

## Banking cord blood stem cells: attitude and knowledge of pregnant women in five European countries

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**BACKGROUND:** This study explores pregnant women's awareness of cord blood stem cells and their attitude regarding banking options in France, Germany, Italy, Spain, and the UK.

**STUDY DESIGN AND METHODS:** Questionnaires were distributed in six maternities. This anonymous and self-completed questionnaire included 29 multiple-choice questions based on: 1) sociodemographic factors, 2) awareness and access to information about cord blood banking, 3) banking option preferences, and 4) donating cord blood units (CBUs) to research.

**RESULTS:** A total of 79% of pregnant women had little awareness of cord blood banking (n = 1620). A total of 58% of women had heard of the therapeutic benefits of cord blood, of which 21% received information from midwives and obstetricians. A total of 89% of respondents would opt to store CBUs. Among them, 76% would choose to donate CBUs to a public bank to benefit any patient in need of a cord blood transplant. Twelve percent would choose a mixed bank, and 12%, a private bank. A total of 92% would donate their child's CBU to research when it is not suitable for transplantation.

**CONCLUSION:** The study reveals a strong preference for public banking in all five countries, based on converging values such as solidarity. Attitudes of pregnant women are not an obstacle to the rapid expansion of allogeneic banking in these EU countries. Banking choices do not appear to be correlated with household income. The extent of commercial marketing of cord blood banks in mass media highlights the importance for obstetric providers to play a central role in raising women's awareness early during their pregnancy with evidence-based medical information about banking options.

Clinical development of cord blood transplantation has had a dramatic impact on banking activities the past decade.<sup>1</sup> The debate over umbilical cord blood banking (UCBB) has focused mostly on scientific and bioethical issues. Only a few studies, conducted on a national scale, have so far analyzed parents' expectations and motivations on whether to have their child's umbilical cord incinerated or to store the cord blood unit (CBU) in a bank.<sup>2,3</sup> In this study, we present a comparative analysis of five European countries: France, Germany, Italy, Spain, and the UK. This study explores pregnant women's awareness of cord blood stem cells and their attitude regarding the three banking models that have emerged:

- Public banks that store undirected units for allogeneic transplantation (noncommercial activity). Public banks store CBUs free of charge and anonymously. These samples can be used to treat any patient. These

**ABBREVIATIONS:** CBU(s) = cord blood unit(s); UCBB = umbilical cord blood banking.

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banks are financed with public money, but are developing slowly due to limited funds.

- Private banks that store directed units for an exclusive intrafamilial usage (commercial activity). Private banks charge a fee to store CBUs exclusively for the benefit of the newborn’s family. These units cannot be distributed to patients outside the family.
- Mixed banks that store directed units (intrafamilial usage, commercial activity) that can potentially be used by public health authorities for allogeneic transplantations (noncommercial activity). Two types of mixed banks exist: one of them stores newborns’ CBUs for a fee, but in an emergency, the whole unit can be attributed to a patient outside the family, upon requisition from the health authorities. In this case, the family will receive a full refund of the storage fee. Another model splits the unit into two parts—the family pays a fee to store 20% of the unit for potential future use, whereas 80% is donated to a public bank for allogeneic purposes.<sup>4</sup>

These three models—public, private, and mixed—have developed worldwide, but do not systematically coexist in all countries, due to heterogeneous national regulatory frameworks. Such disparities may have an impact on the level of information conveyed by obstetric providers to pregnant women. The survey analysis also takes into account cord blood banking organizational differences in each country, particularly the number of collecting maternities, collection rates, and CBU availability based on Netcord international standards (Table 1).

The study seeks to evaluate pregnant women’s degree of information and the means of access to this information; the choice to destroy or store the cord blood for therapeutic or scientific purposes; the choice of a maternity depending on banking options; the preference for storing in a public, private, or mixed cord blood bank; the principal reasons that motivate this choice; the influence of household income on banking choices; parents’ expectations regarding the price of storage in private and mixed banks; whether fathers should have a say in the decision process; and the impact of national regulatory frameworks on banking options.

