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«Machtfaktor Patient 3.0» – Patienten verändern das Gesicht des Gesundheitswesens

"The power of patients 3.0" – Patients are changing the face of health care

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Sharing personal electronic health record information: perspectives of patients and their health care providers

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Teaser: This qualitative study explores perspectives of patients with colorectal cancer and their health care providers on sharing health information within a personal electronic health record.

Background, objective: Patients with chronic conditions (e.g. colorectal cancer) have complex health care needs. In the course of treatment, personal health data is collected in different health care settings. A personal electronic health record (PEPA) as part of the project Health Regions of the Future (INFOPAT), funded by the Federal Ministry of Education and Research (BMBF) is being developed with the aim of improving the regional and cross-sectorial health care, especially for chronically ill people. This PEPA owned by patients could strengthen patient participation in their health care process. The record could summarize data from different settings and provide these to health care process participants. With this concept, patients decide who gains access to their record and its data. This qualitative study explores perspectives of patients with colorectal cancer and their health care providers regarding the question who should gain access to a patients' PEPA and which information should be shared.

Approach, methods, patient engagement: Overall 8 focus groups were performed, collecting views of three potential user groups (patients and representatives of patient support (n=14), medical doctors (n=10) and other health care professionals (n=16)). All data were audio- and videotaped, fully transcribed and thematically analyzed using qualitative content analysis.

Findings: First results show that overall patients like to share their health information with others. Discussed are themes like giving general record access, especially to their GP or in case of an emergency. Sharing their record with family members like spouses or trusted persons is also important for patients. However, the opportunity to withdraw access is wished. Medical doctors from different settings (hospital, GP's, ambulatory specialists) wished to have full access to all information in the record in order to make appropriate treatment decisions. Otherwise, from their perspective the PEPA would be useless.

Discussion and implications: Patients are willing to share their health information with health care professionals and others like family members. Giving access to family members could become relevant for instable situations in chronic conditions or in case of an emergency. Managing the access to a PEPA and its data gives patients the chance to take on an active part in their health care process. Arising challenges like professionals' concerns about practicability will be discussed.

Key terms: personal electronic health record, patients with colorectal cancer, sharing health information, sharing access