Received: 22 August 2022 | Revised: 28 October 2022 | Accepted: 8 November 2022

DOI: 10.1002/bdr2.2133

Birth Defects Research | Society for Birth Defects Research & Prevention | WILEY

RESEARCH ARTICLE

The quality and the accuracy of codes for terminations of pregnancy for fetal anomalies recorded in hospital databases in three countries in northern Europe

Ester Garne[1] | **Stine Kjaer Urhoj**[1,2] | **Marian Bakker**[3] | **Mika Gissler**[4,5] | **Joanne Given**[6] | **Anna Heino**[5] | **Elisabeth Limb**[7] | **Maria Loane**[6] | **Hermien de Walle**[3] | **Joan Morris**[7]

[1]Department of Paediatrics and Adolescent Medicine, Lillebaelt Hospital, University Hospital of Southern Denmark, Kolding, Denmark

[2]Section of Epidemiology, Department of Public Health, University of Copenhagen, Copenhagen, Denmark

[3]Department of Genetics, University Medical Center Groningen, University of Groningen, Groningen, The Netherlands

[4]Karolinska Institutet, Department of Molecular Medicine and Surgery, Stockholm, Sweden

[5]Department of Knowledge Brokers, THL Finnish Institute for Health and Welfare, Helsinki, Finland

[6]Faculty of Life and Health Sciences, Ulster University, Belfast, UK

[7]Population Health Research Institute, St George's, University of London, London, UK

Correspondence
Ester Garne, Department of Paediatrics and Adolescent Medicine, Lillebaelt Hospital, University Hospital of Southern Denmark, Kolding, Denmark.
Email: ester.garne@rsyd.dk

Funding information
Horizon2020, Grant/Award Number: 733001

Abstract

Background: The number of terminations of pregnancy for fetal anomalies in Europe (TOPFA) has increased over recent decades. Therefore, it is important that TOPFAs, in addition to all other birth outcomes, are included in the surveillance of congenital anomalies and in studies on possible teratogenic risks of pregnancy exposures. The aim of this study was to evaluate the quality and the accuracy of codes identifying TOPFA cases in hospital databases.

Methods: TOPFA cases recorded in three EUROCAT congenital anomaly registries (Finland, 2010–2014; Funen in Denmark, 2005–2014; and northern Netherlands, 2013–2014) were linked to hospital databases using maternal IDs.

Results: A total of 2,114 TOPFA cases over the study period were identified in the registries and 2,096 (99%) of these pregnancies were identified in the hospital databases. An end of pregnancy code was present for 91% of the cases and a code for a congenital anomaly was present for 82% (with some differences across registries). The proportion of TOPFA cases with a code for a specific congenital anomaly was <50% for cases with a structural anomaly (range 0%–50%) and 70% for cases with a chromosomal anomaly.

Conclusion: Hospital databases have limited information or codes to identify TOPFAs for specific anomalies and the data are not detailed enough for surveillance of congenital anomalies or for studies analyzing pregnancy exposures and risk of congenital anomalies. However, hospital data may be used to identify the occurrence of a TOPFA to enable more detailed information to be obtained from the medical records.

KEYWORDS

accuracy of codes, congenital anomaly, hospital databases, surveillance, termination of pregnancy for fetal anomaly

1 | INTRODUCTION

It is important that all fetuses with congenital anomalies are included in surveillance of congenital anomalies and in studies on possible teratogenic risks of pregnancy exposures (Boyle et al., 2018; Charlton, Weil, Cunnington, & de Vries, 2010; Garne et al., 2010). As terminations of pregnancy after prenatal diagnosis of congenital anomaly (TOPFA) are more frequent among fetuses with severe congenital anomalies, a significant proportion of these anomalies will be excluded from surveillance, if based on live born infants and fetal deaths only. Initially, case ascertainment in the European surveillance of congenital anomaly (EUROCAT) registries depended on individual case identification, either sent to the registry by clinicians or actively searched for in clinical records, whereas in recent years it is common for registries to request downloads of electronic healthcare records to identify potential cases (Astolfi et al., 2016; Greenlees et al., 2011). There are increasing public and ethical concerns about granting access to identifiable medical records and therefore focus has turned to the possibility of using routinely collected data from electronic hospital databases for surveillance of congenital anomalies.

