



RECAP preterm

“Research on European Children and Adults born Preterm”

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Deliverable 10.5. Final report on dissemination activities

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PU	Public	X
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

The basis of the dissemination activities on RECAP preterm were the identified target group and a planning of respective outreach tools.

Aim of the outreach strategy was to create a maximum of attention and awareness for the project, its aims, milestones and results. The different stakeholders should gain an increased understanding of the participating partners, cohorts and the benefits and use of the RECAP preterm Cohort Platform.

Communication and outreach on RECAP preterm will not stop with the end of the funding period, but will continue, as publications are still outstanding and the RECAP preterm Cohort Platform is now ready for use by researchers of diverse backgrounds. With continued communication, the different stakeholders will become or remain aware of RECAP preterm, so that, in the coming years, the RECAP Preterm Cohort Platform will become a widely used tool among researchers to look into data gathered from very preterm and very low birth weight cohorts across the world, so that the fruits of this EU funded project will grow.

RECAP Consortium Partners

Project Number ¹	733280	Project Acronym ²	RECAP preterm		
List of Beneficiaries					
No	Name	Short name	Country	Project entry date ⁸	Project exit date
1	NEDERLANDSE ORGANISATIE VOOR TOEGEPAST NATUURWETENSCHAPPELIJK ONDERZOEK TNO	TNO	Netherlands		
2	THE UNIVERSITY OF WARWICK	UoW	United Kingdom		
3	INSTITUT NATIONAL DE LA SANTE ET DE LA RECHERCHE MEDICALE	INSERM	France		
4	INSTITUTO DE SAUDE PUBLICA DA UNIVERSIDADE DO PORTO	ISPUP	Portugal		
5	VAN VEEN EVERT BERNARD	MEDLAW	Netherlands		31/03/2018
6	INESC TEC - INSTITUTO DE ENGENHARIADE SISTEMAS E COMPUTADORES, TECNOLOGIA E CIENCIA	INESC TEC	Portugal		
7	UNIVERSITY OF LEICESTER	ULEIC	United Kingdom		
8	TERVEYDEN JA HYVINVOINNIN LAITOS	THL	Finland		
9	EUROPEAN FOUNDATION FOR THE CARE OF NEWBORN INFANTS	EFCNI	Germany		
10	NORGES TEKNISK-NATURVITENSKAPELIGE UNIVERSITET NTNU	NTNU	Norway		
11	KAROLINSKA INSTITUTET	KI	Sweden		
12	UNIVERSITÄTSKLINIKUM BONN	UKB	Germany		
13	HELSINGIN YLIOPISTO	UH	Finland		
14	OSPEDALE PEDIATRICO BAMBINO GESU	OPBG	Italy		
15	REGION HOVEDSTADEN	RegionH	Denmark		
16	PHILIPPS UNIVERSITÄT MARBURG	UMR	Germany		
17	TARTU ÜLIKOOL	UTARTU	Estonia		
18	UNIVERSITEIT ANTWERPEN	UANTWERPEN	Belgium		
19	Concentris Research Management GmbH	concentris	Germany		
20	EXTENSIVE LIFE OY	ELO	Finland		
21	STICHTING MLC FOUNDATION	MLC Foundation	Netherlands	01/01/2018	

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1 INTRODUCTION

1.1 Introduction

RECAP preterm “Research on European Children and Adults born Preterm” is a project funded under the European Horizon 2020 Research and Innovation Programme. It features a powerful network of experts from various disciplines as well as patient organisations and research institutions.

Over five years (2017-2021) the RECAP preterm Consortium developed a sustainable platform for research on children and adults born preterm. The platform enables stratified sub-group analyses of sociodemographic and clinical characteristics, neonatal complications, and otherwise rare medical conditions that cannot be studied in national population cohorts.

RECAP preterm will make it possible to investigate the many open questions on long term effects of very preterm birth/ very low birth weight going beyond state of the art.

Furthermore, it can help to reduce ethical, administrative and technical barriers to collaboration in research and create positive incentives for engagement from research teams around the world. This will enable timely responses to emergent questions about best care and social policy for children and adults born preterm or with low birth weight.

Aim of the outreach strategy was to invite the different stakeholders and broader public to explore the unique work of the RECAP preterm project: to inform about the objectives, set-up and result of an intense collaboration and productive learning within the project Consortium comprising 20 partners from 12 European countries.

By communicating broadly on RECAP preterm, the consortium partners hope that the different stakeholders will be aware of RECAP preterm and its aims and that, in the coming years, the RECAP Preterm Cohort Platform will become a widely used tool among researchers to look into data gathered from very preterm and very low birth weight cohorts across the world, so that the fruits of this EU funded project will grow.

1.2 Outreach Strategy

1.2.1 Target Groups

Information about the project needed to be broadly spread and targeted a variety of stakeholders, such as

- A broad group of professionals (e.g. healthcare professionals and researchers in the fields of neonatology, epidemiology, psychology, therapists, etc.) and their respective societies at national, European and international levels
- Parents and persons with lived experience and their respective organisations at local, national, EU and international levels,
- Policy makers, key decision makers at national and EU levels
- The broader public

The target groups and with them concrete stakeholders were identified by the consortium partners with a “stakeholder mapping” exercise during the General Assembly Meeting in Frankfurt in 2018. The list of stakeholders was finetuned in the months after the meeting.

1.2.2 Outreach Channels

In order to reach the identified target groups, communication tailored for the individual target groups was shared via those communication channels preferred by the respective individual target group.

The RECAP preterm Steering Committee weighed the pro and contra of starting new communication channels and having to build a community over the years versus using the communication channels of a consortium partner with well-established connections to the majority of the identified target groups. It was decided that EFCNI as experienced and strong networking partner would accompany the communication around the RECAP preterm project from their established communication channels, with all consortium partners supporting the communication outreach via their institutional and/or private communication channels.

The following communication channels were used:

- Websites: RECAP preterm website, EFCNI and other consortium partners' website sections
- Project related communication material: Flyer, Presentation template, Project Brochure, Policy Brief, animated video
- Social Media: RECAP preterm YouTube, Facebook, Twitter, Linked-In, Instagram channels from EFCNI and social media channels from all consortium partners' as available
- Contributions to blogs of networking partners
- Press and media with support from all consortium partners at local and national, international levels
- Newsletters and news sections of RECAP preterm, EFCNI and all consortium partners as available
- Congresses, conferences, (networking) meetings attended by consortium partners
- Summer School

1.2.3 Outreach Topics

Communication around RECAP preterm aimed at keeping stakeholders and a broader public informed about the project's aims, milestones and actions. To create a better understanding for the project, the consortium partners, their professional backgrounds, and cohorts involved were presented. General facts about preterm birth and information on how the project could support improvements in this health area linked the project to the disease area and enabled inclusion of the topic and the project into the communication and action steps of stakeholders.

To increase visibility and show commitment, RECAP preterm joined every year the global movement around "World Prematurity Day" – the international awareness day on preterm birth, celebrated each 17 November.

Main outreach language was English, but translations into further languages were offered locally by the consortium partners where and when possible.

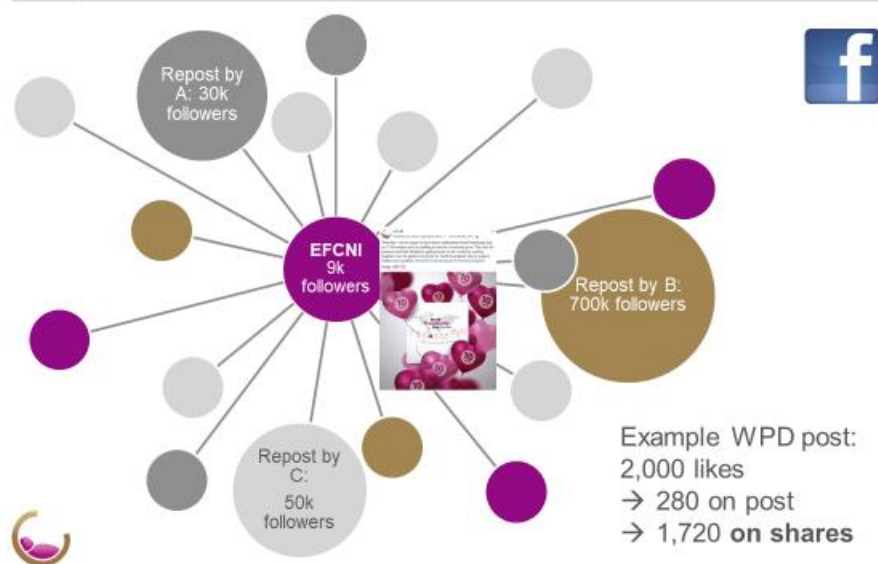
2 OUTREACH

Since its start in 2017 the social media communication about RECAP preterm on EFCNI channels alone gained per year about 50.000 impressions and had a reach of approx. 35.000 on Facebook, with additional 16.000 impressions on Twitter and 2.000 impressions on Instagram (as new, upcoming social media channel).

Examples for the best performing single (organic) posts on EFCNI social media communication channels: (2019) 14.964 and 1.587 engagements or (2020) 10.917 and 775 engagements (please see 3.3. Social Media)

To understand the success of the social media outreach strategy, it is important to be aware of the power of networks: A social media post from one consortium partner with strong network (example: EFCNI) reaches the direct community. However, these national network partners also have their own broad national and local networks and keep promoting, sharing and liking the original posts, thus creating a snowball-effect with broadest outreach effect.

The power of the network



3 EXAMPLES FOR OUTREACH ACTIVITIES

3.1 Websites

An important outreach tool addressing the different target groups was the RECAP preterm website (<https://recap-preterm.eu/>; please see also D10.1). In addition, the consortium partners' institutions established sub-sites and included news about the project on their “news section” to inform their communities and networks.

Example: RECAP preterm website



Example: EFCNI sub-site on RECAP preterm and “news section” featuring updates on the project



European Foundation for the Care of Newborn Infants

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[Pregnancy](#)
[Preterm Birth](#)
[Socks for Life](#)
[Policy & Action](#)
[Partners](#)

Who we are

What we do

Landmark 2017

Our Projects

- European Standards of Care for Neonatal Health
- Milk banks
- Web camera systems in the NICU
- SmPS project
- World Prematurity Day
- Socks for Life

Policy & Action

Our organisational structure

The EFCNI Award

Statutes & Financials

Donations

Career

Newsletter



RECAP preterm – Research

Background: from data collection to data analysis

The overall aim of the EU-funded research project RECAP preterm is very low birth weight (VLBW):

- VLBW: less than 1500 g
- VLBW: less than 32 weeks of gestation

The innovative element of RECAP preterm is to provide the bridge between exploiting data of European cohort studies with babies, children, and understanding, diagnosis and evidence-based, personalised preterm treatments, especially the use of (off-label) medication applied for. By developing research applications, the cohort participants shall communicate technology for collecting health data, delivery of health care, and research results.

RECAP Preterm Summer School

Discover the RECAP preterm digital Summer School from the comfort of your home.

The E-learning programme will be online from 1 July 2021 and will include:

- 1. Very preterm cohorts and collaborative research principles and methods
- 2. New research on children and adults born very preterm based on RECAP preterm
- 3. How to implement a collaborative research protocol – including harmonising data, the technological aspects of storing and sharing data

Register today via <https://recap-preterm.eu/> for the exclusive link to the course.

