



# The informed consent as legal and ethical basis of research data production

Sybil Krügel<sup>1</sup>

<sup>1</sup> FORS

## WARNING:

This guide contains outdated information and is no longer up to date.  
The laws, regulations, or practices referenced may have changed.  
A revision is underway and will be released soon.

FORS Guide No. 05, Version 1.1

January 2019

**Abstract:**

The trend toward and the obligation for sharing and long-term preservation of research data is in conflict with increasingly restrictive data protection legislation and practices on personal data in Europe, such as the General Data Protection Regulation (GDPR). Qualitative research data, in particular, often cannot be completely de-identified without compromising the usability of the data. In consequence, the informed consent plays a crucial role in forming the basis of ethical and legal research to allow for the processing (collecting, storing, re-use) of data collected at considerable expense. This guide is concerned with the definition of the concept, the legislation governing it, and the best practices for drafting and obtaining informed consent from a social science perspective.

**Keywords:** data protection, personal data, legal framework, social sciences

**How to cite:**

Kruegel, S. (2019). The informed consent as legal and ethical basis of research data production. *FORS Guides*, 5, Version 1.1, 1-14. <https://doi.org/10.24449/FG-2019-00005>

**The FORS Guides to survey methods and data management**

The [FORS Guides](#) offer support to researchers and students in the social sciences who intend to collect data, as well as to teachers at university level who want to teach their students the basics of survey methods and data management. Written by experts from inside and outside of FORS, the FORS Guides are descriptive papers that summarise practical knowledge concerning survey methods and data management. They give a general overview without claiming to be exhaustive. Considering the Swiss context, the FORS Guides can be especially helpful for researchers working in Switzerland or with Swiss data.

**Editor:**

FORS, Géopolis, CH-1015 Lausanne  
[www.forscenter.ch/fors-guides](http://www.forscenter.ch/fors-guides)  
Contact: [info@forscenter.ch](mailto:info@forscenter.ch)

**Copyright:**

*Creative Commons: Attribution CC BY 4.0.* The content under the Creative Commons license may be used by third parties under the following conditions defined by the authors: You may share, copy, freely use and distribute the material in any form, provided that the authorship is mentioned.

## 1. INTRODUCTION – DATA PROTECTION AND DATA SHARING AS BEST PRACTICE

The social sciences in Europe have in recent years increasingly been caught in an area of tension between the trend to open research data and tightening legal restrictions. On the one hand, there is the promotion of Open Research Data (SNSF, 2017a) and Findable, Accessible, Interoperable and Re-usable Data (FAIR) (SNSF, 2017b), and the introduction of the mandatory Data Management Plan (DMP) by the Swiss National Science Foundation (SNSF) in autumn 2017 (SNSF, 2017c) resulting in a tightening of the requirements to store and share research data in Switzerland.<sup>1</sup> On the other hand, there is the enactment of more restrictive data protection legislation, such as the European General Data Protection Regulation (GDPR) to which Switzerland is partially subject by the rule of extraterritoriality.

At the heart of the issue of sharing research data is the balancing of future data usability and analytical potential, on the one hand, and the protection of participants from unauthorised identification, disclosure, and potential ensuing damage, on the other. The informed consent aims at regulating these conflicting pursuits in order to make data accessible and usable in the long-term while at the same providing for the legal and ethical protection of participants, as well as of researchers themselves.

This FORS Guide clarifies the term informed consent, the legal regulations to which it is subject, and its relevance for research. Furthermore, best practices for drafting and obtaining informed consent primarily within the existing legal framework are presented and discussed.<sup>2</sup>

