Utrecht
University

Data Privacy Survey

English (United Kingdom) ⌄

Information_letter

Survey: Handling Personal Data in Research

This survey is meant for Utrecht University (UU) researchers working with (sources of) personal data. Our aim is to gain insight into the type of (personal) data researchers typically work with, and their experiences and needs in handling personal data. Your input will help us identify common topics that researchers may struggle with. By participating, you will be helping us create better information, tools, and trainings that are useful for all researchers who deal with personal data.

This survey is part of the Data Privacy Project at Research Data Management Support (University Library), which aims to make dealing with (sources of) personal data easier for researchers, by providing the information and tools necessary to do so.

Survey structure

This survey consists of 19-23 questions (depending on your responses) that are structured in the following sections:

- About you and your research (5 questions)
- Measures and documents (4-6 questions)
- Data sharing, archiving and publication (3-4 questions)
- Finding support (3-4 questions)
- Improving our services (4 questions)

The survey takes about **10 minutes** to complete. It is possible to stop and come back to finish it later (using the same web browser, without deleting cookies). Participation is completely voluntary, and you may exit the survey at any time, without providing a reason why.

Privacy

This privacy statement is also available on our project website: link to privacy statement

▶ **Click to expand the privacy statement**

Questions or exercising your rights

If you would like to exercise your rights, or have questions or comments about this survey, please contact (one of) the project coordinators by email:

- Dorien Huijser: d.c.huijser@uu.nl
- Neha Moopen: n.moopen@uu.nl

You may also directly contact UU's Data Protection Officer via privacy@uu.nl, or, on a national level, the Dutch Data Protection Authority (Autoriteit Persoonsgegevens).

More input welcome!

Besides this survey, we would be happy to discuss this topic more personally in a conversation, which would give us a more complete view of your experiences and needs in handling personal data. **If you are interested in speaking with us, please get in touch** (see above). You can also leave your e-mail address at the end of this survey.

Consent

I have read the information above and agree to participate under the conditions described. I know that my participation is voluntary and that I can exit the survey at any time (incomplete responses will be saved; if you want us to remove your data entirely, please contact us).

- ◯ Yes, go to survey
- ◯ No, end survey

Research

About you and your research (1/5 - 5 questions)

This section focuses on who you are and what kind of data (sources) you work with. This will help us determine which faculties and types of research are represented, and what type(s) and level(s) of support is required.

In which UU **faculty/faculties** do you currently work?
Multiple responses possible

- ☐ Faculty of Geosciences
- ☐ Faculty of Humanities
- ☐ Faculty of Law, Economics and Governance
- ☐ Faculty of Medicine (UMC Utrecht)
- ☐ Faculty of Science
- ☐ Faculty of Social and Behavioural Sciences

- [ ] Faculty of Veterinary Medicine
- [ ] Other part of the UU
- [ ] None of the above (end survey)

You indicated not to work at Utrecht University. As this questionnaire is aimed at UU researchers working with personal data, this questionnaire may therefore not be for you.

Please select "Yes" and click "Next" to finish the survey, or click "Previous" to edit your response and continue the survey.

○ Yes, end survey

In which **department(s)** do you currently work?
Multiple responses possible

- [ ] Earth Sciences
- [ ] Physical Geography
- [ ] Sustainable Development
- [ ] Human Geography and Spatial Planning
- [ ] [_____]Other, namely:

In which **department(s)** do you currently work?
Multiple responses possible

- [ ] History and Art History
- [ ] Languages, Literature and Communication
- [ ] Media and Culture Studies
- [ ] Philosophy and Religious Studies
- [ ] [_____]Other, namely:

In which **department(s)** do you currently work?
Multiple responses possible

- [ ] Law
- [ ] Economics
- [ ] Governance
- [ ] [_____]Other, namely:

In which **department(s)** do you currently work?
Multiple responses possible

- ☐ Biology
- ☐ Physics
- ☐ Mathematics
- ☐ Chemistry
- ☐ Information and Computing Sciences
- ☐ Pharmaceutical Sciences
- ☐ [_____] Other, namely:

In which **department(s)** do you currently work?

