

HARMONY



We need your help to improve MDS research

What is crucial in management and treatment of Myelodysplastic Syndromes?

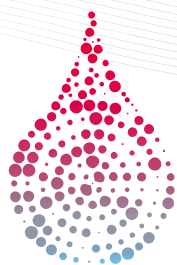


Several new treatments for Myelodysplastic Syndromes (MDS) are currently being tested in studies across the world. Only few of these studies assess the effects of the drugs on the patients' quality of life. In addition, each study uses its own measures to assess whether the treatment works. For instance, patients' survival may be described with overall survival, progression free survival, or event free survival. This makes it difficult to compare and combine the studies. So, it is difficult to draw firm conclusions about which treatments are best.

Therefore, a large European alliance of researchers and medical professionals called '**HARMONY**' is now running a so-called **Delphi study**. The study aims to identify the most important outcome measures for MDS research – they call this a '**core outcome set**'. These core outcomes should be used in future studies, so that studies can more easily be compared and combined. **We need your help** to determine which outcome measures matter most to patients with MDS and their carers.

What is a core outcome set and why do we need your help?

Visit the HARMONY Delphi survey projects webpage to find factsheets explaining Core Outcome Sets and the surveys: www.harmony-alliance.eu/delphi-projects



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Your participation is entirely voluntary. Participation means answering a series of three online surveys about what you think should be included in the core outcome set;

- Completing one survey round will take approximately 30 minutes.
- After all participants have finished the first round, we will invite you to participate in the second round. We will provide you with your own answers from the first round and an anonymized, graphical suMDSary of the other participants' answers. You can then revise your previous ranking if you wish.
- We will suMDSarize the results of the second survey round and ask you to take a third survey to foster consensus.
- Any rating you will give will be anonymized and confidential. During the study, your personal data will be stored on a secure server at the University of Liverpool. After completion of the study, all personal data will be deleted.

How does the MDS Delphi study work?

Read all about it at www.harmony-alliance.eu/delphi-projects

It will help the HARMONY project team running the study if everyone completes each round of the survey to guarantee meaningful results. However, you are free to withdraw from the project at any time. In this information leaflet, we will explain the study in more detail. We would be happy to answer any further questions you may have.

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