

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

Katya Rascovsky, PhD

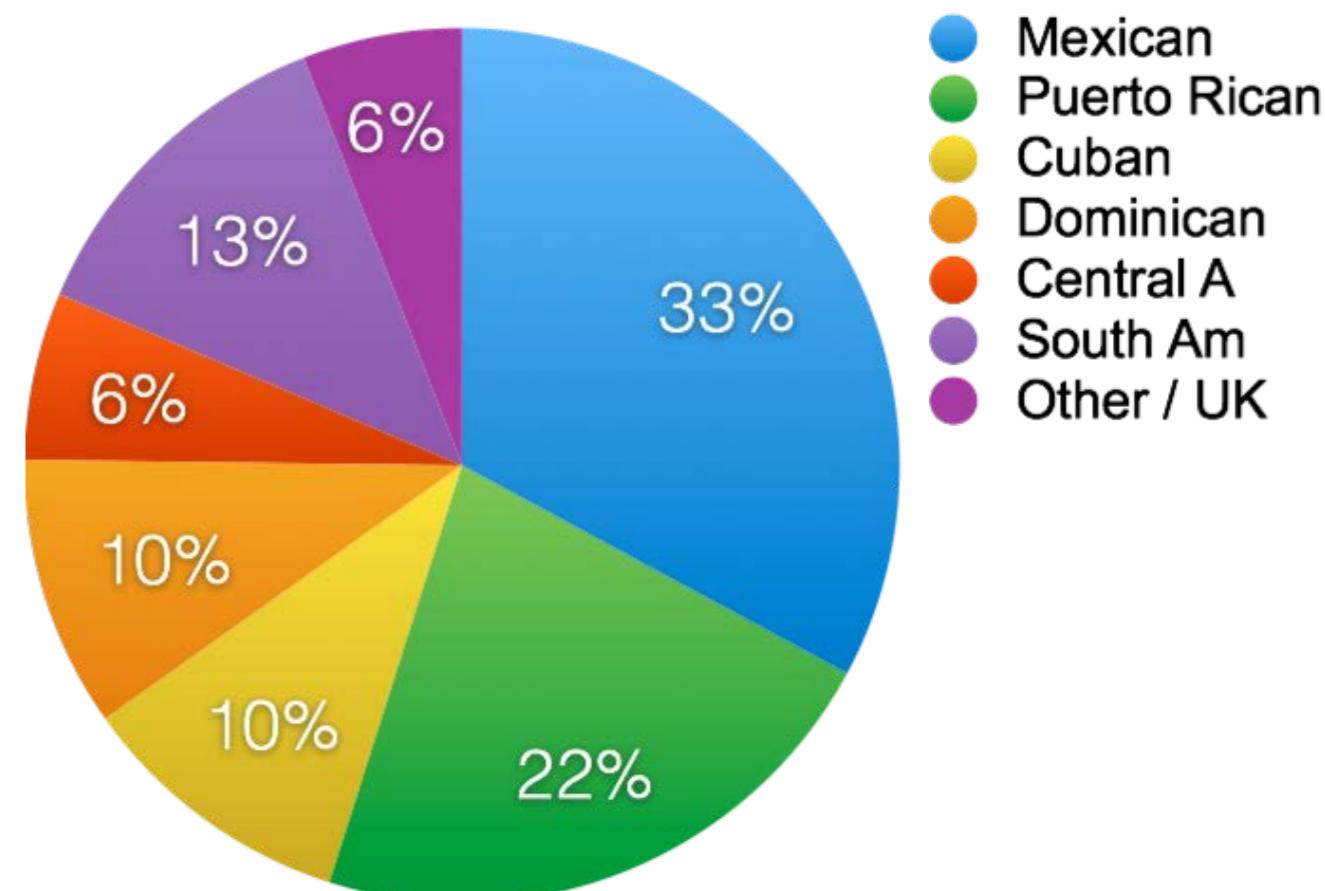
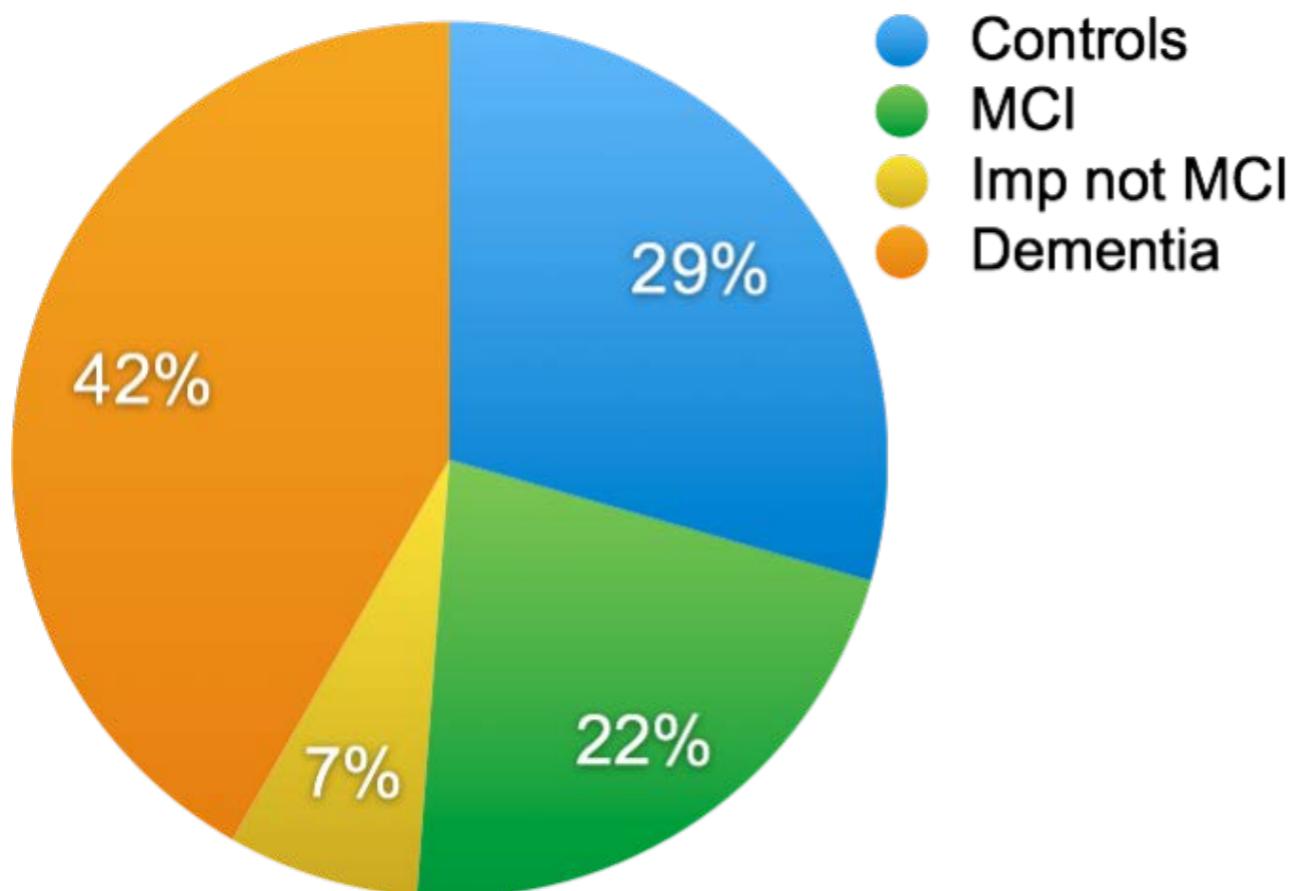


