The Future on FHIR - CIBMTR Reporting APP

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The CIBMTR[®] (Center for International Blood and Marrow Transplant Research[®]) is a research collaboration between the National Marrow Donor Program[®] (NMDP)/Be The Match[®] and the Medical College of Wisconsin (MCW).

Overview

- Who we are and what we do.
- Outline the current data collection and its challenges.
- Introduce HL7 FHIR Resources.
- The CIBMTR Reporting App for Epic using FHIR.
- Where we are headed next.





Our mission: We save lives through cellular therapy



What we do?

- For those suffering from a blood cancer like leukemia or lymphoma or those suffering from a blood disease like sickle cell anemia **a cure exists**. Most of these patients are in need of a blood stem cell transplant from either a related or unrelated donor. For those who do not have a match in their family they turn to Be The Match.
- Be The Match operates the world's largest and most diverse volunteer donor registry
- Be The Match facilitates transplants by 3 different types of cell sources
 - Marrow
 - Peripheral Blood Stem Cells (most common)
 - Umbilical Cord Blood
- Since 1987 BTM has helped facilitate more than 97,000 transplant
- In 2019 we facilitated nearly 6,600 transplants





Our Network



NMDP/Be The Match

Established outcomes registry and research repository in 1986 CIBMIR CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

Medical College of Wisconsin

Established outcomes registry in 1972; NIH funded since 1985

The CIBMTR is a research collaboration between **NMDP/Be The Match** and the **Medical College of Wisconsin**



Research

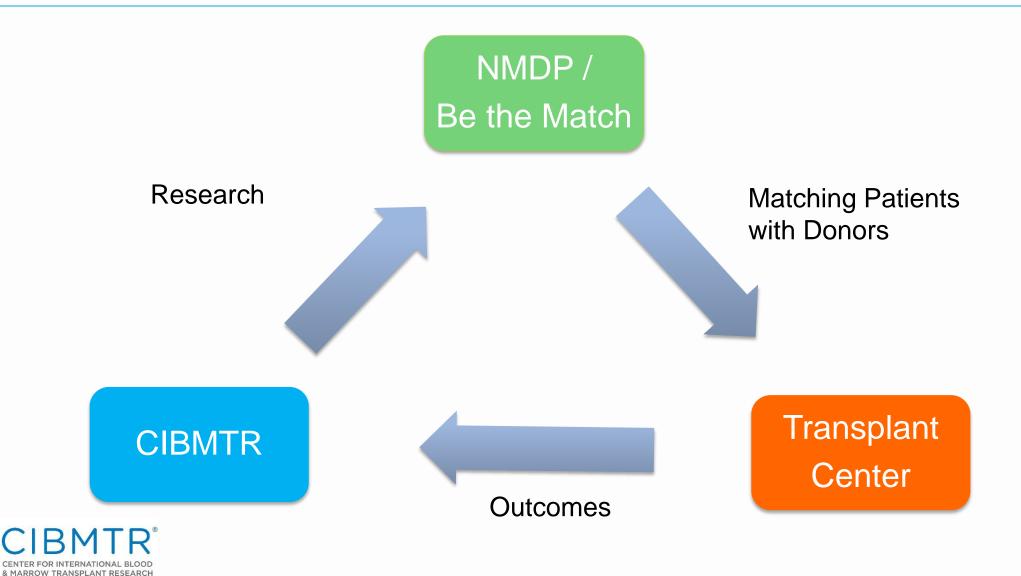
RESEARCH STUDIES IN PROCESS

We conduct research through our research program, CIBMTR® (Center for International Blood and Marrow Transplant Research®), in collaboration with the Medical College of Wisconsin (MCW). Our research leads to more lives saved and an enriched quality of life for thousands of patients.





Research Data Flow



Numbers of Patients Reported by Year

	Transplant Essential Data (TED)	Comprehensive Report Forms (CRF only)	Cellular Therapy Transplant Essential Data (CTED)
TOTAL	69,232	15,099	2,474
2016	24,282	5,464	587
2017	25,340	5,089	1,072
2018*	19,610	4,546	815



