

Exciting but exhausting: experiences with participatory research with chronically ill adolescents

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Abstract

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Background Adolescents with chronic conditions are major users of paediatric hospitals, but seldom participate in the evaluation of services or in research. Little is known about the usefulness of the participatory approach in adolescent health research.

Objective To evaluate the feasibility, benefits and limitations of a participatory research (PR) project involving chronically ill adolescents as co-researchers.

Design, setting and participants Nine adolescents, aged 15–17 years, acted as co-researchers in a hospital-based PR project. They co-developed an interview protocol and during a disco party held for this purpose interviewed each other and 25 fellow patients (12–19 years). They provided advice on the draft report and participated in the dissemination of the results, but were not involved in the design of the project or analysis of results.

Results Involving adolescents in participatory health research was feasible and appreciated by researchers and youth alike, but had its drawbacks too. The peer-research attracted few participants, the interviews lacked depth and did not yield substantial new insights. Maintaining a high level of participation of the chronically ill co-researchers also proved difficult.

Conclusions Adolescents with chronic conditions like to have a say in the design and evaluation of hospital services. But their participation as co-researchers demands ample resources from all parties involved without automatically improving research quality. PR does not seem the most effective and efficient way to make services more responsive. We therefore recommend further exploration of other creative and sustainable ways for involving youth in health-care service development and innovation.

Introduction

Over the last decade, the active involvement of patients in decision-making processes has become a policy priority aimed at making health-care services more patient-centred. The Netherlands Ministry of Health, for example, stimulates transition from a supply-driven to a demand-driven health-care system, expecting users to be active consumers selecting those services that best suit their needs.¹ Following the consumerist rhetoric, patient or user participation refers to consultation and involvement of patients in all health-care decisions on the individual and collective level; in the development and evaluation of services; and also in health research.² Although the notion of patients as partners in the research process is of fairly recent date, the participatory approach is quite popular with health researchers.^{3–5}

Participatory research (PR) is a collaborative undertaking aimed at more involvement of the community being studied in all aspects of the research process. It is carried out *with* and *by* the research subjects rather than *on* them.^{6,7} Core elements are co-learning and reciprocal transfer of expertise, shared decision-making power and mutual ownership of process and products of the research enterprise.^{3,6,8,9}

From a review by Viswanathan *et al.*⁸ it appears that well-conducted PR enhances competencies and capacities of the community; improves research quality; leads to more effective and efficient interventions; and results in better health outcomes. In contrast, dissenting voices question the effectiveness and impact of consumer involvement in research¹⁰ and there are indications that the benefits of PR are not equitably spread, nor gained without considerable cost.¹¹

The call for securing patients' voice and choice in health care does not only apply to adults, but also to minors.^{12–14} Children and adolescents are major users of paediatric health-care services and have special needs.¹⁵ This holds true in particular for those with chronic illnesses or disabilities, who will need to take over responsibility from their parents to manage their own health.^{16,17}

The right of minors to express their views and be involved in decision making in all matters affecting them is grounded in the United Nations Convention on the Rights of the Child (UNCRC 1989; Article 12). However, participation of adolescents with chronic conditions in medical decision making, in services evaluation or in health research is by no means self-evident, nor easy to accomplish. For example, the Dutch Medical Treatment Act (WGBO; 1995) states that adolescents aged 12–15 years have the right to co-decide with parents in treatment decisions, and that those over 16 may decide for themselves. Still, to date their active participation is still fairly limited in primary care^{18,19} or hospital care²⁰ in the Netherlands. Similar observations come from other countries.^{21–25}

Giving young people a collective voice in the development and evaluation of health-care services, implies their views should be listened to^{14,26–28} and acted upon.²⁹ Given the opportunity, young people are quite willing and able to make decisions about services they want,^{30–33} but disabled children tend to be less involved in participation activities than non-disabled children, according to Franklin and Sloper.³⁴

An important barrier to children's partnership in health care is related to concerns about offering choices to them.^{33,35,36} Nevertheless, the traditional view of children's incompetence to give consent for treatment and for research participation has been contested. Children are now observed as social actors, competent to be commentators on their own lives and to be involved in decision making.³⁷ Chronically ill children often prove to be capable of making informed, 'wise' decisions in their own best interests.^{17,29,38} Still, young people are often not recognized as service users,³⁰ seeing that the parents' perspective tends to be the basis for measuring quality of paediatric hospital care.³⁹ However, the parents' perspective may not accurately represent their children's views.^{40,41}

Inclusion of young people themselves in research is therefore being considered essential. The Guidelines for Adolescent Health Research³⁵ propose a task for adolescent research subjects in working out research priorities and purposes.

According to Litt,⁷ the next logical step would be inviting adolescents' input into a study's design and execution. PR has been used for children suffering from cancer,^{42,43} diabetes^{44,45} and for disabled children.^{28,34,46} Furthermore, it was applied in exploring children's preferences for hospital care or design^{30,47–50} and in promoting health and providing services to marginalized or underserved groups, such as homeless or human immunodeficiency virus positive youth.^{51–55}

In view of the potential benefits of participation, we used several forms of consultation and involvement in the 'On Your Own Feet Project, launched to explore chronically ill adolescents' self-care competencies and their preferences. In the present study, adolescents participated as *co-researchers*, i.e. they interviewed fellow patients about their preferences and experiences with hospital care. The aim of this study is to assess the feasibility, advantages and limitations of working with chronically ill adolescents in PR.

