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european surveillance of congenital anomalies

Special Report: Geographic Inequalities in Public Health Indicators Related to Congenital Anomalies
(2014)

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Executive Summary

EUROCAT first introduced a set of "public health indicators" for congenital anomalies in 2011. A public health indicator generally refers to a quantitative summary which can guide public health policy and indicate the effect of policy interventions. It is particularly useful for EUROCAT to use a small set of public health indicators as a summary of the vast amount of epidemiological information that EUROCAT publishes on an annual basis regarding prevalence, pregnancy outcome, perinatal mortality, and prenatal diagnosis of 91 congenital anomaly subgroups. A small set of summary indicators is more focused to the needs of policymakers. Indicators can be used to make geographical comparisons, or to track change over time. This report builds on the previous work, analysing the most recent 5 years of data (2008-2012) for 31 full member registries and particularly focussing on geographical comparisons.

Key Findings

Perinatal mortality due to congenital anomaly

The average perinatal mortality due to congenital anomaly across EUROCAT registries is 0.9 per 1,000 births. The perinatal mortality due to CA indicator should be interpreted alongside the TOPFA indicator – for example where TOPFA are illegal (Malta, Ireland), perinatal mortality is expected to be higher. Malta has high perinatal mortality, particularly first week deaths, due to CA, at over 3 per 1,000 births. The Irish registries have the second highest perinatal mortality at 2 per 1,000, and Ukraine also has a relatively high perinatal mortality of 1.5 per 1,000 or above.

Congenital anomaly prenatal diagnosis prevalence

The EUROCAT average for prenatally diagnosed CA is 9.5 per 1,000 births, of which approximately one third are chromosomal and two thirds non-chromosomal cases. The prevalence of prenatally diagnosed congenital anomaly cases varies from less than 5 per 1,000 births in some countries up to 18 per 1,000 in Switzerland and France

Termination of pregnancy for fetal anomaly (TOPFA)

The overall prevalence of TOPFA across EUROCAT is 4.4 per 1,000. The prevalence of TOPFA varies from zero in countries where this is illegal (Ireland, Malta) to around 8 per 1,000 in France and Switzerland. Paris has the highest TOPFA prevalence – over 10 per 1,000 births, Compared to prenatally diagnosed cases, the prevalence of TOPFA is approximately half i.e. half of prenatal diagnoses on average in Europe result in TOPFA.

Down syndrome prevalence

The average total prevalence of Down Syndrome in EUROCAT is 2.3 per 1,000 births, of which 44.6% are livebirths, 2.5% late fetal deaths/stillbirths, and 52.9% TOPFA. The total prevalence varies by country and this variation has been shown in separate analyses to be due to variation in maternal age at delivery.

Total Down Syndrome prevalence has increased over time, also shown in separate analyses to be due to rising maternal age across Europe. The livebirth prevalence has remained stable over the last five years due to the increasing rate of TOPFA.

Neural tube defects (NTD) total prevalence

The average total prevalence of neural tube defects is 0.9 per 1,000 births, of which nearly one quarter are livebirths. The highest total prevalence of NTD is in Ukraine with 1.8 per 1,000 births. The NTD prevalence has not changed in Europe, despite the fact that it is known that periconceptional folic acid supplementation can

prevent neural tube defects, and that levels of supplementation in the European population are low and therefore reinforced efforts at implementing preventive strategies are needed.

Congenital anomaly pediatric surgery

The average total prevalence of the category of anomalies typically requiring surgery is over 5 per 1,000 births. Most (by definition) are livebirths. Eight registries have data on surgery, which show that the average prevalence of

babies requiring surgery one or more times is nearly 10 per 1,000 births and that just under half of these are "anomalies typically requiring surgery".

Conclusion

It was found that there are huge geographic inequalities in public health indicators relating to congenital anomalies. The reasons for any inequalities cannot be ascertained from the indicators alone and require further investigation within and between countries. Some differences may reflect the social and cultural diversity of Europe.

A comparison with the previously published indicators for 2004-2008 show that there has been very little change, either in the average situation, or in the inequalities between countries. This suggests that the last decade has seen little progress towards improving public health indicators for congenital anomalies, or addressing within or between country inequities where they exist.

The report concludes with a series of questions that member registries may wish to present to the Public Health Authorities in their respective countries to address some of the inequalities highlighted.

Introduction

In 2011, EUROCAT introduced a set of "public health indicators" for congenital anomalies [1]. A public health indicator generally refers to a quantitative summary which can guide public health policy and indicate the effect of policy interventions [1]. It is particularly useful for EUROCAT to use a small set of public health indicators as a summary of the vast amount of epidemiological information that EUROCAT publishes on an annual basis regarding prevalence, pregnancy outcome, perinatal mortality, and prenatal diagnosis of 91 congenital anomaly subgroups [2]. A small set of summary indicators is more focused to the needs of policymakers. Indicators can be used to make geographical comparisons (the focus of this report), or to track change over time.

Materials and Methods

The process by which the Public Health Indicators were agreed has been described previously [1].

The EUROCAT Central Database

The information on which these indicators are based is available within the EUROCAT central database which contains individual anonymised data. We used data on all cases {livebirths, fetal deaths, or stillbirths after 20 weeks of gestation and terminations of pregnancy for fetal anomaly (TOPFA)} of congenital anomalies from 31 full member population-based registries of EUROCAT (http://www.eurocat-network.eu/) that could provide data for at least 3 years during the period from 2008 to 2012. Note that the full population coverage of countries by EUROCAT registries, both full and associate members, can be found at http://eurocat-network.eu/content/EUROCAT-Population-Table-I-Year2012.pdf. Table 1 shows the years of data included, population, country coverage and number of CA cases in each registry during this period. Some analyses on surgical cases are restricted to registries that are known to have good recording of surgical data These 8 registries are highlighted in Table 1.

Cases were classified as chromosomal (ICD10 Q90-Q92, Q93, Q96-Q99) or non-chromosomal (not having any chromosomal diagnosis).

Table 1 Synopsis of Registries Covered

Registry	Years included	Birth Population (in years included)	% of country covered (based on 2012 figs)	No. CA cases (in years included)
Styria, Austria	2008-2012	51569	13.1	1355
Antwerp, Belgium	2008-2012	105725	16.7	2545
Hainaut, Belgium	2008-2012	64724	10.1	1517
Zagreb, Croatia	2008-2012	39341	19.8	751
Odense, Denmark	2008-2012	25109	7.9	743
French W Indies, France	2009-2012	42221	1.2	888
Isle de la Reunion, France	2008-2012	72526	1.7	2099
Paris, France	2008-2012	133390	3.1	4385
Mainz, Germany	2008-2011	12770	0.5	592
Saxony Anhalt, Germany	2008-2012	86196	2.5	2691
Hungary	2008-2011	375769	100	14170
Cork and Kerry, Ireland	2008-2012	51923	13.9	1272
Dublin, Ireland	2008-2012	136593	38.6	1857
S E Ireland	2008-2012	39013	10.4	608
Emilia Romagna, Italy	2008-2012	207225	7.4	4708
Tuscany, Italy	2008-2012	152792	5.6	3261
Malta	2008-2011	16755	100	406
N Netherlands	2008-2012	87415	9.4	2339
Norway	2008-2012	310634	100	8225

Wielkopolska, Poland	2008-2010	123258	9.8	2905
S Portugal	2008-2011	76791	18.9	705
Basque Country, Spain	2008-2011	84927	4.7	2344
Valencia Region, Spain	2008-2011	212353	10.4	4896
Vaud, Switzerland	2008-2012	40037	10.1	1449
Ukraine	2008-2012	158062	6.3	4014
E Mids & S Yorks, UK	2008-2012	376591	9.4	7623
N England, UK	2008-2012	169647	4.2	3808
Thames Valley, UK	2008-2012	154978	3.8	3398
S W England, UK	2008-2012	255281	6.4	7585
Wales, UK	2008-2012	178258	4.4	6006
Wessex, UK	2008-2012	154250	3.9	3266

Definition of the Public Health Indicators

The six indicators that are discussed in this Report are as follows:

1. **Perinatal mortality due to congenital anomaly -** [an indicator of mortality burden]

    Perinatal mortality associated with a congenital anomaly, is defined as the rate of late fetal deaths or stillbirths from 20 weeks' gestation + first week deaths, per 1000 births in the population. Terminations of pregnancy for fetal anomaly are excluded from the calculation.

2. **Congenital anomaly prenatal diagnosis prevalence -** [an indicator of the degree to which prenatal screening services are detecting cases of congenital anomaly]

Prevalence (per 1000 births) of prenatally diagnosed cases of congenital anomaly. Chromosomal anomalies are analysed separately from non-chromosomal anomalies as they are known to have different screening methods.

3. **Termination of pregnancy for fetal anomaly (TOPFA) –** [an indicator of the degree to which TOPFA is the choice following prenatal diagnosis, and the degree to which TOPFA may be affecting perinatal mortality and livebirth prevalence]

Prevalence (per 1000 births) of terminations of pregnancy for fetal anomaly (TOPFA). The indicator is split into chromosomal and non-chromosomal because these have different screening methods, and a different proportion of prenatally diagnosed cases leading to TOPFA.

4. **Down syndrome prevalence –** [an indicator of the combined effect of prenatal screening policy and termination of pregnancy for fetal anomaly]

Down syndrome cases (per 1000 births). Specific prenatal screening programs have been established in many European countries for this anomaly. Delayed childbearing is known to be a contributing factor in Down syndrome prevalence.

5. **Neural tube defects (NTD) total prevalence –** [an indicator of the success of preventative programs]

The prevalence of NTD (per 1000 births) is analysed. Because many countries have focused their primary preventive efforts on prevention of NTD by folic acid supplementation, this indicator allows the success of these preventive programs to be measured.

6. **Congenital anomaly pediatric surgery –** [an indicator of the overall public health burden in terms of need for surgery]

Prevalence of selected anomalies usually requiring surgery (per 1000 births). Liveborn congenital anomalies differ in severity and consequences for services. Therefore total prevalence is given, broken down by type of birth (livebirths, fetal deaths, and TOPFA) to show, in particular, the impact that TOPFA may have on the number of liveborn surgical cases.

