Informed Consent

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FORS webinar series

1.	Informed consent

2. **Data documentation** / October 11th

3. **Quantitative data anonymisation** / November 1st

4. **Qualitative data anonymisation** / November 22nd

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About FORS

Swiss Centre of Expertise in the Social Sciences

What we do

Infrastructure
Project catalogue, data archiving and dissemination service, support

Data Production
National (SHP, Selects) and international surveys (ESS, MOSAiCH-ISSP, SHARE, EVS)

Research
Thematic, methodological, and epistemological research

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

Development
Cutting-edge tools, data collection, and data linking

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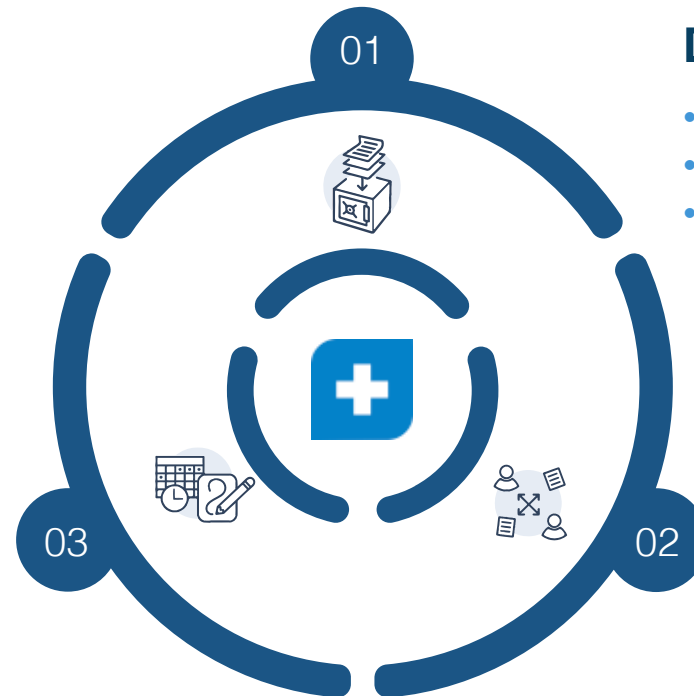
FORS Data Archive

Data Archiving

- New requirements
- Long-term preservation
- Enhance the value of research projects

Data Access

- Direct access to datasets and project descriptions

Data Management Support

- Consultancy
- Trainings
- Guides

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Research ethics

A little bit of history

The history of research is punctuated with "horror stories"

- Nazi doctors experiments

- Tuskegee Study (1932 - 1972)

- Milgram Experiment (1961)

- Stanford Prison Study (1971)

- Laud Humphreys (1960s)

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A little bit of history

The participants in these research / studies / experiments either:

- did not have the **choice** to participate or…

- did not have all the **information** to make up their minds.

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A little bit of history

- When these stories became known, they caused great scandal

- Following these scandals, research ethics became institutionalized (laws, regulations, charters, ethics committees, etc.)

Protecting participants first!

Research ethics aims to **protect the human beings** who take part in scientific research.

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The three pillars of research ethics

The regulation of research ethics is based on three principles:

- **Autonomy** 🔍

- Beneficence & Nonmaleficence

- Justice

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Principle of autonomy

"To respect an autonomous agent is to acknowledge a person's right to make choices, to hold views, and to take actions based on personal values and beliefs"

https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-017-0241-6

It's a matter of **freedom** and **self determination**

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Respecting autonomy through consent

Consent is used to put the concept of autonomy (self-determination) into practice.

To be valid, it must meet **two conditions**:

- Participants should not be **pressured** to participate to a study

  - No hierarchical relationships (students, prisoners, etc.)

  - No excessive compensation (poor people, etc.)

- Participants should receive **all the necessary information**

  - Without knowledge there is no opinion

  - Without opinion there is no consent

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Informed consent

Law and consent

Consent is not just an ethical but also a legal issue (**data protection**).

- Public institutions (such as universities, etc.) generally operate under the principle of **legality** (≠ lawfulness).

- This means that they can only do what is **expressly** permitted, not anything that is not prohibited (-> legal basis).

Law and consent

When it comes to collecting and processing **sensitive data**, consent is often the only legal basis available.

- Cantonal research institutions rarely have an explicit legal basis for the collection of personal data.

- ETH are among the only research institutions in Switzerland with a clear legal basis.

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Law and consent

Moreover, even if there are cases where consent could (theoretically) be dispensed with, **informating people (participants) is always mandatory** when personal data is collected (directly or indirectly)!

It is therefore not necessarily easier or lighter to work without consent.

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Reminder: Personal Data

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Personal data and data protection

- Knowing whether or not you are processing personal data is crucial.

- Processing personal data implies that you have to comply with **data protection** laws and regulations.

- Data protection laws and regulations set out the main frameworks (obligations) for consent.

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Personal data

"All information relating to an identified person" (Art. 3 lit. a FADP)

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

The most common: name, date of birth, home address, phone number, email, IP address, picture, etc.

But also: opinions, original ideas, a style of writing, the way of walking, etc.

Personal data can be "objective" or "subjective"

Examples of personal data

Contact details	Quotes	Picture
First name: Paul Last name: Dupont Phone number: 123456 Email: paul@dupont.ch	"I would like to die on Mars. Just not on impact"	

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.

