




# Using different definitions affected the reported prevalence of neurodevelopmental impairment in children born very preterm

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## Abstract

**Aim:** We investigated the impact of varying definitions on the prevalence of neurodevelopmental impairment (NDI) in children born very preterm at 6.5 years of age.

**Methods:** Cognitive development and neurosensory impairments were assessed in 91 children (40/51 girls/boys) born <32 gestational weeks, in 2004-2007 in Uppsala county, Sweden. The results were compared with data from a reference group of 67 children born full term. The prevalence of NDI in the present cohort was reported according to definitions used by seven contemporary studies of children born very or extremely preterm.

**Results:** The prevalence of severe NDI varied from 2% to 23% depending on the definition used. The prevalence of cognitive impairment varied from 2% (−3 SD according to test norms) to 16% (−2 SD according to control group), the prevalence of cerebral palsy from 0% (severe) to 9% (any) and the prevalence of severe visual impairment from 0% (blindness) to 1% (visual acuity < 0.3). There were no children with severe hearing impairment.

**Conclusion:** A high variability in definitions affects the reporting of the prevalence of NDI in long-term follow-up studies of very or extremely preterm born children. There is a need for a better consensus to enable comparisons across studies.

## KEYWORDS

cerebral palsy, cognitive impairment, hearing impairment, long-term follow-up, visual impairment

## 1 | INTRODUCTION

Preterm birth increases the risks for adverse neurodevelopmental outcomes such as cerebral palsy, cognitive impairment, visual and hearing impairment.<sup>1</sup> Previous population-based reports

demonstrate variable results in the rates of severe neurodevelopmental disabilities up to school age.<sup>2-7</sup> Direct comparisons between different cohorts are challenging because of the lack of consistency in measures of outcome and definitions used.<sup>8</sup> The use of normative data or a control group also makes the comparison

**Abbreviations:** EXPRESS, Extremely Preterm Infants in Sweden Study; LOVIS, Longitudinal VISual follow-up of visuomotor development; NDI, neurodevelopmental impairment.

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difficult as well as whether the age is corrected for prematurity or not.

It has been previously reported that definitions of severe neurodevelopmental impairment (NDI) significantly influences its' incidence in extremely preterm born children at 21 months' corrected age.<sup>9</sup> The scientific literature concerning long-term neurodevelopment in preterm born children often refers only to outcomes in toddler age or early childhood.<sup>10</sup> However, prospective follow-up at later ages is important, because the degree of disability can be more clearly defined at preschool age.

The aim of this study was to investigate whether the prevalence of NDI in a population-based cohort of children born very preterm at 6.5 years of age varied according to the different definitions used in seven contemporary large population-based prospective follow-up cohorts<sup>11-17</sup> of very or extremely preterm born children. The hypothesis was that the definitions used in the different studies would cause variation in the prevalence of NDI, as would cut-offs derived from test standardisation norms or from reference data from a control group.

