BMC Medical Informatics and Decision Making

BioMed Central

Research article

Open Access

Monitoring of IVF birth outcomes in Finland: a data quality study

Mika Gissler*[1], Reija Klemetti[2], Tiina Sevón[2] and Elina Hemminki[2]

Address: [1]STAKES National Research and Development Centre for Welfare and Health, Information Division. Helsinki, Finland and [2]STAKES National Research and Development Centre for Welfare and Health. Division for Social and Health Care Services, Helsinki, Finland

Email: Mika Gissler* - mika.gissler@stakes.fi; Reija Klemetti - reija.klemetti@stakes.fi; Tiina Sevón - tiina.sevon@stakes.fi; Elina Hemminki - elina.hemminki@stakes.fi

* Corresponding author

Published: 10 March 2004

BMC Medical Informatics and Decision Making 2004, **4**:3

Received: 25 September 2003
Accepted: 10 March 2004

This article is available from: http://www.biomedcentral.com/1472-6947/4/3

© 2004 Gissler et al; licensee BioMed Central Ltd. This is an Open Access article: verbatim copying and redistribution of this article are permitted in all media for any purpose, provided this notice is preserved along with the article's original URL.

Abstract

Background: The collection of information on infertility treatments is important for the surveillance of potential health consequences and to monitor service provision.

Study design: We compared the coverage and outcomes of IVF children reported in aggregated IVF statistics, the Medical Birth Register (subsequently: MBR) and research data based on reimbursements for IVF treatments in Finland in 1996–1998.

Results: The number of newborns were nearly equal in the three data sources (N = 4331–4384), but the linkage between the MBR and the research data revealed that almost 40% of the reported IVF children were not the same individuals. The perinatal outcomes in the three data sources were similar, excluding the much lower incidence of major congenital anomalies in the IVF statistics (157/10 000 newborns) compared to other sources (409–422/10 000 newborns).

Conclusion: The differences in perinatal outcomes in the three data sets were in general minor, which suggests that the observed non-recording in the MBR is most likely unbiased.

Background

IVF services and children born as a result of IVF treatments have been monitored carefully due to the ethical, legal and economic aspects of assisted reproduction and due to the suggested health risks for treated women and IVF children. In this article we define IVF to include classical IVF, its modifications (mainly ICSI) and frozen embryo transfers (FETs).

Information on IVF treatments and their outcomes has been gathered by three methods: 1) the collection of aggregated, statistical information on the number of treatments and their results, 2) the collection of individual-level information on all IVF treatments and their results, and 3) the collection of individual-level information on all children born as a result of IVF treatments [1]. The European reporting systems have been varyingly administered, most often by a health authority, an independent official body, or an association, typically a national fertility society. No routine monitoring system exists in some countries, but ad hoc data collection from IVF clinics has been used to obtain data for international comparisons [1].

In Finland, health authorities have used the two methods to monitor IVF. First, information on all successful IVF treatments, i.e. those leading to births and newborns, has been gathered since October 1990 in the Medical Birth Register (subsequently: MBR), which is one of the mandatory health registers. Second, aggregated IVF statistics based on initiated treatment cycles have been gathered since January 1992 [2,3]. Both existing data sources have

their limitations. The MBR does not include information on women whose treatment did not result in a birth. Aggregated IVF statistics do not enable background-adjusted comparisons between clinics, studies on the use and accumulation of services at individual level, or the follow-up of women or newborns after the perinatal period.

The main requirements for the use of administrative health registers are that they be complete and that their content corresponds to reality [4]. Even though many Finnish health registers have been shown to have high completeness and validity [4,5], the case may be different for relatively rare events such as infertility treatments. A previous study suggested that information on IVF treatments in the MBR is missing for 15% of IVF children [6]. Reasons may include problems in distinguishing between different infertility treatments when filling in the data collection form in the delivery hospitals; a lack of data in pregnancy records; or mothers' wishes to conceal their utilisation of infertility treatments. The validity of Finnish IVF statistics has not been evaluated.

To estimate the completeness and validity of the two routinely collected data bases – MBR and IVF statistics – we compared their information to ad hoc research data for the period 1996 to 1998. The ad hoc data set was created for research purposes by using information on reimbursements for health care services and prescriptions. The main focus of this study was the newborn outcomes of IVF children, since there was extensive information on this subject in all data sources.

