



YouCount
Youth Citizen Science

D2.1

Collaboration with ethical boards and secured formal approvals on local levels

Julie Ridley¹, Reidun Norvoll²

- 1 School of Social Work, UCLan, Preston, UK
- 2 Work Research Institute, OsloMet, Oslo, Norway



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 101005931

Project Acronym	YouCount
Project Name	YouCount – Empowering youth and cocreating social innovations and policymaking through youth-focused citizen social science
Grant Agreement no.	101005931
Start date of the project	01/ 02/ 2021
End date of the project	31 / 01 / 2024
Work Package producing the document	WP 2, Multiple case study
WP Leader	Partner No. 4, UCLan
Other Partners involved	Partner No. 1, OsloMet, Partner No. 7, KTU All partners
Deliverable identifier	D 2.1
Deliverable lead beneficiary	Partner No. 4, UCLan
Internal Scientific Reviewer	Partner No. 7, KTU, Raminta Pučėtaite
Date of delivery	31 January, 2022
Version	Version 1
Author(s)	Julie Ridley, Partner No. 4, UCLan Reidun Norvoll, Partner No. 1, OsloMet
Classification	Public

Disclaimer: This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No101005931. The opinions expressed in this document reflect only the author's view and reflects in no way the European Commission's opinions. The European Commission is not responsible for any use that may be made of the information it contains.

Table of Contents

D2.1 COLLABORATION WITH ETHICAL BOARDS AND SECURED FORMAL APPROVALS ON LOCAL LEVELS ...	4
EXECUTIVE SUMMARY	7
1 INTRODUCTION	7
1.1 YouCount	8
1.2 Ethical principles in the project.....	9
2 SECURING OF DATA PROTECTION AND ETHICS STANDARDS ON NATIONAL LEVEL	11
3 RECRUITMENT AND INFORMED CONSENT PROCEDURES	12
4 FORMAL (ETHICS) APPROVALS	13
4.1 Multiple case study	16
4.2 Evaluation study	17
4.3 YouCount app	17
5 CONCLUSION	19
APPENDIXES.....	20

List of tables

TABLE 1: REVISION HISTORY.....	5
TABLE 2: TERMS AND ABBREVIATIONS.....	6
TABLE 3. OVERVIEW NATIONAL REGULATIONS FOR FORMAL APPROVALS AND APPROVAL STATUS.....	14
TABLE 4: APPENDIXES	20

D2.1 Collaboration with ethical boards and secured formal approvals on local levels

This deliverable adds to the ethics requirements and safeguarding of ethical standards of the EU YouCount project by securing proper recruitment and informed consent procedures and ethics/safety considerations on local level, especially for participating youths under 18 years and vulnerable groups. The report shortly describes the establishment of collaboration with the local data protection office/ethical approval institutions and the Safety and Ethics Board (SEB) as well as procedures and status of formal ethics approvals of the multiple case- and evaluation studies according to General Data Protection Regulation (GDPR) and national regulations.

The report is a continuation of the main procedures and principles for the YouCount project that are described in detail in D7.1 Ethics protection of personal data (POPD) Requirement No. 2, D6.2 Data Management Plan (DMP) and D6.6 Recruitment and Consent Procedures. The deliverable also relates to D1.2 Report on the Conceptual, Innovative, Evaluation and Ethical Framework for youth citizen social science (Y-CSS), which presents an ethical framework to address other ethical issues related to Y-CSS. All reports will provide a basis for D6.5 Final Report on Ethical Issues, which will be produced at the end of the project.

The vision of YouCount is twofold, addressing and combining both the scientific and societal needs of our time. The *scientific* vision of YouCount is to strengthen the transformative and participatory aspects of CS and social science, by enabling citizen participation in all facets, reaching out for a more egalitarian way of conducting science. The *societal* vision of YouCount is to contribute to create inclusive and innovative societies for European youths and to empower them in promoting active citizenship and a just and equitable future, particularly for youths with disadvantages.

