visiting is acceptable although initially visits took much longer due to the extra tasks of weighing infants, completing weight percentile charts and extra record keeping. It may be assumed if visits actually take longer they will be more beneficial to parents and subsequently the care of infants will be improved, as was indicated when parents were interviewed.

The author's personal time as Infant Surveillance Co-ordinator has always been only a proportion of her job. The Portsmouth Study has however demanded six months sabbatical leave and several periods of annual leave to evaluate the effectiveness of risk related intervention and to complete this thesis.

The scales, thermometers and respiration monitors/apnoea alarms have been purchased from charity moneys.

There has been additional financial cost to the Health Authority for: computer hardware and software; additional paper; health promotion leaflets and maintenance of equipment.

If another District Health Authority wished to implement a similar Infant Surveillance Scheme, in addition to the above equipment and stationary it would be essential to employ a clerk with some basic computer knowledge and the number of hours worked each week would depend on the work generated by the numbers of births in the District.

It would also be crucial to employ a knowledgeable part-time Risk Related Intervention Co-ordinator:

- to allow a refocusing of health visiting activity;
- to participate in training of all staff involved;
- to be available for advice;
- to monitor the number and causes of all infant deaths;
- to evaluate the effectiveness of risk related intervention.

These **costs** can be objectively balanced against an actual reduction in the numbers of PPPD, with an associated decline in bereavement visits and less support required by grieving parents, but it is impossible to measure the amount of grief and mourning which will be saved in nuclear and extended families if infant deaths are prevented.

Opinions of 'Infant Surveillance'

The scoring system and risk related intervention was known to all of the professionals involved with it as **'Infant Surveillance'**.

Health visitors, when asked for their opinions of Infant Surveillance commented it was very acceptable, because:

- their practice had been improved by clear objectives and a constructive approach to visiting;
- the weighing scales and percentile charts allowed them to be more professional and effective;
- it was an excellent system which was well worth doing and worthy of replication.

There were only minimal adverse comments from health visitors regarding lack of attention to other care groups and increased paperwork.

General practitioners also showed a very positive response towards Infant Surveillance. They stated:

- it was a good alerting system;
- it allocated special care to infants who needed it and allowed the best use to be made of limited resources;
- parents benefited by being more involved in the care of their infants;
- the system encouraged close co-operation between members of the primary health care team.

Their negative comments were also very minimal.

A **paediatrician** assessed Infant Surveillance as being 'a timely intervention in child care management'.

The sample of **Parents** who were seen were fully aware of the purpose of Infant Surveillance and viewed it very positively. They were most enthusiastic about the care they had received from doctors and health visitors, which some stated was far better than they had received previously with their other children. It seems to be preferable to be honest with parents and involve them in the partnership of caring for their infants, instead of pretending there are no problems but then to raise their anxiety levels by giving frequent unsolicited attention.

I would suggest the use of a scoring system and risk related intervention has been beneficial to infants and has been acceptable to both professionals and parents in Portsmouth and South East Hampshire Health District.

Sudden Infant Deaths - The five quotes listed below show how little actual progress has been made in the understanding of SIDs during the past 25 years.

> "It is likely that cot deaths may arise from a variety of causes, and no single hypothesis can fully explain all of them" (Carpenter and Shaddick, 1965).
>
> "Many hypotheses have been put forward for the cause of SID, but as yet none have been proved" (Emery, 1984).
>
> "In 1984 we have no more complete understanding of the basic cause of cot death than we had when the term was first coined" (Kleinburg, 1984).
>
> "After two decades of increased public awareness and intensified research into the causes and prevention of SIDs its cause or causes are unknown and its prevalence unchanged" (Thach, 1986).
>
> "Despite ever increasing new physiologic and epidemiologic information a precise and specific pathophysiologic cause of SIDs has yet to be identified" (Hunt and Brouillette, 1987).

The Portsmouth Study has not provided any additional information nor suggestions as to the causes of SIDs, but it has validated the opinion they are very similar to PPPD.

The Government has acknowledged that infant mortality rate is one of the key indicators of the Nation's health (DHSS, 1989; Mellor, 1989) and proposed a major initiative to address why particular babies die. The initiative comprises five main points:

- a multidisciplinary confidential enquiry into stillbirths and infants deaths;
- regional epidemiological surveys of stillbirths and neonatal deaths;
- a paediatric pathologist in each Region by April 1991;
- targets to be set to improve performance, however it was recognised some infants will die despite all efforts to save them;
- Research to include a major review of the literature relating to SID.

The Government believe these initiatives will reduce infant mortality to the lowest possible level although information and financial support regarding the five developments has not yet been forthcoming. In Portsmouth changes have already been implemented: confidential enquiries into PPPD are held which have already resulted in changes in professional practices; responses have been made to Wessex Regional Health Authority regarding rates of all infant deaths and note has been taken by all Health Districts to improve their targets; a pathologist specialising in infant pathology has been in Portsmouth for several years; current literature is regularly discussed within a multidisciplinary group, so hopefully with the increased effort the rate of infant deaths in Portsmouth will continue to decrease.

The Parliamentary Secretary for Health (Dorrell, 1990) in a Press Release announced the 1989 figures for infant deaths had reached an all time low which was very encouraging, but there are still considerable variations between Health Districts. If the Government initiatives continue to be effective and all infants deaths are reduced there will probably be a corresponding reduction in the numbers of SIDs.

The World Health Organisation (1978) said that risk strategy should have far reaching effects on the whole organisation and lead to improvements in both the coverage and quality of health care, particularly at primary care level. The use of a scoring system and risk related intervention in Portsmouth Health District has directed scarce resources to infants who were estimated as being most at risk of PPPD and NAI until funds are available to provide a high level of care for all infants. It has also heightened professional and parental awareness to the needs of infants and therefore improved their care.

The Portsmouth Study has created interest both nationally and internationally, as shown by over 300 written requests for information and by visits from staff in many other District Health Authorities as well as from Holland, Germany, America and New Zealand. The author has been asked to speak about the Portsmouth Study on very many occasions to doctors, health visitors, midwives, student nurses and to members of the general public.

The Portsmouth Surveillance System has been replicated exactly in some Health Districts, for example, in Cornwall and the Scilly Isles

(Appendix 36). In other Health Districts, only some of the System has been used for example in Central Nottinghamshire (Appendix 37), Basildon and Thurrock (Appendix 38), and Worthing (Appendix 39). Some health visitors in other Health Districts have used the Portsmouth scoring system with their individual case loads and have copied the visiting patterns, the weighing recommendations and the use of percentile charts.

There are many health visitors in the United Kingdom who now have their own portable baby scales and thousands of babies throughout the country now have weight percentile charts as a result of the Portsmouth Study, from which it can be assumed the care to many infants has improved and this might possibly have influenced the reduction in the numbers of infant deaths Nationally.

CHAPTER 7

CONCLUSIONS

The Portsmouth Study of risk related intervention and other changes in infant care have shown:

- The rates of possibly preventable postperinatal deaths in Gosport and Portsmouth in the five years prior to intervention fell by 60% and 32% respectively in the five years since intervention.

- A standardised surveillance system of practice and procedures has been welcomed by health visitors, by midwives, by doctors and also by parents.

- Risk related intervention is a practical method of targeting health care to infants who are calculated to be at increased risk and is workable by professionals.

- It is calculated that the reduction of mortality of infants in the High Risk group was reduced by 86% and this was thought to be due mainly to the extra home visiting and attention given by health visitors.

- The three risk predictors:
    * month score for sudden infant death;
    * non accidental injury factors;
    * previous child deaths,

all predict infant death and also non accidental injury.

- A scoring system is advantageous to health visitors, doctors and managers as it:

  * selects out infants at greatest risk;
  * is an alerting system;
  * is a constant reminder regarding individual infants;

- The computer system which has been developed provides improved communications between professionals, as well as being a useful tool for management, planning and research.

- The provision of respiration monitors/apnoea alarms and the accompanying support which is available from professionals has been welcomed by parents.

- The findings of the Portsmouth Study into possibly preventable postperinatal deaths were very similar to the results of studies into sudden infant deaths only, when comparing typical patterns of age, sex, season, day, time, illnesses, overheating, smoking and infant feeding.

The aim of the Portsmouth Study to reduce the numbers of possibly preventable postperinatal deaths, including sudden infant deaths, in Portsmouth and South East Hampshire Health Authority has been realised. The system of risk related intervention and improvements in the health care offered to all infants appears to have been effective and is acceptable to professionals and to parents.

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LIST OF APPENDICES

Page number

Appendix 1 - BIRTH QUESTIONNAIRES 1982-1989

Appendix 2 - 4 WEEK QUESTIONNAIRES 1982-1989

Appendix 1.A.

The Infant Surveillance Birth Questionnaire Completed by Midwives for all Gosport Infants Born 1.1.82.- 31.3.83.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT
GOSPORT INFANT SURVEILLANCE

GIS 1/....
For Office Use Only

Surname
Christian Name
Address
D.O.B.
G.P.
OR PATIENT'S LABEL

Marital Status:
M / S / W / D / Sep. / Co-Hab.

Please tick or circle, or enter comments to each question.
Fill in appropriate number of forms if multiple births.

PREVIOUS OBSTETRIC HISTORY

No. of previous pregnancies - 0 1 2 3 4 5 6 7 8 9+

No. of abortions - Spontaneous ..... Induced ....

Previous Stillbirth - Yes/No

Previous Child Death - YES/No If yes - age .....

Cause -

Mother's Blood Group - A O B AB Not Known

THIS PREGNANCY

Smoking - Yes/No If yes, number per day .....

Urinary Tract Infection - Yes/No

Feeding intention of Mother - Breast .... Bottle ....

DELIVERY Date .... Time ....

Labour - Spontaneous .....
Induced ..... State Method -

Delivery - Normal ....
Forceps ....
Ventouse ....
Caesarian Section ....
Any Complications - Please state -

Duration of Second Stage - Less than 5 minutes ....
5 - 14 minutes ....
15 - 30 minutes ....
31 - 2 hours ....
More than 2 hours ....
Caesarian Section ....
B.B.A. ....

BABY Birthweight ...... gms. Sex - M / F

Twin - Yes/No Apgar - .... 1 min. ...... 5 mins.

Appears normal - Yes/No If no, define abnormality -

S.C.B.U. - Yes/No If yes, state reason -

WOULD YOU PLEASE CHECK THAT YOU HAVE COMPLETED ALL SECTIONS; IF YOU WISH TO ADD FURTHER COMMENTS, USE BACK OF FORM; STAPLE THIS FORM TO THE BABY'S BIRTH NOTIFICATION FORM.

Date Form Completed: Signature:

THANK YOU VERY MUCH FOR YOUR CO-OPERATION

JP/JJ/29.12.81/1225

Appendix 1.B.

The Infant Surveillance Birth Questionnaire completed by Midwives for all Infants delivered in Portsmouth Health District 1.4.83.-31.12.84.

JP/JJ/24.2.83/1313

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

Surname:
Christian Name:
Address:

D.O.B.:
G.P.:

OR PATIENT'S LABEL

PLEASE TICK OR CIRCLE, OR ENTER COMMENTS TO EACH QUESTION. FILL IN APPROPRIATE NUMBER OF FORMS IF MULTIPLE BIRTHS.

Delivered at: St. Mary's ___ GP Unit ___ Blackbrook ___ Blake ___ The Grange ___ Home ___

Marital Status: M / S / W / D / Sep. / Co. Hab.

MATERNAL HISTORY - Mental / Emotional Illness - Yes / No / Not Known
Physical Handicap / Chronic Disease - Yes / No
If Yes state:-

PREVIOUS OBSTETRIC HISTORY

No. of previous pregnancies - 0 1 2 3 4 5 6 7 8 9 +
No. of abortions - spontaneous ___ induced ___
No. of previous stillbirths - None / ___
No. of previous child deaths - None / ___ Age at death ___
Cause of death:
No. of previous abnormal babies - None / If any, state abnormality:

THIS PREGNANCY - Duration ________ weeks.
Smoking - Yes / No If Yes, number per day ________
Urinary Tract Infection - Yes / No
Feeding intention of mother - Breast ___ Bottle ___
Further comments:-

DELIVERY Date: ________ Time: ________
Labour - Spontaneous ___ Accelerated ___
Induced ___ - state method:
Delivery - Normal ___ Blood Loss ______ mls.
Forceps ___ Placenta -
Ventouse ___ Membranes -
Caesarian Section ___
B.B.A. ___
Duraction of 1st Stage ___ hrs. ___ mins.
Duraction of 2nd Stage ___ hrs. ___ mins.
Duration of 3rd Stage ___ hrs. ___ mins.
Any complications - please state:

BABY Sex: M / F Birthweight: ______ gms
Length: ______ cm. Head Circumference: ______ cm.
Twin: Yes / No Apgar: ______ 1 min. ______ 5 mins.
Appears normal: Yes / No If No, define abnormality:
Vit. K: Given / Not Given
S.C.B.U.: Yes / No If Yes, state reason:
Date Form Completed: Signature:

WOULD YOU PLEASE CHECK THAT YOU HAVE COMPLETED ALL SECTIONS; IF YOU WISH TO ADD FURTHER COMMENTS, USE BACK OF FORM: STAPLE THIS FORM TO THE BABY'S BIRTH NOTIFICATION.

I.S/1

Portsmouth and South East Hampshire Health Authority Birth Notification Form and Questionnaire (PCH1a) completed by Midwives for all Infants Born in Portsmouth Health District 1.1.85.- 31.12.89.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
CHILD HEALTH SYSTEM – NOTIFICATION OF BIRTH

PCH1a

Number :
Surname :
Forename :
Address :

(PLEASE CIRCLE, OR ENTER COMMENTS TO EACH QUESTION. FILL IN APPROPRIATE NUMBER OF FORMS IF MULTIPLE BIRTHS.)