Penn
Frontotemporal
Degeneration Center



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



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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

ID del sujeto _____ Fecha ____ / ____ / ____ Iniciales del examinador _____



MINT (Prueba Multilingüe de Denominación)

INSTRUCCIONES Y CLAVES

DIGA: Le voy a enseñar unos dibujos de objetos, uno a la vez. Por favor dígame el nombre de cada objeto, es decir, dígame como se llama. Si ve un dibujo y no puede recordar el nombre, trate de adivinar. Si no sabe qué es el objeto, yo trataré de ayudarle. ¿Tiene alguna pregunta?

Descontinue la prueba después de seis fallas consecutivas.

#	Ítem	Clave semántica	Respuesta(s) espontánea(s)	Sin clave		Clave semántica		Clave fonológica	
				correcta	incorrecta	correcta	incorrecta	correcta	incorrecta
1	tambor tambora bombo	un instrumento musical							
2	dube	se encuentra en el cielo							
3	hueso	se encuentra en un esqueleto							
4	candado	se usa para impedir el abrir algo							
5	enfermera	una persona entrenada para cuidar a los que no se sienten bien							
6	payaso	se encuentra en el circo							
7	bruja	una mujer con poderes mágicos							
8	rey	el líder de una monarquía							
9	oso	un animal							
10	nido	es donde los pájaros ponen sus huevos							
11	recogedor de basura pala de residuos	se usa para retirar polvo y basura							
12	caracol baboso/a	un animal							
13	jaula	un recinto para animales							
14	bufanda chalina rebozo	ropa que se pone sobre el cuello							
15	pluma	se encuentra sobre el cuerpo de un pájaro							
16	arcoíris	es colorido y se encuentra en el cielo después de llover							
17	peluca	se pone sobre la cabeza							

De la Prueba Multilingüe de Denominación, Tamar H. Gollan, PhD; reproducido con permiso. No se puede copiar o distribuir sin permiso del autor. Formulario creado como parte de la Base de Datos Uniforme del Centro Coordinador Nacional de Alzheimer, copyright© 2013 Universidad de Washington.

- **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

FTLD IVP, FVP, Neuropsychology

The cover features a large stylized 'UDS' logo in blue and white. The text includes:

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The cover features a large stylized 'UDS' logo in orange and white. The text includes:

- NACC
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NACC
National Alzheimer's Coordinating Center

Implementation

INITIAL VISIT PACKET NACC UNIFORM DATA SET (UDS)

Form Z1X: Form Checklist



ADC name: _____ Subject ID: _____ Form date: ____ / ____ / ____
 Visit #: ____ Examiner's initials: ____

INSTRUCTIONS: This form is to be completed by clinic personnel.

