Title: 'It was very easy to become an isolationist': understanding patient quality-of-life following haematopoietic cell transplant.

Supportive Care in Cancer

Supplementary file B – Participant Information Sheet

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Participant Information Sheet

Patient perspectives on the use of patient reported outcome measures (PROMs) following haematopoietic stem cell transplant: a qualitative interview study

Thanks for agreeing to take part in an interview!

Before you decide to take part, we would like you to understand why this interview study is being done and what it would involve for you.

Please ask if there is anything that is not clear or if you would like more information.

Why is Anthony Nolan doing this interview study?

Patient-reported outcome measures (PROMs) are self-reported questionnaires that collect information from patients about how well they are feeling or functioning. Often patients are asked to complete this type of questionnaire before and after treatment so change (improvement or decline) in how they are feeling can be assessed.

Anthony Nolan is about to start a large study collecting information about patient quality-of-life after receiving a stem cell transplant. However, before we start this work, we would like to know what patients think about the measures (i.e. questionnaires) we are planning to use.

We would like to interview 24 stem cell transplant patients and explore what they think about patient reported outcome measures. We are interested to know:

- what questions patients think should be asked
- how patients would like to report their physical, emotional, and social function
- when patients think quality-of-life data should be collected
- how they think the data should be used.

What will taking part in an interview involve?
During the interview we will ask you about your experience of receiving a stem cell transplant and how this affected your quality of life. We will then ask you to look at two questionnaires which are commonly used to measure quality of life among stem cell transplant patients. We will ask you what you think about these questionnaires and whether the questions reflect your experience of life post-transplant.

You are welcome to ask a family member of caregiver to join you during the interview.

The interviews will be held over the phone or by video call using Zoom or Microsft Teams. It is up to you whether you choose to take part over the phone or if you would prefer to have a video call.

The interview will last between 45 – 60 minutes and will be very informal.

What are the benefits of taking part?
As a **THANK YOU** for taking part you will receive a **£25** shopping voucher. The shopping voucher will be sent to you via email after you have taken part in the interview.

Are there any risks?
There are no risks involved with taking part in the interview. You may find that talking about your experience of receiving a transplant is upsetting. It is unlikely that this will happen as the interview guide has been tested with patients, however if you do find the interview upsetting you may stop the interview or ask for a break at any time.

What data will be recorded, how will it be used and who will have access to it?
All interviews will be recorded and transcribed. The data recorded will be handled in accordance with the General Data Protection Regulation (GDPR) 2018. This means that we will responsibly store the data in a secure manner and take all necessary steps to make sure that the data remains confidential. We will only use personal data, such as your email address, for the purposes of contacting you about taking part in the study. We will anonymise the data recorded to ensure that you cannot be identified

in any resulting publication or other outputs. Access to the data recorded will be strictly limited to members of the Anthony Nolan research team only. Your personal data, such as contact information, will not be passed to any third parties.

Can you change your mind about being involved in this project after you have said "Yes"?
Yes, it is completely up to you whether you take part in the interview study. If you agree to take part, you are free to change your mind at any time without giving us a reason. If you choose to withdraw from the study during the interview we will include any recorded data up to your withdrawal in our analysis.

How can I find out about the results of the study?
Findings from the study will analysed and written up for publication in a peer-reviewed journal and presented at scientific conferences. We will share with all participants a lay summary of the results.

Who do I contact if I have a concern, or I wish to complain?
Please contact Dawn Hart, Director of Patient Services, Anthony Nolan by emailing dawn.hart@anthonynolan.org and a member of the Patient Services team will respond as soon as possible.

Who should I contact if I need additional support?
A potential risk of taking part is that you may find sharing personal details about your social circumstances and quality of life upsetting. We can assure you that the questionnaire has been designed to minimise distress and has been reviewed by Anthony Nolan patient representatives. If you are distressed or upset by the contents of the questionnaire or need support, the Anthony Nolan helpline is available on 0303 303 0303 from 9am-5pm Mon-Fri (excluding bank holidays). If you require support outside these hours, please contact your healthcare team.

Consent to participate

Please provide the following information:

- **Your name**
- **Your age**
- **Your telephone number**
- **Your home address**
- **Your email address**
- **Your ethnicity**
- **Whether you belong to any of the following groups**
    - Black or ethnic minority
    - live far away from a major treatment centre or in a rural area
    - receive benefits
    - have caring responsibilities for children or elderly parents
- **When you received your transplant**
    - Month
    - Year
- **What type of transplant you received**
    - matched related
    - matched unrelated
    - haploidentical
    - mis-matched unrelated donor
    - cord blood
- **Your diagnosis**
    - Open text

Please read the following statements carefully and place a tick in each box to acknowledge your agreement.

- I confirm that I have read and understood the participant information sheet.
- I have had the opportunity to consider the information and have been able to ask questions about the interview study and my questions have been answered to my satisfaction.
- I understand that my participation in the interview study is voluntary and that am free to withdraw at any time, without giving reason.
- I understand that taking part in the interview study involves Anthony Nolan sharing my personal experience of receiving a stem cell transplant and that the information that I provide will be recorded and transcribed.
- I agree to the use of anonymised quotes in research reports and publications.
- I understand that personal information collected about me that can identify me, such as my name, telephone number and email address will only be used for the purpose of this interview study and will not be shared with Third Parties beyond Anthony Nolan.
- I agree to taking part in the interview study.

Signature
Date