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# Encouraging greater empowerment for adolescents in consent procedures in social science research and policy projects

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## Summary

The United Nations Convention on the Rights of the Child emphasizes the importance of allowing children and adolescents to influence decisions that are important to them following their age and maturity. This paper explores the principles, practices, and implications around using parental versus child/adolescent consent when participating in social science research and policy development. Experiences from two studies are presented: *The Confronting Obesity: Co-creating policy with youth* (CO-CREATE) and the *Health Behaviour in School-aged Children* (HBSC) study, a *World Health Organization* (WHO) *Collaborative Cross-National study*. Although parental consent may be an important gatekeeper for protecting children and adolescents from potentially harmful research participation, it may also be considered an obstacle to the empowerment of children and adolescents in case they want to share their views and experiences directly. This paper argues that evaluation of possible harm should be left to ethics committees and that, if no harm related to the research participation processes is identified and the project has a clear perspective on collaborating with the target group, adolescents from the age of 12 years should be granted the legal capacity to give consent to participate in the research project. Collaboration with adolescents in the development of the research project is encouraged.

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## KEYWORDS

adolescent consent, CO-CREATE study, HBSC study, parental consent

## 1 | INTRODUCTION

Child and adolescent participation in research is valuable, and it is important to understand and integrate this age group's perspectives in policy and intervention development.<sup>1–3</sup> The United Nations Convention on the Rights of the Child (UNCRC)<sup>4,5</sup> and guidelines developed by the European Commission and UNICEF<sup>6</sup> underscore the importance of children's and adolescents' participation in matters that affect them, including research, and uphold their right to express their views freely.<sup>7</sup> The UNCRC emphasizes that children's and adolescents' views should be given weight according to their evolving capacities and differentiate between young children and adolescents nearer adulthood.

By allowing this age group to share their lived experiences, the inclusion of children and adolescents in social science research that investigates various aspects of their social life, behavior, and interactions provides more comprehensive and nuanced research findings for use in targeted policy development. Considering the experiences of children and adolescents from different backgrounds, including those who may be more vulnerable or marginalized, may reduce disparities and promote equity in interventions and policy. However, it is crucial to ensure that ethical considerations, such as informed consent, privacy, confidentiality, and protection from harm, are addressed carefully when involving young people in research.<sup>3</sup> Irrespective of their age and given their psychological evolving maturity and incomplete ability to understand the consequences of their actions or choices, children and adolescents should receive special protection from maltreatment, neglect (UNCRC article 19), and economic exploitation (UNCRC article 32).

Parental consent is the process of obtaining permission from at least one parent or legal guardian of minors to involve them in research studies. In most countries, it is an ethical and legal requirement to ensure the well-being and protection of children and their rights. The requirement for parental consent relates primarily to biomedical research but also applies to social science research.<sup>2,8</sup> Obtaining parental consent assumes that parents or legal guardians (hereafter referred to as “parents”) are in the best position to make decisions on behalf of their children by considering their best interests, safety, and welfare. Consent helps ensure that minors are not subjected to research that could harm them physically, psychologically, or emotionally. The consent process typically involves providing parents with detailed information about the research study, including its purpose, procedures, potential risks and benefits, and any measures taken to protect participants' privacy and the confidentiality of their data. The parents are then asked to provide their voluntary and informed consent on behalf of the minor. Parental consent aims to ensure that parents are fully informed about the nature of the research and can make decisions in the best interest of their child by weighing the potential risks and benefits involved.

Parental consent is usually provided in an active or passive form. Active parental consent means that the parents approve their child's participation in a research project by providing active confirmation, for instance, by signing an informed consent form. By contrast, passive consent means that parents receive information and respond only if they do not want their child to participate in the research activity. Collection of the active consent of parents remains a widespread requirement of ethics committees reviewing research projects. However, the ideal form of consent (active or passive) has been debated for decades.<sup>9–11</sup>

Depending on the nature of the research, additional assent from the minor may also be required. Assent is the child's or adolescent's agreement or affirmative response to participate in the research, which is separate from parental consent. It recognizes young people's evolving capacity for decision-making and allows them to express their willingness to participate.<sup>2</sup> Assent typically involves providing age-appropriate information about the research study to the child or adolescent, explaining the purpose, procedures, potential risks and benefits, and any measures to protect their privacy and confidentiality. The information should be presented in a manner that the young person can understand by using language and concepts tailored for their age and cognitive development.<sup>12</sup>

