The Norwegian Neonatal Network

«Norsk Nyfødtmedisinsk Kvalitetsregister»

Outline:

Purpose

Legal basis

Cooperating parties

Participation

Infrastructure

Basic concept

Activity

Purpose:

Establish a structured, prospective collection of population based data regarding newborn infants health and disease, medical treatment and outcomes of such treatments in short and long term perspective for the use in quality assurance, quality improvement and newborn research.

Approval as national medical quality registry in 2004
-governmental funding

2004 – most Norwegian neonatal units using the same data application – The Neonatal Program
- not linked to a national database yet

Legal basis:

The Norwegian Medical Birth Registry Regulation,
The Filing Systems Act and The Personal Data Act

The Medical Birth Registry and the Norwegian Neonatal Network is basically one registry – different focus

Both registries has approval for collecting personal identifiable data without consent – long term tracking possible

- can exchange and merge data between MBR and NNN without further legal approval

Cooperation:

The Norwegian Pediatric Association – neonatal branch
The Norwegian Institute of Public Health
Oslo University Hospital – Neonatal Department

The Norwegian Institute of Public Health – Data controller
Oslo University Hospital – Data handler

NNN Consultative Board – representatives from cooperating parties and patient organizations

Director of NNN – at Oslo University Hospital, Neonatal Department

Infrastructure:

Web based infrastructure – dot.net application
“Everyone knows Windows” – all hospitals can serve this technology
No additional investments needed
Absolutely no paperwork's

Locally placed databases – full access to own data at any time

Integration with other hospital systems (ie. Partus, Obstetrix)

Monthly bulk transfer of locally registered data to national database

Encrypted data transfer through the Norwegian Health Network

Basic concept: Neo-2015 - «The Neonatal Program»

Entering of patient related treatment and monitoring activity <u>on a daily basis</u>

- ensures data quality
- the activity is entered when performed
- **support** in local quality surveillance and improvement
- **support** in daily activity management

Automated diagnosis and procedure acquisition and registering

- ”Tell me what you do – I’l do the rest”
- important for uniform registrations
- correct diagnostics
- economic implications (if you are in the DRG sphere)

Extensive automated internal algorithms and functionality for validation and correct entering of essential data

- the Neo-2015 coaches the user through the data entering process
- extensive internal data validation

Status – December 2018

20 of 20 neonatal units participating

100 % coverage at institutional level

99 % coverage at individual level

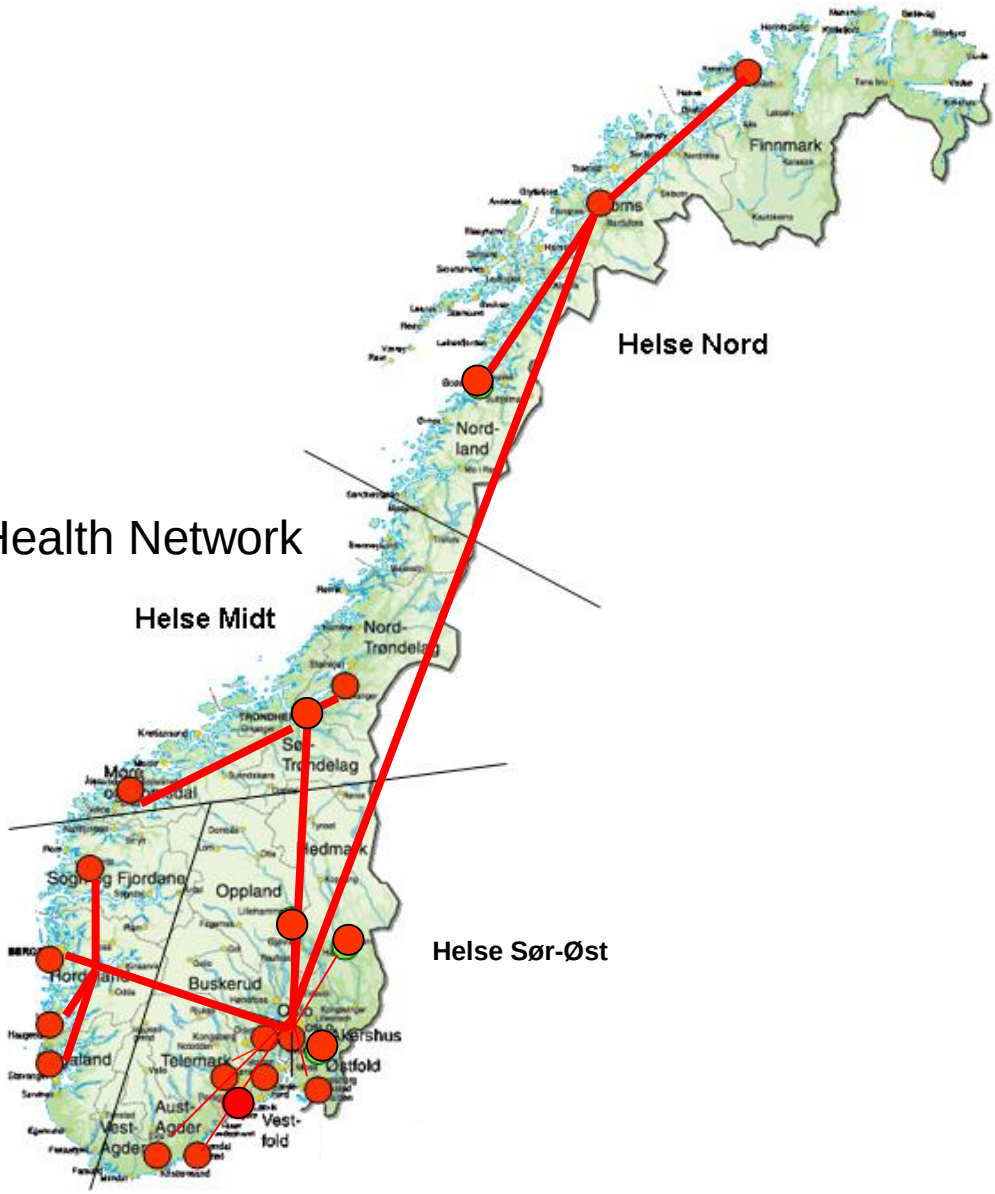
Encrypted data transfer via Norwegian Health Network

Annual registry conferences

Annual reports to participating units

Established research groups

Data for external statistics and research



Structure of the Norwegian Neonatal Network

Local departments – have their own databases




Norwegian Health Network

National database at
Oslo University Hospital

Annual admissions to Norwegian NICU's 2005-2017

Rapporterende sykehus	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014	2015	2016	2017	Totalt
Rikshospitalet	751	717	768	716	711	703	654	681	630	595	690	663	643	9603
Haugesund sjukehus	288	343	278	359	301	403	350	250	240	250	267	327	272	4178
Sykehuset Østfold - Fredrikstad		397	483	507	495	368	353	364	376	310	355	403	408	5183
Ullevål universitetssykehus		776	835	855	746	736	700	751	690	624	698	670	659	9491
Sykehuset Buskerud		328	312	334	290	286	301	387	410	393	452	446	444	4770
Sykehuset Levanger		100	127	163	126	121	138	139	115	121	132	138	125	1684
Ålesund sjukehus		236	266	219	245	257	353	345	379	267	240	269	307	3728
Stavanger universitetssykehus		1	775	600	555	603	604	514	587	453	495	508	446	6655
St. Olavs Hospital			445	531	497	477	544	511	485	460	433	436	428	5758
Førde Sentralsjukehus			93	122	136	124	140	168	156	155	180	186	225	1853
Haukeland universitetssykehus			20	399	460	465	437	472	458	520	525	527	437	5192
Akershus universitetssykehus			484	457	557	550	661	695	601	699	664	678	654	7395
Helse Finnmark Klinikk Hammerfest				74	59	70	61	63	47	50	73	47	63	670
Universitetssykehuset Nord-Norge				365	270	301	334	314	304	224	275	239	256	3196
Nordlandssykehuset HF avd Bodø				175	226	247	231	234	228	232	197	223	225	2452
Sørlandet Sykehus HF, Kristiansand				276	337	387	452	436	431	412	456	439	420	4482
Sørlandet Sykehus HF, Arendal				14	169	151	176	178	165	146	99	0	0	1276
Sykehuset Telemark, Skien				284	265	292	322	291	311	324	289	280	222	3171
Sykehuset Innlandet HF Lillehammer					183	216	199	178	215	223	222	245	242	2101
Sykehuset Innlandet Elverum-Hamar					16	54	147	151	114	115	144	108	140	1140
Sykehuset i Vestfold, Tønsberg							41	132	496	275	232	230	297	1835
Missing				1		3								4
Totalt	1039	2898	4886	6451	6644	6814	7198	7254	7438	6836	7118	7062	6913	85805

The Norwegian Neonatal Network

NIPH
Norwegian Institute of Public Health

Oslo University Hospital

Norwegian Pediatric Association

The Norwegian Neonatal Network

Ressursregistrering | Annen terapi/pros. | Ernæring/veske | Cerebral UL/CT/MR | Nevrofysiologi | Mikrobiologi | Notat

Vekt (g) 505 HO (cm) Lengde (cm) Registrerende lege Thor Willy Ruud Hansen Visit ansv. lege Thor Willy Ruud Hansen Registrering avsluttet

