

The availability of perinatal health indicators in Europe

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Abstract

This paper uses the results of the PERISTAT feasibility study to assess the extent to which the participating countries of Europe were able to provide data to construct the core and recommended indicators of perinatal health defined in the project. After describing the approaches used for data collection in participating countries, this paper describes the extent to which they were able to provide the data requested to construct the indicators. It documents data sources within each country and their characteristics. The paper then discusses influences on the agenda, particularly the extent to which data collection occurs as a by-product of other processes such as civil registration and the administration of health care and how these processes can both enable and impede data collection. It closes by suggesting how data collection in Europe can be improved in order to widen the scope of the agenda for compiling perinatal indicators.

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Keywords: Perinatal health indicators; PERISTAT; Civil registration; Birth registers; Birth surveys; Official statistics

1. The availability of perinatal health indicators in Europe

This paper describes the feasibility study undertaken to assess the extent to which the participating countries of Europe were able to provide data to construct the core and recommended indicators defined in the PERISTAT project. It discusses the results of this and relates them to the ways in which data are collected within the countries.

After describing the approach made to participating countries, this paper describes the extent to which they were able to provide the data we requested to construct the indicators. It documents the data sources from each country which were used for PERISTAT and briefly describes their characteristics. This is followed by a discussion of factors which influence their scope, in particular the advantages and disadvantages of collecting data as a by-product of other processes such as civil registration and the administration of health care. The paper closes by suggesting how data collection in Europe can be improved and extended in order to widen the agenda for perinatal indicators.

2. How the indicator data were compiled

In order to collect the aggregated data required to construct the indicators, the members of the Scientific Advisory Committee were first asked to provide information about the routine data collection systems in their countries, including both routine administrative and clinical systems and periodic sample surveys. For each system, the information provided included the name of the statistical, clinical or other organisation running it and the contact details of a person within the organisation who could be approached to provide the data for PERISTAT.

For each indicator, one or more blank tables were set up to show the layout of the aggregated data required to construct it. Although most of the indicators are expressed in terms of rates and ratios, numbers were requested in order to be able to calculate rates on a common basis.

The members of the Committee then compiled the tables using routine data for their country for the year 2000 or the most recent year. Some members compiled at least some tables themselves using data from published sources in consultation or collaboration with colleagues in the relevant organisations. Often the categories used in the PERISTAT tables differed from those used in routine publications, especially where PERISTAT tables had quite detailed

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tabulations, to enable common cut-offs to be selected when constructing the indicators. In these and other cases, they asked their contacts within the relevant organisations to compile the data needed to complete the tables. In many cases, this included requests for ad-hoc tabulations which were run especially for PERISTAT.

Participants were asked to provide national data for their country, as far as possible. If data were available for some but not all components of any given table, participants were asked to provide the available data and mark the remaining cells as ‘unavailable’. Where data were not available for all parts of a country, but population-based data were available from one or more regions, these data could be provided instead.

The requests were for population-based data. If such data were not available but the relevant data items were collected in hospital-based systems, then data from these sources could be used. Participants were asked to record the names of the data source or sources used to compile each table. They were also asked to complete a questionnaire about each data source used overall.

If it was possible to derive the indicators from more than one source of data, participants were asked to provide data from both. In particular, if some limited national data were available, but better quality or more detailed data were available at a regional level, participants were asked to provide these in addition to the national data.

In cases where it was not possible to provide data in the form requested, because the definition used within a country was different from that used by PERISTAT, participants were asked to provide the data available. They were asked to document clearly the definitions used and how they differed from the definitions used in PERISTAT.

3. Data collection within participating countries

Information about data collection systems identified by participants and used to contribute data to PERISTAT are summarised in [Tables 1–5](#). The systems are summarised and tabulated by country in [Appendix A](#). These do not necessarily cover all relevant data available in each country. In some countries, there may be sources which were not identified or were known but not used. In some cases, requests for data from specific sources may not have been successful, because of pressures of other work. For example, data on births by birthweight are collected in the French PMSI hospital data system but are not published. This means that participants would have needed to make a specific request for data and do the analysis. Some sources may not be readily visible, as data from them may have been linked with others and submitted jointly to PERISTAT.

3.1. Civil registration

Civil registration systems for each participating country are listed in [Table 1](#). The legal criteria for civil registration

usually affect those used in other data collection systems in the same country. In most countries, civil registration systems are the most complete source of data in terms of inclusiveness. Civil registration is required by law and needed for legal purposes and access to identity documents. On the other hand, in some countries, such as The Netherlands and Greece, there is evidence of under-reporting of stillbirths and neonatal deaths in their civil registration systems in circumstances where people may be unaware of the legal requirements [1,2].

Other events may be omitted from civil registration. Some countries do not include births to and deaths of non-residents or non-citizens. Countries may also exclude births to and deaths of their citizens and residents which take place outside the country. In some cases, these are simply people who live near national borders and cross the borders to give birth. For example, some women who live in the Irish Republic give birth in maternity units in Northern Ireland and vice versa. A perhaps more serious issue is the potential for under-registration of births to and deaths of migrants. People without identity papers, including illegal migrants, refugees and asylum seekers are the most likely to be missed out. As women in such circumstances and their children may be at a high risk of adverse outcome compared to the citizens and residents of countries, their omission may cause important biases even when they are relatively few in number [3,4]. Other biases can arise from differences in how countries deal with data they do collect about non-residents.

While the most complete in terms of inclusion of records of events, most civil registration systems include very little clinical information about births and factors leading to deaths or about the care given. Most include information about the clinical causes of stillbirth and death but little else. In the case of some pregnancy-related deaths, the death may be registered but the pregnancy may not be recorded. On the other hand, civil registration records may include information about the parents’ or deceased person’s social background which does not appear on hospital or clinical records. This can include items such as occupations, countries of birth, ethnic origins and level of education.

3.2. Population-based clinical registers

A number of countries have established population-based registers at a national, regional or local level, based on notifications by midwives, doctors or other clinical informants. These are summarised in [Table 2](#). Some of these were established for specific clinical purposes. For example, the local child health computer systems in the United Kingdom were established to support the provision of health visiting services and immunisation to families with new babies whose births had been notified by midwives.

