Organ, Tissue and Marrow Donation

Context of the proposal

Medical advancements have opened new doors of hope to millions of people who used to die of medical illnesses and conditions through organ, blood and marrow donation. Many have hailed organ donation to be one of the most important medical advancements in recent history. Today one can expect not only a prolonged life but also an improved quality of life for many patients and families. With all this known to almost all of us still there are several challenges which lead to a major gap between the number of transplant donors and transplant recipients worldwide. It may seem to be a simple process where a person can volunteer as a donor during one’s life or pledge to donate after one’s life. Several constraints lie in the way, however, which can vary from ethical, social and religious diversity factors to regional and cultural differences such as the lack of strong laws and guidelines regarding the topic.

If we look at the global picture regarding organ, blood or marrow transplants taking place we will understand that although organ transplantation is now performed in medical facilities in more than 100 countries around the world, the rate at which it occurs varies enormously, as do the circumstances under which it is carried out.

Background and Problem Statement

**Organ transplantation** can involve the kidneys, small bowel, liver, pancreas, heart, lungs, corneas and sclera (from the eyes), skin, bone, tendons and cartilage. Transplants may be needed because of a primary organ disease, such as chronic inflammatory disease of the kidneys, or because of secondary effects of a disease – for example, people with diabetes needing kidney, islet cell and/or pancreas transplants, or people with cystic fibrosis needing lung transplants. In 2011, 112'631 transplants were reported globally, an increase of 11.6% since 2008. This does not only indicate that the number of transplants has increased during the past couple of years, but also the number of donors. However, it is still difficult to estimate exactly how much is the gap between demand and availability.

There is a shortage of organs for transplantations resulting in long waiting periods and a significant number of deaths among individuals awaiting transplantation, and among those not considered for transplantation because of organ scarcity.

There are various issues revolving around the organ donation system which can be categorized in various social issues. For example: people coming from different strata of the society viewing the organ donation process in different ways. In addition, it frequently occurs that underprivileged people are sometimes forced into organ trade activities as an option to earn money and this activity is seen more commonly in less developed or developing countries. Religious barriers such as misconceptions about organ donation linked with religious beliefs, lack of universal laws governing the organ donation process in different countries is a challenge to combat medical tourism for organ transplant. Misconceptions and lack of knowledge is prevalent at individual as
well as society level and lack of motivation at individual to healthcare professional to country leadership level is missing.

The organ trafficking is also one of the biggest challenges being faced as its market is on the rise worldwide. Lack of legal and ethical regulations have given rise to this activity. Despite efforts to boost altruistic organ donation and resolutions to curb transplant tourism, their implementation has been compromised. At the same time, the worldwide escalation in the number of patients who require the transplants coupled with a shortage in the supply of transplants continues to fuel this trade. Healthcare providers and workers such as the physicians and transplant surgeons have the responsibility to ensure to the best of their ability that the organs they transplant must be obtained upholding the highest standards of ethics and abiding by the law and hence the medical fraternity must be educated and be motivated to contribute to this. Also bringing about thorough changes in transplant practices requires more than academic and professional sanctions; governments of all countries must also bring about political will to adopt and enforce bans on organ purchases and transplant tourism.

**Blood Transfusion** or donation saves lives and improves health, but many patients requiring transfusion do not have timely access to safe blood. According to the WHO, about 108 million blood donations are collected worldwide and more than half of these are collected in high-income countries, home to 18% of the world’s population. Blood donation rate in high-income countries is 36.8 donations per 1000 population; 11.7 donations in middle-income and 3.9 donations in low-income countries. Providing safe and adequate blood should be an integral part of every country’s national health care policy and infrastructure.

