

RESEARCH ARTICLE

REVISED **“Why have I not been told about this?”: a survey of experiences of and attitudes to advance decision-making amongst people with bipolar [version 2; peer review: 3 approved]**

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Abstract

Background: The idea that people with severe mental illness should be able to plan in advance for periods of illness as a means of enhancing autonomy has been long debated and is increasingly being enshrined in codes of practice and mental health legislation. It has been argued that the ethical imperative for this is especially pronounced in bipolar (BP), a condition in which sufferers often experience episodic crises interspersed with periods of wellness. However, there is a paucity of published research investigating experiences of advance decision making (ADM) in people with BP or their attitudes towards it.

Methods: An online survey of BPUK's mailing list was conducted. 932 people with BP completed the survey (response rate 5.61%). Descriptive statistics and regression analysis were conducted to compare experience of with attitudes towards ADM and variables associated with interest in ADM.

Results: A majority indicated a desire to plan care in advance of losing capacity (88%) but most had not done so (64%). High numbers of respondents expressed a wish to request as well as refuse treatment and most wanted to collaborate with psychiatrists, including on issues around self-binding. The most frequent motivation to utilise ADM was a desire to be more involved in mental health decisions. Interest in self-binding was associated with experience of compulsory treatment and trust in mental health services. Interest in refusals of all medication was associated with younger age and lack of trust in mental health services. Interest in ADM in general was associated with younger age but not educational level, ethnicity or gender.

Conclusions: This study demonstrates an appetite for ADM amongst people with bipolar that is independent of educational status and ethnicity. As states reform their mental health laws, attention needs to be given to the distinctive attitudes toward ADM amongst people with bipolar.

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Any reports and responses or comments on the article can be found at the end of the article.

Keywords

Bipolar, survey, advance decision making, mental capacity, human rights

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REVISED Amendments from Version 1

Following the comments we have received, we have made the following main changes to our manuscript:

1. We have provided a more detailed and thorough description of the limitations of our study. This includes the limitations of our sample and therefore generalisability of our findings, the survey methodology and the potential for misunderstanding among our respondents, and the scope of our survey which focused on medical decision making. We have also suggested alternative methodologies that would address these limitations.
2. We have provided more explicit definitions for some of the terms used in the questionnaire itself. This includes a definition for informal ADM and how the idea of self-binding and SBDs have been handled in the questionnaire.
3. Our survey had an implicit focus on medical ADM. We have made this explicit in the introduction and the aims.

See referee reports

Abbreviations

BP – Bipolar

ADM – Advance decision making

AD – Advance decision

MCA – Mental Capacity Act 2005

ADRT – Advance decision to refuse treatment

LPA – Lasting power of attorney

MHA – Mental Health Act 1983

SBD – Self-binding directive

BPUK – Bipolar UK

Introduction

Bipolar (BP) is a common and severe mental illness¹. It has a worldwide prevalence of approximately 1% and is associated with 10–20 years shorter life expectancy^{2,3}. Given its preponderance to present in adolescence and early adulthood and persist throughout a person's life course, it carries a substantial future burden of disease^{4,5}.

A defining feature of BP is its fluctuating course, characterised by marked and prolonged changes in mood and energy levels interspersed between periods of wellness¹. These episodic “crises”, which are described as either manic, depressive or mixed depending on the predominant polarity of affect, occur relatively frequently. Angst *et al.* reported a median of 1 episode every 2.5 and 3 years for BP I and II patients respectively⁶. Episodes can bring an array of destructive sequelae. During a manic phase this may include substance misuse, overspending, self-harm and psychotic features⁶. In order to prevent harm from such episodes, inpatient psychiatric admission and medication may be indicated. However, episodes often lead to the loss of capacity to make such treatment decisions (hereby referred to as capacity) and individuals may uncharacteristically refuse treatment and disengage with services when unwell⁷.

Decision-making capacity and advance decision-making

Capacity for treatment is a central (although not universal) concept in current, international, medico-legal thinking which has applications across medical, psychiatric and social care settings. Based upon the principle of self-determination, it demands that a person's decision is respected so long as it is made with capacity. If the individual has been judged to lack capacity, various mechanisms have been proposed to either make a decision that most closely represents the individual's wishes or to act in the person's best interests^{8,9}.

For scenarios where an individual can anticipate that capacity will be lost and they have particular views on treatment or other issues, advance decision-making (ADM) can be employed. ADM is a broad term that encompasses both legally binding decisions as well as non-legally binding plans and may include information about specific decisions, more generic information that can inform best interest decisions or the designation of a substitute decision maker. ADM may be communicated verbally or in writing, resulting in a document that is sometimes referred to as an advance directive or advance care plan. ADM may be undertaken by the individual alone or in collaboration with family, friends and/or professionals¹⁰. It can also contain information about various aspects of an individual's life such as medical treatment, financial affairs or arrangements for work. This study focuses primarily on medical treatment.

Legal provision for advance decision making in England and Wales

In England and Wales, the Mental Capacity Act 2005 (MCA) details criteria for determining whether a person has capacity to decide upon a matter, and the process to follow when this is judged to be lacking. This is applicable to any situation in which consent is required from an individual. Lack of capacity refers to decision making inabilities due to any condition which may affect the working of the mind or brain, meaning it is not specific to severe mental illness. In situations where capacity is lost, the MCA has provisions for ADM in the form of an advance decision to refuse treatment (ADRT), an advance statement of wishes and preferences or the appointment of a lasting power of attorney (LPA)¹¹.

There is a second piece of legislation in England and Wales, the Mental Health Act 1983 (MHA), that enables compulsory treatment for mental disorder. This is of particular relevance to people with mental illness such as BP, as they are far more likely to be treated under the MHA than the MCA (although if they were to be treated for a physical health condition, the MCA would still apply). The MHA does not use a capacity-based system to determine the need for compulsory treatment, rather focusing on the degree of risk of harm to the individual or others. Furthermore, in terms of inpatient treatment, it does not currently have any statutory provisions for ADM beyond the refusal of non-urgent electroconvulsive therapy.

The disparity between provisions for ADM under the MCA and the MHA and, by association, people with and without mental illness, is two-fold. Firstly, as described above, the MCA has various mechanisms for ADM inbuilt while the options are far

more limited under the MHA. Secondly, if an individual with a mental illness attempts to make a legally-binding advance plan using the MCA (e.g. ADRT), the MHA can be used to overrule it. In the MHA Code of Practice health professionals are advised to take the wishes of the person being detained into account. However, there is no provision for this within the MHA itself. To some people with mental illness and professionals this is disempowering and discriminatory.

Autonomy (Self-determination) and ADM

People living with BP (and other mental illnesses) may experience the loss of a sense of autonomy, or the ability to act autonomously at multiple levels. Firstly, they may, in retrospect experience periods of illness as inauthentic i.e. not arising from their true sense of self. Secondly, during periods of illness an individual may experience a loss of self-control, engaging in behaviours they would never consider when well. Thirdly, treatment may involve coercive measures. There is pressure from the international human rights community to ensure that those with disabilities have access to social and legal resources which support autonomy, equal to those without disabilities. The United Nations Convention of the Rights of Persons with Disabilities asserts that those with disabilities (including mental disabilities) should be able to exercise control, equal to that of people without disabilities, over all areas of their lives including the management of the disability itself¹². ADM is seen as one tool by which this aspiration could be achieved. Within a European context, the Council of Europe (2009) recommends that ‘States should promote self-determination for capable adults in the event of their future incapacity, by means of continuing powers of attorney and advance directives to promote self-determination where future incapacity is anticipated’¹³. It is of note that the United Nations Committee on the Rights of Persons with Disabilities does not approve a model which relies on an assessment of capacity to determine whether an individual’s choices are respected. Instead they advocate for the use of supported decision making and understand ADM to be a means to this end¹⁴.

The potential for ADM to support autonomous decision making relies on the notion of precedent autonomy¹⁵. This is

the concept that a person’s prior preferences expressed when capacitous be given precedence over preferences expressed at a later time, when lacking in capacity¹⁶. In a mental health setting, particular ethical controversies arise as people may wish their advance preferences around external coercion to be respected during a crisis. For example, they may request early intervention and hospital admission in advance yet during a crisis refuse it. A full discussion of the ethical issues is beyond the scope of this paper. Suffice to say that some, including the authors of this paper, maintain that enabling people with BP to use ADM which requests coercion is an autonomy-maximising measure¹⁶.

Advance decision-making and bipolar

Within the medical profession, ADM has been widely discussed in relation to end-of-life care and life-limiting conditions such as dementia. For example, a PubMed search of ADM and dementia generates 426 citations, compared to BP’s 14, and includes several systematic reviews^{17–19}. However, one of the philosophical criticisms of ADM for conditions such as dementia is that the individual has never had personal experience of the decisions they are making in advance and they are unlikely to regain capacity²⁰.

This is in stark contrast to the experience of someone with BP. Not everyone with BP will experience loss of capacity as defined by the MCA. However, loss of capacity for treatment decisions has been shown to be highly prevalent during manic episodes and can occur during a severe depressive episode⁷. Given its fluctuating course, capacity can therefore be said to fluctuate in association with affect as depicted in Figure 1¹⁶. Loss of capacity is also common in other severe mental illnesses, although its fluctuating course is probably less predictable than that of BP²¹.

Theoretically, this suggests that ADM would be well suited to BP. The first survey exploring interest in current MCA provision amongst people with bipolar in England and Wales strengthens this supposition^{22,23}. The majority of respondents were in favour of using MCA provision to facilitate advance care planning for mental health crises. However use of the provisions for ADM under the MCA was low²².

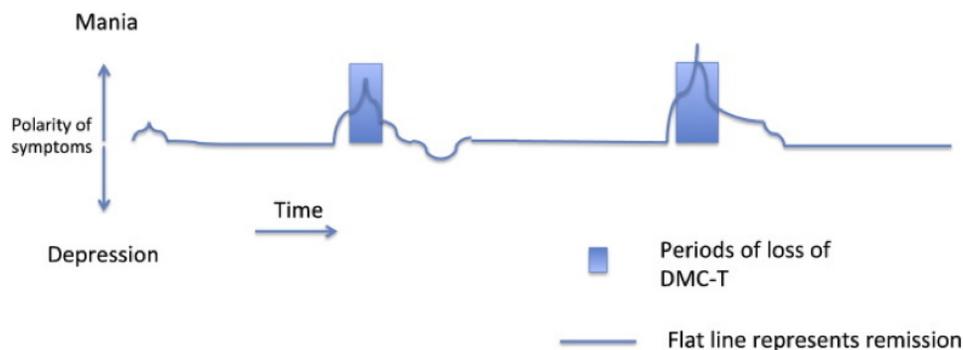


Figure 1. Fluctuating capacity (DMC-T) and remission in mania¹⁶.

If ADM is to be expanded amongst the BP community, it is important to refine our understanding of the views of those with BP and how existing provision might be tailored to meet the needs of those using it. In particular, it is possible that people with BP may be practicing ADM without awareness of the MCA. In order to make this distinction, we have referred to “informal ADM” to mean advance plans that were created outside of the MCA framework for advance planning.

What’s more, as discussed above, those with BP may require compulsory inpatient admission and treatment and are therefore likely to want ADM provision to plan for this eventuality.

One model of ADM which offers this is a self-binding directive (SBD) or Ulysses contract^{24,25}. Gergel and Owen propose a model tailored for use by people with bipolar according to existing legal provision in England and Wales¹⁶. An individual with bipolar works with a known clinician and family and/or friends to create a personalised capacity assessment. The information in the document would also inform the assessment for involuntary treatment with the aim that a person could be contained, according to their advance specifications, in hospital at an earlier stage in their episode of mania before significant damage occurs. Kane proposed an alternative account of this model which relies on a personalised notion of ‘risk to self’ rather than mental capacity²⁶. However, at the heart of both accounts is a willingness to engage with the idea of “self-binding” – the concept that the individual wants the contents of their plan to be respected even if they no longer agree to it when they are unwell.

In summary, the following has been discussed: BP is a severe mental illness in which capacity is likely to be lost during episodes of illness, ADM for such episodes is an autonomy promoting tool which has international support and is possible within multiple legal jurisdictions including England and Wales, the setting for this study. In addition, SBDs may be particularly pertinent for those with BP. Given these issues the challenge is to work towards a model of ADM which is satisfactory for people with BP. With this end in mind, the aims of this survey are outlined below.

