RECAP Preterm

"Research on European Children and Adults born Preterm"

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Deliverable 3.2

Report of cohort descriptions to aid future research

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Open Issues

No:	Date	Issue	Resolved
1	27/03/2019	PIPARI and LOLLIPOP metadata not yet received from cohorts due to delays in third party agreement	
2	27/03/2019	GNN metadata incomplete due to delays in third party agreement	
3	27/03/2019	EPICE metadata not yet finalized due to queries over final structuring of the EPICE network on the data platform.	
4	27/03/2019	Data dictionary generation by cohorts is ongoing	
5	27/03/2019	Data Dictionary mapping to the schema is ongoing	

SUMMARY

This deliverable describes the characteristics of the cohorts participating in RECAP Preterm. We start by outlining our inventory process for documenting the characteristics of the cohorts, followed by a description of the cohorts including:

Study Populations
Exposures
Data Collection Events
Methods
Data collection instruments

This inventory carried out in collaboration with the cohorts involved in RECAP Preterm provided rich cohort metadata, which will facilitate data harmonisation and pooled analyses. The metadata detailed in this report will be made available via the metadata catalogue on the RECAP Preterm data platform and within the variable definitions included in the cohort datasets.

TABLE OF CONTENTS

1 INTRODUCTION

1.1 Purpose and Scope

This document describes the characteristics of the cohorts participating in RECAP Preterm. Cohort metadata have been surveyed by Work Package 3 (WP3) in collaboration with participating cohort leads to identify the methodologies used and data items collected. Details of the populations, inclusion and exclusion criteria, data collection events, sample size and follow up rates have been collected, along with protocols, questionnaires, and other study documentation. The original documents are included in an inventory of study documentation which is available on the RECAP Preterm intranet site for use by RECAP Preterm Partners. The extracted metadata described in this report are available on the RECAP Preterm data platform https://recap-preterm.inesctec.pt/cat/. The RECAP Preterm metadata catalogue will be continually updated by the cohorts as future data collections are carried out or new metadata are generated. In conjunction with this Deliverable Report, an additional Deliverable Report D3.1 Meta-data Catalogue with Cross-Cohort Mapping describes the creation and structure of the RECAP Preterm metadata catalogue.

The wealth of study documentation available will provide a vital resource during data harmonization, enabling those carrying out the process (led by WP3) to understand the provenance of the data items, as well as the methodologies and characteristics of the cohorts. The metadata also provides detailed information for researchers carrying out analyses using RECAP Preterm cohort data to aid in the identification of variables and cohorts to include in their analyses. Finally, the metadata catalogue will form the public-facing section of the RECAP Preterm data platform and will aid the discoverability of the RECAP Preterm cohorts by external parties. This has the potential to aid the dissemination of activities carried out as part of RECAP Preterm, and to generate new collaborations with non-RECAP Preterm cohorts.

1.2 References to other RECAP Documents

- RECAP Preterm Research and Innovation action
- RECAP Preterm Horizon 2020 Full Proposal
- RECAP Preterm D4.1 A specification of the RECAP Data Platform
- RECAP Preterm D3.1 Meta-data catalogue with cross-cohort mapping

1.3 Definitions, Abbreviations and Acronyms

Table 1 List of Abbreviations and Acronyms

Abbreviation/ Acronym	DEFINITION
VPT	Very Preterm, <32 weeks gestational age
VLBW	Very Low Birthweight, <1500g
EPT	Extremely Preterm, <28 weeks gestational age
ELBW	Extremely Low Birthweight, <1000g
NICU	Neonatal Intensive Care Unit
GA	Gestational Age
WP	Work Package
ULEIC	University of Leicester

Table 2 List of Cohort Abbreviations

Cohort Abbreviation	Cohort Name
ACTION	Accesso alle Cure e Terapie Intensive Ostetrico Neonatali (Access to Obstetrical and Neonatal Intensive Care)
AYLS	Arvo Ylppö Longitudinal Study
BEST/BLS	Bayerische Entwicklungsstudie/ Bavarian Longitudinal Study
DNBC	Danish National Birth Cohort
EPIBEL	Extremely Preterm Infants in BELgium
EPICE/SHIPS	Effective Perinatal Intensive Care In Europe/ Screening to Improve Health in Very Preterm Infants in Europe
EPICE/SHIPS-PT	Effective Perinatal Intensive Care In Europe - Portugal/ Screening to Improve Health in Very Preterm Infants in Europe - Portugal
EPICure	EPICure
EPICure 2	Epicure 2
EPIPAGE1	Étude épidémiologique sur les petits âges gestationnels
EPIPAGE2	Étude épidémiologique sur les petits âges gestationnels 2
EST 2002-2003	Estonia 2002-2003 ELBWI, <29GW at 5y
EST 2007-2008	Very low gestational age infants born in Estonia in 2007-2009
ESTER	ESTER (Preterm Birth and Early Life Programming of Adult Health and Disease)
ETFOL	Treatment of extremely preterm infants: parents attitudes.
EXPRESS	Extremely preterm infants in Sweden study
GNN	German Neonatal Network
HeSVA	Helsinki Study of Very Low Birth Weight Adults
LOLLIPOP/Pinkeltje	Longitudinal Preterm Outcome Project/ Preterm Infants: Knowledge on Target Height and Outcome
NTNU LBW Life	NTNU Low Birth Weight in a Lifetime Perspective Study
PEP	Project Extreme Prematurity
POPS	Project On Preterm and Small for gestational age infants

2 COHORT CHARACTERISTICS

2.1 Cohort Document Inventory and Metadata Catalogue

The Work Package 3 team carried out a survey of the participating cohorts to identify the methodologies used and data items collected by each cohort. A template (Metadata Request Form) was developed to facilitate the characterization of the sample, and to describe the sampling frames, population denominators (including cases and controls), sample sizes, inclusion and exclusion criteria, timing of data collection events and follow-up rates in the participating cohorts. Along with the information collected in the metadata request form, all protocols, questionnaires and other study documentation was also requested to allow characterisation of the exposure and covariate data collected, and content of outcome assessments. The cohort document inventory process is described in more detail in Deliverable Report D3.1 Meta-data catalogue with cross-cohort mapping.

The cohort metadata presented in this report forms the basis of the Metadata catalogue within the RECAP Preterm data platform. The metadata catalogue architecture has been developed by WP3 in conjunction with the RECAP Preterm data platform developers (WP4). The RECAP Preterm metadata catalogue is described in detail in Deliverable Report D3.1 Meta-data catalogue with cross-cohort mapping. The individual cohort study pages within the metadata catalogue are available to view on the RECAP Preterm data platform at the following link: https://recap-preterm.inesctec.pt/cat/.

2.2 Cohort Characteristics

2.2.1 Inclusion and exclusion criteria

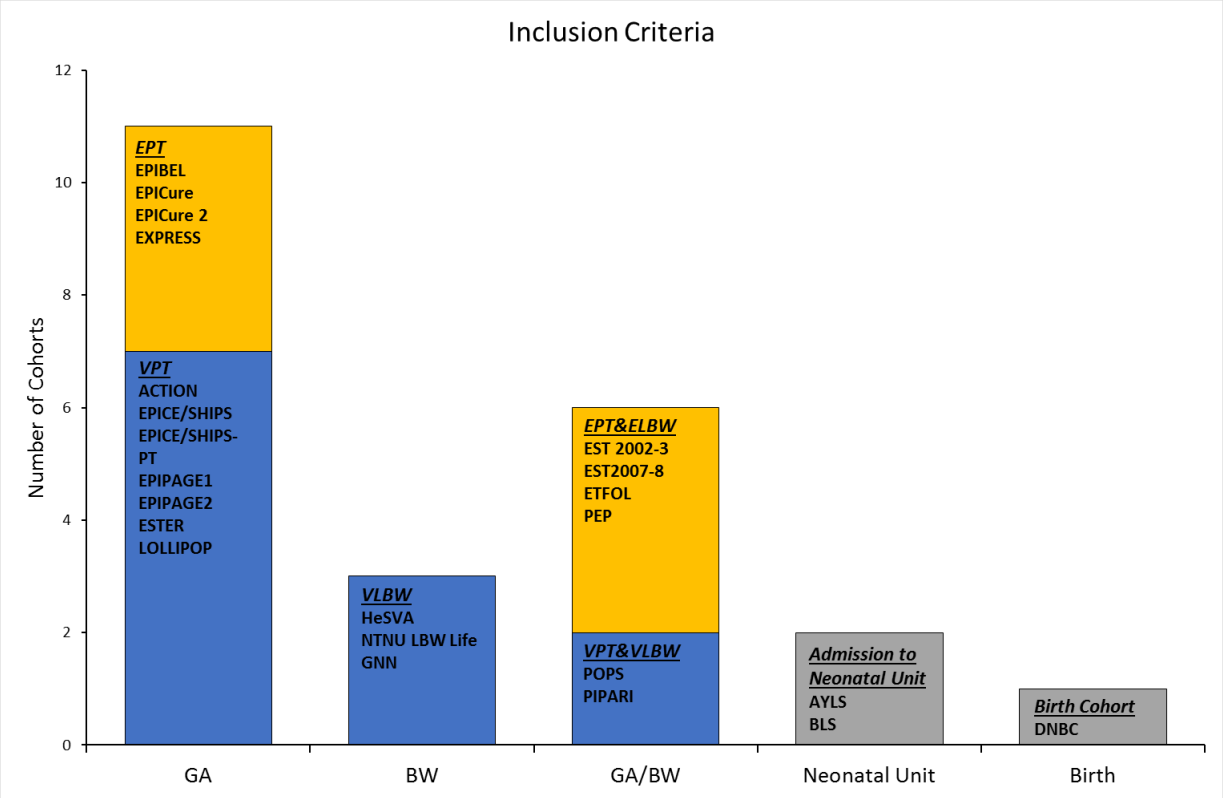
Information on inclusion and exclusion criteria collected from participating cohorts is presented in Table 3. This illustrates the heterogeneity in the inclusion criteria used to define the index populations. As shown in Figure 1 Overview of inclusion criteria used by the cohorts participating in RECAP Preterm), 10 of the RECAP Preterm cohorts used a gestational age defined cut-off as their inclusion criteria. Of these 10 cohorts, 4 cohorts followed up infants born extremely preterm (EPT; <28 weeks' gestational age) and an additional 6 cohorts followed up those born very preterm (VPT; <32 weeks' gestational age). Three cohorts recruited those born at very low birthweight (VLBW; <1500g). A further 5 cohorts used a combination of preterm birth and/or birthweight to define their index group; 4 cohorts recruiting those born extremely preterm and/or at extremely low birthweight (<28 weeks' gestation and/or <1000g; ELBW), and 1 using VPT and/or VLBW in combination (<32 weeks' gestation and/or <1500g). In addition, 2 participating cohorts (BLS and AYLS) recruited infants who had been admitted to a neonatal unit in the first days after birth; these populations have enriched levels of VPT and VLBW infants, however preterm births may be present in both the index and control groups. The remaining cohort DNBC, is a national birth cohort that recruited 96,834 live born infants, hence while the proportion of very preterm births is small, the absolute number of VPT and VLBW births is around 950.

For those cohorts where the inclusion criteria is not defined by gestational age or birthweight, it is possible to define an index group of VPT/VLBW born individuals based on the inclusion criteria of

interest, and analyses on the effects of VPT/VLBW birth on outcomes have previously been performed in these cohorts.

Figure 1 Overview of inclusion criteria used by the cohorts participating in RECAP Preterm

The inclusion criteria displayed are simplified for graphical representation. More detailed descriptions of the inclusion criteria used by a number of cohorts are described in Table 3. GA – Gestational Age, BW – Birthweight, GA/BW – Gestational Age and/or Birthweight, VPT – Very Preterm, EPT – Extremely Preterm, VLBW – Very Low Birthweight, ELBW – Extremely Low Birthweight.



As described in Table 3, as research priorities have changed over time several cohorts have chosen to stratify their samples for follow up data collections and assessed only a subsample of the original cohort. For example, BLS initially recruited infants who were admitted to a neonatal unit within the study area, however for later waves of follow up (phase II and III) a subsample of the original cohort was assessed comprising a group of VP/VLBW children and a quota-sample of children born at >31 weeks gestational age randomly drawn within the stratification factors sex, socioeconomic status and neonatal risk. The Estonia 2007-2008 cohort assessed a subsample of all live births at <32 weeks' gestational age, born in 2007 at the 2 year data collection event; but at 5 years a different subsample consisting of all live births at <29 weeks gestational age, <1000g, born in 2007-2008 were assessed. For the German Neonatal Network, from 2009-2016 infants with a birthweight <1500g and gestational age <37 weeks who were admitted to NICU were recruited and followed up at 5 years; however from 2017 onward only those infants with a birthweight <1000g or <29 weeks of gestation who were admitted to NICU have been recruited to the study. It is important that these changes in cohort composition are documented and taken into account when planning analyses.

Table 3 RECAP Preterm Cohort Inclusion and Exclusion Criteria

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
ACTION	2003-2004	• Italy • ACTION 1: Lombardy, Friuli Venezia Giulia (FVG), Tuscany, Marche, Lazio and Calabria (6 regions) ACTION 2: FVG, Tuscany, Marche, Lazio and Calabria (5 regions) ACTION 3: FVG, Tuscany, Lazio (3 regions)	Births in all hospitals with NICUs plus transferred infants in Calabria and Lombardy.	Inclusion: All live and still births between 22+0 and 31+6 weeks of gestation in FVG, Tuscany, Marche and Lazio. Live births in Calabria and Lazio. Exclusion: none	Inclusion: Italian 2-years children born at term recruited in FVG, Tuscany, Marche, Lazio and Calabria. Exclusion: Infants born preterm and those from foreign mothers.	• 2 y • 8-11 y	• 2943
AYLS	1985-1986	• Finland • Uusimaa	All hospitals in area of Uusimaa	Inclusion: All infants born alive and admitted to neonatal wards in obstetric units or transferred to the Neonatal Intensive care unit between 15 March 1985 and 14 March 1986 in the study area. No specific inclusion criteria related to gestational age or birth weight. Exclusion: none	Inclusion: An infant born after every second hospitalized infant and without evidence of neonatal illness was identified from one of the three biggest maternity hospitals in the study area during the same period. Exclusion: none	• 5 mths • 20 mths • 56 mths • 24-26 y	• 1535 • (n=480 preterms)
BLS	1985-1986	• Germany • South Bavaria	The BLS started off as a geographically whole population study of infants admitted to neonatal special care in South Bavaria (Germany). The children and their families were recruited from 16 children's	Inclusion: All infants born between February 1985 and March 1986 who required admission to a neonatal unit within the first 10 days after birth. Phase I: N=7505, including n=682 VP/VLBW (<32 weeks gestational age or <1500g birth weight). Phase II: reduced sample including (1) VP/VLBW children and (2) a quota-sample of children born >31	Inclusion: Healthy infants who were cared for on the normal postnatal wards in the same obstetric hospitals (Phase I: N=916) Exclusion: none	*Phase I* • 5 mths • 20 mths • 56 mths *Phase II* • 6;3 y • 8;5 y *Phase III* • 12-13 *Phase IV* • 26 y	• 7505 • (n=682 VPT/VLBW)

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
			hospitals, including 153 neonatal units.	weeks GA randomly drawn within the stratification factors sex, socioeconomic status and neonatal risk. Phase III and IV: follow up of VP/VLBW adolescents/adults Exclusion: none			
DNBC	1996-2002	• Denmark • All counties in Denmark	A population based pregnancy cohort following up mothers and infants. Participating infants were born in 1996-2002. The cohort includes births at all gestational ages (it is not specifically a preterm birth cohort), however, an index group can be defined based on gestational age or birthweight.	Inclusion: As DNBC is a pregnancy and child cohort there is no predefined index or control group. However, it is possible to define an index group (e.g. based on gestational age and/or birthweight). Exclusion: Women who could not speak Danish well enough to participate in a telephone interview		• 6 mths • 18 mths • 7 y • 11 y	• 96834 • (n=951 VPT)
EPIBEL	1999-2000	• Belgium • All of Belgium	All NICU's in Belgium	Inclusion: During a 2-year period (January 1, 1999, to December 31, 2000), data of all inborn births with a GA between 22 and 26 completed weeks, i.e, up to 26 weeks and 6 days' postmenstrual age, were collected in all perinatal centres in Belgium.	n/a	• 3 y • 11-15 y	• 525

