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Exploring the impact of patient and public involvement with young people with a chronic condition: A multilevel analysis

Femke van Schelven¹, Peter Groenewegen^{1,2}, Peter Spreeuwenberg¹ Jany Rademakers^{1,3}, Hennie Boeije¹

¹ Department Perspective of patients and clients in healthcare, Netherlands Institute for Health Services Research, Utrecht, The Netherlands

² Department of Sociology and Department Human Geography, Utrecht University, Utrecht, The Netherlands

³ Department of Family Medicine, Care and Public Health Research Institute (CAPHRI), Maastricht University, Maastricht, The Netherlands

Abstract

Background: Patient and Public Involvement (PPI) of young people with a chronic condition (YPCC) receives increasing attention. However, evidence of its impact is lacking. This study explores the impact of PPI on outcomes of projects in health and social care, using quantitative measures.

Methods: Data were collected from projects funded by a 4-year participatory program addressing the social position of YPCC. These projects addressed challenges associated with, for example, going to college with a physical disability, transitions in care and finding a job. Project coordinators filled out project reports with questions about PPI, that is, to what extent were YPCC involved, were they involved as co-deciders and were they involved in developing the project idea. YPCC filled out questionnaires with questions about PPI, that is, the number of PPI activities and self-perceived importance for the project. They also answered questions about the influence of the project on their social position. Based on these questions, a project outcome scale was developed.

Results: The data concerned 17 projects and 146 YPCC. Variation existed in project outcomes, of which 27% was associated with differences between projects. Using multilevel analyses, a significant relation was found between the self-perceived importance of YPCC for the project and the project outcomes they experience (0.232, $p < 0.01$). There was no significant association with the other PPI variables.

Conclusions: This study provided some first quantitative evidence that PPI has a positive impact on the YPCC involved. It is suggested that the meaningfulness of PPI matters more to them than the number of activities and amount of influence provided to YPCC. We strongly recommend conducting more research that critically examines impact of PPI.

1 Introduction

The challenges associated with having a chronic condition can adversely affect the lives of young people with a chronic condition (YPCC). Several studies have shown that YPCC experience social disadvantages compared to their peers in the areas of, for example, school (Lum et al., 2017) and social participation (Sattoe et al., 2014). To address these social disadvantages, scientific research projects have been developed to increase our knowledge about the barriers YPCC face (Chappell, 2014; Schalkers et al., 2015) and practice-oriented implementation projects to create tools and interventions to resolve these barriers (Castensoe-Seidenfaden et al., 2017; Coyne et al., 2016; Sattoe et al., 2013).

In the past, YPCC have had a passive role in projects in health and social care (for brevity, the term 'projects' will be used to cover both research and implementation projects). They were research subjects, receivers of an intervention and users of a tool. Nowadays, there is a growing consensus that YPCC should be actively involved in matters that concern them. This has been termed 'Patient and Public Involvement' (PPI). In 1992, Hart defined PPI with young people in general as 'the process of sharing decisions which affect one's life and the life of the community in which one lives.' More recently, INVOLVE (2013) has formulated a more practical definition, emphasizing that PPI is about projects being carried out 'with' or 'by' members of the public instead of 'to,' 'about' or 'for' them. This definition may apply to YPCC and other (potential) patients, carers, people who use health and social care services and people from organizations that represent people who use services.

An important rationale for involving YPCC is its expected impact. First, it is believed that PPI contributes to the personal development of the YPCC involved (Chappell et al., 2014; Flicker, 2008; Lightfoot & Sloper, 2003). Second, it is expected to indirectly contribute to the social position of other YPCC by improving the quality and relevance of projects (Chappell et al., 2014; Flicker, 2008; Kramer et al., 2013; Stevenson, 2014; Van Staa et al., 2010). YPCC are able to provide new insights from their lived experience, which can improve, for example, data collection and analysis in research (Chappell et al., 2014; Flicker, 2008) and dissemination of results (Flicker, 2008; van Staa et al., 2010).