*Patients continue to be registered for 2018; Data are incomplete

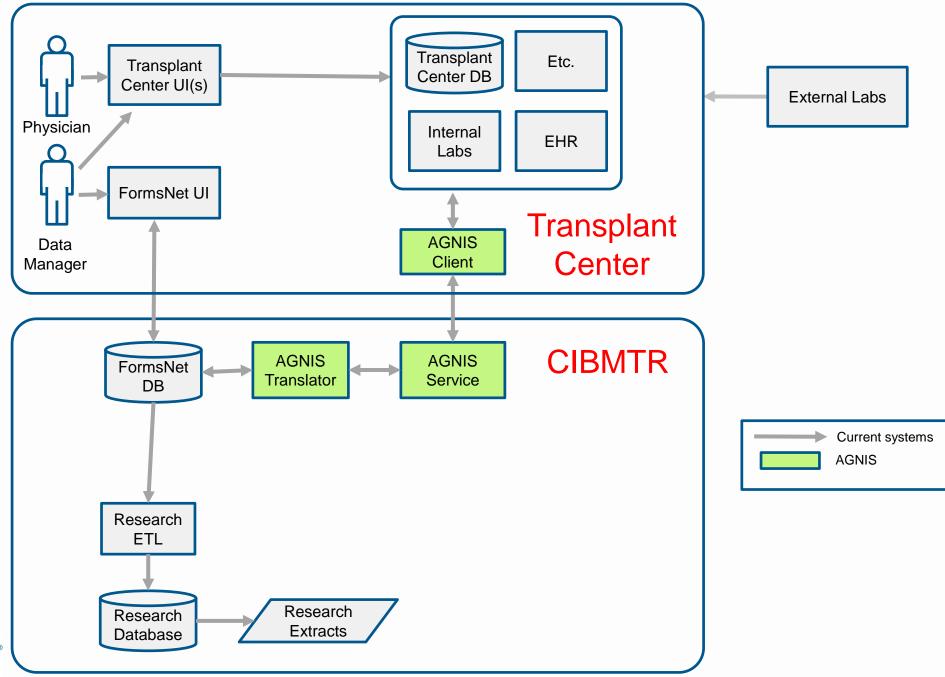
Completed Forms 2017-2019*

All Sections

	2017	2018	2019
Center Type	Count of Forms	Count of Forms	Count of Forms
Apheresis Centers	3047	3250	1926
Collection Centers	1035	964	458
Donor Centers	77303	78747	52325
Transplant Centers	297871	317653	214299
Grand Total	379256	400614	269008



High Level Overview



The Problem We Are Trying To Solve

- Data Managers are not medical experts but have to interpret the data
- Data is often found in federated systems
 - Transplant centers store the same data in different systems and formats
 - EHR, transplant databases, Lab systems
- We expect more and more complex data, e.g. molecular sequences.
- Mapping burden mapping center data points to CIBMTR forms for electronic data submission is time consuming.
- Form Revisions Forms are frequently changing to keep up with science



How Do We Attack This Problem

- Use of widely accepted health care standards for exchanging data
- Standards that are supported by existing healthcare applications, e.g.: EHRs
- Collect data that are mapped to establish healthcare standards, LOINC, SNOMED, caDSR
- We don't want to reinvent the wheel



Health Care Related Standards

BIV

CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

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Type of Standard	Description	Examples
Terminologies and Ontologies	Definitions concepts and their relationships; Used to construct data elements and value sets	SNOMED, LOINC, RxNORM, MedDRA, NCI Thesaurus
Data Elements (variables)	Detailed description of how a data point should be captured including: definition, data type, max length, allowed values	caDSR, ISO 11179, CDISC CDASH, CDISC SDTM
Data Models	Organize data elements based on defined domains such as Patient, Labs, Treatment; Similar to database structure	BRIDG, OMOP (OHDSI), Sentinel, i2b2, PCORNet, FHIR Profiles
Collections of Data Elements	Collection of data elements for a specific purpose; Include data elements from multiple domains; Frequently used to represent the minimum info needed for a purpose	US Core, mCODE, Registries on FHIR , FHIR IGs
CIRMTD		

HL7 FHIR and Resource Examples



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Health Level 7 International

- Non-profit, ANSI-accredited healthcare Standards Developing Organization (SDO)
- "HL7 provides standards for interoperability that improve care delivery, optimize workflow, reduce ambiguity and enhance knowledge transfer among all of our stakeholders, including healthcare providers, government agencies, the vendor community, fellow SDOs and patients"



HL7 asked a question...

What would healthcare exchange look like if we started from scratch using modern approaches?