Data analysis

A congenital anomaly was any case with one or more codes in the Q chapter of International Classification of Diseases 10 plus a very limited set of conditions coded outside the Q chapter, namely D215, D821, D1810, P350,

P352, and P371. Fetal deaths included stillbirths and any spontaneous abortion from 20 weeks' gestation but excluded TOPFA.

TOPFA refers to cases where prenatal diagnosis of a congenital anomaly is made in a live fetus and the pregnancy is then terminated. Prenatal diagnosis was defined as suspicion of a major congenital anomaly (excluding soft markers) in a live fetus. Cases typically requiring surgery were based on six anomalies/subgroups that are known to have both a high proportion of livebirths and high rates of surgery performed (or expected to be performed). These subgroups were determined previously using 2005-2006 data from Vaud and Odense registries as sample data. In the current time period (2008-2012), 45% of all surgery (performed or expected to be performed) is captured by these 6 anomalies/subgroups.

Prevalence of congenital anomaly, prenatal diagnosis, TOPFA, pediatric surgery, and perinatal mortality were calculated per 1000 births. Chromosomal cases were excluded from the analyses where appropriate ie. in the NTD and surgery calculations. The data was analysed at individual registry level, at country level and also over time.

Perinatal mortality was split into fetal deaths and deaths within the first week of life. Prevalence of prenatal diagnosis was calculated for all anomalies but broken down by cases prenatally diagnosed for a chromosomal condition, those prenatally diagnosed for a non-chromosomal condition, those not prenatally diagnosed, and those for which timing of diagnosis was not known (ie whether prenatal or postnatal). Prevalence of TOPFA was divided into chromosomal and non-chromosomal cases. Prevalence of Down syndrome and NTDs were analysed by type of birth (livebirth, fetal death, or TOPFA). Our most relevant figure for NTD is the total prevalence, which can help evaluate prevention policies related to folic acid. NTD prevalence data by type of birth (livebirth, fetal death, TOPFA) is presented to show outcome.

The six EUROCAT subgroups comprising the 'typically surgical' group were:

1. severe congenital heart defect (includes single ventricle, hypoplastic left heart, hypoplastic right heart, Ebstein's anomaly, tricuspid atresia, pulmonary valve atresia, common arterial truncus, atrioventricular septal defects, aortic valve atresia/stenosis, transposition of great vessels, tetralogy of Fallot, total anomalous pulmonary venous return, and coarctation of aorta)

2. omphalocele

3. gastroschisis

4. digestive system (includes oesophageal atresia with or without tracheo-oesophageal fistula, duodenal atresia or stenosis, atresia or stenosis of other parts of the small intestine, anorectal atresia and stenosis, Hirschsprung's disease, atresia of bile ducts, annular pancreas, and diaphragmatic hernia),

5. craniosynostosis

6. oro-facial clefts (includes cleft lip with or without cleft palate and cleft palate).

(see section 3.3, EUROCAT Guide 1.3 available on the website: (http://www.eurocat-network.eu/aboutus/datacollection/guidelinesforregistration/guide1_3instructionmanual)

Looking at this 'typically surgical' group of anomalies only, we analysed the prevalence by type of birth (livebirth, fetal death, TOPFA). Assessment of time trends was done by pooling data from all registries together.

The denominator for analysis is the number of live and stillbirths registered in each population. The constancy of the denominator is very important to allow comparison across indicators. The use of births as a denominator, rather than proportions of cases (e.g. proportion of cases prenatally diagnosed) makes the data more comparable across registries and countries as the total prevalence of congenital anomalies recorded in countries varies considerably due to ascertainment differences with regard to later diagnosed or less severe congenital anomalies.

Data is analysed by registry and by country (where multiple registries within a country are pooled). The purpose of the "by registry" analysis is to highlight that variation in some indicators occurs within countries.

We choose not to give confidence intervals in this report, to improve the accessibility of the presentation of figures. Numbers are generally large added across 5 years, and the commentary concentrates on large differences that would not be statistically chance variation.

Commentary on the Results

The distribution of congenital anomalies by type of anomaly

Figure A gives an overview of the relative numbers of the different congenital anomalies included in the EUROCAT public health indicators. Chromosomal anomalies (including Down Syndrome) all together make up 15.2% with an addition 2.5% for other genetic syndromes (mainly monogenic or microdeletions). Neural tube defects account for 3.6% of all major CA. Excluding Down Syndrome and Spina bifida which have their own indicators, other anomalies which typically require surgery account for an additional 19.8% of major CA, and the major CA contributing to this category are shown in Figure A – severe congenital heart defects and digestive system defects being the most numerous.

**Figure A: Distribution of Congenital Anomalies**

Craniosynostosis 0.9%
Oro-facial clefts 4.9%
Severe CHD 6.8%
Omphalocele 0.7%
Digestive system 6.2%
Gastroschisis 1.1%

'Typical surgery' 19.8%
Other 58.9%
Down Syndrome 8.9%
NTD 3.6%
Chromosomal (excl DS) 6.3%
Genetic syndromes 2.5%

Limb 13.8%
Urinary 11.3%
Genital 7.9%
VSD 9.7%
ASD 6.1%
Miscellaneous 13.2%

All categories within pie are mutually exclusive. NTD and Typically Surgery exclude genetic/chromosomal syndromes. Categories in insets may add up to more than the total % in pie as one child can have more than one anomaly.

Perinatal mortality due to congenital anomaly

Figure 2a shows perinatal mortality associated with CA per country. The average across EUROCAT registries is 0.9 per 1,000 births, approximately half being fetal deaths and half first week deaths. Malta clearly stands out as having high perinatal mortality, particularly first week deaths, due to CA, at over 3 per 1,000 births. The Irish registries have the second highest perinatal mortality at 2 per 1,000, and Ukraine also has a relatively high perinatal mortality of 1.5 per 1,000 or above.

The perinatal mortality due to CA indicator should be interpreted alongside the TOPFA indicator (see section 4) – for example where TOPFA are illegal (Malta, Ireland), perinatal mortality is expected to be higher.

Figure 2a Perinatal Mortality due to CA by Country 2008-2012
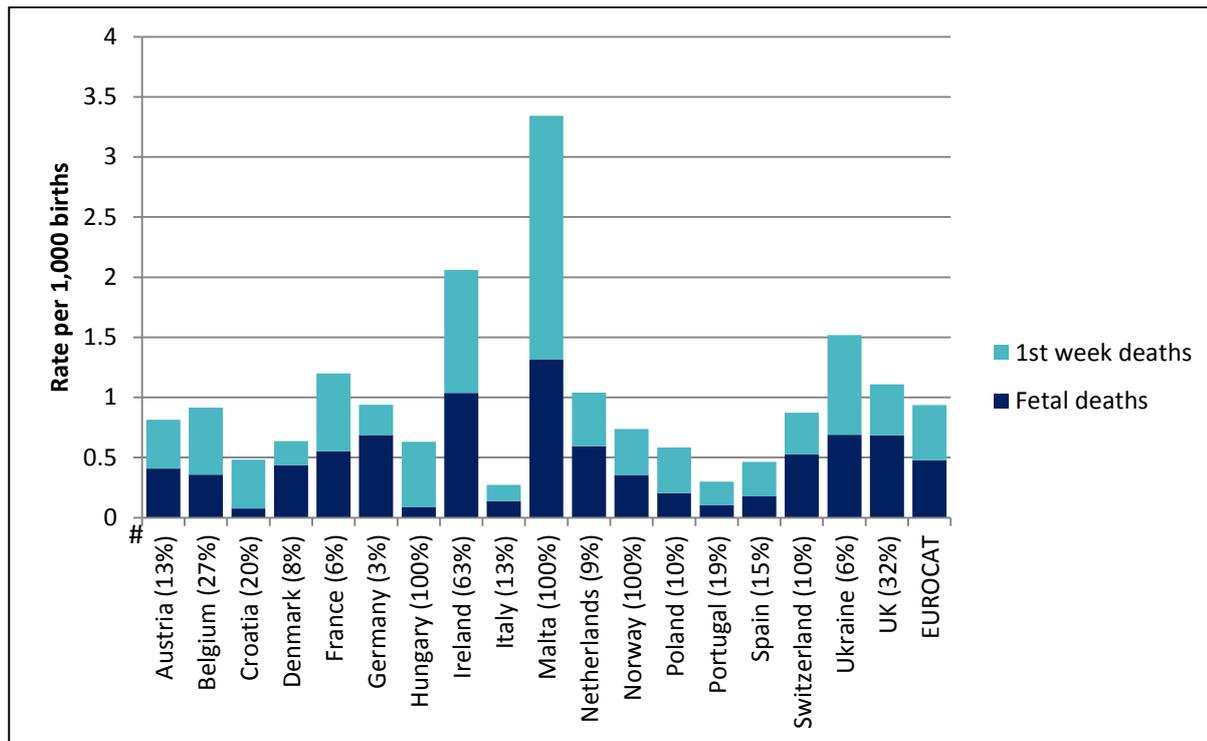
(#the figures in brackets show the percentage of the country covered by the EUROCAT registries within that country)

Figure 2b shows that there is variation *within* countries – for example Ile de la Reunion has higher perinatal mortality due to CA than other registry areas in France.

