



Co-designing Citizen Social Science for Collective Action

#2.3 Report on Informed Consent Procedure Requirements and Challenges

Innovative Moments of Informed Consent in Practice



This document is shared under Creative Commons Attribution 4.0 International License (**CC BY 4.0**).

Cite as: Malik, Mariam, Wintersteller, Teresa, Bonhoure, Isabelle, Arza, Valeria, Actis, Guillermina, Mayer, Katja, Wöhrer, Veronika, Perelló, Josep, & Danz, Shenja Vasanthi Kumari (2021). CoActD2.3: Report on Informed Consent Procedure Requirements and Challenges. Zenodo. <http://doi.org/10.5281/zenodo.6078642>

DISCLAIMER: The present Project Deliverable has been submitted to the European Commission for review. The information and views set out in this report are those of the author(s) and do not necessarily reflect the official opinion of the European Union. Neither the European Union institutions and bodies nor any person acting on their behalf may be held responsible for the use which may be made of the information contained therein.

Date – 28 December 2021

Dissemination level – Public

Responsible Partner – University of Vienna (UNIVIE)

Author(s) – Mariam Malik, Teresa Wintersteller, Isabelle Bonhoure, Valeria Arza, Guillermina Actis, Katja Mayer, Veronika Wöhrer, Josep Perelló, Shenja Vasanthi Kumari Danz

Reviewers – Teresa Wintersteller, Stefanie Schürz, Isabelle Bonhoure, Valeria Arza, Guillermina Actis, Katja Mayer, Veronika Wöhrer, Josep Perelló, Shenja Vasanthi Kumari Danz, David Scheller



The CoAct project has received funding from the European Union's Horizon 2020 Research and Innovation programme under grant agreement No. 873048

Document History			
Version	Date	Contributors	Comments
1.0	20 July 2020	Mariam Malik, Teresa Wintersteller	<i>Working Paper</i> on informed consent approaches and challenges shared with all partners
2.0	6 September 2020	Stefanie Schürz, Katja Mayer, David Scheller, Isabelle Bonhoure	<i>Working Paper</i> reviewed by partners
3.0	23 November 2021	Mariam Malik, Teresa Wintersteller, Isabelle Bonhoure, Valeria Arza, Guillermina Actis, Katja Mayer, Veronika Wöhrer, Shenja Vasanthi Kumari Danz	First version of D2.3 shared with all partners
4.0	13 December 2021	Teresa Wintersteller, Isabelle Bonhoure, Valeria Arza, Guillermina Actis, Katja Mayer, Veronika Wöhrer, Shenja Vasanthi Kumari Danz, Josep Perelló	First version of D2.3 reviewed by partners
5.0	28 December 2021	Mariam Malik, Teresa Wintersteller, Isabelle Bonhoure, Valeria Arza, Guillermina Actis, Katja Mayer, Veronika Wöhrer, Josep Perelló, Shenja Vasanthi Kumari Danz	Final version of D2.3



Table of Contents

List of Figures	7
List of Tables	7
List of Abbreviations	8
Executive Summary	10
1. Introduction	11
2. Developments of Informed Consent	12
2.1 The History of Informed Consent	14
2.2 Legal and Guiding Frameworks	15
3. Informed Consent: Foundations and Points of Criticism	20
3.1 Centring Individual Autonomy	21
3.2 Points of Criticism Based on Research Practices	22
4. Alternative Approaches to Informed Consent	23
4.1 Relationality and Particularity in Informed Consent	23
4.2 Reflexivity, Positionality, and Informed Consent as a Process	25
4.3 Inequality, Power, and Informed Consent	27
4.4 Informed Consent and Community	29
4.5 Informed Consent and Citizen Social Science	31
5. Informed Consent in Practice	32
5.1 CoAct General Information and Concepts	32
5.2 Informed Consent Activities in the Consortium	33
5.3 RIA #1—Mental Health	36
5.3.1 Introduction	36
5.3.2 Target Groups	37



5.3.3 Informed Consent Activities	38
5.3.4 Challenges	41
5.3.5 Innovative Moments	44
5.3.6 Reflections on Collaborative Work Within the Consortium	50
5.4 RIA #2—Youth Employment	51
5.4.1 Introduction	51
5.4.2 Target Groups	52
5.4.3 Informed Consent Activities	53
5.4.4 Challenges	56
5.4.5 Innovative Moments	58
5.4.6 Reflection on Collaborative Work Within the Consortium	65
5.5 RIA #3—Environmental Justice	66
5.5.1 Introduction	66
5.5.2 Target Groups	67
5.5.3 Informed Consent Activities	68
5.5.4 Challenges	71
5.5.5 Innovative Moments	74
5.5.6 Reflections on Collaborative Work Within the Consortium	77
5.6 Co-Evaluation	78
5.6.1 Introduction	78
5.6.2 Informed Consent Activities	79
5.6.3 Challenges	79
6. Concluding Remarks	80
6.1 Informed Consent as a Process	81



6.2 Relationality and Particularity	81
6.3 Reflexivity and Positionality of the Researchers	82
6.4 Community Aspects in Informed Consent	83
6.5 CoAct Policies	83
7. Appendix	86
8. References	86



List of Figures

Figure 1: Informed consent as the nexus of ethics, research ethics, and legal requirements	13
Figure 2: Citizen Social Science in Action with citizen groups, a specific concern, and with the support of the Knowledge Coalition	33
Figure 3: Activities with CoRes and IC-related contents in RIA #1	44
Figure 4: IC-related contents from the open call for CoRes video	46
Figure 5: IC-related contents from the Chatbot promotional video	47
Figure 6: IC-related contents in the printed Research Diary for CoRes	48
Figure 7: Examples of the IC procedure in the “CoActuem per la Salut Mental” Telegram Chatbot	49
Figure 8: Visualisation of data management process in RIA #2	60
Figure 9: Screenshot from the Actionbound “Action Research on Education and Employment”	63
Figure 10: Screenshot from a video in the Actionbound “Action Research on Education and Employment” on how to anonymise and pseudonymise data	64
Figure 11: Screenshot from a quiz in the Actionbound “Action Research on Education and Employment”	64
Figure 12: CoAct research cycle for RIA #3 on environmental justice	67
Figure 13: Excerpt from the RIA #3 “CoAct–Ciencia Ciudadana para la Justicia Ambiental en el Riachuelo” informative video (in Spanish)	75
Figure 14: Excerpt from IC Gform for RIA #3 “CoAct – Ciencia Ciudadana para la Justicia Ambiental en el Riachuelo” (in Spanish)	76
Figure 15: Documentation of the IC procedure on Gitlab in RIA #3	77

List of Tables

Table 1: Questions on Reflection Sheets	36
Table 2: Informed consent activities in RIA #2	55



List of Abbreviations

ACUMAR	Autoridad de Cuenca Matanza-Riachuelo
CLR	Citizen-led research
CoAct	Co-Designing Citizen Social Science for Collective Action
CoRes	Co-researchers
CSO	Civil society organisation
CSS	Citizen social science
DPO	Data Protection Office
E&T up to 18	Education and Training up to 18
FABA	Frühe AusBildungsAbbrecherInnen
FARN	Fundación Ambiente y Recursos Naturales
FSMC	Federació Salut Mental Catalunya
GDPR	General Data Protection Regulation
Gform	Google Forms
IC	Informed consent
KC	Knowledge Coalition
OKF	Open Knowledge Foundation
PAR	Participatory Action Research
PISA	Plan Integral de Saneamiento Ambiental
PLR	Participant-led research
REC	Research ethics committee
RIA	Research and Innovation Action



RRI Responsible Research and Innovation

UB Universitat de Barcelona

UNIVIE Univeristy of Vienna

UNSAM Universidad Nacional de San Martín

WP Work Package

ZSI Zentrum für Soziale Innovation



Executive Summary

In *CoAct (Co-Designing Citizen Social Science for Collective Action)*, the Research and Innovation Actions (RIA) on mental health, youth employment, and environmental justice engage with co-researchers (CoRes) in the research process who are directly affected by social concerns. By employing a participatory approach, the project demonstrates the scientific relevance of co-designed knowledge production. *CoAct* not only contributes to the citizen social science (CSS) approach, but to ongoing discussions on how to implement informed consent (IC) in CSS projects by highlighting specific challenges and reflecting on innovative moments from the research practice.

This report constitutes the Deliverable 2.3, *Report on Informed Consent Procedure Requirements and Challenges. Innovative Moments of Informed Consent in Practice* for Work Package 2 (WP2), and describes continuing discussions about how regulations like the *General Data Protection Regulation 2016/679* (GDPR, European Commission, 2018b) and other research-guiding principles impact CSS and their IC practices. By recognising IC as a nexus of legal requirements, research ethics, and research practice, we go beyond ‘formalised informed consent,’ which is a legal agreement governed by the GDPR, among others, and acknowledge its ethical dimensions. This report uses relational understandings to depict ethical dimensions of IC, and alternative approaches as to how it can be conceptualised. This is closely linked to a processual understanding, which requires incorporating scientific responsibility and accountability into its social contexts and in recognition of power imbalances that shape research and IC practices. Moreover, acknowledging that IC is an individual and autonomous decision, but also a relational and socially embedded practice, can sharpen how ethically relevant moments of obtaining and/or refusing consent are perceived. Community-based concepts of consent highlight scientific responsibility towards individuals as well as communities in terms of, for example, representation and demonstrate the broader importance of social responsibility outside of the specific project.

The report’s primary objective is to combine theoretical discussions in the fields of IC and research ethics with participatory approaches and to provide insight about challenges and best



practices in CSS research cycles. In that sense, we aim to establish a reflexive space to explore the ethical dimensions of IC within CSS. The report concludes with our policy proposals for researchers that serve as guidelines for conceptualising consent as a social endeavour.

1. Introduction

The *Report on Informed Consent Procedures Requirements and Challenges* is a Deliverable within Work Package 2 (WP2). Its overarching purpose is to combine theoretical ethical concepts, contemporary discussions on legal requirements, and the Research and Innovation Actions (RIA) research practice within *CoAct*. To better distinguish between informed consent (IC) approaches, we use ‘formalised informed consent’ to describe IC as a legal agreement requested under the *General Data Protection Regulation* (GDPR) for data processing and ‘informed consent’ to address its broader ethical dimensions.

Informed consent has become an integral component of research projects. Regulations, especially the GDPR and guidelines like the *Responsible Research and Innovation* (RRI) principles, as well as ethics committees, shape how IC is currently perceived and applied. The GDPR’s impact and its data protection requirements concerning the further development CSS and Open Science are an ongoing discussion (Suman & Pierce, 2018; Gefenas et al., 2021; Duchesne & Ferry, 2021). We contribute to the discussion about implementing IC in CSS by presenting innovative insights from the RIA research practice and by providing *CoAct* policies for IC procedures derived from our continuous reflections throughout the project.

This report discusses developments in IC, namely from the medical research field and the historical context of human rights violations in the name of science. We illustrate the implications of these origins for contemporary ethical challenges, especially in terms of applying IC to social sciences or participatory research. Furthermore, other relevant values and norms influence the work carried out in the *CoAct* project, including those from the GDPR legal framework, the RRI paradigm, and the Open Science movement (*Chapter 2*). Next, we address principles concerning the validity of IC and the underlying value of individual autonomy in light of criticisms towards the notion of an autonomous subject who possesses the ability to consent. First, the individual is



embedded in social structures, meaning decision-making processes are inherently influenced by their social surroundings. Second, the social sciences are premised upon the idea that research is a process. Therefore, when IC procedures are only implemented at the beginning of a social science research project, they fail to do justice to its process-oriented approach (*Chapter 3*). Following these critiques on centring individual rights within contemporary legal frameworks and their interpretations of consent, we discuss alternative approaches to IC that acknowledge the relationality of individuals and their embeddedness in social structures in greater detail. This section focuses on ethical dimensions of how consent can be conceptualised as a social endeavour (*Chapter 4*). *Chapter 5* describes both the *CoAct* project and the RIA on mental health, youth employment, and environmental justice. This chapter describes the research process, and gives information on target groups, and the IC procedures of each RIA. Furthermore, it provides accounts of collaborative activities and outcomes from the ongoing and collaborative, reflexive process within the research cycles, paying special attention to challenges and innovative moments. Finally, *Chapter 6* offers our closing remarks, where we draw upon the theoretical discussions from *CoAct* and its innovative practices before concluding the report with policy recommendations for other projects on IC in the research process.

2. Developments of Informed Consent

Informed consent has gained prominence in research, especially in debates surrounding research ethics. This development can be traced to the biomedical research field, where the concept's importance emerged from a historical lack of protection for human subjects in medical science and the prioritisation of scientific research over the individual interests (Oberle et al., 2019, 3). Today, the prevailing understanding of IC is primarily rooted in Anglo-American developments (Hostiuc, 2018, 15), which this chapter draws upon to illustrate its history and implications for contemporary ethical discussions. Besides these historically relevant frameworks, we address other values that influence the work from the *CoAct* project. After describing the ongoing discussions of how the GDPR has impacted the research practice and exploring how such data protection requirements might hinder the progress of CSS and Open Science (Suman & Pierce, 2018; Gefenas et al., 2021; Duchesne & Ferry, 2021), we illustrate the importance of ethical



research and IC as a general personal right. At the same time, however, some principles are not always easily implemented in participatory research and thus require transparency and flexibility throughout negotiations between the involved actors. Research is also informed by the RRI approach, which advocates for a stronger alignment between research, societal values and needs, and highlights the responsibility of (social) science in ensuring this. A core principle in the CSS framework is its emphasis on promoting inclusive and reflexive research about socially relevant problems. Likewise, Open Science approaches prioritise the accessibility, reproducibility, and reusability of scientific knowledge, which helps to advance the democratisation of scientific knowledge production and responsible research practices in relation to research participants as well as society.

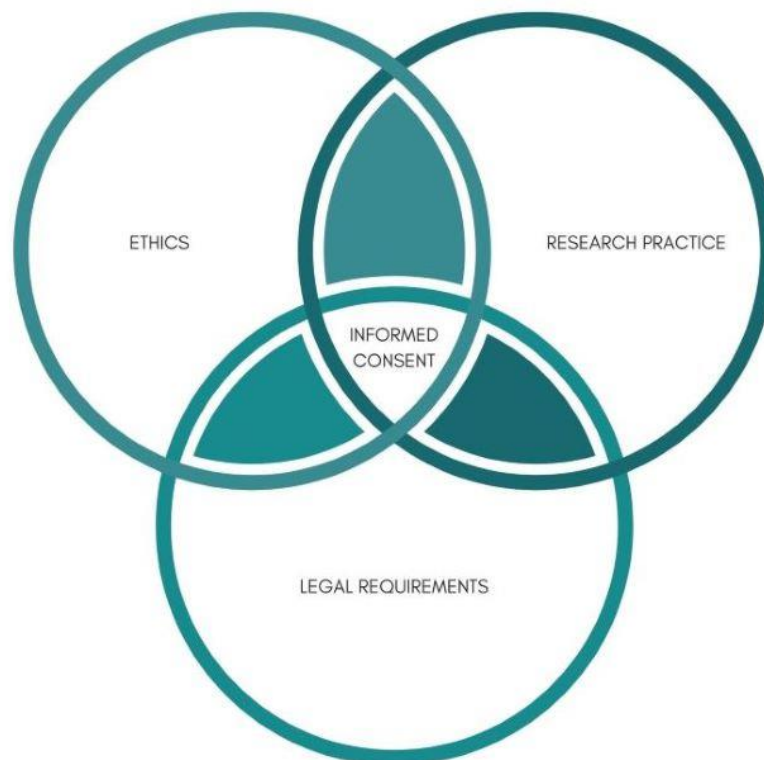


Figure 1: Informed consent as the nexus of ethics, research ethics, and legal requirements

Accordingly, we recognise IC as the outcome of the nexus of ethics, research practice, and legal frameworks—all of which determine IC. The next chapters illustrate how these areas also



overlap; for example, how historically unethical research led to stricter consent requirements, or how ethics, per se, informs how IC is conceptualised.

2.1 The History of Informed Consent

The first steps towards establishing ethical guidelines for conducting research arose from the *Nuremberg Code* in 1947, which was a direct response to the human rights violations committed under National Socialism between 1933 and 1945 (Miller & Boulton, 2007, 2202). The *Code* prescribed voluntary consent, i.e., consent given without coercion and with the subject's comprehension; clearly stated risks and benefits of a study; as a condition for medical experiments (Nijhawan et al., 2013; Weindling, 2001). From a legal perspective, *Salgo v. Leland Stanford Jr. University Board of Trustees* of 1957 is considered the starting point for contemporary understandings of IC. In this case, the attending physician was found guilty of not providing sufficient information to the participants for them to make rational decisions for or against a procedure (Hostiuc, 2018, 40). Because of the historical lack of individual protection, early discussions on IC were characterised by an emphasis on the researcher's obligation to inform. Later, the additional matter of the participant's understanding of the information and the right of authorisation or refusal emerged (Sutrop & Lök, 2020, 214).

The World Medical Association's *Declaration of Helsinki* from 1964 as well as the *Belmont Report* from 1979 have considerably influenced how medical research is implemented by defining ethical principles for conducting research with human subjects (Nijhawan et al., 2013, 135). To date, both are regularly updated and still serve as reference points for conducting ethical research. At the international level, the *Nuremberg Code* and the 2013 revision of the *Declaration of Helsinki* entail ethical research standards, including IC procedures (Resnik, 2019, 2). Following these developments in the medical realm, practical codes of conduct and ethical research guidelines were also established in the social sciences, where ethical review boards began applying guidelines to projects that are informed by the international instruments mentioned above. However, since the idea of protecting social science research subjects is derived from medical research, guiding principles are informed by a particular notion of research and its relation to research subjects (see *Chapter 3*). Current ethical discussions raise the question as to whether



and to what extent these ethical guidelines are sufficiently transferable to the social sciences (Marzano, 2012; Capous-Desyllas et al., 2020).

Medical research reveals a history of exploitation and medical experimentation on people in the name of science (King, 1998; Washington, 2007). The *Tuskegee Syphilis Study* from 1932 is frequently referenced to illustrate violations to the principles of beneficence, justice, nonmaleficence, and research subject autonomy. During this four-decade long study on the natural progression of syphilis, the participating impoverished Black men were deliberately misled about the study's purpose, while being simultaneously denied the known, effective treatment for syphilis (Brall et al., 2017, 28). After concluding in 1972, debates about the *Tuskegee Syphilis Study* largely centred on the absence of consent, which was highlighted as the reason for its unethical nature. However, these debates tended to neglect the structural components of race and class exploitation that enabled the subjects' exploitation (King, 1998, 97). Hence, the exploitative nature of medical research points not only to a lack of ethical standards, but also shows how societal power dynamics influence research ethics and shape research relations between the dominant scientists and oppressed research subjects. When describing the *Final Report of the Tuskegee Syphilis Study Ad Hoc Advisory Panel from 1973*, King (1998, 98) states that this teaches us “not only that the vulnerable can easily be exploited, but also that those in positions of authority cannot always be expected to act in the best interest of [research] subjects.” Hence, it is essential for contemporary discussions of research ethics to address societal power relations in terms of race, gender, class, age, and disability—and how these may contribute to the exploitation of certain groups in scientific research.

2.2 Legal and Guiding Frameworks

Besides the historically relevant instruments for conducting contemporary ethical research, various legal and ethical frameworks outline research participants' IC and the accurate documentation of consent procedures. In *CoAct*, the GDPR and approaches from RRI and Open Science are vital to shaping the research practice, especially regarding IC practices. Furthermore, *CoAct* builds on scientific codes of conduct for scientific integrity and quality control, as well as on ethical considerations for research practices in the social sciences and humanities such as the



Ethics in Social Sciences and Humanities (European Commission, 2018a). Finally, CoAct activities are guided by national legal frameworks and institutional policies. These contexts must all be considered when describing the environment for the IC process. In the following, we will highlight three areas that were particularly influential in planning the CoAct IC activities: the GDPR, RRI, and Open Science.

General Data Protection Regulation

The GDPR (2018) is the basis of general data protection law in the EU. It explicitly lists the following six principles for processing personal data in *Article 5*:

1. Lawfulness, fair processing, transparency
2. Purpose limitation (processing only for specified, explicit, and legitimate purposes)
3. Data minimisation ("adequate and relevant to the purpose and limited to what is [...] necessary")
4. Accuracy ("all reasonable steps must be taken to ensure that [inaccurate] personal data are erased or rectified without undue delay")
5. Storage limitation (data must be "kept in a form which permits identification of data subjects for no longer than is necessary [...]")
6. Integrity and confidentiality ("appropriate security of personal data [...], including protection against unauthorised or unlawful processing and against accidental loss, destruction or damage").

