

# Klinisk Kvalitetskonferens

## Aalborg, Danmark Nov 29-30, 2022

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*Universitetssjukhuset*

# Disclosures

	No, nothing to disclose
X	Yes, please specify:

<i>Company Name</i>	<i>Honoraria/ Expenses</i>	<i>Consulting</i>	<i>Funded Research</i>	<i>Royalties</i>	<i>Stock Options</i>	<i>Ownership/ Equity Position</i>	<i>Employee</i>	<i>Other (please specify)</i>
Swedish Patient Insurance		x						
Karolinska Institutet & Region Sthlm			x				x	
Childhood Foundation of Swed. Order of Freemasons			x					
Chiesi Pharma	x							
Studentlitteratur and Liber AB				x				
Eva & Mikael Norman AB						x		

# Outline of talk

- About the Swedish Neonatal Quality Register
- Contributions to quality improvement/research
- Nordic collaborative register study



# Swedish Neonatal Quality Register

# Population registers – kept by authorities



## National Quality registers

Started with an agreement between the government and SALAR to build National Q-registers (>20 yrs ago).

## National Quality registers

Driven by the profession (not the authorities) Aim: to add valuable knowledge and improve the health care system.

Today: about 130 registers.

## National Quality registers

Financed by taxes and department/hospital fees.

Each register created around a specific diagnosis (Cancer, Stroke) or treatment (Transplant), or category of care (SNQ, SIR).



# Swedish Neonatal Quality Register

## Vision

**Each family/baby** should receive **the neonatal care they need, when** they need it (and **where** they want it), with **excellent family experience** and with **highest quality of care**.

## Mission

to **provide** decision-makers, profession and public with **data and knowledge** that stimulate improvements in neonatal care, research and development.

# Greater regions in SNQ and neonatal units

## ● North

- Gällivare sjukhus
- Luleå, Sunderby sjukhus
- Skellefteå lasarett
- Sundsvalls sjukhus
- Umeå, Norrlands universitetssjukhus
- Örnsköldsviks sjukhus
- Östersunds sjukhus

## ● Mid

- Eskilstuna, Mälarsjukhuset
- Falu lasarett
- Gävle, Länssjukhuset
- Hudiksvalls sjukhus
- Karlstad, Centralsjukhuset
- Uppsala, Akademiska sjukhuset
- Västmanlands sjukhus, Västerås
- Örebro, Universitetssjukhuset

## ● East

- Stockholm, KS-Danderyd
- Stockholm, KS-Huddinge
- Stockholm, KS-Solna
- Stockholm, Södersjukhuset
- Visby lasarett

## ● South-east

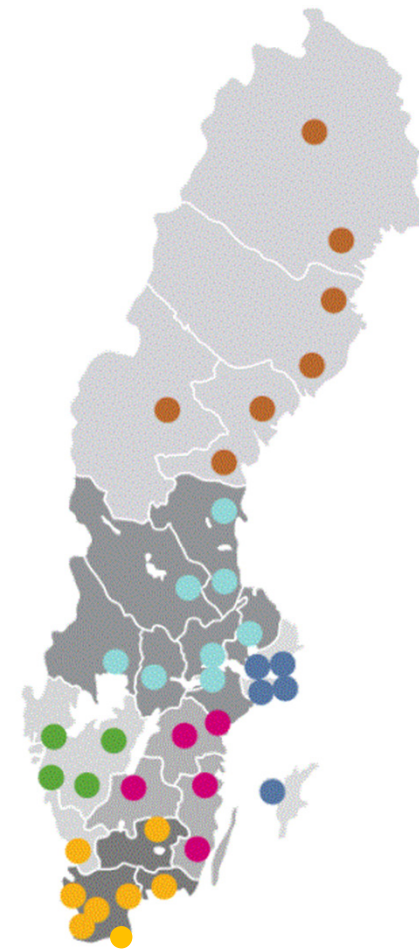
- Jönköping, Länssjukhuset Ryhov
- Kalmar, Länssjukhuset
- Linköping, Universitetssjukhuset
- Norrköping, Vrinnevisjukhuset
- Västerviks sjukhus

