

INTERNATIONAL VARIATIONS IN APPLICATION OF THE BEST INTEREST STANDARD ACROSS THE AGE SPECTRUM

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ABSTRACT:

Objective: Ethically and legally, assertions that resuscitation is in a patient's best interest should be inversely correlated with willingness to forego intensive care (and accept comfort care) at the surrogate's request. Previous single country studies have demonstrated a relative devaluation of neonates when compared with other critically ill patients.

Study Design: In this international study, physicians in Argentina, Australia, Canada, Ireland, The Netherlands, Norway, and the United States were presented with 8 hypothetical vignettes of incompetent critically ill patients of different ages. They were asked to make assessments about best-interest, respect for surrogate autonomy and to rank the patients in a triage scenario.

Result: 2237 physicians responded (average response rate 61%). In all countries and scenarios, participants did not accept to withhold resuscitation if they estimated it was in the patient's best interest, except for scenarios involving neonates. Young children (other than neonates) were given high priority for resuscitation, regardless of existing disability. For neonates, surrogate autonomy outweighed assessment of best interest. In all countries, a 2 month old infant with meningitis and a multiply disabled 7 year-old were resuscitated first in the triage scenario, with more variable ranking of the two neonates, which were ranked below patients with considerably worse prognosis.

Conclusion: The value placed on the life of newborns is less than that expected according to predicted clinical outcomes and current legal and ethical theory relative to best interests. Value assessments on the basis of age, disability, and prognosis appear to transcend culture, politics and religion in this domain.

INTRODUCTION

Technological advances in medicine have led to higher survival rates of critically ill patients, but some patients survive with a compromised quality of life. Life-threatening conditions such as meningitis, trauma, or asphyxia can leave survivors with profound neurologic sequelae, and may lead to complex decision-making about continued medical care. The majority of neonatal and pediatric deaths, both within and outside of ICUs, generally follow withholding or withdrawing life-sustaining interventions^{1,2}. Across the age spectrum, when critically ill patients are unable to participate in life-and-death decisions about their own care surrogate decision-makers are called upon to provide insights which inform physician's management decisions.

Decision-making surrounding withholding or withdrawing life-saving interventions involves assessment of survival and outcome, a calculus which indirectly involves value-judgments about the patient's life. Traditional legal and ethical teaching states that assessment of the patient's best interest should guide the care of incompetent patients³. The best interest standard calls upon surrogates to determine "the highest net benefit among available options," taking into account risks and benefits, quality-of-life considerations, and, for previously competent patients, their known personal preferences⁴. If an intervention is considered to be in the patient's best interest, and significant harm is caused by not intervening, refusal of treatment is generally not ethically or legally permissible.

In 2008, *Janvier et al* published a study demonstrating systematic devaluation of neonates during resuscitation decisions in comparison to older patients with worse prognoses⁵. Accepting a family's refusal of resuscitation, even among participants who thought that resuscitation was in the patient's best interest, was much more common for newborns. Although

this study demonstrated high response rates and internal validity, the external validity is unclear due to the predominately student participant cohort at a single university center. The purpose of this study was to evaluate how life and death decisions are made for incompetent patients in seven different countries using the same questionnaire. Specifically, we sought to describe whether the best interest principle was followed for resuscitation decisions in critically ill patients.

METHODS

The questionnaire was developed by Janvier⁵ and was translated, pilot tested, and administered to physicians in 7 different countries: Argentina, Australia, Canada, Ireland, The Netherlands, Norway, and the United States (U.S.). Results were collected and analyzed by individual investigators in each country; the studies in the U.S., Norway, Ireland, and Australia were independently published^{6,7,8,9}. Differences between countries in the survey instrument and data collection methods prohibit the analysis of these results as a single data set. Specific sampling and survey methods by country are described in Table 1. Between-country differences in the survey instrument are described below.

