

How Exactly Does One Access NASA Space Life Sciences Data?

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2013 HRP Investigators' Workshop
Plenary Session

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Data Accessibility

- Until ~2010, the only astronaut data available to researchers was de-identified or grouped data archived within the Life Sciences Data Archive (LSDA)
- We are developing processes to enable release of individual data from both research and medical archives
- Survey questions you answered at registration are used to give us continuing insight into what data researchers need and how it is used, so we can continue to evolve to better meet the needs of the research and operational communities



Prospective Research

- HRP has well-established data sharing processes for purely prospective data
 - Flight research facilitated by ISS Medical Project (ISSMP):
 - Integrates informed consent briefings with crew
 - Develops Increment-specific Data Sharing Plans
 - Exchange of research data among PIs with attention to protecting rights of first publication
 - Documents medical data to be released from LSAH for research studies
 - Flight Analog research facilitated by Flight Analogs Project (FAP)
 - Analogs: such as Bed Rest Study at UTMB, and NEEMO
 - Similar, campaign-specific Data Sharing Plans for the exchange of research data
 - Bed rest data available includes Standard Measures data



Retrospective Research via Life Sciences Data Repositories

LSDA

Life Sciences Data Archive

Research Data

Active archive of HRP research

Historical flight data 1961-Shuttle

Ground-based and flight analog data

Human, animal and plant data

Animal biospecimens available for research

LSAH

Lifetime Surveillance of Astronaut Health

Medical Data

Data for all astronauts selected to the corps beginning in 1959, including retirees who return for annual exams

Includes ground & flight medical exam & mission health data (e.g., MRID/MEDB, vehicle, environment data)

Future Plans

Human Performance Database

Information on Public Website

lsda.jsc.nasa.gov



[HOME](#)
[RESEARCH](#)
[MEDICAL](#)
[DATA REQUESTS](#)
[JUST FOR FUN](#)
[e-BOOKS](#)

Life Sciences Data Repositories @ Johnson Space Center, Houston, Texas

Search Publicly Available Information and Data [RSS](#)

[Experiment](#)
[Mission](#)
[Personnel](#)
[Biospecimens](#)
[Documents](#)
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[Dataset](#)
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NASA Research Announcement

Released July 30, 2012: NASA Research Announcement NNJ12ZSA002N Research and Technology Development to Support Crew Health and Performance in Space Exploration Missions [Full announcement](#).

NASA Human Research Program (HRP)

NASA's Human Research Program (HRP) conducts research and develops technologies that allow humans to travel safely and productively in space. The Program uses evidence from data collected on astronauts, as well as other supporting studies. These data are stored in the research data repository, Life Sciences Data Archive (LSDA).



More about HRP: [HRP Home](#) | [Human Research Roadmap](#) | [Evidence Book](#) | [Education & Outreach](#)

[Research Data Repository: Life Sciences Data Archive \(LSDA\)](#)
[NASA Space Medicine](#)
[Medical Data Repository: Lifetime Surveillance of Astronaut Health \(LSAH\)](#)
[Missions or Studies in Progress](#)

Data Request



Data can be requested from one or both repositories.

Images Added to the Archive






Searching for Specific LSDA Data




[HOME](#)
[RESEARCH](#)
[MEDICAL](#)
[DATA REQUESTS](#)
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Life Sciences Data Archive @ Johnson Space Center, Houston, Texas

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Search

Search:
Using: All Words [Help](#)

Show 20 50 100 results

Research Area
 (Any research area) ▼

Species Studied
 (Any species) ▼

Experiment Title
 (Any experiments) ▼

Space Flight Mission/Ground-Based Study
 (Any Space Flight Mission/Ground-Based Study) ▼

Payload
 (Any payload) ▼

Hardware Item
 (Any Hardware) ▼

Investigator
 (Any investigator) ▼

Search by keyword or other parameters through the 'Dataset' portal



Experiment-Specific Information

The Effects of EVA and Long-Term Exposure to Microgravity on Pulmonary Function (96-E044)

Principal Investigator [+ West, John B.](#)

Research Area Pulmonary physiology

Species Studied *Homo sapiens* (Human)

Data are available for this experiment

Description

OBJECTIVES:

This experiment examined the effect of long-term exposure to microgravity (μG) and the effects of Extra Vehicular Activity (EVA) on pulmonary function. A longitudinal study was performed of four crews of the International Space Station (ISS), measuring aspects of pulmonary function that may be affected by long-term exposure to μG per se, and by exposure to noxious gases, or particulate matter present in the atmosphere of the ISS. The investigators proposed to evaluate the effect of EVA on the lung by studying those crewmembers who perform EVAs before and after single and repeated EVAs. Crewmembers who did not perform EVAs served as a flying control group for this aspect of the study. Because EVA poses a significant risk of decompression sickness including bubble events within the pulmonary circulation, non-invasive tests of pulmonary function that are altered by changes in the pulmonary vasculature presented an ideal way to follow a subject over the course of multiple EVAs.

