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Evaluation of factors affecting the decision to register as a potential bone marrow donor.

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Abstract:

Introduction. Allogenic hematopoietic stem cell transplants (HSCT) are the curative treatment for a number of hematological ailments. A number of transplants from matched unrelated donor (MUD) is increasing. The search for donors and the exchange of information in the international space is possible thanks to the global organization of the World Marrow Donor Association (WMDA) and Bone Marrow Donors Worldwide (BMDW). The DKMS is a Polish organization involved in the registration of potential bone marrow donors (PBMD).

Purpose of work. The objective of the study was to assess the factors that influence the decision to register as a PBMD.

Material and method. 124 people took part in the survey and filled the original questionnaire. Some of the surveys were collected during the registration of PBMD organized by the DKMS Foundation and some were filled in electronically. Questions were divided into groups. The first part concerned the determination of demographic characteristics of surveyed people. Then there were single-choice and multiple-choice questions. The results were analyzed with computer program Microsoft Excel 2011.

Results. 86.3% of the respondents were women, while men - 13.7%. The majority of respondents live in cities with a population of 150 000 - 500 000 residents. 8.9% of respondents confirmed that someone from their environment required a bone marrow stem cell transplant. When asked about how fast they made the decision concerning the issue of registration as PBMD, 44.4% of the respondents made the decision on the day of the registration.

Conclusion. In this group classical altruistic motives are top drivers for registering as PBMD. The knowledge about factors which influence people's decision to become PBMD is important to target recruitment efforts.

Keywords: unrelated donors, bone marrow transplantation, attitude, decision making, registry

Introduction

Allogenic hematopoietic stem cell transplants (HSCT) are the curative treatment for a number of hematological ailments, including leukemia, genetic diseases and autoimmune disorders. Peripheral blood stem cell (PBSC) donation, a simpler and less invasive alternative, has replaced bone marrow harvest in 75% of cases (1). A number of transplants from matched unrelated donor (MUD) is increasing – w Europe in 2006, out of 30.8 % allogenic transplants 20.52 % were from family donor and 17.48% from MUD. In 2008 39 % transplants were allogenic, out of them 19.89 % were from family member and 19.11% from unrelated donors (2). Survival after unrelated donor HSCT has nearly doubled since the first unrelated donor transplants in the late 1980's. Currently, 1-year survival of 60-70% can be expected for patients with high-risk acute leukemia who receive an unrelated donor HSCT relatively early in their disease course (3,4). From 2006 to the end of 2015 over 4 000 patients in Poland received allogenic hematopoietic stem cell transplantation in the treatment of blood cancers and many other bone marrow diseases, including 2457 transplants from unrelated donors. The transplantation from an unrelated donor is very often the only chance for recovery, especially if a family donor is not available. It is hoped that the patient will find an HLA-matched unrelated donor , often from the same country, but sometimes from all over the world. The search for donors and the exchange of information in the international space is possible thanks to the global organizations of the World Marrow Donor Association (WMDA) and Bone Marrow Donors Worldwide (BMDW), which establish the principles of cooperation for a network of centers and institutions involved in the development of bone marrow donation and transplantation around the world. At present, the registry contains over 1 million active Polish records, ranking Poland in the sixth place in the world, and third in Europe (after the German and British registry) in terms of the number of potential donors of hematopoietic cells. WMDA emphasizes the importance of international cooperation for the development of stem cell transplantation, because 27 million potential donors are still inadequate due to the genetic diversity of antigens and further recruitment of donors is encouraged, especially in regions outside Western Europe (5). Therefore, it seems to be important to assess the factors, which influence the decision to register as a potential bone marrow donor. This knowledge will allow for the construction of new educational programs or advertisements about becoming a potential donor, which will be positively received by a wider group of people than before.

Aim of study

The objective of the study was to assess the factors that influence the decision to register as a potential bone marrow donor (PBMD) and to analyze the occurrence of anxiety in already registered people.