Despite the widespread assumption that PPI improves project outcomes, robust evidence for its impact is lacking (Brady & Preston, 2020; Van Schelven et al., 2020). Most studies describe PPI processes rather than impact and reporting often includes the informal sharing of knowledge and experiences rather than a consistent collection of comparable data. Furthermore, virtually all research on PPI with YPCC is qualitative (van Schelven et al., 2020). Although qualitative studies have provided rich insights into experiences, lessons learned and meaningfulness of impact, quantitative evaluations would be a valuable addition to this area of research. Looking at PPI and its impact from this different, quantitative perspective can improve our understanding of the relations between different PPI variables.

Key messages

- This quantitative exploration indicates that Patient and Public Involvement (PPI) of young people with a chronic condition can have a positive impact on the young people involved, when they consider their PPI meaningful.
- The number of PPI activities and the amount of influence provided to young people with a

chronic condition are less relevant in achieving impact.

- It is strongly recommended to conduct more research that critically examines the impact of PPI with young people with a chronic condition.

Young people can be involved in different phases of a project. They can contribute to the preparation of a project, for example, during a grant application (Rosen-Reynoso et al., 2010), in the execution, for example, by codesigning a questionnaire (Kramer et al., 2013) or training (Rosen-Reynoso et al., 2010), and in the implementation of project results, for example, by cocreating a youth-friendly report (Flicker, 2008). Within these project phases, they can play different roles with different degrees of agency, as depicted by Hart's ladder of young people's involvement (Hart, 1992). Hart distinguishes between non-participation roles, for example, tokenism, roles in which young people are informed and consulted, and roles in which they are provided with decision-making power. Over the years, Hart's ladder has been criticized. Especially the hierarchy implied by the ladder has received criticism. However, the notion that young people can play different roles in a project remains highly relevant and a lot of thinking about PPI roles of young people is still based on the principles of Hart's work.

How and when YPCC are involved in a project may affect their impact. Several assumptions can be made about how PPI should be organized. One assumption may be that YPCC should be provided with the opportunity (when feeling comfortable and confident) to have the highest degree of agency, that is, as co-deciders. In PPI with young people and with users of health services in general, researchers have argued that we should avoid hierarchal thinking about involvement roles; higher degrees of agency are not necessarily superior to lower degrees of agency (Hart, 2008; Tritter & McCallum, 2006). However, it is likely that co-deciding allows YPCC to have a more direct impact on project decisions than, for example, providing feedback. A second assumption is that their impact increases when YPCC are involved in as many activities as possible within projects (Castensoe-Seidenfaden et al., 2017; Kramer et al., 2013). A third widespread assumption is that involvement from the beginning of a project facilitates their impact, as it allows them to be involved before project proposals are set in stone (Castensoe-Seidenfaden et al., 2017; Lightfoot & Sloper, 2003; Marshall, 2012). Although these assumptions are fundamental to the design of many participatory trajectories, they are predominantly based on personal experiences and observations of YPCC and researchers.

Between 2015 and 2019, a large participatory program, called Care and Future Prospects, ran in the Netherlands. The aim of this program was to resolve the social disadvantages experienced by YPCC, and several projects were funded that contributed to this aim (Box 1). Central to both the program and the projects it funded was the involvement of YPCC in decision-making. A participatory youth panel was set up by the program organization to advise the program and projects that received funding (Van Schelven et al., 2019). All projects were assigned one panel member, who informed and advised the project team and co-monitored the project's progress. The program also encouraged project teams to involve YPCC who were not part of the youth panel in their decision making; this was a condition for receiving funding.

In the period from 2016 to 2019, we conducted an evaluation study of Care and Future Prospects. The data we collected included information about how and when individual YPCC (not part of the panel) were involved in the projects and project outcomes. This provided us with the unique opportunity to quantitatively study the relation between PPI and project outcomes, that is, the impact. It should be noted that the available sample of projects and YPCC was limited. The aim of the current study was, therefore, to do a first quantitative exploration. Such an exploration is a valuable addition to this area of research, in which virtually all findings are derived from qualitative methods.

We have studied the following research question: how is PPI of YPCC and how PPI of YPCC is organized related to outcomes of research and implementation projects in health and social care?

It should be noted that this is an exploratory study because the available data concerned only a small sample of YPCC and projects. However, we expected a quantitative exploration to be a valuable addition to this area of research, in which virtually all findings are derived from qualitative methods.

