# Appendix A: How this guideline was developed

This guideline was developed in accordance with the process and methods set out in Developing NICE guidelines: the Manual (2014).

The review questions used to develop the guideline were as follows:

- 1. Which aspects of the experience of using adult social care services are positive or valued by people who use services?
- 2. For people who use adult social care services, what are the barriers related to improving their experience of care?
- 3. For people who use adult social care services, what would help improve their experience of care?
- 4. What methods and approaches for gathering, monitoring and evaluating the experiences of people using adult social care services are effective and cost-effective?

### 1. Search strategy

The evidence reviews used to develop the guideline recommendations were underpinned by systematic literature searches, following the methods described in the <u>manual</u>. The aim of the systematic searches was to comprehensively identify the published evidence to answer the review questions developed by the Guideline Committee and NICE Collaborating Centre for Social Care (NCCSC).

A single search strategy for the review questions was developed by the NICE Collaborating Centre for Social Care. The research questions were translated into a framework of four concepts:

- (1) views and experiences including: views, experience, preference, perspective, satisfaction, dissatisfaction feedback, learn, attitudes, expectation, complaint
- (2) Setting (social care services) including: social care, social provision, social service, community, residential, home, personal budget, direct payment, care plan
- (3) Population (adults) including: adults, older people, frail, elderly, homeless, disabled, disability

(4) Study type and outcomes – including: quality studies, evaluation studies, measures or outcomes, economic studies

These concepts were translated into search strategies using subject heading and free text terms. The strategies were run across a number of databases.

To help maximise the relevance of the results and to keep the search focused we combined difference terms near each other for 'service user' such as consumer, client, customer, people with terms used to elicit people's views and experiences, such as perspective, satisfaction, feedback, experience.

The search was restricted to human studies in the English language and published from 2000.

Economic evidence was searched for as part of the single search strategy, and included searching within the economic databases the NHS Economic Evaluation Database (NHS EED) and the Health Economic Evaluations Database (HEED).

Additional searches of websites of relevant organisations were undertaken to capture literature that might not have been found from the database searches.

A call for evidence from stakeholders, providing an opportunity for any groups or organisations to submit relevant evidence was also carried out at the beginning of the review which ran on the NICE website up to the end of March 2016.

Guideline Committee members were also asked to alert the NICE Collaborating Centre for Social Care to any additional evidence, published, unpublished or in press, that met the inclusion criteria throughout the review.

The database and website searches were undertaken in March 2016. Update searching of the bibliographic databases searches took place in January 2017. When the update searches were ran an adjustment was made to the original search strategy to include the term 'disabled' in the population segment of the search.

#### Additional methods used

To ensure that we were including the views from different groups in this review and to capture the direct user experience it was necessary to look at additional evidence sources and types of evidence for this review.

We searched the Leeds Disability Rights Unit database and the Skills for Care Archive to identify any studies likely to contain the direct views and experiences of people from diverse groups using social care services.

The GC highlighted, from their experience, the compelling nature of video evidence on direct user experience. We additionally searched databases which contained a range of relevant video evidence accompanied by transcripts. This included SCIE Social Care TV and Think Local Act Personal (TLAP) video collection.

#### 2. Sources searched

The following sources were searched.

### Bibliographic databases

#### Social care and social science:

Ageline (Ebsco)

Applied Social Sciences Index & Abstracts (ASSIA) (Proquest)

International Bibliography of the Social Sciences (IBSS) (Proquest)

Social Policy and Practice (SCO, CPA, CLA, IDOX Information) (Ovid)

Social Work Abstracts (SWA) (Ovid)

Social Services Abstracts (SSA) (Ovid)

SocINDEX (Ebsco)

Sociological Abstracts (Proquest)

#### Health:

Cumulative Index to Nursing and Allied Health Literature (CINAHL) (Ebsco)

Medline (Ovid)

PsycINFO (Ovid)

Other databases:
Campbell Collaboration Library
Centre for Reviews and Dissemination database (includes NHS EED¹ - economic
database and DARE)
Social Care Online (SCO)
The Cochrane Library
Websites:
ADASS
ESRC
IPPR
Ipsos MORI
Joseph Rowntree Foundation
King's Fund
Leeds Disability Rights Unit database
LGA
NATCEN
National Voices
NIHR
Nuffield Trust
OPENgrey (European grey literature)

NIHR funding to produce DARE and NHS EED ceases at the end of March 2015. However, both databases can be accessed via the CRD website.

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 $<sup>^{\</sup>rm 1}$  Bibliographic records will be published on DARE and NHS EED until 31st March 2015.

### OPM

Picker Institute Europe

**Professional Standards Authority** 

SCIE Social Care TV

Skills for Care Archive

Social Policy Research Unit

Social Services Knowledge Scotland

Think Local Act Personal (TLAP) video collection

### 3. Search strategies for the bibliographic database searches

### 1. Ageline (Ebsco)

Date searched: 16/03/2016

No. of records: 3325

Date limits: after 31Dec2000

Date update search: 24/01/2017

No. of update records: 107

Note: No equivalent term or got 0 results for following phrases so left out.

"expert by experience"

TI (carer\* n3 feedback) or AB (carer\* n3 feedback)

TI (consult\* n3 expectation\*) or AB (consult\* n3 expectation\*)

TI (carer\* n3 complaint\*) or AB (carer\* n3 complaint\*)

TI (participation n3 complaint\*) or AB (participation n3 complaint\*)

#	Query	Results
S1	(DE "satisfaction")	1,226
S2	(ZE "attitudes")	6,281
S3	DE "Caregivers"	8,307
S4	DE "Service Involvement"	148
S5	TI (lived n3 experience*) or AB (lived n3 experience*)	313
S6	DE "Advocacy"	1,510
S7	TI (carer* n3 attitud*) or AB (carer* n3 attitud*)	9

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S8	TI (carer* n3 (choice* or choos* or control)) or AB (carer* n3 (choice* or choos* or control))	5
S9	TI (carer* n3 expectation*) or AB (carer* n3 expectation*)	4
S10	TI (carer* n3 experience*) or AB (carer* n3 experience*)	57
S11	TI (carer* n3 learn*) or AB (carer* n3 learn*)	6
S12	TI (carer* n3 perspective*) or AB (carer* n3 perspective*)	13
S13	TI (carer* n3 preference*) or AB (carer* n3 preference*)	2
S14	TI (carer* n3 (satisf* or dissatisf*)) or AB (carer* n3 (satisf* or dissatisf*))	12
S15	TI (carer* n3 view*) or AB (carer* n3 view*)	17
S16	TI (client* n3 attitud*) or AB (client* n3 attitud*)	32
S17	TI (client* n3 (choice* or choos* or control)) or AB (client* n3 (choice* or choos* or control))	98
S18	TI (client* n3 complaint*) or AB (client* n3 complaint*)	6
S19	TI (client* n3 expectation*) or AB (client* n3 expectation*)	17
S20	TI (client* n3 experience*) or AB (client* n3 experience*)	99

004	TI / II / M O.C. II I I AD / II / M O.C. II I I I	10
S21	TI (client* n3 feedback) or AB (client* n3 feedback)	10
S22	TI (client* n3 learn*) or AB (client* n3 learn*)	33
S23	TI (client* n3 perspective*) or AB (client* n3 perspective*)	35
S24	TI (client* n3 preference*) or AB (client* n3 preference*)	24
S25	TI (client* n3 (satisf* or dissatisf*)) or AB (client* n3 (satisf* or dissatisf*))	132
S26	TI (client* n3 view*) or AB (client* n3 view*)	38
S27	TI (consult* n3 attitud*) or AB (consult* n3 attitud*)	2
S28	TI (consult* n3 (choice* or choos* or control)) or AB (consult* n3 (choice* or choos* or control))	18
S29	TI (consult* n3 complaint*) or AB (consult* n3 complaint*)	5
S30	TI (consult* n3 experience*) or AB (consult* n3 experience*)	24
S31	TI (consult* n3 feedback) or AB (consult* n3 feedback)	5
S32	TI (consult* n3 learn*) or AB (consult* n3 learn*)	6
S33	TI (consult* n3 perspective*) or AB (consult* n3 perspective*)	7

S34	TI (consult* n3 preference*) or AB (consult* n3 preference*)	2
S35	TI (consult* n3 (satisf* or dissatisf*)) or AB (consult* n3 (satisf* or dissatisf*))	8
S36	TI (consult* n3 view*) or AB (consult* n3 view*)	6
S37	TI (consumer* n3 attitud*) or AB (consumer* n3 attitud*)	64
S38	TI (consumer* n3 (choice* or choos* or control)) or AB (consumer* n3 (choice* or choos* or control))	231
S39	TI (consumer* n3 complaint*) or AB (consumer* n3 complaint*)	25
S40	TI (consumer* n3 expectation*) or AB (consumer* n3 expectation*)	13
S41	TI (consumer* n3 experience*) or AB (consumer* n3 experience*)	39
S42	TI (consumer* n3 feedback) or AB (consumer* n3 feedback)	9
S43	TI (consumer* n3 learn*) or AB (consumer* n3 learn*)	13
S44	TI (consumer* n3 perspective*) or AB (consumer* n3 perspective*)	63
S45	TI (consumer* n3 preference*) or AB (consumer* n3 preference*)	71

S46	TI (consumer* n3 (satisf* or dissatisf*)) or AB (consumer* n3 (satisf* or dissatisf*))	88
S47	TI (consumer* n3 view*) or AB (consumer* n3 view*)	43
S48	TI (customer* n3 attitud*) or AB (customer* n3 attitud*)	1
S49	TI (customer* n3 (choice* or choos* or control)) or AB (customer* n3 (choice* or choos* or control))	2
S50	TI (customer* n3 complaint*) or AB (customer* n3 complaint*)	6
S51	TI (customer* n3 expectation*) or AB (customer* n3 expectation*)	9
S52	TI (customer* n3 experience*) or AB (customer* n3 experience*)	10
S53	TI (customer* n3 feedback) or AB (customer* n3 feedback)	4
S54	TI (customer* n3 learn*) or AB (customer* n3 learn*)	6
S55	TI (customer* n3 perspective*) or AB (customer* n3 perspective*)	2
S56	TI (customer* n3 preference*) or AB (customer* n3 preference*)	3
S57	TI (customer* n3 (satisf* or dissatisf*)) or AB (customer* n3 (satisf* or dissatisf*))	51

S58	TI (customer* n3 view*) or AB (customer* n3 view*)	3
S59	TI (individual* n3 attitud*) or AB (individual* n3 attitud*)	126
S60	TI (individual* n3 (choice* or choos* or control)) or AB (individual* n3 (choice* or choos* or control))	496
S61	TI (individual* n3 complaint*) or AB(individual* n3 complaint*)	34
S62	TI (individual* n3 expectation*) or AB (individual* n3 expectation*)	43
S63	TI (individual* n3 experience*) or AB (individual* n3 experience*)	549
S64	TI (individual* n3 feedback) or AB (individual* n3 feedback)	22
S65	TI (individual* n3 learn*) or AB (individual* n3 learn*)	140
S66	TI (individual* n3 perspective*) or AB (individual* n3 perspective*)	187
S67	TI (individual* n3 preference*) or AB (individual* n3 preference*)	168
S68	TI (individual* n3 (satisf* or dissatisf*)) or AB (individual* n3 (satisf* or dissatisf*))	89
S69	TI (individual* n3 view*) or AB (individual* n3 view*)	146

S70	TI (involv* n3 attitud*) or AB (involv* n3 attitud*)	47
S71	TI (involv* n3 (choice* or choos* or control)) or AB (involv* n3 (choice* or choos* or control))	150
S72	TI (involve* n3 complaint*) or AB (involve* n3 complaint*)	10
S73	TI (involv* n3 expectation*) or AB (involv* n3 expectation*)	25
S74	TI (involv* n3 experience*) or AB (involv* n3 experience*)	135
S75	TI (involv* n3 feedback) or AB (involv* n3 feedback)	14
S76	TI (involv* n3 learn*) or AB (involv* n3 learn*)	98
S77	TI (involv* n3 perspective*) or AB (involv* n3 perspective*)	36
S78	TI (involv* n3 preference*) or AB (involv* n3 preference*)	24
S79	TI (involv* n3 (satisf* or dissatisf*)) or AB (involv* n3 (satisf* or dissatisf*))	89
S80	TI (involv* n3 view*) or AB (involv* n3 view*)	24
S81	TI (participation* n3 attitud*) or AB (participation* n3 attitud*)	51

S82	TI (participation* n3 (choice* or choos* or control)) or AB (participation* n3 (choice* or choos* or control))	59
S83	TI (participation* n3 (choice* or choos* or control)) or AB (participation* n3 (choice* or choos* or control))	59
S84	TI (participation* n3 expectation*) or AB (participation* n3 expectation*)	20
S85	TI (participation* n3 experience*) or AB (participation* n3 experience*)	59
S86	TI (participation* n3 feedback) or AB (participation* n3 feedback)	6
S87	TI (participation* n3 learn*) or AB (participation* n3 learn*)	59
S88	TI (participation* n3 perspective*) or AB (participation* n3 perspective*)	11
S89	TI (participation* n3 preference*) or AB (participation* n3 preference*)	20
S90	TI (participation* n3 (satisf* or dissatisf*)) or AB (participation* n3 (satisf* or dissatisf*))	92
S91	TI (participation* n3 view*) or AB (participation* n3 view*)	21
S92	TI (people* n3 attitud*) or AB (people* n3 attitud*)	359

S93	TI (people* n3 (choice* or choos* or control)) or AB (people* n3 (choice* or choos* or control))	244
S94	TI (people* n3 complaint*) or AB (people* n3 complaint*)	24
S95	TI (people* n3 expectation*) or AB (people* n3 expectation*)	40
S96	TI (people* n3 experience*) or AB (people* n3 experience*)	585
S97	TI (people* n3 feedback) or AB (people* n3 feedback)	1
S98	TI (people* n3 learn*) or AB (people* n3 learn*)	166
S99	TI (people* n3 perspective*) or AB (people* n3 perspective*)	128
S100	TI (people* n3 preference*) or AB (people* n3 preference*)	48
S101	TI (people* n3 (satisf* or dissatisf*)) or AB (people* n3 (satisf* or dissatisf*))	90
S102	TI (people* n3 view*) or AB (people* n3 view*)	230
S103	TI (user* n3 attitud*) or AB (user* n3 attitud*)	11
S104	TI (user* n3 (choice* or choos* or control)) or AB (user* n3 (choice* or choos* or control))	28

S105	TI (user* n3 complaint*) or AB (user* n3 complaint*)	1
S106	TI (user* n3 expectation*) or AB (user* n3 expectation*)	5
S107	TI (user* n3 experience*) or AB (user* n3 experience*)	54
S108	TI (user* n3 feedback) or AB (user* n3 feedback)	7
S109	TI (user* n3 learn*) or AB (user* n3 learn*)	13
S110	TI (user* n3 perspective*) or AB (user* n3 perspective*)	19
S111	TI (user* n3 preference*) or AB (user* n3 preference*)	13
S112	TI (user* n3 (satisf* or dissatisf*)) or AB (user* n3 (satisf* or dissatisf*))	45
S113	TI (user* n3 view*) or AB (user* n3 view*)	12
S114	TI (engag*) or AB (engag*)	3,994
S115	TI (advocacy) or AB (advocacy)	1,554
S116	DE "Informal Support Systems"	2,723
S117	TI ("peer support") or AB ("peer support")	100
S118	TI (tech*) or AB (tech*)	8,272
S119	DE "Information Technology"	540
S120	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR	33,655

S124	TI ("direct payment*" or "individual budget*" or micro?commissioning or "personal budget*" or "personal health budget*" or personali?ed or personali?ation or "person-centred" or "self-directed support") or AB ("direct payment*" or "individual budget*" or micro?commissioning or "personal budget*" or "personal health budget*" or personali?ed or	437
S123	DE "Supportive Services"	2,327
S122	DE "Social Work"	1,055
S121	DE "Social Services"	3,001
	S116 OR S117 OR S118 OR S119	
	OR S111 OR S112 OR S113 OR S114 OR S115 OR	
	S105 OR S106 OR S107 OR S108 OR S109 OR S110	
	OR S100 OR S101 OR S102 OR S103 OR S104 OR	
	S93 OR S94 OR S95 OR S96 OR S97 OR S98 OR S99	
	OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR	
	S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86	
	OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR	
	S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73	
	OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR	
	S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60	
	OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR	
	S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47	
	OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR	
	OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34	
	S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	

	personali?ation or "person-centred" or "self-directed support")	
S125	TI ("care plan*") or AB ("care plan*)	3,200
S126	DE "Service Coordination"	236
S127	TI ("social work*" or "social care" or "social service*" or "social provision") or AB ("social work*" or "social care" or "social service*" or "social provision")	6,309
S128	TI ((community or home or residential or day) n3 (care or help or provision or provider* or service* or support)) or AB ((community or home or residential or day) n3 (care or help or provision or provider* or service* or support))	17,679
S129	S121 OR S122 OR S123 OR S124 OR S125 OR S126 OR S127 OR S128	26,098
S130	DE "Adults of All Ages" OR DE "Adults" OR DE "Middle Aged" OR DE "Old" OR DE "Older Adults" OR DE "Young Adults" OR DE "Young Old"	115,813
S131	TI "adult*" or AB "adult*	45,610
S132	TI homeless or AB homeless	201
S133	TI ("older people" or "older person*" or "older adult*") or AB ("older people" or "older person*" or "older adult*")	42,537

TI (geriatric or "very old" or elder* or frail* or disabilit* or disabled) or AB (geriatric or "very old" or elder* or frail* or disabilit* or disabled)	51,339
DE "Homeless"	148
DE "Disabilities" OR DE "Disabled"	4,106
DE "Minority Groups"	1,474
S130 OR S131 OR S132 OR S133 OR S134 OR S135 OR S136 OR S137	126,152
TI (child* or adolescen* or youth*) or AB (child* or adolescen* or youth*)	10,847
DE "Children"	1,445
DE "Adolescents"	582
S139 OR S140 OR S141	11,312
S138 NOT S142	115,653
DE "Meta Analyses"	430
DE "Randomized Controlled Trials"	1,455
DE "Controlled Clinical Trials"	152
DE "Literature Reviews"	2,731
	disabled) or AB (geriatric or "very old" or elder* or frail* or disabilit* or disabled)  DE "Homeless"  DE "Disabilities" OR DE "Disabled"  DE "Minority Groups"  S130 OR S131 OR S132 OR S133 OR S134 OR S135 OR S136 OR S137  TI (child* or adolescen* or youth*) or AB (child* or adolescen* or youth*)  DE "Children"  DE "Adolescents"  S139 OR S140 OR S141  S138 NOT S142  DE "Meta Analyses"  DE "Randomized Controlled Trials"  DE "Controlled Clinical Trials"

S148	TI (systematic*) or AB (systematic*)	2,240
S149	TI (review*) or AB (review*)	19,325
S150	TI (meta analys*) or AB (meta analys*)	466
S151	TI (random*) or AB (random*)	6,870
S152	ti (trial*)	1,079
S153	DE "Qualitative Research"	4,587
S154	TI ("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research")or AB ("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research")	179
S155	DE "Narratives"	457
S156	DE "Personal Accounts"	2,826
S157	DE "Data Collection"	5,004
S158	DE "Ethnography"	407
S159	DE "Focus Groups"	989
S160	TI ("focus group*") or AB ("focus group*)	1,887
S161	DE "Longitudinal Studies"	7,662

S162	DE "Minimum Data Set"	148
S163	DE "National Surveys"	585
S164	DE "Participant Observation"	180
S165	DE "Proxy Respondents"	227
S166	DE "Self Report Measures"	895
S167	DE "State Surveys"	505
S168	DE "Statistical Analysis"	6,601
S169	DE "Study Participation"	438
S170	DE "Surveys"	3,767
S171	DE "Interviews"	577
S172	DE "Survey Questionnaires"	3,207
S173	DE "Self Report Measures"	895
S174	TI ("process evaluation*" or "outcome evaluation*" or "service evaluation*") or AB ("process evaluation*" or "outcome evaluation*" or "service evaluation*")	105
S175	TI (qualitative or interview* or audit* or feedback or indepth or story or stories or questionnaire* or narrative* or narration* or survey* or observation* or case or cohort or study or studies) or AB (qualitative or interview* or audit* or feedback or in-depth or story or	82,449

	stories or questionnaire* or narrative* or narration* or survey* or observation* or case or cohort or study or studies)	
S176	TI (discourse or discurs*) n3 (analys*)or AB (discourse or discurs*) n3 (analys*)	96
S177	TI (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or theoretical sampl* or purposive sampl* or realist* or thematic or empirical) or AB (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or theoretical sampl* or purposive sampl* or realist* or thematic or empirical)	4,889
S178	TI (synthes*) or AB (synthes*)	589
S179	TI (analys*) or AB (analys*)	25,323
S180	DE "Outcomes"	2,681
S181	DE "Activities of Daily Living"	2,743
S182	TI ("activities of daily living") or AB ("activities of daily living")	4,423
S183	DE "Program Evaluations"	2,767
S184	DE "Quality of Care"	3,295
S185	DE "Quality of Life"	4,517

S186	TI (effectiveness or empower or monitored or monitoring or improve* or measur*) or AB (effectiveness or empower or monitored or monitoring or improve* or measur*)	39,866
S187	TI (ASCOT or instrument* or independence or intervention or models or outcome* or quality or wellbeing) or AB (ASCOT or instrument* or independence or intervention or models or outcome* or quality or wellbeing)	48,329
S188	TI ("co-design" or "co-production*") or AB ("co-design" or "co-production*")	4
S189	DE "Service Involvement"	148
S190	TI (cost*) or AB (cost*)	14,383
S191	TI (economic*) or AB (economic*)	8,462
S192	DE "Costs"	1,653
S193	DE "Cost Effectiveness"	774
S194	DE "Models"	3,744
S195	DE "Econometric Models"	472
S196	DE "Budgets"	281
S197	DE "Socioeconomic Levels"	1,761

