Factors affecting the comparability of data sources: Birth & death registration at the limits of viability

Lucy Smith and Beatrice Blondel

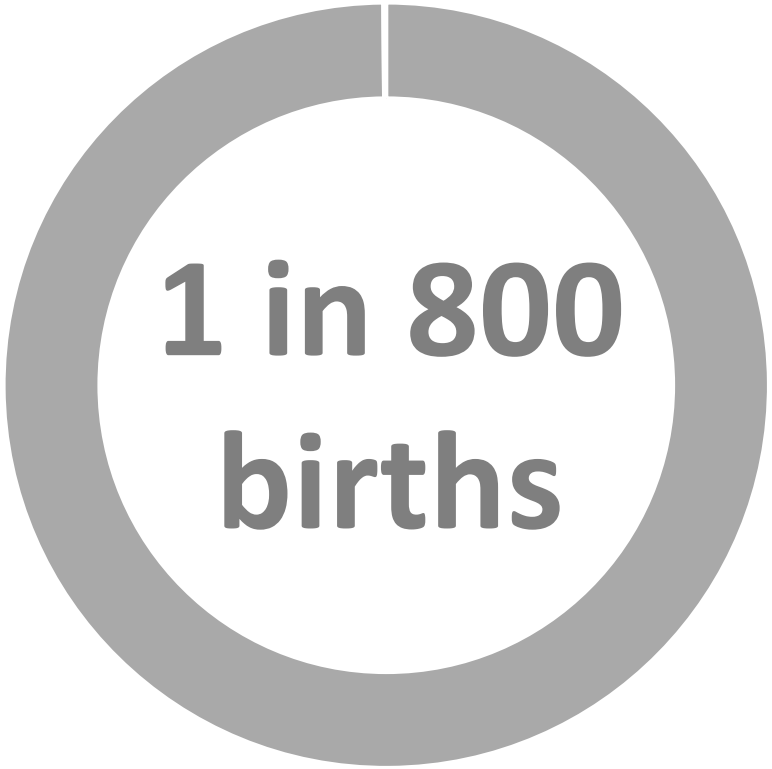
UNIVERSITY OF LEICESTER

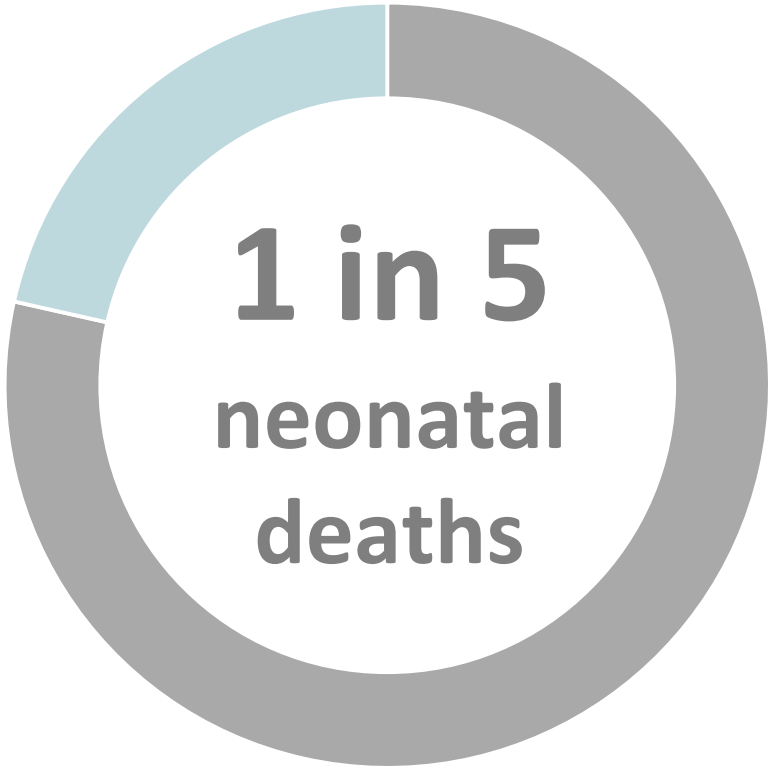
Workshop plan

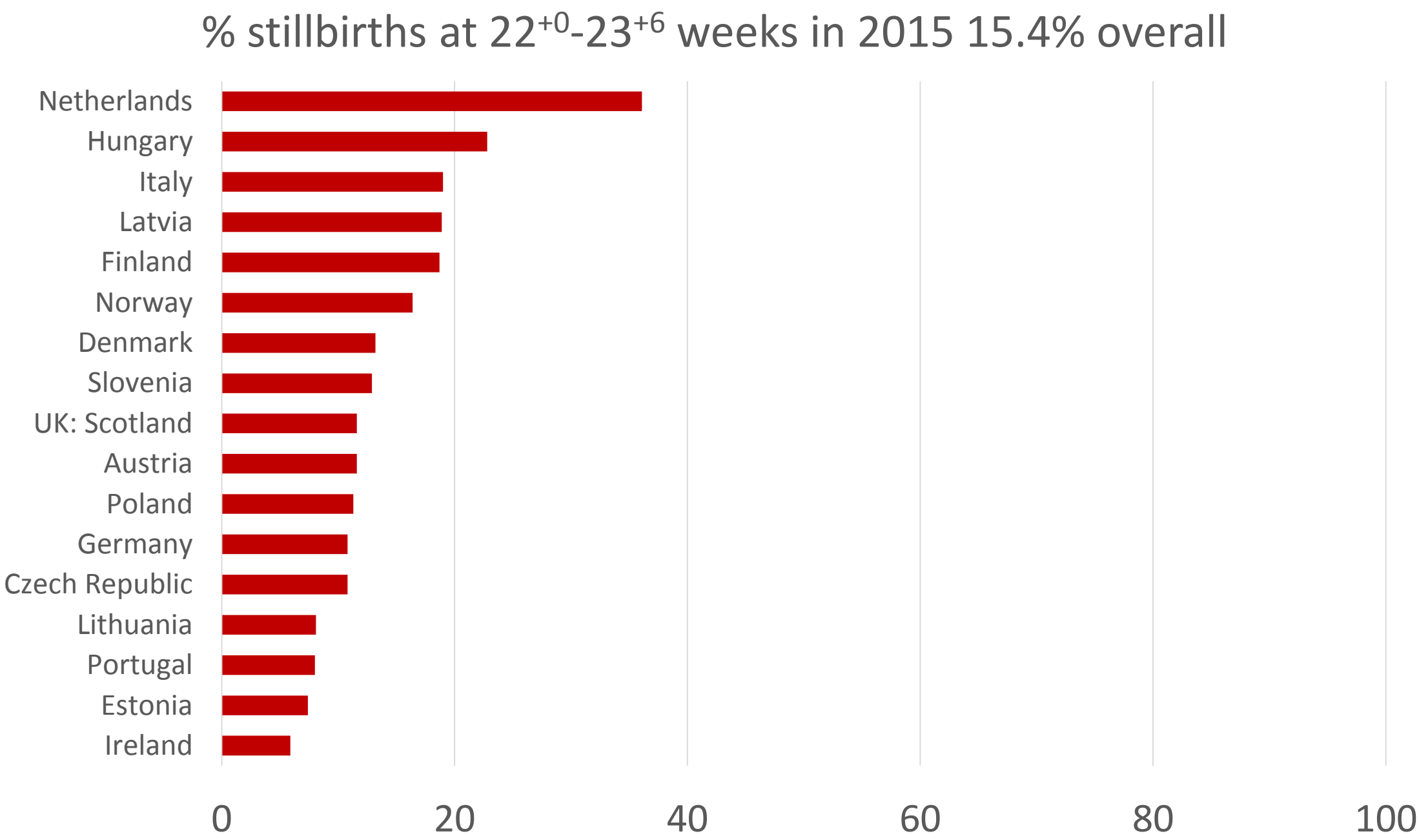
- Birth and death registration at the limits of viability
- Termination of pregnancy
- Small group discussions of vignettes
- Group discussion

