Workshop of the WBMT in cooperation with the WHO
Developing an Outcomes Database
Nov. 11, 2011
Hanoi, Vietnam

What is the minimum dataset suggested by APBMT for programs with limited resources?

Yoshiko Atsuta
for the APBMT

APBMT

Asia-Pacific Blood and Marrow Transplantation Group

Australia
Mainland China
Hong Kong
India
Indonesia
Iran
Japan
Korea
Malaysia
New Zealand
Pakistan
Phillipines
Taiwan
Thailand
Singapore
Vietnam

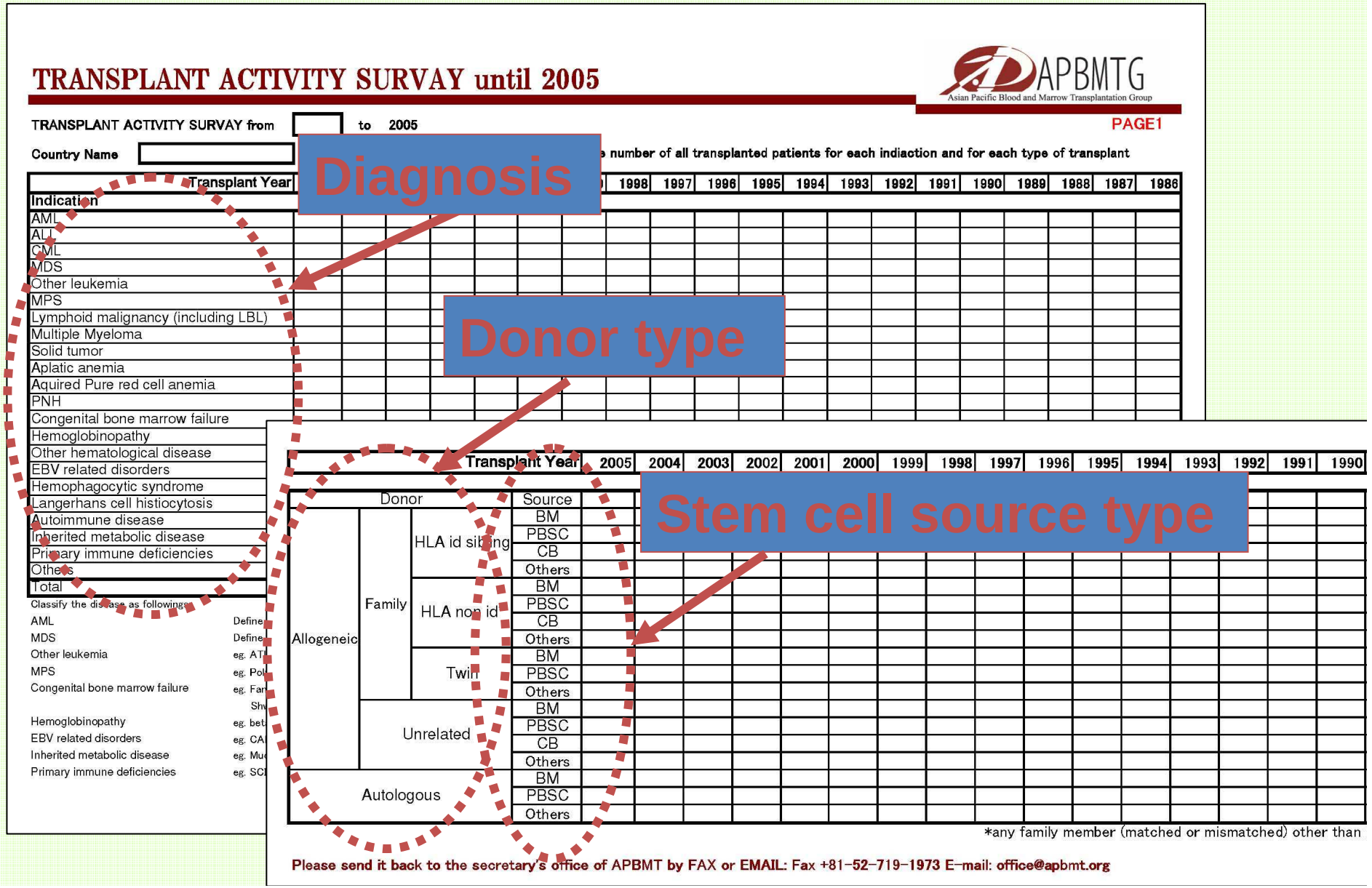
APBMT Meetings

No	Year	City	President
1st	199		
2nd	19		
3rd	19		
4th	19		
5th	19		
6th	199		
7th	2000		Issaragagrisil, Surapol
8th	2002		Advani, Suresh
9th	2004	hran	Ghavamzadeh, Ardeshir
10th	2005	Hangzhou	Lu, Dao-Pei
11th	2006	Nagoya	Kodera, Yoshihisa
12th	2007	Beijing	Lu, Dao-Pei
13th	2008	Taipei	Chen, Po-Min
14th	2009	Seoul	Kim, Chun-choo
15th	2010	Phuket	Jooter, Saengsuree
16th	2011	Sydney	Ma, David and Rowlings, Philip

- Agreed to launch APBMT registry
- To know the activity of transplant in this area.
- To create original data from Asia-Pacific region