## MATERIALS AND METHODS

This comparative survey was conducted in six maternities: Hôpital Privé d’Antony (Antony, France); the Royal Victoria Infirmary (Newcastle, UK); Universitätsklinikum Dresden and St Joseph Stift (Dresden, Germany); Fondazione Ospedale Maggiore Policlinico, Mangiagalli e Regina Elena (Milan, Italy); and Centre de Transfusió i Banc de Teixits, Hospital Vall d’Hebron (Barcelona, Spain). These maternities were selected according to the following criteria: urban or suburban areas, annual

TABLE 1. Cord blood banking activities in five EU countries (March 2009)

Country	Collecting maternities for public banks	Allogeneic CBUs collected during 2008	Allogeneic CBUs stored during 2008	CBUs (based on Netcord-registered CBUs)	Population (million inhabitants)	Public banks (number of CBUs per 10,000 inhabitants, based on Netcord-registered CBUs)		
						Private banks	Mixed banks	Not authorized <sup>13</sup>
France	7 <sup>13</sup>	3,789 <sup>13</sup>	1113 <sup>14</sup>	7,051 <sup>13</sup>	64.3 <sup>15</sup>	1.1	Not authorized <sup>16</sup>	Not authorized <sup>13</sup>
Germany	~200	Not available	2418 <sup>17</sup>	20,013 <sup>18</sup>	82.2 <sup>19</sup>	2.4	Authorized	Authorized
Italy	290 <sup>20</sup>	11,517 <sup>20</sup>	3167 <sup>20</sup>	17,526 <sup>20</sup>	60.1 <sup>21</sup>	2.9	Not authorized <sup>8</sup>	Not authorized <sup>8</sup>
Spain	107 <sup>22</sup>	Not available	7204 <sup>22</sup>	35,802 <sup>23</sup>	45.8 <sup>24</sup>	7.8	Not authorized <sup>25</sup>	Authorized <sup>25</sup>
UK	6 <sup>26</sup>	4,359 <sup>27</sup>	1812 <sup>27</sup>	29,769 <sup>23</sup>	61.5 <sup>28</sup>	4.8	Authorized	Authorized

number of births (>1000), and social diversity of pregnant women. The target population included pregnant women who had not previously enrolled in any type of UCBB program. The distribution of questionnaires was coordinated in consultation waiting areas and during antenatal courses. The questionnaire was anonymous and self-administered. It was approved by the national or local ethics committees, as well as the medical teams of the maternities involved in the study. The questionnaire included 29 multiple choice questions articulated around three sections: 1) attitude toward blood and marrow donation, 2) access to information about UCBB, and 3) preference among UCBB options. These questions were compiled based on a pilot study conducted in France from February to April 2008, involving 105 pregnant women. Complete data collection was achieved on April 1, 2009.

### Statistical analysis

We report descriptive data (number and/or proportion of respondents) and *p* values computed using the Welch formulation, which assumes different sample sizes and unequal variances. To compare differences between countries, we performed pairwise comparisons (i.e., we compared each country to one another, as opposed to comparing each country to the total mean). Therefore, with five countries studied, we performed 10 statistical tests per question. When comparing a country to another, a statistical threshold of a *p* value of less than 0.05 (two-tail tests) was considered to be significant. Sample size may vary from one question to the other due to the nature of the questionnaire. According to how respondents answered questions at the start of the questionnaire, they were directed to different sets of questions throughout the questionnaire. Therefore, respondents did not all answer the same set of questions.

### Limits of the study

Questionnaires were conducted anonymously. Respondents' ethnicity was not reported because some hospital ethics committees considered this criterion to be potentially discriminatory. It would have been interesting to study the attitudes of donors from ethnic minorities and correlate these results with their underrepresentation within public banks. Further studies should be conducted specifically to focus on this aspect. For practical reasons, the survey in Germany had to be conducted during antenatal classes because pregnancy consultations take place in obstetricians' surgeries and not in hospitals. As a result, two maternities—as opposed to one—were selected in Germany to meet other countries' sample size.

