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RECAP

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Dissemination Level		
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)	
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EXECUTIVE SUMMARY

Particularly the patient networks are often well connected with national health ministries and key decision makers at national, regional and/or local levels and meanwhile have become key drivers for change and improvements. With the aim to sustainably translate the findings of RECAP preterm into practice, EFCNI, UMR, ISPUP and UoW organised a **workshop "translating research into practice"**, bringing together health professionals, parents and patients at national, EU and international levels, aiming to gain a better understanding of the situation in the different countries, and how a RECAP preterm and particularly the newly developed data platform can help to address the current challenges and gaps in the countries with regard to treatment and care of hospitalized infants and the need for follow-up of the children after discharge from hospital.

In a second step, the RECAP preterm policy brief 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/ caregivers, adults born preterm or healthcare professionals and their respective organisations as well as policy makers and decision makers).

The RECAP preterm policy brief can be combined with the RECAP preterm project brochure (deliverable 10.6) and further communication tools developed during the project for exchange with European/ national or local decision makers, press and interested public.

RECAP Consortium Partners

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

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1 INTRODUCTION

1.1 Background

Although very preterm or very low weight births constitute fewer than 2% of all births across Europe, they account for up to half of perinatal and infant deaths, children with impairments and disabilities and more than a third of the health and educational budgets for children.

Moreover, babies born very preterm or with very low birth weight have higher risks of cerebral palsy, visual and auditory deficits, impaired cognitive ability, psychiatric disorders and social problems than infants born at term. They may also face higher risks of non-communicable disease as they age. There is emerging evidence for increased risks of reduced mental health, quality of life, partnering, family life as well as employment chances and wealth in adulthood

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 babies 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 optimize the use of population data for research and innovation in healthcare, social and education policy.

The establishment of this collaborative European platform enables us to take current knowledge, research methods and tools as well as translation into practice beyond the current state of the art. This will benefit VPT/VLBW children, their families and society.

1.2 Translation of Research into Policy

Workshop "Translation of Research into Policy"

Particularly the patient networks are often well connected with national health ministries and key decision makers at national, regional and/or local levels. Therefore, the RECAP Preterm beneficiaries EFCNI, UMR, ISPUP and UoW organised a half-day workshop at EFCNI's annual global parent organisation summit, bringing together healthcare professionals and patient representatives with the aim to gain a better understanding of the situation in the different countries, and to discuss how RECAP preterm project and particularly the newly developed data platform can help to address the current challenges with regard to treatment and care of hospitalized infants and the need for follow-up of the children after discharge from hospital.

The workshop took place on 25 January 2020 in Freising, Germany with 20 participants from different EU countries.

Learning objectives of the workshop:

- Know the structural elements of the policy brief
- Learn how to capture the interest of key decision makers
- Gain insights into the RECAP preterm research project and make a connection how RECAP preterm can help improving the situation at national level
- Be able to transfer research findings into action points for decision makers

Workshop with national patient representatives "Translating research in to policy"
25 January 2020, EFCNI annual parent organisation summit

RECAP preterm Policy Brief

The RECAP preterm policy brief was developed at the end of the project, considering the learnings, experiences and outcome of the project as well as the outcome of the workshop held on 25 January 2020 (see Chapter 4). The RECAP preterm Policy Brief is a helpful tool allowing the consortium partners to introduce the research and recommendations developed under the project to a broader audience. The sharing of the Policy Brief to start a discussion with individual stakeholders is one step in the translation of research findings into practice.

The RECAP preterm Policy Brief 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/ caregivers, adults born preterm or healthcare professionals and their respective organisations as well as policy makers and decision makers).

The RECAP preterm Policy brief can be combined with the RECAP preterm project brochure (deliverable 10.6) and further communication tools developed during the project for exchange with international/ European/ national or local decision makers, press, interested public and other key stakeholders as defined by the consortium partners during a stakeholder mapping exercise in January 2018.

