Health-Related Quality of Life from Adolescence to Adulthood Following Extremely Preterm Birth

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Abbreviations

ELBW: extremely low birth weight

VLBW: very low birth weight

HRQL: health-related quality of life

HUI3: Health Utilities Index Mark 3

MAU: multi-attribute utility

SAU: single attribute utility

IQR, interquartile range

Objective To examine self-reported and parent-reported health-related quality of life (HRQL) in adults born extremely preterm compared with term-born controls and to evaluate trajectories of health status from adolescence to early adulthood.

Study design The EPICure study comprises all births <26 weeks of gestation in the United Kingdom (UK) and Ireland in 1995 and term-born controls recruited at age 6. 129 participants born extremely preterm and 65 controls were followed up at the 19-year assessment. HRQL was measured by the Health Utilities Index Mark 3 (HUI3) multi-attribute utility (MAU) scores. Only parent-reported HRQL was available at 11 years of age.

Results Participants born extremely preterm without neurodevelopmental impairment had significantly lower MAU scores at 19 years than controls (median [interquartile range]: 0.91 [0.79, 0.97] vs 0.97 [0.87, 1.00], p=0.008); those with impairment had the lowest scores (0.74 [0.49, 0.90]). A 0.03-0.05 difference is considered clinically significant. Parent-reported findings were similar. Participants born extremely preterm with impairment rated their health significantly better than their parents (0.74 vs 0.58, p=0.01), in contrast to those without impairment and controls. Between 11 and 19 years median parent-reported MAU scores decreased from 0.87 to 0.77 for participants born extremely preterm (p=0.01) and from 1.00 to 0.97 for controls (p=0.02).

Conclusions Among young adults born extremely preterm, both participants and parents rated their health status less favorably than term-born controls. The decline in MAU scores from adolescence to early adulthood following extremely preterm birth indicates continuing health issues in young adult life.

Advances in neonatal care since the 1990s have significantly improved survival rates of infants born extremely preterm (<26 weeks of gestation), but these individuals are at increased risk of a wide range of long-term cardiorespiratory, neurological, cognitive, and psychosocial problems.[1-4] The World Health Organization (WHO) defines quality of life as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns.[5] To provide a holistic picture of an individual's health-related quality of life (HRQL), measures have been developed to assess the impact of health on an individual's overall psychological, social, and physical well-being. One such measure is the Health Utilities Index Mark 3 (HUI3) that covers eight basic attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition, and pain.[6-9] Function within each attribute is graded on a 5- or 6-point scale corresponding to the level of severity, ranging from normal function (level 1) to severe impairment (levels 5-6).[8] The impact of these levels of impairment is rated by community participants (Canadian citizens in the case of the HUI 3 norms) as ranging from "rather be dead" to "perfect health". A published utility algorithm synthesizes all attribute responses into an overall multi-attribute utility (MAU) score ranging from -0.36 (worse than death) through 0.00 (dead) to 1.00 (perfect health).[8] The HUI3 has been shown to be reliable, responsive, and valid,[6] and has been used in EP populations.[10-12]

Evidence is limited regarding preference-based HRQL among adults born extremely preterm compared with term-born controls.[13, 14] We aimed to examine HRQL differences between these two groups at 19 years of age using both self-reports and parent-reports, and to investigate the correspondence between self and parent reports and HRQL trajectories from adolescence to early adulthood. We hypothesized that adults born extremely preterm would have significantly lower MAU scores than controls and that there would be no improvement in the HRQL trajectory for participants born extremely preterm over time.

Methods

Participants: The EPICure study comprises all births at <26 weeks of gestation in all 276 maternity units in the United Kingdom (UK) and Ireland between March and December 1995. Of 812 infants admitted to neonatal intensive care units, 315 survived to discharge and were followed longitudinally at ages 2.5, 6, 11, and 19 years. Recruitment and participation in each phase have been described in detail previously.[15-18] Nine deaths occurred between discharge and the 19-year assessment. Of 306 eligible participants born extremely preterm, 129 (42%) were assessed at 19 years of age. To provide a reference group, 160 children born at ≥37 weeks of gestation were recruited at 6 years of age. Among these, 110 were reassessed at 11 years of age and 43 new controls were identified. At age 19, 65/153 (42%) were reassessed. Participants born extremely preterm and controls not assessed at 19 years had either declined participation or did not respond to study invitations. A flow chart detailing dropout and recruitment of controls is presented in Figure I (available at www.jpeds.com).

Procedure: Participants were invited to attend an assessment at University College London Hospital conducted by a psychologist and a clinician over two consecutive days. Eleven participants were assessed at home where travel was limited by disability or prior commitments. Written informed consent was obtained for all participants. For those with severe intellectual impairment, consent was provided by a parent/guardian. The study was approved by the South Central Hampshire A Research Ethics Committee (Reference: 13/SC/0514).

Measures: HRQL was assessed at 11 and 19 years of age by parent report using the 15-item HUI questionnaire. At the 19-year follow-up, participants also completed this questionnaire. Responses were mapped onto the HUI3 health status classification system. An overall MAU score for each participant was calculated using a published utility algorithm based on

preferences of a randomly selected general population sample of Canadian adults[19] to allow direct comparison with other studies in the field. Thus, MAU in this study indicate adolescents' and young adults' health status and HRQL based on societal standards. A score difference of 0.03-0.05 is considered clinically significant.[6] Attributes were also converted into single attribute utility (SAU) scores ranging from 0.00 (worst level of function) to 1.00 (best level of function), providing insight into a person's HRQL in each specific area. Utilities were categorized into four levels of disability to evaluate stability from 11 to 19 years (no disability 1.00; mild disability 0.89-0.99; moderate 0.70-0.88; severe <0.70),[8] and a three-category variable was then computed (worsening, stable, or improving). Additionally, function within each attribute was recorded as suboptimal if any level of functional impairment (level 2 or above) was reported.[20, 21] The number of single attributes that were suboptimal was then calculated.

Neurodevelopmental impairment was determined at 11 years.[16] It was defined as ≥ 1 of the following: cognitive impairment (classified as a score >2 standard deviations below the mean of controls using the Kaufman-Assessment Battery for Children), visual impairment/blindness, hearing loss with aids/profound hearing loss, or moderate/severe neuromotor impairment (the Gross Motor Function Classification System or the Manual Abilities Classification System levels 3-5).[16] Missing values were imputed using data from previous assessments (n=8).[17, 18]

Demographic and perinatal variables included participant sex assigned at birth (male versus female), age at assessment, birth weight (grams), gestational weeks, and maternal education. Maternal education was collected at 11 years using parent questionnaires and classified using the International Standard Classification of Education (ISCED): (1) low level: equivalent to ISCED 0 to 2; (2) Medium: ISCED 3 to 5; (3) High: ISCED 6 to 10. Missing values were imputed using data collected previously.

Statistical Analyses. Analyses were performed in STATA 15.1. Group scores (participants born extremely preterm with impairment, participants born extremely preterm without impairment, and controls) were compared using the Kruskal-Wallis H test as the scores were not normally distributed. Median and interquartile range (IQR) were reported. Non-parametric pairwise comparisons were examined using Dunn's test when a Kruskal-Wallis test was rejected.[22] Differences between participants born extremely preterm and controls in the number of suboptimal attributes and HRQL stability over time were investigated using Wilcoxon rank-sum tests. Differences between self-reports and parent-reports and changes in HRQL from adolescence into early adulthood were examined using Wilcoxon matched-pairs signed-ranks tests. We applied multiple imputations to adjust for missing data and selective attrition.[23] Missing data were imputed by chained equations using the STATA "MI" procedure. Imputation model variables included both those potentially predicting non-response and/or MAU scores in participants born extremely preterm. Percentages of values missing for each variable and models used to predict missing data are shown in Table I (online). Missing data in HUI3 were handled at the item score level.[24, 25] MAU scores were calculated using imputed HUI attributes. Imputation models were based on the missing at random assumption and twenty imputed datasets.[26, 27] Original and imputed results were overall similar (Table II; online), so we only report the original results.

Results

Participant characteristics: There were no significant differences in age, sex, and maternal education between EP and control groups. Participants born extremely preterm had significantly higher rates of cognitive, motor, and visual impairment at 11 years than controls (Table III). Compared with the non-assessed participants born extremely preterm at 19 years (n=177), those assessed (n=129) had lower rates of cognitive impairment and intellectual disability, and higher developmental/intelligence test scores at previous assessments, but they

were representative of the original cohort in terms of sex, gestational age, birth weight, maternal education and overall neurodevelopmental impairment (Table IV online); there was no significant difference in MAU scores at 11 years between those assessed and not assessed at age 19. For controls, those assessed at 19 years had mothers with higher educational levels than those not assessed; there were no significant differences in cognitive test scores and MAU scores at 11 years.

