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PANEL
Ethics in Research with
Children and Adolescents in Times of COVID-19

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Panel Abstract

The United Nations Convention on the Rights of the Child (1989) emphasizes that children must participate in shaping decisions that affect them, including through research and evaluation. However, children are often considered a *vulnerable* population at risk of exclusion from evidence generation and decision-making. By preventing children from participating in research, not only may their rights be violated, and children excluded from the benefits of research, but society at large misses out on their insights to better respond to their needs. This inequity was heightened globally in times of pandemic. Some researchers have been exploring ways to meaningfully involve young people in studies and initiatives aimed at improving children's lives. This session will (a) present cases from nine countries and reflect on the ethical challenges and opportunities experienced, and (b) engage the audience in the discussion of best practices to ethically involve young people in research in times of pandemic.

Individual Papers

1. **Ethics of Relationality in Research with Young People During COVID-19**

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- **Thematic importance:** The COVID-19 pandemic has had significant impact on children and adolescents, yet many policy and program responses do not reflect children's priorities. To inform policies, programs, and risk mitigation strategies in future outbreaks, researchers need to obtain children's perspectives and priorities in relation to their needs and fulfilment of their rights during the pandemic. This must be done balancing children's rights to protection and participation and with special attention to the best interests of children and to their local contexts.
- **Introduction and objectives:** Institutional Ethics Frameworks and Guidelines for research involving children in emergency situations exist to guide researchers and to prevent negative outcomes for children and communities. However, research ethics processes are not always ethical and critical disconnections remain between those frameworks and how research is conducted in the field. Researchers have planned and conducted studies to better understand children's lived experiences during the pandemic. This presentation maps out the ethical tensions that emerge as researchers negotiate the challenges of balancing ethics committees' requirements with actual fieldwork processes in local contexts, with emphasis on power relations.
- **Method:** Critical considerations in child-focused studies and interventions in COVID-19 are outlined following Berman's (2020) post-emergency guidelines

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[which include institutional capacity to involve children in research ethically; understanding and managing power relations; informed consent; privacy and confidentiality; weighing harms and benefits; compensation; and appropriate communication of findings.] The authors draw primarily on their own field xperiences from research conducted with young people in Italy, Canada, Madagascar, Namibia, and Lesotho in 2021 and 2022.

- **Results**: Engaging and building trusting relationships with children, communities, and local gatekeepers and addressing the asymmetries in power relations between researchers, with children, their families and communities, may be hindered by unequal access to resources, physical distancing, and other public health measures. Responsiveness to local needs and priorities requires familiarity with local politics, power dynamics and relationships. Whenever possible, collaboration with young people and communities need to begin upon inception of research projects in order to mitigate risks during actual data collection. To nurture safe and respectful relations, it is crucial to treat young people as equal partners, commit to frequent and transparent communication (online and in-person), and diversify methods, including in research dissemination phases. To ensure the inclusion of children with low socio-economic backgrounds, in remote areas and with no access to the Internet, alternative ways to engage with them and their communities prior and during the start of data collection is crucial. Participatory, creative, and visual methods can facilitate engagement and dialogue, also in the absence of a long-term relationship. Additional reflections may be needed when researchers themselves experience the crisis while investigating its effects on their research participants.

- **Conclusions and implications:** Ethical research is produced through negotiated spaces and continuous reflexivity that are centred on relationships between researchers, study participants, and communities. Researchers need to critically examine issues of positionality and power and minimize power differentials and dynamics with and within families and communities, and in relationships with and between children.

2. **Ethical considerations in research and action with children and youth in times of COVID-19 pandemic**

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- **Thematic importance**: Questions of the ethics of children's right to participation were underlined during the COVID pandemic. Research shows that children and young people have fewer emotional tools to deal with the new realities such as social distancing. They are heavily impacted by the failure of children's services to respond to the demands of the pandemic. This is evident in education, welfare, health systems, but also in the justice system.

- **Introduction and objectives:** This presentation focuses on ethical considerations from research and in observations of the implementation of new policies. The analysis stresses a rights-based approach to child and youth involvement in public policies from two perspectives. The first analyses research carried out since 2018 involving young councillors at the Children's Rights Council of Volta Redonda, Rio de Janeiro, and their activism in the Youth Forum of the Sul Fluminense in Action (FJSFA), a

social movement led by young people in the city. The second examines the challenges within the justice system as it adapts in a child-friendly manner, specifically during the pandemic, to respecting children´s rights.

- **Method**: The study on young people's activisms is based on an ethnographic examination of the experience of young people appointed as councillors from 2018 to 2020 in the Children's Rights Council of Volta Redonda and their protagonism in the Youth Forum during the pandemic in 2021. The court study was based on analyses in 36 countries on judicial improvements to adapt structures and proceedings to enable children to participate in the decision-making process in all matters that affect them. These challenges are increased in the pandemic, despite changes to enable the continuity of judicial activities, organizing on-line hearings and virtual courts, which could enable child participation in judicial systems. If digitalization has resulted in in better and speeder access for many including children, those systems maintain a managerial ethos which inhibits participation.

- **Results**: The research conducted with young researchers during the pandemic faced limitations such as lack of stable internet access to conduct interviews and also to disseminate the results of the study. It also intensified some ethical challenges such as the guarantee of anonymity of the interviewees since adequate spaces were not always possible for the youth involved. The young people affirmed that they had made gains personally and socially from participation. It is not clear what impact they had on actual decisions of the Council. The young people did, however, win some important potent procedural changes. The research on judicial systems from a number of countries shows that changes in those systems still do not provide enough support for children to have their views sufficiently weighed in court decisions.