Methods and sample

The 'On Your Own Feet' Project took shape between 2004 and 2007 in the Erasmus MC – Sophia Children's Hospital, Rotterdam, the Netherlands. This hospital treats over 4000 adolescents with chronic conditions, but has no specialized adolescent in-patient facilities and only a handful of outpatient youth clinics. The hospital board supported the idea of consulting patients in a participatory project to better adjust services to their needs. However, a hospital is not an ideal setting for community-based research. Thus, we decided to organize a disco party to be held outside the hospital at an attractive location, in a real discotheque, which usually is not easily accessible to adolescents with chronic conditions. During this event the co-researchers were to interview their fellow patients. We describe the design and execution of the study in four subsequent stages.

Recruitment of co-researchers

Adolescents were sought who were both motivated to act as co-researchers and willing to give their opinion about the care they received. A

representative sample of adolescents was not intended. Ten nurse specialists working in different subspecialty departments in the hospital were asked to identify adolescents > 15 years of age whom they thought would be interested in participating. These nurses had co-operated in a previous 'On Your Own Feet' study. We expected that young people would be more willing to participate if they were invited by familiar care providers.

Together with the Communications Department we developed a leaflet explaining the aim, method and expected requirements of potential co-investigators. The study was also announced on two websites, the project-related site <http://www.oepenbenen.nu> and a hospital-based site for patients: <http://www.sophiakids.nl>.

Eight of 10 nurse specialists eventually approached adolescents. Sixty information leaflets were printed, but we do not know how many were handed out. Ten adolescents consented, but as one girl with cystic fibrosis needed to be hospitalized, nine (two boys and seven girls; aged 15–17 years) actually participated (Table 1). Their chronic conditions included dermatologic disorders ($n = 2$), blood disorders ($n = 2$), neuromuscular diseases ($n = 2$), renal failure ($n = 2$) and diabetes mellitus ($n = 1$).

Table 1 Characteristics of study participants

	Interviewees $n = 25$ (%)	Co-researchers $n = 9$ (%)	P-value*
Gender			
Boys	9 (36.0)	2 (22.2)	0.68
Girls	16 (64.0)	7 (77.8)	
Age (years)			
12–15	20 (80.0)	3 (33.3)	0.03
16–19	5 (20.0)	6 (66.7)	
Age at diagnosis chronic condition (years)			
At birth and < 6 years	10 (40.0)	4 (44.4)	1.00
> 6	15 (60.0)	5 (55.6)	
Visits outpatient department past 3 years			
< 12 visits	21 (84.0)	1 (11.0)	< 0.01
> 12 visits	4 (16.0)	8 (89.0)	

*Fisher's exact test; 2-sided.

Training programme and designing of interview protocol

As the co-researchers had no research experience at all, introducing them to interviewing techniques was necessary. To make a training session appealing to participants, the research team (AvS, SJ, JML) organised a site-visit to the national newspaper *nrc.next* for a training session on location. The aim of the training was to jointly develop an interview protocol and prepare the co-researchers for their task as interviewers.

The chief editor received our co-researchers as VIPs and first provided a short introduction on running a newspaper. They then visited the newspapers' offices before the actual training session, which lasted three hours. Following a brief introduction on the aim of interviewing, the co-researchers worked in pairs to interview each other while another co-researcher and a member of the research team observed them. They discussed their experiences with hospital staff by posing the sample question: 'What is a good doctor?' Afterwards, the observers evaluated the technique of interviewing. Then followed a single role play acted out in front of the group demonstrating how to pose probing questions to a non-co-operative respondent. The researchers provided the adolescents with tips and tricks.

Finally, the themes and topics to be included in the interview protocol were discussed. The research team presented a short draft protocol, divided into several general themes. Some open-ended questions were inspired by our previous interview study about adolescents' health-care preferences²⁰ and by a child-friendly questionnaire designed in another Dutch paediatric hospital.⁵⁶ Working in small groups, the co-researchers re-phrased the questions where needed and added new topics.

In the weeks after the training session, the research team categorized and merged the provisional questions. After several discussion rounds with the co-researchers through e-mail, the interview protocol was finalized (Table 2).

Setting of research: disco party

The research team organized a disco party on a Saturday afternoon in a Rotterdam club, in May 2006. Recruitment of potential guests started 4 weeks before. Parents were not allowed, but the patients could bring a friend. Most adolescents would not know other participants and we anticipated that a friend's presence could help them feel more comfortable. Colourful posters announcing the event were put up throughout the Sophia Children's Hospital and an information flyer was distributed via the counters of the six outpatient departments to all visiting patients over 12 years of age. Eight nurse specialists and the Communications Department sent this flyer to their adolescent patients or contacts with a personal invitation. Approximately 1000 leaflets were distributed in this short period.

The disco party was staged with the help of many volunteers including a well-known Dutch radio DJ, club staff, students, and graffiti and break dance artists. Several workshops (such as break-dance, rap, graffiti and nail art) were offered in addition to the disco dancing itself.

