

Building a data lake and integrating remotely collected data

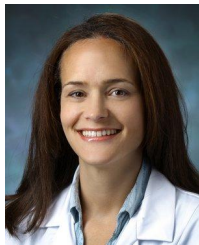
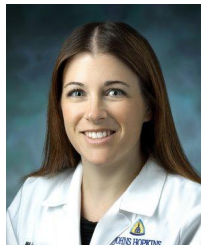
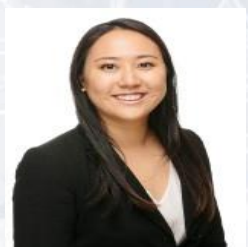
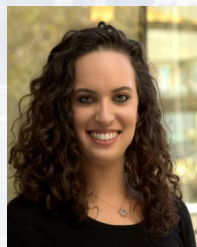
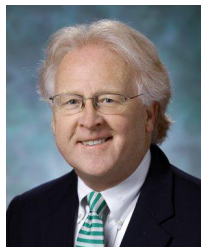


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MEDICINE

Ryan Roemmich, PhD
Kennedy Krieger Institute/Johns Hopkins Medicine

LeaRRn Summit
9/24/2024

Our team



Standardized patient-centered measures

TABLE 1 - The standard assessment battery for PT



	Clinical Setting and Timeframe		
	Acute Care	Inpatient Rehabilitation	Outpatient
Body structure and function			
Fugl-Meyer Assessment ^a	E	E ^b	E, 30, 90, D/C
Manual Muscle Testing ^c	E	E	E, 30, 90, D/C
Modified Ashworth Scale ^d	E	E	E, 30, 90, D/C
Activity			
10-Meter Walk Test	E	E	E, 30, 90, D/C
BBS (if score >52, then complete FGA)	E	E	E, 30, 90, D/C
Participation			
AM-PAC Basic Mobility	E	E	E, 30, 90, D/C
Stroke Impact Scale 16	N/A	N/A	E, 30, 90, D/C

Timeframe: E, at initial evaluation in the specified practice setting; 30, 30 days after initial evaluation in the specified practice setting; 90, 90 days after initial evaluation in the specified practice setting; D/C, at discharge; N/A, not applicable.

^a Lower extremity portion only completed by physical therapy.

^b Only administered for patients who were not assessed in acute care, for example, because of admission from an outside hospital.

^c Manual muscle testing completed for knee extension, hip flexion, ankle dorsiflexion, and ankle plantarflexion.

^d Modified Ashworth Scale completed for knee extensors and plantar flexors.

AM-PAC, Activity Measure for Post-Acute Care; BBS, Berg Balance Scale; FGA, Functional Gait Assessment.

Establish the rehabilitation data repository



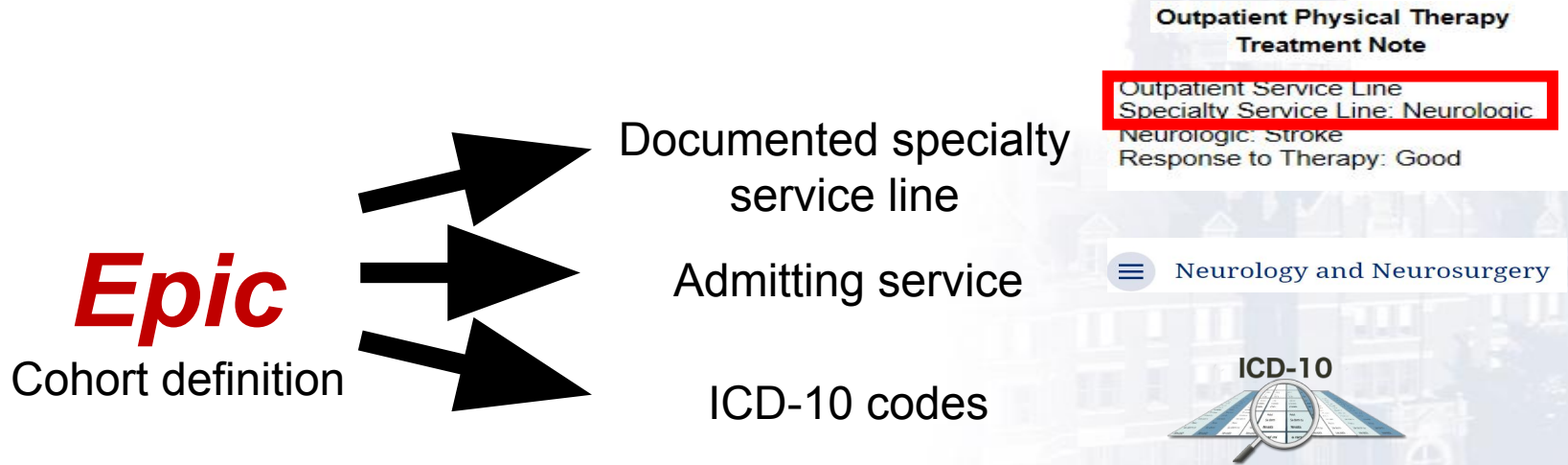
eIRB2



CORE FOR CLINICAL RESEARCH DATA ACQUISITION (CCDA)

