

Barriers to Stem Cell Donor Registration: The Role of Altruism, Awareness, and Financial Incentives

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ABSTRACT

Out of the many patients in America diagnosed with diseases that can be treated with stem cell donation, only some are able to find a match to save their life. Despite this need for more donors on the registry, many people who have heard of stem cell donation still do not know much about how it actually works, and most are never given a direct chance to register. Common misconceptions and other fears continue to be some of the reasons why people choose not to join the donor registry. This study examined the barriers preventing stem cell donor participation through a narrative literature review and a cross-sectional survey of 79 respondents attending community events.

The findings of this study show that altruistic motivation is the primary motivator for people joining the stem cell donor registry. Views on financial incentives were mixed with about half the respondents preferring no incentive, though few felt that incentives reduced the altruistic nature of donation. Although only 15.2% of respondents registered prior to the event, 65.8% stated that they were willing to register at the event itself. Since the participant's willingness was not measured prior to the events, this study will not be able to determine whether the events themselves increased willingness to register. It only has the ability to report that respondents at the event reported high willingness to register. A majority of the respondents reported that they would still donate without the payments and did not see modest incentives as reducing the altruistic nature of donation. On the other hand, factors that they believed would make registering to be a donor easier were clearer information and greater convenience rather than payment.

INTRODUCTION

Hematopoietic stem cell transplantation is an important treatment for certain blood cancers, blood disorders, and immune-system conditions. It is a way for one person to give another a second chance of life. Hematopoietic stem cells, which are found mainly in bone marrow and circulating blood, produce red blood cells, white blood cells, and platelets. When an individual has leukemia, lymphoma, or any other serious blood disorder, their bone marrow may fail to produce healthy blood cells or may produce abnormal cells. Stem cell transplants allow doctors to replace damaged or disease blood-forming cells with healthy donor cells.

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One of the greatest barriers regarding awareness around the topic of stem cell donation is that most people are unfamiliar with the process of stem cell donation. The most common method is peripheral blood stem cell (PBSC) donation, which accounts for 90% of the donations. PBSC does not require surgery, but it is not instantaneous: for the five days leading up to donation, the donor receives daily injections of a medication called filgrastim so that more blood forming cells are moved to the bloodstream. These injections can cause some side effects that include headaches or bone and muscle aches that resolve shortly after collection. During donation, blood is drawn from a needle in one arm and passed through a machine that separates out the blood forming cells. The rest is then returned through the other arm, in a process that requires about four to eight hours. The other 10% of the donors are asked to donate marrow. This is a surgical outpatient procedure that is performed under the effects of anesthesia. Donors also do not have the ability to choose what they are donating. Donation happens only if a person is identified as a match, which may be soon after joining the registry, years later, or never. While serious complications are rare, the process involves real preparation and time commitment that potential donors may not expect (National Marrow Donor Program (NMDP)).

Even though the science behind stem cell transplants is strong, there is a major problem with the donor registry. There are not enough people who are willing to donate for the amount of people that need stem cell donation in the United States. Each year, there are many people in the United States that are diagnosed with a blood disease where a stem cell transplant could potentially save their lives (NYU Langone Health, 2025). But out of all those people, only 30% are able to find donors that are related to them (NMDP). Finding these donors is a difficult task as matches depend on HLA markers (tiny genetic details that have to line up perfectly). Even with the millions of people who are already on the registry, many patients will never be able to find that one person who matches with them.

This challenge is even greater for patients who come from certain racial or ethnic backgrounds. For white patients, the chances of finding an unrelated donor can reach as high as 75-93% but for minorities such as Black, Asian, Hispanic, Native, and mixed-race patients, match rates fall down to 20-40% or lower (Gragert et al., 2014). These disparities reflect both the lower representation of certain populations in the registry and the variation in the distribution and diversity of HLA types.

One of the biggest barriers to stem cell donation is the lack of public knowledge that surrounds this topic (Narayanan et al., 2016). A significant number of people lack understanding about the process of stem cell donation and assume that it is complicated or painful. In fact, in a study by Bayrak and Çınar (2022), conducted to analyze knowledge and willingness regarding stem cell donation for health sciences students in Turkey, only 19.2% of the students knew what stem cell donation was. Fear of side effects and health risks associated with donations were one of the largest reasons for unwillingness to donate among the students as 57.6% of people responded with this being their main reason.

Another significant issue related to people's perception on stem cell donation includes time commitment and inconvenience. Although the collection itself is generally completed within one day, many potential donors are scared of missing work, school, or any other obligations. Additionally, since stem cell donation

is not common for people to think about, there is a clear lack of salience—people do not prioritize registering to become a donor if they are not personally connected to the cause in any way (Hamed et al., 2023). Without getting invited to register to become a donor, the majority of people would never even consider it a possibility for them to sign up, even though they can potentially save a life.