## 2. DEFINITIONS AND LEGAL REGULATIONS OF DATA PROTECTION AND INFORMED CONSENT

### 2.1 PERSONAL DATA AND CONSENT

The protection of personal data is considered a fundamental right already in the European Convention on Human Rights of 1950 where it is stated that “the mere storing of data relating to the private life of an individual amounts to an interference...” (ECHR, 2018). Such data must therefore be processed in a way that avoids damage to the person concerned. The Charter of Fundamental Rights of the European Union of 2000 regulates the processing of these data on the basis of the *consent* of the person concerned (Charter, 2000, title 2, art. 8). The European General Data Protection Regulation (GDPR), which aims at giving people more control over their data, defines personal data as “any information relating to an identified or identifiable natural person (‘data subject’)” (GDPR, art. 4§1) such as e.g. names, addresses, identification numbers, online identifiers, genetic identity, etc.. This includes direct identifiers as well as pseudonymised data, but excludes

---

<sup>1</sup> For the data management plan see also CESSDA ERIC (2018).

<sup>2</sup> For ethical questions in research data production see Diaz (2019).

anonymised data.<sup>3</sup> *Sensitive data* is a special category of personal data “revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, [...] and genetic and biometric and health data as well as data concerning a natural person’s sex life or sexual orientation” (GDPR, art. 9§1). Sensitive data are subject to even more restrictive regulations concerning their processing (i.e. collecting, depositing in repositories, and dissemination for re-use).<sup>4</sup> Anonymised data fall outside of the scope of the GDPR, since anonymised data are not considered personal data if the disclosure risk is non-existent or minimal. Their processing therefore also does not require an informed consent.

The GDPR prohibits, with various exemptions, for example scientific research and archiving in the public interest<sup>5</sup> all processing of unanonymised<sup>6</sup> personal data without the *consent* of the person concerned (‘data subject’) (GDPR, art. 6§1,a) and thereby increases the accountability of the researcher. It defines the concept of “informed consent” as follows: “‘consent’ of the data subject means any freely given, specific, informed and unambiguous indication of the data subject’s wishes by which he or she, by a statement or by a clear affirmative action, signifies agreement to the processing of personal data relating to him or her” (GDPR, art. 4§11). The Consortium of European Social Science Data Archives (CESSDA) relates a narrower, more research-specific definition: “Informed consent is the process by which a researcher discloses appropriate information about the research so that a participant may make a voluntary, informed choice to accept or refuse to cooperate” (CESSDA ERIC, 2017) with the processing of the data.

The adequate informing of participants lays the groundwork for legal and ethical research that ideally allows for depositing/archiving in a repository and re-use of the collected data (see Diaz, 2019). Trust and a confidential relationship between the data collector and the participant are crucial, and the informing of the participant should ideally include transparency about the future use of the data.

In any event, to reduce the disclosure risk and the ethical and legal challenges to researchers, special consideration in the drafting of collection instruments should be given to the *minimisation of the data collection* (GDPR, art. 5§1) or the principle of proportionality (as little information as possible and as much as strictly required for the research aim).

## 2.2 SWISS DATA PROTECTION LEGISLATION IN TRANSITION

In Switzerland, the processing of personal data is currently governed by the Federal Data Protection Act (DPA) of 19<sup>th</sup> June 1992, together with the Federal Data Protection

---

<sup>3</sup> GDPR, art. 4§5 defines pseudonymisation as “processing of personal data in such a manner that the personal data can no longer be attributed to a specific data subject without the use of additional information...” while anonymised data is considered irreversibly de-identified. See for example RatSWD (2017, p. 14.)

<sup>4</sup> GDPR, art. 9; see also Federal Act on Research involving Human Beings (Human Research Act, HRA) of 30<sup>th</sup> September 2011.

<sup>5</sup> See for example GDPR, art. 6§1,e: Lawfulness of processing “processing is necessary for the performance of a task carried out in the public interest...” *ibid.* art. 17§3,d: “exemptions from erasing personal data “for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes”.

<sup>6</sup> There are different degrees of anonymisation: absolute anonymisation which renders the identification of the respondent with current technical means impossible, factual anonymisation which allows for identification only with disproportionate means, and formal anonymisation which is restricted to removing direct identifiers and therefore does not fully qualify as anonymised, see RatSWD (2017, p.14f.), see also Finnish Social Science Data Archive (2017b).