Transplant Activity Survey started in 2007

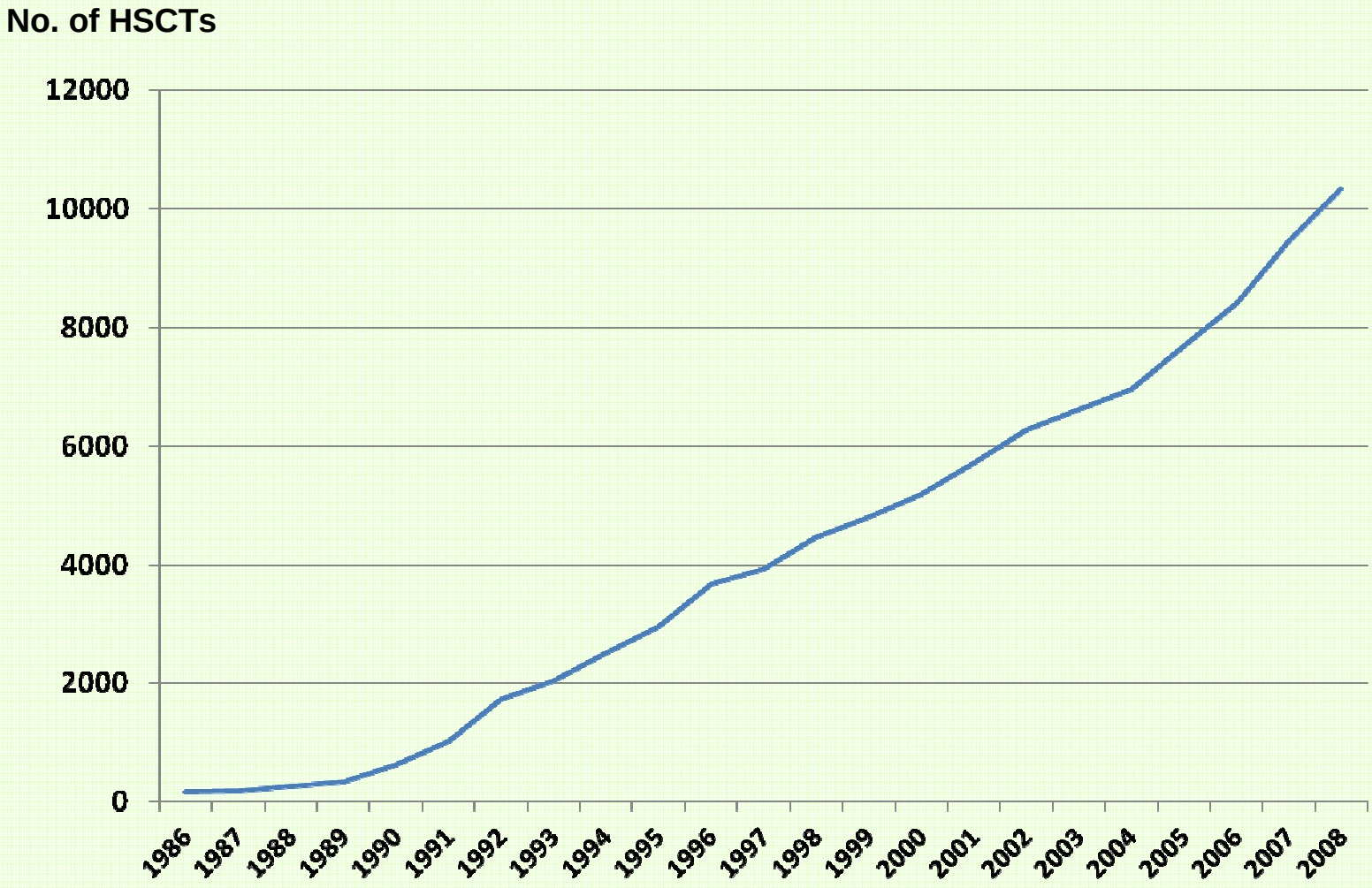
Two sheets per country or per center



No. of Transplantations and Centers

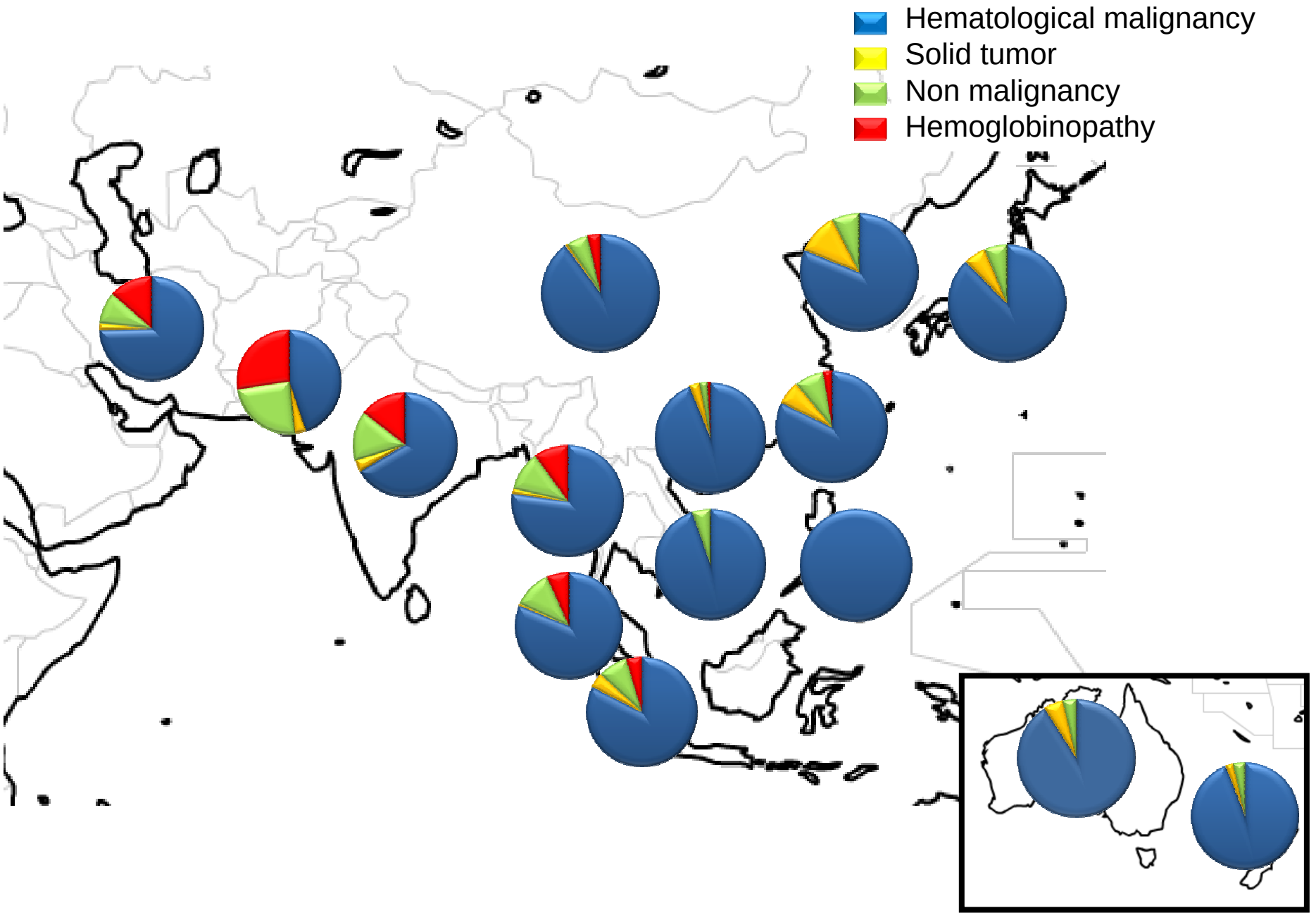
	HSCTs from 1986 to 2008	Centers in 2008	HSCTs in 2008
Australia	16205	41	1209
China	5211	38	1604
Hong Kong	1986	2	133
India	970	19	409
Iran	2446	5	389
Japan	47436	370	4204
Korea	12388	42	1459
Malaysia	1490	10	181
New Zealand	1674	6	171
Pakistan	219	2	29
Philippines	27	1	3
Singapore	1108	3	115
Taiwan	2953	12	337
Thailand	1223	5	131
Vietnam	81	3	19
Total	95417	559	10393

Total No. of HSCTs

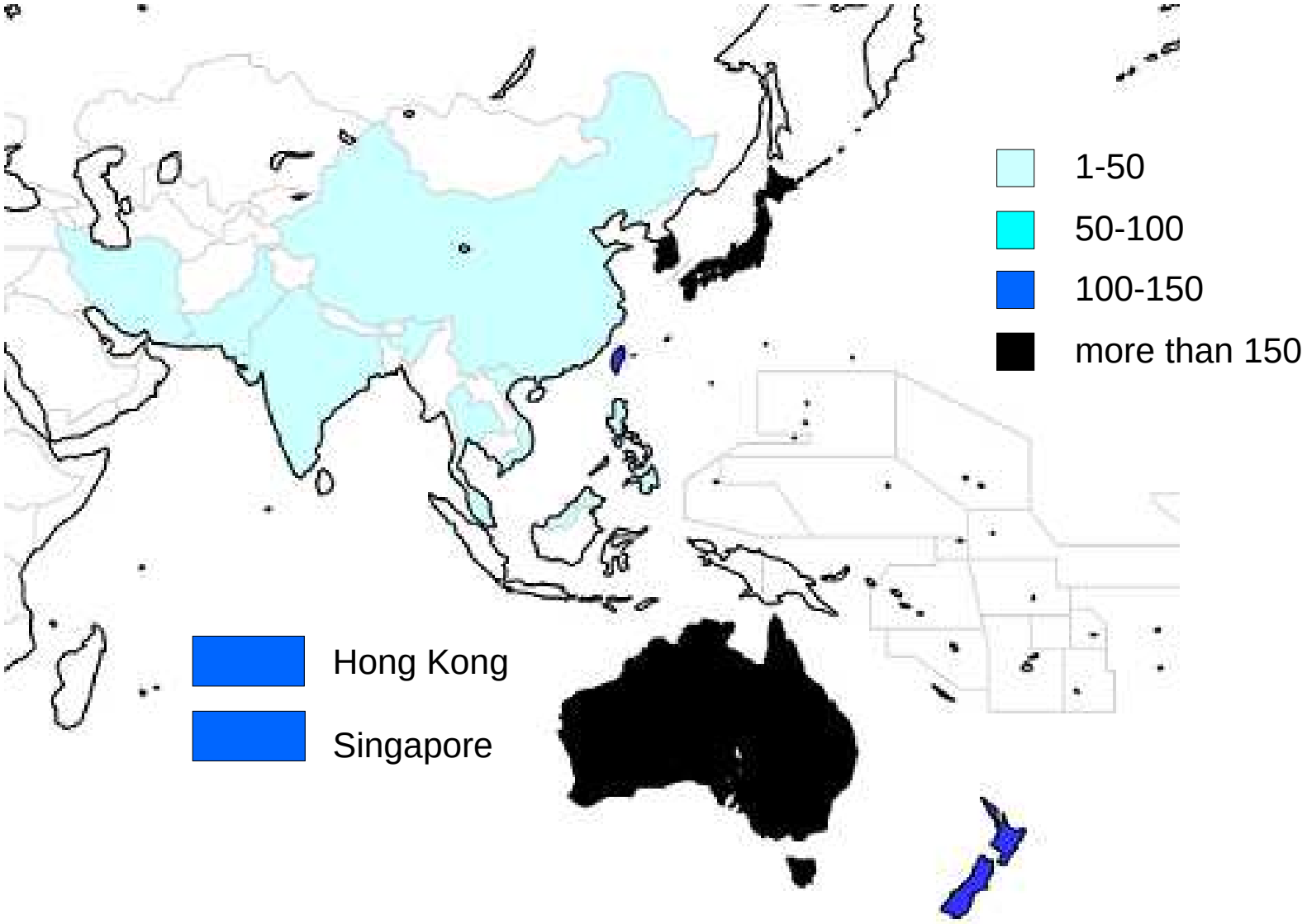


Iida M et al. APBMT 2010

Major Division of Disease Types by Country in 2008



No. of Allogeneic Transplants per 10 million population



APBMT HSCT Registry

- APBMT Transplant Activity Survey

- APBMT Outcome Registry
  - Long discussion
  - Launched in July, 2010

What is an Outcomes Database

- Database consisted with baseline-, disease-, transplant-information, and transplant outcome information of each single patient
- Possible analyses:
- Transplant outcome summary including engraftment rate, incidence of complications, and survival probabilities
  - According to diagnosis, disease stage at transplant, donor-type, stem cell source type, recipient age, conditioning regimen…
- Risk factors affecting transplant outcome

