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Country: Slovakia 

Affiliations:

- **Slovak Medical University in Bratislava**
 - Faculty of Medicine – Department of Clinical Pharmacology
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 - Outpatient Office for Clinical Pharmacology & Hepatology
- **Hep Help Klub Slovakia**
- **European Liver Patients ´ Association**

Function: clinical pharmacologist - physician and university teacher with focus on liver diseases

Main expertise: clinical pharmacology, hepatology, clinical research, research ethics, rare diseases, patient education



VHPB Regional meeting
*Elimination of Viral Hepatitis in the Czech Republic, Hungary, Poland and Slovakia:
Lessons Learnt and the Way Forward*
PRAGUE, CZECH REPUBLIC; 29-30 October 2024
Session 5: Treatment policies and linkage to care

The role of patient organizations in hepatitis elimination - local Slovakian example and international / global insights

Helena Glasova

*Slovak Medical University, Slovakia
Hep Help Klub, Slovakia
European Liver Patient Association (ELPA)*



- organization of patients with liver diseases, their relatives and other concerned persons
- in collaboration with medical specialists aims at improving their access to reliable professional information
- enables mutual contacts, support, and possibilities of various beneficial activities
- organizes patients' educational events and other works
- works in collaboration with partner patients' organizations in Slovakia and abroad and scientific societies such Slovak Society of Hepatology and Slovak Society of Clinical Pharmacology
- www.hephelpklub.sk



- belongs to the oldest patients' organizations of patients with liver diseases in Slovakia
- established in 2006 responding to the spontaneously felt need of mutual support, help, and education of patients and their relatives during some time ago very demanding course of active treatments of chronic viral hepatitis B and C
- at present, after the advent of very effective and usually also well-tolerated drugs for the treatment of viral hepatitis B and C, we see an increasing need to help the patients with other serious liver diseases, such as non-alcoholic steatohepatitis (NASH; more recently depicted as metabolically-associated steatohepatitis (MASH)), autoimmune hepatitis (AIH), liver fibrosis and cirrhosis, primary biliary cholangitis (PBC), primary sclerosing cholangitis (PSC), drug -induced liver injury (DILI), cholestasis of pregnancy, and others
- member of the European Liver Patients Association (ELPA)
- member of the World Hepatitis Alliance

Cooperation of the Hep Help Klub and Šanca pre pečeň with the WHO Country office - Slovakia

- a project implemented by the Institute of Epidemiology of the Faculty of Medicine of the Comenius University in Bratislava (LF UK), in cooperation with the Society of General Physicians of Slovakia (SVLS) and the Alliance of General Practitioners (GPs) of Slovakia (AVLS)
- financed by a grant from the office of the World Health Organization (WHO) in Slovakia
- aims to obtain a more realistic view of the occurrence of sexually and blood-transmitted infections in the Slovak population and to raise awareness of this issue
- distribute 3,000 rapid tests aimed at the detection of syphilis, HIV, HBV and HCV to selected outpatient clinics of general practitioners in the Bratislava, Banská Bystrica and Košice regions.
- prepared an information leaflet in connection with this project, the purpose of which is to point out the importance of this issue, will be printed in A5 size, double-sided, in a run of 16,000 copies, and will be distributed to GP surgeries; it includes a link to initiatives, non-profit organizations and associations that have been involved in this issue for a long time

The image displays four informational leaflets related to sexually transmitted infections (STIs) and blood-borne infections. The top-left leaflet, titled 'Sexuálne a krvou prenosné infekcie', discusses the transmission of these infections and lists bacterial and viral pathogens. The top-right leaflet, 'Prevencia', provides advice on using condoms, vaccination, and safe sexual practices. The bottom-left leaflet, 'Mýty a fakty', addresses common misconceptions about STIs. The bottom-right leaflet, 'Iniciatívy', lists various support organizations and services available in Slovakia, including ZNIE, HIV/AIDS, HEPHELP KLUB, and others. Each leaflet includes QR codes for further information.