There are no clear definitions of birth registers or perinatal databases or documentation of how they differ. Finland and Sweden have what are described as national birth registers. Denmark’s system is known as a perinatal database and the

Table 1
Civil registration of births and deaths in participating countries

Country	Source code	Statistical office	Inclusion criteria		Coverage	Informant
			Stillbirths	Live births		
Austria	A1-2001	Statistics Austria	WHO	WHO	All births occurring in Austria to Austrian residents, 100% coverage	Parents/civil registrar, doctors
Belgium	B1-1995	National Institute of Statistics, Scientific Institute of Public Health	22 weeks, 500 g	22 weeks, 500 g	All Belgium	Doctor, community ministries of health
Flanders	B4-2000	Ministerie van de Vlaamse Gemeenschap	22 weeks		100% of Flanders	Midwife/doctor and parents
Finland	FIN5-2000	Statistics Finland	22 weeks, 500 g	22 weeks, 500 g	All births occurring in Finland	Maternity hospitals to Population Register
	FIN2-2000	Statistics Finland Cause of death register	22 weeks, 500 g	22 weeks, 500 g	All deaths of Finns and foreign citizens with a permanent residence in Finland	Certifying doctors
France	F2-2000	INSEE	28 weeks in 2000, now 22 weeks, 500 g	22 weeks, 500 g		Parents
Germany	D2-1999	Statisches Bundesamt, Deutschland, Wiesbaden	WHO	WHO	Births and deaths of mothers whose official place of residence is Germany, 100%	Parents at local register offices
Ireland	IR2-1999	Central Statistics Office	24 weeks, 500 g	All	100%	Parents and attending doctor or midwife
Italy	I1-1998	ISTAT	180 days		System dismantled after 1998 and being re-established	
Luxembourg	L1-2000	Direction de la Sante, Service des Statistiques	WHO	WHO	Deaths of persons living in Luxembourg	Certifying doctors
	L3-2000	STATEC, Annuaire Statistique			Statistics about residents of Luxembourg	
Portugal	P1-1999	Instituto Nacional de Estatistica (INE)	WHO	WHO	Births to residents and Portuguese citizens delivering abroad, 100% coverage	Doctors plus clerical staff at INE
Spain	E1-1999	National Institute for Statistics (INE)	28 weeks			
United Kingdom	England and Wales	Office for National Statistics	24 weeks	All	Births and deaths occurring in England and Wales	
	Scotland	General Register Office (Scotland)	24 weeks	All	Births and deaths occurring in Scotland	
	Northern Ireland	General Register Office (Scotland)	24 weeks	All	Births and deaths occurring in Northern Ireland	

Irish Republic has a National Perinatal Reporting System derived from its four-part birth notification. Austria's birth register is made up of data collected locally through civil registration.

Wales had a national child health system, initiated by statutory notification of birth. Although birth data for 2000 derived from this system were used for PERISTAT, it was then discontinued. The National Assembly for Wales may replace it with a new system, subject to funding. In Northern Ireland, data derived from birth notification to its four area health and social services boards are then merged to produce perinatal information for Northern Ireland as a whole. The majority of these systems were established for a range of

health monitoring and epidemiological purposes, particularly those in the Nordic countries such as Finland, where linkage with other data collection systems is possible. Where they exist at a national level, these registers tend to be almost complete, although, as Table 2 shows, some births can be missing. Their advantage, compared with most civil registration systems, is that considerably more data items are recorded, particularly about care given at delivery and its outcome. In contrast, France maintains a register based on compulsory returns about the baby's health on the eighth day of life. Although data are available for over 90% of births, many individual data items are missing, so it was not used for PERISTAT.

Table 2
Population-based medical/ clinical birth and death registers in participating countries

Country	Source code	Register	Organisation running register	Inclusion criteria		Coverage	Informant
				Stillbirths	Live births		
Austria	A1-2001	Austrian birth register	Statistics Austria	WHO	WHO	All births in Austria to Austrian residents, 100% coverage	Parents/civil registrar, doctors
Belgium Flanders	B2-2000		Studiecentrum voor Perinatale Epidemiologie Registry	20 weeks, 500 g	20 weeks, 500 g	Flanders region hospitals, 100%	Responsible gynaecologist
French community	B3-2000	Avis de Naissance	Office de la Naissance et de l'Enfance			90–95% of French community hospitals	Nurse/social worker
Denmark	DK1-2000	Danish perinatal database	National Board of Health, Denmark and Rigshospitalet	196 days		100% of births in Denmark	Health care personnel
Finland	FIN1-2000	Medical birth register	STAKES, National Research and Development Centre for Welfare and Health	22 weeks, 500 g	22 weeks, 500 g	98–99% of births in Finland	Hospital staff
France	F3-1999	Medical death register: neonatal death register	Centre d'Epidemiologie sur les causes de Deces (CepiDc) INSERM		22 weeks, 500 g	Dying up to 28 days after live birth: 91.5% of neonatal deaths, 1999	Certifying doctors
	F5-2000	Burgundy regional database	Perinatal Network of Burgundy	22 weeks, 500 g		Burgundy region, two missing units	Health care personnel
Germany	D1-2000	Perinatal surveys	Quality assurance programmes in participating Lander	WHO	WHO	Over 95% of births in each bundesland. Data compiled from nine bundesländer, approximately 70% of all German births	Midwife/obstetrician
Ireland	IR1-1999	National Perinatal Reporting System	Economic and Social Research Institute (ESRI)	500 g	500 g	100%	Midwife or other health professional
Luxembourg	L2-2000	Fiche Medical de Naissance (FIMENA)	Direction de la Sante	WHO	WHO	About 90% coverage	Hospital staff
Portugal	P3-2000	Voluntary register	Perinatal Society			Almost complete	
Sweden	S1-2000	Swedish Medical Birth Register	National Board of Health and Welfare, Sweden	Born after 27 weeks	Born after 27 weeks	97% of all women delivering children	
United Kingdom Wales	UK5-2000	Child health system	National Assembly for Wales	24 weeks	All	All births in Wales up to 2000. Funding being sought for new system	Midwife or other health professional
Northern Ireland	UK7-2000	Perinatal Information Northern Ireland	Northern Ireland Perinatal Information Project	24 weeks	All	All births in Northern Ireland, aggregated from four child health systems	Midwife or other health professional

Although aiming to be population-based, many collect their data through hospitals in which the majority of births occur, as can be seen in article 6 in this volume. The exceptions are The Netherlands and, to a lesser extent, the United Kingdom. The German system has a strong hospital focus. It was established on a regional basis to enable the construction of 'quality indicators' to compare hospitals. Although only nine out of 16 Länder contributed to PERISTAT, there is a good response from hospitals in most participating Länder and 73% of births

in Germany are included. The situation in Belgium, where the Flemish and French databases relate to language groups rather than to populations, is difficult to classify.

