The Alzheimer's Disease Centers Program: updates

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Presented at Directors Meeting, October 20, 2018, Atlanta, GA

Polleverywhere Feedback

- **Using the Poll Everywhere app on your smartphone:**

1. Search for "Poll Everywhere" in your phone's app store and download it (it's free).
2. Launch the app.
3. Join the presentation: **uwnacc240** (PollEv.com/uwnacc240).
4. Look for the active survey presentation.
5. Press Start Survey and begin your instant feedback on the screen.

- **Using your phone by texting (without downloading app):**

1. Text **UWNACC240** to **22333** to join survey
2. You will receive a reply "You've joined UW NACC's session (UWNACC240)
3. Your phone number is private.
4. Text your answers during the active survey question. Listen to the presenter.

ADC Meeting Structure

- May 2019
  - Date change to Thursday/Friday, May 2 and 3
- Spring Meetings
  - AAN requests that we shift to Thursday/Friday if they're helping us book discounted space. We can accept or book our own space keeping Friday/Saturday
- Virtual Site Visits
  - Volunteers have not been forthcoming
  - May 2019 – Biomarkers
  - Oct 2019 – REC Junior Faculty Poster Session

Applications

- No more P50 revision applications; focus on your new application
  - NOT-AG-18-031
- Submit Final – RPPR when you are a P50 transitioning to the new FOA in your final year.

- We don't know when the new FOA will be out.

Rec Table 1 – from ADC Progress Report Instruction

Table 1. _____ Summary Table of REC Trainees – Year XX			
Last, First Name	**Level of Training**	**Area of Research**	**Progress**
Adams, P.	Post-Doctoral	Episodic memory on decision making	Co-authored paper, poster presentation, experience in a number of labs

Modified Rec Table 1

Table 1. _____ Summary Table of REC Trainees – Year XX				
RPPR year	**Last, First Name**	**Level of Training**	**Area of Research**	**Progress track**
2017	Adams, P.	Post-doctoral	Episodic memory on decision making	# of co-authored papers, # posters, training award, experience in multiple labs
2018				
2019				
2020				
2021				

Summary of REC trainees (2018)

ADCs (10)	REC Trainees	Junior faculty	Postdoc Residents	Predoc PhD, MD,	Under-graduates	Publications Grants
Range	5-60	3-12	1-15	6-26	4-18	3-20
Total	263	28	74	110	52	105

Mark your calendar for upcoming REC activities

Workshop for REC postdocs

- **March 13, 2019**
- Grant writing workshop
- 30 post-doctoral trainees
- Conjunction with ADRD summit March 14-15, 2019
- Bethesda, MD

REC Junior faculty

- **Oct 11, 2019**
- Presentation (5 min)
- Poster Sessions
- 30 Junior faculty
- Conjunction with Fall ADC meeting, Oct 11-12, 2019
- St. Louis, MO

Staff Updates

Dr. Cerise Elliott is now officially:

Co-Director of the ADC Program!

Dr. Yuan Luo will be guiding the RECs

NEUROPATHOLOGY STEERING CMTE

- NeurobioBank
- Tissue and Biospecimen Resource Locator - NACC
- Transmissibility meeting
- TDP43 Meeting
- DS Autopsy

Current Steering Committees

- Elected Representation
  - ADC Executive Committee – July
  - NACC Steering Committee - July
  - Administrators Steering Committee – August/September
  - Clinical Core Steering Committee - January
  - Neuropathology Core Steering Committee - July
  - ORE Core Steering Committee - July
  - Data Core Steering Committee - July

Biomarker Steering Committee?
REC Steering Committee?

Interest Groups

- 2017 – Listservs created
  - Disclosure Work Group
  - African American Recruitment
  - Latino
  - Imaging
  - Biomarkers

UDS Workgroup update

- Survey completed
- Results compiled: looks like very few whole forms would be eliminated. One that stuck out was **biomarkers**
- Met with group to review with Bud – pointed out that many are already optional
- Next steps:
  - Other ways to evaluate utility/effectiveness
  - Should any additional items be made optional
  - Are there gaps? Are we at the cutting edge, leading the field?
  - Control visits – annual?

FY2018 NACC Augmentations

- Imaging
- Digital Biomarkers
- CSF study
- Down Syndrome
- FTD and DLB modules
- Affiliated Studies

Attention, ADCs

Promote your studies and **share** them with researchers around the world

Does your Center have a study that may be a resource for researchers outside your ADC? If so, NIA invites you to promote it on the NACC website.