ELPA Clinical Trials Program –
Second Part
"Building Patient Experts in
Clinical Trials,, May 12-13, 2023
extraordinary international
course organized by ELPA in
cooperation with the
Department of Clinical
Pharmacology, Faculty of
Medicine and the Institute of
Medical Ethics and Bioethics,
Faculty of Nursing and Medical
Professional Studies at the
Slovak Medical University
in Bratislava, Slovakia





Šanca pre pečeň/ A chance for the liver

- civil association of patients with liver disease, mainly viral and non-alcoholic, of their family members, friends and sympathizers
- organises events for members and the general public with lectures by doctors and specialists - experts in health, nutrition and lifestyle
- mission of the association is education, support of education and expansion of professional knowledge in the field of medicine and public health, with a focus on the issue of liver diseases
- in relation to the rights and obligations of patients with liver diseases
- support and organization of various activities for members of the association and other interested parties in accordance with the mission and goals of the association
- <https://www.siriushepi.sk/>
- <https://www.sancaprepecen.eu/>



ASSOCIATION FOR THE PROTECTION OF PATIENTS' RIGHTS (AOPP)

- national umbrella patient organization in Slovak republic
- founded in 2001
- currently unites 50 patient organizations - focused on various individual diagnoses
- provides patients with medical, social and legal advice, informs them about their rights and obligations, as well as about the functioning of the health care system
- actively participates in creating Slovak and European legislation
- represents Slovak patient organizations abroad; member of EPF and IAPO
- dedicated to educating the general public as well as its members on current patient topics



AOPP

Asociácia na ochranu práv
pacientov SR, o. z.

Project „Medications wisely“ of AOPP with support of Ministry of Health of SR

Sem napíšte čo Vás zaujíma



Beriete lieky s rozumom?

VŠETKO,
ČO BY STE MALI VEDIET
O ROZUMNOM
UŽÍVANÍ LIEKOV



AOPP

Asociácia na ochranu práv
pacientov SR, o. z.

O PROJEKTE

AKO NA LIEKY S ROZUMOM?

UŽITOČNÉ LINKY

UŽÍVANIE

INTERAKCIE

VEDĽAJŠIE ÚČINKY

TYPY LIEKOV

KVÍZY A VIDEÁ

ZDRAVOTNÍCTVO

TEHOTENSTVO/DETI

ANTIBIOTIKÁ

the guarantor of the project was the Institute of Pharmacology, Clinical and Experimental Pharmacology, Faculty of Medicine and Institute of Medical Ethics and Bioethics, Slovak Medical University in Bratislava

Patient organisations in Slovakia – Liver Diseases – Viral Hepatitis – Elimination/Treatment Policies

- long lasting and meaningful tradition of active involvement of patient organisation's representatives in various initiatives and efforts in the field of liver diseases in Slovakia
- Slovak Society of Hepatology and Slovak Society of Clinical Pharmacology – participation of patient's representatives at Annual Conferences, with special educational programme/panel discussions
- thematic courses of continuous education - educational programme for patients organised by the Institute of Pharmacology, Clinical and Experimental Pharmacology at the Faculty of Medicine, Slovak Medical University in Bratislava „Patient and Drug“ – in line with and by active participation in the IMI EUPATI project
- participation of patient representatives at multi-stakeholder meetings and negotiations on issues such as access to care and development and creation of national recommendations / guidelines, participation in the legislative process

International symposium "Liver and Drugs '08, Viral hepatitis - a health priority in the European Union"