The co-researchers had been briefed before. They were instructed to use the interview protocol as a guide – not as a structured questionnaire. The interviews were held in a designated area: the discotheque's café. The co-researchers worked in pairs to support each other and were seated at round tables. Each pair was assisted by a student who directly typed the respondents' answers into a laptop.

All in all, 25 young patients – predominantly younger girls (12–15 years) – and 26 healthy friends attended. Thirty-four patients participated in the peer-interviews, i.e. 25 attendants and nine co-researchers (Table 1).

Data analysis and dissemination of results

The co-researchers were also invited to help with the data-analysis. Regrettably, establishing a date for a 'real-life' meeting to discuss the preliminary results with the co-researchers proved impossible. Instead, the research team

Table 2 Interview protocol designed in collaboration with co-researchers

I Your general impression of the hospital
1. If I say, Sophia Children's Hospital, what do you think?
2. What is best in the Sophia Children's Hospital?
3. What is worst in the Sophia Children's Hospital?
II Doctors, nurses and other staff
4. According to you, what is a good doctor?
5. How are your experiences with doctors at Sophia Children's Hospital? Please give examples of both positive and negative experiences.
6. How are your experiences with other health care workers, such as nurses, dieticians and social workers at Sophia Children's Hospital? Please give examples of both positive and negative experiences.
7. What is your number one advice for hospital staff?
8. How do you feel about the fact that you'll have to leave Sophia Children's Hospital when you turn eighteen?
9. Do you think you're ready to transfer to adult care?
III When visiting the outpatient department
10. What is most important to you when you're at the outpatient department?
11. Do you feel that the doctor focuses mostly on you?
12. What happens if you have a different opinion than the doctor?
13. Would you prefer to talk with the doctor alone sometimes?
14. If you could change the organization of the outpatient department, what would you do?
IV When admitted to hospital
15. What do you miss most when you have to stay in hospital?
16. How are your experiences with the Acute Care department at Sophia Children's Hospital?
17. Suppose, you get a bag full of money for the hospital, what would you buy?
V Activities in the hospital
18. How do you feel about the activities organized in the hospital?
19. What is your opinion on the hospital clowns?
20. Do you think it is important to meet fellow patients? How should the Sophia Children's Hospital make this possible?
21. Do you think young patients should get a greater say in the hospital? How should this be organized?
22. Is there anything else you have on your mind about the Sophia Children's Hospital?

analysed the anonymous transcripts and invited co-researchers to comment on draft versions of the report through e-mail. To establish the additional value of the participatory approach, we compared the peer-interviews to qualitative interviews.²⁰

The co-researchers participated in several media activities: David was interviewed by a national newspaper, others were interviewed on national radio or on the hospital-based Sophia Television. Dorine and Britt contributed to a popular article about the project in *ZieSo*; a magazine for patients and parents distributed in the hospital's waiting areas.

The results of the overall project 'On Your Own Feet' including those of the disco party were disseminated in a national conference that started with a theatre play created by adolescents (April 2007, Rotterdam). For the recruitment of the young actors we used the same

strategy as described above. The original co-researchers were also invited, but refrained from participating. A group of nine young people worked with a professional drama teacher to create the play, using role-play and improvisation. The play was the highlight of the conference, attended by 500 delegates – including health professionals, young patients and their parents. After the show the young actors handed the first copy of the book summarizing the project's findings to representatives of the hospital board. Their self-created rap urged the hospital board to listen to young people and adjust care to their needs.

Ethical standards and procedures

The study was approved by the Erasmus MC Medical Ethics Review Board. All participants and their parents received written information

about the project and provided their written consent. The co-researchers received €75 remuneration for their input, estimated at 15 h each. Participants of the disco party could win attractive prizes in a raffle. The young actors participating in the drama project received €75 as well.

Results

To assess the benefits and limitations of this participatory approach, we describe the effects on (a) the co-researchers, respondents and the research team; (b) research quality; and (c) improvement of services in Sophia Children's Hospital. Table 3 presents an overview.

Effects on respondents, co-researchers and research team

At first glance, the project seemed successful. For most *visitors*, a discotheque was a place they had never seen the inside of and all seemed to enjoy the party. The research team received many compliments from parents and young people alike. Adolescents felt the hospital should organize more age-appropriate activities during which they can meet fellow-patients. Also, all

attending patients were willing to share their experiences and ideas about the hospital. They liked having the opportunity to speak out their appreciation for the hospital, while at the same time grabbing the opportunity to ventilate critical comments and make recommendations. Many participants talked about the importance of 'being heard and listened to' by the hospital staff and some recommended to consult youth more frequently. A national radio reporter asked one of them how she enjoyed being interviewed by peers and she answered it was 'a great idea'.

The *volunteers* who helped organizing the event were very willing to co-operate and were impressed about the adolescents' resilience as most of them were unfamiliar with youth with disabilities. *Parents* were also positive about the project; some were prepared to drive for hours to bring their child.

Hospital staff, notably the nurse specialists and the Communications Department, were very supportive. They relished the chance to invite their patients for an activity in which they could meet fellow patients. Staffs were also genuinely interested in young people's opinions. Through their personal approach, recruitment of peer-researchers had been rather easy.

