

Virtual 3rd EULAC PerMed Summer School

“Implementing PM Research into practice: Ethical, Legal and Societal Aspects perspective “

24th- 26th November 2020

READING & SUPPORT MATERIALS

A.- Bibliography (last consultation date 09.11.2020)

- Aicardi C et al. Emerging ethical issues regarding digital health data. On the World Medical Association Draft Declaration on Ethical Considerations Regarding Health Databases and Biobanks. *Croat Med J.* 2016;57:207-13 doi: 10.3325/cmj.2016.57.207
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- Jun Arai R et al, Personalizing Precision Oncology Clinical Trials in Latin America: An Expert Panel on Challenges and Opportunities *The Oncologist* 2019;24:e709–e719 www.TheOncologist.com
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- Lucivero F &, Prainsack B. The lifestylisation of healthcare? ‘Consumer genomics’ and mobile health as technologies for healthy lifestyle. *Applied & Translational Genomics* 4 (2015) 44–49
- McCabe &, Husereau, 2014. Personalized Medicine and Health Care Policy: From Science to Value. *Policy Brief No. 9* February 2014

- Randy Vogenberg et al. Personalized Medicine, Part 2: Ethical, Legal, and Regulatory P&T Vol. 35 No. 11 • November 2010
- Romeo Casabona et al. Retos Éticos y Necesidades Normativas en la Actividad Asistencial. En Medicina Personalizada de Precisión. 1-165. Fundacion Roche.2018
- Rojas Mezarina et al. Need for the Development of a Specific Regulatory Framework for Evaluation of Mobile Health Apps in Peru: Systematic Search on App Stores and Content Analysis. JMIR Mhealth Uhealth 2020 | vol. 8 | iss. 7 | e16753 |
- Sariyar M and Schlünder I (2019)Challenges and Legal Gaps of Genetic Profiling in the Era of Big Data. Front. Big Data 2:40. doi: 10.3389/fdata.2019.00040
- Tibor van Rooij, Donna M Wilson & Sharon Marsh ,2012 Personalized medicine policy challenges: ensuring clinical utility at point of care, Expert Review of Pharmacoeconomics & Outcomes Research, 12:3, 289-295, DOI: 10.1586/erp.12.15
- Wallace SE, Kirby E and Knoppers BM (2020) How Can We Not Waste Legacy Genomic Research Data? Front. Genet. 11:446. doi: 10.3389/fgene.2020.00446

B.- Sitography (last consultation date 09.11.2020):

- <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6616181/>
- <https://svn.bmj.com/content/2/4/230>
- <https://www.sciencedirect.com/science/article/pii/S254266051930232X>
- https://www.who.int/chp/chronic_disease_report/part1/en/index3.html
- <https://www.who.int/bulletin/volumes/98/4/19-237487-ab/en/>
- https://edpb.europa.eu/our-work-tools/our-documents/publication-type/guidelines_en
- https://www.icpermed.eu/media/content/ICPerMed_Actionplan_2017_web.pdf
- https://www.icpermed.eu/media/content/Vision_Paper_2019.pdf
- <https://en.unesco.org/themes/ethics-science-and-technology/human-genome-and-human-rights>
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- OECD Guidelines on Human Biobanks and Genetic Research Databases. <http://www.oecd.org/sti/emerging-tech/44054609.pdf>
- http://www3.weforum.org/docs/WEF_Genomic_Data_Policy_and_Ethics_Framework_pages_2_020.pdf
- <https://fr.weforum.org/reports/precision-medicine-vision-statement-a-product-of-the-world-economic-forum-global-precision-medicine-council>