- Newest standard
- FREE!
- History
 - 2011 Proposed
 - 2012 First version
 - 2017 Standard for Trial Use 3
 - 2018 Release 4
 - Normative
- Aligns with REST services
 - XML, JSON

- Active Testing
 - Three Connectathons a year
 - 22nd in Sep 2019 (7+ yrs)
- Immense interest
 - Argonaut
 - vendor initiated project
 - Epic, Cerner, MEDITECH, Athena, McKesson, Mayo, Intermountain, Partners, etc.
 - ONC
 - Sync For Science
 - Sync For Genes
 - ASCO workshops



Federal Government Rules for Consumer Access

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ONC Information-Blocking Rule

- Establishes that data sharing among providers, patients, and health plans can only be prevented in excepted cases
- · Defines information-blocking exceptions
- Establishes that FHIR APIs are the mechanism for such exchange
- Expands the information that must minimally be shared (USCDI)
- Regulates API pricing
- · Sets fines on providers and vendors for violations

CMS Interoperability Rule

- Requires gov't associated health plans to make available to patients FHIR-based APIs
- · Strongly encourages private plans to do the same
- Allows patients to permit access to 3rd parties, such as providers
- Allows patients to direct that plans share their data in event of plan change
- Requires that Medicare Advantage plans participate in "trusted exchange networks"

ONC Trusted Exchange Framework Rule

- Establishes a national governance and policy framework for clinical data-sharing networks
- Establishes an organization to set and enforce policies

Source:



HL7[®] FHIR[®] is used by... Project Argonaut

"The purpose of the Argonaut Project is to rapidly develop a first generation FHIR-based API and Core Data Services specification to enable expanded information sharing for electronic health records and other health information technology based on Internet standards and architectural patterns and styles."

http://www.healthcareitnews.com/news/epic-cerner-others-join-hl7-project

HL7

Epic, Cerner, others join HL7 project

Top vendors and providers join forces to spur standardsbased interoperability

By Mike Miliard | December 05, 2014 | 11:17 AM





Health Level Seven International has launched the Argonaut Project – a collaborative comprising healthcare heavy-hitters such as Epic, Cerner, MEDITECH, Mayo Clinic, Intermountain and Partners HealthCare – to speed the development and adoption of HL7's standards framework, FHIR.

As it works to spread FHIR – it's pronounced "fire," and stands for Fast Healthcare Interoperability Resources – HL7's Argonaut Project touts the participation of blue chip EHR developers, health systems and research groups, including:

[See also: Interoperability is 'impossible in the abstract']

- athenahealth
- Beth Israel Deaconess Medical Center
- Cerner
- Epic
- Intermountain Healthcare
- Mayo Clinic
- MEDITECH
- McKesson
- Partners HealthCare System
- SMART at the Boston Children's Hospital Informatics Program
- The Advisory Board Company

FHIR is billed as a next-generation framework that makes use of the latest Web-based standards, with a focus on putting them to work in healthcare interoperability. HL7



So... what exactly is FHIR?



Resources

- "Resources" are:
 - The "R" in "FHIR"
 - Small logically discrete units of exchange
 - Defined behaviour and meaning
 - Known identity / location
 - Smallest unit of transaction
 - "of interest" to healthcare





What's a Resource?

Examples

- Administrative
 - Patient, Practitioner, Organization, Location, Coverage, Invoice
- Clinical Concepts
 - Allergy, Condition, Family History, Care Plan, Observation, Specimen, DiagnosticReport
- Infrastructure
 - Document, Message, Profile, Conformance

Non-examples

- Gender
 - Too small
- Electronic Health Record
 Too big
- Blood Pressure
 - Too specific
- Intervention
 - Too broad





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http://hl7.org/implement/standards/fhir/resourcelist.html