Figure 2b Perinatal Mortality due to CA by Registry 2008-2012
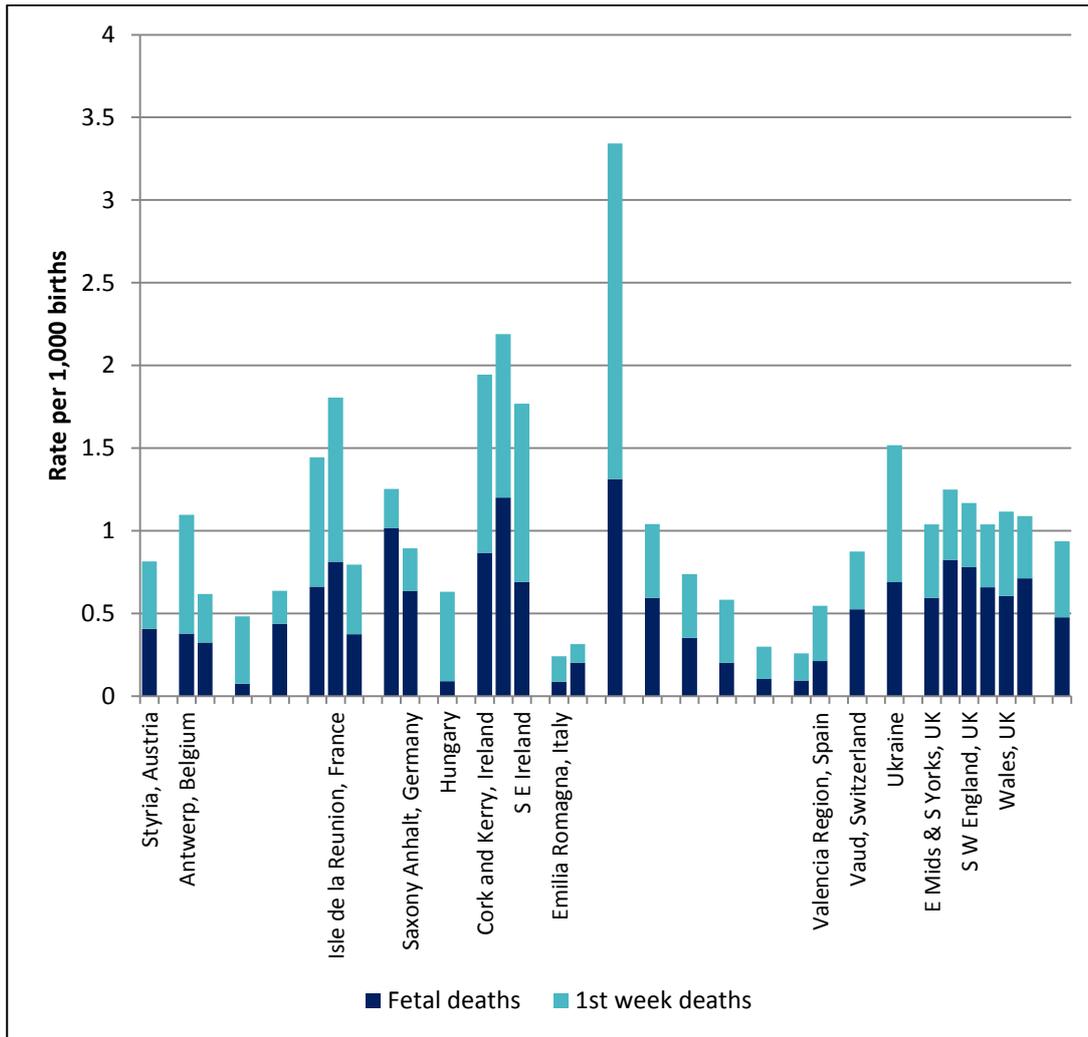
The particularly low perinatal mortality recorded in some countries, particularly in relation to late fetal deaths/stillbirths may relate to the recording of cause of death and its availability to registers.

Perinatal mortality due to CA has very slightly increased during the time period (Figure 2c).

Figure 2c Perinatal Mortality due to CA over Time 2008-2012
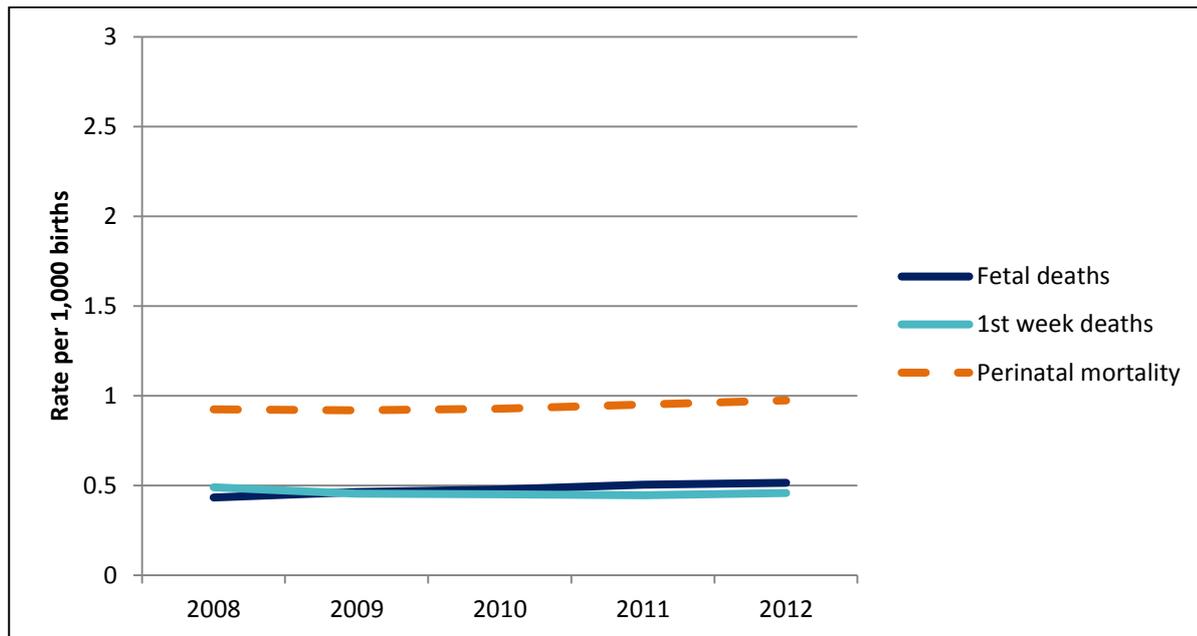
Prenatal diagnosis

Figure 3a shows the prevalence of prenatally diagnosed babies with CA per 1,000 births. Terminations of pregnancy are included in this prevalence. The EUROCAT average is 9.5 per 1,000 births, of which approximately one third are chromosomal and two thirds non-chromosomal cases. The prevalence of prenatally diagnosed CA cases varies from less than 5 per 1,000 births in some countries up to 18 per 1,000 in Switzerland and France.

Figure 3a Prenatal Diagnosis by Country 2008-2012
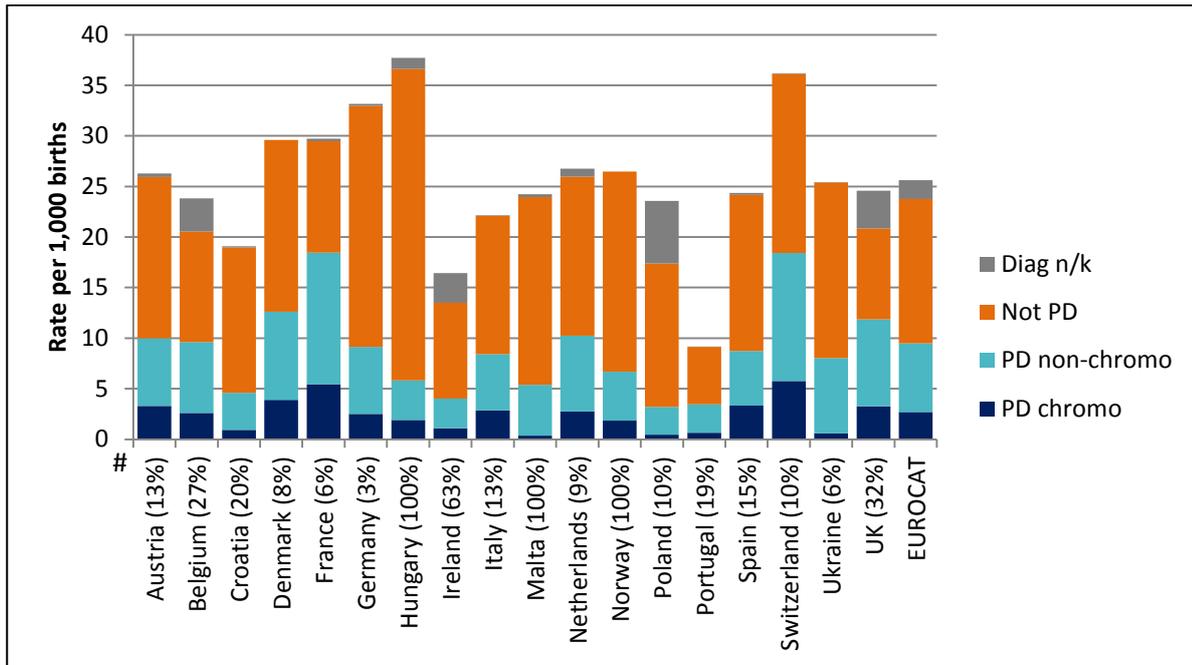
(#the figures in brackets show the percentage of the country covered by the EUROCAT registries within that country)

Within France, variation is found with high prenatal diagnosis rates in Paris (Figure 3b).