- on the grounds of the Ministry of Health of the Slovak Republic in Bratislava
- resulted in the so-called **Bratislava Declaration**
- multi-stakeholder event / participating organizations:
 - National Reference Centre for Treatment of Chronic Hepatitis of the Slovak Medical University, Ministry of Health of the Slovak Republic, WHO Europe, WHO Country Office Slovakia, Slovak Society of Hepatology of the Slovak Medical Association, European Parliament Committee on the Environment, Public Health and Food Safety (ENVI EP), European Association for the study of the Liver (EASL), WHO Euro, WHO Slovakia, DG SANCO (DG SANTE - Directorate-General for Health and Food Safety), European Centre for Disease Prevention and Control (ECDC), The European Union Drugs Agency, known until 2024 as the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA), National Drug Monitoring Center, national health insurance companies, national patient organisations representatives and ELPA

BRATISLAVA DECLARATION 2008

1. Chronic viral hepatitis B and C (CHB/CHC) is a serious medical, public health, social and economic problem on a global scale, in Europe as a whole, and in Central and Eastern Europe in particular. Unfortunately, in Europe, especially in Central and Eastern Europe, there is still no adequate monitoring of the incidence and prevalence of hepatitis B and C.
2. We support and join the initiatives of the European Association for the Study of the Liver (EASL), the European Liver Disease Association (ELPA) and the World Hepatitis Alliance (WHA) in the field of prevention and active health and research policy in the field of CHB/CHC.
3. It is necessary to emphasize prevention, proactive screening and timely diagnosis of persons from risk groups (users of injected drugs, prisoners, people infected with HIV, immigrants from endemic countries, hemophiliacs, health workers, children, pregnant women, etc.).
4. It is necessary to initiate and support the development and financing of comprehensive and well-managed national information campaigns.
5. It is necessary to develop innovative and economically effective preventive measures and programs with the aim of reducing the prevalence and incidence of hepatitis B and C and their complications.
6. We request that the 27 EU member states adopt the Recommendation of the European Council on targeted screening of hepatitis B and C in Europe. This would ensure earlier diagnosis and wider availability of treatment and health care.
7. It is important to ensure effective and safe treatment of hepatitis B and C, which would be in accordance with current European standards (professional recommendations - English guidelines). Rational pharmacotherapy can reduce
8. It is also necessary to improve the clinical infrastructure to ensure care for patients with hepatitis B and C.
9. The goal of health care providers and payers, the health and pharmaceutical industry, as well as responsible state authorities should be to ensure the provision of high-quality, affordable and sustainable health care for patients with CHB/CHC with the aim of improving their quality of life and prolonging it. It is essential to ensure coordinated activities and participation of all relevant institutional, intergovernmental and non-governmental partners.
10. The goal of expanded cooperation and partnership in the field of hepatitis B and C is to achieve greater efficiency and economy.
- 11. Patient organizations should publicly promote and support effective models of cooperation at the national and international level.**
12. It is essential to support initiatives aimed at increasing public and private funding of public health, clinical and socio-economic research on hepatitis B and C at the EU level, as well as at the national and wider international level.

NÁRODNÝ PROGRAM PREVENČIE CHORÔB PEČENE

História a perspektíva odboru hepatológia

Jozef Holomáň, Jozef Glasa, Ľubomír Skladaný, Ester Ďuráková, Oľga Štefanická
Ústav farmakológie, klinickej a experimentálnej farmakológie Lekárskej fakulty SZU v Bratislave

- **National Program of Liver Disease Prevention**

- Jozef Holomáň, Jozef Glasa, Ľubomír Skladaný = Slovak Society of Hepatology
- Ester Ďuráková = Hep Help Klub = liver patient's organization
- Oľga Štefanická = Šanca pre pečeň = liver patient's organization

Stručná osnova Národného programu prevencie chorôb pečene (NPPCHP):