Table 3 Strengths and limitations of participatory research

	Strengths	Limitations
Young patients	Liking to give opinion about their own care Opportunity to meet fellow patients in non-medical context Having a nice time and new experience	Relatively few attendees. Disco party and contact with fellow patients probably not appealing to all ages and all patients
Co-researchers	Enthusiasm to participate in data collection Empowering experience Increased self-esteem Added status; earning some money	Demanding in terms of energy and time investment Difficult to maintain enthusiasm for participation Representativeness
Hospital staff	Enjoying the opportunity to contribute to a positive experience Being inspired to giving young patients a greater say in their own care	Difficult to guarantee that suggestions are being acted upon Doubts about generalisability of results
Research team	Stronger commitment to youth' needs and preferences Enhanced public exposure; facilitating dissemination of results Exciting to collaborate with adolescents	High time and resources expenditure Quality of peer- interviews disappointing Recruitment and quality of data not better than with traditional (qualitative) research strategies

As a consequence of this sampling strategy, most *co-researchers* were well-known to the hospital staff and they had extensive hospital experience. They were significantly older than the other disco-attendees and had visited the outpatient department of the hospital more often in the past 3 years (Table 1). The co-researchers felt grateful towards hospital staff and yearned to give something in return. Their motivations for wanting to be co-researcher included: opportunity to learn interviewing skills; enjoying the prospect of visiting a newspaper office; eager to meet fellow-patients and to give feedback to hospital staff. The opportunity to earn a little money was also attractive.

From most co-researchers we learnt they found the experience worthwhile, albeit strenuous. Our disease-burdened co-researchers had lower energy levels than their healthy peers. The training programme and interview sessions at the disco party exhausted them. Britt commented in her report on the training session: *'it was a rather strenuous afternoon, but I learnt a lot'*. She also commented that it would probably take her three days to recover from the disco party, but that it was worth it. The research team had organized support for the co-researchers during the interviews and arranged for them to take turns, but we had not realized how burdensome this task was for some of them.

Participation of the co-researchers after data collection was limited. Attempts were made to involve them in the data analysis, but despite several recalls, no more than four of the nine co-researchers commented on the draft report, stating *'all is OK'* and claiming the results were recognizable to them. So most co-researchers seemed to have lost interest, but one girl agreed to be an advisor to the board of the research project together with her mother. Several attended the national conference.

Being a co-researcher was empowering in some respects. Not only did they learn new skills and felt useful as a researcher, they also enjoyed receiving a VIP-treatment. Being interviewed in the media added to their self-confidence. One mother commented that being a co-researcher helped her daughter to turn her illness into

something positive. Another co-researcher decided to become a journalist. The remuneration also increased their feelings of self-esteem: for most this was the first money they had ever earned.

As *research team* we enjoyed working with these youth, and it certainly increased our sensitivity towards their perspective. It was exciting to work intensely with them during the research endeavour. Being connected to these adolescents and to share experiences with them strengthened our resolve to focus research efforts on improving quality of adolescent health care. Consequently, we invested more time and energy than anticipated in disseminating the research results and translating them into practice. All in all, the participatory process was exciting for all parties involved. It was fun, but also hard work and exhausting. While we had anticipated that the project would take some 500 working hours, we spent more than double. The money investment was some €5000.

Despite the large investments of resources in recruitment and preparation of the disco party, a disappointing number of no more than 25 adolescents attended. As it was the end of the spring holidays, we had expected more visitors. The low number may be as a result of the somewhat rushed, indirect recruitment strategy, and choice for and timing of the event, but it also goes to show that a participatory approach does not necessarily facilitate recruitment.

Effects on research quality

The training programme was limited to one afternoon. Busy school schedules and exams limited availability of the co-researchers and several lived outside Rotterdam or were seriously disabled, making them dependent upon adults for transportation. The co-researchers played an active part in the training session and provided several interesting interview topics, for example, their experiences in the Emergency Department and with hospital clowns. Yet, only general aspects of interviewing could be presented and practiced. Consequently, they were not very well-prepared for interviewing their

fellow-patients. Most of the interviews lasted no longer than 10 min and additional questions to clarify and explore answers were not often posed. The interview protocol was used as a structured questionnaire rather than a guide for open conversation as recommended. We had expected that these adolescents would speak more freely with each other than with trained researchers, but there are no indications that this was the case.

The typists' interpretation of what was said during the interviews cannot be verified. The café area where the interviews were held was a crowded and somewhat noisy spot. The interviews could therefore not be audio-recorded and were transcribed on the spot. Based on our observations, we conclude that the comments were recorded fairly literally but briefly, and that important details and nuances may have been missed.

Compared with our previous face-to-face interviews with adolescents with chronic conditions, the peer-interviews yielded few new insights, preferences for hospital care being fairly similar in both. Most useful proved the co-researchers' comments and suggestions on the sample research questions, and these were used, together with some quotes of the peer-interviews, in a follow-up questionnaire.⁵⁷

One of the most interesting outcomes of the peer-interviews is related to the desired level of participation in service evaluation. To the question 'Do you think young patients should get a greater say in the hospital?' many young people answered they did not think this was necessary, because 'you already have enough to say in Sophia's' or 'all is fine as it is'. Adolescents who were most explicit about the need of having a greater say, proved to be the co-researchers themselves. One felt that 'doctors should listen better to what children have to say'. Another said: 'we ought to do more such studies, so that young people themselves can tell what they prefer'. Some co-researchers recommended the installation of a youth forum in the hospital, although not all of them thought this was necessary. Compared with other participants, co-researchers seemed more articulate about the need for youth participation.

