Data sharing in the light of the new data protection law

Symposium

12 September 2023

13:30 - 15:30



Some logistics

- The event will be recorded.
- Post your questions in the chat.
- The presentations will be made available.
- We will send you an email once the event materials are available.



FORS – Swiss Centre of Expertise in the Social Sciences www.forscenter.ch



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We offer consulting services for social science researchers.

We do thematic and methodological research in empirical social sciences.









FORS – Swiss Centre of Expertise in the Social Sciences

- Research infrastructure of national scope intended for any institution or person active in the social sciences
- Mostly funded by the Swiss National Science Foundation (SNSF) and hosted by the University of Lausanne
- Founded in 2008



FORS – Swiss Centre of Expertise in the Social Sciences



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Data production

National and international surveys

Research

Thematic, methodological, and epistemological research

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At the national and international level, in all our active domains

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Cutting-edge tools, data collection, and data linking



Data sharing in the light of the new data protection law

- 1st of September 2023: The new Federal Act on Data Protection
- High relevance for social science research: Sensitive data
- Increasing requests for sharing research data and related materials.

Today's symposium:

- What do data protection laws imply for my research?
- How can I share my research data and related materials while respecting the legal requirements?
- Where can I share my data and research materials safely?



Programme

- 1. Sharing data in the light of data protection Pablo Diaz (FORS UNIL)
- 2. Data protection and reproducible research Marieke Heers (FORS)
- SWISSUbase: The platform for sharing research data Jennifer Dean (SWISSUbase – FORS)
- 4. The FORS Replication Service: The place to share replication materials Emilie Morgan de Paula (FORS)
- 5. Good research practices for reproducible research Mauro Cherubini (UNIL)



Data Protection and Reproducible Research

Marieke Heers

FORS

12 September 2023

Symposium: Data Sharing in the light of the new data protection law



Data protection vs. open science

Strong data protection requirements for sensitive data



Push towards *open* data and reproducible research

- Funders
- Journals
- Peers



Reproducible research

What is it?

- Sharing data and research materials, particularly analysis code, so that others can understand what you did and build on your work.
- Important part of the open science movement.

Benefits for researchers

- Increases the quality of the data and research.
- Makes research and results more visible.
- Gives publications a citation advantage.
- Encourages new collaborations and new avenues of research.



Data protection and open data

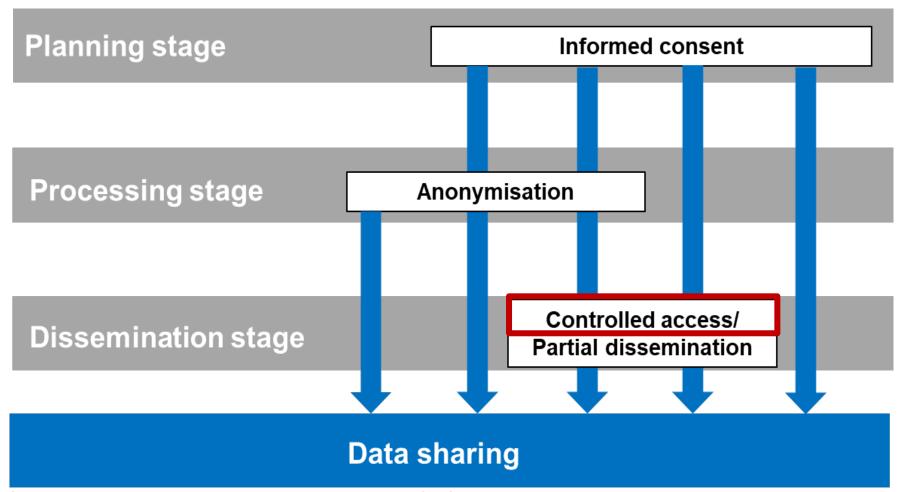
Completely open data



Completely closed data



Sharing sensitive data: The three-layered approach



Source: Data management support team at FORS.



Where to share research data and materials?









Final remarks

- Check out our resources
 - FORS Guides: https://forscenter.ch/publications/fors-guides/
 - Data management webinar series: https://forscenter.ch/data-management-webinar-series/
 - ... and many more on www.forscenter.ch
- Share your data and replication materials
 - SWISSUbase: www.swissubase.ch, support@swissubase.ch
 - FORS Replication Service: https://resources.swissubase.ch/replication/
- Reach out if you need support with data access and deposit: <u>dataservice@fors.unil.ch</u>
 - Contact us:
 - pabloandres.diaz@unil.ch
 - marieke.heers@unil.ch
 - emilie.morgandepaula@fors.unil.ch
- Subscribe to our newsletter

Are you an early career researcher and work with FORS data?

- Win the FORS Data Re-use Award 2023 worth 1'000CHF.
- Submission deadline: 1st of October.





We need your opinion

Go to www.wooclap.com and enter the code FORS





Thank you!



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Sharing data in the light of data protection

Symposium: "Data sharing in the light of the new data protection law Pablo Diaz, UNIL / FORS









What is Data Protection?

Data protection is commonly defined as the principles, rules and strategies designed to protect **peoples privacy**.

- Privacy is the "right to be left alone" (Warren & Brandeis)
- In the field of data protection, privacy is mainly apprehended through the notion informational self-determination, which refers to the authority of the individuals to decide themselves when and within what limits information about their private life should be FORMunicated to others.

Informational self-determination is guaranteed by a number of **fundamental texts**.

- Universal Declaration of Human Rights (art. 12)
- European Convention on Human Rights (art. 8)
- Swiss Federal Constitution (art. 13)







Swiss Federal Constitution:

«Every person has the right to privacy in their private and family life and in their home, and in relation to their mail and telecommunications» (art. 13 al. 1)

«Every person has the right to be protected against the **misuse** of their **personal data**» (art. 13 al. 2)





Anyone who processes **personal data** must comply with data protection laws!







Some definitions









Personal data

"Any information relating to an identified or identifiable **natural** person" (art. 5 let. a FADP*)

Very broad notion: everything that can be related to a specific person is personal data!

Obvious: names, addresses (including IP), phone numbers, pictures, recordings, etc.

Subtle: original ideas, the style of writing, the way of walking, etc.

^{*} Federal Act on Data Protection (FADP), RS 235.1





The way you dance is unique, and computers can tell it's you

Nearly everyone responds to music with movement, whether through subtle toe-tapping or an all-out boogie. A recent discovery shows that our dance style is almost always the same, regardless of the type of music, and a computer can identify the dancer with astounding accuracy.