Ordinance (DPO) of 14<sup>th</sup> June 1993,<sup>7</sup> and, for certain health-related personal data, the Federal Act on Research involving Human Beings (Human Research Act, HRA) of 30<sup>th</sup> September 2011, as well the various cantonal data protection legislations. As a result of the enactment of the European GDPR in May 2018, a revision of Swiss legislation is required to align with the European legislative framework. As the new Swiss regulations are still under deliberation (as of December 2018), we here refer to the GDPR, which has already become effective and to which Switzerland is partially subject by the rule of extraterritoriality (GDPR, art. 3, Territorial scope). In consequence research carried out in Switzerland needs to be compliant with the GDPR under certain conditions.<sup>8</sup>

### 3. BEST PRACTICES FOR INFORMED CONSENT

#### 3.1 SPECTRUM OF INFORMED CONSENT PRACTICES AND THEIR UNDERLYING FACTORS

There is a wide range of practices of informed consent, from highly formal, explicit, comprehensive written consent, to less formal, oral, opt-in, or even implicit or tacit modes of consenting (note that the GDPR requires an explicit consent, see above 2.1.). Factors that may determine the form of consent include: the sampling methods; the type of data collected (quantitative or qualitative); the time method; the media of the data collection (e.g. audio-visual data, etc.); the nature of the population of respondents (e.g. vulnerable or marginalised groups, underage persons); the sensitivity of the data generated; the future intended use and re-use of the data, and, most importantly, the disclosure risk associated with the data production and re-use.

Qualitative research tends to involve sensitive areas and processes of society that often necessitate more direct access to and intensive interaction with respondents, benefiting from an established relationship of trust between the researcher and the respondent such that the data produced tend to be more context-sensitive. Full anonymisation, so as to exclude disclosure risk completely, is an ideal that rarely matches the reality of the qualitative data collection, far less than is the case with quantitative data. Not only is the risk of violation of privacy more probable with, for example, in-depth interviews, the collected data usually contain a density of information on the participants, most notably with video, audio, or image data, and therefore carry considerable disclosure risk. Furthermore, de-identifying of qualitative data is complex and costly and might result in reduced usability of the data (e.g. a video-recorded interview in which the face is pixelated and the voice altered, and therefore mimics and voice modulation are largely lost to secondary analysis). In sum, it is often the case that qualitative data cannot be fully anonymised or sufficiently pseudonymised without compromising their analytical potential for secondary analysis.<sup>9</sup>

---

<sup>7</sup> For an overview over the Swiss data protection legislations see Stauffacher and Bader (2018).

<sup>8</sup> Data processed or controlled by physical persons *established* in the EU regardless of whether the processing takes place on the territory of the EU and data that relates to physical persons in the EU even if the processor is established outside of the EU are subject to the GDPR if among other factors services are offered to persons within the EU.

<sup>9</sup> For a discussion on the potential of secondary analysis of qualitative data see Bambey, Meyermann, and Prozelts (2017), RatSWD (2015) and UK Data Service (2017b).

Quantitative data, on the other hand, are easier to anonymise and the process is less costly and time-consuming. Further, the disclosure risk and the risk of compromising analytical potential and data usability by de-contextualisation is considered lower.

Mainly with respect to qualitative data, best practice in de-identifying has not yet been firmly established in the social science research community. Thus, to make up for these current inadequacies and to protect participants, as well as to comply with data protection legislation and assure long-term preservation of the data, it is recommended to seek a more formalised informed consent from participants in qualitative research.<sup>10</sup> This is treated in the following sections.

### 3.2 FORMS OF CONSENT

As quantitative data are easier to de-identify and can more easily be disseminated in anonymised form, the consent sought from respondents is often less formal and in some cases amounts to an *implicit* or *tacit* consent by virtue of participation. This practice is often preceded by an invitation or information sheet that contains at an absolute minimum the following information: the aim of the survey; the persons/institutions responsible for the data collection and processing; the procedure for safeguarding personal information and maintaining confidentiality; the voluntary nature of the participation; and, importantly, a specification of the future use of the data. It is recommended, however, even with a less formal consent procedure, to precede the actual data collection (e.g. a web-based questionnaire) with an explicit consent, for example an active opt-in method, or an introductory phrase indicating voluntary, informed participation (note that the GDPR prohibits pre-checked boxes).