Aims

This study aimed to address the following objectives, with a focus on medical treatment:

1. To compare experiences of ADM with preferences for ADM amongst people with BP
2. To describe experiences of using ADM in crisis
3. To explore attitudes towards ADM including drivers for and barriers to ADM
4. To identify demographic and clinical variables that associate with interest in ADMs in general and SBDs in particular

Methods

Design

This study was an exploratory internet-based survey of people with BP in collaboration with Bipolar UK, the UK’s leading bipolar charity.

After reviewing the literature, a pilot questionnaire was designed addressing the study aims. This was reviewed by the research group which comprised two consultant psychiatrists, a research fellow with personal experience of BP, a specialist trainee in psychiatry and a specialist barrister in capacity law. The revised questionnaire was reviewed by two experienced BPUK employees before it was piloted on 13 people with BP and carers who provided written feedback. Follow-up interviews were conducted with a carer and a service-user to discuss the feedback in detail and trial possible alterations. The questionnaire was revised a second time by the research group. This resulted in the final questionnaire covering the following areas:

1. Experiences of ADM: use of ADM and experiences of utilising ADM during a crisis
2. Preferences for ADM: interest in ADM, content and production of ideal ADM document, attitudes toward self-binding
3. Attitudes towards ADM: drivers, barriers and concerns about ADM
4. History of mental illness: diagnosis, comorbidities, current care and history of BP episodes
5. Demographics: age, gender, ethnicity, education

A variety of single answer closed questions, multiple answer closed questions and open questions were utilised. Attitude and belief questions employed five-point Likert-type scales which have been shown to have adequate reliability and validity in a wide range of settings²⁷. Where possible, item-specific response scales were chosen rather than agree to disagree scales. This has been shown to reduce the degree of participant acquiescence and provide higher measurement quality^{28,29}. “I don’t know” options were included in the majority of items. This was in response to feedback that the subject matter was too foreign for some pilots to provide a valid opinion.

The finalised questionnaire was uploaded on to “Bristol Online Surveys”³⁰. This is an online survey platform that is utilised by over 300 research organisations including 130 UK universities. A copy of this survey can be found on Harvard Dataverse³¹. Please note that during the design and implementation of this survey, we used the term ‘advance care planning’ specifying if statutory or informal kinds were meant. For a single term, incorporating statutory and informal processes, we think “ADM” is preferable and use this for the purposes of the paper.

Sample and distribution

The survey was distributed to the BPUK mailing list in October 2017. At time of distribution, this comprised 20,134 people who had registered their email and provided consent to be contacted by the charity.

The survey was open for 6 weeks. This was initially advertised by a dedicated email containing the URL to the online questionnaire with a description of the project and a request for participants. BPUK continued to promote the survey via social media, monthly newsletters, a reminder email and direct communication via support groups throughout the 6-week period to maximise response rate.

After 6 weeks 3418 people accessed the questionnaire. A total of 1131 completed the questionnaire or a parallel carer's questionnaire. This constituted a response rate of 5.61%. There were 50 complete questionnaires excluded either due to lack of consent, no diagnosis of BP or lack of diagnosis by an appropriate professional. A total 149 respondents completed the carer's questionnaire. This left 932 people with BP who met the inclusion criteria (Figure 2).

Analysis

Descriptive statistics were calculated using Microsoft Excel Professional Plus 2013® and Stata 15.0®.

To test for association, we generated the following binary outcomes of interest (dependent variables) from the raw data:

Outcome of interest 1: endorsement of ADM

This outcome was generated from the item “If you were supported by your mental health team to make an advance care plan, would you like to make one?” (Supplementary Table 1³¹)

Outcome of interest 2: interest in self-binding AND willingness to collaborate with a doctor

This outcome was generated from two items. The first asked “Some people think a ‘self-binding statement’ is a good idea. This states that the person wants the contents of their advance care plan to be respected even if they no longer agree with it when they are unwell. Do you think this is a good idea?” The second asked “Would you like to collaborate with your psychiatrist or GP to produce an advance care plan that they could sign showing they agree with the contents of the plan?” (Supplementary Table 2³¹) This was designed as a proxy measure for interest

in SBDs as these are essential components to the model as proposed by Gergel and Owen¹⁶.

As there was an unexpectedly high proportion of respondents who indicated a preference for refusing all medication, we conducted a post-hoc analysis using a third outcome of interest:

Outcome of interest 3: preference for refusing all medication

This outcome was generated from the item “What information do you think an advance care plan should contain? – a) iii) refusing all medication?”

Demographics, history of mental illness and attitudes towards involvement in decision making and trust in mental health practitioners were tested for association with the 3 outcomes of interest using χ^2 tests when all expected values were greater than 5 and Fisher's exact tests when any expected values were less than 5 for categorical variables. T-tests and Mann-Whitney U tests were applied for normally distributed continuous variables and non-normally distributed continuous variables respectively. Using a cut-off of 0.05 significance, variables that were found to be significantly associated with the outcomes of interest were included in univariate logistic regression and multivariate regression corrected for potential confounders.

Multiple comparisons

As our objectives are exploratory, we have presented findings with an initial threshold for statistical significance of <0.05. We subsequently used the Bonferroni-Holm method to correct for multiple comparisons. Results which cross this more rigorous threshold are indicated by ** and discussed in the text.

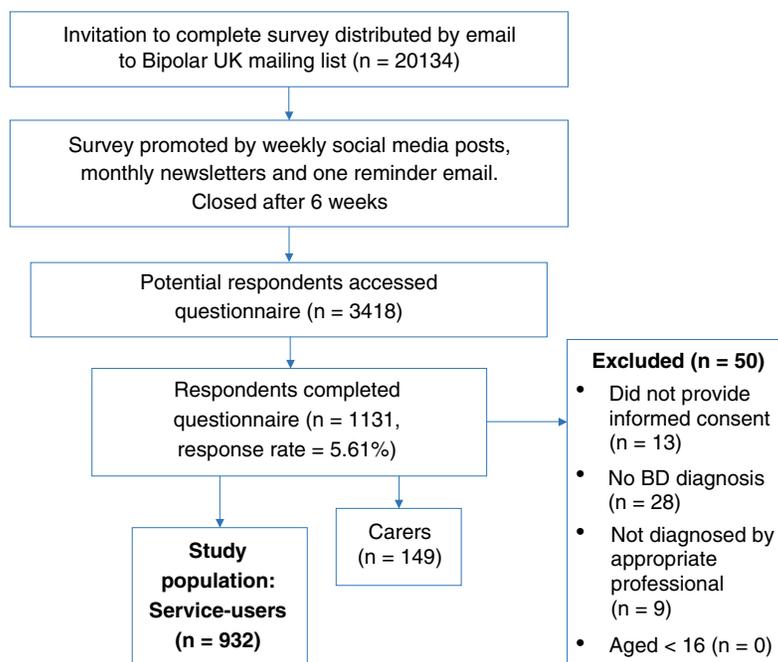


Figure 2. Flowchart describing survey distribution and generation of study population.

Missing data

When presenting descriptive statistics, missing values have only been reported when greater than 5% total sample. When missing values are not reported, proportion of missing values is equal to the difference between the summed percentages and 100.

When performing logistic regression, missing data was assumed to be missing completely at random if missing values were less than 5% total sample. In these cases, a complete records analysis was conducted.

Two variables, “age” and “years since diagnosis”, had greater than 5% missing values. This data was assumed to be missing at random and so multiple imputation was applied when using these variables. Further details can be found in Supplementary Table 3^{31,32}.

Ethics

Ethical approval was provided by the London – Surrey Borders Research Ethics Committee and Health Research Authority (REC reference number 17/LO/1071).

Informed consent was sought from potential participants prior to commencing the survey. Participants were given the opportunity to provide personal email addresses if they wanted to receive more information about the project in the future. These were uncoupled from the data prior to analysis to prevent loss of anonymity. No other identifying information was sought in the questionnaire.

Results

Sample demographics and disease characteristics

A total of 932 people with BP completed the survey and met the inclusion criteria. The sample had a mean age of 47.6 years and was predominantly female (71%), white British (87%) and had received a university level education (64%). Mean length of time since diagnosis was 12.7 years with 42% of respondents having received their diagnosis at least 10 years ago. In total, 61% had experience of hospitalisation and 56% were receiving secondary care or higher. A minority had experience of compulsory treatment (33%) (Table 1).

Comparing experience of ADM with preferences for ADM

A total of 337 (36%) people responded positively to the item “have you ever written down or told someone about what you would like to happen to you or your affairs when you become unwell?” Comparatively, 487 (52%) responded definitely yes and 337 (36%) responded probably yes to the question “If you were supported by your mental health team to make an advance care plan would you like to make one?”. A smaller majority of people thought that a self-binding statement was either definitely a good idea (n = 356; 38%) or probably a good idea (n = 363; 36%).

Types of ADM. The majority of those with experience of ADM (66%) described their plans as “informal” (Figure 3). Of the MCA provisions for ADM, advance statements of wishes

Table 1. Sample demographics and disease characteristics.

Variable	n	% (n = 932)	
Age (years) Mean = 47.6 SD = 12.6	< 30	85	9
	31 – 45	291	31
	46 – 60	357	38
	> 60	148	16
	Missing	51	6
Gender	Male	251	27
	Female	665	71
	Other	10	1
Ethnicity	White British	808	87
	Other white	63	7
	Black British/ Caribbean/mixed	15	2
	Asian/mixed Asian	14	2
	Other	21	2
Relationship status	Married or cohabiting	501	54
	Other	421	45
Education	GCSE or lower	166	18
	A-levels	161	17
	University	598	64
Years since diagnosis Mean = 12.7 SD = 10.6	Less than 5	229	26
	5–10	258	28
	10 or more	395	42
	Missing	50	5
Comorbidity	Anxiety	444	48
	Post-traumatic stress disorder	109	12
	Panic disorder	100	11
	Emotionally unstable PD	99	11
	Other	343	37
Level of care	CMHT or similar	522	56
	Primary care	402	43
Hospital admission	Ever	573	61
	Never	348	37
Compulsory treatment	Ever	305	33
	Never	616	66

and preferences were most common (17% of total sample), while ADRTs and LPAs for health and welfare and property and finance were less than half as prevalent (6% and 8% respectively). A significant proportion of all forms of ADM were communicated verbally (42%; n = 274). A total of 129 (38%) respondents reported owning one or more legally binding form of ADM, 82 (24%) of which had been communicated in writing.

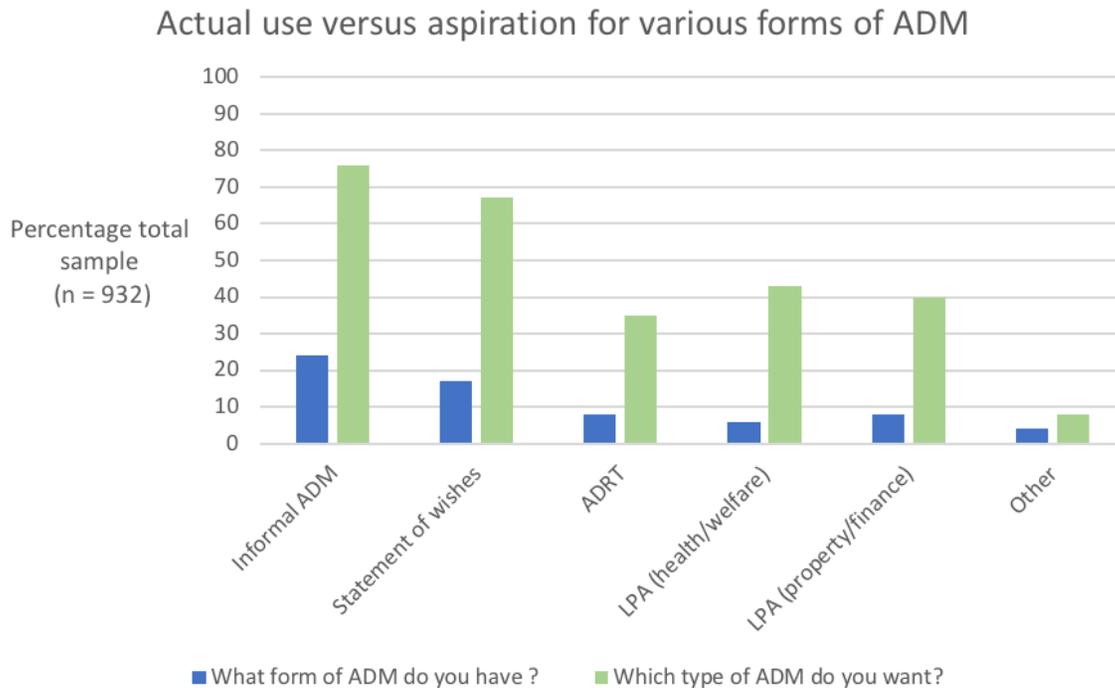


Figure 3. Bar chart comparing actual use with aspiration for various types of ADMs.

