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OBJECTIVES

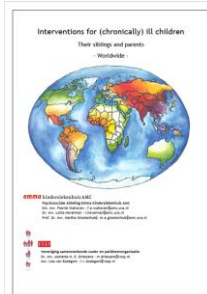
- to 1) get insight into the psychosocial problems that children with rare diseases experience
- 2) give an overview of existing e-health interventions, and
- 3) describe and learn from the implementation process of the KLIK project.

METHOD

- 50 Patient organisations and psychosocial departments of 4 Dutch children's hospitals completed a survey on 1) psychosocial problems and 2) existing e-health interventions
- 3) KLIK was implemented for Haemophilia, NF-1, and EB. The implementation process was evaluated for barriers and good practices.

RESULTS

- Patient organisations reported emotional problems (anxiety and depression, 89%), social problems (63%) and behavioural problems (56%)
- Overview of existing (ehealth) interventions. (copies available)



- KLIK is widely used for rare diseases in Amsterdam, other hospitals willing/using.
- Barriers: professional (e.g. resistance against renewal), health care team (e.g. motivation of every member), hospital (e.g. financial resources, coordinator, wish: ICT, coupling to Electronic Patient Dossier), patient (computer (iPad at consult), language problems).

GENERAL NUMBERS KLIK uptake

| | |
|------------------------------|--|
| Amsterdam | 16 of 30 CoE use KLIK |
| Quick wins (country wide) | CF, hemophilia, endocrinology, neuromuscular, marfan, metabolic |
| questionnaires | Monitoring: PedsQL, Tapqol, Screening: CBCL, SDQ, PTSS Research: ... |
| 8 children's hospitals in NL | Yes: Rotterdam, Nijmegen, Maastricht, Groningen, Leiden, ? Utrecht |



CONCLUSIONS/RECOMMENDATIONS

- Patient organisations see value: collaboration to develop PROMS: testimonials to support use
- Research: scientific papers
- Clinical Trials for children with cancer: SKION will use KLIK as system to measure quality of life
- Professionals: Pediatricians, Psychologists etc. Convince their scientific societies)
- National Implementation Agenda eHealth in the Netherlands: develop factsheet & organise support to convince decision makers (hospital board), Health care insurers. Common agenda/wishlist.
- Mention eHealth tools in quality standards
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