

CONFERENCE ABSTRACT

Involving young people with a chronic condition in participatory research and implementation projects: what is the impact?

ICIC20 Virtual Conference – September 2020

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Introduction

Internationally, there is growing attention for participation of young people with a chronic condition (YPCC). As an important value of integrated care, participation promotes the inclusion of YPCC in decision-making that concern them. Research (e.g. scientific) and implementation (e.g. practice-oriented) projects aimed at improving their health and quality of lives are, therefore, increasingly carried out with rather than for them. Yet, high quality evidence of the impact of their participation is missing.

Methods

The dearth of evidence on impact of YPCC's participation can be related to a lack of shared understanding of what 'participation' entails and the absence of systematic evaluation methods. We have conducted a scoping review to map reported definitions, goals, activities, experiences and impact of YPCC's participation and possible shifts herein over time. Searches were conducted in five databases; twenty-three articles were included. Following the review, we initiated a study to quantitatively explore the relation between YPCC's participation in research and implementation projects and outcomes of these projects. Data were collected among project leaders of 17 participatory projects and 146 YPCC involved in these projects.

Results

The past decades, limited progress has been made in the evidence base on the impact of YPCC's participation. Our review has shown that, over time, definitions of participation continue to be broad and diverse and that studies report similar experiences and challenges time and again.

These findings have led to the initiation of the quantitative exploration mentioned earlier. Results show that 27 percent of the variation in project outcomes is a result of differences between projects. We investigated whether this variation can be explained by participation variables. One significant relation was found: when participating YPCC considered themselves important for a project, they experienced better project outcomes. This is in line with studies suggesting that YPCC experience personal growth, when they consider their role in a project meaningful.

Discussion

It is imperative that a consistent evidence base on YPCC's participation and its impact is built. This can contribute to the validity and reliability of participation by teaching us about what works for whom and under what circumstances.

Conclusions

Limited progress has been made in the evidence base on YPCC's participation and its impact. Our quantitative exploration provides insight into the relation between YPCC's participation and outcomes, but more research is needed to learn about effective participation.

Lessons learned

To move the evidence base forward, changes need to be made in how participation is studied. This includes building on previous work (instead of reinventing the wheel), defining and thoroughly reporting what is meant by participation and using systematic impact measurements.

Limitations

In the review, some articles may have been overlooked, due to the broad search string on chronic conditions and inconsistencies in how participation is defined. In the quantitative study, findings are based on a relatively small project sample.

Suggestions for future research

More well-reported research should be conducted that uses systematic and objective evaluation methods and builds on previous studies to improve the evidence base on the impact of YPCC's participation.