D7. Agreed Public Contents about Results and Network to Disseminate to Each Selected Target Audience
Dissemination strategies are well defined and introduced in the European Neonatal Network (ENN) since its start. A communication plan was designed, communication activities developed and appropriate communication of results to stakeholders driven. Each year these are routinely implemented, discussed and agreed by the Steering Committee (SC) members in their biannual face to face meetings.

Dissemination strategies are the following:

There are several different ways to disseminate ENN, depending on the purpose and the target audience: to raise awareness of the ENN concept to the general public, benefits and objectives; to attract other units or regional/national networks to join the initiative; to release the results of exploiting data from the network to achieve the network’s objectives to European and international stakeholders, including health regional/national authorities, public health officials, agencies and personnel involved in maternal/perinatal/neonatal/childcare (neonatologists, nurses, obstetricians, neurologists, psychologists…), as well as specialists on child education, epidemiology, social workers, parental associations and any other party that might be interested in our expected results, output and deliverables.

To spread the word of ENN objectives and aims, the Web Site is maintained as up to date as possible and dissemination documents are produced and available for the general public. This is crucial to ensure that the rationale behind the network is rapidly understood, increasing the likelihood of adoption and thus impact on health of newborn infants, our mission: that all VLBWI/VLGAI born in Europe receive the best possible health care, no matter where born to overcome existing inequalities.

ENN Web Site (www.euroneonet.org) is the visible face of the network, so documents and information uploaded is reviewed periodically and although Bilbao coordination center (BCO) is the one in charge of its maintenance, SC members participate actively delivering and proposing documents, information and activities to be uploaded.

General information on the initiative, dissemination and promotional information is available in the main page of the Web Site. There are permanent documents, updated periodically such us the ENN Annual Report and the ENN Promotional Leaflet and temporal specific newborn information diffusion campaigns (i.e. “International Neonatology Association Conference (INAC 2015)” Marrakech, Morocco from 21-23 March, 2015). Permanent documents are discussed by the SC Members and agreed in our biannual meetings.

To maintain privacy, the Web Site is divided in a public part and a private part which is exclusively available for ENN registered organizations that have been approved by the BCO. Mission and Aims, Steering Committee Members, Project Status and Documents are in the open, available for any internet user.
Documents uploaded in the Web Site respond to different needs. ENN Policy documents, data management related documents (Data collection sheets, Manuals and DataSets), exploiting data for a research proposal (Protocol for Research using ENN data), General Reports (ENN General Report (2006-2011)), information on participating Units, Dissemination Slides (To Promote the Network in National/International Pediatric/Neonatal Meetings, key stakeholders,….) and a list of all the ENN Publications.

Reports, Dissemination Slides and Promotional Documents are released to SC Members. These will disseminate them principally to clinicians in their Units (to benchmark), and to any key stakeholders interested in results or in supporting the initiative in a national basis (parent’s associations, pediatric societies, public officials, professionals, parents, official bodies and general public).

On top of this, ENN Coordinator and SC Members, present abstracts, oral presentations and communications at forums and meetings of European societies.

This year documents have been updated routinely. The draft ENN 2013 Annual Report has been performed and the final version is being developed and is due to be released before February 2015. Promotional documents, such as ENN Promotional Leaflet, Participating Units and ENN publications have also been updated.

Unfortunately, due to the sad event of Prof.’s Valls sudden death at the end of 2013, Policy Documents have had to be updated and corrected. The whole ENN structure has decided under analysis and discussion to build up a renovated and successful organization structure.

ENN’s new structure, as mentioned above, is going through deep structural and organizational changes in order to adapt to the new challenges raised by substantial changes in SC composition and changing European research environment.
List of 2013-2014 ENN Communications at National/ International meetings is:

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<th>No.</th>
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<td>A. Valls-i-Soler, A. Azpeitia on behalf of the European Neonatal Network (<strong>EuroNeoNet</strong>). “Combined Adverse Neonatal Outcome (Death or Survival with Severe Intraventricular Hemorrhage (IVH) and/or Chronic Lung Disease (CLD) in Very Low Gestational Age (VLGA) infants. A <strong>EuroNeoNet</strong> Study”. 3rd International Congress of Union of European Neonatal and Perinatal Societies (UENPS). Porto-Portugal, November 2013.</td>
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European Neonatal Network (EuroNeoNet)

Steering Committee

Terms of Reference

1. PURPOSE.

The EuroNeoNet Steering Committee (SC) is the decision-making committee of the EuroNeoNet. EuroNeoNet is a network conducting benchmarking, quality improvement initiatives and clinical trial dedicated to improve of neonatal-perinatal health and health care in Europe.

2. AREA OF RESPONSIBILITY OF THE STEERING COMMITTEE:

2.1 Shall set policies designed to permit EuroNeoNet to achieve its objectives, as outlined in the EuroNeoNet Policies and Procedures.

2.2 Shall monitor on-going operations of EuroNeoNet and the extent to which EuroNeoNet operations achieve its objectives.

2.3 Shall monitor revenues and expenditures of EuroNeoNet funds.

2.4 Shall have the final say over the approval and implementation of all EuroNeoNet policies and procedures.

2.5 Shall develop strategies to grow and strengthen the EuroNeoNet as sustainable research collaboration.

2.6 Must decide on the request to use practical data subscribed by other SC members, network members or any type of researchers. Request will be approved, denied or modified by SC criteria.

2.7 SC Members shall promote the join collaboration between national networks and individual researchers at national and international forums.
3. **MEETINGS.**

3.1 The SC will hold quarterly teleconferences/virtual meetings.

3.2 The SC shall meet in person at least once a year at the EuroNeoNet annual meeting.

3.3 The SC must decide on the request to use data subscribed by other SC members, network members or other researchers. Request will be approved, denied or modified by SC criteria.

3.4 In addition to the quarterly meetings, the SC may be invited to attend ad hoc teleconferences to provide advice and assistance where necessary.

3.5 In the event that a SC member is unable to attend a meeting, a designated representative will be temporarily appointed in place of the committee member to ensure a fair and represented vote always occur.

3.6 Members will respect the confidentiality of the SC discussions. Minutes from the SC meetings will be distributed to the SC Members by the coordinating centre and are not to be distributed to others.

4. **QUORUM.**

The SC will operate by consensus whenever possible. In case of not reaching a consensus, a vote will be set. In case of a tie, the coordinator vote will decide.

5. **MEMBERSHIP.**

5.1. SC membership includes the Chairperson and Network leaders or their appointed representative.

5.2. A list of members is available at the end of the Terms of Reference.
6. COORDINATOR.

6.1 The coordinator of the project is Consultant Begoña Loureiro

6.2 The Coordinator shall guide the development of SC meeting agenda and minutes.

6.3 The Coordinator shall ensure all discussion items end with a decision, action or definite outcome.

7. SUPPORT.

7.1. Meeting minutes and agenda will be complied and circulated by EuroNeoNet Coordinating Centre in Bilbao, Spain.

7.2. Meeting minutes and agenda must be available for any EuroNeoNet member, and e-mailed if requested.

7.3. The minutes shall be checked by the Coordinator and accepted by Committee members as a true and accurate record at the commencement of the next meeting.

8. EVALUATION.

The Terms of Reference are in effect indefinitely and shall be reviewed as necessary. They may be altered to meet the current needs of all committee members, by consensus of all committee members.
9. EuroNeoNet STEERING COMMITTEE MEMBERS:

<table>
<thead>
<tr>
<th>Name</th>
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<tr>
<td>Mikko Hallman</td>
<td>University of Oulu</td>
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<td>Olivier Claris</td>
<td>University of Lyon</td>
<td>France</td>
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<td>Helmut Hummler</td>
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<td>Marina Cuttini</td>
<td>Ospedale PediatricoBambino Gesu</td>
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<td>Carlo Corchia</td>
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<td>Tom Stiris</td>
<td>Ulleval University Hospital</td>
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<td>Carmen Rosa pallás</td>
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<td>Javier de la Cruz</td>
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<td>Begoña Loureiro</td>
<td>Hospital Universitario Cruces</td>
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<td>Jose Ignacio Pijoán</td>
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<td>Linda Johnston</td>
<td>The Queen’s University of Belfast</td>
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<td>Henry Halliday</td>
<td>Belfast</td>
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For The EuroNeoNet Project

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Bizkaia (Spain)

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Fax: +34 94 600 60 76
e-mail: info.euroneonet@euskalnet.net
EUROPEAN NEONATAL NETWORK (EuroNeoNet)

Publication Policy

1. PURPOSE.

The following outlines for the policy on publications/manuscripts/abstracts/presentations are based on results produced from the European Neonatal Network (EuroNeoNet) and its related projects and databases. Any publication from EuroNeoNet will be authored using the rules laid out below for EuroNeoNet investigators, paid staff members, non-paid contributors and other professionals and researchers.

2. MAIN PUBLICATIONS: The set of primary publications that will result from the main analyses in EuroNeoNet Project.

2.1 The first author will carry the responsibility for conceptualisation and assume the primary responsibility for the completion of the manuscript to publication or paper/poster abstract to presentation subsequent order is determined by descending degree of contribution. No tasks automatically confer authorship privileges.

2.2 The “European Neonatal Network” will be included as the final author in each main publication and presentation. A Writing Group may be assigned.

2.3 The Steering Committee will be the arbitrator of authorship order on the derived main publications in the event of a dispute.

2.4 Contributions will generally determine authorship order. General agreement on authorship order and contributions of co-authors is reached before beginning preparation of manuscripts and will be kept as a written record.

2.5 In the case of a Writing Group, each working group leader will be responsible for allocating lead authorship and writing responsibilities for publications. In the event of a disagreement, a decision will be made by the EuroNeoNet Steering Committee.
2.6 Among other things, to be named as an author, individuals must be able to defend the work publicly, and therefore have a reasonable understanding of related literature, the methods used, results obtained and interpretation of the study. They must also contribute to the manuscript or abstract write-up; ghost authorship will not be permitted.

2.7 The Writing Group has primary responsibility in mapping out manuscripts and presentations, and the Steering Committee adjudicates any differences of opinion. Manuscripts must be submitted to the Steering Committee prior to being submitted to a publisher. The Steering Committee has two weeks to respond.

3. SECONDARY PUBLICATIONS: The various publications that will result from ongoing, additional and secondary analyses of the data.

3.1 First author status is determined by an individual taking the lead and assuming primary responsibility for completion of the secondary publication.

3.2 Anyone interested in leading a manuscript or abstract must submit a one page outline to the Coordinative Centre regarding their intent. Then, Steering Committee will provide clearance to commence after decision is reached.

3.3 Publications must be submitted to the Steering Committee for approval prior to submission to a journal. The Steering Committee should respond within 2 weeks.

3.4 If EuroNeoNet will be the first author, writing group will proposed.

3.5 General agreement on writing group order and contributions of co-authors should reached before beginning preparation of manuscripts and such agreements will be kept as a written record. Authorship order may change based on contribution to the manuscript. The manuscript must be completed within 6 months. An extension may be granted by the Steering Committee.

3.7 The above procedures also apply to the development of any presentations based on secondary or grey literature reports that are not publicly available.
4. FOR CO-INVESTIGATORS.

Their names will be included in the author’s list when one of the following conditions is met:

4.1 The investigator initiated the project resulting in a publication OR

4.2 The investigator is involved in the working group for this project OR

4.3 The investigator is involved in the publication and is put forward by the project initiator to the Steering Committee to be an author.

5. PUBLICATIONS/MANUSCRIPTS/ABSTRACTS/PRESENTATIONS USING EURONEONET DATA.

5.1 Manuscripts and abstracts resulting from EuroNeoNet and individual units or regional/national networks site data must be reviewed by the Steering Committee BEFORE submission for publication.

5.2 A copy of manuscripts resulting from EuroNeoNet data must be forwarded to the Coordinating Centre.

6. GENERAL

The policies outlined in this document are subject to review and change by the EuroNeoNet Steering Committee, as required from time to time.
General Contact Information
For The EuroNeoNet Project

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Begoña Loureiro Gonzalez
ENN/ENS Coordinator
Participating Units (with data)

Can be found at:

Membership Rights

EuroNeoNet Rational

We propose to develop a Network of Excellence of Neonatal Units throughout Europe, link by an up-to-date technology interactive Website. Units will share a minimal, standardised perinatal Dataset of risk factors, prevalentive interventions and long term outcomes of Very-Low-Birth-Weight premature infants (VLBWI) of less that 1501 g of birth weight Perinatal and follow-up data of VLBWI born throughout Europe cared for at participating neonatal intensive care units (NICU) would be included. The website would process data of individual units as well as data at regional, national and European levels, to help identify areas of health improvement as a quality-control method. The Network would also develop educational programs, perform outcome research and non-industry promoted randomised clinical trials to evaluate frequent interventions.

We are prepared and ready to fully develop and implement the Network proposed for a better integration of the research capacities in neonatal care in Europe. The group has all the necessary skills needed and to foresee not only the need, but also the opportunity to develop such a Network as well as the interest of neonatal units in this proposal that could integrate public and private efforts in a pan-Europe scale.

The proposed use of a computer network base on an interactive Website in Internet in a virtual environment with easy-to-use friendly interface to promote wide scale consensus in care policies and strategies in the care of VLBW infants. The use of dependable and secure platforms with novel development tools is an added asset to be gained by these initiatives. The expertise technological gains in this proposal could be used latter to solve other prevalent health problems. The Network is planed also to enhance transparency, decentralised and more democratic control of quality of care tools. The aims of the network will include research, integration activities and activities of spreading excellence.

In the last decade, neonatal intensive care has improved overall neonatal (from 10-12 to 3-4‰) and infant mortality rates (from 12-15 to 5-6‰). The possibility to improve intact survival requires identification of risk factors and the evaluation of the effects of different interventions in the outcomes. To allow inter-institutional comparisons, homogeneous criteria should be used, all cases must be registered, prognostic factors and inter-centre variability of outcomes studied to establish effective and efficient preventive and therapeutic strategies.

In other areas of the world, several initiatives have solved this problem gathering specific information on VLBW infants, like the Vermont-Oxford and the National Research Network of the Institute of Child Health In the USA, and similar networks in Australia and New Zealand, and Canada. Such a network does not exist in Europe.

"Data-Pic"

A Data Collection software has been developed specifically for this Project ("Data-Pic") which includes quality and ranges control procedures. It is a module for data collection able to register and control the clinical activity of Neonatal Intensive Care Unit (NICU) and allows electronic data entry and secure submission of de-identified data files via e-mail.
It features a simple, menu-driven user interface, extensive range and error checking, on-line help, including all data item definitions, containing an individual password to install it and downloading of new versions via the Website. This software also allows to send data that does not identify individual patients (according to regulations of the Spanish Data Protection Agency and of similar European Agencies) for later study and comparative analysis and/or publication.

The program is designed to work under MS Windows 9x, Win ME, Win XP, Win NT and Win 2000 or higher environments.

“Data-Pic” is free to all Network members.

**Data analysis**

Basic descriptive statistics will be interactively performed in real-time by individual participating units via Internet. Results could be adjusted by weight and gestational age subgroups. Frequency, percentiles and extreme values will be calculated to identify possible risk factors and its possible association with outcomes, using standard statistical and epidemiological procedures (odd ratio, relative risk and 95% CI, multiple regression and logistic analysis). Each centre could periodically and upon demand, perform planned and unplanned general statistics, and know its relative position in comparison all units, units of similar size, region, country and so on. Each centre will be also informed of any situation of extreme values.

**Data Analysis Reports**

Periodical data analysis reports of whole population dataset will be performed by the Bilbao Coordination Office (BCO), supervised by the Steering Committee and published in the Website and scientific journals. It will also be transmitted to participating units and disseminated in the general press for general knowledge.

The computing centre will be the responsible for the analysis and eventual publication of the data. Any publication that contains information on the EuroNeoNet database, it will have to take its origin.

All publication on the data, it will also acknowledge name of all associated centres, as well as that of its representative.

Yearly, the computing centre will issue a general report and submit it to each centre, along with a comparative report of its relative position in relation to the whole group.

Comparisons among centres are not permitted. A centre might compare its own results to all in database, or with other centres of similar characteristics, but could not know identity data of any other Unit.

**Newsletter**

A Newsletter will be published periodically during the year, which keeps members up to date on all the Network’s projects and areas of activity. The Newsletter offers insights into current and future developments in the field of Neonatology.
EuroNeoNet (European Neonatal Network) is a platform to promote networking among European neonatologists. The initiative is affiliated to the European Society for Paediatric Research and the European Society for Neonatology (ESPR/ESN).

**Mission**

To enhance neonatal networking to help neonatologists promote a culture for quality of care improvements and patient safety, family-centered and developmental care and dissemination of evidence-based interventions, e-learning, and to effectively conduct academically-driven clinical trials, case-control, cohort, cluster and nested studies.

**General Aim**

We propose to develop a Network of Excellence of European Neonatal Units, linked by an interactive website. Units will share a minimal, standardised perinatal risk factors, prevalent interventions and long term outcomes of Very-Low-Birth-Weight premature infants (VLBWI) of less than 1501 g of birth weight.

**Specific Aims**

1. To promote cooperative actions to measure the efficacy and effectiveness of the health services provided to VLBW infants
2. To establish unified protocols to guarantee the quality of these services.
3. To provide each participating unit the possibility to have standardised comparisons with other institutions or countries with different health systems and resources.
4. To help participating units to identify opportunities to improve the attention and monitor success of their efforts in specific areas.
5. To evaluate emerging technologies for its possible incorporation into clinical practice.
6. To facilitate exchange of experiences and personal communication of the professionals with colleagues of other European countries.
7. To promote outcome research, cohort studies, and to perform academically-driven randomised clinical trials.
8. To provide a platform for continued education for neonatologist by e-learning.
General Report for Very-Low-Birth-Weight/Very–Low-Gestational-Age Infants

Data from 2006 to 2011
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1 BACKGROUND

Prematurity, that is birth before the 37 completed week of gestation, is a significant health problem in Europe. Its prevalence is increasing as is the rate of Very-Low-Birth-Weight (VLBW) infants. Those very immature, of less than 32 completed weeks of gestation and of a birth weight of less than 1,500 g, have an increased risk for mortality and for short- and long-term morbidity.

Prematurity and VLBW are prevalent health problems, but in Europe there is no systematic recording of standardised specific morbidity data. An Information System on this topic is much needed for epidemiologic surveillance and evaluation of care given by units health systems because:

a) VLBWI mortality represents 70% of all neonatal deaths and over 60% of infant mortality, percentages that are even higher in relation to neonatal and long-term morbidity.

b) VLBWI are few (1.5% of births), are all born at hospitals setting, and cared at neonatal units.

c) Its outcome is related not only on prenatal events, but also on the quality of perinatal and neonatal care received.

d) Evidence-based, effective and efficient prenatal and neonatal interventions are available but not always used.

e) Surviving infants might have neurological and respiratory handicaps in need of follow-up, multiple therapeutic and rehabilitation interventions, prolonged care and re-hospitalisations.

f) Overall, perinatal, neonatal and long-term care of VLBWI is one of the most demanding health problems in Europe, draining increasingly large health resources.

Currently, to evaluate perinatal and neonatal care, EU countries collect and report data for overall neonatal mortality, prematurity, Low- and Very-Low-Birth-Weight rates, along with perinatal-related statistics.

This report summarises the results of neonatal mortality and morbidity of a cohort of VLBW infants born at participating neonatal units from 2006 to 2011.
2 INTRODUCTION

EuroNeoNet (The European Neonatal Network) is a collaborative Network aiming to give European neonatologists a tool to perform their own quality assurance and benchmarking, and a framework to facilitate the development of high-quality outcome epidemiological research as well as academic driven randomised clinical trials.

EuroNeoNet (ENN) dataset has been developed to meet the specific needs of Very-Low-Birth-Weight (VLBW) and Very-Low-Gestational-Age (VLGA) infants assisted in Europe. The perinatal minimal dataset includes prenatal and neonatal risk factors, frequent interventions and short-term outcomes.

Although ENN also records a follow-up minimal dataset for long-term outcomes evaluated at 48 months, this report only focuses on the perinatal dataset.

EuroNeoNet is structured as an up-to-date technological neonatal platform based on the Internet. Units are able to submit data electronically via e-mail or by specific software in an anonymous manner. Basic statistics and quality control checks are accessible interactively, immediately and independently of the Coordinating Centre.

EuroNeoNet data has been collected prospectively since 2006, in nearly 200 units from 18 countries, recording over 40,000 VLBW/VLGA infants' registers. National and regional networks, such as Belgium, Italy (Lazio), Portugal, Spain, Sweden, Switzerland, collaborate with data to EuroNeoNet, together with single Units from other European and non-European Countries.

Procedures have been standardised and protocolised to assure data and analysis consistency. We, therefore offer to all interested units the possibility to join this effort and obtain a good toll to perform unit's quality assurance and benchmarking.

More information on EuroNeoNet can be found in www.euroneonet.org.

In this report, data has not been analysed by unit, instead all registers have been considered as a single population.

Severe outcomes have been selected over the ENN data set and analysed by Birth Weight, Gestational Age and Gender subgroups.

Rates and their 95% CI have been performed for units with more than 35 admitted babies, for the general case, and for subgroups analysis, this limit has been set in 20 admitted babies.

This report includes also information on length of stay for inborn babies discharged home. Basic descriptive statistics have been calculated for this.
3 GENERAL DATA

3.1 Countries participating in the initiative

Neonatal Units from 18 European countries participate in this project since 2006 that are listed below:

- Austria
- Belgium
- Czech Republic
- Finland
- France
- Germany
- Greece
- Italy
- Poland
- Portugal
- Russia
- Slovenia
- Spain
- Sweden
- Switzerland
- The Netherlands
- Turkey
- UK

3.2 Sample Size

The total number of cases included since January 2006 to December 2011 is 38,035 complete registers. In order to analyse morbidity and mortality, rates are calculated at 28 days of life. This is: babies alive and admitted to the NICU at day 28 and all dead babies no matter when. Hence, sample size used is 37,042 babies from different European countries. (See Graph 2.2.1.).

2.2.1. Graph

![Graph showing initial sample size, excluded, and included cases](image-url)
4  DESCRIPTIVE ANALYSIS

4.1  Neonatal Mortality Rate

4.1.1  Overall Neonatal Mortality Rate

The mortality rate for this cohort of infants has been of 12.4%, with a 95% confidence interval (CI) of [12.1;12.7].

