

## Planning for Incapacity by People with Bipolar Disorder under the Mental Capacity Act 2005<sup>1</sup>

### I. INTRODUCTION

International human rights law increasingly expects the will and preferences of persons with mental disabilities to be pivotal in decision-making about them. Article 12 of the United Nations Convention on the Rights of Persons with Disabilities enjoins States Parties to ‘recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.’ (United Nations, General Assembly, A/61/611, Art 12(2)). The Committee on the Rights of Persons with Disability, the United Nations body charged with the implementation of the Convention, interprets this to mean that States Parties are to move away from systems where decisions are taken about people with disabilities without their involvement, to systems where the person with disability is supported to make decisions himself or herself. In its General Comment about Article 12, the Committee states that for convention compliance, decisions must be based on the will and preferences of the person with disabilities rather than the objective best interests of that individual (United Nations Committee on the Right of Persons with Disabilities 2013, para 21). The Committee considers the right to engage in advance planning to be part of this new legal framework:

For many persons with disabilities, the ability to plan in advance is an important form of support, whereby they can state their will and preferences which should be followed at a time when they may not be in a position to communicate their wishes to others. All persons with disabilities have the right to engage in advance planning and should be given the opportunity to do so on an equal basis with others. States parties can provide various forms of advance planning mechanisms to accommodate various preferences, but all the options should be non-discriminatory. Support should be provided to a person, where desired, to complete an advance planning process. (United Nations Committee on the Right of Persons with Disabilities 2013, para 17)

Systems of advance planning are therefore likely to become increasingly important in disability law. Introduction of such systems does not, of course, mean that they will be used, and the current empirical literature suggests that they are not. Bond, summarising international studies, notes:

Surveys of doctors and patients have shown consistently positive attitudes to all forms of anticipatory decisions in principle. However, they been found to have little impact on physician decision-making in practice. (Bond and Lowton, 2011, 451)

The present study examines the use of advance planning mechanisms by people with bipolar disorder under the Mental Capacity Act 2005 in England (hereinafter the ‘MCA’). It explores both the ways in which the mechanisms are used, and, importantly, the experiences of service users and practitioners in the process of implementation. As such, it examines not merely how the mechanisms are or are not being implemented, but also why.

The MCA formalised, clarified, and extended the law in England and Wales relating to advance planning for people with capacity, envisaging times when they might lack capacity. Powers of attorney for property and affairs, when expressly intended to do so, had since the Enduring Powers

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of Attorney Act 1985 been allowed to remain in effect following incapacity of the donor, and the MCA extended these provisions to include powers of attorney for personal decision-making. Statements of wishes, whether oral or written, were placed on a statutory footing, and are required to be considered when a decision is to be made on behalf of an individual lacking capacity. Advance decisions to refuse treatment were similarly placed on a statutory footing, with formalities requirements introduced for treatment refusals that involved life-sustaining treatment.

While they do not go as far as the Committee on the Rights of Persons with Disabilities would want, these were viewed as significant amendments at the time, adopting a new approach to mental disability and placing service users at the centre of the decision-making process. While the benefits of that approach have recently been re-stated by a committee concerning the MCA of the House of Lords, (House of Lords 2014) little systematic empirical work exists as to how extensively these new mechanisms of advance planning have been implemented, and in particular little empirical work that takes into account the views of service users themselves. The present paper concerns the use of advance planning under the MCA among people with bipolar disorder. This is an additional departure from the existing literature. Empirical studies concerning the implementation of lasting powers of attorney (hereinafter 'LPOAs') under the MCA, whether covering property and affairs or personal decision-making have focussed mainly on people with dementia or in care homes (Bond and Lowton, 2011; Manthorpe et al 2011; Samanta 2012; Samsi et al 2011; Samsi and Manthorpe 2011a; Wilson et al, 2010). Systematic study of advanced decisions to refuse treatment ('ADRTs') is limited to acute hospital care (Phair and Manthorpe 2012) and care of older people (Bond and Lowton 2011).

