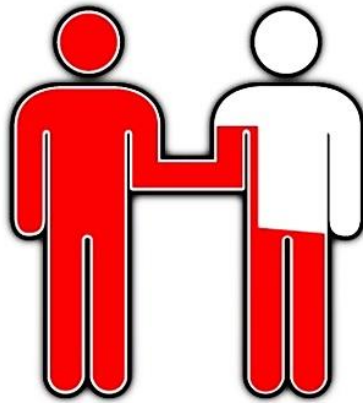


D3.1 Donor recruitment programmes and resources



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Description:

This Deliverable includes evidence-based programmes and associated resources to support the recruitment of donors from high-demand and under-represented population groups. The product is a website with the following information:

- Descriptions of global patterns of stem cell supply and demand, specifying the ethnic groups where patient need and unmet need is highest.
- Examples of recruitment materials targeting specific population groups.
- Examples of good and best practice reflecting the experience and practice of high-performing member organisations.
- Toolkits and checklists to support the execution of targeted donor recruitment activities.
- Common pitfalls and barriers and how to overcome them.
- Frequently Asked Questions.

Product:

<https://share.wmda.info/x/Q7ubEw>

The different pages of this website include:

Project: Donor recruitment and resources

- Best practices
- Common pitfalls and barriers
- Examples of recruitment materials
- Frequently asked questions
- Global patterns to support recruitment
- Toolkits and checklists

Best practices

Donor recruitment is a challenge for many organisations. It is difficult to recruit donors from different ethnic backgrounds and it is also difficult to stay connected with a donor. WMDA has organised an educational event on November 7, 2018. During this event the WMDA shared their best practices how to recruit donors in different populations and how to stay connected with a donor.

Find below 6 presentations how organisations present their best solutions:

- [Presentation Anthony Nolan United Kingdom](#)
- [Presentation DKMS Chile](#)
- [Presentation Anthony Nolan United Kingdom](#)
- [Presentation NMDP - Be The Match USA](#)
- [Presentation Matchis The Netherlands](#)
- [Presentation Finnish Stem Cell Donor Registry](#)

Common pitfalls and barriers

Donor registries have different backgrounds in how they have been starting up their organisation. Sometimes they start from dedicated patient families. Other possibilities are starting through an university hospital department, such as a HLA laboratory or a blood bank.

WMDA is frequently approached by enthusiastic volunteers who are keen to start up a registry and to start to recruit donors. Setting up a registry is more than recruiting donors. An infrastructure needs to be developed to get connected to donors, to keep in contact with donors and to collect a high-quality stem cell products from donors.

A registry, or donor centre, should be responsible not only for recruiting adult volunteer donors, but also for ensuring that all donors have received appropriate counselling and have given the necessary signed, informed consent. The registry or donor centre is also responsible for coordinating the typing of prospective adult volunteer donors.

Registries and donor centres should feel responsible for the care and wellbeing of the donor and should also be aware of the standards required for managing donor care. The registry or donor centre has an obligation to respect the donor's rights and to act in accordance with ethical principles.

At the time of registration, donors should be made aware that they need to be willing and physically able to donate either bone marrow or peripheral blood stem cells (PBSC). It has to be clear that becoming a donor is absolutely voluntary. It is vital to get the donor's informed consent (either written or digital for online donor recruitment) for typing their blood or saliva sample and also for storing their personal data in the registry or donor centre database.

The donors should be made aware of the matching process and should understand that having their details listed does not mean they will automatically be asked to donate their stem cells or bone marrow. The registry must inform the donors about the registration regulations and also their right to withdraw their agreement at any time.

If a donor is selected to donate, the type of collection process required should be discussed with the donor again during the work-up process, taking into account the needs of the patient. The donor's decision regarding the process will be respected at all times. If the donor does not agree to undergo the collection procedure requested by the transplant centre, it may be necessary to look for an alternative donor. This is why informed consent at the recruitment stage is so vital.

The main tasks involved with donor recruitment are to:

- Attract people's attention to the issue of bone marrow and stem cell donation and show them how they can support the cause.
- Educate new potential donors in a thorough and transparent way.
- Offer simple and transparent methods of donor recruitment.
- Strive for retention and reliability of new donors, which can be evidenced by donors' interest in supporting the registry or donor centre and by examining donor availability and rates of withdrawal.