- Write up discussion for BJOG commentary piece

Births at the limits of viability – 22^{+0}-23^{+6} weeks gestation






% stillbirths at 22+0-23+6 weeks in 2015 15.4% overall
Netherlands
Hungary
Italy
Latvia
Finland
Norway
Denmark
Slovenia
UK: Scotland
Austria
Poland
Germany
Czech Republic
Lithuania
Portugal
Estonia
Ireland
0
20
40
60
80
100

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

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

Babies born at the limits of viability: A mixed methods approach

Develop knowledge

Update UK evidence base | Compare evidence in Europe

Build intelligence

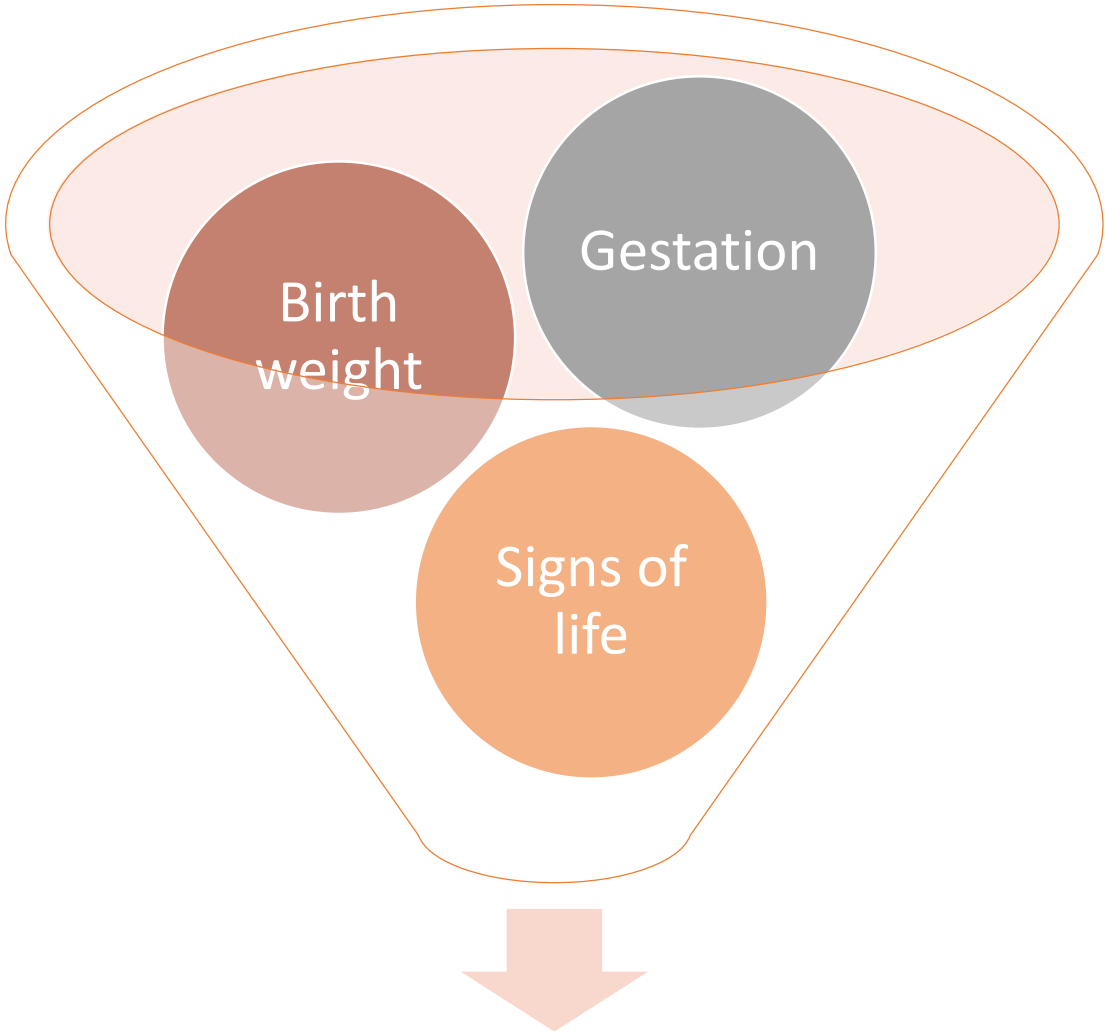
Understand how clinicians certify births | Explore parents' experiences

Translate knowledge into action

Develop clinical training | Develop parental support | Recommend best practice

Improve health and reduce inequalities

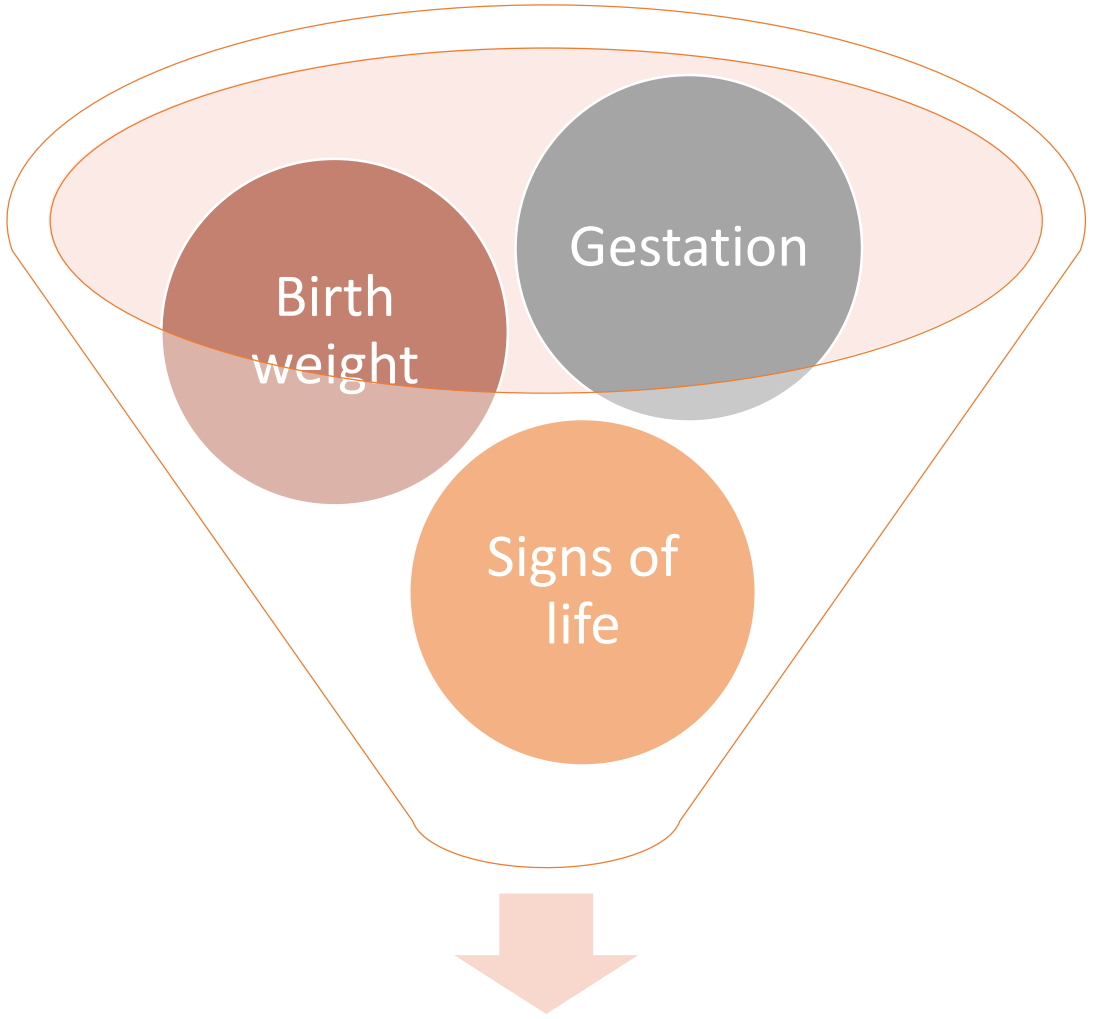
Reduce variation in service provision | Increase parental support



