Who is an author? Who owns data and results? How to store sensitive data?

January 23, 2019 @ Terkko Health Hub, 3-5 PM

Marjukka Mylläriemi, Vice Dean for Research: Welcome words.
Pekka Louhiala, University lecturer, Vice Chair of the Finnish National Board on Research Integrity: Who is an author?
Sofia Kuitunen, Legal services UH: Ownership of data and research results.
Ville Tenhunen, IT Services UH: Storing sensitive data.
Siiri Fuchs & Katri Larmo: UH Data Support & Services.

Floor is open for any questions, discussion and ideas.

Chair: Riikka Palonkorpi, Senior advisor, UH
WHO IS AN AUTHOR?

Pekka Louhiala
Docent, University lecturer
Paediatrician
Department of Public Health University of Helsinki
ICMJE CRITERIA

• **Substantial** contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data for the work; AND

• Drafting the work or revising it *critically* for **important intellectual** content; AND

• Final approval of the version to be published; AND

• Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.
EXAMPLE 1.

• Research group A needs specific kind of transgenic mice to complete a study

• Two options:
  • They create such mice for their own use
    • That would take 2 years / 30 000 euros
  • They accept samples from group B abroad and agree to list the names of the providers as authors

• What should A do?
EXAMPLE 2.

- A and B conduct a small follow-up study
- They need some help in statistics and turn to C who spends 3 hours to do the job
- C is included as an author in the report

- Should C be included as an author?
US firm accused of manipulating journal articles and paying millions to authors

Michael McCarthy

The US medical device company Medtronic was “heavily involved in drafting, editing, and shaping the content of medical journal articles authored by its physician consultants,” who were paid hundreds of millions of dollars by the company through royalties and consulting fees, a US Senate Finance Committee staff investigation has found.¹
Potential conflicts of interest: Dr Papakostas has served as a consultant for Abbott Laboratories, AstraZeneca PLC, Avanir, Brainsway, Bristol-Myers Squibb, Cephalon, Dey Pharma LP, Eli Lilly, Genentech, GlaxoSmithKline, Evotec AG, H. Lundbeck A/S, Inflabloc, Jazz, Novartis AG, Otsuka, PAMLAB, Pfizer, Pierre Fabre, Ridge Diagnostics (formerly known as Precision Human Biolaboratories), Shire, Sunovion, Takeda, Theracos, and Wyeth; has received honoraria from Abbott Laboratories, AstraZeneca PLC, Avanir, Bristol-Myers Squibb, Brainsway, Cephalon, Dey Pharma LP, Eli Lilly, Evotec AG, GlaxoSmithKline, Inflabloc, Jazz, H. Lundbeck A/S, Meiji Seika, Novartis Pharma AG, Otsuka, PAMLAB, Pfizer, Pierre Fabre, Ridge Diagnostics, Shire, Sunovion, Takeda, Theracos, Titan, and Wyeth; has received research support from AstraZeneca PLC, Bristol-Myers Squibb, Forest, National Institute of Mental Health, PAMLAB, Ridge Diagnostics (formerly known as Precision Human Biolaboratories), Sunovion, and Theracos; and has served (not currently) on the speaker’s bureau for Bristol-Myers Squibb and Pfizer. Drs Iovieno and Østergaard report no financial or other relationship relevant to the subject of this article.

Funding/support: None reported.
Example 5: too many authors?
EXAMPLE 6: TOO MANY PAPERS?

Can a medical researcher have too many publications?

