FORS GUIDES

to survey methods & data management

Informed consent: ethical and legal considerations

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Abstract:
This guide examines the ethical and legal foundations of informed consent in social science research involving human participants. It outlines the criteria for valid consent, discusses how consent can be obtained, documented, and maintained over time, and explores challenges relating to data protection, data sharing and reuse, vulnerable populations, internet research, deception, and other complex research settings. Its aim is to support responsible, transparent, and context-sensitive consent practices.

Keywords: autonomy, transparency, accountability, data governance, vulnerability, consent, ethics

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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.

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Statement on the use of artificial intelligence:

For this guide, the authors used DeepL and Microsoft Copilot to improve the linguistic quality, readability, and fluency of the text, as the authors are not native English speakers. After using these tools, the authors carefully reviewed and edited the content as necessary and take full responsibility for the final publication.

1. INTRODUCTION

Informed consent is the process through which a competent individual freely decides to participate in research after receiving adequate, relevant, and understandable information (UCD Human Research Ethics Committee, 2021). It is a cornerstone of research ethics, whose function is to give practical effect to "respect for persons", one of the three fundamental principles established by the Belmont report (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).[1]

Beyond its central role in research ethics, informed consent is also one of the principal legal bases for the processing of sensitive data. This is particularly true in legal frameworks aligned with the General Data Protection Regulation (GDPR)[2], where the processing of such information without consent is regarded as exceptional and subject to strict conditions (Diaz, 2022). Because social science research frequently involves the collection of data relating to individuals' health, political opinions, religious or philosophical beliefs, personal experiences or other aspects of their private lives, obtaining informed consent is, in many cases, legally required (Vinck & Roca i Escoda, 2021).

The challenges raised by informed consent in the social sciences extend beyond the sensitivity of the data collected. In these disciplines, research often unfolds through relationships, interactions, and contexts that evolve over time, making it difficult to anticipate fully at the outset the conditions under which participation will take place (Genard & Roca i Escoda, 2019). Information may emerge progressively, participants' perspectives may change, and new ethical questions may arise as the research advances. In this context, informed consent cannot be reduced to a single decision taken at the outset of a study. Rather, it should be understood as an ongoing and reflexive process through which participation is continuously revisited and participants' autonomy is maintained throughout the research lifecycle (Burton-Jeangros, 2017; Guillemin & Gillam, 2004).

This guide takes these challenges as its starting point. It begins by setting out the perspective from which informed consent is approached, then examines the conditions under which it can be considered valid, before exploring how these requirements can be translated into research practice. The overall aim is to provide a coherent and accessible framework for supporting responsible research involving human participants.

2. SCOPE, NORMATIVE FOUNDATIONS, AND PERSPECTIVE OF THE GUIDE

This chapter establishes the foundations and overall positioning of the guide. It clarifies its role, situates it within the interplay between ethics and law, and sets out the normative framework on which it draws. It also explains the perspective adopted, in particular the focus on research contexts in which consent is especially complex and demanding.

2.1 WHAT THIS GUIDE IS — AND IS NOT

This guide is conceived for social science researchers as a reflective tool to support ethical decision-making in research practice. It does not aim to provide ready-made solutions,

[1] The Belmont Report (1979), published by the U.S. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, articulated three fundamental ethical principles for research involving human participants — respect for persons, beneficence, and justice — which are widely regarded as the foundational pillars of modern research ethics. Although developed in a U.S. biomedical context, the report has had a lasting and far-reaching influence on research ethics across disciplines and jurisdictions.

[2] The General Data Protection Regulation (GDPR) is the European Union's legal framework governing the processing of personal data.

standardized consent forms, or boilerplate language that could be applied mechanically across contexts.

Rather, it offers a structured framework to help researchers think through consent requirements, clarify the principles at stake, and anticipate ethical and legal challenges. Conceived as a guide to think with, it supports reflection and judgement rather than functioning as a checklist guaranteeing ethical or legal compliance.

The purpose of the guide is not to replace disciplinary standards, institutional policies, local regulations, or context-specific ethical judgement. Rather, it seeks to provide a common point of reference for reflecting on informed consent across a wide range of research situations while remaining attentive to the particularities of each research context.

2.2 NORMATIVE FOUNDATIONS: ETHICS AND DATA PROTECTION LAW

This guide rests on a shared normative foundation, combining internationally recognized principles of research ethics with data protection law. Rather than treating these as separate domains, the guide approaches them as complementary and mutually reinforcing. Ethical principles help identify the interests, values, and rights at stake, while the law helps to translate these concerns into concrete obligations and enforceable safeguards (Floridi & Taddeo, 2016).

From an ethical perspective, this document draws on well-established international reference texts that articulate the core principles governing research involving human participants (e.g. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979; Council for International Organizations of Medical Sciences [CIOMS], 2016; World Medical Association, 2024). Although these principles were originally developed in the context of biomedical research, they are now widely recognized across disciplines and provide a common framework for ethical reflection. They are nevertheless presented here at a general level, as their interpretation and implementation are further refined through disciplinary codes, professional standards, and institutional guidelines (see, for example, Berthod et al., 2010).

The legal dimension of this guide is primarily grounded in the Swiss Federal Act on Data Protection (FADP, 2020)[3], which constitutes the general legal framework governing the processing of personal data in Switzerland. As a result, it does not address research activities governed by sector-specific legislation, such as the Human Research Act (HRA, 2011), which establishes its own rules and procedures.[4] Because the FADP is closely aligned with the GDPR, the legal principles discussed here may also serve as a useful reference for researchers working under comparable data protection regimes beyond Switzerland, especially in the European Union.

Because it is anchored in a specific normative framework, this guide should be used with due caution in international research contexts. Although the ethical and legal principles on which it is based have broad relevance, their interpretation and practical implications may vary across legal systems, institutional environments, and cultural settings. Researchers are therefore encouraged to consider the local realities within which their projects unfold and to complement the guidance provided here with any applicable local requirements, standards, or practices (CIOMS, 2016).

2.3 PERSPECTIVE ADOPTED: FOCUSING ON SENSITIVE AND HIGH-RISK CONSENT SITUATIONS

Informed consent can take different forms depending on the research context, the methods employed, the nature of the data collected, and the potential implications for participants.

[3] Research activities in Switzerland are often subject to cantonal regulations, particularly within public institutions such as universities. The FADP nevertheless serves as the primary legal reference for this guide in light of the ongoing alignment of cantonal data protection regimes with federal standards.

[4] Researchers whose projects fall within the scope of the Human Research Act should refer to the guidance made available by swissethics, which provides detailed information on the ethical review process, informed consent requirements, and other obligations specific to human research: https://swissethics.ch/

Across the social sciences, consent practices range from highly formalized, explicit, and documented procedures — typically in written form — to more informal ones, such as oral consent, opt-in procedures, or, in some cases, implicit or tacit forms of agreement (Wiles et al., 2005).

This guide does not aim to provide an exhaustive overview of this full spectrum of consent practices. Its primary concern lies with research situations in which consent is particularly demanding, notably those involving sensitive data, contexts where data processing, reuse, or long-term storage may entail significant risks, or settings characterized by asymmetries of power, dependency, or information.

In these situations, consent constitutes a substantive and ongoing dimension of research practice. It raises concrete questions about how consent is sought, expressed, documented, and revisited over time, and about how responsibilities toward participants are understood as research situations evolve. Accordingly, this document does not seek to standardize consent across all contexts; rather, it focuses on strengthening consent practices where the ethical and legal stakes are highest, by articulating principles that support informed judgement and responsible decision-making.

3. CORE CRITERIA FOR VALID INFORMED CONSENT

This chapter sets out five criteria that informed consent should meet in order to be considered valid and meaningful. Four of these criteria correspond to the elements of valid consent identified by the European Data Protection Board (EDPB) in its Guidelines 05/2020 on consent under the GDPR, namely those relating to the specificity of consent, the freedom with which it is given, the information on which it is based, and the manner in which agreement is expressed (EDPB, 2020). The present framework complements these elements with the requirement that consent be given by a person capable of judgement, which derives from general principles of Swiss civil law and conditions the validity of any expression of will (Swiss Civil Code, art. 16).

Accordingly, informed consent should be:

- given by a person capable of judgement;
- specific with respect to both the research objectives and the intended uses of the data;
- freely given, without coercion or undue influence;
- informed, on the basis of adequate, relevant, and intelligible information;
- and explicitly expressed through a clear indication of agreement.