Methods

IVF statistics

The collection of Finnish IVF statistics was started in 1992 on the initiative of the Finnish Society of Obstetrics and Gynecology. Since 1994, STAKES (National Research and Development Centre for Welfare and Health) has had responsibility for data compilation. The data collection is voluntary and is based on aggregated data on initiated IVF treatments [3]. All clinics participate in the data collection. Since 1994 the data has been collected by using the international data collection form and definitions recommended by the International Working Group for Registers on Assisted Reproduction [7]. The form includes questions on the number of treatments, on the age of the treated women and their cause of infertility, on the number of transferred embryos, on the results of transfers (number of clinical pregnancies, miscarriages, ectopic pregnancies, induced abortions, stillbirths, live births, gestational age) and on newborn outcomes (birth weight, perinatal mortality and congenital anomalies) [3].

Medical Birth Register (MBR)

The MBR was started in 1987, and is run by STAKES. The register includes the mother's and child's unique, personal identification numbers, and it collects information on maternal background, on care and interventions during pregnancy and delivery and on the newborn's outcome up until the age of seven days. Data are compiled at the time of birth, using mothers' prenatal cards as one of the information sources. The information on IVF (defined as IVF, ICSI, FETs and equivalent treatments in the MBR instructions) has been collected since October 1990. Additionally, since 1996, information on both IVF and other assisted reproduction (defined as insemination, ovulation induction and equivalent treatments) has been collected. Data linkage between the MBR data and the IVF research data (see later) showed that items referring to IVF and 'other assisted reproduction' could not be separated in the MBR, and the majority of children born after 'other assisted reproduction' were in fact born as a results of IVF. Thus the two items were merged in this study.

The MBR data are collected from all delivery hospitals and in the case of home births is collected by the assisting health care personnel [2]. Less than 1% of all newborns are missing from the MBR; information on them can be obtained by making data linkages to the Central Population Register and the Cause-of-Death Register kept by Statistics Finland, but no medical information, including information on IVF, is available for these births. After this data linkage the MBR is considered to be complete in terms of numbers of births and newborns. According to two data quality studies, the majority of the MBR content corresponds well or satisfactorily with hospital records [2,8].

The MBR data are based on the year of birth, while the other data sources are based on the date of conception. Therefore, the date of conception was calculated for all IVF newborns in the MBR by using the date of birth and the information on the best estimate of the gestational age [9].

Ad hoc research data

For research purposes data on IVF treatment cycles and other infertility treatments (including ovulation inductions) performed in the 1996–1998 period were collected from national insurance reimbursement files [10]. The first data source was information on reimbursed costs for private health care services including physicians' consultations, laboratory and radiological examinations, and infertility treatment procedures. Private services provide some 60% of initiated IVF treatments in Finland [3]. The reimbursements are based on physicians' itemised bills, and they are filed at the National Social Insurance

Institution in an electronic register under women's personal identification numbers.

The second source was information on drugs prescribed by physicians in outpatient care, covering both the public and private sectors. The National Social Insurance Institution reimburses all drug prescriptions for IVF, and it has kept records on reimbursed prescriptions in an electronic register since 1996. The data includes the woman's personal identification number, municipality of residence, name and class of the drug prescribed, the size and numbers of packages, the recommended dose, the dates prescribed and bought, and the code of the prescribing physician. Information on the indication is not recorded. An algorithm, based on theoretical rules on the use of drugs specific to infertility treatments and their combinations, sequence and dosages, was created to classify women into two groups: women receiving IVF treatments and women receiving other ovulation inductions [10].

In order to find births resulting from infertility treatments, information on treatments undertaken was linked to the MBR. Exact dates of treatments were not available, so we used the time difference between the beginning of the last treatment cycle and the birth of the child to estimate which births resulted from IVF or ovulation induction, and which births were the results of spontaneous conception. The time limit of 44 weeks was used as a standard, but another limit of 72 weeks (subsequently: loose definition) was utilised to take into account the uncertainty caused by missing information on exact treatment dates.