## ● West

- Borås lasarett
- Göteborg, Östra sjukhuset
- Skövde, Kärnsjukhuset
- Trollhättan, NÄL

## ● South

- Halmstads länssjukhus
- Helsingborgs lasarett
- Karlskrona, Blekingesjukhuset
- Kristianstads sjukhus
- Lund, Skånes universitetssjukhus
- Malmö, Skånes universitetssjukhus
- Växjö centrallasarett
- Ystad Lasarett





### **IT-service/platform:**

MedSciNet/CSAM Health

### **Daily web-based reporting**

### **Online-supports:**

[info@snq.se](mailto:info@snq.se) (Lena 25%)

[dataservice@snq.se](mailto:dataservice@snq.se) (Stellan 25%)

### **Contents**

- 200,000 babies (850 regist. users)
- >600 process- and outcome indicators (neonatal care, transport)
- Follow-up at 2 and 5½ years
- Parental questionnaire (PREM)
- Nursing care (pain, skin-skin care, skin damage, nutrition/breastfeeding)
- NEC-surgery
- Capacity (Q to units every 3 years)

# Collaborations

## Swedish Pregnancy Register

- one **cohesive chain of care**: pregnancy – delivery – neonatal care – follow-up
- **same IT-supplier** (MedSciNet AB), a **common database**

## Parents Organization (<http://prematurförbundet.se/>)

## Authorities and stakeholders

- **SALAR** ("Neonatalvården i fokus")
- **National Board of Health and Welfare**
- **Public Health Agency of Sweden**
- **Medical Products Agency**
- **The Swedish National Council on Medical Ethics (SMER)**
- **Swedish Research Council (Register Utiliser Tool)**
- **Media**

## International

- The International Network for Evaluation of Outcomes (iNeo) in neonates; <http://www.ineonetwork.org/>
- Nordic collaboration



Neonatalvården  
i fokus

TRYGG HELA VÄGEN  
- FÖRE, UNDER OCH EFTER GRAVIDITET





# www.snq.se



START OM SNQ RESULTAT RESULTATTAVLOR REDOVISNING FÖRÄLDRAENKÄT FÖR FORSKARE FÖRÄLDRAINFORMATION KONTAKTA OSS

LOGGA IN



NYHETSREV

PÅGÅENDE STUDIER

VETENSKAPLIGA PUBLIKATIONER

ÅRSRAPPORTER

VERKSAMHETSBERÄTTELSE

LÄNKAR

## Välkommen till Neonatalvårdsregistret



### Statistik från registret

Antal mödrar:	172447
Antal barn:	198482
Antal vårdtillfällen:	259606

### Aktuellt

Arkiv: [2019](#) [2020](#) [2021](#) [2022](#)