Nivå 5	Nivå 4	Nivå 3	Nivå 2	Nivå 1
☐ Dødsdag	☑ Respirator (konvensjonell) 24 timer	☐ n-CPAP	☑ Nasogastrisk sonde	☑ Får enteral ernæring
☐ Mottak av livstruende syk pasient	☐ NIPPV / BiPAP	☐ High-flow kanyle	☐ Blærekatetrisering	☐ Probiotika
☐ NO-behandling	☐ Oscillator	☐ Manuell luftveisventilasjon	☐ Total (kun) enteral ernæring i sonde	☐ Ernæringsforsterkning
☐ N2-Behandling	☐ Oral intubasjon i avd	☐ Innl av perifer arteriekran	☐ Perifer AK	☑ Morsmelk / bankmelk
☐ CO2-Bhandling	☐ Nasal intubasjon i avd	☐ Innl av CVK (perk)	☐ CVK	☐ Seng
☐ Respiratorpasient ledsaget til annet sykehus	☐ Ekstern hjertekompresjon	☐ Pågående medikamentell ductuslukning	☑ Veneflon	☐ Permisjon-Føde/Barsel
☐ Respiratorpasient flyttet innen sykehuset til undersøkelse	☐ Pleuradren innl i avd	☐ Innl av NAK	☑ NVK	☐ Permisjon-hjem-dag
☐ Assistanse under operasjon	☐ PDA ligert i avdeling	☐ Innl av NVK	☑ NAK	☐ Permisjon-hjem-natt
☐ Særlige forhold	☐ Pleuratapping	☐ Pasienten extubert siste 24 timer	☑ Glukoseinfusjon	☐ Barnet innskrevet Neo-2012 men ligger i barselavdelingen
☐ ECMO	☐ Peritoneal dialyse	☑ PN inkl. lipider	☑ IV antibiotika [Endre] Ampicillin Gentamicin	
☐ Terapeutisk hypotermi	☐ Bruk av temporær pacemaker	☐ PN eksl. lipider	☑ Blodsukker x 6-8	
	☑ GA<28 uker/FV<1000g dag 0-6	☐ Blodtransfusjon	☑ Oxygentilskudd	
	☐ Surfactant utover fødestue denne dag	☑ Trombocytt transfusjon Antall: 1 Sum ml: 7	☑ Fototerapi ? timer	
	☐ PGE infusjon	☐ Volumekspansjon 0.9% NaCl	☐ Inhalasjon av steroider	
	☐ Encefalopati hos nyfødt grad 2-3	☐ Volumekspansjon Alb/plasma	☐ Steroider iv (CLD)	
	☐ Postop dag 0-6 thorax/abd/CNS	☑ Dopamin ? timer max ? ug/kg/min	☐ Steroider po (CLD)	
	☐ Eksternt shuntet hydrocephalus	☐ Dobutamin	☑ Kuvøse (lukket)	
	☐ Isolat 1 pas	☐ Adrenalin	☐ Kuvøse (åpen)	
	☐ Uavklart cardial tilstand (maks. 3 d)	☐ Isoprenalin	☐ Varmeseng	
	☐ Henvist utredning nevro	☐ Noradrenalin	☐ I.v. sedasjon	
	☐ Henvist utredning metabolsk	☐ Insulininf	☐ Blærekateter	
	☐ Henvist utredning syndrom	☐ Annen medikamentinfusjon	☑ Overvåkning med SaO2 eller Tc verdier	
	☐ Henvist utredning lever-gastro	☐ Pre-+post-ductal SaO2 overvåkning	☑ Foreldre gir < 4 av 8 måltider	
	☐ Utskrivningsdag kuvøse-pasient	☐ Kramper siste 24 timer - behandlet	☐ Kramper > 24 timer siden anfall - behandlet	
	☐ Barn av stoffmisbrukende mødre (abst.beh. 0-14d)	☐ EEG / CFM-monitorering	☐ Pasient ledsaget til us	
		☐ Tracheostoma		

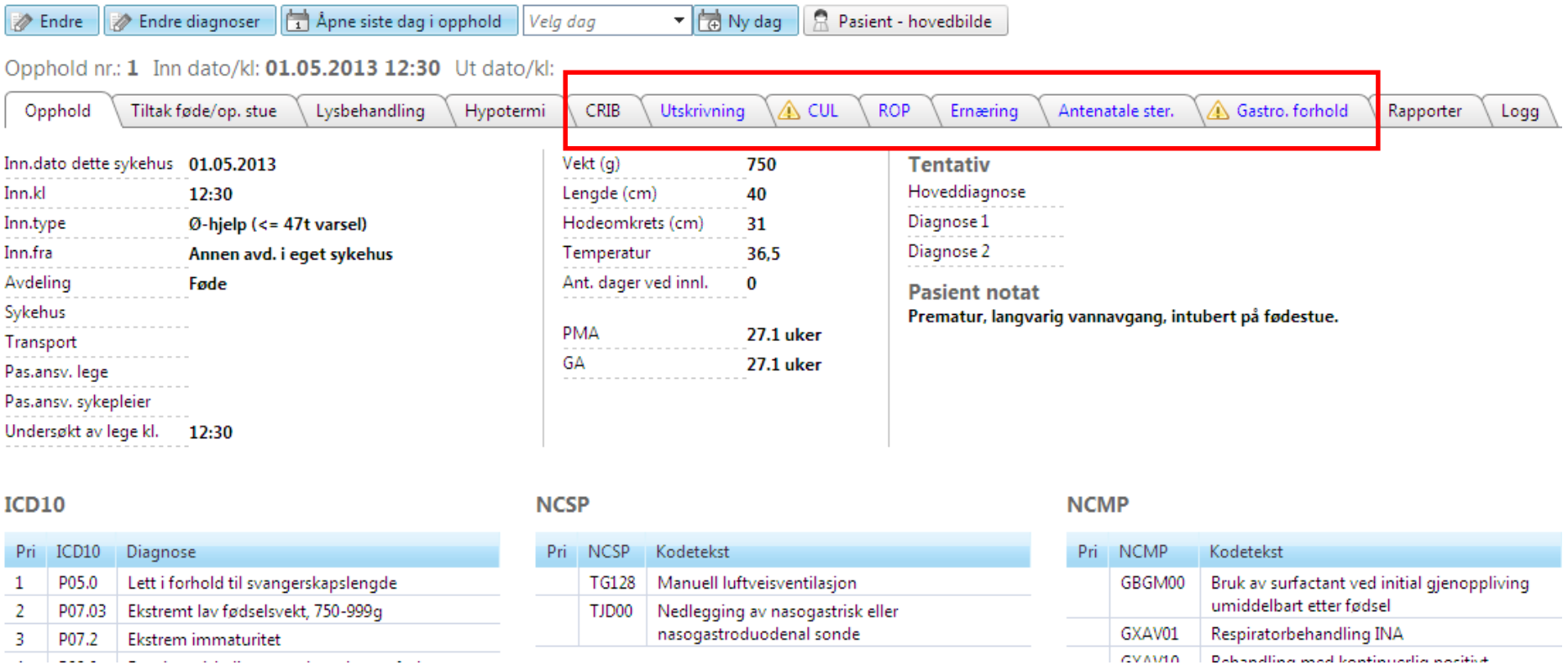
Genererer 4041

NIPH Norwegian Institute of Public Health

Oslo University Hospital

Norwegian Pediatric Association

Focus areas – BW < 1500 g or GA < 32 w



Quality indicators:

Completeness in reporting a predefined set of treatment and outcome variables

Survival in comparable patient groups

Mechanical ventilation (days) in comparable patient groups

Length of stay in comparable patient groups

Chronic lung disease (BPD) in infants < 28 w GA

Cerebral complications (ICH ≥ gr 3 or PVL) in premature infants GA < 32 w

Necrotizing enterocolitis in infants < 32 w

Systemic antibiotics (genera and duration) in comparable patient groups

Sepsis (verified) in comparable patient groups

Annual report

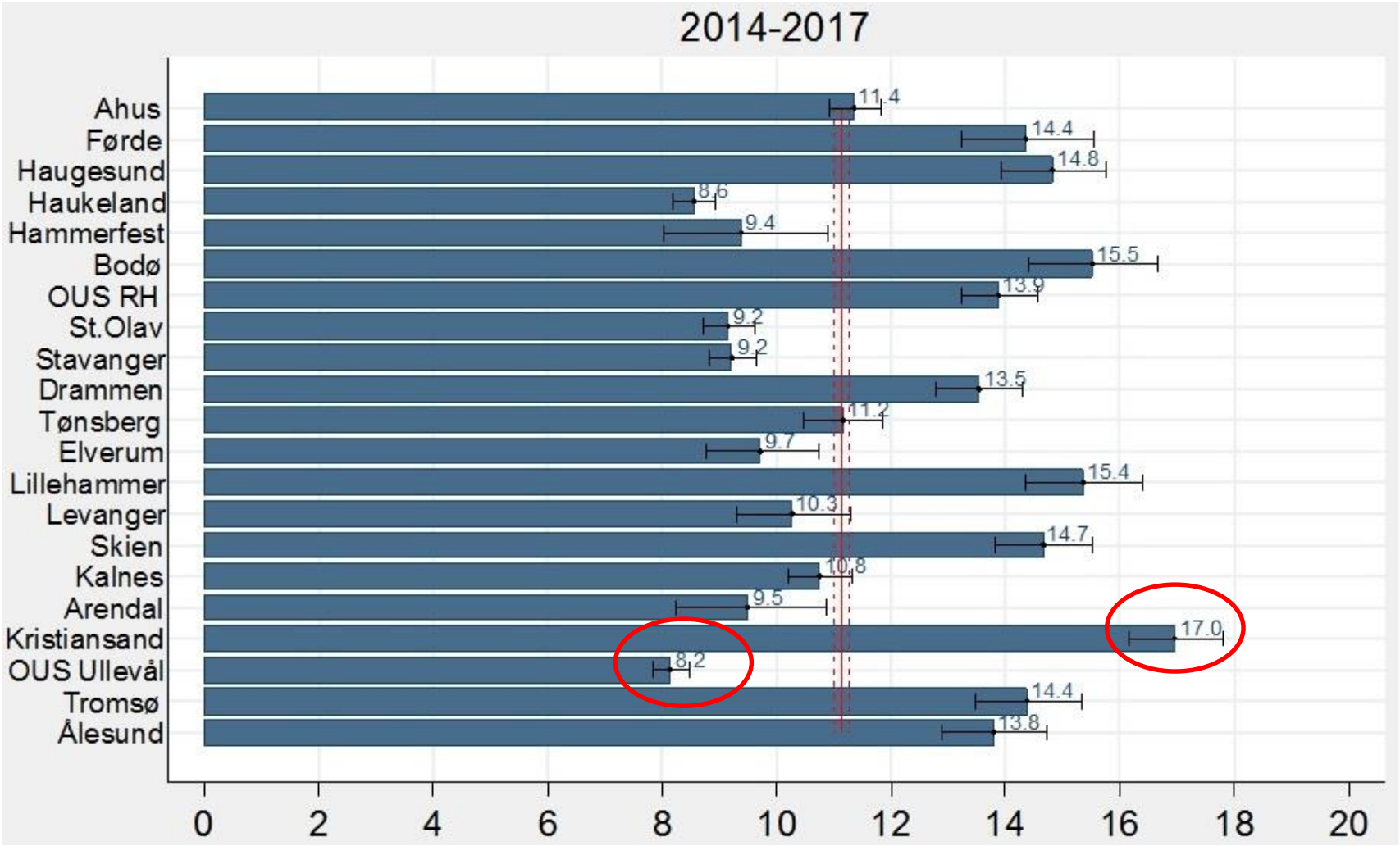
153 items (digitally)