For more sensitive data or data with a higher disclosure risk, a more formal, comprehensive consent and information process is required, either in written or in oral form.<sup>11</sup> The written consent accords more legal protection to the researcher and the participant, whereas the oral consent may be more convenient to implement, especially for populations that might be reluctant to sign paper forms. Nonetheless, the oral consent needs to be recorded in some form and preserved (GDPR, Recital 42). In any event, all information given to the participant, including the written and oral information, should be carefully documented by the researcher.

Note that children under 16 years of age cannot consent to participating, and collecting their personal data is only lawful if authorised by the holder of parental responsibility over the child according to the GDPR (GDPR, art. 8§1). Yet, children under 16 can themselves withdraw consent to the continued use of their personal data.

### 3.3 INFORMATION GIVEN TO THE PARTICIPANT

To allow potential participants to understand the purpose of the research project and the risks and benefits involved, and to enable them to consent in an informed manner, information on the project has to be made available to them. In a more formalised consent procedure this is ideally done in written form which should enable the participants to make an informed decision *prior* to consenting to participating and agreeing to the informed consent. In a less formalised procedure this information can be more briefly conveyed, for

---

<sup>10</sup> For examples of consent forms see UK Data Service (2017a) and UK Data Archive (2018).

<sup>11</sup> GDPR, art. 7, exceptions are some health-related personal data, see above.

example in an invitation letter to participate in a survey. Depending on the circumstances of the research setting it can also be done orally or on the consent form itself. This information conveyed to the participants prior to the signing of the informed consent should include at the very least: a description of the research project and its purposes, the names of the responsible persons, the process for withdrawing, as well as the strategy deployed to secure confidentiality and the further intended use of the data (for more details see 4. The informed consent in a nutshell: recommendations). When *sensitive* data are collected, the information conveyed to the participant as well as the consent for some health-related personal data need to be in written form. The consent for health-related data needs to specify in detail the future use of the data at the time of the data collection (see for example HRA, art. 7, art. 16-17).

### 3.4 EXTENT OF THE CONSENT

A crucial part of the informed consent that is likely to affect a participant's reaction is the specification of the extent of future use of the data ranging from a restricted use by the primary research team to a wider sharing, for example the deposit in a repository and the formal dissemination of research data:

- *Specific use* expressly restricts the use of the data to the processing and publication by the primary research team. This low-threshold option is easily available and frequently utilised, yet it constitutes an obstacle to depositing the data in a repository, wider data sharing, and replication.
- *Extended use*, also frequently employed, restricts the re-use and sharing vaguely to further research projects linked on a formal or informal basis to the primary research team. It has the same disadvantages as the specific use consent.
- *Unspecified use*,<sup>12</sup> a concept similar to the *broad consent*, relates to any future use limited to scientific research purposes with specific access conditions. These consent forms allow for depositing in a repository and more formal dissemination of the data for secondary analysis. Yet, depending on the nature of the data collected and the population, participants might not be inclined to agree to such a broad and unspecified consent.

*Granular consent forms* are currently widely used and have the advantage of offering to the participant several options for the future use of the data to choose from. Options range from the processing by the primary research team, unanonymised sharing, pseudo-nymised or de-identified wider sharing, formal deposit in a repository (archiving), to formal dissemination for scientific research purposes with a data user agreement. The disadvantages of this form of consent are obviously that the participants might tend to check a restricted further use of the data. Also, this can result in complicated access conditions that vary across participants and that are difficult to manage.

If applicable and realistic, *specific* and *extended* uses should be avoided since they limit the further use of the data for research purposes. The aim should not only be to protect the participant's rights, but to make available the collected data to a wider scientific use beyond the primary research project. Therefore it is often not possible to fully identify all future use for scientific research purposes at the time of data collection (GDPR, Recital 33).

