Euro-Peristat Action:
Data collection procedures

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Euro-Peristat Action:
Data collection procedures

Data collection instrument of previous project

Data collection instrument

> Designed in Excel

> Advantages:
>> All countries have Excel program
>> No data entry needed
>> Easy to import in statistical software programs

> Instrument consists of four separate files:
>> Peristatcore.xls
>> Peristatrecommended.xls
>> Peristatfuture.xls
>> Datasource.xls

Ten core indicators

› C1: Fetal deaths
› C2: Neonatal deaths
› C3: Infant deaths
› C4: Distribution of birth weight
› C5: Distribution of gestational age
› C6: Maternal mortality
› C7: Multiple birth rate
› C8: Distribution of maternal age
› C9: Distribution of parity
› C10: Mode of delivery

Ten core indicators

› C1: Fetal deaths >>> differentiate with and without TOP
› C2: Neonatal deaths
› C3: Infant deaths
› C4: Distribution of birth weight
› C5: Distribution of gestational age
› C6: Maternal mortality
› C7: Multiple birth rate
› C8: Distribution of maternal age
› C9: Distribution of parity
› C10: Mode of delivery

EURO-PERISTAT II Questionnaire
CORE INDICATORS OF PERINATAL HEALTH

The PERISTAT project is collecting data on indicators as part of the European Commission Health Monitoring Project. These data will be used to develop recommendations on perinatal health indicators for a European health information system by the PERISTAT scientific advisory committee.

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General instructions

1. To run this Excel file correctly, the Macro security of the Excel program should be set to 'medium' (Go to Tools -> Macro -> Security). This should be done before starting the Peristatcore.xls file.

2. Please provide data for the year **2004**, or most recent year available **before** 2004.

3. We would like **COUNTRY**-level data. If country-level data are not available, but population-based data are available from one or more regions, please use this source.

4. If several data sources can be used to fill in an indicator, it is the country's responsibility to choose which data source to use.

5. If data are provided for different regions within one country please copy and fill in one Peristatcore.xls file **per region**. However, always include country-level data if available.

6. We would like **POPULATION**-based data. If population-based data are not available, but hospital-based data (e.g. hospital discharge data) are available, please use this source.

7. For each table, please register the name of the data source you have used. For each source of data, please complete a data source information form (Press button 'to data source information form' on the INDEX sheet OR button 'new data source' on each indicator sheet).

8. For items not defined explicitly in the text use the WHO recommended definitions (push button):　　WHO ICD-10 Definitions

9. We are specifically requesting that you provide us **WITH NUMBERS**. Rates will be calculated based on the numbers you provide.

10. All tables for Core Indicators can be accessed from the INDEX sheet by clicking on the corresponding 'Go to indicator' button.

11. In the tables totals will be calculated automatically. Please use these as a check.

12. After filling in a table and returning to the index sheet via the button 'Save and return to INDEX' the box of the corresponding table will be ticked, indicating that data on this indicator have been filled in.

To INDEX sheet

Index sheet *CORE* Indicators

Core Indicator	Indicator			Data source used:
Core Indicator # 1				
	fetal mortality by gestational age	☐	Go to indicator	\<Unknown\>
	fetal mortality by birthweight	☐	Go to indicator	\<Unknown\>
Core Indicator # 2				
	neonatal mortality by gestational age	☐	Go to indicator	\<Unknown\>
	neonatal mortality by birthweight	☐	Go to indicator	\<Unknown\>
Core Indicator # 3				
	infant mortality by gestational age	☐	Go to indicator	\<Unknown\>
	infant mortality by birthweight	☐	Go to indicator	\<Unknown\>
Core Indicator # 4				
	distribution of birthweight	☐	Go to indicator	\<Unknown\>
	distribution of birthweight by gestational age	☐	Go to indicator	\<Unknown\>
Core Indicator # 5				
	distribution of gestational age	☐	Go to indicator	\<Unknown\>
Core Indicator # 6				
	maternal mortality by maternal age	☐	Go to indicator	\<Unknown\>
	maternal mortality by mode of delivery	☐	Go to indicator	\<Unknown\>
Core Indicator # 7				
	multiple births	☐	Go to indicator	\<Unknown\>
Core Indicator # 8				
	distribution of maternal age	☐	Go to indicator	\<Unknown\>
Core Indicator # 9				
	distribution of parity	☐	Go to indicator	\<Unknown\>
Core Indicator # 10				
	mode of delivery	☐	Go to indicator	\<Unknown\>
	mode of delivery by parity	☐	Go to indicator	\<Unknown\>
	mode of delivery by previous Caesarean	☐	Go to indicator	\<Unknown\>
	mode of delivery by presentation	☐	Go to indicator	\<Unknown\>
	mode of delivery by plurality	☐	Go to indicator	\<Unknown\>