Birth registration

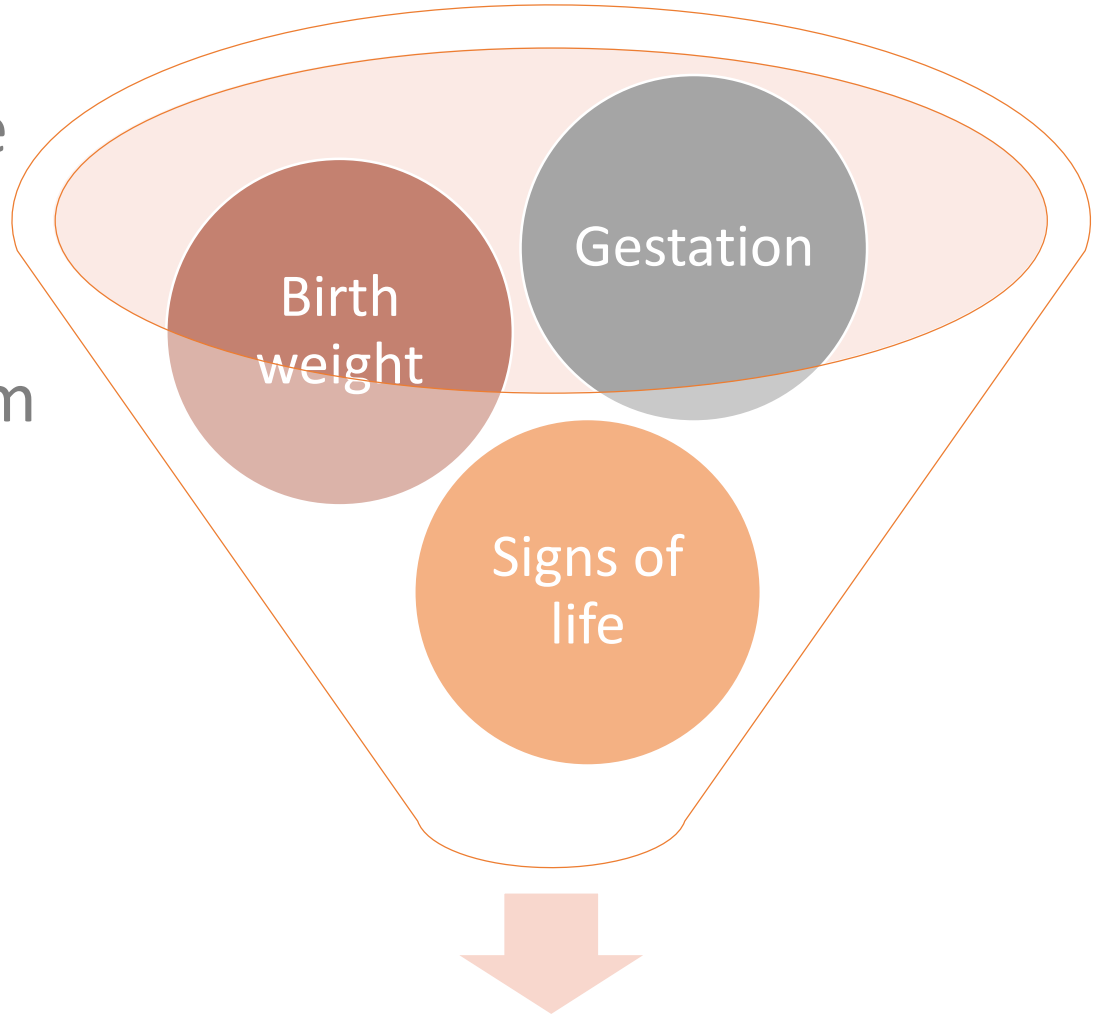
Birth weight

- Where birth occurs
- Policy on time to birth for antepartum stillbirths



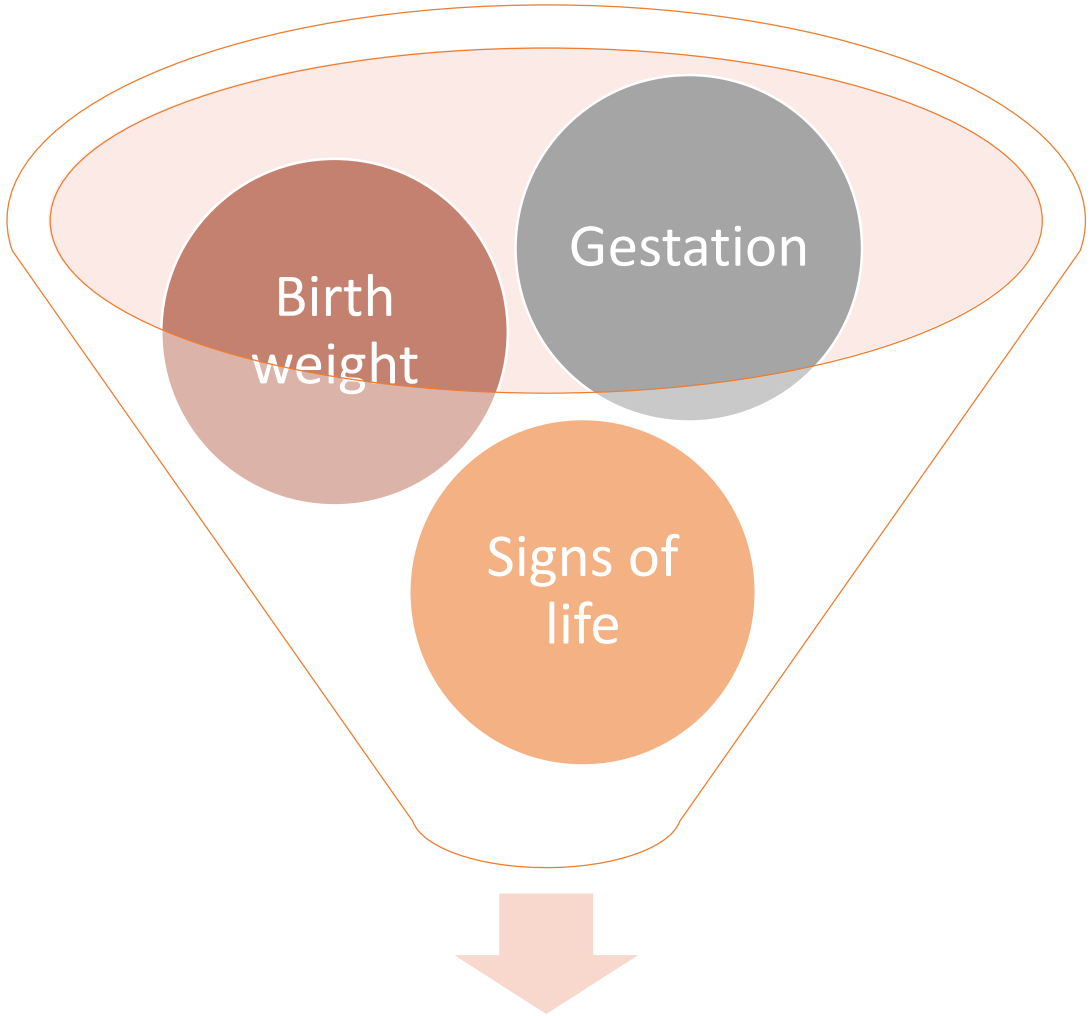
Gestation

- Whether the mother booked for care
- Clinical dating information
- Interventions to delay birth
- Policy on time to birth for antepartum stillbirths
- Gestation at death (Including multiples)
- Timing of anomaly scans