Parental consent aims to uphold principles such as respect for autonomy, beneficence, and non-maleficence. However, the requirements to obtain parental consent for the participation of children and adolescents in social science research may have unfortunate side effects in some cases.<sup>2,13</sup> First, minors willing to participate in research may be prevented from doing so if their parents disapprove. This may interfere with the principles in article 12 of the UNCRC outlining the child's right to be heard and may also be contradictory to current research developments that acknowledge the importance of youth-led involvement in research.<sup>2,14,15</sup> Mathews<sup>2</sup> emphasizes that this is both an individual right and a collective value regarding the impact children and adolescents can and should be able to have in terms of having their lived experiences validated and included in policy development for the betterment of society. While involvement of children and adolescents in research and policymaking has been increasing over the last decades, it might come under pressure and scrutiny soon. In an increasing number of countries, anti-feminist and anti-gender movements are growing and influencing politics.<sup>16</sup> This often goes hand in hand with redefining children and adolescents as being in danger and in need of adult protection. More broadly, there is a reduced emphasis on civil society participation in policy discussions and decision, where children and marginalized groups are especially affected. Pavarini et al.<sup>17</sup> highlight the importance of both treating children and adolescents as objects of research studies and inviting them to become active participants in the design of the research and later interpretation and dissemination of findings.

The second potential side effect is that collecting the active consent of parents is more challenging than collecting their passive consent, despite the development of digital solutions for parental consent.<sup>13</sup> Obtaining consent from parents of low socioeconomic status can be difficult because they may not perceive the research as relevant or may find participation difficult given logistical issues such as lack of transportation, limited availability of time, or language barriers.<sup>13,18,19</sup> The lack of response from parents may lead to biased representation in research projects. However, reduced representativeness in social science research aiming to guide policy and practice development is problematic because the needs of all societal groups may not be considered.<sup>2</sup>

There are also circumstances in which the requirements to collect parental consent is problematic or inappropriate (e.g., research on parental violence). In international research projects, collecting parental consent may be challenging as consent requirements vary across countries. For instance, parental consent is required for adolescents up to the age of 18 years in Poland and Portugal, whereas adolescents can consent to participate in research themselves from the age of 16 years in Hungary and the Netherlands and from the age of 12 years in Croatia and the Czech Republic.<sup>20</sup> Such variations in consent requirement make it difficult for research projects to harmonize consent collection procedures when the research takes place in various countries.

Arguments have been made that requiring parental consent for adolescents aged 16 years or older is an expression of overprotection<sup>2,21–23</sup> and may not be legally justified in social science research.<sup>2</sup> Perhaps, the same claim can be made for adolescents as young as 12 years given that adolescents have been shown to have a greater capacity and maturity to understand the significance of research and the implications of the risk and benefits to themselves than expected.<sup>2,17,24</sup> A recent study across a wide range of countries indicated that a sharp advance in the ability for cognitive appraisal occurs from the age of 10 years and plateaus at the age of 16 years, whereas psychological maturity continues to develop into the 20s.<sup>25</sup> In most of the countries included in that study, the cognitive development was considered to be advanced at the age of 12 years.

In the UNCRC, the age of 12 years is specified as the age from which the view of the child should be given special weight and consideration. Review studies have reported that children participating in research investigating sensitive topics, such as violence and health-risk behaviors, see their participation as important and worthwhile even if some short-term stress is experienced.<sup>2,26,27</sup> The General Data Protection Regulation introduced in the European Union in 2016<sup>28</sup> acknowledges adolescents' ability to consent themselves to the use of their data, for instance, from social media platforms and online applications, from the age of 13 years.<sup>29</sup> This highlights that young people are recognized as having the ability to assess risks and benefits associated with data use. However, it is important to acknowledge that personal participation in research may differ from the use of one's data and may have other impacts on participants.

This paper argues that adolescents as young as 12 years should be granted legal consent in social science research provided that it is identified as nonharmful by a competent research ethics committee. We build

our argument on the experiences from two research studies. The first study is the CO-CREATE project (“Confronting Obesity: Co-creating policy with youth”), in which young people aged 16–18 years were invited to cocreate research and policy development. The second is the “Health Behaviour in School-aged Children (HBSC). A World Health Organization (WHO) Collaborative Cross-National study,” in which survey data are collected every 4 years from 11-, 13-, and 15-year-olds. We demonstrate how youth involvement have contributed to the survey development and also how varying requirement in terms of active or passive parental consent may impact the research conducted.

