



IMPLEMENTING THE EXPANDED DATA MODEL

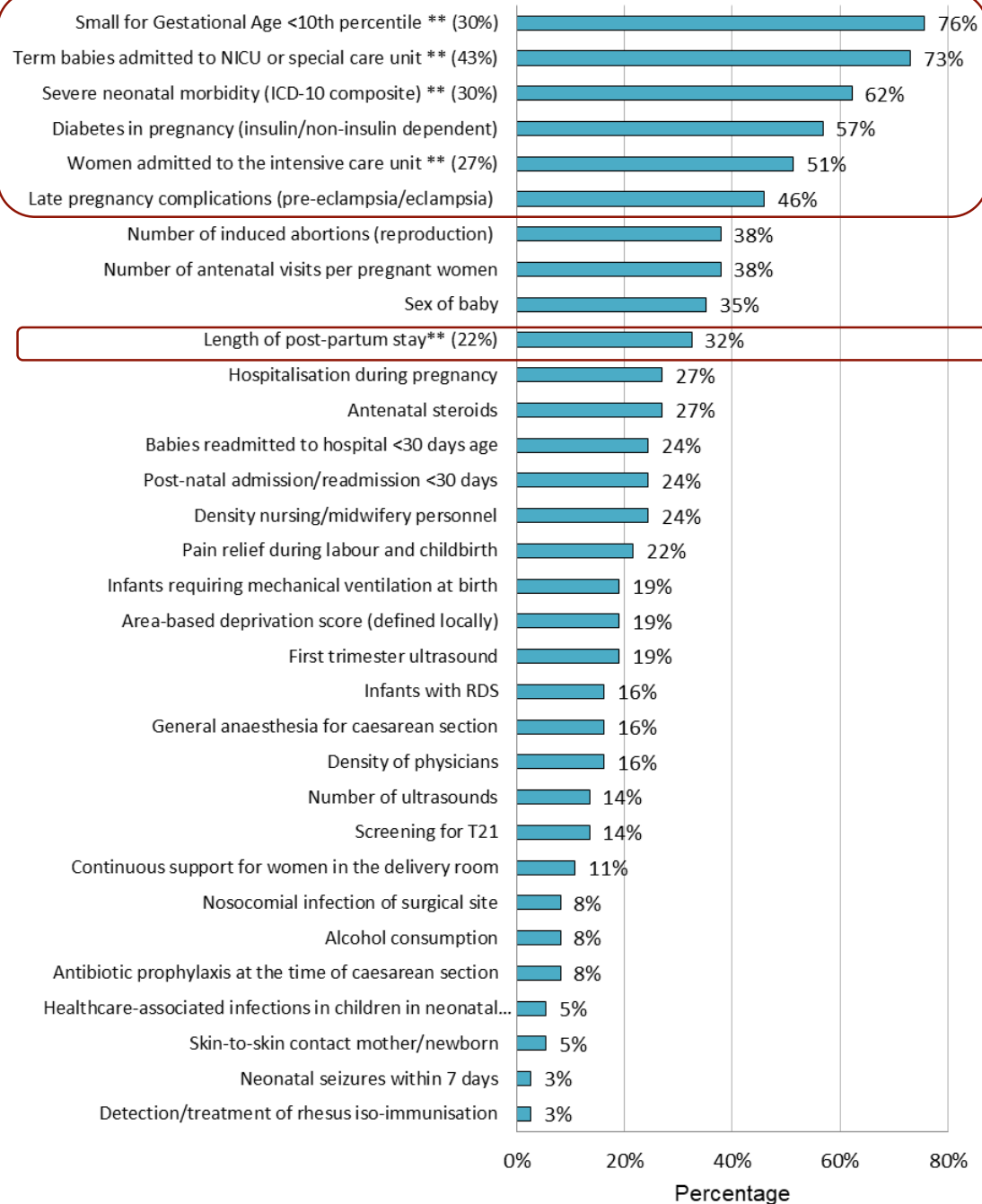
Euro-Peristat Meeting, 28th March, Rolduc, Netherlands

