



**Participatory Research:
Adolescents with Chronic
Conditions Interviewing Fellow
Patients about Health Care
Preferences**

Peer-Research During a Disco-party

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why participatory research?

1. to be involved / to participate in issues and decisions concerning yourself is not only a legal right or a moral imperative, but it will also enhance competencies of youth
2. benefits for the research: the insiders’ view
3. benefits for the participants: nice and rewarding experience for both youth and researchers; to learn from each other and increase mutual understanding

global design of participatory study On Your Own Feet

1. recruitment of young co-researchers (March 2006)
2. training session (26th April)
3. development of questionnaire in dialogue
4. recruitment of participants for disco-party / of volunteers (March-May)
5. organisation of disco-party (13th May)
6. analysis of interviews and writing of report (May-July)
7. results used as input for web-based survey (October)

1. recruitment co-researchers

- not difficult thanks to collaboration nurse specialists
- selection of 9 co-researchers over 15
- with different chronic conditions, both congenital and acquired
- all were very experienced patients
- time investment: max. 15 hrs; reward € 75

2. training-session **nrc·next**

- introduction about a ‘young’ newspaper
- tips & tricks for interviewing: introduction by chief editor
- excursion to newspaper offices
- participatory development of questionnaire
- training and role-play practising interviewing
- e-mail feedback on draft questionnaire

3. development of questionnaire

- was developed in dialogue
- use of child friendly examples
- only open questions, suggestions to further elaborate on topics
- questions related to five themes
 - a. general impression of Sophia
 - b. doctors, nurses and other providers
 - c. during consultations
 - d. when admitted to hospital: the wards and hospital facilities
 - e. youth activities in the hospital



4. recruitment of participants and volunteers for disco-party

- use of flyer distributed through nurse specialists in the hospital
- explaining aim of disco-party and research
- short preparation time
- holiday / exam period
- hard to reach youth
- collaboration from volunteers was more easily accomplished
- many VIP's and institutions offered free collaboration

5. organisation disco-party

- parents not invited
- they could bring in a friend
- they were treated as VIP's
- workshops and disco
- lottery
- peer-research in café area
- answers were directly typed into laptop



participants of the disco-party / respondents

- app. 50 participants, half of them were healthy friends, no patients: 25 patients / 9 co-researchers
- response 100%
- total number of interviews: **34**
- gender:**
11 male; 23 female (68%)
- age**
 - 12-15 y: 23 (68%)
 - age 16-19 y: 11

6. analysis of interview data

- thematic analysis performed by research group
- systematic comparison of themes and answers
- results were fed back to co-researchers in two rounds (by e-mail)
- it proved hard, if not impossible, to retain co-researchers' participation after data collection
- half of them did not comment on the final draft
- but some continued to be involved in the research, for example: contribution to popular article in hospital magazine

results

- youth are very positive about healthcare provision in the children's hospital
- they appreciate the qualities of hospital staff

"They really focus on children; they do everything to make your visit as pleasant as possible."

"capable doctors who listen to me.. the nurses are even better."

results

BUT

- they want more attention for needs of older children
- they have clear preferences as to how they like to be involved in care
- they hate it to be treated in a childish way

"If you're a teenager, they act too childish. They should treat you according to your age."

"They should talk to me, not only to my parents."

results

AND

- they hate waiting all the time
- they would like more age-appropriate activities and decoration in the hospital

"Those hospital clowns may be nice for young kids, but I am really too big for that. Their jokes are silly and they are stupid, not my cup of tea"

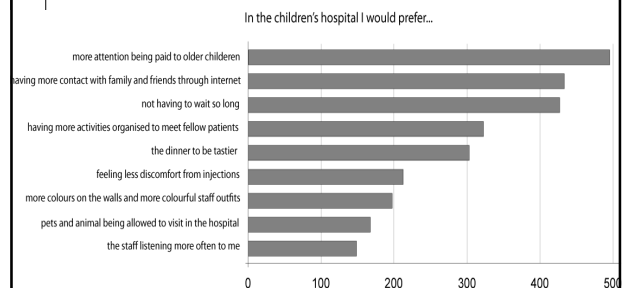
"Everything is so white! I would paint it all pink!"

"Decorations and toys are all for toddlers, not teenagers"

7. development web-based survey

- results were used as input for a large web-based survey into preferences for care (among other topics)
- for example, we asked adolescents to rank their priorities for change in the children's hospital

priorities for change in children's hospital (survey; n=995)



discussion

- is participatory approach feasible in adolescent health research?
 - YES, but with serious limitations
 - YES, but at high cost
- how beneficial is participatory research?
 - for research
 - for researchers
 - for adolescent participants

is participatory research the answer?

- participatory research is exciting but also exhausting
 - from a mere researcher perspective: complex, not very cost-effective and not necessarily reliable
- HOWEVER
- from a moral perspective: a perfect way to form partnership
 - from a service perspective: useful and user-friendly
 - from a public relations perspective: very clever marketing strategy

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Student researchers

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Team On Your Own Feet

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participants of the disco-party / respondents