Another ongoing debate regarding stem cell donation involves whether financial incentives should be implemented in order to get more people to join the stem cell donor registry. One side of the argument is that offering monetary rewards could increase the number of people deciding to participate by lowering opportunity costs (time, inconvenience, missed work, etc.). Others worry that financial incentives may change the views on stem cell donation from an altruistic act to a market transaction. The issue with this is that it erodes intrinsic motivation. Other reasons why people fear the use of financial incentives include the influence on lower-income individuals to donate for the wrong reasons (Iajya et al., 2013). Due to the fact that stem cell donation generally relies on altruistic participation, determining whether or not to use financial incentives remains a critical question in the hopes to increase the number of people on the stem cell donor registry.

In this study, I conducted a literature review on existing research that covers stem cell donation, focusing on altruistic and intrinsic motivation, financial incentives, and demographic disparities on stem cell donor registries. I used findings from prior economic, medical, and behavioral studies to identify common barriers in stem cell donation. Using this information, I have designed a questionnaire that collects demographics, friends/family background, awareness and understanding, willingness to register, financial incentives, and thoughts on how stem cell donation can be made easier. I have modeled these questions based on trends observed in past studies. The literature review and survey provide a structured approach to evaluate the best behavioral strategies to increase willingness to join the stem cell donor registry.

LITERATURE REVIEW

Since there is very limited research that looks specifically at financial incentives for hematopoietic stem cell registry enrollment, this review also draws on the studies of blood, plasma, and kidney donation, where incentive effects have been studied more directly. These settings are not identical to stem cell donation. Blood and plasma donation are low-burden and can be repeated often, kidney donation involves major surgery in every scenario, and the incentive studies below measure effects on donation itself rather than on joining a registry. Stem cell registry enrollment is different again: joining requires just a cheek swab, but actually donating happens later if the person is identified as a match. This involves several weeks of preparation. These findings are used to understand the general patterns in how incentives and motivations affect prosocial behavior, not as direct evidence about what would happen with stem cell registration.

Lacetera and Macis (2010) conducted a survey to analyze how financial incentives affect willingness to donate blood. Out of the 467 donors in this study, 13% declared that they would stop donating if they were offered €10 in cash. Cash can identify the act as a pure market interaction rather than a meaningful

gift. Standard economic theory states that any additional reward should be able to increase the willingness of an individual to perform that activity. In theory, that means that incentives would increase the number of people who would join the registry; however, this paper shows that the resulting ‘crowding out effect’ of offering direct cash can have negative effects. The crowding out effect happens when rewards such as money reduce an individual’s intrinsic motivation to be involved in activities that benefit society.

While direct cash payments might prove to do more harm than good, material incentives (vouchers for books or food) are shown to be much more effective. Bruers et al. (2025) conducted a large-scale field experiment in Belgium that introduced small quasi-cash incentives (€1.50 vouchers) to plasma donors. By only providing the incentives to plasma donation, they analyzed the shifts between plasma and blood donation, allowing researchers to review substitution effects across different types of donations. These small quasi-cash rewards showed an increase in plasma donations by 7.15%. They also showed that rewarding plasma donation causes a 3.3% decrease in regular blood donation. An estimated one-sixth of the total increase in plasma donations resulted directly from donors switching away from regular blood products. What made this striking was how small the incentive was. Even a modest reward was enough to create meaningful influence in donor behavior.

Iajya et al. (2013) conducted a randomized controlled trial in Argentina that tested the effects of information campaigns, social incentives, and various vouchers that carried different values on blood donor participation using two different groups: the exposed group and the control group. The exposed group was a group of individuals who were randomly assigned to one of the six different incentives such as informational flyers, social recognition, shirts, or supermarket vouchers to see which incentives would increase donor participation. The control group consisted of individuals who only received a simple invitation to donate without any real incentives. In this sample from Argentina, only higher-valued economic vouchers (which are 4.5 hours’ worth of daily wages) were successful in increasing the number of donors on donor registries. Thus, the theory of using small rewards to increase donor participation has different conditions such as the location or country. Different countries have different standards, which has to be considered when deciding whether or not increasing the amount of money on vouchers would increase donor turnout.

A major concern in the debate on whether or not to use financial incentives is whether these incentives attract “risky” donors who might fake their medical history in order to receive a reward, potentially providing unsafe blood. While this concern is frequently raised, evidence from Iajya et al. (2013) suggests it may be overstated. This study found that offering economic incentives did not compromise the safety or usability of donated blood, directly challenging the assumption that financial incentives may pull in risky donors. The rates of medical ineligibility (4.1%) and infectious disease rejections (4.5%) among the donors who were incentivized to donate from the vouchers were similar to the people who were deemed to be non-incentivized donors (3.5% and 4.0% respectively).

Goette and Tripodi (2024) used an experimental design using blood donors and randomly assigned treatments of social recognition such as public name listings on Facebook to measure donation

willingness and behavior. While social prestige is often viewed as a motivator, this study shows that it can be counterproductive for established donors as those who have donated multiple times worry it will make them look concerned about their image rather than truly altruistic.