D o B :
G.P. Name/Address :

Consultant :
Ward :

Booked for
Delivered at : ST MARY'S / GP UNIT / BLACKBROOK / BLAKE / THE GRANGE / HOME / ELSEWHERE (state)
Marital Status : M / S / W / D / Sep / Co Hab

MATERNAL HISTORY – Mental/Emotional Illness : YES / NO / UNKNOWN
Physical Handicap/Chronic Disease : YES / NO
If YES, state :-
Mother needs Rubella Immunisation : YES / NO

PREVIOUS OBSTETRIC HISTORY
No of previous pregnancies : 0 / 1 / 2 / 3 / 4 / 5 / 6 / 7 / 8 / 9 / state:-
No of spontaneous abortions : ______ No of induced abortions : ______
No of previous stillbirths : NONE / ______
No of previous child deaths : NONE / ______ Age at death : ______
Cause of death :-
No of previous abnormal babies : NONE / ______ If any, state abnormality

THIS PREGNANCY
Duration : ______ weeks : Estimated / Calculated
Smoking : YES / NO If YES, number per day : ______
Urinary Tract Infection : YES / NO
Feeding intention of mother : BREAST / BOTTLE
Antenatal Care : YES / NO
Complications : NONE / APH / ECLAMPSIA / PRE-ECLAMPSIA / POSSIBLE RUBELLA INFECTION /
OTHER state :-

DELIVERY
Date : ______ Time: ______
Labour : SPONTANEOUS / ACCELERATED / INDUCED – state method :-
Delivery : NORMAL / BREECH / FORCEPS / VENTOUSE / CAESARIAN SECTION / BBA
Bloodloss : ______ mls
Duration of 1st stage : ______ hrs ______ mins
Duration of 2nd stage : ______ hrs ______ mins
Duration of 3rd stage : ______ hrs ______ mins
Placenta :
Membranes :
Manual Removal : YES / NO
Anaesthetic : NONE / SPINAL / EPIDURAL / GENERAL / BOTH (EP & GEN)
Episiotomy : YES / NO
Tear : NONE / 1st / 2nd / 3rd } Sutured by : Midwife / Doctor
Any complications state :-

BABY
Surname if different from mother :-
LIVE / STILLBIRTH / DIED
If DIED, date of death : ______
SEX : M / F
Birthweight : ______ gms
Length : ______ cms
Head Circumference : ______ cms
Number born this confinement : ______
No of this birth (if multiple) : ______
Apgars : ______ 1 min ______ 5 mins ______ 10 mins Onset of regular respirations ______ mins
Vit K : GIVEN / NOT GIVEN
Appears Normal YES / NO If No state :-
SCBU : YES / NO If YES, state reason :-

CONGENITAL MALFORMATIONS : Specify
and complete Part 2 overleaf.
OR if none write none.

Delivered by: UMW / CMW / DOCTOR Signature: Date:

WOULD YOU PLEASE CHECK THAT YOU HAVE COMPLETED ALL SECTIONS: IF YOU WISH TO ADD FURTHER COMMENTS, USE BACK OF FORM.

The forms were amended a second time to allow all Infant Surveillance questions, extra midwifery details and birth notification information to be recorded on one form and for additional data to be computerised.

A Computer Printout (PCH 1B) issued to Appropriate Health Visitors for each Infant born in Portsmouth Health District 1.1.85.- 31.12.89.

HV : MRS FODEN   BIRTH SCORE = 536   PCH1B

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
CHILD HEALTH SYSTEM - NOTIFICATION

Surname : COLES
Forename : FREDA
Address : 40 FROXFIELD ROAD
FAREHAM
HANTS
Dob : 07/06/61
Marital Status : M

Hv No : 334
G.P. : DR J E BATEMAN
Consultant : MR FRANCIS
Labour ward : 6
Booked for : ST MARYS
Delivered at : ST MARYS

MATERNAL HISTORY
Rubella Immunisation needed : NO
Mental/Emotional illness : NO
Physical Handicap/Chronic Disease : NO
details :-

PREVIOUS OBSTETRIC HISTORY
No of previous pregnancies : 3
No of spontaneous abortions : 0
No of previous child deaths : 1
Cause of death :- SUDDEN INFANT DEATH
No of previous abnormal babies : 0
Abnormality :-

No of previous stillbirths : 0
No of induced abortions : 0
Age at death : 11 wks

THIS PREGNANCY
Duration : 40 (calculated)
Smoking : YES   No per day : 10
Urinary Tract Infection : YES
Feeding intention of mother : BREAST
Antenatal Care : YES
Complications : NONE

DELIVERY
Date : 31/05/86   Time : 04:29
Labour : SPONTANEOUS
Delivery : NORMAL   Bloodloss : 200 mls
Duration of stages 1st : 05:00   2nd : 00:35   3rd : 00:07
Placenta/membranes : COMPLETE   Manual Removal : NO
Anaesthetic : NONE
Episiotomy : YES   Tear : 2ND
Sutured by : MIDWIFE
Complications : NONE

BABY
Status : LIVE
SEX : FEMALE
Length : 450 mms
No born this confinement : 1
Apgar 1 min : 8   5 mins : 9   10 mins : 9
Onset of reg resp : 1 mins
SCBU : NO
Baby App : NORMAL
CONGENITAL MALFORMATIONS : NO
Delivered by : UMW

Surname : COLES
Dod :
Birthweight : 1045 gms
Head Circum : 300 mms
No of this birth : 0
Vit K : YES
Reason :

Date : 17/07/86

These PCH 1B Printouts contain very useful information and are filed in the health visitors records.

Appendix 2.A.(i)

Gosport Infant Surveillance 4 week Questionnaire (Page 1) completed by Health Visitors, with the Co-operation of Parents of Gosport Infants born 1.1.82.-31.3.83.

CONFIDENTIAL

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT
GOSPORT INFANT SURVEILLANCE - 4 WEEK SCORE

G.I.S. No. 2..........

Birth Score ....

Health Visitor -

Ethnic Group -

Gestational age at birth .... weeks. Weight today ______ gms.

Age baby discharged to community ______ days.

Cyanotic or apnoeic attack before 4 weeks Yes / No ....

In patient admission before 4 weeks Yes / No ....

Difficulty establishing feeding by 4 weeks Yes / No ....

Feeding now Breast / Bottle / Both / Mixed

Brand of artifical milk -

Interval to last live birth ______ months.

OR first baby ....

Father's occupation - Civilian / Service / Unemployed

Age at completing full time education Mother ______ years
Father ______ years

Housing Owner Occupied / Married Quarter / Council / Other

Please state:-

Number of residents normally living at above address ______ adults.
______ at school
______ pre school

Smoking - Mother Yes / No - No. per day ______
Father Yes / No - No. per day ______
Other residents Yes / No - No. per day ______

Family known to Social Services Dept. / Naval Family Services Yes / No

Handicapped sibling Yes / No

Please state handicap:-

Any pets in the household, state type and number:-

13.1.82

TOTAL

Gosport Infant Surveillance Questionnaire (Page 2), completed by Health Visitors immediately after their 4 week visit on all Gosport Infants born 1.1.82.-31.3.83.

Score brought forward ....

This should be filled in immediately after the 4 week visit.

Previous child in care Yes / No

Previous child at risk of N.A.I. Yes / No

	Excellent	Good	Average	Fair	Poor
District / Neighbourhood					
State of repair of house, furnishings and equipment					
State of hygiene					
Heating					
General Care of Baby					
Feeding of Baby					
Attitude Mother / Baby i.e. the way she relates and responds to baby					
Maternal Competence					

Number of home visits by Health Visitor prior to this visit

.... visits.

Relevant Health Visiting comments:-

Would you consider this baby to be high risk Yes / No

Date of completion:-

Signature:-

TOTAL SCORE

JP/JJ/13.1.82

Portsmouth Infant Surveillance 4 week Questionnaire (Page 1), completed by Health Visitors with the Co-operation of Parents of Infants born in the Health District 1.4.83.- 31.12.84.

CONFIDENTIAL

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
INFANT SURVEILLANCE - 4 WEEK QUESTIONNAIRE

BABY'S NAME	Ref No
DOB	Birth Score
SEX M/F	Health Visitor
	Weight today kgms

Cyanotic or apnoeic attach before 4 weeks Yes / No
In-Patient admission before 4 weeks Yes / No
Difficulty establishing feeding by 4 weeks Yes / No
Feeding now: Breast / Bottle / Both / Mixed
Brand of artificial milk:

Interval to last live birth: months OR first baby

Father's Occupation: Civilian / Service / Unemployed

Housing: Owner occupied / Married quarter / Council / Other
Please state:

Smoking: Mother Yes / No - No. per day
Father Yes / No - No. per day
Other residents Yes / No - No. per day

JP/1.4.83 IS/2

Portsmouth Infant Surveillance 4 week Questionnaire (Page 2) Completed by Health Visitors Immediately after Their 4 week Visit on Infants Born 1.4.83. - 31.12.84.

THIS FORM SHOULD BE COMPLETED IMMEDIATELY AFTER THE 4 WEEK VISIT

Has mother a history of mental/emotional illness — Yes / No

Previous child in care/or at risk of NAI — Yes / No

Have the parents a stable relationship — Yes / No / Not Known

	Excellent	Good	Average	Fair	Poor
District Neighbourhood					
State of Repair of house furnishings & equipment					
Attitude mother/baby ie the way she handles, relates & responds to baby					

Number of home visits by Health Visitor prior to this visit: visits

Would you consider the baby to be high risk of SID — Yes / No

Would you consider the baby to be high risk of NAI — Yes / No

Any previous infant deaths — Yes / No

Relevant Health Visitor comments:

Signature

Date of completion

JP/LM 1.4.83

IS/2

Portsmouth Infant Surveillance 4 week Questionnaire (Page 1) completed by Health Visitors, with the Co-operation of Parents of Infants born 1.1.85.- 31.12.89.

PCH 2 (a)

CONFIDENTIAL

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

CHILD HEALTH AND SURVEILLANCE PACKAGE – 4 WEEK SCORE

BABY'S NAME DOB SEX M / F Dr.	Birth Score Weight today kgms

Cyanotic or apnoeic attack before 4 weeks Yes / No

In–Patient admission before 4 weeks Yes / No

Difficulty establishing feeding by 4 weeks Yes / No

Feeding now: Breast / Bottle / Both / Mixed

Brand of artificial milk:

Interval to last live birth: months OR first baby

Father's Occupation: Civillian / Service / Unemployed

Housing: Owner occupied / Married quarter / Council / Other

Please state:

Smoking: Mother Yes / No – No. per day

Father Yes / No – No. per day

Other residents Yes / No – No. per day

Is there any family history of inner ear deafness Yes / No

Relationship to baby:

Did any of the family wear a hearing aid before the age of 16 Yes / No

Relationship to baby:

PP

The form was amended at the request of a consultant, who wanted to attempt research into childran at risk of deafness

Portsmouth Infant Surveillance Four Week Questionnaire (Page 2) completed by the Health Visitors immediately after their 4 week visit of infants born 1.1.85.- 31.12.89.

PCH 2 (b)

THIS FORM SHOULD BE FILLED IN IMMEDIATELY AFTER THE 4 WEEK VISIT

Has mother a history of mental/emotional illness — Yes / No

Previous child care / or at risk of NAI — Yes / No

Have the parents a stable relationship — Yes / No / Not Known

	Excellent	Good	Average	Fair	Poor
District / Neighbourhood					
State of Repair of house furnishings and equipment					
State of hygiene					
Attitude Mother / baby i.e. the way she handles, relates & responds to baby.					

Number of home visits by Health Visitor prior to this visit: — visits

Would you consider the baby to be high risk of SID — Yes / No

Would you consider the baby to be high risk of NAI — Yes / No

Any previous infant deaths — Yes / No

Has baby had any ototoxic drugs — Yes / No

State type:—

Duration:—

Has baby had encephaltis, meningitis, cytomegalovirus — Yes / No

Has baby needed treatment for jaundice — Yes / No

Pre—auricular appendiges or abnormalities around the ear — Yes / No

Famileal Harelip / Cleft Palate — Yes / No

Relevant Health Visitor comments:

Signature

Date of completion

The form was amended at the request of a consultant who wanted to attempt research into children at risk of deafness

The Gosport Infant Surveillance Birth Scoring System 1.1.82.- 31.3.83 using the 'Sheffield Factors'

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

GOSPORT INFANT SURVEILLANCE

BIRTH SCORING SYSTEM

MOTHERS AGE	10 x (50 -age in years)			....
NUMBER OF PREVIOUS PREGNANCIES	0	-	0	
	1	-	21	
	2	-	43	
	3	-	64	
	4	-	85	
	5	-	107	
	6	-	128	
	7	-	149	
	8	-	171	
	9 or more	-	192	....
MOTHERS BLOOD GROUP	O, B, AB	-	44	
	A	-	0	
	Unknown	-	22	....
URINARY TRACT INFECTION	YES	-	54	
	NO	-	0	
	Unknown	-	5	....
FEEDING INTENTION	Breast only	-	0	
	Bottle or both		38	....
DURATION OF 2ND STAGE OF LABOUR	Less than 5 min		127	
	5 - 14 min		100	
	15 - 29 min		72	
	30 min - 2 hr		45	
	More than 2 hr		18	
	Caesarean Section		76	
	B B A		76	....
BIRTH WEIGHT	Less than 2000 g		93	
	2000 - 2499 g		78	
	2500 - 2999 g		62	
	3000 - 3499 g		47	
	3500 - 3999 g		31	
	4000 - 4499 g		16	
	4500 - 5500 g		0	....
TWIN	Yes	-	103	
	No	-	0	....

CUT POINT FOR TOTAL SCORE	500
HIGH RISK	500 and over
LOW RISK	499 and under

Reference: Carpenter and Emery 1977.

The Gosport Infant Surveillance Four Week Scoring System 1.1.82.- 31.3.83. using the 'Sheffield Scoring Factors'

GOSPORT INFANT SURVEILLANCE

4 WEEKS SCORING SYSTEM

Birth Score — B/F ....

Cyanotic or apnoeic attack before completion of form

YES - 237
NO - 0 ....

In patient admission before completion of form

YES - 155
NO - 0 ....

Difficulty establishing feeding before completion of form

YES - 83
NO - 0 ....

Interval in months between this birth and last live birth

2 x (100 -number of months)
If first live birth - 128 ....

State of repair of the house, furnishings and equipment

Excellent - 9
Good - 43
Average - 78
Fair - 112
Poor - 147
Not seen - 73 ....

CUT POINT 754
High Risk 754 or more
Low Risk 753 or less

JP/JW/Jan 82

Reference: Carpenter and Emery, 1977.

Appendix 3.B.(i)

Portsmouth Infant Surveillance Birth Scoring System Commenced 1.4.83 using only 7 of the 8 'Sheffield Factors' Blood Group was Replaced by Smoking.

PORTSMOUTH INFANT SURVEILLANCE SYSTEM

BIRTH SCORING

MOTHERS AGE	10 x (50 - age in years)	
NUMBER OF PREVIOUS PREGNANCIES	0 -	0
	1 -	21
	2 -	43
	3 -	64
	4 -	85
	5 -	107
	6 -	128
	7 -	149
	8 -	171
	9 or more -	192
MOTHERS SMOKING	Non Smoker -	0
	1 - 10	20
	11 + -	40
URINARY TRACT INFECTION	Yes -	54
	No -	0
	Unknown -	5
FEEDING INTENTION	Breast only -	0
	Bottle or both	38
	Unknown -	9
DURATION OF 2nd STAGE OF LABOUR	Less than 5 min.	127
	5 - 14 min.	100
	15 - 29 min.	72
	30 min. - 2 Hr.	45
	More than 3 Hr.	18
	Ceasarian Section	76
	B.B.A.	76
	Unknown	76
BIRTH WEIGHT	Less than 2000 g.	93
	2000 - 2499 g.	78
	2500 - 2999 g.	62
	3000 - 3499 g.	47
	3500 - 3999 g.	31
	4000 - 4499 g.	16
	4500 +	0
	Unknown	46
TWIN	Yes -	103
	No -	0
CUT POINT FOR BIRTH SCORE	500	
HIGH RISK	500 and over	
LOW RISK	499 and under	

Final Scoring Overleaf

Reference: Carpenter and Emery, 1977.