## 2 | PATIENTS AND METHODS

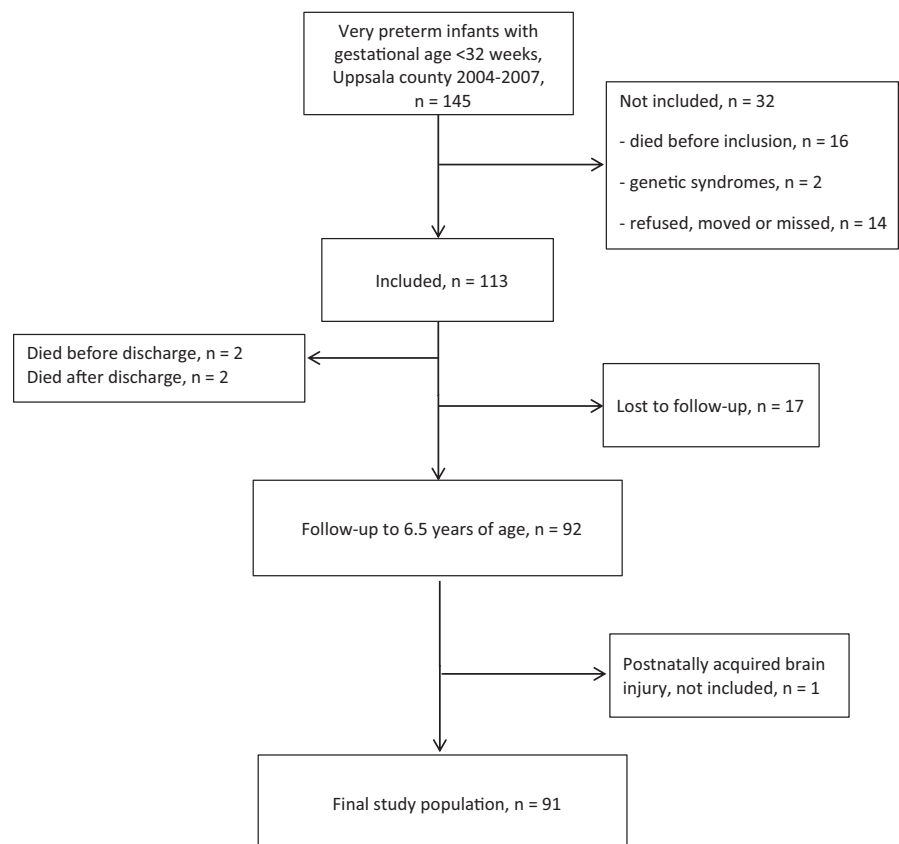
### 2.1 | Participants

The LOngitudinal VISual follow-up of visuomotor development (LOVIS) project is a multidisciplinary population-based prospective

#### Key notes

- Variations in assessment methods and definitions make comparisons difficult between long-term follow-up studies evaluating neurodevelopment in children born preterm.
- Neurodevelopment was assessed in a regional cohort of Swedish children born very preterm according to published criteria in large international follow-up studies.
- There was a considerable variation in the prevalence of neurodevelopmental impairment in the Swedish cohort depending on the definitions used, and a consensus is called for.

follow-up study of very preterm infants born <32 weeks of gestational age, in 2004-2007 in Uppsala County, Sweden.<sup>18</sup> A flow chart describing the study population is shown in Figure 1. A total of 92 children born very preterm were assessed at 6.5 years of chronological age, corresponding to 84.4% of survivors in the original cohort. Data from one child were excluded due to a postnatally acquired brain injury unrelated to very preterm birth, and the final study population was consequently 91 LOVIS children (n = 40, 44.0% girls). Results from a regional control group of full term (gestational age ≥ 37 weeks) children (n = 67; and n = 29, 43.3% girls) within the national Extremely Preterm Infants in Sweden Study (EXPRESS),



**FIGURE 1** Flow chart of the LOngitudinal VISual follow-up of visuomotor development (LOVIS) study population, a population-based prospective study of preterm infants with gestational age <32 wk, born 2004-2007 in Uppsala county, Sweden

born during the same period as the LOVIS children, were used for comparison with permission from the EXPRESS Steering committee.<sup>11</sup> Background characteristics of the very preterm LOVIS group and the full term reference group are shown in Table 1.

Parental written consent was obtained after written and oral information. The LOVIS study had ethical approval from the Regional research ethics committee in Uppsala (nr Ups 03-665).

## 2.2 | Neurodevelopmental assessments

The children's cognitive level was evaluated at 6.5 years of chronological age. Licensed psychologists at Uppsala University Hospital used the Swedish version of the Wechsler Intelligence

Scale for Children—Fourth edition<sup>19</sup> giving full-scale intelligence quotient, a measure of general intelligence. A total of four children were assessed with the Wechsler Preschool and Primary Scale of Intelligence—Revised<sup>19</sup> and one with the Griffiths Scales of Child Development—Second edition,<sup>20</sup> depending on level of functioning. The controls were assessed according to the same study protocol (the same measures and procedures by the same assessors). A clinical diagnosis of autism was based on the Autism Diagnostic Observation Schedule<sup>21</sup> and parental interviews.

