

# Babies born at the limits of viability:

## Understanding variation in birth & death certification

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# Reducing infant mortality rates

- **Leicester, UK**

- Population: 330000
- 5500 births per year
- 31% children in poverty
- Infant mortality rate:

**7.0 /1000 births**

Worst 25<sup>th</sup> percentile

22-23 week gestation births

4 in 5 recorded live born

- **Comparison area, UK**

- Population: 250000
- 4500 births per year
- 45% children in poverty
- Infant mortality rate:

**5.2 /1000 births**

Similar to England average

22-23 week gestation births

1 in 5 recorded live born

Both regions: Infant mortality rate >**24 weeks** gestation ~ 4.8/1000 births

# Births born at the limits of viability

## Births at 22-23 weeks

- Rare events  
0.1-0.2% of all live births
- Poor survival  
1% at 22 weeks  
19% at 23 weeks  
Many live for only a few minutes
- **Large impact** on infant mortality  
1/5 of **all** infant deaths



# Certifying births: Example of England

- No guidelines exist on birth certification in pre-viable infants
- Officially:  
All live births of any gestation are certified  
Only fetal deaths from 24 weeks are certified
- So fetal deaths at 22-23 weeks do not contribute to **any** mortality statistics  
Infant mortality (deaths < 1 year)  
Stillbirth rate

Application No. \_\_\_\_\_ QHX \_\_\_\_\_

CAUTION—There are offences relating to falsifying or altering a certificate and using or possessing a false certificate.  
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**CERTIFIED COPY OF AN ENTRY**

1. No. of entry	Registration District Cambridgeshire	
2. Date and country of birth of child	England	Sub-district Cambridgeshire Second
3. Name and surname of child		
4. Sex of child		
5. Name and surname of adopter or adopters		
6. Date of adoption order and description of court by which made	Cambridgeshire	
7. Date of entry	Application Number _____	
8. Signature of officer deputed by Registrar General to attest the entry		

**CERTIFIED to be a true copy of the Register maintained at the GENERAL REGISTER OFFICE, under the provisions of the Act of 1836.**

This certificate is issued pursuant to the Adoption and Children Act 2002 (No. 28) and is a true copy of the original as entered in the Register of Births and Deaths maintained at the General Register Office, London.

**WARNING: A CERTIFICATE IS NOT EVIDENCE OF IDENTITY.**

Application Number \_\_\_\_\_ QBDX \_\_\_\_\_

**CERTIFIED COPY OF AN ENTRY**

**DEATH**

Registration district CAMBRIDGESHIRE	Entry No. Administrative area County of Cambridgeshire and Isle of Ely
Sub-district CAMBRIDGESHIRE	
1. Date and place of death	3. Sex
2. Name and surname	4. Maiden surname of woman who has married
5. Date and place of birth	
6. Occupation and usual address	
7 (a) Name and surname of informant	(b) Qualification
(c) Usual address	
8. Cause of death	
9. I certify that the particulars given by me above are true to the best of my knowledge and belief	Signature of informant
10. Date of registration	11. Signature of registrar