Studying how people move to music is a powerful tool for researchers looking to understand how and why music affects us the way it does. Over the last few years, researchers at the Centre for Interdisciplinary Music Research at the University of Jyväskylä in Finland have used motion capture technology—the same kind used in Hollywood—to learn that your dance moves say a lot about you, such as how extroverted or neurotic you are, what mood you happen to be in, and even how much you empathize with other people.









Sensitive personal data

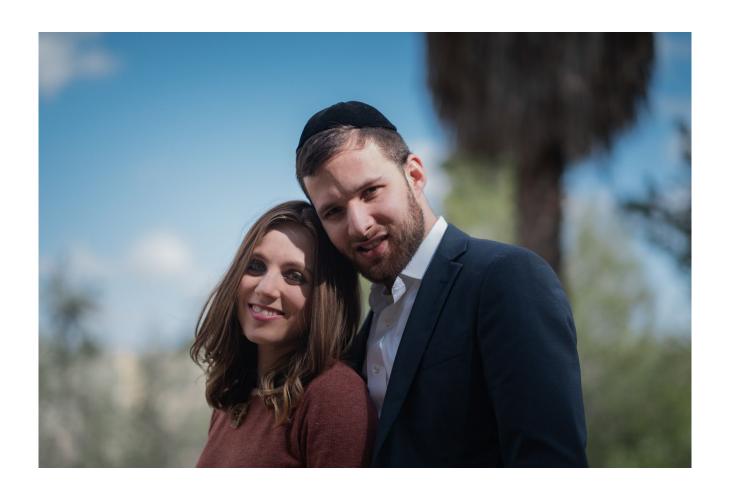
- 1. data relating to religious, philosophical, political or trade union-related views or activities,
- 2. data relating to health, the private sphere or affiliation to a race or ethnicity,
- 3. genetic data,
- 4. biometric data that uniquely identifies a natural person,
- 5. data relating to administrative and criminal proceedings or sanctions,
- 6. data relating to social assistance measures (art. 5 let. c FADP)

Depending on the **context**, almost all data can be considered sensitive (name, photo, job, etc.)







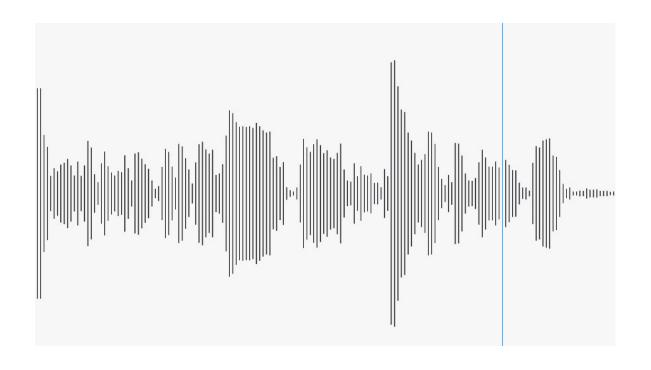


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⚠ The voice is biometric data (= sensitive)









Are you processing personal data?





In the social sciences, it is very difficult to have anonymous data.

It is therefore generally safer to assume that we are dealing with personal data.







In Switzerland, there are laws at two levels:

- Federal (e.g. FADP, Human Research Act, etc.)
- Cantonal







This presentation focuses on the recently revised **federal** law (FADP) because :

- The FADP takes account of recent technological and social developments and the associated risks (highest standard).
- The FADP is in line with the GDPR.
- Cantonal laws will be harmonised in line with the FADP.

A Research that falls within the scope of the HRA is subject to a special legal regime (not covered





- The FADP provides a legal basis for two types of actors: private individuals and federal bodies.
- In this presentation, we will present the legal bases that apply to **federal bodies**, as they are the closest to cantonal laws (which apply to public bodies such as universities).







Conditions for sharing research materials including personal data







C1: To have collected the data legally

- Public institutions (such as universities, etc.) need a legal basis to collect personal data.
- Consent is often the only legal basis available for the collection / processing of sensitive data.
- If the persons concerned have made their personal data accessible to everyone without explicitly objecting to collection, there is no need for a legal basis for collection (other obligations remain).

⚠ In all cases, **Informing** individuals of *any* collection of personal data about them is **mandatory** (even from third-parties), unless it is impossible to do so.







What information do you need to provide?

Participants to a research project **must be notified** as a minimum of the following:

- the controller's (PI) identity and contact details
- the purpose of processing
- if applicable, the recipients or the categories of recipients to which personal data is disclosed (+ country if disclosure abroad).

⚠ If you plan to share personal data, it is important to inform people of the categories of recipients (including the repository and other subcontractors such as cloud-based tools).







C2: To have the right to hold the data

- Personal data cannot be kept for no reason
- It is the purpose of the collection (as announced to the participants) that determines the time limit for the retention of personal data
- If medium- to long-term preservation is envisaged, it must be consistent with the purpose of the collection.

If you intend to share personal data, it is important to establish a more or less **long-term** purpose (e.g. research programme) or even to include sharing as one of the **aims** of the research.





C3: Not to have promised total confidentiality

- Promises made at the time of information are as binding as a contract
- If you promised that only you and your team would have access to the data, you cannot share it unless you renegotiate the terms.

This condition is not, strictly speaking, included in the FADP, but it does affect the possibility of sharing data.





C4: To rely on the right legal bases

There are two *main* ways to make the sharing of research materials including personal data possible:

- Sharing on the basis of informed consent
- Sharing on the basis of "research privilege"







Sharing on the basis of informed consent

- Informed consent is the best option for collecting, processing and sharing personal data.
- That said, having consent to share personal data does not give you the right to do whatever you want with them (there is no such thing as "all-inclusive "consent).





Sharing on the basis of informed consent

- It is important to formulate the purposes of the collection in a sufficiently general and precise way (find the balance).
- It is important to be clear about the categories of recipients (e.g. researchers, repository, subcontractors, etc.).
- It is important to control the purpose of re-use (and therefore to control data access).









Sharing on the basis of research privilege

Without the individual's consent, it is possible to share personal data under certain conditions (art. 39 nFADP):

- To have the right to possess the data and not be prohibited from sharing them.
- To share the data for research purposes only.
- To require data recipients to publish the results of their analyses in a form that does not allow individuals to be identified.
- To require data recipients to destroy their data at the end of their analyses / processing..

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C5: To establish a subcontractor agreement

- Sharing data through an external repository (such as SWISSUBase) is a form of subcontracting.
- The PI (as data controller) outsources the sharing of its data to a third-party service provider (the repository)

A Responsibility for the data remains with the researcher / institution depositing the data.









