

Data Management in BMT

Sadhana Kannan
OIC, Department of Clinical Biostatistics
ACTREC, Tata Memorial Centre
skannan@actrec.gov.in



Importance of data in BMT

- Data is not just paperwork or documentation. It is patient care, quality assurance, and future science rolled into one.
- Data drives patient outcomes in BMT
 - Monitor engraftment, graft failure, GVHD, infections, relapse, and survival
 - Detect complications early through trend analysis
 - Support individualized clinical decision-making
 - Compare outcomes across conditioning regimens, donor types, and stem cell sources
- HSCT databases are the backbone of any quality transplant program to achieve desired end states as per the institutional lines of efforts.
- Data ensures quality and safety
 - Systematic data collection allows programs to:
 - Track key quality indicators (100-day mortality, non-relapse mortality, infection rates)
 - Identify deviations from standard protocols
 - Conduct audits, root-cause analyses, and continuous quality improvement (CQI)
 - Benchmark outcomes against national and international standards
 - Without high-quality data, quality assurance becomes subjective rather than evidence-based

Importance of data in BMT...

- Data enables clinical research and innovation
 - Supports retrospective and prospective studies
 - Enables real-world evidence generation
 - Helps answer clinically relevant questions where RCTs are impractical
 - Facilitates hypothesis generation for future trials
 - Many landmark BMT practices (conditioning intensity, donor selection, GVHD prophylaxis) are data-driven discoveries.
 - Registry data improves global learning
- Data management is crucial for determining trends, developing quality observational studies, and answering the questions that can't be answered otherwise to improve HSCT knowledge nationally and globally.
- If data collection is sufficiently comprehensive, outcomes findings from patient registries can be widely generalizable.

Source of Data for BMT

1. Source documents- original records where patient data is first recorded

- Patient case files/EMR
- Consent forms
- Chemotherapy and conditioning orders
- Stem cell collection records
- Transfusion charts
- GVHD assessment notes
- Lab reports (CBC, chimerism, CMV PCR)
- Discharge summaries and follow-up clinic notes

Primary data, legally valid, directly used for patient care and Gold standard for verification and Audits

Source of Data for BMT...

2. BMT Registries

- Structured databases that capture selected, standardized data elements abstracted from source documents for analysis and reporting.
- BMT practice evolves rapidly, often driven by registry-based evidence rather than large RCTs.
 - CIBMTR- **C**enter for **I**nternational **B**lood **a**nd **M**arrow **T**ransplant **R**esearch (**CIBMTR**)
 - EBMT- **E**uropean **S**ociety for **B**lood and **M**arrow **T**ransplantation
 - APBMT- **A**sia **P**acific **B**lood and **M**arrow **T**ransplantation **G**roup
 - ISBMT- **I**ndian **S**ociety for **B**lood and **M**arrow **T**ransplantation
 - National / institutional transplant registries

Secondary data source, Standardized definitions, designed for population-level analysis, benchmarking, and research

Source documents versus BMT registries

Aspect	Source documents	BMT registries
Nature	Primary data	Secondary data
Purpose	Patient care & legal record	Research, audit, benchmarking
Data entry	Real-time, clinician-generated	Abstracted by data managers
Level of detail	Very detailed	Selective and standardized
Flexibility	High	Limited to predefined fields
Accuracy	Highest (original)	Depends on abstraction quality
Modifiable	Yes (with audit trail)	Restricted
Legal validity	Yes	No
Used for	Clinical decisions	Outcomes reporting & policy decisions

Types of Data Collected: Pre-Transplant

- Patient demographics
- Diagnosis & staging (AML, ALL, Lymphoma, etc.)
- Disease risk index
- HCT-CI comorbidity scoring
- Baseline organ function (cardiac, pulmonary, renal, hepatic)
- Past treatments (chemotherapy, radiation, prior transplants)
- HLA typing (patient & donor)
- Infection status (CMV, HBV, HCV, HIV)
- CBC, LFT, RFT values
- Ejection fraction, DLCO, Creatinine clearance
- Cytogenetics & molecular markers
- Performance status (ECOG/Karnofsky)
- Psychosocial assessment

Types of Data Collected: During Transplant

- Conditioning regimen details (drug name, dose, dates)
- Stem cell collection & product characteristics
- CD34 count, volume infused
- Infusion reactions & immediate complications
- Supportive care: antimicrobials, transfusions, TPN
- Daily labs (CBC, electrolytes, renal/hepatic panel)
- Engraftment tracking (neutrophils, platelets)
- Day 0 infusion log
- Daily toxicity assessment (CTCAE)
- Transfusion details (PRBC, platelets)
- Antibiotic escalation records
- Central line issues
- ICU transfer events

Types of Data Collected: Post Transplant

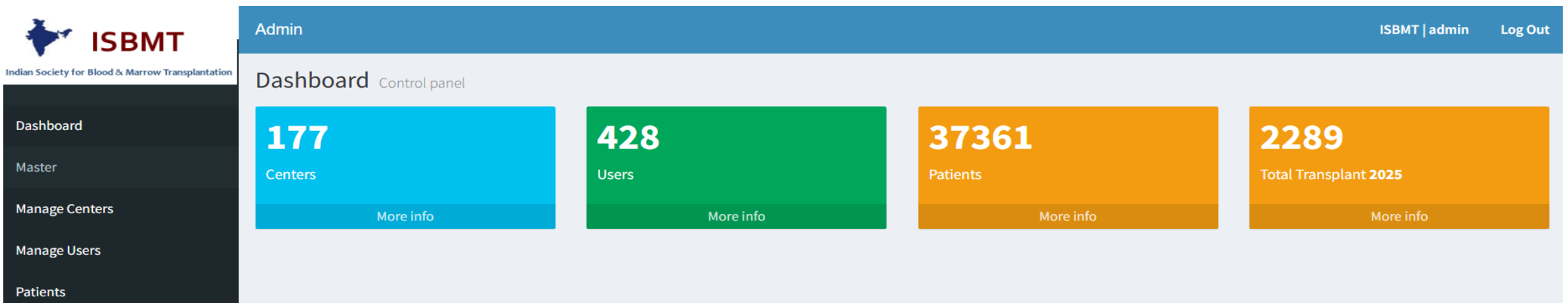
- Engraftment milestones
- Acute GVHD: onset, grade, organs
- Chronic GVHD scoring
- Infections: CMV reactivation, fungal infections
- Hospital readmissions
- Survival outcomes: OS, DFS, NRM
- Long-term follow-up (late effects, QOL)
- Day +30, +60, +100 evaluations
- CMV PCR weekly trends
- Immunosuppression tapering notes
- Pulmonary function tests
- Endocrine and fertility assessments
- Second malignancy surveillance

