

DATA COLLECTION OPTIONS

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PAPER

- Available for short forms
- Requires manual data entry
- Scoring (use scoring manuals)
- PROMIS and Neuro-QOL have ready-to-use PDFs



WHY ONLINE DATA COLLECTION?

- Geographically dispersed samples
- No need for data entry staff
- Time/date verification
- Accessibility –
 - increase font size
 - screen readers
 - audio
- Data back-up
- Easier item/instrument randomization
- IRT administration and IRT scoring



AVAILABLE SYSTEMS

- Assessment Center
- Assessment Center API
- REDCap
- Epic
- BrightOutcome
- Madigan Army Medical Center
- Sasken
- OBERD (interested user)
- Lamda (interested user)
- Assessment Center iPad App (in progress)
- And growing....

ASSESSMENT CENTER

WHY DID WE CREATE IT?

Assessment CenterSM

- PROMIS and NeuroQOL investment in creation of item banks that can be administered as CATs
- No off-the-shelf platform for CAT administration to participants
- Researchers typically use more than CATs in a single study
- NIH Toolbox required platform for self-report and proctor-administered outcome instruments

WHAT IS ASSESSMENT CENTER?

Assessment CenterSM

- Web-based research management tool
 - Not an IRT analysis tool
- Enables creation of study-specific URLs
 - Participant interface for data collection
 - Administration of PROMIS, NeuroQOL, NIH Toolbox short forms and CATs
 - Researcher-completed instruments
- User can create custom short forms
- Single time-point or multiple timepoint studies

MORE FEATURES

Assessment CenterSM

- Research study feature (multiple study arms, randomization of items/instruments, accrual tracking)
- Real-time data export
 - Separation of PRO data, registration data (PHI), and consent data (more PHI)
- Automated data dictionary

ACCESS TO ASSESSMENT CENTER

Assessment CenterSM

- **Assessment Center is sponsored by the NIH**
 - **Hardware, software maintenance and new feature development, help desk**
- **Support and hosting fees will be assessed in the near future**
- **Contact information**
 - **help@assessmentcenter.net**

ASSESSMENT CENTER INSTRUMENT LIBRARY

Assessment CenterSM

- Distribution mechanism for:
 - NeuroQOL, PROMIS, NIH Toolbox
 - Permission to access NIH Toolbox is readily available to qualified users, see link at:
 - <http://www.nihtoolbox.org/HowDoI/HowDoIStartAStudy/Pages/default.aspx>
- Online administration or download PDFs

MORE INFORMATION

Assessment CenterSM

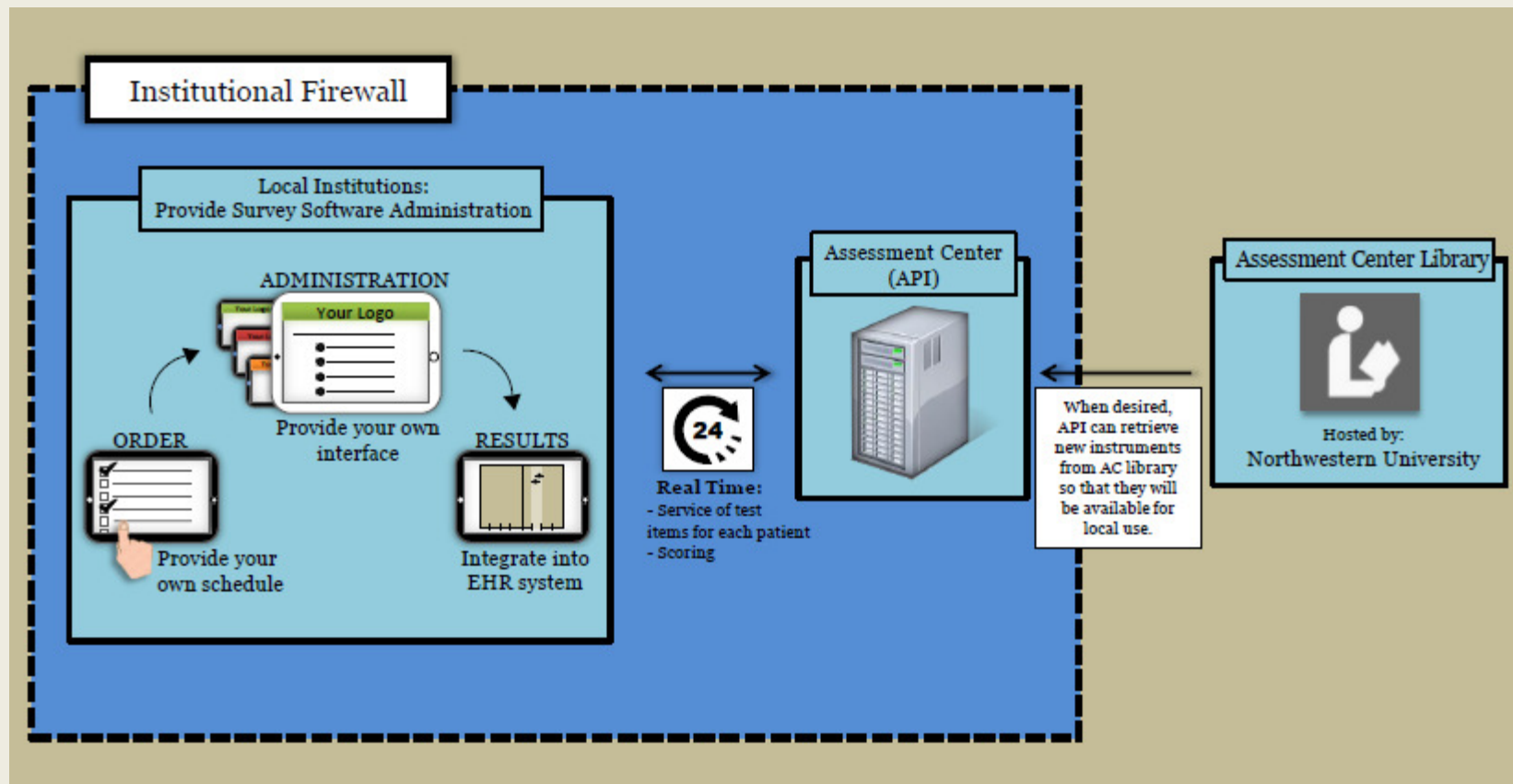
Assessment Center: www.assessmentcenter.net

