Instructions:

This form is designed to be completed in Word. The response boxes will automatically expand to match the amount of text entered. To move from one field to the next one, use the “Tab” key.

The Participant Information form must be printed with the institutional letterhead where research will be performed. To make any required changes to the form content, this include addition of the institutional logo in header on page 1, unprotect the document, make changes, protect and save the document.

A copy of the Participant Information form must be given to the participant. All information provided in this document must be clear and in plain language.

These instructions can be deleted once form has been completed

|  |  |
| --- | --- |
| Date of Participant Information |  |
| Scientific/ grant application title |  |
| Plain English title of project |  |
| Names, institutions and positions of investigators |  |

# Commonly asked questions

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| 1. What is the purpose of this project? |
| (In plain English provide an outline of the background/ rationale and aims of the project) |
| 1. Why have I been selected to participate in the project? |
| (state why and how the participant was selected) |
| 1. Do I have to participate in this project and can I withdraw my sample? |
| Participation in this project is completely voluntary. Your decision whether or not to participate will not affect your relationship with the ABMDR or (Insert Chief Investigator Institution).  **This project will use material or data:**  *Instructions: Researchers are allowed to delete the material/ data use option below that doesn’t apply for the project.*  **Potentially re-identifiable (de-identified)** (where identifying information is removed but where it is possible to re-identify your sample): If you decide to participate, you may change your mind and withdraw your consent at any time.  (Researchers must Include an example of identifying information)  **Anonymised** (where it is not possible to re-identify the sample) If you decide to participate, you may change your mind and withdraw your consent prior to providing the material. Once the material has been collected, all identifying information is removed and it is not possible to identify them. It is never possible to withdraw information gained from research involving your sample. |
| 1. What is the process for me to be involved and what do you require from me? |
| (Describe the involvement required of the participant, procedures)  (Explicit direction on what, how where and when, total time required, frecuency and follow-up if applicable) |

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| 1. Are there any risks involved? | | |
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| 1. Are there any implications of this research for me and my relatives or family? | | |
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| 1. What are the possible benefits of taking part in this research? | | |
| (If applicable, describe any benefits to the participant reasonably to be expected.)  You will not receive any direct benefit from this project but indirectly your involvement may improve the care of future patients and advance scientific knowledge. | | |
| 1. Will all information about me, including my test results, be kept confidential? | | |
| (This section should include details of how the data will be kept confidential and who will have access to the data)  In accordance with the current regulations, any information that is obtained in connection with this research and that can be identified with you will remain confidential and will be disclosed only with your permission or except as required by law.  Any publications arising from this research will use de-identified information and no individual participants will be able to be identified in any publications or reports arising from this research. | | |
| 1. Who is funding this project? | | |
| This section should describe who the sponsor is and what arrangements are made for reimbursing/covering any expenses born by the participants. | | |
| 1. Does participation in this project affect my ability to be available for bone marrow donation? | | |
| The participation in this research does not affect your ability to be available for bone marrow or blood stem cells. If during the research you are selected as a donor you may be excluded from the research project. | | |
| 1. If I have any questions about this research whom can I contact? | | |
| You are welcome at any time to contact the researchers or the ABMDR (see details in question 12) to answer questions about the project. Contact details are listed below: | | |
| Name:  Position:  Institution: | | Address:  Phone number:  Email: |
| 1. Who do I contact if I have any concerns, complaints or if I want to withdraw from this research project? | | |
| This research has received the support of the ABMDR Research and Release Governance Committee and been approved by the Australian Red Cross Lifeblood Ethics Committee. If you have any concerns about the conduct of the research or your rights as a research participant, you may contact: | | |
| Chief Executive Officer ABMDR  Phone: +61 2 9052 3333  Email: [abmdr.research@abmdr.org.au](mailto:abmdr.research@abmdr.org.au) | Lifeblood HREC Secretary  Phone: +61 2 9234 2411  Email: ethics@redcrossblood.org.au | |

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| Scientific/ grant application title |  |
| Plain English title of project |  |
| Names, institutions and positions of investigators |  |

I acknowledge that:

1. I have read or have had read to me by (add name of person obtaining consent) the Participant Information Form relating to this research and understand the general purpose, methods, demand and possible risks and inconveniences which may occur during the research.
2. I have had the opportunity to ask any questions and am satisfied with the answers I have received.
3. I have been advised that the researcher will conduct this research in a manner conforming to ethical and scientific principles set out by the National Health and Medical Research Council of Australia (NHMRC).
4. I have been advised that this research is authorised by (name of Chief Investigator and institution) and the ABMDR Research and Release Governance Committee.
5. I am volunteering to take part in the project as described in the Participant Information Form above. I understand that I can withdraw at any time (subject to the limitations outlined in the Participant Information Form) and this will not affect my relationship with the ABMDR nor have any bearing on the treatment of any patient with whom I may be identified as a match.
6. I agree that research data gathered from the results of the project may be published, provided that I cannot be identified.
7. I understand I will not benefit financially from taking part (e.g. if research leads to commercial development of a new treatment).
8. I will be given copies of the Participant Information and the Consent to Participate in Research Forms.

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| Donor name |  | | |
| Signature |  | Date  (day/month/year) |  |
| Name and nature of witness |  | | |
| Signature |  | Date  (day/month/year) |  |
| Interpreter name  (If applicable) |  | | |
| Signature |  | Date  (day/month/year) |  |