

Quality of Life Measure for people with PSC

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Overview

- Aim: to develop a provisional questionnaire to measure quality of life in people with primary sclerosing cholangitis (PSC)
- **Approach**: based on guidelines developed by the Quality of Life group of the European Organisation for Research and Treatment of Cancer (EORTC)





Approach

Stage 1

• Generate list of quality of life issues which may affect people with PSC

Stage 2

 Construct and pre-test provisional questionnaire

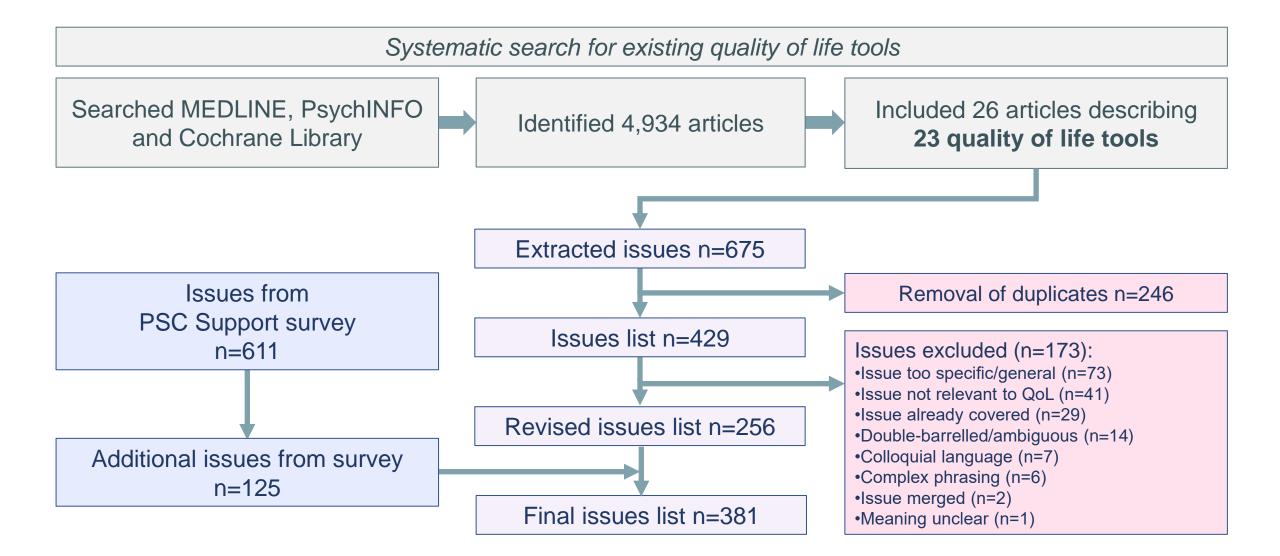
Stage 3

• Field validation





Generation of issues





Stage 1

Generate a list of quality of life issues which may affect people with PSC

Extract issues from existing QoL tools

Extract issues from the PSC Support Survey

Run Focus groups with clinicians and people with PSC



Stage 2 and 3

Construct and pre-test provisional questionnaire

Turn issues into questionnaire items and construct provisional questionnaire

Test questionnaire with people with PSC

Refine questionnaire to produce a final version Field validation (international element not yet fully funded)



Summary

- Development of a high quality questionnaire to measure quality of life in people with primary sclerosing cholangitis (PSC)
 - Patient-centred and funded
 - Quality of methodology
 - Regulatory approval
 - Independent