In hospital databases the pregnant woman is the index patient; hence, the TOPFA procedure is coded under the maternal identification number and TOPFA fetuses do not have their own identity in the health care system. The prenatal diagnosis before the TOPFA may have been coded in relation to maternal contacts with the health system, but ICD-9 and ICD-10 have limited codes for this purpose. In ICD-10, there are codes in subchapter O35 such as O350: "Maternal care for (suspected) central nervous system malformation in fetus" and O351: "Maternal care for (suspected) chromosomal abnormality in fetus". The final diagnosis may not be known before results of examinations performed after TOPFA are available (genetic tests, postmortem examinations). These diagnoses will not be visible in the hospital databases as there is no identity related to these diagnoses. With a very early diagnosis of an anomaly such as anencephaly or Down syndrome, the termination procedure may just be coded as O04: "legal termination of pregnancy" without mentioning any anomalies. In twin pregnancies, a prenatal diagnosis of a severe anomaly in one fetus may be followed by a fetal reduction procedure. The procedure code will usually be given for an outpatient contact for the mother during the pregnancy. There is neither an ICD-9 nor ICD-10 code for this situation and the following birth of the co-twin may be recorded as a birth of a healthy singleton.

The aim of this EUROlinkCAT study is to evaluate the quality and the accuracy of codes identifying TOPFA cases in hospital databases and to evaluate the quality of these codes for specific congenital anomalies.

2 | MATERIALS AND METHODS

Three EUROCAT registries (Finland, Funen–Denmark, and northern Netherlands) able to link data on TOPFA cases to their hospital databases as part of the EUROlinkCAT study (Morris et al., 2021) were included in this study.

Cases were all TOPFA cases recorded in each EUROCAT registry for a specific study period: birth years 2005–2014 in Funen, Denmark, 2010–2014 in Finland, and 2013–2014 in northern Netherlands (Table 1). The short period in northern Netherlands was due to a new database system starting in 2012.

EUROCAT registries have coded congenital anomalies in ICD-10 since 2005, except for Finland who used ICD-9. All registries have standardized congenital anomaly subgroups based on EUROCAT definitions. From the EUROCAT registries, we obtained information on gestational age (GA) at TOPFA/birth and the EUROCAT congenital anomaly subgroups. The date of the TOPFA and the gestational length at TOPFA recorded in the EUROCAT registries were used to estimate the date of conception.

The maternal ID for each TOPFA case was linked to the hospital discharge databases. The hospital databases

TABLE 1 Number of TOPFA cases per EUROCAT registry and distribution of GA

Registry	Birth years	Number of TOPFA	GA < 15 weeks	GA 15–21 weeks	GA +22 weeks
Denmark, Funen	2005–2014	323	155 (48%)	155 (48%)	13 (4%)
Finland	2010–2014	1,694	639 (38%)	775 (46%)	280 (17%)
Northern Netherlands[a]	2013–2014	95	30 (32%)	30 (32%)	30 (32%)
Total		2,114	824 (39%)	960 (45%)	325 (15%)

Note: Statistically significant differences between registries $p < .001$.

Abbreviations: GA, gestational age; TOPFA, termination of pregnancy for fetal anomaly.

[a]Numbers rounded to nearest 5. No cases with unknown GA.

in the three countries were coded in ICD-10 in the years included in the study. From the hospital discharge databases, we obtained information on all diagnosis (ICD codes) recorded under the maternal ID during the period of the pregnancy (from estimated date of conception to 2 weeks after the end of the pregnancy) and any procedure codes for fetal reduction. The 2 weeks period after the date of the TOPFA was added to be sure that all women were discharged after the TOPFA as complications could occur. Diagnoses for late TOPFA registered as stillbirth or livebirth in vital statistics were also included during the period of the pregnancy. For Finland and Funen, Denmark the data included both inpatient diagnosis and outpatient diagnosis and procedure codes. Data from northern Netherlands included inpatients only.

