NASA Life Sciences Data Repositories:

Update on Data Access and Lessons Learned 2012

NASA Data Repository Goals

Improve dissemination of and access to NASA life sciences data and information

Goal of Today’s Presentation

Set realistic expectations for access to NASA data sets
# NASA Repositories

## Clinical Data Repository

**Lifetime Surveillance of Astronaut Health (LSAH)**

- Astronaut Clinical Data
- NASA’s Occupational Surveillance Program
- Data collected to examine the incidence of acute & chronic morbidity and mortality of astronauts
- All astronauts selected into the US space program will be monitored throughout their NASA career and retirement from the astronaut corps

## Research Data Repository

**Life Sciences Data Archive (LSDA)**

- Human Research Data (astronauts, ground subjects)
- Animal research data and biospecimens
- Data collected during NASA-funded life sciences research (Mercury to International Space Station(ISS), and ground studies)
Evidence Based Working Group (EBWG) is the initial clearinghouse for request reviews

- Membership from both LSAH and LSDA repositories

- LSDA and LSAH will partner with each requester to understand their needs & provide the most relevant data...
  ...whether medical, research, or a combination of both

- Requests for attributable data referred to LSAH Policy Board

- 142 Data Requests Processed FY2011
Challenges
#1 De-Identification of Data

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Data Request Example(s)</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>NASA human subject data are governed by the Privacy Act of 1974</td>
<td>Intracranial pressure eyeball data (small number of subject)</td>
<td>De-identified, pooled data are made available to requesters</td>
</tr>
<tr>
<td>Several key factors render these data hard to de-identify (non-attributable to the subject)</td>
<td>Brain Magnetic Resonance Images (MRIs)</td>
<td>Where possible, research data (and limitations, constraints) will be made available on the LSDA website</td>
</tr>
<tr>
<td>• Small subject “n”</td>
<td>Space Motion Sickness (SMS)/SMS Medication across Shuttle flights</td>
<td>Continued development of de-identification procedures and other solutions</td>
</tr>
<tr>
<td>• Gender</td>
<td></td>
<td>• (e.g. software solution to de-identify MRI metadata, other identifiers)</td>
</tr>
<tr>
<td>• Public figures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Spaceflight experience</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Duration is sometimes specific to mission</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
#2 Crewmember Consent

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Data Request Example(s)</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Crews must be “re-consented” for:</td>
<td>Video of On-Orbit Crew Exercise</td>
<td>Actions pertaining to data privacy were issued by JSC CPHS last year</td>
</tr>
<tr>
<td>• Use of their medical data for research purposes</td>
<td>Bone Densitometry (DXA) Data during Mir</td>
<td>Final review and approval for LSAH and LSDA repositories expected in March 2012</td>
</tr>
<tr>
<td>• Use of their research data for reasons other than the original investigator’s informed consent</td>
<td></td>
<td>Re-consent process will begin shortly thereafter</td>
</tr>
<tr>
<td>Consenting for each study is a time consuming process</td>
<td></td>
<td>• Prior to each ISS mission</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Annual physical exams</td>
</tr>
<tr>
<td>Challenge</td>
<td>Data Request Example(s)</td>
<td>Progress</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Setting user expectations regarding time to fill requests</td>
<td>Requester asking NASA for data only 2 days prior to proposal submission</td>
<td>Work to improve communication with each requester to verify data needed and provide realistic schedule for each request</td>
</tr>
<tr>
<td>Many factors determine the simplicity or complexity of filling data requests:</td>
<td>Dental Events in the Astronaut Corps-Hard Copy Records</td>
<td>Work to quantify data requests into general “small/medium/large” categories in terms of effort required will be provided with data request schedule early in the process</td>
</tr>
<tr>
<td>• # of subjects</td>
<td>Note: While pdf files are electronic, the content is not fully searchable.</td>
<td></td>
</tr>
<tr>
<td>• # parameters</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Is informed consent needed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Is attributable data required?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Completeness of data sets in repository</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Data storage format in NASA systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Manual retrieval of data</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Level of statistical analysis required</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Output format desired</td>
<td></td>
<td></td>
</tr>
<tr>
<td>...and many more!</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
#4 Gaps in the Research Repository