The actor responsible for the data—often called the data controller—must demonstrate compliance with all six principles. This also applies to the sciences and especially to the social sciences, which often handle sensitive personal data. The collection, processing, and use of personal data are therefore subject to data protection and research ethics regulations. Thus, IC is of central importance to all scientific research. Consent to participate in scientific research must be voluntary, the person must be able or allowed to consent, the information must be understandable, and the consent given must be revocable.

Consent is considered an expression of the right to informational self-determination derived from general personal rights. The consent process, and especially the consent form, is frequently the only document that governs the cooperation between research participants and researchers.



In participatory research projects, where the outcome can neither always be precisely determined nor the data collection precisely planned, some central principles of the GDPR are not always directly compliant or may require intensive dialogue during the research design phase. Some examples include determining a project's exact purpose beyond completion or openly sharing data with the research subjects, other collaborators, or even publicly (see the section on Open Science below). In participatory projects, the IC procedure must be designed very transparently and integrate feedback cycles, and should entail dynamic IC management. This means that if the project's circumstances or the research process itself change—or research participants change their minds—that the IC be flexible enough to be renegotiated or revoked. *Chapter 4* elaborates upon issues that arise by applying GDPR principles to dynamically changing, participatory research projects.

Protecting the rights of all research participants requires social scientists and other involved organisations like NGOs to apply diverse measures such as data separation, encrypting data files, pseudonymisation, or data anonymisation. A research data management plan, which includes the risks of the collected data as well as measures to protect individuals, is a valuable guide for managing the technical activities behind the research work, among others. It also helps to determine which data can be shared with whom at an early stage, along with which set of rules to follow.

Responsible Research and Innovation (RRI)

“Responsible Research and Innovation is a transparent, interactive process by which societal actors and innovators become mutually responsive to each other with a view to the (ethical) acceptability, sustainability and societal desirability of the innovation process and its marketable products.” (Schomberg, 2013)

Responsible Research and Innovation (RRI) is an approach to designing and managing research and innovation processes. At its core, RRI is about a stronger alignment between research and innovation, on the one hand, and societal values and needs on the other. Appropriate procedures, which particularly include the early involvement of stakeholder groups, users, and citizen—as well as drawing on additional sources of knowledge—are intended to ensure greater reflexivity in research and innovation design and governance and place it on a broader, more



diverse, and thus more legitimate footing. Ultimately, RRI initiated a paradigm shift in research and innovation governance, including for the social sciences, by no longer predominantly focusing on technoscientific- and innovation-induced risks and their reactive–regulatory containment. Rather, it emphasised the most democratic, inclusive possible understanding of which futures should be promoted through scientific research and innovation. RRI shifted the perspective of scientific research and innovation, as well as governance, to an anticipatory stance, to first ask what matters and then (co-)design potential solutions. In summary, RRI encourages all actors to make research and innovation more diverse and inclusive, open and transparent, anticipative and reflective, as well as responsive and able to adapt to changes.

CoAct is designed from the ground up in line with RRI principles. The project not only builds on all partners' longstanding experiences in working with these features, but also on an intensive and highly reflexive collaborative process to design the project's ethical framework. This process facilitates thoroughly assessing and discussing issues concerning data protection, gender equality, governance, open access, and the employed formats of participation and public engagement. At the same time, it is worth noting all participatory forms of social science have long dealt with these issues, which represents an essential stepping stone in addressing longstanding problems surrounding the power differentials between researchers and research subjects. However, the RRI—along with GDPR principles—offered valuable guidance for designing the project's policies and developing its process governance. Likewise, RRI provides useful principles for both guiding how the consent process and associated forms are developed, and a flexible approach given the highly variable circumstances of the research project. However, the notions of "becoming mutually responsive to each other" (Schomberg, 2013) and "responsibility" (Felt, 2017) once again challenge the common understanding of research ethics review boards as well as well-established, project-based logics of interactions between researchers and research subjects. Therefore, RRI can serve as set of principles, but not as a blueprint for actions.

Open Science



Like RRI, Open Science shares its basic values of openness, inclusion, and democracy. Above all, RRI focuses on a responsible process that involves all relevant stakeholders. When viewed through this lens, RRI also provides a framework for Open Science, which is premised upon all forms of scientific knowledge being openly shared as early as is practical in a research process. Thus, Open Science entails the accessibility, reproducibility, and further reusability of scientific findings and research data, including those produced in the social sciences and humanities. As an outcome of the digital transformation, the *modus operandi* of science has also changed: Researchers increasingly use online tools to collaborate, share data and educational materials, and communicate via social media—both with their colleagues and the wider public. Therefore, Open Science belongs to a much broader shift in networked societies that are experimenting with new modalities of co-creation, shared production, use and (re-)distribution of knowledge, and the realisation of new environments for public engagement and participation.

Most contemporary scientific publications are primarily available electronically and thus no longer bound by the economy of printing. Open Science argues that access to publicly funded research should be open and free of charge to readers. This principle is already mainstreamed in EU research funding, which mandates access to scientific publications (*open access*) as well as their underlying data (*open research data*). However, Open Science also includes other features like: *Open source/open methods*, which provide access to source code and detailed information on the research methods used; *open infrastructures*, which concerns the governance and structural sustainability of technical platforms needed for research and collaboration; *open evaluation*, which increases the transparency of assessing scientific performance and review processes; *open education*, which enables the creation and free use of accessible educational resources for teaching and training; *citizen science*, which promotes co-designing or collaborating on scientific projects with interested individuals, groups, or organisations that share a social concern. Therefore, CSS initiatives like CoAct advocate for opening science up and increasing the democratisation of knowledge production that aligns with principles of responsible research and innovation. However, combining citizen participation with opening the research process up involves several challenges. For example, when designing optimal IC procedures, all aspects



mentioned above that apply to the open policy of the research process must be considered ethically and legally from the project's onset.

Both institutional review boards and ethics committees—once again—act as a bottleneck here, but are also an important touchstone for ensuring that the approach does not conflict with other applicable regulations (Grant & Bouskil, 2019). While being responsible for ethical and legal compliance, these actors are often hesitant to or overwhelmed by Open Science efforts, especially when ethically sound research designs do not align with planning the IC procedure. For example, open data policies impact the mode of cooperation with citizens and require strong ethical principles and research integrity in participatory projects. They must also adhere to the GDPR, as described above. Hence, open data policies require a detailed data management plan and must also find their way into the IC procedure. Since IC is the only contract between research participants and researchers or research performing organisations, it is an important aspect of data governance and should define the benefits participants can gain from the data. This is not always easy, especially in novel research fields and unconventional collaborative environments, where participants require training to realise their roles and functions within participatory projects. Such a broad IC debate often produces scepticism and reluctance to cooperate. Nevertheless, for ethical and legal reasons, it is important to integrate this challenge into the project's operation, which might therefore require working with specialised facilitators, moderators, or legal experts.

3. Informed Consent: Foundations and Points of Criticism

Discussions surrounding ethics in the (social) sciences have highlighted underlying principles of IC and the values that should be protected. The institutionalised form of IC relies on a liberal understanding of individual autonomy. This chapter addresses the link between IC, the notion of the autonomous subject, and the emerging challenges these create for IC practices in social research.



3.1 Centring Individual Autonomy

Informed consent is closely linked to legal and ethical guidelines that govern its institutionalisation. Insights from the (social) sciences illustrate how the validity of formal consent depends on certain critical elements. Drawing on Sutrop & Lők (2020), the principles of IC are: (1) Disclosing the research project's aims, content, intentions, or finances in recognition of the historical context of (medical) research and as a prerequisite and basis for autonomous decision-making. Next, the (2) participants' understanding of the study they consent to and how the consequences of their consent serve to protect the individual are closely linked to the (3) legal ability to decide, which is sometimes denied to certain groups like children or people with mental illness. Another prerequisite is the (4) voluntariness of the decision (i.e., no persuasion or coercion from others). Besides direct influences, indirect influences on the decision-making process must be considered; for example, access to certain resources like health care throughout participation in the study. In addition, IC needs an (5) act of authorisation where the consenting person authorises another person to include them in the study (Sutrop & Lők, 2020, 219; Beauchamp, 2010, 62f). These preconditions are an expression of the values that consent is intended to protect: respect for individual autonomy, doing no harm, weighing benefits and risks, and the right to equal treatment (Beauchamp, 2010, 36ff.).

Because of a historical lack of individual protection, currently established ethical guidelines strongly emphasise the respect for individual choice, which aligns with the philosophical tradition of the Enlightenment (Hostiuc, 2018, 15). Focusing on assurance rights in the sense of 'rights are trumps' (Tronto, 2008, 185), i.e., assessing the strength of individuals in a society by their rights, is premised upon the liberal notion of prioritising individual rights over collective rights or communal value systems (Lomelino, 2015; Mackenzie & Stoljar, 2000). In this context, autonomy means having the ability to make decisions uninfluenced by their environment and that are based on an understanding of the matter and a personal formation of will. This is rooted in a traditional understanding of autonomy, wherein autonomous decisions are made by a rational, reflexive individual whose acts are uninfluenced by others (Faden et al., 1986, 7f.; Lomelino, 2015, 23ff.). This foundational understanding shapes how IC is generally perceived. The recognised value of autonomous decision-making when conceiving consent has been at the expense of collective



values such as reciprocity or solidarity, along with relations of inequality. This is because focusing on the individual is incompatible with collective interests or social structures, or simply excludes these from a traditional understanding of autonomy (Sutrop & Lök, 2020, 230; Lomelino, 2015, 39f.).

3.2 Points of Criticism Based on Research Practices

Citizen social science builds upon knowledge about IC gained from citizen-led research (CLR), social research, and qualitative and participatory research. In particular, the last two research approaches have been the site of a longstanding debate on how to design IC that respects and takes into consideration the social relations within the research field and context, which are at times shaped by power relations (Malik et al., 2021). Within social research, advances in IC regulations have been critically observed and partly rejected by researchers since ‘procedural ethics’ (Guillemin & Gillam, 2004)—namely measures taken to protect research participants from harm—were not suitable for social research settings. A primary concern in both qualitative and participatory research is that research processes are not ultimately predictable (von Unger et al., 2016; Marzano, 2012; Miller & Bell, 2002). For qualitative research in particular, certain topics along with risks and benefits only arise during the research process itself, which contradicts the notion that formalised IC is obtained at the beginning of a research process after being approved by a research ethics committee (REC).

Moreover, trust is an important component of qualitative and participatory research, which can be compromised by the mandatory requirements for a formalised consent form. This is especially true when working with research partners who prefer other forms of consent (Sikes, 2013, 530). Formalised IC can furthermore lead to ethical dilemmas, particularly when research participants are in a dependent relationship, such as in work environments or when dealing with minors who cannot rely on legal guardians to support their research participation (McCormick, 2012). Notably, a contributing factor to implementing IC within a legal framework is further complicated in participatory research if content, study aim, or the data to be collected is decided upon collaboratively. From a legal perspective, IC does not favour ongoing negotiations between researchers and co-researchers throughout the research process. This critique is well illustrated



by citizen-led research or participant-led research (PLR), as further illustrated below (*Chapter 4.5*).

In order to give justice to the conditions of qualitative or participatory research, alternative approaches to IC assume that establishing it as a formal process alone is insufficient. These approaches see it as an ethical research dimension, which is continuously negotiated throughout a project. Of course, not all research projects require the same level of engagement with IC, e.g., traditional quantitative surveys require different ethical negotiations with research partners than a participatory CSS project. However, most deliberations over power, vulnerability, or relationality in regard to IC are also applicable to less-interactive research processes.

4. Alternative Approaches to Informed Consent

This chapter discusses alternative approaches to IC by broadening its ethical background using relational approaches. It demonstrates that valid IC in participatory research is not only achieved by following legal regulations, but by the continued engagement with the community and co-researchers about consent. Therefore, rather than focusing on how to properly ensure IC under GDPR regulations, the primary objective of this chapter concerns ensuring ethical IC that acknowledges contemporary theories of inequality and autonomy and aligns with CSS research practices.

4.1 Relationality and Particularity in Informed Consent

As elaborated upon in *Chapter 3*, IC is built upon a specific set of ethical principles. Nevertheless, this important foundation has received critiques from multiple perspectives in recent decades. One of the most prominent concepts in this regard is the ‘ethics of care,’ developed by Gilligan (1982), which several authors have applied to IC procedures (e.g., Tronto, 2008; Sutrop and Lõuk, 2020; Osuji, 2018). Instead of applying the concept of consent and its underlying principles like doing no harm, voluntariness to an individual, and rational autonomous subject, the ethics of care develops a relational understanding of autonomy (Mackenzie & Stoljar, 2000).

Gilligan (1982) argues that the idea of moral conduct should consider care and relationships between people, which challenges the notion of autonomous subjects who think and act



independently from others. Within an ethics of care, subjects are recognised as relational beings who are connected to their environment. Therefore, they do not decide autonomously, but act in consideration and inclusion of their social, societal, and historical context. This conceptualisation has prominent implications for IC procedures. For example, determining voluntary autonomous consent requires judging social factors, e.g., histories of oppression or peer pressure.

Ethics of care emerged as a response to a universalist, androcentric ethics that exclude women from scientific knowledge. However, its original iteration largely focused on the experiences of women—and especially white women—which led to critiques and reformulations that stressed how experiences based on, e.g., class or race, must also be factored into ethics (Graham, 2007, 196). Likewise, Hankivsky (2014) advocates for an intersectional ethics of care that more precisely explores how various forms of discrimination influence decision-making processes concerning IC procedures.

Corresponding to an ethics of care, another concern is the particularity of ethics IC procedures. The universalist notion of ethics within Western knowledge systems (Smith, 1999) has been challenged by Indigenous scholars for how it “overlooks their cultural and bias and epistemic positioning” (Hudson, 2009, 131). Ethical guidelines provided by Anglo–Western institutions are often accepted as universal, while neglecting that they, too, are shaped by specific historical and cultural norms (Anthony-Okeke, 2020, 101; Hudson, 2009, 125–126). Therefore, making space for alternative approaches, which stem from critiques of European colonialism and geopolitical power imbalances in scientific knowledge production, requires deconstructing the Western ethical framework as the sole model (Anthony-Okeke, 2020, 101). For example, consent and competence to understand the research project and to voluntarily participate are culturally shaped,¹ meaning there are variations in how consent is interpreted. Moreover, universal ideas of IC processes imply that every individual requires the same information and support for the decision-making process. Rather, the understanding of consent is informed by the social context.

¹ Drawing on Holliday (2013, 540–541), culture is conceptualised as a diverse set of complex cultural practices that does not apply a hierarchical structure to ethical conceptions or meanings.



For instance, countries without institutionalised IC procedures require different procedures and information for research subjects or co-researchers to ascertain the research and all its implications compared to a social context where IC procedures are common. Thus, as Anthony-Okeke (2020) argues, the meaning of IC must extend beyond the hegemony of Western ethics.

4.2 Reflexivity, Positionality, and Informed Consent as a Process

When building IC—not only on a principlist approach, which is usually deployed by ethics committees and based on formal regulations, but on virtue ethics as well—researchers and their competences are at the centre of interest. Within a research context, virtue ethics ask what a researcher must bring to a research endeavour to ethically act and judge (Banks, 2018):

“For example, taking the principle of respect for autonomy, we might ask what it might mean for someone to be respectful towards the autonomy of others. This is one useful way of starting to think about how to put the principles into practice.” (Banks, 2018, 23–24)

A complementary concept allows for both approaches—principlist and virtue ethics—to exist as equivalent values. It is relevant to exploring virtues within the context of research and IC insofar as the researcher is both responsible for applying the rules of IC as, e.g., prescribed by the GDPR and doing so in an ethical manner. As Banks (2018, 27) argues in her remarks on researcher integrity as a virtue, the research practice, which means what is done in a research project, is usually under observation. This is guided by principles and standards outlined in documents (such as “do no harm”). However, it is equally important to reflect upon the researchers’ integrity which,

“in its thick sense, is about researchers being aware of, and critically committed to, the purpose, values, ethical principles and standards of their discipline and/or broader research field; making sense of them as a whole; and putting them into practice in their research work, including upholding them in challenging circumstances.” (Banks, 2018, 30)

Put this way, researcher integrity—in line with RRI principles—also requires a strong aptitude for (self-)reflection and critical thinking (Banks, 2018, 29). Similarly, Guillemin and Gillam (2004) argue that researchers need to reflect upon their positionality in the research process to



recognise “ethically relevant moments” (Guillemin & Gillam, 2004), because positionality affects how researchers acquire their knowledge. Referring to McGraw et al. (2000, 68), Guillemin & Gillam (2004, 276) define reflexivity to mean monitoring one’s own actions closely and remaining alert to the ethical dilemmas that might affect the research process and thus IC. This approach is summarised as ‘ethics-in-practice’ (Guillemin & Gillam, 2004). The governance of research ethics is increasingly organised through the establishment of research ethics committees and institutional review boards, which bear the responsibility to judge the ethical implications of a specific research project. These ‘procedural ethics’ (Guillemin & Gillam, 2004) include guidelines that protect participants from harm and exploitation as well as other potential risks. While European universities often have this formalised procedure in place, it is important to include other ethical considerations that accompany any research project where human participants are involved but are not covered by such procedural ethics. Hence, ethics-in-practice (Guillemin & Gillam, 2004) may help capture unforeseen ethical issues, such as the unanticipated disclosure of sensitive information. Ethics, as a concept that focuses on micro practices in research, is therefore not a one-time affair, but an ongoing process that lasts the whole research project and beyond. Recent discussions on research ethics extend this notion, stressing the need to look beyond the individual’s responsibility for conducting research ethically. In that regard, they advocate for including the social context of the research—namely the multi-layered field of stakeholders such as funders, universities, editors and publishers, colleagues, research subjects, and associations—who all share responsibilities concerning ethics and scientific integrity (Brall et al., 2017, 29). Conceptualising research ethics this way considers the norms and values of social network as well as their potential for ethically developing research. Nevertheless, the researcher’s own responsibility must not be underestimated.

Since it is often not restricted by RECs or institutional regulations, PLR is a leader in addressing how to design IC as a process. For example, in a medical study on the variability of blood lipid levels (Grant et al., 2019), citizen researchers ensured ethical research and consent by installing several modes for discussing these issues, e.g., a webinar, engaging with a research ethicist, providing accessible information, and holding one-on-one meetings. Furthermore, risks and benefits, as well as mitigating actions, were discussed and collected continually throughout the



project. In line with arguments made in other contexts, the authors emphasise the need for dedicated ethical guidelines for participant-led research, as its modes of research-relevant decision-making differ from traditional research studies:

“(...)in PLR, participants and participant-organisers seek to uncover project risks and benefits collaboratively. The very concept of risk and benefit is altered when experimental questions are determined by participants rather than by a Principal Investigator. For example, PLR participants may alter their course of investigation at any point (...).” (Grant et al., 2019, 9)

In summary, the various critics of IC presented in this chapter argue that consent procedures must be designed to account for the social embeddedness of subjects, and thus of the co-researchers as well as the scientific researchers. Furthermore, consent is conceptualised as a process, rather than a singular act, and therefore promotes adaptations to changes in the research project along with the changing conditions of the research partners’ involvement.

4.3 Inequality, Power, and Informed Consent

As mentioned above, handling IC procedures requires taking the greater societal context and power relations that influence consent into account. These implications are well-illustrated by ‘informed refusal’ (Benjamin, 2016), which states that IC is only possible if there is access to informed refusal. Benjamin (2016) describes how asylum seekers’ refusal to undergo DNA testing led to them being scrutinised by authorities and deemed dishonest, which affected the outcome of their asylum procedure. Benjamin argues that this DNA testing violated a main IC principle—voluntariness—despite participants being assured by those responsible that their participation was voluntary. She draws attention to how principles of IC should be understood in the context of society as a whole, which is inextricably linked with the researchers’ responsibility to limit elements that compromise or prevent self-determined decision-making. Mackenzie et al. (2013) draw on the concept of vulnerability for this dilemma and argue that although all people are vulnerable, some people are particularly impacted by exploitation due to power relations, dependency, sociopolitical environments, or limited abilities. Vulnerabilities are often addressed



in a paternalistic, protective manner. However, the authors argue that individual autonomy and agency (e.g., of research participants) can be fostered by building social relations:

“[O]bligations arising from vulnerability extend beyond protection from harm to the provision of the social support necessary to promote the autonomy of persons who are ‘more than ordinarily’ vulnerable.” (Mackenzie et al., 2013, 17)

In practice, this could mean engaging in a discussion about how relationships in research processes, e.g., between co-researchers and researchers—or in a research group—can be shaped to promote autonomy. Overall, this perspective means that assessing the extent to which individuals consent to a research project voluntarily and in an informed manner must also take power differences within a community and society into account. Moreover, researchers bear the responsibility to find ways to support research participants in their agency and decision-making capability by reacting to identified obstacles.

