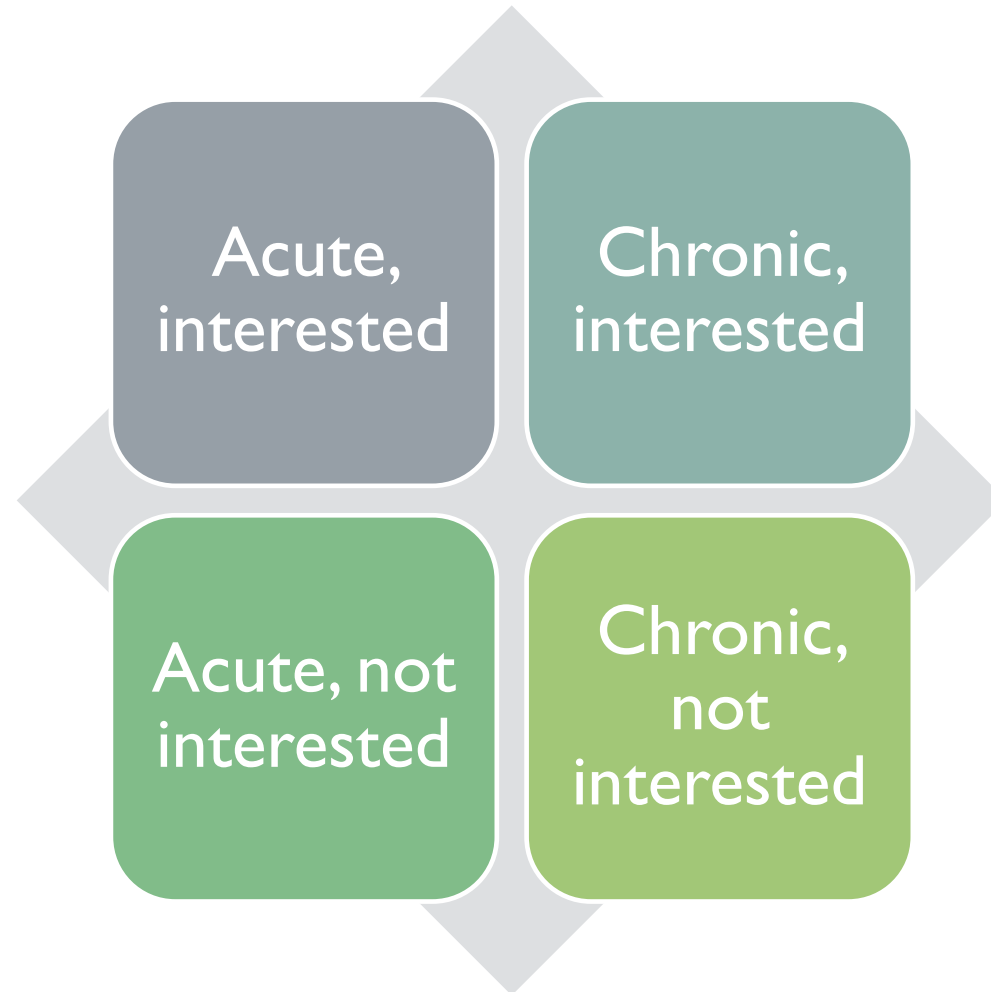


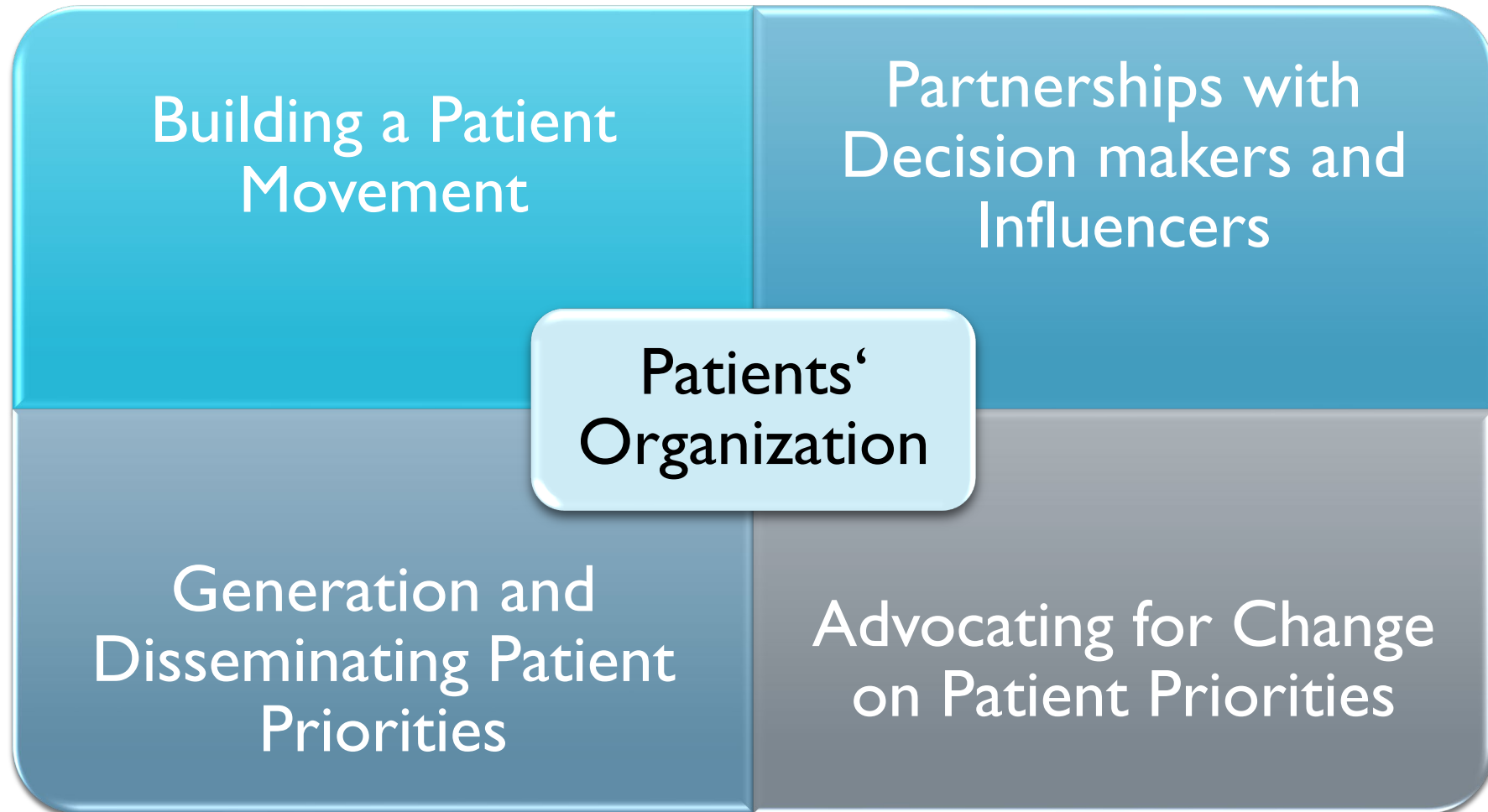
ROLE OF PATIENT  
ASSOCIATIONS

**VHPB BALKAN  
MEETING**  
*SESSION 4*  
*LITERATURE SESSION*

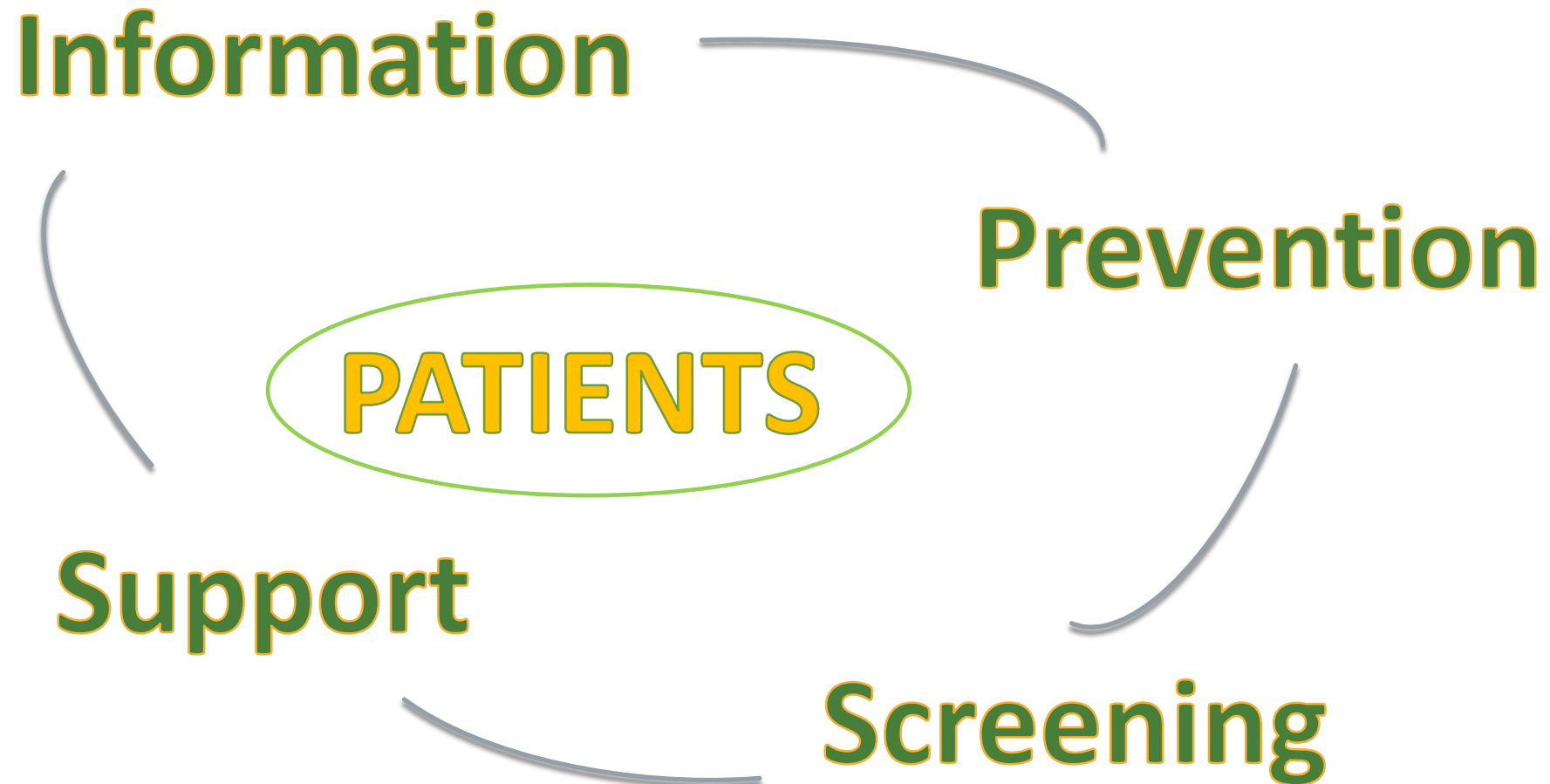
# DIFFERENT PATIENTS – DIFFERENT EXPECTATIONS – DIFFERENT LEVEL OF ENGAGEMENT



# ROLE OF PATIENT ASSOCIATIONS I



## ROLE OF PATIENT ASSOCIATIONS II



# ROLE OF PATIENT ASSOCIATIONS III



Involving patients in the communication with general public