## RESULTS

### Sample profile (Table 2)

Among the 1785 returned questionnaires, 165 were insufficiently completed and considered invalid. Validated questionnaires were distributed as follows: 318 in France (validation rate, 96%), 290 in the UK (validation rate, 82%), 313 in Germany (validation rate, 83%), 323 in Spain (validation rate, 96%), and 376 in Italy (validation rate, 97%). The mean age of pregnant women who completed the questionnaire was 32 years. More than three-quarters of respondents have a family monthly income below €3000. Almost two-thirds of respondents (65%) were in their final trimester of pregnancy. Regarding their attitude toward donation, almost three-quarters (74%) of the women never donate blood. Among women who do not give blood, 21% cannot give their blood due to medical reasons. On the other hand, the study revealed that more than three-quarters (79%) of women would be willing to donate their marrow to save another life.

The following section presents six categories of questions. To best reflect the opinion of the tested sample, the following tables provide the two answers most frequently given by respondents to each question. In Tables 3 to 7, the two principle arguments in favor or against the selected question are reported.

### Information and knowledge about cord blood (Table 8)

More than three-quarters of pregnant women (79.4%) declare having a poor knowledge of cord blood banking (from 70.7% in Italy to 89.8% in France, *p* < 0.001). The vast majority of respondents would have liked to receive information on this topic, ranging from 93.3% in Italy to 52.7% in the UK (*p* < 0.001). In all five countries, more than half of pregnant women (59.6%) received information through mass media (press, television, radio, Internet). Only 20.6% received information from a general practitioner, obstetrician, or midwife (6.7% in France to 24.8% in Germany, *p* < 0.001). Although signature of an informed consent is required only by the expectant mother, overall 90.6% of

**TABLE 2. Sample profile**

Total (n = 1620)	Number of respondents (%)
Mean age (n = 1552)	32 years
Level of studies (n = 1584)	
Primary school	46 (2.9)
Secondary school	760 (48.0)
University	778 (49.1)
Family monthly income (n = 1447)	
<3000 €	1110 (76.7)
≥3000 €	337 (23.3)
Stage of pregnancy (n = 1505)	
<3 months	115 (7.1)
3-6 months	405 (25.0)
>6 months	985 (60.8)

**TABLE 3. Attitude regarding cord blood banking**

Cord blood banking choices	Number	(%)
Wish to store the child's umbilical cord blood (n = 1689)		
Mean	1498	(88.7)
Italy	387	(98.0)
Spain	318	(94.9)
France	318	(89.8)
UK	238	(82.9)
Germany	237	(74.5)
In a public bank (n = 1376)		
Mean	1052	(76.5)
UK	201	(88.9)
France	239	(86.6)
Spain	232	(80.0)
Germany	150	(68.2)
Italy	230	(63.2)
In a private bank (n = 1376)		
Mean	163	(11.8)
Italy	80	(22.0)
Germany	34	(15.5)
Spain	26	(9.0)
UK	16	(7.1)
France	7	(2.5)
In a mixed bank (n = 1376)		
Mean	161	(11.7)
Germany	36	(16.4)
Italy	54	(14.8)
Spain	32	(11.0)
France	30	(10.9)
UK	9	(4.0)

**TABLE 4. Attitude regarding public banking**

Storage in public banks	Number	(%)
Would store in a public bank because everyone can benefit from the unit in case of need (n = 983)		
Mean	580	(59.0)
UK	117	(66.9)
France	143	(62.4)
Spain	133	(61.0)
Italy	123	(56.9)
Germany	64	(44.1)
Would store in a public bank because storage is free (n = 983)		
Mean	256	(26.0)
Germany	63	(43.4)
UK	46	(26.3)
France	60	(26.2)
Italy	46	(21.3)
Spain	41	(18.8)
Would not store in a public bank because it cannot guarantee the availability of a CBU match if needed by the family (n = 238)		
Mean	131	(55.0)
Spain	24	(61.5)
Germany	30	(60.0)
Italy	64	(57.7)
UK	5	(41.7)
France	8	(30.8)
Is not prepared to change maternity to give birth in one that collects CBU (n = 1010)		
Mean	766	(75.8)
France	214	(91.1)
Germany	116	(78.9)
Spain	167	(76.6)
UK	135	(71.1)
Italy	134	(60.9)