3.3. Hospital- and profession-based data collection systems

Many countries have hospital discharge systems to record information about all stays in their hospitals, as shown in

Table 3
Hospital-based and professional data collection systems

Country	Country code	Type of register	Organisation running register	Inclusion criteria		Coverage	Informant
				Stillbirths	Live births		
Finland	FIN3-2000	Hospital Discharge Register	STAKES, National Research and Development Centre for Welfare and Health	22 weeks, 500 g	22 weeks, 500 g	All in-patient and day case episodes in Finnish public and private hospitals, 95% complete	Hospital staff; via computer systems
Netherlands	NL1-1999	National Perinatal Database for primary care by independent midwives	LVR-1	16 weeks	16 weeks	Pregnancies cared for by midwives	Midwives. One of three linked databases
	NL1-1999	National Perinatal Database for secondary care by obstetricians	LVR-2	16 weeks	16 weeks	Pregnancies cared for by obstetricians	Obstetricians. One of three linked databases
	NL1-1999	National Neonatology Database	LNR			All admissions of babies to neonatal departments within the first 28 days of life and all readmissions	Neonatologists, one of three linked databases
Spain	E2-2000	Hospital survey	Spanish Society of Neonatology (SEN)	22 weeks 500 g		74% of births in 2000 in Madrid, Comunidad Valenciana, Pais Vasco and Navarra, 22% of live births in Spain	Hospital staff
United Kingdom							
England	UK4 2000/01	Maternity Hospital Episode Statistics	Department of Health	24 weeks		67% of maternities in England in 2000/01	Hospital staff
	UK17 2000/01	Hospital Episode Statistics	Department of Health			All hospital stays in non-maternity wards in England	Hospital staff
Wales	UK18-2000/01	Patient Episode Database Wales	National Assembly for Wales			All hospital stays in non-maternity wards in Wales	Hospital staff
Scotland	UK6-2000	Scottish Morbidity Record SMR02 System	Information and Statistics Division, Scotland	All events in maternity wards plus home births	All events in maternity wards plus home births	98% of births and pregnancies in Scotland	Hospital staff

Table 3. Information about stays during which delivery takes place can then be collected through these. Such information may be limited, unless provision is made for the fact that one person, the mother, goes into hospital and two or more are discharged at the end of the stay. Where delivery information is appended to the core record, as in England, Wales and Northern Ireland, it can often be omitted, unless maternity departments have good quality information systems linked to the hospital's main computer system [5,6]. These problems do not arise in Scotland, which has a special system for collecting data about stays in maternity departments [7]. Scotland's SMR02 system could almost be classified as a clinical birth register except that information about some births outside hospital is missing.

A different approach is used in The Netherlands, where obstetricians and midwives have separate profession-based data collection systems. This means that if a woman is transferred from primary care by a midwife to secondary care by an obstetrician, she will be recorded twice. In

contrast, if she is delivered by a general practitioner, as is the case in about seven per cent of births, the birth will go unrecorded, as Dutch general practitioners have not yet established a database for births [1]. For an earlier project, data from these systems were combined to produce a pooled database [1]. In doing so, duplicated records were eliminated allowance was made for the missing data about deliveries supervised by general practitioners. Unfortunately, funds were not available to repeat this exercise in its entirety for PERISTAT.

3.4. Condition-specific registers

As only congenital anomalies and cerebral palsy were included in the PERISTAT indicators, we did not attempt a comprehensive ascertainment of the existence of registers containing data about conditions relevant to the perinatal period. As Table 4 shows, Finland, Sweden, Spain, England, Wales and Scotland have national systems for collecting

Table 4
Condition-specific registers and confidential enquiries into adverse events

Country	Country code	Type of register	Organisation running register	Coverage	Informant
Austria	A2-00/01	Confidential Enquiry into Maternal Mortality	Prof. Ch. Vutuc, Prof. A. Beck, Division of Epidemiology, Institute of Cancer Research, Medical University of Vienna	National	Department of Obstetrics, Institute of Pathology, Institute of Forensic Medicine
Finland	FIN4-2000	Finnish Register of Congenital Malformations	STAKES, National Research and Development Centre for Welfare and Health	Live and stillbirths. Terminations and miscarriages included experimentally	Health care staff
France	F4-98/99	Confidential Enquiry into Maternal Mortality		National	
	F6-2000	Congenital anomalies	Paris Register of Congenital Anomalies	Paris Region, Eurocat criteria	Clinicians, multiple sources of ascertainment
Germany	D3-1999-00	Confidential Enquiry into Maternal Deaths	Prof. H. Welsch	Bavaria	
	D4-2000	IVF register	DIR		
Portugal	P3-2000	Congenital anomalies		Voluntary national register, 75% coverage	
Spain	E3-2000	Spanish Collaborative Study of Congenital Anomalies	ECEMC		
	E7-1995-97	Confidential Enquiry on Maternal Mortality	Spanish Society for Gynaecology and Obstetrics (SEGO)	69 hospitals, 32% of pregnancies, 1995–1997	Health care staff
Sweden	S2-1996-2000	Vital records linkage			
United Kingdom	UK12-1997-99	Confidential Enquiries into Maternal Deaths	Since April 2003, the Confidential Enquiry into Maternal and Child Health has had overall responsibility	Report on combined data from separate confidential enquiries into maternal deaths in England, Wales, Scotland and Northern Ireland	Ascertained from death registration and also notified by clinicians.
	UK16-1999/2000-2000/01	Procedures carried out in clinics in the UK under the Human Fertilisation and Embryology Act	Human Fertilisation and Embryology Authority	All clinics in the United Kingdom	Clinics
England	UK8-2000	Confidential Enquiry into Stillbirths and Deaths in Infancy	Since April 2003, the Confidential Enquiry into Maternal and Child Health has had overall responsibility.	Fetal deaths at 20–23 weeks, stillbirths and infant deaths in England	Notified by clinicians and cross-checked with stillbirth and death registration
Wales	UK9-2000	All Wales Perinatal Survey	Since April 2003, the Confidential Enquiry into Maternal and Child Health has amalgamated data with those for England and Northern Ireland	Fetal deaths at 20–23 weeks, stillbirths and infant deaths in Wales	Notified by clinicians and cross-checked with stillbirth and death registration
England and Wales	UK13-2000	National Congenital Anomaly System	Office for National Statistics	Congenital anomalies among stillborn and live born babies	Notification by clinicians and transfer of data from local registers.