A lot of work in the form of awareness camps, voluntary blood donation camps and many countries conduct national program to motivate blood donation in countries. Blood donation programs are being taken seriously by many countries and the impact can be seen in many developed countries, the developing countries still need to work on developing a voluntary and unpaid donor pool to meet country requirements of safe blood donation system. Developed countries must also keep putting in efforts to sustain the donor pool and developing countries must introduce country level reforms to enhance and improve the process by introducing policies to promote voluntary blood donation taking into account components such as religious, social, cultural barriers. It should be made a priority on the government agenda to make safe and sufficient amount of blood to anyone in need and ensure no death due to shortage of safe blood. It takes many donors to help save a hospital patient. Some examples include:

- up to 50 donors to help save just 1 person seriously hurt in a car crash,
- up to 5 donors to save someone who needs cardiovascular surgery, and
- up to 8 donors a week to help someone going through treatment for leukemia.

The medical fraternity must unite and work towards ensuring this public health issue is taken up seriously and ensure steps are taken to promote it globally. Every year the number of transplants being carried out is increasing but still there remains a shortage of donor organs worldwide. Of the world’s 6 billion population, four-fifth is from the developing countries and the unfortunate part is that the transplant rates in the developing world are much less compared to the developed countries. With a rise in
non-communicable diseases in developed as well as developing countries such as cancer, cardio vascular diseases, diabetes a sharp rise is expected in the demand of organ donors but we are not ready to face such a situation. We must take action. Therefore to overcome the aforementioned obstacles a collaborative effort is required from various stakeholders including the medical colleges and hospitals, community leaders, policy makers, health system workers and international organisations to extend support where required. There should be a collaborative effort by all in understanding the ethical, social, cultural and religious beliefs of a multiethnic population is important, as this could be used to explore negotiable limits of those beliefs and values.

**Bone marrow transplant** is a special therapy to transfuse healthy bone marrow cells into a person after his or her own unhealthy bone marrow has been treated to kill the abnormal cells for patients with certain cancers or other diseases. A bone marrow transplant is done by transferring stem cells from one person to another. Stem cells can either be collected from the circulating cells in the blood (the peripheral system) or from the bone marrow. Bone marrow transplant is essential for treatment of illness or condition that affects bone marrow (such as leukaemia, lymphomas, aplastic anaemia, immune deficiency disorders, and some malignant solid tumors), or treatment with chemotherapy or radiotherapy to boost healthy blood cells. Ideally bone marrow should be donated by a family member, however only 30 per cent of patients identify a 'match' with someone closely related to them. The vast majority rely on compatible donors from the bone marrow register - so the more people on it, the better the chance for a match. However it is difficult estimate the number of donors and receipts of bone marrow on a global level but according to Bone Marrow Donors Worldwide 25 million people are currently listed as potential marrow donors on worldwide donor registries. Although many challenges faced by bone marrow transplant programs are similar to the organ donor program challenges but also the complications associated with the transplant process such as use of anaesthesia or getting hospitalised for the donation process etc. and health care workers can play a very important role in bridging the knowledge gap as well as motivating people to register as donors.

**Target Group**

**Medical students and healthcare faculties** | Medical students are as future healthcare professionals key players in promoting organ and bone marrow donation both in professional contexts and in the general community. To enhance the knowledge and quality of the donation process the medical students should be well educated. Therefore the curriculum outlined by the healthcare faculties should include an adequate course concerning the topic. Furthermore, the medical students should be aware and consider the ethical aspects of donation and be able to communicate these in a sensible way.

**Current and healthcare professionals** | Several types of healthcare professionals (i.e. nurses, assistants) are in contact with the transplantation process. To enhance the success rate, not only the scientific but also the emotional handling of families, education of all types of medical staff must be considered of great importance.
National transplant organisations | The main administrators of the transplantation coordination. They are responsible for the forming and implementing of donation guidelines and for the coordination behind donation. They possess great knowledge and professional contacts which medical students and students’ organizations can draw on.

Governments and policymakers | Governments and policymakers are fellow-players along with the national transplant organisations in making the path from donor to recipient as short and transparent as possible. It’s important that the governments and policymakers are encouraged to help strengthen the laws concerning donation.

