

HARMONY



How does the MDS Delphi study work?

What is a Delphi study?

To decide which outcomes are important, researchers need to get the opinion of various stakeholder groups, such as doctors, patients, researchers, drug developers and regulatory bodies, and try to reach agreement, or 'consensus', on the most important outcomes. One way of doing this is by using something called a 'Delphi' study. In a Delphi study, researchers first identify groups of stakeholders. In the MDS Delphi study, these are:

- people with personal experience of the disease, for example, patients, carers and service users (it doesn't matter how long the person has had the disease for, their opinion is incredibly valuable),
- healthcare professionals with expertise in treating and caring for people with MDS,
- regulators,
- members of the European Federation of Pharmaceutical industries and associations (EFPIA).

We will ask representatives of these four groups to give their opinion on what outcomes are most important. The study is anonymous to make sure everyone has an equal say.

How was this Delphi study prepared?

A project team from the [HARMONY Alliance](#) has developed a list of approximately 60 possible outcomes that they want to ask you about. They created this list after looking at research papers and interviewing healthcare professionals and patient groups. The list has been converted into an online survey. Representatives of the four stakeholder groups are invited to participate in the survey.

What will happen if you participate?

In the survey, you will be asked to score the importance of each outcome in the list. If, in your opinion, there are key outcomes missing from the list, we encourage you to add these to the list. We refer to this as '**Round 1**' of the Delphi study.

Each participant sends their ratings back to the research team, who then summarize the responses from the stakeholder group as a whole and send this summary back to you in what we refer to as '**Round 2**' of the Delphi process. At this stage, you are given a reminder of how you scored the outcome last time and the range of scores of the rest of your stakeholder group.

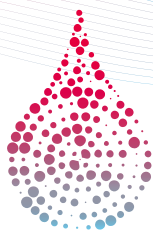
No-one in the group can see another individual's scores; they can only see the overall results for the group as a whole. Using this information, you are asked to reflect on your own view and on the view of the group and to decide whether to stick with your original rating or change it. Through the whole process, no-one is under any pressure to change their rating if they don't want to. It is perfectly fine for participants to stick with their original rating even if they rated the outcome differently to the rest of the group.

The responses of the participants are then sent back again to the research team who again collate the information. Every time the researchers ask the participants for their opinions, we call this a 'round' of the Delphi. Each time, the idea is that the participants review their previous score based on what the group rated in their last round. The MDS Delphi will consist of three rounds.

What will happen after the last survey round?

After several rounds of the survey, a final consensus meeting will take place to discuss the results and reaffirm the defined COS. You do not have to attend if you do not want to. At the end of this process, the project team will produce a report on the core outcomes for MDS. This will be made publicly available.





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Will information you provide be confidential?

Any rating you will give will be anonymized and confidential. This also applies to your personal data (name, mail address, and home country). All this data will be stored for the duration of the survey only, on a secure server provided by the DelphiManager. The DelphiManager is a web-based system designed to facilitate the building and management of Delphi surveys, provided by the COMET initiative:

www.comet-initiative.org/delphimanager.

The Delphi Process Summary

Round 1

A list of outcomes is produced by the research team and sent to each patient and health professional to score the importance of each one.

Round 2

Round 1 results are summarised and sent back to each person, together with a reminder of the person's own score for each outcome. Each person is asked to think about the group's results and decide if they want to change their score.

Further rounds

The process of seeing the results and re-scoring the outcomes can be repeated in a 3rd round.

Face to face meeting of people taking part to discuss their results.

Report produced identifying agreed outcomes of importance (core outcomes)

What is the HARMONY Alliance?

#Bigdataforbloodcancer

The MDS Delphi survey is organized by the HARMONY Alliance, a European public-private partnership for big data in hematology. HARMONY unites over 140 organizations, such as hospitals, universities, pharmaceutical companies and patient organizations. By joining forces HARMONY aims to use big data analytics to improve the treatment of blood cancers. Read more at www.harmony-alliance.eu.

HARMONY and core outcome sets

One of HARMONY's aims is to increase consistency in future studies, allowing for the results to be compared and combined. Therefore, HARMONY researchers are developing core outcome sets for several blood cancers. A pilot study was already performed for Acute Myeloid Leukemia. The experiences from this pilot were used to design the MDS Delphi study.

HARMONY and the International MDS Alliance

Among HARMONY's partners are seven European Patient Umbrella Organizations, including the International MDS Alliance. These seven organizations form the HARMONY Patient Cluster. The Patient Cluster and their patient communities are consistently involved in defining outcomes, designing Research Projects and communicating with patients.

The MDS Delphi study counts on the collaboration of the International MDS Alliance to ensure that patient preferences are properly incorporated and ethical procedures are guiding all stages of the project. The study protocol has been peer reviewed by the International MDS Alliance.

Information

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Source: COMET Initiative | Read more at www.comet-initiative.org
Check also COMET information for, and resources relevant to patients and the public, patient organisations and researchers involving patients in their core outcome set work www.comet-initiative.org/Patients