These criteria are intended to be considered together, as interdependent dimensions. Applied across different research contexts, they provide a structured point of reference for designing and reflecting on consent practices.

3.1 GIVEN BY A PERSON CAPABLE OF JUDGEMENT

In order for individuals to give valid consent, they must have the capacity of judgement, defined as “the ability to use and understand information to make a decision, and to communicate any decision made” (National Health Service [NHS], 2022, para. 2). This capacity is generally assessed on the basis of four key criteria: the individual’s ability to understand the information provided; to evaluate risks and consequences; to reason based on that information; and to communicate a coherent and stable choice (Véron, 2020; Würth, 2024).

On this basis, and according to the literature, special attention is required when the population under study includes minors, elderly people, persons with cognitive or psychiatric disorders, individuals with impaired consciousness, people in acute physical or psychological distress, or

persons under guardianship or curatorship (Académie Suisse des Sciences Médicales [ASSM], 2019).

Under Swiss law, when an individual lacks capacity of judgement, a legal representative must act on their behalf (Swiss Civil Code Art. 19c). This legal requirement does not imply that the person concerned should be excluded from the consent process. On the contrary, their views, preferences, and any signs of discomfort or refusal must always be taken seriously and respected. Recognizing agency, even in situations of limited capacity, remains an ethical imperative (ASSM, 2019).

3.2 SPECIFIC

For consent to be valid, it must be specific, meaning that it must relate to sufficiently defined research purposes and reasonably foreseeable uses of the data (Rosenthal, 2020; Métille, 2022). Participants must therefore receive clear and sufficiently precise information about the objectives of the research, the methods employed, the anticipated uses of the data, and any foreseeable implications of their participation. Consent cannot be regarded as valid where it rests on vague, overly broad, or indeterminate descriptions of the activities involved. This requirement has two main implications for consent practices.

First, specificity applies to the different forms of data processing envisaged within the research framework. Consent should not take the form of a single, undifferentiated authorization covering all possible operations. Activities such as participation in a study, the recording of interviews, the long-term storage of sensitive data, data sharing with other researchers, or reuse for future research may raise distinct issues and implications for participants. These different forms of processing should therefore be identified and clearly distinguished, so that consent meaningfully relates to the activities involved (EDPB, 2020).

Second, specificity places limits on the future use of data. Unlike research projects governed by the HRA, where broader forms of consent may be permitted under certain conditions (Erard, 2024), general data protection law requires consent to relate to sufficiently defined purposes and reasonably foreseeable uses of the data (El-Sayed & Paspalj, 2024). The challenges raised by this requirement, as well as the opportunities and limitations associated with the reuse of research data, are examined further in Chapter 4.

These constraints call for a proportionate approach to specificity. Consent must be sufficiently precise to support an informed decision, while remaining transparent about uncertainties and the limits of foreseeability. One way of operationalizing this balance is through granular consent (EDPB, 2020) — not as a requirement to multiply options excessively, but as a way of distinguishing what is essential to participation from what is optional. Grouping together data uses that are necessary for the conduct of the research, while separating additional or secondary uses, helps ensure that consent remains specific without becoming burdensome or unintelligible for participants.

3.3 FREE

Respect for participants' autonomy presupposes genuine freedom of choice: a decision cannot be considered autonomous if it is made under constraint, dependency, or disproportionate influence (De Broca, 2007). In research settings, threats to freedom of choice rarely stem from explicit coercion alone. They more often arise from structural conditions that shape how participation is perceived and experienced.

Power asymmetries, relationships of dependency, institutional hierarchies, or the use of incentives may lead individuals to perceive participation as expected or difficult to refuse. Even when participation is formally described as voluntary, anticipated negative consequences — such as academic disadvantages, loss of access to services, or strain on social relationships — may undermine the authenticity of consent (Streiner et al., 2024). Particular caution is also required where financial or material compensation, though intended as fair remuneration, becomes

disproportionate in relation to participants' socio-economic situation and functions as an undue inducement rather than a neutral form of compensation (Williams & Walter, 2015).

Ensuring that consent is genuinely free therefore requires active attention to how recruitment and consent procedures are designed and implemented, especially in contexts involving vulnerable populations, hierarchical recruitment settings, or situations in which researchers act on behalf of institutions endowed with social, economic, or legal authority (Araiza, 2019). This involves anticipating circumstances in which freedom of choice may be constrained and implementing safeguards to mitigate these effects. Such safeguards may include avoiding recruitment through intermediaries who exercise authority over potential participants — for example employers, teachers, or service providers — clearly separating research participation from evaluation or service provision, offering genuine alternatives to participation, and explicitly demonstrating that refusal carries no direct or indirect negative consequences.

Accordingly, freedom of consent should be assessed not only in formal terms, but also from the perspective of how participation is experienced and perceived by those concerned. Situations involving minors and students — where dependency and asymmetries of power are particularly salient — require specific attention and are discussed in greater detail in Chapter 8.

3.4 INFORMED

Information lies at the heart of informed consent: without it, consent cannot be considered meaningful (Faden & Beauchamp,1986). It is through the information provided that participants are able to understand what they are being asked to take part in and to decide whether they wish to do so. In this sense, information defines the terms under which participation takes place and structures the agreement established between researchers and participants (Manson & O'Neill, 2007).

Providing information is not merely a procedural requirement but a core ethical component of informed consent. Respect for persons requires researchers to communicate clearly and honestly about the nature of the research, including what participation involves as well as its limits, uncertainties, and constraints (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979). In this sense, informed consent is not simply a mechanism for obtaining authorization, but a practice through which researchers demonstrate accountability toward participants (Guillemin & Gillam, 2004).

Determining what information must be provided, how it should be conveyed, and when it should be delivered raises important practical challenges. These questions are examined in greater detail in Chapters 5, 6 and 7.

3.5 EXPLICIT

Where research involves the processing of sensitive personal data, data protection law requires that consent be expressed explicitly (FADP, Art. 6(7)(a)). Concretely, this means that it must take the form of a clear and unambiguous affirmative action and cannot be inferred from silence, inaction, or mere participation (Métille, 2022).

This heightened requirement reflects the specific risks associated with the processing of sensitive data, which often relate to intimate aspects of individuals' lives and may expose them to risks of discrimination, stigmatization, or significant social and personal harm (CIOMS, 2016). In such contexts, implicit or indirect forms of consent may fail to adequately capture participants' awareness of what is at stake or their willingness to accept these implications. Requiring an explicit expression of agreement therefore reduces ambiguity and helps ensure that consent is genuinely informed and deliberate rather than presumed (Manson & O'Neill, 2007).

In practice, explicit consent may be obtained through a range of methods, depending on the research context and the characteristics of the participants, provided that the expression of agreement is clear and unequivocal. Signed consent forms, the active selection of an unchecked consent option (such as ticking a box), or an explicit affirmative response to a clearly

formulated question may all serve this purpose, as long as they clearly demonstrate the participant's intention to consent (Métille, 2022).

Where a research activity involves several distinct data processing operations, the use of modular consent can further support explicitness by ensuring that participants express their agreement with respect to each operation.

4. THE SCOPE AND LIMITS OF CONSENT: ANTICIPATING DATA USE, SHARING, AND REUSE

The requirement of specificity raises a central question for research involving sensitive data: how far consent can extend beyond the initial context in which it is obtained. While consent is given at a specific moment, data are often stored, shared, and reused over time, across contexts that may evolve in ways not fully determined at the outset.

This chapter examines how the requirement of specificity shapes both the scope and the limits of consent in such situations. It focuses on the relationship between initial agreement and subsequent data use, with particular attention to the conditions under which consent can continue to support data sharing and reuse.

To do so, the chapter first analyses how specificity functions as a framework for assessing future data use. It then clarifies the boundary between uses that fall within the scope of consent and those that do not. Finally, it considers the implications of these limits for the design of consent processes in research practice.

4.1 SPECIFICITY AND THE BOUNDARIES OF FUTURE DATA USE

Specificity determines how far consent can extend by setting the conditions under which subsequent data uses can still be related to the initial agreement. The scope of consent depends on whether those uses remain connected to the circumstances under which consent was obtained: where this connection is maintained, data use can be understood as an extension of the original agreement; where it is not, it can no longer be meaningfully grounded in that consent (Goicovici, 2022).

