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PERFORMANCE AND EFFICIENCY

EuroHOPE VLBW: Material, Methods and Indicators

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Introduction and objectives

The main aim of the EuroHOPE VLBW project is to compare performance in the care of very low birth weight and very preterm infants between countries and over time. This comparison is made for various purposes. We will implement European-wide benchmarking of outcomes, quality and costs. This will enable decision-makers and health professionals to learn from the best practices. We will investigate the relationship between outcomes/quality and costs/resources between European countries and selected providers (based on numerosity of cases), applying a multilevel approach. Finally, we will explore reasons behind the differences in outcomes and costs. In particular, our focus will be on policy driven factors such as treatment practices (e.g. ventilation, catheterism), organisation of services with a particular focus on transfers and back-transfers, and financing.

This paper defines specific protocols for international comparisons that are based on the data of medical birth registrers, hospital discharge registers, mortality registers, and other available registers (such as use of drugs, use of outpatient services in specialist care or medical emergency registers etc.). The protocol has been used in preparing both **national VLBW databases for each country and for an international comparative VLBW database** which is produced from the national VLBW databases. The comparative database has been used for basic reporting on care of VLBW, and for research on reasons behind differences in performance.

This protocol defines how we have produced indicators at national levels. The basic report includes basic information on patients (number of very preterm and very low weight infants born, gestational age and weigth distribution, co-morbidity), indicators on content of care (use of services and procedures, costs, treatment practices, process indicators), and indicators of outcomes.

This paper is a joint work established (in alphabetical order) by Giovanni Fattore, Unto Häkkinen, Amber van der Heijden, Tor Iversen, Peter Mihalicza, Dino Numerato, Mikko Peltola, Timo T. Seppälä, Sofia Svereus, Fabrizio Tediosi and Rinaldo Zanini.

Definition of VLBW

Infants born with a weight under or equal to 1500 g or below 32 weeks of gestational age.

National Databases

Every country has established a national VLBW database. From medical birth registers were included very low birth weight and very preterm new born infants, with weight 1500 g or below and with gestational age less than 32 weeks.

A**t present the database includes** very low birth weight and very preterm new infants **born between years 2006 and 2008** and is formed combining patient level data of each country's national registers.

Using personal identification number we have linked patients' information from the following registers:

- Medical birth registers
- Register of congenital malformations (when the information is not included in the Medical birth register)
- Hospital discharge registers
- Outpatient services in specialist care / hospitals
- Emergency services registers
- Drug utilisation registers
- National mortality registers

International database used for calculating indicators

Data restrictions

Infants born with a weight under or equal to 1500 g or below 32 weeks of gestational age between 2006 and 2008.

Following infants have been excluded:
- with a major disparity between birth weight and GA (LGA or SGA) or missing data on either one of these variables
- with missing data on the initial hospitalisation period or with incomplete Medical Birth Register data, which would prevent a comparative analysis
- with an incomplete personal identification number (this can also be an incomplete social security number) or other information, which would prevent data linkage
- with lethal congenital malformations Appendix 1
- with gestational age lower than 22 weeks and higher than 40 weeks

The main analysis will be carried out by using the data collected from medical birth registers and national discharge registers. The specific information of registers in each country is provided in Appendix 2. Appendix 3 describes the definitions that have been used in preparing and analysing the data.

Definition of the first hospital episode

Total episode of care was defined as the entire treatment pathway from the day of birth to the end of the treatment throughout any hospital admissions, other health service provisions or purchased medication in order to solve the health problem at hand in a specified time frame (Figure 1).

First hospital episode: hospital inpatient treatment beginning on the day of birth including also possible discharge to another hospital and terminating on the first discharge to home, one year of continuous inpatient care or death (Figure 1). If the patient is transferred to inpatient rehabilitation center this is included in the first hospital episode (Häkkinen and Peltola 2012).
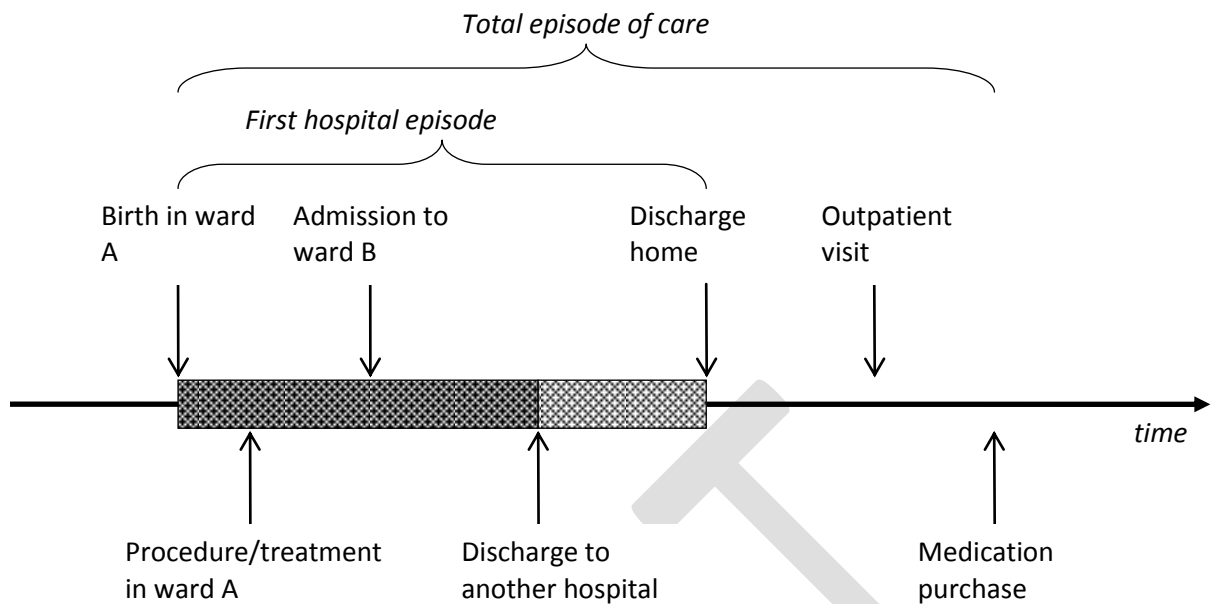
Figure 1. A schematic presentation of the follow-up of patients throughout the treatment pathway demonstrating the definitions of first hospital episode and the total episode of care.