S198	TI (Fiscal or funding or financial or finance) or AB (Fiscal or funding or financial or finance)	14,897
S199	TI Socioeconomic* or AB Socioeconomic*	2,588
S200	TI ((Personal or pool*) n3 budget*) or AB ((Personal or pool*) n3 budget*)	24
S201	TI (price* or commission* or pricing) or AB (price* or commission* or pricing)	3,841
S202	TI ("cash for care") or AB ("cash for care")	9
S203	TI (Personal health n3 budget*) or AB (Personal health n3 budget*)	3
S204	S144 OR S145 OR S146 OR S147 OR S148 OR S149 OR S150 OR S151 OR S152 OR S153 OR S154 OR S155 OR S156 OR S157 OR S158 OR S159 OR S160 OR S161 OR S162 OR S163 OR S164 OR S165 OR S166 OR S167 OR S168 OR S169 OR S170 OR S171 OR S172 OR S173 OR S174 OR S175 OR S176 OR S177 OR S178 OR S179 OR S180 OR S181 OR S182 OR S183 OR S184 OR S185 OR S186 OR S187 OR S188 OR S189 OR S190 OR S191 OR S192 OR S193 OR S194 OR S195 OR S196 OR S197 OR S198 OR S199 OR S200 OR S201 OR S202 OR S203	126,938
S205	S120 AND S129 AND S143 AND S204	6,698
S206	S120 AND S129 AND S143 AND S204 Limited by Date: 2000-Current	3,325

# 2. ASSIA (Proquest)

Date searched: 23/03/2016

No. of records: 2728

Date limits: after 31Dec2000

Date update search: 27/01/2017

No. of update records: 356

Set	Query	Results
S3	ti,ab(lived NEAR/2 experience) OR ti,ab("expert by	76394
	experience") OR SU.exact("CLIENT	
	SATISFACTION") OR SU.exact("CONSUMER	
	SATISFACTION") OR SU.EXACT("User	
	involvement") OR SU.EXACT("Experiences") OR	
	SU.EXACT("Perceptions") OR SU.EXACT("Public	
	perception") OR SU.EXACT("Attitudes") OR	
	SU.EXACT("Advocacy") OR SU.EXACT("Consumer	
	participation") OR SU.EXACT("Client participation")	
	OR SU.EXACT("Carers") OR SU.EXACT("Users")	
	OR ((attitude OR complaint OR choice OR choos*	
	OR control OR satisf* OR dissatisf* OR expectation	
	OR experience OR feedback OR learn OR	
	perspective OR preference OR view) NEAR/3 (Carer	
	OR Client OR consult* OR consumer OR Customer	
	OR Individual OR Involv* OR participation OR people	
	OR user)) OR TI,AB(engag*) OR TI,AB(advocacy)	
	OR TI,AB("peer support") OR TI,AB("technol*") OR	
	SU.EXACT("Consumer representation") OR	
	SU.EXACT("Support networks") OR	
	SU.exact("SOCIAL SUPPORT") OR	
	SU.EXACT("Technical aids")	

S5	TI,AB(attitude OR complaint OR (choice OR choos* OR control) OR (satisf* OR dissatisf*) OR	331956
	expectation OR experience OR feedback OR learn	
	OR perspective OR preference OR view NEAR/3	
	Carer OR Client OR consult* OR consumer OR	
	Customer OR Individual OR Involv* OR participation	
	OR people OR user)	
S7	TI,AB(engag* OR advocacy OR "peer support" OR	42137
	"technol*") OR SU.EXACT("Consumer	
	representation" OR "Support networks" OR "SOCIAL	
	SUPPORT" OR "Technical aids")	
S8	SU.EXACT("Advocacy") OR SU.EXACT("Consumer	8341
	participation") OR SU.EXACT("Client participation")	
	OR SU.EXACT("Carers")	
S10	ti,ab(lived n/2 experience) OR ti,ab("expert by	29950
	experience") OR SU.exact("CLIENT	
	SATISFACTION") OR SU.exact("CONSUMER	
	SATISFACTION") OR SU.EXACT("User	
	involvement") OR SU.EXACT("Experiences") OR	
	SU.EXACT("Perceptions") OR SU.EXACT("Public	
	perception") OR SU.EXACT("Attitudes")	
S11	S5 OR S7 OR S8 OR S10	355183
S12	SU.EXACT("Social work" OR "service provision" OR	29001
	"Services" OR "Service delivery" OR "Free services")	
	OR TI,AB("direct payment" OR "individual budget"	
	OR "personal budget" OR "personal health budget"	
	OR personalised OR personalized OR	
	personalisation OR personalization OR "person-	
	centred" OR "self-directed support" OR "Care plan"	
<u> </u>	I	

	OR "social work" OR "social care" OR "social	
	service" OR "social provision") OR TI,AB((community	
	OR home OR residential OR day) NEAR/3 (care OR	
	help OR provision OR provider OR service OR	
	support))	
040	(TLAD(-1.11) OD TLAD(b	74440
S13	(TI,AB(adult) OR TI,AB(homeless) OR TI,AB("older	74110
	people" OR "older person" OR "older adult") OR	
	TI,AB("geriatric" OR "very old" OR elder OR frail OR	
	disabilit* OR disabled) OR SU.EXACT("Adults") OR	
	SU.EXACT("Middle aged people") OR	
	SU.EXACT("Homeless people") OR	
	SU.EXACT("Elderly people") OR SU.EXACT("Young	
	adults") OR SU.EXACT("Disadvantaged people") OR	
	SU.EXACT("Minority groups") OR	
	SU.EXACT("Disability")) NOT	
	(SU.EXACT("Children") OR TI,AB(child* OR	
	adolescen* OR youth) OR	
	SU.EXACT("Adolescents"))	
S14	((SU.EXACT("Qualitative research") OR	461070
	SU.EXACT("Qualitative analysis") OR	
	SU.EXACT("Qualitative data") OR	
	SU.EXACT("Qualitative methods") OR	
	SU.EXACT("Data collection") OR SU.EXACT("Data	
	collection") OR SU.EXACT("Cohort analysis") OR	
	SU.EXACT("Case controlled studies") OR	
	SU.EXACT("Focus groups") OR	
	SU.EXACT("Interviews") OR SU.EXACT("Focus	
	group interviews") OR SU.EXACT("Grounded	
	theory") OR SU.EXACT("Questionnaires") OR	
	SU.EXACT("Surveys") OR	
	SU.EXACT("Observational research") OR	

SU.EXACT("Narratives") OR SU.EXACT("Personal narratives")) OR (TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" OR "behavioural research" OR "conversation analysis" OR "evidence synthesis" OR "personal narratives" OR "survey research") OR TI,AB(qualitative OR interview OR audit OR feedback OR "in-depth" OR story OR stories OR questionnaire OR narrative OR narration OR survey OR observation OR case OR cohort OR study OR studies) OR TI,AB((discourse OR discurs\*) NEAR/3 (analys\*)) OR TI,AB(ethno\* OR emic OR etic OR phenomenolog\* OR "grounded theory" OR "constant compar\*" OR "theoretical sampl\*" OR "purposive sampl\*" OR realist\* OR thematic OR empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")) OR (SU.EXACT("Evaluation") OR SU.EXACT("Needs assessment") OR SU.EXACT("Outcomes") OR SU.EXACT("Activities of daily living") OR SU.EXACT("User involvement") OR SU.EXACT("Wellbeing") OR SU.EXACT("Quality of life") OR SU.EXACT("Quality of care")) OR (TI,AB("process evaluation" OR "outcome evaluation" OR "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness OR empower OR monitored OR monitoring OR improve OR measure) OR TI, AB (ASCOT OR instrument OR independence OR intervention OR models OR outcome OR quality OR wellbeing) OR TI,AB("co-design" OR "coproduction")) OR (SU.EXACT("Economic analysis") OR SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Econometric models")) OR (TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal OR funding OR financial OR finance) OR

	TI,AB(Socioeconomic) OR TI,AB((Personal OR pool)	
	NEAR/3 (budget)) OR TI,AB(price OR commission	
	OR pricing) OR TI,AB("cash for care") OR	
	TI,AB("Personal health" NEAR/3 budget)))	
S15	S11 AND S12 AND S13 AND S14	3281
S16	AND pd(20000101-20160331)	40827
S17	S15 AND S16	277
S18	la.exact("English")	666957
S19	S17 AND S18	2728
	•	

# 3. CINAHL (Ebsco)

Date searched: 16/03/2016

No. of records: 4144

Date limits: after 31Dec2000

Date update search: 24/01/2017

No. of update records: 72

#	Query	Results
S1	(MM "Patient Attitudes")	11,692
S2	MM "consumer satisfaction"	2,706
S3	(MM "Patient Satisfaction")	10,626
S4	(MM "Perception")	6,235

S5	(MM "Consumer Advocacy")	1,225
S6	(MM "Patient Advocacy")	4,316
S7	(MM "Consumer Participation")	6,103
S8	MM "Caregivers"	11,674
S9	TI (lived n3 experience*) or AB (lived n3 experience*)	3,941
S10	TI (carer* n3 attitud*) or AB (carer* n3 attitud*)	57
S11	TI (carer* n3 (choice* or choos* or control)) or AB (carer* n3 (choice* or choos* or control))	93
S12	TI (carer* n3 complaint*) or AB (carer* n3 complaint*)	2
S13	TI (carer* n3 expectation*) or AB (carer* n3 expectation*)	28
S14	TI (carer* n3 experience*) or AB (carer* n3 experience*)	564
S15	TI (carer* n3 feedback) or AB (carer* n3 feedback)	19
S16	TI (carer* n3 learn*) or AB (carer* n3 learn*)	118

S17	TI (carer* n3 perspective*) or AB (carer* n3 perspective*)	210
S18	TI (carer* n3 preference*) or AB (carer* n3 preference*)	32
S19	TI (carer* n3 (satisf* or dissatisf*)) or AB (carer* n3 (satisf* or dissatisf*))	165
S20	TI (carer* n3 view*) or AB (carer* n3 view*)	245
S21	TI (client* n3 attitud*) or AB (client* n3 attitud*)	185
S22	TI (client* n3 (choice* or choos* or control)) or AB (client* n3 (choice* or choos* or control))	349
S23	TI (client* n3 complaint*) or AB (client* n3 complaint*)	17
S24	TI (client* n3 expectation*) or AB (client* n3 expectation*)	128
S25	TI (client* n3 experience*) or AB (client* n3 experience*)	909
S26	TI (client* n3 feedback) or AB (client* n3 feedback)	93
S27	TI (client* n3 learn*) or AB (client* n3 learn*)	290

S28	TI (client* n3 perspective*) or AB (client* n3 perspective*)	491
S29	TI (client* n3 preference*) or AB (client* n3 preference*)	104
S30	TI (client* n3 (satisf* or dissatisf*)) or AB (client* n3 (satisf* or dissatisf*))	657
S31	TI (client* n3 view*) or AB (client* n3 view*)	332
S32	TI (consult* n3 attitud*) or AB (consult* n3 attitud*)	57
S33	TI (consult* n3 (choice* or choos* or control)) or AB (consult* n3 (choice* or choos* or control))	197
S34	TI (consult* n3 complaint*) or AB (consult* n3 complaint*)	28
S35	TI (consult* n3 expectation*) or AB (consult* n3 expectation*)	46
S36	TI (consult* n3 experience*) or AB (consult* n3 experience*)	340
S37	TI (consult* n3 feedback) or AB (consult* n3 feedback)	68
S38	TI (consult* n3 learn*) or AB (consult* n3 learn*)	92

S39	TI (consult* n3 perspective*) or AB (consult* n3 perspective*)	96
S40	TI (consult* n3 preference*) or AB (consult* n3 preference*)	40
S41	TI (consult* n3 (satisf* or dissatisf*)) or AB (consult* n3 (satisf* or dissatisf*))	191
S42	TI (consult* n3 view*) or AB (consult* n3 view*)	129
S43	TI (consumer* n3 attitud*) or AB (consumer* n3 attitud*)	162
S44	TI (consumer* n3 (choice* or choos* or control)) or AB (consumer* n3 (choice* or choos* or control))	547
S45	TI (consumer* n3 complaint*) or AB (consumer* n3 complaint*)	26
S46	TI (consumer* n3 expectation*) or AB (consumer* n3 expectation*)	119
S47	TI (consumer* n3 experience*) or AB (consumer* n3 experience*)	249
S48	TI (consumer* n3 feedback) or AB (consumer* n3 feedback)	42

S49	TI (consumer* n3 learn*) or AB (consumer* n3 learn*)	73
S50	TI (consumer* n3 perspective*) or AB (consumer* n3 perspective*)	461
S51	TI (consumer* n3 preference*) or AB (consumer* n3 preference*)	183
S52	TI (consumer* n3 (satisf* or dissatisf*)) or AB (consumer* n3 (satisf* or dissatisf*))	435
S53	TI (consumer* n3 view*) or AB (consumer* n3 view*)	272
S54	TI (customer* n3 attitud*) or AB (customer* n3 attitud*)	16
S55	TI (customer* n3 (choice* or choos* or control)) or AB (customer* n3 (choice* or choos* or control))	32
S56	TI (customer* n3 complaint*) or AB (customer* n3 complaint*)	19
S57	TI (customer* n3 expectation*) or AB (customer* n3 expectation*)	45
S58	TI (customer* n3 experience*) or AB (customer* n3 experience*)	48

S59	TI (customer* n3 feedback) or AB (customer* n3 feedback)	31
S60	TI (customer* n3 learn*) or AB (customer* n3 learn*)	18
S61	TI (customer* n3 perspective*) or AB (customer* n3 perspective*)	42
S62	TI (customer* n3 preference*) or AB (customer* n3 preference*)	11
S63	TI (customer* n3 (satisf* or dissatisf*)) or AB (customer* n3 (satisf* or dissatisf*))	434
S64	TI (customer* n3 view*) or AB (customer* n3 view*)	26
S65	TI (individual* n3 attitud*) or AB (individual* n3 attitud*)	604
S66	TI (individual* n3 (choice* or choos* or control)) or AB (individual* n3 (choice* or choos* or control))	2,758
S67	TI (individual* n3 complaint*) or AB(individual* n3 complaint*)	110
S68	TI (individual* n3 expectation*) or AB (individual* n3 expectation*)	203

S69	TI (individual* n3 experience*) or AB (individual* n3 experience*)	3,294
S70	TI (individual* n3 feedback) or AB (individual* n3 feedback)	259
S71	TI (individual* n3 learn*) or AB (individual* n3 learn*)	1,014
S72	TI (individual* n3 perspective*) or AB (individual* n3 perspective*)	668
S73	TI (individual* n3 preference*) or AB (individual* n3 preference*)	656
S74	TI (individual* n3 (satisf* or dissatisf*)) or AB (individual* n3 (satisf* or dissatisf*))	408
S75	TI (individual* n3 view*) or AB (individual* n3 view*)	500
S76	TI (involv* n3 attitud*) or AB (involv* n3 attitud*)	240
S77	TI (involv* n3 (choice* or choos* or control)) or AB (involv* n3 (choice* or choos* or control))	1,362
S78	TI (involve* n3 complaint*) or AB (involve* n3 complaint*)	39

S79	TI (involv* n3 expectation*) or AB (involv* n3 expectation*)	105
S80	TI (involv* n3 experience*) or AB (involv* n3 experience*)	1,026
S81	TI (involv* n3 feedback) or AB (involv* n3 feedback)	121
S82	TI (involv* n3 learn*) or AB (involv* n3 learn*)	769
S83	TI (involv* n3 perspective*) or AB (involv* n3 perspective*)	276
S84	TI (involv* n3 preference*) or AB (involv* n3 preference*)	153
S85	TI (involv* n3 (satisf* or dissatisf*)) or AB (involv* n3 (satisf* or dissatisf*))	241
S86	TI (involv* n3 view*) or AB (involv* n3 view*)	271
S87	TI (participation n3 attitud*) or AB (participation n3 attitud*)	189
S88	TI (participation n3 (choice* or choos* or control)) or AB (participation n3 (choice* or choos* or control))	300
S89	TI (participation n3 complaint*) or AB (participation n3 complaint*)	5

S90	TI (participation n3 expectation*) or AB (participation n3 expectation*)	82
S91	TI (participation n3 experience*) or AB (participation n3 experience*)	551
S92	TI (participation n3 feedback) or AB (participation n3 feedback)	57
S93	TI (participation n3 learn*) or AB (participation n3 learn*)	285
S94	TI (participation n3 perspective*) or AB (participation n3 perspective*)	128
S95	TI (participation n3 preference*) or AB (participation n3 preference*)	140
S96	TI (participation n3 (satisf* or dissatisf*)) or AB (participation n3 (satisf* or dissatisf*))	332
S97	TI (participation n3 view*) or AB (participation n3 view*)	132
S98	TI (people n3 attitud*) or AB (people n3 attitud*)	995
S99	TI (people n3 (choice* or choos* or control)) or AB (people n3 (choice* or choos* or control))	1,211

S100	TI (people n3 complaint*) or AB (people n3 complaint*)	67
S101	TI (people n3 expectation*) or AB (people n3 expectation*)	147
S102	TI (people n3 experience*) or AB (people n3 experience*)	3,509
S103	TI (people n3 feedback) or AB (people n3 feedback)	55
S104	TI (people n3 learn*) or AB (people n3 learn*)	2,734
S105	TI (people n3 perspective*) or AB (people n3 perspective*)	533
S106	TI (people n3 preference*) or AB (people n3 preference*)	167
S107	TI (people n3 (satisf* or dissatisf*)) or AB (people n3 (satisf* or dissatisf*))	262
S108	TI (people n3 view*) or AB (people n3 view*)	723
S109	TI (people n3 view*) or AB (people n3 view*)	723
S110	TI (user* n3 attitud*) or AB (user* n3 attitud*)	178
S111	TI (user* n3 (choice* or choos* or control)) or AB (user* n3 (choice* or choos* or control))	575

S112	TI (user* n3 complaint*) or AB (user* n3 complaint*)	28
S113	TI (user* n3 expectation*) or AB (user* n3 expectation*)	141
S114	TI (user* n3 experience*) or AB (user* n3 experience*)	1,343
S115	TI (user* n3 feedback) or AB (user* n3 feedback)	233
S116	TI (user* n3 learn*) or AB (user* n3 learn*)	198
S117	TI (user* n3 perspective*) or AB (user* n3 perspective*)	569
S118	TI (user* n3 preference*) or AB (user* n3 preference*)	234
S119	TI (user* n3 (satisf* or dissatisf*)) or AB (user* n3 (satisf* or dissatisf*))	790
S120	TI (user* n3 view*) or AB (user* n3 view*)	629
S121	TI (engag*) or AB (engag*)	28,967
S122	TI (advocacy) or AB (advocacy)	7,051
S123	TI ("peer support") or AB ("peer support")	1,377
S124	(MM "Telecommunications")	777

S125	TI "advocacy" or AB "advocacy"	7,048
S126	TI technol* or AB technol*	47,869
S127	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S83 OR S94 OR S95 OR S96 OR S97 OR S98 OR S99 OR S100 OR S101 OR S102 OR S103 OR S104 OR S105 OR S106 OR S111 OR S112 OR S113 OR S114 OR S115 OR S116 OR S117 OR S122 OR S123 OR S124 OR S125 OR S126	164,051
S128	MH "social work service"	5,431

S129	(MM "Social Work")	6,084
S130	TI ("social work*" or "social care" or "social service*" or "social provision") or AB ("social work*" or "social care" or "social service*" or "social provision")	19,414
S131	TI ((community or home or residential or day) n3 (care or help or provision or provider* or service* or support)) or AB ((community or home or residential or day) n3 (care or help or provision or provider* or service* or support))	45,170
S132	(MM "Health Care Delivery, Integrated")	3,306
S133	TI ("care plan*") or AB ("care plan*)	10,897
S134	TI ("direct payment*" or "individual budget*" or micro?commissioning or "personal budget*" or personal health budget*" or personali?ed or personali?ation or "person-centred" or "self-directed support") or AB ("direct payment*" or "individual budget*" or micro?commissioning or "personal budget*" or "personal health budget*" or personali?ed or personali?ation or "person-centred" or "self-directed support")	4,800
S135	S128 OR S129 OR S130 OR S131 OR S132 OR S133 OR S134	85,626

S136	(MH "Adult+")	798,943
S137	TI "adult*" or AB "adult*	131,864
S138	TI (geriatric or "very old" or elder* or frail* or disabilit* or disabled) or AB (geriatric or "very old" or elder* or frail* or disabilit* or disabled)	107,014
S139	TI ("older people" or "older person*" or "older adult*") or AB ("older people" or "older person*" or "older adult*")	37,253
S140	TI homeless or AB homeless	3,559
S141	(MM "Minority Groups")	3,632
S142	(MM "Disabled")	14,399
S143	(MM "Homeless Persons")	2,238
S144	(MH "Adolescence+")	227,081
S145	(MH "Child+")	322,208
S146	TI (child* or adolescen* or youth*) or AB (child* or adolescen* or youth*)	238,860
S147	S136 OR S137 OR S138 OR S139 OR S140 OR S141 OR S142 OR S143	892,163
S148	S144 OR S145 OR S146	506,896

S149	S147 NOT S148	698,489
S150	MH systematic review	25,229
S151	(MH "Meta Analysis")	17,242
S152	(MM "Meta Synthesis")	33
S153	(MM "Randomized Controlled Trials")	471
S154	(MM "Literature Review")	327
S155	TI (systematic*) or AB (systematic*)	50,343
S156	TI (review*) or AB (review*)	232,964
S157	TI (meta analys*) or AB (meta analys*)	17,248
S158	TI (random*) or AB (random*)	126,038
S159	TI (trial*)	48,696
S160	(MM "Qualitative Studies")	2,200
S161	(MM "Interviews")	1,285
S162	(MM "Focus Groups")	450
S163	(MM "Narratives")	1,347
S164	(MM "Self Report")	1,888