Pregnancies ending in TOPFA were identified in the hospital databases using four different categories: a pregnancy code (ICD-10 codes O00-O84, Z34, Z35, Z36, and Z37), with an end of pregnancy code (ICD-10 codes O00-O06, O80-O84, Z37, and Z38), with any congenital anomaly code (ICD-10 codes in Q chapter) and/or with a subgroup-specific congenital anomaly code (examples neural tube defect or congenital heart defect [CHD]; see Table 1). The term "code" is used for any code in ICD-9 or ICD-10 used in the hospital databases.

A common data model was developed and the local variables in hospital discharge records in each country were standardized and mapped to this common data model. Analysis scripts were written to obtain analytic and aggregate data on outcomes from each registry (Morris et al., 2021). GA at outcome was categorized according to completed weeks into three categories (<15, 15–21, and 22+ weeks).

All data from northern Netherlands were rounded to the nearest five due to restrictions on small numbers.

3 | STATISTICAL ANALYSIS

Overall estimates were obtained by aggregating the data from the three registries. The 95% confidence intervals were calculated on the aggregated data using exact binomial confidence intervals. Chis-squared tests were used to compare the distributions of GA across registries. Data on specific congenital anomalies from northern Netherlands was not available for analysis due to the restrictions on small numbers.

4 | RESULTS

During the study period there were 323 TOPFA recorded in Funen, Denmark, 1,694 TOPFA cases in Finland and 95 TOPFA cases in the registry of northern Netherlands. Distribution of GA is presented in Table 1. There were some differences by registry in the distribution of GA with lower GA in Funen Denmark and higher GA in northern Netherlands ($p < .001$). The number of TOPFA cases with successful linkage of the maternal data to the hospital databases were 320 in Funen Denmark (99%), 1,686 in Finland (99.5%), and 90 in northern Netherlands (94.7%; Table 2).

In Funen, Denmark, and Finland all linked TOPFA cases had a pregnancy code in the hospital databases. For northern Netherlands only 78% of the TOPFA cases had a pregnancy code. An end of pregnancy code was present in 97% of the TOPFA cases in Funen, Denmark, 90% in Finland, and 78% in northern Netherland. Overall, there was a code for any congenital anomaly present in the hospital databases for 82% of the cases with differences by registry: 48% (95% CI: 42%–53%) in Funen, Denmark, 67% (95% CI: 56%–76%) in northern Netherland, and 90% (95% CI: 88%–91%) in Finland (Table 2).

TABLE 2 Presence of pregnancy codes and codes for congenital anomaly in the hospital databases

Registry	Number of TOPFA cases	Linked TOPFA cases to maternal ID (% linkage)	Any pregnancy code present (%)	Pregnancies with an end of pregnancy code (%)	Any code for congenital anomaly present (%)
Denmark, Funen	323	320 (99.1%)	320 (100%)	308 (97%)	152[a] (48%)
Finland	1,694	1,686 (99.5%)	1,686 (100%)	1,524 (90%)	1,512 (90%)
Northern Netherlands[b]	95	90 (94.7%)	70 (78%)	70 (78%)	60 (67%)
Total	2,114	2096 (99.1%)	2076 (99%)	1902 (91%)	1724 (82%)

Note: Statistically significant differences between registries $p < .001$.
Abbreviation: TOPFA, termination of pregnancy for fetal anomaly.
[a]Including diagnosis from 12 TOPFA fetuses registered as livebirths.
[b]Numbers rounded to nearest 5.

TABLE 3 Specific congenital anomalies and presence of congenital anomaly codes in the hospital databases in Denmark and Finland

