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#### **Author**

JC Partridge

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# Physician counselling practices and decision-making for extremely preterm infants in the Pacific Rim

Alma M Martinez,<sup>1</sup> J Colin Partridge,<sup>1</sup> Victor Yu,<sup>2</sup> Keng Wee Tan,<sup>3</sup> Chap-Yung Yeung,<sup>4</sup> Jen-Her Lu,<sup>5</sup> Hiroshi Nishida<sup>6</sup> and Nem-Yun Boo<sup>7</sup>

<sup>1</sup>*Department of Pediatrics, University of California, San Francisco, San Francisco, California, United States of America,*

<sup>2</sup>*Department of Neonatology, Monash Medical Center, Melbourne, Victoria, Australia,* <sup>3</sup>*Department of Neonatology,*

*Kandang Kerbau Hospital, Singapore,* <sup>4</sup>*Department of Pediatrics, Queen Mary Hospital, University of Hong Kong,*

<sup>5</sup>*Department of Pediatrics and Pediatric Cardiology, Veteran General Hospital, Taipei, Taiwan,* <sup>6</sup>*Neonatal Division, Maternal and Perinatal Center, Tokyo Women's Medical College, Tokyo, Japan,* <sup>7</sup>*Department of Pediatrics, University Kebangsaan Malaysia, Kuala Lumpur, Malaysia*

**Objectives:** This study was undertaken to evaluate physician counselling practices and resuscitation decisions for extremely preterm infants in countries of the Pacific Rim. We sought to determine the degree to which physician beliefs, parents' opinion and medical resources influence decision-making for infants at the margin of viability.

**Methods:** A survey was administered to neonatologists and paediatricians who attend deliveries of preterm infants in Australia, Hong Kong, Japan, Malaysia, Taiwan and Singapore. Questions were asked regarding physician counselling practices, decision-making for extremely preterm infants and demographic information.

**Results:** Physicians counsel parents antenatally with increasing frequency as gestational age increases. Most physicians discuss infant mortality and morbidity with parents prior to delivery. Physicians less frequently discuss the option of no resuscitation of an extremely preterm infant, withdrawal of support at a later time, or financial costs to parents. Severe congenital malformations, perception of a poor future quality of life, parental wishes and a high probability of death for the infant are influential in limiting resuscitation in very preterm infants for a majority of physicians. Less influential factors are parent socioeconomic status, language barriers, financial costs for the family, allocation of national resources, moral or religious considerations, or fear of litigation. Physician thresholds for resuscitation of infants ranged between 22 and 25 weeks gestation and between 400 and 700 g birthweight.

**Conclusions:** We report physician beliefs and practices regarding resuscitation and the counselling of parents of extremely preterm infants in Pacific Rim countries. While we find variation among countries, physician practices appear to be determined by ethical decision-making and medical factors rather than social or economic factors in each country.

**Key words:** neonatal mortality; neonatal outcomes; physician counselling.

Numerous studies document chances for survival, risk of neurodevelopment abnormalities and morbidity outcomes for preterm infants as early as 22 weeks of gestation.<sup>1–6</sup> For very premature infants born after 1970, survival rates vary between 30 and 40% and morbidity estimates are reported between 8 and 12% for cerebral palsy, mental retardation, or blindness in survivors.<sup>7,8</sup> Delivery room decisions regarding resuscitations are complicated by uncertain gestational age, uncertainty regarding future prognosis and controversy about appropriate levels of intervention for infants born at the margin of viability. Additionally, the high costs (both financial and emotional) of intensive care for these infants and for their long-term care weigh heavily in the minds of the parents as well as the medical caregivers for these infants.

Little is known about how information of potential outcomes for extremely preterm infants is presented to prospective parents or how physicians view parents' role in determining the extent of support for these infants. It is also unclear how decisions are made to resuscitate (or not) an infant born at the margins of viability. It is clear that decision-making and limitation of resuscitation for these infants are dilemmas for physicians everywhere.<sup>9,10</sup>

We previously developed a network of intensive care units in seven countries of the Pacific Rim with the goal of studying

morbidity and mortality outcomes for extremely low birthweight (ELBW) infants. We enlisted this multicultural consortium to evaluate parent counselling practices and physician resuscitation decision-making for preterm infants in the same countries of the Pacific Rim. We wished to determine which factors influence preterm infant resuscitation practices. We also wished to study the degree to which physician beliefs, parents' opinion and medical resources influence decision-making for extremely preterm infants. This study provides an opportunity to study cultural differences in parent counselling and decision-making.