Anthony F Jorm

The most prolific researchers may not be adhering to authorship guidelines
Pressure to ‘publish or perish’ may discourage innovative research, UCLA study suggests

The researchers’ conclusions are drawn from a database they assembled of more than 6 million scholarly publications in biomedicine and chemistry

Phil Hampton | October 08, 2015

Drawing on their analysis of scientific rewards, Foster and his colleagues argue that researchers who confine their work to answering established questions are more likely to have the results published, which is a key to career advancement in academia. Conversely, researchers who ask more original questions and seek to forge new links in the web of knowledge are more likely to stumble on the road to publication, which can make them appear unproductive to their colleagues. If published, however, these innovative research projects are more highly rewarded with citations. And scientists who win awards — especially major ones, like a Nobel Prize — have more of these innovative moves in their research portfolio.
EXAMPLE 8: INFLATION OF AUTHORSHIP

Acceptance Letter

July 23, 2014

Dear Margaret Simpson, Kim Jong Fun, Edna Krabappel,

Congratulations! As a result of the reviews and revisions, we are pleased to inform you that your following paper has been formally accepted for publication in Journal of Computational Intelligence and Electronic Systems (http://www.aspbs.com/jcies/).
The incentive structure of a scientist’s life is increasingly mimicking economic principles. While intensely criticized, the journal impact factor (JIF) has taken a role as the new currency for scientists. Successful goal-directed behavior in academia thus requires knowledge about the JIF. Using functional neuroimaging we examined how the JIF, as a powerful incentive in academia, has shaped the behavior of scientists and the reward signal in the striatum. We demonstrate that the reward signal in the nucleus accumbens increases with higher JIF during the anticipation of a publication and found a positive correlation with the personal publication record (pJIF) supporting the notion that scientists have incorporated the predominant reward principle of the scientific community in their reward system. The implications of this behavioral
"FINAL" SOLUTION?

• Change academic reward system
• Goodbye "author"
• Welcome "contributor" (and a list of activities)
MEANWHILE

Tieteellisten julkaisujen tekijyydestä sopiminen

Att komma överens om upphovsmannaskapet
till vetenskapliga publikationer

Agreeing on authorship
Recommendation for research publications
RIGHTS TO DATA
Legal Review

Sofia Kuitunen
Legal Counsel, Research Services
• The legal status of the ownership of the data depends on the following factors:

- What kind of data is in question?
- How data was created?
- What kind of information data contains?
- What kind of intellectual property rights applies to data?
Different Types of Data

- **Research data**
  - "primary data" for example collected health information
  - "derivative works" for example research results generated by using the collected data

- **Biological material**
  - Use is restricted by the law or by a consent of a patient

- **Personal data**
  - Could be a part of research data or biological material, but use is restricted for legitimate purposes (consent, public interest)
Ownership rights

- Data as knowledge, who can own knowledge?

However, access/exploitation can be restricted in two cases:

- Data is treated as confidential information
- Data is regarded as intellectual property
Intellectual Property Rights

• Research results can be covered by:
  – Copyrights (e.g. publications, software, educational materials)
  – Database rights
  – Catalogue rights
  – Trade secret (protected usually by contractual arrangements)
  – Patents (Inventions)
Copyright

- A legal right which belongs to its creators without a separate registration
- Expression of work shall be unique and creative
- The knowledge is not protected, only the expression

Patent

- Protects an invention, but requires a "registration"
- Invention may be a technical device, method composition or process
- Novelty and uniqueness required, compared to state of art
Moral Rights (copyright)

- A part of copyright
- Personal rights of the author
- Cannot be transferred from the author
- Right of attribution:
  - Author’s name should be always stated or referred
- Right of integrity:
  - Works cannot be changed without permission
  - Reputation cannot be harmed
Derivative Works

• Permission to make such works is required from the original creator/copyright holder

• In case modifications of original work is permitted, only the new material is covered by a new copyright and the original material is still covered by an existing copyright
Data as Confidential Information

• In case data is not publicly available, and cannot be covered by intellectual property rights, it can be kept confidential and as protected as a “trade secret”→ protected only as long as kept secret (e.g. recipe of Coca-Cola)

• The access to confidential data can be regulated by contractual provisions (NDA, MTA, DTA) --> different types of rights:
  – Right to use exclusively/non–exclusively
  – For commercial purposes/ non-commercial purposes (research and education)
  – Right to transfer further to third parties
Ownership rights

