

# Development of the Huntington Support App: from design directions to prototype

## BACKGROUND

eHealth seems promising in overcoming some important barriers to HD care provision, including the availability/accessibility of care and distance of care centers<sup>1</sup>. However, research on eHealth in HD is limited<sup>2-6</sup> and fails to include services specifically designed to fit the expectations of HD gene expansion carriers (HDGECs) and their families. Together with end-users (i.e., HDGECs, partners of HDGECs, and health care providers), we developed a first prototype of the Huntington Support App<sup>7</sup>: a European eHealth platform targeting quality of life of HDGECs and partners at home (HEALTHE-RND HD-eHelp study).

## HEALTHE-RND CONSORTIUM

Collaboration between:

- The Netherlands
- United Kingdom
- Czech Republic
- Germany
- Ireland
- Italy



**AIM:** to provide an update on the development process of the Huntington Support App, including design directions and choices for the prototype

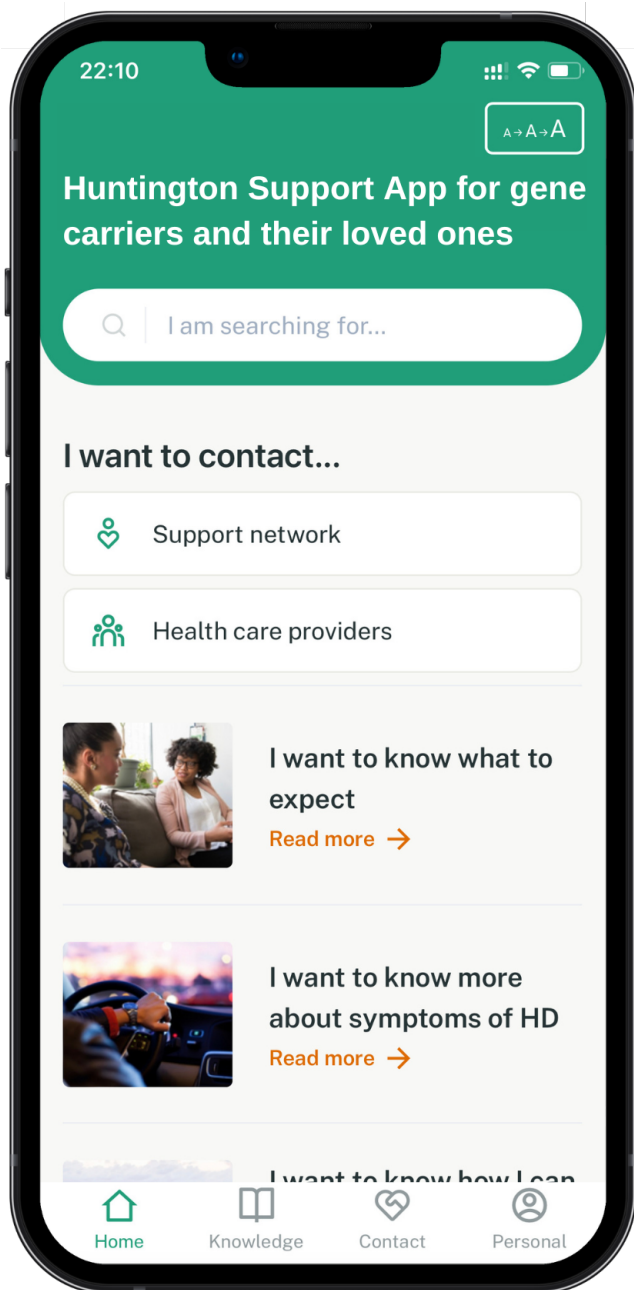


Figure 1. Home screen of the Huntington Support App prototype

## METHODS

Dutch HDGECs (n=12), partners (n=12), and health care providers (n=12) were involved as end-users in all stages of the user-centered design process:



1. Exploring needs/wishes
2. Developing concepts
3. Detailing of prototype

Data was checked and complemented with the available data and input from the other participating countries.

## OUTCOMES

Exploration of needs and wishes of end-users yielded several design directions:

Increase accessibility of care and support

Facilitate navigation through knowledge landscape

Tools for coping with symptoms

Elaborations on these directions with the same end-users resulted in definite design choices for the prototype: **a trustworthy safety net with reassuring and reliable information/tools, referrals, and peer/professional support** (Figure 1).

## FUTURE PERSPECTIVES

A first prototype of the Huntington Support App has been developed together with end-users to ensure suitability with their wishes and needs. Subsequent evaluation by end-users will assist further development into a fully functional app for implementation in all countries involved.

## CORRESPONDENCE

P.J.C. (Pearl) van Lonkhuizen, MSc  
p.j.c.van\_lonkhuizen@lumc.nl

Dept of Public Health and Primary Care,  
Leiden University Medical Center

## REFERENCES

- <sup>1</sup> Edmondson MC, et al. Contemporary health care for HD. Handbook of Clinical Neurology. 144 (3rd series) Huntington Disease. Elsevier. 2017
- <sup>2</sup> de Man J, et al. E-health support for community residing HD patients: report of a pilot-project. J Neurol Neurosurg Ps. 2016;87(Suppl 1):A82-A3
- <sup>3</sup> Bull MT, et al. A pilot study of virtual visits in HD. J Huntingtons Dis. 2014;3(2):189-95
- <sup>4</sup> Hawkins AK, et al. Providing predictive testing for HD via telehealth: results of a pilot study in British Columbia, Canada. Clin Genet. 2013;84(1):60-4
- <sup>5</sup> Hawkins AK, et al. Developing a comprehensive, effective patient-friendly website to enhance decision making in predictive testing for HD. Genet Med. 2013;15:466-72
- <sup>6</sup> Frich JC, et al. Health care delivery practices in HD specialty clinics: an international survey. J Huntingtons Dis. 2016;5:207-13
- <sup>7</sup> van Lonkhuizen PJC, et al. Study protocol for the development of a European health platform to improve quality of life in individuals with HD and their partners (HD-eHelp study): a user-centered design approach. Front Neurol. 12:7194560