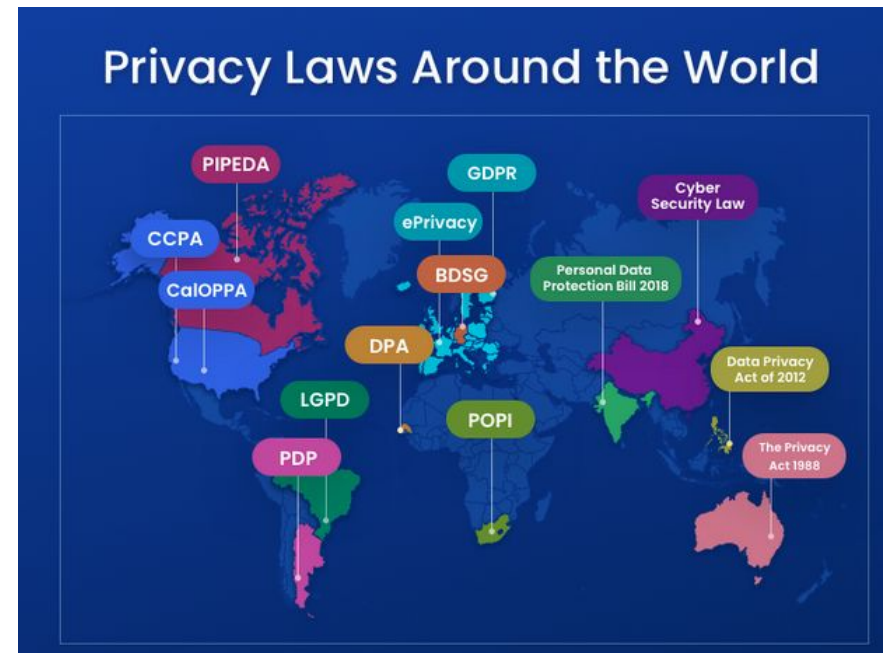


Introductions & Status update
Discussion on direction/focus
and proposals
future planning

WELCOME !



<https://termly.io/resources/infographics/privacy-laws-around-the-world>



Freyja says hi & apologies



Background

Initially a Working Group aimed to explore issues related to scientific research data sets that contains human subject information, as well as related datasets that have the potential to be combined in a way that can expose private information.

The goal of the group was to :

- develop a framework for how researchers and repositories should appropriately manage human-subject datasets,
- develop a metadata set to describe the privacy-related aspects of research datasets, and
- build awareness of the privacy implications of research data sharing.

With the aim to:

- 1) Improve the understanding of the privacy issues that relate specifically to research data from distinct stakeholder perspectives.
- 2) Support a worldwide dialogue about the privacy issues that surround the sharing, combination, and reuse of research data.
- 3) Reduce the risk of an unintentional release of personally identifiable information through the sharing or reuse of research data.

Background/update workplan

INITIAL Workplan

To focus on world-wide legal frameworks and the impacts these frameworks have on data sharing, especially with human-subject data.

- A systematic literature review comparing the differences and similarities,
- formulate a set of principles that will provide guidance to the researcher and repository communities on how to govern personal data.
- define a set of use cases on how the principles will be applied.
- Share proposed guidelines for (RDA) endorsement and adoption

NEW Workplan

- best practice for pseudonymization of data
- best practice for effective anonymization (degree of anonymity) of data
- **[insert your proposal here]**

NEXT STEPS

- UPDATE WORKPLAN
- [OPEN VACANCY] NON-EU CO-CHAIR
- FREQUENCY AND NEXT MEETING(S)

THANK YOU !

AND

ENJOY THE REST OF THE PLENARY