Bipolar disorder provides a particularly relevant context for the study of advanced planning. It is a cyclical condition affecting 1.4 per cent of the population (Merjkangas et al 2007; Merjkangas and Lamers 2012) and is characterised by periods of moderate to severe depression and separate periods of mania (elated mood, over activity, reckless behaviour, overspending, over-confidence). During these episodes, there is the potential for the person to cause lasting harm to themselves or others e.g. through overspending through impaired judgement as a result of the temporary change in mental state (Chamorro et al 2012). If symptoms are severe enough, both the mania and depression phases of the condition may result in a loss of capacity to make at least some decisions. In between episodes of illness, the vast majority of people with bipolar disorder return to their normal capacity. These experiences repeat over the course of the individual's life. Following onset, generally from the age of 13 to 30 years, an individual can expect ten recurrences of symptoms over the course of his or her life (Merjkangas et al, 2007; Macklin and Young 2005). Furthermore, each relapse into episodes of mania and depression tend to show the same early idiosyncratic pattern of symptoms and behaviour over a few weeks before full relapse occurs, (Jackson et al, 2003) potentially alerting the person, their carers and health professionals to the possibility of periods of time when the capacity may be temporarily lost.

Advance decision-making is therefore particularly appropriate for people with bipolar disorder. While a person making planning in anticipation of dementia, for example, will have to speculate as to how he or she will feel at the time the decision is acted upon, after the first episode, a person with bipolar disorder making an advance decision will have direct experience of the condition and therefore what he or she will or will not want. This is thus a paradigm case of the appropriateness of advance planning. Consistent with this, the National Institute for Health and Care Excellence has since 2006 advised clinicians to collaborate with patients in the development of advance decision-making plans (National Institute for Health and Care Excellence 2006, para 1.1.1.4), and this advice has been recently reaffirmed (National Institute for Health and Care Excellence 2014).

The present paper reports on a study of the use of advance decision-making among people with bipolar disorder. It is based on a quantitative study of 549 people with bipolar disorder and 650 psychiatrists, buttressed with qualitative interviews of fourteen service users and eight psychiatrists. The study was funded by the National Institute of Health Research (NIHR) as part of the PARADES (Psychoeducation, Anxiety, Relapse, Advance Decision Evaluation and Suicidality) study.

## II. ADVANCE DECISION-MAKING IN THE MCA: THE LEGAL CONTEXT

The advance planning elements of the MCA are of two forms. The first allows a person with capacity to determine who will make decisions on his or her behalf during subsequent incapacity, and the second, within bounds, allows the individual to influence and in some cases determine how, substantively, decisions will be taken in the event of subsequent incapacity.

The key mechanism for selecting who is to make decisions is the LPOA (MCA s 9-14). These allow the donor to appoint any adult who is not bankrupt (a 'donee') to make decisions on his or her behalf, in the event that the donor loses capacity. LPOAs are based on the model of Enduring Powers of Attorney (EPOA), introduced in 1985, but where EPOAs had been limited to property and affairs, the MCA opens them up to include personal care decisions. Since the MCA came into effect, no new EPOAs can be created, but those created before the MCA came into effect are still valid. In 2011-12, over 17,000 EPOAs were registered, so they are still certainly relevant.

If an individual does not make an LPOA, the Court of Protection can make relevant decisions for that individual, and if necessary can appoint a 'deputy' to make decisions when an individual loses capacity. This occurs most frequently when significant property and affairs decisions are to be made. For personal care and treatment matters, the Court is generally reluctant to appoint a deputy, (see *G v E and Manchester City Council* [2010] EWHC 2512 (COP)) and decisions will usually be taken under a residual provision that creates a defence for people providing care or treatment in the best interests of people lacking capacity (MCA s 5-6). In practice, this means that local authority employees and medical professionals are at the centre of decision-making for people lacking capacity without LPOAs. In principle, they (like the Court, LPOAs and deputies) are to be meant to consult with persons such as family members engaged in the care of the person lacking capacity as part of the determination of the individual's best interests (MCA, s 4(7)), but in practice it is questionable how extensive and effective such consultation is (Williams et al 2012, 93-4; House of Lords 2014, para 93-101). If a person wishes to determine who will make decisions, particularly in medical and personal welfare matters, the completion of LPOAs is therefore essential.

The LPOA determines who makes decisions in the event of the donor's incapacity; it does not determine how decisions will be made. The donee must do nothing inconsistent with a valid and applicable decision to refuse treatment, but otherwise must still make decisions consistent with the best interests of the individual, as defined by the Act (s 4-6). The best interests criteria do include subjective elements relevant to the donor's wishes and feelings both when competent and when the decision is made, and also the donor's beliefs and values – factors that the person selected as donee may well be well-acquainted with. Nonetheless, if an individual wishes to influence how decisions are to be taken, not merely who will take them, additional advance planning is appropriate.

