



RECAP

“Research on European Children and Adults born Preterm”

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Winter or Summer School

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<i>Deliverable Leader:</i>	EFCNI
<i>Email:</i>	nicole.thiele@efcni.org
<i>Contributors</i>	EFCNI, UMR, UoW, ISPUP, TNO

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PP	Restricted to other programme participants (including the Commission Services)	
RE	Restricted to a group specified by the consortium (including the Commission Services)	
CO	Confidential, only for members of the consortium (including the Commission Services)	

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EXECUTIVE SUMMARY

A training curriculum (“Summer School”) is developed with input from all partners, targeting clinicians and researchers, e.g. neonatologists, epidemiologists, psychologists, and others (practitioners from varied fields ranging from psychology to neuro-imaging) involved in the long-term care of preterm born children. The curriculum focusses on the newly created data platform, its structure, accessibility and utilization.

The training was planned to take place as a five-day workshop between 28 November – 3rd December 2020. Because of the COVID-19 pandemic, the Steering Committee decided to change the format from a face-to-face training meeting to an e-learning event.

On 1st July 2021, the e-learning was launched as “Summer School” and since then can be accessed via a password protected section on the RECAP preterm website. It provides registered participants with an overview of very preterm cohorts and collaborative research principles and techniques. Through a mixture of interviews with consortium partners and presentation videos, the participants 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, involvement of patient representatives, procedures for harmonizing data, the technological aspects of storing and sharing data, and analytic approaches and software.

Between 1st July and 30th September 2021, an online Discussion Forum allowed for an interactive exchange between the participants and consortium partners. Additionally, participants could obtain a certificate for the successful answering of a multiple-choice quiz set up by the project partners.

RECAP Consortium Partners

Abbv	Participant Organization Name	Country
TNO	NEDERLANDSE ORGANISATIE VOOR TOEGEPAST NATUURWETENSCHAPPELIJK ONDERZOEK TNO	Netherlands
UoW	THE UNIVERSITY OF WARWICK	UK
INSERM	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE	France
ISPUP	INSTITUTO DE SAUDE PUBLICA DA UNIVERSIDADE DO PORTO	Portugal
MEDLAW	MedLawconsult (Van Veen, Toegepast Gezondheidsrecht)	Netherlands
INESC TEC	INSTITUTO DE ENGENHARIA DE SISTEMAS E COMPUTADORES, TECNOLOGIA E CIENCIA	Portugal
ULEIC	UNIVERSITY OF LEICESTER	UK
EFCNI	EUROPEAN FOUNDATION FOR THE CARE OF NEWBORN INFANTS	Germany
NTNU	NORGES TEKNISK-NATURVITENSKAPELIGE UNIVERSITET	Norway
KI	KAROLINSKA INSTITUTET	Sweden
UKB	UNIVERSITAETSKLINIKUM BONN	Germany
UH	HELSINGIN YLIOPISTO	Finland
OPBG	OSPEDALE PEDIATRICO BAMBINO GESU	Italy
HH	Hvidovre Hospital	Denmark
UMR	PHILIPPS UNIVERSITAET MARBURG	Germany
UTARTU	TARTU ULIKOOL	Estonia
UANTWERPEN	UNIVERSITEIT ANTWERPEN	Belgium
concentris	Concentris Research Management GmbH	Germany
THL	TERVEYDEN JA HYVINVOINNIN LAITOS	Finland

TABLE OF CONTENTS

Executive summary.....	2
Table of contents.....	4
1 Introduction.....	5
1.1 Purpose and Scope.....	5
1.1.1 The E-Learning Concept: Four main elements form the digital Summer School.....	5
2 Realisation Phase.....	7
2.1 Timeline.....	7
2.2 The RECAP preterm website: Hosting the digital Summer School.....	8
2.3 Promoting the digital Summer School.....	9
3 Outreach.....	10
4 Conclusion.....	11
5 Outlook.....	12
6 Thank You.....	13
7 Appendices.....	14

1 INTRODUCTION

1.1 Purpose and Scope

In the description of Action the RECAP preterm consortium planned a **five-day Summer School event for maximum 30 persons**, targeting clinicians and researchers including neonatologists, epidemiologists, psychologists, and others (practitioners from varied fields ranging from psychology to neuro-imaging) involved in the long-term care of preterm children. The aim of the Summer School was to inform and train interested researchers in setting-up multidisciplinary and cross-country collaboration for future research projects and the use of the newly developed RCAP preterm Cohort Platform.