## 2 | EXPERIENCES FROM TWO RESEARCH STUDIES

### 2.1 | Confronting Obesity: Co-creating policy with youth (CO-CREATE)

#### 2.1.1 | Objectives and youth perspectives

The objective of the Horizon 2020 project CO-CREATE was to collaborate with young people through a youth-led participatory action approach to identify the policy-relevant factors driving adolescent obesity and overweight and to suggest policy actions in collaboration with adolescents.<sup>30–33</sup> The project aimed to give young people a voice throughout the research process, from the design of the study to the dissemination of the results. Youth representatives from Press–Save the Children youth organization in Norway (<https://press.no/>) were invited to participate in the executive board of the project at the time of the establishment of the project consortium, which jointly developed the project and the project application. The role of Press on the executive board was to voice the interest and concerns of young people throughout the project duration.

#### 2.1.2 | Recruitment, consent, and ethics approval

The project recruited adolescents in the United Kingdom, Poland, Portugal, the Netherlands, Norway, and South Africa. Main channels of recruitment included schools, youth policy organizations (e.g., youth councils), and youth activity organizations (e.g., scouts). A snowball approach to recruitment was also applied, and recruited youth were encouraged to invite friends and colleagues to participate in the project.

A core part of the initial discussions among the executive board was the age of the participants to be recruited. Initially, the project wanted to recruit 10–18-year-olds because, by this age, they have become more independent of their parents and start establishing their own lifestyle patterns. The intention to reach children and adolescents during the age period where overweight and obesity, in principle, still can be prevented was seen as important.<sup>34</sup> The project's executive board however feared that obtaining parental consent across several participating countries for this age group would be challenging. Instead, it was decided to approach 16–18-year-olds because they could still be recruited through the school system or organized youth activities and

they would have the legal capacity to provide their individual consent to participate in the project in most European countries. Parental consent however had to be obtained in three countries (Poland, Portugal, and South Africa)<sup>35–37</sup> for children under the age of 18 years. In the Netherlands, some young people under the age of 16 years expressed interest in participating in the project, and procedures were established to include them in the project, collecting their assent and their parents' consent. Participants could withdraw at any time from all activities or could decide to not participate in individual activities.

In these countries, adolescent assent was also collected. Each project partner collecting data obtained ethical approval in accordance with the regulations in their institution and country, and General Data Protection Regulation on storage of personal contact information (such as email and mobile phone number) were followed.

### 2.1.3 | CO-CREATE activities

In the project, the young people were invited to participate in three consecutive activities: system mapping workshops, youth alliances, and dialog forums. In addition, surveys were regularly organized. The activities aimed to facilitate collaboration between the adolescents, researchers, and other stakeholders to identify challenges related to adolescent obesity and ways to overcome these challenges through policy development.<sup>32,33</sup> The activities also enabled data collection for research purposes. Adolescent consent was obtained separately to participate in each activity, and groups of adolescents could vary from one activity to the other.

In the system mapping workshops, the adolescents worked in groups to identify factors they believed to influence overweight and obesity in children and adolescents. Interestingly, the young people raised novel aspects that had not previously been identified through research, namely, social media and mental health as drivers of adolescent overweight and obesity.<sup>38,39</sup> In the youth alliances, which mainly consisted of groups of 5–15 adolescents, the young people worked together to develop policy ideas to reduce childhood obesity. The discussions were facilitated by one young adult and field notes were taken by a cofacilitator. The focus of the discussions was at societal rather than individual level to protect the privacy of alliance participants, or their families and friends, from potential stigmatization. As part of the process, a number of activities were introduced and flexibly implemented, altered, and expanded in line with youth and staff goals.<sup>32,33</sup> Policy ideas were developed, tested, and changed over a period of several months up to a year. Different approaches were used to conduct the work, including Photovoice, a tool commonly used in qualitative research, to document issues related to overweight and obesity in the local communities of the youth and to later inform the development of policy ideas<sup>32,33,40</sup> and advocate for change in their communities.<sup>15,41</sup> The participants and, when required, their parents were informed about the use and purpose of Photovoice. Only Poland asked for consent to use photos for research purposes.<sup>40</sup> Photos that would not identify individuals were encouraged.