Tools & Platforms Used

- EMR systems
- REDCap / clinical databases
- Custom transplant registries (ISBMT)
- International registries (CIBMTR, EBMT)

Indian Society for Blood and Marrow Transplantation Registry (ISBMTR)

- Registry established in 1983, to maintain an accurate database for stem cell transplants done in India by coordinating with the various transplant centers.
- 176 units registered contributing data from 1983 till date ~37000 transplants data being captured on the registry portal
 - **Activity**
 - **Minimal Outcome Data (MOD)**
 - **Cellular Therapies Data (CART)**
- Disease specific working groups data collection is under process



Data entry in ISBMTR portal

Source Document



Excel Template

Physicians

Data Managers
Physicians



Indian Society for Blood & Marrow Transplantation

- Manage Centers
- Patients
- Data Validation
- MOD Followups
- Forms
- Export Data
- Reports
- Technical Support
- Change Password

999 - Test John Henry | johnhenry@bsoftsystem.com Log Out

New Patient

ISBMT - Activity Data

ISBMT Center No	999	APBMT Center No	999999
ISBMT UP NO * 999		Date of birth *	DD-MM-YYYY
Center UP NO		Age (Years)	Age
Date of Transplant (HSCT Date) *	DD-MM-YYYY	Sex *	<input type="radio"/> Male <input type="radio"/> Female
Country of residence of the patient:	--Select any one--	Is this First Transplant:	<input type="radio"/> Yes <input type="radio"/> No
Type of Product (Source of Stem Cell)	<input type="checkbox"/> BM <input type="checkbox"/> PB <input type="checkbox"/> CB	Diagnosis (Disease)	--Select--
APBMT Disease Classification			
Type of transplant (Type of HSCT):	<input type="radio"/> Allogeneic <input type="radio"/> Autologous		
Notes	<input type="text"/>		

Submit

Data Managers
Physicians

	Q	R	S	T	U	V	W	X	Y	Z
1										
2	IT									
3	Registry(If MUD)	Haplo only HLA-mismatched relative	HLA type	allele mismatch(Donor Mismatch details)	Type of product	Diagnosis	Status at transplant (only for AML/ALL/CML/	Cond Regimen	Cond Regimen(further details)	Engraftment(Neut phils $\geq 0.5 \times 10^9$, unsupported for 3 days)
4		1- (1 HLA antigen mismatch)	10/10, 9/10, 8/10, 5/10 etc	A, B, C, DRB, DQB, DPB- (first 4 digits of donor mismatch allele only)	BM = 1	by center	1st CR		refer sheet 2 for more details	1-Yes
5		2 - (> 2 HLA antigen mismatch)	.		PB = 2		Not in 1st CR			2-No
6					CB = 3		1st CP			3-Not known
7					BM+PB=4		Not in 1st CP			
8					BM+CB=5		Luc class-I			
9					PB+CB=6		Luc class-II			
10	If others, please specify				BM+PB+CB=7		Luc class-III			
11										
12										
13										
14										
15										
16										
17										
18										
19										

Survival Status	Date of LFU	Date of Death	Cause of Death	Received a Subsequent HSCT
Alive-0	dd/mm/yyyy	dd/mm/yyyy	RRT-1	Yes-1
Dead-1			Infection-2	No-0
Died before HSCT-2			GVHD-3	
			PD-4	
			Others-5	
			Unknown-6	

ACTIVITY FORM:

New Patient

— ISBMT - Activity Data

ISBMT Center No

APBMT Center No

ISBMT UP NO * 999

Date of birth *

Center UP NO

Age (Years)

Date of Transplant (HSCT Date) *

Sex * Male Female

Country of residence of the patient:

Is this First Transplant: Yes No

Type of Product (Source of Stem Cell) BM PB CB

Diagnosis (Disease)

APBMT Disease Classification

Type of transplant (Type of HSCT): Allogeneic Autologous

Notes

Submit

Manage Centers

Patients

Data Validation

MOD Followups

Forms

Export Data

Reports

Technical Support

Change Password

ACTIVITY FORM(Autologous):

— ISBMT - Activity Data

ISBMT Center No 999

ISBMT UP NO * 999 0277

Center UP NO 277

Date of Transplant (HSCT Date) * 02-12-2009

Country of residence of the patient: India

Type of Product (Source of Stem Cell) BM PB CB

APBMT Disease Classification PCD-Myeloma

Status at Transplant

Type of transplant (Type of HSCT): Allogeneic Autologous

Notes

APBMT Center No 999999

Date of birth * 01-01-1997

Age (Years) 12

Sex * Male Female

Is this First Transplant: Yes No

Diagnosis (Disease) Multiple myeloma

Update

MOD FORM (Autologous):

— ISBMT - Minimal Outcome Data (MOD)

Diagnosis

Status at HSCT

Date of birth

Age (Years)

