

Clinical use of registers and data recording - the Scandinavian experience

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Nordic Perinatal Statistics

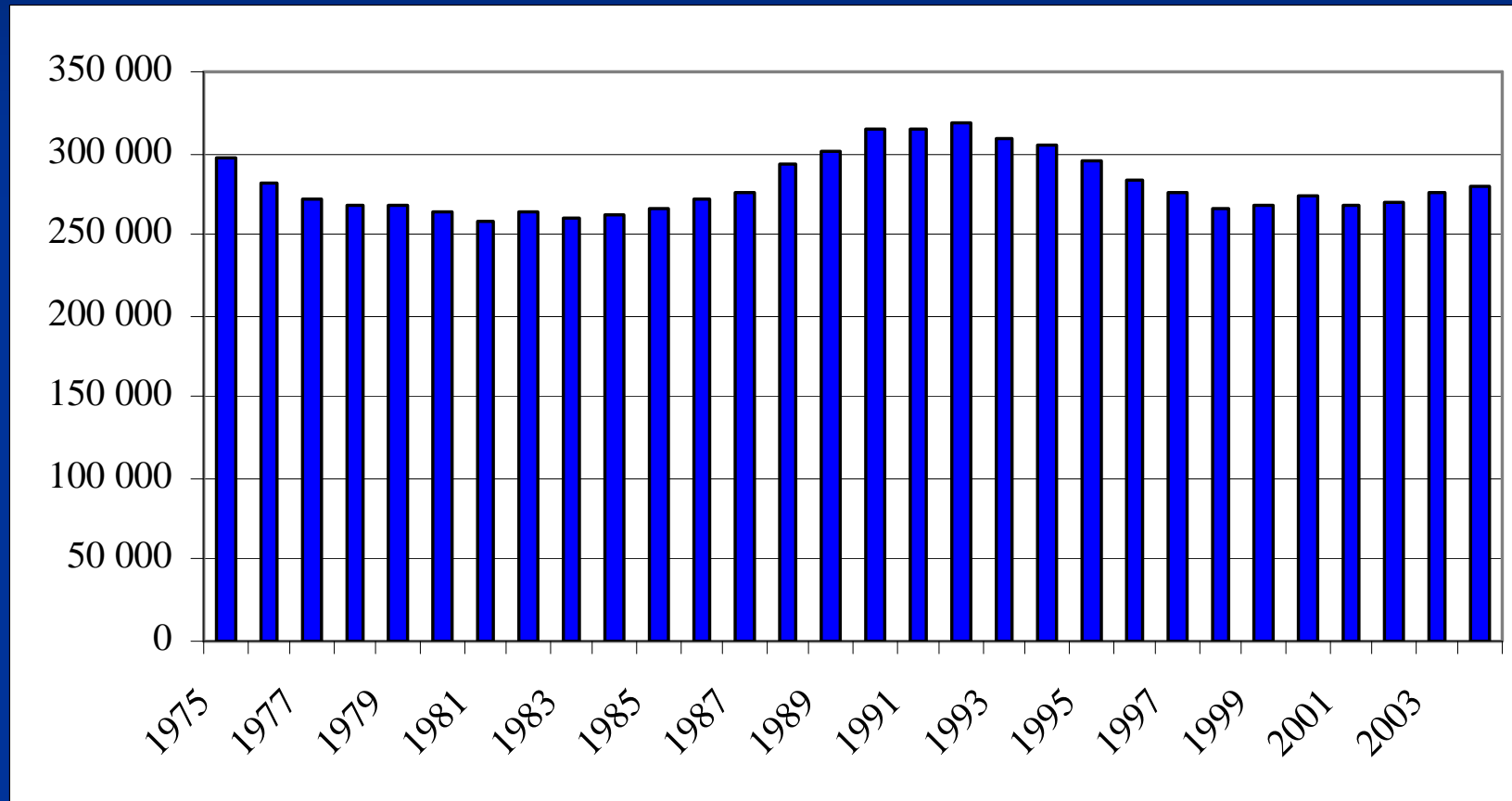