- Assessment Center User Manual
- Video tutorials
- Assessment Center Online Help
- Help Desk

ASSESSMENT CENTER API

- The application programming interface (API) exposes the Assessment Center instrument library (including CATs) for external system consumption.

ASSESSMENT CENTER API



ASSESSMENT CENTER API

- What is available?
 - Limited number of PROMIS banks
- When is it available?
 - V.2012 is available now
 - Summer 2014
 - v.2014 PROMIS Banks and Short Forms. May include Neuro-QOL and NIH Toolbox self-report measures (this does not include cognition, motor or sensory)

ASSESSMENT CENTER API

- **Costs**
 - Flat fee per server installation
- **Current users**
 - REDCap (<http://project-redcap.org>), Sasken (www.sasken.com), Madigan Army Medical Center (www.mamc.amedd.army.mil)
- **Interested users**
 - Cerner (www.cerner.com), Pearson (www.pearson.com), Ortech Systems (www.ortechsystems.com), McGill University (www.mcgill.ca), OBERD (www.oberd.com), Lamda (<http://crisalisllc.com>)
- **Contact information**
 - help@assessmentcenter.net

RESEARCH ELECTRONIC DATA CAPTURE (REDCAP)



- Web-based data collection for research
- Initial focus on researcher-completed database
- Survey component for participant report
- Audit trails on data manipulation/user activity
- Automated exports
- Project calendar (e.g., blood draw)
- Scheduling module
- Ad hoc reporting tools (e.g., frequency distributions)
- Branching logic
- English, Chinese
- 1,052 active partners and 148,000 users

RESEARCH ELECTRONIC DATA CAPTURE (REDCAP)



- What is available?
 - PROMIS SFs
- When is it available?
 - Fall 2014 Expanded library of PROMIS short forms plus CAT
- Cost:
 - No cost for REDCap Consortium Partners (CTSA, GCRC, RCMI-funded institutions)
- Contact information:
 - <http://project-redcap.org>

EPIC



- Patient access via MyChart (patient portal)
- Requires specific version of Epic, installation at local site, establish assessment content and triggers
- Scored in real-time and available in medical record
- What is available?
 - Select PROMIS short forms
- When is it available?
 - Epic 2012 Limited PROMIS short forms using raw score scoring
 - Fall 2014 Larger set of PROMIS short forms with IRT scoring
 - Epic 2015 or Epic 2016: PROMIS CATs (direct inquiries to EPIC MyChart Team)

EPIC



- **Costs:**
 - No cost for Epic user
- **Contact Information**
 - info@epic.com

BRIGHT OUTCOME



- Innovative health information technology (HIT) solutions
- Focus on PRO and HIT
- Enable customers to:
 - measure their population's health status
 - inform their clinical/research decisions
 - empower their patients/subjects and healthcare consumers

BRIGHT OUTCOME



- Collaborative Symptom Management System
- Focused on chronic conditions
- Web, phone, hand-held device
- Single/multiple timepoints
- Patient completes Symptom Tracker
 - Can create history of symptoms/side-effects
 - Can link with reliable educational information
 - Can alert when to call care provider for concerning problem
- Treatment Tracker
 - Can combine PRO data with clinical treatment records

BRIGHT OUTCOME



- What is available?
 - PROMIS item banks and short forms
- When is it available?
 - Summer 2014
- Costs
 - Contact Bright Outcomes for more information
- Contact Information
 - dershung.yang@brightoutcome.com
 - www.brightoutcome.com

ASSESSMENT CENTER IPAD APP

- Offline administration of the NIH Toolbox and PROMIS instruments on the iPad
- Instrument administration, scoring, reporting, data aggregation and data export
- No study management

ASSESSMENT CENTER IPAD APP

- **When is it available?**
 - **Current:** Field testing in progress.
 - **Late 2014/Early 2015:** NIH Toolbox Cognition and Emotional Health Measures available for select group of early adopters
 - **Later in 2015:** Most NIH Toolbox and major PROMIS instruments available for general research and clinical use
- **Cost**
 - **Download fee and likely annual upgrade cost estimated <\$1,000 per installation (exploring model of licensing per site/researcher/clinician, not per iPad).**
 - **Complete licensing information available late 2014.**
- **Contact information**
 - **help@assessmentcenter.net**

SELECTING DATA COLLECTION TOOL: KNOW WHAT YOU NEED

- Type of items
- Type of instruments (CATs, branched, researcher-completed)
- Mode of administration/data collection location
- Study timeline
- Language(s)
- Data storage location

SELECTING DATA COLLECTION TOOL: KNOW WHAT YOU NEED PART 2

- Automated reminders/prompts
- Real-time analysis (e.g., tracking accrual, calculating means)
- Available funding
- Staff skills (e.g., data entry/backup/scoring) versus online study set-up
- If your institution uses any of the platforms discussed, it is our suggestion that you use your institution's platform.

THANK YOU!