INTERLINK is always striving to improve its educational tools which guide candidates through one of the most important decisions of their life: selecting the transplant facility and team. The quality of the transplant will impact the recipient for the remainder of their life, so hopefully they will consider the many options open to them. With disappearing lifetime benefit limits, choosing a transplant team wisely has become even more important for the patient and the health plan. There is a lot of transplant data available on the web, and this webinar is designed as a guided tour of the most relevant websites and discussions around how and when to share those outcome sources and measures. This segment is designed to include a more in-depth review of the primary sites and incorporates a Comparison Spreadsheet to record and compare transplant program outcomes.

Section Objectives:

- To navigate primary CLINICAL transplant websites to find volume and outcomes data.
- Develop a conversational understanding of the primary CLINICAL measures and be able to communicate them to patients.
- To become familiar with GENERAL resource transplant websites and how they may be used.
- To understand how website data can be applied in every day transplant case management.

Transplant Web Resources
There are several transplant websites available to the public that are excellent resources for gathering information and comparing transplant centers. The websites we will tour consolidate transplant program outcome information, review it for inconsistency and subsequently post the program outcomes in tables in an apples-to-apples comparison format. Some of the websites, such as the Scientific Registry of Transplant Recipients (SRTR) and Stem Cell Therapeutic Outcomes Database (SCTOD), employ statistical methods to adjust outcomes to reflect the risks of the transplant recipient population for a specific reporting period. In all of healthcare, transplant outcome data, transplant pricing and program performance information is perhaps the most transparent of all.

There are often deeper levels of information made available to transplant networks. Clinical information supplied by the primary CLINICAL websites serves as the foundation for nearly all COE programs. In the early days, COE networks created time-intensive Request For Information (RFI) and providers were required to complete them for initial consideration and annually thereafter to retain their COE status. The CLINICAL websites greatly simplified the process for both the centers and networks for exchanging information. Now most networks use web data, gather additional information from private web access, and often supplement those data sources with a short RFI for specific information. If you feel your candidate would benefit from deeper levels of information, you should contact your COE vendor as they likely have it.

The difficulty with transplant CLINICAL outcomes and websites is that information is often broken down into so many different tables and charts it becomes hard to determine what is important. In our web tour we intend to take you to specific websites and review with you selective tables of information. In an attempt to simplify transplant outcome websites, we are going to break them into three categories:

1) Websites with CLINICAL information
2) Websites with GENERAL information
3) Websites with PROGRAM specific information
Websites with Clinical Information

When gathering information about volumes and outcomes, you will be gathering that information from websites containing clinical transplant outcome information. There are many websites that contain clinical information, but for transplant care there are two primary websites for solid organ outcomes and two websites for bone marrow transplantation information. From these four websites, you can gather nearly all the volume and outcome information needed to have a meaningful and productive conversation with your member.

Solid Organ Websites with Clinical Information

The Organ Procurement and Transplant Network (OPTN)

History: The U.S. Congress established the Organ Procurement and Transplantation Network (OPTN) when it enacted the National Organ Transplant Act (NOTA) of 1984. The act called for a unified transplant network to be operated by a private, non-profit organization under federal contract.

The United Network for Organ Sharing (UNOS) was awarded the initial OPTN contract on September 30, 1986, and has continued to administer the OPTN process for more than 16 years and spanned four successive contract renewals.

How this works: When a candidate is “listed,” a transplant team has determined the patient meets transplant criteria, and has placed them on the national organ waiting list maintained by the United Network of Organ Sharing (UNOS). All organs and all patients are paired through UNOS according to very tightly defined criteria. There are many advantages of having one organization track and pair organs, such as:
• Once procured, many organs must be transplanted quickly and UNOS creates an expedited distribution process so few organs are wasted.

• To receive an organ, it often is awarded to the sickest person on the list, so uniform reporting criteria is employed for fairness.

• All patients and organs listed at the same organization ensures these life saving organs are used appropriately and fairly.

OPTN is the website you will use to gather transplant outcome information like:

• Wait List Information

• Number of transplants performed by organ type and year

**Website Specifics:**

• [http://optn.transplant.hrsa.gov](http://optn.transplant.hrsa.gov)

• Data Update Frequency: regularly

• Direct Website Links: Included on the Comparison Worksheet

• Resources Available: MELD/PELD calculator

• Transplant Living Guide for patients and families – [www.transplantliving.org](http://www.transplantliving.org)

• OPTN Policies
Scientific Registry of Transplant Recipients (SRTR)

**History:** The Scientific Registry of Transplant Recipients (SRTR) supports the ongoing evaluation of the status of solid organ transplantation in the United States. It is administered by the Chronic Disease Research Group of the Minneapolis Medical Research Foundation.

Their responsibilities include designing and carrying out rigorous scientific analyses of data and disseminating information to the transplant community, including transplant programs, organ procurement organizations, policy makers, transplant professionals, transplant recipients, organ donors and donor families, and the general public. In addition, the SRTR helps facilitate research in the area of solid organ transplantation by providing access to data for qualified researchers interested in studying various aspects of solid organ transplantation.

