Update on Latino Task Force and Spanish Translation of UDS-3

Katya Rascovsky, PhD
Latinos and NACC

Latino subjects - NACC

• Ever enrolled: n=2775, 7.6% NACC subjects
• Currently enrolled: n=812, 6.4% NACC subjects
• Decrease in currently enrolled: n=940 (2016) to n=812 (2017)
• 70% Latinos reported Spanish as primary language
Goal: Translate and adapt the UDS-3 modules for use in diverse Spanish-speaking Latino populations.

Preliminary translation and content review by expert clinicians. Pilot testing in US and Latin America.

Participating Sites

University of California, San Diego
University of Southern California
Mount Sinai School of Medicine
Memory Clinic at the Institute on Aging, Pontificia Universidad Javeriana School of Medicine (MCIA). Bogota, Colombia.
Fundación para la Lucha contra las Enfermedades Neurológicas de la Infancia (FLENI). Buenos Aires, Argentina.
Instituto Nacional de Neurología y Neurocirugía “Manuel Velasco Suárez” (INNMVS). Mexico City, Mexico.
Peru Young-Onset Dementia Network (PYN): Universidad Peruana Cayetano Heredia, Clínica Internacional, Resocentro Imaging Center. Lima, Peru
UDS-3 IVP, FVP and TFV

Rascovsky, Katya
UDS-3 Cognitive Battery

No issues with translation:

• Benson Copy / Recall
• Number Span
• Category Fluency
• Trail Making Test A & B

Significant adaptations:

• MoCA (original translation)
• Craft Story (minor)
• Verbal Fluency (P & M)
• Multilingual Naming Test
Multilingual Naming Test

- **Items not suitable for monolingual populations.**
  - *e.g., “pestle”* has 8 *regional variations:*
    - “pistilo”
    - “mano de pilón”
    - “mano de mortero”
    - “majadero”
    - “maja”
    - “temolote”
    - “tejolote”
    - “temachín”
- Named by 15% Spanish-speaking controls

- Data-driven adaptation based on 68-item MINT
- Itemized data from 129 subjects (75 controls, 54 AD/aMCI patients)
- 32-items with largest control – patient discrepancy

<table>
<thead>
<tr>
<th>#</th>
<th>Item</th>
<th>Clave semántica</th>
<th>Respuesta(s) espontánea(s)</th>
<th>Sin clave</th>
<th>Clave semántica</th>
<th>Clave fonológica</th>
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<tbody>
<tr>
<td>1</td>
<td>Lámpara</td>
<td>un instrumento musical</td>
<td>correcta</td>
<td>correcta</td>
<td>incorrecta</td>
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<tr>
<td>2</td>
<td>Giro</td>
<td>se encuentra en el cielo</td>
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<td>3</td>
<td>Hueso</td>
<td>se encuentra en un esqueleto</td>
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<td>4</td>
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<td>se usa para impulsar el ataraje</td>
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<td>una persona entrenada para cuidar a los que no se sientan bien</td>
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<td>8</td>
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<td>el líder de una monarquía</td>
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<td></td>
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<td>10</td>
<td>Gil</td>
<td>es donde los pijaros ponen sus huevos</td>
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<td>Corredor de batas / pila de residuos</td>
<td>se usa para rellinar polvo y batería</td>
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<td>14</td>
<td>Hidra</td>
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<td>15</td>
<td>Gliuma</td>
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<td>16</td>
<td>Gogois</td>
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<td>17</td>
<td>Goluca</td>
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</table>
Spanish FTLD-NACC

FTLD IVP, FVP, Neuropsychology

Rascovsky, Katya
## Implementation

**NACC Uniform Data Set (UDS)**

### Form Z1X: Form Checklist

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<td>Co-participant Demographics</td>
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<td>Subject Family History</td>
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<td>Subject Medications</td>
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<td>Subject Health History</td>
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<td>EVALUATION FORM — Physical</td>
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<td>Clinician Diagnosis</td>
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**FTLD Module**

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<td>Imaging Available</td>
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<td>E3F</td>
<td>1 2</td>
<td>Imaging in Diagnosis</td>
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**CLS Form**

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<td>CLS</td>
<td>1 2</td>
<td>Subject’s Language History</td>
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<td>Submit only once</td>
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### Form CLS: Linguistic History of Subject

**AOC name:** ____________  
**Subject ID:** _______________  
**Form date:** ____________ / ____________ / ____________  
**Visit #:** ____________  
**Examiner's initials:** ____________

**INSTRUCTIONS:** This form must be completed by the examiner based on subject interview or informant report. Select only one option for each question.

