

# The Forum For Collaborative Research PSC Forum 4

## ERN Survey and Treatment Guidance

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board member Liver Patients International

**8 November 2022**

**ERN RARE-  
LIVER**

European Reference  
Network on  
Hepatological  
Diseases

**No disclosures**

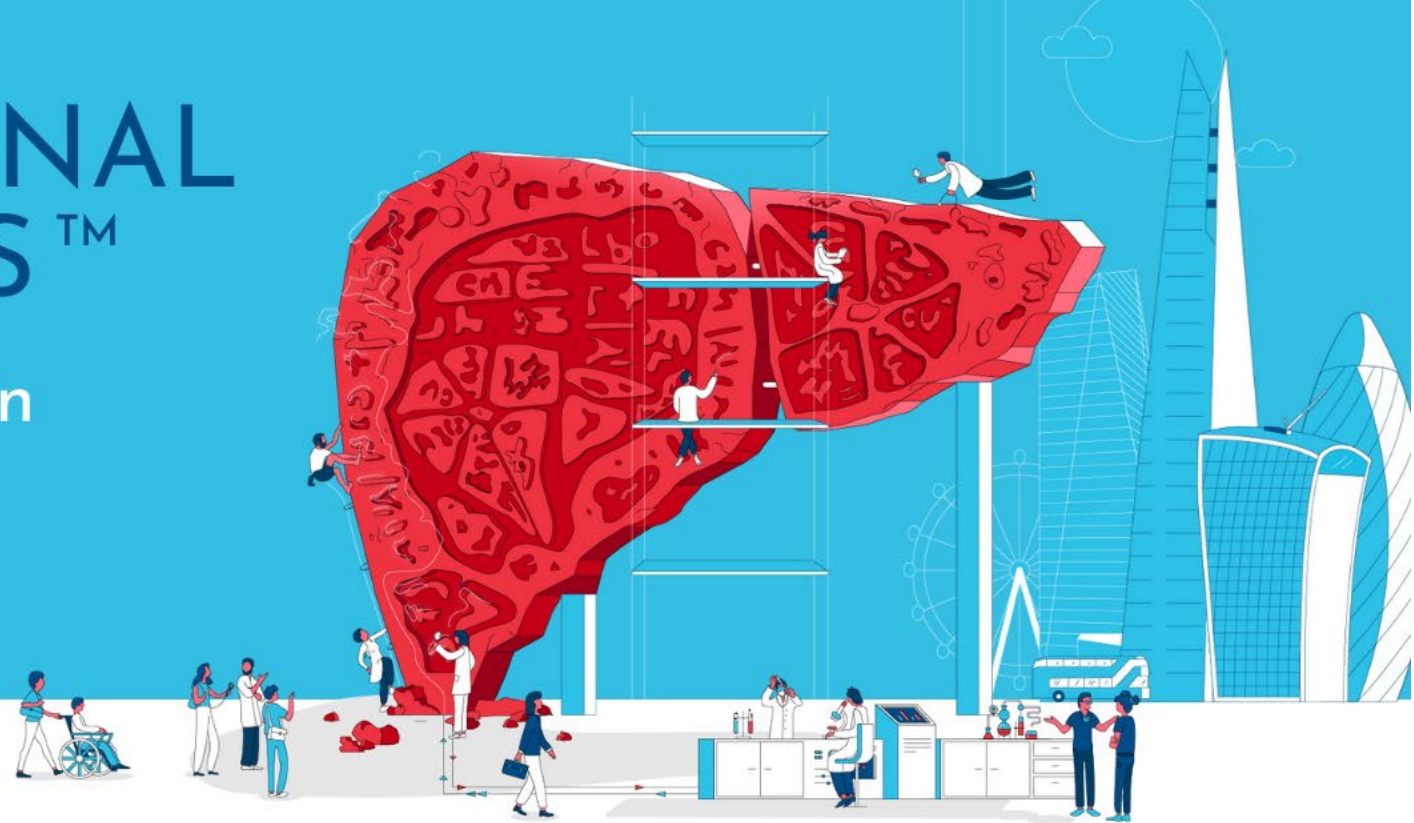
## European Reference Network

- programme of the European Commission
- appr. 8000 rare diseases in 24 clusters
- Rare Liver is one of them
- cross border healthcare, data bases etc.
- hospitals are members
- patient advocates are added to the ERN (to guarantee patients perspective)
- Rare Liver has appr. 10 working groups: PSC is 1 of them

