

# Reporting Outcomes of Extremely Preterm Births

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Published reports of extremely preterm birth outcomes provide important information to families, clinicians, and others and are widely used to make clinical and policy decisions. Misreporting or misunderstanding of outcome reports may have significant consequences. This article presents 7 recommendations to improve reporting of extremely preterm birth outcomes in both the primary and secondary literature. The recommendations should facilitate clarity in communication about extremely preterm birth outcomes and increase the value of existing and future work in this area.

Extremely preterm births constitute a small proportion of all births worldwide but a large portion of perinatal death and morbidity.<sup>1,2</sup> They are a heterogeneous group with a wide range of potential outcomes, with the probability of infant survival ranging from 0% to >80% in the setting of modern intensive obstetric and neonatal care.<sup>3</sup>

Clinicians who care for families facing extremely preterm birth require accurate prognostic information to counsel families about what to expect and to inform clinical decision-making. However, prognostic data are important well beyond the period immediately before and after delivery. Survival after extremely preterm birth has improved in recent decades,<sup>4-8</sup> and clinicians of various specialties are now more likely than ever to care for survivors in all stages of their lives.<sup>9</sup> Moreover, policy makers, administrators, researchers, and others require information on extremely preterm birth outcomes to plan for the delivery of medical care, education, and other services and to improve how such services are provided.

For these reasons and others (Table 1), large studies of infant outcomes after extremely preterm birth have been performed around the world, often at great public expense.<sup>10</sup> To increase their value and to avoid waste, it is imperative that such studies are not only well conducted but are also accurately reported and in ways that encourage comparability across studies.<sup>11,12</sup> The need for proper reporting applies to both primary research and secondary reports, such as popular media, reviews, and practice guidelines.

In this article, we provide recommendations for reporting outcomes of extremely preterm births. This list of practices is not intended to be comprehensive but highlights several issues related to reporting that are commonly overlooked.<sup>13</sup>

**TABLE 1** Uses of Extremely Preterm Birth Outcome Data

Counseling and decision-making before and after birth
Preparing survivors and caregivers for what to expect across the life course
Planning for services and allocating resources
Benchmarking hospital or regional outcomes
Identifying research questions and hypotheses

## abstract

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We believe that following these few simple practices should reduce bias and increase the value of outcome data for families, clinicians, and society.

## RECOMMENDATIONS

Good research starts with meaningful and important questions, and research reporting should reflect this. A well-composed question about extremely preterm birth outcomes should include a specific (1) patient population, (2) set of “exposures” (ie, factors that may affect the outcome), and (3) outcome (or set of outcomes).<sup>14</sup> Our recommendations address each of these aspects separately.

### Population

Important considerations in extremely preterm birth outcomes reporting include describing the study’s source population and defining the study’s inception point.

#### *Recommendation 1: Describe the Source Population*

Birth outcomes should be reported with information on the setting in which the data were collected. Such information informs how data are interpreted and applied. Given changes in medical care over the past 2 decades, outcome data for extremely preterm births in 1995 may not wholly predict outcomes for births in 2016. Similarly, data from a low-resource setting may not be applicable to a well-resourced one. Reports of extremely preterm birth outcomes should include dates, geographic location, and any other information important to understanding the context of the study.

Studies of extremely preterm births generally report outcomes from single centers, multicenter networks, or geographically defined areas. Because the hospital level of maternal and newborn care is associated with

the likelihood of infant survival,<sup>15,16</sup> geographically defined studies (ie, those that include both community and referral hospitals as well as births outside of hospitals) are likely to produce outcomes that are different from outcomes from studies of single referral hospitals or networks of referral hospitals. The latter studies do not include infants who died before transfer to a higher level of care or who were healthy enough to avoid transfer altogether. A study’s source population, whether single-center, multicenter, or geographically defined, should be clearly specified.

Of note, the appropriateness of a study’s source population depends on the question asked or the decision to be made with the data. To provide prognostic information to the family of an infant born in a hospital providing highly specialized maternal and newborn care (eg, with a level 3 or 4 NICU),<sup>17</sup> statistics from that or similar units are preferred. However, for a policy maker concerned about resource allocation or a researcher interested in the effects of care regionalization, geographically defined studies provide the most appropriate information on these topics. Comparing birth outcomes from geographically defined studies (which include community hospitals and out-of-hospital births) with outcomes from tertiary care centers, without appropriate stratification, is uninformative and should be avoided.