Representation

Issues of representation also relate to consent and power relations, since IC procedures usually include consenting to the publication of the research results, e.g., in journals or non-scientific mediums. However, research participants rarely have any say in how the collected data is analysed, nor how an individual or a group of people is represented. Representation always occurs in a powerful arena where multiple lines of difference are effective (Spivak, 2008). A fundamental critique of Western intellectuals (e.g., Michel Foucault and Gilles Deleuze) or Western scholars is their systematic ignorance of colonial discourses and lack of reflection on their own involvement within them (Spivak, 2008, 21f.). Epistemic violence accompanies representation, which reflects the powerful construction of certain people as 'others' that perpetuates oppressive discourses (*Ibid.*, 42). Recognising the limits of representation regarding the postcolonial 'other' raises the question of how the relationship between researchers and subalterns can become ethical and responsible (Kapoor, 2004; Griffiths, 2018). Spivak's theoretical work provides guidance for an ethical framing of how the postcolonial 'other' is represented. For example, researchers should be able to recognise and avoid essentialisations, deconstruct dominant Western discourses about the subaltern, acknowledge differences and



sameness between themselves and research participants, maintain a sensitive and self-reflective approach, and perceive the structural aspects in particularities (Griffiths, 2018, 309). Therefore, referencing postcolonial theory can prevent researchers from losing sight of representation issues and addressing them within a research team.

4.4 Informed Consent and Community

Community ethics fosters a design of IC processes that helps consider the social embeddedness of individuals as well as the particularity of ethics and consent concepts. The approach sees research ethics as a twofold process comprising its individual and collective notions. Hudson (2009, 127) extends ‘internal ethicality,’ which encompasses protecting the research subject, to ‘external ethicality,’ which includes protecting the entire community and addresses justice, cultural and social responsibility, harm minimisation, as well as respect and compensation for the community. Currently, ethics committees give primacy to individual IC rather than more collective approaches (Hudson, 2009, 126), which often neglect questions of responsibility towards the community and how the research project impacts community as a whole—who has neither consented to nor participated in the research. This is exacerbated by how social justice is rarely the primary concern of either ethics committee or academic researchers, which may cause a project to disregard its role in “creating, intensifying or maintaining inequalities in the wider community” (Hudson, 2009, 127). To counter these tendencies, community ethics can be implemented through concepts such as ‘community consent’ (Xiaomei, 2012), ‘community advisory boards’ (Strauss et al., 2001), ‘community peer review’ (Liboiron et al., 2018), or ‘community consultation’ (Dickert & Sugarman, 2005). These concepts involve individuals or organisations to various extents as representatives of the community that the research project is about or affects. While community consent has the potential to consider consent within a larger societal framework, it must also be discussed in light of restrictive social structures within these communities. For example, institutional regulations, precarious living conditions, or gatekeepers may prevent people from participating in a research project (Leadbeater et al., 2006). CSS has the capacity and means to incorporate some forms of community consent, since individuals who share a common concern or social issue are perceived as partners with equal rights and agency within the research project. This means that representatives of specific



communities who are affected by a problem are ideally involved in the whole research process and, therefore, are also actively involved in the data collection and its interpretation regarding “their” community. Nevertheless, like elsewhere, CSS projects must reflect upon their general definitions of ‘community’ and those of specific communities under study. This helps discern who is excluded from accessing the research project and how the power imbalances within the research group established by professional researchers and co-researchers might affect the consent processes.

Dynamic Consent

One proposal for actively fostering the continuing engagement of research participants or co-researchers in IC is ‘dynamic consent.’ It acknowledges that IC is a process rather than an event and meets the requirements for modifying research participants’ consent concerning the further use of their data. Dynamic consent is a digital concept comprised of the following main features: ongoing communication between researchers and research participants and engaging research participants in the consent process. Kaye et al. (2015, 142) define dynamic consent as

“a new approach for engaging individuals about the use of their personal information. It is also an interactive personalised interface that allows participants to engage as much or as little as they choose and to alter their consent choices in real time.”

Providing research participants with a platform to alter their consent and how they want to engage with an ongoing or future research project takes the fluidity of consent into consideration (Budin-Ljøsne et al., 2017). Furthermore, it enables participants to trace how their data has been used (Kaye et al., 2015, 143) and provide researchers with opportunities to communicate new projects and research results. Although dynamic consent is an important tool for empowering research participants in regards to data usage, a shift to digital consent might also unequally exclude certain participants (Steinsbekk et al., 2013, 899). For example, since not all groups can participate equally in internet-based activities because of issues like lack of access to devices or skills (Kaye et al., 2015, 143). The model of dynamic consent provides research participants information on several occasions. However, “more” information in itself does not always



translate to “adequate” or “relevant” information. Therefore, it is important to note that participants may have difficulties differentiating between relevant and irrelevant information (Steinsbekk et al., 2013, 899), and information overload may hinder an informed decision. Furthermore, it is not yet clear if dynamic consent is usable under GDPR regulations (Tauginiene et al., 2020).

4.5 Informed Consent and Citizen Social Science

Involving citizens in research opens up further debates about IC, because laypeople have traditionally been relegated to the position of research subjects. However, laypersons can occupy both roles in citizen (social) science: as citizen scientists and as research subjects. The novel issues that emerge from this confluence have profound implications on questions of research integrity (Resnik, 2019, 1). Moreover, when research subjects become participants or co-researchers, this implies a significant contextual reorganisation that requires re-examining the emphasis on how ethics committees should protect and prevent harm (Oberle et al., 2019) while also re-evaluating notions of research integrity (Resnik, 2019, 1). Oberle et al. (2019, 1) argue that the shift from research subject to participant stimulates dialogue about how ethics committees review low-risk, participant-led research. Evolving methodological and epistemological perspectives are changing the question of who constitutes the research subject. As described above, some ethical principles that are currently applied to social research originated in the realm of medical research. However, the specific configuration and the degree of research subjects’ vulnerability in social research differs from medical research. For example, the participant or co-researcher’s role is more in line with that of the academic researcher, which is why Oberle et al. (2019, 9) suggest re-examining ethical review boards instead of applying “hegemonic ethical rules” to every research proposal. Furthermore, Resnik (2019) argues that Open Science activities cause new ethical considerations to arise concerning, e.g., data sharing, negotiating authorship, and disseminating results. This is because of the need to balance the protection of individual rights and anonymity against the benefits attained through the participants’ involvement in these areas, e.g., when acting as co-authors for scientific papers.



This chapter illustrated how there is a vast debate about how to apply IC in light of a relational understanding of individual autonomy, the complex relationships and research settings often present in social research processes, and the all-encompassing—yet specific—power relations that affect involved research participants. The CSS research approach already targets some of the aforementioned problems, especially by involving people as co-researchers instead of only as research participants, and instead as active actors and decision-makers in a research project. However, this also necessitates constant reflection about how IC is ethically implemented and negotiated by all members of the research coalition.

5. Informed Consent in Practice

This chapter provides general information about the *CoAct* project and the CSS approach. Moreover, it briefly describes each RIA,² their target groups, and the IC activities from the co-creation process. The co-evaluation activities are illustrated in relation to IC, as well as collaborative activities within the *CoAct* Consortium.

5.1 CoAct General Information and Concepts

CoAct (Co-designing Citizen Social Science for Collective Action) proposes a new understanding of CSS as participatory research, co-designed and directly driven by citizens and citizen groups who share a social concern (see Figure 2). It advocates for engaging citizens in vulnerable situations to confront four “wicked” global social issues. The approach represents a novel conceptualisation of the underexplored field of CSS, inferred here as participatory research co-designed with citizen groups who share a social concern. The joint effort will result in implementing new or improved science-related policies and advancing the CSS approach regarding its applicability in concrete fields of research.

² RIA #4 on gender equality is not part of this report because its activity timeline differed from the three other RIAs, meaning it was not part of the collaborative processes on IC.





Figure 2: Citizen Social Science in Action with citizen groups, a specific concern, and with the support of the Knowledge Coalition

All CoAct RIAs (mental health care, youth employment and environmental justice) placed vulnerably situated citizens at the centre of the research and conceptually recognised their role and dedication as co-researchers (CoRes). In parallel, the Knowledge Coalition (KC) is a network of stakeholders who are informed about the RIAs’ goals, and play an active role in either participating or co-designing different actions to harness CoRes’ efforts and implement policies and measures based on scientific evidence.

5.2 Informed Consent Activities in the Consortium

Developing Expertise

The University of Vienna (UNIVIE) facilitated various activities to enhance the reflection and discussion on the topic of IC within the CoAct Consortium. This effort was motivated by the need for exchanging knowledge and expertise, which goes beyond the legal framework of IC. The present support structures are mainly located in the institutionalised realm, such as university ethics committees or the data protection offices, which intends to provide legal protection at the beginning of the project. However, no subsequent institutionalised channels of support and exchange exist between researchers throughout the research projects regarding IC. For the medical field, Nusbaum et al. (2017) identify a lack of training opportunities to help scientific researchers develop IC skills and expertise. Developing such expertise includes accompanying support throughout the research process. Based on the considerations about the lack of institutionalised support and exchange, internal sessions were established to promote the exchange of expertise within the CoAct Consortium. Thus, IC remained a fundamental topic



throughout the research cycle, and supportive structures for ethical questions within the Consortium were established.

Between May 2020 and July 2021, internal sessions were organised that were oriented towards the researchers’ needs and questions. The first session addressed simplifying IC forms and incorporating plain language into the process. This was followed by a practical session where Consortium members rewrote passages in existing IC forms using plain language. Later sessions dealt with different approaches to digital IC and its notion beyond legal documentation. The last session allowed researchers to discuss ethically important moments from the co-creation process and explore how the approval and refusal of participation and IC can be linked to societal power imbalances. This session was dedicated to reflecting upon the scientific researchers’ social positioning in relation to the CoRes, the privileges and marginalities that result from this, and the importance of relational and power-sensitive approaches towards IC.

Process-Oriented Documentation

Ethics-in-practice (Guillemin & Gillam, 2004) posits that ethically relevant moments occur throughout the research process. These can be moments of uncertainties, rejection, failure, or actors expressing different needs. As a process that is negotiated in participatory research, IC means that reflecting on these moments is a vital component of the research process. However, legal IC forms are often the only documentation of consent between the scientific researchers and co-researchers, and do not document emerging ethical questions and challenges. In response, the UNIVIE research team developed *Reflection Sheets*, which fostered a process of reflection and documentation for the RIAs. We believe that questions about IC should be centred throughout the research process and enable ongoing engagement.

Reflection Sheet 1	Reflection Sheet 2	Reflection Sheet 3
<i>Anticipated Challenges (May 2020)</i>	<i>Informed Consent in Practice (October 2020)</i>	<i>Digital Informed Consent (May 2021)</i>



<p>What were your IC procedures so far? What are good practices so far? What were challenges so far?</p>	<p>What were your experiences with IC in the field (online or f2f) so far?</p>	<p>How did you implement digital IC in the sessions with the Knowledge Coalition/CoRes? What went well and what didn't?</p>
<p>How have you reflected upon/discussed the anticipated challenges? How are you going to deal with those challenges (in future)?</p>	<p>What was the reaction of the participants to the IC procedure? If the participants asked questions, what were they? How did you answer the question?</p>	<p>What were the main differences in regards to digital IC with these two different groups?</p>
<p>How do you plan to make your IC forms accessible to your target groups?</p>	<p>What were challenges for you/the research team? How did you handle the challenges? What is needed for the next time to deal with the challenges in a more efficient way?</p>	<p>What were your best practices? What contributed to that?</p>
<p>Are there any other IC procedures you are planning to apply besides the IC forms?</p>	<p>What did you learn from the experience with the IC procedure? What went well? What went bad? How could it have gone better?</p>	<p>What were challenges for you? How did you handle these challenges? What is needed for the next time to deal with the challenges in a more efficient way? Were there moments of failure that couldn't be resolved in regards to digital IC?</p>



<p>If the research actions cannot be continued as planned due to the current COVID-19 situation, have you thought about using (additional/different) online formats for the research?</p>	<p>What open questions would you like to discuss with others?</p>	<p>Are there any open questions you would like to discuss with others?</p>
<p>If yes, please elaborate upon the anticipated changes: How will this affect your IC procedures? What are the anticipated challenges for doing IC virtually?</p>	<p>Is there anything else you would like to share?</p>	<p>Tell us one story (1/2–1 page) about the most important situation/occurrence regarding digital IC.</p>

Table 1: Questions on Reflection Sheets

5.3 RIA #1—Mental Health

5.3.1 Introduction

RIA #1 focuses on mental health care and specifically on mental health social support networks. Social support networks refer to people's social environment, which is generated informally rather than professionally. In this regard, CoRes, who are persons with self-experience³ in mental health and relatives, acted as experts in the co-design of RIA #1. They participated in all research steps with its promoters, Universitat de Barcelona (UB) and Federació Salut Mental Catalunya (FSMC).

Research on social support networks in mental health is important because those with self-experience and their families assert the importance and effectiveness of social support networks in facilitating recovery processes and improving quality of life. Social support during emotional suffering is a determining element of evolution and recovery (Knapp et al., 2007; Pernice-Duca,

³The term ‘people with self-experience in mental health’ is used in accordance with the FSMC practices and CoRes’ self-denomination. Within this community, people reject terminology that highlight illness. Therefore, by using the self-denomination, we show the importance of self-representation (see *Chapter 4.3*).



2010; Cooke, 2015). A positive family environment is identified as a key protective factor against further risks such as social exclusion and homelessness (Mental Health Europe, 2008). Studies show that people living with mental illness who are provided with well-planned, comprehensive community support have a better quality of life, develop improved levels of functioning and social contact, and have fewer relapses (Merton & Bateman, 2007). Reports by the FSMC and the Activament Catalunya Associació (FSMC & Activament Catalunya Associació, 2017) showed that people with self-experience in mental health point to social support networks (e.g., family and friends) as key elements of recovery, well-being, and crisis management. However, scientific research on family and other social support networks' role in recovery model remains scarce.

Our research, thus, focuses on social support networks that consider people with experience in mental health as experts in the field. The research outcomes provide scientifically valuable knowledge and also contribute to empowerment within the mental health community. In light of these concepts, RIA #1 was renamed “CoActuem per la Salut Mental” (*CoAct for Mental Health*) to facilitate local communication and engagement actions. This RIA builds on previous UB experience regarding research co-design (Senabre et al., 2018; Cigarini et al., 2020) and on the earlier collaborations between UB and FSMC to address community mental health care (Cigarini et al., 2018). It also builds on UB's background in collective experiments and digital platforms (Sagarra et al., 2016; Vicens et al., 2018).

5.3.2 Target Groups

Currently (October 2021), *CoAct for Mental Health* actively involves three different groups as research participants, who have thus authorised IC:

- 1) The Knowledge Coalition (KC) is comprised of representatives from public administration, civil society organisations (CSO), educational organisations, and CoRes, who act as representatives of their institutions. Relevant institutions were prioritised by considering their commitment to improving mental health care at different actions' levels (Mitats Carmona et al., 2020). The KC's diversity meant that some representatives had experience with IC procedures and had access to technological devices, while others, such as representatives of small CSOs were not familiar with IC procedures and had limited access to technological devices.



2) Co-researchers (CoRes) include persons with self-experience in mental health and their relatives who act as experts in the field. They co-designed a collective research tool with UB and FSMC researchers in the form of a *Telegram* Chatbot. The primary form of ‘collective digital conversation’ content, namely micro stories, is built through co-creation mechanisms that allow CoRes to reach consensus and agreement while including different perspectives and viewpoints. CoRes include a diversity of individuals in terms of life and work experience. While some work in areas with various degrees of connection to technology and research, have access to technological devices, and some knowledge of the research process, others were quite unfamiliar with the research context or had limited access to technological tools. However, all CoRes were well-versed in using teleconference tools.

3) Citizen scientists participate in the collective digital conversation through the *Telegram* Chatbot described above. This conversation establishes a welcoming environment for collective and anonymised conversation using the mobile phones of all registered participants who are interested in improving mental health social networks. Safety is defined by the fact that participants’ anonymity is maintained and that their privacy is further ensured by not exposing their individual opinions before any other participant. The participants receive micro stories written by CoRes and have the opportunity to react to them with their own experiences. All micro stories are planned and framed such that participants can self-express their own perspectives based on their own experiences. The goal is to collectively generate new, interconnected, and multi-layered data that encompasses the complexity and the diversity of mental health social support networks. The results will later be transformed into evidence-based actions. When designing the IC procedure within the *Telegram* Chatbot, we hypothesised that the citizen scientists were not familiar with this procedure and carefully explained its goal.

5.3.3 Informed Consent Activities

Preparation

Preparing IC forms has been a routine practice for many years, since Open Systems’ activities include collective behavioural experiments involving human participants. However, the *CoAct for Mental Health* project’s specificities compelled us to question our current practices and improve many aspects of our IC procedure.



One of the first aspects we discussed internally concerned participants' direct relation with mental health. All CoRes had a personal lived experience with mental health—either personal by the participants themselves having a mental health condition, and/or being the informal caregiver of a person with one. Additionally, some KC members who were representatives of mental health associations shared these same lived experiences in mental health. Hence, the participation of people with self-experience in mental health is highly relevant, but also embodies the special care required to not increase their vulnerability. In this regard, the FSMC's expertise in mental health community care was of great help.

One of the first outcomes of these debates was that the research process timeframes needed specific adaptations to build mutual knowledge and trust before going deeper into the research process itself. Additionally, given the sensitivity of the research theme and the nature of the CoRes' involvement (writing micro stories about their own lived experiences), we determined that it was of particular importance to fully inform the CoRes about the details of their future involvement. We therefore started our interaction with the different groups by presenting the project to the KC (one session) and to the CoRes (two sessions, including a demonstration of the micro stories writing process) before asking them if they wished to confirm their participation in the project. We were also explicit about how this writing process could provoke intense emotions, which was likewise detailed in the IC. We explained all the measures taken to minimise this possibility, such as constant communication with the CoRes, the presence of a psychologist in all sessions, and the decision to work in small groups.

Another internal discussion addressed the necessity for a clear and understandable policy regarding privacy and personal data protection. As in previous occasions, we included the compulsory legal information and practices in the IC, in accordance with the GDPR. However, we also gradually introduced information concerning our privacy and data protection practices into our presentation sessions using simple terms. For example, we explained that we will not share their contact details with anybody. Additionally, we explained that we will work in small groups and that all people inside each small group will make a compromise not to disclose any content to anyone outside of the group. We also made it clear that micro stories will remain anonymous and under which conditions they will be shared inside the Chatbot. These explanations were



especially important to us, as we made sure that all participants understood the privacy and personal data protection measures we were taking before accepting to participate to the research.

Research Cycle

All IC forms were reviewed by the UB Data Protection Office (DPO), and different IC activities were implemented for each group:

1) Knowledge Coalition: After the first online presentation session, we sent the IC by email and asked the participants to sign and return the completed IC by email. The IC was explained in detail during the next session and missing IC approvals were orally collected.

2) CoRes: Different IC items were gradually introduced over two online presentation sessions. The IC procedure was introduced at the end of session two, clarifying that this was a necessary prerequisite for CoRes' effective participation in the research. After signing the IC, another session was devoted to mutual knowledge and trust-building within the small groups, before proceeding to the micro stories writing task. As explained in the previous section, this gradual approach was especially relevant given the specific profile of the CoRes. The IC was also included in the printed *Research Diary* that we sent to the CoRes at their homes during the COVID-19 pandemic.

