How Exactly Does One Access NASA Space Life Sciences Data?

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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**

<table>
<thead>
<tr>
<th>Research Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active archive of HRP research</td>
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<tr>
<td>Historical flight data 1961-Shuttle</td>
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<tr>
<td>Ground-based and flight analog data</td>
</tr>
<tr>
<td>Human, animal and plant data</td>
</tr>
<tr>
<td>Animal biospecimens available for research</td>
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</tbody>
</table>

## LSAH
**Lifetime Surveillance of Astronaut Health**

<table>
<thead>
<tr>
<th>Medical Data</th>
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<tbody>
<tr>
<td>Data for all astronauts selected to the corps beginning in 1959, including retirees who return for annual exams</td>
</tr>
<tr>
<td>Includes ground &amp; flight medical exam &amp; mission health data (e.g., MRID/MEDB, vehicle, environment data)</td>
</tr>
</tbody>
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## Future Plans

**Human Performance Database**
Information on Public Website ldsa.jsc.nasa.gov
Searching for Specific LSDA Data

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 on 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 crew members who perform EVAs before and after single and repeated EVAs. Crew members who did not perform EVAs served as a 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 measured by the measurement of intra-breath respiratory exchange ratio (intrabreath RER), a hyperventilation distribution of pulmonary perfusion, slow spirometry for lung volume sub-section, and the measurement and expiratory pressures to test the hypotheses.

++ -- View more

Publications

Prisk GK, Fire JM, Cooper TK, and West JB. Pulmonary gas exchange is not impaired 24h after return to Earth. Am J Physiol. 2005;288:2233-2238. [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://sda.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 (MRD'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.

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Click on an category image for relevant MRID information:

- **Behavioral Health and Performance**
- **Bone, Muscle, Exercise**
- **Cardiovascular**
- **Environmental Health**
- **Extravehicular Activity (EVA)**
- **Immunology**
- **Neurology**
- **Nutrition**
- **Radiation**
- **Therapeutics and Clinical Care**
- **View All Medical Requirements**

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

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

**LSAH Data**
- Confirm with Requester

**LSDA Data**

**Assimilate Data from Various Sources**
- Mission Medical Records
- LSDA Archive
- Training Records
- Clinic/LSAH Records
- Vehicle Environmental Data
- Biospecimen Data
- Research Study/Laboratory Data
- Questionnaires/Surveys

**Request Approval Process:**
- Request purpose?
- Merit established?
- Attributable data?
- IRB review required?
- Consent necessary?

**Data Availability Check**

**Data Requested**
- Retrieve missing data
- Perform Data Quality Assurance
- Consent Forms Complete (if req’d)

**Data Sent to Requester**
- Requester notified of anticipated schedule; signs data use agreement if required

**Modified Request**
- Notify requester; modify request
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*

**LSAH Advisory Board**

- **Occupational Health/Clinical**
  - Occupational Health Branch Chief
  - Medical Operations Group Lead
  - JSC Clinic Medical Director
  - Crew Health & Safety Physician Liaison
  - LSAH Program Manager

- **Operational**
  - Information Systems Architecture Branch Chief
  - ISSMP Representative*
  - HRP Chief Scientist
  - Biomedical Research & Environmental Systems Division Chief
  - Human Systems Engineering & Development Division Chief
  - LSDA Manager
  - BDRA Project Manager*
  - International Science Office Chief

- **Research**

- **Other Key Members**
  - Astronaut Office Physician Representative
  - JSC Legal Office Representative
  - JSC Institutional Review Board Chair
  - NSBRI Representative (physician)

*Dual assignment*
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

**EBWG Members**
- 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)
- Human Performance Data Base staff
- Other archive managers

**EBWG Data**
- Research Data
- Medical Data
- Information Systems
- Ad Hoc Members

**Future?**
- Human Performance Data Base staff
- Other archive managers
Data Request Successes

- FY13 to date
- FY12
- FY11

- LSDA
- LSAH

FY11 to date
**Evidence Based Reporting**

**Clinical Intervention**
- Causation Determination
- Standards & Requirements

**Operational Health Mgmt**
- Inform risk mitigation
- Inform research planning
- Inform ops planning

**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

**Clinical Data Warehouse**
- EMR
- LSAH
- PACS
- MMR
- LSDA

**KEY:**
- Incorporation Method if pulled to LSAH
  - Electronic/Automated
  - Manual Entry
  - Manual Import
  - Hybrid

**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

**Coding for enhanced data searches; detect & correct data gaps**