Subgroup	Number linked EUROCAT TOPFA cases (through maternal ID)	Any pregnancy code present	Pregnancies with an end of pregnancy code	Any CA code present	Subgroup-relevant CA codes present
		n (%)	*n* (%)	*n* (%)	*n* (%)
Nervous system	505	505 (100)	459 (91)	421 (83)	124 (25)
Neural tube defects	271	271 (100)	242 (89)	220 (81)	104 (38)
Anencephalus and similar	123	123 (100)	107 (87)	102 (83)	61 (50)
Encephalocele	64	64 (100)	57 (89)	47 (73)	16 (25)
Spina bifida	84	84 (100)	78 (93)	71 (85)	24 (29)
Hydrocephalus	78	78 (100)	68 (87)	62 (79)	12 (15)
Severe CHD	247	247 (100)	222 (90)	218 (88)	14 (6)
Hypoplastic left heart	79	79 (100)	71 (90)	68 (86)	sn
Diaphragmatic hernia	26	26 (100)	25 (96)	22 (85)	0 (0)
Omphalocele	127	127 (100)	107 (84)	114 (90)	sn
Bilateral renal agenesis	27	27 (100)	26 (96)	23 (85)	sn
Skeletal dysplasias	9	9 (100)	9 (100)	3 (33)	0 (0)
Chromosomal	1,111	1,111 (100)	1,029 (93)	896 (81)	777 (70)
Trisomy 21	584	584 (100)	549 (94)	457 (78)	448 (77)
Trisomy 13	229	229 (100)	207 (90)	199 (87)	145 (63)
Trisomy 18	88	88 (100)	80 (91)	73 (83)	52 (59)

Abbreviation: sn, small number.

In the analysis by type of anomaly (Table 3) including Funen, Denmark, and Finland a code for any congenital anomaly was present for ≥80% of TOPFA cases for most congenital anomaly subtypes. The lowest percentage at 33% was for TOPFA cases with skeletal dysplasias. In the analysis of specific subgroup relevant codes, a code for a chromosomal anomaly was recorded in hospital databases for 70% of TOPFA cases with a chromosomal anomaly, and a specific code for neural tube defects was recorded in 38% of TOPFA cases with neural tube defects. Only 6% of TOPFA cases with a severe CHD had a specific code for CHD.

There was a significant association with higher percentages of any code for a congenital anomaly with higher GA for all TOPFA cases, TOPFA cases with chromosomal anomalies and TOPFA cases with severe CHDs ($p < .001$). For neural tube defects, the pattern was less clear ($p = .08$; Figure 1).

The proportion with a code for any congenital anomaly appeared slightly higher for twin pregnancies (37/42 = 88%) compared with single pregnancies (1,615/1964 = 82%; $p > .05$). In total, 16 of the 42 twin pregnancies had a procedure code for fetal reduction.

5 | DISCUSSION

This study from three countries in northern Europe showed that pregnancies resulting in TOPFA were visible in the hospital databases with a pregnancy code and an end of pregnancy code related to the maternal ID. Codes for any congenital anomalies were less visible with 82% of the pregnancies having a code for a congenital anomaly, but very few cases had a code identifying the organ system of the anomaly.

To our knowledge, this is the first study to evaluate the quality of the ICD codes to identify TOPFA cases in routinely collected data in hospital databases. A study from British Columbia in Canada (Samiedaluie, Peterson, Brant, Kaczorowski, & Norman, 2016) showed a high degree of accurate capture (>99%) of abortion procedure events for abortions with social indication in their health administrative data. The registrations were based on ICD codes and procedure codes. A study from Quebec in Canada (Tairou, de Wals, & Bastide, 2006) covering the years 1993–2002 found that a combination of hospital discharge data and death certificates for stillbirths and infant deaths showed a high ascertainment for inclusion