Brief outline of the National program of liver disease prevention

- A. Preambula
- B. Ciele, základné princípy tvorby a poslanie NPPCHP
- C. Epidemiologická situácia v SR a EU
- D. Narastajúca prevalencia, závažnosť, medicínska, ekonomická a spoločenská záťaž chorôb pečene
- E. Prioritné problémy - primárna prevencia, aktívny skríning, dispenzár, sekundárna prevencia, transplantačný program pečene
- F. Národné registre najzávažnejších chorôb - chronické hepatitídy (cirhózy pečene) hepatocelulárny karcinóm pečene
- G. Prioritné diagnózy a ich riešenie - NAFLD, ALD, chronické vírusové hepatitídy, cirhóza pečene, rakovina pečene
- H. Štandardy a kvalita - odborné odporúčania (Metodické listy racionálnej farmakoterapie), odborné usmernenia (Vestník MZSR)
- I. Výskum v hepatológii - koordinácia, národné a medzinárodné angažovanie
- J. Pacientske organizácie - spolupráca, edukácia, implementácia
- K. Špecifikácia nástrojov a zdrojov na implementáciu, plnenie, monitorovanie a hodnotenie NPPCHP - finančné zdroje, vládne organizácie, mimovládne organizácie, súkromný sektor, ...
- L. Členstvo a spolupráca na národnej a medzinárodnej úrovni
- M. Adresy
- N. Info stránka 1. HEP-NET SK, 2. EASL....
- O. Prílohy - grafy, tabuľky, normy NPPCHP, koordinačný výbor, ekonomické analýzy, zoznam literatúry, zoznam skratiek

J. Patient organisations –
cooperation, education,
implementation



Innovative Medicines Initiative



The European Patients' Academy on Therapeutic Innovation (EUPATI)

- multi-stakeholder public-private partnership
- originally launched by the IMI-EUPATI project (2012-2017)
- hosted by the European Patients' Forum (EPF) from 2017 to 2020
- today established as an independent non-profit foundation in the Netherlands
- successful programme
- provides education and training to increase the capacity and capability of patients and patient representatives to understand and meaningfully contribute to medicines research and development (R&D) and to improve the availability of medical information for patients and other stakeholders



The European Patients' Academy on Therapeutic Innovation (EUPATI)

- it does so by conducting its established **Patient Expert Training Programme** which has trained more than 330 Patient Experts (EUPATI Fellows)
- more than 1170 currently enrolled via the **EUPATI Open Classroom**
- in addition, EUPATI provides an **open-access multilingual Toolbox** that has served more than 7.5 million users in 14 languages around the world to date



Online Toolbox



Open Classroom



Learning Lab



EUPATIConnect



National Platforms

What is Meaningful Patient Engagement?

