

Validating a web-based intervention for teenagers with chronic illness and their parents

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1 Background & Objectives:

In a previous wave of co-creational research, with teens with Juvenile Idiopathic Arthritis (JIA) or Paediatric Plaque Psoriasis (PP), their parents, and rheumatology and dermatology nurses, we were able to identify relevant support needs and solutions for self-managing disease and treatment.

The feedback was that a web-based intervention as part of a wider support programme is favoured by teenage patients and their parents.^{1,2} A functioning prototype of the website was designed and written based on the insights taken from the first wave of research. A user-testing approach was applied, as this has shown to be effective for validating a web-based programme from the user perspective.³

The aims of this research were:

- To obtain feedback about the web-based intervention to inform final refinements to the programme
- To test acceptance of tone, style; also to test relevance of the content and illustrations, ease of navigation and usability

2 Sample & Methods

The same 60 participants from the UK and Italy, who took part in our previous research phase were contacted, including teens (n=14) with JIA or PP, their parents (n= 31), and rheumatology and dermatology nurses (n= 15).

FEATURES OF THE INTERVENTION

The prototype was a preview of the proposed website, consisting of complete articles, video thumbnails, and semi-functional trackers and tools.



INTERVIEW PROCEDURE

All participants took part in one-to-one, semi-structured, qualitative interviews, which were web-assisted. Participants were

asked to explore the website prototype on a provided link. Interviewers gained feedback about the website prototype using the Think Aloud technique.⁴

Before being shown the prototype, participants completed a neutral Think Aloud exercise as a warm-up. Each interview lasted 45-60 minutes and an audio recording was created for analysis.

CONTENT ANALYSIS

The data were analysed by two researchers using a qualitative content analysis approach to elicit structured feedback about the presented stimuli.⁵

3 Results: Participants’ recommendations for a web-based intervention



ENGAGING & POSITIVE VISUALS

- Images should be relatable and feature real people
- Imagery should convey positivity and hope
- Colourful star icons for goal-tracking activity were deemed too childish and inappropriate for teenagers

INTERACTIVE & MULTI-CHANNEL FEATURES

- Interactive **trackers** with personalised feedback
- **Video clips** featuring patients or parents sharing tips for managing a chronic illness
- Option to access mobile-friendly website or **app version**
- **Reminder alerts** for medical appointments
- **Self-reward systems** more applicable to lifestyle goals, but less applicable to adherence goals



CONCISE & HOLISTIC CONTENT

- Information should be delivered in a compact, concise format for limited user burden
- Demand for holistic advice (e.g. on lifestyle and mood) without specific mention of disease
- There is a risk of patronising the user if information is too basic or prescriptive

OPPORTUNITIES TO FACILITATE SOCIAL SUPPORT

- Communication with other patients/parents via online forum
- Messaging service/online chat with HCP for specific advice on demand
- Regular telephone or face-to face support with a health coach



SPECIFIC CONSIDERATIONS FOR TEENS VS PARENTS

- Teenagers prefer interactive websites with trackers, tools and videos, rather than receiving information passively
- A balanced mixture of traditional (e.g. written articles) and interactive channels (e.g. trackers, videos) is favourable for parents.

What brings users back?

- Clear and easy-to-use layout decreases user burden (time, effort) and allows convenient access to relevant information
- Information should be up-to-date and come from a credible medical source to reinforce relevance
- Customised and frequently refreshed content increases perceived need for repeated use
- Website should look attractive and come with a range of activities to engage teenagers over a long period
- Reminder messages via different channels prompting to content and tools are helpful in maintaining regular use
- Personalisation of activities adds relevance and meaning to support

4 Conclusion

The research demonstrated that a web-based intervention is desirable for teenagers with a chronic condition and their parents, if it is customised to individual support needs around disease and treatment.

Newly gained and particularly important insights can be summarised as:

- The preferences of teenagers vs parents regarding communication channels support the need for the intervention to be tailored to the audience
- There is a demand for holistic advice and support on a range of life domains, as patients and parents don’t always want to be reminded of the condition
- Despite the benefits of, and interest in, digital interventions, maintaining a complementary human element, for example via health-coach or peer-to-peer contact, continues to be highly important to parents and patients

The feedback from the interviews should be considered when designing supportive interventions to address particular needs and preferences of these target groups.

¹ Wehling, H., O’Sullivan, A. & NiMhurchadha, S. Teenagers’ experiences of growing up with a chronic illness. *Poster session presented at 12th UKSBM Annual Scientific Meeting*; 2016 Dec 1-2; Cardiff.

² O’Sullivan, A., Wehling, H. & NiMhurchadha, S. Parent’s experiences of raising a child with a chronic illness. *Oral presentation at the 12th UKSBM Annual Scientific Meeting*; 2016 Dec 1-2; Cardiff.

³ Rosenbaum, S. E., Glenton, C., Nylund, H. K., & Oxman, A. D. (2010). User testing and stakeholder feedback contributed to the development of understandable and useful Summary of Findings tables for Cochrane reviews. *Journal of Clinical Epidemiology*, 63(6), 607-619.

⁴ Willis, G. B. (2004). *Cognitive interviewing: A tool for improving questionnaire design*. Sage Publications.

⁵ Mayring, P. (2014). *Qualitative content analysis: theoretical foundation, basic procedures and software solution*. URN: <http://nbn-resolving.de/urn:nbn:de:0168-ss0ar-395173>