Potential donors | Organ donation has no age-limit. Bone marrow donation has an age-limit (registry has to happen before a certain age), yet the age-limit still being high. Therefore, all people are potential donors with only few medical conditions being excluded. Transplants involving young donors have a higher success rate. Furthermore, young adults are typically open-minded towards difficult topics and can be challenged when confronted with ethical questions concerning donation. They are also a useful source to open a discussion concerning donation with the elder generations in their family.

Social leaders | Role models and sources of inspiration are able to influence the general community. The social leaders are able to create a positive view towards and demystify a difficult subject.

Beneficiaries:

Recipients | Organ and bone marrow donation is for a recipient either a cure of an end stage disease or an enormous increase in quality of life.

The general community | Creating awareness among the general population will help demystifying death and donation, and help raise some of the important ethical aspects concerning organ donation. When a person registers to the organ register he or she spares the families of making difficult decisions in enormous emotional situations. Last, a study suggests that transplantation of a kidney is more cost-effective compared to dialysis.

Healthcare system | The healthcare system will be able to heighten the quality of donation processes when the medical students are more qualified to understand and handle donation. The health care system will benefit from the increased number of donors.

Medical students and future research | Education of medical students shall create spokespeople who can promote organ and bone marrow donation in an informative way and in the long term make them better communicators and health promoters. Furthermore, the increased focus on donation can help increase the interest of research in transplantation and enhance successful future outcomes.
Transplant organisations (national and international) | The increase in organ and bone marrow donations not only benefits the single country. Through collaborations between national transplant organisations, organs and bone marrow can aid matched recipients transnational.

Logical framework of interventions

End-goal and assumptions

End goal
A. Increase the availability of organs, marrow and tissues through living and deceased donation in a safe and ethical manner

Assumptions
- **Organ, marrow and tissue donation is important**: Organ, marrow and tissue transplantations are life-saving treatments and/or significantly improve quality of life of patients in many diseases, including several end-stage diseases.
- **We can get organs, marrow and tissues from donors**: Organ, marrow and tissue procurement techniques from donors have been matured to the point where benefits definitely outweigh risks.
- **We need more organs, marrow and tissues**: There is significant discrepancy between supply and demand in organ and tissue.
- **We can get more donors and more donated organs/tissues per donor**: There is significant gap between the number of potential donors and actual donors, and between the number of potentially donated organs and the number of actually donated organs.
- **We can do more to increase the number of donors and donated organs/tissues per donor**: Multiple strategies, such as raising awareness in the community, exist to increase availability of organ and tissues.
- **Medical students can be part of this**: Medical students can partake in awareness and advocacy activities to increase availability and decrease misconceptions across the general population.

B. Increase the safety of donors

Assumptions
- **Donors should be safe**: Even if living donors are exposed to a certain amount of risks, both modifiable and non-modifiable, it is their right to benefit from the safest interventions and suffer from the least amount of risks for adverse outcomes.
- **Donors are sometimes not safe**: In some instances, procurement of organs from living donors is not performed under the safest conditions, which result in disability or death in donors.
• **We can improve safety of donors:** Some countries exhibit fewer adverse outcomes in living donors, and even in those countries adverse outcome rate is not 0%.
  • **We can do more to improve safety of donors:** Multiple factors including research and infrastructures play a large role in improving safety of donors.
  • **Medical students can be part of this:** Medical students can contribute through advocacy for example, calling on policy makers and governments to ensure safety of those willing to better the lives of others.

C. Promote ethical donation practices

**Assumptions**
• **Ethics are important:** Donation from humans need to be guided by ethical principles.
• **Ethical issues still exist:** Unethical practices that are being performed worldwide pose a serious threat to public health.
• **We can have more ethical practice:** Multiple strategies including stronger legislation and monitoring contribute to promoting ethical practice.
• **Medical students can do a lot:** Medical students can use their voice to advocate for the implementation of ethics promotion strategies.

**Preconditions and backwards mapping**

In order to achieve the end goal, action should be divided into three keystones: availability, safety and ethics. Each of these keystones has its own preconditions that need to be fulfilled.

