

Gö-VIP-13: Perry, J., Wöhlke, S., Heßling, A. C., & Schicktanz, S.

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Originalpublikation: *Why take part in personalised cancer research? Patients' genetic misconception, genetic responsibility and incomprehension of stratification – an empirical-ethical examination.* In: *European Journal of Cancer Care*, August, 2016, 12 p.,

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**Zusammenfassung des wissenschaftlichen Inhalts
(Perry et al. 2016)**

Our innovative research findings, based on an empirical-ethical study, for the first time in international research were able to reveal that patients do not grasp future stratification in cancer treatment by means of a biomarker. These findings are highly relevant for the ensuring of an informed consent procedure in clinical genetic research projects.

Despite enormous progress in treatment, cancer is still one of the most feared diseases of our time. A good diagnostic and treatment consultation therefore requires high communication skills both on the part of the physician and of the patient. Therapeutic misconception is a well-known challenge for informed decision-making for cancer research participants. From an ethical and clinical perspective this continues to be a serious problem. What is still missing, is a detailed understanding of the impact of 'personalised' treatment research (e.g. biomarkers for stratification) on research participants. For this, within our sub-

project 9 of the UMG's clinical research group (KFO 179/2), we conducted, the first longitudinal empirical-ethical study based on in-depth interviews with colorectal cancer patients (n=40). These patients were enrolled in biomarker research concerning (neo)adjuvant treatment response, in which context we analysed their understanding of and perspectives on research and treatment with qualitative methods.

Our findings provide insight into how cancer patients involved in personalised cancer research assess and (mis)interpret the information provided. We found misconception based on patients' confusion of research and treatment, and here triggered by misled motivation, information paternalism or incomprehension, we identified genetic misconception and genetic responsibility as new problematic issues.

Patients predominantly were not aware of the major research aim of future stratification into responders and non-responders nor did they fully acknowledge this as an essential aim of personalised cancer research. This shows that ethical and practical reflection on informed decision-making in cancer treatment and research needs to more strongly take into account the complexity of lay interpretations of modern personalised medicine. Further, given the detected low impact of written information, such as ICFs, the role of these documents should be critically assessed. Despite the high level of formal safeguarding of written consent forms through ethics committees, the actual practical consultations are not sufficiently examined or reflected on, constituting an ethical problem in the context of IC in clinical trial participation. Especially, if the content of the ICFs does not give patients the possibility of comprehensibly informing themselves, these must be altered and possibly combined with alternative strategies, entailing a more personalised communication approach to inform and motivate patients for cancer research.

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