3) Citizen scientists: Because they participate anonymously through a *Telegram* Chatbot, we have no ability to establish one-on-one contact with citizen scientists. Nevertheless, we implemented the same strategy as with the CoRes. The first Chatbot content, which we internally called 'Welcome,' carefully explains the project aim in plain language, along with the expected contributions from the participants, measures taken to safeguard their privacy, and why the Chatbot is a safe digital tool. At the end of the Welcome, all information is included in the IC, which can be downloaded as a PDF or read on a webpage.

Reflections



After implementing the IC process with the KC, there was clear room for improvements. We noticed that it was useful to introduce the different concepts contained within the IC well before signing it, and articulated in a plain manner.

The gradual process that we implemented with the CoRes was successful in that we later checked that all the information we provided was properly understood and helped create a trustful and relaxed atmosphere. The clarity of the measures taken to safeguard their privacy also served to legitimate the academic team as a reliable partner.

Concerning the IC procedure implemented through the Chatbot, we observed that a small number of participants did not accept the IC and, thus, did not take part in the research process. Although we will need to further investigate this phenomenon, we do not necessarily interpret it negatively, as it shows that the participants are conscious of their participation in a research process and may therefore carefully reflect upon their willingness to do so.

5.3.4 Challenges

Embrace the specificities of the mental health community

During the first project months, we anticipated that we would need to consider several specificities of the mental health community within which we were working. Namely, the main actors in our research are involved as CoRes with self-experience in mental health and their relatives. The potential difficulties we anticipated at that time related to language abilities and disabilities, language skills (for CoRes with migration experiences), reading comprehension of the complex information, unfamiliarity with the open nature of the participatory process, lack of knowledge towards the research cycle, and data literacy. However, the COVID-19 context meant that some anticipated risks did not materialise. For example, we were unsuccessful in involving CoRes with migrations experiences because the pandemic exacerbated existing challenges of reaching these individuals. These communities did not respond to our call via email or similar means. We were not able to use other strategies that entail closer relationships and physical meetings, which were not possible when the open call was launched. By contrast, the online formats specifically enabled including CoRes who were based outside of the Barcelona metropolitan area, e.g., some were living in rural areas that were more than a one-hour driving



distance from Barcelona. We also realised that we overestimated other challenges, as most of the 32 CoRes who were ultimately recruited had previous experience in participating and moderating collective processes, while some had outstanding oral and written expression skills. We overcame the other challenges surrounding literacy and the research by progressively introducing the IC contents and using innovative materials (see *Chapter 5.3.5*). Furthermore, the close collaboration with the FSMC allowed us to clearly foresee the potential participant risks and implement measures to minimise them, such as ensuring the presence of a psychologist in every session.

Imbalance of sharing about personal experience

Another anticipated challenge was to approach the potential risks of participants correctly and ethically, since they could face negative consequences by sharing their personal experiences in mental health. Likewise, we reflected on the imbalance of sharing knowledge between the researchers and the CoRes:

“In the collaborative research, CoRes and researchers work together to create micro stories for a Chatbot that helps to discuss everyday problems of people with mental health problems and their social networks. There is the risk of the CoRes sharing a lot of their personal lives by speaking about their experiences and stories with mental health issues. This creates an imbalance, because the researchers do not necessarily have a history with mental health challenges or do not want to share them. So, the following question arises: Should the researchers share personal stories, although they might not be that relevant for the research topic, to create a balance in the sharing process?” (16 December 2020⁴)

Keep the informed consent procedure simple

Another challenge that we were conscious of was the risk of over-complicating the IC procedure. Because CoRes would participate in different processes, such as co-creation and co-evaluation actors, this could indicate the need for different IC procedures and create further complexities

⁴This experience was reflected upon in an internal session with other members of the Consortium on 16 December 2020. The session’s objective was to broadly discuss ethically relevant moments that related to IC in each RIA research practice.



and burdens for the participants. Additionally, because participants would be asked to share intimate experiences, we wanted to avoid framing the activities in an unclear manner as much as possible, since this could lead to distrust. To overcome this challenge, we based our activities upon ‘privacy-by-design’ principles, and implemented a precise and restrictive framing of personal data-sharing issues from the beginning of the interaction with the CoRes. Describing the personal data-sharing conditions in the IC gave us a clear view of concrete opportunities and allowed us to plan all activities within this frame, without having to repeat the IC procedures because of changes in the personal data-sharing policy.

Adapting to the pandemic online environment

The COVID-19 pandemic began three months after the project started, when some activities were not yet designed. While all KC and CoRes sessions were initially visualised as being face-to-face and in a welcoming physical space, the pandemic required all activities to take place online through video conferencing platforms. This digital environment was anticipated to be less hospitable, which might make the necessary trust-building and mutual knowledge process more difficult. Additionally, our need to record the online sessions could have caused distrust if we could not articulate its importance for research purposes. Time constraints posed another limitation to the online environment, since we did not want to exceed 90 minutes, despite each being ‘multi-purpose’ sessions that had to achieve several goals. We hence noticed that it was hard to have sessions longer than 90 minutes, because of participants’ time availability and because of the difficulty in maintaining everyone’s concentration beyond that. This made it challenging to dedicate the time needed to fully explain all IC contents. In response, we chose to consider the IC procedure more holistically and to introduce concepts and contents in different materials and timeframes than initially planned instead of conceptualising the IC as a time-sensitive procedure requiring efficiency.

Changing the informed consent perception

We experienced that the IC procedure was not always well-perceived within the academic community. For example, it was sometimes seen as a burden that takes time away from a project’s “true” research goals. In our case, the researchers’ perception of the IC procedure



evolved throughout the project, although some internal advocacy was initially needed to reach a consensus about the necessity of a well-done IC procedure. To some researchers, the IC procedure is no longer merely a compulsory legal step, but also a way to implement ethically responsible research and thus to improve how the research is implemented from multiple approaches.

5.3.5 Innovative Moments

Making the IC procedure a journey

Because of the challenges outlined in the previous section, it soon became clear that we should introduce the IC procedure at multiple steps of the research process instead of only focusing on its contents when the participants had to sign it at the project’s start. Based on the knowledge acquired from the IC procedure with the KC, we planned a different approach for the CoRes. As Figure 3 shows, we deeply integrated IC contents and concepts into our activities with CoRes. This was facilitated by how we established a months-long relationship with them, which is an uncommon approach in most citizen science projects.



Figure 3: Activities with CoRes and IC-related contents in RIA #1



This integration was materialised through, e.g., the video we prepared for the open call for the CoRes, explanations we shared during presentation sessions, and the printed materials we prepared, which are described in further detail below. However, integrating the IC also entailed the constant integration of the project's goal-specific contents, its timeline, and multiple occasions of explaining the research cycle and how the CoRes are involved in it. Further data literacy activities that targeted, e.g., the planned type of data to be collected through the Chatbot, promoted a deeper understanding of all IC contents.

As with every journey, it may also imply some unexpected events and additional opportunities to increment CoRes' participation. For example, as the mutual trust between the academic team grew alongside collective achievements like the Chatbot, the CoRes proposed their greater involvement in further activities, including writing first-hand testimonials, participating in a testimonial video, and acting as co-presenters at conferences. These activities, which also have important privacy implications, require updating the IC for the people that chose to take part in the project. It is clear to us that a more dynamic form of IC is a needed for our CSS project, although there is no straightforward, practical way to implement it.

'Out of the form' IC-related contents

While we have established that the IC form is useful and necessary for centralising all contents and for legal issues, there are other ways to concisely explain its contents. In our case, the diverse types of content are a benefit, since not everyone is equally receptive to visual, oral, or written messages.

1. IC contents embedment in promotional videos

To date, we have prepared two different videos using animated content and a narrator's voice. The first was for the CoRes open call,⁵ and its goal was to inform about the project and motivate those with personal mental health experiences to participate in the project. It shared information about measures to protect the participants, privacy and confidentiality, the right to drop out of the project, and the conditions for participation, as summarised in Figure 4.

⁵ Video to promote the open call for CoRes: <https://vimeo.com/472726240>



Similarly, as we prepared the “Join the *CoAct for Mental Health Chatbot*” video⁶ to promote our collective digital conversation, we also introduced IC-related contents (see Figure 5). These related to the participants’ anonymity inside the Chatbot, the confidentiality of their answers, and the conditions for participation. The video also clarified possible misconceptions about the Chatbot, since it was exclusively offered as a psychological support tool when discussing mental health. These concepts are all further explained in the Chatbot’s introductory section, which is later followed by the Chatbot IC that participants must accept.



Figure 4: IC-related contents from the open call for CoRes video

⁶ Video “Join the CoAct for Mental Health Chatbot”: <https://vimeo.com/639902984>





Figure 5: IC-related contents from the Chatbot promotional video

2) Embedding IC contents in the Research Diary

The Research Diary is a hardcover publication that was tailor-made for RIA #1 and was envisioned to guide the CoRes during the micro stories co-creation process. It has proved to serve as a useful bridge between the online co-creation sessions that took place during the COVID-19 pandemic and the CoRes' offline, individual tasks of writing micro stories related to their personal experiences. The publication was sent to their homes and served as a reference document for the project's duration. Consequently, the IC was wholly included in the publication, while some related contents that were elaborated upon concerned respect, inclusion, and confidentiality aspects, as shown in Figure 6. Because we could only interact with CoRes through digital spaces, it was important to materialise the mutual compromise of the academic team and the CoRes in a tangible form, which could be easily consulted and reviewed to increase continuous self-reflection and fully-informed participation throughout the research process.





5. **Com ho farem?**

Et proposem participar en un procés guiat i acompanyat per persones que garantiran que no hi hagin estigmatitzacions i que totes les converses es duguin a terme amb respecte i de forma segura. És important que sàpigues que pots deixar de participar en qualsevol moment.

Valors per a les sessions de co-creació

Respecte	Inclusió	Confidencialitat
<ul style="list-style-type: none"> Tenir un tracte cordial. Respectar els torns de paraula. No donar consells. No jutjar. No discriminar. 	<ul style="list-style-type: none"> Disposar totes de torn de paraula. No acaparar molta estona la paraula. Contextualitzar els temes. Garantir la comprensió de les normes. 	<ul style="list-style-type: none"> No explicar les experiències personals que es comparteixen a les sessions a altres persones. No treure de context les experiències compartides a la sessió.

Annex: **Full informatiu**

Et convidem a participar al projecte de recerca CoActuem per la Salut Mental.

L'objectiu d'aquest projecte és reforçar les xarxes de suport social en salut mental mitjançant una investigació participativa. El projecte és una proposta del grup OpenSystems de la Universitat de Barcelona i de la Federació Salut Mental Catalunya (FSMC), que formen l'equip promotor de la recerca. Ha rebut fons del programa de recerca i innovació Horitzó 2020 de la Unió Europea. Tindrà una durada de tres anys, des de l'1 de gener del 2020 fins el 31 de desembre de 2022.

Et proposem que hi participis com a persona coinvestigadora.
 T'hem convidat a participar com a persona coinvestigadora perquè ets una persona amb experiència pròpia en salut mental (primera persona) o bé una persona familiar d'una primera persona. Pensem que el teu coneixement i les teves vivències ajudaran a entendre com funcionen les xarxes de suport en salut mental, donar-les a conèixer i proposar accions que les promoguin, amplin i enforteixen. La teua participació és totalment voluntària i pots deixar de participar en qualsevol moment.

Et teu paper serà participar en sessions de co-creació de la recerca.
 Et proposem participar a la co-creació de la recerca a través de sessions en petits grups, conduïdes en una plataforma online privada i segura. Les sessions inclouran, a més d'altres persones coinvestigadores com tu, especialistes en salut mental, ciència ciutadana, disseny gràfic, elaboració de relats i creació de converses digitals. Et demanarem compartir les teves vivències i coneixements relacionats amb les xarxes de suport social en salut mental. Aquestes sessions seran enregistrades en àudio i vídeo amb finalitats exclusivament de recerca. No es compartiran amb les persones coinvestigadores que no estiguin presents a la sessió ni amb ningú de fora de l'equip promotor de la recerca. Totes les persones participants es comprometen a respectar la màxima confidencialitat i a no divulgar cap contingut personal que s'hagi compartit durant les sessions.

Tot fent col·laborarà per tal que aquest material es convertirà en microrelats anònims eventualment il·lustrats, que serviran per interactuar en una conversa digital oberta, en forma de chatbot anònim de Telegram. Totes les persones preocupades per la salut mental podran participar al chatbot. Més endavant, podràs participar també en espais d'interpretació dels resultats i dades fruit de la conversa digital per així transformar-les en propostes d'accions col·lectives per millorar i enfortir les xarxes de suport social en salut mental.

Figure 6: IC-related contents in the printed Research Diary for CoRes

3) IC contents as Chatbot messages

In the current phase of the project, citizen scientists participate in *CoAct for Mental Health* through a digital conversation via a Chatbot. During their participation, these citizen scientists are invited to give their consent in order to participate. Because we could directly interact with the Chatbot participants, we introduced the IC contents through short messages with emojis, as illustrated in Figure 7. Upon entering the Chatbot, participants start their research involvement by responding to the micro stories written by the CoRes. Occasionally, they receive reminder messages about the project's goals and the information contained in the IC. We will include emojis in our future IC forms to help facilitate their reading.



The CoAct project has received funding from the European Union's Horizon 2020 Research and Innovation programme under grant agreement No. 873048

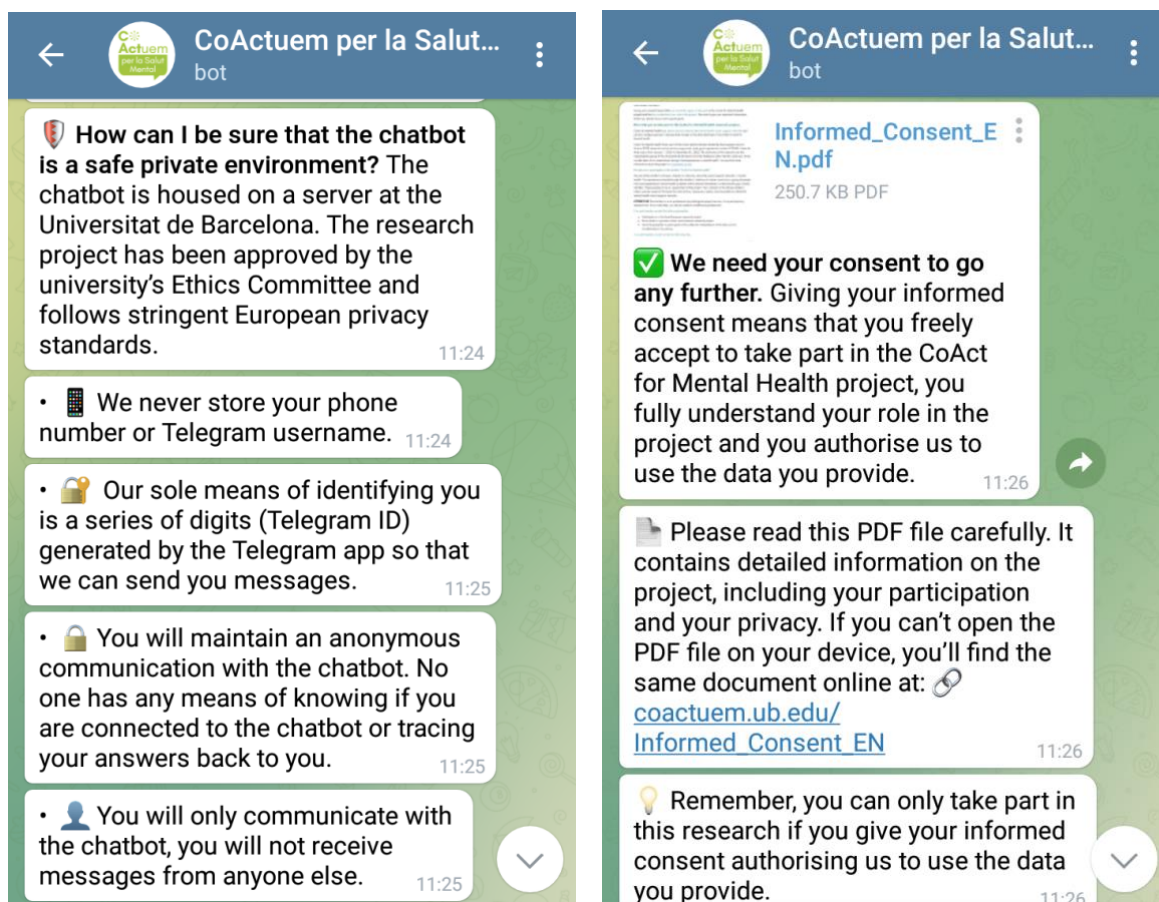


Figure 7: Examples of the IC procedure in the “CoActuem per la Salut Mental” Telegram Chatbot

Beyond IC forms: a deeper reflection

Keeping in line with *CoAct Ethical Values*,⁷ further developing the IC forms and procedures also promoted reflecting upon how to ensure that participants’ vulnerability was not exacerbated. Hence, we opted for a very restrictive approach to sharing personal CoRes data. Likewise, the Chatbot contents were carefully reviewed, first, not to harm the participants, but to also to avoid disseminating content that potentially could increase the stigma associated with mental health problems. The Chatbot’s vocabulary was scrutinised using appropriate language guides, while the micro stories—especially those addressing particularly sensitive themes—were also assessed by suicide prevention associations. In the case of micro stories with especially sensitive contents, resources in the form of help pages were also provided to the participants.

⁷ CoAct Ethical Values: <https://coactproject.eu/our-ethical-values/>



The strong sense of compromise that the CoRes acquired by sharing their personal experiences in the form of micro stories absolutely forced us to carefully define the role of all people participating to the co-creation session, including the promoting team and the facilitator. Actors had to make explicit and implicit decisions about their behaviour during the co-creation sessions. For example, the promoting research team and the facilitators were discreet about their personal lives, which they only mentioned when it was directly relevant to their project participation. The rationale was to avoid blurring any lines in their roles and to maintain the CoRes' 'experts-in-the-field' role. Therefore, the promoting team and the facilitator focused on designing session materials and upholding dynamics without engaging in the experience-sharing itself. In future projects, an interesting practice might entail preparing an IC for the academic and facilitation teams, since their deep engagement implies that they also share their personal data and have potential risks arising from the sensitive theme. Doing so would allow us to develop a two-way agreement and further enhance a more horizontal and mutual relationship between the CoRes and the academic and facilitation teams. Likewise, these could enhance cooperation and reciprocity among all participants involved.

Outside of the IC procedure, another feature is the time-consuming nature of establishing mutual trust, respect, and getting to know each other, which therefore implies a different timescale than the actual IC procedure. Hence, we also determined that it was worth occasionally reminding participants about IC contents after establishing this mutual relationship to ensure they were fully cognizant of the terms of their participation.

5.3.6 Reflections on Collaborative Work Within the Consortium

The working group on IC, which was created within CoAct, was clearly a positive resource, especially when the COVID-19 pandemic required implementing all co-creation activities through online sessions. Being able to discuss IC-related challenges openly and directly was beneficial, especially since all partners experienced similar challenges because of the CoRes' vulnerable situation, which was exacerbated by the pandemic. Moreover, the UNIVIE's support during the process was highly effective, as were their practical tips regarding resources such as the ones provided concerning plain language (see *Chapter 5.2*).



The Consortiums' activities were useful for drawing inspiration from other partners' practices. For example, we first considered introducing IC-related video content after seeing the IC video prepared by the RIA #3 team. The welcoming space established by UNIVIE, where partners could openly share successes and failures regarding the IC procedure, was another successful action. When the RIAs started to involve the KC members in mid-2020, their dependable support was especially relevant for establishing a meaningful IC procedure through online processes.

Collecting and putting concepts and experiences into practices, like plain language writing or existing digital IC forms, produced rewarding and useful practices, since the project-specific forms are qualitatively distinct from our previous IC forms.

Finally, reflecting upon the IC gave us opportunities to see its broader scope, whether through gaining inspiration about practices from other partners or through incorporating inclusive research and participatory action research (PAR) concepts. This reinforced how we perceived IC's potential as a wide and continuous process, independent of disciplines and research themes.