Multiple responses possible

- ☐ Education
- ☐ Youth & Family
- ☐ Development & Education of Youth in Diverse Societies
- ☐ Clinical Child & Family Studies
- ☐ Interdisciplinary Social Science
- ☐ Cultural Anthropology
- ☐ Methodology & Statistics
- ☐ Sociology
- ☐ Clinical Psychology
- ☐ Developmental Psychology
- ☐ Experimental Psychology
- ☐ Social, Health & Organisational Psychology
- ☐ [_____] Other, namely:

In which **department(s)** do you currently work?

Multiple responses possible

- ☐ Biomolecular Health Sciences
- ☐ Clinical Sciences
- ☐ Population Health Sciences
- ☐ [_____] Other, namely:

In which other part of the organisation do you currently work?

Multiple responses possible

- ☐ Centre for Academic Teaching
- ☐ University College Roosevelt
- ☐ University College Utrecht
- ☐ University Library
- ☐ University Corporate Office

☐ Information Technology Services

☐ [_____] Other, namely:

What is your current position?

Multiple responses possible

☐ Student (bachelor or master)

☐ PhD, junior or post-doctoral researcher

☐ Assistant or Associate Professor

☐ Full or Emeritus professor

☐ Teacher / Lecturer

☐ Research supporter (e.g., research assistant, data manager, research engineer, etc.)

☐ [_____] Other, namely:

With which source(s), type(s) or format(s) of data do you work in your research?

Please select all that apply:

☐ Textual data
   E.g., literature, text corpora, interview transcripts

☐ Tabular data
   Rows and columns of data from data collection, e.g., surveys, experimental tasks, etc.; e.g., csv, Excel, SPSS or STATA data files

☐ Video data
   E.g., video observation, social media materials, etc.

☐ Images
   E.g., photos, medical imaging

☐ Audio data
   E.g., sound recordings, interviews

☐ Bio-medical samples and data
   E.g., cells, DNA material, blood, laboratory cultures, hormone samples, neuroimaging

☐ Physiological measurements
   E.g., height, heart rate, sweat response

☐ Physical samples
   E.g., biological materials like plants or fungi, rocks, pottery sherds, etc.

☐ Computer code, scripts, theoretical models

☐ Geographical data

☐ Other, namely:
   [_____]

☐ None of the above (end survey)

You indicated not to work at with research data of any kind. As this questionnaire is aimed at UU researchers working with (personal) research data, this questionnaire may therefore not be for you.

Please select "Yes" and click "Next" to finish the survey, or click "Previous" to edit your response and continue the survey.

○ Yes, end survey

With which types or sources of **personal data** do you work in your research project(s)?
Please select all that apply:

☐ I don't know what personal data is

☐ Direct identifiers
E.g., (full) name, Driver's license number, images, videos

☐ Sensitive direct identifiers
E.g., medical record numbers, health insurance number

☐ Demographic information
E.g., date of birth, family composition, gender, workplace information, education

☐ Sensitive demographic information
E.g. race, religious beliefs, sexual orientation, political opinion, criminal offense data

☐ Health/physical information
E.g., medical data, dental data, genetic data, biometric data used to identify an individual (e.g., facial images, fingerprint data)

☐ Contact information
E.g., city, country, email address, phone number, postal code, state, street

☐ Derived personal data
E.g., Device ID, Cookie ID, IP address, research ID, other unique IDs

☐ Human behaviour
E.g., social media data, browsing history, location data, media consumption

☐ Other, namely:

☐ None of the above (end survey)

You indicated not to work at with personal data of any kind. As this questionnaire is aimed at UU researchers working with personal (research) data, this questionnaire may therefore not be for you.

Please select "Yes" and click "Next" to finish the survey, or click "Previous" to edit your response and continue the survey.

○ Yes, end survey

Measures_documents

Measures and documents (2/5 - 4-6 questions)

This section concerns organisational and technical measures you may use when working with personal data. Responses from this section will be used to determine which measures deserve more of our attention and how we can better organise faculty- or university-wide privacy-related procedures.

