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About the Center for International Blood and Marrow Transplant Research and the National Marrow Donor Program®/Be The Match®

The Center for International Blood and Marrow Transplant Research (CIBMTR) collaborates with the global scientific community to advance hematopoietic cell transplantation and cellular therapy research worldwide. A combined research program of the National Marrow Donor Program (NMDP) and the Medical College of Wisconsin, CIBMTR facilitates critical research that has led to increased survival and an enriched quality of life for thousands of patients. Our prospective and observational research is accomplished through scientific and statistical expertise, a large network of transplant centers and a clinical database of more than 330,000 transplant recipients. The CIBMTR collects outcomes data on every allogeneic transplantation performed in the U.S., as required by U.S. law. U.S. transplant centers also voluntarily submit autologous transplantation data, and transplant centers worldwide voluntarily submit both autologous and allogeneic transplantation data. Computerized checks for discrepancies, physicians' review of submitted data, and on-site audits of participating centers ensure data quality. Observational studies conducted by the CIBMTR are performed in compliance with all applicable federal regulations pertaining to the protection of human research participants. Protected Health Information used in the performance of such research is collected and maintained in CIBMTR’s capacity as a Public Health Authority under the HIPAA Privacy Rule.

NMDP/Be The Match® is the global leader in providing a cure to patients with life-threatening blood cancers - like leukemia and lymphoma - or other diseases. The nonprofit organization matches patients with their matching marrow donor or cord blood donation, educates health care professionals and conducts research so more lives can be saved. The NMDP also provides patient support and enlists the community to join the Be The Match Registry®, the world’s largest listing of potential marrow donors and donated cord blood units, or to contribute financially and volunteer.

List of Abbreviations

ALL Acute lymphoblastic leukemia
AMA American Medical Association
AML Acute myeloid leukemia
BMT Blood and marrow transplantation
CIBMTR Center for International Blood and Marrow Transplant Research
CML Chronic myeloid leukemia
FACT Foundation for the Accreditation of Cellular Therapy
FTE Full time equivalent
GVHD Graft-versus-host disease
HCT Hematopoietic cell transplantation
HLA Human leucocyte antigen
HRSA Health Resources and Services Administration
IQR Interquartile range
MDS Myelodysplastic syndrome
NMDP National Marrow Donor Program
US United States
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Introduction

Transplant Center and Provider Characteristics

Approximately 20,000 patients receive autologous or allogeneic HCT in the US each year. As a result of several advances in the field of HCT, this number is expected to steadily increase over the next decade. These advances include availability of safer transplantation techniques, availability of alternative sources of hematopoietic stem cells, expanding indications of HCT and an increase in the overall number of patients with hematologic cancers because of an aging population.

The infrastructure and resources available at transplant centers can vary. As a result, centers of similar size may have different resources and personnel and vary widely in the number of transplant procedures that they perform each year. Some of this variation is the result of center experience and local institutional forces (e.g., competition with other departments for resources and institutional commitment towards the value and services provided by the transplant program). Individual center models of delivery of care can influence the number of transplants that a center can perform efficiently. Some variation occurs due to factors outside the centers’ control. For example, referral patterns and preferences of patients, referring physicians and patient insurance providers can dictate whether a patient goes to a particular transplant center for HCT consultation.

System Capacity Barriers to the Anticipated Growth of HCT

The majority of patients who need a transplant can find a suitable donor source. Hence, human resources, structural constraints and patient access barriers have emerged as critical system capacity barriers to the anticipated growth of HCT. Human resource constraints include a projected shortage of physicians, physician assistants, nurse practitioners, nurses, pharmacists and other health care professionals who make up the HCT workforce. Structural constraints include availability of adequate facilities, efficient and safe care delivery models, and the infrastructure required to meet the demand for HCT. Key patient access barriers include health disparity issues for underserved, minority, low-income and rural populations, transportation and financial burdens, lack of caregiver support, and limited access to transplant-related patient information. The increasing number of transplant survivors will add to the resource constraints faced by transplant centers.