Just fill out a quick questionnaire, and NACC will post a brief description, along with your logo and a link to the study website.

GET THE QUESTIONNAIRE: naccmail@uw.edu

Down Syndrome

- ABC-DS Alzheimer's Biomarkers Consortium — Down Syndrome https://www.nia.nih.gov/research/abc-ds
- https://www.nih.gov/include-project
- Autopsy
- DS module
- DS Work Group

Exploring the Connection Between Down Syndrome and Alzheimer's Disease

The ABC-DS study is a joint study conducted by two groups of research collaborators —Neurodegeneration in Aging Down Syndrome (NiAD) and Alzheimer's Disease in Down Syndrome (ADDS)—and is currently funded at $43 million by the National Institute on Aging (NIA) and the *Eunice Kennedy Shriver* National Institute of Child

INCLUDE Project Research Plan

Thinkstock

The INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndromE) project was launched in June 2018 in support of a Congressional directive in the fiscal year (FY) 2018 Omnibus Appropriations. The directive calls for a new trans-NIH research initiative on critical health and quality-of-life needs for individuals with Down syndrome. NIH is dedicating $22.2 million for INCLUDE research, bolstering total funding for Down syndrome research in FY2018 to an estimated $59 million, with further support anticipated in FY2019 and beyond, pending availability of funds.

INCLUDE will investigate conditions that affect individuals with Down syndrome and the general population, such as Alzheimer's disease/dementia, autism, cataracts,

Research Centers Collaborative Network (RCCN)

- Goal: Catalyzing cross-disciplinary research across the NIA Center Programs
- Webinar Series
- Workshop: Achieving and Sustaining Behavior Change in Older Adults, December 6-7th, 2018 in Bethesda, MD.10 travel awards
- RFA for Pilot Awards to foster inter-center program collaborations will be issued in **December** on "Achieving and Sustaining Behavior Change in Older Adults."
- Workshop: May/June 2019 on Sex/gender differences in aging
- www.rccn-aging.org @rccnaging

Wisconsin Alzheimer's Disease Research Center
UNIVERSITY OF WISCONSIN
SCHOOL OF MEDICINE AND PUBLIC HEALTH