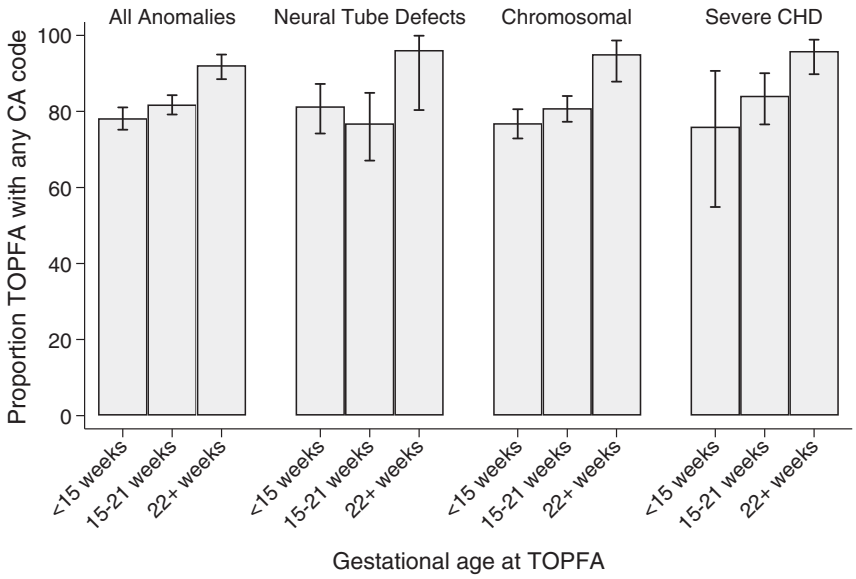

FIGURE 1 Presence of ICD codes for any congenital anomaly by gestational age groups for TOPFA. CHD, congenital heart defect; TOPFA, terminations of pregnancy for fetal anomalies

of all cases with neural tube defects in the population including terminations of pregnancy. However, it was necessary to review medical records to exclude coding errors and to classify unspecified cases.

In the EUROlinkCAT study, 11 regions in 8 countries were able to link their liveborn children with congenital anomalies to their hospital databases (Urhoj et al., 2022). However, only three registries were able to contribute to this study analyzing the quality of the coding of TOPFA cases in the hospital databases. The other registries did not have access to data on TOPFA cases, because these were not present in the hospital databases in some regions or special permissions were needed to access the data as these are considered very sensitive. Therefore, evaluation of the quality of the coding congenital anomalies for TOPFA cases in hospital databases could only be evaluated in countries from northern Europe.

The ICD-10 coding system has limited codes to identify pregnancies with a diagnosed congenital anomaly and has only specific codes to identify a central nervous system anomaly and chromosomal anomaly. Countries may have defined new codes within their coding systems to overcome some of the problems in the coding of TOPFA cases. Future versions of the ICD coding system that include diagnosis for TOPFA with specific codes for the types of anomalies are essential for the surveillance of congenital anomalies using only hospital databases. Our study showed that the coding of TOPFA cases in the three countries included in the study may be sufficient to conduct studies on congenital anomalies in general, but studies on specific congenital anomalies are not possible using the routinely collected data in the hospital databases. The presence of multiple anomalies in a case cannot explain the lack of data on specific anomalies as the majority of the TOPFA cases had only one diagnosis in the EUROCAT database. Clinical databases collecting data on prenatal diagnosis may be an additional data source to include in the surveillance of congenital anomalies and in studies on pregnancy exposures, but follow-up after birth to confirm the diagnosis is needed.

For surveillance of congenital anomalies, identifying clusters and trends and investigating risks of pregnancy teratogenic exposures, it is important that all cases are included in the study and not only the liveborn and stillborn cases. In the beginning of EUROCAT (1980–1989), 6.3% of all reported cases with major congenital anomalies were TOPFA. In the most recent 5-year period (2015–2019), 21% of all cases reported to EUROCAT were TOPFA (www.eurocat-network.eu, assessed on April 1, 2022). This highlights the importance of including TOPFA cases in surveillance and studies on risk factors for congenital anomalies. The EUROCAT registries have special permissions to report TOPFA cases to the central EUROCAT database for surveillance and monitoring of clusters and trends (Kinsner-Ovaskainen et al., 2018).

In countries with a high prenatal detection rate and high rate of TOPFA, livebirths will be a selected proportion of all the cases in the population (Boyle et al., 2018; Charlton et al., 2014; Khoshnood, 2020). If TOPFA cases are not recorded and visible in hospital data, or the use of hospital data to identify TOPFA cases is not allowed, a significant number of the cases with congenital anomalies will be missing, when using hospital data for surveillance and research.

In studies on pregnancy exposures, it is important to study specific congenital anomalies. Known human teratogens are associated with specific congenital anomalies or a spectrum of anomalies, and do not result in a

detectable increase in all congenital anomalies (Czeizel, 2008; Khoury et al., 1994). Studies on pregnancy exposures such as medications will be biased if based on livebirths only, as fetuses with the most severe anomalies may be terminated in some countries and therefore will not be included. In countries with lower prenatal detection rate and low rates of TOPFA the inclusion of TOPFA may be less important (Heinke et al., 2020).