S165	(MM "Surveys")	2,570
S166	(MM "Observational Methods")	293
S167	(MM "Grounded Theory")	272
S168	(MM "Data Collection")	2,672
S169	(MM "Cross Sectional Studies")	62
S170	(MM "Prospective Studies")	482
S171	(MM "Case Control Studies")	123
S172	TI ("focus group*") or AB ("focus group*)	15,404
S173	TI ("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research") or AB ("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research")	1,396
S174	TI (qualitative or interview* or audit* or feedback or in-depth or story or stories or questionnaire* or narrative* or narration* or survey* or observation* or case or cohort or study or studies) or AB (qualitative or interview* or audit* or feedback or in-depth or story or stories or questionnaire* or narrative* or narration* or survey* or	915,570

	observation* or case or cohort or study or studies)	
S175	TI (discourse or discurs*) n3 (analys*)or AB (discourse or discurs*) n3 (analys*)	1,231
S176	TI (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or theoretical sampl* or purposive sampl* or realist* or thematic or empirical) or AB (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or theoretical sampl* or purposive sampl* or realist* or thematic or empirical)	46,618
S177	TI (synthes*) or AB (synthes*)	14,929
S178	(MM "Consumer Participation")	6,103
S179	(MM "Program Evaluation")	5,324
S180	(MM "Evaluation")	352
S181	(MM "Treatment Outcomes")	17,516
S182	(MM "Activities of Daily Living")	4,779
S183	(MM "Clinical Effectiveness")	315
S184	(MM "Quality of Life")	21,658
S185	TI ("process evaluation*" or "outcome evaluation*" or "service evaluation*")or AB	1,612

	("process evaluation*" or "outcome evaluation*" or "service evaluation*")	
S186	TI ("activities of daily living") or AB ("activities of daily living")	6,836
S187	TI (effectiveness or empower or monitored or monitoring or improve* or measur*) or AB (effectiveness or empower or monitored or monitoring or improve* or measur*)	492,642
S188	TI (ASCOT or instrument* or independence or intervention or models or outcome* or quality or wellbeing) or AB (ASCOT or instrument* or independence or intervention or models or outcome* or quality or wellbeing)	539,214
S189	TI ("co-design" or "co-production*") or AB ("co-design" or "co-production*")	90
S190	(MM "Economic Value of Life")	160
S191	(MM "Costs and Cost Analysis")	2,072
S192	(MM "Budgets")	2,722
S193	TI (cost*) or AB (cost*)	72,269
S194	TI (economic*) or AB (economic*)	28,191

S195	TI (Fiscal or funding or financial or finance) or AB (Fiscal or funding or financial or finance)	33,596
S196	TI Socioeconomic* or AB Socioeconomic*	13,977
S197	TI ((Personal or pool*) n3 budget*) or AB ((Personal or pool*) n3 budget*)	190
S198	TI (price* or commission* or pricing) or AB (price* or commission* or pricing)	16,417
S199	TI ("cash for care") or AB ("cash for care")	20
S200	TI (Personal health n3 budget*) or AB (Personal health n3 budget*)	62
S201	S150 OR S151 OR S152 OR S153 OR S154 OR S155 OR S156 OR S157 OR S158 OR S159 OR S160 OR S161 OR S162 OR S163 OR S164 OR S165 OR S166 OR S167 OR S168 OR S169 OR S170 OR S171 OR S172 OR S173 OR S174 OR S175 OR S176 OR S177 OR S178 OR S179 OR S180 OR S181 OR S182 OR S183 OR S184 OR S185 OR S186 OR S187 OR S188 OR S189 OR S190 OR S191 OR S192 OR S193 OR S194 OR S195 OR S196 OR S197 OR S198 OR S199 OR S200	1,378,265
S202	S127 AND S135 AND S149 AND S201	5,029

	S127 AND S135 AND S149 AND S201	
S203	Limited by English	4,144
	Limited date=2000-Current	

## 4. IBSS (Proquest)

Date searched: 15/03/2016

No. of records: 946

Date limits: after 31Dec2000

Date update search: 27/01/2017

No. of update records: 20

#### **VIEWS**

SU.EXACT("Satisfaction") OR SU.EXACT("Attitudes") OR SU.EXACT("Public opinion") OR SU.EXACT("Advocacy") OR SU.EXACT("Caring") OR SU.EXACT("Social support")

TI,AB(lived n/2 experience) OR TI,AB("expert by experience")

TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*") attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*) OR expectation OR experience OR feedback OR learn OR perspective OR preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR Customer OR Individual OR Involv\* OR participation OR people OR user

#### **SETTING**

TI,AB("direct payment" OR "individual budget" OR "personal budget" OR "personal health budget" OR personalised OR personalised OR personalisation OR personalization OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision") OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))

SU.EXACT("Social work") OR SU.EXACT("Social services") OR SU.EXACT("Community services") OR SU.EXACT("Quality of service")

#### **POPULATION**

(TI,AB(adult) OR TI,AB(homeless) OR TI,AB("older people" OR "older person" OR "older adult") OR TI,AB("geriatric" OR "very old" OR elder OR frail OR disabilit\* OR disabled) OR

SU.EXACT("Adulthood") OR SU.EXACT("Middle age") OR SU.EXACT("Aged") OR SU.EXACT("Homeless people") OR SU.EXACT("Minority groups") OR SU.EXACT("Disability") NOT (SU.EXACT("Children") OR TI,AB(child\* OR adolescen\* OR youth) OR SU.EXACT("Adolescence"))

#### STUDY TYPE/METHODS

SU.EXACT("Review articles") OR TI,AB(systematic) OR TI,AB(review) OR TI,AB(meta-analysis)

#### **QUALIATITIVE STUDIES**

SU.EXACT("Empirical research") OR SU.EXACT("Qualitative analysis") OR SU.EXACT("Data collection") OR SU.EXACT("Cluster analysis") OR SU.EXACT("Cohort analysis") OR SU.EXACT("Secondary analysis") OR SU.EXACT("Survey analysis") OR SU.EXACT("Data analysis") OR SU.EXACT("Focus groups") OR SU.EXACT("Interviews") OR OR SU.EXACT("Questionnaires") OR SU.EXACT("Surveys") OR SU.EXACT("Narratives")

TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research") OR TI,AB(qualitative or interview or audit or feedback or "indepth" or story or stories or questionnaire or narrative or narration or survey or observation or case or cohort or study or studies) OR TI,AB((discourse or discurs\*) N/3 (analys\*)) OR TI,AB(ethno\* or emic or etic or phenomenolog\* or "grounded theory" or "constant compar\*"or "theoretical sampl\*" or "purposive sampl\*" or realist\* or thematic or empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")

#### **MEASURES**

SU.EXACT("Programme evaluation") OR SU.EXACT("Evaluation techniques") OR SU.EXACT("Evaluation") OR SU.EXACT("Well-being") OR SU.EXACT("Quality of service") OR SU.EXACT("Quality of life") OR SU.EXACT("Organizational effectiveness")

TI,AB("process evaluation" or "outcome evaluation" or "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness or empower or monitored or monitoring or improve or measure) OR TI,AB(ASCOT or instrument or independence or intervention or models or outcome or quality or wellbeing) OR TI,AB("co-design" or "co-production")

#### **ECONOMIC STUIDES**

SU.EXACT("Economic research") OR SU.EXACT("Cost analysis") OR SU.EXACT("Cost-benefit analysis") OR SU.EXACT("Economic impact analysis") OR SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Econometric models") OR SU.EXACT("Cost-effectiveness")

TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal or funding or financial or finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal or pool) N/3 (budget)) OR TI,AB(price or commission or pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" N/3 budget)

#### **SEARCH STATEMENTS**

((TI,AB(lived NEAR/2 experience) OR TI,AB("expert by experience")) OR (TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*")) OR (TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*")) OR (attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*) OR expectation OR experience OR feedback OR learn OR perspective OR preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR Customer OR Individual OR Involv\* OR participation OR people OR user)) AND ((TI,AB("direct payment" OR "individual budget" OR "personal budget"

OR "personal health budget" OR personalised OR personalized OR personalisation OR personalization OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision") OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))) OR (SU.EXACT("Social work") OR SU.EXACT("Social services") OR SU.EXACT("Community services") OR SU.EXACT("Quality of service"))) AND ((TI,AB(adult) OR TI,AB(homeless) OR TI,AB("older people" OR "older person" OR "older adult") OR TI,AB("geriatric" OR "very old" OR elder OR frail OR disabilit\* OR disabled) OR SU.EXACT("Adulthood") OR SU.EXACT("Middle age") OR SU.EXACT("Aged") OR SU.EXACT("Homeless people") OR SU.EXACT("Minority groups") OR SU.EXACT("Disability")) NOT (SU.EXACT("Children") OR TI,AB(child\* OR adolescen\* OR youth) OR SU.EXACT("Adolescence"))) AND ((SU.EXACT("Review articles") OR TI,AB(systematic) OR TI,AB(review) OR TI,AB(meta-analysis)) OR (SU.EXACT("Empirical research") OR SU.EXACT("Qualitative analysis") OR SU.EXACT("Data collection") OR SU.EXACT("Cluster analysis") OR SU.EXACT("Cohort analysis") OR SU.EXACT("Secondary analysis") OR SU.EXACT("Survey analysis") OR SU.EXACT("Data analysis") OR SU.EXACT("Focus groups") OR SU.EXACT("Interviews") OR SU.EXACT("Questionnaires") OR SU.EXACT("Surveys") OR SU.EXACT("Narratives")) OR (TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" OR "behavioural research" OR "conversation analysis" OR "evidence synthesis" OR "personal narratives" OR "survey research") OR TI,AB(qualitative OR interview OR audit OR feedback OR "indepth" OR story OR stories OR questionnaire OR narrative OR narration OR survey OR observation OR case OR cohort OR study OR studies) OR TI,AB((discourse OR discurs\*) NEAR/3 (analys\*)) OR TI,AB(ethno\* OR emic OR etic OR phenomenolog\* OR "grounded theory" OR "constant compar\*" OR "theoretical sampl\*" OR "purposive sampl\*" OR realist\* OR thematic OR empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")) OR (SU.EXACT("Programme evaluation") OR SU.EXACT("Evaluation techniques") OR SU.EXACT("Evaluation") OR SU.EXACT("Well-being") OR SU.EXACT("Quality of service") OR SU.EXACT("Quality of life") OR SU.EXACT("Organizational effectiveness") TI,AB("process evaluation" OR "outcome evaluation" OR "service evaluation") OR

TI,AB("activities of daily living") OR TI,AB(effectiveness OR empower OR monitored OR monitoring OR improve OR measure) OR TI,AB(ASCOT OR instrument OR independence OR intervention OR models OR outcome OR quality OR wellbeing) OR TI,AB("co-design" OR "co-production")) OR (SU.EXACT("Economic research") OR SU.EXACT("Cost analysis") OR SU.EXACT("Cost-benefit analysis") OR SU.EXACT("Economic impact analysis") OR SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Econometric models") OR SU.EXACT("Cost-effectiveness")) OR (TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal OR funding OR financial OR finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal OR pool) NEAR/3 (budget)) OR TI,AB(price OR commission OR pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" NEAR/3 budget)))

#### **SEARCH RESULTS**

Search run 15 March 2016 on IBSS on Proguest platform

Total results before limits: 1125

English: 1008

With English and date limit 2000-Current: 946

# 5. MEDLINE (Ovid) (In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) <1946 to Present>

Date searched: 17/03/2016

No. of records: 6991

Date limits: after 31Dec2000

Date update search: 24/01/2017

No. of update records: 691

Set	Searches	Results
1	patient satisfaction/	64208
2	(Lived adj2 experience\$).ti,ab.	3142

3	Perception/	24322
4	Attitude/	41678
5	Consumer Satisfaction/	18345
6	Patient Advocacy/	22685
7	patient participation/	19600
8	patient preference/	4207
9	"expert by experience".ti,ab.	6
10	Caregivers/	24523
11	(carer\$ adj3 attitud\$).ti,ab.	65
12	(carer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	78
13	(carer\$ adj3 expectation\$).ti,ab.	31
14	(carer\$ adj3 experience\$).ti,ab.	555
15	(carer\$ adj3 feedback).ti,ab.	28
16	(carer\$ adj3 learn\$).ti,ab.	31
17	(carer\$ adj3 perspective\$).ti,ab.	192
18	(carer\$ adj3 preference\$).ti,ab.	33
19	(carer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	181
20	(carer\$ adj3 view\$).ti,ab.	197
21	(client\$ adj3 attitud\$).ti,ab.	261

22	(client\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	411
23	(client\$ adj3 complaint\$).ti,ab.	47
24	(client\$ adj3 expectation\$).ti,ab.	232
25	(client\$ adj3 experience\$).ti,ab.	872
26	(client\$ adj3 feedback).ti,ab.	114
27	(client\$ adj3 learn\$).ti,ab.	208
28	(client\$ adj3 perspective\$).ti,ab.	473
29	(client\$ adj3 preference\$).ti,ab.	207
30	(client\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	1187
31	(client\$ adj3 view\$).ti,ab.	354
32	(consult\$ adj3 attitud\$).ti,ab.	166
33	(consult\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	412
34	(consult\$ adj3 complaint\$).ti,ab.	139
35	(consult\$ adj3 experience\$).ti,ab.	855
36	(consult\$ adj3 feedback).ti,ab.	120
37	(consult\$ adj3 learn\$).ti,ab.	154
38	(consult\$ adj3 perspective\$).ti,ab.	130
39	(consult\$ adj3 preference\$).ti,ab.	103
40	(consult\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	510

41	(consult\$ adj3 view\$).ti,ab.	273
42	(consumer\$ adj3 attitud\$).ti,ab.	477
43	(consumer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	1324
44	(consumer\$ adj3 complaint\$).ti,ab.	108
45	(consumer\$ adj3 expectation\$).ti,ab.	310
46	(consumer\$ adj3 experience\$).ti,ab.	367
47	(consumer\$ adj3 feedback).ti,ab.	86
48	(consumer\$ adj3 learn\$).ti,ab.	74
49	(consumer\$ adj3 perspective\$).ti,ab.	624
50	(consumer\$ adj3 preference\$).ti,ab.	785
51	(consumer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	937
52	(consumer\$ adj3 view\$).ti,ab.	525
53	(customer\$ adj3 attitud\$).ti,ab.	33
54	(customer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	64
55	(customer\$ adj3 complaint\$).ti,ab.	63
56	(customer\$ adj3 expectation\$).ti,ab.	138
57	(customer\$ adj3 experience\$).ti,ab.	83
58	(customer\$ adj3 feedback).ti,ab.	43
59	(customer\$ adj3 learn\$).ti,ab.	34

60	(customer\$ adj3 perspective\$).ti,ab.	60
61	(customer\$ adj3 preference\$).ti,ab.	34
62	(individual\$ adj3 attitud\$).ti,ab.	1209
63	(individual\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	13894
64	(individual\$ adj3 complaint\$).ti,ab.	383
65	(individual\$ adj3 expectation\$).ti,ab.	447
66	(individual\$ adj3 experience\$).ti,ab.	7700
67	(individual\$ adj3 feedback).ti,ab.	900
68	(individual\$ adj3 learn\$).ti,ab.	2517
69	(individual\$ adj3 perspective\$).ti,ab.	1249
70	(individual\$ adj3 preference\$).ti,ab.	2552
71	(individual\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	883
72	(individual\$ adj3 view\$).ti,ab.	1435
73	(involv\$ adj3 attitud\$).ti,ab.	506
74	(involv\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	18049
75	(involv\$ adj3 complaint\$).ti,ab.	212
76	(involv\$ adj3 expectation\$).ti,ab.	229
77	(involv\$ adj3 experience\$).ti,ab.	2027
78	(involv\$ adj3 feedback).ti,ab.	1917

79	(involv\$ adj3 learn\$).ti,ab.	3626
80	(involv\$ adj3 perspective\$).ti,ab.	463
81	(involv\$ adj3 preference\$).ti,ab.	500
82	(involv\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	484
83	(involv\$ adj3 view\$).ti,ab.	760
84	(participation adj3 attitud\$).ti,ab.	343
85	(participation adj3 (choice\$ or choos\$ or control)).ti,ab.	704
86	(participation adj3 complaint\$).ti,ab.	14
87	(participation adj3 expectation\$).ti,ab.	109
88	(participation adj3 experience\$).ti,ab.	649
89	(participation adj3 feedback).ti,ab.	81
90	(participation adj3 learn\$).ti,ab.	366
91	(participation adj3 perspective\$).ti,ab.	145
92	(participation adj3 preference\$).ti,ab.	214
93	(participation adj3 (satisf\$ or dissatisf\$)).ti,ab.	512
94	(participation adj3 view\$).ti,ab.	245
95	(people adj3 attitud\$).ti,ab.	1366
96	(people adj3 (choice\$ or choos\$ or control)).ti,ab.	2341
97	(people adj3 complaint\$).ti,ab.	185

98	(people adj3 expectation\$).ti,ab.	166
99	(people adj3 experience\$).ti,ab.	4159
100	(people adj3 feedback).ti,ab.	77
101	(people adj3 learn\$).ti,ab.	1592
102	(people adj3 perspective\$).ti,ab.	523
103	(people adj3 preference\$).ti,ab.	239
104	(people adj3 (satisf\$ or dissatisf\$)).ti,ab.	386
105	(people adj3 view\$).ti,ab.	922
106	(user\$ adj3 attitud\$).ti,ab.	336
107	(user\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	1731
108	(user\$ adj3 complaint\$).ti,ab.	81
109	(user\$ adj3 expectation\$).ti,ab.	264
110	(user\$ adj3 experience\$).ti,ab.	3005
111	(user\$ adj3 feedback).ti,ab.	762
112	(user\$ adj3 learn\$).ti,ab.	404
113	(user\$ adj3 perspective\$).ti,ab.	861
114	(user\$ adj3 preference\$).ti,ab.	549
115	(user\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	1888
116	(user\$ adj3 view\$).ti,ab.	932

117	engag\$.ti,ab.	104857
118	advocacy.ti,ab.	10160
119	social support/	56115
120	"peer support".ti,ab.	2156
121	technol\$.ti,ab.	301554
122	or/1-121	738725
123	Social Work/	13784
124	("direct payment\$" or "individual budget\$" or micro?commissioning or "personal budget\$" or "personal health budget\$" or personali?ed or personali?ation or "person-centred" or "self-directed support").ti,ab.	21224
125	Care plan\$.ti,ab.	9912
126	Delivery of Health care, Integrated/	9405
127	("social work\$" or "social care" or "social service\$" or "social provision").ti,ab.	21431
128	((community or home or residential or day) adj3 (care or help or provision or provider\$ or service\$ or support)).ti,ab.	66486
129	or/123-128	130156
130	adult\$.ti,ab.	910741
131	Adult/	4189893
132	aged/	2496248

133	frail elderly/	7717
134	middle aged/	3554691
135	"Aged, 80 and over"/	687240
136	Young Adult/	480901
137	("older people" or "older person\$" or "older adult\$").ti,ab.	65962
138	(geriatric or "very old" or elder\$ or frail\$ or disabilit\$ or disabled).ti,ab.	345091
139	Homeless Persons/	5957
140	homeless.ti,ab.	5987
141	or/130-140	6516529
142	(child\$ or adolescen\$ or youth).ti,ab.	1212347
143	Child/	1455785
144	Adolescent/	1708932
145	or/142-144	2810428
146	141 not 145	5013658
147	systematic\$.ti,ab.	276830
148	review\$.ti,ab.	1466579
149	review/	2078817
150	Meta-Analysis/	62640

151	meta?.ti,ab.	294350
152	Meta-Analysis as Topic/	14603
153	Randomized Controlled Trials as Topic/	101460
154	random\$.ti,ab.	812473
155	Randomized controlled trial.pt.	409860
156	Controlled clinical trial.pt.	90286
157	Trial\$.ti.	200094
158	Case-Control Studies/	208915
159	Cohort Studies/	189335
160	Cross-Sectional Studies/	208885
161	or/147-160	4585731
162	("behavio?ral research" or "conversation analys?s" or "evidence synthesis" or "personal narratives" or "survey research").ti,ab.	4658
163	behavioral research/	2718
164	cohort studies/	189335
165	data collection/	84923
166	ethnopsychology/	615
167	Evaluation Studies as Topic/	120308
168	"Focus Group\$".ti,ab.	27374

169	Focus Groups/	19491
170	interview/	26591
171	interviews as topic/	46050
172	needs assessment/	24272
173	narration/	5854
174	observational study/	18988
175	qualitative research/	25831
176	"Surveys and Questionnaires"/	336448
177	Self report/	13469
178	Grounded theory/	177
179	Personal Narratives/	2045
180	Program Evaluation/	50140
181	("process evaluation\$" or "outcome evaluation\$" or "service evaluation\$").ti,ab.	4244
182	(qualitative or interview\$ or audit\$ or focus group\$ or feedback or in-depth or story or stories or questionnaire\$ or narrative\$ or narration\$ or survey\$ or observation\$ or case or cohort or study or studies).ti,ab.	8999196
183	((discourse or discurs\$) adj3 analys?s).ti,ab.	1387

184	(ethno\$ or emic or etic or phenomenolog\$ or grounded theory or constant compar\$ or theoretical sampl\$ or purposive sampl\$ or realist* or thematic or empirical).ti,ab.	177313
185	synthes\$.ti,ab.	814127
186	analys\$.ti,ab.	3409367
187	Treatment Outcome/	715432
188	"Activities of Daily Living"/	53528
189	"activities of daily living".ti,ab.	17636
190	(effectiveness or empower or monitored or monitoring or improve\$ or measur\$).ti,ab.	4380381
191	(ASCOT or instrument\$ or independence or intervention or models or outcome\$ or quality or wellbeing).ti,ab.	2594844
192	("co-design" or "co-production\$").ti,ab.	714
193	or/162-192	13141642
194	cost\$.ti,ab.	417196
195	economic\$.ti,ab.	179438
196	Direct service costs/	1080
197	Capital expenditures/	1970
198	Value of life/	5484
199	Budgets/	10377
200	(Fiscal or funding or financial or finance).ti,ab.	97390
	I control of the cont	l .