<http://www.stakes.info>

NOMBIR

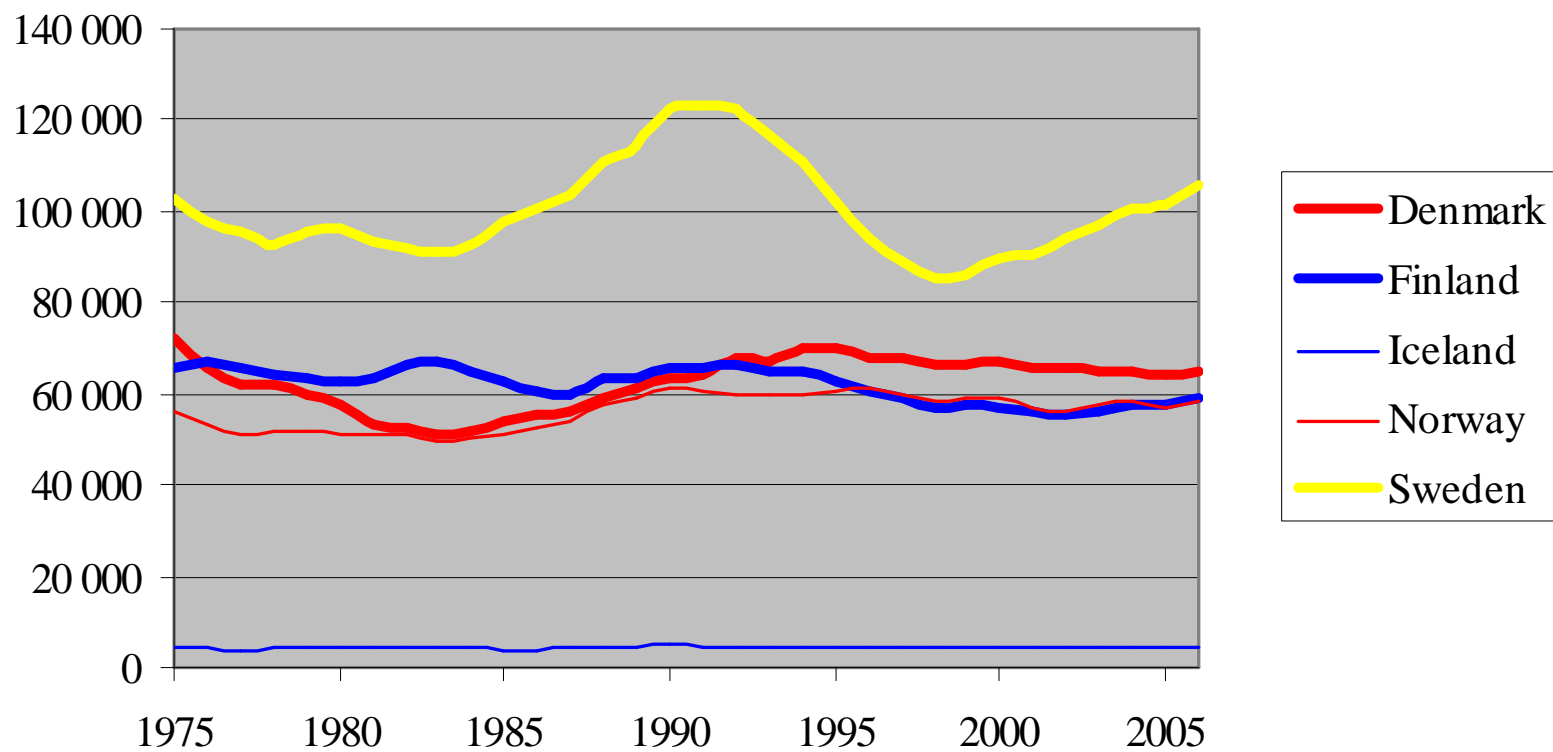
**Nordic Medical Birth
Registries**

2007

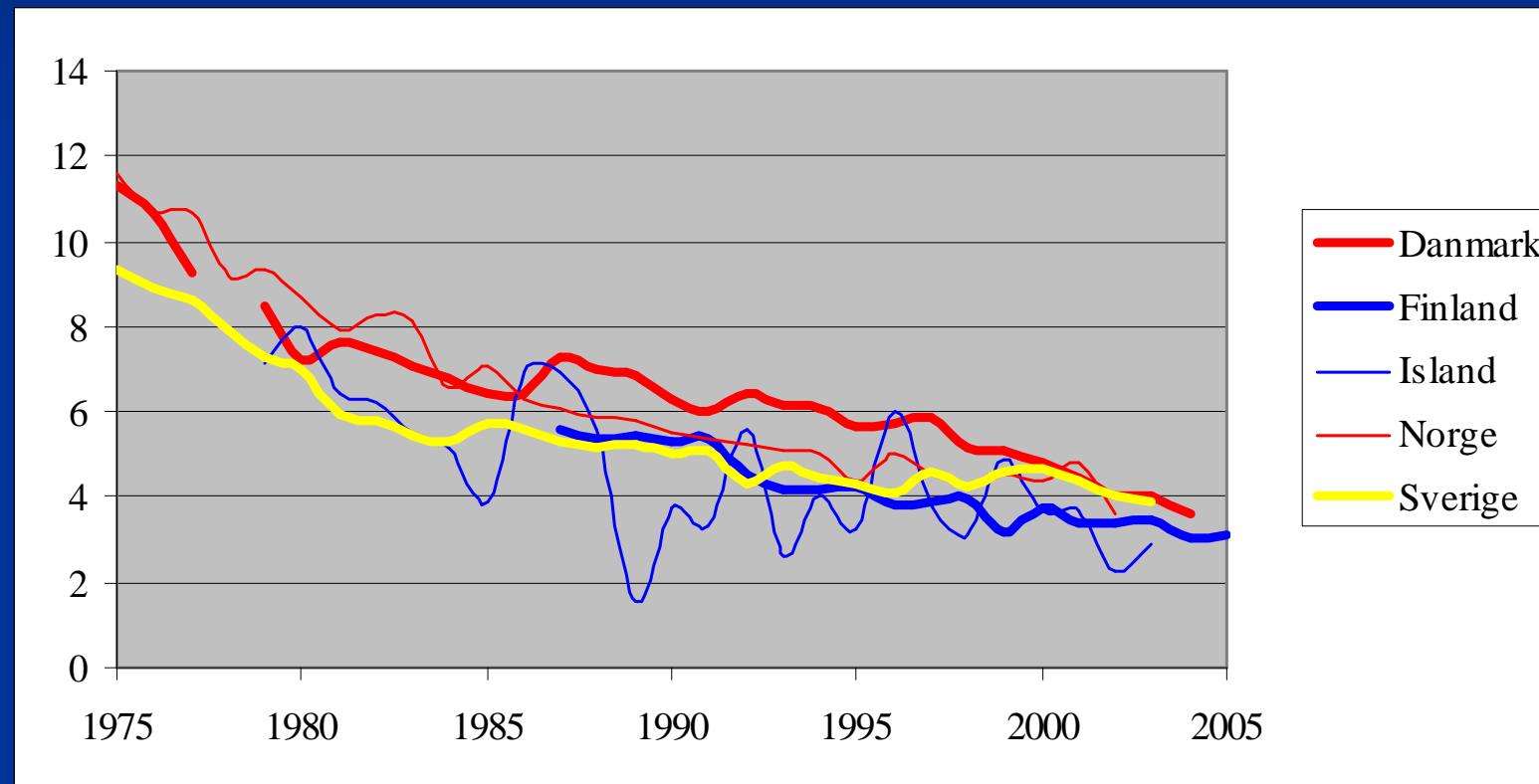
Deliveries in the Nordic countries 1975-2005



