



PSC Forum 7

Tuesday, June 4, 2024

Starhotels Business Palace

Via Privata Pietro Gaggia, 3, 20139, Milan, Italy

PSC FORUM CHOLANGITIS WORKING GROUP
PATIENT EXPERIENCE SUB-WORKING GROUP UPDATE

MARTINE WALMSLEY,

HEAD OF RESEARCH STRATEGY

PSC SUPPORT





DISCLOSURES

- Consultancy (unpaid or paid to PSC Support)
 - Chemomab, Gilead, Ipsen, Pliant, Escient, Mirum
- Grants (to PSC Support)
 - Chemomab, Mirum, Falk, Ipsen



PATIENT EXPERIENCE SUB-WORKING GROUP UPDATE

- Help! What's wrong with me?
- Goals
- Achievements so far
- Next steps
- Outputs
- Members



CHOLANGITIS – HELP! WHAT’S WRONG WITH ME?

■ Challenges

- Recognising the signs (patients)
- Recognising the signs (clinicians)

■ Consequences

- Sepsis
- Access to appropriate care
- Huge milestone

■ PSC Alert Card

- Developed by UK-PSC and PSC Support
- Understand symptoms
- Support treatment decisions (non-specialists).
- Available digitally in app (UK only)
- ERN-RARE LIVER website



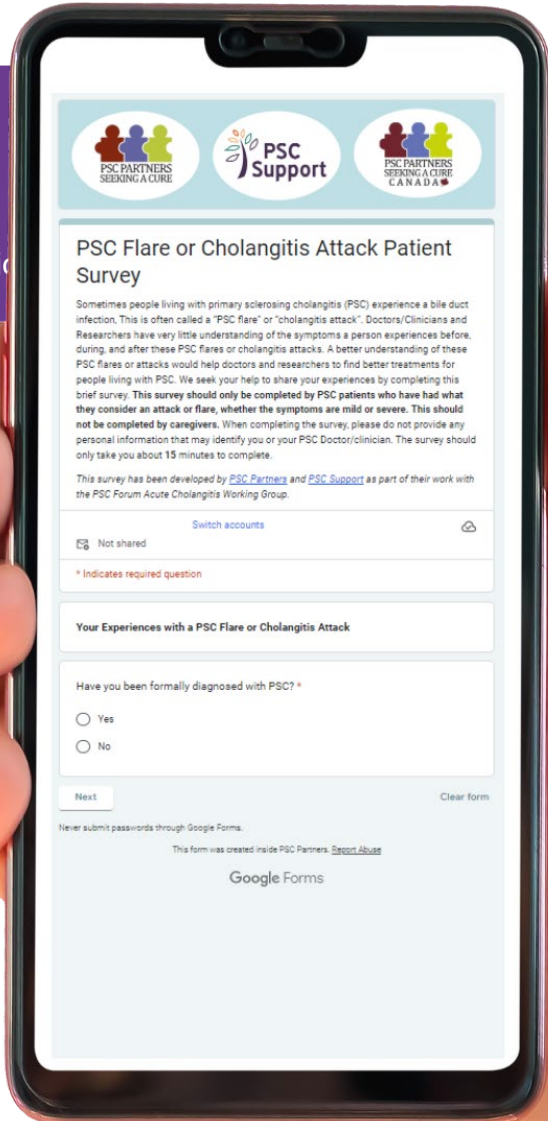


PATIENT GOALS

- Understand the **patient experience** of cholangitis
 - Mixed methods approach (surveys, qualitative interviews)
- Understand the **quality of care**
 - Actual care in relation to guideline recommendations
- Understand **impact of an intervention** on cholangitis
 - Use of PROs depends on findings in this group's work



