

Series of RECAP cohorts – part 6: Follow-up of the POPS cohort in the Netherlands – EFCNI

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In 1983, a unique nationwide cohort of 1,338 very preterm (below 32 weeks of gestation) or VLBW (birth weight below 1500 g) infants in the Netherlands was collected and followed at several ages; the POPS (Project On Preterm and Small for gestational age infants) cohort. The studies with the POPS cohort have provided insight into how Dutch adolescents who were born very preterm or VLBW reach adulthood.



Picture: POPS-19 magazine

At 19 years of age a more extensive follow-up study was done for which the POPS participants visited the academic hospital closest to their home. The 19 year examination included questionnaires, tests on a computer and a full physical exam. At 19 years, 705 POPS participants participated (74% of 959 still alive).

The POPS participants showed more impairments on most outcome measures at various ages, compared to norm data. Major handicaps remained stable as the children grew older, but minor handicaps and disabilities increased. At 19 years of age, only half (47.1%) of the survivors had no disabilities and no minor or major handicaps. Especially those born small for gestational age (SGA) seemed most vulnerable.

The POPS participants were informed about the outcomes through the “POPS-19 magazine”, a glossy which also included interviews with POPS participants and advice on what health outcomes they should regularly check. At 14 years of age the POPS participants and their parents had also received a booklet with outcomes of the POPS cohort: “Even little ones grow up”. The POPS-19 magazine can also be downloaded through the website (www.tno.nl/pops) and POPS participants can also update their contact details on the website.

These long-term cohort outcomes help to support preterm and SGA born children and adolescents in reaching independent adulthood, and stress the need for long term follow-up studies and to promote prevention of disabilities and of preterm birth itself. The RECAP ICT platform, which will combine the data of 20 European cohorts of children and adults born very preterm or very low birth, will also contribute to this.

Please note:

The RECAP preterm project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 733280.

