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## Knowledge, Beliefs, and Decisions of Pregnant Australian Women Concerning Donation and Storage of Umbilical Cord Blood: A Population-Based Survey

Jordens CF, Kerridge IH, Stewart CL, O'Brien TA, Samuel G, Porter M, O'Connor MA, Nassar N. (2014)

### ABSTRACT

**Background:** Many women giving birth in Australian hospitals can choose to donate their child's umbilical cord blood to a public cord blood bank or pay to store it privately. We conducted a survey to determine the proportion and characteristics of pregnant women who are aware of umbilical cord blood (UCB) banking and who have considered and decided about this option. The survey also sought to ascertain information sources, knowledge and beliefs about UCB banking, and the effect of basic information about UCB on decisions.

**Methods:** Researchers and/or hospital maternity staff distributed a survey with basic information about UCB banking to 1,873 women of at least 24 weeks gestation who were attending antenatal classes and hospital clinics in 14 Public and private maternity hospitals in New South Wales.

**Results:** Most respondents (70.7%) were aware of UCB banking. Their main information sources were leaflets from hospital clinics, print media, antenatal classes, TV, radio, friends and relatives. Knowledge about UCB banking was patchy, and respondents overestimated the likelihood their child would need or benefit from UCB. Women who were undecided about UCB banking were younger, less educated or from ethnic or rural backgrounds. After providing basic information about UCB banking, the proportion of respondents who indicated they had decided whether or not to donate or store UCB more than doubled from 30.0% to 67.7%.

**Conclusions:** Basic information for parents about UCB banking can affect planned decisions about UCB banking. Information should be accurate and balanced, should counter misconceptions, and should target specific groups.

**Keywords:** Antenatal care; Health information; Blood banks; New South Wales, Australia

### INTRODUCTION

Due to success in cord blood transplantation, there is now a global network of public cord blood banks that collect, process, cryopreserve and distribute cord blood units for unrelated donor transplants. This network has an estimated common inventory of 600,000 cord blood units, and more than 20,000 units have been distributed to transplant centres to treat patients with life-

threatening haematological disease (1). There are three public cord blood banks in Australia with 11 collection centres. Four are in New South Wales (NSW). As of June 2012, these banks had 24,725 cord blood units available for searching by transplant centres (2).

Alongside this public network, there are now 225 private banks that offer, for a fee, to store a child's cord blood for potential subsequent personal or family use (3). This service is promoted to prospective parents as 'bio-insurance': their child is provided with a source of cord blood stem cells that can be used for transplantation or in tissue regeneration therapies (even though all clinical applications of cord blood stem cells other than haematopoietic stem cell transplantation remain purely speculative (1, 4-8). Globally, one million cord blood units are stored in private cord blood banks. Three operate in Australia, and it is estimated they currently store over 40,000 cord blood units.

Previous studies in several countries have found high levels of public awareness of cord blood banking and strong support for public banks based on community solidarity (9-11). Nevertheless, as the figures above indicate, there has been a dramatic increase in private storage of cord blood. There is also evidence of poor public understanding of its medical utility (9, 12-14). This raises questions about the degree to which parental choices are informed and satisfy stated values and preferences (15). One recent study examined preferences of parents faced with a choice between donation and private storage (11), but no study has yet examined the influence of information on parental preferences, or the possible influence of publicity about 'regenerative medicine' in the lay and academic press.

To explore awareness and understanding of cord blood banking among Australian women, and the effect of information on planned choices about disposal of cord blood, we conducted a survey of pregnant women in NSW.

## **METHODS**

### **Setting and participants**

Participants were pregnant women accessing antenatal services in 14 public and private maternity hospitals in metropolitan (n=8), regional (n=4) and rural (n=2) NSW, including three of the four NSW hospitals that facilitate public cord blood donation. Hospitals were selected so as to recruit a sample that was representative in terms of cultural, ethnic, socio-economic and geographic factors. The survey included women of 24 weeks gestation and above and excluded women in high-risk categories, including those presenting with cardiac disease, hypertensive disorders, twins and higher multifetal pregnancies.