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
				Exclusion: Outborn infants (16% of EPT infants admitted) are not included			
EPICE	2011-2012	• Belgium, Denmark, Estonia, France, Germany, Italy, Netherlands, Poland, Portugal, UK, Sweden • Belgium – Flanders Denmark – Eastern Region Estonia – Whole country France – Nord-Pas-de-Calais, Burgundy, Île-de-France Germany – Hesse, Saarland Italy – Lazio, Emilia, Marche Netherlands – East Central Poland – Wielkopolska Portugal – Northern, Lisbon UK – Northern, East Midlands, Yorkshire and Humber Sweden – Stockholm	All births in maternity units within the regions. Later follow up of the cohort in the SHIPS study (follow up at 5 years is in progress). Marche region did not participate in SHIPS.	Inclusion: All live and still births between 22 and 31 weeks of gestation. Exclusion: none	n/a	• 2 y • 5.5 y	• 10329
EPICure	1995	• UK, Republic of Ireland • All of United Kingdom and Republic of Ireland	All maternity units in the United Kingdom and Republic of Ireland (276 units)	Inclusion: All births between 20 and 25 completed weeks of gestation Exclusion: none	Inclusion: Age, sex and ethnic group matched classmate of index child born ≥37 weeks of gestation. Control group included for 6, 11, 19 year follow up. Where possible the same control child was used at the 6	• 2.5 y • 6 y • 11 y • 19 y	• 309 long term survivors

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
					and 11 year follow up, if not a new child was selected. Exclusion: Birth before 37+0 weeks gestational age.		
EPICure 2	2006	• UK • All of England	All maternity units in England	Inclusion: all births in England between 22 and 26 completed weeks of gestation Exclusion: none	Inclusion: Age and sex matched classmate of index child born ≥37 weeks of gestation recruited at age 11. Control group included at 11 year follow up. Exclusion: Birth before 37 weeks of gestation	• 2.5 y • 11 y	• 3133 births
EPIPAGE1	1997-1998	• France • Alsace, Franche-Comté, Languedoc-Roussillon, Lorraine, Midi-Pyrénées, Pays de la Loire, Haute Normandie, Nord-Pas-de-Calais, Paris and its immediate suburbs (9 regions)	Population based cohort - all births (live births, still births and termination of pregnancy) in all maternity units in the 9 regions. The control group consists of infants born at 39-40 weeks.	Inclusion: All infants live born or stillborn and all terminations of pregnancy between 22 and 32 completed weeks of gestation (recruited between January 1 and December 31, 1997) + a sample of moderate preterm births (births and terminations of pregnancy) born between 33 and 34 completed weeks (2 month recruitment - April to October, 1997) + A sample of infants live born between 22 and 26 weeks GA in 8 of the 9 regions between January 1 and December 31, 1998 Exclusion: none	Inclusion: Infants born alive between 39 and 40 completed weeks (one week recruitment in 1997) Exclusion: none	• 2 mths after discharge • 9 mths • 1 y • 2 y • 3 y • 4 y • 5 y • 8 y	• 3581
EPIPAGE2	2011	• France • 25 French regions: 21 of the 22 metropolitan regions, and 4 overseas regions.	Population based cohort - All births (live births, still births and terminations of pregnancy) in	Inclusion: All infants (live born, stillborn) and all terminations of pregnancy between 22 and 31 completed weeks + a sample of moderate preterm births (all births	Inclusion: 600 infants born at term (>=37 weeks) in 2011 are recruited from the Elfe study as a control group at the 5 and a half year follow up.	• 1 y • 2 y • 5.5 y	• 5170

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
		Alsace, Aquitaine, Auvergne, Basse-Normandie, Bretagne, Bourgogne, Centre-Val de Loire, Champagne-Ardenne, Corse, Franche-Comté, Haute-Normandie, Île-de-France, Languedoc-Roussillon, Limousin, Lorraine, Midi-Pyrénées, Nord-Pas-de-Calais, PACA, Pays de la Loire, Picardie, Rhône-Alpes, Guyane, Martinique, La Réunion, and Guadeloupe.	maternity units within the regions	and late terminations) at 32–34 weeks. Recruitment between March 28, 2011 and December 31, 2011. Exclusion: none	Exclusion: none		
EST 2002-2003	2002-2003	• Estonia • All of Estonia	Population based cohort consisting of all live births <1000g, <29 weeks of gestational age in maternity units within Estonia registered in Estonian Medical Birth register.	Inclusion: all live births <1000g, <29 GW Exclusion: Stillborn	n/a	• 5 y	• 80
EST 2007-2008	2007-2008	• Estonia • All of Estonia	Population based cohort - all births <32 weeks gestational age born in 2007-2008 in maternity units within Estonia registered in Estonian Medical Birth	Inclusion: 2year follow up – all live births <32GW, born in 2007 5 year follow up – live births <29GW, <1000g, born in 2007-2008 Exclusion: Stillborn	Inclusion: Term healthy infant matched with the study group by sex , age and birth hospital Exclusion: Illness and intensive care requirement within 1st week of life	• 2 y • 5 y	• 187

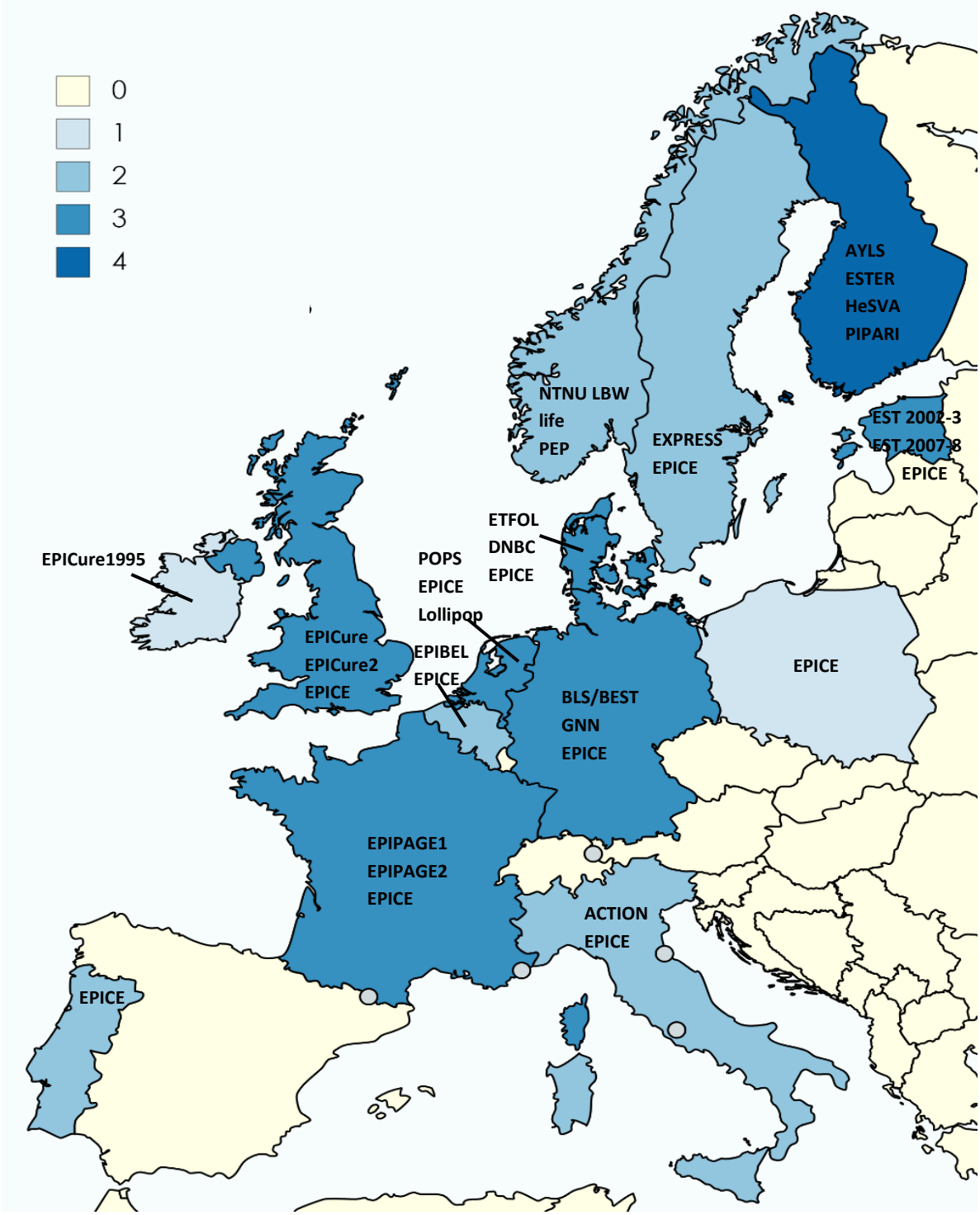
Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
			register				
ESTER	1985-1986	• Finland • Northern Regions (Oulu and Lapland Provinces)	Population-based cohort from Northern Finland. Participants were recruited between 1985 and 1989 via the Northern Finland Birth Cohort 1986 (NFBC) for those born 1985-1986, or were born in the same geographical area in 1987-1989 and identified through the Finnish Medical Birth Register.	Inclusion: Preterm birth – <34 wks, late 34-36 wks (subgroup VLBW) Exclusion: Invited as born preterm but in birth record review turned out to be born at term.	Inclusion: Term birth – at or above 37 wks (a random sample of source population born at term) Exclusion: moved to appropriate preterm group) if invited as control but in birth record review turned out having been born preterm	• 16 y • 23 y	• 397
ETFOL Cohort	1994-1995	• Denmark • All of Denmark	All Danish Hospitals with a neonatal unit – 18 units participated	Inclusion: Birth year 1994 – 1995, very low birth weight below 1000 g or very low gestational age below 28 weeks Exclusion: none	Inclusion: Babies born at term – control group Exclusion: none	• 2 y • 5y	• 477
EXPRESS Cohort	2004-2007	• Sweden • All of Sweden	Population based cohort consisting of all live born and still born infants delivered extremely preterm in Sweden from April 1, 2004, to March 31, 2007	Inclusion: All live-born (gestational age equal to or less than 26 weeks+6 days) and stillborn infants (gestational age 22 weeks+0 days – 26 weeks+6 days) delivered extremely preterm in Sweden from April 1, 2004, to March 31, 2007 Exclusion: Women delivering extremely preterm but not residing in Sweden in study period.	Inclusion: Selection criteria for controls were singleton at-term birth with a 5-minute Apgar score greater than 3 with matching of control participants for place of living, sex, day of birth, and maternal country of birth. Exclusion: none	• 2.5 y • 6.5 y •	• 1011

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
				Terminations of pregnancy and infants born outside of Sweden and transferred to Sweden for neonatal care were also excluded.			
GNN Cohort	2009-present	• Germany	All preterm birth less than 1500g birth weight in participating centres. Documentation (birth weight, gestational age, survival, major complications) of all eligible but not included VLBW.	Inclusion: 2009-2016 – birth weight <1500g and gestational age <37 weeks admitted to NICU Since 2017 – birth weight<1000g or < 29 weeks of gestation admitted to NICU Exclusion: Missing consent.	Inclusion: No control group at birth For 5 year follow up – Survey of Neonates in Pomerania (SNiP II) inclusion criteria: living in certain geographical region (determined by postcode) Exclusion: Missing consent, children placed for adoption, insufficient knowledge of German language for interviews.	• 5 y	• 6103
HeSVA Cohort	1978-1985	• Finland • Uusimaa	VLBW infants born 1978-1985 and discharged alive from neonatal intensive care unit (NICU) at Children's Hospital in Helsinki, which is the only NICU serving a geographically defined area (province of Uusimaa).	Inclusion: All infants born at < 1500g discharged alive from the NICU at Children's Hospital in Helsinki between 1978 and 1985 Exclusion: Death before discharge from NICU. Lived more than 110 km away from Helsinki in 2004.	Inclusion: Control subjects were group-matched by age, sex and birth hospital. They had to be singleton, term born and not SGA (Birth weight SDS not < -2.0 according to current Finnish criteria (Pihkala J 1989, Duodecim). Exclusion: Lived more than 110 km away from Helsinki in 2004.	• 15 mths • 5 y • 18-27 y • 20-29 y • 22-30 y	• 335
NTNU LBW Life Cohort	1986-1988	• Norway • Mid-Norway (Counties of South and North Trøndelag, Møre and Romsdal, City of Trondheim)	Single centre cohort, all VLBW infants admitted to the NICU at St. Olavs Hospital, Trondheim University Hospital.	Inclusion: VLBW: All infants admitted to the NICU at St. Olavs Hospital, Trondheim University Hospital ≤ 1500 g. Exclusion: Congenital anomalies and syndromes	Inclusion: All babies born at term with weight >10th percentile in the Trondheim region in 1986-1988. A 10% random sample was selected for follow up.	• 1 y • 5 y • 14 y • 18 y • 19-20 y • 23 y	• 121

Cohort Name	Year of Birth	Country	Sampling Frame	Index Group Inclusion and Exclusion Criteria	Control Group Inclusion and Exclusion Criteria	Age at Follow Up	Number of Participants at birth
			Control group consisted of all children born to mothers of a 10% random sample in the Trondheim region in the same years as the VLBW group.		Exclusion: Congenital anomalies and syndromes	• 26 y	
POPS Cohort	1983	• Netherlands • All of the Netherlands	Population based and nation-wide cohort, VPT or VLBW infants live-born in the Netherlands in 1983	Inclusion: Very preterm (<32 weeks of gestation) and/or very low birth weight (<1500 g) infants Exclusion: No exclusion criteria	n/a	• 3 mths • 6 mths • 12 mths • 2 y • 5 y • 9 y • 10 y • 11 y • 14 y • 19 y • 28 y	• 1338
Project Extreme Prematurity	1999-2000	• Norway • All of Norway	Population based, all extreme preterm births in Norway 1999-2000	Inclusion: Extremely preterm birth GA less than 28 weeks or BW less than 1000 gram Exclusion: none	Inclusion: control group included in subcohort study at 11 year follow up. Exclusion: None.	• 2 y • 5 y • 11 y	• 636

2.2.2 Geographical Location

Figure 2 Locations of Cohorts involved in RECAP Preterm



Cohorts involved in RECAP Preterm recruited participants from geographical regions within 14 European countries. The distribution of the cohorts is shown in Figure 2 Locations of Cohorts involved in RECAP Preterm). As noted in the inclusion criteria in Table 3, a number of cohorts involved RECAP Preterm are regional/single centre cohorts, however, the majority cover large regions of the

respective country or recruit participants from the whole country. In addition, RECAP Preterm also includes the EPICE cohort, which recruited participants from 19 European regions in 11 countries, of which 18 were included in the 5 year follow up of EPICE as part of the SHIPS study, with only Marche in Italy not participating in data collection at 5 years.