Finally, the young people were invited to participate in dialog forums to discuss their policy ideas with policymakers and other

relevant stakeholders. Making the youth feel comfortable and empowered to share their opinions and experiences with the policy-makers and to enter into discussions with them on equal terms were emphasized. A Dialog Forum Tool Kit was developed with the youth and used to secure a climate of dialog and equity between the youth and the adult stakeholders representing policymakers and food businesses.<sup>42</sup> In addition to system mapping workshops, youth alliances, and dialog forums, regular anonymous surveys were organized to investigate the youth's political and civic engagement, readiness for action, and attitudes toward obesity prevention.<sup>43,44</sup>

The adolescents engaged in the project for more than a year. As the project developed and policy ideas flourished, in 2020, the youth organization Press—Save the Children Youth Norway took the initiative to establish a Youth Task Force gathering six young representatives from the Youth Alliances in Norway, Poland, and Portugal. The group developed a [Youth Declaration on adolescent obesity](#) and helped organize the CO-CREATE youth conference in March 2022. In addition, Press developed a new [Youth Advocacy Toolkit \(Youth-Led Change: A Systems Thinking Activity Toolkit\)](#). It was designed by World Obesity Federation and builds on the activities in the youth alliances and the dialog forums. The toolkit can be used to develop innovative policy ideas and advocate for policy change within any area of interest. The Youth Task Force has presented the toolkit at various national and international conferences.

### 2.1.4 | Experiences of the consent process in CO-CREATE

Overall, we experienced that the consent process was well understood by the youth and that their participation in the project was on their own will.<sup>31</sup> The youth alliance cofacilitators coordinating meetings had the possibility to report in their field notes on any behavior or comment from the youth indicating discontent or reluctance to participate in activities. Out of 135 adolescents across five countries (United Kingdom, Poland, Portugal, the Netherlands, and Norway) participating in the youth alliances, only 24 had raised issues. Some adolescents did not want to participate in a specific activity, for example, did not want to be photographed. In case of disagreement, the facilitators and cofacilitators discussed with the youth and reminded them of the possibility to withdraw. Emphasis was put on letting the young people express their views and concerns and establish a dialog of equals. In most cases, the adolescents decided to continue participation. Other adolescents simply did not show up at meetings anymore, for unknown reasons. Fieldnotes from a Dutch facilitator exemplify further:

A lot of participants did not take part in an online meeting. The reasons are not known. After a lockdown of the schools, we created a poll at Fb group to ask who of the participants would like to meet online, and only six responded “yes.” Most of the participants taking part in the online meeting rejected the first action planned to be carried out within the policy idea concerning the free choice of PE lessons because they

decided that they don't want to engage in action if they don't believe in the policy connected to this action.

In short, we can say that issues related to consent were dynamically managed where adults and adolescents continuously renegotiated the terms of collaboration.<sup>33</sup>

### 2.1.5 | Policy relevance

CO-CREATE is one of the few projects where adolescents have been contributing actively and have shared their views regarding policy actions that can be implemented to prevent overweight and obesity in their age group, addressing challenges at a systemic rather than individual level.

## 2.2 | Health Behaviour in School-aged Children. A WHO Collaborative Cross-National study

### 2.2.1 | Objectives and youth perspectives

The HBSC ([www.hbsc.org](http://www.hbsc.org)) aims to monitor and understand the development of adolescent health and health behaviors.<sup>45</sup> It undertook its first nationally representative survey among 11-, 13-, and 15-year-olds in four member countries in 1983 and, since 1985, has collected data every 4 years from the sampled age groups in an increasing number of member countries.<sup>46,47</sup> Today, 52 countries are members of the network. In all the participating countries, the survey addresses health behaviors, health perceptions such as health complaints, life satisfaction, and their social context correlates related to experiences in school, leisure, with friends, and in the family context. In addition, countries may choose to include optional packages that provide more in-depth studies of the abovementioned or complementary areas such as violence and injuries or mental well-being.

The perspective of young people has been emphasized from the beginning of the network's activities. In the first surveys, this occurred through systematic pilot studies of all questionnaire items and focus group interviews with children and adolescents when new topic areas were to be identified and developed. Young people were invited to comment on the perspectives presented in the international reports from the study. A youth-friendly format and allowing youth to share their views and perspectives on the findings were emphasized. During the past two decades, a more proactive role of youth involvement has been facilitated by inviting young people to participate in youth boards in several of the participating countries. These boards have provided inputs on topics important to youth and what they find imperative to include in surveys whose aims are to improve adolescent health.