Material and methods

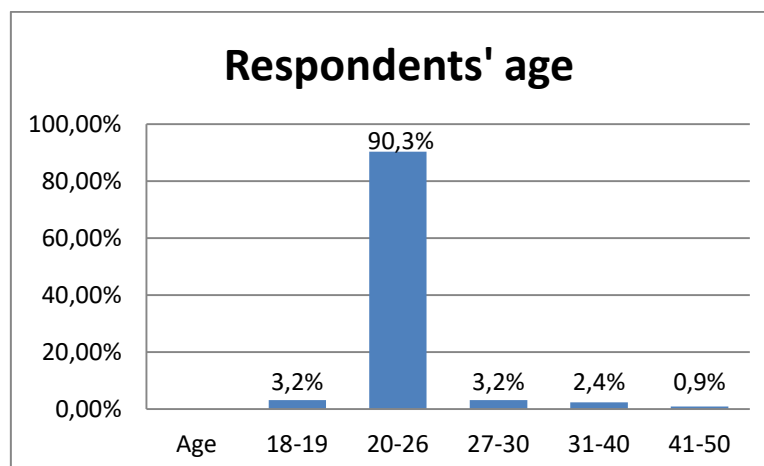
124 people who took part in the survey filled the original questionnaire prepared for the analysis. Some of the surveys were collected during the registration of PBMD organized by the DKMS Foundation, and some were filled in electronically. The way to obtain completed surveys did not affect the results obtained as in both cases the respondents had to complete a sheet consisting of identical questions. Questions were divided into 4 groups. The first part concerned the determination of demographic characteristics of

surveyed people such as: sex, age, education, the direction of the education obtained, permanent residence, marital status and family status (the fact of having children or not). The second part contained single-choice questions that checked whether the surveyed person knew personally someone who was already registered as a PBMD or knew someone who has donated bone marrow stem cells. It was also checked whether there were cases of blood cancer or the need to undergo a bone marrow stem cells transplantation procedure in the family or among the respondents. The survey also included a question about the time spent by the respondent to think about the fact of registering as a PDKM and the fact of consulting the decision with the family. The third part consisted of a multiple-choice question test about the source of knowledge from which information about the possibility of becoming a PBMD was gathered and the question in which it was recommended to select no more than 3 factors that influenced the final decision. The fourth part concerned the assessment of factors that previously prevented respondents from registering and determining the fears associated with the registration. The results were analyzed with computer program Microsoft Excel 2011.

Results

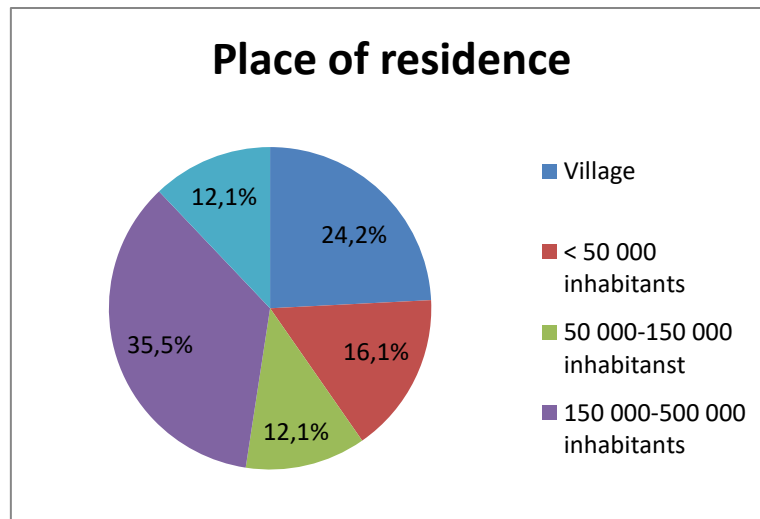
Demographic structure

86.3% of the respondents were women, while men - 13.7%. The respondents were dominated by people aged 20-26 (90.3%). The detailed age structure is shown in the graph (Graph 1).



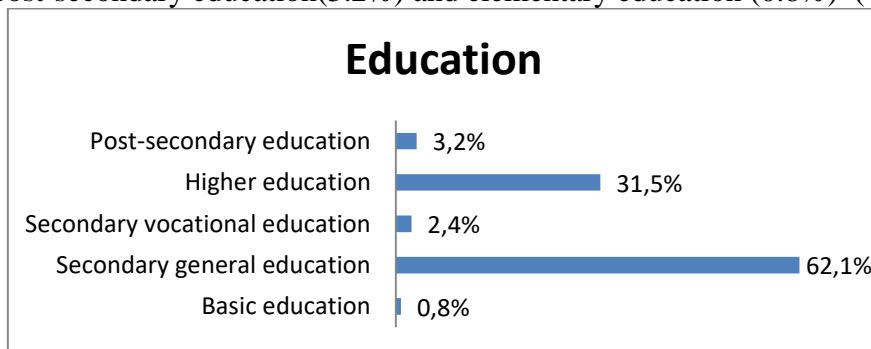
Graph 1.

