

# PATIENT-REPORTED QUALITY OF CARE IN PSC

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# PATIENT-REPORTED QUALITY OF CARE IN PSC



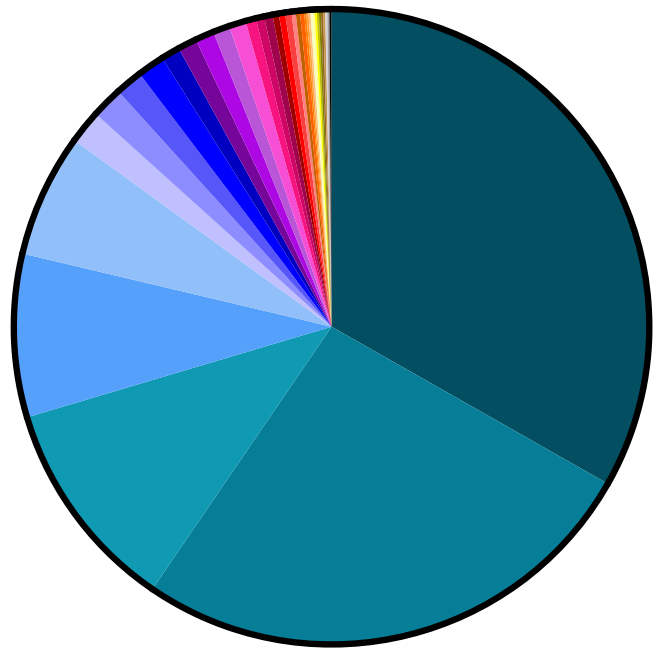
- European Reference Network for Rare Liver Diseases (ERN RARE-LIVER)
  - PSC Working Group
- Survey
  - Patient – centred questions
  - 11 languages
  - 29 Oct 2021 to 26 January 2022
  - Statistics: **Dávid Tornai, University of Debrecen, Hungary**
- Aim
  - to assess **patient reported quality of care** in people with PSC to identify and increase awareness of the most important areas for improvement



European  
Reference  
Networks



# PARTICIPATING COUNTRIES



**Total=939**

United Kingdom	33.2%	Poland	0.3%
France	26.3%	Portugal	0.3%
Netherlands	10.9%	Algeria	0.2%
Sweden	8.3%	Luxembourg	0.2%
Germany	6.3%	Norway	0.2%
USA	1.7%	Azerbaijan	0.1%
Israel	1.6%	Bosnia and Herzegovina	0.1%
Canada	1.4%	Brasil	0.1%
Italy	1.4%	Denmark	0.1%
Belgium	1.0%	Iran	0.1%
Croatia	1.0%	Puerto Rico	0.1%
Spain	1.0%	Republic of Djibouti	0.1%
Ireland	0.9%	Republic of Serbia	0.1%
Switzerland	0.9%	Romania	0.1%
Australia	0.5%	Saint Barthélemy	0.1%
Morocco	0.4%	Samaria	0.1%
New Zealand	0.4%	Singapore	0.1%
Hungary	0.3%	Uruguay	0.1%

# OVERVIEW OF RESULTS

Summary	All	Non-transplanted	Transplanted	P value
N (%)	939 (100%)	798 (84%)	141 (16%)	–
Age (mean ± SD)	46.3 ± 15.6	45.5 ± 15.7	48.2 ± 14.3	0.0001
Sex (m/f)	387/551 (41%/59%)	303/494 (38%/62%)	84/57 (60%/40%)	<0.0001
European	871 (93%)	740 (93%)	131 (93%)	ns
AIH	144 (15%)	120 (15%)	24 (17%)	ns
Cirrhosis*	242 (26%)	161 (20%)	81 (57%)	<0.0001
Symptoms*	811 (86%)	690 (87%)	121 (86%)	ns
Medication (PSC)	754 (80%)	636 (80%)	118 (84%)	ns
Medication (Itch)	320 (34%)	253 (32%)	67 (48%)	0.0003
Clinical trial offered	420 (45%)	330 (41%)	90 (64%)	<0.0001
Sufficient info now	312 (33%)	228 (29%)	84 (60%)	<0.0001





