

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

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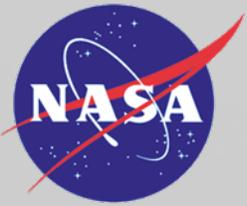
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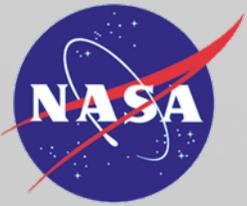
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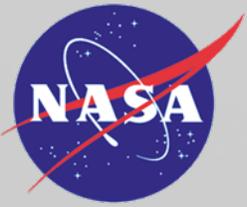


- The data repositories
- Requirement for attributability review
- Example of celebrity privacy concern
- Purpose of attributability review
- Procedures for requesting review
- Process of performing review
- Characteristics that trigger concerns



# 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**

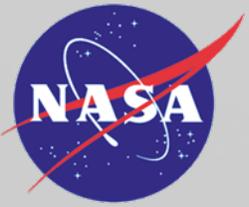
5 U.S.C. § 552a

**HIPAA**

Public Law 104-191

**Genetic Information Non-Discrimination Act (GINA)**

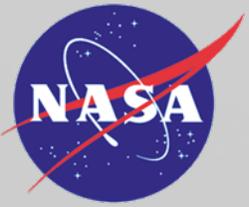
Public Law 110-233



# Requirement for Attributability Review

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.



# Example of Celebrity Privacy Concern

- 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

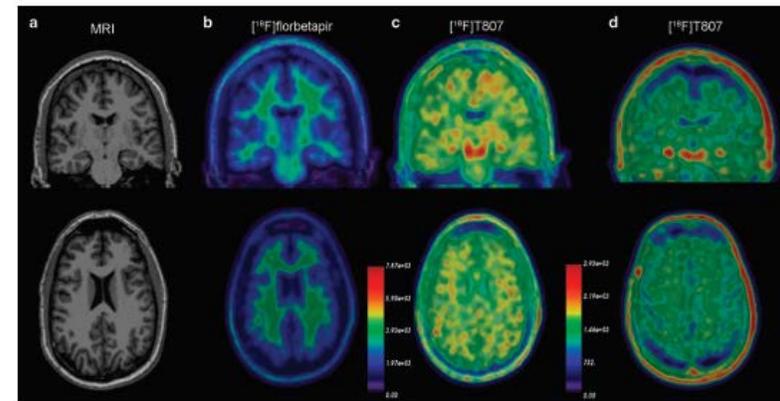
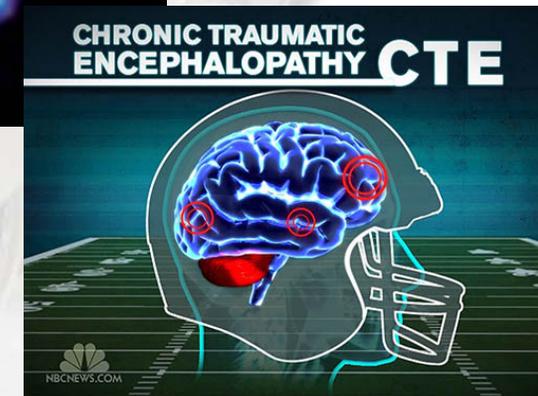
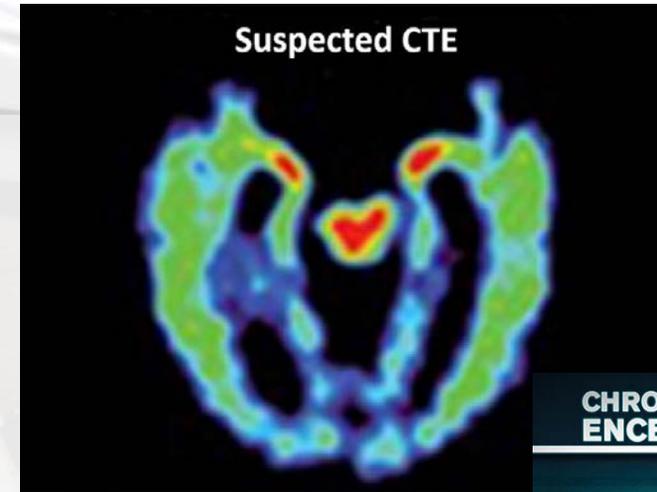
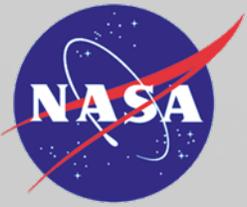
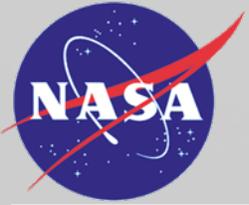


Figure 4. PET imaging from a 39-year-old retired NFL player. (a) structural MRI image, (b)  $[^{18}\text{F}]$ florbetapir PET image, (c)  $[^{18}\text{F}]$ T807/AV1451 PET image, (d)  $[^{18}\text{F}]$ T807/AV1451 PET image from a healthy age-matched control subject. Note that the  $[^{18}\text{F}]$ florbetapir image was negative for amyloid accumulation, while the  $[^{18}\text{F}]$ T807/AV1451 image shows extensive cortical ligand retention, especially at the junction of the gray and white matter, as is characteristic of the distribution of tauopathy in CTE. The PET scales represent ligand uptake in Bq/ml. CTE, chronic traumatic encephalopathy; MRI, magnetic resonance imaging; PET, positron emission tomography.



# 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



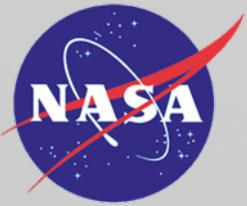
# Example of Celebrity Privacy Concern

- 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



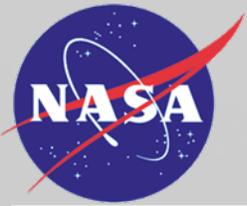
# Example of celebrity privacy concern

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**



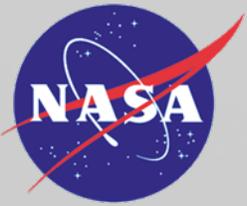
# Procedures for Requesting Review

- Send your abstract, graphs, tables, manuscripts and presentations **SECURELY** to:
  - LSAH mailbox: [jsc-lsah@mail.nasa.gov](mailto: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](mailto:Mary.VanBaalen-1@nasa.gov)
  - Mary Wear, KBRwyle Epidemiology Discipline Lead [Mary.L.Wear@nasa.gov](mailto:Mary.L.Wear@nasa.gov)
- If you don't get a response within 1-2 days, call us or re-send



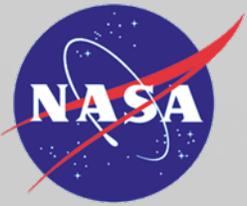
# Procedures for Requesting Review (cont.)

- 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



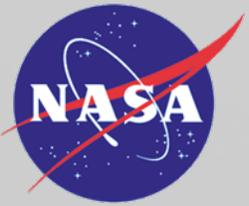
# Procedures for Requesting Review (cont.)

- 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



## Conclusion slide

- 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.