To data source information form

Core indicator #10: Mode of delivery (by parity)

Definition: The number of births associated with each of the following modes: Spontaneous, Instrumental vaginal, Caesarean undertaken before or at onset of labour/elective*, Caesarean undertaken during labour/emergency*, as a proportion of all still and live births.

For the definition of the used Caesarean categories, see Future Indicator #7.

Attention: only include births at or after 22 completed weeks of gestation.

Are you able to provide data using this definition? ☐ yes ☐ no

Data source: [0] ▼   [New data source]

Please rate the quality of this indicator: ○ good   ○ some concerns   ○ bad

Comments: [   ]

SAVE and return to INDEX

To INDEX without saving

Reset this page

Select one of these options:

○ option 1 (preferred)   ○ option 2   ● option 3   ○ None

Mode of delivery	Nullipara	Multipara	Parity Unknown	Calc. Totals
Vaginal				0
Caesarean				0
Mode Unknown				0
Calculated totals	0	0	0	0

Country	Indicator	Option	Del_Mod	Parity	N
A	C10b	3	1 (vaginal)	1 (nulli)	
A	C10b	3	1 (vaginal)	1 (multi)	
A	C10b	3	1 (vaginal)	99 (unknown)	
A	C10b	3	2 (CS)	1 (nulli)	
A	C10b	3	2 (CS)	1 (multi)	
A	C10b	3	2 (CS)	99 (unknown)	
A	C10b	3	99 (unknown)	1 (nulli)	
A	C10b	3	99 (unknown)	1 (multi)	
A	C10b	3	99 (unknown)	99 (unknown)	
B	C10b	3	1 (vaginal)	1 (nulli)	
B	C10b	3	1 (vaginal)	1 (multi)	
B	C10b	3	1 (vaginal)	99 (unknown)	
B	C10b	3	2 (CS)	1 (nulli)	
B	etc.	etc.	etc.	etc.	
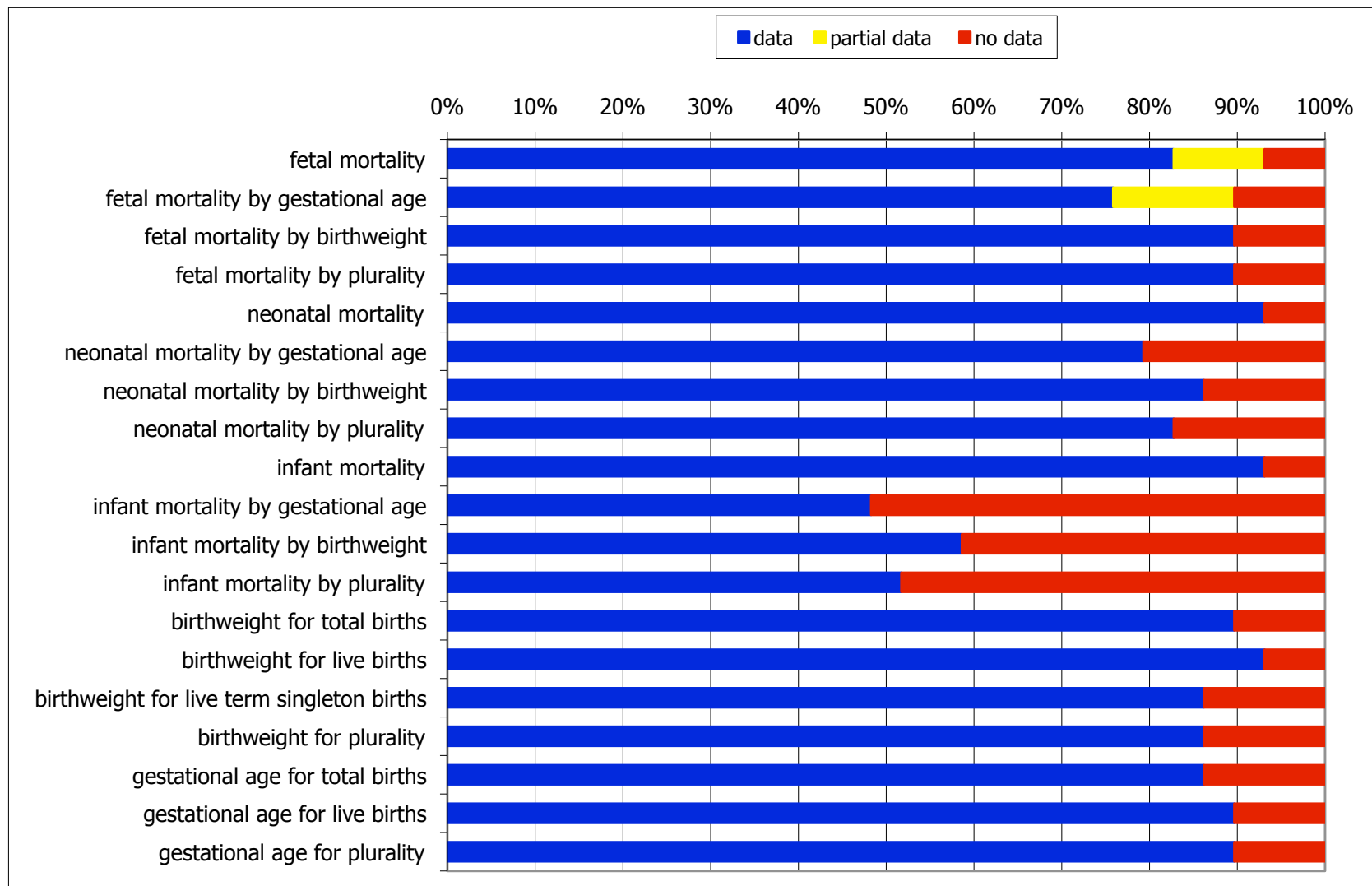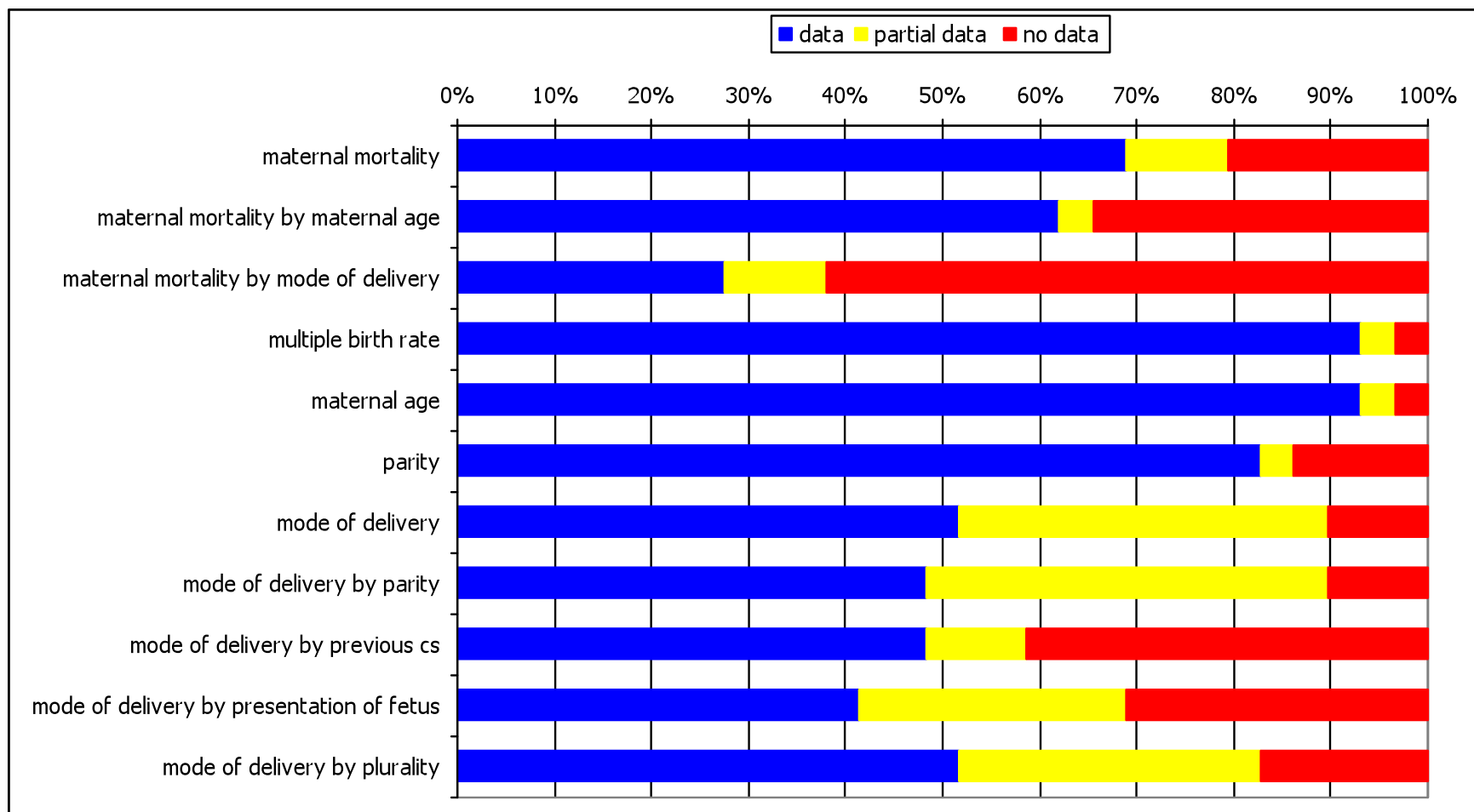
EURO-PERISTAT II Questionnaire
RECOMMENDED INDICATORS OF PERINATAL HEALTH

