National survey and analysis of barriers to the utilisation of the 2005 Mental Capacity Act by people with bipolar disorder in England and Wales.

Abstract

Background: The Mental Capacity Act (2005) (MCA) provides a legal framework for advance planning for both health and welfare in England and Wales for people if they lose mental capacity e.g. through mania or severe depression.

Aims: To determine the proportion of people with bipolar disorder (BD) who utilise advance planning, their experience of using it and barriers to its implementation.

Methods: National survey of people with clinical diagnosis of BD of their knowledge, use and experience of the MCA. Thematically analysed qualitative interviews with maximum variance sample of people with BD.

Results: 544 respondents with BD participated in the survey; 18 in the qualitative study. 403 (74.1%) believed making plans about their personal welfare if they lost capacity to be very important. 199 (36.6%) participants knew about the MCA. 54 (10%), 62 (11%) and 21 (4%) participants made advanced decisions to refuse treatment, advance statements and lasting power of attorney respectively. Barriers included not understanding its different forms, unrealistic expectations and advance plans ignored by services.

Conclusion: In BD the demand for advance plans about welfare with loss of capacity was high but utilisation of the MCA was low with barriers at service user, clinician and organisation levels.

199 words

Key words: Advance directives; advance health care planning; bipolar disorder; health legislation.

Declaration of Interests.

The authors report no conflict of interests.

Introduction

Important processes in recovery from serious mental health problems are self-agency, personal empowerment and the maintenance of identity (Chiu et al, 2013; Leamy et al, 2011; NICE, 2011). Various jurisdictions in the world have wrestled with ways to support such recovery processes by maintaining some personal autonomy in decision-making when a person loses capacity to make such decisions (Bogdanoski, 2009; Davidson et al, 2016; Geller, 2000; Srebnik and La Fond, 1999). Psychiatric advance directives may be associated with short-term improvements in therapeutic alliance between clinical teams and people with serious mental illness (SMI) (van Dorn et al, 2010). Randomised controlled trials of psychiatric advance directives or joint crisis planning in SMI show conflicting evidence whether such approaches reduce compulsory admission (Henderson et al, 2004; Papageorgiou et al, 2002; Swanson et al, 2006a; Thornicroft et al, 2013).

The Mental Capacity Act 2005 (MCA) in England and Wales is an established enabling piece of legislation to provide a legal framework for personal welfare and financial decisions to be made on behalf of individuals, who due to an impairment or disturbance of functioning in the mind or brain, may be unable to make these decisions for themselves (Ministry of Justice, 2005). The right of an individual to make decisions themselves is enshrined in the Act and can only be overridden once a thorough capacity assessment has been completed. If capacity is lost, a decision can be made on behalf of the person based on what is in their best interests taking consideration of their wishes using three specific provisions of the MCA:

1. Advance Directive to Refuse Treatment (ADRT), a legally binding provision preventing specific treatment ;
2. Advance Statement of Wishes and Feelings (ASWF), a non-legally binding statement of preferences for treatment, and/or personal and financial affairs;

3. Lasting Power of Attorney, a legally binding direction identifying who will look after the person's personal and/or financial affairs (an Enduring Power of Attorney before 2007 remains valid).

The Mental Capacity Act (2005) has been studied in people with gradually progressive brain disorders that result in the loss of capacity such as dementia (Lewis 2006; Hope et al, 2009). Much less studied is the utilisation of the MCA in changeable mental health conditions where capacity can be lost and regained quickly e.g. in bipolar disorder (BD) due to mania or severe depression. Moreover in a condition such as BD, additional issues of concern include overspending during mania (Christopher et al, 2012) that the MCA might curtail through advance planning. Therefore we examined the attitudes, knowledge and experiences of people with BD in relation to the MCA five or more years after it was implemented.

Methods

Objectives and design

1. To determine whether people with bipolar disorder (BD) wish to use the MCA, know accurately about its provision, and to explore their experience of its use.
2. To determine the characteristics of people with BD who know of and have utilised it.
3. To identify barriers and drivers to its effective use.

An anonymised national survey was completed by people with BD using the internet or in written or telephone forms according to participant preference followed by face to face or telephone qualitative interviews with a maximum variance sample of people with BD to understand contextually their experience of utilising it. Before conducting the survey and qualitative study, and to improve the focus and wording of the questions in the survey and the topic guide, a pilot qualitative study was conducted with people with BD and staff actively involved with the implementation of the MCA. Finally we asked each of the participants to help design and then comment on a booklet the authors have produced to help people with BD to utilise the MCA (http://www.emahsn.org.uk/mental-health/bipolar-disorder).