Self-report HUI3 data were available for 117 participants born extremely preterm and 62 controls at 19 years of age. Reasons for non-completion included intellectual disability or non-participation. We did not collect proxy informant-reports for those unable to complete the HUI3 due to impairment. Parent-report data were available for 118 participants born extremely preterm and 55 controls. Of the self-reports, MAU data were missing for 7 participants born extremely preterm due to missing values in one or more of the eight attributes required to compute the score. Similarly, among parent-reports, MAU data were missing for four participants born extremely preterm and two controls. Therefore, at 19 year-assessment, self-report MAU scores were available for 110 participants born extremely preterm and 62 controls, whereas parent-report scores were available for 114 participants born extremely preterm and 53 controls.

HRQL at 19 years of age: Participants born extremely preterm without neurodevelopmental impairment reported significantly lower MAU scores at 19 years compared with controls (median [IQR] 0.91 [0.79, 0.97] vs 0.97 [0.87, 1.00], p=0.008); those with impairment reported the lowest scores (median 0.74 [0.49, 0.90]; in comparison with controls or adults born extremely preterm without impairment, both p<0.001). Similar results were found when using parent-report (Table V). Sex and maternal education were unrelated to MAU scores (Table VI and VII online). Compared with controls, participants born extremely preterm with impairment had significantly lower SAU scores in speech, ambulation, dexterity, cognition,

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and pain, whereas those without impairment reported only differences in speech and cognition (Table V). On parent-report, participants born extremely preterm with impairment had lower SAU in speech, ambulation, dexterity, emotion, cognition, and pain compared with controls; parent-report differences for participants born extremely preterm without impairment were only found in emotion and cognition. Both self-reports and parent-reports showed that participants born extremely preterm had more suboptimal attributes than controls (both $p<0.001$; Figure II); they also had significantly higher proportions of moderate disability (defined as an MAU score 0.70-0.88; EP vs controls: self-report 27% vs 19%; parent-report 27% vs 11%) and severe disability (MAU score <0.70; EP vs controls: self-report 26% vs 6%; parent-report 40% vs 6%) as defined by HUI3 (both $p<0.001$).

Comparing parent-reports and self-reports: Among 43 participants born extremely preterm with impairments who had both parent-reported and self-reported MAU scores, parents reported significantly lower scores than participants themselves did at 19 years of age ($p=0.01$; Table V); differences were found in ambulation, dexterity, emotion, and cognition compared with self-report (Table V), whereas no differences were found in vision, hearing, speech, and pain. Compared with self-report, parents of adults born extremely preterm with impairments also reported more suboptimal attributes for their children at 19 years of age ($p=0.04$; Figure II) and higher proportions of severe HUI3 disability ($p=0.006$; Table VIII online). Differences in MAU scores, the number of suboptimal attributes, and HUI3 disability between parent and self-reports were not found for participants born extremely preterm without impairment and controls.

Changes in HRQL over time: MAU scores using parent reports at both 11 and 19 years of age were available for 95 participants born extremely preterm and 49 controls. Participants born extremely preterm and controls had similar stability, as measured by changes in HUI3 disability from 11 to 19 years (EP: stable 46%, improved 20%; controls: stable 45%,

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improved 12%; p=0.21). From 11 to 19 years of age, median MAU scores decreased from 0.87 to 0.77 for participants born extremely preterm (p=0.01) and from 1.00 to 0.97 for controls (p=0.02), driven by decreases in vision, emotion, and pain (Table IX online); with similar findings among participants born extremely preterm with impairment (0.72 to 0.55; Figure III).

Discussion

In this longitudinal study following births before 26 weeks of gestation, participants born extremely preterm with and without neurodevelopmental impairment had poorer MAU scores in early adulthood compared with controls, using both self-reports and parent-reports. Participants born extremely preterm with impairment rated their HRQL higher than their parents, in contrast to controls and those without impairment in whom similar results were observed. Furthermore, across adolescence, we observed a decline in MAU scores, which was greatest for those with impairment. The findings are in line with our hypotheses. Differences between participants born extremely preterm with impairment and controls were driven by deficits in almost all areas of functioning. This was anticipated from the findings on clinical assessment and the known pervasive multidomain effects of extremely preterm birth. For participants born extremely preterm without impairment, the clearest difference was in cognition, the most frequent domain affected by preterm birth. This was reported by both participants and their parents. Participants born extremely preterm further rated their speech to have lower single attribute utility. Quality of speech is less frequently assessed than other areas of functioning in preterm children's follow-up[28] but was considered important for HRQL by participants born extremely preterm.

Studies in more mature populations have inconsistent findings.[10, 29-31] Saigal and colleagues[11] followed an extremely low birth weight cohort (mean gestational age 26-27

weeks) in early adolescence (12-16y), young adulthood (22-26y), and as adults at 29-36 years, with similar findings to ours using the same reference range. Participants born extremely preterm without impairment showed stable MAU scores over adolescence and young adulthood (mean 0.83 at each age) with a decline to 0.77 as adults. Those with impairments declined from 0.68 through 0.65 to 0.60 as adults. Controls remained relatively stable from 0.88 to 0.85. In contrast, an Australian cohort reported similar MAU scores in participants born preterm (mean gestational age 26.6 weeks) and controls at 18 years (0.93 versus 0.95).[10] This study was biased towards the inclusion of fewer individuals with impairment (9% versus 33% among non-responders). Three smaller studies (31-52 participants) from Sweden and Norway (mean gestational age 26.7-27.4 weeks) using different instruments (Child Health Questionnaire, Short Form Health Survey-36, Visual Analogue Scale), showed similar findings.[29-31] It is suggested that HUI is a more sensitive measure of HRQL than other instruments in populations born preterm.[14]

Large very low birth weight (VLBW) population studies from Germany and the Netherlands showed low MAU scores compared with controls[32] or population norms[33, 34] but mean scores were higher than in this study. MAU scores appear lower in less mature populations, which mirrors the increasing frequency of neurosensory impairment and lower cognitive scores in such populations.

Adults born extremely preterm with impairment rated their HRQL higher than did their parents, consistent with the German study of VLBW adults.[32] One interpretation is that parents may compare their child to all peers of the same age,[14, 20, 35] whereas adults born extremely preterm may compare themselves with their immediate peers who are at the same education or occupational level. Parents' views may also be influenced by the burden of care-giving, and their own well-being and concerns.[36] Conversely, individuals born preterm who have impairments may find satisfaction in overcoming their challenges while growing up and

have different perceptions of their health and life in ways that external observers (i.e. parents) may not understand.[37] Similarly to previous findings,[14, 20, 36] differences between parent and self-report were mainly found in psychological domains (i.e. emotion and cognition), whereas few differences were found in observable and physical domains (i.e. vision, hearing, and speech).

MAU scores for individuals born extremely preterm decreased substantially from adolescence to adulthood in parent reports, implying clinical relevance and corroborating findings from adults born very preterm or VLBW in Germany.[32] Studies using self-reported HUI scores tend to show no change in MAU.[11, 32, 33, 38] A distinctly low trajectory was observed in participants born extremely preterm with impairment, similar to findings in the Canadian study.[11] Lower ratings were driven primarily by changes in vision, emotion, and pain domains in our study. These changes may be due to increasing challenges experienced in the transition to adulthood such as career/study decisions, living independently, or finding a partner.[33] Low MAU scores in adults born very preterm or VLBW are strongly related to economic and social functioning problems, such as unemployment, receiving social benefits, having few friends, and decreased likelihood of dating a romantic partner.[32] Notably, we show a greater decrease in parent-reported MAU scores from adolescence to adulthood compared with the German study. Although this might be due to differences in compensating social or cultural factors, participants born extremely preterm, especially those with impairment, may be more vulnerable when entering adulthood.

This study has several strengths, including a long-term follow-up of a population-based cohort of infants born <26 weeks of gestation in 1995, the recruitment of a comparison group, the comparison between self- and parent-reported HQRL at 19 years, the use of multiple imputation as a sensitivity analysis to account for selective dropouts and missing

data, and stratified analyses to demonstrate the effect of neurocognitive impairment on HRQL.

