Monitoring fetal and infant survival using regional birth notification data in north east London

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Abstract

Objective—To demonstrate the use of aggregated, locally collected birth notification data to examine trends in birthweight specific survival for singleton and multiple births.

Design—Retrospective analysis of 171 527 notified births and subsequent infant survival data derived from computerised community child health records. Validation of data completeness and quality was undertaken by comparison with birth and death registration records for the same period.

Setting—Notifications of births in 1989–1991 to residents of the North Thames (East) Region (formerly North East Thames Regional Health Authority).

Outcome measures—Birthweight specific stillbirth, neonatal, and postneonatal death rates.

Results—There was close correspondence between the notification and registration data. For 96% of the registered deaths a birth notification record was identified and for the majority of these the death was already known to the Community Child Health Computer. Completeness of birthweight data, particularly at the lower end of the range, was substantially better in birth notification data. Comparison with the most recent published national data relating to birthweight specific survival of very low birthweight singleton and multiple births suggests that the downward trend of mortality is continuing, at least in this Region.

Conclusions—The use of routinely collected aggregated birth notification data provides a valuable adjunct to existing sources of information about perinatal and infant survival, as well as other information regarding process and outcome of maternity services. Such data are required for comparative audit and may be more complete than that obtained from registration or hospital generated data.

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death rates.¹ However between 1989 and 1993 there was a deterioration in the completeness of the birthweight data transferred to registrations,² particularly for neonatal deaths.

Information on birth weight is collected by Registrars of Births, Deaths and Marriages from the statutory³ notification of births made by the midwife in attendance to the local Health Authority. If the birth is registered before the notification is received, it will not be entered on the draft birth certificate. There is little standardised information requested from midwives for birth notification, most of the form being at the discretion of the local Director of Public Health. The information is to provide health visitors with details of the birth, to generate a local child health record, and is also used to warn health visitors if a death has occurred.

This account illustrates the use of birth notification information to monitor birthweight specific infant death rates. The data is from computerised Community Child Health records in the 15 Districts that comprised the North Thames Regional Health Authority (East) (originally North East Thames Regional Health Authority—NETRHA). The data set was produced by a Regional project that started in 1991. It makes possible the estimation of stillbirth, neonatal, and postneonatal death rates by birthweight, and allows comparison with previously published national data.

Methods

COMMUNITY COMPUTERISED CHILD HEALTH DATA

In 1986 NETRHA, which had been a user of the National Child Health System, set up its own Regional Interactive Child Health System (RICHS). By 1989 all 15 districts in NETRHA used the same system, supported by a Regional Computer Centre. The basis for each record is the notification of a birth. Where the birth is to a resident of another district the information is copied and forwarded, although the district of birth should retain the information. Place of residence as well as hospital of birth is entered, so that records can be assigned either by place of residence, or by place of delivery.

AGGREGATION OF DISTRICT DATA

The birth notifications for all children born in the years 1989 to 1991 were downloaded in a standardised format with the help of the Regional Computer Centre. The retention of forwarded notifications means that when district data are aggregated, the regional data set includes duplicates. Before selecting records of births to residents a check was made of the

Table 1 Completeness of linkage of records relating to stillbirths and infant deaths from RICHs records relating to residents of North Thames (East) and OPCS birth and death registration records for the birth cohorts 1989–1991

Community child health records (RICHs)	Records from death registrations			
	Matches with RICHs			
Age at death	SB	NND	PNND	Total
SB	794	2	—	796
NND	3	701	1	705
PNND	—	—	422	422
Inconsistent age	5	17	8	30
Death date not recorded	24	9	24	57
Total	826	729	455	2010
Deaths expected from registrations	842	755	472	2069
Deaths apparently missing from child health sources (%)	14 (2)	24 (3)	17 (4)	57 (3)

SB=stillbirths, NND=neonatal deaths, PNND=postneonatal deaths.

consistency of data items relating to area of residence, including postcode. A single variable defining residence status at the time of birth was derived. This eliminated the problem of duplication of records. However particularly in these early years of RICHs data the completeness of recording of full postcode varied.