To test the hypotheses researchers used the following: the standard respiratory function measurement of intra-breath respiratory exchange ratio (intra-breath R), a hyperventilation-induced distribution of pulmonary perfusion, slow spirometry for lung volume subdivision, and the measurement of expiratory pressures to test the hypotheses.

[++ -- View more](#)

Publications

Prisk GK, Fine JM, Cooper TK, and West JB. Lung function is unchanged in the 1 G environment microgravity. *Eur J Appl Physiol.* 2008;103(6):617-623. [[PubMed](#)]

Prisk GK, Fine JM, Cooper TK, and West JB. Pulmonary gas exchange is not impaired 24h after microgravity. *Physiol.* 2005;99:2233-2238. [[PubMed](#)]

Prisk GK, Fine JM, Cooper TK, and West JB. Vital capacity, respiratory muscle strength, and pulmonary function after long-duration exposure to microgravity. *J Appl Physiol.* 2006;101:439-447. [[PubMed](#)]

Data Information

Data Preservation Status	Preservation complete
Data Availability	This experiment has both unrestricted and restricted data (potentially attributable to human subjects).  + View unrestricted data.
	Please visit https://risda.jsc.nasa.gov to view the restricted data catalog. This site is restricted to the JSC Internal Network (JIN) only.  + Data request for restricted records

Information on Public Website lsda.jsc.nasa.gov



Medical Operations

The Space Medicine Division mission is to optimize the health, fitness, and well being of flight crews.

Astronaut medical data are collected per requirements detailed in the + [Medical Requirements Integration Documents \(MRID's\)](#). Data collected during these medical tests are generally housed in the Lifetime Surveillance of Astronaut Health (LSAH) repository. These test protocols are divided into areas as shown below. Each MRID will give an indication of the type of testing performed as well as the frequency of such tests.

FIND IT @ LSDA

Search

Click on an category image for relevant MRID information:



Note: The Medical Requirements Integration Documents (MRIDs) reflect the Medical Requirements documented in Requirements Document (AMERD), JSC 24834, the ISS Medical Operations Requirements Document (ISS MORD), Medical Operations Requirements Document (MORD) JSC 13956.

The screenshot shows the NASA Life Sciences Data Repositories website. The navigation bar includes links for HOME, RESEARCH, MEDICAL (circled in blue), DATA REQUESTS, JUST FOR FUN, and e-BOOKS. Below the navigation bar, there is a search bar and a grid of icons for various data types: Experiment, Mission, Personnel, Bioprecursors, Documents, Hardware, Dataset, and Photo Gallery. The main content area features a "NASA Research Announcement" section with a date of July 30, 2012, and a "NASA Human Research Program (HRP)" section with a sub-header "NASA's Human Research Program (HRP) conducts research and develops technologies that allow humans to travel safely and productively in space." Below this, there are links for "More about HRP" including HRP Home, Human Research Roadmap, Evidence Book, and Education & Outreach. At the bottom, there are links for "Research Data Repository: Life Sciences Data Archive (LSDA)", "NASA Space Medicine", "Medical Data Repository: Lifetime Surveillance of Astronaut Health (LSAH)", and "Missions or Studies in Progress".



LSAH Publicly Available Information

Newsletters

- Published semi-annually to keep participants and stakeholders informed on the program's findings

Medical Requirements

- Documents outline medical tests performed on ISS crew
- Click blue text to see testing details to help determine the data you need



