

Table 1 Generic quality of life questionnaires and disease-specific quality of life questionnaires

Questionnaires	Scale (item)	Domains description	Scoring/administration
Disease-specific quality of life questionnaires			
PBC-40 <sup>[17]</sup>	6(40)	Fatigue, emotional, social, cognitive, itch and symptoms	5 point scale,1(not at all) to 5(very much) Total and subscale score Higher score indicates poorer health
PBC-27 <sup>[12]</sup>	7(27)	Other Symptoms, dryness, itch, fatigue, cognitive, emotional and social	5 point scale,1(not at all) to 5(very much) Total and subscale score Higher score indicates poorer health
PBC-10 <sup>[15]</sup>	6(10)	Fatigue, emotional, social, cognitive, itch and symptoms	5 point scale,1(not at all) to 5(very much) Total and subscale score Higher score indicates poorer health
CLDQ <sup>[18]</sup>	6(29)	Abdominal symptoms, fatigue, systemic symptoms, activity , emotional function, worry	7 point scale,1(not at all) to 7(very much) Total and subscale score Higher score indicates poorer health
CLDQ-I <sup>[19]</sup>	6(28)	Abdominal symptoms, fatigue, systemic symptoms, activity , emotional function, worry	6 point scale,1(not at all) to 7(very much) Total and subscale score Higher score indicates poorer health
LDSI 2.0 <sup>[20]</sup>	18	Itch, joint pain, pain in the right upper abdomen, sleepiness during the day, worry about family situation, decreased appetite, depression, fear of complications and jaundice, nine other items measure the hindrance	5 point scale,1(not at all) to 5(to a high extent) Subscale score Higher score indicates poorer health

of these symptoms to daily activities

#### Generic quality of life questionnaires

SF-36 <sup>[21]</sup>	8(36)	Physical functioning, physical role functioning, limitation emotional role limitation, bodily pain, mental health, social functioning, vitality and general health perception	100 point scale,0(not at all) to 100(very much) Total and subscale score Higher score indicates greater health
SF-12 <sup>[22]</sup>	2(12)	Physical component and mental summary	100 point scale,0(not at all) to 100(very much) Total and subscale score Higher score indicates greater health
15D(generic) <sup>[23]</sup>	15	Breathing, mental function, speech (communication), vision, mobility, usual activities, vitality, hearing, eating, elimination, sleeping, distress, discomfort and symptoms, sexual activity, and depression	5 point scale,1(not at all) to 5(very much) Total score Higher score indicates poorer health
NIDDK LTD-QOL <sup>[24]</sup>	5(21)	Measures of disease, psychological status, personal function, social and role function, and general health perception	5 point scale,0(not at all) to 4(extremely) Total and subscale score Higher score indicates poorer health
NIDDK-QA <sup>[16]</sup>	4(47)	Liver disease symptoms, physical functioning, health satisfaction and overall well-being	5 point scale,0(not at all) to 4(extreme) Total and subscale score Higher score indicates greater health
HUI-Mark-2 <sup>[25]</sup>	7(15)	Sensation, mobility, emotion, cognition, selfcare, pain and fertility	2 point scale,0(not at all) to 1(very much) Total and subscale score Higher score indicates greater health
HUI-Mark-3 <sup>[26]</sup>	8(15)	Vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain	2 point scale,0(not at all) to 1(very much) Total and subscale score Higher score indicates greater health

NHP <sup>[27]</sup>	6(38)	Energy, sleep, pain, emotional reactions, social isolation, and physical mobility	2 point scale,0(no) to 1(yes) Total and subscale score Higher score indicates poorer health
NHANES III ( <a href="https://www.cdc.gov/nchs/nhanes/nhanes3/default.aspx">https://www.cdc.gov/nchs/nhanes/nhanes3/default.aspx</a> )	4(83) 90	Articular symptoms, activity limitations (in both household and job-related activities), hobbies and leisure activities, and social life	Total and subscale score Higher score indicates poorer health
PROMIS-29(generic) <sup>[28]</sup>	7(29)	Physical function, depression, anxiety, fatigue, sleep disturbance, ability to participate in social roles and activities (social roles), pain interference, and one pain intensity item	5 point scale,1(not at all) to 5(very much) Total and subscale score Higher score indicates poorer health

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Table 2 Summary of psychometric properties of the identified HRQOL questionnaires

Questionnaires	Validity	Reliability	Responsiveness and floor/ceiling effects	Minimal important difference
PBC-40	<b>Construct validity</b> Moderate to high correlations with the SF-36 and ESI-55 scales, except for "Physical functioning" domain of the SF-36 and "Itch" domain of the PBC-40 <sup>[17]</sup>	<b>Internal consistency</b> Cronbach's alpha >0.7 for all scales <sup>[13]</sup> Cronbach's alpha >0.7 for all scales <sup>[14]</sup> Cronbach's alpha >0.7 for all scales <sup>[17]</sup> <b>Test-retest</b> ICC ranged 0.83-0.96 <sup>[17]</sup>	<b>Floor and ceiling effects</b> There were no ceiling effects but there was a noticeable floor effect in the itch domain (36.7%) <sup>[15]</sup>	
PBC-27	<b>Convergent validity</b> minor correlations between the PBC-27 social factor and the SF-36 social functioning, but moderate to high correlations in majority of scales <sup>[12]</sup>	<b>Internal consistency</b> Cronbach's alpha >0.7 for all scales <sup>[12]</sup> Cronbach's alpha >0.7 for all scales, except for domains "Dryness", "Symptoms" and "Fatigue" <sup>[13]</sup>		
PBC-10	<b>Content validity</b> Generally good, developed by hepatology experts in PBC <sup>[15]</sup>	<b>Internal consistency</b> Internal consistency was excellent with Cronbach's alpha of 0.936. <b>Test-retest</b> ICC=0.945 for all scales <sup>[15]</sup>	<b>Floor and ceiling effects</b> There were no ceiling effects but a floor effect was obvious <sup>[15]</sup> responsiveness ratio of 0.38, effect size of 0.39 and standardised response mean of 1.25. <b>Responsiveness</b> Small to moderate responsiveness <sup>[15]</sup>	The minimal important difference was 3.539 <sup>[15]</sup>
NIDDK-QA	<b>Concurrent validity</b> Small to high correlations with the SF-36 scales, P <0.01 <sup>[16]</sup>	<b>Internal consistency</b> Cronbach's alpha ranged from 0.87 to 0.94 <b>Test-retest</b> Pearson coefficients: 0.82-0.99, P <0.01 <sup>[16]</sup>		