How many medical

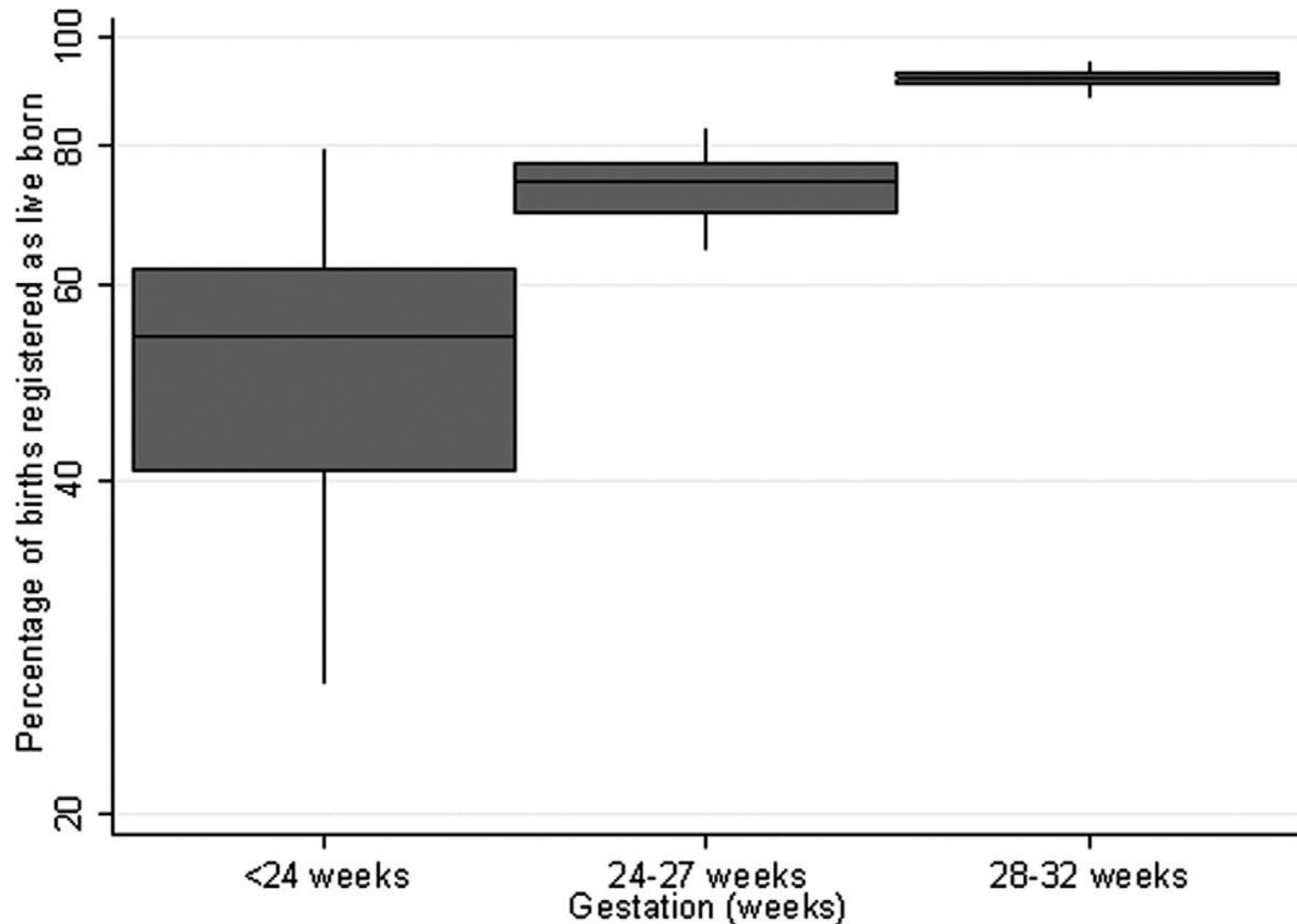
**CERTIFIED to be a true copy of an entry in the certified copy of a register of Births or Deaths in the District above mentioned. Given at the GENERAL REGISTER OFFICE, under the Seal of the said Office on 12th December 2006**

**CAUTION: THERE ARE OFFENCES RELATING TO FALSIFYING OR ALTERING A CERTIFICATE AND USING OR POSSESSING A FALSE CERTIFICATE. ©CROWN COPYRIGHT**

**WARNING: A CERTIFICATE IS NOT EVIDENCE OF IDENTITY.**

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# Variation in the certification of births: Example of England