A major limitation of this study was that only 42% of the eligible participants born extremely preterm were evaluated at 19 years of age and dropout was associated with childhood cognitive impairment. Neither did we collect proxy ratings for participants born extremely preterm who were too impaired to report. The use of proxy reports is challenging, as previous research and our results indicate that parents tend to underestimate their children's HRQL.[14, 32, 36] Importantly, multiple imputation corroborated the main results. A further limitation was that controls were recruited only from mainstream schools and they might be slightly healthier than the general population. Thus, group differences found may have been overestimated. However, this impact is considered minimal, as most children with special educational needs in the UK are integrated into mainstream schools and only 1% of children are placed in special schools.[39] Consequently the inclusion of classmates for participants born extremely preterm attending special schools would inappropriately bias the comparison group. It might be argued that our controls seemed to have a relatively high HUI3 score (mean 0.92) compared with a previous British study (1983-1984 births; 0.89) and studies in Canada (1977-1982 births; 0.89) and Germany (1985-1986 births; 0.89). This might be due to social changes in the previous decade. A third limitation was that we did not have self-reported HRQL data to assess trajectories as HRQL was not assessed during adolescence via self-report. Finally, HUI3 is an indirect measure of HRQL reflecting community preferences. We used Canadian norms to allow us to compare results between this study and results from other countries and it is possible that using UK-based norms from the HUI2 classification system[40] would alter these findings. HUI2 MAU scores are systematically higher than HUI3 scores.[7] A replication using the direct standard gamble

technique reflecting individual preferences may be required. Mean standard gamble scores tend to be higher than mean HUI3 MAU scores.[7, 11, 41]

In summary, individuals born extremely preterm had lower MAU scores in early adulthood, indicating less optimal HRQL compared with typically developing individuals born at term, which were lower still in those with neurodevelopmental impairment. They appeared to decline from adolescence to early adulthood, particularly in the domains of vision, emotion, and pain. It is clear that even those without recognized impairments may have health-related issues following extremely preterm birth that continue to exert important effects on quality of life in early adulthood. Medical services need to be aware of the challenges faced in adaptation to adult life and to recognize that ongoing support may be needed to successfully bridge this critical stage in development. Further investigation is required to evaluate the reasons for this observed decline in criterion-referenced MAU scores. Interventions are also needed to improve HRQL in future generations given recent evidence suggesting worsening HRQL in children born extremely preterm across eras.[42] An early intervention program in the neonatal period with a focus on enhancing parents' understanding of their child's expressions and promoting sensitive and positive parent-child interactions may have long-lasting positive effects on HRQL in children born preterm in middle childhood, as suggested by a randomized clinical trial in Norway.[43]

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Figure Legends:

Figure I (available online). Flowchart of participants born extremely preterm and term-born controls in the EPICure Study

Figure II. The number of HUI3 single attributes that were suboptimal for EP and control participants at 19 years of age

Figure III. Trajectories of MAU scores for participants born extremely preterm and controls from adolescence to young adulthood using parent reports

Figure I. Flowchart of participants born extremely preterm and term-born controls in the EPICure Study
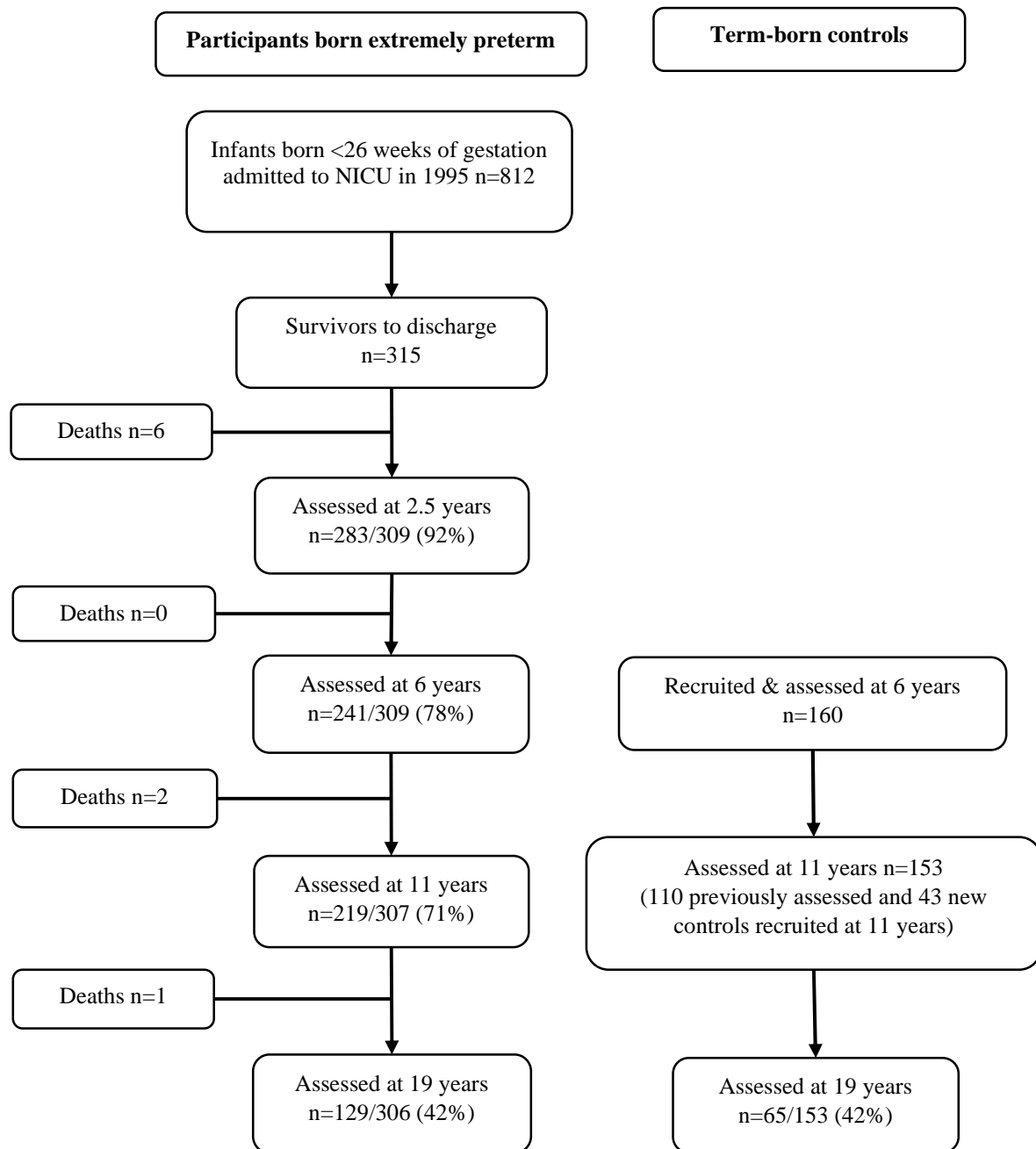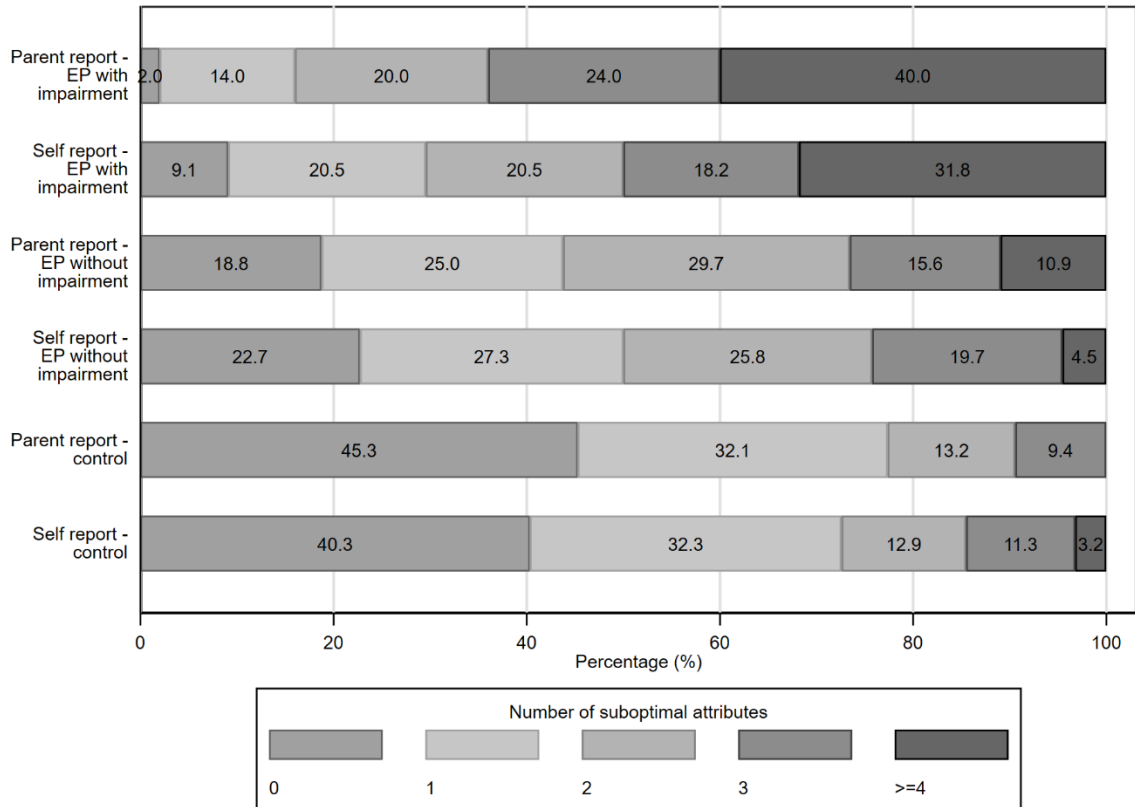
Differences in the numbers of single attributes that were suboptimal between groups were examined using Wilcoxon rank sum tests. The difference in the numbers of single attributes that were suboptimal between parent- and self- reports was examined using Wilcoxon matched-pairs signed-ranks tests. Parent-reports: EP (n=114) vs controls (n=53), $p<0.001$. Self-reports: EP (n=110) vs controls (n=62), $p<0.001$. Parent- vs self-reports for EP participants with impairment (n=43), $p=0.04$. Parent- vs self-reports for EP participants without impairment (n=59), $p=0.22$. Parent- vs self-reports for controls (n=53), $p=0.92$.
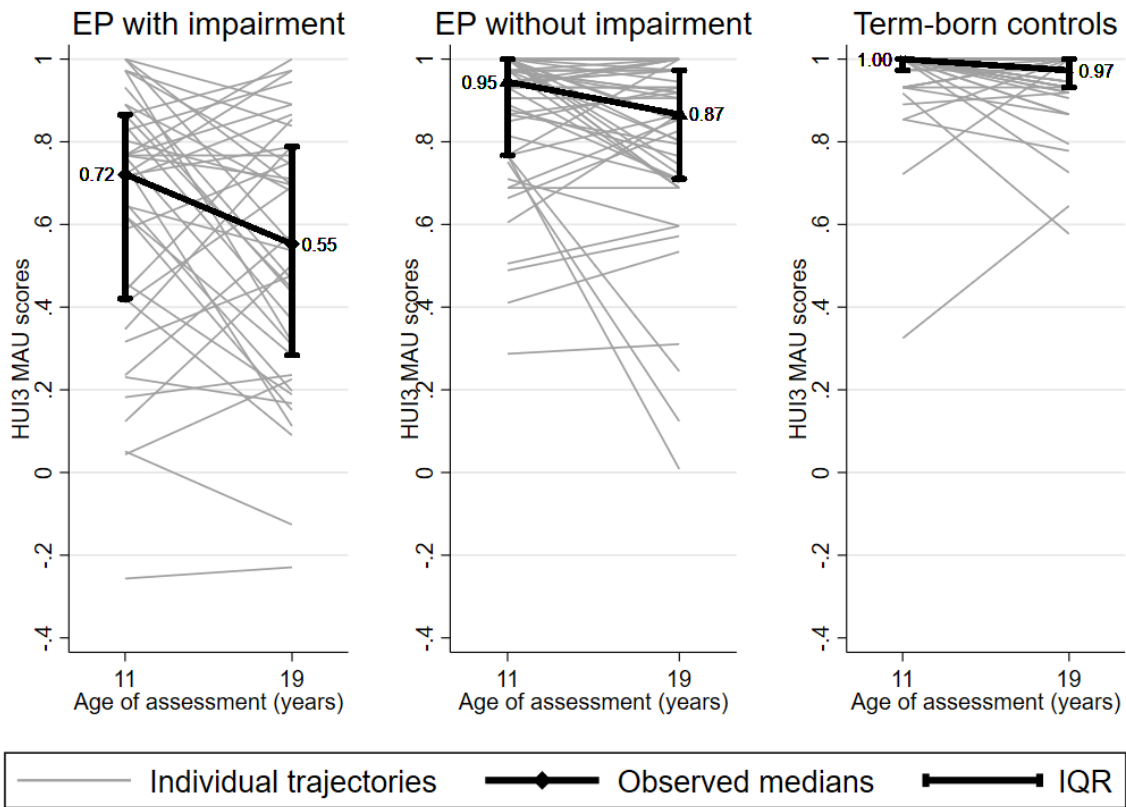
Data are shown for participants assessed at both ages. Change from 11 to 19 years was tested using Wilcoxon matched-pairs signed-ranks tests: $p=0.013$ for EP participants (n=95); $p=0.070$ for EP with impairment (n=41); $p=0.061$ for EP without impairment (n=54); $p=0.018$ term-born controls (n=49).