Congenital anomalies

In the IVF statistics, a short description of each major congenital anomaly – excluding e.g. minor birthmarks of the skin, postural talipes, or clicky hips – leading to a selective induced abortion or to a birth is requested from all IVF clinics. The reported congenital anomalies are reviewed by a clinical expert, and all minor anomalies or outcomes other than congenital anomalies are removed from the statistics. Since the other two data sources did not include information on induced abortions, only congenital anomalies among stillbirths and live births were included in our comparisons. The MBR and the IVF research data were combined with the Finnish Register of Congenital Malformations (subsequently: Malformation Register) by using mothers' personal identification numbers and the dates of birth, and its definitions and classifications were used (see: Definitions). The Malformation Register collects information on all newborns with a congenital anomaly or birth defect through several data sources, including a special data collection form completed by delivery hospitals, and diagnosis data from the MBR, from the Hospital Discharge Register, from the Cause-of-Death Register and from cytogenetic laboratories until the age of one year.

Definitions

The definition of stillbirth was the same in the MBR and in the IVF research data (a gestational age of 22 weeks or more or a birth weight of 500 grams or more), but was found to be looser in the IVF statistics (gestational age of 20 weeks or more). The same definition of SGA (small-for-gestational age), based on national standards given by Pihkala et al. [11], was utilised in the MBR and in the IVF research data. The Malformation Register defines a major congenital anomaly as a significant congenital structural anomaly, chromosomal defect or congenital hypothyroidism. This does not include hereditary diseases and other diseases not associated with congenital anomalies, dysfunction of organs or tissues, developmental disabilities, congenital infections, isolated minor dysmorphic features, normal variations and common less significant congenital anomalies, which are on the exclusion list utilised by the Malformation Register. The exclusion list for minor congenital anomalies is comparable to the list which is utilised by the European Surveillance of Congenital Anomalies EUROCAT [12].

Data analysis

The comparison of information in the IVF statistics with other sources could only be performed on an aggregated level, since this data source contains no personal-level data. The MBR data and the IVF research data were compared at an individual level using women's unique personal identification numbers as the linkage key. The statistical comparisons were done using the chi-square test, the t-test, the test for relative proportions, Fischer's exact test and κ-statistics.

Data protection issues

According to national data protection legislation, a limited number of health registers – including the MBR – can be collected using the personal identification number. Since compilation of IVF data is not included in these statues, only aggregated data can be collected without informed consent from each patient. The ad hoc research data was received from the Social Insurance Institution after a special permission for its use in scientific research was given. The data linkage between this data and the MBR was performed after the register keeping organisations and the National Data Protection Authority had authorised it.

Results

The number of initiated cycles was 16% higher and the number of transfers 3% higher in the IVF research data than in the IVF statistics. The number of births was almost equal in all data sets. The proportion of multiple births

Table 1: Number of IVF treatments and outcomes according to three data sources, Finland 1996–1998.

	IVF statistics	MBR[1)]	IVF research data
Number of treated women	n.a.	n.a.	9175
Number of treatments	20 912	n.a.	24 318
Number of transfers	18 750	n.a.	19 246
Number of clinical pregnancies	4770	n.a.	n.a.
Lost of follow-up	112	n.a.	n.a.
Number of births	3535	3557	3594
- of which multiples, %	22.6	22.3	21.6
Number of newborns	4331	4383	4384
- of which twins, %	35.9	34.6	34.6
- of which triplets, %	1.0	2.1	1.1

1) MBR = Medical Birth Register. n.a. = not available

Table 2: Data linkage between the MBR (N = 176 698) and the IVF research data (N = 8651), Finland, 1996–1998.

		MBR		
		IVF	Other	Total
IVF research data	IVF	3296	1088	4384
	Other OI[1)]	493	3774	4267
	Not in data	594	167 453	168 047
	Total	4383	172 315	176 698

OI = Ovulation induction.

varied between 22% and 23%, and all these differences between the three data sets were statistically insignificant. The variation in the number of newborns followed the same pattern as observed for births. There were, however, more IVF triplets in the MBR (2.1% of all births) than in the IVF statistics (1.0%; $p < 0.001$) and in the IVF research data (1.1%; $p < 0.001$) (Table 1). We also performed all analyses using a looser definition for IVF in the ad hoc research data. This gave 3876 births and 4680 newborns, which respectively were 7.8% and 6.8% higher than the number received by using the strict definition. When comparing the two definitions, the proportion of multiples was somewhat lower (20.3%, $p = 0.190$) than that determined using the strict definition, but no statistically significant differences were found.