EXPANDED DATA MODEL: METHODOLOGY

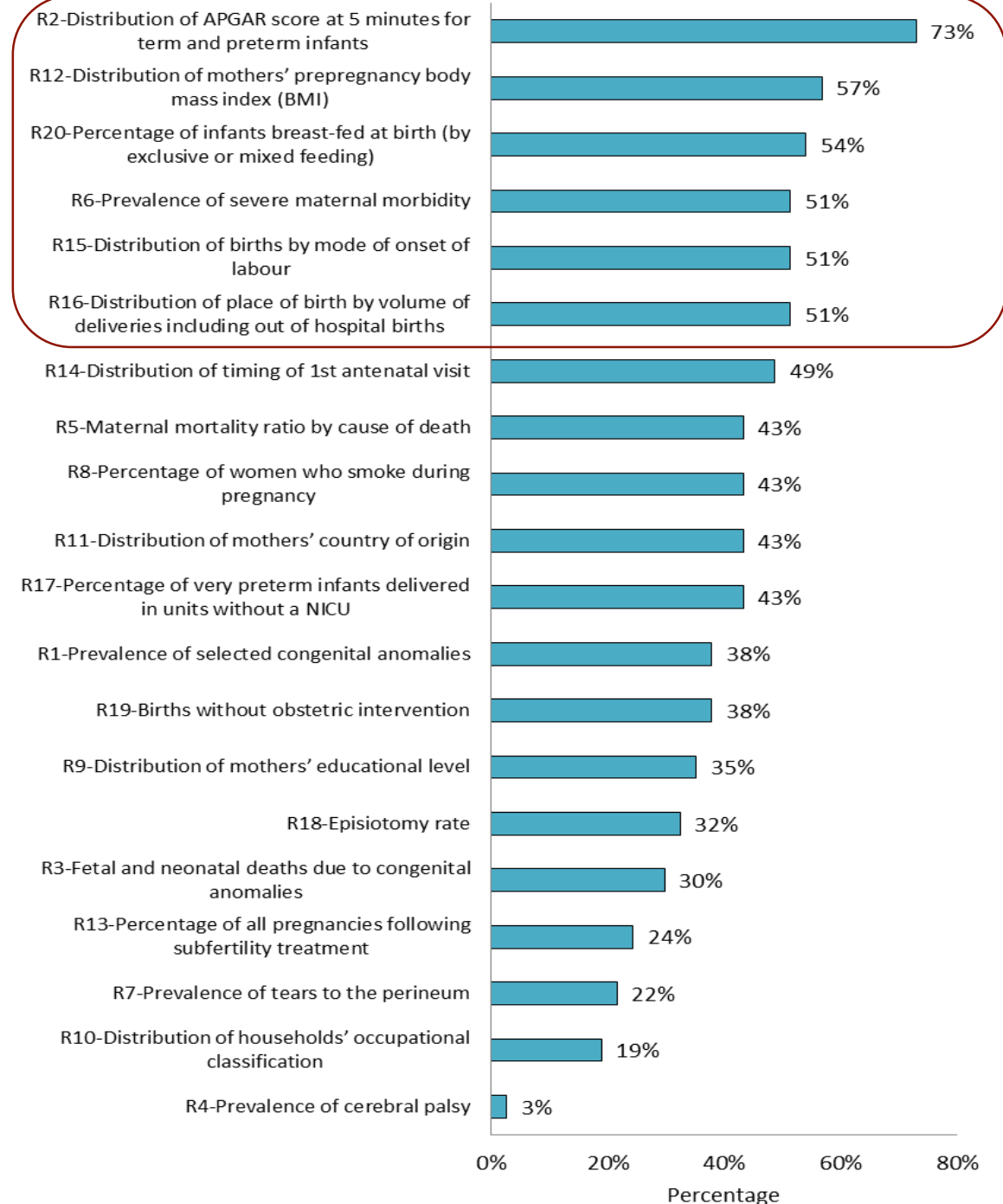
- Common Data Model (17 variables)
 - the core Euro-Peristat indicators
 - the socioeconomic variable
- DELPHI process: A three-round on-line consensus process was undertaken to select the Euro-Peristat recommended indicators and new indicators for PHIRI
- Criteria of choice were availability and feasibility
- Results of Delphi : Expanded CDM (18 variables) with indicators on:
 - healthcare services and utilisation (transfer of the baby to a neonatal intensive care unit or the mother to an adult intensive care unit)
 - length of postpartum stay and level of care and size of the hospital of birth
 - morbidities (Apgar, maternal pregnancy complications and morbidities)
 - maternal risk factors such as maternal body mass index and breastfeeding

