Disparities between perceived and true outcomes of infants born at 23-25 weeks' gestation

Running head: Perceptions of outcomes of 23-25 week infants

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Contributions

RAB designed the study, wrote the ethics, distributed the survey, analysed the data with LWD, and wrote the draft manuscript. JLC and LWD supervised and contributed to the study design, statistical analysis, and edited the manuscript. JLC, SK, MJS and LWD all edited the manuscript. Each author has reviewed the manuscript and approved submission of this version. The authors take full responsibility for the manuscript.

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ABSTRACT

Background

Decision-making for infants born at 23-25 weeks involves counselling parents about survival and major disability risks. Accurate information is needed for parents to make informed decisions about their baby's care.

Aims

To determine if perinatal clinicians had accurate perceptions of outcomes of infants born 23-25 weeks' gestation, and if accuracy had changed over a decade.

Materials and methods

A web-based survey was sent to midwives, nurses, neonatologists, and obstetricians working in tertiary and non-tertiary hospitals, and the neonatal retrieval service in the state of Victoria in 2020. A similar survey had been completed in 2010.

Clinicians' estimates of survival and major neurodevelopmental disability rates were compared with true rates for actively managed infants overall, and by infant birthplace and gestational age, and professional workplace and discipline. Accuracy of outcomes was compared between eras.

Results

Overall, 165 surveys were received. Participants underestimated survival (absolute mean difference [%] -14.4; 95% confidence interval (CI) -16.6, -12.3; p<0.001) and overestimated major disability (absolute mean difference [%] 32.7; 95% CI 29.7, 35.8; p<0.001) rates overall, and at each week of gestation, and were worse for outborn compared with inborn infants. Perceptions of clinicians in tertiary centres were similar to those of non-tertiary clinicians. Nurses/midwives were more pessimistic, and paediatricians were more optimistic. Clinicians' perceptions of outcome were less accurate in 2020 than in 2010.

Conclusions

Most perinatal clinicians underestimate survival and overestimate major disability of infants born at 23-25 weeks' gestation, which may translate into overly pessimistic counselling of parents.

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Most perinatal clinicians underestimate survival and overestimate major disability of infants born at 23-25 weeks' gestation, which may translate into overly pessimistic counselling of parents.

INTRODUCTION

Decision-making for infants born between 23-25 weeks' gestation involves parent counselling about survival chances and risks of major neurodevelopmental disability if neonatal intensive care is offered.[1] It is essential that shared decision-making about provision of intensive care to these infants is based on accurate knowledge of outcomes for the infant.[2-4] Previous studies, including our own,[5] have demonstrated that many clinicians underestimate survival chances and overestimate the risk of major neurodevelopmental disability in surviving children born preterm. [5-11] These studies highlight the need for a readily available tool for clinicians to calculate outcomes for individual infants based on perinatal risk factors and local outcome data, as outcomes differ between geographic regions.[5 12] The current study was conducted to determine contemporary perceptions of outcomes for infants born at 23-25 weeks' gestation prior to implementation of a preterm birth outcome predictor tool.

The aims of the current study were to determine how accurately perinatal clinicians estimated rates of a) survival, and b) major disability in survivors among livebirths at 23-25 weeks' gestation who were to be offered active management from birth. We also aimed to determine how accuracy of perceptions of outcome varied according to place of birth (inborn versus outborn birth) and gestational age of the infants, and clinician workplace (tertiary or non-tertiary service) and discipline of the respondents. Our final aim was to determine if accuracy of clinicians' perceptions of outcomes had changed over the past decade.

MATERIALS and METHODS

Survey Design

We designed a survey in REDCap™ (Research Electronic Data Capture, Vanderbilt University, Tennessee, USA), (Appendix 1). Participants were asked to state their profession and the perinatal service in which they practised (tertiary, non-tertiary or

neonatal emergency retrieval service), and their total years of experience in perinatal care.

Participants were asked to estimate the chances of survival to one year following livebirth and active management, and the chances of major disability at school age in survivors under several different scenarios: 'outborn' (born in a non-tertiary hospital) versus 'inborn' (born in a tertiary centre) status, at each of 23, 24 and 25 weeks' gestation. Sliding scales from 0% (no chance of survival/disability) to 100% (all survive/are disabled) were provided that permitted participants to select an exact number between 0% and 100% and gave a visual representation of their response on the sliding scale. Major neurodevelopmental disability was defined as an intelligence quotient (IQ) <-2 SD relative to term-born controls, moderate or severe cerebral palsy, blindness, or deafness requiring hearing aids or worse.[13]

True outcome data for infants born at 23-*25 weeks' gestation in Victoria*

Data on infant survival and major disability rates were derived from two population-based data collections, both obtained with prior ethical approval. Perinatal data and infant survival rates for all livebirths in Victoria in 2014-2017 were obtained from the Consultative Council on Obstetric and Paediatric Mortality and Morbidity. Major neurodevelopmental disability rates in surviving 23-25-week children at 8 years of corrected age were obtained from three Victorian Infant Collaborative Study (VICS) cohorts, born in 1991-92, 1995 and 2005. [13]

Ethics

The Human Research Ethics Committee at the Royal Children's Hospital approved the study: HREC/65384/RCHM-2020.