Portsmouth Infant Surveillance Four Week Scoring System Commenced 1.4.83. using all 5 of the Sheffield Risk Factors and in Addition, 6 Factors Predicting Non-Accidental Injury and/or the Experience of a Previous Child Death in the Family.

4 WEEK SCORING

Birth Score/Brought Forward

Cyanotic or apnoeic attack before completion of form

Yes	-	237
No	-	0
Unknown	-	9

In patient admission before completion of form

Yes	-	154
No	-	0
Unknown	-	6

Difficulty establishing feeding before completion of form

Yes	-	83
No	-	0
Unknown	-	36

Interval in months between this birth and last live birth

2 x (100 - number of months)

If first live birth - 128

State of repair of the house, furnishings and equipment

Excellent	-	9
Good	-	43
Average	-	78
Fair	-	112
Poor	-	147
Not seen	-	73

CUT POINT	
LOW RISK	753 or less
HIGH RISK	754 - 999
VERY HIGH RISK	1000 or more

PREVIOUS CHILD DEATH

If the family have experienced a previous child death, the subsequent infants will be scored high risk.

FACTORS PREDICTING NON-ACCIDENTAL INJURY TO CHILDREN

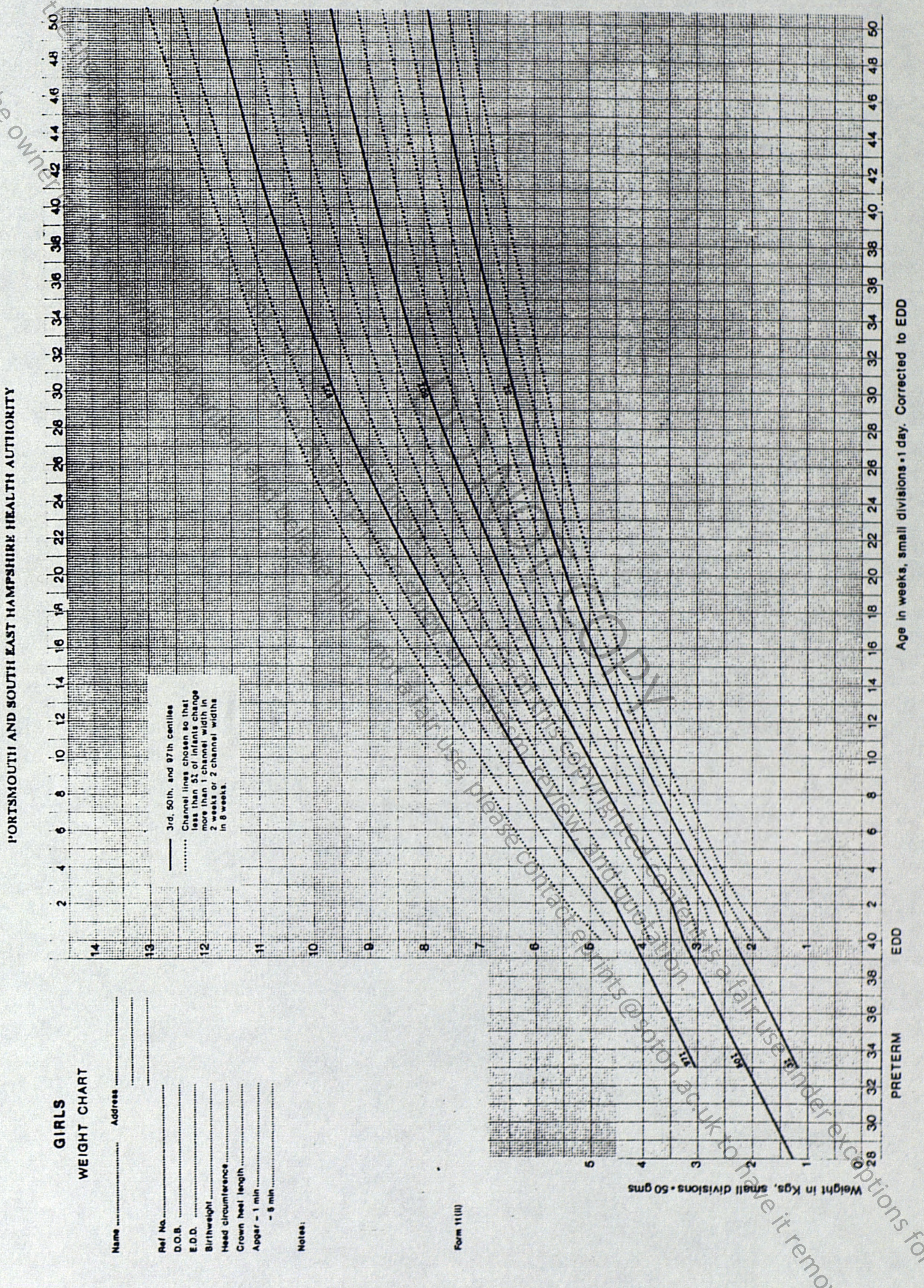
Baby admitted to Special Care Baby Unit
Mother's history of emotional/psychiatric illness
Midwife/Health Visitor concern re handling of baby
Family known to Social Services Dept.
Marital instability
Under 20 when first child born

Baby scores High Risk if three or more of these factors are indicated.

January 1986

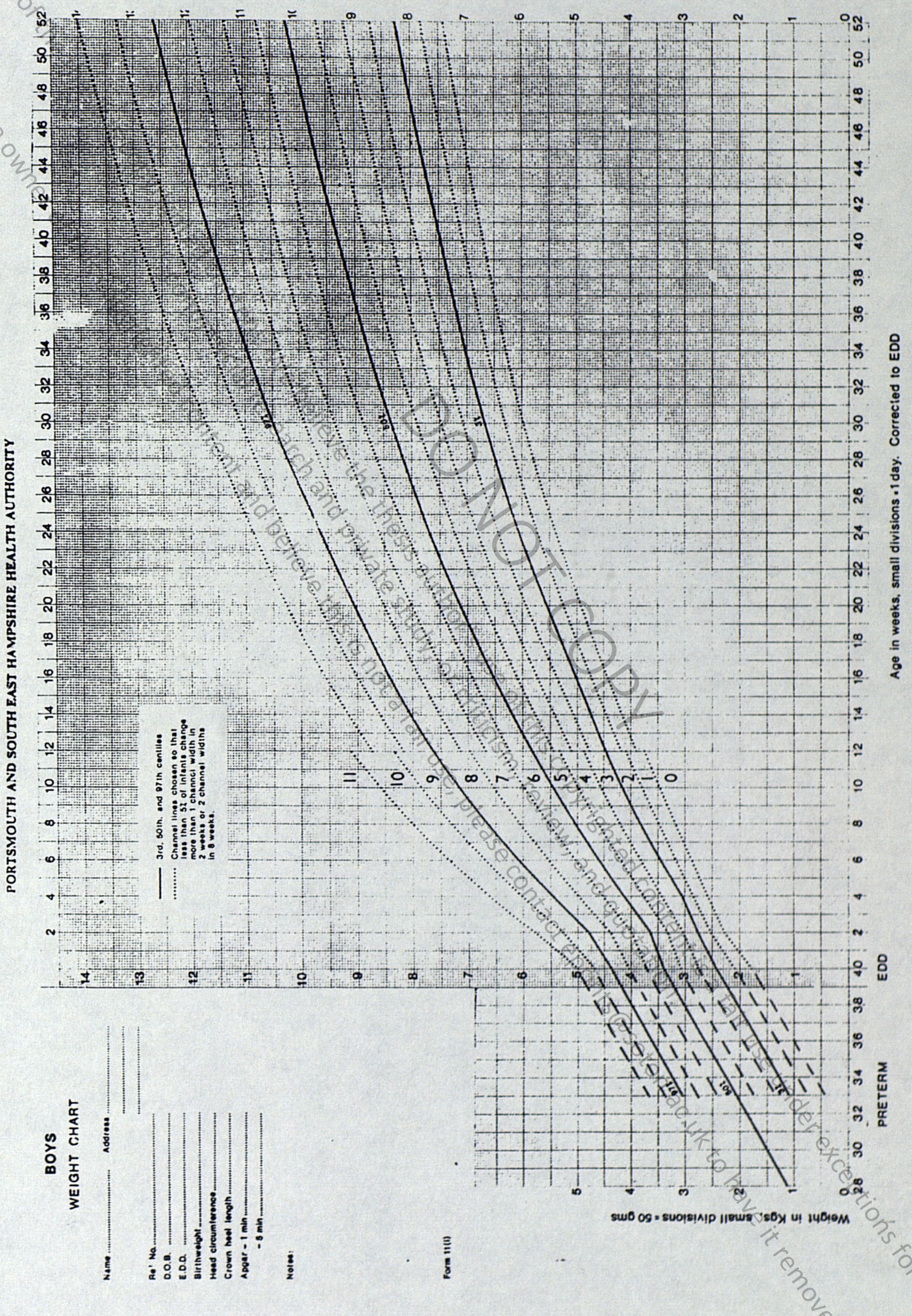
Reference: Carpenter and Emery, 1977; Powell, 1985.

'Sheffield Type' Weight Percentile Charts
used for High Risk Infants only from 1.1.82.- 31.12.83.
but since then used for all Infants in Portsmouth Health District.



Reference: Carpenter and Gardner, 1985 and 1989.

'Sheffield Type' Weight Percentile Charts with Channels marked 0-11 and the Channels approximated for Premature Infants.



Reference: Carpenter and Gardner, 1985 and 1989.

Portsmouth Infant Surveillance Guidelines for use with 'Sheffield Type' Weight Percentile Charts.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

PORTSMOUTH INFANT SURVEILLANCE - GUIDELINES REGARDING THE USE OF WEIGHT PERCENTILE CHARTS

These weight percentile charts have been designed by Dr R G Carpenter.

The scale across the bottom indicates the age in weeks, and the small divisions correspond to one day. The verticle scale represents the weight in kilograms, with heavy lines at each half Kg (500g) and small divisions correspond to 50g.

The lines on the chart indicate the normal pattern of growth in children. The 3 heavy black lines correspond to the percentile points usually shown on growth charts. At any time only 3% of infants are likely to be below the lower heavy line, 50% will be below the middle line and 50% above it, only 3% will be above the upper heavy line (indicated 97%).

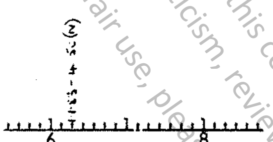
95% of all babies will not deviate from the channel in which they start at birth by more than one channel width in any subsequent 2 weeks period or 2 channel widths in any subsequent 8 weeks period. If the deviation is greater than this there is cause for concern.

The channels change in width at 8 weeks for girls and 12 weeks for boys because weight gain stabilises around this age. At this stage, weight gain should be assessed by the narrower channel width.

a. The chart has been designed to account for prematurity. If an infant is 4 weeks premature, start the chart at 36 weeks, which will ensure prematurity is accounted for throughout the infant's first year.

b. All babies must be weighed naked whenever possible. Calculate the exact date when weighed in weeks and days, then plot the weight accurately in the correct place.

c. It is preferable to indicate on the chart in the appropriate place:- the date the infant was weighed, the amount it weighed and whether the infant was naked or dressed, eg:-



To assess whether the weight gain is satisfactory, every time you plot a weight you must:

1. Compare with 2 weeks previously.
2. Compare with 8 weeks previously.

IF THE CHILD'S WEIGHT IS NOT PROGRESSING AS EXPECTED - REFER THE CHILD FOR MEDICAL ASSESSMENT.

The charts can be used for indicating other details of baby's first year.

a. Feeding information - draw a green line on the appropriate day of birth and at the top of the line indicate how baby is being fed, ie B.F. or A.F. - Milumil. If there are changes in feeding, draw a green line at the appropriate place and indicate changes ie BF AF-SMA, mixed feeding, cow's milk, etc.

b. Problems/Crises - draw a red line on the chart in the appropriate place and indicate any problems or periods of illness, any referrals to GP or paediatrician.

JP/CMC/1.4.83 IS/D

Reference: Carpenter and Gardner 1985.

Gosport Infant Surveillance 'Notification of Risk' sent to General Practitioners and Health Visitors for Infants born 1.1.82 - 31.3.83.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

Community Health Services - Western

CONFIDENTIAL

From: Mrs J Powell
Nursing Officer/Health Visiting

To: Dr.
: Health Visitor

Date

GOSPORT INFANT SURVEILLANCE

Baby..............................D.O.B...............

Scored on the G.I.S. Multistage scoring system.

JP/JJ/1.1.82.

Appendix 6.B.

Portsmouth Infant Surveillance 'Notification of Risk' sent to General Practitioners and Health Visitors for All Infants born in the District 1.4.83.- 31.8.84.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

CONFIDENTIAL

From Mrs J.Powell(N.O./H.V.)   To HV JANNER

Baby BAILEY   D.O.B. 1 1 83

scored LOW on the multistage scoring system.   Date 10 2 83   I.S/5

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

ONFIDENTIAL

From Mrs J.Powell(N.O./H.V.)   To Dr THOMAS

Baby BAILEY   D.O.B. 1 1 83

scored LOW on the multistage scoring system.   Date 10 2 83   I.S/5

Appendix 6.C.

Notification of Risk Status sent to General Practitioners and Health Visitors for Infants born after 31.8.84.

SPECIMEN COPY

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
CHILD HEALTH AND SURVEILLANCE SYSTEM (PCH5b)

CONFIDENTIAL

To Dr : DR J E BATEMAN

Baby : COLES   Dob : 31/05/86   (F)   40 FROXFIELD ROAD

Scored HIGH 861 on the multistage scoring system

MA	PP	MS	UTI	FI	2ND	BW	TW	C/A	IP	D/F	PLB	SoR	Total	PCD
260	64	20	54	0	45	93	0	0	154	0	128	43	861	1

U20

Date 17/07/86

SPECIMEN COPY

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
CHILD HEALTH AND SURVEILLANCE SYSTEM (PCH5a)

CONFIDENTIAL

To HV : MRS PODEN

Baby : COLES   Dob : 31/05/86   (F)   40 FROXFIELD ROAD

Scored HIGH 861 on the multistage scoring system

MA	PP	MS	UTI	FI	2ND	BW	TW	C/A	IP	D/F	PLB	SoR	Total	PCD
260	64	20	54	0	45	93	0	0	154	0	128	43	861	1

U20

Date 17/07/86

Appendix 7.A.

Portsmouth Infant Surveillance Communication sent to General Practitioners and Health Visitors to inform them how they would be notified of the 'Risk Status' of Infants born 1.4.83.- 31.8.84.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

NOTIFICATION OF 'AT RISK' STATUS - Low, High or Very High Risk, Regarding Sudden Infant Death, Child Abuse and/or Previous Child Death in the Family.

Notification at 4 weeks for HV and GP

GPs will receive a slip informing them only if the baby is Low, High or Very High Risk.