- **Conclusions and implications:** There now exists a new seed of youth participation in decision making forums started in Volta Redonda with the possibility of spreading the model to other cities. Changes within the justice system question how abstract consideration of individuals permits inequality, due to unequal digital inclusion, the diversity of socioeconomic realities, and the devaluation of face-to-face contacts with children.

3. Considering the ethical implications of conducting youth-led research into vaping during the COVID-19 pandemic

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- **Thematic relevance**: Adolescent vaping had become a major public health concern in British Columbia, Western Canada prior to the COVID-19 pandemic. A youth-led study to explore vaping during the pandemic raised ethical considerations about the use of a Youth Participatory Action Research approach during a public health crisis.

- **Introduction and objectives:** In 2018, results from the population-level BC Adolescent Health Survey showed that 27% of BC youth aged 12 to 19 had vaped in the month prior to taking the survey. Public health officials were concerned that vaping among this age group would be exacerbated by the pandemic, and the sharing of vaping devices would increase the risk of cross infection. A local community-based research organization (McCreary Centre Society) was commissioned to conduct a study, and chose to take a Youth Participatory Action Research approach.

- **Method**: A group of 28 youth researchers were recruited and trained from diverse communities across BC to co-develop and deliver online surveys to their peers. The study included survey respondents aged 12 to 19 from across BC and was comprised of three different online surveys. The first survey was available three months after physical distancing regulations came into effect in BC (June 2020; 1,120 surveys were completed), and subsequent surveys took place in September 2020 (686 surveys) and December 2020 (1,774 surveys). The youth researchers met regularly from May 2020 to January 2021 to develop survey items; review and provide context to results; and discuss dissemination strategies. The researchers shared each wave of the survey with their peers through various social media channels, such as Instagram and Facebook, as well as through their class 'chat' and school websites.
- **Results**: Over 3,500 surveys were collected and results showed that youth were more likely to have stopped vaping or to have vaped less since the pandemic started than they were to have vaped more or to have started vaping. However, among youth who vaped daily, 75% had their first vape within 30 minutes of waking up, including 34% who had their first vape within five minutes of waking up. Most youth who vaped (93%) had shared a vaping device, including 56% who shared one during the pandemic. Youth who vaped were less likely than those who did not vape to trust health officials and adults in their life (such as teachers) for health-related information. Ethical considerations raised by the project included how to ensure safety and support for researchers and participants remotely; how to ensure data collection followed current public health protocols; how to ensure the survey was accurately capturing current issues; how to support participants who reached out for help with their vaping; and how to keep the youth researchers meaningfully engaged post-data collection.
- **Conclusion and implications:** The results highlighted the important role of youth researchers and their ability to successfully develop appropriate indicators and reach their peers during a public health crisis. The success of the methodology and findings raised a number of ethical considerations which can help to inform Youth Participatory Action Research moving forward.

4. University ethics procedures versus ethics of doing research

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- **Theme:** This paper considers ethical learnings in youth-led research undertaken in Brazil and India, as part of the project 'Shaping Youth Futures: Youth livelihood options in creating inclusive cities.' The paper addresses the two conference themes on innovations in research design and impacts of COVID-19 by examining the ethical procedures of doing research with young people during the pandemic.
- **Introduction:** This paper reflects on negotiating these formal ethics requirements and on-the-ground issues when undertaking the research during COVID-19. We ask the question: Who is being safeguarded, from what and what are the (unintended) ramifications of this? Apart from safeguarding research participants, institutional

ethics processes also safeguard universities. In doing so, ethical "norms" of doing research are perpetuated, which are developed by academic institutions and exist outside the cultural contexts of the research. We discuss the ramifications of this and look at who carries the burden of doing these formal procedures.

- **Methods:** This project is a collaboration between partners in the UK (as lead partner), Brazil and India, with partners including universities, NGOs and government bodies. The research project involves co-production with young people aged 15 to 26 years, across two countries. Young people advise and co-research projects on youth livelihoods in their cities using interviews, focus groups and surveys. Multi-institutional ethics approval was required before research commenced.

- **Results:** Current institutional ethical processes pose limitations to international co-produced research with young people in various ways: (1) the requirement for one ethics application submitted prior to project commencement is incompatible with co-produced research, where research design is developed over time; (2) lengthy procedures, with time delays, place a burden on partners in the majority world in terms of paperwork and added complexities to project management; (3) the process tends to rely on access to digital technology irrespective of location and context; (4) the default position requires anonymisation of youth as a form of 'protection', when in fact young people in co-produced research may want recognition for their contributions. Through this project, the dissonance between formal institutional ethics procedures and community-based research practices became increasingly apparent. This was further exacerbated by institutional risk-related restrictions placed on research projects in response to COVID-19. Exceptional requests were needed to continue, particularly for in-person research (rather than digital). With the requirement to follow regulations set out within lead partner institutions, there was little consideration of practitioner- and community-based research, which fit within the everyday activities of local people. Nor was there flexibility in taking the changing COVID-19 policies in different contexts and countries into account.

- **Implications:** Further research is needed on how robust ethical approvals can consider co-produced research, in effective and efficient ways. With growing research in the majority world (funded by the minority world), the expertise of experienced local civic society organisations in ethical research and safeguarding needs to be recognised. Especially considering the pandemic, it is pertinent to reflect how partners with local experiences of community residents, organisers and organisations can be better supported rather than encumbered by norms set by external institutions.