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# Roybal Dementia Care Centers –

# **Common Measures**

#  **Call Minutes**

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| Date: | Wednesday, January 8, 20204:30pm – 5:30pm (EST) | Moderator: | Karina Davidson, PhD P.I., Roybal Coordinating Center (RCC)  |

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| Participants: | **Site Representatives:** Sarah Gothard, Scott Halpern, Kathi Heffner, Ken Hepburn, Susan Hughes, Jeffrey Kaye, Allison Lindauer, Molly Perkins **Guest:**  Laura Hanson, MD - Patient & Caregiver Reported Outcomes Core Leader, NIA IMPACT Collaboratory  |

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| Purpose:  | To discuss common measures utilized in dementia care pilots by Roybal AD/Dementia care sites. |

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| Summary:  | * Sites shared investigative foci of their respective Centers and broadly discussed measures being utilized in their pilot projects (**details below**).
* OHSU data specialist has offered to consolidate list of current measures utilized by Alzheimer’s Disease-/dementia-focused sites as a follow-up to this discussion.
* Dr. Hanson discussed the NIA IMPACT Collaboratory’s role as a resource for the Roybal Alzheimer’s Disease-/Dementia-focused sites and provided an update regarding their long-term goal of creating a measures repository (**details below**).
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| Action Item for Sites : | Please respond to the Coordinating Center email to confirm/list measures utilized by your pilot projects. |

## Detailed Minutes

### Roybal Updates

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| **Site Name****& Representative**  | **Site Focus** | **Pilots**  | **Measures**  |
| Roybal Translational Research Center to Promote Context-Specific Caregiving of Community-Dwelling Persons Living with Alzheimer’s Disease or Related Disorders **(Emory University)**Ken Hepburn, PhD - Primary Investigator | The development of caregiving mastery  | * 1. Caregiving for persons with Primary Progressive Aphasia.
	2. Caregivers from a sexual-orientation minority group.
 | **Common Measures:** * + Pearlin Caregiver’s Stress Scales, Standard measures of depression, PTSD, Anxiety, and Zarit Burden Inventory. Most pilots will use these in addition to their own measures.
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| ORCASTRAIT: Oregon Roybal Center for Care Support Translational Research Advantaged by Integrating Technology **(Oregon Health & Science University)**Jeffrey Kaye, MD - Primary Investigator & Director of ORCATECHAllison Lindauer, PhD, NDSarah Gothard, Data Specialist  | Integrating technology in care support to improve assessments and ultimately interventions in care-provision studies.  | * 1. Delivering an intervention of direct home video interactions with a professional care provider in their homes. All interactions are done directly at home by video. There are two outcomes measured.
	2. "Shared Sense" - developing an intervention for care planning in early stage dementia, integrating in-home, objective sensing.

  | **Pilot 1*** + Conventional measures: Zarit Burden scale, RMBC - Revised memory behavior problems checklist, Quality of Life AD Scale, Depression Assessment, and an Anxiety Scale)
	+ Digital Behavior Measures: outcomes are measured through a suite of objective home assessment technologies such as time together, sleep, time out of the home, mobility activity, and other digital behavioral markers.

