eNewborn
Neonatal benchmarking network

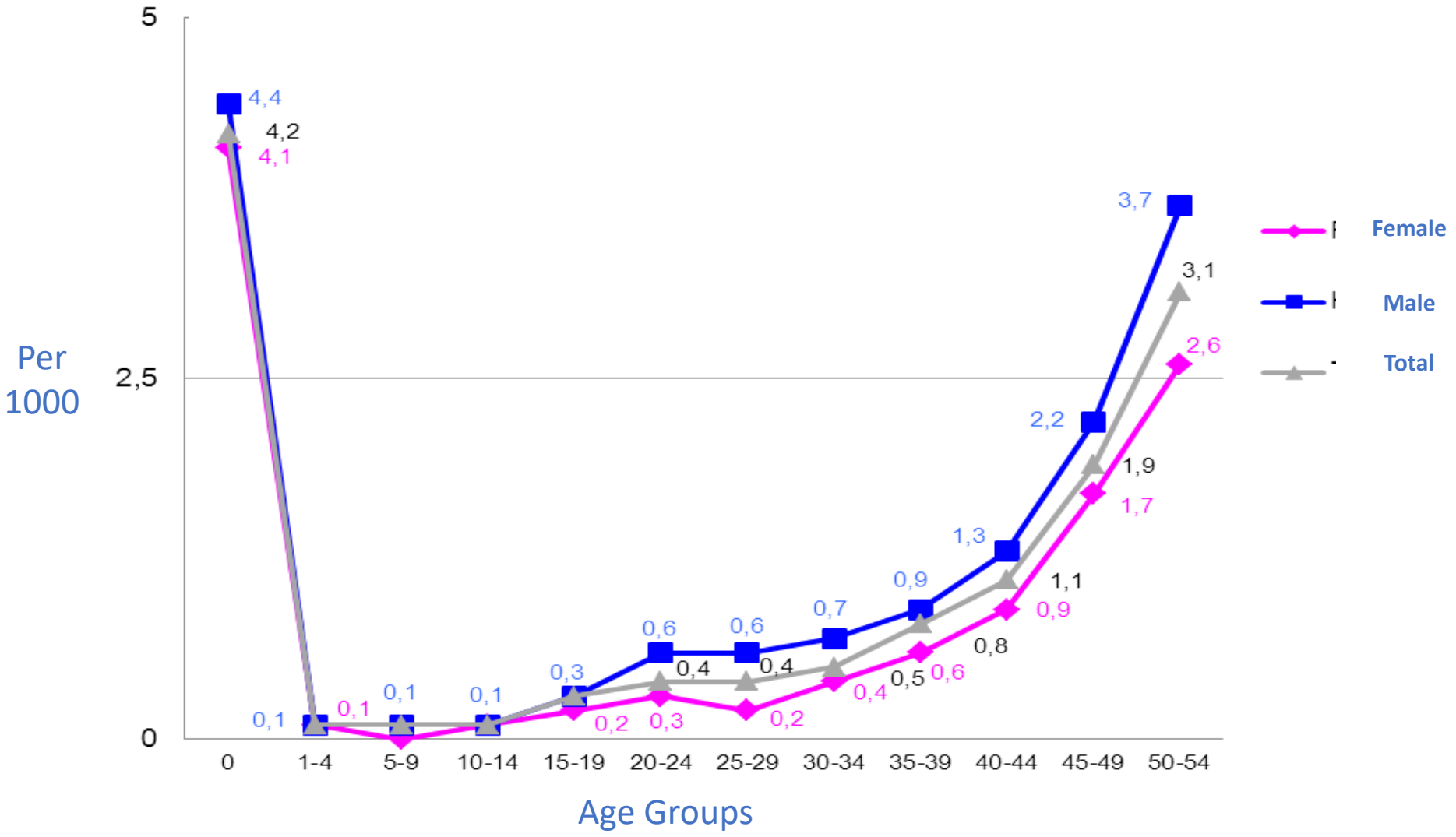
UNIVERSITÉ LIBRE DE BRUXELLES

Future challenges for eNewborn The European Neonatal Network

Dominique Haumont

Lisboa 5 december 2019

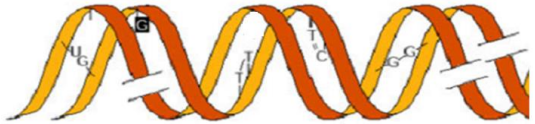
Neonatal Period: Highest Risk in Mortality



Preterm birth and long term consequences

- Cerebral palsy: 2-3 per 1000 at full term
  vs 200 per 1000 at 24-25 weeks
- Learning and cognitive problems: 6-7% at 36 weeks
  vs >50% at 24-25 weeks
- Psychiatric morbidity: 1 in 4 of the most premature infants
- Increased incidence of lung and cardiovascular diseases
- Depressive symptoms and financial burden on parents

Improving outcome in Neonatology
Future perspectives



- Prenatal, fetal diagnosis
- (Epi)genetics, gene therapy
- New insights and technology: metabolomics, microbioma, imaging, nutrition
- Simulation techniques
- Moving towards family centered couplet care, Collaboration with parents
- Allocating required resources by authorities
- Drug development
- …….
- ***Big data, Real World Data and IT tools***
- ***Neonatal Networks***

GLOBAL HEALTH

PROJECTS

How does my unit perform?

« If you cannot measure it, you cannot improve it »

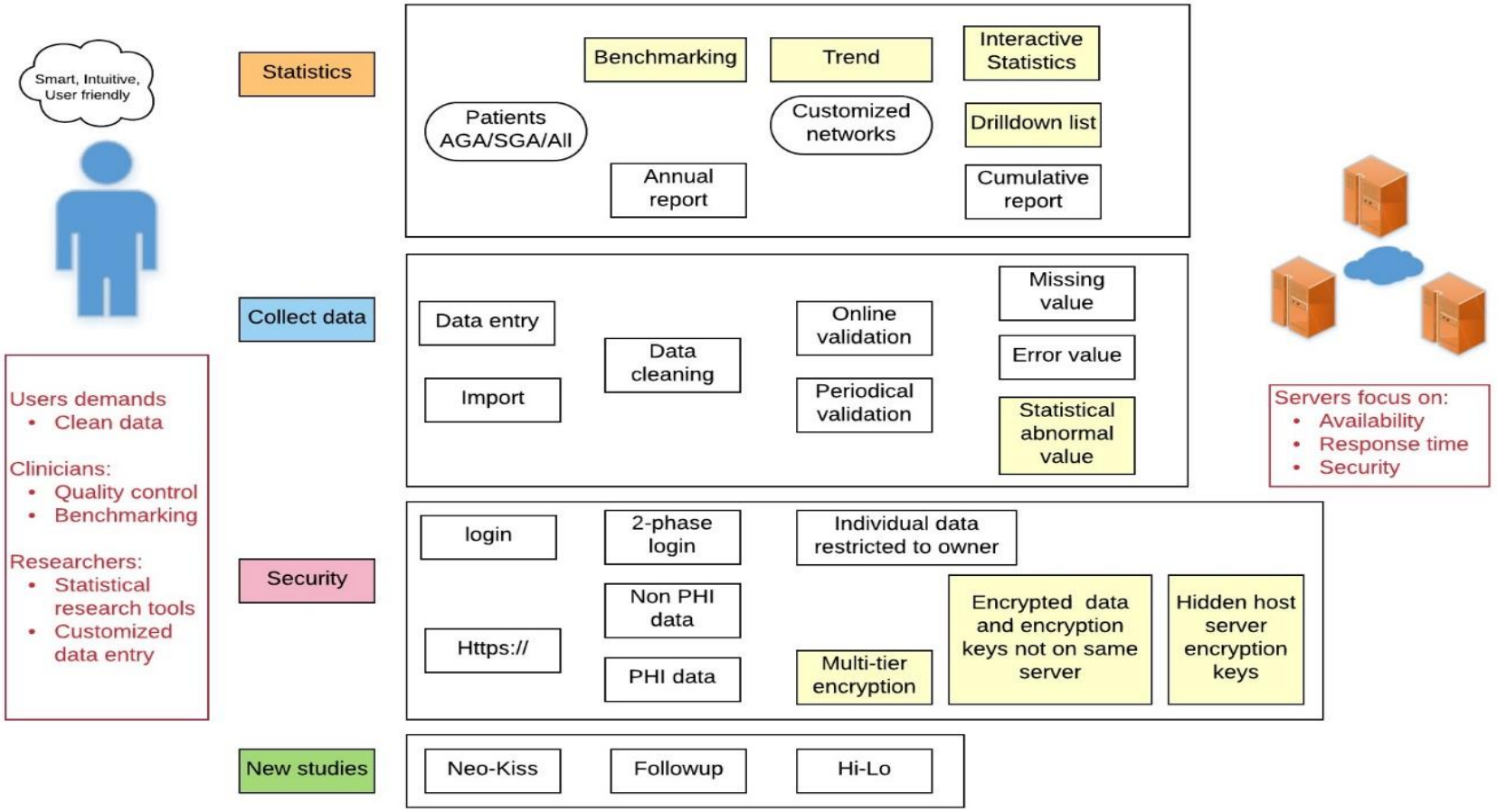
Lord Kelvin

1824-1907

Prerequisits for building a valuable database

- Well defined study population
- Appropriate items
- Precise definition of the items
- Feasibility of correct data entry/ data mapping
- Motivation of the units/networks to enter clean data
- *USER FRIENDLY SOFTWARE*
- *SUSTAINED FUNDING*

eNewborn Benchmarking Engine Functionalities



Neonatology 2017;111:388–397 DOI: 10.1159/000464267

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eNewborn webbased project

Phase I (2008): College of Physicians- Belgium Federal Public Health www.newborn-college.be
Phase II (2010) : link with ENN
Phase III (2014): bringing networks together on a common platform www.enewborn.org

Phase III Bringing Networks together

Partnership

eNewborn
Professor Dominique Haumont
Université Libre de Bruxelles
Database expert at the College of Physicians, Federal Public Health Service, Belgium
Database officer European Society of Neonatology

NNRD-UK
Professor Neena Modi
Director, Neonatal Data Analysis Unit
Professor of Neonatal Medicine
Imperial College London
President of the Royal College of Paediatrics and Child Health

Scientific collaborators:

Professor Mark Turner
Senior Lecturer in Neonatal Medicine
Chair, European Network of Paediatric Research at the EMA
University of Liverpool

Professor Kate Costeloe
Professor of Paediatrics
Queen Mary University of London
Co-chair, Neonatal Data Analysis Unit Steering Boar

Professor Ola Saugstad
Director
Department of Pediatric Research
University of Oslo

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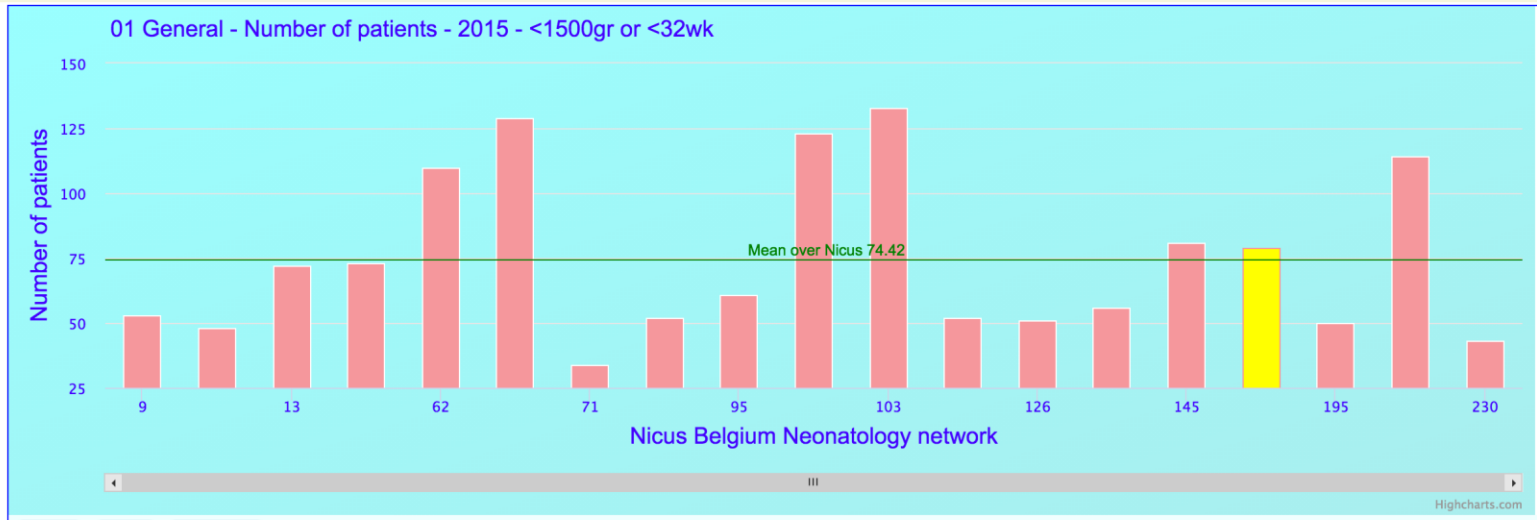
International Neonatal Network