A. Increase the availability of organs and tissues through living and deceased donation

A.1. Increase population consent towards donation
A.1.1. Ensure the coordination of local and national strategies to raise awareness among the general population, in particular the medical students, given their roles as future physicians, advisors and advocates
A.1.1.1. Ensure strong presence of a central leadership in the coordination of awareness efforts
A.1.1.2. Prepare promotional materials such as toolkits for awareness purposes
A.1.1.3. Train volunteers to be competent in raising awareness among their communities
A.1.1.4. Use effective awareness strategies according to targeted population groups
A.1.2. Facilitate the expression of consent
A.1.2.1. Implement a multi-platform, population-centered and easily accessible registration in the donation registry
A.1.2.2. Use awareness strategies as means to inform the population but also offer opportunities of consenting to donation
A.2. Increase donation system efficiency in the healthcare system
A.2.1. Establish a network of healthcare professionals competent in donation
A.2.1.1. Ensure adequate donation training of healthcare professionals
A.2.1.1.1. Integrate donation education in the medical and nursing curricula
A.2.1.2. Ensure advanced donation education and regular training updates for healthcare professionals working in donation-related environment
A.2.1.2. Ensure balanced and sufficient presence of healthcare professionals with special mandate in donation in hospitals
A.2.1.2.1. Ensure sufficient funding of hospitals to hire leaders specialized in donation
A.2.1.2.2. Encourage healthcare professionals to be leaders specialized in donation
A.2.2. Ensure adequate logistical framework for donation in hospitals
A.2.2.1. Develop and implement a coordinated guideline-based donation management procedure and structure in each hospital
A.2.2.2. Ensure that healthcare professionals have access to time resources, materials, facilities and administrative structures for optimal donation procedure
A.2.2.2.1. Ensure that healthcare professionals have the time and tools needed to convey prognosis and offer donation option to families
A.2.2.2.2. Ensure that healthcare professionals have access to intensive care resources for donor maintenance
A.2.2.2.3. Ensure that transplant surgeons have access to operating rooms for organ procurement
A.2.3. Optimize organ allocation system to maximize donation potential of donors
A.2.4. Develop controlled Donation after Cardiovascular Death as potential donor criteria
A.2.5. Use research as an evidence-based approach to increase efficiency
A.2.5.1. Increase research funding in donation-related studies
A.2.5.2. Promote research investigations and evidence disseminations
A.2.5.2.1. Promote research interests and opportunities among medical students
A.2.6. Establish a central leadership to coordinate and monitor the donation procedure
B. Increase the safety of donors
B.1. Improve quality of care from physicians and transplant surgeons
B.1.1. Implement adequate training for healthcare professionals carrying out organ procurement procedure
B.1.2. Establish risk mitigation strategies related to quality of care in hospitals
B.2. Improve infrastructures and ensure safety guidelines enforcement in hospitals
B.3. Use research as an evidence-based approach to increase safety of donors
B.3.1. Increase research funding in donation safety-related studies
B.3.2. Promote research investigations and evidence disseminations
B.3.2.1. Promote research interests and opportunities among medical students
B.4. Establish a central leadership to monitor transplantation safety and establish standardized guidelines
C. Promote ethical donation practice
C.1. Ensure scientific and ethical validity of potential donor criteria
C.1.1. For deceased donors
C.1.1.1. Ensure that all efforts are done to save the patient’s life before considering him as a donor.
C.1.1.2. Ensure that the diagnosis of death is made on evidence based criteria
C.1.1.3. Provide patient’s family with adequate and human conditions for grieving, accepting diagnosis/prognosis and considering donation
C.1.2. For living donors
C.1.2.1 Ensure that the decision of donation is well-informed and willing and is not taken under external influence
C.1.2.2 Ensure that the potential donor’s quality of life and functional capacities won’t be significantly diminished following donation
C.2 Respect the voluntary character of donation
C.2.1 Obtain and respect informed decision of living donors or of next of kin for deceased donors
C.2.1.1 Respect religious beliefs towards donation
C.2.1.2 Respect the withdrawal of living donors
C.3. Ensure equitable allocation of available organs and tissues
C.3.1 Adopt ethical laws to regulate donation and allocation
C.3.2 Prohibit organ and tissue trade
C.4 Protect the privacy of donor’s and recipient’s data
C.4.1 Adopt laws to ensure privacy and confidentiality
C.5 Implement a national transparent and accountable system to monitor ethical donation practices in hospitals