Participants

Inclusion/exclusion criteria:

Survey:

a) Age over 18 years. No upper age limit;
b) Participants were required to confirm that they have received a diagnosis of bipolar disorder from a primary care or secondary mental health care clinician;
c) Given written or electronically endorsed consent to the survey.

Qualitative interview:

a) Give personal contact details to research team;
b) Met DSM-IV criteria for bipolar disorder (American Psychiatric Association, 1994) following a semi-structured diagnostic interview (First et al, 1997);
c) Gave further written informed consent to first qualitative interview and follow up interview to receive feedback on the booklet.

Procedure:

Survey:

We aimed to recruit a national sample of 500 participants in a 12 month period. No data were available for a formal power calculation. The study was advertised with the help of the National

Institute of Health Research funded Mental Health Research Network (MHRN), the Royal College of Psychiatrists and the charity Bipolar UK in each region.

Qualitative interview:

Participants were selected via purposive sampling on the basis of the following characteristics: geographical location to ensure that participants' experiences related to different services across England and Wales; ethnicity; range of experience of advance planning, those who had made some form of advance plan and those who had tried but had not succeeded. In the former, the overall objective was to examine in greater detail the issues faced by participants when trying to make their advance plan, including content and advice received. In the latter, reasons why participants had not made an advance plan were explored. Before the interview was conducted, the diagnosis of BD according to DSM-IV criteria (American Psychiatric Association, 1994) was confirmed by a structured psychiatric interview (SCID) (First et al, 1997).

All qualitative interviews were conducted by a single interviewer (MM), digitally recorded and transcribed verbatim. Questioning was structured by the interviewer to cover main topics according to a topic guide developed during the pilot phase that was co-produced with a panel of people with BD as well as the research team, but it was also responsive to issues emerging from participants' accounts. The interviewer used a combination of open questions to elicit free responses, and focused questions for probing and prompting. Emerging themes were explored throughout the data collection process and developed in further interviews. Interviews were conducted until themes were saturated.

As part of the interview process, each participant received a copy of a specific guide to the Mental Capacity Act for people with BD. A further digitally recorded and later transcribed telephone interview elicited feedback from each participant concerning the form and content of the booklet.

Revisions were made in light of feedback received e.g. paragraphs were shortened and the layout and images were changed but the wording and examples given were not changed.

Measures.

The Mood Disorder Questionnaire (MDQ) (Hirschfeld, 2000), a screening instrument for DSM-IV bipolar 1 disorder, bipolar 2 disorder and bipolar disorder not otherwise specified with good sensitivity and specificity in out-patient clinics. The original scoring method was used.

The main *survey* was split into seven sections which addressed the following topics:

Section A: Preliminary information; age, ethnicity, relationship status, education, employment, membership of service user support groups.

Section B: Advance decisions to refuse treatment (ADRT), detention under the Mental Health Act; reasons for not making an advance decisions to refuse treatment. Participants were first asked whether or not they had ever made an ADRT.

Section C: Lasting powers of attorney (LPOA) for personal welfare.

Section D: Advance statements of wishes and feelings (ASWF)

Section E: Financial planning

Each section consisted of a mixture of open and closed question. Participants were encouraged to answer every relevant question in the survey. For the online version, participants were automatically directed to the relevant question, whereas those who completed a hard copy version of the survey were directed to the relevant question via written prompts.

Analysis.

Descriptive statistics were employed in the survey. The responses of participants were split into those who had made at least one form of advance plan (ADRT, ASWF, LPOA and Enduring Power of

Attorney) and those who had not. Multivariate logistic regression was conducted to explore whether any demographic or service use factors were associated with binary dependent variables (prior knowledge of the MCA or not, or use of the MCA or Enduring Power of Attorney or not).

The qualitative analysis was led by MM. Thematic analysis was used, allowing the themes to emerge out of the data without any prior assumptions (Braun and Clarke, 2006). Themes, categories and memos were coded into N-Vivo, and then refined and elaborated in the light of incoming data and analysis. Findings and themes were discussed regularly by an interdisciplinary team comprising of researchers with different professional backgrounds (law, psychiatry, psychology), and presented to a panel of people with bipolar disorder, thereby increasing the trustworthiness of the analysis (Stiles, 1999).