Survey distribution

An invitation to participate in the survey was sent to the directors of neonatal services and of obstetric services at the three tertiary perinatal centres in the state, and to the director of the neonatal intensive care unit (NICU) at the stand-alone Children's Hospital, and the neonatal retrieval service ('transport team') in Victoria. Similar letters were sent to the nurse/midwifery unit managers at 41 non-tertiary public and private hospitals with a special care nursery in Victoria, and to the consultant paediatricians at these hospitals. The invitation to participate was extended to the specialist obstetricians in one non-tertiary health service. Individual consent was implied by voluntary completion of the survey.

Statistical analysis

Data were imported from REDCap™ into Stata 16 (StataCorp, College Station, Texas) for analysis. Participants were categorised according to their workplace: tertiary centre versus non-tertiary hospital, and into four professions: 1) midwifery/nursing, 2) paediatrics/neonatology, 3) obstetrics, and 4) neonatal transport team. Staff from the transport team were also categorised as 'tertiary' as the service is located at a tertiary centre.

The true rates of survival and major disability for each of the six combinations of gestational age by inborn/outborn status were subtracted from each participant's estimations for each combination, and the mean values compared with the null value of zero. For overall summaries of survival and major disability rates we used linear regression with models fitted using generalised estimating equations (GEEs) to allow for the lack of independence of multiple responses from the same participant. Differences between predicted and actual rates of survival and major disability related to birthplace (inborn versus outborn), gestational age, workplace of respondents (tertiary versus non-tertiary) and profession were analysed by linear regression. For outcomes with only one response per participant we used standard linear regression.

To compare differences in clinicians' perceptions of outcome from our current survey with a similar survey we conducted in Victoria in 2010,[5] we used data for 24-week infants from each survey, as this was the only gestational age that was common to both surveys. We calculated the differences between predicted and actual rates of survival and major disability for both inborn and outborn infants born at 24 weeks' gestation for each era (2020 and 2010), and then compared differences between eras using linear regression with GEEs to allow for lack of independence of response from the same participant. Mean differences, 95% confidence intervals (CIs) and p-values were reported from all regression analyses.

RESULTS

The survey was open for a period of 3 months, from 23 July 2020 to 4 October 2020. In total, 165 surveys were received, of which 154 (93%) contained complete survival data and 152 (92%) had complete major disability data. The overall response rate was 28% (165/591), excluding the non-tertiary obstetricians, for whom the denominator was unknown.

A wide range of clinicians responded, of whom 42% (N=69) practised in a non-tertiary hospital, 50% (N=82) in a tertiary centre with a NICU, and 8% (N=14) were from the neonatal retrieval service (transport team). The years of perinatal experience of the respondents ranged from less than one year (6 respondents) to forty years (median 10 years, interquartile range 6, 20). Response rates by professional group and workplace are shown in Table 1.

Perceptions of survival to one year

Survival rates for all infants combined were underestimated by a mean absolute difference of -14.4% (95% CI -16.6, -12.3%), p<0.001 (Table 2).

a) inborn infants

The true survival rates for actively managed inborn livebirths in Victoria in 2014-2017 are shown in Table 2. Respondents under-estimated survival chances for inborn

infants at each week of gestation (Table 2), with a mean overall absolute difference of -11.2% (95% CI -13.4, -9.0%), p<0.001 (Table 3).

b) outborn infants

The true survival rates for actively managed outborn livebirths in Victoria in 2014-2017 are shown in Table 2. Respondents under-estimated survival chances for outborn infants at each week of gestation (Table 2), with a mean overall absolute difference of -17.7% (95% CI -20.3, -15.2%), p<0.001 (Table 3).

c) relationship with perinatal and demographic variables (Table 3)

The underestimation in survival was less for inborn than for outborn infants and was similar across all three gestational age groups (Table 3). While there was no substantial difference in survival estimates between respondents from tertiary versus non-tertiary hospitals, there were differences according to respondent profession: nurses/midwives were more pessimistic and paediatricians less pessimistic than other professions.