The Neonatal Units with more than 35 eligible babies admitted to the NICU with observed deaths have been studied, being the highest mortality rate observed a 37.4% and the lowest a 2.1%.

<table>
<thead>
<tr>
<th>Neonatal Mortality Rate</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%)</th>
<th>Best Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12.4</td>
<td>[12.1;12.7]</td>
<td>37.4</td>
<td>2.1</td>
</tr>
</tbody>
</table>
4.1.2 Neonatal Mortality Rate by Birth Weight

<table>
<thead>
<tr>
<th>Birth Weight (g)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 501</td>
<td>62.0</td>
<td>[58.0;65.9]</td>
<td>8.9</td>
<td>18.2</td>
</tr>
<tr>
<td>501-750</td>
<td>41.6</td>
<td>[40.1;43.1]</td>
<td>93.8</td>
<td>8.4</td>
</tr>
<tr>
<td>751-1000</td>
<td>18.0</td>
<td>[17.2;18.9]</td>
<td>55.7</td>
<td>4.5</td>
</tr>
<tr>
<td>1001-1250</td>
<td>6.2</td>
<td>[5.7;6.7]</td>
<td>33.8</td>
<td>0.0</td>
</tr>
<tr>
<td>1251-1500</td>
<td>3.4</td>
<td>[3.1;3.8]</td>
<td>12.9</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 1500</td>
<td>3.2</td>
<td>[2.7;3.7]</td>
<td>19.0</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>12.4</td>
<td>[12.1;12.7]</td>
<td>37.4</td>
<td>2.1</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the birth weight class.

As birth weight increases, the neonatal mortality rate decreases, being the mortality rate for babies above 1500g but of less than 32 weeks was 3.2%.
### 4.1.3 Neonatal Mortality Rate by Gestational Age

<table>
<thead>
<tr>
<th>Gestational Age (weeks)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;24</td>
<td>69.3</td>
<td>[66.0;72.6]</td>
<td>100.0</td>
<td>22.4</td>
</tr>
<tr>
<td>24-25</td>
<td>42.3</td>
<td>[40.7;43.9]</td>
<td>98.1</td>
<td>7.5</td>
</tr>
<tr>
<td>26-27</td>
<td>18.4</td>
<td>[17.4;19.3]</td>
<td>80.8</td>
<td>0.0</td>
</tr>
<tr>
<td>28-29</td>
<td>7.7</td>
<td>[7.2;8.3]</td>
<td>35.9</td>
<td>0.0</td>
</tr>
<tr>
<td>30-31</td>
<td>3.4</td>
<td>[3.0;3.7]</td>
<td>19.7</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt;31</td>
<td>3.4</td>
<td>[3.0;3.9]</td>
<td>14.3</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>12.4</td>
<td>[12.1;12.7]</td>
<td>37.4</td>
<td>2.1</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gestational age class.

As gestational age increases, the neonatal mortality rate decreases, being the neonatal mortality rate for babies older than 32 weeks but of a Birth Weight < 1500g was 3.4%.
4.1.4 Neonatal Mortality Rate by Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>13.5</td>
<td>[13.1;14.1]</td>
<td>42.1</td>
<td>2.2</td>
</tr>
<tr>
<td>Female</td>
<td>11.1</td>
<td>[10.7;11.6]</td>
<td>34.0</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>12.4</td>
<td>[12.1;12.7]</td>
<td>37.4</td>
<td>2.1</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within gender classes.

Neonatal Mortality Rate for females is lower than for males (11.1% vs. 13.5%).

4.1.5 Neonatal Mortality Rate Evolution (2006-2011)

Neonatal Mortality rate for all the time period was of a 12.4%. This rate has varied from 13.9% in 2007 and 2008 to 10.3% in 2010. The latest rate reported was of 10.7% in 2011.
4.2 **Periventricular – Intraventricular Haemorrhage (PIVH)**

Peri - Intraventricular haemorrhage is a bleeding at or close to the ventricles of the brain.

This condition usually occurs in very premature babies because the vessels in their developing brains are especially fragile and can bleed easily.

The sample size used in this section turned out to be 33,620 after excluding from the initial simple size (outcomes at 28 days of life) the babies without a cranial imaging done.

Data for the 33,620 infants with a cranial ultrasound done was reported.

### 4.2.1 Severe PIVH (Grades III or IV) Rate

<table>
<thead>
<tr>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%)</th>
<th>Best Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.2</td>
<td>[7.9;8.5]</td>
<td>25.3</td>
<td>1.8</td>
</tr>
</tbody>
</table>

The Severe PIVH rate for this cohort of infants was 8.2%, with a 95% confidence interval (CI) of [7.9;8.5].

The Neonatal Units with more than 35 eligible babies admitted to the NICU with observed PIVH have been studied, being the highest rate observed of 25.3% and the lowest of 1.8%.
4.2.2 Severe PIVH by Birth Weight

<table>
<thead>
<tr>
<th>Birth Weight (g)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 501</td>
<td>18.2</td>
<td>[14.7;21.8]</td>
<td>30.4</td>
<td>9.3</td>
</tr>
<tr>
<td>501-750</td>
<td>20.9</td>
<td>[19.7;22.2]</td>
<td>40.0</td>
<td>3.0</td>
</tr>
<tr>
<td>751-1000</td>
<td>13.5</td>
<td>[12.7;14.3]</td>
<td>31.8</td>
<td>0.0</td>
</tr>
<tr>
<td>1001-1250</td>
<td>6.0</td>
<td>[5.5;6.5]</td>
<td>30.8</td>
<td>0.0</td>
</tr>
<tr>
<td>1251-1500</td>
<td>3.2</td>
<td>[2.8;3.5]</td>
<td>14.3</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 1500</td>
<td>2.5</td>
<td>[2.0;2.9]</td>
<td>9.4</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>8.2</td>
<td>[7.9;8.5]</td>
<td>25.3</td>
<td>2.9</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the birth weight class.

As birth weight increases, Severe PIVH rate decreases.
4.2.3 Severe PIVH by Gestational Age

<table>
<thead>
<tr>
<th>Gestational Age (wks)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;24</td>
<td>32.7</td>
<td>[28.9;36.5]</td>
<td>41.9</td>
<td>20.8</td>
</tr>
<tr>
<td>24-25</td>
<td>26.3</td>
<td>[24.8;27.7]</td>
<td>65.2</td>
<td>5.7</td>
</tr>
<tr>
<td>26-27</td>
<td>14.0</td>
<td>[13.1;14.9]</td>
<td>40.0</td>
<td>0.0</td>
</tr>
<tr>
<td>28-29</td>
<td>6.3</td>
<td>[5.8;6.9]</td>
<td>24.0</td>
<td>0.0</td>
</tr>
<tr>
<td>30-31</td>
<td>2.2</td>
<td>[1.9;2.5]</td>
<td>14.3</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt;31</td>
<td>1.3</td>
<td>[1.0;1.6]</td>
<td>9.5</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>8.2</td>
<td>[7.9;8.5]</td>
<td>25.3</td>
<td>2.9</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gestational age class.

As gestational age increases, Severe PIVH rate decreases.
4.2.4 Severe PIVH Rate by Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>9.2</td>
<td>[8.8;9.6]</td>
<td>23.8</td>
<td>0.0</td>
</tr>
<tr>
<td>Female</td>
<td>7.1</td>
<td>[6.7;7.5]</td>
<td>28.9</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>8.2</td>
<td>[7.9;8.5]</td>
<td>25.3</td>
<td>2.9</td>
</tr>
</tbody>
</table>

(*) Excluded Units with less than 20 infants admitted within gender class.

Severe PIVH Rate for females is lower than for males (7.1% vs. 9.2%).

4.2.5 Severe PIVH Rate Evolution (2006-2011)

Severe PIVH rate for all the time period was of an 8.2%. This rate has varied from 8.8% in 2007 to 7.4% in 2011. The latest rate reported was of 7.4% in 2011.

![Severe PIVH Rate Evolution Chart]
4.3 Bronchopulmonary Dysplasia (BPD)

Babies who are born prematurely and experienced respiratory problems shortly after birth are at risk for Bronchopulmonary Dysplasia (BPD), sometimes called Chronic Lung Disease of prematurity. Although most infants fully recover from BPD and have few long-term health problems, BPD can be a serious condition requiring intensive and prolonged medical care.

A child is not born with BPD, it is something that develops as a consequence of prematurity and progressive lung inflammation.

BPD involves abnormal development of lung tissue. It is characterized by inflammation and scarring in the lungs.

BPD is typically diagnosed if an infant still requires additional oxygen after 36 weeks' postconceptional age (that is, after 36 weeks have elapsed from the time of birth).

4.3.1 BPD

The sample size used in this section is composed by babies whose total length of stay has been at least 36 weeks of adjusted gestational age alive.

Data for BPD comes from the 18,738 babies who were alive at 36 weeks of life adjusted to gestational age.

The BPD rate at 36 weeks of adjusted gestational age for this cohort was of 16.7%, with a 95% confidence interval (CI) of [16.2;17.3].

The Neonatal Units with more than 35 eligible babies admitted to the NICU with observed babies needing oxygen at week 36 of adjusted gestational age has been studied, being the highest rate observed a 53.3% and the lowest of 0.0%.

<table>
<thead>
<tr>
<th>Bronchopulmonary Dysplasia (BPD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate (%)</td>
</tr>
<tr>
<td>----------</td>
</tr>
<tr>
<td>16.7</td>
</tr>
</tbody>
</table>
4.3.2 BPD Rate by Birth Weight

<table>
<thead>
<tr>
<th>Birth Weight (g)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 501</td>
<td>58.9</td>
<td>[52.1;67.6]</td>
<td>55.6</td>
<td>55.6</td>
</tr>
<tr>
<td>501-750</td>
<td>47.3</td>
<td>[45.0;49.6]</td>
<td>92.9</td>
<td>3.6</td>
</tr>
<tr>
<td>751-1000</td>
<td>27.8</td>
<td>[26.4;29.2]</td>
<td>74.8</td>
<td>1.7</td>
</tr>
<tr>
<td>1001-1250</td>
<td>12.0</td>
<td>[11.1;12.9]</td>
<td>53.3</td>
<td>0.0</td>
</tr>
<tr>
<td>1251-1500</td>
<td>5.4</td>
<td>[4.8;5.9]</td>
<td>36.6</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 1500</td>
<td>6.4</td>
<td>[5.0;7.9]</td>
<td>30.0</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>16.7</td>
<td>[16.2;17.3]</td>
<td>53.3</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the birth weight class.

As birth weight increases, the BPD at 36 weeks of adjusted gestational age rate decreases, being this rate for babies above 1500 g but of less than 32 weeks was 6.4%.
4.3.3 BPD Rate by Gestational Age

<table>
<thead>
<tr>
<th>Gestational Age (wks)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤24</td>
<td>57.0</td>
<td>[48.1;66.0]</td>
<td>51.7</td>
<td>51.7</td>
</tr>
<tr>
<td>25-26</td>
<td>50.4</td>
<td>[47.8;53.0]</td>
<td>95.9</td>
<td>2.8</td>
</tr>
<tr>
<td>27-28</td>
<td>33.5</td>
<td>[31.9;35.2]</td>
<td>83.1</td>
<td>2.2</td>
</tr>
<tr>
<td>29-30</td>
<td>16.9</td>
<td>[15.8;18.0]</td>
<td>66.7</td>
<td>0.0</td>
</tr>
<tr>
<td>31-32</td>
<td>7.4</td>
<td>[6.7;8.1]</td>
<td>59.0</td>
<td>0.0</td>
</tr>
<tr>
<td>≥33</td>
<td>3.6</td>
<td>[3.0;4.1]</td>
<td>23.8</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>16.7</td>
<td>[16.2;17.3]</td>
<td>53.3</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gestational age class.

As gestational age increases, BPD at 36 weeks of adjusted gestational age rate decreases.
4.3.4 BPD Rate by Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Highest Rate (%)</th>
<th>Lowest Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>19.6</td>
<td>[18.8;20.4]</td>
<td>5.49</td>
<td>0.0</td>
</tr>
<tr>
<td>Female</td>
<td>13.8</td>
<td>[13.1;14.5]</td>
<td>52.2</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>16.7</td>
<td>[16.2;17.3]</td>
<td>53.3</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gender classes.

Overall BPD at 36 weeks of adjusted gestational age rate in females is lower than in males (13.8% vs. 19.6%).

4.3.5 BPD Rate Evolution (2006-2011)

BPD rate for all the time period was of a 16.7%. This rate has slightly varied from 15.4% in 2007 to 17.6% in 2011. The latest rate reported was of 17.6% in 2011.
4.4 Cystic Periventricular Leukomalacia (Cystic PVL)

Periventricular leukomalacia (PVL) is a type of brain injury in which small areas of brain tissue around fluid-filled areas (ventricles) of the brain are infected. The tissue infected creates "holes" in the brain.

Babies with PVL are at risk for significant neurological problems, especially those that involve movements such as sitting, crawling, walking, and moving the arms. Patients may need physical therapy. A baby diagnosed with PVL should be monitored by a neonatologist or a paediatric neurologist, in addition to the child's regular paediatrician.

4.4.1 Cystic PVL Rate

The sample size used in this section turned out to be 35,826 after excluding from the initial simple size (outcomes at 28 days of life) the babies without Cystic PVL's result recalled.

The Cystic PVL rate for this cohort was of 5.3%, with a 95% confidence interval (CI) of [5.0;5.5].

The Neonatal Units with more than 35 eligible babies admitted to the NICU with observed babies with Cystic PVL has been studied, being the highest rate observed a 83.6% and the lowest of 0.0%.

<table>
<thead>
<tr>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%)</th>
<th>Best Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.3</td>
<td>[5.0;5.5]</td>
<td>83.6</td>
<td>0.0</td>
</tr>
</tbody>
</table>
4.4.2 Cystic PVL Rate by Birth Weight

<table>
<thead>
<tr>
<th>Birth Weight (g)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 501</td>
<td>8.5</td>
<td>[6.1;10.9]</td>
<td>43.5</td>
<td>0.0</td>
</tr>
<tr>
<td>501-750</td>
<td>8.8</td>
<td>[7.9;9.6]</td>
<td>92.6</td>
<td>0.0</td>
</tr>
<tr>
<td>751-1000</td>
<td>7.7</td>
<td>[7.0;8.3]</td>
<td>37.9</td>
<td>0.0</td>
</tr>
<tr>
<td>1001-1250</td>
<td>4.3</td>
<td>[3.8;4.7]</td>
<td>21.1</td>
<td>0.0</td>
</tr>
<tr>
<td>1251-1500</td>
<td>3.3</td>
<td>[3.0;3.7]</td>
<td>17.8</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 1500</td>
<td>4.4</td>
<td>[3.8;5.1]</td>
<td>21.6</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5.3</td>
<td>[5.0;5.5]</td>
<td>83.6</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the birth weight class.

As birth weight increases, the Cystic PVL rate decreases, being this rate for babies above 1500 g but of less than 32 weeks was 4.4%.
4.4.3 Cystic PVL Rate by Gestational Age

<table>
<thead>
<tr>
<th>Gestational Age (wks)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤ 24</td>
<td>11.4</td>
<td>[9.0;13.9]</td>
<td>34.1</td>
<td>0.0</td>
</tr>
<tr>
<td>25-26</td>
<td>10.9</td>
<td>[9.9;11.9]</td>
<td>100.0</td>
<td>0.0</td>
</tr>
<tr>
<td>27-28</td>
<td>7.9</td>
<td>[7.3;8.6]</td>
<td>38.8</td>
<td>0.0</td>
</tr>
<tr>
<td>29-30</td>
<td>4.8</td>
<td>[4.3;5.2]</td>
<td>20.8</td>
<td>0.0</td>
</tr>
<tr>
<td>31-32</td>
<td>3.7</td>
<td>[3.4;4.1]</td>
<td>20.8</td>
<td>0.0</td>
</tr>
<tr>
<td>≥ 33</td>
<td>1.8</td>
<td>[1.4;2.1]</td>
<td>14.3</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5.3</td>
<td>[5.0;5.5]</td>
<td>83.6</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gestational age class.

As gestational age increases, Cystic PVL rate decreases.
4.4.4 Cystic PVL Rate by Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>5.7</td>
<td>[5.3;6.0]</td>
<td>89.3</td>
<td>0.0</td>
</tr>
<tr>
<td>Female</td>
<td>4.8</td>
<td>[4.5;5.2]</td>
<td>77.8</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>5.3</td>
<td>[5.0;5.5]</td>
<td>83.6</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gender classes.

Cystic PVL rate in females is lower than within males (4.8% vs. 5.7%).

4.4.5 Cystic PVL Rate Evolution (2006-2011)

Cystic PVL rate for all the time period was of a 5.3%. This rate has varied from 8.9% in 2006 to 4.0% in 2010. The latest rate reported was of 4.9% in 2011.
4.5 Retinopathy of Prematurity (ROP)

Retinopathy of prematurity (ROP) is abnormal blood vessel development in the retina of the eye in a premature infant. The blood vessels of the retina begin to develop 3 months after conception and complete their development at the time of normal birth. When an infant is born very prematurely, the infant's eye development will be disrupted.

In infants who develop ROP, the vessels grow abnormally from the retina into the normally clear gel that fills the back of the eye. Here, without support, the vessels are fragile and often haemorrhage into the eye. This is followed by scar tissue development which pulls the retina loose from the inner surface of the eye and draws it toward the centre of the globe, producing a retinal detachment. This can reduce vision or, if severe, result in complete blindness.

Many premature infants develop transient and mild abnormal retinal blood vessel growth that converts to normal growth without treatment. Approximately 1 out of 10 infants with early changes will develop more severe retinal disease.

Today, the risk of developing ROP is proportional to the severity of prematurity. Typically all babies less than 32-34 weeks gestation are screened for the condition. However, only the smallest premature babies, no matter what their gestational age, have the highest risk.

The majority of infants with mild ROP can be expected to recover completely. Severe ROP may lead to marked visual abnormalities or blindness. Again, the most important factor in the outcome is early detection and treatment by a paediatric ophthalmologist.

The sample size used in this section turned out to be 1449 after excluding from the initial simple size (outcomes at 28 days of life) the babies without a cranial imaging done or babies with a cranial imaging done but with ROP Grade 0.

4.5.1 ROP (Grades >= III) Rate.

The ROP (Grades >= III) rate for this cohort was of 4.3%, with a 95% confidence interval (CI) of [4.1;4.6].

The Neonatal Units with more than 35 eligible babies admitted to the NICU with observed babies with ROP (Grades >= III) has been studied, being the highest rate observed a 25.0% and the lowest of 0.0%.
4.5.2 ROP (Grades >= III) Rate by Birth Weight

<table>
<thead>
<tr>
<th>Birth Weight (g)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 501</td>
<td>25.9</td>
<td>[20.0;31.9]</td>
<td>50.0</td>
<td>50.0</td>
</tr>
<tr>
<td>501-750</td>
<td>17.7</td>
<td>[16.1;19.2]</td>
<td>44.9</td>
<td>0.0</td>
</tr>
<tr>
<td>751-1000</td>
<td>7.2</td>
<td>[6.5;7.9]</td>
<td>29.2</td>
<td>0.0</td>
</tr>
<tr>
<td>1001-1250</td>
<td>2.0</td>
<td>[1.6;2.3]</td>
<td>12.5</td>
<td>0.0</td>
</tr>
<tr>
<td>1251-1500</td>
<td>0.6</td>
<td>[0.4;0.8]</td>
<td>6.7</td>
<td>0.0</td>
</tr>
<tr>
<td>&gt; 1500</td>
<td>0.3</td>
<td>[0.1;0.5]</td>
<td>10.3</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4.3</td>
<td>[4.1;4.6]</td>
<td>25.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the birth weight class.

As birth weight increases, the ROP (Grades >= III) rate decreases, being this rate for babies above 1500 g but of less than 32 weeks was 0.3%.
4.5.3 ROP (Grades >= III) Rate by Gestational Age

<table>
<thead>
<tr>
<th>Gestational Age (wks)</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%) *</th>
<th>Best Rate (%) *</th>
</tr>
</thead>
<tbody>
<tr>
<td>≤24</td>
<td>36.0</td>
<td>[29.9;42.2]</td>
<td>67.6</td>
<td>45.5</td>
</tr>
<tr>
<td>25-26</td>
<td>21.5</td>
<td>[19.7;23.3]</td>
<td>47.8</td>
<td>0.0</td>
</tr>
<tr>
<td>27-28</td>
<td>6.7</td>
<td>[6.0;7.5]</td>
<td>33.3</td>
<td>0.0</td>
</tr>
<tr>
<td>29-30</td>
<td>2.1</td>
<td>[1.7;2.4]</td>
<td>22.6</td>
<td>0.0</td>
</tr>
<tr>
<td>31-32</td>
<td>0.6</td>
<td>[0.4;0.8]</td>
<td>7.1</td>
<td>0.0</td>
</tr>
<tr>
<td>≥33</td>
<td>0.3</td>
<td>[0.1;0.5]</td>
<td>8.3</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4.3</td>
<td>[4.1;4.6]</td>
<td>25.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gestational age class.

As gestational age increases, ROP (Grades >= III) rate decreases.
4.5.4 ROP (Grades >= III) Rate by Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Rate (%)</th>
<th>95% CI</th>
<th>Worst Rate (%)</th>
<th>Best Rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>4.7</td>
<td>[4.3;5.0]</td>
<td>25.0</td>
<td>0.0</td>
</tr>
<tr>
<td>Female</td>
<td>3.9</td>
<td>[3.6;4.3]</td>
<td>25.0</td>
<td>0.0</td>
</tr>
<tr>
<td>TOTAL</td>
<td>4.3</td>
<td>[4.1;4.6]</td>
<td>25.0</td>
<td>0.0</td>
</tr>
</tbody>
</table>

* Excluded Units with less than 20 infants admitted within the gender classes.

ROP (Grades >= III) rate in females is lower than in males (3.9% vs. 4.7%).

4.5.5 ROP (Grades >= III) Rate Evolution (2006-2011)

ROP (Grades >=III) rate for all the time period was of a 4.3%. This rate has varied from 5.2% in 2006 to 3.4% in 2010 and 2011. The latest rate reported was of 3.4% in 2011.
4.6 Total Length of Stay at the Neonatal Units

In this section the babies studied are inborn babies, discharged home.

If the baby survived in this section we will study which was its total length of stay, since it was born till it was discharged home.

The Sample size used in this section has been of 22,943 babies. This is babies that were discharged home (no mater the length of stay) and with data available.