Results

Survey

The survey was completed by 550 participants, one of whom was excluded because they had not been diagnosed with BD and five who were not normally resident in England or Wales. Therefore 544 participants were included in the analysis. On the MDQ, 538 (98.9%) symptomatically met the criteria for possible BD but the remaining six had received a diagnosis of BD from a specialist mental health or primary care clinician. In 513 (94.3%) participants, the mania symptoms reported in the MDQ had led to moderate or serious problems, 24 (4.4%) to minor problems, 6 (1.1%) to no problems with one (0.2%) missing answer.

Direct face-to-face contact with clinical studies officers working for the Mental Health Research Network (MHRN) resulted in the recruitment of 209 (38.4%) participants, 129 (23.7%) through psychiatrists, 114 (21.0%) by other means including Twitter or web sites (24, 4.4%), or through Pendulum Magazine (the magazine of Bipolar UK, a large national charity run for and by people with bipolar disorder) (30, 5.5%) or a variety of other informal sources e.g. friends, family, local radio. Participants were recruited between May 2011 and June 2012.

Table 1 about here

Table 1 shows that the demographic and service use characteristics of the sample contained participants of all ages with the majority 34 to 64 years old. Only 39 (7.2%) were of non-white origin and 319 (58.6%) had at least A level education. The vast majority were in current specialist mental health care but few had ever been detained under the 1983 Mental Health Act (MHA).

Table 2 about here

Table 2 shows that only 199 (36.6%) participants had heard of the MCA prior to the survey. However 403 (74.1%) believed making plans about their personal welfare if they lost capacity to be very important. Yet only 91 (16.6%) participants had formally used any of the three mechanisms of the MCA; 71 (12.9%) used more than one.

Advance Directives to Refuse Treatment (ADRT)

Only 54 (9.9% of total) participants made an ADRT but only 27 (5.0%) of these were written down, the rest being oral; 26 (48%) utilised the help of mental health professionals, one (2%) a lawyer. Fifteen (28%) participants kept a copy only to themselves. Twenty-four (44%) gave a copy to their psychiatrist, 24 (44%) to a family member, and 26 (48%) had a copy in their mental health service record. Sixteen (2.9%) had an ADRT in place when they were detained under the MHA but only two of the 16 (12.5%) participants stated that their ADRT was respected while they were formally detained. Only two participants (0.4%) reported that they were deterred from making an ADRT because it may be ignored if they were detained under the MHA. Only one (0.2%) participant reported being talked out of making an ADRT by a mental health professional.

Advance statements of wishes and feelings (ASWF).

Only 62 (11.4% of total) participants had made an ASWF: 38 (63%) stated who to notify in the event of serious illness; 17 (28%) whom not to contact in the same circumstances; 30 (50%) for particular medication; 32 (54%) against some form of medical treatment, 19 (32%) about accommodation; six (10%) about child care; four (7%) about other dependents; and 15 (25%) care of pets. Written ASWFs were always shared with others although only 13 (21.7%) were in their mental health service case records.

Lasting powers of attorney (LPOA) for property and affairs.

Only 21 (3.9% of total) of participants had made a LPOA under the MCA and a further 25 (4.6%) an enduring power of attorney prior before 2007. However, 165 (30.3%) participants stated that they had made an informal indication about what they wanted with regards to their property and finances should they lose mental capacity. Of these 165, 114 (69.1%) had discussed these issues with a family member; 40 (24.2%) with a friend; 18 (10.9%) with their psychiatrist; 13 (7.9%) with a lawyer; eight (4.8%) with a bank; eight (4.8%) with a GP; seven (2.4%) with a social worker; and seven (4.2%) with service user groups. Specifically, 69 (41.8%) participants had cut up their credit cards; 30 (18.1%) had set up spending limits on their bank account, and seven (4.2%) had appointed a co-signatory on their bank account.

Tables 3 and 4 about here

Demographic and service user variables associated with use of the MCA.

Using multivariate analysis, Table 3 shows that knowledge of the MCA before the survey was positively associated with having a degree, a counsellor, an occupational therapist and belonging to a NHS or non-NHS support group. Table 4 shows that the use of any provision of the MCA or Enduring Power of Attorney was positively associated with having a care co-ordinator or belonging to an NHS support group. Only age over 55 years was associated with Lasting Power of Attorney in multivariate analysis.