WMDA has set up educational materials to describe the common pitfalls and barriers. Below you will find these outlined per step of the process:

- [General organisation of a registry](#)
- [Recruitment of volunteer donors](#)
- [Donor Search Request](#)
- [Collection and transport](#)
- [Post donation](#)
- [Cord Blood Banking](#)
- [Information Technology and data management](#)
- [Finance and administration](#)

Examples of recruitment materials

WMDA has over 100 member organisations, that are actively recruiting donors. You can visit the WMDA homepage and visit the global map with the red hearts. If you click on a heart you will find the contact details of the organisation and links to their social media channels. The link to the WMDA website is: <https://www.wmda.info>

In addition, you can find here presentation that are developed by several registries for recruiting donors:

EXAMPLES OF A EUROPEAN MEMBER ORGANISATIONS

- France: <https://www.youtube.com/user/DonDeMoelleOsseuse>
- Belgium: <http://www.31millionchances.org>
- Cyprus: <https://twitter.com/Karaiskakio>
- Greece:
- Portugal:
- Lithuania: <https://www.youtube.com/channel/UCt-3NfIYhbCln7r0u9phjrA>
- Romania: [Animatie-V2.mp4](#)
- Spain:
- Sweden:

LARGEST RECRUITMENT ORGANISATION: DKMS

DKMS is the largest donor centre in the world. They have established organisations in: Poland, Germany, United Kingdom, India and Chile. On this webpage you will find several educational movies to educate donors:

https://www.youtube.com/channel/UCTHI0999ldUHziDadn57k6g?sub_confirmation=1

EXAMPLE FROM SWITZERLAND

The Swiss Blood Stem Cells Registry is a part of the Swiss Blutspende SRK Schweiz AG. This is a good example on how to provide complete information about the whole donor journey:

http://en.blutspende.ch/_pdf/bch_broschuere_sbsc_en_web.pdf

EXAMPLE FROM ITALY

The Italian Bone Marrow Registry is collaborating with ADMO. They jointly launched the campaign: Match it Now. Find here all details on this campaign: <http://matchitnow.it>

CHINESE EDUCATIONAL MOVIE

In the Chinese culture the role of the family, especially the grandparents is important. This is a movie to explain to grandparents about stem cell donation, in case a grand child is asked to donate stem cells.

Find here the link:

RECRUITMENT EXAMPLES FOR YOUNG MILITARIES IN THE USA

This organisation is focusing the recruitment on young militaries. The website provides educational materials and a YouTube movie: <https://www.salutetolife.org/learn-more>

If you have interesting links to share, send us a message and we will add these materials on this webpage. Our mail address is: mail@wmda.info

Frequently asked questions

How do I set up a registry?

WMDA recommends you to become a WMDA service member. This means that you will get all support from the international community and you will get access to the WMDA electronic handbook on how to set up a registry. you can apply for WMDA service membership [here](#).

How do I know that a donor is suitable to donate?

WMDA has developed a wiki to help donor recruiters to determine if the donor is medically fit to donate. It is a web based tool, which you can visit on: <https://share.wmda.info/x/FABtEQ>. You can also read the summary and general guidelines in the article published by the WMDA medical working group: <https://www.nature.com/articles/bmt201467>

How do I request services from international partner organisations?

WMDA has developed WMDA form templates which you can use to request stem cells or other services from WMDA member organisations. The forms have been released December 2018. You can download the templates [here](#).

How many transplants take place annually?

WMDA is collecting data from all over the world to count the number of unrelated transplants taking place. You can download [here](#) the 2017 data.

Global patterns to support recruitment

Below, the Registry of Unmet Needs poster is shown. This poster was presented at the WMDA meeting in June 2018 in Munich and includes global patterns to support the recruitment of donors for patients that the collective donor pool of WMDA is currently not able to serve.



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Toolkits and checklists

WMDA Toolkit to set up a registry

- General organisation of a registry
- Recruitment of volunteer donors
- Donor Search Request
- Collection and transport
- Post donation
- Cord Blood Banking
- Information Technology and data management
- Finance and administration

WMDA Toolkit to celebrate World Marrow Donor Day

WMDA has celebrated World Marrow Donor Day on September 15th, 2018. The event was focused on thanking the donors for their donation and also to focus the recruitment on population groups that are currently underrepresented in the global file. Find here the materials, that WMDA has developed for this day:

- [Link to event website](#)
- [Link to WMDD 2018 after movie](#)
- [Link to report about World Marrow Donor Day: https://spark.adobe.com/page/vjqa3xj8bE2Ln/](#)
- [Link to promotion materials](#)

WMDA Tips to take into account when you are recruiting donors

- [Presentation made by the WMDA registries working group](#)