

## CIBMTR surveys patients' feelings and their quality of life

A patient-reported outcome (PRO) is any report of a patient's health condition that comes directly from the patient, without interpretation by a doctor or anyone else. PROs help doctors understand research about survival and quality of life.

In late 2020, the Center for International Blood and Marrow Transplant Research (CIBMTR) started sending surveys to patients about how patients feel physically, emotionally, and socially.

By late 2023, nearly 1,000 patients had filled out a PRO survey. Everyone who received surveys was an adult and was treated in the US at 25 medical centers. Patients answered surveys about how they felt before and after blood or marrow transplant (BMT) or chimeric antigen receptor T cell therapy (CAR-T).

Patients had a variety of blood problems, in order of most to least:

- multiple myeloma or plasma cell disorders,
- leukemia,
- lymphoma,
- myelodysplastic syndromes,
- and others.

One example of what PROs can help us understand is how patients' functioning may change over time. These surveys showed **that before BMT and CAR-T, people were mildly impaired physically.** This is expected due to illness and side effects of treatments. But **1 year later, people on average said they were the same or even better than before treatment and were functioning as well as average Americans.**

### Keep in mind

Although BMT & CAR-T can cure blood cancers, they also can have serious effects. Some of these effects are hard for doctors to measure with lab tests. Talk with your doctor about how you feel physically, emotionally, socially, financially, and more.

### What's next

CIBMTR continues to collect PROs in English and Spanish.



### Learn more about

- [One-on-one guidance](#) at NMDP.org
- [Summary of patient-reported outcomes](#) at CIBMTR.org
- [PRO data collection](#) at CIBMTR.org
- [More study summaries](#) at CIBMTR.org

### Source

Cusatis R, Litovich C, Feng Z, et al. [Current Trends and Outcomes in Cellular Therapy Activity in the United States, Including Prospective Patient-Reported Outcomes Data Collection in the Center for International Blood and Marrow Transplant Research Registry.](#) *Transplantation and Cellular Therapy.* 2024;30(9):917.e911-917.e912. Epub 2024 June 27. PMID: 38944153.

### About this research summary

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