Scotland	UK11-2000	Scottish Perinatal and Infant Mortality and Morbidity Review	Scottish Programme for Clinical Effectiveness in Reproductive Health (SPCERH), working in partnership with Information and Statistics Division.	Fetal deaths at 20–23 weeks, stillbirths and infant deaths in Scotland	Death registration, SMR02, reports of perinatal mortality meetings and voluntary notification of late fetal deaths by clinicians.
	UK14-1999	Scottish Congenital Anomalies Register	Information and Statistics Division, Scotland	Congenital anomalies among stillborn and live born babies	Linkage of data from SMR1 and SMR11 hospital discharge returns and from the Scottish Perinatal and Infant Mortality and Morbidity Review
Northern Ireland	UK10-2000	Confidential enquiry into Stillbirths and Deaths in Infancy in Northern Ireland	Since April 2003, the Confidential Enquiry into Maternal and Child Health has amalgamated data with those for England and Wales	Fetal deaths at 20–23 weeks, stillbirths and infant deaths in Northern Ireland	Notified by clinicians and cross-checked with stillbirth and death registration

Table 5
Surveys

Country	Country code	Type of survey	Organisation running survey	Coverage	Who completes questionnaires
France	F1-1998	Enquete Nationale Perinatale	INSERM U149	All births in France in 1 week in 1998	Data from medical records plus interview with mother
Greece	EL1-1998	Population-based survey	Chryssa Bakoula	14,659 women with live and stillbirths born in 8 weeks in 1998	
Spain	E4-1997	Breastfeeding survey	Spanish Society of Paediatrics		
United Kingdom	UK15-2000	Infant Feeding Survey	Commissioned by Department of Health for England on behalf of the Department of Health, the Scottish Executive, The National Assembly for Wales and the Department of Health, Social Services and Public Safety in Northern Ireland	Five yearly. Infant feeding 2000	Postal survey of mothers

data about congenital anomalies. In addition, most participating countries have regional or local registers which, like the register in the Paris Region in France and the register in the Basque Country in Spain, are affiliated to the European Concerted Action on Congenital Anomalies and Twins (EUROCAT). Members of EUROCAT compile population-based registers using agreed common definitions and use their data to monitor time trends [8,9]. The PERISTAT indicator for selected congenital anomalies was developed so that it could be compiled from national birth data if there were no national anomalies registers. This indicator is intended to complement information compiled by EUROCAT.

Registers of cerebral palsy are less common than those monitoring congenital anomalies, probably because children have to be followed to at least 4 years before diagnoses can be confirmed. The Surveillance of Cerebral Palsy in Europe (SCPE) collaboration has brought together representatives from 14 registers in eight countries. The project's working groups have established common definitions and classifications [10].

A number of participating countries have established registers to monitor the use of assisted conception but most are set up in a way which made it difficult to use them for PERISTAT. Apart from the register in Flanders, they do not cover ovarian stimulation. The remainder do not necessarily cover all forms of assisted conception and data tend to be compiled by date of procedure rather than by date of birth [11].

3.5. Confidential enquiries into adverse events

Also listed in Table 4 are confidential enquiries into maternal deaths and into stillbirths and deaths in infancy. Confidential enquiries into individual maternal deaths using reviews of case notes and other clinical reports and linked to data from routine sources were developed in Scotland, England and Wales in the 1920s and 1930s [12].

Enquiries into maternal death were established on a routine basis in a number of countries in the latter half of the twentieth century. A number of the participating countries had confidential enquiries into maternal deaths in the 1990s and contributed information from them to an earlier European collaboration [13]. Despite this, only France, Bavaria, Spain, Austria and the countries of the United Kingdom passed data from confidential enquiries to PERISTAT.

From the late 1970s onwards, attention switched to perinatal mortality. A number of regional, national and international audit projects took place [14,15]. After pioneering an individual case record approach from 1977 onwards [16], Scotland dropped this aspect in 1983 when incorporating the monitoring of perinatal mortality into its national system of routine maternal and child health statistics [17]. A number of countries which took part in PERISTAT have a tradition of perinatal audit and were also involved in the Euronatal collaboration on perinatal mortality. This took place in the late 1990s and included a confidential enquiry approach [18]. Despite this, they do not appear to have used data of this type for PERISTAT. The Confidential Enquiry into Stillbirths and Deaths in Infancy, established in England, Wales and Northern Ireland in 1992, was the only enquiry of this sort which contributed to PERISTAT, as Table 4 shows. These data came from its 'rapid report forms' rather than from the confidential enquiry process itself.

3.6. Surveys

Only four countries used surveys as sources of data for PERISTAT, as Table 5 shows. These surveys differed considerably from each other. The best known are the French surveys of samples of births. These have been carried out periodically at a national level since 1972 to monitor changes in obstetric practice and the health and demographic structure of the childbearing population [19]. Data from these surveys are also used for international comparisons [20].

The survey in Greece had been undertaken especially to collect data for the Euronatal project and the focus was therefore on perinatal death [18]. A survey of live births, stillbirths and neonatal deaths in Greece had been conducted for eight consecutive weeks of 1998. The previous national survey in Greece had taken place 15 years earlier, in 1983 [2]. More frequent surveys would be needed if they were to form part of a European health monitoring system.