SELECTION OF DATA

The present account is based on records of births in 1989–1991 to mothers who were regional residents at the time of delivery, regardless of place of occurrence of the birth.

VALIDATION OF INFORMATION RELATING TO DEATHS

Stillbirths or infant deaths born between 1989 and 1991 to regional residents were ascertained from the Standard Regional Birth and Death Data sent to regions by the Office of Population Censuses and Surveys—OPCS (now part of the Office of National Statistics). A match for each of these stillbirths and infant death registrations was sought from RICHs records, searching on date of birth, date of death, infant sex, and multiplicity. Where there were unmatched deaths RICHs district managers were asked to carry out special searches of their own systems, an exercise that found some missing cases and enhanced the data of local systems.

RICHs records not identified as a death were assumed to be survivors and completed the denominators. RICHs records included 95 stillbirths, 19 neonatal, and four postneonatal deaths that were not found in the registrations. Many of these “stillbirths” were below registerable gestation and technically a late miscarriage. Some of these deaths occurred outside the UK or to US army personnel whose births and deaths are not registered in this country. All these 118 unmatched RICHs deaths have been excluded from the present data set.

CALCULATION OF DEATH RATES

Stillbirth rates are calculated by dividing by total births and expressed per 1000. Rates of neonatal death (before 28 days) and postneonatal deaths (between 28 and 365 days) were estimated by dividing these by live births and expressing the result per 1000.

ANALYSIS

Matching and analysis was carried out using the Statistical Analysis System (SAS) and confidence intervals calculated using Stata software.

CONFIDENTIALITY

Agreement for setting up the aggregated Regional file of RICHs birth notification data was obtained from the local research ethics committee. Written agreement for release of data was obtained from each of the data custodians of the Child Health data. Data are held on a password protected mainframe computer, which does not include names or addresses and as far as possible all personal identifiers are obscured.

Results

VALIDATION OF DEATH MATCHING

Almost complete recording of deaths in the community child health system is demonstrated by the linkage summarised in table 1, which found 826 (97%) of stillbirths and 729 (96%) neonatal and 455 (92%) postneonatal deaths expected from registration sources.

Table 2 presents annual numbers of live births, stillbirths, neonatal, and postneonatal deaths in published OPCS tables² and the RICHs data set. It should be noted that for years covered in this study published OPCS data are based on registrations in the calendar year, while the notification data relates to occurrences in the calendar year.⁴ The number of total live births in the two sets differ from each other by less than 1% in each of the three years shown. Although the correspondence varies a little by year and district, in the most recent year of this study, 1991, the difference never exceeded 3%.

MOVEMENT BETWEEN DISTRICTS AND REGIONS

The data can be used to study movements at the time of birth. For instance in 1991, where postcode information was fairly complete, 80% of the 57 710 births, occurred in their district of residence, 17% elsewhere in the region and 3% outside the region.

MISSING BIRTH WEIGHTS

Between 1989 and 1991 only 0.1% of live birth notifications have missing or unlikely birth weights, compared with 4% of birth registrations (table 2). For stillbirths little difference in completeness over the years is found, with only slightly more complete recording of birthweight in the RICHs data. For infant deaths 4% of notifications were missing valid birth weight compared with 12% in registration data (table 2).