# Regional variation in certification in England

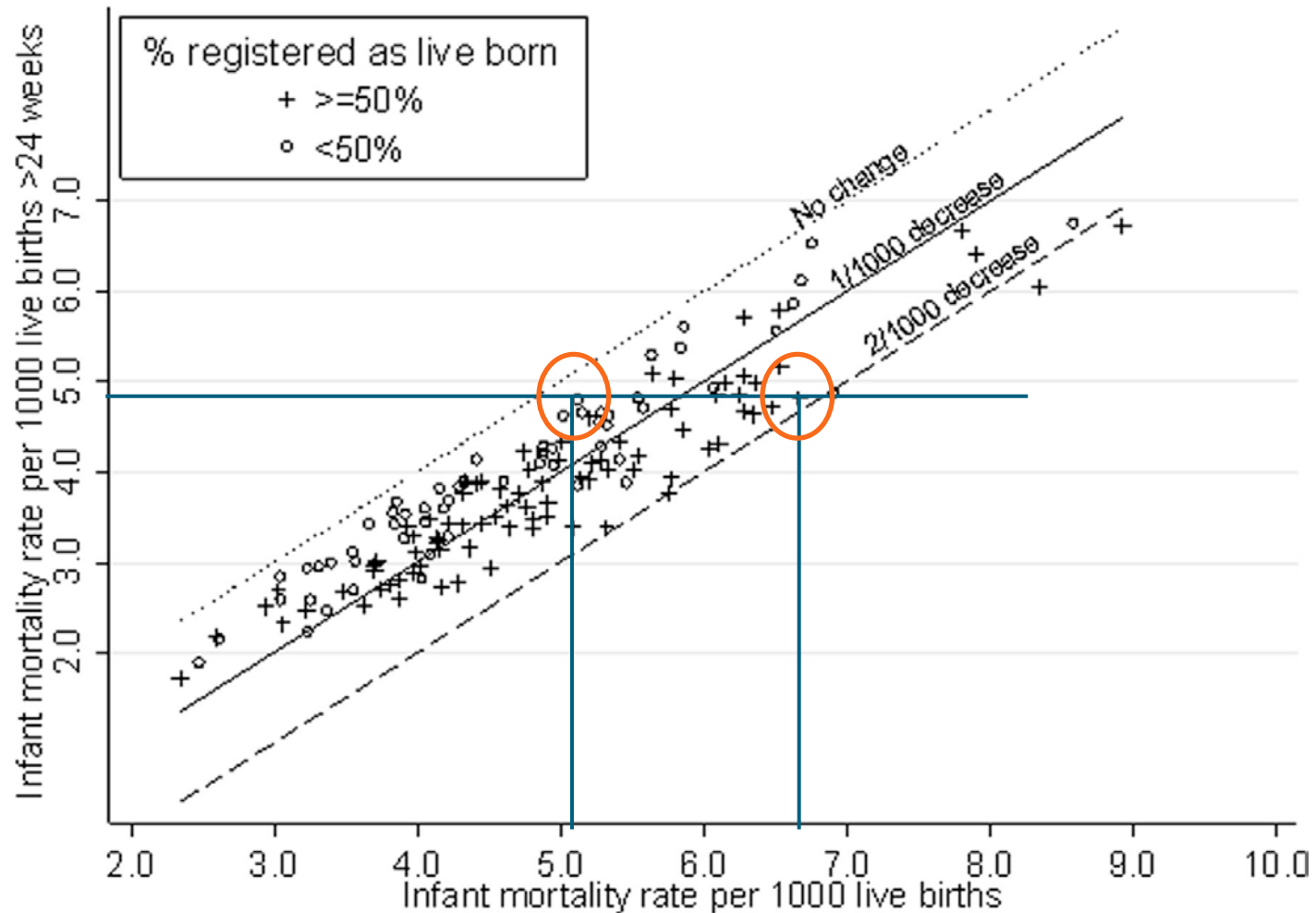
20-80% certified live born

Up to 30% higher infant mortality rates  
solely due to 22-23 week gestation



Artefactual  
differences in  
infant mortality  
rates

# Impact on infant mortality



Smith L, Draper ES, Manktelow BN, Pritchard C, Field DJ.