2 REALISATION PHASE

2.1 Timeline

17 January 2018	Workshop with consortium partners at the General Assembly Meeting in Frankfurt, Germany: Identification of potential key stakeholders for RECAP preterm at international, European and national levels with the help of a stakeholder mapping exercise. Sharing of the respective final lists with consortium partners for individual outreach opportunities
25 January 2020	Workshop “Translating Research into Policy” at the EFCNI annual Parent Organisations in Freising, Germany: • Exchange on the current situation and needs within the individual countries • Brainstorm on possible call to action items for the different target groups (parents/ patients, healthcare professionals, policy makers) • Learn about purpose and content of policy briefs in general and how a RECAP preterm Policy Brief could help to approach key decision makers and call for action to improve the situation at country and EU levels
July - September 2021	Development and design of RECAP preterm policy brief based on experiences and results of the project and the learnings from the exchange with the parent/ patient networks
October 2021 and beyond	• Finetuning of RECAP Policy Brief with consortium partners • Sharing of RECAP policy brief and stakeholder lists with consortium partners for individual outreach and action • Sharing of RECAP Policy Brief with parent/ patient organisations for outreach to national / local decision makers and other key stakeholders to address the topic preterm birth and necessary action steps.

3 OUTLOOK

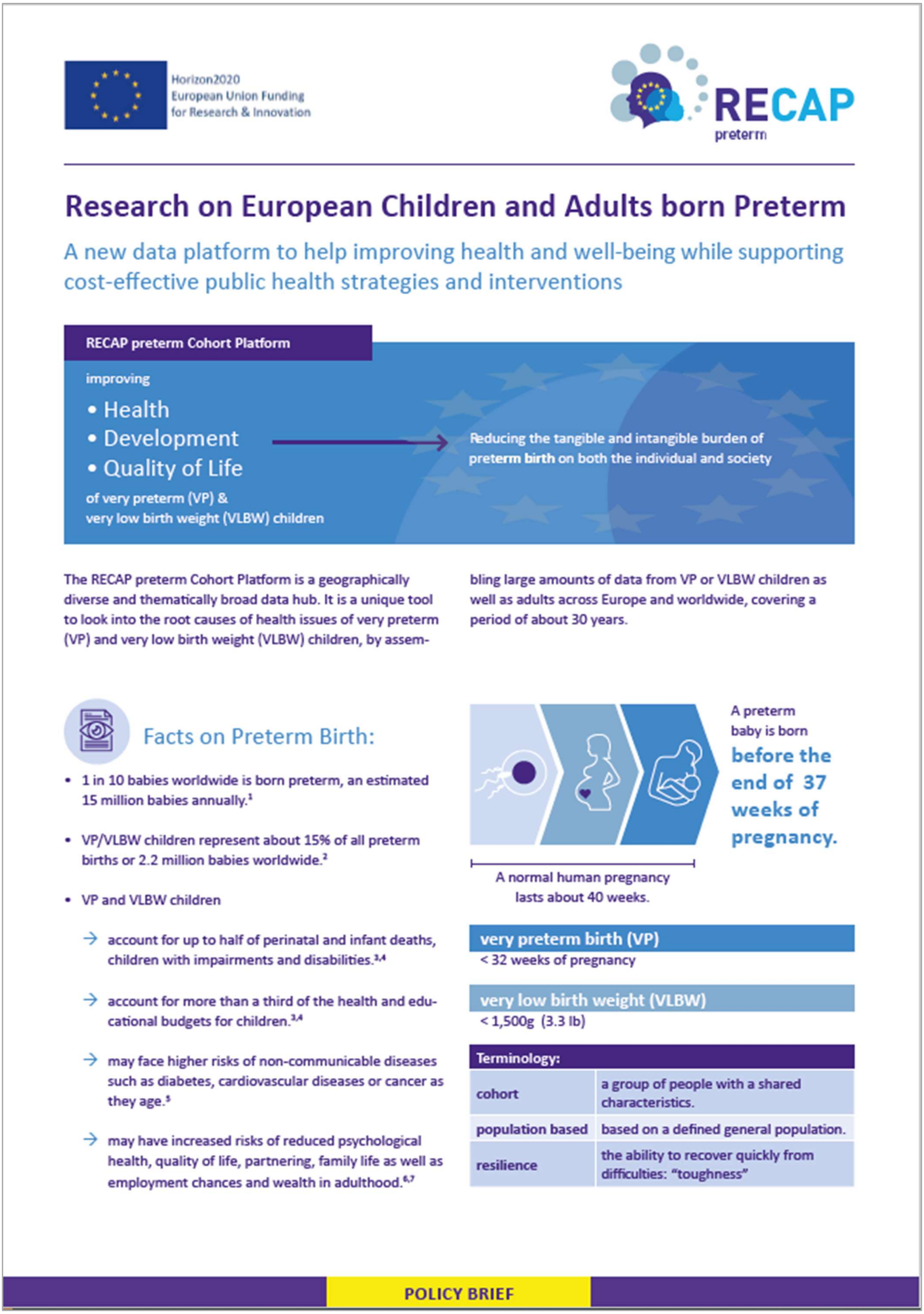
During autumn 2021, the RECAP Policy Brief will be finetuned with support of all consortium partners.