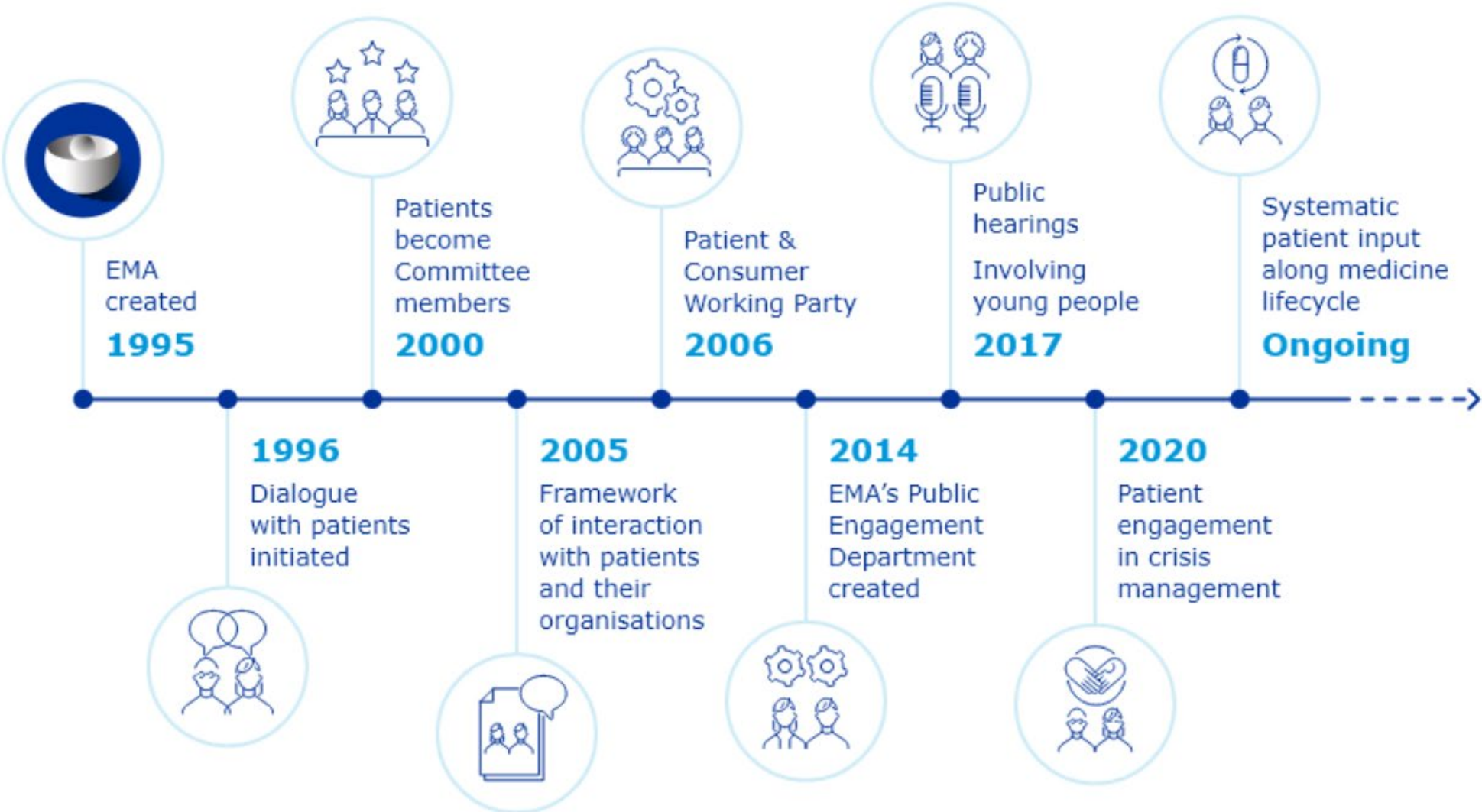
Existing codes of practice for patient involvement with various stakeholders do not comprehensively cover the full scope of research and development (R&D). The European Medicines Agency (EMA) has developed a comprehensive [framework of interaction with patients and consumer](#) organisations since 2006.

The European Patients' Academy (EUPATI) guidance documents aim to support the integration of patient involvement across the entire process of medicines research and development with regulatory agencies, health technology assessment (HTA) bodies, ethics committees and the pharmaceutical industry.