Most people stated a preference for non-legally binding ADM. In total, 771 (76%) indicated they would make informal ADs and 627 (67%) advance statement of wishes and preferences. Fewer respondents expressed an interest in making ADRTs (35%), LPA health and welfare (43%) or LPA property and finance (40%) (Figure 3).

In all types of ADM there was a mismatch between aspiration and actuality with higher percentages wanting to engage in ADM than had experience of ADM.

Content of Advance Decisions. Respondents indicated that “contact details of who to notify” and “who makes decisions if you are unable to make decisions for yourself” were the most frequent pieces of information contained in their AD (71% and 68%, respectively). A total of 40% requested specific medication, 35% refused specific medications and 33% requested hospitalisation; 10 respondents (3%) had attempted to refuse all medication (Table 2).

A similar pattern is presented when participants were asked what information ADs should relate to, with “contact details of who to notify” and “who makes decisions if you are unable to make decisions for yourself” also being the most frequently selected (87% and 89% of the total sample, respectively). An equivalent proportion of the total sample wanted to request specific medications (69%) as well as refuse specific medication (68%) and request hospitalisation (68%). A substantial number of people indicated a wish to refuse all medication (20%) (Table 2).

For all content there was a mismatch between aspiration and actuality with respondents indicating a preference for ADs that cover a broad range of options. The content aspiration in the subsample with experience of ADM was similar to the total sample (Table 2).

Support and storage. Respondents most frequently produced their ADM with the support of family/friends (42%) or a CPN/care co-ordinator (37%) (Table 3a); 14% had worked with a psychiatrist and 7% with a GP. A minority of ADMs was present within psychiatric (36%) or GP (21%) notes. In contrast, 70% of participants indicated a preference to collaborate with a psychiatrist and 55% with a GP. Family and friends remained the most popular group with 79% preferring their support. Most respondents reported a preference for ADMs to be kept within psychiatric or GP notes (79% and 83%) as well as with family and friends (70%) (Table 3b).

Again, there was an actuality/aspiration mismatch for support and storage with higher percentages wanting support and storage than had it. The support and storage aspiration in the subsample with ADM was similar to the total sample.

Making ADs and their use in crisis

In total, 45% of respondents with ADs were satisfied with the contents of their plan, 49% felt more in control because of their plan and 51% felt more involved in decisions about their healthcare. Despite this, a minority (26%) of respondents had experience of their ADs being used in a crisis (Table 4).

Table 2. Table comparing the actual content of people's ADs (coloured blue) with the aspirational content (coloured green). Aspirational content is divided into two samples (1) the subsample with ADs and (2) the total sample.

Content of ADs	What information does your AD contain?		What should an AD contain?			
	People with ADs		People with ADs		Total sample	
	n	% (n = 337)	n	% (n = 337)	n	% (n=932)
Requesting specific medications	134	40	237	70	639	69
Refusing specific medications	118	35	245	73	636	68
Refusing all medications	10	3	78	23	190	20
Requesting ECT	17	5	95	28	241	26
Refusing ECT	104	31	229	70	585	63
Requesting hospitalisation	110	33	220	65	631	68
Where to be treated	108	32	246	73	649	70
Where not to be treated	102	30	212	63	581	62
Description of behaviour or speech used when in a crisis	154	46	253	75	642	69
Planning your discharge	33	10	211	63	568	61
Who makes decisions if you are unable to make decisions for yourself	230	68	313	90	827	89
Who takes responsibility for your finances	159	47	258	77	720	77
Contact details of who to notify	238	71	294	87	806	87
Who not to notify	80	24	182	54	485	52

Table 3. Table comparing (a) who was actually involved in producing the advance decision making (ADM) (blue) with aspiration for who should be involved (green) and (b) where ADM is actually stored (blue) with aspiration for where it should be stored (green). Aspirations are divided into two samples (1) the subsample with ADs and (2) the total sample.

a) Support-giver	Who else was involved in producing your AD?		Who else should be involved in producing an AD?			
	People with ADs		People with ADs		Total sample	
	n	% (n = 337)	n	% (n=337)	n	% (n=932)
Psychiatrist	48	14	232	69	650	70
GP	24	7	181	54	517	55
Care co-ordinator/CPN	124	37	209	62	505	54
Family/friends	141	42	265	79	736	79
Lawyer	16	5	79	23	218	23
Alone	57	17	18	5	36	4
Other	40	12	78	23	191	20
b) Storage method	Where is your AD stored?		Where should an AD be stored?			
Psychiatric notes	122	36	283	84	737	79
GP notes	70	21	283	84	775	83
At home	111	33	184	55	385	41
Family/friends	116	34	266	79	657	70
Other	43	13	37	11	85	9
I don't know	38	11	5	1	24	3

Table 4. Experiences of making an advance decision (AD).

Question/statement	Collapsed Likert scale	n	% (n = 337)
<i>How satisfied are you with the contents of your AD?</i>	Satisfied	152	45
	Neutral or Unsatisfied	135	40
	I don't know	45	13
<i>I feel more in control as a result of my AD</i>	Agree	162	48
	Neutral or disagree	131	39
	I don't know	23	7
<i>I feel more involved in decisions about my healthcare as a result of my AD</i>	Agree	173	51
	Neutral or disagree	122	36
	I don't know	19	6
	Missing	23	7
<i>How many times has your AD been used in a crisis?</i>	Never	207	61
	Ever	88	26
	I don't know if it's been used	25	7

Of these respondents (n = 88), 50% felt their AD was highly or completely respected by mental health staff, 60% felt they had recovered faster as a result of their AD and 60% had a better experience of health services; 55% were happy with how their AD had been used in general. ADs were reported to be more effective in reducing harm to relationships (44% very or extremely helpful) and physical harm (34%) than reducing overspending (23% very or extremely helpful) (Table 5).

Drivers for and barriers to ADM

The most frequently selected reason to make an AD was “I would be more involved in decisions about my mental health” (84% of respondents). This was followed by “reduce pressure on family and friends to make decisions on my behalf”, “improve my experience of being treated by mental health services” and “I would be more in control of my illness” (74% and 70%, respectively) (Table 6).

In terms of barriers, a minority (25%) agreed with the statement “I don't see the point because Advance Decisions to Refuse Treatment can be overruled by the Mental Health Act”, despite a majority (71%) indicating that it is very or extremely important that ADM should be legally binding. 47% indicated that they thought it would be difficult to make an AD while only 19% felt it would be too distressing to do so. A significant minority agreed with the statement “I don't understand enough about advance care planning” (47%) although most respondents believed that they understood their condition well enough to make an AD (72%) (Table 7).

Table 5. Experiences using an advance decision (AD) in a crisis.

Question	Collapsed Likert scales	n	% (n=88)
<i>To what extent did mental health staff respect the contents of your AD?</i>	Highly - completely	44	50
	Slightly - moderately	31	35
	Not at all	12	14
<i>What effect did your AD have on your recovery from your crisis?</i>	Faster	53	60
	No effect	26	32
	Slower	2	2
	I don't know	7	8
<i>What effect did your AD have on your experience of treatment?</i>	Better	53	60
	No effect	29	33
	Worse	6	7
	I don't know	4	5
<i>How helpful was your AD in reducing physical harm?</i>	Very - extremely	30	34
	Slightly - moderately	25	28
	Not at all	18	20
	Missing	15	17
<i>How helpful was your AD in reducing harm to relationships?</i>	Very - extremely	39	44
	Slightly - moderately	26	30
	Not at all	14	16
	Missing	9	10
<i>How helpful was your AD in reducing overspending?</i>	Very - extremely	20	23
	Slightly - moderately	35	40
	Not at all helpful	21	24
	Missing	12	14
<i>How happy are you with how your AD has been used in general?</i>	Happy	48	55
	Neutral or unhappy	39	44

Demographic and clinical variables associated with interest in ADM and SBDs, and preference for refusing all medication

Of the respondents, 824 (88%) registered an interest in ADM (Supplementary Table 1³¹) and 641 (69%) responded positively to the self-binding concept and to collaboration with a doctor (Supplementary Table 2³¹).

Table 8 shows associations with ADM in general. Of note there was no association with gender, ethnicity or education. There was a statistically significant association at the 0.05 threshold between interest in ADM and a younger age, shorter time since diagnosis, higher level of care, ever experiencing mania and a greater trust in healthcare professionals (Supplementary Table 4). After controlling for key demographic variables,

Table 6. Attitudes towards drivers for ADM.

Which of the following do you think are the most important reasons to make an advance decision?	n	% (n = 932)
<i>I would be more involved in decisions about my mental health</i>	787	84
<i>Reduce pressure on family and friends to make decisions on my behalf</i>	690	74
<i>Improve my experience of being treated by mental health services</i>	655	70
<i>I would be more in control of my illness</i>	643	69
<i>Reduce harm to relationships</i>	557	60
<i>Faster recovery from an episode of mania or depression</i>	545	59
<i>Reduce harm to myself during an episode</i>	509	55
<i>Reduce risk of overspending</i>	485	52
<i>Reduce harm to property</i>	261	28
<i>I don't think there are any significant benefits</i>	17	2

younger age, history of manic episodes and trust in healthcare professionals remain significantly associated. Only the association with younger age remained significant after correction for multiple comparisons.

Table 9 shows associations with interest in self-binding with a doctor's involvement. There was no association with age, ethnicity, educational level or gender (Supplementary Table 4³¹). Interest in self-binding with doctor's involvement was significantly associated with experience of compulsory treatment, detention by police and greater trust in healthcare professionals. The association with all three variables remained significant after controlling for key demographics. Only the association with trust in healthcare professionals was significant after Bonferroni-Holm correction.

To explore the possibility of a confounding effect between compulsory treatment and detention by police, we performed further multivariate regression analysis. There was moderate collinearity between these variables ($r = 0.39$, $p < 0.00005$). When controlling for detention by police, the association between a history of involuntary detention and interest in self-binding

Table 7. Attitudes towards potential barriers to ADM.

Collapsed Likert scales	Agree	Neutral	Disagree
n = 932	n (%)	n (%)	n (%)
<i>I don't understand enough about ADM</i>	434 (47)	202 (22)	275 (30)
<i>I don't understand my condition well enough to make an AD</i>	104 (11)	134 (14)	673 (72)
<i>I don't see the point because Advance Decisions to Refuse Treatment can be overruled by the Mental Health Act</i>	233 (25)	317 (34)	360 (39)
<i>Mental health workers have more than enough time to help with ADM</i>	141 (15)	183 (20)	599 (64)
<i>It would be too distressing to think about times when I have been unwell during the process of making an AD</i>	173 (19)	207 (22)	531 (57)
<i>I don't think mental health teams would be able to access an AD when they need it</i>	338 (36)	303 (33)	275 (30)
<i>I don't think mental health practitioners would respect an AD</i>	313 (34)	318 (34)	284 (30)
	Easy	Neutral	Difficult
<i>How easy do you think it is to make an AD?</i>	198 (21)	298 (32)	433 (47)
	Very/extremely	Slight/moderately	Not at all
<i>How important is it to you that an AD should be "legally binding"?</i>	665 (71)	227 (24)	32 (3)

Table 8. Interest in any ADM: univariate and corrected associations. Univariate regression of age and years since diagnosis, and all multivariate regression were conducted using multiple imputation.