Ethics approval was granted by human research ethics committees at the NSW Cancer Institute, the Australian Bone Marrow Donor Registry, and Sydney West Area Health Service.

### **Survey Design**

The survey was a modified version of an existing, self-administered questionnaire (16) with most questions in multiple choice format (copy available from the first author on request). The first section elicited demographic information and estimated the proportion of respondents who are aware of cord blood donation and banking, who have considered these options, and who have made a decision about it. It also asked about information sources and assessed knowledge about cord blood banking. The survey then provided information about what umbilical cord blood is; what makes it medically useful, and what is involved in either donating it to a public bank or paying to have it stored privately. The final section explored opinions and planned choices in light of the

information provided. The questionnaire was translated from English into the 10 next most commonly spoken languages in NSW: Arabic, Greek, Croatian, Spanish, Italian, Mandarin, Cantonese, Farsi, Vietnamese and Korean (17).

### Survey Administration

The survey was distributed by study researchers and/or hospital maternity staff to pregnant women attending antenatal classes and hospital clinics between March 2009 and March 2010. Given that the 14 selected maternity hospitals varied in terms of size and number of births, an estimated proportion and required number of completed surveys was determined for each site, and the surveys were distributed accordingly. Consent was gained through a participant information sheet and consent form. Women completed the survey immediately or returned it by post. To allow for language or literacy difficulties, we accepted surveys that were completed with the help of a friend or relative of the pregnant woman.

### Data analysis

Frequency tabulations and contingency analyses (Chi-squared tests) were conducted to compare responses by various maternal characteristics, including age, education, ethnic and linguistic background, and religious beliefs. Analyses were conducted using SAS release 9.1 (SAS Institute, Cary, NC, USA). P-values <0.05 were considered statistically significant.

## RESULTS

The survey was distributed to 2,050 participants and completed by 1,873 pregnant women attending antenatal clinics at 14 NSW hospitals. The overall response rate was 86.7% and varied at each maternity hospital, ranging from 74.5% to 100%. Women at all 14 hospitals had the opportunity to privately store their baby's cord blood. Donation to a public bank was an option at only 3 urban hospitals. The median age of respondents was 30 years; half (51.7%) were university educated, and most were attending one of 11 public hospitals (78.7%) and/or lived in a metropolitan area (78.3%) (Table 1). The majority of women (62.4%) and their partners (58.8%) were born in Australia. Almost half (45.4%) identified an ethnic background other than Northern European and 24.1% spoke a language other than English at home. Of those who identified as religious, 58.8% professed an Abrahamic faith (Christian, Muslim, Jewish) and 15.6% an Eastern faith (Buddhist, Hindu or Sikh) (Table 1). About two thirds of women were having their first baby and 80% were surveyed before term (<37 weeks pregnancy). The sample was statistically no different to the general population of NSW mothers in terms of median age, age distribution, urban/rural split, ethnic background and the proportion born in Australia (18).

**Table 1: Demographic characteristics of survey respondents**

Characteristics	Percent (N=1,873)
Age (years)	
<20	2.1
20-34 years	74.8
35+ years	23.1
Parity	
Primiparous	66.8
Multiparous	33.2

Education	
High school	25.1
Post-secondary technical education	23.2
University	51.7
Hospital	
Public	78.7
Private	21.3
Location	
Urban	78.3
Rural	21.7
Ethnic background	
Northern European	54.7
Southern and Eastern European	8.7
Indian	8.2
Middle Eastern	8.1
North-East Asian (Chinese/ Japanese)	7.9
South-East Asian	5.3
Other*	7.0
Language other than English at home	24.1
Religion	
Abrahamic	58.8
Eastern faith	15.6
Other/ No faith	25.6

\*Other category comprises of women from Pacific Islander (2.8%), Aboriginal/Torres Strait Islander (1.7%), Southern and Central American (0.8%), African (0.8%) and other nations (0.9%)

### Awareness and knowledge of cord blood banking

At the time of the survey, only 181 respondents (12.9%) had been asked if they wanted to bank their baby's cord blood. Of these, 27.0% had been asked about public donation, 23.9% about private storage, and 20% about both options. The remaining 29% were unsure which option they had been asked about. Nevertheless, a majority (n=1324, 70.7%) indicated they were aware of cord blood banking. Those who were not aware of this option were more likely to live in rural areas, deliver in public hospitals, be aged less than 25 years, be educated only up to high school, be born overseas, and be from Indigenous (Aboriginal or Torres Strait Islander), non-Caucasian and non-English speaking backgrounds—particularly Middle Eastern, Pacific Islander, Indian and Japanese backgrounds (P<0.01).