From this perspective, future data use unfolds along a continuum between continuity and rupture. Some uses remain continuous with the original research framework, as they extend the purposes, contexts, or actors initially presented without fundamentally altering them. This may include continued analysis within the same project, storage for verification purposes, reuse for closely related research questions, data sharing within a defined research field, access by identifiable categories of recipients such as academic researchers or recognized repositories, and reuse under clearly defined governance conditions. In these situations, data continue to circulate within a form that remains aligned with what participants were in a position to understand (Becker et al., 2024).

By contrast, uses fall outside this scope when they introduce elements that cannot be traced back to what participants could reasonably anticipate. This is the case where data are shared with previously unidentified third parties, transferred across institutional or legal contexts that were not described, or used for purposes that substantially differ from those initially presented. In such situations, the connection between the participant's agreement and the subsequent processing becomes too weak to sustain the validity of the original consent, meaning that further use of the data requires renewed justification on an appropriate legal and/or ethical basis (McKeown et al., 2021).

4.2 IMPLICATIONS FOR DESIGNING CONSENT PROCESSES

The limits outlined above have direct implications for the design of consent processes in research practice, particularly in contexts involving long-term data retention, sharing, and reuse.

First, anticipated forms of data use must be incorporated into the consent process from the outset. Rather than treating future use as an open-ended possibility, researchers should identify the main forms of processing that are reasonably envisaged and explain the purposes for which data may subsequently be used. Consent materials should therefore provide participants with a sufficiently clear understanding of the scope of the activities for which authorization is being sought (Becker et al., 2024).

Second, consent documentation should be structured in a way that clearly distinguishes different forms of data use. Core research activities, data sharing, and future reuse should be presented as separate components rather than merged into a single description. This can be achieved through separate sections, layered information, whereby essential information is presented first and supplemented with more detailed explanations where needed, or differentiated consent options, allowing participants to understand how each type of use relates to their participation (EDPB, 2020).

Third, descriptions of future data use must be sufficiently precise to support meaningful agreement. Vague or open-ended formulations — such as “any future research” or “general scientific purposes” — should be avoided, as they do not provide participants with a clear basis for assessing what they are authorizing (Goicovici, 2022). Instead, consent materials should refer to identifiable research domains, indicate categories of potential recipients, and describe foreseeable forms of data use in concrete terms.

Fourth, the anticipated lifecycle of the data should be made explicit. Participants should be informed about how long data will be retained, whether they may be archived for long-term preservation, and under what conditions they may be shared, accessed, or reused in the future. Making these elements visible enables participants to understand not only the immediate purposes of data collection but also how their data may continue to circulate over time (Becker et al., 2024).

Finally, consent design requires ensuring consistency between what is communicated to participants and what is implemented in practice. The information provided during the consent process defines the boundaries within which subsequent data use remains legitimate. This requires aligning consent materials with data management plans, sharing practices, and governance arrangements so that future uses remain consistent with the conditions originally presented.

Taken together, these considerations shift the focus of consent design away from the breadth of authorization and towards the clarity of its articulation. Consent is more likely to remain valid over time when future data use is presented as a set of identifiable, structured, and intelligible possibilities rather than as an undifferentiated or open-ended range of potential activities.

5. WHAT PARTICIPANTS NEED TO KNOW

Ensuring that consent is truly informed requires determining what information must be provided to participants. The information given is not merely intended to ensure transparency; it enables participants to make a meaningful and autonomous decision about their involvement. At the same time, it sets the terms under which participation takes place. By clarifying what the research entails, how data will be used, and which rights participants retain, it effectively lays the foundation of the agreement between participants and researchers. In doing so, it gives rise to a set of expectations and corresponding responsibilities that structure the conduct of the research and bind researchers both ethically and, in many cases, legally.

This chapter focuses on the content of that information. While the level of detail may vary depending on the research context, the nature of the data, and the level of risk involved, ethical and legal frameworks converge on the need to address a core set of elements to ensure that the object of consent is sufficiently clear:[5]

- who is conducting the research and how they can be contacted;
- why the research is being conducted and why individuals are invited to participate;
- what participation involves, including its duration and practical conditions;
- what data are collected, including whether sensitive data are involved;
- what risks and benefits participation may entail;
- how data are protected, who may access them, and whether they may be shared or archived;
- how results will be disseminated;
- what rights participants have, including the voluntary nature of participation and withdrawal options;
- and whether conflicts of interest exist.

Together, these elements define what participants agree to and the conditions under which this agreement operates. The chapters below examine each of them in turn, explaining their role in ensuring valid consent and how they may be addressed in a context-sensitive and ethically robust manner.

5.1 WHO IS CONDUCTING THE RESEARCH AND HOW THEY CAN BE CONTACTED

Participants must be informed about the individuals and organizations involved in the research project. This includes the principal investigator, members of the research team, their institutional affiliations, and any third parties involved in data collection, processing, storage, or analysis. Such information enables participants to understand the respective roles and responsibilities of the actors involved. They should be able to identify who will interact with them directly, who may have access to their data, and who is responsible for the conduct of the research and the decisions made throughout the project. This is particularly important where certain tasks are delegated to third parties or carried out by students, research assistants, technical service providers, or collaborating institutions.

Where the identity of all actors cannot be specified in advance, or where doing so would add unnecessary complexity, participants should at least be informed of the categories of persons or organizations that may be involved. Depending on the context, this may include members of the research team, transcription providers, cloud service providers, data repositories, external collaborators, or other categories of recipients likely to access or process the data. What matters is that participants are able to understand who may handle the information collected and in what capacity.

If the research is conducted in partnership with external organizations or institutions, their role should also be described. In particular, it should be made clear whether they are involved solely in facilitating recruitment, provide logistical or technical support, or have access to the data.

[5] The identification of these elements is informed primarily by the templates for participant information and consent documents developed by swissethics, the umbrella organisation of the Swiss research ethics committees, which provides the reference templates used for research projects falling within the scope of the HRA. Beyond the templates themselves, swissethics also provides detailed guidance on how participant information and consent documents should be drafted, including recommendations on structure, content, language, and the presentation of information to prospective participants. See swissethics (n.d.).

The same applies when recruitment is carried out through intermediaries such as organizations, employers, professional associations, or public services. Participants should be informed about the role of these intermediaries and whether they have access to any information relating to participation. This is especially important where intermediaries occupy a position of authority or influence, as clearly defining these boundaries helps reduce perceived pressure to participate.

Finally, the contact details of the principal investigator must be provided in a clear and easily accessible manner. Participants should know whom to contact if they wish to ask questions, seek clarification, raise concerns, or exercise their rights. Providing this information reinforces the idea that consent is not a one-off administrative formality, but part of an ongoing relationship between researchers and participants.

5.2 WHY THE RESEARCH IS BEING CONDUCTED AND WHY THE PERSON IS INVITED TO PARTICIPATE

Participants must be informed about the purpose of the research and the reasons why they have been invited to participate. This enables them to make an informed decision by understanding both the nature of the study and their relevance to it.

When drafting this section, the aim is to explain the research in terms that are sufficiently clear to support an informed decision without overwhelming participants with unnecessary methodological or theoretical detail. Participants should be able to understand, in broad terms, the topic or issue under investigation.

This section should also explain why the individual has been invited to participate. Recruitment is typically based on particular experiences, characteristics, roles, or forms of involvement that are relevant to the research question. Making inclusion criteria explicit helps participants understand why they were selected and how they relate to the objectives of the study.

Where relevant, the same logic should extend to exclusion criteria. Participants should be informed of any conditions that may render participation inappropriate or impossible. Such criteria may relate to the scientific objectives of the study, methodological considerations, or ethical and practical concerns, including the need to minimize risks, avoid excessive burden, or prevent participation in circumstances where it would not be meaningful or safe.

5.3 WHAT PARTICIPATION INVOLVES

Participants must be able to understand what participation entails in practical terms. This section should describe the activities they are invited to take part in and the conditions under which these activities will take place, allowing them to make an informed assessment of their involvement.

The focus should be on what participants will actually be asked to do rather than on the methodological design of the study. This typically includes the nature of the activity (e.g. interview, questionnaire, observation, or group discussion), the expected duration and frequency of participation, the setting in which it will take place, and any practical requirements or constraints.