A diagnosis of cerebral palsy, including the grading of functional severity by the Gross Motor Function Classification System,<sup>22</sup> was ascertained after a systematic clinical follow-up.

Ophthalmological examination at 6.5 years included test of the child's best corrected visual acuity using the Lea Hyvärinen chart

**TABLE 1** Background characteristics for the very preterm study group and the full term reference group. Values are mean (standard deviations), ranges and numbers (percentages)

Neonatal characteristics	Very preterm born children, n = 91	Full term born children, n = 67
Gestational age, mean (SD) [min, max], wk	28.5 (2.4) [22.3, 31.9]	39.7 (1.2) [37,41], (n = 64)
Birth weight, mean (SD) [min, max], g	1201 (344.9) [520, 2030]	3660 (416) [2740, 4404]
Females, n (%)	40 (44.0)	29 (43.3)
Antenatal steroids, n (%)	67 (73.6)	NA
Caesarean section, n (%)	50 (54.9)	NA
Small for gestational age, n (%)	14 (15.4)	NA
Bronchopulmonary dysplasia, n (%)	20 (22.0)	NA
Sepsis, n (%)	18 (19.8)	NA
Retinopathy of prematurity, stage $\geq 3$ , n (%)	6 (6.6)	NA
Intraventricular haemorrhage grade 3-4, or periventricular leucomalacia, n (%)	9 (10.0), (n = 90)	NA
Characteristics at 6.5 y of age		
FSIQ, mean (SD) [minimum, maximum]	94.4 (15.0) [40, 131]	99.6 (9.9) [68, 122]
<-1 SD based on the test norms, n (%)	23 (25.3)	5 (7.5)
<-1 SD based on the results of the controls, n (%)	36 (39.6)	11 (16.4)
<-2 SD based on the test norms, n (%)	4 (4.4)	1 (1.5)
<-2 SD based on the results of the controls, n (%)	15 (16.5)	2 (3.0)
<-3 SD based on the test norms, n (%)	2 (2.2)	0 (0.0)
<-3 SD based on the results of the controls, n (%)	3 (3.3)	1 (1.5)
Cerebral palsy, n (%)	8 (8.8)	0 (0.0)
GMFCS I	6 (75.0)	
GMFCS II	1 (12.5)	
GMFCS III	1 (12.5)	
GMFCS IV-V	0 (0.0)	
FSIQ, mean (SD) [min, max]	94.0 (19.2) [60, 112]	
Autism	6 (6.6)	0 (0.0)
FSIQ, mean (SD) [min, max]	78.3 (21.4) [40, 103]	
Visual acuity in the better eye, mean (SD) [min, max]	0.95 (0.19) [0.25, 1.60], (n = 74)	0.99 (0.12) [0.80, 1.60], (n = 64)
Visual acuity < 0.1 in the better eye, n (%)	0 (0.0)	0 (0)
Visual acuity < 0.3 in the better eye, n (%)	1 (1.4)	0 (0)

Abbreviations: FSIQ, full-scale intelligence quotient; GMFCS, Gross Motor Function Classification System; NA, not available.

at three metres. In case the child needed glasses, the test was performed with the child's habitual spectacles.<sup>23</sup>

Hearing was examined by otoacoustic emissions before discharge from hospital. In addition, infants with gestational age less than 28 weeks were examined with auditory brainstem responses at four to 6 weeks of corrected age. The diagnosis of severe hearing impairment was done by audiologist or otologist.