Patients and consumers

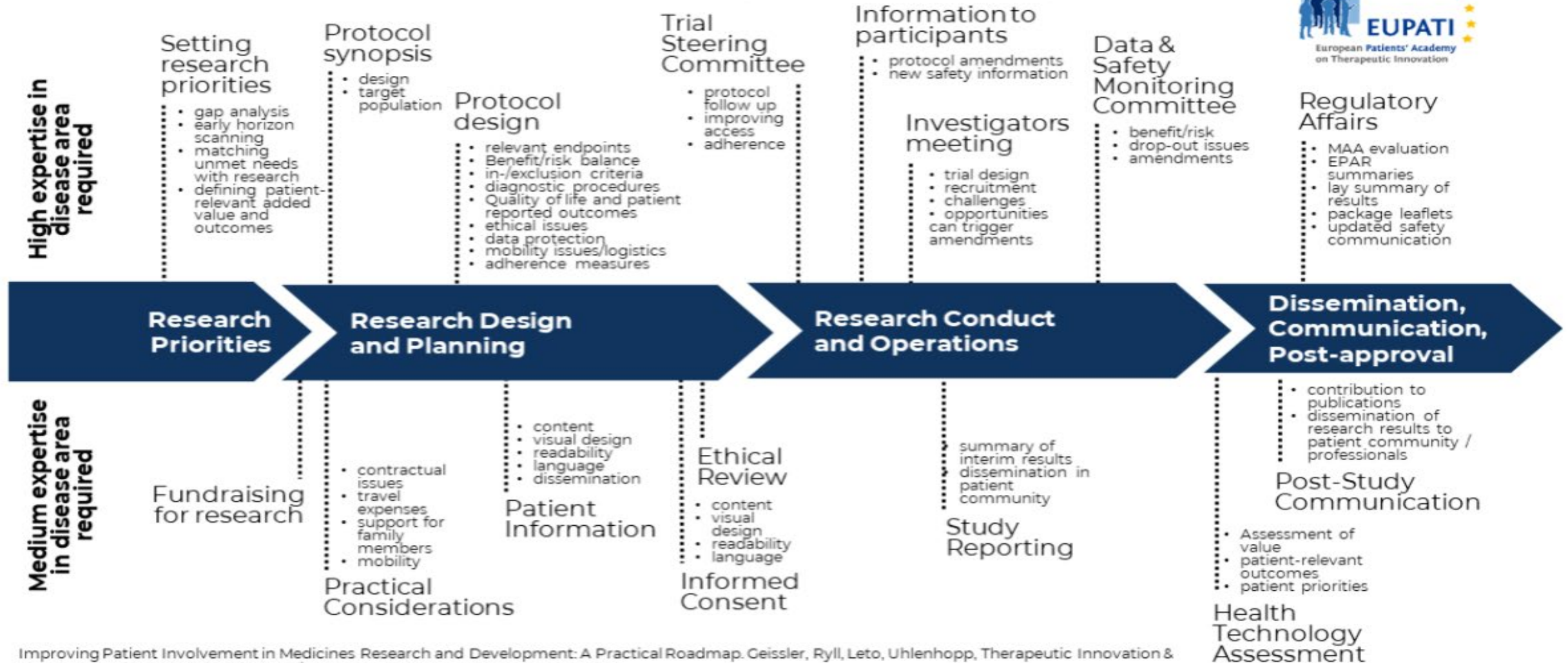


The European Medicines Agency (EMA) and patients have been actively interacting since the creation of the Agency in 1995. This cooperation was extended to include consumer groups with an interest in medicines.



What is Meaningful Patient Engagement?

Patient involvement in medicines R&D: a practical roadmap



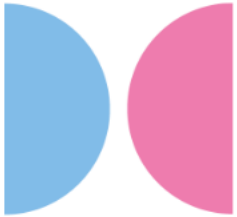


- international network of organisations working in over 100 countries towards the goal of eliminating hepatitis by 2030.
- WHA network comprises civil society and community organisations across the world (ELPA as well as the Hep Help Klub Slovakia is a long time member)
- Leads the fight against hepatitis through advocacy, capacity building and awareness raising
- led and governed by people with lived experience of hepatitis and ensure that people with lived experience of hepatitis are at the heart of everything they do
- <https://www.worldhepatitisalliance.org/>




Hepatitis Delta Global Landscape Survey

Tackling Data Gaps To Increase Awareness And Prioritisation



**The
Hepatitis Delta
Global Landscape
Survey**



**Encuesta
Mundial sobre el
Panorama de la
Hepatitis Delta**



**Enquête
Mondiale sur
le Paysage de
l'hépatite Delta**



[BE PART OF OUR GLOBAL SURVEY HERE](#)



Break the silence around hepatitis stigma and discrimination.