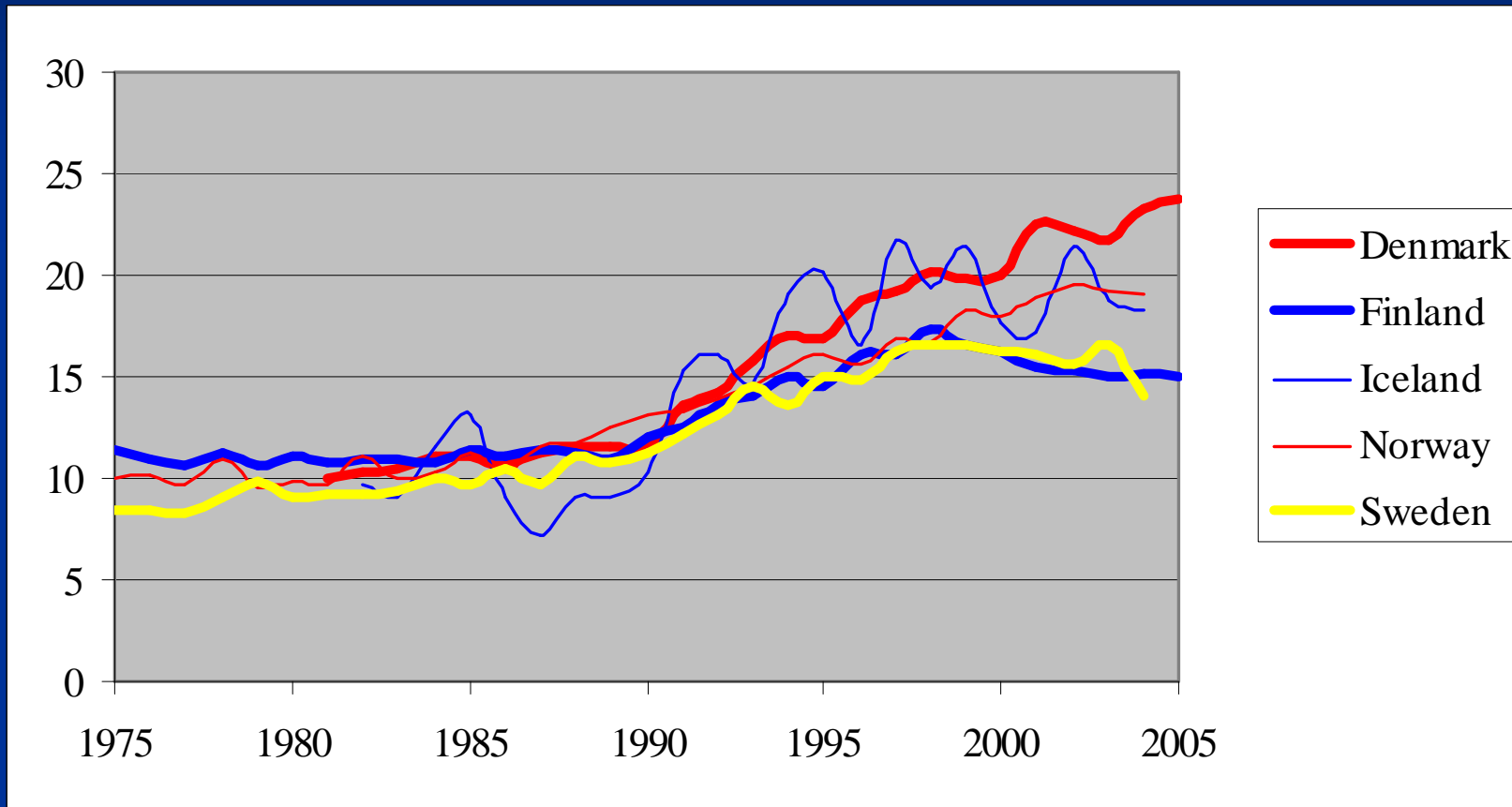
Live births 1975-2006