Table 1: Revision history

VERSION	DATE	CREATED BY	COMMENTS
1.0	20 / 01/ 2022	Partner 4, UCLAN	First draft
1.1	25/01/2222		For review of GA and reviewer
1.2	29/01/2022	Partner 3, UClan	Second draft
1.3	31 / 01/ 2022	P1, Reidun Norvoll	Final version submitted

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

Cited as: Ridley, J. & Norvoll, R. (2022). *D.2.1 Collaboration with ethical boards and secured formal approvals on local levels*. 10.5281/zenodo.5920572

Table 2: Terms and Abbreviations

Abbreviation	Full term
CS	citizen science
CSS	citizen social science
C-YCS	young citizen scientist from the local community or targeted youth group
D	deliverable
DMP	data management plan
DPO	data protection officer
EC	European Commission
EC-GA	European Commission - Grant Agreement
EU	European Union
GDPR	General Data Protection Regulation
IRB	Institutional Review Board
LL	living labs
NSD	Norwegian Centre for Research Data
POPD	protection of personal data
RRI	responsible research and innovation
R-YCS	young citizen scientist participating in the research team
SEB	Safety and Ethics Board
YCS	young citizen scientist
Y-CSS	youth citizen social science

Executive Summary

D2.1 adds to the ethics requirements and ensuring of ethical standards of the EU YouCount project by securing proper recruitment and informed consent procedures and formal approvals in each case country as well as continuous ethical and safety deliberations, especially for participating youths under 18 years and vulnerable groups.

D2.1 describes how these fundamental rights and ethical principles will be ensured during the implementation period. The report briefly introduces the YouCount project and aims for this deliverable. Thereafter, it provides a description of recent measures that have been taken at project level for securing obligations pertaining General Data Protection Regulation (GDPR) and ethical requirements. These measures include the signing of a joint responsibility agreement for data processing between case partners as well as the continuous collaboration with SEB members. The report then provides updated information about the use of informed consent letters and the status of securing formal approvals from national supervisory bodies and ethics committees according to GDPR and national regulations in each partner country. Finally, the ongoing process of assessing formal approval for, the forthcoming YouCount app is described.

1 Introduction

The protection of natural persons in relation to the processing of personal data is a fundamental right and underlined in Chapter II (e.g., Principles and Articles 5 and 7) and Chapter III (Rights of the Data Subject) of the GDPR 2016/679, which are transferred to the appropriate national regulations.

The YouCount project will adhere to relevant EU and UK legislation, ethical guidelines, and codes for good conduct of research. All partners have stated their commitment to secure confidentiality and ethical conduct of research as part of the Grant Agreement (EC-GA), Consortium Agreement (CA), and detailed their commitments in several deliverables, including:

- D6.1 Project Executive Handbook that underlines the ambitions of good conduct of research.
- D6.2 YouCount Data Management Plan (DMP) which provides details concerning the data and the storage and transfer of data cross consortium partners.
- D7.1 POPD Requirement No. 2 where the YouCount partners have declared that they are aware of the need to protect personal data collected during the project, guarantee ethics in publishing results, and to protect the rights of individuals generally.
- D6.6 Recruitment and Consent Procedures that provide a more detailed description of the criteria and procedures that will be used to identify and recruit participants in the project, and

- D1.2 Developing a Conceptual and Methodological Framework for Youth Citizen Social Science (Y-CSS) that includes in-depths considerations concerning the ethical challenges when undertaking Y-CSS and how to deal with these in the best ways.

This deliverable D2.1 will contribute to ensuring compliance with the GDPR and ethical principles in all YouCount activities during the implementation of research and innovation activities.

1.1 YouCount

The overarching objective of the YouCount project is to generate new knowledge and innovations to increase the social inclusion and empowerment of youth at risk of exclusion through co-creative youth citizen social science (Y-CSS) and to provide evidence of the actual outcomes of Y-CSS. The project will include young people ranging in age from 13 to 30 years (most over 16 years). The project will focus on youths in general but will address the circumstances of youths who are most at risk of exclusion in terms of, for example, poverty, migration, disability, and unemployment, or living in disadvantaged urban or rural areas. The vulnerability and circumstances of the participating young citizen scientists (YCS) will differ. However, challenges related to vulnerability will be addressed throughout the research process.