C5: To establish a subcontractor agreement

As a result:

- You need to establish a contract that sets out the tasks and responsibilities of each party (data deposit agreement = subcontractor agreement).
- As outsourcing data sharing to an external service provider (a repository) constitutes data disclosure, participants must be informed of this.







C6: To maintain control over access / re-use

It is important to maintain a degree of control over data *access* and *re-use*. To achieve this, it is a wise decision to choose a repository that allows you to:

- control access to data;
- have user contracts that set out the conditions to be met for the re-use of data; and
- Monitor and keep track of data downloads, (re)use, publication, etc.







C6: To maintain control over access / re-use

Be aware that to disclose personal data **abroad**, special provisions apply:

- Personal data may only be transferred to a third country if the third country in question ensures an adequate level of protection (the Federal Data Protection and Information Commissioner maintains a list of countries offering such guarantees).
- If the country does not offer an adequate level of protection (e.g. the USA), contractual **measures** must be taken or **explicit consent** must be obtained.
- ⚠ Putting personal data on the cloud = data disclosure







C7: Carry out a risk assessment

- Where the proposed processing is likely to result in a high risk to the personality or fundamental rights of the data subject, the controller (PI) shall carry out an impact assessment relating to the protection of personal data.
- The impact assessment contains a description of the proposed processing operation, an assessment of the risks to the data subject's personality or fundamental rights, and the measures planned to protect the data subject's personality and fundamental rights.





Thank you!









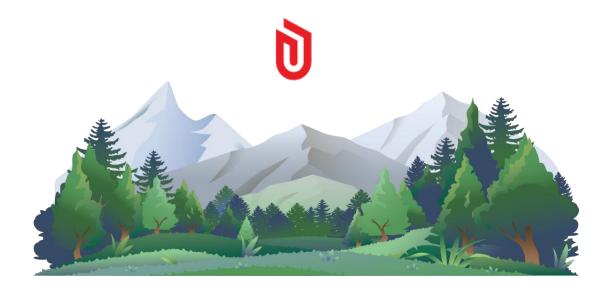


Sharing data with SWISSUbase

Jennifer Dean, Project Manager

Our mission

To serve the Swiss scientific community to share and preserve research data for future reuse.



SHARE & PRESERVE.



What is SWISSUbase?



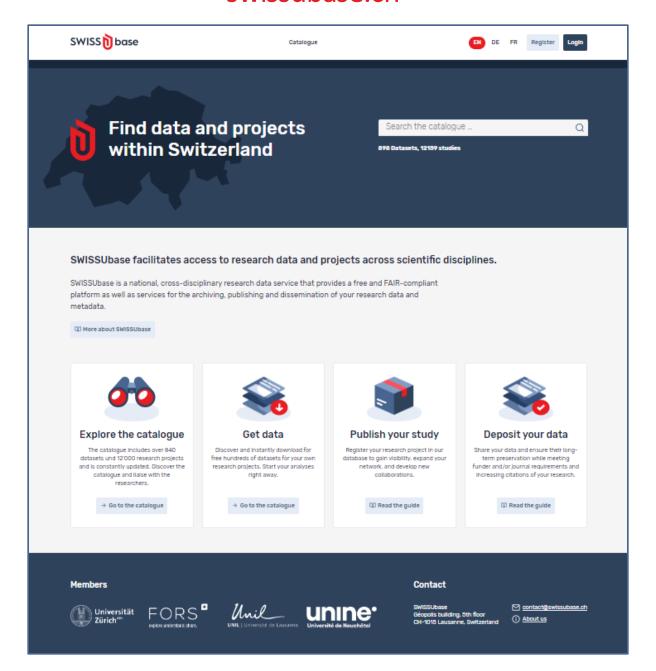
- >Online Platform multidisciplinary platform for the sharing and preserving of Swiss research data, with tailored metadata for:
 - → Long-term preservation, access and reuse.



> Data Services – Data curation, support and consultation services direct to researchers.

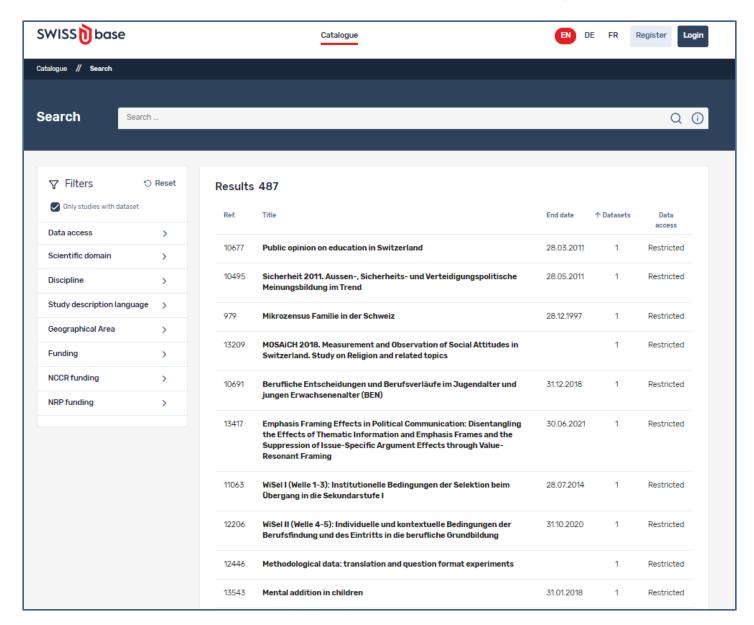


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SWISSUbase public catalogue





A Consortium built among Partners

2021





Social Sciences



Dec. 2021





Linguistics







General (non discipline-specific)







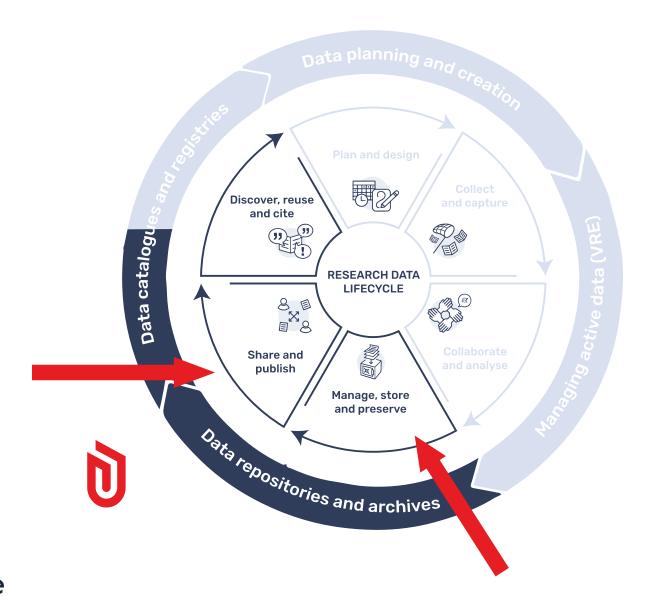
General (non disciplinespecific)



2023



Data deposit at the end of the data life cycle





Benefits of SWISSUbase

- >General and discipline-specific metadata
- >Multilingual user interface (EN, FR, DE)
- >Personal support & consultation services
- >Data curation by data experts
- >Data hosted on Swiss servers (SWITCH)
- >Free for researchers (!)