Classification of diseases

Number

Sex Male Female

— Conditioning Regimen

- | | |
|--|--|
| <input type="checkbox"/> ALG, ATG (before d0) | <input type="checkbox"/> Anthracycline |
| <input type="checkbox"/> Bleomycin | <input type="checkbox"/> Busulfan |
| <input type="checkbox"/> Carboplatin | <input type="checkbox"/> Carmustine (BCNU) |
| <input type="checkbox"/> Cisplatin | <input type="checkbox"/> Corticosteroids |
| <input type="checkbox"/> Cyclophosphamide | <input type="checkbox"/> Cytarabine (Ara-C) |
| <input type="checkbox"/> Etoposide (VP16) | <input type="checkbox"/> Fludarabine |
| <input type="checkbox"/> Ifosfamide | <input type="checkbox"/> Imatinib mesylate (Gleevec, Glivec) |
| <input type="checkbox"/> Lomustine(CCNU) | <input checked="" type="checkbox"/> Melphalan(L-PAM) |
| <input type="checkbox"/> Mitoxantrone | <input type="checkbox"/> Monoclonal antibody (MAb) |
| <input type="checkbox"/> Paclitaxel (Taxol , Xyotax) | <input type="checkbox"/> Radiolabeled MAb |
| <input type="checkbox"/> Tenoposide (VM26) | <input type="checkbox"/> Thiotepa |
| <input type="checkbox"/> Treosulfan | <input type="checkbox"/> TBI |
| <input type="checkbox"/> TLI, TNI, TAI | <input type="checkbox"/> TMLI |
| <input type="checkbox"/> TMI | <input type="checkbox"/> other, specify : |

Follow-up

Relapse Yes No

Survival Status: Alive Dead

Date of Death

Cause of Death Post Transplant: Regimen Related Toxicity (RRT) Infection Progressive Disease Others Not Known

Death during Conditioning Regimen : Yes No

Did the Recipient receive a Subsequent HSCT ? Yes No

ACTIVITY FORM(Allogeneic):

— ISBMT - Activity Data

ISBMT Center No

ISBMT UP NO * 999

Center UP NO

Date of Transplant (HSCT Date) *

Country of residence of the patient:

Type of Product (Source of Stem Cell) BM PB CB

APBMT Disease Classification

Type of transplant (Type of HSCT): Allogeneic Autologous

APBMT Center No

Date of birth *

Age (Years)

Sex * Male Female

Is this First Transplant: Yes No

Diagnosis (Disease)

Status at HSCT :(Only For AML/ALL/CML/Thal)
ALL : CR1 Non CR1

Donor Details

Gender Male Female

Relation :

Date of Birth : *

Related Haploidentical

DONOR (Allogeneic Only)

HLA match type:

- Syngeneic (monozygotic twin) (1)
- HLA-identical sibling (may include non-monozygotic twin)(2)
- HLA- identical matched relatives other than sibling(3)
- HLA-mismatched relative (4)

Notes

Update

RELATED:

Related Haploidentical

DONOR (Allogeneic Only)

HLA match type:

- Syngeneic (monozygotic twin) (1)
- HLA-identical sibling (may include non-monozygotic twin)(2)
- HLA- identical matched relatives other than sibling(3)
- HLA-mismatched relative (4)
- 1 HLA antigen/allele mismatched
- 2 HLA allele mismatched

--Select any one--
5/6
7/8
9/10
11/12

Mention which allele mismatch
(Please enter Donor Mismatch details)

--Select any one--
--Select any one--
A
B
C
DRB
DQB
DPB

Notes

Update

MUD:

Donor Details

Gender Male Female

Date of Birth : * 02-01-1990

Relation : Unrelated

MUD

DONOR (Allogeneic Only)

HLA match type:

Full Match (6)

HLA-mismatched relative (4)

1 HLA antigen/allele mismatched

9/10

--Select any one--

5/6

7/8

9/10

11/12

--Select any one--

Marrow Donor Registry, SL. Raheja Hospital, Mumbai

Arjan Vir Foundation, New Delhi

DKMS Foundation, Bangalore

DATRI Blood stem cell donor registry, Chennai

Others

Which registry

DKMS Foundation, Bangalore

Mention which allele mismatch

(Please enter Donor Mismatch details)

A

1101

HAPLO:

Related Haploidentical

DONOR (Allogeneic Only)

HLA match type:

HLA-mismatched relative (4)

> 2 HLA antigen/allele mismatched related

9/12



- Select any one--
- 3/6
- 4/8
- 5/8
- 5/10
- 6/10
- 7/10
- 6/12
- 7/12
- 8/12
- 9/12

Mention which allele mismatch
(Please enter Donor Mismatch details)

A



1101

Mention which allele mismatch
(Please enter Donor Mismatch details)

DRB



2603

Mention which allele mismatch
(Please enter Donor Mismatch details)

DQB



1203

MOD FORM (ALLOGENEIC):

— ISBMT - Minimal Outcome Data (MOD)

Diagnosis

Status at HSCT

Date of birth

Age (Years)

Classification of diseases

Number

Sex Male Female

— Conditioning Regimen

ALG, ATG (before d0)

Bleomycin

Carboplatin

Cisplatin

Cyclophosphamide

Etoposide (VP16)

Ifosfamide

Lomustine(CCNU)

Mitoxantrone

Paclitaxel (Taxol , Xyotax)

Tenoposide (VM26)

Treosulfan

Anthracycline

Busulfan

Oral

IV

Both

Carmustine (BCNU)

Corticosteroids

Cytarabine (Ara-C)

Fludarabine

Imatinib mesylate (Gleevec, Glivec)

Melphalan(L-PAM)

Monoclonal antibody (MAB)

Radiolabeled MAB

Thiotepa

TBI

GVHD Prophylaxis : Yes No

GVHD Prophylaxis Agent :

--Select any one--
 Cyclosporine
 Tacrolimus
 Methotrexate (MTX)