You want to learn more about RECAP preterm? Check out the image video for an overview of the RECAP preterm project currently being developed and that will be launched this coming autumn. At the moment, there are already an impressive 22 individual study variables available.

Core steps

RECAP preterm will...

1. create a sustainable data platform of national and European cohorts of VLBW children and adults to optimise the use of healthcare and policy (over time)
2. develop hypothesis-driven research on health status and medical care of VLBW children and adults that builds on the unit of combined cohorts and the added value of their geographic and temporal diversity
3. integrate exchange with various stakeholders to disseminate results and to translate them into evidence-based care and policy
4. emphasise patient and public involvement in order to reflect real-world needs

Members and Partners



Map of RECAP cohorts

Milestones by EFCNI

- EFCNI's role in RECAP preterm has particularly in leading all activities regarding dialogue, dissemination, and sustainability by reaching out to the academic community, clinicians, healthcare professionals, patient organisations, the general public, policy makers, and other potential stakeholders at the national, European, and international level to increase the visibility as well as the health and societal impact of RECAP preterm. A particular focus will be placed on parents in the information and dissemination strategy in particular to identify and answer user-driven research questions and policy needs.
- By organising a workshop on "Translation of Research into Policy" EFCNI and all RECAP preterm partners will reach out to the European policy level.
- We will also support our project partners to conduct a summer school with clinicians and researchers to promote the RECAP preterm platform and to base them on the evidence generated by the project.

Next steps for 2017

- Start stakeholder mapping process
- Validate the upcoming research findings in order that they are easier to understand for non-expert target groups like the general public or parents and patients

Links and Downloads

Have a look at the official project website to gain deep insights into the project.

[RECAP preterm website](#)

Have a look at the project flyer to learn more about the aim and scope of RECAP preterm, its supporting partners, and the structure of the project.

[RECAP preterm project flyer](#)

Please note

This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 650724



Research news

04 February 2021

Both preterm and post-term birth increases risk of Autism Spectrum Disorder

The causes of autism spectrum disorder (ASD) are complex and remain unclear. A recent study, involving more than 3.5 million children, now shows that the risk of ASD may slightly...

[Read More](#)

02 February 2021

RECAP preterm Cohort Platform will soon be accessible

RECAP preterm is a research project developing a unique data platform that will allow researchers to find and use data from very preterm and very low birth weight cohorts to answer...

[Read More](#)

01 February 2021

Generational effects of COVID-19: Elevated anxiety during pregnancy has negative impact on infants

A self-report questionnaire in pregnant women in Alberta reveals that stress resulting from specific concerns about COVID-19 exceeds expected levels and is higher than that experienced by other groups of...

[Read More](#)

RECAP preterm

Research on European Children and Adults born Preterm (RECAP preterm) project members: To emphasise their commitment for preterm children and their families, the RECAP preterm project members supported World Prematurity Day by a joint online campaign coordinated by EFCNI.

[View more \(RECAP preterm website\)](#)



Image: Winning picture of the drawing contest 2017 (c) ISPU, Portugal

[To top](#)

Members of "Workpackage 10": Dr Verena Lindacher, Johanna Walz and Nicole Thiele from EFCNI welcomed Professor Rolf Maier from the Philipps Universität Marburg at the EFCNI office in Munich to a "Workpackage 10" meeting as part of the RECAP preterm project. Like all members of the RECAP preterm project, they supported World Prematurity Day and shared a social media message with the research community.

[View more \(Facebook\)](#)



Image: Dr Verena Lindacher, Professor Rolf Maier, Johanna Walz, and Nicole Thiele expressed their support of World Prematurity Day 2017 (c) EFCNI

[Contact us](#)

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3.2 Project related Communication Material

3.2.1 Flyer/ Factsheet

The project flyer / factsheet has been available for download on the RECAP preterm website (see also D10.1). The flyer was shared as printed version with the different stakeholders by all consortium partners throughout the project and served as a digital promotion via social media channels:

Example: English RECAP preterm flyer



The flyer is titled "RECAP preterm in a nutshell" and features a blue and white color scheme. It includes the following information:

- Acronym:** RECAP preterm
- Start date:** 01.01.2017
- Duration:** 51 months
- Participants:** 20 transdisciplinary institutions from 12 different countries
- EC funding:** € 9,713,230
- Full project title:** Research on European Children and Adults born Preterm
- Contact:**
 - Project Coordination:** Maaike Beltman and Prof Erik Verrips, Netherlands Organisation for Applied Scientific Research (TNO)
 - Prof Dieter Welke, University of Warwick (UoW)
 - Dr Jennifer Zeklin, Institut national de la santé et de la recherche médicale (INSERM)
 - Project Management Office:** Juliane Dietrich, concentris research management juliane.dietrich@concentris.de
- Please feel free to contact the Project Management Office if you have a child or adult VPT/ VLBW cohort anywhere in the world and would like to join the Network.**
- Find more information online:** Have a look at the project website for more information about the background, methods, topics, and people involved. Visit us at: www.recap-preterm.eu
- This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 733280.**
- Editing and design:** EFCNI

The flyer also features the RECAP preterm logo, a QR code, and a photograph of a person holding a small object.

Example: Promotion of Dutch Flyer version



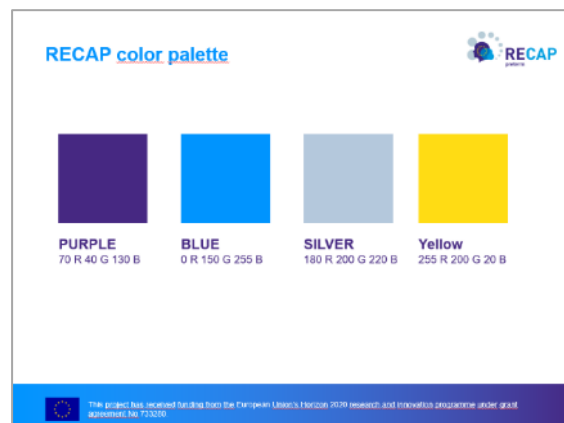
The flyer is titled "RECAP-preterm in een notendop" and features a blue and white color scheme. It includes the following information:

- Acronym:** RECAP-preterm
- Startdatum:** 01/01/2017
- Duur:** 51 maanden
- Deelnemers:** 20 transdisciplinaire instituten uit 13 Europese landen
- EU financiering:** € 9,713,230
- Volledige projectnaam:** Research on European Children and Adults born Preterm
- Contact:**
 - Projectcoördinatie:** Maaike Beltman en Prof. Erik Verrips, Nederlandse Organisatie voor Wetenschappelijk Onderzoek (TNO)
 - Prof. Dieter Welke, University of Warwick (UoW)
 - Dr. Jennifer Zeklin, Institut national de la santé et de la recherche médicale (INSERM), France
 - Project Management Office:** Juliane Dietrich, concentris research management juliane.dietrich@concentris.de
- Aarzel niet ons het Project Management te contacteren in het geval u beschikt over data van een studie rond vroeggeboorten, en geïnteresseerd bent om te aan te sluiten bij het RECAP-platform.**
- Vind meer informatie online:** Bezoek de website van het project voor meer informatie over de doelen, methoden, onderzoeken en betrokken personen. <http://www.recap-preterm.eu>
- Dit project wordt gefinancierd door het "Horizon 2020 programma" van de Europese Unie (publieke oproepingsaanpak nr. 733280).**
- Opmaak en ontwerp:** EFCNI

The flyer also features the RECAP preterm logo, a QR code, and a photograph of a person holding a small object.

3.2.2 Presentation Slides

A RECAP preterm powerpoint presentation template was used by all partners for external presentations on the project. The continuous use of the slides and corporate colours was an important factor for recognition of the project among the stakeholders.



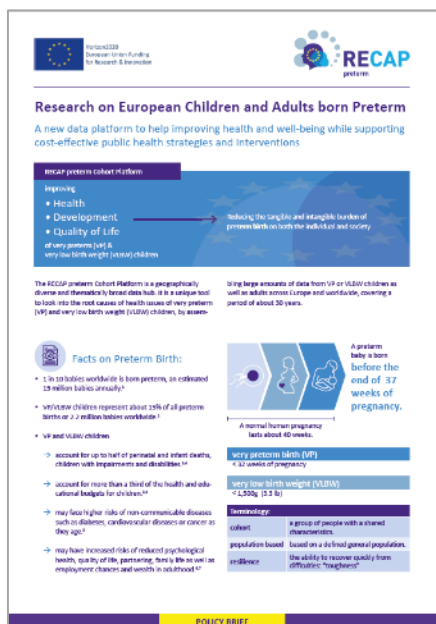
3.2.3 Project Brochure

The Project Brochure (see also D.10.6) in A5 format was produced at the end of the project, considering the learnings, experiences and outcome of the project, and particularly the RECAP preterm Cohort Platform. The brochure will be available for download on the RECAP preterm website. An electronic version will be shared with the different stakeholders by all consortium partners following the project to maintain interest and awareness.



3.2.4 Policy Brief

The RECAP preterm policy (see also D10.2) was developed at the end of the project, considering the learnings, experiences and outcome of the project and the outcome of the workshop. The policy brief is a tool allowing the consortium partners and their close networks to introduce the research and recommendations developed under the project to a broader audience as a step towards translating the findings of the research project into practice. The document gives a general overview on the definition of preterm birth and main challenges to individuals, families and societies as a whole, summarizes features and goals of the RECAP preterm Cohort Data Platform as a result of the RECAP preterm research. It ends with an explanatory description why investment in live is key and concludes with a Call to Action for the different target groups (parents/ careviges, adults born preterm or healthcare professionals and their respective organisations as well as policy makers and decision makers).



3.2.5 Animated Video

The animated video is a 2-minutes description of project RECAP preterm, its background and goals. It can be viewed via the RECAP preterm website and RECAP preterm YouTube channel <https://youtu.be/fu7D18WgfCc>.

First translations of the video into further languages like e.g. Hungarian are being prepared.

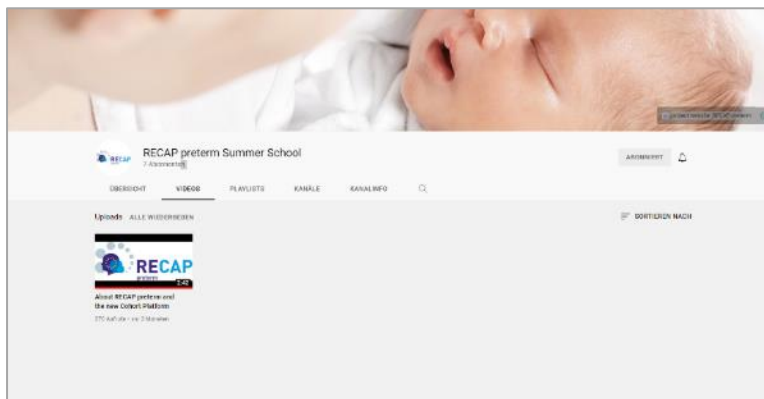


3.3 Social Media

The identified different target groups all use social media for exchange of information and communication on topics meaningful to them. However, the different target groups prefer different social media channels and different information and/or ways of information. The social media outreach was therefore tailored to the different target group's preferences and needs, from information on latest publications in journals to general information about preterm birth or nice graphics and information for an easy share. Social media channels used: YouTube, Facebook, Instagram, Twitter, Linked-in

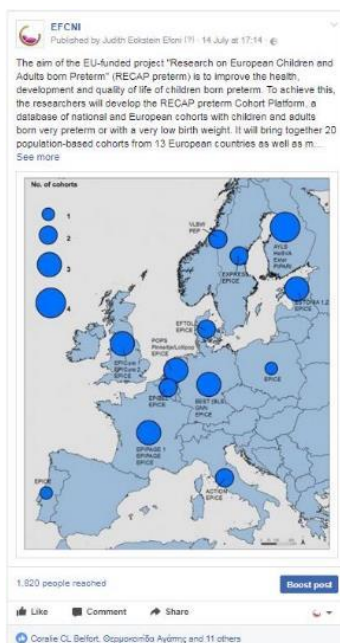
Example: The RECAP preterm YouTube Channel

The [RECAP preterm YouTube channel](#) hosts the animated video and the Summer School video contributions:



For an immediate successful outreach on the project to the broader public, the project partners preferred using the well-established account of EFCNI with meanwhile 8.1 K subscribed followers and networks, instead of creating a new account and having to build up the followers over the next years. In addition, all partners shared, if possible, the communication via their own channels to increase the outreach to a maximum. The social media communication on the project, its milestones and findings as well as general facts and information around preterm birth and follow-up was supported by several campaigns or “communication series”, such as the “RECAP preterm professionals” (examples) or “RECAP preterm cohorts” series to keep the momentum and attention and to increase the understanding of the project and the networks involved.