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Even Anonymous Coders Leave Fingerprints

Researchers have repeatedly shown that writing samples, even those in artificial languages, contain a unique fingerprint that's hard to hide.

RESEARCHERS WHO STUDY stylometry—the statistical analysis of linguistic style—have long known that writing is a unique, individualistic process. The vocabulary you select, your syntax, and your grammatical decisions leave behind a signature. Automated tools can now accurately identify the author of a forum post for example, as long as they have adequate training data to work with. But newer research shows that stylometry can also apply to *artificial* language samples, like code. Software developers, it turns out, leave behind a fingerprint as well.

Rachel Greenstadt, an associate professor of computer science at Drexel University, and Aylin Caliskan, Greenstadt's former PhD student and now an assistant professor at George Washington University, have found that code, like other forms of stylistic expression, are not anonymous. At the DefCon hacking conference Friday, the pair will present a number of studies they've conducted using machine learning techniques to de-anonymize the authors of code samples. Their work, some of which was funded by and conducted in collaboration with the United States Army Research Laboratory, could be useful in a plagiarism dispute, for instance, but also has privacy implications, especially for the thousands of developers who contribute open source code to the world.

Sensitive data

Personal data on: religious, ideological, political or trade-union related views or activities; health, the intimate sphere or the racial origin; social security measures; administrative or criminal proceedings and sanctions (Art3. lit. c FADP)

The list provided by FADP is **exhaustive** (e.g. in Switzerland salary is not considered sensitive data)

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

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Examples of sensitive data

Contact details	Quote	Picture
First name: Pedro Last name: Ruiz Gender: Trans Job: Trade-Unionist	"We are now in the process of defeating the radical left, the Marxists, the anarchists, the agitators, the looters, and people who, in many instances, have absolutely no clue what they are doing"	

Sensitive data (?)

Sensitive data (?)

Consent and data protection

How to ensure that the consent is valid?

Regarding the form of consent:

- Consent may be: **oral** or **written**

  - This said, it's always useful to have proof
  - For HRA research, consent must be written

- Where **sensitive** data is involved, consent must be **explicit**

  - Simply answering a questionnaire, for example, cannot be considered as consent.

Procedural VS processual consent

- Consent is often understood in a **procedural** way. It usually consists of a document signed at the beginning of the research.

- This said, some researchers (e.g. **anthropologists**) may find it difficult to present research subjects with a complete description of their research design at the beginning of the research process.

Procedural VS processual consent

- People may forget the status of a researcher who is present for a long time.

- People do not always know what they are going to say in an interview (and therefore what they are committing to).

- Consent can be collected at several points in the life cycle of the research project.

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What information should be provided?

- The **identity** of the researchers in charge of the project

- **Understandable** statements describing the purpose of the research, the nature and duration of participation, and the research methods.

- A **clear description** of the foreseeable risks and benefits of participation

- The **nature** of the data collected and its usefulness

- An **honest and complete description** of the protection/security measures

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What information should be provided II ?

- The guarantee of being **free to decide** not to participate in the project, to withdraw without losing acquired rights and to have the possibility at any time to continue or not to participate

- Contracts with/disclosure to **third parties** (list)

- The right to **access** and **rectify** data

- The existence of any **conflict of interest**

- **Preservation** and **reuse** of data

- The possibility of being informed of the **results**

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Assessing Consent Form Statements

All information gathered will be totally anonymised, dealt with in the strictest of confidence and used at an aggregated level.

What is 'totally anonymised', what do we mean when we say, 'strictest of confidence'. Best practice is to be clear with participants what steps will be taken to anonymise the data and how confidence is proposed to be maintained.

BE DESCRIPTIVE !

Make lists of the direct and indirect identifiers you are going to delete and don't make false promises (anonymity being very difficult to achieve).

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Assessing Consent Form Statements

This project adopts an ethnographic approach of the hypothetico-inductive type, using the analytical principles of Grounded Theory. Anthropology has developed an expertise in the in-depth qualitative study of the environment of small communities and the knowledge, practices and meanings of their surroundings. Its method - ethnography – consists of conducting "research and writing about groups of people by systematically observing and participating (to a greater or lesser degree) in the lives of the people they study.

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Assessing Consent quality

- A professor uses his/her students as participants in a research project. Participation in the study is rewarded with 3 ECTS credits.

- A researcher gets recruited as an intern in a company in order to study it.

- A researcher pays students 1'000 CHF to participate in a research project.

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Covert observation

- Covert observation is a practice that has often been used in sociology/anthropology.

- It is seen as a method of gaining access to things that one would not otherwise have access to.

- Yet it is legally prohibited when processing personal data

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Deception

"Deception is when a researcher gives false information to subjects or intentionally misleads them about some key aspect of the research. This could include feedback to subjects that involves creating false beliefs about oneself, one's relationship, or manipulation of one's self-concept. Incomplete Disclosure is a type of deception that involves withholding some information about the real purpose of the study, or the nature of the research procedures"

https://research.oregonstate.edu/irb/research-involving-deception#_ftn3

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Is deception equal to covert observation ?

- When using deception, people still know they are participating in a research project

- People are aware they are giving personal data for research

- The research purpose is globally understood

- There generally is a debriefing (after a short experiment)

- Deception is (legally) more acceptable than covert observation

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Some consent form examples

https://swissethics.ch/en/templates/studieninformationen-und-einwilligungen

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Questions ?