Please take this survey

Hepatitis Stigma Survey: exploring the experiences of living with hepatitis B and/or C

Exploring the experiences of living with hepatitis B and/or C



European Liver Patients' Association

Aim

- to promote the interests of people with liver disease
- to highlight the size of the problem
- to promote awareness and prevention;
- to share experience of successful initiatives;
- to work with professional bodies such as EASL and with the EU to ensure that treatment and care are harmonised across Europe to the highest standards

Mission

- ELPA emerged from a desire amongst European liver patient groups to share their experiences of the often very different approaches adopted in different countries.
- In June 2004, 13 patient groups from 10 European and Mediterranean Basin countries met to create the association
- ELPA formally launched in Paris on April 14th 2005 during the annual conference of the European Association for the Study of the Liver (EASL)
- now has 39 members from 29 countries



Activities of European Liver Patient's Association (ELPA) – opportunities and inspirations for our circumstances

EU Research Projects



ELPA Projects



Projects, working groups



- Social Media Work
- International and ELPA's Social Media Campaigns
- ELPA Educational Training
- EU Advocacy work putting liver disease higher on the agenda of MEPs and policy-makers
- EU Testing Week
- HOT TOPIC on AIR series
- Improving the knowledge about the liver as an organ
- HepFreeBadge
- Women and HBV
- Epiphone PWIDs
- Harm reduction working group
- Working group for lifestyle management of liver patients and seminars on quality of life
- Multicultural working group
- Music4Life
- ELPA Screening Initiative
- ELPA Scientific Work
- ELPA Medical Research
- Advertisement in ELPA's Annual report
- Call CENTERS - COVID19 Call centre for liver patients
- ELPA members' national project support
- Roundtable on clinical trials and data ownership
- Mapping liver cancer treatments across Europe – a collaboration with DiCE
- Liver Paediatric Diseases



International projects, consortia of the European Commission



IP-cure-B has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847939



LIVERHOPE has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 731875



LIVERSCREEN has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847989



MICROB-PREDICT has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825694



A-TANGO has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 945096



DECISION has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 847949



GALAXY has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 668031



ESCALON has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No. 825510



FisPlat has received funding from the EIT Health under grant agreement No. 20308



COvid-19 vaccination and Biomarkers in cirrhosis And post-Liver Transplantation (COBALT)



Communication and Collaboration with stakeholders - Network



- European Medicines Agency
 - PRAC committee
- European Society for Medical Oncology (ESMO)
- International Liver Cancer Association (ILCA)
- European Patient Forum
- European Association for the Study of the Liver (EASL)
- United European Gastroenterology (UEG)
- European Patients' Academy on Therapeutic Innovation (EUPATI)
- World Health Organisation
- ...



European Liver Screening Week 2024



European Liver Patients' Association

30 September at 20:28 · 🌐

🚩 For the FIRST TIME EVER on the Esplanade in front of the European Parliament, we have not one but TWO liver units in action! 🇺🇰 🇫🇷

Our incredible member from France 🇫🇷, SOS Hépatites, is here with their unstoppable team, making history as part of the BIGGEST European Liver Screening Week! 🌟🌟

This is what ELPA is all about — standing tall with our patient community, driving change, and delivering life-saving screenings at the heart of Europe! Let's show the world what we can achieve together! 🤝💚

Under the patronage of the European Parliament and the president Roberta Metsola

#EuropeanLiverScreeningWeek #ELPA #LiverHealth #BreakingBarriers #MakingHistory

#LiverHealth #EU #ELPA #Liver4Life #EuropeanParliament #HealthMatters

October #LiverCancerAwarenessMonth

#RobertaMetsola #EuropeanParliament #LiverHealth #FreeScreening #SOSHépatites

#EUCancerPlan



European Liver Patients' Association

7 October at 12:47 · 🌐

We are deeply grateful to our incredible supporters who have made this year's #EuropeanLiverScreeningWeek a #groundbreaking #success! 🙌 With over 400 individuals (MEP, Staff...) screened in one week, powered by two dedicated units—Liver4Life from the UK and SOS Hépatites France—and an extraordinary team of 20 passionate patient advocates, scientists and nurses, we brought liver screening to the heart of Brussels like never before.