## METHODS

A survey was developed and mailed to physicians to determine parental counselling practices, physician thresholds for resuscitation of an extremely preterm infant and physician decision-making for these infants. Surveys were sent to all neonatologists in Japan, Australia, Hong Kong, Singapore and Taiwan. In Malaysia, where there are approximately only 35 neonatologists, we also surveyed general paediatricians because they make resuscitation decisions and provide neonatal care for preterm infants. Physician addresses were obtained from local medical society directories by the investigator in each country.

**Table 1** Demographic information of responding physicians in six Pacific Rim countries

	Taiwan	Hong Kong	Singapore	Malaysia	Japan	Australia
Response rate, %	82	46	73	55	38	68
Male, %	81	64	46	43	95	85
Age, mean $\pm$ SEM	40 $\pm$ 1	34 $\pm$ 1	39 $\pm$ 1	40 $\pm$ 1	45 $\pm$ 1	46 $\pm$ 1
Years of practice, mean $\pm$ SEM	12 $\pm$ 1	8 $\pm$ 1	11 $\pm$ 2	12 $\pm$ 1	20 $\pm$ 1	18 $\pm$ 1
Neonatal training, %	100	54	81	39	81	92
Hospital deliveries per year, mean $\pm$ SEM	4075 $\pm$ 760	3223 $\pm$ 291	9723 $\pm$ 291	7806 $\pm$ 857	620 $\pm$ 45	3647 $\pm$ 264
NICU admits, %	16	6	4	11	36	15

NICU, neonatal intensive care unit; SEM, standard error of mean.

Physicians were surveyed from December 1999 through December 2000. Surveys were translated into Japanese and Chinese and were mailed with an English version of the survey to accommodate physician language preference. Site directors reviewed the survey for clarity, language and cultural relevance in each country and added a covering letter explaining the purpose of the study. A stamped return envelope was enclosed for the physician to mail the completed survey to investigators in California. For logistical reasons, a second mailing was not attempted.

Demographic information for physicians was obtained including age, sex, ethnicity, number of years in practice, extent of training, nursery delivery size and number of neonatal intensive care unit admissions per year. Physicians were asked their usual counselling practices for parents expecting an extremely preterm infant as well as questions regarding their views of parental role in determining the extent of medical care for their infant. Physicians were asked to state the birthweight and gestational age threshold below which they would not perform intubation, mechanical ventilation, cardiac massage, drug resuscitation, or chest tube insertion during resuscitation. Questions on antenatal counselling practices and attitudes regarding parental roles in the resuscitation decision were structured using a Likert scale. Responses were grouped corresponding to the frequency of practice: never (<5%), rarely (5–20%), sometimes (21–60%), often (61–95%) and always (>95%). We combined the 'often' and 'always' into a 'yes' group and the 'rarely' and 'never' responses into a 'no' group for analysis. For simplification in the paper, we report the 'yes' responses only. We do not include data for responses marked as 'sometimes' in these analyses. Because physicians could choose to not answer all questions in the survey, the responses may not always add up to 100%.

Completed surveys were mailed to the investigators in San Francisco. Data were compiled and analysed using True Epistat, Version 5.3 (Richardson, Texas). The data are shown as percentages or as mean  $\pm$  standard error of the mean. Analysis of variance (ANOVA) with post hoc analysis using Student–Newman–Keuls for multiple comparisons was used to determine differences in threshold data between countries. Kruskal–Wallis ANOVA was used for multiple comparisons of non-parametric data. Cochran Q test was used in making multiple comparisons of proportional data. Univariate analyses were used to examine the association of predictors (physician age, years of practice, level of training) with threshold data. For all data, the level of significance was  $P < 0.05$ . Approval from the Committee for Human Research was obtained at the University of California, San Francisco and at each site prior to the study.

