



# Registration of Births and Deaths in Europe: The Challenges

Ashna Mohangoo and Jennifer Zeitlin





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- › Variation in mortality rates
- › Registration of live and stillbirths
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# Euro-Peristat



- › Euro-Peristat collects data on births and deaths from 22 completed weeks of gestation



## WHO definition



- › The WHO defines the perinatal period by gestational age
- › starting from the 22<sup>nd</sup> completed week of pregnancy
- › but recommends that countries collect data on stillbirths based on birth weight



## WHO definition



- › A stillbirth is defined as death of a fetus that has reached a birth weight of 500 grams
- › if the birth weight is unavailable
- › a gestational age of 22 completed weeks or a crown-to-heel length of 25 cm is used



The first EPHR showed  
wide variability in  
perinatal mortality rates

The highest mortality rates  
were approximately 3.5  
times higher than the  
lowest



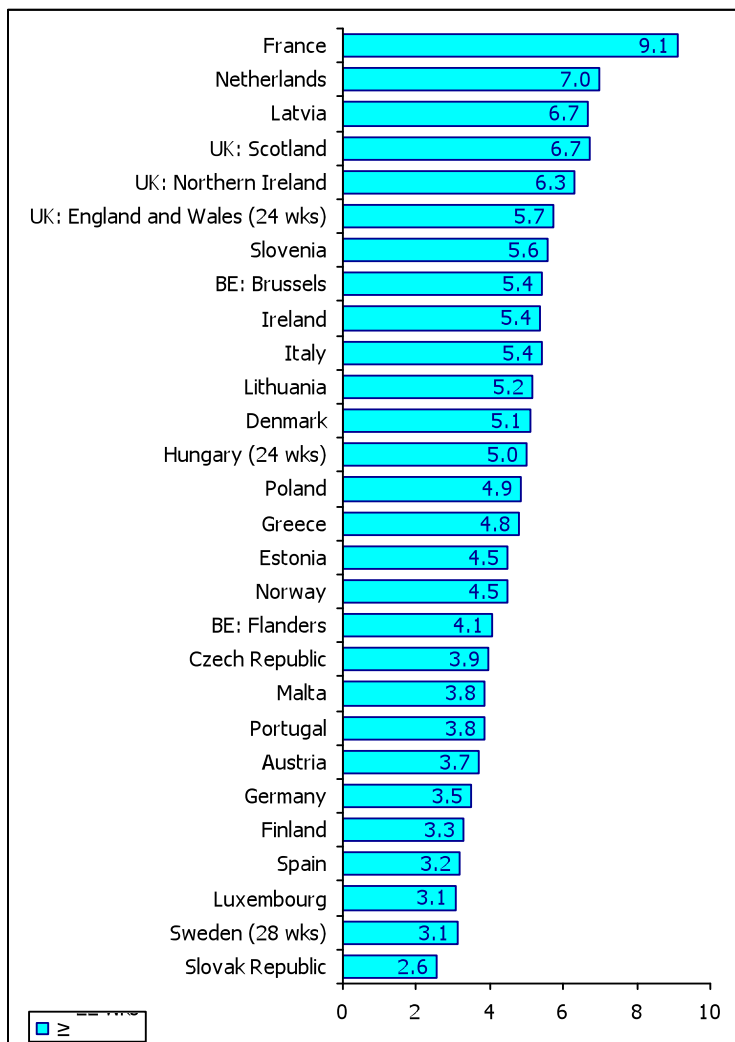
## EUROPEAN PERINATAL HEALTH REPORT

by the EURO-PERISTAT project  
in collaboration with  
SCPE, EUROCAT & EURONEONET

