



Commentary

Youth Participation in the Health Behaviour in School-aged Children Study



Colette Kelly, Ph.D., M.Sc.^{a,*}, Cátia Branquinho, Ph.D.^b, Anna Dzielska, Ph.D.^c, Margarida Gaspar de Matos, Ph.D.^b, Marina Melkumova, M.D.^d, Daria Pavlova, Ph.D.^e, William Pickett, Ph.D.^f, and Saoirse Nic Gabhainn, Ph.D., M.A.^a

^aHealth Promotion Research Centre, NUI Galway, Ireland

^bFaculdade de Motricidade Humana, University of Lisbon, Lisbon, Portugal

^cDepartment of Child and Adolescent Health, Institute of Mother and Child, Warsaw, Poland

^dArabkir Medical Centre-Institute of Child and Adolescent Health, Yerevan, Armenia

^eUkrainian Institute for Social Research, Kyiv, Ukraine

^fDepartment of Public Health Sciences, Queen's University School of Medicine, Kingston, Ontario, Canada

Participatory research approaches emerged in the 1970s and have gained growing recognition since. Today, active public involvement in research is a fundamental aspect of many publicly funded research programs. As a consequence, frameworks, principles, and standards for involving the public have emerged [1,2]. The adoption of the United Nations Convention on the Rights of the Child 1989 [3] focused attention on youth participation in particular. In this Convention, article 12 states that children and young people should have their opinions taken into account in all major decisions affecting their lives. This applies to child health research, which is likely to affect knowledge generation, service provision, policy developments, and professional practice related to children's lives.

Youth participation refers to their active participation and real influence in the decisions that affect their lives, not to their token or passive contribution. Participation quality is measured by not only its scope but also its effect, when youth effect the process, influence a particular decision, or produce a more favorable outcome. Traditionally, children's and young people's role in research has been viewed as a "resource." However, participatory research engages youth to do more than give responses to research instruments designed by adults. These methods explicitly concern power within the research cycle and the

importance for research to be both empowering and health promoting [4]. Ethical principles and tensions that arise in real-world contexts are also at the fore of research involving children and youth participation [5].

To date, much work has focused on the involvement of youth in the design and implementation of programs and policies that affect them and their peers; and their engagement is now seen as an essential element of practice. Models and frameworks have been developed to better understand youth participation [6]. Meaningful engagement, with effective and appropriate structures and supports, leads to healthier, more just, and egalitarian communities [7]. The rights-based or empirical rationales for involving youth are viewed by Ozer et al. [8] as complementary but they also call for more systematic evidence about the fundamental process involved and the documentation of associated outcomes. Gal (2017) [9] proposes an ecological model for understanding the ability of children and youth to participate meaningfully in decision-making processes. This ecological model draws on existing theoretical and empirical writing on child participation [9]. The Lancet Commission on Adolescent Health and Wellbeing provided an overview of youth engagement and health and proposed a conceptual framework of the essential elements in meaningful youth engagement with due consideration to the barriers [10].

The HBSC network considers it essential to actively involve youth in research that is relevant to them. We have developed a range of research methodologies designed to facilitate active participation of young people in the research process. Young people have been involved in data generation, devising research themes and questions, data analysis, data interpretation and dissemination, and advocacy initiatives developed on the back of research findings.

Disclosure: This supplement was supported by the World Health Organization European Office and the University of Glasgow. The articles have been peer-reviewed and edited by the editorial staff of the Journal of Adolescent Health. The opinions or views expressed in this supplement are those of the authors and do not necessarily represent the official position of the funder.

Conflicts of interest: The authors have no conflicts of interest to declare.

* Address correspondence to: Colette Kelly, Ph.D., M.Sc., National University of Ireland, Galway, University Road, Galway H91TK33, Ireland.

E-mail address: colette.kelly@nuigalway.ie (C. Kelly).

