

Supplementary file 2: Search terms

Medline

# ▲	Searches	Results
1	*dementia/ or *alzheimer disease/ or exp *dementia, vascular/ or exp *frontotemporal lobar degeneration/	98,731
2	*Cognitive Dysfunction/	4,368
3	(dementia* or alzheimer*).ti.	92,750
4	((mild* or early* or preclinical or pre-clinical) adj2 (cognitive impair* or cognitive dysfunction or cognitive decline)).ti.	5,582
5	1 or 2 or 3 or 4	118,970
6	*"Quality of Life"/	69,834
7	("quality of life" or "quality of wellbeing" or "quality of well-being").ti.	55,455
8	(qol or hqol or hrqol or hrql or hr-qol or hr-ql or euroqol or euro qol or eq5d or eq-5d or eq-vas or vas or whoqol or who qol or reqol*).ti,ab.	81,919
9	(sf6 or sf6d or sf12 or sf16 or sf20 or sf36).ti,ab.	2,656
10	((sf or shortform or short-form) adj ("6" or 6d or "12" or "16" or "20" or "36" or six or twelve or sixteen or twenty or thirtysix or thirty six)).ti,ab.	26,238
11	(icepop or icecap* or duke health profile or dhp or core outcome measure? or core om).ti,ab.	2,772
12	(aaiqol or aai-qol or cdqlp or qolas or qolad or qol-ad or qold or dqol or demqol or adrql or adrql or oqold or oqolda or seiql or rsoc-qol or qualid or qualidem or qwb-sa or hsq-12 or zbi or zarit or ces-d or "activity and affect indicator*" or dcm or pwbcip or pwb-cip or npi-d or ham-d or basquid or basqid or stai or stai-5 or bdi or gds or gps or hui or hui-ii or hui-iii or isd or pds or pes-ad or pesad or pes-ad-aes or pesadaes or ghq or cas or cbs or qwb or cbi or bsi or srb or phq-9).ti,ab.	82,505
13	(modified coop* or modified wonca* or "psychological well-being in cognitively impaired persons").ti,ab.	23
14	*Personal Satisfaction/ or *Patient Satisfaction/	31,894
15	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj satisfaction).ti.	7,129
16	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj (experience? or preference? or perspective?)).ti.	8,647
17	(wellbeing or well-being).ti.	11,493
18	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj (experience? or preference? or perspective?)).ti.	8,647
19	caregiver time.ti,ab.	140
20	14 or 15 or 16 or 17 or 18 or 19	51,145
21	"surveys and questionnaires"/ or self report/	394,101
22	(questionnaire? or survey?).ti,ab.	804,666
23	self report.ti,ab.	42,432
24	((patient* or carer? or caregiver? or spous* or wife or wives or husband? or proxy) adj report?).ti,ab.	7,095
25	21 or 22 or 23 or 24	976,414

26	20 and 25	23,719
27	*Caregivers/ and *"Cost of Illness"/	1,619
28	((carer? or caregiver? or care or spous* or wife or wives or husband?) adj2 (burden* or cost?)).ti.	5,142
29	burden interview?.ti.	50
30	"value of life".ti.	87
31	*"Activities of Daily Living"/	17,986
32	("activities of daily living" or acdl or funtional status).ti.	1,772
33	*quality-adjusted life years/	1,917
34	("quality adjusted life years" or "disability adjusted life years" or qaly? or daly? or qald or qale or qtime or qaly).ti.	764
35	*Health Status/	34,353
36	*sickness impact profile/	2,623
37	(standard gamble or "time trade off" or utility index or visual analog*).ti,ab.	48,455
38	(health utilit* or disutilit* or utility value?).ti,ab.	2,889
39	health status.ti.	9,145
40	6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39	322,206
41	5 and 40	4,530
42	limit 41 to yr="1990 -Current"	4,445
43	(case reports or clinical trial phase i or comment or editorial or letter).pt. or Clinical Trials, Phase I as Topic/ or (case report or case study or letter? or editorial).ti.	3,400,815
44	grounded theory/ or exp qualitative research/ or (qualitative research or qualitative study or qualitative interview* or grounded theory or hermeneutic*).ti,ab.	67,630
45	43 or 44	3,466,599
46	42 not 45	4,087