A Youth Engagement Advisory Group was introduced in the international HBSC study from the early 2000s. In this group, young people are involved as equal stakeholders presenting their perspectives on HBSC research, future priorities, and policy and program actions. When conferences are organized by the HBSC network, young people participate in the planning process and have roles during the

conference event, which emphasizes adolescents sharing their perspective on the research undertaken in the HBSC network.

### 2.2.2 | Ethics approval, recruitment, and consent practices

Each HBSC country follows their country's regulations for ethics approval for research involving children and adolescents. Most of the HBSC countries require and receive ethics approval from one of three levels (institutional, regional, or a national body), whereas only three countries do not need ethics approval to undertake the national survey. Some countries also require the approval of their ministry of health or ministry of education to undertake the survey. In some cases, the ministry requires to approve the items to be included in the survey. The HBSC team in Turkey has not been granted permission from their ministry to undertake the survey in the last two cycles.

Participating youth are recruited through invitations sent to schools where the equivalent of one class (about 25 students) is recruited for each of the relevant age groups. In some countries (e.g., where the school starting age is broad), HBSC teams recruit all classes within the age range of 11–18 years and later select those that meet the age criteria (where the aim is to have a mean age of 11.5, 13.5, or 15.5 years for each age group).<sup>45</sup>

Six countries (Germany, Greece, Poland, Portugal, Serbia, and Slovenia) in the 2021/2022 survey were required to obtain active consent from the parents of the participating children, whereas the others were granted use of passive parental consent (for a complete list of HBSC member countries, see <https://hbsc.org/network/countries/>). These numbers have been relatively stable over the survey years. For both modes of parental consent, written information is typically sent home to parents in their child's backpack or shared on a digital platform for communication between the school and the parents. When active consent is required, parents either respond through digital means or return a paper slip to school confirming that their child can participate. For passive consent, parents can withhold consent for their child to participate by reporting to the school that they do not want their child to participate. The three countries that did not require parental ethics approval did not have any procedures for requesting parental approval for their child to participate.

During the past two decades, in many countries, it has become increasingly difficult to recruit schools to participate in the HBSC study. The principal investigators in the participating countries report that this relates to the increasing demands on schools to undertake national reporting to authorities in combination with a growing number of research studies wishing to collect data in classrooms, including empirical work by master's and PhD students. In countries where active parental consent is required, it is expected that schools are more reluctant to accept the request to participate in research because it requires a substantial amount of time for teachers to follow-up on the dialog with the parents.

An increasing number of schools are declining to participate because of their total workload, which adds to the bias related to the low participation of children with a low socioeconomic status whose

parents are less likely to confirm their child's participation. When schools decline to participate, the representativeness of the sample must be maintained either through oversampling or by finding a matching school in terms of size, rural/urban placing, private/public funding, and socio-economic profile in the same geographical region. In addition, the requirement of parental consent is sometimes reported by teachers as an additional burden because it requires communication with the parents on a topic that is not directly related to the teaching obligations.

Norway is one of the few HBSC countries in which the requirements for active or passive consent have been changed by the Privacy Ombudsman or the Regional Ethics Committee during the different survey years. In 2017/2018, the Norwegian study was required by the Regional Ethics Committee to obtain active consent from parents of 11- and 13-year-olds for their child to be able to participate, whereas the 15-year-olds were considered to be sufficiently mature to evaluate their own participation. In 2021/2022, this was changed back to the previous requirement and only passive consent was required for the 11- and 13-year-olds based on the argument that the findings from the study are being used to develop policy and practice initiatives. The Regional Ethics Committee stated that the findings would be biased if fewer students from lower socioeconomic groups participated compared with their counterparts from higher socioeconomic groups, as shown by other studies that required active parental consent.<sup>13,18,19</sup> The participation rate from different socioeconomic groups for Norway in the survey years 2013/2014, 2017/2018, and 2021/2022 declined severely during the survey year requiring active parental consent (2017/2018) for the group with the lowest socioeconomic status. Based on information about the father's occupation, the percentages for participation by the lowest socioeconomic groups were 12.1%, 5.1%, and 9.7% for the survey years 2013/2014, 2017/2018, and 2021/2022, respectively. The equivalent percentages based on the mother's occupation were 10.6%, 2.9%, and 6.1%, respectively. There were no significant gender differences for participation rates in the lowest socioeconomic groups based on father's occupation in any of the survey years, whereas there were small significant gender differences for all the survey years for participation rates in the lowest socioeconomic by mother's occupation. For the 2013/2014 survey, there were slightly more boys (11.3%) than girls (9.9%) in the lower socioeconomic group based on mother's occupation ( $p = 0.016$ ). For the 2017/2018 ( $p = 0.004$ ) and the 2021/2022 ( $p = 0.031$ ) surveys, there were slightly more girls, 3.4% and 6.6%, respectively, than boys, 2.5% and 5.6%, respectively, in the lowest socioeconomic group based on mother's occupation.