Providing this information allows participants to anticipate the time, attention, and level of engagement required, and to determine whether participation is compatible with their personal, professional, or family circumstances. Where participation comprises several stages or optional components, these should be clearly distinguished so that participants understand which activities form part of the core study procedures and are therefore necessary for participation, and which are additional components that they may choose to accept or decline without affecting their involvement in the study.

Where relevant, this section should also indicate whether participants will receive compensation or reimbursement for expenses incurred through participation. This may take the form of financial compensation, vouchers, or reimbursement of travel and related costs. Such information should be presented neutrally as part of the practical arrangements of the study rather

than as an incentive to participate. Where no compensation is provided, stating this explicitly contributes to transparency and helps avoid misunderstandings.

5.4 WHAT DATA ARE PROCESSED

Participants must be informed about the types of information they will be asked to provide and how that information will be used within the research project. This section should provide a clear overview of the data that will be collected, generated, or recorded through participation, enabling individuals to understand what aspects of their experiences, views, behaviours, circumstances, or activities may be documented and used for research purposes.

The objective is not to provide an exhaustive list of variables or data points, but to describe the main categories of data involved. Depending on the study, this may include biographical or socio-demographic information, opinions and attitudes, accounts of experiences or practices, or observations of behaviour and interaction.

Particular attention should be paid to sensitive data. Where the research involves information relating to health, political opinions, religious or philosophical beliefs, financial circumstances, or aspects of private or intimate life, this should be stated explicitly. The collection of such information may significantly influence participants' assessment of the risks associated with participation and, consequently, their decision to take part.

Where relevant, it may also be useful to distinguish between data provided directly by participants — such as responses to questions or contributions to interviews and discussions — and data generated through the research process itself, including recordings, transcripts, or observational notes. Doing so helps participants understand not only what information they provide, but also how information about them may be produced — and managed — during the course of the research.

The purpose of this section is to clarify the nature of the data involved. Questions relating to data protection, storage, access, sharing, and reuse should be addressed separately in the sections dedicated to those issues.

5.5 WHAT RISKS AND BENEFITS PARTICIPATION MAY ENTAIL

Participants must be informed about any foreseeable risks and potential benefits associated with participation. This section should help individuals understand what participation might involve for them beyond the practical aspects already described, so that they can weigh their decision in a realistic and informed way.

When completing this section, the focus should be on reasonably foreseeable risks in light of the research context, methods, and topics addressed. In social science research, risks are most often nonphysical and may include psychological, emotional, social, professional, economic, or legal dimensions. For example, participation may involve discussing sensitive topics, reflecting on difficult experiences, expressing opinions that differ from those of others, or being identifiable within a small group or community.

The aim is neither to trivialize nor to exaggerate these risks. Researchers should consider how participation could realistically affect participants during or after the research, and describe these possibilities in a balanced manner. Where risks are limited or minimal, stating this explicitly can help avoid unnecessary concern, provided that this assessment is supported by the characteristics of the research, including its methods, subject matter, and participant population.

It is also important to indicate the measures envisaged to limit or mitigate identified risks, such as allowing participants to skip questions, take breaks, stop participation, or contact the research team if difficulties arise. Where relevant, participants may be directed to appropriate support resources. These elements reassure participants that their wellbeing has been considered, without framing participation as inherently dangerous.

In parallel, participants may be informed about potential benefits, where these exist. In many social science studies, there is no direct personal benefit, and this should be stated clearly. Possible benefits may include the opportunity to reflect on one's experiences, to make one's perspective heard, or to contribute to broader understanding or societal debate. Such benefits should be described cautiously and without overstatement, so as not to create unrealistic expectations or undue inducement.

5.6 HOW DATA WILL BE PROTECTED

Participants must receive clear information about how their data will be protected throughout the research process. This includes the measures adopted to ensure confidentiality and security, the duration and conditions of data storage, any steps taken to reduce the identifiability of the data, the circumstances in which data may be shared and with whom, and, where applicable, the conditions under which data will be archived, reused, or destroyed.

The purpose of this section is not to provide a detailed technical description of data management practices, but to enable participants to understand how their data will be protected in practice. Information should therefore be clear, realistic, and consistent with the measures actually implemented. Researchers should avoid broad assurances that data will be "anonymous" or "anonymized", as such statements may create a misleading impression of protection while obscuring important limitations and residual risks. Instead, they should describe the safeguards that will actually be applied to reduce identifiability, together with the limitations of those safeguards (Flory & Emanuel, 2004).

Rather than relying on general statements, researchers can explain how data will be handled in practice, for example whether names and contact details will be removed, pseudonyms used, identifying information stored separately, or certain details modified before information is analyzed, shared or published. Such explanations promote both understanding and transparency by helping participants appreciate not only the safeguards that will be applied, but also what those safeguards can realistically achieve. This is particularly important where the nature of the information collected leaves a residual possibility of recognition despite the safeguards adopted (Stam & Kleiner, 2020; Stam & Diaz, 2023). In such situations, information materials should explicitly address the limits of the protection that can be provided. Participants should understand that safeguards may substantially reduce the risk of (re)identification without necessarily eliminating it altogether and, where relevant, should be informed of the circumstances in which (re)identification or recognition may remain possible.

Participants should also be informed about which categories of persons or organizations may access the data, for what purposes, and subject to which safeguards. Depending on the project, this may include research partners, transcription providers, hosting services, repositories, archives, cloud-based platforms, generative AI services, or other technical service providers involved in the storage, processing, or analysis of data.

Where personal data may be transferred abroad, participants should be informed of this possibility and of any implications that may result from the legal framework applicable in the destination country. Where the recipient is located in a country that is not recognized by the Swiss authorities as providing an adequate level of data protection[6], the safeguards adopted to protect the data should also be explained. Providing this information enables participants to make an informed decision about whether they agree to such transfers.

Finally, where data may be archived, deposited in a repository, shared, or reused for future research, this should be explained. Participants should be informed about the form in which the data may be made available, the conditions governing future use, the categories of potential users, and any options available regarding such uses. Where data are to be deposited in

[6] See Annex 1 to the Swiss Federal Council's Data Protection Ordinance for the list of States, territories, specific sectors within a State, and international bodies recognized as providing an adequate level of data protection (Swiss Federal Council, 2022).

a repository or archive managed by a third party, the role of that entity should also be explained. This enables participants to understand not only how their data will be used within the project itself, but also how it may continue to circulate beyond its initial scope.

5.7 HOW RESULTS WILL BE DISSEMINATED

Participants must be informed about how the results of the research are expected to be communicated. This section should provide them with a general understanding of the forms of dissemination envisaged, the audiences that may be reached, and the ways in which their contributions may be represented in research outputs.

It is generally sufficient to describe the main outputs and communication channels anticipated, such as academic publications, reports, conference presentations, professional communications, policy documents, educational materials, or other forms of public dissemination. Detailed publication plans are unnecessary, provided that participants can understand the nature and likely reach of the outputs that may result from the study.

Researchers should also explain how participants' contributions may be represented within those outputs. Findings may be presented in aggregated, de-identified, or otherwise non-attributable form. In qualitative research, however, quotations, excerpts, images, case descriptions, or other illustrative materials may also be used. Where this is anticipated, participants should be informed accordingly.

Particular attention should be given to situations in which the dissemination of findings may create a risk that participants could be (re)identified. Researchers should explain, in general terms, the measures that will be taken to reduce this risk and should avoid creating unrealistic expectations regarding confidentiality. Rather than providing absolute assurances that (re)identification is impossible, they should acknowledge any residual possibility of (re)identification where this is reasonably foreseeable. This may be especially important when dissemination relies on detailed narratives, visual materials, or information relating to small, distinctive, or otherwise easily identifiable populations.

In this context, information about the intended audience may also be relevant. The likelihood of (re)identification often depends not only on the information disclosed, but also on who is likely to encounter it. While (re)identification may sometimes result from information being linked with other available sources, it may be particularly likely among individuals who are already familiar with the persons, communities, organizations, or circumstances concerned. Participants may therefore reasonably wish to know whether findings are intended primarily for academic audiences or whether they are also likely to reach professional, institutional, community, or public audiences.