8.1.2 Resource Content

ructure	UML	XML	JS	ON	Turtle	R3 Diff	All	
tructure								
lame			Flags	Card.	Type		Description & Constraints	
Patient			N	Gurui	DomainRe	source	Information about an individual or animal receiving health care services	
- () identi	fier		Σ	0*	Identifier		Elements defined in Ancestors: id, meta, implicitRules, language, text, contained, extension, modifierExte An identifier for this patient	ision
- active			<u>?!</u> Σ	01	boolean		Whether this patient's record is in active use	
🇊 name			Σ	0*	HumanNa	me	A name associated with the patient	
🅥 teleco	m		Σ	0*	ContactPo	int	A contact detail for the individual	
💷 gende	er		Σ	01	code		male female other unknown	
💴 birth[ate		Σ	01	date		AdministrativeGender (Required) The date of birth for the individual	
-@ decea			2 ?!Σ	01	dute		Indicates if the individual is deceased or not	
T	ceasedBool	ean			boolean			
	ceasedDate				dateTime			
- 🗊 addre			Σ	0*	Address		An address for the individual	
🕥 marit				01	Codeable	Concept	Marital (civil) status of a patient	
	pleBirth[x]			01			Marital Status Codes (Extensible) Whether patient is part of a multiple birth	
T	ItipleBirthE	Boolean			boolean			
	IltipleBirthI				integer			
🕥 photo		5		0*	Attachme	nt	Image of the patient	
- 🚞 conta	ct		I	0*	Backbone	Element	A contact party (e.g. guardian, partner, friend) for the patient	
- 🇊 rel	ationship			0*	Codeable	Concept	+ SHALL at least contain a contact's details or a reference to an organization The kind of relationship	
🍅 na	me			01	HumanNa	me	v2 Contact Role (Extensible) A name associated with the contact person	
- () tel				0*	ContactPo		A contact detail for the person	
🕥 ad				01	Address		Address for the contact person	
💷 ge				01	code		male female other unknown	
			_				AdministrativeGender (Required)	
	anization		I	01		(Organization		
🏐 ре				01	Period		The period during which this contact person or organization is valid to be contacted relating to this patient	
T	unication			0*	Backbone		A language which may be used to communicate with the patient about his or her health	
	guage			11	Codeable	loncept	The language which can be used to communicate with the patient about his or her health Common Languages (Extensible but limited to All Languages)	
pre				01	boolean	(O)	Language preference indicator	
- 🔄 gener	alPractition	er		0*	Reference Practitio Practitione	ner	n Patient's nominated primary care provider	
- 🖪 mana	gingOrgani	zation	Σ	01			on) Organization that is the custodian of the patient record	
🔤 link			?!Σ	0*	Backbone	Element	Link to another patient resource that concerns the same actual person	
- 🗗 otl	ner		Σ	11	Reference RelatedPe	•	The other patient or related person resource that the link refers to	
- 💳 typ	e		Σ	11	code		replaced-by replaces refer seealso - type of link LinkType (Required)	

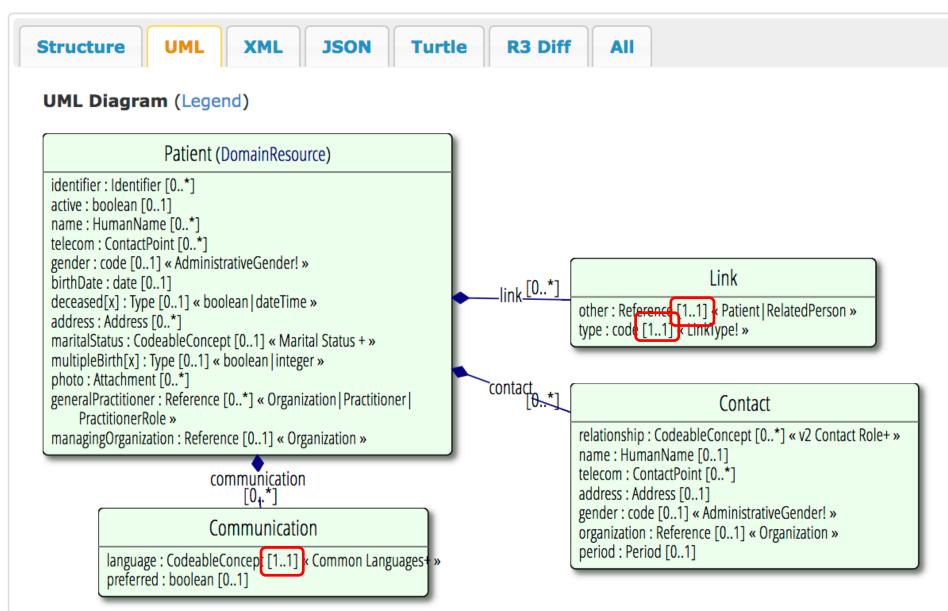
Patient Resource Structure

8.1.2 Resource Content

Patient

Resource

Structure



Simple example: Patient.xml

<Patient xmlns="http://hl7.org/fhir">

```
<name>
     <family value="Storm"/>
     <given value="John"/>
</name>
<identifier>
   <system value="http://mynamespace"/>
   <value value="123"/>
 </identifier>
<gender value="male"/>
<br/>
<birthDate value="1974-12-25"/>
```

</Patient>



The Solution : - Take advantage of EHR's FHIR API



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EHR Vendor FHIR API Capabilities