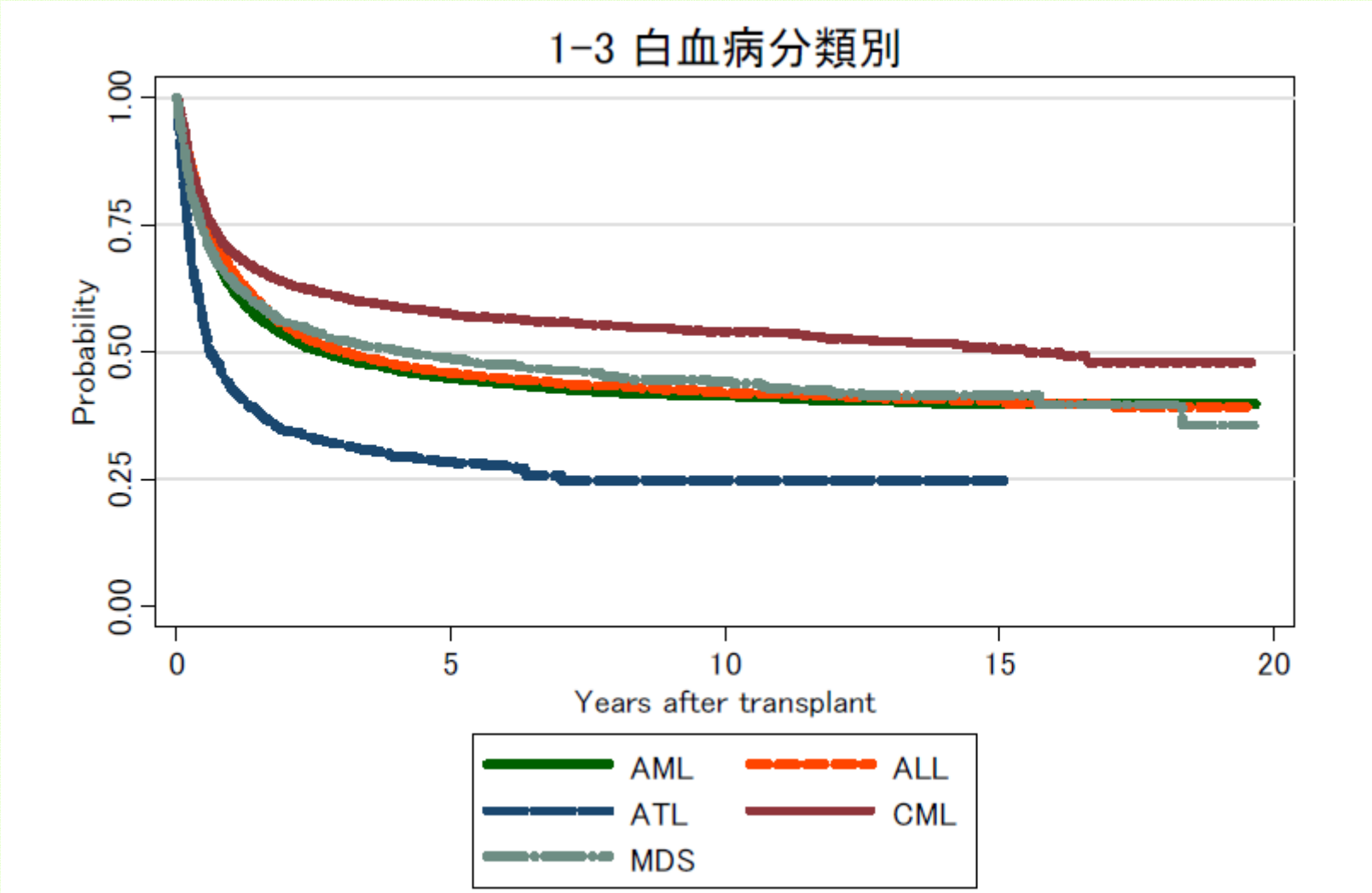
Outcome database

What was done to whom, how the patient did after

- 30 y/o male
- Acute myeloid leukemia in second remission
- Bone marrow from HLA identical sibling

- Neutrophil recovery on day 16
- Grade 2 acute GVHD (skin stage 3)
- No chronic GVHD
- No relapse
- Alive, without disease on day 500

Overall survival curve of leukemia



Japan Society for Hematopoietic Cell Transplantation

JSHCT Annual Report of Nationwide Survey 2011

Registry study

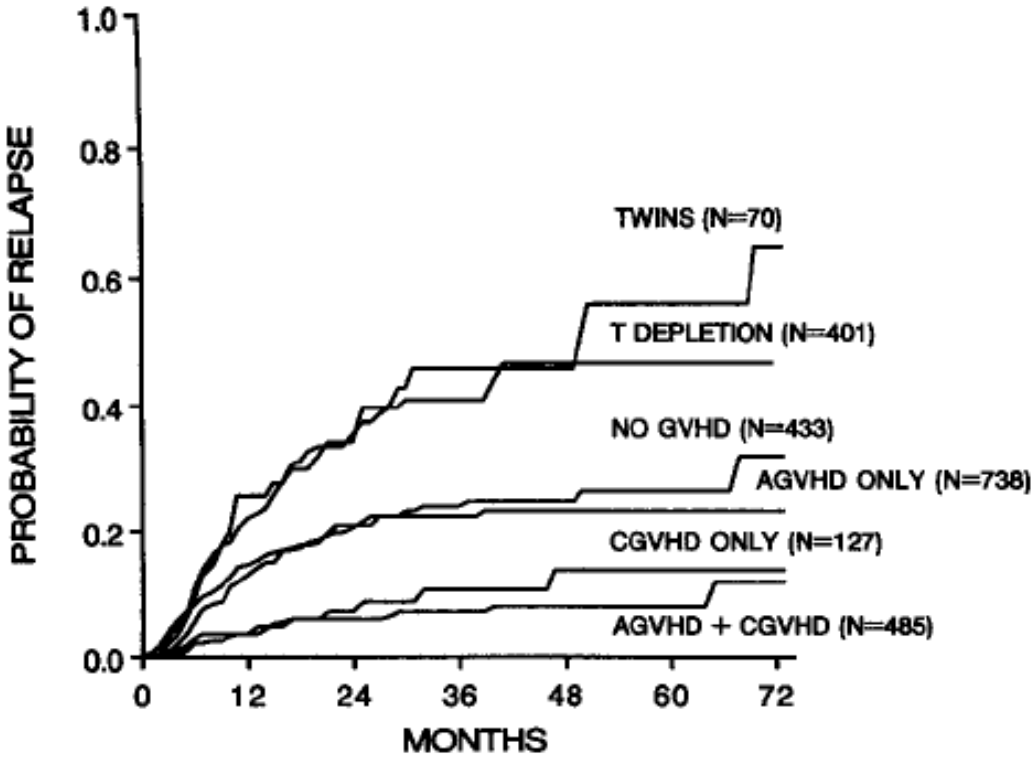
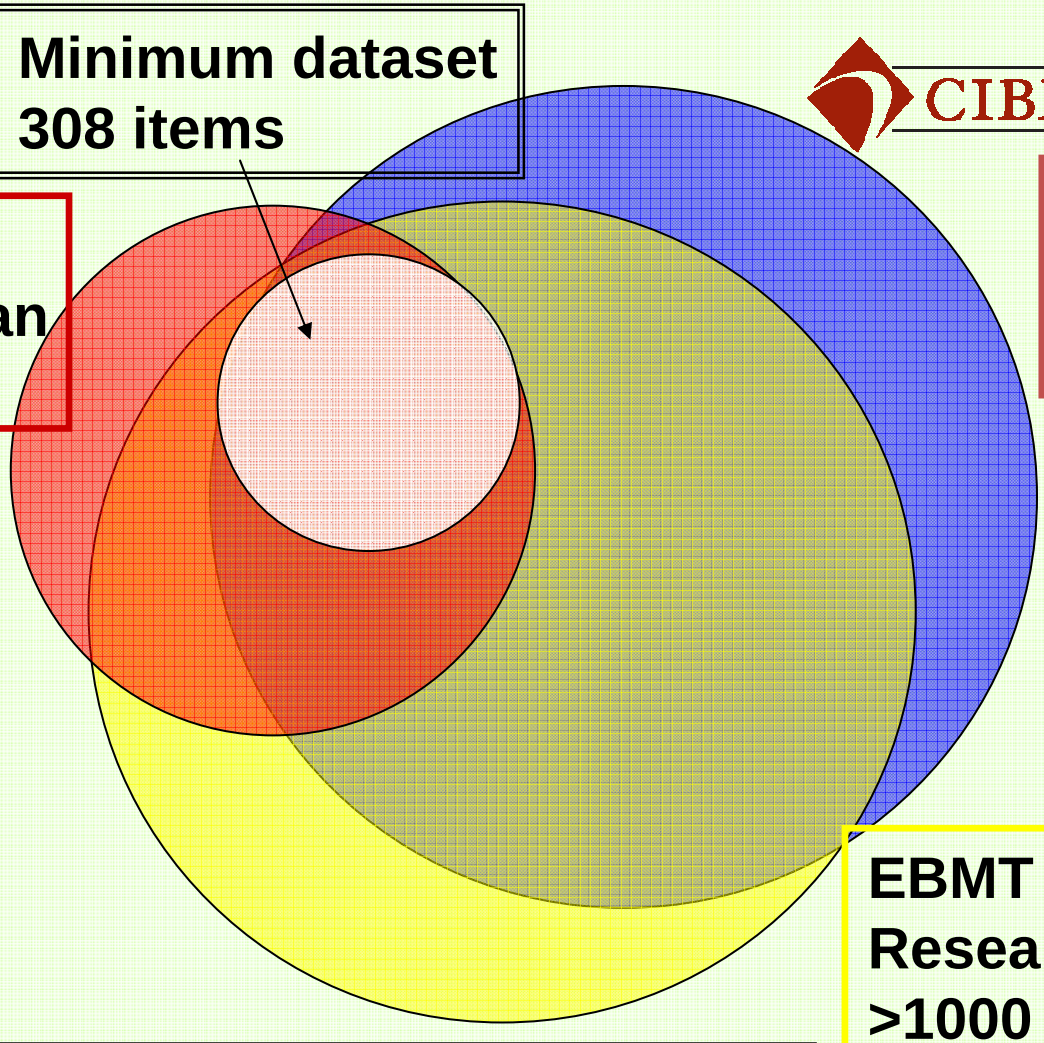


Fig 1. Actuarial probability of relapse after bone marrow transplantation for early leukemia according to type of graft and development of GVHD.