Youth participation in the HBSC network

Building partnerships and collaborations with young people is essential to the work of the HBSC network and we recognize that children have a unique “insider” perspective critical to our understanding of their worlds [11]. The efforts are underpinned by a youth engagement strategy with specific goals, with a dedicated youth engagement advisory team. We strive to involve youth in our biannual meetings of the HBSC international network, and at the 30th anniversary meeting in Scotland (2013) we had a dedicated youth participation day with 24 young people from five countries (Canada, Ireland, England, Scotland, and Wales). The development of appropriate methodologies for actively engaging children and young people is crucial to improving our work in this area, and such developmental work requires sharing emerging practices and challenges in the search for improvements in research practice.

How HBSC works with young people

The young participation initiatives undertaken by the HBSC member countries have involved adolescents in the research cycle in different ways, giving due consideration to financial and organizational resources. Children and adolescents have been engaged in setting the research agenda and developing questionnaire items (e.g., Ireland and Canada), while some countries have also involved youth in field work and data collection processes (e.g., Armenia) and in producing reports and outputs for youth by youth (e.g., Scotland and Canada) [12]. Involving youth in interpreting and disseminating findings to a range of stakeholders (e.g., teachers, politicians, and other young people) is becoming common practice for HBSC countries. Examples of specific initiatives that illustrate our range of activities and the partnership approach to youth engagement are presented in the following Box.

Summary

HBSC aims to drive youth participation as standard in adolescent research and to provide data that are meaningful to young people, are reflective of current lifestyles, and are of value to policy and program development. Further to significant benefits within the research process, the active and meaningful involvement of young people results in important and positive impacts on youth themselves. Underscoring our commitment to young people across all participating member countries, we work within the HBSC network to collaborate in theorizing on relevant issues in youth participation, cocreating participative research methodologies, supporting one another in the application of theory, and method and promoting opportunities for dissemination and debate.

Youth engagement in HBSC forms a unique combination of integrated knowledge translation and Public and Patient Involvement in health-related research, drawing on elements of both of these approaches. Evidence of impact on policy and practice has been clearly demonstrated, but challenges remain in convincing research funding bodies, journal editors, and some researchers that engaging youth is of sufficient value and interest.

Examples of Youth Engagement Initiatives Among HBSC Countries

CANADA

The Students Commission of Canada, the Centre of Excellence for Youth Engagement has been working with the Public Health Agency of Canada to support youth engagement on the HBSC study. Young people from across Canada have provided direction about established and newly emergent priorities surrounding their health. This was used to prioritize the introduction of optional survey items to the Canadian survey. A series of youth-centered events, workshops, activities, and youth-generated videos/materials that engaged with the HBSC study findings have also been developed.

IRELAND

The HBSC Ireland team worked in partnership with the national government Department of Children and Youth Affairs and facilitated a series of participative research workshops with young people on all aspects of the HBSC research cycle. Questions were specifically developed by young [13] people and have been used in the last two survey rounds of data collection in Ireland. Some of these youth-developed items have been adopted as national indicators of progress for the national policy framework for children in Ireland the “Better Outcomes, Brighter Futures” strategy [14]

POLAND

By invitation of the First Lady of Poland, a Debate entitled “*Experts ask youth*” was conducted at the Presidential Palace of the Republic of Poland. Young people (n = 250) from all over the country participated in workshops to debate and explain Polish HBSC results and to prioritize areas for action. Moreover, essential to these debates were framing young people as equal stakeholders with health experts, politicians, and the media [15]

PORTUGAL

Dream Teens (<https://www.dreamteens-en.aventurasocial.com/>) aims to enhance both Portuguese young people’s involvement and social responsibility through an active citizenship process. Using Youth-led Participatory Action Research, and social media as a tool for engagement, this national network aims to make these teens’ lives visible by giving them “voice” and increasing their social and civic participation in issues such as health [16].