FHIR Resource	Allscripts	athenahealth	Cerner	Epic	Meditech
Patient	Read	Read, Write	Read, Write	Read, Write	Read
Provider	Read	Read	Read	Read	Read
Allergy	Read	Read	Read, Write	Read, Write	Read
Care Plan	Read	Read	Read	Read	Read
Condition	Read	Read	Read, Write	Read, Write	Read
Contract			Read		
Device	Read	Read	Read	Read	Read
Diagnostic Report	Read	Read	Read	Read	Read
Document	Read	Read	Read, Write	Read	Read
Encounter		Read	Read	Read	
Family history				Read	
Immunization	Read	Read	Read	Read	Read
Location				Read	
Medication	Read	Read	Read	Read	Read
Medication Order	Read	Read	Read	Read	Read
Observation	Read	Read	Read	Read, Write	Read
Person			Read		
Procedure	Read	Read	Read	Read	Read
ProcedureRequest			Read		
RelatedPerson			Read		
Schedule			Read, Write	Read, Write	



Current State

Data transmission protocols between Transplant Centers (TCs) and CIBMTR has not kept pace with the changing technological landscape of healthcare informatics.

- GOAL: a production-ready solution for electronic submission of patient data to CIBMTR.
 - Includes patient demographics and Graft Versus Host Disease (GVHD) information.
- Majority of TCs use the EPIC EHR software product.
 - Leverage the EPIC supported "App Orchard" functionality to integrate with the EPIC system.
- EPIC App Orchard enables third party partners to create "add-on" applications that integrate with the EPIC EHR product.
 - Authorized third party apps can access authorized patient data in their EHR via FHIR specification.
- **CIBMTR Reporting App**, after installation an authorized TC user can leverage the App to **electronically submit patient data** to CIBMTR via the industry standard **FHIR** format.



CIBMTR Reporting App

- A new messaging interface using healthcare informatics standards (HL7 FHIR) that embraces modern approaches to data exchange.
- Reduces data submission burden for centers by introducing greater interoperability between CIBMTR and transplant center EHR solutions & HLA Laboratory systems.
- 2019 Expanding Proof of Concept Application to:
 - Exchange patient demographic and assign unique CRID
 - Exchange aGVHD (Acute Graft Versus Host Disease) data
 - Exchange recipient HLA typing



OpenEpic & FHIR

- Founding member of Argonaut Project
- Integral FHIR Server in all current installations

EXPLORE . INTEROPERATE . MY APPS .	CONTACT . LOG IN
FHIR®, or Fast Healthcare Interoperability Resources, provides a lighter access layer for standard HL7-defined data models.	Weight REST-based
Patient + Provider	explore the spec \rightarrow
This basic FHIR service covers data about persons (or, technically, ar despite all our jokes about cows, we aren't really pursuing) receiving	
related services. It focuses on the demographic information necessar	y to support
administrative, infancial, or logistic purposes.	
AlergyIntolerance	explore the spec \rightarrow
The AllergyIntolerance data models describe a patient's intolerance to	o a foreign substance
and an associated reaction that occurs from exposure.	
Medication + MedicationOrder + MedicationStatement	explore the spec \rightarrow
The Medication, MedicationOrder and MedicationStatement data mo model a patient's reported and prescribed medication orders and ins	
Condition	explore the spec \rightarrow
Conditions can encompass acute and chronic problems and condition encounter diagnoses.	ns, as well as
Observation	explore the spec \rightarrow
	 FHIR®, or Fast Healthcare Interoperability Resources, provides a light access layer for standard HL7-defined data models. <u>Patient + Provider</u> This basic FHIR service covers data about persons (or, technically, ar despite all our jokes about cows, we aren't really pursuing) receiving related services. It focuses on the demographic information necessar administrative, financial, or logistic purposes. <u>AlergyIntolerance</u> The AllergyIntolerance data models describe a patient's intolerance to and an associated reaction that occurs from exposure. <u>Medication + MedicationOrder + MedicationStatement</u> data moment of a patient's reported and prescribed medication orders and institutions can encompass acute and chronic problems and condition encounter diagnoses.

https://open.epic.com/Interface/FHIR



Epic App Orchard

- Identify mappings of CIBMTR patient data to FHIR resource
- Using these mappings, develop a free Epic App for transplant centers to collect Patient demographic data to report to CIBMTR
- Mappings are public, and may be applied to other EHRs



Healthcare is better together.

The App Orchard is where developers can learn about Epic's APIs and list their apps for Epic community members to explore and access.

Marketplace for apps

Access a marketplace of apps for reporting, visualizations, content, and more.