The data linkage between the MBR and the IVF research data indicated a substantial general concordance of the IVF item in these two data sources: the proportion of children with a correctly reported IVF status (yes/no) was 98.7% and κ-statistics 0.75 (95% confidence interval: 0.74–0.76). If only IVF children were included in the analysis, the quality was poorer: the percentage of children with a correctly reported IVF status declined substantially to 60.2%. The individual linkage revealed, that 24.8% of IVF children (N = 1088) identified in the IVF research data lacked IVF information in the MBR, but on the other hand 24.8% of IVF children (N = 1087) in the MBR were not found in the IVF research data. Thus, even though the total numbers were very similar, 39.8% of children reported to the two data sources as IVF children were different children (Table 2). These results did not vary by maternal age, parity, maternal smoking and perinatal outcome (data not shown).

Identical κ-statistics were received when using the loose definition, but the proportion of correctly reported IVF children decreased to 59.0%. The proportion of IVF children in the IVF research data for whom IVF information was lacking in the MBR increased to 28.2%, and the proportion of IVF children in the MBR who were not identified in the IVF research data decreased to 23.3%.

Age distributions of women with initiated cycles could be determined from the IVF statistics (excluding FETs) and from the IVF research data. The age distributions were similar (data not shown). Also the proportion of women aged less than 25 years (2.3% vs. 2.5%, $p = 0.151$) and the proportion of women aged 35 years or more (43% vs. 44%, $p = 0.226$) were similar.

Table 3: Background characteristics of IVF mothers in the MBR and in the IVF research data, Finland 1996–1998, %[1)]

	MBR	IVF research data	p
Deliveries	3557	3594	
Age at birth, years			0.029
Less than 25 years	2.9	2,9	
25–29	19.0	17.3	
30–34	40.7	40.7	
35–39	29.4	29.4	
40 or more	8.1	9.7	
Mean age	33.6	33.9	0.005
SD	4.5	4.5	
Single mother	3.8	2.9	0.024
Number of previous pregnancies			0.744
0	50.0	49.5	
1	26.1	26.3	
2	12.4	12.0	
3 or more	11.5	12.2	
Number of previous births			0.299
0	70.8	72.0	
1	22.0	21.4	
2	5.1	4.3	
3 or more	2.1	2.3	
Smoked during pregnancy	7.1	6.5	0.339
Socioeconomic position			< 0.001
Upper white-collar	24.9	26.7	
Lower white-collar	48.7	49.6	
Blue-collar	13.3	14.9	
Other[2)]	13.1	8.8	

1) No information available in the IVF statistics. 2) Including entrepreneurs, farmers, students, unemployed, retired, housewives and others for whom no social class could be stated.

Information on the backgrounds of parturients was available from the MBR and from the IVF research data. The mean maternal age was some three months lower in the MBR ($p = 0.005$), and the proportions of mothers aged 35 years or more (37% in the MBR and 40% in IVF research data, $p = 0.053$) and of mothers aged 40 years or more (8 and 10%, respectively, $p = 0.002$) were lower in the MBR than in the IVF research data. There were fewer single IVF mothers in the MBR (3%) than in the IVF research data (4%) ($p = 0.023$). The distributions of socioeconomic position differed between the MBR and the IVF research ($p < 0.001$), but this difference disappeared after those with an undefined socioeconomic position were excluded from the analysis ($p = 0.357$). There were small differences in parturients' residence: the MBR reported more IVF in south-east Finland, but less in southern Finland (including the capital area) and in central Finland than did the IVF research data (data not shown). The differences in the number of previous pregnancies and births and in maternal smoking were minor (Table 3).

All three data sources showed more perinatal health problems for IVF children compared to all children born in the study period. With the exception of congenital anomalies, the infant outcomes were similar in all three IVF data sets (Table 4). The incidence of premature births varied from 17% to 18%, the incidence of low birth weight from 19% to 21%, the incidence of SGA from 6.9% to 7.0%, and the perinatal mortality rate from 12 per 1000 to 14 per 1000. None of the differences were statistically significant. The same was true for differences among singletons, but among multiples the MBR reported more premature births than did the IVF statistics (49% vs. 43%, $p = 0.019$) and the MBR indicated more low birth-weight children than did the IVF research data (46% vs. 43%, $p = 0.013$) or the IVF statistics (46% vs. 42%, $p = 0.002$) as a consequence of the excess number of triplets.