Qualitative analysis:

Eighteen participants (14 from the survey, 4 from the pilot study) provided interviews that were transcribed and analysed: 13 were women and 5 men; they were aged between 30 and 70 years; 15 were white British, two South Asian and one was Latin American; 14 were married, two single, one separated and one widowed. Eleven had used the MCA (nine ASWF, four ADRT and two LPOA) and seven had not (four had previous knowledge of the MCA and three had not). The qualitative data identified practical barriers which affected successful implementation of advance planning. Figure 1 reports barriers to participants who tried unsuccessfully to take part in advance planning and Figure 2 reports barriers to the successful use of advance planning in those who made ADRTs, ASWFs or LPOAs.

Figures 1 and 2 about here

Draft MCA booklet devised by study team.

Telephone interviewees (14 out of 18 participants) stated that the booklet was informative and provided useful information. Various suggestions were made to improve the layout of the booklet whose overall look was co-produced by panels of people with BD and members of the public recruited through the Collaboration for Leadership in Applied Healthcare and Research East Midlands and the Academic Health Science Network East Midlands. Since its release in November 2014, the booklet has been downloaded or printed over 70,000 times in the United Kingdom and internationally.

Discussion

Although three quarters of people with BD in this survey considered advanced planning for their personal welfare very important, uptake amongst people with BD was low with only 17% of respondents having made any provisions for their welfare in advance if they lost capacity through illness. Interviews that we conducted with psychiatrists in England and Wales confirmed this low uptake among people with BD (Bartlett et al, 2016). The main reason was that only 36% of participants had knowledge of their rights under the MCA before the current survey.

Completion of advance planning under the MCA was associated with having a care co-ordinator or a NHS service user support group. Information through the media or health services was superficial and did not directly to lead to advance plans. Education and activism on the part of the person with BD through attendance at service user support groups, family or social connections were required to gain an understanding of the MCA. There was some evidence that non-medical professionals helped publicise the MCA and enabled advanced planning to take place, and only one example of a mental health professional dissuading a participant from advance planning. Whether or not the MCA was completed, there were concerns about its availability in mental health service records when it would be required. ADRTs in particular were sometimes not shared with anyone else so they may not be accessible if the person lost capacity. The survey gave reassuring evidence that ADRTs and ASWFs were used sensibly with no-one refusing all treatment. Important welfare concerns were addressed about who was to be contacted or not contacted, and care of dependents and pets. There were some unrealistic expectations of the MCA around preventing the use of detention under the Mental Health Act and care of children which are covered by other legislation. Our data also shows that some participants did not see the need to make any provision under the MCA because they trusted family members or health professionals to protect their interests.

Strengths and limitations

We recruited a large national sample of participants who reported a diagnosis of BD with 90 per cent currently receiving specialist mental health services and 94 per cent reporting mania that had led to moderate or severe problems. Given that we advertised widely to both health professionals and people with BD, it is impossible to know that proportion of people with BD might have seen advertisements for the survey so we cannot report a response rate. Our sample included a high proportion with degree education and people in contact with service user support groups, both of which were associated with knowledge of the MCA. Other more disadvantaged or isolated people with BD may or may not be interested in knowing about or utilising the MCA.

The sample largely recruited people between the ages of 34 and 64 years and a relatively low proportion of people from black and minority ethnic (BME) groups. Therefore our results may not generalise to younger or older people with BD nor those from BME groups, where there might be additional barriers to utilisation of the MCA. Older people with BD may have a higher uptake of LPOAs since age over 55 years was associated with LPOA uptake.

The qualitative interviews provided additional information to the survey, particularly in relation to how people with BD had gained the knowledge and help to utilise the MCA. A maximum variance sample was successfully drawn from participants who took part in the study. Although we did not select on the basis of degree education, having a care co-ordinator or being in a support group, all of which were associated with knowledge and uptake of the MCA, some but not all qualitative interview participants displayed these characteristics. Saturation of themes was achieved but the findings of the qualitative analysis have the same demographic limitations as the survey.

Results in relation to other literature.