Access to hundreds of APIs

Get documentation for Epic's APIs, including examples and a testing sandbox.

Opportunities to collaborate

Attend conferences with others working on the Epic platform.

Support from Epic developers

Our team will be there to lend a hand if you get stuck.

Interested?

Sign up to learn more about what you can do with the App Orchard including available APIs and other services.

Login 🗸

Learn More

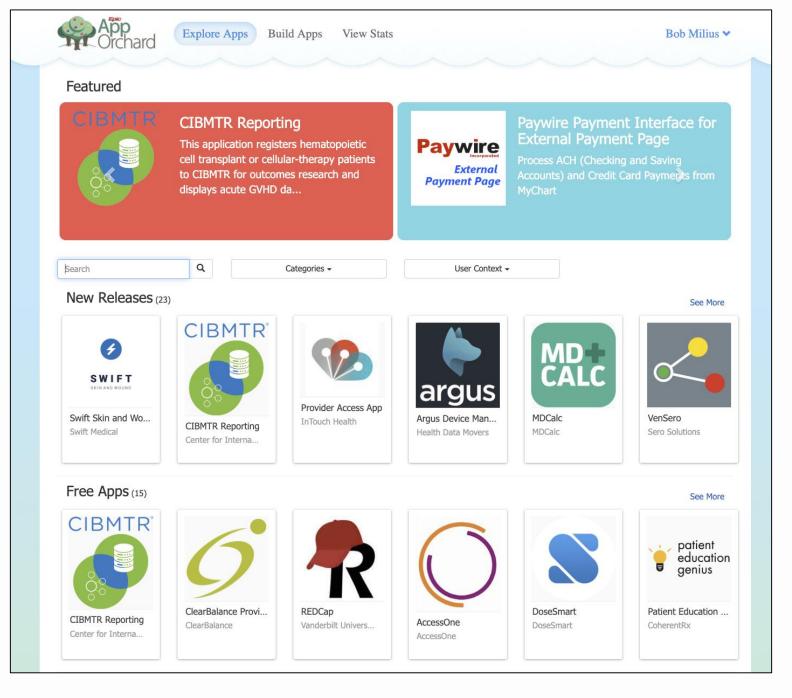
Announcements

August 2017: Registration for the App Orchard Conference is now open. Follow the link to register.