5.4 RIA #2—Youth Employment

5.4.1 Introduction

RIA #2 emphasises participatory research with young people between the ages of 15 and 21⁸ who participate in the measures of the 'Education and Training up to 18' (*E&T up to 18*) legal framework. In 2016, the Austrian government introduced a new law called the *Ausbildungspflichtgesetz (2021)* (*Compulsory Education or Training Act*), which made attending school, vocational training, or a preparatory measure mandatory up until the age of 18. This extended the country's existing educational and training landscape through new measures designed to enable young people to acquire social and technical skills. This framework represents an attempt to reduce unemployment and poverty, as well as existing inequalities faced by youths at the margins of the educational system, and to meet labour market demands. It aims to address

⁸ *E&T up to 18* makes it obligatory for young people under the age of 18 to be in education or training. The offered measures, however, are addressed to youth between the ages of 15 to 21.



challenges faced by early school dropouts (*FABA—Frühe AusBildungsAbbrecherInnen*⁹) who are at the intersection of the school system, the labour market, and alternative educational and training measures.

This RIA aims to involve young people participating in the *E&T up to 18* measures in conceptualising and improving them so that they can suggest changes according to their circumstances and needs. By centring the perspectives of affected young people, we aim to foster reflexive processes with the CoRes to develop new ideas and approaches towards education and training. Importantly, other actors in the *E&T up to 18* field are also involved in the project. The RIA #2 KC consists of representatives from public administration, civil society organisations, policy institutions, youth organisations, and educational institutions, as well as practitioners and scientific researchers. The KC members are invited to discuss recent issues from *E&T up to 18* and comment and reflect upon potential implementations of the results from the co-researching process. The cyclical interactions with the KC are a critical part of the research cycle for including multifaceted perspectives from *E&T up to 18* (Wintersteller et al., 2020).

5.4.2 Target Groups

Co-Researchers: The main collaborative research activities are structured in research weeks, where scientific researchers guide CoRes in their social research project. The CoRes are young people who are currently participating in the *E&T up to 18* measures, and are considered a vulnerable social group, as their marginal position in the educational system as dropouts contributes to further difficulties like unemployment or poverty. The *E&T up to 18* target group is diverse in many respects: Some contributing factors to the group composition include disabilities, mental illness, learning difficulties, traumatic experiences, family problems, poverty, care responsibilities, and negative experiences in educational institutions (Bacher et al., 2014; Steiner et al., 2019). Furthermore, the COVID-19 pandemic heightened existing inequalities (Lichtenberger & Ranftler, 2020) through its effects on the educational sector and the labour market. Online research during COVID-19 lockdowns might serve as an example for challenges

⁹ Statistik Austria (2021) defines *FABA* as people aged 15 and older who have only obtained a compulsory school education and who are not in any kind of education or training.



linked to the socioeconomic background of this target group, such as a lack of technical resources and privacy. This added to further difficulties regarding the co-creation process and the IC activities.

Knowledge Collation: The KC consists of people working at different levels and fields within the of *E&T up to 18* framework (political institutions, administration, educational institutions, and social workers) as well as academic researchers. The form of collaboration and involvement varies depending on members' resources, needs, and expertise. We define the KC as a dynamic network of stakeholders that is continuously growing through the opportunity to join at any stage of the project. Online meetings were generally about the project, its progress, and the actors' expectations towards RIA #2. Separate online meetings with practitioners gave additional space to discuss the challenges faced by youth workers.

5.4.3 Informed Consent Activities

Preparation

When preparing the IC forms, we used templates provided by the university, and the final versions were reviewed by its ethics committee. The CoRes' ages required handling visual data such as videos or pictures with extra care, which led to the decision to only collect certain data through a fully anonymised form. During this phase, our main obstacle was in aligning the legal requirements with necessary content simplification to ensure its legibility for our target groups. For example, we discussed how to adopt formats that made the forms youth-oriented. Our first strategy was to write parts of the legal document in plain language without abbreviations. This included using shorter sentences, one idea per sentence, bullet points, numbering, and considering how both the content and the layout contribute to its readability.

Additionally, we included how the issue of consent extends beyond the IC forms in our preparatory reflections. We recognise consent as a process between actors, which is negotiated in moments throughout the co-creation process. We thought of potential scenarios where



consent could be subtly withdrawn (e.g., “This is something I am only telling you.”), which requires the scientific researchers to be sensitive about the temporary withdrawal of consent and to document these instances accordingly.

Research Cycle

Informed consent was implemented differently depending on the target group and the data collection format. We adapted the project to online activities such as the *Actionbound* app (see *Chapter 5.4.5*) or anonymised talks on well-being during the COVID-19 lockdown because of how the pandemic restricted on-site co-creation sessions for an extended period. All procedures entailed in-depth discussions about implementing IC, which are summarised in Table 2:

	Knowledge Coalition	Co-Researcher
Online	<p>Online meetings/interviews</p> <ul style="list-style-type: none"> • IC forms via email beforehand • Written consent 	<p><i>Actionbound</i></p> <ul style="list-style-type: none"> • No personal data collected • No written consent • Provided information on the project, its aims, and the data collection • Instructions for the CoRes on how to anonymise and pseudonymise their data



In-person	Interviews	Research Project Week
	<ul style="list-style-type: none"> • Going through IC forms together • Written consent 	<ul style="list-style-type: none"> • IC Session: Discussions and visual materials to support the simplification • Written consent (from participants and if needed from their legal guardians) • Continuous negotiation of consent in the process

Table 2: Informed consent activities in RIA #2

For KC meetings or interviews, we sent the IC forms via email beforehand to obtain written consent and provided opportunities for questions and remarks at the beginning of the meeting or interview.

For online activities with the young CoRes, we chose not to collect personalised data because of the limited options to adequately address the topic of IC in the digital space; however, we provided instructions and explanatory videos about how to anonymise and pseudonymise data they upload on the *Actionbound* app. The in-person activities, namely each research project week included a full session on IC, where CoRes could deepen their understanding of data, discuss and share their ideas on sensitive data, ask questions, or voice their concerns. These sessions were accompanied by visual materials. Because of the participatory nature of the co-creation process, negotiations of consent remained present beyond the IC session.

Reflections

After our first experiences with IC with the young CoRes, we realised that time is fundamental to the quality of IC activities. We learned that working in smaller groups—and, if needed, in individual settings—helps CoRes better understand the information. Therefore, we adapted our procedures in this respect. Moreover, combining explanations of IC with general discussions about data aligns with the participatory approach. We learnt that having these discussions with the young CoRes acknowledged their lived experiences. The scientific researchers encouraged the CoRes to voice their personal opinions and experiences regarding data. Another reflection from our research practice was how digital communication can act as a barrier to fostering an atmosphere of trust and openness, which is needed to engage in participatory interactions.



Additionally, long-term engagement with the CoRes was not possible, which led to the decision to not collect personal data during the digital co-research. This resulted in the internal discussion about the loss of potential data; however, because digital activities made it difficult to foster trust, interactions, and mutual understanding, we could not make the contents of IC accessible and understandable for the young CoRes as we had hoped for. Thus, the best solution was to not collect any personal data in these cases.

5.4.4 Challenges

Two different frameworks—legal and youth-oriented

During the phase used to create the official documents, namely the IC and participant information sheets, we faced the challenge of navigating between the legal and youth-oriented approaches to IC: Although legal documents were essential, their bureaucratic approach could not adequately allow the target group of young people to make informed decisions. This required creative methods to bridge the gap between the two IC approaches.

Youth as a heterogenous group

The CoRes belong to heterogenous groups, making it difficult to assess the target group's specific needs. Characteristics like the diversity of language (dis)abilities, language skills (in German or other languages), age, biographical experiences (such as negative experiences with educational and bureaucracy institutions), learning difficulties, and attention span strongly influence the requirements for CoRes to sufficiently understand IC and make an informed decision. We addressed this overarching challenge through constant reflection on the particularity and heterogeneity of the target group in order to adapt the IC procedures.

Negotiating consent

Even though consent has been obtained at the beginning of the research activity, moments of negotiations or refusal of consent can occur throughout the research practice. This was reflected upon in the following situation:

“Interviews are a good tool to do collaborative research with young people, because the audio devices are easy to use and the audio files are a good basis to analyse what was



said in the interview. At one moment in the research process, a young person commented that it was very weird to listen to one's own voice recorded via an audio device. He then continued that he didn't want anyone to listen to the audio files in which his voice could be heard. The researcher took up this comment and explained who would be listening to the audio files (namely, only the people doing the research together), and regained consent from the young person that it would be okay if only the collaborative research team would listen to the files. The question that arises is: How can one negotiate the use of data in a collaborative research group and what does a refusal to process data further during the research process mean?" (16 December 2020¹⁰)

Time and timing

Time constraints posed challenges to sufficiently explaining IC during KC member interviews, as well as in the co-creation sessions with the CoRes. Explaining and demonstrating IC relies on resources like time and personnel. We faced the additional problem of insufficient physical space to allow, for instance, moving to another room for individual conversations, providing privacy, and not disturbing the group's workflow.

Parental consent

The in-person co-creation sessions lasted four to five days, with IC discussed on the second day (the first day was used to introduce the project and get acquainted with each other). Parental consent was required for young CoRes if they were minors. Here, the short time notice to obtain parental consent was a challenge. Moreover, there was a risk that some CoRes would not be able to obtain their guardian's signature for reasons including difficult relationships, not living in the same household, or their parents' work schedules. In one case, we felt that a participant was hesitant after learning about the parental consent requirement. We spoke with them in an individual setting about whether or not it was feasible to get parental consent. They did not

¹⁰ This experience was reflected upon in an internal session with other Consortium members on 16 December 2020. The session's aim was to broadly discuss ethically relevant moments regarding IC in each RIA research practice.



disclose the reason for the hesitation, but ultimately obtained parental consent for the research activities.

Online co-creation and IC

We faced difficulties with adapting the planned IC session to a suitable format for the online activities with the CoRes. Since our experience has demonstrated the great importance of a trusting environment, open space for discussion and personal interaction, and appropriately handling uncertainties, we did not expect that these would be feasible in a digital format. Moreover, parental consent was difficult to gain due to the short notice for the online sessions and the lack of technical resources in the young people's households like printers and scanners. Thus, we decided to not collect personal data, and instead only anonymised minutes and posters made by CoRes. Here, we prioritised the young people's anonymity over the collection of personal and sensitive data.

5.4.5 Innovative Moments

Timing of the informed consent session

During the research project weeks with the CoRes, we introduced the topic of IC on the second day of the research cycle. This was done in a session dedicated to topic using smaller groups or—if needed—in an individual setting. One advantage of conducting the IC session on the second day is that the CoRes have had the chance to familiarise themselves with the research approach of co-designing. On the first day of the research project week, we emphasise the group dynamic by getting to know each other, discussing social research practices, and deciding upon research topics. However, verbal consent to audio-record the sessions is obtained at the beginning of the research week. By not starting with the heavy topic of IC on the first day, CoRes have time to experience what the project is about and to get acquainted with each other and their new surroundings. After choosing the research topic, the young people have a better idea of what they might share with each other and the scientific researchers. In addition to explaining data protection and IC, we believe it is necessary to demonstrate how these topics look in practice so that the CoRes can use this practical knowledge to make an informed decision about their participation.



Informed consent session embedded in discussions

The IC session is embedded in discussions and explanations. At the beginning, we encourage a group discussion using the following questions:

- What do you think data is?
- Where do you share data in your daily life?
- What do you not like sharing?

This open discussion allows the young people to reflect upon data collection in their daily life and their own evaluation of sensitive data: Which data do they share with whom and which data do they not want to share? In general, the CoRes demonstrated an awareness of data sensitivity, especially regarding social media platforms. This approach allowed us to gain insights about how the CoRes evaluate data—especially sensitive data—and the group discussion format promoted opportunities to voice their general ideas and concerns. Thus, the academic researchers could address these voiced concerns within the context of the project’s data collection.

In RIA #2, IC is continuously negotiated with the CoRes in addition to the formalised procedures. This was illustrated when after the academic researcher explained the different data formats collected in the project (audio, transcripts, minutes, pictures, and videos), one CoRes asked whether it was obligatory to take pictures. The open discussion contributed to learning that some CoRes felt uneasy with pictures. Therefore, informed by the participatory approach, the scientific researchers assured the CoRes that data collection methods are not predefined, but open to collaborative negotiation. Thus, pictures were not part of the data collection for this group of CoRes. This situation illustrated how even though the consent to data collection may be obtained at one point in the research projects, multiple other moments of IC emerge through interactions. Here, we believe that part of the researcher’s responsibility is to be sensitive and reflexive to acknowledge CoRes who show scepticism or resistance.

Visual material to support informed consent forms



Visual material was created to support the text-based IC forms, which included a project description, as well as explanations of IC, the data collection, and the CoRes' rights. The visual material includes plain language, short sentences, and iconographic support.

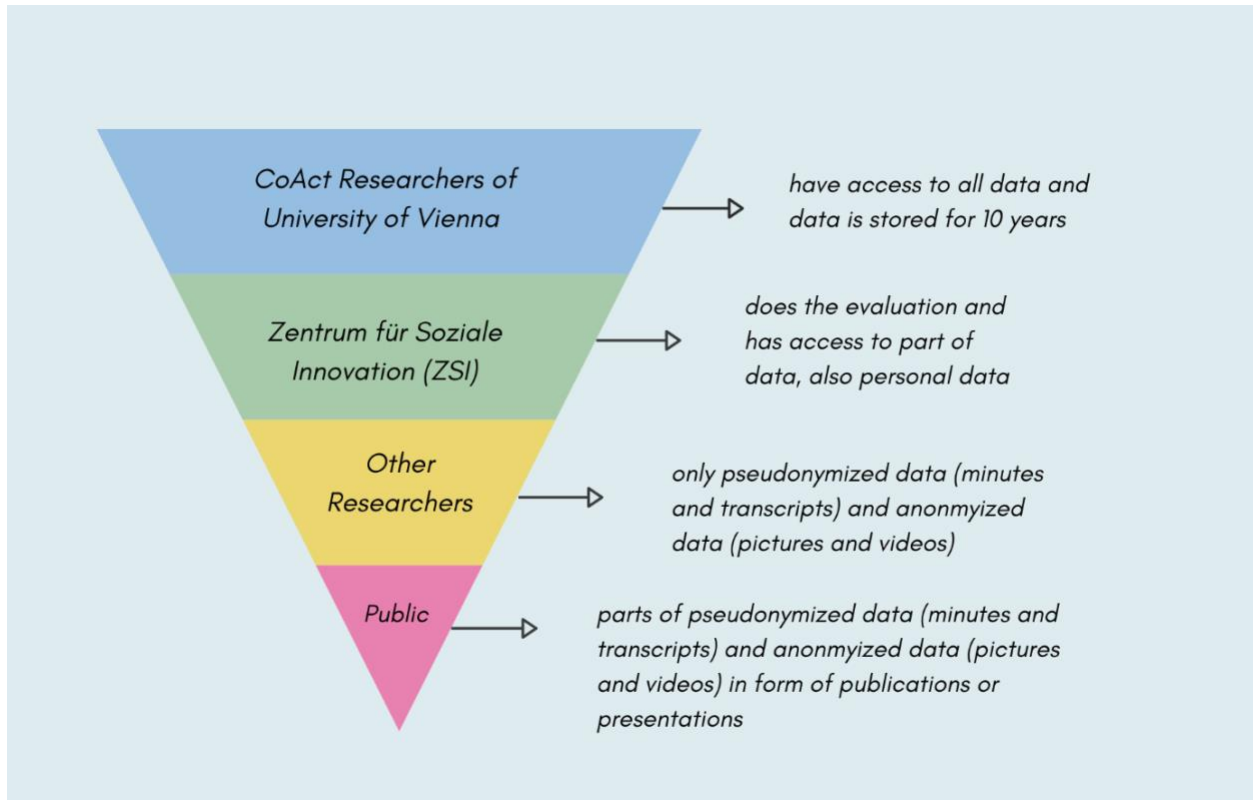


Figure 8: Visualisation of data management process in RIA #2

This model was developed to explain the data management process, which made clear who had access to which data.

Acknowledging different needs

The CoRes had different experiences with IC forms: Some had never previously signed them, and others did in previous educational or training institutions. Hence, the young people showed different needs regarding time, space, and the extent of explanations needed to fully comprehend the form contents. It is the scientific researcher's responsibility to be sensitive to diverse needs. The session dedicated to IC was conducted in a group setting; however, we provided an individual setting if needed. For example, one CoRes refused to sign the forms in the group setting, but our individual conversation revealed that this young participant felt like things



were moving too quickly in the group. After discussing their concerns, the implications of the signature, and CoRes' rights—especially the right to withdraw—they felt confident to sign the form to participate. This demonstrates that certain resources are required to facilitate a setting that can adapt to the CoRes' needs. Likewise, time is a major factor in allowing a team of scientific researchers to react flexibly. Moreover, after explaining the information from the IC forms with the assistance of the visual posters, we asked the CoRes if they want to read the forms for themselves and discuss questions afterwards, or if we should read them out loud. This provided another space for the group's heterogeneous needs regarding their reading, concentration, and information processing skills.

Dynamic and continuous IC

Moments of data collection are present throughout the research process: At the beginning of the project week, recording equipment is placed in the room and we disclose that the sessions will be recorded. The technical equipment attracted the young people's attention during every project week, and they asked questions and wanted to try out the recorder themselves. This induced a playful and practical approach to data in the research project and helped CoRes to develop a self-determined approach to dealing with data collection. For example, they sometimes chose not to speak about a certain topic in the presence of the recording device, or they paused the recording and we encouraged moments of negotiating consent in the research process. This illustrates that consent was not only dealt with in the IC session, but was continuously and dynamically negotiated between the academic researchers and the CoRes in our research practice.

Digital IC

During and after the COVID-19 lockdown, we adapted the co-creation activities to digital tools by using the *Actionbound* app. Its gamification of IC was a substitute for the in-person IC session. Gamification can be defined as using game design elements that are usually linked with the idea of entertainment for educational purposes (Denteringer et al., 2012). In our case, using gamification principles made action research accessible and usable to young people. Besides



consisting of plain language, less text, and more visuals, the material also contained quizzes, polls, and explanatory videos.

In the introductory part of the *Actionbound* “Action Research on Education and Employment”, we explained what will happen with the uploaded data, e.g., who will be able to access it. The young CoRes used the app with a username; however, we encouraged them to think about what they want to share with the researcher team (Figure 9). Moreover, we created an explanatory video. The main objective of the explanatory video was to visualise how participants can anonymise and pseudonymise their and other people’s data before uploading it to the platform. It showed each data format (text, audio, pictures, and videos) and methods to anonymise and pseudonymise them (Figure 10). Additionally, *Actionbound* contained a repetitive element about how to upload depersonalised data which helped to convey its importance. Additionally, we used the function of quizzes to deepen the most important aspects of data, privacy, and depersonalisation of data (Figure 11).



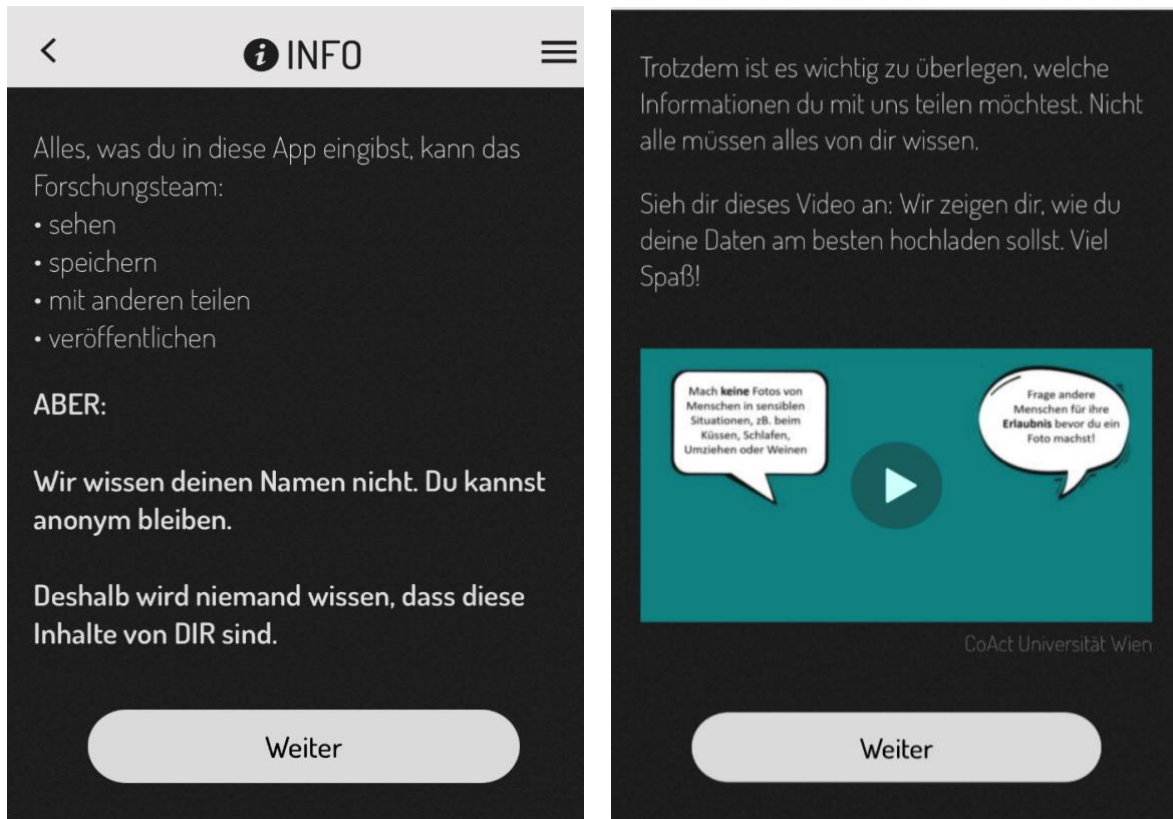


Figure 9: Screenshot from the Actionbound “Action Research on Education and Employment”

Translation: Everything you type in/upload to the app, can be seen, saved, shared, and published by the research team (from the University of Vienna). BUT: We don’t know your name. You are anonymous. Therefore, no one will know that it is your content.

