

Parallel Short Course 5

ETHICAL AND LEGAL ISSUES IN PERSONALISED MEDICINE

Magdalena Flatscher-Thöni, Verena Stühlinger

Department of Public Health and Hta, Umit, Hall in Tyrol, Austria

Course Level: Beginner

Course Objectives: This short course aims at providing participants with a fundamental understanding of ethical and legal principles relevant in personalized medicine, focusing on the crucial issues of medical decision making.

Course Description:

Personalised medicine is commonly understood as “the targeting of therapies to individuals on the basis of their biological or genetic characteristics” (Goldman et al. 2013: 121). Hence, the concept of personalized medicine often promises a more “patient-centred” and a more “participatory” approach to health care (Juengst et al. 2012: 35). By promoting easy access to genetic testing, patients shall be able to control their own health risks and to prevent severe illnesses. Additionally, newly developed molecular markers and diagnostics shall tailor therapies more precisely to individual characteristics and thereby empower patients.

However, ethical and legal issues are often not sufficiently considered in personalized health care strategies. Examples can be found in the rising pressure on patients (and their family members) for conducting certain tests or interventions, potentially endangered disability rights, newly developed privacy and informed consent issues, unsecure access to health care for stratified and classified patient subgroups, or discrimination issues.

Given these developments, our short course is in a first step aiming at clarifying the underlying ethical and legal framework by discussing its key principles of health technology assessment in the context of personalised medicine. In the second part of the short course, we will present and discuss specific cases stressing ethical and legal issues in connection with clinical decision making and personalised medicine.

This short course is in part funded by the ONCOTYROL Center for Personalized Cancer Medicine GmbH. ONCOTYROL is a COMET Center funded by the Austrian Research Promotion Agency (FFG), the Tyrolean Future Foundation and the Styrian Business Promotion Agency (SFG).

Equipment:

Participants are not required to bring any special equipment.