In some projects, additional measures may be adopted to further reduce these risks. For example, participants may be offered the opportunity to review quotations, extracts, images, or other materials before publication. While such practices are neither required nor appropriate in all research contexts, they should be mentioned where they form part of the research design.

Taken together, these elements enable participants to understand how findings from the study may be communicated, how their contributions may be represented within research outputs, and what risks of identification or re-identification may persist despite the safeguards adopted. Such understanding is important for informed decision-making, as it allows participants to assess not only the immediate conditions of participation but also the ways in which information derived from their involvement may subsequently circulate.

5.8 WHAT RIGHTS PARTICIPANTS HAVE

Participants must be informed about the rights they retain throughout the research process. The purpose of this section is to make clear that participation is voluntary and that participants remain free to make decisions about their involvement in the research and, where applicable, about the use of their personal data.

At a minimum, participants should be informed that taking part in the research is entirely voluntary and that choosing not to participate will not result in any disadvantage. They should also understand that agreeing to participate does not oblige them to remain involved until the end of the study and that they may discontinue their participation at any time.

Information materials should explain, in practical terms, how participation can be discontinued, including whom to contact where this is necessary. They should also explain the consequences of withdrawal, particularly in relation to data that have already been collected. Participants should be informed, in general terms, whether previously collected data may be withdrawn or deleted and of any limitations that may apply. Such limitations may arise, for example, where data have already been anonymized, incorporated into analyses, disseminated, or archived. The practical and legal implications of withdrawal are discussed further in Chapter 7.6.

Participants should also be informed of any rights they may have in relation to their personal data and of any important limitations that may apply in the research context. Where relevant, information materials should explain whether participants may request access to information concerning them, seek the correction of inaccurate information, or request the deletion of data.

Finally, participants should be told whom they may contact if they have questions about the research, wish to exercise their rights, or have concerns about how their information is being handled. Information materials should identify the appropriate contact person or procedure for doing so.

5.9 FUNDING AND CONFLICTS OF INTEREST

Participants should finally be informed about the sources of funding of the research and any interests that may reasonably be perceived as influencing its conduct, interpretation, or dissemination. The purpose of this section is to provide sufficient transparency for participants to understand the broader context in which the research is being conducted.

Funding information should identify the main sources of financial support, whether these originate from public funding bodies, research grants, foundations, private sponsors, or other organizations. Where relevant, participants should also be informed about any role that funders or partner organizations play beyond providing financial support, particularly if they contribute to the design of the project, the collection or analysis of data, or the dissemination of results.

Conflicts of interest should be disclosed whenever they exist or could reasonably be perceived to exist. These may arise from financial relationships, institutional affiliations, professional responsibilities, personal interests, or collaborative arrangements that could affect, or appear to affect, the independence of the research. The objective is not to suggest misconduct or bias, but to ensure that participants are aware of circumstances that may be relevant to their assessment of the project.

The information provided should remain proportionate and accessible. Detailed legal, financial, or organizational explanations are rarely necessary. What matters is that participants are able to identify who supports the research, whether particular interests are involved, and whether these interests may influence how the research is conducted or used.

6. HOW CONSENT SHOULD BE OBTAINED

Providing participants with the relevant information is only one aspect of informed consent. Equally important is how that information is communicated, how participants are able to express their decision, and how that decision is documented throughout the research process.

The same information may support meaningful consent in one context and fail to do so in another, depending on the language used, the opportunities participants have to ask questions, the way agreement is sought, and the circumstances in which it is expressed. Consent therefore depends not only on what participants are told, but also on how that information is communicated, discussed, and translated into a decision (Beauchamp & Childress, 1994).

This chapter examines the practical conditions that support effective consent. It begins by considering questions of language and intelligibility, before examining how agreement may be expressed and documented in practice. It then turns to the relational and contextual factors that may influence participants' ability to make and communicate a voluntary decision.

6.1 LANGUAGE AND INTELLIGIBILITY

Information must be presented in a form that is understandable to the people for whom it is intended. Participants can only make a meaningful decision if they are able to grasp the nature of the research, what participation involves, and the implications of taking part.

This requires adapting the information provided and the consent process to participants' age, educational background, language proficiency, cognitive abilities, and, where relevant, to any form of disability or vulnerability. Such factors shape how information is received, interpreted, and acted upon (Flory & Emanuel, 2004).

Particular attention should therefore be paid to language and formulation. Technical terminology, legal jargon, abstract concepts, or the uncritical reuse of wording drawn from research protocols may create unnecessary barriers to understanding. Information should be expressed in clear and accessible language and, where appropriate, illustrated through examples or situations that resonate with participants' everyday experience (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979).

A useful practical benchmark is whether participants could explain, in their own words and at least in broad terms, what the research concerns and what they are being asked to do. If key aspects of the study cannot be reformulated without relying on specialized vocabulary or implicit knowledge, additional clarification may be needed. Attention should be paid not only to individual words, but also to sentence structure, document length, and the overall density of information.

Language is only one dimension of intelligibility. The way information is communicated also matters. Written documents provide a stable reference that participants can revisit over time, but they are rarely sufficient on their own. Understanding is often strengthened through opportunities for discussion, clarification, and questions, which allow information to be contextualized and potential misunderstandings to be identified.

Depending on the research setting, additional forms of support may be needed to ensure accessibility. These may include visual aids, demonstrations, simplified summaries, interpreters, or other adapted communication tools (Jackson et al., 2023). Where appropriate, researchers may also benefit from involving individuals who are familiar with, or belong to, the population concerned in the preparation or review of consent materials. Their input can help identify unclear terminology, culturally inappropriate formulations, or assumptions that may not be apparent to the research team, thereby improving the clarity and accessibility of the information provided (CIOMS, 2016).

6.2 MODALITIES AND FORMS OF CONSENT

Consent may be expressed in a variety of ways, including written, oral, digital, or other explicit forms of agreement. No single modality is universally appropriate (Métille, 2022). The choice should depend on the characteristics of the participants, the research setting, the sensitivity of the data involved, and the practical realities of the study. What matters is not the form itself, but whether it supports an informed, voluntary, and identifiable expression of participants' wishes.

Written consent, typically recorded through a signed consent form, is often used because it provides both a clear record of agreement and supporting information that participants can consult later. In many contexts — particularly where research involves more than minimal risks, sensitive data, or specific institutional requirements — written consent represents a proportionate and robust approach.

However, written consent is not always the most appropriate solution. In some contexts, it may be impractical, culturally inappropriate, or may even increase participants' vulnerability, for example when working with individuals who are illiterate, socially marginalized, or in an irregular administrative situation. In such circumstances, oral consent or other explicit forms of agreement may be preferable, provided that participants receive the necessary information and that their understanding is adequately supported (CIOMS, 2016).

Digital research environments introduce additional challenges. Consent may be expressed through online forms, checkboxes, electronic signatures, or other interactive mechanisms (Métille, 2022). Researchers should ensure that these procedures encourage genuine engagement with the information provided and do not reduce consent to a purely technical action performed without reflection.

In certain observational, ethnographic, or participatory research settings, consent may be sought within ongoing interactions rather than through a single isolated encounter (see chapter 7.4). Even in these situations, consent should take the form of a recognizable act of agreement. Continued presence, cooperation, or participation should not be treated as synonymous with consent (Murphy & Dingwall, 2007). Researchers should ensure that agreement is expressed through an identifiable action, such as verbal confirmation, written acknowledgment, or another deliberate indication of willingness to participate.

Ultimately, the choice of modality should be guided by a simple question: does it allow participants to express a free, informed, and explicit decision in a way that is appropriate to the research context?

6.3 DOCUMENTING AND DEMONSTRATING CONSENT

Documenting consent serves both ethical and practical purposes. From an ethical perspective, it provides a stable record of what was communicated and agreed to during the consent process. From a practical perspective, it allows researchers to demonstrate that valid consent was obtained should questions, disagreements, or concerns arise at a later stage. This is particularly important because the responsibility for demonstrating consent rests with the researcher rather than with participants. Researchers should therefore be able to explain how consent was obtained and on what basis they concluded that it was valid (EDPB, 2020).

Written consent forms often fulfil this function by recording participants' agreement while also preserving the information on which that agreement is based. They provide researchers with a trace of the consent process and, at the same time, offer participants a stable point of reference that they can consult throughout the research. However, the existence of a signed document does not, by itself, demonstrate that consent was informed. Conversely, the absence of written consent does not necessarily imply that consent was invalid. What matters is whether the process can be understood, reconstructed, and justified in light of the information provided and the circumstances in which agreement was obtained. For this reason, documentation should focus on the substance of the process rather than on the mere existence of a signature.