We confirm in people with BD that the majority of people with SMI, including some participants with BD, want to complete advance directives when they lose mental capacity (Srebnik et al, 2003; Swanson et al, 2003; Swanson et al, 2006b). We also confirm that lack of consumer knowledge, lack of consumer support, unrealistic consumer expectations, hostile or lack of clinician support, poor consumer and service organisation are barriers to the utilisation of advance directives, while active support from a health care professional facilitated their use (Elbogen et al, 2006; Peto et al, 2004; Swanson et al, 2003; Thornicroft et al, 2013; von Dorn et al, 2010; Wauchope et al, 2010). While our survey of the experiences of people with BD highlighted few examples of outright resistance to the MCA from health professionals, we found some evidence of opposition to the use of ADRTs in people with BD under any circumstances from a minority of psychiatrists (Bartlett et al, 2016). We were not allowed to record gender in the survey by a NHS ethics committee for data protection reasons and few participants had been previously detained under the MHA so the effects of gender and formal detention on the knowledge and use of the MCA in BD are unclear. The relationship between the use of the MCA and MHA in England and Wales is complex and controversial (see Griffiths 2014 for further discussion). Like previous studies in the United States we found that the MCA was not used to refuse all treatment (von Dorn et al, 2010). Therefore the barriers and facilitators of implementing the MCA in BD in England and Wales are similar to the implementation of other legislation on psychiatric advance directives in other countries.

In England and Wales, the House of Lords heard much evidence about the failure of implementation of the MCA and pointed to lack of knowledge amongst the public and GPs (House of Lords, 2014). However, we found little evidence that people with BD who routinely attend specialist mental health services are familiar with the MCA and how to get help to utilise it. Key recommendations made by the House of Lords were more training for health service professionals, and ensuring MCA utilisation was a subject of health service inspection (Department of Health, 2014). In a separate national survey of 650 psychiatrists conducted by us (Bartlett et al, 2016), training in the MCA was almost universal so training in the MCA needs to extend broadly to all health professionals and service user support organisations. However, a recent re-audit in one NHS Trust four years found only marginal improvements in the recording of the use of the MCA in patient records after changes to training of health professionals and documentation procedures (Dunlop and Sorinwade, 2014). Therefore the failure of implementation of the MCA may require more than further training of health professionals and health service inspection.

With respect to the specific problem of overspending, we found that people with BD often preferred to make informal arrangements than use the MCA. The MCA cannot be utilised until mental capacity has been lost by which time considerable debt may have been incurred. Early warning symptom interventions identifying clinical signs of impending mania relapse before overspending has occurred are probably a more effective way of preventing overspending when it is related to mania (Morriss et al, 2007; NICE, 2014; Perry et al, 1999).

Implications for practice and further research.

Overall, the data in this study provides evidence for the need for more direct ways of informing people with BD about the MCA routinely, clearly identified sources of assistance with completion, and improved procedures for documentation of ADRTs, ASWF and LPOAs in patient records if the MCA is to be utilised by all those who might wish to use it. The study team's booklet may supply the first of these three requirements if it was routinely distributed by health services. The vast majority of it applies to people with any health condition leading to either a temporary or permanent loss of capacity. If knowledge of the MCA increased e.g. through the use of our co-produced MCA booklet, people with BD without active support from their family or support groups may struggle to complete advance directives. For this reason we have recently engaged Recovery Colleges (peer run training courses supported and funded by publically funded mental health services) in England and Wales to run courses based on the booklet but also providing more active support in helping people with BD to draw up ADRTs, ASWFs and LPOAs (Perkins et al, 2012). Further research might consider the implementation of the MCA beyond the production of our booklet as well as broader benefits of the MCA on the recovery, function and quality of life of people with BD.

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3,980 words

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Table 1: Socio-demographic and service use characteristics of sample (n=544)

	Characteristic	**Number**	**%**
Age – years:	18-34	103	19.9
	35-44	124	22.8
	45-54	168	30.9
	55-64	107	19.7
	65+	38	7.0
	Missing	4	0.7
Ethnicity:	White British/Irish	490	90.0
	White other	12	2.2
	South Asian	12	2.2
	Black	12	2.2
	Mixed	14	2.6
	Chinese	1	0.2
	Missing	3	0.6
Married or co-habiting:		248	45.6
Children:		321	59.0
Highest level of education	No qualifications	63	11.6
	GCSE/NVQ	153	28.1
	A Level/Diploma	154	28.3
	Degree or higher	165	30.3
	Missing	9	1.7
Employment status	Employed/self-	216	39.7
	employed/student	218	40.1
	Sick/disability/retired	90	16.5
	Unemployed	20	3.6
	Missing		
Previous detention under Mental Health Act		16	2.9
Current care[1]	Psychiatrist	437	80.3
	Care co-ordinator	139	25.6
	Community psychiatric	167	30.7
	nurse	54	19.9
	Social worker	38	7.2
	Counsellor	44	8.1
	Psychologist/psychotherapist	34	6.3
	Occupational therapist	53	9.8
	None of the above		
Support groups	NHS support group	116	21.3
	Non-NHS support group	99	18.2

