NIH HEAL INITIATIVE

Group Discussions:

Data Sharing and Harmonization Across HEAL

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Group Discussion:

Clinical Research: Implementation and Sustainability

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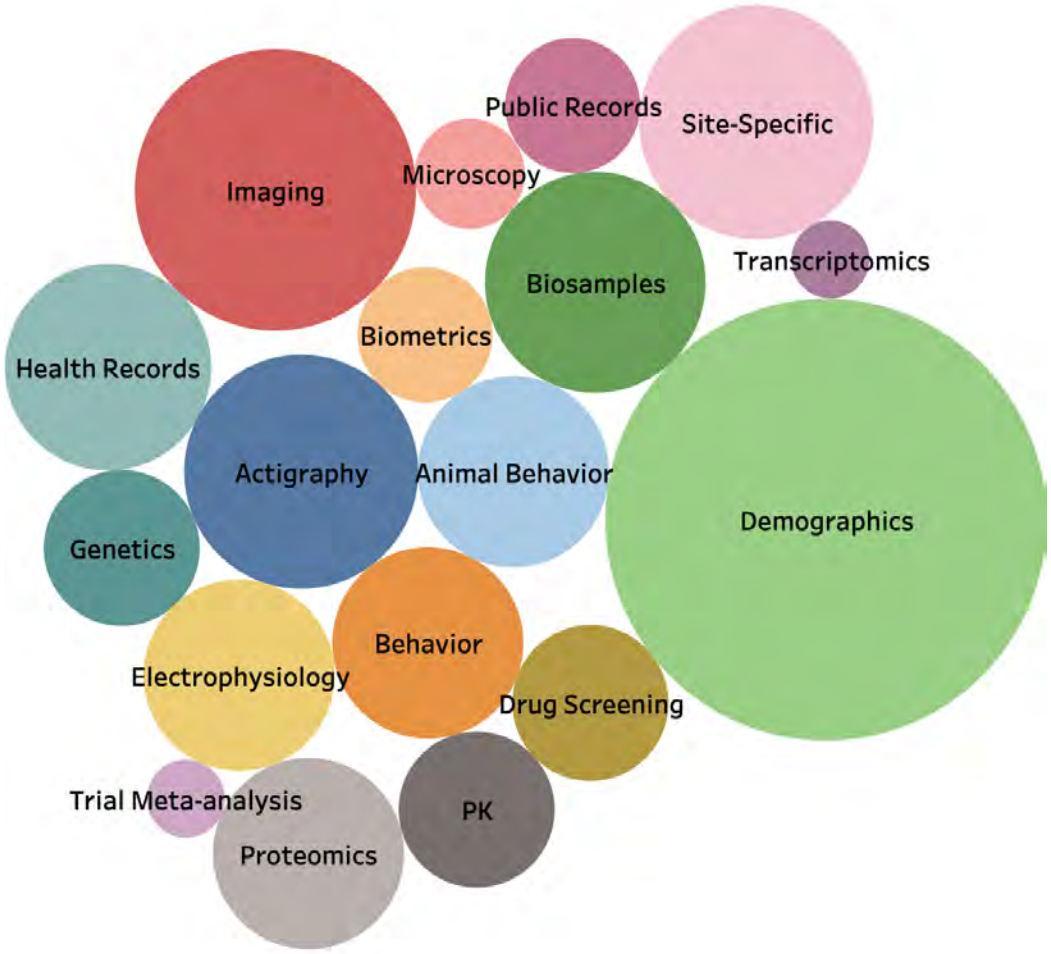
Example Clinical Research: Implementation and Sustainability Programs

- HBCD (HEALthy Brain and Child Development)
- Pragmatic and Implementation Studies for the Management of Pain to Reduce Opioid Prescribing (PRISM)
- Optimizing Collaborative Care for People with Opioid Use Disorder and Mental Health Conditions
- Preventing At-Risk Adolescents Transitioning into Adulthood from Developing Opioid Use Disorder
- Justice Community Opioid Innovation Network
- HEALing Communities Study
- Behavioral Research to Improve Medication-Based Treatment

All HEAL High-level Data Types



A HEAL Data Strategy assessment was conducted in 2019. Bubble size is proportional to number of assessment interviews mentioning an example of the data type.