Researchers should be able to demonstrate what information was provided, how it was communicated, when consent was obtained, and through which modality it was expressed (CIOMS, 2016).

The specific form that documentation takes may vary according to the context. Where written consent is not appropriate or feasible, alternative forms of documentation may be used, including contemporaneous notes, audio recordings of consent statements, confirmation emails, screenshots of digital consent procedures, or other records adapted to the research setting. The objective is not to document every interaction exhaustively, but to retain information sufficient to demonstrate how participants were informed and how their agreement was obtained.

The level of documentation should remain proportionate to the nature and sensitivity of the research. What ordinarily requires documentation are the key elements of the consent process, including the information provided, the manner in which it was communicated, the point at which agreement was obtained, and the form through which it was expressed. A low-risk survey collecting non-sensitive data may therefore require little more than a record confirming that participants received the relevant information and agreed to take part. By contrast, studies involving sensitive topics, vulnerable populations, extensive data sharing, or long-term data retention may justify more detailed records of the information provided, questions raised by participants, safeguards discussed, and the agreement ultimately obtained. Ultimately, documentation should remain closely aligned with the consent process itself. Its purpose is not to accumulate evidence, but to preserve a credible and intelligible account of how information was communicated, how agreement was expressed, and how understanding was supported. Documentation should support meaningful consent, not replace it.

6.4 RELATIONAL AND CONTEXTUAL ASPECTS OF CONSENT

Consent is not established through information and documentation alone. It emerges within a broader set of interactions through which participants encounter the research, assess what is being proposed, and communicate their decision. The practical conditions under which these interactions take place can influence not only how information is understood, but also whether participants feel able to make and express a genuinely voluntary choice (Miller & Boulton, 2007).

This is particularly important in research settings shaped by institutional arrangements, professional relationships, dependency relationships, or other forms of social proximity. Participants do not encounter research as isolated individuals; their perceptions and decisions are often influenced by existing relationships, expectations, routines, obligations, and social norms. Researchers should therefore pay attention not only to the content of the information provided, but also to how, when, where, and by whom it is communicated. The timing of the invitation, the setting in which discussions take place, the presence of third parties, and the broader social environment may all influence whether participants feel able to ask questions, express reservations, decline participation, or take time to reflect before reaching a decision (CIOMS, 2016).

For this reason, meaningful participation in decision-making requires more than simply providing information. The consent process should be organized in a way that gives participants genuine opportunities to seek clarification, raise concerns, and express hesitation or disagreement without feeling pressured or judged. Depending on the context, this may involve allowing time for reflection, creating opportunities for follow-up discussions, ensuring that conversations can take place in an appropriate and private setting, or offering alternative channels through which participants can communicate questions or decisions.

Attention to these relational and contextual dimensions does not require researchers to eliminate every potential influence on participants' decisions. Rather, it requires recognizing that consent is shaped by social circumstances as well as by information and taking reasonable steps to ensure that participants can make and communicate their decisions as freely and confidently as possible.

7. CONSENT OVER TIME

Consent should not be understood as a single event occurring at the moment agreement is expressed. Research involving human participants unfolds across multiple phases — including recruitment, data collection, analysis, dissemination, and, in some cases, long-term storage or reuse of data — and may evolve in ways that cannot always be fully anticipated at the outset. Respect for autonomy therefore requires attention not only to how consent is obtained, but also to how it is maintained and managed throughout the research lifecycle (UCD Human Research Ethics Committee, 2021).

Participants' understanding, preferences, and circumstances may change over time, while research projects themselves may develop in unforeseen ways or give rise to new questions concerning the use of data (CIOMS, 2016; Parent, 2025). As a result, consent cannot always be reduced to a decision made at a single point in time.

The temporal dimension of consent becomes visible at several stages of the research process. Information must first be provided before any decision can be made. Participation may then begin, data may be collected and processed, and circumstances may arise that justify revisiting earlier decisions or offering opportunities for withdrawal. The sections below examine these different stages and their implications for consent practices.

7.1 BEFORE PARTICIPATION: INFORMATION AND REFLECTION

Meaningful consent presupposes a prior phase of information and reflection. Participants should receive the information necessary to understand the research before they are asked to make any decision concerning participation. This includes not only access to relevant information, but also a genuine opportunity to consider it, ask questions, and seek clarification where needed (CIOMS, 2016).

The time required for this process will vary according to the complexity of the study, the sensitivity of the topics addressed, and the characteristics of the participant population. A simple questionnaire may require only a brief period of consideration, whereas participation in a longitudinal study or research involving sensitive personal information may justify a more extended reflection period. Regardless of the context, the underlying principle remains the same: participants should not be placed under unnecessary pressure to decide immediately.

This stage serves a distinct purpose within the consent process. Its primary function is not to obtain agreement, but to support understanding (Faden & Beauchamp,1986). Participants are given the opportunity to assess what participation may involve, what consequences it may have, and whether they wish to contribute to the research before any commitment is requested.

7.2 ENTERING THE STUDY: AGREEMENT TO PARTICIPATE

Once participants have received the relevant information and have had a reasonable opportunity to reflect, they may be invited to decide whether they wish to take part in the research.

This initial decision forms part of the consent process but does not necessarily complete it. Participants may be able to make an informed decision about whether to take part in the research, while remaining unable to assess certain uses of information that has not yet been generated. In such cases, further consent decisions may be required once the content and implications of the data become sufficiently foreseeable.

This is particularly true in interviews, focus groups, observations, ethnographic research, and other forms of open-ended inquiry. The content of the data has not yet been produced. Experiences, opinions, memories, emotions, or other personal information may emerge during the course of the interaction, and their significance, sensitivity, or potential identifiability can only be appreciated once they exist (Guillemin & Gillam, 2004; Murphy & Dingwall, 2007; Miller & Boulton, 2007).

The decision obtained at this stage is therefore an informed agreement to participate in the research process. Proper consent is sought later, once participants are able to assess the information generated through their participation and the implications associated with its use.

7.3 AFTER DATA COLLECTION: EXPLICIT CONSENT TO DATA PROCESSING

At the outset of a study, participants can decide whether they are willing to contribute to the research. What they cannot yet assess is the precise nature and sensitivity of the information that their participation will ultimately generate. Consent is therefore sought only once that information exists and its implications can be evaluated in context. In this sense, consent is grounded not only in what participants anticipate they might disclose, but also in what they have actually disclosed.

In practice, consent may often be obtained immediately after participation has taken place. Once an interview, focus group, observation, or questionnaire has been completed, participants are generally in a position to decide whether the information produced through their contribution may be used for research purposes. In some cases, however, additional safeguards may be appropriate. Where the information produced is particularly sensitive or potentially identifiable, researchers may, for example, invite participants to review quotations, excerpts, transcripts, or other materials before deciding whether these may be used (Parent, 2025; Burton-Jeangros, 2017).

The objective is not to impose a particular procedure, but to ensure that consent is obtained at a point when participants possess the information necessary to make a meaningful decision. The information and reflection that precede participation remain essential because they allow individuals to decide whether they wish to engage in the research process. Consent, however, is obtained once participants are able to determine, in full knowledge of the circumstances, whether the material actually produced through their participation may be used for research purposes. Participation and consent are therefore treated as distinct stages of a single process: the first allows data to be generated, while the second determines whether those data may subsequently be used.

7.4 DURING THE RESEARCH: MAINTAINING CONSENT

In research involving repeated interactions, prolonged engagement, or immersive fieldwork, consent cannot be reduced to decisions taken at the beginning of the project. Participants' circumstances, expectations, and willingness to remain involved may change over time, while researchers themselves may refine their questions or adapt aspects of the study as the research progresses.

This issue is particularly salient in ethnographic and other long-term qualitative research settings, where participation often develops through ongoing relationships rather than through discrete encounters (Berthod et al., 2010). In such contexts, consent may gradually lose its practical significance unless it is actively maintained. Participants may forget that data continue to be collected, become uncertain about how information is being used, or no longer readily associate ongoing interactions with the research project itself (Huber & Imeri, 2021).