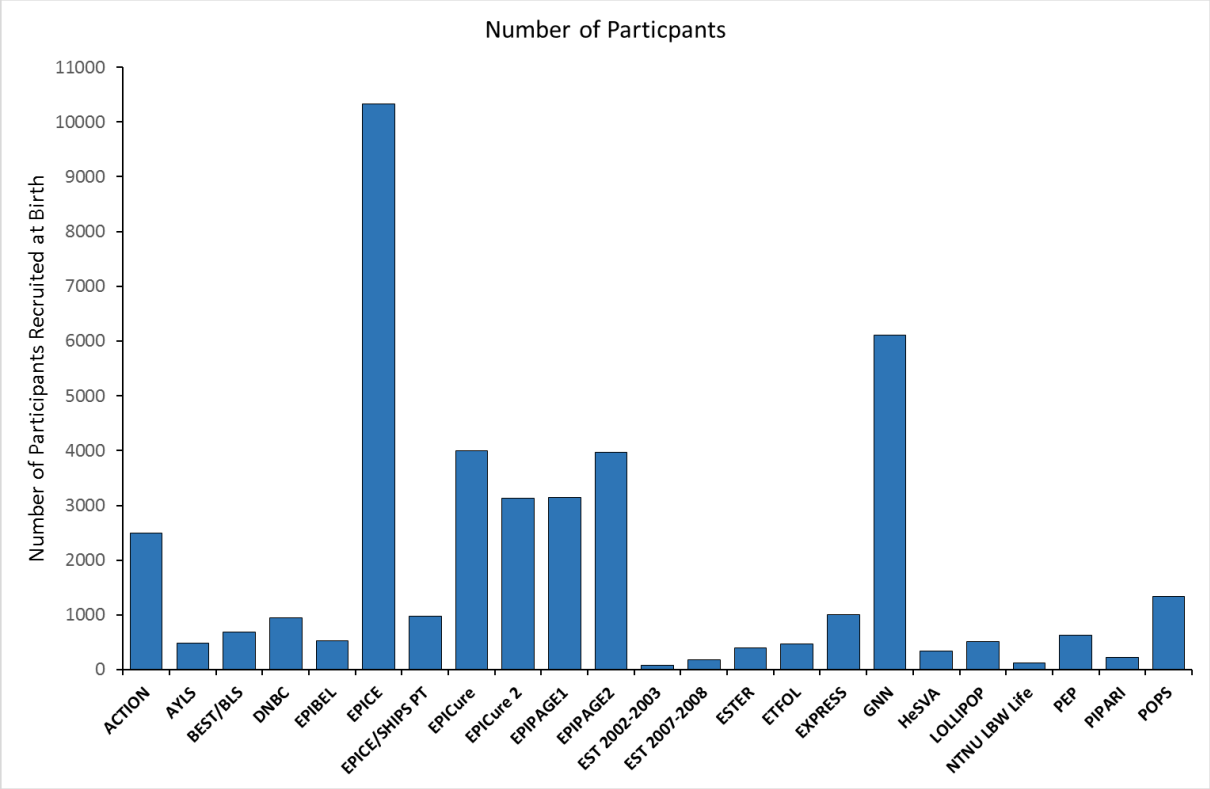
2.3 Sample Size and Follow Up Rates

The number of participants in the index group recruited at birth is shown for each cohort in Figure 3 Number of Participants in Index Group Recruited at Birth. Figure 3. This varies from 80 in the Estonia 2002-2003 cohort to 10329 in the EPICE cohort. For cohorts where the inclusion criteria was not defined using gestational age or birthweight (AYLS, BLS and DNBC), the numbers displayed represent the number of VPT births within the study population as this is more indicative of the available VPT/VLBW population available for analysis. For example DNBC includes 951 participants who were born VPT out of a total sample size of 96834 (this subsample size information was provided by the cohort leads). Details of the full sample size for these cohorts are presented in Table 3 **RECAP Preterm Cohort Inclusion and Exclusion Criteria**.

When evaluating the sample size available for follow up in the cohorts, the details of the inclusion criteria, such as whether stillborn infants and terminations of pregnancy were included are important considerations as well as changes in inclusion criteria for later follow up time points. Numbers of participants assessed at each follow up wave are shown for each cohort in Section 3 Cohort Descriptions.

Figure 3 Number of Participants in Index Group Recruited at Birth.

For cohorts where the index group was not defined as VPT or VLBW birth (BLS, AYLS, DNBC), the numbers of VPT/VLBW births provided by the cohorts are displayed to aid in the comparison between cohorts.



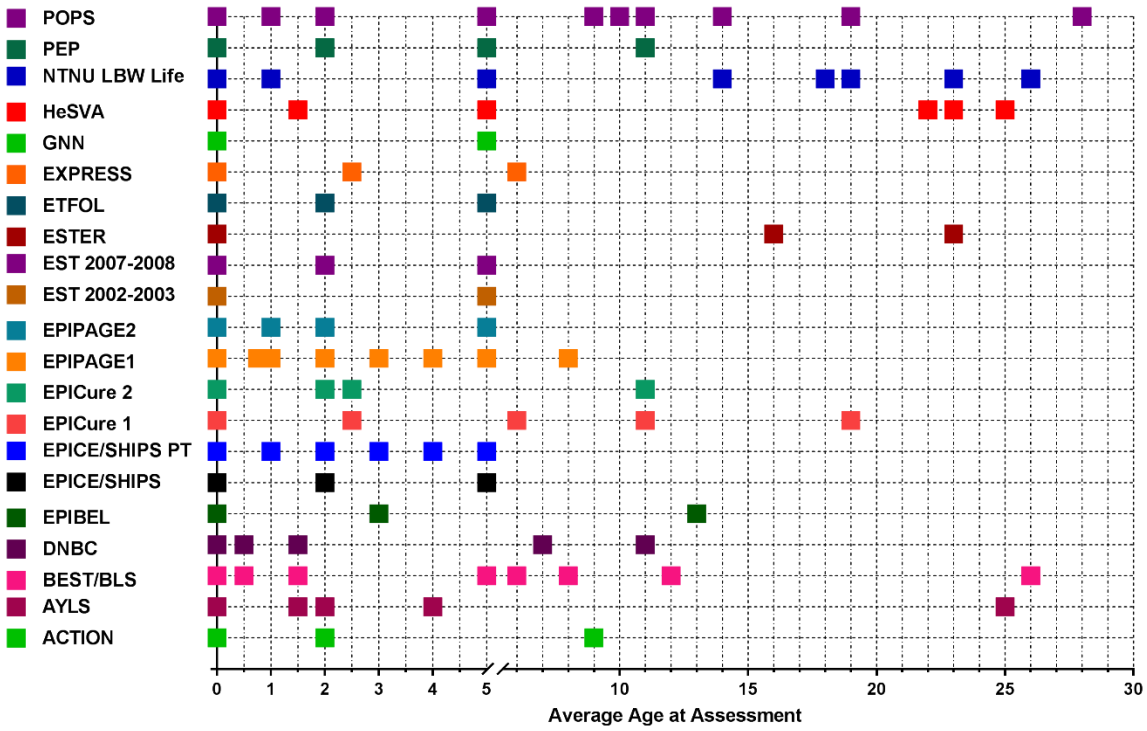
2.4 Age at data collection

The participating cohorts have all completed at least one follow up data collection event, with the largest number of follow up data collections being 11 waves in the POPS cohort. The average age of participants at each data collection is presented in Figure 4 Average age at assessment of the cohorts).

There is a clustering of data collection events at 2 years of age, with 11 cohorts carrying out follow up at this age. This increases to 17 cohorts if the age window is expanded to 1.5-2.5 years of age. Another cluster of data collection events occurs around 5 years of age, with 13 RECAP Preterm cohorts carrying out a data collection at 5-5.5 years of age. Beyond this age, clusters are smaller with 5 cohorts followed up at age 11, and a broader cluster of 5 cohorts followed up at approximately 23-26 years of age.

Figure 4 Average age at assessment of the cohorts

*The average age at assessment for each data collection to the nearest 0.25/1 year. This data is also presented in tabular form in Table 3 RECAP Preterm Cohort Inclusion and Exclusion Criteria****Error! Reference source not found.****.*


POPS
PEP
NTNU LBW Life
HeSVA
GNN
EXPRESS
ETFOL
ESTER
EST 2007-2008
EST 2002-2003
EPIPAGE2
EPIPAGE1
EPICure 2
EPICure 1
EPICE/SHIPS PT
EPICE/SHIPS
EPIBEL
DNBC
BEST/BLS
AYLS
ACTION
0
1
2
3
4
5
10
15
20
25
30
Average Age at Assessment

3 COHORT DESCRIPTIONS

3.1 ACTION - Accesso alle Cure e Terapie Intensive Ostetrico Neonatali (Access to Obstetrical and Neonatal Intensive Care)

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	07/2003	06/2005			2493		
2 Year Follow Up	09/2005	10/2007	1466	1406	1196	446	Full cohort assessed
8-11 Year Follow Up	11/2012	12/2014	1096	1095	804	n/a	Full cohort Assessed

Perinatal Assessment

Perinatal assessment included collection of data on maternal obstetric history and prenatal care, pregnancy complications, delivery room care, pregnancy outcomes, infant condition and characteristics at birth, neonatal morbidity, medical treatment during the stay in the NICU, conditions at 36 weeks postmenstrual age and at discharge from the NICU, hospital admissions and transfers, infant survival, and maternal sociodemographic factors.

2 Year Follow Up

At 2 years of age, participants attended a hospital examination to assess general health. This included assessment of health conditions, medication usage at time of follow up, vaccination history, surgical history and hospital admissions since discharge from neonatal unit, and respiratory infections since discharge. Participants also underwent screening for neurosensory impairments including psychomotor functioning, presence of CP, visual and hearing function and use of aids.

Parents of the participant completed a postal questionnaire consisting of the Parent Report of Children's Abilities Revised (PARCA-R) and the Bates Infant Characteristics Questionnaire (ICQ) to assess the development and temperament of the child.

A structured telephone interview with the parents of the participant was carried out to collect information on parental education and profession, maternal physical and mental health, difficulties related to the birth of the preterm child, information about family life, child health, sleep, feeding, and stressful life events since the birth of the child (such as death or disease of loved ones, divorce, job loss, economical and legal problems). The General Health Questionnaire 12 item version (GHQ-12) was used to measure current maternal mental health at the time of interview.

Four participating hospitals also used the BSID-II as a routine screening tool. This data was also used in the validation process for the Italian translation of the PARCA-R.

3.2 AYLS - Arvo Ylppö Longitudinal Study

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1985	1986			1535	658	Cohort followed up those admitted to NICU within first 10 days. Full cohort consisted of 2193 infants. Among hospitalized infants – preterm births n=463 and n=1070 term births. Among controls – n=17 preterm births and n=641 term births.
5 Month Follow Up	1986	1986			1379	622	Full Cohort assessed. Among hospitalized infants n=390 preterm born and n=989 term born infants. Among control infants – n=16 preterm born and n=606 term born infants.
20 Month Follow Up	1987	1987			1345	640	Full Cohort assessed. Among hospitalized infants – n=379 preterm born and n=966 term born infants. Among controls n=17 preterm born and n=623 term born infants.
56 Month Follow Up	1991	1991			1451	654	Full Cohort assessed. Number of participants who have any information via clinical study, hospital registers or from phone calls to parents. Among hospitalized infants n=414 preterm and n=1037 term born infants. Among controls n=17 preterm born and n=637 term born infants.
24-26 Year Follow Up	2009	2012			754	382	Full Cohort assessed. Among hospitalized infants n=211 preterm born and n=543 term born participants. Among controls n=10 preterm born and n=372 term born participants.

Perinatal Assessment

Perinatal data were collected on gestational age, maternal smoking during pregnancy, pregnancy complications, delivery and birth, infant sex, length, weight, head circumference, parental socioeconomic status, infant nutrition/breastfeeding, neonatal morbidity, respiratory support, hospital admissions and discharge from the NICU.

5 Month Follow Up

At 5 months of age, participants underwent a neurological and clinical assessment, measurement of length, weight, head circumference, and administration of the Griffiths Scale of Babies Abilities.

Parents of the participants completed the Parent-Infant Relationship Index (PIRI), Family Adversity Index (FAI) and Psychosocial Stress Index (PSI) questionnaires. The parents were also interviewed about the feeding history and sleep problems of the participant.

20 Month Follow Up

At 20 months of age, participants underwent a clinical and neurological examination to assess length, weight, head circumference, cerebral palsy, visual and hearing impairment. The Griffiths scale of Babies Abilities was administered to assess cognitive ability. Parents of the participants also completed the Family Adversity Index (FAI) and Psychosocial Stress Index (PSI) questionnaires, and were interviewed about the participants' sleep and sleep problems.

56 Month Follow Up

At 56 months, a clinical and neurological examination was carried out to assess height, weight, head circumference, neurological measurements, cerebral palsy, and visual and hearing impairment. Cognitive Assessments performed included the Columbia Mental Maturity Scale (CMMS), Beery Developmental Test of Visual-Motor Integration - Revised (Beery VMI), the Finnish translation of the Aktiver Wortschatztest (AWST) to assess verbal competence, and the Logopädisher Sprachverständnis Test (LSVTA) to assess language comprehension.

Parents of the participants also completed the Family Adversity Index (FAI) and Psychosocial Stress Index (PSI) questionnaires and were interviewed about the participants' sleep problems. The assessor also provided ratings of parent behavior, parent-child interactions and child behavior based on observation of the dyad.

24-26 Year Follow Up

At 25 years of age, a full clinical assessment was performed to assess weight, height, waist circumference, waist anteroposterior diameter, blood pressure, 24 hour ambulatory blood pressure, body composition, and spirometry. Sleep time, sleep quality and daytime physical activity were measured by actigraphy (Actigraph®), cardiorespiratory fitness was measured using Åstrand Ryhming step test, and muscular fitness was measured using hand grip strength and UKK institute modified push up test. Skin prick allergy testing was performed. Participants also completed a Food frequency questionnaire. Fasting serum and plasma samples were taken for analysis of fasting glucose and fasting insulin levels, triglycerides, total cholesterol, LDL-cholesterol, HDL cholesterol, inflammatory markers and cytokines, DNA. Second urine volume was also obtained at clinical examination.

The participants completed questionnaires about employment, education, living arrangements, parental socioeconomic status, social relationships, exercise and recreational activities, puberty, reproductive history, details of children, health, dental health, bone health and fractures, allergies, visits to medical professionals, family medical history, height, weight, parental height and weight, weight control, eating disorders including completion of the Eating Disorder Inventory (EDI- 2), alcohol consumption, smoking and drug usage, and religion.

Additionally, the participants completed a psychological assessment consisting of the Munich-composite International Diagnostic Interview (M-CIDI), Parental Bonding Instrument (PBI), Traumatic Experiences Checklist (TEC), Screen for Posttraumatic Stress Symptoms (SPTSS), Toronto Alexithymia Scale (TAS-20), Cook-Medley Hostility Scale, Social Support Questionnaire (SSQR), Sexual Orientation

Questionnaire, Beck Depression Inventory (BDI), Basic Nordic Sleep Questionnaire (BNSQ), Adult ADHD Rating Scale (ASRS v1.1), Beck Anxiety Inventory (BAI), Behavior Rating Inventory of Executive Function (BRIEF), Life Orientation Test- Revised (LOT-R), State-Trait Anger Expression Inventory-2 (STAXI-2), State-Trait Anxiety Inventory (STAI), Schizotypal Personality Questionnaire- Brief (SPQ-B), Autism-Spectrum Quotient (AQ), NEO Personality Inventory (NEO-PI) and a questionnaire on stressful life events during the last 12 months.

3.3 BLS/BEST – Bayerische Entwicklungsstudie/ Bavarian Longitudinal Study

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1985	1986			682		7505 infants recruited including 682 VPT/VLBW
5 Month Follow Up			508	508	458	839	Numbers shown are for a VPT/VLBW subset of the whole cohort
20 Month Follow Up			504	504	418	798	Numbers shown are for a VPT/VLBW subset of whole cohort
56 Month Follow Up		1990	504	504	384	757	Numbers shown are for a VPT/VLBW subset of whole cohort
6 year 3 month Follow Up	1991		496	453	378	344	Reduced sample size and index group changed to VPT/VLBW. Control group size was reduced to match the VP/VLBW group
8 year 5 month Follow Up		1993	496	453	396	336	VP/VLBW group and control group
12-13 year Follow Up	1998	1999	494	451	339	294	VP/VLBW group and control group
26 Year Follow Up	2010	2014	411	411	260	229	VP/VLBW group and control group

Perinatal Assessment

Perinatal data were collected from medical records and clinical assessments on gestational age, maternal smoking during pregnancy, pregnancy complications, delivery and birth, infant sex, length, weight, head circumference, parental socioeconomic status, infant nutrition/breastfeeding, neonatal morbidity, respiratory support, hospital admissions and discharge from the NICU. Additionally, the parents of the infant completed the Family Adversity Index (FAI), Psychosocial Stress Index (PSI) and the Parent-Infant Relationship Index (PIRI) during an interview.

5 Month Follow Up

At 5 months of age, the participant underwent a neurological and clinical assessment, measurement of length, weight, head circumference, and administration of the Griffiths scale of Babies Abilities.

During an interview, parents of the participant completed the Parent-Infant Relationship Index (PIRI), Family Adversity Index (FAI), Psychosocial Stress Index (PSI) and answered questions about the feeding history and sleep problems of the participant.

20 Month Follow Up

At 20 months of age, participants underwent a clinical and neurological examination to assess length, weight, head circumference, cerebral palsy, and visual and hearing impairment. The Griffiths scale of Babies Abilities was administered to assess cognitive ability. Parents of the participants were interviewed about the participants' sleep and sleep problems and completed the Family Adversity Index (FAI) and Psychosocial Stress Index (PSI).

56 Month Follow Up

At 56 months, participant height, weight and head circumference were measured along with neurological and clinical examination to assess cerebral palsy, and visual and hearing impairment.