NACC expects and intends that all UDS forms will be attempted on all subjects, but we realize this may be impossible when the patient is terminally ill, or when there is no co-participant, or for other reasons. An explanation is required below for forms that are not submitted.

UDS

Form	Language: English Spanish	Description	Submitted: Yes <input type="checkbox"/> No <input type="checkbox"/>	If not submitted, specify reason (see KEY):
A1	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Subject Demographics	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
A2	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Co-participant Demographics	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
A3	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Subject Family History	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
A4	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Subject Medications	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
A5	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Subject Health History	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
B1	<input type="checkbox"/> 1 <input type="checkbox"/> 2	EVALUATION FORM Physical	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
B4	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Global Staging — CDR: Standard and Supplemental	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
B5	<input type="checkbox"/> 1 <input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT NPI-Q	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
B6	<input type="checkbox"/> 1 <input type="checkbox"/> 2	BEHAVIORAL ASSESSMENT GDS	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
B7	<input type="checkbox"/> 1 <input type="checkbox"/> 2	FUNCTIONAL ASSESSMENT NACC FAS	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
B8	<input type="checkbox"/> 1 <input type="checkbox"/> 2	EVALUATION FORM Neurological Examination Findings	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
B9	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Clinician Judgment of Symptoms	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
C2	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Neuropsychological Battery Scores	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
D1	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Clinician Diagnosis	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
D2	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Clinician-assessed Medical Conditions	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required

FTLD MODULE

Form	Language: English Spanish	Description	Submitted: Yes <input type="checkbox"/> No <input type="checkbox"/>	If not submitted, specify reason (see KEY)*:
A3a	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Record of Consent for Biologic Specimen Use	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
B3F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Supplemental UPDRS	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
B9F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Clinical PPA and bvFTD Features	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
C1F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Neuropsychological Battery Summary Scores	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
C2F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Social Norms Questionnaire	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
C3F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Social Behavior Observer Checklist	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
C4F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Behavioral Inhibition Scale	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
C5F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Interpersonal Reactivity Index	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
C6F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Revised Self-monitoring Scale	<input type="checkbox"/> 1 <input type="checkbox"/> 0	---
E2F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Imaging Available	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required
E3F	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Imaging in Diagnosis	<input type="checkbox"/> 1 <input type="checkbox"/> 0	Required

CLS FORM

Form	Language: English Spanish	Description	Submitted: Yes <input type="checkbox"/> No <input type="checkbox"/>
CLS	<input type="checkbox"/> 1 <input type="checkbox"/> 2	Subject's Language History	<input type="checkbox"/> 1 <input type="checkbox"/> 0

KEY: If the specified form was not completed, please enter one of the following codes: 95=Physical problem 96=Cognitive or behavioral problem 97=Other problem 98=Verbal refusal

*KEY FOR FTLD MODULE ONLY: Allowable codes are 95–98 as above, as well as 99=Unknown or inadequate information.

Linguistic History (CLS Form)



Form CLS: Linguistic History of Subject

ADC 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 8=Si/Yes).

1. In what language do you prefer to be evaluated (English or Spanish)? Please choose one (you can't say "both"): _____	<input type="checkbox"/> English <input type="checkbox"/> Spanish
2. How many years have you lived in an environment where people generally speak Spanish (in a Latin American country or other Spanish-speaking country)?	____ - ____ (years, range 0-110)
3. How many years have you lived in an environment where people generally speak English (in the USA, other English-speaking country or military base where English is the primary language)?	____ - ____ (years, range 0-110)
4. Please approximate the percentage of time during a normal/average day that you use Spanish:	____ - ____ (% , range 0-100%)**
5. Please approximate the percentage of time during a normal/average day that you use English:	____ - ____ (% , range 0-100%)**

** Note: The sum of percentages in Questions 4 and 5 cannot exceed 100%.

6. In your opinion, what is your level of proficiency when you speak Spanish? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
7. In your opinion, what is your level of proficiency when you read Spanish? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker

Subject ID: _____ Form date: ____ / ____ / ____ Visit #: ____

8. In your opinion, what is your level of proficiency when you write in Spanish? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
9. In your opinion, what is your level of proficiency for understanding spoken / oral Spanish? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
10. Average Spanish level (average of Questions 6-9, range 1-7; leave blank, and NACC will calculate) _____	
11. In your opinion, what is your level of proficiency when you speak English? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
12. In your opinion, what is your level of proficiency when you read English? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
13. In your opinion, what is your level of proficiency when you write in English? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
14. In your opinion, what is your level of proficiency for understanding spoken/oral English? Please use the following scale:	<input type="checkbox"/> Almost none <input type="checkbox"/> Very poor <input type="checkbox"/> Fair <input type="checkbox"/> Functional <input type="checkbox"/> Good <input type="checkbox"/> Very good <input type="checkbox"/> Like native speaker
15. Average English level (average of Questions 11-14, range 1-7; leave blank, and NACC will calculate) _____	

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



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