#### *Recommendation 2: Define a Study’s Inception Point*

Related to a study’s source population is its inception point. Studies of extremely preterm births vary in the point at which researchers begin to observe outcomes. Studies may collect data for all births (including intrapartum and antepartum stillbirths),<sup>5</sup> all fetuses alive at presentation to the hospital<sup>18</sup> (or at the onset of labor<sup>19</sup>), all live births,<sup>7</sup> or for only those

infants who survive to admission to the NICU.<sup>20</sup>

A study’s inception point influences outcome statistics.<sup>21</sup> Survival among infants admitted to the NICU will be higher than survival for all live-born infants, because the former excludes deaths that took place in the delivery room. Likewise, survival for live births will be higher than for fetuses alive at the onset of labor because the former excludes intrapartum stillbirths.<sup>22</sup>

As with a study’s source population, the questions asked or decisions to be made should determine the appropriate inception point. For example, outcomes data intended for making decisions related to an impending extremely preterm birth should include the possibility of an intrapartum stillbirth. Data used to answer questions about outcomes after admission to a NICU should convey the relevant outcomes beginning at that point.

Studies should avoid reporting mixed inception points. For example, 1 study reported outcomes for all live-born infants born at 22 or 23 weeks’ gestation at 48 tertiary care hospitals (including those who died in the delivery room) together with outcomes for infants transferred to those hospitals from an outside hospital within 28 days after birth (therefore excluding infants who died before potential transfer or who survived without transfer).<sup>23</sup> Statistics based on such a mixed group are difficult to meaningfully apply to any particular question or decision.

### Exposures

Because of their significant impact on birth outcomes and on decisions made surrounding birth, we recommend that studies reporting extremely preterm birth outcomes take into account at least 2 factors: gestational age at birth and whether

perinatal treatment was directed toward survival or palliation.

### *Recommendation 3: Stratify Outcomes by Gestational Age at Birth*

Although other factors affect the outcome of extremely preterm birth, the duration of fetal maturation is among the most important.<sup>24</sup> Infants born at 20 weeks' gestation are too immature to survive, whereas, in many places, the majority of infants born at 25 weeks' gestation survive. Moreover, many hospitals,<sup>25</sup> professional societies,<sup>26</sup> and countries<sup>27</sup> have developed policies surrounding medical care on the basis of gestational age.

Importantly, the margin of error for gestational age estimation may vary depending on its timing.<sup>28,29</sup> Whenever possible, the best obstetric estimate (preferably based on first-trimester ultrasound) should be used to characterize infant gestational age.

Reports that combine births across multiple gestational ages (eg, 22–25 weeks) may obscure important information. For example, in the Extremely Preterm Infant in Sweden Study (EXPRESS), which included births from across Sweden from 2004 to 2007, the average rate of 1-year survival for 501 infants born alive at 22 to 25 weeks' gestation was 64%.<sup>8</sup> However, of the 51 infants born at 22 weeks, 10% survived, and of the 205 born at 25 weeks, 81% survived. The average for infants born at 22 to 25 weeks conceals substantial differences in outcomes. When possible, primary reports of extremely preterm birth outcomes should stratify by gestational age week or smaller units.<sup>30</sup>

Of note, many factors beyond gestational age may affect extremely preterm birth outcomes. Due to the influence of factors such as infant birth weight, infant sex, antenatal corticosteroids, and plurality (ie, being a twin, triplet, etc), the rate of survival for certain subgroups of infants born at 22

weeks' gestation is higher than the rate for other subgroups of infants born at 25 weeks' gestation.<sup>24,31</sup>

Small sample sizes limit the ability of many studies to report on subgroups beyond gestational age. However, when studies are large enough, authors may consider reporting outcomes across multiple variables including gestational age. Multivariable modeling provides a potential approach for taking into account several prognostic factors simultaneously.<sup>24,32</sup>

### *Recommendation 4: Report on Decisions Regarding Treatment*

Decisions surrounding the treatment of extremely preterm birth affect infant outcomes directly and should be accounted for in all reports.