Archives of Disease in Childhood-Fetal and Neonatal Edition 2013;98(2):F103-F107

# Regional variation in certification

20-80% certified live born  
Up to 30% higher infant mortality rates  
solely due to 22-23 week gestation

Artefactual  
differences in  
infant mortality  
rates

Biased evidence base  
Invalid regional comparisons  
Not comparing “Like with like”  
Inappropriate implementation of  
services

Inequalities in  
access to services  
and benefits for  
parents

E.g. Official birth & death certificate  
Maternity pay  
Maternity / paternity leave  
Child benefit for 8 weeks  
Free prescriptions & dental care  
Coroner’s investigation



# Impact on parents

## The personal side

financial impact

emotional impact



# Impact of 22&23 weeks births on mortality in Europe

OPEN ACCESS Freely available online

PLOS one

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

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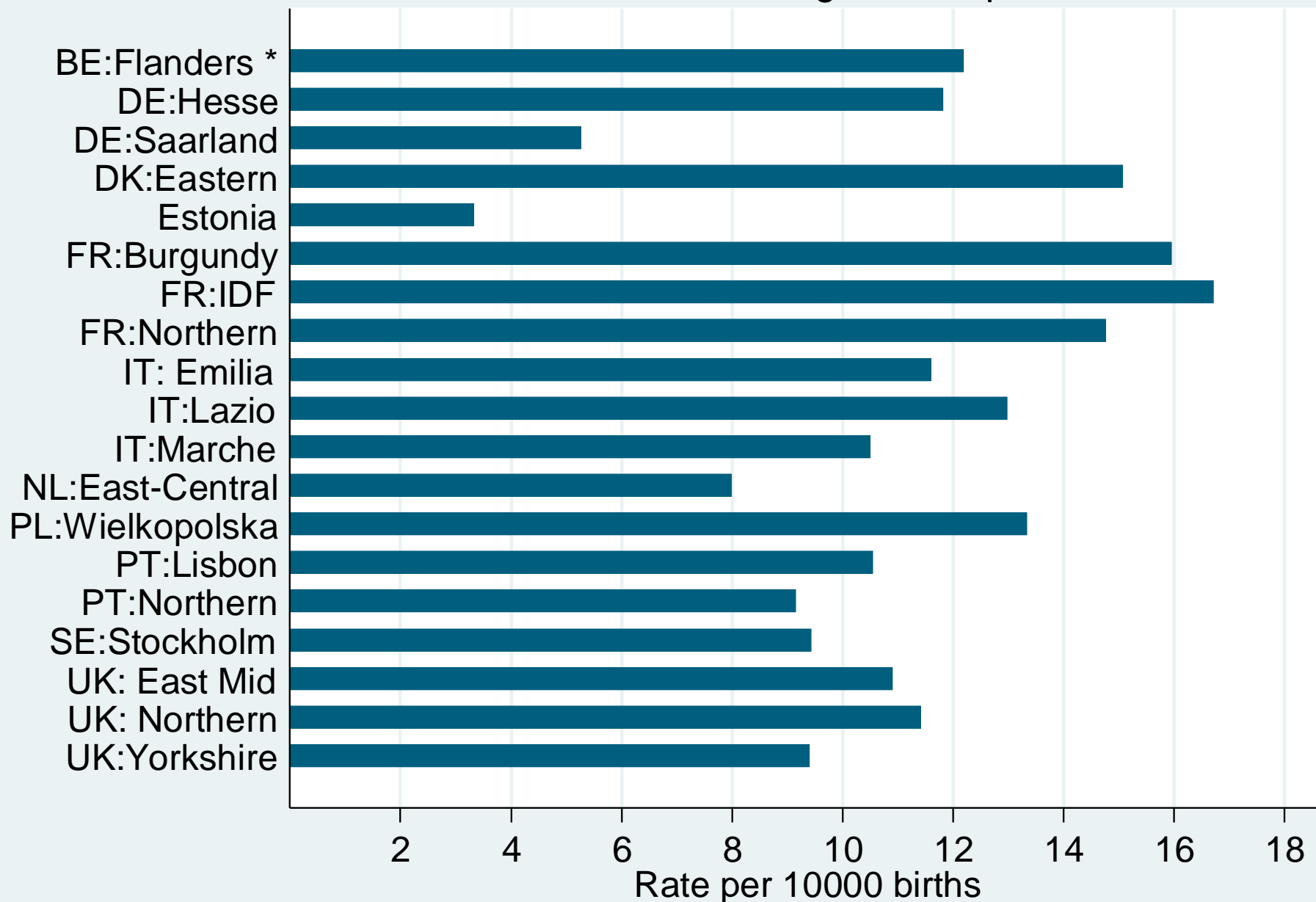
### Abstract