Bayrak and Çınar (2022) conducted a cross-sectional survey study of health sciences students in Turkey, assessing knowledge levels, attitudes, and willingness regarding stem cell donation using questionnaires. This study revealed that there is a gap in knowledge finding that 80.8% of health sciences students did not know what stem cell donation was.

Similarly, Narayanan et al. (2016) surveyed medical students at a medical school in Rochester, Minnesota using questionnaires, analyzing donor registration status alongside students' knowledge and demographics. The questionnaire included questions regarding the process of stem cell donation to assess knowledge amongst the students. They achieved average correct response rates of 57.7% and 63.7% on donor eligibility and donation process questions, respectively. While 43% of the students surveyed were registered donors, their participation was more closely linked to a history of prior blood donation than to high levels of knowledge regarding the stem cell donation process. This research indicated that older students and those further along in training tended to know more and feel more comfortable with the donation process. This points to the clear takeaway that education is a crucial factor.

Majhail et al. (2012) reviewed clinical referral data and transplant outcome studies to understand disparities in patient access, referral rates, and treatments for hematopoietic stem cell transplantation across different racial groups. They found that racial disparities in stem cell transplantation do not come from one single issue but show up through multiple areas: who is represented on registries, who gets referred for transplant, and who ultimately has access to the best matched donor.

At a biological level, matching is dependent on HLA markers, and those markers vary across populations. HLA patterns vary across populations, and some HLA profiles are less well represented in current registries since certain racial and ethnic populations are underrepresented on the registry. Gragert et al. (2014) used genetic registry data and probabilistic modeling to estimate the chances of match based on HLA variation across racial and ethnic groups in the United States. They found that white patients of European descent have a 75-93% probability of finding an optimal match, while African American patients face probabilities as low as 16-19%. Beyond these genetic discrepancies, black patients are 2.35 times more likely not to be referred for hematopoietic stem cell transplantation (HSCT) and experience longer times to referral than white patients.

Switzer et al. (2013) analyzed registry participation and follow-up data to measure post registration drop out rates across racial groups and found that even when people do register, dropout is a significant issue. Minority attrition has been estimated to be around 60% compared to the 40% for white registrants.

Public perception often suggests patients of mixed race usually have a low chance of finding a match. However, Bergstrom et al. (2012) used matching simulations along with economic modeling to estimate

the match probabilities for patients of mixed race. They showed that match probabilities for biracial patients range from 50-87% with Hispanic-White patients having the highest odds among mixed race groups. Due to the registry being heavily dominated by white donors (approximately 6 million), most multiracial patients find their matches within the White donor pool rather than among donors of their own race. Furthermore, Bergstrom et al. (2012) found that recruiting biracial registrants is cost effective. It also provides a public good for the entire registry as these donors cover rare genetic combinations that may match with patients with rare haplotypes.

Two additional studies that are referred to in Table 1 show how incentive effects depend on the situation and context. Mellström and Johannesson (2008) ran a field experiment on blood donation in Sweden and found that offering a small cash payment reduced willingness to donate among women, while men were largely unaffected, which is consistent with the crowding-out concern raised by Lacetera and Macis (2010). Underhill (2019) used hypothetical kidney-donation vignettes and found that large cash incentives increased stated willingness to donate but also introduced racial bias in who participants were willing to help. Since Underhill's study concerns kidney donation and uses hypothetical scenarios instead of real donation decisions, this cannot completely be applied to stem cell donation, but it is a helpful reminder that incentives can carry unintended effects that are beyond the question of whether incentives help get more people to register.

Overall, the literature that already exists suggests that altruistic motivation, public awareness, financial incentives, and demographic disparities are the biggest factors that affect stem cell donation. Although there have been studies that examined each of these individual factors, I have not seen many that evaluate how these factors affect people in the real world while they are deciding whether they want to join the stem cell donor registry. The next section explains how this study combines findings from existing literature with original survey data to understand the different aspects that influence whether someone is willing to join the registry.

METHODOLOGY

The purpose of this study was to examine three primary outcomes among individuals completing the questionnaire at community registration drives: knowledge of stem cell donation, willingness to register as a stem cell donor, and the influence of financial incentives on willingness to donate if identified as a match.

This study uses two separate approaches to successfully determine these key factors in stem cell donation. The first is a review of prior studies on incentive-based donation strategies, which is done in the literature review. Second, it analyzes data and responses to the survey collected directly from the individuals at several registration drives. By combining these two methods, this study's main objective is to find ways to increase registry participation without removing the altruistic aspect of donation.

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Instead of using a meta-analysis, this study uses a structured narrative review. The goal of the literature review is to find consistent patterns across the multiple studies. These patterns include: whether cash incentives would increase donor participation, whether small quasi rewards are more effective than actual cash incentives, whether incentives create a crowding out effect, whether incentives would cause donor displacement from other types of donations, and how different demographic groups respond to different types of incentives.

In order to keep this comparison organized, studies were evaluated based on donation type, incentive structure, method, and outcome. Using this, I was able to design the survey questions that were used in this study.