Effects on improvement of services

The project was designed in collaboration with hospital staff so as to ensure their involvement as well as a focus on relevant issues for daily practice. This would also ensure their commitment towards improving services based on adolescents' preferences and needs. During recruitment and organization of the disco party the level of participation of nurse specialists and staff from the Communications Department was high. Through them we not only gained access to young patients, but we also learnt from their practical experience. Nurses had valuable comments on the information leaflets and the way to involve youth. The idea to create a disco party came from the head of the Communications Department, who had organized several other youth activities before and managed to involve many volunteers and VIPs. Without the active involvement of hospital staff, this project would never have been realized. However, this does not guarantee that adolescents' recommendations will be acted upon.

There are not many direct results to boast about. A striking one, however, is the aroused interest in the overall project from the media and from health-care providers both in the hospital and nationwide. Especially the drama play performed by adolescent actors was a great success. Partly as a consequence of the overall 'On Your Own Feet' Project, awareness increased among professionals in the hospital of the special health-care needs and preferences of adolescents with chronic conditions. Several professionals developed new initiatives such as transition clinics, and involving young people in the design of peer activities and educational materials. These are the first steps in making health-care services in Sophia Children's Hospital more age-appropriate – an important recommendation from adolescents that were interviewed.

Discussion

Children and adolescents are able to express views on living with chronic illness or disability;⁵⁸ they can specify their health-care needs and have constructive ideas about improving quality and

service development.^{26,28,29,59} Most studies indicate that they want to be involved, respected and listened to,^{30,34,38} but young people may also be critical about participation if not carried out properly, or if not meaningful to them.³⁰ Stafford *et al.*³¹ consulted 200 young people about their experiences with consultation. It is judged meaningful when it concerns issues directly affecting them and when it is likely to yield results.

Youth participation should not be used for window dressing or tokenism. In the overall 'On Your Own Feet' Project this was avoided by having adolescents 'on board' during all stages. So on the one hand it proved feasible to involve young people with chronic conditions in the evaluation of health services. On the other hand, we feel that the participatory approach did not live up to our expectations.

Abma *et al.*⁹ reports on several projects involving patients as equal research partners. Our intention had indeed been to share responsibility with the adolescents in the design, execution and presentation of the study. This goal has not been attained. True, the adolescents acted as respondents, advisors and interviewers, but they were not equal research partners. Not only the number of young patients reached, but also their level of involvement and the outcomes were rather meagre compared in view of the effort invested by the research team and co-researchers alike. Since mutual learning, openness, and respect are guiding principles for collaborations in PR,⁹ we feel it is justified to discuss not only the benefits of the participatory approach, but also the limitations and drawbacks we were confronted with.

Strengths of participatory research

Increased commitment of the research team and hospital staff towards the adolescents' perspective may very well be the most important advantage of PR.⁵³ Also, young participants were positive of the opportunity given to them to be listened to - a feature of PR generally perceived as a strength.^{11,48,53} Meeting fellow-patients outside a medical context can be seen as another advantage, as most of the visitors to the

disco party appreciated this. Yet, not all young people with chronic conditions prefer to meet fellow-patients.²⁰

For the co-researchers, the peer-research seems empowering and rewarding, even though their participation had been limited in time and impact. Others have reported similar benefits for patient research partners.^{9,11,53}

The research team enjoyed to collaborate with young people and it inspired us to disseminate the findings to a much wider public than academics alone and to experiment with alternative ways to involve youth such as the use of drama.⁴⁷ If user consultation and public relations are desired outcomes, participation of the researched subjects may be a good strategy.

Limitations of participatory research

An important claim for PR is that the *research itself* benefits from collaboration with the researched - through better questions, recruitment, data collection, analysis and dissemination.^{3,8,11,53} On the whole, we were more content with the PR process than with the outcomes. The project implied a lot of work for the research team, hospital staff, volunteers and co-researchers alike. If research quality or recruitment really should improve, this would be worth it. In this case, however, the research benefitted less than we had hoped for, both in terms of quantity of participants and of research quality.

An explanation for the limited attendance to the disco party may be that young patients do not wish to focus on their disease or on hospital care, but rather on normalizing their condition and using their energy for participating in the 'healthy' world. Moreover, they were rather pleased with care-as-usual in the children's hospital compared with high-risk and out-of-the-mainstream youth in other projects.^{51,55} Lightfoot and Sloper's³⁰ evaluation of six hospital-based initiatives involving adolescents in service provision in the UK also demonstrated that few young people actually participated.

A possible issue for concern is *representativeness*.¹⁰ The co-researchers differed from their

fellow patients in being more outspoken about preferences, more critical of care received and more self-confident in talking to staff and peers. To enable informed decision making these viewpoints provided a good starting point, but they needed to be completed by survey data from a representative sample of users.