Box 1 The Care and Future Prospects program

The Dutch organization FNO—a fund that stimulates and supports initiatives that improve the opportunities of vulnerable people—developed the program Care and Future Prospects. Within this program, FNO hosted and funded numerous research and implementation projects to improve the social position of young people with chronic conditions in five areas: care, school, work, sport and personal strength.

A wide variety of projects were funded. In research projects several topics were studied, for example, the unpredictability of chronic conditions and its consequences for participating in daily life, the effectiveness of an intervention aimed at improving functioning at school and challenges in primary care. Implementation projects addressed, for example, the development of an intervention to help young people to find a job and the creation and dissemination of vlogs about going to college with physical disabilities. Projects targeted young people with diverse chronic conditions, both physical (e.g., rheumatism, diabetes and acquired brain injury) and mental (e.g., depression and learning disabilities).

All projects were carried out by a project team and were led by a project coordinator who maintained contact with FNO and was responsible for the progress of the project.

2 Methods

2.1 Participants and procedure

Data were collected from project reports filled out by coordinators of CFP projects and from questionnaires among YPCC involved in these projects.

We started with 32 project reports hand in by project coordinators. The reports were based on a fixed format and contained open-and closed-ended questions about PPI projects.

A questionnaire was developed to evaluate project processes and outcomes from the perspective of YPCC. Several YPCC have tested a pilot version of a questionnaire to make sure the questions were relevant and comprehensible. At the end of a project, coordinators were asked to invite YPCC who were in any way involved in their project to fill out an online or written questionnaire. In total, 226 YPCC participating in 19 projects were surveyed. The number of YPCC that filled out the questionnaire varied from 1 to 46 per project.

Only projects for which data from both questionnaires and project reports were available were included in the current study. We excluded data from participants who were older than 30 years ($n = 15$). In total, data from 17 projects and 146 YPCC were included in the analyses. The included projects were a good representation of the projects funded within CFP in terms of focus (i.e., care, school, work, sport and personal strength) and YPCC and the number of YPCC involved.

2.2 Measures

2.2.1 Outcome variable

A project outcome scale was developed to assess the self-perceived contribution of projects to the social position of YPCC. The scale was based on all nine items in the questionnaire that addressed

project outcomes, including ‘Because I participated in the project ... (1) “ ... I am more self-confident,” (2) “ ... I am more independent,” (3) “ ... I am able to do the things I want to do,” (4) “ ... I am more positive about life with my condition or disability,” (5) “ ... I have the same opportunities in life as young people without a condition or disability,” (6) “ ... I see more opportunities to be physically active,” (7) “ ... I see more opportunities to find a job (in the future),” (8) “ ... I see more opportunities to finish the education I prefer” and (9) “ ... I have more faith in the care I receive for my condition or disability”.’ Items are followed by a 5-point scale (1 = ‘Strongly disagree,’ 2 = ‘Disagree,’ 3 = ‘No opinion,’ 4 = ‘Agree,’ and 5 = ‘Strongly agree’). Reliability of the scale in the present sample was 0.87 on the individual level, and 0.59 on the project level, based on the total sample of YPCC.

2.2.2 Individual characteristics

We included three variables to control for characteristics of YPCC, that is, age, sex and chronic condition. Age was measured with the item ‘How old are you?’, and sex with the item ‘Are you a boy or a girl?’ The burden of their chronic condition was assessed with the item ‘How much does your chronic condition burden you in your daily life?’, followed by a 5-point scale (1 = ‘Not at all,’ 2 = ‘A little,’ 3 = ‘Pretty much,’ 4 = ‘A lot,’ and 5 = ‘Really a lot’).

2.2.3 Predictors

The independent variable of interest in our study was PPI. We measured this with three project-level variables and two individual-level variables.

The first item on the project level included ‘To what extent did you involve young people with a chronic condition in your project?’ (scale 0–10, 0 = ‘Not at all,’ 10 = ‘Fully’). Another item was ‘How did you involve young people with a chronic condition in your project?’, followed by seven answering possibilities. We translated this item into a dummy variable of whether (1) or not (0) YPCC did co-decide. The third project-level predictor was ‘In what phases of the project did you involve young people with a chronic condition?’, followed by eight answering possibilities. We translated this item into a dummy variable of whether (1) or not (0) young people were involved during the development of the project ideas.