35.5% of respondents live in cities with a population of 150 000 - 500 000 residents. 24.2% of the respondents are rural area residents, 16.1% were people from cities with a population of up to 50 000. 12.1% are residents of towns with a population of 50 000 - 150 000 and 12.1% are residents of towns above 500 000 residents (Graph 2).



Graph 2.

62.1% are people with general secondary education. 31.5% had higher education. The remaining group of respondents declared obtaining secondary vocational education (2.4%), post-secondary education(3.2%) and elementary education (0.8%) (Graph 3).

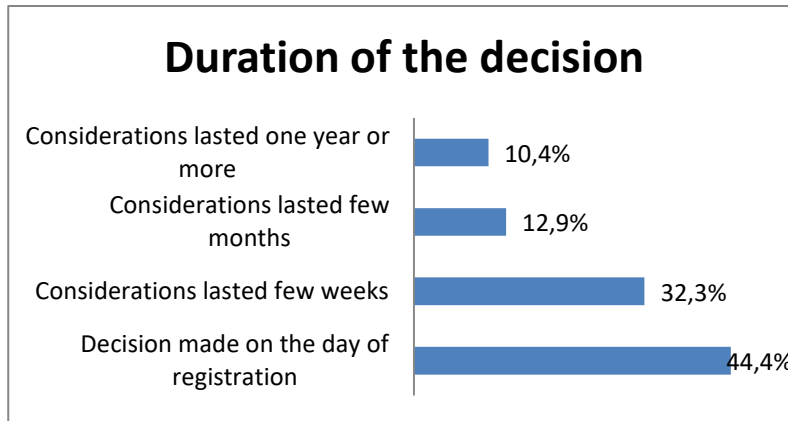


Graph 3.

84.7% of respondents defined their education profile as "Biological and chemical". 2.4% chose the answer "Humanistic", 1.6% "Biological-humanistic" and 0.8% "Mathematical-physical". 10.5% of the respondents chose the answer "Others".

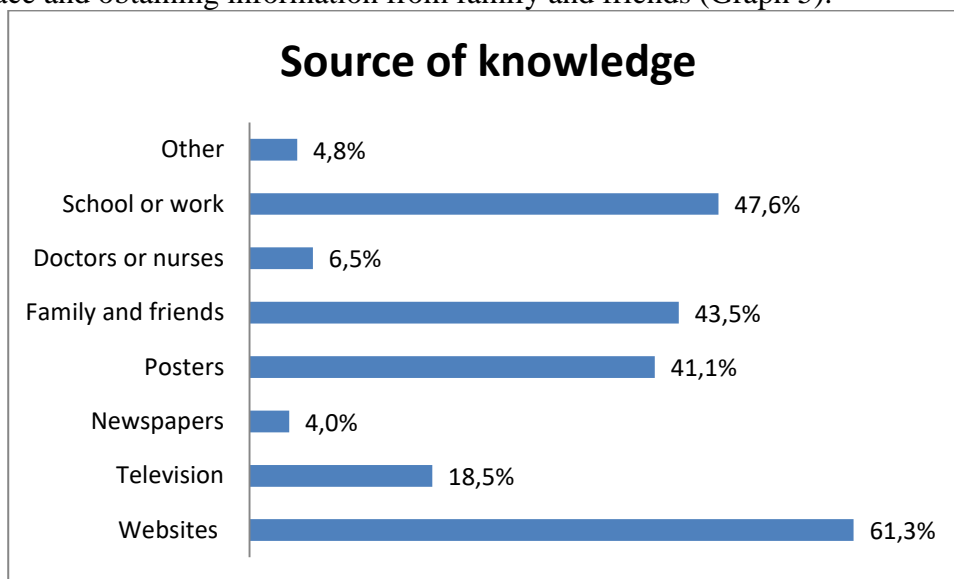
Main part of the survey

79% of respondents declared that there weren't blood cancer patients in their family or friends. 8.9% of respondents confirmed that someone from their environment required a bone marrow stem cell transplant. 72.6% have a person registered as a PBMD among family or friends and 32.3% of respondents know a person who has donated bone marrow stem cells. 79% of respondents did not consult their decision with their family. When asked about how much time they devoted to considering the issue of registration as PBMD, 44.4% of the respondents made the decision on the day of the registration, 32.3% considered for several weeks, 12.90% of the respondents considered that issue for several months. 10.40% of respondents have considered for one year or more (Graph 4).