		Univariate regression		Model corrected for age, gender, ethnicity, education and comorbidity	
		Odds ratio (95% CIs)		Odds ratio (95% CIs)	
Age*		0.97 (0.95 – 0.98)	p < 0.0005**	0.97 (0.95 – 0.98)	p < 0.0005**
			n = 922		n = 896
Years since diagnosis		0.97 (0.96 – 0.99)	p = 0.002	0.99 (0.96 – 1.01)	p = 0.222
			n = 926		n = 896
Level of care	GP	1.00		1.00	
	CMHT or higher	1.62 (1.07 – 2.46)	p = 0.024	1.49 (0.96 – 2.31)	p = 0.074
			n = 916		n = 894
Manic episode	0	1.00		1.00	
	1–4	3.02 (1.13 – 8.12)	p = 0.028	3.34 (1.24 – 9.35)	p = 0.021
	5 or more	3.36 (1.26 – 8.99)	p = 0.016	4.55 (1.62 – 12.81)	p = 0.004
	Don't know	1.85 (0.61 – 5.66)	p = 0.279	2.03 (0.64 – 6.58)	p = 0.232
			n = 913		n = 891
Trust in healthcare professionals	Agree	1.00		1.00	
	Neutral	0.595 (0.35 – 1.02)	p = 0.058	0.64 (0.37 – 1.11)	p = 0.116
	Disagree	0.48 (0.29 – 0.79)	p = 0.004	0.49 (0.29 – 0.83)	p = 0.008
			n = 916		n = 896

**Indicates statistical significance after Bonferroni-Holm correction for multiple comparisons.

Table 9. Interest in SBD: univariate and corrected associations. Multivariate regression was conducted using multiple imputation.

		Univariate regression		Model controlling for age, gender, ethnicity, education and comorbidity	
		Odds ratio (95% CIs)		Odds ratio (95% CIs)	
Involuntary detention	Never	1.00		1.00	
	Ever	1.37 (1.01 – 1.86)	p = 0.042	1.55 (1.13 – 2.13)	p = 0.007
			n = 918		n = 894
Detention by police	Never	1.00		1.00	
	Ever	1.42 (1.02 – 2.00)	p = 0.040	1.45 (1.02 – 2.06)	p = 0.036
			n = 908		n = 898
Trust in healthcare professionals	Agree	1.00		1.00	
	Neutral	0.57 (0.40 – 0.81)	p = 0.002	0.58 (0.40 – 0.83)	p = 0.003
	Disagree	0.43 (0.30 – 0.81)	p < 0.0005**	0.43 (0.31 – 0.61)	p < 0.0005**
			n = 921		n = 901

**Indicates statistical significance after Bonferroni-Holm correction for multiple comparisons.

with clinician involvement was no longer significant (OR 1.22, CIs 0.87-1.70, $p = 0.242$). When controlling for experience of involuntary detention, the association with detention by police also became non-significant (OR 1.32, CIs 0.92-1.91, $p = 0.134$). There was no significant interaction between these two variables.

A preference for refusing all medications as part of ADM was associated with younger age, fewer years since diagnosis, never experiencing hospitalisation, female gender and a lack of trust in healthcare professionals (Supplementary Table 5³¹). When controlling for confounders, only younger age, female gender and lack of trust in healthcare professionals remained significant. Younger age and lack of trust in healthcare professionals remained significant after correction for multiple comparisons (Table 10). There was no association between preference for refusing all medication and an interest in ADM ($\chi^2 = 0.45$, $p = 0.504$), or interest in self-binding with doctor's involvement ($\chi^2 = 0.91$, $p = 0.341$).

Discussion

This study is the largest survey of attitudes towards ADM amongst people with BP, who have traditionally been a hard to reach group. It provides an important step forward in understanding experiences and attitudes towards ADM in this group. Furthermore, it offers insight into how people with BP would like ADM provision to be shaped. In a field where the results of empirical studies are conflicting but the intervention seemingly has high-levels of support among service-users and clinicians alike³³⁻³⁵, this understanding is vital in developing accurately tailored interventions.

Most strikingly, a large majority of this study's sample have indicated that they would like to plan their care in advance of losing capacity (88%) but most have not done so (64%). Of those who have engaged in ADM, a minority have experience of their plans being used in crisis. When they are used, respondents report generally positive experiences, with 50% feeling that their ADs were respected either highly or completely, 60% indicating that they recovered faster and 60% experiencing better treatment because of their ADs. There is also a notable interest in SBDs, with 69% expressing an interest in self-binding as well as a willingness to collaborate with doctors.

Limitations

There are several important limitations to this study. This is a predominantly white (94%), female (71%), well-educated sample (64% university educated) which is not representative of the wider population of people with bipolar in the UK (88.8% white, 48.9% female, and 36% university educated)³⁶. The use of BPUK mailing list as the sampling frame and a low response rate introduce further selection bias. People with a prior awareness or interest in ADM are likely to be over-represented. It is therefore difficult to generalise these findings and the study should be seen as exploratory.

Nonetheless, representative opinions of people with severe mental illness are hard to access and the only comparable study performed in the UK reported a sample size of 544 with an unknown response rate due to the sampling methodology employed²². This study's larger sample size and transparent methodology thus helps take the literature a step forward. The use of other

Table 10. Preference for advance refusal of all medication: univariate and corrected associations. Univariate regression of age and years since diagnosis, and all multivariate regression was conducted using multiple imputation.

		Univariate regression		Model controlling for age, gender, ethnicity, education and comorbidity	
		Odds ratio (95% CIs)		Odds ratio (95% CIs)	
Age		0.97 (0.95 – 0.98)	p < 0.0005**	0.97 (0.96 – 0.98)	p < 0.0005**
			n = 924		n = 897
Years since diagnosis		0.97 (0.95 – 0.99)	p < 0.0005**	0.99 (0.97 – 1.01)	p = 0.322
			n = 928		n = 897
Hospitalisation	Never	1.00		1.00	
	Ever	0.71 (0.44 – 0.98)	p = 0.038	0.75 (0.54 – 1.06)	p = 0.103
			n = 921		n = 891
Gender	Male	1.00		1.00	
	Female	1.75 (1.18 – 2.61)	p = 0.005	1.58 (1.05 – 2.38)	p = 0.029
	Other	2.56 (0.63 – 10.36)	p = 0.188	2.70 (0.64 – 11.40)	p = 0.177
			n = 926		n = 897
Trust in healthcare professionals	Agree	1.00		1.00	
	Neutral	1.27 (0.84 – 1.94)	p = 0.260	1.22 (0.79 – 1.89)	p = 0.366
	Disagree	2.35 (1.61 – 3.41)	p < 0.0005**	2.08 (1.41 – 3.08)	p < 0.0005**
			n = 923		n = 897

**Indicates statistical significance after correction for multiple comparisons.

methodologies to sample the attitudes of hard-to-reach groups such as respondent-driven sampling may be useful³⁷. While in order to understand the generalisability of these findings, a simplified version of the survey should be conducted using a more representative sampling technique such as convenience sampling through outpatient clinics or systematic sampling through the use of a patient research database such as the Clinical Record Interactive Search system³⁸.

It is notable that only a minority of our sample have experience of involuntary detention (33%). Arguably, this could suggest that the majority of this sample have a less severe manifestation of BP, are therefore less likely to lose capacity during episodes, meaning ADM may not be relevant for these respondents. However, the majority do have experience of hospitalisation which is an important indicator of severity. In addition, during an inpatient admission which coercion, leverage and treatment pressures can be present in the absence of legally mandated detention^{39,40}. What is more, there was no association between experience of compulsory treatment and interest in ADM, suggesting that ADM does appeal to people who have not experienced involuntary detention.

We utilised a proxy-measure for interest in SBDs by combining interest in self-binding statements with a willingness to collaborate with doctors. This was because we decided that attempting to explain SBDs in a survey was likely to generate confusion. This means our results cannot be interpreted as a direct endorsement for SBDs. We have conducted focus groups in which SBDs were discussed as part of a parallel study which will help to triangulate these findings.

A quantitative survey was employed to explore and characterise a large number of people's views. The use of closed response options, however, limits the depth of opinions and experiences reported. What's more it is possible that some participants misunderstood some of the complex concepts contained within the questionnaire. Our focus on ADM in relation to medical treatment may have added to this potential misunderstanding. ADM can relate to financial or work matters and it is possible that some of our respondents may have been referring to these in some of their responses. Further structured qualitative analysis of the free text boxes included in the survey will be reported in a future publication, helping to disambiguate this. While further research is needed to explore to what extent these findings compare to other forms of ADM.

Consistency with previous studies

Some of our results replicate findings reported by Morriss *et al.* in a survey of the utilisation of the MCA by people with BP²². Use of advance statement of wishes and feelings and LPAs (property/finance) were somewhat more prevalent among our study's sample (17% and 8%, respectively) compared to Morriss *et al.* (11.4% and 3.9%, respectively). It is possible that use of these provisions has increased over time. Use of ADRTs and LPAs (health/welfare) was more equivalent, 8% and 6% compared to 9.9% and 5.7%, respectively, obtained by Morriss *et al.* In terms of interest, 74.1% "believed making plans about

their personal welfare if they lost capacity to be very important" compared to 88% of our sample that expressed interest in ADM²².

Comparable findings have been reported in wider populations of people with severe mental illness rather than just BP. Swanson and colleagues found that 4–13% of people with mental illness in a large multicentre cohort from the US had psychiatric advance directives while 66–77% of this sample wanted to make one⁴¹.

Therapeutic potential of ADM in crisis care and beyond

In this study, of the minority of respondents who did have experience of using ADM in crisis, 50% indicated their plan was highly or completely respected and 60% felt they had recovered faster and had a better experience of being treated by mental health services. This builds on Srebnik and Russo's finding in the U.S. that two thirds of treatment decisions were consistent with participants' psychiatric advance directives⁴². This is preliminary evidence that ADM produced outside of an "experimental" setting *can* be used in crisis with therapeutic effect and that they tend to be respected when they are used, although it is worth noting that significant proportions of our sample did not report these positive experiences.

Usability and respect have previously been raised as critical issues facing the implementation of ADM⁴³. However, as previously discussed, in England and Wales the current legal framework may act as a barrier to ADM implementation for those with mental illness in that there is no MHA provision for formal recognition of ADM; Morriss *et al.* found only 12.5% of people with ADRTs had their plans respected when detained under the MHA²².

Half of those with ADs felt more in control because of their plan and felt more involved in decisions about their healthcare. Wauchope *et al.* reported similar positive changes in feelings of independence, control and motivation in the majority of people who were assisted in making ADM⁴⁴. This suggests there are benefits of ADM beyond its role in crisis and that even if specific legal provision for ADM for people with mental illness is not available in the near future, ADM is still experienced as worthwhile by a large proportion of people with mental illness.

Desire for mental health service involvement

The limited involvement of psychiatrists and GPs in the production and storage of ADs is striking. Only 21% of ADs were made with the help of either a psychiatrist or GP and only 36% were present in psychiatric notes. This suggests that, for most people, ADM is practised outside of the medical sphere and for many it is a "do-it-yourself" exercise with family and friends alone. Morriss *et al.* report similar findings, with only 48% of ADRTs having being produced with the help of mental health professionals and 48% present in mental health notes²².

The extent to which mental health services currently engage with ADM is likely to be a key factor, although little is known about current practice in the UK at NHS Trust level. Bartlett

et al. reported that psychiatrists “would discuss more if patients requested it”²³. Internationally, a degree of ambivalence among mental health professionals has also been described. Elbogen reported that only 47% of psychiatrists, psychologists and social workers believed that ADM “would be helpful to consumers”⁴⁵ and only 28% of Scottish psychiatrists thought advance directives were needed in Atkinson and colleagues’ survey⁴⁶. Swanson demonstrates the wide gap between clinicians and service-users attitudes, with 78.43% of service users believing that “advance instruction will help people...stay well” compared to only 43.9% clinicians⁴⁷.

Some have suggested that this is the way ADM should be conducted: for ADM to truly enhance autonomy, they should be completed without the involvement of mental health professionals^{41,46,48-51}. In fact, Henderson *et al.* reported a preference among US veterans for plans to be produced outside of a mental health setting and the need for “nonpartisan assistance”⁵². What’s more, Ruchlewska *et al.* found that “crisis plans” facilitated by non-clinicians performed better in a “crisis plan quality checklist” than crisis plans completed with clinicians, although there was no difference in performance clinically^{34,53}.

In our sample there was a clear preference for doctors to be involved and for plans to be present in medical notes, and interest in ADM was associated with *increased* trust in mental health professionals. Similar attitudes have been reported among service users previously as well as other key stakeholders and this collaborative approach has been employed by several clinical trials of ADM-type interventions^{34,43,54,55}. This would suggest that our sample favours a “therapeutic alliance” approach with clinical “buy-in” rather than an anti-medical model⁴³.

These inconsistent findings in the literature may be due to sampling biases, as well as cultural differences between different countries. However, it also highlights the breadth of attitudes present and the challenges in identifying the “right” way to implement such an intervention.