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Data Request Example(s)</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caused by lack of data return to NASA</td>
<td>In general, timely return of data to NASA improves our ability to then further utilize that data for data requests</td>
<td>Data return expectations set in new NASA Research Announcements (NRAs) and award letters</td>
</tr>
<tr>
<td></td>
<td>Experimental conditions about the data need to be well documented</td>
<td>Data submission agreement (DSA) established between investigator and LSDA</td>
</tr>
<tr>
<td></td>
<td>• Time points of data collection</td>
<td>Enabling communications between investigators</td>
</tr>
<tr>
<td></td>
<td>• Medication usage</td>
<td>Use of clinical data if applicable</td>
</tr>
<tr>
<td></td>
<td>• Exercise logs</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• etc.</td>
<td></td>
</tr>
<tr>
<td>Original meta data necessary to understand data set – need for collaboration with original investigator</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
#5 Gaps in the Clinical Repository

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Data Request Example(s)</th>
<th>Progress</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Documentation by Exception”</td>
<td>Medications are prescribed and available, but medication use may be poorly documented</td>
<td>Significant efforts in last year to fill data gaps</td>
</tr>
<tr>
<td>• Focus on clinical care and treating symptoms</td>
<td>• Incomplete or no information regarding dose, mode of administration, dates meds were started/stopped, effectiveness, side effects, adverse events</td>
<td>• Manual abstraction of paper records, mission audio (Private Medical Conferences)</td>
</tr>
<tr>
<td>• Main focus was resolving complaint, not always determining etiology</td>
<td>• Sometimes only the drug class is provided (e.g., “sleep med taken”)</td>
<td>• Verifying data integrity across multiple sources (e.g., NBL training records)</td>
</tr>
<tr>
<td>• Limited diagnoses</td>
<td>• Contents of ISS medication kits only provides what medications and quantity are launched and returned, not individual use</td>
<td></td>
</tr>
<tr>
<td>• Data not collected with research design (i.e., ‘standardized data’) in mind</td>
<td>• Medication data, if it exists, may reside in several different locations....</td>
<td></td>
</tr>
<tr>
<td>• Data located in multiple places and in varying formats</td>
<td>..... EMR, private medical conference, research protocol, post-mission medical debriefs – poor recollection regarding med use weeks or months ago</td>
<td>Work with physicians to document why a medical test was waived</td>
</tr>
<tr>
<td>Lead time for this type of data is long; data often must be manually abstracted/entered and data from multiple sources verified against one another</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
## #6 Competing Customers

<table>
<thead>
<tr>
<th>Challenge</th>
<th>Data Request Example(s)</th>
<th>Progress</th>
</tr>
</thead>
</table>
| LSAH is NASA’s occupational health program charged “to investigate and describe the incidence of acute and chronic morbidity and mortality of astronauts and to determine whether the unique occupational exposures encountered by astronauts are associated with increased risks of morbidity or mortality | **2009 Crew Health NRA**  
  - Shuttle MRI data to validate models for Sonographic Astronaut Vertebral Examination (SAVE)--NNX10AM34G | When resources permit, LSAH still supports these research data requests                              |
|                                                                          | **2010 Crew Health NRA**  
  - Request for brain MRI data for new investigation NNX11AR02G  
  - Request for ISS crew interaction data for new investigation NNX12AB40G | LSAH is working with HRP to develop dedicated resources to support research data requests and analyses |
|                                                                          | **Directed Research**  
  - PI for recently concluded ISSMP Spinal Elongation experiment is interested in complementary data |                                                                                                       |
WEBSITE ACCESS REMINDERS
Life Sciences Data Archive URL: http://lsda.jsc.nasa.gov
The portal provides guidance to researchers on requesting data from the LSDA and LSAH repositories.
Online Data Request Form

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 characters: a-z, A-Z, 0-9, @, #, dash, comma and dot. Asterisks indicate required fields *.

- Enter your Name: *
- E-Mail: *
- Phones: 

Request Need Date: 

Mission: (if applicable)

Data Type Requests: (if applicable) □ Tissue (LSDA) □ Research (LSDA) □ Medical (LSAH) □ I don’t know

Grant or Contract Number: (if already in place) 

*One request form for all repositories (LSDA, LSAH, and Animal Biospecimens)
Annual Data Accessibility Survey

Help us improve our understanding of your needs

Complete the 2012 Data Accessibility Survey by Feb 22nd

Survey can be found at:
http://sisl.jsc.nasa.gov/Surveys/2012_Data_Accessibility/HTMLE/2012_HRP-Data-Access_revised.htm

Problems or questions with the survey?
Contact Dana.Bolles@nasa.gov
Backup
Clinical Data: Medical Tests Performed

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 (MRIDs). Data collected during these medical tests are generally focused 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.