To understand and address system capacity challenges to the future growth of HCT, the NMDP has organized a series of multi-year symposia: “Hematopoietic Cell Transplantation in 2020: A System Capacity Initiative”. The symposia have used a deliberative process model to collaboratively develop creative options for complex issues affecting the delivery of HCT. Participants have included professionals, academic organizations, experts and other important stakeholders.

Transplant Center Survey

This report presents the results of a national survey of US transplant centers that was conducted in 2012 and describes their personnel, infrastructure and care delivery models. Survey results will assist transplant centers, policy makers, and other stakeholders understand transplant center characteristics and capacity, and will facilitate planning for the projected increase in the need for HCT in the immediate future.
Survey Findings: Adult Centers

Synopsis of Survey Design and Methods

Survey design and methods are described in detail on page 42.

The survey inquired about four broad domains: (1) physician and healthcare provider characteristics, (2) transplant unit activities and resources, (3) medical care team structure and processes, and (4) medical center characteristics.

The survey was a 42-item web-based instrument that was administered to medical directors of transplant centers in the US that reported any allogeneic HCT to the CIBMTR in calendar year 2011.

Among 108 eligible centers that provided care for adult HCT recipients, 85 responded to the survey (response rate = 79%). Total HCT volume for 2010 could not be verified for one center which was excluded from the analysis. Hence, characteristics of 84 adult centers are described in this report.

To describe survey results, centers with similar HCT volumes were combined together into one category. Adult centers were categorized into 9 size categories based on their total HCT volume (allogeneic and autologous) that was reported to the CIBMTR in calendar year 2010.
**Adult Centers: Patient Demographics**

Table A1 shows demographics of HCT recipients from centers that are included in the analysis.

**Table A1: Demographics for adult center transplant recipients***

<table>
<thead>
<tr>
<th>Variable</th>
<th>Center total HCT volume (autologous + allogeneic, 2010)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>≤ 30 HCT</td>
</tr>
<tr>
<td>Number of centers, N</td>
<td>10</td>
</tr>
<tr>
<td>Number of autologous and allogeneic HCT recipients represented, N</td>
<td>200</td>
</tr>
<tr>
<td>% of all recipients at the center who received allogeneic HCT, Median (IQR)</td>
<td>23 (13-36)</td>
</tr>
<tr>
<td>% of all allogeneic HCT recipients at the center who received myeloablative conditioning, Median (IQR)</td>
<td>50 (22-86)</td>
</tr>
<tr>
<td>% of all allogeneic HCT recipients who received unrelated donor HCT, Median (IQR)</td>
<td>0 (0-50)</td>
</tr>
<tr>
<td>% of unrelated donor allogeneic HCT recipients who received umbilical cord blood, Median (IQR)</td>
<td>0 (0-50)</td>
</tr>
</tbody>
</table>

IQR indicates interquartile range (lower quartile [25th percentile] and upper quartile [75th percentile])

* Based on data submitted by centers to the CIBMTR for HCT performed in calendar year 2010
**Adult Centers: Hospital Characteristics**

Most centers (N=67, 80%) were affiliated with a teaching hospital (hospital with an AMA-approved residency program or member of the Council of Teaching Hospitals) (Figure A1).

**Figure A1: Affiliation with teaching hospital**

![Figure A1: Affiliation with teaching hospital](chart1.png)

Centers were privately owned (N=62, 74%; non-profit 92% and for-profit 8%) or government owned (N=22, 26%; non-federal 77% and federal 23%) (Figure A2).