**TABLE 5. Attitude regarding private banking**

Storage in private banks	Number	(%)
Would store in a private bank because research is promising to treat other diseases in the future (n = 153)		
Mean	78	(51.0)
Germany	18	(64.5)
Italy	41	(53.2)
Spain	13	(50.0)
UK	4	(40.0)
France	2	(28.6)
Would store in a private bank because, even though the probability of using the CBU for the family is low, it is not nil (n = 153)		
Mean	15	(9.8)
France	3	(42.9)
Italy	9	(11.7)
Germany	2	(6.1)
Spain	1	(3.8)
UK	0	(0)
Would not store in a private bank because the price is too high (n = 1028)		
Mean	541	(52.6)
Germany	110	(69.2)
UK	107	(60.5)
Spain	113	(51.6)
France	123	(51.5)
Italy	88	(37.6)
Would not store in a private bank because when a life is at stake, helping others is a duty (n = 1028)		
Mean	305	(29.7)
Spain	86	(39.3)
Italy	81	(34.6)
France	82	(34.3)
UK	36	(20.3)
Germany	20	(12.6)

pregnant women consider that fathers should also have a say in what happens to their child's CBU (86.3% in the UK to 93.4% in Spain,  $p = 0.004$ ). Almost all pregnant women (91.6%) believe that they should systematically be informed of the therapeutic benefits of cord blood (80.1% in the UK to 97.8% in Italy,  $p < 0.001$ ).

### Cord blood banking choices (Table 3)

On average, a vast majority of pregnant women (88.7%) are willing to store their child's cord blood for therapeutic or scientific purposes (74.5% in Germany to 98.0% in Italy,  $p < 0.001$ ). Only 11.3% prefer to destroy it. Significant country differences can be observed. For instance, the survey shows that 25.5% of German respondents prefer to destroy their child's cord blood rather than donate it. This value is 12 times higher than in Italy (2%,  $p < 0.001$ ), five times higher than in Spain (5.1%,  $p < 0.001$ ), and significantly higher than in France (10.2%,  $p < 0.001$ ) and the UK (17.1%,  $p = 0.011$ ). Among German respondents who opt for destruction, their primary concern is to protect their child's genetic data from third parties (43%).

Among those who opt for storage in all five countries, more than three-quarters (76.5%) would choose to donate the CBU to a public bank. The rest of pregnant women

**TABLE 6. Attitude regarding mixed banking**

Storage in mixed banks	Number	(%)
Would store in a mixed bank because birth is a unique chance to store the newborn's CBU, it should not be missed (n = 134)		
Mean	46	(34.3)
Italy	18	(40.9)
Spain	10	(38.5)
Germany	10	(32.3)
UK	2	(25.0)
France	6	(24.0)
Would store in a mixed bank because the CBU can save the life of a person outside the family if needed (n = 134)		
Mean	31	(23.1)
UK	3	(37.5)
Germany	10	(32.3)
France	6	(24.0)
Italy	8	(18.2)
Spain	4	(15.4)
Would not store in a mixed bank because the price is too high (n = 898)		
Mean	473	(52.7)
UK	100	(65.8)
Germany	97	(65.5)
Spain	87	(51.8)
France	88	(46.6)
Italy	101	(41.9)
Would not store in a mixed bank because body parts should not be the source of commercial profit (n = 898)		
Mean	267	(29.7)
France	80	(42.3)
Spain	59	(35.1)
Italy	76	(31.5)
Germany	26	(17.6)
UK	26	(17.1)

would equally choose a mixed bank (11.8% on average) or a private bank (11.7% on average). The choice of a private bank ranged from 2.5% in France to 22.0% in Italy ( $p < 0.001$ ), despite commercial banks not being authorized in both countries. It is therefore striking that low proportions of pregnant women in the UK (4.0%) would choose commercial UCBB, where private and mixed banks are authorized.

