ANALYSIS OF THE RUSSIANS' AWARENESS OF BONE MARROW DONATION AND THE FEDERAL BONE MARROW DONOR REGISTRY INFRASTRUCTURE

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Bone marrow transplant is the leading method to treat hematologic malignancies, immunodeficiency, and hereditary metabolic disorders. The Federal Bone Marrow Donor Registry effectiveness depends directly on public awareness of bone marrow donation and infrastructure development. A comprehensive approach to public awareness is necessary to increase the system effectiveness. The study aimed to investigate factors that influence joining the Federal Bone Marrow Donor Registry, with a focus on motivation, sources of information, impact of infrastructure, environment, and common myths. The respondents (potential donors registered in the Federal Registry; $n = 3100$) filled an online questionnaire of 24 questions aimed at studying and assessing the socio-demographic characteristics, motivation, sources of information, influence of the environment, awareness of bone marrow donation, and readiness to donate. It was found that young adults aged 18–36 ($n = 1860$) more often join the Federal Registry through informal channels, such as work/school events ($n = 843$; 27.2%), while respondents over the age of 37 ($n = 1240$) prefer healthcare institutions ($n = 1590$; 51.3%). Women make up the majority of potential donors ($n = 2304$; 74.3%), especially in Moscow ($n = 1650$; 74.5%), while higher prevalence of myths is reported for the regions ($n = 1646$; 53.1%). The findings emphasize the need for the differentiated approach to information policy, which will make it possible to increase the donor movement effectiveness nationwide. A key factor in scaling this work is partnership with commercial laboratories, which significantly expands the Federal Registry recruitment network and provides convenient conditions for donors to join.

Keywords: donation, bone marrow, hematopoietic stem cell, transplantation, BMT, HSCT, Federal Bone Marrow Donor Registry

Author contribution: Butunts MA — study planning, literature review, recruiting potential bone marrow donors, cooperation with medical institutions, statistical analysis, manuscript writing; Dyuzhina KA — literature review, data acquisition, analysis, and interpretation, recruiting potential bone marrow donors, cooperation with medical institutions; Nifatova ES — study planning, literature review, recruiting potential bone marrow donors; Muradyan TG — study planning, literature review, data analysis and interpretation, cooperation with medical institutions, statistical analysis, manuscript writing.

Compliance with ethical standards: all the sociological syrvey participants submitted the informed consent to the study; the survey was anonymous, the data were treated confidentially.

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Received: 26.05.2025 **Accepted:** 17.06.2025 **Published online:** 26.06.2025

DOI: 10.24075/brsmu.2025.032

АНАЛИЗ ОСВЕДОМЛЕННОСТИ РОССИЯН О ДОНОРСТВЕ КОСТНОГО МОЗГА И ИНФРАСТРУКТУРЫ ФЕДЕРАЛЬНОГО РЕГИСТРА ДОНОРОВ КОСТНОГО МОЗГА

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Трансплантация костного мозга — ведущий метод лечения злокачественных новообразований крови, иммунодефицитных состояний и наследственных метаболических нарушений. Эффективность Федерального регистра доноров костного мозга напрямую зависит от уровня информированности населения о донорстве костного мозга и развития инфраструктуры. Для повышения эффективности системы необходим комплексный подход к информированию населения. Целью исследования было изучить факторы, влияющие на вступление в Федеральный регистр доноров костного мозга, с акцентом на мотивацию, источники информации, влияние инфраструктуры, окружения и распространенных мифов. Респонденты (потенциальные доноры, состоящие в Федеральном регистре; $n = 3100$) заполняли онлайн-анкету из 24 вопросов, направленных на изучение и оценку социально-демографических характеристик, мотивации, источников информации, влияния окружения, осведомленности о донорстве костного мозга и готовности к донации. Установлено, что молодые люди 18–36 лет ($n = 1860$) чаще вступают в Федеральный регистр через неформальные каналы, такие как акции на работе/учебе ($n = 843$; 27,2%), респонденты старше 37 лет ($n = 1240$) предпочитают медицинские организации ($n = 1590$; 51,3%). Женщины составляют большинство потенциальных доноров ($n = 2304$; 74,3%), особенно в Москве ($n = 1650$; 74,5%), в регионах отмечается более высокая распространенность мифов ($n = 1646$; 53,1%,). Полученные результаты подчеркивают необходимость дифференцированного подхода в информационной политике, что позволит повысить эффективность донорского движения в масштабах страны. Ключевой фактор масштабирования этой работы — партнерство с коммерческими лабораториями, которое значительно расширяет рекрутинговую сеть Федерального регистра и обеспечивает удобные условия для вступления доноров.