Hold **Ctrl** or **Command** and click to select multiple items.**Engraftment (Neutrophils $\geq 0.5 \times 10^9/L$ unsupported for 3 days)** No Yes Not Known

Date of ANC recovery :

16-01-2010

(Platelets $\geq 20 \times 10^9/L$ unsupported for 7 days) No Yes Not Known

Date of platelets recovery :

31-01-2010

GVHD

Classification of Acute GVHD

Modified Glucksberg

Acute GVHD Yes No

GVHD-Acute Date 01-02-2010

Chronic GVHD Yes No

GVHD-Chronic Date 01-08-2010

Acute GVHD Grade I II III IV Present but grade unknown Not ApplicableChronic GVHD Grade Limited Extensive Unknown

Follow-up

Relapse Yes No

Date of Relapse : 01-11-2010

Rejection Yes NoSurvival Status: Alive Dead

Date of last followup

01-12-2025

Did the Recipient receive a Subsequent HSCT ?

 Yes

Subsequent transplant date :

01-01-2013

 No

CART T-CELL Therapy:

— ISBMT - CAR T CELL THERAPY

ISBMT Center No

ISBMT UP NO

Sex Male Female

Diagnosis (Disease)

Status at CAR T CELL

Number of prior lines of therapy

Date of Admission

Conditioning therapy (Date of start of Lympho-depletion)

CELL DOSE / KG

CELL INFUSION BOLUS FRACTIONATED

PRIOR TRANSPLANT Yes No

BRIDGING THERAPY Yes No

CRS(Cytokine release syndrome) Yes No

ICANS(Immune effector cell-associated neurotoxicity syndrome) Yes No

DAY 28/30 STATUS

Relapse or Progression Yes No

Survival Status: Alive Dead

APBMT Center No

Date of birth

Classification of diseases

Number

Date of Apheresis

Date of Discharge

Date of CAR T INFUSION

CAR T CELL PRODUCT

DISEASE STATUS PRIOR TO INFUSION

DAY 90 STATUS

Date of Last follow up

Challenges faced in data management- ISBMTR

- Diagnosis
- Multiple transplants data
 - Use of same ISBMT UP NO
 - Chronology of dates
 - Outcomes reporting
- HLA match type
- Under reporting of GVHD
- Survival Outcomes data not updated
 - Relapse
 - Last follow-up date & Status
 - Date and cause of death

HLA Match Type:

		Full Match		Mismatch	Mismatch type	Antigen/Allele mismatch
Related	Syngenic Monozygotic Twin	Yes	6/6, 8/8, 10/10, 12/12	No	-	
	HLA identical sibling (May include non-monozygotic twin)	Yes	6/6, 8/8, 10/10, 12/12	No	-	
	HLA identical matched relatives other than sibling	Yes	6/6, 8/8, 10/10, 12/12	No	-	
	HLA mismatch relative	No	NA-	Yes	One allele mismatch	5/6, 7/8, 9/10, 11/12
					Two allele mismatch	4/6, 6/8, 8/10, 10/12
MUD		Yes	6/6, 8/8, 10/10, 12/12	Yes	One allele mismatch	5/6, 7/8, 9/10, 11/12
HAPLO		No	NA	Yes	More than 2 allele mismatch	3/6, 4/8, 5/8, 5/10, 6/10, 7/10, 6/12, 7/12, 8/12, 9/12