**Figure A2: Center ownership**

![Figure A2: Center ownership](chart2.png)
Thirty-seven (44%) centers were affiliated with a National Cancer Institute Comprehensive Cancer Center (Figure A3)

**Figure A3: NCI Comprehensive Cancer Center Affiliation**

Hospital size, defined as the total number of inpatient hospital beds for all services, varied among centers (Figure A4)

**Figure A4: Hospital size**
Most centers used an electronic medical record in the inpatient and/or outpatient setting (N=78, 93%). Most centers with electronic medical record capability used it both in the inpatient and outpatient settings (N=62, 79%) and reported that their system allowed electronic order entry for medications (N=73, 94%) (Figure A5).

**Figure A5: Availability of electronic medical record**

![Figure A5: Availability of electronic medical record](image)
**Adult Centers: Inpatient Resources**

Most centers had inpatient beds exclusively dedicated for the care of HCT recipients (N=78, 93%). Among these 78 centers, beds were located either within a standalone BMT unit (N=52, 67%) or as part of a hematology-oncology unit (N=26, 33%) (Figure A6).

*Figure A6: Location of inpatient beds for HCT*

Among these 78 centers, the number of beds varied by center size (Figure A7).

*Figure A7: Number of inpatient beds dedicated to care of HCT recipients*
Figure A8 shows the number of transplants per bed for these 78 centers.

* N=78 centers with dedicated inpatient beds for HCT
Adult Centers: Outpatient Resources

Most centers had a separate outpatient clinic (standalone or as part of another ambulatory area) dedicated to the care of HCT recipients (N=54, 64%) (Figure A9).

Figure A9: Availability of dedicated outpatient clinic for HCT

![Figure A9](image)

Among the 54 centers with a dedicated outpatient clinic area for HCT patients, infusion chairs were available in 52 (96%) centers (Figure A10).

Figure A10: Availability of infusion chairs in outpatient clinic*

![Figure A10](image)

* N=54 centers with dedicated outpatient clinic area for HCT
Forty-eight (57%) centers reported that they performed outpatient autologous and/or allogeneic transplants (transplantation intended to avoid some or all inpatient hospitalization between onset of conditioning and neutrophil engraftment) (Figure A11).

**Figure A11: Outpatient transplants**

![Outpatient transplants chart](image)
Adult Centers: Other Center Resources

Most centers had a stem cell processing laboratory on site/on campus (N=75, 89%). In most centers, these laboratories were FACT accredited (Figure A12).

**Figure A12: Stem cell processing laboratory on site**

Center participation in clinical trials through a cancer cooperative group within the previous 12 months varied (e.g., BMT CTN, Alliance for Clinical Trials, ECOG, SWOG, COG) (Figure A13).

**Figure A13: Participated in cooperative group clinical trial in past 12 months**
Some programs had a dedicated survivorship clinic (or long-term followup clinic) and/or chronic GVHD clinic (Figure A14).

**Figure A14: Availability of survivorship or chronic GVHD clinic**

Most programs were affiliated with a hematology and/or oncology fellowship training program (N=67, 80%) (Figure A15).

**Figure A15: Affiliation with hematology and/or oncology fellowship program**
**Adult Centers: FACT Accreditation**

Most centers were FACT accredited (N=80, 95%). Among FACT accredited centers, most were accredited for both autologous and allogeneic HCT (N=72, 90%) (Figure A16).

*Figure A16: FACT accreditation status*
Adult Centers: Center Personnel

The number of attending physicians who provided clinical care for HCT recipients, irrespective of an individual physician’s clinical effort dedicated to transplantation, varied by center size (Figure A17).

Figure A17: Number of BMT attending physicians

![Figure A17: Number of BMT attending physicians](image)

Figure A18 shows the number of transplants performed per attending physician.

Figure A17: Number of transplants per attending physician

![Figure A17: Number of transplants per attending physician](image)
The clinical effort of BMT attending physicians (care of HCT recipients vs. non-HCT patients) varied among centers (Figure A19).

**Figure A19: Clinical effort of the majority (>50%) of attending physicians**

Most programs (N=78, 93%) used mid-level providers (i.e. nurse practitioner or physician assistant) to assist with the clinical care of HCT recipients (Figure A20).