Compliance with International Standards

Data











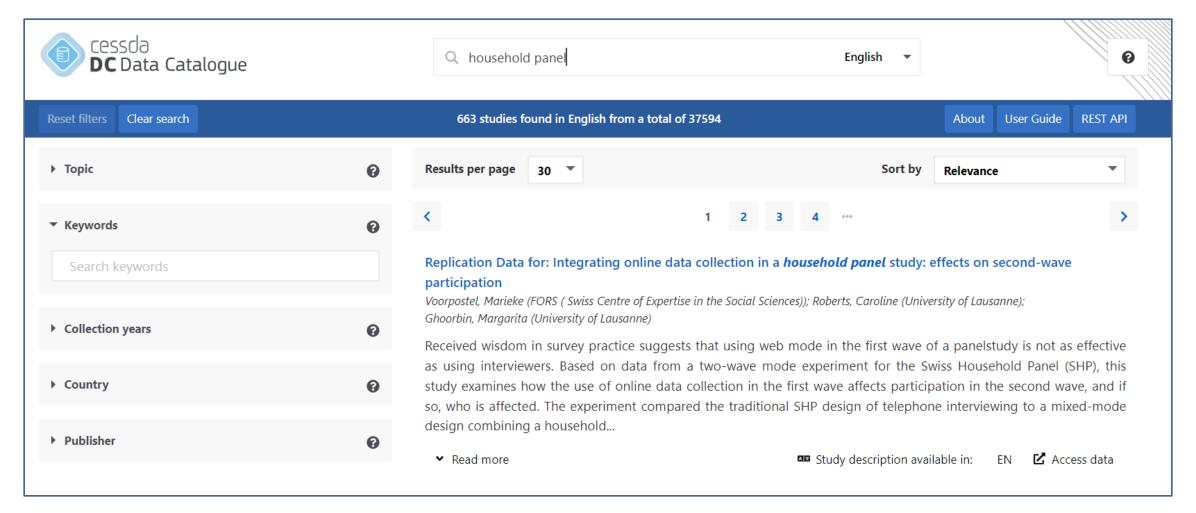








Metadata from SWISSUbase is harvested by CESSDA Data Catalogue





What makes SWISSUbase unique?

> Rich metadata









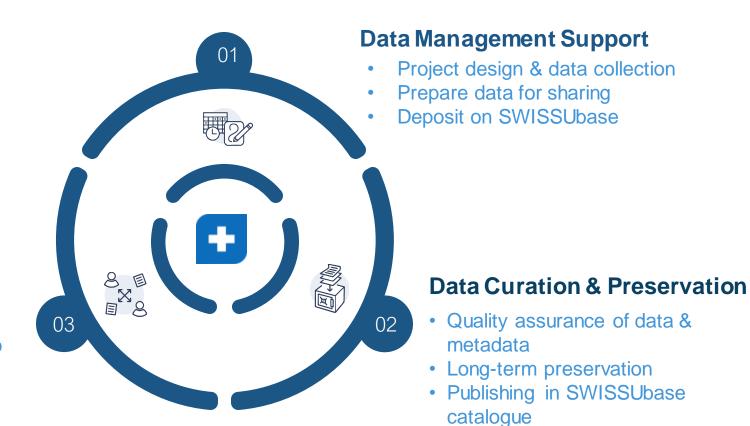
Network of Data Service Units



- > FORS Data Service: Social sciences all CH
- > LaRS (Language Repository of Switzerland): Linguistics all CH
- > UNIL Data Service: Across 7 UNIL faculties
- > UNINE Data Service: Across 4 UNINE faculties



Support services across the research data lifecycle



Data Access & Reuse

 How to access & reuse to datasets and project descriptions









How can SWISSUbase help me respect data protection requirements?

Storage & physical security









Storage & Physical Security

- > Infrastructure and Storage: Swiss servers (SWITCH) compliance with SDPA & GDPR
- > Encryption: currently not offered by SWITCH, but on the roadmap for 2024
- > Role-based access control: authentification with SWITCH Edu-ID to ensure affiliation with Swiss higher education institution
- > Physical security of office and personal computers: everyone's responsibility!









Trust & Identity



Network



Infrastructure & Data Services



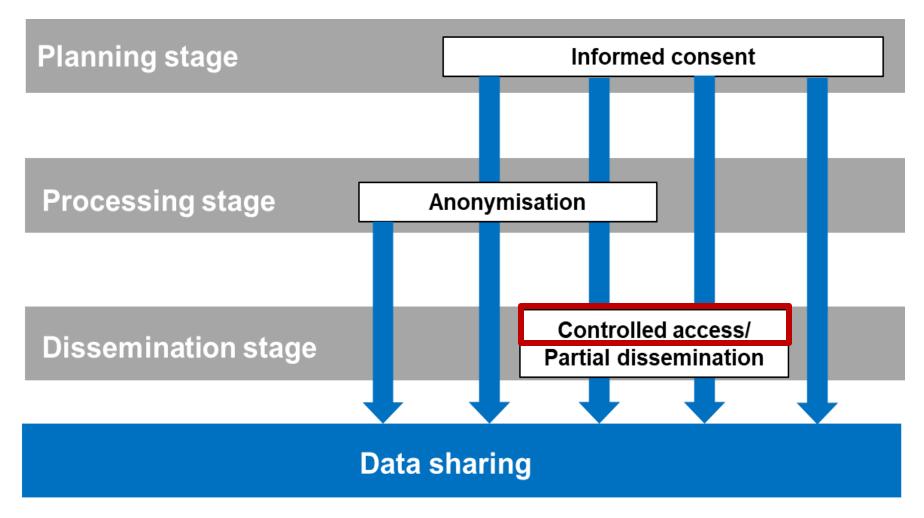
Digital Solutions & Coordination



Autres



Sharing sensitive data in a secure way



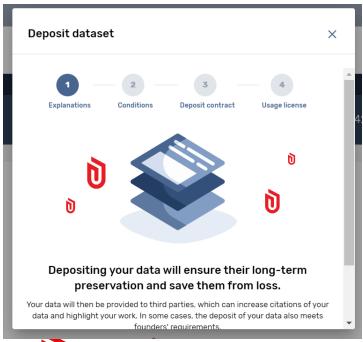
Source: FORS Data Management Support team.



