Accessing NASA Astronaut Medical and Research Data

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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 have been developing processes to enable and streamline the release of individual data from both research and medical archives
Prospective Research

- NASA’s Human Research Program (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
- EVA Suit Exposure Tracking
Astronaut Data: Number of Requests by Fiscal Year

<table>
<thead>
<tr>
<th>Fiscal Year</th>
<th>LSAH - Medical</th>
<th>LSDA - Research</th>
<th>Total</th>
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<td>FY16</td>
<td>60</td>
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<td>139</td>
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Smaller numbers, increased size & complexity
Information on Public Website: https://lsda.jsc.nasa.gov
Searching for Specific LSDA (Research) Data

Search by keyword or other parameters through the ‘Dataset’ portal
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 Involved**: Homo sapiens (Human)

**Data are available for this experiment**

**Description**

**OBJECTIVES:**
This experiment examined the effects 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 notable 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 static and respiratory function, the measurement of intra-brachial respiratory exchange ratio (intra-RER), a hyperinflation distribution of pulmonary perfusion, slow spirometry for lung volume assessment, and the inspiratory and expiratory pressures to test the hypotheses.

**Publications**


**Data Information**

- **Data Preservation Status**: Preservation complete
- **Data Availability**: This experiment has both unrestricted and restricted data (potentially attributable to human subjects).

Please visit [https://iriss.nasa.gov](https://iriss.nasa.gov) to view the restricted data catalog. This site is restricted to the JSC Intranet Network (JIN) only.
Medical Information on Public Website: https://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 (MRDs). Data collected during these medical tests are generally housed in the Life Sciences Data Archive (LSDA) repository. These test protocols are divided into areas as shown below. Each MRD will give an indication of the type of testing performed as well as the frequency of such tests.

FIND IT @ LSDA

Click on a category image for relevant MRD information:

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

Note: The Medical Requirements Integration Documents (MRDs) reflect the Medical Requirements documented in the Requirements Document (ANERD), JSC 24834, the ISS Medical Operations Requirements Document (ISS MORD), SSF, and the Medical Operations Requirements Document (MORD) JSC 13956.
LSAH Publicly Available Information

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>
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<td>+ Private Psychological Conferences (PPCs)</td>
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<td>+ Call Volume Measurement</td>
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<tr>
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<td>MEDB 5.1</td>
<td>+ Functional Fitness Assessment</td>
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</tr>
<tr>
<td>Bone, Muscle, Exercise</td>
<td>MR006L</td>
<td>+ Exercise Treadmill Test</td>
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</tr>
<tr>
<td>Bone, Muscle, Exercise</td>
<td>MR019L</td>
<td>+ Heart Rate Monitoring</td>
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</tr>
</tbody>
</table>

LSAH Newsletters

- Published periodically to keep participants informed on the program's findings
Requesting Data Not Available on Website

• Individual astronaut data are not downloadable
  ▪ Potentially attributable to an individual subject
  ▪ Protected by the Privacy Act

• HOWEVER, individual data can be requested for research, medical and operational purposes
  ▪ Currently, medical data are available for US crewmembers only
  ▪ Usually requires funded, peer-reviewed study, IRB protocol, crew consent

https://lsda.jsc.nasa.gov
Data Request Form

Your request must include:

- Contact Information
- Date when data are required (>3 months)
- Grant, NRA#, or current project that data will support
- Institution
- “Data Request Description” - i.e., what data you are requesting? Be detailed
- “Data Request Justification” - i.e., why do you need this data? If requesting individual data, why can’t de-identified or grouped data be used?
- More detail, the faster your request can be scoped

Read these guides!
The timeline for any single data request (DR) depends on many factors, and no two are the same.

- **Easiest/fastest**: Demographic data or incidence of a particular issue on small number of ISS crew (US only) and single aim.
- **Hardest/slowest**: Large number of variables or multiple types of data (e.g., imaging, video, textual) and a large number of crew, mixed ISS and previous programs, multiple aims; needing International Partner crew; any dataset with missing data that need to be retrieved (e.g., EVA injury, medications, exercise) or where policy/data sharing hasn’t been determined (e.g., any genetic information).
EVA Data Request Considerations

• Most NASA medical data was collected for clinical care purposes and may not include parameters required for your research
  ▪ Diagnoses may not comply with research definitions because focus is on clinical care treatment
  ▪ Testing is conducted to diagnose and treat; may not meet research standards in terms of parameters collected, consistency of schedule or constraints

• Suggestions for Data Mining Study Development
  ▪ Consult with LSAH personnel early during study development
    ◦ We can assist you in understanding exactly what data is available, what the necessary lead time is for pulling/cleaning/processing, and other potential issues
    ◦ Data we have MAY be available for re-interpretation with proper permissions
  ▪ If your study has an inflight component, consult with HRP, ISSMP (ISS Medical Project) personnel for special time, hardware, other requirements
EVA Data Availability

- **EVA Suit Exposure Tracker (SET)** - LSAH has compiled all available US astronaut EVA training runs into one database.
  - Over 12,000 training runs from neutral buoyancy training for 232 astronauts
  - Data quality is best after 1985; earlier records inconsistent
  - NASA Technical Memo describing the dataset just published:
  - Need approval from the NASA EVA community to release datasets to internal or external requesters (anticipated in FY18)
  - Suit fit runs and non-EMU training records were excluded
  - Data for some runs has not been location although photographic evidence exists (training partner data was used in some cases)
  - These data were compiled with assistance from Randall McDaniel, Kevin B. Thomas, Marc Ciupitu & GCTC staff
EVA Data Availability (cont.)