Ключевые слова: донорство, костный мозг, гемопоэтические стволовые клетки, трансплантация, ТКМ, ТГСК, Федеральный регистр доноров костного мозга

Вклад авторов: М. А. Бутунц — планирование исследования, анализ литературы, рекрутинг потенциальных доноров костного мозга, взаимодействие с медицинскими организациями, статистический анализ, подготовка рукописи; К. А. Дюжина — анализ литературы, сбор, анализ и интерпретация данных, рекрутинг потенциальных доноров костного мозга, взаимодействие с медицинскими организациями; Е. С. Нифатова — планирование исследования, анализ литературы, рекрутинг потенциальных доноров костного мозга, Т. Г. Мурадян — планирование исследования, анализ литературы, анализ и интерпретация данных, взаимодействие с медицинскими организациями, статистический анализ, подготовка рукописи.

Соблюдение этических стандартов: все участники социологического опроса дали добровольное информированное согласие на проведение исследования; опрос анонимный, данные обрабатываются конфиденциально.

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Статья получена: 26.05.2025 **Статья принята к печати:** 17.06.2025 **Опубликована онлайн:** 26.06.2025

DOI: 10.24075/vrgmu.2025.032

Bone marrow and peripheral blood hematopoietic stem cell transplant (BMT/HSCT) represents a high-tech treatment method. It is used for a broad range of disorders, including hematologic malignancies, immunodeficiency, and hereditary metabolic disorders [1]. The method is based on substitution of the recipient's abnormal hematopoiesis through administration of hematopoietic stem cells obtained either from the patient him/herself (autologous HSCT), or from the donor (allogeneic HSCT) [2]. In turn, allogeneic HSCT is classified into procedures involving cells obtained from the HLA-identical related donors, haploidentical related donors, and unrelated bone marrow donors showing acceptable compatibility. Historically, the first successful allogeneic HSCT from the HLA-matched related donor (sister) was performed by R. A. Good in 1968 in the USA in a 5-month-old boy with primary immunodeficiency, while the first successful allogeneic HSCT from the HLA-matched unrelated donor was performed by E. D. Thomas in a 5-year-old child with severe combined immunodeficiency in 1973, also in the USA. In Russia, such intervention was first performed in 1985, and the first pediatric HSCT from the related donor was performed in 1991 by B. V. Afanasyev: a 5-year-old boy with acute lymphoblastic leukemia was the recipient, and his brother was a donor. In recent years, more than 2000 HSCT procedures are annually performed in the country, and the rate of allogeneic procedures is growing steadily (in 2023 it was above 1000 cases) [3].

It should be noted, that the bone marrow donor registry represents a key element of the allogeneic HSCT system. In 2014, a unified Bone Marrow Donor Search (BMDS) database was created in Russia at the Pavlov First Saint Petersburg State Medical University. In 2022, the Federal Registry of the Bone Marrow and Hematopoietic Stem Cell Donors, Donor Bone Marrow and Hematopoietic Stem Cells, Bone Marrow and Hematopoietic Stem Cell Recipients (Federal Registry) was formed, and the Federal Medical Biological Agency was made the Registry operator [4]. Today, it contains about 470,000 records of potential bone marrow donors (potential donors), among them 312,000 are available for search. However, it is necessary to expand the Federal Registry to 1 million people in order to ensure effective selection of potential donors for 80% of patients [5].

It is important to note that the processes ensuring the bone marrow donation are funded from the state budget (HLA typing, medical examination of bone marrow donors, bone marrow donation, transfer of bone marrow donors).