Those who were aware of cord blood banking were more likely to know someone who had a bone marrow transplant (13.2% v 5.1%, P<0.001) or an organ or tissue transplant (19.4% v 9.5%, P<0.05). In response to questions about where they had obtained information about cord blood banking (public or private), they most commonly identified leaflets from hospital clinics (42.8%), print media (22.2%), antenatal classes (21.1%) television and radio (18.9%) and friends and relatives (16.8%).

Of those who had heard about cord blood banking, half (55.8%) indicated they were aware there were two kinds (i.e. private and public); 36% were unsure. They were more likely to know about private storage of cord blood than public donation (80.4% versus 66.2%, respectively;  $P=0.001$ ), however awareness about both options was greater (~82%) among women giving birth in hospitals where donation was an option compared with those in other hospitals. Respondents were less likely to be knowledgeable about cord blood banking if they were from rural areas, from non-English speaking backgrounds, attending public hospitals, and educated only to high school level ( $P<0.01$ ).

Most respondents who were aware of cord blood banking (93.5%) knew they could not control who receives publicly donated cord blood. Only 10% were aware that they could not use privately stored cord blood for themselves and 40% were unsure about this. Almost half (46.5%) thought it unlikely their child or another child would need their baby's cord blood in future, but 36% were unsure. Most (88%) correctly identified cord blood transplantation as a treatment for leukaemia, but respondents were less certain (and correct responses were more variable) for questions about unproven applications of cord blood, including the treatment of asthma (93.7% correct responses), diabetes (77.6% correct), cystic fibrosis (59.2% correct), and spinal cord injury (50.3% correct).

### Decisions about cord blood banking

Before receiving any information about cord blood banking in the questionnaire, approximately 1400 respondents indicated whether they had made a decision to store or donate their baby's cord blood. Of these, 30.0% said they had made a decision; 31.3% indicated they were undecided, and 38.7% indicated that they had not yet considered this option (Table 2). Respondents who were undecided or who had not made a decision were more likely to be from rural areas ( $P<0.01$ ), less educated ( $P<0.01$ ) and from non-English speaking backgrounds ( $P=0.01$ ). Of those who indicated they *had* made a decision ( $n=420$ ), one in five (20%) had decided not to store or bank their baby's cord blood, 63.7% had decided to donate, 6.4% to store, and 10.1% had decided to bank their baby's cord blood but were unsure whether to donate or store.

After reading the information about cord blood banking that was provided in the questionnaire, the majority of respondents (60.9%) indicated they would consider donating or storing cord blood; 6.8% indicated they would not consider it, and the remainder (32.3%) were unsure (Table 2).

**Table 2: Reported decisions about cord blood banking before and after receiving information about it**

Decisions regarding cord blood banking	Responses before information* (N=1,400)	Responses after information (N=1,831)
Would consider donating or storing cord blood	30.0%	60.9%
Would not consider donating or storing cord blood	38.7%	6.8%
Unsure about whether to donate/store cord blood	31.3%	32.3%

\*Questions were slightly different before information was presented, with the survey asking women whether they were 'decided' about cord blood banking.