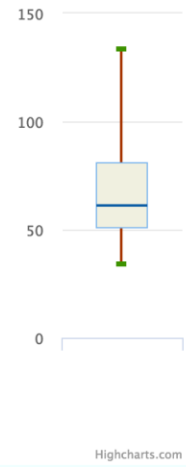
Belgium Newborn College Network

CHU Saint-Pierre
HSP

List | Benchmark | Trend | Report | Export | Import

Population: <1500gr or <32wk Year: 2015 Network: Belgium Favorite Benchmark on Displayed Nicu All Nicus Change Main Item Focus on Reset

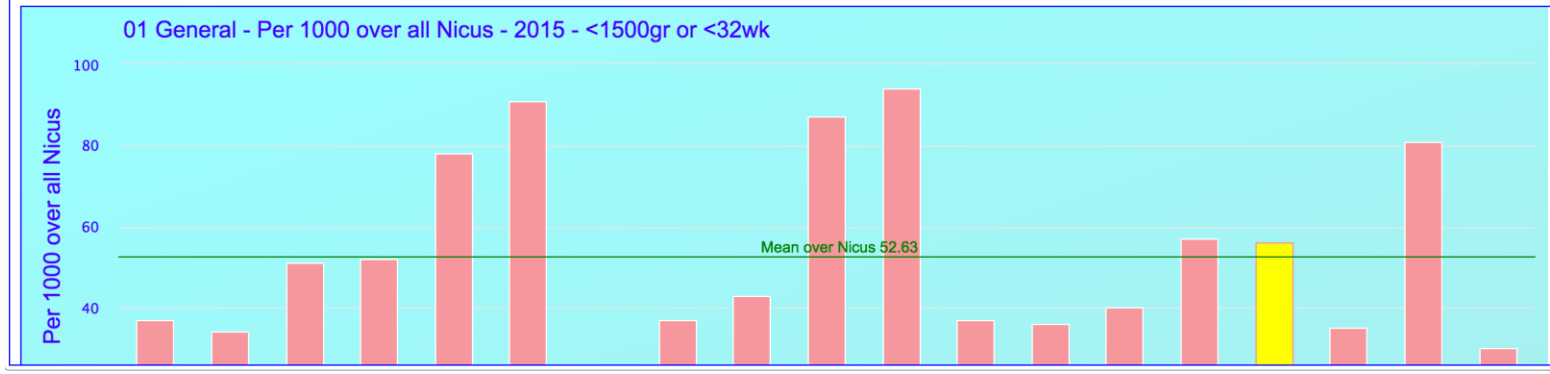


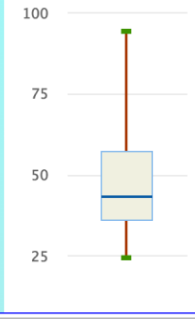


Focus On

Summary over Nicus	
Nicus	19
Nicus not included	0
Patients	1414
Patients Not included	0
Mean	74.42
STD deviation	31.73
Maximum	133
Upper Quartile	81
Median	61
Lower quartile	51
Minimum	34
Context count	-
Global count	-
Global percent	-

Zoom + Zoom - Reset zoom Rank Reset rank





Focus On

Summary over Nicus	
Nicus	19
Nicus not included	0
Patients	1414
Patients Not included	0
Mean	52.63
STD deviation	22.48
Maximum	94
Upper Quartile	57
Median	43
Lower quartile	36
Minimum	24
Context count	-

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Secure https://www.enewborn.org/international/modules/neonat/index.php?op=benchmark

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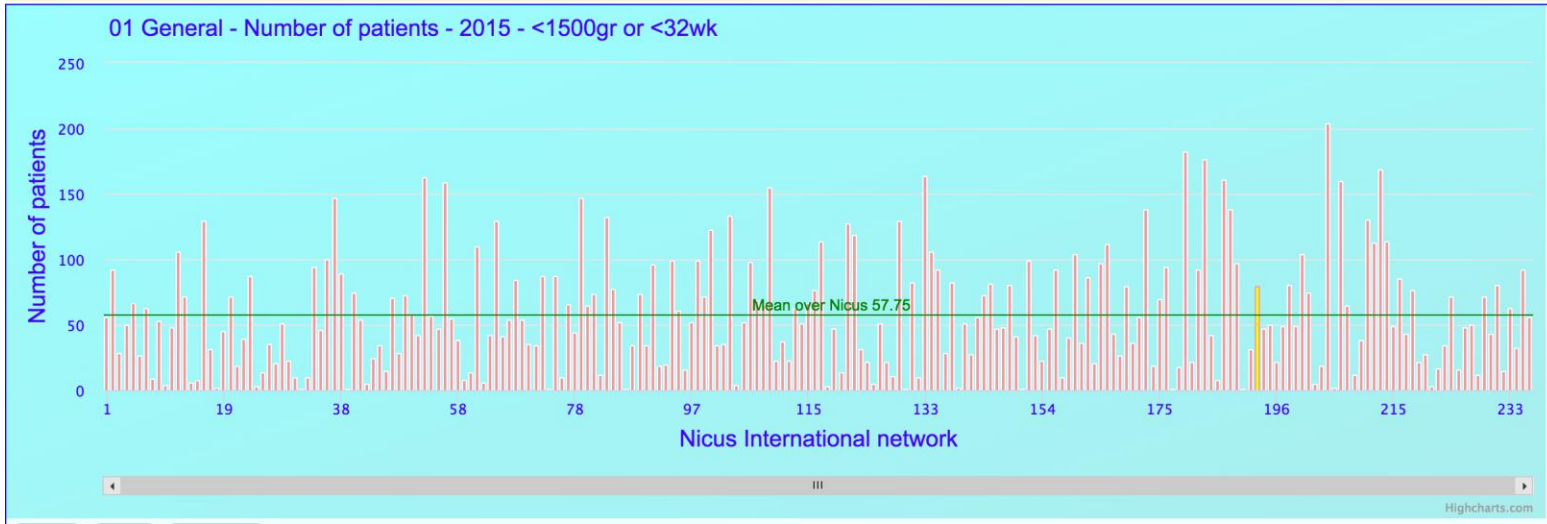
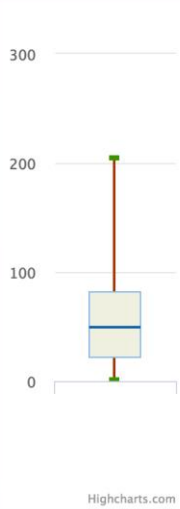
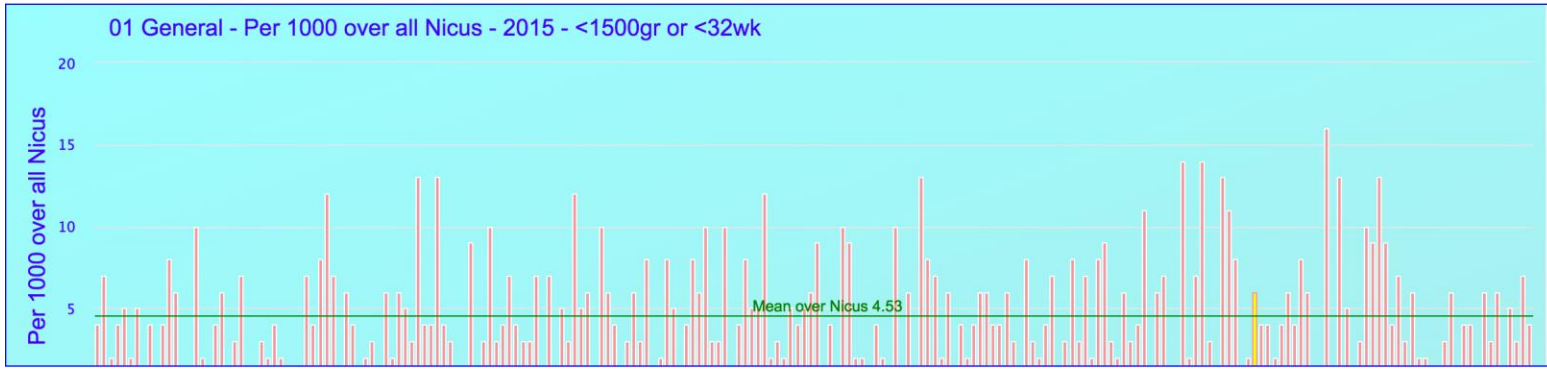


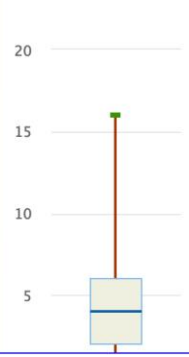


Focus On

Summary over Nicus	
Nicus	220
Nicus not included	0
Patients	12706
Patients Not included	0
Mean	57.75
STD deviation	43.42
Maximum	204
Upper Quartile	82
Median	49
Lower quartile	22
Minimum	1
Context count	-
Global count	-
Global percent	-

Zoom + Zoom - Reset zoom Rank Reset rank





Focus On

Summary over Nicus	
Nicus	220
Nicus not included	0
Patients	12706
Patients Not included	0
Mean	4.53
STD deviation	3.45
Maximum	16
Upper Quartile	6
Median	4
Lower quartile	2
Minimum	0
Context count	-

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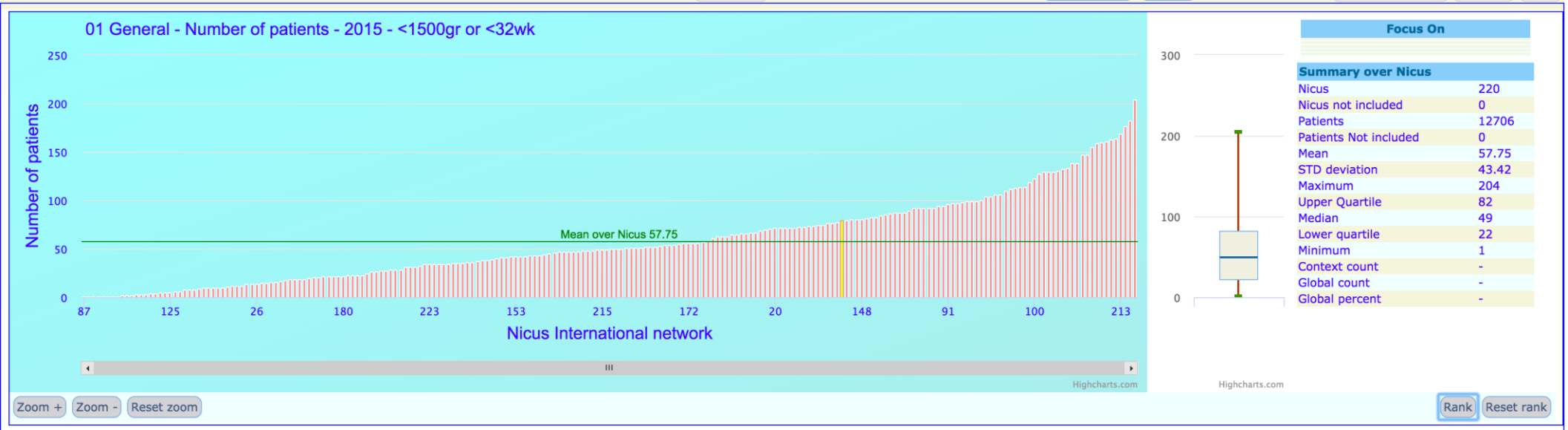