Neurodevelopmental impairment was classified according to definitions used in seven large population-based long-term prospective follow-up studies (Table 2). These studies were chosen since to our knowledge they are the most significant contemporary studies providing comparable information about NDI in very or extremely preterm born children at preschool or early school age. The definition of NDI was in all studies based on varying degrees of cerebral palsy, visual and hearing impairments, and cognitive impairment. Thus, the most severe degree of any impairment was included in the definition of severe NDI in the present study.

### 2.3 | Statistical analysis

The prevalence of severe NDI in the present study cohort was calculated by using the cut-offs described in the original publications.<sup>11-17</sup> When classifying outcome in the present investigation, the original approach used in the studies was followed as closely as possible, including the use of control group or normative reference data cut-offs. When a cut-off was defined according to a control group, this was translated into the corresponding cut-off in our reference data. For the sake of comparison, also tests other than the Wechsler scales were handled in the same way, although the construct behind these tests were recognised to be different. Statistical analyses were performed using the computer program SPSS version 25.0 (IBM Corp).

## 3 | RESULTS

Depending on the definition used, the prevalence of severe NDI at 6.5 years of age in the LOVIS group varied from  $n = 2$  (2%) to  $n = 21$  (23%) as shown in Table 2. Further, the prevalence of cognitive impairment varied from  $n = 2$  (2%) to  $n = 15$  (16%), when defined as  $-3$  SD according to test norms or  $-2$  SD according to control group distribution. The prevalence of cerebral palsy varied from  $n = 0$  (0%) to  $n = 8$  (9%), when defined as severe or any cerebral palsy, respectively. The prevalence of severe visual impairment varied between  $n = 0$  (0%) and  $n = 1$  (1%), when defined as blindness or visual acuity  $< 0.3$  in the better eye, respectively. The variation of cognitive outcome in the LOVIS group according to the different definitions of severe cognitive impairment is shown in Figure 2.

## 4 | DISCUSSION

This study showed that there is a high variability in the definitions of severe NDI within contemporary prospective follow-up studies of

children born very or extremely preterm affecting reported prevalence of these impairments and limiting comparability.

Most of the variance in the prevalence of severe NDI was due to whether the definition of cognitive impairment was based on the test norms or on the control group. At an individual level, this may be crucial as disagreements in the classification system have consequences for diagnosis and access to support services. At the level of a population, the variability in definitions may prevent decision makers to get a clear notion of the needs of the population.<sup>24</sup> Various assessment methods such as Kaufman Assessment Battery for Children<sup>13,14</sup> and the Wechsler scales<sup>11,12,15-17</sup> have different theoretical assumptions when measuring general intelligence, advising caution when comparing outcome between studies. The use of different definitions makes comparisons even more difficult.

Some of the studies used Gross Motor Function Classification System<sup>22</sup> for the classification, while others described different grades of cerebral palsy such as walking status (ambulatory/nonambulatory) in defining the severity of cerebral palsy. Moreover, some studies included any degree of cerebral palsy in their definition of severe NDI while others included only severe cerebral palsy. Also, the age at the time of assessment may have influenced the classification of the severity as the Gross Motor Function Classification System is different at different ages and may change over time.<sup>25</sup>

The World Health Organization defines severe visual impairment as visual acuity  $< 0.1$ . According to this definition, there were no children with severe visual impairment in the LOVIS cohort. The definitions in the included studies varied from blindness to visual acuity of  $< 0.3$ , resulting in a prevalence varying between 0% and 1% in the LOVIS cohort. It is also noteworthy that not all studies described the type of test of visual acuity used, whether the visual acuity was tested with glasses or whether an ophthalmologist or orthoptist performed the test. In the LOVIS Study, one orthoptist performed all assessments of visual function and visual acuity was assessed with the child's habitual spectacles, when applicable.<sup>23</sup>

Autism may be as debilitating as cognitive impairment or cerebral palsy, but it is still not commonly included in follow-up studies of very preterm children. In the LOVIS cohort, the prevalence of clinically diagnosed autism was reported. None of the reference studies included autism in their overall outcomes, and only one study<sup>16</sup> reported the prevalence of autism alongside neurodevelopmental outcome.