Cognitive assessments included the Columbia Mental Maturity Scale (CMMS) to assess general reasoning ability, Beery Developmental Test of Visual-Motor Integration - Revised (Beery VMI) to assess visual-motor integration, the Aktiver Wortschatztest to assess verbal competence, and the Logopädisher Sprachverständnis Test (LSVTA) to assess language comprehension.

During an interview, parents of the participants completed the Family Adversity Index (FAI) and Psychosocial Stress Index (PSI) and answered questions about the participants' sleep problems. The assessor also provided ratings of parent behavior, parent-child interactions and child behavior, based on observation of the dyad.

6.3 Year Follow Up

At 6 years of age, the participants underwent a clinical neurological assessment, including Test of Motor Impairment (TOMI), Beery VMI, clinical evaluation of cerebral palsy, visual and hearing impairment, height, weight, head circumference, waist and hip circumference.

The parents of the participant were interviewed about cognitively stimulating parenting, socioeconomic status (SES), and living conditions. A semi structured family and friendship interview was used to assess the participant's friendships, and the Manheimer Parent Interview to obtain DSM diagnoses and information about bullying. ADHD diagnoses were made according to the Mannheim Parent Interview. Parents also completed the Child Behavior Checklist (CBCL), and Emotionality Activity and Sociability (EAS) Temperament Survey questionnaires.

Child behavior was evaluated by a psychologist during a cognitive assessment using the Tester's Rating of Child Behavior (TCRB), and a consensus model of attention evaluated by entire research team (TEAM rating of child behavior). Mother-child interactions were also rated by a psychologist using a standardised coding system, the Assessment of Mother-Child-Interaction with the Etch-a-Sketch (AMCIES). The Kaufman Assessment Battery for Children (KABC) was used to assess cognitive performance, and academic attainment was assessed using school reports along with parent interviews.

Language development was measured using four subtests from the Heidelberger Sprachentwicklungstest (HSET) plural-singular rules (PS), correction of semantically inconsistent sentences (KS), sentence production (SB) and understanding grammatical structures (VS). Rhyming and sound-to-word matching tasks were performed to assess pre-reading skills, and quality of speech and grammatical correctness were evaluated by the research team at the end of the assessment.

8.5 Year Follow Up

At 8 years of age, participants underwent a clinical assessment to assess cerebral palsy, visual and hearing impairment.

Parents of the participant were interviewed about socioeconomic status (SES), living conditions, and cognitively stimulating parenting. A semi-structured friendship and family interview was used to

assess the participant's friendships, and the Mannheim Parent Interview to obtain DSM IV diagnoses and information about bullying. The participant completed the Harter Scales Self-Perception Profile for Children. Kaufman Assessment Battery for Children (KABC) was used to assess cognitive function and the participant also completed language, reading, spelling and maths tests. School success was determined from school reports and parent interview.

Mother-child interactions were also rated by a psychologist using a standardised coding system, the Assessment of Mother-Child-Interaction with the Etch-a-Sketch (AMCIES). Child behavior was evaluated by a psychologist during a cognitive assessment using the Tester's Rating of Child Behavior (TCRB), and a consensus model of attention evaluated by entire research team (TEAM rating of child behavior). Parents also completed the Child Behavior Checklist (CBCL) and Emotionality Activity and Sociability (EAS) Temperament Survey questionnaires.

12-13 Year Follow Up

At 12/13 years of age, parents of the participants completed a number of postal questionnaires to collect information on socioeconomic status, living conditions, school reports, bullying, emotional problems (Strengths and Difficulties Questionnaire; SDQ), self-esteem, health related quality of life (Health Utilities Index; HUI), school success, and anthropometric measurements (height, weight, and head, waist and hip circumference) of the participant.

26 Year Follow Up

At 26 years of age, participants were interviewed about socioeconomic status, living conditions, life course and bullying. The Munich Composite International Diagnostic Interview (M-CIDI) and Psychosis like Symptoms Interview (Pliksi) structured interviews were used to assess mental health. Participants also completed the Broad Autism Phenotype Questionnaire (BAPQ) and Warwick Edinburgh Mental Wellbeing Scale (WEMWEBS) to evaluate mental health and the Rosenberg Self-Esteem Scale to assess self-esteem. Behavior was assessed using the Young Adult Self Report (YASR). Personality was assessed using the Big Five Inventory 10 item version (BFI-10) amd Arnett Inventory of Sensation Seeking (AISS). To assess quality of life and functional status the participants completed the Health Utilities Index (HUI), World Health Organisation Quality of Life Instrument Short Version (WHOQoL-BREF), Satisfaction with Life Scale (SLS), 12-Item Short Form Survey (SF-12), and London Handicap Scale (LHS). Parents of the participant completed the Impact on Family Questionnaire, Young Adult Behavior Checklist (YACBL), Adult ADHD rating scale (Kooij J.J.S. et al, 2005), and the German version of the Social Communication Questionnaire (FSK). Wealth, financial and educational functioning were identified from questions at interview and questionnaire.

Participant behavior was assessed via observation during a cognitive task (Tester's Rating of Adult Behavior (TRAB)), and throughout the assessment day by the entire assessment team via a consensus model (TEAM Rating of Adult Behavior). Cognitive ability was measured using the Weschler Adult Intelligence Scales (WAIS). Executive Function was investigated using Visual Search and Attention Test (VSAT), Colour-Word Interference Test (Stroop), Alerting and Orienting Attentional Network Task (ANT I), Prospective Memory, Rapid Automatized naming (RAN RAS), Regensburg Word Fluency Test. Non-verbal communication skills were assessed using the Diagnostic Analysis of Non-Verbal Accuracy (DANVA). Anthropometric measures (body height, weight, head circumference, waist- and hip circumference) were taken during the assessment.

A subcohort of the main BLS cohort also underwent neuroimaging including structural MRI (Diffusion Tensor Imaging, T1 and T2 weighted, FLAIR) and fMRI during completion of executive function tasks (Attentional Network Task and N-Back task). In addition, participants completed the State-Trait Anxiety Inventory (STAI), Beck Depression Inventory (BDI) and Edinburgh Handedness Inventory (EHI) questionnaires. The Hariri face matching task and Bullying tasks were performed and the Cyberball program was used to examine ostracism and social exclusion.

Parental Mental Health was assessed using the SF-12.

3.4 DNBC – Danish National Birth Cohort

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1996	2002	951	951	951	95876	full cohort assessed
6 Month Follow Up			774	774	304	69972	full cohort assessed
18 Month Follow Up			773	773	283	65446	full cohort assessed
7 Year Follow Up	2005	2010	764	764	363	56912	full cohort assessed
11 Year Follow Up	2010	2014	762	762	281	49677	full cohort assessed Number assessed - Adult questionnaire <28wks - 52, 28-31 wks - 233, controls (>31wks) – 49677 Child questionnaire <28 wks - 52, 28-31wks - 229, controls (>31 wks) - 47465

Perinatal Assessment

During gestational weeks 12 and 30, the mothers were interviewed by telephone about their obstetric history and fertility treatment, general health, health during pregnancy, antenatal examinations, drug use, alcohol and tobacco use, work and home environment, diet, vitamins and dietary supplements, sleep, exercise, oestrogen, psychosocial stress, socioeconomic status. Data were linked to national register data to provide additional socioeconomic, exposure and medical data.

Mothers also received a Food Frequency questionnaire at 25-26 weeks of gestation to collect data on their dietary habits during the previous 4 weeks and any changes to their dietary habits during pregnancy.

6 Month Follow Up

At 6 months, the mothers completed a telephone interview about the final part of pregnancy (after 30 weeks) and the first 6 months of the infant's life. Data were linked to the National Birth Register. For extremely preterm births, mothers answered questions about symptoms experienced during pregnancy or resulting from child birth. Women who gave birth after 30 weeks were asked about bladder and kidney problems, other infections and inflammation, medication, vaccinations, pregnancy complications, seizures, fetal growth, employment during final part of pregnancy, vitamins and supplements, diet, smoking, caffeine, alcohol, physical exercise, and symptoms experienced during pregnancy or resulting from childbirth.

The mother answered questions about the first 6 months since the birth of the infant including diet and breastfeeding, maternal medication during breastfeeding, maternal employment, time spent with infant, childcare arrangements, exposures (tobacco, alcohol and drug usage), health problems, congenital anomalies, asthma and allergies, medications, crying, mother-infant relationship, relationship with partner, living arrangements, infant development, maternal stress and mental health, and details of both parent's childhood.

18 Month Follow Up

When the child was 18 months old, a phone interview with the mother was conducted to collect data about the period from 6 to 18 months of age including details of pregnancies and births since the birth of the participating child, breastfeeding, parental smoking and alcohol use, diet, vitamins and supplements, exposure to pets or animals, health problems, medication, vaccinations, allergies, asthma, eczema, hearing and vision problems, congenital anomalies, anthropometric measurements (height, weight, head circumference from records of 5 and 12 month examinations), dental information, and infant development.

The mother was also asked about childcare arrangements, parent-child relationships, maternal stress, living arrangements, maternal and paternal education level, income, parental anthropometric measurements (height, weight, waist circumference), and social support network.

7 Year Follow Up

At 7 years of age, mothers completed a paper or online questionnaire about the child including details of motor skills, handedness, development, language development, diet, vitamins and supplements, physical activity, health problems, vaccinations, medications, allergy and asthma, anthropometric measurements (height, weight, waist circumference) and completed the Strengths and Difficulties Questionnaire (SDQ) to provide information on the behavior of the child. Parents also answered questions about living arrangements, parent's own behavior during childhood, parental smoking, parental alcohol consumption, parental anthropometric measurements (height, weight, waist measurement), parental birth weight, parental employment, parental social network, parental mental health, parental history of high blood pressure, high cholesterol, type 2 diabetes and maternal mobile phone usage.

11 Year Follow Up

At 11 years of age, parents and participants completed online questionnaires. The parental questionnaire included questions on the child's diet, vitamins and supplements, sun exposure and use of sunscreen, vaccinations, phone and wireless network use, swimming, details of the residence, and indoor environmental exposures. Additionally, information was collected about the child's health and physical characteristics including health problems, illness, disability, asthma, allergy, eczema, coeliac disease, diabetes, medication, vision problems, hearing problems, speech problems, tooth brushing, enuresis, tics, anthropometric measurements (height, weight, waist circumference), physical characteristics, and gender identity. Parents also answered a number of questions about family medical history, parental anthropometric measurements (height, weight, waist circumference), maternal physical characteristics and maternal smoking.

The child completed a questionnaire to collect data on age, living arrangements, siblings, social relationships, bullying, emotional wellbeing, stressful life events, gender identity, school and academic achievement, sleep, dietary habits, eating disorders, physical activity and sedentarity, sport, travel to school, smoking, drug and alcohol use, and mobile phone usage. Health data was also collected including general health, dental health, mental health, medication, physical characteristics and pubertal staging. The parent and child also completed the appropriate Strengths and Difficulties Questionnaire (SDQ) forms to assess behavioral problems.

3.5 EPIBEL – Extremely Preterm Infants in BELgium

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1999	2000	322		322		525 recruited, 322 liveborn infants
3 year Follow Up	2002	2004	175	95	91	n/a	Subset of cohort from Flanders region. A smaller subset from Flanders also took part in an addtional subcohort study (15 index, 19 control participants assessed)
11-15 Year Follow Up			175	79	53	n/a	Subset of cohort from Flanders region (Dutch Speaking)

Perinatal Assessment

Data were collected from hospital records using a standardised form. Data were collected on maternal sociodemographic information, maternal medical and obstetric history, pregnancy course, maternal transfers, pregnancy complications, treatment to maintain pregnancy, delivery, infant characteristics at birth, delivery room care, congenital anomalies, decisions to withhold or withdraw treatment, neonatal transfers, neonatal morbidity and medical treatment, nutrition, respiratory support, mortality and discharge information.

3 Year Follow Up

At 3 years of age, a subset of participants from the Flanders region (Dutch-speaking) underwent a clinical examination and developmental assessment by a team consisting of a pediatrician or pediatric neurologist, a physiotherapist and a psychologist. Participants underwent a clinical examination including recent medical history, seizures, anthropometric assessment (height, weight, head circumference), medical treatment and hospital admissions, use of medication, aids and special medical support. Additionally, a standardised neurological assessment was performed adapted from Standard recording of central motor deficit (Dev Med Child Neurol, 1989, 31, 117-129), and intellectual impairment, vision problems, hearing problems, communication difficulties were also assessed.

For children up to 30 months, a psychologist administered the Dutch version of the Bayley Scales of Infant Development First Edition (BSID) to assess psychomotor and mental development, or for those children who were not tested before 30 months the Second edition (BSID-II-NI) was used. Behavior and emotional development during the last 12 months were assessed. Data on parental education level and stressful life events were also collected.

11-15 Year Follow Up

At 11-15 years of age, participants from the Flemish (Dutch-speaking) Flanders region were assessed. Neurosensory impairment was assessed (motor impairment, cerebral palsy, visual impairment and auditory impairment).

Autism symptoms were evaluated using the Social Communication Questionnaire (SCQ) and Social Responsiveness Scale (SRS). Autism diagnoses were obtained using Autism Diagnostic Observation

Schedule (ADOS) and the Autism Diagnostic Interview-Revised (ADI-R), along with questions about pre-existing clinical autism diagnoses.

The Weschler Intelligence Scale for Children Third Edition (WISC-III) was used to assess cognitive function (the Similarities, Picture Concepts, Block Design, and Vocabulary subscales were used to calculate an IQ score). Language development was assessed using the Dutch version of the Clinical Evaluation of Language Fundamentals (CELF-IV-NL).

Behavior was assessed using the ASEBA parent, teacher and self-report forms: Child Behavior Checklist (CBCL), Teacher Report Form (TRF), and Youth Self Report form (YSR). The Disruptive Behavior Disorders Rating Scales (DBDRS), and Vragenlijst voor gedragsproblemen bij kinderen 6-16 jaar (VvGK) were also completed. A questionnaire was also completed on medical and psychological diagnosis and treatment history, and academic achievement.

3.6 EPICE/SHIPS – Effective Perinatal Intensive Care In Europe/ Screening to Improve Health in Very Preterm Infants in Europe

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	2011	2012			10329		
2 Year Follow Up	2013	2014	6761	6761	4424	n/a	full cohort assessed
5 Year Follow Up	2016	2019	Ongoing				full cohort assessed

Perinatal Assessment

Perinatal data were collected from obstetric and neonatal medical records using a pretested standardised questionnaire. Data were collected on maternal and infant health characteristics, maternal sociodemographic characteristics, pregnancy complications, maternal obstetric and medical history, details of pregnancy, interventions during pregnancy, labour and delivery, pregnancy outcomes, neonatal morbidity and medical treatment, congenital anomalies, and nutrition during the neonatal period (e.g. breastfeeding). Maternal and infant hospital admission history, and neonatal outcomes (death or discharge from the neonatal unit) were also recorded.

Additionally, a survey of maternity and delivery units was carried out. Data were collected on the characteristics and practices of the maternity and neonatal units such as policies, protocols, unit activity levels, and decision making processes etc.

2 Year Follow Up

EPICE participants were followed up at 2 years of age via a postal questionnaire completed by parents. Neurodevelopment was assessed using the PARCA-R questionnaire supplemented with additional questions on walking, feeding, sight and hearing. Parents also completed questions on the health of the participant, healthcare resource utilisation, additional help received and follow up care received. Height, weight and head circumference were provided based on the latest measurements recorded by a health professional in the child's health record book. Additionally, details on breastfeeding, living arrangements, family structure, childcare and socioeconomic status and demographic information were collected.

5 Year Follow Up

The full EPICE cohort was assessed as part of the Screening to Improve Health in Very Preterm Infants in Europe (SHIPS) research project, which builds on EPICE and continues the follow up of the children at 5 years. A psychologist assessed the children's development using a number of standardised tests. General cognitive function, processing speed and working memory were assessed using the Weschler Preschool and Primary Scale of Intelligence Third or Fourth Edition (WPPSI-III or WPPSI-IV), motor performance was assessed using the Movement Assessment Battery for Children (Movement ABC-II),, visuospatial processing was assessed using the Arrows and Design Copying subtests of the NEPSY II developmental neuropsychological test.