All Medical Requirements			
Discipline	MRID#	MEDB#	Medical Requirement Title
Behavioral Health and Performance		MEDB 7.7	+ Behavioral Observation of Training
Behavioral Health and Performance		MEDB 7.4	+ Mood Assessment
Behavioral Health and Performance		MEDB 7.1	+ Preflight Behavioral Health Status Check
Behavioral Health and Performance	MR027L	MEDB 7.5	+ Post-flight Psychiatric/Psychological Evaluation
Behavioral Health and Performance	MR027L	MEDB 7.2	+ Preflight Evaluations
Behavioral Health and Performance	MR031L		+ Private Psychological Conferences (PPCs)
Behavioral Health and Performance	MR032L		+ ISS Private Family Conferences (PFCs)
Behavioral Health and Performance	MR032S		+ Private Family Conferences (PFCs) for Shuttle Crews
Behavioral Health and Performance	MR085L	MEDB 7.6	+ Neurocognitive Assessment
Bone, Muscle, Exercise		MEDB 5.4	+ Calf Volume Measurement
Bone, Muscle, Exercise		MEDB 5.1	+ Functional Fitness Assessment
Bone, Muscle, Exercise	MR006L		+ Exercise Treadmill Test
Bone, Muscle, Exercise	MR019L		+ Heart Rate Monitoring
Bone, Muscle, Exercise	MR026L		+ Postflight Rehabilitation

Requesting Data Not Available on Website



- Individual astronaut data are not downloadable
 - Potentially attributable to a subject
 - Protected by the Privacy Act
- **HOWEVER**, individual data can be requested for research, medical and operational purposes

<http://lsda.jsc.nasa.gov>

The screenshot shows the NASA Life Sciences Data Repositories website. The top navigation bar includes links for HOME, RESEARCH, MEDICAL, **DATA REQUESTS** (circled in red), JUST FOR FUN, and e-BOOKS. Below the navigation bar is a search bar and a section for "Search Publicly Available Information and Data" with an RSS icon. A red "OR" is placed between the navigation bar and a "Data Request" icon, which is also circled in red. The page content includes a section for "NASA Research Announcement" and a section for "NASA Human Research Program (HRP)" with a photo of an astronaut in space.

Data Request Form



REQUEST DATA

Please use the form below to enter your data requests.
Please be as specific as possible and fill out the fields completely.
Acceptable alpha numeric character: a-z, A-Z, 0-9, @, \, dash, comma and dot.
Asterisks indicate required fields *

Enter your Name: *

E-Mail: *

Phone:

Request Need Date:

 (MM/DD/YYYY)

Mission: (if applicable)

Data Type Requested: (if applicable) Tissue (LSDA) Research (LSDA) Medical (LSAH) I don't know

Grant or Contract Number: (if already in place)

Company / Institution:

Data Request Description and Comments:
(Please provide the description of your project, specific aims, and methods along with a list of tests and/or specific parameters you are requesting.) *

Data Request Justification:
(Please provide the purpose of your request, specify study question, and how the data will be utilized.)

Enter Text Below: *

User's Guide for Requesting NASA Data

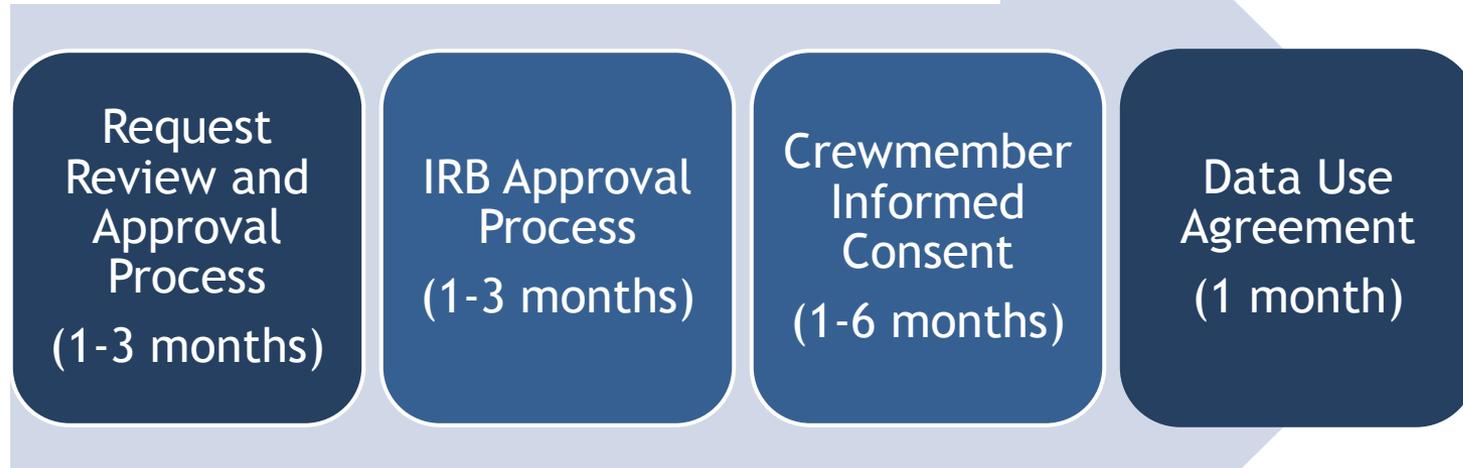
Research Data Repository (LSDA)
Medical Data Repository (LSAH)
Data Categories
Requesting Human Data
Applicable Laws and Regulations
Requesting Animal Tissues
[Data Accessibility: Video Presentation](#)