Example: Selection of general posts on RECAP preterm



EFCNI
Published by Judith Eckstein Efcni [?] · 23 March at 15:15 · 🌐

Why do preterm babies need special care? Preterm babies are not fully prepared to live outside their mother's womb. The earlier in pregnancy babies are born, the less developed their organs will be. Many health conditions can result from the immaturity of important organs and systems including lung, heart, digestive tract, brain, immune system, ears, and eyes. Medical support aims at helping a baby born preterm to achieve similar growth and development as in the womb at the same age. The medical team needs to recognise and monitor the special needs of a preterm baby to provide appropriate care and support until the baby reaches maturity of most important body functions.

In addition to an increased risk for physical impairments, babies born the earliest and the smallest are also at higher risks of psychological and social problems than infants born at term.

The Research on European Children and Adults born Preterm (RECAP preterm) project aims to understand the causes of these difficulties faced by very preterm children and adults in order to improve the health, development and quality of life of these individuals.

Learn more at: <https://www.efcni.org/activities/projects/recap/>

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

#ResearchImpactEU
#RECAPpreterm
Photo credit: EFCNI



14,964 People reached 1,587 Engagements [Boost Post](#)

👍❤️ Oxana Gladkaya, Enrique Tapia and 98 others 11 comments 91 shares

EFCNI
29. Januar 2018 um 10:00 · 🌐

Time flies so quickly! It's been a year since the EU-funded project Research on European Children and Adults born Preterm (RECAP preterm) came into being. EFCNI as a proud project partner and coordinator congratulates to 12 eventful months of stimulating meetings, fruitful debates, encompassing data collection and promising long-term follow up research! Happy Birthday #RECAPpreterm! 🎉🎂👶

Read more: bit.ly/2DE7gNT



👍 Gefällt mir 💬 Kommentieren ➦ Teilen

EFCNI
10 March 2017 at 15:00 · 🌐

A new EU research programme, Research on European Children and Adults born Preterm (RECAP), coordinated by the University of Warwick, will explore what helps very preterm children overcome the problems they face. Better support for parents and schools, where teachers can learn about the children's special needs and how to handle their difficulties with attention and making friends, can all help, studies show. "What has been repeatedly noted is that after they leave hospital, they require better liaison of services in the community and with educational services to improve their lives," said Professor Dieter Wolke, a psychology professor at the University of Warwick and one of the principal investigators of the project. (Source: The Guardian).



the guardian

Very premature babies at risk of mental health problems – research

Studies reveal greater likelihood of attention disorders, shyness and anxiety in childhood and then adulthood for survivors with very low birth weight of 1kg

THEGUARDIAN.COM

Example: Selection of posts from the social media series about the partners participating in RECAP preterm

EFCNI
Written by Judith Eckstein Efcni [?] · 1 September 2019 at 10:00 · 🌐

Good news from the Research on European Children and Adults born Preterm (RECAP preterm) project:

On 13 August 2019, the RECAP team leader Marit Sæbø Indredavik from the Department of Clinical and Molecular Medicine at NTNU (Norway) was awarded the prestigious 'King's Medal of Merit' for her work and achievements in the medical field. We wholeheartedly congratulate her to these royal honours!


Read more (article in Norwegian): <https://stolav.no/myhe.../2019/mottok-kongens-fortjenstmedalje>

NTNU - Norges teknisk-naturvitenskapelige universitet



STOLAV.NO
Mottok Kongens fortjenstmedalje
Professor og overlege Marit Sæbø Indredavik er tildelt Kongens...

Example: Selection of posts from the social media series introducing the cohorts participating in RECAP preterm



efcni

efcni Recently we reported about follow-up of the POPS (Project On Preterm and Small for gestational age infants) cohort in the Netherlands. The participants of the cohort were informed about the outcomes through the 'POPS-19 magazine'. This magazine contains important health advice for preterm born grown-ups. It informs you about possible long-term health effects of preterm birth (e.g. high blood pressure, lung- and respiratory

Sei der/die Erste, dem das gefällt.

VOR 1 MINUTE

Kommentar hinzufügen...


EFCNI
Written by Judith Eckstein Efori (7) · 17 April 2019 at 17:00 · G

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 Heiti Varendi from the University of Tartu. Read her guest article at: <https://www.efcni.org/news/series-on-cohorts-recap-preterm/>

Photo (c) Heiti Varendi, University of Tartu
#RECAPpreterm #ResearchImpactEU #data #followup




EFCNI - European Foundation for the Care of Newborn Infants
492 Follower
Jetzt

Following our series about cohorts of the EU-funded project „Research on European Children and Adults born Preterm“ (RECAP preterm), we are delighted to give you an insight into The Bavarian Longitudinal Study (BLS)/Bayerische Entwicklungsstudie (BEST). It is led by Professor Dieter Wolke (University of Warwick, UK) and Professor Peter Bartmann (University Hospital Bonn, Germany). The BLS started off as a geographic whole population study of infants, who were born between January 1985 and March 1986 and admitted to neonatal special care in South Bavaria (Germany) within the first 10 days of life.


Read more: <https://lnkd.in/dNzKFyJ>

Image: Pixabay/picjumbo_com



EFCNI
@EFCNIwecare

Following our series about cohorts of the EU-funded project „Research on European Children and Adults born Preterm“ (RECAP preterm), we are thrilled to share a second example from Norway with you, the Low Birth Weight Life study of the @NTNU #RECAPpreterm




Series of RECAP cohorts – part 4: the NTNU Low Birth Weight Life study from Nor...
In our series about cohorts of the EU-funded project „Research on European Children and Adults born Preterm“ (RECAP preterm), we presented the Project ...
efcni.org

EFCNI
Written by Judith Eckstein Efori (7) · 26 June 2019 at 18:31 · G

We are delighted to present you a third example of our series about cohorts of the EU-funded project „Research on European Children and Adults born Preterm“ (RECAP preterm): the Project Extreme Prematurity (PEP) from Norway.

Find out more in this article by the researchers Maria Vollseter, Thomas Halvorsen, and Trond Markestad:
<https://www.efcni.org/.../the-project-extreme-prematurity-pep/>



WAY
Extreme Prematurity

Example: Selection of posts from the social media series introducing the different professions participating in RECAP preterm

EFCNI
Published by Judith Eckstein Efcni · 8 mins ·

The adult cohorts included in RECAP preterm involve among others psychologists, developmental experts, disability researcher, medical and epidemiological specialists. The main focus of a set of adult cohorts lies in defining the major physical, and economic outcomes of preterm birth. Especially, factors changes in neonatal treatment (e.g. steroid use, surfactant nutritional support) and parenting and schooling will be evaluated according to their contribution to long-term outcomes and q. The results generated might inform health monitoring, intervention policies for next generations of very preterms.

View more: <https://recap-preterm.eu/>

University of Warwick #ResearchImpactEU #RECAPpreterm

Please note:
This project has received funding from the European Union 2020 research and innovation programme under grant agreement 733280.

Copyright: EFCNI

RECAP PRETERM'S PROFESSIONALS

Methodologists & data scientists

As a methodologist and data scientist I explore and examine data from multiple sources and big databases. I'm part analyst, part artist by my knowledge in math, statistics and visualisation techniques regarding trends found in the data.

efcni

The methodologists and data scientists within RECAP preterm are in a first step responsible for pooling the data (that means to synthesise or combine data) from the different cohort studies. They will also describe the data, so that later users of the RECAP preterm platform have a kind of dictionary about what data are available. They also identify commonly measured risk factors or outcomes to develop a so called core minimum data set to facilitate comparison in future research projects. Furthermore, specific statistical methods to analyse combined cohort data and to derive individual predictions will be provided. Finally, efforts to improve participation rates in cohort studies on very preterm infants are made.

@uniofleicester #TNO #ISPUP #ResearchImpactEU #RECAPpreterm

Sei der/die Erste, dem das gefällt.

VOR 2 MINUTEN

Kommentar hinzufügen ...

RECAP PRETERM'S PROFESSIONALS

Adult cohort specialists

I am an adult cohort specialist. In my work, I try to find out how birth and neonatal events, neonatal and child healthcare influence development and adult life.

EFCNI @EFCNIwecare · 16 Std.

Health registries are national databases which are predominantly popular in Scandinavia. Within #RECAPpreterm the Nordic researchers will make links between the cohort data & their registry data. bit.ly/3jWMrSs

@THL @NTNU @karolinskaInst @RegionH #ResearchImpactEU

Tweet Übersetzen

RECAP PRETERM'S PROFESSIONALS

Professionals of the Nordic registries

My daily work is characterised by analysing health trends of the population in my country using registry data that is collected from every citizen since birth.

2 2

Example: RECAP preterm supporting every year the awareness campaign “World Prematurity Day”, the international awareness day for Preterm Birth on 17 November with activities in more than 100 countries and outreach to a broader public at global level



Example: Selection of posts from the social media series introducing the new e-cohort HAPPe participating in RECAP preterm



Example: Selection of posts from the social media series promoting the RECAP preterm Summer School

Gepostet von Veronika Mehl • 8.5.2020

EFCNI - European Foundation for the Care of Newborn Infants
882 Follower
Jetzt •

Update: Early bird fee extended until 30th June 2020 due to the global situation.

Please note that the RECAP winter school is currently scheduled to take place in November 2020. Due to the current situation, the global situation is constantly monitored and adjustments are being made accordingly. As there are only limited registrations, the early bird fee will be extended until 30th of June 2020. Take the opportunity and register now!

Your registration is only preliminary at this moment. By the end of August you will be informed about your acceptance to participate in the winter school.