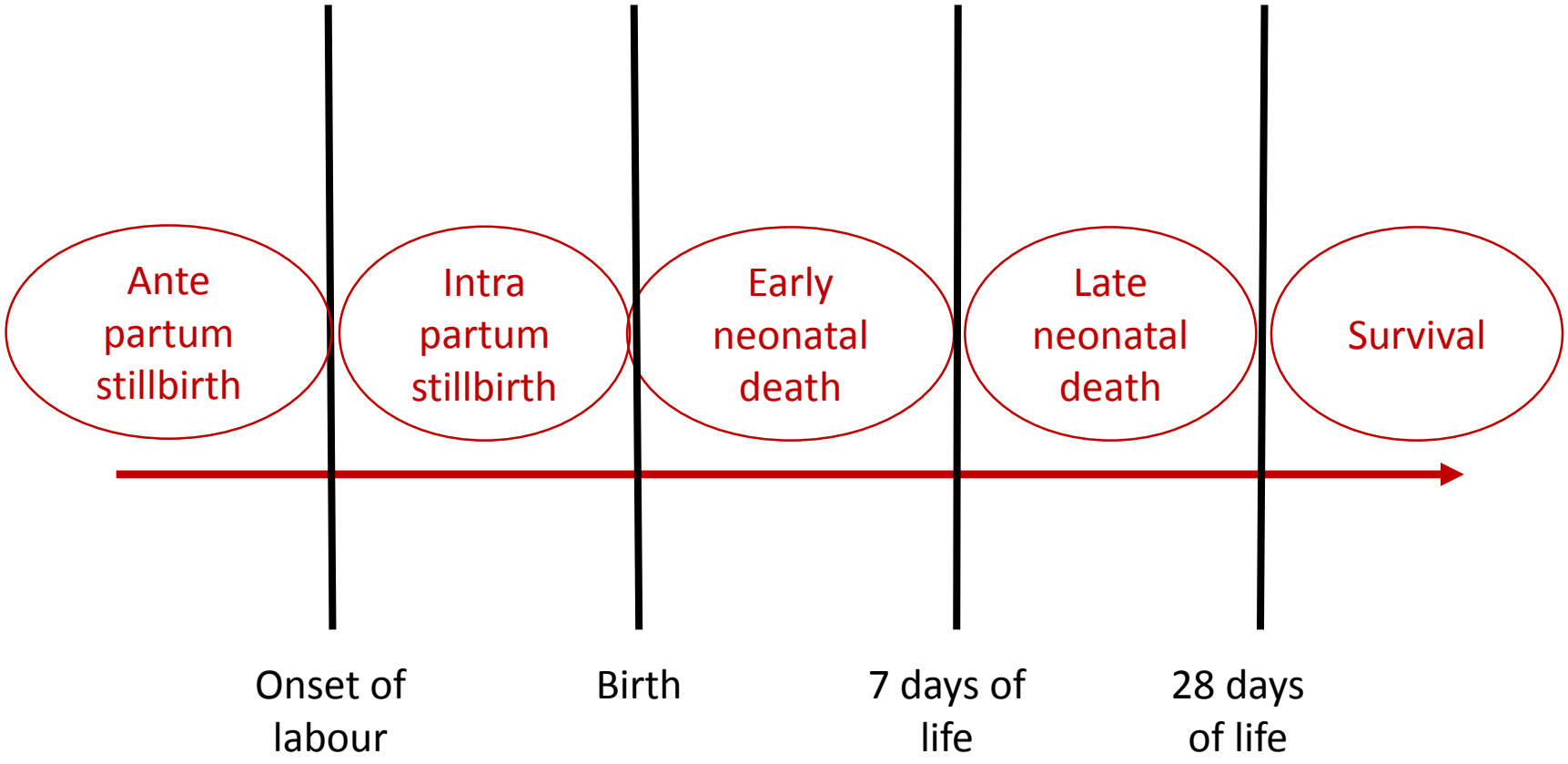


Signs of life

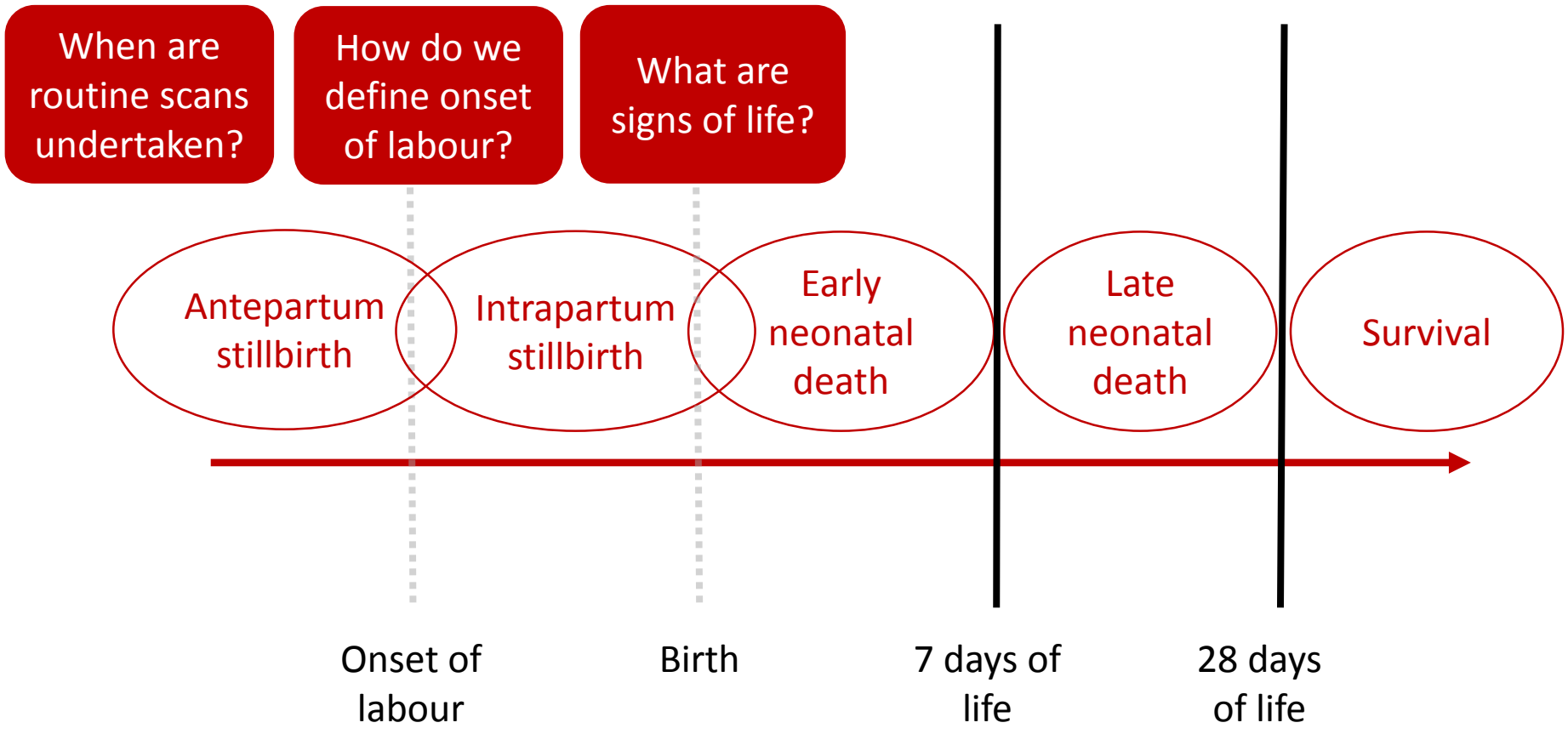
- Definition of signs of life and how they are interpreted
- Attitudes towards viability – hospital, clinician and parent
- Clinical perception of parents' preferences
- Time to death
- Where the death occurs
- Impact of registration on parents