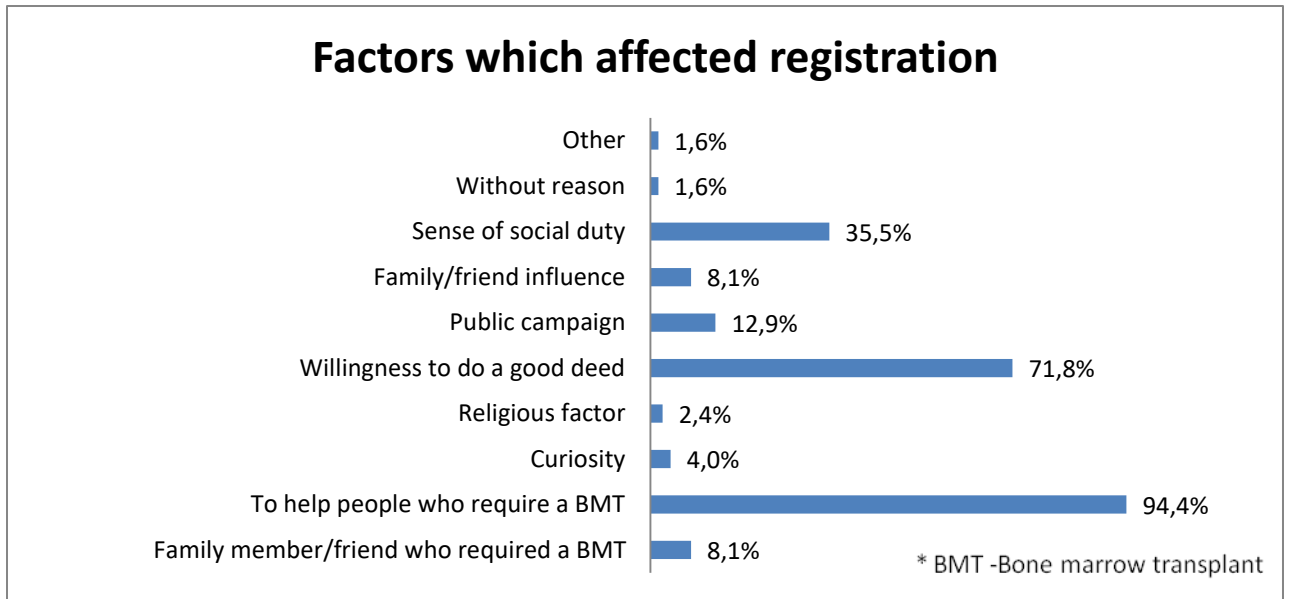
Graph 4.

When asked about the source of knowledge about the possibility of becoming a PBMD (multiple choice question), the most popular answers were: the Internet, school or workplace and obtaining information from family and friends (Graph 5).



Graph 5.

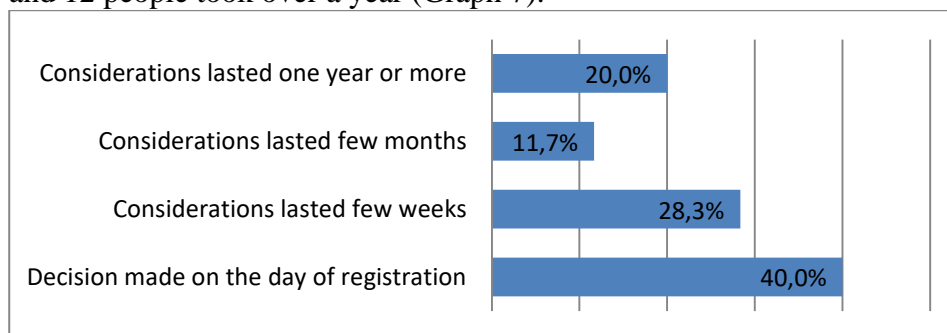
In the multiple-choice question "What prompted you to make a decision to register as a PBMD?" (with a maximum of 3 answers) 94.4% of respondents indicated "Willingness to help people who need a transplant", 71.8% chose "Willingness to do a good deed "and 35.5% indicated the answer "Sense of social duty" (Graph 6).