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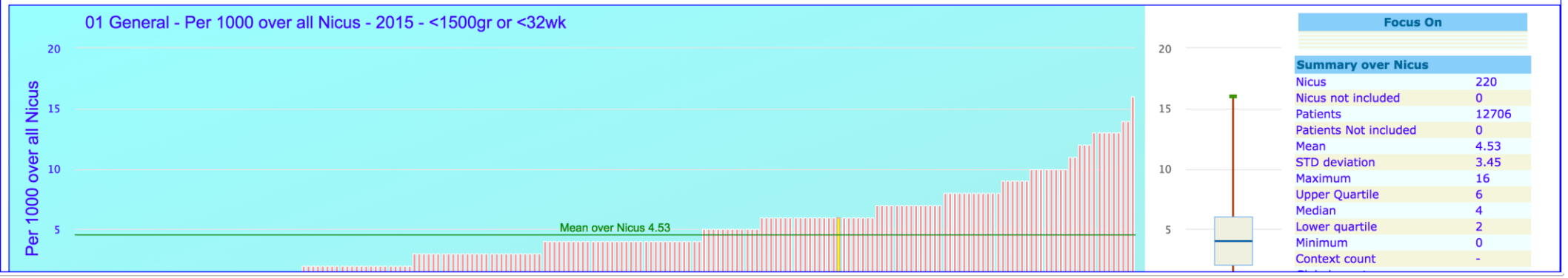

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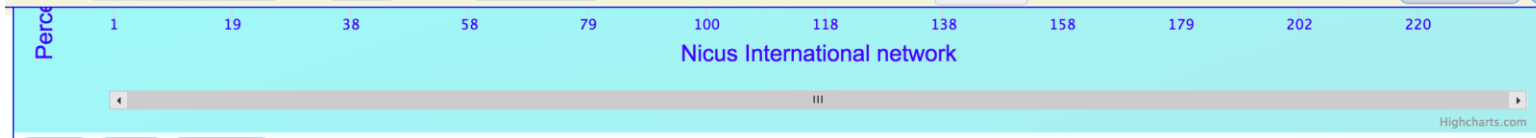
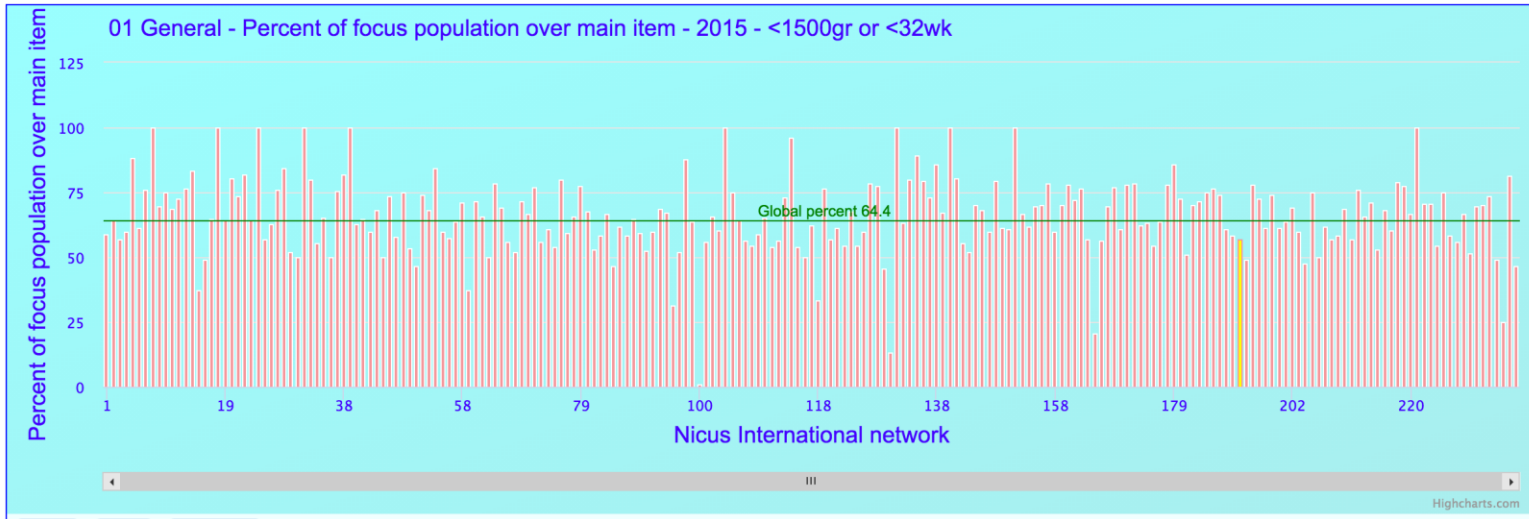
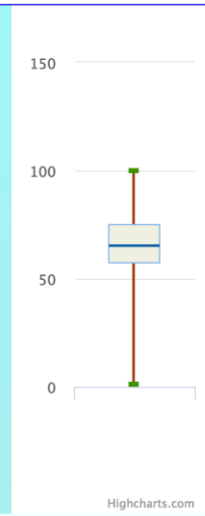


Global percent	100

Zoom + | Zoom - | Reset zoom Rank | Reset rank

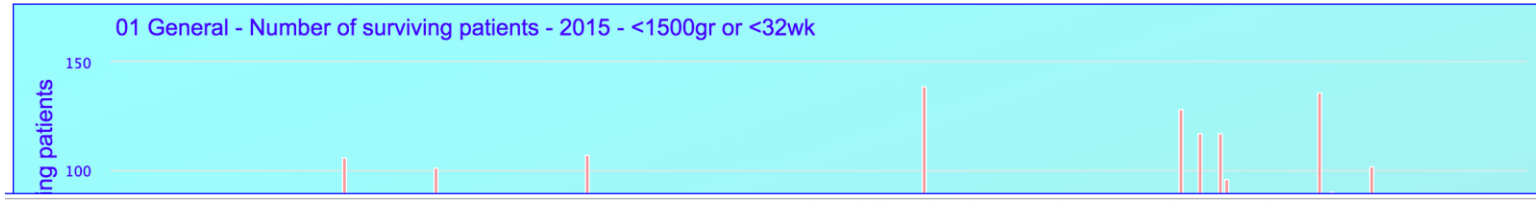


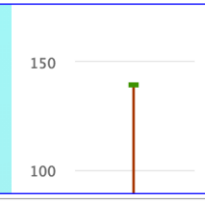


Focus On
Caesarean Section (Yes)

Summary over Nicus	
Nicus	215
Nicus not included	0
Patients	8179
Patients Not included	0
Mean	65.84
STD deviation	14.81
Maximum	100
Upper Quartile	75
Median	65.2
Lower quartile	57.1
Minimum	0.8
Context count	8179
Global count	12706
Global percent	64.4

Zoom + | Zoom - | Reset zoom Rank | Reset rank





Focus On
Caesarean Section (Yes)

Summary over Nicus	
Nicus	215
Nicus not included	0
Patients	8179
Patients Not included	0

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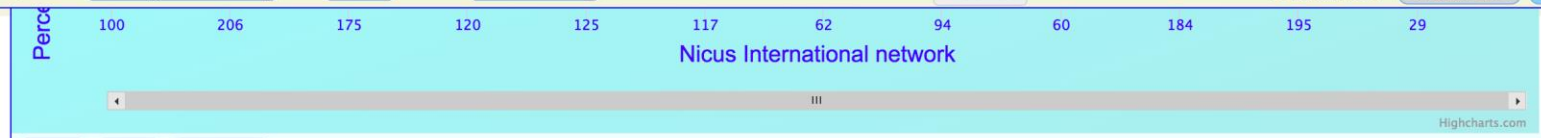
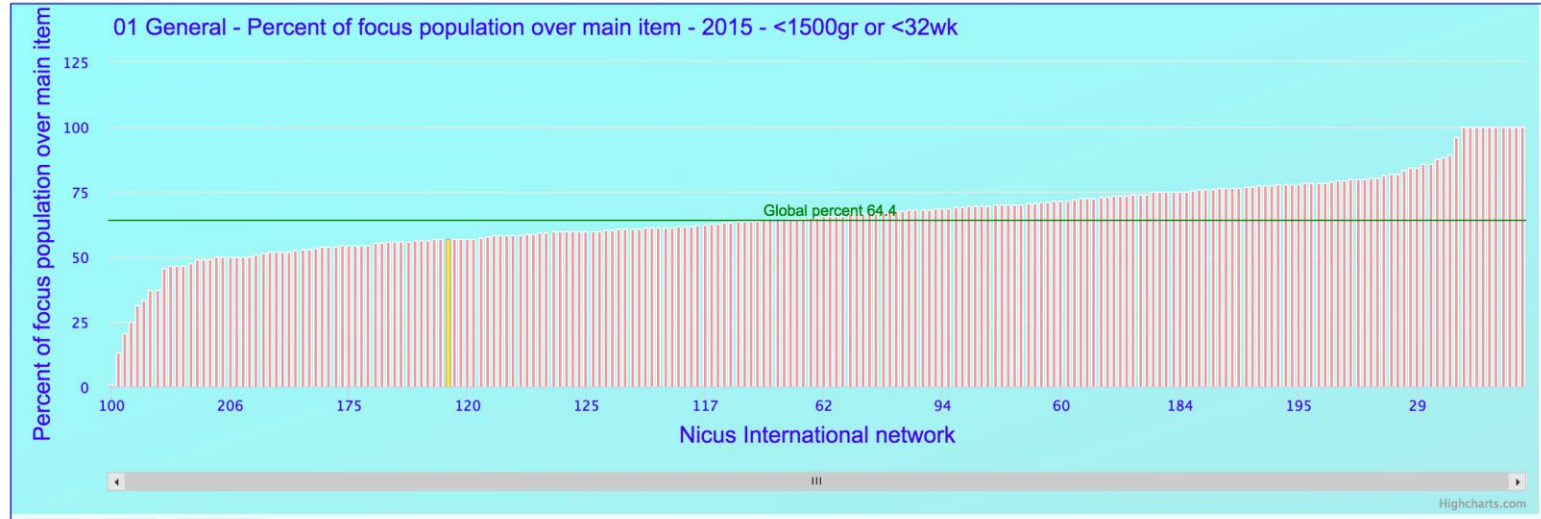
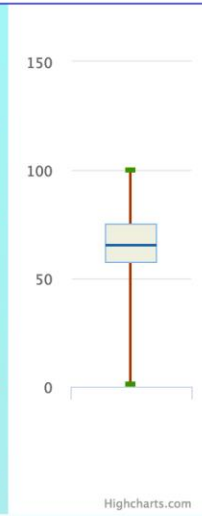


Global percent	100

Zoom + | Zoom - | Reset zoom Rank | Reset rank





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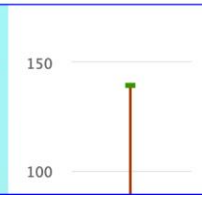