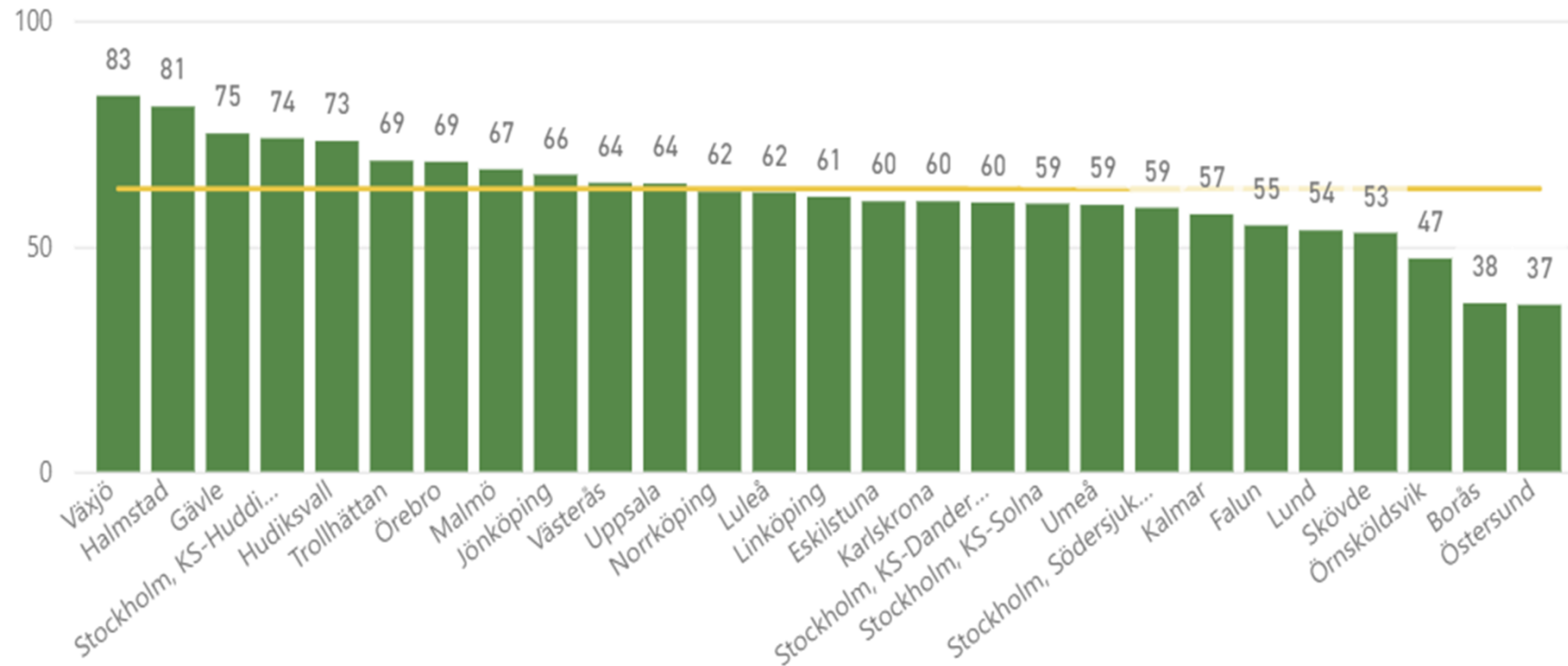
2022-11-21

SNQ-dagarna 16-17 mars 2023 - [anmälan nu öppen](#).

Vi ser fram emot att ses "på riktigt" på Radisson Blu Arlandia hotell. Ingen avgift och övernattnig ingår. Programmet innefattar gästföreläsningar av Sarah Bates från British Association of Perinatal Medicine (BAPM) och Bo Jakobsson, Sahlgrenska akademien och nyheter från registret. Mötesteman är "Användning av registerdata i forskning och för verksamhetsuppföljning", "Förtidsbörd" och "Neonatal uppföljning". En jämförelse av neonatalvården av tidigt födda barn i 21

# Q4. Did you get sufficient information?

Proportions of parents ratings your hospital as ★★★★★



# Indicators in SNQ besides parental experience measures: capacity, processes, and outcome

<i>Hospital/region/nation</i>		
<b>Capacity (structure)</b>	<b>Process</b>	<b>Outcome</b>
<p>In relation to number of births:</p> <ul style="list-style-type: none"> <li>• Availability</li> <li>• Bed-density</li> <li>• Equipment</li> <li>• Staffing</li> </ul> <p><i>Evaluation of fitness for service</i></p>	<ul style="list-style-type: none"> <li>• Timely</li> <li>• Evidence-based</li> <li>• Effective</li> <li>• Equity</li> </ul> <p><i>Adherence to Best Practice, KPI's</i></p>	<ul style="list-style-type: none"> <li>• Safety</li> <li>• Complications</li> <li>• Long-term health</li> <li>• Family-centered care</li> </ul> <p><i>Outcome (mortality, morbidity, health, PREM)</i></p>