The mean total length of stay in the hospital was of 55.1 days with a standard desviation of 30.6 days (σ). This means that a baby normally stay at the hospital around 24.5 to 85.7 days (55.1-30.6 and 55.1+30.6, respectively).

A half of the population stayed 48 days (Q₂) admitted in the Hospital, being the minimum stay of 1 and the maximum of 455 days (a year and nearly 3 months). The 5% of babies (P₅) that stayed the less, stayed at most 22 days. In the other hand, the 5% of babies that stayed the most (P₉₅), stayed at least 111 days (more than 3 months).

<table>
<thead>
<tr>
<th>Total Length of Stay</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
</tr>
<tr>
<td><strong>Mean ± σ</strong></td>
</tr>
<tr>
<td><strong>95% CI (μ)</strong></td>
</tr>
<tr>
<td><strong>Median (Q₂)</strong></td>
</tr>
<tr>
<td><strong>[P₂₅;P₇₅]</strong></td>
</tr>
<tr>
<td><strong>Min - Max</strong></td>
</tr>
<tr>
<td><strong>P₅</strong></td>
</tr>
<tr>
<td><strong>P₁₀</strong></td>
</tr>
<tr>
<td><strong>P₉₀</strong></td>
</tr>
<tr>
<td><strong>P₉₅</strong></td>
</tr>
</tbody>
</table>
5 EXECUTIVE SUMMARY

This report from the European Neonatal Network EuroNeoNet®, (ENN) is based on data from 195 Neonatal Intensive Care Units (NICUs) from 18 European countries which contribute data between January 1, 2006 and December 31, 2011.

EuroNeoNet®, is funded by DG SANCO (European Commission’s Directorate General for Health and Consumers) since 2006 (Grants No. 2005116; 20081311; 2012-317395).

EuroNeoNet® general objectives are to:

- Maintain a neonatal database for risk and protective perinatal factor, demographics, neonatal interventions as well as morbidity and mortality data for VLGA/VLBW infants born throughout Europe.
- Provide benchmarking information to European NICUs, to allow them to identify areas to apply quality improvement initiative to improve the quality of the health care provided to those very high risk infants.
- Support participating NICUs on their quality improvement efforts.
- Provide data to health professionals, policy makers and health managers, parent groups and to any interested individual to allow them to take appropriate decisions.
- Promote high quality research patient oriented, outcome

EuroNeoNet® collects data in a prospective basis. Unit Data Collection procedures have been developed according to the need of units willing to participate. This is:

- Paper data collection form, that can be filled in by pen “in situ” and sent by courier mail to ENN’s BCO in Bilbao. Nowadays, it’s an archaic method, but still useful to test data collection in units and for units that have their first contact with data collection procedures.

- Web Site based data entry chart. It is available only for registered units in the intranet section: Submit Data. Identical Data Collection forms to those in paper are shown and can be filled in the website. Forms are stored in the website and data quality checks are also done at and after entry. (This will be explained in detail in the next section).

- For regional/national networks, above the mentioned methods, technicians from both sides, perform a matching process to convert the regional/national existing database to ENN definitions and formats. Encrypted databases are sent by email or uploaded in any format to a secure zone of the ENN Website. Furthermore, the section Submit Data available in the Web Site, also allows to upload databases. Those have to be in ENN format. This has the advantage that main data quality checks can be done at this stage before sending data to ENN's BCO at Bilbao.
Data that could direct or indirectly identify patients will always remain within the units. Procedures adhere to international protection data and personal identity procedures and legislation. Partners are guarantors of safety of database, which will only be used to achieve the project's aims.

Data collected should full fill data inclusion/exclusion criteria. That is:

Any infant born alive at your hospital, whether or not was admitted to your NICU, should be reported if his/her:

1) Birth Weight (BW) is less than 1501 g

OR

2) Gestational Age (GA) is less than 32 wks (31 + 6 days inclusive).

All livebirths must be reported, no matter if his/her gestational age is below 22 weeks or the birth weight is below 401g.

All outborn infants of same BW and GA as above, admitted to any location in your hospital within 28 days of birth should also be included, only if the baby has never been discharged home.

Outborn babies admitted to the Neonatal Unit after the 28th day of life, should not be included in the Database, since by international definitions those babies are no longer “newborn” but “infants”.

Summarising, to collaborate with data to ENN there are three different options

1) Paper Form: Data Collection Forms are available in the Web Site, and how to fill them in is explained in the EuroNeoNet® Manual (also available via Web). A form has to be filled in for each eligible infant and sent by postal mail to the following address:

   Prof. Adolf Valls i Soler
   BioCruces - Hospital de Cruces
   Neonatal Epidemiological Unit 5ºD
   Plaza de Cruces s/n
   48903 Barakaldo
   Bizkaia (Spain)
   Phone: +34 94 600 63 94
   Fax: +34 94 600 60 76

This method is available for any unit, but it's more suitable for individual units and those that do not record already data in an electronic database. (Forms in Annex III)

2) Electronically: If the Unit already registers data for the eligible infants, both (coordinating centre and Unit) will match this data base to avoid having to enter data twice.
3) Via Web Site: Manual entry and uploading an electronic database is available in the Submit Menu of ENN’s Intranet. Data checks are done at entry and after, in both cases.

There are two options, enter baby by baby (Manual Process) or upload a database containing several babies (Excel). If you chose the second option, you must be sure that the excel file fulfils the specifications described in the web. To enter those web site sections, you must be registered.

Depending on which is the method selected by the unit or network to submit data to ENN, we suggest to build a team to guarantee quality and efficiency in data collection procedures. If data is collected manually either in paper form or via web, we suggest that an experienced nurse must monitor data collection and be the contact person with ENN. If data is recorded electronically or by uploading a file via web, the technician in the unit/network should be the contact person.

To assure compatibility of definitions and data, a data collection test is performed before data is added to the ENN database.

It consists on collecting a small sample size of unit’s data using the data collection procedure that better fits and that is going to be used in the future by the unit. This is checked and validated and if there are no major problems, the unit can start to collaborate with complete cohort data to ENN.

Data quality checks have been developed, revised and modified since 2006. Items collected have been changing since the start of ENN data collection, so do quality checks. These can be divided in three stages or points: data entry, data patterns and inconsistencies validations and double-check post entry validations.

To run data quality checks, data must be stored in the ENN standard database format, so depending on how data has been collected, previous to the checking, data must be mechanized or matched to ENN formats.
In summary, data can arrive by paper or electronically (via Web Site or email). If data is received in paper, data manager mechanize and store it in an ENN standard database. This database is defined with ENN items, formats and categories definitions. If data is received electronically, data manager converts it, if necessary, to ENN formats and stores it in the ENN Standard database. Each unit/region/country is considered separately. Data received by the Website, has a slightly different path, which it’s going to be described later.

After matching formats to ENN, specifically developed for ENN routines are run over data to perform quality checks.

A first routine searches for missing values, for main and secondary items. A second routine looks for simple inconsistencies in data, such us: if a register says that the birth was multiple, the number of foetuses of that birth must be bigger than 1. These could be considered the first stage data collection quality check.

Then, a more complex routine is run, where patterns and inconsistencies are detected. (i.e. if the baby hasn’t reached week 36 adjusted to gestational age at the hospital, item Oxygen on week 36 can’t be answered).

Units receive a document where these errors are listed ordered by ENN code, for them to check out and answer. This process is repeated until the routines do not detect any errors. Sometimes, the missing value can’t be recovered, so ENN assumes that the data will remain missing. If data is missing for Birth Weight or Gestational Age or Initial Disposition (Transferred, Home, Death, Still Hospitalized after a year), the register can’t be considered as valid, and it is completely deleted from the database. (Example document in Annex IV).

After considering data is valid and clean, it is stored in the complete ENN database in an external server, administered by an independent specialised company ensuring its availability, scalability and security. Data is still under checks, or completion.

Finally, some units are double-checked. By chance few units are selected and a random sample size determined. The unit is asked to look up again certain items of those cases to compare to already sent data.

If data is introduced via Website, the first two stages have been programmed, so automatically at entry first stage validations are done and once introduced, before sending data to the BCO, the second stage is performed.

Furthermore, the BCO can produce a data quality check report automatically through the website for any unit sending data.
This General Report is meant to be distributed to all interested stakeholders to disseminate the results of the care of all Newborn infants of Very Low Gestational Age and Very Low Birth Weight Infants (VLGA and VLBW) care for in all participating NICUs.

Data for the 6 year period from 2006 to 2011 shows that there has been a decrease in Neonatal Mortality Rate from a high of 13.9% to a low of 10.3% (a 25% of decrease).

Likewise Severe PIVH decreased from a high rate of 8.8% to a low of 7.4% (16% of decrease) and cystic PVL from 8.9% to 4.9% (45% absolute decrease) and ROP from 5.2% to 3.4% (an absolute decrease of 34.6%).

On the other hand the rate of CLD remained unchanged at about 16.6%.

EuroNeoNet® does great efforts disseminating its results and benefits to Neonatal Intensive Care Units (NICUs) around Europe. Mainly in Congresses, meetings and also in scientific papers.

NICUs participating in ENN receive an Annual Report, which is also available in the Web Site. Reports and Leaflets are also disseminated to diverse stakeholders to introduce ENN to new Units or interested entities.
6 ENN Publications

Book Chapters


International Publications


- A Valls i Soler, M Madrid, C Geffers, H Hummler."Preventing sepsis in VLBW infants: Experience from neonatal networks and voluntary surveillance systems". NeoReviews 2010;11:403-408 (FI: 3,0 NC: )


National Publications

Abstracts

- A Valls i Soler, A Azpeitia, JI Pijoán. “Initial risk store predicts survival without severe intraventricular-hemorrhage (IVH) and/or periventricular-leukomalacia (PVL) in very-low-birthweight (VLBW) or very-low-birthweight (VLBW) or very-low-gestational-age (VLGA) infants”. Pediatr Res 2010;563


- A Valls i Soler, A Azpeitia, JI Pijoán. "Is gestational age (GA) a better indicator of 28 day neonatal mortality than birth weight (BW)?". Pediatr Res 2007; 163 A


- A Valls i Soler on behalf of the EuroNeoStat Sterling Committee. “NEONATAL NETWORKS. Their contribution to research and improvement of neonatal care. EURONEOSTAT: A european information system to monitor outcomes of VLBW and very gestational age infants (VLGA)". J Perinat Med 2007;35:S49


Conferences/Meetings


A Valls i Soler, A Azpeitia, M Madrid, S Kusuda, R Mori, Spanish Neonatal Network (SEN 1500) and Neonatal Research Network of Japan (NRNJ) University of Basque Country (UPV-EHU), "Neonatal mortality rate (NMR) in very low birth weight infants (VLBW). Comparison between neonatal networks from Spain (SEN 1500) and Japan (NRNJ)". 52nd Annual Meeting of the European Society for Paediatric Research, Oct. 14-17, 2011 Newcastle, UK.


A Valls i Soler, A Azpeitia, J Pijoán. “Initial risk store predicts survival without severe intraventricular-hemorrhage (IVH) and/or periventricular-leuomalacia (PVL) in very-low-birthweight (VLBW) or very-low-birthweight (VLBW) or very-low-gestational-age (VLGA) infants”. 3rd Congress of the European Academy of Paediatrics Societies. Copenhagen-Denmark, Octubre 2010.

G Marshall, A Azpeitia, A Valls i Soler, JL Tapia y Grupo Collaborativo. “Score de riesgo predice mortalidad neonatal en recién nacidos de muy bajo peso nacimiento (RNMBPN) en dos redes neonatales internacionales”. IV Congreso Chileno de Neonatología. Santiago-Chile, 29 septiembre al 1 de octubre 2010


A Valls i Soler. “EuroNeoNet”. Tertiary Care Group (TCG) de la Sección de Pediatría de la European Academy of Pediatric. Bruselas, Diciembre 2010


EuroNeoNet
General report for very low birth weight infants. Data from 2006 to 2011


- A Valls i Soler, HL Halliday and H Hummler, on behalf of the Steering Committee of EuroNeoStat project. "Neonatal Networking. A European perspective". Neoreviews 2007;8:275-281 (FI: NC:)


- A Valls i Soler on behalf of the EuroNeoStat Sterring Committee. “NEONATAL NETWORKS. Their contribution to research and improvement of neonatal care. EURONEOSTAT. A european information system to monitor outcomes of VLBW and very low gestational age infants (VLGA)”. 8th World Congress of Perinatal Medicine. Florencia-Italia. Septiembre 2007

EuroNeoNet
General report for very low birth weight infants. Data from 2006 to 2011

EuroNeoNet

A European Information System to improve outcomes of VLGA/VLBW Infants

A. Valls i Soler
Dep. Pediatrics, Hospital de Cruces
Univ. Basque Country, Bilbao, Spain
Advantages for European Units:

1. A more appropriate comparisons:
   - similar? health systems
   - most units with OB services
   (no free-standing Children's hospitals)

2. Less expensive, immediate, interactive results

3. Possible linkage of regional and national networks
   - quasi-population-based clusters

4. Participation in outcome research & RCT’s

5. Educational programs

Why an European Neonatal Network?
EuroNeoNet.org

**Aims:**
1) Quality-assessment of perinatal care VLBWI in Europe
2) Safety initiative ("EuroNeoSafe" project)
3) On-line, interactive continued education (E-learning environment)
4) Promote large RCT's

**Methods**
- A common perinatal data-set, based VON (Copyright)
- Virtual environment by up-to-date technology

**Participation:**
- >180 NICU's from 17 countries
- > 7,000 datasets/year

**Steering Committee:**
“European Information System to Monitor Short- and Long-Term Morbidity Outcomes to Improve Quality of Care and Patient-Safety for VLBWI”

“EuroNeoStat”


Funded in 2005 call for Public Health actions EU Commission, Public Health Section
Mission (Strategic aim)

. To develop I.S. to assess Q-of-C provided to VLGA/VLGA infants (< 1,500 g or < 32 wks) in Europe, to contribute to the improvement of health status & to detect any existing outcome inequalities.

. We aim to **minimise risks** for all babies, so their outcome could be the same no matter where they happen to be born.
EuroNeoNet Coverage

1) Integrated:
   - Belgium
   - Portugal
   - Spain
   - Sweden
   - N Ireland
   - Lazio
   - Switzerland

2) Pending:
   - Estonia
   - Norway
   - Austria
   - Denmark
   - Hungary
   - Ireland
   - France
EuroNeoNet DataBase

- Data Collected since ENS I:

<table>
<thead>
<tr>
<th>Year</th>
<th>Data</th>
</tr>
</thead>
<tbody>
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<td>2006</td>
<td>5,420</td>
</tr>
<tr>
<td>2007</td>
<td>6,360</td>
</tr>
<tr>
<td>2008</td>
<td>6,769</td>
</tr>
<tr>
<td>2009</td>
<td>6,824</td>
</tr>
<tr>
<td>2010</td>
<td>7,585</td>
</tr>
<tr>
<td>2011</td>
<td>2,015</td>
</tr>
<tr>
<td>2012</td>
<td>224</td>
</tr>
</tbody>
</table>

**Total Data Collected:** 35,197
EuroNeoNet Benefits

- Annual Report: Benchmarking with similar European Units
- Participation in International RCT’s
- Participation in QI initiatives.
- Research Publications
Standard EuroNeoNet Report

EuroNeoNet Annual Report for VLGAI
&
Individual Report for Each Unit Practicipating in the EuroNeoNet Project

YEAR 2010
October 2012

. Each Unit that participates with data receives annually an **Standard Report** for its cohort data.
. Units sending data for 5 or more cohorts, receive **GA groups report** for specific outcomes.
Data Collection process

- **Paper forms (standardised):**
  Downloaded in the web side, filled in by hand and sent by postal mail or e-mail. In BCO read by an special OTC scanner.

- **Electronically:**
  Customized for regional and national networks

- **Web Site Based:**
  NEW data entry and management tool via web site (www.euroneonet.org)
EuroNeoNet Web Site

Neonatal European Information System

Network  Statistics  Safety

- Data entry
- On line report
- On line statistics
- General information query
## Mortality against Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>NO N</th>
<th>%</th>
<th>YES N</th>
<th>%</th>
<th>TOTAL N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>511</td>
<td>83,9</td>
<td>98</td>
<td>16,1</td>
<td>609</td>
<td>54</td>
</tr>
<tr>
<td>Female</td>
<td>443</td>
<td>81,9</td>
<td>73</td>
<td>14,1</td>
<td>518</td>
<td>46</td>
</tr>
<tr>
<td>TOTAL</td>
<td>956</td>
<td>84,8</td>
<td>171</td>
<td>15,2</td>
<td>1127</td>
<td>100</td>
</tr>
</tbody>
</table>
EuroNeoNet Output

Annual Report & Subgroup Report

✓ **Annual Reports** for 2006, 2007, 2008, 2009 and 2010 cohorts have already been delivered.

✓ Most units have data for at least five years, therefore **Subgroup analysis**.

✓ **Methodology**: Direct standardized / indirect standardized rates.

✓ **Comparison analysis of similar units** (According to NICU Type)

✓ **Customized comparisons analysis of regions and/or countries** (upon agreement)
Annual Report: Cohort General Description

✓ Items described:

• Perinatal Factors:
  
  BW, GA, Apgar Scores, Gender, Multiple Gestation, Caesarean Section, Prenatal Steroids, Prenatal Care, Major Birth Defects

• Maneuvers and Diagnoses:
  
  Resuscitation, Surfactant administration, Early Bacterial Sepsis, Pneumothorax Diagnose, NEC Diagnose and Focal Gastrointestinal Diagnose

• Morbi-Mortality:
  
  Severe PIVH, BPD, Late Bacterial Sepsis, Cystic PVL and Mortality.
5.2 2010 Cohort General Description: Admitted babies.

Total number of admitted babies in EuroNeoNet NICU’s for 2010 cohort, has been of 7,437.

5.2.1 Perinatal Risk Factors

Birth Weight

Mean birth weight for 2010 babies admitted to the NICU has been of 1,179.3 g. Extreme values are those under 613.6 g, and above 1,720 g (Percentile 5 and Percentile 95).

<table>
<thead>
<tr>
<th>Birth weight</th>
<th>Mean (SD)</th>
<th>95% CI (Mean)</th>
<th>Med [Q1, Q3]</th>
<th>Min-Max</th>
<th>P25-P75</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1,179.3 (342.2)</td>
<td>(1,171.5,1,179)</td>
<td>1,200 [520,1,420]</td>
<td>227 -3,504</td>
<td>613.6 - 1,720</td>
</tr>
</tbody>
</table>

5.2.5 Respiratory System

A 64.6% of babies admitted to the NICU received some kind of resuscitation in Delivery Room, excluding Oxygen.

Need for surfactant rate was of 48.3% and surfactant was administrated within the first hour of life in a 27.5% of babies.

Respiratory Distress syndrome was diagnosed in a 65.1% of babies admitted to the NICU.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resuscitation in DR</td>
<td>4,790</td>
<td>64.6</td>
</tr>
<tr>
<td>Surfactant at any time</td>
<td>3,590</td>
<td>48.3</td>
</tr>
<tr>
<td>Surfactant within the 1st hour of life</td>
<td>1,385</td>
<td>27.5</td>
</tr>
<tr>
<td>RDS Diagnosis</td>
<td>4,752</td>
<td>65.1</td>
</tr>
</tbody>
</table>

Resuscitation in Delivery Room

- Resuscitation in Delivery Room: 64.6%
- Surfactant at any time: 48.3%
- Surfactant within the 1st hour of life: 48.3%
- RDS: 65.1%
5.2.7 Diagnoses

A 3.6% of babies admitted to the NICU were diagnosed of Pneumothorax, a 5.5% of NEC and a 1.8% of Focal Gastrointestinal Perforation.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumothorax Diagnosis</td>
<td>270</td>
<td>3.6</td>
</tr>
<tr>
<td>NEC Diagnosis</td>
<td>404</td>
<td>5.5</td>
</tr>
<tr>
<td>Focal Gastrointestinal Perforation</td>
<td>129</td>
<td>1.8</td>
</tr>
</tbody>
</table>

5.2.8 Mortal Mortality

Mortality rate for babies admitted to the NICU was of a 10.3%.

BPD was diagnosed in a 16.8%, severe PIVH in a 7.8%, Cystic PVL in a 4.4% and a 23.3% had a late bacterial sepsis.

<table>
<thead>
<tr>
<th>Condition</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe PIVH (Grades II-IV)</td>
<td>520</td>
<td>7.8</td>
</tr>
<tr>
<td>Oxygen on week 36 (BPD)</td>
<td>640</td>
<td>16.8</td>
</tr>
<tr>
<td>Late Bacterial Sepsis</td>
<td>1,721</td>
<td>22.3</td>
</tr>
<tr>
<td>Cystic PVL</td>
<td>285</td>
<td>4.4</td>
</tr>
<tr>
<td>Overall Mortality</td>
<td>766</td>
<td>10.3</td>
</tr>
</tbody>
</table>
Benchmarking Section

✓ **Items described:**

- **Perinatal Factors:**
  
  Multiple Gestation, Caesarean Section, Prenatal Steroids

- **Maneuvers and Diagnoses:**
  
  Resuscitation in Delivery Room, Surfactant administration (early and at any time), RDS, Early Bacterial Sepsis, Pneumothorax Diagnose, NEC Diagnose and Focal Gastrointestinal Diagnose, Steroids for CLD

- **Morbi-Mortality:**
  
  Severe PIVH, ROP (Grades $\geq 3$), Oxygen on day 28, Oxygen on week 36 (BPD), Late Bacterial Sepsis, Cystic PVL and Mortality.

✓ **Standardization methods:**

- Indirect standardization at least by BW, GA and gender.
- Specific outcomes are standardized by logistic regression score for complete database.
6.19.3 Mortality Standardized Rate by Perinatal Risk Factors.

Graph 6.19.1, corresponds to the 95% CI for the standardised Mortality adjusted rate.

Graph 6.19.3

The results for Units 1, 5, 14, 16, 17, 25, 74, 76, 77, 81, 83, 90, 94 and 96 reached statistical significant relevance, being the mortality rate for these Units significantly smaller than the one expected according to the standard's population mortality distribution. On the other hand Units 39, 45, 55, 67 and 95 had a bigger significant mortality rate than the one expected according to the standard's population mortality distribution.

Units 2, 48, 59, 60 and 89 didn't register mortality.