Table I. Variables used for multiple imputations, type of variable, model used to predict missing data, and percentages of values missing for each variable included in the imputation model

Variable	Type of variable	Model used to predict missing data	Percentages of values missing[Π]	Percentages of values missing[Ŧ]
Birth weight	Continuous	No missing data	0%	0%
Gestational age	Continuous	No missing data	0%	0%
White ethnicity	Binary	No missing data	0%	0%
Sex	Binary	No missing data	0%	0%
Neurodevelopment impairment at 2.5y	Binary	Binary logistic regression	8.5% (26/307)	2.7% (6/219)
Neurodevelopment impairment at 6y	Binary	Binary logistic regression	21.8% (67/307)	7.8% (17/219)
Neurodevelopment impairment at 11y	Binary	Binary logistic regression	28.7% (88/307)	0%
Maternal education	Three-category	Ordinal logistic regression	9.8% (30/307)	3.2% (7/219)
Maternal age at delivery	Continuous	Linear regression	0.7% (2/307)	0.9% (2/219)
Parent-reported HUI attributes at 11y				
Vision	Continuous	Linear regression	38.8% (119/307)	14.2% (31/219)
Hearing	Continuous	Linear regression	39.7% (122/307)	15.5% (34/219)
Speech	Continuous	Linear regression	39.1% (120/307)	14.6% (32/219)
Ambulation	Continuous	Linear regression	38.8% (119/307)	14.2% (31/219)
Dexterity	Continuous	Linear regression	38.8% (119/307)	14.2% (31/219)
Emotion	Continuous	Linear regression	38.4% (118/307)	13.7% (30/219)
Cognition	Continuous	Linear regression	38.8% (119/307)	14.2% (31/219)
Pain	Continuous	Linear regression	38.8% (119/307)	14.2% (31/219)
Parent-reported HUI attributes at 19y				
Vision	Continuous	Linear regression	62.2% (191/307)	50.2% (110/219)
Hearing	Continuous	Linear regression	61.6% (189/307)	49.3% (108/219)
Speech	Continuous	Linear regression	62.2% (191/307)	50.2% (110/219)
Ambulation	Continuous	Linear regression	61.6% (189/307)	49.3% (108/219)
Dexterity	Continuous	Linear regression	61.6% (189/307)	49.3% (108/219)
Emotion	Continuous	Linear regression	61.6% (189/307)	49.3% (108/219)
Cognition	Continuous	Linear regression	61.9% (190/307)	49.8% (109/219)
Pain	Continuous	Linear regression	61.6% (189/307)	49.3% (108/219)
Self-reported HUI attributes at 19y				
Vision	Continuous	Linear regression	61.9% (190/307)	50.2% (110/219)
Hearing	Continuous	Linear regression	61.9% (190/307)	50.2% (110/219)
Speech	Continuous	Linear regression	63.8% (196/307)	52.5% (115/219)
Ambulation	Continuous	Linear regression	61.9% (190/307)	50.2% (110/219)
Dexterity	Continuous	Linear regression	61.9% (190/307)	50.2% (110/219)
Emotion	Continuous	Linear regression	62.2% (191/307)	50.7% (111/219)
Cognition	Continuous	Linear regression	61.9% (190/307)	50.2% (110/219)
Pain	Continuous	Linear regression	62.2% (191/307)	50.7% (111/219)

All variables were included in the linear predictor of all imputation models. MAU scores were calculated using imputed HUI attributes. [Π]Impute missing values for all survivors up to 11 years (N=307). [Ŧ]Impute missing values for children born extremely preterm assessed at 11 years (N=219).

