Table DS1   Summary of studies providing 'thick' data descriptions

Study reference	Study Design, Method	Country	Site, Setting	*n*	Sample characteristics [mean (SD), range, % as reported]	Care planning context	Summary findings
21	Qualitative Interviews	UK	Multiple Voluntary sector	13 SUs 15 Cs	SMI/dual diagnosis SU: 29-56 yr, 92% M, 62% White C: 41-60 yr, 80% F, 87% White	UC	SUs identify lack of involvement in care planning decisions, recovery goals and care planning meetings, and inadequate staff feedback
22	Mixed methods Survey	UK	Multiple Community	37 SUs	NR	AD	Less than half had heard of the crisis card. Few carried it. Resource and staffing problems identified as potential barriers for effective use. Recognition that it had no legal weight. Quality of relationship with mental health professionals associated with likelihood to complete advance statement. Professionals differ in extent to which they are comfortable allowing SU control
23	Qualitative Focus groups	UK	Multiple Community	6 groups of 4-10 SU/C	NR	UC	Service users and carers expressed the need for more involvement in the planning and delivery of their individual care. Service users felt that the current systems of consultation or involvement were often tokenistic and carers frequently felt excluded. Both wanted their voices heard more powerfully and acted upon where possible, although they recognised that this would not always be possible
24	Qualitative Interviews	UK	Multiple Unclear	7 SUs	Psychotic disorders 18-65 yr, 29% F, 86% White	UC	Participants stressed a need for more individualised recovery-based care plans
25	Qualitative Cooperative inquiry	UK	Single, University	8 SUs 9 student nurses	SMI 28-74 yr	SDM	Barriers to involvement = stigmatising and paternalistic staff, approaches focussed too heavily on diagnosis. Facilitators: respectful, positive attitudes and recognising the expertise of SUs in their own illness. Nurses need to be more critical of medicalising experience and of getting the balance between autonomy and dependency wrong. User-identified facilitators: kindness, civility and respect, withholding premature judgement, communicating hope, maintaining interpersonal contact
32	Qualitative Interviews	UK	Multiple In-patient	151 SUs	SMI 37 (17-65) yr, 39% F, 63% White	UC	Recommended overcoming barriers to SU & C CPA engagement via facilitation of users' own assessment of needs and strengths and improved access to independent advocates
39	Mixed methods Interviews	UK	Multiple Mixed	500 SUs	CPA Top tier 45 yr, 51% F, 37% White	CPA	Consistently showed SU involvement is low at every level. The minority of SUs involved with care planning were happier overall.
40	Qualitative Interviews	USA	Multiple Community	16 SUs	Mixed MI 45 (8.2) yr, 44% F, 38% White	CM	No endorsement of paternalistic care. SUs endorsed shared decision making which promoted autonomy. Where this was not possible, SUs deferred to case manager's judgement. Mistrust due to lack of experience with case managers prohibited user discussion. Congruent decisions arose from trust and respect built up over time
41	Qualitative Interviews	AUS	Multiple Community	14 SUs	NR	UC	Respectful, encouraging approaches regarded as beneficial, as was adequate information provision and a willingness to consider alternatives to a traditional medical model. Barriers: lack of coordination between in-patient and community services, poor links with external agencies and lack of service

feedback. Nurses perceived to display negative attitudes towards SU involvement and lack belief in SUs decision-making capacity. Low acuity high prevalence disorders less likely to be given opportunities to communicate needs