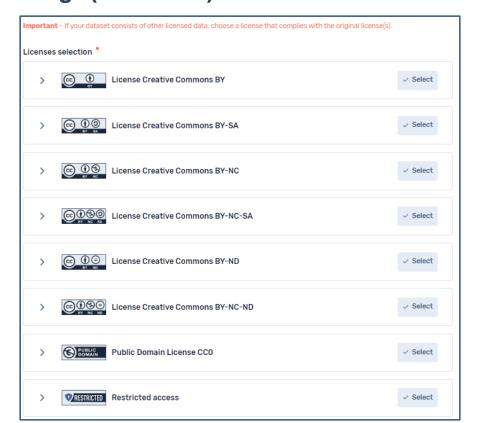
Sharing data in a secure way with SWISSUbase

- > All data types can be shareable! (e.g. qualitative, quantitative, sensitive)
- > Even sensitive data can be shared, but with restrictions and controlled access
- > Keep control of your data: Usage license selection (Open & Restricted) based on data type

Deposit contract – for data depositor

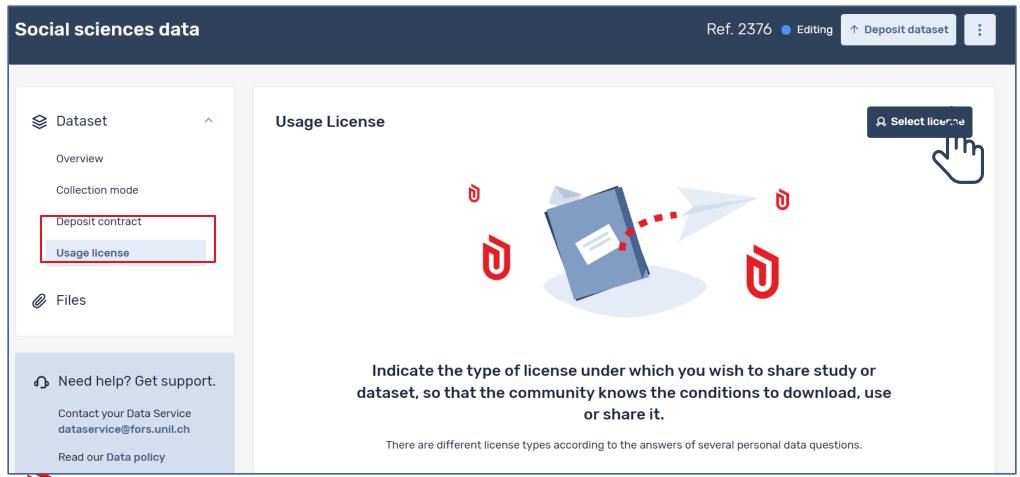


Usage (download) license – for data user



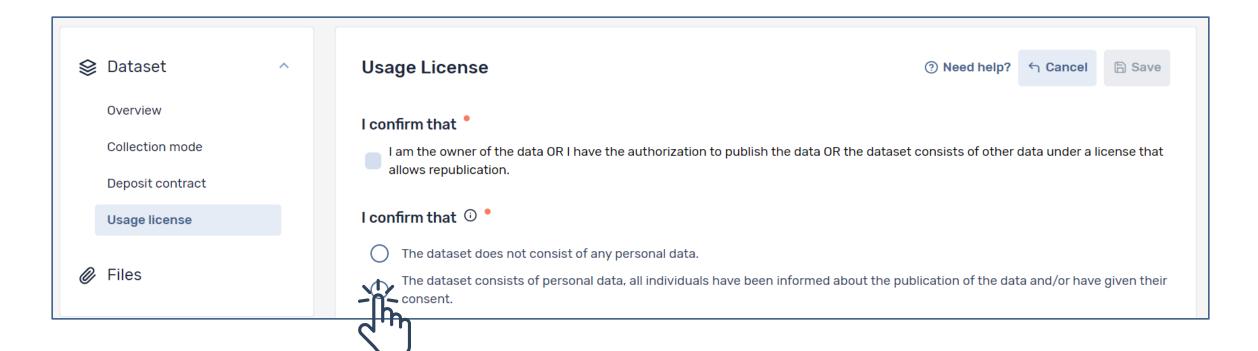


Step 1. Select a usage license for each dataset – to specify conditions of download & use





Step 2. Confirm data ownership and informed consent of participants if the dataset contains personal data







Step 3a. Select the license for sharing & access control

Usage license types:

- >Open licenses: open access for download and use
- >Restricted licenses: access and use conditions defined by each Data Service Unit
- >Special (restricted) licences: licences for specific cases / datasets, access and use defined by the Data Service Unit





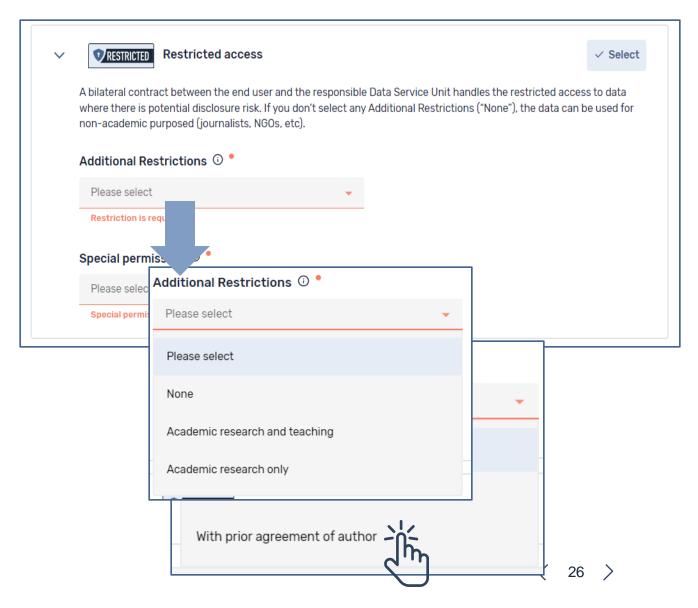


Step 3b. Restricted license – additional options

Additional restrictions:

- > Additional restrictions on usage
- Special permission: Prior agreement of data producer
- > Embargo (metadata can be published, data under embargo)