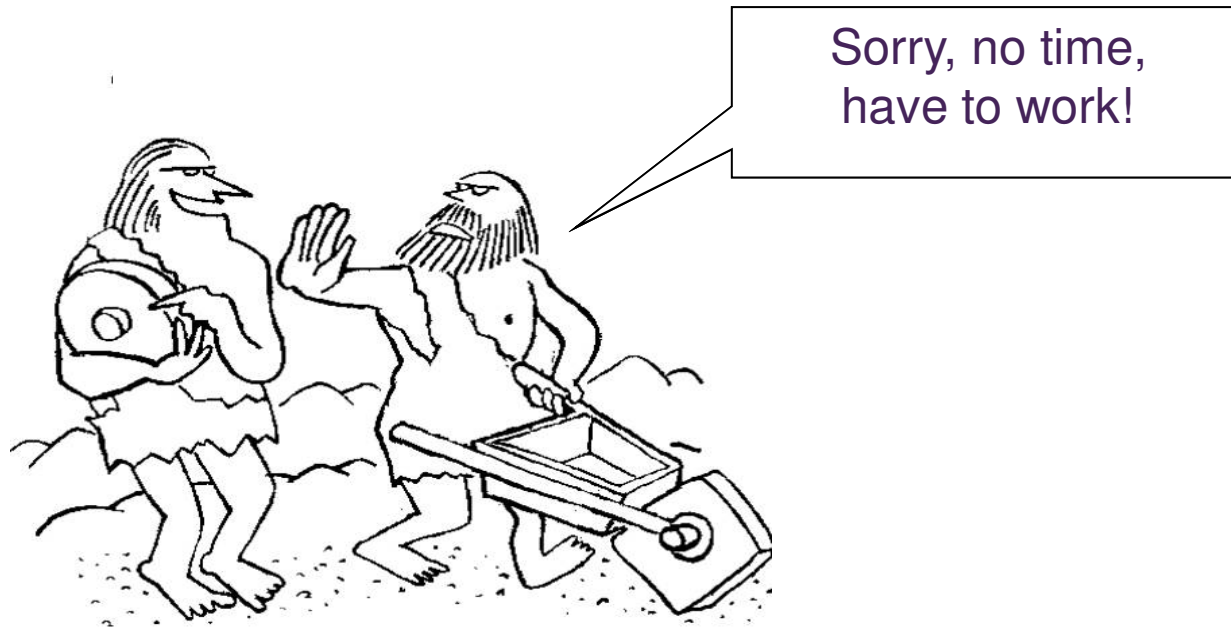


# Contributions to quality improvement & research



# The double task

1. Take care of sick & preterm babies
2. Quality improvement



# Missions for SNQ

1. Lessen the burden of measuring quality (data reporting)
2. Increase the experience of usefulness/value of measuring quality
3. Provide evidence for effects on care

## New modifications of Swedish ROP guidelines based on 10-year data from the SWEDROP register

Gerd Holmström <sup>1</sup>, Ann Hellström,<sup>2</sup> Lotta Gränse,<sup>3</sup> Marie Saric,<sup>4</sup> Birgitta Sunnqvist,<sup>5</sup> Agneta Wallin,<sup>6</sup> Kristina Tornqvist,<sup>3</sup> Eva Larsson <sup>1</sup>

**Conclusion** Modification of Swedish guidelines is proposed, including only infants with a GA of <30 weeks and postponing the first examination with 1 week in infants with GA 26–29 weeks. This would spare many infants from stressful examinations and reduce eye examinations with at least 20%.

# 2

## Data-driven audit of adverse outcomes

- **Severe Visual Disability Among Preterm Children**  
*Norman M et al, JAMA Network Open 2019*
  - *Severe visual impairment...potentially avoidable in 11/17 (65%) children ...untimely or no screening, missed diagnosis, untimely and suboptimal treatment. Large variations in infrastructure (facilities, guidelines, staffing, and annual patient numbers) were also identified as potential contributors to these findings.*
- **Extreme Neonatal Hyperbilirubinemia and Kernicterus**  
Adherence to National Guidelines for Screening, Diagnosis, and Treatment in Sweden.  
*Alkén J et al, JAMA Network Open 2019*
  - *Brain injury potentially avoidable in 11/13 (85%) children...untimely/lack of pre-discharge bilirubin screening, misinterpretation of bilirubin values, untimely/delayed/ no treatment with exchange transfusion.*
  - *6 of 13 affected families had applied for financial compensation from the Swedish Patient Insurance.*