The project includes four substudies:

- Substudy 1. Development of a framework for Y-CSS
- Substudy 2. Implementation of a multiple case study of Y-CSS to explore social inclusion in nine countries across Europe
- Substudy 3. Mixed-methods evaluation of the process, outcomes, and impact of the Y-CSS activities, and a multi-criteria assessment of the costs and benefits of Y-CSS
- Substudy 4. Creation of social and scientific impact through widespread scaling up and continuity.

A transdisciplinary Advisory Board (AB) and Safety and Ethics Board (SEB) with expertise in data protection regulations, ethics, and youth-involved research have been established and will follow the project closely during the project period.

Youths will participate as young citizen social scientists (YCS) in two ways: young people from the community and university students will participate in the whole research process as citizen scientists in research teams (R-YCS). A larger group of youths will serve as citizen scientists from the community or target group (C-YCS) at a lower level of participation by contributing data about positive drivers of social inclusion on the YouCount Citizen Social Science app (henceforth referred to as the 'YouCount app') on the SPOTTERON Citizen Science Platform. YCS will also provide their

perspective on aspects of social inclusion and targeted solutions to exclusion by participating in local dialogue forums (e.g. group conversations or 'listenings'). Each case will establish local living labs (LLs) with multiple stakeholders in the wider community or targeted stakeholder organisations, which will use the research data from YCS to co-create policymaking and innovations in terms of generating new ideas, products, and methods to create social change that are youth-driven.

The groups of participants, therefore, will include:

- Researchers in each case study.
- Young people (13–30 years of age), either as R-YCS or C-YCS.
- Local stakeholders participating in the local LLs or local stakeholders who will be included in the evaluation study (assessing outcomes of the case).
- National stakeholders, e.g., policymakers, public authorities, non-governmental organisations (NGO), academics.
- Local and international stakeholders invited to participate in the community of interest in Y-CSS on the project homepage (see the DMP for more).

The exact use of data collection methods is still to be developed. At this stage, we envisage the collection of the following data types:

- Textual data: Recording templates, minutes, case evaluation self-reports, anonymous/deidentified/pseudonymous summaries from dialogue forums/interviews, transcripts, field notes, and open text comments provided by YCS on the YouCount app.
- Tabular data: Aggregated and anonymised data based on quantitative data collection undertaken in WP 2, 3, and 4 through questionnaires and the YouCount app.
- Image data: Image files including photographs for research illustration and as user-generated data.
- Audio data: Primarily audio recordings (via audio recorder) of interviews and group discussions.
- Other: Interactive data (between YCS) on the YouCount app, online forum for YCS across countries, and presentation of stakeholder organisations on the project webpage.

1.2 Ethical principles in the project

As outlined in the grant agreement (EC-GA), DMP and D6.6 Recruitment and Consent Procedures, the project team will carefully choose the recruitment strategies and implement informed consent procedures in each case country to ensure scientific quality and voluntary participation. They will

also adhere to regulations and ethical guidelines concerning involving potentially vulnerable groups and participants under 18 years in research in the participating case countries, as well as European legislation.

Important ethical principles or values underlying the YouCount recruitment procedures will include respect for privacy, voluntariness (lack of pressure or undue influence to participate), accurate and clear (unbiased) description of the study and avoiding misconception of the outcomes of participation or research results. Those responsible for making initial contact when recruiting participants in the project, including the collaborative institutions and YCS or students, must have a basic knowledge of the study (so they can answer questions) and be trained in ethical principles when conducting research with humans and vulnerable groups.

