

# Live and stillborn very low birthweight infants in Switzerland: comparison between hospital based birth registers and the national birth register

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## Summary

**Background and aim:** Perinatal and infant mortality rates are considered key indicators of medical care. The aim of this investigation was to examine how representative and reliable the official national figures of Switzerland are by comparing them with the data in local birth registers.

**Methods:** 124 of 156 maternity hospitals in Switzerland, catering for about 80% of all newborn infants, participated in the study. The hospital based birth registers were screened for the years 1996 and 2000 for live and stillborn infants weighing less than 1500 g. These data were matched with the data in the official register (federal office for statistics).

**Results:** in 1996 a total of 753 newborn infants and in 2000 820 infants weighing between 300 and 1499 g were officially registered. In the hospital based registers in 1996 101 additional infants and in 2000 94 infants were identified that had not

been officially registered; 31 of these were stillborn before 24 completed weeks. Infants registered only locally had lower birth weight and lower gestational age than those recorded in both registers.

**Conclusion:** In Switzerland a significant number of very low birth weight infants who died soon after birth are not officially registered. If these infants are included, the national perinatal mortality rate would increase from 6.9‰ to 8.0‰. Reasons for underreporting are unclear but may be due to varying definitions of stillbirth and different lower limits for reporting in various cantons. We suggest adopting the WHO-rules for reporting all births and to include gestational age, head circumference, Apgar scores and umbilical artery pH in the national birth register.

**Key words:** *liveborn; stillborn; mortality; very low birth weight infant*

## Introduction

Perinatal and neonatal mortality rates are considered key indicators of quality of medical care and are used to compare the social and economic development of different countries [1]. However, there are several reports questioning the reliability of these statistical figures [2-4]. In Switzerland selected data on all live and stillborn infants after 6 months of gestation (interpreted today as more than 24 completed weeks) have to be communicated to the authorities. These data are transmitted anonymously to the federal office for statistics that generates population-based statistics at regular intervals [5]. No previous investigations of the reliability of these figures have been performed.

The purpose of this paper is to compare infants with birth weight <1500 g registered officially with those registered in the local birth registers in each hospital. We wanted to know how many infants have not been reported to the authorities and the characteristics of the unregistered infants. We also wanted to find out whether there was a difference between the years 1996 and 2000 and whether there was additional information available in the local birth registers which would be worthwhile collecting for the whole country. Finally we have examined how this postulated under-reporting affected the national perinatal and neonatal mortality rate.

## Methods

All 191 women's hospitals in Switzerland (including 9 birth homes run by midwives) were invited to participate in the study. Live and stillborn infants with a birthweight between 300 and 1499 g, born during the years 1996 and 2000, were included. An additional group including all infants weighing 1500 g or more born before 32 completed weeks was also recruited from the local birth registers as only the information of gestational age was available there. The data for each infant was collected manually from birth registers in the delivery room or extracted from an electronic hospital database. The following data was collected: birth date, sex, birth order for multiple births, gestational age, birth weight, length and head circumference at birth, umbilical artery pH, Apgar scores at 1, 5 and 10 minutes, malformations, death before, during or after birth, place of birth; nationality and year of birth of the mother.

The federal office of statistics provided the following data for stillborn and liveborn infants 1996 and 2000: Birth date and hour, sex, weight and length at birth, birth order for multiple births, administrative district (but not birth place), birth year, nationality and domicile of the mother.

### *Matching between local birth registers and official birth register*

Matches between data in the local birth registers and the records in the federal office of statistics were estab-

lished using the criteria sex, date of birth and administrative district. In a second step, matching criteria were relaxed to a) sex and birth date, b) birth date and administrative district, and c) birth date and birth weight. All of these matches could be rendered plausible using the variables birth weight and body length as well as characteristics of the mother.

### *Matching birth records with death records*

To find out how many of the liveborn infants had died before age 1 year, birth records of the federal office of statistics were matched with death records using probability record linkage. Given the limited number and the high risk profile of these infants, we decided to use only sex and date of birth as fixed matching criteria and that other criteria could be dealt with based on probabilities. This method, providing an estimate of the *a posteriori* probability of a correct match for each candidate pair of a birth and a death record, is described in an appendix.