Re-shaping Institutions to be more open to patient advocacy



A multi-stakeholders approach

Increasing funding for Patients' Associations



## ROLE OF PATIENT ASSOCIATIONS – ADDITIONAL GOALS

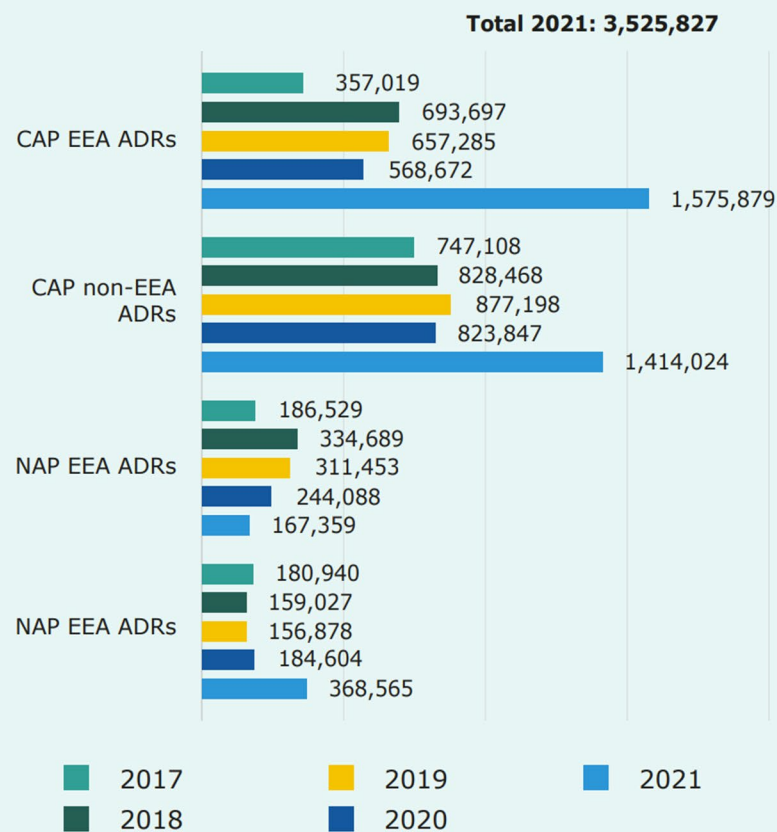
## A more cohesive and harmonious society



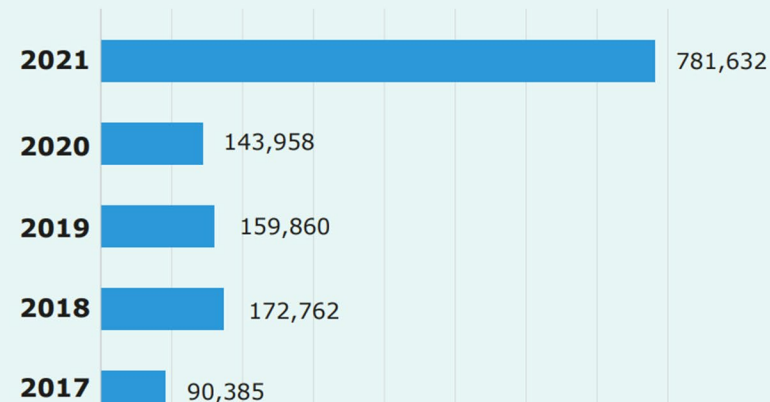
## More trust in the Institutions

# EXAMPLE OF PATIENT ACTIVITIES – QUALITY OF ADR AT EMA

## EEA and non-EEA ADR reports received



## Number of reports from patients



Note: Following the launch of the new EudraVigilance system in November 2017, figures in 2017, 2018, 2019, 2020 and 2021 include reports of non-serious suspected adverse drug reactions.

# EUROPEAN LIVER PATIENT ASSOCIATION

## ELPA MEMBERS

- BELGIUM**  
VHC – Vlaams Hepatitis Contactpunt
- BOSNIA AND HERZEGOVINA**  
The Chronic Viral Hepatitis Patients Association, "B18"
- CYPRUS**  
Cyprus Liver Patients Association
- CROATIA**  
HUHIV
- DENMARK**  
Leverforeningen
- EGYPT**  
Association of Liver Patients' Care – ALPC
- FINLAND**  
The Finnish Kidney and Liver Association
- FRANCE**  
Fédération SOS hépatites France
- GEORGIA**  
Hepatitis C Cured Patient Association
- HUNGARY**  
Hungarian Association of Chronic Hepatitis Patients – VIMOR
- IRELAND**  
Hepatitis C Partnership
- ISRAEL**  
Hetz – Israeli Association For The Health Of the Liver
- NORTH MACEDONIA**  
Association for health education, prevention and better treatment – HEPTA  
Hepar Centar – Bitola
- NORWAY**  
proLAR
- POLAND**  
Star of Hope Foundation