Graft-versus-leukemia effect

Horowitz MM et al. Blood 1990

Survey items to collect



TRUMP
Used in Japan
850 items

CIBMTR® CENTER FOR INTERNATIONAL BLOOD & MARROW TRANSPLANT RESEARCH

CIBMTR
Research form
>1000 items

EBMT

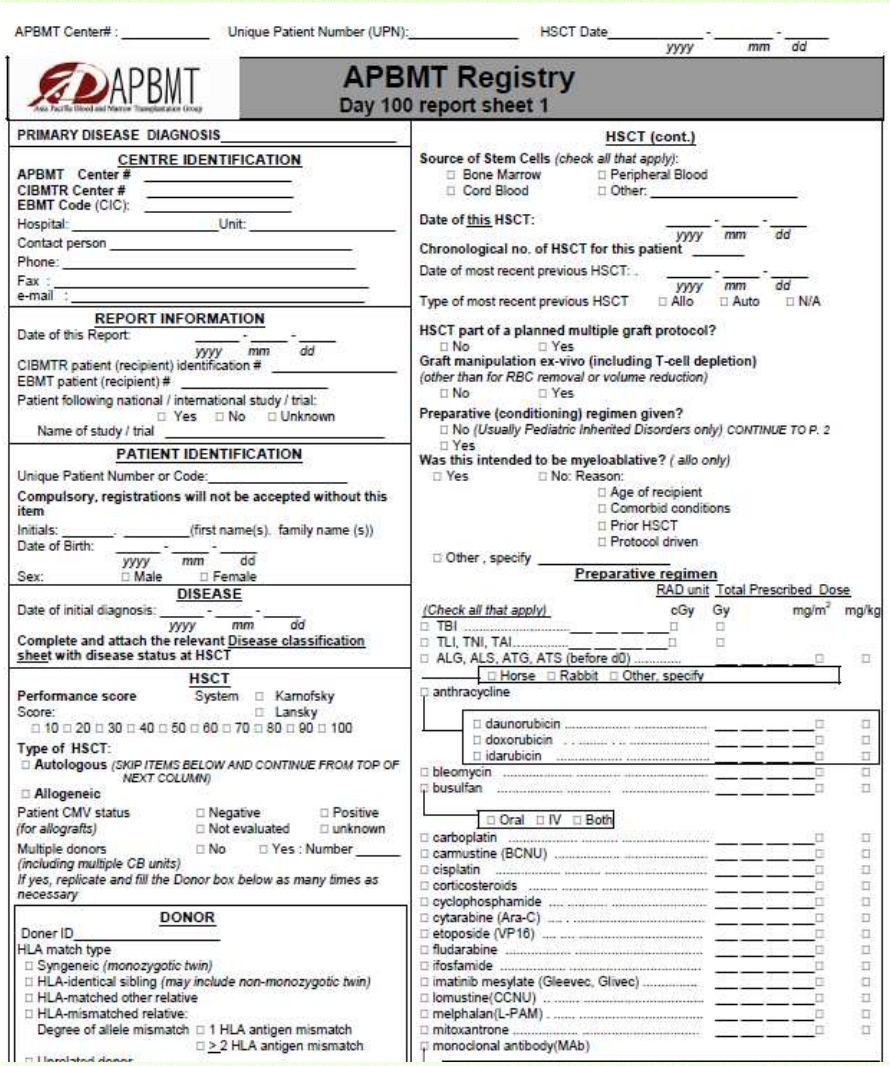
EBMT
Research form
>1000 items

Minimum dataset : revised TED / MED-A

APBMT Report sheets, identical to TED / MED-A

2 pages for 100 day, 2 pages for f/u, 1 for disease

One set required for EACH TRANSPLANT CASE



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy mm dd)

APBMT

APBMT Registry
Day 100 report sheet 1

PRIMARY DISEASE DIAGNOSIS_____

CENTRE IDENTIFICATION
APBMT Center # _____
CIBMTR Center # _____
EBMT Code (CIC): _____
Hospital: _____ Unit: _____
Contact person _____
Phone: _____
Fax : _____
e-mail : _____

REPORT INFORMATION
Date of this Report: _____ - _____ - _____ (yyyy mm dd)
CIBMTR patient (recipient) identification # _____
EBMT patient (recipient) # _____
Patient following national / international study / trial:
□ Yes □ No □ Unknown
Name of study / trial _____

PATIENT IDENTIFICATION
Unique Patient Number or Code:_____
Compulsory, registrations will not be accepted without this item
Initials: _____. _____(first name(s). family name (s))
Date of Birth: _____ - _____ - _____ (yyyy mm dd)
Sex: □ Male □ Female

DISEASE
Date of initial diagnosis: _____ - _____ - _____ (yyyy mm dd)
Complete and attach the relevant Disease classification sheet with disease status at HSCT

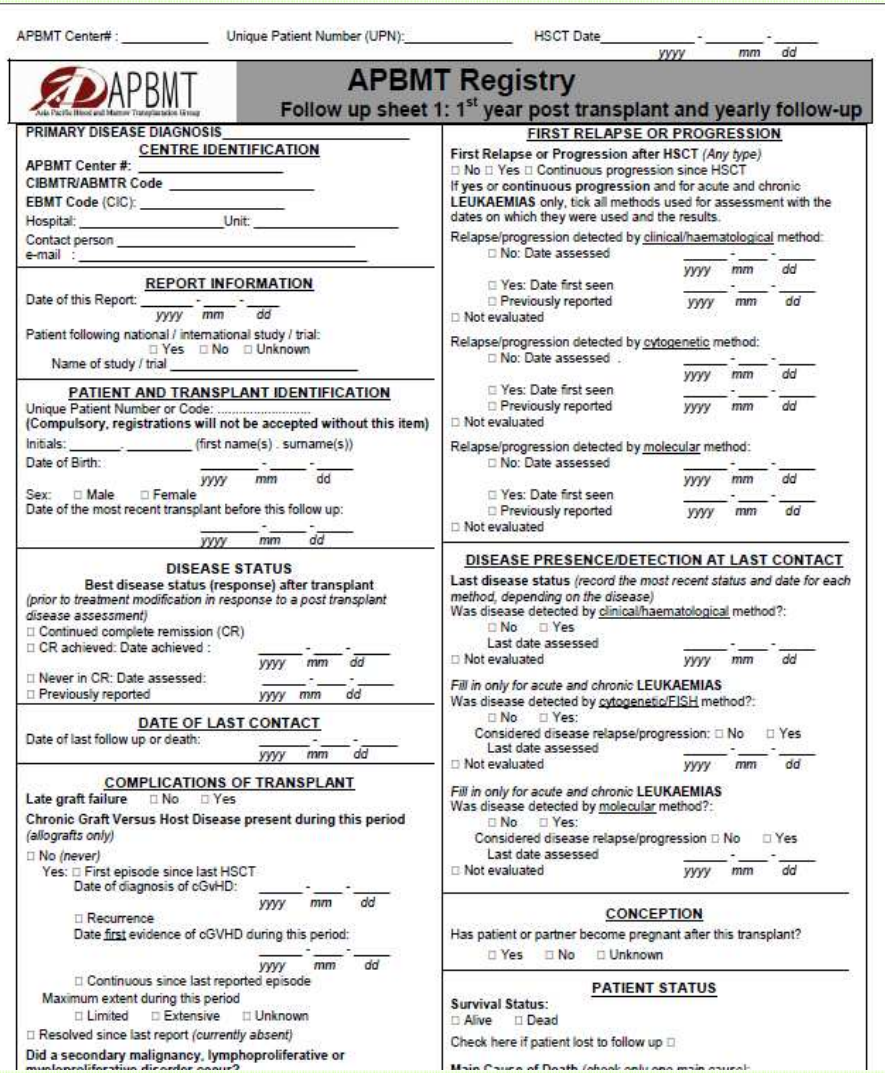
HSCT
Performance score System □ Karnofsky
Score: □ Lansky
□ 10 □ 20 □ 30 □ 40 □ 50 □ 60 □ 70 □ 80 □ 90 □ 100
Type of HSCT:
□ **Autologous** *(SKIP ITEMS BELOW AND CONTINUE FROM TOP OF NEXT COLUMN)*
□ **Allogeneic**
Patient CMV status □ Negative □ Positive
(for allografts) □ Not evaluated □ unknown
Multiple donors □ No □ Yes : Number _____
(including multiple CB units)
If yes, replicate and fill the Donor box below as many times as necessary

DONOR
Doner ID_____
HLA match type
□ Syngeneic *(monozygotic twin)*
□ HLA-identical sibling *(may include non-monozygotic twin)*
□ HLA-matched other relative
□ HLA-mismatched relative:
Degree of allele mismatch □ 1 HLA antigen mismatch
□ ≥2 HLA antigen mismatch
□ Unrelated donor

HSCT (cont.)
Source of Stem Cells *(check all that apply)*:
□ Bone Marrow □ Peripheral Blood
□ Cord Blood □ Other: _____
Date of this HSCT: _____ - _____ - _____ (yyyy mm dd)
Chronological no. of HSCT for this patient _____
Date of most recent previous HSCT: . _____ - _____ - _____ (yyyy mm dd)
Type of most recent previous HSCT □ Allo □ Auto □ N/A
HSCT part of a planned multiple graft protocol?
□ No □ Yes
Graft manipulation ex-vivo (including T-cell depletion)
(other than for RBC removal or volume reduction)
□ No □ Yes
Preparative (conditioning) regimen given?
□ No *(Usually Pediatric Inherited Disorders only)* *CONTINUE TO P. 2*
□ Yes
Was this intended to be myeloablative? *(allo only)*
□ Yes □ No: Reason:
□ Age of recipient
□ Comorbid conditions
□ Prior HSCT
□ Protocol driven
□ Other , specify _____