Graph 6.

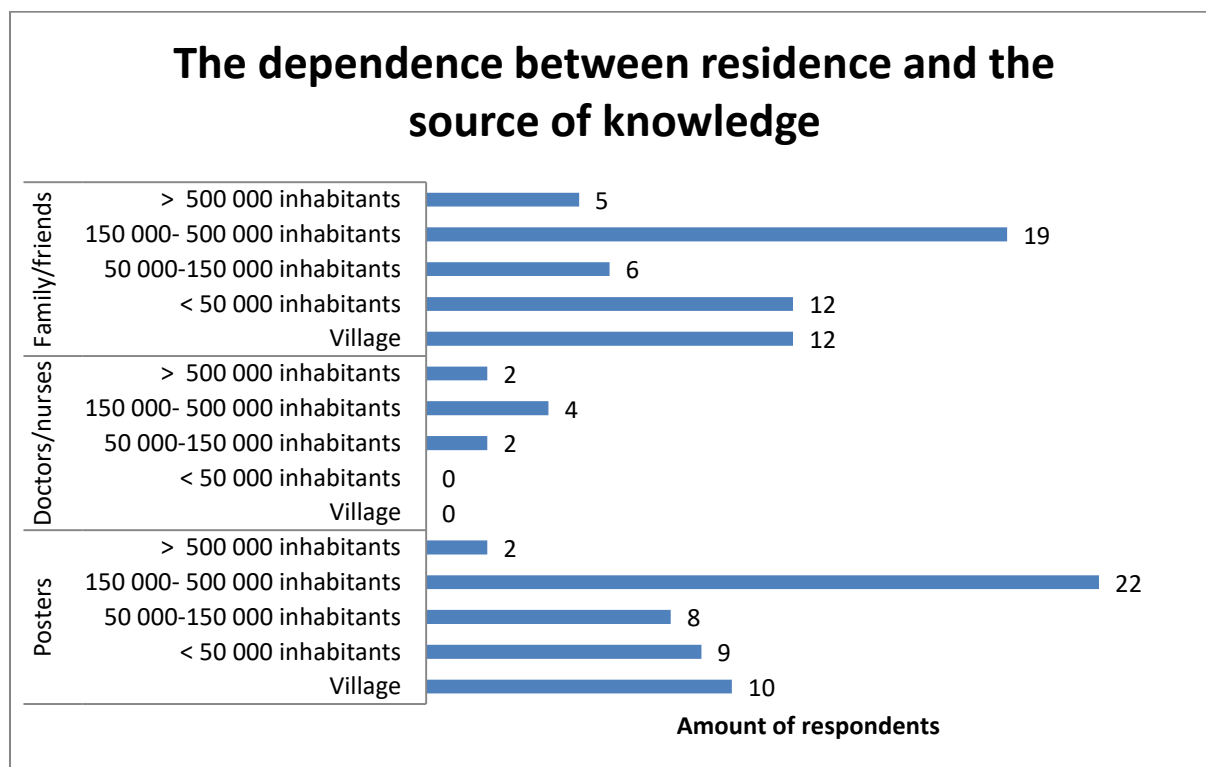
50% of respondents refrained from registering as PBMD due to the lack of possibility to register, 26.6% of respondents waited to reach the adequate age , 11.3% of people did not register due to fear of the bone marrow collecting procedure. For health reasons, 6.5% of the respondents postponed the time of registration to achieve the health state enabling registration, while 5.6% chose that they were afraid because of the possible complications connected with the procedure of bone marrow collection. 8.9% of respondents are afraid of the procedure of collecting stem cells from peripheral blood and 39.5% feel anxiety before the procedure of taking stem cells from the iliac ala. People who are afraid of picking procedures were asked about their fears: 43.5% of respondents chose pain at the injection site, 32.3% of respondents fear general anesthesia, 14.5% of respondents feel fear of infection, 1.6% of respondents are afraid of flu-like symptoms, 1.6% of respondents fear the feeling of numbness in the tongue, mouth and fingers, 6.5% of respondents marked the option "Other".