Note 1: Standardization Items: Birth weight Z-Score by gestational age, Prenatal Steroids use, 1-min Aggar Score, 5-min Aggar Score, Multiple Gestation, Mode of Delivery and Major Birth Defects

Note 2: Units with 5 or less babies admitted have not been analyzed in this section.

EuroNeoNet 2010

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
Specific and Confidential Annex for each Participating Unit

✓ **Items described:**

- **Perinatal Factors:**
  
  BW, GA, Apgar Score, Gender, Multiple Gestation, Caesarean Section, Prenatal Steroids, Major Birth Defects

- **Maneuvers and Diagnoses:**
  
  Resuscitation in Delivery Room, Surfactant administration (early and at any time), RDS, Early Bacterial Sepsis, Pneumothorax Diagnose, NEC Diagnose, Focal Gastrointestinal Diagnose, Steroids for CLD

- **Percentile Positions for Main Results (Star Graph):**
  
  Mortality, Pneumothorax, Severe PIVH, Oxygen on week 36 (BPD), Late Bacterial Sepsis and Prenatal Steroids
Annex for each Participating Unit: Example

8.2.2 Standardized Percentiles

**Manoeuvres and Diagnoses:**

Resuscitation in Delivery Room, Surfactant Need, RDS and Early Onset Sepsis

More than 3% of the population (77.6%) needed some kind of resuscitation in delivery room in addition to Oxygen. A 23.3% of babies needed surfactant at any time of their stay, being the rate of surfactant within the first hour of life a 12.9%.

A 38.8% of babies were diagnosed of Respiratory Distress Syndrome and a 0.9% of admitted babies had an early bacterial sepsis episode.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resuscitation in Delivery Room</td>
<td>50</td>
<td>77.6</td>
</tr>
<tr>
<td>Surfactant at any time</td>
<td>27</td>
<td>32.3</td>
</tr>
<tr>
<td>Surfactant within the first hour of life</td>
<td>15</td>
<td>12.2</td>
</tr>
<tr>
<td>Respiratory Distress Syndrome</td>
<td>46</td>
<td>28.8</td>
</tr>
<tr>
<td>Early Onset Sepsis</td>
<td>1</td>
<td>0.8</td>
</tr>
</tbody>
</table>

Next graph plots the percentile that the previous results represent in the whole year cohort. Results for Surfactant at any time are below the 10th Percentile.

**Diagnoses**

Pneumothorax, Necrotizing Enterocolitis, Focal Gastrointestinal Perforation and Steroids for CLD.

Pneumothorax rate is of 5.2%, Necrotizing Enterocolitis of a 4.3% and a 4.3% for Focal Gastrointestinal Perforation. Steroids for CLD rate was of 2.6%.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumothorax</td>
<td>0</td>
<td>5.2</td>
</tr>
<tr>
<td>Necrotizing Enterocolitis</td>
<td>5</td>
<td>4.3</td>
</tr>
<tr>
<td>Focal Gastrointestinal Perforation</td>
<td>5</td>
<td>4.3</td>
</tr>
<tr>
<td>Steroids for CLD</td>
<td>3</td>
<td>2.6</td>
</tr>
</tbody>
</table>

Next graph plots the percentile that the previous results represent in the whole year cohort. Any of the results were beyond the standard limits (below 10th percentile or above 90th percentile).
Annex for each Participating Unit: Example

Morbidity-Mortality:
Severe PIVH, Rop (Grades >=3), BPD, Late Onset Sepsis, Cystic Leukomalacia and Mortality

Severe PIVH was diagnosed in a 4.6% of babies admitted in Unit Code 70. A 1.4% of admitted babies were diagnosed of Rop (Grades >=3) and Cystic PVL was found in a 2.6% of babies. Oxygen on week 36 rate was of a 19.7%.

A 15.5% of babies had at least one late onset sepsis episode and a 10.3% of admitted babies died at discharge.

<table>
<thead>
<tr>
<th>Condition</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe PIVH</td>
<td>5</td>
<td>4.5</td>
</tr>
<tr>
<td>Rop (Grades &gt;=3)</td>
<td>1</td>
<td>1.4</td>
</tr>
<tr>
<td>BPD</td>
<td>15</td>
<td>19.7</td>
</tr>
<tr>
<td>Late Onset Sepsis</td>
<td>18</td>
<td>15.5</td>
</tr>
<tr>
<td>Cystic Leukomalacia</td>
<td>3</td>
<td>2.8</td>
</tr>
<tr>
<td>Mortality</td>
<td>12</td>
<td>10.3</td>
</tr>
</tbody>
</table>

Next graph plots, the percentile that the previous results represent in the whole year cohort. Any of the results were beyond the standard limits (below 10th percentile or above 90th percentile).

8.3 Main Results

8.3.1 Percentile Position for Main Results.

Graphic 8.3.1 shows the percentile position for main results for Unit Code 70 resulted to all Units included in the study. Main results are considered to be Mortality, Pneumothorax diagnosis, Oxygen on week 36, Prenatal Steroids (Incomplete + Complete), PIVH (Grades III or IV) and Late Bacterial Sepsis.

The percentage shown represents the position that the Unit has inside the total set of Units studied. Unit Code 70 is in percentile 52 for Mortality, in percentile 66 for Pneumothorax, in percentile 64 for Oxygen on week 36, in percentile 74 for Prenatal Steroids (Incomplete + Complete), in percentile 26 for PIVH (Grades III or IV) and finally in percentile 32 for Late Bacterial Sepsis. For all main items a positive result is considered a low percentile.

*This graphic represents the position that the Unit has inside the whole set, NOT its intensity. Intensity is described in 8.3.2 graphic.
### Other Stats

#### Similar Units Comparisons

<table>
<thead>
<tr>
<th>Interventions</th>
<th>Unit 1</th>
<th>Unit 2</th>
<th>X^2 Statistic</th>
<th>p_value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxygen in the delivery room</td>
<td>107</td>
<td>63</td>
<td>28.816</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Ventilation with Bag/mask in the delivery room</td>
<td>100</td>
<td>32</td>
<td>66.430</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Endotracheal intubation in the delivery room</td>
<td>30</td>
<td>40</td>
<td>7.04</td>
<td>0.008 (*)</td>
</tr>
<tr>
<td>Cardiac Compression in the delivery room</td>
<td>2</td>
<td>2</td>
<td>0.086</td>
<td>1</td>
</tr>
<tr>
<td>Epinephrine/Adrenaline in the delivery room</td>
<td>3</td>
<td>0</td>
<td>2.28</td>
<td>0.262</td>
</tr>
<tr>
<td>Resuscitation</td>
<td>107</td>
<td>66</td>
<td>26.544</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Surfactant at any time</td>
<td>48</td>
<td>45</td>
<td>1.375</td>
<td>0.25</td>
</tr>
<tr>
<td>Oxygen after leaving the delivery area</td>
<td>86</td>
<td>36</td>
<td>14.826</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>NCPAP after leaving the delivery area</td>
<td>95</td>
<td>35</td>
<td>50.934</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Conventional Ventilation after the delivery area</td>
<td>54</td>
<td>37</td>
<td>1.039</td>
<td>0.382</td>
</tr>
<tr>
<td>Ventilation HIFI after the delivery area</td>
<td>13</td>
<td>4</td>
<td>3.471</td>
<td>0.076</td>
</tr>
<tr>
<td>Indomethacin/buprofen (Prophylactic)</td>
<td>32</td>
<td>11</td>
<td>6.569</td>
<td>0.013 (*)</td>
</tr>
<tr>
<td>Indom/Ibuprof/Etampri (Therapeutic)</td>
<td>27</td>
<td>12</td>
<td>3.742</td>
<td>0.07</td>
</tr>
</tbody>
</table>

![Graph showing percentage comparison between Unit 1 and Unit 2 for certain interventions](image-url)
Other Stats

✓ National Regional Comparisons

- Cardiac Compression in the delivery room
- Epinephrine/Adrenaline in the delivery room
- Surfactant at any time

<table>
<thead>
<tr>
<th>Country</th>
<th>Cardiac Compression</th>
<th>Epinephrine/Adrenaline</th>
<th>Surfactant</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spain</td>
<td>5.4%</td>
<td>4.3%</td>
<td>1.8%</td>
</tr>
<tr>
<td>Belgium</td>
<td></td>
<td></td>
<td>42.2%</td>
</tr>
</tbody>
</table>

Percentage
Regional/National Comparisons

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Belgium</th>
<th>Spain</th>
<th>(\chi^2)</th>
<th>p_value</th>
</tr>
</thead>
<tbody>
<tr>
<td>PIVH (Grades III or IV)</td>
<td>55</td>
<td>37</td>
<td>23.03</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Cystic Periventricular Leukomalacia</td>
<td>27</td>
<td>54</td>
<td>7.435</td>
<td>0.006(*)</td>
</tr>
<tr>
<td>Early Bacterial Sepsis and/or meningitis early (before day 3)</td>
<td>230</td>
<td>46</td>
<td>228.774</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Late sepsis and/or meningitis late (after day 3)</td>
<td>258</td>
<td>314</td>
<td>0.304</td>
<td>0.605</td>
</tr>
<tr>
<td>Oxygen at 36 weeks adjusted gestational age</td>
<td>58</td>
<td>71</td>
<td>95.993</td>
<td>&lt; 0.001 (*)</td>
</tr>
<tr>
<td>Mortality</td>
<td>118</td>
<td>165</td>
<td>4.21</td>
<td>0.045(*)</td>
</tr>
</tbody>
</table>

Outcomes

Belgium | Spain | c2 Statistic | p_value
--- | --- | --- | ---
PIVH (Grades III or IV) | 55 | 27.5 | 37 | 11.2 | 23.03 | < 0.001 (*)
Cystic Periventricular Leukomalacia | 27 | 3 | 54 | 5.6 | 7.435 | 0.006(*)
Early Bacterial Sepsis and/or meningitis early (before day 3) | 230 | 31.7 | 46 | 4.6 | 228.774 | < 0.001 (*)
Late sepsis and/or meningitis late (after day 3) | 258 | 34 | 314 | 32.8 | 0.304 | 0.605
Oxygen at 36 weeks adjusted gestational age | 58 | 45 | 71 | 10.5 | 95.993 | < 0.001 (*)
Mortality | 118 | 13 | 165 | 16.4 | 4.21 | 0.045(*)
"Extended European Information System to Monitor Short- and Long-term Morbidity Outcomes to Improve Quality of Care and Patient-Safety for VLBWI" (Proposal A/101106)

"EuroNeoStat II" (For: 2010-12)

Agreement No, – 2008 13 11
# Lists of associate partners

**PI: Adolf Valls-i-Soler, JI Pijoán, Bilbao, Spain**

1. H Halliday: Belfast, **UK**
2. M Hallman: Oulu, **Finland**
3. H Hummler, Ulm, **Germany**
4. O Claris, Lyon, **France**
5. C Corchia and M Cuttini, Roma, **Italy**
6. S. Hakadson, Uppsala, **Sweden**
7. T Stiris, Oslo, **Norway**
8. V Carielli, Ancona, **Italy**
9. C Pallás & J de la Cruz, Madrid, **Spain**
10. M Weindling, Liverpool, **UK**
11. D. Liem, **The Netherlands**

1. Portugal: Daniel Virella, Lisboa, **PSN**
2. Ireland: Tony Ryan, Cork
3. Belgium: Bart Van Overmeire, Ambers
4. Greece: Marietta Xanthou, Athens
5. Poland: Janusz Gadzinowski, Poznan
6. Czech Republic: Richard Plavka, Prague
7. Hungary: Miklós Szabó, Budapest
8. Switzerland: Hans U Bucher, Bern
9. Austria: Berndt Urlesberger, Graz
10. UK: Mike Hall, Southampton
11. Turkey: Rahmi Örs, Konya
12. Slovakia: Darina Chovancova, Martin
13. Romania: Florin Stamatian, Cluj-Napoca
14. Russia: Lyubimenko Viacheslau, S. Petersbourg
ENS II Scientific Work Packages (WP)

- WP 4: **Socio-economical indicators** for health inequalities
- WP 5: Standardized comparison of morbidity outcomes
- WP 6: Minimal dataset for **follow-up indicators at 3-4 years of age**
- WP 7: Specific dataset to study causes of **hospital-acquired infection**
- WP 8: **EuroNeoSafe**: Report for incidents and near-misses
- WP 9: Building & assessing evidence-based actions on **Quality of Care**
WP 4: Socio-economical indicators

✓ Specific objectives
  ✓ Expand the Information System
  ✓ Study health inequalities, ethnic and socio-economic factors of impact on outcome of those high-risk babies

WP 6: Follow-up dataset at 4 years

✓ Specific objectives
  ✓ Expansion of the Information System
  ✓ Study of the variability of care process and outcomes
WP 7: Nosocomial infections

✓ Specific objectives

✓ Expansion of the Information System
✓ Study of indicators and actions to prevent adverse events
✓ Surveillance system to monitor infection
✓ Offer an educational package to prevent infection
WP 8: EuroNeoSafe.
Patient Safety Initiative

- Promoted the culture on neonatal patient safety among units from countries with no official policy about it
- Specific website with links, forum, many information...
- Pilot study for a common Web-based incident reporting system
- Develop a common dataset, definitions and grading system (Contract with DATIX): PILOT Study
WP 9: Quality of care Improvement initiatives

- Alternative method (EPNIC)
- Evidence + GCP by consensus in each NICU
- Do not target just one outcome but a few judged significant in each NICUs
- Why not set a European effort “EuroNeoQUI + I”
- Any European NICU or Network might join
Harmonisation process

- International Harmonization process
- Set by Dr George Gacuoia INCDH
- INCDH + CCN + VON ( + ENN)
- Standardize outcomes and definitions
- Specific data subsets: infection, incidents…
- Improve outcomes: Quality improvement initiatives
EuroNeoNet Coordination Center Team

Leader: Adolfo Valls i Soler

Actual Team:

1. Adolf Valls i Soler (Coordinator)
2. Aitor Teneria (Project Manager, Spanish Network)
3. Marisela Madrid (Microbiologist, Spanish Network)
4. Elena Santesteban (PhD - Pharmacist, GRIP)
5. Casilda Arranz (Nurse, Spanish Network)
6. Elisabeth Valls (Documentalist - Data Manager, GRIP)
7. Agueda Azpeitia (Biostatistitian, EGNN)
8. Maite Hoyos (Data Manager, ENS II)
9. Helena Real (Secretary, ENS II)
10. Iker Mata (Administrative, ENS II)
EuroNeoNet Publications

1. **Authors:** N Ruperto, I Eichler, R Herold, G Vassal, C Giaquinto, L Hjorth, A Valls i Soler, C Peters, P J Helms, A Saint Raymond
   **Journal:** Arch Dis Child 2012, 97:185-188
   **Title:** A European network of paediatric research at the European Medicines Agency (Enpr-EMA)
   **Topic:** Accreditation of European Paediatric Networks

2. **Authors:** M Guembe, A Bustiza, M Sánchez Luna, A Carrillo-Álvarez, V Pérez sheriff, E Bouza on behalf of the GEIDI and ECCAUPE study Groups (A Valls i Soler).
   **Journal:** J Hosp Infec 2012;81:123-127
   **Title:** Guidelines for preventing catheter infection: assessment of knowledge and practice among paediatric and neonatal intensive care healthcare workers
   **Topic:** Survey of HAI practices
• **Authors**: A Campino, E Santesteban, M Garcia, M Rueda, A Valls-i- Soler

• **Title**: “Errores en la preparación de fármacos intravenosos en una UCIN. Una potencial fuente de eventos adversos”.

• **Journal**: An Pediatr (Barc) 2012 , (In press)

• **Topic**: Errors on preparation of medications in a NICU
EuroNeoNet Publications
(In Process)

✓ Publications

- Re-submitted: EOS: Pediatrics by Alessandra Mularoni

- “Cooking”:
  . Comparison NEOCOSUR Score: Ivonne d’Aprenent
  . Hospital-acquired Infection: Alessandra Mularoni
  . Congenital malformations; Carlo Corchia

✓ Proposals for new scientific research

  . Ohiana Muga: San Sebastian (BPD (will send proposed protocol)
  . Jon Mazela: BPD, non specified aspects

DATABASE IS AVAILABLE FOR PERFORMING RESEARCH AFTER SC APPROVAL
NEONATAL MORTALITY OF VERY LOW BIRTH WEIGHT INFANTS (VLBWI) FROM SPAIN AND JAPAN NEONATAL NETWORKS.

Marisela Madrid¹, Agueda Azpeitia¹, Adolf Valls i Soler¹ and Rintaro Mori².
¹Neonatal Intensive Care Units, Cruces University Hospital Barakaldo, Spain and
²Department of Global Health Policy, The University of Tokyo, Tokyo, Japan.

I. D’Apremont¹, A.Azpeitia², G.Marshall¹, J.L. Tapia¹, A.Valls-i-Soler² on behalf of Grupo Colaborativo NEOCOSUR and EuroNeoNet
¹Pontificia Universidad Católica de Chile
²Unidad Epidemiología Neonatal, and EuroNeoNet Steering Committee. Cruces University Hospital, Bilbao, Spain.
MALE VERY-LOW-BIRTH-WEIGHT AND VERY-LOW-GESTATIONAL-AGE INFANTS HAVE ADVERSE PERINATAL OUTCOMES

A. Valls-i-Soler¹, A. Azpeitia², European Neonatal Network (EuroNeoNet)
¹Cruces University Hospital, 2BIOEF, Barakaldo, Spain

Conclusions: Male infants of VLBW/VLGA have a higher adjusted NMR and an increased rate of adverse neonatal outcomes.
RISK FACTORS FOR BRONCHOPULMONARY DYSPLASIA IN VERY-LOW-GESTATIONAL-AGE INFANTS

A. Valls-i-Soler¹, A. Azpeitia², H. Hummler³, H. Halliday⁴, European Neonatal Network (EuroNeoNet)⁴

¹Cruces University Hospital, ²BIOEF, Barakaldo, Spain, ³Pediatrics and Adolescent Medicine University Hospital, Ulm, Germany, ⁴Institute Clinical Science, Belfast, UK
EuroNeoNet Reports from Collaboration

✓ Report from collaboration with EFCNI

EFCNI: European Foundation for the Care of Newborn Infants

✓ Silke Mader & Matthias Keller  

http://www.efcni.org/

• White paper on Maternal and Child care in Europe

  Facts and Figures on: 1) Pregnancy and Birth
  2) Neonatal Care
  4) Aftercare, follow-up

- We decided to offer them: . to join our EuroNeoNet SC
  . To be partner in new projects
✓ Reports from Collaborations: GRIP project

GRIP (Global Research in Pediatrics) Roma, Feb 2011

Funded by. 7th FWRP. Call: Medicines for Children: Network of Excellence

• **Objective**: Promotion of safer drugs for children & **neonates**
• **Co.chaired by**: Carlo Giaquinto (PENTA, Padova)
  
  Steve Hirschfeld (NIH, Bethesda, MD)+
• **Consortium**: 19 partners: EMA, NICHD, WHO, NICH Japan ...
EuroNeoNet Collaborations

✓ Collaborations

EnprEMA:

- Accreditation: ENNet classified as Category I3
- Re-evaluation submitted (resolution pending)

1 Document for GCP guidelines: BCO
2 QC & QA & data safety (Public): BCO
3 Training course for RCT over last 2 years

Proposals:

1. To develop a one-day RCT training course for the fall 2011
2. To develop a RCT Platform within EuroNeoNet
EuroNeoNet Workshops

2011

“I Workshop on design of Paediatric Clinical Trials”
one-day RCT training course for the fall 2011

2012

“II Workshop on design of Paediatric Clinical Trials”

. Faculty: Gerard Pons, Jose I Pijoan, Amparo Alemany...
. Funded by Red SAMID
. Supported by: . GRIP project, University Basque country
. SEN. (Spanish Society for Neonatology)
Thank you!
**EuroNeoNet** (European Neonatal Network) aims to give Neonatologist a platform for sharing good practice, promoting excellence, benchmarking performance and contributing to a high quality epidemiological research and quality improvement initiatives.

In order to achieve these objectives two subsets of data have been developed to meet the specific needs of Very Low Birth Weight (VLBW) or Very Low Gestational Age (VLGA) infants born and receiving neonatal care in Europe namely:

1) **Perinatal minimum dataset**
2) **Minimum follow – up dataset** which assesses health and neurodevelopmental status at 2 years of age.

The perinatal minimum dataset includes prenatal and neonatal risk factors, frequent interventions, co-morbidities and short – term outcomes.

Units can submit anonymised data to EuroNeoNet by post, e-mail or by using tailored web-based software.

Based on these datasets each participating unit receives a comprehensive Annual Benchmarking Report on their own data and comparisons with all other NICU’s participating in EuroNeoNet.

EuroNeoNet are also developing a series of new initiatives focusing on **quality assessment** and **patient safety**. These work packages include: a minimal dataset of follow-up indicators at 4 years of age, a dataset to monitor hospital – acquired infection and a system for reporting on patient safety.

Currently, **EuroNeoNet** is growing slowly but steadily with 192 participating NICU’s spread across Europe accounting for more than 5,000 VLBW infants per year from 17 European countries plus Turkey, being the global dataset recorded up to today of 45,296 registers.

Moreover, there are 298 Units affiliated to the ENN Initiative from 49 Countries

Neonatal Units of the following countries participate in EuroNeoNet:

Austria, Belgium, Czech Republic, Finland, France, Germany, Greece, Italy, The Netherlands, Poland, Portugal, Russia, Slovenia, Spain, Sweden, Switzerland, Turkey, United Kingdom.

For more information please contact:

e-mail: info.euroneonet@euskalnet.net

www.euroneonet.org

Our pilot phase is now complete and all our procedures have been tested and validated by our experienced staff.

We would now like to invite new members to join EuroNeoNet and to take advantage of this exciting opportunity to be part of a wider community of neonatologists and researchers working as a team to improve outcomes of neonatal care.
CONFIDENTIALITY AGREEMENT

CONFIDENTIALITY AGREEMENT SIGNED ONE THE ONE HAND BY EuroNeoNet REPRESENTED BY Begoña Loureiro Gonzalez AND ON THE OTHER HAND BY Miss/Mister. _______________________________ THE PROPOSER OF THE STUDY, PURSUANT TO THE FOLLOWING STATEMENTS AND CLAUSES:

STATEMENTS

EuroNeoNet, declares through its representative:

- That is a nonprofit Network
- That is His will to be bound by the terms of this contract.