A possible limitation of this study may be that there were five children born very preterm who were assessed by other cognitive assessment methods than the Wechsler Intelligence Scale for Children—Fourth edition. However, excluding these children from the comparison did not significantly change the results. Furthermore, no detailed data considering hearing were available in the LOVIS cohort. Therefore, the results presented in this study considering severe hearing impairment were already based on a previous categorised definition of this impairment. However, as the prevalence of severe hearing impairment was low, varying from 0.5% to 2% in the other cohorts of children born very or extremely preterm included in this study, the influence of this limitation on the prevalence of severe NDI was assumed to be minor.

TABLE 2 Neurodevelopmental impairment in very preterm children at preschool or early school age

	Definition of severe NDI	Study results	LOVIS study
<b>Victorian Infant Collaborative Study Group (VICS)</b> • Australia • Gestational age < 28 wk • Birth years 1991-1992 • 5 y of corrected age • 98% follow-up rate Doyle et al; Pediatrics. 2001 Jul;108(1):134-41.	Major CP, blindness, deafness, severe intellectual impairment*	*20% (44/221)	*18% (16/91)
	CP of such severity that the child was either not walking or walking with considerable difficulty	7% (15/221)	1% (1/91)
	Bilateral vision < 0.01	2% (4/221)	0% (0/91)
	Sensorineural deafness requiring hearing aids	1% (2/221)	0% (0/91)
	IQ below -2 SD for the normal birth weight control group* (mean 105.3, SD 15.1) (WPPSI-R)	*15% (34/221)	*16% (15/91)
<b>EPICure Study Group</b> • United Kingdom and Ireland • Gestational age < 26 wk • Birth year 1995 • 6 y of chronological age • 78% follow-up rate Marlow et al; N Engl J Med. 2005 Jan 6;352(1):9-19	Nonambulatory CP, blindness, profound sensorineural hearing loss, severe cognitive impairment*	13% (32/241), *22% (53/241)	2% (2/91), *3% (3/91)
	Nonambulatory CP	6% (15/241)	0% (0/91)
	Blindness	2% (6/241)	0% (0/91)
	Profound sensorineural hearing loss	3% (7/241)	0% (0/91)
	MPC below -3 SD (range 39-54, *range 39-69) (K-ABC)	11% (27/241), *21% (50/241)	2% (2/91), *3% (3/91)
<b>Etude Epidémiologique sur les Petits Ages Gestationnels (EPIPAGE)</b> • France • Gestational age < 33 wk • Birth year 1997 • 5 y of chronological age • 77% follow-up rate Larroque et al; Lancet. 2008 Mar 8;371(9615):813-20	Nonambulatory CP, severe visual deficiency, severe hearing deficiency, or MPC < 55	5% (83/1600)	3% (3/91)
	Nonambulatory CP	2% (30/1812)	0% (0/91)
	Severe visual deficiency (<0.3 for both eyes)	1% (12/1697)	1% (1/91)
	Severe hearing deficiency (<70 db or hearing aid)	<1% (8/1784)	0% (0/91)
	MPC <-3 SD of the reference mean value of 100 (<55) (K-ABC)	2% (36/1534)	2% (2/91)
<b>Norwegian Extreme Prematurity Study Group</b> • Norway • Gestational age < 28 wk or birth weight < 1000 g • Birth years 1999-2000 • 5 y of chronological age • 82% follow-up rate Leversen et al; Pediatrics. 2011 Mar;127(3):e630-8.	According to the EPICure: CP (GMFCS level $\geq$ 4), legal blindness, complete deafness, or FSIQ < 55	6% (18/306)	2% (2/91)
	CP (GMFCS level $\geq$ 4)	3% (10/306)	0% (0/91)
	Legal blindness	2% (5/306)	0% (0/91)
	Complete deafness	1% (3/306)	0% (0/91)
	FSIQ <-3 SD of the reference mean value of 100 (<55) (WPPSI-R)	1% (2/306)	2% (2/91)
<b>PIPARI Study Group</b> • Finland • Gestational age < 32 wk or birth weight $\leq$ 1500 g • Birth years 2001-2006 • 5 y of chronological age • 84% follow-up rate Setänen et al; Acta Paediatr. 2013 May;102(5):492-7	CP, severe visual impairment, severe hearing impairment or FSIQ < 85, which is close to a -2 SD level in the control group*	22% (41/186)	*23% (21/91)
	All CP determined during a systematic clinical follow-up by 2 years of corrected age	6% (14/217)	9% (8/91)
	Visual acuity < 0.3, or blindness	0% (0/217)	1% (1/91)
	Hearing loss requiring amplification in at least one ear or hearing impairment with a cut-off of 40 dB	2% (4/217)	0% (0/91)
	FSIQ < 85, which is close to a -2 SD level in the control group* (mean 111.7, SD 14.8) (WPPSI-R, Finnish translation)	17% (31/178)	*16% (15/91)

