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Editorial

Embracing creativity in child and youth health research: Using participatory video to engage young people in rights-based research

There are almost 2.4 billion children and young people (CYP) under 18 years of age in the world being approximately 30% of the global population (Foster et al., 2023; UNICEF, 2023b). This number is important to acknowledge because health outcomes for many CYP are decidedly poor. Whether CYP are facing illness, injury or the prevention of either, CYP are inherently users of and reliant upon relationships with their local and national health care systems (Asher et al., 2023; Garner & Yogman, 2021). The reasons for CYP's poor health outcomes are multifactorial, but have distinct corelations with poverty, marginalisation and future adult manifested disease (Trent, 2022). Negative outcomes are also exacerbated for CYP because of the layering of discriminatory effects which include ethnicity, socioeconomic status, parental beliefs, social standing, gender, and age (Johnson et al., 2013).

Over the last decade, there has been a growing awareness of young people's capacity to offer unique insights into research and policy development (Coyne & Carter, 2024). Yet in many countries and circumstances, there is still a notable hesitancy when it comes to welcoming CYP's views on policy and issues that affect them. CYP's inclusion is frequently overlooked by clinicians and policy makers, where decisions are made by adult proxy—assuming adults know what children are thinking and experiencing (Coyne & Carter, 2024). Ethics committees can also inadvertently sideline CYP's voices in the name of "protecting" them from perceived risk and potential harm. Denying CYP's inclusion in research based on potential risk or harm marginalises CYP disregarding any consideration of resilience or potential for collaborative outcomes. Any systematic approach that leads to the inability for young people to engage and participate, is antithetical to their well-being—a paternalistic approach that denies young people the possibility of contributing to positive changes in the world. This is contrary to the rights granted to all CYP in the UNCRC (1989), which are explicit, and outline the necessity for CYP's inclusion and participation on all things that affect them (Scottish Alliance for Children's Rights, 2021).

In the face of news reports and social media, it is easy to list many things that CYP are vulnerable to such as illness and injury, climate change, ecological degradation, indoor and outdoor pollution, addictive substances, food security, access to education, exposure to violence, self-harm and mental health issues (Maxon et al., 2021; UNICEF, 2023a; United Nations Children's Fund, 2021). However, as child health researchers and advocates, we believe that it is important to balance perceived vulnerabilities with the resilience and resourcefulness that CYP demonstrate. Pieloch, McCullough, & Marks (2016) state that it is important to focus on children's experiences through a lens of recovery and resilience rather than simply potential for risk and harm, as it can bring a more complete picture of young people's lives.

Despite universal ratification of the United Nations Charter on the Rights of the Child (UNCRC, 1989) young people continue to be overrepresented in poor health outcomes and underrepresented in the process of exploring issues to develop tangible solutions to problems. Of concern, New Zealand has the world's second highest youth suicide rate including high truancy, low immunization, poverty, poor housing, food insecurity, and poor mental health outcomes for children (Asher et al., 2023). However, the Council of Europe's (2024) Steering committees recognized the necessity of CYP's inclusion and recently released a comprehensive guide to children's participation in health care decisions that highlights work being done to include children in Europe policy development and healthcare provision. Building on the Council's previous handbook on participation (Crowley, Larkins, & Pinto, 2020), there are a repository of programs and initiatives such as the international ISupport Group who together with CYP, developed rights-based standards for children undergoing clinical procedures (Bray et al., 2023). CYP's voices were integral to the inception and consultation on the standards and the aforementioned guide provides numerous other examples that exemplify the principles of the UNCRC (1989), offering solutions for those ready to commit to "gold standards" of inclusion of CYP. The use of CYP's narratives and storytelling has become an increasingly common strategy in grassroots organising and advocacy efforts aimed at influencing policy change (Moyer et al., 2020). As child and youth health researchers in New Zealand, we acknowledge the progress in Europe as we try to emulate it through our use of participatory video with young people.

Participatory research methods are often used by researchers who wish to engage with communities who are most vulnerable and whose voices are least heard (Lamb et al., 2021). The underlying philosophy of participatory methods is that participants are experts in their own situations, and do not need 'others' to define or represent them, only help to facilitate their expression (Asadullah & Muniz, 2015; Benest, 2010; Lunch & Lunch, 2006). However, participatory approaches can be challenging, time consuming and require careful consideration of the power differential between the researcher and participant, and between participants themselves (Blazek, 2017). Including young people in the process of providing their perspectives on their health and wellbeing supports their active participation in decision making rather than simply treating them as passive recipients.

Participatory video is best considered as a process of involving a group or community in analyzing issues and facilitating the creation of films according to their sense of what is important to them and how they wish to tell their stories (Asadullah & Muniz, 2015; Mistry et al., 2016). Participatory video can enable participants to show

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and tell their insights, connecting with external audiences who can then potentially affect social change (Shaw, 2017). There is now greater availability and affordability of digital technology which brings with it the potential for researchers to apply it more readily within participatory research methods. Our experience as participatory video facilitators has shown CYP are fully capable of critically analyzing their experiences and the world around them. They can use both literal and metaphorical lenses to capture their ideas and aspirations, and show others what, and how, they can contribute to improving their own lives and the lives of other young people (Neufeld & Ripley, 2024). The new knowledge generated by participatory video is easily shared using digital spaces that CYP are already living within, amplifying their impact by presenting perspectives and ideas in their own literal voices. In this way, participatory video can engage and inform those not served by conventional research methods and academic literature.

While we acknowledge the view that participatory research with CYP can be "hard and difficult" to undertake, we also point out that many treatments and health care procedures with children are in fact "hard and difficult". Yet these 'tasks' are done with absolute commitment, skill and efficiency. We encourage all CYP researchers, policy makers and professionals to consider the benefits of participatory video or other creative participatory methods as a means of collaborating with CYP to incorporate their input into decision making processes for health care policy and provision. In so doing, this will enable CYP to be engaged as active citizens, sharing expertise regarding their own lives and the ways in which they are lived.

Declaration of competing interest

None.

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Michael Neufeld
Auckland University of Technology, School of Clinical Sciences, 90 Akoranga Road, Northcote, Auckland, 0627, New Zealand
*Corresponding author.
E-mail address: michael.neufeld@aut.ac.nz

Paul Ripley
Auckland University of Technology, School of Clinical Sciences, 90 Akoranga Road, Northcote, Auckland, 0627, New Zealand
E-mail address: paul.ripley@aut.ac.nz