The main focus of this consultation was to agree on indicators to measure the indirect and overall effects of the SARS-CoV-2 epidemic

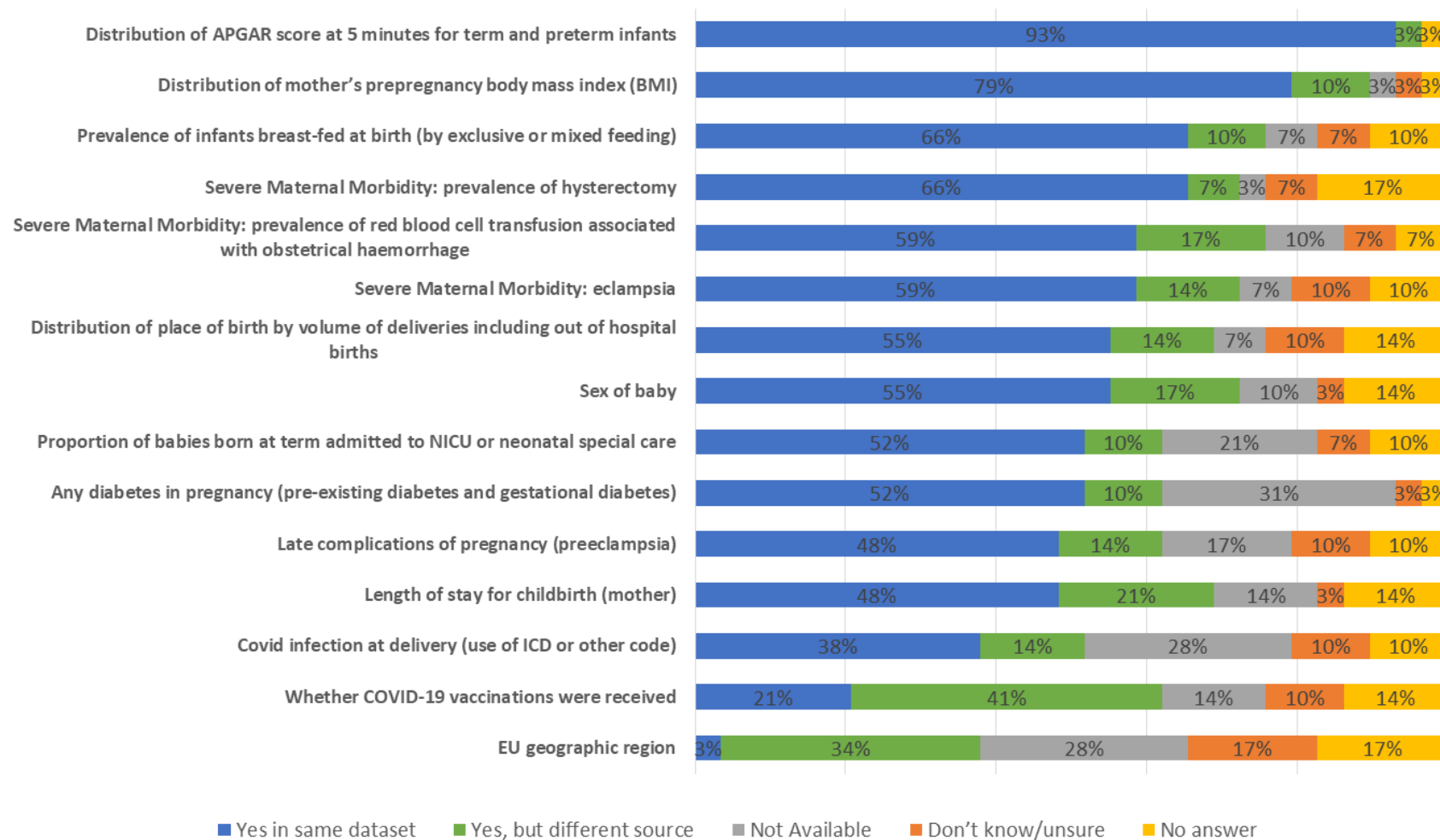
- From the possible new indicators, five indicators were selected as “TOP ten” by at least half of the panel and 10 were selected by more than 30%. Those starred were selected by 20% or more of respondents for possible inclusion in the PHIRI data collection (% shown in parentheses)