Despite the development of infrastructure, including establishing the recruiting centers (RCs) at blood service facilities and other healthcare institutions, there are still a number of systemic problems. Only 35% of the population are ready to become the bone marrow donors, which is due to low awareness and high rate of myths about the procedure [6]. Thus, 47% of Russians believe that bone marrow donation is a health hazard, and 60% expect painful sensations. Limited access to the recruiting centers represents one more barrier: there are no such centers in nine constituent entities, and in the large constituent entities these are far from sufficient [7]. That produces essential difficulties for potential donors, limiting their access to the RCs and forcing them to travel long distances for biomaterial (venous blood or buccal epithelium) sampling, which can be a barrier to join the Federal Registry. Thus, further development of the Federal Registry requires both proactive media policy and expansion of infrastructure.

The study aimed to identify the key factors that influence the person's readiness for the bone marrow donation and the differences in motivational factors that influence entry into the Federal Bone Marrow Donor Registry depending on the respondent's gender, age, and personal experience, including the impact of the rate of myths, trust in professionals, and the Federal Registry infrastructure.

METHODS

The study was conducted in October–November 2024 using the online questionnaire survey. A total of 6900 potential bone marrow donors registered in the Federal Bone Marrow Donor Registry at the time of the survey recruited by the Pirogov University were invited to take part in the study. An online questionnaire was sent to potential donors via e-mail and messengers using the contact data specified when joining the Federal Registry. Among the potential donors invited to take part in the study, 4664 (67.6%) were females and 2236 (32.4%) were males; the median age was 29.0 years (23–36). A total of 3100 respondents registered in the Federal Bone Marrow Donor Registry, who were recruited by the Pirogov University and filled the questionnaire posted on the Google Forms platform (Google LLC, USA), took part in the survey. The questionnaire comprised 24 mandatory questions aimed at investigating socio-demographic characteristics, motivation, sources of information, influence of the environment, awareness of bone marrow donation, and readiness to donate (Appendix).

The results of the respondent questionnaire survey results were process by conducting statistical analysis using the StatTech 4.8.3 software (StatTech, Russia).

The quantitative indicators were tested for normality using the Kolmogorov–Smirnov test. The non-normally distributed data are presented as the median and quartiles (Me [Q_1–Q_3] — interquartile range (IQR)), categorical variables are presented as absolute and relative rates (*n*, %) with the 95% confidence interval (95% CI), the Clopper–Pearson interval. Comparison of two independent groups based on the quantitative trait (when the distribution was non-normal) was performed using the Mann–Whitney *U* test. Comparison of percentages in four-field tables was performed using the Pearson's chi-squared test (with the expected rates ≥ 10.0), and the odds ratio with the 95% CI was calculated to estimate the effect. The analysis of multi-field tables was conducted using the Pearson's chi-squared test. The data were considered significant at $p < 0.05$.

RESULTS

The questionnaire survey conducted showed that there were 2304 (74.3%) females and 796 (25.7%) males among 3100 (100%) respondents, who completed the survey. The respodents' median age was 31.0 years (24–37). The respondents' median age of joining the Federal Bone Marrow Donor Registry was 30.0 years (23–36). The largest number of respondents joined the Federal Registry in Moscow — 2215 (71.5%), Moscow Region — 284 (9.2%), Omsk Region — 113 (3.6%), and Saint Petersburg — 83 (2.7%) respondents, respectively. As for other constituent entities of the Russian Federation (61 constituent entities), the number of the respondents, who joined the Federal Registry, was 0.1–0.8%.

Among surveyed individuals, 2558 (82.5%) people had heard about bone marrow donation before joining the Federal Registry, while 542 (17.5%) people were not aware of that previously.

Social media (information publics and channel, blogs), information campaigns at work/school, stories told by colleagues/friends/relatives were the main sources of information about bone marrow donation for the respondents. When estimating

