

153: USE OF FOCUS GROUPS TO INCORPORATE PATIENTS' VIEWS AND PREFERENCES INTO CLINICAL PRACTICE GUIDELINES (CPG)

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Background:

Patients' preferences are essential in defining optimal cancer treatment because of the uncertain outcomes and important side-effects. Their preferences should therefore be integrated in the development process of CPGs. The SOR project, run by the Federation of the French Cancer Centres (FNCLCC) since 1993, has developed CPG in oncology. The methodology is based on literature review and critical appraisal by a multidisciplinary group of experts, with feedback from specialists in cancer care delivery.

Objective:

To incorporate patients' views and preferences in the development process of CPG.

Methods:

Different focus groups were set up with five cancer patients to review a guideline draft. Participants had been informed about their role in the process. Their views and comments were transcribed and transmitted to the expert panel for inclusion in the final guideline.

Results:

In the CPG itself, the patients were satisfied with the presentation of treatment options but asked for a more detailed description of particular side effects. They said the need to give patients information on the full range of treatment options and the importance of patients' participation in treatment decisions should be emphasized more in the CPG. They considered the fact that the CPG included information on social and psychological aspects was very important, but felt that more information on psychological welfare should be given, and a clear recommendation to offer referral to a psychologist should be made. For the process, they found the scientific information difficult to understand, but considered the clinical algorithms helpful to understand the issues and treatment options. Depending on each patient's experience of their disease, they found reviewing the CPG to be an emotional experience.

Conclusions:

The study demonstrates the feasibility of incorporating patients' views into CPGs. It is important that patients are clearly informed about the purpose and limits of their input. However, the variability of individual preferences raises the question of the representativeness of participating patients. The modality of patients' involvement in the development process should be further investigated.