n=798



n=265

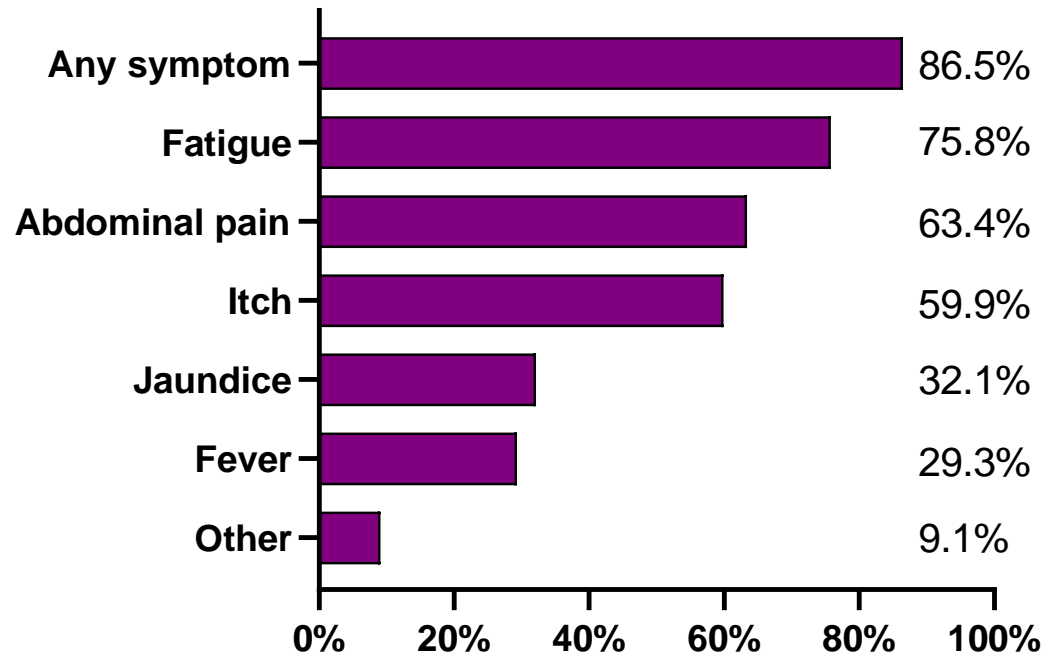
# GENERAL CHARACTERISTICS

Characteristic	All countries (n=798) 	UK only n=265 
Female sex	494 (62.0%)	159 (60.0%)
Mean age, years ( $\pm$ SD)	45.5 $\pm$ 15.7	46.5 $\pm$ 16.6
Children (7-15 yrs)	22 (2.8%)	4 (1.5%)
Young adults (16-25 yrs)	75 (9.4%)	32 (12.1%)
Adults (26-60 yrs)	559 (70.1%)	171 (64.5%)
Seniors (61+ yrs)	142 (17.8%)	58 (21.9%)
IBD	432 (62.1%)	178 (67.2%)
AIH overlap	120 (15.2%)	28 (10.6%)
Cirrhosis	161 (20.2%)	61 (23%)
Symptoms	690 (86.5%)	239 (90.2%)
Any medication for liver disease	636 (79.7%)	171 (64.5%)
Offered participation in a clinical trial or research study	330 (41.4%)	129 (48.7%)