#### Choice for public banks (Table 4)

In all five countries, 59% of women who choose to donate to a public bank wish to benefit others in need of a cord blood transplant (44.1% in Germany to 66.9% in the UK,  $p < 0.001$ ). On average, one-quarter of pregnant women (26%) would prefer to store in a public bank because it is free of charge. In France and Spain, where commercial UCBB is not authorized, respondents considered that body parts should not be turned into profit-making commodities. This argument was given to justify the choice for a public bank (7.9% in France and 8.7% in Spain). The size of this opinion group was approximately 14 times greater than in the UK (0.6%), where commercial UCBB is widespread ( $p < 0.001$  for both France and Spain).

If their maternity is not authorized by health authorities to collect cord blood, one-quarter of pregnant women

**TABLE 7. Attitude regarding donation to research**

Donating to research	Number	(%)
Would donate to research if their child's CBU does not meet transplant criteria (n = 1367)		
Mean	1255	(91.8)
France	267	(95.7)
Italy	335	(94.6)
UK	205	(92.3)
Spain	262	(90.0)
Germany	186	(84.2)
Would donate to research in order to accelerate the development of new treatments (n = 1319)		
Mean	639	(48.4)
Germany	115	(59.6)
France	163	(59.3)
UK	126	(57.8)
Spain	125	(44.0)
Italy	110	(31.5)
Would not donate to research in order to avoid the CBU being used for commercial applications (n = 796)		
Mean	375	(47.1)
France	106	(69.3)
Spain	100	(55.9)
UK	42	(43.8)
Germany	31	(39.2)
Italy	96	(33.2)
Would not donate to research in order to protect the child's genetic identity from third parties (n = 796)		
Mean	139	(17.5)
Germany	34	(43.0)
UK	30	(31.3)
France	30	(19.6)
Spain	23	(12.8)
Italy	22	(7.6)

(24.2%) would be prepared to give birth in another maternity to donate to a public bank. In France, however, only 8.9% would be prepared to change maternity whereas in Italy, up to 39.1% ( $p < 0.001$ ) would change maternity to be able to store their child's CBU. Because donation points in Italy (290 maternities) outnumber by far those in France (seven maternities) in March 2009, women may be more inclined to select a collecting maternity knowing that they stand a greater chance of finding one in their area.

On average, among those who prefer not to store in a public bank (17.6%), more than half of them (55%) fear the lack of availability of a CBU in case of need by their family. Others consider themselves insufficiently informed about public banking (14.3%). Another group considers that this CBU belongs to their family and is not a public good (12.6%).

#### Choice for private banks (Table 5)

On average in the five EU countries, 11.8% of pregnant women are willing to store their child's cord blood in a private bank (2.5% in France to 22% in Italy,  $p < 0.001$ ). Among those who would choose private banking, 51% (28.6% in France to 54.5% in Germany,  $p = 0.21$ ) justify this choice by the progress in medical research and the promises of future treatments. Some respondents (15.7%)