Written permission was obtained from the national expert committee for professional confidentiality in medical research to collect data anonymously on stillborn and very low birth weight liveborn infants for the years 1996 and 2000.

## Results

124 hospitals participated in the study representing 76% of all births in the year 1996 and 84% of all births in the year 2000 (table 1). 35 hospitals (9% of all births in 1996 and 1% of all births in 2000) had been closed and therefore no data could be obtained. 32 hospitals (representing 15% of all

births in both years) did not want to participate or did not reply even after two reminders.

33 hospitals (representing 8% of births in 1996 and 9% in 2000) indicated that they had had no stillborn or liveborn infants below 1500 g. 60 hospitals (38% in 1996 and 40% in 2000) had checked

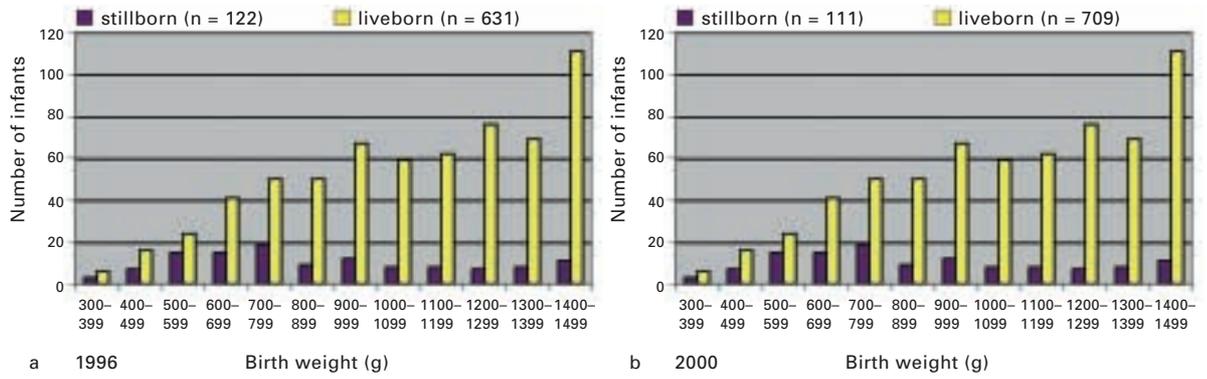
**Table 1**

Maternal and neonatal characteristics and survival in infants with birth weight less than 1500 g included in the national register: comparison between year 1996 and 2000.

		1996		2000		2000		2000	
		stillborn	%	liveborn	%	stillborn	%	liveborn	%
total population	birthweight 0–7000 g	309		83'617		283		79'656	
birth weight	birthweight 300–1499 g	122	100%	631	100%	111	100%	709	100%
	10th, 50th, 90th percentile	515, 800, 1380		640, 1100, 1440		510, 780, 1330		540, 1060, 1420	
	<500 g	10	8%	22	3%	8	7%	58	8%
died	within 24 hours			104	16%			115	16%
	within 7 days			146	23%			153	22%
	within 28 days			164	26%			175	25%
	within 365 days			204	32%			187	26%
survived 365 days			427	68%			522	74%	
birth length (cm)	10th, 50th, 90th percentile	30, 34, 41		31, 37, 42		30, 34, 40		31, 37, 42	
	n <30 cm	11	9%	35	6%	11	10%	43	6%
	unknown	0	0%	4	1%	0	0%	0	0%
sex	male	70	57%	311	49%	52	47%	343	48%
	female	52	43%	320	51%	59	53%	366	52%
nationality of the mother	Swiss	79	65%	422	67%	71	64%	418	59%
	other	43	35%	209	33%	40	36%	291	41%
age of the mother	10th, 50th, 90th percentile	24, 30, 35		24, 30, 37		24, 31, 38		24, 31, 37	