6 | STRENGTH AND LIMITATIONS

The main strength of the study is the routinely collected data in the EUROCAT registries using the same methodology and classification. The information on TOPFA cases were collected based on multiple data sources. A further strength is the linkage quality with almost all maternal ID being identified in the hospital databases. It is a limitation that outpatient data were not available in the registry in northern Netherlands. Some of these women may be registered as outpatients in relation to their diagnosis and early termination of pregnancy. As the registry in Finland is nationwide and thus much larger than the two other registries, the Finnish data have a major impact on the pooled results presented here.

7 | CONCLUSION

Hospital databases have limited information on TOPFA cases and the data are not detailed enough for surveillance of congenital anomalies or for studies analyzing pregnancy exposures and risk of congenital anomalies. However, data from hospital registers can be used to identify a TOPFA and collect more detailed information for the case from medical records.

AUTHOR CONTRIBUTIONS

Joan Morris, Maria Loane, and Ester Garne designed the EUROlinkCAT study and obtained funding. Joanne Given and Maria Loane standardized the data in the three hospital databases together with Stine Kjaer Urhoj, Anna Heino, and Hermien de Walle. Mika Gissler, Hermien de Walle, and Ester Garne were responsible for the data from the EUROCAT registries. Elisabeth Limb programmed the analysis scripts. Joan Morris did the statistical analysis. Ester Garne wrote the first draft of the article. All authors reviewed and revised the article.

FUNDING INFORMATION

This project has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No. 733001. The funders had no role in the study.

CONFLICT OF INTEREST

The authors declare no potential conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

ETHICS STATEMENT

All EUROCAT registries obtained ethical and other permissions for the data linkage according to their national legislations. University of Ulster obtained Ethics permission for the Central Results Repository on September 15, 2017.

ORCID

Ester Garne https://orcid.org/0000-0003-0430-2594
Maria Loane https://orcid.org/0000-0002-1206-3637
Joan Morris https://orcid.org/0000-0002-7164-612X

REFERENCES

Astolfi, G., Ricci, P., Calzolari, E., Neville, A., Pironi, V., Santoro, M., & Bianchi, F. (2016). Validation of an algorithm for identifying cases with congenital malformations by using hospital discharge records. *Epidemiologia e Prevenzione*, *40*(2), 124–130 Italian.

Boyle, B., Addor, M. C., Arriola, L., Barisic, I., Bianchi, F., Csáky-Szunyogh, M., ... Dolk, H. (2018). Estimating global burden of disease due to congenital anomaly: An analysis of European data. *Archives of Disease in Childhood. Fetal and Neonatal Edition*, *103*(1), F22–F28.

Charlton, R. A., Neville, A. J., Jordan, S., Pierini, A., Damase-Michel, C., Klungsøyr, K., ... de Vries, C. S. (2014). Healthcare databases in Europe for studying medicine use and safety during pregnancy. *Pharmacoepidemiology and Drug Safety*, *23*(6), 586–594.

Charlton, R. A., Weil, J. G., Cunnington, m., & de Vries, c. (2010). Identifying major congenital malformations in the UK general practice research database (GPRD). *Drug Safety*, *33*(9), 741–750.

Czeizel, A. E. (2008). Specified critical periods of different congenital abnormalities: A new approach for human teratological studies. *Congenital Anomalies*, *48*, 103–109.

Garne, E., Khoshnood, B., Loane, M., Boyd, P., Dolk, H., & the EUROCAT Working Group. (2010). Termination of pregnancy for fetal anomaly after 23 weeks of gestation: A European register-based study. *BJOG: An International Journal of Obstetrics & Gynaecology*, *117*, 660–666.

Greenlees, R., Neville, A., Addor, M.-C., Amar, E., Arriola, L., Bakker, M., ... Wertelecki, W. (2011). Paper 6: EUROCAT member registries: Organization and activities. *Birth Defects Research. Part A, Clinical and Molecular Teratology*, *91*(Suppl 1), S51–S100.

Heinke, D., Rich-Edwards, J. W., Williams, P. L., Hernandez-Diaz, S., Anderka, M., Fischer, S. C., … National Birth Defects Prevention Study. (2020). Quantification of selection bias in studies of risk factors for birth defects among live births. *Paediatric and Perinatal Epidemiology*, *34*, 655–664.