3.7 EPICE/SHIPS-PT – Effective Perinatal Intensive Care In Europe - Portugal/ Screening to Improve Health in Very Preterm Infants in Europe - Portugal

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	2011	2012	724	724	724		724 livebirths of 974 preterm births. 607 discharged alive 544 consented for follow up.
1 Year Follow up	2012	2013		456	456		Informed consent was provided for 544 of the 607 surviving infants.
2 Year Follow Up	2013	2014		408	408		Full Cohort Assessed
3 Year Follow Up	2014	2015		466	466		Full Cohort Assessed
4 Year Follow Up	2015	2016		445	445		Full Cohort Assessed
5 Year Follow Up	2016	2017		427	427		Full Cohort Assessed

Perinatal Assessment

Perinatal data were collected from obstetric and neonatal medical records using a pretested standardised questionnaire as part of the main EPICE study.

Maternal and infant health characteristics (e.g. maternal complications), maternal and infant socioeconomic status and demographic characteristics, maternal obstetric and medical history (e.g. number of previous births), details of pregnancy and delivery and interventions during pregnancy, labour and postnatal treatment, infant health and medical treatment (general health, BPD, Brain lesions, infections, ROP, NEC, PDA, congenital anomalies, other morbidities; death in utero) and nutrition during the neonatal period (e.g. breastfeeding) were recorded. Data were also collected on hospitalisation history and outcomes at death/discharge. Additionally, data were collected on the characteristics and practices of health care services (e.g. maternity and neonatal units) such as policies, protocols, unit activity levels decision making processes etc.

1 Year Follow up

The 1 year data collection involved a Portuguese sub-cohort of the EPICE population consisting of all infants discharged alive from NICU whose parents provided informed consent to take part in the follow up study. Data were collected on nutritional supplements, cognitive and motor development, sleep behaviour and parent-rated health status.

2 Year Follow Up

EPICE participants were followed up at 2 years of age via a postal questionnaire completed by parents. This follow up involved all EPICE regions. Data were collected on neurodevelopment including the PARCA-R questionnaire (or Ages and stages Questionnaire 24 month version (ASQ 24) in France) supplemented with additional questions on walking, feeding, sight and hearing. Parents also completed a questionnaire on the health of the participant, healthcare resource utilisation, additional

help and follow up care received. Height, weight and head circumference were based on the latest measurements recorded by a health professional in the child's health record book. Additionally, details on breastfeeding, living arrangements, family structure, childcare and socioeconomic status and demographic information were collected.

3 Year Follow Up

At 3 years of age, participants from the two Portuguese regions enrolled in the EPICE cohort were followed up. A structured questionnaire was completed by the parents of the participant via telephone interview. Data was collected on socioeconomic status of the father and mother (e.g. education), living arrangements and childcare, health status, healthcare resource utilisation, follow-up care (vaccines, specialists), height and weight, breastfeeding, food and allergies. In addition, the parents completed a food diary detailing everything the child ate or drank for 3 days.

The parents also completed the Preschool Child Behavior Checklist 1 1/2-5 (CBCL 1 1/2-5-LDS) which was used to assess the social, physical and cognitive development of child, as well as language development and the languages spoken by the child.

4 Year Follow Up

At 4 years of age, participants from the two Portuguese regions enrolled in the EPICE cohort were followed up. The parent/guardian of the participant completed a questionnaire via a telephone interview. Data were collected on childcare provision, health, healthcare resource utilisation, follow-up care, medication and supplements, height, weight and child development.

5 Year Follow Up

The full EPICE cohort was assessed as part of the Screening to Improve Health in Very Preterm Infants in Europe (SHIPS) research project, which builds on EPICE and continues the follow up of the children at 5 years. This follow up involved all EPICE regions.

Parents completed a questionnaire on living arrangements, child care provision, education, parental socioeconomic status, health and disability, healthcare resource utilisation and follow up care, health associated expenditure and financial situation. The Ages and Stages Questionnaire 3 (ASQ-3) 60 months questionnaire was used to assess development of communication and problem solving skills, and the Strengths and Difficulties questionnaire was used to assess behavior and emotional symptoms. Health-Related Quality of Life was assessed using the PedsQL instrument (physical, social, emotional and school problems). Parental mental health was assessed using questions taken from the SF-36 questionnaire.

Neurodevelopmental assessments were carried out via a standardised test battery to examine cognitive and motor development.

3.8 EPICure

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1995	1995			309		Index only assessed 4004 births, 309 long term survivors.
2.5 Year Follow Up			309		283		Index only assessed
6 Year Follow Up			309		241	160	Controls were recruited at the 6 year follow-up by identifying classmates of index children in mainstream schools. Controls were born at term (≥37^{+0} weeks of gestation). Controls were invited to participate in the subsequent assessment at 11 years
11 Year Follow Up	2005	2007	307		219	153	Controls were born at term (≥37^{+0} weeks of gestation). 110 controls were recruited at the 6 year follow-up by identifying classmates of index children in mainstream schools. These controls were invited to participate in the subsequent assessment at 11 years. A further 43 new controls were recruited using the same procedure at the 11 year follow up
19 Year Follow Up	2014	2015	306		**129**	65	Controls assessed at 11 years were invited to participate at 19 years of age.

Perinatal Assessment

Data were collected on maternal characteristics, maternal health and obstetric history, pregnancy complications, use of antenatal steroids, labour, delivery, infant characteristics at birth, respiratory support, neonatal morbidity, selected neonatal procedures and medical treatments, neonatal outcomes such as survival, timing of death or discharge from neonatal unit, and follow on care.

2.5 Year Follow Up

At 2.5 years of corrected age, parents of the participant completed a questionnaire on living arrangements, family, socioeconomic status (employment, occupation, education, income), information about the home, childcare arrangements, nursery/playgroup attendance, parental and child handedness, child temperament and behavior, parental health related quality of life, and recent stressful life events

The participant underwent a clinical and neurological examination to assess type and degree of disability (neurological, cerebral palsy, vision, hearing, communication etc). Neurodevelopment was assessed by a trained pediatrician using the Bayley Scales of Infant Development Second Edition (BSID-

II) Mental Development Index (MDI) and Psychomotor Development Index (PDI). During the clinical visit the parents were also interviewed about the participant's medical history.

In cases where the infant was not assessed at 2.5 years, the physician of the participant completed a questionnaire about the health and development of the child, based on assessments carried out at around 30 months of age. Data were collected on hospital admissions, anthropometric measurements, neuromotor development, vision, hearing, respiratory health, feeding and nutrition, overall development. In case of infant death, the lead pediatrician responsible for the infant's care completed a questionnaire about the condition of the infant prior to death, and the circumstances of the infant's death.

6 Year Follow Up

At 6 years of age, participants underwent a clinical examination and neuropsychological assessment. General cognitive ability and academic achievement was assessed using the Kaufman Assessment Battery for Children (KABC). The NEPSY Developmental Neuropsychological test was used to assess sensorimotor function, attention and executive function, and visuospatial processing. Participants also underwent a neurological examination to assess neurological impairment, vision and hearing impairment, communication problems, respiratory problems, other impairments and anthropometric measurements (height, weight, head circumference and mid arm circumference).

Parents of the participant completed a questionnaire about the child to assess child health, respiratory health, long term illness, medications, hearing, vision, speech, hospital admissions, health and social service use, handedness, feeding problems, sleep, childcare and school. Parents also completed a questionnaire about the family including living arrangements, residence, home environment, parental education level, parental employment, work absence due to the participant's health problems, welfare benefits received, additional costs incurred due to the child's health problems, maternal health and health related quality of life, impact of participant's health on other children, and family relationships. To assess child behavior, parents and teachers completed the Strengths and Difficulties Questionnaire (SDQ), and additional items to assess ADHD. The behavior of the participant was evaluated by the assessor at the end of the neurodevelopmental assessment using the Tester Rating of Child Behavior (TRCB). Teachers also provided details of academic achievement.

11 Year Follow Up

At 11 years of age, the participants underwent a clinical examination to assess growth (height, weight, occipito-frontal circumference), lung function (respiratory medical history, clinical examination, spirometry), blood pressure, neurological examination, assessment of disability, and the NEPSY Developmental Neuropsychological test was administered to assess executive function, visuospatial processing and sensorimotor function. Buccal swabs were obtained and Genomic DNA extracted for analysis of genetic polymorphisms.

Cognitive function was measured using the Kaufman Assessment Battery for Children (KABC). The Weschler Individual Academic Achievement Test (WIAT-II) as used to measure academic achievement and teachers completed the Teacher Academic Attainment Scale (TAAS). Child behavior was measured using the Strengths and Difficulties Questionnaire (SDQ). Psychiatric problems were assessed using the Development and Well Being Assessment (DAWBA), Social Communication Questionnaire (SCQ) and Du Paul ADHD Rating Scale-IV.

Functional health status was assessed using the Health Utilities Index (HUI-3). Questionnaires also provided information on the child's health and abilities, impact of disability, and health and educational resources utilised by the participant. Socioeconomic status and family structure were assessed for new control children and those whose circumstances have changed since assessment at 6 years.

In cases where the family preferred their child not to undergo the assessment, permission was requested to contact their General Practitioner and school to obtain information to assess the level of any disability.

19 Year Follow Up

At 19 years of age, participants underwent a clinical examination including anthropometric measurements (height, weight, seated height, head waist and hip circumference), hand grip strength, Modified Incremental Shuttle Walk Test and details of medication. Cardiovascular function was assessed using blood pressure measurements, radial artery waveform analysis and pulse wave velocity, stroke volume and cardiac output measured by NICOM, and ambulatory blood pressure. Respiratory function was assessed using Forced Expiratory NO Analysis and spirometry (pre- and post-bronchodilator). Participants also took part in an overnight sleep study including measurement of respiration during sleep. A neurological examination was performed including classification of cerebral palsy using the Gross Motor Function Classification System (GMFCS) and Manual Ability Classification System (MACS). MRI (3D T1-weighted MPRAGE) was performed to examine white matter, amygdala and thalamic volumes. Ophthalmological assessments were carried out including Best Corrected Visual Acuity (BCVA), anterior segment examinations, dilated posterior segment examinations, assessment of their refractive status, ocular motility and SD OCT imaging. Biosamples were collected for analysis (fasting blood, saliva, urine and sputum collection).

Parents of the participant completed a questionnaire on socioeconomic status (parental employment, education, marital status), the participant's health, effects of participant's health on the family's ability to work, welfare benefits received, parental health and mental health. Parents also completed the Strengths and Difficulties Questionnaire (SDQ) and an adaption of the Behavior Rating Inventory of Executive Function - Adult Version (BRIEF-A) to assess participant behavior, and the Health Utilities Index (HUI) to assess health status.

Participants completed a health questionnaire including health and disability, use of alcohol, tobacco and drugs, the HUI to assess health status, and Edinburgh Handedness Inventory (EHI). Additional questions were asked on eating, education and training, employment, marital status, relationships with partner, family and friends. Participants also completed the Quality of Life Scale (QOLS, Burckhardt & Anderson, 2003), satisfaction with Life Scale (SWLS), Rosenberg Self-Esteem Scale, ASEBA Adult Self-Report (ASR), BRIEF-A, empathy quotient (EQ), Broad Autism Phenotype Questionnaire (BAPQ), Pain Catastrophising Scale (PCS), 11-item Big Five Inventory (BFI-11),Warwick-Edinburgh Mental Well-Being Scale (WEMWBS). ADHD was assessed using a translation of the Bavarian Longitudinal Study (BLS) ADHD questionnaire that was adapted from Kooij et al, 2003 and DuPaul ADHD Rating Scale-IV, 1998.

Full scale IQ was measured using Weschler Abbreviated Scale of Intelligence Second Edition (WASI-II), and participants also completed the Beery-Buktenica Test of Visual Motor Integration, Verbal Fluency Task, Attentional Network Test, Automated Working Memory assessment (AWMA), Digit Span, Test

of Word Reading Efficiency (TOWRE), Numerical Representation, Woodcock-Johnson III Test of Achievement (WJIII) Math skills - Math Fluency and Calculation (Mathematics) subtests, Frankfurt Test and Training of Facial Affect Recognition (FEFA-2), and Prospective Memory Test.

Participants underwent a Life course interview, Clinical interview Schedule-Revised (CIS-R) semi-structured interview to assess psychiatric symptoms, and Psychosis-Like Symptoms interview (PLIKS). The assessment team rated the participant's behavior according to the Tester's Rating of Adult Behavior (TRAB), and the participant's communication and language skills using the Experimenter Rating of Speech and Language.

3.9 Epicure 2

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	2006	2006			3133		
2.5 Year Follow Up	2008	2009	1031	1031	584		Full cohort assessed
11 Year Follow Up	2017	2018	1031		200	150	Subset of cohort assessed. Controls were recruited at the 11 year follow-up by identifying classmates of index children in mainstream school who were born at term (≥37^{+0} weeks of gestation).

Perinatal Assessment

Data were collected on maternal socioeconomic and demographic characteristics, maternal health and obstetric history, pregnancy course, pregnancy complications, use of antenatal steroids, tocolysis, labour, delivery, infant condition at birth, respiratory support, neonatal morbidity, congenital anomalies, selected neonatal procedures and medical treatments, neonatal nutrition, decisions to withdraw or withhold treatment, neonatal outcomes such as survival, timing of death or discharge from neonatal unit.

In addition a Unit profile study was undertaken to collect data about unit activity, staffing and policies within neonatal units in 2005. Data on policies in associated maternity units was also collected.

2.5 Year Follow Up

At 2 years of age (24 months), a postal questionnaire was sent to parents of the participants to collect data on the participant's health, feeding, development, contacts with the health service and other developmental or educational professionals. The M-CHAT was also used to screen for autism and the PARCA-R questionnaire to assess cognitive and language development.

At 2.5 years of age (30 months), participants underwent a clinical assessment to measure height, weight, head circumference, upper arm circumference, and blood pressure. Neurological and respiratory examinations (as in EPICure1 at 2.5 years) were also performed. Gross Motor Function Classification System (GMFCS) was used to assess motor functional impairment. The Bayley-III Cognitive and Language Scales, and BSID-II Mental Development Index were also administered by the assessor.

The parents were sent a questionnaire to collect health service utilisation, sociodemographic and socio-emotional data. In addition, the parents completed the Brief Infant Toddler Social Emotional Assessment (BITSEA).

11 Year Follow Up

At 11 years of age, participants were invited to take part in a school-based assessment by a clinician and psychologist. Participants underwent a clinical examination including growth measures (height, weight, head circumference), lung function (spirometry), blood pressure and Doppler studies.

Cognitive ability (IQ) was measured using the Kaufman Assessment Battery for Children Second Edition (KABC-II). Neuropsychological skills were assessed using the NEPSY-II Developmental Neuropsychological test, and visuo-spatial working memory was assessed using the Weschler Intelligence Scale for Children (WISC-V) Working Memory Index. Academic attainment was assessed using the Weschler Individual Achievement Test (WIAT-II; Reading and Mathematics scales). Teachers also completed an assessment of the participant's learning attainment and national attainment test results were obtained.

Mental health and behavior were assessed using the Development and Well-Being Assessment (DAWBA), Strengths and Difficulties Questionnaire (SDQ), ADHD Rating Scale-V and Social Communication Questionnaire (SCQ). Health-Related Quality of Life was assessed using the Health Utilities Index (HUI-3).

3.10 EPIPAGE 1 - Étude épidémiologique sur les petits âges gestationnels

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1997	1998			3581		1997: 3334 liveborn infants 2886 discharged alive from the NICU. 1998: 247 liveborn 22-26 weeks GA) 131 discharged alive from the NICU.
2 months after discharge	1997	1998	2780	2780	2070	488	full cohort assessed
9 Month Follow Up	1997	1999	2768	2764	2091	465	full cohort assessed
1 Year Follow up	1998	1999	2768	2753	2276	462	full cohort assessed
2 Year Follow Up	1999	2000	2765	2719	2311/2374	445/415	full cohort assessed
3 Year Follow Up	2000	2001	2761	2706	2283	453	full cohort assessed
4 Year Follow Up	2001	2002	2758	2654	2042	410	full cohort assessed
5 Year Follow Up	2002	2003	2756	2593	2180/2040	396/391	full cohort assessed
8 Year Follow Up	2006	2006	2753	2529	1743	327	full cohort assessed

Perinatal Assessment

Data on pregnancy, delivery and care prior to transfer to the neonatal unit were collected from maternal obstetric records and the obstetric team. This included data on pregnancy, multiples, previous pregnancies, maternal medical history, fertility treatment, assessments and clinical investigations during pregnancy, pregnancy complications, medical treatment during pregnancy, hospital admissions during pregnancy, fetal health, congenital anomalies, pregnancy outcomes, labour and delivery, management of delivery, clinical indicators at birth, management of infant in delivery room, summary of mother's stay in maternity unit, and summary of hospital stay (for control infants not admitted to NICU).