**Figure A20: Number of BMT mid-level providers**
Figure A21 shows the number of transplants performed per provider among the 78 programs that used mid-level providers.

**Figure A21: Number of transplants per mid-level provider**

The average daily nurse-to-patient ratio in the inpatient unit varied among centers (Figure A22).

**Figure A22: Average daily inpatient nurse-to-patient ratio**
The number of transplant coordinator positions varied among centers (Figure A23). The survey asked centers to only report FTEs of coordinators who were involved in the clinical care of transplant patients and exclude FTEs that were dedicated to non-clinical activities such as research. Coordinators could be nurses or other individuals who provided clinical care to HCT recipients.

**Figure A23: Transplant coordinator positions (FTEs)**

The number of pharmacists (inpatient and/or outpatient) who provided care to HCT recipients also varied among centers (Figure A24).

**Figure A24: BMT pharmacist positions (FTEs)**
The number of psychosocial clinicians (e.g., social workers, psychologists) who provided inpatient and/or outpatient care for HCT recipients varied among centers (Figure A25).

Figure A25: BMT psychosocial clinician positions (FTEs)
**Adult Centers: Care Team Models**

The survey inquired about providers who typically participate as a member of the inpatient care team. Besides the attending physician, inpatient care teams at most centers included a hematology-oncology or BMT fellow trainee (N=54, 64%) (Figure A26). Some centers also used resident trainees (N=20, 24%) and other physicians (e.g., hospitalists; N=11, 13%). Centers frequently used mid-level providers (N=65, 77%) and pharmacists (N=73, 87%) (Figure A27). Some centers also reported other providers as routine inpatient care team members (e.g., psychosocial clinicians, dieticians).

**Figure A26: Inpatient care team: Physician providers**

**Figure A27: Inpatient care team: Non-physician providers**
In most centers, patients needing ventilator support were cared for in the critical care unit (N=67, 80%) (Figure A28).

**Figure A28: Inpatient unit for HCT recipients requiring ventilator support**

For the first 100-days post-transplant, physician care models varied between: (1) one physician overseeing care of a patient in the inpatient and outpatient setting (N=11, 13%), (2) more than one physician (e.g., rotating service) for inpatient and one physician for outpatient setting (n=53, 63%), and (3) rotating service for both inpatient and outpatient settings (N=20, 24%) (Figure A29).

**Figure A29: Physician care model for first 100-days post-transplant**
Most centers used a mid-level provider to assist with the care of HCT recipients in the outpatient setting (N=75, 89\%) (Figure A30).

**Figure A30: Mid-level provider role in outpatient care of HCT recipients**
Adult Centers: Discharge Practices

The survey inquired about discharge practices for the majority of allogeneic and autologous HCT recipients (Figure A31 and Figure A32). Centers could respond: (1) varies from provider to provider, (2) referred back to oncologist at a definite time point (e.g., day 100) and typically do not follow at center if no BMT related issues, (3) referred back to oncologist at a definite time point and followup at the center at periodic intervals after HCT, or (4) do not discharge to referring oncologist.

Figure A31: Discharge practices for majority of allogeneic HCT recipients

Figure A32: Discharge practices for majority of autologous HCT recipients
Survey Findings: Pediatric Centers

Synopsis of Survey Design and Methods

Survey design and methods are described in detail on page 42.

The survey inquired about four broad domains: (1) physician and healthcare provider characteristics, (2) transplant unit activities and resources, (3) medical care team structure and processes, and (4) medical center characteristics.

The survey was a 42-item web-based instrument that was administered to medical directors of transplant centers in the US that reported any allogeneic HCT to the CIBMTR in calendar year 2011.

Among 66 eligible centers that provided care for pediatric HCT recipients, 54 responded to the survey (response rate = 82%). Total HCT volume for 2010 could not be verified for one center which was therefore excluded from the analysis. Hence, characteristics of 53 pediatric centers are described in this report.