ACUTE CHOLANGITIS PATIENT EXPERIENCE SUB WORKING GROUP – ACHIEVEMENTS SO FAR



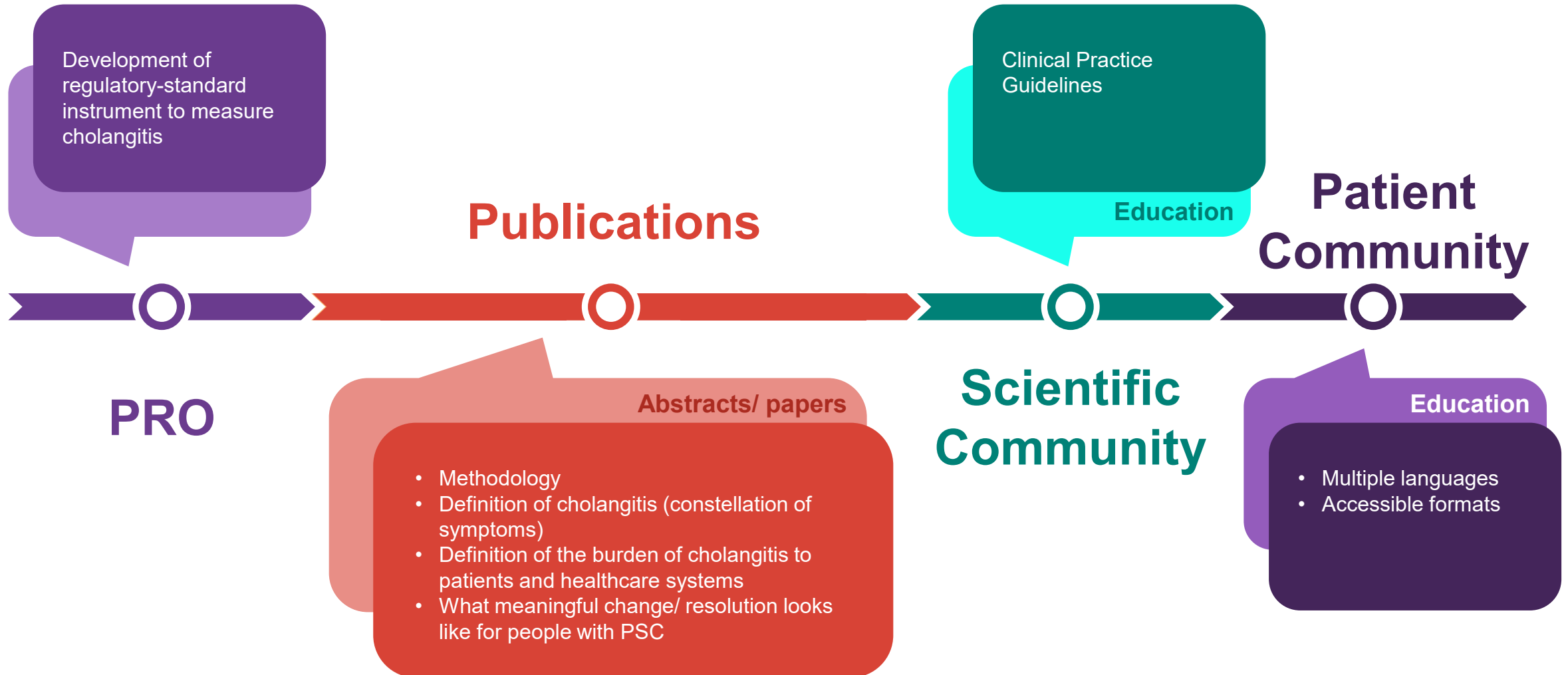


NEXT STEPS - ACUTE CHOLANGITIS PATIENT EXPERIENCE SUB WORKING GROUP

- Characterisation of patient experience of cholangitis
 - patient survey – integrate into PSC Partners Patient Registry
 - qualitative research
- Stakeholders
 - regulatory authorities, industry, academic community (inc QoL groups), global patient community, Liver Forum, European Reference Network for Rare Liver Diseases



OUTPUTS - ACUTE CHOLANGITIS PATIENT EXPERIENCE SUB WORKING GROUP





ACUTE CHOLANGITIS PATIENT EXPERIENCE SUB WORKING GROUP

- Martine Walmsley (PSC Support) - LEAD
- Donna Evon (University of North Carolina)
- Alastair Garfield (Rectify Pharma)
- Joanne Hatchett (PSC Partners)
- Bryce Reeve (Duke University)
- Stephen Rossi (PSC Partners)
- Pam Vig (Mirum Pharmaceuticals)