The willingness of an obstetrician to perform a cesarean delivery has been shown to correlate with whether delivery results in live birth or stillbirth,<sup>33</sup> and large variations in rates of live birth and stillbirth have been shown among countries,<sup>34</sup> within-country regions,<sup>35</sup> and even hospitals within the same city.<sup>36</sup> Moreover, whether live-born infants are resuscitated after birth influences survival statistics, and decisions to resuscitate may vary widely across countries<sup>37</sup> and among tertiary care centers within the same country.<sup>38</sup>

Defining decisions about treatment presents logistic difficulties, but several approaches have been attempted. Bottoms et al<sup>19</sup> collected data directly on obstetricians' and neonatologists' impressions of fetal viability. Serenius et al<sup>39</sup> developed an ordinal scale to capture varying degrees of obstetric and neonatal care. Other studies have simply identified whether intensive care, as a binary (yes or no) variable, was provided after birth.<sup>5,24,38</sup> The appropriate approach depends on the question to be answered with the data.

To include in reported statistics both birth outcomes after active treatment

and birth outcomes that resulted from not initiating active treatment, without distinguishing between them, results in significant bias.<sup>38,40,41</sup> Outcome data for extremely preterm births in which life-sustaining treatment was withheld (where palliation was the intended goal) should not be used to infer the probability of a good outcome for a birth in which life-sustaining treatment is intended. Outcomes for births in which active treatment was intended should be reported separately.<sup>42</sup> This issue is particularly relevant for births at 22, 23, and 24 weeks' gestation, for which the provision of active treatment is most variable.<sup>37,38</sup>

### **Outcomes**

Study outcomes should be well defined, relevant to study users, and reported with information regarding their accuracy and precision.

### *Recommendation 5: Describe Outcome Definitions*

Outcomes reported from extremely preterm birth studies should be meaningful to families, clinicians, and society. The most useful outcomes may be those that are developed a priori and in collaboration with families or other stakeholders who will use the data.

When reporting on composite outcomes such as "neurodevelopmental impairment" or "severe morbidity," both aggregate and component outcomes should be clearly defined. Both primary and secondary reports should avoid mixing or comparing outcomes of varying relevance to families, clinicians, and society. In cases in which composite outcomes are necessary, such as with competing outcomes (ie, where 1 outcome, such as mortality, precludes the possibility of other outcomes, such as developmental delay, blindness, or deafness at 2 years' corrected age),

primary reports should also present data for each component outcome.

Importantly, short-term morbidities should not be equated with long-term sequelae of prematurity in composite outcomes or when making comparisons among studies. Many infants who experience short-term morbidities have no resulting long-term health issues and vice versa.<sup>43,44</sup> Special care should be taken when making comparisons among studies, because morbidities are often defined differently. The use of standardized definitions (eg, those of the British Association of Perinatal Medicine) facilitates the comparison of outcomes across studies.<sup>45,46</sup>

The measurement of outcomes by using developmental scores requires an appropriate reference group, and studies differ in their selection of references. Standardized assessments, such as the Bayley Scales of Infant and Toddler Development, may be compared with historical normative reference data or with data from a concurrent term-born comparison group. The use of a term-born comparison group similar to the preterm population with term and preterm status blinded to the assessor may strengthen the relevance of developmental assessments and reduces the potential for expectation bias (ie, where preconceptions about outcomes at early gestational ages influence the assessment).<sup>47,48</sup>

*Recommendation 6: Describe the Timing of Outcome Assessment*

The time at which an outcome is assessed (eg, at 28 days after birth, at discharge, or at 5 years' corrected age) should be clearly reported as part of the outcome definition. Rates of both survival and morbidity vary depending on the timing of outcome measurement. Developmental outcomes, in particular, vary over time, because some children may "catch up" with their peers, whereas

other deficits may only become apparent at later ages.<sup>49,50</sup>

An additional controversy related to the timing of outcomes concerns whether to correct age for the degree of prematurity. Outcomes may be reported by chronological age (ie, the time since birth) or by "corrected age" (ie, the time since the expected due date).<sup>51</sup> A recent study showed a persistent clinically important bias in cognitive test scores when age was not corrected for prematurity, even into the teenage years.<sup>52</sup>