### 2.2.3 | Policy relevance

In many of the HBSC countries, the HBSC survey provides the only nationally available data on adolescent health and health behaviors and their correlates. In the entire HBSC, the results from the study are presented systematically to national health and education authorities primarily by sharing the international report developed in collaboration with the WHO. In addition, in many of the HBSC countries, national reports are produced that provide more details from the

national findings. Several of the principal investigators in the HBSC countries participate in a systematic dialog with the national health and education authorities and sit on committees that are responsible for developing policy suggestions to improve adolescent health over a range of relevant topic areas, such as eating behaviors, physical activities, smoking behaviors, and mental health.

## 3 | DISCUSSION

The experiences from both the CO-CREATE project and the HBSC study demonstrate that parental consent practices vary substantially across Europe, North America, and western Asia both in terms of modes required (active or passive) and the minimum age of the adolescents for whom parental consent is required. This variation constitutes a clear obstacle when doing international research as the possibility of achieving a representative sample varies substantially and thereby challenges the comparability of the samples across countries. It would be beneficial to writing policy recommendations based on international research if countries would apply the same minimum age for when adolescents themselves can provide their own legal consent, that is, independent of their parents. Previous research and experiences from the HBSC study show that the requirement for active parental consent for children and adolescent participation in research projects can decrease general participation and, in particular, participation of those from the lowest socioeconomic group.<sup>13,18,19</sup> The latter represents a challenge for achieving a representative sample and thereby an adequate basis for the development of policies and interventions to meet challenges or recommendations identified by the research projects.<sup>2</sup>

The requirement for parental consent for adolescents' participation can limit not only the representativeness of the experiences shared by adolescents but also their right to share their views and experiences regardless of parental consent.<sup>2</sup> Thus, the generic requirement for parental consent up to age 15 or 18 years means that a large group of adolescents is deprived of their rights and the opportunities to share their views and contribute to research and policy development of relevance to their age group independent of the approval of their parents. Given their level of cognitive capacity, adolescents could be granted autonomy on the decision to consent to participate in research from a younger age than 15–18 years of age which is the current practice.<sup>2,17,24,25,48</sup>

Research on sensitive topics, such as sexual abuse or home violence, may not receive consent from parents involved in this abuse, and the adolescents affected would be prevented from sharing their experiences. In such cases, the representativeness of the findings may be limited. It is therefore pertinent to discuss whether the requirement for parental consent could be considered a violation of the rights of children and adolescents set out in the UNCRIC,<sup>4</sup> in particular article 13.<sup>2</sup> Another issue to consider is the privacy of adolescents involved in research.<sup>2</sup> Privacy is particularly relevant when the research topics are sensitive, such as adolescent sexual behavior or sexual orientation. Adolescents may wish to share this information for

research and policy purposes but may be averse to participate if it led to questioning by their parents because of the research topic.

The protection of the rights of children and adolescents to share their experiences while retaining privacy from their parents should however be evaluated against the potential risk or harm involved in participating in a research project. Historically and in the UNCRC, parents are given the responsibility for protecting their child from becoming involved in activities that are not beneficial or may be harmful.<sup>2</sup> Research demonstrates that parents generally want to decide which research activities their child participates in and tend to prefer active over passive parental consent. However, parents increasingly accept passive consent for focus group interviews and surveys from the age of entering secondary school, which is typically from the age of 12–13 years of age.<sup>49</sup> Given this point of view, they might also agree to letting their child have the right to legal consent from a lower age than current research practices provided that procedures are in place to protect their child from experiencing harm in research participation.

Lowering the age of child and adolescent consent may resolve some of the issues described above. However, a balance is needed between the empowerment of children and adolescents to participate and the protection of these young people when needed. In other words, it may be a violation of the UNCRC if children were allowed to freely voice their opinion before they reached a level of maturity when they fully understood the consequences of what they were saying. Similarly, it may be a violation of the UNCRC if children are not able to voice their opinion after they have reached a sufficient level of maturity.<sup>7,50</sup> This need for balance may depend on the sensitivity of what children and adolescents are asked to express their opinion about, that is, the more sensitive the topic, the greater the need for protection.