This study uses a cross-sectional survey design conducted at in-person stem cell donation drives with HopeLink Initiative partnered with NMDP and DKMS. Eligibility requirements differed based on the registry organization that was represented at the event. NMDP allowed individuals between the ages of 18 and 35 who met its residency, health, and prior-registration requirements to join. On the other hand, DKMS generally permitted individuals between the ages of 18 and 55 who met its health requirements. These were the organization-specific eligibility rules applied at the drives during the data collection (December 2025 - April 2026). Thus, attendance at the event did not mean that the respondent was eligible to join the registry that was operating that event. Although registry staff determined if individuals could register, the survey did not record each respondent's organization-specific eligibility status. Also, registration eligibility could not be determined for every respondent in the analysis. Data was collected in an actual environment where people are actively deciding on whether or not they should join the stem cell donor registry. With this, the study was able to capture attitudes and decision making at the moment when people were making the critical choice of joining the registry. Although they are deciding to join the registry at the moment, they can still opt out and leave the registry at any time.

The survey was completed on paper and participation was completely optional. Individuals were informed that their survey responses would stay anonymous and that this information was going to be used only for research purposes.

The questionnaire was designed around patterns I found in the research papers that were analyzed in the literature review. Instead of creating opinion-based questions, I used behavioral economics principles including altruism, intrinsic versus extrinsic motivation, opportunity cost, willingness to accept, and the crowding out effect.

This questionnaire consisted of six sections:

1- Demographics: In this section, I collected basic demographics including age, gender, level of education, and ethnicity. These characteristics were used to describe the sample rather than to test

for differences in willingness across groups, given the small sample size and the demographic concentration.

2- Personal background: In this section, participants were asked if they were related to anyone who has had blood cancer or needed a stem cell/bone marrow transplant and if they have ever donated blood or plasma before.

3- Awareness and Understanding: In this section, participants were asked questions on their current knowledge regarding stem cell donation before they were given any information. They were asked if they heard of stem cell donation and their familiarity with the process of stem cell donation. They were also asked which diseases they think stem cell donation can treat and how stem cells are collected. Using these questions, I wanted to determine the common misconceptions and knowledge gaps that surrounded the donation process.

4- Willingness to register as a stem cell donor: Participants were asked whether they had previously joined a stem cell donor registry and whether they were willing to register today as a potential donor.

5- Motivations and Incentives: This section examined respondents' stated views regarding registration, donation, and financial incentives. Participants were questioned on their motivations and barriers to registration, their hypothetical compensation preferences, and whether financial incentives would make donation feel less altruistic. A central element in this study is measuring participants' willingness to accept (WTA) compensation in return for the act of donating stem cells. WTA is defined as the compensation range respondents selected, if they selected any at all, for donating stem cells after they are called up as a match. This questionnaire presented several incentive ranges (ranging from zero to above \$500) to determine the compensation that is required to make them willing to donate if they were later identified as a match. The incentive ranges used in the survey were based on prior literature on donation incentives. The survey also measured WTA if the potential recipient was a friend or family member. This question was used to examine how personal relationships might influence one's behavior and willingness to donate and if financial incentives matter less when someone has a personal connection to the patient.

6- Final Thoughts: Asked participants what factors would make it easier for them to register or donate.

ETHICAL CONSIDERATIONS

This study was conducted independently and was not received by a Formal Institutional Review Board (IRB). Since this study did not undergo any formal review, I designed and carried out the study to follow standard ethical practices with minimal-risk research with human participants, including informed consent, voluntary participation, anonymity, and confidentiality, and I worked under the oversight that is

described below.

All of the participants were adults (aged 18 and above) who attended public events where there were donor recruitment drives. Prior to taking part, each of the participants were informed that this was a research survey regarding why people do or do not want to join the stem cell donor registry, that their responses were anonymous, and that the research survey was separate from the donor-registration process. Consent was completely obtained verbally, and participation was voluntary. In order to register, taking this survey was not required. Participants had the ability to skip questions and stop at any time.

Every part of the survey was completed on paper and did not collect names, contact information, or any other details that could be identified. Only demographic data, such as the age category, gender, education category, and ethnicity, were collected, and none of this information could identify an individual. No reward was provided for participation in the survey, and the rewards discussed in the survey itself were completely fictional.

The survey was conducted under the supervision of my mentor, Dr. Mina Mahmoudi, who helped to design the study, and in collaboration with the HopeLink Initiative, which provided a venue where the survey was conducted. Since the survey was anonymous, only adults participated, no identifying information was collected, and only their attitudes and opinions were questioned, the risks to participants were minimal.

RESULTS

Table 1 summarizes the findings from the literature review regarding the effects of financial incentives on donation behavior across blood, plasma, and kidney donation studies. The evidence provided shows that the effectiveness is dependent on the type of incentive and how big the reward is. Direct cash payments showed unintended consequences such as reduced donation rates from the crowding out effect and, in certain situations, demographic biases. In contrast to the direct cash payments, non-cash or quasi-cash incentives proved to provide more favorable outcomes without as many negative side effects. Some incentive strategies also showed behavioral changes in the potential donors, such as donors shifting from one type of donation to another type of donation based on which one gives better incentives. These findings show that although financial incentives influence donation behavior, they have to be used carefully and all factors must be considered in order to maximize donor participation while also ensuring that no negative consequences come out of this.

