IDENTIFYING GAPS IN PSC PATIENT EDUCATION AND UNDERSTANDING OF CHOLANGIOCARCINOMA SCREENING AND SURVEILLANCE PRACTICES: RESULTS OF A MULTINATIONAL PATIENT SURVEY

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BACKGROUND & OBJECTIVES

- People with primary sclerosing cholangitis (PSC) have up to a 20% lifetime risk of cholangiocarcinoma (CCA), with a 400- to 1500- fold lifetime risk increase versus the general population.
- CCA surveillance strategies are inconsistent across regions and are challenged by poor performance of current screening methods.
- CCA risk and management consistently emerge as high priorities in community surveys led by our patient organizations.
- We report results of a multinational patient survey to assess knowledge and use of current CCA screening methods and patient-provider communication on CCA risk and surveillance results.
- In anticipation of new CCA screening tests potentially offering earlier detection of CCA, we seek to identify gaps in knowledge and communication regarding current practices.

METHODS

- A detailed, de-identified survey for adults with PSC was developed by PSC Partners and PSC Support UK patient organizations and launched in April 2025.
- The survey collected relevant medical history, CCA surveillance tests (MRCP, CA 19-9), risk and results discussion, and CCA education level.
- Summary of survey results, comparative analyses for factors affecting proactive CCA discussion held by providers, and acquisition of annual MRCPs in U.S. patients are presented.

PATIENT POPULATION & CHARACTERISTICS

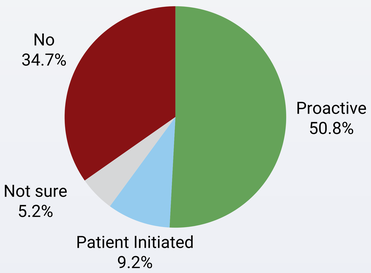
- A total of 623 responses were received, 25 with history of CCA. Respondents with CCA history received an abbreviated survey, reporting medical history and educational resources used or wanted.
- Two responses had critical missing data, leading to **n=596** in the analysis cohort.

Region	USA	262 (44%)
	UK	187 (31%)
	CAN	62 (10%)
	EU	61 (10%)
	Other	24 (4%)
Sex	Female	352 (58%)
	Male	243 (41%)
	Other	1 (<1%)
Current Age	Median: 51, Min: 18, Max: 89	
Age of PSC Dx	Median: 40, Min: 3, Max: 87	

PSC Provider Type	Hep	440 (74%)
	Gastro	141 (24%)
	Other	15 (2%)
CCA Diagnosis (excluded from other analyses)		25 (4%)
Gallbladder Cancer Dx		6 (1%)
Cholecystectomy		226 (38%)

PATIENT-PROVIDER CCA COMMUNICATION

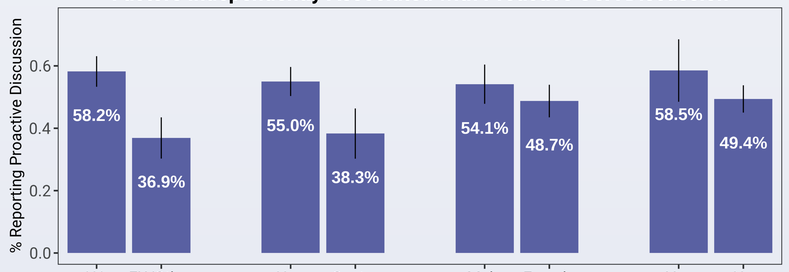
CCA Risk Discussed with Patient



When CCA is proactively discussed without patient prompting (50.8%), **56% of patients report adequate CCA knowledge**.

When providers have not proactively discussed CCA risk (49.2%), **15% of PSC patients report adequate CCA knowledge**.

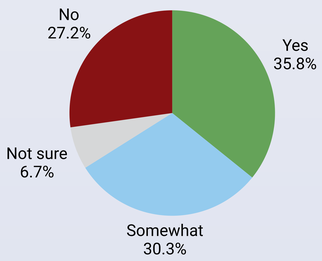
Factors Independently Associated with Proactive CCA Discussion



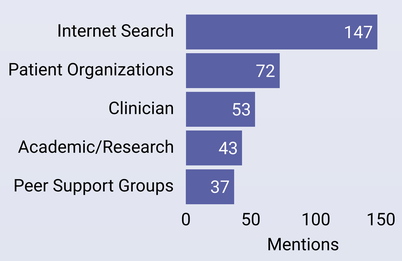
Significance levels: * $p < 0.05$; ** $p < 0.01$; *** $p < 0.001$

CCA INFORMATION & EDUCATIONAL RESOURCES

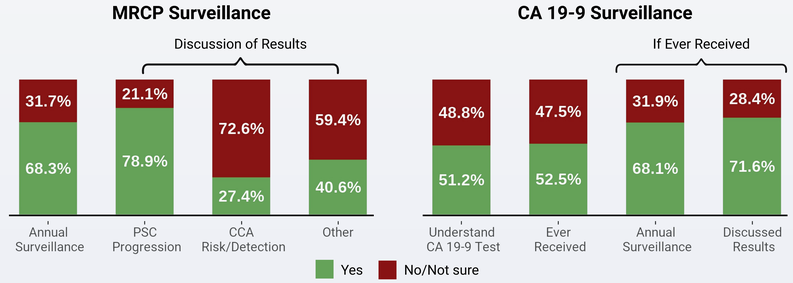
Received Sufficient CCA Information



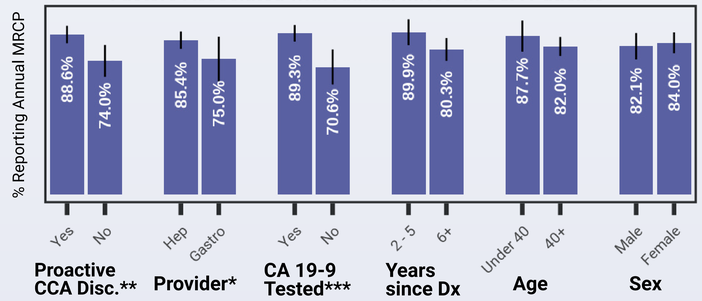
CCA Educational Resources Used



PATIENT-REPORTED CCA SURVEILLANCE & DISCUSSION



Factors Associated with Annual MRCP in USA Patients



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DISCUSSION

- There is high variability in provider-patient discussion of CCA risk and test results and in CCA surveillance practices.
- Proactive discussion on CCA risk is significantly associated with subsequent surveillance.
- PSC patients report significant fear and anxiety regarding CCA in **24%** of open text responses.
- Discussion with providers plays an important role in managing this emotional burden.
- Responses indicate a high need for appropriate CCA educational materials.
- Promising novel biomarkers to detect early CCA and risk will impact current surveillance practices and patient education needs.

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