### Effect of information about cord blood banking on decisions

When we compared initial responses with responses given after information about cord blood banking was provided, the proportion of respondents who indicated they had made a decision about cord blood banking more than doubled from 30.0% to 67.7% (either would or would not consider UCB banking) (Table 2). Of those who initially indicated they had decided to store or donate their child's cord blood, most (87%) were subsequently affirmed in this decision ( $P=0.23$ ). Of those who initially indicated that they were *undecided*, 64.2% subsequently reported that they would consider cord blood banking; one third remained unsure, and 3% said they would not consider cord blood banking ( $P<0.001$ ). Of those who initially indicated they had *not* considered cord blood banking, half (49.8%) subsequently said they would definitely consider donating or storing the cord blood, 43.7% were not sure, and 6.4% said they would not consider either option ( $P<0.001$ ).

Women who remained undecided about cord blood banking even after receiving information about it were more likely to be delivering in rural hospitals, be aged <20 years, educated only to high school level, and from a non-English speaking backgrounds and particularly of Middle Eastern, Indian, African and Pacific Islander ethnic background or of Hindu/Sikh or Muslim religion ( $P<0.01$ ) (Table 3).

**Table 3: Respondent characteristics and whether they would consider umbilical cord blood banking (UCB) following provision of basic information about UCB**

Maternal characteristics	Would consider UCB banking (n=1,116)	Unsure about UCB banking (n=591)	Would not consider UCB banking (n=124)
	%	%	%
Location			
Rural hospital	61.9	32.8	5.3
Urban hospital	60.7	32.1	7.2
Hospital			
Public hospital	59.6	33.3	7.1
Private hospital	66.0	28.4	5.6
Maternal age (years) <sup>§</sup>			
<20	41.0	48.7	10.3
20-34	60.1	32.7	7.3
35+	65.7	29.3	5.0

Education <sup>§</sup>			
High school	54.4	35.6	10.0
Post-secondary technical education	61.6	32.7	5.6
University	63.9	30.3	5.8
Non-English speaking background <sup>§§</sup>			
Yes	41.1	49.0	9.8
No	68.7	25.9	5.4
Ethnic background <sup>§§</sup>			
Northern European	74.2	21.5	4.3
Southern and Eastern European	61.0	33.8	5.1
Indian	35.2	50.0	14.8
Middle Eastern	42.1	45.2	12.7
North-East Asian (Chinese/ Japanese)	39.0	56.1	4.9
South-East Asian	43.2	42.0	14.8
Other*	50.5	38.7	10.8
Religion <sup>§§</sup>			
Abrahamic	59.8	33.2	7.0
Eastern faith	56.0	35.8	8.2
Other/ No faith	68.8	25.0	6.3

<sup>§</sup> P-value <0.05, <sup>§§</sup> P-value<0.001

\*Other category comprises of women from Pacific Islander (2.8%), Aboriginal/Torres Straight Islander (1.7%), Southern and Central American (0.8%), African (0.8%) and other nations (0.9%)

### Preferences and beliefs about cord blood banking

After receiving information, among those who indicated they would consider cord blood banking (n=1,116), 74.7% indicated they would donate to a public bank, 9.1% indicated they would store the cord blood in a private bank, and 16.2% indicated they needed more information before deciding. Of

those who considered either public or private options, 59.2% would hypothetically be willing to pay up to \$250 and 7.6% over \$250 per annum to store the cord blood in a private bank for up to 18 years. However, a third thought there should be no cost and that private banks should be funded by the government. When asked if they would want to decide how cord blood should be used if donated to a public bank, 73.2% believed restrictions should not be placed on its use. Of the 168 women who *would* want to determine how it was used, 18 indicated they would want to restrict the use to certain ethnic or religious groups. Also, 109 indicated they would be agreeable for the blood to be used for medical research.

The majority (93.1%) of participants indicated that pregnant women should be informed about cord blood banking during pregnancy, that they should be advised about both public (99%) and private (95%) options, and that this information should be discussed by their pregnancy care provider (94.7%). Three quarters considered the ideal timing for information would be either before pregnancy or before 30 weeks gestation; 20% believed it should be provided after 30 weeks but before delivery. Nearly all respondents (95.8%) believed the pregnant woman should be involved in the decision about cord blood banking; 77% believed the biological father should also be involved, but most (94.7%) indicated that if there was any disagreement, the pregnant woman should have the final say.