Table II. MAU scores for participants born extremely preterm at 11 and 19 years of age: a comparison of original and imputed results

Variables	Original		Imputed[I]		Imputed[T]	
	11y	**19y**	**11y**	**19y**	**11y**	**19y**
Parent-report	Mean (SD)	Mean (SD)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)	Mean (95% CI)
MAU score	0.79 (0.26) [n=176]	0.68 (0.30) [n=114]	0.74 (0.69, 0.79)	0.66 (0.60,0.72)	0.75 (0.71, 0.79)	0.67 (0.60, 0.75)
Self-report						
MAU score	-	0.77 (0.25) [n=110]	-	0.78 (0.70,0.85)	-	0.78 (0.68, 0.88)

[I]Impute missing values for all survivors up to 11 years (N=307). [T]Impute missing values for children born extremely preterm assessed at 11 years (N=219).

Table III. Characteristics of participants born extremely preterm and controls born at full term at 19 years of age

Variables		EP (N=129)	EP with impairment[¶] (N=52)	EP without impairment[¶] (N=77)	Controls (N=65)	EP vs Controls *p*[Π]
Age at assessment (years)	Mean (SD)	19.3 (0.5) [n=129]	19.2 (0.5) [n=52]	19.4 (0.6) [n=77]	19.2 (0.5) [n=65]	0.162
Male Sex	% (n)	47.3% (61/129)	57.7% (30/52)	40.3% (31/77)	38.5% (25/65)	0.243
Birth weight (g)	Mean (SD)	740.8 (121.9) [n=129]	719.5 (117.2) [n=52]	755.1 (123.7) [n=77]	-	-
Birth weight z-score	Mean (SD)	-0.2 (0.8) [n=126]	-0.3 (0.8) [n=51]	-0.1 (0.7) [n=75]	-	-
Gestational age	Mean (SD)	24.9 (0.8) [n=129]	24.8 (0.8) [n=52]	25.0 (0.8) [n=77]	-	-
<=23 weeks	% (n)	11.6% (15/129)	13.5% (7/52)	10.4% (8/77)	-	-
24 weeks	% (n)	28.7% (37/129)	34.6% (18/52)	24.7% (19/77)	-	
25 weeks	% (n)	59.7% (77/129)	51.9% (27/52)	64.9% (50/77)	-	
Neurodevelopmental impairment at 11 years						
Cognitive impairment[§]	% (n)	34.7% (42/121)	84.0% (42/50)	0.0% (0/71)	0.0% (0/65)	<0.001
Moderate or severe neuromotor impairment	% (n)	9.1% (11/121)	22.0% (11/50)	0.0% (0/71)	0.0% (0/65)	0.009
Visual impairment or blindness	% (n)	7.4% (9/121)	18.0% (9/50)	0.0% (0/71)	0.0% (0/65)	0.028
Hearing loss with aids or profound hearing loss	% (n)	0.8% (1/121)	2.0% (1/50)	0.0% (0/71)	0.0% (0/65)	1.000
Maternal education[¶]						
Low level	% (n)	12.5% (16/128)	19.6% (10/51)	7.8% (6/77)	4.8% (3/63)	0.089
Medium level	% (n)	75.8% (97/128)	78.4% (40/51)	74.0% (57/77)	74.6% (47/63)	
High level	% (n)	11.7% (15/128)	2.0% (1/51)	18.2% (14/77)	20.6% (13/63)	
Number of participants with HUI3 data at 19 years						
Participants with parent-reported HUI3 data	% (n)	91.5% (118/129)	100.0% (52/52)	85.7% (66/77)	84.6% (55/65)	-
Participants with self-reported HUI3 data	% (n)	90.7% (117/129)	90.4% (47/52)	90.9% (70/77)	95.4% (62/65)	-
Participants with parent-reported HUI3 MAU scores [µ]	% (n)	88.4% (114/129)	96.2% (50/52)	83.1% (64/77)	81.5% (53/65)	-
Participants with self-reported HUI3 MAU scores [µ]	% (n)	85.3% (110/129)	84.6% (44/52)	85.7% (66/77)	95.4% (62/65)	-
Participants with both self-reported **AND** parent-reported HUI3 MAU scores	% (n)	79.1% (102/129)	82.7% (43/52)	76.6% (59/77)	81.5% (53/65)	-
Participants with self-reported **OR** parent-reported HUI3 MAU scores	% (n)	94.6% (122/129)	98.1% (51/52)	92.2% (71/77)	95.4% (62/65)	-

[Π] Two-sided p-values from the chi-squared test or Fisher's exact test for categorical variables and t-test for continuous variables.
[¶] Neurodevelopmental impairment was determined in childhood at 11 years, defined as one or more of cognitive impairment[§], visual impairment/blindness, hearing loss with aids/profound hearing loss, or moderate/severe neuromotor impairment (levels 3-5). Neuromotor function was rated using the Gross Motor Function Classification System (GMFCS) and the Manual Abilities Classification System (MACS). Missing values in disability were imputed using disability data from previous assessments (n=8).
[§] Cognitive ability at 11 years was assessed by using the Kaufman-Assessment Battery for Children (K-ABC). Cognitive impairment was classified as a score more than 2 standard deviations below the mean score of the term-born controls. [¶] Maternal education was collected at 11 years using parent questionnaires and classified using the International Standard Classification of Education (ISCED): (1) low level: equivalent to ISCED 0 to 2; (2) Medium level: equivalent to ISCED 3 to 5; (3) High level: equivalent to ISCED 6 to 10.

Missing values were imputed using data collected at previous assessments. ᵘ Missing MAU scores were due to missing values in one or more of the HUI3 eight attributes required to compute the score.

Table IV. Sample characteristics of participants born extremely preterm and controls assessed and not assessed at 19 years of age [a]

Variable		EP assessed N=129 [a]	EP not assessed N=177 [b]	[a] vs [b] p-value [b]	Controls assessed N=65 [c]	Controls not assessed N=88 [d]	[c] vs [d] p-value [b]
Birth characteristics							
Male Sex	n/N (%)	61/129 (47.3)	87/177 (49.2)	0.747	25/65(38.5)	39/88(44.3)	0.440
Birth weight, grams	Mean (SD)	740.8 (121.9) [n=129]	751.4 (108.9) [n=177]	0.422	-	-	-
Birth weight z-score	Mean (SD)	-0.2 (0.8) [n=126]	-0.2 (0.8) [n=177]	0.476			
Gestational age, decimal weeks	Mean (SD)	24.9 (0.8) [n=129]	25.0 (0.6) [n=177]	0.795	-	-	-
Gestational age, weeks							
	22 weeks, n/N (%)	2/129 (1.6)	0/177 (0.0)		-	-	
	23 weeks, n/N (%)	13/129 (10.1)	13/177 (7.3)	0.280	-	-	-
	24 weeks, n/N (%)	37/129 (28.7)	60/177 (33.9)		-	-	
	25 weeks, n/N (%)	77/129 (59.7)	104/177 (58.8)		-	-	
Outcome data at 2.5 years							
Maternal education [c]							
	Low n/N (%)	24/121 (19.8)	38/140 (27.1)		-	-	
	Intermediate n/N (%)	93/121 (76.9)	92/140 (65.7)	0.112	-	-	
	High n/N (%)	4/121 (3.3)	10/140 (7.1)		-	-	
BSID-II MDI [d]	Mean (SD)	84.0 (13.0) [n=117]	79.9 (15.1) [n=130]	0.022	-	-	-
BSID-II MDI <70	n/N (%)	15/117 (12.8)	27/130 (20.8)	0.097	-	-	-
Neurodevelopmental impairment [e]	n/N (%)	57/126 (45.2)	78/154 (50.6)	0.367	-	-	-
Outcome data at 6 years							
Maternal education [c]							
	Low n/N (%)	7/102 (6.9)	14/92 (15.2)		2/50 (4.0)	5/49 (10.2)	
	Intermediate n/N (%)	88/102 (86.3)	71/92 (77.2)	0.162	38/50 (76.0)	41/49 (83.7)	0.076
	High n/N (%)	7/102 (6.9)	7/92 (7.6)		10/50 (20.0)	3/49 (6.1)	
KABC MPC [f]	Mean (SD)	85.6 (17.3) [n=122]	79.1 (19.9) [n=117]	0.008	108.4 (11.3) [n=54]	106.6 (11.5) [n=56]	0.426
Intellectual disability (KABC MPC<70)	n/N (%)	16/122 (13.1)	32/117 (27.4)	0.006	0/54 (0.0)	0/56 (0.0)	-
Cognitive impairment [g]	n/N (%)	41/122 (33.6)	55/117 (47.0)	0.035	0/54 (0.0)	1/56 (1.8)	1.000
Neurodevelopmental impairment [h]	n/N (%)	44/122 (36.1)	56/117 (47.9)	0.065	0/54 (0.0)	1/56 (1.8)	0.324
Outcome data at 11 years							
Maternal education [c]							
	Low n/N (%)	8/107 (7.5%)	10/68 (14.7%)		2/56 (3.6%)	13/80 (16.3%)	
	Intermediate n/N (%)	85/107 (79.4%)	54/68 (79.4%)	0.122	43/56 (76.8%)	55/80 (68.8%)	0.063
	High n/N (%)	14/107 (13.1%)	4/68 (5.9%)		11/56 (19.6%)	12/80 (15.0%)	
KABC MPC [f]	Mean (SD)	86.3 (16.2) [n=121]	80.8 (19.3) [n=95]	0.028	105.7 (11.2) [n=65]	102.9 (10.9) [n=88]	0.111
Intellectual Disability (KABC MPC<70)	n/N (%)	10/121 (8.3)	19/95 (20.0)	0.012	0/65 (0.0)	0/88 (0.0)	-
Cognitive impairment [g]	n/N (%)	42/121 (34.7)	44/97 (45.4)	0.110	0/65 (0.0)	2/88 (2.3)	0.508
Neurodevelopmental impairment [h]	n/N (%)	50/121 (41.3)	47/97 (48.5)	0.292	0/65 (0.0)	2/88 (2.3)	0.508
HUI3 MAU scores at 11 years [i]	Mean (SD)	0.77 (0.26) [n=106]	0.82 (0.25) [n=69]	0.237	0.95 (0.12) [n=60]	0.96 (0.09) [n=81]	0.571