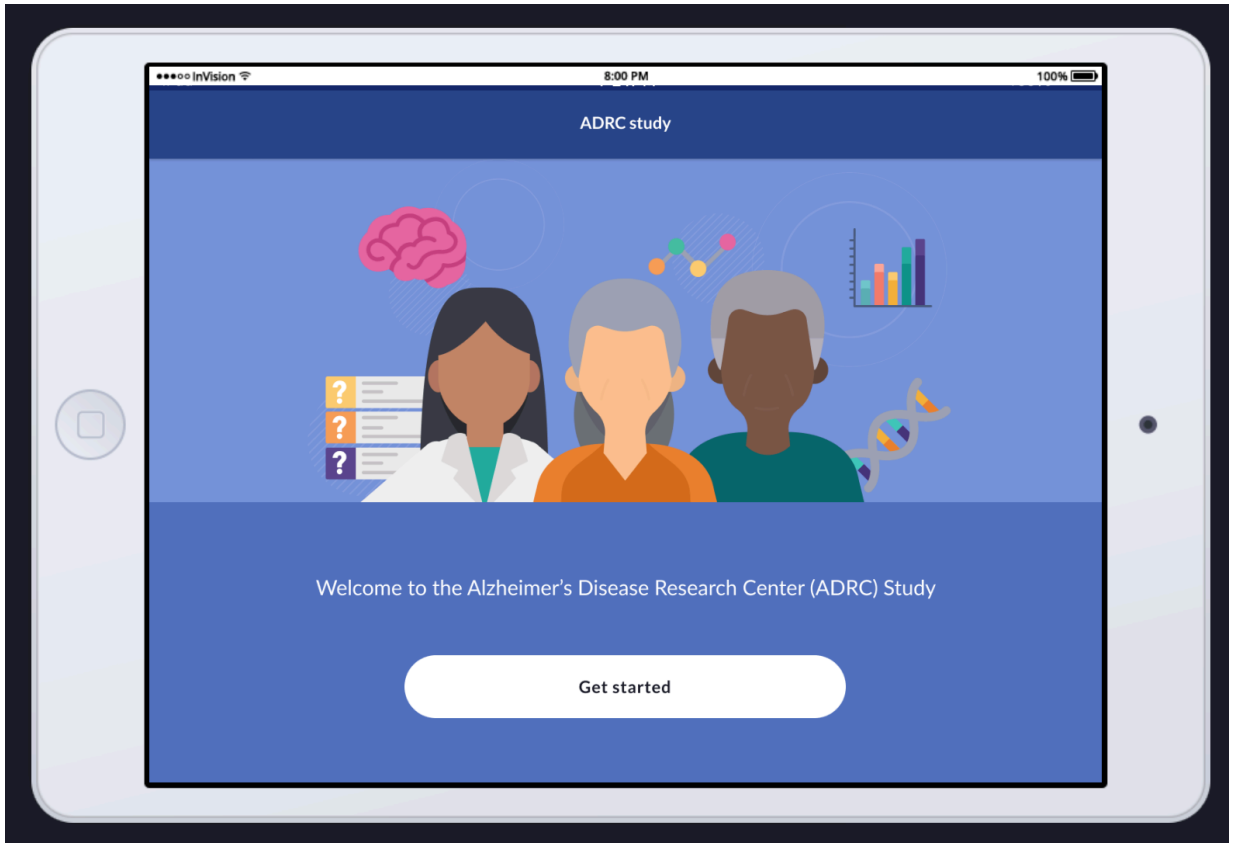
EMORY UNIVERSITY

SageBionetworks

Dorothy Farrar-Edwards
Hannah Blazel
Erin Chin
Nichelle Cobb
Ken Croes

Jim Lah
Cecelia Manzanares
Felicia Golstein

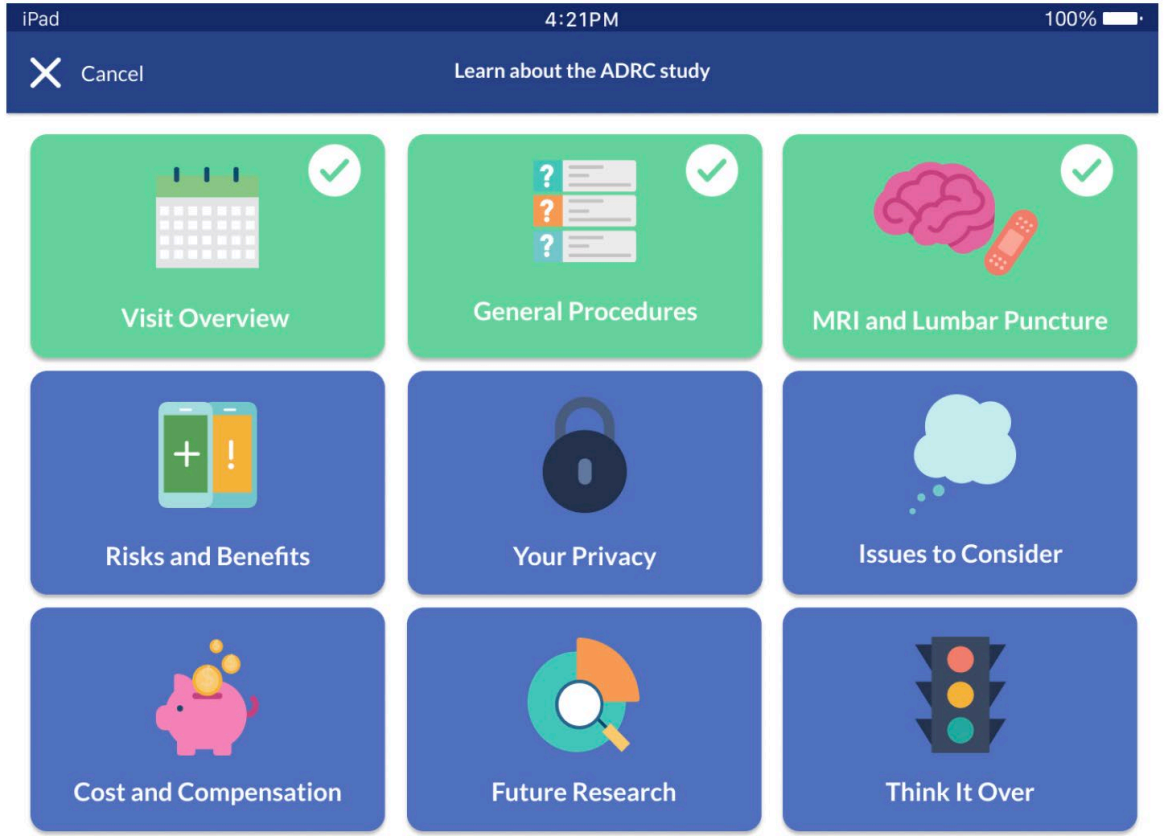
Christine Suver
Woody McDuffy
Stockard Simon
Amy Tran
Jennifer Hamann
Meg Doerr
John Wilbanks
Lara Mangravite