- More than half of respondents identified 6 recommended Euro-Peristat indicators that should be considered for inclusion in the PHIRI data collection



FEASIBILITY



DATA COLLECTION BASED ON EXPANDED DATA MODEL

- Country creates an individual-level dataset with all those variables
 - 17 already in common data model + 18 from expanded data model
- We define new scripts to collect those indicators
- Scripts are run in each institution
- For each one of the variables chosen, at least 50% of countries said they had the information in the same dataset used for the CDM

Associated entity	Label (var_label)	Name (var_concept)	Units	Description/Definition
baby	APGAR	5 minutes APGAR score	1 to 10	Distribution of the APGAR score at 5 minutes (0-10) for live births (to be presented for term and preterm separately)
mother	PREPREG_BMI	mother's prepregnancy body mass index	13 to 50	BMI of the mother before her pregnancy. BMI is defined as the pre- pregnancy weight in kilograms divided by the square of the height in meters (kg/m2).
mother	SMOKING	smoking status of the mother during pregnancy	0=no ; 1=yes (smoking during pregnancy); 99=missing	The number of women who smoke during the third trimester of pregnancy expressed as a proportion of all women delivering live or stillborn babies. When data are not available for the third trimester of pregnancy, data are requested for another time point during pregnancy.
baby	BREASTFED_BIRTH	breastfeeding at birth	0=no breastfeeding at birth; 1=breastfeeding at birth (mixed and or exclusive); 99 missing	Babies who are partially breastfed (infant receives breast milk and the infant is allowed any food or liquid including non-human milk) or who are exclusively breastfed (infant receives breast milk and is allowed to receive drops and syrups) throughout the first 48 hrs of age (WHO definition)
mother	MAT_MORB_HYST	severe maternal morbidity - hysterectomy associated with obstetrical haemorrhage	0=no hysterectomy; 1=hysterectomy; 99=missing	occurrence of hysterectomy (surgical remove of the uterus for stopping the untreatable post partum haemorrhage)
mother	MAT_MORB_TRANS	severe maternal morbidity - RBC transfusion associated with obstetrical haemorrhage	0=No red blood cell transfusion; 1=RBC transfusion; 99 = missing	occurrence of red blood cell transfusion associated with obstetrical haemorrhage (ICD-10 code O72)
mother	MAT_MORB_ICU	women admitted to the intensive care unit. This is a component of severe maternal morbidity (Severe acute morbidity resulting during pregnancy, delivery or the puerperium period (<42 days))	0=no admission in ICU; 1=admission to ICU; 99=missing	ICU >24 hours (admission during pregnancy, delivery or the puerperium to any facility or unit providing intensive or acute care or resuscitation-whether inside or outside of the maternity unit- for greater than 24 hours)
mother	MAT_MORB_ECLAMPسيا	Eclampsia is a component of severe maternal morbidity (Severe acute morbidity resulting during pregnancy, delivery or the puerperium period (<42 days))	0=no eclampsia ; 1=eclampsia; 99=missing	Eclampsia (includes convulsion following specified or unspecified hypertensive disorders (that are not due to unknown epilepsy) during pregnancy, delivery or the puerperium. Corresponds to ICD-10 code O150)
hospital	DEL	volume of deliveries of the birth place	0=home birth; 1=<500 deliveries per year; 2=500-999; 3=1000-2499; 4=2500 and more; 99 missing	volume of deliveries per year in the place of the birth
hospital	NICU_ADM_TERM	term babies admitted to NICU	number of babies	Number of babies born at term (>=37SA) who were admitted at NICU
baby	NEONAT_MORB	neonatal morbidity	ICD-10 codes	ICD10 code of neonatal morbidity
mother	DIAB_PREG	diabetes in pregnancy	0=no diabete in pregnancy; 1=diabete in pregnancy; 99=unknown	diabetes in pregnancy (ICD-10 code=O24.4)
mother	PREECLAMP	preeclampsia	0=no ; 1=preeclampsia; 99=missing	preclampsia (ICD-10 code= O14)
mother	PPSTAY	length of postpartum stay	number of days	length of postpartum stay (in days)
mother	COVID	covid infection at delivery (use of ICD or other code)	ICD code	covid infection at delivery (use of ICD or other code)