42	Mixed methods Nominal group	USA	Single Community	56 Cs	NR	UC	Key themes: a need to be involved in treatment; concerns about the diagnostic process, poor professional communication; a need for individualised treatments, and adequate information provision for SUs and Cs. Feedback perceived as important. Concern that professionals do not see users as complex social beings. Professionals need to have patience and provide hope. Need for dialogue that can be understood
43	Qualitative Interviews	FIN	Multiple Mixed	22 SUs	Mixed MI 39 (20-60) yr, 73% F	UC	Ritualised care context limited knowledge sharing and stagnated caring process. Trust facilitated by regarding the SU as an expert in their own illness, engaging in open, joint discussions and equal distribution of power between SUs and nurses. Trust increased exponentially with autonomy
44	Qualitative Interviews	UK	Multiple Community	NR	NR	CM	There were marked difficulties in integrating the CPA with care management. Care planning was routinised with large numbers of users and standardised procedures. Commitment from staff and services identified as the key driver of change
45	Mixed methods Questionnaire	SWE	Single In-patient	71 SUs	51.3 (18-88) yr, 61% F	UC	Facilitators: staff–user agreement regarding treatment priorities; user-focused review meetings not medically dictated. Barriers: lack of dialogue/access to staff, excessive focus on medical treatments. When expectations were not fulfilled users lose motivation to be involved
50	Mixed methods Interviews, observation	USA	Multiple Community	64 staff	NR	CM	Intensive Broker model, with a focus on facilitating client involvement rather than enforcing compliance with a treatment plan, was deemed the most empowering model of case management. Fluid, exclusively field-based operations staff were best matched to client sociodemographics (ethnicity, age, interests); met with clients exclusively in the community
51	Qualitative Interviews	SWE	Single Mixed	20 SUs	Mixed MI 24-64 yr	UC	Cooperation in the planning of care relied upon adequate information provision, as well as staff respect for SUs right to self-determination. SUs perceive vulnerability when staff exercise power
54	Qualitative Observations, interviews, focus groups, archival research	USA	Multiple Unclear	33 SUs	25-60 yr, 48% F, 48% White	AD	Past experience generated scepticism and pessimism. Memories of traumatic experiences feared as possible triggers of a new episode. Concerns that ADs would not have legal backing or be overridden in practice. Practical difficulties in securing assistance to complete documentation, notifying key persons and setting up procedures for periodic review. Appointing a suitable agent proved the decisive issue, specifically their availability, ability to act and users' fears of rejection
56	Mixed methods Delphi	USA	Multiple Mixed	55 MHPs, SUs, Cs, academics	NR	AD	Differences in the views of consumers and non-consumers. Consumers prefer non-medical settings and assistance from persons outside the treatment team for AD completion. MH out-patient clinics the only setting with positive consensus. Consumer choice of location, with ease, privacy and time stressed as important. Information on AD process missing. Lack of focus on recovery. Negative professional attitudes to ADs generally and people with psychoses/bipolar disorders cited by consumers but not non-consumers
72	Mixed methods Postal survey	UK	Multiple Community	51 SUs	NR	CPA	SUs found CPA difficult to understand, were unaware of treatment programmes, and lacked knowledge regarding care. 16 SUs did not wish to attend the hospital for meetings as it was a reminder of past illness. Most cited feeling under pressure at meetings and insufficient contact with keyworkers. Users expressed

anxiety about being asked to sign documents and the hurried, retrospective manner in which this was done. Physical environment and high levels of unfamiliar staff in attendance negatively influenced meeting attendance. Meeting length, decision speed and lack of feedback difficult for some users

73	Qualitative Survey	UK	Multiple Community	NR	Mixed MI Age, gender NR African–Caribbean representation	CPA	Cs reported general lack of involvement, particularly at the illness start. Felt excluded from the CPA, particularly if from minority ethnic groups. Expressed desire for more information about CPA and care plan. Staff uninterested in Cs' expertise and disregard SU/C views. Meetings not user/carer-centred. Insufficient time available. *Ad hoc* involvement with no standardised procedures.
74	Qualitative Interviews	UK	Multiple Community	45 SUs 5 Managers	18-65 yr; 56% F	CPA	The majority of SUs did not know what CPA was. CPA was effective for those who were aware of its relevance and who received support from recognised keyworkers. Managers were aware care plans were not always in place or reviewed. Managers reported SUs were informed about care plans but not routinely involved unless requested. SUs felt keyworkers failed to listen. SUs needed more information on care plans and a clear method for contacting keyworkers
75	Qualitative Interviews, archival research	NOR	Multiple In-patient	20 SUs 20-25 providers	SMI 18-70 yr, 65% F	UC	SUs reported few opportunities to be involved in decision making, providers reported difficulties in engaging SUs in the care planning process. SUs not clear what involvement meant. Providers described a lack of understanding among SUs and therefore a lack of interest in participating in care planning. Providers found it difficult to motivate users to take ownership of their plan, and too time consuming to make written formulations in a way that SUs would understand. Providers accepted responsibility for involving users in meeting but did not provide real opportunities for them to be seen or heard. Potential facilitators = distance participation for users and clarification of provider responsibilities for updating care plans.
76	Qualitative Focus groups	USA	Multiple Community	38 SUs	20-60+ yr; 42% F	UC	SUs reported that 'real' shared decision making was rare, and expressed a desire to be more involved in decision making. Being believed, information exchange and treatment choice seen as important elements of collaboration
77	Qualitative Focus groups	UK	Multiple Acute in-patient	55 SUs	16-68 yr	UC	SUs main concerns: poor information provision and involvement in treatment planning. SUs felt they were not given enough information about other therapies that may be beneficial to relieving their distress
78	Qualitative Interviews, focus groups	UK	Multiple Unclear	22 Cs 12 SUs 22 Staff	Psychotic disorders C: 51.0 (9.3) yr; 73% F, 59% White SUs: 32 (7.7) yr, 50% F, 33% White	UC	Barriers to C involvement: negative staff attitudes, lack of care continuity, perceived confidentiality. Facilitators: respecting carer expertise, regarding them as part of the MDT. Professionals believed improved relationships and friendliness to Cs would increase involvement
79	Qualitative Focus groups	AUS	Multiple Mixed	31 Cs	Schizophrenia, depression 61% F	UC	Cs needed to be listened to and included in treatment processes from initial point of service contact. Some reported positive experiences, though many felt alienated from care planning. Confidentiality seen as a mechanism to exclude Cs. Respect viewed as fundamental to involvement. Cs concerned about frequency of staff turnover and rigidity of contact mechanisms. Stigma and blame held responsible for professionals' critical condescension
84	Qualitative Interviews	UK	Single Community	45 Cs	Schizophrenia Age, gender NR	CPA	Cs reported feeling more able to discuss issues at CPA meetings with someone independent of their relatives' care. CPA meetings viewed as an intimidating experience by many. Carers wanted to discuss care management and