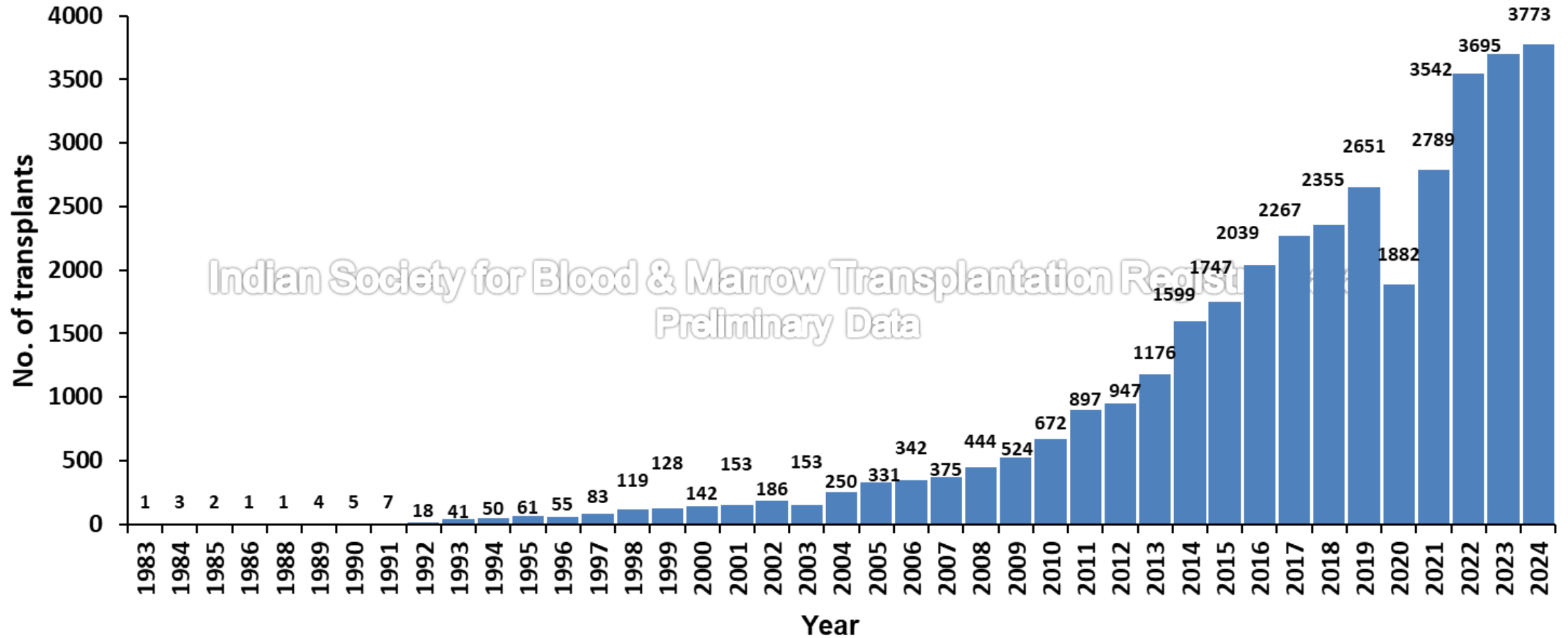
ISBMT

Indian Society for Blood & Marrow Transplantation

ISBMT REGISTRY

1983 to 2024 - Activity report

Number of Transplants – India (N=35510)



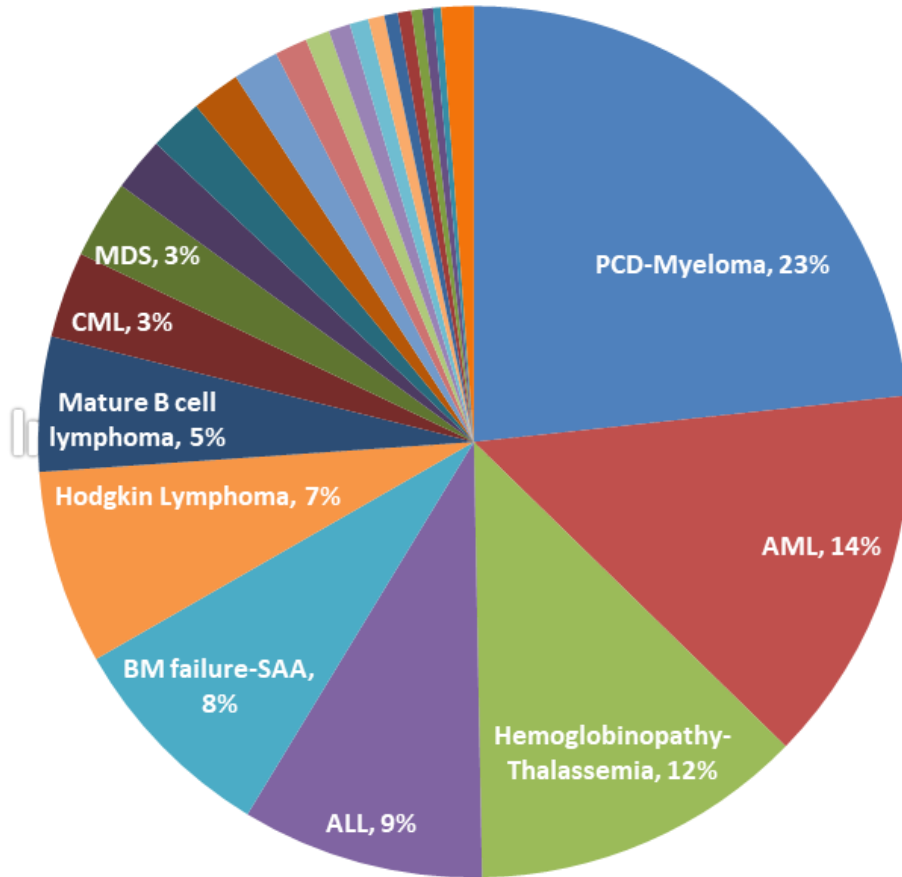
Total HSCT units – 167

© ISBMTR 2025

ISBMT REGISTRY

1983 to 2024 - Activity report

Indications for SCT (N= 35510)