JAMA | **Original Investigation**

## Association of Maternal SARS-CoV-2 Infection in Pregnancy With Neonatal Outcomes



Babies born to mothers with Covid-19 have a low risk of infection, new research shows

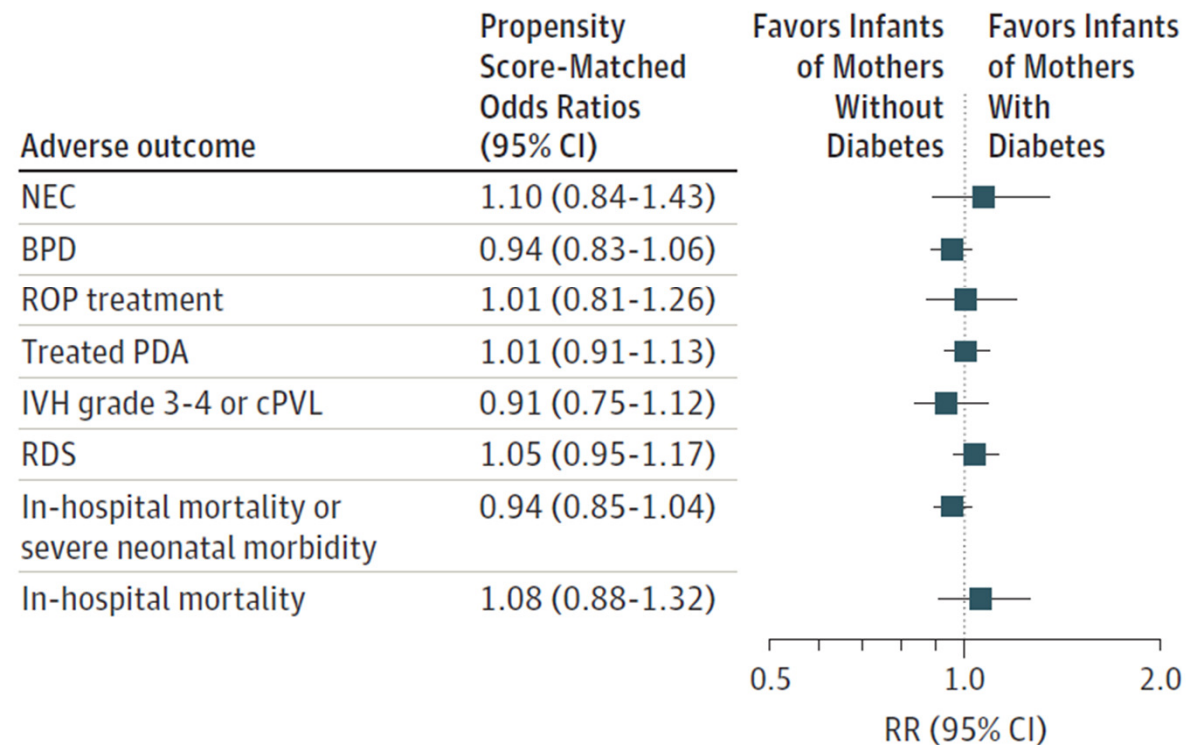
The separation of newborns from mothers who have tested positive for Covid-19 is unnecessary in most cases.