Covering most aspects of neonatal medical care

Each unit will receive their own reported data compared to

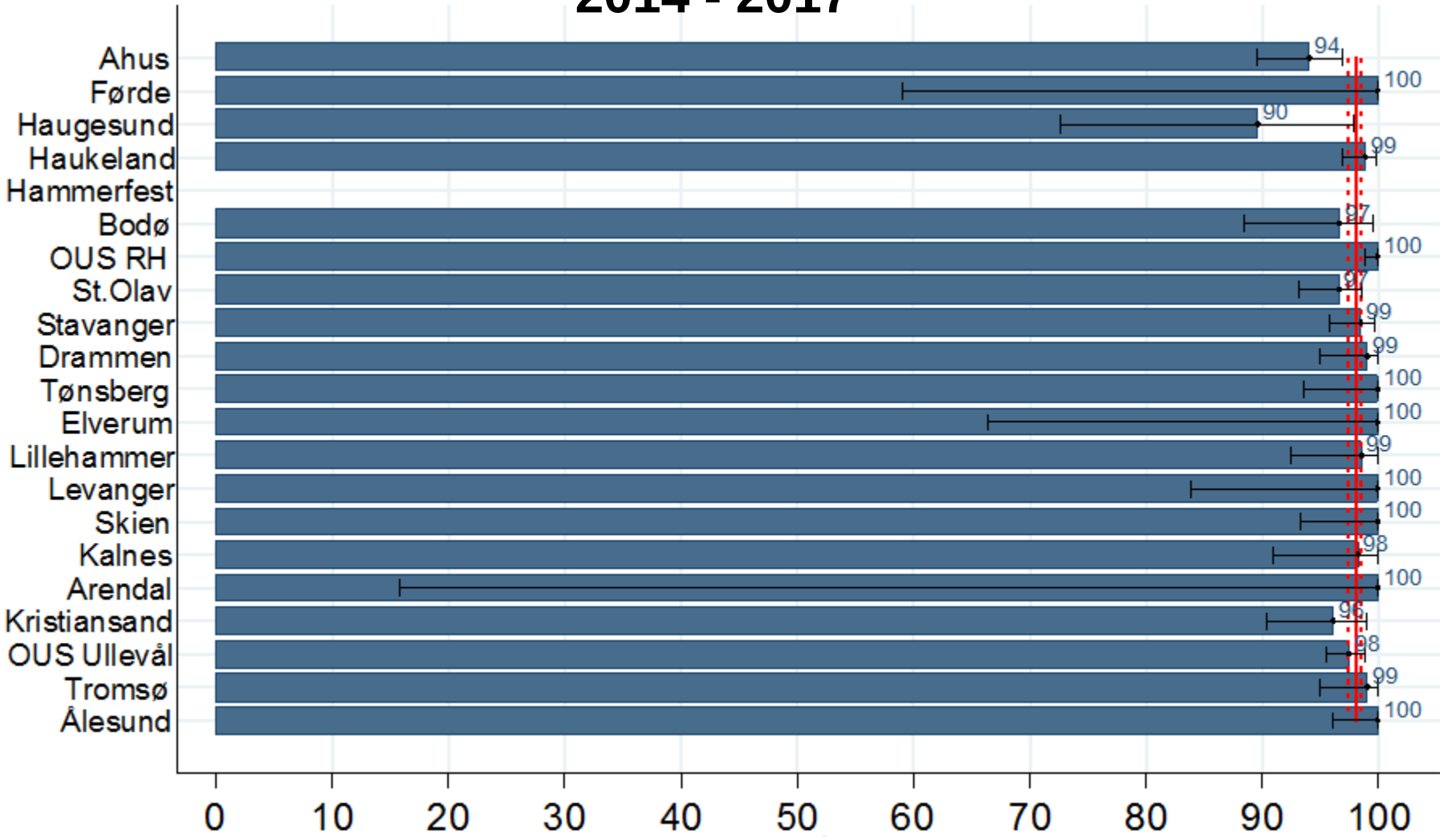
- **national average**
- **regional average**

Admissions in % from own inborn population



Completeness in reported variables

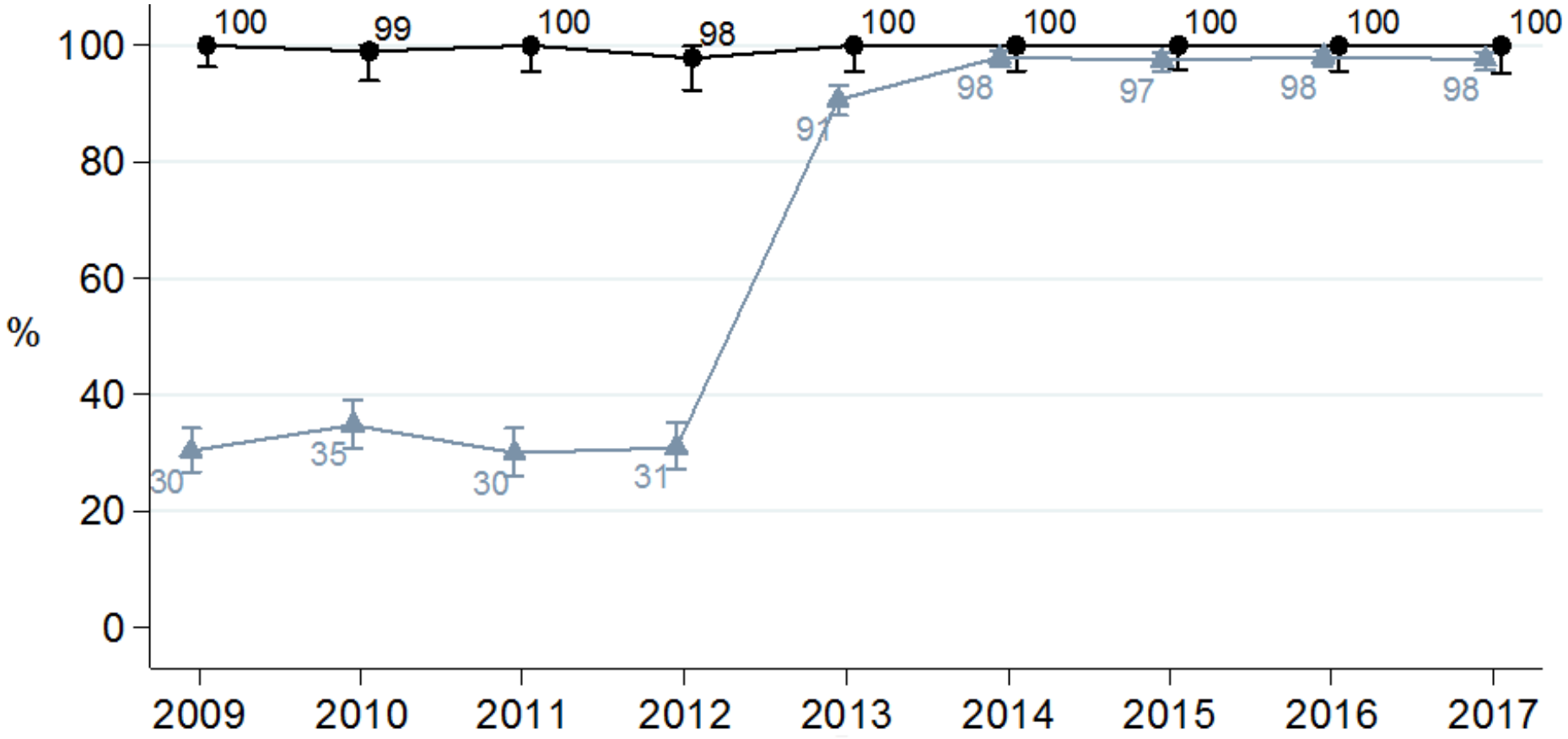
% Completeness reporting cerebral ultrasound results 2014 - 2017