Your request should include:

- Contact Information
- Need-by Date
- Grant, NRA#, or current project data will support
- Institution
- “Data Request Description” - i.e., specific data you are requesting
- “Data Request Justification” - i.e., purpose for which data is required



Data Request Timeline



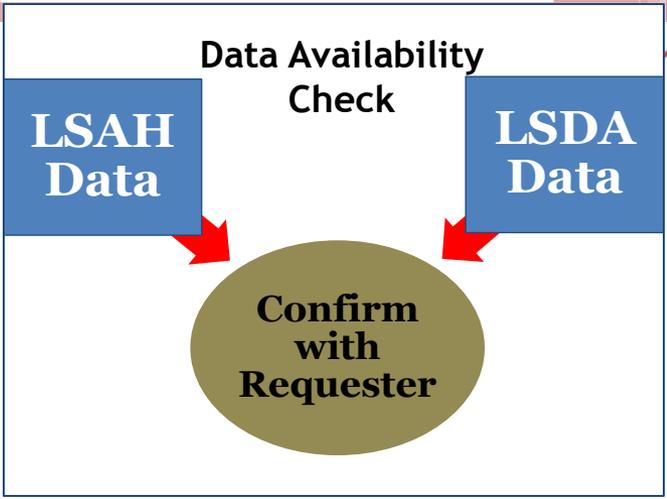
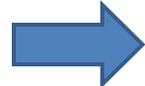
Factors Contributing to Longer Timeline:

- Need for individual, attributable data (such as to match medical with your research data ID codes)
 - Informed consent process can be lengthy, especially for large ‘n’ and obtaining consents from retired astronauts
- Need for large or complex data sets, particularly those with missing data
- Need to share the data with an investigator team far apart geographically (data transfer/security issues)

Data Request Fulfillment



Data Request Clearinghouse



Automated email to requester

Obtain more info

Retrieve missing data

Mission Medical Records
 LSDA Archive
 Training Records
 Clinic/LSAH Records
 Vehicle Environmental Data
 Biospecimen Data
 Research Study/Laboratory Data
 Questionnaires/Surveys

Assimilate Data from Various Sources

Request approved

Request Approval Process:

- ✓ Request purpose?
- ✓ Merit established?
- ✓ Attributable data?
- ✓ IRB review required?
- ✓ Consent necessary?

Requester notified of anticipated schedule; signs data use agreement if required

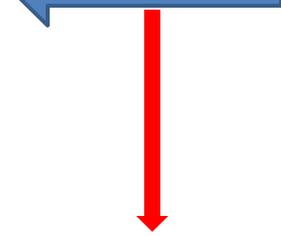
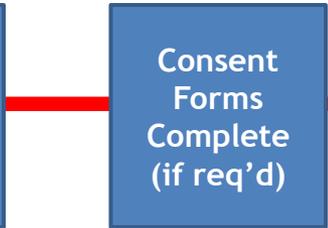
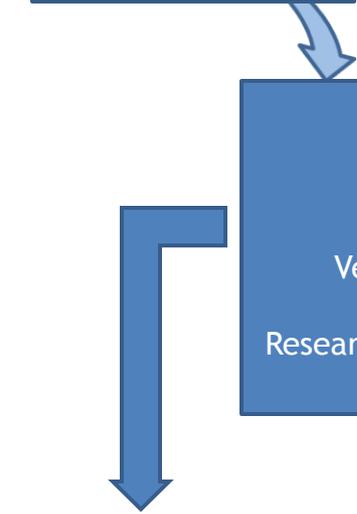
Request not approved

Notify requester; modify request

Perform Data Quality Assurance

Consent Forms Complete (if req'd)

Data sent to Requester





Progress on Challenges from 2011, 2012

- **INFORMED CONSENT**

- LSAH and LSDA Repositories have begun consent process with ISS crewmembers for use of their medical and research data for future approved studies
- Resources for interim consenting for retrospective studies need to be identified until all crewmembers' repository consents are completed

- **DE-IDENTIFICATION OF DATA**

- Privacy challenges, even with some grouped data, due to small 'n', public information available about subjects
- Informed consent will help with this issue
- Meanwhile, continuing to work on manual techniques to remove identifiers from images, metadata



Progress on Challenges from 2011, 2012

(cont.)

