Involvement of Children and Young People in Longitudinal Health Research

A knowledge-sharing exercise

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Abstract

This knowledge-sharing exercise with longitudinal cohort studies globally, driven by Generation Victoria (GenV) and the Born in Scotland (BiS) Data Trust, considered the involvement of children and young people (and/or their representatives) in the design and governance of health research. This paper builds on the broader literature, filling the gap of unpublished experience and providing insights into the strategies and learnings of consumer and community involvement for longitudinal research and birth cohort studies.

Keywords

CCI, PPIE, involvement, consumer, child, young people, longitudinal, birth cohort, health research

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Aboriginal acknowledgement

We acknowledge the Traditional Custodians of the land upon which we are situated. We pay our respect to their Elders - past, present and emerging

Executive Summary

Background

Consumer and Community Involvement (CCI) can strengthen research processes and impact by ensuring that research addresses community needs and enhances public trust and engagement. This extends to children and young people (CYP) who have the right and interest to be involved in decisions that affect them, including health research. This knowledge-sharing exercise, driven by Generation Victoria (GenV) and Born in Scotland (BiS) Data Trust, explores CCI with CYP in the design and governance of health research. Extending our earlier literature review[1] to unpublished approaches and experiences of longitudinal cohort studies, this paper aimed to explore 1) how studies are involving CYP and/or representatives, 2) what CCI approaches they have undertaken, and 3) their perceived benefits and challenges.

Method

We invited early life longitudinal cohort studies known to us to complete an online questionnaire or interview on their CCI with CYP and/or representatives. CCI was defined as research "carried out 'with' or 'by' consumers rather than 'to', 'about' or 'for' them", and 'consumers' in this context includes CYP and/or representatives as either study participants or community members. Questions were designed to assess domains similar to those captured in the earlier review. Responses and transcripts were analysed and summaries later reviewed by the studies themselves for completeness.

Results

Of the 12 studies invited, nine contributed to this knowledge-sharing exercise: 2000 Stories, Avon Longitudinal Study of Parents and Children, Born in Bradford, BRIGHTLIGHT, the Child to Adult Transition Study, Danish National Birth Cohort, Growing up in New Zealand, the Raine Study, and the Centre for Longitudinal Studies (representing a series of cohorts). There were 13 distinct CCI activities described.

The studies' CCI activities involved CYP (10-30 years of age) and/or adult representatives (such as parents/guardians). These consumers were invited to take part in CCI activities through indirect (eg generic callouts), direct (eg personal invitation) or community engagement channels, some with strategies for inclusivity and representation. Activities utilised hybrid modes of communication (eg online and face-to-face) and frequency varied.

Studies involved consumers in all stages of research, from agenda setting to dissemination and translation of findings, but most commonly in the design and application of data collection tools. Four CCI activities also involved consumers in different aspects of data access and sharing. Verbal and written methods were commonly used, primarily focus groups and advisory committees, and largely to facilitate consultation with consumers, often alongside other levels of involvement.

While acknowledging limited empirical evaluation, studies felt that CCI with CYP had numerous benefits: greater relevance of research, study retention and engagement, and social empowerment and professional development opportunities for consumers. No CCI activities were free of challenges, for example limited resources and time, maintaining engagement and ensuring accessibility. Studies shared their recommendations for future CCI, such as planning ahead with adequate resources, using flexible and tailored approaches, managing expectations while empowering agency through positive relationships, genuine action and recognition.

Conclusions

This knowledge-sharing exercise captured previously unpublished approaches and experiences of longitudinal cohort studies from CCI with CYP in health research. Strategies reported focused largely on involvement of adolescents and youth and/or their adult representatives, with CCI most commonly supporting research design and data collection through consultation in focus groups and advisory committees. Perceived benefits and challenges were complementary to findings from the published literature, providing an overview of learnings for CYP and representatives in longitudinal research and birth cohort studies such as GenV and BiS.

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[1] Wyatt K, Bell J, Cooper J, Constable L, Siero W, Pozo Jeria C, et al. Involvement of children and young people in the conduct of health research: A rapid umbrella review. Health Expectations. 2024;27(3):e14081.