## DISCUSSION

This is the largest Australian survey to date concerning umbilical cord blood banking, and it is the first to explicitly assess the influence of information on parents' preferences and decisions. Because it was translated into 10 community languages, it provides information about women from non-English speaking backgrounds. This is important due to the under-representation of certain ethnic groups in adult donor registries and cord blood banks (1,3).

A high proportion of NSW women (70.7%) are aware of cord blood banking. Because all printed information about cord blood banking available in NSW hospitals is in English, it is unsurprising that those unaware of this option are more likely to be from non-English speaking backgrounds and/or born overseas. Higher levels of awareness about private storage compared to public donation might reflect the fact that donation is an option in only three of the 14 hospitals included in the survey. However, women giving birth in these three hospitals were more likely to be aware of both options compared with women sampled from the other 11 hospitals. Although the sample was not randomly selected, the survey was conducted in both public and private hospitals in rural, regional and urban areas, and the sample is demographically similar to the wider population of expectant mothers in NSW (18).

Our findings echo previous studies that have shown both widespread awareness of cord blood banking and limited public understanding. Almost half of the respondents (44.2%) did not know about the public/private split in cord blood banking, and few were aware that, for the most part, privately stored cord blood is meant to be used for the 'donor' baby. Almost half thought it was 'likely' that their child would need the cord blood in future, or they were unsure about this. The true likelihood is estimated to be between 1 in 2,500 and 1 in 20,000 (19). Many respondents mistakenly reported that cord blood can be used to treat asthma, diabetes, cystic fibrosis and spinal cord injury. This probably reflects uncritical enthusiasm in the media about regenerative medicine. Choices about cord blood banking are thus frequently poorly informed.

The overwhelming majority of respondents expressed the opinion that women should be informed about cord blood banking (93.1%), and the results suggest that a small amount of basic information can make a difference to women's decisions about cord blood banking. After being provided with



such information, the proportion of respondents who indicated they had decided whether to donate or store cord blood more than doubled. Providing information does not appear to undermine the decision to bank cord blood; it appears to make those who are undecided about this option more likely to opt for it, and it is likely to have the same effect on about half of those who have not yet considered this option. Importantly, however, the demographic profile of those who would consider cord blood banking reflects groups who are currently over-represented in public cord blood banks (1,3).

A much higher proportion of respondents indicated they would prefer to donate the cord blood to a public bank rather than pay for storage (three quarters compared to one in ten, respectively) both before and—even more so, after—receiving brief information. Nevertheless, NSW women have more limited opportunities for donation than private storage. Whilst the majority of respondents did not believe restrictions should be placed on who should have access to donated cords, one in ten *would* want to put restrictions in place. Use of the blood for research purposes seems to enjoy high levels of support.

### Conclusions and recommendations

Information provided to prospective parents about umbilical cord blood banking should be accurate and balanced, and provide sufficient information about the advantages and disadvantages of both donation and storage so parents can make an informed choice. Parental decisions about cord blood banking are open to influence by “media hype”, promotion by commercial interests, fear of illness, hope for the future, and parental desires to protect children. Thus, information should be both accurate and designed to counter specific misconceptions. The European Group on Ethics in Science and New Technologies has recommended that “appropriate information should be given to consumers willing to use their (commercial [umbilical cord blood] banks’) services, including the fact that the likelihood that the sample may be used to treat one’s child is currently negligible, that the future therapeutic possibilities are of a very hypothetical nature and that up until now there is no indication that the present research will lead to specific therapeutic applications of one’s own cord blood cells” (20). This advice remains justified and has been echoed by other medical authorities (21,22). Extra efforts should be made to inform women who are young, less educated, live in rural areas, born overseas, come from non-English speaking or Indigenous backgrounds or who deliver in public hospitals. As our survey demonstrates, information can be translated into community languages, and this might help to address the under-representation of certain ethnic groups in cord blood banks.

Information about cord blood banking should be provided to women before pregnancy or at least before 30 weeks gestation. Legal and policy bodies should also consider that the overwhelming majority of expectant mothers believe they should be informed and have ultimate control over their decisions about the use of umbilical cord blood.

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