CASE REPORT

Ethical considerations in engaging young people in European obesity prevention research: The CO-CREATE experience

Isabelle Budin-Ljøsne[1] | Sherria Ayuandini[2] | Evelyne Baillergeau[2] |
Christian Bröer[2] | Arnfinn Helleve[3] | Knut-Inge Klepp[4,5] | Bjarte Kysnes[6] |
Nanna Lien[5] | Aleksandra Luszczynska[7] | Samantha Nesrallah[8] |
Ana Rito[9] | Harry Rutter[10] | Oddrun Samdal[6] | Natalie Savona[11] |
Gerlieke Veltkamp[2]

[1]Department of Food Safety, Norwegian Institute of Public Health, Oslo, Norway

[2]Department of Sociology, University of Amsterdam, Amsterdam, The Netherlands

[3]Centre for Evaluation of Public Health Measures, Norwegian Institute of Public Health, Oslo, Norway

[4]Division of Mental and Physical Health, Norwegian Institute of Public Health, Oslo, Norway

[5]Department of Nutrition, Institute of Basic Medical Sciences, University of Oslo, Oslo, Norway

[6]Department of Health Promotion and Development, University of Bergen, Bergen, Norway

[7]Wroclaw Faculty of Psychology, SWPS University of Social Sciences and Humanities, Wroclaw, Poland

[8]EAT, Oslo, Norway

[9]CEIDSS, Lisbon, Portugal

[10]Department of Social and Policy Sciences, University of Bath, Bath, UK

[11]Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, London, UK

Correspondence

Isabelle Budin-Ljøsne, Department of Food Safety, Norwegian Institute of Public Health, PO Box 222 Skøyen, NO-0213 Oslo, Norway.
Email: isabelle.budin.ljosne@fhi.no

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Summary

Engaging youth in obesity prevention research and policy action is essential to develop strategies that are relevant and sensitive to their needs. Research with young people requires critical reflection to safeguard their rights, dignity, and well-being. The CO-CREATE project used various methods to engage approximately 300 European youth aged 15–19 years in the development of policies to prevent adolescent obesity. This paper discusses ethical considerations made in the project pertaining to the youth's voluntary participation, their protection from obesity stigma, respect for their time, data privacy and confidentiality, power balance, and equality of opportunity to participate in the research. We describe measures implemented to prevent or limit the emergence of ethical challenges in our interaction with youth and discuss their relevance based on our experience with implementation. While some challenges seemingly were prevented, others arose related to the youth's voluntary participation, time burdens on them, and the sustainability of participation under the Covid-19 pandemic. Concrete and ongoing ethical guidance may be useful in projects aiming to interact and build collaborative relationships with youth for long periods of time.

KEYWORDS

ethics, obesity, participatory research, youth

1 | INTRODUCTION

It is estimated that one in every seven European youth aged 15 years has overweight or obesity.[1] Obesity increases the risk of a wide range of noncommunicable diseases and is associated with psychosocial comorbidity and reduced quality of life.[2] Developing obesity prevention strategies that specifically target young people and are adapted to their life circumstances and needs is therefore essential. Recent projects have invited young people to contribute to the design of interventions for the promotion of healthy diets and physical activity[3–6] and obtain insights into their perspectives regarding body weight,[7] but such forms of youth engagement in obesity prevention research remain rare.[8]

According to the UNICEF international charter for ethical research involving children,[9] research aiming to engage young people requires critical reflection to ensure that the rights, dignity, and well-being of youth are safeguarded. Researchers should recognize the young people's competencies, offer them opportunities for decision making and be aware of their varying capacities and social environments.[10] In practice, this for instance means providing youth with information adapted to their sphere of understanding,[11] seeking their informed consent, evaluating the limits of parental consent,[12] and assessing whether the young people understand what participation in the research involves and how they can withdraw their consent and involvement.[11] Researchers should as much as possible protect young people and their families from any physical, moral, and informational harm in connection with participation in research and strive to provide them with concrete benefits, for instance by enabling access to services or products emanating from the research.[9] Importantly, conducting research with young people requires awareness through the duration of the project of power relationships between the expert researchers and youth with limited skills and experiences[13,14] and consideration of how participation in the research and the choice of research methods may affect young people.[9,10] Additional considerations apply when inviting young people in obesity research. There is social stigma attached to having overweight or obesity in our society[15] and frameworks have been developed that guide researchers in the identification of potential ethical challenges in obesity prevention interventions such as stigmatization of participants or discrimination against people with overweight or obesity.[16,17]