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Patients Not included	0

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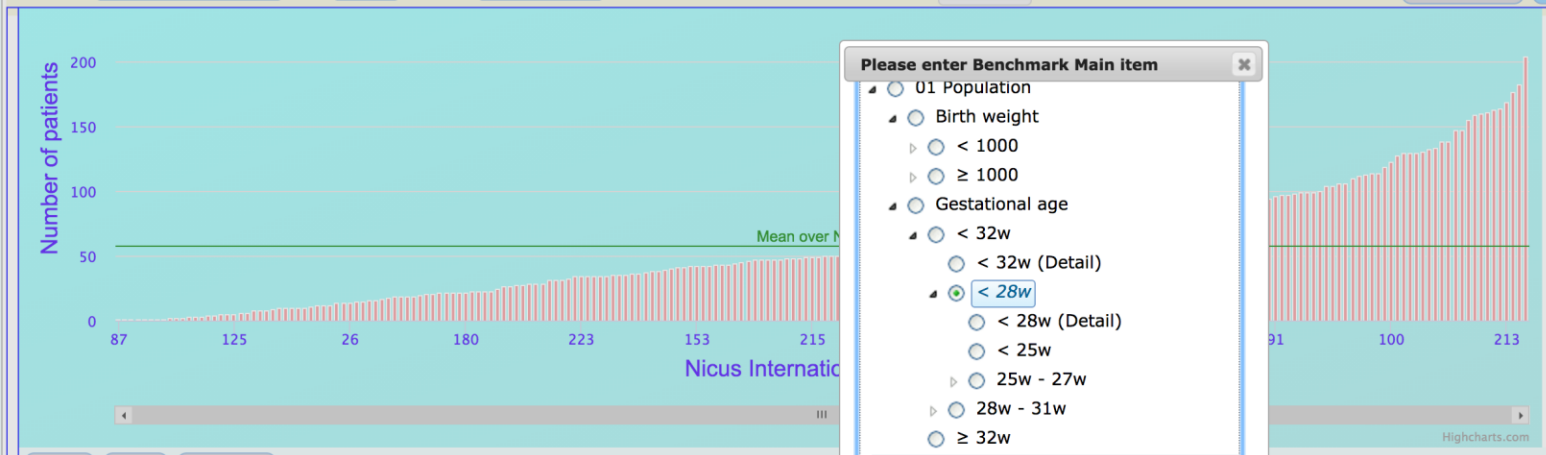
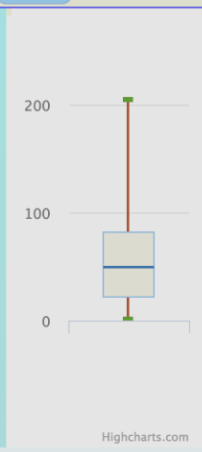
Population: <1500gr or <32wk | Year: 2015 | Network: International | Favorite | Benchmark on: Displayed Nicu | All Nicus | Change Main Item | Focus on | Reset





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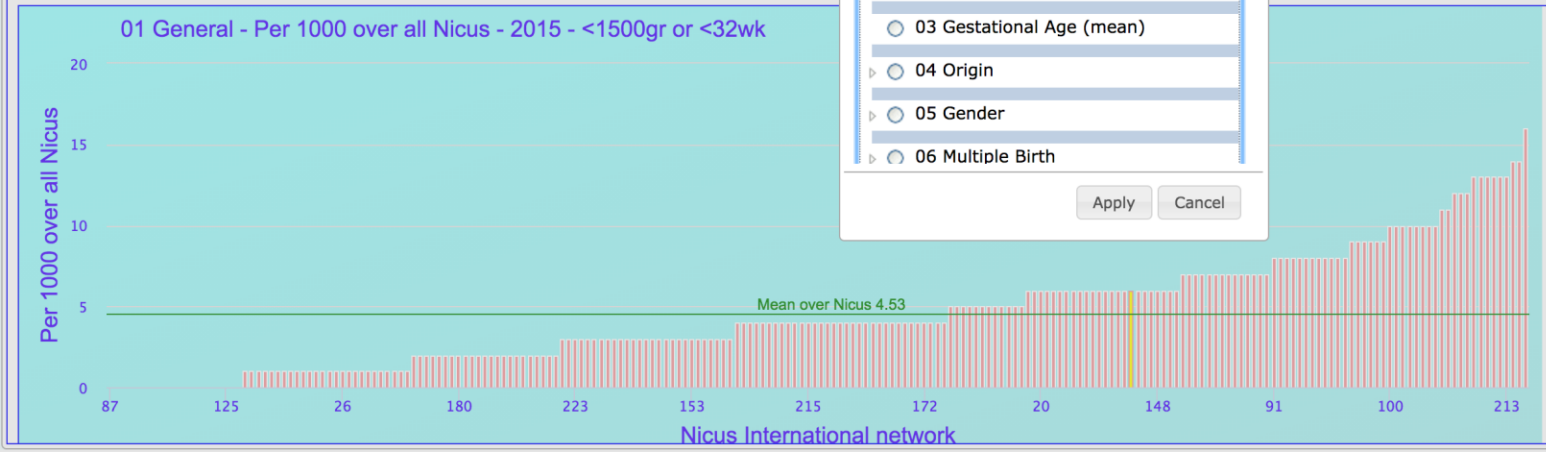
Global count	-
Global percent	-

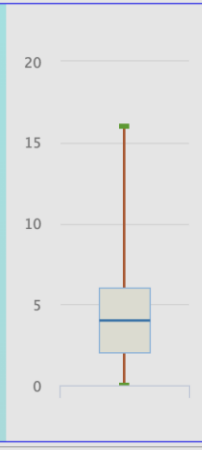
Zoom + | Zoom - | Reset zoom | Rank | Reset rank

Please enter Benchmark Main item

- 01 Population
  - Birth weight
    - < 1000
    - ≥ 1000
  - Gestational age
    - < 32w
      - < 32w (Detail)
      - < 28w
        - < 28w (Detail)
        - < 25w
        - 25w - 27w
      - 28w - 31w
    - ≥ 32w
- 02 Birth Weight (mean)
- 03 Gestational Age (mean)
- 04 Origin
- 05 Gender
- 06 Multiple Birth

Apply | Cancel





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Global count	-
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Secure https://www.enewborn.org/international/modules/neonat/index.php?op=benchmark

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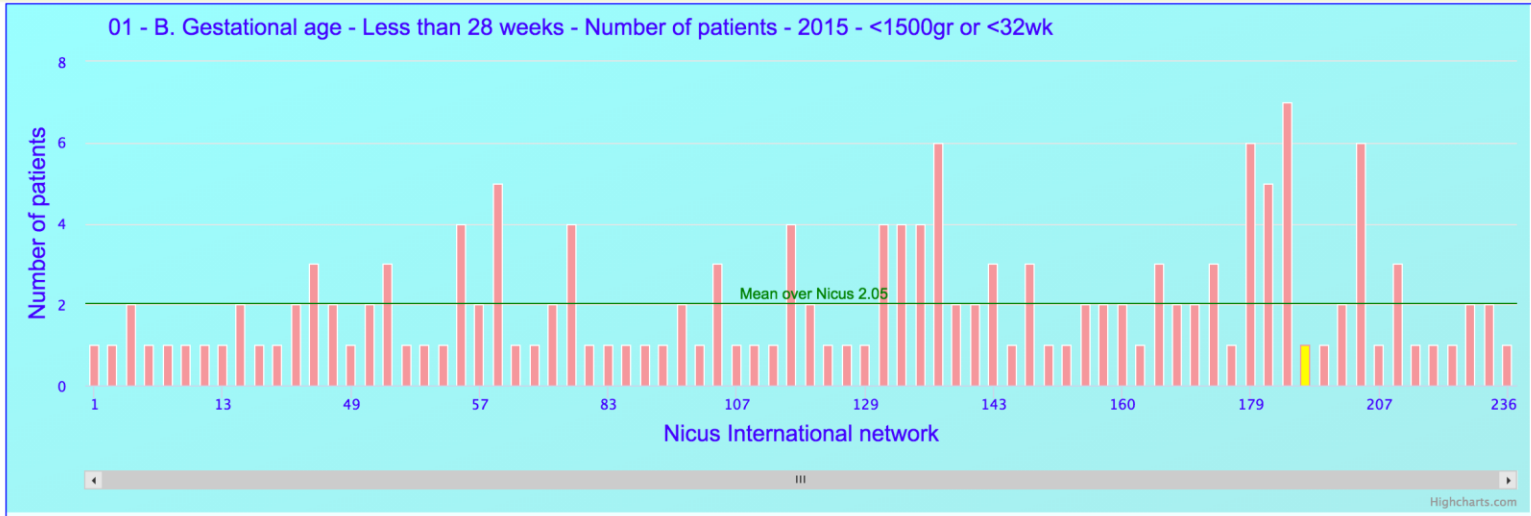
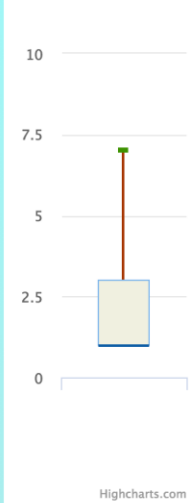
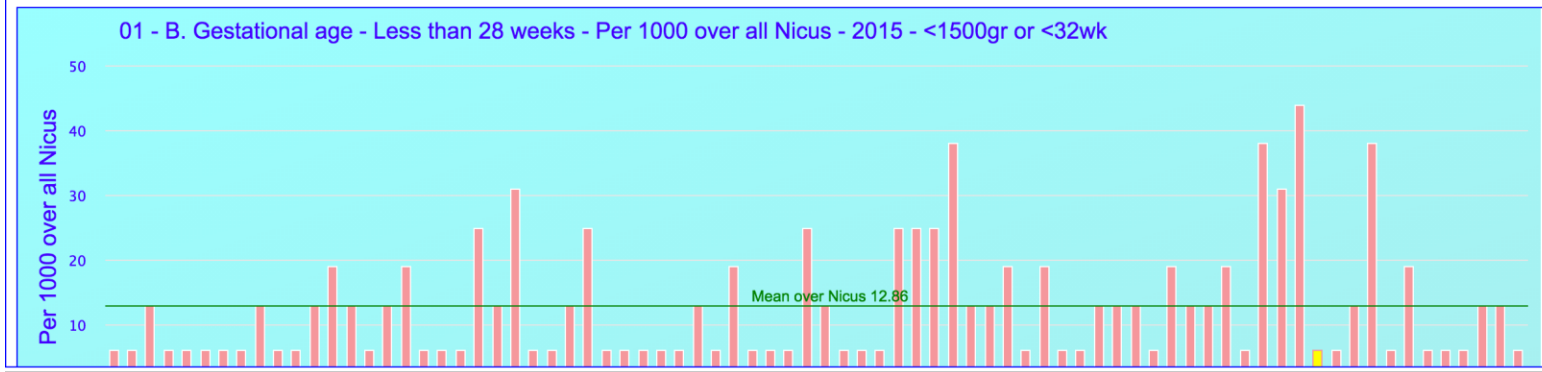


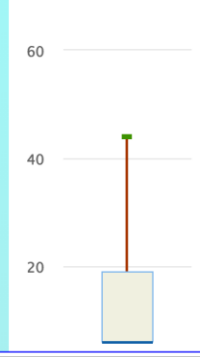


Focus On
Origin - Inborn
No multiple birth
Caesarean Section (No)
Surfactant (No)

Summary over Nicus	
Nicus	78
Nicus not included	0
Patients	160
Patients Not included	0
Mean	2.05
STD deviation	1.45
Maximum	7
Upper Quartile	3
Median	1
Lower quartile	1
Minimum	1
Context count	-
Global count	-
Global percent	-

Zoom + Zoom - Reset zoom Rank Reset rank





Focus On
Origin - Inborn
No multiple birth
Caesarean Section (No)
Surfactant (No)

Summary over Nicus	
Nicus	78
Nicus not included	0
Patients	160
Patients Not included	0
Mean	12.86
STD deviation	9.22
Maximum	44
Upper Quartile	19
Median	6

Nosocomial infections in preterm infants

- Vulnerabilty of preterm infants

  < immaturity immune system
  < fragile skin barrier
  < contact with invasive devices
  < contact with multiple caregivers

- Nosocomial infections: high prevalence in intensive care units

Sohn A, Garrett D, Sinkowitz-Cochran R, et al. J Pediatr 2001

- increased lenght of stay
- increased risk for mortality, cerebral palsy and developmental disorders
- Increase of costs

