Received: 15 September 2019 | Revised: 4 May 2020 | Accepted: 10 May 2020

DOI: 10.1111/ppe.12694

ORIGINAL ARTICLE

Paediatric and Perinatal Epidemiology WILEY

Common Core Assessments in follow-up studies of adults born preterm—Recommendation of the Adults Born Preterm International Collaboration

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Abstract

Background: Of all newborns, 1%-2% are born very preterm (VP; <32 weeks) or with very low birthweight (VLBW; ≤1500 g). Advances in prenatal and neonatal care have substantially improved their survival, and the first generations who have benefited from these advances are now entering middle age. While most lead healthy lives, on average these adults are characterised by a number of adversities. These include cardiometabolic risk factors, airway obstruction, less physical activity, poorer visual function, lower cognitive performance, and a behavioural phenotype that includes inattention and internalising and socially withdrawn behaviour that may affect life chances and quality of life. Outcomes in later adulthood are largely unknown, and identifying trajectories of risk or resilience is essential in developing targeted interventions. Joint analyses of data and maintenance of follow-up of cohorts entering adulthood are essential. Such analyses are ongoing within the Adults Born Preterm International Collaboration (APIC; www.apic-preterm.org). Joint analyses require data harmonisation, highlighting the importance of consistent assessment methodologies.

Objective: To present an expert recommendation on Common Core Assessments to be used in follow-up assessments of adults born preterm.

Methods: Principles of Common Core Assessments were discussed at APIC meetings. Experts for each specific outcome domain wrote the first draft on assessments pertaining to that outcome. These drafts were combined and reviewed by all authors. Consensus was reached by discussion at APIC meetings.

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Funding information
Academy of Finland (to EK, KH, KR, and PH), Canadian Institutes of Health Research Operating grant (#MOP – 119386 to KMM), Cure Kids NZ (to BAD), European Commission (Horizon 2020 award 733280 RECAP-preterm; to EK, DW, EV, KAIE, KH, KR, MSI, PH, SJ, and SvdP), Foundation for Pediatric Research (to EK), National Health & Medical Research Council, Australia (to PJA and LWD), Norface DIAL (Consortium 462-16-040 Premlife to EK, DW, KR), Signe and Ane Gyllenberg Foundation (to EK, KR), and Sigrid Juselius Foundation (to EK).

Results: We present a recommendation by APIC experts on consistent measures to be used in adult follow-up assessments.

Conclusions: The recommendation encompasses both "core" measures which we recommend to use in all assessments of adults born preterm that include the particular outcome. This will allow comparability between time and location. The recommendation also lists optional measures, focusing on current gaps in knowledge. It includes sections on study design, cardiometabolic and related biomarkers, biological samples, life style, respiratory, ophthalmic, cognitive, mental health, personality, quality of life, sociodemographics, social relationships, and reproduction.

KEYWORDS
birthweight, follow-up, preterm, recommendation

1 | BACKGROUND

Approximately 15 million babies worldwide each year, one in ten, are born preterm, before 37 weeks of gestation.[1,2] Advances in prenatal and neonatal care and ensuing improvements in the preterm infants' prognosis have been one of the success stories of modern medicine. This has been particularly evident for those born very preterm (VP; before 32 weeks of gestation) or at very low birthweight (VLBW; 1500 g or less), who constitute 1%-2% of all newborns.[2,3] In high-income countries, their survival has dramatically improved to ~90% today.[4]

Those who first benefited from improved care are now in their 30s and 40s, entering middle age. They represent a substantial proportion of the population in high-income countries: for example, in the United States the number of VP/VLBW survivors born in the 1970s and 1980s is estimated to be over half a million[5] and

Synopsis

- *Study question*: What assessment measures should be used in follow-up assessments of adults born preterm to facilitate joint analyses between cohorts?
- *What is already known*: Adults born preterm are characterised by a number of physical and mental health adversities and risks, and a behavioural phenotype that may affect life chances and quality of life. Existing follow-up cohorts are relatively small, and assessment of risk and resilience factors requires joint analysis of data from different cohorts.
- *What this study adds*: We present a recommendation by APIC experts on consistent measures to be used in follow-up research assessments in adults born preterm.

approaches one million adults in the European Union.[6] With improving survival,[1] their proportion is also increasing in middle- and low-income countries.

1.1 | Adults born VP/VLBW—what is currently known

While most VP/VLBW young adults lead healthy lives[7] and many case histories point to remarkable resilience,[8] VP/VLBW adults on average have more physical, cognitive, behavioural, and social challenges than their peers born at term. These challenges include increased levels of cardiometabolic risk factors,[9,10] airflow obstruction,[11] lower bone mineral density, lower levels of physical activity,[9] lower scores on tests of cognition[12] and educational attainment,[7,13] higher rates of mental health problems,[14,15] difficulties in establishing social relationships, and being less likely to partner and reproduce.[16,17] Studies have thus far extended to young adult life, around the peak of most physiological functions, but late-life outcomes are largely unknown. Even with average rates of physiological decline, individuals at lower peak levels are expected to attain symptomatic levels of impairment earlier. Moreover, adaptations to pre- and neonatal adversities could come at the cost of more rapid rates of decline in cardiovascular, pulmonary, and cognitive function, or "accelerated ageing."

Not all findings are negative, including less externalising and rule-breaking behaviours,[14] and in some studies lower risks of substance abuse,[15] and atopic allergy.[18]

1.2 | Adults born preterm international collaboration and common core assessments recommendation

Most of existing literature comes from register studies or a small number of longitudinal clinically studied case-control cohorts in high-income countries. Clinical cohorts include much more detail on physical and behavioural traits, but typically only range from tens to a few hundred VP/VLBW cases. This prompted researchers in the field to form the APIC Adults Born Preterm International Collaboration (www.apic-preterm.org) to address study questions that cannot be assessed in one study alone. One aim of the collaboration focuses on individual-participant meta-analyses that have been performed for blood pressure,[10] adult behaviour problems,[14] and lung function.[11] Studies are currently underway addressing adolescent psychiatric symptoms, psychiatric diagnoses, adult body size and pubertal growth, handgrip strength, and effects of childhood cognitive and mathematic abilities on adult wealth. Such meta-analyses and cross-validations are only possible if similar measures of adult outcomes have been used. Therefore, the other aim of the APIC collaboration is to agree on common core measures for key outcomes relevant in studying adults born preterm. Many APIC partners also participate in other similar initiatives such as the EU-funded RECAP Research on Children and Adults Born Preterm (www.recap-preterm.eu) that is developing a technical platform for secure distributed analysis of harmonised joint data sets for RECAP partners and non-partners alike.