							medication in the meetings
85	Qualitative Interviews	IRE	Multiple In-patient	8 MH nurses	NR		UC	Nurses described collaborative, negotiated practices where high levels of engagement were used to gain a shared understanding of the patient's problems. There were a number of contradictions to patient centred care reported, particularly around the use of coercion following self-harm
87	Qualitative Interviews	UK	Multiple Mixed	57 SUs	NR		CPA	Only 9% aware of CPA and none felt involved in CPA review. Only a minority recognised the terminology and practice when it was described. Just over one fifth did not know who to contact
88	Qualitative Interviews	UK	Single Community	9 SUs	NR		CPA	Lack of understanding of process and terminology. No opportunity for users to prepare. Logistical and geographical barriers to nominated staff attendance
91	Qualitative Focus groups	GER	Multiple Community	100 SUs	59.5 (13.6) yr, 60% F		UC	Facilitators: professionals to involve SUs in authoring medical reports; transparency and openness in relation to documentation; relationships based on equality between SUs and professionals. SUs acknowledge there are certain treatment stages when involvement is not possible
92	Qualitative Interviews	USA	Multiple Community	11 geriatric case managers	73% F		CM	'Engagement' or 'relationship building regarded as central to effective clinical case management. Capacity to be non-judgmental, genuine, accepting and empathic identified as central to successful engagement
93	Qualitative Interviews	AUS	Single Community	5 SUs	SMI 3-67 yr, 100% F		UC	A central theme of the relationship for patients was 'working in collaboration' which involved being supported, sharing power, having options, being respected, having an ally and having views respected
95	Qualitative Focus groups	AUS	Multiple Community	NR	NR		UC	A respectful attitude was cited by all participants as an integral part of developing a collaborative relationship. Nurses' heavy workloads and geographical distances are barriers to collaborative working. Carer involvement believed to require an assertive outreach approach. Nurses identified difficulties in balancing conflicting needs of users and carers. Encouragement for user involvement needs better embedding in practice
99	Mixed methods Surveys, focus groups	UK	Multiple Community	11 SUs 27 Staff	NR		Client-held records	SUs expressed concern about reading notes about themselves when ill. Open information produced concern about confidentiality issues. Staff identified benefits in terms of increased amount and accuracy of information provided, and more user centred records. SUs felt quality and quantity of care consultation remained unchanged
100	Qualitative Focus groups, archival research	USA	Single In-patient	72 SUs 114 staff	NR		UC	Staff from upper and middle management overestimated user involvement. Effective involvement relied upon the SU's mental state and ability to make decisions, as well as positive attitudes in staff regarding involvement. Organisations must give staff time to involve SUs and implement programmes committed to involvement. Users felt pressure to sign care plans. Staff cited users' lack of capacity, insight and motivation as barriers to participation
123	Qualitative Interviews	USA	Multiple Community	28 SUs	Psychotic disorder Median 42 yr; 57% F, 36% White		AD	Ads viewed as a tool for empowerment and self-determination. SUs described a lack of clinician awareness of ADs and difficulties communicating them to in-patient staff
128	Qualitative Observation, interviews	USA	Multiple Community	15 case managers	NR		ICM	Facilitators: fostering relationships between clients and care teams rather than individual case managers and seeking SU feedback. Barriers: poorly maintained professional barriers, conflict and challenging behaviours

SU: Service User; C: Carer; (S)MI: (Serious) Mental Illness; F: Female; NR: Not Reported; UC: Usual Care; AD: Advanced Directives; CPA: Care Programme Approach; SDM: Shared Decision Making; (I)CM: (Intensive) Case Management; AUS: Australia; GER: Germany; FIN: Finland; SWE: Sweden; NOR: Norway; IRE: Ireland