#RECAP_preterm #ResearchImpactEU #data #followup #EarlyBird #neonatology

<https://lnkd.in/dnsRXg3>

Übersetzung anzeigen

Post Details

EFCNI
10 May

You are a researcher in the fields of neonatology, epidemiology, or psychology and interested to learn more about the newly developed "RECAP preterm cohort platform" for your future research projects? Join us, register via the RECAP preterm website and receive an exclusive link to the RECAP preterm e-learning programme that will be launched on 1st July 2021!
<http://bit.ly/38pdrSa>
#RECAPpreterm #ResearchImpactEU #H2020... See more

RECAP Summer School
preterm

E-LEARNING

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

REGISTER NOW!

and receive an exclusive access to the RECAP digital summer school as of July 1st

Performance for your post

956 People Reached

37 Reactions, comments & shares

30 Like	17 On post	13 On shares
1 Love	1 On post	0 On shares
0 Comments	0 On Post	0 On Shares
6 Shares	6 On Post	0 On Shares

16 Post Clicks:

4 Photo views	9 Link clicks	3 Other Clicks
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NEGATIVE FEEDBACK

0 Hide post	0 Hide all posts
0 Report as spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

EFCNI - European Foundation for the Care of Newborn Infants
882 Follower
2 Monate •

Are you a Researcher in the fields of neonatology and epidemiology? Then join us at the RECAP preterm School.

Übersetzung anzeigen

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 753280.

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

Example: Selection of blog contributions by RECAP preterm

Dutch networking partner “Kleine Kanjers”

and

Australian „Miracle Babies“

Kleine Kanjers

home informatie shop hulpverleners blog contact

Onderzoek bij Europese prematuur geboren kinderen en volwassenen: RECAP preterm
door Kleine Kanjers | apr 16, 2018 | nieuws, zorg en onderzoeken | 0 Reacties



Bekijk de producties van de voor de wereld geboren baby's

- ✓ Vanaf €30,00 gratis verzending (binnen NL)
- ✓ 14 dagen bedenktijd en gratis retourneren
- ✓ Volledig achteraf betalen
- ✓ Koop! Laat het voor je ingekopen en rechtstreeks versturen

Zoek op productcategorie
Bekijk alle producten

Nieuwsbrief
Wil je alle blogs?

NatureLine 1300 622 243 (1300 MBABIES) 24hr family support hotline

miracle babies FOUNDATION

SUPPORT INFORMATION WAYS TO GIVE DONATE

HAPP-e



HAPP-e is an innovative international study on the health and quality of life of adults born preterm. So, what do you need to participate? You must be older than 18 years old and have been born before the 37th week of gestation, anywhere in the world.

To participate, access <https://happ-e.meschee.nl>, register and click the link you receive by e-mail.

It's that easy and you will be contributing to improving knowledge on adult life after preterm birth!

All adults (18+) born before the 37th week of gestation are invited to register and fill HAPP-e's questionnaire

REGISTER HERE

3.4 Press and Media

The consortium partners reached out to their press and media contacts to promote new findings (for details, please refer to outreach summary chapter 4).

Examples: Selection of press and media articles

the guardian

Very premature babies at risk of mental health problems - research

Studies reveal greater likelihood of attention disorders, shyness and anxiety in childhood and then adulthood for survivors with very low birth weight of 1kg



A premature baby's foot. Studies over a 26-year period reveal that children born at very low weight of around 1kg may experience persistent mental health and social problems. Photograph: Getty Images

Ian Sample Science editor
Monday 13 February 2017 14:00 GMT

Children who are born very prematurely are at greater risk of developing mental health and social problems that can persist well into adulthood, according to one of the largest reviews of evidence.

Those with an extremely low birth weight, at less than a kilogram, are more likely to have attention disorders and social difficulties as children, and feel more shyness, anxiety and depression as adults, than those born a healthy weight.

Gepostet von Ulf Schönberg • 14.2.2018 • Jetzt sponsorn

EFCNI - European Foundation for the Care of Newborn Infants
2 Tage

The university of Warwick recently published new findings that preterm born infants at pre-school age are less accepted by their peers. The scientific team was led by Professor Dieter Wolke, member of the EFCNI Scientific Advisory Board.



Premature babies make fewer friends -- but not for long
sciencedaily.com

1 Gefällt mir

USnews HEALTH

Could Early Birth Hinder Adult Success?

By Alan Mozes
HealthDay Reporter



WEDNESDAY, June 6, 2018 (HealthDay News) — Babies born prematurely or very small may not fare as well in life as those born full-term, a new research review suggests.

Adults who were born tiny or early may be more likely to lag behind educationally and professionally. They're also more likely to use social services, according to the review of 23 prior studies from eight countries.

Preterm birth occurs before the 37th week of pregnancy. The difficulties reported in the new study were greater for those born very prematurely -- before 32 weeks.

Despite the findings, study lead author Dieter Wolke stressed that people born early or at a low birth weight are not destined to struggle in adulthood.

"Most preterm-born adults are in employment and live independently. Most do well according to these markers," said Wolke, a professor of psychology at the University of Warwick in Coventry, England.

The studies involved more than 5.9 million adults in all. They were conducted across the United States, the United Kingdom, Canada, Denmark, Finland, Germany, Norway and Sweden.

<https://www.foxnews.com/health-care/articles/2018/06/06/early-born-adults-are-often-struggling>

8/7/2018 Could Early Birth Hinder Adult Success? - Drugs.com MedNews

Drugs.com
Know more. Be sure.

Could Early Birth Hinder Adult Success?

WEDNESDAY, June 6, 2018 -- Babies born prematurely or very small may not fare as well in life as those born full-term, a new research review suggests.



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Nearly 272,000 participants had been born before 37 weeks or weighed less than 5.5 pounds.

In adulthood, this group was less likely to have gone on to college, less likely to have a job, and more likely to receive social benefits, compared with their full-term peers, the study review found.

Examples: Selection of EFCNI e-newsletter articles, outreach: about 5.000 regular readers

Having trouble viewing our newsletter? [Online Version](#)

AUGUST edition | 2021

EFCNI european foundation for the care of newborn infants



Dear friends and supporters

We are proud to announce COVID-19 survey were 4 month, giving detailed in global survey of parents' the pandemic. The result often quite sad – and the important to keep fighting small, or too sick!

Apart from COVID-19, a central concern, this new lots of e-learning opportunities and raise your voices for is the revision process for European Standards of Care of our online learning series (learning!)

As always, we are thank and interest in our work!

Please stay safe and healthy!

Silke Mader and the EFCNI

EFCNI

NUTRITIONAL CARE
Involving parents in infants

EFCNI contributed a chapter to the latest edition of 'World Journal of Nutrition and Children' [www.worldjournalofnutrition.com](#)

Series of RECAP cohorts – part 2: presenting the cohorts of the EPICure Studies in the United Kingdom and Ireland

POSTED ON 15 MAY 2019

In our new series about cohorts of the EU-funded project „Research on European Children and Adults born Preterm“ (RECAP preterm), we recently reported about the ESTONIA I & II cohorts. We are happy to present you a second example, the cohorts of the EPICure studies in the United Kingdom and Ireland. Find out more in this article by the current team of lead researchers, Professor Neil Marlow, Professor Elizabeth Draper, and Dr Samantha Johnson.

EPICure “EPICure” is a series of studies of the survival, health and development of babies who were born extremely preterm – from 22 to 26 weeks of gestation – throughout the United Kingdom and Ireland. The studies aim to understand what happens to extremely preterm babies as they grow up and how neonatal care can be best organised and delivered to give these children the best chance of survival and long term development.

The studies started in 1995 when a team of researchers identified every single baby born before 26 weeks of gestation in all 276 maternity units in the whole of the UK and Ireland. They collected information about how many babies were born and how many survived to find out how neonatal care impacts on babies' outcomes by discharge from hospital. Since then, they have tracked the development of the surviving babies throughout childhood and adolescence, offering them assessments at 2, 6, 11 and 19 years of age, to find out how extremely preterm birth impacts on outcomes later in life.

Neonatal care is a fast developing area of medicine and the way in which doctors and nurses look after extremely preterm babies has changed considerably since 1995. Ten years after the first study, the EPICure team wanted to find out whether the improvements in neonatal care had resulted in improved survival and development for extremely preterm babies. So in 2006, the second EPICure Study – EPICure 2 – commenced. This time the research team identified every single baby born before 27 weeks of gestation in the whole of England and collected information about their outcomes to discharge from hospital and assessed their development at 3 years of age. The results showed that survival rates had increased and developmental outcomes at this early age were slightly better – although there was a similar small proportion of babies with severe disabilities, more children in 2006 had no developmental problems at all compared with those born in 1995. The team are now assessing the surviving children at 11 years of age to find out whether these improvements in early development have translated to better outcomes at school age.

The EPICure research team comprises experts from many different areas of science, including neonatology, paediatrics, psychology, psychiatry, nursing, and cardiovascular and respiratory medicine. The team also acknowledge the help of all the healthcare professionals who were involved in neonatal care throughout the UK and Ireland who helped identify the cohorts and look after the babies at birth.

For more information about the EPICure Studies see www.epicure.ac.uk.

Principal investigators: Prof Kate Costeloe, Dr. Alan Gibson, Prof Neil Marlow

Co-investigators for 10-11 year assessment: Prof Neil Marlow, Prof Kate Costeloe, Prof. Janet Stocks, Prof. Elizabeth Draper, Enid Hennessy

Study managers: Dr Samantha Johnson & Dr Joe Fawke

Follow-up of the POPS cohort in the Netherlands
A guest article by Dr Sylvia van der Pal and Professor Erik Verrips



Picture: POPS-19 magazine

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 cohort. The studies with the POPS cohort have provided insight into how Dutch adolescents who were born very preterm or VLBW reach adulthood.

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.kno.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 29 European cohorts of children and adults born very preterm or very low birth, will also contribute to this.

Special Thanks

Dr Sylvia van der Pal & Professor Erik Verrips
TNO (the Netherlands Organisation for applied scientific research)

Survival rates of extremely preterm infants in France depend on the place of birth
Very Preterm Birth and Parents' Quality of Life 27 Years Later

26.08.2017 Category: News



Image: [corinne_fut_dubay](#)

Having a child born very preterm (VP) or at very low birth weight (VLBW) intensifies parental stress and mental illness symptoms as affected parents experience increased distress early in their children's lives. Physical, emotional, and social problems have been reported to mediate the link between preterm birth and parental stress. Yet it was to date unknown whether the quality of life of parents of preterm children is comparable to that of parents of term children by the time they reach adulthood. Wolke et al. have therefore compiled data to answer the question which short- and long-term consequences of preterm birth affect parental quality of life.

In a longitudinal, whole-population study, carried out in Bavaria, Germany, data from VPs and VLBWs born in January 1985 and March 1986, as well as their parents and parents of term controls were interrogated using questionnaires. For this study at hand, 446 parents of VPs/VLBWs and 227 parents of term controls participated when their grown-up children were 27 years old. To measure quality of life, the findings were arranged in 4 domains: physical health, psychological health, social relationships and environment. The participants then answered domain related questions (e.g., domain 2: “How often do you have negative feelings such as blue mood, despair, anxiety, depression?”), according to the World Health Organization Quality of Life instrument, Short Edition (WHOQOL-BREF). The next instrument of assessment, the Satisfaction with Life Scale, asked for the parents' personal approval or disapproval of the following statements: “In most ways my life is close to my ideal,” “The conditions of my life are excellent,” “I am satisfied with my life,” “So far I have gotten the important things I want in life,” and “If I could live my life over, I would change almost nothing.”. Parents ranked their answers on a scale from 1 to 7 (1 = strongly agree; 7 = strongly disagree). The long-term study also took child functioning into consideration. Relevant factors were e.g., disability, mental health, or academic achievement. Other considered factors were among others sex, maternal age, marital status or family socioeconomic status at birth. All results got first standardised and were then analysed using multiple regression analysis.