Figure 3b Prenatal Diagnosis by Registry 2008-2012
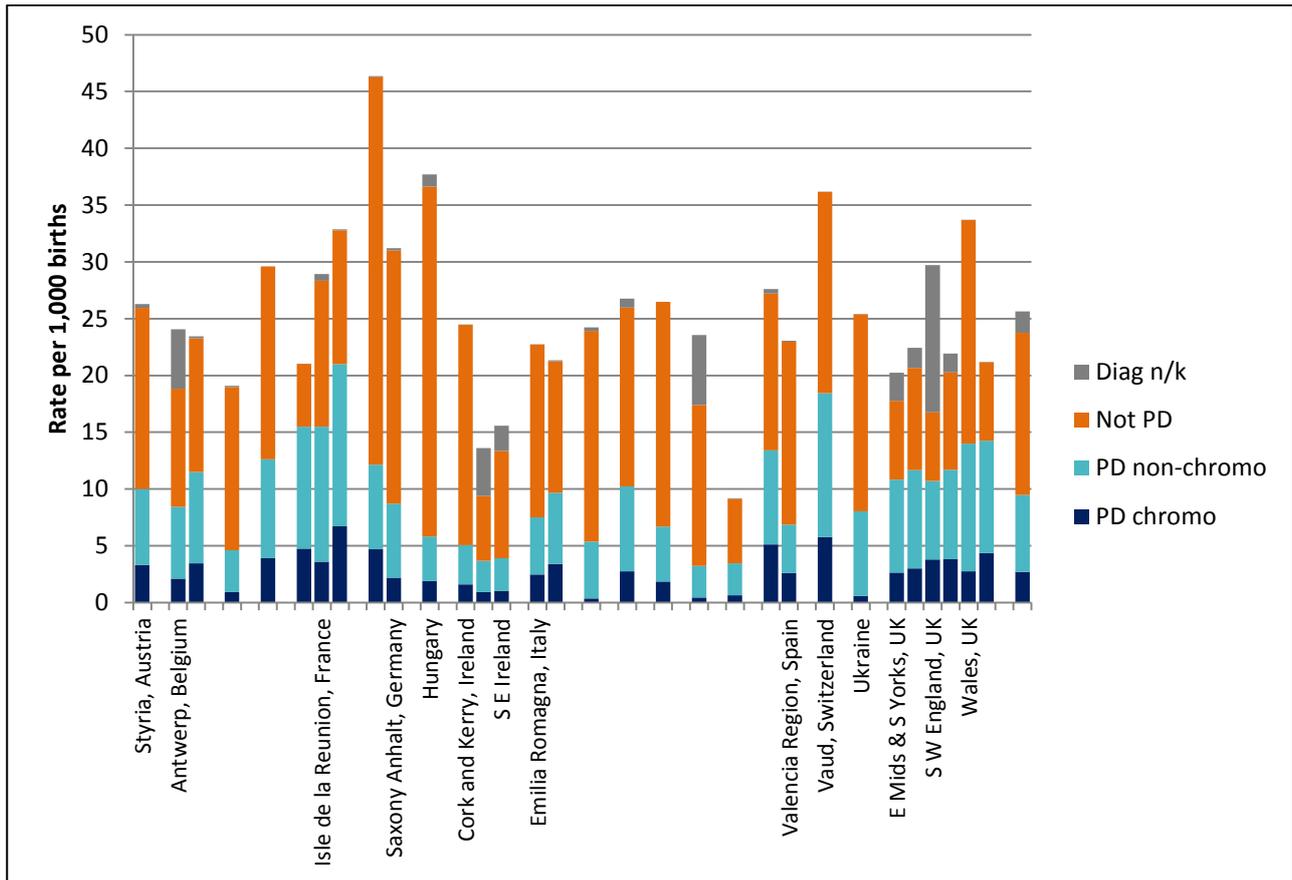
The prevalence of prenatally diagnosed cases is increasing over time (Figure 3c). The recent drop in prevalence of non-prenatally diagnosed cases is likely to reflect late diagnosis or ascertainment of conditions not diagnosed in the perinatal period.

Figure 3c Prenatal Diagnosis over Time 2008-2012
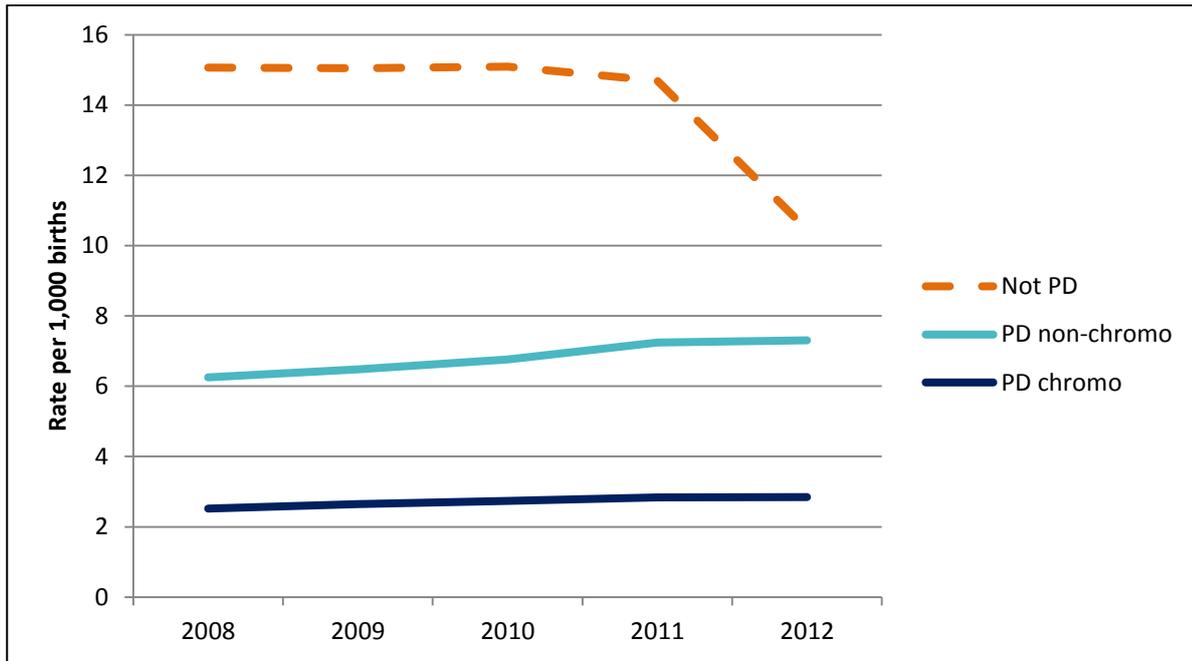
Termination of pregnancy for fetal anomaly

The overall prevalence of TOPFA across EUROCAT is 4.4 per 1,000 of which approximately half are chromosomal and half non-chromosomal. The prevalence of TOPFA varies from zero in countries where this is illegal (Ireland, Malta) to around 8 per 1,000 in France and Switzerland (Figure 4a). Paris has the highest TOPFA prevalence – over 10 per 1,000 births (Figure 4b).

The Irish registries are aware of cases where a congenital anomaly has been prenatally diagnosed but the case does not appear subsequently in the birth statistics suggesting that mothers have sought TOPFA outside the jurisdiction. However, the full extent of this is not known. In Malta it is considered unlikely that this is happening in more than rare instances.

Figure 4a Termination of Pregnancy for Fetal Anomaly by Country 2008-2012
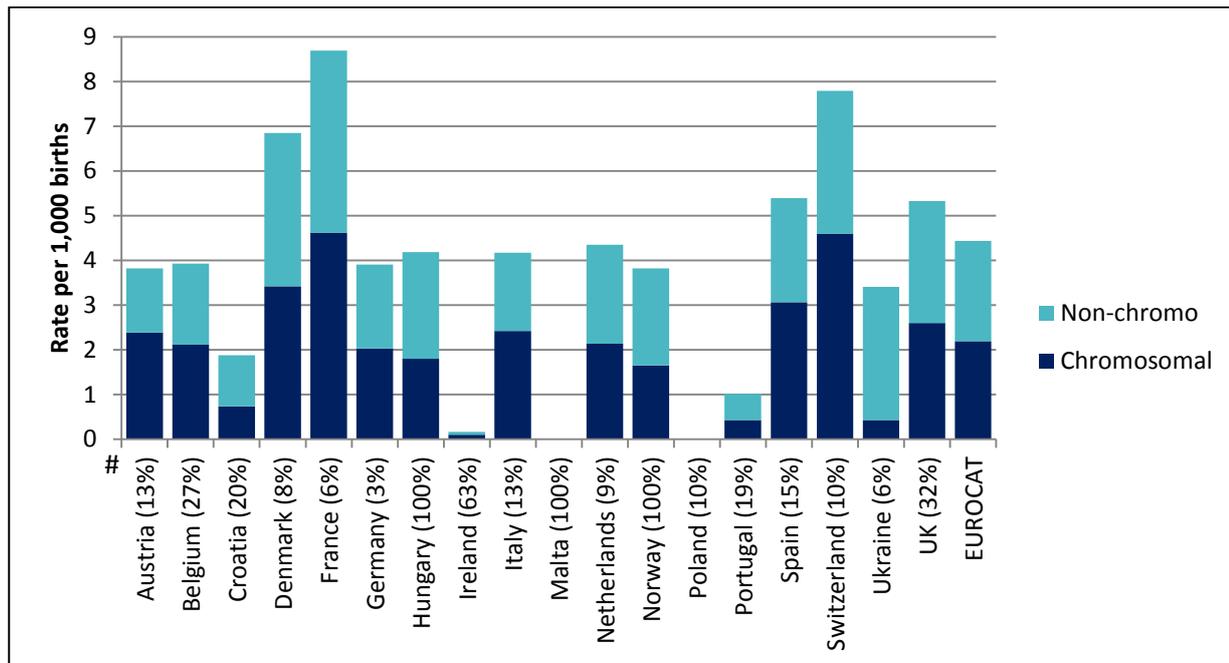
(#the figures in brackets show the percentage of the country covered by the EUROCAT registries within that country)