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General instructions

1. To run this Excel file correctly, the Macro security of the Excel program should be set to 'medium' (Go to Tools -> Macro -> Security). This should be done before starting the Peristatrecommended.xls file.

2. Please provide data for the year **2004**, or most recent year available **before** 2004.

3. We would like **COUNTRY**-level data. If country-level data are not available, but population-based data are available from one or more regions, please use this source.

4. If several data sources can be used to fill in an indicator, it is the country's responsibility to choose which data source to use.

5. If data are provided for different regions within one country please copy and fill in one Peristatrecommended.xls file per **region**. However, always include country-level data if available.

6. We would like **POPULATION**-based data. If population-based data are not available, but hospital-based data (e.g. hospital discharge data) are available, please use this source.

7. For each table, please register the name of the data source you have used. For each source of data, please complete a data source information form (Press button 'to data source information form' on the INDEX sheet OR button 'new data source' on each indicator sheet).

8. For items not defined explicitly in the text use the WHO recommended definitions (push button):

   [WHO ICD-10 Definitions]

9. We are specifically requesting that you provide us **WITH NUMBERS**. Rates will be calculated based on the numbers you provide.

10. All tables for Recommended Indicators can be accessed from the INDEX sheet by clicking on the corresponding 'Go to indicator' button.

12. After filling in a table and returning to the index sheet via the button 'Save and return to INDEX' the box of the corresponding table will be ticked, indicating that data on this indicator have been filled in.

[To INDEX sheet]

Index sheet *Recommended* Indicators

Recommended Indicator # 1   Data source used:
    prevalence of congenital anomalies   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 2
    distribution of apgar score at 5 minutes   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 3
    maternal mortality by cause of death   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 4
    women who smoke during pregnancy   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 5
    mother's education   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 6
    births after fertility treatment   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 7
    timing of 1st antenatal visit   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 8
    mode of onset of labour   ☐ [Go to indicator]   <Unknown>
    mode of onset of labour by gestational age   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 9
    place of birth   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 10
    breastfeeding at birth   ☐ [Go to indicator]   <Unknown>