LOW	-	month score less than 754
	-	no previous child deaths
	-	less than 3 NAI factors
HIGH	-	month score 754 or more
	-	AND/OR a previous child death
	-	AND/OR at least 3 NAI factors
VERY HIGH	-	month score of 1000 or more

The Health Visitor however will receive notification identifying:

LOW	-	as for GP
HIGH	-	month score 754 - 999
	-	AND/OR a previous child death
	-	less than 3 NAI factors
VERY HIGH	-	month score 1000 or more
	-	less than 3 NAI factors
LOW //	-	month score less than 754
	-	no previous child deaths
	-	BUT 3 or more NAI factors
HIGH //	-	month score of 754 - 999
	-	AND/OR a previous child death
	-	AND 3 or more NAI factors
VERY HIGH //		month score 1000 or more
	-	AND 3 or more NAI factors

The notification of 'At Risk' status is only an alerting system, any cause for anxiety by the Health Visitor should be notified to her NO and the usual procedure followed.

GUIDELINES RE HOME VISITING

LOW	-	to be visited re policy "Minimum Standards of Home Visiting"
HIGH	-	to be visited every fortnight until 3 months old
LOW //	-	every month until 6 months old, then routine visiting
HIGH	-	
VERY HIGH	-	visit every week until 3 months old, every 2 weeks
VERY HIGH //		until 6 months then every month until 1 year.

JP/JC/1.4.83

IS/C

Portsmouth Infant Surveillance ' Notification of Risk' sent to General practitioners and Health Visitors from 1.9.84.- 31.12.89. and Memorandum notifying them of the Changes

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
CHILD HEALTH AND SURVEILLANCE SYSTEM (PCH5b)

CONFIDENTIAL

To Dr : DR J E BATEMAN

Baby : COLES Dob : 31/05/86 (F) 40 FROXFIELD ROAD

Scored HIGH 861 on the multistage scoring system

MA	PP	MS	UTI	FI	2ND	BW	TW	C/A	IP	D/F	PLB	SoR	Total	PCD
260	64	20	54	0	45	93	0	0	154	0	128	43	861	1

U20

Date 17/07/86

Below is a example of how the new form will appear and an explanation of the abbreviations.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

CONFIDENTIAL

From Mrs J.Powell (C.N.M./H.V.) To HV MRS ANDERSON

Baby ANDREWS D.O.B. 28 12 83 18 ALTAIR AVE

scored LOW 544 on the multistage scoring system.

MA	PP	MS	UTI	FI	2ND	BW	TW	C/A	IP	D/F	PLB	SoR	Total	PCD
220	21	40	0	0	45	47	0	0	0	0	128	43	544	No

HV MI

I.S/5

MA - Mothers age
MS - Mothers Smoking
FI - Feeding Intention
BW - Birthweight
C/A - Cyanotic or Apnoeic attack
D/F - Difficulty in Feeding
SoR - State of repair of house
PP - Previous pregnancies
UTI - Urinary Tract Infection
2ND - Duration of 2nd stage
TW - Twin
IP - In-Patient
PLB - Interval to last live birth

PCD - Previous child death (if 'Yes' child will be 'HIGH')

In addition to the breakdown of the score, if there are any child abuse factors relating to the child, these will be printed as well using similar codings.

SCBU - Child went to Special Care Baby Unit
M/E - Mother has history of mental/emotional illness
HV - Health Visitor concern re handling of baby
PCIC - Previous child in care/at risk NAI
MI Marital Instability
U20 Under 20 when 1st child born

Gosport Infant Surveillance a Handout 'Do Not Overheat Baby' given to Parents of Infants born 1.1.82 - 31.3.83.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

COMMUNITY HEALTH SERVICES

DO NOT OVERHEAT BABY

Dress baby for the climate, not necessarily for the time of year.

Indoors with room temperature at 65°F, baby should be dressed in vest, nappy, babygro (or nightie/dress/etc), cardigan, plus bootees and mittens if feet and hands are cold.

Feeling baby's neck is a more accurate indication of temperature than hands and feet.

If baby is brought indoors from outside and is well wrapped up REMEMBER to remove some layers of clothing/coverings.

If baby is in a cot or pram indoors in a warm room, a sheet with two or three layers of blanket are usually sufficient. The waterproof pram cover should not be on indoors.

Make sure that some of baby's clothes are made from natural fibres (ie cotton, wool, silk) as man made fibres - nylon, polyester, acrilan etc, are highly insulated and almost non-absorbent to sweat; causing overheating and discomfort.

On long journeys cars can get very warm, check that baby is not covered by too many layers.

If baby is unwell and has a high temperature DO NOT ADD extra blankets, remove some clothing, and contact your doctor.

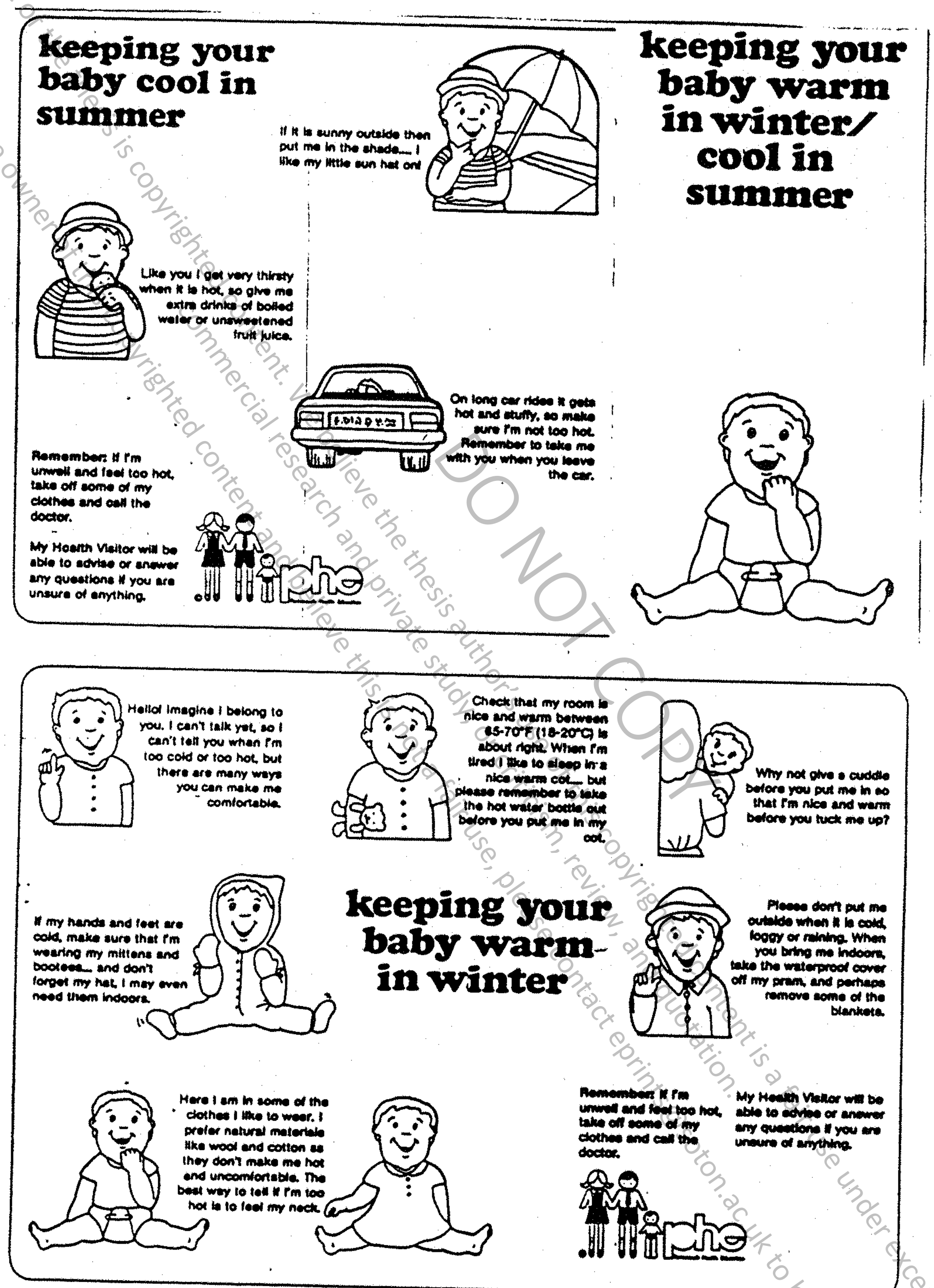
In hot weather keep the pram hood down and shade your sleeping baby from direct sunlight with a sun canopy.

JP/JJ/1.1.82

Handout designed after consideration of the theory that some Sudden Infant Deaths might be caused by overheating (Bacon et al, 1979).

Appendix 8.B.

Portsmouth Infant Surveillance
a Leaflet 'Keeping Your Baby Warm in Winter/Cool in Summer'



The leaflet was produced by Portsmouth Health Education Department in an endevour to educate parents not to overheat their babies. A copy of the leaflet has been given to the parents of every infant in the Health District since 1.4.83.

Portsmouth Infant Surveillance Information Package (Contents Page IS/A) given to all Health Visitors and to Groups of Midwives in Portsmouth Health District from 1.4.83 until 31.7.84.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

(April 1983) IS/A

Appendix 9.B.

Portsmouth Infant Surveillance Revised Information Package (Contents Page IS/A) given to all Health Visitors commencing work in Portsmouth Health District since 1.8.84.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

IS/A	CONTENTS SHEET
IS/B	ROUTINE FROM BIRTH TO ONE YEAR
IS/C	GUIDELINES RE HOME VISITING
IS/D	WEIGHT PERCENTILE CHART
IS/E	SID and NAI FACTORS RE RISK SCORING
IS/F	HEATING/OVERHEATING LEAFLET
IS/G	GUIDELINES ON WHAT TO DO WHEN A BABY DIES SUDDENLY AND UNEXPECTEDLY
IS/H	POLICY ON APNOEA MONITORS AND GUIDELINES RE MONITORS
PCH1a	BIRTH QUESTIONNAIRE COMPLETED BY MIDWIVES
PCH1b	BIRTH INFORMATION FOR HEALTH VISITORS
PCH2a	4 WEEK QUESTIONNAIRE COMPLETED BY HEALTH VISITORS
PCH5a	SCORING RESULT MEMO
PCH5b	EXPLANATION OF CODES
PCH6	WEIGHT CENTILE CHART
PCH11	INFANT DEATH QUESTIONNAIRE
PCH22	CHILD HEALTH CLINIC INFORMATION SLIP
PCH24	GENERAL PRACTITIONER INFORMATION SLIP

IS/A 2/87

Portsmouth Infant Surveillance
Guidelines Regarding Routine, Birth - One Year (IS/B).

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE - ROUTINE FROM BIRTH - 1 YEAR

AT BIRTH	A Birth Questionnaire (IS/1) is completed for every baby born in Portsmouth District. It is attached to the Birth Notification Form and sent to Immunisation/Vaccination Department.
2 - 4 Days	IS/1 details entered onto the computer.
3 - 6 Days	IS/1 is received by the appropriate Health Visitor.
6 - 10 Days	4 Week Questionnaire (IS/2) is sent with the health visiting records plus extra labels in a polythene bag to the Health Visitor.
10 - 14 Days	A community discharge form is to be left in the patients' home by the Community Midwife for the Health Visitor. IF THERE ARE ANY COMPLICATIONS - the Midwife will contact the Health Visitor direct.
10 - 14 Days	Primary visit by Health Visitor. At the end of the visit, explain to the mother that a survey to improve services to babies and mothers is being carried out. This will include weighing baby and completing a small questionnaire. Make an appointment to return in approximately two weeks - write the date of the visit on baby's weight card. Give the mother a copy of the leaflet - Keeping your baby warm in Winter/Cool in Summer.
25 - 31 Days	Home Visit - Weigh baby naked and complete page 1 of the questionnaire with the mother. Page 2 is to be completed immediately after the home visit. Explain to the mother that some babies will be selected out for extra visiting, if her baby is selected you will contact her and visit again in two weeks time. Return the IS/2 to the Immunication/Vaccination Department. If baby has transferred out of the district or is in hospital, complete as much as possible of the form, state the reason it is incomplete and return to the Immunisation/Vaccination Department.
4 - 6 Weeks	IS/2 information entered onto the computer. The scoring result is produced by the computer - (IS/5) for notification to the Health Visitor and the G.P. (via internal mail by the Health Visitor). If baby scores High, High+ or NAI risk, the Health Visitor receives an IS/5 plus:- a weight centile chart (IS/6) for recording baby's weight; a wall thermometer; two contact monitoring forms (IS/7) - one for the high risk baby plus one for the next low risk baby in the birth register as a control.
7 - 8 Weeks	The computer will issue a memo (IS/8) to the Health Visitor requesting the return of IS/2 if this has not already been returned. The memo will be sent via the Nursing Officer.
8 Weeks - 1 Year	Visiting as attached sheet IS/C.

IS/B

Portsmouth Infant Surveillance
Guidelines Regarding Routine, Birth - One Year (IS/B Page 2).

When baby is one year old IS/9 will remind you to return to Immunisation/ Vaccination:-

The Thermometer
The Weight Percentile Chart
The Monitoring sheet for the High Risk Infant and for the control baby.

Please return all of the above if a baby moves out of the District.

IF UNFORTUNATELY BABY DIES please inform Immunisation/Vaccination Department immediately. You will be sent a questionnaire (IS/11). Please return it completed to Immunisation/Vaccination as soon as possible, accompanied by all your records for the baby. It is important to include the name, address and IS reference number of the child before and the child after the dead infant in your birth book, as information about these will be used as control data.

CONFIDENTIALITY

This is extremely important, please store all records in locked filing cabinets. Fold the completed questionnaire, place it in the labelled polythene bags and send to Immunisation/Vaccination Department. Labelled bags will be available from:-

Somers Town Health Centre
Lake Road Health Centre
Dunsbury Way Health Centre
Waterlooville Health Centre
Fareham Health Centre
Community Health Department, Gosport.

When the information is on the computer, the questionnaires will be shredded. Names and addresses will be blanked off the computer as soon as possible. There will be only one list retained of Names, Addresses and Reference Numbers.

If there are any problems, suggestions or comments, please contact Mrs Jean Powell, Nursing Officer/Health Visiting, Community Health Department, Gosport - Tel. Gosport 523221 OR Infant Surveillance Clerk, Immunisation/Vaccination Department, Lombard Street, Portsmouth - Tel. Portsmouth 750666.

JP/LM 1.4.83 IS/B

Portsmouth Infant Surveillance
Guidelines Regarding Home Visiting.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

GUIDELINES REGARDING HOME VISITING

Risk - Low	If scoring 753 or below.
Risk - High SID	If scoring 754 or above.
	If experienced previous infant death - reglardless of score.
Risk - Very High	If scoring 1000+
Risk - High NAI	If scoring 3 or more factors.

Low Risk Infants - to be visited according to policy - 'minimum standards of home visiting'.