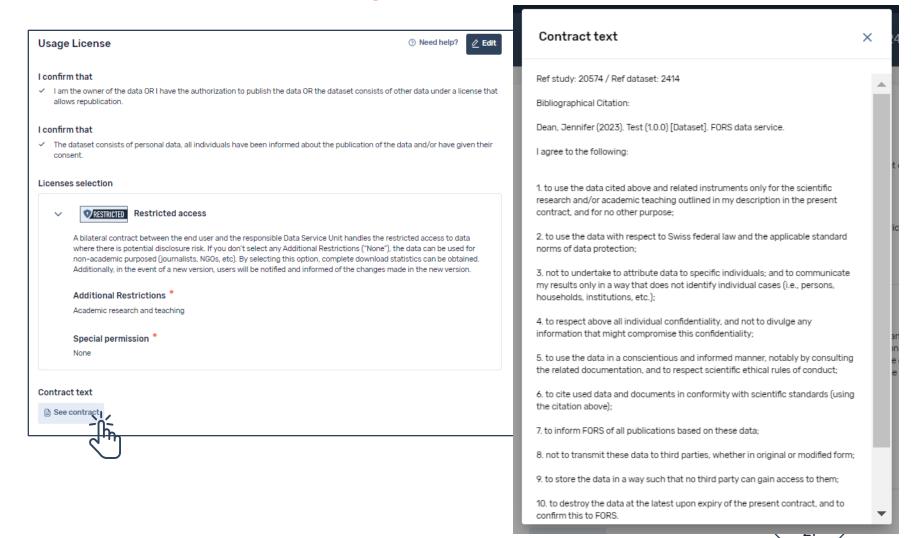
"As Open as possible, as Restricted as necessary."







Step 4. Review the usage license text





Data consumer view: 1a. Restricted license - User request and download

All datasets

ARef. Nr. Dataset title Data access

2415 Données anonymisées pour SWISSUbase Restricted

Données anonymisées pour SWISSUbase Ref. 2415 \(\precedet \) Start download Download dataset **Dataset Overview** Dataset Dataset title Overview **Explanations** usage details DOMINOAU CONTRACT Curation Données anonymisées pour SWISSUbase Collection mode Usage license DOI https://proxy.mock/99.0000/SUB-DOI-MOCK Files D **Dataset description language** French Accept the Download contract in order to access the data.



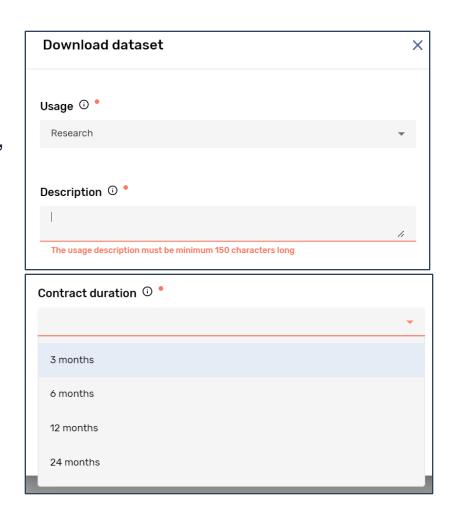
If you conduct secondary analyses of the downloaded data, please cite the data properly to give due credit to the data producers and to increase the reproducibility and discoverability of your research.



1b. Restricted license - User request and download

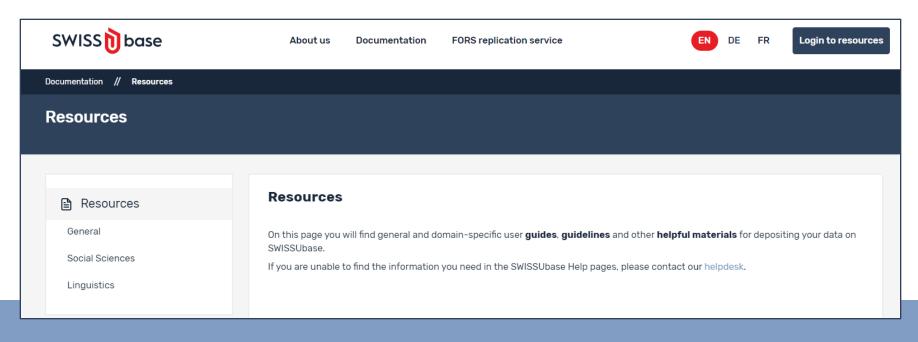
If a user requests to download a restricted dataset, they must:

- 1) Describe the intended use
- Select a contract duration for limited time use of the data (3, 6, 12, 24 months)
- 3) Read and accept the download contract
- **After the contract expiration, the data user can**:
 - > Extend the data use agreement
 - End the data use agreement ("terminate contract")
 - → Contract termination MUST destroy all copies of data files and confirm deletion





SWISSUbase online resources www.resources.swissubase.ch



- General: https://resources.swissubase.ch/help/guide-utilisation/general/
- Linguistics: https://resources.swissubase.ch/help/user-guide/linguistics/
- Social sciences: https://resources.swissubase.ch/help/user-guide/social-sciences/

YouTube – Information & Tutorials: www.youtube.com/@swissubase1824





We are here to support you...

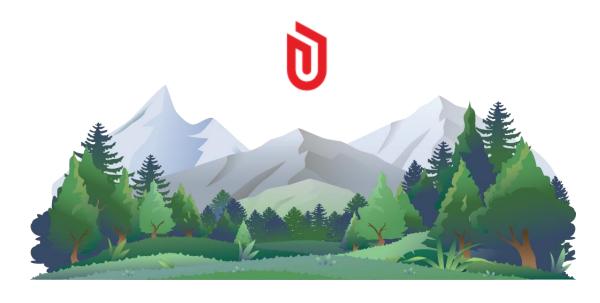
In case of any doubts, contact your local Data Service Unit!

- > FORS Data Service: <u>Dataservice@fors.unil.ch</u> (Social sciences in CH)
- > LaRS (Language Repository of Switzerland): swissubase@ub.uzh.ch (Linguistics in CH)
- > UNIL Data Service: researchdata@unil.ch (All UNIL faculties)
- > UNINE Data Service: contact.ord@unine.ch (All UNINE faculties)





Share and preserve your data for the future.



SHARE & PRESERVE.



Thank you!

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FORS Replication Service

The new FORS service dedicated to replication materials

Emilie Morgan de Paula 12 September 2023

Presentation outline

- About replication
- About FORS Replication service









About replication







Background and definition

- Replication is part of the general movement towards open science and greater transparency in research
- Replication is the «purposeful repetition of previous research to corroborate or disconfirm the previous results» (Maket and Plucker, 2014: p. 2)
- Replication has received increased attention in the social sciences
 - Doubts on scientific research, in particular in psychology and economics
 - Replication crisis in the 2010s









Replication as an opportunity

- Providing access to the data and code ensures that the results can be verified.
- Validation of the work done brings scientific credibility and evidence.
- The code also contains a lot of information about how to make methodological progress.
- The shared data and materials can be used to conduct other projects.
- Good reproducibility habits are not only a moral responsibility to the field and a core principle of scientific progress, they can also be a timesaver in the long term.