[1] Categories not mutually exclusive

Table 2: Knowledge and utilisation of the Mental Capacity Act (MCA) by service users with bipolar disorder

Knowledge and use of MCA	Number (n=544)	%
Knowledge of MCA	199	36.6
When capacity is lost: Plans about personal welfare are very important	403	74.1
Plans about personal welfare are somewhat important	61	11.2
Plans about personal welfare are unimportant	27	5.0
Made ADRT[1]:	54	9.9
Before 2007[2]	28	5.1
After 2007	32	5.9
In writing	27	5.0
ADRT against a brand of medication e.g. haloperidol	31	5.7
ADRT against a class of medication e.g. all antipsychotics	26	4.8
ADRT against electroconvulsive therapy	20	3.7
ADRT against depot antipsychotic medication	10	1.8
Not made ADRT:	440	80.8
Never heard of ADRT	321	59.9
Decided against making ADRT	119	21.9
Unnecessary, trusts health professionals	55	10.1
Unsure how to do it or too complicated	50	9.2
Against the idea	10	1.8
ASWF	62	11.4
Not made ASWF	482	88.6
Never heard of ASWF	387	71.1
Decided against making ASWF	95	17.5
LPOA, personal care	31	5.7
LPOA, property and affairs	21	3.9

ADRT = Advanced Decision to Refuse Treatment
ASWF = Advanced Statement of Wishes and Feelings
LPOA = Leading Power of Attorney

[1] Missing data = 50

[2] ADRT before 2007 recognised in the MCA as an ADRT after the Act's implementation but some completed both before and after 2007.

Table 3: Demographic and service user factors associated with knowledge of the Mental Capacity Act (MCA) by participants with bipolar disorder (n=540)

	Knowledge of MCA				Statistics
	Yes (n=196)		No (N=344)		
Demographic factor	**Number**	**%**	**Number**	**%**	**chi-square**
Children	105	53.5	215	62.5	$x^2 = 4.12, df = 1, p = 0.042$
Married	84	42.9	117	34.0	$x^2 = 4.18, df = 1, p = 0.041$
Degree education	82	41.8	82	23.8	$x^2 = 19.3, df = 1, p < 0.001$
Unemployed	22	11.2	68	19.8	$x^2 = 6.56, df = 1, p = 0.010$
Service use					
NHS service user group	52	26.5	63	18.3	$x^2 = 5.03, df = 1, p = 0.025$
Non-NHS service user group	53	27.0	46	13.3	$x^2 = 15.6, df = 1, p < 0.001$
Counsellor	21	10.7	18	5.2	$x^2 = 5.60, df = 1, p = 0.018$
Occupational therapist	18	9.2	16	4.7	$x^2 = 4.43, df = 1, p = 0.037$

Demographic or service user factor (n=540)	**Wald**	**df**	**Odds ratio**	**95% confidence intervals odds ratio**	**P binary logistic regression**
Degree education	14.48	1	2.15	1.45, 3.20	<0.001
Non-NHS service user group	13.40	1	2.37	1.49, 3.76	0.001
NHS service user group	5.28	1	1.68	1.08, 2.63	0.022
Counsellor	5.26	1	2.23	1.11, 4.47	0.023
Occupational therapist	3.96	1	2.12	1.01, 4.44	0.047

Missing data in four participants, df = degrees of freedom, p=probability of significant result

Table 4: Demographic, belief and service user factors associated with any advance panning under the Mental Capacity Act in people with bipolar disorder (n=531)