---

<sup>12</sup> For some examples see Universiteit Utrecht (n.d.).

The form of consent proposed here, if commensurate with the nature of the data, should ideally employ a *broad* or *unspecified consent* that allows for unspecified further scientific use of the data beyond the primary research project when in keeping with the recognised ethical standards for scientific research (see Diaz, 2019), and for archiving and disseminating the data for research purposes.

Consents that propose a wider dissemination and re-use of data should elaborate on the data protection measures taken and on potential access conditions such as the following:

- Data only accessible with a data protection contract that obliges all users not to undertake any measures to identify the respondent (strongly recommended)
- Prior approval from the primary research team before any dissemination to other parties for secondary analysis,
- Embargoes that delay the dissemination of the data for a specified period to protect the respondent (and also give the primary research team time to fully exploit the collected data before it is made available for secondary analysis). The embargo period should not exceed two years, however, as the data could rapidly become outdated.

### 3.5 TIMING OF THE INFORMED CONSENT

Generally, data protection measures should start as early as possible in the data life cycle, preferably when drafting the data management plan and prior to the drafting of collection instruments. The informed consent can be sought prior to the participants' contribution, as is usually recommended, or, alternatively, immediately after the participants' contribution (e.g. at the end of an interview). Obtaining consent after a contribution has the advantage that the participant knows the information divulged, and the consent can therefore be considered more informed. The latter timing might be best suited for the collection of sensitive data and vulnerable populations. Ideally, if applicable, there is an initial consent to participation and a final consent after the participant has been given the occasion to review his contribution (e.g. the transcript of the interview).

In cases where no consent has been sought or the consent gained at the time of the data collection is too restrictive to allow for data sharing, retrospectively seeking consent, after the completion of the research project, is considered permissible. Yet, it might prove difficult to re-contact participants who might be less likely at this point to consent to the further use of their data. The *retrospective consent* is therefore less practical and effective.

If the opportunity to gain retrospective consent is not feasible, sharing and re-use of the data collected is legally permissible under certain circumstances, specifically if the original consent or the information conveyed at the time of the data collection does not explicitly preclude sharing, if no harm to participants is to be expected, and if the data are sufficiently anonymized (Universiteit Utrecht, n.d.). However, the re-use of data without consent might only be possible after a careful case-by-case assessment and a thorough weighing of the associated risks and potential harm to the participants of the completed research project.

### 3.6 LANGUAGE OF THE CONSENT

The consent should as much as possible be formulated to match the respective participant's or population's ability to provide an informed consent, enabling the participant, most often a layperson, to understand the implications of the processing and sharing of



her/his data. The consent should ideally be worded in comprehensible form, using clear, plain and unambiguous language (GDPR, art.7§2).

### 3.7 WITHDRAWAL FROM PARTICIPATION OR CONSENT

Participants have the right to withdraw from participation and the consent at all times without stating the reasons, but withdrawals from participation and consent are two separate processes with differing implications for the preservation of the data:

- a. Withdrawal from participation results in the participant not continuing in the data collection, but the data already collected prior to the withdrawal will remain unchanged,
- b. Withdrawal from the consent, however, requires a removal of the personal data of the respective participant, the data collected prior to the withdrawal remaining legal insofar as these cannot be linked to the participant (GDPR, art. 7§3).<sup>13</sup>

## 4. THE INFORMED CONSENT IN A NUTSHELL: RECOMMENDATIONS

*Recommendation 1* – The adequate informing of participants in research data production and their consent to participation and the further use of the data lays the groundwork for legal and ethical research.

*Recommendation 2* – As the Swiss data protection legislations are currently being revised and the European General Data Protection Regulation (GDPR, art. 3, Territorial scope) extends by the rule of extraterritoriality to certain cases of Swiss research, if in doubt, chose the stricter standard, which is the GDPR.