Perceptions of major disability at school age in survivors

Overall, the chance of major disability in survivors born at 23-25 weeks was overestimated by an absolute mean difference of 32.7% (95% CI 29.7, 35.8%), p<0.001; more than double the true rate (Table 2).

a) inborn infants

Rates of major disability were over-estimated for inborn infants at each week of gestation (Table 2), with an overall overestimation by an absolute mean difference of 28.3% (95% CI 25.2, 31.5%), p<0.001 (Table 3).

b) outborn infants

Rates of major disability were over-estimated for outborn infants at each week of gestation (Table 2), with an overall overestimation by an absolute mean difference of 37.4% (95% CI 34.3, 40.4%), p<0.001 (Table 3).

c) Relationships with perinatal and demographic variables (Table 3)

The disparity between perceived and true rates of disability was less for inborn than for outborn infants. Overestimation of major disability risk was lower with higher gestational age. There were no substantive differences in estimation of major disability risk comparing responses from respondents from tertiary centres with respondents from non-tertiary hospitals. Nurses/midwives overestimated major disability more than other professions, whereas paediatricians overestimated major disability less than all other professions. There were no substantive differences in estimation of major disability by obstetricians or transport team staff compared with all other professions.

Comparison of the 2020 and 2010 survey results

Survey participants' response rates and demographics were similar in the two surveys (supplementary Table 1). In the 2020 survey, non-tertiary paediatricians were also included, as these clinicians would be involved in parental counselling in a non-tertiary hospital.

In the 2010 survey,[5] respondents were asked to estimate infant survival for all livebirths at 24 weeks' gestation (as opposed to livebirths offered intensive care) and to estimate major disability rates at 2 years of corrected age (as the 8-year outcomes were not known for the 2005 VICS cohort at that time).

Estimations of survival at 24 weeks' gestation were less accurate in 2020 than in 2010 (Figure 1). In 2020, survival was underestimated by an absolute -14.7% compared with -6.7% in 2010 (mean difference -6.7% (95% CI -9.7, -3.7), $p<0.001$).

Estimations of major disability risk were less accurate in 2020 than in 2010 (Figure 1). Major disability risk was overestimated by an absolute 35.0% in 2020 compared with 29.5% in 2010 (mean difference 5.3%; 95% CI 1.6, 9.0; $p=0.005$).

DISCUSSION

Our survey has demonstrated that clinicians providing obstetric and neonatal care in the state of Victoria do not have accurate perceptions of outcomes of infants born at 23-25 weeks' gestation; on average, they are too pessimistic, underestimating survival chances and overestimating the risks of major disability in survivors. Our findings are consistent with our previous survey conducted in Victoria in 2010, [5] and with similar studies conducted in Australia, [7 8 10] Asia,[14] the United States,[6] Ireland,[11] and Canada [9] over the past twenty years. All professions were pessimistic, mostly irrespective of their profession, workplace (tertiary versus non-tertiary hospital), infant gestational age, and inborn/outborn birth status, although overall nurses/midwives were more pessimistic, and paediatricians were more optimistic than others. Of concern, the disparities of perceptions of outcome in the current survey compared with true values were greater than they were a decade earlier.

Implications for parents' counselling and shared decision-making

In our study, we found obstetricians were as pessimistic of outcomes of infants born at 23-25 weeks as other professions. Obstetric perceptions of infant outcomes have a direct impact on decision-making, including decisions such as to transfer in-utero to a tertiary centre, to administer antenatal corticosteroids, to perform a caesarean section for fetal compromise, [6 15] and to involve a paediatrician in discussions about active management of the infant. [7 8 16]

In Victoria, a single-statewide perinatal and neonatal emergency retrieval team is available 24 hours a day for high-risk obstetric and neonatal consultations, and to facilitate in-utero transfer of the mother, or ex-utero transport of the baby.[17] When a woman presents in extremely preterm labour, or if birth at 23-25 weeks' gestation is imminent, a consultant obstetrician and neonatologist from the transport team are

available to provide advice to clinicians regarding management of the women and of their infants, and to provide data regarding infant outcomes if resuscitation is provided. Our findings that perceptions of infant survival and major disability of the transport team are inaccurate may influence clinical decision-making in non-tertiary settings.

Parents may also seek the opinion of their midwife, especially when the midwife has provided their maternity care in this, or previous pregnancies. Although midwives and neonatal nurses do not provide formal parent counselling, they have influence on parents regarding the decision to provide active management.[18 19] In our study, midwives/nurses' perceptions of outcome were the most pessimistic of all professions.

Changes in accuracy of outcome predictions over time

We found that clinicians' estimations of infant outcome were less accurate and more pessimistic for both survival and disability in the current survey than they were a decade earlier. Despite reports of improvements in infant survival in 23-25 week infants the 2010s, [20-22] there is clearly a large gap in translation of survival data into practice. Moreover, it was concerning that major disability risks were perceived to be more than double the true rate, and that overestimations of disability risk were greater in 2020 than a decade earlier.

We had anticipated that clinicians working tertiary centres would have more accurate perceptions of infant outcome than those working in non-tertiary settings, given tertiary clinicians have greater exposure to extremely preterm (EP) infants, but this was not the case. In Victoria, follow up of EP survivors is conducted by dedicated teams of developmental paediatricians at each tertiary centre. Staff caring for EP infants in the NICU or special care nursery after back transfer are not typically involved in these assessments. We speculate this may explain why all professional

groups had similar misconceptions about major disability risk, however, this requires further exploration.