Embase

#	Searches	Results
1	exp *dementia/ or *alzheimer's disease/	177,994
2	*cognitive impairment/	40,861
3	(dementia* or alzheimer*).ti.	119,362
4	((mild* or early* or preclinical or pre-clinical) adj2 (cognitive impair* or cognitive dysfunction or cognitive decline)).ti.	8,090
5	1 or 2 or 3 or 4	223,452
6	exp *"quality of life"/	80,143
7	("quality of life" or "quality of wellbeing" or "quality of well-being").ti.	76,232
8	(qol or hqol or hrqol or hrql or hr-qol or hr-ql or euroqol or euro qol or eq5d or eq-5d or eq-vas or vas or whoqol or who qol or reqol*).ti,ab.	129,834
9	(sf6 or sf6d or sf12 or sf16 or sf20 or sf36).ti,ab.	4,872

10	((sf or shortform or short-form) adj ("6" or 6d or "12" or "16" or "20" or "36" or six or twelve or sixteen or twenty or thirtysix or thirty six)).ti,ab.	37,206
11	(icepop or icecap* or duke health profile or dhp or core outcome measure? or core om).ti,ab.	3,316
12	(aaiqol or aai-qol or cdqlp or qolas or qolad or qol-ad or qold or dqol or demqol or adrql or adrqol or oqold or oqolda or seiqol or rsoc-qol or qualid or qualidem or qwb-sa or hsq-12 or zbi or zarit or ces-d or "activity and affect indicator*" or dcm or pwbcip or pwb-cip or npi-d or ham-d or basquid or basqid or stai or stai-5 or bdi or gds or gps or hui or hui-ii or hui-iii or isd or pds or pes-ad or pesad or pes-ad-aes or pesadaes or ghq or cas or cbs or qwb or cbi or bsi or srb or phq-9).ti,ab.	114,337
13	(modified coop* or modified wonca* or "psychological well-being in cognitively impaired persons").ti,ab.	29
14	*client satisfaction/ or *life satisfaction/	1,991
15	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj satisfaction).ti.	8,839
16	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj (experience? or preference? or perspective?)).ti.	11,228
17	(wellbeing or well-being).ti.	12,234
18	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj (experience? or preference? or perspective?)).ti.	11,228
19	caregiver time.ti,ab.	183
20	14 or 15 or 16 or 17 or 18 or 19	33,365
21	"surveys and questionnaires"/ or self report/	582,726
22	(questionnaire? or survey?).ti,ab.	1,011,521
23	self report.ti,ab.	50,950
24	((patient* or carer? or caregiver? or spous* or wife or wives or husband? or proxy) adj report?).ti,ab.	10,383
25	21 or 22 or 23 or 24	1,187,376
26	20 and 25	14,705
27	*caregiver burden/	1,934
28	((carer? or caregiver? or care or spous* or wife or wives or husband?) adj2 (burden* or cost?)).ti.	6,435
29	burden interview?.ti.	59
30	"value of life".ti.	96
31	*"activities of daily living"/	8,385
32	("activities of daily living" or acdl or funtional status).ti.	2,164
33	*quality adjusted life year/	1,084
34	("quality adjusted life years" or "disability adjusted life years" or qaly? or daly? or qald or qale or qtime or qaly).ti.	898
35	*Health Status/	28,930
36	*sickness impact profile/	689
37	(standard gamble or "time trade off" or utility index or visual analog*).ti,ab.	64,774
38	(health utilit* or disutilit* or utility value?).ti,ab.	4,516
39	health status.ti.	9,969
40	6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39	393,955

41	5 and 40	6,763
42	limit 41 to yr="1990 -Current"	6,613
43	(editorial or letter or note or press).pt. or "phase 1 clinical trial (topic)"/ or case report/ or (case report or case study or letter? or editorial).ti.	4,421,368
44	grounded theory/ or exp qualitative research/ or (qualitative research or qualitative study or qualitative interview* or grounded theory or hermeneutic*).ti,ab.	71,138
45	43 or 44	4,489,168
46	42 not 45	6,122

