AGNIS Strategy Update
Tandem 2017

There are no conflicts of interest to disclose.
AGNIS Overview

• AGNIS started in 2004 as a project funded by the NIH with work done by NMDP and CIBMTR

• Goal was to make data exchange easier by creating a:
  – Data sharing system that facilitates electronic form submission from local databases to CIBMTR
  – Standardized vocabulary for BMT data collection utilizing industry tools like the caDSR, HL7, BRIDG and others

• Main AGNIS challenges include:
  – Growing the number of centers able to utilize and benefit from AGNIS
  – Supporting current users when forms are updated
  – Continuing to look to the future and evolve to maintain industry best practices
AGNIS Supported Forms

• Transplant centers are able to electronically submit and retrieve 16 CIBMTR recipient outcome forms

• These forms represent 85% of recipient data collected through FormsNet or AGNIS.

• This includes
  – Seven TED level forms (pre- and post-TED, HLA, IDM, Infusion, Chimerism, and Selected Post-TED)
  – Unique ID Assignment and Indication
  – Five Comprehensive Forms (Baseline, 100 Day Follow-Up, 6 mo. to 2 yr. Follow-up, Annual Follow-Up, and Death)
  – Two disease-specific inserts (Pre- and Post-HCT Hodgkin and Non-Hodgkin Lymphoma)
AGNIS Domestic Center Activity

- Centers can choose to develop AGNIS capabilities on their own or utilize a vendor solution
- 5 centers make direct submissions or retrieval
  - MD Anderson, Cleveland Clinic, Moffitt, Seidman Cancer Center, Stanford
- 7 vendors with 16 centers submitting data and 37 centers retrieving data
  - Currently there are 9 vendors authorized to submit and/or retrieve via AGNIS
  - Vendor status is documented on the AGNIS.net site
- Currently at least 3 centers and 4 vendors working to develop tools with AGNIS capabilities
### AGNIS Domestic Center Activity

<table>
<thead>
<tr>
<th>User Type</th>
<th>Submission</th>
<th>Retrieval</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Active</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20</strong></td>
<td><strong>18</strong></td>
</tr>
<tr>
<td>Vendors</td>
<td><strong>16</strong></td>
<td><strong>16</strong></td>
</tr>
<tr>
<td>Direct</td>
<td><strong>4</strong></td>
<td><strong>2</strong></td>
</tr>
</tbody>
</table>

*Centers that have authorization for production but have not yet become active*
AGNIS Activity in 2016

1. Patients that have at least one form submitted utilizing AGNIS
   – 14.48% patients have had at least one form submitted via AGNIS in 2016

2. Forms that have been submitted utilizing AGNIS
   – 4.33% of forms were submitted via AGNIS in 2016

<table>
<thead>
<tr>
<th>Users</th>
<th>Patients¹</th>
<th>Forms² (excl 2804)</th>
</tr>
</thead>
<tbody>
<tr>
<td>All AGNIS</td>
<td>21,130</td>
<td>29,009</td>
</tr>
<tr>
<td>Domestic</td>
<td>6,515</td>
<td>10,482</td>
</tr>
<tr>
<td>EBMT</td>
<td>14,615</td>
<td>18,527</td>
</tr>
<tr>
<td>All FN3</td>
<td>124,800</td>
<td>640,794</td>
</tr>
<tr>
<td>Domestic</td>
<td>106,412</td>
<td>560,737</td>
</tr>
<tr>
<td>International</td>
<td>18,388</td>
<td>80,057</td>
</tr>
</tbody>
</table>
AGNIS International Users

• People Tree Hospital
  – Bangalore, India
  – Working with Jagriti Innovations
  – Authorization to submit Unique ID, Indication, Pre-TED, Infectious Disease and HLA Forms

• Maisonneuve-Rosemont Hospital
  – Montreal, Canada
  – Utilizing a RedCap compatible solution (acronym for Research Electronic Data Capture)
  – Authorized to submit the Unique ID Form and testing additional forms
AGNIS Registry Partnerships

- The European Society for Blood and Marrow Transplantation (EBMT)
- Goal is to increase the amount of data available for research
  - Centers submit the MedA forms to ProMIS and then EBMT submits the unique ID assignment, indication, pre-TED, post-TED for all time points and HCT Infusion forms to CIBMTR
  - Over 62,000 form submissions from EBMT – AGNIS in complete status in FormsNet since 2010 and over 30,000 since January, 2016
AGNIS Goals

• Data sharing system that facilitates electronic form submission from local databases to CIBMTR

• Standardized vocabulary for BMT data collection utilizing industry tools like the caDSR, HL7, BRIDG and others
AGNIS challenges

1. Supporting current users and **easing adoption** of change

2. **Growing** the number of centers able to utilize AGNIS and the amount of data that can be shared electronically

3. Continuing to look to the **future** and evolve to maintain industry best practices
Easing Adoption: 2016 Work

- Form Revision: Improved form revision process to release form builder reports to users earlier, in almost all cases before the forms are released in FN3

- Data standardization and CDE reuse: With each new revision the forms are evaluated for CDE reuse, and we are now averaging 60% reuse

- Revision Promotion: Implemented pilot project so centers can submit the previous revision of a form and field that didn’t change can be mapped to the latest revision. Started with the HLA Form - 2005r6
Easing Adoption: Next Steps

• Continue supporting the form revision program
• Review all new forms to see if revision promotion could be useful for helping ease the transition to the new form
• Analysis of how to protect users against administrative changes that don’t reflect new data collection needs, specifically module public id’s
Growing: 2016 Work

• EBMT Automation: Implemented automated prospective data submission process for MedA equivalent forms

• Epic User Group: Developed 3 tools so far, BMT Smartform, aGVHD and cGVHD documentation flow sheets

• New Forms: 4 disease specific inserts available in AGNIS external test environment (AML, ALL, Multiple Myeloma and MDS)
Growing: Next Steps

- Cellular Therapies: AGNIS work to support cellular therapies forms with the next revision, planned for summer 2017.
- Increase the transplant data available for research: Continue working with the EBMT to move more data
- Continue Epic User group: Defining next goal at meeting on Saturday, will undertake BMT module development
- Work with other EMRs: Continue project to share CIBMTR-defined data standards with EMRs to help ease the burden of initial mapping
Future: Next Steps

• Projects to support adapting to evolving data standards: Prototype of use of HL7 FHIR to transfer HLA data (Form 2005) and to invest in enhancements to current systems

• Lead the way in defining standards to enhance development and inter-operability

• Analysis of domain based acquisition to better support flexibility in data collection

• Working group / collaborative session with industry partners to discuss the future of interoperability for BMT

• Continue to make it easy and valuable to share data with CIBMTR
Questions

• Any interest in learning more about AGNIS, just email the team at AGNISsupport@nmdp.org