- University’s rights to research data:
  - Was the data generated in a project funded by an external funding (Business Finland, H2020, companys’ funding etc.)?
    - University has usually granted certain rights to the funding organization
    - all rights shall belong to the university in order to comply with its obligations towards the funding organization
    - rights shall be transferred from a researcher to the university by a separate "transfer of rights"—form in the beginning of a project

  - Was the data generated as a part of open research?
    - data belongs to a researcher
    - University has a secondary right to the data
    - However, data may be subject to confidentiality, data management and storage instructions
• Ownership rights and authorship within the research group are not always related:

→ Even if the university (or sponsor) has some rights to the data (e.g. externally funded research), researchers have always a right to publish the research results UNLESS

1) publication is restricted by an external sponsor (company, funding organization etc.)

2) Publication is requested to be delayed for the time of application period for protection of intellectual property rights (e.g. patent application)

3) Publication is restricted by an agreement (e.g. consortium agreement, joint research)
Authorship in Publications

- Authorship questions are defined by academic and ethical principles and guidelines → connection to moral rights.
- List of authors/ order of names in the list of authors are regulated by academic and ethical principles, not by ownership rights!
- University of Helsinki is committed to TENK guidelines.
- Mutually agreed rules within the research group in the beginning of the project in order to avoid future disputes? → breach of such agreement might be then a legal issue.
Thank you!
IT Services: Storing sensitive data

VILLE.TENHUNEN@HELSINKI.FI
1. Sensitive data, what is it?
2. About sensitive data management
3. Options to storing data
4. Project proposals and upcoming services
5. Contact information
6. More information
Sensitive data, what is it?

Sensitive data by GDPR*:

• personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs;
• trade-union membership;
• genetic data, biometric data processed solely to identify a human being;
• health-related data;
• data concerning a person’s sex life or sexual orientation.

Note: GDPR regulates every data which has people in it

In this presentation we concentrate this.

Remember also these confidential issues**

• Information related to business or professional secrets or technological development projects as well as any basic materials or proposals for scientific research
• Contracts and research proposals related to university research are always confidential and no information on them is given to parties external to the University
• etc.


**) https://flamma.helsinki.fi/en/juristitalvut-tutkimusasiat/HV286590
About sensitive data management

Evaluation is needed

• Sensitivity depends strongly on content
• Risk evaluation should always be made: How sensitive the data is? What could happen in its worst?
• Evaluating sensitivity can be hard – underestimation or overestimation could be expensive
• Contact datasupport or IT security for help

Reason to collect, access control, anonymization, encryption

• Collect only the data you need – by the GDPR it is not legal to collect personal data without reasoning
• Take good care of the access control - who needs access and how long?
• If possible, anonymize or pseudonymize the data
• Encrypt the data if possible
Options to storing sensitive data

- **Umpio**
  - From 10 GB to several terabytes
  - For UH users only, data sharing within group
  - Backups taken every hour
  - Based on NetApp storage cluster technology
  - Access via VDI environment or virtual server
  - Personnel status is needed for VDI usage

- **UH virtual server**
  - Windows or Linux (RHEL, Ubuntu)
  - Recommended for applications
  - Up to 10 TB storage space from the NetApp cluster

- **Dedicated physical server**
  - From 40 TB to 200 TB (approx.)
  - Needs maintenance
  - Lifecycle 5 years

- **CSC virtual server (ePouta)**
  - Cloud computing environment designed for processing sensitive data (ISO27001 and VAHTI 2010 compliant environments)
  - Users can freely administer their own virtual machines and software
  - Different flavors: Standard, GPU, I/O, HPC

- **International projects**
  - ELIXIR (also part of the ePouta)
Project proposals and upcoming services

- **Service for sensitive data storing and sharing**
  - Based on Nextcloud technology (incl. serverside encryption, end-to-end encryption etc.)
  - Project planning phase; budgeting and resourcing is currently unsure

- **Survey tool for the sensitive data**
  - Project planning phase; budgeting and resourcing is currently unsure