Maintaining consent therefore requires more than preserving a signed form. Periodic reminders that research activities remain ongoing, together with opportunities to ask questions, raise concerns, reaffirm participation, or withdraw from the study, help ensure that consent remains meaningful rather than merely presumed (CIOMS, 2016). The objective is not to repeatedly obtain formal consent, but to maintain participants' awareness and freedom of choice throughout the course of the research.

7.5 REVISITING CONSENT OVER TIME

Consent may need to be revisited when significant changes occur during the course of a project. Such situations may arise when new risks become apparent, when research objectives

evolve, when unforeseen ethical issues emerge, or when additional uses of data are envisaged beyond those initially presented to participants.

Renewed consent may be particularly relevant where confidentiality risks increase because of the use of rich qualitative material, where data are archived for long-term preservation, shared with other researchers, reused in new projects, or disseminated through channels that were not originally anticipated (CIOMS, 2016; Diaz, 2022). Similar considerations may apply when substantial modifications are made to the research protocol or when changes affect the assumptions on which participants' earlier decisions were based.

The need to revisit consent reflects the fact that participants' understanding, preferences, and circumstances may evolve over time. Respect for autonomy therefore requires ongoing attention to whether the conditions under which earlier decisions were made remain substantially unchanged.

7.6 WITHDRAWAL AND THE TEMPORAL LIMITS OF CONSENT

The temporal dimension of consent is also reflected in participants' ability to withdraw from the research. As a general principle, consent remains revocable for as long as data remain identifiable and subject to data-protection requirements (Diaz, 2022).

Withdrawal, however, may concern different stages of the research process. When participants withdraw from an ongoing study, the situation is generally straightforward: participation ceases, no further information is collected, and the data already provided by the participant can normally be deleted from the project.

The situation becomes more complex once data have been processed or integrated into the research. While identifiable data can generally be removed, this may no longer be feasible once they have been deeply de-identified, incorporated into analyses, included in publications, shared with third parties, or otherwise rendered inseparable from the research process. These practical and technical limitations do not undermine the principle that consent remains revisable, but they make it essential to explain clearly from the outset what withdrawal means in practice and what its consequences are at different stages of the project (Miller & Boulton, 2007; Métille, 2024).

Researchers should therefore ensure that participants understand both the opportunities and the limits associated with withdrawal. Clear communication on this point helps align expectations and supports informed decision-making throughout the research lifecycle. More broadly, the possibility of revisiting or withdrawing consent illustrates that consent is not simply obtained at the beginning of a study and then presumed to endure unchanged. Ethical research requires ongoing attention to the different decisions that arise throughout the life of a project and to participants’ continuing ability to influence those decisions.

8. SOME SPECIAL CASES

In this chapter, we will examine a few specific cases that challenge the validity criteria set out in this guide namely: minors, students, deception and covert research, data from the internet and public figures.

8.1 DOING RESEARCH WITH MINORS

Research involving minors raises particular challenges with regard to informed consent. Children and adolescents are generally considered a vulnerable population because their cognitive, emotional, and social capacities are still developing (Steinberg, 2009). Their ability to understand the implications of participation, assess potential risks, and make informed decisions may therefore vary considerably from one individual to another. The notion of capacity of

judgment is consequently central when determining whether a minor may validly consent to participation in research (CIOMS, 2016).

Under Swiss law, data-protection rights constitute strictly personal rights and may therefore be exercised by minors who possess the necessary capacity of judgment (Christinat, 2024). Swiss law does not establish a fixed age at which this capacity is acquired. Rather, capacity of judgment must be assessed in relation to the specific decision concerned and the individual's ability to understand its meaning and consequences (Swiss Civil Code, Art. 16). Nevertheless, Swiss human research legislation accords particular significance to early adolescence. For example, the HRA distinguishes between children under the age of 14 and adolescents aged 14 to 17 (Art. 3 let. j-k), reflecting a legislative recognition that many individuals entering adolescence may possess an increasing capacity to participate in decisions concerning research participation (see for example Art. 23 which gives legal significance to the capacity of judgement of adolescent participants when determining the consent requirements applicable to research involving minors). Assessing capacity of judgment requires a case-by-case evaluation that takes account of the minor's maturity, intellectual and emotional development, as well as the complexity and risks of the research.

Where a minor lacks the capacity of judgment required to consent independently, the consent of a parent or legal representative becomes necessary. Parental involvement, however, should not lead researchers to treat minors as passive subjects of decision-making. Even where parental authorization is required, the views and wishes of the minor remain ethically significant. Research involving minors should therefore generally rely on a form of dual consent, combining parental permission with the minor's own agreement whenever this is possible and meaningful. When minors are unable to express their wishes clearly, particular attention should be paid to behavioural signs of discomfort, reluctance, unease, or refusal, which should always be taken seriously (CIOMS, 2016).

Additional caution is required because children and adolescents are often especially sensitive to authority figures. Researchers, teachers, parents, and other adults may exert influence — sometimes unintentionally — on a minor's decision to participate. Ensuring that participation remains genuinely voluntary therefore requires careful attention to how information is presented, how participation is proposed, and how potential pressures or dependencies are managed throughout the research process. Respecting the autonomy of minors means not only protecting them from harm, but also recognizing their developing agency and involving them, as far as possible, in decisions that concern them (Belitz, 2018).

8.2 DOING RESEARCH WITH (YOUR OWN) STUDENTS

Students — particularly those who are new to academic environments — occupy a structurally asymmetrical position in relation to their instructors, which renders them a vulnerable population in the context of research participation (Shen, 2021). This vulnerability stems not only from their relative inexperience but also from the inherent power dynamics embedded in the student-teacher relationship. Instructors hold evaluative authority: they grade assignments, determine academic progression, and often serve as gatekeepers to future opportunities through letters of recommendation or mentorship. These roles place instructors in a position of influence that can inadvertently pressure students into participating in research, even when such participation is framed as voluntary.

The ethical implications of this dynamic are substantial. Students may perceive a request to participate from a researcher, lecturer, supervisor, or other individual in a position of academic authority as carrying implicit expectations, even where participation is entirely voluntary. As a result, they may feel reluctant to decline participation for fear that doing so could negatively affect their academic experience, future opportunities, or relationship with the individuals concerned. This perceived obligation undermines the principle of informed and voluntary consent. Even subtle cues — such as a professor's enthusiasm for the project or the setting in which recruitment occurs — can contribute to a sense of coercion.

For these reasons, it is strongly discouraged to recruit one's own students into research studies. Doing so risks compromising the integrity of the consent process and may lead to ethical violations, especially if participation is tied to academic incentives such as course credit or extra marks. Even when recruiting students who are not directly supervised, researchers must remain vigilant. Alternatives to participation should always be offered — such as equivalent assignments or unrelated activities — to ensure that students do not feel penalized for opting out (Streiner et al., 2024). Transparency, neutrality in recruitment, and a clear separation between academic evaluation and research involvement are essential safeguards to protect student autonomy and uphold ethical standards.

8.3 DOING RESEARCH INVOLVING DECEPTION

In some areas of research, particularly in psychology and the behavioural sciences, researchers may occasionally rely on deception, that is, the deliberate withholding of relevant information or the provision of incomplete or misleading information about certain aspects of a study. Unlike covert observation–discussed in the following section–deception does not necessarily involve concealing the existence of the research itself. Participants are generally aware that they are taking part in a study, but some elements relating to its purpose, procedures, hypotheses or expected outcomes are not disclosed to them in full.

Because deception departs from the ordinary requirements of informed consent, its use raises important ethical concerns and requires careful justification. Professional ethics guidelines generally regard it as acceptable only under restricted circumstances and when the scientific or social value of the research clearly outweighs the ethical costs associated with withholding information. Three conditions are typically regarded as essential. First, the research should address a question of sufficient scientific or societal significance. Second, no alternative design should be capable of producing comparable findings without the use of deception. Third, the deception should expose participants to no more than minimal risk or harm. [7] Only when these conditions are satisfied can a departure from ordinary consent procedures be ethically justified. Even then, researchers remain responsible for minimizing any adverse consequences associated with the deception. Particular attention should be paid to potential psychological, social or reputational harms, and the anticipated benefits of the research should clearly outweigh the ethical costs involved.