With this aim, representatives of all project partners formed a sub-working group led by two senior academics (“Summer School Committee”) and developed a training curriculum with a focus on the newly created data platform, its structure, accessibility and utilization. The ethical and legal aspects of data sharing across Europe, how to download information and how to analyze would be taught and explored. New applications such as collection by mobile devices would be presented as well as examples of findings generated by use of the platform. An overview should be given on collaborative project work and the role of PPI in a research project. The Summer School sessions were planned to be conducted by the Work Package leads. With the help of promotional material, such as presentation slide, flyer, social media posts all partners promoted the event broadly. First registrations to the event were received.

Unfortunately, the pandemic situation did not allow for a face-to-face meeting. The project’s Steering Committee was forced to change the format of the Summer School from a five-day on-site meeting into a digital event. The Summer School Committee developed a new concept based on the originally developed training curriculum, in close exchange with the project’s Steering Committee:

1.1.1 The E-Learning Concept: Four main elements form the digital Summer School

- **11 Modules (“chapters”) of about 60 minutes each**
 - The Modules correspond to the 10 Work Packages, and include an additional Module created by the Early Career Researchers of the project.
 - Each of the 11 Modules consists of
 - An interview with the Work Package lead of about 10 minutes highlighting the core objectives of the Work Package, challenges that were met during their work for the project and how these were solved;
 - 2-6 video contributions created by each Work Package of about 10 – 15 minutes together with a downloadable transcript.
(All contributions are listed in: **Annex 1**)

- Multiple-Choice Quiz

- All partners developed five multiple choice questions based on the learnings from their Module. ISPUP programmed the quiz and EFCNI evaluated the responses.
- Participants needed score of at least 80 % in the multiple-choice questions to pass the quiz.
- Participation in the quiz was possible during the time 1st July – 30 September 2021.

- Certificate

- EFCNI designed the certificate for successful completion of the multiple-choice quiz.
- The certificate is evaluated beginning of October 2021 and sent to those participants who successfully passed the multiple-choice quiz.

- Discussion Forum

- The Discussion Forum was programmed by INESC TEC and filled with first content by INSERM and EFCNI.
- All Work Package partners subscribed to the Forum with at least one representative.
- The Forum allowed for an interactive exchange between participants themselves and between participants and the project partners.
- The Forum was moderated between 1st July – 30 September 2021.

Flyer for the promotion of the digital Summer School:

E-Learning

Target audience



Researchers in the fields of neonatology epidemiology or psychology who wish to learn about cohorts and registers. Particular interest in using the RECAP preterm platform of very preterm birth cohorts for research.

Fee



No charges are involved. Free access. Advance registration required.

Registration



Please register before 1st July 2021 under <https://recap-preterm.eu/>

Technical Settings



The E-Learning is accessible via PC/laptop and tablets. The use of a smartphone is not recommended. A high-speed internet connection is required.

Exchange ideas



Registered participants will have the opportunity to ask questions and/or to exchange ideas with the partners of the RECAP preterm project on the use of the RECAP preterm data platform.

Topics presented by the project teams

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

Overview of adult outcome studies across the world

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

Record linkage for epidemiological research

Managing preterm cohort data using the platform: functionality overview

Preparing for data harmonisation

Carrying out data harmonisation on the platform

How to organise international collaborations

Advanced data harmonisation – Statistical concepts & methods

Advanced data harmonisation – A hands-on practical

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

Involving families as partners in research projects

Conducting research using the RECAP preterm platform

Faculty

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

Professor Henrique Barros, MD, PhD, Institute of Public Health of the University of Porto (ISPUP), School of Medicine, Porto, Portugal

Maaïke 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, Philipps University 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 L.M.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