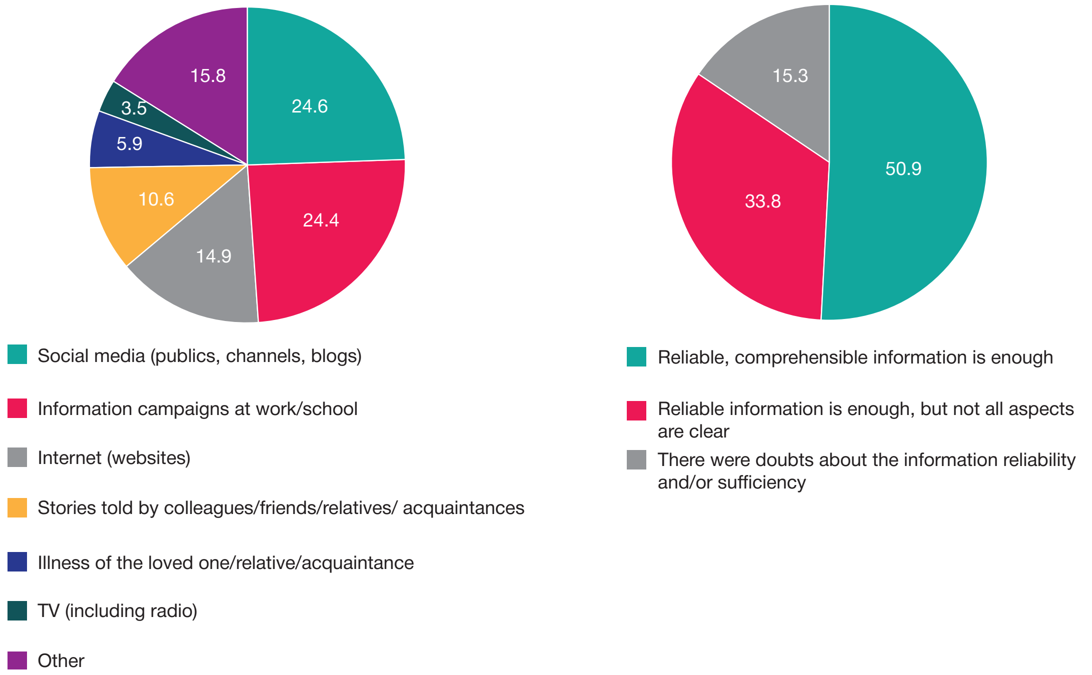

Fig. 1. Channels of information about the Federal Registry: 1 — primary source of information, 2 — completeness and reliability of information, clarity of presentation

reliability of open-source information, 1523 (49.1%) people believed that the information obtained was sufficient and reliable, while 434 (14.0%) expressed doubts about reliability of the information provided (Fig. 1).

Less that a half of the respondents, 1258 (40.6%), knew about the myths related to bone marrow donation, while 1122 (36.2 %) encountered such myths personally. The most common myths were as follows: “The procedure is a health hazard”, “The bone marrow is collected from the spine or spinal cord”, and “The procedure is very painful” (Fig. 2).

The vast majority of the respondents, 2551 (82.3%), got all the questions about bone marrow donation answered when consulting the Federal Registry expert. In 740 (23.9%) respondents, it was the specialist’s advice that helped make the decision to join the Federal Registry (Fig. 3).

The main reasons for joining the Federal Registry were as follows: willingness to health the patients in need of HSCT (2332 people; 75.2%); aspiration to be involved in socially significant activities (666 people; 21.5%). A total of 2273 respondents (73.3%) expressed their willingness to donate bone marrow immediately. Another 623 (20.1%) would like to discuss the issue with their loved ones, but would make the decision independently (Fig. 4).

According to the survey results, only 1175 people (37.9%) received support from their families. Relatives of the majority of the respondents are not registered in the Federal Registry (Fig. 5).

Awareness of the disorders, for which bone marrow transplant is used, is as follows: 2420 people (78.1%) know about these disorders; 2701 respondents (87.1%) have knowledge about the HSCT procedure itself.