1.3 | Common core assessments—process, rationale, and criteria

The process was started by discussing principles of Common Core Assessments at APIC meetings. Experts of specific outcome domains (Appendix 1) wrote the initial draft on assessments pertaining to that domain. These drafts were combined and revised based on review by all contributors. Consensus was reached by discussion at APIC meetings.

The most important benefits of having harmonised measures in VP/VLBW follow-up studies include the following:

- Assessment of hypotheses for which single studies have insufficient power
- Assessment of whether findings are universal versus country-/culture-specific (cross-validation)
- Comparison of adult outcomes of infants born during different periods, which also serves as a "quality control" for prenatal and neonatal treatments during a specific period.

Criteria for selecting core measurements were decided as follows:

- Measures an outcome relevant to study in VP/VLBW adults (ie, the "preterm phenotype")
- Measures an outcome relevant for health, community participation, and quality of life, or is predictive of such an outcome
- Adheres to standard administration and test performance (validity and reliability) criteria
- Is cross-culturally comparable
- Has population-specific norms, if the aim is to use cut-offs (eg to identify impairment)
- Is feasible to administer (in terms of time and training required)
- Measures that are widely used have an advantage (well known, likely to have been used before in VP/VLBW cohorts).

We have focused on methods that are relevant in the follow-up of VP/VLBW adults, because this group carries the highest risks and the largest investments in peri- and neonatal health care resources. Many of the recommended measurements are also relevant in following up adults born at any degree of preterm birth or in general population health examinations. Similarly, many of these adult measures have versions that can be used in childhood and adolescence, and can be useful in assessing continuity across ages.

Another important consideration is appropriate equipment, training of staff, and quality control to allow standardised performance and comparability of measurements. For the core measurements, we describe key methodological aspects, pitfalls, and references to more detailed guidelines.

For each outcome domain, we present a list of *core measures* which we, resources allowing, recommend for every comprehensive cohort assessment. We do not present a priority order between different sets of outcome measures; for this, we refer to ongoing initiatives (http://www.comet-initiative.org/studies/details/842). We also include a list of *optional measures* relevant to currently open study questions, which may, however, not fit the resources and scope of each study.

There are some relevant research areas, for example neuroimaging, which are not included because there is not enough information to recommend specific core measures.

2 | GENERAL ISSUES ON ADULT FOLLOW-UP STUDIES

2.1 | Comparison group

When comparing adults born preterm with the general population, a comparison group born at term or at normal birthweight by far outperforms the use of population standards or test norms which are frequently outdated, inappropriate for specific regions, or dependent on specific details of methodology. Most existing follow-up cohorts include such a group. If a new comparison group is recruited, it is advisable to have as random a sample as possible of the same source population from which the preterm group comes. There are several ways to achieve this (eg, full random selection, stratification, nomination). In select cases, group-matching (eg, socio-economic status, ethnicity) may be warranted, but caution should be taken not to affect the generalisability of the study. Convenience comparison samples such as recruitment through advertisements or among university students involve a substantial risk of bias. Invitation should be similar and research assessment staff should be blinded as to the VP/VLBW or control status.

There are also special study designs. For example, the use of term-born siblings as controls is effective in reducing confounding by genetic effects or shared childhood environment but is based on a number of assumptions[15] and limited to VP/VLBW with siblings willing to participate. Similarly, term-born friends are sometimes used to reduce confounding due to socio-economic factors of life style.

2.2 | Participation and retention rate

Much of the recruitment process focuses on motivation, such as communicating the rationale of the study, being flexible about schedules, and by providing incentives, such as detailed feedback and monetary compensation. Strategies to increase identification as a cohort member include study newsletters, season's greetings, or cohort get-togethers. To evaluate participation bias, it is essential to document key characteristics of non-participants.

There is a substantial body of evidence on specific methods to maximise follow-up rates.[19,20]

2.3 | Prenatal and neonatal data

It is common that perinatal and neonatal data are collected or supplemented later from medical records. Gestational age and birthweight should be recorded as accurately as possible, including the method of gestational age determination. Much of the rationale for pooling of harmonised data lies in assessing the effects of prenatal and neonatal covariates. Important variables include maternal pregnancy factors (eg, age, parity, smoking, alcohol and other substance use, pre-pregnancy BMI), pregnancy disorders that may predispose to spontaneous or medically indicated preterm birth (eg, preterm rupture of membranes, maternal chorioamnionitis, hypertension in pregnancy, gestational diabetes, antenatal glucocorticoid treatment), and key infant complications of prematurity (including, but not limited to, bronchopulmonary dysplasia, intraventricular haemorrhage and other neurological injury, and retinopathy of prematurity), all preferably independently confirmed from medical records. Relevant factors should be available for controls. It may be helpful to include permission to access a participant's medical records in the consent forms.

3 | SPECIFIC RECOMMENDATIONS BY OUTCOME

3.1 | Cardiometabolic and related biomarkers and blood and urine samples

Many of the recommended measurements (Table 1) are widely used in population health surveys, including the European Health Examination Survey (EHES),[21,22] European Health Interview Survey (EHIS),[23] WHO STEPwise approach to risk factor surveillance project (STEPS),[24] the US National Health Examination and Nutrition Survey (NHANES),[25] the US NIH PROMIS® toolbox, and many other national surveys. The EHES manuals[21,22] include thorough hands-on instructions on how to perform the measurements and justifications of the recommendations.

The guidelines include recommendations on avoiding vigorous exercise, smoking, and use of alcohol.[22] Menstrual cycle phase, pregnancy, lactation, and menopause should be recorded; some physiological measurements may not be informative and some may be contraindicated during pregnancy.