- **GAPS IN ARCHIVED DATA**

- New HRP contract requirements will help assure future archiving of research data
- Improved Data Submission Agreements (DSAs) assure all parties have reasonable expectations
- LSAH has had some success compiling medication data and information from other sources such as operations team notes, environmental data
- New tools and processes have been developed to better archive medical data as it is collected (e.g., inflight vision data, private medical conferences, Electronic Medical Record-LSAH interface improvements)

- **REQUESTER EXPECTATIONS**

- We are trying to provide transparency and education about processes and lead times
- We are taking action on comments received in surveys and other feedback
- LSAH received HRP funds this year to better support research community



New Challenges

- **INTEGRATION WITH THE HRP, IRB**
 - Working on processes to integrate better with HRP during research planning - identify early any needs for retrospective data
 - Identifying responsibilities and resources for informed consenting for studies using retrospective data
 - Collaborating with IRB to gain efficiencies, ensure availability and board approval of data requested

- **INCORPORATION OF OTHER DATABASES**
 - New HRP “Human Performance Data Project”
 - Integration of existing human data all in one place, incorporation into the existing LSDA-LSAH model

Conclusion

We are committed to fulfilling your data request needs

Please come see these related posters

- “Improving Acquisition, Preservation, & Distribution of Human Research Data”
- “*The LSDA Animal and Plant Holdings at Ames Research Center*”
- “Human Performance Data Base Project”
- “*Evaluation of Crew Exposure to Mild Hypobaric Hypoxia*”