Preparative regimen

(Check all that apply)	RAD unit cGy	Total Prescribed Dose Gy	Dose mg/m^2	Dose mg/kg
□ TBI	___ ___ ___	□	□	
□ TLI, TNI, TAI	___ ___ ___	□	□	
□ ALG, ALS, ATG, ATS (before d0)			□	□
□ Horse □ Rabbit □ Other, specify				
□ anthracycline				
□ daunorubicin			___ ___ ___	□ □
□ doxorubicin			___ ___ ___	□ □
□ idarubicin			___ ___ ___	□ □
□ bleomycin			___ ___ ___	□ □
□ busulfan			___ ___ ___	□ □
□ Oral □ IV □ Both				
□ carboplatin			___ ___ ___	□ □
□ carmustine (BCNU)			___ ___ ___	□ □
□ cisplatin			___ ___ ___	□ □
□ corticosteroids			___ ___ ___	□ □
□ cyclophosphamide			___ ___ ___	□ □
□ cytarabine (Ara-C)			___ ___ ___	□ □
□ etoposide (VP16)			___ ___ ___	□ □
□ fludarabine			___ ___ ___	□ □
□ ifosfamide			___ ___ ___	□ □
□ imatinib mesylate (Gleevec, Glivec)			___ ___ ___	□ □
□ lomustine(CCNU)			___ ___ ___	□ □
□ melphalan(L-PAM)			___ ___ ___	□ □
□ mitoxantrone			___ ___ ___	□ □
□ monoclonal antibody(MAb)				



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy mm dd)

APBMT

APBMT Registry
Follow up sheet 1: 1st year post transplant and yearly follow-up

PRIMARY DISEASE DIAGNOSIS_____

CENTRE IDENTIFICATION
APBMT Center #: _____
CIBMTR/ABMTR Code _____
EBMT Code (CIC): _____
Hospital: _____ Unit: _____
Contact person _____
e-mail : _____

REPORT INFORMATION
Date of this Report: _____ - _____ - _____ (yyyy mm dd)
Patient following national / international study / trial:
□ Yes □ No □ Unknown
Name of study / trial _____

PATIENT AND TRANSPLANT IDENTIFICATION
Unique Patient Number or Code: .....
(Compulsory, registrations will not be accepted without this item)
Initials: _____. _____ (first name(s) . surname(s))
Date of Birth: _____ - _____ - _____ (yyyy mm dd)
Sex: □ Male □ Female
Date of the most recent transplant before this follow up:
_____ - _____ - _____ (yyyy mm dd)

DISEASE STATUS
Best disease status (response) after transplant
(prior to treatment modification in response to a post transplant disease assessment)
□ Continued complete remission (CR)
□ CR achieved: Date achieved : _____ - _____ - _____ (yyyy mm dd)
□ Never in CR: Date assessed: _____ - _____ - _____ (yyyy mm dd)
□ Previously reported

DATE OF LAST CONTACT
Date of last follow up or death: _____ - _____ - _____ (yyyy mm dd)

COMPLICATIONS OF TRANSPLANT
Late graft failure □ No □ Yes
Chronic Graft Versus Host Disease present during this period
(allografts only)
□ No *(never)*
Yes: □ First episode since last HSCT
Date of diagnosis of cGvHD: _____ - _____ - _____ (yyyy mm dd)
□ Recurrence
Date first evidence of cGVHD during this period: _____ - _____ - _____ (yyyy mm dd)
□ Continuous since last reported episode
Maximum extent during this period
□ Limited □ Extensive □ Unknown
□ Resolved since last report *(currently absent)*
Did a secondary malignancy, lymphoproliferative or

FIRST RELAPSE OR PROGRESSION
First Relapse or Progression after HSCT *(Any type)*
□ No □ Yes □ Continuous progression since HSCT
If **yes or continuous progression** and for acute and chronic **LEUKAEMIAS** only, tick all methods used for assessment with the dates on which they were used and the results.
Relapse/progression detected by clinical/haematological method:
□ No: Date assessed _____ - _____ - _____ (yyyy mm dd)
□ Yes: Date first seen _____ - _____ - _____ (yyyy mm dd)
□ Previously reported
□ Not evaluated
Relapse/progression detected by cytogenetic method:
□ No: Date assessed . _____ - _____ - _____ (yyyy mm dd)
□ Yes: Date first seen _____ - _____ - _____ (yyyy mm dd)
□ Previously reported
□ Not evaluated
Relapse/progression detected by molecular method:
□ No: Date assessed _____ - _____ - _____ (yyyy mm dd)
□ Yes: Date first seen _____ - _____ - _____ (yyyy mm dd)
□ Previously reported
□ Not evaluated

DISEASE PRESENCE/DETECTION AT LAST CONTACT
Last disease status *(record the most recent status and date for each method, depending on the disease)*
Was disease detected by clinical/haematological method?:
□ No □ Yes
Last date assessed _____ - _____ - _____ (yyyy mm dd)
□ Not evaluated
Fill in only for acute and chronic **LEUKAEMIAS**
Was disease detected by cytogenetic/FISH method?:
□ No □ Yes:
Considered disease relapse/progression: □ No □ Yes
Last date assessed _____ - _____ - _____ (yyyy mm dd)
□ Not evaluated
Fill in only for acute and chronic **LEUKAEMIAS**
Was disease detected by molecular method?:
□ No □ Yes:
Considered disease relapse/progression □ No □ Yes
Last date assessed _____ - _____ - _____ (yyyy mm dd)
□ Not evaluated

CONCEPTION
Has patient or partner become pregnant after this transplant?
□ Yes □ No □ Unknown

PATIENT STATUS
Survival Status:
□ Alive □ Dead
Check here if patient lost to follow up □
Main Cause of Death *(check only one main cause)*:

Launched in July, 2010

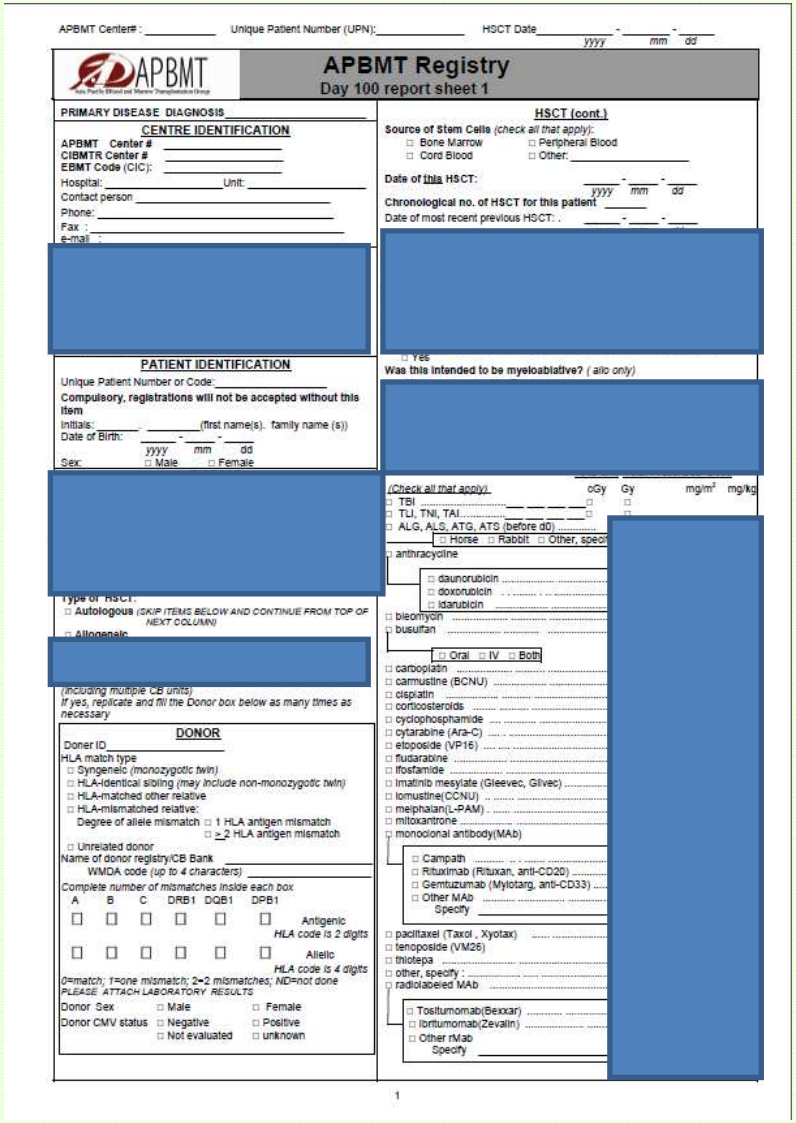
Submission status in 2010

Country / region	Participation in the APBMT Activity Survey	National (international) registry	Submission
Australia and New Zealand	Yes	Yes	No
China	Yes	No	No
Hong Kong	Yes	No	No
India	Yes	Under development	No
Indonesia	No	No	No
Iran	Yes	No	No
Japan	Yes	Yes	Yes
Korea	Yes	Yes	No
Malaysia	Yes	Yes	No
Pakistan	Yes	No	No
Phillippine	Yes	No	No
Singapore	Yes	No	No
Taiwan	Yes	Under development	No
Thailand	Yes	Under development	No
Vietnam	Yes	No	No

What are the barriers?