Description of indicators

Baseline indicators of infants:
- gestational age
- weight
- gender
- apgar (measures used in different countries vary: either apgar at 5 or apgar at 10 minutes is used)

Process indicators:
- Length of stay of first hospital admission, days per infant at three different levels of care as defined by the American Academy of Pediatrics (2012)
    - Level III NICU
    - Level II Specialty Care Nurseries
    - Level I Units
- Length of stay of first hospital episode, days per infant
- Transfer and back-transfers during the first hospital admission
- Total inpatient days per patient over the first year after the birth
- Number and share of patients having with length of stay of the first hospital episode of 90 days or more
- Number and share of patients that received during the first hospital episode catheterization
- Number and share of patients that received during the first hospital episode ventilation
- Number and share of patients that received during the first hospital episode continuous positive airway pressure

Outcome indicators
- Mortality at 1, 7, 30 and 365 days from the day of birth
- Morbidities at birth or during the first hospital episode:
    - Respiratory distress syndrome
    - Neonatal jaundice
    - Anemia of prematurity
    - Persisting ductus arteriosus
    - Other respiratory problems after birth
    - Bronchopulmonary dysplasia
    - Intraventricular hemorrhage
    - Retinopathy of prematurity
    - Necrotizing enterocolitis

Risk adjustment

One of the challenges when comparing health outcomes between countries is to adjust for differences among infants. This is further complicated by the fact that detailed information on the infants may not be available, or that variables can be very differently defined across countries. In order to have comparable performance indicators the indicators have to be adjusted for confounding factors. EuroHOPE aims to solve this problem by using register data available for everyone with a specified health problem, which contains detailed information on variables with effect on the health outcomes.

For each outcome, three different risk adjusted outputs are produced: 1. adjusted for sex and age only, 2. adjusted for sex, age, disease specific co-morbidities based on primary and secondary diagnosis, LOS the year prior to index admission, and 3. identical to 2 except co-morbidities are based on both primary and secondary diagnosis and medication purchase. **For detailed instructions, see Appendix 4.**

Based on the experiences in the PERFECT project (Peltola *et al.*, 2011), the observed/expected approach described in Ash *et al.* (2003) is used, which roughly corresponds to indirect standardization. Specifically, the method uses regression modelling for the risk adjustment. For mortality outcomes up to one year logistic regression is used, while for the LOS outcomes negative binomial regression is used. The method is described more detail in Mogren, Peltola et al 2012. The STATA CODES for calculating indicators are given in Appendix 5.

Case-mix standardisation will be used when comparing countries, regions, hospitals, or years. Variables which are considered potential prognostic factors (and thus confounders) are used for adjustment. These will be derived from medical birth register. We will use
- age (in years, classified)
- gender
- SGA/LGA (small or large for gestational age: counted on the basis of country specific standard fetal growths (e.g. Bertino et al. 2010))
- mode of delivery
- type of delivery
- presence of malformations (narrow and broad definitions will be used in two different risk adjustment models)

Levels of analysis

Indicators are produced at national and within some selected countries also at regional level and eventually hospital level. Regional information is based on patients' place of residence. The definitions for regions have been made in each country according to the local preferences.

Remarks on interpretation of indicators

Here the paper describes what should be taken into account in comparisons of indicators. The most important caveats related to differences in coding practices, availability of data and differences in classifications should be discussed. In particular three main issues will be addressed.