The Policy Brief will then be shared with the consortium partners in combination with the stakeholder mapping, allowing for individual outreach by each partner.

The Policy Brief will be uploaded on the RECAP preterm website (www.RECAP-preterm.eu) and will be shared with the EFCNIs partnering national parent/ patient organisations. These organisations are well connected with the national policy makers and other key decision makers.

Partners and networks can use the RECAP preterm Policy Brief to address the topic preterm birth, necessary action steps, the urgent need for effective follow-up of children and also how RECAP preterm findings provide evidence required to impact healthcare agendas. The Policy Brief will also serve as an introduction tool to exchange with stakeholders on the practical use of the RECAP preterm Cohort Platform to increase knowledge and evidence with the effect for a better quality of life of individuals, families and a positive effect on our societies.

4 APPENDIX
THE RECAP PRETERM POLICY BRIEF



Horizon2020
European Union Funding
for Research & Innovation

RECAP preterm

Research on European Children and Adults born Preterm

A new data platform to help improving health and well-being while supporting cost-effective public health strategies and interventions

RECAP preterm Cohort Platform

improving

- Health
- Development
- Quality of Life

of very preterm (VP) & very low birth weight (VLBW) children

→ Reducing the tangible and intangible burden of **preterm birth** on both the individual and society

The RECAP preterm Cohort Platform is a geographically diverse and thematically broad data hub. It is a unique tool to look into the root causes of health issues of very preterm (VP) and very low birth weight (VLBW) children, by assembling large amounts of data from VP or VLBW children as well as adults across Europe and worldwide, covering a period of about 30 years.

Facts on Preterm Birth:

- 1 in 10 babies worldwide is born preterm, an estimated 15 million babies annually.[1]
- VP/VLBW children represent about 15% of all preterm births or 2.2 million babies worldwide.[2]
- VP and VLBW children
  - → account for up to half of perinatal and infant deaths, children with impairments and disabilities.[3,4]
  - → account for more than a third of the health and educational budgets for children.[3,4]
  - → may face higher risks of non-communicable diseases such as diabetes, cardiovascular diseases or cancer as they age.[5]
  - → may have increased risks of reduced psychological health, quality of life, partnering, family life as well as employment chances and wealth in adulthood.[6,7]

A preterm baby is born **before the end of 37 weeks of pregnancy.**

A normal human pregnancy lasts about 40 weeks.

very preterm birth (VP)
< 32 weeks of pregnancy

very low birth weight (VLBW)
< 1,500g (3.3 lb)

Terminology:	
cohort	a group of people with a shared characteristics.
population based	based on a defined general population.
resilience	the ability to recover quickly from difficulties: "toughness"

POLICY BRIEF

Improving Lives:

- VP/VLBW children's increased risks for poorer long-term health and well-being can become an enormous burden on the individual, families and society.