Khoshnood, B. (2020). Selection bias in studies of birth defects among livebirths: Much ado about nothing? *Paediatric and Perinatal Epidemiology*, *34*, 665–667.

Khoury, M. J., Botto, L., Mastroiacovo, P., Skjaerven, R., Castilla, E., & Erickson, J. D. (1994). Monitoring for multiple congenital anomalies: An international perspective. *Epidemiologic Reviews*, *16*(2), 335–350.

Kinsner-Ovaskainen, A., Lanzoni, M., Garne, E., Loane, M., Morris, J., Neville, A., … Martin, S. (2018). A sustainable solution for the activities of the European network for surveillance of congenital anomalies: EUROCAT as part of the EU platform on rare diseases registration. *European Journal of Medical Genetics*, *61*, 513–517.

Morris, J. K., Garne, E., Loane, M., Barisic, I., Densem, J., Latos-Bieleńska, A., … EUROlinkCAT Consortium. (2021). EUROlinkCAT protocol for a European population-based data linkage study investigating the survival, morbidity and education of children with congenital anomalies. *BMJ Open*, *11*(6), e047859.

Samiedaluie, S., Peterson, S., Brant, R., Kaczorowski, J., & Norman, W. V. (2016). Validating abortion procedure coding in Canadian administrative databases. *BMC Health Service Research*, *16*, 255.

Tairou, F., de Wals, P., & Bastide, A. (2006). Validity of death and stillbirth certificates and hospital discharge summaries for the identification of neural tube defects in Quebec City. *Chronic Diseases in Canada*, *27*(3), 120–124.

Urhoj, S. K., Tan, J., Morris, J. K., Given, J., Astolfi, A., Baldacci, S., … Garne, E. (2022). Hospital length of stay among children with and without congenital anomalies across 11 European regions - A population-based data linkage study. *PLoS One*, *17*(7), e0269874.

How to cite this article: Garne, E., Urhoj, S. K., Bakker, M., Gissler, M., Given, J., Heino, A., Limb, E., Loane, M., de Walle, H., & Morris, J. (2022). The quality and the accuracy of codes for terminations of pregnancy for fetal anomalies recorded in hospital databases in three countries in northern Europe. *Birth Defects Research*, 1–8. https://doi.org/10.1002/bdr2.2133

APPENDIX

TABLE A1 Definitions and list of relevant codes

Item	Description	
Relevant pregnancy duration	The period for searching in hospital records for a possible match (i.e., finding records that relate to the "same" pregnancy) will be from date of conception to 2 weeks after the EUROCAT TOPFA date. Date of conception will be calculated using EUROCAT methodology (EUROCAT TOPFA date—GESTLENGTH). If GESTLENGTH is missing then this is imputed as 24 weeks; this is not an estimate of the true GA but rather to set a wider timeframe within which to find a match in hospital records	
Type of code	ICD-9	ICD-10
Pregnancy codes	630–669, 678–679	O00–O84 Z34, Z35, Z36, and Z37
End of pregnancy codes	630–639 abortions 650–669 deliveries	O00–O06 abortions O80–O84 deliveries Z37 and Z38 outcome of delivery
CA codes	740–759	Q-chapter
	655, excluding 6,557	O35
Subgroup-relevant CA codes	As per section 3.3 of EUROCAT Guide 1.4 Except for al97 severe CHD which should use the following codes (same as CHD)	
	745, 746, 7,470–7,474	Q20–Q26
	al1: 655, excluding 6,557 al2, al3, al4, al5, al6, al7: 6550 al104: None al88, al89, al91, al92: 6551	al1: O35 al2, al3, al4, al5, al6, al7: O350 al104: O352 al88, al89, al91, al92: O351
Fetal reduction (procedure) codes	Finland	MAJ (MAJ00 and MAJ10)
	Northern Netherlands	5,750: Intra-amniotic injection for fetal reduction
	Denmark	KMAJ (KMAJ00 and KMAJ10)

Abbreviation: CHD, congenital heart defect.