[a] Denominators: N=306 survivors born extremely preterm at 19 years; N=153 controls assessed at 11 years.

[b] Two-sided p-values were calculated using x^2 test for categorical variables and t-test for continuous variables.

[c] Maternal education was collected using parent questionnaires and classified using the International Standard Classification of Education (ISCED): (1) low level: equivalent to ISCED 0 to 2; (2) Medium level: equivalent to ISCED 3 to 5; (3) High level: equivalent to ISCED 6 to 10.

[d] BSID-II MDI, the Bayley Scales of Infant Development, 2nd edition, Mental Development Index.

[e] Neurodevelopmental impairment classified as one or more of cognitive, vision, motor or hearing impairment; cognitive impairment BSID-II MDI <70.

[f] KABC MPC, the Kaufman-Assessment Battery for Children 1st Edition, Mental Processing Composite.

[g] Cognitive impairment classified as a score more than 2 SD below the mean score of the term-born controls.

[h] Neurodevelopmental impairment classified as one or more of cognitive [g], vision, motor or hearing impairment.

[i] HUI3, the Health Utilities Index Mark 3; MAU, multi-attribute utility.

Table V. HRQL in young adulthood between participants born extremely preterm and controls using self- and parent- reports: HUI3 MAU and SAU scores at 19 years of age

	EP with impairment [a]		EP without impairment [b]		All EP [c]		Controls [d]		Kruskal-Wallis H test[]	Pairwise Comparison[]			Self vs parent reports[1]			
										[a] vs [d]	[b] vs [d]	[a] vs [b]	[c]	[a]	[b]	[d]
Self-report	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	p	p	p	p	p	p	p	p
MAU score	0.67 (0.27) [n=44]	0.74 (0.49, 0.90)	0.84 (0.20) [n=66]	0.91 (0.79, 0.97)	0.77 (0.25) [n=110]	0.85 (0.69, 0.97)	0.92 (0.12) [n=62]	0.97 (0.87, 1.00)	<0.001	<0.001	0.008	<0.001	0.003	0.013	0.109	0.788
SAU scores																
Vision	0.95 (0.12) [n=47]	1.00 (0.95, 1.00)	0.98 (0.04) [n=70]	1.00 (0.95, 1.00)	0.97 (0.08) [n=117]	1.00 (0.95, 1.00)	0.99 (0.02) [n=62]	1.00 (0.95, 1.00)	0.080	-	-	-	0.053	0.680	0.014	0.564
Hearing	0.97 (0.10) [n=47]	1.00 (1.00, 1.00)	0.99 (0.07) [n=70]	1.00 (1.00, 1.00)	0.98 (0.09) [n=117]	1.00 (1.00, 1.00)	1.00 (0.04) [n=62]	1.00 (1.00, 1.00)	0.058	-	-	-	0.416	0.334	0.991	-
Speech	0.90 (0.19) [n=45]	1.00 (0.82, 1.00)	0.97 (0.08) [n=66]	1.00 (1.00, 1.00)	0.94 (0.14) [n=111]	1.00 (1.00, 1.00)	0.99 (0.03) [n=62]	1.00 (1.00, 1.00)	<0.001	<0.001	0.023	0.005	0.718	0.851	0.757	0.564
Ambulation	0.94 (0.18) [n=47]	1.00 (1.00, 1.00)	0.99 (0.03) [n=70]	1.00 (1.00, 1.00)	0.97 (0.12) [n=117]	1.00 (1.00, 1.00)	1.00 (0.00) [n=62]	1.00 (1.00, 1.00)	0.003	<0.001	0.147	0.007	0.154	0.057	0.317	-
Dexterity	0.96 (0.15) [n=47]	1.00 (1.00, 1.00)	1.00 (0.03) [n=70]	1.00 (1.00, 1.00)	0.98 (0.10) [n=117]	1.00 (1.00, 1.00)	1.00 (0.03) [n=62]	1.00 (1.00, 1.00)	0.007	0.003	0.479	0.002	0.001	0.008	0.046	-
Emotion	0.95 (0.07) [n=46]	1.00 (0.91, 1.00)	0.94 (0.13) [n=70]	1.00 (0.91, 1.00)	0.95 (0.11) [n=116]	1.00 (0.91, 1.00)	0.97 (0.05) [n=62]	1.00 (0.91, 1.00)	0.291	-	-	-	0.002	0.003	0.117	0.344
Cognition	0.84 (0.18) [n=47]	0.86 (0.70, 1.00)	0.91 (0.16) [n=70]	1.00 (0.92, 1.00)	0.88 (0.17) [n=117]	1.00 (0.86, 1.00)	0.95 (0.11) [n=62]	1.00 (1.00, 1.00)	<0.001	<0.001	0.041	<0.001	0.010	0.075	0.070	0.568
Pain	0.87 (0.22) [n=46]	1.00 (0.77, 1.00)	0.97 (0.06) [n=70]	1.00 (0.92, 1.00)	0.93 (0.15) [n=116]	1.00 (0.92, 1.00)	0.98 (0.05) [n=62]	1.00 (1.00, 1.00)	0.012	0.002	0.165	0.018	0.486	0.601	0.630	0.536
Parent-report																
MAU score	0.53 (0.33) [n=50]	0.58 (0.28, 0.79)	0.80 (0.23) [n=64]	0.86 (0.71, 0.97)	0.68 (0.30) [n=114]	0.77 (0.54, 0.93)	0.94 (0.10) [n=53]	0.97 (0.93, 1.00)	<0.001	<0.001	<0.001	<0.001	-			-
SAU scores																
Vision	0.94 (0.15) [n=51]	1.00 (0.95, 1.00)	0.98 (0.02) [n=65]	1.00 (0.95, 1.00)	0.96 (0.10) [n=116]	1.00 (0.95, 1.00)	0.99 (0.02) [n=55]	1.00 (0.95, 1.00)	0.098	-	-	-	-			-
Hearing	0.97 (0.12) [n=52]	1.00 (1.00, 1.00)	0.97 (0.14) [n=66]	1.00 (1.00, 1.00)	0.97 (0.13) [n=118]	1.00 (1.00, 1.00)	1.00 (0.00) [n=54]	1.00 (1.00, 1.00)	0.066	-	-	-	-			-
Speech	0.86 (0.23) [n=51]	1.00 (0.67, 1.00)	0.96 (0.11) [n=65]	1.00 (1.00, 1.00)	0.91 (0.18) [n=116]	1.00 (0.91, 1.00)	0.99 (0.03) [n=55]	1.00 (1.00, 1.00)	<0.001	<0.001	0.063	<0.001	-			-
Ambulation	0.86 (0.26) [n=52]	1.00 (0.83, 1.00)	1.00 (0.02) [n=66]	1.00 (1.00, 1.00)	0.94 (0.19) [n=118]	1.00 (1.00, 1.00)	1.00 (0.00) [n=55]	1.00 (1.00, 1.00)	<0.001	<0.001	0.399	<0.001	-			-
Dexterity	0.87 (0.26) [n=52]	1.00 (0.88, 1.00)	0.99 (0.04) [n=66]	1.00 (1.00, 1.00)	0.94 (0.18) [n=118]	1.00 (1.00, 1.00)	1.00 (0.04) [n=55]	1.00 (1.00, 1.00)	<0.001	<0.001	0.180	<0.001	-			-
Emotion	0.90 (0.18) [n=52]	1.00 (0.91, 1.00)	0.92 (0.15) [n=66]	0.96 (0.91, 1.00)	0.91 (0.16) [n=118]	1.00 (0.91, 1.00)	0.96 (0.08) [n=54]	1.00 (0.91, 1.00)	0.021	0.007	0.008	0.424	-			-
Cognition	0.76 (0.24) [n=51]	0.86 (0.70, 0.92)	0.87 (0.18) [n=66]	1.00 (0.70, 1.00)	0.82 (0.21) [n=117]	0.86 (0.70, 1.00)	0.97 (0.07) [n=55]	1.00 (1.00, 1.00)	<0.001	<0.001	<0.001	<0.001	-			-
Pain	0.85 (0.22) [n=52]	1.00 (0.77, 1.00)	0.97 (0.08) [n=66]	1.00 (1.00, 1.00)	0.92 (0.17) [n=118]	1.00 (0.92, 1.00)	0.98 (0.05) [n=55]	1.00 (1.00, 1.00)	<0.001	<0.001	0.239	<0.001	-			-