Multiple births account for 7% of RICHs records missing birth weight and known preterm births account for at least 17% (table 3) compared with an incidence of 1% and 6% respectively in all births. This disproportionate loss is not unexpected for infants likely to be transferred for intensive care immediately after birth and often before being weighed. The birth notification form would have been completed by the midwife usually in the labour

Table 2 Comparison of numbers of births and deaths of North East Thames residents from OPCS and RICHs by birthweight group

	Stillbirths		Live births		Neonatal deaths		Postneonatal deaths	
	OPCS	RICHs	OPCS	RICHs	OPCS	RICHs	OPCS	RICHs
Birthweight <1500*								
1989	67	67 (4)	562	577 (18)	115	128 (8)	28	25 (0)
1990	69	71 (6)	527	595 (37)	98	124 (9)	21	26 (0)
1991	74	74 (4)	602	683 (52)	120	137 (9)	22	26 (0)
1500–1999 g								
1989	47	45	757	766	18	20	19	14
1990	54	51	741	780	18	20	5	3
1991	43	45	780	820	13	15	7	10
2000–2499 g								
1989	35	38	2504	2525	21	25	16	16
1990	55	54	2510	2578	12	16	15	15
1991	40	41	2594	2696	14	16	18	16
2500 g+								
1989	103	101	50407	51778	71	75	139	117
1990	124	128	51224	53515	63	66	97	99
1991	100	102	50597	53165	52	56	76	67
Missing birthweight†								
1989	14	4	1864	67	35	6	3	7
1990	13	3	3101	65	44	6	15	4
1991	14	2	2486	80	45	19	11	10
All birthweights including missing								
1989	266	255	56094	55720	260	254	205	179
1990	315	307	57999	57537	235	232	153	147
1991	271	264	57079	57444	244	243	134	129

*The number of RICHs records with weights <500 g are shown in parentheses.

†This category includes missing and null birth weights.

ward. It follows that infant death rates in the lowest weight groups are likely to be understated unless special efforts are made to seek birth weights of infants admitted for special or intensive care.

BIRTH WEIGHTS OF LESS THAN 500 g

Details of 121 births with recorded weights of less than 500 g (shown in parentheses in table 2) are given in table 3. There were 71 reported survivors weighing less than 500 g, apparently born at term, which almost certainly represent errors in recording birth weight. Further work to validate and update these data is feasible, given the small numbers involved and would provide valuable information about survival at such very low birth weights.

BIRTHWEIGHT SPECIFIC COMPARISONS BETWEEN REGISTRATIONS AND BIRTH NOTIFICATIONS

The distribution of birth weights are comparable for stillbirths in the two sources (table 2). There are however differences in the numbers of live birth records allocated to the different birthweight groups, with 164 more live births and 62 more infant deaths in the notification data identified as of very low birth weight compared with registration data. The better completed data from birth notifications suggest that birthweight specific estimates from this source, particularly at the lower extremes, are likely to be more informative. These are presented in table 4 for 500 g groups, which gives more detail than is available from routinely published OPCS data.

Table 3 Characteristics of notifications of births weighing less than 500 g at birth

Stillbirth infant characteristics	Birthweight					
	0	1–	100–	200–	300–	400–499
Stillbirths	9	1	1	1	4	7
1989	4	0	0	0	1	3
1990	3	0	1	0	2	3
1991	2	1	0	1	1	1
Neonatal deaths	31	4	0	2	1	19
1989	6	2	0	1	0	5
1990	6	0	0	0	1	8
1991	19	2	0	1	0	6
Postneonatal deaths	21	0	0	0	0	0
1989	7	0	0	0	0	0
1990	4	0	0	0	0	0
1991	10	0	0	0	0	0
Survivors	160	12	7	12	41	9
1989	54	1	1	0	6	2
1990	55	6	4	3	13	2
1991	51	5	2	9	22	5
Plurality*						
missing	15 (13)	0	0	0	0	0
singleton	191 (40)	14 (0)	5 (2)	13 (2)	43 (2)	26 (17)
twin and higher order	15 (8)	3 (1)	3 (1)	2 (3)	3 (3)	9 (9)
Gestation*						
missing	76 (17)	2 (2)	0	1 (0)	0	0
<28	9 (7)	4 (3)	0	1 (1)	1 (1)	18 (18)
28–36	29 (11)	1 (0)	7 (0)	2 (1)	3 (3)	6 (6)
37+	107 (26)	10 (0)	1 (1)	11 (1)	42 (1)	11 (1)
Total	221 (61)	17 (5)	8 (1)	15 (3)	46 (5)	35 (26)

*Number of deaths given in parentheses.