Table DS2   Summary of studies providing 'thinner' data descriptions

Study reference	Design Country	Site, service setting	N, sample	Sample characteristics	Study context	Summary of findings
2	National Consultation UK	Multiple in-patient	68 Acute service leads 551 Ward managers 554 SUs	NR NR SMI	UC	Inadequate or inconsistent practice in engaging service users in care planning processes. SUs not feeling consulted, listened to or sufficiently involved in decision-making. SUs not given a copy or asked to sign their care plans
3	National Consultation UK	Not reported	300 responses from NHS representatives, SU & C events	SMI	CPA	A lack of SU and C involvement in CPA process. Identified limitations in traditional communication processes and recommended new IT systems for managing clinical information. SUs to be given information in suitable formats; be involved in writing care plans and provided with a copy. More open and efficient sharing of care planning information between public, voluntary and other agencies identified
5	Survey UK	Multiple in-patient	>7500 SUs	SMI	UC	Substantial dissatisfaction with user involvement in treatment decisions
6	Survey UK	Multiple community	>14000 SUs	SMI	UC	24% SUs not involved in care planning decisions
26	Survey Germany	Multiple in-patient & out-patient	312 SUs	SMI Out-patients: 45.4 (11.9) yr, 48.0% F In-patients: 43.4 (16.9) yr, 49.5% F	UC	Worst performing domains for service responsiveness: choice and autonomy. Autonomy rated by SUs as the most important service responsiveness domain
27	Survey UK	Multiple community & in-patient	27 398 SUs	SMI 16-65+, 57% F, 93% White	UC	Many SUs wanted more involvement in care and treatment decisions, especially medication decisions, side effect information, diagnosis discussion, understanding and involvement in care reviews and understanding of rights under the MHA
28	Survey & Qualitative UK	Multiple community	NR	NR	UC	Only 40% nationally were 'definitely' involved in their care plan. 25% SUs reported no involvement at all. Needs not reviewed on a regular basis. SUs do not feel engaged in the CPA process or their own care

29	Survey USA	Multiple in-patient	107 SUs	Mixed MI 37.4 (11.1) yr s,39% F, 85% White	UC	Key areas of dissatisfaction: lack of SU and family input in treatment planning. 17% did not feel free to complain. Employment and male gender sig. predictors of satisfaction on the self-actualisation subscale of treatment planning
30	Survey Netherlands	Single community	702 Cs	SMI 55.9 yr (NR), 72% F	UC	36.8% relatives dissatisfied with level of treatment planning involvement. 22.1% dissatisfied with level of professional interest in the information family members could provide. More alterative care provision is required
31	Survey UK	Multiple community & in-patient	58 SUs	SMI 42.7 (NR) yr, 33.6% F, 38% White	CPA	Majority of SUs thought their strengths and abilities were not taken into account. Few were involved in drawing up their care plans and none considered they were involved in CPA reviews
32	Survey UK	Multiple community & in-patient	151 SUs	SMI 37 (17-65) yr, 39% F, 63% White	CPA	Only 14% recorded as signing their care plan and having a copy of it. 25% said they knew a lot about the CPA, 42% had heard of it. 25% involved in drawing up their CPA care plans at discharge. Half of those who did not have a copy of their care plan would have liked one
33	Survey UK	Multiple voluntary sector	357 SUs	Sz, SzA, DD Age NR, 35% F, 89% White	UC	One third did not feel involved in care planning. 71% perceived carers as having appropriate involvement. SUs rank choice as a top priority but report low levels of choice when planning care
34	National Consultation UK	Multiple in-patient & community	NR	NR	UC	Services should move towards an alliance and partnership with SUs in all aspects of service delivery
35	National Consultation UK	NR	NR	NR	UC	Care plans should be determined by the needs of the user. SUs should be involved in risk management plans, all persons involved in their care named on the plan and actions and goals agreed
36	Survey USA	Multiple Community	274 Cs	67% Sz, 67% F, 50% White	UC	36% Cs who had had professional agreed that professionals had consulted them about planned services and medication. Emphasised the need for fostering and maintaining stable relationships between Cs and professionals
37	Survey Canada	Multiple community	85 Cs	Sz 35 (NR) yr	UC	Cs wanted to be involved in treatment. Least satisfied with services help in providing productive activities. Participation helped Cs meet their own needs and was associated with greater service satisfaction. Cs attending educational/support groups rated higher involvement and improved relationships with staff

38	Correlational UK	Multiple community	64 Cs	SMI 48.2 (15.0) yr; 66% F	CPA	Cs more accurately assessed SU impairment than care coordinators. Cs universally lacked information about care plans. Once Cs were made aware of care plans they felt less negatively about them
46	Survey UK	Multiple community	221 SUs	SMI 45.2 yr, 52% F, 35% White	CPA	Patients unaware of how care is coordinated, and even less involved in it. Patients who are more involved in their care tend to be more satisfied. Strengths-focused assessment associated with sig. higher satisfaction in 4 out 5 sites
47	Audit UK	Single community & in-patient	41 SUs	SMI 26-73 yr, 73% White	Rehab./ continuing care	Client defined problems were rare. Problems focused on client weaknesses rather than strengths. Introduction of flexible review meetings led to a sig. increase in client-reported strengths & sig. decrease in use of generic targets. Lack of staff attention to client defined finance and leisure activities remained a concern
48	Survey UK	Multiple acute in-patient	215 SUs	SMI M :39 (NR) yr, F: 42 (NR) yr, 50% F, 85% White	UC	Few referrals for evidence based interventions other than traditional medical or nursing care. Care plan reviews rarely recorded. People generally offered similar services, facilities and environment regardless of circumstances. Crisis response not tailored to individual needs
49	Correlational Canada	Single in-patient	100 SUs	SMI 37.32 (11.40) yr, 45% F	UC at discharge	Greatest disagreement between social workers and SUs was for education/vocation/recreational services. Least disagreement for social support services. SUs less likely to agree with social workers assessments of the amount of social support required if they did not have family members involved in planning process
52	Mixed methods UK	Single community	10 MHNs, social workers, OTs	NR	MANSA assessment tool	The MANSA engaged practitioners in considering recovery-oriented practices from a SU perspective. Evidence of positive changes to care planning following implementation of the tool. Users feared opening discourse that could negatively affect health. Practitioners feared the tool reinforced the negative gulf between present and future. Exploration of social issues led to a crisis of confidence in not knowing how to take the information forward
53	Feasibility UK	Single community	42 SUs	SMI Age, gender NR	JCP	Study assessing feasibility of introducing 'crisis cards' to a CMHT. These state SUs treatment preferences in the event they lose capacity. Lack of insight/unwillingness to acknowledge future relapse were most common refusal reasons. Planning meetings found to be stressful. SUs with less frequent admissions were more likely to consent. Only a minority had concerns regarding