The IVF statistics indicated that there were 157 major congenital anomalies per 10 000 newborns. The incidences were much higher in the MBR (422/10 000 newborns, $p < 0.001$) and in the IVF research data (409/10 000 newborns, $p < 0.001$), but the difference between the figure from the MBR and the IVF research data was not statistically significant ($p = 0.373$) (Table 4). Similar underreporting in the IVF statistics was also observed, when

Table 4: Perinatal outcome by the three data sources, Finland 1996–1998, %[1)]

	MBR	IVF statistics	IVF research data
Births	3535	3557	3594
- singletons	2735	2765	2819
- multiples	800	792	775
Premature births (< 37 weeks), N	582	623	634
%	16.5	17.5	17.6
- among singletons	8.7	8.5	9.4
- among multiples	43.1	49.0	47.7
Newborns	4331	4383	4384
- singletons	2735	2765	2819
- multiples	1596	1618	1565
Low birth weight (< 2500 grams), N	836	906	856
%	19.3	20.7	19.5
- among singletons	6.0	5.9	6.4
- among multiples	42.2	46.2	43.1
Small-for-gestational age, N	n.a.	301	305
%	n.a.	6.9	7.0
- among singletons	n.a.	2.4	3.1
- among multiples	n.a.	15.4	14.4
Birth weight, g			
Mean (SD)	n.a.	3085 (787)	3090 (781)
- among singletons	n.a.	3440 (625)	3421 (644)
- among multiples	n.a.	2475 (650)	2494 (640)
Perinatal mortality, N	61	54	56
per 1000 newborns	14.1	12.3	12.8
- among singletons	8.8	8.3	8.5
- among multiples	23.8	20.4	21.1
Major congenital anomaly cases, N	68	185	179
per 10 000 newborns	157	422	409

1) The following comparisons are statistically significant: - IVF statistics vs. MBR: Premature births among multiples P = 0.019. Low birth-weight among multiples P = 0.002. Major congenital anomaly cases P < 0.001. - IVF statistics vs. IVF research data: Major congenital anomaly cases P < 0.001. - MBR vs. IVF research data: Low birth-weight among multiples P = 0.013. n.a. = not available

studying some single major congenital anomalies, which can be observed at birth, such as trisomy 21 (9.2/10 000 newborns compared to 15.4/10 000 newborns in the IVF research data, p = 0.206), cleft palates (6.9/10 000 vs. 37.3/10 000, p = 0.001), and neural tube defects (2.3/10 000 vs. 11.0/10 000, p = 0.058).

Discussion

Poor perinatal outcomes of IVF children may be caused by higher multiplicity rate, adverse results of IVF technology, or infertility. Previous Finnish research on IVF children has shown that the main cause of increased perinatal health problems is multiplicity, but even IVF singletons have a higher risk for adverse perinatal outcomes than did singletons in general [6,13-16]. These studies have had uncertainties, such as unclear coverage [6,14] and small sample size [15,16]. This study comparing three different nation-wide data sources suggests that poorer perinatal outcomes are unlikely to be due to methodological problems.

Our data showed that the existing two IVF data sets – aggregated data from clinics and individual-level data on newborns – gave short-term outcomes largely identical to those found in the ad hoc IVF research data, with the exception of congenital anomalies. The data linkage between the MBR and the IVF research data revealed, however, that up to two out of five IVF children were not the same individual children. This discrepancy can be explained by the problems in getting information on IVF entered into the MBR; by the problems in forming the IVF research data; and by the differences in the methods used to compile the data sets and in their inclusion criteria.

For one in four IVF children the information on IVF was missing in the MBR. We can suggest three reasons for this. First, there may be difficulties in distinguishing between IVF and other assisted reproduction methods in the maternity hospitals. A closer analysis of the MBR data showed that there were several large hospitals which did not report any IVF but only other assisted reproduction. This suggests that the hospital computer programs were

not updated when the last revision was made to the MBR data collection form in 1996. Therefore, we had to include all children born as a result of assisted reproduction in the IVF group, even though some (at maximum 11%) were not IVF children. This approach accounts for 45% of those "extra" IVF children in the MBR who were not identified as IVF children in the research data. Second, information on the use of infertility treatments may not reach the maternity hospitals. Creating a seamless exchange of information between IVF clinics, antenatal care clinics and maternal hospitals would solve the problem. On the other hand, some women may also be deliberately excluded if the patient has decided to conceal their use of infertility treatments. Third, the formation of the IVF research data was based on administrative register data, which may include incorrect entries, for example, in the drug information or in the treatment codes. This would mean that the IVF research data includes women who did not use IVF, and the missing information on IVF in the MBR is actually correct.