- Define population:
 - All patients – inpatient or outpatient – with a diagnosis of stroke who underwent rehabilitation at Johns Hopkins Medicine since 2016
- Identify and extract data
- Important considerations
 - HIPAA waiver
 - Waiver of consent
 - Data storage and security

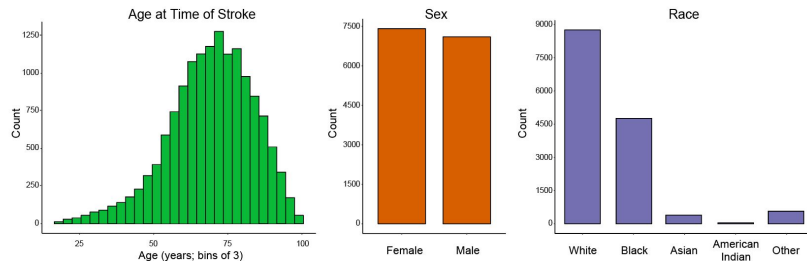
Cohort identification and validation



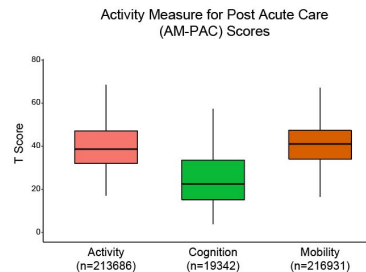
15,805 patients identified

Extracting the demographic and clinical data

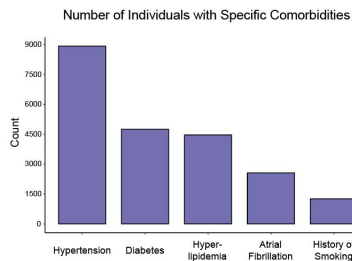
1. Demographic Information



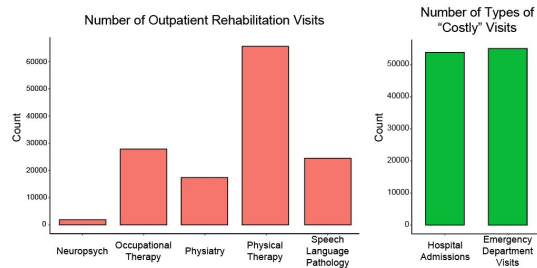
2. Functional Measures



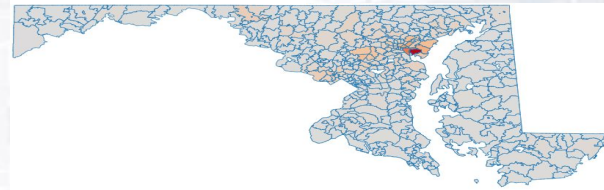
3. Comorbidities



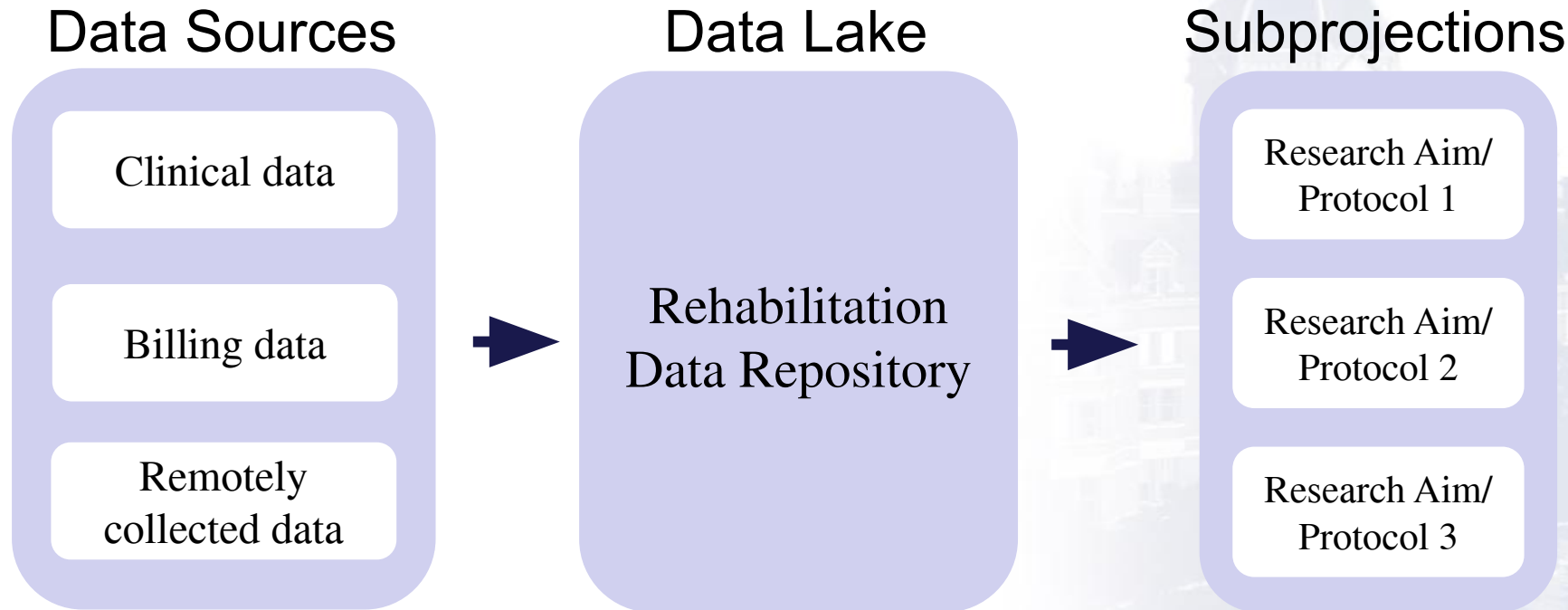
4. Healthcare Utilization



5. Geographic Information



Using the data for research projects




Our system for longitudinal, remote measurement of function









Physical



Psychosocial

 **TESTMYBRAIN**

Test yourself and help us learn more about the mind and brain.

 Go!	Cognitive Speed Estimated Time: 3 minutes How fast are you? Is this related to how you make decisions about the future?  Share	 Go!	Everyday Cognition Estimated Time: 19 minutes See how quickly and accurately you can complete these digital versions of everyday tasks.  Share
 Go!	Visual Reasoning Estimated Time: 8 minutes Spot the pattern to complete the puzzle.  Share	 Go!	Famous Faces Estimated Time: 8 minutes Can you identify famous people from their faces?  Share

Cognitive

Bringing remote data into the repository



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TECHNOLOGY
INNOVATION CENTER



