

INFORMATION SHEET FOR PARTICIPANTS

KCL Ethics Ref Nb - BDM/11/12-32 UK MDS



YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

UK MDS Patients – Assessing the needs for support

We would like to invite you to participate in this original research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to understand why the research is being done and what your participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Why we are conducting this survey:

The information gathered from these questionnaires will be used to develop programmes to assist patients and their families, to educate physicians, nurses, and other allied healthcare professionals.

It will also help us to work with governmental and private agencies/companies to provide better care and service to you, the Myelodysplastic Syndrome patient.

The anonymised data may be used for future publications, and shared with other researchers interested in MDS Quality of Life data. You will not be identifiable in any publications as all data will be used anonymously.

What is MDS?

Myelodysplastic Syndromes (MDS) are a group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells. MDS is also referred to as a bone marrow failure disorder. The prefix *myelo-* means marrow (from the Greek) – and *dysplasia* – meaning abnormal shape (of the blood cells). MDS is primarily a disease of the elderly – the average age at diagnosis being 74 years old. MDS can affect any or all of the types of blood cells – red blood cells, platelets and white blood cells. There are different levels of severity of MDS – ranging from low-risk, Intermediate 1, Intermediate 2 and high-risk MDS. 10% to 30% of patients will progress to acute myeloid leukaemia (AML) – depending on the level of severity of the MDS.

Who can participate?

Anyone who has been formally diagnosed with a form of Myelodysplastic Syndromes.

Do I have to take part?

Your participation is entirely voluntary. The support you receive from MDS UK Patient Support Group will not be affected, nor the treatment you receive from your hospital or GP – whether you participate or not.

What will happen if I take part?

You will receive a self-completion questionnaire of 22 pages, which we estimate will take 30 to 45 minutes to complete. You can complete the questionnaire at your own leisure and either hand in back to MDS UK staff – or post it back to the main office. A reply-paid envelope will be provided.

This questionnaire is designed to be filled in anonymously. There is no need to add your name or contact details. Should you be emailing or posting the completed questionnaire back to us, the document will be anonymised prior to the data being entered in our database.

At no point will your answers be linked back to you.

This questionnaire contains questions concerning your quality-of-life, the referral process you went through, the information you received, the knowledge that you have about MDS as a disease, and the impact that MDS treatments have on your life and the lives of those around you.

There are no right or wrong answers.

Returning a completed questionnaire will imply that you are consenting to the information contained in the questionnaire to be used anonymously by the MDS UK Patient Support Group for the purposes described above. As participation is anonymous it will not be possible for us to withdraw your data once you have returned your questionnaire.

If you do decide to take part, please let us know beforehand if you have been involved in any other study during the last year.

What are the risks?

We are only collecting information – there are no risks to you.

However, some questions do require you to think back to some aspects of your MDS condition that you may have found distressing in the past – or find distressing currently.

What are the possible benefits of participating?

The data collected will assist MDS UK PSG to improve their services to you, the MDS patient, as well as the clinical services provided to MDS patients generally.

Publications resulting from this research will be made available via the MDS PSG website and on individual request.

What about confidentiality?

You will not be identifiable in any publications arising from this research, as all data will be used anonymously.

This research survey has been reviewed and approved by the King's College Research Ethics Committee.

What about the costs?

We will provide you with a reply-paid envelope, should you wish to post your completed questionnaire back to us. You will not receive any compensation for your participation.

Contact for further information

If you have any concern about any aspect of participating, please contact:

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London SE5 9RS
Tel – 020 7733 7558
Email Mds-uk@mds-foundation.org
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If this study has harmed you in any way you can contact King's College London using the details below for further advice and information.

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