Mikael Norman, The Conversation · May 13, 2021 · 11:30 pm

# 4

## Building new knowledge about rare exposures & rare outcomes

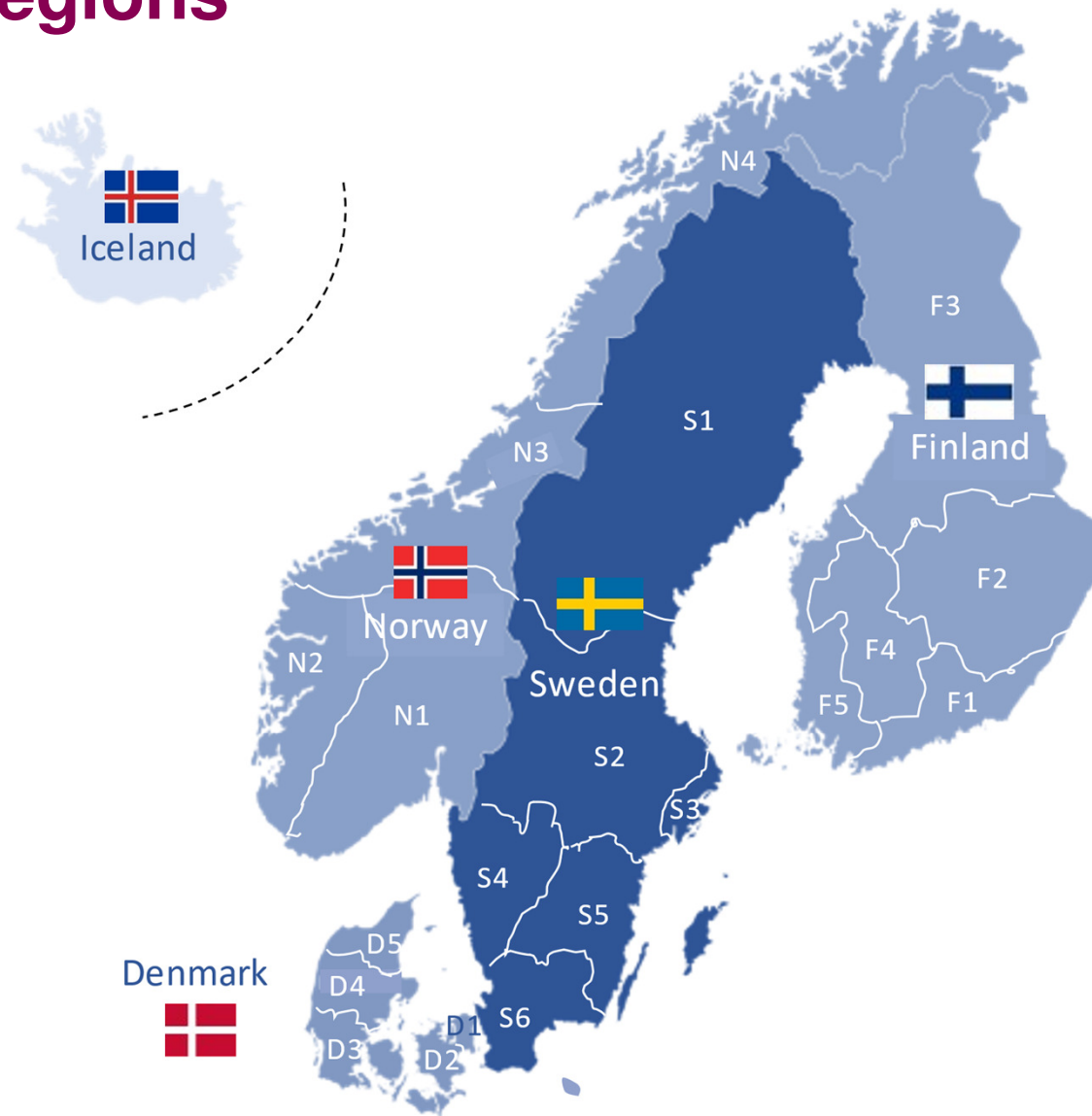
Figure. Association of Maternal Diabetes and Adverse Neonatal Outcomes After Very Preterm Birth