The proposer of the study declares, by:

- Miss/Mr. ___________________________ from the institution ______________________________________ University/Hospital, with ID number._______________ representing itself.
- That is their will to be bound by the terms of this contract.

The parties declare, through their representatives:

1. Who have decided to provide to the proposer with certain confidential information owned by EuroNeoNet Consortium related to health data and quality improvement, which is hereinafter referred to as "Confidential Information" on the purpose and functions of the Network party ___________________________ tasks.

2. Recognizing each other's personality that appear to enter into this agreement and express their free will to be bound by the terms of the following:

CLAUSES

FIRST. The parties undertake not to disclose to third parties, the "Confidential Information" received from the EuroNeoNet Consortium, and give this information the same treatment that would give the confidential information of their property.

For purposes of this Agreement "Confidential Information" includes all information disclosed by either party either oral, visual, written, recorded on magnetic media or any other tangible form and is clearly marked as such when delivered to the receiving party.
SECOND. The receiving party agrees to keep confidential the "Confidential Information" received from the EuroNeoNet Consortium and not give it to a third party other than their technicians, statisticians and methodological advisors who have a need to know such information for the purposes authorized in the Sixth clause of this agreement, and who must agree to keep such information confidential.

THIRD. The receiving party undertakes not to disclose "confidential information" to third parties without the prior written consent of the disclosing party.

FOURTH. The receiving party agrees to take necessary and appropriate precautions to keep confidential the "Confidential Information" property of the other party, including but not limited to, informing employees that handle that information is confidential and not must be disclosed to third parties.

FIFTH. The receiving party agrees that "Confidential Information" received from the other party is and shall remain the property of the latter, to use such information only in the manner and for purposes authorized in Section Six of this contract and this instrument does not, expressly or implied, copyright or any property rights, including but not limited to, licenses for use on the "Confidential Information".

SIXTH. The receiving party agrees to use the "Confidential Information" of any of the other parties, only to perform the tasks detailed in Annex I (Research Proposal) as specified in this contract.

SEVENTH. The parties agree that in case the receiving party fails partly or wholly responsible obligations under this contract, the receiving party shall be liable for damages that the breach were to occur to the disclosing party.

EIGHTH. Notwithstanding the contrary in this agreement neither party shall have an obligation to keep confidential any information:

1. That prior to its disclosure would be known by the receiving party free of any obligation to keep confidential, as evidenced by documentation in its possession;
2. Be developed or developed independently by or on behalf of the recipient or lawfully received free of restriction from another source entitled to disclose it;
3. That is or becomes public knowledge, without any breach of this agreement by the receiving party, and
4. Received from a third party without such disclosure violates or violates an obligation of confidentiality.

NINTH. The term of this agreement shall be indefinite and remains effective as long business relationship between both parties.
TENTH. Within 7 days after the date of termination of this agreement or, where appropriate, its extension, any "Confidential Information" transmitted in written, recorded on magnetic media or other tangible form, to the receiving party from the disclosing, must be returned to the disclosing party or, where appropriate, guarantee its destruction, at the option of the disclosing party.

If the receiving party does not comply with the return or destruction in the presence of an authorized representative of the disclosing party within the period specified in this Section, the receiving party, will earn the penalty set forth in Section Seventh of this Agreement.

ELEVENTH. The obligations under this agreement to the receiving party with respect to confidentiality, the "Confidential Information" and the use thereof, shall survive the termination of this instrument, an unlimited period.

TWELFTH. This agreement constitutes the entire agreement between the parties relating to such confidential information and supersedes any prior understandings, oral or written, that may have existed between the parties.

THIRTEENTH. Neither party may assign its rights and obligations under this Agreement.

FOURTEENTH. This agreement may be amended only by consent of the parties, granted in writing.

Miss/Mr.____________________ Miss/Mr.____________________
____________________________ Street ______________________ Street
City _________________________ City _________________________

Parties aware of the content and scope of this contract is signed to date

____________________________  __________________________
Signature.                      Signature.

Note: Individual, regional and national networks that agreed to share their data to EuroNeoNet (known as “Confidential Information” in this document) do not lose its property. The term “owned by EuroNeoNet” refers to all data as a whole; each individual network retains property of their own data.
EUROPEAN NEONATAL NETWORK (EuroNeoNet)

Data Management and Access Policy

1. SUMMARY.

This document describes the policies of EuroNeoNet projects, networks on providing patient data to researchers for use in research projects, publications and presentations. It will be revised by the EuroNeoNet Steering Committee periodically.

2. DEFINITION.

2.1 Data consists of EuroNeoNet data: patient information collected for/by EuroNeoNet.

2.2 Data collection: A centralized database supplied by the Bilbao EuroNeoNet Coordinating Centre and located at its head office.

2.3 Network: A group of neonatal, perinatal and neonatal follow-up networks and single units that agree to share their patient data amongst themselves by providing a copy of their network data to be shared on the repository. Both, patient and unit will be kept anonymous, by assigning to each register a unique and non-identifying code. The code will be used for research purposes only.

3. SCOPE.

This policy applies to all patient data under the management of EuroNeoNet. It covers data access by EuroNeoNet members, affiliated project members, affiliated network members, paid staff and unpaid contributors.
4. PURPOSE.

The policy is intended to ensure that access to EuroNeoNet anonymized patient data:

- is managed consistently throughout EuroNeoNet;
- is provided in a manner that assures a high degree of security, confidentiality and data integrity;
- adheres to the principles of privacy protection; and
- is consistent with the provisions of the Member Network policies.

5 GOVERNANCE ROLES AND RESPONSIBILITIES.

5.1 EuroNeoNet Steering Committee

EuroNeoNet Steering Committee Roles and Responsibilities are outlined in “EuroNeoNet Steering Committee Terms of Reference”.

5.2 Bilbao Coordinating Centre (BCO)

- Coordinates the implementation of this policy for a defined body of data, related to EuroNeoNet projects and/or networks, by managing data, including its creation or acquisition, completeness, currency, integrity, storage, protection and disposition.

- Undertakes periodic reviews of automated access authorizations for the purpose of terminating expired or inappropriate access authorisations.

- Maintains a record of Data Access and Agreements.

- Creates, manages and maintains the on-going operating of EuroNeoNet Database program and network database linkage.

- Undertakes ongoing compliance monitoring and reporting on implementation of this policy.
6 PRINCIPLES OF CONFIDENTIALITY.

6.1 All information concerning patients and participating units/ NICUS is confidential and is only to be used by individuals who require access to the information for the purpose of carrying out their research activities. EuroNeoNet data will be re-identifying.

6.2 Information within data requests from a researcher will remain confidential and is not to be circulated or discussed outside of the research project team led by the requested researcher.

6.3 Access to data is always restricted to those accessing it for the purpose it was originally collected only. Person wishing to use such data for other purposes are prohibited from access at all times. Site investigator, affiliated project members, affiliated network members, paid staff or non-paid contributors are not entitled to access merely because of status, rank or office.

7 DATA INTEGRITY.

7.1 All data access must incorporate reasonable security arrangements to ensure that the authority and ability to add to, modify, or delete EuroNeoNet data is restricted to authorised individuals so that there is confidence that it has not been tampered with or modified except as authorized.

7.2 No patient data or other related information will be altered, copied, transmitted, interfered with, destroyed or taken unless it has been authorized in writing.

8 PROCEDURE FOR OBTAINING DATA FOR RESEARCH.

8.1 A network member who wishes to use patient data from one network may submit an application directly to that network.

8.2 A network member who wishes to use patient data from more than one network must make a formal request to the EuroNeoNet Steering Committee. The Steering Committee will review the scientific merits and feasibility of the request/study. (Protocol for research using ENN: http://www.euroneostat.org/paginas/publicas/euroneo/euroNeoNet/Documents/PROTOCOL%20FOR%20RESEARCH%20USING%20ENN-1.pdf)
8.3 A non-network affiliated person, institution or corporate body who wishes to use patient data from one or more than one network must make a formal request to the EuroNeoNet Steering Committee and be sponsored by a network. The Committee will review the scientific merits and feasibility of the request/study and provide a decision.

9. PUBLICATION.

“EuroNeoNet Publication Policy” outlines the policy on publications and presentations based on results produced from the EuroNeoNet database and its related projects and databases.

10. GENERAL.

11.1 The policies outlined in this document are subject to review and change by the EuroNeoNet Steering Committee, as required from time to time.

11.2 Without prejudice to any other rights, EuroNeoNet Steering Committee may terminate this data access right if a data recipient does not abide by the terms and conditions herein.

11.3 EuroNeoNet networks reserve all rights not expressly granted to users in this Data Access Policy.

11. DISCLAIMER.

EuroNeoNet Coordinating Centre will use its best effort to guarantee the access to the repository, but cannot be held responsible for the delays caused by system failure, regular maintenance, and any other causes that may affect the operation of the repository. The data is accepted on an “as is” basis and the Coordinating Centre cannot guarantee the accuracy of the data provided by the data collection facility.
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Publications

Book Chapters


International Publications


- A Valls i Soler†, M Madrid, C Geffers, H Hummler.”Preventing sepsis in VLBW infants: Experience from neonatal networks and voluntary surveillance systems“. NeoReviews 2010;11:403-408 (FI: 3,0 NC: )


- A Valls i Soler†, HL Halliday and H Hummler, on behalf of the Steering Committee of EuroNeoStat project. “Neonatal Networking. A European perspective”. Neoreviews 2007;8:275-281

National Publications


Abstracts

- A Valls i Soler†, A Azpeitia, JL Pijoán. “Initial risk store predicts survival without severe intraventricular-hemorrhage (IVH) and/or periventricular-leukomalacia (PVL) in very-low-birthweight (VLBW) or very-low-birthweight (VLBW) or very-low-gestational-age (VLGA) infants”. Pediatr Res 2010:563


- A Valls i Soler†, A Azpeitia, JL Pijoán. "Is gestational age (GA) a better indicator of 28 day neonatal mortality than birth weight (BW)?". Pediatr Res 2007; 163 A


- A Valls i Soler† on behalf of the EuroNeoStat Starring Committee. “NEONATAL NETWORKS. Their contribution to research and improvement of neonatal care. EURONEOSTAT. A european information system to monitor outcomes of VLBW and very low gestational age infants (VLGA)". J Perinat Med 2007;35:S49


- A Valls i Soler†, A Azpeitia, JL Pijoán. "Is gestational age (GA) a better indicator of 28 day neonatal mortality than birth weight (BW)?". Pediatr Res 2007;163A
Conferences/Meetings


- A Valls-i-Soler†, A Azpeitia on behalf of the European Neonatal Network (EuroNeoNet). “Combined Adverse Neonatal Outcome (death or Survival with Severe IVH) and/or CLD in VLGA infants. A EuroNeoNet Study”. Oral Presentation. 54th Annual Meeting ESPR, Oct 10-14th, Porto, Portugal, 2013


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A Valls i Soler†, A Azpeitia, JI Pijoán. “Inicial risk store predicts survival without severe intraventricular-hemorrhage (IVH) and/or periventricular-leukomalacia(PVL) in very-low-birthweight (VLBW) or very-low-birthweight (VLBW) or very-low-gestational-age (VLGA) infants”. 3rd Congress of the European Academy of Paediatrics Societies. Copenhagen-Denmark, Octubre 2010.

G Marshall, A Azpeitia, A Valls i Soler†, JL Tapia and collaboration group. “Score de riesgo predice mortalidad neonatal en recién nacidos de muy bajo peso nacimiento (RNMBPN) en dos redes neonatales internacionales”. IV Chilean Congress of Neonatology. Santiago-Chile, 29th September to 1st October 2010


A Valls i Soler†. “EuroNeoNet”. Tertiary Care Group (TCG) de la Sección de Pediatría de la European Academy of Pediatric. Bruselas, December 2010


• A Valls i Soler†, HL Halliday and H Hummler, on behalf of the Steering Committee of EuroNeoStat project. "Neonatal Networking. A European perspective". Neoreviews 2007;8:275-281 (FI: NC:)


• A Valls i Soler†, A Azpeitia, JI Pijoán. "Is gestational age (GA) a better indicator of 28 day neonatal mortality than birth weight(BW)?. 48th Annual Meeting of the European Society for Paediatric Research. Praga-Republica Checa. October 2007


• A Valls i Soler† on behalf of the EuroNeoStat Sterring Committee. “NEONATAL NETWORKS. Their contribution to research and improvement of neonatal care. EURONEOSTAT: A european information system to monitor outcomes of VLBW and very low gestational age infants (VLGA)". 8th World Congress of Perinatal Medicine. Florencia-Italia. September 2007

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EuroNeoNet Annual Report for VLGAI

&

Individual Report for Each Unit Practicipating in the EuroNeoNet Project

YEAR 2013
September 2014
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1 METHODOLOGICAL INTRODUCTION.

A fundamental base for the individual analysis of Neonatology Units is the comparison of basic indicators. The objective is to identify areas that could improve, help to set priorities and document different results in health, between two or more Units.

Crude mortality or morbidity or other event rates, are useful general measures in the comparative analysis raised above. On the other hand, its use can be inappropriate when the different populations studied are not comparable by reason of gestational age, birth weight, sex, socio-economic status or other factors that can influence the crude rates magnitude and its interpretation. This type of phenomenon is called confounding effect (1,2,3).

To deal with the confounding effect, the use of specific rates determined by well-defined subgroups is a procedure widely spread in this type of comparisons. However, although these specific rates permit study the behaviour of health events and compare different Units in a more accurate way, the problem appears when the number of subgroups defined is big (4). In these cases, to calculate the specific rates spends a lot of time because of the number of operations needed. If sample size for each group is small the specific rates can become imprecise.

Standardisation of rates is a classic epidemiological method that minimises the confounding effect of factors that are assumed to behave in a different way in each population studied. It also provides a summary measure, which is easily understood, and in particular, helpful to those who need a health situation synthetic index.

In our case the factor most frequently used, is birth weight. Standardisation can be used when mortality comparisons between Units are done, because birth weight structure has a huge impact on the absolute risk a baby has.

There are two main approaches to standardisation. The first uses as the standard a population distribution (direct method), and the second, a set of specific rates (indirect method).

In the direct method, the expected rate for the Units studied is calculated assuming its distribution is the same to an established one according to the confounding item. The population used is called “Standard” and its subgroups correspond to the confounding item. The expected rate per Unit is calculated by applying the specific rate for the subgroups of the Standard population to the Units populations.
**Indirect Method.**

The approach in the indirect method is completely different to the one in the direct method. Instead of using a standard population, Standard specific rates (or reference rates) are applied to the populations compared, according to the confusor item. The result of this is the expected number of cases for each Unit and subgroup. If the observed number of cases is divided by the expected number of cases in each Unit and subgroup, the Standardised Mortality/Morbidity Rate (SMR) is obtained.

This rate permits the comparison between each Unit studied with the population whose specific rates have been considered as standard.

Conclusions can be made only by calculating and observing the SMR. If this rate is above 1 (or 100 if is treated as a percentage) the mortality risk in the observed population is greater than the one in the standard population supposing the same experience and risk for the observed population than for the standard one. On the other hand, if the SMR is under 1 (or 100), the mortality risk in the observed population is lower than the expected in the reference population.

In addition indirect method adjusted rates can be calculated multiplying the row rate of each population by its SMR (4). As in the direct method, a unique value is obtained for each population so differences in the population distributions are considered.

SMR are easily calculated and provide relative risk estimation between the standard population and the one studied. These are frequently used in epidemiology to compare different groups.

However, we have to take in account that in some situations these comparisons are not suitable. For instance: when the rates in the studied groups and the standard groups according to the classes of the confusor item are not homogeneous (7). Above this, the comparisons between each group and the reference population is always is outstanding.
In the next table an example using the indirect standardisation method is shown.

**Example.**

Crude mortality rate in the NU (Neonatal Unit) was of 16.4 per 100 VLBWI. The aim is to study if the differences in mortality (or mortality risk) between the Unit studied and the whole set according to the indirect method are statistically significant. For this, the following data are needed.

- The mortality specific rates according to the subgroups in the confusor item in the standard population.
- The UN population divided by groups of birth weight (confounding item).
- The total observed number of deaths in the UN.

First, the expected number of deaths must be calculated multiplying the standard rates to the number of cases in each subgroup of the UN population. (Column (3) = (1) * (2)/100). Then we must add all the expected deaths calculated for each subgroup, and also the observed deaths.

The SMR is obtained by dividing the total number of observed deaths by the total number of expected deaths.

<table>
<thead>
<tr>
<th>Birth Weight (g)</th>
<th>Mortality specific rates according to birth weight groups (1)</th>
<th>NU population (i) (2)</th>
<th>Observed Deaths (3)</th>
<th>Expected deaths in (1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 501 g</td>
<td>75</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>501 - 750 g</td>
<td>52.1</td>
<td>10</td>
<td>6</td>
<td>5.21</td>
</tr>
<tr>
<td>751 - 1000 g</td>
<td>23.4</td>
<td>18</td>
<td>4</td>
<td>4.21</td>
</tr>
<tr>
<td>1001 - 1250 g</td>
<td>9.9</td>
<td>21</td>
<td>1</td>
<td>2.08</td>
</tr>
<tr>
<td>1251 - 1500 g</td>
<td>4.9</td>
<td>24</td>
<td>1</td>
<td>1.18</td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>73</td>
<td>12</td>
<td>12.68</td>
</tr>
</tbody>
</table>

**SMR for UN = 12/12.68 = 0.95.**

**SMR (%) for UN = (12/12.68) * 100 = 95%.**

The value of the SMR (95%) means that the mortality risk in the Unit studied is a 5% less than the expected, had the studied Unit had the standard population specific mortality rates across the different strata of birth weight (confounder in this case). In conclusion the Unit has a slightly lower standardised mortality rate than expected. Usually 95% CI are estimated for the SMR as a measure of its precision and to check whether the "null value" (SMR=1) is included in the interval.

The 95% CI permit us say, that there is a 95% of probability that the SMR is between 0.41 and 1.49. As the "null value" (1) is included we have no evidence that this Unit’s SMR is significantly different from the reference population’s SMR.
As neonates' population is affected not only by birth weight, it has been considered to apply more than one confounding item, and therefore try to solve the homogeneity problem. At least standardization has been done by birth weight, gestational age and gender. For some of the outcomes predictive items resulting form a logistic regression over more than 30,000 thousand registers have been used as confounding items.

To resume, adjusted rates permit more valid comparisons between populations, which will help establishing priorities between groups.

Furthermore, this report not only intends to allow comparisons between units studied, but to draw a picture of the general performing of the unit in relation to the whole set of units.

A way of establishing the position that a Unit has inside the set of Units studied is to calculate the percentile corresponding to each Unit according to the studied item. This percentile shows the position but not the difference in magnitude between Units in the item. A 95 percentile in mortality is a negative result. If differences between units are very small, that is, there is very small variability; the SMR that is in position 95 probably differs from the previous one in only some decimals.

To be able to quantify the position reached by each Unit, the typified score for SMR is calculated. In this report, these are calculated in such a way that a result above 0 is a positive result and the intensity of it is given by the score itself. The length of the bar shows how positive/negative the result is. The bigger the score is, the better the result is; and the smaller (negative score), the worse is. If the stick crosses the discontinuous line (+/- 1.96), the result will be statistically significant.

References:

2 DATABASE ELIGIBILITY CRITERIA.

Any infant born alive at your hospital, whether or not was admitted to your NICU, should be reported if his/her:

Birth Weight (BW) is less than 1501 g

OR

Gestational Age (GA) is less than 32 wks (31 + 6 days inclusive).

All livebirths must be reported, no matter if his/her gestational age is below 22 weeks or the birth weight is below 401g.

All outborn infants of same BW and GA as above, admitted to any location in your hospital within 28 days of birth should also be included, only if the baby has never been discharged home.

Outborn babies admitted to the Neonatal Unit after the 28th day of life, should not be included in the Database, since by international definitions those babies are no longer “newborn” but “infants”.
3 INTRODUCTION.

A statistical analysis of the VLBW/VLGA infants cohort data (defined in protocol), for the cases sent before December of 2013 is performed in this report. These cases correspond to babies born in Units shown in Table 4.1.

The Report consists on two main parts. The first part is common to every unit that has collaborated with data for the cohort analysed (Sections 5 to 7). The second part (Section 8) changes form unit to unit. Each unit will receive an analyses only for their own data (confidentiality is assured).

The common part is divided in three sections, a general descriptive analysis section (#5), a benchmarking section (#6) and a length of stay analysis section (#7).

General descriptive analysis includes a description of babies died in the delivery room (section 5.1) in terms of counts and percentages, means, medians, standards deviations and percentiles depending on the nature of the item described. All items collected for babies died in deliver room are described including major birth defects description and possible causes of death. (After this section, babies died in delivery room are excluded from the rest of the analyses done in the report).

The main population is also described in section 5.2, including perinatal risks factors, interventions, diagnoses and morbidity outcomes. At the end of the section row global rates and stratified rates by birth weight groups and gestational age groups for several items have been calculated.

Once the population has been described, a univariate analysis of each item has been done. These analyses permit to establish the position that each Unit occupies compared with the other Units, and also the position in relation to the whole set (Point 6: Benchmarking). The statistical procedure has been described in the Methodological Introduction (Point 1).

The analysis done in previous sections, shows which is the position that a Unit occupies in relation to the whole set of Units for items considered relevant. In the next section (Point 7), the total stay of VLBW/VLGA inafants that were discharged to home have been analysed.
Finally, once all the items considered relevant according to the study objectives have been analysed, a more accurate description of these and other items for each Unit separately, has been done (Point 8: Annex.). Firstly demographic items are described, including prenatal care, Bag/Mask in delivery room and so on... Secondly, in the next section, items related with Morbimortality have been analysed, and finally, a section called Main Results has been included. This section gives a global view of which is the position of each Unit inside the whole set of Units. On the one hand, this analysis shows the position of the Unit (Point 8.3.1), and on the other hand, it quantifies this position (Point 8.3.2). This section tries to provide a summarised picture of the Unit's condition so just taking a short look to the graph you can get a grasp of the global results for the studied Unit.

To distinguish one Unit from another, a code has been assigned to each. We will provide each Unit ONLY its code at the same time as this report is delivered. This way the confidentiality of data is preserved.
4 GENERAL DATA.

4.1 ENS Project Participating Units.

The following list corresponds to the Units that have sent complete and verified data for the year 2013, before July the 31th of 2014.