						confidentiality
55	Correlational Japan	Multiple community	295 SUs	Psychotic disorders 40.0 (11.3) yr, 36% F	CM	SUs demonstrating highest fidelity to the 'needs-oriented approach' scored highest on service satisfaction
57	CBA USA	Multiple community	231 SUs	Mixed MI I: 18-50+, 78% F, 35% White C: 18-50+, 83% F, 20% White	User-centred planning *v.* UC	African American patients had lower levels of activation at baseline compared with White patients. Self-reported patient activation in treatment discussions increased post intervention. No improvement was observed in user empowerment/confidence in own decisions
58	Case control China	Single community	62 SUs	Sz 21-65 yr, 71% F	CM	User-centred goal setting associated with higher user satisfaction
59	Case control USA	Single in-patient	109 SUs	SMI 37 (10) yr; 37% F	User-centred planning *v.* UC	User-centred planning associated with significantly greater perceived involvement in treatment decisions
60	Survey UK	Multiple in-patient & community	148 SUs	Psychotic disorders 45.8 (11.0) yr, 44% Female, 89% White	CUES-U assessment tool	CUES found to have value in aiding care planning at the individual level
61	RCT Australia	Single community	119 SUs	SMI 36 (9.8) yr; 57% F	Client-focused *v.* standard CM	No sig. differences between groups on quantitative measures of service satisfaction and care burden of care, but significant between-group differences on qualitative measures of service satisfaction
62	Survey & Qualitative UK	Multiple Community	23 SUs	35% F	CM	Most felt that they had some control over care decisions. Very few feel that the case manager is making decisions for them or controlling what they can do
63	UBA Canada	Single in-patient	46 SUs 17 staff	NR	Individualised care	Improvement in the clients' perception of care planning. SUs felt more involved in their care, listened to and respected by staff and were surprised when asked to do a plan together. Staff reported improved documentation and communication between team members and validation of time spent with SUs
64	Survey UK	Multiple in-patient & community	503 SUs	44.6 (18-78) yr, 43% F	CPA	56% knew what a care plan was, 43% had been involved in drawing it up, care plan was explained to 57%, 34% knew when care plan would be reviewed. Substantial differences between trusts in relation to how informed and consulted clients felt. The less clients knew about the care plan, the more dissatisfied they were. 28%

						could not rely on keyworker to turn up at arranged times, 30-40% could not talk to staff about personal problems. Information and keyworker relationship quality marginally better for older clients. Acute patients fared the worst for information provision and involvement
65	Survey Ireland	Multiple community & in-patient	129 SUs 86 Cs	NR	UC	Many SUs and CS satisfied with level of participation. Support provision and access to services viewed as most useful benefits of family participation. Distance considered an obstacle for family involvement. English as second language caused communication barriers. Lack of staff-family contact in hospital in-patients. Improvements in information sharing recommended
66	Survey Sweden	Single community	119 SUs	Mixed MI 40.3 (14.39) yr; 70% F	UC	Poor satisfaction with information provision and influence on treatment planning. Satisfaction increased if user had a designated keyworker
67	Survey UK	Multiple in-patient	112 Ward Managers 1625 Staff 1546 SUs	NR	UC	The most prominent theme suggested that many ward staff overlook the basic skills of talking, actively listening and information giving. During admission 83% of staff *v.* 60% of SUs reported that staff involved patients in decisions about their care. One-third of SUs felt unable to involve the people they rely on for support in their assessments
68	Survey UK	Multiple community	30 SUs 30 Cs	Mixed SMI <20>60yrs, 46% F	UC	Shortfalls revealed in information for carers, accessibility of care coordinators and carer involvement in decision-making
69	Survey Canada	Multiple in-patient	92 users	SMI; 42.7 (12.0) yr; 57% F; Ethnicity: NR	UC	Most patients preferred their relatives to be involved in treatment, and 35.6% were dissatisfied with the lack of notification of their relatives regarding changes to treatment. 20% preferred medication information not to be communicated to relatives. Relatives not always present at care planning meetings
70	National Consultation UK	Multiple setting unclear	NR	NR	UC	Cs report being excluded from providing/receiving care planning information. Felt that they were depended on by health services to provide care, without the information or support needed to do this
71	Survey USA	Multiple community	219 Cs	SMI <44–65+, 73% F, 90% White	UC	Very few Cs received information about a SUs treatment plan. Confidentiality cited as reason for poor information sharing. SUs toward family involvement significantly associated with whether or not they had been encouraged to involve family members by staff