July 2017: The App Orchard now supports Kit, your way to work with

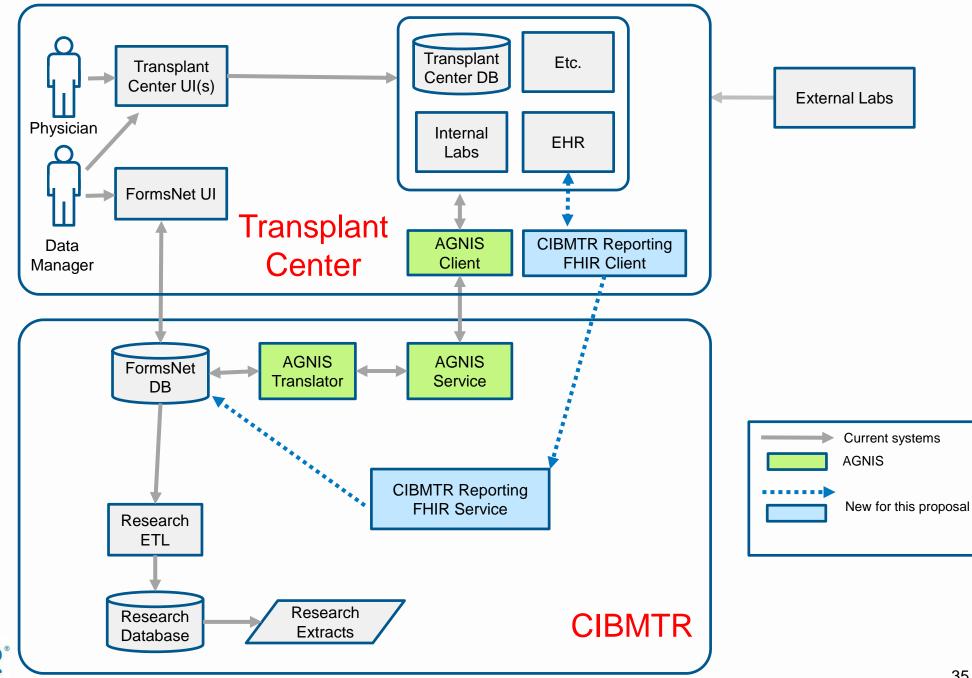
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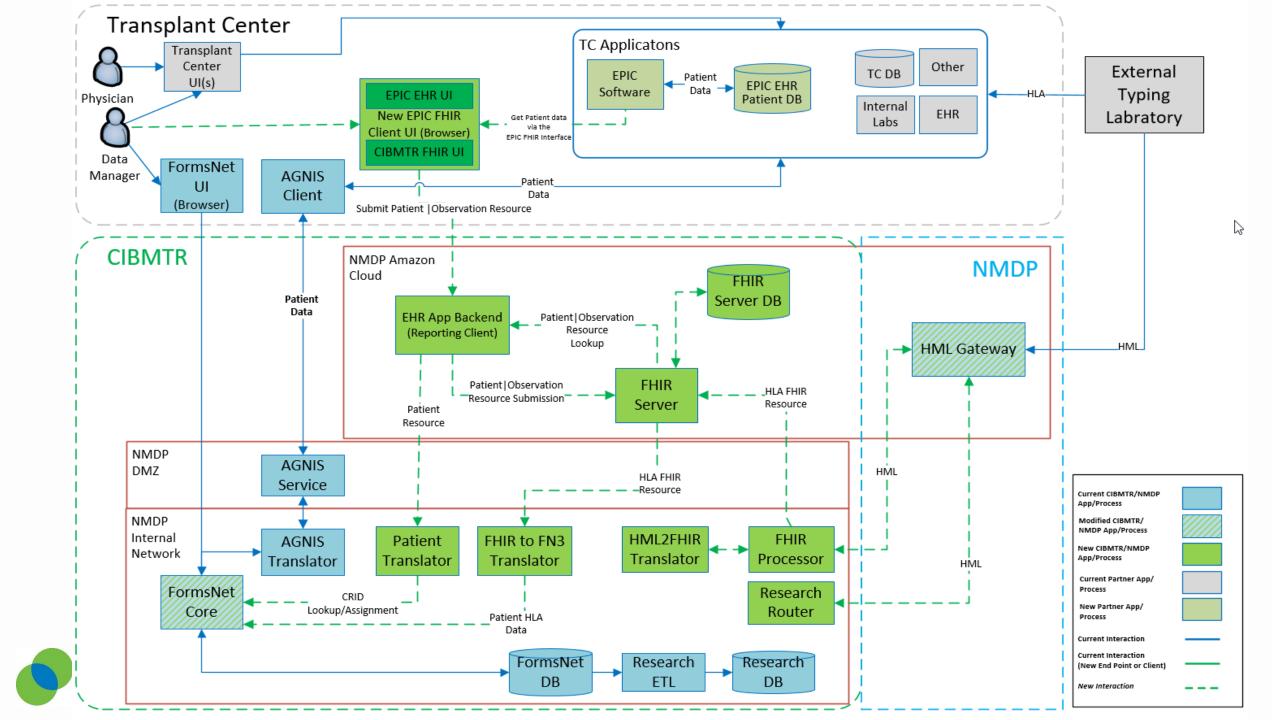






High Level **Overview**





Key Components

Component	Description
CIBMTR Reporting App (Browser-based)	EPIC compliant App to access the EHR patient data via the FHIR interface. Submits Patient Data to the CIBMTR hosted EHR App Backend server.
CIBMTR EHR App Backend server	EHR App Backend server accepts submission requests from the Browser-based Epic FHIR Client, validates user credentials and performs fine-grained authorization.
FHIR Server	Industry standard FHIR server for staging of patient demographic and GVHD data. Supports the transfer of FHIR resources from Epic's FHIR interface to the CIBMTR's FHIR API.
Patient Translator	Service to accept Patient information and make calls to FN3 Core application to determine if patient and exists or if they need to be registered as a new patient.
FHIR to FN3 Translator	Component that monitors the FHIR Server newly submitted FHIR Resource. converts FHIR resources to FN3 Objects and communicates to the FN3 Core Aplication.