**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.

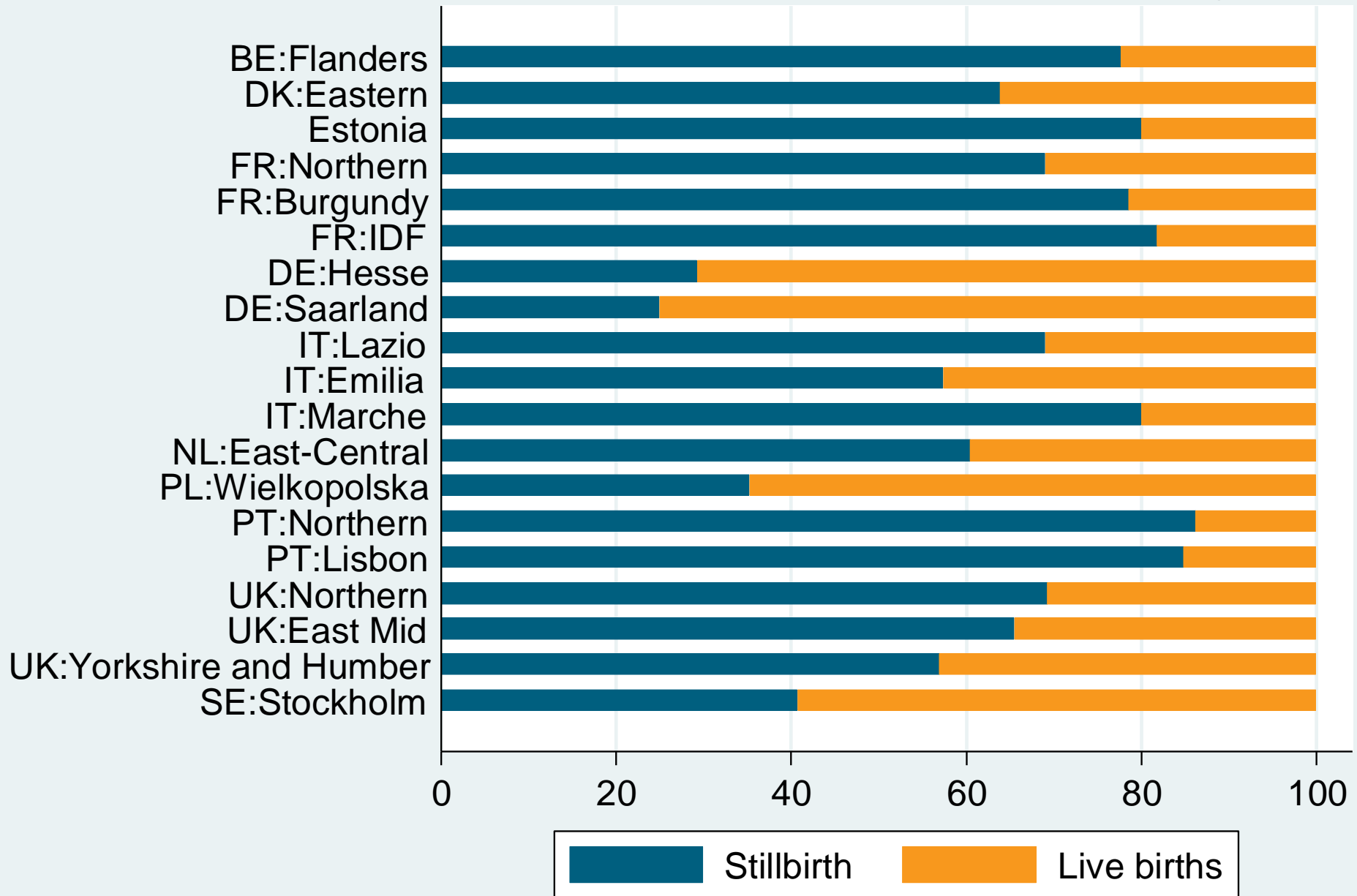
**Methodology/Principal Findings:** Data on 29 countries/regions participating in the Euro-Peristat project were analyzed. Most European countries had no limits for the registration of live births, but substantial variations in limits for registration of stillbirths before 28 weeks of gestation existed. 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.