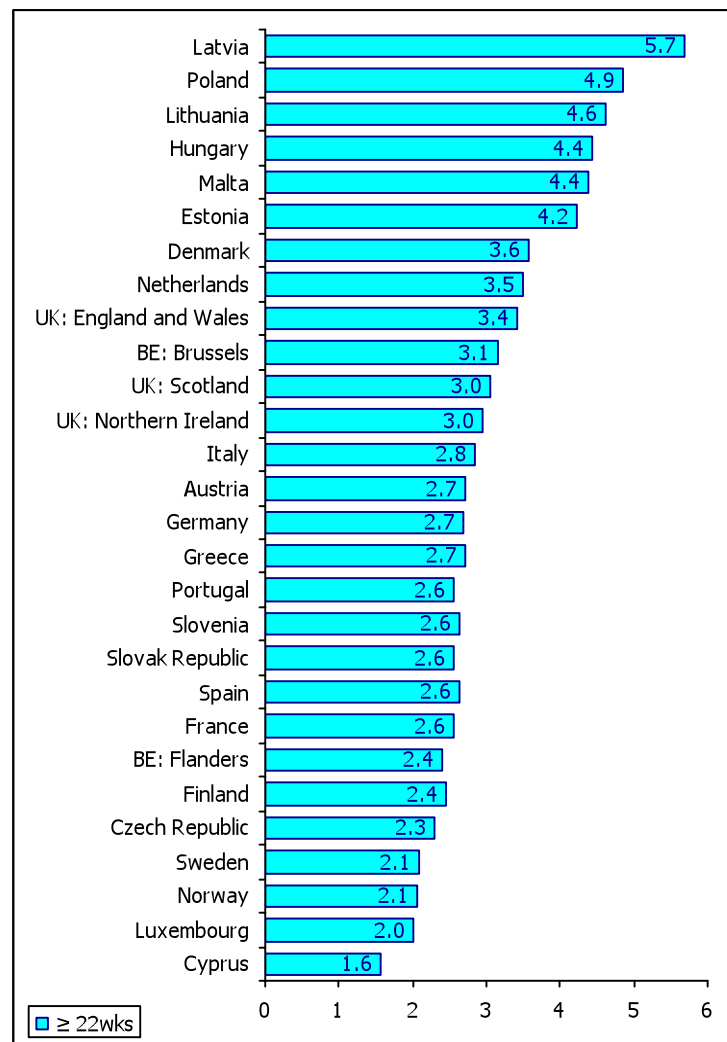
Data from 2004



## Fetal mortality rate per 1000 total births



## Neonatal mortality rate per 1000 live births





# Variability between European countries?

- › Real differences or artefacts?
- › Registration-related differences?
- › Differences in population characteristics?
- › Differences in health care services?
- › Differences in policies towards screening and terminations of pregnancy?





# Gestational Age Patterns of Fetal and Neonatal Mortality in Europe: Results from the Euro-Peristat Project

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## Abstract

**Background:** The first European Perinatal Health Report showed wide variability between European countries in fetal (2.6–9.1‰) and neonatal (1.6–5.7‰) mortality rates in 2004. We investigated gestational age patterns of fetal and neonatal mortality to improve our understanding of the differences between countries with low and high mortality.

**Methodology/Principal Findings:** Data on 29 countries/regions participating in the Euro-Peristat project were analyzed. Most European countries had no limits for the registration of live births, but substantial variations in limits for registration of stillbirths before 28 weeks of gestation existed. Country rankings changed markedly after excluding deaths most likely to be affected by registration differences (22–23 weeks for neonatal mortality and 22–27 weeks for fetal mortality). Countries with high fetal mortality  $\geq 28$  weeks had on average higher proportions of fetal deaths at and near term ( $\geq 37$  weeks), while proportions of fetal deaths at earlier gestational ages (28–31 and 32–36 weeks) were higher in low fetal mortality countries. Countries with high neonatal mortality rates  $\geq 24$  weeks, all new member states of the European Union, had high gestational age-specific neonatal mortality rates for all gestational-age subgroups; they also had high fetal mortality, as well as high early and late neonatal mortality. In contrast, other countries with similar levels of neonatal mortality had varying levels of fetal mortality, and among these countries early and late neonatal mortality were negatively correlated.