There are several potential consequences to mental health services failing to take an active role in ADM. Firstly, our findings suggest that ADM is currently ineffective for many people, with 61% of ADs never having been used in a crisis. This is perhaps unsurprising given 64% of plans are absent from mental health notes. Other UK studies also suggest that only a minority of ADM that are created are recorded in written form^{22,23}. This is of concern given that in England and Wales at least, multiple agencies may be involved in a crisis: mental health services, friends and family, social services and the police. When individuals from these professional groups were asked about ADM, lack of accessibility to electronic and paper documents across services and localities was seen as a key barrier to implementation (Stephenson *et al.*, personal communication).

Secondly, without mental health service involvement, the chance of ADM being a source of conflict and disappointment is higher. This is most evident in the finding that 20% of this sample expressed a wish to refuse all medication. While this may be

achievable for some, it is possible that treatment would be enforced despite their wishes if they were detained under the MHA. Service-users refusing all medication has previously been described as the biggest concern about ADM among healthcare professionals and may contribute to the degree of ambivalence described above^{45,56,57}. We have found that preference to refuse all medication associates with younger age, which may suggest a need for targeted engagement of younger patients to help avoid conflict and disappointment later. However, the strong association with participants who have less trust in healthcare professionals suggests this may be a challenging group to engage.

Thirdly, our sample show high interest in SBDs, particularly amongst those with more experience of compulsory treatment. These are types of ADM that will require collaboration with mental health services to work as they involve requests, rather than refusals, of treatment, often at earlier stages than would otherwise happen under the MHA.

Finally, as awareness of ADM increases among people with BP and other mental illnesses, the need for clinicians to engage at the planning stage may become increasingly evident, as clinicians will be expected to respond to questions about ADM that have clinical implications⁵⁸.

Tailoring advance decision making for bipolar

Medication refusal. The finding that 20% of our sample would like to refuse all medication is substantially higher than findings in equivalent surveys of people with severe mental illness, not specifically BP, with figures typically between 0–5%^{41,59}. Some of our findings are more consistent with samples that are not BP specific. Refusals of ECT, for example, range from 42%⁵⁹ to 72%⁵⁸ while this would be included by 70% of our sample who already had ADs and 63% of the entire sample. However, others appear to differ more significantly. A total of 96% of Scottish advance statements reviewed by Reilly *et al.* included a specific medication refusal, while only 35% of ADs in our sample included this information and 68% of the total sample would include this. Conversely, only 45% of the sample assessed by Reilly *et al.* requested medication, while 68% of our sample would like to include this⁵⁹.

These differences may be due to sampling differences. However, this is the first study to explore these issues among a BP-specific population. It is therefore possible that there are important differences in attitudes between people with different diagnoses and that this provides evidence against a “one size fits all” approach.

Advance requests for coercive treatment: self-binding directives. Difference by diagnosis may also be true for the degree of interest in SBDs. A study of 104 people with schizophrenia found that the majority believed that people should be able to revoke an AD even when lacking capacity for treatment decisions⁴⁷. This attitude is in direct opposition to the capacity based model proposed by Gergel and Owen in the bipolar context which stipulates that the service-user receives compulsory treatment as outlined in their SBD when lacking capacity for treatment decisions in

the knowledge that they may resist this treatment when unwell¹⁶. The majority of bipolar participants in this survey supported the idea that contents of their advance care plan should be respected even if they no longer agree with it when they are unwell.

Our findings also provide an interesting comparison to some of the clinical trials of ADM-type interventions. In our sample, 68% wanted to be able to request hospitalisation as part of an AD. This is in contrast to several of the trials which included reduction of hospitalisation rate as an outcome measure, all of which failed to demonstrate any effect^{33,35,57}. This helps to illustrate a key debate around the appropriate outcome measures for ADM: is reduction in hospitalisation the critical test of their value? The fact that the five most frequently selected reasons to engage in ADM were related to self-determination and relationships suggest that our sample supports a wide view on the appropriate outcome measures for ADM (see Table 6).

Inconsistent attitudes towards legal status

Respondents expressed a preference for non-legally binding forms of ADM which included information about refusing medication or substitute decision makers over legally binding forms that could communicate the same information such as ADRTs and LPAs. This is despite 71% of respondents indicating that they thought it was either very or extremely important that an AD should be “legally binding”. This apparent contradiction may be due to a lack of understanding both of the terminology but also the legal status of different options available. This is supported by the fact that 47% responded that they “*did not understand ADM well enough*”. Low levels of awareness of the MCA has previously been reported among people with BP²² while limited awareness of ADM in the among people with mental illness including dementia has also been identified as a key barrier to its implementation^{60,61}.

Participants’ attitudes in principle may also differ to their attitudes in practice. It is possible that participants believe that it is extremely important that ADMs should be legally binding when asked in general terms. However, when given the choice of making their own plan and invited to consider the practical aspects of making a plan, the idea of “binding” themselves and others to that plan may seem less appealing. This effect has been described in people approaching end-of-life care who may feel “intimidated” by something perceived to be legally binding in practice⁶².

However, this may also reflect a lack of interest in the legally binding provisions currently available in England and Wales. Much of the preferred content for ADM in our sample, including requesting medication and hospitalisation, falls outside of the legally binding provisions under the MCA. ADRTs and LPAs may therefore seem too limited and restrictive despite their legally binding status.

A further possibility is that respondents may prefer the best of both worlds; provision with sufficient legal force for their wishes to be taken seriously yet with sufficient flexibility which accommodates the difficulties of predicting future situations.

Associations with interest in ADM and SBDs

Focus groups exploring psychiatrists’ attitudes towards ADM and SBDs (Stephenson *et al.* personal communication) have elicited assumptions that only a certain “type” of patient will have the resources to engage in ADM. Although there may be subtle associations that are not apparent due to sample size or a non-representative sample, it is notable that there was no evidence that interest in ADM nor SBD with doctors’ involvement are associated with education, ethnicity or gender. This is replicated in the survey by Morriss *et al.*, which identified a positive association between knowledge of the MCA and higher educational level but not use of the MCA²². These assumptions are likely to contribute to the lack of involvement among mental health staff who “*would discuss more if patients requested it*”²³.

In contrast, in their survey of interest in Psychiatric Advance Directives among people with severe mental illness, Swanson *et al.* demonstrated a positive association with women, non-white respondents, lower educational level, recent contact with police, high pressure to take medications and low sense of personal autonomy. This was interpreted as an attempt by a disenfranchised and disillusioned population to regain control⁴¹.

The finding that interest in SBD and ADM are significantly associated with increased trust in healthcare professionals may be evidence against this hypothesis among our sample. Indeed, it is likely that people with less trust in their mental health services do not trust their services to enact an AD and therefore do not express an interest. Similar attitudes were elicited in a qualitative study by Wauchope *et al.* exploring the process of developing ADM for people with severe mental illness, observing that participants with negative experiences of mental health services were more likely to be suspicious of the process⁴⁴.

The variables associated with interest in ADM and SBD otherwise differ. This suggests that the group of people interested in SBD represent a distinct sub-group to those that are interested in ADM in general. Most importantly, interest in SBD was associated with experience of compulsory treatment. Coercive treatment is central to the SBD model, where the service user seeks to have a voice in the kind of coercive treatment that is needed for them based on their past experience of illness episodes¹⁶. This positive association is therefore evidence that the concept has been understood and that there is interest among the people for whom it is most relevant. Meanwhile, the finding that age is inversely associated with interest in ADM is in keeping with a generational effect namely that younger people are more likely to assume an active role in healthcare decisions and less likely to assume medical paternalism⁶³.

Future directions

These results demonstrate sizeable appetite for ADM among a large group of people with BP and a desire for input from mental health services in creating and implementing ADM for therapeutic effect. However, despite this appetite, ADM remains uncommon in clinical practice. Translating this enthusiasm into clinical practice therefore presents a major challenge.

Firstly, it is difficult to envisage mental health trusts prioritising ADM while it remains an afterthought within mental health legislation in England & Wales. However, this may change. The recently published report from the Independent Review of the Mental Health Act, to which data from this survey contributed, has included provision for ADM as one of its key recommendations. This presents an exciting opportunity to think through and promote ADM within mental health with renewed vigour and may lead to new legislation⁶⁴.

Legislation alone is unlikely to be successful. Our findings, and others, suggest a lack of engagement among mental health staff that is likely to stem from resource and training issues, priorities within mental health trusts and assumptions around who may be interested in and able to use ADM^{23,65}.

To enable service users and clinicians to harness the potential of ADM top down facilitation and bottom up pressure is required. Mental health services need appropriate resources and the development of clinically feasible ADM focussed care pathways, resources and guidelines. In addition, ongoing advocacy and awareness raising from third sector organisations such as BP UK can help to raise knowledge of ADM amongst the service user community and encourage informed requests for ADM.

Finally, while it is promising that a large proportion of this sample endorses SBDs, this study's methodology does not allow these attitudes to be explored in depth. There are also several key stakeholders whose input and buy-in is essential for the model to be implemented successfully. We have therefore conducted focus groups with service-users, mental health practitioners and lawyers exploring some of the key ethical and practical aspects of SBDs (Stephenson Unpublished). Building on these findings, we will trial one model of clinician/service-user co-produced SBDs for people with BP which will commence in 2019.

Conclusions

This study explores the attitudes and experiences of people with BP towards ADM in the UK. It has demonstrated that ADM is uncommonly practised despite substantial interest. The results suggest services users with BP want to use ADM and they want collaborative input from mental health services in doing so, although the low response rate mean these results should be generalised with caution. We hope that the results of this study combined with the opportunities provided by the Independent Review of the Mental Health Act, will help to translate this interest into action and enable people with BP to extend their autonomy to situations in which their autonomy is threatened.

Data availability

Underlying data

Due to risk of de-anonymisation, the raw underlying data has not been made freely available. If researchers or referees would like

access to the data for re-analysis, please contact the corresponding author (L.A.S.) by email at lucy.a.stephenson@kcl.ac.uk.

Extended data

Harvard Dataverse: "A survey of experiences of and attitudes to advance decision making amongst people with bipolar: questionnaire and supplementary information", <https://doi.org/10.7910/DVN/WHUYQR>³¹.

The original questionnaire and a document containing Supplementary Tables 1–5 are included as extended data.

Data are available under the terms of the [Creative Commons Zero "No rights reserved" data waiver](#) (CC0 1.0 Public domain dedication).

Author contributions

GH took part in discussions about the conceptualisation of the study, designed the survey, liaised with Bipolar UK, distributed the survey, collected responses, collated and organised data, analysed the data and prepared the first draft

LS took part in discussions about the conceptualisation of the study, assisted in the design of the survey, liaised with Bipolar UK and reviewed and edited the drafts of the paper

ARK was part of the team who secured funding for the study, took part in discussions about the conceptualisation of the study, provided supervision and reviewed and edited drafts of the paper

LR was part of the team who secured funding for the study, took part in discussions about the conceptualisation of the study, provided supervision and reviewed and edited drafts of the paper

TG was part of the team who secured funding for the study, took part in discussions about the conceptualisation of the study, liaised with Bipolar UK, provided supervision and reviewed and edited drafts of the paper

GO led the team which secured funding for the study, conceived the original idea for the study, supervised the survey design and analysis and reviewed and edited drafts of the paper

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The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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Nick Craddock

Institute of Psychological Medicine & Clinical Neurosciences, Cardiff University, Cardiff, UK

The authors have addressed the concerns I raised in my first review by moderating their claims and providing a much improved discussion of the limitations of their study. It is now much improved and is a useful contribution to the literature that it can be hoped will stimulate future systematic studies of advanced decision making in people with bipolar disorder.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: bipolar disorder, genetics

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 24 May 2019

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Soumitra Pathare

Centre for Mental Health Law and Policy, Indian Law Society, Pune, Maharashtra, India

I have read the revised paper, the explanations for revisions provided by the authors and Prof Bartlett's comments on the revised version.

The paper does raise important issues as highlighted by Prof Bartlett in his report on the revised version. For now though, I think the authors' have sufficiently addressed queries raised in my initial review and I am happy to approve it.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Mental Health Law, Human Rights, Advance planning

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 30 April 2019

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Peter Bartlett 

School of Law and Institute of Mental Health, University of Nottingham, Nottingham, UK

I would provide some additional thoughts flowing from the paper and the comments provided by Dr Hindley, in hopes that they may assist in conceptualizing forthcoming elements of the project, most notably the qualitative arm.