3.1.1 | Height, weight, and waist circumference

While the measurement of height and weight may seem trivial, rigorous protocols, appropriate training, and regular calibration of scales are essential. Waist circumference provides a simple measure of abdominal, metabolically harmful obesity, but is particularly prone to error and highlights the importance of training and quality control.[22] Other potentially relevant body proportion measures are listed in Table 1.

TABLE 1 Cardiometabolic measures and related body composition, biomarker, and life style assessments

Domain	Measure	Time required (min)[a]	Rationale
Core measures			
Anthropometry	Height, weight, waist circumference	5	Short height and obesity are risk factors for a wide range of non-communicable disorders
Blood pressure	"Office" blood pressure and heart rate	5	Elevated in VLBW adults.[10] Blood pressure is the most important single risk factor for global disease burden
Blood biomarkers	Fasting blood sample[b]	5-10	Serum/plasma/DNA can be stored for future use
Body composition	Bioelectric impedance analysis	10	Use of the 8-electrode methods is more accurate Measures whole-body fat mass and fat-free mass Alternative methods listed as optional items
	Questionnaire items		
European Minimal Health Module	Self-perceived health, long-standing (6 mo or more) illness and functional limitations; history of major illness and surgery	2	Captures most relevant health conditions, widely used as a "minimum health module" in surveys[22,23]
Family history	Family history of major illness	2	To assess familial confounding
Medication	Use of medication	2	Relevant per se, necessary for reporting and interpretation of other results
Smoking and alcohol use	Questions in national surveys, www.auditscreen.org	2	Relevant to most health outcomes, VLBW/VP may have lower rates[15]
Physical activity	International Physical Activity Questionnaire (https://sites.google.com/site/theipaq/home)	5	Relevant to most health outcomes, VLBW/VP may have substantially lower levels.[9] Available as 7 and 21-item versions. Assesses physical activity during the last 7 d, which may be dependent on season
Other life style factors, for example nutrition and sleep	No consensus on very short (a few items) questions. Questions embedded in national surveys can be used, or use tools listed as optional items	Variable	
Optional measures			
Blood pressure	24-h ambulatory blood pressure	10	More accurate predictor of disease endpoints than office blood pressure. Adults born preterm may have higher variability
Arterial stiffness	Vascular measures: non-invasive pulse wave velocity measurement[55]	~15 (depends on method)	Adults born preterm have increased pulse wave velocity; unclear, whether cause or consequence of higher blood pressure
Glucose tolerance	2-h oral glucose tolerance test	15[c]	Necessary to define type 2 diabetes or impaired glucose tolerance/prediabetes. Fasting and 2-h glucose and insulin concentrations are sensitive indicators of glucose metabolism as continuous variables
	Indices of glucose tolerance and insulin sensitivity from fasting blood samples	Included above	Indices such as HOMA-IR and QUICKI, based on fasting insulin and glucose, can serve as surrogate markers of insulin resistance[56]
Renal function	Glomerular filtration rate (GFR) Methods independent of body mass preferable (eg, inulin)	20[c]	Possible cause of higher blood pressure. Assessment of renal functional reserve is more sensitive but requires stimulation by protein/amino acids.[57] Requires four blood and urine samples
MicroRNA	Blood sample for circulating microRNA extraction	Included above	Emerging biomarker for a wide range of disease processes; robust and survives storage

(Continues)

TABLE 1 (Continued)

Domain	Measure	Time required (min)[a]	Rationale
Urine sample	Spot,[d] overnight, and 24-h samples in increasing order of accuracy and cumbersomeness.[22] Variation in dilution is the most significant problem, which can only partly be adjusted for by measuring urine creatinine	5-10	Various purposes, for example markers of renal function and measuring compounds for which single serum/plasma concentrations are not informative (sodium intake, environmental toxins, and glucocorticoid metabolites)
Stool sample		~10	Microbiome, an emerging candidate mechanism to mediate the lifelong health consequences of VLBW/VP birth
Objective measurement of physical activity and sleep	Accelerometry	10-15	Objective measurement of physical activity, sleep, and diurnal rhythm. Traditionally, physical activity has been assessed by waist-worn and sleep and diurnal rhythm by wrist-worn devices, typically for 7 d. Objective measurement and self-report both provide complementary information
Sleep and chronotype	Pittsburgh Sleep Quality Index,[58] 19-item Horne-Östberg Morningness-Eveningness Questionnaire or a 6-item version (Questions 4, 7, 9, 15, 17, and 19)[59]	5-10	Sleep is a key determinant of health and has been little studied in VP/VLBW adults. Some studies report more morningness, which is a predictor of good health
Food and nutrient intake	Questions on single items embedded in national surveys can be used.[23] More comprehensive analysis requires a food frequency questionnaire or food diary[60]	Variable	Little studied in VP/VLBW adults. Calculation of nutrient intake from data from data on food intake requires a (national) nutrition database, which includes country-/culture-specific average nutrient contents of food items/meals
Substance use	Drug Abuse Screening Test (DAST-10)[27] is a widely used tool to assess the use of substances other than alcohol or tobacco	2	Relevant for most health outcomes
Cardiorespiratory fitness	Gold standard, direct measurements of O_2 and CO_2 in inhaled and exhaled air during maximal exercise are labour-intensive, but estimates of VO_2max can be calculated by various methods based on heart rate during submaximal exercise[61]	Variable	VO_2max, maximal aerobic capacity, is an important predictor of health
Muscular fitness	Handgrip test. Other tests of muscular strength and endurance are described in the American College for Sports Medicine Guidelines[61]	5	Well-established predictor of functional capacity decades later
	Motor skills		Please see Table 4
Body proportions	For example, head circumference, sitting height, prone length, arm span, and knee height	Variable	Measures such as indicate body proportions and may be helpful in assessing growth of individuals with challenge in mobility
Alternative way to measure body composition	Skinfolds	10	Estimates body fat using algorithms. Less accurate than BIA compared to DXA. Very dependent on training of staff and has challenges of reproducibility
	Air displacement plethysmography	15-20	Requires specialised equipment. Measures whole-body fat mass and fat-free mass
	Dual-energy X-ray absorptiometry	20-30	Considered a reference method. Provides bone mineral density as well. Associated with increased expense. Low ionising radiation exposure
	Magnetic resonance imaging	30-60	Provides regional fat information accurately

[a]Time required at clinic (for ambulatory measures, time for giving participant instructions). Time for data extraction and entry not included.