**Conclusions:** For valid European comparisons, all countries should register births and deaths from at least 22 weeks of gestation and should be able to distinguish late terminations of pregnancy from stillbirths. After excluding deaths most likely to be influenced by existing registration differences, important variations in both levels and patterns of fetal and neonatal mortality rates were found. These disparities raise questions for future research about the effectiveness of medical policies and care in European countries.

**Citation:** Mohangoo AD, Buitendijk SE, Szamotulska K, Chalmers J, Irgens LM, et al. (2011) Gestational Age Patterns of Fetal and Neonatal Mortality in Europe: Results from the Euro-Peristat Project. PLoS ONE 6(11): e24727. doi:10.1371/journal.pone.0024727



**Table 1.** Criteria for registration of live births and stillbirths and inclusion of terminations of pregnancy in Europe in 2004.

	Live births	Stillbirths	TOP included	TOP included in a separate data system
Austria	No limit	≥500 grams	No	No
BE: Brussels	No limit	≥22 weeks or ≥500 grams	No	No
BE: Flanders	No limit	≥500 grams	No	No
Cyprus	No limit	No data available	No data available	
Czech Republic	≥500 grams or any birth weight surviving the first 24 hours	≥22 weeks	No	Yes
Denmark	No limit	≥22 weeks	No	Yes
Estonia	No limit	≥22 weeks or ≥500 grams	No	Yes
Finland	No limit	≥22 weeks or ≥500 grams	No	Yes
France	≥22 weeks or ≥500 grams	≥22 weeks or ≥500 grams	Yes	No
Germany	No limit	≥500 grams	No	Yes
Greece	No limit	legal limit of ≥28 weeks	No	No
Hungary	No limit	≥24 weeks or ≥500 grams	No	Yes
Ireland	No limit	≥24 weeks or ≥500 grams	TOP is not legal and not performed	
Italy	No limit	180 days	No	Yes
Latvia	No limit	≥22 weeks	No	Yes
Lithuania	≥22 weeks	≥22 weeks	No	Yes
Luxembourg	No limit	180 days	No	No
Malta	No limit	≥22 weeks or ≥500 grams	TOP is illegal and not performed	
The Netherlands	≥22 weeks or ≥500 grams	≥24 weeks for civil registration ≥16 weeks for perinatal registry	Yes	Yes
Norway	≥12 weeks	≥12 weeks	No	Yes
Poland	≥500 grams	≥500 grams	No	Yes
Portugal	No limit	≥24 weeks	No	No
Slovakia	No limit	≥22 weeks or ≥500 grams	No	Yes
Slovenia	No limit	≥500 grams	No	Yes
Spain	No limit	≥26 weeks (national) ≥22 weeks (region Valencia)	No	Yes
Sweden	No limit	≥28 weeks	No	Yes
UK: England and Wales	No limit	legal limit of ≥24 weeks voluntary notification at 22–23 weeks	Yes	Yes
UK: Northern Ireland	No limit	legal limit of ≥24 weeks voluntary notification at 22–23 weeks	TOP is not legal*	
UK: Scotland	No limit	legal limit of ≥24 weeks voluntary notification at 22–23 weeks	Yes	Yes

\*The legislation which legalised abortion in the rest of the United Kingdom does not cover Northern Ireland, but TOP are occasionally done there under case law.



# No Limits for Registration of Live Births

## › Exceptions

### › Czech Republic:

≥ 500 grams or any birth weight surviving the first 24 hours

### › France and the Netherlands:

≥ 22 weeks or ≥ 500 grams

### › Norway:

≥ 12 weeks

### › Poland:

≥ 500 grams



# Substantial Variation in Registration of Stillbirths

- › BW criteria of  $\geq 500$  grams:  
Austria, Flanders, Germany, Poland, Slovenia
- › GA criteria:
  - $\geq 12$  wks in Norway
  - $\geq 16$  wks in the Netherlands (Perinatal Registry)
  - $\geq 22$  wks Czech Republic, Denmark, Latvia, Lithuania
  - $\geq 24$  wks in Portugal and United Kingdom
  - $\geq 180$  days in Italy and Luxembourg
  - $\geq 28$  wks in Greece and Sweden



