

# Quality of Life Measure for people with PSC

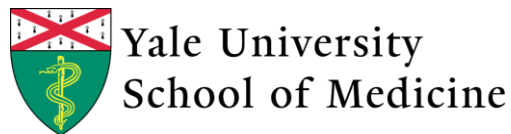
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Chair of Trustees, PSC Support

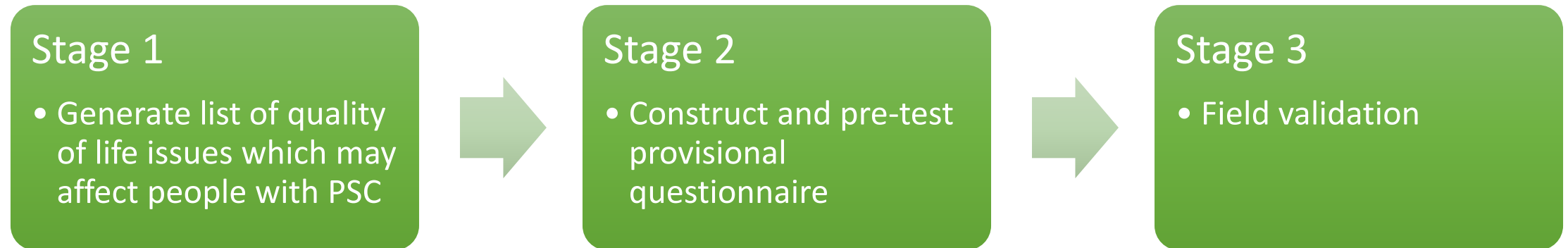
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# Overview

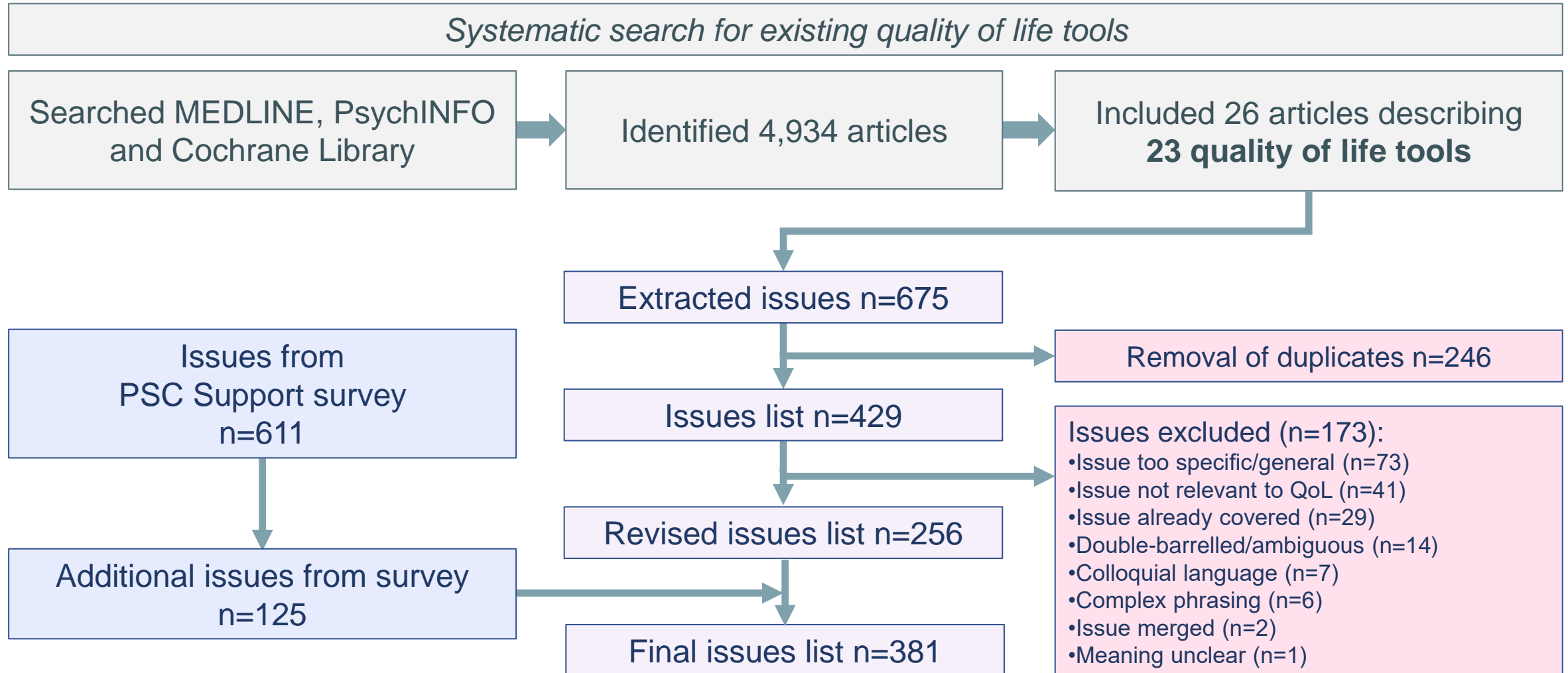
- **Aim:** to develop a provisional questionnaire to measure quality of life in people with primary sclerosing cholangitis (PSC)
- **Approach:** based on guidelines developed by the Quality of Life group of the European Organisation for Research and Treatment of Cancer (EORTC)