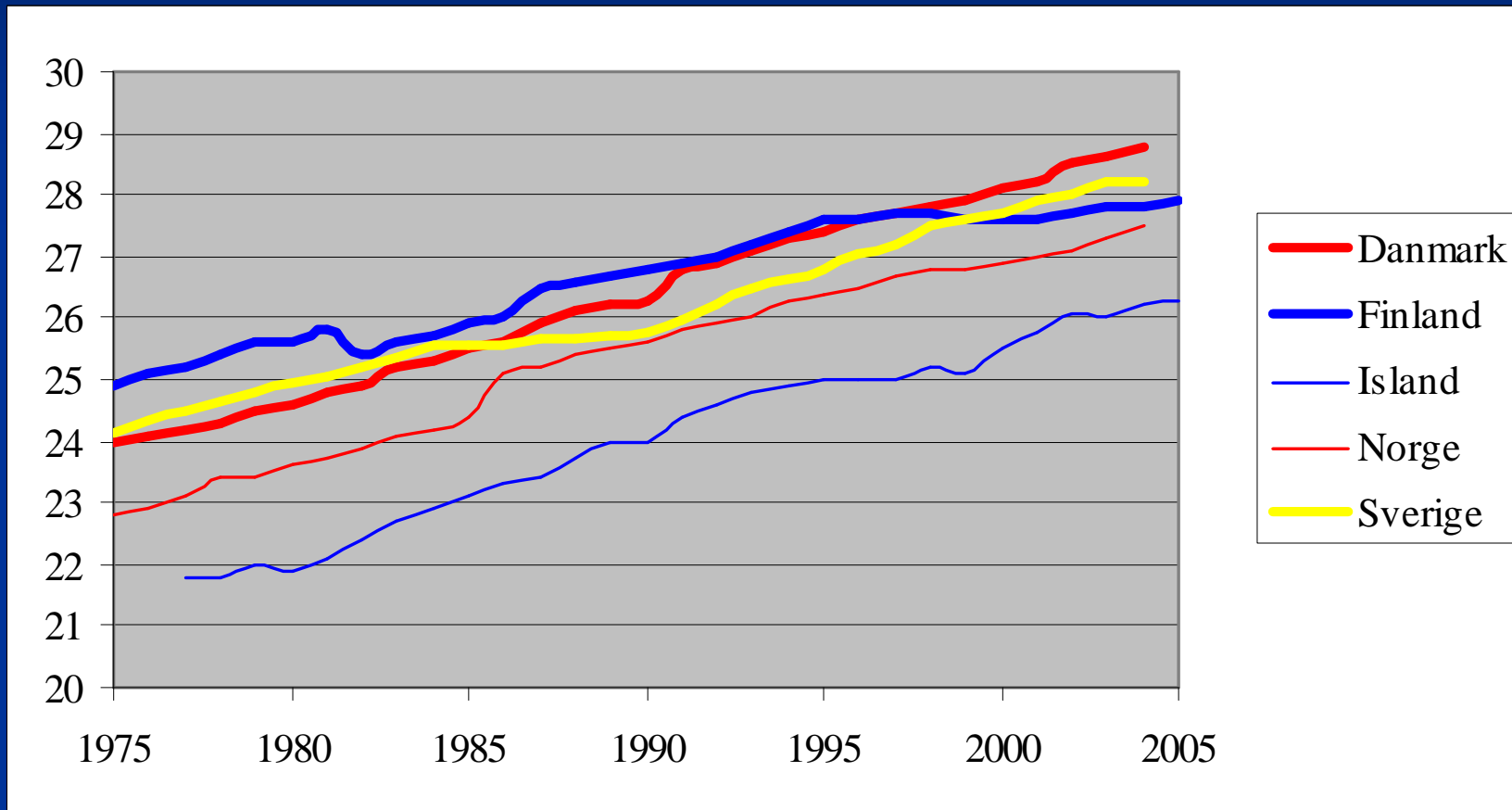
Perinatal death rate (infants above 1000 g)