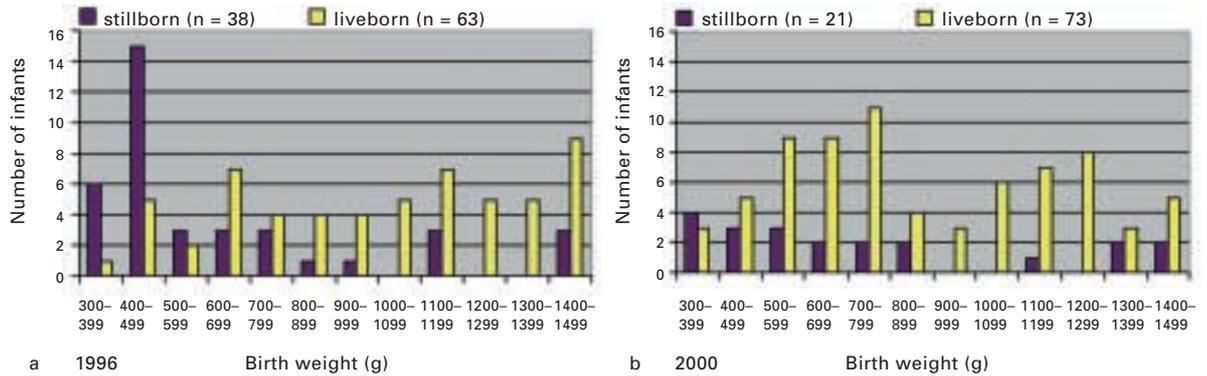
**Figure 1**

Newborn infants with birth weight 300–1499 g registered officially. a: 1996; b: 2000.



**Figure 2**

Newborn infants with birth weight 300–1500 g not registered officially. a: 1996; b: 2000.



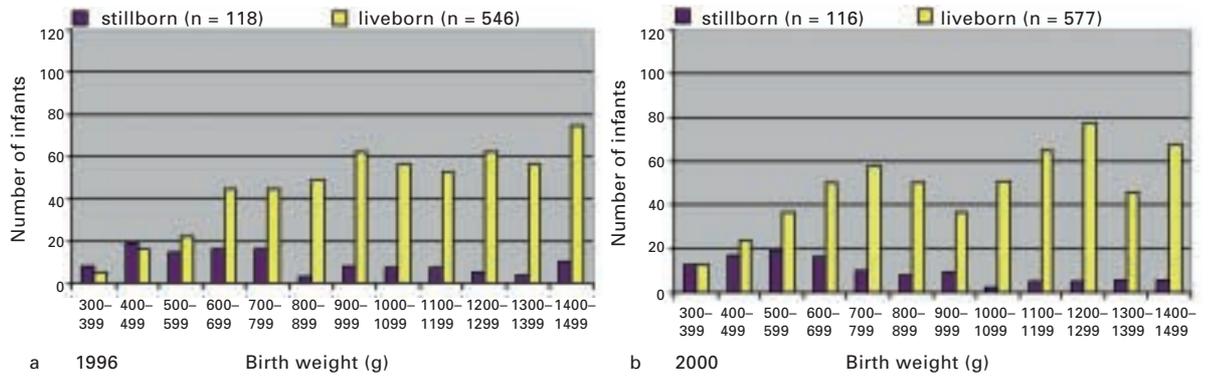
**Table 2**

Characteristics in infants with birth weight less than 1500 g included in the local registers: Comparison between year 1996 and 2000.

		1996		2000		1996		2000	
		stillborn	%	liveborn	%	stillborn	%	liveborn	%
birth weight	unknown	5		4		6		14	
	1–299 g	11		0		11		3	
	<b>300–1499 g</b>	<b>118</b>		<b>546</b>		<b>116</b>		<b>577</b>	
	10th, 50th, 90th percentile	418, 700, 1326		550, 1000, 1420		390, 650, 1290		560, 1040, 1400	
	<500 g	27	23%	21	4%	30	26%	37	6%
gestational age (weeks)	10th, 50th, 90th percentile	22, 26, 33		24, 29, 33		23, 26, 32		24, 28, 33	
	<24	31	26%	33	6%	31	27%	58	10%
	unknown	3	3%	1	0%	1	1%	6	1%
birth length (cm)	10th, 50th, 90th percentile	26, 32, 40		29, 36, 41		26, 32, 40		29, 36, 40	
	n <30 cm	2	2%	32	6%	30	26%	54	9%
	unknown	4	3%	59	11%	20	17%	75	13%
head circumference	10th, 50th, 90th percentile	21, 23, 27		23, 27, 30		20, 23, 28		23, 27, 30	
	unknown	103	87%	303	55%	81	70%	262	45%
sex	male	64	54%	285	52%	52	45%	271	47%
	female	48	41%	257	47%	64	55%	305	53%
	unknown	2	2%	3	1%	0	0%	1	0%
multiple birth	twin	19	16%	85	16%	15	13%	87	15%
	triplet	0	0%	24	4%	0	0%	19	3%
Death in delivery room			65	12%			81	14%	
Severe malformation		18	15%	23	4%	16	14%	18	3%
pH in umbilical artery	<7.15			51/367	14%			52/435	12%
Apgar-score 1 min	<5			131/416	31%			210/458	46%
Apgar-score 5 min	<7			99/4112	24%			144/458	31%