Mapping
Milestones and indicators

Outcome 1: *Increase in population consent towards donation*

**Indicator:** Number of registrations in donation registries, population approval according to surveys, percentage of refusal in hospitals, annual donation rates

**Target groups:** secondary school students, university students, medical students, physicians, patients visiting hospitals, social leaders, general public

**Threshold:** Promotional materials, presentations, kiosk stands, contests, public events, advocacy actions to optimize registries, mass media programs, social media campaigns, celebrities endorsement.

Outcome 2: *Capacity building and training of healthcare professionals on donation*

**Indicator:** Donation competency assessment before and after the training or the course, potential donor identification rate, percentage of refusal in hospitals, annual donation rates, annual number of transplantations.

**Target group:** Medical students, nursing students, physicians, surgeons, nurses.

**Threshold:** Implementation of training in medical and nursing schools curricula, implementation of advanced trainings for healthcare professionals involved in donation.

Outcome 3: *Increase in the healthcare system’s efficiency in donation*

**Indicator:** Number of organs and tissues procurement per hospital, number of healthcare professionals specialized on donation per hospital, potential donor identification rate, percentage of refusal.

**Target group:** Healthcare system’s policy makers

**Threshold:** Advocacy for increasing time and material resources provided to donation, fundraising for improving the hospital’s equipments used for donation.

Interventions

A. Increase the availability of organs and tissues through living and deceased donation

A.1. Increase population consent towards donation

- Establish partnerships with procurement organizations and donation- and transplantation-related organizations to coordinate awareness efforts.
- Prepare brochures, short videos, wearable items and other promotional materials destined for hospital use or awareness activities.
- Develop capacity building of medical students and students in other health science programs to be leaders in raising awareness about donation.
- Invite medical students colleagues to raise awareness about donation among family members and relatives.
- Invite physicians and social leaders to raise awareness about donation in the general public.
- Organize conferences, symposiums, kiosk stands and other awareness activities for university students, with a special emphasis on medical students.
Organize presentations, interactive workshops, creative contests and other awareness activities for secondary school students.

Organize kiosk stands, walks, galas and other awareness outreach activities for the general public.

Consider the use of social media, mass media and endorsement from popular figures to raise awareness or as an addition to existing awareness activities.

Advocate for the creation of an online registry, telephone registry, registry via signing of card and other registry platforms.

Advocate for easier access to registration in the donation registry, including possibilities of registration upon driver license renewal, medical card renewal, university student card renewal, medical visit and pharmacy visit.

Advocate for a more population-centered registration, which offers the option of choosing organs and tissues for donation for example.

A.2. Increase donation system efficiency in the healthcare system
   Establish partnerships with procurement organizations and donation- and transplantation-related organizations to coordinate advocacy efforts in improving donation efficiency
   Create and disseminate a course on donation to medical schools for integration in the curriculum
   Advocate for advanced donation education and regular training updates for all healthcare professionals working in donation-related environment
   Advocate for the development and implementation of a coordinated guideline-based donation management procedure and structure in hospitals
   Advocate for increased funding for hospitals to hire leaders specialized in donation and to reorganize hospital structure enabling adequate access to intensive care resources for donor maintenance and to operating rooms for organ procurement
   Fundraise for improved facilities in hospitals enabling more efficient donation workflow

A.2.3. Optimize organ allocation system to maximize donation potential of donors
   Establish partnerships with procurement organizations and donation- and transplantation-related organizations to coordinate advocacy efforts in optimizing organ allocation system
   Raise awareness on the potential inequity of the allocation system.
   Advocate to improve the equity and the efficiency of the allocation system.