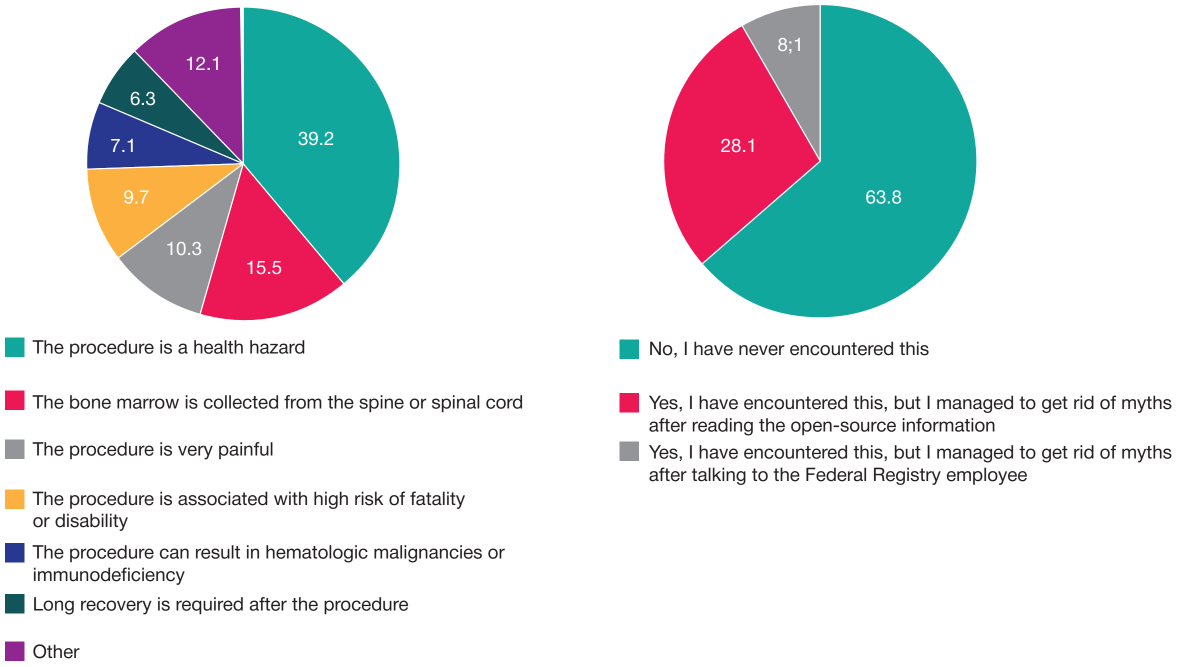

Fig. 2. Myths about bone marrow donation: 1 — the most common myths about bone marrow donation, 2 — experiences in addressing bone marrow donation myths and counterstrategies

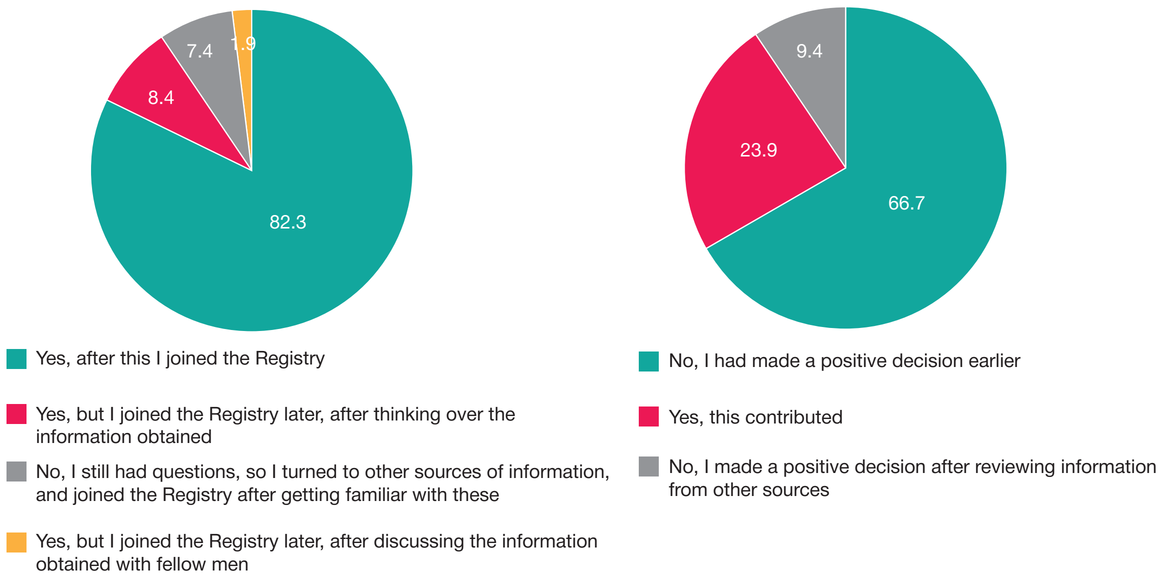

Fig. 3. Consulting the Federal Registry specialist: 1 — potential donors' satisfaction with counseling, 2 — influence on making the decision to join the Federal Registry