## Rate of births 22-23 weeks gestation per 10000 births



# % of live births and stillbirths at 22-23 weeks gestation



# Exploring variation in Europe

- What to do now regarding mortality comparisons
  - Excluding certain gestations; Babies alive at onset of labour
  - Extended perinatal mortality
- Explore variation in certification: fetal or neonatal deaths
  - Differences in determining signs of life
  - Gestation/birth weight criteria for official statistics
- Understanding the impact on parents
  - provision of birth and death certificates
  - access to benefits
  - costs of burial

# European variation in certification – initial findings

Registered live birth  
ONLY if survive till  
admitted to  
neonatal care

Registered live birth  
if Apgar score > 1 at  
1 minute

Only fetal deaths  
over 500g recorded

Births showing signs  
of life <22 weeks  
registered as  
a fetal death

# European variation in impact on parents

Parents must pay  
for burial if birth  
reported as a live  
birth ending in  
neonatal death

Variation in receipt  
of birth and death  
certificates

Variation in  
gestation for  
receipt of maternity  
leave and benefits

Differences in  
whether deaths  
referred for outside  
clinical investigation

# Questionnaire to explore regional practice regarding babies born at the limits of viability

<https://www.surveymonkey.com/r/EURO-PERISTAT>

**EPICE study of babies born at the limits of viability**

We are interested in the OFFICIAL registration of babies born at the limits of viability in your EPICE region. We would like you to respond as a representative of your region rather than based on your own personal practice.

Name  Specialty e.g. obstetrics, neonatology

EPICE region(s) represented

Email address

**Existing guidelines**

Which GUIDELINES are used in your hospital to guide day to day practice when deciding whether a baby is officially reported as a LIVE BIRTH or STILLBIRTH.

☐ Nationally determined guidelines ☐ Local hospital policy  
☐ Regional policy agreed between hospitals ☐ No known guidelines at any level

**Definition of signs of life for LIVE BIRTHS**

In the GUIDELINES in YOUR HOSPITAL, which of the following are considered *specifically* when determining whether a baby is LIVE BORN

**Breathing**  
☐ Any breathing  
☐ Breathing but written reference to excluding fleeting respiratory efforts or gasps  
☐ No reference to breathing  
☐ Don't know

**Heartbeat**  
☐ Any beating of the heart  
☐ Beating of the heart but written reference to exclude transient cardiac contractions  
☐ No reference to heartbeat  
☐ Don't know

**Active body / muscle movement**  
☐ Any definite movement of voluntary muscles whether or not the umbilical cord cut or placenta attached  
☐ Definite movement of voluntary muscles only after the umbilical cord has been cut  
☐ No reference to muscle movement  
☐ Don't know

**Audible cry**  
☐ Any audible cry  
☐ No reference to audible cry  
☐ Don't know

**Pulsation of the umbilical cord**  
☐ Any pulsation of the umbilical cord  
☐ No reference to pulsation of the umbilical cord  
☐ Don't know