# THE INTERNATIONAL LIVER CONGRESS™

Savour science together again

22-26  
JUNE  
2022  
LONDON



## PSC Clinical Practice Guidelines Patient Perspective

Martine Walmsley (PSC Support), Angela Leburgue (ALBI France) and  
José Willemse (Nederlandse Leverpatiënten Vereniging)

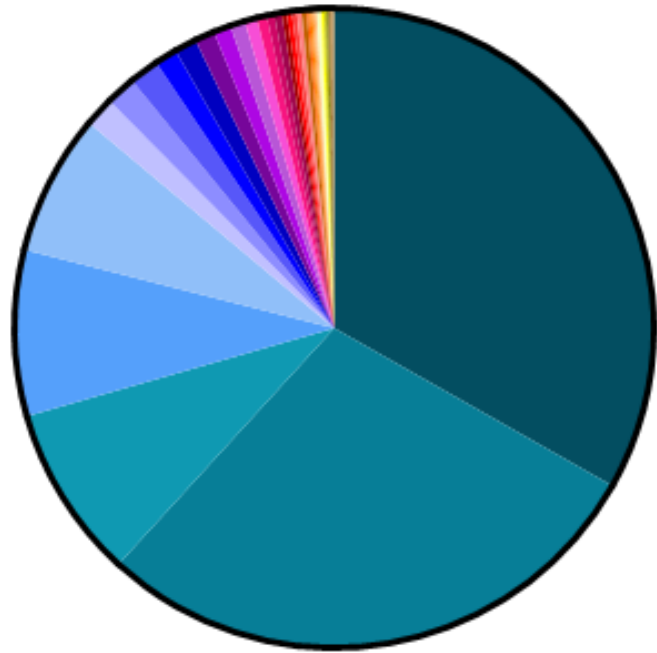
# Challenges for PSC Patients

## Care

- Access to specialist care
- Coordination of care (including transition and co-existing conditions)
- Awareness of the disease among HCPs/ adherence to CPGs
- Getting a (timely) diagnosis
- Quality of life
- Symptom management
- Lack of treatment/ access to treatment
- Increased cancer risks/ lack of effective surveillance