## Substantial Variation in Registration of Stillbirths

- › GA and BW criteria:  $\geq 22$  wks or  $\geq 500$  grams  
Brussels, Estonia, Finland, France, Malta, Slovak Republic
- › GA and BW criteria:  $\geq 24$  wks or  $\geq 500$  grams  
Hungary and Ireland
- › Voluntary vs. obligatory registration:  
United Kingdom:  
Legal limits of  $\geq 24$  wks, but voluntary notification at 22-23 wks  
The Netherlands:  
Civil registration  $\geq 24$  wks, perinatal registration  $\geq 16$  wks



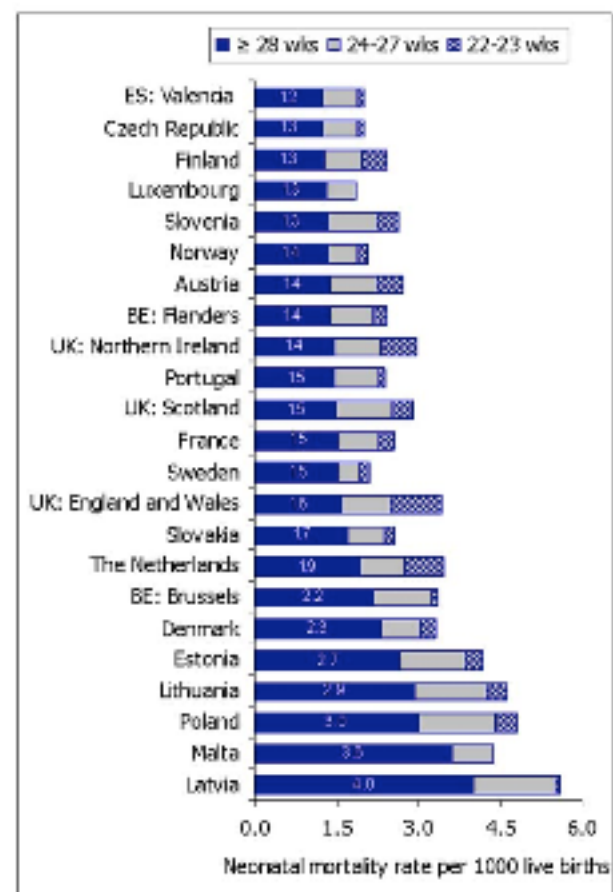
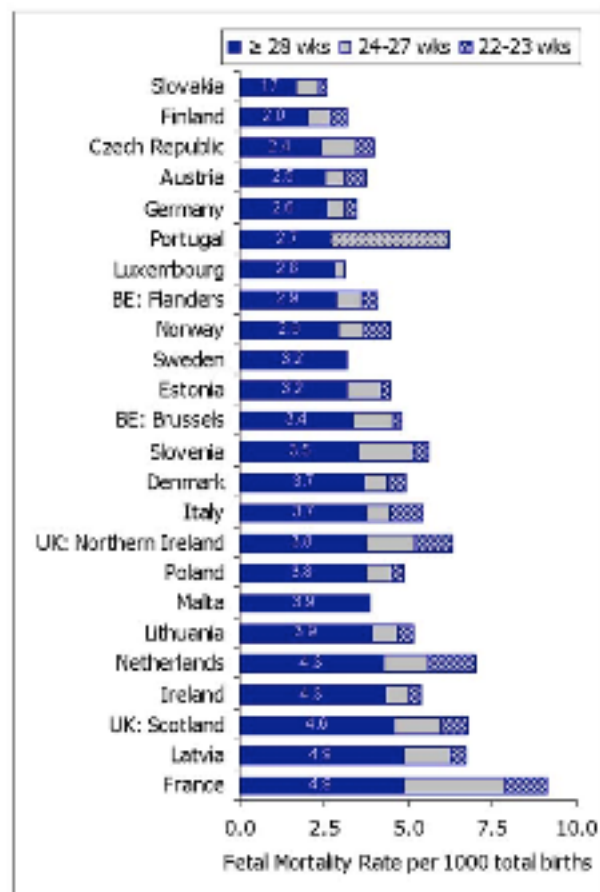
## Differences in Registration and Inclusion of TOP