Data on neonatal care were collected from neonatal records and the neonatology team including information on first 12 hours of life, details of all transfers between units, infant condition at admission to neonatal unit (including following subsequent transfer between neonatal units), neonatal morbidity, neonatal infections, screening tests and clinical assessments performed, medical care and treatments received, nutrition, growth, visits of parents to the unit, discharge from hospital, details of infant death, follow up after discharge.

A questionnaire was also completed by the maternity unit where delivery took place including details of staffing, maternity unit environment and on-site facilities, types of transport used for perinatal transport, management of the mother and management of the newborn.

2 months after discharge

Two months after returning home from the hospital, the mother completed a questionnaire about their experiences of returning home. Data were collected on childcare arrangements, age at discharge, experiences of returning home, feeding, health concerns, confidence in caring for the participant, type of unit the participant was admitted to, satisfaction with care received by mother and infant, follow up consultations, therapies and medical treatments received, sleep, feeding and crying problems, visits to health professionals and hospital admissions. Information was also collected about the mother including maternal health, maternal sleeping and eating routine, maternal medication, living arrangements, employment, and support and help in the home received.

9 Month Follow Up

At 9 months of age, questionnaires were sent to the mother and father of the participant to assess the health and development of the infant, history of hospital admissions and contact with medical professionals, experiences of the healthcare received by the infant, sleep, feeding, temperament and behavior, childcare, maternal physical and mental health, parental profession and employment information, reasons for changes in employment, daily life, paternal involvement in daily tasks, problems with older children, and household finances.

1 Year Follow up

At 12 months, a short questionnaire was sent to the parents of participants to investigate the growth, health, medication usage, hospital admissions, sleep, nutrition and neurodevelopment of the infant. Additionally, questions were included about childcare arrangements, and changes in maternal employment and family situation since the previous follow up at 9 months of age.

2 Year Follow Up

At 2 years of age, the mother of the participant completed a questionnaire on childcare and living arrangements, feeding and nutrition, sleep, behavior, history of hospital admissions and visits to health professionals, concerns about the child's health. Additionally details were collected on maternal health, daily life, family and household structure, problems experienced with other children, parental education, profession, employment, time off due to health of child, and maternal social support.

A clinical examination was performed by a physician which included anthropometric measurements (height, weight, head circumference), a vision and hearing assessment, evaluation of neuromotor skills, and details of any other neurological or clinical symptoms. The behavior of the child during the assessment was also assessed by the physician. During the assessment visit, the person accompanying the child was interviewed about the infant's health, neuromotor skills, vision and hearing, medication usage, and specialist follow up care received.

3 Year Follow Up

At 3 years of age, parents of the participant completed a questionnaire about living and childcare arrangements, anthropometric measurements (height, weight, head circumference), health and medical history, vision and hearing problems, hospital admissions, medication and treatments received, visits to a psychologist, psychological and behavioral problems, sleep problems, feeding problems, global development, and parent-child activities. To investigate child behavior, parents also completed the Strengths and Difficulties Questionnaire (SDQ).

4 Year Follow Up

At 4 years of age, the parents of the participant completed a questionnaire on living arrangements, anthropometric measurements (height, weight, head circumference), general health, respiratory health, vision and hearing problems, hospital admissions, dental health, medication and treatments received, visits to psychologists, parent-child activities, adaptation to school, parental employment, and childcare arrangements. To investigate child behavior, parents also completed the Strengths and Difficulties Questionnaire (SDQ).

5 Year Follow Up

At 5 years of age, the parents of the participant completed a questionnaire about school, childcare arrangements, sleep, diet, and parent-child activities performed. Details of health and development, language and speech, allergies and family history of allergies, visits to health professionals, barriers to obtaining treatment, health insurance, and social care provision were also collected. Child behavior was assessed using the Strengths and Difficulties Questionnaire (SDQ). Parents also completed a questions on living arrangements, place of residence, maternal place of birth and citizenship, maternal education level, employment, maternal health, maternal smoking, other children in the household, daily activities, worries, and their feelings about the time following the birth of the participant.

A clinical examination was performed including anthropometric measurements (height, weight, head circumference), neurological examination (simplified version of examination from Touwen, 1979), assessment of cerebral palsy, cardiopulmonary examination, dental examination, skin examination, other problems, and visual acuity. Behavior during examination was also rated by the clinical assessor.

During the assessment visit, the person accompanying the participant was interviewed about living arrangements, respiratory health, skin health, neurological health, contact with health professionals, vision, hearing, hospital admission, other health problems, long term treatments and family medical history.

8 Year Follow Up

At 8 years of age, parents of the participants completed a questionnaire to assess anthropometric measurements (height, weight, head circumference), health, vision, hearing, language and speech development, coordination problems, visits to health professionals, hospital admissions, asthma and respiratory problems, medication, and barriers to accessing health services. Details on schooling, national test results, difficulties at school, special educational needs support, special aids and equipment were collected. Additionally parents completed questions on the child's activities, social relationships and living arrangements, as well as details of other children, financial difficulties, parental employment and income. Parents also completed the Strengths and Difficulties Questionnaire (SDQ) to assess the behavior of the participant.

3.11 EPIPAGE 2 - Étude épidémiologique sur les petits âges gestationnels

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	03/2011	12/2011			5170		5170 liveborn infants 4467 discharged alive from the NICU
1 Year Follow up	04/2012	03/2013	4445	4290	3841	n/a	full cohort assessed
2 Year Follow Up	04/2013	03/2014	4443	4199	3689	n/a	full cohort assessed
5.5 Year Follow Up	09/2016	12/2017	ongoing				

Perinatal Assessment

Data about pregnancy and birth were extracted from medical records or obtained by questionnaires sent to the maternity unit including maternal SES and demographic characteristics, maternal and paternal medical history, maternal and paternal height and weight, obstetric history, details of current pregnancy, infertility treatment, prenatal screening tests, decisions to withhold or withdraw treatment during pregnancy or in delivery room, hospitalisations during pregnancy, pregnancy complications, drug treatments during pregnancy, maternal transfers, prenatal growth estimates, delivery, treatments during labour, summary of mother's stay in maternity unit, infant's condition during stay in maternity unit, delivery room management, and mortality. Data on the neonatal period were collected from neonatal records or the neonatology team including neonatal complications and morbidity, neurological evaluation, care and treatment, developmental care, nutrition, congenital anomalies, infant condition at discharge, and decisions to withhold or withdraw treatment.

Mothers whose infant was discharged alive from the first neonatal unit or who were discharged from the maternity unit and not transferred, were interviewed about maternal SES and demographic characteristics, health insurance, parental height and weight, smoking before/during pregnancy, fertility treatment, previous pregnancies, antenatal consultations and care, birth plan and reasons for any changes, hospitalisations during pregnancy, maternal transfers for delivery, length of hospital stay before birth, neonatal breastfeeding and nutrition, infant transfers.

Additionally, questionnaires were sent to the maternity and neonatal units to evaluate the type of unit, policies and practices, types of care delivered, staffing, unit environment, treatment to maintain pregnancy/improve infant viability, policies related to delivery, transfers and transport services, liaison between maternity and neonatal units, decisions to withhold or withdraw care, details of intensive care, type of examinations/screening provided to infants, developmental care and parental involvement, breastfeeding, policies and practices related to discharge and follow up after discharge.

1 Year Follow up

At one year of age, a questionnaire was sent to the parents to investigate the participant's anthropometric measurements (height, weight, head circumference), hospital admissions and contacts with healthcare professionals, respiratory illness, skin problems, hearing, vision problems,

neurological problems, other health problems, immunisations and medication, and parental feelings/worries about the participant's health. Parents also completed questions on the development, sleep, diet and breastfeeding of the infant.
The second part of the questionnaire collected data on childcare arrangements, parental smoking, living arrangements, place of residence, parental nationality and country of birth, languages spoken, level of education, employment, time off or leaving employment due to participant's health problems, income, welfare benefits, and health insurance.

2 Year Follow Up
At 2 years of age the parents of the participant completed a questionnaire on anthropometric measurements (height, weight, head circumference), use of aids and equipment, hospital admissions, visits to health professionals, specialist follow up care received, sleep, feeding and diet. Parents also provided information on place of residence, living arrangements, childcare arrangements, parental health (health related QoL - questions from SF-36), worries about child's health/development, parental employment, and details of parental employment and shift work before/during pregnancy.

Parents completed the Ages and Stages 24 Month Questionnaire to assess global development, the French version of the MacArtur Bates Communicative Development Inventory - Les Inventaires Français du Développement Communicatif (IFDC) to assess language development, and the Modified Checklist for Autism in Toddlers (M-CHAT) to assess autism symptoms.

A questionnaire was sent to the participant's physician (general practitioner, pediatrician etc) to be completed during an examination at 2 years. Details of height, weight, psychomotor development, neurological problems, hearing problems, vision problems, respiratory problems, skin problems, follow up care for patent ductus arteriosus, current medical treatments, medications and immunisations, and follow up by other medical professionals were collected.

5.5 Year Follow Up
At 5 years of age, participants underwent a clinical and psychological examination, and parents completed questionnaires. A clinical assessment was performed by a physician including evaluation of respiratory health, neurological health, skin health, hearing and vision problems, other health problems, medication, anthropometric measurements (height, weight, head, brachial, hip, waist circumference, and thigh diameter), blood pressure measurements, visual acuity, dental examination, and a neuromotor examination including assessment of cerebral palsy and classification of motor function using the Gross motor Function Classification System (GMFCS). The Movement Assessment Battery for Children Second Edition (Movement ABC-2) was also administered to assess motor development. During the examination, the mother was asked about obstetric history since participant's birth, and parental chronic disease.

A neurodevelopmental assessment was performed by a trained neuropsychologist including the Weschler Preschool and Primary Scale of Intelligence Fourth Edition (WPPSI-IV), and NEPSY-II. Child behavior was evaluated during neurodevelopmental assessment.

Parents completed a questionnaire on school, special educational needs support, health and development, sleep, hospital admissions, visits to health professionals, follow up care with specialists, satisfaction with child's healthcare, barriers to accessing healthcare, health related expenses and time off work due to health problems of participant. Parents were also asked about living arrangements,

languages spoken in the home, other children in the home, employment, and level of education. Standardised questionnaires were completed by the parents to assess maternal health (Short Form-36; SF-36), diet (Child Eating Behaviour Questionnaire; CEBQ), behaviour (Strengths and Difficulties Questionnaire; SDQ), autism symptoms (Social Communication Questionnaire; SCQ), and health-related quality of life (Pediatric Quality of Life Inventory; PedsQL). In addition the assessment team completed the Home Observation Measurement of the Environment (HOME) questionnaire through observation of parent-child interactions and the home environment, and interview with parents.

3.12 EST 2002-2003 - Estonia 2002-2003 ELBWI, <29GW at 5y

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	2002	2003			80	n/a	
5 Year Follow Up	2007	2008	34	34	33	n/a	Full Cohort Assessed

Perinatal Assessment

Information was collected retrospectively from hospital records for 68 variables related to pregnancy risk factors, delivery, infant condition at birth, mortality, short-term neonatal morbidity, selected neonatal procedures, and length of hospital stay. The Estonian Medical Birth Register was used to obtain the number of births and the number of VPT stillbirths, and to verify that all live-born VLGA infants were accounted for.

5 Year Follow Up

Children underwent a clinical assessment by a pediatrician, psychologist, speech therapist and physiotherapist at 5 years of age. The pediatrician examined the child, measured the child's weight, height, head and upper right arm circumference, the arterial blood pressure, and interviewed the mother about the disease history of the child by organ. Cognitive, linguistic and motor development were assessed using Kaufman Assessment Battery for Children 2nd Edition (KABC-II), Reynell Developmental Language Scales 3rd Edition (RDLS-III), Movement Assessment Battery for Children (Movement ABC). Questionnaires were sent to parents and teachers to assess child and family coping (COPE-D).

3.13 EST 2007-2008 - Very low gestational age infants born in Estonia in 2007-2008

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	2007	2008			187		Different subsamples used for 2 and 5 year studies. 187 infants <32 weeks (for 2 year study) 56 infants <29 weeks (for 5 year study).
2 Year Follow Up	2009	2010	156	155	155	153	Cohort assessed at 2 years was all live births <32 Weeks GA in 2007. This is different from the cohort assessed at 5 years which included those born at <29 weeks of gestation in 2007-8.
5 Year Follow Up	2012	2014	55	55	53	41	

Perinatal Assessment

All live births at <32 GW in Estonia in 2007-2008 were recorded prospectively in a national neonatal research register. The register included 68 variables that were related to pregnancy risk factors, delivery, infant condition at birth, mortality, short-term neonatal morbidity, selected neonatal procedures, and length of hospital stay.

2 Year Follow Up

Children underwent a clinical assessment by a pediatrician to examine physical, ophthalmological and auditory health. A neurological examination was undertaken by a child neurologist using the Pediatric Stroke Outcome Measure (PSOM). In children with Cerebral Palsy the Gross Motor Function Classification System (GMFCS) was used to quantify motor function. An assessment of development was carried out by a clinical child psychologist using the Bayley Scales of Infant and Toddler Development, Third Edition (Bayley-III).

In addition, structured parental interviews were performed and sociodemographic and environmental exposures (parental age and education, family structure and income, number of siblings in the same household, duration of breastfeeding, infants age at day care attendance) as well as the presence of respiratory infections during the first two years of life were recorded.

5 Year Follow Up

At 5 years of age, a physical clinical assessment was carried out. Developmental and neurological outcomes were assessed using the Reynell Developmental Language Scales Third Edition (RDLS-III), Kaufman Assessment Battery for Children 2nd Edition (KABC) and Movement Assessment Battery for Children (Movement ABC). Parents and teachers also completed Movement ABC questionnaires, and the Edinburgh Depression Questionnaire was completed by the mother of participants. Sociodemographic and environmental exposures were identified using a parental questionnaire. Cardiovascular characteristics and blood biomarkers were also measured in subgroups of the cohort.

3.14 ESTER - Preterm Birth and Early Life Programming of Adult Health and Disease

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1985	1986			397		
16 Year Follow Up	2002	2002		300	135	178	Subset of those born 1985-86
23 Year Follow Up	2009	2012		935	376	344	Full Cohort assessed

Perinatal Assessment

Perinatal data for those participants who were recruited through the Northern Finnish Birth Register 1986, were obtained from the cohort database, these data were originally collected from medical records. Corresponding data were collected for those recruited through the Finnish Medical Birth Register from their medical and maternal welfare clinic records.

Data were collected on maternal medical and obstetric history, conditions during pregnancy, maternal smoking during pregnancy, infant characteristics at birth, neonatal morbidity and medical treatment, respiratory support, Bronchopulmonary Dysplasia, and time to discharge from the NICU.

23 Year Follow Up

At 23 years of age, participants underwent a full clinical and neuropsychological assessment. Prior to the clinic visit, participants completed questionnaires on their medical history, dental health, physical activity, alcohol and tobacco use, sociodemographic information, education, plans for further education and eating disorders (Eating Disorders Inventory-2).

A full clinical assessment was performed to assess weight, height, waist circumference, waist anteroposterior diameter, blood pressure, body composition, and spirometry. Participants underwent skin prick allergy testing. 24 hour ambulatory blood pressure was measured using the Spacelabs 90207, and sleep time, sleep quality and daytime physical activity were measured by actigraphy (Actigraph®). Cardiorespiratory fitness was measured using Åstrand Ryhming step test, and muscular fitness measured using hand grip stregnth and UKK institute modified push up test. Fasting serum and plasma samples were taken for analysis of fasting glucose and fasting insulin levels, triglycerides, total cholesterol, LDL-cholesterol, HDL cholesterol, inflammatory markers and cytokines, DNA. Second urine volume was also obtained at clinical examination.

To assess psychological problems participants completed the Screen for Posttraumatic Stress Symptoms (SPTSS), Trauma Experience Questionnaire (TEC), Cook-Medley Hostility Scale, Schizotypal Personality Questionnaire-Brief (SPQ-B), Toronto Alexithymia Scale, Adult Self Report Scale (ASRS), Beck Depression Inventory (BDI), Beck Anxiety Inventory (BAI), ASEBA Adult Self Report (ASR), Behavior Rating Inventory of Executive Functioning - Adult Version (BRIEF-A), NEO Personality Inventory (NeoPI), and Autism Spectrum Quotient (AQ). Participants also completed the Karasek Job Content Questionnaire, Parental Bonding Instrument (PBI), Klein Sexual Orientation Grid, Life Orientation test, and Social Support Questionnaire. The CogHealth 3.0.5 computerised assessment

was used to assess executive functions, working memory, attention, psychomotor function and learning. Participants also completed a Food frequency questionnaire.

