

## Terms of Use Data Requests POPS-cohort

For data requests of the POPS cohort (see [www.tno.nl/pops](http://www.tno.nl/pops) or <https://platform.recap-preterm.eu/pub/study/pops>). This document describes the terms of use and instructions for data requests.

### Article 1. Description of data (metadata)

1. A description of the collected POPS-data and -findings:
  - a. RECAP-platform cohort-description with a description of the POPS-cohort, main publications and follow-up ages and the number of subjects that participated: <https://platform.recap-preterm.eu/pub/study/pops>
  - b. Dutch overview of POPS at Zorggegevens: [Zorggegevens \(second tab contains a description of data and number of subjects\)](#)
  - c. Publication of data until 19 years: Van der Pal-de Bruin KM, van der Pal SM, Verloove-Vanhorick SP, Walther FJ (2015) Profiling the preterm or VLBW born adolescent; implications of the Dutch POPS cohort follow-up studies. Early Hum Dev 91(2):97-102. <https://doi.org/10.1016/j.earlhumdev.2014.12.007>
  - d. A description of data or publications can be requested through [pops@tno.nl](mailto:pops@tno.nl)
2. The data has been pseudomized and is securely stored in the vault of TNO's sharepoint.

### Article 2. Data requests

1. Data requests can be submitted to the research committee by emailing the POPS team at TNO Child Health ([pops@tno.nl](mailto:pops@tno.nl)) with TNO's Child Health Secretary in cc ([zelfstandig-tno-secretariaatchls@tno.nl](mailto:zelfstandig-tno-secretariaatchls@tno.nl)).
2. The data request will be reviewed by the members of the POPS research committee.
3. The data request should include:
  - a. Contact information of the applicant
  - b. Introduction/background of the data request
  - c. Overview of requested data
  - d. Data analysis plan which includes a description of the study's purpose, relevant research questions and hypotheses, and an appropriate statistical analysis plan.
4. After approval, the applicant will receive a quotation of estimated costs of the data request.
5. After signing the quotation by both parties, a Data Transfer Agreement (DTA) will be drafted. Upon signing the DTA by both parties and receipt of the payment by TNO, the requested pseudonymized data will be send through a secured link.
6. Any costs associated with the data request, or preparation of a DTA, are charged to the applicant.

### Article 3. Publication of findings

1. The applicants shall publish their findings.
2. Prior notice of any planned publication shall be given by the applicant to TNO at least 45 calendar days before the publication. Any objection to the planned publication shall be made by written notice to the applicant within 30 calendar days after receipt of the notice. If no objection is made within the time limit stated above, the publication is permitted. Minimally one member of the POPS research committee will be included as one of the co-authors.
3. It is appreciated if applicants inform the research committee about relevant data transformations, problems with the data or contrasting findings.