New series on cohorts of the Research on European Children and Adults born Preterm (RECAP preterm) project – EFCNI

Our new series presents the cohorts of the EU-funded project „Research on European Children and Adults born Preterm“ (RECAP preterm), which aims at contributing to a better understanding on the long-term effects of preterm birth and thus to an improvement of the follow-up of these children. A research cohort is a group of people who share a defining characteristic, e.g. in the case of RECAP preterm, the cohorts consist of children (and later adults) born very preterm or with very low birth weight (VPT/ VLBW cohorts). This group is then accompanied over time to research the different consequences of preterm birth that can occur. RECAP preterm brings together Europe's strongest pregnancy, child to adult cohorts and a highly experienced group of organisations and individual researchers.

We start with the ESTONIA I & II cohorts and are delighted to present you a guest article by the expert in charge, Dr Heili Varendi from the University of Tartu.

RECAP preterm: the ESTONIA I & II cohorts

A guest article by Dr Heili Varendi, associate professor and neonatologist at University of Tartu

The main idea for the cohorts collected in Estonia was to fill a gap – by 2006 there was no national population-based data available about the outcome of very preterm births (VPT) after 7 postnatal days in Estonia. The aim was to collect nationwide data and create a system to assess quality of perinatal and neonatal care.

(c) Dr Heili Varendi, University of Tartu

Paediatricians from three 3rd level maternity units and two regional children hospitals in Estonia initiated a national pilot register for all sick newborns in 2007 – 2008. We also prepared national guidelines for follow-up of high-risk (incl. very preterm) infants until 2 years, that was published in 2008 and had been implemented in 2009. To prepare for these activities, our team collected good examples from Finland and Sweden.

Along with the pilot register, a prospective population-based study of very preterm infants born in 2007-2008 (n= 360) was carried out with follow-up at 2-years corrected age for all VPT (n=155) and at 5 years for a subgroup (n=49) born <1000g and <29 weeks gestational age (Estonia II). For the historical control group, retrospective national perinatal-neonatal data were collected for all very preterm births (n=264) in 2002-2003, and at 5 years assessed the health and development of the subgroup (n=61), born <1000g and <29 weeks GA (Estonia I). We have also collected data about health costs and use of health care resources for all these groups (Estonia I and II, n=624) from birth until 5 years.

Challenges in data collection were: lack of resources (e.g. Tallinn Town Government supported creation of the first database but all paediatricians collected perinatal data on voluntary basis; we applied for a research grant but only received 50% of the requested rate).

It was challenging to select tests for assessment of development; most of the available tests were not translated nor validated in Estonian and Russian.

During last 10 years we have worked to achieve a systematic data collection for high risk newborns from birth to preschool age, and finally, in 2019 we'll get the opportunity to have a chart for very preterm infants until discharge or 44 postmenstrual weeks included in the Estonian Medical Birth Registry.

Results: With these two cohorts we could see changes in perinatal and neonatal care and outcome of very preterm infants in Estonia. We had the opportunity to compare Estonian results internationally and provide feedback to obstetricians and specialists in neonatal care. We saw positive trend in increase of survival without concomitant rise in severe neonatal morbidity and long-term disability. But we faced different unexpected problems in child development at preschool age. Based on these results we could recommend prolongation of follow-up activities and interventions to extremely preterm children beyond 2 years, until school age.

With our cohorts we hope to help the families with very preterm deliveries by demonstrating what the potential prognosis of their VPT children is to survive and develop until preschool age.

View more:

- Overview of RECAP preterm project
- Overview of the different institutions and cohorts participating in RECAP preterm

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