Classification of death

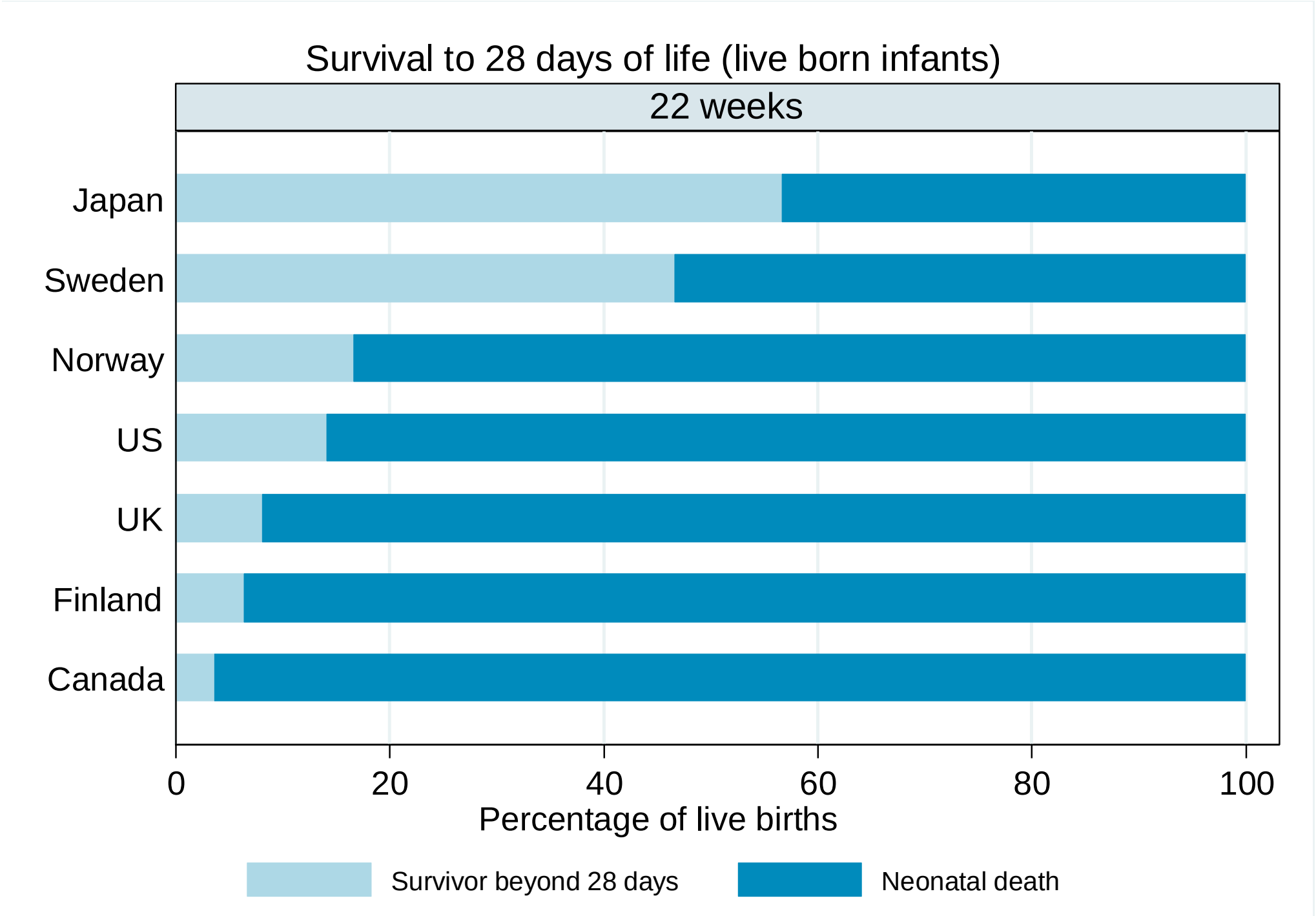


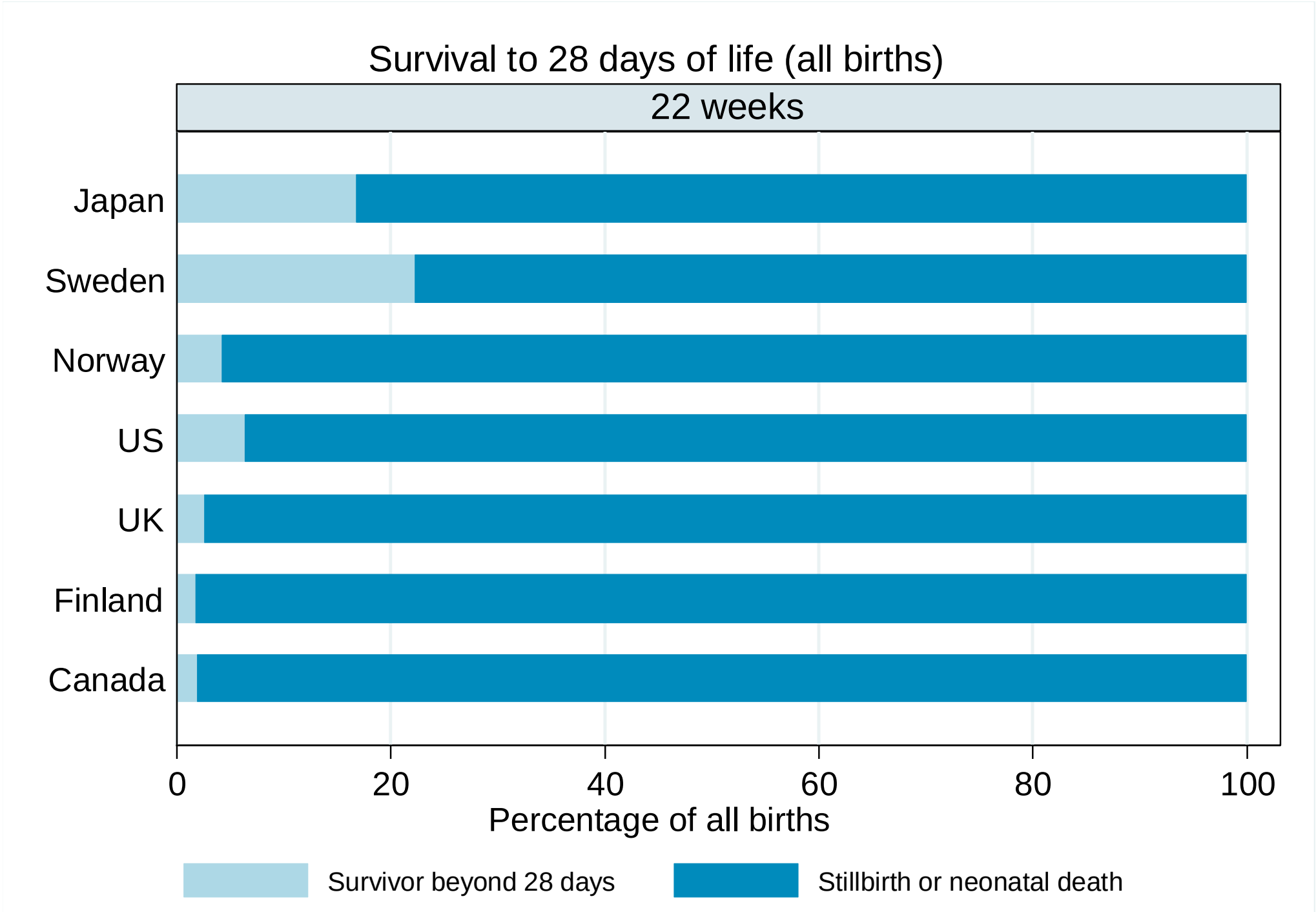
Classification of death

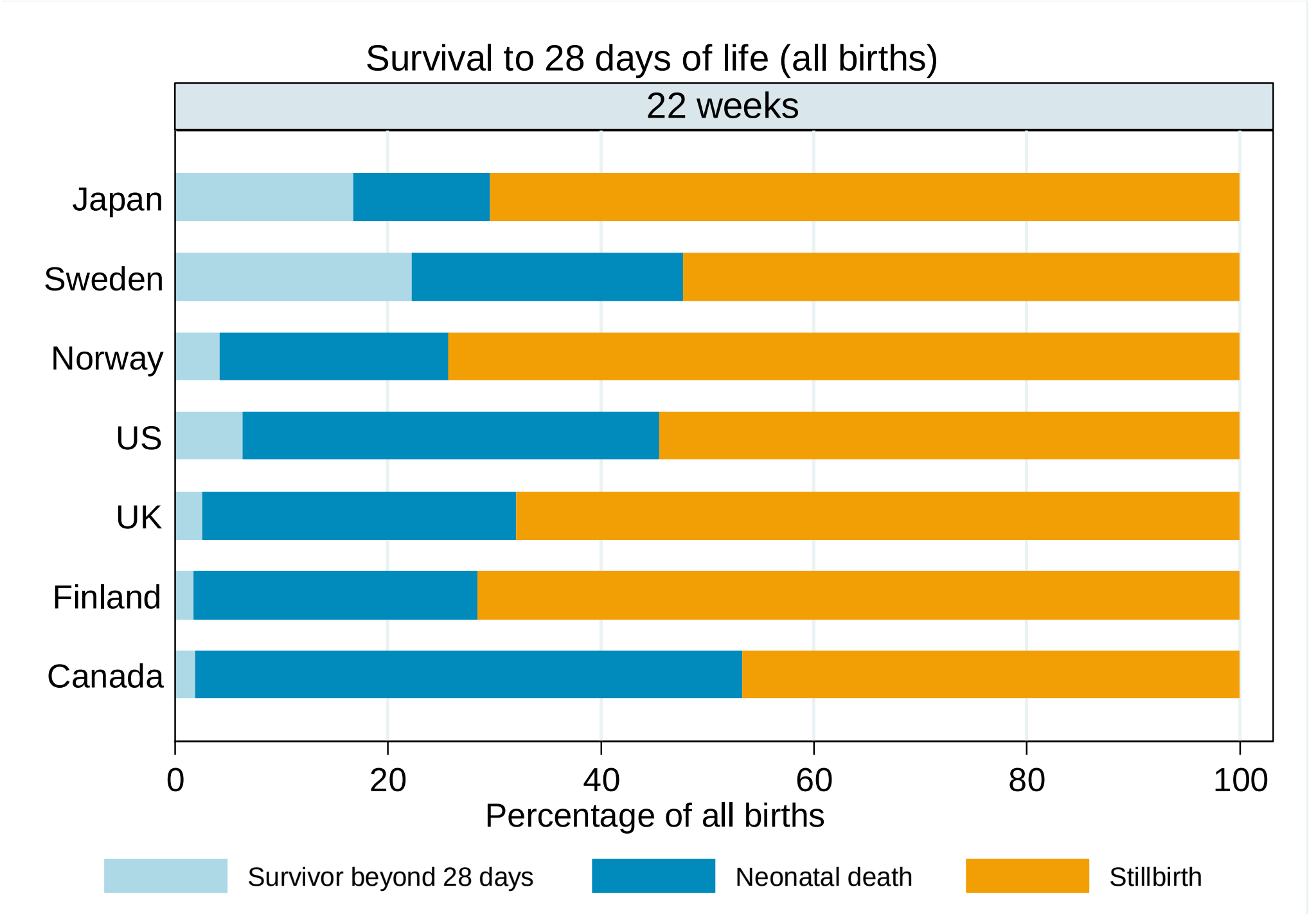


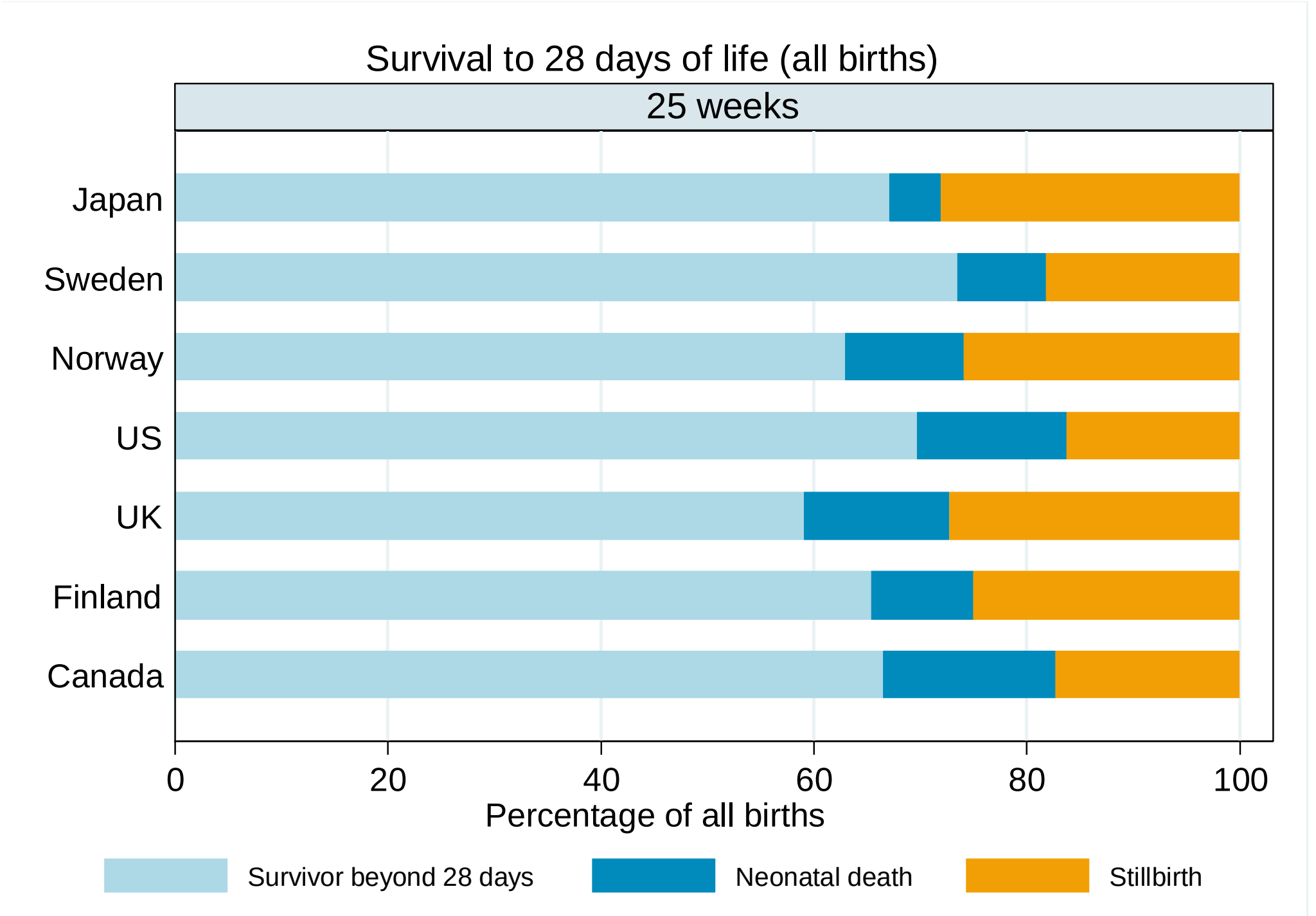
Defining population under study

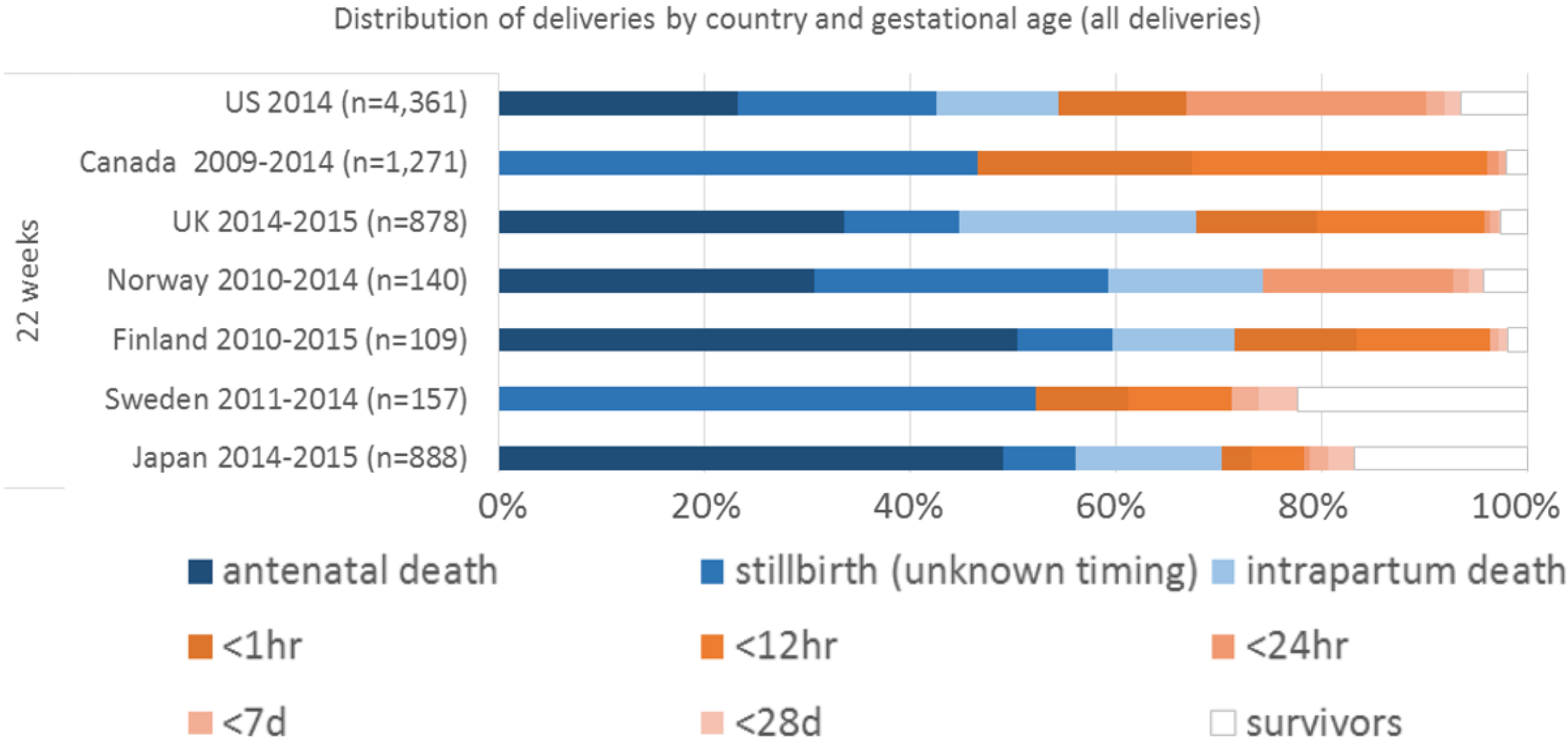
- All births
- Births alive at onset of labour
- Live births
- Live births surviving to neonatal care admission or discharge
- Survival to 24 hours


Survival to 28 days of life (live born infants)
22 weeks
Japan
Sweden
Norway