# PSC Care Survey – Non-transplanted PSC patients



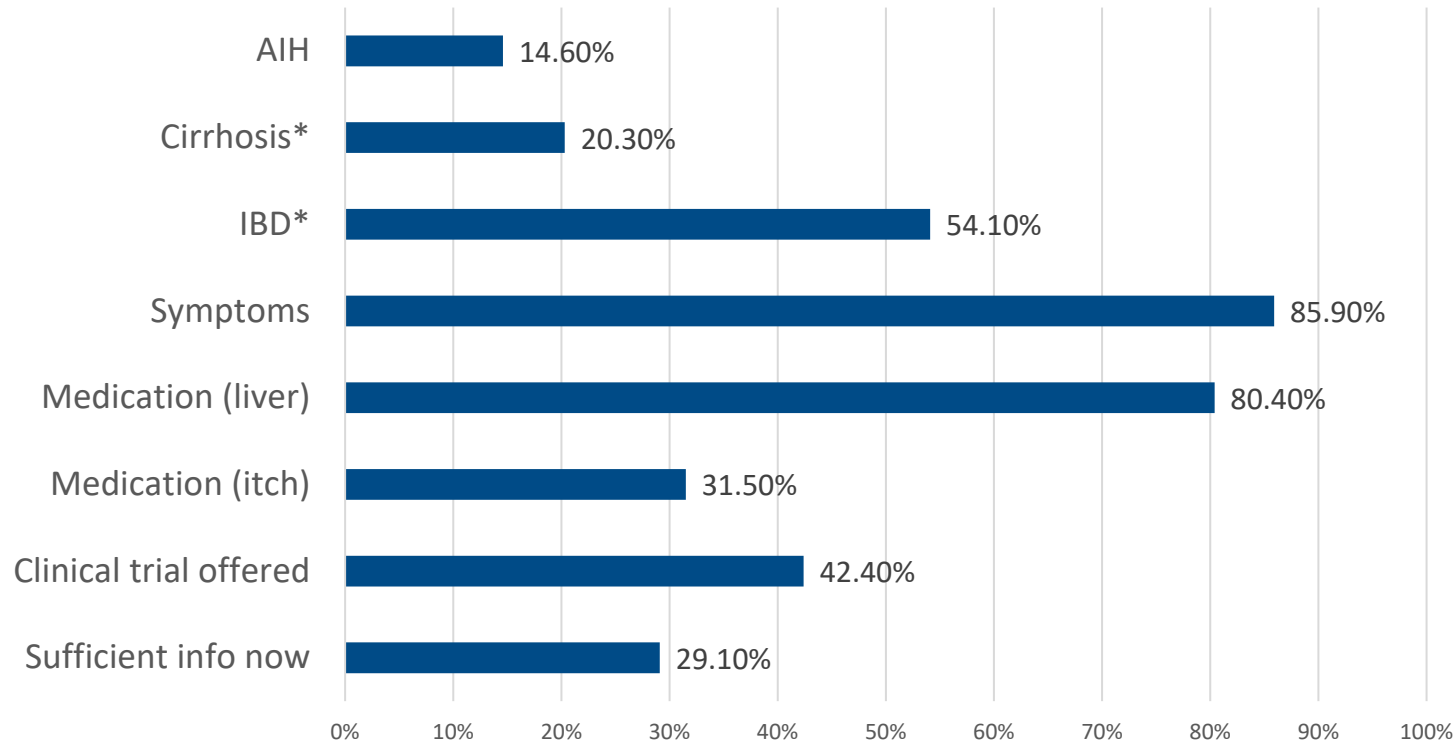
**Total=798**

- |                |                      |
|----------------|----------------------|
| United Kingdom | Algeria              |
| France         | Croatia              |
| Netherlands    | Luxembourg           |
| Sweden         | Poland               |
| Germany        | Portugal             |
| Canada         | Azerbaijan           |
| Israel         | Brasil               |
| USA            | Denmark              |
| Belgium        | Iran                 |
| Italy          | Norway               |
| Ireland        | Puerto Rico          |
| Spain          | Republic of Djibouti |
| Switzerland    | Romania              |
| Australia      | Saint Barthélemy     |
| New Zealand    | Singapore            |
| Hungary        | Uruguay              |
| Morocco        |                      |



# PSC Care Survey – Overview of Results

Overview of Responses (Non-transplanted, European) n=740



Do you also have autoimmune hepatitis?

Have you developed cirrhosis?

Have you ever had symptoms from PSC?

Are you taking any medication for your liver disease?

Have you been treated for itch with...[named medications]?