On the individual level, items included ‘How much did you do in the project’ (1 = ‘Nothing at all,’ 2 = ‘A little,’ 3 = ‘Pretty much,’ 4 = ‘A lot,’ and 5 = ‘Really a lot’), and ‘How important were you for the project?’ (1 = ‘Not important at all,’ 2 = ‘A little important,’ 3 = ‘Important,’ and 4 = ‘Really important’).

2.3 Data analysis

Because of the hierarchical structure of the data (with YPCC nested within projects), we conducted multilevel regression analysis with the outcome scale as a continuous variable (Leyland & Groenewegen, 2020). Several models were fitted to explain the variation in project outcomes. Model 1 was empty and included only the project outcome scale. In this model, we analysed variation in project outcomes, without considering involvement variables. Next, we added characteristics of the YPCC, that is, age, sex and burden of chronic condition, as control variables and the individual-level variables on involvement, for example, how much did they do in the project and what was their importance for the project (Model 2). In Model 3, we included the variables on the project level, for example, level of involvement, involvement as co-deciders and involvement in idea development. Due to the small number of projects in our sample, these variables were added one by one. Analyses were conducted using MLwiN 2.30. P values were significant if ≤ 0.05 .

2.4 Ethical considerations

The study was conducted in accordance with the General Data Protection Regulation. Further ethical approval of this study was not required under the applicable Dutch legislation.

[Table 1]

Results

3.1 Descriptive statistics

Table 1 shows the characteristics of YPCC (n = 146) and projects (n = 17) in the study sample. The mean age of the YPCC was 22.0 years. The sample was 55.2% female and 44.8% male. The mean score on the burden of their chronic condition was 3.0 (SD = 0.9; range = 1–5). YPCC rated how much they did in the project on average a 2.7 (SD = 1.0; range = 1–5) and their importance for the project a 2.7 (SD = 0.8; range = 1–4).

Project coordinators rated the degree of involvement of YPCC in their project on average an 8.6 (SD = 1.6; range = 4–10). Almost half of the project coordinators involved them as co-deciders (47.1%) and a similar part involved YPCC in the project phase of idea development (47.1%).

3.2 Variance between projects

Variance in the outcome scale attributable to project-level differences is estimated by the intraclass correlation coefficient (ICC). The ICC can be derived from the individual-level and project-level variance in the null model (Model 1; Table 2): $0.119 / (0.119 + 0.323) = 0.27$. This means that 27% of the variation in project outcomes, as assessed by the YPCC through the outcome scale, is associated with project differences.

3.3 Multilevel models

[Table 2]

Table 2 presents the results of the multilevel regression analyses. Model 1 is the null model. In Model 2, we added the individual-level variables. We found a significant correlation between the importance of YPCC for the project (from the perspectives of the YPCC themselves) and the outcome scale, controlling for age, sex and burden of their chronic conditions. YPCC who found themselves more important for the project scored higher on the outcome scale (0.232, $p < 0.01$). How much YPCC did in the project (from their perspectives) was not significantly associated with the outcome scale (0.077, $p = 0.17$). The total proportional reduction in unexplained variance in Model 2 compared to the null model (Model 1) is $1 - (0.276 + 0.076) / (0.119 + 0.323)$ or 20.4%.

In Models 3a–3c, we added the project-level variables. The project-level variables degree of involvement (-0.04 , $p = 0.53$), involvement as co-deciders (0.08, $p = 0.66$) and involvement from idea development (0.03, $p = 0.89$), as assessed by project coordinators, did not have a significant association with the outcome scale.

4 Discussion

The aim of the current study was to quantitatively explore how PPI of YPCC and the way it is organized is related to outcomes of research and implementation projects in health and social care. Using multilevel modelling techniques, we have studied the impact of PPI among 146 YPCC involved in seventeen different projects.