2 REALISATION PHASE

2.1 Timeline

December 2017 – March 2020	Steering Committee decides on the format of the Summer School, training curriculum and promotional material are developed. Location is reserved, promotional material is developed. Promotion of the Winter School starts and first registrations are received.
September 2020	The project's Steering Committee decides to change the format of the Summer School into a digital format
October 2020 – January 2021	Development and design of promotion material for the Summer School
January 2021 – September 2021	Promotion of the Summer School by all project partners
October 2020 – March 2021	Development and recording of presentations within each Work Package and by the Early Career Researchers of the project
April 2021	Recording of 11 interviews of the Work Package leads and a representative of the Early Career Researchers
April 2021 – June 2021	Set-up of Summer School subsite on the RECAP preterm website, upload of video contributions and interviews Set-up of Multiple-Choice Quiz and development of certificate
June 2021	Outreach to participants (welcome and invitation to the Discussion Forum)
1 st July 2021	Launch of digital Summer School
July 2021- September 2021	Keeping contact with Summer School participants via Email and the Discussion Forum
28 September 2021	Option for Summer School participants to participate in public session of last RECAP preterm Steering Committee meeting, where results of the project will be presented
October 2021	Evaluation of Multiple-Choice Quiz and sending of certificates

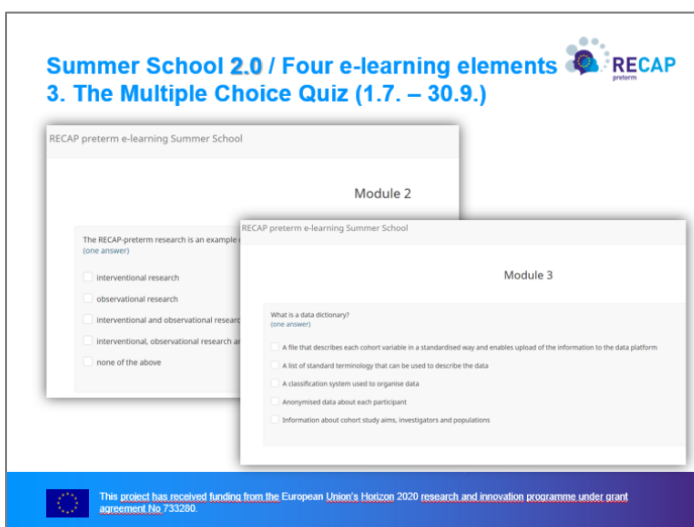
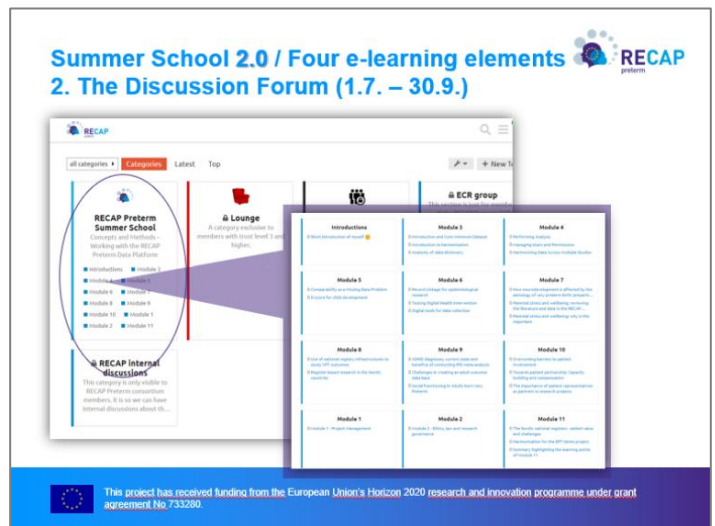
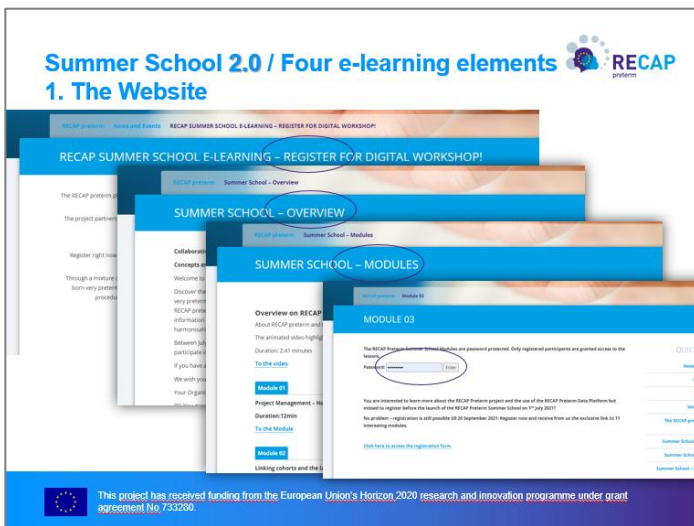
2.2 The RECAP preterm website: Hosting the digital Summer School