## RESULTS

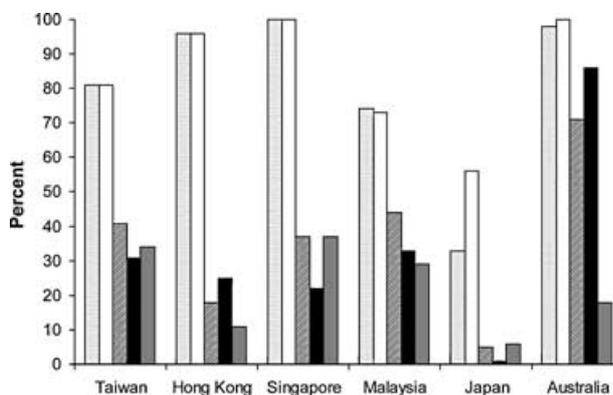
A total of 618 surveys were distributed. Overall, we received 318 responses (51%) to the survey after one mailing. National

**Table 2** Percentage of physicians called by obstetricians to counsel parents prior to the delivery of an ELBW infant. These represent the % of physicians answering 'always' and 'often' in response to the question

	Taiwan	Hong Kong	Singapore	Malaysia	Japan	Australia
22 Weeks	3	18	19	2	12	19
23 Weeks	3	29	48	2	16	50
24 Weeks	19	54	70	2	11	64
25 Weeks	25	64	70	6	10	68

averages ranged between 46 and 82%. The demographic data obtained from the responding physicians are shown in Table 1. The majority of responding physicians were male and with a mean age of 40 years. The majority of physicians (except for Malaysia) were trained in neonatology. We have no data available for physicians who did not respond to the survey.

The percentage of physicians who counsel parents prior to the birth of an extremely preterm infant varies by gestational age as well as by country (Table 2). In most countries, the percentage of physicians who counsel parents increases with increasing gestational age of the infant. Notable exceptions are Japan, where the percentage of physicians counselling parents does not vary over these early gestational ages, and Malaysia, where paediatricians are infrequently called to counsel parents antenatally at any gestational age.

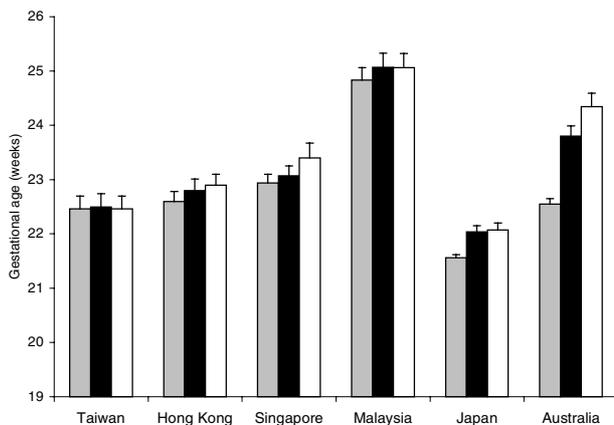


**Fig. 1** Topics discussed by physicians during antenatal counselling of parents expecting an extremely low birthweight (ELBW) infant included morbidity, survival, DNR (do not resuscitate in the delivery room), WDS (withdrawal of support in the nursery after delivery) and financial costs for the parents. These represent the % of physicians answering 'always' and 'often' in response to the question of which topics were discussed with parents during antenatal counselling. □, morbidity; ◻, survival; ◼, DNR; ◼, WDS; ◼, financial cost.

**Table 3** Factors affecting physician discussions and resuscitation options presented to parents during antenatal counselling. These represent the % of physicians answering 'always' and 'often' in response to the question of whether each of these factors influenced their counselling and options presented to parents during antenatal counselling.

	Taiwan	Hong Kong	Singapore	Malaysia	Japan	Australia
Low SES	19	11	15	34	4	12
Previous infant loss	29	36	56	43	4	25
Maternal factors (drug use, illness)	19	30	22	42	8	10
Financial cost (for family)	13	0	30	34	1	2
Teen parents	19	22	26	33	4	12
Language barrier	0	18	7	11	3	18
Health resource allocation	6	0	11	37	1	3
Emotional burden (for family)	23	36	41	36	6	24
Obstetrician opinion	9	36	52	23	20	30

SES, socioeconomic status.