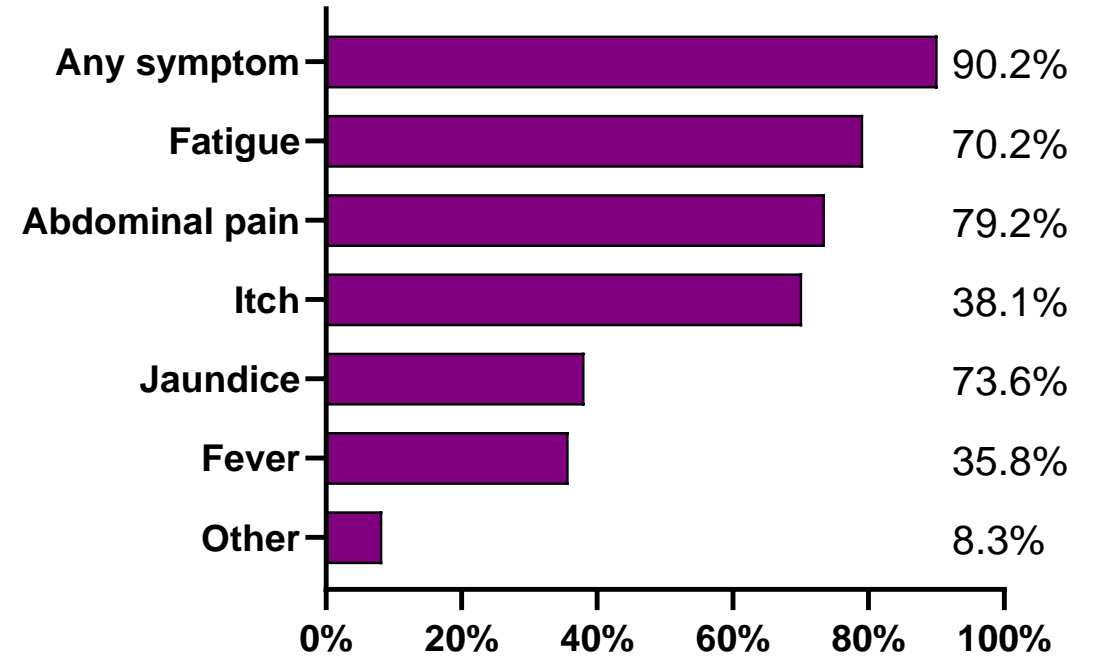
# BURDEN OF SYMPTOMS



## Symptoms