As for the sites for joining the Federal Registry, 2638 people (85.1%) did it in their settlements. In 1445 (46.6%) people, the most popular places were commercial partner laboratories of the Pirogov University (Citylab, Russia; KDL Domodedovo-Test, Russia). When assessing convenience of the facilities, where the respondents successfully joined the Federal Registry, 2515 people (81.1%) reported that they were satisfied with the facility location and working hours (Fig. 6).

The feedback on the biological sample receipt in the laboratory and on entering the HLA typing results in the Federal Registry is important for 3025 (97.6%) respondents.

DISCUSSION

The analysis conducted revealed some patterns and trends. Thus, we managed to find out that the respondents under the age of 37 years 27.2% more often joined the Federal Bone Marrow Donor Registry during the donor events at work or in educational institutions. The study participants aged 37–50 years preferred (in 51.3% of cases) joining the Federal Registry at medical laboratories and blood service institutions ($p < 0.001$).

Analysis of the sources of information showed the strongly marked age-related specifics ($p = 0.048$): the youth gets information primarily from the social media (974 people; 31.4%), friends' stories (428 people; 13,8%) and websites (564 people; 18.2%), while people over the age of 37 years trust TV (257 people; 8.3%), official information campaigns (887 people; 28.6%), and medical sources (282 people; 9.1%) more. We revealed weak support of making the decision to join the Federal Registry from loved ones and relatives (1230 people; 39.7%), as well as their low involvement in bone marrow donation: in 2769 (89.3%), their loved ones and relatives are not registered in the Federal Registry.

The structure of motivation also has some age-related features ($p = 0.013$): the youth is characterized by the desire to help (2117 people; 68.3%) and social activity (787 people; 25.4%), while the older generation is guided by personal experience (270 people; 8.7%) and a conscious choice (1897 people; 61.2%). The gender-based analysis revealed greater willingness to donate in males (607 people out of 796; 76.3%) compared to females (1588 people out of 2304; 68.9%). Moreover, young people often agree immediately (1365 people out of 1860; 73.1%), while people over the

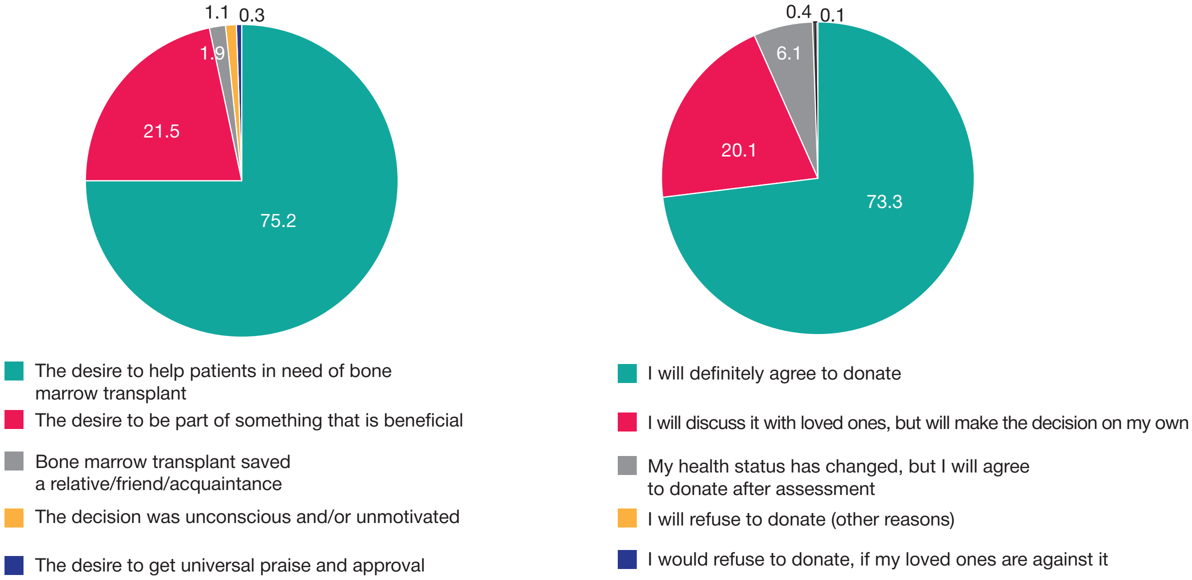

Fig. 4. Motivation to donate bone marrow: 1 — primary motivation to join the Federal Registry, 2 — readiness to donate bone marrow immediately