Debriefing will generally constitute an essential component of the ethical management of deception. Participants should be informed of the true nature and purpose of the study as soon as this can be done without compromising the research. Debriefing helps restore transparency, allows participants to understand why deception was considered necessary, and provides an opportunity to ask questions or express concerns. Where appropriate, participants should also be offered the possibility of withdrawing their data once fully informed. Although some authors have argued that debriefing may exceptionally be omitted under highly restricted circumstances, this remains a controversial position and should be approached with caution (Sommers & Miller, 2013).

8.4 DOING RESEARCH BY RESORTING TO COVERT RESEARCH

Covert research refers to situations in which people are observed or studied without being aware of the research. Historically, such methods played an important role in certain areas of the social sciences because they allowed researchers to access behaviours, interactions, and social phenomena that might otherwise remain inaccessible (Bonnet & Robert, 2009). However, they also remove the possibility of obtaining informed consent before data collection begins and therefore raise significant ethical concerns.

[7] For further guidance on the ethical use of deception in research, see the American Psychological Association's Ethical Principles of Psychologists and Code of Conduct (American Psychological Association, 2017), in particular Standard 8.07 (“Deception in Research”). See also the Health Research Authority's guidance on proportionate approaches to information provision and consent processes (Health Research Authority, n.d.).

Like deception, covert methods should be regarded as exceptional rather than routine research practices (Lauder, 2003). Their use should be limited to situations in which the research addresses an important scientific or social question, no practicable alternative method is available, and the absence of consent gives rise only to risks that are minimal and proportionate to the expected benefits. [8] Where feasible, participants should be informed after the fact and given an opportunity to decide whether information collected about them may be retained and used for research purposes. When post-hoc information or consent is impracticable, the ethical justification for proceeding without consent becomes correspondingly more demanding.

Among the areas of research in which covert methods are most commonly regarded as justified are studies of discrimination, exclusion, and systemic bias. These issues are not only of substantial social importance, but also concern behaviours and practices that may be concealed, altered, or denied when individuals are aware of being observed. In such contexts, covert observation may represent one of the few means of obtaining valid evidence about how people actually behave in natural settings rather than how they choose to present themselves when they know they are being studied (Lauder, 2003; European Commission, 2021).

8.5 DOING RESEARCH WITH DATA FROM THE INTERNET

Research involving internet and social media data has generated extensive ethical debate in recent years. The increasing availability of online content has created valuable opportunities for research while challenging traditional assumptions regarding privacy, informed consent and the protection of research participants (Franzke et al., 2020; Williams et al., 2017).

A central finding of this literature is that the public availability of online content does not automatically make it ethically available for research. Even when information is publicly accessible, it is usually shared within a particular context and with certain expectations regarding who will see it and how it will be used. Ethical assessment therefore requires researchers to consider not only whether data can be accessed, but also whether their collection and reuse are consistent with the expectations of those who shared them (Sloan & Quan-Haase, 2016). This is especially important when online content relates to sensitive topics such as health, migration, religion, political beliefs, sexuality, financial difficulties or personal relationships. Researchers should therefore consider not only the scientific value of such data, but also the potential consequences that their collection, analysis and publication may have for the individuals and communities concerned (Franzke et al., 2020; Straume et al., 2018).

Researchers should also remain attentive to the legal and contractual conditions governing access to online data. Terms of service, privacy policies, intellectual-property rights and platform-specific restrictions may shape whether data can be collected, stored, shared or republished for research purposes. Respecting these conditions forms part of responsible research practice, although compliance with platform rules alone does not resolve the ethical questions raised by internet research (Straume et al., 2018).

Ultimately, research using internet and social media data should be guided by the same principles that apply to other forms of research involving human beings: transparency, proportionality, respect for persons and careful assessment of potential harms. The digital nature of the data does not remove researchers' ethical responsibilities. Rather, it requires those responsibilities to be exercised with particular attention to context, reasonable expectations and the potential consequences of making online content part of the research record (Franzke et al., 2020).

[8] For further guidance on research conducted without consent and the ethical conditions that may justify such practices, see the UK Data Service guidance (UK Data Service, n.d.).

8.6 RESEARCH WITH PUBLIC FIGURES

While all individuals have a right to privacy, certain categories of people are considered to have a "restricted" right to privacy due to their public roles or notoriety. This is the case of public figures who "cannot claim a private life as broad as that of a private individual. It is accepted that their private life is somewhat smaller and that the events that relate to their public activity or that are at the origin of their celebrity do not belong to their private life" (Métille, 2018:12).

When conducting research on public figures, researchers are generally allowed to use publicly available data about them without needing to obtain consent. This said, when the research goes beyond publicly accessible facts, for example when it involves direct participation or the use of sensitive data, obtaining consent remains necessary. Indeed, reduced expectation of privacy does not equate to a loss of autonomy or protection. Researchers must therefore carefully navigate the boundary between public interest and individual rights, including privacy, autonomy, and data-protection. Even if certain aspects of a public figure's life are considered part of the public domain, ethical research demands transparency, respect, and voluntary participation.

Finally, it is important to note that public figures fall into two broad categories: *absolute persons of contemporary history*, who are widely recognized for their positions, functions, or achievements (e.g., elected officials, athletes, scientists, artists); and *relative persons of contemporary history*, who are known primarily for a specific event or circumstance (Swiss Federal Supreme Court, 2001, BGE 127 III 481)). With regard to the latter, it should be noted that their fame is not lasting, as it stems from a specific event. When conducting research, this distinction has important implications for the lawful use of personal data. Information concerning relative persons of contemporary history may be used without their consent only if it directly relates to the event that generated their public recognition. Outside of that context, such individuals do not fall within the scope of public interest, and the processing of their data without consent becomes legally and ethically problematic. Researchers must therefore exercise caution and ensure that any use of personal data is justified by a clear and relevant connection to the public event in question.[9]

9. RECOMMENDATIONS

Recommendation 1 – **Treat consent as a process, not as a form.** Consent should be understood as an ongoing practice of communication and decision-making rather than as a document signed at a single point in time.

Recommendation 2 – **Build consent around participants' understanding.** The validity of consent depends less on the amount of information provided than on participants' ability to understand its implications.

Recommendation 3 – **Say only what you can actually deliver.** Information and consent materials should accurately reflect research practices and avoid promises that cannot realistically be fulfilled.

Recommendation 4 – **Design consent with future data uses in mind.** Anticipated sharing, archiving, and reuse of data should be incorporated into the consent process from the outset.

Recommendation 5 – **Make future uses specific enough to be meaningful.** Participants should be able to understand who may access their data, for what purposes, and under what conditions.

[9] For further discussion of the distinction between absolute and relative persons of contemporary history under Swiss law and its implications for the processing of personal data, see Legler (2021).

Recommendation 6 – **Revisit consent when circumstances change.** Significant modifications to the research, the risks involved, or the intended uses of data should trigger renewed discussion about consent.

Recommendation 7 – **Pay particular attention to power and dependency.** Researchers should actively identify and mitigate situations in which participants may feel unable to refuse, withdraw, or express disagreement.

Recommendation 8 – **Protect confidentiality without overstating anonymity.** Researchers should explain both the safeguards they implement and the limits of protection that can realistically be achieved.

Recommendation 9 – **Adapt consent procedures to the people involved**. The form, language, and documentation of consent should be tailored to participants' capacities, circumstances, and vulnerabilities.

Recommendation 10 – **View consent as part of research accountability**. Obtaining consent creates ethical and, often, legal responsibilities that continue throughout the lifecycle of the research and the data it generates.

10. FURTHER READINGS AND USEFUL WEB LINKS

If you are interested in general guidance on research ethics, you can consult the *International Ethical Guidelines for Health-related Research Involving Humans* published by CIOMS: https://cioms.ch/wp-content/uploads/2017/01/WEB-CIOMS-EthicalGuidelines.pdf. Although they are geared toward biomedical research, they offer highly relevant and universally applicable guidance.

If you are interested in advice on ethics in the social sciences, you can consult the document *Ethics in Social Science and Humanities* published by the European Commission: https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/guidance/ethics-in-social-science-and-humanities_he_en.pdf.

If you are interested in practical documentation and templates relating to consent, you can visit the swissethics website: https://swissethics.ch/en/templates.

Also, you can find practical information and tutorials about informed consent in several previous FORS webinars on the topic at https://forscenter.ch/data-management-webinar-series/.

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