Which privacy-related measures do you (generally) implement in your research?
Please select all that apply:

- ☐ Data Management Plan (DMP)
- ☐ Registering the project in a processing register
- ☐ Data Protection Impact Assessment (DPIA)
- ☐ Privacy review / Pre-DPIA / DPIA-light
- ☐ Access restrictions to the data (Access control, authorisation, user authentication)
- ☐ Logging of who has (which type of) access (e.g., read, write, etc.)
- ☐ Pseudonymisation or anonymisation
- ☐ Encryption of data storage (e.g., a USB-stick)
- ☐ Encryption of data transfer (e.g., SURF filesender, encrypted email)
- ☐ Policy for data retention
- ☐ Privacy training
- ☐ Agreement(s) with external parties
- ☐ Non-disclosure agreement (for external parties or students)
- ☐ Data deletion
- ☐ Preventing the downloading of data or preventing data storage on other locations
- ☐ Other, please specify:

- ☐ None of the above

Where do you store your research data?
Please select all that apply:

- ☐ UU-provided network drive (U-drive, O-drive)
- ☐ UU-provided or -approved cloud drives (YoDa, UU-based OneDrive or Teams, SURFdrive)
- ☐ Non-UU storage location (Dropbox, GitHub, Google Drive, etc.)
- ☐ UU-managed device (e.g., laptop, PC, smartphone)
- ☐ Non-UU managed device (e.g., personal laptop, smartphone)
- ☐ UU-managed external hard disk or USB stick
- ☐ Non-UU managed external hard disk or USB stick

☐ [   ] Other, namely:

☐ Not applicable

You indicated that you use a non-UU storage location (e.g., Dropbox, GitHub, Google Drive, personal laptop, hard disk, etc.). Please note that it is not allowed to store personal (research) data on cloud drives like Dropbox and Google Drive, and we recommend to be careful with non-UU managed devices and hard disks, as they are not backed-up and do not necessarily comply with UU's data security standards.

Please consider using an UU-recommended or -approved storage medium (tip: use the Storage Finder). Feel free to contact RDM Support for additional help and clarification. We can help you move your data to a more secure location.

Click "Next" to continue the survey.

Do you use consent forms in your research?

☐ Yes, I write them myself

☐ Yes, I write/wrote consent forms approved by a privacy officer, legal affairs or ethical committee

☐ Yes, I use(d) a consent form template from our faculty/department

☐ Yes, I use(d) a UU-wide consent form template (e.g., RDM Support, UU website)

☐ No

☐ I don't know what a consent form is

☐ Other, namely:

[   ]

☐ Not applicable

What privacy-related content is in your average information letter and/or consent form?
Please select all that apply:

☐ Which personal data is used

☐ Retention period of the data

☐ Purposes for which the data are used

☐ By whom and where the data are processed

☐ Intentions for data sharing and reuse after the project

☐ Safeguards to protect personal data

☐ Data subjects' rights

☐ Contact information of the Data Protection Officer

☐ Consent for collection, storage and analysis of the data

☐ Consent for processing for another purpose

☐ Consent for sharing data after the end of the project

☐ Other content, namely:

[text box]

☐ None of the above

☐ Not sure

☐ Not applicable

Have you ever conducted, or will you conduct, a Data Protection Impact Assessment (DPIA)?

☐ Yes

☐ No, but I have heard of it / know what it is

☐ No, I have never heard of it

☐ Not applicable

Did/Will you ask for help in conducting the DPIA?

☐ Yes, from RDM Support

☐ Yes, from a Privacy Officer

☐ Yes, from Legal Affairs

☐ [text box] Yes, from someone else:

☐ No

☐ Not applicable

Data_sharing_archiving_publication

Data sharing, archiving and publication (3/5 - 3-4 questions)

This section touches upon UU's ambition to push Open Science forward and goes into your data sharing and publishing practices. This information will help us determine whether any additional tooling or services are needed to help you work more in line with Open Science principles, whilst adhering to the GDPR.

Do you / Will you share research data containing personal data outside of the UU?
Please select all that apply
This includes transfer for data collection, analysis, transcription, storage, sharing and publication

☐ Yes, within the European Economic Area

☐ Yes, outside of the European Economic Area where an [adequate level of data protection](#) applies

☐ Yes, outside the European Economic Area **without** adequate level of data protection

☐ No, I do/will not share data with parties outside the UU

☐ No, I do/will not share data at all (not even within the UU)

☐ Other, please specify:

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What actions do you take to transfer personal data securely outside of the UU?