TRENDS OVER TIME: STILLBIRTH RATES

There is no appreciable trend in birthweight specific rates of stillbirths over time. Numbers and rates of stillbirths in the lowest weight groups are limited by the definition of stillbirths in operation at that time, which included only those of 28 weeks gestation or more, in contrast with live births, which include all cases irrespective of gestation.

TRENDS OVER TIME: INFANT DEATH RATES

Although there are small fluctuations, the trend in infant mortality trend over time is downwards in all birthweight groups. As reported from national data³ the most pronounced change has been the fall in the postneonatal death rate (28%) between 1989 and 1991, although neonatal mortality also fell by 9% (table 4). The reduction is most evident in the babies of 3000–3999 g, where the infant death rate in 1991 was half of that in 1989.

Only 1% of births in each of the years was recorded as weighing less than 1500 g. There is a gradual increase in the numbers and incidence of livebirths weighing less than 1000 g over the three years. There were small improvements in their survival to age one year from 1989 to 1991, 10% in the lowest weight group, 13% for infants weighing 1000–1499 g. Three quarters of single and multiple births weighing 900 to 999 g survived infancy.

In contrast, for babies weighing more than 4000 g there seems to be a deterioration in rates of survival, most noticeable for neonatal mortality where rates have risen by a factor of 3.5 from 0.4 to 1.4 deaths per 1000 live births. Such births represent about 10% of all births and increased almost 10% over the three years. The numbers of deaths are sparse and rates are therefore likely to be unstable, so some caution needs to be exercised in interpreting these results.

BIRTHWEIGHT SPECIFIC OUTCOME FOR SINGLETON AND MULTIPLE BIRTHS

One of the major factors confounding rates of mortality for very small infants is plurality. Multiple births accounted for almost 20% of the births under 1500 g and overall exhibit substantially higher mortality. Table 5 shows that with the exception of the groups weighing 900–999 g and 1400–1499 g, the infant death rates of the multiple births was higher than that of the singletons. However the numbers are small and the variations correspondingly large.

Comparison with the most recently published corresponding data from England and Wales¹ for 1987, shows that for single and multiple births of all but the two lowest weight groups, the infant mortality is consistently and considerably lower in the RICHs data.

Table 4 Birthweight specific death rates of North East Thames residents: RICHs data

Birth weight (g)	Stillbirths 28+ weeks		Live births	Neonatal deaths		Postneonatal deaths		Infant deaths	
	No	Rate		No	Rate	No	Rate	No	Rate
500–									
1989	25	111.1	200	83	415.0	15	75.0	98	490.0
1990	23	110.0	219	86	392.7	12	54.8	98	447.5
1991	19	70.1	252	94	373.9	17	67.5	111	440.5
1000–									
1989	38	95.7	359	37	103.1	10	27.9	47	130.9
1990	42	110.2	339	29	85.5	14	41.3	43	126.8
1991	51	118.6	379	34	89.7	9	23.7	43	113.5
1500–									
1989	45	55.5	766	20	26.1	14	18.3	34	44.4
1990	51	61.4	780	20	25.6	3	3.8	23	29.3
1991	45	52.0	820	15	18.3	10	12.2	25	30.5
2000–									
1989	38	14.8	2525	25	9.9	16	6.3	41	16.2
1990	54	20.5	2578	16	6.2	15	5.8	31	12.0
1991	41	15.0	2696	16	5.9	16	5.9	32	11.9
2500–									
1989	46	4.4	10423	25	2.4	35	3.4	60	5.8
1990	42	4.0	10555	23	2.2	28	2.7	51	4.9
1991	39	3.7	10421	18	1.7	19	1.8	37	3.6
3000–									
1989	27	1.3	20954	23	1.1	46	2.2	69	3.3
1990	50	2.3	21624	21	1.0	40	1.8	61	2.8
1991	27	1.3	21441	17	0.8	24	1.1	41	1.9
3500–									
1989	19	1.2	15331	25	1.6	30	2.0	55	3.6
1990	24	1.5	15906	17	1.1	24	1.5	41	2.6
1991	25	1.6	15763	13	0.8	17	1.1	30	1.9
4000–7999									
1989	9	1.8	5070	2	0.4	6	1.2	8	1.6
1990	12	2.2	5430	5	0.9	7	1.3	12	2.2
1991	11	2.0	5540	8	1.4	7	1.3	15	2.7
Missing birth weight and out of range									
1989	8		92	14		7		21	
1990	9		106	15		4		19	
1991	6		132	28		10		38	
All including missing									
1989	255	4.6	55720	254	4.6	179	3.2	433	7.8
1990	307	5.3	57537	232	4.0	147	2.6	379	6.6
1991	264	4.6	57444	243	4.2	129	2.3	372	6.5