- › TOP were not included by most countries
- › TOP were included  
by France, the Netherlands, England and Wales, Scotland
- › TOP were registered in separate system  
Finland and Italy provided additional data on TOP
- › TOP were not registered  
by Austria, Brussels, Flanders, Greece, Luxembourg, Portugal



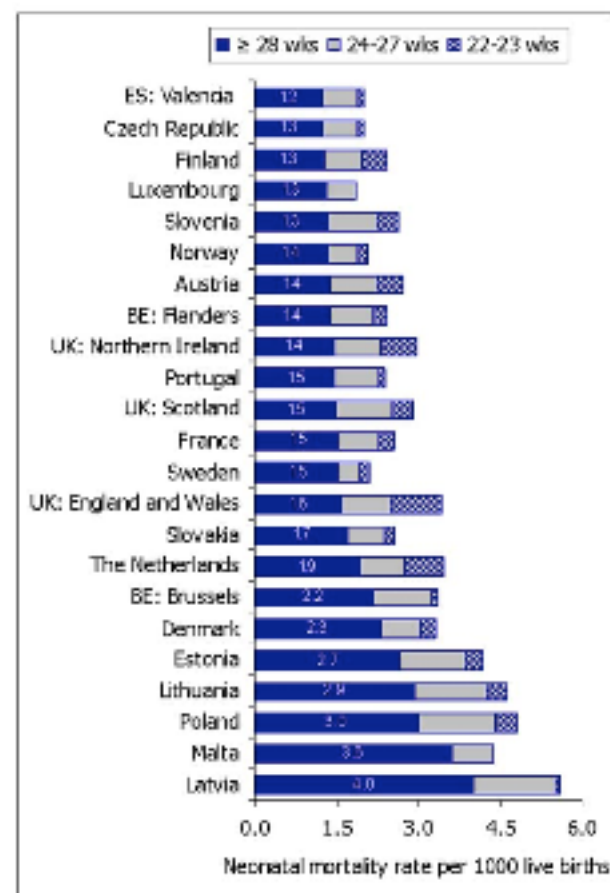
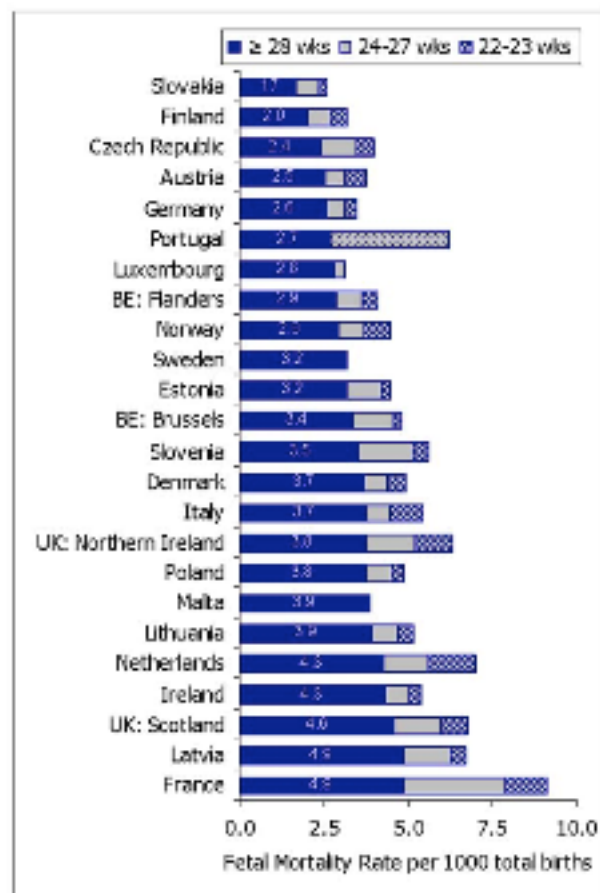
## Differences in Registration and Inclusion of TOP