Click on an category image for relevant MRID information.

Therapeutics and Clinical Care

<table>
<thead>
<tr>
<th>Discipline</th>
<th>MRID#</th>
<th>MEDB#</th>
<th>Medical Requirement Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR009L</td>
<td>MEDB 1.5</td>
<td>+ Pre- and Postflight Physical Exam for Long Duration Crews</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR009S</td>
<td>MEDB 1.6</td>
<td>+ Pre- and Postflight Physical Exam for Short Duration Crews</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR010L</td>
<td>MEDB 1.7</td>
<td>+ Clinical Laboratory Assessment for Long Duration Flights</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR010S</td>
<td>MEDB 1.8</td>
<td>+ Clinical Laboratory Assessment for Shuttle</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR011L</td>
<td>MEDB 1.9</td>
<td>+ Dental Examination</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR012L</td>
<td>MEDB 1.10</td>
<td>+ Audiology for ISS</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR013L</td>
<td>MEDB 1.11</td>
<td>+ Audiology for Shuttle Crews</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR014L</td>
<td>MEDB 1.12</td>
<td>+ Ophthalmology Examination</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR014S</td>
<td>MEDB 1.13</td>
<td>+ Pre- and Postflight Ophthalmology Examination for Short Duration Flights</td>
</tr>
<tr>
<td>Therapeutics and Clinical Care</td>
<td>MR015L</td>
<td>MEDB 1.14</td>
<td>+ Ultrasound Imaging (Sonography)</td>
</tr>
</tbody>
</table>

Annual medical exam & flight-related medical requirements

Other data from tests performed for clinical purposes may also be available.
Online Information: 
Lifetime Surveillance of Astronaut Health

Current LSAH Design
The Lifetime Surveillance of Astronaut Health (LSAH) is a proactive occupational surveillance program for the astronaut corps to screen and monitor astronauts for occupational related injury or disease. The LSAH program examines the incidence of acute and chronic morbidity and mortality of astronauts, and defines health risks associated with the occupational exposures encountered by astronauts. From the evidence obtained through clinical testing, individually tailored follow-up medical examinations and surveillance for particular outcomes will be designed to track the astronaut population more rigorously and to capture sub-clinical medical events.

LSAH-Repository: Research Access to Medical Data
The LSAH Repository (LSAH-R) was established to implement a research component to enable access to astronaut medical data for approved research purposes. Informed consent for use of medical data for research purposes will be obtained from NASA astronauts. The LSAH-R will support research studies through epidemiologic analyses, data exploration and data visualization techniques.

Medical Tests Performed
The mission of the Space Medicine Division is to optimize the health, fitness, and well being of flight crews. As such, requirements exist to ensure accurate and consistent collection of astronaut medical data. Data collected during these medical tests are generally housed in the Lifetime Surveillance of Astronaut Health Repository (LSAH-R). Several types of medical data may be available through the LSAH-Repository.

Information regarding the LSAH history and current design, as well as how researchers can access this medical data, is online at http://lsda.jsc.nasa.gov/lsah_home1.cfm
Clinical Data: Access to LSAH Findings

- Disseminate results of surveillance to participants, stakeholders, the research community, and the public
  - The LSAH newsletter is published semi-annually as a communication vehicle for results gained through the surveillance process and changes to the program.
  - Surveillance results are also published in official NASA technical papers, books, and in peer-reviewed scientific journals.
  - Other vehicles for communication of surveillance results are under development.
Archived non-attributable data can be downloaded directly from the public website.
Online Searchable Catalog: Research Projects

Historical Research Projects

- Apollo Program
- Apollo-Soyuz Test Project (ASTP)
- Artificial Gravity (Fractional Gravity)
- Bion Cosmos Flight Research
- Biosatellite Program
- Biospecimen Sharing Program (BSP)
- Countermeasures Evaluation & Validation Project (CEVP)
- Gemini Program
- Lunar-Mars Life Support Test Project (LMLSTP)
- NASA Ground-Based Investigations
- NASA-Mir Program
- Project Mercury
- Shuttle Detailed Supplementary Objectives (DSO)
- Shuttle Extended Duration Orbiter Medical Project (EDOMP)
- Shuttle Life Sciences Research (Middeck)
- Shuttle Life Sciences Research (Spacelab)
- Shuttle Student Involvement Program (SSIP)
- Skylab Program