*Recommendation 3* – The consent form should contain or be preceded by a procedure of informing the potential respondent of the aim of the research and the risk and benefits of a potential participation.

*Recommendation 4* – There is a wide range of forms that informed consent can take: The sensitivity of the data collected, the disclosure risk and confidentiality, the anonymisation potential, and the respondent population determine the degree of formality of the informed consent procedure and the elaborateness of the information divulged to respondents. As a general rule: The more sensitive the data and the higher the risk of disclosure, the more extended and/or formal the consent and information procedure should be.

*Recommendation 5* – It is good practice to draft consent forms that allow for future scientific use of the data beyond the primary research team. If applicable, use the broad or unspecified consent approach, which allows for long-term preservation in a in a secure environment such as the repository of FORS and unspecified scientific re-use of data in keeping with the recognised ethical standards for scientific research.

*Recommendation 5* – Include in the consent form the procedure followed to protect the identity, confidentiality and the personal data of the participant (anonymization/pseudonymisation, access conditions, user contract, embargo, etc.). Avoid the termino-

---

<sup>13</sup> GDPR, art. 7§3, see also Finnish Social Science Data Archive (2017a).

logies of “fully anonymised” or “strictly confidential”, since these features are hard to achieve in practice.

*Recommendation 6* – Avoid setting an expiration date of the consent, and avoid committing to the destruction of the data after use by the primary research team.

*Recommendation 7* – Best practice consent is sought before and after the data collection.

*Recommendation 8* – Consent can also be sought retrospectively, and in some well-specified cases certain data can be released without consent form.

*Recommendation 9* – The following features constitute the minimal content of information provided to the participant either on the consent form or on a separate information sheet (Universität Zürich, n.d.):

- Research project title, key features and link to project website;
- Names of researchers, affiliated institutions and contact information;
- Short, comprehensive summary of the project aims and purposes
- Benefits, potential risks and disadvantages arising from participation;
- Funding sources, if applicable;
- Implications of participation, e.g. duration of interview;
- Confirmation that the participation is voluntary, that the participant has read and understood the information given and had been given the occasion to ask questions;
- The fact that that the participant has a right to see and correct the personal data;
- Specifications regarding data protection measures (anonymisation, pseudonymisation, etc.) and procedures to secure the confidentiality and protect the personal data of the participant;
- If necessary, the future use of the data, e.g. storing in a secure environment and access for scientific researchers for secondary analysis, conditions of use and access;
- Confirmation that the participant can withdraw from the participation or consent at all times without stating the reasons (best outline these procedures of withdrawal);
- Confirmation that the participant will receive a copy of the consent form;
- Date and signature of both participant and researcher/interviewer.

## 5. TEMPLATE: INFORMED CONSENT

The following template can help you to create your own consent form. Please consider that this template needs to be adapted to the respective research setting, the timing of the consent and the separate information sheet and its content. It also needs to be adapted depending on whether the procedure of an initial and final consent is applied (i.e. the participant is given the occasion to review his contribution), whether a prior agreement of the primary researcher is required for every request for secondary analysis of the data, etc.

## **INFORMED CONSENT FOR PARTICIPATION IN THE RESEARCH PROJECT [TITLE]**

Responsible for research project: [NAME(S)]

Institution: [ADDRESS(ES), EMAIL ADDRESS(ES); TELEPHONE NUMBER(S)]

Contact Information: [ADDRESS, EMAIL ADDRESS; TELEPHONE NUMBER]

Project website, if applicable [LINK]

### **Information on the research project (short summary of its purpose and benefits)**

PROVIDE A SHORT SUMMARY OF THE KEY FEATURES, PURPOSES AND BENEFITS OF THE RESEARCH PROJECT, INCLUDING ITS FUNDING SOURCES. REFER TO THE SEPARATE INFORMATION SHEET HANDED OUT IN ADVANCE, IF APPLICABLE.