- › TOP are illegal and not performed in Malta
- › TOP are not legal and not performed in Ireland
- › TOP are not legal in Northern Ireland, but are occasionally done under case law



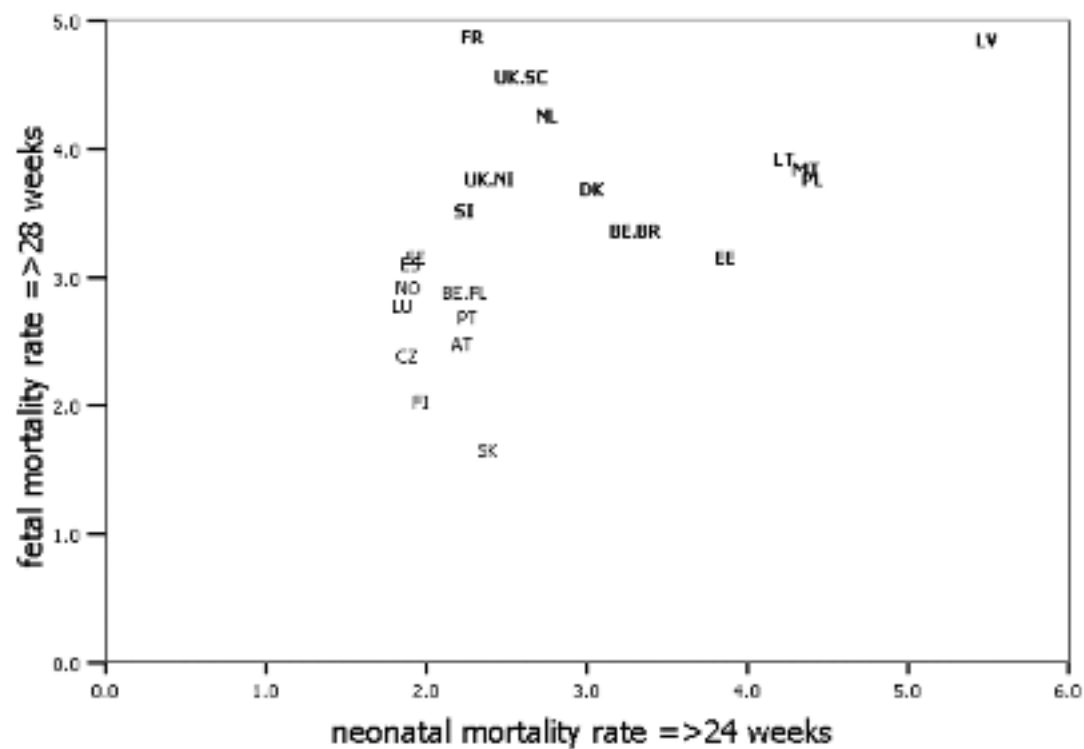
Impact of different inclusion criteria on perinatal mortality rates