Table 4.1

<table>
<thead>
<tr>
<th>Type</th>
<th>Unit</th>
<th>Responsible for the Project</th>
<th>Country</th>
<th>City</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collaborative</td>
<td>Universitäts-Kinderklinik</td>
<td>Miklos Alexy</td>
<td>Austria</td>
<td>Salzburg</td>
</tr>
<tr>
<td>Collaborative</td>
<td>General Hospital of Leoben</td>
<td>Anna Trinkl</td>
<td>Austria</td>
<td>Leoben</td>
</tr>
<tr>
<td>Associated</td>
<td>Oulu University Hospital</td>
<td>Mikko N. Hallman</td>
<td>Finland</td>
<td>Oulu</td>
</tr>
<tr>
<td>Collaborative</td>
<td>CHRU Brest</td>
<td>Jacques Sizun</td>
<td>France</td>
<td>Brest</td>
</tr>
<tr>
<td>Associated</td>
<td>University Children's Hospital</td>
<td>Helmut Hummler</td>
<td>Germany</td>
<td>Ulm</td>
</tr>
<tr>
<td>Collaborative</td>
<td>Ginekologiczno Polozniczy Szpital Kliniczny</td>
<td>Janusz Gadzinowski</td>
<td>Poland</td>
<td>Poznan</td>
</tr>
<tr>
<td>Associated</td>
<td>Spanish Neonatal Network (SEN 1500)</td>
<td>Josep Figueras</td>
<td>Spain</td>
<td>Spain</td>
</tr>
</tbody>
</table>

To preserve units' confidentiality the number of cases and percentage that each unit represent inside the total of infants born in 2013 is not described.

Each year, more units, regional and national networks are interested in the project. This means that the number of units collaborating by country is increasing, being mandatory the need to describe each country’s representativity. In Preliminary Reports, as this one, number of participating units, regions or nations is still not complete, so its representativity inside the network is not definite.

For preliminary 2013 data, an 84% of infants were born in Spain, a 5.4% in Germany, a 4.4% in Austria, a 4% in France and the remaining 2.2% in Finland.
4.2 Sample Size

The total number of cases received for preliminary 2013 VLGAI cohort for Units that have sent complete and verified data were 2,522

The purpose of this report is to help units to perform better by comparing results to other units pertaining the network and to the whole set of data. Therefore, comparisons must be done over reliable data and moreover, restrictions must be applied, if not results would be meaningless.

For that reason, data is divided, firstly, in babies died in delivery room and babies admitted to the NICU.

In 2013 preliminary cohort a 1.6% of babies died in delivery room. That is, 41 babies. These, will be analysed in the following section, separately from babies admitted to the NICU. (Section 5.1 Deaths in delivery room description). General analysis (benchmarking) will be performed over admitted babies in Section 6. A 80.6% of babies admitted to the NICU were discharged home. Length of stay will be analysed globaly and for each unit for those babies in Secion 7.
5 RESULTS

5.1 Deaths in Delivery Room description

Less data is recorded for deaths in delivery room than for admitted babies. Birth weight, gestational age, birth length, birth head circumference, Prenatal Care, Prenatal Steroids, Mode of delivery, Gender, Multiple birth, Major Birth Defects, Apgar Scores, delivery room resuscitation and need for surfactant are recorded, together with information on death. All these information is described for dead in delivery room babies below.

Birth Weight

Mean birth weight for preliminary 2013 cohort babies died in delivery room has been of 681.2 g, with a standard variation of 371.2 g. Extreme values are those under 411 g., and above 1,072 (Percentile 5 and Percentile 95).

<table>
<thead>
<tr>
<th>Birth weight</th>
<th>Mean (SD)</th>
<th>681.2 (371.2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>95% CI (Mean)</td>
<td>(564.0;798.4)</td>
<td></td>
</tr>
<tr>
<td>Med [Q1,Q3]</td>
<td>600 [512.5;720]</td>
<td></td>
</tr>
<tr>
<td>Min-Max</td>
<td>200 – 2,730</td>
<td></td>
</tr>
<tr>
<td>P5-P95</td>
<td>411-1,072</td>
<td></td>
</tr>
</tbody>
</table>
Gestational Age

Median gestational age for preliminary 2013 cohort babies died in delivery room has been of 24 weeks. Extreme values are those under 22 weeks, and above 30.7 weeks (Percentile 5 and Percentile 95).

<table>
<thead>
<tr>
<th></th>
<th>Gestational Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>24.3 (2.9)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(23.4;25.2)</td>
</tr>
<tr>
<td>Med [Q₁,Q₃]</td>
<td>24 [23 ; 24]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>20-38</td>
</tr>
<tr>
<td>P5-P95</td>
<td>22-30.7</td>
</tr>
</tbody>
</table>
**Birth Length and Birth Head Circumference**

Median birth length for preliminary 2013 cohort babies dien in delivery room has been of 31 cm. Extreme values are those under 23 cm (Percentile 5).

For birth head circumference median was of 22.3 cm. Extreme values are those under 17 (Percentile 5).

<table>
<thead>
<tr>
<th></th>
<th>Birth length</th>
<th>Birth head circumference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>31.6 (7.9)</td>
<td>25.4 (7.1)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(27.6;35.7)</td>
<td>(21.6;29.1)</td>
</tr>
<tr>
<td>Med [Q1,Q3]</td>
<td>31 (26;32.5)</td>
<td>22.3 (21.1-32.8)</td>
</tr>
<tr>
<td>Min-Max</td>
<td>23-55</td>
<td>17-39</td>
</tr>
<tr>
<td>P5-P95</td>
<td>23- ---</td>
<td>17- ---</td>
</tr>
</tbody>
</table>

**Note:** Only analysed deaths in Delivery Room.
Apgar Scores

For babies died in delivery room, 1-min and 5-min Apgar Score median has been of 1.

<table>
<thead>
<tr>
<th></th>
<th>1-min Apgar Score</th>
<th>5-min Apgar Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>1.5 (1.3)</td>
<td>1.3 (1.4)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(1.1;1.9)</td>
<td>(0.8 , 1.7)</td>
</tr>
<tr>
<td>Med [Q₁, Q₃]</td>
<td>1 [1;1]</td>
<td>1 [1.1]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>0 -6</td>
<td>0 – 8</td>
</tr>
<tr>
<td>P₅-P₉₅</td>
<td>0 -5.2</td>
<td>0 – 5.5</td>
</tr>
</tbody>
</table>

Perinatal Factors

For died in delivery room population, more than half were male (58.5%). A 34.1% of babies were born by caesarean section, a 31.7% were multiple, a 43.9% of all babies received some prenatal steroids and a 92.1% received prenatal care.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>24</td>
<td>58.5</td>
</tr>
<tr>
<td>Multiple Gestation</td>
<td>13</td>
<td>31.7</td>
</tr>
<tr>
<td>Caesarean Section</td>
<td>14</td>
<td>34.1</td>
</tr>
<tr>
<td>Prenatal Steroids (Inc. + Compl.)</td>
<td>18</td>
<td>43.9</td>
</tr>
<tr>
<td>Prenatal Care</td>
<td>35</td>
<td>92.1</td>
</tr>
</tbody>
</table>

Resuscitation in Delivery Room

A 29.3% of babies died in delivery room needed some kind of resuscitation (excluding oxygen). Oxygen rate was of 31.7%.

<table>
<thead>
<tr>
<th>Delivery Room Resuscitation</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oxygen</td>
<td>13</td>
<td>31.7</td>
</tr>
<tr>
<td>Any Non Aggressive Positive Ventilation</td>
<td>8</td>
<td>19.5</td>
</tr>
<tr>
<td>Endotracheal Intubation</td>
<td>12</td>
<td>29.3</td>
</tr>
<tr>
<td>Adrenaline/Epinephrine</td>
<td>3</td>
<td>7.3</td>
</tr>
<tr>
<td>Cardiac Compression</td>
<td>7</td>
<td>17.1</td>
</tr>
<tr>
<td>Any Resuscitation in Delivery Room (ex. O₂)</td>
<td>12</td>
<td>29.3</td>
</tr>
</tbody>
</table>
Major Birth Defects

A total number of 5 babies that died in delivery room had a major birth defect (12.5%). Only one of them specified which Major Birth Defect had, recording two: a Congenital Malformation of Heart and a Congenital Hydrocephalus.

Need for Surfactant

Only two babies that died in delivery room needed surfactant (4.9%). Both of them receive one single dose, one at 2 and the other one at 4 minutes of life.

Cause of death

Cause of death was only specified for 33 babies of 41 that died in delivery room. Most frequent cause was Respiratory Failure (24.2%), followed by Congenital Malformations (6.1%), although Other had a 66.7% rate..

<table>
<thead>
<tr>
<th>Cause of Death</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respiratory Failure</td>
<td>8</td>
<td>24.2</td>
</tr>
<tr>
<td>Congenital Malformation</td>
<td>2</td>
<td>6.1</td>
</tr>
<tr>
<td>Sepsis</td>
<td>1</td>
<td>3.0</td>
</tr>
<tr>
<td>Other</td>
<td>22</td>
<td>66.7</td>
</tr>
<tr>
<td>Total</td>
<td>33</td>
<td>100</td>
</tr>
</tbody>
</table>

An autopsy was done to 35.3% of babies and therapeutic efforts were limited to a 81.8% of babies died in delivery room. Missing rate in both items is very high.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autopsy</td>
<td>12</td>
<td>35.3</td>
</tr>
<tr>
<td>Therapeutic efforts limited</td>
<td>27</td>
<td>81.8</td>
</tr>
</tbody>
</table>
5.2 2012 Cohort General Description: Admitted babies.

Total number of admitted babies in EuroNeoNet NICU’s for preliminary 2013 cohort, has been of 2,481.

5.2.1 Perinatal Risk Factors

Birth Weight

Mean birth weight for preliminary 2013 babies admitted to the NICU has been of 1,135.1 g. with a standard deviation of 304 g. Extreme values are those under 610.5 g., and above 1,500 g. (Percentile 5 and Percentile 95).

<table>
<thead>
<tr>
<th>Mean (SD)</th>
<th>Birth weight</th>
</tr>
</thead>
<tbody>
<tr>
<td>1,135.1 (304)</td>
<td></td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(1,123.1;1,147)</td>
</tr>
<tr>
<td>Med [Q1,Q3]</td>
<td>1,180 [900;1,380]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>310 -2,540</td>
</tr>
<tr>
<td>P5-P95</td>
<td>610.5 - 1,500</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
Gestational Age

Median gestational age for preliminary 2013 cohort has been of 29 weeks. Extreme values are those under 24 weeks, and above 34 weeks (Percentile 5 and Percentile 95).

<table>
<thead>
<tr>
<th></th>
<th>Gestational Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>29.1 (2.8)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(29 , 29.2)</td>
</tr>
<tr>
<td>Med [Q1,Q3]</td>
<td>29 [27 ; 31]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>22 – 39</td>
</tr>
<tr>
<td>P5-P95</td>
<td>24 - 34</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
Apgar Scores

1-min Apgar Score mean has been of 6.4, and 5-min score mean of 8.1.

<table>
<thead>
<tr>
<th></th>
<th>1-min Apgar Score</th>
<th>5-min Apgar Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>6.4 (2.3)</td>
<td>8.1 (1.8)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(6.3, 6.4)</td>
<td>(8.1, 8.2)</td>
</tr>
<tr>
<td>Med [Q1,Q3]</td>
<td>7 [5;8]</td>
<td>8 [8.9]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>0 – 10</td>
<td>0 – 10</td>
</tr>
<tr>
<td>P5-P95</td>
<td>2 – 9</td>
<td>5 – 10</td>
</tr>
</tbody>
</table>
Perinatal Factors

More than half of the population were male (52.1%). A 71.2% of babies were born by caesarean section and a 32.8% were multiple.

Regarding to prenatal care and prenatal steroids, an 85.4% of babies received prenatal care and an 88.7% received prenatal steroids (incomplete or complete doses).

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1,293</td>
<td>52.1</td>
</tr>
<tr>
<td>Multiple Birth</td>
<td>814</td>
<td>32.8</td>
</tr>
<tr>
<td>Caesarean Section</td>
<td>1,766</td>
<td>71.2</td>
</tr>
<tr>
<td>Prenatal Steroids (Inc. + Compl.)</td>
<td>2,183</td>
<td>88.7</td>
</tr>
<tr>
<td>Prenatal Care</td>
<td>2,058</td>
<td>85.4</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
5.2.2 Respiratory System

A 66.8% of babies admitted to the NICU received some kind of resuscitation in Delivery Room, excluding Oxygen.

Need for surfactant rate was of 47.7% and surfactant was administrated within the first hour of life in a 28.3% of babies.

Respiratory Distress syndrome was diagnosed in a 60.9% of babies admitted to the NICU.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resuscitatin in DR</td>
<td>1,657</td>
<td>66.8</td>
</tr>
<tr>
<td>Surfactant at any time</td>
<td>1,184</td>
<td>47.7</td>
</tr>
<tr>
<td>Surfactant within the first hour of life</td>
<td>667</td>
<td>28.3</td>
</tr>
<tr>
<td>RDS Diagnose</td>
<td>1,507</td>
<td>60.9</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
5.2.3 Early Bacterial Sepsis

Early Bacterial Sepsis was diagnosed in a 3.4% of babies admitted to the NICU. Most frequent pathogen was Escherichia coli (31.8%), followed by Listeria monocytogenes (12.9%).

<table>
<thead>
<tr>
<th>Early Bacterial Sepsis Pathogen</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Escherichia coli</td>
<td>27</td>
<td>31.8</td>
</tr>
<tr>
<td>Listeria monocytogenes</td>
<td>11</td>
<td>12.9</td>
</tr>
<tr>
<td>Group B beta-hemolytic streptococcus</td>
<td>5</td>
<td>5.9</td>
</tr>
<tr>
<td>Staphylococcus epidermidis</td>
<td>5</td>
<td>5.9</td>
</tr>
<tr>
<td>Enterobacter cloacae</td>
<td>3</td>
<td>3.5</td>
</tr>
<tr>
<td>Staphylococcus aureus</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Klebsiella pneumoniae</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Pseudomonas aeruginosa</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Haemophilus influenzae</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Cándida albicans</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Achromobacter spp</td>
<td>2</td>
<td>2.4</td>
</tr>
<tr>
<td>Citrobacter species</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Ureaplasma urealiticum</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Bacteroides spp</td>
<td>2</td>
<td>1.2</td>
</tr>
<tr>
<td>Ralstonia species</td>
<td>16</td>
<td>18.8</td>
</tr>
<tr>
<td>Total</td>
<td>85</td>
<td>100</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
5.2.4 Diagnoses

A 3.3% of babies admitted to the NICU were diagnosed of Pneumothorax, a 4.8% of NEC and a 2.4% of Focal Gastrointestinal Perforation.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumothorax Diagnose</td>
<td>82</td>
<td>3.3</td>
</tr>
<tr>
<td>NEC Diagnose</td>
<td>120</td>
<td>4.8</td>
</tr>
<tr>
<td>Focal Gastrointestinal Diagnose</td>
<td>60</td>
<td>2.4</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
5.2.5 Morbi-Mortality

Mortality rate for babies admitted to the NICU was of a 9.5%.

BPD was diagnosed in a 24%, severe PIVH in a 7.8%, Cystic PVL in a 5.8% and a 24.7% had a late bacterial sepsis.

<table>
<thead>
<tr>
<th>Condition</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe PIVH (Grades III-IV)</td>
<td>180</td>
<td>7.8</td>
</tr>
<tr>
<td>Oxygen on week 36 (BPD)</td>
<td>182</td>
<td>24</td>
</tr>
<tr>
<td>Late Bacterial Sepsis</td>
<td>607</td>
<td>24.7</td>
</tr>
<tr>
<td>Cystic PVL</td>
<td>141</td>
<td>5.8</td>
</tr>
<tr>
<td>Overall Mortality</td>
<td>235</td>
<td>9.5</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
5.2.6 Global Results Summary: Risk factors, interventions and general results.

5.2.6.1 By Birth Weight

<table>
<thead>
<tr>
<th></th>
<th>&lt; 501 gr.</th>
<th>501 - 750 gr.</th>
<th>751 - 1000 gr.</th>
<th>1001 - 1250 gr.</th>
<th>1251 - 1500 gr.</th>
<th>&gt; 1500 gr.</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nº of babies recalled</td>
<td>41</td>
<td>299</td>
<td>485</td>
<td>637</td>
<td>914</td>
<td>105</td>
<td>2481</td>
</tr>
<tr>
<td>Male</td>
<td>14</td>
<td>135</td>
<td>241</td>
<td>367</td>
<td>469</td>
<td>67</td>
<td>1293</td>
</tr>
<tr>
<td>Multiple Gestation</td>
<td>8</td>
<td>195</td>
<td>136</td>
<td>228</td>
<td>346</td>
<td>28</td>
<td>814</td>
</tr>
<tr>
<td>Prenatal Steroids</td>
<td>38</td>
<td>95</td>
<td>267</td>
<td>434</td>
<td>569</td>
<td>782</td>
<td>2183</td>
</tr>
<tr>
<td>Caesarean Section</td>
<td>26</td>
<td>185</td>
<td>335</td>
<td>499</td>
<td>663</td>
<td>58</td>
<td>1766</td>
</tr>
<tr>
<td>Resuscitation in Delivery Area (1)</td>
<td>38</td>
<td>270</td>
<td>385</td>
<td>426</td>
<td>471</td>
<td>67</td>
<td>1657</td>
</tr>
<tr>
<td>Surfactant at any time</td>
<td>38</td>
<td>247</td>
<td>318</td>
<td>295</td>
<td>254</td>
<td>32</td>
<td>1184</td>
</tr>
<tr>
<td>Pneumothorax (2)</td>
<td>2</td>
<td>111</td>
<td>58</td>
<td>30</td>
<td>23</td>
<td>2</td>
<td>85</td>
</tr>
<tr>
<td>Mortality</td>
<td>18</td>
<td>43</td>
<td>16</td>
<td>26</td>
<td>20</td>
<td>2</td>
<td>235</td>
</tr>
<tr>
<td>PIVH (Grades &gt; 0) (3)</td>
<td>12</td>
<td>107</td>
<td>150</td>
<td>133</td>
<td>108</td>
<td>19</td>
<td>529</td>
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<tr>
<td>PIVH (Grades III or IV) (3)</td>
<td>8</td>
<td>50</td>
<td>55</td>
<td>47</td>
<td>19</td>
<td>19</td>
<td>529</td>
</tr>
<tr>
<td>NEC (2)</td>
<td>4</td>
<td>10</td>
<td>33</td>
<td>20</td>
<td>19</td>
<td>1</td>
<td>120</td>
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<tr>
<td>FGP (2)</td>
<td>4</td>
<td>24</td>
<td>16</td>
<td>9</td>
<td>7</td>
<td>7</td>
<td>60</td>
</tr>
<tr>
<td>ROP (Grades &gt; 0) (4)</td>
<td>17</td>
<td>99</td>
<td>130</td>
<td>94</td>
<td>42</td>
<td>7</td>
<td>389</td>
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<tr>
<td>Oxygen on day 28 (5)</td>
<td>19</td>
<td>153</td>
<td>208</td>
<td>113</td>
<td>50</td>
<td>6</td>
<td>549</td>
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<tr>
<td>Oxygen on week 36 (6)</td>
<td>7</td>
<td>57</td>
<td>68</td>
<td>27</td>
<td>21</td>
<td>2</td>
<td>182</td>
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<tr>
<td>Steroids for CLD (2)</td>
<td>8</td>
<td>58</td>
<td>73</td>
<td>25</td>
<td>13</td>
<td>1</td>
<td>178</td>
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<tr>
<td>Cystic PVL (2)</td>
<td>6</td>
<td>30</td>
<td>34</td>
<td>44</td>
<td>27</td>
<td>2</td>
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<tr>
<td>Late Sepsis (2)</td>
<td>15</td>
<td>143</td>
<td>185</td>
<td>141</td>
<td>114</td>
<td>9</td>
<td>607</td>
</tr>
</tbody>
</table>

(1) Excluding Oxygen in Delivery Area.
(2) Deaths in Delivery Room Excluded.
(3) Excluded Babies Died in Delivery Room and Without Cranial Imaging Done.
(4) Excluded Babies Died in Delivery Room and Without Retinal Exam Done.
(5) Excluded Babies Discharged Before Day 28 of Life
(6) Excluded Babies Discharged Before Week 36 Adjusted to Gestational Age.

RDS: Respiratory Distress Syndrome.
NEC: Necrotizing Enterocolitis
ROP: Retinopathy of Prematurity.
PIVH: Periventricular-Intraventricular Haemorrhage.
FGP: Focal Gastrointestinal Perforation.
PVL: Periventricular Leukomalacia.
### 5.2.6.2 By Gestational Age.