To describe survey results, centers with similar HCT volumes were combined together into one category. Pediatric centers were categorized into 6 size categories based on their total HCT volume (allogeneic and autologous) that was reported to the CIBMTR in calendar year 2010.
Pediatric Centers: Patient Demographics

Table P1 shows demographics of HCT recipients from centers that are included in the analysis.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Center total HCT volume (autologous + allogeneic, 2010)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>≤ 10 HCT</td>
</tr>
<tr>
<td>Number of centers, N</td>
<td>7</td>
</tr>
<tr>
<td>Number of autologous and allogeneic HCT recipients represented, N</td>
<td>52</td>
</tr>
<tr>
<td>% of all recipients at the center who received allogeneic HCT, Median (IQR)</td>
<td>65 (60-71)</td>
</tr>
<tr>
<td>% of all allogeneic HCT recipients at the center who received myeloablative conditioning, Median (IQR)</td>
<td>63 (50-83)</td>
</tr>
<tr>
<td>% of all allogeneic HCT recipients at the center who received unrelated donor HCT, Median (IQR)</td>
<td>65 (50-100)</td>
</tr>
<tr>
<td>% of unrelated donor allogeneic HCT recipients who received umbilical cord blood, Median (IQR)</td>
<td>50 (20-100)</td>
</tr>
</tbody>
</table>

IQR indicates interquartile range (lower quartile [25th percentile] and upper quartile [75th percentile])

* Based on data submitted by centers to the CIBMTR for HCT performed in calendar year 2010
Pediatric Centers: Hospital Characteristics

Most centers (N=49, 93%) were affiliated with a teaching hospital (hospital with an AMA-approved residency program or member of the Council of Teaching Hospitals) (Figure P1).

Figure P1: Affiliation with teaching hospital

Centers were predominantly located in privately owned institutions (N=49, 93%; non-profit 98% and for-profit 2%) (Figure P2).

Figure P2: Center ownership
Twenty eight (53%) centers were affiliation with a National Cancer Institute Comprehensive Cancer Center (Figure P3).

Figure P3: NCI Comprehensive Cancer Center Affiliation

Hospital size based on the total number of inpatient hospital beds for all services varied among centers (Figure P4). The survey did not capture whether the transplant program was a part of a standalone children’s hospital.

Figure P4: Hospital size
Most centers used an electronic medical record in the inpatient and/or outpatient setting (N=49, 93%). Most centers with electronic medical record capability used it both in the inpatient and outpatient settings (N=41, 84%) and reported that their system allowed electronic order entry for medications (N=45, 92%) (Figure P5).

**Figure P5: Availability of electronic medical record**
Pediatric Centers: Inpatient Resources

Most centers had inpatient beds exclusively dedicated for the care of HCT recipients (N=49, 93%). Among these 49 centers, the beds were located within a standalone BMT unit in 27 (55%) centers (Figure P6).

Figure P6: Location of inpatient beds for HCT*

* N=49 centers with dedicated inpatient beds for HCT

Among these 49 centers, the number of beds varied by center size (Figure P7).

Figure P7: Number of inpatient beds dedicated to care of HCT recipients

* N=49 centers with dedicated inpatient beds for HCT
Figure P8 shows the number of transplants performed per bed for these 49 centers.

**Figure P8: Number of transplants per inpatient bed**

* N=49 centers with dedicated inpatient beds for HCT
Pediatric Centers: Outpatient Resources

Several centers had a separate outpatient clinic (standalone or as part of another ambulatory area) dedicated for the care of HCT recipients (N=34, 64%) (Figure P9).

Figure P9: Availability of dedicated outpatient clinic for HCT

Among the 34 centers with a dedicated outpatient clinic area for HCT patients, infusion chairs were available in 29 (85%) centers (Figure P10)

Figure P10: Availability of infusion chairs in outpatient clinic*

* N=34 centers with dedicated outpatient clinic area for HCT
Few centers (N=10, 19%) performed outpatient transplantation (transplantation intended to avoid some or all inpatient hospitalization between onset of conditioning and neutrophil engraftment) (Figure P11).