Reminders to sync device in Fitbit app



Rehabilitation Remote
Monitoring Application

Study team



Precision Rehabilitation
Center of Excellence
Data Repository

Data

64



Data

Electronic Health Record

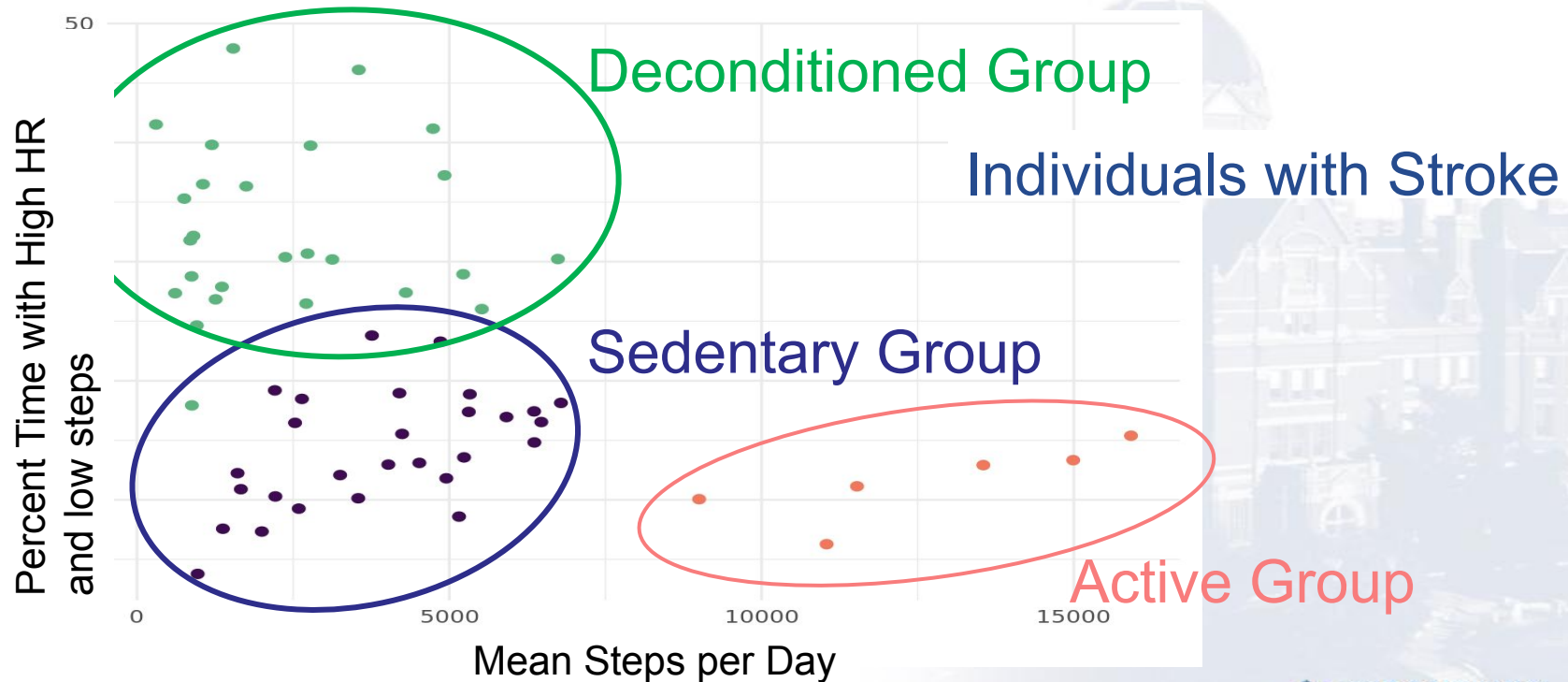


Reminders to take/complete assessments

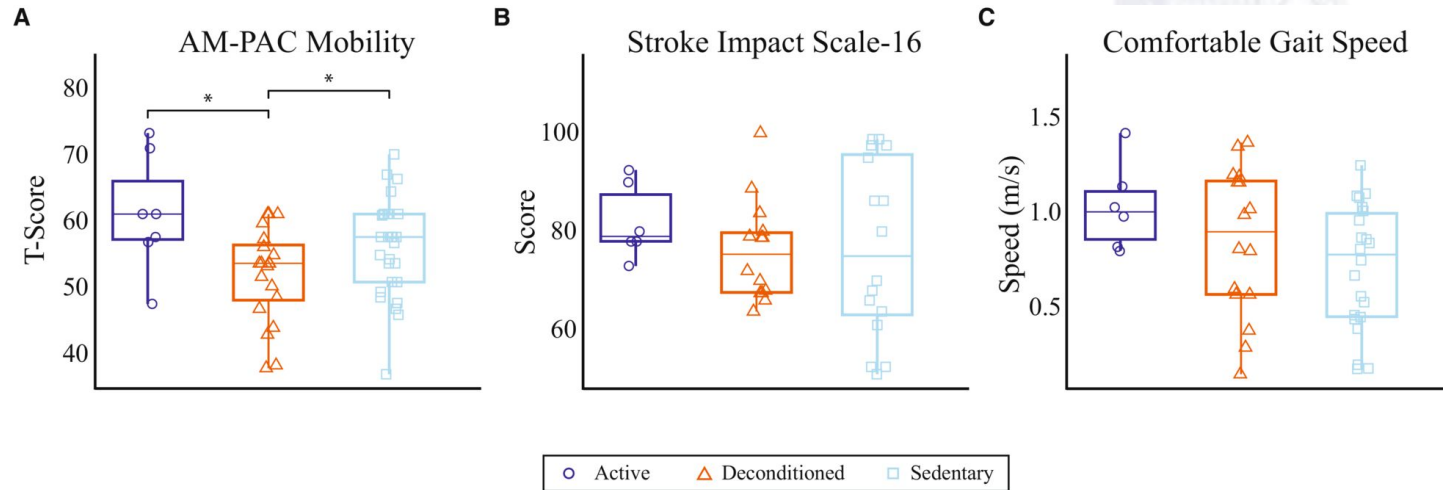


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We identified three unique subgroups of persons post-stroke



The subgroups also differed in clinical metrics of mobility



 **Patient Information**
 Name: "Charles Darwin"
 EMRN: EXXXXXXXXX
 DOB: 10/19/1954



Comfortable Gait Speed



Steps per day



Thanks!

Sheikh Khalifa Stroke Institute



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EMBASSY OF THE
UNITED ARAB EMIRATES
WASHINGTON, DC