Care will be taken when collecting consent from young adolescents since they might be less mature than young adults, which can make them more likely to overlook the possible consequences of participating in research and to reject participation in research when invited by figures of authority (e.g., teachers). Attention must also be paid to how 'vulnerable youths', such as those with disabilities, lower levels of literacy, or disadvantaged life situations, are involved since these factors might affect their sense of voluntariness (e.g., being more dependent on service providers) and capacity for providing informed consent. However, this should not be taken as reason for lack of involvement of 'vulnerable youth' in the project. These young people should, according to their basic human rights, be given the opportunity to voice their opinions in matters that affect their concerns and interests. The project will thus aim to maintain a balance between specific needs for protection and inclusiveness in science. In the case of doubts or uncertainties, the issues will be discussed with the AB and SEB.

2 Securing of data protection and ethics standards on national level

During the project period, it has become clear that it is imperative that all partners secure relevant ethical approval for their own data collected as part of the case study according to the national data protection and ethical requirements. Adopting local responsibility for data is also the most pragmatic approach since raw data will be collected and analysed in local languages. Local data storage adheres to the principle of data minimisation aiming to keep sharing and transfer of personal data to a minimum. Only summarised non-personal data (e.g., case summary reports or summaries of issues or themes from interviews) or de-identified/anonymous/pseudonymous data will thus be shared between consortium partners. The choice of joint responsibility for data processing has also been supported by the Norwegian Centre for Research Data (NSD) who serves as the national supervisory authority/adviser for OsloMet in the case of the YouCount project overall.

OsloMet as project coordinator is thus in the final stage of sending out an agreement on joint processing responsibility pursuant Regulation (EU) 2016/679 of 27 April 2016 Article 26, to be signed by all partners by mid February 2022. The final agreement is based on inputs from all partners.

In practice, this means that all partners will have responsibility for conducting their research and processing data according to the principles pursuant to GDPR, UK GDPR and other relevant national regulations, and to establish procedures for processing and transferring personal data as set out in the signed agreement and YouCount DMP.

Moreover, the SEB consisting of an expert from each partner institution collectively comprises a substantial body of expertise in relevant areas for the YouCount project. The project SEB will assist the consortium in anticipating and dealing with ethical, safety and legal issues pertaining to Y-CSS research as necessary. Up to this point, the project has conducted one meeting (2021) with the SEB discussing the main challenges in the project and how these should be mitigated in the best way (e.g., vulnerable youths, use of the YouCount app). Moreover, the SEB members have been invited and participated in project meetings and provided feedback to deliverables addressing ethics and safety issues in the project. They will also be included throughout the project period.

3 Recruitment and informed consent procedures

The recruitment procedures in the project will be based on the inclusion criteria described in D7.1 and adapted as relevant to the participants in the local case study. All participation in the YouCount project is voluntary. All participants in the project will be asked for consents that are in full compliance with the strengthened conditions of GDPR.

The informed consent procedures will adhere to applicable legal and professional codes of the EU and UK and to the relevant laws in each of the countries the research is undertaken. This includes requirements of collecting parents' consent in the age for young people under 18 years of age. The oral and written information will be clear and relevant, using plain and easily accessible language, so the participants are being fully aware of the purpose for data processing (see for example the information booklet developed by the UK partner, UCLan submitted as supplementary materials to this deliverable).

Following this, all the research teams involved in the multiple case study and evaluation study will create written consent letters in their national/local language adjusted to their targeted youth group. The consent letters will include information of the YouCount project, the local case topic, and information required from the GDPR/UK GDPR (storage, rights, contact information etc.) as well as specific consent options. The information and consent letters in each case country have been tailored for the targeted youth group, age, and national regulations/standards and although they contain common elements, they will vary. Please see the attached written consent letter from UNVIE concerning the outcome survey conducted across partners as an example.

The YouCount app will make use of printed written consent letters for distribution in direct contact with the YCS and two kinds of consent letters integrated in the App: A Term of Use for the SPOTTERON CS platform to be ticked off when signing up to the app provided by SPOTTERON, and a standard research information letter about the YouCount project and consent form (same as the printed version) provided by the research team. For minors, parental/guardian consent is required. The youths must give consent before they can use the app.