201	Socioeconomic\$.ti,ab.	60917
202	Models, Economic/	7282
203	((Personal or pool\$) adj3 budget\$).ti,ab.	118
204	(Personal health adj3 budget\$).ti,ab.	32
205	(price\$ or commission\$ or pricing).ti,ab.	58497
206	"cash for care".ti,ab.	24
207	or/194-206	727946
208	161 or 193 or 207	14656780
209	122 and 129 and 146	9816
210	122 and 129 and 146 and 208	9261
211	Historical Article/	327856
212	Editorial/	396251
213	Comment/	655286
214	Letter/	906101
215	News/	174890
216	or/211-215	1930613
217	210 not 216	9210
218	limit 217 to English language	8617
219	limit 218 to yr="2000-Current"	6991

## 6. PsycINFO (Proquest)

Date searched: 22/03/2016

No. of records: 6262

Date limits: after 31Dec2000

Date update search: 30/01/2017

No. of update records: 597

#### **VIEWS**

MJSUB.EXACT("Satisfaction") OR MJSUB.EXACT("Attitudes") OR
MJSUB.EXACT("Adult Attitudes") OR MJSUB.EXACT("Consumer Attitudes") OR
MJSUB.EXACT("Consumer Satisfaction") OR MJSUB.EXACT("Experiences
(Events)") OR MJSUB.EXACT("Client Attitudes") OR MJSUB.EXACT("Participation")
OR MJSUB.EXACT("Involvement") OR MJSUB.EXACT("Public Opinion") OR
MJSUB.EXACT("Participation") OR MJSUB.EXACT("Client Participation") OR
MJSUB.EXACT("Advocacy") OR MJSUB.EXACT("Caregivers") OR
MJSUB.EXACT("Preferences")

MJSUB.EXACT("Social Support") OR MJSUB.EXACT("Assistive Technology") OR MJSUB.EXACT("Augmentative Communication")

TI,AB(lived n/2 experience) OR TI,AB("expert by experience")

TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*") attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*) OR expectation OR experience OR feedback OR learn OR perspective OR preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR Customer OR Individual OR Involv\* OR participation OR people OR user

### **SETTING**

SU.EXACT.EXPLODE("Social Services") OR SU.EXACT.EXPLODE("Social Casework") OR MJSUB.EXACT("Elder Care")

TI,AB("direct payment" OR "individual budget" OR "personal budget" OR "personal health budget" OR personalised OR personalised OR personalisation OR personalisation OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision")

OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))

#### **POPULATION**

MJSUB.EXACT("Minority Groups") OR MJSUB.EXACT("Homeless") OR MJSUB.EXACT("Disadvantaged") OR MJSUB.EXACT("Disabilities")

(TI,AB(adult) OR TI,AB(homeless) OR TI,AB("older people" OR "older person" OR "older adult") OR TI,AB("geriatric" OR "very old" OR elder OR frail OR disabilit\* OR disabled)

NOT

TI,AB(child\* OR adolescen\* OR youth)

#### STUDY TYPE/METHODS

TI,AB(systematic) OR TI,AB(review) OR TI,AB(meta-analysis)

SU.EXACT.EXPLODE("Literature Review") OR MJSUB.EXACT("Qualitative Research") OR MJSUB.EXACT("Cohort Analysis") OR MJSUB.EXACT("Followup Studies") OR MJSUB.EXACT("Longitudinal Studies") OR MJSUB.EXACT("Data Collection") OR MJSUB.EXACT("Needs Assessment") OR MJSUB.EXACT("Interviews") OR MJSUB.EXACT("Surveys") OR OR MJSUB.EXACT("Observation Methods") OR MJSUB.EXACT("Questionnaires") OR MJSUB.EXACT("Self Report") OR MJSUB.EXACT("Grounded Theory")

## **QUALIATITIVE STUDIES**

TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research") OR TI,AB(qualitative or interview or audit or feedback or "indepth" or story or stories or questionnaire or narrative or narration or survey or observation or case or cohort or study or studies) OR TI,AB((discourse or discurs\*) N/3 (analys\*)) OR TI,AB(ethno\* or emic or etic or phenomenolog\* or "grounded")

theory" or "constant compar\*"or "theoretical sampl\*" or "purposive sampl\*" or realist\* or thematic or empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")

#### **MEASURES**

TI,AB("process evaluation" or "outcome evaluation" or "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness or empower or monitored or monitoring or improve or measure) OR TI,AB(ASCOT or instrument or independence or intervention or models or outcome or quality or wellbeing) OR TI,AB("co-design" or "co-production")

MJSUB.EXACT("Program Evaluation") OR MJSUB.EXACT("Quality of Services")
OR MJSUB.EXACT("Evaluation") OR OR MJSUB.EXACT("Treatment Outcomes")
OR MJSUB.EXACT("Activities of Daily Living") OR MJSUB.EXACT("Well Being")
OR MJSUB.EXACT("Quality of Life") OR MJSUB.EXACT("Empowerment") OR
MJSUB.EXACT("Organizational Effectiveness")

#### **ECONOMIC STUIDES**

MJSUB.EXACT("Costs and Cost Analysis") OR MJSUB.EXACT("Budgets")

TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal or funding or financial or finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal or pool) N/3 (budget)) OR TI,AB(price or commission or pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" N/3 budget)

#### **SEARCH RESULTS**

Search run 22 March 2016 on PsycINFO on Proquest platform

Wasn't able to combine the study type in the search. Without got 8758 results. Exported these results in date batches. Excluded books and dissertations and theses from results list which = 7241. Was able to export 6262 results into and Endnote Library.

In Endnote searched dataset for study type search terms to

With English and date limit 2000-Current:

Adult social care: improving people's experience: consultation draft (July 2017) 67 of 171

# Excluded books and dissertations and theses

# 7. Social Policy and Practice (SPP) (Ovid)

Date searched: 17/03/2016

No. of records: 3817

Date limits: after 31Dec2000

Date update search: 24/01/2017

No. of update records: 174

Set	Searches	Results
1	"user views".de.	6952
2	view\$.de.	5090
3	("service user" or "service users").de.	5098
4	participation.de.	13054
5	opinion\$.de.	209
6	advocacy.de.	2701
7	carers.de.	9186
8	(Lived adj2 experience\$).ti,ab.	589
9	"expert by experience".ti,ab.	10
10	(carer\$ adj3 attitud\$).ti,ab.	68
11	(carer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	86
12	(carer\$ adj3 expectation\$).ti,ab.	35
13	(carer\$ adj3 experience\$).ti,ab.	710

14	(carer\$ adj3 feedback).ti,ab.	25
15	(carer\$ adj3 learn\$).ti,ab.	135
16	(carer\$ adj3 perspective\$).ti,ab.	242
17	(carer\$ adj3 preference\$).ti,ab.	16
18	(carer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	133
19	(carer\$ adj3 view\$).ti,ab.	357
20	(client\$ adj3 attitud\$).ti,ab.	50
21	(client\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	93
22	(client\$ adj3 complaint\$).ti,ab.	5
23	(client\$ adj3 expectation\$).ti,ab.	35
24	(client\$ adj3 experience\$).ti,ab.	316
25	(client\$ adj3 feedback).ti,ab.	36
26	(client\$ adj3 learn\$).ti,ab.	82
27	(client\$ adj3 perspective\$).ti,ab.	115
28	(client\$ adj3 preference\$).ti,ab.	39
29	(client\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	176
30	(client\$ adj3 view\$).ti,ab.	138
31	(consult\$ adj3 attitud\$).ti,ab.	7
32	(consult\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	54

33	(consult\$ adj3 complaint\$).ti,ab.	17
34	(consult\$ adj3 experience\$).ti,ab.	99
35	(consult\$ adj3 feedback).ti,ab.	31
36	(consult\$ adj3 learn\$).ti,ab.	61
37	(consult\$ adj3 perspective\$).ti,ab.	12
38	(consult\$ adj3 preference\$).ti,ab.	7
39	(consult\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	20
40	(consult\$ adj3 view\$).ti,ab.	235
41	(consumer\$ adj3 attitud\$).ti,ab.	37
42	(consumer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	224
43	(consumer\$ adj3 complaint\$).ti,ab.	9
44	(consumer\$ adj3 expectation\$).ti,ab.	22
45	(consumer\$ adj3 experience\$).ti,ab.	51
46	(consumer\$ adj3 feedback).ti,ab.	18
47	(consumer\$ adj3 learn\$).ti,ab.	11
48	(consumer\$ adj3 perspective\$).ti,ab.	84
49	(consumer\$ adj3 preference\$).ti,ab.	66
50	(consumer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	119
51	(consumer\$ adj3 view\$).ti,ab.	140

52	(customer\$ adj3 attitud\$).ti,ab.	16
53	(customer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	31
54	(customer\$ adj3 complaint\$).ti,ab.	9
55	(customer\$ adj3 expectation\$).ti,ab.	17
56	(customer\$ adj3 experience\$).ti,ab.	59
57	(customer\$ adj3 feedback).ti,ab.	19
58	(customer\$ adj3 learn\$).ti,ab.	8
59	(customer\$ adj3 perspective\$).ti,ab.	12
60	(customer\$ adj3 preference\$).ti,ab.	14
61	(customer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	109
62	(customer\$ adj3 view\$).ti,ab.	32
63	(individual\$ adj3 attitud\$).ti,ab.	136
64	(individual\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	385
65	(individual\$ adj3 complaint\$).ti,ab.	11
66	(individual\$ adj3 expectation\$).ti,ab.	33
67	(individual\$ adj3 experience\$).ti,ab.	637
68	(individual\$ adj3 feedback).ti,ab.	18
69	(individual\$ adj3 learn\$).ti,ab.	374
70	(individual\$ adj3 perspective\$).ti,ab.	145

71	(individual\$ adj3 preference\$).ti,ab.	140
72	(individual\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	49
73	(involv\$ adj3 attitud\$).ti,ab.	96
74	(involv\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	215
75	(involv\$ adj3 complaint\$).ti,ab.	23
76	(involv\$ adj3 expectation\$).ti,ab.	39
77	(involv\$ adj3 experience\$).ti,ab.	381
78	(involv\$ adj3 feedback).ti,ab.	15
79	(involv\$ adj3 learn\$).ti,ab.	361
80	(involv\$ adj3 perspective\$).ti,ab.	94
81	(involv\$ adj3 preference\$).ti,ab.	20
82	(involv\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	55
83	(involv\$ adj3 view\$).ti,ab.	166
84	(participation adj3 attitud\$).ti,ab.	63
85	(participation adj3 (choice\$ or choos\$ or control)).ti,ab.	114
86	(participation adj3 complaint\$).ti,ab.	6
87	(participation adj3 expectation\$).ti,ab.	19
88	(participation adj3 experience\$).ti,ab.	160
89	(participation adj3 feedback).ti,ab.	52

90	(participation adj3 learn\$).ti,ab.	195
91	(participation adj3 perspective\$).ti,ab.	56
92	(participation adj3 preference\$).ti,ab.	10
93	(participation adj3 (satisf\$ or dissatisf\$)).ti,ab.	38
94	(participation adj3 view\$).ti,ab.	59
95	(people adj3 attitud\$).ti,ab.	620
96	(people adj3 (choice\$ or choos\$ or control)).ti,ab.	899
97	(people adj3 complaint\$).ti,ab.	53
98	(people adj3 expectation\$).ti,ab.	105
99	(people adj3 experience\$).ti,ab.	3147
100	(people adj3 feedback).ti,ab.	36
101	(people adj3 learn\$).ti,ab.	5803
102	(people adj3 perspective\$).ti,ab.	365
103	(people adj3 preference\$).ti,ab.	79
104	(people adj3 (satisf\$ or dissatisf\$)).ti,ab.	148
105	(people adj3 view\$).ti,ab.	1183
106	(user\$ adj3 attitud\$).ti,ab.	62
107	(user\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	376
108	(user\$ adj3 complaint\$).ti,ab.	25

109	(user\$ adj3 expectation\$).ti,ab.	63
110	(user\$ adj3 experience\$).ti,ab.	760
111	(user\$ adj3 feedback).ti,ab.	121
112	(user\$ adj3 learn\$).ti,ab.	129
113	(user\$ adj3 perspective\$).ti,ab.	431
114	(user\$ adj3 preference\$).ti,ab.	51
115	(user\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	218
116	(user\$ adj3 view\$).ti,ab.	799
117	engag\$.ti,ab.	12803
118	advocacy.ti,ab.	3109
119	social networks.de.	2328
120	peer support.de.	247
121	support groups.de.	995
122	telecare.de.	213
123	assistive technology.de.	1324
124	or/1-123	67839
125	"social work".de.	14341
126	"integrated care".de.	409
127	"adult social care".de.	1275

128	("direct payment\$" or "individual budget\$" or micro?commissioning or "personal budget\$" or "personal health budget\$" or personali?ed or personali?ation or "person-centred" or "self-directed support").ti,ab.	5293
129	Care plan\$.ti,ab.	2270
130	("social work\$" or "social care" or "social service\$" or "social provision").ti,ab.	56030
131	((community or home or residential or day) adj3 (care or help or provision or provider\$ or service\$ or support)).ti,ab.	30148
132	or/125-131	87123
133	"young adults".de.	3932
134	"older people".de.	74283
135	"very old people".de.	265
136	adult\$.ti,ab.	29260
137	("older people" or "older person\$" or "older adult\$").ti,ab.	27039
138	(geriatric or "very old" or elder\$ or frail\$ or disabilit\$ or disabled).ti,ab.	39268
139	homeless people.de.	1626
140	homeless.ti,ab.	4545
141	or/133-140	121629
142	(child\$ or adolescen\$ or youth).ti,ab.	134469

143	child*.de.	92359
144	adolesce*.de.	13821
145	or/142-144	151164
146	141 not 145	97017
147	("systematic review" or systematic reviews).de.	780
148	systematic\$.ti,ab.	4903
149	("literature review" or literature reviews).de.	5945
150	review\$.ti,ab.	43712
151	meta?.ti,ab.	1042
152	random\$.ti,ab.	4646
153	randomised controlled trials.de.	553
154	Trial\$.ti.	1272
155	research methods.de.	4158
156	("behavio?ral research" or "conversation analys?s" or "evidence synthesis" or "personal narratives" or "survey research").ti,ab.	301
157	"Focus Group\$".ti,ab.	4232
158	("process evaluation\$" or "outcome evaluation\$" or "service evaluation\$").ti,ab.	457
159	qualitative research.de.	611
160	questionnaires.de.	1471

161	surveys.de.	8399
162	(qualitative or interview\$ or audit\$ or focus group\$ or feedback or in-depth or story or stories or questionnaire\$ or narrative\$ or narration\$ or survey\$ or observation\$ or case or cohort or study or studies).ti,ab.	143609
163	((discourse or discurs\$) adj3 analys?s).ti,ab.	263
164	(ethno\$ or emic or etic or phenomenolog\$ or grounded theory or constant compar\$ or theoretical sampl\$ or purposive sampl\$ or realist* or thematic or empirical).ti,ab.	8961
165	synthes\$.ti,ab.	1156
166	analys\$.ti,ab.	39135
167	(effectiveness or empower or monitored or monitoring or improve\$ or measur\$).ti,ab.	67789
168	"Activities of Daily Living".de.	678
169	"activities of daily living".ti,ab.	1221
170	evaluation.de.	20049
171	outcomes.de.	13872
172	instruments.de.	1134
173	intervention.de.	8839
174	effectiveness.de.	5002
175	evidence.de.	1818

176	(ASCOT or instrument\$ or independence or intervention or	74989
	models or outcome\$ or quality or wellbeing).ti,ab.	
177	("co-design" or "co-production\$").ti,ab.	339
178	cost\$.de.	7839
179	cost\$.ti,ab.	16041
180	economic\$.de.	9113
181	economic\$.ti,ab.	18538
182	(Fiscal or funding or financial or finance).ti,ab.	24141
183	Socioeconomic\$.ti,ab.	1765
184	((Personal or pool\$) adj3 budget\$).ti,ab.	794
185	(Personal health adj3 budget\$).ti,ab.	69
186	(price\$ or commission\$ or pricing).ti,ab.	18793
187	"cash for care".ti,ab.	85
188	or/147-187	270142
189	124 and 132 and 146 and 188	5518
190	limit 189 to yr="2000-Current"	3817

# 8. Social Services Abstracts (Proquest)

Date searched: 15/03/2016

No. of records: 2052

Date limits: after 31Dec2000

Date update search: 30/01/2017

No. of update records: 218

**VIEWS** 

SU.EXACT("Client Satisfaction") OR SU.EXACT("Experience") OR

SU.EXACT("Satisfaction") OR SU.EXACT("Participation") OR SU.EXACT("Citizen

Participation") OR SU.EXACT("Perceptions") OR SU.EXACT("Attitudes") OR

SU.EXACT("Preferences") or SU.EXACT("Caregivers") or SU.EXACT("Advocacy")

SU.EXACT("Support Networks") OR SU.EXACT("Social Support")

TI,AB(lived n/2 experience) OR TI,AB("expert by experience")

TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*") attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*) OR expectation OR experience OR feedback OR learn OR perspective OR preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR Customer OR Individual OR Involv\* OR participation OR people OR user

## **SETTING**

TI,AB("direct payment" OR "individual budget" OR "personal budget" OR "personal health budget" OR personalised OR personalised OR personalisation OR personalization OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision") OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))

SU.EXACT("Social Work") OR SU.EXACT("Adult Care Services") OR SU.EXACT("Community Services") OR SU.EXACT("Social Services")

#### **POPULATION**

(TI,AB(adult) OR TI,AB(homeless) OR TI,AB("older people" OR "older person" OR "older adult") OR TI,AB("geriatric" OR "very old" OR elder OR frail OR disabilit\* OR disabled) OR SU.EXACT("Adults") OR SU.EXACT("Elderly") OR SU.EXACT("Middle

Aged Adults") OR SU.EXACT("Young Adults") OR SU.EXACT("Homelessness") OR SU.EXACT("Minority Groups") OR SU.EXACT("Disadvantaged")

NOT (SU.EXACT("Children") OR TI,AB(child\* OR adolescen\* OR youth) OR SU.EXACT("Adolescents"))

## STUDY TYPE/METHODS

SU.EXACT("Literature Reviews") OR SU.EXACT("Qualitative Methods") OR SU.EXACT("Observation") OR SU.EXACT("Methodology (Data Collection)") OR SU.EXACT("Surveys") OR SU.EXACT("Interviews") OR SU.EXACT("Group Research") OR SU.EXACT("Cohort Analysis") OR SU.EXACT("Surveys") OR SU.EXACT("Questionnaires") OR SU.EXACT("Narratives") OR SU.EXACT("Observation")

#### **QUALIATITIVE STUDIES**

TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research") OR TI,AB(qualitative or interview or audit or feedback or "indepth" or story or stories or questionnaire or narrative or narration or survey or observation or case or cohort or study or studies) OR TI,AB((discourse or discurs\*) N/3 (analys\*)) OR TI,AB(ethno\* or emic or etic or phenomenolog\* or "grounded theory" or "constant compar\*"or "theoretical sampl\*" or "purposive sampl\*" or realist\* or thematic or empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")

## **MEASURES**

SU.EXACT("Program Evaluation") OR SU.EXACT("Evaluation") OR SU.EXACT("Evaluation Research") OR SU.EXACT("Needs Assessment") OR SU.EXACT("Treatment Outcomes") OR SU.EXACT("Activities of Daily Living") OR SU.EXACT("Quality of Life") OR SU.EXACT("Well Being")

TI,AB("process evaluation" or "outcome evaluation" or "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness or empower or monitored or

monitoring or improve or measure) OR TI,AB(ASCOT or instrument or independence or intervention or models or outcome or quality or wellbeing) OR TI,AB("co-design" or "co-production")

#### **ECONOMIC STUIDES**

SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Economic Models") OR SU.EXACT("Econometric Analysis")

TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal or funding or financial or finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal or pool) N/3 (budget)) OR TI,AB(price or commission or pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" N/3 budget)

#### **SEARCH STATEMENTS**

((SU.EXACT("Client Satisfaction") OR SU.EXACT("Experience") OR SU.EXACT("Satisfaction") OR SU.EXACT("Participation") OR SU.EXACT("Citizen Participation") OR SU.EXACT("Perceptions") OR SU.EXACT("Attitudes") OR SU.EXACT("Preferences") OR SU.EXACT("Caregivers") OR SU.EXACT("Advocacy") SU.EXACT("Support Networks") OR SU.EXACT("Social Support")) OR (TI,AB(lived NEAR/2 experience) OR TI,AB("expert by experience")) OR (TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*")) OR (attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*) OR expectation OR experience OR feedback OR learn OR perspective OR preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR Customer OR Individual OR Involv\* OR participation OR people OR user)) AND ((TI,AB("direct payment" OR "individual budget" OR "personal budget" OR "personal health budget" OR personalised OR personalized OR personalisation OR personalization OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision") OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))) OR (SU.EXACT("Social Work") OR SU.EXACT("Adult Care Services") OR SU.EXACT("Community Services") OR SU.EXACT("Social Services"))) AND

((SU.EXACT("Adults") OR SU.EXACT("Elderly") OR SU.EXACT("Middle Aged Adults") OR SU.EXACT("Young Adults") OR SU.EXACT("Homelessness") OR SU.EXACT("Minority Groups") OR SU.EXACT("Disadvantaged")) NOT (SU.EXACT("Children") OR TI,AB(child\* OR adolescen\* OR youth) OR SU.EXACT("Adolescents"))) AND ((SU.EXACT("Literature Reviews") OR SU.EXACT("Qualitative Methods") OR SU.EXACT("Observation") OR SU.EXACT("Methodology (Data Collection)") OR SU.EXACT("Surveys") OR SU.EXACT("Interviews") OR SU.EXACT("Group Research") OR SU.EXACT("Cohort Analysis") OR SU.EXACT("Surveys") OR SU.EXACT("Questionnaires") OR SU.EXACT("Narratives") OR SU.EXACT("Observation")) OR (TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" OR "behavioural research" OR "conversation analysis" OR "evidence synthesis" OR "personal narratives" OR "survey research") OR TI,AB(qualitative OR interview OR audit OR feedback OR "indepth" OR story OR stories OR questionnaire OR narrative OR narration OR survey OR observation OR case OR cohort OR study OR studies) OR TI,AB((discourse OR discurs\*) NEAR/3 (analys\*)) OR TI,AB(ethno\* OR emic OR etic OR phenomenolog\* OR "grounded theory" OR "constant compar\*" OR "theoretical sampl\*" OR "purposive sampl\*" OR realist\* OR thematic OR empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")) OR (SU.EXACT("Program Evaluation") OR SU.EXACT("Evaluation") OR SU.EXACT("Evaluation Research") OR SU.EXACT("Needs Assessment") OR SU.EXACT("Treatment Outcomes") OR SU.EXACT("Activities of Daily Living") OR SU.EXACT("Quality of Life") OR SU.EXACT("Well Being")) OR (TI,AB("process evaluation" OR "outcome evaluation" OR "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness OR empower OR monitored OR monitoring OR improve OR measure) OR TI,AB(ASCOT OR instrument OR independence OR intervention OR models OR outcome OR quality OR wellbeing) OR TI,AB("co-design" OR "co-production")) OR (SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Economic Models") OR SU.EXACT("Econometric Analysis")) OR (TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal OR funding OR financial OR finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal OR pool) NEAR/3 (budget)) OR TI,AB(price OR commission OR pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" NEAR/3 budget)) OR (TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal OR funding OR financial OR finance) OR TI,AB(Socioeconomic) OR

TI,AB((Personal OR pool) NEAR/3 (budget)) OR TI,AB(price OR commission OR pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" NEAR/3 budget)))

## **SEARCH RESULTS**

Total results before limits: 3309

English: 3184

With English and date limit 2000-Current: 2056

Note when exported results by date range – only 2052 came up for export.