Engaging young people in research can be practiced in various ways.[18] Engagement can be limited to consulting young people at a specific point in time by asking for their opinion on predetermined issues and using their feedback to inform the research. Ideally, engagement implies more participatory approaches, and young people are offered the possibility to share decisions with researchers or policymakers.[19] In youth participatory action research (YPAR), youth are invited to collaborate on equal terms with researchers during all stages of the research, from its design and data collection to the data analysis and decisions regarding how to use the outcomes of the research and reach stakeholders.[13] Such processes of co-creation may however bring specific ethical challenges[20] such as risks brought to the young people by taking a role in exploring salient and at times controversial issues in their communities.[21,22] When youth are engaged in a project spanning several months or years, time constraints may also arise.[23]

Little is known regarding which ethical challenges may be encountered when engaging young people in research to formulate public health policies aimed at reducing obesity prevalence in youth. In this paper, we discuss our experiences of developing such policies with youth in a large-scale European project spanning several levels of youth engagement. We outline six ethical considerations, that is, principles and values that the project partners agreed should guide the conduct of the research and interactions with youth to minimize harms and maximize benefits:

1. Voluntary participation
2. Protection from obesity stigma
3. Respect for the young people's time
4. Data privacy and confidentiality
5. Power balance
6. Equal opportunity to participate in the research.

The considerations were identified by the project partners, including a youth organization, at the start of the project through meetings moderated by an ethics adviser (first author). For each ethical consideration, we describe the measures the project partners implemented with the objective to prevent or limit the emergence of ethical issues when interacting with youth, and we discuss the relevance of these measures. Our assessment is based on discussions between project partners, and analysis of project reports written by the project staff and co-facilitators recruited locally[24] (*Personal reference: CO-CREATE D5.5: Evaluation reports on the sustainable Alliances for overweight prevention policies; CO-CREATE D6.4: Implement and evaluate Dialogue Forums at regional, national and city levels submitted to the European Commission*). The reports provide a description of activities conducted at project sites with youth, group dynamics in the meetings, and processes for the identification and prioritization of obesity prevention policies. Finally, we reflect upon how our experiences of applying an ethical lens while conducting our activities may guide future research.

1.1 | The CO-CREATE project

In 2018, the European Union's Horizon 2020 research and innovation programme funded a 5-year project entitled "Confronting obesity: Co-creating policy with youth" (CO-CREATE).[25] The project gathers 14 research institutions and civil society organizations in Europe. One member of the research consortium is a youth organization, which is represented both on the project's executive board and on project working groups to represent the youth perspectives. The project is present in the Netherlands, Norway, Poland, Portugal, the United Kingdom, Australia, South Africa, and the United States. From 2019 to 2021, the project engaged with approximately 300 European youth aged 15–19 of diverse socioeconomic background in the development of proposals for obesity prevention policies (*Personal*

reference: Klepp KI et al., "Overweight and obesity prevention for and with adolescents: The 'Confronting obesity—Co-creating policy with youth project'", 2022, submitted to Obesity Reviews). Youth were recruited from schools, youth organizations, scouts, and a municipality in the Netherlands, Norway, Poland, Portugal, and the United Kingdom. The young people could participate in three types of activities: system mapping workshops, Youth Alliances and Dialogue Forums (Figure 1—Youth engagement activities and timeline). For youth willing to participate in all activities, the engagement period, from start to end, was planned to last for about a year. However, for methodological reasons, most young people participating in the system mapping workshops did not subsequently pursue their participation in the project, and new groups of youth were recruited to the Youth Alliances. The young people joined two system mapping workshops of 2 h each to discuss systemic factors they perceived to influence obesity, using "group model building."[26] Group model building uses processes to represent these factors in conceptual system maps to illustrate how different parts of the system, for instance food and physical activity, relate to one another to result in obesity.[27,28] Later, new groups of young people were invited to join Youth Alliances to elaborate on the systemic factors identified by their peers during the system mapping workshops and, in collaboration with the researchers, develop policy ideas that support healthy eating and physical activity. The design of the Youth Alliances was inspired by YPAR approaches[29,30] and followed an indicative program of around 10 meetings, each meeting lasting 1–3 h. Although the topic of focus was already decided (development of obesity prevention policies) and our program of activities was ambitious, we hoped that the young people would find the issue relevant to them and their communities