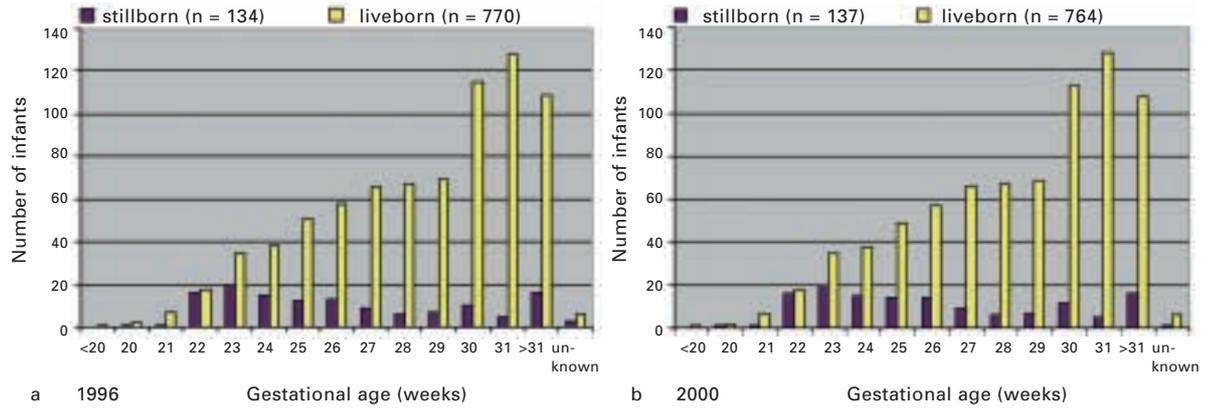
**Figure 3**

Newborn infants with birth weight <1500 g in hospital birth registers. a: 1996; b: 2000.



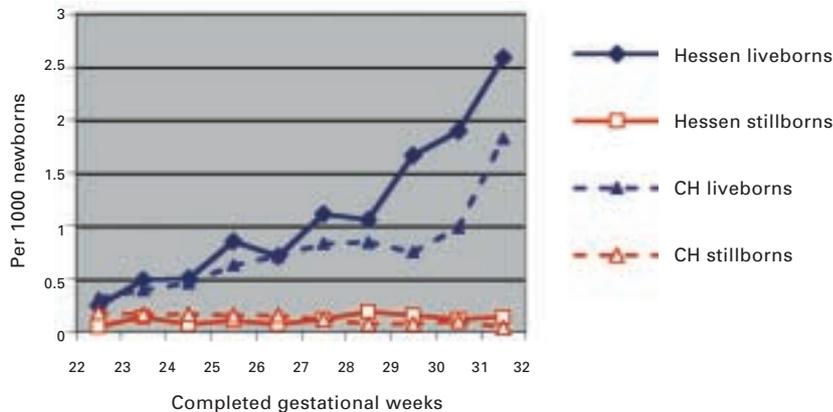
**Figure 4**

Newborn infants with gestational age <32 completed weeks in hospital birth registers. a: 1996 (224 liveborn and 16 stillborn infants weighing >1499 g are included that are not considered for the other figures and tables); b: 2000 (187 liveborn and 21 stillborn infants weighing >1499 g are included that are not considered for the other figures and tables).



**Figure 5**

Liveborn and stillborn rate per gestational week in Hessen and Switzerland for the year 2000. The liveborn rate is almost double for 29 to 31 weeks gestation in Hessen than in Switzerland, whereas the stillborn rates are similar in both countries.



their registers using their own staff and sent the data to us. 31 hospitals were visited by one author (MM) to obtain the anonymous data (29% in 1996 and 35% in 2000).