In addition, the project has developed guidelines and a consent letter for pictures/photographs and videos to be used in the case studies as part of illustrating the research and innovation work. Informed consent letters concerning illustrative materials developed by each university will also be used. The lawful bases for processing these personal data are based on GDPR (Article 6(1)(a) and Article 6(1)(e)).

4 Formal (ethics) approvals

OsloMet has notified NSD of the overall project and received formal approval that the project (including the YouCount app) adheres to the principles of data protection pertaining to GDPR (NSD Issue No 343732, date 05.01.2022). NSD requires that the responsible data processors including SPOTTERON fulfil the requirements of articles 28 and 29 of the GDPR. In the case of substantial changes being made, OsloMet is obliged to notify NSD again.

In addition, all case partners have stated their commitment to GDPR/UK GDPR and ethical principles, and these commitments are integrated in the forthcoming signed joint processing responsibility agreement. Further, The YouCount research team follows appropriate country-specific ethical guidelines and regulations for securing formal ethics approvals including those pertaining to research with minors.

The informed consent letters and formal approvals include the following sub studies:

1. WP2 & 3: Multiple case study including data collection from young people and local stakeholders in living labs through participatory observation, interviews, dialogue forums and additional creative methods (see 1.1).
2. WP4: Evaluation study (pre and post survey and focus groups with R-YCS and interviews with professional researchers. The focus group with R-YCS will be conducted by each case partner.
3. WP2: YouCount App, data collection of youths' views and experiences with social inclusion (GIS, image, text, and tabular data according to GDPR regulations).

The national requirements and procedures concerning formal applications (e.g., university research ethics committee vs. data protection supervisory authorities) vary between the participating countries. While some supervisory /ethics authorities allow for a stepwise assessment- and approval process, other have more fixed procedures. Moreover, the need for formal approvals of social science research differs and is also contingent to the choice of personal data collection in each case (e.g., use of summaries from interviews vs. audio-recordings and transcripts). An overview of national regulations and procedures concerning formal approvals for *social science* research together with approval status for the multiple case study and evaluation study by January 31, 2022, is given in Table 3 below:

Table 3. Overview national regulations for formal approvals and approval status

Country / Partner	National regulations re formal approval		Approval Status			
	Data protection supervisory authority	Ethics committee	Case study	Evaluation study (survey)	Evaluation study (R-YCS)	Evaluation study (professional researchers)
Norway/ OsloMet	NSD/ OsloMet data protection office	Not required	Approved	Approved (UNIVIE)	Approved	not required from this partner, UNIVIE conducts this and applies for IRB approval
Sweden/ SH/VA	Not required	Swedish Ethical Review Authority ('Etikprövningsmyndigheten')	Applied/ Waiting	Approved (UNIVIE)	Applied/ Waiting	not required from this partner, UNIVIE conducts this and applies for IRB approval
UK/ UCLan	Not required	University of Central Lancashire Business, Arts, Humanities &	Approved	Approved (UNIVIE)	Approved	not required from this partner, UNIVIE conducts this and

		Social Science Ethics committee				applies for IRB approval
Spain/ FD	Not required	University of Deusto Committee of Ethics	Applied/ Waiting	Approved (UNIVIE)	Applied/ Waiting	not required from this partner, UNIVIE conducts this and applies for IRB approval
Austria/ UNIVIE	Not required	Ethics committee University of Vienna; Institutional Review Board (IRB) of the Department of Communication at UNIVIE	Approved	Approved (UNIVIE)	Approved	IRB, to be applied soon (rapid process) (UNIVIE)
Lithuania / KTU		Kaunas University of Technology Research Ethics Commission	Approved	Approved (UNIVIE)	Applied/ Waiting	not required from this partner, UNIVIE conducts this and applies for IRB approval