# Approach



# Generation of issues



# Stage 1

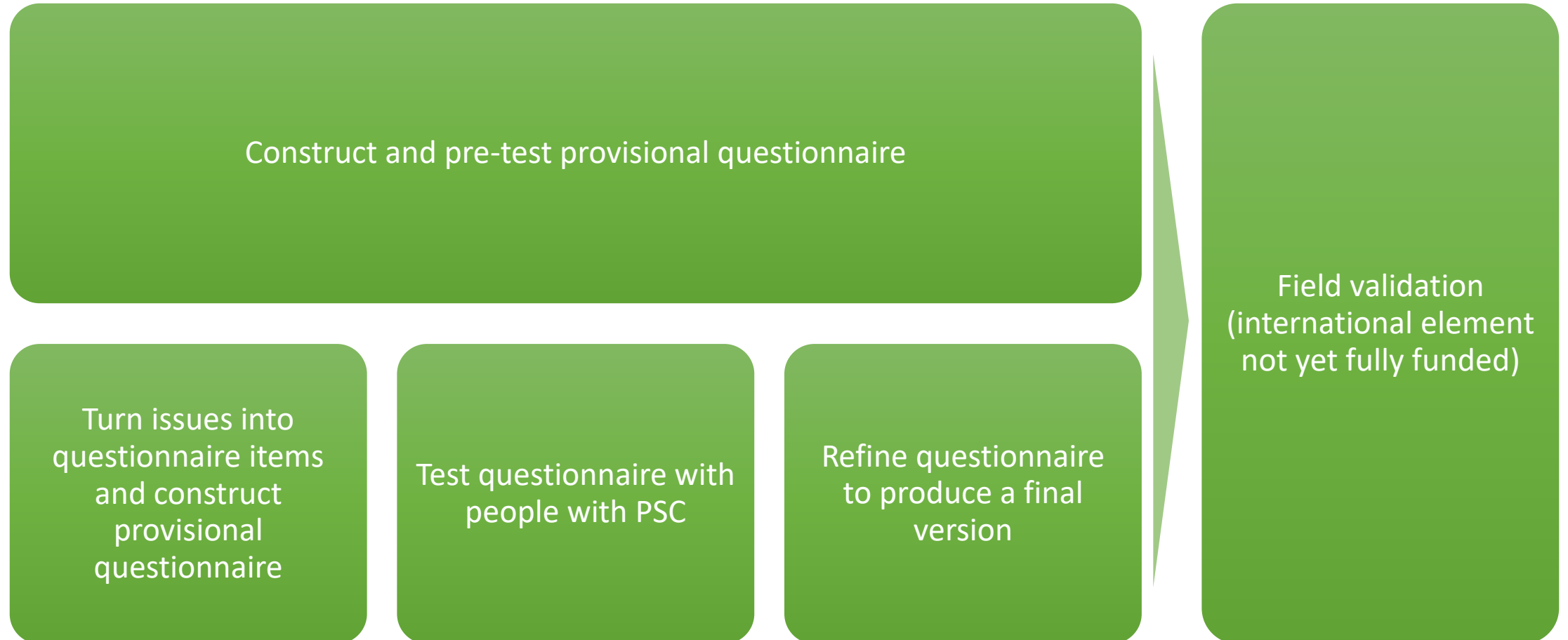
Generate a list of quality of life issues which may affect people with PSC

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



# 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