The Summer School was integrated into the RECAP preterm website (*www.recap-preterm.eu*), where interested users could find cost free:

1. The online registration form
2. An overview on the Summer School and terms of use
3. Password protected access to the 11 Modules and Multiple-Choice Quiz

All registered participants received an individual welcome letter with the Password and were invited to the Summer School Discussion Forum. The Forum should give the participants the opportunity to network among themselves and enter into exchange with the project partners. During 1st July and 30th September, the timeline of the digital Summer School, participants were contacted regularly by email.

The four digital Summer School elements:

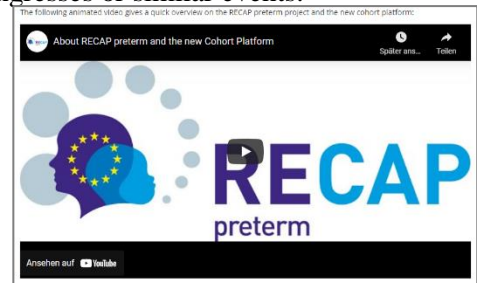


2.3 Promoting the digital Summer School

For promotion of the digital Summer School, EFCNI designed a presentation slide, a print and digital information flyer and diverse social media infographics. The consortium partners promoted the digital Summer School among their networks and during conferences, congresses or similar events.

With support from the partners, TNO produced an animated video describing the challenges of preterm birth and how the RECAP preterm project, with the newly developed platform can contribute to improving the burden of preterm birth. The video also promotes the registration to the digital Summer School.

The animated video is available on the RECAP preterm website.



Examples of promotional material developed for the digital Summer School:



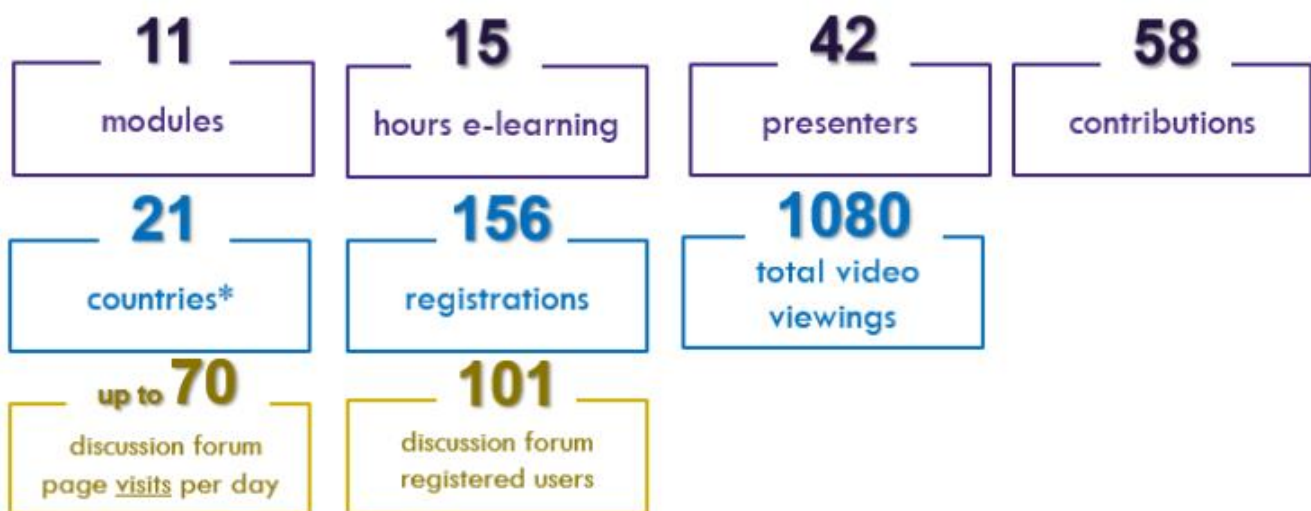
3 OUTREACH

Altogether, 42 presenters, representatives of each project partner and Work Package, among them the Early Career Researchers, developed 58 video contributions and produced 15 hours of valuable video information material.

Thanks to the broad distribution and promotion by all consortium partners and their networks, the information about the digital Summer School was widely spread.

156 registrations to the digital Summer School were received. Registrations came in from 21 countries: Austria, Belgium, Denmark, Estonia, Finland, France, Germany, Hungary, Italy, Iran, the Netherlands, Northern Ireland, North Macedonia, Norway, Poland, Portugal, Qatar, Spain, Sweden, UK, USA.

101 persons registered to the Summer School Discussion Forum. The Forum reached up to 70 visits per day.



*Austria, Belgium, Denmark, Estonia, Finland, France, Germany, Hungary, Italy, Iran, the Netherlands, Northern Ireland, North Macedonia, Norway, Poland, Portugal, Qatar, Spain, Sweden, UK, USA

4 CONCLUSION

Due to the pandemic situation, the concept of the Winter/ Summer School had to be entirely rethought and new ways of training and exchange with and between the Summer School participants had to be found. Although the consortium partners received inspiration from their institutions, university courses they held, meetings or conferences that also had to change into digital events, no blueprint for the organisation of the digital Summer School existed and funds for the realization were limited.

In conclusion, we can say that the digital Summer School received very positive feedback. Nevertheless, the partners and participants missed the degree of personal networking and interactive/ individual discussions, exchange and joint learning that constituted one important element in the original planning of this training.

However, the digital Summer School format allowed us to give the successful collaboration between consortium partners and Work Packages more visibility and to include and give the word to more project members than for an on-site training.

Outreach and information about the RECAP preterm Cohort Platform increased and participants more than quintupled (from 30 to over 150 participants). The digital format allowed participants more flexibility to inform themselves and learn independently from time zones and locations. The short video contributions certainly were helpful in this respect, as they allowed a step-by-step approach.

In this way, the digital Summer School adds to increase awareness for and understanding of the project as well as the benefits and use of the RECAP preterm Cohort Platform.

5 OUTLOOK

With the valuable feedback from the participants and in view of the wealth of information, it was decided by the Summer School Committee to offer the E-Learning in the future in form of open access to the broader public.

As of mid-October 2021, the content of digital Summer School in form of the 11 Modules will be publicly available and change into an E-Learning toolbox. The promotional material will be adapted accordingly and information about the E-Learning toolbox will be continuously shared by the consortium partners. We hope that this step will encourage even more potential users of the RECAP preterm Cohort Platform to inform themselves about RECAP preterm, the organisation of international research collaborations and particularly the benefits and use of the RECAP preterm Cohort Platform.

6 THANK YOU

Sincere thanks to the Summer School Committee members for their time, advice and support, and to all consortium partners for the production of their video contributions and interviews, as well as to the Summer School participants for their patience during the time needed for the reorganisation of the Summer School format, for their interest and feedback.