Denmark/ AAU	AAU Innovation unit, 'Kontrakt- enheden'	Not required	Applied/ Waiting	Approved (UNIVIE)	Applied/ Waiting	not required from this partner, UNIVIE conducts this and applies for IRB approval
Hungary/ ESSRG	Not required	Not required	Not required	Approved (UNIVIE)	Not required	not required from this partner, UNIVIE conducts this and applies for IRB approval
Italy/ UNINA	Not required	Ethical Committee of Psychological Research of the Department of Humanities of UNINA	Approved	Approved (UNIVIE)	Approved	not required from this partner, UNIVIE conducts this and applies for IRB approval

4.1 Multiple case study

As seen from Table 3 above, consortium partners have applied for relevant formal approvals according to national regulations and procedures and will receive the necessary approvals before

the sub-studies start in the beginning of 2022. All partners have also informed and invited local stakeholders to participate in the case study and received a letter of support as part of the proposal process. Some partners are still in progress of finalising additional consent letters to living lab stakeholders since the case studies are in an early stage. The needs for additional consent letters to stakeholders also vary with the case topic and local circumstances in each case.

The approvals include the data to be collected in all cases in relation to young people's' and stakeholders' views on social inclusion and possible innovations in general and on the case topic.

4. 2 Evaluation study

UNIVIE is responsible partner for the evaluation study that will be undertaken in WP4.

As seen from Table 3, UNIVIE has applied for formal approval to the Ethics committee of the University of Vienna (co- creation with youths, survey, focus group with R- YCS /local case study in Austria) and IRB of the Department of Communication at UNIVIE (for interviews with professional scientists in each country). The case study and survey are approved, the decisions regarding focus group interview and interviews with professional scientists in the research teams are expected to come in February and March/April 2022.

Throughout the project process, the need for local teams to conduct focus group interviews with R-YCS instead of UNIVIE (due to e.g., language issues and trust) has become more visible. Subsequently, the case partners have – according to national regulations – notified their national supervisory authority or applied for formal approval of their ethical boards to conduct these interviews on behalf of UNIVIE. Since this decision was made later in the process, some partners are awaiting the final decisions from their ethics boards.

The Project Coordinator has also notified NSD and local supervisory data protection services at OsloMet about the responsibility for distributing and storing the identification key of participating YCS in the survey on behalf of UNIVIE to secure anonymity.

4.3 YouCount app

One important output of the YouCount project is to develop a targeted CS app for data collection of young peoples' views and experiences of social inclusion opportunities in their daily life. These data will be used to identify important drivers for social inclusion through cross- case analysis. The

YouCount app is developed together with and provided by SPOTTERON who is partner in the consortium.

The use of an open app in citizen social science research with young and potentially vulnerable young people on social issues, as well as cross- case data analysis, necessitates comprehensive assessment of the numerous issues with respect to GDPR, ethics and safety. Subsequently, the YouCount app is considered separately by OsloMet as overall project coordinator in collaboration with partners.

The legal and organisational safeguarding for proper data collection and processing of data collected in the YouCount app includes several measures. As outlined in the YouCount DMP and D7.1, the project has established a Data Administrator Group consisting of one researcher from each case partner institution. These researchers will be responsible for safe and proper handling, storage, and transfer of data in collaboration with SPOTTERON and OsloMet and for continuous monitoring of the uploaded data in the app (with respect to proper consent and sensitive personal data) during the data collection period.

Recently, OsloMet as project coordinator, has also established an internal working group for legal-risks-, and safety assessment of the YouCount app. The working group consists of a data protection adviser, a legal adviser, an IT- adviser, the app responsible researcher at OsloMet, and the project coordinator of the project. The group has conducted several meetings to discuss legal and potential security issues including one meeting with SPOTTERON and will complete a risk- and safety assessment of the app as part of the procedures at OsloMet. In addition, the project has sought advice from the SEB members with expertise in the field. The internal group finds that the SPOTTERON CS Platform has the necessary IT security requirements and measures in place. Still, some potential risks- and safety issues will be clearer when there is more knowledge on how the YouCount app is actually used in practice. Risks- and safety issues will thus be constantly evaluated and mitigated throughout the App study.