*Infants registered in the national register*

In the year 1996 753 (0.9%) of 83'316 infants and in 2000 820 (1.03%) of 78'741 infants registered by the federal office of statistics had a birthweight between 300 and 1499 g and therefore were included in the study (table 1, figure 1).

In 1996 122 infants (16%) and in 2000 111 (14%) of the low birthweight infants were stillborn. The stillborns had lower birthweight but did not differ in other aspects from the liveborns. Length at birth and sex of the infant, nationality, age and marital status of the mother did not differ between 1996 and 2000. Mortality of liveborn in-

fants was 16% (2000: 16%) within 24 hours, 26% (25%) within 28 days and 32% (26%) within one year. 427 [68%] (522 [74%]) infants survived the first year.

**Infants registered in the local registers**

In 1996 664 infants with birthweight of 300 to 1499 g and in 2000 693 infants were collected from the birth records in the hospitals (table 2, figure 3).

An additional 11 (2000: 14) infants with birthweight between 1 and 299 g and 9 (20) with unknown birthweight were not included. In 1996 118 infants (18%) and in 2000 116 (17%) of the very low birthweight infants were stillborn. The stillborns had lower weight, shorter length and smaller head circumference at birth than liveborns but did not differ in respect to sex, multiple birth, nationality and age of the mother. 15% of stillborn and

4% of liveborn infants had severe malformations. pH in umbilical artery, Apgar scores at 1, 5 and 10 minutes were recorded in 67% to 79% with an increasing trend from 1996 to 2000. Low Apgar scores (4 or lower at 1 min, 6 or lower at 5 min) increased from 1996 to 2000. Perinatal acidosis (umbilical artery pH <7.15) was documented in 14% of liveborns in 1996 and in 12% in 2000 (table 2).

In the local registers for the year 1996 an additional cohort of 224 (2000: 187) liveborn and 16 (2000: 21) stillborn infants weighing >1499 g were found. The distribution per gestational week of the two cohorts combined is displayed in figure 4.

#### **Infants registered in local registers but not in the official register**

101 infants (15%) in 1996 and 94 (14%) infants in 2000 registered in local registers could not be matched with an infant in the official register. 38% (22%) of those were stillborn. 27 (27%) in 1996 and 15 (17%) in 2000 had birthweight be-

tween 300 and 500 g. The distribution per birthweight of these infants is shown in figure 2.

#### **Comparison of Switzerland with Hessen**

In the year 2000 Switzerland had 78'458 liveborns and 283 stillborns (0.36%), whereas Hessen registered 57'707 liveborns and 192 stillborns (0.33%) in the year 2000 [6]. The relative frequency for each completed gestational week is shown in figure 5.

#### **Perinatal mortality and infant mortality**

The official perinatal mortality for Switzerland is 6.9 per 1000 stillborn and liveborn infants and the infant mortality (death of liveborn infants within first year) is 4.7 per 1000 liveborns [7]. If those infants registered in the local registers and not announced to the authorities are included, perinatal mortality increases to 8.0 and infant mortality to 5.0 per 1000.

## **Discussion**

### **Matching procedure**

For the matching procedure several assumptions based on a previous analysis [5] were made. Varying the *a priori* probability of a correct match between 0.1 (lower limit) and 0.4 (upper limit), and the critical *a posteriori* probability threshold from 0.99 to 0.95 had relatively little effect on the number of matches that were considered correct.

### **Reasons for under-reporting**

Only about 75% of all infants with a birthweight below 1500 g could be found in both registers. About 12% being registered only in the hospital based registers and about 13% registered only in the national register. Under-reporting of stillborn and extremely immature liveborn infants has been previously described in the literature [2, 8, 9].

There is no obvious explanation for the infants not reported to the civil authorities. These infants have lower birth weight than those reported and those found only in the national register. It is therefore highly unlikely that the discrepancy is due solely to imperfect matching.

Reasons for under-reporting may include uncertainty about which infants have to be included. In some cantons the lower limit for reporting is 30 cm length, in others 500 g, in others 24 completed weeks for stillborn and no limit for liveborn infants.