The questionnaire detailed eight scenarios of currently incompetent, critically ill patients of different ages, all with potential neurologic sequelae. All arrived in the emergency department of a university health center without a surrogate decision-maker. Detailed descriptions of the vignettes are shown in Appendix 1. The specific probabilities for each patient's outcome are detailed in Table 2. We did not provide information on gender, marital, or socioeconomic status. Four of the hypothetical patients had a 50% chance of survival: a 24-week gestation premature infant; a term neonate with a known brain malformation (arteriovenous malformation [AVM]); a 2-month-old with bacterial meningitis; and a 50-year-old after a motor vehicle collision (MVC).

If these patients survived, 50% would survive without impairment, 25% mildly or moderately impaired, and 25% severely impaired. For the neonates, the vignettes assumed no previous opportunity for antenatal counseling.

Two other patients were already disabled: a 7 year-old with multiple neurologic and cognitive disabilities (including cerebral palsy [CP], deafness and learning disabilities) with new head trauma, and an 80 year-old with dementia and a new stroke. Both had a 50% chance of predicted survival and, if they survived, a 50% risk of further impairment.

Two patients had a 5% chance of survival: a 14 year-old with acute myeloid leukemia (AML) and sepsis, with a 20% risk of impairment, and a 35 year-old with brain cancer, with a 100% risk of disability with invasive intervention (See Appendix 1).

Following each vignette, participants were asked the following questions:

- “Do you think that intubating, resuscitating, and consulting intensive care for admission is in the patient’s best interest?”
- “If the parents/family asked you not to resuscitate, would you respect their decision?”

For each question, response options included: always, general, exceptionally, or never.

Responses of “always” and “generally” were as analyzed as affirmative answers.

The surveys were quite similar in all countries, with small differences in wording of the survey questions based on country specific emergency care settings and phrasing of clinical presentation, without substantive differences in the scenarios. All countries reported the same prognoses in each vignette. Surveys for Argentina, The Netherlands, and Norway were translated into Spanish, Dutch, and Norwegian respectively. Norway administered the survey as part of a larger questionnaire and excluded the scenarios for the teenager and adult with cancer and a poor prognosis. Of note, although the original survey developed for the Canadian study used an age of

14 years old for the teenage patient with AML, Australia, Ireland, The Netherlands, and The United States used an age of 13. Tables and figures present an age of 13 as this was used by the majority of countries.

Participants were also presented with a scenario in which all 8 patients arrived in the emergency department simultaneously. They were asked to rank the patients by resuscitation priority. Statistical evaluation for some of the previously published data can be found in the original publications^{6,7,8}. For the ranking data, the average position for each of the eight vignettes was used. The study was approved by each institution's IRB where ethics review was required.

RESULTS

A total of 7,148 surveys were received by physicians in 7 countries; a total of 2,237 surveys are presented. The response rate by country ranged from 24% in Argentina to 78% in Australia. The majority of participants were physicians involved in the care of neonates. Additional demographic data are reported in Table 1.

Best Interest

Estimations of the best interest for the 8 patients are shown in Figure 1. The majority of participants considered resuscitation to be in the best interest of all the patients with a 50% chance of survival except the 80-year-old patient. The 2-month-old infant and the 7-year-old child with multiple disabilities had the most participants stating that it was always or generally in the best interest of the patient to be resuscitated (over 90% in every country), followed by the 50-year-old patient where estimations of best interests were over 70% in all seven countries. The majority of participants in all countries felt that resuscitation was not in the best interest of the 80

year-old. There was greater variability among responses to best interest question with the two patients with lower chance of survival (14 year-old AML/sepsis and 35 year-old/brain tumor). The affirmation of best interest for the patients with a 5% probability of survival ranged from 42% in the US to 70% in Argentina.

Best Interest vs. Accepting Non Resuscitation

In all seven countries, four of the vignettes elicited the expected pattern: when resuscitation was estimated to be in the patient's best interest, requests to withhold it were not accepted (2 month-old, 7 year-old, 50 year-old), or conversely (80 year-old) (Figure 1). The one exception was The Netherlands, which favored autonomy over best interest for the 50 year-old.

In contrast, for the two neonates, although the majority of participants estimated that resuscitation would be in their best interest (except for The Netherlands), the majority *would also accept* requests to withhold resuscitation and give comfort care. Best-interest valuations greatly exceeded acceptance of non-resuscitation in Argentina compared to other countries (Figure 1).