[b]Morning sample after overnight fast. The use of a non-fasting sample is possible but will limit the utility of a number of metabolic markers.

[c]Time for drawing blood samples and ingesting glucose/infusing inulin. Assessments that do not require significant mental of physical exertion can be performed between the samples.

[d]A spot urine sample may be random or standardised. A frequently used standardisation is to use "day's 2nd urine": the participant, who attends a clinic for a fasting blood sample, voids urine when getting up at home, comes to the clinic and gives a urine sample at the clinic.

In studies using only questionnaires, we recommend inclusion of self-reported height and weight, which, however, include well-documented sources of error.[26]

3.1.2 | Blood pressure

Blood pressure has the highest global public health burden of all risk factors and is elevated in VLBW[10] and other preterm adults. We propose blood pressure and heart rate as one of the core assessments. A list of validated blood pressure devices and validation standards is available at the British Hypertension Society website (http://www.bhsoc.org/bp-monitors/bp-monitors/). National/regional standards on the arm of measurement and number of recordings vary; the local standard should be used and reported. Sources of measurement variation, which are well characterised,[22] should be minimised. In particular, it is important to use a cuff appropriate to the participant's arm circumference.

3.1.3 | Blood sample

Although venipuncture can be a concern for some adults, feedback on analyses made from a blood sample can also serve as motivation for participation. It is important to involve a biobank or a laboratory experienced in studies in healthy individuals from the planning phase onwards. The sampling conditions should be as standardised as possible,[22] which usually includes obtaining morning samples after an overnight fast. If this is not possible, a random sample can be considered, although it has limited utility for analytes with significant postprandial (eg, glucose, triglycerides, insulin, perhaps epigenetic markers) or diurnal (eg, cortisol) variation. In some cases, a shorter fast (eg, 4 hours[22]) provides a reasonable compromise. In any case, time of day, fasting time, and any irregularities in sampling should be recorded.

Usually, some key analyses are performed immediately or within a few weeks, in part to provide feedback to the participants, while the remaining plasma and serum are stored for later analysis. These analyses often include plasma total, high-, and low-density lipoprotein cholesterol and glucose and may also include haemoglobin A1c (HbA1c), analysed from whole EDTA blood. A blood cell count needs to be analysed from fresh samples. For these analyses, the interassay variation in routine analysers is small enough not to cause concern if the same analyses are run by the same method in the same laboratory along the clinical visits, whereas for some other analytes (eg, insulin), analysis of all samples at the same time may be important to reduce interassay variation.

As for storing samples, most relevant biochemical analyses can be done from serum and plasma, which are stored at −80°C or in liquid nitrogen in small (1 or 1.5[22] mL) aliquots. For DNA extraction, adult studies usually collect one or two ~5- to 10-mL samples of EDTA blood, which can be stored at −20°C. If the pre-extraction storage time is expected to exceed 2 years, storage at −80°C is preferred. If a blood sample is not feasible, DNA can also be obtained from saliva, which can, with adequate preservatives, be stored for years in room temperature. DNA yield is higher in salivary than in buccal swab samples.

When obtaining biological samples for storage, it is important that the consent forms adequately cover the use of samples for future analyses, and for international sharing of pseudonymised data. Consent forms for modern population health surveys and biobanks may be helpful.

3.1.4 | Health, medical history, and medication

We recommend the Minimum European Health Module that comprises three questions on self-perceived health, long-standing (6 months or more) illness, and functional limitations.[22,23] The use of regular medication and medication taken during the day of examination are also important to record, and participants may be asked to bring along their medication packages or prescriptions. It may be helpful to specifically state that the use of medication also includes hormonal contraception, nutritional supplements, and non-oral (inhaled, transdermal, and injected) medication. These questions may be complemented by specifically asking for selected disorders or treatments and family history of conditions of interest.

More detailed instructions including aspects on language translation are presented in the European Health Interview Survey manual.[23]

3.1.5 | Life style: smoking, alcohol and substance use, physical activity, nutrition, and sleep

Lower rates of alcohol use disorders among adults born VP/VLBW have been reported in several studies[15] and lower rates of smoking in some. It is helpful if questions on smoking include current and former smoking and allow the calculation of pack-years and exposure to passive smoking (Table 2).[23] The 10-item WHO Alcohol Use Disorders Identification Test (AUDIT) quantifies alcohol use and produces a single-dimension score to screen for alcohol use disorders (www.auditscreen.org) (Table 1). If use of other substances than alcohol and tobacco is of interest, we recommend 10-item Drug Abuse Screening Test (DAST-10).[27]

Physical activity is a key predictor of health and disease and may be substantially lower among VP/VLBW adults than among those born at term.[9] The International Physical Activity Questionnaire (IPAQ) has 7- and 21-item versions and validated translations to many languages (https://sites.google.com/site/theipaq/home). They allow calculation of estimated metabolic-equivalent minutes per week and classification to low, moderate, and high physical activity. The IPAQ assesses physical activity during the last 7 days, and possible seasonal variation is important to account for. Objective measurement of physical activity and measurement of physical fitness can be relevant (Table 1, Optional measures).