- Limited resources
  - Physicians are the ones who need to fill in the forms
  - Lack of trained data managers
  - Lack of financial support
- Too many items
  - Simplifying the Report Forms to “Least” Minimum Dataset was desired by 11/16 countries / region

Simplifying Forms = Taking variables capable for analyses



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy mm dd)

APBMT

APBMT Registry
Day 100 report sheet 1

PRIMARY DISEASE DIAGNOSIS_____

CENTRE IDENTIFICATION

APBMT Center # _____
CIBMTR Center # _____
EBMT Code (CIC): _____
Hospital: _____ Unit: _____
Contact person _____
Phone: _____
Fax : _____
e-mail : _____

PATIENT IDENTIFICATION

Unique Patient Number or Code:_____
Compulsory, registrations will not be accepted without this item
Initials: _____ _____(first name(s). family name (s))
Date of Birth: _____ - _____ - _____ (yyyy mm dd)
Sex: □ Male □ Female

Type of HSCT :
□ **Autologous** *(SKIP ITEMS BELOW AND CONTINUE FROM TOP OF NEXT COLUMN)*
□ Allogeneic
(including multiple CB units)
If yes, replicate and fill the Donor box below as many times as necessary

DONOR

Doner ID_____
HLA match type
□ Syngeneic *(monozygotic twin)*
□ HLA-identical sibling *(may include non-monozygotic twin)*
□ HLA-matched other relative
□ HLA-mismatched relative:
Degree of allele mismatch □ 1 HLA antigen mismatch □ >2 HLA antigen mismatch
□ Unrelated donor
Name of donor registry/CB Bank _____
WMDA code *(up to 4 characters)* _____
Complete number of mismatches inside each box

A	B	C	DRB1	DQB1	DPB1	
□	□	□	□	□	□	Antigenic
□	□	□	□	□	□	Allelic

HLA code is 2 digits / *HLA code is 4 digits*
0=match; 1=one mismatch; 2=2 mismatches; ND=not done
PLEASE ATTACH LABORATORY RESULTS
Donor Sex □ Male □ Female
Donor CMV status □ Negative □ Positive □ Not evaluated □ unknown

HSCT (cont.)

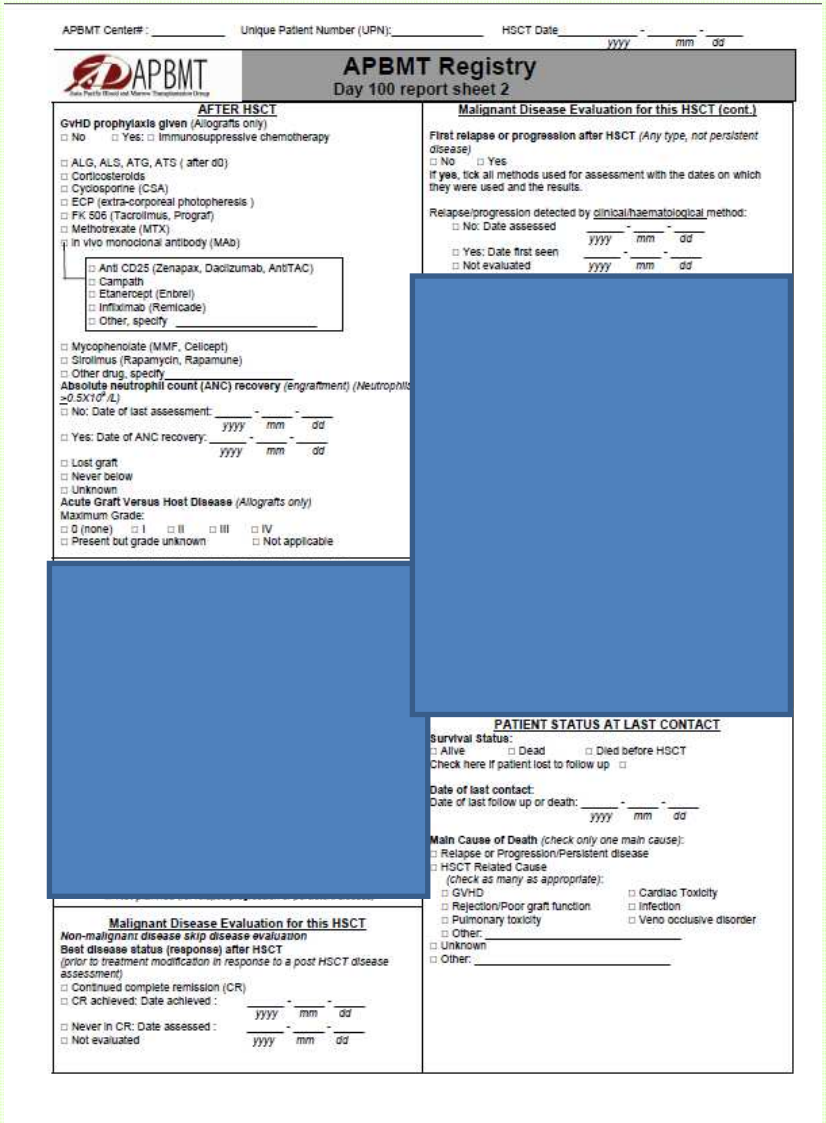
Source of Stem Cells *(check all that apply)*:
□ Bone Marrow □ Peripheral Blood
□ Cord Blood □ Other: _____

Date of this HSCT: _____ - _____ - _____ (yyyy mm dd)
Chronological no. of HSCT for this patient _____
Date of most recent previous HSCT: . _____ - _____ - _____

□ Yes
Was this intended to be myeloablative? *(allo only)*

(Check all that apply) cGy Gy mg/m² mg/kg
□ TBI
□ TLI, TNI, TAI
□ ALG, ALS, ATG, ATS (before d0)
□ Horse □ Rabbit □ Other, specify
□ anthracycline
□ daunorubicin
□ doxorubicin
□ idarubicin
□ bleomycin
□ busulfan
□ Oral □ IV □ Both
□ carboplatin
□ carmustine (BCNU)
□ cisplatin
□ corticosteroids
□ cyclophosphamide
□ cytarabine (Ara-C)
□ etoposide (VP16)
□ fludarabine
□ ifosfamide
□ imatinib mesylate (Gleevec, Glivec)
□ lomustine(CCNU)
□ melphalan(L-PAM)
□ mitoxantrone
□ monoclonal antibody(MAb)
□ Campath
□ Rituximab (Rituxan, anti-CD20)
□ Gemtuzumab (Mylotarg, anti-CD33)
□ Other MAb
Specify
□ paclitaxel (Taxol , Xyotax)
□ tenoposide (VM26)
□ thiotepa
□ other, specify :
□ radiolabeled MAb
□ Tositumomab(Bexxar)
□ Ibritumomab(Zevalin)
□ Other rMab
Specify

1



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy mm dd)

APBMT

APBMT Registry
Day 100 report sheet 2

AFTER HSCT

GvHD prophylaxis given (Allografts only)
□ No □ Yes: □ Immunosuppressive chemotherapy
□ ALG, ALS, ATG, ATS (after d0)
□ Corticosteroids
□ Cyclosporine (CSA)
□ ECP (extra-corporeal photopheresis)
□ FK 506 (Tacrolimus, Prograf)
□ Methotrexate (MTX)
□ In vivo monoclonal antibody (MAb)
□ Anti CD25 (Zenapax, Daclizumab, Anti TAC)
□ Campath
□ Etanercept (Enbrel)
□ Infliximab (Remicade)
□ Other, specify _____
□ Mycophenolate (MMF, Cellcept)
□ Sirolimus (Rapamycin, Rapamune)
□ Other drug, specify _____
Absolute neutrophil count (ANC) recovery *(engraftment)* *(Neutrophils >0.5X10⁹/L)*
□ No: Date of last assessment: _____ - _____ - _____ (yyyy mm dd)
□ Yes: Date of ANC recovery: _____ - _____ - _____ (yyyy mm dd)
□ Lost graft
□ Never below
□ Unknown
Acute Graft Versus Host Disease *(Allografts only)*
Maximum Grade:
□ 0 (none) □ I □ II □ III □ IV
□ Present but grade unknown □ Not applicable

Malignant Disease Evaluation for this HSCT

Non-malignant disease skip disease evaluation
Best disease status (response) after HSCT
(prior to treatment modification in response to a post HSCT disease assessment)
□ Continued complete remission (CR)
□ CR achieved: Date achieved : _____ - _____ - _____ (yyyy mm dd)
□ Never in CR: Date assessed : _____ - _____ - _____ (yyyy mm dd)
□ Not evaluated

Malignant Disease Evaluation for this HSCT (cont.)

First relapse or progression after HSCT *(Any type, not persistent disease)*
□ No □ Yes
If yes, tick all methods used for assessment with the dates on which they were used and the results.