It is unclear what direct impact these misconceptions of infant outcome have on parent counselling and decision-making, including for women presenting to non-tertiary maternity hospitals in preterm labour in Victoria. However, we know that the proportions of infants born 22-24 weeks' gestation being offered active care did not increase between 2009 and 2017 in Victoria.[23] Moreover, outborn infants are less likely to be offered active care in Victoria than inborn infants, especially at 23 weeks' gestation.[23 24] It is possible that the decision to birth in a non-tertiary hospital and not offer intensive care for some infants was based on the risks of death or major disability presented to the parents before birth. It is also possible that parents are taking their infants home from NICU expecting their child's long-term outcome to be worse than it is likely to be.

Implications for practice

Our study has identified an urgent need for a tool to assist clinicians to predict outcomes for extremely preterm infants, which in turn would help parents to make informed choices for their infant based on accurate outcome data. We have developed a web-based preterm birth outcome predictor (NIC-PREDICT available at www.nic-predict.com.au) and a smartphone application for use by perinatal clinicians, based on contemporary Victorian outcome data, which is now available. We will repeat the current survey after its implementation into clinical practice to establish if perceptions of outcomes of infants born 23-25 weeks' gestation have improved.

Strengths and limitations

The major strength of our study was the wide variety of perinatal clinicians from different healthcare settings who took part in this study. We obtained views from tertiary and non-tertiary staff and the neonatal transport team, and included all

disciplines (medical, nursing and midwifery) who provide obstetric and newborn care in the state of Victoria. Other strengths include using contemporary data on survival rates and disability rates at school-age from the whole of Victoria as the basis for the true rates of survival and disability, with a follow-up rate at 8 years of 95%.[13]

The main limitation of our study was the low response rate of 28% overall, which in part led to relatively small sample sizes in some subgroups, limiting the power to find true differences between subgroups if they existed. Furthermore, only ten obstetricians from the four perinatal tertiary centres and four obstetricians working in one non-tertiary healthcare setting in the state of Victoria responded. As such, their views may not be representative of all obstetric clinicians and limits the generalisability of their responses. There were also differences in the 2010 and 2020 surveys, which may have affected comparisons of accuracy between eras.

A possible limitation of our study was that participants were asked to choose a single number for survival chances and for major disability risk for each infant scenario. When counselling parents about potential infant outcome, clinicians might provide a range that an individual infant could fall within, considering other perinatal characteristics, such as sex, plurality and exposure to antenatal corticosteroids, in addition to place of birth and gestational age, rather than a precise rate.[25]

In conclusion, this study found that perinatal clinicians in Victoria are overly pessimistic in their perceptions of outcomes for infants born at 23-25 weeks' gestation, underestimating survival and overestimating major disability. Moreover, their pessimism may be worsening over time.

Table 1: Response rates by profession and workplace

Profession	Workplace: Tertiary or non-tertiary hospital	Total number surveyed N=	Professional role and number of respondents	Total respondents N (%)	Completed all survey fields N (%)
Nursing and midwifery	Tertiary	58	Neonatal Nurse N=16 Midwifery or Nurse Educator N=9 Other N=7	32 (55%)	28 (88%)
	Non-tertiary	76	Neonatal Nurse N=16 Midwife N=13 Midwifery or Nurse Educator N=8 Other N=6	43 (57%)	41 (95%)
Paediatric	Tertiary	141	Consultant Neonatologist N=17 Neonatal Fellow N=11 Neonatal Registrar N=6 Other N=6	40 (28.4%)	35 (88%)
	Non-tertiary	120	Paediatrician N=17 Neonatologist N=5	22 (18%)	22 (100%)
Obstetric	Tertiary	157	Obstetric trainee N=3 Specialist Obstetrician N=2 Obstetric Registrar or Fellow N=4 Other N=1	10 (6.4%)	10 (100%)
	Non-tertiary	NR	Specialist Obstetrician N=4	4 (NR)	3 (75%)
Transport team	Nursing	23	Neonatal Transport Nurse N=7 Neonatal Nurse N=1	8 (35%)	6 (75%)
	Medical	16	Consultant Neonatologist N=2 Neonatal Fellow N=4	6 (38%)	6 (100%)
Total N (%)		591*		**N=165/591 (28%)**	**N=151 (91%)**

NR= Not recorded; * Does not include the non-tertiary obstetricians for whom the total number invited could not be determined

Table 2. Differences in estimates of infant survival and major disability versus actual rates for outborn and inborn infants at 23, 24 and at 25 weeks' gestation