and would be willing to dedicate some time to work with us. The young people could decide on how often to meet, how to organize the alliances, and how to work with policy development, for instance deciding on the kind of activities to conduct, and which prevention strategies to adopt. The alliance members used various tools to support the co-creation of policy ideas such as surveys, advocacy training, a budget, policy forms, and photovoice[31] to learn about policy, to get a better understanding of obesogenic environments and to test their policy ideas of how to change the obesogenic system.[31] The young people received support from the CO-CREATE staff and co-facilitators, which were young people recruited from local youth organizations (Personal reference: Bröer et al., "Negotiating policy-ideas: Analysing 15 participatory action projects across 5 European Countries", 2022, submitted to the European Journal of Cultural and Political Sociology). Finally, from June 2020, youth who had participated in the Youth Alliances, and other youth identified through youth organizations, campaigns, and community initiatives, could participate in a Dialogue Forum of 2 h to discuss and refine their policy ideas with relevant stakeholders such as policymakers and private sector representatives. The Dialogue Forums were conducted using an interactive dialogue tool to facilitate the discussions and could be moderated by young people (Personal reference: CO-CREATE D6.4: Implement and evaluate Dialogue Forums at regional, national and city levels, submitted to the European Commission). Although most activities with the young people were held in schools or at the premises of the organizations through which the youth had been recruited, after March 2020 the outbreak of the Covid-19 pandemic leading to lockdown and other restrictions in most countries, meetings and activities had to be conducted online.

	System mapping workshops	Youth alliances	Dialogue forums
	January - May 2019	Summer 2018 / Summer 2020	June 2020 / March 2022
Activities	Development of system maps to identify key drivers of obesity and generation of policy ideas	Development and refining of policy ideas using policy forms, Photovoice, surveys, and interviews	Finalization of policy ideas and discussion with stakeholders in dialogue forums using a dialogue tool
Group composition	Adolescents of various socio-economic background recruited through schools	Adolescents of various socio-economic background recruited through schools, youth organizations and one municipality	Adolescents from the youth alliances, and new groups of adolescents of various socio-economic background recruited through schools and youth organizations

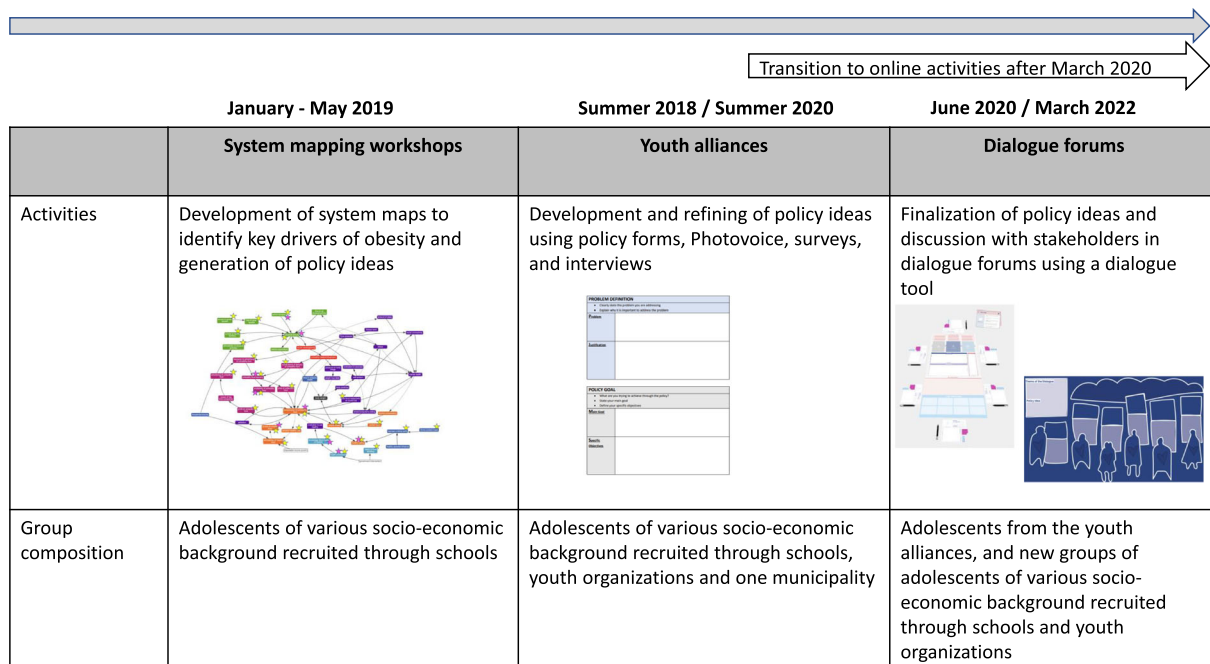Transition to online activities after March 2020