7 APPENDICES

1. Overview on video contributions by Work Packages:

		About RECAP preterm and the new Cohort Platform - animated video
ECR 00	Interview	Interview Early Career Researchers (ECR) group
ECR 01	Morgan	Introduction and Overview of Putting Together a Project
ECR 02	Doetsch Morgan Collins Goncalves Bilsteen	Interview about Demo Project
ECR 03	Collins	Harmonisation for the EPT Demo project
ECR 04	Goncalves	Harmonisation on the RECAP preterm Data Platform
ECR 05	Morgan	Federated Analysis Using the RECAP preterm Platform
ECR 06	Bilsteen	The Nordic National Registers
ECR 07	Doetsch Morgan Collins Goncalves Bilsteen	Interview about Learning from Demonstration Project
ECR 08	Doetsch	Module Summary
WP01_00	(Guests: Maaïke Beltman and Juliane Dittrich)	Project Management
WP02_00	(Guest: Evert Ben van Veen)	Interview- Ethics, Law, and Research Governance
WP03_00	(Guest: Prof. Elizabeth S. Draper)	Interview-Data Mapping and Data Harmonisation
WP03_01	Draper	Introduction and Core Minimum Dataset
WP03_02	Collins	Metadata Catalogue
WP03_03	Bamber	Anatomy of a Data Dictionary
WP03_04	Powell	Introduction to Harmonisation
WP04_00	Artur Rocha	Interview- Data Platform
WP04_01	Goncalves	Overview of the RECAP preterm Data Platform
WP04_02	Goncalves	Setting Up Data in the Data Repository
WP04_03	Goncalves	Adding Metadata in the Study Manager
WP04_04	Goncalves	Harmonising Data Across Multiple Studies
WP04_05	Goncalves	Managing Users and Permissions
WP04_06	Goncalves	Performing Analysis
WP05_00	v.Buuren	Interview -Statistical methods for Integrated Individual Patient Data

WP05_01	v.Buuren	Comparability
WP05_02	v.Buuren	Dscore
WP06_00	Barros	Interview- Improving Data collection, Follow-up & Participant Involvement
WP06_01	Ama Cristina Santos	Digital Tools for Data Collection
WP06_02	Julia Doetsch	Record Linkage for Epidemiological Research
WP06_03	Raquel Teixeira	Testing Digital Health Intervention
WP07_00	Zeitlin	Interview - Hypothesis-Driven Research Agenda for Child VPT Cohorts
WP07_01	Maier	Introduction and Context
WP07_02	Zeitlin	Consensus Process on Research Priorities
WP07_03	Sentenac	Social Factors and Cognitive Development
WP07_04	Morgan	Survival of Extremely Preterm Births
WP07_05	Ylijoki	Impact of the Etiology of Preterm Birth on Outcomes
WP07_06	Cuttini	Parental Stress and Wellbeing - Why Is this Important
WP07_07	Benhammou and Laroche	Parental Stress - Reviewing the Literature and Data in RECAP Preterm Cohorts
WP08_00	Kajantie	Interview - Use of National Registry Infrastructures to Study VPT Outcomes
WP08_01	Hovi	Introduction to the Course, Learning Goals
WP08_02	Kajantie - Opdahl	Registry-Based Research in the Nordic Countries
WP08_03	Plakka	Register Data in the Nordic RECAP Partners
WP08_04	Heikkilä	Identifying Disease Outcomes from Nordic Register Data
WP08_05	Bilsteen	Performing a Research Project, from Scratch to Publication
WP08_06	Pulakka	Case Study: Adding Register Data to a Cohort Study
WP08_07	Gissler	Register-Based Studies on Premature Children
WP09_00	Wolke	Interview- Risk, Protection and Resilience in Adults Born Preterm
WP09_01	Mendonca	Challenges in Creating an Adult Outcome Data Base
WP09_02	Mendonca	Bridging the Gap: Harmonizing the Quality of Life Outcomes of Adults Born Very Preterm
WP09_03	v.d.Paal	Methodological Considerations for Assessing Universal Outcomes of VP Birth.
WP09_04	Eves	Social Functioning in Adults born Very Preterm
WP09_05	Ni	RECAP in action: IPD Meta-Analysis of ADHD in Adults Born Preterm

WP10_00	Thiele	Interview - Dissemination, Translation, and Sustainability
WP10_01	Zimmermann	Patient Involvement: Where Do We Come from And Where Do We Need to Go To?
WP10_02	Walsh	Overcoming Barriers to Patient Involvement
WP10_03	Thiele	Towards Patient Partnership: Capacity Building and Compensation
WP10_04	Nagy	The Importance of Patient Representatives as Partners in Research Projects
WP10_05	Kamphuis	The Value of Patient Representatives