Evaluating their findings, the researchers found no significant differences between the quality of life of parents of, now grown up, VP or VLBW children and parents of even-age term controls. Moreover, the study revealed that child functioning factors like better mental health or better peer relationships in childhood had a stronger positive effect on the parents' quality of life as for example academic achievements.

The authors point out that these findings give evidence for the strong ability of affected parents to cope with physical and mental stress. At the same time, they urge for support and interventions to improve mental health and peer relationships for preterm children as this will be positive for the children's development as well as for the parents' quality of life.

[View more](#) (American Academy of Pediatrics; abstract)

[Back to News Ansicht](#)

3.5 Networking

3.5.1 General Assembly and Steering Committee Meetings

During the meetings, the multidisciplinary partners from 20 different institutions built and strengthened a network fostering a sustainable work of RECAP preterm. All partners brought their own networks into the project, resulting in an opportunity for a broad dissemination of information on the project and the project results: from a variety of different professions, institutions, parents/ carers to persons with lived experience and their respective societies and organisations at national and EU levels


All project meetings were accompanied with respective social media communication, newsletter contributions and a news on the RECAP preterm website to inform the broad network on current project steps.

Examples from 2017 - 2021

EFCNI
26 February 2017 at 11:50

EFCNI is very proud of being a partner in the newly formed research consortium RECAP - Research on European Children and Adults born Preterm. In the next four years all partners aim to build up a platform for harmonising and exploiting data on European cohorts of children and adults who were born very preterm and registry data in order to improve understanding, diagnosis and prevention of the mental and somatic disorders that are associated with preterm birth.


We look forward to working with all of you!



Kick-off meeting of European Children and Adults born Preterm (RECAP)
Picture: Group photo of Research on European Children and Adults born Preterm (RECAP) kick-off meeting in Utrecht, Netherlands
EFCNI.ORG

EFCNI
@EFCNIwecare


Great kick-off meeting: RECAP - Research on European Children and Adults born Preterm
bit.ly/2IMK1b3 @EU_H2020 #ResearchImpactEU



2:35 pm · 24 Feb 2017


EFCNI @EFCNIwecare · 51m

At the #RECAPpreterm meeting in Helsinki, EFCNI & project partner Prof. Rolf E. Maier from @Uni_MR, presented their current topics e.g. how to best inform former participants in studies included in the RECAP preterm platform. Read more: bit.ly/2uIDmN #ResearchImpactEU



EFCNI @EFCNIwecare · 1h

Last week the workpackage-leader teams of #RECAPpreterm met in Helsinki to wrap up achievements & discuss the future project strategy. Thanks go to our partner from @Uni_MR, Prof. Rolf E. Maier, @TNO_Research @concentris_EU, @THLorg & all our partners for their input. #ResearchImpactEU




EFCNI
24 January at 10:14

These days, the RECAP preterm consortium (Research on European Children and Adults born Preterm) is meeting in Rome to wrap up and evaluate the project's second working year. 85 professionals from various fields of medical research gathered to discuss the project's milestones and deliverables. The meeting also featured an Early Career Researcher's workshop and two additional work package sessions.

#ResearchImpactEU #RECAPpreterm

Read more: <https://www.efcni.org/activities/projects/recap/>


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



EFCNI - European Foundation for Children and Adults born Preterm
462 Follower
Jetzt

From 1 to 3 July 2019, the steering committee of the RECAP preterm (Research on European Children and Adults born Preterm) project met in Leiden in the Netherlands. The steering committee also welcomed a guest speaker, Professor Vincent Jaddoe, coordinator of the LifeCycle project.

Read more: <https://lnkd.in/d/fH4CYH>




EFCNI
@EFCNIwecare

These days, 85 professionals from the RECAP preterm consortium (Research on European Children and Adults born Preterm) are meeting in Rome to wrap up and evaluate the project's second working year.

#ResearchImpactEU #RECAPpreterm

Read more: efcni.org/activities/projects/recap/




EFCNI
3. Jul · 0

The RECAP preterm project Steering Committee meets digitally. From 25 to 26 June 2020, the steering committee of the RECAP preterm (Research on European Children and Adults born Preterm) project met for the first time in a digital format. Originally, the meeting was supposed to take place in Leiden, but given the current circumstances, we needed to walk on new paths! Despite the unusual setting, it was a very fruitful meeting with loads of discussions. All work package leaders and several other project members, in total more than 20 participants, joined the meeting.

As the project will terminate next year, the meeting was used to discuss the open milestones for the coming months. Again, the meeting has been a vivid exchange of ideas and we look forward to working on the agreed next steps in the remaining time of the project.


Learn more about the project: www.efcni.org/activities/projects/recap/
#RECAP_preterm #ResearchImpactEU



Post Details

EFCNI
30 January · 0

#RECAPpreterm wants to develop a better understanding of the origins of very preterm birth health and developmental outcomes as well as more effective, evidence-based, personalized interventions and prevention. For this, the project team is working on a platform to combine extensive data from European cohort studies and around the world, making it possible to evaluate changes in outcomes over time while providing important information on how the evolution in care and survival... See more



Performance for your post

1,277 People Reached

36 Likes, Comments & Shares		
32 Likes	26 On Post	6 On Shares
0 Comments	0 On Post	0 On Shares
4 Shares	4 On Post	0 On Shares
24 Post Clicks		
4 Photo views	6 Link clicks	14 Other Clicks

NEGATIVE FEEDBACK

0 Hide post
0 Report as spam
0 Unlike Page

Reported stats may be delayed from what appears on posts.

Get more likes, comments and shares
When you boost this post, you'll show it to more people.

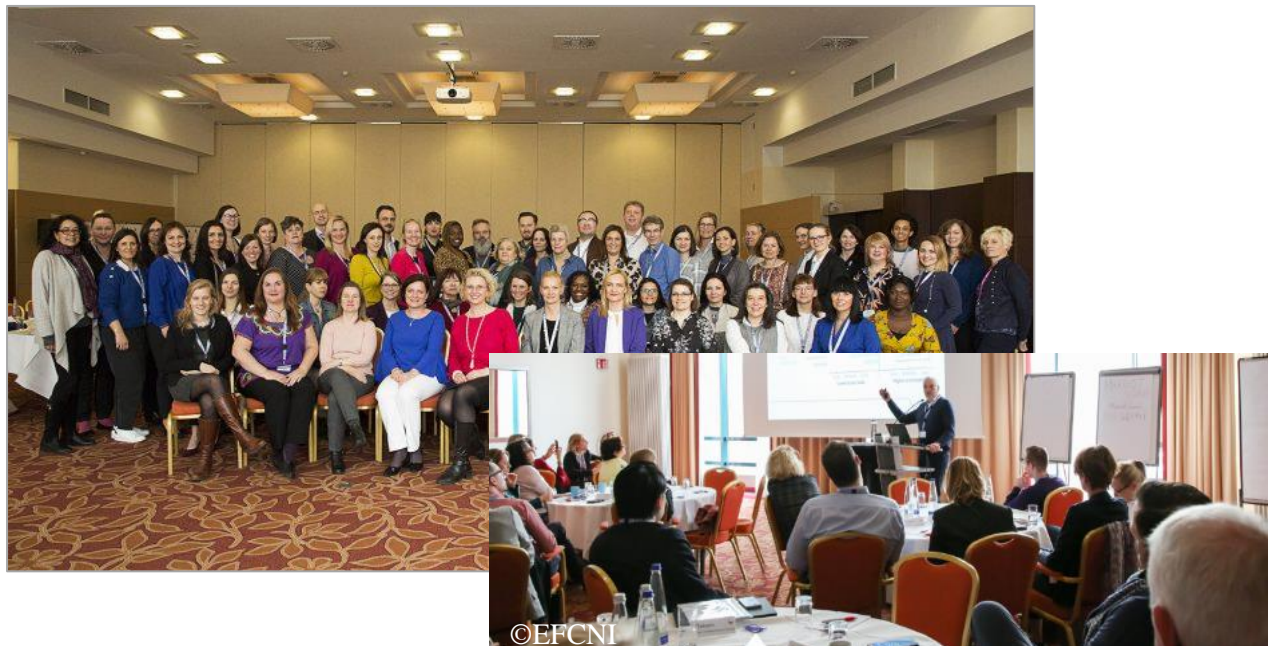
1,277 People reached 60 Engagements

FFCNI, Nicole Thiele, Margo Pritchard and 22 others 4 shares

3.5.2 Regular Exchange with Parents/ Patients

The current milestones of the RECAP project were continuously shared with the patient and consumer networks, via social media or blog contributions (see below) and on the occasion of the EFCNI annual Parent Organisations Summit or regular networking calls of these groups.

A ½ workshop on “translation of research into policy” was organized at the EFCNI annual Parent Organisations Summit in 2020 (see also deliverable D10.2). The summit is attended by about 40 national parent/ patient organisations from EU and across the world.



3.5.3 Conferences, Congresses, (Networking) Meetings

The consortium partners presented the RECAP project regularly on external local, national or international events (for details, please see also outreach report chapter 4) to professionals of different backgrounds but also patient representatives.

Example: Presentation of RECAP preterm at the bi-annual international congress jENS (joint European Neonatal Societies)

Gepostet von Ulf Schönberg · 27.10.2017 · Jetzt sponsern


EFCNI - European Foundation for the Care of Newborn Infants
jetzt

Meet the expert at jENS Congress in Venice: Professor Dieter Wolke (University of Warwick, UK) is one of the project coordinators of the Research on European Children and Adults born Preterm (RECAP preterm) project. On Friday, 03 November 2017, at 3 pm (Parallel Session 32, Room: Firenze), he will talk about "RECAP, a EU Horizon2020 collaborative effort to harmonise existing and new follow-up data on preterm survivor children, adolescents and adults".