Stoll B, Hansen N, Adams-Chapman I, and al. JAMA 2004

What is the aim of creating a neonatal network for the surveillance of NI

- To identify risk factors for NI in preterm infants
- To monitor the pathogens and their resistance to AB
- To benchmark infection rates and identifying units with better practices
- Platform for observation of intervention measures
- Material for scientific studies

NEO KISS

Journal of Hospital Infection (2004) 57, 126-131

Available online at www.sciencedirect.com

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Development of a surveillance system for nosocomial infections: the component for neonatal intensive care units in Germany

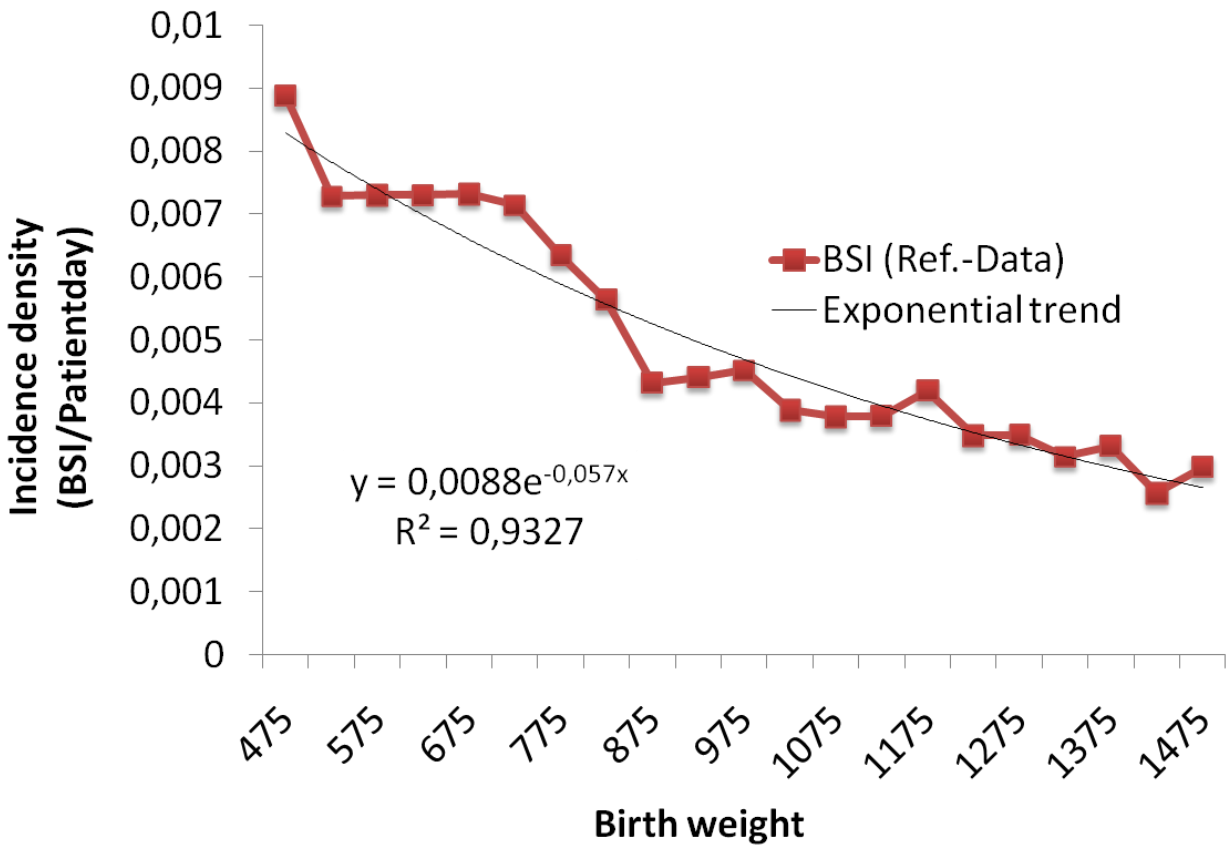
P. Gastmeier[a,*], C. Geffers[b], F. Schwab[b], J. Fitzner[b], M. Obladen[c], H. Rüden[b]

Krankenhaus-Infecktions-Surveillance-System >2000

	NNIS/NHSN	NEO-KISS
Definitions	CDC definitions (children < 1 year)	Modified CDC definitions (for neonates only)
Endpoints	CVC-BSI VAP	**BSI** (CVC-, PVC-, non device-associated) **Pneumonia** (Tube-, CPAP-, non device-associated) **NEC**
Collection of device days	Unit-based (summarized for the unit)	Patient based (for each individual patient)
Birth weight groups	< 750g; 751-1000g 1001-1500g 1501-2500g; >2500g	< 500g 500-999g 1000-1499g
Data entry/analysis	Webbased	webbased

Standardized infection rate

When the database has grown…….



Standardized Infection Rate (SIR)

- Determin number of **expected infections** in a given unit according:
  - Reference data (risk of infection/infant/day for each birthweight)
  - composition of the population of the unit
- Standardized Infection Rate =
  nb infections observed / total nb expected infections

Si ≤ 1 ☺

Si > 1 ☹

Risk/patient/day according BW X nb patient days

			Number of BSI	
Patient no.	Birth weight	Patient days	observed	expected
1	665	81	1	0.540
2	889	40	0	0.207
3	1165	20	0	0.075
4	1436	25	1	0.069
5	748	45	0	0.273
6	650	78	2	0.529
7	887	55	0	0.285
8	1345	12	0	0.037
9	1212	25	0	0.089
10	770	48	0	0.284
11	680	64	1	0.419
Sum			5	2.807
Standardised infection ratio (SIR)			**5 : 2.807 = 1.782**	

More than ½ of infections not explained by BW

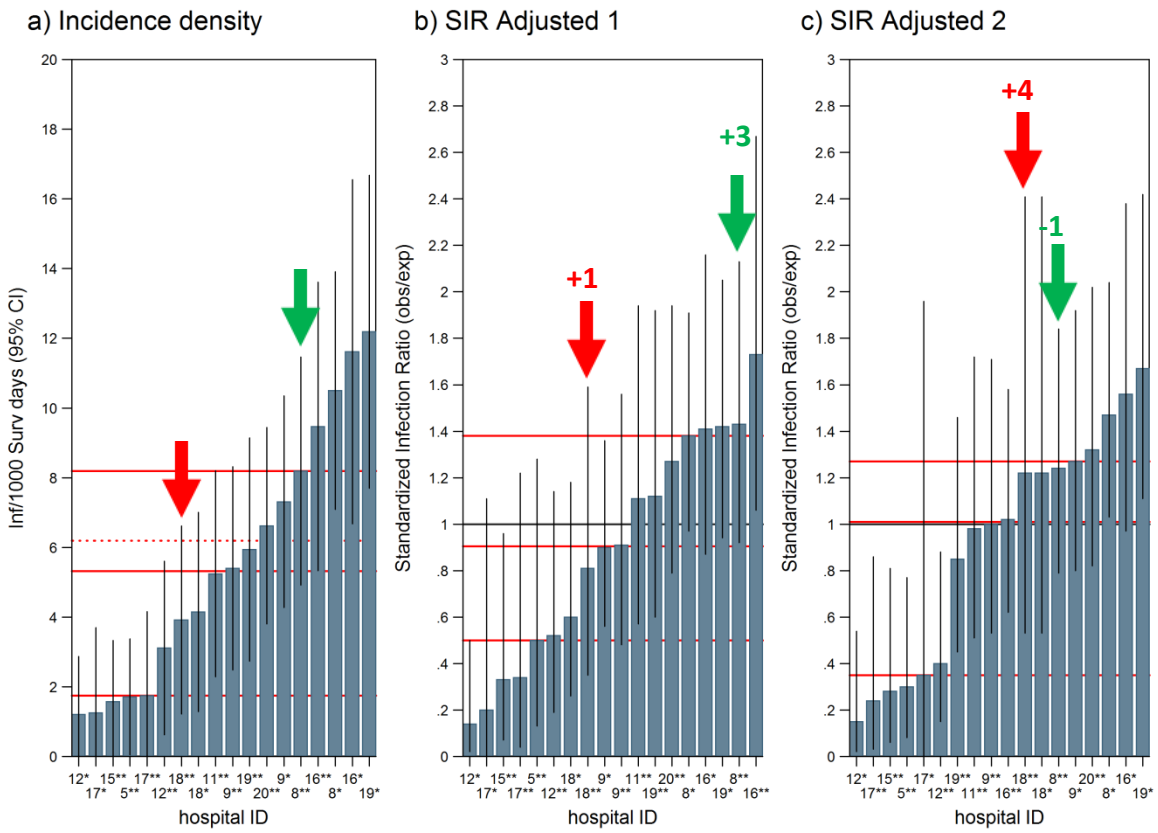
NEO KISS.be

	2011	2012	1st	2nd
Incidence of NI (n patients with NI / 100 patients)				
sepsis	23,6	15,4	26,9	23,2
pneumonia	5,4	3,7	4,5	3,2
Incidence densities (n NI / 1000 patient-days)				
sepsis	8,1	4,68	8,3	7,1
pneumonia	1,67	1,39	1,2	0,8
Device associated infection rates (n NI / 1000 device-days)				
sepsis-CVC	12,98	7,35	13,8	14
sepsis-pVC	5,76	4,56	10,4	8,5
pneumonia-TET	6,31	4,46	3	2,5
pneumonia-CPAP	1,28	1,63	1,6	1,2

Germany : first 2 years of participation of 34 units

Reducing neonatal nosocomial bloodstream infections through participation in a national surveillance system.
Schab, Geffers, Barwolff, Ruden, Gastmeier. *Journal of Hospital Infection* 2007

Standardized Infection Ratio: Bloodstream Infection



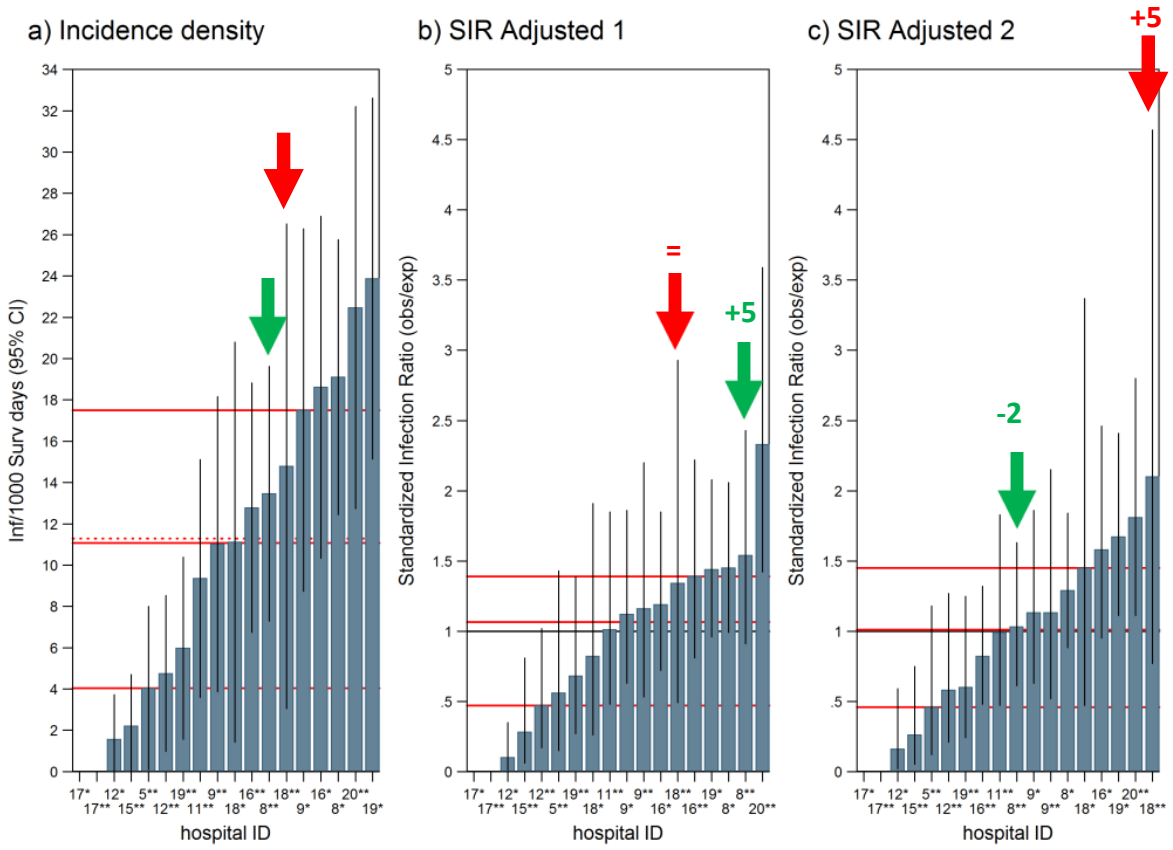
LEGEND: Adjusted 1=only adjusted for birth weight; Adjusted 2=adjusted via multivariate model including indicated covariates; *=2011, **=2012; solid red lines= p25/50/75 percentiles of national distribution; dashed red line= national aggregated mean; solid black line= SIR 1; Vertical black lines= 95% confidence interval of unit incidence or SIR; taken from Neokiss BE report "Standardized Infection Ratio calculation 2011+2012 vs 20140206"