### **Taking part in the study**

Your participation in this research project consists of a [E.G. QUALITATIVE INTERVIEW THAT LASTS ABOUT TWO HOURS AND WILL BE AUDIO-RECORDED]. You will be asked questions on the topic of [E.G. TRANSITION FROM EDUCATION TO JOB].

OPTIONAL I have reviewed my contribution [E.G. THE TRANSCRIPT OF MY INTERVIEW] and don't wish to correct my personal data or retract information.

### **Withdrawal from the participation or the consent**

The participation in this research project is voluntary. You have at all times the right to withdraw from participating in the research project, without having to state the reason. You also have the right to withdraw your consent which will result in your personal information being removed so that it cannot be linked to you anymore.

### **Data protection, confidentiality and future use**

The data collected in the research project [TITLE] will only be used for strictly scientific research purposes. Your name or other identifying information will not be revealed in any publication or handed to third parties, and will be kept confidential.

Your contribution [E.G. THE QUALITATIVE INTERVIEW] will be stored for long-term preservation in the secure environment of the national data archive of FORS,

Swiss Centre of Expertise in the Social Sciences, funded by the State Secretariat for Education, Research, and Innovation. Your information will be de-identified.

Your de-identified information may be made available to accredited researchers and students affiliated with an institution of higher learning for secondary research [OPTIONAL: WITH PRIOR AGREEMENT FROM THE PRIMARY RESEARCH TEAM], only after they have signed a data protection contract obliging them to refrain from trying to identify persons and requiring them to use the data in a way that respects your confidentiality and within the framework of existing data protection legislation.

### Consent

I have read and understood the information in this form [AND THE SEPARATE INFORMATION SHEET, IF APPLICABLE], or it has been read to me. I have been able to ask questions about the research project [TITLE] and these have been answered to my satisfaction.

I consent freely to participating in the research project and I give permission for my contribution to be stored in a secure environment and to be made available in de-identified form for future research and learning.

### Signatures

Name of participant	Signature	Date
Name of researcher	Signature	Date

The participant has received a signed copy of the informed consent form.

## REFERENCES

- Bambey, D., Meyermann, A., & Prozelt, M. (2017). Potentiale der Sekundärforschung mit qualitativen Daten – Ein Workshopbericht. *forschungsdaten bildung informiert* 9. Frankfurt am Main. Retrieved from [http://www.forschungsdaten-bildung.de/files/fdb-informiert\\_nr-7.pdf](http://www.forschungsdaten-bildung.de/files/fdb-informiert_nr-7.pdf)
- CESSDA ERIC (2018). Adapt your data management plan. A list of data management questions based on the expert tour guide on data management. Retrieved from [https://www.cessda.eu/content/download/4302/48656/file/TTT\\_DO\\_DMPExpertGuide\\_v1.2.pdf](https://www.cessda.eu/content/download/4302/48656/file/TTT_DO_DMPExpertGuide_v1.2.pdf)