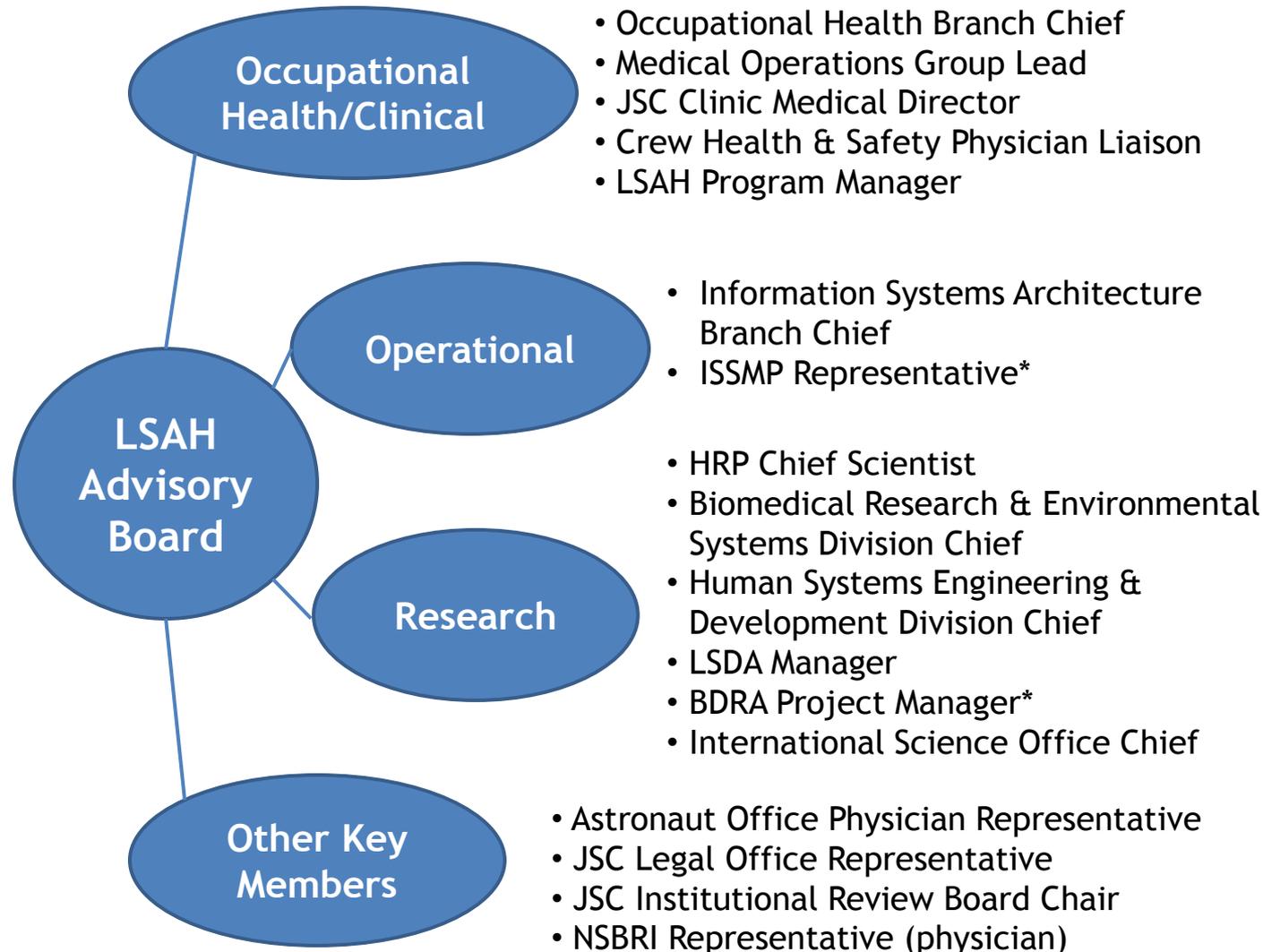


Backup Slides



LSAH Advisory Board

Chair: Chief, Space & Clinical Operations Division or designee



Board Purpose

This board reviews:

- All requests for attributable data (except clinical care)
- Other requests forwarded to the board by EBWG
- Requests where NASA policy is not yet determined