- **Crew Comments Database** -
  - Compilation of over 70,000 comments from post-mission debriefings on a variety of topics
  - Description of data available in the crew comments database published as NASA Technical Presentation
  - https://ntrs.nasa.gov/archive/nasa/casi.ntrs.nasa.gov/20160011585.pdf

- **Human Research Program Evidence Books**
  - https://humanresearchroadmap.nasa.gov/evidence/
Examples of EVA Data Requests Filled in the Past

- Hand Injury / Glove sizing
- Suit sizing and anthropometry*
- EVA Hypoxia and Sleep
- Shoulder, Elbow Injury / Suit Trauma (typically upper body)
- Metabolic data from graded exercise tests, EVAs where available
- Infection rates in EVA crew
- Medical data from annual exams, flight-specific medical requirements
- Vehicle and crew-worn environmental and acoustic data (O2, CO2, radiation, etc.)
- Medication use
- Clinical blood or urine, nutritional parameters

*Limited anthropometry, suit sizing data available; other sources may need to approve, collaborate with dataset
Questions?
Backup Slides
Data Request Fulfillment

Data Request Clearinghouse

- Retrieve missing data
- Automated email to requester
- Obtain more info
- Request approved
- Request not approved

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

Data Availability Check

- Confirm with Requester
- LSAH Data
- LSDA Data

Request Approval Process:

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

Data Request Fulfillment

- Requester notified of anticipated schedule; signs data use agreement if required
- Data sent to Requester
- Consent Forms Complete (if req’d)
- Perform Data Quality Assurance
Key Elements of Retrospective ATTRIBUTABLE Data Request Process
(duration of each step depends on size, complexity of data set)

**DATA REQUESTER ACTIONS:**
- Submit Data Request
- Work with LSAH to Finalize Detailed Data Set & Data Format
- Scoping Data Request (up to 6 months)
- Request Review and Approval Process (2-6 months)
- IRB Approval Process (2-4 months)
- US Crewmember Informed Consent (1-6 months)
- Data Use Agreement/Data Set Audit (2-3 months)

**LSAH/LSDA ACTIONS:**
- Vetting at EBWG
- Assigned archivist/epidemiologist assesses data available, works with requester on details, schedule

**DATA REQUESTER ACTIONS:**
- Verify IRB protocol matches LSAH AB request
- Match subjects vs. Repository consented crew, determine # study consents needed
- ‘Remote Consent’ sent-out by LSAH
  - For US crew members only
  - (longer lead times required for IP data-consent will be conducted by ISSMP)
- Assist with consent form development
- Assist with LSAH AB presentation package
- LSAH AB Approval Letter sent to IRB Chair verifying feasibility of request and approving attributable data release

**LSAH/LSDA ACTIONS:**
- Work with LSAH to complete Data Use Agreement
- Work with EBWG to complete Data Use Agreement

**EVA Technology Workshop 2017**

Staff begins pulling, compiling, and formatting data set after IRB approval
**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

**LSA H**

**Life Sciences Data Warehouse**

**FMC**
e.g., Clinical Exams ECG/PFT/ETT Radiation Reports Clin Lab Reports Immunization Records Clinical Intervention Hx

**Consultant Reports**
Audio (HearTrak) Optometry: Eye Exam/Fundos. Eye OCT/DXA/U/S Dental PDF reports Imagery data

**Mission Medical Data**
MRIDs/MEDBs PMCs

**Other Sources**
Spacecraft Environmental data Questionnaire data Crew Comments Database Training Records IMM

**Research Data**
Astronaut Flight/Ground studies FAP data Animal/Plant specimens & Data

**KEY:**
- Incorporation Method
- Electronic/Automated
- Manual Entry
- Manual Import
- Hybrid

**Clinical Intervention**
Causation Determination Standards & Requirements

**Evidence Based Reporting**
Inform HSRB, risk mitigation Inform research planning Inform ops, DRM

**DATA USES**
- PA CS
- EMR
- LSA H
- LSD A

**Systems leverage IT Infrastructure**
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*

Research
• HRP Chief Scientist
• Biomedical Research & Environmental Systems Division Chief
• Human Systems Engineering & Development Division Chief
• LSDA Manager
• BDRA Project Manager*
• International Science Office Chief

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

- 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 Attributability Continuum

**Attributable:**
- e.g. ‘DSO’ Codes
- Describes variables from an individual such that the recipient of the data set can easily ascertain the identity of the individual, such as to match characteristics across more than 1 data set. Although attributable, individual names are never provided with data set.

**Coded:**
- Random Codes
- Describes variables from an individual, but that individual is assigned a code such that the recipient of the data set cannot ascertain the identity of the individual. The sender of the data maintains the only available key to connect codes to individual subjects.

**Grouped/ Pooled**
- Data variables from a group of individuals are reported together, thereby removing individually identifiable information.

(Consent Required)