**TABLE 8. Information and knowledge of pregnant women**

Information and knowledge or pregnant women	Number	(%)
Poor knowledge of cord blood banking (n = 1555)		
Mean	1234	(79.4)
France	283	(89.8)
UK	226	(81.0)
Germany	246	(79.9)
Spain	218	(76.8)
Italy	261	(70.7)
Would have liked to receive information on this topic (n = 1591)		
Mean	1207	(75.9)
Italy	348	(93.3)
Spain	283	(89.8)
France	256	(82.6)
Germany	172	(55.1)
UK	148	(52.7)
Received this information from a general practitioner, obstetrician or midwife (n = 929)		
Mean	270	(20.5)
Germany	87	(24.8)
Spain	52	(22.9)
Italy	103	(21.5)
UK	17	(18.9)
France	11	(6.7)
Fathers should have a say in what happens to their child's CBU (n = 1598)		
Mean	1448	(90.6)
Spain	296	(93.4)
Germany	284	(93.1)
France	293	(92.4)
Italy	329	(88.0)
UK	246	(86.3)

regard this cord blood as a “life insurance” for their child or their family, regardless of the cost. A further 12.4% believe that birth is a unique chance that must not be missed to store their child’s cord blood (7.8% in Italy to 40.0% in the UK,  $p = 0.07$ ). Others (9.8%) consider that although the probability of using the CBU for their family is low, it is not nil. Among those who opt for private banking, half of the respondents in Spain (50%) and almost half in Italy (47.8%) would pay more than €2000 ( $p = 0.86$ ), whereas none would pay this fee in France (0%) or in the UK (0%), which correlates with lower awareness about cord blood.

On average, in all five countries, more than half the pregnant women (52.6%) would not store in a private bank because they consider the cost to be too high, and 29.7% believe that it is a duty to donate the CBU to help others who could benefit from it.

#### Choice for mixed banks (Table 6)

On average in the five EU countries, 11.7% of pregnant women are prepared to store their newborn’s CBU in a mixed bank, ranging from 4.0% in the UK to 16.4% in Germany ( $p < 0.001$ ). The main reason that pregnant women choose a mixed bank is the belief that birth is a unique chance to store their child’s cord blood and it should not be missed (34.3%). Another motivating factor

is that their child’s cord blood could, if needed, be used to treat a patient outside their family (23.1%). Among the women who would not choose mixed banking, the majority (52.7%) consider this option to be overpriced. Almost one-third (29.7%) believe that body parts should not be turned into profit-making commodities, with a significant difference between France (42.3%) and the UK (17.1%,  $p < 0.001$ ). The survey also reveals that, among the five EU countries, 53.7% of respondents are not ready to pay more than €500 to store in a mixed bank.

#### Banking choices and household income (Fig. 1)

The median household income was calculated for each country, based on respondents’ answers. Household incomes were ranked according to €1000 ranges. Respondents were separated into two categories: “below” and “above” median local income (designated as “low” and “high” incomes, respectively). Table 7 shows that the choice of banking model is independent of income: contrary to what one might expect, high-income respondents do not systematically opt for private or mixed banks. On average in all five countries, they massively prefer public banking (76.6%). Only a fraction of high-income respondents (23.4%) equally opt for private and mixed models. Despite charging on average €2000, low-income customers in France, Germany, Italy, and Spain are strongly represented in mixed banks (on average 56.2%). This trend is similar for private banks, where low-income respondents represent nearly half the potential customers (45.8%). These results illustrate that banking choices are independent of household income.

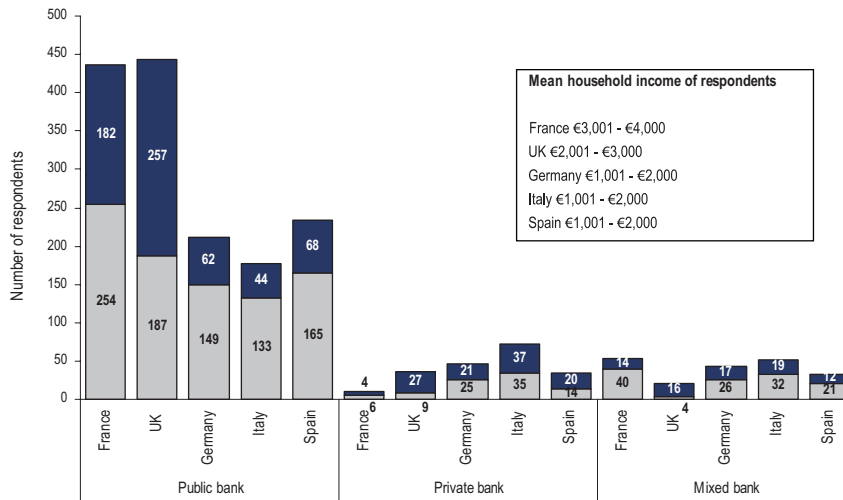
#### Donating to research (Table 7)