UKRAINE

In Ukraine, a strong collaboration with the Junior Academy of Sciences of Ukraine, a nongovernment organization, enabled youth to choose priority topics for the HBSC 2018 Ukrainian survey. Online platforms, such as U-report (<https://ureport.in>) and Knowledge Center (<http://knowledge.org.ua>), have been used successfully to engage youth and disseminate findings to health professionals, respectively.

Acknowledgments

HBSC is an international study carried out in collaboration with the WHO/EURO. The International Coordinator is Dr Jo Inchley, University of Glasgow, UK, and the Data Bank Manager is Professor Oddrun Samdal, University of Bergen, Norway. The authors thank and acknowledge the contributions of past and present members of the HBSC Youth Engagement Advisory Group. The HBSC survey is conducted by principal investigators in 50 member countries. HBSC teams are funded by government organizations within their own country. For details, see <http://www.hbsc.org>.

References

- [1] INVOLVE. Better public involvement for better health and social care research. Available at: <https://www.invo.org.uk/wp-content/uploads/2019/11/UK-standards-for-public-involvement-v6.pdf>. Accessed March 13, 2020.
- [2] INVOLVE. Involving children and young people in research: Top tips and essential key issues for researchers. Available at: <https://www.invo.org.uk/wp-content/uploads/2019/10/Involving-children-and-young-people-as-advisors-in-research.pdf>. Accessed March 13, 2020.
- [3] United Nations Convention on the rights of the child adopted and opened for signature, ratification and accession by general assembly resolution 44/25 of 20 November 1989. Entry into force 2 September 1990, in accordance with article 49.

- [4] Wong NT, Zimmerman MA, Parker EA. A typology of youth participation and empowerment for child and adolescent health promotion. *Am J Community Psychol* 2010;46:100–14.
- [5] Walter T. Ethical issues in participatory research with children and young people. In: Coyne I, Carter B, eds. *Being participatory: researching with children and young people*. Cham: Springer; 2018.
- [6] Villa-Torres L, Svanemyr J. Ensuring youth's right to participation and promotion of youth leadership in the development of sexual and reproductive health policies and programs. *J Adolesc Health* 2015;56:S51–7.
- [7] Suleiman AB, Soleimanpour S, London J. Youth action for health through youth-led research. *J Community Pract* 2006;14:125–45.
- [8] Ozer EJ, Afifi R, Gibbs L, Mathur RT. Youth engagement and participation: Field-building across research and practice. *J Adolesc Health* 2018;63:671–2.
- [9] Gal T. An ecological model of child and youth participation. *Child Youth Serv Rev* 2017;79:57–64.
- [10] Patton GG, Sawyer SM, Santelli JS, et al. Our future: A Lancet commission on adolescent health and wellbeing. *Lancet* 2016;387:2423–78.
- [11] Kellett M. Small shoes, big steps! Empowering children as active researchers. *Am J Community Psychol* 2010;46:195–203.
- [12] Craig W, Pickett W, King M. The health and wellbeing of Canadian adolescents: Findings from the 2018 health behaviour in school-aged children study. Ottawa: Public Health Agency of Canada; 2020. 154p; 2020.
- [13] Daniels N, Burke L, O'Donnell A, et al. Expanding the role of young people in research: Towards a better understanding of their lives. *Public Health Governance* 2014;12:36–44.
- [14] Department of Children and Youth Affairs. *Better outcomes, brighter futures: The national policy framework for children & young people 2014 - 2020*. Dublin: Stationery Office; 2014.
- [15] Pierwszadama. Available at: <https://www.prezydent.pl/pierwsza-dama/aktywnosc/art,118,eksperci-pytaja-mlodych.html>. Accessed March 13, 2020.
- [16] Frasilho D, Ozer EJ, Ozer EM, et al. Dream teens: Adolescents-led participatory project in Portugal in the context of the economic recession. *Health Promot Pract* 2016;19:51–9.