- **EUDAT: Secure B2SHARE**
  - Sensitive data in a secure storage
  - Access needs two phase authentication (REMS)
  - Computing in the ePouta
  - Secure desktop access
Contact information

Services produced by University of Helsinki
• Datasupport: https://datasupport.helsinki.fi/ or datasupport@helsinki.fi
• Helpdesk: https://help.helsinki.fi or helpdesk@helsinki.fi

CSC services:
• CSC customer portal: https://sui.csc.fi or servicedesk@csc.fi

EUDAT services:
• https://www.eudat.eu
More information

Policies and guidelines:
• Making a research project understandable - Guide for data documentation: https://doi.org/10.5281/zenodo.1914401
• Information security and terms of use: https://www.helsinki.fi/en/it/information-security-and-terms-of-use
• Cloud Server Policy: https://flamma.helsinki.fi/en/HY304902
• UH One Drive EULA: https://flamma.helsinki.fi/content/res/pri/HY329132
• IT Center’s price list: https://flamma.helsinki.fi/en/HY277495

Service catalogs:
• IT services at the university: https://www.helsinki.fi/en/it/it-services-at-the-university
• CSC’s service page: https://www.csc.fi/services, Pouta services: https://research.csc.fi/pouta-user-guide
• Cloud guide: https://wiki.eduuni.fi/display/cloudguide/Cloud+Guide
• EUDAT Services: https://www.eudat.eu/catalogue
Thank you!

@VTENHUNEN
UH Data Support
Research data management

23.1.2019
Siiri Fuchs
Services

1. Help in any matter regarding research data

2. Training, workshops, and DMP commenting service

3. Guides & wizards

4. Other important services by UH library:
   - Saving publications to an open archive
   - Open access: journal discounts
1. Help in any matter regarding research data

2. Training, workshops, and DMP commenting service

- Research data management basic lecture
  - for researchers & PhD students, 1,5h

- **DMP workshops**
  - How to prepare a Data management plan (DMP) using DMPTuuli i.e. for Academy of Finland (AoF).

- **DMP commenting service**
  - during AoF fall call.

- Other workshops depending on demand
  - How to handle sensitive data
  - Storage & archiving throughout the life cycle of research data
  - Suggest!

http://dmptuuli.fi
3. Guides & wizards

- DMPTuuli for making an Data Management Plan
  - [http://dmptuuli.fi](http://dmptuuli.fi)

- Find services on research data management
  - [http://datasupport.helsinki.fi](http://datasupport.helsinki.fi)

- Guides on research data management
  - [http://libraryguides.helsinki.fi/rdm](http://libraryguides.helsinki.fi/rdm)
  - [https://libraryguides.helsinki.fi/datanhallinta](https://libraryguides.helsinki.fi/datanhallinta)
4. Other important services by UH library:

Open access publishing of articles, options:

A. Publish in an open access journal; (Gold OA); involves article processing charge

B. Publish in a subscription based journal but pay your article open; (Hybrid OA; double dipping => not recommended); involves article processing charge

C. Publish in a subscription based journal & store a copy of the final peer reviewed version (or some other version) to an open archive; no costs (Green OA)
   - How? Just email the article to us: openaccess-info@helsinki.fi
   - We’ll do the archiving to Tuhat & Helda (UH repository, indexed also in Google)
4. Other important services by UH library:

- Library has negotiated discounts: [http://libraryguides.helsinki.fi/apc/journals_discounts](http://libraryguides.helsinki.fi/apc/journals_discounts)
- Further information: [http://libraryguides.helsinki.fi/oa/eng](http://libraryguides.helsinki.fi/oa/eng)
- Any questions: openaccess-info@helsinki.fi & hulib-apc@helsinki.fi (publication fees)
To remember:

datasupport@helsinki.fi
openaccess-info@helsinki.fi

http://datasupport.helsinki.fi
http://libraryguides.helsinki.fi/oa/eng
https://www.terkko.helsinki.fi/
https://www.terkko.helsinki.fi/data-support-open-science