TABLE 2 Respiratory measures

Domain	Measure	Time required (min)[a]	Rationale
Core measures			
History	Tobacco smoking	5	Tobacco smoking affects health in multiple ways, particularly its direct effects on respiratory health. See also Section 3.1.5
	Medications—bronchodilators, inhaled or systemic corticosteroids		Medications need to be documented accurately. See also Section 3.1.4
	Respiratory health questionnaire (eg, St George's Respiratory Questionnaire[62])		Respiratory-related health associated with asthma or other lung disease
Lung function: airflow and vital capacity	Spirometry; airflow: FEV1—forced expired volume in 1 s; and FEF25%-75%—forced mid-expiratory flow. Instantaneous flows at 25% and 75% of forced vital capacity (FVC) would be desirable	60	Lung function tests should be performed according to standard guidelines of the American Thoracic Society or European Respiratory Society by technicians blinded to clinical details of participants. Interpretation requires knowledge of height, age, sex and ethnicity of the participant. All of these variables influence lung growth, and hence the expected values for healthy people[63]
Reversibility	Spirometry repeated after a bronchodilator		To determine how much airway obstruction is reversible
Lung volumes	Body plethysmograph: TLC—total lung capacity; RV—residual volume		
Gas exchange	DL_{CO}, diffusing capacity of the lung for carbon monoxide		Measures alveolar-capillary membrane pathology (also called TL_{CO} in Europe).
Optional measures			
Exercise capacity			See Table 1 (Cardiometabolic measures)
Ventilation heterogeneity	Multiple breath nitrogen washout (MBW), from which the following variables can be obtained: Ventilation heterogeneity indices in the conductive (Scond) and acinar (Sacin) airways; lung clearance index (LCI)	30	Provides more details about lung architecture related to ventilation heterogeneity

[a]Time required at clinic. Time for data extraction and entry not included.

3.2 | Body composition

Clinically, body mass index (BMI; weight [kg]/height^2 [m^2]) is utilised as a simple measure of obesity. VLBW or extremely low-birthweight (ELBW; <1000 g) adults have lower lean mass[28,29] and increased fat mass for height[28] compared with term-born controls. BMI does not differentiate between lean mass and fat and may under-represent increased adiposity.

Body composition can be estimated in multiple ways (Table 1). All methods require training, and most require specific equipment. Balancing accuracy, reproducibility, and ease of measure, the use of bioelectric impedance analysis (BIA) is likely the preferred method. BIA measurement requires specialised equipment, but is easy to conduct and of relatively low cost. BIA is based on the measurement of impedance of an electric signal and calculates total body water generally by proprietary device- and population-specific formulas, and from that, estimates lean mass and, by subtraction, fat mass. The most accurate methods use 8 electrodes. Measurement can be influenced by dehydration, exercise immediately before, and meal consumption. It is most useful in longitudinal measurement and for comparing groups.

3.3 | Respiratory outcomes

Adults born preterm have impaired airflow.[11] Table 2 lists recommended common core assessments recommended for studies of respiratory outcomes, in addition to basic demographic and perinatal data concerning the cohort. Perinatal data specifically relevant to respiratory outcomes include surfactant, durations of assisted ventilation of all types, and oxygen, BPD, and prenatal and postnatal corticosteroids.

3.4 | Ophthalmic outcomes

There are few comprehensive data on visual outcomes in VP/VLBW adults. In early childhood, there is an increased risk of problems including myopia, strabismus, and amblyopia as well as cerebral visual impairment associated with white matter damage. Table 3 lists common core assessments recommended for visual outcomes, which will be impacted by the presence of retinopathy of prematurity (ROP) and its severity, treatment, and other morbidities,[30] all of which

should ideally be prospectively documented. Current population-based studies suggest around 22% of VLBW infants will have some acute ROP.[31]

3.5 | Cognitive and motor function

Cognitive impairment is one of the primary concerns for parents of very preterm infants. Extensive research has shown that children and adolescents born VP have on average lower general intelligence (IQ) than full-term peers,[12,32] performing approximately two-thirds of SD lower than expectations.[33] Research assessing cognitive functioning in adults born VP is lacking, and more research is needed, especially focusing on specific domains of cognition. For instance, it is still poorly known to what extent and in what circumstances cognitive deficits reported in very preterm children persist, improve, or worsen with the transition to adulthood and middle age.

It is important to note that a large number of cognitive profiles can explain below-average IQ, such as attention and working memory difficulties, language delay, visual-spatial processing deficits, and executive dysfunction, to name a few. Understanding population-specific cognitive profiles is important for determining underlying neurological mechanisms, prognostic counselling, surveillance programmes, and structuring intervention and management strategies. This requires neuropsychological measures beyond IQ.

Numerous standardised measures are available for assessing cognitive functioning. The selection is often personal or local preference; however, there are several factors that should be considered. Measures should have strong psychometric properties, including construct validity, test-retest reliability, and inter- and intra-tester reliability. Preference should also be given to well-standardised instruments that have appropriate and current, locally relevant population norms. The selection of measures in Table 4 is based on these considerations, as well as familiarity of follow-up groups around the world. To minimise assessment time, abbreviated measures of IQ are often administered, which is generally appropriate given very preterm adults are likely to have had IQ testing in earlier follow-up time points. For specific cognitive domains (eg, attention, memory, executive function, motor, academics), subtests are typically selected by researchers that focus on the specific cognitive skills of interest (eg, impulse control, working memory, episodic memory, sustained attention, mathematics). In general, a brief neuropsychological assessment would take 40-60 minutes, while a comprehensive assessment would exceed 2 hours.

Motor delay has been consistently reported in VLBW populations during the first months and years of life. It is a sensitive early predictor of motor problems (poor fine and gross motor function) by school entry and other neurodevelopmental problems later. Motor problems remain in adolescence.[34] Studies in adulthood are few, and we recommend a motor performance test as a core assessment (Table 4).

3.6 | Mental health

VP/VLBW birth is associated with a specific cluster of mental health problems that manifests in a high prevalence of ADHD, predominantly the inattentive subtype, anxiety, and autism spectrum traits and disorders across the life course, with some evidence for increased rates of depression.[14,35,36] Accordingly, VP/VLBW adults have been described as easily worried, rigid in communication, and socially withdrawn.[14,35-37] This preterm behavioural phenotype is evident in studies using both screening tools and diagnostic interviews.

Diagnostic studies represent the gold standard, and we recommend a structured clinical diagnostic interview when psychiatric diagnoses are of interest. While these assessments of dichotomous outcomes may lack statistical power in individual studies,[37] the data can be relatively easily harmonised and adequate power achieved through data pooling with other cohorts.