Triage Scenario

In every country, participants would resuscitate the 2 month-old or the multiply disabled 7 year-old patient first or second, and the 80 year-old patient was consistently ranked last. The 3rd through 7th ranks varied greatly between countries (Table 3). The results from the Netherlands were the most incongruous; here the premature infant was ranked second to last, followed only by the 80 year-old.

DISCUSSION

This evaluation of how the best interest standard is applied for incompetent, critically ill patients across the age spectrum is the first to examine variations among physicians across

multiple culturally different countries. When the initial iteration of this survey was published in 2008, many clinicians hypothesized that the apparent systematic devaluation of neonates was the result of cultural characteristics, the Canadian universal health care system, and limitation in sampling. We hypothesized that the results of this same questionnaire in culturally diverse countries would differ, but overall we found striking similarities in ethical decision-making. In fact, the results of these surveys are similar to those found among students of diverse academic disciplines⁵ and among physicians who care for patients across the age spectrum.

Legally and ethically, assertions that resuscitation is in the patient's best interest should be inversely correlated with willingness to forego resuscitation at the family's request. The majority of participants estimated that resuscitation was in all patients' best interests, except for the 80 year-old. For the elderly patient, few asserted that resuscitation was in this patient's best interest and the majority would accept a family's request for comfort care. For the 2 month-old with meningitis, the 7 year-old with multiple impairments and the 80 year-old with dementia and new stroke, the application of the best interest standard was applied similarly in all seven countries. For the two children, physicians favored prolongation of life, even over the parents' objections. However, for the two neonates, although the majority estimated resuscitation was in their best interest, the majority were also willing to provide comfort care at the family's request.

The age of the patient appeared to be the strongest influence in the valuation of the patient's life, except for neonates. In the best-interest assessments and the triage scenario, the healthy 2 year-old with meningitis and the 7 year-old with pre-existing multiple disabilities were uniformly valued most highly. The 14 year-old with poor prognosis leukemia was ranked relatively highly in the triage scenario, despite having the same or worse prognosis as some of the older patients presented. Younger persons may be seen as having more potential and

therefore “more to lose”. This is also known to as the “fair innings” argument, in which health care resources should be distributed to “reduce inequalities in people's lifetime experience of health”¹⁰. However, our findings for the 2 newborn vignettes are inconsistent with this argument. Although the majority of participants were involved in the care of neonates, their answers were probably not guided by their clinical perspective. Indeed, the physicians in Norway who were not pediatricians provided similar answers, as did previous cohorts where participants were university students without medical background⁵. It seems the unique response to the neonatal vignettes transcends clinical specialty and profession.

The prognosis provided for all three of the infants (preterm, term and 2 month-old) was explicitly described and was the same, but we found striking differences in decision-making within this group. The 2 month-old with meningitis was consistently ranked first or second in the triage scenario, and participants followed the best interest standard for this scenario, but the two neonates were consistently ranked lower in the triage scenario – as low as 5th or 7th position in some countries and the majority accepted comfort care for them.

We have demonstrated systematic devaluation of neonates in a seven culturally diverse countries. There are a number of possible explanations for our findings. One is persistent bias against extremely preterm infants, despite advances in technology which have allowed improvements in the rates of mortality and morbidity in this population. The lack of personhood that is seemingly associated with premature babies could explain these findings^{5, 11}. Previous explanations of this devaluation have examined the concept of “saving” vs. “creating” a disabled life, which leads to differential decision-making for children with existing disabilities, as opposed to allowing the lives of neonates to begin and assuming responsibility for their disabilities^{12, 13}. This kind of bias is reinforced by existing policies and guidelines regarding the

resuscitation of marginally viable neonates, which recommend careful and deliberate provision of prognostic information to expectant parents based on weeks of completed gestation and do not presume that resuscitation will occur¹⁴. Default options may be strong influencers of decision-making in the delivery room.¹⁵ In contrast, resuscitation of older children and older adults tends to be the default option and is not governed by institutional and organizational norms in the same way^{12, 16}.