**Figure 4b Termination of Pregnancy for Fetal Anomaly by Registry 2008-2012**
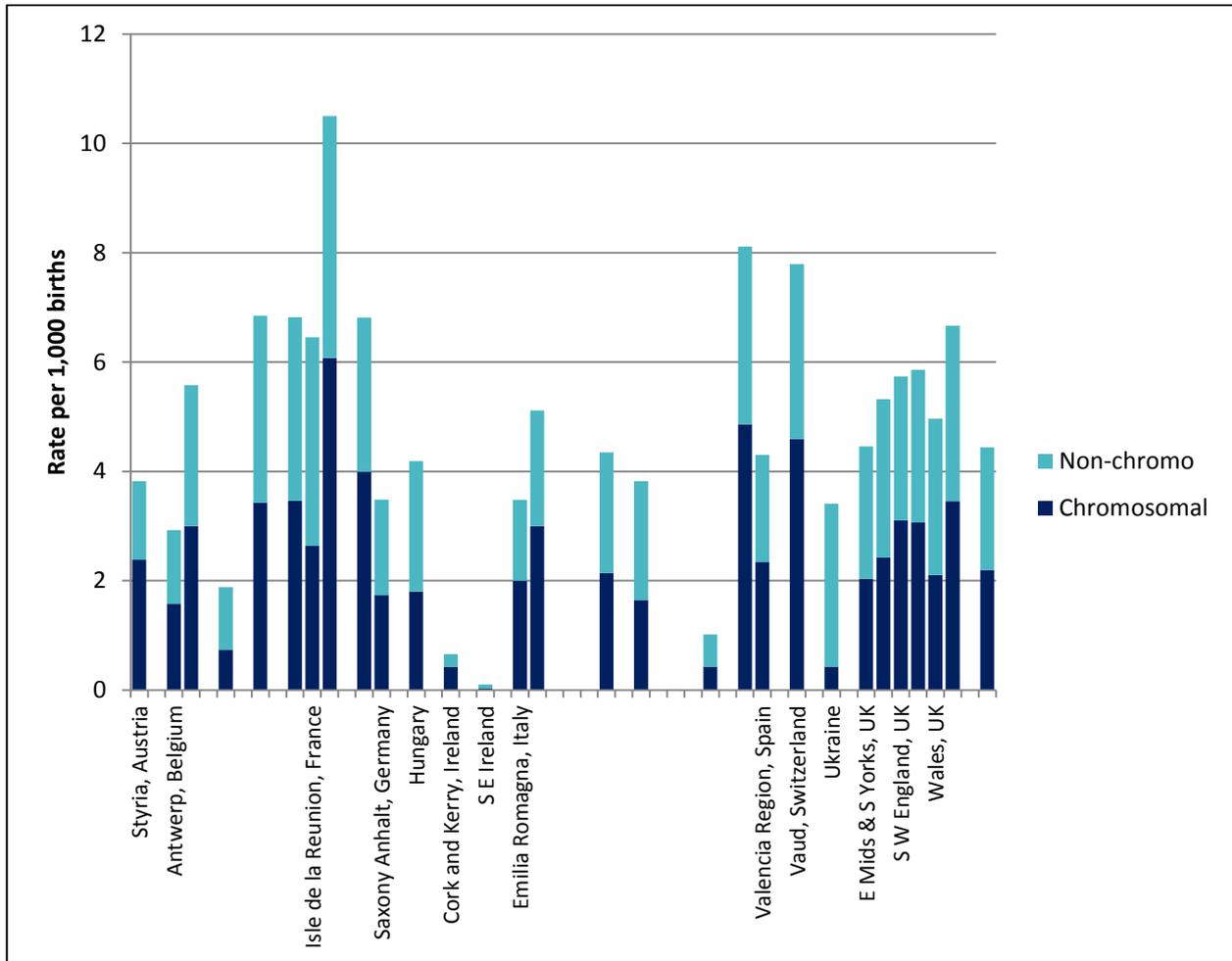
Ukraine has a particularly low termination prevalence for chromosomal anomalies compared to non-chromosomal anomalies, probably indicating lack of antenatal screening services for chromosomal anomalies.

Compared to prenatally diagnosed cases, the prevalence of TOPFA is approximately half i.e. half of prenatal diagnoses on average in Europe result in TOPFA. Comparing Fig 3a to Fig 4a, some variations in this ratio can be seen across countries.

There is a shallower increase in TOPFA over time (Fig 4c) than prenatal diagnosis (Fig 3c).

Figure 4c Termination of Pregnancy for Fetal Anomaly over Time 2008-2012
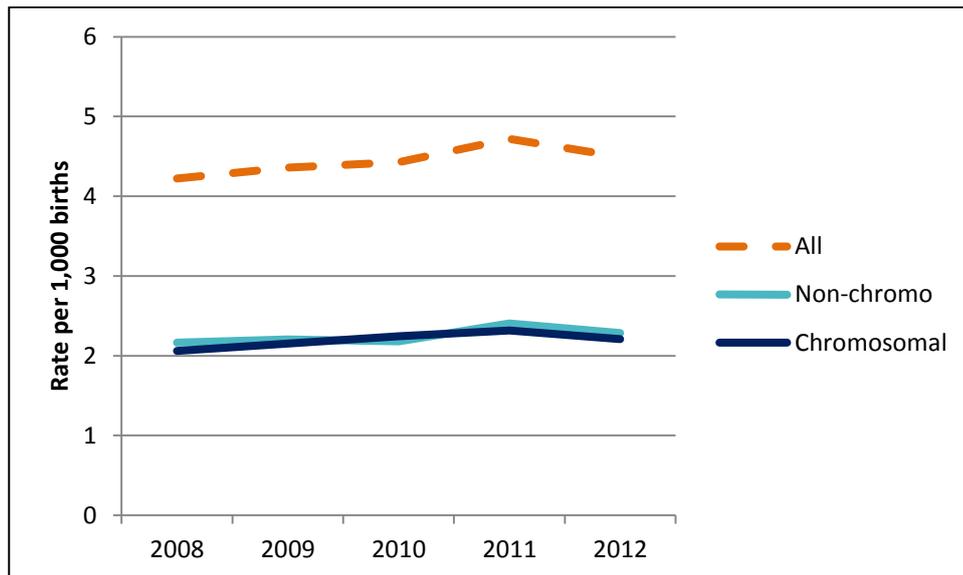
Down Syndrome

The average total prevalence of Down Syndrome in EUROCAT is 2.3 per 1,000 births (Fig 5a), of which 44.6% are livebirths, 2.5% late fetal deaths/stillbirths, and 52.9% TOPFA. The total prevalence varies by country and this variation has been shown in separate analyses to be due to variation in maternal age at delivery [4].

Figure 5a Down Syndrome by Country 2008-2012
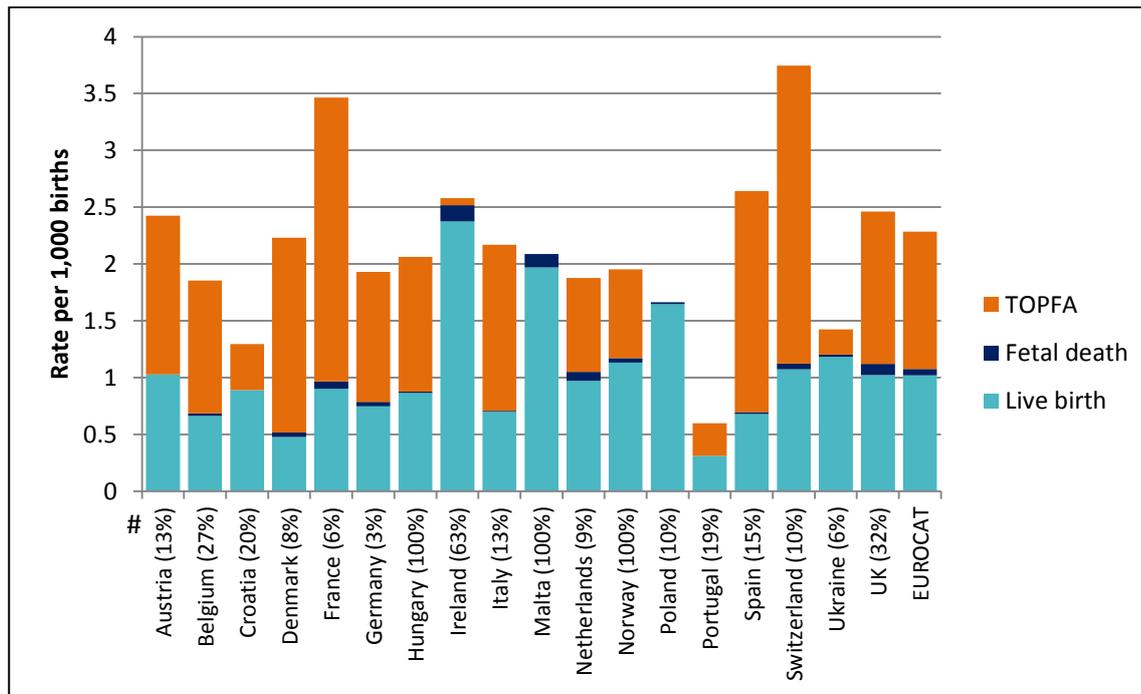
(# the figures in brackets show the percentage of the country covered by the EUROCAT registries within that country)

The average livebirth prevalence is 1 per 1,000 (Fig 5a). The highest livebirth prevalence is in Ireland with 2.3 per 1,000, followed by Malta and Poland, all countries where there is no TOPFA for Down Syndrome.

The total Down Syndrome prevalence has increased over time (Fig 5b), shown by EUROCAT Statistical Monitoring to be due to changes in maternal age over time [6]. The TOPFA prevalence has increased similarly to the total prevalence, suggesting that the main factor is again maternal age rather than a change in prenatal diagnosis or subsequent decision making. The livebirth prevalence has remained stable over the last five years.