Despite our efforts, co-researchers' involvement was fairly limited compared with other reports.^{9,11} They fully participated in data collection only, not in analysis. Keeping their initial enthusiasm at the same level through all phases of the project proved rather difficult. Also, not all forms of participation were successful. For our adolescent co-researcher it proved virtually impossible to make a meaningful contribution as advisor to the research board. In contrast, the young persons' involvement in the drama project was a great way to stimulate self-expression and to disseminate results.⁴⁷

Disadvantages of using consumer involvement for research quality are not frequently reported.^{8,10} The data collected also did not substantially add to our previous knowledge gained from interviews. There are no indications that enhanced rapport between co-researchers and their peers reduced the bias resulting from lack of confidence between interviewer and interviewee, as is sometimes claimed.³ The conversations lacked depth, demonstrating that interviewing is no easy job. So, would we 'do it again'? Yes, but differently. We would search for more effective and efficient forms of youth participation than peer-research.

The more participation, the better?

Most PR initiatives report satisfaction with both the process and the results.^{3,8,60} PR is claimed to add value to all stages of the research process for both academic and non-academic partners.^{3,5,9} The downsides of PR are not often discussed or are labelled as challenges only.^{8,53} On closer examination, however, others have also reported PR to be more resource intensive, time-consuming, complicated and less efficient than traditional research.^{8,10,11,53}

Advocates of participation usually stress that obstacles need to be overcome by more, proper, genuine, sustainable participation.^{32,38} From isolated consultations like ours, we should move to 'embedded' participation in organizational cultures, according to Sinclair.³² Indeed, few challenge the basic romantic notion that moving toward maximum patient participation in all aspects of research is optimal. And few wonder whether young people themselves want to be included in organizational structures or in decision making. A recent study of Knopf *et al.*⁶¹ demonstrated that the largest proportion of chronically ill adolescents under study tended to favour a passive role in treatment (preferred by 46%) over shared decision making (37%).

Offering youth the choice to their level of participation would be more ideal than assuming that 'more is always better'.¹¹ 'Embedded' participation also involves the risk of creating participation elites. The level of participation should be negotiated, equitable rather than equal participation being the ultimate goal.³ Participation seems a *hurray-word* like democracy or partnership.⁶² But even advocates of participation note evidence of limited impact, of lack of measurable outcomes and of disillusionment in young people engaged in consultation and decision making.^{34,38}

According to Coad and Shaw³³, it is unclear whether having a choice for children leads to more responsive services. Partnerships with young people in research require that their suggestions are not only listened to, but also acted upon. Researchers, however, are not the ones who change policies or practices. User consultation with those in charge of health-care services could perhaps be more effective in achieving responsive services. In Experience-Based Co-Design, for example, user experiences are directly made accessible to the providers of services.⁶³ Staff and patients discuss the designing together. All in all, adolescents with chronic conditions may benefit more from being integral part of service improvement and innovation than from being research partners.

Conclusion

Adolescents with chronic conditions like to have a voice in the design and evaluation of health-care services, but the desirable extent of patient partnership in research and consultation is still undefined. A PR approach may be helpful in increasing their social competency and disseminating research results. Adolescents are able to participate to a certain extent and researchers find it exciting to work with them. Yet, PR is no easy job. It demands high commitment, extensive resources, and hard work while not always succeeding in providing meaningful results. Finding a balance between the benefits and costs of participation is necessary to ensure sustainability of efforts, commitment and credibility of results.

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References

1 VWS. *Met zorg kiezen [Choosing with care]*. VWS Publication TK 2000–2001, 27 807 No. 2. The Hague: Netherlands Ministry of Health, Welfare and Sport, 2001.

- 2 van de Bovenkamp H, Grit K, Bal R. *Inventarisatie patiëntenparticipatie in onderzoek, kwaliteit en beleid [Inventarisation of Patient Participation in Research, Quality and Policy]*. Rotterdam: Erasmus MC University Medical Center, 2008.
- 3 Cargo M, Mercer SL. The value and challenges of participatory research: strengthening its practice. *Annual Review of Public Health*, 2008; **29**: 325–350.
- 4 Caron-Flinterman JF, Broerse JE, Teerling J, Bunders JF. Patients' priorities concerning health research: the case of asthma and COPD research in the Netherlands. *Health Expectations*, 2005; **8**: 253–263.
- 5 Abma TA. Patients as partners in a health research agenda setting: the feasibility of a participatory methodology. *Evaluation & the Health Professions*, 2006; **29**: 424–439.
- 6 Hart RA. *Children's Participation: From Tokenism to Citizenship*. Innocenti Essays No 4. Florence: UNICEF, 1992.
- 7 Litt IF. Research with, not on, adolescents: community-based participatory research. *Journal of Adolescent Health*, 2003; **33**: 315–316.
- 8 Viswanathan M, Ammerman A, Eng E *et al.* *Community-Based Participatory Research: Assessing the Evidence*. Summary, Evidence Report/Technology Assessment: No. 99. AHRQ Publication No. 04-E022-1. Rockville, MD: Agency for Health care Research and Quality, 2004. <http://www.ahrq.gov/clinic/epcsums/cbprsum.htm>.
- 9 Abma TA, Nierse CJ, Widdershoven GA. Patients as partners in responsive research: methodological notions for collaborations in mixed research teams. *Qualitative Health Research*, 2009; **19**: 401–415.
- 10 Boote J, Telford R, Cooper C. Consumer involvement in health research: a review and research agenda. *Health Policy*, 2002; **61**: 213–236.
- 11 Flicker S. Who benefits from community-based participatory research? A case study of the Positive Youth Project. *Health Education & Behavior*, 2008; **35**: 70–86.
- 12 Hart C, Chesson R. Children as consumers. *British Medical Journal*, 1998; **316**: 1600–1633.
- 13 Dixon-Woods M, Young B, Heney D. Partnerships with children. *British Medical Journal*, 1999; **319**: 778–780.
- 14 Aynsley-Green A, Barker M, Macfarlane A *et al.* Who is speaking for children and adolescents and for their health at the policy level? *British Medical Journal*, 2000; **321**: 4.
- 15 Viner RM, Barker M. Young people's health: the need for action. *British Medical Journal*, 2005; **330**: 901–903.
- 16 Britto MT, Slap GB, DeVellis RF *et al.* Specialists understanding of the health care preferences of chronically ill adolescents. *Journal of Adolescent Health*, 2007; **40**: 334–341.