Strikingly, in The Netherlands, the premature baby was ranked only higher than the 80 year-old patient with dementia and new brain injury. Although the Netherlands have levels of intervention similar for many pathologies, their policy statement for extremely preterm infants is non-interventionist compared to other countries¹⁷. Indeed, at the time of the survey, the policy statement informed neonatologists that intervention for a neonate born at 24 weeks was not indicated¹⁸. We speculate that policy statements may drive this anomalous finding, and may lead to a self-fulfilling prophecy.

Alternatively, an explanation for these findings is that participants simply did not accept the prognostic data we provided⁸. It is possible that participants did not read the outcome data we provided or did not believe the data for neonates. On the other hand, because the majority still estimated resuscitation was in their best interest, this is unlikely to be the only explanation.

Although our findings were similar in all countries, we did identify some interesting differences. In regards to the seemingly polarizing neonatal scenarios, physicians from Australia, Canada and the Netherlands tended to defer to family requests for non-resuscitation over best-interest valuations, whereas those from Argentina and Ireland favored resuscitation. These variations between countries may represent systematic differences in cultural views of reproductive autonomy, access to and employment of pregnancy termination, and predominant

religion. Differences in approach to systems for financing healthcare in these countries may also be relevant. Although substantive consideration of how these contextual features impacted our findings was not informed by our survey questions, these influences are worthy of further study employing additional research methods.

Physicians from the U.S. and Norway occupied an interesting position on the spectrum of decision-making. For the term infant with a brain vascular malformation, opinion appeared to be consistent with responses from Argentina and Ireland, favoring resuscitation over parental autonomy (although less dramatically). For the extremely preterm infant, U.S. and Norway physicians showed a more unique pattern of decision-making for our survey, in which nearly equal numbers supported both the best-interest assertion and deferral to the family about resuscitation. Again, this finding is thought-provoking, but our study design does not allow for its systematic analysis in the political, religious, economic, and cultural contexts of these countries.

These findings^{6,8} are similar to those noted in the Canadian cohort of students and trainees not included in this study^{5,11}, supporting the claim that neonates, particularly those who are born extremely prematurely, represent a unique population when it comes to ethical decision making, in which traditional ethical principles break down and neither best-interest assessments nor parental autonomy prevail. Future work in this domain could further explore the complexed and nuanced values of expectant parents are considered by physicians, as these are increasingly emphasized in guidance for antenatal consultation^{19,20}.

This study has limitations. Most importantly, variations in survey methods including modality, sampling frame, survey instrument, and population surveyed preclude analysis of these individual studies as a single data set, which would have allowed for additional statistical

analyses and may have strengthened the significance and interpretability of the findings. These variations may also have been a significant factor affecting the response rates, which were quite variable. The responses we present are those for hypothetical scenarios; anticipated behaviors and decision-making might differ significantly from real life situations, and the discrepancy between intent and behavior has been well described²¹. However, marked variation in the care of neonates has been demonstrated in the literature, suggesting that our findings may represent true decision-making patterns of physicians^{4,22}.

Nonetheless, this paper presents a large cohort of survey responses from around North America, Europe, and Australia with surprisingly consistent findings in a number of domains, suggesting that for some bioethical questions, physician attitudes transcend the political, religious, and cultural climate of the country of origin.

Conclusions

Physicians in seven different countries do not consistently apply the best interest standard across the age spectrum. Age, prognosis, and previous disability all appear to influence medical decision-making and respect for surrogate autonomy. A unique pattern of ethical analysis appears to apply to preterm and term neonates, who are devalued compared to other vulnerable patients, independent of culture or country.

Conflict of Interest: The authors declare no conflict of interest.

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Figure 1: Is resuscitation in the best Interest of the patient vs. Would you agree to withhold resuscitation and give comfort care that the family's request? Percent Affirmative

Responses Vignette and Country* (CP – cerebral palsy, MVC – motor vehicle collision, AML – acute myelogenous leukemia, C-spine – cervical spine) ** Norway did not present the two scenarios with a poor prognosis for survival (14 year-old, 35 year-old)

Figure 1: Is resuscitation in the best Interest of the patient vs. Would you agree to withhold resuscitation and give comfort care that the family's request? Percent Affirmative Responses Vignette and Country* (CP – cerebral palsy, MVC – motor vehicle collision, AML – acute myelogenous leukemia, C-spine – cervical spine) ** Norway did not present the two scenarios with a poor prognosis for survival (14 year old, 35 year old)