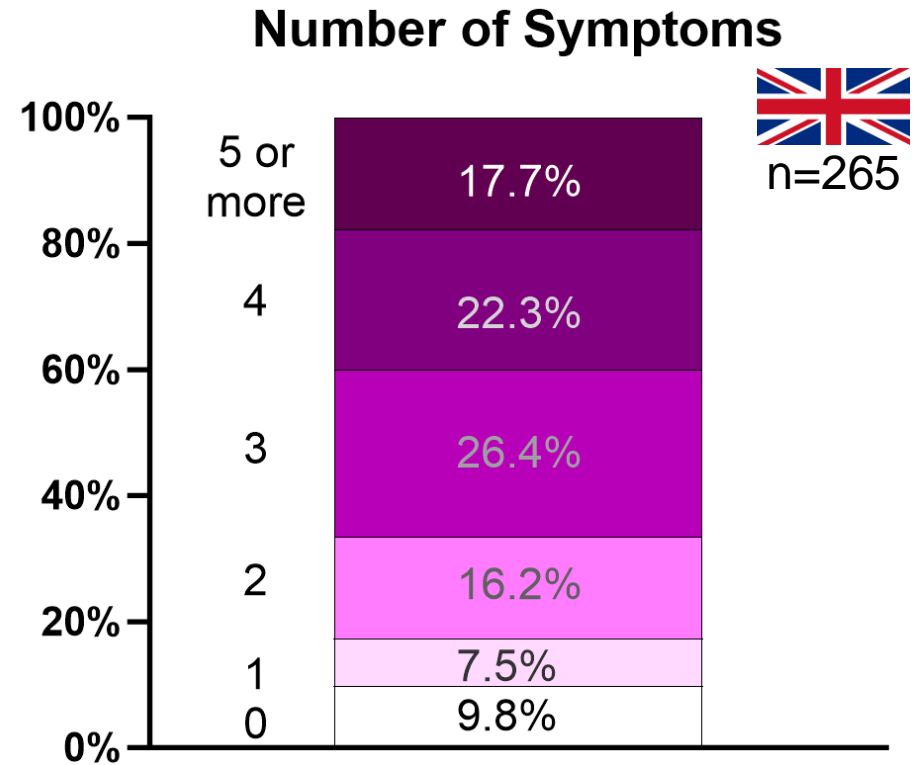
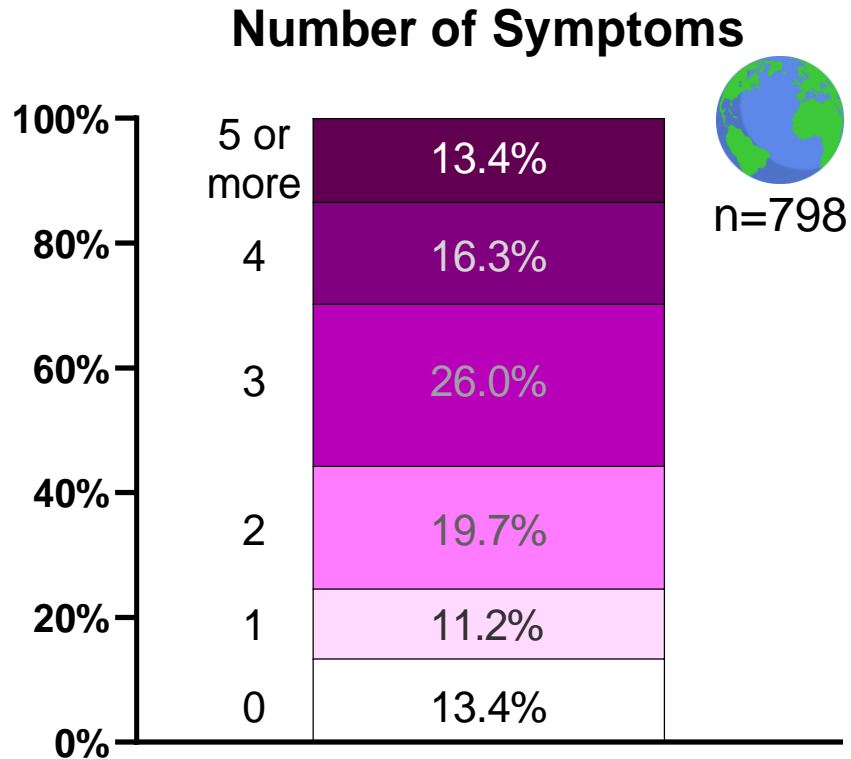


