Neonatal intensive care has been one of the success stories of the past 30 years, with steadily improving survival and slowly improving long-term outcomes for infants born early. In the 1980s, few infants born at 25 through 26 weeks of gestation survived, but now high survival and low morbidity rates are expected throughout the developed world. The outcome for infants born at the decreasing limit of viability has continually evoked anxiety in terms of the balance between poor survival with high rates of neuroimpairment and the burden of providing intensive care for many weeks or months. In 1980, this limit was 25 through 26 weeks; now it is 23 weeks. This issue is frequently described as an ethical dilemma as to whether intensive care should be instituted for these children.

One of the major issues that confound attempts to provide hard management guidelines is the continual improvement in mortality, which brings with it changes in attitudes toward survival. Large epidemiologic studies have been performed worldwide, such as EPICure and EPICure 2 in the United Kingdom,6 a series of reports from Victoria, Australia,3 the first EPIPAGE (Étude Epidémiologique sur les Petits Ages Gestationnels) study from France,4 the EPIBEL (Extremely Preterm Infants in Belgium) study from Belgium,2 and EXPRESS (Extremely Preterm Infants in Sweden Study) from Sweden.6 This issue of JAMA Pediatrics contains the headline report from the EPIPAGE-2 iteration, covering births in France in 2011.7 Such studies are expected to provide the hard management guidelines necessary to help plan and develop services. For example, in the United Kingdom, we have recently evaluated outcomes against published data, 2014. Outcomes vary even more because numbers are smaller. Thus, use of national or regional data instead of local data to inform decisions? First, local data are subject to variation; when aggregate data were used during 4 years, the CIs of survival in my institution varied from 22% to 70% at 23 weeks of gestation and 55% to 88% at 24 weeks (N.M., unpublished data, 2014). Outcomes vary even more because numbers are smaller. Thus, use of national or regional data improves the precision of the estimate and provides a benchmark against which individual institutions can evaluate their own performance. Second, population studies can identify trends that can help plan and develop services. For example, in the United Kingdom, we have recently evaluated outcomes against the clinical setting in which the birth occurs, finding better sur-
vival for the fetus in labor and after delivery where birth occurs in an appropriate setting, with further improvement in hospitals that have a larger throughput. Third, these data can help identify areas where practice may be improved or should be subjected to study. Obstetric factors are one such area; one example might be the increasing trend to use cesarean section to deliver infants at extremely low gestational ages, which currently has an inconsistent evidence base in the literature. Fourth, each of these huge studies is not simply an exercise in survival and complications of neonatal care. All have important long-term outcomes that help explain and develop concepts of the key issues faced by preterm children as they age. The EPICure study, for example, is currently evaluating survivors at 19 years of age to complete our neonatal education about the outcomes and consequences of our care.

How often are studies such as these required? I suggest the answer to this question is when we are able to convince funders of the need for them. Each of these studies will have great value outside simply reporting outcomes. Studies such as EPIPAGE-2 assist in the crystallizing of debates around the institution of care, settle important opinions about outcomes, tell us about the success or failure of our clinical interventions, define where research and change are required, set up key hypotheses for testing, and, importantly, provide reassurance for parents that decision making in this difficult area is subject to regular review and debate.

ARTICLE INFORMATION

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