	Inborn			Outborn			All infants
Gestational age in weeks	**23**	**24**	**25**	**23**	**24**	**25**	**Overall Mean difference: (95% CI) P=**
True survival rate* % (n/N)	53.2 (25/47)	76.7 (89/116)	85.6 (154/180)	50 (5/10)	57.1 (12/21)	72.7 (16/22)	
Perceived survival rate % (mean, 95% CI)	45.6 (43.0, 48.3)	61.9 (59.5, 64.4)	74.3 (72.1, 76.6)	27.6 (25.2, 30.1)	42.4 (39.6, 45.1)	56.5 (53.4, 59.7)	
Mean % difference (95% CI)	-7.6 (-10.2, -4.9)	-14.8 (-17.2, -12.3)	-11.3 (-13.5, -9.0)	-22.4 (-24.8, -19.9)	-14.7 (-17.5, -12.0)	-16.2 (-19.3, -13.0)	-14.4% (-16.6, -12.3) P<0.001
True major disability rate^ %	30	21	19	30	21	19	
Perceived major disability rate % (mean, 95% CI)	62.3 (58.9, 65.6)	51.4 (48.1, 54.7)	41.2 (37.8, 44.6)	71.4 (68.2, 74.6)	60.7 (57.5, 64.0)	50.0 (46.7, 53.3)	
Mean % difference (95% CI)	32.3 (28.9, 35.6)	30.4 (27.1, 33.7)	22.2 (18.8, 25.6)	41.4 (38.2, 44.6)	39.7 (36.5, 43.0)	31.0 (27.7, 34.3)	32.7% (29.7, 35.8%) P<0.001

* True survival rates at one year for all actively managed livebirths in Victoria from 2014-2017

^ True rates of major disability at 8 years of corrected age in actively managed survivors born in Victoria in 1991/92, 1997 and 2005 (averaged over 3 eras)

Table 3. Differences between predicted and actual rates of survival and major disability related to perinatal and demographic variables

Variable	% Survival difference	% Major disability difference
Place of birth		
Inborn	-11.2 (-13.4, -9.0) <0.001	28.3 (25.2, 31.5) <0.001
Outborn	-17.7 (-20.3, -15.2) <0.001	37.4 (34.3, 40.4) <0.001
Mean diff. (95% CI), P-value	6.7 (4.8, 8.6) <0.001	-9.4 (-10.7, -8.0) <0.001
Gestational age (weeks)		
23	-15.0 (-17.3, -12.6) <0.001	36.7 (33.6, 39.9) <0.001
23	-14.7 (-17.0, -12.3) <0.001	35.0 (31.8, 38.1) <0.001
25	-13.7 (-16.1, -11.3) <0.001	26.5 (23.3, 29.7) <0.001
Mean diff.† (95% CI), P-value	0.6 (-0.4, 1.7) 0.23	-5.1 (-6.2, -4.0) <0.001
Workplace of respondents		
Tertiary centre	-14.3 (-17.2, -11.5) <0.001	32.2 (27.7, 36.7) <0.001
Non-tertiary hospital	-14.8 (-18.3, -11.4) <0.001	33.0 (29.2, 36.8)) <0.001
Mean diff. (95% CI), P-value	0.5 (-3.9, 5.0) 0.82	-0.7 (-6.6, 5.1) 0.81
Profession		
Nursing/midwifery		
Nursing/midwifery	-16.9 (-20.4, -13.4) <0.001	38.2 (34.2, 42.1) <0.001
Not nursing/midwifery	-11.9 (-14.4, -9.4) <0.001	27.3 (23.0, 31.6) <0.001
Mean diff. (95% CI), P-value	-5.0 (-9.3, -0.7) 0.022	10.8 (5.0, 16.7) <0.001
Paediatric		

Paediatric	-10.1 (-12.6, -7.7) <0.001	25.7 (20.9, 30.4) <0.001
Not paediatric	-17.4 (-20.6, -14.3) <0.001	37.8 (34.2, 41.4) <0.001
Mean diff. (95% CI), P-value	7.3 (3.3, 11.3) <0.001	-12.1 (-18.0, -6.2) <0.001
Obstetric		
Obstetric	-20.5 (-27.6, -13.4) <0.001	35.7 (26.6, 44.7) <0.001
Not obstetric	-13.9 (-16.2, -11.6) <0.001	32.5 (29.3, 35.7) <0.001
Mean diff. (95% CI), P-value	-6.6 (-13.8, 0.6) 0.07	2.9 (-6.7, 12.5) 0.56
Transport		
Transport	-9.9 (-18.0, -1.9) 0.015	39.9 (31.3, 48.6) <0.001
Not transport	-14.9 (-17.2, -12.7) <0.001	31.9 (28.7, 35.1) <0.001
Mean diff. (95% CI), P-value	5.0 (-3.0, 13.1) 0.22	8.0 (-0.8, 16.9) 0.08

† For each week's increase in gestational age.