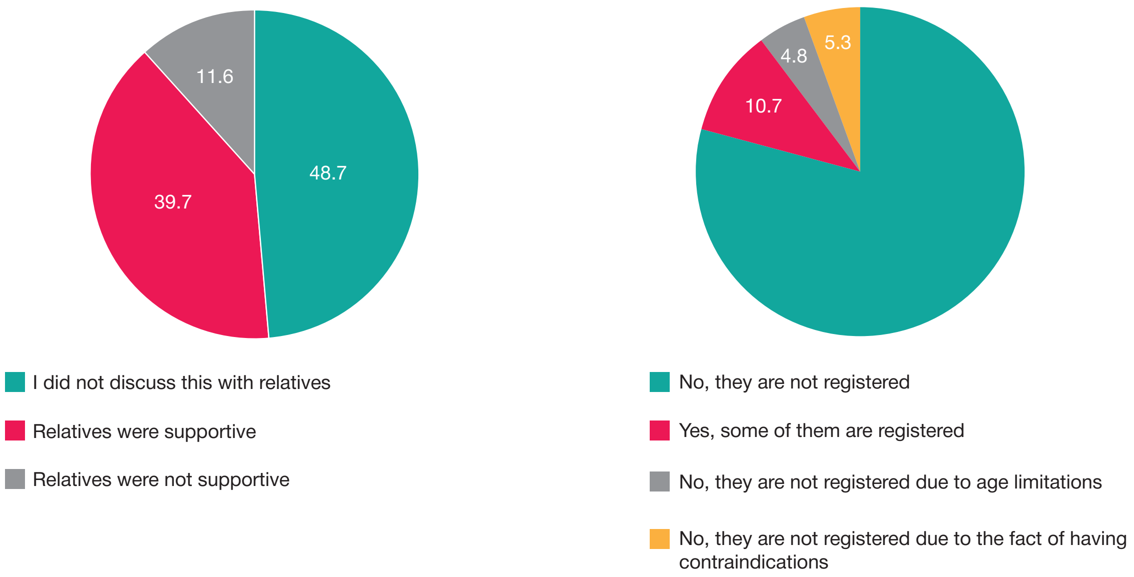

Fig. 5. Support of relatives and their involvement in bone marrow donation: 1 — discussing the plan to join the Federal Registry, 2 — relatives' status in the Federal Registry

age of 37 years need further discussion (786 people out of 1240; 63.4%).

The study has cofirmed a significant influence of myths on decision making (p = 0.047): among 1205 respondents, who had faced those, a total of 172 probable refusals of donation in the future (14.3%) were reported, while only 59 probable refusals (3.1%) were reported among 1895 respondents, who encountered no myths. The youth faces myths more often (792 people out of 1860; 42.6%), than the older generation (369 people out of 1240; 29.8%), and the highest rate of myths is reported for the regions (1646 cases out of 3100; 53.1%) vs. 1004 cases (32.4%) in large cities.

The region and gender-based analysis revealed predominance of females among potential donors in all the regions (2201–2449 people; 71.0–79.0%), with maximum rate in Moscow (1650 females among 2215 donors; 74.5%) and minimum rate in the regions (158–180 females per region, 51.0–58.0%). These data emphasize the need to develop differentiated approaches to information work and donor movement arrangement considering the identified age, gender, and regional features.

