

|                         |   |
|-------------------------|---|
| 1. Record Nr.           | UNINA9910508410103321   |
| Titolo                  | Personalized medicine : legal and ethical challenges / edited by Juli Mansnerus, Raimo Lahti and Amanda Blick   |
| Pubbl/distr/stampa      | Helsinki, : Faculty of Law, University of Helsinki, 2020  |
| ISBN                    | 9789515169419   |
| Descrizione fisica      | 1 online resource : illustrations   |
| Collana                 | Forum Iuris , 1456-842X   |
| Soggetti                | Biomedical Research<br>Gene Editing<br>Legislation, Medical<br>Reimbursement Mechanisms   |
| Lingua di pubblicazione | Inglese   |
| Formato                 | Materiale a stampa  |
| Livello bibliografico   | Monografia  |
| Nota di contenuto       | Preface / Raimo Lahti -- Introduction / Juli Mansnerus, Raimo Lahti and Amanda Blick -- Regulatory schemes in innovative healthcare and biomedicine / Raimo Lahti -- Building the regulatory framework for personalized medicine : case Finland / Sandra Liede -- 'Precision medicine' : critical reflections on Europe's latest healthcare paradigm / Celine E. Dujardin -- Genomic testing and giving consent on behalf of a child / Merike Helander -- Germline gene therapy : safeguarding the best interests of the child / Amanda Blick -- Over ten years since the adoption of the EU regulation on advanced therapy medical products -- lessons learned thus far / Juli Mansnerus -- On the lookout for experience : the legislative experiment of conditional pharmaceutical reimbursement in Finland / Waltter Roslin -- Transatlantic comparative perspectives on patenting genome-editing technologies -- a case study of patents on CRISPR/Cas9 technology / Liisa Vaaraniemi -- Interpretation of the patient's need for help can be supported with machine learning / Lauri Lahti. |
| Sommario/riassunto      | The paradigm of personalized medicine is an emerging topic, triggering some specific legal and ethical challenges as regards data collection, sharing and use, informed consent, privacy and public trust, and the changing status of patients and social equality. These   |

legislative developments and challenges have been discussed in light of the Finnish and the common-European experiences. During recent years, the Finnish legislative processes aiming at generating 'innovation-friendly' legislation for scientific research purposes as well as integrating genomic research results into the clinical setting have been heavily challenged by rapid developments in technology and medicine. In particular, there is a need to pursue the right balance between scientific and commercial interests, public health, and individual rights. We aim at providing insights into the legislative processes surrounding personalized medicine with a special focus on how the freedom of science, equitable access to healthcare, public health, and commercial issues that must be balanced with individual rights as expressed in the EU Charter and the Council of Europe's Oviedo Convention on Human Rights and Biomedicine.

---