FIGURE 1   Youth engagement activities and timeline

At the project start, the project partners developed a consortium ethics policy outlining six ethical considerations.

1.1.1 | Ethical consideration 1—Voluntary participation

A core concern of the project was to ensure the truly voluntary participation of the young people in the project activities. Although the project aimed to recruit youth through various channels, in practice, it turned out to be difficult to collaborate with youth outside existing organizations and most youth were recruited through schools or scouts. We were aware that school recruitment can be challenging "given complexities around adult–child power relations in such contexts which would likely have positioned the researcher in a role of authority".[32] There is a risk that young people attending a school might feel obliged to participate in the research by people of natural or institutional authority such as parents[13,33] and teachers,[32] or fear negative consequences if they refuse to participate.[12] Requests to participate in the research may be perceived as "an already negotiated agreement"[11] between researchers and the school staff.

We implemented several mechanisms to ensure the voluntary participation of youth in the project. Youth were asked for their written informed consent to participate in each type of activity—the system mapping workshops, the Youth Alliances and the Dialogue Forums—and a two-staged procedure for informed consent was applied. The young people first received an information sheet and a sign-up sheet at information meetings, which they could fill in and deliver to the research team or the contact person at the organization to express interest in joining the research. A copy of the informed consent document was also attached for review. The researchers presenting the project at meetings made it explicit that participation in the research was voluntary and not tied to grades or extra credit or other obligations or benefits. Later, after youth had been given sufficient time to discuss the research with their parents and ask questions to the research team, those still interested in joining the project signed the informed consent sheet. In Portugal and Poland where the age of consent is 18, the assent of the young people was required, and the consent of the parents or legal guardians was sought only after youth assent had been collected. During each wave of consent collection, the young people were reminded that that they could cease participation at any time without needing to provide reason.

To the fullest extent of our capabilities, we did not detect any problems when collecting the assent or consent of the young people. The project staff felt that the young people understood their rights and what participation in the research involved, and many youth expressed enthusiasm about participation, although this cannot be interpreted as a guarantee that the youth joined the project of their own will. It was however difficult for the research team to know how the project had been presented to the young people by the school/organizational staff and whether any pressure to participate had been applied. We experienced that in one school a few youth participating in a Youth Alliance expressed frustration over being "forced" to join the meetings, telling the project staff that "participation was mandatory to get the diploma." Even when told that they were free to withdraw, the young people were hesitant to do so. In that same school, the project staff later discovered that the school had incorporated participation in the project as part of the students' curriculum. After discussions with the project staff, the teacher agreed to let youth decide on whether they wanted to pursue their participation in the alliance or join other activities. The project staff also reminded the youth about the possibility to withdraw. To our knowledge, this issue was encountered only in one school.