Table 1: Summary of literature review results on financial incentives

Study	Donation type	Incentive	Method	Outcome
Lacetera and Macis (2010)	Blood	€10 cash	Survey	↓ donations (crowding out)
Iajya et al. (2013)	Blood	Vouchers, shirts, social recognition	Randomized controlled trial	↑ donations (high-value vouchers only)
Bruers et al. (2025)	Plasma	€1.50 quasi-cash voucher	Field experiment	↑ plasma donations; ↓ blood donations
Goette & Tripodi (2024)	Blood	Social recognition (Facebook listing)	Experimental	↓ donations among repeat donors
Mellström & Johannesson (2008)	Blood	SEK 50 cash payment	Field experiment	↓ donations among women (crowding out); no effect for men
Underhill (2019)	Kidney	Cash (\$3000-\$50000)	Randomized vignette study	↑ donations; incentives introduced significant racial bias favoring white patients

After analyzing the survey results, the sample was found to have consisted of 79 respondents who were asked to donate stem cells at in-person stem cell donation drives. The sample skewed toward the middle age, with the largest group being aged 45-54 (30.4%), followed by those aged 25-34 (26.6%) and 35-44 (25.3%). Most of the participants were males (63.3%), with females consisting of 36.7% of the respondents. Most of the respondents were highly educated with over 96% of the respondents holding at least a bachelor's degree and 54.4% holding a graduate degree. A majority of the respondents (84.8%) identified as Asian, which is related to the type of events as they were hosted by HopeLink with most of the cultural events being Asian. The remaining respondents identified as Hispanic/Latino, Black/African American, or White. Full sample characteristics are reported in Table A1.

Approximately 39.2% of the respondents said that they had a personal connection to someone with a serious blood-related illness or who had required a stem cell or bone marrow transplant, while 54.4% reported no such connection. Also, 57.0% of respondents had previously donated blood, plasma, or platelets. Over half of the respondents already have familiarity with medical donation procedures.

A majority (78.5%) of the respondents claimed to have heard of stem cell or bone marrow donation prior to the event, but self-reported familiarity revealed a large gap in knowledge. Only a small percentage (10.1%) described themselves as very familiar with what stem cell donation actually involves, while 35.4% considered themselves somewhat familiar. 40.5% of the respondents had heard of it but knew little, and 13.9% were not familiar with the process at all. This pattern was consistent with the respondents'

answers to what they thought could be treated with stem cell donation. While a majority of the respondents correctly identified leukemia as treatable by stem cell donation, a small portion of them correctly recognized sickle cell disease as a condition that can be treated by stem cell donation as well. Additionally, a notable group of respondents incorrectly believed that diabetes and heart disease are conditions treated by stem cell donation. When questioned on what they think the procedure is for stem cell donation, 41.8% correctly identified that both blood draw and anesthesia-based procedures are used, while 22.8% were uncertain. These responses point to widespread misconceptions about what peripheral blood stem cell donation actually involves.

Another question asked the respondents about their current decision on joining the stem cell donor registry. Despite the fact that only 15.2% of the respondents were already registered to be donors on the registry, a majority (65.8%) showed willingness to register when asked at the event, while the rest either declined or were uncertain. Although this number may point to the fact that in-person outreach causes an increase in willingness to register, I cannot prove this from these questions in the study. Since prior willingness was not assessed before the event, I cannot determine the effect of the in-person approach.

Among the respondents who were unwilling or uncertain about registering (n=27), the main barrier was a lack of information regarding the process of stem cell donation (51.9%). This was selected far more than the other concerns including fear of pain, medical risks, concerns regarding DNA usage, financial costs, time commitment, and other concerns.

When asked about the respondents' motivation to register, there were two distinct groups. The first and dominant group reflects altruistic motivation as a majority (91.1%) selected "helping save someone's life" as a motivating factor. Personal connection to someone affected (31.6%) and wanting more information about safety (26.6%) were secondary motivators that are still considered altruistic. The second, much smaller group preferred financial compensation or recognition for donating. Only 13.9% cited feeling appreciated or receiving recognition, and 8.9% wanted financial compensation. This difference shows that registration behavior in this sample was more associated with intrinsic values than compensation.

Within this sample, financial incentives showed mixed effects. When asked whether direct payment for time and discomfort would make them more likely to donate, 41.8% said that it would not change their decision, 30.4% were uncertain, and 27.8% indicated more interest in donating. In this sample, responses were mixed with most respondents indicating that payment would not change their decision or were unsure and a smaller group showing more interest in donating.

When providing respondents with compensation ranges that would persuade them to donate, over half (52.4%) indicated that they would donate without any compensation, indicating that altruistic motivation stayed dominant in this sample. Among those who required some form of payment, the largest group was the participants that wanted \$500 or more (22.2%) and the rest of the groups had around 6%-10%. More than half of the respondents were willing to donate for free, but a meaningful percentage would still require large amounts of compensation.