Data are mean difference (95% confidence interval) P-value

Figure 1: Differences (%) between predicted and true rates of survival and major disability of infants born at 24 weeks' gestation: 2020 survey compared with 2010 survey. Boxplots show median (solid bar within box), 25th-75th centiles (margins of box), range of data, and outliers (if any).

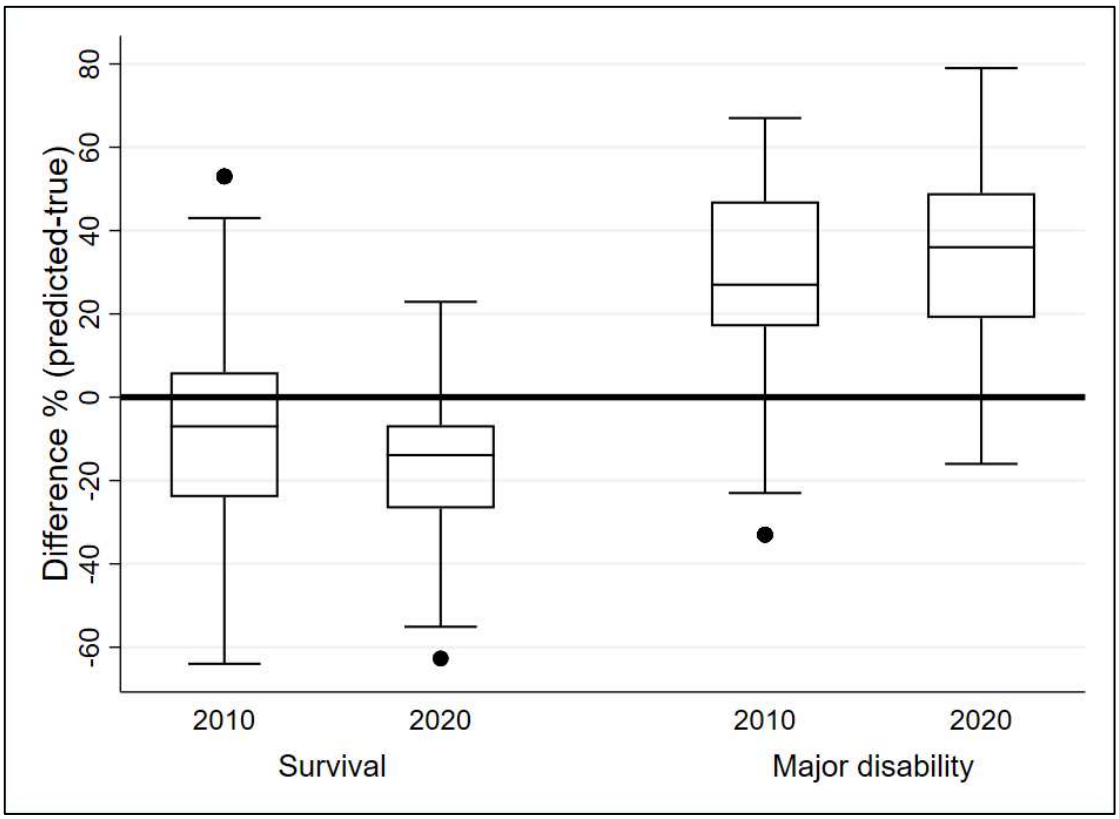

Figure legend:

2010 survey:

% Difference between predicted and true rate of survival to one year of all livebirths in Victoria in 2001-2009, and

% Difference between predicted and true rate of major disability in surviving children at 2 years of corrected age born in Victoria at 24 weeks' gestation in 1991-1992, 1997 and 2005

2020 survey:

% Difference between predicted and true rate of survival to one year of all actively managed livebirths in Victoria in 2014-2017, and

% Difference between predicted and true rate of major disability in surviving children at 8 years of corrected age born in Victoria at 24 weeks' gestation in 1991-1992, 1997 and 2005

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Table 1: Response rates by profession and workplace

Profession	Workplace: Tertiary or non-tertiary hospital	Total number surveyed N=	Professional role and number of respondents	Total respondents N (%)	Completed all survey fields N (%)
Nursing and midwifery	Tertiary	58	Neonatal Nurse N=16 Midwifery or Nurse Educator N=9 Other N=7	32 (55%)	28 (88%)
	Non-tertiary	76	Neonatal Nurse N=16 Midwife N=13 Midwifery or Nurse Educator N=8 Other N=6	43 (57%)	41 (95%)
Paediatric	Tertiary	141	Consultant Neonatologist N=17 Neonatal Fellow N=11 Neonatal Registrar N=6 Other N=6	40 (28.4%)	35 (88%)
	Non-tertiary	120	Paediatrician N=17 Neonatologist N=5	22 (18%)	22 (100%)
Obstetric	Tertiary	157	Obstetric trainee N=3 Specialist Obstetrician N=2 Obstetric Registrar or Fellow N=4 Other N=1	10 (6.4%)	10 (100%)
	Non-tertiary	NR	Specialist Obstetrician N=4	4 (NR)	3 (75%)
Transport team	Nursing	23	Neonatal Transport Nurse N=7 Neonatal Nurse N=1	8 (35%)	6 (75%)
	Medical	16	Consultant Neonatologist N=2 Neonatal Fellow N=4	6 (38%)	6 (100%)
Total N (%)		591*		**N=165/591 (28%)**	**N=151 (91%)**