Bloodstream Infection:

Risk factors in SIR Adj 2 model:

- Day on NICU,
- BW,
- CVC use,
- PVC use,
- INT use,
- CPAP use

SIR: Catheter-associated BSI



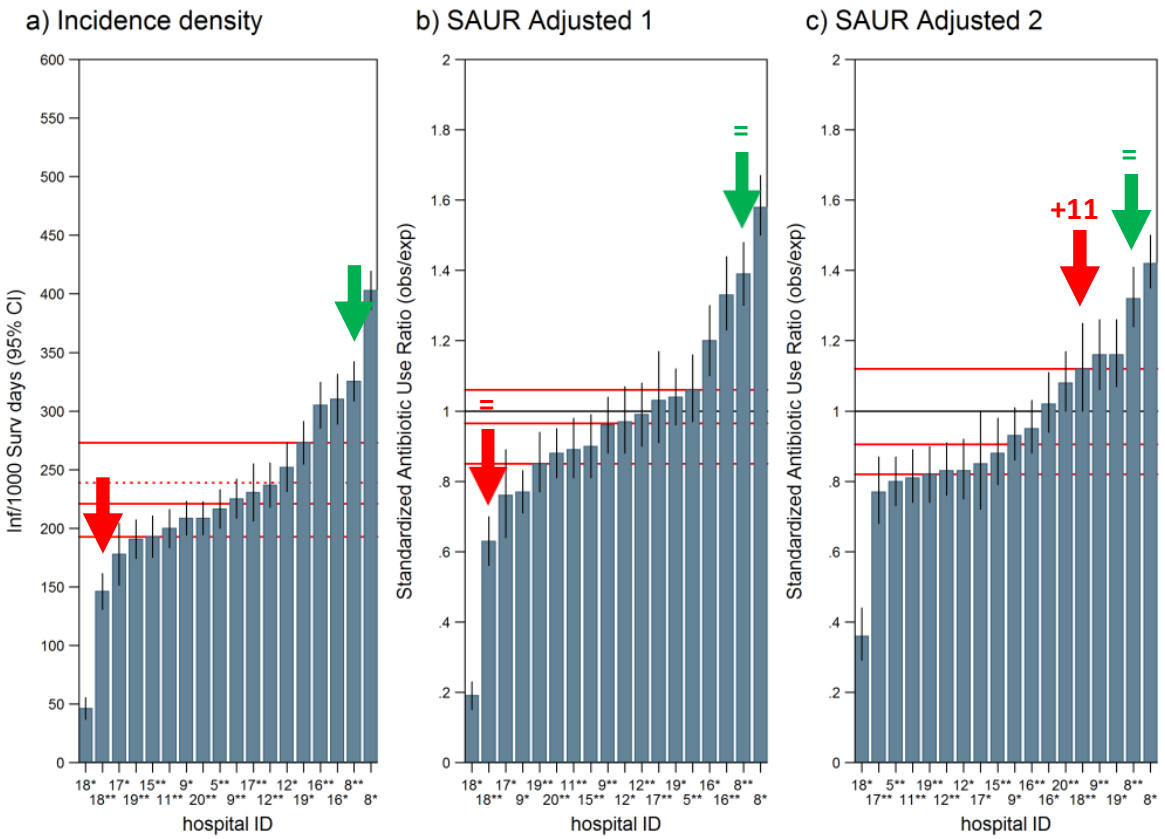
LEGEND: Adjusted 1=only adjusted for birth weight; Adjusted 2=adjusted via multivariate model including indicated covariates; *=2011, **=2012; solid red lines= p25/50/75 percentiles of national distribution; dashed red line= national aggregated mean; solid black line= SIR 1; Vertical black lines= 95% confidence interval of unit incidence or SIR; taken from Neokiss BE report "Standardized Infection Ratio calculation 2011+2012 vs 20140206"

Catheter-associated BSI:

Risk factors in SIR Adj 2 model:

- Day on NICU,
- PVC use,
- INT use,
- CPAP use

Standardized Antibiotic Use Ratio



LEGEND: Adjusted 1=only adjusted for birth weight; Adjusted 2=adjusted via multivariate model including indicated covariates; *=2011, **=2012; solid red lines= p25/50/75 percentiles of national distribution; dashed red line= national aggregated mean; solid black line= SIR 1; Vertical black lines= 95% confidence interval of unit incidence or SIR; taken from Neokiss BE report "Standardized Infection Ratio calculation 2011+2012 vs 20140206"

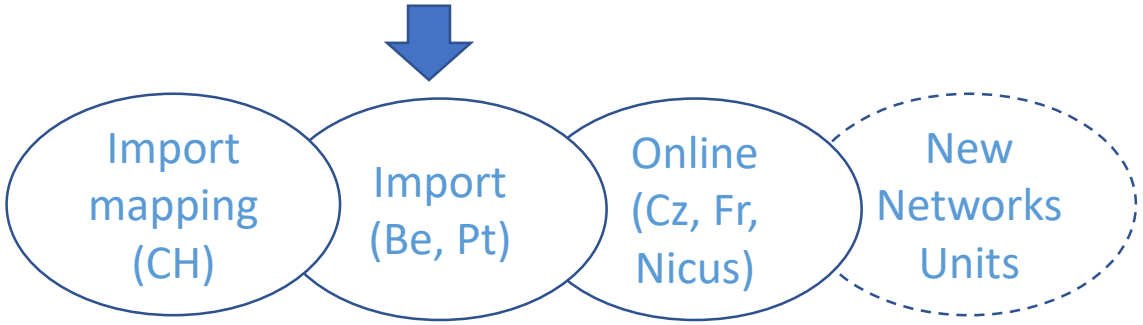
SIR concept applied to Antibiotic use:

Risk factors in SAUR Adj 1 model:

- BW,
- gender,
- CVC use,
- PVC use,
- INT use

The eNewborn Network RWD/RWE

Electronic Health Record (EHR), National databases, On line data entry



NNRD (UK)

Real Word Data

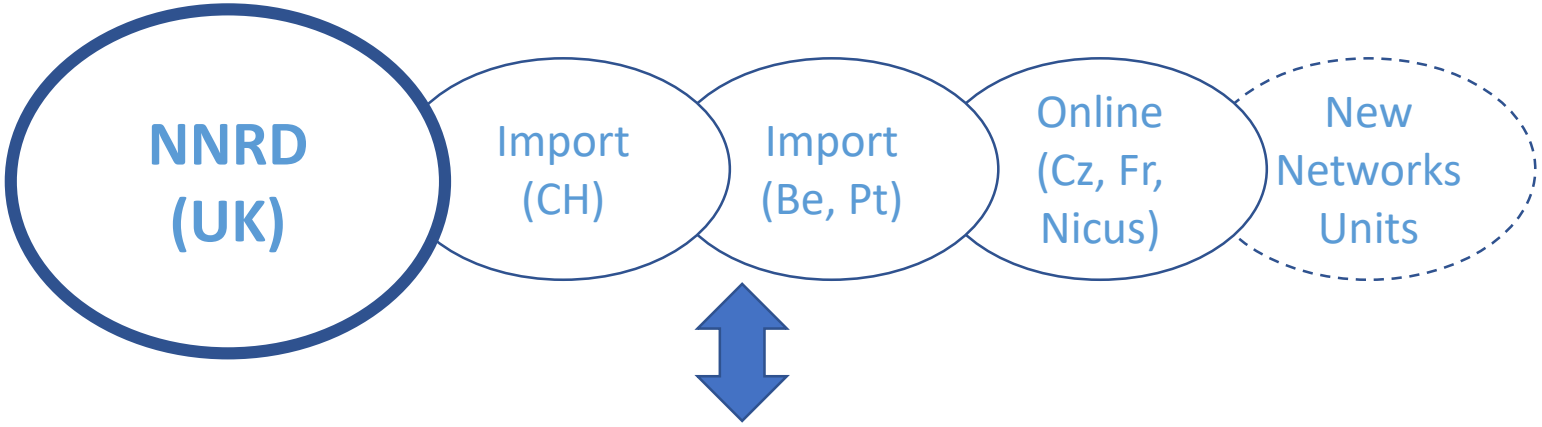
eNewborn dataset for Quality Improvement

Real Word Evidence

- Online interactive benchmarking and reporting at different network levels
- Background information.

eNewborn Network → eNewborn Sciences

RWD/RWE RESEARCH



Real World Evidence

- **Benchmarking**
- **Background information of certain diseases**

Topic experts- Network leads-International Research Units

eNewborn Real World Research Data
Implementation of Research Items in the Platform
Extract Data and Exchange with Research Groups

→

Real World Evidence

- **Innovative Study Results**
- **Fast Response**

Our Vision: eNewborn Sciences

Opportunities:

- Strong existing network and already > 50.000 VLBWI in a common platform
- Deliver RWD and RWE with a flexible platform
- Benchmarking, quality control, RESEARCH

Our Vision: eNewborn Sciences

Challenges:

- Widen the legal basis
- Register new countries
- Strengthen governance and access contracts
- Improve visibility

eNewborn 2014-2016
40.000 patients

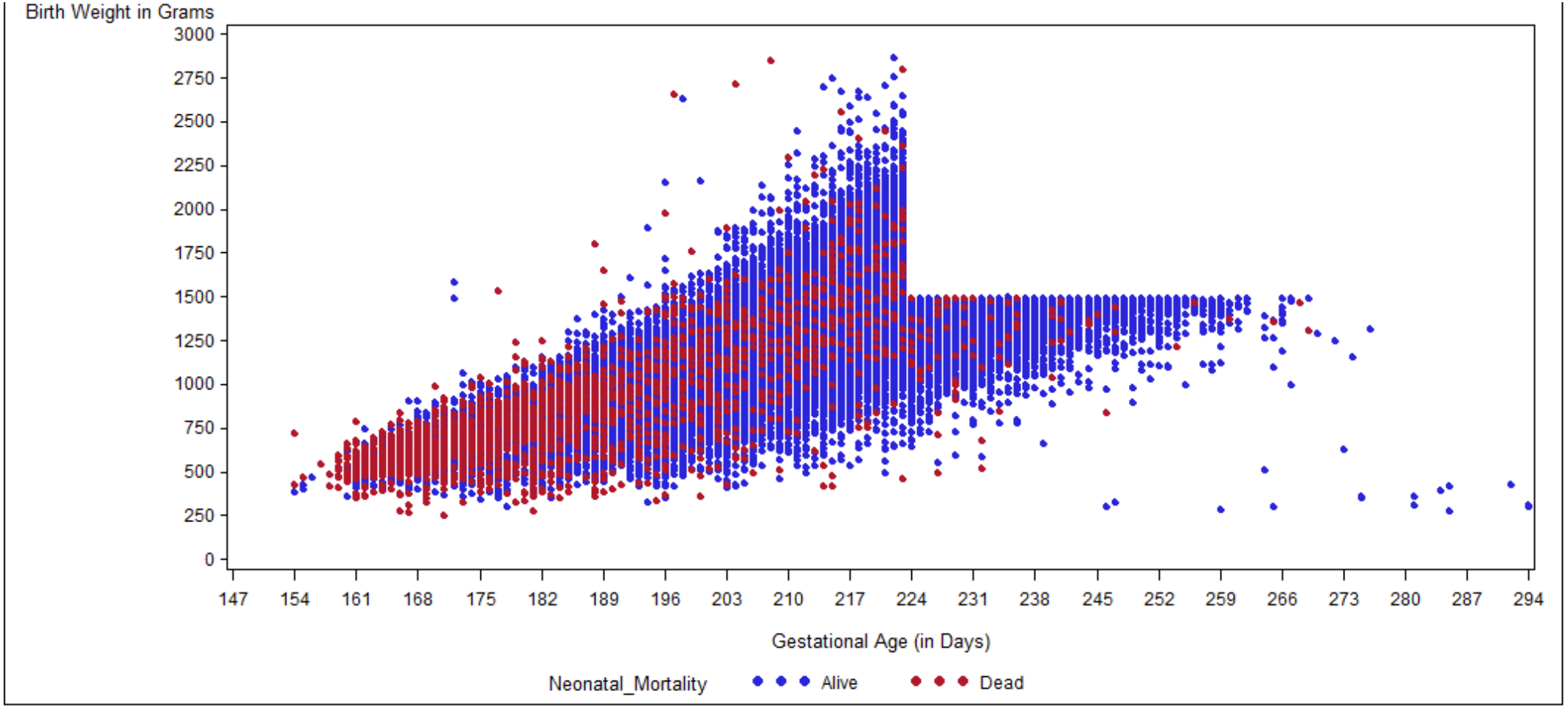
Delivery Room Management and Outcome in Preterm Infants