In Spain, the Spanish Paediatric Society undertook an infant feeding survey in the late 1990s. The infant feeding surveys undertaken every 5 years in the United Kingdom focus on babies in the first year of life although some data are collected about the parents' socio-economic position, the mother's smoking habits and very minimal data about the birth [21]. These are postal surveys based on a sample derived from birth registration. The increasing restrictions on the use of birth registration data which have resulted from European and national data protection legislation have made it impossible to send reminders to non-respondents, making the survey vulnerable to response bias.

4. Availability of data to construct PERISTAT indicators

The extent to which countries were able to provide the data for the proposed indicators is summarised in Fig. 1. A black square for a data item indicates that the data were fully available at a national level. Horizontal stripes indicate that some but not all the data were available and vertical stripes indicate that the data were available either for one or more but not all regions or components of a country or for a sample.

As can be seen, coverage varied widely. The Nordic countries, Ireland and Austria could provide most of the data required, as could Luxembourg. Although relatively few data are available from routine systems in France, it produced a relatively full set of data, based on the 1-week sample collected in 1998. Germany provided relatively full coverage of data items based on the 70% of its births taking place in participating Länder. The Netherlands could potentially contribute a relatively full set of data items but funds for the special exercise to link obstetricians' and midwives' databases were not available, so the Netherlands was unable to contribute a full set of data items to PERISTAT.

The situation was particularly complicated in Belgium and the United Kingdom, both of which have devolved data collection systems. Data for Flanders were forwarded to PERISTAT separately from those for the French speaking community. Data were compiled for each of the four countries of the United Kingdom separately and then aggregated as far as possible before forwarding to PERISTAT. In both cases, the components are shown separately in Fig. 1. This shows that data for Flanders and Scotland are more complete than those for other parts of Belgium and the United Kingdom respectively.

Other countries, notably Spain, Portugal, Greece and Italy, could produce relatively few data routinely at a national level. In Italy, data were available in the past, but data collection has been suspended while a new system is being developed. Meanwhile, some data for 1998 were provided from the old system. This makes it possible to obtain estimates of indicator values in Italy, but not to monitor trends over time as the new data collection system will probably be different. As mentioned earlier, the Greek data were collected on a one-off basis.

4.1. Data items—towards a minimum dataset

The data items required to compile the PERISTAT indicators are listed in Table 6. Even when data items have been agreed internationally by the World Health Organisation (WHO), countries may not adopt these in their legislation or working practices. Definitions of live birth and stillbirth may differ from those proposed by WHO [6,22,23]. This is discussed in detail in paper 4 in this volume.

As Table 1 shows, there are variations in the birthweight and gestational age criteria for civil registration and hence for other data collection systems used within countries. Such differences persisted throughout the twentieth century [23,24]. Even where countries may say that they use 'WHO criteria' it is not always clear whether these relate to both being born after at least 22 completed weeks and weighing at least 500 g or whether babies who satisfy one but not both of these criteria are included. In addition, they may use different definitions for live births and stillbirths. For example, in Finland and in the countries of the United Kingdom, all live births are registered and included in statistics.

It also became clear that even though countries used ICD codes for classifying morbidity, such as perineal trauma, they might not have done so in a consistent way. This added to the already considerable problems of trying to compile indicators based on morbidity. The PERISTAT project took place at a time when some countries had completed the transition from the Ninth to the Tenth revision of the ICD, some were in the process of doing so and others had not yet started. Some countries had implemented special certificates for certifying causes of stillbirth and neonatal death, with separate spaces for maternal, fetal and other causes.

Even greater problems arose for operations and procedures where there is yet to be a classification which is agreed internationally. This means, for example, that definitions of 'elective' and 'emergency' caesarean section differ, both between and also within countries [25]. If the definition of elective caesarean sections includes those which were planned in advance to take place after labour had started spontaneously, then any data compiled using it do not fit in with the PERISTAT definition of being undertaken before labour.

Other factors may not be explicitly covered by WHO definitions. For example, mortality rates can either be constructed on a 'death cohort' basis, by dividing the deaths occurring in