My interest in particular is in the comments provided on what Dr Hindley labels as points 2 and 3 in my comments, notably as regards point 2:

'In terms of the specific examples given, although an LPA may be the only *legal* way to designate a substitute decision maker, we should not assume that all service-users should want to operate on a legal level in this way. The same can be said of ADRTs. This is supported by the fact that 71% of people indicated a preference for informal Ads which suggests that a large proportion are actively seeking non-legal routes (although we accept the issues you raise with this definition and discuss these below).'

and point 3:

'The purpose of differentiating formal from informal in this way was to distinguish between people who had engaged or wanted to engage *knowingly* with the MCA and its associated legal framework from people who had engaged in ADM outside this legal framework.

'ADM is a complex area where the law interacts with medical practice, ethics and, ultimately, challenging and distressing moments in people's lives. Although we agree that any form of ADM has the potential to be interpreted according to the MCA, we were aware that, for some people, this was not necessarily something they had considered when drafting their advance plan and, similarly, may not be something they would like to consider as part of their plan. The reasoning behind this was based on Morriss et al.'s survey which only addressed the MCA provisions for ADM. As our focus was on a broad definition of ADM, not limited to MCA.'

These raise a forest of questions.

To begin with, what is meant in the comment by 'legal' in the response to point 2? If what is meant is that service users wanted a simple way to give people a real power to make decisions over them without signing an LPOA (perceived often and with some justification as a technical process, often involving a lawyer), fair enough – but that is not on offer at the moment. If the point is that the MCA should be amended to make this possible, that is certainly a debate that can be had.

My use of the term 'legal' instead was meant to refer to whether the appointments were actually effective, and unless they are through an LPOA, at the moment they are not. 'Informal' schemes do not create substitute decision-makers; at best they create the purported decision-maker as 'someone to be consulted on the matter in question' [s 4(7)(a) – perhaps surprisingly, a provision we don't see referred to much anywhere in the literature]. When the treatment decision gets made, it is still the clinician who makes it, and he or she must consider whether the treatment is in P's best interests under s 4. If notwithstanding the view of the consultee the clinician thinks that it is in P's best interest, the treatment should go forward, even if the consultee under 4(7)(a) disagrees, and the doctor exposes himself or herself to liability if it does not. In that situation, I suspect the person is likely to get treated, whatever the purported decision-maker identified by P thinks. If what the individual wants is to appoint somebody who has the actual authority to make the decisions in the event of incapacity so that in this example the substitute's refusal holds sway, my original comment stands: the only way to do this at the moment is through an LPOA.

I would encourage the team to explore some of these issues in the qualitative sessions: what exactly do people making 'informal' appointments of this type think they were doing? The status quo may, after all, be precisely the result that the individual wanted – formalized involvement of an identified person but not actually a transfer of decision-making. That is fine, and consistent with the existing Act, but it is not really appointment of a substitute decision-maker.

That leads to the second part of the comment. I certainly take the point that a minority of people will have heard of the MCA in their daily lives, although it is much less clear to me why this is a helpful distinction for purposes of the present paper. To say that the MCA 'may not be something they would like to consider as part of their plan' is much more problematic. With very few exceptions (LPOAs and ADRTs that would result in the risk to life being the obvious examples), the MCA does not impose formalities requirements for statements: anything a person says may be relevant to a best interests determination under the MCA. It is a bit like saying 'I do' at the altar – the bride or groom may not want to think about the legal ramifications at that moment, but they are there nonetheless. I was a part of the team in the Morriss study cited, and I have to say that I disagree with the characterization that we 'only addressed the MCA provisions for ADM'. In our study, almost two thirds of our 650 service user participants had not heard of the MCA before the study: it was manifestly not something they had considered when drafting their advance plans (see Bartlett, Mudigonda, Chopra et al, 270¹). What we did do is look at how those plans intersected with the provisions of the MCA. In the context of medical treatment, I am struggling to think of advance planning that would not be MCA relevant; perhaps the authors of the present paper can put me right on this.

I suggest to the authors that the greater risk is people wishing to ignore or being unaware of the MCA relevance of their plans, when such relevance does exist. That too is a matter to which we drew attention (Bartlett, Mudigonda, Chopra et al, 274-5¹). Again, it would be interesting to know from the qualitative elements of the present project how the people making plans view this set of issues.

All of this moves the discussion a considerable way from the drafting of the present paper, and I am not sure that further re-drafting will be helpful in addressing the ongoing concerns noted above. My initial concerns have been addressed I think as far as they can be given the data. As for the above comments, suffice it to say that I look forward to reading the next stage of the research.

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Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Mental disability law

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Version 1

Reviewer Report 04 March 2019

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Soumitra Pathare

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This paper reports the findings of a self-report online survey of attitudes of persons with Bipolar disorder towards Advance Decision making (ADM).

I liked the paper and it is an important addition to our understanding of this area.

I have two concerns which have been raised by two previous reviewers and an additional concern of my own.

First, issues of representativeness of the sample, both within the membership of BPUK and the broader population of persons with Bipolar Disorder who may not be members of BPUK. The former question (representativeness to membership of BPUK) can possibly be answered by the authors, as BPUK may have some demographic data on their members. The latter question is probably harder to address.

The issue of representativeness is particularly important as the study had a high level of respondents with university education and a relatively high level of respondents who had some experience of ADM.

The second issue of concern has also been flagged by one previous reviewer - the clarity of terms and questions in the questionnaire. For obvious reasons, this cannot now be changed, but it may be useful to take this into account when planning future studies using online self-report methodology.

I am a little concerned by the authors mixing up concepts as are previously understood in the existing literature. Advance planning is an expression of a person's will and preference and does not (and should not) imply that a clinician or family member should be involved (although it maybe a person's choice to have them involved) and they should consent to this advance planning document.

I am therefore concerned about this statement in the questionnaire:

““Would you like to collaborate with your psychiatrist or GP to produce an advance care plan that they could sign showing they agree with the contents of the plan?”

This should not be regarded as an advance planning document and is closer to a joint crisis plan. This question does not acknowledge the power dynamics in the patient-doctor relationship (especially in mental health due the presence of the Mental Health Act) and I am concerned that the authors would regard this as an advance planning document.

Some minor quibbles:

"Angst et al. reported a median of 0.4 and 0.3 episodes per year for BP I and II patients respectively" - For ease of reading can this be converted to years eg. 1 episode in 3 years etc.

Can you include a glossary of all the acronyms - it does get confusing at times when reading the paper.

And finally some self-promotion : you may want to read our review of barriers to advance decision making (see citation below).

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1. Shields LS, Pathare S, van der Ham AJ, Bunders J: A review of barriers to using psychiatric advance directives in clinical practice. *Adm Policy Ment Health*. 2014; **41** (6): 753-66 [PubMed Abstract](#) | [Publisher Full Text](#)

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: I have published academic work on this topic previously. I have also been involved in drafting India's Mental Healthcare Act, 2017 which introduced advance directives into Indian legislation.

Reviewer Expertise: Mental Health Law, Human Rights, Advance planning

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 04 Apr 2019

Guy Hindley, King's College London, London, UK

Thank you for your helpful comments. Please see our responses below:

1. *First, issues of representativeness of the sample, both within the membership of BPUK and the broader population of persons with Bipolar Disorder who may not be members of BPUK. The former question (representativeness to membership of BPUK) can possibly be answered by the authors, as BPUK may have some demographic data on their members. The latter question is probably harder to address.*

The issue of representativeness is particularly important as the study had a high level of respondents with university education and a relatively high level of respondents who had some experience of ADM.

We agree this is an important limitation to our findings and have made several edits to emphasise this point, including demographic information on the population of people with BP in the UK. Please see our replies to Professor Craddock's report above.

2. The second issue of concern has also been flagged by one previous reviewer - the clarity of terms and questions in the questionnaire. For obvious reasons, this cannot now be changed, but it may be useful to take this into account when planning future studies using online self-report methodology.

We agree that this study would have benefited with more clarity at the design stage. We will certainly learn from this for future studies. Please also see our reply to Peter Bartlett's report above.

3. I am a little concerned by the authors mixing up concepts as are previously understood in the existing literature. Advance planning is an expression of a person's will and preference and does not (and should not) imply that a clinician or family member should be involved (although it maybe a person's choice to have them involved) and they should consent to this advance planning document.

I am therefore concerned about this statement in the questionnaire:

““Would you like to collaborate with your psychiatrist or GP to produce an advance care plan that

they could sign showing they agree with the contents of the plan?"

This should not be regarded as an advance planning document and is closer to a joint crisis plan. This question does not acknowledge the power dynamics in the patient-doctor relationship (especially in mental health due the presence of the Mental Health Act) and I am concerned that the authors would regard this as an advance planning document

We agree that this statement is very much in line with the Joint Crisis Plan model. However, we disagree that this means it is therefore no longer an advance planning document, or alternately an advance decision. Although definitions may differ, our understanding of the term advance decision is a decision that is made in advance of someone losing the ability to make that decision for themselves. It therefore makes no judgement on how or with whom this decision is made so long as the individual is involved in that decision-making process.

If we utilise this definition, there can therefore be several different approaches to practicing ADM. Nicaise et al. provide an interesting analysis of the conceptual frameworks behind different psychiatric advance directives breaking it down into "user's autonomy", "therapeutic alliance" and "integration of care-partnership".³ According to this approach, your definition would fall firmly under the "user's autonomy" domain, while Joint Crisis Plans, and the sort of intervention hinted at in the question above would lean more to the "Therapeutic Alliance" domain. What's more, we do make reference to this alternative model for ADMs in the text as you can see below:

"Some have suggested that this is the way ADM should be conducted: for ADM to truly enhance autonomy, they should be completed without the involvement of mental health professionals" (P14)

This is not to say that the power dynamics within the doctor-patient relationship are not a key consideration to this kind of ADM, and perhaps an area that we have not explored sufficiently within our study. Nonetheless, we feel this is, at present, outside the scope of our paper and we remain of the opinion that the model proposed above is consistent with the broader definition for ADM that we and others have used.

4. "Angst et al. reported a median of 0.4 and 0.3 episodes per year for BP I and II patients respectively" - For ease of reading can this be converted to years eg. 1 episode in 3 years etc.

This has been changed accordingly.

5. Can you include a glossary of all the acronyms - it does get confusing at times when reading the paper.

We have removed several of the acronyms and also provided a glossary of the remaining acronyms.

6. And finally some self-promotion: you may want to read our review of barriers to advance decision making (see citation below).

Thank you for pointing us in the direction of your informative review. We hope our findings help elaborate further on many of the themes you have discussed. It was particularly helpful to read your discussion on revocability, enforceability and prior knowledge. We have expanded slightly our discussion on the latter to reflect this and referenced your review accordingly:

“Low levels of awareness of the MCA has previously been reported among people with BP while limited awareness of ADM among people with mental illness including dementia has also been identified as a key barrier to its implementation⁴”

References:

Nicaise P, Lorant V, Dubois V. Psychiatric Advance Directives as a complex and multistage intervention: a realist systematic review. *Health Soc Care Community*. 2013;21(1):1-14. doi:10.1111/j.1365-2524.2012.01062.

Competing Interests: I am the first author of this paper. No other competing interests to declare.

Reviewer Report 18 February 2019

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Peter Bartlett 

School of Law and Institute of Mental Health, University of Nottingham, Nottingham, UK

This article reports the results of an online survey of the attitudes of people with bipolar disorder (n=932) to various forms of advance decision-making in anticipation of a loss of mental capacity. The article is quantitative only: there is no qualitative analysis.

There is much in this article to like. It would appear to be a robust and statistically astute survey, drawn from the contact list of Bipolar UK. Statistical techniques appear appropriate, and, in methodological terms, the findings seem convincing.

I am happy enough with the sample size, but a bit more discussion might be appropriate as to its representativeness. I understand that this cannot be according to the classic statistical rules – it is not ‘random’ in that sense – but it would be helpful to know whether the demographics of the sample broadly match the demographics of the broader population of people with bipolar. I also note that fewer than 1/3 of the people who accessed the questionnaire finished it. As it stands, the response rate is only 5.6%, less almost 1/6 of responses that were excluded [p5]. Some indication of how typical this sample is of people with bipolar would be helpful.