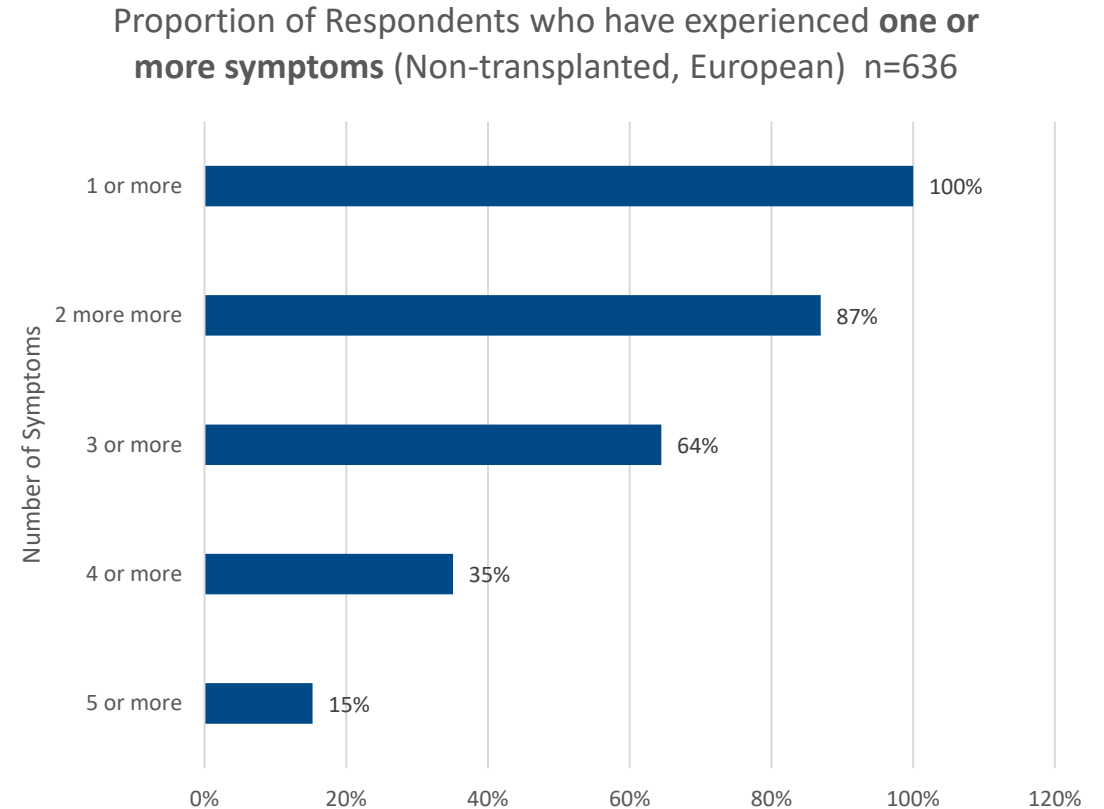
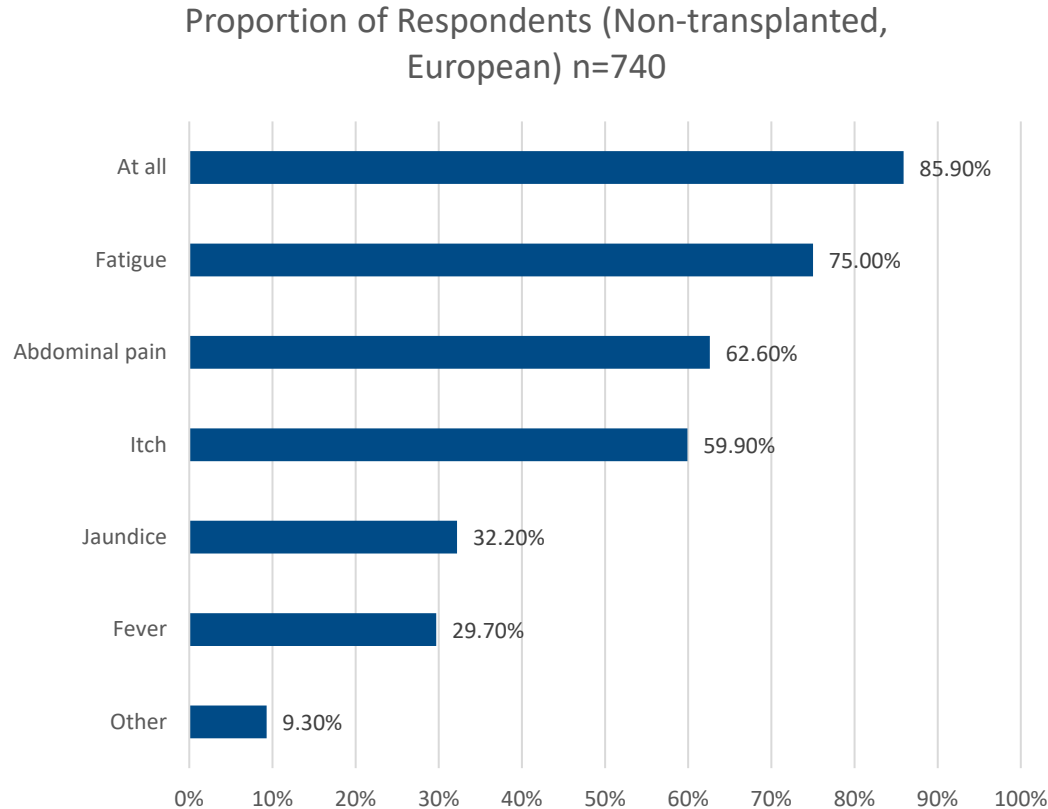
Have you ever been offered participation in a clinical trial or research?