Respecting the rights of the children and adolescents to have their voice heard and simultaneously protecting them from harm are key to ethical research practice. The evaluation of a study's potential harmfulness should be undertaken by ethics committees. These committees evaluate whether the research project follows established codes of conduct in research (see, e.g., The European Code of Conduct for Research Integrity<sup>51</sup>). Before approving a research project, an ethics committee will evaluate five ethical principles of data collection<sup>52</sup>: (1) voluntary participation, (2) informed consent, (3) anonymity, (4) confidentiality, and (5) potential for various types of harm. In particular, the potential for psychological harm relates to protection of the participant's privacy, the sensitivity of the topic researched, the questions asked or the activities invited to participate in, and to what extent these may trigger negative responses such as emotions of shame or anxiety. Social harm relates to any perceived risk, embarrassment, or stigma. Physical harm relates to pain or injury that may result from the study activities. Legal harm relates to the consequences of reporting sensitive data that could lead to legal risk or violation of privacy. How the project deals with the information, privacy, and sensitivity of the topic and, therefore, the potential harm of participation in terms of psychological, social, physical, and legal issues will determine whether the ethics committee will require consent from the parents or only from the participating child/adolescent.

Given the reflections described above, we suggest that research projects that are identified by an ethics committee as not being harmful for children and adolescents could be opened to children older than age 12 years to give their legal consent to participate. This would be consistent with the UNCRC's identification of age 12 years as an appropriate age for giving weight to children's own perspectives about a decision that relates to them.<sup>4,5</sup> Such an approach is also consistent with a suggestion by Hein et al.,<sup>53</sup> who suggest, based on the application of an assessment tool, that children as young as 12 years should be allowed to decide on their participation in clinical research. Perspectives from developmental psychology also underscore that children and adolescents are more mature in terms of their cognitive capacity, which is needed to evaluate their participation in research, than many of today's consent restrictions indicate. However, despite some variation, the current age for adolescent approval is a conservative measure of 15/16 years of age.<sup>2,25,48,54</sup> Mathews<sup>2</sup> has identified that there is no requirement in law requiring a parent to give consent for an adolescent's participation in research within the topics typically covered by the disciplines of social science, including health studies based on lived experiences.

We therefore suggest that international principles on the age of legal consent for adolescents that can be applied by all countries in Europe and beyond should be established. Further, principles on how to prevent harm from research participation should be included. These principles might become part of the UNCRC for identifying the requirements for children and adolescents to be able to consent their participation in research from the age of 12 years. In general, the UNCRC should preferably address the rights of children and adolescents to share their views through research participation as a way of providing influence for the societal good through national and international development of policy and interventions. In some countries, the national UNCRC committee has commented on the importance of developing toolkits for consulting children on policy developments that affect them.<sup>55,56</sup> Consultation processes typically involve few children, and we believe that the general population of children and adolescents should be allowed to influence who represents them, for example, through youth parliaments. To provide full representation of the child and adolescent population, we recommend that the UNCRC should note the importance of consultation and research processes that invite larger groups of children and adolescents to share their experiences, including representative samples on the regional or national level, rather than a few individuals selected to represent their age group.<sup>2,17</sup>

If lowering the age of child and adolescent consent to 12 years, we recommend that, in addition to the condition of competent ethics evaluation, a systematic child and adolescent perspective on research should be required when developing research projects.<sup>15,33,57</sup> Based on the experiences from the CO-CREATE project and the HBSC study, we strongly recommend that adolescent representatives sit on the board of the study and are invited to influence on both the content of the study and the data collection procedures. This way, we can work to ensure that adolescents' needs and interests are considered in the research project. Further, both the ethics committees and the researchers should emphasize having procedures in place when



unexpected experiences from participation in a research project or activity occur.<sup>58</sup> This could include setting up a call line to a relevant health service to talk to a professional about their experience and training researchers as well as adult stakeholders who participate in dialog with adolescents on how to achieve power balance and perceived equity on part of the adolescent participants. From the CO-CREATE project, we experienced that close collaboration and continuous dialog with the adolescent research participants is vital for them to feel empowered and secure in the setting.<sup>31,33</sup>