On the other hand, one in four children reported to be IVF children in the MBR were not found in the IVF research data. Three reasons may explain this. First, there is the problem of wrongly classifying a child as an IVF child in the MBR. Second, the algorithm in the research data was based on current knowledge on drugs used in IVF treatments, but the same drugs may be used for other purposes. We were conservative in defining IVF cases to avoid false negative cases, and may therefore have excluded women who actually had received IVF. Third, it is possible that the IVF research data missed some women who had been treated in the public sector and who had used drugs which were bought and reimbursed earlier to reach the annual ceiling for free medication [17].

Besides these main explanatory factors, a small part of the discordance may be explained by technical factors. Despite the large number of possible sources of bias, their effect on our results and conclusions was estimated to be negligible. First, the study period was defined from the start of treatment in the IVF statistics and in the IVF research data, but was retrospectively determined from the date of conception in the MBR. Second, IVF statistics lacked information on some of the less frequent treatments, such as oocyte donation and assisted hatching. Third, the inclusion criteria differed for foreigners; they were included in the IVF statistics, but not in the MBR or in the IVF research data. Private Finnish IVF clinics provide treatments which are unavailable in some neighbouring countries, such as the use of donated oocytes, and the treatment of single women and lesbian couples. On the other hand, Finnish women who received IVF services in other countries – for example in Estonia due to more inexpensive treatments – cannot be found in IVF statistics of the IVF research data, but they were included in the MBR if their births occurred in Finland. Fourth, women who were entitled to reimbursements but who did not apply for them were not in the IVF research data, but were in the two other sources. This group is assumed to be small, because drugs and treatments are expensive, and the reimbursement is usually already given in the IVF clinic and in the pharmacy. Fifth, the IVF statistics included all pregnancies after 20 weeks of gestation, while the MBR and the IVF research data included births after 22 weeks of gestation [18].

More triplets were reported to the MBR than found in the IVF statistics or in the ad hoc IVF register data. We have no clear explanation for this phenomenon. It may be caused by the fact that the MBR data is collected in the delivery hospitals, and naturally conceived triplets may incorrectly be assumed to have resulted from infertility treatments. Another explanation is that Finnish women who were treated in the neighboring countries more commonly using three occytes or more per transfer gave triplet births in Finland. The most likely explanation, however, is our decision to define all children reported to have resulted from IVF or other assisted reproduction techniques as IVF children due to quality problems in the MBR: some triplets may have resulted from ovulation induction.

With the exception of major congenital anomalies the infant outcomes were similar by data source. It seems that information on congenital anomalies does not reach the IVF clinics, or the received information may be too inaccurate to confirm whether the congenital anomaly is a major one or not. This is also confirmed by recent studies on the connection between IVF and congenital anomalies: Lower proportions of children with major congenital anomalies have been reported in studies based on data collected routinely from IVF clinics, from 2.0% to 3.2% of children [19,20], than in special studies using data linkages to birth and malformation registers [21-24], from 4.8% to 9.0%.

A different follow-up period (one year in the Malformation Register and undefined in the IVF statistics) can explain part of the discrepancy. The monitoring of congenital anomalies related to IVF is important, since previous studies [15,16,21,24] have reported a higher incidence of certain anomalies among IVF children. In this study the incidences of major congenital anomalies in the MBR and in the IVF research data were also higher than that observed for the general population (288/10 000 newborns). The cases of congenital anomalies found in this study will be investigated further with an adequate control group. For this kind of study, it is essential that the Malformation Register or other data sources which can be

linked to this register collects complete background information on infertility and its treatment.

Even though the IVF children in the different data sources were not the same children, most of the data in the two routine IVF data sources were comparable to the IVF research data. This suggests that drop-outs were not selected by outcome. One likely explanation is that children born after inseminations and ovulation inductions with increased risk for adverse perinatal outcome may be reported as IVF children in the MBR. Despite this drawback, our results give confidence that IVF services (IVF statistics) and most short-term infant outcomes of IVF newborns (IVF statistics and the MBR) can be reliably monitored in Finland without ad hoc data collection.