% Completeness reporting cerebral ultrasound results

2009 – 2017

GA < 32 w / BW < 1500 g



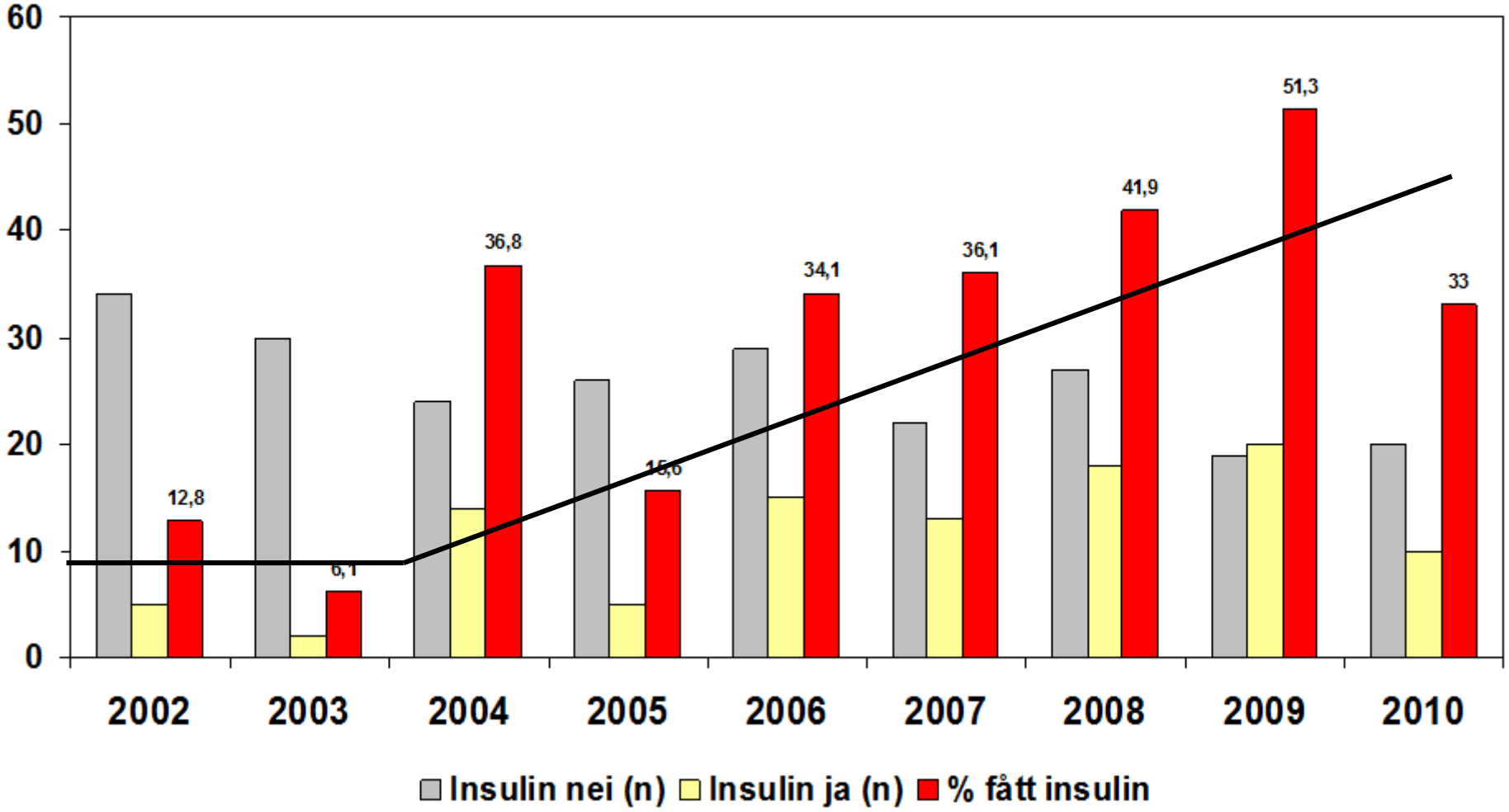
Quality surveillance, improvement and research

NICU at OUS Rikshospitalet:

2005 – 2006: **Redesigning the NICU's parenteral nutritional regimen** **in agreement with recent research and expert opinions.**

From 2007: **The Neonatal program is warning about increased use of insulin in infants with a BW < 1000 g**

Born OUS, RH – BW < 1000 g – use of insulin



NICU at OUS Rikshospitalet:

2005 – 2006: **Redesigning the NICU's parenteral nutritional regimen** **in agreement with recent research and expert opinions.**

From 2007: **The Neonatal program is warning about increased use of insulin in infants with a BW < 1000 g**

From 2010: **Data from the Neonatal program warns about increased mortality in infants with a BW < 1000 g**

Are we doing the right thing?

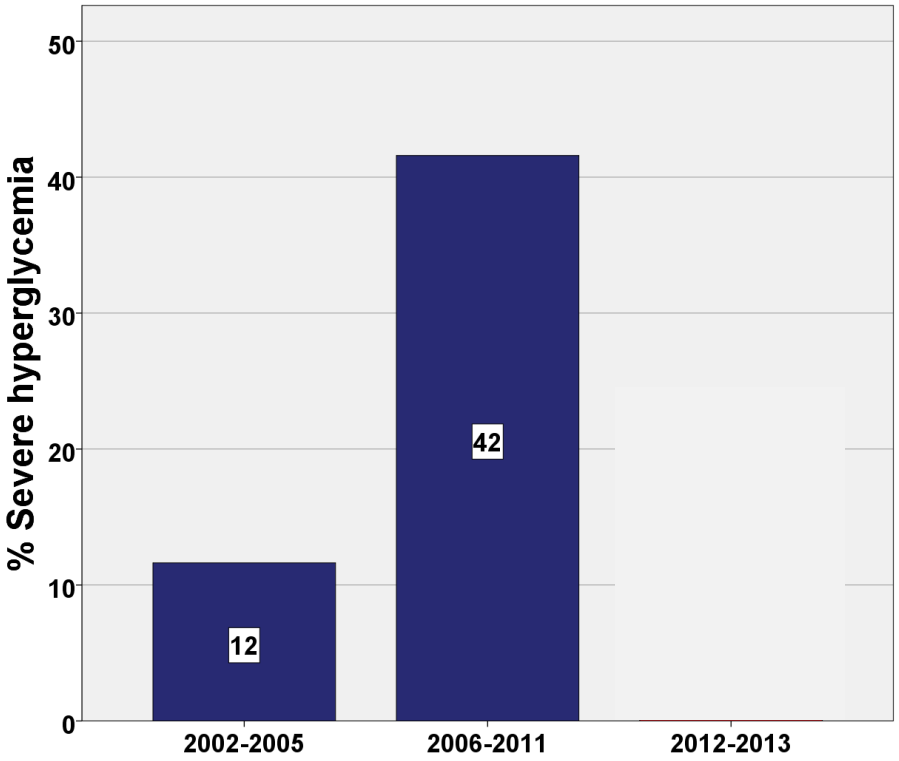
Actions taken:

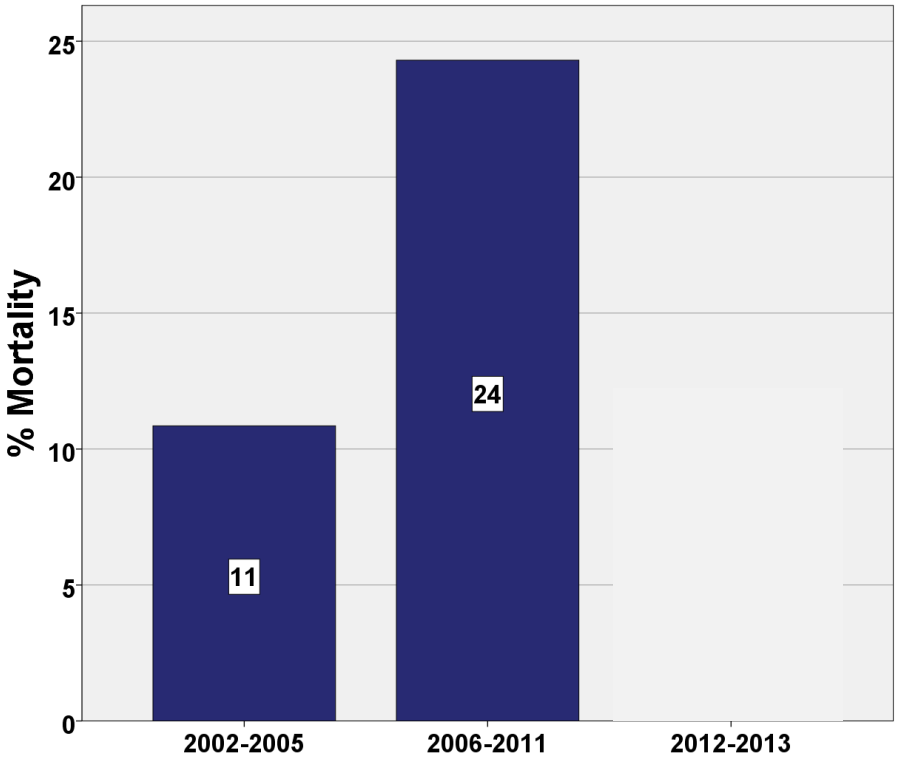
Extensive evaluation of nutritional practice:
Did the premature infants really receive what we aimed at regarding KH, lipids and AA? And in what way?

Conclusion: We identified a large proportion of infants with early severe hyperglycemia. Unbalanced supply of nutritional elements during the day.

Change of practice: Parenteral nutrition regarded as medication – not as “food” – ordinated on a ml/h basis – not on a daily basis.
Improved and optimized AA/protein supply.