An important finding is that the self-perceived importance of YPCC for a project is positively related to the project outcomes they experience. This is in line with studies suggesting that YPCC experience personal growth and development, when they consider their role in a project meaningful and valuable (Flicker, 2008; Franklin & Sloper, 2009; Rich et al., 2014; van Schelven et al., 2019). For example, Rich et al. (2014) have argued that ‘empowering teens to influence change in the hospital

brings the added benefit of their acquiring greater responsibility and increasing their confidence.’ Flicker (2008) has noted that ‘feeling like a necessary part of “something” can help their self-esteem.

We did not find an association between the reports of YPCC about how much they did in a project and project outcomes they experience. This implies that the number of activities is less relevant for achieving impact than the meaningfulness of PPI. This notion is supported by the finding that the extent to which YPCC were involved, reported on the project level, is not related to project outcomes. Previous studies have also indicated that PPI activities should not necessarily be as much as possible (Flicker, 2008; van Staa et al., 2010). Of greater importance is the match between PPI activities, YPCC and projects. Lightfoot and Sloper (2003) have argued that ‘different methods suit different people’ and ‘different methods suit different purposes.’ Involvement activities should be negotiable rather than striving for as much involvement as possible (Lightfoot & Sloper, 2003; van Staa et al., 2010). Helpful here is the suggestion of Franks (2011) to create ‘pockets’ of involvement by discussing with young people the parts of a project they would like to undertake and the parts they prefer researchers to undertake. This enables young people to take ownership of specific phases or facets of a project that are meaningful to them.

Related to this, is the finding that co-deciding, as reported by the project coordinators, is not related to the outcomes of a project. It may not be the amount of influence given to YPCC that makes a difference. In PPI with young people and with users of health services in general, researchers have argued that levels of influence are not hierarchical; more influence is not superior to less influence (Hart, 2008; Tritter & McCallum, 2006). In some cases, asking for advice may lead to the best results, while, in other cases, co-deciding may be preferred. The ‘ideal’ level of influence depends on the wishes and needs of YPCC and on the content of the project. A recent review has pointed out that real team work depends on listening, taking YPCC seriously and discussing issues that matter to them (van Schelven et al., 2020).

Studies have stressed the importance of involving YPCC from the start of a project (Castensoe-Seidenfaden et al., 2017; Lightfoot & Sloper, 2003; Marshall, 2012). We have examined whether involvement in idea development does improve project outcomes, but this was not the case in our sample. However, this does not necessarily mean that early involvement is not beneficial for the impact. Our sample also included projects in which YPCC were not involved in idea development but did play a role in an early phase, for example, writing a project proposal or setting up a project. A more general comparison of projects that involved them in the preparation phase to projects that involved them in later phases, for example, in the execution or dissemination phase, may provide a more complete picture.

Our study provides insight into the relation between the way PPI with YPCC is organized and its impact. An interesting next step would be to investigate more in depth the relation between different PPI approaches and impact among different groups of YPCC. Previous studies have suggested that the best way to involve young people may depend on their characteristics and social background (Brady & Preston, 2020). Special efforts should be made to learn more about the involvement of ‘hard-to-reach’ groups, such as young people with comprehension and communication limitations (Clavering & McLaughlin, 2010). Although examples of their involvement are available (e.g., Bruce & Parker, 2012; Marshall, 2012; Stevenson, 2014), they are currently underrepresented in research on PPI (Clavering & McLaughlin, 2010). Increasing our understanding of how YPCC with different characteristics and backgrounds can be involved can contribute to more inclusive involvement of those who are less frequently heard next to the more usual suspects.

4.1 Strengths and limitations

To our knowledge, this study is the first to explore the impact of PPI with YPCC using quantitative multilevel modelling techniques. The findings are considered explorative, as they are based on a small sample of projects. However, they also provide unique quantitative insights in an area of

research, in which virtually all findings are derived from qualitative methods. Moreover, even in a larger sample, it is unlikely that we would have found an association between the PPI variables on the project level and project outcomes, because coefficients were close to 0 and p values were very high.

