

Participation in Health Care Decision Making by ABI clients

Designing a tool to increase the participation of ABI clients living in a health care organisation in the Netherlands.

Noortje van de Mast

Noortje van de Mast
Industrial Design
University of Twente
The Netherlands
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Vilans is the company providing the assignment. "Vilans is the national Centre of Expertise for Long-term Care in the Netherlands." ("About Us", 2019) Vilans is part of the 'NAH-kennissenetwerk' that executes a subproject of the overarching programme 'Gewoon Bijzonder, Nationaal Programma Gehandicapten' of ZonMw. The subproject is called 'Meer inspraak voor mensen met NAH' and is about participation in health care decisions making for people with acquired brain injury (ABI). The research maps the current situation of participation of ABI clients and tries to find a way to increase their participation. (Breed et al., 2019) The Bachelor Final Assignment was about turning the gained knowledge within the subproject into a tool.

The Bachelor Final Assignment aims to increase participation in health care decision making of people with ABI by designing a tool. Therefore, the research question answered in the report is: *What kind of designed tool is required to increase the participation in health care decision making within a health care organisation of people with ABI living in that health care organisation?*

To find out which tool is required to increase participation in health care decision making of people with ABI, two analyses were performed, and several (test) sessions with the research team 'Gewoon Bijzonder' and target group took place. The first analysis showed the importance of looking at the whole process and form of participation. Also, with the use of scenarios, the diversity of the target group became apparent. The sessions that followed the first analysis emphasised the importance of using both verbal and visual aspects in the tool.

Due to the confusion and the dissatisfaction of the designed tool after the first sessions, a second analysis took place. This analysis focused on defining the scope of the participation process, the goal of the tool, and the target group. It was concluded that the tool would concentrate on the 'discovery' phase, and invites and supports ABI clients and their caretakers to have a conversation with each other about ownership, possibilities, and participation facilitated by the health care organisation. The ABI clients are adults with ABI living in a health care organisation and interested in participation in health care decision making. Again, the analysis was followed by several (test) sessions. The participants of the sessions after the second analysis helped to develop and to fine-tune the tool.

The final result turned out to be a workbook that invites and guides the client and caretaker in having a conversation about participation in health care decision making. The client and caretaker will, together, work through the book and document the conversations they have.

The workbook invites the user by using both visual and verbal aspects fitting the target group of people with ABI and their caretakers. The guidance is provided by asking questions categorised in several sections (such as communication, opinions, and participation). The conversations the client and the caretaker will have while working through the book, cover the preferred way of communicating and other (pre)conditions necessary for participation in health care decision making for the client.

It is concluded that by discussing and documenting the (pre)conditions of participation necessary for the client, the forms of participation, and the topics relevant to the client, in

the preferred way of communicating, the participation of adults with ABI living in a health care organisation will increase. However, this will only count for the clients interested in participation. The ones that are not interested will not participate.

To conclude, the required tool to increase participation is a workbook that guides the user in having a conversation about participation. However, this is tested with a group of people that were involved in the whole project. Therefore, it is recommended to also check it with another group of people, also, over a longer time frame.

For the implementation of the tool in health care organisations, it is recommended to connect the tool to a methodology already used in several health care organisations. A method can be 'Hooi op je vork' (Van Belle & Zadoks, 2011).

For a later stadium, it is recommended to look into online possibilities such as an interactive website or smartphone application. Also, the workbook can be expanded to other target groups. This, first, can be people with different disabilities. Later on, a version can be made for family members, friends, or parents of children with a disability.

References

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