3.15 ETFOL - Treatment of extremely preterm infants: parents attitudes

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1994	1995	407	407	407	n/a	full cohort assessed
2 Year Follow Up	1996	1997	269	269	253	n/a	full cohort assessed
5 Year Follow Up	1999	2000	269	269	252	76	full cohort assessed

Perinatal Assessment

Data were collected prospectively from patient records by the study team using standardised forms and submitted to the project centre at Odense University Hospital. The cohort data was cross-linked with the Danish Medical Birth Register resulting in the identification of a number of additional infants; data were collected retrospectively for these infants. Data were collected on pregnancy course, labour and delivery, whether active care was received, physical characteristics at birth, clinical indicators, respiratory support, neonatal morbidity, developmental care, neuroimaging, brain lesions, discharge, and mortality.

2 Year Follow Up

At 2 years of age, participants underwent a structured clinical examination at outpatient clinics in local pediatric departments. Data were collected about presence of cerebral palsy, epilepsy, visual impairment, hearing impairment, psychomotor impairment. The degree of impairment or handicap was assessed using the Scheffzek scoring system (Scheffzek A, Stahl M, Von Toenges V, 1989).

5 Year Follow Up

At 5 years of age, participants were assessed by a physician and a psychologist. A telephone interview with parents was used to collect details of parental education level. Parents also completed the Parental Sensitivity Assessment Scale (PSAS) questionnaire (Hoff et al, 2004). To assess behavioral and social development parents completed the Conners Abbreviated Symptom Questionnaire for Parents and supplementary questions on social skills, externalising and internalising behavior problems. Data were also collected on hospital admissions, school absence, health, and special educational needs support.

The clinical examination assessed growth, vision problems, hearing problems, and motor problems including cerebral palsy. Motor skills were assessed using the Movement Assessment Battery for Children (Movement ABC). Eight subtests of the Weschler Preschool and Primary Scale of Intelligence Revised Version (WPPSI-R) were administered - Vocabulary, Information, Arithmetic, Similarities, Block Design, Picture Completion, Object Assembly and Animal House. The results were used to calculate full scale IQ scores.

3.16 EXPRESS - Extremely preterm infants in Sweden Study

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	2004	2007			1011		1011 deliveries includes: 238 intrauterine deaths before labor 66 intrapartum deaths 707 liveborn 69 delivery room deaths 638 admitted to NICU (497 survived to 1 year of age.)
2.5 year Follow Up	2006	2010	494		456	701	Full Cohort Assessed
6.5 year Follow Up	2010	2014	486		441	371	202 of control group participated at 2.5 years and 169 newly recriuted).

Perinatal Assessment

Data were collected prospectively by local hospital staff and cross-linked with the National Medical Birth Registry to ensure the accuracy of the information captured. Data on mothers and still births were collected at time of delivery and on liveborns during the first 180 days or until discharge or death. Approximately 220 data items were collected including maternal sociodemographic information, maternal medical and obstetric history, pregnancy course, labour and delivery, infant condition at birth, details on resuscitation, illness severity at admission to neonatal intensive care unit, selected neonatal procedures, and infant outcomes such as survival, neonatal morbidity, time of death, use of hospital resources, and information on neonatal nutrition.

2.5 year Follow Up

Participants were assessed at 30 months by a psychologist and pediatrician or pediatric neurologist. The Bayley Scales of Infant and Toddler Development – Third Edition (Bayley-III) Cognitive, Motor and Language domains were administered by a psychologist. A Neuropediatric assessment and ophthalmologist assessment were also carried out. The parents also answered a health questionnaire by mail or telephone interview.

In the Stockholm region, add on protocols for the Child Behavior Check List (CBCL), Magnetic Resonance Imaging (MRI) of the brain, and measurement of blood pressure and heart rate were also performed.

6.5 year Follow Up

Participants were assessed at 6.5 years of age. Cognitive function was assessed with the Wechsler Intelligence Scale for Children, Fourth Edition (WISC-IV). A neuropediatric assessment was performed (Touwen, 1979). An ophthalmologic assessment (vision, retinal photo and other investigations) was performed by an ophthalmologist. The Movement Assessment Battery for Children - Second Edition (Movement ABC-2) was used to assess motor function, and visuo-motor integration was assessed using the Beery-Buktenica Developmental Test of Visual-Motor Integration - Sixth Edition (Beery VMI).

Parents completed a health questionnaire, the 5-15-R (Nordic questionnaire on children's development and behavior), Strengths and Difficulties Questionnaire (SDQ), and Brown Attention-Deficit Disorder Scales (ADD Brown).

Add-on protocols were performed in some regions. Lung function, physical activity, blood pressure, cardiovascular evaluation (Lund, Stockholm, Umeå), Magnetic Resonance Imaging (MRI) of the brain (Stockholm), Questionnaire for Identifying Children with Chronic Conditions - QUICCC (Göteborg and Umeå), ABAS (Adaptive Behavior Assessment System) (Lund), and regional ophthalmology protocols.

3.17 HeSVA - Helsinki Study of Very Low Birth Weight Adults

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1978	1985			335		
15 Month Follow Up	1979	1979	334	334	334	n/a	Full Cohort assessed
5 Year Follow Up	1983	1990			176	n/a	Subset assessed
18-27 Year Follow Up	03/2004	04/2005	329	255	166	172	Full Cohort assessed. Controls recruited at this follow up.
20-29 Year Follow Up	06/2005	11/2005			52	44	Subset assessed
22-30 Year Follow Up	03/2007	04/2008			113	105	Full Cohort assessed

Perinatal Assessment

Perinatal assessment included collection of data from medical records on maternal medical and obstetric history, conditions during pregnancy, maternal smoking during pregnancy, infant characteristics at birth, neonatal morbidity and medical treatment, respiratory support, Bronchopulmonary Dysplasia, time to discharge from the NICU and sociodemographic information.

18-27 Year Follow Up

At an average age of 22 years (18-27 years), participants underwent a full clinical and neuropsychological assessment.

Prior to the clinic visit, participants completed questionnaires on their medical history, dental health, physical activity, alcohol and tobacco use, sociodemographic information, education, plans for further education and eating disorders (Eating Disorders Inventory-2).

The participants also completed questionnaires during the clinic visit - Basic Nordic Sleep Questionnaire, Behavioral Inhibition System/Behavioral Activation System (BIS/BAS) Scales, Center for Epidemiologic Studies Depression Scale (CES-D), Adult Problem Questionnaire (APQ), Experiences in Close Relationships-Revised (ECR-R), Parental Bonding Instrument (PBI), Spielberger Trait Anger/Anxiety Scale, 15-D health related quality of life scale, and premenstrual symptoms questionnaire (Endicott et al, 1986). The CogHealth 3.0.5 computerised assessment was also used to assess executive functions, working memory, attention, psychomotor function and learning.

A full clinical assessment was performed to assess weight, length, waist circumference, waist anteroposterior diameter, grip strength, jump height, blood pressure, 24 hour ambulatory blood pressure, sleep time and sleep quality measured by actigraphy (Actiwatch®), resting energy expenditure by indirect calorimetry, body composition, 72 hour food diary, skin prick allergy testing, and spirometry. Carotid artery diameter and intima-medial thickness (IMT), flow-mediated dilatation (FMD), brachial blood pressure, left ventricular wall thickness and cardiac function were measured by ultrasonography. Fasting serum and plasma samples were taken for analysis of fasting glucose and

fasting insulin levels, triglycerides, total cholesterol, LDL-cholesterol, HDL cholesterol, inflammatory markers and cytokines, morning cortisol and ACTH, DNA. Second urine volume was also obtained at clinical examination.

After the clinic visit, the participants completed the Satisfaction with Life scale (SWLS), NEO Personality Inventory (NeoPI) and Life Orientation Test-Revised (LOT-R).

20-29 Year Follow Up

At an average age of 23 years (20-29 years), a subset of participants was randomly selected from those who attended the first clinic visit. These participants took part in a stress test including the Trier Social Stress Test (TSST), time course salivary and plasma samples after stress (for measurement of salivary and plasma cortisol levels, plasma ACTH, glucose, insulin and catecholamines), continuous blood pressure and heart rate monitoring during the test, impedance cardiography, ECG, and appraisals of emotional state during test. 48 hour salivary cortisol measurement was also performed with 7 samples per day, including awakening response and administration of dexamethasone on the evening of first day.

22-30 Year Follow Up

At an average age of 25 years (22-30 years), the full cohort was invited for a clinic visit. The participant underwent a clinical examination to assess anthropometric measurements and blood pressure. An intravenous glucose tolerance test was performed. Sleep and physical activity was examined by 7 day physical activity and sleep monitoring (Actiwatch®), completion of a sleep diary, Skogby Sleep Questionnaire, and Morningness-Eveningness Questionnaire (Horne & Ostberg, 1976). Participants also completed the Kuopio Ischaemic Heart Disease Study 12 month and 24 hour physical activity questionnaires.

To assess cognitive function participants completed the Stroop, Verbal Fluency and Rey Complex Figure tests, and 4 subtests of the Weschler Adult intelligence Scale Third Edition (WAIS III; Vocabulary, Digit Span, Similarities, Block Design).

To assess psychological and behavioral problems, the Adult Self Report Scale (ASRS), Beck Depression Inventory 2nd Edition (BDI-II), Beck Anxiety Inventory (BAI), ASEBA Adult Self Report (ASR), Behavior Rating Inventory of Executive Functioning - Adult Version (BRIEF-A), Autism Spectrum Quotient (AQ), Empathy Quotient (EQ) and Conners' Continuous Performance Test 2nd Edition (CPT-II) were also completed by the participant.

The parents of the participants completed postal questionnaires to assess the behavior and mental health of the participant including the parent forms for the Behavior Rating Inventory of Executive Functioning - Adult Version (BRIEF-A), Adult Self-Report Scale (ASRS) and Parent Behavior Inventory.

3.18 NTNU Low Birth Weight in a Lifetime Perspective Study

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1986	1988		121	121	120	Data of VLBW cohort retrieved from hospital records retrospectively, thus included all live-born infants in the cohort. Data of control group prospectively collected in a multicenter study. 88 infants survived to discharge.
1 Year Follow up	04/1987	05/1990	40	39	31	97	Subset Born 1988
5 Year Follow Up	05/1992	12/1994	45	44	29	96	Subset Born 1988 + 5 born 1987
14 Year Follow Up	11/2000	10/2002	88	86	69	87	Full Cohort assessed
18 Year Follow Up	02/2006	02/2006	88	84	46	76	Full Cohort assessed
19 Year Follow Up	08/2006	11/2008	88	84	55	80	Full Cohort assessed
23 Year Follow Up	02/2009	09/2009	88	54	36	37	Subset of Cohort invited
26 Year Follow Up	06/2013	12/2014	88	84	64	90	Full Cohort assessed

Perinatal Assessment

Information on perinatal variables was collected retrospectively from hospital records. Data collected around birth included birth weight, gestational age, head circumference, APGAR scores, days in NICU, days on mechanical ventilator, intraventricular hemorrhage (IVH) and maternal age.

1 Year Follow up

Infants underwent an assessment at 1 year of age to examine anthropometrics, motor and cognitive function and cerebral MRI. A physical assessment was performed including a Neuropediatric examination (based on Touwen, 1979), measurement of height, weight, head circumference, upper arm circumference, subscapular skinfold thickness. Motor and cognitive skills were examined by use of the Bayley Scales of Infant Development (BSID) - Psychomotor Index and Mental Index. Quantitative MRI (2D T1 weighted inversion recovery, T2 weighted spin echo sequences at 1.5 T) was performed to measure volumes for a number of brain structures.

5 Year Follow Up

At 5 years of age, participants underwent an examination to assess physical health, motor function and neurodevelopment, and quantitative cerebral MRI.

Cognitive development was assessed using the Wechsler Preschool and Primary Scale of Intelligence (WPPSI). Yale Children's Inventory (YCI) was used to assess attentional deficits and learning difficulties.

Physical and motor assessments included a neuropediatric examination (based on Touwen, 1979), anthropometric measurements (height, weight, head circumference, upper arm circumference, triceps and subscapular skinfold thickness). Three subscales from Peabody Developmental Motor Scales were also administered (Eye/hand coordination, balance, and locomotor).

Quantitative MRI was performed to measure volumes for a number of brain structures (2D T1 weighted inversion recovery, T2 weighted spin echo sequences at 1.5 T).

14 Year Follow Up

Assessment at 14 years of age included a neuropsychological assessment, questionnaires and diagnostic interviews for psychiatric disorders, assessment of parents' mental health, physical and motor assessment, ophthalmological assessment, quantitative MRI of cerebral white matter, and assessment of (parental) socioeconomic status.

For the psychiatric assessment, the following instruments were used: The diagnostic interview Schedule for Affective disorders and Schizophrenia for School-Age children - Present and Lifetime Version (K-SADS-PL), Children's Global Assessment Scale (CGAS), Achenbach System of Empirically Based Assessment (ASEBA) - Youth Self Report (YSR), ASEBA Child Behavior Checklist (CBCL) and ASEBA Teacher Report Form (TRF), ADHD Rating scale IV, Autism Spectrum Screening Questionnaire (ASSQ), Strengths and Difficulties Questionnaire (SDQ), Child Health Questionnaire (CHQ) - Child Form (CHQ CF87) & Parent Form (CHQ-PF50) and Parental Bonding Instrument (PBI) - self and parent version.

Parents' mental health was assessed using Symptom Checklist-90-R (SCL-90-R).

A neuropsychological assessment was performed including Wechsler Intelligence Scale for Children Third Edition (WISC-III; vocabulary, arithmetic, block design, picture arrangement subscales), Trail Making Test (TMT) - A&B, Stroop, Knox Cube, Visual Motor Integration (VMI-IV), Grooved Pegboard, Wisconsin Card Sorting Test (WCST), and Connors' Continuous Performance Test.

Physical and motor assessments conducted included a neuropediatric examination (based on Touwen, 1979), patient reported medical history, measurement of height, weight, BMI, head circumference, pubertal development (Tanner stage), upper arm circumference, triceps and subscapular skinfold thickness, blood pressure and heart rate, Movement Assessment Battery for Children (Movement ABC), Edinburgh Handedness Inventory, Inter- and intra-sensory modality matching (von Hofsten C, Rösblad B. The integration of sensory information in the development of precise manual pointing. Neuropsychologia 1988;26:805-821).

Visual function was assessed using Snellen letter chart at 4 m distance to test visual acuity, Vistech contrast sensitivity chart for near at 40 cm distance to test contrast sensitivity, TNO test (Lameris Ootech BV, Nieuwegein) and Titmus test (Stereo Optical, Chicago IL, USA) to test Stereoacuity, Alternating prism cover test at distance and near for Strabismus,assessment of all directions of gaze, mono- and binocularly and with magnification during examination in a split lamp to assess nystagmus, and accomodation and convergence were tested using the Royal Air Force (RAF) ruler.

Quantitative MRI was performed to measure volumes for a number of brain structures (3D T1 and T2 weighted spin echo sequences and T1 weighted inversion recovery sequences, Diffusion tensor imaging (DTI) at 1.5 T), MR spectroscopy (1.5T Siemens Symphony).

Parental Socioeconomic status was calculated using Hollingshead Two Factor Index of Social Position (education and occupation).

18 Year Follow Up

At 18 years of age, participants completed questionnaires on smoking habits, asthma and medications. A physical and clinical assessment was performed including measurement of height, weight, BMI, head circumference, upper arm circumference, waist and hip circumference, triceps and subscapular skinfold thickness, blood pressure and heart rate.

Lung function was measured using Spirometry, Carbon monoxide transfer factor (TLCO) measured using the "Single breath" method, Static lung volumes and Maximal O2-uptake. Endothelial function was measured via ultrasound (Vivid 7 system GE Vingmed Ultrasound AS).

19 Year Follow Up

At 19-20 years of age, participants underwent a psychiatric diagnostic interview, neuropsychological assessment, quantitative MRI imaging and assessment of socioeconomic status.

