

“Hepatologia em Rede”: A Portuguese Association for the Study of the Liver (APEF) Initiative for the Improvement of Research in Liver Disease in Portugal

Rui Caetano Oliveira^a Susana Rodrigues^b Joana Espírito Santo^c
on behalf of Hepatologia em Rede

^aGermano de Sousa - Centro de Diagnóstico Histopatológico CEDAP, Coimbra, Portugal; ^bCoimbra Institute for Clinical and Biomedical Research (iCBR), Centre of Investigation on Genetics and Oncobiology (CIMAGO), Coimbra, Portugal; ^cDepartment of Visceral Surgery and Medicine, Inselspital, Bern University Hospital, University of Bern, Bern, Switzerland

“Hepatologia em Rede” — uma iniciativa da Associação Portuguesa para o Estudo do Fígado (APEF) para a investigação em hepatologia em Portugal

Introduction

Liver diseases represent an annual 2 million deaths worldwide [1]. Regarding mortality, cirrhosis is responsible for more than 1 million deaths worldwide, and liver cancer is responsible for almost 800,000 deaths/year [2, 3]. Furthermore, chronic liver disease leads to a high burden of disability and increased health care utilization, and its estimate is likely to be conservative and underestimated [4, 5].

Specifically, in Portugal, liver disease burden is still a major health problem [6, 7]. Liver diseases are the 7th cause of death, with an increase in chronic liver disease, as seen in

Europe globally, mainly due to alcohol consumption and increasing cases of obesity and diabetes mellitus [7, 8].

During the past 3 decades, liver disease research has delivered significant breakthroughs. Promoting continuous cooperation between researchers, stimulating synergies between different research domains and boosting more high-quality research studies will lead to an improvement in management of many high-concern liver diseases more effectively. At present, most studies published in hepatology, in Portugal, are overwhelmingly single-centre and retrospective studies, with inherent biases. Furthermore, some areas of hepatology, such as alcohol-related liver disease have fewer studies supported by the pharmaceutical companies, although they represent a very heavy burden from a public health perspective [9].

Therefore, multicentre and prospective research projects will allow for data that are more accurate and the development of precise strategies for liver diseases. In Portugal, these studies have been very difficult to implement. Although there is a national patient registry platform,

Liver.pt, that was successfully used to perform a Portuguese cohort study in primary biliary cholangitis [10], it has never used to its full potential due to lack of common projects or capacity to coordinate them.

“Hepatologia em Rede” Programme

It is in this context that the programme “Hepatologia em Rede” was born. This initiative from the Portuguese Association for the Study of the Liver (APEF) has a mission to improve national research in hepatology, in basic and clinical fields, support competitive research projects and thus, to amplify the Portuguese scientific position in the global hepatology research community.

The objectives of the network hepatology programme are:

1. To enhance and develop national research in the area of hepatology, in basic and clinical science;
2. To homogenize at a national level the scientific quality of the works produced;
3. To stimulate scientific dialogue and promote cooperation, as well as establishment of partnerships between different national and international hepatology research units, enhancing synergies and networking research projects;
4. To enlarge the scientific production and to promote the realization of research works with increasing quality and relevance;
5. To disseminate in the educational and scientific communities, nationally and internationally, the research carried out in hepatology;
6. To support the training of young researchers;
7. To encourage the submission of projects to specific national and international funding programmes, helping to create the conditions for their feasibility;
8. To centralize reference contacts in foreign institutions for research and specific scientific training;
9. To disseminate its work programme and its results.

Call to Action!

Since its establishment in 2021, “Hepatologia em Rede” has already received several collaborative national cohort projects. One example is a cross-sectional

study on the prevalence of Wilson’s disease in Portugal. This study will be merged with data from the Spanish cohort of Wilson’s disease to produce robust data on an understudied and rare liver disease. Collaboration is an essential principle for scientific advancement, and for this reason, we strongly encourage *all* national centres which regularly treat liver patients to adhere to this programme.

Hepatologia em Rede Committee

José Presa, Helena Cortez-Pinto, Carlos Ferreira, Dalila Costa, Filipe Nery, Susana Gomes Rodrigues, Joana Espírito Santo, Mariana Cardoso, Mariana Machado, Mário Jorge Silva, Rui Caetano Oliveira, Sílvia Vilarinho.

Statement of Ethics

Not applicable.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

Funding Sources

No funding was provided.

Author Contributions

All authors contributed equally to this manuscript.

Data Availability Statement

All data generated or analysed during this study are included in this article. Further enquiries can be directed to the corresponding author.

References

- 1 Mokdad AA, Lopez AD, Shahraz S, Lozano R, Mokdad AH, Stanaway J, et al. Liver cirrhosis mortality in 187 countries between 1980 and 2010: a systematic analysis. *BMC Med.* 2014 Sep 18;12:145. <https://pubmed.ncbi.nlm.nih.gov/25242656/>.
- 2 Beste LA, Leipertz SL, Green PK, Dominitz JA, Ross D, Ioannou GN. Trends in burden of cirrhosis and hepatocellular carcinoma by underlying liver disease in US veterans, 2001–2013. *Gastroenterology*. 2015 Nov 1; 149(6):1471–82.e5; quiz e17–8.

- 3 Asrani SK, Devarbhavi H, Eaton J, Kamath PS. Burden of liver diseases in the world. *J Hepatol*. 2019 Jan 1;70(1):151–71.
- 4 Global Health Data Exchange | GHDx [Internet]. [cited 2022 Jul 5]. Available from: <https://ghdx.healthdata.org/>.
- 5 Pimpin L, Cortez-Pinto H, Negro F, Corbould E, Lazarus JV, Webber L, et al. Burden of liver disease in Europe: epidemiology and analysis of risk factors to identify prevention policies. *J Hepatol*. 2018;69:718–35.
- 6 Silva JM, Silva MJ, Calinas F, Nogueira PJ. Burden of Liver Cirrhosis in Portugal between 2010 and 2017. *GE Port J Gastroenterol*. 2021 Apr 1;28(3):153–61. <https://www.karger.com/Article/FullText/510729>.
- 7 Allaire J, Balk M, Azmi S, Yang K, Barnes G, Sousa R, et al. PGI19 costs and burden of nonalcoholic fatty liver disease in Portugal. *Val Health*. 2020 Dec 1;23:S536. Available from: <http://www.valueinhealthjournal.com/article/S1098301520330412/fulltext>.
- 8 Pinho I, Santos JV, Dinis-Ribeiro M, Freitas A. Burden of digestive diseases in Portugal: trends in hospitalizations between 2000 and 2010. *Eur J Gastroenterol Hepatol*. 2015 Mar; 27(3):279–89.
- 9 Ndugga N, Lightbourne TG, Javaherian K, Cabezas J, Verma N, Barritt AS 4th, et al. Disparities between research attention and burden in liver diseases: implications on uneven advances in pharmacological therapies in Europe and the USA. *BMJ Open*. 2017;7(3):e013620.
- 10 Cortez-Pinto H, Liberal R, Lopes S, Machado MV, Carvalho J, Dias T, et al. Predictors for incomplete response to ursodeoxycholic acid in primary biliary cholangitis. Data from a national registry of liver disease. *UEG J*. 2021 Jul 1;9(6): 699–706. <https://onlinelibrary.wiley.com/doi/full/10.1002/ueg2.12095>.