NR= Not recorded; * Does not include the non-tertiary obstetricians for whom the total number invited could not be determined

Table 2. Differences in estimates of infant survival and major disability versus actual rates for outborn and inborn infants at 23, 24 and at 25 weeks' gestation

	Inborn			Outborn			All infants
Gestational age in weeks	**23**	**24**	**25**	**23**	**24**	**25**	**Overall Mean difference: (95% CI) P=**
True survival rate* % (n/N)	53.2 (25/47)	76.7 (89/116)	85.6 (154/180)	50 (5/10)	57.1 (12/21)	72.7 (16/22)	
Perceived survival rate % (mean, 95% CI)	45.6 (43.0, 48.3)	61.9 (59.5, 64.4)	74.3 (72.1, 76.6)	27.6 (25.2, 30.1)	42.4 (39.6, 45.1)	56.5 (53.4, 59.7)	
Mean % difference (95% CI)	-7.6 (-10.2, -4.9)	-14.8 (-17.2, -12.3)	-11.3 (-13.5, -9.0)	-22.4 (-24.8, -19.9)	-14.7 (-17.5, -12.0)	-16.2 (-19.3, -13.0)	-14.4% (-16.6, -12.3) P<0.001
True major disability rate^ %	30	21	19	30	21	19	
Perceived major disability rate % (mean, 95% CI)	62.3 (58.9, 65.6)	51.4 (48.1, 54.7)	41.2 (37.8, 44.6)	71.4 (68.2, 74.6)	60.7 (57.5, 64.0)	50.0 (46.7, 53.3)	
Mean % difference (95% CI)	32.3 (28.9, 35.6)	30.4 (27.1, 33.7)	22.2 (18.8, 25.6)	41.4 (38.2, 44.6)	39.7 (36.5, 43.0)	31.0 (27.7, 34.3)	32.7% (29.7, 35.8%) P<0.001

* True survival rates at one year for all actively managed livebirths in Victoria from 2014-2017

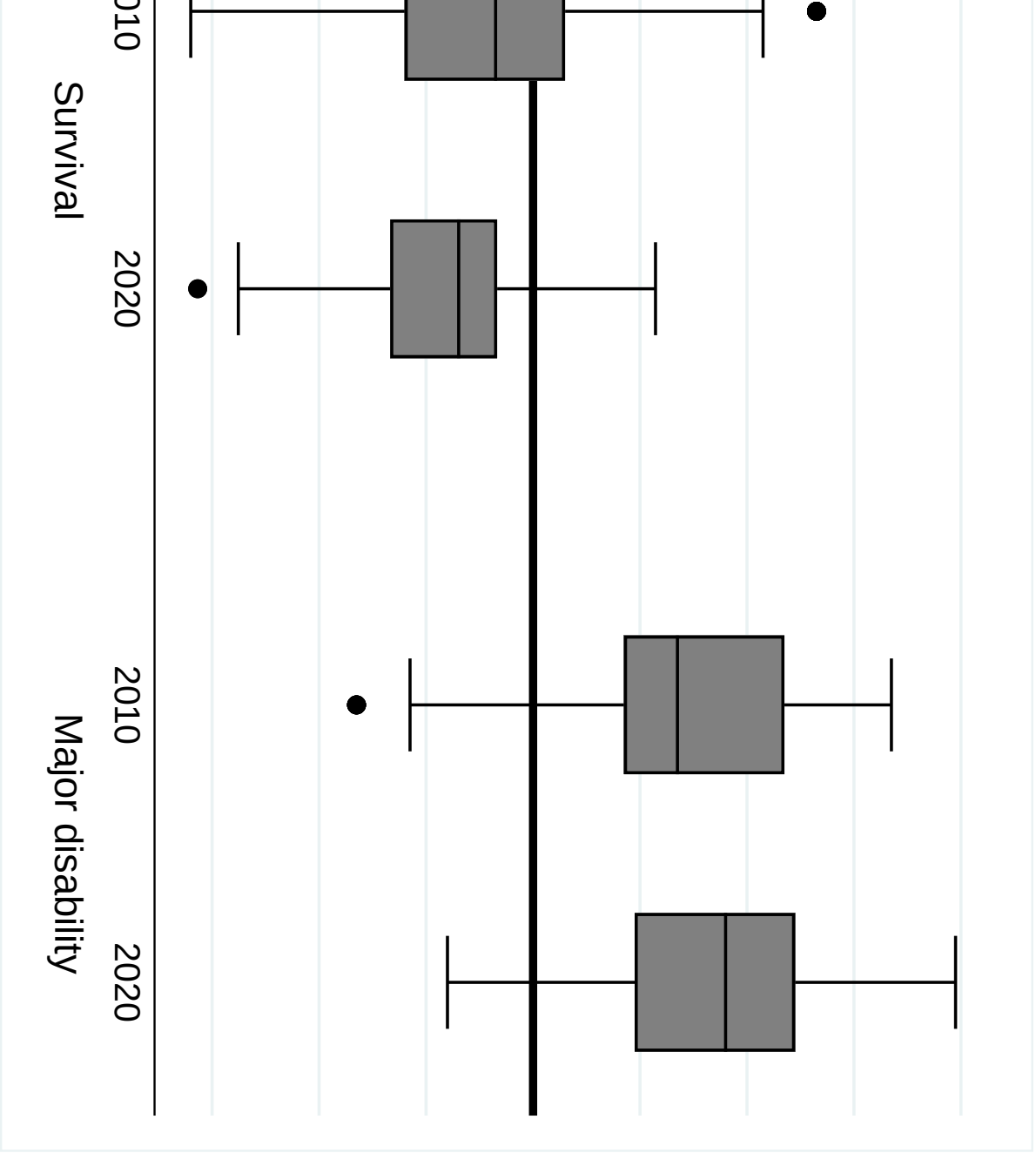
^ True rates of major disability at 8 years of corrected age in actively managed survivors born in Victoria in 1991/92, 1997 and 2005 (averaged over 3 eras)