PsycINFO

#	Searches	Results
1	exp *dementia/ or *alzheimer's disease/	58,737
2	*cognitive impairment/	23,977
3	(dementia* or alzheimer*).ti.	47,312
4	((mild* or early* or preclinical or pre-clinical) adj2 (cognitive impair* or cognitive dysfunction or cognitive decline)).ti.	3,675
5	1 or 2 or 3 or 4	77,854
6	exp *"quality of life"/	28,944
7	("quality of life" or "quality of wellbeing" or "quality of well-being").ti.	17,544
8	(qol or hqol or hrqol or hrql or hr-qol or hr-ql or euroqol or euro qol or eq5d or eq-5d or eq-vas or vas or whoqol or who qol or reqol*).ti,ab.	15,758
9	(sf6 or sf6d or sf12 or sf16 or sf20 or sf36).ti,ab.	243
10	((sf or shortform or short-form) adj ("6" or 6d or "12" or "16" or "20" or "36" or six or twelve or sixteen or twenty or thirtysix or thirty six)).ti,ab.	5,546
11	(icepop or icecap* or duke health profile or dhp or core outcome measure? or core om).ti,ab.	367
12	(aaiqol or aai-qol or cdqlp or qolas or qolad or qol-ad or qold or dqol or demqol or adrql or adrql or oqold or oqolda or seiql or rsoc-qol or qualid or qualidem or qwb-sa or hsq-12 or zbi or zarit or ces-d or "activity and affect indicator*" or dcm or pwbcip or pwb-cip or npi-d or ham-d or basquid or basqid or stai or stai-5 or bdi or gds or gps or hui or hui-ii or hui-iii or isd or pds or pes-ad or pesad or pes-ad-aes or pesadaes or ghq or cas or cbs or qwb or cbi or bsi or srb or phq-9).ti,ab.	27,360
13	(modified coop* or modified wonca* or "psychological well-being in cognitively impaired persons").ti,ab.	14
14	*client satisfaction/ or *life satisfaction/	10,500
15	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj satisfaction).ti.	4,378
16	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj (experience? or preference? or perspective?)).ti.	3,089
17	(wellbeing or well-being).ti.	17,565
18	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) adj (experience? or preference? or perspective?)).ti.	3,089
19	caregiver time.ti,ab.	51

20	14 or 15 or 16 or 17 or 18 or 19	30,716
21	questionnaires/ or surveys/ or self report/	36,535
22	(questionnaire? or survey?).ti,ab.	409,092
23	self report.ti,ab.	49,405
24	((patient* or carer? or caregiver? or spous* or wife or wives or husband? or proxy) adj report?).ti,ab.	2,724
25	21 or 22 or 23 or 24	446,678
26	20 and 25	10,093
27	*caregiver burden/	4,122
28	((carer? or caregiver? or care or spous* or wife or wives or husband?) adj2 (burden* or cost?)).ti.	1,257
29	burden interview?.ti.	42
30	"value of life".ti.	33
31	*"activities of daily living"/	3,835
32	("activities of daily living" or acdl or funtional status).ti.	734
33	("quality adjusted life years" or "disability adjusted life years" or qaly? or daly? or qald or qale or qtime or qaly).ti.	142
34	(standard gamble or "time trade off" or utility index or visual analog*).ti,ab.	6,195
35	(health utilit* or disutilit* or utility value?).ti,ab.	877
36	health status.ti.	2,312
37	6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36	85,145
38	5 and 37	4,392
39	limit 38 to yr="1990 -Current"	4,344
40	case report/ or (case report or case study or letter? or editorial).ti.	62,005
41	grounded theory/ or qualitative research/ or (qualitative research or qualitative study or qualitative interview* or grounded theory or hermeneutic*).ti,ab.	61,499
42	40 or 41	122,316
43	39 not 42	4,208

Cochrane Database of Systematic Reviews, Cochrane Central Register of Controlled Trials, Database Abstract of Reviews of Effects, NHS Economic Evaluation Database

