

## Researchers should ask patients to help plan studies

### Patients and caregivers have useful advice

Scientists at the Blood and Marrow Transplant Clinical Trials Network (BMT CTN) wanted to help patients from all racial and income groups. They wanted to know how to reach more patients interested in clinical research. They created a group that included patients, caregivers and researchers.

The group said researchers should ask for patients' help in 4 parts of research:

- Choosing what to study
- Creating easy-to-read consent forms
- Talking with grassroots groups of patients
- Telling patients about results

One way researchers can reach patients is through grassroots groups such as BMTInfoNet, the Leukemia and Lymphoma Society and sickle cell disease groups.

Researchers should ask groups and patients about what to study. Some researchers overlook things that patients are interested in, such as long-term quality of life and side effects, including tiredness (fatigue), rapid aging, and unusual weight gain.

The group also said patients could help with informed consent forms. These legal forms explain the possible harms and benefits of a study. The forms often are very long and hard to understand. Patients prefer forms that are fewer than 5 pages and also want read-aloud or video versions.

Patients also asked researchers to share info more often: before, during and after a study. They want information written in plain language, not jargon, and also like videos. They also want public, online access to study procedures and forms.

Finally, patients want researchers to tell grassroots groups about studies that are coming up, as well as results of studies.

### What's next

The BMT CTN started a patient and caregiver advocacy committee to take action.

### Learn more about

- [Understand clinical trials](#) at BeTheMatch.org
- [Find a clinical trial](#) at CTsearchsupport.org
- [Read study summaries](#) at CIBMTR.org

*This plain-language summary (PLS) was written by Jennifer Motl at Medical College of Wisconsin and reviewed by an author of the full article. © 2023 by CIBMTR, license [CC BY-SA 4.0](#).*



### Source

Vasu S, Holtan SG, Shimamura A, et al. [Bringing Patient and Caregivers Voices to the Clinical Trial Chorus: A Report From the BMT CTN Patient and Caregiver Advocacy Task Force.](#) *Transplantation and Cellular Therapy.* 2023 Jan;29(1):5-9. Epub 2022 Oct 23. PMC10008748. doi:10.1016/j.jtct.2022.10.016.

### About this research summary

The Blood and Marrow Transplant Clinical Trials Network (BMT CTN) is a collaboration of the Center for International Blood and Marrow Transplant Research® (CIBMTR®); The Medical College of Wisconsin; The National Marrow Donor Program® / Be The Match®; and The Emmes Company®.



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