The U.S. organ transplantation system employs evidence-based allocation policy development through collaborative efforts between the transplant community, the SRTR, and the Organ Procurement and Transplantation Network (OPTN). While policy-making is the OPTN's responsibility, the SRTR plays a critical role in policy development through ongoing data analyses designed to provide policy makers with the information necessary to make informed decisions.

**How this works:** SRTR provides valuable resources to health plans, COE networks, healthcare professionals, and transplant candidates. A foundation concept for COE is that transplant teams have varying skill levels and transplant outcomes are not the same. What SRTR provides is risk adjusted outcomes that are helpful tools when evaluating transplant programs. For example, low risk transplants may happen at the local medical center (who posts stellar outcomes) and highly complex cases are referred to regional or national centers (who transplant low risk and high risk patients) and their unadjusted outcomes may not appear stellar. SRTR adjusts outcomes for patient mix, which makes comparison possible.
In reality, however, it is often wise to encourage your member to use a regional or national transplant team because should their condition deteriorate rapidly or a complication occur (always possible) national programs have the breadth and depth of services and experience to overcome most situations.

SRTR is the website you will use to gather transplant outcome information like:

- Patient survival – one month, one year and three years
- Graft survival – one month, one year and three years
- Median wait time – all blood types
- Other patient outcome data

**Website Specifics:**

- [www.srtr.org](http://www.srtr.org)
- Data update Frequency: biannually
- Direct Website Links: Included on the Comparison Worksheet
Blood and Marrow Websites with Clinical Information

National Marrow Donor Program (NMDP)

**History/Overview:** The NMDP registry — now called the Be The Match Registry — has grown to 9 million donors and nearly 145,000 umbilical cord blood units, the largest and most racially and ethnically diverse registry of its kind in the world.

Medical advances are making marrow and umbilical cord blood transplants available to more patients all the time. Since the NMDP began operations in 1987, they have facilitated more than 43,000 transplants to give patients a second chance at life. Today, they facilitate more than 5,200 transplants a year.

The National Marrow Donor Program® (NMDP) collects data on unrelated donor hematopoietic cell transplants through its Network of affiliated medical organizations. On their website, use the links to see survival graphs illustrating outcomes by disease for both adult and pediatric patients. Each graph includes statistics describing the number of transplants coordinated by the NMDP for the disease and a brief explanation of statistically significant differences in outcomes.

**How this works:** The NMDP is an excellent source of information for transplant candidates who are unable to provide marrow for themselves (autologous) and also do not have a family match (related donor allogeneic) donor available. This website provides excellent educational and survival information for those likely to receive marrow from an unrelated donor or a cord blood for their transplant.

If you have a potential unrelated donor or cord blood transplant candidate, this is an excellent site for information.

- [www.marrow.org](http://www.marrow.org)
- Lists all NMDP facilities
• Provides unrelated and cord blood units to BMT programs
• Currently facilitate > 5,200 transplants a year
• Survival outcomes by disease type
• Match likelihood
• Medical Information / Preparing for an unrelated donor transplant

Center for International Blood and Marrow Transplant Research

History: 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® 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. Their prospective and observational research is accomplished through scientific and statistical expertise, a large network of transplant centers and a clinical database of 340,000 transplant recipients.

How this works: There has been an ongoing dialog over the years about why bone marrow transplants cannot be compared though survival outcomes, because any one program’s population for comparison is too small and the number of patient co-morbidities too high. The good news is that there has been some advancement in this discussion and those outcomes are being released on the CIBMTR website. 100 day survival data is now emerging by transplant program, which is the first outcome comparable data for HCT transplantation. It is likely that over time, there may be many more comparative outcomes available.

• http://www.cibmtr.org
• Brings together expertise and resources of two leaders in the field of blood and marrow transplant research; The NMDP & Medical College of Wisconsin’s International Bone Marrow Transplant Registry and Autologous Blood and Marrow Transplant Registry

• Goal of the partnership is to design, conduct and support clinical trials that involve large number of patients from multiple transplant centers

Administrative and General Education Websites

The websites listed below are what we call ADMINISTRATIVE websites. These organizations make information available through their websites about standards programs must meet to provide transplant services, the transplant process and new emerging treatments. These are great websites to visit and learn more about the transplant process. COE networks use them throughout the year to gather credentialing information, UNOS changes in policy and emerging treatments for our members.

It is unlikely that the website webinar will be able to visit all of the websites below, please take time to explore and become familiar with these sites on your own.