I have enough [PSC-related] information for now



# PSC Care Survey – Burden of Symptoms

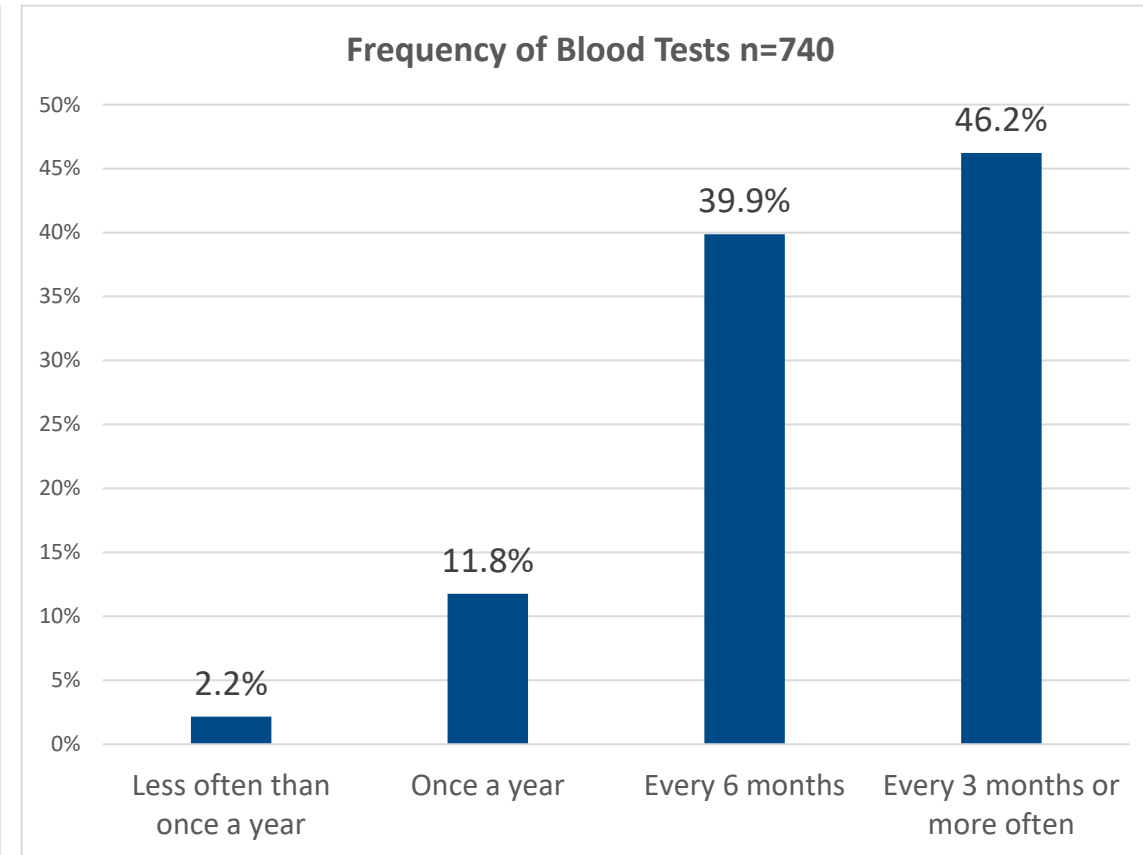
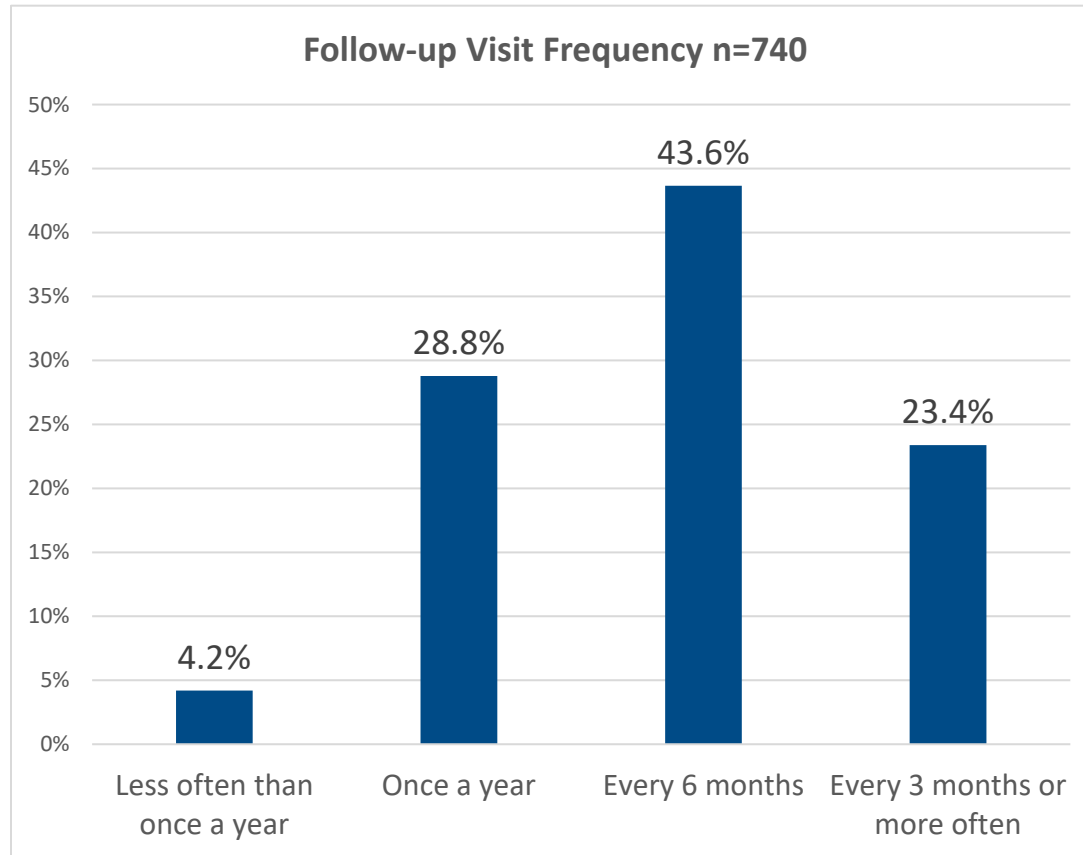
**Have you had any of the following symptoms (check all that apply)?**