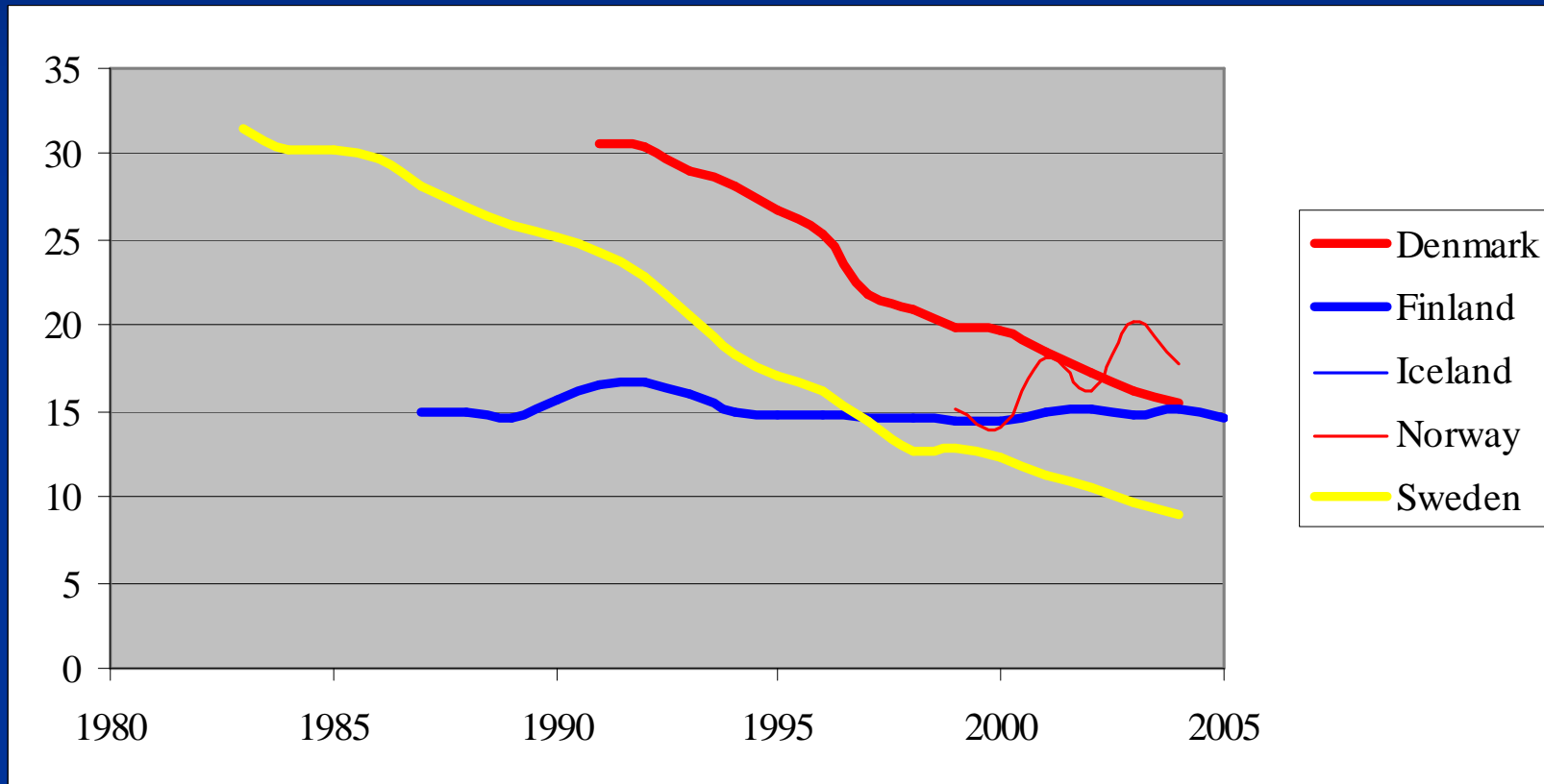
Multiple births



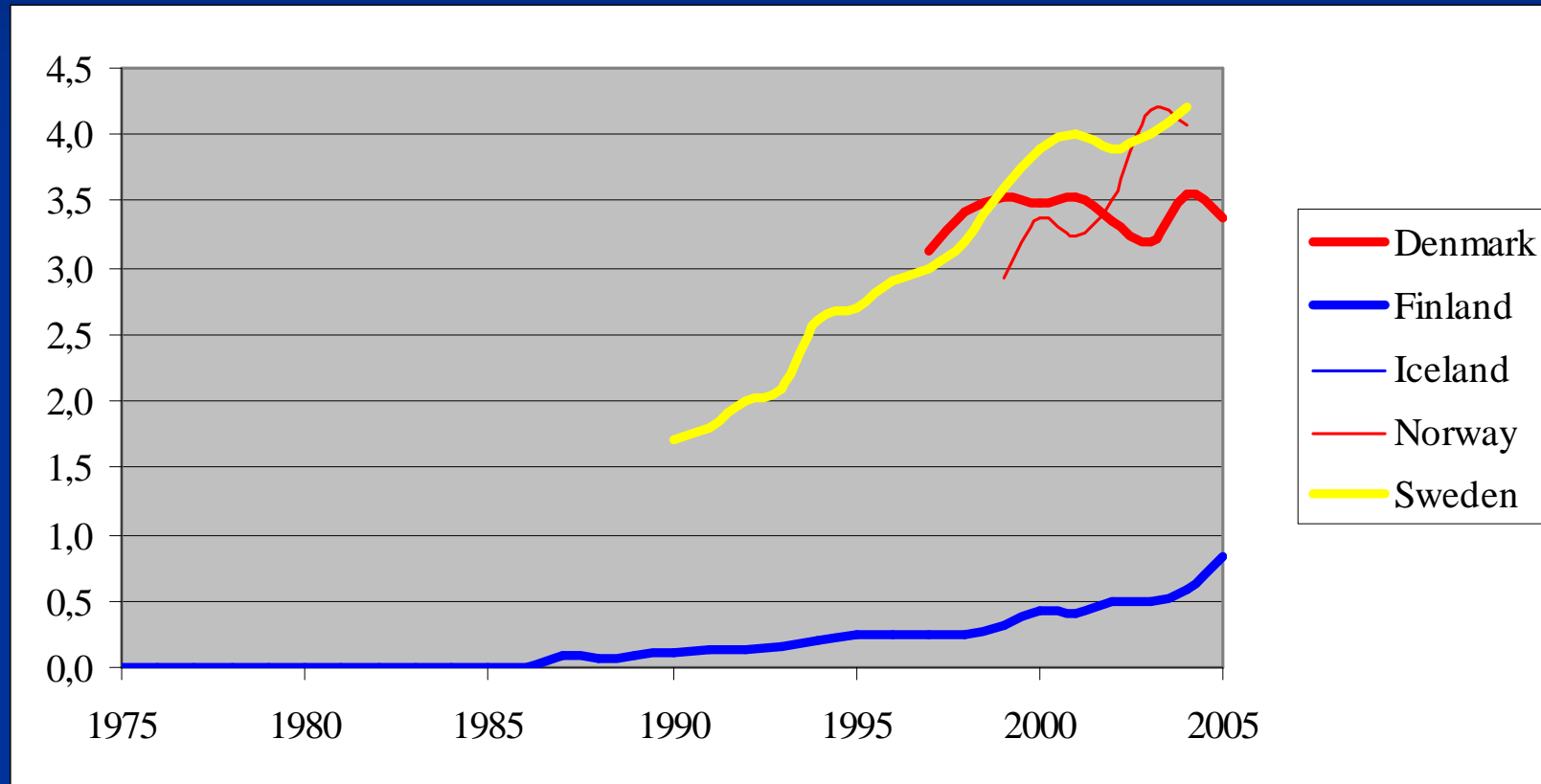