BIOTEAM
Enabling Science

Clinical Research: Implementation and Sustainability Programs Data Types

Demographics	Ethnicity	Location	Gender	Disease States	
Site-Specific	OUD Incidence	OUD Deaths	Census Data	Naloxone Distribution	MAT Data
Health Records	Electronic Medical Records	EDIE * Records	MAT Data		
Public Records	Justice Setting Records	Public Health Records	Social Service Records		
Biometrics	Height	Weight	Hip Circumference		
Clinical Studies	Trial Meta-analysis				
Electrophysiology	Polysomnography (PSG)	EEG	EKG	MEG	
Behavior	Self-reported Pain	Self-reported Mood			
Biosamples	Blood Metabolites	Urinalysis	Microbiome (Feces)	Chemical Clearing (Feces)	Sample IR Spectroscopy
Actigraphy	Steps	Geolocation (GPS)	Sleep States	Heart Rate	Skin Moisture
Imaging	fMRI / MRI	PET	Ultrasound	CT	X-Ray
Genetics	Human WGS	Human Microarray			
Proteomics	Human CNS Protein				
Transcriptomics	Human CNS RNA				
Pharmacokinetics	Drug Metabolites	Intermediary Metabolites			
		* Emergency Department Information Exchange			
Size Key	1 Gigabyte or more	10s to 100s of Megabytes	Less than 10 Megabytes		

A HEAL Data Strategy assessment was conducted in 2019. A small number of Interviewees discussed the data types they would expect in their programs.

HEAL Public Access and Data Sharing

- Electronic copies of publications will be deposited within 4 weeks of acceptance
- Publications will be Published under the Creative Commons Generic License
- Publications will be made publicly available immediately without embargo
- Underlying Primary Data for the Publications will be made broadly available
- Sharing of Underlying Primary Data must be responsive to protecting confidential and proprietary data and is consistent with applicable laws and regulations
- See https://heal.nih.gov/about/public-access-data

HEAL data harmonization and sharing

- To achieve our bold goals some preparatory work will be needed
  - Standardization
  - Uploading and sharing
  - Harmonization
- We also have to consider how research data can be shared and made FAIR
  - Through a HEAL Cloud platform
  - Through HEAL data management services

Goals for Small Group Sessions

- Introduce goals and opportunities of HEAL data harmonization and sharing
- Share NIH's vision and plans to develop a data management infrastructure
- Gather feedback on what resources and communication strategies would benefit investigators
- Gather information on data needs of the investigator community
- Hear about the investigators' concerns
- Gain insight from investigators' plans and best practices