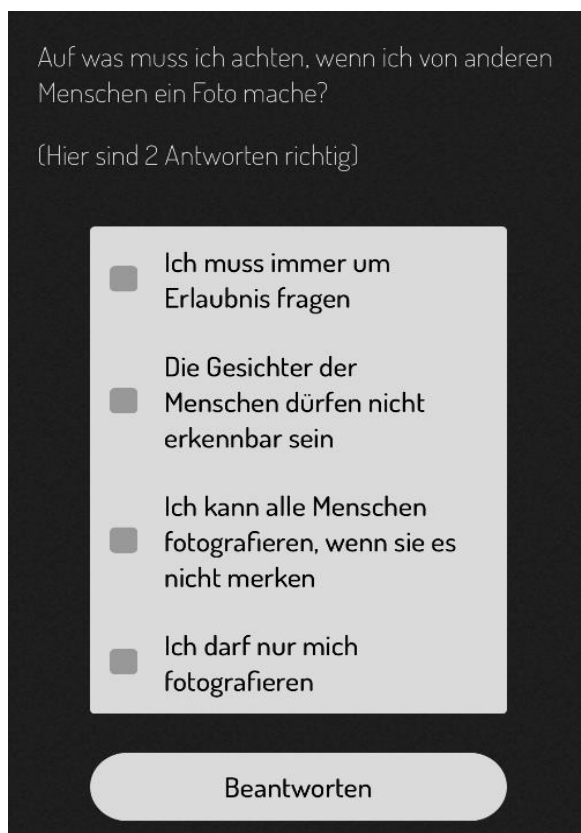
But still, it is important to think about what information you want to share with us. We don’t need to know everything. Watch this video: We will show you how you can upload your data (so that it is anonymised and pseudonymised). Have fun!





Figure 10: Screenshot from a video in the Actionbound “Action Research on Education and Employment” on how to anonymise and pseudonymise data

Translation: Everything you need to know about pictures! You or other people must not be visible on pictures—either you conceal the face before taking the picture or you edit it with an emoji afterwards



Translation: What do you have to be careful of when you take pictures of others (for our research purpose)? (Two answer are correct here)

- I always have to ask for permission.
- People’s faces must not be identifiable.
- I can take pictures of everyone unless they notice it.
- I am only allowed to take pictures of myself.

Figure 11: Screenshot from a quiz in the Actionbound

“Action Research on Education and Employment”



5.4.6 Reflection on Collaborative Work Within the Consortium

Within the *CoAct* Consortium, the UNIVIE research team facilitated internal sessions to enhance discussions about IC in practice. Here, we created a space to highlight successful IC moments in practice; however, we also approached challenging moments and doubts with openness and honesty. The collaborative sessions were used to promote supportive exchange among the RIAs. Additionally, the Reflection Sheets used throughout the research process induced reflections within the RIAs. In doing so, we implemented a way of documenting ethically important moments, the researcher's insights about resolving challenges, and open questions.

The necessity of legal documents for obtaining IC opened up the discussion surrounding information simplification. We not only gained familiarity with plain language, but also created space to try it out. We acknowledged that we were used to academic writing and needed support and practice to present information in plain language. Therefore, we dedicated a collaborative session to rewriting parts of the IC form. Furthermore, over the course of the data management plan (with OFK lead), we reflected on the different types of data in our case study. The differentiation of data and the specification of its usage were also helpful for the research practice.

Finally, beyond the *CoAct* Consortium, the DPO of the University of Vienna was a vital point of contact for doubts and legal questions. Interactions with the DPO contributed to holding a cooperative event for researchers about IC that discussed it from both a legal and ethical perspective. The DPO is a point of contact for researchers at the University of Vienna, which is why this event was designed for this group. Participants learned about the legal background of IC regarding the GDPR and had the opportunity to reflect upon and exchange ideas about IC in practice. By presenting challenging moments from our research, we discussed the influence of different social contexts and their ethical implications for the particular situation, and opportunities for handling the situation in an ethical manner.



5.5 RIA #3—Environmental Justice

5.5.1 Introduction

RIA #3 in Buenos Aires is led by the research organisation Universidad Nacional de San Martín (UNSAM) in collaboration with the non-governmental organisation Fundación Ambiente y Recursos Naturales (FARN). It addresses environmental justice issues in the Matanza-Riachuelo Basin. This highly polluted area is inhabited by more than six million people, where a Supreme Court ruling recently decided to relocate 1,200 families living in slums due to the hazardous sanitation conditions and health risks. The area's contamination is addressed by multiple public policy jurisdictions, coordinated by the national authority the Autoridad de Cuenca Matanza-Riachuelo (ACUMAR) that developed the *Plan Integral de Saneamiento Ambiental* (PISA) on environmental sanitation, which is monitored by a collegial body integrated by non-governmental organisations, including FARN. To foster participation by affected citizens, these stakeholders promoted the platform creation of “Qué pasa Riachuelo?” (“What’s up, Riachuelo,” QPR) through FARN to gather data on the policy implementation for monitoring activities throughout the Basin. Data was mainly gathered during workshops that took place between 2011 and 2014. The platform helped highlight the lack of public information about the policy’s implementation and pressured the authorities’ agenda towards increasing transparency through online data publication.

This RIA builds upon these previous efforts and seeks to advance the participation of the Basin’s population by working with communities in highly polluted areas to promote transformative actions in community and policy practices towards environmental justice. It does so through its use of CSS digital tools for the collective generation and interpretation of data. In particular, we are co-designing a digital platform to collect citizen-driven data and analyse them together with other public sources of information in a way that can promote transformation. This process is participatory, and involves several actors with different interests in various instances.



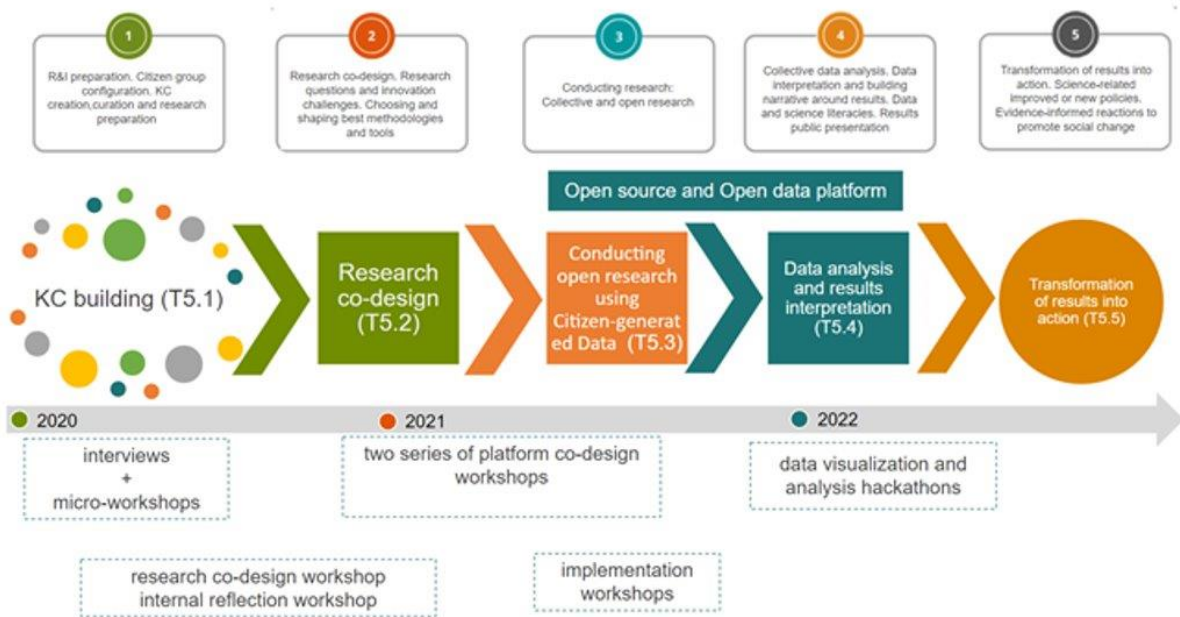


Figure 12: CoAct research cycle for RIA #3 on environmental justice

Through interviews and participatory workshops with the KC, we initially identified themes and purposes for the digital platform and selected three primary themes of great relevance to environmental justice, which are part of FARN’s agenda in the Basin: resettlement processes, water quality, and protecting natural areas. The KC is defined as a network of stakeholders who either have experience in the Basin carrying out different roles, do environmental justice research or work, or have previous experience in participatory knowledge production (Arza, et al., 2020). Due to COVID-19 restrictions, the co-design process was conducted through virtual workshops organised thematically and distributed in different areas of the Basin with the CoRes’ participation. Their goal was to better understand the platform’s potential uses and expectations, to identify issues related to each theme, and to explore prototype-specific functionalities within the platform. CoRes will also be involved in defining the platform’s implementation workshops to generate citizen data, and in identifying its potential use for transformative actions.

5.5.2 Target Groups

Virtual participation required participants to gain access to digital infrastructure and have some experience and/or training about how to communicate virtually, which proved to be challenging in some cases. KC members were classified into three groups: academic researchers, actors from



community and other civil society organisations, and policy makers. Although all CoRes live or work in the Basin, there were different thematic profiles:

- Resettlements: Neighbours affected by the policies, who have either moved or are waiting to complete the process—both those in favour of or resisting it. They belong to the population most impacted by the Basin’s contamination and, therefore, their housing conditions are not always optimal. In addition, they may be affected by socioeconomic inequalities that limit their access to information and digital resources, such as the lack of a stable internet connection and electronic devices. This creates barriers to their participation.¹¹
- Natural areas: Primarily neighbours who are part of local organisations that promote the protection of this area. These CoRes have better access to communication infrastructure than those in the Resettlements profile, and we were able to interact through video calls. However, these CoRes sometimes connected to the internet through tablets or mobile phones, which were not optimal for the planned dynamics.
- Water quality: Librarians working in community libraries and neighbours closely interacting with them. They have previous experience in activities related to disseminating science and technology issues, and are particularly interested in environmental topics. Their internet connectivity is stable but they sometimes face technical challenges with digital tools.

5.5.3 Informed Consent Activities

Preparation

Neither the UNSAM nor FARN teams have ethics committees to guide IC procedures in research activities, although UNSAM has a biomedical research ethics committee. We adopted a strategy to develop our IC forms and procedure by reviewing both the *CoAct* team’s documentation as well as national policies and regulations. We requested an external review from existing ethics committees at national universities and research institutions via email. When this was

¹¹ Although FARN provided prepaid mobile data cards to conduct the workshops, lack of time, urgent needs, and difficulties establishing virtual contact continue limit frequent interactions.



unsuccessful, the UNSAM Vice-Provost's Office - Office of Research, Innovation and Tech Transfer reviewed the project and provided a note of approval, initiating an internal process to establish the ethics committee that could assist other future projects and review their ethical implications.

After some difficulties during the first phase of data collection with different stakeholders, we discussed and adapted the procedure. First, we developed plain language documentation, since we recognised that the legal jargon in the documentation was counterproductive to facilitating a welcoming environment. This reflected similar concerns raised by the *CoAct* partners with whom we collaborated. Second, we provided an option for obtaining oral consent—which was recorded by audio—after jointly revising the documentation at the beginning of the meetings. However, we identified that certain challenges persisted and proceeded to create a video, which aimed to replace the main sections of the written information with digital content and provide alternative means of communication (oral and visual) to participants.

Another instance of modification to the IC forms arose from changes to the types of activities and participants' access to technology. Specifically, recording each participant's consent was not feasible at one large workshop organised with the KC. Therefore, we decided to structure the information in a digital *Google Forms (Gform)* questionnaire and accept email addresses provided by the participants as proof of their agreement. The questionnaire contained the written information, the link to the explanatory project video, and our data management and privacy policies. The *Gform* included a specific section to obtain agreement concerning the exclusionary aspects for which we request consent. Additionally, we provided space to express preferences, like the option to request not to be recorded, or that quotes and all contributions are attributed to the participants instead of anonymised.

Research Cycle

The main activities in the first phase of the RIA were semi-structured interviews and workshops:

- The online interviews started by providing information in a written document via email. We had conversations at the beginning of the video calls to reinforce the explanation of our data policies and the participants' rights. Collecting the participation agreements was also modified by requesting and recording consent during the calls when needed to adapt



to participants' difficulties with printing and signing documents or providing digital signatures.

- We held different types of workshops with CoRes and with the KC, which included discussions about personal and sensitive information. In particular, some community actors were not used to the legal jargon in the IC forms. To make our obligations and commitments as clear as possible, we developed plain language documents with the items they would agree to upon deciding to participate and about our institutional responsibilities. We sent audio messages informally that explained why we requested consent to participate, and we developed an informative video that was used to discuss any doubts or concerns before recording the CoRes' agreement.

During the second research phase, we conducted several co-designed workshops with CoRes from local communities and social organisation members. In most cases, we sent participants the *Gform*, but some groups faced technical challenges. In addition, neither the UNSAM nor FARN teams had met most of these participants in person, which introduced potential trust issues since this population has faced years of political negligence and unfulfilled promises. In such cases, we sent audio messages through *WhatsApp* that commented on the policies in addition to the video and documents. Given the expected technical difficulties, we considered that requesting consent during the video call could be problematic, so we asked participants to send their agreement in advance through the *WhatsApp* group—either written or audio-recorded.

Reflections

The IC forms and procedures were modified and adapted, and our approach has been as flexible as possible to accommodate the diversity of participants and activities in our RIA. The different formats that we tested and implemented were mainly designed in response to concrete obstacles encountered during the project. Both the CSS approach and the exceptional context of the COVID-19 pandemic were conditions that catalysed innovation. For example, one workshop participant was underage; however, we had not previously been informed of this. Because the activity had already started, we allowed them to continue participating and requested their guardian's consent later on. This led to a discussion among the team on how to proceed in future



group activities when an interruption to the discussion or conversation dynamic to request a formal recording of consent could be disruptive or create tension. It prompted the development of the *Gform* to both collect advance consent and centralise the information, as well as to provide participants with a more flexible approach to the information and registering their preferences.

In sum, to promote community participation, we not only consider the formal and legal aspect of IC, but also how to present the information through more accessible formats and processes. Developing alternative media for communications resulted in the implementation of a customised procedure according to what we consider more appropriate for the stakeholders we interact with.

5.5.4 Challenges

Lack of tradition in the country's IC procedures

Argentina lacks a tradition of IC procedures—especially in the social sciences—which meant the team had to dedicate additional time and efforts to develop procedures that were appropriate for the different types of actors that were involved in the project. This challenge also led to the reluctance of some stakeholders towards the procedure, and in some cases, participants did not immediately provide their consent or indicated that the process seemed like an unnecessary bureaucratisation of research. The cases of expressed reluctance mainly came from the academic stakeholder group, who tended to interpret the reference to participation as a commitment of involvement in all project activities, or they did not consider the adoption of data protection and privacy policies to be relevant.

Diversity of participants

The RIA comprises diverse stakeholders, including participants who face socioeconomic difficulties that may include digital illiteracy, lack of access to infrastructure, and time constraints. Data illiteracy (i.e., inexperience or lack of knowledge about data usage, security, and protection) demanded particular attention when explaining the data management and personal data protection considerations of our activities. To improve communication in this context, we remained flexible and allowed for adapting approaches to the different situations we had to



engage with. As mentioned about this RIA's target groups, we had participants from disparate backgrounds, including some (especially among community groups) who had no internet access or previous knowledge of digital tools. In general, all types of participants (including academic) faced digital connectivity issues.

For example, one participant was unable to send their advance signed consent and instead initiated a conversation to provide information. The team chose not to interrupt the interview to request consent, but the participant continued to later be associated with the project and helped us organise a workshop with community members. On that occasion, this person provided oral consent that we recorded. We implemented the option of video- or audio-recording consent procedure in subsequent interviews and gave participants this option in advance when contacting them.

In addition, implementing IC within the mandatory COVID-19 lockdown context was a concern, given potential connectivity issues for some participants. We solved this by combining asynchronous and synchronous procedures: by sending explanatory emails and *WhatsApp* messages (text, audio, and videos) and then going through the information with the participants and allowing them to express doubts or concerns at the beginning of each activity.

There has only been one underage participant so far, for whom parental consent was requested and obtained. Thus, we have not faced major challenges regarding personal data collection that include underage participants. We expect to act similarly if underage participants turn up to our activities without previous notice. If we expect them to be present, we will send the *Gforms* for their parents to complete in advance.

Power imbalances

Virtual formats created a potential risk of unequal access to the communications and participation. First, given that the activities are convened by UNSAM and FARN teams, there is an initial power imbalance in terms of access provision: Only the hosts retain control over admitting participants to the "virtual room." Being aware of this position, we allowed every person requesting access to enter the call, and we provided them with the project information and policies. On one occasion, a co-researcher refused to be recorded because they did not know enough about the project (even though the team had provided informative material). Because of



time constraints, we could not address this concern and the session was not recorded. Instead, we took notes to respect the participant's doubts. After that experience, whenever participants had not completed the *Gform* ahead of time, we paused the recording or delayed it to allow them to complete and send in real-time.

Different procedures for different activities: individual vs. collective; small workshops vs. large workshops virtual vs. onsite

As the RIA moved from individual interviews to more participatory and group activities, we encountered more pressing timeframes during which we had to provide explanations and information. This led to the development of a *Gform* that contained information on the data and information privacy and protection policies as a general format for collecting consent (agreement with both the terms of participation and specific preferences), and eventually adapted its use for different interactions. In particular, we prepared and implemented targeted actions for participants who had lived experiences with vulnerable conditions, and managed to provide more adequate IC forms and means of collecting consent in light of their personal circumstances. For example, for community groups with whom we had no previous contact, we replaced the IC *Gform* with *WhatsApp* voice and text messages, which is the most commonly used messaging platform in Argentina, and complemented them with further explanations and discussions during the online meetings.

In regards to different forms of consent, we reflected upon the following situation from an on-site activity:

“Face-to-face meetings during COVID-19 were rare but from time-to-time possible. At one such meeting that happened, people were going through the IC form together and engaged in discussion about it with the accompanying researcher. The people were eager to switch to the topic of that day's meeting—namely environmental issues. One person didn't return their IC form after reading it and before the discussion started. The researcher didn't want to stop the enthusiastic group discussion and decided not to record the session, because not everybody consented to the data processing, and to just take notes. After the session, that person simply asked a little question and handed in their



form. The question that arises is: How can a researcher deal with different forms of consent during a collaborative research project?” (16 December 2020¹²)

Because of connectivity issues, it was not always optimal to inform large groups of people during virtual workshops, and we intended to reduce the activities’ duration. We noticed that people experienced some fatigue during online meetings as COVID-19 restrictions were extended. We addressed this challenge by implementing the already-mentioned accessible and alternative formats of information provision.