# PSC Care Survey – Frequency of Follow-Up Visits

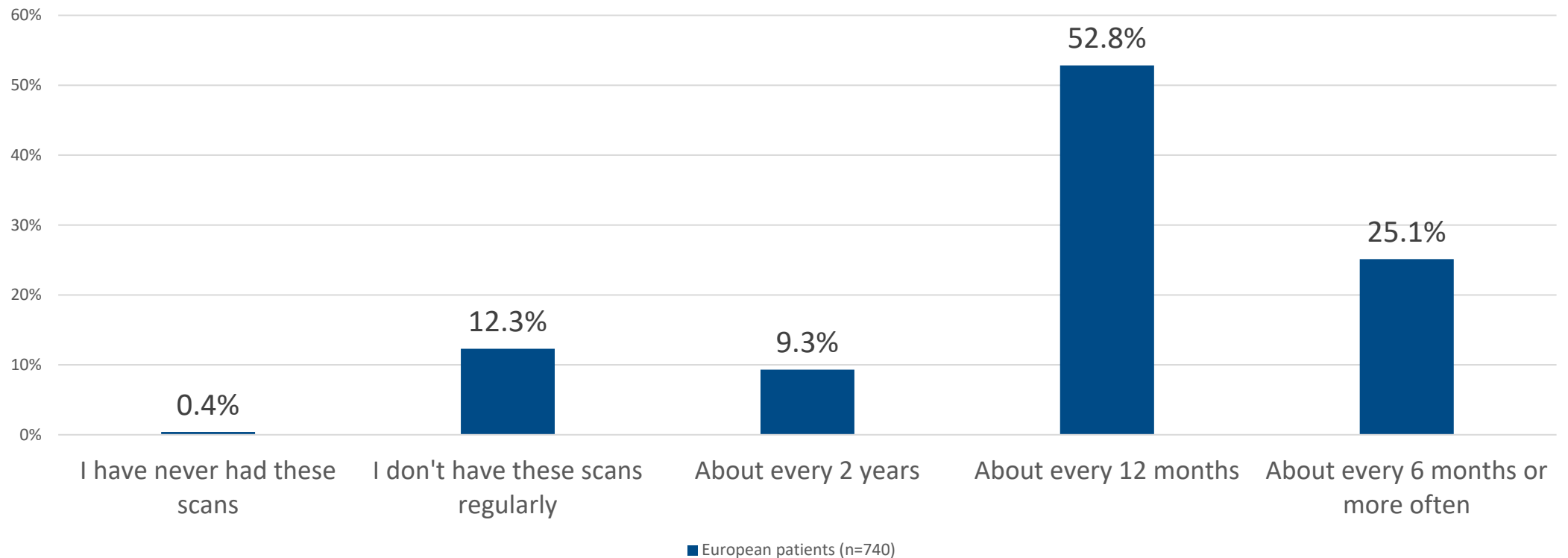
*How often do you generally see the doctor/ medical team that looks after your PSC?*