Complete this form in its entirety if the subject claims Hispanic ethnicity (UDS Form A1, Question B, Spanish).

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 1. In what language do you prefer to be evaluated (English or Spanish)? | ☐ English  
☐ Spanish                                                                 |
| 2. How many years have you lived in an environment where people generally speak Spanish? | ____________ (years, range 0–110)  
☐ Spanish-speaking country  
☐ Latin American country or other Spanish-speaking country |
| 3. How many years have you lived in an environment where people generally speak English? | ____________ (years, range 0–110)  
☐ English-speaking country or military base where English is the primary language |
| 4. Please approximate the percentage of time during a normal/average day that you use Spanish. | ____________ %, range 0–100%  
☐ Like native speaker |
| 5. Please approximate the percentage of time during a normal/average day that you use English. | ____________ %, range 0–100%  
☐ Like native speaker |
| **Note:** The sum of percentages in Questions 4 and 5 cannot exceed 100%.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
</table>
| 6. In your opinion, what is your level of proficiency when you speak Spanish? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 7. In your opinion, what is your level of proficiency when you read Spanish? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 8. In your opinion, what is your level of proficiency when you write in Spanish? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 9. In your opinion, what is your level of proficiency for understanding spoken/spoken Spanish? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 10. Average Spanish level (average of Questions 6–9, range 1–7, leave blank, and NACC will calculate) | ____________  
☐ Like native speaker |
| 11. In your opinion, what is your level of proficiency when you speak English? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 12. In your opinion, what is your level of proficiency when you read English? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 13. In your opinion, what is your level of proficiency when you write in English? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 14. In your opinion, what is your level of proficiency for understanding spoken/spoken English? Please use the following scale: | ☐ Almost none  
☐ Very poor  
☐ Fair  
☐ Functional  
☐ Good  
☐ Very good  
☐ Like native speaker |
| 15. Average English level (average of Questions 11–14, range 1–7, leave blank, and NACC will calculate) | ____________  
☐ Like native speaker |

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| (202) 616-5927  
| naccmail@uw.edu  
| www.azwashington.edu  
UDS Version 3.0, March 2015  
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SEPTEMBER 2017 Form CLS: Linguistic History of Subject  
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Rascovsky, Katya
Latino Task Force

Goals
• provide a forum to discuss issues of assessment, language and acculturation.
• identify facilitators and barriers to Latino research at the center and patient level.
• propose concrete strategies to increase engagement and retention of Latino participants in ADC’s.

Actions
• Listserv
• Implementation of Spanish UDS-3
• Latino needs assessment survey
ADC Latino Needs Assessment Survey

Collaboration with Latinos Against Alzheimer’s

Goal:

• Identify facilitators and barriers to Latino engagement in dementia research.

• Inform and guide concrete strategies to increase engagement and retention of Latino participants in ADC’s.

• Improve research and care for Latino patients and their families
Mil Gracias!

University of Pennsylvania
Murray Grossman
Corey McMillan
Vivianna Van Deerlin
David Irwin
Virginia Lee
John Trojanowski
EunRan Suh
Penn FTD Center
Penn ADC

Colombia
Diana Matallana (PI)
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Jose Manuel Santacruz
Carlos Cano
Angela M. Iragorri
Pablo A. Reyes
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Ignacio Zarante
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Tamar Gollan
David Salmon
Douglas Galasko
Sandra Weintraub
Jennifer Manly
Nina Silverberg
Walter Kukull

University of California, San Diego
University of Southern California
Mount Sinai School of Medicine

Fogarty Center
NACC
NIH / NIA
Colciencias
Penn-Peru Program
Latinos Against Alzheimer’s