US
UK
Finland
Canada
0
20
40
60
80
100
Percentage of live births
Survivor beyond 28 days
Neonatal death


Survival to 28 days of life (all births)
22 weeks
Japan
Sweden
Norway
US
UK
Finland
Canada
0
20
40
60
80
100
Percentage of all births
Survivor beyond 28 days
Stillbirth or neonatal death


Survival to 28 days of life (all births)
22 weeks
Japan
Sweden
Norway
US
UK
Finland
Canada
0
20
40
60
80
100
Percentage of all births
Survivor beyond 28 days
Neonatal death
Stillbirth


Survival to 28 days of life (all births)
25 weeks
Japan
Sweden
Norway
US
UK
Finland
Canada
0
20
40
60
80
100
Percentage of all births
Survivor beyond 28 days
Neonatal death
Stillbirth


Distribution of deliveries by country and gestational age (all deliveries)
22 weeks
US 2014 (n=4,361)
Canada 2009-2014 (n=1,271)
UK 2014-2015 (n=878)
Norway 2010-2014 (n=140)
Finland 2010-2015 (n=109)
Sweden 2011-2014 (n=157)
Japan 2014-2015 (n=888)
0%
20%
40%
60%
80%
100%
antenatal death
stillbirth (unknown timing)
intrapartum death
<1hr
<12hr
<24hr
<7d
<28d
survivors