However, many mental health problems may be best described as a range of symptoms along a continuum rather than a categorical diagnosis. Accordingly, VP/VLBW individuals' daily functioning may be significantly impaired by such subthreshold symptoms and/or not otherwise specified (NOS) disorders. As an economical and ecologically valid alternative, researchers have used standardised, cross-culturally reliable screening questionnaires[14,38,39] to assess symptoms across multiple domains including behaviour, attention, anxiety, mood, social, and communication problems (Table 5). Administering these symptom scales to different informants (eg, parents or partners, and adults themselves) may increase objectivity, validity, and reliability of information as self-reports may underestimate symptom severity.

3.7 | Personality

One reason why adults born VP/VLBW differ from term controls in mental health, social relationships, and risk-taking may be related to differences in personality. Personality refers to relatively enduring traits that differentiate individuals from each other and plays an important role in emotional and social functioning. Yet, relatively few studies have examined personality differences between VP/VLBW adults and term controls.

In line with the VP/VLBW behavioural phenotype,[35] VP/VLBW adults score lower than term controls on extraversion,[40-43] higher on neuroticism,[40,42,43] and higher on agreeableness.[41-43] The groups have not been shown to differ from each other in psychoticism,[40] and findings with regard to conscientiousness and openness to experience are mixed.[41-43] One study has additionally reported that VLBW adults scored lower on impulsivity and hostility.[41]

Table 5 provides a selection of measures with proven psychometric properties that are adapted into different cultures to measure adult personality. Both core measures featured here capture neuroticism and extraversion. Researchers may favour the NEO-PI scales when interest is on facets of personality that comprise the five main

TABLE 3 Ophthalmic measures

Domain	Measure	Time required (min)[a]	Rationale
Core measures			
Glasses prescription	A focimeter or lensometer is used to check glasses prescription	5	A check on refraction results. More preterm than term are prescribed glasses
Ocular alignment, nystagmus		10	
Best corrected visual acuity	LogMAR charts (Early Treatment Diabetic Retinopathy Study: ETDRS), where letter size and spaces remain in proportion, is the gold standard	15	Key measure of vision
Contrast sensitivity	Pelli-Robson chart	5	Reported to be reduced in preterm, ROP and treated ROP
Refraction	Autorefraction is a simple and rapid technique in widespread use. Definitions of myopia and hypermetropia vary. Report results as spherical equivalent—dioptres. Cycloplegia is optional and may not be required in young adults but without it errors can still occur and it is regarded as the gold standard in epidemiological studies[64]	5-10	Standard measure of vision. Myopia more common in preterm than term, ROP versus no ROP, treated ROP versus regressed ROP If cycloplegic refraction is performed, it will need to be at the end of the assessment as full recovery may take several hours
Retinal photographs	Best with cycloplegia so follow above test	5	Detects pigment changes, macular dragging, retinal folds, and detachments
Questionnaire on visual functioning and everyday activities	National Eye Institute Visual Functioning Q-25 (https://nei.nih.gov/sites/default/files/nei-pdfs/vfq_sa.pdf)	10-15	Assesses impact of visual problems on daily life, for example ability to have driving licence. Standardised translations to many languages available
Optional measures			
Visual fields	Standard automated perimetry (SAP) is considered the gold standard. For example, the Swedish interactive threshold algorithm (SITA)-Standard 24-2 test. An alternative is frequency doubling technology perimetry (FDT) as in the Humphrey matrix 24-2 test. At older ages the latter might be better[65]	5	Both ROP and treatment associated with reduced visual fields
Colour perception	Ishihara Color Perception Test (or an alternative test)	5	
Eye movements, binocular function[66]	Observation of horizontal of vertical nystagmus in the primary position; manifest strabismus, ocular palsy (standard eye movement in 6 directions), and smooth pursuit by following moving object Many tests of stereoscopic vision are available including the TNO Stereotest (adult version)	5	
Visual processing	TVPS-R (test of non-motor visual-perceptual skills)[67] has been used up to 20 y	30	Increasing evidence of more subtle visual morbidity associated with cerebral damage
Optical coherence tomography[68]	Spectral domain optical coherence tomography with new-generation portable, hand-held device	5-10	Used to assess structural outcomes, optic disc, and macular thickness

[a]Time required at clinic. Time for data extraction and entry not included.

scales, and time allocated to filling in the scale and funding are available. The EPQ-R scales should be favoured when social desirability is of interest.

3.8 | Sociodemographic factors

Low socio-economic position is a risk factor of preterm birth and many of the outcomes of interest, and thus, family socio-economic position is a key confounding factor. Sociodemographic factors are also key indicators of resources buffering the consequences of preterm birth and thus among the most important potential risk and resilience factors.

The most commonly used indicators are parental educational attainment and occupation. They are not prone to significant changes in time, are usually recalled by the adult offspring, and can be easily categorised according to internationally comparable classifications such as the UNESCO International Standard Classification of

TABLE 4 Cognitive and motor measures

Domain	Measure	Time required (min)[a]	Rationale
Core measures			
IQ estimate (abbreviated test)	Wechsler Abbreviated Scale of Intelligence (WASI-II®)	15-30	Four and two subtest versions that correlate well with full Wechsler scales. Good measure when an estimate of IQ is sufficient
Academics (achievement)	Questions relating to years of schooling, highest qualification, referral and access to remedial assistance, grade repetition	<5	Important information on the level of education acquired and assistance received
Motor functioning	Bruininks Motor Ability Test (BMAT®)	15-20 (short) 60-75 (full)	This is the adult version of the Bruininks-Oseretsky Test of Motor Proficiency (BOT2), which is commonly used in child follow-up programmes
Optional measures			
General Intelligence (IQ)	Wechsler Adult Intelligence Scale (currently WAIS-IV®)	60-70	Most widely used instrument. Standardised in numerous countries. Structure similar to other Wechsler scales designed for younger children and used in many follow-up programmes
Academics (performance assessment)	Wechsler Individual Achievement Test (currently WIAT-III®)	Full battery rarely administered. Individual subtests take approx. 5-10 min	Widely used instrument to assess range of academic skills. It has a wide age range (4 y to adults) enabling its use in longitudinal studies. It is used in many preterm follow-up programmes. Re-standardised in some countries
Attention	Test of Everyday Attention	45-60 (complete) 5-10/subtest	This is the adult version of the Test of Everyday Attention for Children (TEACh), which is used in numerous paediatric follow-up programmes
Memory	Wechsler Memory Scale (currently WMS-IV®)	45-60 (complete) 5-10/subtest	Widely used battery for assessing memory—auditory, visual, immediate, working, and delayed memory. It is the adult version of the Children's Memory Scale, which is often used in paediatric follow-up programmes
Executive function	Delis-Kaplan Executive Function System (currently D-KEFS®)	90 (complete) 10-15/subtest	Popular battery of measures assessing a broad range of executive skills
	BRIEF-A®		Adult version of the Behavior Rating Inventory of Executive Function, which is used extensively in child preterm follow-up programmes
Language/communication	Peabody Picture Vocabulary Test (currently PPVT-5)	10-15	Test of receptive language suitable for young children up to old age. Used extensively in child preterm follow-up programmes
Processing speed	Cogstate®	12-15 (complete) <5/subtest	Well-validated measure of information processing designed to detect subtle deficits including simple and choice reaction time. Used in research with preterm children and adults