Recommended Indicator # 11
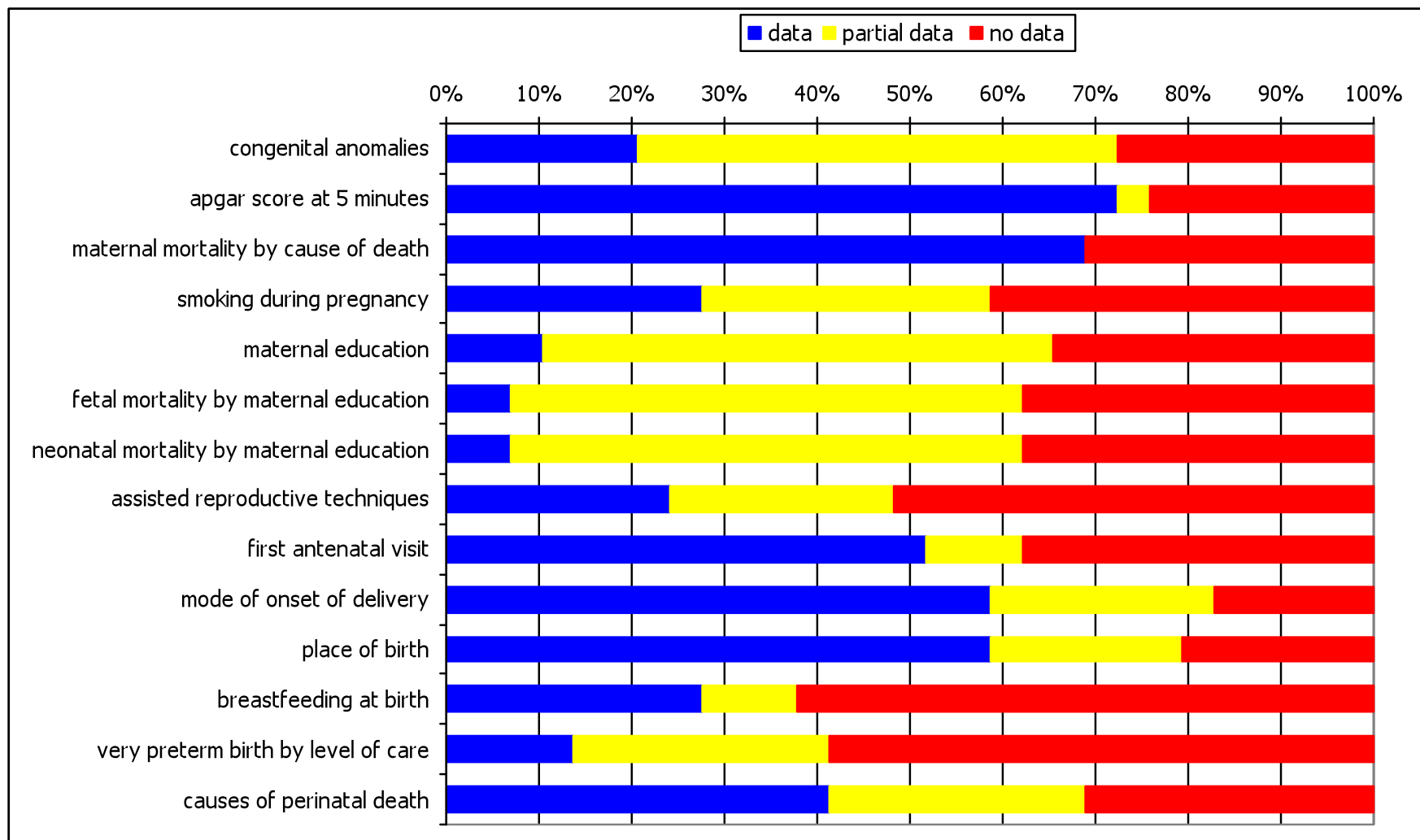   very-preterm births by level of care   ☐ [Go to indicator]   <Unknown>

[To data source information form]

EURO-PERISTAT II Questionnaire
FUTURE DEVELOPMENT INDICATORS OF PERINATAL HEALTH

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General instructions

1. To run this Excel file correctly, the Macro security of the Excel program should be set to 'medium' (Go to Tools -> Macro -> Security). This should be done before starting the Peristatfuture.xls file.

2. Please provide data for the year **2004**, or most recent year available **before** 2004.

3. We would like **COUNTRY**-level data. If country-level data are not available, but population-based data are available from one or more regions, please use this source.

4. If several data sources can be used to fill in an indicator, it is the country's responsibility to choose which data source to use.

5. If data are provided for different regions within one country please copy and fill in one Peristatfuture.xls file per **region**. However, always include country-level data if available.