Psychiatric disorders were diagnosed via a semi-structured diagnostic interview using the Schedule for Affective Disorders and Schizophrenia for School-Age Children – Present and Lifetime Version (K-SADS-PL) and Children's Global Assessment Scale (CGAS). This was supplemented with the Achenbach System of Empirically Based Assessment (ASEBA) Adult Self Report (ASR) form, ADHD Rating Scale IV, Autism Spectrum Quotient (AQ), and Self-Perception Profile for Adolescents, Revised (SPPA-R). Health-Related Quality of Life was measured using the Short Form 36 Health Survey (SF-36).

Participants underwent a neuropsychological assessment including Wechsler Adult Intelligence Scale (WAIS-III), Wisconsin Card Sorting Test (WCST), Stroop, Wechsler Memory Scale III (VMS-III), Connors's Continuous Performance Test (CPT), Visual-Motor Integration (VMI-IV), Grooved Pegboard, Rey Complex Figure Test (RCFT) and Behavior rating inventory of executive function – adult version (BRIEF-A). Selected tests from the Delis-Kaplan Executive Function System (D-KEFS)- Trail Making Test (TMT) 1-5, Verbal Fluency (VF), Design Fluency (DF) were also performed.

Quantitative MRI was performed to measure volumes for a number of brain structures (2D T1 weighted, diffusion tensor imaging (DTI), MR spectroscopy (MRS) at 1.5 T).

Parental Socioeconomic status was calculated using Hollingshead Two Factor Index of Social Position (education and occupation) based on data collected at 14 years.

23 Year Follow Up

At 23 years of age, participants underwent physical, neuropsychological and motor assessment, self-report questionnaires and cerebral MRI.

A physical assessment was conducted including questionnaires on injuries, illness, pain, medications and exercise. The weight, height, BMI and head circumference of the participant were measured. In addition, motor skills were assessed using the Movement Assessment Battery for Children Second Edition (Movement ABC-2), High-Level Mobility Assessment Tool (HiMAT) and Edinburgh Handedness Inventory.

Neuropsychological assessment included Trail Making Test (TMT) 1-5 from the Delis-Kaplan Executive Function System (D-KEFS), Grooved Pegboard and Behavior rating inventory of executive function – adult version (BRIEF-A).

Mental health was assessed using the Achenbach System of Empirically Based Assessment (ASEBA)-Adult Self Report (ASR), and the Beck Depression Inventory (BDI). The Short Form 36 Health Survey (SF-36) was used to measure Health-Related Quality of Life.

Quantitative MRI was also performed to measure volumes for a number of brain structures- 3D T1 (MPRAGE, ADNI sequence), 3D FLAIR (Fluid attenuation inversion recovery), 3D T2, Diffusion tensor imaging (DTI) and fMRI (resting state and attention task).

Parental Socioeconomic status was calculated using Hollingshead Two Factor Index of Social Position (education and occupation) based on data collected at 14 years.

26 Year Follow Up

Participants were assessed at 26 years and underwent a psychiatric diagnostic interview, neuropsychological assessment, clinical physical assessment and MRI imaging. Blood samples were taken for biochemical and genetic analyses.

A semi-structured interview was performed to carry out a psychiatric diagnostic assessment of the participant using the Mini-International Neuropsychiatric Interview (M.I.N.I. Plus). Global Assessment of Functioning (GAF) was scored by the interviewer. Self-report questionnaires included the Achenbach System of Empirically Based Assessment (ASEBA) - Adult Self Report (ASR), Strengths and Difficulties Questionnaire (SDQ), Adult ADHD Self-Report Scale, Autism Spectrum Quotient (AQ), Peters Delusions Inventory, Rosenberg Self Esteem Scale (RSES) and Fatigue Severity Scale. Health-Related Quality of Life was measured using the Short Form 36 Health Survey (SF-36).

Participants underwent a neuropsychological assessment: two subtests from the Delis-Kaplan Executive Functions system (D-KEFS) - Trail Making Test (TMT) and Verbal Fluency (VF), Wechsler Abbreviated Scale of Intelligence (WASI), Wechsler Memory Scale Third Edition (WMS-III), Grooved Pegboard (GP), and selected tests from the Cambridge Neuropsychological Test Automated Battery (CANTAB) - Motor Screening Task (MOT), Big/little Circle (BLC), Paired Associates Learning (PAL), Intra-Extra Dimensional Set Shift (IED), Stockings of Cambridge (SOC), Spatial Working Memory (SWM), Attention Switching Task (AST), Rapid Visual Information Processing (RVP), Emotion Recognition Task (ERT).

A physical and clinical assessment was performed including patient reported medical history, anthropometric measurements (height, weight, BMI, head circumference, upper arm circumference, triceps and subscapular skinfold thickness), blood pressure, heart rate, and dual X-ray absorptiometry (DXA) scan. Questionnaires on physical activity, diet, contraception, pain and sleep were also completed by the participants.

Quantitative MRI was performed to measure volumes for a number of brain structures 3D T1 (MPRAGE, ADNI sequence), 3D FLAIR (Fluid attenuation inversion recovery), 3D T2, Diffusion tensor imaging (DTI), Diffusion kurtosis imaging (DKI).

Fasting blood samples were collected for biochemical and possible genetic analyses. A number of biochemical analyses are available and further processing of the samples is possible for Single Nucleotide Polymorphisms (SNPs) of candidate genes.

Parental Socioeconomic status was calculated using Hollingshead Two Factor Index of Social Position (education and occupation) based on data collected at 14 years.

3.19 PEP - Project Extreme Prematurity

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1999	2000	464	464	376		full cohort assessed 464 admitted to NICU 376 discharged alive from NICU
2 Year Follow Up			373	373	373		full cohort assessed
5 Year Follow Up			372	372	284		full cohort assessed
11 Year Follow Up		2012	372	372	232		full cohort assessed
11 Year Follow Up (Subcohort)		2012	87	61	57	54	Subset assessed. Half of the participants also took part in an fMRI study (28 VPT, 28 Control participants).

Perinatal Assessment

Perinatal data were collected by a local neonatologist investigator using standardised forms and were compared to the information submitted to the Medical Birth Register of Norway. Data were collected on pregnancy course, pregnancy complications, treatments to maintain pregnancy, labour and delivery, resuscitation, respiratory support, neonatal morbidity and medical treatments, details of neonatal screening and other medical tests, hemoglobin, bilirubin levels and metabolic complications, sensory outcome and treatments, nutrition and growth. For stillborn infants, forms about maternal health and pregnancy course were completed by obstetricians.

2 Year Follow Up

At 2 years of age, participants were examined by a pediatrician at a local pediatric department and parents completed questionnaires. A clinical examination was performed including anthropometric measurements (height, weight, head circumference), vision and hearing assessment, assessment of gross and fine motor function, neurological status, mental development assessed using milestones, respiratory history and assessment, gastrointestinal history and symptoms, gastrointestinal assessment, and questions on eating habits and difficulties.

The parental questionnaires provided information on hospital admissions, respiratory morbidity and treatment, psychomotor development including milestones, nutrition and nutritional difficulties, and socioeconomic and family factors (including siblings, parental education, smoking, and type of jobs).

5 Year Follow Up

At 5 years of age, the participants were assessed by a pediatrician, psychologist and physiotherapist at a local pediatric department and parents completed questionnaires.

Participants underwent a clinical examination including assessment of anthropometric measurements (height, weight, head circumference), vision and hearing, motor function including specific milestones, neurological status, mental development (based on milestones), respiratory history and respiratory

assessment, gastrointestinal history and symptoms, gastrointestinal assessment, and details of eating habits and difficulties.

A psychologist administered the Wechsler Preschool and Primary Scale of Intelligence-Revised (WPPSI-R) to assess cognitive development. A trained physiotherapist also performed the Movement Assessment Battery for Children (Movement ABC) test.

Parents completed questionnaires on hospital admissions, respiratory morbidity and treatment including completion of the International Study on Asthma and Allergy in Childhood (ISAAC) questionnaire, general health, allergy and atopic disorders, nutrition, physical activity, gross and fine motor skills, sleep, stool and urinary patterns. They also provided information about attendance at kindergarten, social interaction with peers, language development, family issues, and identified needs from therapists (physiotherapists, psychologists, teachers etc) and completed the Strengths and Difficulties Questionnaire (SDQ) to evaluate child behavior and emotional problems, and Yale Children's Inventory (YCI) to assess ADHD symptoms.

As part of the mandatory health check in Norway, at 4 years of age the children underwent a standardised vision screening test by public health nurses with strict criteria for referral to an ophthalmologist.

11 Year Follow Up

At 11 years of age, the parents and teachers completed questionnaires about the participant. Parents completed questionnaires similar to those at 5 years on hospital admissions, respiratory morbidity and treatment including completion of the International Study on Asthma and Allergy in Childhood (ISAAC) questionnaire, general health, allergy and atopic disorders, nutrition, physical activity, gross and fine motor skills, school, academic attainment, social interaction with peers, language development, sleep, stool and urinary patterns, family issues, and identified needs from therapists (physiotherapists, psychologists, teachers etc).

The appropriate forms of a number of standardised questionnaires were completed by the parents and teachers of the participant to assess psychological and behavioral problems - Strengths and Difficulties Questionnaire (SDQ), Behavior Rating Inventory of Executive Function (BRIEF), Autism Spectrum Screening Questionnaire (ASSQ), Swanson, ADHD Noland and Pelham Teacher and Parent Rating Scale-IV (SNAP-IV), Screen for Child Anxiety Related Emotional Disorders (SCARED), symptoms of Obsessive Compulsive Disorder (OCD), Harter Self-Perception Profile for Children (SPPC) and Kiddie Schedule for Affective Disorders and Schizophrenia-Present and Lifetime Version (K-SADS-PL).

11 Year Follow Up (Subcohort)

At 11 years of age, participants in Western Norway (approximately 20% of the cohort) took part in an additional subcohort study together with matched controls.

Participants underwent a clinical examination by a pediatrician including anthropometric measurements (height, weight and head circumference) and measurements of blood pressure. Respiratory function assessment was carried out including fractional exhaled nitric oxide, spirometry, plethysmography, diffusion capacity for CO, methacholine provocation and reversibility test. Dual-energy X-ray absorptiometry (DXA) was used to assess skeletal density and distribution of soft tissues (fat and muscle). Blood samples were stored for analysis of inflammatory markers, vitamins and

hormones. Half of the index and control group also took part in an fMRI study where participants completed the n-back and Stroop colour-word tasks, while Blood oxygenation level dependent (BOLD) MRI data were acquired.

In addition to the questionnaires completed by parents and teachers as part of the main 11 year data collection, parents and participants also completed KIDSCREEN and Voice Related Quality of Life (VRQOL) questionnaires.

3.20 POPS - Project On Preterm and Small for gestational age infants

Data Collection	Start Year	End Year	Index Group Number Survived	Index Group Number Invited	Index Group Number Assessed	Control Group Number Assessed	Supplementary Information
Perinatal Assessment	1983	1983	1190	1190	1190	n/a	Full Cohort assessed
discharge to 1year	1983	1984	975	975	975	n/a	Full Cohort assessed
2 Year Follow Up	1985	1985	969	969	944	n/a	Full Cohort assessed
5 Year Follow Up	1988	1988	966	966	927	n/a	Full Cohort assessed
9 Year Follow Up	1992	1992	962	962	813	n/a	Full Cohort assessed
10 Year Follow Up	1993	1993	962	962	688	n/a	Full Cohort assessed
11 Year Follow Up	1994	1994					
14 Year Follow Up	1997	1997	962	962	853	n/a	Full Cohort assessed
19 Year Follow Up	2002	2003	959	959	705	n/a	Full Cohort assessed
28 Year Follow Up	2011	2011	957	928	314	n/a	Quick cohort retrieval online questionnaire

Perinatal Assessment

Perinatal data was collected prospectively by pediatricians using a standardised form. Data were collected on maternal sociodemograhic characteristics, maternal obstetric and medical history, pregnancy complications, delivery and birth, infant characteristics at birth, respiratory support, neonatal morbidity and medical treatment, mortality, time to discharge and infant development at time of discharge home.

Discharge to 1 Year

At 3 months of corrected age, data were collected by a neonatologist/padiatrician on infant length, weight and head circumference, diseases, visits to health professionals and hospital admission, socioemotional problems, and maternal and paternal height/length. An age appropriate neurodevelopmental assessment was also performed using the Van Wiechen Assessment.

At 6 months of corrected age, data were collected by a neonatologist/pediatrician on infant length, weight and head circumference, diseases, visits to health professionals and hospital admission and socioemotional problems. An age appropriate neurodevelopmental assessment was also performed using the Van Wiechen Assessment.

At 12 months of corrected age, data were collected by a neonatologist/pediatrician on infant length, weight and head circumference, diseases, visits to health professionals and hospital admission and socioemotional problems. An age appropriate neurodevelopmental assessment was also performed using the Van Wiechen Assessment.

2 Year Follow Up

At 24 months of corrected age, data were collected by a neonatologist/pediatrician on infant length, weight and head circumference, diseases, visits to health professionals and hospital admission and socioemotional problems. An age appropriate neurodevelopmental assessment was also performed using the Van Wiechen Assessment.

5 Year Follow Up

At 5 years of age, parents completed a questionnaire on respiratory problems, health problems, congenital anomalies, medication, otological problems, development, child behavior, emotional wellbeing, academic performance, problems at school, socioeconomic status, obstetric history since the birth of the participant, family structure, visits to health professionals and hospital admissions.

The participant also underwent a physical examination by a pediatrician including assesment of height, weight, head circumference, congenital anomalies, a full neurological examination, audiometry, otological problems, manual dexterity, language skills and speech development, visual function and cognitive impairment.

9 Year Follow Up

At 9 years of age, parents of the participants completed a school-related questionnaire on living arrangements, type of school attended and special educational support received, academic attainment, and behavioral or social problems at school.

10 Year Follow Up

At 10 years of age, the parents of the participant completed a questionnaire to collect details of height and weight, vision and hearing problems, mobility and dexterity, disability and visits to health professionals. They also completed the ASEBA Child Behavior Checklist (CBCL), and the participant completed the Sociale Angstschaal Voor Kinderen (SAS-K) questionnaire. The teacher of the participant completed the ASEBA Teacher Report Form (TRF).

11 Year Follow Up

Participants underwent a neurological examination according to Touwen 1979, and completed the Weschler Intelligence Scale for Children - Revised (WISC-R).

Parents of participants also completed the Dutch version of the Parenting Stress Index (PSI) the Nijmeegse Ouderlijke Stress Index – Kort (NOSIK).

14 Year Follow Up

At 14 years of age the parents of the participants completed the Health Utilities Index (HUI), London Handicap Scale (LHS), TNO AZL Children's Quality Of Life (TACQOL) and questionnaires on family impact, general health and SES.

The participants completed the HUI, TACQOL, Harter Scales (Self Perception Profile for Adolescence), and questionnaires on schooling, growth and puberty.

19 Year Follow Up

At 19 years of age, participants underwent a full clinical assessment including collection of blood and urine samples, blood pressure measurements, skin thickness measurements (triceps, biceps, subscapular, iliac), hip circumference and abdominal circumference, echocardiography and cardiac

ultrasound, neuromotor examination, audiometry, and a cold pressor test. During the clinic visit the participants also answered questions about their medical history including renal history, blood pressure, menstrual history, and medications.

The participants completed questionnaires on health and diseases, contact with medical professionals, work, education, living arrangements and relationships, future plans, and the Health Utilities Index (HUI), London Handicap Scale (LHS), Pain coping Questionnaire (PCQ), ASEBA Young Adult Self Report (YASR), and Generalized Self-Efficacy scale (Schwarzer, R., & Jerusalem, M., 1995).

Additionally, the parents of the participants completed the HUI, LHS, Cognitive Emotional Regulation Questionnaire (CERQ), ASEBA Young Adult Behavior Checklist (YACBL), Generalised Self-Efficacy Scale, and a family impact questionnaire to investigate the impact of preterm birth on work and relationships.

28 Year Follow Up

At 28 years of age, participants completed an online questionnaire at three time points consisting of the Health Utilities Index (HUI), London Handicap Scale (LHS), World Health Organisation Quality of Life Questionnaire short version (WHOQOL-BREF), Course of Life Questionnaire (CoLQ), Hospital Anxiety and Depression Scale (HADS), and questions about health, visits to health professionals, relationships with parents, close relationships and children, and bullying.

4 CONCLUSIONS

The cohort descriptions presented in this report form the basis of the Metadata catalogue entries for the RECAP Preterm data platform. The collected metadata provide detailed information on cohort characteristics that will be an important resource for RECAP Preterm partners during data harmonisation and for aiding decisions about inclusion of cohorts within future analyses.