ID	Search
#1	MeSH descriptor: [Dementia] explode all trees
#2	MeSH descriptor: [Mild Cognitive Impairment] explode all trees
#3	dementia* or alzheimer*:ti (Word variations have been searched)
#4	((mild* or early* or preclinical or pre-clinical) near/2 (cognitive impair* or cognitive dysfunction or cognitive decline)):ti (Word variations have been searched)
#5	#1 or #2 or #3 or #4
#6	MeSH descriptor: [Quality of Life] explode all trees
#7	quality of life or "quality of wellbeing" or "quality of well-being":ti (Word variations have been searched)
#8	qol or hqol or hrqol or hrql or hr-qol or hr-ql or euroqol or euro qol or eq5d or eq-5d or eq-vas or vas or whoqol or who qol or reqol*:ti,ab,kw (Word variations have been searched)

#9	sf6 or sf6d or sf12 or sf16 or sf20 or sf36:ti,ab,kw (Word variations have been searched)
#10	((sf or shortform or short-form) next ("6" or 6d or "12" or "16" or "20" or "36" or six or twelve or sixteen or twenty or thirtysix or thirty six)):ti,ab,kw (Word variations have been searched)
#11	icepop or icecap* or "duke health profile" or dhp or "core outcome measure?" or "core om":ti,ab,kw (Word variations have been searched)
#12	aaiqol or aai-qol or cdqlp or qolas or qolad or qol-ad or qold or dqol or demqol or adrql or adrqol or oqold or oqolda or seiqol or rsoc-qol or qualid or qualidem or qwb-sa or hsq-12 or zbi or zarit or ces-d or "activity and affect indicator*" or dcm or pwbcip or pwb-cip or npd or ham-d or basquid or basqid or stai or stai-5 or bdi or gds or gps or hui or hui-ii or hui-iii or isd or pds or pes-ad or pesad or pes-ad-aes or pesadaes or ghq or cas or cbs or qwb or cbi or bsi or srb or phq-9:ti,ab,kw (Word variations have been searched)
#13	modified coop* or "modified wonca*" or "psychological well-being in cognitively impaired persons":ti,ab,kw (Word variations have been searched)
#14	MeSH descriptor: [Patient Satisfaction] this term only
#15	MeSH descriptor: [Personal Satisfaction] explode all trees
#16	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) next satisfaction):ti,ab,kw (Word variations have been searched)
#17	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) next (experience? or preference? or perspective?):ti,ab,kw (Word variations have been searched)
#18	wellbeing or well-being:ti (Word variations have been searched)
#19	((life or patient* or carer? or caregiver? or spous* or wife or wives or husband?) next (experience? or preference? or perspective?):ti,ab,kw (Word variations have been searched)
#20	caregiver time:ti,ab,kw (Word variations have been searched)
#21	((carer? or caregiver? or care or spous* or wife or wives or husband?) near/2 (burden* or cost?):ti,ab,kw (Word variations have been searched)
#22	burden interview?:ti,ab,kw (Word variations have been searched)
#23	value of life:ti,ab,kw (Word variations have been searched)
#24	MeSH descriptor: [Activities of Daily Living] explode all trees
#25	activities of daily living or acdl or "functional status":ti,ab,kw (Word variations have been searched)
#26	MeSH descriptor: [Quality-Adjusted Life Years] explode all trees
#27	quality adjusted life years or "disability adjusted life years" or qaly? or daly? or qald or qale or qtime or qaly:ti,ab,kw (Word variations have been searched)
#28	MeSH descriptor: [Health Status] this term only
#29	MeSH descriptor: [Sickness Impact Profile] explode all trees
#30	standard gamble or "time trade off" or "utility index" or "visual analog*":ti,ab,kw (Word variations have been searched)
#31	health utilit* or disutilit* or "utility value?":ti,ab,kw (Word variations have been searched)
#32	HEALTH STATUS:ti (Word variations have been searched)
#33	#6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17 or #18 or #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32
#34	#5 and #33

QoL Data Extraction Form

Study ID (<i>surname of first author and year first full report of study was published e.g. Smith 2001</i>)	
Publication Title	
Notes:	

General Information

Date when form was completed (<i>dd/mm/yyyy</i>)	
Name of person extracting data	
Language of study	
Corresponding author contact details	
Publication type (e.g. full report, abstract, letter)	
Notes:	