Stillbirth rates are calculated per 1000 total births; neonatal and postneonatal mortality per 1000 live births.

Discussion

The main aim of this paper has been to show the use of birth notification data for the monitoring of stillbirth and infant death rates. Validation of the data showed that the number of deaths that could not be matched with birth registration data was small. Moreover, these were compensated for by the greater number with known birthweight in the notification data. The failure to record birth weight in registration data tends to be administrative, the baby being registered before the registrar receives details from the birth notification. As shown in this paper, the unrecorded birth weights in the notifications themselves are more often found in babies likely to have been transferred to neonatal units, a fact that needs to be noted when comparing death rates of high risk infants.

The use of these local data allows an increased flexibility of tabulations. As shown here these can be produced in 100 g groups, to enable ongoing monitoring of survival at very low birth weight. Moreover survivors of such low birth weights can be identified, thus helping their follow up, and the planning of the resources needed for the care of those at risk of subsequent disability.⁵

The present exercise has shown that this work has been worthwhile in providing an information system that derives directly from available data without further data collection. While similar results have been obtained from special surveys,^{6,7} this to our knowledge, is the first time routinely collected data has used for surveillance at regional level. The data linkage and editing, costing £125 000 over three years to establish, has been continued with far more modest resources. Regular reports are available to purchasing teams and maternity service providers, and the data can be used as denominator data for programmes such as the Confidential Enquiry for Stillbirths and Deaths in Infancy (CESDI).

The fact that the latest data in this report relate to 1991 is because of the changes that took place in the provision of data to the regions by OPCS, who no longer provide regional data sets, and the change to the regional structure. For the validation of infant, particularly postneonatal deaths, to a birth cohort it is necessary to have available data on all deaths occurring in the next calendar year, as some will occur in the year after that of their birth. Moreover, after 1992 there were many changes in the data processing at OPCS, which held up the release of information. In the future this exercise will be repeated so that updated information will be available.

In other European countries there are concerns with the timeliness of publication of perinatal statistics.⁸ In England and Wales, where detailed reports are produced annually, normally within two years, the limitation lies in the restricted range of details collected at birth registration. Use of the notification system enables registration data to be supplemented with additional information about outcomes such as gestational age specific mortality⁹ and process of obstetric care such as gestation at booking, instrumental and operative delivery, and method of resuscitation. These are a necessary basis for comparative clinical audit. National data are at the present too incomplete to be able to calculate meaningful estimates.