High Risk Infants - to be visited every fortnight until 3 months old, every month until 6 months old, then routine visiting.

Very High Risk Infants - to be visited every week until 3 months, every two weeks until six months, every month until one year, then routine visiting.

At each visit, weigh the infant naked and plot the weight on the percentile chart. If there is any weight loss, according to instructions IS/D refer the infant to the General Practitioner.

Some suggestions when visiting:- Note general appearance, muscle tone, colour, fontanelles, etc.

Discuss with parents:-

Symptoms in baby i.e. snuffles, cough, poor feeding, diarrhoea, skin sepsis, napkin rash, sticky eye, thrush, excessive crying, colic etc.

Feeding - specifically questioning concentration of feeds, sterilisation of equipment, mixed feeding.

Overheating /keeping baby warm.

General care of baby and mothering.

Father's involvement with baby.

Family health since baby's birth, including respiratory tract infections; gastro-intestinal infections; skin infections; mother's wellbeing.

Dangers to the baby of passive smoking.

Caution re taking baby out if weather conditions are unsuitable.

Comments and advice re hygiene of pets.

JP/JJ/24.2.83 IS/C

Head Circumference/Length Percentile Chart (IS/3a) sent to Health Visitors 1.4.83.- 31.3.84, for Infants whose Head or Length Measurements were Outside the Average Range at Birth Regardless of Gestation.

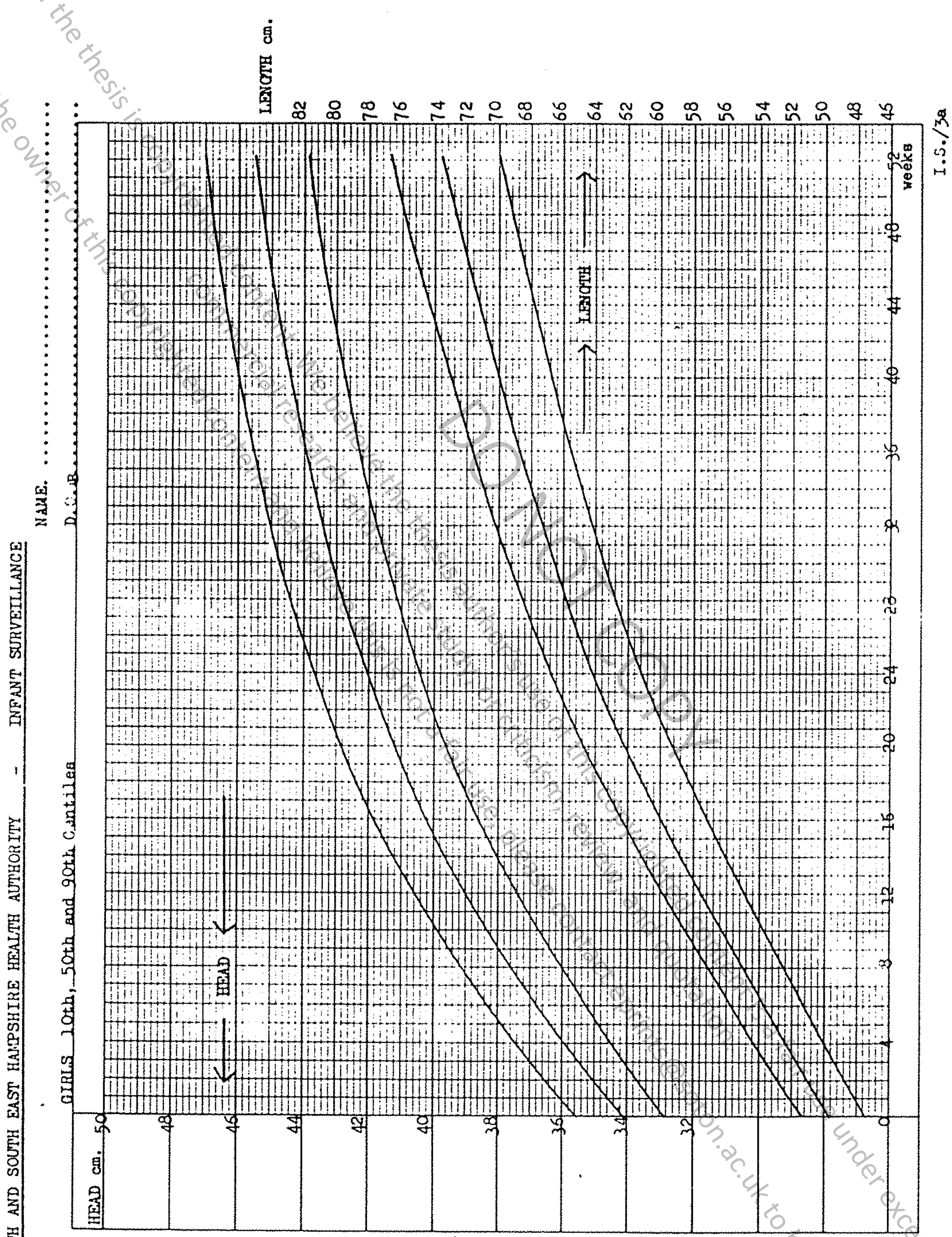


Chart prepared in 1983 by A. Gardner for Portsmouth and S.E. Hampshire Health Authority from J.H.Tanner, et al. Arch. Dis. Child (1966), 41, 613 and D. Gairdner et al Arch. Dis. Child (1971), 46, 783

The normal range of measurements at birth were: Head Circumference 33-35 cms., Length 47-51 cms.,

Computer Forms (IS/3b) sent out with Head Circumference/Length Percentile Charts (IS/3a) and (IS/10) requesting return of IS/3a Charts.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

CONFIDENTIAL

From Mrs J.Powell(N.O./H.V.)   To HV Mrs Moulds

Baby JENKINS   D.O.B. 1 1 83

The above baby's head cicumference/length appears to be outside the normal range. Enclosed is a chart to monitor growth on AT LEAST four occasions throughout the next year, i.e. 4 wks, 5/6 mths, 7/9 mths and 1yr.

Date   5 1 83   I.S/3b

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

CONFIDENTIAL

From Mrs J.Powell(N.O./H.V.)   To HV MISS ROBINSON

Would you please return head circumference/length chart for baby CAVENEY D.O.B. 28 1 84 who is now 1 yr old.

I.S/10

Appendix 13.

Portsmouth Infant Surveillance - Midwifery Discharge Letter (IS/4) sent to Health Visitors on Completion of Midwives Care of Mothers and Infants, usually 10-14 Days after Delivery.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
MIDWIFERY DISCHARGE LETTER

To:
Health Visitor

Re. Baby - D O B -
Address:

Will be discharged to your care on:
Weight on discharge - Kgms.
Feeding - a. Breast. b. Bottle - artificial milk -
c. Breast and complementary feed of -
P K U and Thyroid Test- date when blood taken -
C D H - date tested -
Comments on Infant's condition:

Comments on Mother's Condition:

Signed: Midwife. Date:
JP/JJ/24.2.83 IS/4

Monitoring Form IS/7 Completed by Health Visitors in 1982 and 1983 to Verify Contacts with High Risk Infants and Low Risk Controls, were According to the Recommended Guidelines of the Infant Surveillance Programme.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

Date	Home Visit	N.R. Visit	Clinic Attendance	Other Contact Outside/Phone/etc.	Baby Undressed Y/N	Name D.O.B. I.S. Ref No. Health Visitor Reason For Visit

JP/JJ/10.2.83 I.S./7

Monitoring Forms Completed Retrospectively by Health Visitors in 1984/85 for selected High Risk Infants and Low Risk Controls to Verify Infants were being Contacted According to the Recommended Infant Surveillance Guidelines.

Gosport Health Centre
Bury Road
Gosport P012 3PN

To: Health Visitor

I would be most grateful if you could complete a questionnaire for a high risk baby you were responsible for in 1983 + 1984. Also a questionnaire for the next low risk baby in your birth book, after the high risk one, to use as a control. This request has the approval of your Director of Nursing Services.

Name of baby: Date of Birth High risk or low risk

	Number Home Visits	Number No Reply Visits	Number Clinic attendances	Number Other Contacts 'Phone/outside/etc.	Number times baby weighed	Number times baby weighed naked at home	Number times baby weighed naked at Clinic	Please note in relevant section anything specific regarding this child, for example health, abnormalities etc.
								COMMENTS
up to Birth -/ 3 months								
up to 3 -/ 6 months								
6 - 12 months								

Developmental Test - Y/N Age/s tested

Vision Test - Y/N Necessary to repeat Y/N
Necessary to refer Y/N

Hearing Test - Y/N Necessary to repeat Y/N
Necessary to refer Y/N

Please attach a copy of the percentile chart you kept for this child, and return all the documents to me at the above address via internal mail.

I am most grateful for your co-operation.

Jean Powell.

Gosport Infant Surveillance Questionnaire (IS/11) completed by Health Visitors 1.1.82. - 31.3.83. whenever an Infant Died Suddenly and Unexpectedly.

CONFIDENTIAL

HAMPSHIRE AREA HEALTH AUTHORITY (TEACHING)
PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH DISTRICT
SUDDEN INFANT DEATH

NAME .... D.O.B. ....

ADDRESS .... G.P. ....

TYPE OF ACCOMMODATION .... TYPE OF HEATING ....

FATHER .... AGE .... OCCUPATION ....

MOTHER .... AGE .... OCCUPATION ....

SIBLINGS NAME .... NAME ....
D.O.B. .... D.O.B. ....
NAME .... NAME ....
D.O.B. .... D.O.B. ....

BABY - PRE-NATAL Labour Spontaneous/Induced Duration of labour ....
Delivery-Type .... B.W. ....

POST NATAL Special Factors ....
Breast Fed .... weeks/months
Bottle Fed .... milk
Mixed feeding commenced .... weeks/months

PROPHYLAXIS

Type Injection	Date	Comments
....	....	....
....	....	....
....	....	....
....	....	....

DEATH DATE .... TIME .... PLACE Cot/Pram/Other

ANY OF THE FOLLOWING ILLNESSES IN THREE WEEKS PRIOR TO DEATH

Snuffles ....
Teething ....
Cold ....
Runny Nose ....
Sore Throat ....
Cough ....
Wheeziness ....
Feverishness ....
Sweating ....
Rash ....
Vomiting ....
Diarrhoea ....
Unusual sleepiness ....
Unusual restlessness ....
Other ....

ANY SPECIAL COMMENTS

JP/JJ. 1.1.82

Signed .... Date ....
Health Visitor

Portsmouth Infant Surveillance Amended Questionnaire (IS/11) Completed by Health Visitors in Portsmouth Health District whenever a Possibly Preventable Postperinatal Death has occured 1.4.83.- 31.12.89.

GP/JJ/11.2.83

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE

Name of Child:

Address:

OR PATIENT LABEL

Moved House since delivery: Yes / No

D.O.B.: D.O.D. Time:

Place: Pram / Cot / Other - State:-

Location of above:

Breast Feeding Only: Yes / No

Bottle Feeding partial, or wholly commenced at ..... weeks

Mixed Feeding commenced at ..... weeks

Please tick any of the following, which baby had suffered from during 3 weeks prior to death:

- Respiratory Tract Infection ___
- Gastro-intestinal symptoms ___
- Unusual sleepiness ___
- Unusual restlessness ___
- Persistent crying ___
- Rash / nappy rash ___
- Other - State:

Any infections within family environment: Yes / No

If Yes, please state:-

Any other relevant comments:-

Name, address and I.S. Ref. No. of child before in birth register:

Name, address and I.S. Ref. No. of child after in birth register:

Any relevant comments re above two infants:-

Signed: Health Visitor Date: I.S./11

Appendix 16.

Portsmouth Infant Surveillance
Computer Printout supplied to Clinical Medical Officers (PCH/22) produced for Each Infant Born in Portsmouth Health District since 1.9.84, giving limited Maternal History, Pregnancy and Birth Details and the Midwives Assessment of Normality at Birth.

```
       PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
            CHILD HEALTH AND SURVEILLANCE SYSTEM  (PCH22)

Name     COLES                             H.V  334 MRS FODEN
Address  40 FROXFIELD ROAD                 Doctor    DR J E BATEMAN
         FAREHAM                           B/score    536
         HANTS                             PCH Ref   C420310586F0120

MATERNAL HISTORY
 Previous stillbirths  0
 Previous child deaths  1
  Age :-  11 wks    Cause :- SUDDEN INFANT DEATH
  Age :-   0 wks    Cause :-

PREGNANCY AND BIRTH                        CHILD DETAILS
 Gestation      40 wks                      Sex              FEMALE
 Born at        ST MARYS                    Weight           1845 gms
 Date           31/05/86                    Length           450  mm
 Time           04:29                       Head Circum      300  mm
 Delivery       NORMAL                      Apgars            8- 9- 9
 Duration 1st   05:00                       Twin             NO
          2nd   00:35                       Feeding intent   BREAST
          3rd   00:07                       SCBU             NO
COMPLICATIONS                               Reason
 Pregnancy NONE
 Delivery  NONE
 Baby App  NORMAL
I consent to this information being included in my child's records.
Parents Signature                                      Date
```

These printouts were designed to be filed, after the mother has given her consent, in the Child Health Clinic Records. It is believed Portsmouth Infant Surveillance is unique in providing this facility.

Appendix 17.

Portsmouth Infant Surveillance
Computer Memorandum (PCH24) supplied to General Practitioners for each Infant born in Portsmouth Health District since 1.9.84. giving Birth Details and the Midwives Assessment of Normality

SPECIMEN COPY

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
CHILD HEALTH AND SURVEILLANCE SYSTEM (PCH24)

Name COLES
Address 40 FROXFIELD ROAD
FAREHAM
HANTS

Doctor DR J E BATEMAN
H.V 334 MRS FODEN
B/score 536
PCH ref C420310586F0120

PREGNANCY AND BIRTH

Gestation	40 wks
Born at	ST MARYS
Date	31/05/86
Time	04:29
Delivery	NORMAL
Duration 1st	05:00
2nd	00:35
3rd	00:07

COMPLICATIONS

Pregnancy	NONE
Delivery	NONE
Baby App	NORMAL

CHILD DETAILS

Sex	FEMALE
Weight	1845 gms
Length	450 mm
Head Circum	300 mm
Apgars	8 - 9 - 9
Twin	NO
Feeding intent	BREAST
SCBU	NO
Reason	

THE ABOVE DETAILS WERE RECORDED AT TIME OF DELIVERY

It is understood Portsmouth and South East Hampshire Health Authority are unique in providing this service, which is very much appreciated by General Practitioners.

Portsmouth Infant Surveillance
Letter sent to all 308 General Practitioners in The Health District, Informing them of the Commencement of the Surveillance System 1.4.83.

