Data Management and Security: National Falls Prevention Database

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Session Overview

- TA Role of NCOA
- Database by the Numbers
- Security Measures
- Database Updates
- Quality Assurance Practices
- Tips for Working with Vendors
Technical Assistance – What can NCOA do for you?

- Getting you set up in the database
- Troubleshooting
- Assistance with creating reports and numbers
- Data analyses & evaluation
8 Programs in Database

- FallScape
- Matter of Balance
- Otago Exercise Program
- Stay Active and Independent for Life (SAIL)
- Stay Safe, Stay Active
- Stepping On
- Tai Chi for Arthritis
- Tai Ji Quan: Moving for Better Balance
Impetus for Increased Security Measures

- Database stores sensitive, identifiable information
  - Personally Identifiable Information (PII): Name, zip code
  - Protected Health Information (PHI): Physical/mental health condition

- Exchange data on a frequent basis, both internally and externally

- Cybersecurity attacks are on the rise
You’ve Been Hacked
WannaCry? Everyone is Vulnerable!
A More Secure Future
Keep Your Data Safe: General Safeguarding Practices

- Let your IT department guide your security protocols
- Centralize data management; create accountability
- Use the National Falls Prevention Database or other secure database
  - Salesforce- HIPAA compliant with security features
    (trust.salesforce.com)
- Train all staff handling survey forms and electronic data
  - Review the NCOA Privacy and Security Basics Training PowerPoint
- Require non-disclosure agreements
- Do not share accounts and/or passwords
Protect Personally Identifiable Information

- Provide data summaries in aggregate form – no case-specific data

- De-identify data
  - Strip data of zip codes, phone numbers, names, medical record numbers, etc. (total of 18 identifiers).

- Limit the number of users accessing the database

- Let us know as soon as someone leaves so we can deactivate their account

- Discard forms once the data has been entered into a secure database
What is a Data Use Agreement?
Contractual document used for the transfer of data that has been developed by nonprofit, government or private industry, where the data is nonpublic or is otherwise subject to some restrictions on its use.

When is it needed?
- With research partners wanting full data exports (or excerpts of it) containing detailed case-level data? **YES**
- Use when sharing aggregate data to funder, partner, or the media? **NO**
Protect Against Hackers

Follow national security standards (e.g. NIST)

Password protect files

Install data encryption software on computers

Exchange PII data using encryption via email (e.g. SharePoint, One Drive)

Use HIPAA compliant software to store data (e.g. Salesforce)

Use complex passwords in National Database, email accounts, etc.

Stay current with patches & anti-virus updates

Be aware of “social engineering”
What’s new?

- Data Entry
  Tools to enter program data into the system. Users can enter information about workshops, participant demographics, first and last session surveys, and attendance.

- Program Management
  Tools to assist in managing workshop program data. Users can create new sites or leaders and edit existing site or leader information.

- Reporting
  Reports on program data to summarize demographics, survey results, and attendance rates. Evaluation and program reports are also available.

- Assistance
  Questions, comments, issues, and suggestions can be submitted here.
Updates to the National Falls Prevention Database

- Timed Up and Go (TUG) and Chair Stand tests added (optional)
Updates to the database

- Reports: Outcomes Dashboard

ACL National Evidence-Based Falls Prevention Database

Outcomes Dashboard includes participants in workshops that concluded between 9/1/2014 and 4/30/2017

All Grantees, All Programs, Total Participants with Pre/Post Surveys: 26,914

Self rating of health in general

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>1-2</th>
<th>3+</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre Q10 / Post Q1</td>
<td>1414 (70%)</td>
<td>4268 (24%)</td>
<td>1043 (5%)</td>
<td>3466 (17%)</td>
</tr>
</tbody>
</table>

Time fallen, falls with injury, past 3 mo. (pre-survey)

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>1-2</th>
<th>3+</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre Q11a (Falls with injury)</td>
<td>11072 (45%)</td>
<td>1793 (14%)</td>
<td>117 (1%)</td>
<td>7834 (30%)</td>
</tr>
</tbody>
</table>

Time fallen, falls with injury, since program began (post-survey)