ADRC Study coordinators
Volunteers

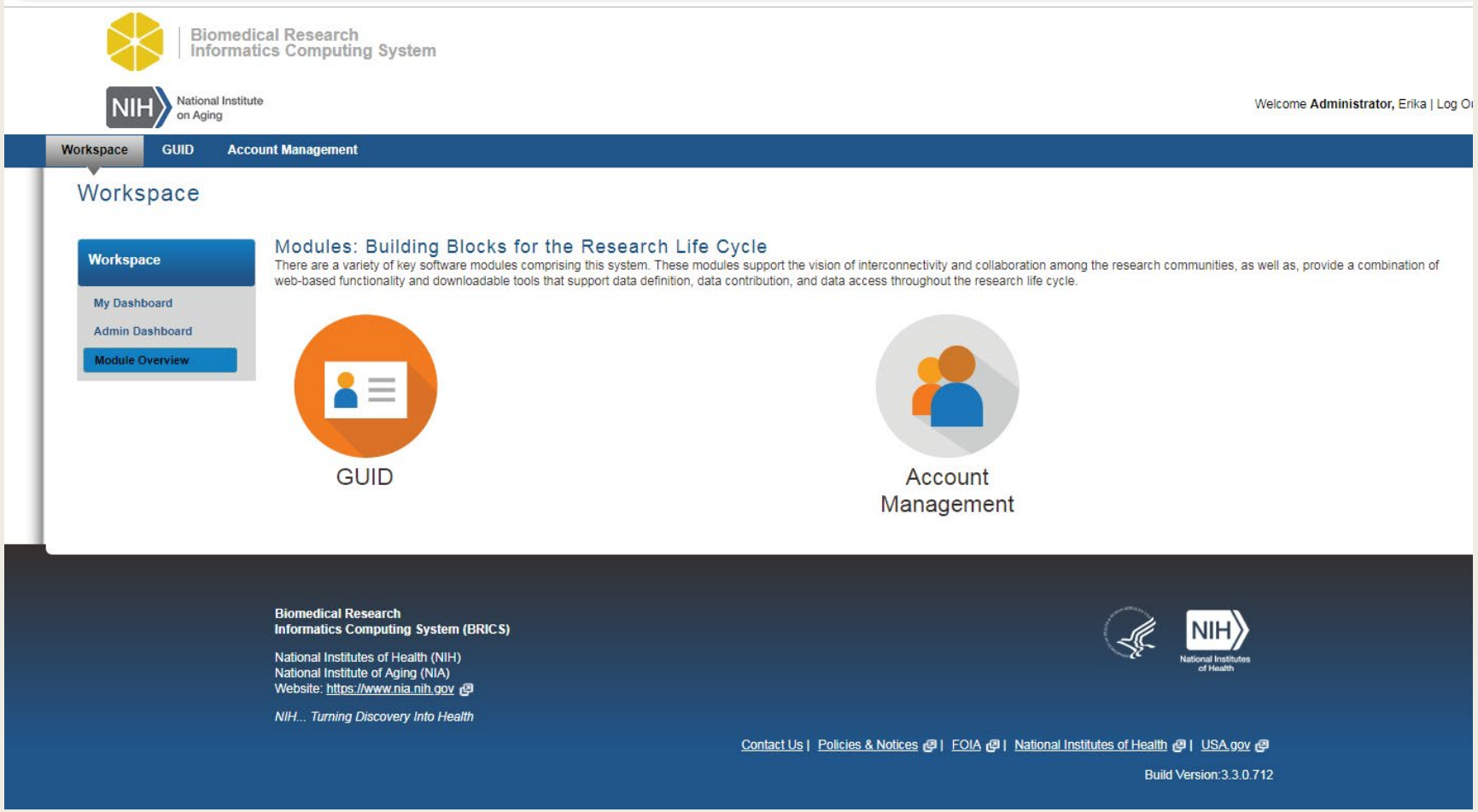
eConsent Narrative

Self-guided exploration

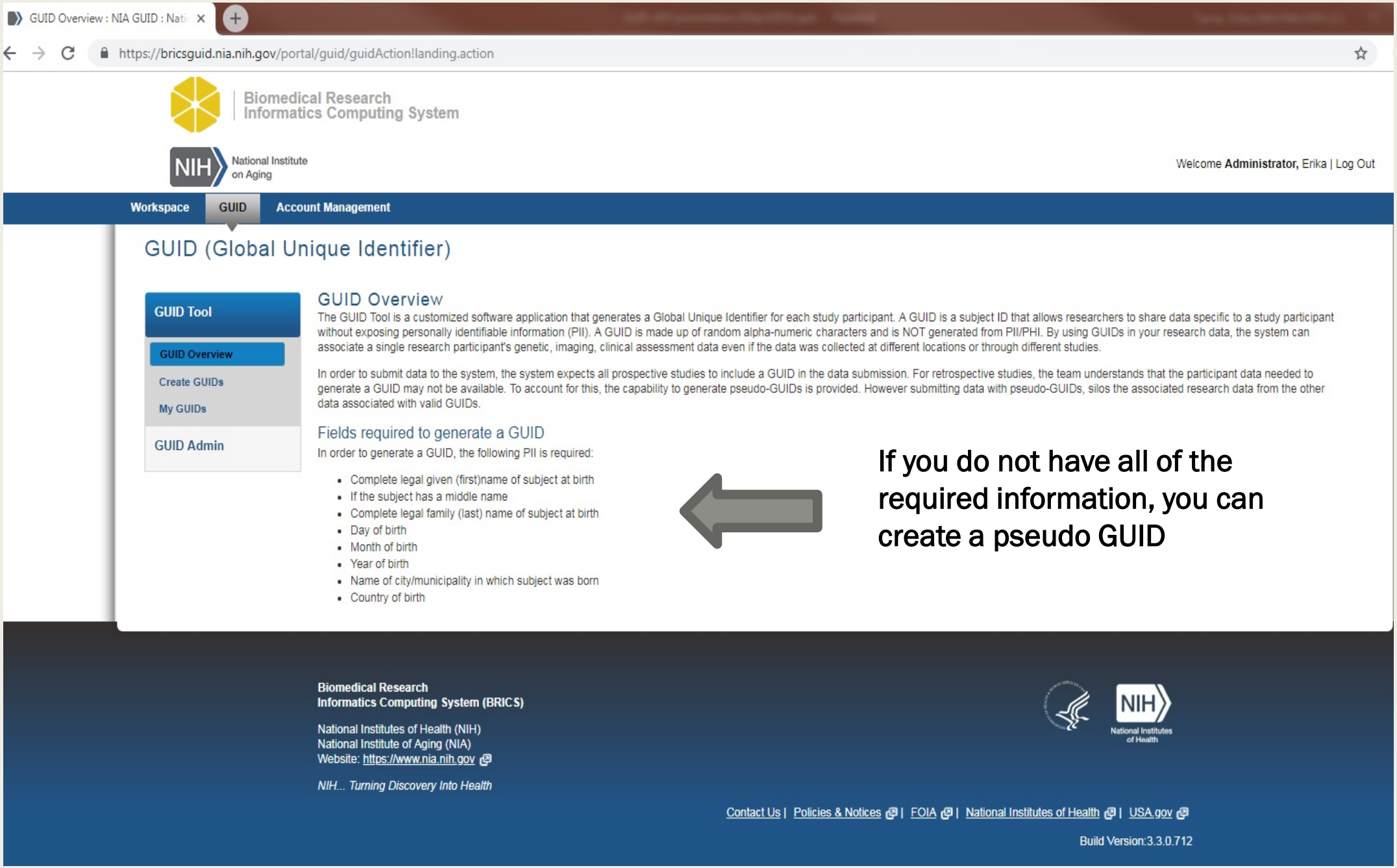


NIA GLOBAL UNIQUE IDENTIFIER (GUID) PORTAL

Progress to Date & Next Steps



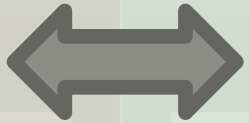
- Live NIA GUID portal launched July 1 and rolled out to ADCs on July 17;
- Portal allows users to:
  - *create actual and pseudo GUIDS;*
  - *Upload batch information to generate multiple GUIDS*
- Account access and set-up is managed by NIA BRICS Operations Team
  - *25 Users*
  - *52 GUID entries*


