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

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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

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ePRO System Development

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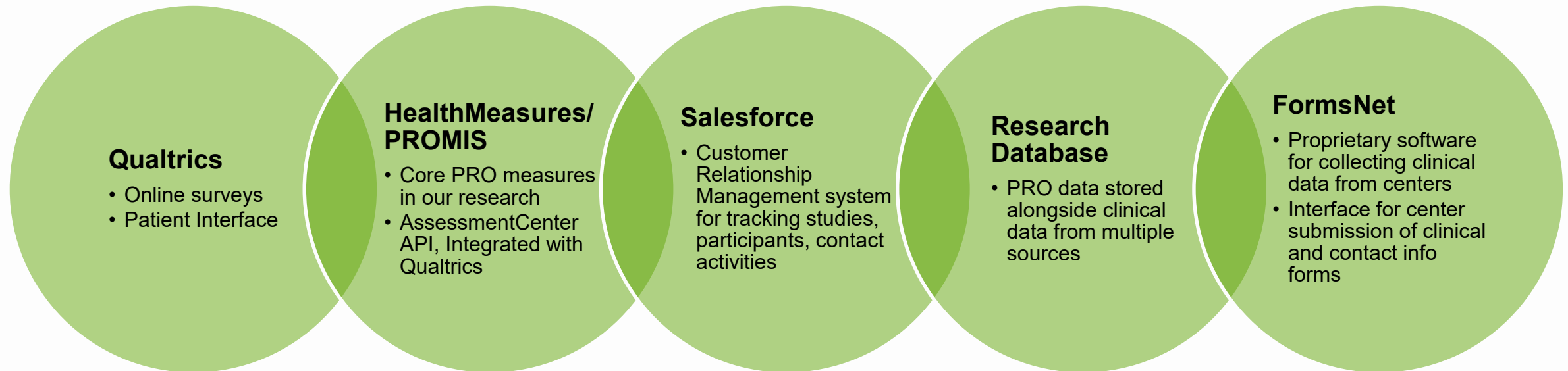
- Pre-transplant PRO are predictors of survival and post-transplant QoL
- PRO are outcomes that are most important to patients and caregivers
- Support long term follow-up requirements for cellular therapies

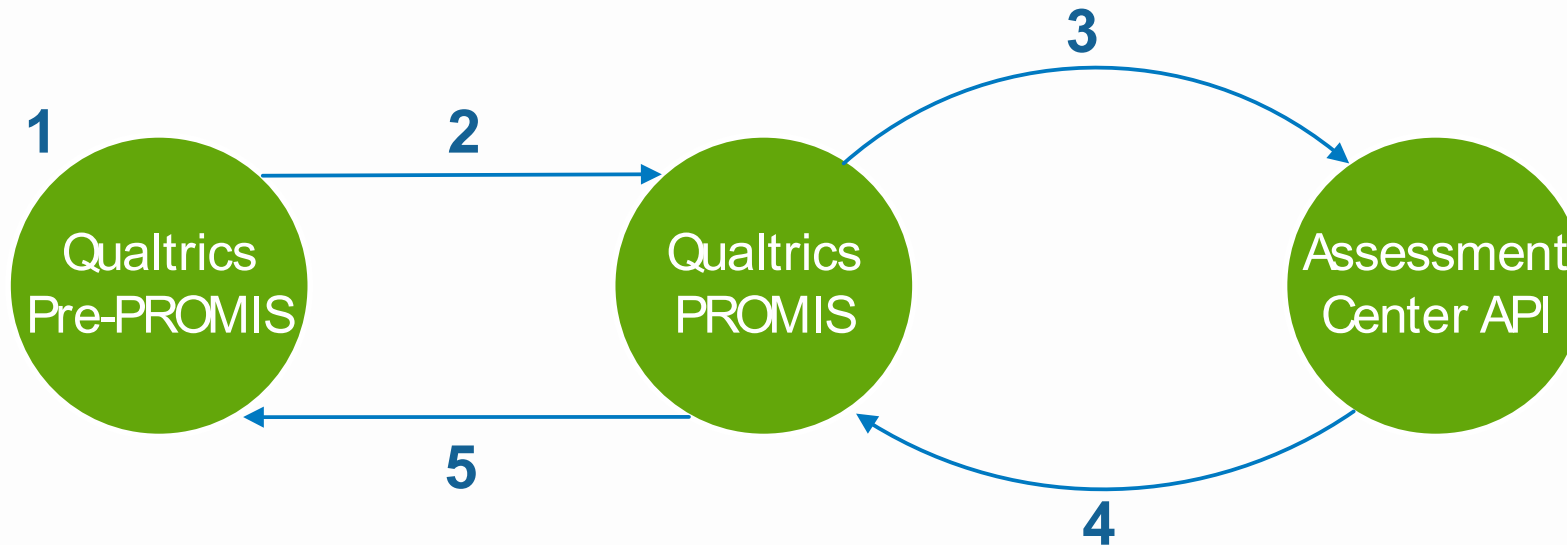Developed electronic PRO system for efficient, centralized PRO collection

- 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

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Qualtrics Pre-PROMIS → Qualtrics PROMIS → Assessment Center API

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* Seamless survey experience for patients

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.

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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

Edit Contact - Deborah Mattila

First Name
Deborah

Email
dmattila@nmdp.org

Last Name
Mattila

External Data Reference
UID002

Language
Language...

Subscription Status
☐ Opted Out

Recipient ID
MLRP_cVkcAX1wk4wdr0x

Add embedded data for this contact in the box below. Enter one field and its associated value per line and ensure the field name does not contain spaces.

Add Embedded Data

sfId, [ID for Salesforce study subject record]
tpId, [ID for Salesforce study time point record]
Assessments, PhysFuncEngAd|DepressionEngAd
Study ID, 9999999
Study site, 1234
Transplant Date, 2019-01-10 00:00:00
Study Consent Signature Date, 2019-05-10 00:00:00

Close   Save

Patient Experience

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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