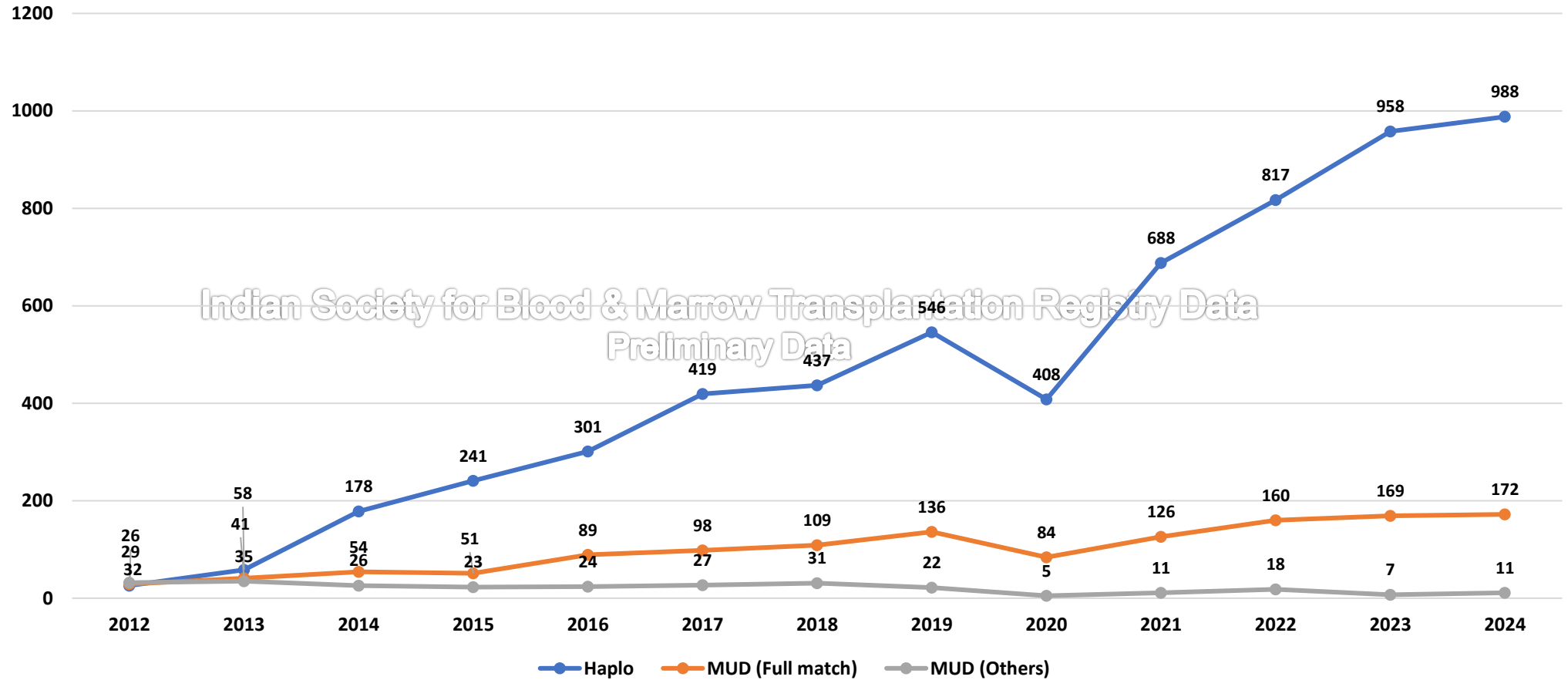
Diagnosis	N	%
PCD-Myeloma	8276	23.3
AML	4976	14
Hemoglobinopathy-Thalassemia	4389	12.4
ALL	3190	9
BM failure-SAA	2856	8
Hodgkin Lymphoma	2553	7.2
Mature B cell lymphoma	1780	5
CML	1153	3.2
MDS or MDS/MPN	1037	2.9
Congenital bone marrow failure	699	2
Neuroblastoma	697	2
Primary immune deficiencies	633	1.8
Hemoglobinopathy-other	594	1.7
Mature T/NK cell lymphoma	426	1.2
Other solid tumor	333	0.9
PCD-other	298	0.8
MPN	238	0.7
Autoimmune disease	228	0.6
Other leukemia	181	0.5
Inherited metabolic disease	176	0.5
Hemophagocytic syndrome	137	0.4
PNH	128	0.4
Other hematological disease	109	0.3
others	423	1.2
Total	35510	100

Total HSCT units – 167

ISBMT REGISTRY

2012 to 2024 - Activity report

Trends in MUD (N=1590) and Haplo (n=6065) SCT



Total HSCT units – 167

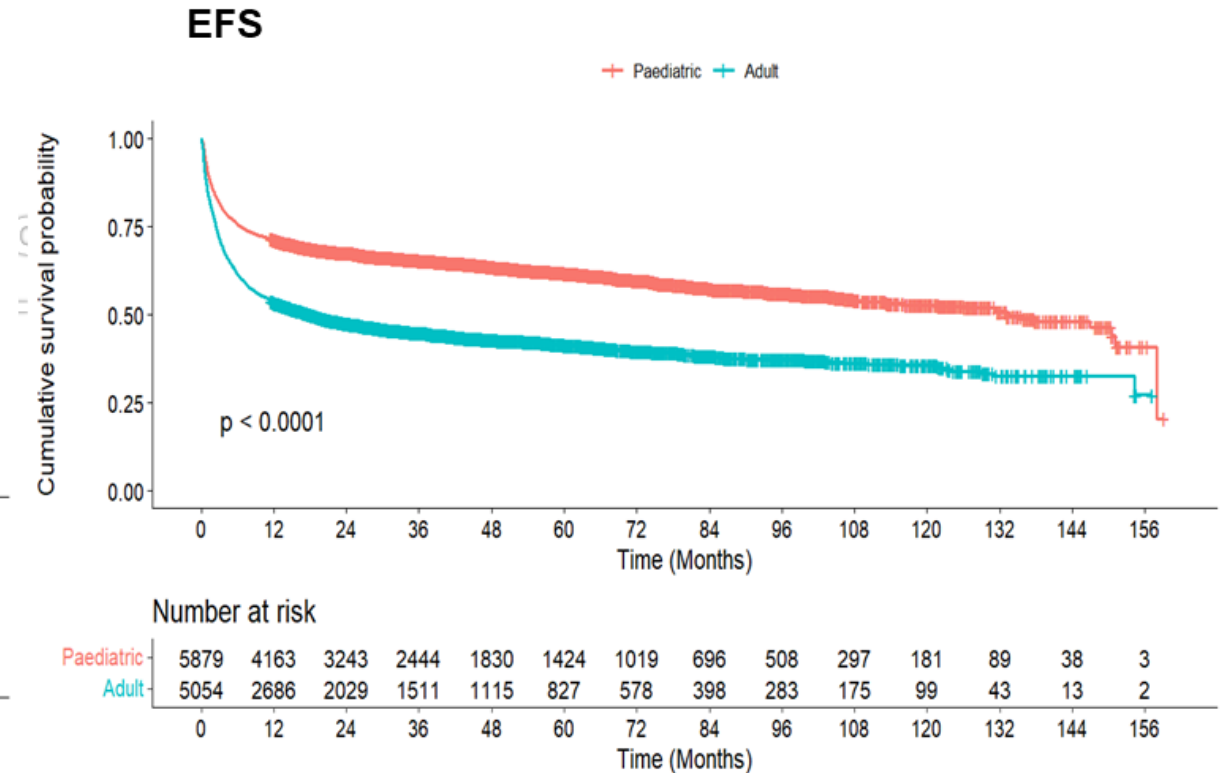
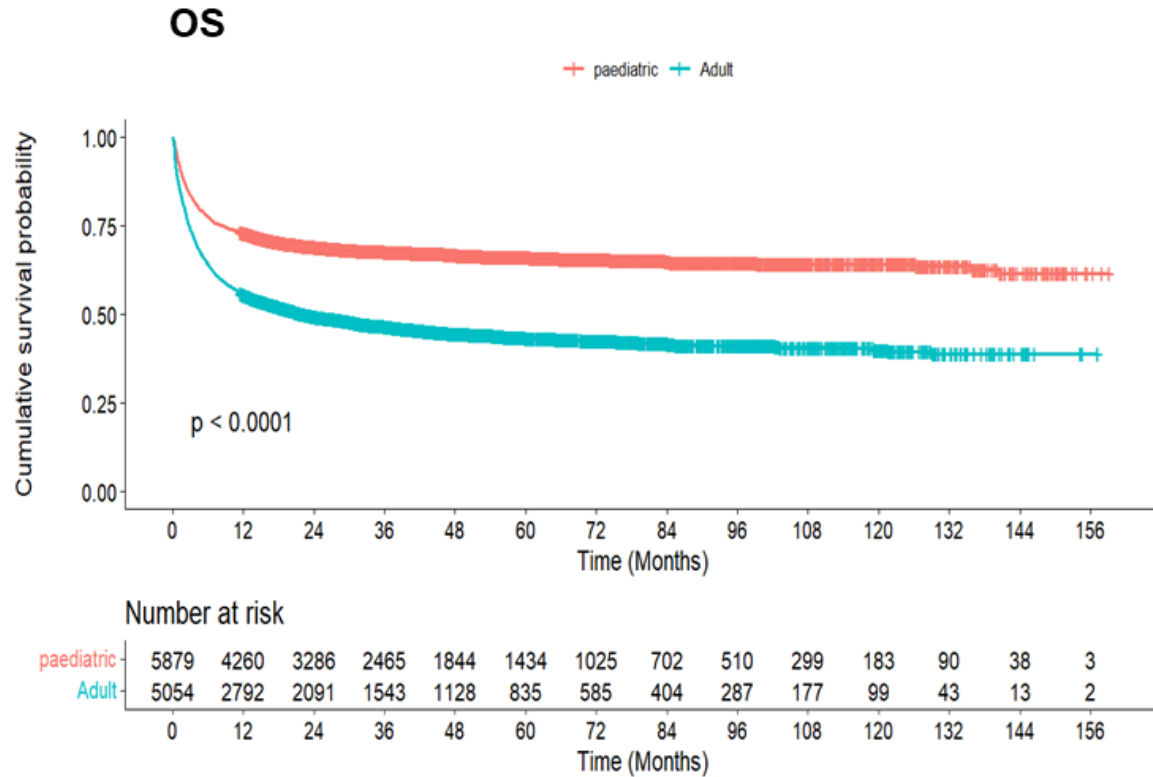
*Note: HLA type details were not available for 29 MUD patients