Please select all that apply:

☐ Pseudonymise the data

☐ Consult with a privacy officer

☐ Consult with RDM Support or a data manager

☐ Set up a data transfer agreement

☐ Set up a data processing agreement

☐ Use a UU-approved tool or device

☐ Give the external party access to the data without moving the data

☐ Use Standard Contractual Clauses

☐ Other, namely:

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☐ None of the above

☐ Not applicable

Have you ever published a dataset containing personal data (e.g., in a repository)?

With a dataset, we mean the data (sources) used for analysis, not the results written in a manuscript

☐ Yes, the whole dataset

☐ Yes, but only the metadata (descriptive information on the dataset)

☐ No

In what format was the data published?

☐ Anonymised

☐ Pseudonymised

☐ Not anonymised or pseudonymised

☐ I don't know

☐ Not applicable

Why didn't you publish your data?
Please select all that apply:

☐ I don't want/need to

☐ I don't know if I can/am allowed to

☐ I don't know how

☐ The dataset is/was too large

☐ There is/was no legal basis (e.g., no consent)

☐ The dataset can/could not be anonymised/pseudonymised

☐ (My colleagues and) I am (are) still working on / publishing from the dataset

☐ Other reason, namely:

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☐ I don't know

☐ Not applicable

Finding_support

Finding support (4/5 - 3-4 questions)

Your responses in this section will help us identify which channels we can best use to advise you in handling personal data.

Do you know who your faculty privacy officer is?

○ Yes

○ No

Have you ever looked for UU-specific information, in-person support or tools on handling personal data?

○ Yes

○ No

○ Not yet

Did you find what you were looking for (e.g., information, support, tools)?

○ (Almost) always

○ Often

○ Sometimes

○ (Almost) never

Which channels do you use to find information about handling personal data?
Please select all that apply:

☐ University website, e.g., RDM support pages

☐ Faculty or department-specific webpages on data management / privacy

☐ UU intranet privacy and information security pages

☐ UU Tooladvisor

☐ Website of the Dutch Data Protection Authority

☐ Website(s) from another university or research institution

☐ Other online resources, including Google

☐ Faculty privacy officer

☐ Privacy officer at Legal Affairs (Juridische Zaken)

☐ Data Protection Officer / Functionaris Gegevensbescherming

☐ Data manager / data steward at my department or faculty

☐ RDM support

☐ Information Security

☐ My colleagues

☐ A training at UU

☐ A training outside of UU

☐ I can never find the information I need on handling personal data

☐ I never search for information about handling personal data

☐ Other:

☐ Not applicable

Improving_our_services

Improving our services (5/5 - 4 questions)

These final questions concern your challenges and needs in terms of information, support and tools on handling personal data. **Any comments or ideas you may have about our current and future support are greatly appreciated!**

Do you see dealing with personal data as an obstacle in open science and research data management?

○ (Almost) always

○ Sometimes

○ (Almost) never

○ Not sure

Which challenges concerning the handling of personal data do you run into most often?
For example: how to pseudonymise data, where to go for help, lack of tools, unsuitable tools, etc.

What specific **information** or **tools** about handling personal data are you missing from existing sources?
If you need a specific tool, please let us know for what purpose and type of data you would need it (e.g., collecting, managing, deidentifying, transcribing, sharing data, etc.)

What can we do better to support you in handling personal data in research?
Please select all that apply and let us know any other suggestions you may have:

☐ More hands-on workshops

☐ More/Better privacy-related tooling

☐ More concrete information materials (e.g., infographics, checklists, etc.)

☐ Walk-in privacy support hours

☐ (Mandatory) privacy trainings

☐ Larger visibility of data support staff (e.g., privacy officer, security officer, data manager)

☐ Greater availability of data support staff (e.g., privacy officer, security officer, data manager)

☐ A university-wide policy for dealing with personal research data

☐ Other **(we welcome all suggestions!)**:

End

If you have any questions about this survey or the Data Privacy Project, feel free to contact:

- Dorien Huijser (d.c.huijser@uu.nl)
- Neha Moopen (n.moopen@uu.nl)

Are you open to being contacted for a conversation on this topic?

○ No

○ [   ] Yes, email me via:

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