CONCLUSIONS

The findings conclusively demonstrate the need for a comprehensive differentiated approach to the development of the Federal Bone Marrow Donor Registry. The data analysis has shown considerable variability of motivation, information channels, and the factors affecting making the decision to join the Federal Registry across varios socio-demographic groups. According to the data, 46.6% of potential donors joined the Federal Registry via commercial partner laboratories of the Pirogov University, while only 11.1% did it in blood service facilities, which confirms the important role of the commercial partner laboratory participation in the Federal Registry development. Such situation results from significant representation of the networks of medical offices of commercial laboratories in both central large cities, where there are blood service institutions, and in the towns with no donor infrastructure, as well as from convenient working hours (most often from 8:00 to 20:00, including weekends). This is especially important for the core audience — young adults (students, employees), whose

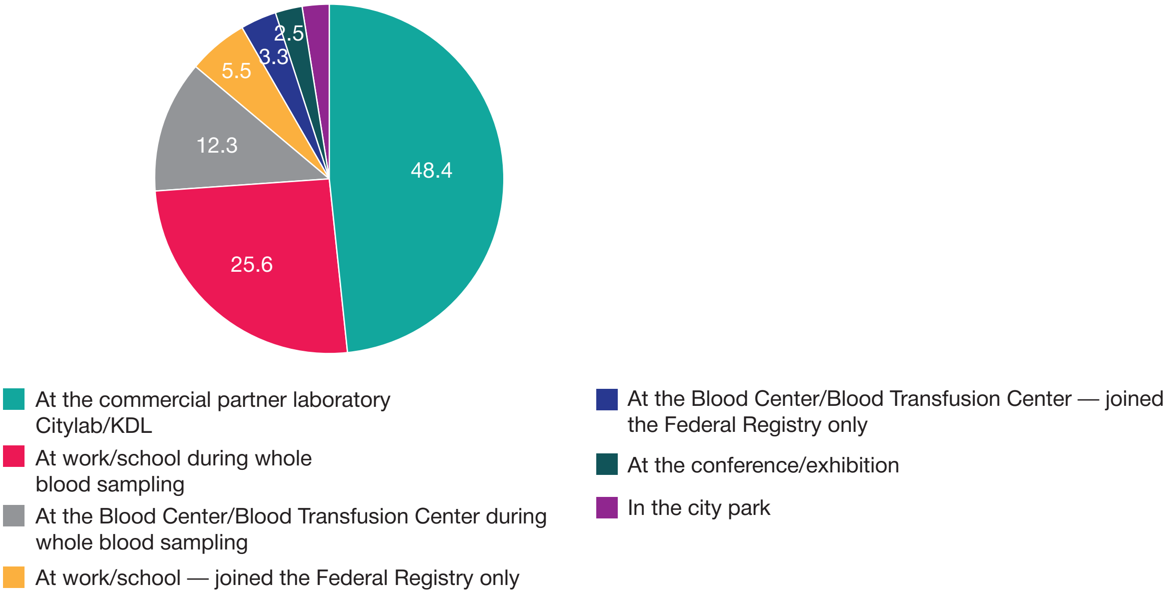

Fig. 6. Sites most convenient for joining the Federal Registry

training or work schedule coincides with the schedule of blood service facilities. Thus, commercial partner laboratories significantly improve accessibility of joining the Federal Registry due to offered convenient terms: schedule and geographical proximity. The study confirms critical importance of the information campaign personalization considering age-and-gender features and regional specifics. Taking into account the influence of relatives on making the decision to join the Federal Registry, special attention should be paid to information work with the older audience, i.e. the young adults' parents, on whom the existing myths and misconceptions of bone marrow donation resulting in the refusal to join the Federal Registry or donate bone marrow to recipients upon receiving the request from the transplant center, are projected. Optimization of the information system and arrangement of bone marrow donation popularization require the development of the multidimensional communication system combining digital technology with conventional formats, as well as strengthening the role of professional medical community in educational work. The feedback from the Federal Registry represents an important aspect of information policy. Implementation of such approach will make it possible to improve the effectiveness of attracting deliberate potential donors to the Federal Bone Marrow Donor Registry and the quality of their support at all stages of cooperation, as well as to achieve the main goal, i.e. the donors' consent to donate bone marrow upon receiving appropriate requests of the transplant centers. Furthermore, reduction of the share of refusals of bone marrow donation will result in more effective spending budget funds through eliminating the costs of expensive laboratory tests: primary and/or follow-up HLA typing of donor blood samples and medical assessment of the bone marrow donors joining the Federal Registry without realizing.

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