Severe hyperglycemia and mortality before 2012



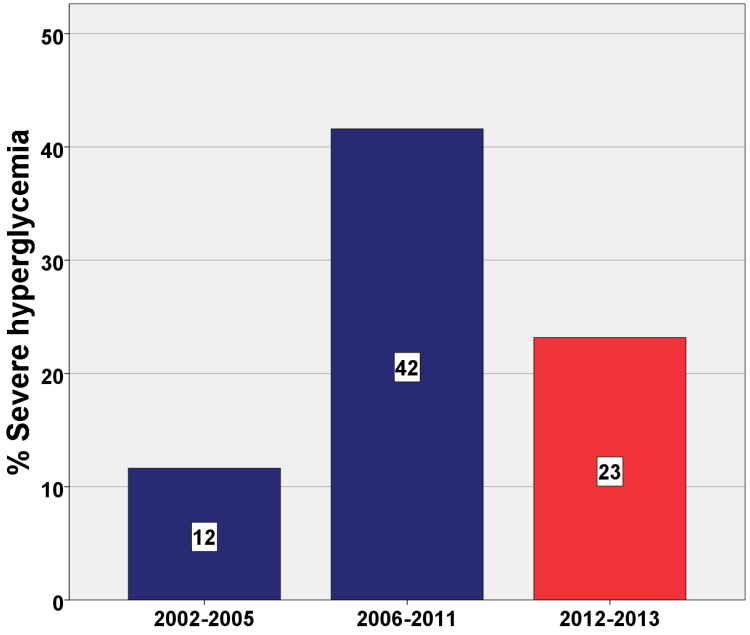


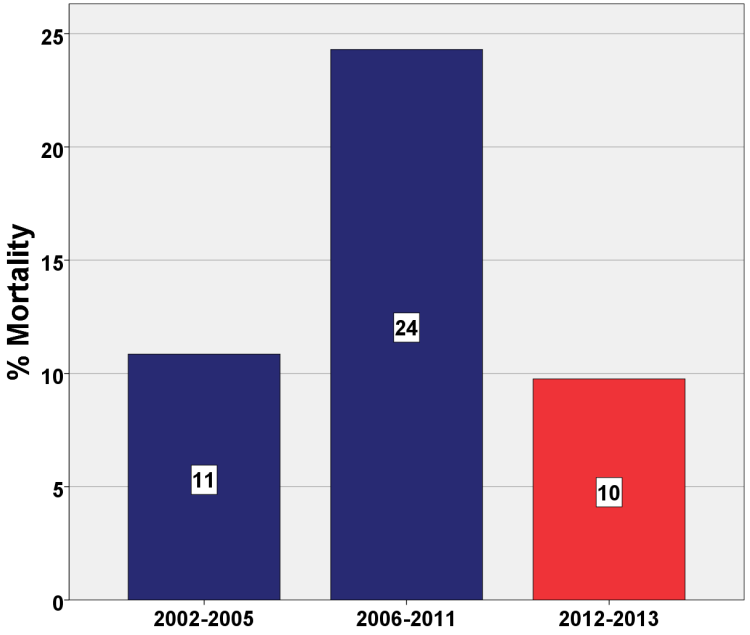
JAMA Pediatrics
Formerly *Archives of Pediatrics & Adolescent Medicine*

Original Investigation

Early Enhanced Parenteral Nutrition, Hyperglycemia, and Death Among Extremely Low-Birth-Weight Infants

Hans Jorgen Stensvold, MD; Kenneth Strommen, MD; Astri M. Lang, MD, PhD; Tore G. Abrahamsen, MD, PhD; Eline Kjorsvik Steen, BSc; Are H. Pripp, PhD; Arild E. Ronnestad, MD, PhD

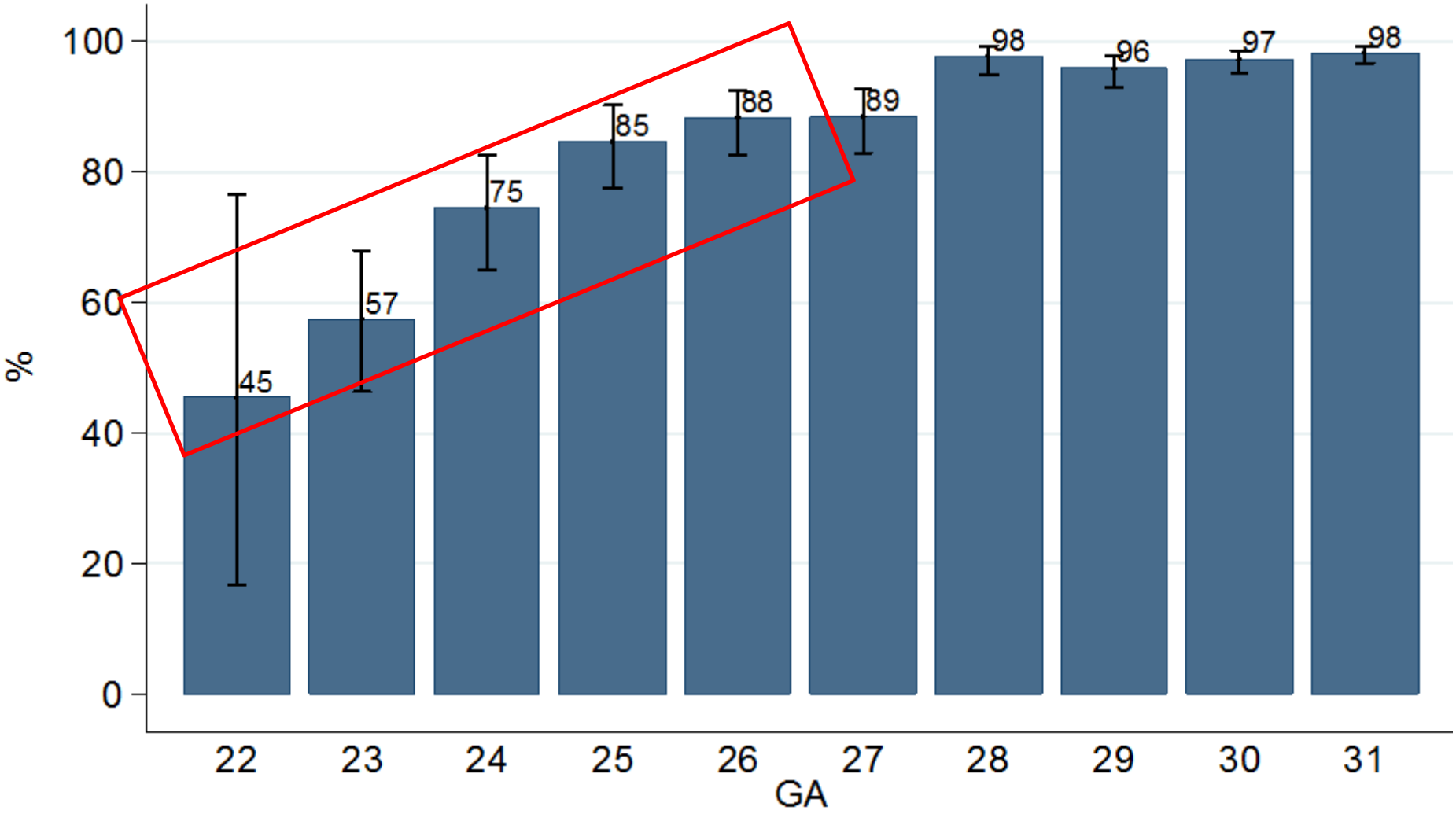




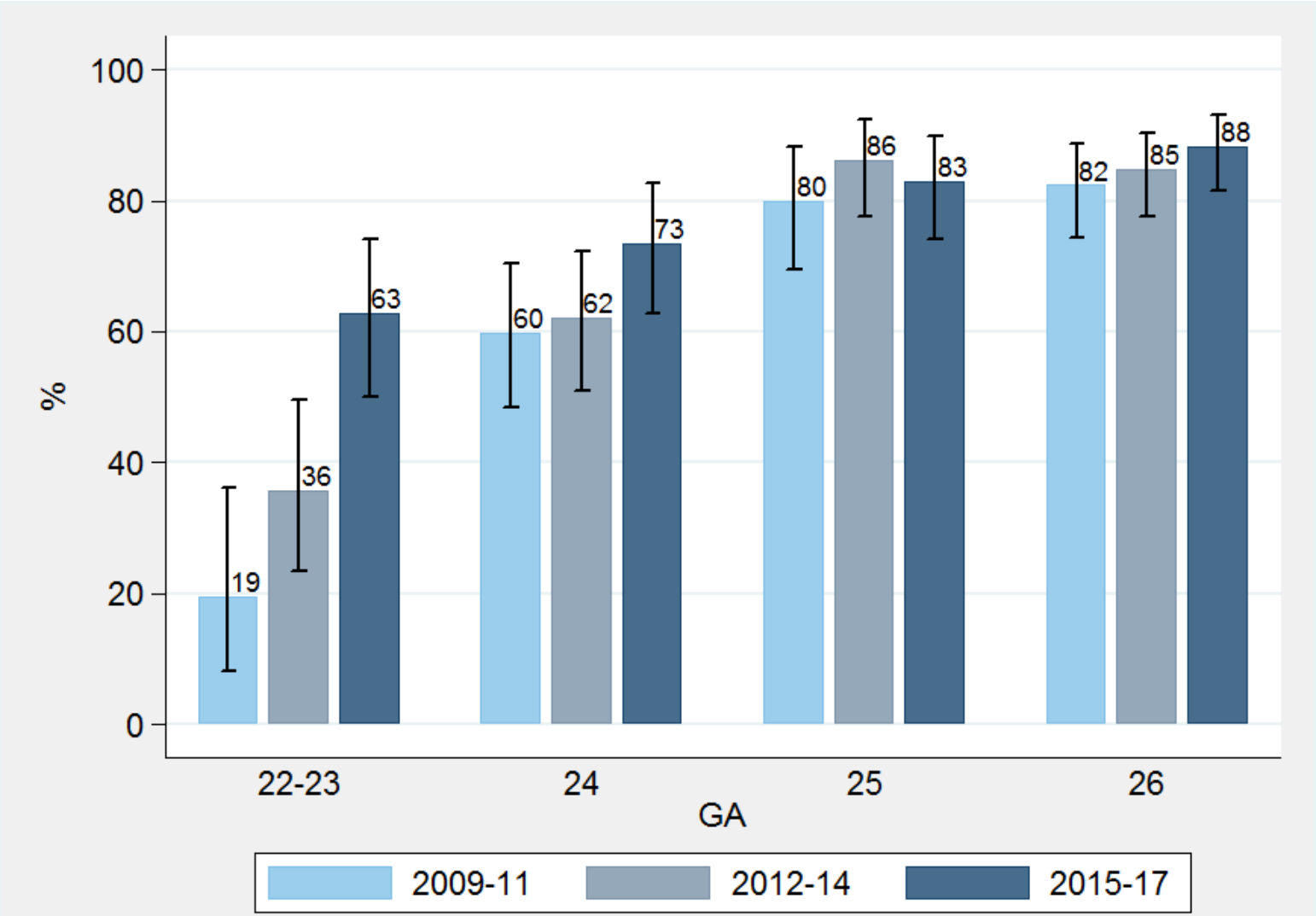
Short term outcome variables

Survival in premature infants

% survival - GA< 32 w – Norway 2014 - 2017

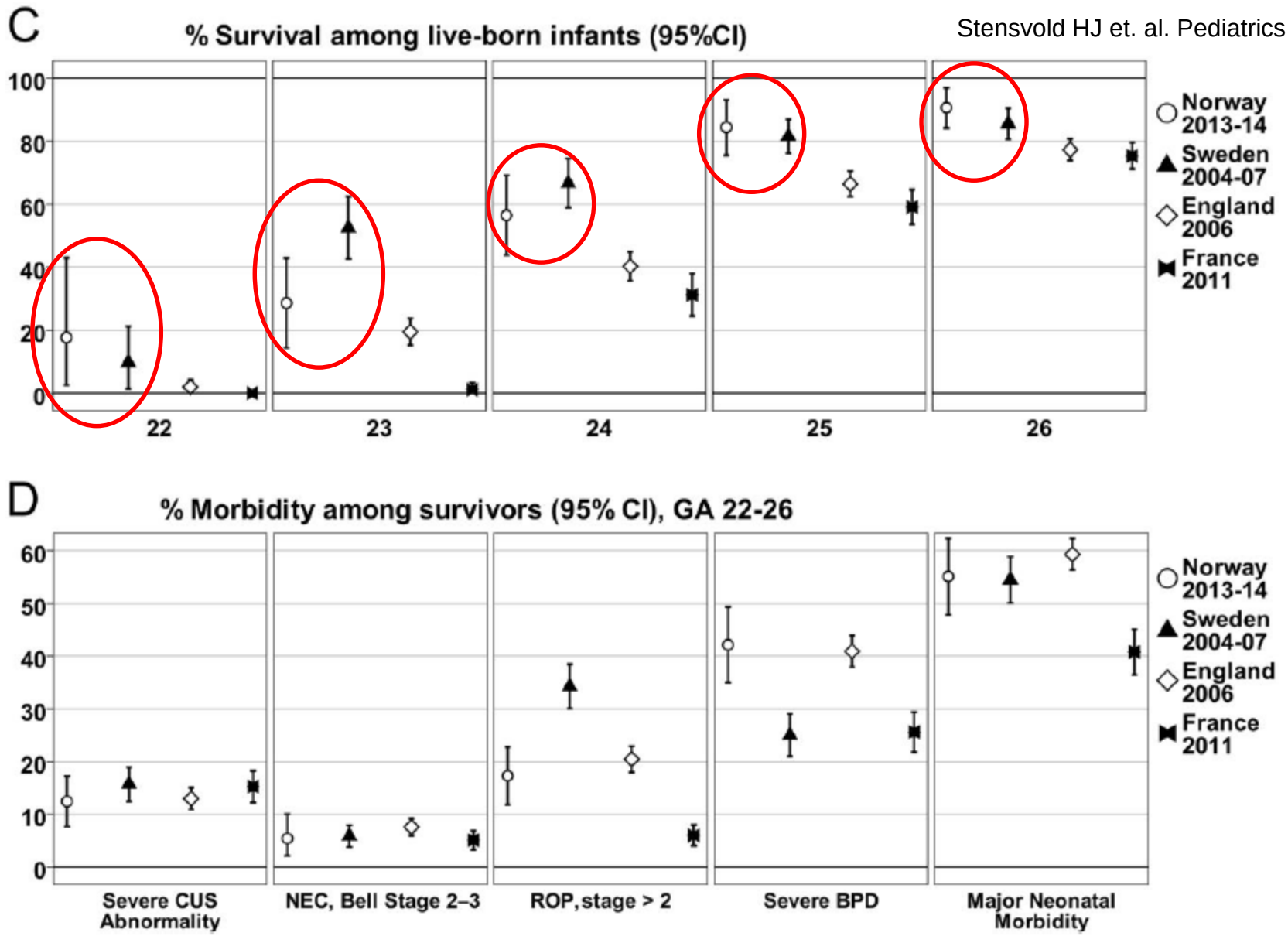


Survival – GA < 27 w – 2009-2017



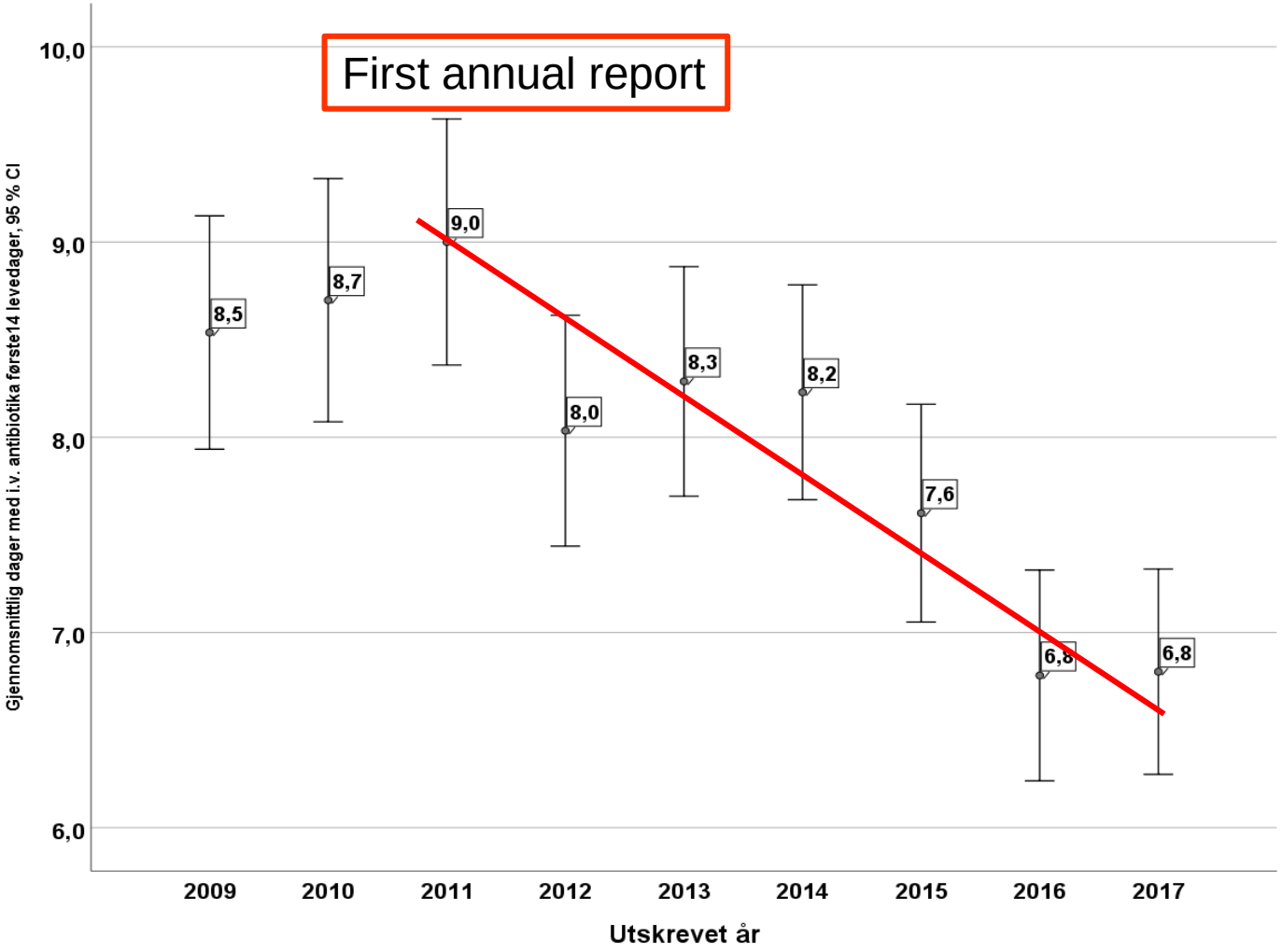
The Norwegian Neonatal Network

Stensvold HJ et. al. Pediatrics 2017



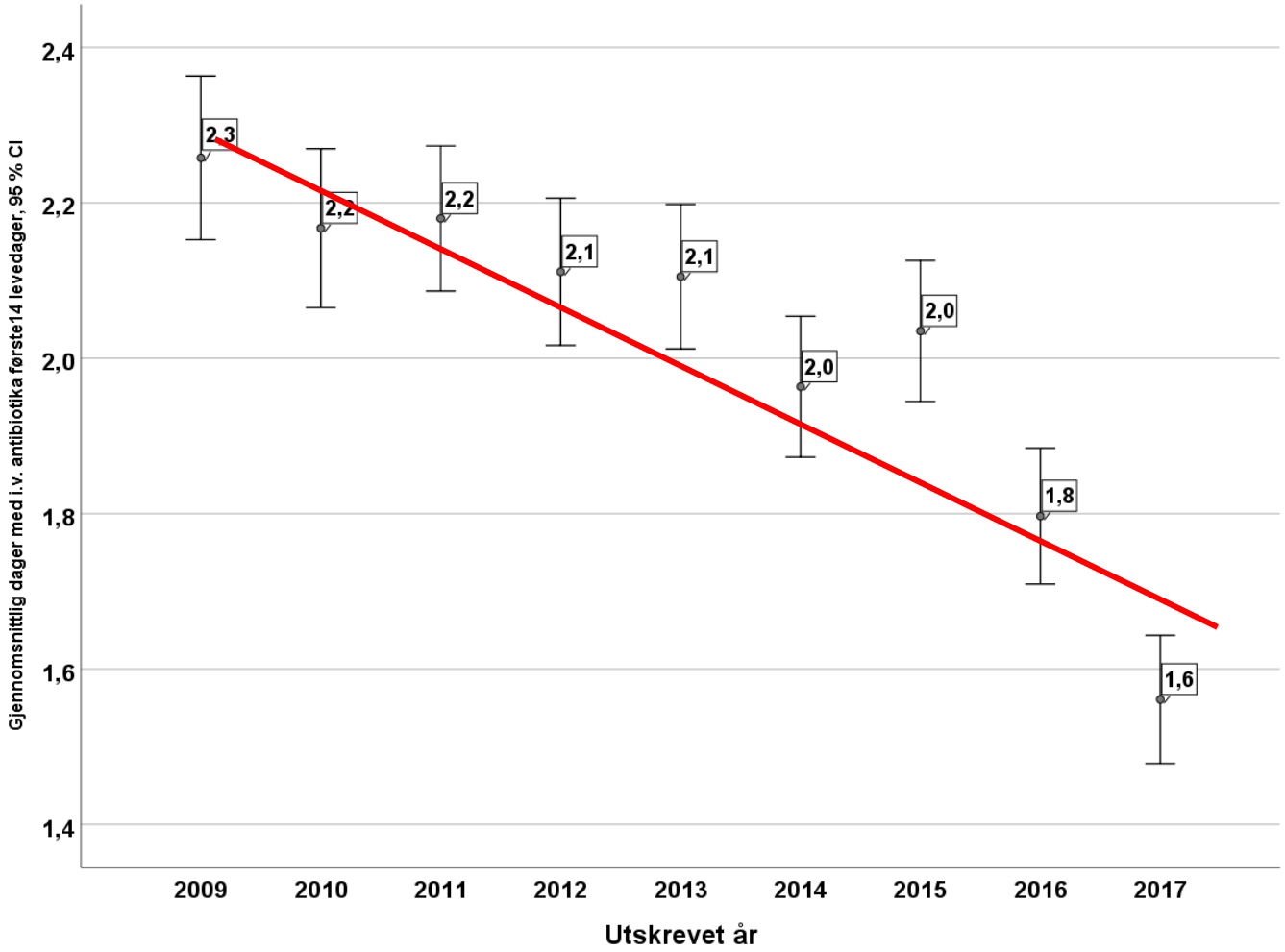
Exposure to systemic antibiotics

Days with antibiotics first 14 DOL – GA < 28 weeks



Anova
p < 0,001

Days with antibiotics first 14 DOL – GA 37 - 42 w

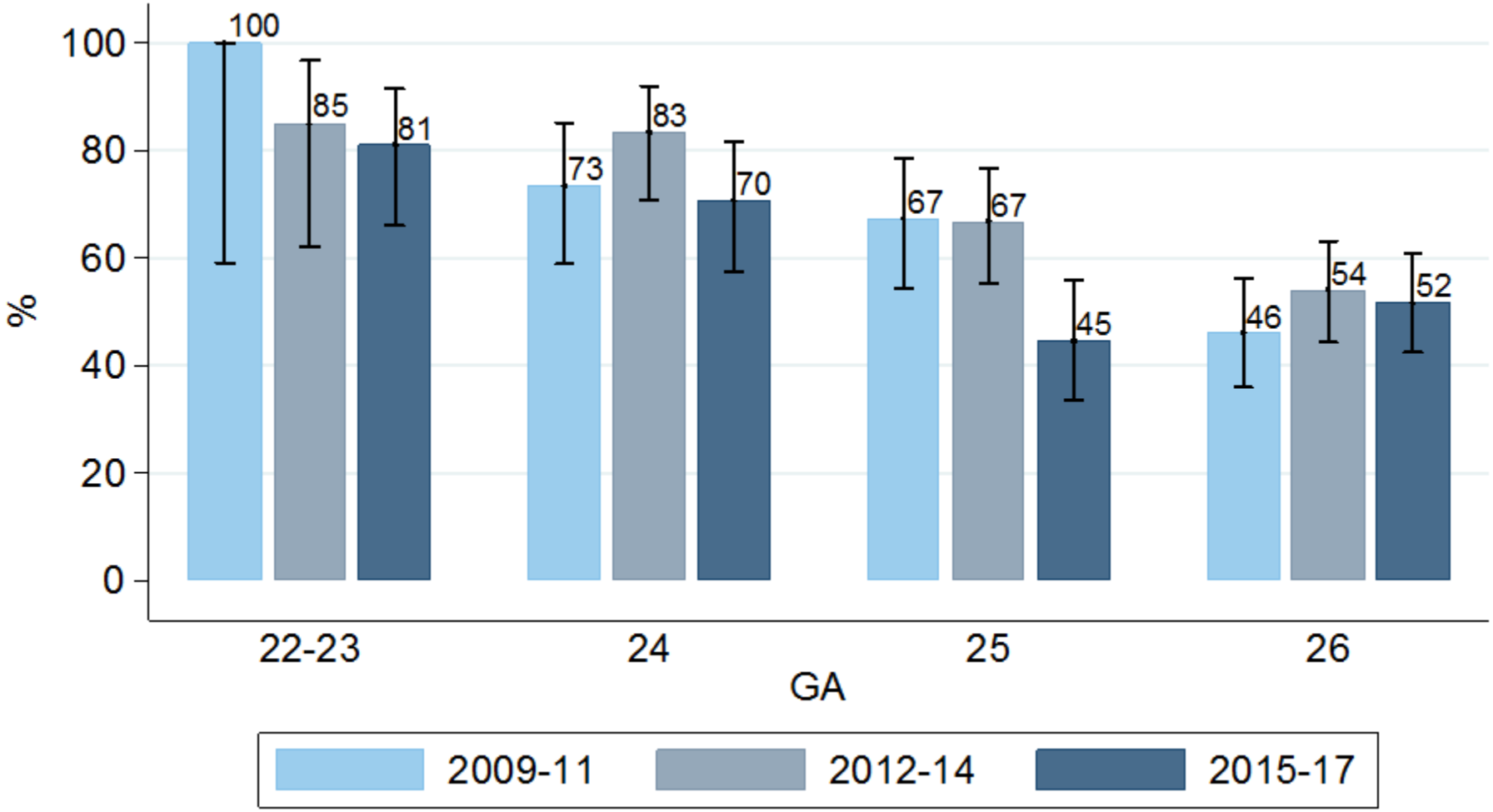


Anova
p < 0,001

Bronchopulmonary dysplasia (BPD)

Moderate to severe BPD in survivors - % (95% CI)

Oxygen or ventilatory support at 36 w PMA



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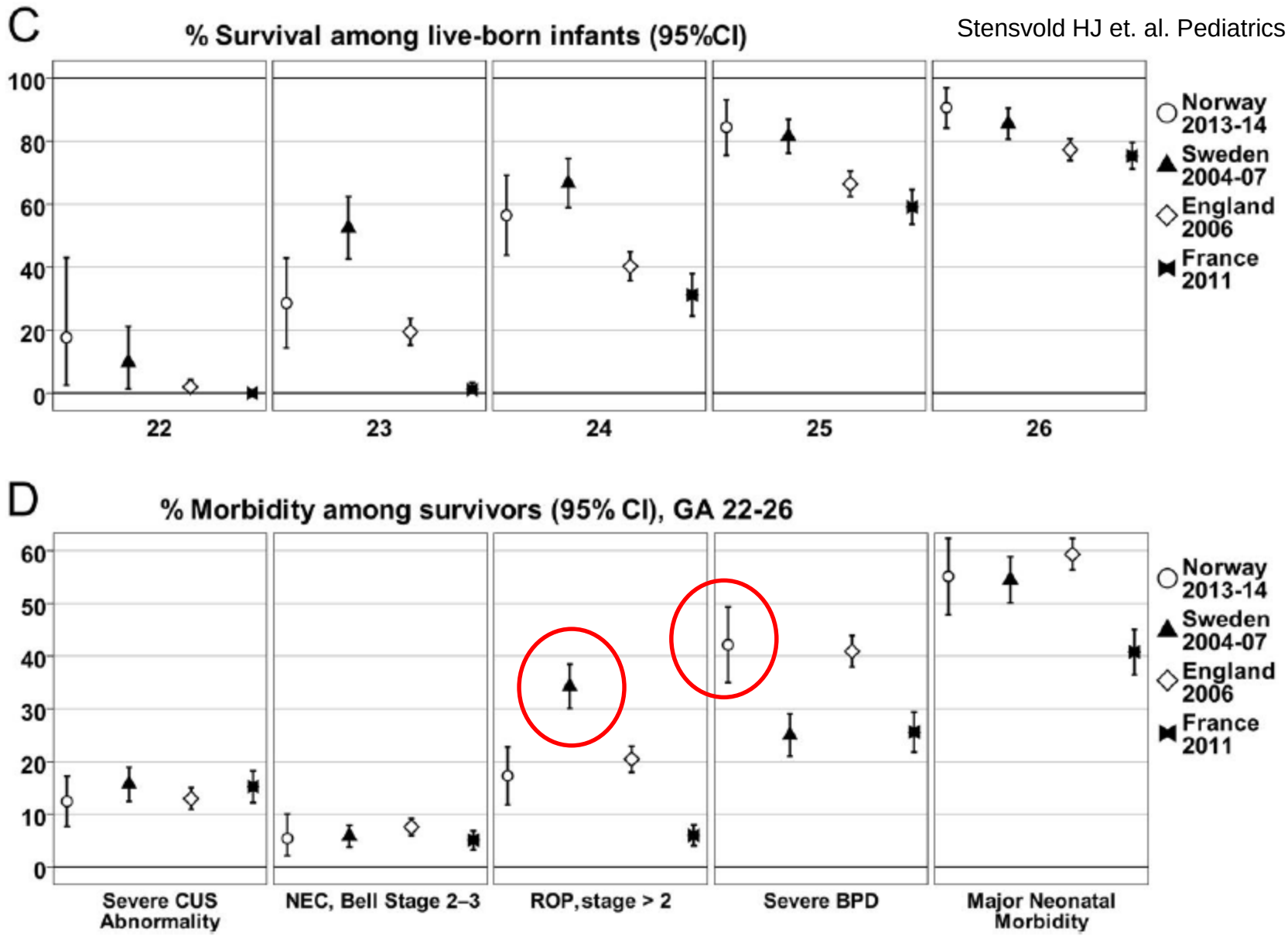
Stensvold HJ et. al. Pediatrics 2017