1.1.2 | Ethical consideration 2—Protection from obesity stigma

Body weight is still largely seen as an individual responsibility in our societies.[16] Although the project did not actively seek to recruit youth living with obesity, we were aware that if some youth had overweight or had close family or friends with overweight or obesity, they might experience enacted stigma from peers or other people external to the project due to their participation in CO-CREATE. We therefore decided to recruit youth at a group level rather than individually, and it was communicated that the only criteria for participation was age although diversity in backgrounds and experiences was encouraged. It was made clear during information meetings, the recruitment process, and research activities that lack of respect toward peer participants, or any form of bullying, would not be accepted and could lead to exclusion from the project. When starting the activities, the young people were invited to reflect upon issues of stigmatization and identify strategies to address them. Similarly, stakeholders involved in the Dialogue Forums to discuss the youth's policy ideas were also required to commit in writing and by signing a code of conduct to be respectful of the youth in their interaction with them and avoid any form of physical, verbal or emotional abuse.

Incidences of obesity stigma were not reported in any of the reports written by project staff, although such instances might have occurred unobserved by project staff or have taken place outside of project activities. The young people seemed respectful of each other, and some found it worrisome that peers encounter stigma at such an early age. Some youth took the initiative to make a video about fat shaming, where they shifted from a focus on individual responsibility for obesity to the way a culture looks at people. Others were critical of a national campaign consisting of posters hanging in buses and tram stops that, in their view, strengthened the stereotypical image of obesity and contributed to the discrimination and stigmatization of people dealing with the condition. The issue of stigma was also discussed by youth in Dialogue Forums, often with the aim of identifying measures to reduce stigma by peers. In a Dialogue Forum held at the European Youth Parliament, youth participants identified several calls to action to address stigma such as reinforcing mental health support.

1.1.3 | Ethical consideration 3—Respect for the young people's time

There is a risk that encouraging youth to engage in extracurricular activities put unreasonable pressure on them and negatively impacted their academic results.[23] We had an ambitious plan for youth engagement in the project. To reduce the time and logistical burden on youth, we held meetings either before or after school hours, or within school hours/scout meetings depending on youth preferences and other obligations. In one country, the project team consulted youth during pre-alliance meetings. After presentation of the initial plans for Youth Alliances, the young people indicated that they wanted to limit the number of meetings; consequently, the plans were revised, and the number of meetings reduced.

Despite our efforts to accommodate the youth's school agenda, the project staff observed that some young people struggled to manage conflicting obligations such as having to prepare for exams, working on school projects and homework, taking care of siblings, or having to reach the last bus to get home. Some were tired and unfocused if the meetings were held after school hours, and a few informed that they would not attend meetings because of other obligations or did not show up. Some youth did not work with alliance tasks between meetings as agreed upon, although it is unclear whether this was due to lack of time or rather lack of interest. Time conflicts seemed to be particularly challenging for those young people in their final year of upper secondary school, who were focused on their exams, and youth who needed to put additional efforts to follow the educational program, for instance, due to language issues.

Other young people reported that they felt less engaged in the activities after a while and would rather focus on their school tasks but pursued their work for a longer period out of feeling guilty toward their peers (before they decided to quit and focus on their exams after all). In some schools, the project staff also experienced that some young people at times (and varying over time) physically expressed disengagement in the activities (e.g., hiding face under hoodie or playing with phone), complained that the project was boring, that the meeting was too early in the morning, that they did not know how to proceed, participated in the work only when the teacher was present, did not attend the meetings in the absence of the teacher, or in some occasions dropped out. Though the impacts of COVID-19 on productivity and school performance are unclear, the pandemic may have served as an additional deterrent. We also struggled to accommodate the demands of youth regarding different meeting times due to restrictions on the availability of meetings rooms in the schools, thus resulting in Youth Alliance meetings sometimes colliding with exams or classes, or not happening immediately after school. From March 2020, the Youth Alliance meetings and the Dialogue Forums were transferred to online platforms due to the lockdowns in the project countries. This led to more engagement as several new young people could join the meetings remotely. It also created an additional burden on youth as most of their school activities were held digitally, leading some young people to experience digital burnout, as a result of which they dropped out of the project.