The existing routine Finnish data sources do not, however, answer all relevant study questions, such as explaining the variation in success rates by clinics in controlling for confounding factors. For these purposes, a nation-wide IVF register would be useful. Furthermore, such a register incorporating personal identification number would enable data linkages to other health outcome sources, for example getting more accurate information on congenital anomalies or to study the long-term health outcomes of treated women and children born as a result of IVF treatments.

The Finnish health information system is based on individual-level register data with the unique personal identification number that is given to all Finnish citizens and permanent residents. In general, the possibility to identify each individual with certainty improves the quality of any data collection and the utilisation of a single register, but also enables technically easy data linkages between various registers. There have been proposals to change the national data protection legislation so that a launch of an IVF register could be made possible [6,25], but the idea has not been explored thoroughly. Close co-operation between IVF clinics and the register-keeping organisation is required to ensure high quality register data, to minimise the extra work load in the IVF clinics and to protect the privacy and confidentiality of treated women.

IVF is highly specialised care given by a limited number of clinics, and therefore information can be gathered relatively easily. The case is different for other infertility treatments, since they are given more widely. Information on certain surgical procedures has been collected in the Finnish Hospital Discharge Register since 1986, but its use in questions related to infertility treatments is challenged by the limitations in the national classification on operative interventions. Data on inseminations and ovulation inductions has been collected for administrative purposes on an aggregated level [26], and regionally as ad hoc clinical information [27]. Since other infertility treatment methods including ovulation induction may have similar risks as IVF, it is important to monitor also these treatments and their outcomes.

Conclusions

The existing two IVF data sets, which are routinely collected by the Finnish health authorities, can be used in monitoring of IVF services and their short-term outcomes in general. Information on congenital anomalies as well as on long-term outcome of treated women and IVF children, however, has to be collected separately.

Abbreviations

ICSI intracytoplasmic sperm injection

IVF in vitro fertilisation

FET frozen embryo transfers

STAKES National Research and Development Centre for Welfare and Health

Competing interests

None declared.

Authors' contributions

MG planned the study, made the data analysis regarding IVF statistics, and drafted the article. RK and EH helped with the interpretation of results and writing process. TS made the data linkages and data analysis regarding the Medical Birth Register and the ad hoc data. All authors read and approved the final manuscript.

References

1. Nygren KG, Andersen AN: **Assisted reproductive technology in Europe, 1997. Results generated from European registers by ESHRE. European IVF-Monitoring Programme (EIM), for the European Society of Human Reproduction and Embryology (ESHRE).** *Human Reprod* 2001, **16:**384-391.
2. Gissler M, Teperi J, Hemminki E, Merilainen J: **Data quality after restructuring a national medical registry.** *Scand J Social Medicine* 1995, **23:**75-80.
3. Gissler M, Tiitinen A: **IVF Treatments and Their Outcomes in Finland in the 1990s.** *Acta Obstetr Gynaecol Scand* 2001, **80:**937-944.
4. Gissler M: *Administrative registers in health research – a cohort study of Finnish children born in 1987* 1999, **STAKES Research Report 97:**.
5. Gissler M, Ulander V-M, Hemminki E, Rasimus A: **Declining induced abortion rate in Finland: Data-quality of the Abortion Register.** *Int J Epidemiol* 1996, **25:**376-380.
6. Gissler M, Malin Silverio M, Hemminki E: **In-vitro fertilization pregnancies and perinatal health in Finland 1991–1993.** *Hum Reprod* 1995, **10:**1856-1861.
7. De Mouzon J, Lancaster P: **World Collaborative Report on In Vitro Fertilization. Preliminary data from 1995. International Working Group for Registers on Assisted Reproduction.** *J Assist Reprod Gen* 1997, **14:**251-264.
8. Teperi J: **A Multi-method Approach to the Assessment of Data Quality in the Finnish Medical Birth Registry.** *J Epidemiol Community Health* 1993, **47:**242-247.
9. Koudstaal J, Braat DDM, Bruinse HW, Naaktgeboren N, Vermeiden JPW, Visser GHA: **Obstetric outcome of singleton pregnancies**