- CESSDA ERIC (2017). Data management expert guide. Retrieved from <https://www.cessda.eu/content/download/3844/35033/file/20171117DMPQuestionsCESDAExpertTourGuide.pdf>
- Diaz, P. (2019). Ethics in the era of open research data: some points of reference. *FORS Guides*, 3, Version 1.0, 1-18. doi:10.24449/FG-2019-00003
- Charter of Fundamental Rights of the European Union (2000). Retrieved from <http://fra.europa.eu/en/charterpedia/title/ii-freedoms>.
- European Court of Human Rights (2018). Factsheet – Personal data protection. Retrieved from [https://www.echr.coe.int/Documents/FS\\_Data\\_ENG.pdf](https://www.echr.coe.int/Documents/FS_Data_ENG.pdf)
- General Data Protection Regulation (GDPR) (2016). Retrieved from <https://gdpr-info.eu/>
- Federal Act on Data Protection of 19 June 1992 (Status as of 1 January 2014) (English translation). Retrieved from [www.admin.ch/opc/en/classified-compilation/19920153/index.html](http://www.admin.ch/opc/en/classified-compilation/19920153/index.html)
- Federal Act on Research involving Human Beings (Human Research Act, HRA) of 30 September 2011 (Status as of 1 January 2014). Retrieved from <https://www.admin.ch/opc/en/classified-compilation/20061313/index.html>
- Finnish Social Science Data Archive (2017a). Informing research participants. Retrieved from <http://www.fsd.uta.fi/aineistonhallinta/en/informing-research-participants.html>
- Finnish Social Science Data Archive (2017b). Anonymisation and personal data. Retrieved from <http://www.fsd.uta.fi/aineistonhallinta/en/anonymisation-and-identifiers.html#tidentifier-type-table>
- Rat für Sozial- und Wirtschaftsdaten (RatSWD) (2015). Archivierung und Sekundärnutzung von Daten der qualitativen Sozialforschung – Eine Stellungnahme des RatSWD. RatSWD Output 1(5). Berlin. Retrieved from [https://www.ratswd.de/dl/RatSWD\\_Output1\\_Qualidaten.pdf](https://www.ratswd.de/dl/RatSWD_Output1_Qualidaten.pdf)
- Rat für Sozial- und Wirtschaftsdaten (RatSWD) (2017). Handreichung Datenschutz. RatSWD Output 5 (5). Berlin. Retrieved from [https://www.ratswd.de/dl/RatSWD\\_Output5\\_HandreichungDatenschutz.pdf](https://www.ratswd.de/dl/RatSWD_Output5_HandreichungDatenschutz.pdf)
- Stauffacher, M., & Bader, M. (2018). Data protection in Switzerland: overview. Retrieved from <https://uk.practicallaw.thomsonreuters.com/9-502-5369>
- Swiss National Science Foundation (2017a). Open research data. Retrieved from [http://www.snf.ch/en/theSNSF/research-policies/open\\_research\\_data/Pages/default.aspx](http://www.snf.ch/en/theSNSF/research-policies/open_research_data/Pages/default.aspx)
- Swiss National Science Foundation (2017b). FAIR Daten Prinzipien. Retrieved from <http://www.snf.ch/Teaser/Inhalt/Seiten/open-research-data-fair-daten-prinzipien-fuer-forschungsdatenmanagement.aspx>.
- Swiss National Science Foundation. (2017c). Data management plan – Guidelines for researchers. Retrieved from [http://www.snf.ch/en/theSNSF/research-policies/open\\_research\\_data/Pages/data-management-plan-dmp-guidelines-for-researchers.aspx](http://www.snf.ch/en/theSNSF/research-policies/open_research_data/Pages/data-management-plan-dmp-guidelines-for-researchers.aspx)

- UK Data Service. (2017a). Consent for data sharing. Retrieved from <https://www.ukdataservice.ac.uk/manage-data/legal-ethical/consent-data-sharing/consent-forms>
- UK Data Service. (2017b). Maintaining the balance between confidentiality and usefulness of the data. Retrieved from <https://www.ukdataservice.ac.uk/deposit-data/stories/gush>
- UK Data Archive. (2018). Consent form. Retrieved from <http://data-archive.ac.uk/media/210661/ukdamodelconsent.doc>
- Universiteit Utrecht. (n.d.). Informed consent for data sharing. A guide to best practices in informed consent for enabling the sharing of research data beyond the purposes for which your data was collected. Retrieved from <https://www.uu.nl/en/research/research-data-management/guides/informed-consent-for-data-sharing>
- Universität Zürich, Faculty of Arts and Social Sciences, Ethics Committee. (n.d.). Minimum content of a consent form. Retrieved from [https://www.phil.uzh.ch/dam/jcr:f480b23d-65db-4abc-ac83-8f0c971a33fa/141128\\_PhF\\_Ethics\\_Committee\\_Minimum\\_Content\\_Consent\\_Form.pdf](https://www.phil.uzh.ch/dam/jcr:f480b23d-65db-4abc-ac83-8f0c971a33fa/141128_PhF_Ethics_Committee_Minimum_Content_Consent_Form.pdf)