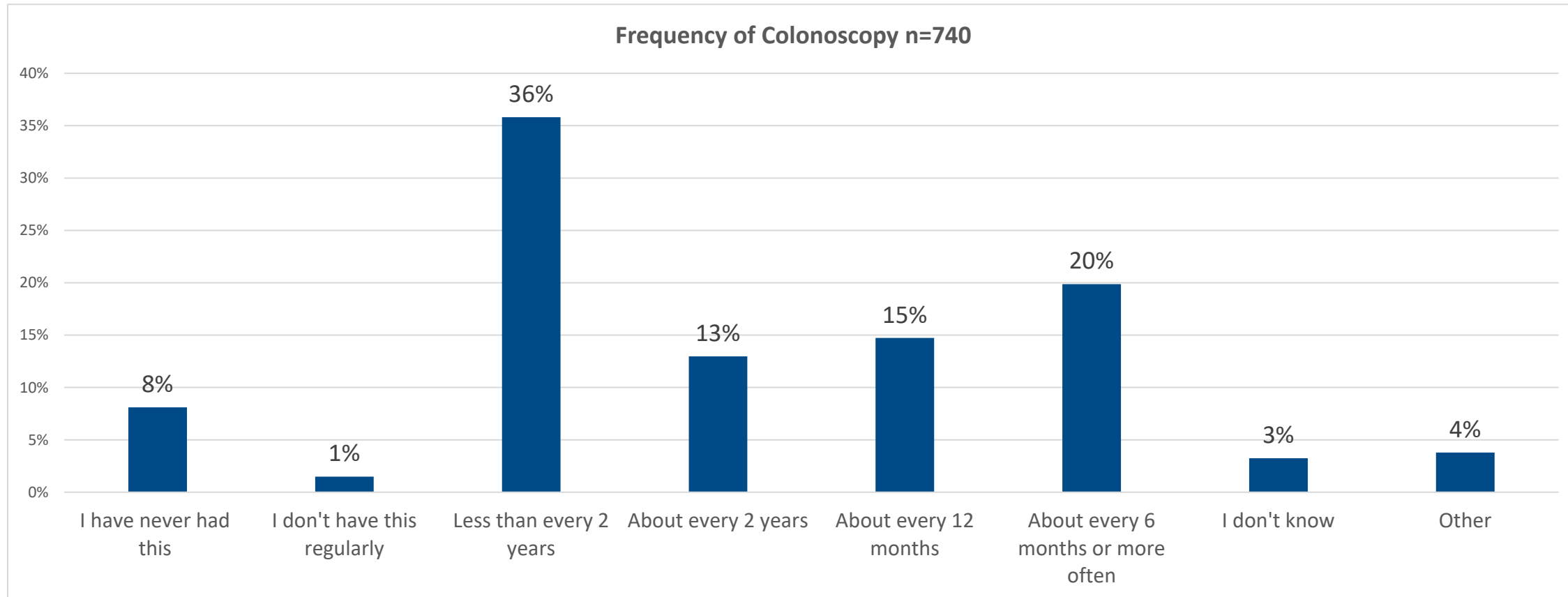
# PSC Care Survey – Frequency of Imaging (Ultrasound/MRCP)