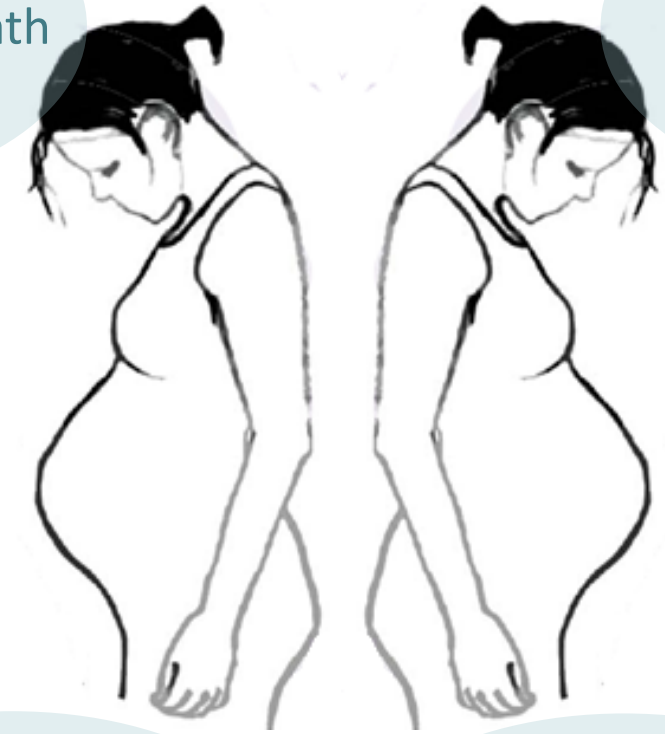
A woman experiencing a loss at 22 or 23 weeks in the UK…

A neonatal death

A "miscarriage"

Official record
Official birth and death certificates

No official record
Only informal birth and death certificates are available



Time to grieve
Maternity and paternity leave

No time to grieve
Only sick pay is available

Official coroner's investigation

No official investigation

Financial aid
Maternity pay and free prescriptions, dental care

No financial aid

Vignette 1a

A pregnant woman attends an anomaly scan at **21^{+5} weeks gestation**. It is a singleton pregnancy. The baby's heartbeat cannot be found during the ultrasound scan and the baby is confirmed to have died. It is not known when the death occurred but a heartbeat was recorded at an appointment at **20^{+2} weeks**.

The woman is given the option of having the birth induced

a) on that day (21^{+5});
b) two days later (22^{+0});
c) allow the birth to happen naturally.

Vignette 1a – discussion points

1. Where would the birth take place – obstetrics v gynaecological ward?
2. Do the different options for induction impact on the stillbirth registration?
    - If not is there a gestation at which this would impact?
3. What gestation is used for registration purposes?
    - Gestation at birth; when death confirmed; other
4. How will these factors impact on the parents?
    - Funerals; Maternity/paternity pay & leave; Registration
5. Is registration of births outside the criteria possible?
    - Optional or informal registration of births
6. Are there international differences that would affect data comparability?

Vignette 1b

A pregnant woman attends a midwifery unit for a routine check at **23^{+5} weeks gestation**. It is a singleton pregnancy. The baby's heartbeat cannot be found using a Doppler. An ultrasound scan confirms the baby has died. It is not known when the death occurred but a heartbeat was recorded at an appointment at **22^{+2}** weeks.

The woman is given the option of having the birth induced

a) on that day (23^{+5});
b) two days later (24^{+0});
c) allow the birth to happen naturally.

As vignette 1a but later gestation

Vignette 1b – discussion points

- Are the answers to questions 1-4 the same after changing the gestation at the time death confirmed?
- Are there earlier or later gestational ages which would lead to different answers?

Vignette 1c

A pregnant woman expecting twins attends an anomaly scan at 21^{+5} weeks gestation.

Twin 1's heartbeat cannot be found during the ultrasound scan and the baby is confirmed to have died. It is not know when the baby died but the last confirmed heartbeat was at the dating scan at 13^{+0}.

Twin 2 is alive.

Similar to vignettes 1a and 1b but in a multiple pregnancy

Vignette 1c – discussion points

1. Would twin 1 be registered as a stillbirth if
   a) Twin 2 is live born at 22^{+0} or 24^{+0} or 36^{+0}
   b) Twin 2 is live born but dies within 7 days of life
   c) Twin 2 is stillborn at 22^{+0} or 24^{+0} or 36^{+0}
2. What gestation is used for registration purposes?
3. How will these factors impact on the parents?
4. Are there international differences that would affect data comparability?

Vignette 2a

A pregnant woman arrives at the maternity unit following rupture of membranes and pain at 23^{+5}. She is admitted to the unit.

The next day the obstetrician explains that extremely preterm birth is likely. The parents decide that they would rather opt for a termination of pregnancy than risk their child having poor quality of life following extremely preterm birth.

The obstetrician agrees and a plan for induction of labour is made. The obstetrician arrives to induce the labour but on examination the woman is already fully dilated and she gives birth at 23^{+6}. The baby shows faint signs of life.

Vignette 2a – discussion points

1. What signs of life define a live birth registration?
2. Does the gestation impact on how clinical signs of life are interpreted?
3. In what circumstances would resuscitation and active treatment be initiated? Based on gestation at birth? Including/irrespective of parents wishes ?
4. How is the birth registered if it is a) live birth or b) intrapartum stillbirth?
5. Are there circumstances where this would be recorded as a termination of pregnancy?
6. How will Q1-5 impact on the parents?
7. Are there international differences that would affect data comparability?

Vignette 2b

A pregnant woman arrives at the maternity unit following rupture of membranes and pain at 23^{+5}. She is admitted to the unit.

The next day the obstetrician explains that extremely preterm birth is likely. The parents decide that they would rather opt for a termination of pregnancy than risk their child having poor quality of life following extremely preterm birth.

The obstetrician agrees and a plan for induction of labour is made. **A feticide is undertaken and the labour is induced. The baby is born showing no signs of life at 24^{+0}.**

As Vignette 2a but the induction is undertaken

Vignette 2b – discussion points

1. How is the birth registered?
2. Would a feticide always be legally required?
3. What signs of life would lead to a live birth registration of a termination of pregnancy?
4. Will there be an impact on the parents?
5. Are there international differences that would affect data comparability?

Live birth registration - Summarise points from discussion

- How do gestation and birth weight criteria vary?
- Rules about registration that may be interpreted differently by different people?

- How might any of these variations impact on international comparisons?
- Are additional data available to minimise this impact?

Stillbirth registration - Summarise points from discussion

- How do gestation and birth weight criteria vary?
- Rules about registration that may be interpreted differently?
- Are stillbirths registered as a birth or birth and death?

- Is gestation based on time of birth or death?
  - Does the same rule apply in a multiple birth when one death occurs early in pregnancy?

- How might any of these variations impact on international comparisons?

Clinical issues - Summarise points from discussion

- Does place of birth impact on registration e.g. maternity unit v gynaecological unit?
- Are unregistered live births and stillbirths recorded in a different dataset?
- Are signs of life interpreted differently based on gestation and impact on parents?
- Are guidelines on how to interpret/detect signs of life available?
- How might any variations impact on international comparisons?

Impact on parents - Summarise points from discussion

- How do registration criteria impact on parents in different countries?
  - Funerals; Maternity/paternity pay & leave; Registration
- Does this impact on clinical behaviour
  - e.g A tendency to certify a birth as live born or stillborn because of the consequences on parents?
- Is registration of births outside the criteria possible?
  - Optional registration of births
  - Informal registration of births

Optimising comparability - Questions for discussion

- What gestational age and/or birth weight cut-offs are required for international comparisons?
- How do we compare data that include TOPs?
- What population should be used in analyses?
  - All births
  - Births alive at onset of labour
  - All live births
  - Live births surviving to discharge or admission to a neonatal unit
- What are the issues surrounding these definitions? E.g. defining and recording of alive at onset