The respondents were then tested on their preferences of financial incentives by switching the way the question was asked. In this question, the respondents were asked about their willingness to donate if an organization offered them \$250; 55.7% indicated that they would accept while the rest refused or were unsure. When asked earlier on how much compensation is needed to donate, 52.4% of the respondents said that they would do it for free. Although over half of the respondents said that they are willing to do it for free, a large portion said that they would accept a \$250 payment if called as a match, suggesting that offering a modest payment was not associated with lower reported willingness to donate among the participants in this sample.

A shift in WTA emerged when the recipient was identified as a friend or family member rather than a complete stranger. In this scenario where the patient in need was close to the respondent, a substantial 73.4% indicated that they would donate for free, compared to the 52.4% that were willing to donate for free without any connection to the recipient, a difference of 21%. Simultaneously, the percentage of respondents that required \$500 or more dropped from 22.2% to 7.6%. In this sample, reported willingness to donate for free was higher when the recipient was a friend or family member than when the participant was a complete stranger. This may suggest that social proximity can be associated with a reduced role for financial incentives, though the survey cannot establish this as a causal effect.

Only 16.5% of the respondents believed that financial incentives would reduce the altruistic nature of stem cell donation, while 41.8% disagreed, and the same percentage remained uncertain. When asked which type of incentive they would prefer, 50.6% showed no preference for any incentive, while small groups preferred gift cards, free meal/merchandise, or recognition. These findings show that while close to half prefer different types of incentives, about half do not prefer the use of any type of incentive and prefer donation to remain purely voluntary.

When questioned on what would make it easier for the respondents to donate, the most common response was improved information about the process and risks (64.6%) and greater convenience in location and timing (38.0%) as the most important factors for increasing participation. Hearing patient stories (31.6%) and speaking with a prior donor (22.8%) were also commonly selected. The factors that have the greatest chance of making registration or donation easier, according to the participants, were clearer information regarding the process and risks and greater convenience in location and timing.

DISCUSSION

This paper examined the barriers to participation in the stem cell donor registry through a structured literature review and a cross-sectional survey that was conducted at in-person donor registration drives with DKMS and NMDP. By combining what was found in prior research in behavioral economics, medical sociology, and the science behind donation with original data collected at HopeLink community

events, this study analyzed how altruistic motivation, financial incentives, and public awareness shape willingness to join the stem cell donor registry.

Helping save someone's life was the most frequently selected motivation for joining the stem cell donor registry among respondents in this sample. This far outweighed any preference for financial compensation or recognition. This finding is consistent with the finding of Lacetera and Macis (2010), who believed that intrinsic motivation plays a massive role in donation behavior. However, unlike Lacetera and Macis, respondents in my study did not believe moderate financial incentives reduced altruism. This became far more evident when the potential recipient was identified to be a friend or family member, where willingness to donate for free was higher. Personal connections appear to matter more when it comes to donation behavior.

When questioned on financial incentives, the results were more balanced than some prior literature such as Lacetera and Macis (2010) suggests. While these incentives alone were not a major motivator, respondents were split on whether they reduced the altruistic nature of donation, and many were unsure either way. Over half of the respondents were willing to accept the \$250 reward if asked to donate, and only a few felt that the use of financial incentives made donation feel less altruistic. These findings suggest that, in this sample, modest financial incentives were not perceived as undermining altruism, though the survey does not have the ability to establish whether they would increase actual registration or donation.

Another important finding of this study was the difference between the number of people who were already on the registry and stated willingness to join the registry at the event. Although only 15.2% of the respondents said that they were already registered, 65.8% stated that they were willing to join the registry at the event. Many respondents who were not already registered reported that they were willing to register when they were surveyed at these community events. Since willingness was not measured prior to the events, this study does not have the ability to determine whether in-person setting caused this willingness.

This study does have limitations worth noting. The sample was small and heavily skewed toward highly educated Asian respondents due to the location of the drives, meaning that these findings have a limit to being broadly applied. Future research should look at more diverse populations, especially the racial and ethnic minority groups which face the lowest match rates because some populations are underrepresented in the registry and have higher HLA diversity, which reduces the likelihood of identifying a suitably matched unrelated donor. Other limitations worth noting are self-selection bias and social desirability bias: people who agree to take a survey at events are probably more receptive than the general population, and people may overstate willingness to donate for free when answering a paper survey handed to them by someone running the drive.

Based on the reports from the respondents, financial incentives alone are not likely to be the main driving force of registration, and respondents more often believed that education, convenience, and direct

outreach were to increase their willingness. Most respondents did not perceive small rewards as undermining the altruistic nature of donation; however, the survey does not provide evidence that payment alone would cause an increase in willingness to donate. When asked about direct payment, more respondents said it would not change their decision (41.8%) or were unsure (30.4%) than said it would make them more likely to donate (27.8%) and about half preferred no cash incentive at all (50.6%). Based on the response, organizations may want to focus on education, convenience, and direct outreach. They should also treat small non cash incentives such as gift cards, meals, or merchandise only as possible supporting tools instead of being the main strategy.

