

2.2.9 Involvement of the target group in the development process


Introduction

Health information that address laypersons should be oriented towards the target groups. It can be assumed that laypersons often have a different expectation of the contents and presentations in health information compared to the professionals. Other information is more important for laypersons or perhaps they find other information interesting, which from a medical point of view is thought to be less important (1). It can therefore be assumed that health information is more target-group-oriented if users of health information are included in the development or evaluation process.

Question

1. What effects does the involvement of the target group in the development process have?

Recommendation

	<p>Recommendation</p> <p>“The target groups should be involved in the development process of health information.”</p> <p>Agreed: 9, Disagreed: 0, Abstentions: 1</p> <p>Quality of the evidence: low quality</p>
<p>Comment on the recommendation:</p> <p>The recommendation refers to the comparison of producing of health information with and without the involvement of target groups in the preparation process.</p> <p>One study shows a positive effect in favor of inclusion for the cognitive outcome <i>knowledge</i>. This is also evident in <i>comprehensibility / readability</i> (in one out of two studies), <i>acceptance / attractiveness</i> (in two out of two studies) and in the relevance of the information (in two out of two studies). Overall, however, the impact of including the target group in the development of health information has hardly been examined.</p>	

Summary of the findings

Characteristics of the included studies

For this comparison three studies with a total of 436 participants were included. The sample sizes were between 24 and 235 and the age range was between 19 and 85 years, depending on the target group. The studies were carried out in the USA (2), Great Britain (3) and Norway (4). The included participants were women with breast cancer (2), and patients of both sexes who were awaiting surgery (3) or an endoscopy (4).

One intervention consisted of a website where the original was compared with the revised version (2), which had taken research on user preferences and guidelines on usability into consideration. The other interventions comprised health information on the subjects patient-controlled analgesia (3) and endoscopic operations (4), which were revised following interviews with affected people or after holding focus group meetings with the members of the target group.

Results for the relevant outcomes

Positive effects for including the target group were found for the outcomes *knowledge*, *acceptance / attractiveness* and the *relevance of the information* (2-4). For the outcome *comprehensibility / readability* no consistent effect was shown; however, there was a positive tendency towards inclusion (2, 3).

Evidence table

Table 26: Evidence table „Developing health information including versus not including the target group into the developing process”

Certainty assessment						Summary of findings				
						No. of participants per group		Effect estimates		
Outcomes [No. of studies]	Study design	Risk of bias	Inconsistency	Indirectness	Imprecision	Intervention	Control	Effects	Quality of evidence	Importance
Developing health information involving versus not involving the target group into the developing process										
Knowledge [1] Chumbley (3)	RCT	very serious (-2)	not serious	not serious	not serious	N= 50	N= 50	In one study effect for involvement (3).	low	critical
Comprehensibility / readability [2] Atkinson (2) Chumbley (3)	RCT	very serious (-2)	not serious	not serious	not serious	N= 127	N= 50	In one study effect for involvement (clarity) (3). In one study no effect (clarity) (2), but an effect for involvement regarding ease of navigation (2).	low	important but not critical
Acceptance / attractiveness [2] Aabakken (4) Atkinson (2)	RCT	very serious (-2)	not serious	not serious	not serious	N= 120	N= 115	In two studies effects for involvement (2, 4)	low	limited importance
Relevance of the information [2] Atkinson (2) Chumbley (3)	RCT	very serious (-2)	not serious	not serious	not serious	N= 127	N= 50	In two studies effects for involvement (2, 3)	low	not defined

References

1. Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. The Cochrane database of systematic reviews. 2006(3):CD004563. Epub 2006/07/21.
2. Atkinson NL, Massett HA, Mylks C, McCormack LA, Kish-Doto J, Hesse BW, et al. Assessing the impact of user-centered research on a clinical trial eHealth tool via counterbalanced research design. *Journal of the American Medical Informatics Association : JAMIA*. 2011;18(1):24-31. Epub 2010/12/21.
3. Chumbley GM, Hall GM, Salmon P. Patient-controlled analgesia: what information does the patient want? *Journal of advanced nursing* [Internet]. 2002; (5):[459-71 pp.]. Available from: <http://onlinelibrary.wiley.com/o/cochrane/clcentral/articles/833/CN-00444833/frame.html>.
4. Aabakken L, Baasland I, Lygren I, Osnes M. Development and evaluation of written patient information for endoscopic procedures. *Endoscopy*. 1997;29(1):23-6. Epub 1997/01/01.
5. Deutsches Netzwerk Evidenzbasierte Medizin. *Gute Praxis Gesundheitsinformation*. Version 2.0. Berlin: 2015. <http://www.ebm-netzwerk.de/gpgi> (Zugriff 05.01.2016).