Maternal age - primipara



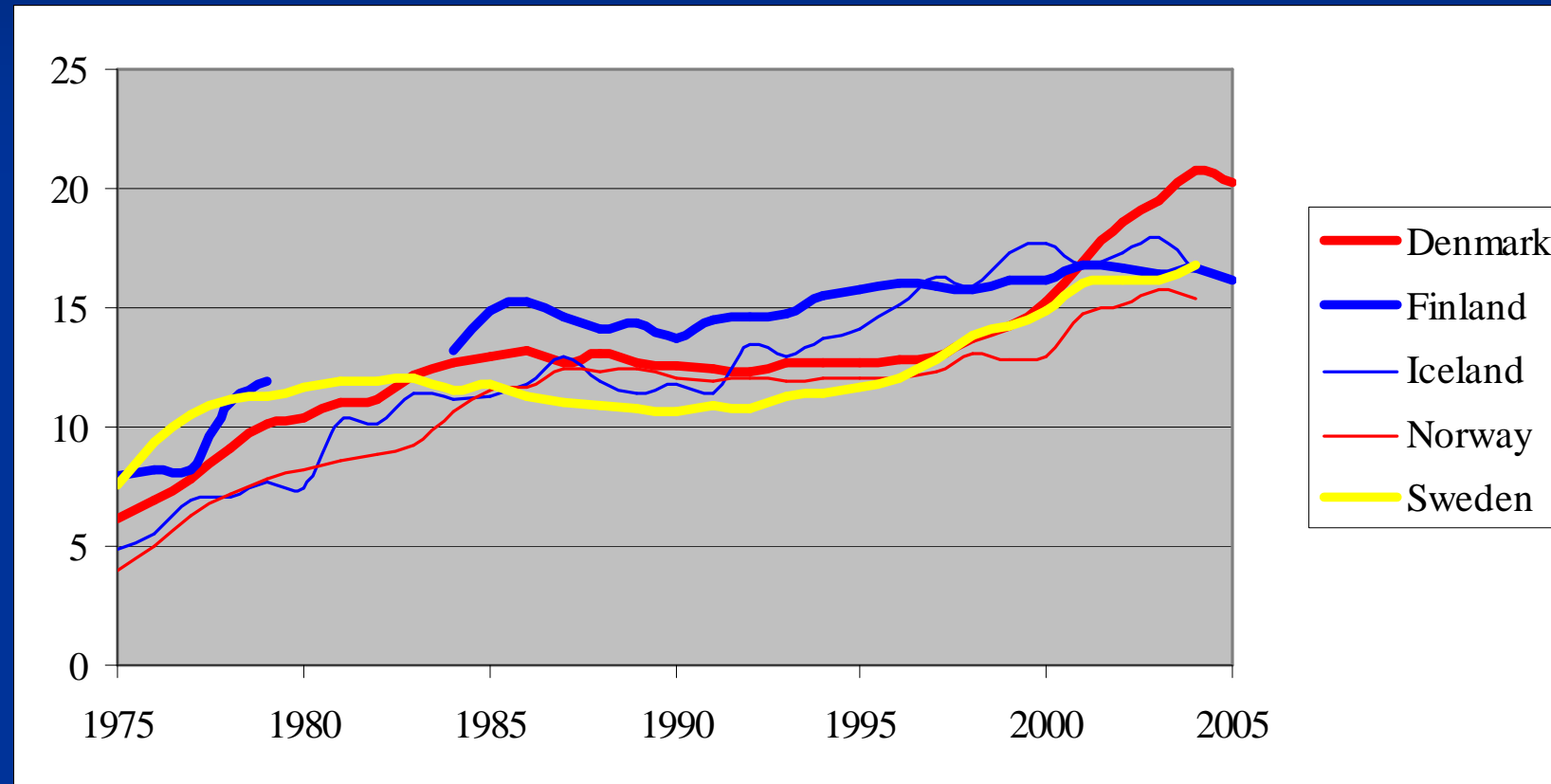
Smoking during pregnancy (%)