<table>
<thead>
<tr>
<th></th>
<th>&lt; 24 wk.</th>
<th>24 - 25 wk.</th>
<th>26 - 27 wk.</th>
<th>28 - 29 wk.</th>
<th>30 - 31 wk.</th>
<th>&gt; 31 wk.</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nº of babies recalled</td>
<td>N³</td>
<td>%</td>
<td>N³</td>
<td>%</td>
<td>N³</td>
<td>%</td>
<td>N³</td>
</tr>
<tr>
<td>Male</td>
<td>13</td>
<td>38,2</td>
<td>128</td>
<td>50,6</td>
<td>229</td>
<td>54,9</td>
<td>358</td>
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<tr>
<td>Multiple Gestation</td>
<td>8</td>
<td>23,5</td>
<td>60</td>
<td>23,7</td>
<td>117</td>
<td>28,1</td>
<td>201</td>
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<tr>
<td>Prenatal Steroids</td>
<td>25</td>
<td>78,1</td>
<td>225</td>
<td>89,6</td>
<td>368</td>
<td>88,7</td>
<td>579</td>
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<td>Caesarean Section</td>
<td>5</td>
<td>14,7</td>
<td>121</td>
<td>47,8</td>
<td>273</td>
<td>65,5</td>
<td>476</td>
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<tr>
<td>Resuscitation in Delivery Area (1)</td>
<td>29</td>
<td>85,3</td>
<td>238</td>
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<tr>
<td>Surfactant at any time</td>
<td>30</td>
<td>88,2</td>
<td>232</td>
<td>91,7</td>
<td>325</td>
<td>77,9</td>
<td>369</td>
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<tr>
<td>Surfactant within the first hour of life</td>
<td>21</td>
<td>67,7</td>
<td>155</td>
<td>68,3</td>
<td>208</td>
<td>53,2</td>
<td>189</td>
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<td>RDS Diagnose (2)</td>
<td>33</td>
<td>100</td>
<td>237</td>
<td>94,4</td>
<td>371</td>
<td>89,2</td>
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<tr>
<td>Male</td>
<td>1</td>
<td>3</td>
<td>16</td>
<td>6,5</td>
<td>27</td>
<td>6,5</td>
<td>26</td>
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<tr>
<td>Multiple Gestation</td>
<td>16</td>
<td>47,1</td>
<td>91</td>
<td>36</td>
<td>67</td>
<td>16,1</td>
<td>41</td>
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<tr>
<td>Prenatal Steroids</td>
<td>4</td>
<td>11,8</td>
<td>25</td>
<td>10</td>
<td>17</td>
<td>4,1</td>
<td>20</td>
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<tr>
<td>Caesarean Section</td>
<td>18</td>
<td>62,1</td>
<td>97</td>
<td>42,4</td>
<td>147</td>
<td>38,2</td>
<td>147</td>
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<tr>
<td>Surfactant at any time</td>
<td>11</td>
<td>37,9</td>
<td>50</td>
<td>21,8</td>
<td>64</td>
<td>16,6</td>
<td>41</td>
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<tr>
<td>Surfactant within the first hour of life</td>
<td>3</td>
<td>8,8</td>
<td>34</td>
<td>8,2</td>
<td>35</td>
<td>5,4</td>
<td>16</td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>14,7</td>
<td>23</td>
<td>9,2</td>
<td>13</td>
<td>3,1</td>
<td>14</td>
</tr>
<tr>
<td>Multiple Gestation</td>
<td>14</td>
<td>93,3</td>
<td>103</td>
<td>66</td>
<td>127</td>
<td>38,8</td>
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<tr>
<td>Prenatal Steroids</td>
<td>5</td>
<td>14,7</td>
<td>23</td>
<td>9,2</td>
<td>13</td>
<td>3,1</td>
<td>14</td>
</tr>
<tr>
<td>Caesarean Section</td>
<td>18</td>
<td>94,7</td>
<td>147</td>
<td>93</td>
<td>197</td>
<td>67,2</td>
<td>142</td>
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<tr>
<td>Surfactant at any time</td>
<td>4</td>
<td>36,4</td>
<td>56</td>
<td>64,4</td>
<td>45</td>
<td>37,8</td>
<td>44</td>
</tr>
<tr>
<td>Surfactant within the first hour of life</td>
<td>5</td>
<td>14,7</td>
<td>64</td>
<td>25,3</td>
<td>69</td>
<td>16,6</td>
<td>27</td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>3,3</td>
<td>25</td>
<td>10,3</td>
<td>41</td>
<td>10</td>
<td>45</td>
</tr>
<tr>
<td>Multiple Gestation</td>
<td>9</td>
<td>27,3</td>
<td>127</td>
<td>52</td>
<td>170</td>
<td>41,1</td>
<td>155</td>
</tr>
</tbody>
</table>

(1) Excluding Oxygen in Delivery Area.  
(2) Deaths in Delivery Room Excluded.  
(3) Excluded Babies Died in Delivery Room and Without Cranial Imaging Done.  
(4) Excluded Babies Died in Delivery Room and Without Retinal Exam Done.  
(5) Excluded Babies Discharged Before Day 28 of Life  
(6) Excluded Babies Discharged Before Week 36 Adjusted to Gestational Age.

RDS: Respiratory Distress Syndrome.  
NEC: Necrotizing Enterocolitis  
ROP: Retinopathy of Prematurity.  
PIVH: Periventricular-Intraventricular Haemorrhage.  
FGP: Focal Gastrointestinal Perforation.  
PVL: Periventricular Leukomalacia.

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
6 RESULTS.

6.1 Multiple Gestation Rate

Definition: any birth involving more than one infant.

The global multiple gestation rate for 2013 cohort has been of 32.8%, with a variation of 8% and 100% within units.

6.1.1 Multiple Gestation Standardized Rate by Perinatal Risk Factors.

Graph 6.1.1, corresponds to the 95% CI for the standardised multiple gestation adjusted rate.

The general interpretation for graphs like 6.1.1 is the following:

- If the standardised rate is under 1, the male rate in the Unit studied is below the one expected in the standard population. Moreover, if the complete CI for the standardised rate is under 1, this rate will be below the standard population rate with a 95% confidence, for any sample of the studied Unit.

- If number 1 is inside the 95% CI, sometimes the rate will be below the standard population rate or above it.

- On the other hand, when the 95% CI is completely above number one, the rate for the Unit studied will be above the standard population rate in any sample you choose for that Unit with a 95% confidence.

The explanation for Unit 7 is the following:

- The standardised multiple gestation rate is under 1, so the multiple gestation rate in the studied Unit is lower than the rate in the standard population. However, number one is inside the 95% CI, so with a 95% confidence level the standardised multiple gestation rate will sometimes be under and above one. Therefore there is no statistical significant evidence that the multiple gestation rate for Unit 7 is different to the standard's population rate. (See graph in next page)
Results for Units 11, 19, 35 and 40 reached statistical significant relevance; being the adjusted multiple gestation rate for these Units significantly smaller than the one expected according to the standard’s population multiple gestation distribution. On the other hand, results for Unit 54 are significantly higher than the one expected according to standard's population multiple gestation distribution.

Note 1: Standardization items: Birth weight Z-Score by gestational age and gender.  
Note 2: Units with 5 or less babies admitted have not been analyzed in this section.
6.2 Prenatal Steroids Rate.

**Definition**: Betamethasone, dexamethasone or hydrocortisone given prior to delivery (Incomplete and Complete administration).

6.2.1 Prenatal Steroids Standardized Rate by Perinatal Risk Factors.

The global prenatal steroids (Inc. + Compl.) rate for 2013 cohort has been of 88.7%, with a variation of 33.3% and 100% within units.

Graph 6.2.1

Results for Unit 52 reached statistical significant relevance, being the adjusted prenatal steroids rate for these Unit significantly smaller than the one expected according to the standard’s population prenatal steroids distribution.

**Note 1**: Standardization items: Birth weight Z-Score by gestational age and gender.  
**Note 2**: Units with 5 or less babies admitted have not been analyzed in this section.

EuroNeoNet 2013
6.3 Caesarean section Rate.

Definition: any caesarean delivery (elective or emergency).

6.3.1 Caesarean Section Standardized Rate by Perinatal Risk Factors

The global Caesarean Section rate for 2013 cohort has been of 71.2%, with a variation of 36.4% and 100% within units.

Results for Units 53 reached statistical significant relevance, being the adjusted caesarean section rate for these Unit significantly smaller than the one expected according to the standard's population caesarean section distribution

Note 1: Standardization items: Birth weight Z-Score by gestational age and gender.  
Note 2: Units with 5 or less babies admitted have not been analyzed in this section.

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
6.4 **Resuscitation in Delivery Room rate.**

**Definition:** Any respiratory support given in the delivery area. Resuscitation in Delivery Room rate does not consider Oxygen in Delivery Room.

6.4.1 **Resuscitation in Delivery Room Rate by Perinatal Risk Factors.**

The global resuscitation in delivery room rate for 2013 cohort has been of 66.8%, with a variation of 0% and 90.9% within units.

![Graph 6.4.1](image)

Results for Units 3, 36, 39, 47 and 51 reached statistical significant relevance, being the adjusted resuscitation in delivery room rate for these Units significantly smaller than the one expected according to the standard's population resuscitation in delivery room distribution. On the other hand, Units 1, 26, 48 and 54 had a bigger significant adjusted resuscitation in delivery room rate than the one expected according to the standard's population resuscitation in delivery room distribution.

Unit 33 didn’t record any baby that needed resuscitation in delivery room

**Note 1:** Standardization items: Birth weight Z-Score by gestational age and gender.

**Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.

---

**Note:** Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
6.5 Surfactant at any Time Rate.

**Definition**: exogenous surfactant given to the infant at any time.

6.5.1 Surfactant at any time Standardized Rate by Perinatal Risk Factors.

The global surfactant at any time rate for 2013 cohort has been of 47.7%, with a variation of 19.2% and 73.4% within units.

![Graph 6.5.1](image)

Results for Units 2, 6, 24 and 48 reached statistical significant relevance, being the adjusted surfactant at any time rate for these Units significantly smaller than the one expected according to the standard’s population surfactant at any time distribution. On the other hand, Units 51 and 54 had a bigger significant adjusted surfactant at any time rate than the one expected according to the standard’s population surfactant at any time distribution.

**Note 1**: Standardization items: Birth weight Z-Score by gestational age and gender.  
**Note 2**: Units with 5 or less babies admitted have not been analyzed in this section.
6.6 **Surfactant within the First hour of Life Rate.**

**Definition:** Surfactant administrated within the first hour of life. No surfactant administration was considered as a NO.

**Note:** In this section Units NOT RECORDING time of administration have been excluded.

6.6.1 **Surfactant within the First hour of Life Standardized Rate by Perinatal Risk Factors.**

The global surfactant within the first hour of life rate for 2013 cohort has been of 28.3%, with a variation of 0% and 67.3% within units.

Graph 6.6.1

Results for Units 2, 3, 4, 9, 15, 19, 21, 24, 34, 36, 47 and 48 reached statistical significant relevance, being the adjusted surfactant within the first hour of life rate for these Units significantly smaller than the one expected according to the standard’s population surfactant within the first hour of life distribution. On the other hand, Units 1, 14, 18, 51 and 54 had a bigger significant adjusted surfactant within the first hour of life rate than the one expected according to the standard's population surfactant within the first hour of life distribution.

Units 7, 8 and 28 didn’t record any baby with surfactant within the first hour of life.

**Note 1:** Standardization items: Birth weight Z-Score by gestational age and gender.  

**Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.
6.7 RDS Rate.

Definition: RDS defined as: A and B.
A: A PaO2 <50 mmHg (<6.6 Kpa) in room air, central cyanosis in room air, or a requirement for supplemental oxygen to maintain PaO2 >50 mmHg (>6.6 Kpa).
B: A chest radiogram consistent with RDS (low lung volumes and reticulogranular appearance of lung fields, with or without air bronchograms).

6.7.1 RDS Standardized Rate by Perinatal Risk Factors.

The global RDS rate for 2013 cohort has been of 60.9%, with a variation of 20% and 94.4% within units.

Graph 6.7.1

Results for Units 6, 12, 13, 24, 34 and 36 reached statistical significant relevance, being the adjusted RDS rate for these Units significantly smaller than the one expected according to the standard's population RDS distribution. On the other hand, Units 1 and 14 had a bigger significant adjusted RDS rate than the one expected according to the standard's population RDS distribution.

Note 1: Standardization items: Birth weight Z-Score by gestational age and gender.
Note 2: Units with 5 or less babies admitted have not been analyzed in this section.
6.8 **Early Sepsis Rate.**

**Definition:** if a bacterial pathogen from the list in Appendix I (ENS Manual) was recovered from a blood and/or cerebrospinal fluid culture obtained before day 3 of life.

6.8.1 **Early Sepsis Standardized Rate by Perinatal Risk Factors.**

The global Early sepsis rate for 2013 cohort has been of 3.4%, with a variation of 0% and 17.1% within units.

Graph 6.8.1

Results for Units 12 and 27 reached statistical significant relevance, being the adjusted early bacterial sepsis rate for these Units significantly smaller than the one expected according to the standard's population early bacterial sepsis distribution. On the other hand, Units 18 and 20 had a bigger significant adjusted early bacterial sepsis rate than the one expected according to the standard's population early bacterial sepsis distribution.

Units 1, 8, 11, 13, 14, 21, 24, 26, 30, 33, 35, 36, 37, 39, 42, 43, 47, 51 and 53 didn’t record any case of early bacterial sepsis.

**Note 1:** Standardization items: Birth weight Z-Score by gestational age and gender.  
**Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.

**Note:** Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
6.9 Pneumothorax Rate.

Definition: if the infant had extrapleural air diagnosed by chest radiograph or needle aspiration (thoracentesis).

For infants who had thoracic surgery and a chest tube was placed at the time of surgery OR if free air was only present on a Chest Radiograph taken immediately after thoracic surgery and was not treated with a chest tube, check NO.

For infants who had thoracic surgery and then later developed extrapleural air diagnosed by Chest Radiograph or needle thoracentesis, check YES.

6.9.1 Pneumothorax Standardized Rate by Perinatal Risk Factors.

The global pneumothorax rate for 2013 cohort has been of 3.3%, with a variation of 0% and 27.8% within units.

Results for Units 12 and 48 reached statistical significant relevance, being the adjusted pneumothorax rate for these Units significantly smaller than the one expected according to the standard’s population pneumothorax distribution.

Units 2, 5, 6, 8, 9, 10, 11, 13, 17, 24, 29, 30, 33, 34, 35, 37, 38, 40, 42 and 51 didn’t record any baby diagnosed for pneumothorax.

Note 1: Standardization items: Birth weight Z-Score by gestational age, 1-min Apgar Score, 5-min Apgar Score, Gender, Multiple Birth and Major Birth Defects

Note 2: Units with 5 or less babies admitted have not been analyzed in this section.

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
6.10 PIVH (Grades III or IV) Rate.

**Definition:** If a cranial imaging was performed, enter grade based on criteria below:

- **Grade 0** - No subependymal or intraventricular hemorrhage.
- **Grade 1** – Subependymal germinal matrix hemorrhage only.
- **Grade 2** – Intraventricular blood, no ventricular dilation.
- **Grade 3** - Intraventricular blood, ventricular dilation.
- **Grade 4** – Intraparenchymal hemorrhage.

If multiple ultrasounds were done on or before day 28 record the most severe grade. Value calculated only for babies with a cranial imaging done, and grades recorded.

6.10.1 PIVH (Grades III or IV) Standardized Rate by Perinatal Risk Factors.

The global PIVH (Grades III or IV) rate for 2013 cohort has been of 7.8%, with a variation of 0% and 30.8% within units.
Results for Units 21, 26, 38, 46, 48, 49 and 54 reached statistical significant relevance, being the adjusted PIVH (Grades III or VI) rate for these Units significantly smaller than the one expected according to the standard’s population PIVH (Grades III or IV) distribution. On the other hand, Unit 41 had a bigger significant adjusted PIVH (Grades III or IV) rate than the one expected according to the standard’s population PIVH (Grades III or IV) distribution.

Units 13, 25, 28, 33, 36, 42 and 47 didn’t record any baby with PIVH (Grades III or IV).

Note 1: Standardization items: Prenatal Care, Gender, Prenatal Steroids use, 1-min Apgar Score, 5-min Apgar Score. Mode of Delivery, Multiple Birth and Major Birth Defects.

Note 2: Units with 5 or less babies admitted have not been analyzed in this section.

Note: Excluded babies died in Delivery Room and babies without cranial imaging done. Analyzed population: Admitted babies with a cranial imaging done.
6.11 NEC Rate.

**Definition:** if the infant had NEC diagnosed at surgery, at postmortem examination or clinically and radiographically using the following criteria:

A. - One or more of the following clinical signs present:
   1. - Biliious gastric aspirate or emesis
   2. - Abdominal distension
   3. - Occult or gross blood in stool (no fissure)

   **AND**

B. - One or more of the following radiographic findings present:
   1. - Pneumatosis intestinalis (cystic or linear)
   2. - Hepato-biliary gas
   3. - Pneumoperitoneum

**Note 1:** Infants should be coded as having FOCAL GASTROINTESTINAL PERFORATION, not as NEC even if satisfying the definition of NEC but, are found at surgery or postmortem examination for that episode to have a Focal Gastrointestinal Perforation.

### 6.11.1 NEC Standardized Rate by Perinatal FIrsk Factors.

The global NEC rate for 2013 cohort has been of 4.8%, with a variation of 0% and 50% within units.
Results for Units 1 and 32 reached statistical significant relevance, being the adjusted NEC rate for these Units significantly smaller than the one expected according to the standard’s population NEC distribution. On the other hand, Unit 15 had a bigger significant adjusted NEC rate than the one expected according to the standard’s population NEC distribution.

Units 2, 6, 7, 8, 10, 13, 24, 28, 29, 31, 33, 34, 35, 38, 39, 42, 45 and 47 didn’t register any baby diagnosed of NEC

Note 1: Standardization items: Birth weight Z-Score by gestational age and gender.  
Note 2: Units with 5 or less babies admitted have not been analyzed in this section.

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
6.12 Focal Gastrointestinal Perforation Rate.

**Definition**: if the infant had a Focal Gastrointestinal Perforation separate from NEC. This diagnosis will be based on visual inspection of the bowel at the time of surgery or postmortem examination that demonstrates a single focal perforation with the remainder of the bowel appearing normal.

6.12.1 Focal Gastrointestinal Perforation Standardized Rate by Perinatal Risk Factors.

The global Focal Gastrointestinal Perforation rate for 2013 cohort has been of 2.4%, with a variation of 0% and 50% within units.

Graph 6.12.1

Any of the results reached statistical significance.

Units 2, 5, 6, 7, 9, 10, 11, 13, 14, 17, 19, 24, 25, 28, 29, 30, 33, 34, 36, 37, 42, 44, 45, 46 and 49 didn’t record any baby diagnosed of focal gastrointestinal perforation.

**Note 1**: Standardization items: Birth weight Z-Score by gestational age and gender.  
**Note 2**: Units with 5 or less babies admitted have not been analyzed in this section.
6.13 ROP (Grades >=3) Rate.

**Definition:** if an indirect ophthalmologic examination for ROP was performed at any time, the WORST grade, according to the following classification is registered.

- Grade 0 – No evidence of ROP lesions.
- Grade 1 – White demarcation line between vascular and avascular retina.
- Grade 2 – Elevated demarcation line or ridge.
- Grade 3 – Ridge with extraretinal fibrovascular proliferation.
- Grade 4 – Subtotal retinal detachment.
- Grade 5 – Total retinal detachment.

6.13.1 ROP (Grades >=3) Standardized Rate by Perinatal Risk Factors.

The global ROP (Grades >= 3) rate for 2013 cohort has been of 4.8%, with a variation of 0% and 25% within units.

**Note:** Excluded babies died in Delivery Room and without retinal exam done. Analyzed population: Admitted babies with retinal exam done.
Results for Units 26 and 27 reached statistical significant relevance, being the adjusted ROP (Grades >=3) rate for these Units significantly smaller than the one expected according to the standard's population ROP (Grades >=3) distribution. On the other hand Unit 53 have a significantly bigger rate than the one expected according to standard's population ROP (Grades >=3) distribution.

Units 1, 2, 4, 5, 7, 10, 11, 13, 15, 19, 21, 22, 23, 24, 28, 29, 30, 33, 34, 36, 39, 42, 44, 45, 46, 47 and 48 didn’t register any baby with ROP (Grades >=3).

**Note 1:** Standardization items: Birth weight Z-Score by gestational age, 1-min Apgar Score, 5-min Apgar Score, Gender and Mode of Delivery.

**Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.

**Note:** Excluded babies died in Delivery Room and without reinal exam done. Analyzed population: Admitted babies with retinal exam done.
6.14 $O_2$ on day 28 Rate.

**Definition:** if the infant was still in hospital and received any supplemental oxygen on day 28.

**Note 1:** if the infant died or was discharged prior to day 28, and was not readmitted on or before day 28, the item is Not Applicable, so not listed in these results.

**Note 2:** Excluded babies discharged before day 28.

6.14.1 $O_2$ on day 28 Standardized Rate by Perinatal Risk Factors.

The global Supplemental Oxygen on day 28 rate for 2013 cohort has been of 45.6%, with a variation of 0% and 100% within units.

Results for Units 2, 3, 4, 5, 9, 10, 12, 14, 15, 16, 17, 18, 19, 20, 21, 22, 23, 24, 26, 28, 29, 32, 34, 35, 36, 39, 41, 42, 43, 44, 45, 46, 49, 51, 52 and 54 reached statistical significant relevance, being the adjusted Oxygen on day 28 rate for these Units significantly smaller than the one expected according to the standard’s population Oxygen on day 28 distribution.

Units 33 and 47 didn’t record any baby with Oxygen on day 28.

**Note 1:** Standardization items: Birth weight Z-Score by gestational age and gender.

**Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.
6.15 \textbf{O}_2 \textit{on week 36 Rate.}

\textbf{Definition:} if the infant was still in hospital and received any supplemental oxygen on the date when the infant was 36 weeks post-conceptional age.

\textbf{Note 1:} if the infant was not alive in your hospital on the date at which the infant was 36 weeks adjusted gestational age or if the infant had a gestational age after rounding off to the nearest week, of 36 weeks or more at birth, the item is Not Applicable, so not listed in these results.

\textbf{Note 2:} Excluded babies discharged before week 36 adjusted to gestational age.

\textbf{6.15.1 O}_2 \textit{on week 36 Standardized Rate by Perinatal Risk Factors.}

The global Oxygen at week 36 adjusted to Gestational Age rate for 2013 cohort has been of 24\%, with a variation of 0\% and 100\% within units.

\textbf{Note:} Excluded babies died in Delivery Room and without retinal exam done. Analyzed population: Admitted babies with retinal exam done.
Results for Units 4, 7, 9, 11, 12, 14, 16, 18, 19, 20, 21, 22, 26, 27, 29, 31, 32, 34, 43, 44, 46, 48, 49, 50, 51, 53 and 54 reached statistical significant relevance, being the adjusted Oxygen on week 36 rate for these Units significantly smaller than the one expected according to the standard’s population Oxygen on week 36 distribution.

Units 2, 3, 5, 6, 10, 13, 15, 17, 23, 24, 28, 33, 35, 36, 39, 42 and 47 didn’t register any baby with Oxygen on week 36.

6.16 Late Bacterial Sepsis Rate.

Definition: if a bacterial pathogen from the list in Appendix I (ENS Manual) is recovered from a blood and/or cerebrospinal fluid culture obtained after day 3 of life.

Note 1: The date of birth counts as day 1 regardless of the time of birth.

6.16.1 Late Bacterial Sepsis Standardized Rate by Perinatal Risk Factors.

The global Late Sepsis rate for 2013 cohort has been of 24.7%, with a variation of 0% and 100% within units.
Results for Units 6, 9, 33, 47, 48, 51, 52, 53 and 54 reached statistical significant relevance, being the adjusted Late Onset Sepsis (LOS) rate for these Units significantly smaller than the one expected according to the standard's population LOS distribution. On the other hand Units 3, 5, 16 and 32 had a bigger significant adjusted LOS rate than the one expected according to the standard's population LOS distribution.