View more: <https://lnkd.in/gCm6vHV>

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

Photo credit: candy1812/ Fotolia.de



Post Details

EFCNI
18 September

Final day at jENS! Our picks of the day: Join the parallel session 34 at 8.30 am to gain insights into the long-term outcomes of preterm born infants. Starting with a presentation of the RECAP preterm cohort, the session also informs about parental bonding effects, music therapy and the predictive power of newborn neurobehaviour on cognitive and neurodevelopmental outcomes after preterm birth. If you are interested in how artificial intelligence enables a whole new spectrum o... See more



jENS
Congress of joint European Neonatal Societies
VIRTUAL SPACE TO BE
LIVE ONLINE CONGRESS
14-18 September 2021
PRE-CONGRESS COURSES
11-12 September 2021
jenscongress.eu

62nd ESPR Annual Meeting
11th International Congress of UENPS
3rd International Congress of EFCNI

European Society for Paediatric Research
EFCNI
UENPS

Performance for your post

413 People Reached

2 Likes, Comments & Shares

2 Likes	2 On Post	0 On Shares
0 Comments	0 On Post	0 On Shares
0 Shares	0 On Post	0 On Shares

2 Post Clicks

0 Photo views	2 Link clicks	0 Other Clicks
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NEGATIVE FEEDBACK

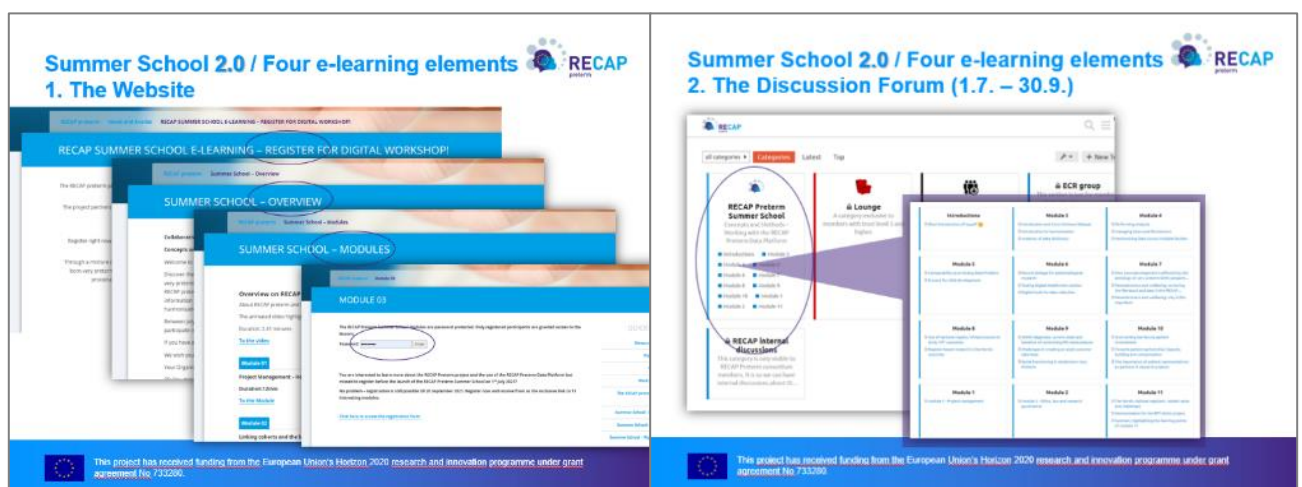
0 Hide post	0 Hide all posts
0 Report as spam	0 Unlike Page

Reported stats may be delayed from what appears on posts

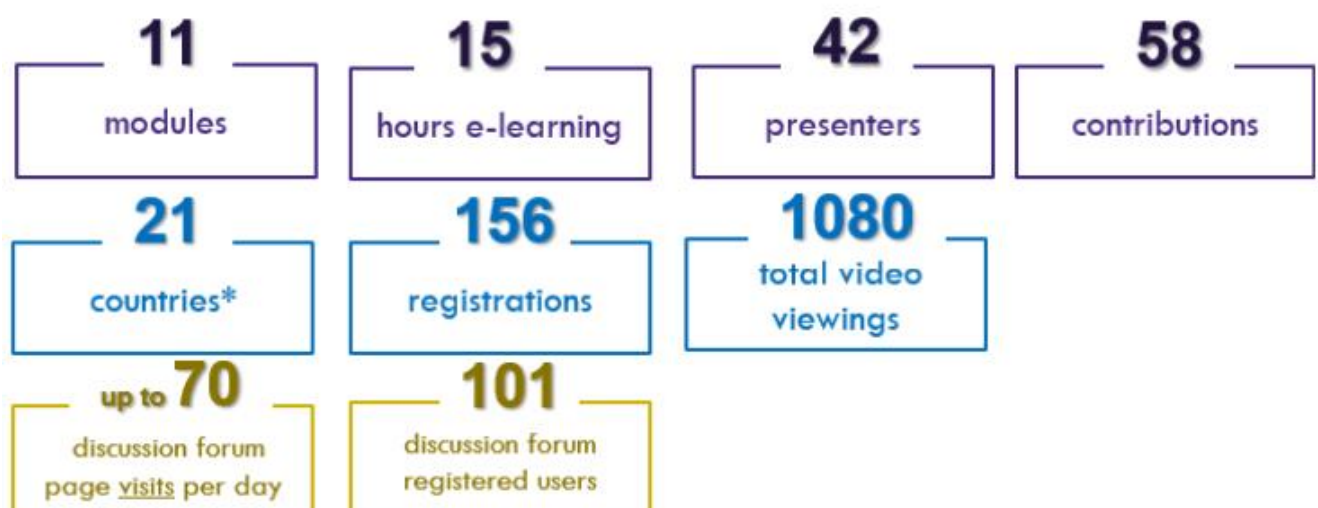
3.5.4 Winter/ Summer School

On 1st July 2021, the RECAP preterm digital “Summer School” was launched (see also D.10.5) and since then can be accessed the RECAP preterm website. It provides 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.



As of October 1st, 2021, the following outreach was achieved via the RECAP preterm Summer School:



*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 OUTREACH ACTIVITIES – OVERVIEW PER REPORTING PERIOD

4.1 Period 1

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
Partner 01 TNO	All	Presentation: APIC meetings in San Francisco and Venice
Partner 01 TNO	All	Presentation: b. Dutch national experts on neonatology; Landelijke Neonatologie Federatie
Partner 02 University of Warwick	WP9	Poster presentation at the Pediatric Academic Society (PAS) conference in Toronto (5-8 th of May 2018) - <i>Adults Born Preterm:</i> <i>A Meta-Analysis on Relational Transitions and Socio-Emotional Outcomes</i>
Partner 02 University of Warwick	WP9	Poster presentation at the (PAS) conference in Toronto (5-8 th of May 2018) – <i>Preterm Birth/Low Birth Weight and Adulthood Wealth: A meta-analysis</i>
Partner 02 University of Warwick	WP9	Presentation at the Adults Born Preterm International Collaboration (APIC) meeting, Toronto, 4 th of May 2018 - <i>RECAP preterm, a EU Horizon2020 collaborative effort to harmonize existing and new follow-up data on preterm survivor children, adolescents and adults</i>
Partner 02 University of Warwick	WP9	University of Warwick Event – Celebrating Impact and Innovation (Monday 14th May 2018). Speaker: Professor Dieter Wolke – Informing the Standards of follow-up care for infants
Partner 02 University of Warwick	WP9	Poster presentation at the Pediatric Academic Society (PAS) conference in Toronto (5-8 th of May 2018) - <i>Adults Born Preterm:</i> <i>A Meta-Analysis on Relational Transitions and Socio-Emotional Outcomes</i>
Partner 02 University of Warwick	WP9	Poster presentation at the (PAS) conference in Toronto (5-8 th of May 2018) – <i>Preterm Birth/Low Birth Weight and Adulthood Wealth: A meta-analysis</i>
Partner 02 University of Warwick	WP9	Presentation at the Adults Born Preterm International Collaboration (APIC) meeting, Toronto, 4 th of May 2018 - <i>RECAP preterm, a EU Horizon2020 collaborative effort to harmonize existing and new follow-up data on preterm survivor children, adolescents and adults</i>
Partner 02 University of Warwick	WP9	Publication: Bilgin, A., Mendonca, M., & Wolke, D. (2018). Preterm Birth/Low Birth Weight and Markers Reflective of Wealth in Adulthood: A Meta-analysis. <i>Pediatrics</i> .

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
Partner 03 INSERM	All	Presentation: The RECAP preterm platform: the opportunities and challenges of bringing together data from European cohorts of children and adults born very preterm. Conference on Epidemiological Birth Cohort and Longitudinal Studies - 3rd Paula Rantakallio Symposium 13rd – 15th, June, 2018
Partner 03 INSERM	All	Differences in perinatal care and newborn outcomes in Europe, Conference 99 NICU, Stockholm 13 11-15 June 2017
Partner 03 INSERM	All	Prematurity and fetal growth restriction: research priorities and opportunities. Fetal Growth Conference in Cork 21-22nd, September 2017
Partner 04 ISPUP	WP6	13 April 2018, one-day meeting of WP6 on “Improving data collection, follow-up, and participant involvement”, Porto, Portugal.
Partner 07 University of Leicester	WP3	SJ attended the full day (8 hours) APIC meeting on 4 th May in Toronto, Canada. During the meeting, SJ gave a presentation about RECAP preterm, focusing on WP3’s data harmonisation activities, along with DW and MM (UoW).
Partner 10 NTNU	All	30 min talk to the Norwegian parent organisation Prematurforeningen at seminar to celebrate World’s Prematurity Day, Nov 2017, St. Olavs hospital, Trondheim, Norway (10-15 participants)
Partner 10 NTNU	WP9	15 min talk to the international network: Adults Born Preterm International Collaboration (APIC) about EndNote database of references related to adolescent and adult cohorts in RECAP preterm, meeting prior to PAS conference, May 2018, Toronto, Canada (approx. 30 participants)
Partner 10 NTNU	All	15 min talk at seminar for Department of Clinical and Molecular Medicine, NTNU, June 2018, Trondheim, Norway (approx. 40 participants)
Partner 10 NTNU	All	15 min talk at seminar for Department of Mental Health, NTNU, June 2018, Trondheim, Norway (approx. 50 participants)
Partner 11 Karolinska Institutet	WP3, 7	Information and discussion about the cohort part within the EXPRESS steering and project groups (both national).
Partner 13 University of Helsinki	All	Brief Project description on the Developmental Psychology (DEPSY) research groups website.
Partner 13 University of Helsinki	WP 8	Blog post about the use of the Finnish and Nordic Registers for RECAP preterm
Partner 13 University of Helsinki	All	Facebook post announcing RECAP preterm project in DEPSY Facebook group
Partner 14 OPBG	All	Presentation about the RECAP preterm aims and methods at the workshop organised with the regional reference members of the ACTION cohort (Florence, May 11, 2017)

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
Partner 14 OPBG	All	Invited talk on “Follow-up dei nati pretermine: ricadute assistenziali”(Follow-up of preterm infants and effects on health care plans) at the National Conference of the Italian Society of Neonatology (Milan, 27 September 2017; about 70-80 people present at this talk) and distribution of ReCAP leaflets.
Partner 14 OPBG	All	Two presentations using the Italian Epice and Action data at a conference on Perinatal and Pediatric Epidemiology (Florence, 10-12 May 2018; about 60-70 people present)
Partner 14 OPBG	All	Two “articles” dedicated to the participation of OPBG in research regarding very preterm infants were published on the OPBG website for the Prematurity Day 2017, and so far had so far 452 and 426 visitors respectively
Partner 17 UTARTU	WP 10	Talk about follow-up of very preterm infants and introduction of RECAP preterm
Partner 17 UTARTU	WP 10	Presentation: how to predict future of very preterm infants incl RECAP preterm introduction
Partner 17 UTARTU	WP 10	Talk about follow-up of very preterm infants and introduction of RECAP preterm
Partner 17 UTARTU	WP 10	Presentation about ROP and follow-up of preterm infants (introduction of SHIPS and RECAP preterm)
Partner 17 UTARTU	WP 10	Meeting with RECAP preterm partner KR
Partner 17 UTARTU	WP 10	Meeting with RECAP preterm partners MC, PB
Partner 18 University of Antwerp	WP10	Developing a Dutch version of the RECAP preterm flyer to inform parents about RECAP preterm and prematurity. Activity in collaboration with WP10.
Partner 18 University of Antwerp	WP10	Liking and following the Facebook page of EFCNI.
Partner 18 University of Antwerp	WP10	Attendance ‘Preterm Day’ in Leiden (NL), 17/11/2017
Partner 19 concentris	WP 10	Regularly tweets about RECAP preterm meetings and other news
All partners	WP 3, 7	Spreading RECAP preterm leaflets regionally and nationally on conferences