Study Design

	Descriptions as stated in the study
Aim of the study	
Type of study	Interventional study: <ul style="list-style-type: none"> Randomised controlled trial <input type="checkbox"/> Non-randomised controlled trial <input type="checkbox"/> Cross-over randomised controlled trial <input type="checkbox"/> Before-and-after study <input type="checkbox"/> Observational study: <ul style="list-style-type: none"> Case-control study <input type="checkbox"/> Cohort study <input type="checkbox"/> Cross-sectional study <input type="checkbox"/> Other (specify): Register based study <input type="checkbox"/> Other design (specify):
Type of analysis	Prospective <input type="checkbox"/> Retrospective <input type="checkbox"/> Unclear <input type="checkbox"/>
QoL instrument(s)	

QoL instrument language	
QoL instrument mode of administration (e.g. paper copy; electronic; telephone; face-to-face interview)	
Outcomes measured other than QoL?	
Start date	
End date	
Follow up (in months)	
Ethical approval needed/ obtained for study	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear

Participants

	Description as stated in paper/report
Country (ies)	
Population Description	
Type of Participant	Patients <input type="checkbox"/> Caregivers <input type="checkbox"/> Other: <input type="checkbox"/>
Setting	Community <input type="checkbox"/> Institutional <input type="checkbox"/> Primary Care <input type="checkbox"/> Secondary Care <input type="checkbox"/> Tertiary Care <input type="checkbox"/> Mixed <input type="checkbox"/> Unclear <input type="checkbox"/> Other: <input type="checkbox"/>
Enrolment Eligibility	
A. Inclusion Criteria	A.
B. Exclusion Criteria	B.
Recruitment Process	
Sample Size	
Mean age of patients	
Patients gender (% of females in the sample)	
Mean age of caregiver	
Caregiver gender (% of females in the sample)	
Caregiver relationship to patient	Spouse _____% Daughter/son-in-law _____% Daughter _____% Grandchild _____%

	Son _____% Friend _____% Brother _____% Other: _____ and _____% Sister _____%
Any other relevant sociodemographic information	
Notes:	

Dementia Diagnosis

	Description as stated in paper/report
Type of Dementia	Alzheimer's Disease <input type="checkbox"/> Lewy Body Dementia <input type="checkbox"/> Vascular Dementia <input type="checkbox"/> Mixed <input type="checkbox"/> Other: <input type="checkbox"/>
Disease Severity	Pre-clinical dementia <input type="checkbox"/> Early symptoms <input type="checkbox"/> MCI <input type="checkbox"/> Prodromal AD <input type="checkbox"/> Mild dementia <input type="checkbox"/> Moderate dementia <input type="checkbox"/> Severe dementia <input type="checkbox"/> End of Life <input type="checkbox"/>
Assessment of Disease Severity	Tool Used: Details:
Notes	

Interventions

	Description as stated in paper/report	
Type of Intervention		
Timing of Intervention		
Duration of Intervention Period		
No. of people in each group	Comparison Group	Intervention Group
Implementation		

Outcomes

	Description as stated in paper/report
Outcome Measure	

Time Points Measured	Single Time Point Only <input type="checkbox"/> Baseline <input type="checkbox"/> Follow Up – Details: <input type="checkbox"/>
Group Measured	Patient <input type="checkbox"/> Caregiver <input type="checkbox"/>
Source (who the information on outcome measured is obtained from)	Patient <input type="checkbox"/> Caregiver <input type="checkbox"/> Clinician <input type="checkbox"/> General public <input type="checkbox"/> Other: <input type="checkbox"/>
Tool Used	
Details	Score Range:
Outcome tool validated	Yes <input type="checkbox"/> No <input type="checkbox"/> Unclear <input type="checkbox"/>
Notes	

Results

Results	Description as stated in paper/report								
	Pre-clinical	Early symptoms	MCI	Prodromal AD	Mild dementia	Moderate dementia	Severe dementia	End of Life	Total
Patients' QoL: A. Baseline B. Follow-up									
Caregivers' QoL: A. Baseline B. Follow-up									
Comparison Group:	Baseline		Follow Up		Effect Size		95% CIs		
Intervention Group	Baseline		Follow Up		Effect Size		95% CIs		
Statistical Analysis									
Conclusion									
Any other results reported?									

Conclusions

	Description as stated in paper/report
Author's conclusions	
Reviewer's conclusions	
Correspondence required for further study information (<i>from whom, what and when</i>)	
Notes	