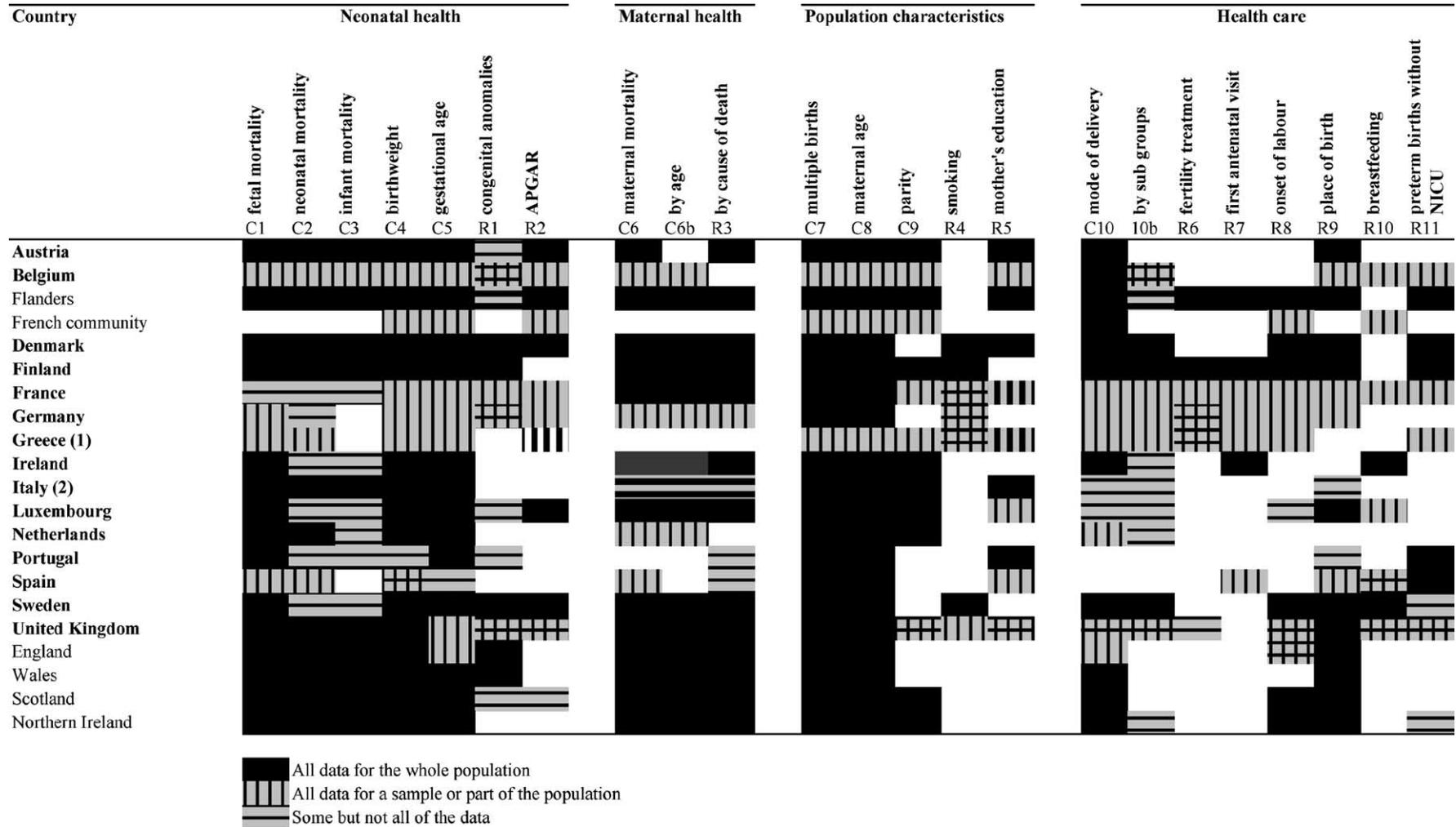


Fig. 1. Provision of data to construct PERISTAT indicators, by country. NOTE: (1) Data for Greece based on one-off perinatal survey for 8 weeks of 1998. (2) Data related to 1998 since when the system has been suspended.

Table 6
Data items required to construct PERISTAT indicators

Mother
Unique identifier
Demography and life style
Area of residence
Date of birth/ age
Parity—previous live and stillbirths
Previous caesarean sections
Socio-economic status
Ethnic origin
Country of birth
Smoking before and during pregnancy
Pregnancy
Use of ovulation induction or assisted conception
Timing of first antenatal contact with maternity services
Gestational age at end of pregnancy
Outcome of pregnancy—termination/miscarriage/birth
For pregnancies resulting in live or stillbirth
Multiplicity singleton/multiple
Method of onset of labour
Use of episiotomy
Unique identifier of each baby
Outcome for mother
Death—cause and date
Perineal trauma
Faecal incontinence
Eclamptic seizures
Blood transfusion
Surgery or embolisation
Admission to intensive care unit for over 24 h
Baby or fetus
Termination/miscarriage
Fetal anomalies
Live or stillbirth
Unique identifier of baby
Unique identifier of mother
Live/stillborn
Date of birth
Place of birth
Singleton/multiplicity
Birth order within multiple set
Presentation
Method of delivery
Birthweight
Sex
Congenital anomalies
Live birth
APGAR score at 5 min
Death in first year of life—age and cause
Method of feeding in first 48 h after birth
Hypoxic–ischaemic encephalopathy
Cerebral palsy

a given year by the births occurring in the same year or on a ‘birth cohort’ basis, in which mortality rates for babies are calculated as deaths among babies born in a given year divided by births during the given year. The ‘death cohort’ basis is the most widely used internationally and if the

numbers of births remain constant over time, there is little difference between the two rates.

On the other hand, at a time when numbers of births are declining, the widespread use of ‘death cohort’ rates introduces bias. Rates are calculated on both these bases in England and Wales [26]. In general, ‘death cohort’ rates are used for preliminary analyses, while ‘birth cohort’ rates are used for more detailed analyses, for example, those by multiplicity which were requested for PERISTAT.

Most countries compile statistics for calendar years. The countries of the United Kingdom have adopted the practice of using ‘financial years’ running from April to March for some data, particularly for those related to health services. The rationale for this is to enable comparison with financial data, which are compiled on the same basis. On the other hand, this practice makes it difficult to compare them with registration data and with data for other countries which have been compiled on a calendar year basis.

5. Discussion

The extent to which data could be provided depended firstly on whether the data items needed were recorded within a country. Most of the data items will have been recorded somewhere, on paper even if not on a computer. Other factors played an equally important part in determining whether this information became translated into national statistics. These included where and how the data were recorded locally, whether they found their way into national systems, the quality and coverage of these systems and whether there was any linkage between them.

Although it is possible to identify common factors in countries, which are successful in compiling national statistics, there are also differences and thus no hard and fast rules. The organisation of health care systems is an important factor. Many of the countries with good data collection systems have publicly run health care systems in which the compilation of routine statistics is more likely to take place as a part of the administrative process. This is the case in Finland, Denmark, Sweden and Scotland. On the other hand, the Irish Republic has based its National Perinatal Reporting System on notifications from 26 public and private hospitals and 16 independent midwives [27]. Despite this, most countries which had few routine data at national level were more likely to be those which had a mixture of public and private hospitals. As a result, data could not be derived from administrative systems and explicit efforts have to be made by professional, research and other organisations to collect data. The national perinatal surveys undertaken in France, the data collection for ‘quality indicators’ within German Länder, and the separate databases maintained by obstetricians and midwives in The Netherlands are three examples of different approaches to this.

These countries with well organised data collection systems are also small in terms of the sizes of their populations

and numbers of births. It may be that having relatively small numbers of maternity units and clinicians involved makes it easier to establish and maintain momentum in the collection of data. In Germany where data are collected on a regional basis within each Land, the same could apply. PERISTAT did not collect any information which would have enabled these hypotheses to be tested, but in England a decline in the availability of perinatal data was observed after collection and compilation of data at a regional level was abolished [28]. Another frequent claim which was not tested in PERISTAT is that the quality and completeness of routine data collection reflects the status and quality of training of medical records staff.

Irrespective of this, there are some data items, notably those relating to demographic and socio-economic status, which are likely to be better collected in non-clinical data collection systems in which information is collected from parents and other relevant informants, than in those where the emphasis is on clinical information. In order to relate these socio-demographic factors to clinical information, record linkage is then required. The countries involved in PERISTAT varied in the extent to which they used record linkage. Little use was made of this in countries with poor availability of data, but there were also marked differences between countries with relatively complete data. For example, the approach used in Denmark, which relies on a single database, differed markedly from that used in Finland which makes extensive use of record linkage.

