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RESEARCH RESOURCES | All of Us Research Program Data Sharing Tools

The National Institutes of Health’s All of Us Research Program aims to partner with one million or more people across the U.S. to build one of the largest, most diverse health databases in history. CTSI has been involved with All of Us since its inception in 2015, and over 30,000 participants have been enrolled through our All of Us Pennsylvania Program, the local arm of the national effort.

A wealth of valuable health data has been collected to date, which includes contributions from more than 462,000 participants and encompasses a wide variety of data types, including survey responses, physical measurements, electronic health records, biological samples, and wearables data. Approved researchers can now access All of Us data and tools to conduct studies that help improve our understanding of human health.

Tools have varying degrees of data security. The Public Tier dataset contains only anonymized, aggregate data. These data are available to everyone through Data Snapshots and the Data Browser, interactive tools available on the Research Hub. The Data Browser provides interactive views of the publicly available All of Us Research Program aggregate-level participant data, including EHR domains, survey responses, and physical measurements. Similarly, the Data Snapshots feature provides aggregated, public-facing data snapshots that deliver an overview of All of Us Research Program participant characteristics and the types of data that is collected from participants.

The Registered Tier curated dataset contains individual-level data, available only to approved researchers on the Researcher Workbench. The Registered Tier currently includes data from electronic health records, wearables, and surveys, as well as physical measurements taken at the time of participant enrollment. These data have been modified to protect participant privacy.

A Data Use and Registration Agreement (DURA) for accessing Registered Tier level data has been executed between the University of Pittsburgh and Vanderbilt University Medical Center. Researchers wishing to access the data will need to accept an associated code of conduct and submit a signed copy to the Office of Sponsored Programs as a new DUA in MyRA with reference to the DURA: DUA0000222. IRB approval or exemption should be secured prior to launching any research project using All of Us data.
CTSIs February newsletter announced the launch of two valuable trainings, Equitable Selection of Subjects and Minimizing Risks in Research. Both are designed to enhance knowledge about ethical issues in research.

The idea of equity in the selection of research participants reflects standards derived from the Belmont report’s principle of justice, namely that no one should be either targeted for inclusion or excluded from studies without valid scientific and ethical reasons. OHRP’s training helps explain methods for ensuring equity in research inclusion/exclusion.

Minimizing risks to participants is also a key concept for protecting the rights of human subjects. OHRP’s Minimizing Risks in Research reviews different types of risk to research participants—physical, psychological, social, financial, and reputational. The presentation includes helpful case scenarios that illustrate ways to consider and mitigate risks.

Dr. Bulls work focuses on cancer pain management and the effect of stigma and discrimination, which are well-established barriers to quality healthcare. The issue of stigma around the use of prescription opioids for pain management has been magnified by the opioid crisis and complicates treatment. While there is pressure on providers to minimize the use of opioids, there remains a significant problem with undermanaged pain in cancer patients which disproportionately affects members of racial and ethnic minorities. Dr. Bulls notes that “From what we know of racial and ethnic disparities, undermanaged pain is even more pronounced in people of color, often specifically in Black patients. We think that opioid stigma can cause a lot of challenges in opioid pain management, including stressful patient-clinician communication, emotional stress, avoidance of healthcare settings, and disrupted opioid prescription behaviors, which ultimately lead to worse pain management and quality of life. As we explore this idea and generate ways to successfully improve it, it’s important for us to hear from a broad variety of people, especially people already at high risk for pain under-treatment.”

Dr. Bulls draws inspiration for her work from the lived experiences of her patients: “I have always been drawn to a challenge, and cancer pain management – especially in light of the opioid crisis – is a big challenge with a big potential impact. More specifically, I was drawn to develop the concept of opioid stigma because of inspiration from my patients, who have generously shared stories about navigating an often complex system and their sometimes difficult, stigmatizing experiences trying to obtain pain care. Everyone should have access to personalized, effective, and equitable cancer pain care, and the exciting thing about this line of research is that it offers a chance for us to work towards that goal at many different levels, including working with patients themselves, their clinicians, and the healthcare systems more broadly.”

Registration is currently open for this virtual presentation and can be accessed here. Past Lunch and Learn presentations are also available for viewing on the CTSI website.
DEAR CTSI,

**Question:** Our research team is preparing for the migration from PittBox to Microsoft OneDrive. What should we do to prepare? Does the migration impact the Electronic Data Management Section of our PittPRO protocols?

**Answer:** Pitt will be ending its license with Box by August 2022, and Microsoft OneDrive will become the preferred cloud storage and collaboration solution. Accordingly, Pitt Information Technology will migrate users’ Box data to Microsoft OneDrive, and has recommended steps prior to migration that include:

- Deleting any unnecessary Box files and folders and emptying your Box Trash folder; removing yourself from any shared Box folders or files to which you no longer need access.

- Reviewing and organizing your Box folders, since your files will be migrated to OneDrive as they are organized in Box. Transferring folder ownership, as necessary, and informing external collaborators that your collaboration with them will be moving from Box to OneDrive.

**HRPO guidance** stipulates the following in regards to migration and the Electronic Data Management section of protocols:

- Researchers moving from PittBox to Pitt’s OneDrive or SharePoint do not need to submit an immediate modification. Researchers can update the Electronic Data Management section at the next submitted modification.

- Researchers who are moving data from PittBox to locations other than Pitt’s OneDrive or SharePoint need to submit the modification immediately.

- Researchers who are unaffected by this migration do not need to take any action.

**QUESTIONS FOR US?**

We’d love to hear from you:
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