Parents, midwives or doctors may wish to avoid the administrative burden of a very tiny liveborn infant who died soon after birth. According to Swiss Civil Rights (Article 46) all liveborn infants have to be reported to the authorities and included in the family booklet. The wish to avoid this registration may be another reason for not report-

ing. Some liveborn infants with lethal malformation after induction of labor may have not been reported or reported as stillborn. However, the number of liveborn infants that are registered as stillborns is small (less than 15 infants per year).

The 259 infants in 1996 and 334 infants in 2000 registered in the national birth register that could not be traced in the hospital based birth registers may be born in the 61 hospitals not participating in the study. However, a comparison between the birth districts of these infants showed that this could only be a minority. Also home birth can practically be excluded as almost all women who deliver a stillborn or a very immature infant at home are transferred to a hospital after delivery.

### **Comparison between 1996 and 2000**

The number of liveborn infants with birth weight below 1500 g increased from 1996 to 2000 in both registers but the number of stillborns did not change. Such an increase in very low birth weight infants has also been reported from other industrialised countries. As the total number of liveborn infants decreased in the same time from 83'316 to 78'741 the relative increase in very low birth weight infants is even more important (from 7.6‰ in 1996 to 9.0‰ in 2000). The characteristics of liveborn and stillborn infants did not differ between 1996 and 2000.

### **Gestational age**

Traditionally population statistics are based on birth weight rather than gestational age, mainly because birth weight has been more reliable than gestational age calculated from the last menstruation. However with the introduction of routine

ultrasound screening in the first trimester of pregnancy the assessment of gestational age has become much more reliable [10]. Gestational age is a better prognostic factor for mortality and later outcome than birth weight. Therefore we collected gestational age from the local registers and displayed the distribution in figure 4. The number of liveborn infants increases with a marked step of about 50% from 29 to 30 weeks in both years, 1996 and 2000. This step increase is not correlated to the birth weight distribution. It is also seen in the data from Hessen starting one week earlier, eg, between 28 and 29 weeks (figure 5). This step increase may reflect a threshold for induced delivery to save infants with intrauterine stress.

### Comparison with other countries

Comparison of perinatal and neonatal mortality rates require uniform definition of stillbirth and of the lower limit for both stillborn and liveborn infants. The legal definition in Switzerland for liveborn infants includes breathing and heart beat whereas the WHO recommends as additional criteria "pulsation of the umbilical cord" and "definite movement of voluntary muscles". In Switzerland there is no lower limit for registration for liveborns, the WHO defines 22 completed weeks, some countries 16 weeks, some 24 and some as many as 28 weeks. The lower limit for registration of stillborns in Switzerland is 6 months (corresponding to 24 completed weeks) whereas the WHO gives 22 weeks or 500 g, in some countries it is 400 g, 16 weeks or 30 or 35 cm for length at birth. Some cantons in Switzerland continue to use the 30 cm limit for length.

There are only few published data on stillborn and liveborn rates compared to birthweight and even fewer compared to gestational age. Figure 5 compares the Swiss data with those from Hessen (Germany) [6]. Both regions are comparable re-

garding population size and standard of living. In both regions the stillborn rate is similar and remains stable from 22 to 32 gestational weeks. However, there is a higher liveborn rate in Hessen than in Switzerland. Under-reporting may explain only part of this difference. The almost double rate of preterm infants above 28 gestational weeks in Hessen may be due to different management of women with preterm labor. Further investigation of this difference including the infants' outcome is indicated and could be a clue for prevention of preterm birth.

### Effect of under-reporting on perinatal and infant mortality

Perinatal and infant mortality vary considerably within industrialised countries. Perinatal mortality in Switzerland increases from 6.9‰ to 8.0‰ if infants not reported to the national register are included. Thus if industrialised countries are ranked by perinatal mortality, Switzerland moves from one of the first positions to the middle.

Differences between countries may be due to under-reporting, different definitions for stillbirth and for lower limits for reporting. There may also be differences in the definition of perinatal mortality, the denominator being 1) only livebirths or 2) stillbirths and livebirths. The OECD recommends definition 1) whereas the WHO gives definition 2) [11].