Figure P11: Outpatient transplants
Pediatric Centers: Other Center Resources

Most centers had a stem cell processing laboratory on site/on campus (N=37, 70%). In most centers, these laboratories were FACT accredited (Figure P12).

Figure P12: Stem cell processing laboratory on site

Most centers participated in clinical trials through a cancer cooperative group within the previous 12 months (e.g., BMT CTN, COG) (Figure P13).

Figure P13: Participated in cooperative group clinical trial in past 12 months
Several programs (N=34, 64%) had a dedicated survivorship clinic (or long-term followup clinic) and/or chronic GVHD clinic (Figure P14).

**Figure P14: Availability of survivorship or chronic GVHD clinic**

Most programs were affiliated with a hematology oncology fellowship training program (N=43, 81%) (Figure P15).

**Figure P15: Affiliation with hematology oncology fellowship program**
Pediatric Centers: FACT Accreditation

Most centers were FACT accredited (N=49, 93%). Among FACT accredited centers, most were accredited for both autologous and allogeneic HCT (N=48, 98%) (Figure P16).

Figure P16: FACT accreditation status
Pediatric Centers: Center Personnel

Figure P17 shows the number of attending physicians who provided clinical care for HCT recipients, irrespective of an individual physician’s clinical effort dedicated to transplantation (Figure P17).

Figure P17: Number of BMT attending physicians

Figure P18 shows the number of transplants performed per transplant physician.

Figure P18: Number of transplants per attending physician
The clinical effort of BMT attending physicians (care of HCT recipients vs. non-HCT patients) varied among centers (Figure P19).

**Figure P19: Clinical effort of the majority (>50%) of attending physicians**

Most programs (N=51, 96%) used mid-level providers (i.e. nurse practitioner or physician assistant) to assist with the clinical care of HCT recipients (Figure P20).

**Figure P20: Number of BMT mid-level providers**
Figure P21 shows the number of transplants performed per provider among the 51 programs that used mid-level providers.

**Figure P21: Number of transplants per mid-level provider**

The average daily nurse-to-patient ratio in the inpatient unit varied among centers (Figure P22).

**Figure P22: Average daily inpatient nurse-to-patient ratio**
The number of transplant coordinator positions varied among centers (Figure P23). The survey asked centers to report FTEs of coordinators who were involved in the clinical care of transplant patients and exclude FTEs that were dedicated to non-clinical activities such as research. Coordinators could be nurses or other individuals who provided clinical care to HCT recipients.

**Figure P23: Transplant coordinator positions (FTEs)**

The number of pharmacists (inpatient and/or outpatient) who provided care to HCT recipients also varied among centers (Figure P24).

**Figure P24: BMT pharmacist positions (FTEs)**
The number of psychosocial clinicians (e.g., social workers, psychologists) who provided inpatient and/or outpatient care for HCT recipients varied among centers (Figure P25).

**Figure P25: BMT psychosocial clinician positions (FTEs)**
Pediatric Centers: Care Team Models

The survey inquired about providers who typically participate as a member of the inpatient care team. Besides the attending physician, inpatient care teams at most centers included a hematology-oncology or BMT fellow trainee (N=36, 68%) (Figure P26). Centers also used resident trainees (N=24, 45%) and other physicians (e.g., hospitalists; N=10, 19%). Centers frequently used mid-level providers (N=45, 85%) and pharmacists (N=47, 89%) (Figure P27). Centers also reported other providers as routine inpatient care team members (e.g., psychosocial clinicians, dieticians).

Figure P26: Inpatient care team: Physician providers

Figure P27: Inpatient care team: Non-physician providers
In most centers, patients needing ventilator support were cared for in the critical care unit (Figure P28).

**Figure P28: Inpatient unit for HCT recipients requiring ventilator support**

For the first 100-days post-transplant, physician care models varied between: (1) one physician overseeing care of a patient in the inpatient and outpatient setting (N=9, 17%), (2) more than one physician (e.g., rotating service) for inpatient and one physician for outpatient setting (n=28, 53%), and (3) rotating service for both inpatient and outpatient settings (N=16, 30%) (Figure P29).

**Figure P29: Physician care model for first 100-days post-transplant**
Most centers used a mid-level provider to assist with the care of HCT recipients in the outpatient setting (N=48, 91%) (Figure P30).

**Figure P30: Mid-level provider role in outpatient care of HCT recipients**
Pediatric Centers: Discharge Practices

The survey inquired about discharge practices for the majority of allogeneic and autologous HCT recipients (Figure P31 and Figure P32). Centers could respond: (1) varies from provider to provider, (2) referred back to oncologist at a definite time point (e.g., day 100) and typically do not follow at center if no HCT related issues, (3) referred back to oncologist at a definite time point and followup at the center at periodic intervals after HCT, or (4) do not discharge to referring oncologist.

Figure P31: Discharge practices for majority of allogeneic HCT recipients

Figure P32: Discharge practices for majority of autologous HCT recipients
Survey Design and Methods

Survey Domains

The survey inquired about four broad domains of provider and center characteristics (Figure M1).

Survey Development and Administration

The survey was developed in consultation with the Protocol Team that included transplant center medical directors and experts in health services and survey research. The final instrument was a 42-item web-based instrument.

Transplant center medical directors were the primary audience for this survey, although they were given the option to forward the survey to a colleague who was familiar with the information being asked (e.g., physician or center administrator). Eighty-eight percent of survey respondents were transplant center medical directors.

The survey was piloted with medical directors of 5 transplant centers (3 adult centers, 1 pediatric center and 1 combined adult-pediatric center) to evaluate survey content validity and to obtain an estimate of the time needed to complete the survey.

The survey was administered using web-based survey software (SurveyGizmo). Based on the results of the survey pilot, we estimated it would take 15-20 minutes for respondents to complete the survey. An incentive of $50 in the form of a VISA gift card was provided to survey respondents.
Medical directors were invited to participate in the survey via email and scheduled email reminders were sent to non-respondents. The study Protocol Chair provided a phone reminder to center medical directors who had not responded to the series of planned email reminders.

The study was conducted under guidance from the NMDP’s Institutional Review Board.

**Center Selection for the Survey**

The survey was administered to transplant centers in the US that reported any allogeneic HCT to the CIBMTR in the calendar year 2011.

The CIBMTR holds a contract from the Health Resources and Services Administration to maintain the US Stem Cell Therapeutic Outcomes Database part of the C.W. Bill Young Transplantation Program. Under the purview of this Program that went into effect in 2007, transplant centers in the US are mandated to report outcomes for all allogeneic HCT recipients to the CIBMTR. Hence, the CIBMTR captures nearly all allogeneic HCT activity in the country. In addition, we estimate that the CIBMTR captures approximately 80% of autologous HCT activity in the US.

Some institutions with separate pediatric and adult transplant programs submit data to the CIBMTR as one center. In 2011, there were 41 such combined centers. We established multiple processes to determine whether these 41 centers had a “true” combined pediatric-adult program versus standalone adult and pediatric programs. First, we examined the age distribution of all HCT recipients reported by these centers to the CIBMTR. Second we conducted a survey of transplant center data personnel to inquire about the organization of pediatric and adult programs at these centers. Finally, we contacted the medical directors of each program for this information. Centers with one medical director for both pediatric and adult programs were classified as “true” combined pediatric and adult programs. For centers with separate medical directors, we invited the medical director of both the pediatric and adult programs to participate in the survey.