Figure 5b Down Syndrome over Time 2008-2012
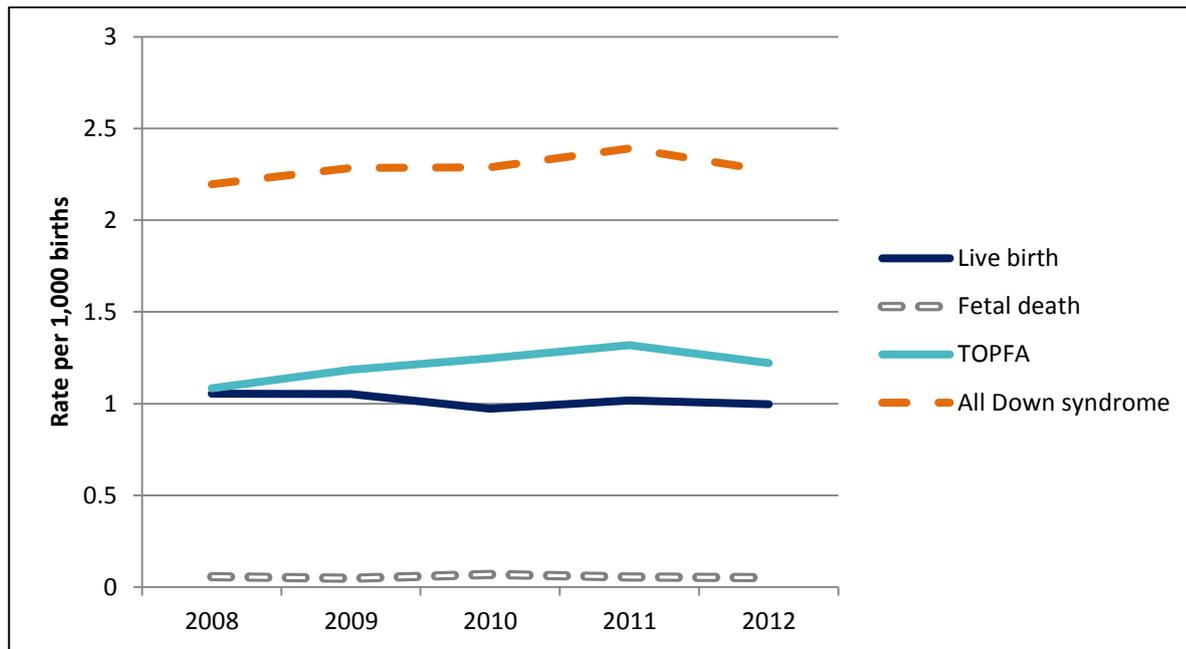
Neural Tube Defects

The average total prevalence of neural tube defects is 0.9 per 1,000 births (Fig 6a), of which nearly one quarter are livebirths. The highest total prevalence is in Ukraine with 1.8 per 1,000 births.

**Figure 6a Neural Tube Defects by Country 2008-2012**
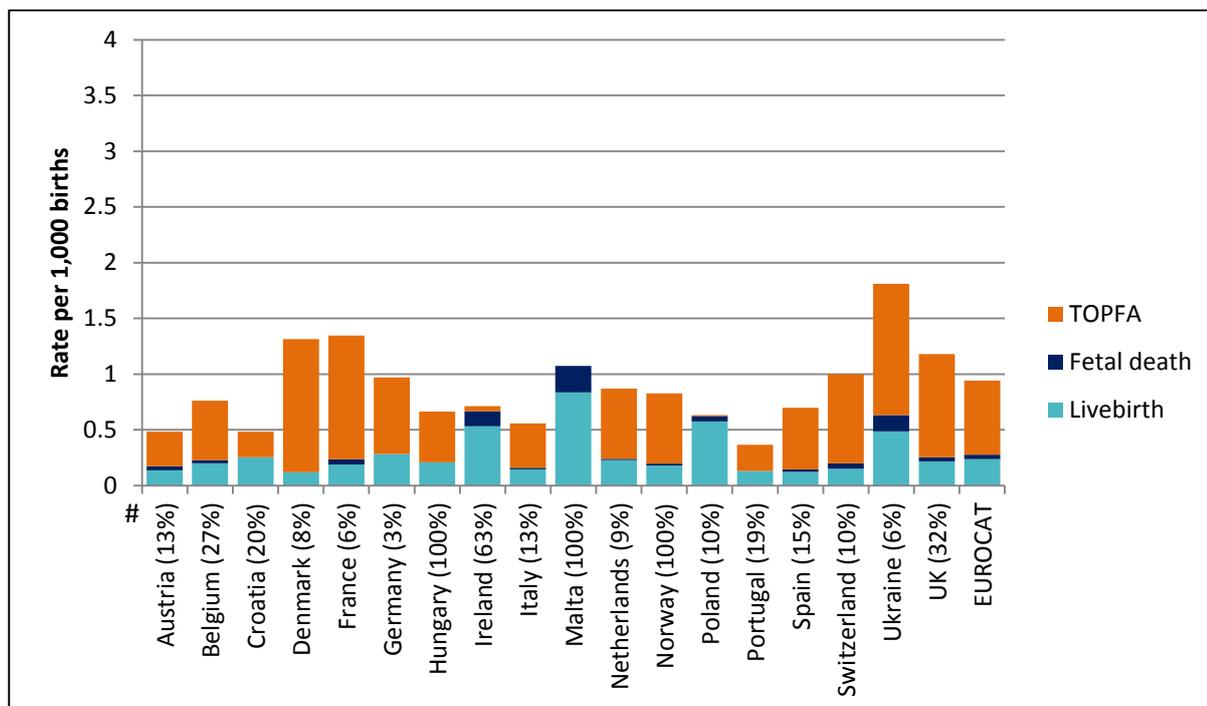
(# the figures in brackets show the percentage of the country covered by the EUROCAT registries within that country)

The average livebirth prevalence is 0.2 per 1,000. Relatively high livebirth prevalences are found in Malta (0.8 per 1,000), Ireland (0.5 per 1,000), Poland (0.6 per 1,000) as these are countries where TOPFA is either not legal or not practiced. These are therefore countries which need to provide more extensive services for children with spina bifida.

Ukraine despite having a high rate of TOPFA also has a high livebirth rate (0.5 per 1,000) reflecting its high total rate of NTD. Ukraine has frequently expressed concerns about its high NTD rate, in relation to radiation from Chernobyl, nutrition and folic acid intake, and alcohol consumption [7].

The neural tube defect prevalence has not changed (Fig 6b), despite the fact that it is known that periconceptional folic acid supplementation can prevent neural tube defects, and that levels of supplementation in the European population are low and therefore reinforced efforts at implementing preventive strategies are needed.

Figure 6b Neural Tube Defects over Time 2008-2012
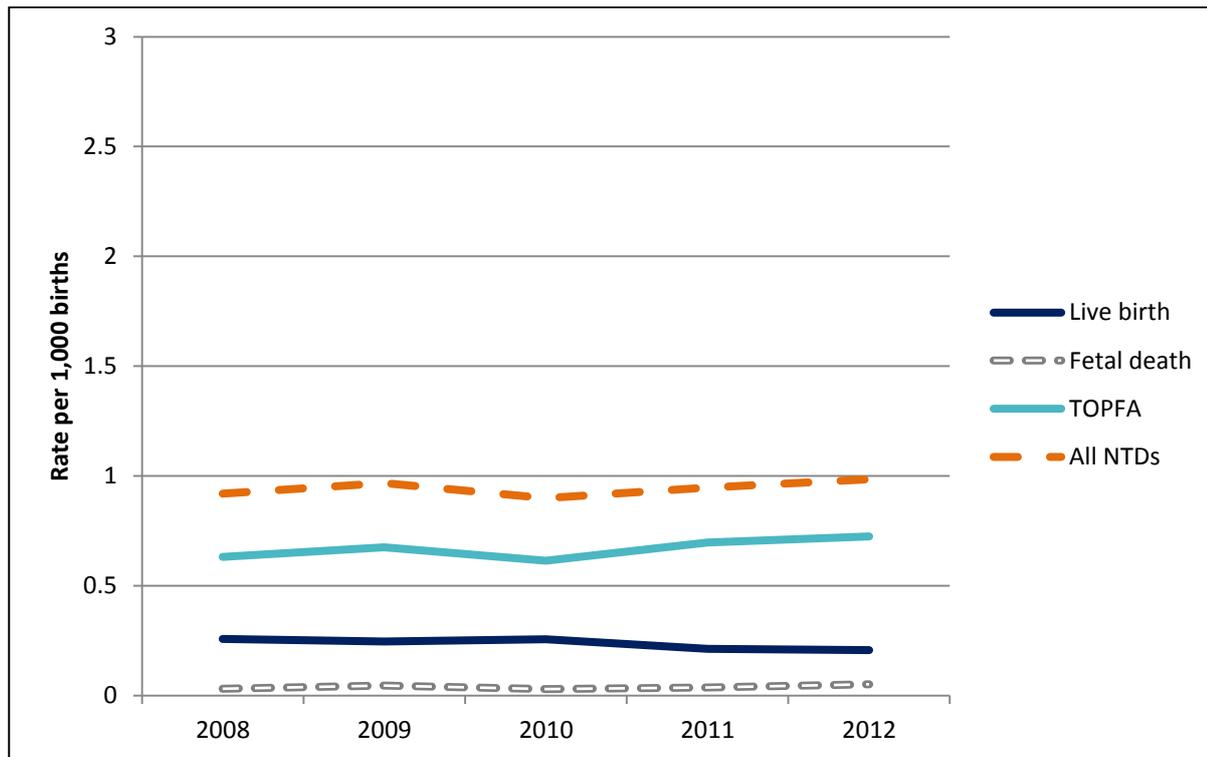
Congenital Anomalies typically needing surgery

The average total prevalence of the category of anomalies typically requiring surgery is over 5 per 1,000 births (Figure 7a). Most (by definition) are livebirths. A recent drop in prevalence (Figure 7b) may reflect late case ascertainment in some registries.