The maintenance of high quality standardisation and compatibility of child health data over as wide a range as possible of health authorities and provider units is essential if these valuable data, in part collected on a statutory basis can continue to be used for audit and planning purposes. Unfortunately few regions have been as far sighted as the North Thames (East), many district providers being tempted to purchase incompatible data collection systems, which lead to fragmentation of the data base. As many births occur outside the district of residence this fragmentation makes it impossible to meet the government

Table 5 Birthweight specific mortality of infants born to residents of NETRHA 1989–1991 categorised by multiple birth status and compared with published national data

	Number of live births (LB) and infant deaths (ID)						Infant death rates and 95% confidence intervals					
	Singleton births		Multiple births		Missing multiple birth status		Singleton births England and Wales 1987	NT (E) 1989–1991		Multiple births England and Wales 1987	NT (E) 1989–1991	
Birth weight (g)	LB	ID	LB	ID	LB	ID	IMR	IMR	95% CI	IMR	IMR	95% CI
500–599	76	52	13	13	0	0	804	684	567.2, 785.9	933	1000	732.0, 1000*
600–699	94	57	22	21	0	0	793	606	500.3, 705.5	862	955	771.1, 999.8
700–799	110	46	10	7	1	1	567	418	342.8, 515.9	727	700	347.2, 933.2
800–899	151	53	23	12	1	1	449	351	252.2, 432.7	751	522	305.7, 731.9
900–999	139	36	31	8	0	0	323	259	188.4, 340.4	403	258	111.8, 446.1
1000–1099	124	27	24	7	1	1	289	218	148.6, 300.6	288	292	126.2, 510.9
1100–1199	164	31	38	10	2	2	206	189	132.1, 257.5	225	263	134.1, 430.8
1200–1299	171	12	43	5	0	0	155	70	36.1, 119.4	202	116	38.8, 250.9
1300–1399	177	12	58	9	0	0	128	68	35.4, 115.3	80	155	73.4, 274.4
1400–1499	217	16	58	1	0	0	111	74	42.7, 116.9	61	17	4.4, 92.3
1500–1999	1728	72	634	9	4	1	69	42	32.7, 52.2	29	14	6.5, 26.7
2000–2499	6494	87	1304	17	1	0	17	13	10.7, 16.5	12	13	7.6, 20.8
2500–2999	30079	138	1313	8	7	2	5	5	3.9, 5.4	12	6	2.6, 12.0
3000–3499	63518	168	489	3	12	0	2	3	2.3, 3.1	8	6	1.3, 17.8
3500+	62943	160	93	2	4	0	1	3	2.2, 3.0	10	22	2.6, 75.5
Birth weight missing or out of range	287	50	28	16	15	12						
Total	<16 472	1017	4181	147	48	20		6	5.7, 6.5		35	29.8, 41.9

*One tailed test.

KEY POINTS

- The increasing demand for data relating to outcomes of maternity services suggests alternative sources of data need to be explored to meet current requirements. Birth notification data are a universal source of such information, if these can be aggregated and shown to be of sufficient quality.
- Notification data provides more complete data on birth weight and can be used to provide more detailed and timely information than that available at the present time from birth registration sources. The use of record linkage provides a means of quality assurance and a possible mechanism for improving national data.
- Special efforts need to be made to counter the loss of birthweight data relating to very small and very ill infants transferred to neonatal units immediately after birth, before being weighed.
- A wider range of birthweight grouping than that routinely published by OPCS is required to effectively monitor the changes in still birth and infant mortality at the extremes of birth weight.
- The increasing survival of infants at the lower extremes of birth weight requires ongoing scrutiny in view of their high risk of disability.

requirements that planners and consumers should have access to population based information regarding the quality and outcome of maternity services. Analyses of birth information by district of occurrence is possible in these but confounded by patient selection by different hospitals, and comparisons between districts become difficult. The present report has shown the use of aggregated data to review births data for residents of a regional level.

Annual tables of birth notifications are produced by RICHs for residents of each district and for the commissioning authorities, and it is planned soon to add mortality data for more recent years.

The attention of Maternity Services Liaison Committees should be drawn to the importance of such data for their work and consideration should be given to the possibility of increasing data exchange between the birth notification and birth registrations systems. There is already provision for such exchanges.¹⁰

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