PORTSMOUTH AND SOUTH EAST
HAMPSHIRE HEALTH AUTHORITY

Community Health Services (Western)
133 Stoke Road
GOSPORT
Hants PO12 1BP

Gosport 23221 Ext. 40
Please ask for Mrs Powell
Our Ref JP/JJ
28th March 1983

Dear Dr

Portsmouth and South East Hampshire Health Authority
Infant Surveillance

The number of babies dying annually in Portsmouth and South East District in the post-perinatal period (from one week to one year - which includes Sudden Infant Deaths or Cot Deaths) is slightly above the national figures. In recent years it has been increasing instead of decreasing. Some Districts have been able to reduce their infant mortality figures, sometimes by 50%, by introduction of the 'Sheffield' scoring system, which selects out infants for intensive health visiting, backed by general practitioners support and paediatricians investigations and care.

In Gosport we have carried out retrospective, on-going and prospective studies, and it would appear that using 13 variables selected from questionnaires filled in at birth by the midwives and at four weeks by the health visitor, then giving the required back-up has resulted in an improvement in the standard of baby care and a reduction in the death rate. (A copy of the 'Sheffield' scoring system is enclosed, with alterations specific to Portsmouth District made after consultation with Dr R G Carpenter, MA, PhD, FSS, Hon. Sec. of the Foundation for the Study of Sudden Infant Deaths - Appendix I).

All babies are visited at one month old when they are weighed naked. All high risk infants are then visited and weighed each fortnight until they are three months old, then each month until they are six months old, thereafter routine visiting is given. It is estimated that approximately 13% of babies will require extra visiting. When the babies are weighed, the weights are plotted on a percentile chart (Appendix II). The percentile charts were designed by Dr Carpenter based on work by Dr Kristiansson, a Swedish Paediatrician, who has completed several studies on low rate of weight gain in infancy and early childhood (Appendix III). The local paediatricians are aware of the surveillance system and the percentile charts, and they are willing to investigate any children you may wish to refer.

Appendix IV is a sample of a computer printout. As we are all working for the health and wellbeing of the babies in our care I propose sending you one of these via your health visitor on every infant born after 1.4.83 registered with your practice, informing you whether the baby is high or low risk, which could then be filed in the infant's notes if you so wish. If you prefer not to be sent these, perhaps you would be kind enough to let me know.

The surveillance system was discussed with the general practitioners who attended the District Committee of General Practitioners meeting on 24th March 1983, and it was given their full approval.

If you wish to discuss any part of the research or surveillance system, I would be delighted to come to your practice to speak to you and your colleagues at a mutually convenient time.

Yours sincerely

Mrs J Powell
Nursing Officer/Health Visiting

Enc

Appendix 19.

Guidelines on What to do When an Infant dies Suddenly and Unexpectedly.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

GUIDELINES ON WHAT TO DO WHEN AN INFANT DIES SUDDENLY AND UNEXPECTEDLY

These guidelines are being issued to avoid confusion between various disciplines when dealing with parents who have lost a child suddenly and unexpectedly. Consultation has taken place with each discipline involved and approval given for their inclusion.

AMBULANCE CREW

If there is any doubt about baby being dead, it should be taken *immediately* to the nearest Casualty Department – St. Mary's Hospital, Royal Naval Hospital Haslar or Queen Alexandra Hospital. A dead infant should be taken to C2 at St. Mary's Hospital or Casualty at Haslar Hospital, after police permission has been given. In all cases THE PARENTS SHOULD BE ENCOURAGED TO ACCOMPANY THE BABY.

Inform: Hospital that a paediatric emergency is imminent
Control at Winchester

POLICE

The duty Detective Inspector should attend the scene, he will decide what action is to be taken. The child should be moved to hospital as soon as possible, ACCOMPANIED BY PARENTS IF POSSIBLE.

Inform: The General Practitioner
The Coroner
Social Services Department

GENERAL PRACTITIONER

If called first to the home and the baby is dead, he should inform the police to attend before the body is removed to hospital. If he has not been called, he will be informed of the death, so that he can attend immediately if he wishes or on the following day, to offer support and counselling to the family.

CASUALTY STAFF

C2 at St. Mary's Hospital, Haslar Hospital or Queen Alexandra Hospital.

1. Verification of death should be made in the department, not in ambulance.
2. Baby's rectal temperature should be taken and a naso-pharangeal aspiration should be obtained into a nasal trap (to be sent to the laboratory within eight hours).
3. If only one parent is present and agrees, contact the other parent or relative. Ensure that a suitable person is looking after the baby's siblings.
4. A room for privacy for the distressed parents should be found, where a detailed and *SYMPATHETIC* history should be obtained from a parent or guardian.
5. Record history and examination in case notes, especially search for a history of major or minor illness, obvious signs of injury, recent consultation with medical practitioner, family illness or if the parental attitude arouses suspicion. Record the name of the General Practitioner.
6. Explain that it is the coroner's duty to investigate all sudden deaths of unknown cause, that it will be necessary to have a post mortem examination and that they will be asked to make a statement to the coroner's officer or the police, who may visit them at home.
7. CLOTHE THE INFANT AND MAKE HIM AS PRESENTABLE AS POSSIBLE. OFFER THE PARENTS AN OPPORTUNITY TO SEE AND HOLD THEIR BABY FOR AS LONG AS THEY DESIRE.
8. The hospital Social Worker may be available and should be called if necessary.
9. The chaplain is available and should be called if the parents need his support and counselling.
10. Offer the parents the leaflets 'Information for Parents Following the Sudden and Unexpected Death of their Baby' and 'Support for Parents Bereaved by an Unexpected Infant Death'. Reassure them that they will be visited by their General Practitioner and Health Visitor. If the mother is breast-feeding, counsel her regarding lactation. Ensure that the parents have transport to take them home.
11. Baby's body can then be taken to the hospital mortuary. If parents have not accompanied the baby to hospital and they have to identify the body later in the mortuary, they should be accompanied by the chaplain or a member of staff.

Inform: The Virology Technician – St. Mary's Hospital (ext. 218/215)
The Coroner's Officer or Police, if office closed (if not already involved)
The Pathologist – St. Mary's Hospital (ext. 212) or Royal Naval Haslar Hospital (ext. 2228)
The General Practitioner (if not already aware of death)
Immunisation/Vaccination Department – Portsmouth 834689

PATHOLOGIST

Pathology to be completed as soon as possible. Post mortem report to be sent to the General Practitioner, Paediatrician and Infant Surveillance Co-ordinator.

Inform with preliminary findings:
General Practitioner
Infant Surveillance Co-ordinator – Gosport 584201

GENERAL PRACTITIONER

It is important for the General Practitioner to explain to the parents as soon as possible the initial post mortem findings and the registered cause of death.

PAEDIATRICIAN

It may be desirable for the parents to be counselled by a paediatrician in some circumstances.

HEALTH VISITOR

It may be necessary to give support to the family for several months, intensively visiting initially, gradually diminishing as the family feel able to cope. Various leaflets can be supplied by the Infant Surveillance Co-ordinator, made available by the Foundation for Sudden Infant Death. The name of the local contact person for the Hampshire Group – Friends of the Foundation for the Study of Sudden Infant Deaths should also be given to the parents, as they can offer valuable support and experience at this time.

Any correspondence or query regarding these guidelines should be sent to the Infant Surveillance Co-ordinator, Mrs. Jean Powell, Clinical Nurse Manager/Health Visiting, Gosport Health Centre, Bury Road, Gosport, PO12 3PW – Telephone: Gosport 584201.

These guidelines were designed, after consultation with representatives from various disciplines, to avoid confusion, duplication or omission when an infant has died. 1000 copies were printed and distributed to relevant persons throughout Portsmouth Health District. The Foundation for the Study of Sudden Infant Death circulated them to other Health Districts in the United Kingdom as an example of good practice.

Apnoea Monitors Available in the United Kingdom 1985.

Four types of apnoea monitor are available to detect cessation of chest or abdominal movement, or both. None is designed to detect obstructive apnoea.

(1) The Graseby Dynamics MR10 Respiration Monitor

(2) The Vickers Apnoea Alarm Mk 3 and mattress

(3) The Eastwood Eastleigh Apnoea Respiration Monitor RE200 (battery), RE134 Apnoea Monitor (pressure pad) (mains)

(4) The impedance systems, for example Healthdyne, Airshields, and Hewlett Packard.

(1) Graseby Dynamics MR10 Respiration Monitor
This system monitors breathing movements via an air filled capsule which is attached by sticky tape to the abdominal wall. As the baby breathes the abdominal wall distorts, causing pressure changes within the capsule which are relayed down a length of plastic tubing to a small monitoring device. The monitor is battery operated and is easily portable and can be used whatever surface the baby is lying on. The Graseby Dynamics MR10 (and impedance systems) have the disadvantage that they measure movement at a single site. It is possible that some babies have phases of breathing when either the chest or abdominal wall is almost stationary.[8] The monitor will also alarm when the sensor becomes detached from the baby's skin.

(2) Vickers Apnoea Alarm Mk 3
This is also widely used in the UK. The mattress on which the baby is placed consists of separate compartments rather like a ripple mattress. Tubes from each of the compartments run to a manifold allowing pressure equilibration to occur. As the baby breathes the weight distribution alters, causing air to run through the manifold which contains a heated thermistor. If the baby is totally still, air movement will stop and an alarm triggered after a preset interval, usually 20 seconds. The mattress has a specific problem related to mattress inflation pressure, as too high or too low a pressure will reduce the sensitivity. It is battery operated.

(3) Eastwood RE 134 Apnoea Monitor/Eastleigh Apnoea Respiration Monitor RE 200
This system is based on a pressure-sensitive pad lying under the baby between a thin mattress and a solid cot base which measures changes in the weight distribution during breathing. RE134 is mains operated, RE200 is battery operated. The advantage of this system is that sensor capsules and electrodes do not have to be kept attached to the baby's skin; however, the device can only be used on a stable flat surface and mattress thickness is critical.

(4) Impedance systems
Impedance systems have been developed, for example Healthdyne, Airshields, and Hewlett Packard, which measure the change in conductivity between two electrodes attached to the axillary chest wall. As the baby breathes, the ratio of air to conducting tissue alters, changing the voltage measured between the two electrodes. Cessation of these changes triggers the alarm signal after a preset interval. The specific disadvantages of this system are that it measures movement at a single site and that the baby is attached to electrodes which may come off, may cause local skin excoriation and certainly makes nursing and rearing the child more difficult. It is mains operated.

Reprinted from "Apnoea Monitors and Sudden Death" by Milner A.D., Archives of Disease in Childhood, January 1985; Vol. 60, No. 1 : 76-80.

A Policy on the Use of Respiration Monitors/Apnoea Alarms agreed in Portsmouth Health District in 1985 by Paediatricians, General Practitioners, Midwives, Paediatric Nurses and Health Visitors.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

POLICY ON THE USE OF APNOEA MONITORS

This policy was written by a working party consisting of a Paediatrician, a General Practitioner, a Midwife, a Health Visitor and an Administrator. It has been approved by representative meetings of each discipline.

Objectives

- To reassure and relieve the anxiety of parents.
- To give parents immediate warning of an apnoea attack, so that emergency action can be taken.

Eligibility Criteria

- Subsequent siblings of USID victims.
- Surviving twin of USID victims.
- An infant who has had a significant apnoea attack.
- Medically recommended.

Allocation System

- Subsequent siblings of USID can be issued with a monitor or scales on the recommendation of the General Practitioner, Community Midwife and Health Visitor after joint consultation.
- A Paediatrician must recommend monitoring for the other criteria.
- Application for equipment is made to the Infant Surveillance Co-ordinator, Community Health Department, Civic Offices, Portsmouth 834675. Eventually the District Medical Loans Service will be responsible for distribution of equipment, for collection, for maintenance and for record keeping.

Emergency Response

In the event of the monitor alarm sounding, parents will be responsible for responding. Auditory stimulation from the alarm or picking baby up will sometimes be enough to start the baby breathing. In other instances basic resuscitation techniques may have to be applied by the parents. The General Practioner or Paediatrician will be responsible for teaching parents how to resuscitate their baby when he gives them a monitor, and for giving them comprehensive written guidelines.

Health Visitors and ward staff can also teach parents how to use the monitors. The General Practitioner and Health Visitor will routinely be informed initially by a telephone message from ward staff when an infant is to be discharged on a monitor, followed by written notification. This will allow maximum support to be given to each family.

A Policy on the Use of Respiration Monitors/Apnoea Alarms (page 2) agreed in Portsmouth Health District in 1985 by Paediatricians, General Practitioners, Midwives, Paediatric Nurses and Health Visitors.

Equipment and Funding

Two models of respiration monitor are available:– Graseby Dynamics MR10 using a sensor which is attached to baby's abdomen, and the Eastwood-Eastleigh R.E.200 which has a pressure pad fitting under the baby's mattress. They are both battery operated and portable.

A model 'Resusci–Baby' is available for demonstration purposes.

The 40 monitors we have at present have mainly been provided by voluntary funding from various groups and individuals throughout the District.

The Hampshire Group of Friends of the Foundation for the Study of Sudden Infant Deaths has generously agreed to contribute £300 per annum for the purchase of sensors and pads.

It is the responsibility of parents to provide batteries.

The doctor may prescribe non-allergic tape.

Scales for daily weighing and A1 size weight charts are available as an alternative method of monitoring.

Equipment will be loaned for a period of six months or two months beyond the age of death of the previous infant, whichever is the longer, or for a specific time recommended by the doctor in charge.

It is recognised the use of respiration monitors gives no guarantee against morbidity or mortality, and parents should be made aware of this.

If however, the use of these devices is controlled and recommended by trained medical personnel who offer a 24 hour-a-day support programme, the parents' level of stress is tolerable, the outcome is usually excellent, and the costs are acceptable (Shannon D C, Kelly D H, 'SIDS and Near Sids', The New England Journal of Medicine, April 29 1982 pp 1022-1028).

Encl – Instructions re Graseby MR10 monitor and resuscitation technique.
– Instructions re Eastwood-Eastleigh monitors and resuscitation technique.

Distribution – All Paediatricians
All Groups of General Practitioners
Nurse Managers/Community/Midwifery/Paediatrics
Paediatric Nurses
Midwives
Health Visitors

RMP1/86

Printed Instructions Available to Parents of Infants in Portsmouth Health District who are Allocated a Graseby Monitor when a Demonstration has been given on how to use It.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

GRASEBY MR10 APNOEA MONITORS

General Information

To minimise the number of false alarms, remember to check regularly that the sensor is firmly attached to the baby's abdomen. Also check the breath light for warning of battery failure.

The sensor pad can be damaged by frequent removal and re-taping onto the baby. A young baby can be left with the sensor attached until it needs to be re-newed. When the baby is not being monitored the tubing can be safely coiled into the baby's clothing.

Remove tape deposits on sensor with surgical spirit before re-applying.

In an older baby, who has learnt to reach and grasp objects, it is safer that the sensor pad is completely removed when the child is not being monitored.

An alkaline battery will usually last approximately 3 weeks. Have a spare one available.

If the monitor develops a fault, please contact your Health Visitor.

The monitor will be loaned to you for approximately six months. It is usually helpful to yourselves if towards the end of this period you have gradually reduced the number of hours per day your baby is monitored, so that you are not using it at all by the end of the loan period.

