Development of a Community-Based Clinical Registry for Patients with Cochlear Implants

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Disclosures

• 501(c)3
• Supporters
  – Cochlear
  – Advanced Bionics
  – Wichita Falls Area Community Foundation
  – United Regional Health Care System
  – Midwestern State University
  – Echometer
  – J.S Bridwell Foundation
  – Bryant Edwards Foundation
  – Jim & Vicky McCoy
  – Board Members
Background

• Why is better data needed in the Cochlear Implant Community?
  – Reach new markets
  – Affect public policy
  – Negotiate with payers
  – Improve care for patients
How is Data Managed?

• Electronic Health Records
  – Advantages
    • Clinical documentation, billing
  – Disadvantages
    • Siloed
    • Non-standardized
    • Myopic view of patient’s journey
How is Data Managed?

• Patient Registry
  – A patient registry is an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves a predetermined scientific, clinical, or policy purpose(s).
  
  (AHRQ.gov)
Data management technology in a value-driven world

- HIPAA-secure
- Cloud-based
- Built around collaboration
- Patient centered – data follows patients
- Uniquely identifies patient/provider/organization
- Encourages evidence-based care
Methods

• Cochlear implant data management platform

Data Elements

• Supported by literature
  – Elements evaluated based on
    • Feasibility
    • Keeping data set concise
    • Value to body of knowledge
Methods

• Logistics
  – Data entry must not create double work
  – Integrated into workflow to minimize disruptions and ideally saves the clinician time

• Data Access
  – Access to data granted to providers involved in patient’s care (Care Team)
Methods

- Technical Requirements: Implementation
  - RESTful API
  - Tokenized access (session management)
  - Widget based system
  - UI/UX design based on workflow and for throughput
  - Designed for Data aggregation
  - Input Validation
  - NIST Level II Security
  - Auditing and Logging
Methods

• Technical Requirements: Security
  – Encrypted Disk Storage and Database
  – Two Factor Authentication
  – VPN (Secure Socket Access)
  – Firewalled
  – Intrusion Detection
  – Penetration Testing
  – Raid (Redundant Storage)
Results

• Care Teams

  – Maintain HIPAA security by granting access only to those involved in patient’s care

  – Use “Invitation” and “Accept/Reject” procedure
Care Teams
Results

• Data Input
  – Care Phases (Milestone Visits)
    • Key Information organized according to patient’s progress along their implant journey

- To view all data elements, please visit
  - aii-hermes.org/dataElements.php
Input: Care Phases
Results

• Data Input
  – Toolbar (Non-Milestone Visits)
    • Demographics
    • Syndromes/Etiologies
    • Surgeries
    • Medications
    • Hearing Aid Information
    • Audiometric Testing (Non-Milestone)
    • Speech and Language Development Information
Input: Toolbar
Results

• Data Output

– Patient Reports
Output: Patient Reports
Results

- Data Output

- Data Query Tool

<table>
<thead>
<tr>
<th>Patient (Event)</th>
<th>Demographics: Date of Birth (DOB)</th>
<th>Demographics: Sex</th>
<th>Demographics: Race</th>
<th>Demographics: Body Mass Index (BMI)</th>
<th>Demographics: Height (in inches)</th>
<th>Demographics: Weight (in pounds)</th>
<th>Non-milestone: What is the patient's primary insurance?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adams, Andy</td>
<td>1976-06-01</td>
<td>Male</td>
<td>White</td>
<td>14.35</td>
<td>14</td>
<td>99</td>
<td>Medicare</td>
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<td>(N/A)</td>
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<td>Adams, Andy</td>
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<td>Male</td>
<td>White</td>
<td>23.01</td>
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<td>Medicare</td>
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<tr>
<td>Adams, Amy</td>
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<td>White</td>
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<td>148</td>
<td>Medicare</td>
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<tr>
<td>(Right CI)</td>
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</tr>
</tbody>
</table>

Auditory Implant Initiative
Research • Collaboration • Outreach
Output: Data Query Tool
Results

<table>
<thead>
<tr>
<th>Statistics</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participating Facilities</td>
<td>11 (7 active, 4 pending)</td>
</tr>
<tr>
<td></td>
<td>(5 academic, 6 private)</td>
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<tr>
<td>Patients recorded</td>
<td>79</td>
</tr>
<tr>
<td>Total annual CI caseload</td>
<td>~520</td>
</tr>
<tr>
<td>States Represented</td>
<td>4 (Texas, California, Arizona, Ohio)</td>
</tr>
<tr>
<td>Services Represented</td>
<td>Surgery, Audiology, Speech, Education</td>
</tr>
</tbody>
</table>

States Represented: Texas, California, Arizona, Ohio

Services Represented: Surgery, Audiology, Speech, Education

Auditory Implant Initiative
Research • Collaboration • Outreach
Conclusion

• As we re-imagine how data is managed, we can
  – Improve collaboration among providers
  – Arm our cause with robust datasets that affect policy
  – Improve care for our patients
Acknowledgements

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  – Aii Executive Director & Database Manager

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