**Pilot 2** * + Using the same type of measures as the first pilot to assess the decision-making of the dyads.
	+ Specific measures: Care values and preference scale, the decision making involvement scale, the dyadic strain subscale of the dyadic relationship scale.
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| Midwest Roybal Center for Health Promotion and Translation **(University of Illinois At Chicago)**Susan Hughes - Principal Investigator, Center Co-Director | Develops evidence-based interventions focusing on four areas: physical activity, mobility (broadly defined to include cognition), adherence interventions, and use of cutting edge technology in order to introduce uniformity in terms of the fidelity of the interventions. Recently received an ADRD supplement.  | 1. Testing the impact of a virtual reality dance program on balance, cognition, and structural and functional connectivity within the cognitive motor areas of the brain in frail older adults
2. Using EMA to test the impact of an app to disrupt sedentary time on cognition and physical function and functional and structural brain connectivity among older Latinos.
 | **Common Measures:**  * + NIH Toolbox measures for both cognition and motor function: picture vocab, Flanker Inhibitory Control & Attention, List Sorting Working Memory, Dimensional Change Card Sort, Pattern Comparison, Processing Speed, Picture Sequence Memory, Oral Reading Recognition, Oral Symbol Digit, Auditory Verbal Learning, Picture Sequence Memory Test, Grip Strength, Standing Balance, 4 Meter Walk Gait Speed Test, 9-Hole Pegboard, Dexterity Test, Two-Minute Walk Endurance Test
	+ Physical activity using both self-reported and performance measures such as MRI imaging to see physical activity effects on areas of the brain that are hypothesized to be affected by the intervention.
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| Transforming residential palliative care for persons with dementia through behavioral economics and data science **(University of Pennsylvania)**Scott Halpern, MD, PhD - Principal Investigator | Uses insights from data science and behavioral economics in an effort to improve palliative care delivery and long-term support facilities for persons with dementia and their caregivers.  | * 1. Adapting a web-based, advanced care planning module that is disease non-specific for use by persons w/ dementia and their caregivers. The intervention is particularly adaptable in the nursing home setting.
	2. Administering battery of assessments to clinicians and advanced care providers in ~ 200 nursing homes around the country to understand which behavioral characteristics and sociological constructs are associated with more aggressive treatment patterns for persons with dementia, including likelihood of being admitted to the hospital and having multiple transitions to the end of life.
 | **Common Measures:** * + Among a few common measures to be used will be a measure using the Decisional Conflict Scale for persons on a spectrum of cognitive impairment.
	+ No caregiving measures used
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| Roybal Center for Social Ties and Aging Research [STAR Center] **(University of** **Rochester)**Kathi Heffner, PhD - Principal Investigator | Develop behavioral interventions that can reduce isolation and promote social connectedness in caregivers.  | * 1. Qualitative study with both caregivers and those working with caregivers in community/care managers/local caregiver organizations to gain understanding about the way caregivers conceptualize social connectedness.
	2. Problem-solving, therapy-based intervention in which you identify priorities around social connectedness (i.e., time with loved ones, engaging in rewarding social activities outside of the home) and then developing solutions around the problem.
 | **Common Measures:**The Roc STAR Core Battery that will be used for pilot studies includes measures across 5 domains:* + **Demographics**
	+ **Measures of social connectedness**: UCLA Loneliness Scale, de Jong-Gierveld Loneliness Scale, Berkman-Syme Social Network Index, Interpersonal Needs Questionnaire (belonging, perceived burden on others), Unidimensional Relationship Closeness Scale (quality of relationship between caregiver and family member with dementia), PROMIS social health computerized adaptive tests (social isolation, emotional support, instrumental support, satisfaction with roles & activities, companionship).
	+ **Measures of the caregiving experience**: Montgomery Borgatta Caregiver Burden Scale, Perceived Stress Scale (PSS-10), Modified Caregiver Strain Index, Caregiver Reaction Scale, Neuropsychiatric Inventory self-administered questionnaire (NPI-Q), FAST (Functional Asssessment Staging in Dementia), Modified Cornell Services Index (formal & informal health and social services use).
	+ **Heath Indicators:** Self-report of medical and mental health diagnoses and current medications, TICS (Telephone Interview for Cognitive Status-Modified), Examiner (Selected modules), Pittsburgh Sleep Quality Index , WHODAS, PROMIS pain interference and fatigue, Columbia Suicide Severity Rating Scale.

**Well-being:** WHOQOL, PROMIS CATs (meaning & purpose, depression, anxiety), Geriatric Depression Scale. |

### Laura Hanson, NIA IMPACT Collaboratory (<https://impactcollaboratory.org/>).

**The charge of the overall IMPACT Collaboratory** is to fund pilot studies and support AD/Dementia Research Investigators.

* + A **twice-a-year pilot opportunity** serves as a call for and subsequent awarding of proposals as a joint initiative between the Collaboratory investigators and the NIA.
	+ Each of the Collaboratory Cores is charged with supporting investigators who applied for or are awarded pilots in addition to investigators who are working in the field much more broadly (e.g., **Roybal Center investigators**).

Dr. Hanson’s PCRO Core is charged with three tasks:

* + Pull together **an initial library of pragmatic/practical measurement tools** (for both caregiver reporting and patient reporting) that can also be data-captured out of the electronic health record or administrative data sets
	+ Provide advising and best-practice information around measurement collection strategies
	+ Serve as freely available advisors and consultants to investigators who are working in the field and help them improve their work

The PCRO Core’s advice and consulting will be **available to future Roybal pilot applicants’ pilot designs and measurement strategies** (as long as they are connected to the NIA/NIH and involve Alzheimer’s disease and/or related dementias). The Core will strive to have links to appropriate references and investigator websites when available, and they will incorporate notes on when and how these measures have been used—in addition to some commentary on their properties—in the library.

### Follow-Up: Action Items for Coordinating Center

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| Item | Expected Completion Date  |
| Create a link to the NIA Collaboratory on the Roybal website  | Completed  |
| Explore permissibility of joint pilot funding with Dr. Onken  | 1/27/2020 |
| Forward list of sites’ data measures to Sarah Gothard (OHSU) for data map creation  | 2/15/2020 |