80	Correlational Sweden	Multiple in-patient	50 SUs	Mixed MI 18->64, 46% F	UC	Poor satisfaction with information provision related to opportunity to read case notes, treatment alternatives and complaints procedure. SUs moderately satisfied with information regarding treatment planning. Satisfaction not related to user personality. Users with affective disorders more satisfied than those with Sz
81	National Consultation UK	Multiple community	NR	SMI	CPA	Many SUs unaware of their legal right. Need for improved information provision available in a variety of formats suitable for diverse requirements of SUs
82	Evaluation UK	Multiple community	52 SUs/SU reps 24 Cs/support workers	SMI 20-50+, 64% F, 8% White	CPA	SUs want CPNs to have understanding and knowledge to work in an empowering way, more systematic involvement in care planning and involvement of Cs. Multi-agency working and interagency communication seen as absent or poor, with too few staff to properly implement CPA. Review meetings unnerving. SUs want staff to be trained in involvement and information provision
83	Evaluation UK	Single community	71 SUs	SMI 34.6 (18-65) yr, 58% White	CPA	More than half were not involved in care planning, almost half were not aware who their key worker was. Staff identified a mean of 2.8 (1.6) needs/person, SUs identified a mean of 3.86 (2.1)
86	Survey & Qualitative UK	Multiple In-patient (mixed mental/physical health)	NR	NR	UC	Approximately three-quarters of staff thought that carers were either always or regularly involved in the discharge process. It was believed that carers should 'undoubtedly' be involved because they have the information needed for a safe and effective discharge
89	Survey UK	Single Community	123 SUs	NR	CM	63.4% SUs knew of their care plan, although 76% said they had discussed it with their key worker. Some did not understand purpose of review meeting and unlikely to have the confidence to clarify their understanding at the time. Concerns that for some, case management meant little and action was necessary to ensure the process became more meaningful. Raising staff awareness seen as a key factor in achieving this
90	Survey USA	Single community & in-patient	113 providers 106 SUs	44 (22-75) yr, 50% F, 62% White	UC	Providers attribute too much responsibility for lack of involvement to SUs, and underestimate extent to which SUs wish to be involved. Most common provider barriers: user disability, non-compliance and lack of interest. Lack of training not perceived as a barrier by professionals. SU barriers: lack of staff time, lack of relevant treatment goals and uncertainty regarding own ability
94	Qualitative	Multiple in-	10 psychiatric staff	65% F	UC	Respecting SU rights to participate in care identified as a core

	Sweden	patient & community	10 care associates			concept of psychiatric care quality
96	Audit UK	Multiple in-patient & community	27 team leader interviews	NR	UC	Facilitators to involvement: staff willingness to relinquish personal control, involvement of advocates and the use of informal, creative and flexible approaches
97	Survey UK	Multiple In-patient	310 ward manager 53 staff	SMI Age, gender NR	UC	60% ward managers had access to crisis plans developed in the community. 59% did not have access to advance directives drawn up by the service user. 99% stated that service users could invite an advocate, carer and/or family members to care planning discussions, and that they were made aware of this
98	Survey USA	Multiple, setting unclear	85 SUs 25 Cs 30 clinicians	SMI 53.4 (13.01) yr, 66% F, 0% White	AD	SUs significantly interested in ADs, particularly in terms of involving Cs or surrogate decision makers. Some concern that they would not influence treatment. Clinicians less likely than SUs/Cs to believe ADs would help. Documents seen as cumbersome. Users reluctant to sign legal documents. Almost half lacked someone to trust
101	Survey USA	Multiple community	1704 SUs	18-55+ yr, 74% F, 71-91% White	UC	60% SUs reported positive effects of showing respect. Staff required to spend time with users, listening carefully and explaining thing better
102	Qualitative USA	Multiple community	51 Sus	Sz 40.5 (26-59) yr, 24% F, 26% White	UC	One of the user priorities in the user-provider relationship was input into treatment. Conveying familiarity with users' care preferences contributed to being known. Experiences of making requests and having them honoured conveyed a sense of control
103	Survey Multinational	Multiple in-patient/community	1345 OTs	20-50+ yr	UC	SU involvement in care plans is the preferred option in OT practice but not always possible due to nature of mental illness. Lack of insight during some phases of delusional states cited as a factor making involvement difficult. 51% of respondents related their intention to involve patients in treatment planning
104	Survey Australia	Multiple in-patient	47 nurses, psychiatrists allied health staff	36.7 yr, 62% female; ethnicity NR	UC	Participants supportive of SU participation in general, but less so when it related to their own specific areas of responsibility. Professionals disagreed that users should have unrestricted access to their notes and make written contributions to their files. Believed users should have limited say about prescribed medications due to decisional complexity
105	Survey	Multiple in-	47 nurses, psychiatrists	36.7 yr, 62% female; ethnicity NR	UC	Clinical experience, and length of time worked on the unit influenced attitudes toward use involvement. Female and less