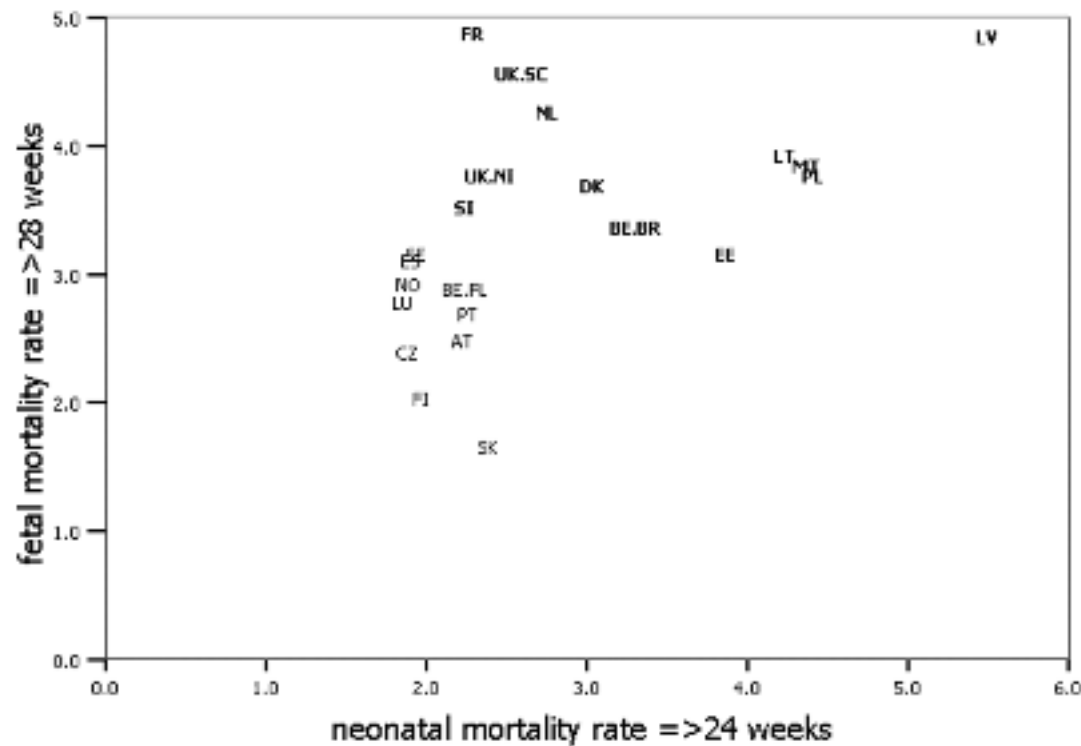


Impact of different inclusion criteria on perinatal mortality rates

The exclusion of early preterm births and deaths affects ranking



**Figure 3. Correlation between fetal and neonatal mortality rates, after exclusion of deaths most likely influenced by registration differences.** High mortality countries are presented in bold. Correlation for fetal and neonatal mortality:  $\rho = 0.646$  ( $p = 0.001$ ).  
doi:10.1371/journal.pone.0024727.g003



**Figure 3. Correlation between fetal and neonatal mortality rates, after exclusion of deaths most likely influenced by registration differences.** High mortality countries are presented in bold. Correlation for fetal and neonatal mortality:  $\rho = 0.646$  ( $p = 0.001$ ).  
doi:10.1371/journal.pone.0024727.g003

Fetal deaths at 22-27 wks and neonatal deaths at 22-23 wks  
were excluded to minimize the effect of differences in  
registration requirements and TOP legislation



## Euro-Peristat's Limitations

- › Despite efforts of Euro-Peristat to ensure comparability in definitions
- › Euro-Peristat's lack of knowledge about the extent to which these were applied uniformly in all countries
- › Limits Euro-Peristat's ability to assess real fetal mortality at 22-27 weeks and real neonatal mortality at 22-23 weeks



## Euro-Peristat's Limitations

- › A related issue is the registration of TOP, which is managed very differently from one country to another, and TOP are not always included as fetal deaths
- › TOP varied between 3-28% of total fetal deaths in those countries where this proportion could be computed
- › In France, even an larger proportion of early fetal deaths is estimated to be TOP



# Challenges for Euro-Peristat Action

- › Collect comparable data on European level
- › Assess *real* fetal mortality at 22-27 weeks
- › Assess *real* neonatal mortality at 22-23 weeks
- › Differentiate between fetal mortality with and without TOP
- › Assess the *real* proportion of total fetal deaths that is TOP



## Euro-Peristat's vs. countries criteria

- › If countries were not able to provide data using the Euro-Peristat's definition
  - › local definition was used
  - › e.g. different inclusion criteria for registration of stillbirths
- › To what extent should these countries who provided data using their own definitions be included for international comparisons?



## Euro-Peristat's versus WHO criteria

- › Continue data collection on births and deaths based on Euro-Peristat inclusion criteria of 22 completed weeks of gestation?
- › Change the inclusion criteria to WHO criteria, which is not solely based on gestational age?





Thank you!

Rebecca Lagos