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>1-2</th>
<th>3+</th>
<th>NA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Post Q2a (Falls with injury)</td>
<td>14836 (86%)</td>
<td>2173 (13%)</td>
<td>282 (2%)</td>
<td>3823 (27%)</td>
</tr>
</tbody>
</table>

How fearful of falling

How sure... find a way to get up if fallen

How sure... find a way to reduce falls

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## Updates to the database

### Accessing reports

<table>
<thead>
<tr>
<th>Action</th>
<th>Report Name</th>
<th>Report Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Select</td>
<td>Demographic Profile</td>
<td>Demographic profile for participants in workshops that end between selected dates, compared to all grantees, all State grantees, or all Tribal grantees.</td>
</tr>
<tr>
<td>Select</td>
<td>Demographics and Survey Responses</td>
<td>Demographics and pre- and post-survey responses for participants in workshops that end between selected dates, compared to all grantees, all State grantees only, or all Tribal grantees only.</td>
</tr>
<tr>
<td>Select</td>
<td>Falls Semi Annual Report</td>
<td>Prevention and Public Health Fund Evidence-Based Falls Prevention Program Semi-Annual Performance Report</td>
</tr>
<tr>
<td>Select</td>
<td>Full Data Export: Leader Data</td>
<td>Export all data for leaders. File includes one row for each leader.</td>
</tr>
<tr>
<td>Select</td>
<td>Full Data Export: Participant Data</td>
<td>Export all data for workshops with end date during specified date range. File includes one row for each participant, with all demographic, survey, attendance, workshop, implementation site, and host organization details.</td>
</tr>
<tr>
<td>Select</td>
<td>Full Data Export: Workshop Data</td>
<td>Export all data for workshops with end date during specified date range. File includes one row for each workshop, with all workshop, implementation site, and host organization details.</td>
</tr>
<tr>
<td>Select</td>
<td>Outcomes Dashboard</td>
<td>Pre/post survey response comparison for your programs, filterable by date and program type. Use with Outcomes Dashboard (All Grantees) for comparison to national data.</td>
</tr>
<tr>
<td>Select</td>
<td>Outcomes Dashboard (All Grantees)</td>
<td>Pre/post survey response comparison all grantees, filterable by date, program type, and grantee type. Use with Outcomes Dashboard.</td>
</tr>
<tr>
<td>Select</td>
<td>Pre/Post Survey Summary</td>
<td>Frequency of response for pre and post surveys for participants in workshops that end between selected dates.</td>
</tr>
</tbody>
</table>
Updates to the database

- Reports: Compare data to all grantees nationally, or filter by Tribal or State grantees
Updates to the database

- Roll up report data to specific subset/group of host organizations
  - Available by request: submit list of organizations to include in a group
Updates to the database

- Option to collect insurance data on participants
  - Submit list of insurance companies for your state/region
Upcoming changes to the database

- Changes in coming months
  - Tai Chi for Arthritis and Tai Ji Quan: Moving for Better Balance
  - Home Practice Hours

Home Practice Hours coming soon
Upcoming changes to the database – data security

- Changes in coming months
  - Procedures with data migration – in short term, use password-protected files. Longer term, upload files directly to the Salesforce platform.
  - Password policies (more complex, require regular change)
  - Deactivation of inactive users
  - Changes to data collection forms in 2018
Data security

- Continuing security practices
  - Use of the secure Salesforce platform
  - User-access controls
  - Resources and training around handling forms and data privacy
Data quality assurance

- New users should review training webinar video
Data quality assurance

- Have clear responsibilities for staff/volunteer roles, from collecting data forms in the workshops to data entry
  - Maintaining data privacy, handling forms responsibly and securely
  - Reviewing forms for completeness, accuracy
  - Reviewing data after it’s entered for completeness, accuracy
Data quality assurance

- To check data quality, try double-data-entry on a random set of forms and check for accuracy
- Run reports to catch outliers, unexpected missing data
  - Attendance data is required for participants to show up in reports
Data quality assurance: Reduce missing data

- Make it a priority to build in time, taking advantage of Session ‘0’.
- Assist participants with forms. Consider literacy, and language barriers and cognitive challenges.
- Review Group Leader Script during training, emphasize the value of data to future support of these programs.
- Build excitement for data by sharing reports with implementation sites/partners.