Table 3. Differences between predicted and actual rates of survival and major disability related to perinatal and demographic variables

Variable	% Survival difference	% Major disability difference
Place of birth		
Inborn	-11.2 (-13.4, -9.0) <0.001	28.3 (25.2, 31.5) <0.001
Outborn	-17.7 (-20.3, -15.2) <0.001	37.4 (34.3, 40.4) <0.001
Mean diff. (95% CI), P-value	6.7 (4.8, 8.6) <0.001	-9.4 (-10.7, -8.0) <0.001
Gestational age (weeks)		
23	-15.0 (-17.3, -12.6) <0.001	36.7 (33.6, 39.9) <0.001
23	-14.7 (-17.0, -12.3) <0.001	35.0 (31.8, 38.1) <0.001
25	-13.7 (-16.1, -11.3) <0.001	26.5 (23.3, 29.7) <0.001
Mean diff.† (95% CI), P-value	0.6 (-0.4, 1.7) 0.23	-5.1 (-6.2, -4.0) <0.001
Workplace of respondents		
Tertiary centre	-14.3 (-17.2, -11.5) <0.001	32.2 (27.7, 36.7) <0.001
Non-tertiary hospital	-14.8 (-18.3, -11.4) <0.001	33.0 (29.2, 36.8)) <0.001
Mean diff. (95% CI), P-value	0.5 (-3.9, 5.0) 0.82	-0.7 (-6.6, 5.1) 0.81
Profession		
Nursing/midwifery		
Nursing/midwifery	-16.9 (-20.4, -13.4) <0.001	38.2 (34.2, 42.1) <0.001
Not nursing/midwifery	-11.9 (-14.4, -9.4) <0.001	27.3 (23.0, 31.6) <0.001
Mean diff. (95% CI), P-value	-5.0 (-9.3, -0.7) 0.022	10.8 (5.0, 16.7) <0.001
Paediatric		
Paediatric	-10.1 (-12.6, -7.7) <0.001	25.7 (20.9, 30.4) <0.001
Not paediatric	-17.4 (-20.6, -14.3) <0.001	37.8 (34.2, 41.4) <0.001
Mean diff. (95% CI), P-value	7.3 (3.3, 11.3) <0.001	-12.1 (-18.0, -6.2) <0.001
Obstetric		
Obstetric	-20.5 (-27.6, -13.4) <0.001	35.7 (26.6, 44.7) <0.001
Not obstetric	-13.9 (-16.2, -11.6) <0.001	32.5 (29.3, 35.7) <0.001
Mean diff. (95% CI), P-value	-6.6 (-13.8, 0.6) 0.07	2.9 (-6.7, 12.5) 0.56
Transport		
Transport	-9.9 (-18.0, -1.9) 0.015	39.9 (31.3, 48.6) <0.001
Not transport	-14.9 (-17.2, -12.7) <0.001	31.9 (28.7, 35.1) <0.001
Mean diff. (95% CI), P-value	5.0 (-3.0, 13.1) 0.22	8.0 (-0.8, 16.9) 0.08

† For each week's increase in gestational age.

Data are mean difference (95% confidence interval) P-value



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