Primary reports should report the number of participants for whom data were not available at the time of assessment. They should report on differences between the participants with and without follow-up data available to convey whether the group with known outcomes is representative of the original cohort.<sup>53</sup>

*Recommendation 7: Report the Statistical Uncertainty of the Outcome*

Many studies of extremely preterm birth report outcomes such as survival or "neurodevelopmental impairment" as proportions. These outcomes represent the number of individuals with an outcome (the

numerator) from a specified group (the denominator): for example, 1169 of 2034 (57%) infants born alive at 22 to 26 weeks' gestation survived to 28 days.<sup>5</sup> In some cases, outcomes are reported on a numeric scale (eg, hemoglobin concentration of 12.6 g/dL or a 1-minute Apgar score of 3) or as counts of recurring events (eg, average number of emergency department visits per child during the first 2 years of life).

When reporting outcomes of extremely preterm births, which often involve small numbers, it is critical to convey the precision of the outcome estimate. Because larger sample sizes confer more statistically precise estimates, reports should include information on both the number of infants included in the denominator of the statistic and a 95% confidence interval (CI) of the estimate. For example, if 33% of infants born at 23 weeks' gestation survived, it is important to indicate whether 33% (95% CI: 16%–56%) of 18 infants survived, 33% (95% CI: 28%–39%) of 300 infants survived, or 33% (95% CI: 31%–36%) of 1200 infants survived. Clearly, the last estimate is much more precise than the first; with only 18 infants, the 95% CI includes rates both half and

**TABLE 2** Recommendations for Reporting Extremely Preterm Birth Outcomes

Recommendation	Specific Examples
1. Describe the source population	Report the study dates and location. Define whether geographically based, single-center, or multicenter.
2. Define the study's inception point	Report statistics from a time point relevant to a specific question or decision (eg, for counseling when presenting to the hospital in labor, include all fetuses alive at presentation to the hospital). Avoid combining multiple time points.
3. Stratify outcomes by gestational age	Report outcomes by gestational age week. Larger studies may include other relevant subgroups.
4. Report on decisions regarding treatment	Report outcomes for births in which active treatment is intended separately from those where it was not.
5. Describe outcome definitions	Describe the components of outcomes such as "neurodevelopmental impairment" or "severe morbidity." Avoid combining outcomes of varying relevance.
6. Describe the timing of the outcome assessment	Report the time at which outcomes were obtained and the number of participants for whom outcomes were available.
7. Report the statistical uncertainty of the outcome	Include the 95% CI and denominator size ( <i>n</i> ) for each outcome statistic.

nearly twice as large as the point estimate of 33%. Information on the precision of outcome estimates is critical to making informed decisions and to comparing outcomes among studies.

## CONCLUSIONS

The use of a more standardized approach to report extremely preterm birth outcomes will facilitate clarity in communication about outcomes and increase the value of existing and future data. Our recommendations (Table 2), which draw attention to issues related to outcome reporting for extremely preterm births, accord with existing and more general guidelines for reporting clinical outcomes. Guidelines for primary reports of observational studies (eg, Strengthening the Reporting of Observational Studies in Epidemiology [STROBE]<sup>54</sup>) or for reviews<sup>55</sup> and meta-analyses of prognosis statistics (eg, those in development by the Cochrane Methods Prognosis Group<sup>56</sup>) should be used, where applicable, to promote accurate and complete reporting.

Although issues surrounding the reporting of extremely preterm birth outcomes are in many ways unique, many of the practices listed above could be used to improve outcomes reporting for other perinatal conditions, such as hypoxic-ischemic encephalopathy<sup>57</sup> or congenital diaphragmatic hernia,<sup>58</sup> in which similar issues of small sample size and wide variation in treatment occur.

Accurate information about extremely preterm birth outcomes is critical for making informed judgments about medical care. Such data can inform us about the success and failure of our efforts and guide our understanding of where further research is required. We owe it to patients and families, who

participate in studies of extremely preterm birth outcomes, and to the public, who fund many such studies, to provide accurate, transparent reports of outcomes in the primary and secondary literature. Following the above-listed practices may help to increase the usefulness of outcome statistics for extremely preterm births, avoid bias and waste, and allow families, clinicians, and the public-at-large to make better-informed decisions.

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## ABBREVIATION

CI: confidence interval

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