

## **TRANSCRIPT: The Nordic national registers - Added value and challenges, ECR module**

### Slide1

Hi, I'm Josephine Bilsteen. I'm a researcher at Department of Paediatrics at the Hvidovre Hospital, Denmark, and section of epidemiology at University of Copenhagen. Today I would like to talk to you about the added values of combining the clinical cohort and the Nordic national registers.

### Slide2

In RECAP project, we bring together clinical cohorts, including individuals born preterm from all over Europe. In addition, four countries also have access to national registers. These countries are Norway, Sweden, Finland, and Denmark. And these have a long tradition for the Nordic national registers, which includes everyone born in the country. These registers can therefore be seen as large cohorts. The main differences between clinical cohorts and the national registers are that the Nordic registers are set up for administrative purposes, and therefore, the individual researcher has less opportunity of changing the variables. On the other hand, these registers have been ongoing since the establishment [of the Medical Birth Register] so they might have a longer time series of data points. For instance, the Norwegian Medical Birth Register was established already back in 1967.

So now let's take a look at how the Nordic registers can provide new insights to the research to the research question in this demonstration project.

### Slide3

In this demonstration project, we wanted to investigate whether there are sex differences in survival to discharge in infants born at 22 to 26 completed weeks of gestation. First, we identified in these infants from the Medical Birth Registers is then each of the four Nordic countries. Then we started harmonising variables not only with the clinical cohorts but also internally as some variables such as gestational age changes over time. So for instance, for the Danish Medical Birth Register gestational age was recorded in completed weeks in the beginning of the period, and later in days. Then we also harmonized between the clinical cohorts and the Nordic registers. So for instance, the outcome survival to discharge was defined as surviving to six months as we in the Nordic national registers have information about the exact date of death. So now let's take a look at the population.

### Slide4

So for this presentation, I would like to focus on the Danish registers as I had

access to those for this demonstration project. And the first thing I did was to divide the data from the Danish Medical Birth Register into three time periods. One called the “pre-surfactant era” starting in 1978 and ending in 1989. Then a period I called “introduction to surfactant”, which covered the 1990s and a time period called “post-surfactant era” starting from 2000 and ending in 2016, which was the latest year I have information from the Danish Medical Birth Register.

Then from this table, you can see that the number of [liveborn] individuals formed from 22 to 26 complete weeks, it increases from the earliest period to the later periods. You can also see that the proportion of infants born from 22 to 24 weeks it increased from the “pre-surfactant era” into the 1990s to the “post-surfactant era”.

#### Slide5

If we now zoom in on the death before six months among females and males, then you can see that in the “pre-surfactant era”, then the proportions of males and females who died were quite similar. However, for the later periods, then males had a higher proportion of death before six months than females.

#### Slide6

So, in a model specifying mortality before six months, I included information on sex, gestational age, and time period as defined before. In addition, we also took into account singleton and multiple status. And what you see from this graph showing the preliminary findings is that the mortality decreases with higher gestational age and with a later birth year. So the highest mortality rates were found for individuals born at the earliest gestational ages in the “pre-surfactant era”. If we zoom in on the sex differences in the “pre-surfactant era”, then they are very small, the mortality patterns are almost the same for males and females. If we look at the 1990s, then the differences by sex are visible for those born in week 25, and 26. In the “post-surfactant era”, then we also see these differences in mortality between females and males, for those born in 25, and 26.

So these were the preliminary findings. And I think that can add to the findings from the clinical cohorts. As you can see, these are time trends. And we also chose to show results by gestational age which might provide some different insights. For instance, the gender differences in mortality seems to be smaller in infants on from 22 to 24.

#### Slide7

So in this presentation, I provided as a brief introduction to the Nordic national registers, and I showed some preliminary findings and highlighted the challenges

but also the added value of by using the Nordic national registers and combining this data source with the clinical cohorts.

Thank you so much for your attention.