Technology

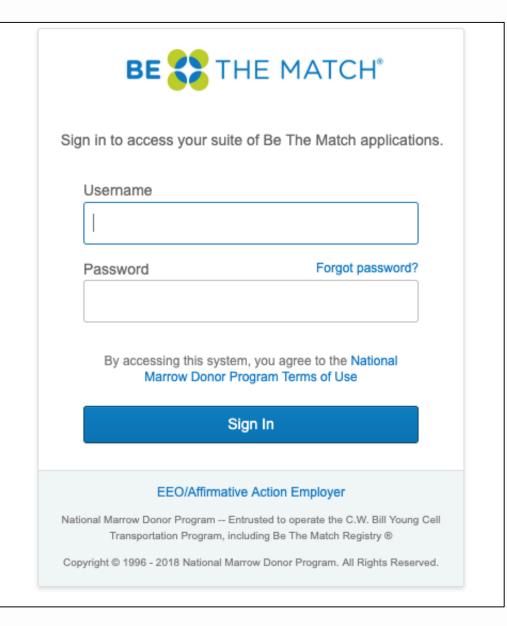
Technology	Description	Justification
Java	NMDP supported open source language. Java was selected because we believed we would be better be able to implement security features.	Used for the prototypes, so continue to leverage for the production solution.
Angular	NMDP preferred open source language for java- scripting is Angular 7 Javascript platform.	Angular 7 is the latest version of the Angular platform.
Spring Boot	NMDP preferred Microservice Standard	
MySQL	Amazon RDS MySQL, which is the Amazon database service leveraged by other existing applications.	Licensing costs are prohibitive for leveraging Oracle in AWS
Docker	Delivers a repeatable technology stack regardless of server platform.	Application Idempotence.



Security Considerations

- Reporting App obtains credentials when logging into CIBMTR identity provider.
- FHIR security labels assigned to all resources based on user credentials
- General Data Access Policy
 - Limited based on CIBMTR user credential; only see data for center that user has been granted access.
- Redaction of Patient Identifiable Information (PII) that is not needed to support application functionality.







User login to CIBMTR/NMDP. The user is required to have a FormsNet username and password.

IBMTR Lo	gout	CENTER FOR	BMT INTERNATIONAL B TRANSPLANT RESE	LOOD
	register the Patient with CIBMTR	FI 12		
	nch Context Patient FHIR Version: ST	103		
Name	Identifier	D.O.B.	Gender	CRID
		D.O.B.		CRID

Information is displayed about current patient selected in the Epic system. The CRID is displayed if the patient is already registered with CIBMTR. If not, the patient may be registered by clicking on **Register**.



CIBMTR Reporting CIBMTR Logout	CIBMTR® CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH
EHR Launch Context Patient	FHIR Version: STU3
Name Identifier	D.O.B. Gender CRID

E3940, Z6065, TaMyIWDvBh1bq0IrR4419QBAXR6NGaeGWDGkAbexWETUB, eyQ4e4Hfq5yH.4vWYwqI9PA3, Z6065, 203649,

				Register
Collections				
aGVHD Count: 93	Details			

1973-09-

21

male

3889349

The patient has been registered and the assigned CRID is shown.



Arnold

undefined

Н

MTR Reporting		Observation Details						
		Date Retrieved : 2019-07-25 17:06		Expand All		& MARROW	TRANSPLANT	RESEARCH
IR Launch Context Patient		ECOG Score	Count : 7	Show	▲ STU3	J3		
ame	Identifier	Skin Biopsy Date	Count : 1	Show		D.O.B.	Gender	CRID
rnold I	E3940, Z6065, TaMyIWDvBh undefined	Karnofsky Score	Count : 7	Show	49,	1973-09- 21	male	3889349
		Overall Grade (Przepiorka)	Count : 6	Show				
		Skin Biopsy Result	Count : 1	Show	н			Register
ollections		Skin Biopsy Result	Count : 1	Show				
aGVHD Count: 93 Details		Was therapy used to treat Graft- versus-Host Disease since last entry?	Count : 1	Show				
		Corticosteroids (Systemic)	Count : 4	Show				
		Tacrolimus	Count : 6	Show	.			
		Close		Submit to CIBMTR				

After clicking on the **Details** button, a summary of acute GVHD data is grouped by observation code. Individual observations may be displayed by clicking on **Show**. All observations may displayed by clicking on **Expand All**.

Where We Are Headed

- Increase transplant center adoption of reporting App.
- Improve user interface and user experience in the App.
- Add to the number of supported FHIR Resources.
- Developing App's for other EHRs.
- Investigate more ways of ingesting real world data.



Summary

- Who we are and what we do.
- Outlined the current data collection challenges.
- Introduced HL7 FHIR Resources.
- Creation the CIBMTR Reporting App for Epic using FHIR.
- Where we are headed next.



Questions





Appendix



The CIBMTR[®] (Center for International Blood and Marrow Transplant Research[®]) is a research collaboration between the National Marrow Donor Program[®] (NMDP)/Be The Match[®] and the Medical College of Wisconsin (MCW).