PROTECTING ASTRONAUT MEDICAL PRIVACY: REVIEW OF PRESENTATIONS AND PUBLICATIONS FOR ATTRIBUTABILITY

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• The data repositories
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• Purpose of attributability review
• Procedures for requesting review
• Process of performing review
• Characteristics that trigger concerns
The Data Repositories

• Retrospective research and medical data collected on astronauts can be requested by researchers
  • Lifetime Surveillance of Astronaut Health Repository (LSAH-R)
  – Astronaut medical data
• Life Sciences Data Archive Repository (LSDA-R)
  – Life sciences research data
• Data can be requested from the repositories through the LSDA website: https://lsda.jsc.nasa.gov/Request/DataRequestFAQ
Requirement for Attributability Review

• Several Federal Laws & Regulations Apply
• NASA research and medical data are contained in separate ‘systems of record’:
  • 10HIMS (Health Information Management System) – data collected for medical purposes
  • 10HERD (Human Experimental & Research Data) – data collected for research purposes

The Common Rule
45 CFR part 46

The Privacy Act of 1974
5 U.S.C. § 552a

HIPAA
Public Law 104-191

Genetic Information Non-Discrimination Act (GINA)
Public Law 110-233
For all data released by LSAH, even some de-identified datasets:

• All final versions of abstracts, graphics, presentations, posters, and manuscripts must be reviewed by LSAH prior to submission to a conference, journal, or other venues
  – For NASA investigators, the attributability review should be done before submitting material to the NASA Export Control Document Availability Authorization (DAA) system]
• If material undergoes multiple revisions (e.g., journal editor comments), the final version must also be reviewed by LSDA/LSAH prior to each re-submission to the journal.
NFL players are celebrities with many details of their careers and personal lives in the public domain.

Cerebral \([18F]T807/AV1451\) retention pattern in clinically probable CTE resembles pathognomonic distribution of CTE tauopathy.  

- Dickstein et al., *Transl Psychiatry* (2016) 6, e900; doi:10.1038/tp.2016.175
Example of Celebrity Privacy Concern

• A case report containing very specific information on age, occupation/employer and health outcomes for a public figure
• A 39-year-old retired National Football League player
• Had 22 concussions over 11 year career
• Manifested progressive neuropsychiatric symptoms, emotional lability and irritability
• Serial neuropsychological exams revealed a decline in executive functioning, processing speed and fine motor skills
Example of Celebrity Privacy Concern

- Details provided that may narrow the possible candidates
  - Are any of the authors or their institutions associated with a specific NFL team either by media reports or inferred from location
  - Age 39 at time of study in 2015
  - Four concussive events resulted in loss of consciousness; Last concussion ~9 months before 2010 evaluation at the Boston University Center for Traumatic Encephalopathy
  - MRI in 2011 (Quest Diagnostics) and 2015 (at Icahn School of Medicine at Mount Sinai (ISMMS) Hess Center for Science and Medicine - Time between scans was 3.9 years
  - Married at time of study in 2015
Example of celebrity privacy concern

• Details provided that do narrow the possible candidates
  – Played college football in 1995-1998 seasons
  – Graduated from college
  – Drafted into NFL in 1999
  – Career ended with 2009 season (last game played in 2010)
  – Graph detailing exact number of games played each season
Example of celebrity privacy concern

• Sources for identifying the study subject
  – Wikipedia
  – NFL.com
  – News media sources

• Details used to narrow subject pool
  – Drafted into NFL in 1999
  – Career ended with 2009 season with last game played in 2010
  – Played 4 years of college football
  – Graph detailing exact number of games played each season
Example of celebrity privacy concern

- Picked in 1999 NFL Draft = \(253\)
- Played in NFL through 2009 season = \(15\)
- Played 4 years of college football = \(11\)
- Played less than 10 games in 2002 = \(4\)
Procedures for Requesting Review

• Send your abstract, graphs, tables, manuscripts and presentations SECURELY to:
  – LSAH mailbox: jsc-lsah@mail.nasa.gov
  – The LSAH Epidemiologist or LSDA Archivist who provided the dataset to you

• Copy the following:
  – Mary Van Baalen, NASA LSAH Project Manager Mary.VanBaalen-1@nasa.gov
  – Mary Wear, KBRwyle Epidemiology Discipline Lead Mary.L.Wear@nasa.gov

• If you don’t get a response within 1-2 days, call us or re-send
Procedures for Requesting Review (cont.)

• Options to send your materials securely:
  – Email using PKI/Entrust encryption
    • Must have a NASA email
  – NASA NOMAD Large File Transfer (LFT)
    • Must have a NASA email to initiate the message, or
    • Ask LSAH or LSDA staff to initiate a NOMAD LFT message and you can reply to it, attaching the files for review
  – Kryptiq eScriptMessenger
    • Must have Kryptiq account with permissions to initiate message, or
    • Ask LSAH or LSDA staff to initiate Kryptiq email message and you can reply to it, attaching files for review
Procedures for Requesting Review (cont.)

• Include the following information:
  – Venue for release (conference, publication, internal meeting, etc.)
  – Title of presentation, abstract or manuscript
  – Authors and affiliations
  – Date comments are needed – allow a minimum of 2 weeks for review
  – Complete set of materials must be provided
    • Full text, tables, graphs, figures, pictures, images, supplemental materials
Process of Performing Review

- One epidemiologist or archivist is assigned to be the Lead Reviewer
- Three epidemiologists/archivists (Lead and 2 others) conduct an independent review of the materials
  - The reviewers provide comments to the Lead Reviewer
  - The reviewers may meet to discuss concerns
- Lead Reviewer compiles comments and sends recommendations to the requester
- Material is not approved for release until a clear statement of approval is received from LSAH or LSDA staff
Process of Performing Review (cont.)

• Every time the content is changed, it must be reviewed again
  – Reviewer suggestions
  – Editorial changes
  – Each iteration of a manuscript, including final galley proofs
  – Final final version of presentation, poster, manuscript
• For each version or iteration, approval must be given before the material can be released, sent back to the editor, or presented
• Material is not approved for release until a clear statement of approval is received
Characteristics that Trigger Concerns

• Age (current, at selection, at launch)
• Sex
• EVA (conducted, # on a mission, cumulative # EVA over career)
• Mission type (e.g. ISS, STS, Skylab)
• Date of launch/landing (any specific calendar dates)
• Time from one individual’s mission to the next mission
• Mission duration, special inflight activities, Space agency affiliation
• Cumulative time in space, number of missions flown
• Many other variables alone or in combination can identify subject
• There are people who try to figure out the identity of astronauts in published papers, articles, books.
• It is our regulatory obligation per the Privacy Act, Common Rule, 10HIMS and 10HERD to protect subjects’ PII.
• It is also our ethical obligation to protect astronaut privacy.
• The Attributability Review protects researchers from inadvertent release of PII.