

Fresh start for data privacy – reorientation and next steps

24th Plenary Meeting Collaborative Notes

Group(s) name(s) organising the session: RDA Privacy Implications of Research Data Sets IG

Session link:

https://www.rd-alliance.org/groups/rdaniso-privacy-implications-research-data-sets-wg/plenary-participation/?application_id=174595

Session scheduled date/time/breakout session: 10.04.2025, Breakout 8, 07:00 UTC

Slides:

https://docs.google.com/presentation/d/1P_R3ZAtw7Tyda96nBf1_O2rMqprJhIGI

Session summary (for Group co-chairs)

We will use the content in the table below to highlight your work to the RDA community as a report organised by the Technical Advisory Board.

Please complete ALL fields below by **Friday 25th April, close of business** to be included in the report & social media activities.

Summarise your session in three sentences:
Key outcomes/actions/takeaways
1. <i>Example</i> 2. <i>Example</i>
Synergies and/or possible collaborations identified with RDA groups and other groups:

Get involved in [RDA Community](#)

This meeting will take place according to the [RDA Code of Conduct](#)

Attendee Check-in

Please complete this table to indicate your attendance (add rows as needed):

Full Name	Affiliation	Location	Email
Miha Peče	ZRC SAZU	Ljubljana, Slovenia	miha.pece@zrc-sazu.si

Francoise Genova	Observatoire Astronomique de Strasbourg	Strasbourg, France	francoise.genova@astr o.unistra.fr
Matthieu Pourieux	CNRS-CREM (UMR 6211), Université de Rennes	Rennes, France	matthieu.pourieux@uni v-rennes.fr
Ryan O'Connor	RDA Europe AISBL	Cork, Ireland	ryan.oconnor@rda-fou ndation.org
Kosuke Tanabe	National Institute for Materials Science	Tsukuba, Japan	TANABE.Kosuke@nims. go.jp
Suzie Lavoie	Orygen, the University of Melbourne	Melbourne, Australia	suzie.lavoie@orygen.or g.au
Joerg Geiger	University of Wuerzburg	Wuerzburg, Germany	joerg.geiger@uni-wuer zburg.de
Dieuwertje Bloemen	KU Leuven	Leuven, Belgium	dieuwertje.bloemen@k uleuven.be
Andrew S. Hoffman	Leiden University	NL	a.s.hoffman@cwts.leid enuniv.nl
Lars Eklund	Uppsala University/NBIS/SND	Uppsala, Sweden	lars.eklund@it.uu.se
Kiera McNeice	Cambridge University Press	UK	kiera.mcneice@cambri dge.org
Janez Štebe	ADP/UL	Si	Janez.Stebe@fdv.uni-lj. si
Stéphanie Cheviron	Université de Strasbourg	Strasbourg, France	scheviron@unistra.fr
Jennifer Palethorpe	Nantes Université	Nantes, France	jennifer.palethorpe@un iv-nantes.fr

Which privacy issues are relevant for you?

(Enter the topic or if it is already in the list vote it up)

Topic	vote
Alternative legal grounds for processing personal data beyond 'informed consent' and how this relates to data archiving/sharing (Mostly an EU-specific concern, as this relates to GDPR)	+5
Preserving Rights of Privacy throughout federated reuse of data	+1
How to share pseudonymized data while respecting legal obligations wrt privacy (open science v. privacy)	+2
Ethics of Privacy and AI	+1
Cross domain and cross legal boundaries of privacy issues	+1

How do/can privacy issues affect your work?

(Enter the topic or if it is already in the list vote it up)

Topic	vote
Research data as it relates to the GDPR	+3
Legal/organizational uncertainty stemming from certain mis-fits between requirements for GDPR compliance and the realities of qualitative/ethnographic methods in SSH (esp. data minimization, purpose limitation, consent in mixed/quasi-public settings when doing fieldwork, what counts as 'philosophical beliefs')	+3

Which topics would you think should be worked on?

(Enter the topic or if it is already in the list vote it up)

Topic	vote
Gather guidance documents produced in different regions/countries/thematic domains to build a collection, using the RDA community global reach (likely many documents available, in different languages)	
Collaboration with the Artificial Intelligence & Data Visitation	+1

WG?	
Modular/nested consent documentation with specific provisions for varying levels of consent for data storage/data archiving/data sharing/publication	+2
Topics from the list	
Glossary	+2
In the concept of privacy can a subject actually give up their data ownership when they share data.	
Laws & Regulation Registry (revision/update)	
Privacy FAQ	+1
Best practices/implementation for preserving privacy in research data	+4
High-dimensional data	
Distributed computing	
AI	
Contextual dependence of the concept of privacy esp. In relations to laws and regulations on data sharing	
Anonymity - Pseudonymity	
Consent wording and elaboration of situations	+1