I think the article would be significantly improved if some of the concepts and categories were explained more carefully, and/or the apparent incoherences discussed more carefully. On page 7, for example, we are told that 68% of respondents wanted to state who should make decisions for them in the event that they lost capacity, but only 40-43% would make an LPA, without any acknowledgement that the only legal way to do the former is to do the latter – that is what an LPA is, and without it, any view as to who should make decisions for you has no effect - it is still (for medical decisions) the treating physician. There is similarly nothing to suggest that the people who wished to refuse specific medications understood that the way you do that is through an ADRT (the numbers are similar for each - if they were the same people, that

should be explained, but I would be surprised). I suspect what is going on here is that the respondents have limited and sometimes incorrect knowledge of the legal provisions. That is fair enough – normal people do not sleep with copies of the MCA under their pillows, and cannot readily parrot out its terms – but if in fact they do not really understand the provisions, and may misunderstand them in different ways, it raises questions as to how we interpret their responses.

The paper similarly speaks of ‘informal’ plans, as distinct (it would seem) from ADRTs and statements of wishes. It is not at all clear what this means. It is possible that some respondents read it as a distinction between oral and written statements, since the questionnaire refers to ADRTs and statements of wishes as ‘legal documents’. In this the questionnaire is deficient, since there is no requirement under the MCA that statements of wishes nor (with exceptions not relevant here) that ADRTs be in any particular form: in both cases quite informal statements, including oral statements, are meant to have legal effect. (I think there is a sensible argument to the effect that the MCA should not have taken that approach, but that is an issue for another time: that is the approach it takes.) At other times, though, the questionnaire seems to view advance care plans or crisis plans (presumably whether oral or in writing?) as ‘informal’, in juxtaposition to ADRTs and statements of wishes. Again, it is not at all clear what distinction is being drawn here, as wishes or treatment refusals contained in care plans or crisis plans are manifestly statements of wishes or ADRTs under the MCA. This lack of clarity again makes analysis of the results difficult: what did the people think they were agreeing to?

Page 4 of the draft contains an explanation of what is meant by ‘self-binding directive’, a concept that is discussed at some length in the paper. There is a difficulty that the detail of this definition is not reflected in the only question about SBDs in the questionnaire, which refers only to ‘the person want[ing] the contents of their advance care plan to be respected even if they no longer agree with it when they are unwell.’ Again, I am not sure that one can slide between the two articulations in quite the way that the paper does.

There is an ambiguity running throughout the questionnaire as to whether it is about treatment for mental health conditions or advance decision-making much more broadly. The questionnaire tends to phrase advance decision-making in the context of involvement by the care team and medical professionals, suggesting the former, while there are references in addition to much broader planning, albeit often placed in the context of a care plan (which is generally understood as a relatively medical mechanism). These distinctions are not always teased out as carefully as they might have been. Thus one might well imagine an affected person P wanting to discuss his or her medical treatment choices with medical and care professionals; it is much less obvious that he or she would, if running a business, want to discuss with medical and care professionals how the business should be run in the event of incapacity. The paper does seem to elide these differences at times, and I am afraid I did not find this convincing, and when respondents are discussing who they would seek advice from, it is not obvious which sort of decision they had in mind.

These issues I think really are problematic, and it is difficult to see how they can be remedied since they flow from the questionnaire itself. The ambiguities do make it somewhat difficult to see how the analysis of the results should be understood, however.

I have a number of lesser criticisms that the authors might wish to consider.

In the discussion of the MCA and MHA, it would be worth noting that the MHA covers only treatment for mental disorder: If a person with bipolar has a somatic health disorder, the MCA applies.

The discussion of ADs and their use in crisis situations is interesting but begs the question of the 50% of respondents who did not feel that their plan was respected in the crisis, the 40% that did not think they recovered faster, the 40% that did not report improved experience of health services, the 45% that were not happy with how their plan had been used in the crisis, the 56% that did not find that the plans were very or extremely helpful in reducing harm to relationships, the 66% that did not report a reduction in physical harm, and the 77% that did not find them very or extremely helpful in reducing overspending. It does feel rather that we are being told half a story here!

The fact that after the statistical beeps and whistles get applied, the only correlation with support of SBDs is shown to be trust in medics is in a sense profoundly unsurprising – although still worth saying. It does return to the question of what is meant by an SBD, and medical contextualisation. Do we know whether they were thinking of medical SBDs here (as would be my guess) as distinct from SBDs, say, as to how a business will be run?

Finally, I think that for a paper of this size, there is too much of a deluge of acronyms – BP, SMI, DMC-T, ADM, ADRT, EPA, UNCRPD (used only once in the body of the text), MHA, MCA, AS, SBD, BPUK. Are they all really necessary? Only about half will be known to people who work in the field; even for them the paper will therefore be hard going. For neophytes, this is likely to be a serious barrier.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Partly

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Yes

Are all the source data underlying the results available to ensure full reproducibility?

Yes

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Mental disability law

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 04 Apr 2019

Guy Hindley, King's College London, London, UK

Thank you for your detailed and insightful comments. Please see below for responses to the issues you have raised:

- 1. I am happy enough with the sample size, but a bit more discussion might be appropriate as to its representativeness. I understand that this cannot be according to the classic statistical rules – it is not ‘random’ in that sense – but it would be helpful to know whether the demographics of the sample broadly match the demographics of the broader population of people with bipolar. I also note that fewer than 1/3 of the people who accessed the questionnaire finished it. As it stands, the response rate is only 5.6%, less almost 1/6 of responses that were excluded [p5]. Some indication of how typical this sample is of people with bipolar would be helpful.*

This is certainly an important limitation that is discussed in depth in Professor Nick Crawford’s report above. As mentioned above, we are unfortunately unable to compare the demographics of our sample directly to the BPUK’s mailing list as they do not store this information. Nor are we able to compare the demographics of people who started the survey to people who finished the survey, which would also provide some insight into the response rate, as the demographics was at the end of the survey. Nonetheless your suggestion to compare our demographics to those of the wider population of people with bipolar is helpful. We have therefore added the following to our discussion:

“This is a predominantly white (94%), female (71%), well-educated sample (64% university educated) which is not representative of the wider population of people with bipolar in the UK (88.8% white, 48.9% female and 36% university educated) ¹.”

- 2. I think the article would be significantly improved if some of the concepts and categories were explained more carefully, and/or the apparent incoherences discussed more carefully. On page 7, for example, we are told that 68% of respondents wanted to state who should make decisions for them in the event that they lost capacity, but only 40-43% would make an LPA, without any acknowledgement that the only legal way to do the former is to do the latter – that is what an LPA is, and without it, any view as to who should make decisions for you has no effect - it is still (for medical decisions) the treating physician. There is similarly nothing to suggest that the people who wished to refuse specific medications understood that the way you do that is through an ADRT (the numbers are similar for each - if they were the same people, that should be explained, but I would be surprised). I suspect what is going on here is that the respondents have limited and sometimes incorrect knowledge of the legal provisions. That is fair enough – normal people do not sleep with copies of the MCA under their pillows, and cannot readily parrot out its terms – but if in fact they do not really understand the provisions, and may misunderstand them in different ways, it raises questions as to how we interpret their responses.*

We attempted to prevent this by providing succinct definitions of each of the provisions for ADM currently available under the MCA at the beginning of the questionnaire (p2, supplementary material). This was presented on its own page on the online version which we hoped would encourage people to read these definitions.

Nonetheless, survey methodology is certainly vulnerable to validity problems due to misunderstanding of questions. We had previously made reference to this in the limitations section, but we have made this more explicit as follows:

“What’s more it is possible that some participants misunderstood some of the complex concepts contained within the questionnaire.”

However, it is important to note that misunderstanding is not the only possible explanation for these inconsistencies. In terms of the specific examples given, although an LPA may be the only *legal* way to designate a substitute decision maker, we should not assume that all service-users should want to operate on a legal level in this way. The same can be said of ADRTs. This is supported by the fact that 71% of people indicated a preference for informal ADs which suggests that a large proportion are actively seeking non-legal routes (although we accept the issues you raise with this definition and discuss these below). This is further supported by unpublished findings from focus groups that we have conducted which suggest that ambiguous attitudes towards legally-binding ADM is a real finding, not just an artefact of our survey design.

We discuss this ambiguity in the section *“Inconsistent attitudes towards legal status”*. We have expanded this section as follows to include the two further examples that you have suggested:

“Respondents expressed a preference for non-legally binding forms of ADM which included information about refusing medication or substitute decision makers over legally binding forms that could communicate the same information such as ADRTs and LPAs.”

Unfortunately the number of people wishing to refuse specific medication (68%) was significantly higher than those who wanted to make an ADRT (35%) and so the additional analysis suggested was not informative.

3. The paper similarly speaks of ‘informal’ plans, as distinct (it would seem) from ADRTs and statements of wishes. It is not at all clear what this means. It is possible that some respondents read it as a distinction between oral and written statements, since the questionnaire refers to ADRTs and statements of wishes as ‘legal documents’. In this the questionnaire is deficient, since there is no requirement under the MCA that statements of wishes nor (with exceptions not relevant here) that ADRTs be in any particular form: in both cases quite informal statements, including oral statements, are meant to have legal effect. (I think there is a sensible argument to the effect that the MCA should not have taken that approach, but that is an issue for another time: that is the approach it takes.) At other times, though, the questionnaire seems to view advance care plans or crisis plans (presumably whether oral or in writing?) as ‘informal’, in juxtaposition to ADRTs and statements of wishes. Again, it is not at all clear what distinction is being drawn here, as wishes or treatment refusals contained in care plans or crisis plans are manifestly statements of wishes or ADRTs under the MCA. This lack of clarity again makes analysis of the results difficult: what did the people think they were agreeing to?

The purpose of differentiating formal from informal in this way was to distinguish between people who had engaged or wanted to engage *knowingly* with the MCA and its associated legal framework from people who had engaged in ADM outside this legal framework.

ADM is a complex area where the law interacts with medical practice, ethics and, ultimately, challenging and distressing moments in people’s lives. Although we agree that any form of ADM has the potential to be interpreted according to the MCA, we were aware that, for some people, this was not necessarily something they had considered when drafting their advance plan and, similarly, may not be something they would like to consider as part of their plan. The reasoning behind this was based on Morriss et al.’s survey which only addressed the MCA provisions for

ADM. As our focus was on a broad definition of ADM, not limited to MCA.

Nonetheless, we agree that this distinction was not made clear in the write-up and we can understand why this may have been confusing. We have therefore added the following to the introduction:

“If ADM is to be expanded amongst the BP community, it is important to refine our understanding of the views of those with BP and how existing provision might be tailored to meet the needs of those using it. In particular, it is possible that people with BP may be practicing ADM without awareness of the MCA. In order to make this distinction, we have referred to “informal ADM” to mean advance plans that were created outside of the MCA framework for advance planning.”

In the process of doing this we accept that our definitions at the beginning of the questionnaire are simplified and do not capture the nuances of the MCA. In particular, we agree that ADRTs and ASWFs could have been communicated verbally. This is clearly one of the important limitations to survey methodology when tackling such a complicated and nuanced topic: simplifications are hard to avoid. We hope that our focus-group work and analysis of the free text boxes will help to triangulate these findings. We have discussed this in the limitations as follows:

“What’s more it is possible that some participants misunderstood some of the complex concepts contained within the questionnaire.... Further structured qualitative analysis of the free text boxes included in the survey will be reported in a future publication to help deepen our understanding of the respondents’ views.”

4. Page 4 of the draft contains an explanation of what is meant by ‘self-binding directive’, a concept that is discussed at some length in the paper. There is a difficulty that the detail of this definition is not reflected in the only question about SBDs in the questionnaire, which refers only to ‘the person want[ing] the contents of their advance care plan to be respected even if they no longer agree with it when they are unwell.’ Again, I am not sure that one can slide between the two articulations in quite the way that the paper does.

We agree that the questionnaire item relating to SBDs is a simplified version of the discussion of SBDs as given in the introduction. Nonetheless we feel this does tackle the central concept at the heart of self binding:*the concept that the individual wants the contents of their plan to be respected even if they no longer agree to it when they are unwell.* We were wary of providing a lengthier ethical or legal definition given the nature of surveys. This was discussed during the piloting phase and our pilots agreed with this decision.

Nonetheless, we accept that it may be misleading to use the same term for both the discussion of SBDs given in the introduction and the item which we use in the survey. As this is an issue of how the information from the questionnaire is represented in the paper rather than incoherencies within the questionnaire itself, we feel this can be remedied. In order to make the distinction we have added the following to the introduction:

“However, at the heart of both accounts is a willingness to engage with the idea of “self-binding” – the concept that the individual wants the contents of their plan to be respected even if they no longer agree to it when they are unwell.”