Figure 7a Typically Requiring Surgery by Country 2008-2012 (Excl. Chromosomal Cases)
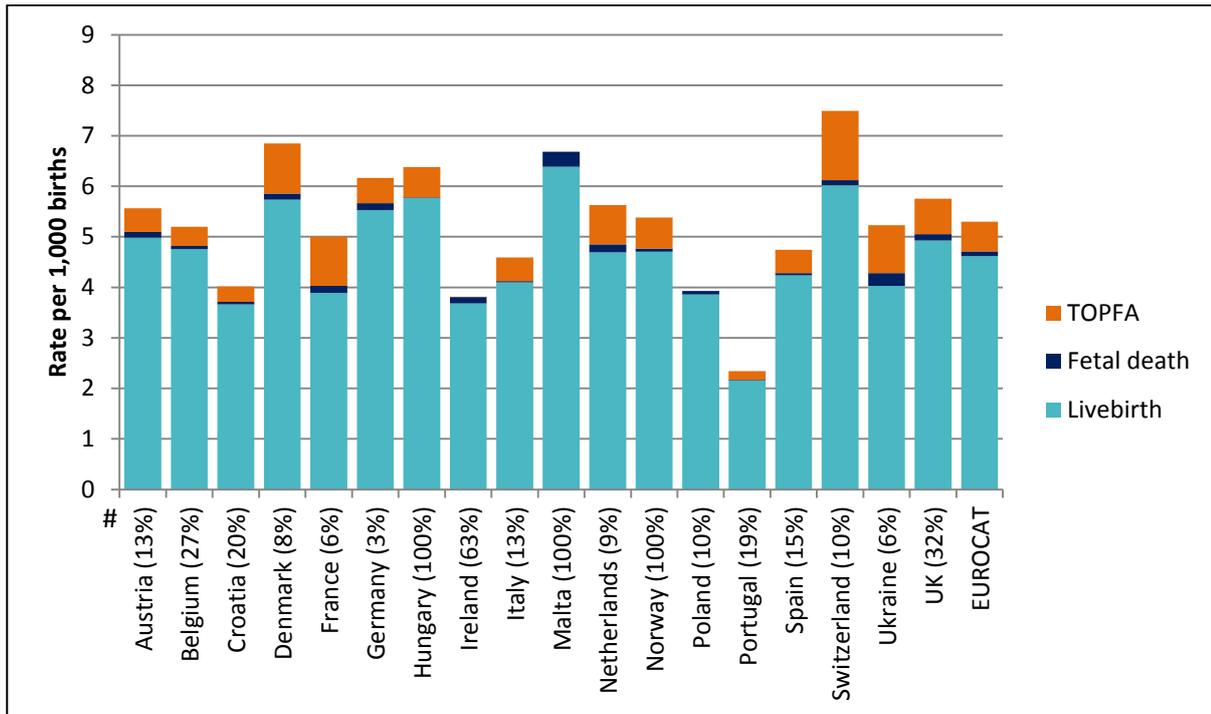
(#the figures in brackets show the percentage of the country covered by the EUROCAT registries within that country)

Figure 7b Typically Requiring Surgery over Time 2008-2012 (Excl. Chromosomal Cases)
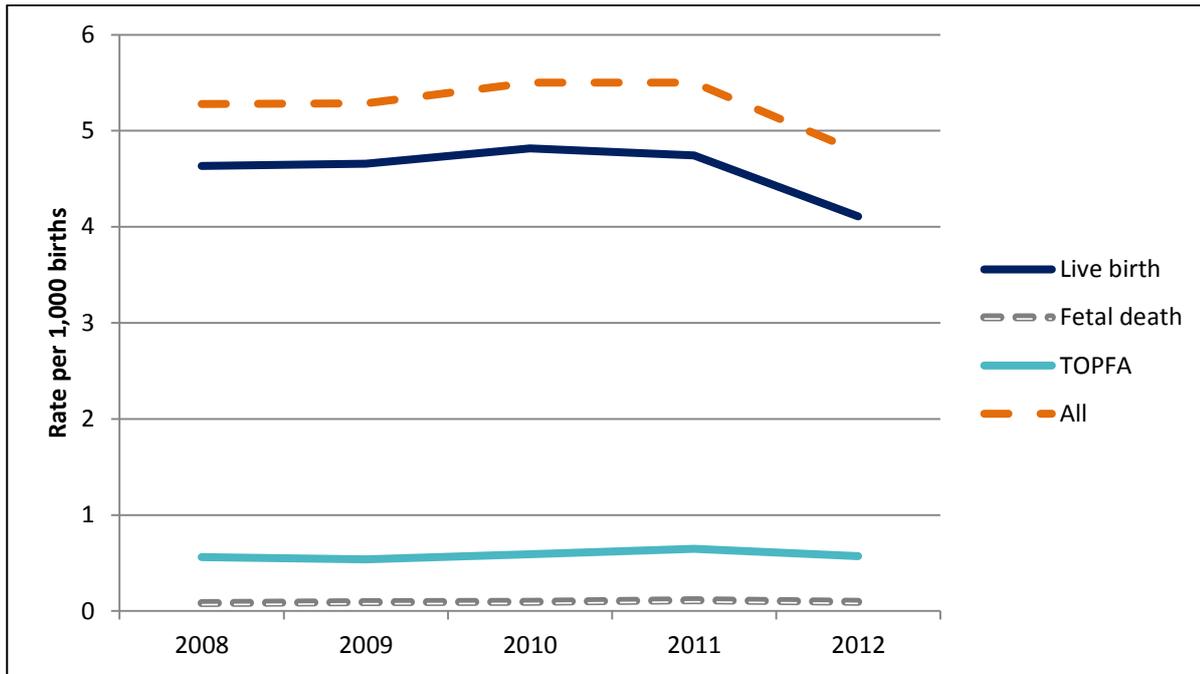

Figure 8a includes 8 registries where individual data on whether surgery has been or will be performed is available. The data from these registries show that the average prevalence of babies requiring surgery one or more times is nearly 10 per 1,000 births and that just under half of these are "anomalies typically requiring surgery". Figure 8b shows that the top two CA subgroups requiring surgery outside of the "typically requiring surgery" group are limb defects and hypospadias.

Figure 8a Prevalence of Surgery in Registries (n=8) with >80% Use of Surgery Codes
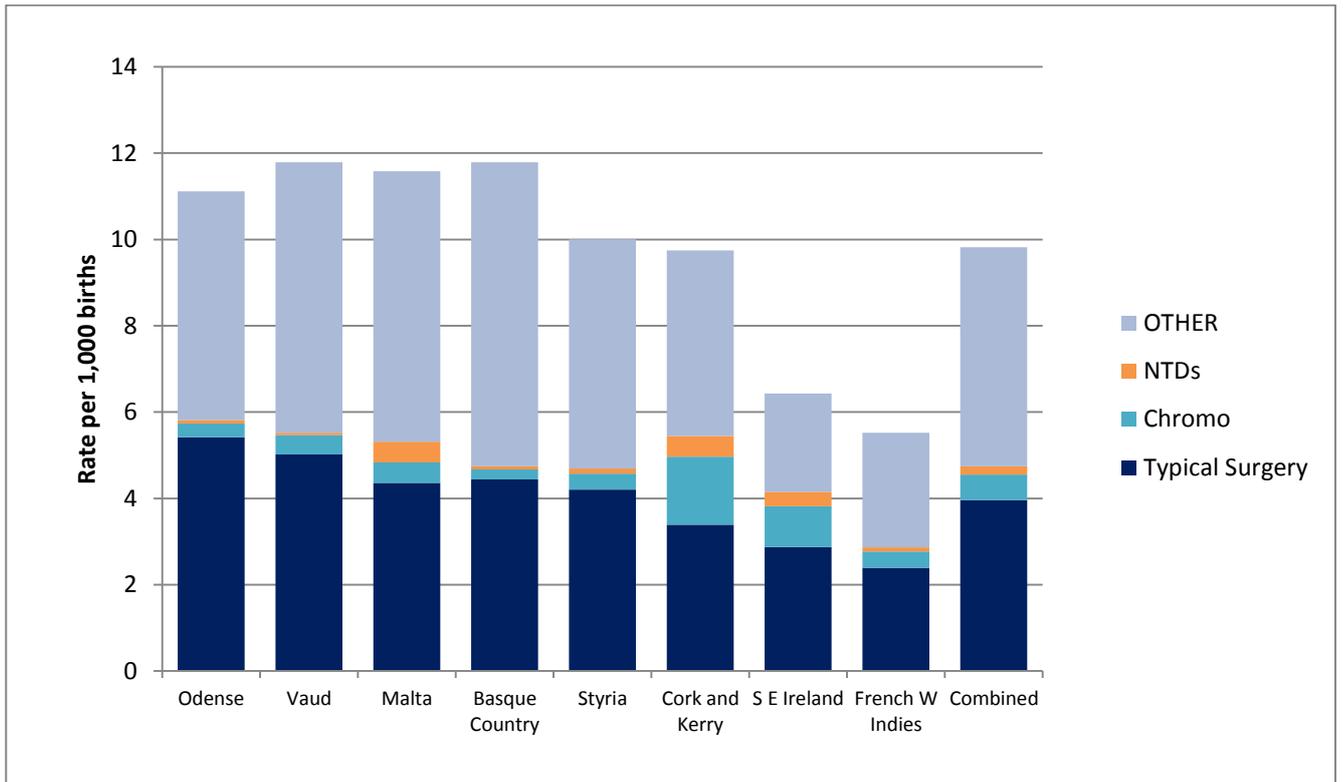