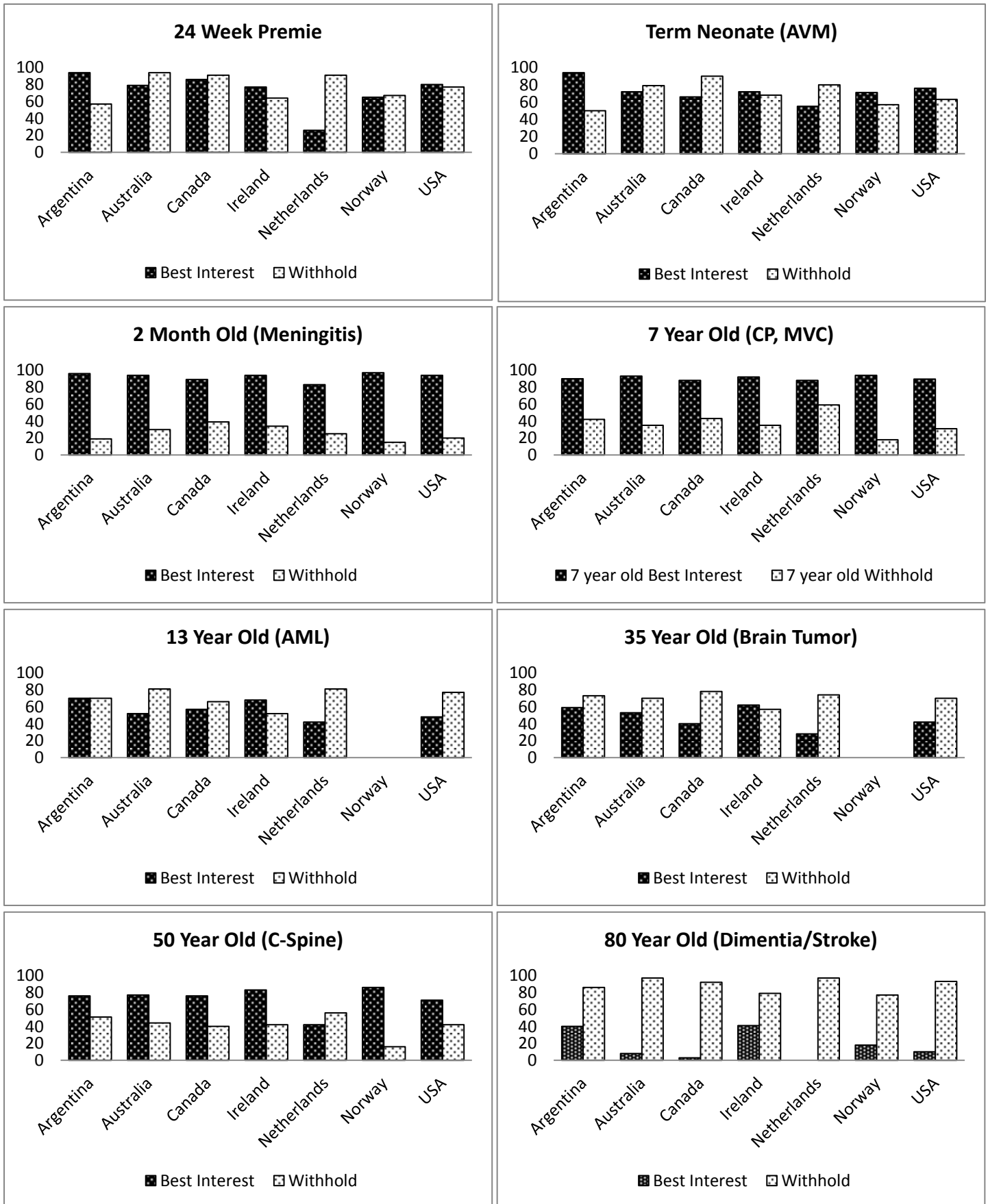


Table 1: A summary of survey methods and sampling frames in each country ^{6,7,8}