## 9. Social Work Abstracts (Ovid)

Date searched: 09/03/2016

No. of records: 315

Date limits: after 31Dec2000

Date update search: 30/01/2017

No. of update records: 6

Searches	Results	Search Type
1	attitudes.de.	984
2	satisfaction.de.	153
3	perception.de.	262
4	(Lived adj2 experience\$).ti,ab.	140
5	"expert by experience".ti,ab.	2
6	Caregivers.de.	965
7	(carer\$ adj3 attitud\$).ti,ab.	3
8	(carer\$ adj3 expectation\$).ti,ab.	4

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9	(carer\$ adj3 experience\$).ti,ab.	21
10	(carer\$ adj3 perspective\$).ti,ab.	7
11	(carer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	5
12	(carer\$ adj3 view\$).ti,ab.	7
13	(client\$ adj3 attitud\$).ti,ab.	51
14	(client\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	70
15	(client\$ adj3 complaint\$).ti,ab.	8
16	(client\$ adj3 expectation\$).ti,ab.	30
17	(client\$ adj3 experience\$).ti,ab.	161
18	(client\$ adj3 feedback).ti,ab.	18
19	(client\$ adj3 learn\$).ti,ab.	39
20	(client\$ adj3 perspective\$).ti,ab.	74
21	(client\$ adj3 preference\$).ti,ab.	30
22	(client\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	110
23	(client\$ adj3 view\$).ti,ab.	80
24	(consult\$ adj3 attitud\$).ti,ab.	1
25	(consult\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	6
26	(consult\$ adj3 experience\$).ti,ab.	16
27	(consult\$ adj3 feedback).ti,ab.	3

28	(consult\$ adj3 learn\$).ti,ab.	8
29	(consult\$ adj3 preference\$).ti,ab.	2
30	(consult\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	3
31	(consult\$ adj3 view\$).ti,ab.	7
32	(consumer\$ adj3 attitud\$).ti,ab.	8
33	(consumer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	26
34	(consumer\$ adj3 expectation\$).ti,ab.	2
35	(consumer\$ adj3 experience\$).ti,ab.	18
36	(consumer\$ adj3 feedback).ti,ab.	7
37	(consumer\$ adj3 learn\$).ti,ab.	2
38	(consumer\$ adj3 perspective\$).ti,ab.	33
39	(consumer\$ adj3 preference\$).ti,ab.	18
40	(consumer\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	56
41	(consumer\$ adj3 view\$).ti,ab.	14
42	(customer\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	1
43	(customer\$ adj3 complaint\$).ti,ab.	1
44	(customer\$ adj3 expectation\$).ti,ab.	2
45	(customer\$ adj3 perspective\$).ti,ab.	1
46	(individual\$ adj3 attitud\$).ti,ab.	54

47	(individual\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	85
48	(individual\$ adj3 complaint\$).ti,ab.	4
49	(individual\$ adj3 expectation\$).ti,ab.	16
50	(individual\$ adj3 experience\$).ti,ab.	185
51	(individual\$ adj3 feedback).ti,ab.	10
52	(individual\$ adj3 learn\$).ti,ab.	46
53	(individual\$ adj3 perspective\$).ti,ab.	42
54	(individual\$ adj3 preference\$).ti,ab.	31
55	(individual\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	27
56	(individual\$ adj3 view\$).ti,ab.	50
57	(involv\$ adj3 attitud\$).ti,ab.	23
58	(involv\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	41
59	(involv\$ adj3 complaint\$).ti,ab.	4
60	(involv\$ adj3 expectation\$).ti,ab.	13
61	(involv\$ adj3 experience\$).ti,ab.	67
62	(involv\$ adj3 feedback).ti,ab.	2
63	(involv\$ adj3 learn\$).ti,ab.	37
64	(involv\$ adj3 perspective\$).ti,ab.	31
65	(involv\$ adj3 preference\$).ti,ab.	2

66	(involv\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	19
67	(involv\$ adj3 view\$).ti,ab.	25
68	(participation adj3 attitud\$).ti,ab.	23
69	(participation adj3 (choice\$ or choos\$ or control)).ti,ab.	20
70	(participation adj3 expectation\$).ti,ab.	5
71	(participation adj3 experience\$).ti,ab.	19
72	(participation adj3 feedback).ti,ab.	1
73	(participation adj3 learn\$).ti,ab.	13
74	(participation adj3 perspective\$).ti,ab.	11
75	(participation adj3 preference\$).ti,ab.	4
76	(participation adj3 (satisf\$ or dissatisf\$)).ti,ab.	25
77	(participation adj3 view\$).ti,ab.	13
78	(people adj3 attitud\$).ti,ab.	61
79	(people adj3 (choice\$ or choos\$ or control)).ti,ab.	31
80	(people adj3 complaint\$).ti,ab.	2
81	(people adj3 expectation\$).ti,ab.	9
82	(people adj3 experience\$).ti,ab.	150
83	(people adj3 learn\$).ti,ab.	48
84	(people adj3 perspective\$).ti,ab.	19

85	(people adj3 preference\$).ti,ab.	3
86	(people adj3 (satisf\$ or dissatisf\$)).ti,ab.	8
87	(people adj3 view\$).ti,ab.	50
88	(user\$ adj3 attitud\$).ti,ab.	2
89	(user\$ adj3 (choice\$ or choos\$ or control)).ti,ab.	14
90	(user\$ adj3 expectation\$).ti,ab.	5
91	(user\$ adj3 experience\$).ti,ab.	35
92	(user\$ adj3 feedback).ti,ab.	5
93	(user\$ adj3 learn\$).ti,ab.	6
94	(user\$ adj3 perspective\$).ti,ab.	20
95	(user\$ adj3 preference\$).ti,ab.	5
96	(user\$ adj3 (satisf\$ or dissatisf\$)).ti,ab.	11
97	(user\$ adj3 view\$).ti,ab.	15
98	engag\$.ti,ab.	2693
99	social support.de.	715
100	advocacy.ti,ab.	944
101	"peer support".ti,ab.	127
102	technology.de.	672
103	technol\$.ti,ab.	1276

104	or/1-103	9819
105	Social work.de.	3006
106	("direct payment\$" or "individual budget\$" or	112
	micro?commissioning or "personal budget\$" or "personal	
	health budget\$" or personali?ed or personali?ation or "person-	
	centred" or "self-directed support").ti,ab.	
107	Care plan\$.ti,ab.	145
108	("social work\$" or "social care" or "social service\$" or "social	18393
	provision").ti,ab.	
109	((community or home or residential or day) adj3 (care or help	3093
	or provision or provider\$ or service\$ or support)).ti,ab.	
110	or/105-109	20920
111	adults.de.	273
112	elderly.de.	183
113	adult\$.ti,ab.	5615
114	aged.de.	2307
115	("older people" or "older person\$" or "older adult\$").ti,ab.	1676
116	(geriatric or "very old" or elder\$ or frail\$ or disabilit\$ or	4895
	disabled).ti,ab.	
117	Homelessness.de.	520
118	homeless.ti,ab.	747

119	or/111-118	11093
120	(child\$ or adolescen\$ or youth).ti,ab.	20822
121	child*.de.	15401
122	adolesce*.de.	3875
123	or/120-122	23230
124	119 not 123	7264
125	systematic\$.ti,ab.	1250
126	review\$.ti,ab.	6103
127	"meta analysis".de.	49
128	meta?.ti,ab.	239
129	random\$.ti,ab.	2164
130	"Conceptual frameworks".de.	512
131	"Social work research".de.	327
132	research.de.	12519
133	Trial\$.ti.	207
134	("behavio?ral research" or "conversation analys?s" or "evidence synthesis" or "personal narratives" or "survey research").ti,ab.	152
135	"Focus Group\$".ti,ab.	781

136	("process evaluation\$" or "outcome evaluation\$" or "service evaluation\$").ti,ab.	130
137	"qualitative research".de.	145
138	(qualitative or interview\$ or audit\$ or focus group\$ or feedback or in-depth or story or stories or questionnaire\$ or narrative\$ or	40018
	narration\$ or survey\$ or observation\$ or case or cohort or study or studies).ti,ab.	
139	surveys.de.	225
140	questionnaires.de.	49
141	narratives.de.	435
142	((discourse or discurs\$) adj3 analys?s).ti,ab.	60
143	(ethno\$ or emic or etic or phenomenolog\$ or grounded theory or constant compar\$ or theoretical sampl\$ or purposive sampl\$ or realist* or thematic or empirical).ti,ab.	3800
144	synthes\$.ti,ab.	354
145	analys\$.ti,ab.	11050
146	"activities of daily living".ti,ab.	151
147	(effectiveness or empower or monitored or monitoring or improve\$ or measur\$).ti,ab.	13131
148	(ASCOT or instrument\$ or independence or intervention or models or outcome\$ or quality or wellbeing).ti,ab.	16719
149	participation.de.	146

150	("co-design" or "co-production\$").ti,ab.	6
151	outcomes.de.	380
152	collaboration.de.	520
153	budgets.de.	35
154	cost\$.ti,ab.	2153
155	Cost\$.de.	243
156	economics.de.	323
157	economic\$.ti,ab.	3446
158	(Fiscal or funding or financial or finance).ti,ab.	2492
159	Socioeconomic\$.ti,ab.	1091
160	((Personal or pool\$) adj3 budget\$).ti,ab.	7
161	(price\$ or commission\$ or pricing).ti,ab.	551
162	"cash for care".ti,ab.	7
163	or/125-162	55380
164	104 and 110 and 124 and 163	507
165	limit 164 to yr="2000-Current"	315

# 10. SocINDEX (Ebsco)

Date searched: 16/03/2016

No. of records: 1879

Date limits: after 31Dec2000

Date update search: 26/01/2017

No. of update records: 120

Set	Search Terms	Results
S1	DE "CLIENT satisfaction"	168
S2	DE "ATTITUDE (Psychology)"	18,660
S3	DE "PUBLIC opinion"	7,980
S4	DE "PERCEPTION"	7,220
S5	DE "SOCIAL advocacy"	783
S6	DE "PATIENT participation"	522
S7	DE "CAREGIVERS"	6,534
S8	DE "SUPPORT groups"	1,304
S9	TI (lived n3 experience*) or AB (lived n3 experience*)	2,327
S10	DE "Advocacy"	758
S11	TI (carer* n3 attitud*) or AB (carer* n3 attitud*)	22
S12	TI (carer* n3 (choice* or choos* or control)) or AB (carer* n3 (choice* or choos* or control))	25
S13	TI (carer* n3 complaint*) or AB (carer* n3 complaint*)	5
S14	TI (carer* n3 expectation*) or AB (carer* n3 expectation*)	13

S15	TI (carer* n3 experience*) or AB (carer* n3 experience*)	190
S16	TI (carer* n3 feedback) or AB (carer* n3 feedback)	8
S17	TI (carer* n3 learn*) or AB (carer* n3 learn*)	35
S18	TI (carer* n3 perspective*) or AB (carer* n3 perspective*)	77
S19	TI (carer* n3 preference*) or AB (carer* n3 preference*)	7
S20	TI (carer* n3 (satisf* or dissatisf*)) or AB (carer* n3 (satisf* or dissatisf*))	41
S21	TI (carer* n3 view*) or AB (carer* n3 view*)	84
S22	TI (client* n3 attitud*) or AB (client* n3 attitud*)	299
S23	TI (client* n3 (choice* or choos* or control)) or AB (client* n3 (choice* or choos* or control))	452
S24	TI (client* n3 complaint*) or AB (client* n3 complaint*)	37
S25	TI (client* n3 expectation*) or AB (client* n3 expectation*)	188
S26	TI (client* n3 experience*) or AB (client* n3 experience*)	817
S27	TI (client* n3 feedback) or AB (client* n3 feedback)	97
S28	TI (client* n3 learn*) or AB (client* n3 learn*)	192

S29	TI (client* n3 perspective*) or AB (client* n3 perspective*)	324
S30	TI (client* n3 preference*) or AB (client* n3 preference*)	119
S31	TI (client* n3 (satisf* or dissatisf*)) or AB (client* n3 (satisf* or dissatisf*))	524
S32	TI (client* n3 view*) or AB (client* n3 view*)	363
S33	TI (consult* n3 attitud*) or AB (consult* n3 attitud*)	41
S34	TI (consult* n3 (choice* or choos* or control)) or AB (consult* n3 (choice* or choos* or control))	109
S35	TI (consult* n3 complaint*) or AB (consult* n3 complaint*)	19
S36	TI (consult* n3 expectation*) or AB (consult* n3 expectation*)	20
S37	TI (consult* n3 experience*) or AB (consult* n3 experience*)	221
S38	TI (consult* n3 feedback) or AB (consult* n3 feedback)	24
S39	TI (consult* n3 learn*) or AB (consult* n3 learn*)	74
S40	TI (consult* n3 perspective*) or AB (consult* n3 perspective*)	43

S41	TI (consult* n3 preference*) or AB (consult* n3 preference*)	19
S42	TI (consult* n3 (satisf* or dissatisf*)) or AB (consult* n3 (satisf* or dissatisf*))	40
S43	TI (consult* n3 view*) or AB (consult* n3 view*)	110
S44	TI (consumer* n3 attitud*) or AB (consumer* n3 attitud*)	531
S45	TI (consumer* n3 (choice* or choos* or control)) or AB (consumer* n3 (choice* or choos* or control))	948
S46	TI (consumer* n3 complaint*) or AB (consumer* n3 complaint*)	162
S47	TI (consumer* n3 expectation*) or AB (consumer* n3 expectation*)	142
S48	TI (consumer* n3 experience*) or AB (consumer* n3 experience*)	304
S49	TI (consumer* n3 feedback) or AB (consumer* n3 feedback)	32
S50	TI (consumer* n3 learn*) or AB (consumer* n3 learn*)	89
S51	TI (consumer* n3 perspective*) or AB (consumer* n3 perspective*)	302
S52	TI (consumer* n3 preference*) or AB (consumer* n3 preference*)	489

S53	TI (consumer* n3 (satisf* or dissatisf*)) or AB (consumer* n3 (satisf* or dissatisf*))	442
S54	TI (consumer* n3 view*) or AB (consumer* n3 view*)	282
S55	TI (customer* n3 attitud*) or AB (customer* n3 attitud*)	58
S56	TI (customer* n3 (choice* or choos* or control)) or AB (customer* n3 (choice* or choos* or control))	96
S57	TI (customer* n3 complaint*) or AB (customer* n3 complaint*)	39
S58	TI (customer* n3 expectation*) or AB (customer* n3 expectation*)	82
S59	TI (customer* n3 experience*) or AB (customer* n3 experience*)	69
S60	TI (customer* n3 feedback) or AB (customer* n3 feedback)	13
S61	TI (customer* n3 learn*) or AB (customer* n3 learn*)	17
S62	TI (customer* n3 perspective*) or AB (customer* n3 perspective*)	41
S63	TI (customer* n3 preference*) or AB (customer* n3 preference*)	45
S64	TI (customer* n3 (satisf* or dissatisf*)) or AB (customer* n3 (satisf* or dissatisf*))	(425)

S65	TI (customer* n3 view*) or AB (customer* n3 view*)	(46)
S66	TI (individual* n3 attitud*) or AB (individual* n3 attitud*)	(1,900)
S67	TI (individual* n3 (choice* or choos* or control)) or AB (individual* n3 (choice* or choos* or control))	(3,670)
S68	TI (individual* n3 complaint*) or AB(individual* n3 complaint*)	(114)
S69	TI (individual* n3 expectation*) or AB (individual* n3 expectation*)	(428)
S70	TI (individual* n3 experience*) or AB (individual* n3 experience*)	(3,654)
S71	TI (individual* n3 feedback) or AB (individual* n3 feedback)	(197)

S72	TI (individual* n3 learn*) or AB (individual* n3 learn*)	(1,164)
S73	TI (individual* n3 perspective*) or AB (individual* n3 perspective*)	(1,054)
S74	TI (individual* n3 preference*) or AB (individual* n3 preference*)	(1,211)
S75	TI (individual* n3 (satisf* or dissatisf*)) or AB (individual* n3 (satisf* or dissatisf*))	(849)
S76	TI (individual* n3 view*) or AB (individual* n3 view*)	(1,344)
S77	TI (involv* n3 attitud*) or AB (involv* n3 attitud*)	(668)

S78	TI (involv* n3 (choice* or choos* or control)) or AB (involv* n3 (choice* or choos* or control))	(1,433)
S79	TI (involve* n3 complaint*) or AB (involve* n3 complaint*)	(91)
S80	TI (involv* n3 expectation*) or AB (involv* n3 expectation*)	(191)
S81	TI (involv* n3 experience*) or AB (involv* n3 experience*)	(1,013)
S82	TI (involv* n3 feedback) or AB (involv* n3 feedback)	(75)
S83	TI (involv* n3 learn*) or AB (involv* n3 learn*)	(787)
S84	TI (involv* n3 perspective*) or AB (involv* n3 perspective*)	(395)

S85	TI (involv* n3 preference*) or AB (involv* n3 preference*)	(143)
S86	TI (involv* n3 (satisf* or dissatisf*)) or AB (involv* n3 (satisf* or dissatisf*))	(372)
S87	TI (involv* n3 view*) or AB (involv* n3 view*)	(538)
S88	TI (participation n3 attitud*) or AB (participation n3 attitud*)	(437)
S89	TI (participation n3 (choice* or choos* or control)) or AB (participation n3 (choice* or choos* or control))	(467)
S90	TI (participation n3 complaint*) or AB (participation n3 complaint*)	(8)

S91	TI (participation n3 expectation*) or AB (participation n3 expectation*)	(99)
S92	TI (participation n3 experience*) or AB (participation n3 experience*)	(480)
S93	TI (participation n3 feedback) or AB (participation n3 feedback)	(43)
S94	TI (participation n3 learn*) or AB (participation n3 learn*)	(353)
S95	TI (participation n3 perspective*) or AB (participation n3 perspective*)	(216)
S96	TI (participation n3 preference*) or AB (participation n3 preference*)	(82)
S97	TI (participation n3 (satisf* or dissatisf*)) or AB (participation n3 (satisf* or dissatisf*))	(232)

S98	TI (participation n3 view*) or AB (participation n3 view*)	(247)
S99	TI (people n3 attitud*) or AB (people n3 attitud*)	(2,062)
S100	TI (people n3 (choice* or choos* or control)) or AB (people n3 (choice* or choos* or control))	(1,825)
S101	TI (people n3 complaint*) or AB (people n3 complaint*)	(58)
S102	TI (people n3 expectation*) or AB (people n3 expectation*)	(400)
S103	TI (people n3 experience*) or AB (people n3 experience*)	(3,999)
S104	TI (people n3 feedback) or AB (people n3 feedback)	(54)

S105	TI (people n3 learn*) or AB (people n3 learn*)	(2,100)
S106	TI (people n3 perspective*) or AB (people n3 perspective*)	(813)
S107	TI (people n3 preference*) or AB (people n3 preference*)	(367)
S108	TI (people n3 (satisf* or dissatisf*)) or AB (people n3 (satisf* or dissatisf*))	(491)
S109	TI (people n3 view*) or AB (people n3 view*)	(1,901)
S110	TI (user* n3 attitud*) or AB (user* n3 attitud*)	(173)

S111	TI (user* n3 (choice* or choos* or control)) or AB (user* n3 (choice* or choos* or control))	(413)
S112	TI (user* n3 complaint*) or AB (user* n3 complaint*)	(17)
S113	TI (user* n3 expectation*) or AB (user* n3 expectation*)	(56)
S114	TI (user* n3 experience*) or AB (user* n3 experience*)	(597)
S115	TI (user* n3 feedback) or AB (user* n3 feedback)	(66)
S116	TI (user* n3 learn*) or AB (user* n3 learn*)	(99)
S117	TI (user* n3 perspective*) or AB (user* n3 perspective*)	(267)

S118	TI (user* n3 preference*) or AB (user* n3 preference*)	(69)
S119	TI (user* n3 (satisf* or dissatisf*)) or AB (user* n3 (satisf* or dissatisf*))	(220)
S120	TI (user* n3 view*) or AB (user* n3 view*)	(342)
S121	TI (engag*) or AB (engag*)	(51,088)
S122	TI (advocacy) or AB (advocacy)	(9,101)
S123	TI ("peer support") or AB ("peer support")	(805)
S124	DE "INFORMATION & communication technologies"	(768)

