

THE CHALLENGES OF RELEASING HUMAN DATA FOR ANALYSIS

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The NASA Johnson Space Center's (NASA JSC) Committee for the Protection of Human Subjects (CPHS) recently approved the formation of two human data repositories: the Lifetime Surveillance of Astronaut Health Repository (LSAH-R) for clinical data and the Life Sciences Data Archive Repository (LSDA-R) for research data. The establishment of these repositories forms the foundation for the release of data and information beyond the scope for which the data was originally collected. The release of clinical and research data and information is primarily managed by two NASA groups: the Evidence Base Working Group (EBWG), consisting of members of both repositories, and the LSAH Policy Board. The goal of unifying these repositories and their processes is to provide a mutually supportive approach to handling medical and research data, to enhance the use of medical and research data to reduce risk, and to promote the understanding of space physiology, countermeasures and other mitigation strategies.

Over the past year, both repositories have received over 100 data and information requests from a wide variety of requesters. The disposition of these requests has highlighted the challenges faced when attempting to make data collected on a unique set of subjects available beyond the original intent for which the data were collected. As the EBWG works through each request, many considerations must be factored into account when deciding what data can be shared and how – from the Privacy Act of 1974 and the Health Insurance Portability and Accountability Act (HIPAA), to NASA's Health Information Management System (10HIMS) and Human Experimental and Research Data Records (10HERD) access requirements. Additional considerations include the presence of the data in the repositories and vetting requesters for legitimacy of their use of the data. Additionally, fair access must be ensured for intramural, as well as extramural investigators. All of this must be considered in the formulation of the charters, policies and workflows for the human data repositories at NASA.