INDIAN SOCIETY FOR BLOOD AND MARROW TRANSPLANTATION REGISTRY 2012-2022

Minimal Outcome Data (MOD) (N=10933/13356, 81%) Allogeneic – Adult vs Pediatric

OS	Events	3-Yr survival
Paediatric	1925	67.7% (66.5%, 68.9%)
Adult	2757	46.6% (45.2%, 48.07%)

EFS	Events	3-Yr survival
Paediatric	2204	65.4% (64.2%, 66.7%)
Adult	2896	44.8% (43.4%, 46.2%)



Why registries are essential in BMT (despite not being source data)

- BMT is a low-volume, high-complexity field
- Single-center studies are underpowered
- Registries enable:
 - Real-world evidence
 - Rare disease and rare toxicity analysis
 - Center performance benchmarking
 - Hypothesis generation for RCTs
 - Guideline development
 - High-quality comparative effectiveness analyses (Advanced methods to mimic trial like experience)
 - Research Publications (Dr. Punit Jain et.al; Adult ALL- Allo transplants- Multicentric data, accepted for Tandem meeting in Feb 2026)

International Registry- APBMT

- The Asia-Pacific Blood and Marrow Transplantation Group (APBMT) uses REDCap as the platform for its electronic data capture (EDC) system to collect transplant activity and outcome data from participating centres

REDCap-SaaS 4010-0001 アジア太平洋造血細胞移植学会
APBMT Outcome Registry

Record Home Page

The grid below displays the form-by-form progress of data entered for the currently selected record. You may click on the colored status icons to access that form/event.

Choose action for record

Legend for status icons:

- Incomplete
- Incomplete (no data saved)
- Unverified
- Complete
- Many statuses (all same)
- Many statuses (mixed)

Record ID: 5840010 Date of 1st HSCT: Blood Transfusion Hematology Hospital

Data Collection Instrument	Registered Year	2020	archived	2019
Day100				
Disease				
Follow Up				

Repeating Instruments

Follow Up 2019

1	Date of follow-up data entry =
---	--------------------------------

+ Add new



Research Electronic Data Capture (REDCap) is a **Free, open source**, web-based software for EDC developed by Vanderbilt University to capture data for clinical research and create databases and projects.