  ► More strategies at:
  https://www.ncoa.org/resources/maximizing-complete-accurate-data/
Vendor / external database may be

- A third-party product
- An existing intervention-specific database (like Otago)
- An internal organization or statewide system to track participant data
Working with vendors

Data forms

Other Database

Key in data

Export data to spreadsheet

Submit for import

National Falls Prevention Database

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### Working with vendors

- Other database must capture all required variables
Working with vendors

- Variables must be coded as the Falls database codes them, or be converted prior to submitting
- You (or your vendor) need recode before submitting
- We can help!

<table>
<thead>
<tr>
<th>Other database’s Self-rating of General Health variable</th>
<th>Falls database’s Self-rating of General Health variable</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Excellent</td>
</tr>
<tr>
<td>4</td>
<td>Very Good</td>
</tr>
<tr>
<td>3</td>
<td>Good</td>
</tr>
<tr>
<td>2</td>
<td>Fair</td>
</tr>
<tr>
<td>1</td>
<td>Poor</td>
</tr>
</tbody>
</table>

convert to
### Working with vendors

- **Template defines format in which we need to receive data (available on request)**

<table>
<thead>
<tr>
<th>A1</th>
<th>A2</th>
<th>A3</th>
<th>A4</th>
<th>A5</th>
<th>A6</th>
<th>A7</th>
<th>A8</th>
<th>A9</th>
<th>A10</th>
<th>A11</th>
<th>A12</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant data (including Demographics, Surveys and Attendance)</td>
<td></td>
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<td></td>
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<td></td>
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<tr>
<td>Required fields</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>WorkshopID</td>
<td>ParticipantID</td>
<td>Healthcare Referral</td>
<td>Age</td>
<td>Live Alone</td>
<td>Gender</td>
<td>Hispanic</td>
<td>Race</td>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Must match Workshop ID provided in Workshop tab.</td>
<td>First 2 letters of First Name + First 2 letters of Last Name + Last 2 digits of year of birth. Use &quot;*00&quot; if no year of birth provided.</td>
<td>Enter one of following or leave blank if no response</td>
<td>Integer</td>
<td>Enter one of following or leave blank if no response</td>
<td>Male</td>
<td>Yes</td>
<td>American Indian or Alaska Native</td>
<td>Select one or more of the following; if multiple values selected, separate values with a comma. If no response, leave blank.</td>
<td>Select one of the following: Some H</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>10</td>
<td>11</td>
<td>12</td>
<td>13</td>
<td>14</td>
<td>15</td>
<td>16</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>Yes</td>
<td>Male</td>
<td>Yes</td>
<td>American Indian or Alaska Native</td>
<td>Last ths</td>
<td>Asian</td>
<td>Some H</td>
<td>Black or African-American</td>
<td>Some c</td>
<td>College</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>No</td>
<td>Female</td>
<td>No</td>
<td>Asian</td>
<td>Some H</td>
<td>Black or African-American</td>
<td>Native Hawaiian or Pacific Islander</td>
<td>Native Hawaiian or Pacific Islander</td>
<td>Native Hawaiian or Pacific Islander</td>
<td>College</td>
<td></td>
</tr>
<tr>
<td>Example:</td>
<td>S02309</td>
<td>MASM34</td>
<td>No</td>
<td>71</td>
<td>Yes</td>
<td>Female</td>
<td>No</td>
<td>Black or African-American, White</td>
<td>College</td>
<td></td>
<td></td>
</tr>
<tr>
<td>TCA3110D</td>
<td>CH1100B</td>
<td>No</td>
<td>No</td>
<td>Male</td>
<td>No</td>
<td>Asian</td>
<td>Some c</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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What to ask a vendor

- Know what you need.
  - Does it capture grant-required data in addition to anything else you need it for? If not, can it be customized? (Cost?)

- Clarify vendor’s role in data maintenance, cleaning and preparation of export files.
  - Can data be exported on schedule you require (monthly or quarterly)?
    - Or can you generate exports yourself on demand?

- Ensure that software has protections and supports security practices that meet your organization’s requirements.
  - Vendor must agree to exchange of data with NCOA in secure format.
Contact Us

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