6. We would like **POPULATION**-based data. If population-based data are not available, but hospital-based data (e.g. hospital discharge data) are available, please use this source.

7. For each table, please register the name of the data source you have used. For each source of data, please complete a data source information form (Press button 'to data source information form' on the INDEX sheet OR button 'new data source' on each indicator sheet).

8. For items not defined explicitly in the text use the WHO recommended definitions (push button):   WHO ICD-10 Definitions

9. We are specifically requesting that you provide us **WITH NUMBERS**. Rates will be calculated based on the numbers you provide.

10. All tables for Future Development Indicators can be accessed from the INDEX sheet by clicking on the corresponding 'Go to indicator' button.

11. After filling in a table and returning to the index sheet via the button 'Save and return to INDEX' the box of the corresponding table will be ticked, indicating that data on this indicator have been filled in.

To INDEX sheet

Index sheet *FUTURE DEVELOPMENT* Indicators

Future Development Indicator # 1

Data source used:

| causes of fetal and neonatal death | ☐ Go to indicator | <Unknown> |

Future Development Indicator # 2

severe maternal morbidity; Eclampsia	☐ Go to indicator	<Unknown>
severe maternal morbidity; ICU admission	☐ Go to indicator	<Unknown>
severe maternal morbidity; Blood transfusion	☐ Go to indicator	<Unknown>
severe maternal morbidity; Hysterectomy	☐ Go to indicator	<Unknown>
severe maternal morbidity; Embolisation	☐ Go to indicator	<Unknown>

Future Development Indicator # 3

| trauma to the perineum-episiotomy | ☐ Go to indicator | <Unknown> |
| trauma to the perineum-tears | ☐ Go to indicator | <Unknown> |

Future Development Indicator # 4

| mother's 'origin' | ☐ Go to indicator | <Unknown> |
| mother's current nationality | ☐ Go to indicator | <Unknown> |

Future Development Indicator # 5

| maternal and child support | ☐ Go to indicator | n.a. |

Future Development Indicator # 6

| care for high risk newborns | ☐ Go to indicator | <Unknown> |

Future Development Indicator # 7

| birth without obstetric intervention | ☐ Go to indicator | <Unknown> |

Future Development Indicator # 8

| indicators on neonatal morbidity | ☐ Go to indicator | n.a. |

To data source information form

Data management

› Data management and analysis in SPSS

› Advantages:
  › Less error prone than Excel
  › All performed data changes and analyses traceable via syntax files
  › Data management and analyses more automated

› Always possible to return from SPSS to Excel or other programs

› Transfer of data from Excel to SPSS using Visual Basic programs

› First step, visual check of received data

Example of Issues

› Not corresponding totals between indicators
  › Handling of missing cases
  › Different applications of the inclusion criteria
  › Use of different data sources

› Interpretation of empty cells
  › Is it zero or missing value?

Example of Issues

> TOP were not systematically included as stillbirths
>> France, the Netherlands, England and Wales, and Scotland included TOP in same registries
>> Finland and Italy register TOP in separate registries and did not include these as fetal deaths, but were able to provide the data afterwards
>> Information was not available in most countries
>> Rates with and without TOP could not be calculated

Example of Issues

› TOP were not systematically included as stillbirths
  › France, the Netherlands, England and Wales, and Scotland included TOP in same registries
  › Finland and Italy register TOP in separate registries and did not include these as fetal deaths, but were able to provide the data afterwards
  › Information was not available in most countries
  › Rates with and without TOP could not be calculated

  › How to process these differences in registration?

Example of Issues

› Different options used per indicator
  › How to process this?
    › Analyze subgroup of countries with data on most detailed level
    › Aggregate all countries to less detailed level

› Different regions within one country
  › Belgium: Flanders and Brussels
  › UK: England and Wales, Scotland and Northern Ireland
  › Spain: Valencia region

Example of Issues

› Different data sources per indicator within one country
  › e.g. Estonia: input from Medical Birth Registry and Statistics Estonia for most of the data

› Limited input
  › e.g. Cyprus: only data on a few indicators and only on live births

Time schedule

* Jan-Mar 2012: updates and pilot

* Apr-May 2012: data collection

* Jun-Sep 2012: visual checks and queries

* Oct-Dec 2012: output tables

Thank you!

Rebeca Lagos