

## Appendix 8: Comparison of patient preferences with other stakeholder groups

Study	Condition	No of patients	Stakeholder groups in addition to patients	Summary
Morss 1993 <sup>39</sup>	Schizophrenia	33	Psychiatrists	The preference values obtained from patients and psychiatrists were relatively equivalent, but patients ranked the three side effects in the opposite order of psychiatrists. Patients rated akathisia highest, followed by tardive dyskinesia and then parkinsonism, which was the worst side effect and ranked lowest. There were no statistically significant differences between psychiatrists' and patients' ranking..
Revicki 1996 <sup>49</sup>	Scizophrenia	49	Psychiatrists, caregivers	The preferences were strongly correlated between the groups. Caregivers rated six out of six states higher than the patients. Psychiatrists' preferences for hypothetical states were not statistically significantly different from those of patients. The hospitalised state was rated the worst by all three groups. No differences in patients' and caregivers' preferences were found, that were both statistically significant and consistent across the two methods applied.
Lenert 1997 <sup>46</sup>	Schizophrenia, schizoaffective disorder	22	Healthy volunteers	No statistically significant differences were found in preferences for side effects (parkinsonism, tardive dyskinesia and akathisia) between patients and healthy volunteer subjects.
Lee 2000 <sup>44</sup>	Schizophrenia	20	Family members, health providers and community members	Persons with schizophrenia valued the disease states higher and placed more negative significance on the effects of pseudo-parkinsonism than the other groups. Pseudo-parkinsonism resulted in a larger decrease in the desirableness of health states for patients compared to family members, health providers and community members ( $p=0.024$ ). Ratings by health professionals and community members tended to be lower for the health states. Family members had very similar preference ratings to those of the patients. Differences between patients and community volunteers were statistically significant for the disease states and for the effect of pseudo-parkinsonism.
Lenert 2000 <sup>28</sup>	Schizophrenia	148	Family members, health professionals	The differences in preferences between the groups were systematic, but the magnitude of the differences was modest. Patients' and family members' utilities for health states averaged from 0.10 to 0.15 units higher than those of health professionals, and the difference between the groups was statistically significant. The disutility placed on pseudo-parkinsonism was less for health professionals than patients and family members. Differences between groups for pseudo-parkinsonism were statistically significant. Health professionals tended to prefer control of disease above prevention of adverse drug effects. Health professionals preferred states with mild symptoms and pseudo-parkinsonism to moderate symptoms without the side effect, whereas patients and family members found the two states equally preferable. The differences between the groups were statistically significant. Family members had values that were more similar to those of patients, compared to those of health professionals.
Shumway 2003 <sup>45</sup>	Schizophrenia	50	Clinicians, family members, members	Patients rated extrapyramidal symptoms as more important than clinicians, family members, and members of the general public. Clinicians rated social functioning as more important than patients

			of the general public	and family members did. Clinicians and family members rated vocational functioning as more important than patients and the general public did. The differences were statistically significant. All stakeholders rated positive symptoms and social functioning as more important than negative and extrapyramidal symptoms.
Briggs 2008 <sup>40</sup>	Schizophrenia, schizoaffective disorder	50	Laypersons	The utility values varied considerably according to the population from which the values were derived. Patients with stable schizophrenia were less willing to trade years of life to avoid schizophrenia-related symptoms, compared to laypersons. Patients reported significantly higher utilities than laypersons for stable schizophrenia (0.92 vs. 0.87), EPS (0.72 vs. 0.57) and relapse (0.60 vs. 0.48). The ranking of the health states by patients and laypersons was similar.
Bridges 2013 <sup>36</sup>	Schizophrenia	105	Psychiatrists	There was a significant difference between patients and psychiatrists regarding their valuation of treatment goals. Psychiatrists tended to focus on "textbook" outcomes, while patients were more concerned with functioning and living a normal life. Psychiatrists overvalued improved capacity for emotion by 63%, improved sexual pleasure by 45 %, decreased mistrust/hostility by 37 %, decreased irritability by 25% and improved self-confidence by 20%. The psychiatrists undervalued improved activities for daily living (21%), improved capacity for work (18%), improved satisfaction (16%), improved self-independence (15%) and decreased depressive thoughts and feelings (13%).

Reference numbers refer to the reference list in the main article.