



# Donormanagement

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# Topic : donor information & IC

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Involvement



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Why this topic?

We have noticed that too often, in all stages, from registration as a donor and when a donor is asked for ET, VT and WU, this donor is not well enough informed about what is happening and what he might experience when he proceeds



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This leads to embarrassing and disappointing situations.

They are also costly.

Sometimes it's because the registration has been done a long time ago and the donor has forgotten about the procedures.

Sometimes it's because the procedures have changed and the donor hasn't been informed.



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In these situations we have failed, not the donor. The main reason is that it was too expensive to keep in contact with the donor by mail.

Now we can do this by e-mail, which costs nothing, but therefore we absolutely need to incorporate the e-mail addresses in the database.



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The aim is to improve the efficiency by making sure a good donor information is provided all along the way.

WMDA guidelines & recommendations.



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Stages in which information is involved:

1. Recrutement
2. Registration
3. ET/VT
4. WU



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Recruitment: Information to be provided to the general public

Haematopoietic stem cell donation is used for the treatment of both adult and paediatric patients with various kinds of severe malignant, metabolic and immunologic diseases.

Compatibility is primarily based on Human Leucocyte Antigen (HLA)(histocompatibility) identity.

Haematopoietic stem cell donation is:

- Undertaken voluntarily, and withdrawal of the volunteer is permitted at all times
- Not remunerated ~~but incurred expenses are met and may include loss of earnings~~





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- Guaranteed to be anonymous for both patient and donor
- Health restricted including a requirement that the individual volunteer must not be at high risk of transmittable diseases
- The minimum age must be determined by the legal requirement (i.e. 18 y).
- The maximum age will be determined by the policy of the responsible Registry (i.e. 50)
- Registration of a donor implies a general offer to be available for any patient in need of a haematopoietic stem cell transplant anywhere in the world, irrespective of the patient's age, gender, nationality, creed or ethnicity.
- It should be made clear to volunteers that patients are only eligible for transplant/cell therapy as defined under the WMDA standards (SOP)



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## Registration:

### Info

- Information may be given through literature, video, the telephone or face to face. (We organise info-session)
- The volunteer must be provided with information on the principles, general procedures, restrictions and risks of providing blood samples and haematopoietic stem cells (either via marrow or peripheral blood donation).



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**Consent (IC):** A consent form must be signed by the volunteer, which confirms that he/she understands and agrees to the following:

- Join the Registry as a potential haematopoietic stem cell donor and provide relevant samples for HLA typing and IDM testing\*. It should be made clear to the volunteer that some of the sample material may be stored for an indeterminate period for the purposes of undertaking further HLA typing and IDM testing\*.
- The principles and risks of haematopoietic stem cell donation, and the implications of transmission of infectious diseases from donor to patient.
- Be available to the donor centre for further requests to provide blood samples for additional histocompatibility testing and possibly to provide haematopoietic stem cells for transplantation.



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- Complete a medical evaluation questionnaire.
- Haematopoietic stem cell donation not being remunerated.
- Cell donation being anonymous for both patient and donor.
- Donation for any recipient in need.
- It should be made clear to volunteers that patients are only eligible for transplant/cell therapy as defined under WMDA standards. (SOP)
- The confidentiality of personal data.
- HLA type, blood group\*, and IDM\* being available to international registries and transplant centres
- To the best of his/her knowledge, he/she is not at high risk of transmitting infectious diseases



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VT

NB: the information given at the time of a ET is the same as for registration with the explanation why this sample is drawn. IC is useful

**INFO** to donor

- Blood samples taken at this stage are sent to the appropriate transplant centre, where they are subject to histocompatibility testing
- Haematopoietic stem cell harvesting will be undertaken by bone (spinal or general), or by peripheral blood stem cell (PBSC) collection following G-CSF mobilisation.
- The side effects and risks associated with the procedures must be discussed with the volunteer. In particular about all aspects of G-CSF administration (side effects)



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- As a preference for PBSC may be expressed by the transplant centre, the volunteer will be asked to consider both forms of donation. However, he/she does not have to make a decision at this stage
- Final stage confirmatory testing has determined the donor's likely selection. The current probability of being selected and the likely time frame donate. The commitment to the donor that he/she receives the results.
- The location of the collection centre.
- The potential time commitment involved in either of the donation procedures and subsequent recovery period.
- The right to withdraw at any stage
- A medical examination is necessary to assess the donor's fitness



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- No remuneration for donation
- The probability for the treatment to be successful for the patient. General terms should be used
- **Consent:** All the foregoing information should also be contained in an information sheet and the volunteer should sign a consent form confirming that he/she has read, understood and agrees to all the above procedures  
A further medical questionnaire must be completed by the volunteer at the time of final stage confirmatory testing



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WU

INFO to donor

NB: This information should be given by a trained and qualified medical doctor, ideally face to face, may be preceded by a preliminary telephone conversation

The volunteer should be able to invite a person of their choice to be present and have the opportunity and be encouraged to ask all questions he/she feels necessary, and detailed, accurate, answers given. The volunteer should be offered the opportunity to talk to one or more volunteers

A donor advocate should be available to discuss the approaching donation with the volunteer. The advocate must be an independent third party





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The information session should be conducted with the aid of a comprehensive checklist to ensure that all aspects have been covered. The check-list should be signed by the person conducting the information session and countersigned by the volunteer. A copy must be provided to the donor.

NB: The information to be given at donor at this time and the specification of the consent form are beyond the scope of this presentation. The recommendation can be found at the WMDA site