[] Across group differences (EP with impairment, EP without impairment, and controls) were determined using the Kruskal-Wallis H test as HUI scores were not normally distributed. Nonparametric pairwise multiple comparisons were examined using Dunn's test when a Kruskal–Wallis test was rejected. [1]p values from Wilcoxon matched-pairs signed-ranks test.

Table VI. MAU and SAU scores at 19 years of age between participants born extremely preterm and controls: by sex

	EP		Control		EP Males vs females	Controls Males vs females
	Females	**Males**	**Females**	**Males**		
Self-report	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	p^1	p^1
MAU score	0.78 (0.24) [n=59]	0.77 (0.26) [n=51]	0.91 (0.13) [n=39]	0.93 (0.10) [n=23]	0.685	0.684
SAU scores						
Vision	0.97 (0.05) [n=64]	0.96 (0.11) [n=53]	0.98 (0.02) [n=39]	0.99 (0.02) [n=23]	0.205	0.697
Hearing	0.97 (0.09) [n=64]	0.99 (0.07) [n=53]	1.00 (0.00) [n=39]	0.99 (0.06) [n=23]	0.358	0.193
Speech	0.94 (0.15) [n=60]	0.93 (0.12) [n=51]	0.99 (0.04) [n=39]	1.00 (0.00) [n=23]	0.320	0.273
Ambulation	0.98 (0.09) [n=64]	0.96 (0.15) [n=53]	1.00 (0.00) [n=39]	1.00 (0.00) [n=23]	0.326	-
Dexterity	0.99 (0.04) [n=64]	0.97 (0.14) [n=53]	0.99 (0.04) [n=39]	1.00 (0.00) [n=23]	0.154	0.443
Emotion	0.96 (0.07) [n=63]	0.93 (0.15) [n=53]	0.97 (0.06) [n=39]	0.98 (0.04) [n=23]	0.583	0.657
Cognition	0.87 (0.18) [n=64]	0.89 (0.16) [n=53]	0.96 (0.13) [n=39]	0.95 (0.09) [n=23]	0.460	0.398
Pain	0.92 (0.15) [n=63]	0.95 (0.16) [n=53]	0.97 (0.07) [n=39]	0.99 (0.02) [n=23]	0.213	0.139
Parent-report						
MAU score	0.71 (0.29) [n=62]	0.65 (0.32) [n=52]	0.95 (0.08) [n=34]	0.90 (0.14) [n=19]	0.259	0.539
SAU scores						
Vision	0.97 (0.08) [n=62]	0.96 (0.12) [n=54]	0.99 (0.02) [n=35]	0.98 (0.02) [n=20]	0.177	0.911
Hearing	0.97 (0.12) [n=62]	0.97 (0.14) [n=56]	1.00 (0.00) [n=35]	1.00 (0.00) [n=19]	0.561	-
Speech	0.92 (0.17) [n=62]	0.91 (0.19) [n=54]	1.00 (0.00) [n=35]	0.98 (0.06) [n=20]	0.846	0.059
Ambulation	0.97 (0.12) [n=62]	0.91 (0.24) [n=56]	1.00 (0.00) [n=35]	1.00 (0.00) [n=20]	0.165	-
Dexterity	0.97 (0.12) [n=62]	0.90 (0.23) [n=56]	0.99 (0.05) [n=35]	1.00 (0.00) [n=20]	0.013	0.450
Emotion	0.91 (0.16) [n=62]	0.90 (0.17) [n=56]	0.98 (0.06) [n=34]	0.93 (0.11) [n=20]	0.677	0.165
Cognition	0.84 (0.20) [n=62]	0.81 (0.23) [n=55]	0.98 (0.05) [n=35]	0.96 (0.09) [n=20]	0.464	0.183
Pain	0.92 (0.15) [n=62]	0.91 (0.19) [n=56]	0.98 (0.05) [n=35]	0.98 (0.06) [n=20]	0.679	0.686

[1] p values from the Wilcoxon rank sum test.

Table VII. MAU and SAU scores at 19 years of age between participants born extremely preterm and controls: by maternal education

| | EP | | | Kruskal-Wallis H test [1] | Pairwise comparisons [1] | |
| | **Low** | **Intermediate** | **High** | | **Intermediate vs Low** | **High vs Low** |
Self-report	**Mean (SD)**	**Mean (SD)**	**Mean (SD)**	*p*	*p*	*p*
MAU score	0.69 (0.32) [n=14]	0.79 (0.23) [n=83]	0.78 (0.28) [n=12]	0.471	-	-
SAU scores						
Vision	0.95 (0.10) [n=15]	0.97 (0.08) [n=88]	1.00 (0.01) [n=13]	0.058	-	-
Hearing	0.96 (0.10) [n=15]	0.99 (0.07) [n=88]	0.96 (0.14) [n=13]	0.407	-	-
Speech	0.97 (0.07) [n=14]	0.93 (0.15) [n=84]	0.97 (0.07) [n=12]	0.482	-	-
Ambulation	0.91 (0.26) [n=15]	0.98 (0.08) [n=88]	1.00 (0.00) [n=13]	0.151	-	-
Dexterity	0.93 (0.26) [n=15]	0.99 (0.05) [n=88]	1.00 (0.00) [n=13]	0.314	-	-
Emotion	0.95 (0.08) [n=15]	0.94 (0.12) [n=87]	0.95 (0.08) [n=13]	0.998	-	-
Cognition	0.91 (0.12) [n=15]	0.89 (0.17) [n=88]	0.82 (0.25) [n=13]	0.919	-	-
Pain	0.83 (0.29) [n=15]	0.94 (0.12) [n=87]	0.96 (0.09) [n=13]	0.278	-	-
Parent-report						
MAU score	0.56 (0.30) [n=15]	0.70 (0.30) [n=86]	0.71 (0.34) [n=12]	0.112	-	-
SAU scores						
Vision	0.96 (0.07) [n=15]	0.96 (0.11) [n=88]	0.99 (0.02) [n=12]	0.072	-	-
Hearing	0.93 (0.19) [n=15]	0.99 (0.05) [n=90]	0.87 (0.31) [n=12]	0.020	0.009	0.399
Speech	0.92 (0.13) [n=15]	0.91 (0.20) [n=88]	0.97 (0.10) [n=12]	0.388	-	-
Ambulation	0.87 (0.32) [n=15]	0.94 (0.17) [n=90]	1.00 (0.00) [n=12]	0.273	-	-
Dexterity	0.92 (0.26) [n=15]	0.93 (0.18) [n=90]	1.00 (0.00) [n=12]	0.274	-	-
Emotion	0.92 (0.09) [n=15]	0.91 (0.17) [n=90]	0.89 (0.19) [n=12]	0.824	-	-
Cognition	0.84 (0.18) [n=15]	0.83 (0.21) [n=89]	0.79 (0.25) [n=12]	0.880	-	-
Pain	0.78 (0.30) [n=15]	0.93 (0.14) [n=90]	0.97 (0.07) [n=12]	0.071	-	-

[1] Across group differences were determined using the Kruskal-Wallis H test as HUI scores were not normally distributed. Nonparametric pairwise comparisons were examined using Dunn's test when a Kruskal–Wallis test was rejected.