1.1.4 | Ethical consideration 4—Data privacy and confidentiality

The project produced research data based on our observations of young people and used mechanisms for data handling, pseudonymization, and storage following standard ethical requirements. In addition, youth collected their own data, for instance using online surveys or photovoice,[31] although these data primarily served to inform the young people's policy ideas and were not directly used as part of the research process. Ensuring the privacy and confidentiality of such data may be challenging if the young people do not adhere to, or do not understand, data management rules. For instance, we feared that they might share information about their peers through social media without their approval.[14,31] There was also a risk that they shared information about themselves with a degree of openness that might jeopardize their privacy.[33,34]

To address potential issues of data privacy and confidentiality, the project partners provided youth, facilitators, and co-facilitators with training in ethics and management of written and visual information. The training included discussion of principles of informed consent, privacy, data security and confidentiality, and examples of how to take pictures with angles that obscure individual identity or omit the name of a particular establishment when using photovoice. The risks and unintended consequences of taking pictures and sharing information about oneself and others were also extensively discussed with youth.

The project staff conducting meetings with youth experienced that the young people were interested in the topic of data privacy protection, were attentive to the ethics and data management training, and agreed on how the data collected should be interpreted or used. Overall, we did not detect issues regarding data handling although we might not have been fully aware of how data were used by youth.

1.1.5 | Ethical consideration 5—Power balance

Issues of power imbalance are likely to arise in research projects aiming to engage youth. Some young people may have more rhetoric and leadership skills than others,[33] and the researchers have more natural authority than young people due to their experience.[12] There is also a risk that stakeholders might manipulate youth or put pressure on them to prevent any change in existing power relations.[14,20] We implemented several mechanisms to limit the emergence of such issues. In the Youth Alliances, young people were asked to outline written group agreements describing ground rules for interaction with each other such as respecting others' opinion, giving space for others to participate or not laughing at each other. In connection with Dialogue Forums, similar written agreements were implemented that stakeholders had to comply with, and a balanced representation (50/50) of youth and stakeholders in the meetings was required. In addition, all Dialogue Forums organizers were invited to use a stakeholder risk assessment table to evaluate levels of risk when inviting

different types of stakeholders such as food manufacturers, civil society organizations, and policymakers, to join the forums.[35] Youth were also provided with strategies on how to cease participation in the Dialogue Forums if they encountered situations of discomfort or distress, and those willing to moderate meetings were trained in ways to mitigate power imbalances and apply safeguards against conflicts of interest.

Overall, the project staff observed good group dynamics between the youth in the Youth Alliances. Enabling equal levels of participation in larger groups was however challenging as some young people were more vocal and eager to take the lead than others. Some tension could also be observed between youth and schoolteachers present at meetings although it was not possible to identify the origins of these tensions. The project staff experienced that the young people behaved in a trustful manner with them, asked questions, and shared viewpoints and stories, although some youth seemed to be intimated by the project staff during the first meetings, possibly because of their profile as nutrition experts. We aimed to be observant of potential issues of power imbalance between the project staff and youth but had little possibility to capture issues due to our position toward youth. It is also possible that the project staff refrained from reporting power imbalance issues.

When contacting stakeholders, some young people who were not used to write formal emails and make phone calls felt nervous and expressed fear to make mistakes. Though youth experiences with power imbalance were not documented in a standardized way, discussions with youth participants and moderators after the Dialogue Forums did demonstrate that at times, select stakeholders dominated the conversation, tried to convince youth to adapt or modify their opinion, and responded in condescending ways to young people's questions.

1.1.6 | Ethical consideration 6—Equal opportunity to participate in the research

The project aimed to reach out to diverse youth in terms of gender, ethnicity, health status, political experience, and socioeconomic background. Fieldwork had been conducted to identify geographical areas of varying socioeconomic characteristics where youth could be recruited and recruiting youth through schools in various socioeconomic areas was helpful. As a result, approximately 10% of the youth participating in the Youth Alliances came from families of low socioeconomic status. We experienced difficulty in achieving gender balance in the project as most young people participating in the Youth Alliances were girls, with only one Alliance having a majority of boys. Although lack of gender balance might partly be explained by school class composition, we do not know why boys had lower participation in the project. We discussed with project partners and youth already participating in the project how to recruit more boys but did not manage to identify successful strategies. Limited participation of boys suggests that participation in the project was indeed based on personal interest and therefore voluntary.