In 2011, 172 transplant centers in the US reported allogeneic HCT to the CIBMTR and were eligible to participate in the survey (Figure M2). Among these centers, 89 reported allogeneic transplants on adult recipients, 42 on pediatric recipients and,
as noted above, 41 reported data on both pediatric and adult recipients. As described above, we obtained further information from the 41 centers that reported data on both the pediatric and adult age groups. From these, 26 centers were determined to be standalone pediatric and adult programs with separate medical Directors and 15 centers were classified as “true” combined pediatric-adult programs.

Based on this assignment, a total of 198 US transplant centers were eligible for our study and included 115 adult programs, 68 pediatric programs and 15 combined pediatric-adult programs. This report describes survey results for adult and pediatric centers. Combined pediatric-adult centers are not described given their small number and large variability in transplant volume.

**Survey Response Rate**

From the 183 adult and pediatric centers invited to participate in the survey, 9 centers were deemed ineligible for inclusion in the final analysis. Reasons included (1) centers had reported no allogeneic HCT to the CIBMTR in 2008-2010 (N=6 centers; a secondary objective of the survey study was to investigate associations between center factors and allogeneic HCT survival), (2) centers were no longer active at the time of the survey (N=2 centers), or (3) center was not independent (N=1 center which reported data to the CIBMTR separately but shared most resources and personnel with the primary transplant program at that institution). From these 174 eligible adult and pediatric centers, survey response rate was 79% for adult centers (85/108 centers) and 82% for pediatric centers (54/66 centers).

Some centers do not routinely report all autologous HCT activity to the CIBMTR. We identified these centers from survey respondents and contacted them to verify their autologous HCT volume for 2010. We were not able to verify autologous HCT volumes for two centers (1 adult, 1 pediatric) and they were excluded from the analysis. Hence, the survey report describes characteristics for 84 adult and 53 pediatric programs.

The centers that did not respond to the survey were generally small volume centers. Among adult non-responding centers, the median total HCT volume in 2010 was 46 (compared to median volume of 101 for responding centers). Among pediatric non-responding centers, the median total HCT volume in 2010 was 16 (compared to median volume of 25 for responding centers).

**Patient Data**

Patient demographic, disease and transplant related information was obtained from the CIBMTR (see [www.cibmtr.org](http://www.cibmtr.org) for more details). CIBMTR participating centers report these data for all consecutive transplants. Patients are then followed longitudinally until they die or are lost to follow up. Computerized checks for discrepancies, physicians’ review of submitted data and on-site audits of participating centers ensure data quality.

**Center Size Categories**

For describing survey results, centers were categorized based on their total HCT volume (allogeneic and autologous) that was reported to the CIBMTR in the calendar year 2010. There was good
correlation between the total HCT and allogeneic HCT volume for centers included in the analysis (Figure M3).

**Figure M3: Correlation between center total HCT and allogeneic HCT volumes**

To meaningfully describe center characteristics, centers with similar total HCT volumes were grouped together, such that each category included approximately 10 centers. Adult centers (N=84)
were grouped into 9 categories (Figure M4) and pediatric centers (N=53) were grouped into 6 categories (Figure M5).

Figure M4: Center size categories (adult centers)

Figure M5: Center size categories (pediatric centers)
Survey Limitations

Some caveats have to be considered in interpreting the survey data. The survey reports resources that were available at transplant centers at the time of its administration. It does not necessarily represent what may be considered optimal for the number of transplants performed at a given center. Centers could be recruiting personnel or in the process of expanding their facilities and this was not captured by the survey. Some providers may not dedicate all their time to the clinical care of HCT recipients (e.g., work part-time or spend time doing research or taking care of non-transplant patients) and the actual transplant specific FTE’s of physicians and mid-level providers at centers may be lower than their total number. There is considerable variation in how transplant centers are structured and innovatively utilize their available resources. Two centers with the same annual transplant volume and comparable transplant outcomes could have very different resource profiles. Hence, we caution using these data for “benchmarking” infrastructure and personnel for transplant centers.
References