A.2.4. Develop controlled Donation after Cardiovascular Death as potential donor criteria
   Establish partnerships with procurement organizations and donation- and transplantation-related organizations to assess the need for donation after cardiovascular death and develop this donation criteria
   Increase research on controlled donation after cardiovascular death
• Advocate for the inclusion and expansion of controlled donation after cardiovascular death as a donor criteria
• Educate medical students and healthcare professionals on the benefits of controlled donation after cardiovascular death as a donor criteria

A.2.5. Use research as an evidence-based approach to increase efficiency
• Establish partnerships with procurement organizations, donation- and transplantation-related organizations and research agencies to assess the need for research and promote research in donation
  • Advocate for increased funding dedicated for research in donation
  • Promote research interests and opportunities in donation among medical students through journal clubs, student interests groups and networking with donation experts, procurement and transplantation organizations
  • Advocate for the creation of a scholarship funding students undertaking donation research
  • Conduct research studies in donation-related areas.

A.2.6. Establish a central leadership to coordinate and monitor the donation procedure
• Establish partnerships with procurement organizations and donation- and transplantation-related organizations to assess the need and ways for improving central leadership
  • Advocate for the establishment of a central leadership to coordinate and monitor the donation procedure

B. Increase the safety of donors
• Establish partnerships with procurement organizations and donation- and transplantation-related organizations to assess the need and ways for increasing safety of donors
  • Advocate for advanced donation education and regular training updates for transplant surgeons
  • Fundraise for improved infrastructure in hospitals enabling safer donation practices

C. Promote ethical donation practice
• Establish partnerships with procurement organizations and donation- and transplantation-related organizations to assess the need and ways for promoting ethical donation practice
  • Create and disseminate interactive workshops among medical students to discuss ethical issues of donation
  • Promote a multicultural approach towards donation through collaborations between NMOs of different regions, social leaders and medical students for them to understand social points of view towards donation.
  • Advocate for legislation on mandatory initiation of donation procedure for any potential donor
Narrative

The Program on Organ, Tissue and Marrow Donation aims to increase the availability of organs and tissues through living and deceased donation in a safe and ethical manner. In order to increase availability of organs and tissues through donation, appropriate awareness strategies, including presentations, public events and social media campaigns, are necessary, and participating NMOs should advocate for easier expression of consent. Furthermore, to ensure that hospitals possess the adequate human and other resources, donation training should be mandatory for all healthcare professionals and steps must be taken to equip hospitals with sufficient logistical necessities. In order to ensure safety of donors, quality of care and infrastructures should be the center of advocacy efforts from NMOs. Finally, promoting ethical donation practices entails the consideration of ethical donation criteria, privacy, equitable allocation and voluntary aspect of donation.

Organisational context and needed resources

Human Resources

- Trained IFMSA workshop coordinators.
- Trained participants from the IFMSA workshops or similar workshops.
- Students who join local and national working groups and committees.
- Certain organ and blood donation professionals including medical professionals.

Program Materials

- Workshop slides.
- Specific campaign and project guides.
- Training manuals and materials.
- Samples of IFMSA Activities Forms on Organ and Tissue Donation from NMOs and previous transnational project on Organ Donation Awareness.
- Donation cards or bills related to donation reservations.
- Related leaflet and poster templates and samples.

Collaboration

- NMOs are strongly encouraged to work with other health and students organizations to improve the efficacy and consistency of action.
- NMOs are invited to work with other NMOs on understanding different approaches towards the issue keeping in mind the vastly oriented minorities in the territory.
- Local, national and international organ and blood donation councils and organizations.
- Organisations going international on Bone Marrow Donation. Ex. Marrow UK.
Budgetary aims

- Transportation and accommodation for workshop coordinators.
- Public relations and marketing (for example community organising servers such as nation builder, creation of professional videos and other materials).
- Financial support to needing NMOs in program related activities.

Resources

1. IFMSA Policy Statement On Organ Donation: https://drive.google.com/file/d/0B4mZbJa1UyHEZHN5TDA2dVFUs1E/view?usp=sharing