The widespread lockdowns due to the Covid-19 pandemic had an impact on the project. Most Youth Alliances were running at the time and several digital tools were tested and adopted to pursue activities. The project staff worked to keep youth engaged digitally, for instance by organizing quizzes as group building activity when starting the online meetings or using breakout rooms for smaller group discussions. The Dialogue Forums had been planned to take place physically and the project team had to redesign and adapt the Dialogue Forum tool for digital use.[35] Adjustments were made to the ground rules for participation to account for any risks that may emerge online, and training was also provided to the youth in the use of the digital tool. Due to limited resources, it was not possible to provide digital access to those lacking it.

Most youth found ways to continue their engagement online and opportunities to exchange ideas digitally with youth in other partner countries arose. However, we observed that the young people were reluctant to use their video during the meetings. This was presumed to be because they were not comfortable exposing their home surroundings or did not have a private space at home to participate in the meetings. The project staff found it difficult to assess nonverbal reactions and missed being able to serve food and talk informally with the youth, which was seen as important for a good group dynamic and relationship building. Youth required more prompting during meetings and seemed less willing to participate in discussions. This was particularly challenging with those young people who right from the beginning had been quiet. In some groups, the project staff felt that they were taking more responsibility for driving the meeting than ideal when aiming to engage young people. The project staff also struggled to multitask by showing presentations to the youth, organizing breakout rooms and responding to questions in the chat, and this at times made communication challenging between the staff and the young people. In some cases, the online meetings were longer in duration than in-person meetings, mainly due to technical problems, and as a result, some youth seemed to find them too demanding. Some youth also could not participate in the online meetings because they did not have the necessary equipment or access to software. Others experienced technical issues connecting, had other obligations such as taking care of siblings or going to their part-time jobs, or did not respond to online messages.

2 | DISCUSSION

Our project engaged a large and diverse sample of European youth in the development of policies for obesity prevention through the organization of system mapping workshops, Youth Alliances and Dialogue Forums. The project aimed to minimize risks to the youth and identified six ethical considerations believed to require particular attention. Several mechanisms were established aiming to prevent the emergence of ethical issues, including a two-stage consent collected in connection with each new wave of activities, written group agreements, youth training in ethics and flexibility in the organization and timing of meetings with youth. Importantly, the project staff including

a youth organization was encouraged to continuously be aware of ethical aspects in the project and reflect upon their role toward youth. Although some ethical challenges seemingly did not emerge, some were encountered related to the young people's voluntary participation in the project, time burdens on them, and equal opportunity to remain in the project under the Covid-19 pandemic.

Ethical guidelines put large emphasis on ensuring the voluntary participation of young people in research by providing them with sufficient information about the research and collecting their informed consent.[9] We experienced that the informed consent process, even conducted at multiple time points, was not sufficient to give us the assurance that all young people were joining the project of their own free will.[12,36] As commonly practiced in research engaging youth, we recruited many of our young participants through schools. We were aware that such recruitment can be ethically challenging due to the complexity of "adult–child power relations".[32] By targeting schools of different socioeconomic backgrounds, we managed to invite youth usually under-represented in research and give them a voice in an important issue affecting them. In countries such as Poland, school recruitment was the most secure option for the conduct of research with minors due to stringent legal safety regulations. Conducting project activities in schools likely made it easier for youth to participate in the project, although it did not fully eliminate time and logistical issues. School-based recruitment also helped secure enough participants and to some extent prevent attrition. Mechanisms are however needed that go beyond standard consent requirements and enable the project staff to continuously reassess the young people's willingness to remain in the project and engage in activities for an extended period.[20,33]

Engaging young people in obesity prevention research has the potential to bring benefits to the youth and their communities.[37] In CO-CREATE, although we did not systematically assess which benefits were brought to the youth through their participation in the project, we observed that the young people developed new awareness of systemic factors influencing obesity, acquired decision-making and observation skills, and learned to use new tools such as Photovoice. We also experienced that some young people were accepted on higher school levels or finished their follow-up education sooner than expected as a direct result of their participation in the Youth Alliances. Others decided to pursue their work with local authorities after their participation in the project had ended to implement their policy ideas. (*Personal reference: CO-CREATE D5.5: Evaluation reports on the sustainable Alliances for overweight prevention policies*). However, achieving such benefits required that youth dedicate some of their time to the project. Despite our attempts to ally early on with youth to design project activities and accommodate their time schedules, it was sometimes too demanding for the young people to combine participation in the project with school, family, and work obligations. Traditionally, research projects offer limited possibility to change plans over time. Our experience is that it may be useful in projects spanning several months or years[38] to adopt a reflexive approach in project design and development[10] by regularly evaluating progress, and making amendments to the project plan integrating the perspectives of the young