Almost all of pregnant women (91.8%) who wish to store their child’s cord blood would be willing to donate it to research if this unit does not meet the biomedical criteria required to be transplanted in a patient. The main reasons for this choice are to accelerate the development of new treatments (48.4%). This argument is considered to be important by only 31.5% of respondents in Italy and by almost double in Germany (59.6%,  $p < 0.001$ ). Among the women who would refuse to donate to research, almost half (47.1%) fear the possibility of this cord blood being used for commercial applications (33.2% in Italy and 69.3% in France,  $p < 0.001$ ). A smaller proportion (17.5%) wishes to protect their child’s genetic identity: the proportion of these respondents is over five times greater in Germany (43.0%) than in Italy (7.6%,  $p < 0.001$ ).

## DISCUSSION

#### Strong preference for public banking

One of the most striking results of the survey is the high fraction of pregnant women (88.7%) willing to store their



**Fig. 1. Correlation between bank choice and household income.** (□) Below-average income; (■) above-average income.

child's cord blood for therapeutic or scientific purposes. Among therapeutic banking options, survey results reveal a strong preference for public banking (76.5%) in all five countries, mostly to contribute to public health care resources (59%) and because it is free of charge (26%). This confirms that attitudes of pregnant women are not an obstacle to the rapid expansion of allogeneic CBU collections in these EU countries. Among those who prefer not to store in a public bank (23.5%), more than half fear the lack of availability of a CBU to meet public needs (55%). This high proportion might reflect the population's concern that health care authorities are unprepared to cope with increasing demands for cord blood transplantations. Motivation to donate CBU for research purposes is homogeneous in all five countries (91.8%), mainly to contribute to scientific and medical progress.

### Collecting maternities as local access points

Although the vast majority of women would spontaneously prefer to donate their child's cord blood rather than destroy it, they are often unable to do so because of the absence of collecting facilities in their area. However, three-quarters of pregnant women (75.8%) are not prepared to change maternities to give birth in a maternity that collects cord blood. This result highlights the loss of potential donations and therefore the need to expand national networks of collecting maternities to offer widespread opportunities for pregnant women to donate. Besides, this reveals that collecting maternities may improve their local attractiveness over those who do not collect cord blood.

### Access to medical information

The study also shows a poor knowledge of many pregnant women regarding cord blood banking (79.4%). This result

confirms the findings of previous studies conducted in Canada<sup>2</sup> and the United States.<sup>3</sup> It also indicates that appropriate information campaigns could significantly contribute to raise the number of CBU banked in those countries. The survey reveals that the majority of pregnant women (59.6%) who had heard about therapeutic indications of cord blood cells were informed via mass media, including the Internet, where commercial marketing is widespread. Only 20.6% were informed by medical staff, that is, obstetric providers or midwives. Extensive and harmonized medical training programs in those European countries could help obstetricians and midwives to better inform their patients about evidence-based therapeutic applica-

tions of cord blood. This could also contribute to reposition medical staff as central gatekeepers to ensure good medical practices, from informed consent to collection and storage procedures.

### Fathers' voice

Besides awareness and access to information, one of the key findings of this study is that 90.6% of pregnant women consider that fathers should be included in the decision to donate. Although not formally associated with the process of informed consent, fathers nevertheless have a key role in the decision making and therefore should also receive appropriate information regarding UCBB.