Record linkage is used for a different purpose when investigating maternal deaths. In this case, the death will have been registered, but the woman's pregnancy may not be recorded on the death certificate, especially for causes which are not direct obstetric deaths. This may be ascertained of death records of woman of child-bearing age are linked with files of birth records. Finland, Belgium, Sweden, Scotland and England and Wales use this approach to increase ascertainment of maternal deaths [3,29].

Although there are moves towards a greater usage of record linkage, linkage of even anonymised records may be increasingly restricted by the European Data Protection Act, the European Human Rights Act and legislation to implement these within individual countries. Even though all current members follow the EU directive on data protection, there are differences in the ways in which countries have interpreted and implemented it. For example, the Swedish medical birth register automatically links in information on the mother's country of birth from the central population register. By contrast, the Finnish medical birth register is restricted to acquiring information about whether or not the mother is a Finnish citizen and only women with a social security number are included.

Even if routine systems are enhanced and made more consistent, there are limits in the extent to which they can collect all the data proposed for the PERISTAT indicators. The emphasis on in routine systems is on notification of events, including adverse events, service utilisation and

demographic factors related to populations. To collect long term outcome in terms of morbidity for mothers and children, long term follow up is needed. To collect data with precise definitions, disease-specific registers are needed. These systems need focused collection of data which are unlikely to be gathered as a by-product of administrative processes. Thus they need explicit funding which may not be readily available. It follows that additional administrative or research-based data collection is sometimes needed. In order to continue, extend and enhance existing data collection systems or to develop new systems, commitment is needed to long term funding and good co-operative working with clear roles defined for the clinical, government and research organisations involved.

Even if improved and extended, these dedicated systems will not be able to provide all the data needed to compile the full range of PERISTAT indicators, in particular many of those proposed for further development. Some of these, notably the indicator of 'user satisfaction' and the indicators proposed in the midwives' DELPHI exercise, described in article 2 in this volume, can be collected only by approaching service users. Although considerable work has been done within countries to develop techniques for ascertaining users' views, further work is needed to take account of cultural factors and to enable comparisons to be made between countries [30,31].

6. Conclusions and recommendations

The work done in the PERISTAT project has been considerable. As well as leading to data which can be compared internationally, it has identified major gaps in the data collected in the participating countries. Like so many projects of this type, it has produced a list of subjects for further work in addition to its own results.

In comparison with other international indicator sets, described in article 1 in this issue, the gaps in the data available to construct the PERISTAT indicators seem considerable. Although the crude indicators in the other sets appear to be nearly complete, many are difficult to compare because the definitions used to compile them vary between countries. In its endeavour to overcome these problems, PERISTAT has been more demanding in its data requests. It is to be hoped that PERISTAT's recommendations will stimulate the development of data collection systems in a way that will enhance the quantity and quality of information available within countries as well as enable countries to provide valid data to inform international comparisons.

The first requirement is for an agreed minimum dataset for European comparisons and mechanisms for updating this. Following closely on this, common definitions are needed firstly for the items in the minimum dataset and then for other data items which are frequently used when comparing two or more countries and may be then subjects of indicators in the future.

Countries should review their routine data collection systems and their disease and condition-specific registers used to collect data relevant to the perinatal period to identify ways of increasing their capacity to compile data for the PERISTAT indicators. Discussion should continue about the indicators requiring further development.

Even if routine systems are enhanced, it must be admitted that some countries may never be able to collect the data required routinely and that special data collection exercises will be needed. In addition, there are items which cannot be collected routinely, even in countries which have good systems. In particular, these are somewhat suspect as sources of data about users' views of services: vary considerably in the methods they use and the questions asked. There is therefore scope for developing a European perinatal survey

to be undertaken on a regular basis. Although a continuous survey is unlikely to be needed, such a survey could have a similar basis to the EU labour force survey, with countries being required to undertake it. It could have two components. The first could be the collection of clinical data about samples of women, with more rigour and focus than is possible in routine data collection. The second component could be a retrospective survey of the same sample of women in the weeks and months after delivery. Such a survey could collect information about their views of the services provided, their children's nutrition and development and their own and their children's health. Although PERISTAT did not make any formal recommendations about launching such a survey, we see scope for exploring this option more fully.

Appendix A. List of sources by country (see separate Excel workbook ch3tabs.xls)

Data sources used for constructing PERISTAT tables

Member state	Country code	Data source	Organisation or person responsible	Year(s) provided	Coverage, if not whole country	Total births, where relevant
Austria	A1-2001	Civil registration and birth register	Statistics Austria	2001		75,707
Austria	A2-00/01	Confidential Enquiry into Maternal Deaths	Division of Epidemiology, Institute of Cancer research, Medical University of Vienna	2000/2001		152,684
Belgium	B1-1995	Civil registration	National Institute of Statistics and Scientific Institute of Public Health	1995		116,122
Belgium	B2-2000	Birth register	Studiecentrum voor Perinatale Epidemiologie (SPE)	2000	Flanders	62,122
Belgium	B3-2000	Birth register	Office de la Naissance et de l'Enfance (ONE)	2000	French community	44,328
Belgium	B4-2000	Civil registration	Ministrie van Vlaamse Gemeenschap, Administratie Gezondheidszorg	2000	Flanders	62,585
Denmark	DK1-2000	Danish perinatal database		2000		67,337
Finland	FIN1-2000	Medical birth registry	STAKES	2000		56,768
Finland	FIN2-2000	Cause of death registry	Statistics Finland	2000		
Finland	FIN3-2000	Hospital discharge register	STAKES	2000		
Finland	FIN4-2000	Register of congenital malformations	STAKES	2000		
Finland	FIN5-2000	Population statistics	Statistics Finland	2000		
France	F1-1998	National Perinatal Survey	INSERM U149	1998	Representative sample	13,718
France	F2-2000	Civil registration	INSEE	2000		778,341
France	F3-1999	Medical death register	Centre d'Epidemiologie sur les Causes de Deces (CepiDc) INSERM	1999		
France	F4-9899	Confidential Enquiry into Maternal Mortality		1998–1999		
France	F5-2000	Regional birth register	Perinatal Network of Burgundy	2000	Burgundy	17,226
France	F6-2000	Paris Register of Congenital Anomalies		2000	Paris	39,400
Germany	D1-2000	BAQ perinatal survey	Quality assurance surveys in each bundesland	2000	Nine bundeslander representing 72.6% of all births ^a	558,079
Germany	D2-1999	Civil registration	Federal Bureau of Statistics, Wiesbaden	1999		770,744