[a]Time required at clinic. Time for data extraction and entry not included.

Education (ISCED)[44] and ILO International Standard Classification of Occupations (ISCO).[45]

Another widely used indicator is income, which is more variable with time and is often analysed in percentile ranks. Cohort outcomes in different countries may be compared using the proportion of people whose income falls below the poverty line (eg, OECD definition). In countries with strong social stratification by place of residence, area-based indices may be helpful. In low- and middle-income settings, various asset indices have been developed to indicate ownership/access to daily life items. Data on family structure, race/ethnicity, or other locally relevant social groups (eg, caste) are important; however, their interpretation is specific to the local cultural context.

Existing cohorts may have collected such information earlier; information can also be collected in retrospect from the adult study participants. For example, data on lifetime attained education of parents may be as indicative of childhood environment as information on degrees that the parents had earned before the preterm child was born. Data should be collected conforming to international classifications and for both parents. Detailed questionnaires and instructions are available from several European,[23] WHO,[24] and US[25] sources.

TABLE 5 Mental health, personality, and quality-of-life measures

Domain	Measure	Time required (min)[a]	Rationale
Core measures			
Mental health problems	Achenbach Adult Self Report (ASR), 180-item Adult Behavior Checklist (ABCL)[38]	30-40	The ASEBA scales offer age-appropriate, reliable screening instruments that can be administered to different informants and have been used by several VP/VLBW studies.[14] Country-specific continuous reference scores and categorical cut-off values are available
	Or *alternatively*, 25-item Strengths and Difficulties Questionnaire (SDQ), plus 8-item impact supplement[39]	10-15	The adult SDQ offers a widely used and freely accessible, shorter *alternative*; currently translated and normed in different languages and populations
Psychiatric diagnoses	Clinical diagnostic interview: Composite International Diagnostic Interview (CIDI), Structured Clinical Interview for DSM-IV (SCID); or Mini-International Neuropsychiatric Interview (MINI)	>60 (each) 30	Most reliable gold standard but costly; international consistency has been shown[69] Potentially focus on documented areas of impairment after VP/VLBW birth including assessment of anxiety, mood, and social disorders[36]
Personality	NEO-FFI (60 items)	10-15	The Neuroticism-Extraversion-Openness (NEO) scales offer reliable and valid instruments to measure five personality traits: neuroticism, extraversion, openness to experience, agreeableness, and conscientiousness. Depending on the version, the instrument also captures traits that are associated with each of the five dimensions. The self-reported NEO scales have been adapted to various cultures
	Or *alternatively*, EPQ-RS (48 items)	10-15	Eysenck Personality Questionnaires (EPQ) offer reliable and valid instruments to measure neuroticism, extraversion and psychoticism. Depending on the version, the instrument also captures traits that are associated with each of the three dimensions. The EPQ also includes an additional social desirability scale. The self-reported EPQ scales have been adapted to various cultures
Quality of life	12-item Short Form Health Survey (SF-12v2)[47]	2-3	The SF-12 is a 12-item subsample of SF-36 items yielding an 8-dimension health status profile. SF-12 data can be mapped into a 6-dimension health status classification system (SF-6D), with a health utility function yielding 1 preference-based health utility score.[48] A licence for the use of the SF-12 is available through Optum[b]
Optional measures			
ADHD symptoms	ADHD adult rating scale or WHO Adult ADHD Self-Report Scale (ASRS)	5 (each)	Widely used, allow detailed screening for ADHD subtypes
Anxiety and depressive symptoms	Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI)[70]	10-15	Widely used, symptom self-report strongly associated with clinical diagnoses,[71] may allow better differentiation of anxiety and depressive symptoms than other self-report questionnaires[72]
Autism spectrum traits	Autism spectrum quotient (AQ) or Broad Autism Phenotype Questionnaire (BAPQ)	15 10	Allow detailed screening for autism spectrum disorders and symptoms providing categorical and dimensional outcomes, and good psychometric properties, used by other VP/VLBW studies[42]
Personality	NEO-PI (180 items)	30-40	For description of the NEO and EPQ personality scales, see core measures
	NEO-PI-R (240 items)	45-60	
	NEO-PI-3 (240 items)	45-60	
	EPQ-R (100 items)	20-30	

(Continues)

TABLE 5 (Continued)

Domain	Measure	Time required (min)[a]	Rationale
Self-esteem	Rosenberg Self-Esteem Scale (http://fetzer.org/sites/default/files/images/stories/pdf/selfmeasures/Self_Measures_for_Self-Esteem_ROSENBERG_SELF-ESTEEM.pdf)	5	A 10-item scale that measures positive and negative feelings about the self
Eating disorder traits	Eating Disorder Inventory (EDI-II)	10	To assess traits related to eating disorders including body image

[a]Time required at clinic. Time for data extraction and entry not included.