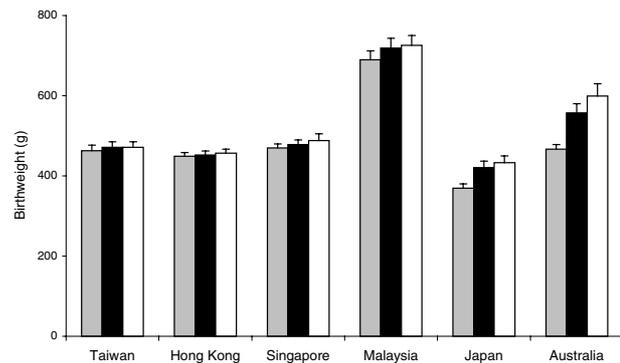


**Fig. 2** Gestational age thresholds for resuscitation of very premature infants for endotracheal intubation, cardiopulmonary resuscitation (CPR) includes chest compressions, and giving medications (epinephrine, adrenaline) in the delivery room. Thresholds for Malaysia (intubation, CPR and Meds) and for Japan (intubation only) are significantly different (ANOVA,  $P < 0.05$ ). □, intubation; ■, CPR; ▣, medications.

The majority of physicians discuss morbidity and survival when counselling parents before the birth of an extremely preterm infant (Figure 1). Morbidity is less often discussed in Japan ( $P < 0.05$ ). Discussions of no resuscitation in the delivery room or the withdrawal of support during later neonatal care are variable in the countries surveyed. Physicians in Australia regularly discuss these scenarios, while Japanese physicians report they infrequently discuss these topics ( $P < 0.05$ ).

Parental factors that influence physician-counselling practices for parents expecting the delivery of an extremely preterm infant are shown in Table 3. Financial factors (including financial cost to family, socio-economic status of parents, young maternal age, maternal risk factors, resource allocation) are more influential in countries where families carry the financial burden for hospitalization costs (Malaysia, Singapore). This finding contrasts with countries where financial considerations are less influential because of government support or insurance plan coverage for neonatal intensive care (Japan, Australia, Hong Kong). The emotional burden for the family is variable in the degree of importance for physicians. The influence of obstetric opinion on paediatricians' practice is also quite variable in importance (range of 9–52%).

The majority of physicians use personal threshold criteria for initiating resuscitation of infants in the delivery room (data not shown, range 15–66%). Only in Singapore, does a majority of



**Fig. 3** Birthweight thresholds for resuscitation of very premature infants for endotracheal intubation, cardiopulmonary resuscitation (CPR) includes chest compressions, and giving medications (epinephrine, adrenaline) in the delivery room. Thresholds for Malaysia (intubation, CPR and Meds) and for Japan (intubation only) are significantly different (ANOVA,  $P < 0.05$ ). □, intubation; ■, CPR; ▣, medications.

physicians (66%) practice under a written hospital resuscitation policy for extremely preterm infants. Figures 2 and 3 show the gestational age and birthweight thresholds for intubation, cardiac massage/chest compression, or medications for resuscitation of premature infants in the delivery room. Overall, the gestational age and birthweight limits are similar in the countries except for higher gestational age and birthweight thresholds in Malaysia and lower gestational age thresholds in Japan (ANOVA,  $P < .05$ ).

Factors that influence limitations of resuscitation in the delivery room for infants born between 23 and 25 weeks gestation are shown in Table 4. The majority of physicians (except those in Japan) feel that the presence of severe congenital anomalies and the perception of a poor future quality of life are important considerations in making the decision to limit resuscitation for very preterm infants. The majority of physicians (except in Japan) report parental wishes and the high probability of death despite resuscitation efforts are also important for limiting resuscitation. Less commonly considered factors are perception of infant pain and suffering, moral and religious considerations, or emotional burden for parents (except in Malaysia). Considerations of financial costs and allocation of resources are more important in countries where financial burden of medical care directly affects parents (Malaysia and Singapore).

We asked physicians who should make the final decision regarding resuscitation for very premature infants when parents and physicians disagree. In Malaysia, the majority of physicians feel that the final decision-maker should be the physician (Table 5). Conversely, in Taiwan and Australia a slim majority of

**Table 4** Factors affecting physicians' decisions to limit resuscitation in the delivery room for infants born between 23 and 25 weeks gestation. These represent the % of physicians answering 'always' and 'often' in response to the question of whether these factors influences their decision to limit resuscitation.

