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## A new method for patient participation in the Netherlands: 'a WIKI-based pilot study'

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**Background:** Although one of the items of the AGREE instrument stipulates that a high quality guideline should take patients' preferences into account, it still seems to be difficult to realize. Since there is not an ideal way of patient participation in guideline development we started a wiki-based pilot study. A wiki is a website-based collaboration tool where everyone can read, edit, and organize the contents.

**Purpose:** To investigate whether this innovative method is useful for patient participation in a national multidisciplinary subfertility guideline.

**Methods:** A broad collaboration of stakeholders was set up to develop a multidisciplinary guideline for subfertility. Apart from representatives of the Dutch patient organization we added an innovative method of direct patient participation, using WIKI-technology. Based on in-depth interviews we collected patients' preferences for subfertility care. Preferences were translated into a start set of 90 recommendations. From May till December 2008 content changes could be made on WIKIfreya ([www.freya.nl/web\\_wiki](http://www.freya.nl/web_wiki)). After moderating and categorizing, preferences were placed on WIKIfreya to prioritize in a big five combined with an evaluation questionnaire. This big five was used as direct input to our multidisciplinary guideline.

**Results:** A total of 265 unique recommendations were made and moderated in 289 recommendations. Overall 36.473 pages were viewed and 298 unique visitors could be identified. Even 81 visitors were prepared to give additional information. Website evaluation was completed by 45 patients and 80 patients prioritized recommendations into a big five. The vast majority was highly educated and within all different stages of subfertility treatment.

**Discussion:** This innovative method of patient participation seems to be promising regarding to the enthusiasm and willingness of patients to contribute. Nevertheless we see challenges for improvement in terms of developing a format for recommendations, continuous prioritizing method and bonding activities. Further research is recommended.