

AIRR Community Legal & Ethics Working Group

Report 2019/20

2020-12-08

AIRR Community Meeting V

Presentation outline

- WG overview
- Goals for reporting period
- Activities in reporting period
- Proposed actions and activities for 2020/21

WG structure

Purpose/Mission

To address issues pertaining to legal (e.g., IP) and/or ethical (e.g., human subjects) standards for the AIRR Community

WG Members (alphabetical order)

Alexander Bernier, Tania Bubela (Co-Chair), Christian Busse (Co-Chair), Artur Rocha, Jamie Scott, Jacob Sherkow

WG Demographics

- Country of residence: CA 2, US 2, DE 1, PT 1
- Female:male 2:4
- Percentage active members: 100%

Goals for 2019/20

Goals

- Support Daniel Emerling, who plans to develop a survey to determine if researchers are holding AIRR-seq data from publication or sharing, and if so, to discover what are their reasons for doing so.
- Clarify IP regarding software developed by the combined efforts of WGs and/or teams of AIRR Community members.
- Provide advice on whether software developed by the AIRR Community's efforts should be licensed to industry as opposed to being made available through open licensure.
- Develop ethical standards for AIRR Community members to follow when generating or using AIRR-seq data from humans.

Activities in 2019/20

Survey

- Several calls took place in late 2019 / early 2020 and included both members of this WG as well as the TAbS Initiatives Committee
- Survey should broadly cover the potential reasons why researchers refrain from sharing AIRR-seq data, e.g., lack of incentives, concerns about jeopardizing potential IPR and (supposed or real) restrictions based on GDPR and related legal norms.
- The initial planning phase for the survey is nearly completed by now.

Other activities

- Software IP & licensing: Was not followed up during the reporting period
- Ethical guidelines: Was not followed up during the reporting period

Proposed plans for 2020/21

Goals

- Finalize, conduct and evaluate the survey
- Provide guidance on GDPR issues
- Understand the restrictions on data sharing currently imposed by European database protection laws (i.e., Directive 96/9/EC), especially in the context of reference sequence sets (in cooperation with GLDB WG)
- Develop an ethical framework for patient engagement and studies involving indigenous people
- Evaluate legal and ethical aspects of current Open Science practises and recommendations in collaboration with other stakeholders (e.g., RDA, IUIS)

Proposed plans for 2020/21

Products

- Survey results

Proposed WG Co-leaders

- Tania Bubela, tdb