Compliant ready: 21 CFR Part 11 complaint

Base : PHP


Institutions : 5907

Countries: 145

Projects: 1.5 Million projects

19,097 journal articles cite REDCap

Instruments

 **REDCap**[®]

🔒 Logged in as **sanjana.pawar** | [Log out](#)

📁 My Projects or ⚙️ Control Center

💬 REDCap Messenger

👤 View project as user: -- select a user --

Project Home and Design

🏠 Project Home · ⚙️ Project Setup

📄 Designer · 📖 Dictionary · 📄 Codebook

■ Project status: **Development**

Data Collection

📊 Record Status Dashboard
- View data collection status of all records

📄 Add / Edit Records
- Create new records or edit/view existing ones

Show data collection instruments

Applications

- 📄 Project Dashboards
- 🔔 Alerts & Notifications
- 🌐 Multi-Language Management
- 📅 Calendar
- 📄 Data Exports, Reports, and Stats
- 📄 Data Import Tool
- 🔗 Data Comparison Tool
- 📄 Logging and 📧 Email Logging
- 🗨️ Field Comment Log
- 📁 File Repository
- 👤 User Rights and 👥 DAGs



TATA MEMORIAL CENTRE
ADVANCED CENTRE FOR TREATMENT, RESEARCH & EDUCATION IN CANCER

Demo projects PID 267

- 🏠 Project Home
- ⚙️ Project Setup
- 📄 Online Designer
- 📖 Data Dictionary
- 📄 Codebook

📷 Create snapshot of instruments

Last snapshot: never ?

📺 VIDEO: [How to use this page](#)

The Online Designer will allow you to make project modifications to fields and data collection instruments very easily using only your web browser. NOTE: While in development status, all field changes will take effect immediately in real time.

Data Collection Instruments






+ Create a new instrument from scratch

📄 Import a new instrument from the official [REDCap Instrument Library](#) ?


📄 Upload instrument ZIP file from another project/user or [external libraries](#) ?

Form options:

🗑️ Form Display Logic

Instrument name	Fields	View PDF	Instrument actions
Patient Demographic Information	25		Choose action ▾
Randomization	7		Choose action ▾
Follow Up Details	17		Choose action ▾
Toxicity	28		Choose action ▾
Eortc Qlqc30	32		Choose action ▾

Multicentric Studies



Logged in as **sanjana.pawar** | Log out

My Projects or Control Center

REDCap Messenger

View project as user: -- select a user --

Project Home and Design

- Project Home
- Project Setup
- Designer
- Dictionary
- Codebook

Project status: **Development**


Data Collection

- Record Status Dashboard
- Add / Edit Records

Show data collection instruments

Applications

- Project Dashboards
- Alerts & Notifications
- Multi-Language Management
- Calendar
- Data Exports, Reports, and Stats
- Data Import Tool
- Data Comparison Tool
- Logging and Email Logging
- Field Comment Log
- File Repository
- User Rights and DAGs



TATA MEMORIAL CENTRE
ADVANCED CENTRE FOR TREATMENT, RESEARCH & EDUCATION IN CANCER

Demo projects PID 267

Project Home | Project Setup | User Rights | **Data Access Groups**

[VIDEO: How to use Data Access Groups](#)

Access to certain project records may be limited by using Data Access Groups (DAGs), in which only users within a given Data Access Group can access records created by users within that group. This may be useful in the case of a multi-site or multi-group project that requires that groups not be able to access another group's data. Once you have created DAGs, if you would like your users to be in multiple DAGs, you may use the optional DAG Switcher feature to allow users to move themselves in and out of specific DAGs on their own. [Additional instructions](#)

Upload or download DAGs/User-DAG assignments

+ Create new groups: Add new data access groups to which users may be assigned.

Enter new group name

Assign user to a group: Users may be assigned to any data access group. To assign users to [multiple groups](#), use the DAG Switcher at the bottom.

Assign user to

Data Access Groups	Users in group	Number of records in group	Unique group name (auto-generated)	Group ID number	Delete group?
Center 1	user1 (user 1)	0	center_1	18	✖
Center 2	user2 (user 2), user3 (user 3)	0	center_2	19	✖
Center 3		0	center_3	20	✖

User rights

Editing existing user "user1"

Basic Privileges

📅 Expiration Date (D/M/Y)
(if applicable)

Highest level privileges:

- ☐ Project Design and Setup
- ☐ User Rights
- ☐ Data Access Groups

Other privileges:

- ☑ Calendar
- ☑ Add/Edit/Organize Reports
Also allows user to view ALL reports (but not necessarily all data in the reports)
- ☑ Stats & Charts
- ☐ Data Import Tool
- ☐ Data Comparison Tool
- ☐ Logging
- ☑ File Repository
- ☑ Data Quality
[What is Data Quality?](#)
 - ☐ Create & edit rules
 - ☐ Execute rules

Privileges for Viewing and Exporting Data

Data Viewing Rights pertain to a user's ability to view or edit data on pages in the project (e.g., data entry forms, reports). Users with 'No Access' Data Viewing Rights for a given instrument will not be able to view that instrument for any record, nor will they be able to view fields from that instrument on a report. Data Export Rights pertain to a user's ability to export data from the project, whether through the Data Exports page, API, Mobile App, or in PDFs of instruments containing record data. Note: Data Viewing Rights and Data Export Rights are completely separate and do not impact one another.

	Data Viewing Rights			Data Export Rights			
	No Access (Hidden)	Read Only	View & Edit	No Access	De-Identified*	Remove All Identifier Fields	Full Data Set
Patient Demographic Information	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Randomization	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Follow Up Details	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Toxicity	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Eortc Qlqc30	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

* De-identified means that all free-form text fields will be removed, as well as any date/time fields and Identifier fields.

Assign user to a Data Access Group

Assign To DAG:

External Modules: Configuration Permissions

Save Changes

Cancel

Remove user

Thank You
For Your Attention

Causes of death in BMT

- **Early phase (0-30 days)**
 - The early days are very risky because of **infections** and organ damage.
- **Intermediate phase (30-100 days)**
 - In the middle phase, patients face risks from **graft-versus-host disease (GVHD)** and infections.
- **Late phase (beyond 100 days)**
 - The late phase sees a rise in disease **relapse and chronic GVHD risks**

Data Flow

BMT Data Flow

Referral

Registration

Pre-BMT Evaluation

Donor Identification

Conditioning

Transplant Day 0

Post-Transplant Monitoring

Engraftment

Long-term Follow-up

Reporting