Survey analysis: Dávid Tornai, MD, PhD - University of Debrecen, Hungary

Frequency of Imaging (Ultrasound and/or MRCP)

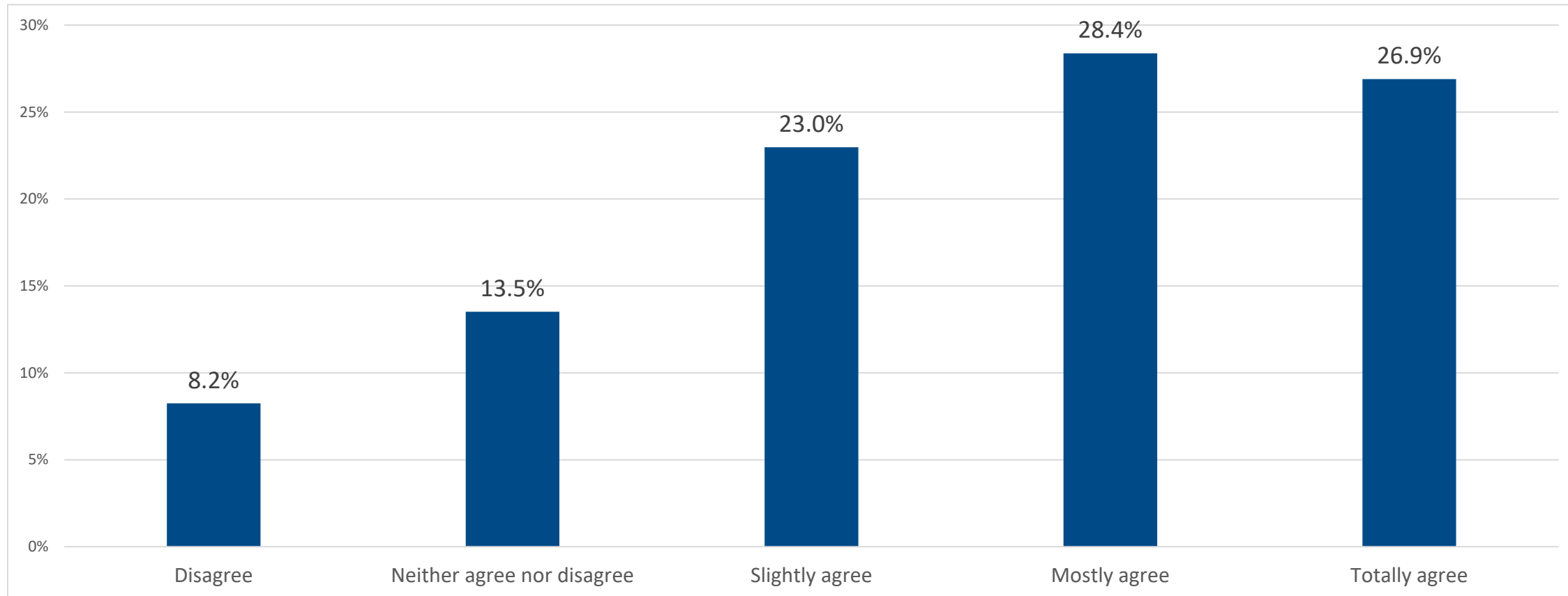


# PSC Care Survey – Frequency of Colonoscopy



# PSC Care Survey – Confidence in Care

*I am confident about the medical care I receive for PSC*



# Take home message

Clinical Practice Guidelines

JOURNAL  
OF HEPATOLOGY

## **EASL Clinical Practice Guidelines on sclerosing cholangitis<sup>☆</sup>**

European Association for the Study of the Liver\*

- CPGs are only as good as those who read and act on them
- Every PSC patient, wherever they live, must have access to quality care

Read

Act

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