S125	DE "ASSISTIVE computer technology"	(4)
S126	DE "COMMUNICATION devices for people with disabilities"	(37)
S127	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66 OR S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 O	(141,571)
S128	DE "Social Services"	(37,193)
S129	DE "Social Work"	(2,282)

S130	DE "HOME care services"	(2,369)
S131	DE "ADULT care services"	(497)
S132	DE "COMMUNITY-based social services"	(875)
S133	DE "SOCIAL case work"	(3,836)
S134	TI ("direct payment*" or "individual budget*" or micro?commissioning or "personal budget*" or "personal health budget*" or personali?ed or personali?ation or "person-centred" or "self-directed support") or AB ("direct payment*" or "individual budget*" or micro?commissioning or "personal budget*" or "personal health budget*" or personali?ed or personali?ation or "person-centred" or "self-directed support")	(2,589)

S135	TI ("care plan*") or AB ("care plan*)	(3,276)
S136	TI ("social work*" or "social care" or "social service*" or "social provision") or AB ("social work*" or "social care" or "social service*" or "social provision")	(65,872)
S137	TI ((community or home or residential or day) n3 (care or help or provision or provider* or service* or support)) or AB ((community or home or residential or day) n3 (care or help or provision or provider* or service* or support))	(33,740)
S138	S128 OR S129 OR S130 OR S131 OR S132 OR S133 OR S134 OR S135 OR S136 OR S137	(109,202)
S139	DE "ADULTS"	(3,173)
S140	TI "adult*" or AB "adult*	(76,739)
S141	DE "MIDDLE age"	(1,503)

S142	DE "MIDDLE-aged persons"	(169)
S143	DE "OLD age"	(3,474)
S144	DE "OLDER people"	(14,348)
S145	DE "YOUNG adults"	(4,969)
S146	DE "HOMELESS persons"	(2,516)
S147	TI homeless or AB homeless	(5,649)
S148	DE "MINORITIES"	(9,486)

S149	DE "PEOPLE with disabilities"	(5,493)
S150	TI ("older people" or "older person*" or "older adult*")	(16,677)
	or AB ("older people" or "older person*" or "older adult*")	
S151	TI (geriatric or "very old" or elder* or frail* or disabilit* or disabled) or AB (geriatric or "very old" or elder* or frail* or disabilit* or disabled)	(48,433)
S152	S139 OR S140 OR S141 OR S142 OR S143 OR S144 OR S145 OR S146 OR S147 OR S148 OR S149 OR S150 OR S151	(147,071)
S153	DE "SOCIAL case work with children" OR DE "SOCIAL work with children" OR DE "ADOLESCENCE" OR DE "YOUTH" OR DE "CHILDREN"	(51,612)
S154	TI (child* or adolescen* or youth*) or AB (child* or adolescen* or youth*)	(290,360)

S155	S153 OR S154	(295,287)
S156	S152 NOT S155	(100,123)
S157	DE " meta-analysis"	(2,113)
S158	DE "CLINICAL trials"	(2,963)
S159	DE "RANDOMIZED controlled trials"	(1,322)
S160	DE "Literature reviews"	(2,092)
S161	TI (systematic*) or AB (systematic*)	(24,636)

S162	TI (review*) or AB (review*)	(605,693)
S163	TI (meta analys*) or AB (meta analys*)	(3,105)
S164	TI (random*) or AB (random*)	(29,791)
S165	ti (trial*)	(7,331)
S166	DE "QUALITATIVE research"	(10,587)
S167	DE "narratives"	(2,069)
S168	AB "personal account"	(240)

S169	DE "data collection"	(2,213)
S170	DE "ETHNOLOGY"	(13,549)
S171	DE "FOCUS groups"	(2,673)
S172	TI ("focus group*") or AB ("focus group*)	(9,980)
S173	TI ("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research")or AB ("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research")	(2,936)
S174	DE "INTERVIEWING"	(9,950)

S175	DE "CONVERSATION analysis"	(767)
S176	DE "PARTICIPANT observation"	(1,317)
S177	DE "CONVERSATION analysis"	(767)
S178	DE "PARTICIPANT observation"	(1,317)
S179	DE "EVENT history analysis"	(326)
S180	DE "Minimum Data Set"	(26)
S181	DE "National Surveys"	(68)

S182	DE "Proxy Respondents"	(4)
S183	DE "Self Report Measures"	(6)
S184	DE "State Surveys"	(25)
S185	DE "Statistical Analysis"	(57)
S186	DE "Surveys"	(18,562)
S187	DE "Interviews"	(7,268)

S188	TI ("process evaluation*" or "outcome evaluation*" or "service evaluation*") or AB ("process evaluation*" or "outcome evaluation*" or "service evaluation*")	(1,253)
S189	TI (qualitative or interview* or audit* or feedback or indepth or story or stories or questionnaire* or narrative* or narration* or survey* or observation* or case or cohort or study or studies) or AB (qualitative or interview* or audit* or feedback or in-depth or story or stories or questionnaire* or narrative* or narration* or survey* or observation* or case or cohort or study or studies)	(792,145)
S190	TI (discourse or discurs*) n3 (analys*)or AB (discourse or discurs*) n3 (analys*)	(3,858)
S191	TI (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or theoretical sampl* or purposive sampl* or realist* or thematic or empirical) or AB (ethno* or emic or etic or phenomenolog* or grounded theory or constant compar* or theoretical sampl* or purposive sampl* or realist* or thematic or empirical)	(100,611)
S192	TI (synthes*) or AB (synthes*)	(7,450)
S193	DE "OUTCOME assessment (Social services)"	(353)

S194	DE "SOCIAL services Evaluation"	(205)
S195	DE "QUALITY of life"	(9,966)
S196	DE "WELL-being"	(6,176)
S197	DE "Quality of Care"	(292)
S198	DE "ACTIVITIES of daily living"	(1,256)
S199	TI ("activities of daily living") or AB ("activities of daily living")	(1,221)

S200	TI (effectiveness or empower or monitored or monitoring or improve* or measur*) or AB (effectiveness or empower or monitored or monitoring or improve* or measur*)	(252,240)
S201	TI (ASCOT or instrument* or independence or intervention or models or outcome* or quality or wellbeing) or AB (ASCOT or instrument* or independence or intervention or models or outcome* or quality or wellbeing)	(354,249)
S202	TI ("co-design" or "co-production*") or AB ("co-design" or "co-production*")	(272)
S203	DE "COST"	(1,878)
S204	OR DE "COST effectiveness" OR DE "PRICES" OR DE "ECONOMICS" OR DE "COST effectiveness" OR DE "PRICES"	(30,962)
S205	DE "ECONOMICS"	(25,802)
S206	DE "PRICES"	(2,767)

S207	DE "BUDGET"	(3,478)
S208	DE "PERSONAL budgets"	(101)
S209	TI (cost*) or AB (cost*)	(68,012)
S210	TI (economic*) or AB (economic*)	(187,615)
S211	DE "ECONOMETRIC models"	(1,893)
S212	DE "Models"	(137)

S213	TI (Fiscal or funding or financial or finance) or AB (Fiscal or funding or financial or finance)	(78,302)
S214	TI Socioeconomic* or AB Socioeconomic*	(22,936)
S215	TI ((Personal or pool*) n3 budget*) or AB ((Personal or pool*) n3 budget*)	(209)
S216	TI (price* or commission* or pricing) or AB (price* or commission* or pricing)	(56,970)
S217	TI ("cash for care") or AB ("cash for care")	(48)
S218	TI (Personal health n3 budget*) or AB (Personal health n3 budget*)	(12)
S219	S157 OR S158 OR S159 OR S160 OR S161 OR S162 OR S163 OR S164 OR S165 OR S166 OR S167 OR S168 OR S169 OR S170 OR S171 OR S172 OR S173 OR S174 OR S175 OR S176 OR S177 OR S178 OR	(1,718,113)

	S179 OR S180 OR S181 OR S182 OR S183 OR S184	
	OR S185 OR S186 OR S187 OR S188 OR S189 OR	
	S190 OR S191 OR S192 OR S193 OR S194 OR S195	
	OR S196 OR S197 OR S198 OR S199 OR S200 OR	
	S201 OR S202 OR S203 OR S204 OR S205 OR S206	
	OR S207 OR S208 OR S209 OR S210 OR S211 OR	
	S212 OR S213 OR S214 OR S215 OR S216 OR S217	
	OR S218	
S220	S127 AND S138 AND S156 AND S219	(2,369)
S221	S127 AND S138 AND S156 AND S219	(1,933)
	Date limit: 01/01/2000 - Current	
S222	S220 AND S221	(1,933)
S223	S127 AND S138 AND S156 (without study type)	(2,854)
S224	S220 AND S221	1879
	(limited to English Language)	

### 11. Sociological Abstracts (Proquest)

Date searched: 15/03/2016

No. of records: 945

Date limits: after 31Dec2000

Date update search: 30/01/2017

No. of update records: 156

#### **VIEWS**

SU.EXACT("Client Satisfaction") OR SU.EXACT("Experience") OR SU.EXACT("Satisfaction") OR SU.EXACT("Participation") OR SU.EXACT("Citizen Participation") OR SU.EXACT("Perceptions") OR SU.EXACT("Attitudes") OR SU.EXACT("Preferences") or SU.EXACT("Caregivers") or SU.EXACT("Advocacy")

SU.EXACT("Support Networks") OR SU.EXACT("Social Support")

TI,AB(lived n/2 experience) OR TI,AB("expert by experience")

TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*")

attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*)
OR expectation OR experience OR feedback OR learn OR perspective OR
preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR
Customer OR Individual OR Involv\* OR participation OR people OR user

#### **SETTING**

TI,AB("direct payment" OR "individual budget" OR "personal budget" OR "personal health budget" OR personalised OR personalised OR personalisation OR personalization OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision") OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))

SU.EXACT("Social Work") OR SU.EXACT("Adult Care Services") OR SU.EXACT("Community Services") OR SU.EXACT("Social Services")

### **POPULATION**

(TI,AB(adult) OR TI,AB(homeless) OR TI,AB("older people" OR "older person" OR "older adult") OR TI,AB("geriatric" OR "very old" OR elder OR frail OR disabilit\* or

disabled) OR SU.EXACT("Adults") OR SU.EXACT("Elderly") OR SU.EXACT("Middle Aged Adults") OR SU.EXACT("Young Adults") OR SU.EXACT("Homelessness") OR SU.EXACT("Minority Groups") OR SU.EXACT("Disadvantaged")

NOT (SU.EXACT("Children") OR TI,AB(child\* OR adolescen\* OR youth) OR SU.EXACT("Adolescents"))

### STUDY TYPE/METHODS

SU.EXACT("Literature Reviews") OR SU.EXACT("Qualitative Methods") OR SU.EXACT("Observation") OR SU.EXACT("Methodology (Data Collection)") OR SU.EXACT("Surveys") OR SU.EXACT("Interviews") OR SU.EXACT("Group Research") OR SU.EXACT("Cohort Analysis") OR SU.EXACT("Surveys") OR SU.EXACT("Questionnaires") OR SU.EXACT("Narratives") OR SU.EXACT("Observation")

#### **QUALIATITIVE STUDIES**

TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" or "behavioural research" or "conversation analysis" or "evidence synthesis" or "personal narratives" or "survey research") OR TI,AB(qualitative or interview or audit or feedback or "indepth" or story or stories or questionnaire or narrative or narration or survey or observation or case or cohort or study or studies) OR TI,AB((discourse or discurs\*) N/3 (analys\*)) OR TI,AB(ethno\* or emic or etic or phenomenolog\* or "grounded theory" or "constant compar\*"or "theoretical sampl\*" or "purposive sampl\*" or realist\* or thematic or empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")

### **MEASURES**

SU.EXACT("Program Evaluation") OR SU.EXACT("Evaluation") OR SU.EXACT("Evaluation Research") OR SU.EXACT("Needs Assessment") OR SU.EXACT("Treatment Outcomes") OR SU.EXACT("Activities of Daily Living") OR SU.EXACT("Quality of Life") OR SU.EXACT("Well Being")

TI,AB("process evaluation" or "outcome evaluation" or "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness or empower or monitored or

monitoring or improve or measure) OR TI,AB(ASCOT or instrument or independence or intervention or models or outcome or quality or wellbeing) OR TI,AB("co-design" or "co-production")

### **ECONOMIC STUIDES**

SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Economic Models") OR SU.EXACT("Econometric Analysis")

TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal or funding or financial or finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal or pool) N/3 (budget)) OR TI,AB(price or commission or pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" N/3 budget)

#### **SEARCH STATEMENTS**

((SU.EXACT("Client Satisfaction") OR SU.EXACT("Experience") OR SU.EXACT("Satisfaction") OR SU.EXACT("Participation") OR SU.EXACT("Citizen Participation") OR SU.EXACT("Perceptions") OR SU.EXACT("Attitudes") OR SU.EXACT("Preferences") OR SU.EXACT("Caregivers") OR SU.EXACT("Advocacy") SU.EXACT("Support Networks") OR SU.EXACT("Social Support")) OR (TI,AB(lived NEAR/2 experience) OR TI,AB("expert by experience")) OR (TI,AB(engag\*) OR TI,AB(advocacy) OR TI,AB("peer support") OR TI,AB("technol\*")) OR (attitude OR complaint OR (choice OR choos\* OR control) OR (satisf\* OR dissatisf\*) OR expectation OR experience OR feedback OR learn OR perspective OR preference OR view NEAR/3 Carer OR Client OR consult\* OR consumer OR Customer OR Individual OR Involv\* OR participation OR people OR user)) AND ((TI,AB("direct payment" OR "individual budget" OR "personal budget" OR "personal health budget" OR personalised OR personalized OR personalisation OR personalization OR "person-centred" OR "self-directed support") TI,AB(Care plan) OR TI,AB("social work" OR "social care" OR "social service" OR "social provision") OR TI,AB((community OR home OR residential OR day) NEAR/3 (care OR help OR provision OR provider OR service OR support))) OR (SU.EXACT("Social Work") OR SU.EXACT("Adult Care Services") OR SU.EXACT("Community Services") OR SU.EXACT("Social Services"))) AND ((SU.EXACT("Adults") OR SU.EXACT("Elderly") OR SU.EXACT("Middle Aged

Adults") OR SU.EXACT("Young Adults") OR SU.EXACT("Homelessness") OR SU.EXACT("Minority Groups") OR SU.EXACT("Disadvantaged")) NOT (SU.EXACT("Children") OR TI,AB(child\* OR adolescen\* OR youth) OR SU.EXACT("Adolescents"))) AND ((SU.EXACT("Literature Reviews") OR SU.EXACT("Qualitative Methods") OR SU.EXACT("Observation") OR SU.EXACT("Methodology (Data Collection)") OR SU.EXACT("Surveys") OR SU.EXACT("Interviews") OR SU.EXACT("Group Research") OR SU.EXACT("Cohort Analysis") OR SU.EXACT("Surveys") OR SU.EXACT("Questionnaires") OR SU.EXACT("Narratives") OR SU.EXACT("Observation")) OR (TI,AB(random\*) OR TI(trial) OR TI,AB("behavioural research" OR "behavioural research" OR "conversation analysis" OR "evidence synthesis" OR "personal narratives" OR "survey research") OR TI,AB(qualitative OR interview OR audit OR feedback OR "indepth" OR story OR stories OR questionnaire OR narrative OR narration OR survey OR observation OR case OR cohort OR study OR studies) OR TI,AB((discourse OR discurs\*) NEAR/3 (analys\*)) OR TI,AB(ethno\* OR emic OR etic OR phenomenolog\* OR "grounded theory" OR "constant compar\*" OR "theoretical sampl\*" OR "purposive sampl\*" OR realist\* OR thematic OR empirical) OR TI,AB(synthes\*) OR TI,AB("focus group")) OR (SU.EXACT("Program Evaluation") OR SU.EXACT("Evaluation") OR SU.EXACT("Evaluation Research") OR SU.EXACT("Needs Assessment") OR SU.EXACT("Treatment Outcomes") OR SU.EXACT("Activities of Daily Living") OR SU.EXACT("Quality of Life") OR SU.EXACT("Well Being")) OR (TI,AB("process evaluation" OR "outcome evaluation" OR "service evaluation") OR TI,AB("activities of daily living") OR TI,AB(effectiveness OR empower OR monitored OR monitoring OR improve OR measure) OR TI,AB(ASCOT OR instrument OR independence OR intervention OR models OR outcome OR quality OR wellbeing) OR TI,AB("co-design" OR "co-production")) OR (SU.EXACT("Costs") OR SU.EXACT("Budgets") OR SU.EXACT("Economic Models") OR SU.EXACT("Econometric Analysis")) OR (TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal OR funding OR financial OR finance) OR TI,AB(Socioeconomic) OR TI,AB((Personal OR pool) NEAR/3 (budget)) OR TI,AB(price OR commission OR pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" NEAR/3 budget)) OR (TI,AB(cost) OR TI,AB(economic) OR TI,AB(Fiscal OR funding OR financial OR finance) OR TI,AB(Socioeconomic) OR

TI,AB((Personal OR pool) NEAR/3 (budget)) OR TI,AB(price OR commission OR pricing) OR TI,AB("cash for care") OR TI,AB("Personal health" NEAR/3 budget)))

### 12. Social Care Online (update search only)

This database is part of the SPP database, however the SPP database is only updated quarterly so to make sure that the most recent published studies were included we additionally searched this database, which is updated daily.

Date searched: 01/02/2017

No. of records: 285

AllFields:'views' OR 'experience' OR 'perspective'

AND

SubjectTerms: "service users" OR SubjectTerms: "user views"

AND

PublicationYear:'2016 2017'

### 4. Scoping searches

Scoping searches were undertaken in July-August 2015 using the following websites and databases:

### **Databases**

Centre for Reviews and Dissemination databases (Dare, HTA, NHS EDD)

PubMed Health

SPP - Social Policy & Practice

**SWA- Social Work Abstracts** 

Systematic Review Journal

The Campbell Collaboration

The Cochrane Database

### Websites

BASW - British Association Social Workers

CQC - Care Quality Commission

EHRC – Equality and Human Rights Commission

**EPPI** Centre

HSCIC - Health and Social Care Information Centre

NHS England

NHS Confederation

PSSRU - Personal Social Services Research Unit

QORU - Quality and Outcomes of Person-centred Care Policy Research Unit

RIP & RIPfa - Research in Practice for adults and children

Browsing or simple search strategies were employed. The search results were used to provide information for scope development and project planning.

Guidance/policy	Research evidence
Department of Health (2014) Care Act. London: The Stationary Office	Beresford P, Shamash M, Forrest V et al. (2005) Developing social care: service users' vision for adult support: Shaping our Lives. London: SCIE
Department of Health (2012) The Health and Social Care Act (2012). London: The Stationary Office	Health & Social Care Information Centre (2014) Personal Social Services Adult Social Care Survey, England - 2013-14. London: HSCIC
King's Fund (2011) Experience- based co-design: working with patients to improve health care. London: King's Fund	Leadership Alliance for the Care of Dying People (2014) One Chance to Get it Right - Improving people's experience of care in the last few days and hours of life. London
Levin E (2004) Involving service users and carers in social work education. SCIE Guide 4. London: SCIE	Rahilly T, Hendry E (2014) Promoting the Wellbeing of Children in Care - Messages from Research. London: National Society for the Prevention of Cruelty to Children
National Institute for Health and Care Excellence (2012) CG138 Patient experience in adult NHS services. London: NICE.	Social Care Institute for Excellence (2005) SCIE Research briefing 11: The health and well-being of young carers. London: SCIE
National Institute for Health and Care Excellence (2011) CG136 Service user experience in adult mental health. London: NICE.	Social Care Institute for Excellence (2009) At a glance 19: Building user and carer involvement in social work education. London: SCIE
National Institute for Health and Care Excellence (2010) Looked-after children and young people. London: NICE.	Social Care Institute for Excellence (2012) People not processes: the future of personalisation and independent living. London: SCIE

# 5. Review questions and objectives

### 1. Views and experiences of services users

Component	Description
Review No & Question	1. Which aspects of the experience of using adult
Scope section:	social care services are positive or valued by people who use services?

### **Objectives**

To identify evidence from 2000 onwards about what people who use adult social care services value as positive aspects of their experience. This should also include what people think works well or contributes to a positive experience. We will use a grounded approach to build a thematic framework that may be used to inform the analysis in subsequent reviews. If possible, themes around negative experiences will also be identified.

# Criteria for considering studies for the review

**Population:** Adults aged 18 or over who use social care services

**Setting:** All UK settings where adult social care services are delivered.

**Intervention:** This is not an intervention review. It focuses on synthesizing evidence from a range of sources about service user views.

**Outcome:** For this question, there is likely to be a considerable amount of evidence from qualitative data, although some types of quantitative or mixed methods studies may also be included. Both service user and service level outcomes may be included as appropriate. Relevant outcomes could include views about:

- 1 Wellbeing and quality of life (related to health, mental health and social wellbeing).
- 2 Engagement with services and care, including understanding relevant care and management issues where appropriate.
- 3 Choice and control.
- 4 Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).