Figure 8b Top 5 Anomalies Requiring Surgery within OTHER Category in Registries (n=8) with >80% Use of Surgery Codes
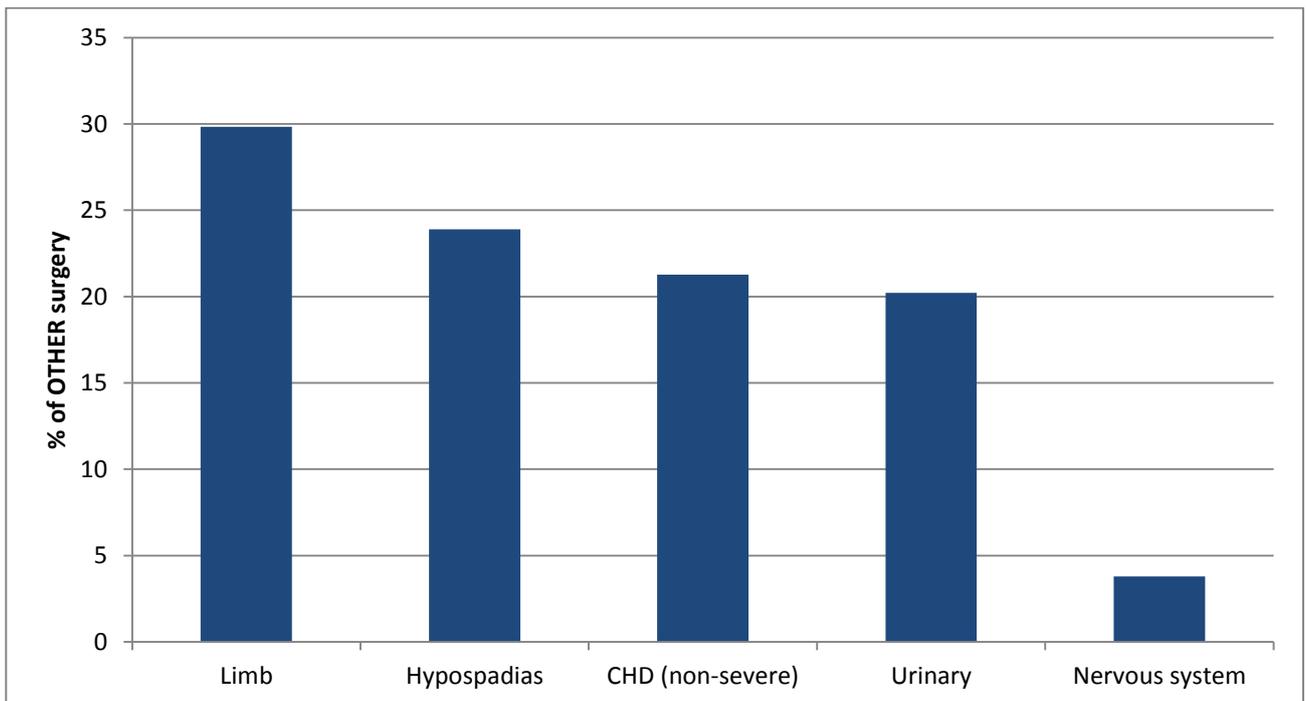
Figure 8c shows that the category "too severe for surgery" is infrequent, but most represented in Malta. In Malta, due to the fact that there are no TOPFA, more very severe CA may be born, but the Irish registry Cork and Kerry where TOPFA are also illegal, have a lower prevalence of anomalies too severe for surgery. Nearly 30% of babies with CA too severe for surgery (Table 2) have a chromosomal syndrome.

Figure 8c Prevalence of Cases Having Surgery, No Surgery Required, Too Severe for Surgery, or Not Known
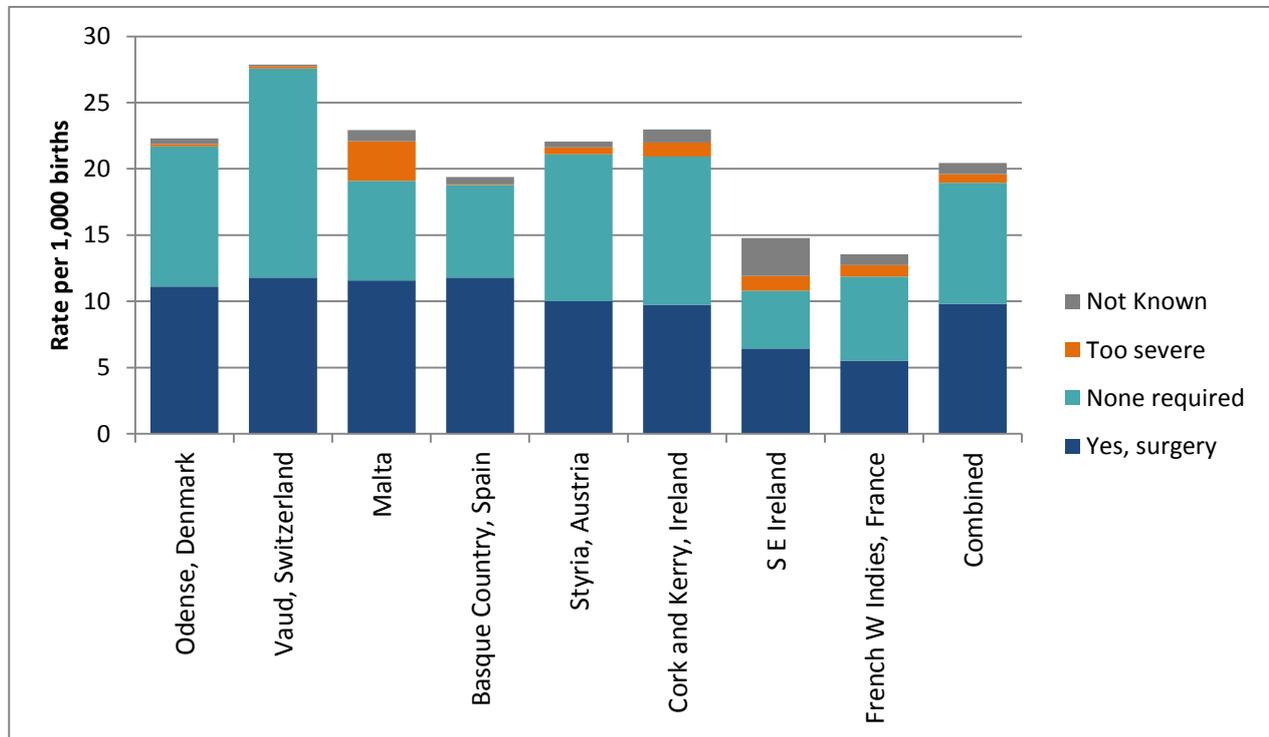
Table 2 Breakdown of Cases Too Severe for surgery

Centre	Non-Chromosomal Number (%)	Chromosomal Number (%)
Odense	* (50.0%)	* (50.0%)
Vaud	6 (85.7%)	* (14.3%)
Malta	40 (80.0%)	10 (20.0%)
Basque Country	* (25.0%)	* (75.0%)
Styria	18 (66.7%)	9 (33.3%)
Cork & Kerry	35 (64.8%)	19 (35.2%)
SE Ireland	29 (65.9%)	15 (34.1%)
French West Indies	28 (77.8%)	8 (22.2%)
Combined	159 (70.4%)	67 (29.6%)

*data suppressed to protect the confidentiality of individuals

Discussion: implications for public health authorities

There are huge geographic inequalities in public health indicators relating to congenital anomalies. The reasons for the inequalities cannot be ascertained from the indicators alone and require further investigation within and between countries. Some differences may reflect the social and cultural diversity of Europe.

A comparison with the previously published indicators for 2004-2008[1] show that there has been very little change, either in the average situation, or in the inequalities between countries. This suggests that the last decade has seen little progress towards improving public health indicators for congenital anomalies, or addressing within or between country inequities where they exist.

Public Health Authorities of European countries should take note of these inequalities and address the following questions:

- To what extent are high rates of perinatal mortality due to health services not meeting the highest standards of care?

- To what extent are low rates of prenatal diagnosis due to health services not meeting the highest standards of care?

- To what extent are children being born with congenital anomalies for which there are known modifiable environmental risk factors but where public health measures for prevention have not been implemented or have not been successful? Public Health Authorities can refer to the EUROCAT/EUROPLAN Recommendations for Primary Prevention of Congenital Anomalies [3, 4] to make this assessment.

- Are the data underpinning these public health indicators of sufficient quality to guide policy, and if not, what is being done to give the registries the appropriate resources to improve data collection?

- How can differences in public health indicators within countries be explained and are there inequities that need to be addressed within countries? Is the geographical coverage of the country by EUROCAT registries (full and associate) sufficient to reveal inequities within countries?

- Are the health services being provided for babies born with CA who survive the first week of life, and their families, taking into account the level of need that is specific to each country. For example, Ireland and Malta have considerably higher number of babies with Down Syndrome since TOPFA is illegal in these countries, and services must recognise these needs.

From 2015, the co-ordination of EUROCAT is moving from Ulster University (where it has been since 2000) to the EU Joint Research Centre at Ispra. The continued surveillance of public health indicators at JRC should be a high priority for the future.

References

(1) Khoshnood B, Greenlees R, Loane M, Dolk H, EUROCAT Project Management Committee and EUROCAT Working Group (2011). Paper 2: EUROCAT public health indicators for congenital anomalies in Europe. *Birth Defects Research (Part A)*. 91: S16-S22

(2) http://www.eurocat-network.eu/AccessPrevalenceData/PrevalenceTables
http://www.eurocat-network.eu/accessprevalencedata/keypublichealthindicators
http://www.eurocat-network.eu/PrenatalScreeningAndDiagnosis/PrenatalDetectionRates

(3) EUROCAT and EUROPLAN (2013). Primary Prevention of Congenital Anomalies: Recommendations on Policies to be Considered for the Primary Prevention of Congenital Anomalies in National Plans and Strategies on Rare Diseases. *EUROCAT Central Registry, University of Ulster* http://www.eurocat-network.eu/content/EUROCAT-EUROPLAN-Primary-Preventions-Reccomendations.pdf

(4) Taruscio D, Arriola L, Baldi F, Barisic I, Bermejo E, Bianchi F, Calzolari E, Carbone P, Curran R, Garne E, Gatt M, Latos- Bielenska A, Khoshnood B, Irgens L, Mantovani A, Martinez-Frias M-L, Neville A, Rissmann A, Ruggeri S, Wellesley D and Dolk H (2014). European Recommendations for Primary Prevention of Congenital Anomalies: A joined Effort of EUROCAT and EUROPLAN Projects to Facilitate Inclusion of This Topic in the National Rare Diseases Plans. *Public Health Genomics*. 17: 115-123

(5) Loane M, Morris J, Addor M-C, Arriola L, Budd J, Doray B, Garne E, Gatt M, Haeusler M, Khoshnood B, Klungsoyr Melve K, Latos- Bielenska A, McDonnell R, Mullaney C, O'Mahony M, Queisser-Wahrendorf A, Rankin J, Rissmann A, Rounding C, Salvador J, Tucker D, Wellesley D, Yevtushok L and Dolk H (2013). Twenty-year trends in the prevalence of Down syndrome and other trisomies in Europe: impact of maternal age and prenatal screening. *European Journal of Human Genetics*. 21: 27-33

(6) http://www.eurocat-network.eu/content/Stat-Mon-Report-2012.pdf

(7) Wertelecki W (2010). Malformations in a Chornobyl-impacted region. *Pediatrics*. 125: e836