

Proposal for NASA/JSC at ICBO 2014

NASA Human Health and Performance Information Architecture Panel

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Introduction - 10 min

Overview of Human Health and Performance Directorate

The Human Health and Performance (HH&P) Directorate at NASA's Johnson Space Center has a mission to enable optimization of human health and performance throughout all phases of spaceflight. All HH&P functions are ultimately aimed at achieving this mission. Our activities enable mission success, optimizing human health and productivity in space before, during, and after the actual spaceflight experience of our crews, and include support for ground-based functions. Many of our spaceflight innovations also provide solutions for terrestrial challenges, thereby enhancing life on Earth.

Overview of standards, policies, and regulations pertinent to information architecture

Medical and research life sciences data at JSC are housed in two separate systems: The Lifetime Surveillance of Astronaut Health (LSAH) and the Life Sciences Data Archive (LSDA). The LSAH data system holds all ground and flight medical data for astronauts, vehicle environmental data, and data from non-flight assignable retirees who return to JSC annually for occupational health surveillance monitoring. Data in this system is managed according to NASA's Health Information Management System (10HIMS) Federal System of Records. The LSDA holds all research data collected as part of NASA-funded life sciences investigations. The LSDA holdings include data collected on astronauts, control and ground analog subjects, and plants and animals. LSDA is managed according to NASA's Human Experimental and Research Data Records (10HERD) Federal System of Records. The 10HIMS and 10HERD systems of record are part of NASA's implementation of the Privacy Act of 1974, as Amended (5 United States Code (USC), Part 552a). Data uses for research are subject to human subjects regulations (45 CFR Part 46, Protection of Human Subjects) and the agency also voluntarily adheres to the guidelines of the Health Insurance Portability and Accountability Act (HIPAA) of 1996 (45 CFR Part 160 and Part 164, Subparts A and E).

HH&P IT and Analytics Capabilities- 20 min

NASA has information systems that support astronaut clinical services, mission medical support, occupational health surveillance, and research into the effects of spaceflight on humans. As biomedical research and healthcare generate increasing amounts of data and new frontiers such as genomics open up, it is critical that NASA is positioned to effectively manage the rise in incoming human health and performance data. An overview of NASA's systems and capabilities will be provided.

Case Study: Visual Impairment/Intracranial Pressure VIIP

What is VIIP? – 10 min

Over the last 40 years there have been reports of visual acuity impairments associated with spaceflight through testing and anecdotal reports. Until recently, these changes were thought to be transient, but a comparison of pre and post-flight ocular measures have identified a potential risk of permanent visual changes as a result of microgravity exposure. There are limited pre and post-flight measures to define the risk and even less in-flight data is available. These data show that there is a subset of crewmembers that experience visual performance decrements, cotton-wool spot formation, choroidal fold development, optic-disc edema, optic nerve sheath distention, and/or posterior globe flattening with varying degrees of severity and permanence. These changes define the visual impairment/intracranial pressure (VIIP) syndrome.

Data Management Characteristics

The astronaut corps is a small, healthy population where the focus is on maintaining health for mission success. The VIIP syndrome is complex and the data management of it in this small group leads to many of the gaps identified in our HH&P IT and analytics. External providers use varying reporting formats with structured and free text for tests that have changed over the course of many years. The data is not always collected in a clinical setting as the measurements taken in-flight can vary greatly and tests change over time. As such symptoms are reported with an emphasis on treatment, charting is done by exception and diagnoses are limited.

In Depth Discussion #1 – 15 min

Data acquisition: Determine the balance between structured and free text when goals include: completeness of data, retrieval of data, and analysis of data

In Depth Discussion #2 – 15 min

Storage of data context: Implement metadata and associated data to facilitate retrieval and analysis

In Depth Discussion #3 - 15 min

Discovery: Implement a system such that sentinel events or trends can be identified