Meets 4th Tuesday of each month



Evidence Base Working Group Membership

Group Purpose

EBWG is the clearinghouse for all incoming data requests

Releases public or un-attributable data

Facilitates data requests through approval processes to release

Meets every other Monday

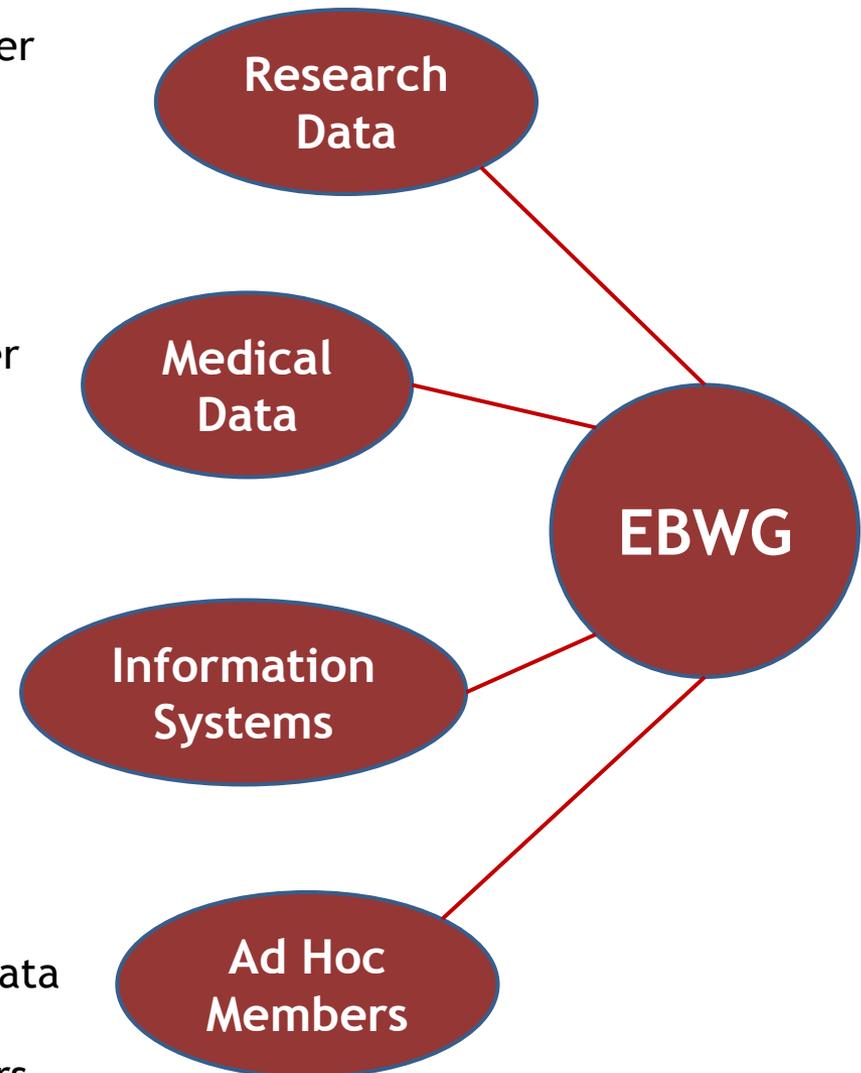
- LSDA NASA Manager
- LSDA Archivists

- LSAH NASA Manager
- Epidemiology Manager
- LSAH Epidemiologists
- BDRA Epidemiologist

- Information Systems Architecture Branch Chief
- *Space Medicine, LSDA IT staff (consultants)*

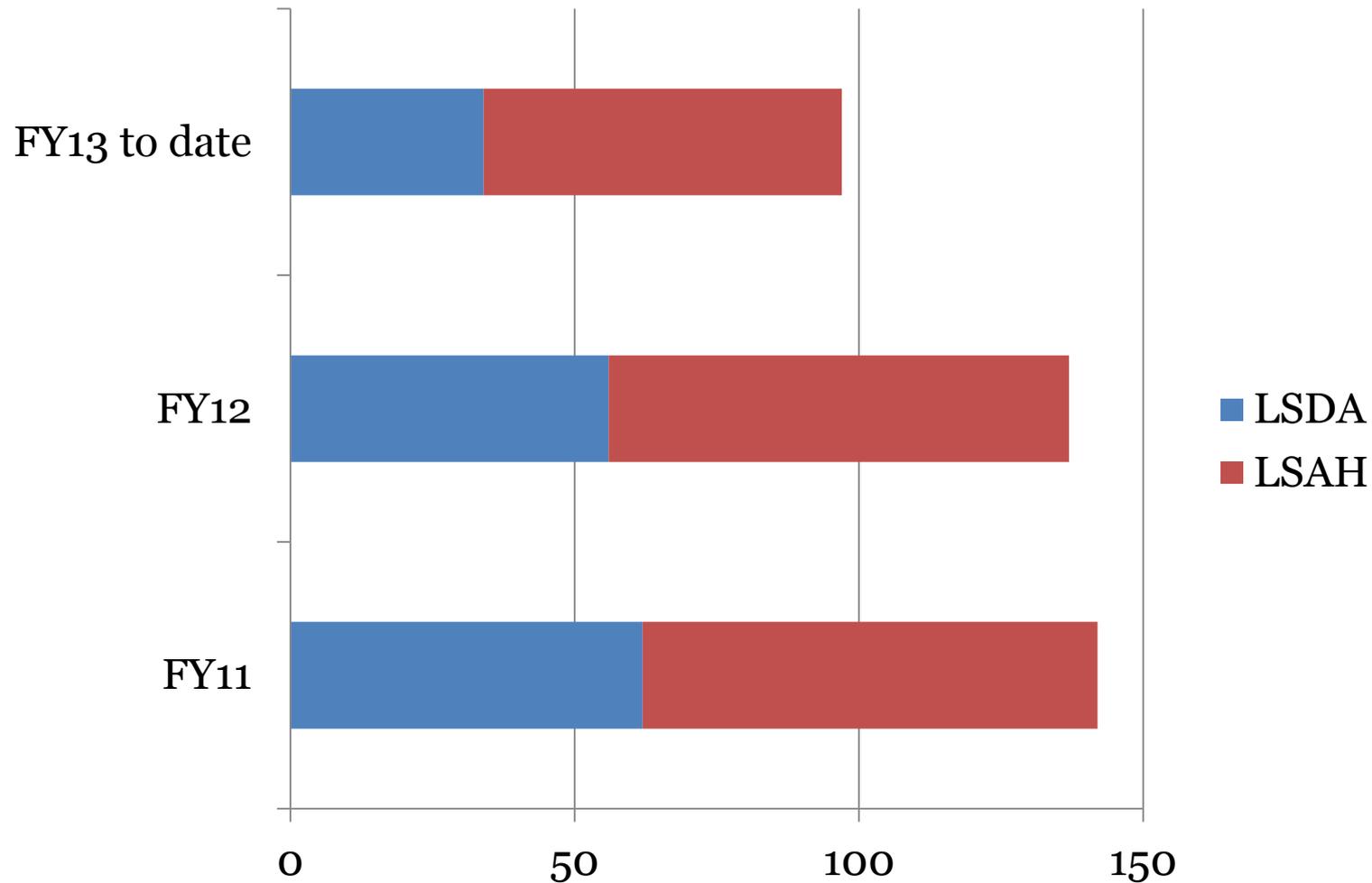
FUTURE?