(Continues)

TABLE 2 (Continued)

	Definition of severe NDI	Study results	LOVIS study
<i>Extremely Preterm Infants in Sweden Study Group (EXPRESS)</i> <ul style="list-style-type: none"> <li>• Sweden</li> <li>• Gestational age &lt; 27 wk</li> <li>• Birth years 2004-2007</li> <li>• 6.5 y of chronological age</li> <li>• 91% follow-up rateSerenius et al; JAMA Pediatr. 2016 Oct 1;170(10):954-963.</li> </ul>	CP (GMFCS level $\geq$ 4), blindness, deafness, or FSIQ below $-3$ SD ( $<65.2$ ) according to the control group*	*13% (59/441)	*3% (3/91)
	GMFCS level $\geq$ 4	1% (5/441)	0% (0/91)
	Blindness (visual acuity of $< 0.05$ in the better eye)	2% (9/441)	0% (0/91)
	Deafness (impairment not corrected with hearing aid)	0.5% (2/435)	0% (0/91)
	FSIQ below $-3$ SD ( $<65.2$ ) according to the control group* or severe cognitive disability determined by a clinical examination or medical record view (WISC-IV)	*11% (49/441)	*3% (3/91)
<i>Neuroimaging and Neurodevelopmental Outcomes study (NEURO) of the National Institute of Child Health and Human Development (NICHD) Neonatal research Network (NRN)</i> <ul style="list-style-type: none"> <li>• USA</li> <li>• Gestational age &lt; 28 wk</li> <li>• Birth years 2005-2009</li> <li>• 6-7 y of chronological age</li> <li>• 83% follow-up rateHintz et al; Pediatrics. 2018 Jul;142(1):2017-4058.</li> </ul>	CP (GMFCS level $\geq$ 4), severe vision impairment, severe hearing impairment, or FSIQ $< 55$	NA	2% (2/91)
	CP (GMFCS level $\geq$ 4)	NA	0% (0/91)
	Severe vision impairment (blind or able to perceive only light in both eyes or only perceive light in one eye, with the other eye with impairment not correctable with glasses or lenses)	1.3% (5/386)	0% (0/91)
	Severe hearing impairment (having no useful hearing even with hearing aid(s), implant(s), or other amplification device or if impairment is profound and considered not responsive to amplification)	0.3% (1/386)	0% (0/91)
	FSIQ $< -3$ SD of the reference mean value of 100 ( $<55$ ) (WISC-IV)	NA	2% (2/91)

Note: Comparison of different study definitions for results in the present LOngitudinal VISual follow-up of visuomotor development (LOVIS) Study population.

According to test standardisation norms, \*according to reference data from control group.

