

Patients want info about quality of life after transplant

Patients can help researchers design studies



It's useful to study patients' quality of life. That's from a survey of 800 patients, health care providers, and caregivers. EBMT, the European professional group for blood and marrow transplant and cell therapy, conducted the survey.

Nearly 100% of people said that it's very **important that researchers ask patients directly about their quality of life**, especially:

- Symptoms (pain, fatigue)
- Emotions

Patients want easy ways to share

8 of 10 people preferred to take surveys **online** rather than on paper or over the phone. And 7 of 10 patients preferred to do surveys **at home**, not at the hospital.

Patients can help plan studies

Almost everyone (9 of 10 people) said it's very important to invite patients to help design studies. The top 2 reasons were:

- To make sure research helps patients in practical ways
- To focus on what matters to most patients

After a study is done, doctors should share the results with patients who helped in that study.

Reporting patients' experiences in the US

In the US, the Center for International Blood and Marrow Transplant Research (CIBMTR) surveys patients about their experiences—called patient-reported outcomes. Their research showed that patient-reported

outcomes can help predict patients' health. Patients' quality of life is just as important to measure as lab values.

Learn more about

- [Your data may save lives](#) at CIBMTR.org
- [Survivorship](#) at NMDP.org
- [Patient-reported outcomes](#) at CIBMTR.org
- More [study summaries](#) at CIBMTR.org

Source

Schoemans H, Burns LJ, Liptrott SJ, et al. [Patient engagement in hematopoietic stem cell transplantation and cell therapy: a survey by the EBMT patient engagement task force & transplantation complications working party](#). Bone Marrow Transplantation. 2024. Epub 2024/06/19. PMC11371514. doi: 10.1038/s41409-024-02290-7.

About this research summary

This information is provided on behalf of the Consumer Advocacy Committee of CIBMTR® (Center for International Blood and Marrow Transplant Research®). CIBMTR is a research collaboration between the Medical College of Wisconsin and NMDP.

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