| Country (year) | Method | Sampling Frame (% completed training) | N participants/ response rate | Age or years in practice | % women | % with children |
|--------------------|----------|---|--|--|-----------|-----------------|
| Argentina (2008) | Internet | Convenience sample of neonatologists in Argentina (100%) | 112 (24%) | Years in practice: Mean 17.3 SD 9.7 | Not asked | Not asked |
| Australia (2009) | Internet | All neonatologists (100%) | 109 (78%) | 18% 30-39 41% 40-49 30% 50-59 11% > 60 | 37% | Not asked |
| Canada (2008) | Mail | All neonatologists (100%) | 93 (70%) | Years in practice: 67% > 5 years | 47% | 86% |
| Ireland (2009) | Mail | Cork University Hospital consultant and non-consultant doctors in neonatology, pediatrics, obstetrics, and emergency medicine (18%) | 90 (70%) | Not asked | 48% | Not asked |
| Netherlands (2009) | Mail | All neonatologists (93%) | 69 (33%) | 4% 25-30 36% 30-36 33% 40-49 20% 50-59 7% > 60 | 63% | 67% |
| Norway (2008) | Mail | Random sampling (n=1650) of all members of the Norwegian Medical Association (n=20225) 3.3% pediatricians (100%) | 1069 (66%) | Mean age 48 (47.3-48.7 95% CI) | 41% | Not asked |
| USA (2009) | Internet | All neonatologists and high-risk obstetricians in largest professional societies 85% neonatologists (94%) | 695 (16 %) (total deployed survey links) (70% of opened links) | Years in practice 16% <5 yrs 13% 5-10 yrs 12% 10-15 yrs 15% 15-20 yrs 44% > 20 yrs | 40% | 84% |

Table 2: Probability of Outcomes for Each of the 8 Patient Scenarios

| Description of Patient | Probability of survival | Probability of normal outcome among Survivors | Probability of new significant disability |
|--|--------------------------------|--|--|
| 24 week preterm infant | 50 | 50 | 25 |
| Term infant with arteriovenous malformation | 50 | 50 | 25 |
| 2 month old infant with meningitis | 50 | 50 | 25 |
| 7 year-old child with cerebral palsy, status post MVC* | 50 | 0 | 50 |
| 14 year-old with aggressive leukemia | 5 | 80 | 20 |
| 35 year-old with aggressive brain tumor | 5 | 0 | 100 |
| 50 year-old status post MVC with cervical spine injury | 50 | 50 | 25 |
| 80 year-old with dementia, new stroke | 50 | 0 | 50 |

* Motor-vehicle collision

Table 3: Summary of ranking data in triage scenario by country*

| Ranking | Argentina | Australia | Canada | Ireland | Netherlands | Norway | USA |
|---------|-------------------------------|-------------------------------|-------------------------------|---|-------------------------------|-------------------------------|---|
| 1 | 2-month-old | 2-month-old | 2-month-old | 7-year-old | 2-month-old | 7-year-old | 2-month-old |
| 2 | 7-year-old | 7-year-old | 7-year-old | 2-month-old | 7-year-old | 2-month-old | 7-year-old |
| 3 | Premature Infant (24 week GA) | Premature Infant (24 week GA) | Premature Infant (24 week GA) | Term Infant | Term Infant | 50-year-old | Premature Infant (24 week GA) & Term Infant |
| 4 | Term Infant | Term Infant | 14-year-old | 14-year-old | 14-year-old | Term Infant | |
| 5 | 14-year-old | 14-year-old & 50-year-old | Term Infant | Premature Infant (24 week GA) & 50-year-old | 35-year-old | Premature Infant (24 week GA) | 14-year-old |
| 6 | 50-year-old | | 50-year-old | | 50-year-old | | |
| 7 | 35-year-old | 35-year-old | 35-year-old | 35-year-old | Premature Infant (24 week GA) | | 35-year-old |
| 8 | 80-year-old | 80-year-old | 80-year-old | 80-year-old | 80-year-old | 80-year-old | 80-year-old |

* Norway did not present the two scenarios with a poor prognosis for survival (14 year-old, 35 year-old)