after IVF: a matched control study in four Dutch university hospitals. *Human Reprod* 2001, **15:**1819-1825.
10. Hemminki E, Klemetti R, Rintapaavola M, Martikainen J: **Identifying exposures from drug reimbursement files: A study on unintended effects of in-vitro fertilization in Finland.** *Med Inform Internet Med* 2003, **28:**279-89.
11. Pihkala J, Hakala T, Voutilainen P, Raivio K: **Uudet suomalaiset sikiön kasvukäyrät.** *Duodecim* 1989, **105:**1540-1546.
12. EUROCAT: *European Surveillance of Congenital Anomalies* [http://www.eurocat.ulster.ac.uk/surveillance/]. As accessed January 15, 2004
13. Gissler M, Hemminki E: **The danger of overmatching in studies on the health of infants born after assisted conception.** *Eur J Obstetr Gynecol* 1996, **69:**73-75.
14. Klemetti R, Gissler M, Hemminki E: **Comparison of perinatal health of children born from in vitro fertilization in Finland in the early and late 1990s.** *Human Reprod* 2002, **17:**1755-1761.
15. Koivurova S, Hartikainen A-L, Sovio U, Gissler M, Hemminki E, Järvelin M-R: **Neonatal outcome and congenital malformations in children born after in vitro fertilization.** *Human Reprod* 2002, **17:**1391-1398.
16. Hansen M, Kurinczuk J, Bower C, Webb S: **The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilization.** *N Engl J Med* 2002, **346:**727-730.
17. NOMESCO: *Health Statistics in the Nordic Countries 1999 Nordic Medico-Statistical Committee 61. Copenhagen*; 2001.
18. Gissler M, Ollila E, Teperi J, Hemminki E: **Impact of induced abortions and statistical definitions on perinatal mortality figures.** *Pediatr Perinat Epidemiol* 1994, **8:**391-400.
19. Hurst T, Lancaster P: **Assisted conception Australia and New Zealand 1999 and 2000.** *AIHW Cat. No. PER 18. Australian Institute of Health and Welfare. National Perinatal Statistics Unit (Assisted Conception Series N. 6). Sydney* 2001.
20. Anthony S, Buitendijk SE, Dorrepaal CA, Lindner K, Braat DDM, den Ouden AL: **Congenital malformations in 4224 children conceived after IVF.** *Hum Reprod* 2002, **17:**2089-2095.
21. Bergh T, Ericson A, Hillensjö T *et al.*: **Deliveries and children born after in-vitro fertilisation in Sweden 1982–95: a retrospective cohort study.** *Lancet* 1999, **354:**1579-1585.
22. Westergaard HB, Tranberg Johanssen AM, Erb K, Nyboe Andersen A: **Danish National In-Vitro Fertilization Registry 1994 and 1995: a controlled study of births, malformations and cytogenetic findings.** *Hum Reprod* 1999, **14:**1896-1902.
23. Ericson A, Källén B: **Congenital malformations in infants born after IVF: a population-based study.** *Hum Reprod* 2001, **16:**504-509.
24. Hansen M, Kurinczuk J, Bower C, Webb S: **The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilization.** *N Engl J Med* 2002, **346:**727-730.
25. Hemminki E: **When research knowledge is unwelcome: studying the health effects of in vitro fertilization.** *J Health Services Research & Policy* 2002, **7:**4-9.
26. STAKES: *Stakesin työryhmän ehdotus hedelmättömyyshoitoa koskevien lakiehdotusten valmistelun kiirehtimiseksi (A proposal by a STAKES working group to accelerate the preparation of legislative proposals on fertilisation treatments, In Finnish)* 1996, **Aiheita 14:**40-47.
27. Nuojua-Huttunen S, Gissler M, Martikainen H, Tuomivaara L: **Obstetric and perinatal outcome of pregnancies after intrauterine insemination (IUI).** *Human Reprod* 1999, **14:**2110-2115.

Pre-publication history

The pre-publication history for this paper can be accessed here:

http://www.biomedcentral.com/1472-6947/4/3/prepub

Publish with **BioMed Central** and every scientist can read your work free of charge

"BioMed Central will be the most significant development for disseminating the results of biomedical research in our lifetime."

Sir Paul Nurse, Cancer Research UK

Your research papers will be:

- available free of charge to the entire biomedical community
- peer reviewed and published immediately upon acceptance
- cited in PubMed and archived on PubMed Central
- yours — you keep the copyright

Submit your manuscript here:
http://www.biomedcentral.com/info/publishing_adv.asp

BioMedcentral