Collaborative Session Notes *(To be used by participants and chairs during the session)*

Round-the-table introduction of the participants

Short report on IG history and current status - Joerg Geiger

Slides

Initially funded at NISO, funding expired

P18: two NISO co-chairs left, adjust the scope

There is also a Sensitive data IG: collaboration and differentiate privacy from sensitive data

Afterwards planned regular meetings poorly attended and subsequently abandonne

P18 & P19: important issue, continue the issue

Resume the legacy projects

Glossary

Laws & Regulation registry

Privacy FAQ

Project: collect examples

The problem remains

Trust is key

Understanding of privacy has many aspects

Possible strands of work: see above

Consent issue when researcher promise to subject they will be the only one to process the data vs. legal obligations regarding public access to data.

Regarding informed consent the AI/DV WG has done some good work on this topic, but there are still lots of work to do in these areas to make it more general.

Control use of shared data, prevent dual use -> consent?

Modular consent opt in/out

Possible legal obligation to share data in contradiction to consent regulations

Huge need for guidance and collaborative work

Understanding what anonymity means /

- > Tools for pseudonymisation

Transcript of the chat

00:34:17 Connie Clare (she/her) - RDA: Welcome all please sign in to the collaborative notes:

<https://docs.google.com/document/d/1KyvmdeblCERDIdf6O9sjenCWzKKASb1v/edit#heading=h.9rqq07bgmuca>

00:49:14 Lars Eklund: Welcome to the RDA family Matthieu

00:49:21 Matthieu Pourieux: Reacted to "Welcome to the RDA f..." with ❤️

01:25:39 Dieuwertje Bloemen (KU Leuven): I have to leave because of another meeting starting. Thank you for the interesting intro to the group

01:31:51 Matthieu Pourieux: About trust : I Believe it is actually a realluy great argument to incentivize researcher to take into account privacy issues : because it impacts the quality of collected data

01:32:17 Lars Eklund: Reacted to "About trust : I Beli..." with 👍

01:33:42 Lars Eklund: Regarding informed consent the AI/DV WG has done some good work on this topic, but there are still lots of work to do in these areas to make it more general

01:34:47 Matthieu Pourieux: In addition to guidance/recommandations : examples of actual research situations to engage people with the recommandations ?

01:35:06 Lars Eklund: Reacted to "In addition to guida..." with 👍

01:35:30 Miha Peče, ZRC SAZU: Reacted to "In addition to guida..." with 👍

01:45:38 Andrew Hoffman: Sorry, I have to run and prep for my next meeting - this was very interesting, my contact info is on the notes so please keep me posted on how this group/discussion evolves. Enjoy the rest of your day!

01:47:01 Matthieu Pourieux: Anonymity is destroying data

01:47:09 Lars Eklund: Reacted to "Anonymity is destroy..." with 👍

01:48:00 Lars Eklund: I really like the concept of pseudonymity which is what we generally deal with in data

01:48:12 Matthieu Pourieux: Reacted to "I really like the co..." with 👍

01:49:23 Lars Eklund: There are some interesting tools, interestingly many feel that $k=10$ that is that there is a 1 in 10 risk of reidentification to be classified as anonymised. I find it highly dubious at those levels.

01:50:18 Lars Eklund: Me and my colleagues at the SND have held workshop on pseudonymisation.

01:51:55 Jennifer Palethorpe: Reacted to "I really like the co..." with 👍

01:52:01 Ryan O'Connor (RDA Europe): Join the IG here:

<https://www.rd-alliance.org/groups/rdaniso-privacy-implications-research-data-sets-wg/work-statement/?sow=169666>

01:53:50 Ryan O'Connor (RDA Europe): Collab notes -

<https://docs.google.com/document/d/1KyvmdebICERDIdf6O9sjenCWzKKASb1v/edit>

01:53:56 Lars Eklund: Would be nice to meet quite soon in like two weeks or so (considering easter is next week)

01:55:52 Lars Eklund: I would love to be a co-chair

01:56:11 Francoise Genova: Reacted to "I would love to be a..." with 🙌

01:56:19 Matthieu Pourieux: Reacted to "I would love to be a..." with 🙌

01:57:00 Ryan O'Connor (RDA Europe): Reacted to "I would love to be a..." with 🎉

01:57:03 Matthieu Pourieux: Thank you for organizing this very interesting session !

01:57:32 Jennifer Palethorpe: Thank you. I am reading the notes and I look forward to finding out more!

01:57:36 Matthieu Pourieux: Bye, see you

01:57:36 Janez Štebe, ADP/UL: Thanks!