	Taiwan	Hong Kong	Singapore	Malaysia	Japan	Australia
Congenital anomaly	75	93	93	96	61	87
Poor quality of life	72	71	74	75	24	76
Parents' wishes	50	74	70	50	12	86
Probable death	63	68	78	87	20	81
Infant pain	22	14	22	28	5	29
Morals/religion	34	11	26	42	3	29
Emotional burden (for family)	31	30	33	55	5	21
Financial cost (for family)	16	4	30	26	1	5
Health resource allocation	6	11	19	45	2	5
Litigation fear	22	15	15	20	5	3

**Table 5** The final decision-maker in cases of disagreement in resuscitation decision-making between parents and physicians. These represent the % of physicians who responded 'always' and 'often' in response to the question

	Taiwan	Hong Kong	Singapore	Malaysia	Japan	Australia
Parents	53	33	46	20	23	57
Physician	28	37	46	72	49	37
Ethics Committee	19	22	8	8	15	2

physicians feel that parents should have the final say. Physicians are more divided in opinion in other countries. Most physicians agree that ethics committees have a very minor role in making these decisions.

## DISCUSSION

We report a study of physician practices regarding resuscitation and counselling of parents of extremely preterm infants in six Pacific Rim countries. In general, paediatricians counsel parents with increasing frequency as gestational age increases and discuss risk of infant mortality and morbidity with parents. Physicians report that they less frequently discuss withholding resuscitation in the delivery room or later withdrawal of support in the neonatal intensive care unit (NICU). Physicians infrequently consider parental socio-economic status, maternal risk factors, language barriers, or costs of medical care for the family and to society when counselling parents prior to the delivery of a preterm infant. Factors that influence physicians to limit resuscitation of very preterm infants include severe congenital malformations, perceived poor future quality of life for the infant, parental wishes, or a high probability of death despite continued medical treatment. Physicians are less influenced by religious considerations, perception of infant pain and suffering, financial cost issues (to both family and society) and fear of litigation in making resuscitation decisions. With minor variation, thresholds for resuscitation practices are comparable in the six Pacific Rim countries.

One of the main goals of this study was to explore how physicians counsel parents expecting an extremely preterm infant. Physicians are more likely to counsel parents as viability becomes more likely with increasing gestational age. We have previously shown in California that by 24 weeks gestation, about 80% of paediatricians report being called by obstetricians to counsel parents expecting a very low birthweight infant.<sup>11</sup> In this

current study, we found a marked variability in the percentages of physicians who are called by obstetricians to counsel parents antenatally. Paediatricians in Malaysia, Japan and Taiwan are infrequently called to counsel parents antenatally. There may be a number of explanations for these low percentages including a local disinclination towards counselling of parents where antenatal counselling represents an unusual medical practice. Additionally, physicians may not counsel parents if they have a routine medical style of managing all premature infants. The low numbers of antenatal counselling in some countries may reflect either routine resuscitation of premature infants at each centre, or the reverse, that there is a low expectation by obstetricians for neonatal survival.

Our survey results show that once paediatricians are called to counsel parents, the majority of physicians discuss survival and future morbidity, while other topics are less frequently discussed. An exception is Australia, where physicians report they commonly discuss the option of no resuscitation in the delivery room and withdrawal of support in the nursery. Physicians report they are infrequently influenced by factors such as parental socio-economic status, teen parents, financial costs for the family, language barriers, health resource allocation and maternal factors such as illness or drug use. Physicians appear to strive for medical decision-making without undue influence of these factors. Despite economic, religious and cultural differences among the countries, physician counselling appears to be determined by medical factors rather than socio-economic variables.

We have previously reported physician counselling practices and thresholds for resuscitation for neonatologists and obstetricians practicing in California.<sup>11,12</sup> In our previous studies, we found the thresholds for infant resuscitation for California physicians to be similar to those thresholds reported in this current study of the Pacific Rim. Thresholds reported by neonatologists in California were birthweight between 450 and 500 g and gestational age between 22 and 24 weeks and are similar to the thresholds presented in this current study. In this current report, we found little variation in physician resuscitation practices among countries studied in the Pacific Rim. Since the majority of physicians do not practice in hospitals with written guidelines for resuscitation, we speculate that these thresholds reflect physician knowledge of viability and infant outcomes for premature infants in their local communities as well as those reported for extremely premature infants. The reported thresholds are similar to guidelines made by the American Academy of Paediatrics that states that non-initiation of resuscitation is appropriate for infants with confirmed gestation <23 weeks, birthweight <400 g, anencephaly, or known trisomy 13 or 18.<sup>13</sup>