Additional challenges that appeared were mainly associated with in-person situations. During the first 20 months, there were very few project activities that we could organise onsite due to strict social distancing protocols. Therefore, building a fluid conversation or developing trusting relationships with participants who live in vulnerable conditions has been difficult and has demanded more time than anticipated. Virtual environments are not helpful for these purposes. When we approached participants that had initially been contacted through digital means about in-person activities, the IC procedure included an oral explanation. This sometimes involved using a projector to show IC policies to everyone and discussing the form’s content during the meeting. Once most participants had signed IC forms, we approached new participants in one-on-one conversations. After answering each actor’s questions—on several occasions, when we felt that others in the group may have similar concerns—we addressed the topics aloud to ensure that everyone was informed. We printed the IC forms for these on-site activities and there were no significant obstacles or manifested concerns in terms of the project’s policies.

5.5.5 Innovative Moments

The innovative moments from our RIA were catalysed by the intention to ensure accessibility and a comprehensive understanding of the IC forms. The most important events were led by a simplification approach that was advanced by the CoAct Consortium as the different RIAs began

¹² This experience was reflected upon in an internal session with other members of the Consortium on 16 December 2020. The session’s aim was to discuss ethically relevant moments relating to IC in a broader sense for each RIA research practice.



to face the COVID-19 lockdown and social distancing measures, which created obstacles to implementing the planned procedures.

After the Consortium discussion and a specific session about language simplification in the IC forms, our RIA further advanced its development of additional resources. Based on the simplified forms, the UNSAM team prepared a script for an informative video (Figure 13) to share in an asynchronous conversation with micro-workshop participants. The video was developed by the FARN communications team.



Figure 13: Excerpt from the RIA #3 “CoAct–Ciencia Ciudadana para la Justicia Ambiental en el Riachuelo” informative video (in Spanish)¹³

The video led us to consider how to provide information to participants in formats that are closer to their regular content-sharing practices. At the same time, we discussed the importance of organising and preserving consent in the context of virtual interactions, since most of our activities included either email discussions or video calls (for interviews and workshops), and diversifying collection approaches (from scanned copies of the forms to recorded audio or video agreements). In order to centralise the information and ensure its digital preservation in the context of home office activities, we developed a *Gform* (Figure 14) that contained information on the *CoAct* project, our RIA, and the data privacy protection and information management policies. These were in addition to two subsections where participants could both indicate their agreement and preferences (e.g., to indicate if they would like to be acknowledged, or if they did not want to be recorded or have their image used for communication purposes).

¹³ RIA #3 “CoAct–Ciencia Ciudadana para la Justicia Ambiental en el Riachuelo » informative video in Spanish: <https://www.youtube.com/watch?v=paEHUmLzkDw>





Figure 14: Excerpt from IC Gform for RIA #3 “CoAct – Ciencia Ciudadana para la Justicia Ambiental en el Riachuelo” (in Spanish)

The IC *Gform* was a preferable format for most participants, as this tool is commonly used for information registration purposes in Argentina, as well as for surveys. We did not encounter major obstacles to implementing this procedure, and it was even used trouble-free with groups of participants who faced cultural and technical difficulties. In addition, the challenges faced with certain CoRes allowed us to improve the IC materials and procedures through a lifeworld-oriented approach. In particular, a CoRes with whom FARN had previous contact did not send the signed document, but continued participating and co-organising activities, and expressed interest in and commitment to the project. Therefore, we decided to try the approach we had implemented with other CoRes who experienced technical difficulties and could not print and sign a document: We requested an audio recording via *WhatsApp*. The IC was provided a few hours later, which allowed us to use the collected information for further research. The content in the informative section of the *Gform* was also modified by changing the text at the beginning to introduce readers to the content that they would encounter and to clarify our broad interpretation of participation. The procedure was also reviewed and we added a step to send



the *Gform* in PDF format, along with a link to complete it when participants were contacted through email to allow them to preview the form content.

We have kept a record of the procedure modifications and innovations to our project’s documentation approach through the open-source *GitLab* platform. Figure 15 shows an example from the last modifications:

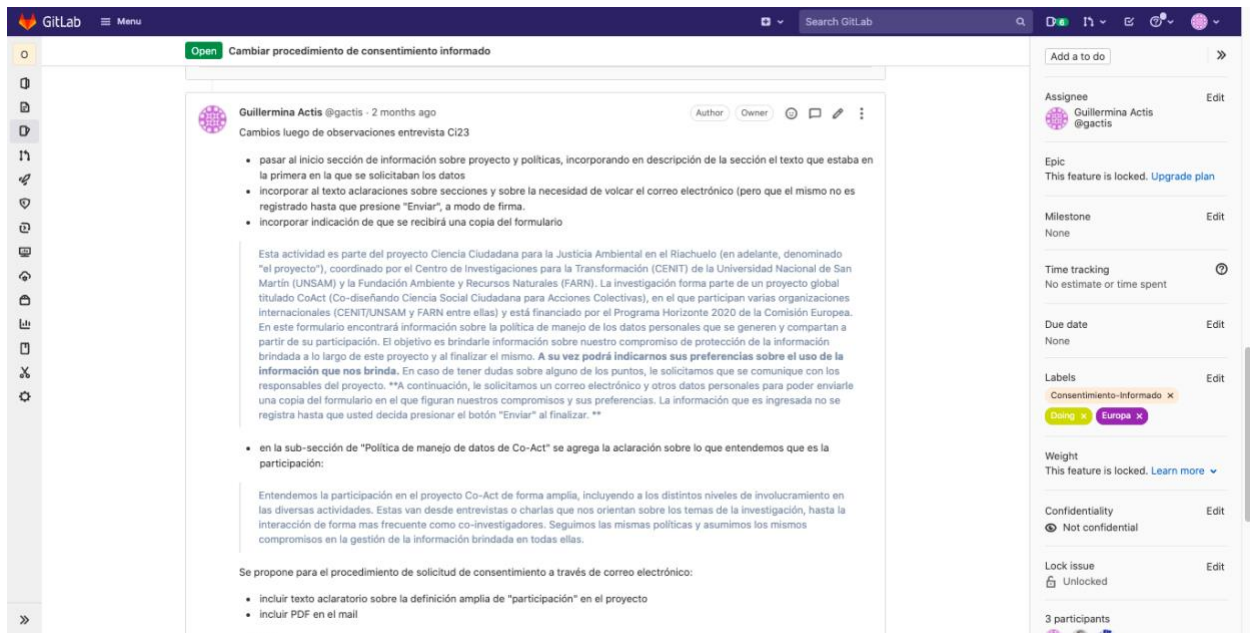


Figure 15: Documentation of the IC procedure on *Gitlab* in RIA #3

5.5.6 Reflections on Collaborative Work Within the Consortium

The RIA #3 institutions do not have neither committees, institutional review boards, or institutional data protection offices. At the beginning of the process, we reached out to other local institutions to seek advice with little success, as these issues are not extensively addressed in Argentina and its institutional capabilities are not yet fully developed. Therefore, we found a great amount of support from the Consortium partners, who shared their experiences and concerns regarding the IC procedures, and provided us with help and assurance in cases where we followed new approaches and developed innovations.

During the IC form development process, we received support from our *CoAct* international consortia partners: UB, UNVIE, and ZSI provided suggestions and comments for the first draft of



the IC forms and were later part of the sessions on plain language translation, which helped us further reflect upon our procedures' accessibility and simplification.

The regular weekly calls coordinated by UB were also of support, as we discussed the potential innovations and different situations that we found problematic to our procedures (for example, whether we should discuss the forms during the activities or send them in advance to allow participants to develop questions before the workshops). In terms of procedures, on several occasions during our weekly regular calls, we reflected upon and discussed the encountered obstacles with different partners. They gave recommendations about actions and strategies to follow under different circumstances where we faced difficulties in applying the IC procedure. We reflected jointly about the tools and media being used to request consent.

Finally, we consulted with our partner, OKF, about the *Gform* development to clarify if the tool was appropriate for collecting participant consent, and to review that the provided information included all the mandatory criteria.

5.6 Co-Evaluation

5.6.1 Introduction

The objective of WP7 is to develop and implement an evaluation framework to enable, foster, and assess multi-level impacts that are envisioned by connecting citizen groups, citizen initiatives, scientists, and public bodies—and thus placing citizens at the centre of the RIA. The WP activities are closely coordinated with other RIA WP leaders. For this purpose, the Zentrum für Soziale Innovation (ZSI) has developed a co-evaluation approach, which refers to a form of participatory evaluation that already initiates the conversation about expectations, objectives, and impacts at the start of the project. This either occurs when the research design is co-created with different stakeholders, or at least when the actors' participation is negotiated. The main difference between co-evaluation and conventional types of research evaluation is that participants are also involved in the decision-making about project goals and evaluation instruments.

Both the general execution of the co-evaluation approach, as well as the expected role of the ZSI team in each of these processes, were negotiated and operationalised according to the needs of each specific case. There were initial doubts about how to best integrate the ZSI team into the



co-research process without breaking tentative bonds of trust in the context of sensitive societal issues like mental health disorders. This required a special effort to establish a relationship of trust in addition to the existing data control agreements, as the COVID-19 pandemic prevented us from being on-site. Therefore, the partners had to do many evaluation activities on our behalf and integrate them into their own tasks and interactions with the KC or the CoRes. Over the course of the project and across the many different evaluation and co-evaluation activities, ZSI co-developed an assessment framework based on a three-dimensional approach: Bringing together the scientific, the citizen, and the socio-ecological perspective; taking into account expected outputs, as well as intermediate and long-term outcomes for co-researchers, citizen scientists, professional researchers, and KC members; the timelines as roadmaps for each of the RIAs. A mapping of useful research and innovation indicators developed in each RIA shows commonalities and differences between cases and serves as a reference point for overarching, cross-action discussion, and analysis.

5.6.2 Informed Consent Activities

The IC procedures for the co-evaluation activities were relatively straightforward: We created standardised IC forms that conform to the GDPR in English, Spanish, and German for the online surveys and personal interviews. All other activities were covered in each partner's IC procedures for each RIA.

5.6.3 Challenges

For ZSI, IC-related challenges mostly occurred at the beginning of the project. The COVID-19 crisis prevented ZSI from joining the *CoAct* partners on-site for the co-evaluation activities and to negotiate their process. Hence, we had to integrate our activities into their (mostly online) interactions with the project stakeholders. Not all *CoAct* partners shared the same information with us, and the level of access to the project's KC and CoRes differs widely across RIAs. Most information we receive is anonymised; however fully anonymised data makes it difficult to follow up for further co-evaluation activities, and may therefore complicate the participatory process. Furthermore, developing evaluation criteria also requires discussing data-sharing policies with the participants at an early stage, especially since some participants need special data protection (e.g., youth, politically exposed people, and patients). This was not feasible, so we had to “step



back” and use those opportunities where the topic of sharing data produced in the project was nevertheless part of the partner’s activities. The only way that ZSI could tackle those challenges would require becoming even more flexible and adapt to the RIAs’ needs and temporal structures.

During the co-evaluation process, no additional innovative moments regarding IC have occurred, because ZSI was supporting the RIAs and adding to existing IC procedures. However, we wish to highlight the explanatory videos from our *CoAct* partners that are used to describe the project in a complementary manner to the IC procedure. In this regard, those alternative approaches taught us a valuable lesson in that common GDPR-derived standards and available tools might not work outside our (legal) and very Eurocentric context. It was therefore a great learning opportunity for us to adapt our IC approach by closely following the expertise of our colleagues in Buenos Aires, instead of simply imposing our common approach upon the project. In some cases, this meant that our usage of the data generated by the partners was mentioned during their oral IC procedures.

6. Concluding Remarks

Chapter 6 discussed the main outcomes of the RIA and focused on reflections, challenges, and innovative moments in the research cycle, as well as outcomes from the collaborative activities within the *CoAct* Consortium. By portraying processes related to informed consent, we showed that they go beyond traditional, formalised procedures, and provided insights about the informed consent practice based on alternative approaches. In doing so, we contributed to existing ethical frameworks such as the ‘ethics of care’ (Gilligan, 1982) and ‘ethics-in-practice’ (Guillemin & Gillam, 2004) by linking them to informed consent procedures and providing insights into research practices. Likewise, we further shaped the discussions on informed consent procedures in citizen social science and participatory research approaches that go beyond ‘bureaucracies of virtue’ (Felt, 2017). In the following, we link the innovative moments from the research process with alternative frameworks of how informed consent is understood beyond formalised procedures. Here, we emphasise selected, existing theoretical discussion that were presented in *Chapter 4*.



6.1 Informed Consent as a Process

While institutionalised procedures of informed consent are often the default at European universities, it is nevertheless important to include other ethical considerations. Here, ethics-in-practice (Guillemin & Gillam, 2004) helps deepen the understanding of informed consent and capture unforeseen ethical issues. Ethics as a concept that focuses on micro practices in research is therefore not a one-time affair, but an ongoing process with crucial moments of ethics-in-practice. Through continuous exchange within and beyond the RIAs on ethics-in-practice, we aimed to sharpen our understanding of informed consent in order to spot these decisive moments. A processual understanding of informed consent was applied, e.g., in RIA #1 on mental health. Since the informed consent procedures were explained in multiple steps during the research process, instead of only at the beginning when the co-researchers signed the informed consent forms, consent was continually discussed with them. In RIA #2, internal reflections on ethically important moments were part of the preparatory work so that the scientific researchers could increase their awareness of such moments. These reflections included discussions on ways to negotiate informed consent between co-researchers and researchers. As illustrated here, moments of changing consent can occur. Co-researchers can express this very differently throughout the research project. For example, in a co-designing activity that is being recorded, a co-researcher may say that they are only disclosing something to one specific person, or they add “do not tell anyone else.” It is the researcher’s responsibility to acknowledge moments where consent changes in interactions and address this in an ethical manner, such as by providing space to discuss and renegotiate the data sharing.

6.2 Relationality and Particularity

Ethics of care (Gilligan, 1982) has been discussed in relation to informed consent (Tronto, 2008; Sutrop & Lõuk, 2020; Osuji, 2018). Here, subjects are recognised as relational actors that are embedded in social, societal, and historical contexts. For informed consent activities, this translates to acknowledging that the competence to understand the research project and decide whether to participate is socially shaped. Thus, universal notions of informed consent or required supportive measures are not universally helpful and must be adapted to the respective target groups, such as by using oral consent or visual material to complement the formalised informed



consent procedures. In *CoAct*, discussions about making informed consent accessible to the target groups and simplification procedures were at the centre of reflection from the beginning. Moreover, we made different efforts to adapt formats to the co-researchers' needs, such as videos, visual material, and oral explanations besides the written consent forms themselves. In RIA #1, micro stories were presented prior to the co-creation sessions to support the understanding of the planned activities and to demonstrate what participation entails—namely creating own micro stories. Because of the sensitive topical nature of mental health illnesses and support networks, a psychologist was present at the co-creation sessions in case their support was needed. In RIA # 3, informed consent forms were not a standard practice for research projects, thus they can create mistrust and require extra care to inform and empower people in the decision-making process. Furthermore, after ascertaining the co-researchers' social contexts, especially in terms of the lack of access to technological devices, the scientific researchers provided the option of oral consent. These measures enabled RIAs to respond to the specific conditions of their research setting. In keeping with an understanding of informed consent as a social endeavour, potential exclusionary factors were mitigated as best as possible.

6.3 Reflexivity and Positionality of the Researchers

Researcher integrity requires a high aptitude for (self-) reflection and critical thinking (Banks, 2008, 29), which entails reflecting on how one's own assumptions and actions inform the research process. Additionally, self-reflection is necessary to recognise ethically important moments (Guillemin & Gillam, 2004). In *CoAct*, reflections on doubts, the researcher's role in relation to the co-researchers, power imbalances, and how these affect the research practice were part of several activities within the Consortium such as the Reflection Sheets or the internal support meetings. RIA #1 continuously reflected upon the dilemma that the co-researchers and scientific researchers did not share personal information equally, thereby creating an imbalance of power. RIA #2 dealt with the issue of positionality through the problem of voluntariness. Understanding the co-researcher's social context was important for recognising that the young people were obligated to attend the *E&T up to 18* measure if they wanted to receive monetary support. Thus, the scientific researchers needed to explicitly communicate that participating in the *CoAct* project was not part of the *E&T up to 18* measure and therefore voluntary. Reflecting



upon such possible power imbalances helped the researchers consider the social inequalities and vulnerabilities of all research participants and to understand how they affect consent—and especially the requirement of voluntariness.

6.4 Community Aspects in Informed Consent

Community-related informed consent procedures combine individual ethics, such as protecting the individual co-researcher with community ethics that include the protection of an entire community and pose questions of representation, social justice, and cultural and social responsibility (Hudson, 2009). Citizen social science has the potential and means to incorporate aspects of community consent; for example, *CoAct* employs the Knowledge Coalition concept, which is based upon the idea of community involvement, since the Knowledge Coalition is a dynamic network of people from the respective field (mental health, youth employment, and environmental justice). In all three RIAs, the Knowledge Coalition encompasses diverse actors who are affected differently by the social issue at the core of the research cycle. Representatives of specific communities, such as mental health professionals, people with mental health experiences, youth representatives, and environmental justice activist groups shape the Knowledge Coalition network. Throughout the co-creation process, cyclical exchange between Knowledge Coalition members was facilitated to include their insights into the process. For informed consent, this translated into understanding the social context of the target group and learning from the expertise of the Knowledge Coalition members. In doing so, we included different affected actors in the research process and further appreciate them as partners with equal rights and agency.

6.5 CoAct Policies

Citizen social science draws on a multidisciplinary debate about research ethics and informed consent that aims to improve research collaborations between researchers, participants, and communities. As discussed in *Chapter 2*, various guidelines and principles govern informed consent. *CoAct* incorporates these principles and goes beyond the ‘bureaucracies of virtue’ (Felt, 2017) to illustrate that informed consent is a process of responsibility, accountability, and building trust. *CoAct* contributed to this endeavour and therefore integrated and further



developed various approaches discussed above into research practice. As a result, we propose the following policies for informed consent:

- **Accessibility:** Actively engage in making the informed consent procedure understandable to the research participants by ensuring the simplicity of its content. This can be done by writing informed consent forms in plain language and presenting informed consent in accessible formats according to the needs of the target groups.
- **Alternative tools:** The informed consent procedures should not solely rely on written language, but also include interactive and visual tools. If deemed appropriate for the target group or if necessary due to geographical distance or COVID-19 regulations, this can imply digital tools as well.
- **Atmosphere:** In order to minimise obstacles for research participants, informed consent forms should at minimum be read out loud once and discussed collectively. Simultaneously, special attention should be placed on creating an atmosphere of trust in which asking questions is encouraged.
- **Dynamic process:** Throughout the process, researchers must ensure an ongoing discussion of informed consent with the co-researchers and provide opportunities to only opt in to certain aspects of the research or completely opt out at any given point. Also, because changes can occur during the co-creation phase, the informed consent procedures must be adaptive.
- **Collaborative reflections:** Within the project team, ongoing discussions about informed consent (challenges, doubts, and best practices) should be encouraged, along with collective thinking about dynamic and adaptive informed consent procedures that include a diversity of actors.
- **Commitment to improvement:** Reflecting upon informed consent procedures and questions of good practice and improvements should be subject to internal discussions within the project consortium.
- **Reflection upon potential harms and risks:** A discussion of potential harms and risks needs to be part of the informed consent procedure. This should align with core values of



autonomy and participation and should not reproduce paternalistic patterns that downplay or restrict the co-researchers' agency.

- **Self-determination:** The research participants' self-determined agency must be respected, valued, and encouraged. Ensuring their active reflection upon informed consent and its implications is necessary for them to make self-determined decisions.
- **Power-sensitive reflection:** Power dynamics and different positionalities broadly exist in our respective societies, but also specifically within the research project. The implications of power dynamics within the research setting are a matter of ongoing reflection also together with the co-researchers.
- **Self-reflection:** The scientific researchers should reflect upon their positionalities and how they implicate the research process and knowledge production. This entails questioning one's own assumptions of the target group.
- **Revocation of consent:** Co-researchers should be encouraged to voice questions and uncertainties, and be informed of their right to withdraw the previously given consent at any time.
- **Engagement of the community:** The research process and its results will be made available and discussed with different communities. This can take place in various formats, such as meetings, through newsletters, the *CoAct* homepage, or events. Any potential for harm raised by the community should be acknowledged and handled in a serious manner.



7. Appendix

The [informed consent forms](#) from each RIA and those used for co-evaluation are accessible on *Zenodo*. Please note that the forms were created and used for co-creation activities within the *CoAct* project between beginning of 2020 and the end of 2021. They comply with the current GDPR requirements and were reviewed by the universities ethics committees and data protection offices for RIAs #1 and #2, and by the UNSAM Vice-Provost's Office - Office of Research, Innovation and Tech Transfer for RIA #3.