Shuttle Detailed Supplementary Objectives (DSO)

Conducted aboard the Space Shuttle, Detailed Supplementary Objectives (DSO) were medical investigations supplementary to the primary Shuttle payload performed voluntarily by the crewmembers. DSOs flown on Shuttle missions were designed to require minimal crew time, power and stowage. DSOs focused on studying adaptation to microgravity (specifically space motion sickness) as well as cardiovascular deconditioning, muscle loss, changes in coordination and balance strategies, radiation exposure, pharmacokinetics and changes in the body’s biochemistry.

Related Experiments

- Acceleration Detection Sensitivity (DSO 465)
- Adaptation to Linear Acceleration After Space Flight (DSO 207)
- Air Monitoring and Atmosphere Characterization (DSO 611)
- Ambulatory Monitoring (DSO 416)
- Anatomical Observation (DSO 422)
- Animal Enclosure Module In-flight Test (DSO 421)
- Assessment of Circadian Shifting in Astronauts by Bright Light (DSO 484)
- Assessment of Human Factors (DSO 904)
Research Publications: Electronic Books

Links are provided to related websites

**CURRENT NASA PROJECTS:**

- **Human Research Program (HRP)**
  - Human Research Roadmap Evidence Book
  - Science Progress Reports
  - SPACELINE Current Awareness List
  - selected recent publications of interest

- **Lifetime Surveillance of Astronaut Health (LSAH)**
  - The Lifetime Surveillance of Astronaut Health program monitors and monitors astronauts for occupational and non-occupational health concerns. The LSAH Repository (LSAH-R) was established to implement a research component to enable analysis of astronaut medical data.
  - View LSAH Newsletters

- **Medical Operations**
  - The Medical Requirements Integration Document (MRID Book) defines integration activities to support the medical requirements (MR) for both short-duration and long-duration human space flight for the Space Shuttle/International Space Station (ISS) programs. Or View Individual Medical Requirements
  - Recent publications: See ASTP and Skylab in Completed NASA Projects.

- **NASA Technical Reports Server**
  - Since it was first released in 1994, the NTRS serves as a valuable resource for students, educators, researchers, and the public for access to NASA's current and historical technical literature.

**COMPLETED NASA PROJECTS:**

- **Project Mercury**
  - Space Medicine in Project Mercury

- **Gemini Program**
  - Gemini Mid-Program Conference

- **Apollo Program**
  - Biomedical Results of Apollo

- **Apollo-Soyuz Test Project**
  - Medical Report

- **Skylab Program**
  - Biomedical Results of Skylab

- **Shuttle Program**
  - The Shuttle Spacelab Mission: Neuroscience Research in Space
  - Extended Duration Orbiter Medical Project - Final Report
  - Isolation: NASA Experiments in Closed-Environment Living
  - Whole book
  - Each chapter

- **Lunar Mars Life Support Test Project (MLSTP)**
  - Life in Spacelab, Volumes 1, 2 and 3 - Fundamental Biology

Research program publications can be read online or downloaded
Animal Research Data: Biospecimen Sharing Program

- Animal biospecimens include organisms that have flown in space and subjects of related ground control studies
  - Available samples are surplus (unassigned) biospecimens
- Applicants may submit proposals specifically for analysis of materials obtained from this program or as a supplementary component of an experiment proposal in another research area

The search term “Muscular” returns the following result:

<table>
<thead>
<tr>
<th>Name</th>
<th>ID</th>
<th>Species</th>
<th>Collection Phase</th>
<th>Session Type</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adductor longus</td>
<td>4822</td>
<td>Rat</td>
<td>Postflight</td>
<td>Flight</td>
</tr>
<tr>
<td>Adductor longus</td>
<td>4823</td>
<td>Rat</td>
<td>Preflight</td>
<td>Basal</td>
</tr>
<tr>
<td>Adductor longus</td>
<td>4824</td>
<td>Rat</td>
<td>Postflight</td>
<td>Flight control</td>
</tr>
<tr>
<td>Adductor longus</td>
<td>4825</td>
<td>Rat</td>
<td>Postflight</td>
<td>Ground control</td>
</tr>
</tbody>
</table>