DISCUSSION

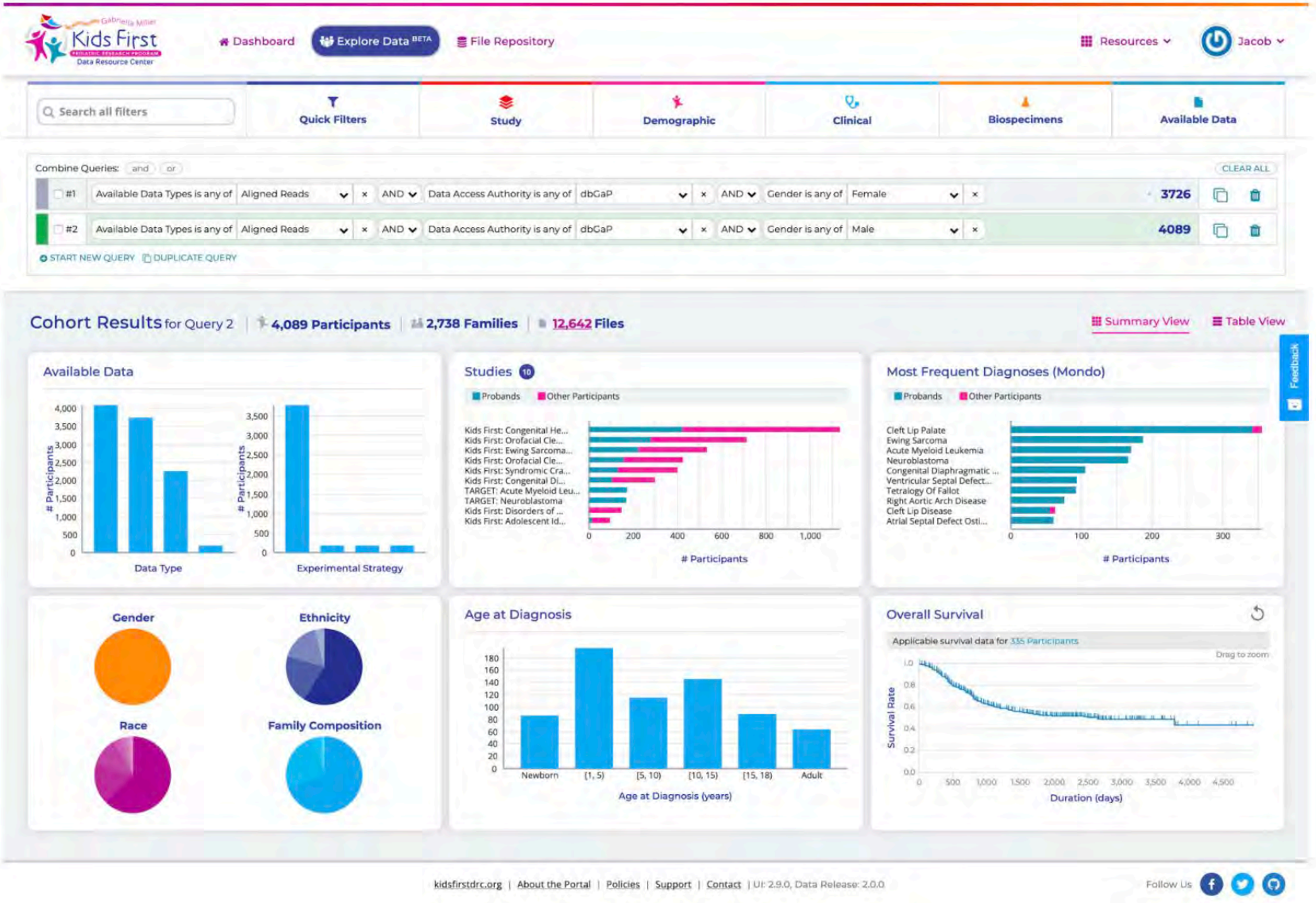
HEAL Data Harmonization

- Many programs have specific data coordinating centers awarded and in place … and many programs do not.
- Some are actively working on strategies, some are more likely to let look to HEAL for direction.
- HEAL is planning to support scientific teams and PIs through additional data management and harmonization services.
- NIH plans to support investigators in being compliant with letter and spirit of the party

Enabling the HEAL Cloud Platform

- NIH is a world-leader in awarding and build Cloud research platforms.
- At this time HEAL leads the platform design and build, while awardees focus on research
- NIH has established STRIDES to facilitate Cloud storage and compute – essential for data science goals
- NIH will make STRIDES and other resources available to HEAL awardees so that data can be placed in the Cloud

The Cloud Platform and Your



The Cloud Platform and Your Research

- The platform will
  - enable synthetic cohorts
  - discover rare signals in large data sets, and co-occurring conditions
  - enable study across previously unconnected domains.
  - enable you to take advantage of cutting edge tools easily.
  - give you access to unique data sets.
  - have archival and active storage
  - simplify data submission
  - be fully search-able
  - be secure, and easy-to-access

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