people,[32] although this may mean that renewed ethics approval for each new research cycle is required.[18,20] Recent frameworks to support reflective practice may provide useful guidance on this matter.[39] Reflexivity and flexibility are particularly important under changing circumstances. In principle, digital technology is a powerful tool to democratize decision-making processes that offers youth and researchers an opportunity to experiment with other forms of engagement.[40] In practice, under the Covid-19 pandemic, we experienced that the transition to digital tools exacerbated inequalities between youth with and without digital access and competence, although it also enabled others to engage. Future projects considering using digital technologies should ensure that youth have access to the necessary equipment and digital infrastructure and provide capacity building to be inclusive.[41]

In our work to identify ethical considerations in the project, our focus was primarily on issues usually highlighted in research ethics such as ensuring the truly voluntary consent of the youth and protecting them against stigma.[30] As the project developed, we however realized that the traditional way of thinking "ethics" had some shortcomings and did not fully support participatory approaches under which youth are encouraged to endorse a role of research collaborators (who develop policy ideas) rather than research participants (who fill in questionnaires and are being observed).[20] We also noted that communicating early in the project regarding the distinction between these roles would have been useful. Ethics tools may be needed that aim to ensure good and safe interaction between project staff and participants rather than solely focus on protecting participants from potential harm. We experienced that dealing with the "everyday ethical issues" in a large-scale research project such as CO-CREATE required continuous attention,[32] and such tools may help project staff identify and possibly assess ethical issues that emerge after a project has received ethics approval and has started its activities. For instance, researchers may need concrete mechanisms and support, possibly from ethics committees, to address power imbalance issues. Likely, our project staff's ability to detect issues with a critical eye while being immersed in the daily work with youth was limited. It might also have been hampered by fears that one may be held responsible for the emergence of the issues or concerns that addressing ethical problems may be too demanding and detrimental to the project. Ethics committees may consider providing more concrete guidance to researchers regarding ethical issues arising in interactions and relationships between researchers and young people.[12] Designing with the young people ethical principles and frameworks for securing basic protection and consent may also be considered.[12,18,20,42]

Our assessment of ethical issues in the project has an important limitation. We did not specifically consult the young people involved in the project regarding the ethical aspects of their participation although they could at any time raise issues if they wanted to. This is primarily because we had not planned for doing so when designing the project but rather aimed to ask the young people about how their participation in the project had influenced their readiness for action. Organizing additional requests for feedback was difficult due to resource and time constraints. We however discussed the results from

our assessment with the representative from the youth organization involved in the project. An important suggestion was to secure continuity after project end by ensuring that the tools developed by the young people in the project become available to other youth and their communities for their own use. The Dialogue Forum toolbox[35] has been made publicly available and other project outputs will follow in the coming months.

Young people deserve the opportunity to be fully engaged in research that relates to them. Research should engage with young people in ways that place those young people at the heart of the process, and we hope that the principles we describe here will help other researchers to learn from and build on our experiences to take an open, ethical, and self-reflective approach to working with youth.

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CONFLICT OF INTEREST

No conflict of interest was declared.

ORCID

Isabelle Budin-Ljøsne https://orcid.org/0000-0002-4610-1662
Arnfinn Helleve https://orcid.org/0000-0003-0650-6531
Knut-Inge Klepp https://orcid.org/0000-0002-3181-6841
Nanna Lien https://orcid.org/0000-0003-1486-4769
Aleksandra Luszczynska https://orcid.org/0000-0002-4704-9544
Samantha Nesrallah https://orcid.org/0000-0003-0890-2175
Harry Rutter https://orcid.org/0000-0002-9322-0656
Natalie Savona https://orcid.org/0000-0002-3006-3681

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