# Nordic collaborative study on preterm birth

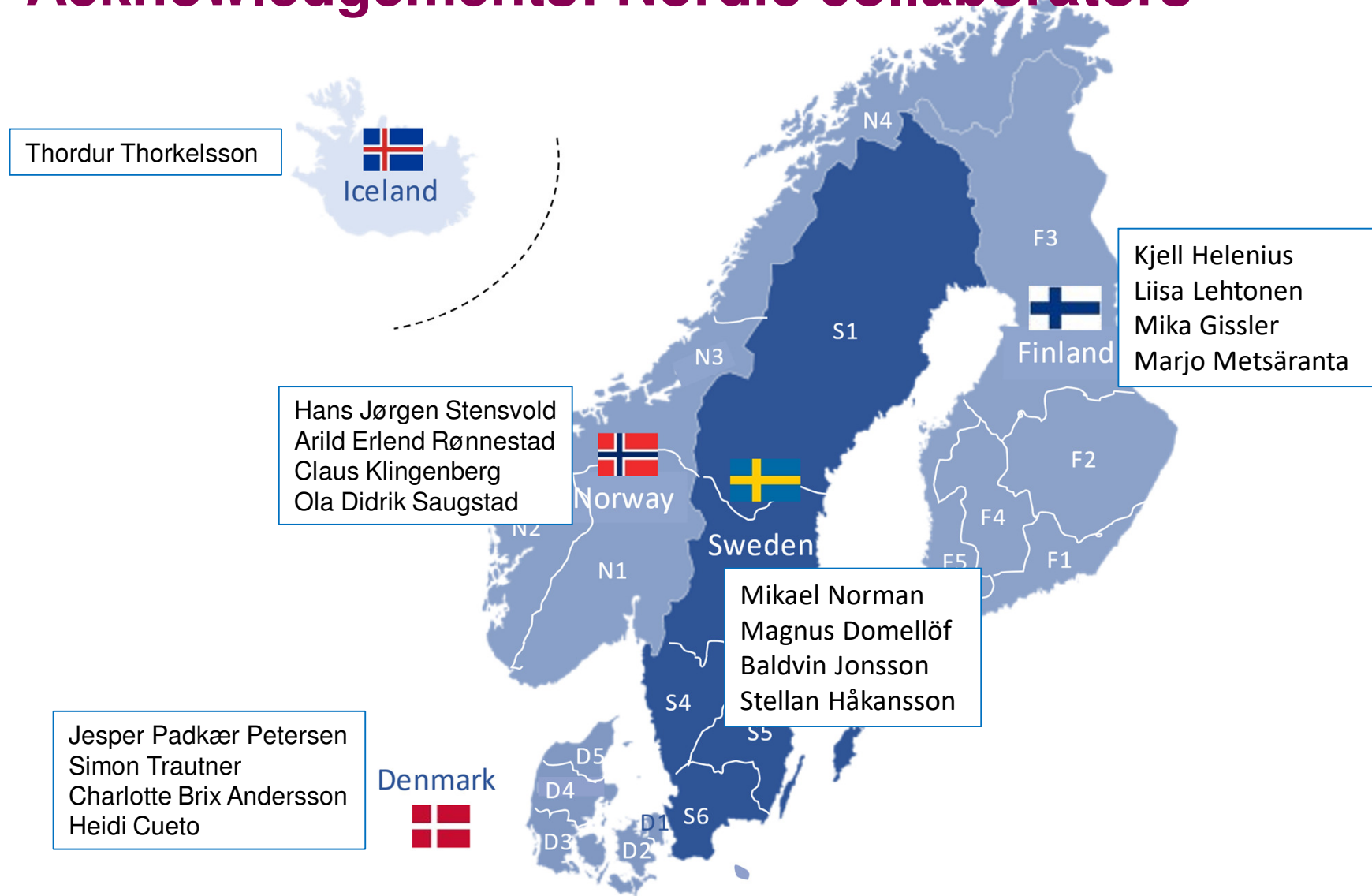
- Data from **one year**: 2021: approx. 300,000 livebirths
  - Danish Newborn Quality Database
  - Norwegian Neonatal Network
  - Childrens hospital, Iceland
  - Swedish Neonatal Quality Register
  - Finnish Medical Birth Register
- **21 greater regions**
- Stillbirths **not included** (no data)

# Greater regions





# Acknowledgements: Nordic collaborators



Thank you for your attention

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