## Symptoms



Have you ever had symptoms from PSC?/ Have you had any of the following

# BURDEN OF SYMPTOMS



Have you ever had symptoms from PSC?/ Have you had any of the following

# MEDICATION



Medication	All countries (n=798)	UK only n=265
Vancomycin	12 (1.5%)	5 (1.9%)
UDCA	566 (70.9%)	134 (50.6%)

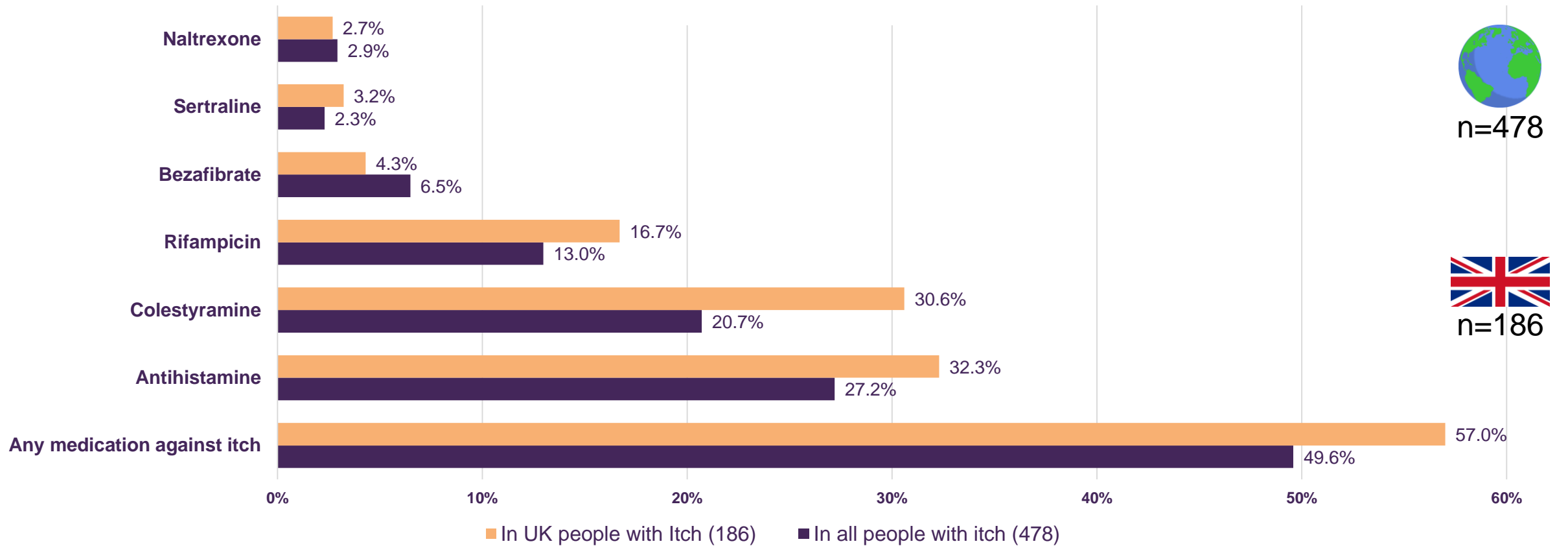


UK age group	Vancomycin	UDCA
Children (7-15 yrs) (4)	0 (0%)	4 (100%)
Young adults (16-25 yrs) (32)	4 (12.5%)	12 (37.5%)
Adults (26-60 yrs) (171)	1 (0.6%)	80 (46.8%)
Seniors (61+ yrs) (58)	0 (0%)	38 (65.5%)

Which medication are you taking for your liver disease (check all that apply)?



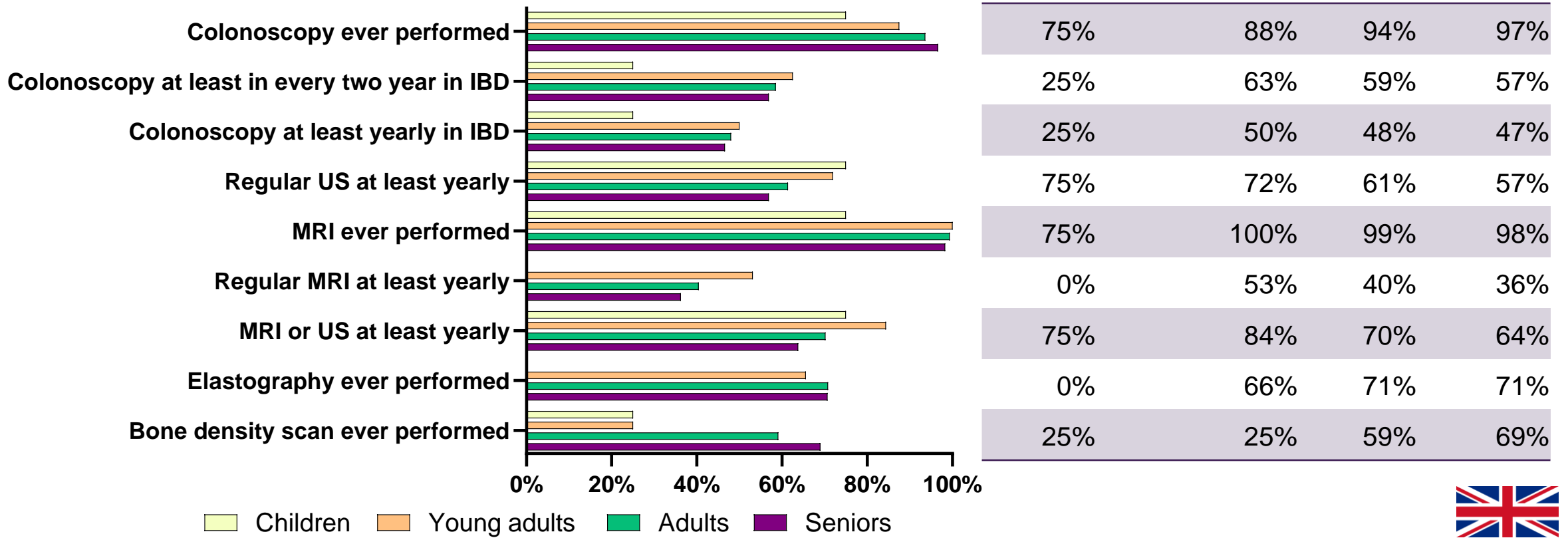
# ITCH MEDICATION – PEOPLE WHO HAD HAD ITCH



Have you been treated for itch with any of the following (check all that apply)?