5 Perceived and objectively measured independence. 6 Ability to carry out activities of daily living with or without support. 7 Continuity of care. 8 Participation in social and community activities, including training and education, paid and unpaid employment. 9 Resource use. 10 Security and personal safety. Evidence type Research about the views and experiences of people who use services about the service they receive. This could be: qualitative, quantitative or mixed. Qualitative assessments Quantitative studies such as surveys where views are gathered. Mixed methods studies • Systematic reviews - if they address the same research question Changes made in the Study type restricted to studies that are rich in course of the review qualitative data, directly reported by people using services themselves in each of the main settings (residential care, own home, hospital and community). Used this framework to identify gaps in the evidence. Used the 'scoping framework' to identify themes. When a theme became saturated, we didn't include more of those studies. Additional search for directly reported views papers (silver standard), and video transcript that address these gaps for three groups: people with learning

disabilities, including autism; people with sensory impairments, people employing Personal Assistants.	
Consider people with particular needs and	
characteristics when reviewing additional evidence:	
<ul> <li>Studies of people with learning disabilities (LD), including autism</li> <li>Studies of people hard of hearing, with multiple sensory impairments</li> <li>Studies of Personal Assistants (PAs).</li> <li>LGBQT</li> <li>BME</li> </ul>	

# 2. Barriers to improving the experience of care

Component	Description
Review No & Question	2. For people who use adult social care
Scope section:	services, what are the barriers related to
	improving their experience of care?
Objectives	To identify barriers to improving the experience of
	adult social care services. The themes identified in
	Question 1 will be used to help focus this review.
	Factors that may limit or prevent people's positive
	experience of care might include barriers to people
	being engaged in their care planning and delivery;
	lack of information about what services users
	value or need; evidence about the characteristics
	of services where improvements in user
	experience are either not evaluated, or not
	improved following negative evaluation.
	improved following negative evaluation.

# Criteria for considering studies for the review

**Population:** Adults aged 18 or over who use social care services

**Setting:** All UK settings where adult social care services are delivered.

**Intervention**: This is not an intervention review. It seeks to synthesize evidence from a range of sources about the barriers and facilitators to improving the experience of adult social care services

Outcomes: For this question, there is likely to be a considerable amount of evidence from qualitative data, although some types of quantitative or mixed methods studies may also be included. Both service user and service level outcomes may be included as appropriate. Relevant outcomes could include measures or information relating to:

- 1 Wellbeing and quality of life (related to health, mental health and social wellbeing).
- 2 Engagement with services and care, including understanding relevant care and management issues where appropriate.
- 3 Choice and control.
- 4 Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
- 5 Perceived and objectively measured independence.
- 6 Ability to carry out activities of daily living with or without support.

	7 Continuity of care.
	8 Participation in social and community activities,
	including training and education, paid and unpaid
	employment.
	9 Resource use.
	10 Security and personal safety.
Evidence type	Intervention or evaluation studies where barriers
	or facilitators are assessed
	Qualitative assessments
	Quantitative studies such as surveys where
	views are gathered.
	Mixed methods studies
	Systematic reviews - if they address the same
	research question
Changes made in the	Included settings restricted to residential care, own
course of the review	home, hospital and community. Prioritised
	residential care studies because residential care
	considered an area where people's experience may
	be especially poor, and people may be more
	excluded from research.
	Study type restricted to those that are rich in
	qualitative data, directly reported by people using
	services themselves in each of the main settings
	(residential care, own home, hospital and
	community), except for residential care in which
	studies reporting views from people other service
	users were included.
	Used the 'scoping framework' to identify themes.
	When a theme became saturated, we didn't include
	more of those studies.

Addition	onal search for directly reported views papers
(silver	standard), and, video transcript that address
these	gaps, as a way of prioritising
Consid	der people with particular needs and
charac	eteristics when reviewing additional evidence:
0	Studies of people with learning disabilities (LD), including autism Studies of people hard of hearing, with multiple sensory impairments Studies of Personal Assistants (PAs). LGBQT
BME	

# 3. Facilitators to improving the experience of care

Component	Description
Review No & Question	3. For people who use adult social care services,
Scope section:	what would help improve their experience of
	care?
Objectives	To identify facilitators to improving the experience of
	adult social care services. The themes identified in
	Question 1 will be used to focus this review. Factors
	that help improve people's experience of care might
	include use of different kinds of information about
	service users' needs or views to inform
	development; engagement with formal groups or
	advocates, and so on. It is likely that there will be
	considerable overlap between the papers included in
	review 2 and 3, and some overlap between papers
	included in reviews 1 and 3.
Criteria for considering	Population: Adults aged 18 or over who use social
studies for the review	care services

**Setting:** All UK settings where adult social care services are delivered.

**Intervention:** This is not an intervention review. It seeks to synthesize evidence from a range of sources about the barriers and facilitators to improving the experience of adult social care services.

**Outcomes:** For this question, there is likely to be a considerable amount of evidence from qualitative data, although some types of quantitative or mixed methods studies may also be included. Both service user and service level outcomes may be included as appropriate. Relevant outcomes could include measures or information relating to:

- 1 Wellbeing and quality of life (related to health, mental health and social wellbeing).
- 2 Engagement with services and care, including understanding relevant care and management issues where appropriate.
- 3 Choice and control.
- 4 Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
- 5 Perceived and objectively measured independence.
- 6 Ability to carry out activities of daily living with or without support.
- 7 Continuity of care.

8 Participation in social and community activities, including training and education, paid and unpaid employment. 9 Resource use. 10 Security and personal safety. Evidence type Intervention or evaluation studies where barriers or facilitators are assessed Qualitative assessments Quantitative studies such as surveys where views are gathered. Mixed methods studies Systematic reviews - if they address the same research question Changes made in the Study type restricted to studies that are rich in course of the review qualitative data, directly reported by people using services themselves in each of the main settings (residential care, own home, hospital and community). Used this framework to identify gaps in the evidence. Used the 'scoping framework' to identify themes. When a theme became saturated, we didn't include more of those studies. Additional search for directly reported views papers (silver standard), and video transcript that address these gaps for three groups: people with learning disabilities, including autism; people with sensory impairments, people employing Personal Assistants. Consider people with particular needs and characteristics when reviewing additional evidence:

<ul> <li>Studies of people with learning disabilities</li> </ul>
(LD), including autism
<ul> <li>Studies of people hard of hearing, with</li> </ul>
multiple sensory impairments
<ul> <li>Studies of Personal Assistants (PAs).</li> </ul>
o LGBQT
o BME

# 4. Effectiveness and cost effectiveness of methods for evaluating experiences

Component	Description
Review No & Question	4. What methods and approaches for gathering,
Scope section:	monitoring and evaluating the experiences of
	people using adult social care services are
	effective and cost-effective?
Objectives	There is some evidence – much of it from research
	on community engagement - that engagement in
	service design and delivery can improve both
	service and individual outcomes. The objective of
	this review question is to identify evidence from
	2000 onwards about what works in terms of the
	different ways that services collate information about
	the views and experiences of people who use adult
	social care services; specifically, the question will
	focus on and how these activities impact on
	individual outcomes, including effectiveness and
	cost effectiveness.
Criteria for considering	Population: Adults aged 18 or over who use social
studies for the review	care services
	Setting: All UK settings where adult social care
	services are delivered.
	Intervention: This question focuses on different
	approaches to gathering, synthesizing and using the

views of adults who use services in service development and improvement.

Outcomes: For this question, there is likely to be a range of interventions such as different models of consultation or service management, support services, such as advocacy and peer support, devices and technologies. Studies with a comparative design, including before / after designs, controlled trials, randomised controlled trial, cost effectiveness studies and other evaluation designs where a comparison group is used will be included, where individual outcomes are reported. Relevant outcomes could include measures or information relating to:

- 1 Wellbeing and quality of life (related to health, mental health and social wellbeing).
- 2 Engagement with services and care, including understanding relevant care and management issues where appropriate.
- 3 Choice and control.
- 4 Satisfaction of people who use services (including carer, family and advocate perceptions of how satisfied the people who use services are).
- 5 Perceived and objectively measured independence.
- 6 Ability to carry out activities of daily living with or without support.
- 7 Continuity of care.

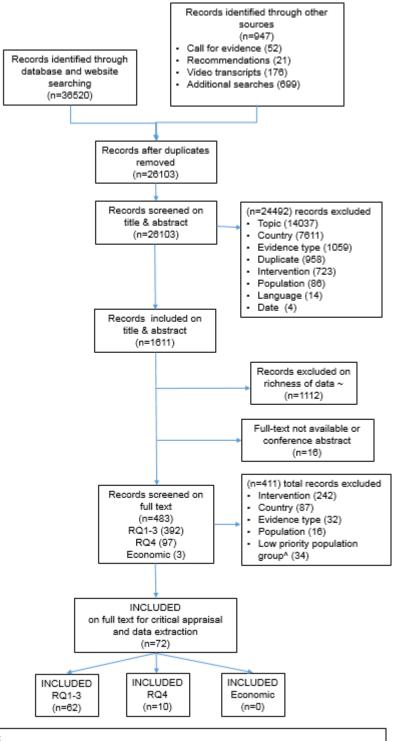
8 Participation in social and community activities, including training and education, paid and unpaid employment. 9 Resource use10 Security and personal safety. Evidence type • Before / after or other controlled design, which measure and report on relevant individual outcome measures. Controlled trials or RCTs Studies of cost effectiveness Evaluation studies where a control or comparison group is used Systematic reviews of effectiveness studies Changes made in the Using our original review protocol criteria we course of the review identified only two studies. We therefore explored options for identifying additional literature. We considered: amending our UK-only inclusion criteria to include studies with a control group from other countries; or, amending our criteria in relation to study design. On closer review, the latter option seemed more appropriate and useful for answering our question. It was suggested by the GC7 that we include studies evaluating the ASCOT toolkit as evidence for RQ4. We ran a specific search of studies of our EPPI database of studies (including the updated search studies) evaluating ASCOT. To be in scope and in keeping with processes developed for evidence presented to previous GC meetings, we set the

criteria that these studies not only had to be

evaluating the effectiveness of ASCOT but had to

ideally also include direct user views in the
evaluation.

### 6. Figure A1. Flowchart summarising excluded studies



#### Note:

- ~ studies were excluded on richness of data. See the review questions and objectives section of Appendix A for further information
- ^ update searches only

### 7. Lists of studies excluded at full text screening stage by exclusion criteria

### Research questions 1, 2 and 3

Study	Reason for exclusion
Abbott D, Jepson M and Hastie J (2016) Men living with long-term conditions: exploring gender and improving social care. Health & Social Care in the Community 24, 420-427	Low priority
Abma T, Bruijn A, Kardol T et al. (2012) Responsibilities in elderly care: Mr Powell's narrative of duty and relations. Bioethics 26, 22-31	Country
Agar-Jacomb K and Read J (2009) Mental health crisis services: what do service users need when in crisis? Journal of Mental Health 18, 99-110	Country
Ahlström G (2006) Personal assistance for patients living with a severe neurological disorder. Journal of Neuroscience Nursing 38, 183-193	Country
Alander H, Prescott T and James IA (2015) Older adults' views and experiences of doll therapy in residential care homes. Dementia: The International Journal of Social Research and Practice 14, 574-588	Intervention
Allcock N, Elkan R and McGarry J (2002) Management of pain in older people within the nursing home: a preliminary study. Health and Social Care in the Community 10, 464-471	Intervention
Altrum Risk Research Team (2011) Working Together in Adult Support and Protection: Views and tools of people who access support. Edinburgh: Thistle Foundation	Intervention
Aminzadeh F, Molnar F, Dalziel WB et al. (2013) An Exploration of Adjustment Needs and Efforts of Persons with Dementia After Relocation to a Residential Care Facility. Journal of Housing for the Elderly 27, 221-240	Country
Andersson I, Pettersson E and Sidenvall B (2007) Daily life after moving into a care homeExperiences from older people, relatives and contact persons. Journal of Clinical Nursing 16, 1712-1718	Country
Audit Commission et al. (2000) A report of the joint review of social services in Staffordshire County Council. London: Ofsted	Population
Awang D (2002) Older people and participation within Disabled Facilities Grant processes. The British Journal of Occupational Therapy 65, 261-268	Intervention
Ayalon L and Roziner I (2016) Satisfaction with the relationship from the perspectives of family caregivers, older adults and their home care workers. Aging & Mental Health 20, 56-64	Country

Barnes C, Mercer G, and Din I (2003) Research Review on User Involvement in Promoting Change and	Intervention
Enhancing the Quality of Social 'Care' Services for Disabled People: Literature review. Leeds: Centre for	
Disability Studies, University of Leeds	
Barnes C, Morgan H and Mercer G (2001) Creating Independent Futures: An Evaluation of Services Led by	Intervention
Disabled People. Stage Three Report. Leeds: The Disability Press	
Beresford P et al. (2016) From mental illness to a social model of madness and distress. London: Shaping Our	Intervention
Lives	
Blank A (2004) Clients' experience of partnership with occupational therapists in community mental health.	Intervention
British Journal of Occupational Therapy 67, 118-124	
Blood I, Copeman I and Pannell J (2016) Hearing the voices of older people in Wales: what helps and hinders	Intervention
us as we age? Research report. Cardiff: Social Services Improvement Agency	
Bock C, Demiris G, Choi Y et al. (2016) Engaging older adults in the visualization of sensor data facilitated by	Country
an open platform for connected devices. Technology and health care 24, 541-50	
Bollig G, Gjengedal E and Rosland JH (2016) They know!—Do they? A qualitative study of residents and	Intervention
relatives views on advance care planning, end-of-life care, and decision-making in nursing homes. Palliative	
medicine 30, 456-470	
Bone H (2009) Being Positive in Bradford: An Analysis of the Social Support Needs of people affected by HIV &	Intervention
AIDS in the Bradford District. Bradford: City of Bradford	
Bowles KH and Baugh AC (2007) Applying research evidence to optimize telehomecare. The Journal of	Intervention
cardiovascular nursing 22, 5-15	
Bradshaw SA, Playford ED and Riazi A (2012) Living well in care homes: a systematic review of qualitative	Country
studies. Age and ageing 41, 429-40	
Brookes N, Palmer S and Callaghan L (2016) "I live with other people and not alone": a survey of the views and	Low priority
experiences of older people using Shared Lives (adult placement). Working with Older People 20, 179-186	
Brown J and Addington-Hall J (2008) How people with motor neurone disease talk about living with their illness:	Intervention
A narrative study. Journal of Advanced Nursing 62, 200-208	
Brown K, Worrall L, Davidson B et al. (2010) Snapshots of success: an insider perspective on living	Intervention
successfully with aphasia. Aphasiology 24, 1267-1295	
Brown K, Worrall L, Davidson B et al. (2011) Living Successfully with Aphasia: Family Members Share Their	Intervention
Views. Topics in Stroke Rehabilitation 18, 536-548	
Burton AE, Gibson JM and Shaw RL (2016) How do older people with sight loss manage their general health?	Intervention
A qualitative study. Disability and Rehabilitation: An International, and Multidisciplinary Journal 38, 2277-2285	

Durton E. Louin C. and Boldy D. (2012) Parriara and Mativators to Boing Physically Active for Older Home Care	Country
Burton E, Lewin G and Boldy D (2013) Barriers and Motivators to Being Physically Active for Older Home Care Clients. Physical and Occupational Therapyin Geriatrics 31, 21-36	Country
Burton E, Lewin G and Boldy D (2015) Physical activity preferences of older home care clients. International	Intervention
Journal of Older People Nursing 10, 170-178	intervention
Byrne K, Sims-Gould J, Frazee K et al. (2011) "I'm Satisfied But": Clients' and Families' Contingent	Country
Responses About Home Care. Home Health Care Services Quarterly 30, 161-177	Country
Caldwell J and Heller T (2003) Management of respite and personal assistance services in a consumer-	Intervention
directed family support programme. Journal of Intellectual Disability Research 47, 352-366	intervention
Care and Social Services Inspectorate Wales (2016) 'Above and beyond': national review of domiciliary care in	Low priority
Wales. Merthyr Tydfil: Care and Social Services Inspectorate Wales	Low priority
Care Quality Commission (2016) 2016 community mental health survey: statistical release. London: CQC	Intervention
Care Quality Commission (2016) A different ending: addressing inequalities in end of life care: lesbian, gay,	Evidence type
bisexual or transgender people. London: CQC	
Care Quality Commission (2016) A different ending: addressing inequalities in end of life care: older people.	Evidence type
London: CQC	,,
Carlsson ME (2014) A separate structured conversation with relatives of patients enrolled for advanced	Population
palliative home care: A care development project. Palliative & Supportive Care 12, 107-115 9	
Christiansen A and Roberts K (2005) Integrating health and social care assessment and care management:	Evidence type
Findings from a pilot project evaluation. Primary Health Care Research and Development 6, 269-277	
Clare L, Rowlands J, Bruce E et al. (2008) The experience of living with dementia in residential care: an	Intervention
interpretative phenomenological analysis. The Gerontologist 48, 711-20	
Clark L (2006) A comparative study on the effects of community care charging policies for personal assistance	Evidence type
users. Dissertation. Leeds: University of Leeds.	
Commission For Social Care Inspection (2007) Hello, how can I help?: an analysis of mystery shoppers'	Intervention
experiences of local council social care information services. London: Commission for Social Care Inspection	
Commission For Social Care Inspection (2008) Raising voices: views on safeguarding adults. London:	Intervention
Commission for Social Care Inspection	
Commission For Social Care Inspection (2008) See me, not just the dementia: understanding people's	Intervention
experiences of living in a care home. London: Commission for Social Care Inspection	ļ
Cook EJ, Randhawa G, Sharp C et al. (2016) Exploring the factors that influence the decision to adopt and	Low priority
engage with an integrated assistive telehealth and telecare service in Cambridgeshire, UK: a nested qualitative	
study of patient 'users' and 'non-users'. BMC health services research 16, 137	

Cook GA (2008) Older people actively reconstruct their life in a care home. International Journal of Older	Intervention
People Nursing 3, 270-273	intervention
Cooper C, Selwood A and Livingston G (2008) The prevalence of elder abuse and neglect: a systematic	Country
review. Age and Ageing 37, 151-160	
Cornbleet MA, Campbell P, Murray S et al. (2002) Patient-held records in cancer and palliative care: a	Intervention
randomized, prospective trial. Palliative Medicine 16, 205-212	
Cornish N, Edgar K and Hewson A et al. (2016) Social care or systematic neglect? Older people on release	Low priority
from prison. London: Prison Reform Trust	
Courtney KL (2008) Privacy and senior willingness to adopt smart home information technology in residential	Country
care facilities. Methods of information in medicine 47, 76-81	
Craftman AG, Westerbotn M, von Strauss E et al. (2015) Older people's experience of utilisation and	Country
administration of medicines in a health and social care context. Scandinavian Journal of Caring Sciences 29,	
760-768	
Crane M, Joly L and Manthorpe J (2016) Rebuilding lives: formerly homeless people's experiences of	Low priority
independent living and their longer-term outcomes. London: King's College London. Social Care Workforce	
Research Unit	
Cunliffe AI, Dewey ME, Gladman JR et al. (2004) Sooner and healthier: a randomised controlled trial and	Intervention
interview study of an early discharge rehabilitation service for older people. Age and Ageing 33, 246-252	
Cutchin MP, Chang P and Owen SV (2005) Expanding Our Understanding of the Assisted Living Experience.	Country
Journal of Housing for the Elderly 19, 5-22	
Davies J and Burke C (2016) Workforce development for people with intellectual disabilities: the perspective	Intervention
from people with intellectual disabilities. London: Foundation for People with Learning Disabilities Health	
Education England	
Denson LA, Winefield HR and Beilby JJ (2013) Discharge-planning for long-term care needs: the values and	Country
priorities of older people, their younger relatives and health professionals. Scandinavian Journal of Caring	
Sciences 27, 3-12	
Department of Health (2014) NHS and social care: public perceptions 2013. London: DH.	Intervention
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Social Care Institute for Excellence (2011) Prevention: Reablement. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2011) The mental health and wellbeing of elders in black and minority ethnic communities: working together for mental wellbeing. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2012) Personal budgets: risk enablement and mental health. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2013) Commissioning for personalisation: London. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) Dementia: participation in development of dementia care. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) Dignity in care: choice and control. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) Early onset dementia: living at home with nursing support. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) End of life care: achieving dignity for those with dementia. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) Older people and quality of life: better life in residential care. SCIE TV Transcript. London: SCIE	Intervention
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Social Care Institute for Excellence (2014) Quality in social care: achieving excellence in care homes for older people. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) Quality in social care: achieving excellence in supported living services. SCIE TV Transcript. London: SCIE	Intervention
Social Care Institute for Excellence (2014) Quality in social care: what is excellence? SCIE TV Transcript.  London: SCIE	Intervention
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Specchio EC (2004) Making a life: grounded theory of living in a nursing home as a working-age adult.  Dissertation. UMI Dissertation Services, ProQuest	Evidence type
St Mungo's (2016) Stop the scandal: the case for action on mental health and rough sleeping. London: St. Mungo's	Intervention
Stainton T, Boyce S and Phillips CJ (2009) Independence pays: a cost and resource analysis of direct payments in two local authorities. Disability & Society 24, 161-172	Intervention
Stein J, Luppa M, König H et al. (2014) Assessing met and unmet needs in the oldest-old and psychometric properties of the German version of the Camberwell Assessment of Need for the Elderly (CANE)—A pilot study. International Psychogeriatrics 26, 285-295	Intervention
Stephens JM (2014) Differential Equity in Engagement with vs. Delivery of Oncological Psychosocial Support Services. Dissertation. UMI Dissertation Services, ProQuest	Intervention
Sterba KR, Zapka J, Gore EI et al. (2013) Exploring dimensions of coping in advanced colorectal cancer: implications for patient-centered care. Journal of Psychosocial Oncology 31, 517-39	Intervention
Stevens M (2006) Moral Positioning: Service User Experiences of Challenging Behaviour in Learning Disability Services. The British Journal of Social Work 36, 955-978	Intervention
Steventon A, Bardsley M and Billings J (2013) Effect of telecare on use of health and social care services. Age and Ageing 42, 501-508	Intervention
Stickley T (2012) Review of Creative approaches to health and social care education: Knowing me, understanding you? Social Work Education 31, 803-804	Evidence type
Storli SL and Hamran T (2014) Older individuals' experiences during the assistive technology device service delivery process. Scandinavian Journal of Occupational Therapy 21, 305-312	Country
Sublette VA, Smith SK, George J et al. (2015) The Hepatitis C treatment experience: Patients' perceptions of the facilitators of and barriers to uptake, adherence and completion. Psychology & Health 30, 987-1004	Intervention
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Sutcliffe C, Roe B and Jasper R et al. (2015) People with dementia and carers' experiences of dementia care and services: outcomes of a focus group study. Dementia: the International Journal of Social Research and Practice 14(6), 769-787	Intervention
Svanstrom R, Sundler AJ, Berglund M et al. (2013) Suffering caused by care-elderly patients' experiences in community care. International Journal of Qualitative Studies on Health and Well-Being 8, 1-10	Country

