

Empowering parents: Developing a digital tool to guide parents of children with disabilities to the right information



Brain Center
Rudolf Magnus



M.W. Alsem MD¹, K.M. van Meeteren BSc¹, M.J.W.M. Schmitz, MSc², M. Klem³, M. Verhoef MD PhD¹, B. Piškur PhD⁴, M. Ketelaar PhD¹

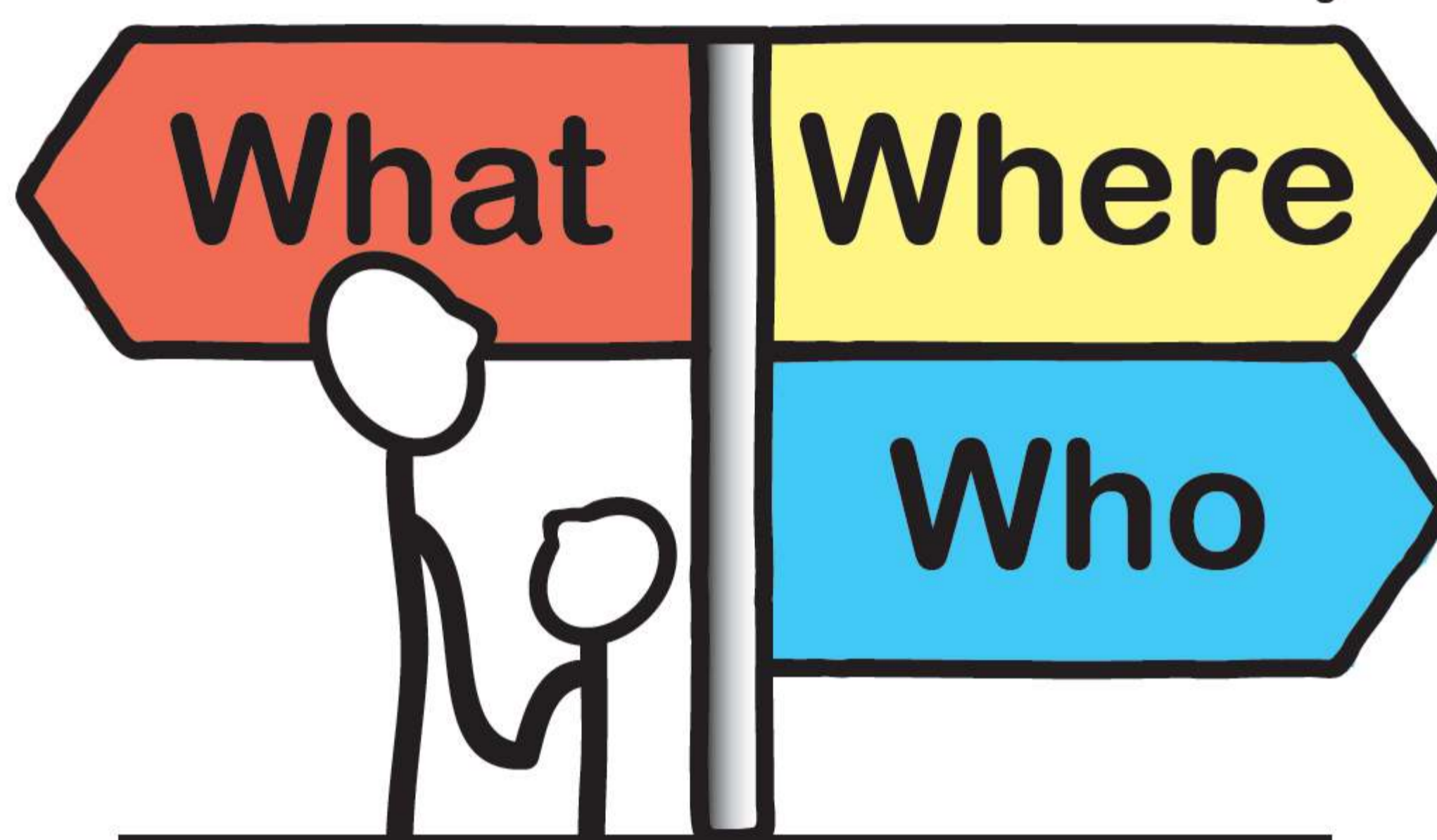
¹Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation, Utrecht, The Netherlands. ²Zuyd University, Faculty ICT, Heerlen, the Netherlands. ³BOSK Association of persons with congenital physical handicaps, Utrecht, the Netherlands. ⁴Zuyd University, Research Center Autonomy and Participation, Heerlen, the Netherlands.

Background

Parents of children with physical disabilities do a lot to support their child in daily life but also come across several challenges. They show a large scale of unmet needs (e.g. around financial issues, adaptations or finding suitable leisure activities). In the consultation process with physicians parents indicate a lack of information. Getting information about different aspects of care is difficult.

