

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 centers¹. However, research on eHealth in HD is limited²⁻⁶ 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 App⁷: 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

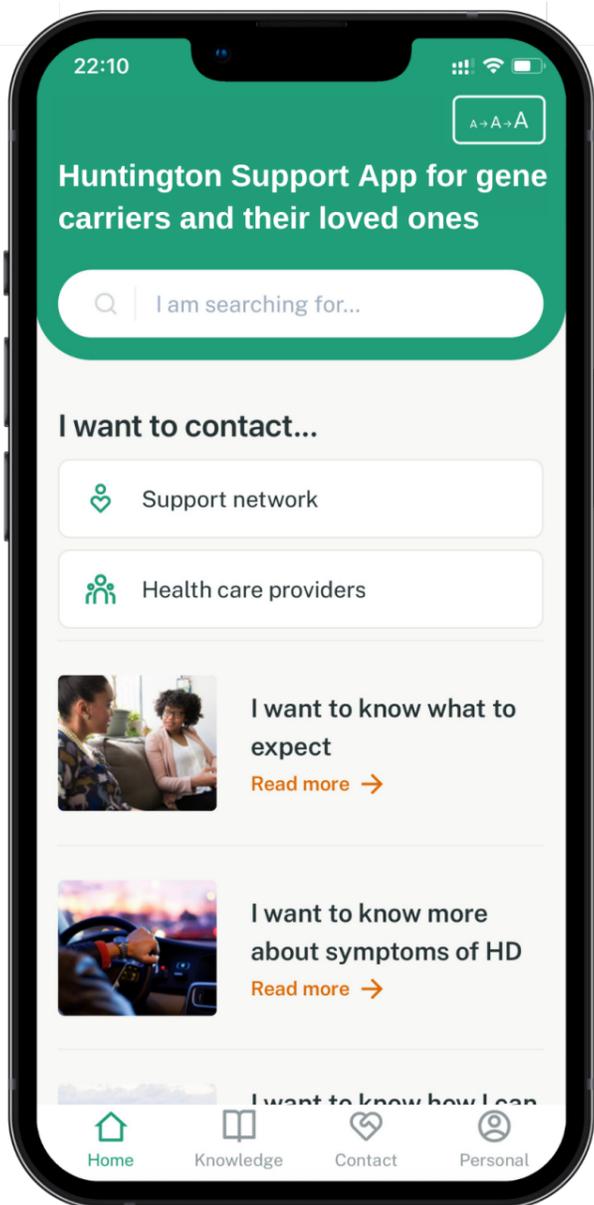


Figure 1. Home screen of the Huntington Support App prototype

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.

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