Units 8 and 28 didn’t register any baby with late bacterial sepsis.

Note 1: Standardization items: Birth weight Z-Score by gestational age, 1-min Apgar Score, 5-min Apgar Score, Prenatal Steroids, Mode of Delivery, Gender and Multiple Gestation.

Note 2: Units with 5 or less babies admitted have not been analyzed in this section.

Note: Excluded babies died in Delivery Room and babies with no cranial ultrasound or other technique done to diagnose PVL. Analyzed population: Admitted babies with a cranial ultrasound or other technique done to diagnose PVL done.
6.17 Steroids for CLD Rate.

**Definition:** If corticosteroids were used after birth to treat or prevent BPD-CLD.

### 6.17.1 Steroids for CLD Standardized Rate by Perinatal Risk Factors.

The global Steroids for CLD rate for 2013 cohort has been of 7.2%, with a variation of 0% and 33.3% within units.

Graph 6.17.1

Results for Units 15, 48 and 53 reached statistical significant relevance, being the adjusted Steroids for CLD rate for these Units significantly smaller than the one expected according to the standard’s population Steroids for CLD distribution. On the other hand Units 27, 37 and 41 had bigger significant adjusted Steroids for CLD rate than the one expected according to the standard’s population Steroids for CLD distribution.

Units 2, 9, 11, 12, 19, 21, 28, 31, 33, 35, 36, 42, 47 and 50 didn’t register any baby with Steroids for CLD.

**Note 1:** Standardization items: Birth weight Z-Score by gestational age and gender.  
**Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.
6.18 Cystic PVL Rate.

**Definition:** If CYSTIC PVL, NON-CYSTIC PVL OR BOTH were diagnosed, please check the type as diagnosed by cranial ultrasound or other imaging technique.

**Note 1:** To be considered cystic PVL there must be multiple small periventricular cysts identified. Periventricular echogenicity without cysts should not be coded as cystic PVL. A porencephalic cyst in the area of previously identified intraparenchymal hemorrhage should not be coded as cystic PVL.

6.18.1 Cystic PVL Standardized Rate by Perinatal Risk Factors.

The global Cystic PVL rate for 2013 cohort has been of 5.8%, with a variation of 0% and 45.9% within units.

**Graph 6.18.1**

Results for Units 1, 12, 19, 26, 32, 50 and 54 reached statistical significant relevance, being the adjusted Cystic PVL rate for these Units significantly smaller than the one expected according to the standard’s population. On the other hand Units 9, 27 and 45 had bigger significant adjusted Cystic PVL rate than the one expected according to the standard’s population Cystic PVL distribution.

Units 4, 5, 6, 10, 13, 21, 24, 25, 36, 42, 47, 48, 51 and 52 didn’t register cystic PVL.

**Note 1:** Standardization items: Birth weight Z-Score by gestational age and gender. **Note 2:** Units with 5 or less babies admitted have not been analyzed in this section.

EuroNeoNet 2013
6.19 Mortality Rate.

**Definition:** if the infant died on or before his/her first birthday at your hospital prior to being discharge home or transferred and if the infant died in the delivery room (if your Unit has one).

6.19.1 Mortality Standardized Rate by Perinatal Risk Factors.

The global Mortality rate for 2013 cohort has been of 9.5%, with a variation of 0% and 33.3% within units.
Results for Unit 53 reached statistical significant relevance, being the adjusted mortality rate for these Units significantly smaller than the one expected according to the standard’s population mortality distribution. On the other hand Units 16 and 44 had a bigger significant adjusted mortality rate than the one expected according to the standard’s population mortality distribution.

Units 8, 13, 25, 28, 33, 37, 43 and 54 register any death.

Note 1: Standardization items: Birth weight Z-Score by gestational age, Prenatal Steroids use, 1-min Apgar Score, 5-min Apgar Score, Multiple Gestation, Mode of Delivery, Gender, Prenatal Care and Major Birth Defects

Note 2: Units with 5 or less babies admitted have not been analyzed in this section.
6.19.2 Excess/Defect analysis.

As the study of mortality is one of the main objectives of the ENS Project, in this section we will try to explain in more detail how the different Units behave in relation with the standard population.

Table 6.19.4 shows the observed number of deaths, the expected number of deaths according to the sample size in each Unit and the difference between these two numbers. All these calculations have been done considering the different groups by birth weight.

**The explanation for Table 6.19.4 is the following:**

When SMR is under 1, the table will give us the number of deaths that did not appear and should in relation with general population; whereas when the SMR is above 1, the table shows the excess number of deaths.

### Table 6.19.4

<table>
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<tr>
<th>Unit Code</th>
<th>Observed nº of deaths</th>
<th>Expected nº of deaths by BW</th>
<th>SMR</th>
<th>Excess/Defect nº of deaths</th>
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<td>Expected nº of deaths by BW</td>
<td>SMR</td>
<td>Excess/Defect nº of deaths</td>
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7 LENGTH OF STAY ANALYSIS FOR VLGAI DISCHARGED TO HOME.

7.1 Sample Size

In this section the length of stay of VLGAI is going to be analysed. Firstly the sample size has to be determined. From the global set of data, infants that died, were transferred or are still hospitalised are going to be excluded of the analysis in this section. The only infants to be considered in this analysis are those discharged home. The valid sample size is the following:

In all this section, sample size will exclude:

1. Deaths in Delivery Room.
2. Babies not discharged home (died, transferred or still hospitalized as of first birthday)
3. Units with 5 or less babies with valid data for Age at discharge.
7.2 Length of stay (days) description

The valid sample size finally has been of 1,955 infants.

Table 7.2.1 shows the parametric and non-parametric statistics for the Length of Stay. The global mean stay for the 54 Units analysed has been of 36 days with a standard deviation of 30.9 days.

Note: Missing Age at admission has been considered as 0 days.

Table 7.2.1

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<th>Unit Code</th>
<th>N</th>
<th>( \mu \pm \sigma )</th>
<th>95% CI (( \mu ))</th>
<th>Q2</th>
<th>[Q1,Q3]</th>
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<td>54.4 ± 26.1</td>
<td>[47.2;61.6]</td>
<td>49</td>
<td>[36;70]</td>
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<td>17.9 ± 14.2</td>
<td>[10;25.8]</td>
<td>19</td>
<td>[3;26]</td>
</tr>
<tr>
<td>3</td>
<td>39</td>
<td>13.2 ± 12.1</td>
<td>[9.2;17.1]</td>
<td>9</td>
<td>[4;19]</td>
</tr>
<tr>
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<td>[21.4;36.8]</td>
<td>22</td>
<td>[13;40.5]</td>
</tr>
<tr>
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<td>29</td>
<td>32.2 ± 18.7</td>
<td>[25.1;39.4]</td>
<td>28</td>
<td>[17;47.5]</td>
</tr>
<tr>
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<td>17.5 ± 12.4</td>
<td>[10.25]</td>
<td>12</td>
<td>[8.5;29]</td>
</tr>
<tr>
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<td>16</td>
<td>34.8 ± 20.3</td>
<td>[24;45.6]</td>
<td>30</td>
<td>[19.3;48.8]</td>
</tr>
<tr>
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<td>62.8 ± 39.9</td>
<td>[21;104.7]</td>
<td>40.5</td>
<td>[36.5;114]</td>
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<tr>
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<td>37.2 ± 30.5</td>
<td>[29.5;44.9]</td>
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<td>[14;54]</td>
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<td>14.6 ± 18</td>
<td>[4.2;25]</td>
<td>7</td>
<td>[3;24.5]</td>
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<td>39.4 ± 21.9</td>
<td>[28.2;50.7]</td>
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<td>[18.5]</td>
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<td>[6.2;11.4]</td>
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<td>[13;32.5]</td>
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<td>[15;54]</td>
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<td>[18;50]</td>
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<td>[16.35]</td>
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<td>[11;52.5]</td>
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</table>

Note: Excluded babies died in Delivery Room, units with 5 or less babies admitted in the NICU and babies not discharged home.
### Length of Stay by Unit Participating in the ENS Project

<table>
<thead>
<tr>
<th>Unit Code</th>
<th>N</th>
<th>$\mu \pm \sigma$</th>
<th>95% CI ($\mu$)</th>
<th>Q$_2$</th>
<th>[Q$_1$, Q$_3$]</th>
</tr>
</thead>
<tbody>
<tr>
<td>31</td>
<td>19</td>
<td>35.7 ± 50.6</td>
<td>[11.3;60.1]</td>
<td>25</td>
<td>[10.4;22.5]</td>
</tr>
<tr>
<td>32</td>
<td>107</td>
<td>33.5 ± 31.7</td>
<td>[27.4;39.6]</td>
<td>22</td>
<td>[9;49]</td>
</tr>
<tr>
<td>33</td>
<td>16</td>
<td>19.8 ± 10.3</td>
<td>[14.4;25.4]</td>
<td>20</td>
<td>[11.8;29.3]</td>
</tr>
<tr>
<td>34</td>
<td>35</td>
<td>39.6 ± 20.5</td>
<td>[32.5;46.6]</td>
<td>34</td>
<td>[24;51]</td>
</tr>
<tr>
<td>35</td>
<td>17</td>
<td>21.9 ± 14.2</td>
<td>[14.6;29.3]</td>
<td>20</td>
<td>[11.5;33.5]</td>
</tr>
<tr>
<td>36</td>
<td>24</td>
<td>9.2 ± 8.1</td>
<td>[5.8;12.6]</td>
<td>7</td>
<td>[4.3;10]</td>
</tr>
<tr>
<td>37</td>
<td>21</td>
<td>36.5 ± 30</td>
<td>[22.8;50.2]</td>
<td>24</td>
<td>[16.5;53]</td>
</tr>
<tr>
<td>38</td>
<td>36</td>
<td>50.1 ± 29.1</td>
<td>[40.2;59.9]</td>
<td>51.5</td>
<td>[38;73.5]</td>
</tr>
<tr>
<td>39</td>
<td>24</td>
<td>26.7 ± 21.2</td>
<td>[17.7;35.6]</td>
<td>20</td>
<td>[10.3;36]</td>
</tr>
<tr>
<td>40</td>
<td>16</td>
<td>71.1 ± 54.7</td>
<td>[42;100.3]</td>
<td>57</td>
<td>[39;96.3]</td>
</tr>
<tr>
<td>41</td>
<td>52</td>
<td>20.2 ± 23</td>
<td>[13.8;26.6]</td>
<td>9</td>
<td>[4;31.5]</td>
</tr>
<tr>
<td>42</td>
<td>19</td>
<td>25 ± 13.7</td>
<td>[18.4;31.6]</td>
<td>22</td>
<td>[15.35]</td>
</tr>
<tr>
<td>43</td>
<td>27</td>
<td>49 ± 20.9</td>
<td>[40.7;57.2]</td>
<td>44</td>
<td>[33;59]</td>
</tr>
<tr>
<td>44</td>
<td>33</td>
<td>36.5 ± 22.9</td>
<td>[28.3;44.6]</td>
<td>38</td>
<td>[24;48]</td>
</tr>
<tr>
<td>45</td>
<td>33</td>
<td>38.3 ± 24.8</td>
<td>[29.5;47.1]</td>
<td>34</td>
<td>[15.5;53]</td>
</tr>
<tr>
<td>47</td>
<td>16</td>
<td>19.8 ± 12.1</td>
<td>[13.4;26.7]</td>
<td>15.5</td>
<td>[13.28]</td>
</tr>
<tr>
<td>48</td>
<td>73</td>
<td>49.6 ± 27.1</td>
<td>[43.3;56]</td>
<td>46</td>
<td>[27.5;63.5]</td>
</tr>
<tr>
<td>49</td>
<td>33</td>
<td>29.3 ± 25.3</td>
<td>[20.3;38.3]</td>
<td>25</td>
<td>[11.4;40]</td>
</tr>
<tr>
<td>50</td>
<td>76</td>
<td>37.9 ± 27.4</td>
<td>[31.6;44.1]</td>
<td>35.5</td>
<td>[20.51]</td>
</tr>
<tr>
<td>51</td>
<td>44</td>
<td>56 ± 27.5</td>
<td>[47.7;64.4]</td>
<td>49.5</td>
<td>[34.8;78]</td>
</tr>
<tr>
<td>52</td>
<td>41</td>
<td>48.1 ± 21.3</td>
<td>[41.4;54.9]</td>
<td>42</td>
<td>[31;64]</td>
</tr>
<tr>
<td>53</td>
<td>91</td>
<td>75 ± 40.4</td>
<td>[66.6;83.4]</td>
<td>69</td>
<td>[42;98]</td>
</tr>
<tr>
<td>54</td>
<td>29</td>
<td>56.7 ± 22.9</td>
<td>[47.9;65.4]</td>
<td>55</td>
<td>[38;70.5]</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>1955</strong></td>
<td><strong>36 ± 30.9</strong></td>
<td><strong>[34.6;37.4]</strong></td>
<td><strong>30</strong></td>
<td><strong>[12;51]</strong></td>
</tr>
</tbody>
</table>

**Note:** Excluded babies died in Delivery Room, units with 5 or less babies admitted in the NICU and babies not discharged home
Graph 7.2.2 corresponds to the 95% CI for the global stay measured in days. The discontinuous line shows the stay mean for the global set of Units.

Kruskal-Wallis test for independent samples has been performed. Showing that the length of stay is statistically different between Units (p<0.001).

Note: Excluded babies died in Delivery Room, units with 5 or less babies admitted in the NICU and babies not discharged home
8 ANNEX

Number of babies reported by Unit 48 that fulfilled **ENN data inclusion criteria** are 87.

Any baby died in delivery room. Admitted babies (87) will be described in detail in section 8.2 and 8.3.

Reminder of ENN Data Inclusion Criteria:

Any infant born alive at your hospital, whether or not was admitted to your NICU, should be reported if his/her:

- Birth Weight (BW) is less than **1501 g**
- OR
- Gestational Age (GA) is less than **32 wks** (**31 + 6 days inclusive**).

All livebirths must be reported, **no matter** if his/her gestational age is below 22 weeks or the birth weight is below 401g.

All outborn infants of same BW and GA as above, admitted to any location in your hospital within 28 days of birth should also be included, only if the baby has never been discharged home.

Outborn babies admitted to the Neonatal Unit after the 28th day of life, should not be included in the Database, since by international definitions those babies are no longer “newborn” but “infants”.
8.1 *Delivery Room Deaths Description*

No babies died in Deliver Room were reported
8.2 Demographic Individual Data

8.2.1 Birth Weight

Mean birth weight for Unit 48 in 2013 cohort babies has been of 1,261.8 gr. with a standard deviation of 287.6 gr. Extreme values are those under 759 (P₅) and above 1,780 (P₉₅).

<table>
<thead>
<tr>
<th>Birth weight (gr.)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>1,261.8(287.6)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(1,200.5;1,323)</td>
</tr>
<tr>
<td>Med [Q₁,Q₃]</td>
<td>1,330[1,070;1,440]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>645-1,870</td>
</tr>
<tr>
<td>P₅-P₉₅</td>
<td>759-1,780</td>
</tr>
</tbody>
</table>

Birth weight (grams)
Mean= 1261.75
Std.Dev= 287.6
N=87
8.2.2 Gestational Age

Median gestational age for Unit 48 in 2013 cohort babies has been of 30 weeks, ranging from 28 (Q₁) to 32 (Q₃). Extreme values are those under 25 (P₅) and above 34 (P₉₅).

<table>
<thead>
<tr>
<th></th>
<th>Gestational Age (wks.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>29.9(2.6)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(29.3;30.4)</td>
</tr>
<tr>
<td>Med [Q₁,Q₃]</td>
<td>30[28;32]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>24-35</td>
</tr>
<tr>
<td>P₅-P₉₅</td>
<td>25-34</td>
</tr>
</tbody>
</table>

Mean= 29.87
Std.Dev= 2.636
N=87

Gestational Age (weeks)

Mean= 29.87
Std.Dev= 2.636
N=87

Gestational Age (weeks)
8.2.3 Apgar Scores

Admitted babies in Unit 48 for 2013 cohort had a 1-min Apgar Score mean of 6, and 5-min score mean of 8.1 points.

<table>
<thead>
<tr>
<th></th>
<th>1-min Apgar Score</th>
<th>5-min Apgar Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>6(2.4)</td>
<td>8.1(1.7)</td>
</tr>
<tr>
<td>95% CI (Mean)</td>
<td>(5.5;6.5)</td>
<td>(7.6;8.5)</td>
</tr>
<tr>
<td>Med [Q1,Q3]</td>
<td>7[4;8]</td>
<td>8[7;9]</td>
</tr>
<tr>
<td>Min-Max</td>
<td>0-10</td>
<td>0-10</td>
</tr>
<tr>
<td>P5-P95</td>
<td>1-9</td>
<td>4.8-10</td>
</tr>
</tbody>
</table>

![Box plot showing Apgar test results at 1 and 5 minutes](image-url)

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
8.2.4 Perinatal Risk Factors

Less than half of the population of admitted babies in Unit 48 were male (48.3%). A 41.4% of babies were multiple and a 57.5% of admitted babies were born by Caesarean Section. A 95.4% received at least one cycle of Prenatal Steroids and a 98.9% received Prenatal Care. Finally, a 4.6% of the babies presented a Major Birth Defect.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>42</td>
<td>48.3</td>
</tr>
<tr>
<td>Multiple Gestation</td>
<td>36</td>
<td>41.4</td>
</tr>
<tr>
<td>Caesarean Section</td>
<td>50</td>
<td>57.5</td>
</tr>
<tr>
<td>Prenatal Steroids (Inc. + Compl.)</td>
<td>83</td>
<td>95.4</td>
</tr>
<tr>
<td>Prenatal Care</td>
<td>86</td>
<td>98.9</td>
</tr>
<tr>
<td>Major Birth Defects</td>
<td>4</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Note: Excluded babies died in Delivery Room. Analyzed population: Admitted babies.
8.2.5 Standardized Percentiles

Manoeuvres and Diagnoses:
Resuscitation in Delivery Room, Surfactant Need, RDS and Early Onset Sepsis

More than 2/3 of the population (86.2%) needed some kind of Resuscitation in delivery room in addition to Oxygen. A 25.3% of babies needed Surfactant at any time of its stay, being the rate of Surfactant within the fist hour of life an 9.2%.

A 47.1% of babies were diagnosed of Respiratory Distress Syndrome and a 3.4% of babies had an Early Bacterial Sepsis episode.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resuscitation in Delivery Room</td>
<td>75</td>
<td>86.2</td>
</tr>
<tr>
<td>Surfactant at any time</td>
<td>22</td>
<td>25.3</td>
</tr>
<tr>
<td>Surfactant within the 1st hour of life</td>
<td>8</td>
<td>9.2</td>
</tr>
<tr>
<td>Respiratory Distress Syndrome</td>
<td>41</td>
<td>47.1</td>
</tr>
<tr>
<td>Early Onset Sepsis</td>
<td>3</td>
<td>3.4</td>
</tr>
</tbody>
</table>

Next graph plots, the percentile that the previous results represent in the whole year cohort. Results for resuscitation in Delivery Room and Surfactant at any time were beyond the standard limits, the first between the 90th and the 95th percentile limits and the second between the 5th and th 10th percentile limits.
**Diagnoses:**

Pneumothorax, Necrotizing Enterocholitis, Focal Gastrointestinal Perforation and Steroids for CLD.

A 1.1% of the babies were diagnosed of Pneumothorax. Necrotizing Enterocholitis rate was of 2.3% and another 1.1% was diagnosed of Focal Gastrointestinal Perforation. Finally, Steroids for CLD rate was of a 3.4%.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pneumothorax</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Necrotizing Enterocholitis</td>
<td>2</td>
<td>2.3</td>
</tr>
<tr>
<td>Focal Gastrointestinal Perforation</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Steroids for CLD</td>
<td>2</td>
<td>3.4</td>
</tr>
</tbody>
</table>

Next graph plots, the percentile that the previous results represent in the whole year cohort. Any of the results were beyond the standard limits (above the 90th percentile or below the 10th percentile limits).
**Morbi-Mortality:**
Severe PIVH, Rop (Grades >=3), BPD, Late Onset Sepsis, Cystic Leukomalacia and Mortality

Severe PIVH was diagnosed in a 1.1% of babies admitted in Unit 48, none of the babies were diagnosed of Rop (Grades >=3) nor Cystic PVL. An 18.3% of the babies had Oxygen on week 36.

A 12.6% of babies had at least one Late Onset Sepsis episode and a 4.6% of the babies died before discharge.

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe PIVH</td>
<td>1</td>
<td>1.1</td>
</tr>
<tr>
<td>Rop (Grades &gt;= 3)</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>BPD</td>
<td>11</td>
<td>18.3</td>
</tr>
<tr>
<td>Late Onset Sepsis</td>
<td>11</td>
<td>12.6</td>
</tr>
<tr>
<td>Cystic Leukomalacia</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Mortality</td>
<td>4</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Next graph plots, the percentile that the previous results represent in the whole year cohort. Any of the results were beyond the standard limits (above the 90th percentile or below the 10th percentile limits).
8.3 Main Results

8.3.1 Percentile Position for Main Results.

Graphic 8.3.1 shows the percentile position for main results for Unit Code 48 related to all Units included in the study. Main results are considered to be Mortality, Pneumothorax diagnose, Oxygen on week 36, Prenatal Steroids (Incomplete + Complete), PIVH (Grades III or IV) and Late Bacterial Sepsis.

The percentage shown represents the position that the Unit has inside the total set of Units studied. Unit Code 48 is in percentile 26 for Mortality, in percentile 41 for Pneumothorax, in percentile 80 for Oxygen on week 36, in percentile 20 for Prenatal Steroids (Incomplete + Complete), in percentile 15 for PIVH (Grades III or IV) and finally in percentile 24 for Late Bacterial Sepsis. For all main items a positive result is considered a low percentile.

*This graphic represents the position that the Unit has inside the whole set, NOT its intensity. Intensity is described in 8.3.2 graphic.
8.3.2 Typified Scores for Main Results

Graphic 8.3.2 corresponds to the typified score for the standardised rate adjusted by Birth Weight for items considered as main results.

A score above 0 means a positive result and its intensity is given by the score itself. As larger the score is, the better is the result (when positive) and when negative; as larger it is, the worse is the result. If the stick crosses the discontinuous line then the result will be statistically significant.

Any of the results reached statistical significance.
General Contact Information
For The ENN Project

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