- 17 Alderson P, Sutcliffe K, Curtis K. Children as partners with adults in their medical care. *Archives of Disease in Childhood*, 2006; **91**: 300–303.
- 18 Tates K, Meeuwesen L. 'Let mum have her say': turntaking in doctor-parent-child communication. *Patient Education and Counseling*, 2000; **40**: 151–162.
- 19 Tates K, Elbers E, Meeuwesen L, Bensing J. Doctor-parent-child relationships: a 'pas de trois'. *Patient Education and Counseling*, 2002; **48**: 5–14.
- 20 van Staa AL, Jedeloo S, Kuijper M, Latour JM. *Op Eigen Benen. Jongeren met chronische aandoeningen: wat willen en kunnen zij in de zorg? [On Your Own Feet. Young People with Chronic Conditions: What are Their Preferences and Competencies for Health Care?]*. Rotterdam: Rotterdam University, 2007.
- 21 Coyne I. Consultation with children in hospital: children, parents' and nurses' perspectives. *Journal of Clinical Nursing*, 2006; **15**: 61–71.
- 22 Young B, Dixon-Woods M, Windridge KC, Heney D. Managing communication with young people who have a potentially life threatening chronic illness: qualitative study of patients and parents. *British Medical Journal*, 2003; **326**: 305.
- 23 Runeson I, Martenson E, Enskar K. Children's knowledge and degree of participation in decision making when undergoing a clinical diagnostic procedure. *Pediatric Nursing*, 2007; **33**: 505–511.
- 24 Sartain SA, Clarke CL, Heyman R. Hearing the voices of children with chronic illness. *Journal of Advanced Nursing*, 2000; **32**: 913–921.
- 25 Hallstrom I, Elander G. Decision-making during hospitalization: parents' and children's involvement. *Journal of Clinical Nursing*, 2004; **13**: 367–375.
- 26 Oppong-Odiseng AC, Heycock EG. Adolescent health services—through their eyes. *Archives of Disease in Childhood*, 1997; **77**: 115–119.
- 27 Sloper P, Lightfoot J. Involving disabled and chronically ill children and young people in health service development. *Child Care Health and Development*, 2003; **29**: 15–20.
- 28 Cavet J, Sloper P. The participation of children and young people in decisions about UK service development. *Child Care Health and Development*, 2004; **30**: 613–621.
- 29 Curtis K, Liabo K, Roberts H, Barker M. Consulted but not heard: a qualitative study of young people's views of their local health service. *Health Expectations*, 2004; **7**: 149–156.
- 30 Lightfoot J, Sloper P. Having a say in health: involving young people with a chronic illness or physical disability in local health services development. *Children & Society*, 2003; **17**: 277–290.
- 31 Stafford A, Laybourn A, Hill M, Walker M. 'Having a say': children and young people talk about consultation. *Children & Society*, 2003; **17**: 361–373.
- 32 Sinclair R. Participation in practice: making it meaningful, effective and sustainable. *Children & Society*, 2004; **18**: 106–118.
- 33 Coad JE, Shaw KL. Is children's choice in health care rhetoric or reality? A scoping review. *Journal of Advanced Nursing*, 2008; **64**: 318–327.
- 34 Franklin A, Sloper P. Supporting the participation of disabled children and young people in decision-making. *Children & Society*, 2009; **23**: 3–15.
- 35 Santelli JS, Smith Rogers A, Rosenfeld WD *et al.* Guidelines for adolescent health research. A position paper of the Society for Adolescent Medicine. *Journal of Advanced Nursing*, 2003; **33**: 396–409.
- 36 Alderson P. Competent children? Minors' consent to health care treatment and research. *Social Science & Medicine*, 2007; **65**: 2272–2283.
- 37 Prout A. Researching children as social actors: an introduction to the children 5-16 programme. *Children & Society*, 2002; **16**: 67–76.
- 38 Hill M, Davis J, Prout A, Tisdall K. Moving the participation agenda forward. *Children & Society*, 2004; **18**: 77–96.
- 39 Ygge BM, Arnetz JE. Quality of paediatric care: application and validation of an instrument for measuring parent satisfaction with hospital care. *International Journal for Quality in Health Care*, 2001; **13**: 33–43.
- 40 Chesney M, Lindeke L, Johnson L, Jukkala A, Lynch S. Comparison of child and parent satisfaction ratings of ambulatory pediatric subspecialty care. *Journal of Pediatric Health Care*, 2005; **19**: 221–229.
- 41 Battrick C, Ghasper EA. The views of children and their families on being in hospital. *British Journal of Nursing*, 2004; **13**: 328–336.
- 42 Fallon S, Smith J, Morgan S, Stoner M, Austin C. 'Pizza, patients and points of view': Involving young people in the design of a post registration module entitled the adolescent with cancer. *Nurse Education in Practice*, 2008; **8**: 140–147.
- 43 Aldiss S, Horstman M, O'Leary C, Richardson A, Gibson F. What is important to young children who have cancer while in hospital? *Children & Society*, 2009; **23**: 85–98.
- 44 Dedding C, Reis R, Ramaker C, Wolf B. Hoe denken kinderen over hun diabetes [How do children view their diabetes]. *Nederlands Tijdschrift voor Diabetologie*, 2004; **3**: 86–89.
- 45 Waller A, Franklin V, Pagliari C, Greene S. Participatory design of a text message scheduling system to support young people with diabetes. *Health Informatics Journal*, 2006; **12**: 304–318.
- 46 Watson D, Abbott D, Townsley R. Listen to me, too! Lessons from involving children with complex healthcare needs in research about multi-agency services. *Child Care Health and Development*, 2007; **33**: 90–95.