Another limitation of the study is that YPCC were only involved in pilot testing the questionnaire. Involving them in the interpretation of the findings could have provided more insights into questions posed by the data and areas for future research. This would therefore be a suggestion for future research. Furthermore, we invited all YPCC who were involved in projects in any way to fill out the questionnaire and also those who played a passive role, for example, receivers of an intervention or users of a tool created in the projects. During the study, it became clear that some YPCC were not able to define whether they played a PPI role or a passive role. Ideally, we would have made a clear distinction, as this would have allowed us to investigate whether PPI contributes to project outcomes for those passively involved, for example, receiving the intervention or using the tool. Also, there is a risk of common method bias in the data we used (Jordan & Troth, 2019). Among YPCC, we have collected data on the predictor variables and the outcome variable simultaneously, using the same method, that is, the questionnaire, which may have inflated the estimates of the relationship between those variables. However, the correlation between both variables was relatively low ($r = 0.39$).

Finally, the findings of the current study are based on data from YPCC who were involved in projects within a Dutch participatory program, and we have compared projects that involved YPCC to at least some degree. Results may thus not apply to other settings and other countries. However, the findings are derived from diverse projects in various settings involving YPCC with various chronic conditions, which improves generalizability. Future research should compare the outcomes of participatory and non-participatory projects to learn more about impact.

4.2 Conclusion

The current study provides quantitative evidence concerning the impact of PPI in projects on the YPCC involved. A substantial part of the variation in project outcomes is due to differences between projects. Some of this variation can be explained by the positive relation between the self-perceived importance of YPCC for a project and project outcomes they experience. No relation with project outcomes was found for the other PPI variables. It is suggested that the meaningfulness of PPI is more important than the number of activities and the amount of influence given to young people. We do, however, strongly recommend conducting more research that critically examines the impact of PPI. The current study was the first quantitative exploration, but we need more critical measures to learn about effective ways of working together. These measures are also needed to convince a broad public of the validity and relevance of PPI.

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ORCID

Femke van Schelven <https://orcid.org/0000-0003-1728-5025>

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Tables

Table 1 Sample characteristics

Variables	n	Mean (SD) or percentage
Overall number of YPCC	146	—
Characteristics of YPCC		
Age (years)	143	22.0 (5.1)
Sex (%)		
Male	64	44.8
Female	79	55.2
Burden of chronic condition	139	3.0 (0.9)
Involvement (perspective YPCC)		
How much did YPCC do	132	2.7 (1.0)
Importance of YPCC for project	101	2.7 (0.8)
Overall number of projects	17	—
Involvement (perspective project coordinators)		
Degree of involvement	17	8.6 (1.6)
Involvement as co-deciders (%)		
Yes	8	47.1
No	9	52.9
Involvement in idea development (%)		
Yes	8	47.1
No	9	52.9

Abbreviations: SD = standard deviation, YPCC = young people with a chronic condition.

Table 2 Multilevel analysis on the association between involvement variables and project outcomes, estimates (SEM)

Variables	Model 1	Model 2	Model 3a	Model 3b	Model 3c
Intercept	3.013 (0.110)	3.041 (0.101)	3.355 (0.514)	3.085 (0.144)	3.030 (0.133)
Characteristics of YPCC					
Age	—	0.012 (0.013)	0.018 (0.013)	0.018 (0.013)	0.018 (0.013)
Sex	—	-0.147 (0.105)	-0.147 (0.104)	-0.145 (0.104)	-0.147 (0.105)
Burden of chronic condition	—	0.031 (0.056)	0.031 (0.056)	0.030 (0.056)	0.031 (0.056)
Involvement (perspective YPCC)					
How much did YPCC do	—	0.077 (0.056)	0.079 (0.056)	0.074 (0.056)	0.078 (0.056)
Importance of YPCC for project	—	0.232 (0.076)*	0.232 (0.076)*	0.231 (0.076)*	0.232 (0.076)*
Involvement (perspective project coordinators)					
Degree of involvement	—	—	-0.036 (0.058)	—	—
Involvement as co-deciders	—	—	—	-0.082 (0.188)	—
Involvement in idea development	—	—	—	—	0.025 (0.191)
Random part					
Individual-level variance	0.323 (0.043)	0.276 (0.034)	0.276 (0.037)	0.276 (0.037)	0.276 (0.037)
Higher level variance	0.119 (0.066)	0.076 (0.046)	0.074 (0.045)	0.076 (0.046)	0.075 (0.046)

Abbreviation: YPCC = young people with a chronic condition.

* $p < .05$.