8. References

Ausbildungspflichtgesetz (2021).

<https://www.ris.bka.gv.at/GeltendeFassung.wxe?Abfrage=Bundesnormen&Gesetzesnummer=20009604>

Anthony-Okeke, L. (2020). Researching young people's experiences. An African-centered perspective of consent and ethics. In P. Billett, M. Hart, & Martin, Dona (Eds.), *Complexities of researching with young people, youth, young adulthood and society* (pp. 101–114). Routledge.

Arza, V., Actis, G., Velarde, M., Cane, S., Buchsbaum, M., & Swistun, D. (2020). *CoActD5.1: Knowledge coalition building. Environmental justice*. <https://doi.org/10.5281/zenodo.4443441>

Bacher, J., Braun, J., Burtscher-Mathis, S., Dlabaja, C., Lankmayer, T., Leitgöb, H., Stadlmayr, M., & Tamesberger, D. (2014). *Unterstützung der arbeitsmarktpolitischen Zielgruppe 'NEET' : Studie von ISW, IBE und JKU im Auftrag des Bundesministeriums für Arbeit, Soziales und Konsumentenschutz*. Verl. des ÖGB. <http://media.obvsg.at/AC12133663-2001>



- Banks, S. (2018). Cultivating researcher integrity: Virtue-based approaches to research ethics. In N. Emmerich (Ed.), *Virtue ethics in the conduct and governance of social research* (pp. 21–44). Emerald Publishing Limited.
- Beauchamp, T. L. (2010). *Standing on principles: Collected essays*. Oxford University Press.
- Benjamin, R. (2016). Informed refusal: Toward a justice-based bioethics. *Science, Technology, & Human Values*, 41(6), 967–990. <https://doi.org/10.1177/0162243916656059>
- Brall, C., Maeckelberghe, E., Porz, R., Makhoul, J., & Schröder-Bäck, P. (2017). Research ethics 2.0: New perspectives on norms, values, and integrity in genomic research in times of even scarcer resources. *Public Health Genomics*, 20(1), 27–35. <https://doi.org/10.1159/000462960>
- Budin-Ljøsne, I., Teare, H. J. A., Kaye, J., Beck, S., Bentzen, H. B., Caenazzo, L., Collett, C., D’Abramo, F., Felzmann, H., Finlay, T., Javaid, M. K., Jones, E., Katić, V., Simpson, A., & Mascalzoni, D. (2017). Dynamic consent: A potential solution to some of the challenges of modern biomedical research. *BMC Medical Ethics*, 18(1), 4. <https://doi.org/10.1186/s12910-016-0162-9>
- Capous-Desyllas, M., Mountz, S., & Pestine-Stevens, A. (2020). Critically examining participation, power, ethics and the co-construction of knowledge in a community-based photovoice research project with LGBTQ former foster youth. In P. Billett, M. Hart, & D. Martin (Eds.), *Complexities of researching with young people* (pp. 158–169). Routledge.



Cigarini, A., Vicens, J., Duch, J., Sánchez, A., & Perelló, J. (2018). Quantitative account of social interactions in a mental health care ecosystem: cooperation, trust and collective action.

Scientific Reports, 8(1), 3794. <https://doi.org/10.1038/s41598-018-21900-1>

Cigarini, A., Vicens, J., & Perelló, J. (2020). Gender-based pairings influence cooperative expectations and behaviours. *Scientific Reports*, 10(1), 1041. [https://doi.org/10.1038/s41598-](https://doi.org/10.1038/s41598-020-57749-6)

[020-57749-6](https://doi.org/10.1038/s41598-020-57749-6)

Cooke, A. (2015). *Comprender la psicosis y la esquizofrenia*. The British Psychological Society.

<https://consaludmental.org/publicaciones/Comprender-psicosis-esquizofrenia.pdf>

Deterding, S., Khaled, R., Nacke, L. E., & Dixon, D. (2011). Gamification: Toward a definition. *CHI 2011 Gamification Workshop Proceedings*, 12–15. [http://gamification-research.org/wp-](http://gamification-research.org/wp-content/uploads/2011/04/02-Deterding-Khaled-Nacke-Dixon.pdf)

[content/uploads/2011/04/02-Deterding-Khaled-Nacke-Dixon.pdf](http://gamification-research.org/wp-content/uploads/2011/04/02-Deterding-Khaled-Nacke-Dixon.pdf)

Dickert, N., & Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health*, 95(7), 1123–1127. <https://doi.org/10.2105/AJPH.2004.058933>

Duchesne, S., & Ferry, M. (2021). Is time ‘on the side of change’? Incorporating the GDPR in (some of) our research practices. *Bulletin of Sociological Methodology/Bulletin de Méthodologie Sociologique*, 150(1), 106–124. <https://doi.org/10.1177/0759106321995709>

<https://doi.org/10.1177/0759106321995709>

European Commission. (2018a). *Ethics in social science and humanities*.

https://ec.europa.eu/info/sites/default/files/6_h2020_ethics-soc-science-humanities_en.pdf

European Commission. (2018b). *Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of*



personal data and on the free movement of such data, and repealing Directive 95/46/EC.

<https://eur-lex.europa.eu/eli/reg/2016/679/oj>

Faden, R. R., Beauchamp, T. L., & King, N. M. P. (1986). *A history and theory of informed consent* (Vol. 6). Oxford University Press.

<http://web.a.ebscohost.com.uaccess.univie.ac.at/ehost/ebookviewer/ebook/bmxlYmtfXzE1MD E4OF9fQU41?sid=2e33a069-6653-494c-83be-ac16fb3277d0@sessionmgr4007&vid=0&format=EB&rid=1>

Felt, U. (2017). “Response-able practices” or “new bureaucracies of virtue”: The challenges of making RRI work in academic environments. In L. Asveld, R. van Dam-Mieras, T. Swierstra, S. Lavrijssen, K. Linse, & J. van den Hoven (Eds.), *Responsible Innovation 3: A European Agenda?* (pp. 49–68). Springer International Publishing. https://doi.org/10.1007/978-3-319-64834-7_4

FSMC & Activament Catalunya Associació. (2017). *Conceptes i eines per a la recuperació i el benestar: Significats i estratègies de les persones amb experiència de trastorn mental*. Federació Salut Mental Catalunya i Activament Catalunya Associació.

<http://activatperlasalutmental.org/wp-content/uploads/2018/10/2.-Estudi-qualitatiu.-Conceptes-i-eines-per-la-recuperacio-i-benestar.pdf>

Gefenas, E., Lekstutiene, J., Lukaseviciene, V., Hartlev, M., Mourby, M., & Cathaoir, K. Ó. (2021).

Controversies between regulations of research ethics and protection of personal data:

Informed consent at a cross-road. *Medicine, Health Care and Philosophy*.

<https://doi.org/10.1007/s11019-021-10060-1>



Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Harvard University Press.

Graham, M. (2007). The ethics of care, Black women and the social professions: Implications of a new analysis. *Ethics and Social Welfare*, 1(2), 194–206.

<https://doi.org/10.1080/17496530701450372>

Grant, A. D., Wolf, G. I., & Nebeker, C. (2019). Approaches to governance of participant-led research: A qualitative case study. *BMJ Open*, 9(4), e025633. <https://doi.org/10.1136/bmjopen-2018-025633>

Grant, S., & Bouskill, K. E. (2019). Opinion: Why institutional review boards should have a role in the open science movement. *Proceedings of the National Academy of Sciences*, 116(43), 21336–21338. <https://doi.org/10.1073/pnas.1916420116>

Griffiths, M. (2018). For speaking against silence: Spivak's subaltern ethics in the field. *Transactions of the Institute of British Geographers*, 43(2), 299–311.

<https://doi.org/10.1111/tran.12226>

Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*, 10(2), 261–280. <https://doi.org/10.1177/1077800403262360>

Hankivsky, O. (2014). Rethinking care ethics: On the promise and potential of an intersectional analysis. *American Political Science Review*, 108(2), 252–264.

<https://doi.org/10.1017/S0003055414000094>



Holliday, A. (2013). The politics of ethics in diverse cultural settings: Colonising the centre stage.

Compare: A Journal of Comparative and International Education, 43(4), 537–554.

<https://doi.org/10.1080/03057925.2013.797775>

Hostiuc, S. (2018). Introduction. In S. Hostiuc & O. Buda (Eds.), *The age of informed consent: A European history* (pp. 1–14). Cambridge Scholars Publishing.

Hudson, M. (2009). Think globally, act locally: Collective consent and the ethics of knowledge production. *International Social Science Journal*, 60(195), 125–133.

<https://doi.org/10.1111/j.1468-2451.2009.01706.x>

Kapoor, I. (2004). Hyper-self-reflexive development? Spivak on representing the Third World 'other'. *Third World Quarterly*, 25(4), 627–647.

<https://doi.org/10.1080/01436590410001678898>

Kaye, J., Whitley, E. A., Lund, D., Morrison, M., Teare, H., & Melham, K. (2015). Dynamic consent:

A patient interface for twenty-first century research networks. *European Journal of Human Genetics*, 23(2), 141–146. <https://doi.org/10.1038/ejhg.2014.71>

King, P. (1998). Race, justice, and research. In J. P. Kahn, A. C. Mastroianni, & J. Sugarman (Eds.), *Beyond consent: Seeking justice in research* (pp. 88–110). Oxford University Press.

<http://public.ebookcentral.proquest.com/choice/publicfullrecord.aspx?p=271074>

Knapp, M., McDaid, D., Mossialos, E., & Thornicroft, G. (Eds.). (2007). *Mental health policy and practice across Europe. The future direction of mental health care*. Open University Press.



Leadbeater, B., Riecken, T., Benoit, C., Banister, E., Brunk, C., & Glass, K. (2006). Community-based research with vulnerable population: Challenges for ethics and research guidelines. In B. Leadbeater, E. Banister, C. Benoit, M. Jansson, A. Marshall, & T. Riecken (Eds.), *Ethical issues in community-based research with children* (pp. 3–21). University of Toronto Press.

Liboiron, M., Zahara, A., & Schoot, I. (2018). *Community peer review: A method to bring consent and self-determination into the sciences* [Preprint].

<https://doi.org/10.20944/preprints201806.0104.v1>

Lichtenberger, H., & Ranftler, J. (2020). Von Superspreadern und Kinderarmut

Zu den intersektionalen Auswirkungen der Corona-Krise auf Kinder und den Folgen für die

Soziale Arbeit. *soziales_kapital wissenschaftliches journal österreichischer fachhochschul-*

studiengänge soziale arbeit, 24, 149–164. <http://www.soziales->

[kapital.at/index.php/sozialeskapital/article/view/699/1250.pdf](http://www.soziales-kapital.at/index.php/sozialeskapital/article/view/699/1250.pdf)

Lomelino, P. J. (2015). *Community, autonomy and informed consent: Revisiting the philosophical foundation for informed consent in international research*. Cambridge Scholars Publishing.

<http://site.ebrary.com/id/11019554>

Mackenzie, C., Rogers, W., & Dodds, S. (2013). Introduction. In C. Mackenzie, W. Rogers, & S.

Dodds (Eds.), *Vulnerability: New essays in ethics and feminist philosophy* (pp. 1–30). Oxford

University Press. <https://doi.org/10.1093/acprof:oso/9780199316649.003.0001>

Mackenzie, C., & Stoljar, N. (2000). Introduction. Autonomy refigured. In N. Stoljar & C. Mackenzie (Eds.), *Relational autonomy feminist perspectives on autonomy, agency, and the social self* (pp.

3–31). Toronto : Oxford University Press. <http://www.mylibrary.com?id=53517>



Malik, M., Wintersteller, T., & Wöhrer, V. (2021). Einverständniserklärungen für eine feministische Forschungspraxis. Überlegungen zur prozesshaften Gestaltung und gesellschaftlichen Einbettung von Einwilligung. *Femina Politica – Zeitschrift für feministische Politikwissenschaft*, 30(1). <https://doi.org/10.3224/feminapolitica.v30i1.08>

Marzano, M. (2012). Informed consent. In J. Gubrium, J. Holstein, A. Marvasti, & K. McKinney (Eds.), *The SAGE handbook of interview research: The complexity of the craft* (pp. 443–456). SAGE Publications, Inc. <https://doi.org/10.4135/9781452218403>

McCormick, M. (2012). Feminist research ethics, informed consent, and potential harms. *The Hilltop Review*, 6(1), 23–33.

Mental Health Europe. (2008). *From exclusion to inclusion – The way forward to promoting social inclusion of people with mental health problems*. <https://consaludmental.org/publicaciones/Delaexclusionalainclusion.pdf>

Merton, R., & Bateman, J. (2007). *Social inclusion, its importance to mental health*. Mental Health Coordinating Council. <https://www.mhcc.org.au/wp-content/uploads/2018/05/mhcc-social-inclusion.pdf>

Miller, T., & Bell, L. (2002). Consenting to what? Issues of access, gate-keeping and ‘informed’ consent. In M. Mauthner, M. Birch, J. Jessop, & T. Miller (Eds.), *Ethics in qualitative research* (pp. 53–69). SAGE Publications.



Miller, T., & Boulton, M. (2007). Changing constructions of informed consent: Qualitative research and complex social worlds. *Social Science & Medicine*, 65(11), 2199–2211.

<https://doi.org/10.1016/j.socscimed.2007.08.009>

Mitats Carmona, B., San Pío Tendero, M. J., Cigarini, A., González Virós, I., Bonhoure, I., & Perelló, J. (2020). *CoActD3.1: Report on knowledge coalition building. Mental health care*.

<https://doi.org/10.5281/zenodo.4495118>

Nijhawan, L., Udupa, N., Bairy, K., Bhat, K., Janodia, M., Muddukrishna, B., & Musmade, P. (2013).

Informed consent: Issues and challenges. *Journal of Advanced Pharmaceutical Technology & Research*, 4(3), 134. <https://doi.org/10.4103/2231-4040.116779>

Nusbaum, L., Douglas, B., Damus, K., Paasche-Orlow, M., & Estrella-Luna, N. (2017).

Communicating risks and benefits in informed consent for research: A qualitative study. *Global Qualitative Nursing Research*, 4, 1–13. <https://doi.org/10.1177/2333393617732017>

Oberle, K. M., Page, S. A., Stanley, F. K., & Goodarzi, A. A. (2019). A reflection on research ethics and citizen science. *Research Ethics*, 15(3–4), 1–10.

<https://doi.org/10.1177/1747016119868900>

Osuji, P. I. (2018). Relational autonomy in informed consent (RAIC) as an ethics of care approach to the concept of informed consent. *Medicine, Health Care and Philosophy*, 21(1), 101–111.

<https://doi.org/10.1007/s11019-017-9789-7>

Pernice-Duca, F. (2010). Family network support and mental health recovery. *Journal of Marital and Family Therapy*, 36(1), 13–27. <https://doi.org/10.1111/j.1752-0606.2009.00182.x>



- Resnik, D. B. (2019). Citizen scientists as human subjects: Ethical issues. *Citizen Science: Theory and Practice*, 4(1), 1–7. <https://doi.org/10.5334/cstp.150>
- Sagarra, O., Gutiérrez-Roig, M., Bonhoure, I., & Perelló, J. (2016). Citizen science practices for computational social science research: The conceptualization of pop-up experiments. *Frontiers in Physics*, 3, 93. <https://doi.org/10.3389/fphy.2015.00093>
- Schomberg, R. von. (2013). A vision of responsible research and innovation. In R. Owen, J. R. Bessant, & M. Heintz (Eds.), *Responsible innovation: Managing the responsible emergence of science and innovation in society* (pp. 51–74). John Wiley.
- Senabre, E., Ferran-Ferrer, N., & Perelló, J. (2018). Diseño participativo de experimentos de ciencia ciudadana. *Comunicar: Revista científica de comunicación y educación*, 26(54), 29–38. <https://doi.org/10.3916/C54-2018-03>
- Sikes, P. (2013). Working together for critical research ethics. *Compare: A Journal of Comparative and International Education*, 43(4), 516–536. <https://doi.org/10.1080/03057925.2013.797765>
- Smith, L. T. (1999). *Decolonizing methodologies: Research and Indigenous peoples*. Zed Books ; University of Otago Press ; Distributed in the USA exclusively by St. Martin's Press.
- Spivak, G. C. (2008). *Can the subaltern speak? Postkolonialität und subalterne Artikulation* (Unveränd. Nachdr). Turia + Kant.
- Statistik Austria. (2021). *Bildungsbezogenes Erwerbskarrierenmonitoring – BibEr*. https://www.statistik.at/web_de/statistiken/menschen_und_gesellschaft/bildung/bildungsbezogenes_erwerbskarrierenmonitoring_biber/index.html



- Steiner, M., Pessl, G., Leitner, A., Davoine, T., Forstner, S., Juen, I., Köpping, M., Sticker, A., Litschel, V., Löffler, R., & Petanovitsch, A. (2019). *AusBildung bis 18. Wissenschaftliche Begleitung der Implementierung und Umsetzung des Ausbildungspflichtgesetzes* [Research Report]. <https://irihs.ihs.ac.at/id/eprint/5174/>
- Steinsbekk, K. S., Kåre Myskja, B., & Solberg, B. (2013). Broad consent versus dynamic consent in biobank research: Is passive participation an ethical problem? *European Journal of Human Genetics*, 21(9), 897–902. <https://doi.org/10.1038/ejhg.2012.282>
- Strauss, R., P., Sengupta, S., Crouse Quinn, S., Goepfing, J., Spaulding, C., Kegeles, S. M., & Millett, G. (2001). The role of community advisory boards: Involving communities in the informed consent process. *American Journal of Public Health*, 91(12), 1938–1943.
- Suman, A. B., & Pierce, R. (2018). Challenges for citizen science and the EU open science agenda under the GDPR. *European Data Protection Law Review*, 4(3), 284–295. <https://doi.org/10.21552/edpl/2018/3/7>
- Sutrop, M., & Lõuk, K. (2020). Informed Consent and Ethical Research. In R. Iphofen (Ed.), *Handbook of research ethics and scientific integrity* (pp. 213–232). Springer. https://doi.org/10.1007/978-3-319-76040-7_8-1
- Tauginienė, L., Butkevičienė, E., Vohland, K., Heinisch, B., Daskolia, M., Suškevičs, M., Portela, M., Balázs, B., & Prūse, B. (2020). Citizen science in the social sciences and humanities: The power of interdisciplinarity. *Palgrave Communications*, 6(1), 1–11. <https://doi.org/10.1057/s41599-020-0471-y>



Tronto, J. C. (2008). Consent as a Grant of Authority: A care ethics reading of informed consent. In H. Lindemann, M. Verkerk, & M. Urban Walker (Eds.), *Naturalized bioethics: Toward responsible knowing and practice* (pp. 182–198). Cambridge University Press.

<https://doi.org/10.1017/CBO9781139167499.011>

Vicens, J., Perelló, J., & Duch, J. (2018). Citizen Social Lab: A digital platform for human behavior experimentation within a citizen science framework. *Plos One*, 13(12), 1–20.

<https://doi.org/10.1371/journal.pone.0207219>

von Unger, H., Dilger, H., & Schönhuth, M. (2016). Ethikbegutachtung in der sozial- und kulturwissenschaftlichen Forschung? Ein Debattenbeitrag aus soziologischer und ethnologischer Sicht. *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 17(3).

<https://doi.org/10.17169/fqs-17.3.2719>

Washington, H. (2007). *Medical Apartheid: The Dark History of Medical Experimentation on Black Americans From Colonial Times to the Present*. Doubleday.

Weindling, P. (2001). The origins of informed consent: The international scientific commission on medical war crimes, and the Nuremburg Code. *Bulletin of the History of Medicine*, 75(1), 37–71.

<https://doi.org/10.1353/bhm.2001.0049>

Wintersteller, T., Malik, M., & Wöhrer, V. (2020). *CoActD4.1: Knowledge coalition building. Youth employment*. <https://doi.org/10.5281/zenodo.4443418>

Xiaomei, Z. (2012). Community Consent. In R. Chadwick (Ed.), *Encyclopedia of applied ethics* (pp. 522–529). Elsevier. http://www.123library.org/book_details/?id=43710





The CoAct project has received funding from the European Union's Horizon 2020 Research and Innovation programme under grant agreement No. 873048