We have subsequently referred to “self-binding” rather than SBDs in the results and discussion whenever referring to this specific item.

Despite this, the outcome of interest relating to SBDs combines this item with an item about willingness to collaborate with a doctor. We think this is justified as these are, according to Gergel and Owen's model, the two essential components of SBD. We have made this more explicit in the methods by adding the following:

"This was designed as a proxy measure for interest in self binding directives as these are essential components to the model as proposed by Gergel and Owen ²."

We have also added the following paragraph in the limitations:

"We utilised a proxy-measure for interest in SBDs by combining interest in self-binding statements with a willingness to collaborate with doctors. This was because we decided that attempting to explain SBDs in a survey was likely to generate confusion. This means our results cannot be interpreted as a direct endorsement for SBDs. We have conducted focus groups in which SBDs were discussed as part of a parallel study which will help to triangulate these findings."

5. There is an ambiguity running throughout the questionnaire as to whether it is about treatment for mental health conditions or advance decision-making much more broadly. The questionnaire tends to phrase advance decision-making in the context of involvement by the care team and medical professionals, suggesting the former, while there are references in addition to much broader planning, albeit often placed in the context of a care plan (which is generally understood as a relatively medical mechanism). These distinctions are not always teased out as carefully as they might have been. Thus one might well imagine an affected person P wanting to discuss his or her medical treatment choices with medical and care professionals; it is much less obvious that he or she would, if running a business, want to discuss with medical and care professionals how the business should be run in the event of incapacity. The paper does seem to elide these differences at times, and I am afraid I did not find this convincing, and when respondents are discussing who they would seek advice from, it is not obvious which sort of decision they had in mind.

As you rightly point out, our questionnaire has an implicit focus on mental health treatment and there are whole domains of advance planning relating to financial affairs, work and relationships that we have not fully addressed. For our reader's sake, we have made this more explicit by including the following to the introduction:

"It can also contain information about various aspects of an individual's life such as medical treatment, financial affairs or arrangements for work. This study focuses primarily on medical treatment."

And adding the following to the Aims:

"This study aimed to address the following objectives, with a focus on medical treatment:"

This does not, however, address the ambiguity within the questionnaire itself. We have therefore made reference to this in the limitations section, as well as the fact that we do not explore other forms of ADM as follows:

"What's more it is possible that some participants misunderstood some of the complex concepts contained within the questionnaire. Our focus on ADM in relation to medical treatment may have

added to this potential misunderstanding. ADM can relate to financial or work matters and it is possible that some of our respondents may have been referring to these in some of their responses. Further structured qualitative analysis of the free text boxes included in the survey will be reported in a future publication, helping to disambiguate this. While further research is needed to explore ADM for matters such as finances and work.”

6. *These issues I think really are problematic, and it is difficult to see how they can be remedied since they flow from the questionnaire itself. The ambiguities do make it somewhat difficult to see how the analysis of the results should be understood, however.*

We hope we have addressed these concerns by drawing attention to the broader issue of misunderstanding between participants and researchers in the limitations section, clarifying our definitions of “informal ADM” and the self-binding item and making our medical focus more explicit. We are therefore confident that our findings remain sufficiently valid for us to draw important, if tentative, conclusions, despite these limitations.

7. *In the discussion of the MCA and MHA, it would be worth noting that the MHA covers only treatment for mental disorder: If a person with bipolar has a somatic health disorder, the MCA applies.*

Thanks for picking up on this. We do state that the MHA “enables compulsory treatment for mental disorder” (p3). However to make this more explicit we have added the following:

“Although if they were to be treated for a physical health condition, the MCA would still apply.”

8. *The discussion of ADs and their use in crisis situations is interesting but begs the question of the 50% of respondents who did not feel that their plan was respected in the crisis, the 40% that did not think they recovered faster, the 40% that did not report improved experience of health services, the 45% that were not happy with how their plan had been used in the crisis, the 56% that did not find that the plans were very or extremely helpful in reducing harm to relationships, the 66% that did not report a reduction in physical harm, and the 77% that did not find them very or extremely helpful in reducing overspending. It does feel rather that we are being told half a story here!*

This was in fact a discussion we had during the drafting of the paper and we decided it was a good example of the “glass half full vs glass half empty” debate! The point we are trying to make here is that even the fact that, for example, 50% of ADMs were highly or completely respected, this is a notable finding given the scepticism around the implementation of ADM in clinical practice. This is therefore worth stressing. Nonetheless, we agree that this could be misleading and so we have added the following:

“This is preliminary evidence that ADM produced outside of an “experimental” setting can be used in crisis with therapeutic effect and that they tend to be respected when they are used, although it is worth noting that significant proportions of our sample did not report these positive experiences.”

In addition, there is in fact a lot less than half of the story being told here as there is only so much we can understand by these quantitative survey responses. We hope to reveal much more of the detail underlying these responses during the analysis of the free text boxes.

9. *The fact that after the statistical beeps and whistles get applied, the only correlation with*

support of SBDs is shown to be trust in medics is in a sense profoundly unsurprising – although still worth saying. It does return to the question of what is meant by an SBD, and medical contextualisation. Do we know whether they were thinking of medical SBDs here (as would be my guess) as distinct from SBDs, say, as to how a business will be run?

Although this finding may seem obvious, the debate over the role of medical practitioners in the production of ADM documents is ongoing (as can be seen in Prof Pathare's report below). This finding may, therefore, be more surprising to people who would advocate a patient driven SBD motivated, for example, by distrust that doctors deliver continuity of care based on prior knowledge of them.

The fact that trust in medics was significantly associated with interest in SBDs would suggest that a sufficient number of respondents understood that we were talking about medical SBDs and we think the effect of any ambiguity in the questionnaire would be to underestimate the strength of this association.

10. Finally, I think that for a paper of this size, there is too much of a deluge of acronyms – BP, SMI, DMC-T, ADM, ADRT, EPA, UNCRPD (used only once in the body of the text), MHA, MCA, AS, SBD, BPUK. Are they all really necessary? Only about half will be known to people who work in the field; even for them the paper will therefore be hard going. For neophytes, this is likely to be a serious barrier.

On re-reading the paper after some time away, I couldn't agree more with you on this point! As Professor Pathare suggested, we have therefore added a glossary of terms to make this a little less daunting. We have also removed the following acronyms: SMI, DMC-T, DMC, UNCRPD and AS.

Competing Interests: I am the first author of this paper. No other competing interests to disclose.

Reviewer Report 12 February 2019

<https://doi.org/10.21956/wellcomeopenres.16350.r34714>

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Nick Craddock

Institute of Psychological Medicine & Clinical Neurosciences, Cardiff University, Cardiff, UK

This paper describes a self-report questionnaire study about experiences of, and attitudes towards, advance decision making (ADM) in individuals with bipolar disorder. The sampling frame population is the Bipolar UK charity mailing list. The response rate is quoted as 5.61% of those on that list but the main analyses presented relate to self-reported patients and excludes self-reported carers - a total of 932 respondents out of 20,134 people who had registered their email addresses to be contacted by the charity.

The authors report various summary statistics that demonstrate that many in their sample has an interest in ADM and that their access to experience of ADM falls short of their ideal wish. The authors state that this is the largest study to date of this issue and is a "leap forward" in understanding.

The use of ADM in bipolar disorder is an issue that has complicated ethical and practical issues that require attention and it is helpful to have research that helps to inform these discussions. However, there are substantial limitations with the current study that greatly reduce the ability to make any generalisations or broad conclusions.

The fundamental limitation is the difficulty in knowing to what extent the sample studied relates to the population of individuals with a bipolar disorder in the UK. Their respondents are a very small proportion of those on the email contact list of the charity bipolar UK who have self identified as having a bipolar diagnosis (who are in turn a subset of the broader membership of bipolar UK) - it would be helpful to know how the demographics of those on the email list as a whole compare with those in sample studied.

Those who chose to volunteer for the questionnaire study are likely to be substantially biased towards those who have particular views they would like to articulate - and, of course, the authors acknowledge the high level of university-level education.

Of course, the study shows that there are individuals who want to use ADM and that people have experiences of ADM that are inadequate or unavailable. However, it is not straightforward, with the data and analyses presented to know how this may generalise to the wider population of those with bipolar disorder diagnoses within the UK.

The claim that this is a "leap forward" seems inappropriately hyperbolic. This is a useful first step to looking at the issue. However, wording such as "suggests the need for more systematic study" would be much more academically circumspect, together with a more detailed discussion about the difficulties in generalising. It would be helpful if the authors could indicate what they would consider a study design that would provide more systematic and generalisable data that would give robust conclusions.

In summary - an interesting preliminary study of an important topic but substantial caution is required in generalising from findings because of the low response rate and the sample biases.

Is the work clearly and accurately presented and does it cite the current literature?

Yes

Is the study design appropriate and is the work technically sound?

Yes

Are sufficient details of methods and analysis provided to allow replication by others?

Yes

If applicable, is the statistical analysis and its interpretation appropriate?

Partly

Are all the source data underlying the results available to ensure full reproducibility?

Partly

Are the conclusions drawn adequately supported by the results?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: bipolar disorder, genetics

I have read this submission. I believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 04 Apr 2019

Guy Hindley, King's College London, London, UK

Dear Professor Craddock,

Thank you for your thoughtful comments. Please see below for responses to the issues raised in your report:

1. The fundamental limitation is the difficulty in knowing to what extent the sample studied relates to the population of individuals with a bipolar disorder in the UK. Their respondents are a very small proportion of those on the email contact list of the charity bipolar UK who have self identified as having a bipolar diagnosis (who are in turn a subset of the broader membership of bipolar UK) - it would be helpful to know how the demographics of those on the email list as a whole compare with those in sample studied.

We agree that this is an important limitation to our study. In the limitations section we do note this ourselves:

“The use of BPUK mailing list as the sampling frame and a low response rate introduce further selection bias. People with a prior awareness or interest in ADM are likely to be over-represented. These findings must therefore be generalised with caution and the study seen as exploratory.”

However we accept that it would be helpful to also include it in the concluding paragraph. We have therefore added the following sentence to the conclusions:

“The results suggest services users with BP want to use ADM and they want collaborative input from mental health services in doing so. However, the low response rate mean further research is needed to determine the generalisability of these findings.”

We also agree that comparing responders to non-responders would allow us to assess how representative our sample is of the demographics of the BPUK mailing list (although this would still not address the issue of selection bias towards people with a prior interest in ADM). Unfortunately, BPUK do not keep this kind of demographic information about the members of their mailing list and so this was not possible.

2. Of course, the study shows that there are individuals who want to use ADM and that people have experiences of ADM that are inadequate or unavailable. However, it is not straightforward, with the data and analyses presented to know how this may generalise to the wider population

of those with bipolar disorder diagnoses within the UK.

We accept that given the methodology used and the response rate achieved, it is very difficult to comment on the generalisability of these findings. In the limitations section we currently say:

“These findings must therefore be generalised with caution and the study seen as exploratory.”

To make this limitation more explicit we have edited this sentence as follows:

“It is therefore difficult to generalise these findings and the study should be seen as exploratory.”

Nonetheless, as we note in the limitations section, the results of this survey do still represent the opinions and experiences of almost 1000 people with bipolar in the UK. Although these findings may not be generalisable to the entire population, they are likely to represent a subset of this population. Given the dearth of research on this topic within this population, particularly with regards to *experiences* of ADM, we feel our findings do still represent an important step forward in the field’s understanding.

3. The claim that this is a “leap forward” seems inappropriately hyperbolic. This is a useful first step to looking at the issue. However, wording such as “suggests the need for more systematic study” would be much more academically circumspect, together with a more detailed discussion about the difficulties in generalising. It would be helpful if the authors could indicate what they would consider a study design that would provide more systematic and generalisable data that would give robust conclusions.

We agree that, given the limitations, it would be preferable to change the language used here. We have therefore changed this sentence to read:

“It provides an important step forward in understanding experiences and attitudes towards ADM in this group.”

With regard to the discussion of generalisation and study design we have already mentioned respondent-driven sampling which can be utilised in hard to reach groups and given a reference (reference 36). In addition to the changes already discussed above, we have also indicated a study design that could help provide more generalisable findings in clinical settings, as suggested:

“While in order to understand the generalisability of these findings, a simplified version of the survey should be conducted using a more representative sampling technique such as convenience sampling through outpatient clinics or systematic sampling through the use of a patient research database such as the Clinical Record Interactive Search system”

Competing Interests: I am the first author of this article. No other competing interests to disclose.