Instructions

Attach sensor pad securely to the abdomen, approximately one inch from the umbilicus using the non-allergic tape. Do not fix sensor to the chest area.

The unit will tick and the breath light will flash green with each breath movement.

The apnoea monitor should be set to go off at 20 seconds after baby stops breathing.

WHEN THE ALARM SOUNDS

Most alarms will be false, but the following routine should be carried out on each occasion:—

CHECK TO SEE WHETHER THE BABY IS BREATHING

If baby is BREATHING, check for faults in the alarm system:—

: Ensure the sensor is taped firmly to the baby's abdomen — renew tape if necessary.

: Check that the sensor tubing is plugged into the monitor socket.

: Check that the battery power is satisfactory — low power is indicated by breath light flashing red as baby breathes, and later by alarm signal that cannot be cancelled by reset button.

: Check that monitor is switched to 20 second setting.

: Observe that monitor registers each breathing movement by green breath light and audible click — if every movement is not detected renew the sensor pad.

Printed instructions Available to Parents of Infants in Portsmouth Health District who are Allocated an Eastleigh Monitor when a Demonstration has been given on how to use It.

PORTSMOUTH & SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

EASTWOOD–EASTLEIGH R.E.200 APNOEA MONITOR

General Information

The flat pressure sensitive sensor pad is generally placed under the mattress in a cot. The sensor can easily be cleaned with surgical spirit.

A PP3 alkaline battery will usually last approximately 3 weeks.

Each breath sensed by the monitor will be indicated by a visual light and an audible 'click'. If it is preferred, the audible click can be turned off.

In an older baby, who has learnt to reach and grasp objects, it is safer for the sensor pad to be completely removed when the child is not being monitored.

The monitor will be loaned to you for approximately 6 months. It is usually helpful to yourselves if towards the end of this period you have gradually reduced the number of hours per day your baby is being monitored, so that you are not using it at all by the end of the loan period.

If the monitor develops a fault, please contact your Health Visitor.

The monitor is set to go off 20 seconds after the baby stops breathing. A loud pulsating alarm is given in addition to a flashing red light, to summon assistance for the baby.

WHEN THE ALARM SOUNDS

Most alarms will be false, but the following routine should be carried out on each occasion:–

CHECK TO SEE WHETHER THE BABY IS BREATHING

If baby is breathing, check for faults in the alarm system:

: Is the sensor tubing plugged into the monitor socket?

: Is the battery power satisfactory? Low power is indicated by a red light flashing together with a pulsating audible alarm.

: Is the monitor registering each breathing movement by a green flashing light and an audible click?

Appendix 21.C.

Printed instructions Available to Parents of Infants in Portsmouth Health District who are Allocated a Densa Monitor when a Demonstration has been given on how to use It.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

COMMUNITY HEALTH SERVICES AND SMALL HOSPITALS UNIT

DENSA APNOEA ALARM

General Information

To minimise the number of false alarms, ensure that you regularly check that the sensor is correctly positioned.

The sensor, whilst robust, can be damaged, so please handle it carefully. Particular care should be taken to protect the clip on the plug.

In an older baby, who has learnt to reach and grasp objects, it is safer that the sensor pad is completely removed when the child is not being monitored.

The batteries will usually last 3 weeks. Have a spare set available and be sure to change all the batteries when the low battery warning signal is heard.

If the monitor develops a fault, please contact your Health Visitor.

The monitor will be loaned to you for approximately six months. It is usually helpful if towards the end of this period you have gradually reduced the number of hours per day your baby is monitored, so that you are not using it at all by the end of the loan period.

Specific Instructions

It is essential that you read the instructions supplied with the monitor on fixing the sensor and be sure to place the sensor correctly in the holder.

THE ALARM

There are 3 reasons for the alarm to sound.

1. To indicate that the sensor has lost contact with the infant and should be replaced.

2. To show that the sensor is defective. If the sensor is defective the alarm will not cancel when the reset button is pressed. The defective sensor should be returned to your Health Visitor.

3. THE MAIN REASON for the alarm to sound is a pause in baby's breathing exceeding the delay, which is normally set at 20 seconds.

WHEN THE ALARM SOUNDS

CHECK TO SEE WHETHER THE BABY IS BREATHING

If baby is breathing, check:

a. The sensor is correctly positioned and the switch is set to 20 seconds.

b. If the alarm will not be cancelled by the reset button, change to the spare sensor.

c. If you are still hearing a high pitched sound and no bleep but the green breath light is flashing this is the low battery warning and the batteries should be changed.

Printed instructions on Resuscitation Techniques given to Parents of Infants in Portsmouth Health District who are Allocated either a Graseby, Eastleigh or Densa Monitor.

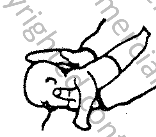
If baby is NOT BREATHING

: Pick baby up, gently shake him to establish whether or not he is unconscious.

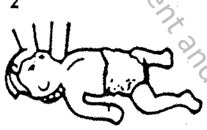
If unresponsive

: The airway may be obstructed. Use a finger to remove foreign matter which is visible in the mouth. Use a combination of Back Blows and Gravity to dislodge solid foreign matter from lower airways, and move it into the mouth.

1



2



3

4

1 : Turn baby onto his front, firmly tap his back 2 – 3 times to dislodge any mucus blocking his throat.

2 : Place the baby on his back on a table or any other firm surface. Suck out the back of his throat with the mucus extractor.

If baby does not gasp and breathe:–

Support the back of his neck, tilt his head backwards and hold his chin upwards.

Open your mouth wide and breathe in.

3 : Seal your lips round his mouth and nose

Breathe gently into his lungs until his chest rises.

4 : Remove your mouth to allow the air to come out and let his chest fall.

Repeat gentle inflations a little faster than your normal breathing rate removing your mouth after each breath – approximately 30 times per minute.

Baby should begin to breathe within a minute or so.

DIAL 999 FOR AN AMBULANCE – YOUR BABY MUST HAVE IMMEDIATE MEDICAL ATTENTION

IF BABY IS STILL NOT BREATHING

REPEAT 1 – 4 UNTIL HELP ARRIVES

RMP2/86

Appendix 22.

Questionnaire on Respiration Monitors/Apnoea Alarms (AM/1) Completed by a Health Visitor, a Midwife or a Paediatric Nurse when the First 45 Monitors were Allocated for Parental use with Infants in Portsmouth Health District.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

APNOEA MONITOR QUESTIONNAIRE

NAME:

ADDRESS:

D O B:

MONITOR SERIAL NO:

DATE MONITOR LOANED:

DATED TO BE RETURNED:

SENSORS SUPPLIED :

PREVIOUS HISTORY OF CHILD/FAMILY:

COMMENTS:

AM/1 - January 1983

Questionnaire on the use of Respiration Monitors/Apnoea Alarms (AM/2) Completed by the Parents of 45 Infants in Portsmouth Health District who had been Allocated Monitors.

PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

APNOEA MONITOR QUESTIONNAIRE

NAME OF CHILD :

ADDRESS :

D O B :

Date when the monitor was issued :

Date when the monitor was returned :

Ideal time to have a monitor issued (Please tick) : IN HOSPITAL
AFTER 2 WEEKS AT HOME
OTHER - PLEASE STATE:

Ideal time to discontinue using a monitor (Please tick): 3 MONTHS
6 MONTHS
OTHER - PLEASE STATE:

List the benefits of having a monitor:

List the disadvantages of having a monitor:

How many times did baby need vigorous stimulation to make him breathe?

How many false alarms did you experience per week, on average?

How many sensors did you use in total?

Other comments:

AM/2 - January 1983

Appendix 24.

Computer Printout for Senior Clinical Medical Officer (IS/25) to Enable Selection of Infants Estimated to be at Risk of Developmental Delay, thus allowing them to be Placed on a Special Needs Register.

```
                    To Senior Clinical Medical Officer (Child health)
EXAMPLE                                                                         661185
                    PORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY
                    ====================================================
                                    INFANT SURVEILLANCE
                                    ===================
Mothers Details
===============
Name   EXAMPLE         GAIL                        D of B    9  5  57
Address   13 EXAMPLE RD                            GP        DR SPECIMEN
          SOUTHSEA                                 HV   999MRS SPECIMEN
          PO5 1AA                                  B.Score   580
Past History
------------
Gravida  8   Parity  3
Present pregnancy
-----------------
Duration:  33   U.T.I:None      Feed:Breast              Smoking:No
Labour
======
Born at : St Mary's      Induced : Method : Caesar
Delivery : caesar              Date :  4  11  85     Time of delivery :  1112
Duration of stages 1st  0   0   Bloodloss :  300
                   2nd  0   0
                   3rd  0   0
Placenta & membranes : complete
Complication : APH
Baby's details
==============
Sex : Male      Birth weight :  1860    Length :  450     Head circ :  395
Apgars :   9 - 9 Twin : no              Appears normal : yes
Baby went to SCBU because : premature growth retarded
Further notes/comments :

Problems in first four weeks
============================
Was an in patient in first four weeks
Home background
===============
Interval to last live birth is  20  months
Total monthy score =  937
                                                                           I.S/25
```

Appendix 25.

Computer Printout for Casualty Consultant (IS/41) Listing Infants at High Risk of Sudden Infant Death to alert Staff to their Risk Factor.

CONFIDENTIAL

FORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE (Portsmouth 834689)

Print for Haslar Hospital
Babies residing in Gosport and Fareham

491185	EXAMPLE	3	11	85	DR SPECIMEN	763
3951185	ANOTHER	14	11	85	DR WHO	544 - PCD
6641185	PERSON	24	11	85	DR NO	1050

IS/41

Appendix 26.

Computer Printout for Community Nurse Managers/Health Visiting (IS/40) Listing Infants at Risk of Sudden Infant Death, Child Abuse or if the family have experienced a Previous Child Death and also the name of the Health Visitor responsible for each Infant.

CONFIDENTIAL

FORTSMOUTH AND SOUTH EAST HAMPSHIRE HEALTH AUTHORITY

INFANT SURVEILLANCE (Portsmouth 834689)

High risk babies in Gosport

191185	CATTON	1	11	85	MRS ANDERSON	864
321185	BENN	3	11	85	MRS BELCHER	529
431185	TAYLOR	3	11	85	MRS CROUCH	763
661185	BROOMFIELD	4	11	85	MRS DOUGHTY	937
731185	THWAITES	4	11	85	MRS EVANS	1118

End of list

I.S/40

These IS/40 communications enabled the nurse managers to monitor the complexities of Health Visitor Case Loads

Appendix 27.

Computer Printout for Clinical Nurse Managers/Health Visiting (IS/14x) is supplied Each Month listing the Names of each Health Visitor and the Numbers of Infants in High and Low Risk Categories born in that Month Allocated to Each of Them.

```
Summary of babies born in OCTOBER  83
-------------------------------------

    GOSPORT
    -------

    Total births                          554
    Total births for Gosport HV's         113 ( 20 % of total)

    Number of high scoring babies          15
    Number of low scoring babies           98

            Mrs Hennessy              500
                 Low scoring babies           2
                 High scoring babies          0

            Mrs Beadsworth            501
                 Low scoring babies           3
                 High scoring babies          0

            Mrs Crack                 503
                 Low scoring babies           3
                 High scoring babies          3

            Mrs Langdon               504
                 Low scoring babies           8
                 High scoring babies          0

            Mrs Williams              505
                 Low scoring babies          12
                 High scoring babies          2

            Mrs Cook                  506
                 Low scoring babies           5
                 High scoring babies          1

            Mrs Evans                 507
                 Low scoring babies           2
                 High scoring babies          2

            Mrs Southeard             508
                 Low scoring babies           3
                 High scoring babies          1

            Mrs Moulds                509
                 Low scoring babies          11
                 High scoring babies          0

                                                          I.S/14g
```

The IS/14 printout is useful to the nurse manager as she is able to monitor the numbers of infants allocated to each Health Visitor and their risk factors. This allows a more even distribution of workloads.

Appendix 28.

Computer Printout for Directors of Nursing Services (IS/14) listing the Total Numbers of Infants born each Month in the Health District, the Numbers of Infants in each Specific Locality and the Percentages of Total Births.

Summary of babies born in OCTOBER 83

DISTRICT

Total births	554	
Total high scoring babies	52	9 %
Total low scoring babies	479	86 %
Total Gosport births	113	20 %
High scoring babies	15	
Low scoring babies	98	
Total Fareham births	62	11 %
high scoring babies	3	
Low scoring babies	59	
Total Waterlooville births	67	12 %
High scoring babies	7	
Low scoring babies	60	
Total Havant births	73	13 %
High scoring babies	9	
Low scoring babies	64	
Total North Portsmouth births	121	21 %
High scoring babies	8	
Low scoring babies	113	
Total South Portsmouth births	95	17 %
High scoring babies	10	
Low scoring babies	85	
Total Out of Area births	0	0 %
High scoring babies	0	
Low scoring babies	0	

I.S/14d
1984

The information contained on the IS/14 printout allows monitoring of trends in birth population, and the changing responsibilities and work load of health visiting staff in various parts of the Health District

Appendix 29.

Computer Printout of Birth Data (IS/100) supplied to the Assistant Director of Nursing Services/Midwifery and to the Infant Surveillance Co-ordinator each Month, which contains a Collation of Information obtained from all of the IS/1 Birth Questionnaires.

Birth Statistics for OCTOBER 83 IS/100

Total births for month 554

Number of Stillbirths 0

Place of birth

	St. Mary's	GP Unit	Blackbrook	Blake	The Grange	Home
Totals	463	51	8	19	8	5

Mothers Marital Status

	Married	Single	Widowed	Divorced	Seperated	Co-habit
Totals	477	44	0	9	3	21

Mother Ment/Emot Illness

	Yes	No	Unknown
Totals	31	464	59

Previous Pregnancies

	0	1	2	3	4	5	6	7	8	9	>9
Totals	218	171	100	36	14	12	3	0	0	0	0

Mothers Spont abortions

	0	1	2	3	4	>=5
Totals	466	71	14	3	0	0

These IS/100 printouts are useful to the Midwifery and Community Units as they show trends and contain useful information for planning purposes.

Computer Printout of Monthly Data (IS/101) is supplied each Month to the Infant Surveillance Co-ordinator and contains Collation of Information obtained from the IS/2 Questionnaires.

Monthly statistics for [illegible] IS/101

(compiled from I.S/2's)

Total births for month 554

Forms returned by 6 4 84	511
Forms not being returned	43
Unaccounted for	0
Children low - HIGH risk SID	23
Children high - LOW risk SID	23

Reasons forms not being returned

	baby died	moved out of area	adopted	Still in hospital	out of area	other
Totals	2	7	1	0	20	5

	mother refused	form lost	Stillbirth
Totals	1	0	7

Weight at one month (gms)

	not weighed	1 -2000	2001 -2500	2501 -3000	3001 -3500	3501 -4000
Totals	24	1	0	12	53	115

	4001 -4500	4501 -5000	5001 -5500	5501 -6000	>=6001
Totals	164	103	28	8	3

These IS/101 printouts contain valuable epidemiological information which is interesting to managers and health visitors as well as being useful for planning purposes

Computer Printout Tabulating Birth Data (IS/102) supplied each Month to the Midwifery Manager, giving the Dates, Times and Places of all the Births.