	Australia	patient	allied health staff			experienced staff more likely to support SU participation
106	Correlational Italy	Single community out-patient	84 SUs 17 psychiatrists	Mixed mild-mod MI SU: 43.6 (13.0) yr, 61% F Psychiatrists: 38.0 (9.7) yr	UC	Psychiatrists demonstrated poor skills in user involvement. Degree of involvement unrelated to patient or psychiatrist characteristics
107	Mixed methods UK	Multiple community	120 User ratings	NR	User-centred training *v.* standard training	Sig. higher proportion of service users cared for by programme educated nurses reported good user-centred assessment and care planning. Baseline knowledge of facilitating therapeutic cooperation was modest. Awareness of power differentials made students more conscious of sharing decision making and needs led approaches
108	Naturalistic inquiry Australia	Multiple community	6 SUs 4 OTs	Psychotic disorders SUs: 28-54 yr, 70% F, 100% White OTs: 100% female	Occupational Performance Interview Tool	Use of tool improved SUs sense of partnership with OTs and perceived level of treatment involvement
109	Correlational USA	Multiple community	55 SUs 43 case managers	Psychotic disorders SUs: 38.7 (10.4) yr, 45% F,86% White Case managers: 32.7 (10.17) yr, 47% F, 95% White	CM	When consumers focused on case managers, positive connection predicted higher treatment participation (B=0.270,*P*=0.039) . When case managers focused on consumers, positive connection (B=0.415, *P*=0.006) and higher autonomy (B=0.456, *P*=0.081) predicted greater participation. When case managers focused on themselves, only connection was significantly associated with treatment participation (B=0.521, *P*=0.009). A positive connection with a case manager was associated with higher satisfaction overall
110	Survey USA	Multiple community & in-patient	597 professionals	47.3 (11.6) yr, 57% F, 90% White	AD	Almost 50% health professionals felt ADs would be beneficial to SUs *v.* 38% social workers. Clinicians expressed more positive views when they were aware they were not bound by state law to comply. Psychiatrists more likely to endorse user choice where they perceived insight, therapeutic alliance, treatment adherence and family support for user preferences. Psychiatrists more likely than other groups to view family opinions as more important than patient autonomy
111	Survey UK	Single community	45 users	SMI Modal average 41-50 yr; 51% F	CPA/UC	Those on CPA more likely than those not on CPA to perceive choice in their care; to have been asked if they want a carer involved, and to feel that their carer's views had been listened to. Those on CPA satisfied with their care plans and felt they were being helped to become independent. Meetings in hospital with large numbers of staff seen as unhelpful. Most users tended to agree rather than

						disagree with family, carers and care teams
112	Survey Canada	NA	150 legal professionals 150 mental health professionals	NR	AD	Benefits of AD: documenting SU wishes, respecting autonomous choice and fostering collaboration. Disadvantages: unplanned for circumstances arising, require that users understand the concept, ethical concerns around treatment refusal
113	RCT Germany	Multiple in-patient	113 SUs	Sz I: 35.5 (11.9) yr, 41% F C: 39.6 (10.8) yr, 53% F	Decision aid *v.* UC	Printed decision aid associated with sig. greater illness knowledge & perceived involvement. Psychiatrists rated most SUs as interested and capable of understanding topics discussed, but believed only 51% capable of decisions. Those considered more capable indicated most interest in participating and had lower PANSS negative scores
114	Survey USA	Multiple in-patient & community	1118 SUs	Mixed MI 18-55+ yr, 88%F, 77% White	MCP	49% of managed care enrollees felt that they were involved as much as they wanted to be in treatment. White enrollees living in non-urban areas were more likely to feel satisfied with involvement
115	Case control USA	Single community	35 SUs 16 non-SUs	SMI SUs: 33.9 (8.9) yr; 45.7% F, 42.9% White; Non-SUS: 29.1 (8.1) yr, 75% F, 81.2 % White	Rehab/continuing care	SUs reporting of needs less reliable than controls. Levels of agreement significantly associated with presence of thought disturbance. Responses to unstructured needs assessment significantly less reliable than standardised assessments
116	Correlational Sweden	Multiple in-patient	455 Cs	Mixed MI 40 (18-69) yr; 58% F	UC	Spouses more likely to be sufficiently involved in treatment than other subgroups of relatives. More involvement for relatives of users with affective disorders than other diagnoses
117	Survey UK	Single community	86 SUs 73 Care coordinators	Mixed MI 44 (12.6) yr; 52% F	CUES-U problem identification tool	The use of the CUES-U as an adjunct to care planning led to a change in clinical care for 49% respondents. CUES-U considered a useful tool by 64% of care-coordinators. A longer duration of mental disorder made it sig. more likely that staff would discuss CUES with users, but sig. less likely this would make a difference to their care plan. Users' age did not influence degree of care plan change. Greater expressions of user dissatisfaction associated with staff being more likely to take action to address their concerns
118	RCT	Multiple community	65 SUs	SMI	JCP *v.* UC	Participants felt more in control of their illness when using a JCP, and empowered to seek their preferred choice of care. 66% case managers made no further use of it. Perceived improvement in