[b]Website Optum: https://www.optum.com/solutions/life-sciences/answer-research/patient-insights/sf-health-surveys/sf-12v2-health-survey.html

TABLE 6 Social relationships, economic independence, and reproduction

Domain	Measure	Time required (min)[a]	Rationale
Core measures			
Life course transitions	Life course interview	10-15	Key outcomes relevant to health and well-being; adults born VP/VLBW have more challenges
Highest educational qualification and educational history	UNESCO ISCED classification[44]		
Employment history	ILO classification[45]		
Receipt of social benefits	Country-specific listing of social benefits (eg, unemployment benefit, disability benefit, housing benefit, tax credit, and child benefit)		
Independent living	Living on their own or with a partner/community housing/with parents or within parents' home/protected housing, history of living arrangements		
Romantic partnership	Ever having been in a romantic partnership, when and how long		
Sexual relationships	Ever had sexual relations including sexual intercourse; structured measure[73]	2-6	Having no experience on sexual intercourse more common.[51,52]
Sexual orientation and gender identity	Self-identification, grading ranging from exclusively heterosexual to exclusively homosexual and exclusively female to exclusively male	1	Non-heterosexual self-identification more common.[52] No data on gender identity
Peer relationships/Social support	Number of friends, reciprocity of friendships, social support by friends	3-8	
Reproductive history	Pregnancies, "time of attempting pregnancy," pregnancy outcomes, fertility treatments. Can be incorporated in life course interview; or survey questions such as the UK National Women's Health Study[74] can be used. While these questions have been designed for women, most are relevant also for men and couples	5-10	Adults born VP/VLBW start partnerships later and have less children,[50-52] but the reasons are not known
Optional measures			
Quality of partnership	Romantic Attachment[75] Dyadic Adjustment Scale[76] Conflicts Tactic Scale[77]	5-15	
Peer relationships/Social support	Ratings of closeness to parents, siblings, grandparents; number of friends, closeness to friends		

(Continues)

TABLE 6 (Continued)

Domain	Measure	Time required (min)[a]	Rationale
Sexual orientation	9-item Klein Sexual Orientation Grid[78]		Non-heterosexual self-identification more common[52]
Hyperandrogenism and polycystic ovary syndrome (PCOS) in women	History of symptoms: hirsutism, menstrual irregularity[79]	5	Significant causes of female subfertility that may have prenatal origins
	Serum androgen concentrations (eg, testosterone, sex hormone–binding globulin)	Included in blood sample	
	Ovary ultrasound to detect polycystic ovaries	30	Significant cause of female subfertility, no studies in adults born preterm.
Semen quality	Semen sample	30	Significant cause of male subfertility, no studies in adults born preterm.

[a]Time required at clinic. Time for data extraction and entry not included.

Many of the same indicators, assessed for the adult VP/VLBW individual, are relevant as social outcomes (Section 3.10). This is discussed in Section 3.10.

3.9 | Health-related quality of life

It is important to consider an individual's subjective evaluation of their health status, which refers to functional issues and limitations. Health-related quality of life (HRQoL) implies a subjective appraisal of an individual's health status, preferably by the individuals themselves. Such an appraisal is related to, but not directly determined by, health status. Behavioural (adaptation, development of alternative skills), cognitive (adaptation of standards, coping), and social factors (changes in expectations and demands by significant others, adapted homes, medical devices) are also relevant for the appraisal of functional issues faced by an individual.

Many instruments aiming to measure HRQoL have been documented. Confusingly, the concepts of health, HRQoL, and quality of life are often used interchangeably.[46] In long-term follow-up of preterms, multidimensional profile measures such as the 36-item Short Form Health Survey (SF-36) enable a comprehensive appraisal of functioning in several domains of health. Alternatively, preference-based utility measures, such as the Health Utilities Index, lead by a preference-based utility function to a single utility health score, which may be used in calculating quality-adjusted life years enabling health-economic evaluations.

Both approaches have advantages and drawbacks. Therefore, in long-term follow-up research of preterm birth, we propose to combine the two approaches by using the SF-12.[47] The SF-12 is a 12-item subsample of SF-36 items yielding an eight-dimension health status profile. In addition, SF-12 data may be directly mapped into a six-dimension health status classification system (SF-6D) that comes with a health utility function yielding a single preference-based health utility score.[48] Psychometric performance of SF-12 has been documented and validated in many language versions worldwide.

3.10 | Social relationships, economic independence, and reproduction

Differences in physical, mental, and cognitive health and childhood social experiences[49] may affect life chances such as independent living, income and social relationships with peers, partnering, and having own children.[13] Fewer women and men born VP have children compared with their peers born at term.[50] Whether this is a voluntary choice or due to the lack of a partner,[51] sexual orientation,[52] or biological fertility problems is not known. Fertility remains a substantial gap of knowledge. Moreover, women and possibly men born preterm have an increased risk of having a preterm child or other pregnancy complications themselves.[50]

We recommend a life course interview with focus on transition to adulthood and pregnancy history; depending on resources and study focus, the information may in part be collected by questionnaire. The core items are shown in Table 6.

It is also important to realise that preterm birth may have a substantial impact on the birth family. Giving preterm birth is an important predictor of at least maternal health including cardiovascular disease. Families that give birth to a preterm child have fewer subsequent children,[53] and preterm birth may have a deep lasting impact on the siblings.[54] While this paper focuses on measures in adults born preterm, researchers may wish to consider incorporating elements of follow-up of parents and siblings.

4 | CONCLUSIONS

The suggested measures are intended to help current and future researchers or clinicians involved in follow-up of adults born preterm to compile an assessment programme. Adopting these recommendations of well-tested measures will allow for consistent comparisons of outcomes across cohorts and countries, often hampered by heterogeneity of measures or missing measures on key areas of functioning.

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How to cite this article: Kajantie E, Johnson S, Heinonen K, et al.; APIC Adults Born Preterm International Collaboration. Common Core Assessments in follow-up studies of adults born preterm—Recommendation of the Adults Born Preterm International Collaboration. *Paediatr Perinat Epidemiol*. 2021;35:371–387. https://doi.org/10.1111/ppe.12694

APPENDIX 1

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These expert authors have written the first draft of each specific outcome domain, after which the recommendation has been revised with input from all authors and other contributors listed under the APIC Adults Born Preterm International Collaboration. After Eero Kajantie as the first author, authorship order of the manuscript has been randomised.