Table VIII. A comparison between parent- and self- reported suboptimal function and HUI3 disability in young adulthood for participants born extremely preterm and controls

HUI3 disability[Π]	All EP		EP with impairment		EP without impairment		Control		EP Parent vs self-report	EP with impairment Parent vs self -report	EP without impairment Parent vs self -report	Controls Parent vs self -report
	Parent-report	Self-report	Parent-report	Self-report	Parent-report	Self-report	Parent-report	Self-report				
	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	% (n)	p [Τ]	p [Τ]	p [Τ]	p [Τ]
No	11.4% (13/114)	17.3% (19/110)	2.0% (1/50)	9.1% (4/44)	18.8% (12/64)	22.7% (15/66)	45.3% (24/53)	40.3% (25/62)	0.003	0.006	0.129	0.787
Mild	21.1% (24/114)	29.1% (32/110)	12.0% (6/50)	20.5% (9/44)	28.1% (18/64)	34.8% (23/66)	37.7% (20/53)	33.9% (21/62)				
Moderate	27.2% (31/114)	27.3% (30/110)	22.0% (11/50)	27.3% (12/44)	31.3% (20/64)	27.3% (18/66)	11.3% (6/53)	19.4% (12/62)				
Severe	40.4% (46/114)	26.4% (29/110)	64.0% (32/50)	43.2% (19/44)	21.9% (14/64)	15.2% (10/66)	5.7% (3/53)	6.5% (4/62)				

[Π] Multi-attribute utility scores were categorised into four disability levels (no disability 1.00; mild disability 0.89-0.99; moderate 0.70-0.88; severe <0.70).

[Τ] p values from Wilcoxon matched-pairs signed-ranks test.

Table IX. HQOL from adolescence to young adulthood for participants born extremely preterm and controls using parent reports

Variables		EP with impairment 11 years	EP with impairment 19 years	EP without impairment 11 years	EP without impairment 19 years	All EP 11 years [a]	All EP 19 years [b]	Controls 11 years [c]	Controls 19 years [d]	EP p^T [a] vs [b]	Controls p^T [c] vs [d]
HUI3 SAU scores											
Vision	Median (IQR)	1.00 (0.05) [n=75]	1.00 (0.05) [n=51]	1.00 (0.00) [n=113]	1.00 (0.05) [n=65]	1.00 (0.05) [n=188]	1.00 (0.05) [n=116]	1.00 (0.00) [n=141]	1.00 (0.05) [n=55]	0.003	0.007
Hearing	Median (IQR)	1.00 (0.00) [n=74]	1.00 (0.00) [n=52]	1.00 (0.00) [n=111]	1.00 (0.00) [n=66]	1.00 (0.00) [n=185]	1.00 (0.00) [n=118]	1.00 (0.00) [n=141]	1.00 (0.00) [n=54]	0.987	-
Speech	Median (IQR)	1.00 (0.18) [n=75]	1.00 (0.33) [n=51]	1.00 (0.00) [n=112]	1.00 (0.00) [n=65]	1.00 (0.00) [n=187]	1.00 (0.09) [n=116]	1.00 (0.00) [n=141]	1.00 (0.00) [n=55]	0.548	0.322
Ambulation	Median (IQR)	1.00 (0.00) [n=76]	1.00 (0.17) [n=52]	1.00 (0.00) [n=112]	1.00 (0.00) [n=66]	1.00 (0.00) [n=188]	1.00 (0.00) [n=118]	1.00 (0.00) [n=141]	1.00 (0.00) [n=55]	0.054	-
Dexterity	Median (IQR)	1.00 (0.00) [n=76]	1.00 (0.12) [n=52]	1.00 (0.00) [n=112]	1.00 (0.00) [n=66]	1.00 (0.00) [n=188]	1.00 (0.00) [n=118]	1.00 (0.00) [n=141]	1.00 (0.00) [n=55]	0.417	0.989
Emotion	Median (IQR)	1.00 (0.00) [n=76]	1.00 (0.09) [n=52]	1.00 (0.00) [n=113]	0.96 (0.09) [n=66]	1.00 (0.00) [n=189]	1.00 (0.09) [n=118]	1.00 (0.00) [n=141]	1.00 (0.09) [n=54]	<0.001	0.007
Cognition	Median (IQR)	0.86 (0.30) [n=76]	0.86 (0.22) [n=51]	1.00 (0.14) [n=112]	1.00 (0.30) [n=66]	0.92 (0.30) [n=188]	0.86 (0.30) [n=117]	1.00 (0.00) [n=141]	1.00 (0.00) [n=55]	0.498	0.702
Pain	Median (IQR)	1.00 (0.08) [n=75]	1.00 (0.23) [n=52]	1.00 (0.00) [n=113]	1.00 (0.00) [n=66]	1.00 (0.08) [n=188]	1.00 (0.00) [n=118]	1.00 (0.00) [n=141]	1.00 (0.00) [n=55]	0.020	0.007
HUI3 disability[]											
No	% (n)	8.8% (6/68)	2.0% (1/50)	36.1% (39/108)	18.8% (12/64)	25.6% (45/176)	11.4% (13/114)	68.8% (97/141)	45.3% (24/53)	0.022	0.005
Mild	% (n)	20.6% (14/68)	12.0% (6/50)	28.7% (31/108)	28.1% (18/64)	25.6% (45/176)	21.1% (24/114)	18.4% (26/141)	37.7% (20/53)		
Moderate	% (n)	30.9% (21/68)	22.0% (11/50)	22.2% (24/108)	31.3% (20/64)	25.6% (45/176)	27.2% (31/114)	9.2% (13/141)	11.3% (6/53)		
Severe	% (n)	39.7% (27/68)	64.0% (32/50)	13.0% (14/108)	21.9% (14/64)	23.3% (41/176)	40.4% (46/114)	3.5% (5/141)	5.7% (3/53)		
The number of single attributes that were suboptimal											
0	% (n)	8.8% (6/68)	2.0% (1/50)	36.1% (39/108)	18.8% (12/64)	25.6% (45/176)	11.4% (13/114)	68.8% (97/141)	45.3% (24/53)	0.001	0.003
1	% (n)	27.9% (19/68)	14.0% (7/50)	35.2% (38/108)	25.0% (16/64)	32.4% (57/176)	20.2% (23/114)	19.9% (28/141)	32.1% (17/53)		
2	% (n)	23.5% (16/68)	20.0% (10/50)	14.8% (16/108)	29.7% (19/64)	18.2% (32/176)	25.4% (29/114)	7.8% (11/141)	13.2% (7/53)		
3	% (n)	14.7% (10/68)	24.0% (12/50)	11.1% (12/108)	15.6% (10/64)	12.5% (22/176)	19.3% (22/114)	2.8% (4/141)	9.4% (5/53)		
4	% (n)	10.3% (7/68)	12.0% (6/50)	1.9% (2/108)	7.8% (5/64)	5.1% (9/176)	9.6% (11/114)	0.7% (1/141)	0.0% (0/53)		
5	% (n)	7.4% (5/68)	14.0% (7/50)	0.0% (0/108)	1.6% (1/64)	2.8% (5/176)	7.0% (8/114)	0.0% (0/141)	0.0% (0/53)		
6	% (n)	7.4% (5/68)	12.0% (6/50)	0.9% (1/108)	1.6% (1/64)	3.4% (6/176)	6.1% (7/114)	0.0% (0/141)	0.0% (0/53)		
7	% (n)	0.0% (0/68)	2.0% (1/50)	0.0% (0/108)	0.0% (0/64)	0.0% (0/176)	0.9% (1/114)	0.0% (0/141)	0.0% (0/53)		

[T] Changes in SAU scores, HUI disability and the number of single attributes that were suboptimal over time were tested using Wilcoxon matched-pairs signed-ranks tests. [] Multi-attribute utility scores were categorised into four disability levels (no disability 1.00; mild disability 0.89-0.99; moderate 0.70-0.88; severe <0.70).