4.2 Period 2

Partner	Type of dissemination & Title of dissemination (if applicable)	Name of event (if applicable)	Place, Country (if applicable)	Date	Type of audience
08 THL	Organisation of a Conference	Adults Born Preterm International Collaboration Meeting	Baltimore, USA	26.04.2019	Scientific Community
1TNO	Organisation of Adult Preterm International Collaboration meeting in Maastricht	Bi-yearly Adult Preterm International Collaboration meeting	Maastricht, the Netherlands	17.09.2019	Scientific Community
09 EFCNI	Organisation of a workshop: A systematic and easy way to read and understand complex research studies.	Annual EFCNI Parent Organisation Meeting	Munich, Germany	27.01.2019	Patients & Relatives
09 EFCNI	Webinar	Journal club: How to read/ understand scientific literature	online	04.09.2019	Patients & Relatives
1TNO	Oral presentation – Issues in quality of life of adults born very preterm compared to adults born full term	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	20.09.2019	Scientific Community
1TNO	Poster & short presentation – Follow-up of the reproductive outcomes of 35 year old adults born very preterm	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	19.09.2019	Scientific Community
2 UoW	Invited oral presentation at jENS conference in Maastricht "Gender and victimisation, not prematurity, predicts self-esteem trajectories into adulthood"	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	19-21 September, 2019	Scientific Community
2 UoW	Invited oral presentation at jENS conference "Association of	3 rd Congress of the Joint European Neonatal	Maastricht, Netherlands	19-21 September, 2019	Scientific Community

Partner	Type of dissemination & Title of dissemination (if applicable)	Name of event (if applicable)	Place, Country (if applicable)	Date	Type of audience
	preterm birth and low birth weight with romantic partnership, sexual intercourse and parenthood in adulthood: A systematic review and meta-analysis"	Societies (jENS)			
2 UoW	Poster presentation "Small for gestational age; Cognitive performance from infancy to adulthood	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	20.09.2019	Scientific Community (higher education, Research)
2 UoW	Keynote Lecture - Long-term Outcome of Preterm Infants	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	19-21 September 2019	Scientific Community
2 UoW	Keynote Lecture - Psychiatric diseases in children born preterm - is it an issue? How? Why? (ASD, schizophrenia ASDS) - clinical symptoms, behavioural problems	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	19-21 September 2019	Scientific Community
2 UoW	Keynote Lecture - RECAP-Preterm: Research on Children and Adults Born Preterm	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	19-21 September 2019	Scientific Community
14 OPBG	Invited oral presentation - Parental experiences with follow-up care offered to their very preterm infants: results of a qualitative study. (SHIPS data)	3 rd Congress of the Joint European Neonatal Societies (jENS)	Maastricht, Netherlands	19-21 September 2019	Scientific Community
2 UoW	Invited oral presentation at symposium "Explaining attention differences of the very and extremely preterm	19 th European Conference on Developmental Psychology	Athens, Greece	29.08.2019	Scientific Community

Partner	Type of dissemination & Title of dissemination (if applicable)	Name of event (if applicable)	Place, Country (if applicable)	Date	Type of audience
	compared to term born adults				
2 UoW	Invited lecture - Mission: Im possible - Take Responsibility for newborn health in Europe	Launch of European Standards of Care at the European Parliament	Brussels, Belgium	27-28 November 2018	Scientific Community
2 UoW	Invited lecture - Very preterm birth: effects on children and parents into adulthood	Neonatal Trust Parents at Council of International Neonatal Nurses Conference (COINN) 2019	Auckland, New Zealand	4-9 May 2019	General Public
2 UoW	Keynote Lecture - Adult Outcome after Very Preterm Birth: Vulnerability and Resiliency	Council of International Neonatal Nurses Conference (COINN) 2019	Auckland, New Zealand	4-9 May 2019	Scientific Community
2 UoW	Keynote Lecture - The long term development of very preterm infants into adulthood	45 th Annual meeting of the Society for Pediatric Intensive Care and Pediatric Infectious Diseases	Leipzig, Germany	23-25 May 2019	Scientific Community
2 UoW	Keynote Lecture - Long term outcome into adulthood after very preterm birth	XXVII Congress of Neonatal & Perinatal Medicine & VII Congress of the Spanish Society of Neonatal Nursing	Madrid, Spain	2-4 October 2019	Scientific Community
03 INSERM	Oral presentation of RECAP Preterm project as part of a broader presentation on European research on very preterm infants	European Congress of Perinatal Medicine	Saint Petersburg, Russia	07.09.2018	Scientific Community

Partner	Type of dissemination & Title of dissemination (if applicable)	Name of event (if applicable)	Place, Country (if applicable)	Date	Type of audience
04 ISPUP	Poster Presentation - "Description of retention strategies adopted by European cohorts of very preterm infants"	XXXVI Reunião Científica da SEE and XIII Congresso da APE	Lisbon, Portugal	11.09.2018	Scientific Community
04 ISPUP	Oral Presentation - "Quality Provision of Maternal and Newborn Health Care for Very Preterm Infants in Portugal in the context of neoliberal policies: A Mixed-Method Approach"	3rd World Conference on Qualitative Research – WCQR2018	Lisbon, Portugal	17.10.2018	Scientific Community
04 ISPUP	Poster Presentation - "Neoliberal Policy Impact on Health Care Provision for Parents of Very Preterm Born Infants in Portugal: A Quality Analysis on Perceived Care"	11 th ASPHER Young Researchers' Forum	Ljubljana, Slovenia	28.11.2018	Scientific Community
04 ISPUP	Oral Presentation - "Follow-up of cohorts of very preterm infants: a systematic review on participation and determinants of attrition"	11 th ASPHER Young Researchers' Forum	Ljubljana, Slovenia	28.11.2018	Scientific Community
04 ISPUP	Poster Presentation - "Obstetric interventions among native and migrant women: a survey of episiotomy in Portugal"	11 th European Public Health Conference	Ljubljana	22-10-2018	Scientific Community
06 INESC TEC + 04 ISPUP	Poster Presentation - "RECAP Preterm: Harmonização de dados de coortes de crianças e adultos nascidos pré-termo, com recurso a plataformas digitais"	XXXVI Reunião Científica da SEE and XIII Congresso da APE	Lisbon, Portugal	11.09.2018	Scientific Community
07 ULEIC	Oral presentation "Have neurodevelopmental	Journées Francophone de recherches	Paris, France	13/12/2018 - 14/12/2018	Scientific Community

Partner	Type of dissemination & Title of dissemination (if applicable)	Name of event (if applicable)	Place, Country (if applicable)	Date	Type of audience
	outcomes for extremely preterms improved over time?"	de neonatologie			
07 ULEIC	Oral presentation - Networking, recruiting of panel members for DELPHI process	British Maternal and Fetal Medicine Society Conference	Edinburgh, UK	28/03/2019 - 29/03/2019	Scientific Community
07 ULEIC	Oral presentation on RECAP preterm WP3 DELPHI process	Paediatric Academic Societies conference	Baltimore, USA	24/04/2019 - 01/05/2019	Scientific Community
07 ULEIC	Oral keynote presentation "Outcome of preterm birth - assimilation of outcomes across Europe"	5th Annual Preterm Birth Conference	Birmingham, UK	30.09.2019	Scientific Community
14 OPBG	Oral presentation - Does a parent-report assessment at 2 years corrected age predict later cognitive development in very preterm infants?	European Association of Neonatology	Rotterdam, Netherlands	September 1-3, 2019	Scientific Community
14 OPBG	Invited presentation -I dati perinatali PERISTAT	21 st Italian Congress of the Society for Perinatal Medicine	Bologna, Italy	November 7-9, 2019	Scientific Community
06 INESC TEC	Oral presentation - Distributed Statistical Analysis Using DataSHIELD in Epidemiological Studies	Datashield Workshop 2018	Newcastle, UK	06.09.2018	Scientific Community
06 INESC TEC	Oral presentation - Studying very preterm birth in Europe: methodological challenges and how to tackle them with DataSHIELD	Datashield Workshop 2019	Newcastle, UK	12.09.2019	Scientific Community
06 INESC TEC	Oral presentation - From basic statistics onwards: an	Datashield Workshop 2019	Newcastle, UK	12.09.2019	Scientific Community

Partner	Type of dissemination & Title of dissemination (if applicable)	Name of event (if applicable)	Place, Country (if applicable)	Date	Type of audience
	experience with DataSHIELD				
06 INESC TEC	Oral presentation - CORAL - Docker container based deployment for OBiBa stack	Datashield Workshop 2019	Newcastle, UK	13.09.2019	Scientific Community
10 NTNU	Invited oral presentation for parent organisation "Prematurforeningen": EFCNI Standard of Care project	30 year anniversary for "Prematurforeningen", Oslo University Hospital	Oslo, Norway	13.12.2018	General Public, Patients & Relatives
04 ISPUP	Newsletter - "Quality of Maternal and Neonatal Health Care for Very Premature Born Children in the Context of the Economic Crisis: A Qualitative Analysis in Portugal"	EPICE Newsletter	International	Mrz 19	General Public
04 ISPUP	Press release Best Poster Communication - "Neoliberal Policy Impact on Health Care Provision for Parents of Very Preterm Born Infants in Portugal: A Quality Analysis on Perceived Care"	ASPHER Newsletter	International	16.03.2019	Scientific Community
04 ISPUP	Social media: HAPP-e project's Social Media pages (Facebook, Twitter, Instagram and Pinterest)		International	16.12.2019	General Public
09 EFCNI	Social media: 66 posts and newsletters Facebook, Twitter, Instagram, LinkedIn posts + Newsletter		International	01.07.2018 - 31.12.2019	General Public

4.3 Period 3

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
1 TNO	All	Flyers: POPS-Newsletter about the POPS-35 results and about RECAP for the POPS participants and others who are interested in the POPS cohort studies
1 TNO	All	Participation to an event other than a conference or workshop: Presentation about the POPS cohort studies and RECAP for the Dutch Network of Former Preterms (part of the Dutch parents organisation Care4NEO): https://www.youtube.com/watch?v=yiHIUeV08CM
1 TNO	All	Website: Update on RECAP on the website and facebook page of the POPS cohort: https://www.tno.nl/pops
1 TNO	All	Press release: On World Prematurity Day (17 november) 2020 TNO issued a news item about the latest POPS-35 results and RECAP: https://www.tno.nl/nl/over-tno/nieuws/2020/11/world-prematurity-day-de-zwangerschappen-van-35-jarigen-die-zelf-te-vroeg-geboren-zijn/
1 TNO	All	Communication campaign (e.g radio, TV): Radio interview on national radio NPO1 (program Spraakmakers; 248.000 listeners; less during summer vacation period) about the POPS cohort and the importance of follow-up of adults born preterm (together with the Dutch Network of Former Preterms (part of the Dutch parents organisation Care4NEO): https://www.nporadio1.nl/fragmenten/spraakmakers/00c1a751-f610-47b4-b0f5-928b4c3c368c/2021-07-13-wimar-bolhuis-en-sylvia-van-der-pal-over-ex-couveusekinderen-en-effecten-op-latere-leeftijd
1 TNO	All	Participation to an event other than a conference or workshop: Interviews for RECAP summer school e-learning by Maaike Beltman and Erik Verrips & presentation about HRQoL by Sylvia van der Pal for WP9: https://recap-preterm.eu/summer-school-modules/
1 TNO	All	Video/film: Animated video that highlights the aims of RECAP preterm and the work of the RECAP preterm Cohort Platform. https://www.youtube.com/watch?v=fu7D18WgfC
2 UoW	WP 9	Participation to a workshop: Workshop - Translation of research into policy/practice.
2 UoW	WP 9	Participation to a conference: Longterm outcome after very preterm birth - what makes a difference in childhood?
2 UoW	WP 9	Participation to a conference: Adult Outcomes after Very Preterm Birth
2 UoW	WP 9	Participation to a conference: Frühgeboren 26 Jahre Später
2 UoW	WP 9	Participation to a conference: Mobbing ehemaliger Frühgeborener (Bullying of former premature babies)
2 UoW	WP 9	Participation to a conference: Psychiatric and behavioural symptoms in children born preterm from childhood into adulthood.
2 UoW	WP 9	Participation to a conference: Die wesentlichen Befunde der Langzeitnachuntersuchungen des RECAP-preterm.eu Verbundes in Europa. (The main findings of the long-term follow-up examinations of the RECAP-preterm.eu network in Europe)
2 UoW	WP 9	Participation to a conference: Zwischenmenschliche Beziehungsfähigkeit (Interpersonal relationship skills)