	Made any provision of MCA[1]				**Statistics**
	Yes (n=116)		**No (N=415)**		
Demographic factor:	**Number**	**%**	**Number**	**%**	**chi-square**
Age over 55 years	41	35.0	104	24.8	$x^2 = 4.78, df = 1, p = 0.029$
Service factor: Care co-ordinator	47	40.2	90	21.5	$x^2 = 16.7, df = 1, p < 0.001$
NHS service user group	45	38.5	72	17.2	$x^2 = 25.5, df = 1, p < 0.001$
Belief: Very important to have plans about welfare	76	65.0	324	77.5	$x^2 = 7.64, df = 1, p = 0.009$
Demographic or service user factor (n=540)	**Wald**	**df**	**Odds ratio**	**95% confidence intervals odds ratio**	**P binary logistic regression**
NHS service user group	21.15	1	3.04	1.89, 4.07	<0.001
Care coordinator	11.87	1	2.26	1.42, 3.60	0.001
Very important to have plan for welfare	7.22	1	0.53	0.33, 0.84	0.007

[1] Making of a provision includes 91 participants who made a provision under the Mental Capacity Act and 25 participants who made an Enduring Power of Attorney before the MCA.

Missing data in 13 participants, df = degrees of freedom, p=probability of significant result

Figure 1: Barriers to setting up advance planning when participants tried.

i. Failure of follow up to complete advance planning.

Some participants reported that the process of finding out about and/or creating an advance plan had been initiated by a healthcare team member within their Trust. However, there had ultimately been inadequate follow up so it was either not completed at all or without the participant in full possession of the relevant information.

"When I was part of a service user group, we used to have lots of meetings with advice and helpers. This guy… I don't even know who he was… came along and told us all about [advance planning]… I think I sat down and wrote what I wished. Nothing came of that. I haven't got a copy at home and I know nobody else has got a copy." (SU4)

ii. Failure to adequately store the advance plan.

Participants also voiced suspicions about whether their advance plan had been stored appropriately and whether it would be accessible when needed.

"I had a new care coordinator since… probably the end of last year… and we've gone through a new care plan, but it was very informal… sort of like my wishes were written down… I don't think anybody would even find them on the system to be perfectly honest with you!" (SU13)

Figure 2. Barriers to successful implementation of advance planning once it was set up.

i. Sources of information.

In keeping with awareness levels in general, information sources were also somewhat varied. The media were highlighted as one source of information on advance planning and the MCA in general; this included *"radio [and] newspaper articles"* as well as information about other conditions *"advertising literature put out by Age Concern… the Alzheimer's society website"*. However, media information was incomplete and further information was required to help the participant complete advance planning. Participants reported increased awareness through their family friends who worked in mental health services, self-help courses or as in this example their own activism:

> *"I pick up a lot of stuff from my service user activist stuff from Twitter, blogging and working closely with the big charities: Mind, Rethink and Sane." (SU 4)*

Healthcare services themselves did not feature as highly as might have been expected. This is highlighted in the following examples:

> *"My care coordinator's never mentioned it [advance planning] and neither has my psychiatrist…" (SU5)*

ii. Lack of awareness of different forms of advance planning.

Data revealed that participants were unaware of the distinction between advance decisions to refuse treatment and advance statements. For instance a participant states that they had not made an advance decision to refuse treatment, yet stresses their desire to avoid compulsory medical treatment:

> *"An Advance Statement yes, but not the one about treatment. I feel very strongly about that. I don't want to have treatment forced upon me when it's not going to be my wishes."* (SU3)

iii. Lack of realism about the scope of the Mental Capacity Act.

Data from participants who had made some form of advance plan suggested that there was lack of awareness about how realistic some of the expressed wishes were. The following examples refer to wishes that go beyond the remit of the MCA and thus may not realistically be enforced in practice:

> *"I wish to have my property secured against further intrusion… police, ambulance.. which is what I have experienced in the past. I don't want that kind of thing repeated. Whether that kind of thing is legally binding I don't know… there was no guidance."* (SU2)

iv. Advance planning ignored by NHS services.

A couple of participants recalled episodes of care when their advance statements were ignored. For instance:

> *"I was a voluntary patient… I've always been able to give voluntary permission. So I admitted myself and on the ward I showed them my bracelet, asked them to get my advance directive from Medicalert and they didn't do it! I mean, they carried on with their assessment and things and gave me an antipsychotic… for the next couple of days I was still very high on the ward and still hadn't got my directive. I went to the nurse and said that they had to get it. So he found a fax machine and had it sent through. We had an argument about it actually. He said that he had hearing problems and didn't like the fax machine being on…"* (SU14)