**Registration of births**

What are the criteria used to decide whether a birth is registered and contributes to national statistics?  
For example  
Where only births showing signs of life are reported as live births if they are EITHER greater than 22 weeks gestation OR have a birth weight of at least 500g:  
Record as: 22 weeks gestation AND/OR 500g weight  
Where only births showing signs of life are reported as live births if they are BOTH greater than 22 weeks gestation AND have a birth weight of at least 500g:  
Record as: 22 weeks gestation AND/OR 500g weight

**LIVE BIRTH:** criteria for formally reporting a birth showing signs of life as a live birth

Gestation  weeks AND / OR\* Birth weight  grams AND / OR\* Survival time  minutes

**STILLBIRTH:** criteria for formally reporting a fetal death as a stillbirth to be included in national statistics

Gestation  weeks AND / OR\* Birth weight  grams

\* Delete as appropriate

**Following the death**

We are interested in what procedures are in place following the death for the following categories:

Official live birth ending in neonatal death: Neonatal deaths that would be recorded in official statistics  
Official reported stillbirth: Stillbirths that would be recorded in official statistics  
Other fetal death not fulfilling reporting criteria: Fetal deaths that are not included in guidelines for reporting

**Referral for outside investigation**

Which of the following deaths would be routinely referred for legal or clinical outside investigation?

	Yes	No	Don't know
Official live birth ending in neonatal death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Official reported stillbirth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other fetal death not fulfilling reporting criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Provision of birth and death certificates**

Are birth and death certificates provided for parents following a death?

	BIRTH CERTIFICATES			DEATH CERTIFICATES		
	Official	Unofficial	None	Official	Unofficial	None
Official live birth ending in neonatal death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Official reported stillbirth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other fetal death not fulfilling reporting criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Who determines the provision of birth and death certificates for these deaths?

	National policy	Regional policy	Hospital policy
Official live birth ending in neonatal death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Official reported stillbirth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other fetal death not fulfilling reporting criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Provision of birth and death certificates**

At what gestation are maternity and paternity leave and benefits available?  
Enter gestation in weeks or NK for "Not Known" or NA for "Not Available"

	Maternity leave	Maternity pay	Paternity leave	Paternity pay
Official live birth ending in neonatal death	<input type="text"/> weeks	<input type="text"/> weeks	<input type="text"/> weeks	<input type="text"/> weeks
Official reported stillbirth	<input type="text"/> weeks	<input type="text"/> weeks	<input type="text"/> weeks	<input type="text"/> weeks
Other fetal death not fulfilling reporting criteria	<input type="text"/> weeks	<input type="text"/> weeks	<input type="text"/> weeks	<input type="text"/> weeks

**Legal funeral requirements and expenses available**

Is it required by law to have a formal burial or cremation?  
Are parents entitled to receive help or financial aid with arranging the funeral.

	BURIAL/CREMATION REQUIRED			BENEFITS AVAILABLE		
	Yes	No	Don't know	State	Hospital	None
Official live birth ending in neonatal death	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Official reported stillbirth	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other fetal death not fulfilling reporting criteria	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Thank you for your help. Any questions please contact me at lks1@leicester.ac.uk  
Please return to: Lucy Smith, Department of Health Sciences, University of Leicester, LEICESTER, LE1 6TP, UK



# Babies born at the limits of viability

## Develop knowledge

Update UK evidence base

Compare evidence in Europe



## Build intelligence

Understand how clinicians certify births

Explore parents' experiences



## Translate knowledge into action

Develop clinicians' training package

Develop parents' support package

Recommend best practice for comparisons



## Improve health and reduce inequalities

Optimise service provision

Reduce inequalities in parents' access to benefits

Improve parents' experiences

# Thank you

We need your help with this research project

<https://www.surveymonkey.com/r/EURO-PERISTAT>