



Developing an Outcomes Database and Transplant Registries

WBMT/WHO Workshop

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Discussion: Importance, Development and Participation in Transplant Outcomes Databases and Transplant Registries.

Panelists	Country
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Panel Discussion

- **Why** transplant data collection is important?
 - Center, Regional and International perspectives
- **What** data to collect?
 - **Levels** of transplant data collection
- **Challenges** and barriers for data collection.



Is there a value of collecting data?



- Identifying population
- Understanding outcomes
- Collaboration to study important regional issues.
- Integration across registries.

Gains from Contributing to Centralised Data Collection

- Continuing Medical Education
- Quality Assurance Programs
- Provides data to governments to apply for enhanced resources
- Participate in national and international research projects



What data to collect?

- Center vs. patient level data
- Registry vs. outcome databases
- Limited, minimal and comprehensive level data.
- Importance of utilizing the same data elements.

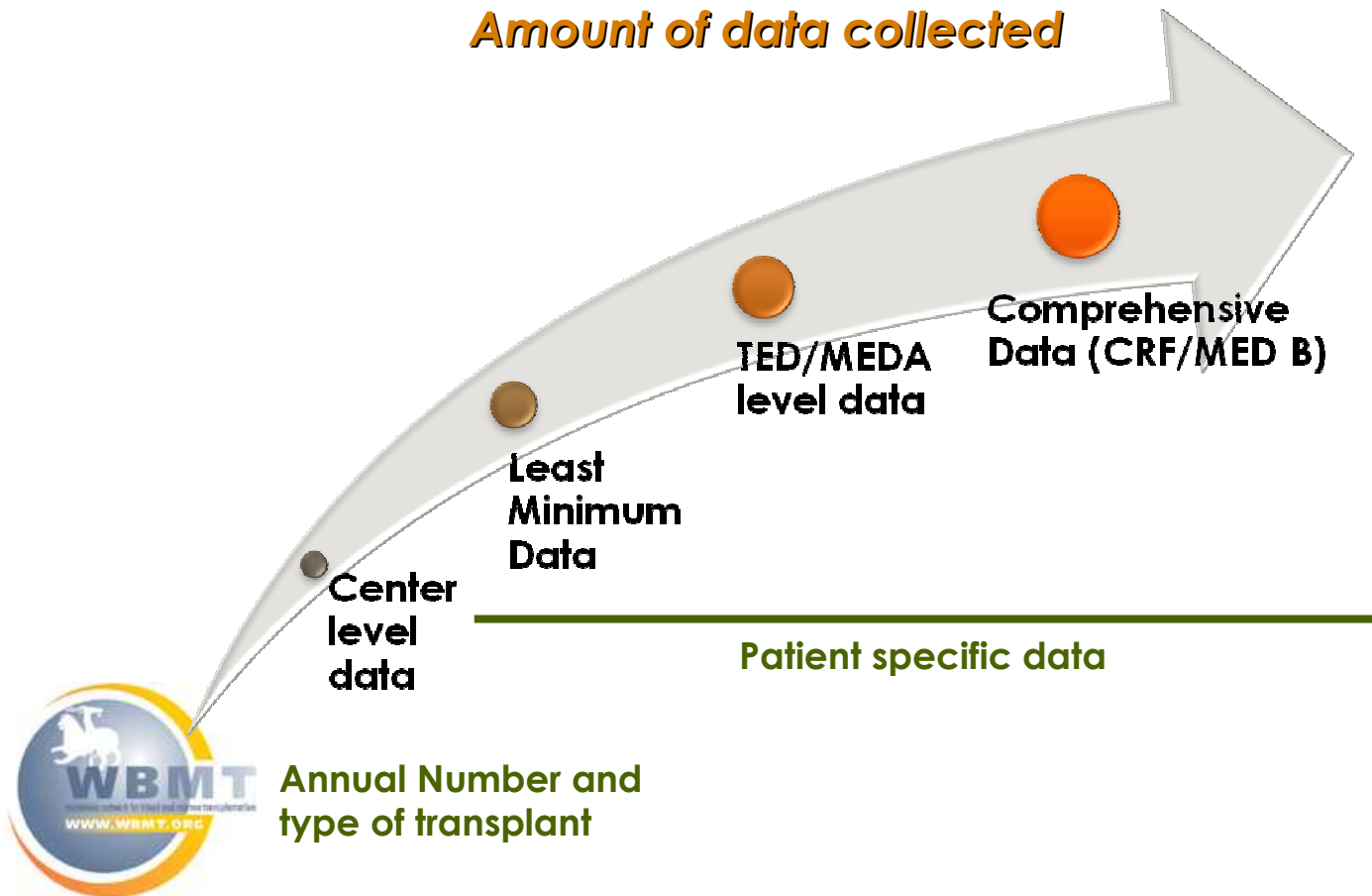


APBMT Least Minimum Data Items

Characteristics	Fields
Identification	Center and patient numbers
Patient	age, gender
Disease	disease status and subtype
Transplant	Date, graft type, conditioning regimen (intensity, agents, irradiation),GVHD prophylaxis
Donor type	Donor type, multiple donors, HLA match, donor gender and relation
Outcome	
Engraftment	Date, graft failure
GVHD	Acute, date of maximum grade, date of chronic
Disease status post transplant	Response, relapse and date
Survival	Status at last f/u, cause of death
Follow up	
Data collection calendar	100 days, 6 months, 1 year and yearly thereafter.

Levels of data collection

Amount of data collected



Data collection: overcoming challenges

- Mandatory vs. Voluntary data collection.
- Trained personnel for data collection.
- Ongoing training.
- Incorporation of data collection in daily transplant related activities.
- Frequent interaction between transplant center and registry.

