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A comparative study of patient involvement in cancer Guideline Development Groups: Project De-Colle

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The translation of research evidence into clinical practice guidelines (CPGs) by guideline development groups (GDGs) is determined by the evidence itself as well as by a variety of context variables, such as culture, organization of care and societal values. It has been shown that discrepancies between GDGs' recommendations and patient preferences [CABANA 1999, Schers 2001] are barriers to practice conformity. Patient and public involvement has been identified as a factor of quality for guideline development of CPGs (AGREE 2003). However there is wide variation in how patients values and preferences are taken into account in the guideline development process. [NILSEN2006].

Objective: understanding the mechanisms of collective decision-making and particularly the interaction between patients and experts in the guideline development process.

Methods: Qualitative study involving comparative observation of four French cancer guideline development groups (GDG) (breast cancer, lung cancer, 2 supportive care CPGs) and interviews with participating patients and experts. All but one GDG involved patient representatives

Results: Observation so far from three GDGs shows the feasibility of involving patients in the development of cancer CPGs in France. The decisions made by the GDGs (with or without patients) constitutes a dynamic process influenced by biomedical rationalities and complex rationalities as well as varieties of reasoning linked to the world outside of the GDG. Barriers and facilitators to patient involvement can be divided into four groups: disease specific, guideline development methodology, individuals and interactions among the panel members. The present study has been consecutively funded by the French National Health Authority (HAS) and the French National Cancer Institute (INCa).

The results of our study allows to better understand some of the mechanisms that intervene in patient involvement in cancer guideline development. Our presentation aims at depicting the results of this study and discussing it's meaning for patient involvement in cancer guidelines.