The results were analyzed to determine the factors that influenced the decision to become a PBMD. It was checked whether the fear of taking bone marrow stem cells had an impact on the duration of making decision about registration as PBMD. 60 people declared a sense of fear, of which 24 people decided to become PBMD on the day of registration, 17 people took several weeks, 7 people made the decision within a few months and 12 people took over a year (Graph 7).



Graph 7.

The place of residence of registered as PBMD and sources of knowledge from which they learned about the possibility of becoming a donor was compared. The knowledge coming from posters and from family or friends was mostly owned by people from cities of 150 000 -500 000 citizens. Only 8 people from among the respondents learnt about the possibility of registration from a doctor or nurse. Newspapers turned out to be the least popular source of knowledge (Graph 8).



Graph 8.

A group of respondents was divided into subgroup of people who had blood cancers in a family or in group of friends and a subgroup of people where blood cancers did not occur. It was analyzed whether the occurrence of blood cancer in the family or in friends influenced the amount of time devoted to considering becoming PBMD (Table 1).

Time devoted to making a decision	Hematological ailments occurred (26 respondents)	Hematological ailments didn't occur (98 respondents)
Decision made on the day of registration	10 respondents (38,5%)	45 respondents (45,9%)
Considerations lasted few weeks	10 respondents (38,5%)	30 respondents (30,6 %)
Considerations lasted few months	3 respondents (11,5%)	13 respondents (13,3%)
Considerations lasted one year or more	3 respondents (11,5%)	10 respondents (10,2 %)

Table 1.

It was assessed whether consultation of respondents' decision with their family was related to their place of residence. The results are presented in Table 2.

Place of residence	Decision was consulted (26 respondents)	Decision was not consulted (98 respondents)
Village	9	30
< 50 000 inhabitants	2	20
50 000-150 000 inhabitants	4	15
150 000-500 000 inhabitants	9	44
> 500 000 inhabitants	2	15

Table 2.

It was checked whether the type of factor that prompted registration had an impact on the duration of thinking about becoming a PBMD. The results are included in Table 3.

	Family member/friend who required a bone marrow transplant	To help people who require a bone marrow transplant	Curiosity	Religious factor	Willingness to do a good deed	Public campaign	Family/friend influence	Sense of social duty	Without reason	Other
Decision made on the day of registration	4	49	3	3	36	8	5	21	2	1
Considerations lasted few weeks	4	40	1	0	32	2	3	15	0	1
Considerations lasted few months	2	16	1	0	11	5	0	3	0	0
Considerations lasted one year or more	0	12	0	0	10	1	2	5	0	0

Table 3.

Discussion

Interestingly, Bart T et al., who conducted the survey in Switzerland, found similar motives to register as potential bone marrow donor (6). However, the top two obstacles to enroll on the blood stem cell registry were the lack of general information on blood stem cell donation and on its risks, whereas in our study: the lack of possibility to register and unsuitable age.

Galen E. Switzer et al. reported that specific motives for donation appear to be associated with donor background characteristics. This relationship seems especially strong for

donors' gender, which was associated with three of the five motive types central to our analysis; women were most likely to cite expected positive feelings, empathy and the desire to help someone (7).

Those people who had discussions with their family about tissue donation had greater probability to be registered as a PBMD. It seems that a positive attitude of the family plays an important role in a member's decision to become a donor. Also, people with a relative or a friend registered as a PBMD were more likely to become a volunteer. The information is important in people's decision to be registered as a PBMD since a great number of people do not understand the magnitude of problem. Many people do not know the approach to be registered as a PBMD. People are mobilized by appropriate, complete information (8). Those who have been informed about bone marrow transplantation were more often registered as PBMD, these findings were confirmed by McCullough et al. (9).

Conclusion

In this group classical altruistic motives are top drivers for registering as potential bone marrow donor. A quite important factor in our society is the attitude of the family, which forms a model to follow. This is especially evident in smaller towns where mass media play a smaller role in the diffusion of information. It is also worth paying attention to the sources of obtaining information, mainly such as the Internet, school or workplaces. In addition, the means of providing information should be properly selected, both in the city and in the village. Most people make decisions on the day of registration, which point out the need to organize activities, which allow people to register directly. However, making quick decisions may cause refusing donation, when recipient will be found. The majority of respondents are afraid of pain, but is not a factor that extends the time of reflection. Knowledge of these factors is important to target recruitment efforts.

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