- 47 Jackson AM. 'Follow the Fish': involving young people in primary care in Midlothian. *Health Expectations*, 2003; **6**: 342–351.
- 48 Moules T. (ed.) Whose quality is it? Young people report on a participatory research project to explore the involvement of children in monitoring quality of care in hospital. *Paediatric Nursing*, 2004; **16**: 30–31.
- 49 Coad J, Coad N. Children and young people's preference of thematic design and colour for their hospital environment. *Journal of Child Health Care*, 2008; **12**: 33–48.
- 50 Coad J. Using art-based techniques in engaging children and young people in health care consultations and/or research. *Journal of Research in Nursing*, 2007; **12**: 487–497.
- 51 Flicker S, Guta A, Larkin J *et al.* Survey design from the ground up: collaboratively creating the Toronto Teen Survey. *Health Promotion Practice*, 2008; doi:10.1177/1524839907309868 [Epub ahead of print].
- 52 Powers JL, Tiffany JS. Engaging youth in participatory research and evaluation. *Journal of Public Health Management & Practice*, 2006; **12** (Suppl.): S79–S87.
- 53 Harper GW, Carver LJ. "Out-of-the-mainstream" youth as partners in collaborative research: exploring the benefits and challenges. *Health Education & Behavior*, 1999; **26**: 250–265.
- 54 Wilson N, Minkler M, Dasho S, Wallerstein N, Martin AC. Getting to social action: the Youth Empowerment Strategies (YES!) Project. *Health Promotion Practice*, 2008; **9**: 395–403.
- 55 de Winter M, Baerveldt C, Kooistra J. Enabling children: participation as a new perspective on child-health promotion. *Child Care Health and Development*, 1999; **25**: 15–23. discussion 25.
- 56 Snel MC. Dokter, dit vind ik! Verbeterpunten voor een megacool ziekenhuis [Doctor, this is my opinion! Ideas for a megacool hospital]. *Kind en Ziekenhuis*, 2006; **29**: 18–22.
- 57 van Staa AL, van der Stege HA, Jedeloo S. *Op Eigen Benen Verder. Jongeren met chronische aandoeningen op weg naar zelfstandigheid in de zorg [On Your Own Feet Ahead. Young People With Chronic Conditions on Their Way to Independence in Health Care]*. Rotterdam: Rotterdam University, 2008.
- 58 Birks Y, Sloper P, Lewin R, Parsons J. Exploring health-related experiences of children and young people with congenital heart disease. *Health Expectations*, 2007; **10**: 16–29.
- 59 Beresford BA, Sloper P. Chronically ill adolescents experiences of communicating with doctors: a qualitative study. *Journal of Adolescent Health*, 2003; **33**: 172–179.
- 60 Flicker S, Savan B, Kolenda B, Mildemberger M. A snapshot of community-based research in Canada: who? what? why? how? *Health Education & Behavior*, 2008; **23**: 106–114.
- 61 Knopf JM, Hornung RW, Slap GB, DeVellis RF, Britto MT. Views of treatment decision making from adolescents with chronic illnesses and their parents: a pilot study. *Health Expectations*, 2008; **11**: 343–354.
- 62 Trappenburg M. *Genoeg is genoeg. Over gezondheidszorg en democratie. [Enough is Enough. About Health Care and Democracy]*. Amsterdam: Amsterdam University Press, 2008.
- 63 Bate P, Robert G. Experience-based design: from redesigning the system around the patient to co-designing services with the patient. *Quality & Safety in Health Care*, 2006; **15**: 307–310.