Being informed is a major requirement for the process of empowerment and shared decision making. Parents who are better informed are able to prepare better for the consultation with different health care professionals, able to support each other and become equal partners in negotiating care or supporting child's participation.

www - roadmap



roadmap for parents of
children with a disability

Aim

We developed, the WWW-wijzer (In English: WWW-roadmap) that will enable parents to explore their needs (**What do you want to know?**), help in their search for information (**Where can you find information**), and refer to appropriate professionals (**Who can further assist you?**).

Development of the tool

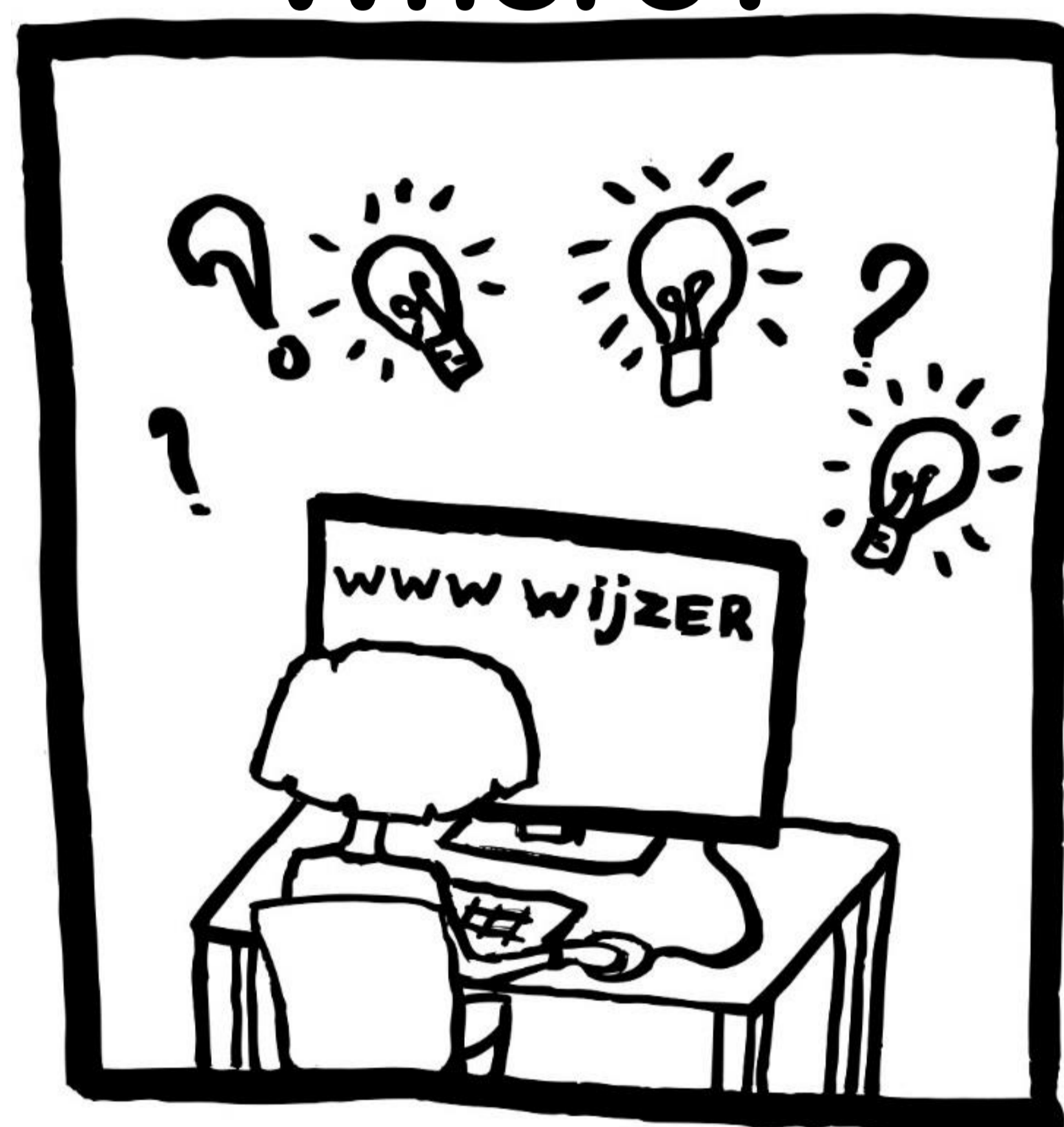
In a collaboration between parents, healthcare professionals, IT-specialists and clinical researchers we designed the tool. In an iterative, user-centered process clinical usability and feasibility were cared for.

Browse through
possible questions
and topics



What?

Where?



Find information in
the tool and on the
internet

Take a question
prompt list to the
consultation



Who?

Conclusion

- The WWW-roadmap aims to help parents in formulating and asking questions and finding information.
- Using the WWW-roadmap, parents can prepare themselves for a consultation with a (rehabilitation) physician. This facilitates parental empowerment, self-efficacy and shared-decision making.

Study

Currently we investigate the effects of the use of the WWW-roadmap of parents on the consultation with the rehabilitation physician. In a sequential cohort design we study effects on parental empowerment, parent and physician satisfaction, parental self-efficacy and family centered care.

In 5 different settings a control cohort and an intervention cohort, both with 100 parents will be included in spring and summer of 2016.