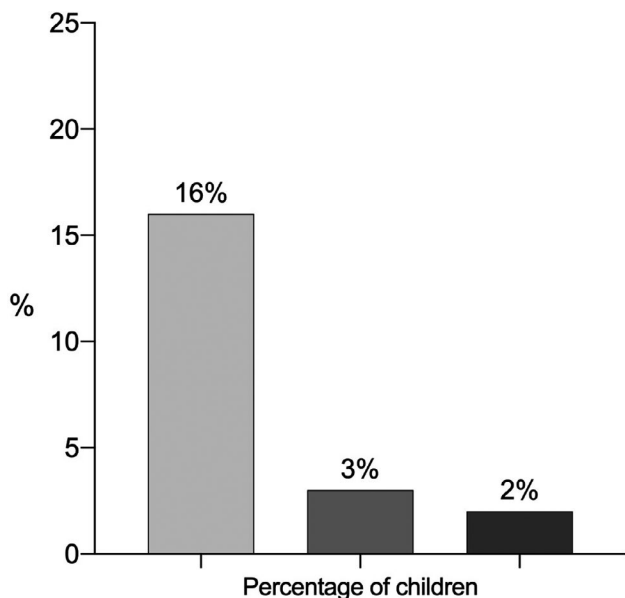
Abbreviations: CP, cerebral palsy; FSIQ, full-scale intelligence quotient; GMFCS, Gross Motor Function Classification System; K-ABC, Kaufman Assessment Battery for Children; MPC, Mental processing composite score; na, not available; WISC-IV, Wechsler Intelligence Scale for Children—Fourth edition; WPPSI-R, Wechsler Preschool and Primary Scale of Intelligence, Revised.

When comparing outcomes in different study populations, it is important to consider how the data regarding children who have not completed the follow-up protocol have been handled. For example, some studies have used a chart review of medical records, which probably is sufficient to make a decision on severe disabilities, but may not distinguish between milder impairments. Also, the composite outcomes should be defined and their completeness reported precisely when describing neurodevelopmental outcome in different study populations.<sup>24</sup> It could be noted that several variables, included in the definition of the composite outcome of NDI, were not available in all studies. However, it should be emphasised that the present study aimed to describe the impact of varying definitions on the prevalence of severe NDI in a regional cohort of children born

very preterm but not to compare the overall outcome between the contemporary follow-up cohorts. For that reason, a drop-out analysis was not performed.

There was a considerable variation in the prevalence of severe NDI (2%-23%) at 6.5 years of age in this Swedish cohort of children born very preterm depending on the definitions used. These results confirm previous findings of the impact on the prevalence of severe NDI (3.5%-14.9%) in a preterm Canadian cohort at around 2 years of age.<sup>9</sup> Our results highlight that caution should be taken when comparing the prevalence of NDI across studies. In future follow-up studies of children born very preterm, it would be important to reach consensus and use clearly described definitions of NDI when reporting outcomes.<sup>24,26</sup>





- <-2 SD according to the control group (VICS, PIPARI)
- <-3 SD according to the control group (EPICure, EXPRESS)
- <-3 SD according to the test norms (EPICure, EPIPAGE, Norwegian, NEURO)

**FIGURE 2** The prevalence (%) of cognitive impairment in children born very preterm in the LOVIS Study population at 6.5 y of chronological age according to the different cut-offs used by seven prospective follow-up cohorts of children born very or extremely preterm. PIPARI, PIPARI Study Group; Finland. VICS, Victorian Infant Collaboration Study Group; Australia. EPICure, EPICure Study Group; United Kingdom and Ireland. EXPRESS, Extremely Preterm Infants in Sweden Study Group; Sweden. EPIPAGE, Etude Epidémiologique sur les Petits Ages Gestationnels; France. Norwegian, Norwegian Extreme Prematurity Study Group; Norway. NEURO, NEURO study (a subgroup of the SUPPORT cohort), USA

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## CONFLICT OF INTEREST

The authors have no conflicts of interest to declare.

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