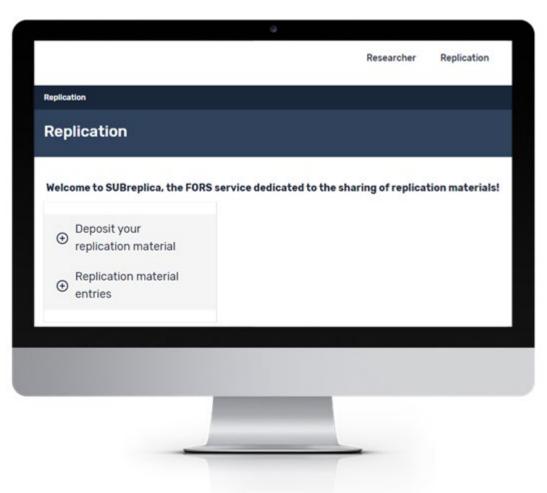
About FORS Replication Service







What is FORS Replication Service for?



- It is a tool for the dissemination of replication materials related to publications.
- It enables uploading replication materials and obtaining a DOI.
- It provides access to scientific journals or any other interested people to replication materials.

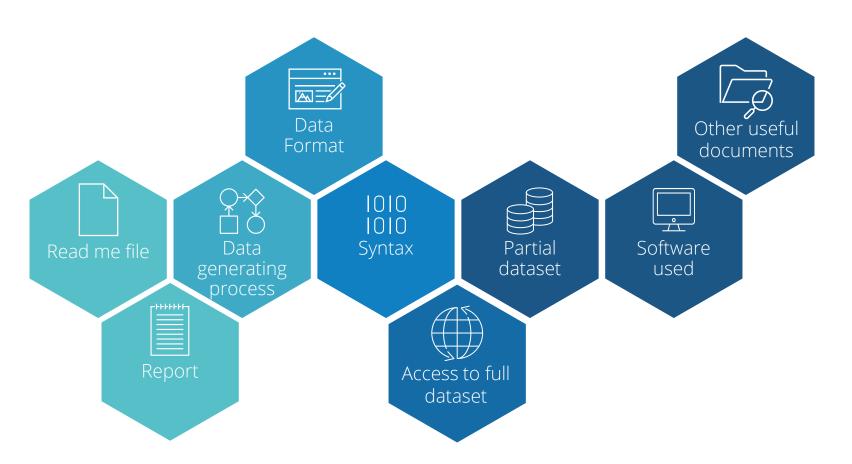








Which replication materials and related information can be shared?











How does the FORS Replication Service work?

The deposit of replication materials

Once the replication materials are ready for sharing, it is very easy to proceed with their deposit on the platform <u>FORS Replication Service</u> (https://resources.swissubase.ch/replication/)



Download

Click on «Deposit your replication material» and download the deposit form

- Deposit your
 replication material
- Replication material entries



Complete

Download the deposit form and complete the metadata

Choose

Choose the creative commons license you want your replication material to be under





Send

Send the completed deposit form and all the replication materials to dataservice@fors.unil.ch



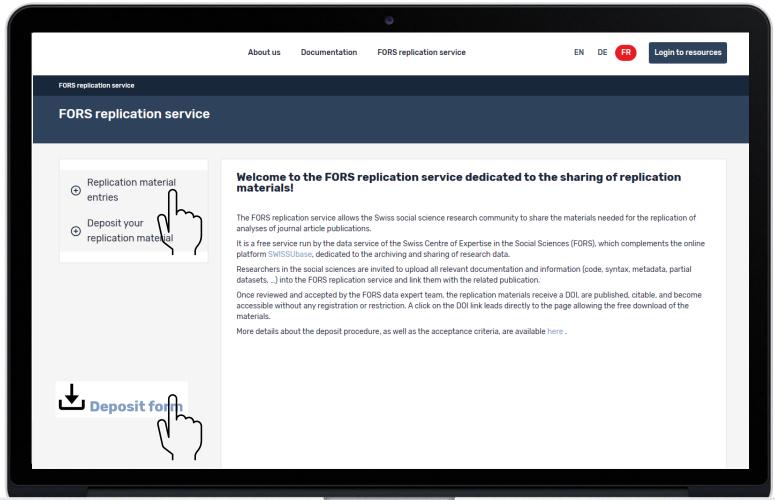






Download the deposit form









Complete the metadata



*Name of the depositor: (Please indicate the full name and contact information of the depositor)

*Affiliation: (Please type in the name(s) of the institution(s) with which the author(s) is (are) affiliated)

*Title - Replication materials for: (Please indicate the full article citation including, if available, DOI)

Subject(s): (Please identify the relevant topics using keywords)

Geolocation: (Please type in the geographic area of study using the most appropriate level)

*Article abstract: (Please provide the abstract of the article or a short description of the article)

*Materials description: (Please list the names of all the provided files (data and documentation). The names should indicate the content of the file, e.g. syntax or report.)

*Source of data: (Please provide access information for the data, link or DOI)

*Software information: (Please type in software and version used for data processing)

Complementary information: (Please add any information that may be helpful and relevant)

*Publication date: (Please type in your desired date of publication of the replication materials in SUBreplica)





Choose a license



Please indicate which Creative Commons license you wish to apply to your replication material:

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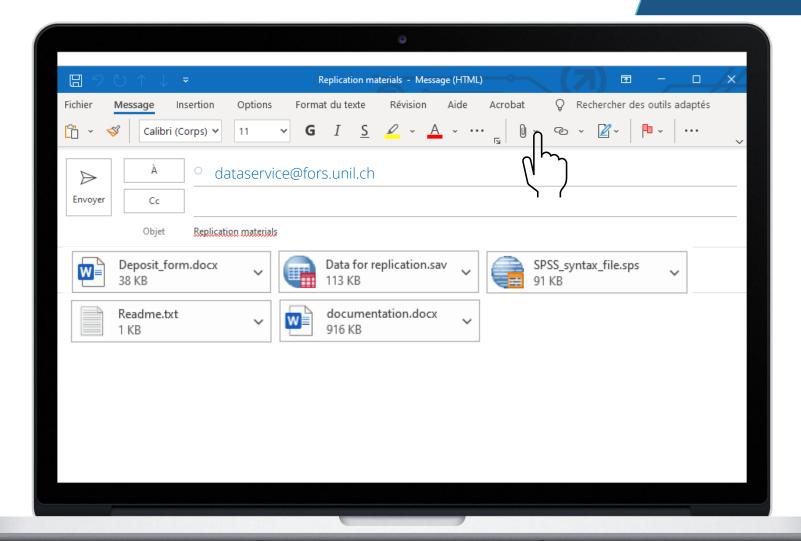