### Beyond ethical and legal frameworks

Regarding banking options all five countries, almost one-third of pregnant women (29.7%) believes that body parts should not be turned into profit-making commodities, with a significant difference between France (42.3%) and the UK (17.1%,  $p < 0.001$ ). This result could echo the French tenets regarding the noncommercialization and nonownership (*non-patrimonialité*) of human body parts, a humanistic principle inscribed at the core of the French Code Civil<sup>5</sup> and the Oviedo Convention adopted by the Council of Europe in 1997.<sup>6</sup> In contrast, the UK results may illustrate more utilitarian values and liberal principles illustrated by the thriving cord blood banking business over the past decade.<sup>7</sup>

Despite distinct national approaches, the survey reveals converging values in all five countries such as "solidarity," which is the prevailing motivation (59%) for public banking. National health regulatory frameworks do not seem to be systematically correlated with parents'

banking preferences. For instance, 88.9% of UK parents would choose public banking, despite the fact that private banking is authorized by health authorities. On the other hand, only 63.2% of Italian parents would choose public banking, which is the only authorized option for them.<sup>8</sup>

### Household income and price sensitivity

The survey results indicate that a wide variety of variables influence parents' banking choices. For instance, in all five countries, 11.8% of respondents would choose to store in a private bank, based on the advances of medical research. Among them, half of Spanish respondents (50%) and Italian respondents (47.8%,  $p = 0.855$ ) are willing to pay more than €2000, suggesting that the price is not a determining factor of their choice, whereas fewer respondents in Germany (16.1%) and no respondents in France (0%) and UK (0%) are willing to pay such a price. Among parents in all five countries who would not store in a private bank, 52.6% consider the price as a barrier to entry. Furthermore, survey results (Table 8) indicate that household income is not a determining factor in terms of banking choice. To fully understand parents' attitudes to cord blood banking, further investigations could analyze correlations between banking choices and national information programs, as well as marketing campaigns advertising commercial cord blood banking.

### Donating to research

In all five countries, the high proportion of parents willing to donate for research (91.8%) is predominantly motivated by the development of new treatments. In all five countries, however, very few programs are conducted to organize scientific cord blood banking to facilitate the access to human bioresources for research in cell therapy. With one of the highest fertility rates in Europe, France, for instance, still incinerates almost all CBU that could otherwise serve research.<sup>9</sup> Setting up and scaling up scientific banking raises not only organizational challenges but also ethical issues. In Germany, the concern expressed by respondents regarding genetic confidentiality (43%) should be addressed through the adoption of common European standards for informed consent.<sup>10</sup> This confirms the urgent need for European countries to adopt a harmonized regulation on biobanking through initiatives such as the pan-European Biobanking and Biomolecular Resources Research Infrastructure, funded by the European Commission.<sup>11</sup>

## CONCLUSION

The survey reveals striking disparities between women's awareness about UCBB and the information they actually receive from their midwives and obstetricians. However,

pregnant women would spontaneously prefer to donate their child's CBU to public banks through free and anonymous donations. Hence, pregnant women's preferences are convergent with national health authorities' programs to expand allogeneic banking. In the meantime, the gap between the high demand for donations and slow expansion of public banks—resulting mainly from a lack of public funding—is progressively being filled by a growing number of commercial banks.<sup>12</sup> These commercial banks have developed direct-to-consumer advertising campaigns that often bypass obstetricians and midwives. Obstetrics providers need to be given the means to provide evidence-based medical information to pregnant women to raise their awareness about cord blood banking options. To achieve this objective, education programs for medical staff in maternities should be implemented and intensified. These education programs for health professionals would contribute to improving information consistency, but also quality assurance and compliance with national and international accreditation standards. In addition, the survey highlights the importance of a structured network of collecting maternities as access points for CBU donations, both for therapeutic and for scientific purposes. Beyond country specificities, approved maternity networks and continuous medical education for obstetrics providers are clearly the key drivers to developing excellence in cord blood banking in Europe.

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### CONFLICTS OF INTEREST

AHS is the CEO of the DKMS Lifeline Cord Blood Bank, a public cord blood bank. All other co-authors declare no conflict of interest.

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