	UK		39 case managers	Age, gender: NR	staff-user relationship quality for minority of users
119	Feasibility USA	Multiple in-patient & community	20 SUs	SMI Age, gender: NR	JCP	The intervention was acceptable to users and providers and promoted shared decision making
120	RCT USA	Mixed in-patient & community	469 SUs	SMI 42 (10.7) yr, 60% F, 39% White	Facilitated *v.* non-facilitated AD	61% of the intervention group completed AD compared with 3% control group. The F-AD was positively associated with improved working alliance and a greater perception that services were meeting user needs
121	RCT USA	Multiple community	469 SUs	SMI 43 (10.7) yr, 60% F, 40% White	AD	Structured facilitation of ADs improved completion rates. Users with bipolar disorder less likely to report completion barriers than Sz
122	RCT USA	Multiple community	469 SUs	Psychotic disorders 42 (10.7) yr, 60% F, 39% White	Facilitated *v.* non-facilitated AD	Confidence to complete AD (understanding) was predicted by premorbid IQ, female gender, lower symptoms, higher abstract thinking and better memory. Users with psychoses performed lower than users with affective disorders. F-AD demonstrated greater improvement, particularly for users with pre morbid IQ <100
124	RCT UK	Multiple in-patient	161 SUs	SMI I: 35.5 (11.3) yr, 47% F C: 36.3(12.6) yr, 34% F 54% White	AD *v.* UC	Psychiatrists viewed ADs as another administrative burden. No significant differences in user satisfaction
125	Audit USA	Multiple community	106 SUs	SMI 41.9 (9.1) yr; 55% F, 76% White	AD	The average rate of care consistent with advance directives was 67%. Instructions regarding medication, pre emergency interventions, alternatives to hospital were complied with in nearly all cases. Less consistent were instructions around surrogate decision makers, choices of hospitals, & seclusion and restraint
126	RCT UK	Multiple in-patient	161 SUs 31 consultant psychiatrists	SMI 18-65 yr	AD *v.* UC	SUs capable of drawing up realistic, logical rational and consistent ADs and did not use them to refuse treatment. Most consultant psychiatrist did not regard them as useful in planning or managing care
127	Correlational Norway	Multiple community & in-patient	1080 SUs	Mixed MI 45 (17.1) yr, 56% F	UC	Overall SUs professionals and teams demonstrated high agreement on needs. Disagreements were predominantly a result of professionals identifying more needs than users. Health workers

						identified 72% of the needs identified by users. In cases where the patient disagreed with the health worker's assessment, clinical teams concurred with health workers and rejected SU perspectives. Where need was identified by a patient and not professionals, teams tended to agree with users
129	Mixed methods Australia	Multiple community	38 Sus	SMI M: 39 yr, F: 46 yr, 55% F	Patient-centred care	Collaborative care planning combined with a problems and goals focused approach, resulted in improved self-management and mental functioning at 3-6 months follow-up
130	UBA UK	Multiple in-patient	26 SUs 132 casenote audit	Mixed MI Age, gender NR	User-centred staff training	Statistically significant improvements in terms of assessment, care planning and provision of therapeutic care
131	Mixed methods UK	Multiple in-patient	70 Sus	SMI	CPA	57.1% CPA care plans demonstrated no involvement. Care coordinators allocated in less than half of patients, and often changed several times in the previous 12 months
132	Action Research UK	In-patient	Not reported	NR	CPA	Although only 2 profiles were made, when used in CPA meetings the multi-media intervention appeared to have a positive impact on SU's ability to communicate their needs to their clinical teams
133	RCT USA	Single community	51 Sus	Mixed MI Median 25 yr; 53% F, 41% White	CM	CM associated with sig. more SU contact, and more contact in SUs own environment than standard care. CM users more likely to be involved in vocational training

SU: Service User; C: Carer; CBA: Controlled Before/After study; UBA: Uncontrolled Before/After Study; (S)MI: (Serious) Mental Illness; F: Female; M: Male; NR: Not Reported; UC: Usual Care; AD: Advanced Directives; CPA: Care Programme Approach; JCP: Joint Crisis Plans; CM: Case Management