Germany	D3-1999-2000	Confidential Enquiry into Maternal Mortality	Maternal mortality committee	1999–2000	Bavaria	120,000 year
Germany	D4-2000	IVF register	DIR	2000		
Greece	EL1-1998	Population based perinatal survey undertaken in 1998	Dr. Chryssa Bakoula	1998	Representative sample	14,659
Ireland	IR1-1999	National Perinatal Reporting System	Economic and Social Research Institute (ESRI)	1999		54,302
Ireland	IR2-1999	Birth and death registration	Central Statistics Office	1999		54,242
Italy	I-1998	Civil birth and death registration	ISTAT	1998	Suspended since 1998.	533,808
Luxembourg	L1-2000	National statistics on cause of death	Direction de la Sante	2000		
Luxembourg	L2-2000	FIMENA 2000	Direction de la Sante	2000		5,430
Luxembourg	L3-2000	Civil registration	STATEC	2001		5,723
Netherlands	NL-1999	Merged database from professional registers		1999	LVR: data on course of pregnancy and delivery; LNR: diagnoses of the child, duration of hospital stay, treatments	201,600
Portugal	P1-1999	Estatisticas Demograficas, Estatisticas de Saude	INE, Instituto Nacional de Estatistica	1999		120,871
Portugal	P2-1999	Voluntary national register of congenital malformations		1999	75% coverage of national births	
Portugal	P3-2000	Register	Perinatal Society	2000	Voluntary register (almost complete)	979
Spain	E1-1999	Civil registration	National Institute for Statistics (INE)	1999		397,632
Spain	E2-2000	Hospital survey	Spanish Society of Neonatology	2000	Madrid, Valencia, Pais Vasco (74% of births)	86,656 live births
Spain	E3-2000	Spanish collaborative study of congenital anomalies	ECEMC	2000		
Spain	E4-1997	Infant feeding survey	Spanish Society of Paediatrics	1997		
Spain	E5-2000		GEN (Valencian group for neonatal studies)	2000	Valencia	33,467
Spain	E6-2000		General Direction of Public Health	2000	Valencia	33,467
Spain	E7-1995-97	Confidential Enquiry into Maternal Deaths	Spanish Society of Obstetrics and Gynecology	1995–1997	Hospital survey of 69 hospitals	363,589

Appendix A. (Continued)

Member state	Country code	Data source	Organisation or person responsible	Year(s) provided	Coverage, if not whole country	Total births, where relevant
Sweden	S1-2000	Medical birth register	National Board of Health and Welfare, Sweden	2000		89,722
Sweden	S2-1996-2000	Vital records linkage for maternal deaths		1996–2000		
United Kingdom	UK1-2000	Civil registration	Office for National Statistics	2000	England and Wales	607,644
United Kingdom	UK2-2000	Civil registration	General Register Office Scotland	2000	Scotland	53,076 live births
United Kingdom	UK3-2000	Northern Ireland, civil registration	General Register Office, Northern Ireland	2000	Northern Ireland	21,512 live births
United Kingdom	UK4-00/01	Maternity Hospital Episode Statistics	Department of Health	2000/01	England	
United Kingdom	UK5-2000	Child health system	National Assembly for Wales	2000	Wales	
United Kingdom	UK6-2000	Scottish Morbidity Record, SMR2, Maternity Discharge Sheet	Information and Statistics Division	2000	Scotland	52,413
United Kingdom	UK7-2000	Perinatal Information, Northern Ireland, aggregated data from child health systems	Northern Ireland Perinatal Information Project	2000	Northern Ireland	21,794
United Kingdom	UK8-2000	Confidential Enquiry into Stillbirths and Deaths in Infancy	Since April 2003, the Confidential Enquiry into Maternal and Child Health has had overall responsibility	2000	England	
United Kingdom	UK9-2000	All Wales Perinatal Survey	Since April 2003, the Confidential Enquiry into Maternal and Child Health has amalgamated data with those for England and Northern Ireland	2000	Wales	
United Kingdom	UK10-2000	Confidential Enquiry into Stillbirths and Deaths in Infancy, Northern Ireland	Since April 2003, the Confidential Enquiry into Maternal and Child Health has amalgamated data with those for England and Wales	2000	Northern Ireland	
United Kingdom	UK11-2000	Scottish Perinatal and Infant mortality and Morbidity Review	Scottish Programme for Clinical Effectiveness in Reproductive Health (SPCERH), working in partnership with Information and Statistics Division	2000	Scotland	

United Kingdom	UK12-97-99	Report on combined data from separate Confidential Enquiries into Maternal Deaths in England, Wales, Scotland and Northern Ireland	Since April 2003, the Confidential Enquiry into Maternal and Child Health has had overall responsibility	1997–1999		
United Kingdom	UK13-2000	National Congenital Anomaly System	Office for National Statistics	2000		England and Wales
United Kingdom	UK14-1999	Scottish Congenital Anomalies Register	Information and Statistics Division, Scotland	1999		Scotland
United Kingdom	UK15-2000	Infant Feeding Survey	Commissioned by Department of Health for England on behalf of the Department of Health, the Scottish Executive, The National Assembly for Wales and the Department of Health, Social Services and Public Safety in Northern Ireland	2000		Five-yearly sample survey 21,709
United Kingdom	UK16-1999/00-2000/01	Register of procedures carried out under the Human Fertilisation and Embryology Act in clinics in the UK	Human Fertilisation and Embryology Authority			Procedures carried out in United Kingdom
United Kingdom	UK17-2000/01	Hospital Episode Statistics	Department of Health			England
United Kingdom	UK18-2000/01	Patient Episode Database Wales	National Assembly for Wales			Wales

^a Bayern, Baden-Württemberg, Berlin, Hessen (data from 2001), Niedersachsen & Bremen, Nordrhein, Sachsen, Thüringen, Westfalen-Lippe.

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