### Additional data for the birth register

The majority of local registers contain additional information, such as gestational age, Apgar scores, umbilical artery pH and head circumference. Moreover, the number of recorded parameters has increased from 1996 to 2000. Inclusion of these data in the national register is essential for documenting quality of care and for comparison of the Swiss newborn population with other countries.

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## Conclusion

The national statistics on perinatal and infant mortality underestimate the real situation. Based on our inquiry in the hospital based birth registers the perinatal mortality rate in Switzerland including stillborn infants and infants dying within seven days of life (168 hours) reaches 8.0‰ compared with the official 6.9‰.

With increasing interest in infants at the limit of viability, the lower limit for official registration becomes essential for reliably documenting mortality and survival rates. We recommend redefining the rules for registration using the same lower limit for stillborn and liveborn infants, namely 22 completed gestational weeks and if this information is not available a birthweight of 300 g.

Gestational age, as well as Apgar scores, umbilical artery pH and head circumference at birth

should be registered nationally in addition to date of birth, hour of birth, sex and birthweight. On the other hand, length at birth could be dropped, as it is the most imprecise measurement and possesses less prognostic value than the other proposed data.

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## Appendix: Description of record linkage

Let  $D_i$  denote the value of the  $i$ -th matching variable of a given death record  $D$  and let  $B_i$  denote the corresponding value in a randomly selected birth record. Then  $P(B_i = D_i)$ , the probability of  $B_i = D_i$ , may be estimated by the relative frequency of all birth records  $B'$  satisfying  $B'_i = D_i$ . To be able to compute joint probabilities of agreements and disagreements in several matching variables, we assumed that all matching variables were mutually independent among birth records.

To see how joint probabilities were estimated, we assume a situation with only three matching variables (eg, district of birth, hour of birth and age of mother) and with  $B_1 = D_1$ ,  $B_2 \neq D_2$  and  $B_3 = D_3$ . Let  $p_1$ ,  $p_2$  and  $p_3$  denote the relative frequencies of  $B'_1 = D_1$ ,  $B'_2 = D_2$  and  $B'_3 = D_3$ , respectively, among all birth records  $B'$ . Then  $P(B_1 = D_1, B_2 \neq D_2 \text{ and } B_3 = D_3)$  would be estimated by  $p_1 \cdot (1 - p_2) \cdot p_3$ . This probability is denoted by

**P (observed agreement between B and D | random pair),**

to avoid complicated notation.

However, if  $(B, D)$  were known to be a correct match, then the probability  $P(B_i = D_i)$  would be close to 1, since a disagreement would only occur by chance. This probability can be estimated by focusing on pairs  $(B, D)$  likely to represent correct matches. By determining the relative frequency of  $B_i = D_i$  among such pairs, the probability

**P (observed agreement between B and D | correct match)**

is then estimated in analogy to the probability  $P(\text{observed agreement} | \text{random pair})$ . If  $(B, D)$  is a pair of records, then

**Q (B; D) = P ([B, D] = correct match | obs. agreement between B and D)**

can be estimated using the the Bayes formula:

$$Q = \frac{Q \cdot P(\text{obs. agreement between B and D} | \text{correct match})}{q \cdot P(\text{obs. agreement between B and D} | \text{correct match}) + (1 - q) \cdot P(\text{obs. agreement betw. B and D} | \text{random pair})}$$

where  $q$  is a suitable estimate of the *a priori* probability of a correct match. Here, we assumed that

**P (obs. agreement betw. B and D | false match) = P (obs. agreement betw. B and D | random pair),**

which requires that the number of candidate birth records is sufficiently large.

A first estimate of  $q$  was obtained by considering the fraction of eligible pairs  $(B, D)$  with a very high agreement in the matching variables. For a pair  $(B, D)$  to be eligible, we required agreement in the matching variables sex and birth date. On the basis of our decision to accept a given eligible pair  $(B, D)$  as a correct match if  $Q(B, D) > 0.99$ , we found that  $q = 0.25$  entailed that about 25% of eligible pairs  $(B, D)$  satisfied  $Q(B, D) > 0.99$ . Therefore, we considered  $q = 0.25$  an appropriate choice. In case of multiple acceptable matches, the match with the highest probability would have been chosen. However, since these cases occurred exclusively in multiplets, the respective matching probabilities were always equal and record linkage had to be done manually.