- Human Performance Data Base staff
- Other archive managers





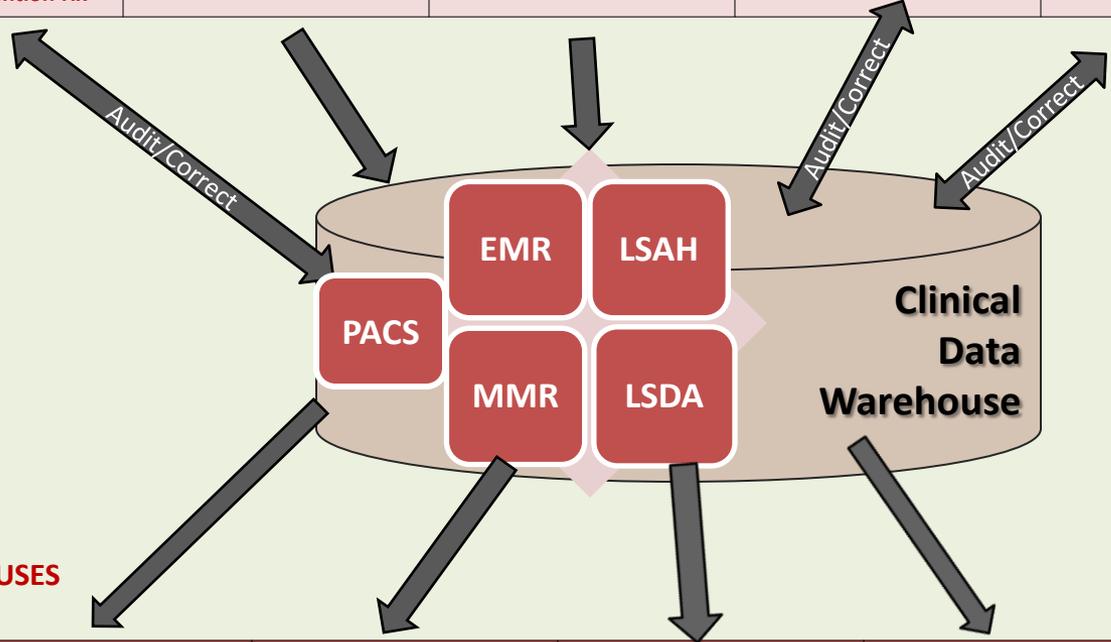
Data Request Successes





FMC e.g., Clinical Exams ECG/PFT/ETT Radiation Reports Clin Lab Reports Immunization Records Clinical Intervention Hx	Internal Consultants Audio (HearTrak) Optometry: Eye Exam/Fundosc. Eye OCT/DXA/U/S	External Consultants Dental PDF reports Imagery data (e.g., mammogram, x-ray, colonoscopy, MRI)	Mission Medical Data MRIDs PMCs	Other Sources Spacecraft Environmental data Questionnaire data Crew Comments Database Training Records IMM
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KEY: Incorporation Method if pulled to LSAH
Electronic/Automated
Manual Entry
Manual Import
Hybrid



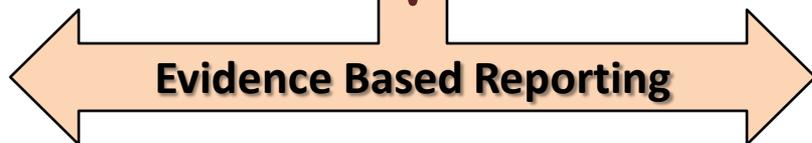
Coding for enhanced data searches; detect & correct data gaps

DATA USES

Clinical Care Support • Data/analyses to SD physicians for indiv. patient care	Occupational Surveillance • Cohort analyses/data • Monitor for trends • Directed Analyses • Char. Occ Exposures	Operational Investigations • Cohort analyses/data • Decision support analyses (e.g., EMU) • Informing risk mgmt • Informing med ops	Research Support • Combine with LSDA data, biospecimens • Support HRP research • Data to external requesters
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Occupational Health Mgmt

Clinical Intervention
 Causation Determination
 Standards & Requirements



Inform risk mitigation
 Inform research planning
 Inform ops planning