Once resuscitation has been initiated, the majority of physicians use factors such as the presence of severe congenital

anomalies, future poor quality of life, high probability of death despite continued support and parental wishes in the decision to limit further resuscitation. Other investigators have also shown that neonatologists are influenced by parental wishes and the presence of congenital anomalies in making the decision to resuscitate a very preterm infant.<sup>14</sup> We found that factors such as costs of care, resource allocation, fear of litigation and religious factors are less influential for the majority of physicians. The notable exception to these generalizations is seen with physicians in Japan. Except for the presence of severe congenital anomalies, Japanese physicians report that they are infrequently influenced by additional factors in limiting resuscitation after delivery of an extremely preterm infant. This finding may reflect Japan's Eugenic Protection Act that defines viability at 22 completed weeks of gestation.<sup>1</sup> We speculate that this legal definition of viability provides a more consistent approach to resuscitation of a preterm infant that limits physician autonomy and decision-making in the delivery room. Overall, our results suggest that physicians base their medical decisions on ethical decision-making and medical factors rather than sociodemographic or economic variables.

The degree to which physicians allow parents the responsibility in decision-making for their critically ill infants remains variable. Physician perceptions that limit parental decision-making include possible parental feelings of guilt, parental inability to make decisions because of incomplete understanding of medical information, or decisions made that are not in the 'best interest' of the child. In a retrospective study from Scotland, parents were interviewed about their role in the decision to withdraw support in their critically ill infants.<sup>15</sup> A majority of parents (56%) reported they made the decision to withdraw support for their preterm infant and were satisfied with the process. A few parents reported that they wished they had taken more responsibility in the decision. Factors that were associated with parental satisfaction were full disclosure of information and evidence for poor infant prognosis. In our survey, during antenatal counselling, most physicians report they discuss infant mortality and morbidity with parents, yet discussion of withdrawal of support or limits in resuscitation does not as frequently occur. Antenatal counselling sessions are often the first time parents learn about what to expect with a preterm delivery. Limitation of information during these counselling sessions might be viewed as limitations to parental autonomy. We speculate that the extent to which physicians counsel and educate parents correlates with the extent to which physicians allow parental decision-making to occur.

We found variability in physicians' choice of the final decision-maker for resuscitation in cases of disagreement between parents and physicians. In Malaysia, the majority of respondents (72%) report that physicians should make the final decision, while the majority of Australians (57%) feel that parents should make the final decision. While physicians in the other countries were split in deciding between parents and physician as the final decision-maker, the majority of physicians agree that ethics committees do not have precedence over parents or physicians in cases of disagreement. We previously reported that neonatologists in California are in agreement with Pacific Rim physicians that ethics committees have little role in cases of disagreement between parents and physicians.<sup>11</sup> In California, <1% of neonatologists would look to their local ethics committee for resolution of disagreements regarding the resuscitation of a premature infant.

Potential limitations of the study must be acknowledged. Because of the great distances involved, a second mailing of the survey was not attempted. We have no way of ascertaining how many addresses were incorrect and did not reach physi-

cians, or how many physicians chose to not answer our survey. We also do not have any demographic information about physicians who did not participate in the study. Despite these logistic limitations, we were quite pleased with the overall response rate of 51%. On closer scrutiny, some of the country's responses were quite high (73% and 82%, for example). This leads us to believe that physicians worldwide find the topics addressed in our survey to be important and pertinent to their medical practice. Another limitation of our study is that these data represent an analysis of physicians' reported practices. We do not know what physicians actually do in these situations, nor do we know the reasons for physicians' beliefs and practices in these situations. Despite these limitations, physician resuscitation practices across the various countries are quite similar and lead us to believe that our findings are representative of physician practices in the countries studied. Additionally, similar findings between the current report and our previous report of California neonatologists support our impression that physician practices and decision-making for preterm infants are determined by a shared medical culture.

In summary, we report parent counselling and physician resuscitation practices for extremely low birthweight infants in various countries of the Pacific Rim. We speculate that the variability in the counselling practices among countries reflects cultural differences and customary local medical practices in each country. We found significant agreement in resuscitation practices among the physicians. Overall, birthweight and gestational age thresholds were similar (with few statistical differences noted) among the physicians. Despite economic, religious and cultural differences and influences, we speculate that physician resuscitation practices are determined by medical factors (such as viability limits) rather than socio-demographic or economic variables in each country.

## ACKNOWLEDGEMENT

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