Building a Novel and Flexible Electronic Patient-Reported Outcome Collection System for Cellular Therapy Research

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About Us

The National Marrow Donor Program® (NMDP)/Be The Match® saves lives through cellular therapy. We maintain the Be The Match Registry of volunteer marrow and stem cell donors, and help patients get the life-saving cellular therapies they need.

The Center for International Blood and Marrow Transplant Research (CIBMTR®) is a research collaboration between NMDP and the Medical College of Wisconsin. We maintain an outcomes registry and conduct and support clinical research related to hematopoietic stem cell transplant and other cellular therapies.

www.cibmtr.org | https://bethematch.org
NMDP and CIBMTR Research

• Research is focused on outcomes from hematopoietic stem cell transplant and other cellular therapies
  – Stem Cell Transplant Outcomes Database
  – Observational research, Prospective clinical trials, Long term follow-up
  – Small to large multi-site trials. Sponsored by federal, foundation, hospital grants, internal program dollars. Close partnerships between CIBMTR and Site PIs
  – Health services research, Legislative research, Market research, Program evaluation

• Research includes everyone involved in stem cell transplant and other cellular therapies
  – Recipients, caregivers/family, donors, Be The Match Registry members, physicians
Historically, QoL/PRO only included if in specific aims of a study. In 2017 CIBMTR established need for PRO data to become core element to research

- Pre-transplant PRO are predictors of survival and post-transplant QoL
- PRO are outcomes that are most important to patients and caregivers
- Support long term follow-up requirements for cellular therapies

Developed electronic PRO system for efficient, centralized PRO collection

- Secure, flexible, interconnected with existing systems and processes
ePRO Data Collection System - components

CIBMTR has integrated several applications into the ePRO data collection system

- **Qualtrics**
  - Online surveys
  - Patient Interface

- **HealthMeasures/PROMIS**
  - Core PRO measures in our research
  - AssessmentCenter API, Integrated with Qualtrics

- **Salesforce**
  - Customer Relationship Management system for tracking studies, participants, contact activities

- **Research Database**
  - PRO data stored alongside clinical data from multiple sources

- **FormsNet**
  - Proprietary software for collecting clinical data from centers
  - Interface for center submission of clinical and contact info forms
AssessmentCenter API/Qualtrics Integration

1. Patient opens unique link to Pre-PROMIS survey and sees instructions and some initial questions
2. Patient is redirected to PROMIS Survey
3-4. Qualtrics calls AssessmentCenter API to get first question of first assigned domain. When patient answers question, data sent back to API to generate initial score and select next question. Qualtrics and API continue calls until domain is completed, and to deliver each assigned domain.
5. Patient finishes last PROMIS domain, are redirected back to Pre-PROMIS survey, answers remaining non-PROMIS questions and submits survey. Scores and raw data stored in Qualtrics.

* Seamless survey experience for patients
Assessment Center API Survey “Shell”

Qualtrics survey for AssessmentCenter API integration

- “Shell” questions that have space to pipe in question and response text.
- Each question has up to 15 responses
- Shell survey accommodates up to 40 questions (to support longer Profile instruments)
- Java script integrates with contact/participant data. Maintains participant’s session of a HealthMeasures survey in progress
  - Populates question and response text from API
Qualtrics Contact record

- External Data Reference tracks session of HealthMeasures/Qualtrics calls
- Embedded Data
  - Assessments assigns PROMIS measures to patient
  - Salesforce IDs support study participation tracking
  - Other data get included in PRO data set
Patient Experience

Transplant Quality of Life Study

Does your health now limit you in doing yard work like raking leaves, weeding, or pushing a lawn mower?

- Cannot do
- Quite a lot
- Somewhat
- Very little
- Not at all

In the past 7 days, I felt hopeless

- Never
- Rarely
- Sometimes
- Often
- Always

Contact the research study team at: transplantQoLstudy@nmdp.org | 888-298-6711
Deborah Mattila has been Supervisor of the CIBMTR Survey Research Group since 2013. She led design and development of the CIBMTR ePRO system, represents PRO in protocol teams, and leads the PRO data collection team.

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Andrew Westin has been with CIBMTR-IT as a Support Analyst and currently a Systems Administrator since 2012. He helped build the CIBMTR ePRO system infrastructure and currently maintains it from a systems standpoint.

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