Publications

Original Investigation

Early Enhanced Parenteral Nutrition, Hyperglycemia, and Death Among Extremely Low-Birth-Weight Infants

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JAMA Pediatr. doi:10.1001/jamapediatrics.2015.1667

ORIGINAL STUDIES

Early-onset Sepsis and Antibiotic Exposure in Term Infants

A Nationwide Population-based Study in Norway

Jon W. Fjalstad, Hans J. Stensvold, MD,† Håkon Bergseng, MD, PhD,‡§ Gunnar S. Simonsen, MD, PhD,¶‖ Bodil Salvesen, MD, PhD,** Arild E. Rønnestad, MD, PhD,† and Claus Klingenberg, MD, PhD*††*

(*Pediatr Infect Dis J* 2016;35:1–6)

NIPH Norwegian Institute of Public Health

Oslo University Hospital

Norwegian Pediatric Association

Inotropic Therapy in Newborns, A Population-Based National Registry Study

Margrete Larsen Burns, MD[1]; Hans Jørgen Stensvold, MD[2]; Kari Risnes, MD[3,4]; Hans Jørgen Guthe, MD[5]; Henriette Astrup, MD[6]; S. Marianne Nordhov, MD, PhD[7]; Terje Reidar Selberg, MD[8]; Arild Rønnestad, MD, PhD[2,9]; Astri Maria Lang, MD, PhD[2]; on behalf of the Norwegian Neonatal Network

Pediatric Critical Care Medicine 2016

Neonatal Morbidity and 1-Year Survival of Extremely Preterm Infants

Hans Jorgen Stensvold, MD,[a,b,c] Claus Klingenberg, MD, PhD,[d,e] Ragnhild Stoen, MD, PhD,[f,g] Dag Moster, MD, PhD,[h,i,j] Kristin Braekke, MD, PhD,[a] Hans Jorgen Guthe, MD, PhD,[h] Henriette Astrup, MD,[k] Siren Rettedal, MD, PhD,[l] Morten Gronn, MD, PhD,[m] Arild E. Ronnestad, MD, PhD,[a,b,c] on behalf of the Norwegian Neonatal Network

PEDIATRICS Volume 139, number 3, March 2017:e20161821

Journal of Nursing Management, 2017, **25**, 569–576

Patient acuity and nurse staffing challenges in Norwegian neonatal intensive care units

MARI O. OHNSTAD MSNC, RN[1] and MARIANNE T. SOLBERG PHD, MSN, RN[2]

REGULAR ARTICLE

Acta Pædiatrica ISSN 0803-5253

Strictly controlled glucose infusion rates are associated with a reduced risk of hyperglycaemia in extremely low birth weight preterm infants

Hans Jorgen Stensvold (hstensvo@ous-hf.no)[1,2,3], Astri M. Lang[1], Kenneth Strommen[1,4], Tore G. Abrahamsen[2,5], Bjorn Ogland[1], Are H. Pripp[6], Arild E. Ronnestad[1,2,3]

1.Neonatal Department, Division of Paediatric and Adolescent Medicine, Oslo University Hospital Rikshospitalet, Oslo, Norway
2.Faculty of Medicine, Institute for Clinical Medicine, University of Oslo, Oslo, Norway
3.Norwegian Neonatal Network, Oslo University Hospital Rikshospitalet, Oslo, Norway

Acta Pædiatrica ISSN 0803-5253

REGULAR ARTICLE

Phototherapy is commonly used for neonatal jaundice but greater control is needed to avoid toxicity in the most vulnerable infants

Khalaf Mreihil (khalaf.mreihil@medisin.uio.no)[1,2], Jūratė Šaltytė Benth[2,3], Hans Jørgen Stensvold[2,4], Britt Nakstad[1,2], Thor Willy Ruud Hansen[2,4], the Norwegian NICU Phototherapy Study Group*, and the Norwegian Neonatal Network

Acta Pædiatrica ISSN 0803-5253

REGULAR ARTICLE

Uniform national guidelines do not prevent wide variations in the clinical application of phototherapy for neonatal jaundice

Khalaf Mreihil (khalaf.mreihil@medisin.uio.no)[1,2], Britt Nakstad[1,2], Hans Jørgen Stensvold[2,3], Jūratė Šaltytė Benth[2,4], Thor Willy Ruud Hansen[2,3], the Norwegian NICU Phototherapy Study Group*, and the Norwegian Neonatal Network

The Norwegian Neonatal Network

The Norwegian Neonatal Healthcare Atlas, 2009-2014

An analysis of admissions and treatments of infants at units for sick neonates in Norway in the period 2009-2014

December 2016

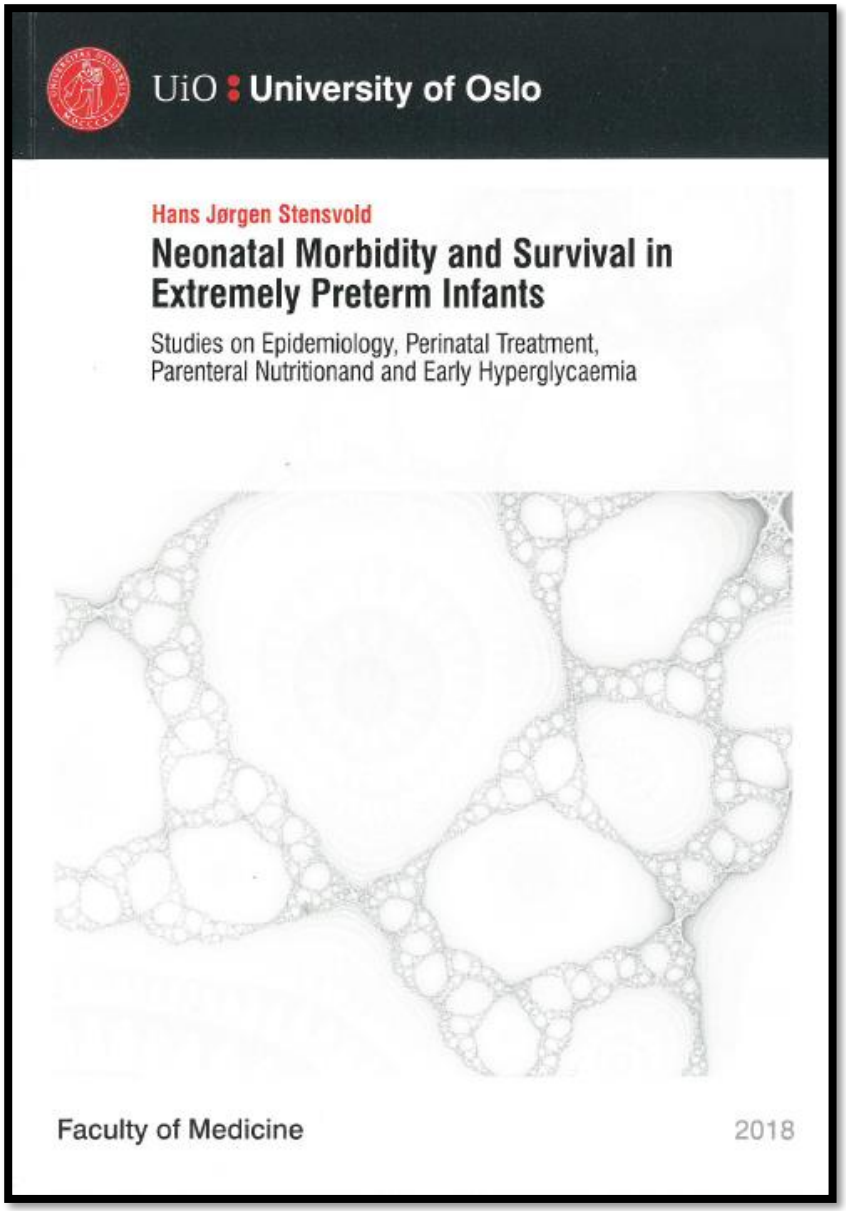
HELSEATLAS SKDE

Norsk Nyfødtmedisinsk Kvalitetsregister

NIPH Norwegian Institute of Public Health

Oslo University Hospital

Norwegian Pediatric Association



First dissertation from the Norwegian Neonatal Network

MD, PhD Hans Jørgen Stensvold

May 2018

Ongoing projects

Risk factors and outcome from sepsis in premature infants < 32 weeks GA.

REK approval 2015

Birth asphyxia in term infants with and without therapeutic hypothermia treatment, risk factors and outcomes

- during the neonatal period
- at 2 years of age
- at 5 years of age

PhD project
REK approval 2017

Predictors for successful weaning from mechanical ventilation in extremely premature infant (GA < 27 W)

PhD project

REK approval 2018

Causes of stillbirths, neonatal and infant mortality over 10 years in Norway 2009 - 2018

REK approval 2018

Necrotizing enterocolitis in Norway and Sweden – long term consequences

PhD project

REK application submitted


Thank you for your attention