Sweeney A, Gillard S, Wykes T et al. (2015) The role of fear in mental health service users' experiences: a	Intervention
qualitative exploration. Social Psychiatry and Psychiatric Epidemiology 50, 1079-87	
Szanton SL, Thorpe RJ, Boyd C et al. (2011) Community aging in place, advancing better living for elders: A	Intervention
bio-behavioral-environmental intervention to improve function and health-related quality of life in disabled older	
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mental health needs, and carers, across the UK. London: Mental Health in Later Life Inquiry	 
Theurer K, Mortenson W, Stone R et al. (2015) The need for a social revolution in residential care. Journal of	Evidence type
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Think Local Act Personal (2010) Jennie's personal budget story. Video transcript. London: TLAP	Intervention
Think Local Act Personal (2010) Lewis' personal budget story. Video transcript. London: TLAP	Intervention
Think Local Act Personal (2012) Making it Real - Alan Chrone. Video transcript. London: TLAP	Intervention
Think Local Act Personal (2012) Making it real - full length film. Video transcript. London: TLAP	Low priority
Think Local Act Personal (2012) Making it Real – Sally Percival. Video transcript. London: TLAP	Intervention
Think Local Act Personal (2014) Making it real for everyone - a personalised response to Winterbourne View:	Intervention
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Tod A, Kennedy F, Stocks AJ et al. (2016) Good-quality social care for people with Parkinson's disease: a	Low priority
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Trappes-Lomax T, Ellis A, and Terry R et al. (2003) The user voice I, II and III: three qualitative studies of the	Evidence type
views of older people concerning rehabilitation services they received in hospital, in social services/NHS	1
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Traynor U (2010) 2GoDirect: The experience of two people using direct payments to employ a personal	Evidence type
assistant. Dublin: Centre for Independent Living	,
Tregea S and Brown K (2013) What makes a successful peer-led aphasia support group? Aphasiology 27,	Intervention
581-598	
Trivedi D, Goodman C, Gage H et al. (2013) The effectiveness of inter-professional working for older people	Intervention
living in the community: a systematic review. Health & Social Care in the Community 21, 113-128	
Tuckett A, Hodgkinson B, Rouillon L et al. (2015) What carers and family said about music therapy on	Intervention
behaviours of older people with dementia in residential aged care. International Journal of Older People	
Nursing 10, 146-157	
Tune P and Bowie P (2000) The quality of residential and nursing-home care for people with dementia. Age	Intervention
and Ageing 29, 325-328	
Turjamaa R, Hartikainen S, Kangasniemi M et al. (2014) Living longer at home: A qualitative study of older	Country
clients' and practical nurses' perceptions of home care. Journal of Clinical Nursing 23, 3206-3217	
Vaismoradi M, Wang I, Turunen H et al. (2016) Older people's experiences of care in nursing homes: a meta-	Country
synthesis. International Nursing Review 63, 111-121	
Van Berckelaer Anje, DiRocco D, Ferguson M et al. (2012) Building a patient-centered medical home: obtaining	Country
the patient's voice. Journal of the American Board of Family Medicine 25, 192-8	Country
van Haeften-van Dijk AM, van Weert JC, Dröes RM (2015) Implementing living room theatre activities for	Country
people with dementia on nursing home wards: a process evaluation study. Aging & Mental Health 19, 536-47	Journal
Vik K and Eide A (2012) The exhausting dilemmas faced by home-care service providers when enhancing	Country
participation among older adults receiving home care. Scandinavian Journal of Caring Sciences 26, 528-536	Country
participation among order addits receiving nome care. Scandinavian Journal of Caring Sciences 26, 326-336	

Vik K and Eide A (2013) Older adults who receive home-based services, on the verge of passivity: the	Country
perspective of service providers. International Journal of Older People Nursing 8, 123-130	
Visser S, McCabe M, Hudgson C et al. (2008) Managing behavioural symptoms of dementia: Effectiveness of	Intervention
staff education and peer support. Aging & Mental Health 12, 47-55	
Wada Y (2016) Older people's exercising of choice in long-term care: a comparative analysis of England and	Low priority
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Waggett N (2012) Ghosts in the care home: the nature of relationships in a home for people with learning	Population
disabilities. Journal of Social Work Practice 26, 443-457	
Wakelin K and Street AF (2015) An Online Expressive Writing Group for People Affected by Cancer: A Virtual	Country
Third Place. Australian Social Work 68, 198-211	
Nalseth LT, Abildsnes E and Schei E (2011) Patients' experiences with lifestyle counselling in general practice:	Intervention
a qualitative study. Scandinavian Journal of Primary Health Care 29, 99-103	
Walter ZC, Jetten J, Dingle GA et al. (2016) Two pathways through adversity: Predicting well-being and	Country
nousing outcomes among homeless service users. British Journal of Social Psychology 55, 357-374	
Warren S and Giles J (2013) An Ordinary Life The way forward. London: Paradigm	Intervention
Watts J and Priebe S (2002) A phenomenological account of users' experiences of assertive community	Intervention
treatment. Bioethics 16, 439-54	
Weinman WL, Buzi RS and Smith PB (2005) Addressing Risk Behaviors, Service Needs, and Mental Health	Intervention
ssues in Programs for Young Fathers. Families in Society 86, 261-266	
Wetle T, Teno J, Shield R et al. (2004) End of life in nursing homes: experiences and policy recommendations.	Country
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Wherton J, Sugarhood P, Procter R et al. (2015) Co-production in practice: how people with assisted living	Intervention
needs can help design and evolve technologies and services. Implementation Science 10, 75	
Whittaker E, George K, Hasson F et al. (2007) Palliative care in nursing homes: exploring care assistants'	Population
knowledge. International Journal of Older People Nursing 2, 36-44	
Vilcox E (2013) Biscuits and perseverance: Reflections on supporting a community intellectual disability team	Intervention
o reflect. Advances in Mental Health and Intellectual Disabilities 7, 211-219	
Williams L, Rycroft-Malone J, Burton CR et al. (2016) Improving skills and care standards in the support	Intervention
workforce for older people: a realist synthesis of workforce development interventions. BMJ Open 6, e011964	
Wilson CB (2008) Using relationships to develop practice that values the contribution of older people, families	Intervention
and staff. International Journal of Older People Nursing 3, 274-277	

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## Research question 4

Study	Reason for exclusion
Ahmad S (2009) Improving services and support for people with dementia: using a Web forum to capture the views of people with dementia and their carers to inform a national audit office report. Dementia 8, 140-141	Evidence type
Atherly A, Kane RL and Smith MA (2004) Older adults' satisfaction with integrated capitated health and long-term care. The Gerontologist 44, 348-57	Intervention
Ayalon L (2015) Reports of Elder Neglect by Older Adults, Their Family Caregivers, and Their Home Care Workers: A Test of Measurement Invariance. The journals of gerontology. Series B, and Psychological sciences and social sciences 70, 432-42	Country
Bardsley M, Billings J and Chassin LJ et al. (2011) Predicting social care costs: a feasibility study. London: Nuffield Trust	Intervention
Benbow SM and Kingston P (2016) 'Talking about my experiences at times disturbing yet positive': producing narratives with people living with dementia. Dementia: the International Journal of Social Research and Practice 15, 1034-1052	Low priority
Bossaert G, Kuppens S, Buntinx W et al. (2009) Usefulness of the Supports Intensity Scale (SIS) for persons with other than intellectual disabilities. Research in Developmental Disabilities 30, 1306-1316	Country
Chan H and Pang S (2011) Readiness of Chinese frail old age home residents towards end-of-life care decision making. Journal of Clinical Nursing 20, 1454-1461	Intervention
Chesterman J, Bauld L and Judge K (2001) Satisfaction with the Care-Managed Support of Older People: An Empirical Analysis. Health & Social Care in the Community 9, 31-42	Low priority
City Health Care Partnership (2011) Prisoner Health Passport. Hull: City Health Care Partnership	Intervention
City Health Care Partnership (2011) Prisoners Handbook: your guide to help during your time in Prison. Hull: City Healthcare Partnership	Intervention
City of Bradford Metropolitian District Council (2016) Getting an assessment from Adult services: information that you may find useful. Bradford Metropolitian District Council	Intervention
Cree VE, Jain S and Hillen P (2016) The Challenge of Measuring Effectiveness in Social Work: A Case Study of an Evaluation of a Drug and Alcohol Referral Service in Scotland. British Journal of Social Work 46, 277-293	Low priority
Donnelly SM, Carter-Anand J, Cahill S et al. (2013) Multiprofessional Views on Older Patients' Participation in Care Planning Meetings in a Hospital Context. Practice 25, 121-138	Intervention

Doughty K and Mulvihill P (2013) Digital reablement a personalised service to reduce admissions and	Intervention
readmissions to hospitals and nursing homes. Journal of Assistive Technologies 7, 228-234	
Duff P and Hurtley R (2012) Challenges facing domiciliary care agencies delivering person centred care.	Evidence type
Working with Older People 16(2), 61 - 68	
ECDP (2011) User Engagement Research – Final report for HealthWatch Essex. Chelmsford: ECD	Intervention
Edvardsson D and Innes A (2010) Measuring Person-centered Care: A Critical Comparative Review of	Intervention
Published Tools. The Gerontologist 50, 834-46	
Engström C (2009) Social workers' ability to assess how clients experience investigation sessions with and without the ASI. Journal of Social Work 9, 309-321	Intervention
Firbank OE (2012) Connecting the voices of users, caregivers and providers on service quality: a study of	Country
home-care services. International journal of health care quality assurance 25(5), 403-20	
Gambling T and Long A (2010) Tailoring advice and optimizing response: a case study of a telephone-based	Intervention
support for patients with type 2 diabetes. Family practice 27, 179-85	
Hadjistavropoulos HD, Sagan M, Bierlein C et al. (2003) Development of a case management quality	Country
questionnaire. Care management journals: Journal of case management, and The journal of long term home	
health care 4(1), 8-17	
Hall S, Opio D, Dodd RH et al. (2011) Assessing quality-of-life in older people in care homes. Age and Ageing	Intervention
40, 507-512	
Hockley J, Watson J, Oxenham D et al. (2010) The integrated implementation of two end-of-life care tools in	Evidence type
nursing care homes in the UK: an in-depth evaluation. Palliative Medicine 24, 828-838	
Hughes R, Saleem T and Addington-Hall J (2005) Towards a culturally acceptable end-of-life survey	Population
questionnaire: a Bengali translation of VOICES. International journal of palliative nursing 11, 116-23	
Kinley J, Froggatt K and Bennett MI (2013) The effect of policy on end-of-life care practice within nursing care	Intervention
homes: A systematic review. Palliative Medicine 27, 209-220	
Kulnik ST and Nikoletou D (2014) WHODAS 2.0 in community rehabilitation: A qualitative investigation into the	Intervention
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Multidisciplinary Journal 36, 146-154	
Lambert S, Thomas V and Gardner L (2007) 'Introducing yourself to strangers': Nurses' views on assessing	Low priority
older people with complex care needs. Journal of Research in Nursing 12, 349-361	
LaPlante MP (2010) The classic measure of disability in activities of daily living is biased by age but an	Country
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Social Sciences 65B, 720-732	

LeBlanc LA, Cherup SM, Feliciano L et al. (2006) Using choice-making opportunities to increase activity	Country
engagement in individuals with dementia. American journal of Alzheimer's disease and other dementias 21, 318-25	Country
Leng FY, Yeo D and George S et al. (2014) Comparison of iPad applications with traditional activities using person-centred care approach: Impact on well-being for persons with dementia. Dementia: the International Journal of Social Research and Practice 13(2), 265-273	Intervention
Lutz D, Fisher KR and Robinson S (2016) Sharing the focus: Engaging with support workers to include people with communication needs in research. British Journal of Learning Disabilities 44, 138-145	Low priority
MacPherson R, Gregory N, Slade M et al. (2007) Factors associated with changing patient needs in an assertive outreach team. The International Journal of Social Psychiatry 53, 389-96	Intervention
Makai P, Brouwer WB, Koopmanschap MA et al. (2014) Quality of life instruments for economic evaluations in health and social care for older people: A systematic review. Social Science & Medicine 102, 83-93	Intervention
Makai P, Perry M, Robben S et al. (2014) Evaluation of an eHealth Intervention in Chronic Care for Frail Older People: Why Adherence is the First Target. Journal of Medical Internet Research 16(6), e156	Country
Malley J and Netten A (2009) Measuring outcomes of social care. Research Policy and Planning 27(2), 85-96	Intervention
McKeown J, Clarke A, Ingleton C et al. (2010) The use of life story work with people with dementia to enhance person-centred care. International Journal of Older People Nursing 5, 148-158	Intervention
Miller JJ, Frost MH, Rummans TA et al. (2007) Role of a medical social worker in improving quality of life for patients with advanced cancer with a structured multidisciplinary intervention. Journal of Psychosocial Oncology 25, 105-19	Intervention
Milte CM, Walker R, Luszcz MA et al. (2014) How important is health status in defining quality of life for older people? An exploratory study of the views of older South Australians. Applied Health Economics and Health Policy 12, 73-84	Intervention
Mockford C, Murray M and Seers K et al. (2016) A SHARED study-the benefits and costs of setting up a health research study involving lay co-researchers and how we overcame the challenges. Research Involvement and Engagement 2(8)	Intervention
Mohr C, Tonge BJ, Taffe J et al. (2011) Inter-rater reliability of the Developmental Behaviour Checklist for Adults in community accommodation settings. Journal of Intellectual Disability Research 55, 710-713	Country
Money AG, Fernando S, Lines L et al. (2009) Developing and evaluating web-based assistive technologies for older adults. Gerontechnology 8, 165-177	Evidence type
Muntinga ME, Mokkink LB, Knol DL et al. (2014) Measurement properties of the Client-centered Care Questionnaire (CCCQ): Factor structure, reliability and validity of a questionnaire to assess self-reported client-	Country

centeredness of home care services in a population of frail, older people. Quality of Life Research 23, 2063-2072	
National Development Team For Inclusion (2013) The impact of advocacy for people who use social care	Intervention
services: a review of the evidence. London: NDTI	1.4
National Voices (2014) Supporting shared decision-making: A summary of the evidence. London: National Voices	Intervention
Netten A, Beadle-Brown J and Trukeschitz B (2010) Measuring the outcomes of care homes. Canterbury:	Intervention
PSSRU, University of Kent	intervention
Netten A, Burge P, Malley J et al. (2012) Outcomes of social care for adults: developing a preference-weighted	Intervention
measure. Health Technology Assessment 16, 1-166	
Netten A, Trukeschitz B, Beadle-Brown J et al. (2012) Quality of life outcomes for residents and quality ratings	Intervention
of care homes: is there a relationship? Age and Ageing 41, 512-7	
Norrie C, Manthorpe J, Cartwright C et al. (2016) The feasibility of introducing an adult safeguarding measure	Intervention
(survey) for inclusion in the adult social care outcomes framework (ASCOF): projecting costs. Journal of Adult	
Protection 18, 71-85	
Nota L, Soresi S and Perry J (2006) Quality of life in adults with an intellectual disability: The Evaluation of	Intervention
Quality of Life Instrument. Journal of Intellectual Disability Research 50, 371-385	
Oakes PM (2000) Quest: a system of evaluation for residential support services for people with learning	Intervention
disabilities. Journal of Learning Disabilities 4, 7-26	
Or CK, Karsh BT, Severtson D et al. (2011) Factors affecting home care patients' acceptance of a web-based	Intervention
interactive self-management technology. Journal of the American Medical Informatics Association 18, 51-9	
O'Reilly-de Brun M, de Brun T, Okonkwo E et al. (2016) Using Participatory Learning & Action research to	Intervention
access and engage with 'hard to reach' migrants in primary healthcare research. BMC health services research	
16, 25	
Phillips JL, West PA, Davidson PM et al. (2013) Does case conferencing for people with advanced dementia	Intervention
living in nursing homes improve care outcomes: Evidence from an integrative review? International Journal of	
Nursing Studies 50, 1122-1135	
Proctor EK (2008) Notation of Depression in Case Records of Older Adults in Community Long-Term Care.	Country
Social Work 53(3), 243-253	
Prusaczyk B, Cherney S, Carpenter C et al. (2017) Informed Consent to Research with Cognitively Impaired	Intervention
Adults: Transdisciplinary Challenges and Opportunities. Clinical Gerontologist 40, 63-73	

Qureshi H and Henwood M (2000) Older people's definitions of quality services. York: Joseph Rowntree	Intervention
Foundation Reid G, Kneafsey R and Long A (2007) Change and transformation: the impact of an action-research	Intervention
evaluation on the development of a new service. Learning in Health and Social Care 6, 61-71	intervention
Roberts G, Morley C, Walters W et al. (2015) Caring for people with dementia in residential aged care:	Intervention
Successes with a composite person-centered care model featuring Montessori-based activities. Geriatric	Intol vontion
Nursing 36, 106-110	
Robinson L, Dickinson C, Rousseau N et al. (2012) A systematic review of the effectiveness of advance care	Intervention
planning interventions for people with cognitive impairment and dementia. Age and Ageing 41, 263-9	
Roe B, Beech R, Harris M et al. (2011) Improving quality of life for older people in the community: Findings	Intervention
rom a local Partnerships for Older People Project innovation and evaluation. Primary Health Care Research	
and Development 12, 200-213	
Rosenberg D and Hillborg H (2016) Systematizing knowledge of user influence: a study of user advisory	Intervention
poards in substance abuse and mental health services. Social Policy and Administration 50, 336-352	
Ryan M, Netten A, Skatun D et al. Using Discrete Choice Experiments to Estimate a Preference-Based	Intervention
Measure of Outcome An Application to Social Care for Older People. Journal of Health Economics 25, 927-	
944	
Sackley CM, van den Berg M , Lett K et al. (2009) Effects of a physiotherapy and occupational therapy	Intervention
ntervention on mobility and activity in care home residents: a cluster randomised controlled trial. British	
Medical Journal 339, 670-673	
Sandhu S, Killaspy H, Krotofil J et al. (2016) Development and psychometric properties of the client's	Low priority
assessment of treatment scale for supported accommodation (CAT-SA). BMC psychiatry 16, 43	
Schubart JR, Levi BH, Camacho F et al. (2012) Reliability of an Interactive Computer Program for Advance	Intervention
Care Planning. Journal of Palliative Medicine 15, 637-642	
Schwartz C and Rabinovitz S (2003) Life satisfaction of people with intellectual disability living in community	Intervention
esidences: perceptions of the residents, their parents and staff members. Journal of Intellectual Disability	
Research 47, 75-84	
Sicotte C, Pare G, Morin S et al. (2011) Effects of home telemonitoring to support improved care for chronic	Intervention
obstructive pulmonary diseases. Telemedicine journal and e-health : the official journal of the American	
Telemedicine Association 17, 95-103	1.6
Simmons CD and Griswold LA (2010) Using the Evaluation of Social Interaction in a community-based program	Intervention
or persons with traumatic brain injury. Scandinavian Journal of Occupational Therapy 17, 49-56	

Smith N and Barnes M (2013) New jobs old roles working for prevention in a whole-system model of health	Intervention
and social care for older people. Health & Social Care in the Community 21(1), 79-87	
Speight J, Sinclair AJ, Browne JL et al. (2013) Assessing the impact of diabetes on the quality of life of older	Intervention
adults living in a care home: validation of the ADDQoL Senior. Diabetic Medicine 30, 74-80	
Steel E, Gelderblom GJ, de Witte LP (2011) Development of an AT selection tool using the ICF model.	Intervention
Technology & Disability 23, 1-6	
Stewart S, Harvey I, Poland F et al. (2005) Are occupational therapists more effective than social workers when	Intervention
assessing frail older people? Results of CAMELOT, a randomised controlled trial. Age and ageing 34, 41-6	
Tait L, Birchwood M, and Trower P (2002) A new scale (SES) to measure engagement with community mental	Intervention
health services. Journal of Mental Health 11, 191-198 8p	
Thompson S, Bott M, Boyle D et al. (2011) A measure of palliative care in nursing homes. Journal of Pain and	Intervention
Symptom Management 41, 57-67	
Trend P, Kaye J, Gage H et al. (2002) Short-term effectiveness of intensive multidisciplinary rehabilitation for	Intervention
people with Parkinson's disease and their carers. Clinical Rehabilitation 16, 717-25	
van der Roest H, Meiland F, Jonker C et al. (2010) User evaluation of the DEMentia-specific Digital Interactive	Population
Social Chart (DEM-DISC). A pilot study among informal carers on its impact, user friendliness and, usefulness.	
Aging and Mental Health 14(4), 461-470	
Vanderboom CE, Holland DE, Lohse CM et al. (2014) Enhancing patient-centered care: Pilot study results of a	Intervention
community care team intervention. Western Journal of Nursing Research 36, 47-65	
Vanderplasschen W, Wolf J, Rapp R et al. (2007) Effectiveness of different models of case management for	Intervention
substance-abusing populations. Journal of Psychoactive Drugs 39, 81-95	
Vickery L (2007) I'll do it my way. Housing Care and Support 10(1), 12-17	Intervention
Walton D, Fullerton M and Patel S (2011) Development of joint user/patient outcome measures for older adults	Intervention
with mental health problems. Quality in Ageing & Older Adults 12, 210-216	
Webb SA (2008) Modelling service user participation in social care. Journal of Social Work 8, 269-290	Intervention
Whitney J, Close J, Lord S et al. (2012) Identification of high risk fallers among older people living in residential	Intervention
care facilities: A simple screen based on easily collectable measures. Archives of Gerontology and Geriatrics	
55, 690-695	
Whitney J, Jackson S, Close J et al. (2013) Development and validation of a fall-related impulsive behaviour	Intervention

Wilhelmson K, Duner A, Eklund K et al. (2011) Design of a randomized controlled study of a multi-professional and multidimensional intervention targeting frail elderly people. BMC Geriatrics 11, 24	Intervention
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