Relapse/progression detected by clinical/haematological method:
□ No: Date assessed _____ - _____ - _____ (yyyy mm dd)
□ Yes: Date first seen _____ - _____ - _____ (yyyy mm dd)
□ Not evaluated

PATIENT STATUS AT LAST CONTACT

Survival Status:
□ Alive □ Dead □ Died before HSCT
Check here if patient lost to follow up □

Date of last contact:
Date of last follow up or death: _____ - _____ - _____ (yyyy mm dd)

Main Cause of Death *(check only one main cause)*:
□ Relapse or Progression/Persistent disease
□ HSCT Related Cause
(check as many as appropriate):
□ GVHD □ Cardiac Toxicity
□ Rejection/Poor graft function □ Infection
□ Pulmonary toxicity □ Veno occlusive disorder
□ Other: _____
□ Unknown
□ Other: _____

2

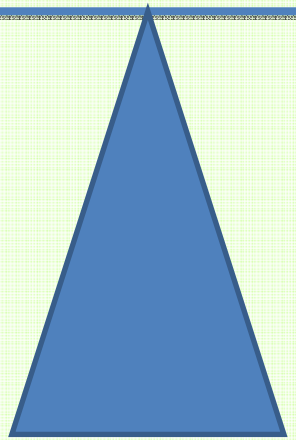
Balance between what we can do and what we need

What we can do

Forms as simple as possible

The burden to the centers vary according to the supporting situation;

Financial support
Data managers



What we need

Items needed for analyses

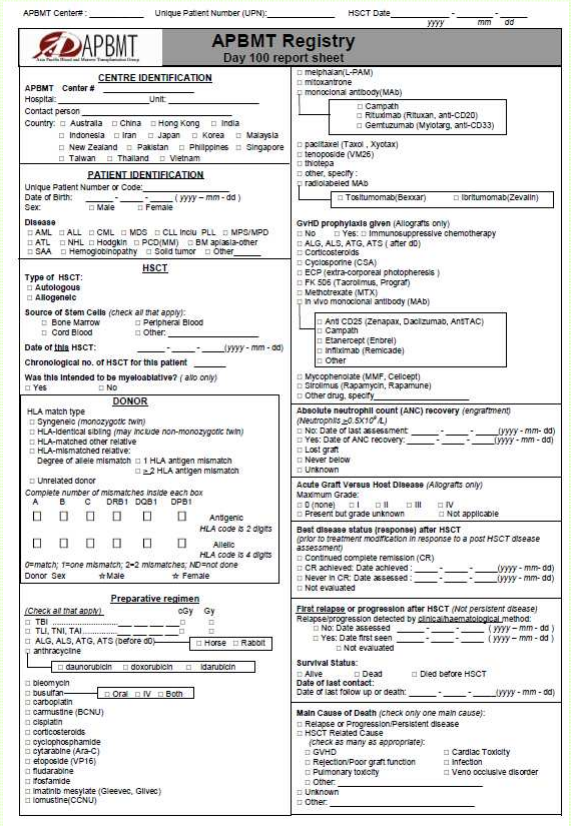
Depends on what you want to know from the analyses;

For research purposes, the number of items required are usually large.

What was taken out for the simplified version

- Dose information of the agents used for preparative regimen
- Cytogenetic / molecular test results of the disease status post transplant (only clinical / hematological test considered)
- Additional treatment including cell infusion
- Disease information at diagnosis (only information at transplant)

Least Minimum Dataset



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy - mm - dd)

APBMT Registry
Day 100 report sheet

CENTRE IDENTIFICATION

APBMT Center # _____
Hospital: _____ Unit: _____
Contact person _____
Country: □ Australia □ China □ Hong Kong □ India □ Indonesia □ Iran □ Japan □ Korea □ Malaysia □ New Zealand □ Pakistan □ Philippines □ Singapore □ Taiwan □ Thailand □ Vietnam

PATIENT IDENTIFICATION

Unique Patient Number or Code:_____
Date of Birth: _____ - _____ - _____ (yyyy – mm - dd)
Sex: □ Male □ Female

Disease
□ AML □ ALL □ CML □ MDS □ CLL Inclu PLL □ MPS/MPD
□ ATL □ NHL □ Hodgkin □ PCD(MM) □ BM aplasia-other
□ SAA □ Hemoglobinopathy □ Solid tumor □ Other_____

HSCT

Type of HSCT:
□ **Autologous**
□ **Allogeneic**

Source of Stem Cells *(check all that apply)*:
□ Bone Marrow □ Peripheral Blood
□ Cord Blood □ Other: _____

Date of this HSCT: _____ - _____ - _____ (yyyy - mm - dd)
Chronological no. of HSCT for this patient _____
Was this intended to be myeloablative? *(allo only)*
□ Yes □ No

DONOR

HLA match type
□ Syngeneic *(monozygotic twin)*
□ HLA-identical sibling *(may include non-monozygotic twin)*
□ HLA-matched other relative
□ HLA-mismatched relative:
Degree of allele mismatch □ 1 HLA antigen mismatch □ ≥ 2 HLA antigen mismatch
□ Unrelated donor

Complete number of mismatches inside each box

A	B	C	DRB1	DQB1	DPB1	
□	□	□	□	□	□	Antigenic *HLA code is 2 digits*
□	□	□	□	□	□	Allelic *HLA code is 4 digits*

0=match; 1=one mismatch; 2=2 mismatches; ND=not done
Donor Sex ☆Male ☆ Female

Preparative regimen

(Check all that apply) cGy Gy
□ TBI ..... ___ ___ ___ ___ □ □
□ TLI, TNI, TAI ..... ___ ___ ___ ___ □ □
□ ALG, ALS, ATG, ATS (before dd)——□ Horse □ Rabbit
□ anthracycline
□ daunorubicin □ doxorubicin □ idarubicin
□ bleomycin
□ busulfan——□ Oral □ IV □ Both
□ carboplatin
□ carmustine (BCNU)
□ cisplatin
□ corticosteroids
□ cyclophosphamide
□ cytarabine (Ara-C)
□ etoposide (VP16)
□ fludarabine
□ ifosfamide
□ imatinib mesylate (Gleevec, Glivec)
□ lomustine(CCNU)
□ melphalan(L-PAM)
□ mitoxantrone
□ monoclonal antibody(MAb)
□ Campath
□ Rituximab (Rituxan, anti-CD20)
□ Gemtuzumab (Myotarg, anti-CD33)
□ paclitaxel (Taxol , Xyotax)
□ tenoposide (VM26)
□ thiotepa
□ other, specify :
□ radiolabeled MAb
□ Tositumomab(Bexxar) □ Ibritumomab(Zevalin)

GvHD prophylaxis given (Allografts only)
□ No □ Yes : □ Immunosuppressive chemotherapy
□ ALG, ALS, ATG, ATS (after dD)
□ Corticosteroids
□ Cyclosporine (CSA)
□ ECP (extra-corporeal photopheresis)
□ FK 506 (Tacrolimus, Prograf)
□ Methotrexate (MTX)
□ In vivo monoclonal antibody (MAb)
□ Anti CD25 (Zenapax, Daclizumab, AntiTAC)
□ Campath
□ Etanercept (Enbrel)
□ Infliximab (Remicade)
□ Other
□ Mycophenolate (MMF, Celcept)
□ Sirolimus (Rapamycin, Rapamune)
□ Other drug, specify_____

Absolute neutrophil count (ANC) recovery *(engraftment)*
(Neutrophils ≥0.5X10⁹ /L)
□ No: Date of last assessment: _____ - _____ - _____ (yyyy - mm- dd)
□ Yes: Date of ANC recovery: _____ - _____ - _____(yyyy - mm - dd)
□ Lost graft
□ Never below
□ Unknown

Acute Graft Versus Host Disease *(Allografts only)*
Maximum Grade:
□ 0 (none) □ I □ II □ III □ IV
□ Present but grade unknown □ Not applicable

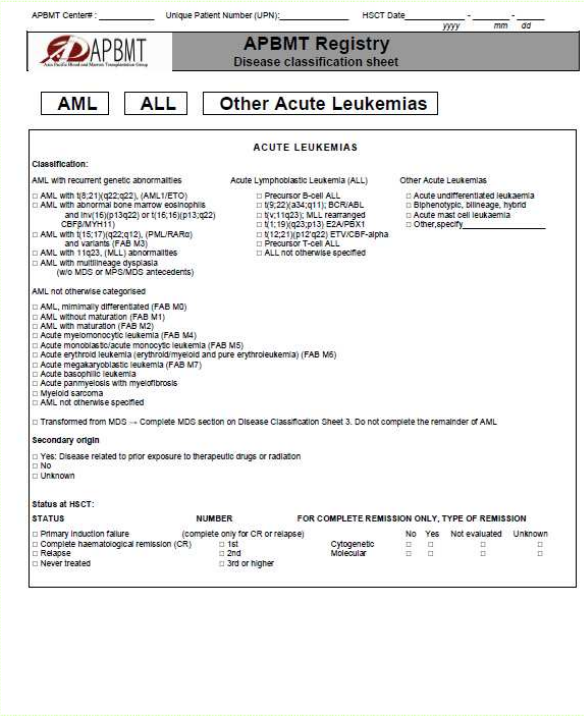
Best disease status (response) after HSCT
(prior to treatment modification in response to a post HSCT disease assessment)
□ Continued complete remission (CR)
□ CR achieved: Date achieved : _____ - _____ - _____(yyyy - mm- dd)
□ Never in CR: Date assessed : _____ - _____ - _____(yyyy - mm- dd)
□ Not evaluated

First relapse or progression after HSCT *(Not persistent disease)*
Relapse/progression detected by clinical/haematological method:
□ No: Date assessed _____ - _____ - _____ (yyyy – mm - dd)
□ Yes: Date first seen _____ - _____ - _____ (yyyy – mm - dd)
□ Not evaluated

Survival Status:
□ Alive □ Dead □ Died before HSCT
Date of last contact:
Date of last follow up or death: _____ - _____ - _____(yyyy - mm - dd)

Main Cause of Death *(check only one main cause)*:
□ Relapse or Progression/Persistent disease
□ HSCT Related Cause
(check as many as appropriate):
□ GVHD □ Cardiac Toxicity
□ Rejection/Poor graft function □ Infection
□ Pulmonary toxicity □ Veno occlusive disorder
□ Other: _____
□ Unknown
□ Other: _____

One page for day100 report



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy - mm - dd)

APBMT Registry
Disease classification sheet

AML **ALL** **Other Acute Leukemias**

ACUTE LEUKEMIAS

Classification:

AML with recurrent genetic abnormalities
□ AML with t(8;21)(q22;q22), (AML1/ETO)
□ AML with abnormal bone marrow eosinophils and inv(16)(p13q22) or t(16;16)(p13;q22) CBFB/MYH11)
□ AML with t(15;17)(q22;q12), (PML/RARα) and variants (FAB M3)
□ AML with 11q23, (MLL) abnormalities
□ AML with multilineage dysplasia (w/o MDS or MPS/MDS antecedents)

Acute Lymphoblastic Leukemia (ALL)
□ Precursor B-cell ALL
□ t(9;22)(a34;q11); BCR/ABL
□ t(v;11q23); MLL rearranged
□ t(1;19)(q23;p13) E2A/PBX1
□ t(12;21)(p12;q22) ETV/CBF-alpha
□ Precursor T-cell ALL
□ ALL not otherwise specified

Other Acute Leukemias
□ Acute undifferentiated leukaemia
□ Biphenotypic, bilineage, hybrid
□ Acute mast cell leukaemia
□ Other,specify_____

AML not otherwise categorised
□ AML, mimimally differentiated (FAB M0)
□ AML without maturation (FAB M1)
□ AML with maturation (FAB M2)
□ Acute myelomonocytic leukemia (FAB M4)
□ Acute monoblastic/acute monocytic leukemia (FAB M5)
□ Acute erythroid leukemia (erythroid/myeloid and pure erythroleukemia) (FAB M6)
□ Acute megakaryoblastic leukemia (FAB M7)
□ Acute basophilic leukemia
□ Acute panmyelosis with myelofibrosis
□ Myeloid sarcoma
□ AML not otherwise specified

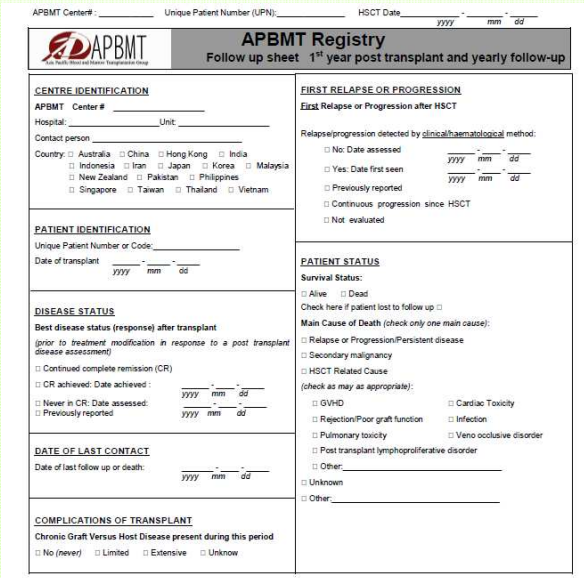
□ Transformed from MDS → Complete MDS section on Disease Classification Sheet 3. Do not complete the remainder of AML

Secondary origin
□ Yes: Disease related to prior exposure to therapeutic drugs or radiation
□ No
□ Unknown

Status at HSCT:

STATUS	NUMBER	FOR COMPLETE REMISSION ONLY, TYPE OF REMISSION				
			No	Yes	Not evaluated	Unknown
□ Primary induction failure	(complete only for CR or relapse)					
□ Complete haematological remission (CR)	□ 1st	Cytogenetic	□	□	□	□
□ Relapse	□ 2nd	Molecular	□	□	□	□
□ Never treated	□ 3rd or higher					

One page for disease items



APBMT Center# : _____ Unique Patient Number (UPN):_____ HSCT Date_____ - _____ - _____ (yyyy - mm - dd)

APBMT Registry
Follow up sheet 1st year post transplant and yearly follow-up

CENTRE IDENTIFICATION

APBMT Center # _____
Hospital: _____ Unit: _____
Contact person _____
Country: □ Australia □ China □ Hong Kong □ India □ Indonesia □ Iran □ Japan □ Korea □ Malaysia □ New Zealand □ Pakistan □ Philippines □ Singapore □ Taiwan □ Thailand □ Vietnam

PATIENT IDENTIFICATION

Unique Patient Number or Code:_____
Date of transplant _____ - _____ - _____ (yyyy - mm - dd)

DISEASE STATUS

Best disease status (response) after transplant
(prior to treatment modification in response to a post transplant disease assessment)
□ Continued complete remission (CR)
□ CR achieved: Date achieved : _____ - _____ - _____ (yyyy - mm - dd)
□ Never in CR: Date assessed: _____ - _____ - _____ (yyyy - mm - dd)
□ Previously reported

DATE OF LAST CONTACT

Date of last follow up or death: _____ - _____ - _____ (yyyy - mm - dd)

COMPLICATIONS OF TRANSPLANT

Chronic Graft Versus Host Disease present during this period
□ No *(never)* □ Limited □ Extensive □ Unknow

FIRST RELAPSE OR PROGRESSION

First Relapse or Progression after HSCT

Relapse/progression detected by clinical/haematological method:
□ No: Date assessed _____ - _____ - _____ (yyyy - mm - dd)
□ Yes: Date first seen _____ - _____ - _____ (yyyy - mm - dd)
□ Previously reported
□ Continuous progression since HSCT
□ Not evaluated

PATIENT STATUS

Survival Status:
□ Alive □ Dead
Check here if patient lost to follow up □
Main Cause of Death *(check only one main cause)*:
□ Relapse or Progression/Persistent disease
□ Secondary malignancy
□ HSCT Related Cause
(check as may as appropriate):
□ GVHD □ Cardiac Toxicity
□ Rejection/Poor graft function □ Infection
□ Pulmonary toxicity □ Veno occlusive disorder
□ Post transplant lymphoproliferative disorder
□ Other:_____
□ Unknown
□ Other:_____

One page for follow-up

Launched in July, 2010

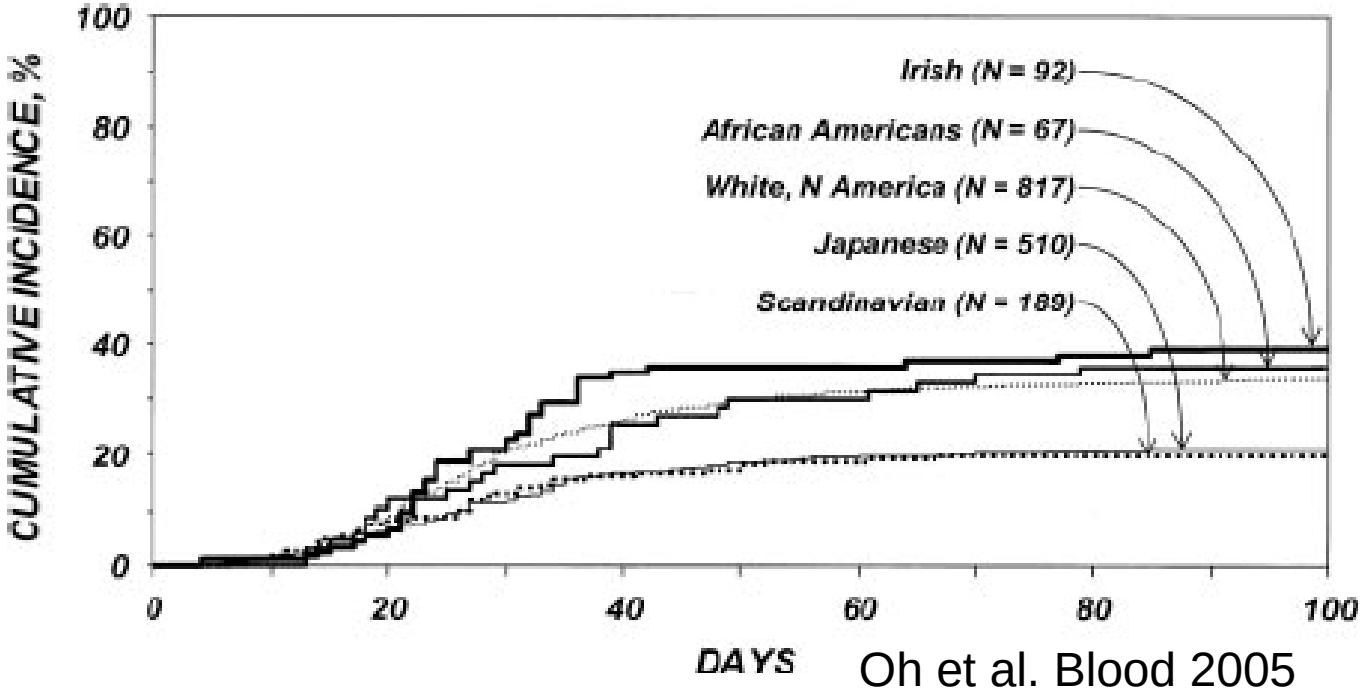
Submission status in 2011

Country / region	Participation in the APBMT Activity Survey	National (international) registry	Submission
Australia and New Zealand	Yes	Yes	No
China	Yes	No	Yes
Hong Kong	Yes	No	No
India	Yes	Under development	No
Indonesia	No	No	No
Iran	Yes	No	No
Japan	Yes	Yes	Yes
Korea	Yes	Yes	No
Malaysia	Yes	Yes	No
Pakistan	Yes	No	Yes
Phillippine	Yes	No	Yes
Singapore	Yes	No	Yes
Taiwan	Yes	Under development	Yes
Thailand	Yes	Under development	No
Vietnam	Yes	No	No

The role of APBMT Outcome Registry

- Many important clinical questions
  - Ethnic differences in outcomes

Incidence of Grade 2-4 Acute GVHD



Oh et al. Blood 2005

Why is building outcome database important?

It is important for

- Transplant teams (physicians and nurses)
- Governments
- Patients

Because

- Summarized result of the outcomes of transplant
- To find answers for clinical questions
- Leads to the improvement of transplant practice

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