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Appendix A: Data collected from the questionnaire

Survey Response Frequency Tables (N = 79)

SECTION 1 — BASIC DEMOGRAPHICS

Table A1

Sample Characteristics (N = 79)

Variable	Category	N	%
Age	18–24	8	10.1%
	25–34	21	26.6%
	35–44	20	25.3%
	45–54	24	30.4%
	55+	6	7.6%
Gender	Male	50	63.3%
	Female	29	36.7%
Education	High School Graduate	1	1.3%
	Some College	2	2.5%
	Bachelor's Degree	33	41.8%
	Graduate Degree	43	54.4%
Ethnicity	Asian	67	84.8%
	Black/African American	4	5.1%
	Hispanic/Latino	5	6.3%
	White	3	3.8%

SECTION 2 — PERSONAL BACKGROUND

Table A2

Personal Connection to Someone with Blood Cancer or a Blood Disorder (N = 79)

Response Option	N	%
Yes	31	39.2%
No	43	54.4%
Not sure	5	6.3%

Response Option	N	%
Total	79	100%

Table A3

Prior Blood, Plasma, or Platelet Donation (N = 79)

Response Option	N	%
Yes	45	57.0%
No	34	43.0%
Total	79	100%

SECTION 3 — AWARENESS & UNDERSTANDING

Table A4

Prior Awareness of Stem Cell or Bone Marrow Donation (N = 79)

Response Option	N	%
Yes	62	78.5%
No	17	21.5%
Total	79	100%

Table A5

Self-Reported Familiarity with Stem Cell Donation (N = 79)

Response Option	N	%
Very familiar	8	10.1%
Somewhat familiar	28	35.4%
Heard of it, but don't know much	32	40.5%
Not familiar at all	11	13.9%
Total	79	100%

Table A6

Conditions Respondents Believe Stem Cell Donation Can Help Treat (N = 79)

Response Option	N	%
Leukemia	54	68.4%

Response Option	N	%
Lymphoma	41	51.9%
Sickle Cell Disease	21	26.6%
Diabetes	20	25.3%
Heart disease	20	25.3%
Not sure	25	31.6%

Note. Multiple responses permitted; percentages sum to more than 100%.

Table A7

Perceived Stem Cell Collection Method (N = 79)

Response Option	N	%
Through a blood draw	22	27.8%
Through a procedure under anesthesia	6	7.6%
Both methods exist	33	41.8%
I don't know	18	22.8%
Total	79	100%

SECTION 4 — WILLINGNESS TO REGISTER

Table A8

Prior Registration as a Potential Stem Cell Donor (N = 79)

Response Option	N	%
Yes	12	15.2%
No	67	84.8%
Total	79	100%

Table A9

Willingness to Register at the Event (N = 79)

Response Option	N	%
Yes	52	65.8%
No	9	11.4%
Maybe / Need more info	18	22.8%
Total	79	100%

SECTION 5 — MOTIVATIONS & INCENTIVES

Table A10

Factors That Would Motivate Registration (N = 79)

Response Option	N	%
Helping save someone's life	72	91.1%
Personal connection to someone affected	25	31.6%
Knowing more about how safe it is	21	26.6%
Feeling appreciated / recognition	11	13.9%
Getting compensated	7	8.9%

Note. Multiple responses permitted; percentages sum to more than 100%.

Table A11

Main Reason for Being Unwilling or Uncertain About Registering (n = 27)

Response Option	N	%
I don't know enough about the process	14	51.9%
Fear of pain	3	11.1%
Time commitment	1	3.7%
Other	1	3.7%
Financial costs (travel / missed work)	4	14.8%
I'm uncomfortable with my DNA being stored	1	3.7%
Fear of medical risks	3	11.1%
Total	27	100%

Table A12

Effect of Financial Incentives on Likelihood to Donate (N = 79)

Response Option	N	%
Yes	22	27.8%
No	33	41.8%
Maybe	24	30.4%
Total	79	100%

Table A13

Hypothetical Compensation Required to Donate, by Recipient Relationship

Compensation Range	Stranger (%)	Family/Friend (%)
\$0 – Would donate for free	33 (52.4%)	58 (73.4%)
\$50–\$100	6 (9.5%)	4 (5.1%)
\$100–\$250	6 (9.5%)	2 (2.5%)
\$250–\$500	4 (6.3%)	9 (11.4%)
\$500+	14 (22.2%)	6 (7.6%)

Note. Percentages for the stranger scenario are based on the 63 respondents who answered that question; 16 respondents skipped it for unknown reasons. Percentages for the family/friend scenario are based on all 79 respondents. Because the two scenarios have different denominators, they are reported separately and are not a matched within-person comparison.

Table A14

Preferred Non-Cash Incentive Type (N = 79)

Response Option	N	%
None – I prefer no incentives	40	50.6%
Small gift card	22	27.8%
Recognition (certificate / shoutout)	6	7.6%
Free meal or merchandise	11	13.9%
Total	79	100%

Note. Percentages may not sum to exactly 100% due to rounding.