Competent ethics evaluation further requires that the ethics committee is trained in developmental psychology in terms of children's and adolescents' cognitive capacity and where the limit of distress needs to be set.<sup>59</sup> This training should also address relevant adolescent participatory processes and participant perspectives in a study. Preferably all ethics committees should also include representatives with expertise in the developmental capacity of children and adolescents as well as representatives from adolescence when projects are targeting their age group. A research study that clearly communicates awareness of children's and adolescents' perspectives and how these have been considered in the study, preferably by collaborating with the target group, is also more likely to not represent a threat. This would be consistent with principles established for collaborative research involving young people, and which were also applied in both the CO-CREATE and HBSC studies.<sup>14,15,57</sup>

In research projects in which children and adolescents themselves can decide to participate without requiring permission from their parents, it is vital that the information about the research project's purpose, focus, implications of participation, and financial framework is clear and accessible to the child or adolescent so that they can make an informed choice when deciding whether to participate. Experiences from researchers working with younger children<sup>12,54,60</sup> may be helpful in this regard. These researchers can provide excellent guidance on supporting children and adolescents in their decision by using photos, drawings, and narratives that are more accessible to children than plain descriptive text, which currently is frequently used to inform participants in research studies, including children and adolescents.

Both the CO-CREATE and HBSC studies sought collaboration with young people in the design of the study. Both studies have emphasized the provision of clear information to the participants on what the project is about, what participation implies, and avoidance of a focus or questions that could lead to psychological, social, or legal harm. No potential physical harms were identified in any of the projects. We therefore believe that the CO-CREATE project could have approached age groups younger than 16–18 years as initially desired and applied adolescent consent for these younger age groups. For example, in the CO-CREATE project, no questions on a participant's height or weight were included to avoid perceived stigma related to the project's topic of preventing overweight in adolescents. Instead, the questions focused on the adolescents' sense of their capability to achieve change at the societal level through own initiatives to influence policy development.<sup>43,44</sup>

The strong focus on youth-led participatory research in the CO-CREATE study is another argument for allowing participants as

young as 12 years that could have been granted legal consent to participate in the project. Given CO-CREATE's content and close collaboration with youth throughout all steps of the design development and the study's activities and the sensitivity given to the participants' responses, we argue that there was no potential harm to the participants. To the contrary, we found that they experienced the participation as stimulating their agency and influence on policy development relevant for their age group in a way that was consistent with the principles of youth-led research and the right to have their voice heard.<sup>2,14,15,32,33,57</sup> Our fieldnote data showed that the adolescents' ability to withdraw at any time and to negotiate partial participation in a cocreative setting worked.

More research is needed into how children and adolescents from the age of 12 years experience their participation in research and what can be done to ensure that research becomes a way for young people to influence the development of policy and intervention through their research participation and where they feel empowered to not participate or withdraw should they want to. For such research to be successful in identifying young people's experiences, the adolescents should be invited as stakeholders when designing the research project as well as disseminating the findings. We recommend that the design process includes both the researchers' and participants' perspectives so that the representation of young people ensures the integration of their interests as well as those of the researchers and that this extends to the recruitment processes, including who is recruited and how. Respecting children's and adolescents' needs and interests in these processes is vital to meeting the objectives of ethical research and the UNCRC, where the best interest of children and adolescents should always guide decisions and there is a clear emphasis on the management of the power imbalance between child and adolescent stakeholders/participants and adult researchers.<sup>7,15,31–33,42,57,61</sup>

## 4 | CONCLUSIONS

Today's research practices vary widely across nations in terms of the age limit and ethical conditions required for children and adolescents to provide their consent for participation in research independent of their parents. Consistent with the UNCRC, a balance is needed between children's and adolescents' rights to have their voice heard through participation in research and policy development and the need to protect them from harm. The CO-CREATE project and HBSC study have demonstrated the importance of adolescent participation because both projects have been a key to policy development for adolescent health and well-being. Looking at the experiences within CO-CREATE, we also see that adolescents are perfectly able to voice their concerns and renegotiate participation and consent in the process. We propose that children and adolescents from the age of 12 years should be able to give their legal consent to participate in research studies in social and behavioral sciences provided that the ethics committees cannot identify any harm for them in their participation and that the research approach has a clear integration of children's and adolescents' perspectives and needs, preferably as a collaboration with representatives from the target group. For this to

be a viable approach, ethics committees should be trained in the needs, perspectives, and cognitive capacity of children and adolescents. A representative with competence in this area should be included in the ethics review process where possible. We also recommend that young people are represented on ethics committees. International principles should be set for both minimum age for consent and the evaluation of potential harm.

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## CONFLICT OF INTEREST STATEMENT

No conflict of interest statement.

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