## **About the Winter School**

The RECAP preterm platform promotes collaborative research by pooling data from very preterm cohorts and provides exciting opportunities to generate new knowledge about the consequences of preterm birth. This Winter School will provide you with an overview of very preterm cohorts and collaborative research principles and techniques. Through a mixture of lectures and workshops, you will learn about existing very preterm cohorts in Europe, new research on children and adults born very preterm based on pooled data, and how to implement a collaborative research protocol including the ethical and legal requirements, procedures for harmonising data, the technological aspects of storing and sharing data, and analytic approaches and software. The program will be accompanied daily by group work in which you will use your new knowledge to create your own collaborative research project that can be carried out using the RECAP preterm data platform. Participants are expected to come with ideas for research projects to be developed.

A minimum of 20 and a maximum of 35 participants will be accepted. The course will be in English.

## **About RECAP preterm**

The overall aim of the RECAP preterm project is to improve the health, development and quality of life of these children and adults by developing the RECAP preterm cohort platform, a sustainable, geographically diverse and multidisciplinary database of national and European cohorts of infants born very preterm or with very low birth weight (VPT/ VLBW cohorts). This network contains cohorts constituted over a 30 year time span and is designed to optimise the use of population data for research and innovation in healthcare, social and education policy.



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 733280.



### Winter School

Collaborative Research on Very Preterm Birth: Concepts and Methods – Working with the RECAP Preterm Data Platform

5-day workshop: 29 November – 3 December 2020 Castle Fürstenried, Munich, Germany







# Workshop

# **Target audience**



Researchers in the fields of neonatology and epidemiology who wish to learn about cohorts and registers, and especially how to use the RECAP preterm platform of very preterm birth cohorts for research.

#### Fee

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Early Bird: EUR 780 (before 31<sup>st</sup> March 2020)

Standard: EUR 850

Accommodation and board are included in the registration fee. Participants are responsible for organising and covering their own travel expenses.

# Registration



Registration opens on 1<sup>st</sup> February 2020 and closes on 30<sup>th</sup> June 2020. Early Bird registration is available until 31<sup>st</sup> March 2020.

For more information please visit https://recap-preterm.eu/

## **Group work**



There will be daily group work in which participants will use their new knowledge to create their own collaborative research project that can be carried out using the RECAP preterm data platform. Participants are expected to come with ideas for research projects to be developed.

### Sessions/Topics

Very preterm birth: consequences and outcome in childhood & future research

Jennifer Zeitlin & Rolf Maier

Overview of adult outcome studies across the world Dieter Wolke

Whole countries as cohorts – Nordic registers as tools to assess long-term outcomes of preterm birth

Eero Kajantie & Petteri Hovi

Linking cohorts and the law

Evert-Ben van Veen

Managing preterm cohort data using the platform: functionality overview

Artur Rocha & Rui Camacho

Preparing for data harmonisation

Elizabeth S. Draper

Carrying out data harmonisation on the platform

Elizabeth S. Draper & Artur Rocha

How to organise international collaborations

Maaike Beltman

Advanced data harmonisation – Statistical concepts & methods

Stef van Buuren & Leonhard Bakker

Advanced data harmonisation – A hands-on practical Stef van Buuren & Leonhard Bakker

The making of a cohort participant: challenges and achievements in a long-term journey

Henrique Barros

Involving families as partners in research projects Nicole Thiele

Conducting research using the RECAP preterm platform Andrei Morgan

Guided group work

# Faculty

Leonhard Bakker, MSc, Netherlands Organization for Applied Scientific Research TNO, Leiden, The Netherlands

Professor Henrique Barros, MD, PhD, Institute of Public Health University of Porto, Portugal

Maaike Beltman, MSc, Netherlands Organization for Applied Scientific Research TNO, Leiden, The Netherlands

**Professor Stef van Buuren**, PhD, 1) Netherlands Organization for Applied Scientific Research TNO, Leiden; 2) Dept of Methodology & Statistics, University of Utrecht, Utrecht, The Netherlands

**Professor Rui Camacho**, PhD, Researcher at LIAAD, INESC TEC, Teacher at Faculty of Engineering University of Porto, Portugal

Professor Elizabeth S. Draper, PhD, Professor of Perinatal & Paediatric Epidemiology, University of Leicester, UK

**Petteri Hovi**, MD, Senior Researcher, National Institute for Health and Welfare, Helsinki, Finland

**Professor Eero Kajantie**, MD, Research Manager, National Institute for Health and Welfare, Helsinki and Oulu, Finland, Professor of Lifecourse Medicine, University of Oulu, Finland

**Professor Rolf F. Maier**, MD, Children's Hospital, University Hospital Marburg, Germany

Andrei Morgan, MBChB, MRCPCH, MSc, PhD, Neonatologist / Epidemiologist, National Institute of Health and Medical Research (INSERM), Paris, France

Artur Rocha, Area Leader, INESC TEC, Porto, Portugal

**Nicole Thiele**, MBA, EUPATI-Fellow, Vice Chair of the Executive Board, European Foundation for the Care of Newborn Infants, Munich, Germany

Evert-Ben van Veen Ll.M., MLC Foundation, The Netherlands

**Professor Dieter Wolke**, Ph.D. Dr rer nat h.c., Dipl-Psych., Department of Psychology and Warwick Medical School, University of Warwick, UK

**Professor Jennifer Zeitlin**, D.Sc, Director of Research, Obstetrical, Perinatal and Pediatric Epidemiology, National Institute of Health and Medical Research (INSERM), Paris, France