Table A15

Willingness to Accept a \$250 Payment if Called as a Match (N = 79)

Response Option	N	%
Yes	44	55.7%
No	16	20.3%
Not sure	19	24.1%
Total	79	100%

Table A16

Whether Financial Incentives Make Donation Feel Less Altruistic (N = 79)

Response Option	N	%
Yes	13	16.5%
No	33	41.8%
Not sure	33	41.8%
Total	79	100%

SECTION 6 — FINAL THOUGHTS

Table A17

Factors That Would Make It Easier to Donate or Register (N = 79)

Response Option	N	%
More clear information on the process and possible risks	51	64.6%
Convenience (location/time)	30	38.0%
Hearing stories of patients who need donors	25	31.6%
Talking to someone who has donated	18	22.8%
Other	1	1.3%

Note. Multiple responses permitted; percentages sum to more than 100%.

Appendix B: Survey Instrument

Below is the exact wording on the questionnaire that was used at the in-person donor registration events.

Section 1 — Basic Demographics

1. Age:

F ☐ Under 18 ☐ 18–24 ☐ 25–34 ☐ 35–44 ☐ 45–54 ☐ 55+

2. Gender:

☐ Male ☐ Female ☐ Non-binary

3. Highest level of education:

☐ Less than high school ☐ High School Graduate ☐ Some college
☐ Bachelor's degree ☐ Graduate degree

4. Ethnicity:

- ☐ Asian ☐ Black/African American ☐ Hispanic/Latino ☐ White
☐ Middle Eastern ☐ Native American ☐ Mixed

Section 2 — Background

5. Do you have any family or friends who have had cancer, blood disorders, or needed a stem cell/bone marrow transplant?

- ☐ Yes ☐ No ☐ Not sure

6. Have you ever donated blood, plasma, or platelets before?

- ☐ Yes ☐ No

Section 3 — Awareness & Understanding

7. Before today, have you heard of stem cell or bone marrow donation?

- ☐ Yes ☐ No

8. How familiar are you with what stem cell donation actually is?

- ☐ Very familiar
☐ Somewhat familiar
☐ Heard of it, but don't know much
☐ Not familiar at all

9. Which of the following do you think stem cell donation can help treat? (Check all that apply)

- ☐ Leukemia
☐ Lymphoma
☐ Sickle Cell Disease
☐ Diabetes
☐ Heart disease
☐ Not sure

10. How do you think stem cells are collected?

- ☐ Through a blood draw
☐ Through a procedure under anesthesia

- ☐ Both methods exist
- ☐ I don't know

Section 4 — Willingness to Register

11. Before today, were you registered as a potential stem cell donor?

- ☐ Yes
- ☐ No

12. Are you willing to register today as a potential stem cell donor?

- ☐ Yes
- ☐ No
- ☐ Maybe / Need more information

Section 5 — Motivations & Incentives

13. What would motivate you to register? (Check all that apply)

- ☐ Helping save someone's life
- ☐ A personal connection to someone affected (family/friend)
- ☐ Knowing more about how safe it is
- ☐ Getting compensated
- ☐ Feeling appreciated / recognition
- ☐ Other: _____

14. If you are NOT willing or unsure about registering, what is the MAIN reason?

- ☐ I don't know enough about the process
- ☐ Fear of pain
- ☐ Fear of medical risks
- ☐ I'm uncomfortable with my DNA being stored
- ☐ Financial Costs (possible travel and missed work)
- ☐ Time Commitment
- ☐ Other: _____

15. Would financial incentives such as direct payment for your time and discomfort make you *more likely* to donate if you were asked as a match?

- ☐ Yes
- ☐ No
- ☐ Maybe

16. If yes, what range would feel appropriate?

- ☐ \$0 – I would do it for free
- ☐ \$50–\$100
- ☐ \$100–\$250

- ☐ \$250–\$500
- ☐ \$500+

17. If the person in need is a friend/family member, what range would feel appropriate to make you willing to donate?

- ☐ \$0 – I would do it for free
- ☐ \$50–\$100
- ☐ \$100–\$250
- ☐ \$250–\$500
- ☐ \$500+

18. If you don't prefer direct payment, which type of incentive would make you more willing to donate?

- ☐ Small gift card
- ☐ Free meal or merch
- ☐ Recognition (certificate, social media shoutout)
- ☐ None, I prefer no incentives

19. Suppose the organization offered you \$250 to donate if you were a match. Would you accept?

- ☐ Yes
- ☐ No
- ☐ Not sure

20. Do incentives make stem cell donation feel less “altruistic” to you?

- ☐ Yes
- ☐ No
- ☐ Not sure

Section 6 — Final Thoughts

21. What would make it easier for you to donate or register?

- ☐ More clear information on the process and possible risks
- ☐ Hearing stories of patients who need donors
- ☐ Talking to someone who has donated
- ☐ Convenience (location/time)
- ☐ Other: _____