IMPLEMENTING THE EXPANDED DATA MODEL (EDM) OBJECTIVES OF THE 3 WORKING GROUPS

- **Final decision on the variables to retain in the model**
 - Do we want to exclude the other recommended indicators?
 - Collected in 2000, 2004 and 2010
- **Decide on definitions for the EDM and methods to validate them**
 - For all recommended indicators, we kept the definition used in Euro-Peristat
 - BUT, the protocol for data collection has changed
 - For the new indicators, we don't have operational definitions
 - need to develop (and validate?) comparable definitions

NEWBORN HEALTH OUTCOMES

Agreed upon for the expanded data model:

- Recommended (R2): **APGAR score at 5 minutes** (0-10) for live birth
- New indicator: **Transfer to NICU**
- New indicator: **Neonatal morbidity (ICD codes?)**

Recommended indicators that were not kept for the expanded data model

- Congenital anomalies (R1)
- Fetal and neonatal deaths due to congenital anomalies (R3)
- Cerebral palsy (R4)

MATERNAL HEALTH OUTCOMES

Agreed upon for the expanded data model:

- Recommended(R6): Maternal morbidity with update of definition validated:
- New indicator: Gestational diabetes (**diabetes in pregnancy (ICD-10 code=O24.4)**)
- New indicator: Preeclampsia (**preclampsia (ICD-10 code= O14)**)

Recommended indicators that were not kept for the expanded data model:

- Maternal mortality by cause (R5)
- Tears to the perineum (R7)

HEALTH CARE / MEDICAL PRACTICES

Agreed upon for the expanded data model:

- Recommended (R16): Place of birth
- Recommended (R20): Breastfeeding at birth
- New indicator: **Postpartum hospital stay (mother):length of postpartum stay (in days)**

Recommended indicators that were not kept for the expanded data model:

- Pregnancies following subfertility treatment (R13)
- Timing of 1st prenatal visit (R14)
- Very preterm infants delivered in units without NICU (R17)
- Episiotomy (R18)
- Births without obstetric intervention (R19)

COVID EXPOSURES

- New indicator: COVID infection (ICD or other code)
 - **New indicator: COVID vaccination? (whether covid vaccinations were received)**
 - New indicator: **Geographic location (NUTS) :EU geographic code**
- **To discuss in plenary session after working groups**

POPULATION RISK FACTORS

- Recommended (R8): women who smoke during pregnancy
 - Definition: Smoking during pregnancy is defined as the proportion of women who smoked during pregnancy among those with live born or stillborn babies. When possible, data were collected for two time periods: an earlier (ideally, first trimester) and a later (ideally, third trimester) phase.
- Recommended (R11): mother's country of birth
 - These data will be presented by: 1. Geographic regions (as per UN World Regionsa and components with Europe further sub- divided into EU27b and non-EU27b) 2. Regions grouped by income level (as per World Bank or UNDP, using regions defined by income distribution rather than solely gross national income)
 - a. United Nations: <http://www.un.org/depts/dhl/maplib/worldregions.htm>
 - b. European Union: http://europa.eu/abc/european_countries/index_en.htm
 - c. <http://go.worldbank.org/D7SN0B8YU0>.
 - d. United Nations Development Programme
- Recommended (R12): Body mass index
 - Definition: BMI of the mother before her pregnancy. BMI is defined as the pre-pregnancy weight in kilograms divided by the square of the height in meters (kg/m²)



TIME TO PRODUCE EXPANDED DATA MODEL

- Implementing the expanded CDM was estimated to require :
 - between **one hour to one month of work**
- But many respondents were not able to provide an accurate assessment since some of the indicators in the expanded dataset had not previously been collected by Euro-Peristat and checks would have to be made to their coding and conformity to the requested definition.
- Will also depend on the final list of variables and work to validate the indicators