Dominique Haumont, Ola D Saugstad, Neena Modi, Rosine Antetere, Cuong NguyenBa,
Mark Turner, Kate Costeloe and Willem H Aelvoet

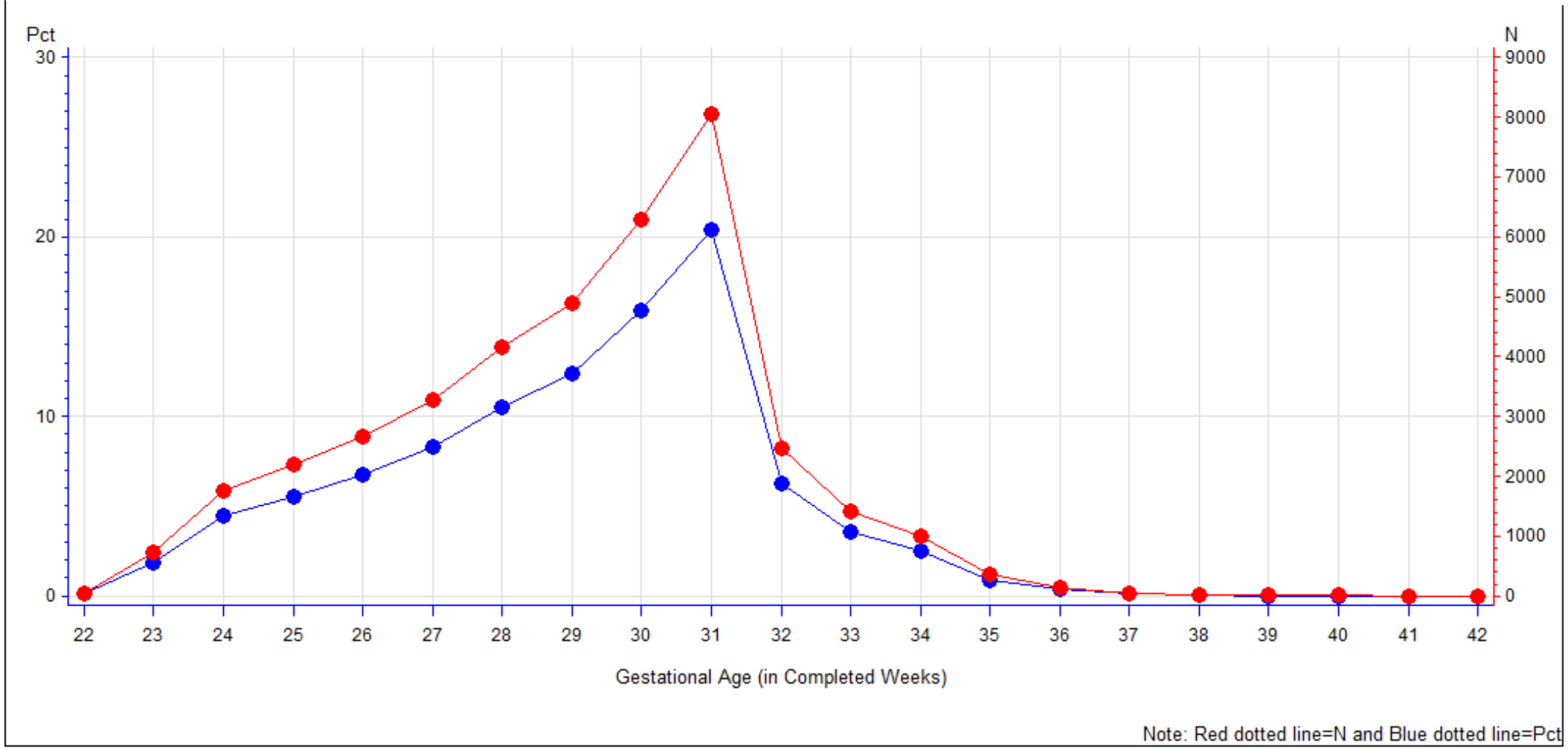
Neonatal Mortality by Gender. Gestational Age and Birth Weight

Boys	GA	Birth weight												Total	
		250-499g		500-749g		750-999g		1000-1249g		1250-1499g		1500+g			
		%	N	%	N	%	N	%	N	%	N	%	N	%	N
		%	N	%	N	%	N	%	N	%	N	%	N	%	N
	22	63	8	77	13	.	0	.	0	.	0	.	0	71	21
	23	67	39	44	342	36	11	.	0	.	0	.	0	46	392
	24	38	26	34	678	26	218	0	3	.	0	.	2	32	927
	25	52	25	22	306	18	811	37	27	.	0	.	0	20	1169
	26	45	20	12	219	11	868	11	301	0	7	0	1	12	1416
	27	8	13	10	182	6	609	4	888	5	103	25	4	5	1799
	28	25	4	6	163	5	475	4	961	5	585	7	54	5	2242
	29	25	4	13	72	3	325	3	676	3	1134	3	409	3	2620
	30	100	2	9	22	1	239	3	573	2	1220	2	1405	2	3461
	31	0	0	0	9	4	102	1	429	1	962	1	2858	1	4360
	32+	0	6	29	7	4	68	2	477	1	1817	.	0	2	2375
	Total	46	147	26	2013	10	3726	4	4335	2	5828	2	4733	6	20782
Girls															
	22	50	12	56	9	.	0	.	0	.	0	.	0	52	21
	23	39	57	43	284	100	3	.	0	.	0	.	0	43	344
	24	36	45	25	690	19	89	100	1	0	1	.	0	25	826
	25	37	49	16	511	11	449	40	5	.	0	50	2	15	1016
	26	38	39	11	265	9	804	7	136	0	3	100	1	10	1248
	27	42	19	11	218	6	658	4	536	11	38	0	2	6	1471
	28	20	10	11	177	4	541	4	850	3	312	17	24	4	1914
	29	13	8	4	73	4	388	3	812	2	812	3	175	3	2268
	30	50	2	4	45	1	223	2	678	1	1143	2	737	2	2828
	31	100	1	0	14	3	127	1	497	2	1115	1	1942	2	3696
	32+	0	8	20	10	2	82	2	638	1	2331	.	0	1	3069
	Total	36	250	20	2296	7	3364	3	4153	1	5755	2	2883	5	18701

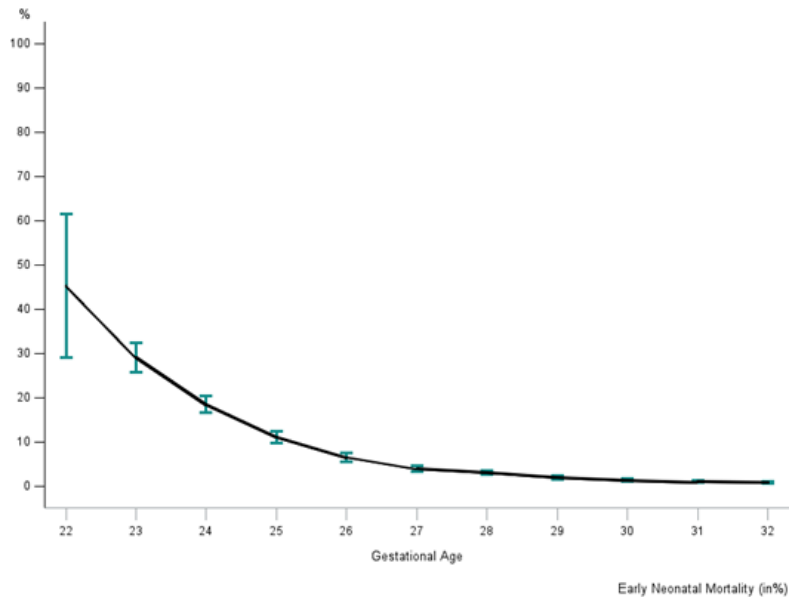
Neonatal Mortality by Gestational Age and Birthweight



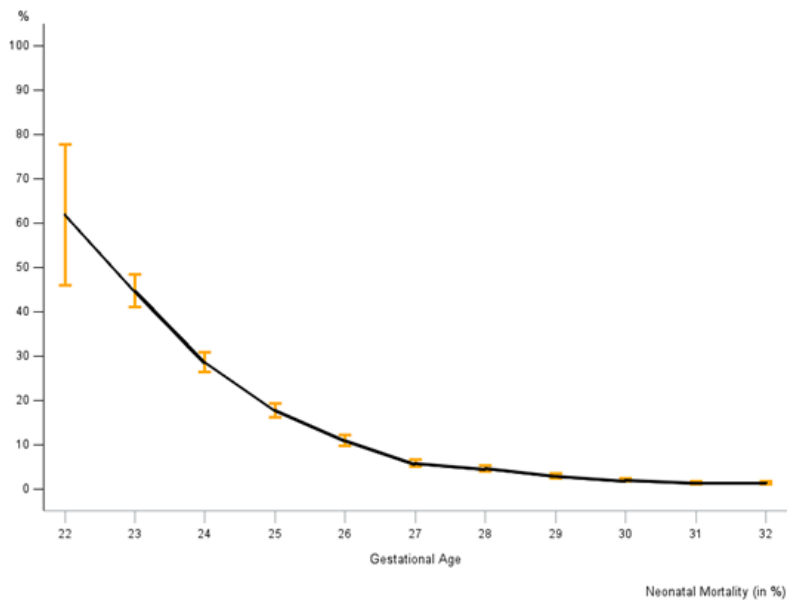
Distribution of the Study Population according Gestational Age