Moreover, as described above, the first outline of the YouCount app has been notified to NSD and approved. NSD has required that the responsible data processors including SPOTTERON fulfil the requirements of articles 28 and 29 of the GDPR. The consortium partners are also responsible for ensuring that internal procedures for data collection and processing data from the app are conducted according to the joint responsibility agreement for data processing. In the case of substantial changes being made, OsloMet is obliged to notify NSD again for formal assessments of the final version of the app.

Consequently, OsloMet will generate and sign a specific data processing agreement between SPOTTERON and OsloMet as project coordinator on behalf of the whole consortium. In addition, a joint responsibility procession agreement outlining the procedures for processing app data will be

signed with all case partners. These documents will be attached to the agreement on joint processing responsibility as described above.

5 Conclusion

The many deliverables concerning data management and ethics requirements reflect the focus on implementing ethical standards and responsible research and innovation (RRI) as key parts of the citizen social science approach in the YouCount project. Even so, ethical and data protection concerns are not “fixed” issues but instead are dynamic and need to be incorporated in all parts of the project to be considered throughout the entire research process.

This deliverable outlines the status of informed consent and formal approvals so far in the project. Even if the most important consent letters and formal approvals are settled, the final legal agreements and approvals are still in progress and will be completed as the project evolves in practice.

Appendixes

Table 4: Appendixes

APPENDIX	SUBJECT	PAGE
Appendix A	Informed consent letters from UNIVIE	19
Supplementary resources	UCLan Information booklet YouCount version 1 October 28th 2021	
Supplementary resources	GDPR Pictures and Videos YouCount 2021	

Appendices A. Example of consent letter used in YouCount

YouCount – Information for participants and declaration of consent (UNIVIE)

1 Version 1.0 03.01.2022

Information for participants and declaration of consent to participate in the study:

Surveying citizen scientists and professional researchers in YouCount

Dear participant,

We would like to invite you to participate in the study mentioned above.

Your participation in this study is voluntary. You can refuse to participate at any time, without having to give a reason, or also withdraw your agreement to participate once the study has already started. There will be no negative consequences for you if you refuse to participate or if you withdraw from this study early.

This kind of study is necessary to gain new, reliable *academic* research results. However, we can conduct this study only with your consent to participating in the study. Please take time to read the following information carefully, and do not hesitate to ask questions.

Please only click on “I consent to participating in the study”

- if you have fully understood the type and procedure of the study,
- if you are willing to give your consent to participate, and
- if you are aware of your rights as a participant in this study.

1. What is the purpose of this study?

The purpose of this study is to inform us in the evaluation team about your attitudes, knowledge, and efficacy regarding science, citizen science, and social inclusion of youths. Citizen science means that members of the public work along with professional scientists on scientific projects.

Specifically, we in the evaluation team are interested in knowing more about what participating in the YouCount project resulted in for you personally. This helps us in the evaluation team to know more about what works well and where potential for improvement in citizen science projects is. By participating in the study, you can therefore make a valuable contribution to citizen science.

2. What is the procedure of the study?

This study consists of a pre-survey and a post-survey that we send to every citizen scientist and professional scientist who is at least 16 years old. You will get the pre-survey when you start working in the YouCount project or from February 2022 on, and the post-survey when you stop working in YouCount. If you decide to stop working in YouCount, please do let us know (Reidun.Norvoll@oslomet.no; +47 982 45 145), so we can send you the post-survey.

3. What are the benefits of participating in the study?

You can help us improve citizen science through evaluating what worked and what did not work.

4. What are the possible risks of taking part this study?

There should be no risks to you from your participation in the study.

5. What obligations arise from participation and when will the study be terminated prematurely?

There are no obligations for you arising from participation, you can interrupt or terminate your participation at any time without any consequences and without giving reasons.

6. How will the data collected in this study be used?

We treat your data strictly confidential. Only participants in the study have access to the data, but they are bound to secrecy.