CMS – Center for Medicare and Medicaid Services

• http://www.cms.hhs.gov/CertificationandCompliance/Downloads/ApprovedTransplantPrograms.pdf

• Generally, health plans require the transplant program to be CMS approved for consideration as a covered benefit

UNOS – United Network for Organ Sharing

• www.unos.org

• Non-profit, scientific and educational organization

• Collect and manage data about every transplant event occurring in the U.S.
- Facilitate the organ matching and placement process
- Develop organ transplantation policies

FACT – Foundation for the Accreditation of Cellular Therapy
- www.factwebsite.org
  - Establishes standards for high quality medical and laboratory practice in cellular therapies

BMT /CTN – The Blood and Marrow Transplant (BMT) Clinical Trials Network (CTN)
- https://web.emmes.com/study/bmt/index.html
  - Established October 2001 to conduct large multi-institutional clinical trials
  - Consists of 16 Core Clinical Centers

BMT Infonet – Blood and Marrow Transplant Information Network
- www.bmtinfonet.org
- Provides BMT education information on:
  - Transplant centers
  - Drug database
  - Resource directory

TRANSPLANT PROGRAM WEBSITES
Even though we will not be visiting a transplant program website during the webinar series, we thought we should discuss them with you and how they might benefit you and your members. There is a lot of great information on a specific TRANSPLANT CENTER AND PROGRAM website. Program history, transplant team and staff, pictures of the facility, special recognitions and access instructions can all be gathered from these websites. Although the primary purpose of a PROGRAM website is to attract new business, it is a comforting process to have your candidates familiarize themselves with the transplant program they may likely use.

For our AATMC nurses, we recommend contacting the INTAKE transplant coordinator for much of the information you need. There is little commonality among website design and layout and often the information you need can be gathered easily through the transplant coordinator.

**INTERLINK Health Services Transplant Resources**

After talking to reinsurers for many years, it is our opinion that the two primary reasons transplant cases are moved from one case management vendor to another has to do with timely access to transplant specific data and the ability to participate in the candidate facility selection process. Transplant programs are often selected very quickly, and to participate in that decision process requires prompt access to transplant type information, the ability to gather key outcomes measures quickly and the ability to communicate that information to the member. We will cover these tools briefly during the AATMC webinar series.

The **INTERLINK Quick Reference Guide (QRG)** contains information on each transplant type providing a compilation of all relevant information about transplant indicators, procedures, costs and frequencies. Within the guide there is a resource section for case managers that should be useful in advising patients and their families about finances, travel, support organizations and other non-medical aspects of their referral to a transplant center. In addition, there are a number of website references containing valuable information about organ transplantation and transplant programs within the United States.
The INTERLINK Candidate Education Booklet is meant to assist patients and their family support system as they navigate through the transplant process starting with selecting a transplant center. Our booklet is customized to provide solid organ or hematopoietic stem cell (HCT) information. Some of the various sections of discussion include: seeking transplantation on a national basis, frequently asked questions concerning solid organ or HCT transplantation along with patient resources, such as, a housing guide, network map, web links, and so on. The Candidate Education Booklet is an important tool that your member can have by their side throughout their transplant continuum of care.

The INTERLINK Facility Outcome Data Sheets provide a snapshot of program specific transplant data and facts. These data sheets provide a starting point for researching transplant-specific information on each “Centers of Excellence” transplant program. A facility program transplant data sheet is inserted in each Candidate Education Booklet. This booklet is available upon request.

The INTERLINK Medical Roundtable series is targeted to case managers and other healthcare professionals. This educational program was established to educate our clients about various facets of transplantation. INTERLINK’s Medical Team hosts a Round Table Webinar discussion for 1 hour 8-10 times per year. During this time, INTERLINK invites medical experts from its transplant “COE” Network to speak on specific topics related to transplantation. At the end of each discussion, time is provided for a question and answer session. A number of our Medical Roundtable presentations are certified by the Commission for Case Manager Certification (CCMC).
UNOS (contains several resources):

- www.unos.org

OrganDonor.Gov:

- www.organdonor.gov
Navigate through SRTR (source for outcomes data, wait times, length of stay, etc.):

- Go to www.srtr.org
- Select “Program + Hospital Data”
- Select Find a “Transplant Center”
- Select Organ Type
- Search by State
- Select State from the drop down menu
- Locate the center you would like to look up and click on the “Report” link
- Click the down arrow located next to “Program Summary” and you will see a drop down menu with several different tables

- Table 00: Summary Page- Find transplant volume for past year, waiting list outcomes, post- transplant outcomes.

Table 06: Time to Transplant, Waitlist Patients- Find Median Wait times

Table 9C: Transplant Characteristics (choose deceased or living donor based on transplant type;

then view median length of stay by specific center, OPO, region and national) Table 10CL: Graft survival by donor type

Table 11: Patient survival outcomes
Navigate through OPTN (source for volume data):

- Go to www.optn.org
- Place cursor on data and select view data reports
- Select “Center Data”
- Step 1: Click on the state where center is located
- Step 2:
  - Choose Center
  - Choose category = transplant
  - Choose Organ Type
- Step 3:
  
  - Click on link “Transplants by Donor Type”

Navigate through NMDP (source for Center specific BMT information):

- Go to www.bethematch.org
- Select the “Patients & Families” tab at the top of the page
- Select “Getting a Transplant”
- Select “Choosing a Transplant Center”
- Select “US Transplant Centers”
- Select the state where the center is located
- Select the specific center: Displays program description, transplant experience, outcome information, etc.