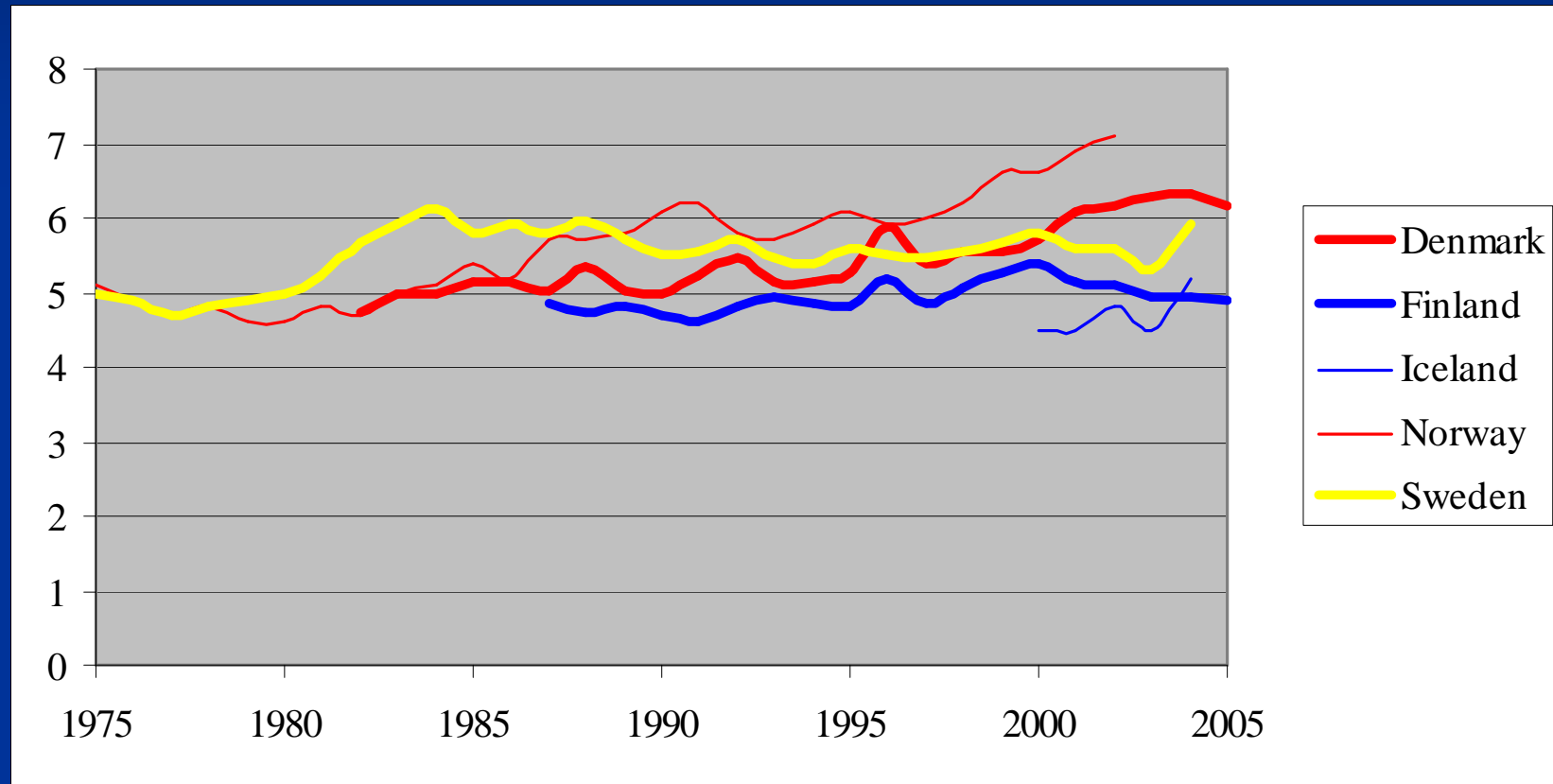
Perineal sphincter rupture (grade III and IV) %



Caesarean deliveries %



Preterm delivery %



Denmark

- National Patient Registry for all purposes (medical (diagnoses, surgery, interventions), organization of care, DRG/economy etc.).
- Case-based data (by unique personal ID)
- Reporting is mandatory for all public health care (>99%)

Denmark

- The Danish Birth Registry included in the National Patient Registry
- In 2000 reports were delayed for 3-4 years.
- Timely feedback to clinicians
- Collaboration between
 - National Board of Health
 - Danish Society of Obstetricians and Gynaecologists

Denmark – two types of reports

- Free choice of (all) different variables, by year, by region, by hospital, by parity, by gestational age group, by Robson groups
 - http://www.sst.dk/Informatik_og_sundhedsdata/Download_sundhedsstatistik/Foedsler_fertilitetsbehandling_og_abort/foedsler1.aspx?lang=da

Denmark – two types of reports

- Tables of selected perinatal indicators for each hospital compared with the region and the country.