- Healthcare costs for these children are higher and parents have to spend more time on taking care of their child which, in turn, lowers family earnings and well-being.

- It is important to identify those children at risk for health and development difficulties early and to find treatments or factors in the environment that protect them against adverse outcomes. This way, we can build on their strengths, giving them the opportunity to develop to their best potential.

- Working with the broad data hub of the RECAP preterm Cohort Platform will open new windows of opportunities to gain additional knowledge about root causes, best prevention, treatment and care measures and effective support for children born preterm. The well-being of preterm born children and their families will be improved by fostering the health and development of the children, and lowering stress and costs for the family.

- The knowledge gained by using the RECAP preterm Cohort Platform shall feed into policies for more cost-effective care. It can thus contribute to lower not only the burden of the individual and family, but also medical, social and educational costs.

The data hub of the RECAP preterm Cohort Platform is a tool to deliver important information to parents, VP/ VLBW adolescents or adults, clinicians or policy makers.

The Data Platform:

- For the development of the RECAP preterm Cohort Platform, experts from multiple fields and the patient side worked closely together, including for example life course epidemiology, methodology, neonatology, paediatrics, non-communicable disease research, epigenetics, economics, psychology, eHealth applications, or communication.

- The RECAP preterm Cohort Platform is a sustainable, geographically diverse, multidisciplinary database. Currently, it contains data from 20 population-based cohorts of children and young adults born very preterm from 12 European countries and further regions of the world, constituted over a 30-year time span.

Access to cross country data hub from cohort studies (child, adult) and Nordic registers

Determine universal outcomes of VP/ VLB children or adults

Train researchers on the use of the platform

Investigate protective and resilience factors

Goals:

- Support the development of more effective, evidence-based, personalised interventions and prevention measures.

- Improve the health, development, well-being and quality of life of VP/VLBW children and adults and their families.

- Establish cost-effective care and lower medical, social and educational costs.

Importance:

- The large amounts of data assembled by the RECAP preterm Cohort Platform on European and worldwide cohorts can help to identify the root causes of VP/VLBW children's health issues. Beyond that, the Platform will reflect broad geographic, cultural and health system diversity.

- Harmonizing and merging these data to increase the number of children included in the studies is valuable for studying rare exposures and diseases. It also allows for immediate validation and replication of a finding in one country and assessment of cross-country differences.

- The establishment of this collaborative European data platform enables us to take current knowledge, research methods and tools as well as their translation into practice beyond the current state of the art.

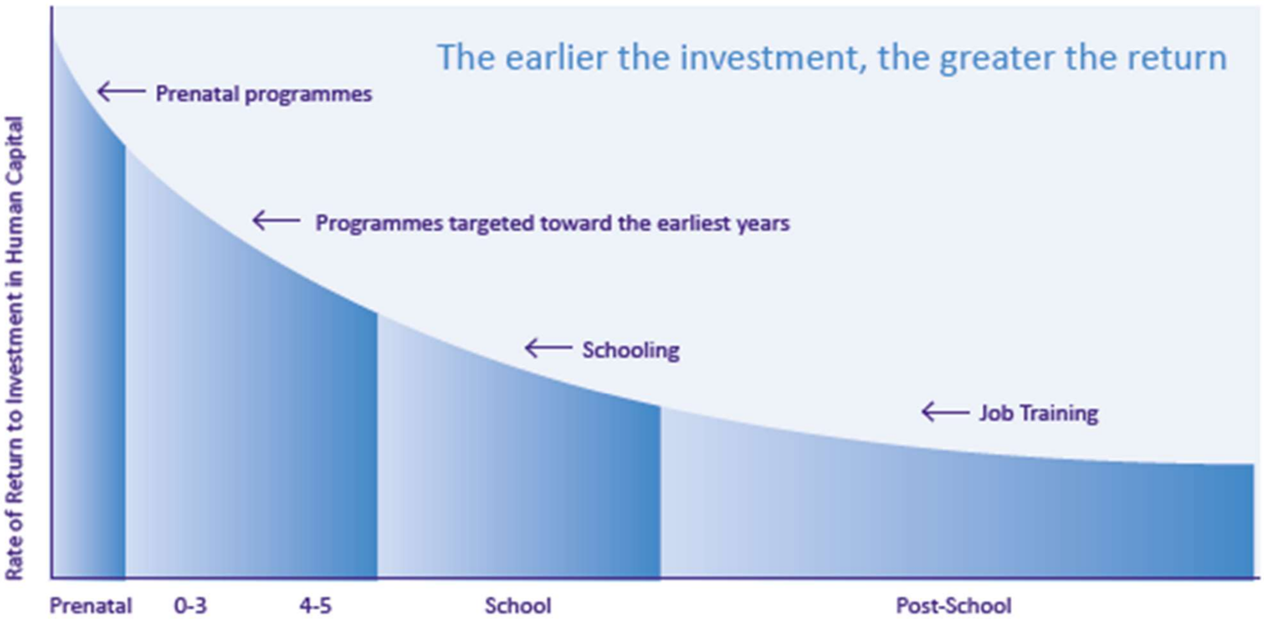
- Working with the RECAP preterm Cohort Platform can benefit VP/VLBW children, their families and society. It also can help to reduce the economic burden of preterm birth:

  - Financial burden on healthcare insurance[8]

  - Substantial financial burden on families (e.g. therapies, reduced working capacities)[9]

  - The highest rate of economic returns comes from the earliest investments in children, as shown in the below graph by James Heckman[10]

  - Money spent to improve the long-term health of preterm born children is a "Smart Investment" for society.



Source: James Heckman, Nobel Laureate in Economics

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10. The Heckman Equation. https://heckmanequation.org/resource/the-heckman-curve/

Call to Action:

For professionals and parents/ adults born preterm:

Support the promotion and use of the RECAP preterm Cohort Platform:

1. Campaign about the importance of data collection by parents and particularly adults born preterm to extend and deepen the data, e.g. by contributing to the first e-cohort for adults born preterm, HAPP-e, accessible via the RECAP preterm website.

2. Encourage further cohorts to cooperate with the RECAP preterm Cohort Platform.

3. Establish new cohorts and encourage their cooperation with RECAP preterm.

4. Support training of professionals, early career researchers and scientists on the purpose and use of the RECAP preterm Cohort Platform, e.g. with the E-Learning available on the RECAP preterm website.

5. Use the RECAP preterm Cohort Platform for future research projects and encourage colleagues to do so.

For politicians:

Support the implementation of equitably accessible, effective follow-up programmes at national level and standards of care at European and national levels:

1. Recognise newborn care as one pillar for securing the health and well-being of our future society. Integrate it into ongoing European and national strategies on public health, chronic conditions, healthy ageing and research.

2. Nominate a policy officer in the health ministry responsible for neonatal and child health.

3. Support the provision of an international forum for the sharing of best practice among countries and set up a national working group for the development and implementation of national neonatal and follow-up policies.

4. Prioritise and allocate funding for coordinated perinatal and neonatal research and research on effective follow-up programmes to improve the prevention, treatment, care and outcomes of preterm birth.

5. Promote the establishment of national centralised registries and harmonised, comparable European data sets for epidemiology, as well as cost and quality outcome data associated with preterm birth to allow for comprehensive study and comparative analysis and the monitoring of prevalence, mortality, acute morbidity and long-term impairment, outcomes and costs.

Please feel free to contact the Project Coordination via the contact forms on the RECAP preterm website if you have questions, or if you would like to add your cohort to the RECAP preterm Cohort Platform.

Visit the RECAP preterm website: **https://recap-preterm.eu/**

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