During the study, some of your data are pseudonymized, which means that the one person who has your name and identification key can assign them to you using the key. We, who are conducting the survey, however, do not know your name. It is therefore not possible for us or for anyone else who does not have the list of names and identification keys of participants to infer who you are. Pseudonymization during the duration of the study is necessary in order to be able to determine at the end of the project what has changed during your participation in the project. At the end of this study, from May 2023 on, your data will be anonymized by destroying the list that

connects names and identification keys. The anonymized data allows no inference to your person. The anonymized data will be saved long-term.

In order to increase the integrity of science and our work, the anonymized data (and only this, meaning not the pseudonymized data!) will be stored on a publicly accessible project archive (e.g., Open Science Foundation, OSF) after completion of the study.

If you wish to have your data deleted or want to get access to your data, you can request this in writing or by telephone without giving any reasons, provided that your data have not yet been anonymized (because they can then no longer be traced back to you), by contacting the name and identification key coordinator, Reidun Norvoll (Reidun.Norvoll@oslomet.no; +47 982 45 145). If you want to get access to your data, the name and identification key coordinator will forward the request along with the identification key to the study coordinator. The study coordinator then sends your data to the name and identification key coordinator who will give you the access. However, in this process we cannot guarantee anonymization, since the name and identification key coordinator will have access to your name and data at this point.

7. Will there be any costs for the participants? Will they receive reimbursement or remuneration?

There will be no costs for you. You can win awards and prizes by participating.

8. Possibility to discuss further questions

For further questions in connection with the study, please contact the study coordinator or principal investigator. Of course, we are happy to answer any questions concerning your rights as a participant in the study.

Names of the contact person(s): Study coordinator	Name: Isabelle Freiling E-Mail: isabelle.freiling@univie.ac.at Phone: +43-1-4277-493 87
Study coordinator	Name: Melanie Saumer E-Mail: melanie.saumer@univie.ac.at
Principal investigator	Name: Joerg Matthes E-Mail: joerg.matthes@univie.ac.at Phone: +43-1-4277-493 07
Name and identification key coordinator	Name: Reidun Norvoll E-Mail: Reidun.Norvoll@oslomet.no Phone: +47 982 45 145

9. Declaration of consent

I got clear and detailed information about the objectives, significance, and scope of the study, as well as about the requirements resulting from my participation in the study. In addition, I have read the information text for participants and the declaration of consent, especially section 4 (regarding risks). I had enough time to decide whether I would like to participate in this study. At the moment, I have no further questions.

I will follow the instructions that are necessary for conducting this study. However, I have the right to end my voluntary participation at any time, without any disadvantages for me. If I want to withdraw from the study, I can do so at any time by contacting the name and identification key coordinator, Reidun Norvoll (Reidun.Norvoll@oslomet.no; +47 982 45 145), either in writing or verbally.

At the same time, I agree that my data collected in this study are recorded and analyzed.

I agree that my data will be stored electronically in pseudonymized form during the study and then stored permanently in or anonymized form. The data will be stored in a form that is accessible only to the study coordinator and principal investigator and secured according to current standards.

I agree that my data will be stored in anonymized form on a publicly accessible project repository (e.g., Open Science Foundation, OSF) after completion of the study to increase the integrity of science and our work.

Should I wish to have my data deleted at a later date or get access to my data, I can request this in writing or by telephone without giving reasons, provided that my data have not yet been anonymized (because they can then no longer be traced back to me), by contacting the name and identification key coordinator, Reidun Norvoll (Reidun.Norvoll@oslomet.no; +47 982 45 145). I understand that if I request to access my data, anonymization of my data cannot be guaranteed for the name and identification key coordinator.

- I consent** to participating in the study “Surveying citizen scientists and professional researchers in YouCount.”
- I do not consent** to participating in the study “Surveying citizen scientists and professional researchers in YouCount.”



YouCount

Youth Citizen Science

PARTNERS:

