Updating the indicator list

London

January 12th 2011

Perinatal Indicators –
What are they?

- Measures of maternal, fetal and infant health during pregnancy, delivery and the postpartum period, as well as the health consequences of events that occur in the perinatal period.

- Measures of demographic, medical, social and health system factors that impact perinatal health.

Developing Euro-Peristat indicators

1. <u>Reviewed existing indicators</u>

- Those reported on International/European level

  - *EUROSTAT, WHO/HFA, OECD*

- Recommendations by international collaborations

  - *ECHI, EAPM, FIGO, EUROPET*

    WHO – OBSQUID, WHO – Reproductive Health Working Group

- National recommendations

  - *Nordic countries, Australia, Canada, Denmark, France, Germany, Italy, Spain, UK, USA*

Developing Euro-Peristat indicators

2. Delphi Consensus Process

- Peristat I: Scientific Advisory Group (one clinician and one statistician/epidemiologist from 15 MS)

- Peristat I: Panel of 10 Midwives (added an indicator on births without medical/obstetric intervention)

- In Euro-Peristat II: statisticians/epidemiologists from the 10 new MS + Norway (modified definitions, added 4 for further development).

3. Results from data collection

- List updated after Euro-Peristat II – working groups and data collection (no NEW indicators, definitions modified and changed future → recommended)

EURO-PERISTAT Indicators

✓ **10 Core Indicators**

✓ **24 Recommended Indicators**

- 17 for immediate implementation

- 6 for further development

Sub-group analyses

- Stillbirth rate by gestational age, birthweight and plurality

- Neonatal mortality rate by timing of death, gestational age, birthweight, plurality

- Distribution of birthweight by plurality, vital status at birth, gestational age

- Distribution of gestational age by plurality, vital status at birth

- Mode of delivery by parity, plurality, presentation, previous C-section

Selecting an indicator set for monitoring and evaluating perinatal health in Europe: criteria, methods and results from the PERISTAT project

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Overview of Indicators

Neonatal Health

Maternal Health

Population Characteristics or Risk Factors

Health Care Services

Indicators
of Neonatal Health

- Fetal mortality rate
- Neonatal mortality rate
- Infant mortality rate
- Birth weight distribution
- Gestational age distribution

RECOMMENDED

- Prevalence of selected congenital anomalies
- Distribution of APGAR score at 5 minutes
- Perinatal deaths due to congenital anomalies
- Prevalence of CP
- Severe neonatal morbidity among babies at high risk **
- Prevalence of neonatal encephalopathy **

* sub-groups for analysis – gestational age, birthweight, multiplicity

Indicators
of Maternal Health

CORE

- Maternal mortality ratio by age (and mode of delivery)

RECOMMENDED

- Maternal mortality ratio by cause of death
- Prevalence of severe maternal morbidity
- Prevalence of tears to the perineum
- Prevalence of faecal incontinence **
- Postpartum depression**

Population Characteristics and Risk Factors

CORE

- Multiple birth rate by number of fetuses
- Distribution of maternal age
- Distribution of parity

RECOMMENDED

- Percentage of women who smoke during pregnancy
- Distribution of mother's education
- Distribution of mother's country of origin

Health Care Services

CORE

- Distribution of births by mode of delivery

  by parity, plurality, presentation, previous CS

RECOMMENDED

- Percentage of all births following fertility treatment
- Distribution of timing of first antenatal visit
- Distribution of births by mode of onset of labour
- Distribution of place of birth
- Percentage of infants breastfeeding at birth
- Percentage of very preterm births delivered in units without a NICU
- Births without obstetric intervention
- Episiotomy rate
- Neonatal screening policies **
- Content of antenatal care **

Updating list

- React to new public health priorities
- Improve definitions, remove ambiguities (« our common vocabulary »)
- In the "Action Plan for Sustainable Perinatal Health Reporting", majority in favor of review of list, but:

- "changes are not always easy so they cannot be done too frequently." "Stable core indicator list, review of recommended before every data collection exercise" "we do not want to give the impression that we are changing statistical data collection all the time."

How often should the indicator list be reviewed and modified?

Response	N	Percent
➔ No systematic review, updated on an ad-hoc basis	0	0%
➔ Systematic review before every data collection exercise	6	18%
➔ Systematic review every 5 years	21	64%
➔ Systematic review every 10 years	5	15%
➔ Other: stable core indicator list, review of recommended or newly developed before every data collection exercise	1	3%
Total responses	33	100%

Methods

- Consensus process (not a formal DELPHI)

- Request for comments on list (add indicators? Remove indicators? Modify definitions?)

- Discuss in group (NOW)

- Send proposals to group for comment and vote

- Refine and then endorse final decisions

Responses

- 12 responses (of which 5 no changes)

Interesting ideas

Proposals also based on work by Eurocat

EUROCAT Public Health Indicators for congenital anomalies in Europe

1. *CA Perinatal Mortality *
2. *Prenatal Diagnosis Prevalence - NO*
3. *CA Termination of pregnancy - NO*
4. *Down Syndrome live birth prevalence *
5. *CA Paediatric Surgery *
6. *Neural Tube Defect total prevalence * (Partial)*

Euro-Peristat CA indicators

R1. Prevalence of selected congenital anomalies

Definition: The number of neural tube defects, oral clefts, and Down's syndrome as a proportion of all live births, fetal deaths and induced abortions collected in the following categories:

- Anencephaly and similar anomalies (ICD10-Q00)
- Spina bifida (ICD10-Q05)
- All congenital anomalies of the central nervous system (ICD10-Q00-Q07)
- Down's syndrome (ICD10-Q90)
- Cleft lip (ICD10-Q36)
- Cleft palate with cleft lip (ICD10-Q37)
- Cleft palate (without cleft lip) (ICD10-Q35)

R3. Causes of perinatal deaths attributed to congenital anomalies subdivided by gestational age and plurality

The number of deaths in the fetal and neonatal period, subdivided into those attributed to congenital anomalies and those attributed to remaining causes.

Proposal

- Harmonize definitions (and data collection) of Euro-Peristat CA indicators with Eurocat public health indicators
  - Maximize complementary aspects of each project and avoid overlap
- Meeting in London in March to discuss with Helen Dolk and others from Eurocat
- Who wants to be involved?

Indicators of Neonatal Health

CORE *

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- Neonatal mortality rate
- Infant mortality rate
- Birth weight distribution
- Gestational age distribution

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* sub-groups for analysis – gestational age, birthweight, multiplicity

Indicators
of Neonatal Health

CORE *

- Fetal mortality rate
  Differentiate by TOP
- Neonatal mortality rate
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of Neonatal Health

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  Differentiate by TOP
- Neonatal mortality rate
- Infant mortality rate
- Birth weight distribution
- Gestational age distribution

RECOMMENDED

- Prevalence of selected congenital anomalies
- Distribution of APGAR score at 5 minutes **(PH instead?)**
- Perinatal deaths due to congenital anomalies
- Prevalence of CP
- Severe neonatal morbidity among babies at high risk **
- Prevalence of neonatal encephalopathy **

* sub-groups for analysis – gestational age, birthweight, multiplicity

Indicators
of Neonatal Health

CORE *

- Fetal mortality rate
  Differentiate by TOP
- Neonatal mortality rate
- Infant mortality rate
- Birth weight distribution
- Gestational age distribution

RECOMMENDED

- Prevalence of selected congenital anomalies
- Distribution of APGAR score at 5 minutes **(PH instead?)**
- Perinatal deaths due to congenital anomalies **(Other causes of death – with classification to be developed + by GA and BW?)**
- Prevalence of CP
- Severe neonatal morbidity among babies at high risk **
- Prevalence of neonatal encephalopathy **

* sub-groups for analysis – gestational age, birthweight, multiplicity

Indicators
of Maternal Health

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of Maternal Health

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Move maternal mortality ratio by cause of death to core

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- **Postpartum depression** - realistic?**

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- **Postpartum depression** - realistic?**
- **Maternal chronic diseases during pregnancy ****

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of Maternal Health

CORE

- Maternal mortality ratio by age (and mode of delivery)

Move maternal mortality ratio by cause of death to core

Collect maternal deaths for 5 not 2 years

RECOMMENDED

- Maternal mortality ratio by cause of death
- Prevalence of severe maternal morbidity
- Prevalence of tears to the perineum
- Prevalence of faecal incontinence **
- **Postpartum depression** - realistic?**
- **Maternal chronic diseases during pregnancy ****

Population Characteristics and Risk Factors

CORE

- Multiple birth rate by number of fetuses
- Distribution of maternal age
- Distribution of parity

RECOMMENDED

- Percentage of women who smoke during pregnancy
- Distribution of mother's education
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Population Characteristics and Risk Factors

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- Multiple birth rate by number of fetuses
  Remove sub-group
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- Percentage of women who smoke during pregnancy
- Distribution of mother's education
- Distribution of mother's country of origin
- **Distribution of mother's BMI before pregnancy**

Population Characteristics and Risk Factors

CORE

- Multiple birth rate by number of fetuses
  Remove sub-group
- Distribution of maternal age
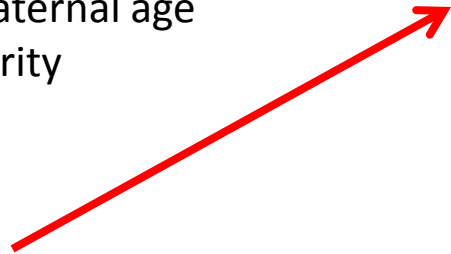- Distribution of parity

RECOMMENDED

- Percentage of women who smoke during pregnancy
- Distribution of mother's education
- Distribution of mother's country of origin
- **Distribution of mother's BMI**
- **Smoking <u>before</u> pregnancy**
- **Maternal height**
- **Marital status**
- **Obstetrical history (previous induced abortions)**

Population Characteristics and Risk Factors

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- Multiple birth rate by number of fetuses
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- Distribution of parity

Simplify definition of education
Discussion tomorrow

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- Percentage of women who smoke during pregnancy
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Population Characteristics and Risk Factors

CORE

Move to core

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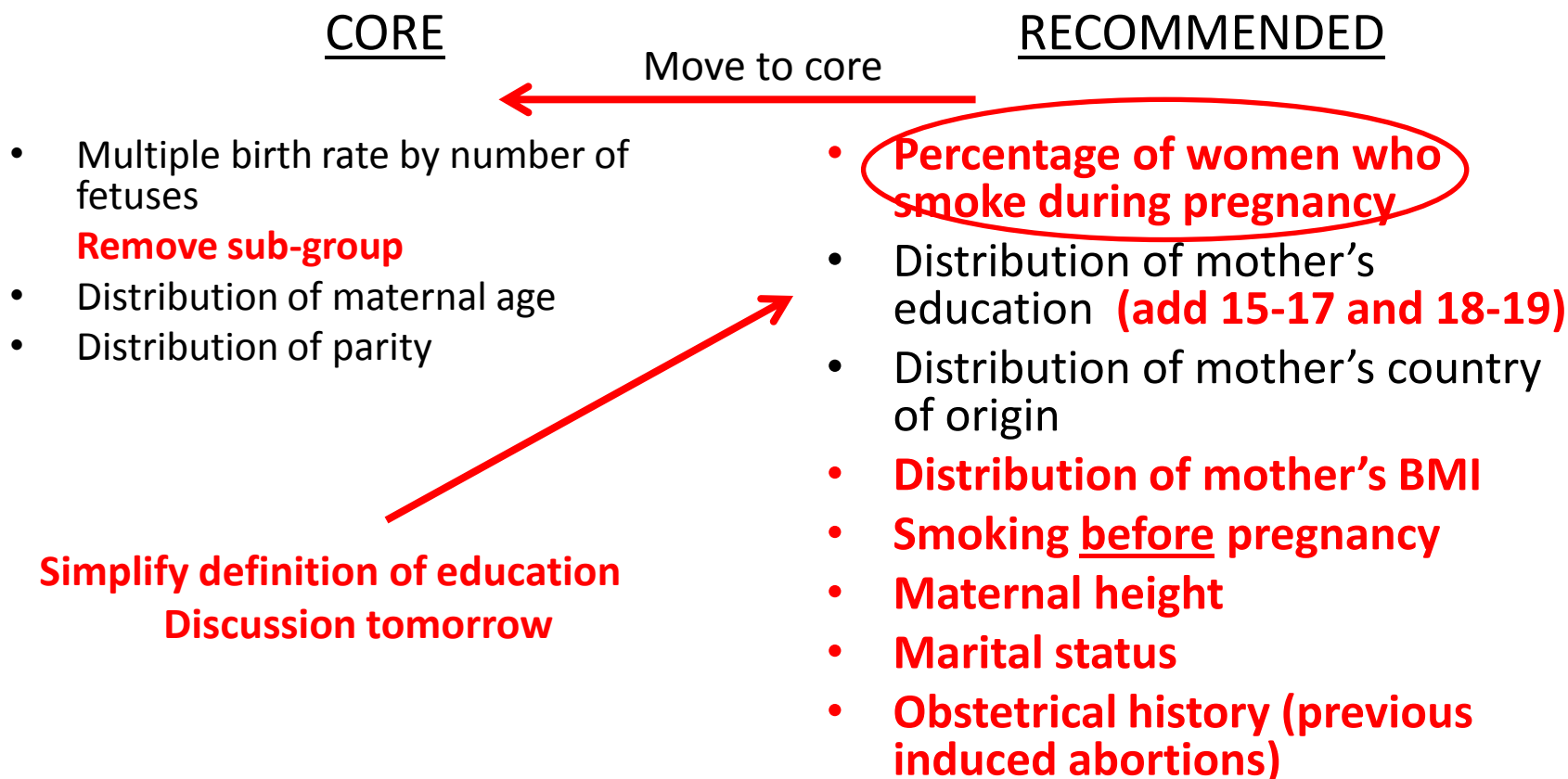- Distribution of maternal age
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Simplify definition of education
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Population Characteristics and Risk Factors

CORE

Move to core

- Multiple birth rate by number of fetuses
  Remove sub-group
- Distribution of maternal age
- Distribution of parity

Simplify definition of education
Discussion tomorrow

RECOMMENDED

- **Percentage of women who smoke during pregnancy**
- Distribution of mother's education **(add 15-17 and 18-19)**
- Distribution of mother's country of origin
- **Distribution of mother's BMI**
- **Smoking before pregnancy**
- **Maternal height**
- **Marital status**
- **Obstetrical history (previous induced abortions)**

Health Care Services

CORE

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  by parity, plurality, presentation, previous CS

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By gestational age

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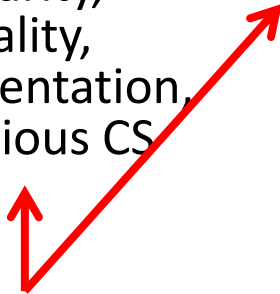
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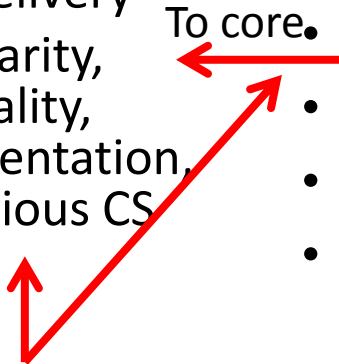
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- Births without obstetric intervention
- Episiotomy rate **(by mode of delivery)**
- Neonatal screening policies **
- Content of antenatal care **
- **Prophylactic surfactant administration**

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Health Care Services

CORE

- Distribution of births by mode of delivery by parity, plurality, presentation, previous CS

By gestational age

To core

RECOMMENDED

- Percentage of all births following fertility treatment
- Distribution of timing of first antenatal visit
- Distribution of births by mode of onset of labour
- Distribution of place of birth
- Percentage of infants breastfeeding at birth
- Percentage of very preterm births delivered in units without a NICU
- Births without obstetric intervention
- Episiotomy rate **(by mode of delivery)**
- Neonatal screening policies **
- Content of antenatal care **
- **Prophylactic surfactant administration**