- All deliveries and all intended vaginal deliveries

- http://www.sst.dk/Informatik_og_sundhedsdata/Registre_og_sundhedsstatistik/Beskrivelse_af_registre/Foedselsregister/Kvalitetesindikatorer_foedsler/Kvalitetsindikatorer_foedsler_moedre.aspx?lang=da

- Low risk primipara

- http://www.sst.dk/Informatik_og_sundhedsdata/Registre_og_sundhedsstatistik/Beskrivelse_af_registre/Foedselsregister/Kvalitetesindikatorer_foedsler/Kvalitetsindikatorer_foedsler_lavrisikogruppen.aspx?lang=da Term infants

- Term and preterm infants

- http://www.sst.dk/Informatik_og_sundhedsdata/Registre_og_sundhedsstatistik/Beskrivelse_af_registre/Foedselsregister/Kvalitetesindikatorer_foedsler/Kvalitetsindikatorer_foedsler_boern.aspx?lang=da

Denmark

- The two types of reports are accessible

for all

without password

- on the Internet

Good Obstetric Quality

- Few interventions and a low rate of minor complications
- And even less severe complications
- The optimal balance

Rare Obstetric Disorders – Why are they important?

- Individually uncommon, together a considerable burden
- Difficult to study, under researched
- Clinical practice rarely based on robust evidence
- “Near-miss” events

Rare serious complications and outcomes

- UKOSS – case-control surveys of individual indicators (in a setting without a population based "case based reporting")

UK Obstetric Surveillance System (UKOSS)

- Monthly prospective case collection from obstetrician, midwife, obstetric anaesthetist and risk midwife (individualised by hospital)
- Cohort or case control studies conducted as well as descriptive studies
- Rolling programme of studies
- Central data collection

We prepared for an EU project based on UKOSS

- EUROSS – which unfortunately was not funded

Why not use the existing Nordic Birth Registers?

- Rare serious complications and outcomes are supposed to be reported to national birth registers
- What are the implications of the rising CS rate in DK on subsequent pregnancies? (uterine rupture, placenta previa/percreta, peripartum hysterectomy etc.).
- Do the Nordic rates of reported rare serious maternal conditions and pregnancy complications differ?

Serious rare events (preparation for EUROSS)

	FINLAND		DENMARK		SWEDEN	
	2004 2005	/ 10.000	1997- 2006	/ 10.000	1999- 2005	/ 10.000
Placenta accreta requiring active management	1539	135,2	102	1,5	5	0,1
Uterine rupture	134	11,8	200	3,0	485	7,8
Eclampsia	74	6,5	254	3,8	453	7,6
Extreme obesity BMI >50	38	3,3	204	10,4		
Renal transplant	-	-	34	0,5	-	-
Alloimmune Thrombocytopenia	44	3,9	9	0,1	6	0,1
Amniotic fluid embolism	3	0,3	7	0,1	12	0,2
Antenatal pulmonary vascular disease	8	0,7	631	9,6	31	0,6
Antenatal myocardial infarction	0	0,0	273	4,1	1	0,0
Pemphigoid gestationis	15	1,3	126	1,9	90	1,8
Peripartum hysterectomy	17	1,5	236	3,6	59	1,1

Uterine rupture

- Total and partial rupture (dehiscence) do not have different ICD10-codes.
- Accidental findings of dehiscence cannot be sorted out.
- A suspected uterine rupture (indication for a CS) may be coded as uterine rupture – even though it is not verified.

Placenta accreta

- Placenta accreta has a specific ICD10 code
- No codes for placenta increta or percreta
- Antenatal diagnosis by ultrasound may not reflect the condition at delivery – different codes are needed.

Control groups

- Criteria for selection of controls are specific for a research question.
- To study several issues more than one control group is often needed.
- The Nordic Birth Registries (as opposed to UKOSS) provide case-based information on the total population that allow for different control groups.

In conclusion

- Registration of serious, rare adverse events in obstetrics need to be improved.
- Collaboration with UKOSS may provide mutual benefits (advantageous)
- The Nordic Birth Registries can provide several control groups ideal for each research question – thanks to the population based case-based registration



Nordic workshop

Obstetricians and the Medical Birth registries

Hven, 18-19 September 2008

Results of the Hven 2008 workshop

- Nordic Obstetricians and Nordic Medical Birth Registries agree on codes and definitions.
- Nordic prospective data collection in collaboration with UKOSS to start April 2009:
 - Placenta accreta, increta and percreta
 - Uterine rupture
- Detailed questionnaires for cases and controls to be elaborated in Skanör, Sweden, February 2009.

Perspectives

- A Nordic project high-lighting regional differences in obstetric practice focusing on both rare serious adverse outcomes and levels of interventions and minor complications.
- Interactive reporting system in a common Nordic electronic patient record.

Research

- Longitudinal (inter-generational) studies based on the National Patient Register, Civil Registers, Cause of Death Register etc.

in combination with

- The Danish National Birth Cohort of 100.000 pregnant women followed from start of pregnancy with follow up of infants. Includes extensive questionnaires and bloodsamples (DNA etc.) from mother, (father) and infant.