First, the issue of linkage between medical birth register and other hospital discharge registers affected similarly to previous research (e.g. Pezzotti et al. 2009) the EuroHOPE project and is discussed. Whereas the majority of countries had an opportunity to employ deterministic linkage based either on unique ID, some countries had to use stochastic linkage methodologies combinig not only the medical birth register or the hospital discharge register related infants, but also a hospital discharge register related to mothers. The experiences from different countries demonstrate that deterministic linkage can have some particular limits in case of multiple births. A duplication of the collected information in medical birth registers and hospital discharge registers its might have further affected the analysis.

Second, different coding systems used across countries together with different coding practices and a differentnumber of diagnoses and procedures in medical birth registers or hospital discharge registers limit the comparative potential of the EuroHOPE research.

Third, an absent classification of levels of care according to the American Academy of Pediatrics lead in several countries to the creation of only approximative definition of these levels.

This section will be finalized after indicators of all are available.

References

American Academy of Pediatrics:Policy Statement: Levels of Neonatal Care COMMITTEE ON FETUS AND NEWBORN Pediatrics 2012; 130:3 587-597.

Ash AS, Schwartz M, Peköz EA. Comparing outcomes across providers. In: Iezzoni LI, editor. *Risk adjustment for measuring health care outcomes*. 3rd ed. Chicago: Health Administration Press; 2003. p. 297-333.

Bertino, E., Spada, E., Occhi, L., Coscia, A., Giuliani, F., Gagliardi, L., Gilli, G., et al. (2010). Neonatal anthropometric charts: the Italian neonatal study compared with other European studies. *Journal of Pediatric Gastroenterology and Nutrition*, *51*(3), 353–361.

Häkkinen U . Peltola M. et all 2012. Some general definitions and principles used in EuroHOPE ; Long-term care, rehabilitation, hospital classification and regions EuroHOPE discussion paper xx

Moger T, Peltola M et all 2012. Risk adjustment in EuroHOPE. EuroHOPE discussion paper xx

Peltola M, Juntunen M, Häkkinen U, Rosenqvist G, Seppälä TT, Sund R. A methodological approach for register-based evaluation of cost and outcomes in health care. *Annals of Medicine*. 2011; 43, S1: S4–S13.

Pezzotti, P., Mantovani, J., Benincori, N., Mucchino, E., & Lallo, D. Di. (2009). Incidence and risk factors of hospitalization for bronchiolitis in preterm children: a retrospective longitudinal study in Italy. *BMC Pediatrics*, 9, 56.

Appendix 1: List of Lethal Congenital Malformations as Criterion of Exclusion

Malformation	ICD-9-CM	ICD-10
Anencephaly/Acrania	740.0	Q00.0
Transposition of great vessels	745.1X	Q20.1, Q20.3, Q20.5, Q20.8
Hypoplastic left heart syndrome:	746.7	Q23.04
Renal agenesis and dysgenesis	753.0 (better only agenesis (bilateral) - not allowed by ICD-9-CM, possible with ICD-10)	Q60.2, Q60.5
Anomalies of diaphragm: Absence of diaphragm, Congenital hernia: diaphragmatic, foramen of Morgagni, Eventration of diaphragm	756.6 (better only absence of diaphragm, not allowed by ICD-9-CM, possible with ICD-10)	Q79.0, Q79.1,
Patau's syndrome	758.1	Q91.7
Edward's syndrome	758.2	Q91.3

Appendix 2. Particular characteristics of national registers and databases

Appendix 3. Variable definitions

Appendix 4. Instructions for adjustment for confounding (apply for between and within country comparisons).

List Malformations for risk adjustment (narrow definition)[2]

Malformation	ICD-9-CM	ICD-10
Tetralogy of Fallot	745.2	Q21.3
Common ventricle	745.3	Q20.4
Endocardial cushion defects	745.6X	Q21.2
Anomalies of pulmonary valve congenital	746.0X	Q22.0-3
Other specified congenital anomalies of heart	746.8X	Q24.0-6, Q24.8
Patent ductus arteriosus	747.0	Q25.0
Coarctation of aorta (preductal) (postductal)	747.10	Q25.1
Anomalies of pulmonary artery	747.3	Q25.5, Q25.6, Q25.71, Q25.72, Q25.79
Agenesis, hypoplasia, and dysplasia of lung	748.5	Q33.2, Q33.3, Q33.6
Tracheoesophageal fistula, esophageal atresia and stenosis	750.3	Q39.0-4
Atresia and stenosis of small intestine	751.1	Q41.9

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[2] Broad definition: ICD-9: 740–759; ICD-10: Q00–Q89

Atresia and stenosis of large intestine, rectum, and anal canal	751.2	Q42.9
Congenital single renal cyst	753.11	Q61.01
Polycystic kidney	753.12-14	Q61.2, Q61.3, Q61.19,
Renal dysplasia	753.15	Q61.4
Other specified cystic kidney disease	753.19	Q61.8
Anomalies of abdominal wall	756.7	Q79.2-4, Q79.51, Q79.59
Other conditions due to autosomal anomalies: Accessory autosomes NEC, Triploidy	758.5	Q92.7