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
3 INSERM	WP 7	Presentation of the WP7 RECAP activities to Inserm team Obstetrical, Perinatal and Pediatric Epidemiology Research Team, Center for Epidemiology and Statistics Sorbonne Paris Cité, INSERM UMR 1153 (Mariane Sentenac): "Maternal education and cognitive development in children born very preterm: A meta-analysis of 15 European cohorts"
3 INSERM	WP 7	Participation to a conference: Oral presentation (A Morgan): "Comparative survival analyses of births between 22 and 26 weeks of gestation in the EXPRESS, EPICure-2 and EPIPAGE-2 cohorts"
3 INSERM	WP 7	Participation to a conference: Oral presentation (M Sentenac): "Maternal education and cognitive development in children born very preterm: A meta-analysis of 15 European cohorts"
3 INSERM	WP 7	Participation to a conference: Oral presentation (Andrei Morgan): "International comparisons of perinatal outcomes (Difficulties, and the importance of understanding the data...)"
3 INSERM	WP 7	Oral presentation (Andrei Morgan): "International comparisons of perinatal outcomes (Difficulties, and the importance of understanding the data...)"
3 INSERM	WP 7	Oral presentation (online) (Mariane Sentenac): "Methodological issues on reviews and studies on the very preterm population and developmental outcomes"
3 INSERM	WP 7	Participation to a conference: Oral presentation and chair session (Jennifer Zeitlin): "Consequences of increased survival in extreme premature infants"
3 INSERM	WP 7	Participation to a conference: Presentation/demonstration (Andrei Morgan): "DataSHIELD: what is it and when is it useful?"
3 INSERM	WP 7	Participation to a conference: Oral presentation (Mariane Sentenac): "What gestational age and birthweight inclusion criteria should be used in selecting studies for meta-analyses of very preterm birth and cognition?"
3 INSERM	WP 7	Participation to a conference: Oral presentation (Adrien Aubert): "Movement difficulties at the age of 5 years in children born extremely preterm: prevalence and risk factors in the European EPICE-ships cohort."
3 INSERM	WP 7	Participation to a workshop: Oral presentation (Jennifer Zeitlin): "Garbage in-Garbage out: harmonizing and validating data"
3 INSERM	WP 7	Participation to a conference: Oral presentation (Jennifer Zeitlin): "Long term outcome (RECAP preterm cohort)"
3 INSERM	WP 7	Participation to a conference: Oral presentation (Lena Wohlers): "Wellbeing of mothers of 5-year-old children born very preterm: prevalence and influential factors in a European COHORT (SHIPS)"
4 ISPUP	WP 6	Participation in a conference: Elsa Lorthe- HEALTH OF ADULT PEOPLE BORN PRETERM - AN E-COHORT PILOT STUDY (HAPP-E)
4 ISPUP	WP 6	Social media (Instagram, Facebook and Twitter): HAPP-e
4 ISPUP	WP 6	Participation in a conference: Raquel Teixeira oral presentation- "PREDICTING ATTRITION IN A COHORT OF VERY PRETERM INFANTS USING CLASSIFICATION ALGORITHMS"
4 ISPUP	WP 6	Participation in a conference: Julia Doetsch oral presentation- HEALTH OF ADULT PEOPLE BORN PRETERM - AN E-COHORT PILOT STUDY (HAPP-e)
4 ISPUP	WP 6	Web-site HAPP-e launched

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
4 ISPUP	WP 6	Participation in a conference : Julia Doetsch oral presentation- Quality Provision of Maternal and Newborn Health Care for Very Preterm Infants in Portugal in the context of neoliberal policies: A mixed method approach.
4 ISPUP	WP 6	Julia Doetsch oral presentation- Neoliberal Policy Impact on Health Care Provision for Parents of Very Preterm Infants in Portugal: A Quality Analysis on Perceived Care
4 ISPUP	WP 6	Participation in a conference: Raquel Teixeira oral presentation - Follow-up of cohorts of very preterm infants: a systematic review on participation and determinants of attrition
4 ISPUP	WP 6	TV programme: Ana Cristina Santos "HAPP-e"
4 ISPUP	WP 6	Participation in a conference: Julia Doetsch- poster - Equitable perinatal healthcare for migrants, Portugal: Comparative analysis of a self-assessment tool
4 ISPUP	WP 6	Participation in a conference: Julia Doetsch- poster - Record linkage of routine data with cohorts' data of infants under European and Portuguese law
4 ISPUP	WP 6	Participation in a conference: Julia Doetsch- Oral presentation- Impact of macro-socioeconomic determinants on perinatal healthcare quality for very preterm (VPT) infants in Portugal
06 INESC TEC	WP 4	Video/film: Video presentation - MANAGING PRETERM COHORT DATA USING THE PLATFORM – Overview of the RECAP Preterm Data Platform
06 INESC TEC	WP 4	Video/film: Video presentation - MANAGING PRETERM COHORT DATA USING THE PLATFORM – Setting Up Data in the Data Repository
06 INESC TEC	WP 4	Video/film: Video presentation - MANAGING PRETERM COHORT DATA USING THE PLATFORM – Adding Metadata in the Study Manager
06 INESC TEC	WP 4	Video/film: Video presentation - MANAGING PRETERM COHORT DATA USING THE PLATFORM – Harmonising Data Across Multiple Studies
06 INESC TEC	WP 4	Video/film: Video presentation - MANAGING PRETERM COHORT DATA USING THE PLATFORM – Managing Users and Permissions
06 INESC TEC	WP 4	Video/film: Video presentation - MANAGING PRETERM COHORT DATA USING THE PLATFORM – Performing Analysis
06 INESC TEC	WP 4	Press release: A press release reporting on the roles of both INESC TEC and ISPUP on the RECAP Preterm project.
07 ULEIC	WP 10	Video/film: Oral presentation (speaker: Liz Draper)
08 THL	WP 10	Video/film: Oral presentation (speaker: Eero Kajantie)
09 EFCNI	WP 10	Training: e-learning
09 EFCNI	WP 10	Participation to an event other than a conference or workshop: Oral presentation of RECAP preterm and the e-cohort HAPP-e, an overview, call for promotion among national networks
9 EFCNI	WP 10	Participation to an event other than a conference or workshop: Oral presentation of RECAP preterm and the e-cohort HAPP-e, an overview, call for promotion among national networks
9 EFCNI	WP 10	Participation to an event other than a conference or workshop: Oral presentation of RECAP preterm, project update
9 EFCNI	WP 10	Participation in activities organised jointly with other H2020 project(s): Oral presentation of RECAP preterm, update and promotion of public session GA meeting

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
9 EFCNI	WP 10	Participation to an event other than a conference or workshop: Oral presentation of RECAP preterm project, update
9 EFCNI	WP 10	Organisation of a Conference: Co-organiser of the congress: Chairing/moderation of a two hours session on RECAP preterm with presentations on the project and topic of preterm birth
9 EFCNI	WP10	Organisation of a Conference: Co-organiser of the congress; Promotion of RECAP preterm and the Summer School on the digital EFCNI booth
9 EFCNI	WP 10	Website: Sub-page on EFCNI website
9 EFCNI	WP 10	Other: Short article RECAP preterm and particularly HAPP-e, information and call to action
9 EFCNI	WP 10	Other: Short article:, project status
9 EFCNI	WP 10	Other: Short article: preterm,overview and promotion Winter/ Summer School
9 EFCNI	WP 10	Other: Short article: preterm,overview and promotion Winter/ Summer School
9 EFCNI	WP 10	Other: Short article: overview and promotion Winter/ Summer School
9 EFCNI	WP 10	Other: Short article: overview and promotion Winter/ Summer School
9 EFCNI	WP 10	Other: Short article, RECAP preterm, overview and promotion Winter/ Summer School
9 EFCNI	WP 10	Social media:60 posts Facebook, Twitter, Instagram, LinkedIn posts +
9 EFCNI	WP 10	Flyers: 4pager, overview on RECAP preterm and call to action
9 EFCNI	WP 10	Flyers: Project Brochure
10 NTNU	All	Other: Oral digital presentation, NTNU and St Olavs hospital
10 NTNU	WP 10	Other: Oral digital presentation and social media interaction
14 OPBG	All	Participation to a conference: Two oral presentations (on Recap project and SHIPs project); leaflets
14 OPBG	All	Participation to a conference: Oral presentation
14 OPBG	All	Participation to a Conference: Oral presentation
15 RegionH	All	Participation to an event other than a conference or workshop: Ph.d. defence (Josephine Funck Bilsteen)
16 UMR	WP 10	Organisation of a workshop: Organisation RECAP preterm Summer School
16 UMR	WP 10	Video/film: Oral presentation (speaker: Rolf F. Maier)
16 UMR	WP 7	Participation to a conference: Oral presentation (speaker: Lena Wohlers)
16 UMR	WP 10	Participation to a conference: Oral presentation (speaker: Rolf F. Maier)
17 UTARTU	WP7	Training: oral presentation/ neonatal outcome/EPICE/SHIPS/RECAP
17 UTARTU	WP 10	Flyers: spread through emails
17 UTARTU	WP 10	Website: newsletter about RECAP summer school
17 UTARTU	WP 10	Training: oral presentation/ neonatal outcome/EPICE/SHIPS/RECAP
17 UTARTU	WP 10	Participation to a workshop: oral presentation, slide, flyers of RECAP summer school
17 UTARTU	WP 10	Participation to a conference: slide about RECAP summer school
17 UTARTU	WP 10	Participation to a workshop: Discussions

Partner name (institution name)	Work package	Short description of activity (e.g. talk, congress, event, communication via social media, press or media)
18 UAntwerpen	All	Social media: Shared RECAP youtube video via post on personal LinkedIn account
18 UAntwerpen	WP 10	Website: Preparation of informative website for stakeholders and participants
18 UAntwerpen	All	Participation to an event other than a conference or workshop: Oral presentation [local quality meeting of neonatologists across Flanders]
18 UAntwerpen	All	Other: Newsletter preparations for stakeholders and participants
19 concentris	WP 1	Video/film: Oral presentation (speaker: Juliane Dittrich)
19 concentris	WP 10	Video/film: Video production for summer school
21 MLC	WP10	Video/film: Oral presentation (speaker: Evert-Ben van Veen)
21 MLC	WP2	Training: Webinar on joint controllers in large research consortia, https://www.lygature.org/webinar-joint-controllers-large-research-consortia