GUID Overview : NIA GUID : Nati
https://bricsguid.nia.nih.gov/portal/guid/guidAction!landing.action
Biomedical Research
Informatics Computing System
NIH National Institute on Aging
Welcome Administrator, Erika | Log Out
Workspace
GUID
Account Management
GUID (Global Unique Identifier)
GUID Tool
GUID Overview
Create GUIDs
My GUIDs
GUID Admin
GUID Overview
The GUID Tool is a customized software application that generates a Global Unique Identifier for each study participant. A GUID is a subject ID that allows researchers to share data specific to a study participant without exposing personally identifiable information (PII). A GUID is made up of random alpha-numeric characters and is NOT generated from PII/PHI. By using GUIDs in your research data, the system can associate a single research participant's genetic, imaging, clinical assessment data even if the data was collected at different locations or through different studies.
In order to submit data to the system, the system expects all prospective studies to include a GUID in the data submission. For retrospective studies, the team understands that the participant data needed to generate a GUID may not be available. To account for this, the capability to generate pseudo-GUIDs is provided. However submitting data with pseudo-GUIDs, silos the associated research data from the other data associated with valid GUIDs.
Fields required to generate a GUID
In order to generate a GUID, the following PII is required:
Complete legal given (first)name of subject at birth
If the subject has a middle name
Complete legal family (last) name of subject at birth
Day of birth
Month of birth
Year of birth
Name of city/municipality in which subject was born
Country of birth
If you do not have all of the required information, you can create a pseudo GUID
Biomedical Research
Informatics Computing System (BRICS)
National Institutes of Health (NIH)
National Institute of Aging (NIA)
Website: https://www.nia.nih.gov
NIH... Turning Discovery Into Health
NIH National Institutes of Health
Contact Us | Policies & Notices | FOIA | National Institutes of Health | USA.gov
Build Version:3.3.0.712

Next Steps

LAUNCH NIA GUID PORTAL (July 2018)

Initial Launch to ADCs



Provide continuous user feedback to developers

CENTRALIZED NIA/NINDS PORTAL (December 2018)

Synchronize records of participants in NIA- and NINDS-funded clinical studies

ADOPTION OF PORTAL ACROSS NIA CLINICAL SITES (October 2019)

Roll out portal to all NIA Sites

Office of Research and Development
Three Strategic Priorities

Access to High Quality Clinical Trials

Increase Veterans' access to clinical trials.

Greater choice for Veterans.

Modernizing our system.

Focus resources more efficiently.

Access.

Lead: Grant Huang, MPH, PhD

Substantial Real-World Impact

Increase the real-world impact of VA research.

Modernizing our system.

Focus resources more efficiently.

Lead: Amy Kilbourne, PhD, MPH

VA Data as a National Resource

Increase the good that VA Data can do.

Modernizing our system.

Focus resources more efficiently.

Lead: Scott Duvall, PhD

Background

- Clinical trials are a key part of the national healthcare and research landscape.

- Trial sponsors include federal, non-profit and industry sources.
  - Industry trials have grown at the largest rate (17%) since 2006 (Ehrhardt, et al. JAMA, 2015)

- Clinical trials offer several opportunities:
  - Patient access to cutting edge therapies
  - Clinician access to research and collaborative activities
  - Mutually beneficial partnerships

- VA has strong clinical trials capabilities and resources
  - Much are internally focused and directed

Access to Clinical Trials Initiative

- Goals:
  - Establish an organized national capability for VA to partner in high quality clinical trials
    - Efficient processes and capabilities for initiating clinical trials in VA health care system
    - Models for partnerships
  - Provide more Veterans and investigators to opportunities to participate in industry and federally sponsored clinical trials on novel therapies

- Long-term: To advance VA's role in the national clinical trials enterprise

Access to Clinical Trials (ACT) for Veterans

- Since April 2018 Summit, monthly updates continue to be provided to stakeholders (clinicaltrials@navref.org)
- 5 work groups established to address priorities for initiating trials:
  - Single point of contact model
  - Establishing set of key VA capabilities, assets and processes for industry partners interested in initiating opportunities
  - Establishing set of requirements VA needs to fully consider opportunities
  - Creating and maintaining a process map for start-up activities
  - Developing VA Central IRB capabilities to accommodate industry-sponsored trials

NCI And VA Interagency Group to Accelerate Trials Enrollment (NAVIGATE)

- 12 sites selected for infrastructure support and to provide leadership for national network for NCI funded trials
  - 1 VA/CSP supported coordinating center

Collaboration between NCI and the VA to facilitate enrollment of Veterans into NCI funded clinical trials.

- Opportunity for government agencies to partner at the national level to make clinical trials more accessible, *and*
- Accelerate cancer research by testing new cancer therapies to lessen the burden of cancer and its symptoms, as well as novel approaches to the prevention and early detection of cancer