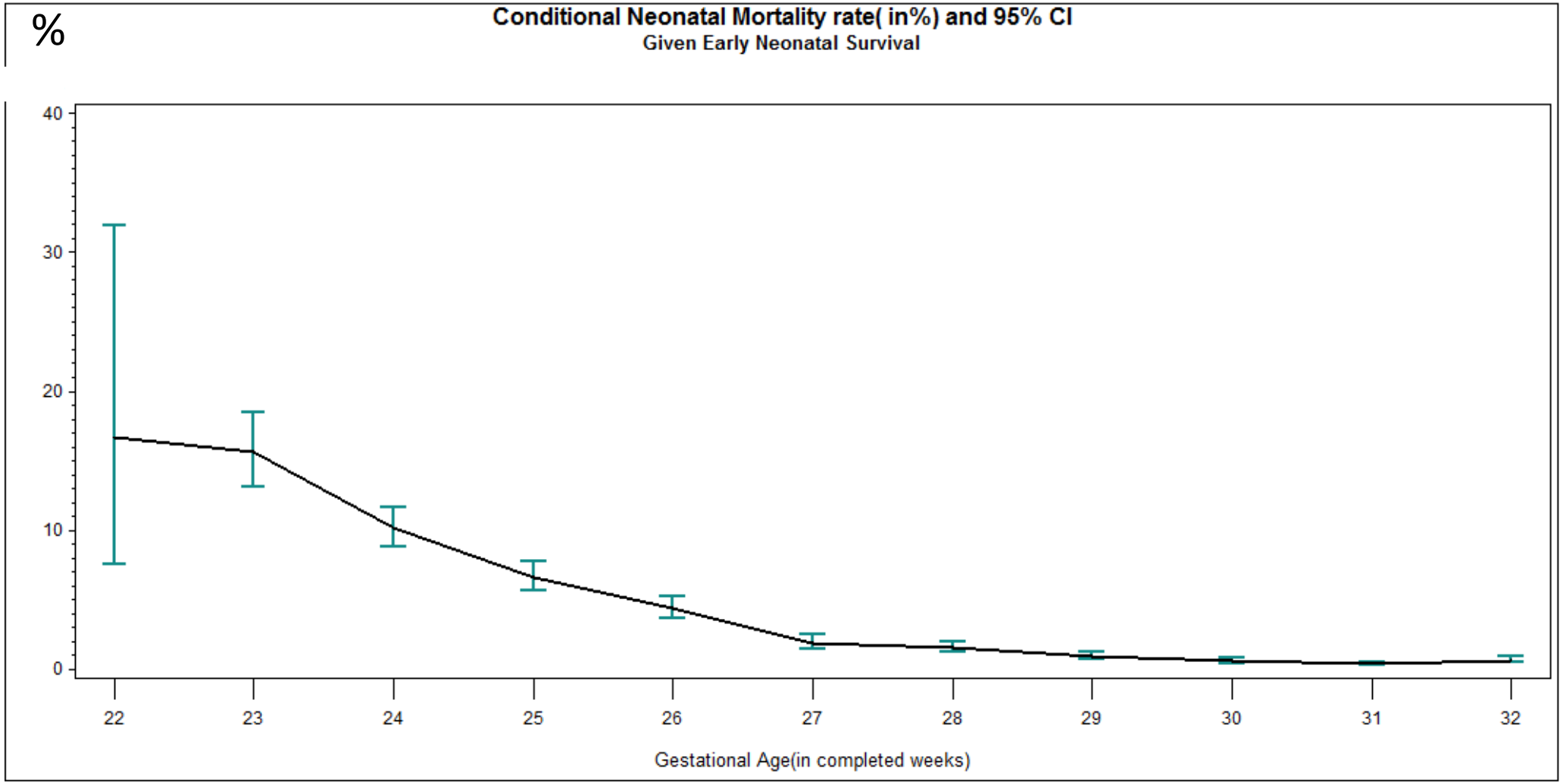
Probability of Dying (95 % CI) by Gestational Age



Early Neonatal Mortality



Neonatal Mortality

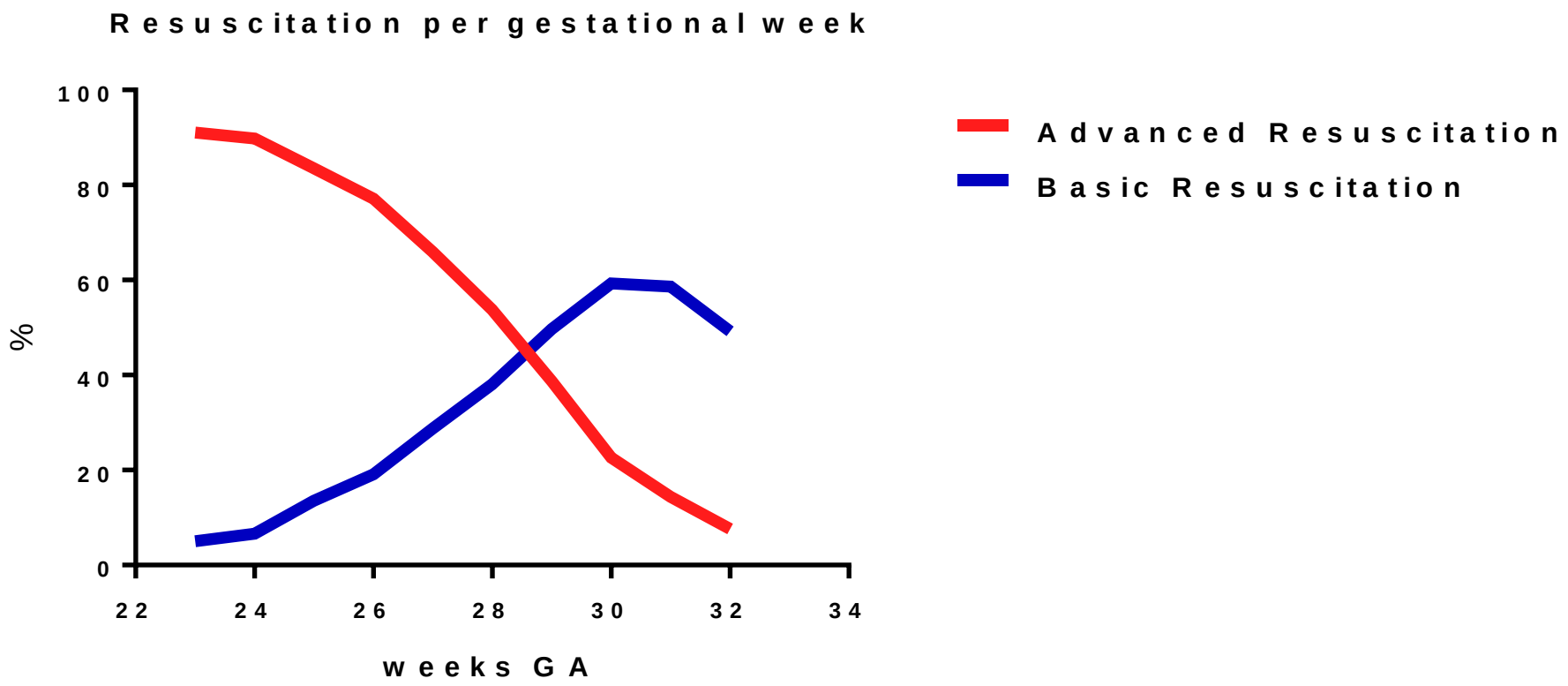

%
Conditional Neonatal Mortality rate(in%) and 95% CI
Given Early Neonatal Survival
40
30
20
10
0
22
23
24
25
26
27
28
29
30
31
32
Gestational Age(in completed weeks)

Odds ratios of Mortality by Delivery room handling, Gestational Age, Birth Weight, Prenatal steroids, Multiple births and Gender

			Early neonatal mortality			Neonatal mortality		
			OR	95%CI		OR	95%CI	
DRH	AdvRes	vs None	2.58	1.91	3.49	2.52	1.98	3.22
DRH	Basic	vs None	0.78	0.57	1.08	0.98	0.76	1.27
Gestational Age	22	vs 31	24.65	10.26	59.23	50.59	21.62	118.36
Gestational Age	23	vs 31	16.33	11.47	23.27	28.02	20.71	37.91
Gestational Age	24	vs 31	10.65	7.68	14.77	16.12	12.25	21.20
Gestational Age	25	vs 31	6.16	4.42	8.60	9.00	6.83	11.86
Gestational Age	26	vs 31	3.56	2.52	5.02	5.24	3.96	6.95
Gestational Age	27	vs 31	2.15	1.50	3.08	2.75	2.04	3.69
Gestational Age	28	vs 31	1.82	1.27	2.60	2.31	1.72	3.10
Gestational Age	29	vs 31	1.40	0.97	2.03	1.68	1.24	2.28
Gestational Age	30	vs 31	1.24	0.85	1.80	1.38	1.02	1.88
Gestational Age	32	vs 31	0.42	0.26	0.69	0.56	0.38	0.82
Birth weight	ESGA	vs AGA	3.03	2.27	4.04	3.33	2.63	4.22
Birth weight	SGA	vs AGA	1.51	1.19	1.93	1.48	1.21	1.81
Prenatal Steroids	None	vs Complete	3.23	2.72	3.84	2.76	2.38	3.19
Prenatal Steroids	Incomplete	vs Complete	1.35	1.15	1.58	1.24	1.09	1.41
Prenatal Steroids	None	vs Incomplete	2.40	1.97	2.92	2.22	1.88	2.63
Multiple Births	Yes	vs No	1.16	1.00	1.34	1.14	1.01	1.28
Gender	Boys	vs Girls	1.17	1.02	1.33	1.20	1.07	1.33

Odds ratios of Early neonatal and Neonatal Mortality by Apgar 1 minute, Gestational Age, Birth Weight (SGA) , Prenatal Steroids, Multiple Birth and Gender

			Early neonatal mortality			Neonatal mortality		
			OR	95%CI		OR	95%CI	
Apgar 1 minute	0-3	vs 7-10	5.34	4.35	6.55	3.41	2.90	4.00
Apgar 1 minute	4-6	vs 7-10	2.42	1.97	2.97	1.86	1.59	2.18
Gestational Age	22	vs 31	22.15	9.03	54.29	43.13	17.35	107.23
Gestational Age	23	vs 31	18.84	13.40	26.49	35.11	25.75	47.86
Gestational Age	24	vs 31	12.99	9.53	17.70	20.96	15.90	27.64
Gestational Age	25	vs 31	7.46	5.44	10.23	11.71	8.86	15.47
Gestational Age	26	vs 31	4.62	3.33	6.41	7.10	5.34	9.43
Gestational Age	27	vs 31	2.64	1.87	3.73	3.52	2.61	4.76
Gestational Age	28	vs 31	2.27	1.61	3.20	2.93	2.17	3.96
Gestational Age	29	vs 31	1.67	1.16	2.40	2.04	1.49	2.80
Gestational Age	30	vs 31	1.27	0.88	1.84	1.46	1.06	2.01
Gestational Age	32	vs 31	0.48	0.29	0.77	0.60	0.40	0.88
Birth weight	ESGA	vs AGA	2.88	2.18	3.82	3.24	2.54	4.14
Birth weight	SGA	vs AGA	1.43	1.12	1.82	1.44	1.17	1.77
Prenatal Steroids	None	vs Complete	2.94	2.47	3.51	2.56	2.19	3.00
Prenatal Steroids	Incomplete	vs Complete	1.24	1.06	1.45	1.15	1.01	1.32
Prenatal Steroids	None	vs Incomplete	2.37	1.94	2.89	2.22	1.86	2.66
Multiple Births	Yes	vs No	1.27	1.10	1.47	1.22	1.08	1.38
Gender	Boys	vs Girls	1.19	1.04	1.36	1.20	1.07	1.34


Resuscitation per gestational week
100
80
60
40
20
0
%
22
24
26
28
30
32
34
weeks GA
Advanced Resuscitation
Basic Resuscitation

Conclusions

What has been achieved?

- European Evaluation Programme and Benchmarking Platform
- Easy access with on line or mapped uploaded data
- Close to population based database
- Most important European database on preterm infants

How did it happen?

- Original IT architecture
- Common vision of the scientific committee and network leads

Conclusions

eNewborn Objectives

- To secure perennity, sustainability and governance
- To prioritize new regulations, legal issues, security and GDPR compliance
- To consolidate contacts with our participants
- To increase participation
- To monitor quality of care
- To enter new research strategies of research with new technology
- To enclose parents in the vision of the network
- To step in the new area of real world and big data
- To become a major partner in neonatal health care actors

Conclusions

How to reach these goals

- Structure the organisation under an academic umbrella
- Consolidate the funding model: grants, partnership with pharma, research studies, public health, quality control, scientific societies ….

YOUR SUPPORT : DATA SHARING!

eNewborn

https://www.enewborn.org

Thank You