# MEDICAL EXAMINATIONS

Medical examinations by age groups





## TEST RESULTS AND COMMUNICATIONS

- Timely tests
- Timely results/ clear explanation
- Timely opportunity to discuss next steps/ impact on care
- Consultants in clinics to answer tricky questions



# INFORMATION





Topic of Information	All (798) 	UK (265) 
Food, diet and supplements	420 (52.6%)	128 (48.3%)
The disease	199 (24.9%)	55 (20.8%)
How I can improve my health	383 (48.0%)	107 (40.4%)
Prognosis	396 (49.6%)	110 (41.5%)
Reasons for tests, scans, colonoscopies, etc	92 (13.6%)	30 (11.3%)
PSC and pregnancy	72 (9.0%)	11 (4.2%)
Liver transplantation	168 (21.1%)	37 (14%)
Complementary medicine	205 (25.7%)	52 (19.6%)
Transferring from paediatric care to adult care	31 (3.9%)	8 (3%)
Other	34 (4.3%)	7 (2.6%)

I need more information about...

# RESEARCH PARTICIPATION



General characteristics	PSC patients (n=798) 	UK PSC patients (n=265) 
Offered participation in a CT or research study	330 (41.4%)	129 (48.7%)

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

# PATIENT-REPORTED QUALITY OF CARE IN PSC – WHAT DID WE LEARN?



Current practice  
needs to improve  
and change

High symptom  
burden for people  
with PSC

Timely  
monitoring AND  
follow-up

New  
recommended  
itch treatments

Timely, clear  
communications

Channel to ask  
questions

Facilitate research  
participation

# EASL 2022 CPG RECOMMENDATIONS



## Key Clinical Practice Guidelines EASL recommendations (4)

## Patient reported current practice

Liver elastography and/or serum fibrosis tests at least every 2 to 3 years

(LoE 3, strong recommendation, 96% consensus)

**24% never had elastography**

Liver ultrasound and/or abdominal MRI/MRCP every year

(LoE 3, weak recommendation, 96% consensus)

**78% are investigated with MRI or ultrasound every 12 months or more often**

Assessment of bone mineral density is recommended in all people with PSC at the time of diagnosis using dual energy X-ray absorptiometry (DEXA).

(LoE 4, strong recommendation, 92% consensus)

**51% had ever had a bone density scan**

UDCA at doses of 15-20mg/kg/d can be given since it may improve serum liver tests and surrogate markers of prognosis.

(LoE 1, weak recommendation, 76% consensus)

**71% are treated with UDCA**

Long-term use of antibiotics is not recommended for treatment of PSC in the absence of recurrent bacterial cholangitis.

(LoE 3, strong recommendation, 100% consensus)

**23 % of children with PSC was treated with vancomycin**

Pharmacological treatment of moderate to severe pruritus in sclerosing cholangitis with bezafibrate or rifampicin is recommended.

(LoE 4, strong recommendation, 83% consensus)

**6.5% of people with PSC and itch was treated with bezafibrate and 13% with rifampicin**

Ileocolonoscopy with biopsies from all colonic segments including the terminal ileum, regardless of the presence of lesions, is recommended at the time of PSC diagnosis

(LoE 3, strong recommendation, 100% consensus)

**8 % had never had colonoscopy**

Initial expert consultation for people with PSC at diagnosis and referral for those with symptomatic and/or progressive PSC to an experienced centre with ready access to PSC clinical trials and a dedicated multidisciplinary team are recommended.

(LoE 5, strong recommendation, 100% consensus).

**41% had been offered participation in clinical trials or research**