Send the form and the files









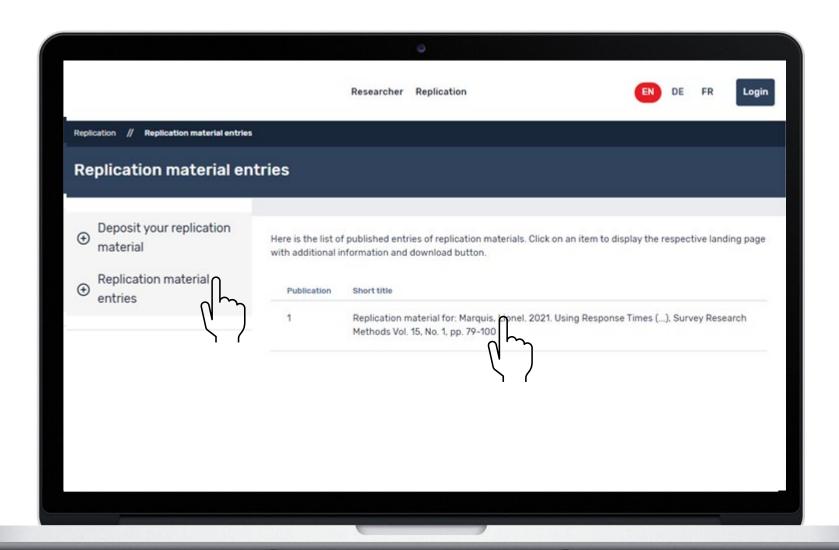
The work of FORS data experts







Download replication materials







Access to published replication material







Any questions?







Further readings and useful resources

- FORS Replication Service (https://resources.swissubase.ch/replication/)
- SwissRN. (2021). The Swiss Reproducibility Network. https://swissrn.org
- Baker, L., Cristea, I. A., Errington, T.M., Jasko, K., Lusoli, W., MacCallum, C. J., Parry, V., Périghon, C., Simko, T., Winchester, C. (2020) Reproducibility of scientific results in the EU Report.
 https://cdn2.euraxess.org/sites/default/files/reproducibility_of_scientific_resluts_in_the_eu.pdf
- Makel, M.C., & Plucker, J. A. (2014). Facts Are More Important Than Novelty: Replication in the Education Sciences. Educational Researcher, 43(6), 304-316. https://doi.org/10.3102%2F0013189X14545513
- Sandve, G.K., Nekrutenko, A., Taylor, J., Hovig, E. (2013). Ten Simple Rules for Reproducible Computational Research. PLoS Comput Biol 9(10): e1003285. https://doi.org/10.1371/journal.pcbi.1003285
- Heers, M. (2021). Replication in the Social Sciences. FORS Guide No. 16, Version 1.0. Lausanne (FORS). http://doi.org/10.24449/FG-2021-00016





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explore.understand.share.



Good Research Practices for reproducible research

Talk at FORS event - 12.9.23

Questions!

1. Out of 100 empirical papers, randomly selected, how many would report ethical approval from an IRB?

2. Out of 100 empirical papers that presented software, randomly selected, how many would make their source code available as supplementary material?

Answers

1. Did the study receive **ethical approval from an IRB? 50%**

2. Is the source **code of the software** shared? → **21**%

Changes in Research Ethics, Openness, and Transparency in Empirical Studies between CHI 2017 and CHI 2022

osf.io/n25d6/





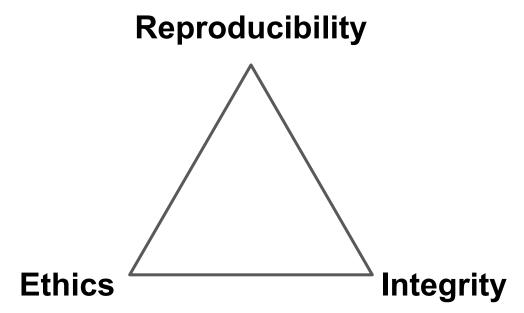
Kavous Salehzadeh Niksirat¹, Lahari Goswami¹, Pooja S. B. Rao¹, James Tyler¹, Alessandro Silacci^{1,2}, Sadiq Aliyu¹, Annika Aebli¹, Chat Wacharamanotham³, Mauro Cherubini¹



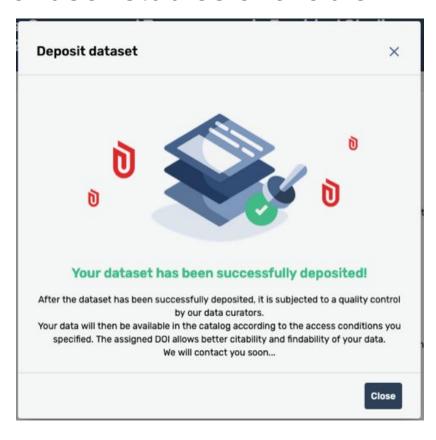




The three pillars of good research



Make datasets of user studies available



Transparency vs. Ethics

Earlier debates in the CHI community: transparency practices and research ethics may be in conflict.

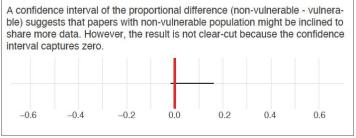
n = 71 paperswithvulnerablepopulation



n = 174 paperswithoutvulnerablepopulation

A weak support for the trade-off between ethics and transparency. Future studies should further investigate this trade-off.



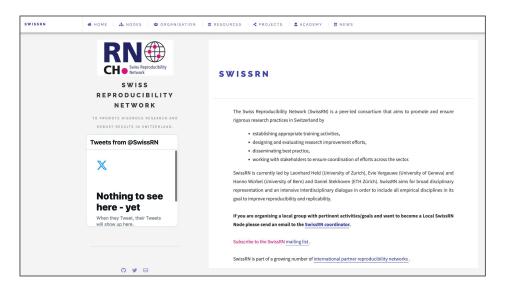


We need training on Good Research Practices



- Update skills and work methodologies
- Learn new technologies
- Adapt to new technological opportunities
- Protect ethics and integrity against new technological threats

We need to create a community of practices



- Good practices are created by the community
- We need to raise awareness and standards

https://www.swissrn.org/

Q&A

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