

**S1 Table. Characteristics of included studies.**

	Author	Year	Country	Population	Sample size (n)	Response rate (n)	Age, mean (SD)	Female (%)	Ethnicity	Employment status (%)	Education status	
1	Appelbaum <i>et al</i>	1999	USA	Clinical trial participants in a psychotherapy RCT for recurrent depression.	26	26	39 (10.45, range 24-49)	100	No data	No data	No data	
2	Appelbaum <i>et al</i>	2012	USA	Clinical trial participants from 4 academic medical centres in different geographic regions. Various trial phases and clinical areas.	220	189 (86%)	No data	45	No data	Employed 55 Retired 40 Looking for work 14 Domestic duties 5 Other 40	No data	
3	Chou & O'Rourke	2012	Canada USA Australia New Zealand	Study 1: Instrument development. Community dwelling mid-life and older adults recruited through membership lists, websites, and postings on older adult bulletin boards. Hypothetical clinical trial example.  Study 2: Instrument validation. Clinical trial participants	Study 1 464  Study 2 37	No data	Study 1 59.8 (6.2, range 50-84)	Study 1 59	Study 1 White/Caucasian/European 94.5%	Study 1 Retired 54  Full-time 27  Part-time 13	Study 1 Average 13.9 years formal education (SD=4, range 0-25)	
4	Guarino <i>et al</i>	2006	USA	Set within an RCT of Gulf War Veterans' illnesses.	1086	3 months: 906(83%) 6 months: 929 (86%) 12 months: 910 (84%)	40.7 (range 27-72)	15	White non-hispanic 53%  Black non-hispanic 24% Hispanic 20%	No data	Mean education 14.1 yrs (SD=1.9)	
5	Hutchison <i>et al</i>	2007	UK	Hospital based. Various participant groups: research nurses from a variety of specialties; and cancer patients (2 groups: previous RCT and no previous RCT)	78	78 Study recruited additional participants to account for non-responders	Patient: 57 (range 38-76) Previous RCT Patient: 63 (range 43-81) No RCT Research Nurse 41 (range 28-57)	Patient: 62 Previous RCT Patient: 70 No RCT Research Nurse 92	No data	No data	No data	
6	Jeste <i>et al</i>	2007	USA				Patients	Patients 36		Patient Health y	No data	No data

				Set within a larger study of informed consent among middle aged and older persons with schizophrenia. Simulated clinical drug trial.	127 patients 30 health comparators	127 patients 30 health comparators	51.8 (7.3)  Healthy comparators 55.9 (9.0)	Healthy comparators 57	White Black Latino Other	63 17 11 9	73 10 7 10				
7	Joffe <i>et al</i>	2001	USA	Patients and parents of paediatric patients enrolled in Phase I, II or III clinical trials. Tool was developed with intention to be used across clinical areas.	Pilot 1: 9 (5 patients and 4 parents)  Pilot 2: 10 (7 patients and 3 parents)	Not reported	No data	No data	No data	No data	No data	Pilot 1: not reported  Pilot 2: ranged from high school to graduate.			
8	Miller <i>C et al</i>	1996	USA	Set within 4 prospective double-blind RCTs of anti-infective agents.	275	275 Reliability measured on 50 and validity on 200 responses.	36 (12.8)	63	No data	No data	No data	Mean yrs 14.4 (SD = 2.3, range 10-24)			
9	Miller <i>J et al</i>	2011	USA	Online survey populations. The probability samples were weighted to reflect existing Population Survey findings.	Sample 1 (public) : 1200  Sample 2 (cancer survivor): 2057	Sample 1 (public) : 1027  Sample 2 (cancer survivor): 1788	Sample 18-24 25-34 35-44 45-54 55-64	1 (n) 91 210 234 197 132	2 (n) 34 - 117 223 331	Sample 1 (public) : 52  Sample 2 (cancer survivor): 54	No data	No data	Sample < high school High school Some college Baccalaureate Graduate or professional	1 (n) 13 36 28 3 14 10 1	2 (n) 82 38 64 5 39 28 0

							65-74	109	467				
							>75	54	614				
10	Miller V <i>et al</i>	2011	USA	Parents/carers, of seriously ill children, recruited through paediatric hospital and who had made decision in the past days either about research (62.1%) or informed consent for treatment (32.9%).	250	231 (219 included in analysis)	37.1 (8.1)	74		Black Or African American 46 American Indian/Alaskan Native 1 Asian 10 White 14 Other 7 Missing 14	Family income (\$) <19999 26 20000-39999 39 40000-59000 35 60000-79000 40 80000-99999 27 >100000 49 Missing 3	Some high school High school Vocational or some college College degree Postgrad Professional or graduate degree	12 32 72 56 12 34
11	Porteri C <i>et al</i>	2008	Italy	Set within 2 Phase III placebo controlled drug RCTs for Alzheimer's disease.	42 patients 21 caregivers	42 patients 21 caregivers	Patients 74.6 (7.3, range 60-88) Caregivers 53.7 (11.7, range 35-76)	Patients 71 Caregivers 62	No data	No data	No data	No data	No data
12	Prentice <i>et al</i>	2007	USA	Schizophrenia patients enrolled in clinical trials	11	11	No data	No data	No data	No data	No data	No data	No data
13	Resnick <i>et al</i>	2007	USA	Nursing home residents being recruited for to an RCT of a restorative care intervention.	346	346	86.1 (7.3)	84	95% Caucasian	No data	No data	No data	No data
14	Sugarman <i>et al</i>	2005	USA	Set within 8 different parent RCTs	632	632	67 (7.2)	26	93% white 4% black 3% other	No data	72% had some college education		