- PORTUGAL**  
SOS Hépatites
- ROMANIA**  
APAH-RO Romania
- RUSSIA**  
Humanitarian Action  
United Against Hepatitis
- SERBIA**  
Liver Patients' Association – HRONOS
- SLOVAKIA**  
HEP HELP KLUB  
Šanca pre pečeň
- SLOVENIA**  
Slovenian Association for patients with viral hepatitis - SLOVENIA HEP

- SPAIN**  
Catalan Association of Liver Patients – ASSCAT  
National Federation of Liver Patients and Transplanted - FNETH  
Spanish Patient Organization Lysosomal Acid Lipase Deficiency - AE LALD
- SWEDEN**  
Riksföreningen Hepatit C – RHC
- TURKEY**  
HEPYAŞAM – Living with Hepatitis Association
- UNITED KINGDOM**  
British Liver Trust  
HEP C POSITIVE  
Liver4Life



**32 MEMBERS  
FROM  
25 DIFFERENT COUNTRIES**

**ELPA**  
European Liver  
Patients' Association





# BUILDING PATIENT EXPERTS

- ELPA has 8 Working Groups.
- Headed by a leader, each Group can count up to 5 members.
- ELPA Working Groups are a way to create Expert Patients in a specific field of liver disease.

## 1 Hepatitis B elimination

Leader:

Marinela Debu



Romania

## 2 Primary Liver Cancer

Leader:

Dr. Teresa Casanovas T. M.D.



Spain

## 3 MAFLD/NASH

Leader:

Yiannoula Koulla



Cyprus

## 4 Rare Liver Diseases

Leader:

Sindee Weinbaum



Israel

## 5 Clinical Trials

Leader:

Julio Burman



Israel

## 6 Prevention

Leader:

Ivana Dragojević



Serbia

## 7 Harm reduction

Leader:

Aleksey Lakhov



Russia

## 8 Cirrhosis

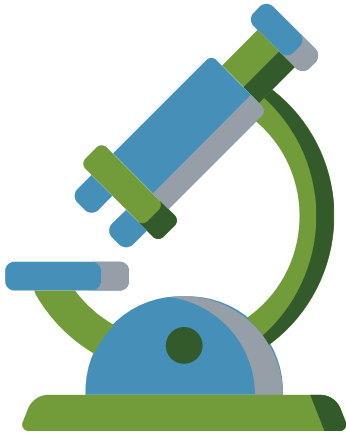
Leader:

Marko Korenjak



Slovenia

# EUROPEAN LIVER PATIENT ASSOCIATION



■ 10

■ Medical Research Project



■ +72

■ Million € for liver research



■ +140

■ Partners

18 / 5

New Application

# ELPA AND EU STAKEHOLDERS



# ELPA AND EU STAKEHOLDERS

## **Member of VHPB**

Member of Advisory Forum at ECDC

Member of expert group on HBV and HCV at ECDC

Member of Advisory Forum at Health Emergency Preparedness and Response Authority – HERA

Member of Patient and Consumer Working Party at European Medicine Agency

Member of Pharmacovigilance Committee at European Medicine Agency

Member of Policy and Public Health Committee at European Association for the Study of the Liver

Member of Task force on Liver Cancer at European Association for the Study of the Liver

Member of association ACHIEVE

Member of WHO committee on HIV, TB and viral hepatitis in WHO European region

...

# EUROPEAN LIVER PATIENT ASSOCIATION

**TOGETHER**  
*We are*  
**STRONGER**

## European Liver Patients' Association

Schuman Roundabout 2-4, Level 6,  
1040 Brussels, Belgium

[office@elpa.eu](mailto:office@elpa.eu)

T: +32 (0) 478155224

[www.elpa.eu](http://www.elpa.eu)