Births by unit/day/time for OCTOBER 83 IS/102

St Mary's
=========

\\Time \\ Date \\	00-02	02-04	04-06	06-08	08-10	10-12	12-14	14-16	16-18	18-20	20-22	22-24	Unk	Tot
1 \\	2	4	0	1	2	2	1	3	2	0	1	2	0	20
2 \\	1	1	1	1	0	2	1	3	2	1	1	1	0	15
3 \\	1	0	1	0	3	1	1	2	2	1	0	0	0	12
4 \\	3	1	0	0	3	4	3	2	1	0	0	0	0	17
5 \\	2	1	1	0	0	1	0	2	3	1	2	6	0	19
6 \\	1	1	0	2	2	2	3	1	0	3	1	0	0	16
7 \\	2	1	4	1	1	1	0	2	0	5	2	1	0	20
8 \\	3	2	1	1	4	2	2	2	1	0	1	4	0	23
9 \\	1	0	1	2	1	0	1	1	0	0	0	1	0	8
10 \\	1	3	1	3	1	2	0	1	4	1	1	1	0	19
11 \\	5	0	0	2	3	1	1	4	0	2	1	0	0	19
12 \\	0	0	1	2	0	0	1	0	2	1	2	1	0	10
13 \\	1	1	0	0	1	0	4	2	0	5	0	1	0	15
14 \\	1	2	0	1	2	0	3	1	0	0	1	2	0	13
15 \\	3	1	2	0	1	3	0	0	1	1	1	2	0	15
16 \\	1	2	0	3	2	2	0	2	0	0	1	2	0	15
17 \\	0	2	1	1	1	1	0	1	3	3	1	0	0	17
18 \\	1	3	2	3	0	2	2	1	0	2	2	3	0	21
19 \\	1	1	2	0	1	2	2	4	0	1	3	1	0	18
20 \\	0	1	1	1	2	3	1	0	0	3	1	0	0	13
21 \\	0	1	1	1	3	2	2	0	3	1	0	0	0	14
22 \\	2	1	0	1	0	0	1	0	2	3	1	0	0	11
23 \\	0	1	0	0	0	1	4	1	2	0	1	0	0	10
24 \\	0	0	2	1	1	0	0	1	3	0	1	3	1	13
25 \\	0	2	1	0	1	1	2	2	3	1	0	0	0	13
26 \\	4	1	0	0	3	1	0	2	3	4	2	1	0	21
27 \\	1	0	1	0	0	1	0	0	4	1	0	1	0	9
28 \\	2	1	2	1	1	2	1	2	0	3	0	0	0	15
29 \\	0	1	0	2	0	0	0	2	1	0	2	2	0	10
30 \\	1	0	0	1	2	0	0	0	0	2	0	2	0	8
31 \\	2	1	1	0	0	0	1	3	1	4	0	1	0	14
Totals	42	36	30	31	41	39	37	47	43	49	29	38	1	463
														463

Stillbirths 0 (not included above)

Caesarians 52

B.B.A.'s 0

G.P.U.
======

\\Time \\ Date \\	00-02	02-04	04-06	06-08	08-10	10-12	12-14	14-16	16-18	18-20	20-22	22-24	Unk	Tot
1 \\	0	0	0	0	0	0	0	1	0	0	0	0	0	1
2 \\	1	1	0	0	0	0	0	0	0	1	0	0	0	3
3 \\	0	0	1	1	0	0	0	0	0	0	0	1	0	3
4 \\	0	0	0	0	0	0	0	0	0	0	0	0	0	0
5 \\	0	0	0	0	0	0	0	1	0	0	0	0	0	1
6 \\	0	0	0	0	0	0	0	0	0	0	0	0	0	0

The IS/102 printout allows planning of Midwifery Services to become more specific.

Appendix 32.

Questionnaire Completed by 20 Health Visitors, One Sixth of the Health District Total, Regarding the Advantages and Disadvantages of the Portsmouth Infant Surveillance System.

PORTSMOUTH INFANT SURVEILLANCE SYSTEM

Questionnaire to be completed by Health Visitors
- October 1985

I would be most grateful if you could list below your opinion as to the -

ADVANTAGES OF THE INFANT SURRVEILLANCE SYSTEM

1.

2.

3.

DISADVANTAGES OF THE INFANT SURVEILLANCE SYSTEM

1.

2.

3.

OVERALL OPINION:-

Thank you very much for your help. Jean Powell.

Questionnaire Completed by 30 General Practitioners, One Tenth of the District Total, Regarding the Advantages and Disadvantages of the Portsmouth Infant Surveillance Sytem.

Gosport Health Centre
Bury Road
Gosport
PO12 3PN

Dear Doctor

I am currently evaluating the research we have attempted with regard to risk related intervention for the prevention of sudden infant death.

An essential part of the evaluation is to know the opinions of the general practitioners involved with the Infant Surveillance System. I would be most grateful therefore if you could list below your opinion as to the advantages and disadvantages of the Infant Surveillance System, and return it to me at the above address.

Thank You very much

Yours sincerely

Jean Powell

ADVANTAGES OF THE INFANT SURVEILLANCE SYSTEM:-

1

2

3.

DISADVANTAGES OF THE INFANT SURVEILLANCE SYSTEM:-

1

2

3

OVERALL OPINION

Appendix 34.(i).

Semistructured Questionnaire used to Interview 24 Randomly Selected Parents to ascertain their Views and Understanding of the Portsmouth Infant Surveillance System.

CHILD HEALTH SERVICES IN GOSPORT

Questions to be asked in semi-structured questionnaire:-

1 How many children do you have? -

2 Who is your health visitor? -

3 How often does she visit you? -

4 Were you visited as frequently with your other children? Y/N

5 Do you attend a baby clinic? Y/N

6 Which clinic do you attend? -

7 What do you like about the clinic? -

8 What do you dislike about the clinic? -

9 Why does Mrs visit as often as she does? -

10 What do you like about being visited at home? -

11 What do you dislike about being visited at home? -

12 What type of problems do you discuss with Mrs ? -

Semistructured Questionnaire (page 2) used to interview 24 Randomly Selected Parents to Ascertain their Views and Understanding of the Portsmouth Infant Surveillance System.

13 Do you prefer to see Mrs at home?

at clinic?

either/neither?

14 Do any of your family live locally? - Y/N

15 Where do your most of your extended family live? -

16 Do any of your husband´s family live locally?- Y/N

17 Where do most of your husband´s extended family live? -

18 Do you have a telephone? - Y/N

19 Do you drive? - Y/N

20 Do you have a car available to you? - Y/N

21 Who would you contact in an emergency - i.e. baby unwell?

22 Would you like to make any comments or suggestions regarding services for children in Gosport:-

Questionnaire Completed by 35 Health Visitors, 29% of the Health District Total, Regarding Factors They Considered Predicted Infants at Risk of Sudden Infant Death and of Child Abuse.

PORTSMOUTH INFANT SURVEILLANCE SYSTEM

A QUESTIONNAIRE TO BE COMPLETED BY HEALTH VISITORS

I should be grateful if you would list FIVE FACTORS in order of importance, which you consider predict children at risk of

SUDDEN INFANT DEATH:-

Most important 1

2

3

4

5

CHILD ABUSE:-

Most important 1

2

3

4

5

In YOUR OPINION, which is more effective - a home visit or a clinic visit:-

Many thanks for your co-operation.

Jean Powell

Documentation from Cornwall and Isles of Scilly Health Authority Infant Surveillance

CORNWALL AND ISLES OF SCILLY HEALTH AUTHORITY

INFANT SURVEILLANCE

C/IS/A	CONTENTS SHEET
C/IS/INTRO	AN INTRODUCTION
C/IS/CAN	CHILD ABUSE AND NEGLECT
C/IS/B	BIRTH TO ONE YEAR
C/IS/C	BIRTH SCORING SYSTEM
C/IS/D	'AT RISK'
C/IS/E	GUIDELINES ON HOME VISITING
C/IS/F	USE OF WEIGHT CHARTS
C/IS/G	HEATING LEAFLET
C/IS/1	BIRTH QUESTIONNAIRE
C/IS/2	4 WEEK QUESTIONNAIRE
C/IS/3	SCORING RESULT MEMO
C/IS/4	WEIGHT CENTILE CHART
C/IS/5	MONITORING FORM
C/IS/6	REQUEST RE RETURN OF C/IS/2
C/IS/7	BABY ONE YEAR OLD, PLEASE RETURN WEIGHT CHART AND THERMOMETER
C/IS/8	INFANT DEATH QUESTIONNAIRE
C/IS/9	CHILD HEALTH CLINIC INFORMATION SLIP

Appendix 37.

Documentation from Central Nottinghamshire Health Authority Mother and Child Health Survey.

STRICTLY CONFIDENTIAL

CENTRAL NOTTINGHAMSHIRE HEALTH AUTHORITY

MOTHER AND CHILD HEALTH SURVEY

MCHS1	CONTENTS SHEET
MCHS2	INTRODUCTION
MCHS3	BIRTH TO 1 YEAR
MCHS4	GUIDELINES RE. HOME VISITING
MCHS5	GUIDEINE RE. WEIGHT CENTILE CHART
MCHS6	BIRTH SCORING SHEET
MCHS7	SAMPLES OF CHANNEL WIDTH WEIGHT CHART (MCHS7)
	TYPICAL COMPUTER PRINT OUT:
MCHS8	MOTHER AND CHILD CONTACT SLIP (MCHS8)

MCHS/1

Appendix 38.

Documentation from Worthing District Health Authority Infant Surveillance.

WORTHING DISTRICT HEALTH AUTHORITY

FAMILY HEALTH DIVISION

INFANT SURVEILLANCE PROGRAMME FOR CHILDREN WHO REQUIRE ENHANCED CARE

1.1 Aim To enable Health Visitors to identify children who may be at an increased mortality and morbidity and those who may be at risk of inadequate care. To enable the Health Visitor to give some priority to this group in order to reduce these risks.

1.2 Research and practice has shown that Health Visitors using their professional skills will highlight children at risk to a variable extent. It is necessary to provide a Score system to enable evaluation to be consistent.

1.3 A study undertaken at Portsmouth designed a programme based on a score system which weighs different risk predictors appropriately and accumulated the contribution of all the variables. This score system has been used to set a protocol for Health Visitors to identify children in need of enhanced care.

1.4 Minimum standards have been devised for Health Visitors to contact children who require enhanced care in the light of the scoring system.

1.5 Whilst it is possible to undertake a manual system it is very time consuming. By using a computer and software package evaluation is more systematic and will provide statistics and information quickly.

1.6 It will be necessary to monitor the system to ensure that all babies/children are scored.

1.7 Evaluation of the systems will be undertaken to ensure that children who require enhanced care receive it.

1.8 Education for those involved will include midwives, health visitors, clinical nurse managers, clinical medical officers, general practitioners and paediatric departments.

Basildon and Thurrock Health Authority
Risk Related Intervention Programme for Families.

BASILDON AND THURROCK DISTRICT HEALTH AUTHORITY

1. An essential part of the development of a risk related health visiting programme is the provision of details pertaining to the pregnancy and labour of each woman delivered whilst under care of the Maternity Services. Without the co-operation of the Director of Midwifery Services and her staff, the scheme would be invalidated. Therefore, full discussion must take place on the subject with that Department.

2. Co-operation between the Health Visitors, Family Practitioners and Paediatricians is essential to this project, therefore, nurse managers will seek to inform their medical colleagues of the rationale behind this innovation.

3. A pilot scheme should be commenced, one in Basildon and one in Thurrock for a six monthly period. Evaluation and modification will take place then, if found necessary.

4. The Health agencies alone cannot prevent child deaths, morbidity from disease and child abuse. It is recommended that this report be made available to members of the Area Review Committee on Child Abuse and also the Standing Review Committee in order to inform and to seek co-operation from agencies represented on those committees.

5. That discussion take place with the Directors of Social Services and the District General Manager of the Health Authority with a view to making application for joint funding for the purchase of equipment and materials necessary for the implementation of the project district wide. Costs would be in the region of £9,000 - capital outlay, with very small recurring costs for maintenance, charts etc.

6. Parents who have suffered the loss of a child through the Sudden Infant Death Syndrome deserve sensitive care from all of the many disciplines who become involved in this event. It is recommended that guidelines on "What to do if a child dies suddenly and unexpectedly" be designed.

7. It is recommended that the Health Visitor or School Nurse should weigh and chart the weight and height (where appropriate) of all children whose names are entered on the Central Register of Child Abuse, as frequently as Conference requests and that these charted measurements should be available to Conference, to aid in the decision making process, as recommended by Taitz (8).

8. That during the pilot study, use of the predicting factors of child abuse should be evaluated.

National Healthcare Associated Microsystems

NHS NATIONAL HEALTHCARE SYSTEMS

A suite of programmes have been developed for a comprehensive on-line PREVENTATIVE HEALTHCARE SYSTEM. These embrace the following modules:-

1 Maintenance of a Child/Patient Register
2 Immunisation and Vaccination appointment scheduling.
3 Infant surveillance.
4 Developmental Assessment for pre-school children.
5 School Health Assessment.
6 Other 'Call and Re-Call' systems, such as Cervical Cytology, Diabetics Register, Breast Cancer Scanning, etc.

In addition other modules could be added to the overall system to include a comprehensive Patient Administration System, Geriatric Care System, and other specialist applications.

All of the above modules are written under the auspices of the UNIX operating system for ease of transportability to many different computer sytems. The system also utilises the facilities offered by the database system UNIFY.

The combination of UNIX and UNIFY provides a highly flexible system and is independent of any particular manufacturer of hardware. This is essential if long term options on hardware and software are to be kept open.

The system has many features built in as standard:-

1 Fully on-line, no waiting for batch jobs.
2 Full recognition of the requirements of the Körner minimum data sets.
3 Immunisation and vaccination data automatically extracted from the National Child Register System.
4 Calculation of "birth scores" according to established criteria and the generation of standard infant surveillance forms.
5 Maintenance of a Treatment Centre and G.P. file, holding data on various appointment schemes.
6 Health Visitor file.
7 Cross correlation of family members.
8 Full Call and Re-call system with the automatic generation of appointment schedules, post cards, labels. Registration of Births, parental letters, etc.
9 Use of advanced computing facilities including bar-coding, laser printing, and modem communication support.
10 Use of advanced database techniques for maximum flexibility, allowing structural changes to be easily carried out.
11 Tailoring of the system to the particular requirements of a Health District easily accommodated.

A diagram of the full system is shown overleaf.

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ARTICLES

BY THE AUTHOR AND CO-AUTHORS

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The following published papers were included in the bound thesis. These have not been digitised due to copyright restrictions, but the links are provided.

https://doi.org/10.2307/2981486

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