This can take two forms. The first, and most robust, is the advance decision to refuse treatment (ADRT) (MCA, s 24-26). This allows an individual when competent prospectively to refuse treatment (generally understood to be medical treatment) during a subsequent period of incapacity, in conditions (if any) stipulated in the ADRT. At the time the treatment would be given, the effect of the ADRT is the same as if the individual had capacity and refused the treatment. Subject to

comments below about treatment under the Mental Health Act 1983 (the 'MHA'), the treatment cannot therefore be given. If the ADRT is a refusal of life-sustaining treatment, it must be in writing and signed both by the donor and a witness, but otherwise there are no formality requirements for an ADRT. That said, for evidential purposes, it is almost certainly desirable to put ADRTs in writing and insofar as possible, to notify relevant professionals of their existence before they are relied on. The implications of the ADRT can also be avoided if the donor has done anything clearly inconsistent with the ADRT after it has been made.

ADRTs allow for the refusal of treatments; they do not allow for treatment to be demanded. They are also restricted to 'treatment'. This is most obviously medical treatment, and while there may be some grey area around the term, it would certainly not apply, for example, to decisions regarding property and affairs. To affect the way in which decisions are taken outside the parameters of ADRTs, the MCA allows for statements of wishes and feelings.

Unlike ADRTs, statements of wishes influence but do not determine the outcome of decisions, but rather fall into the mix that constitutes determination of the incapable individual's best interests. As noted, absent an ADRT, whoever makes a decision for a person lacking capacity must make it according to the statutory definition of best interests: there is no opt-out of the statutory criteria. The best interests criteria require the decision-maker to take account of 'the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity)' along with the individual's beliefs and values and any other factors the individual would be likely to consider if he were able to do so (s 4(6)(a)) – matters that can certainly be articulated in a statement of wishes – these are not the only relevant factors in the best interests assessment. The MCA requires the decision-maker to take account of 'all the relevant circumstances' in assessing best interests, whether or not the individual would have prioritised those circumstances. Recent jurisprudence from the Supreme Court has reinforced that best interests decision-making should 'consider matters from the patient's point of view' (*Aintree University Hospitals Foundation Trust v James* [2013] UKSC 67, para 85), presumably buttressing the significance of statements of wishes, but such statements nonetheless still merely influence decisions; they do not determine them.

The MCA is not restrictive in the form that statements of wishes will take, although written statements made while the individual has capacity are stated to have particular relevance (s 4(6)(a)). That said, statements (whether oral or written) made after some reflection, or in some understanding that they will be relied upon, are likely to have more influence than statements made in a spirit of relative informality or frivolity. That does not mean the latter are necessarily to be ignored; but it may affect the weight accorded to the statement.

The MCA mechanisms do not create an independent right to services. The right to services of a person lacking capacity, whether he or she has made an advance plan or not, is the same as any other service user – no more, no less.

Of particular relevance in the case of bipolar disorder is the interaction between the MCA mechanisms and the MHA. These arise in two ways. First, people who lack capacity to make decisions regarding their admission to hospital can often be admitted if the statutory best interests test is met. If the conditions of the MCA 'deprivation of liberty safeguards' ('DOLS') are met, they can be further detained there.<sup>2</sup> The use of the DOLS is not permitted, however, when the proposed treatment is subject to an ADRT (MCA, sch A1, para 19). The legislation is ambiguous as to the effect

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<sup>2</sup> Proposals for substantial amendment to the deprivation of liberty safeguards are currently under consideration by the Law Commission (Law Commission, 2015). Proposals for reform from the Commission are expected at the end of 2016.

of an advance plan other than an ADRT. Certainly, if the present (*ex hypothesi* incapable) wishes of the patient are against admission to hospital for psychiatric treatment, the DOLS cannot be used (MCA, sch 1A, para 5(4)), but the degree to which prior wishes are to be taken into account is unclear. The provision is phrased in the present tense, and states that 'regard is to be had to circumstances from the past only so far as it is still appropriate to have regard to them' (MCA, sch 1A, para 5(7)). That suggests that where appropriate, regard should be had to circumstances from the past (including, presumably, wishes regarding admission and care), but only if 'appropriate', and there is no guidance as to what that word means in this context. In any event, neither of these provisions restricts the use of the compulsory admission provisions of the MHA, where the criteria for such admissions are met.

Second, part IV of the MHA allows treatment by medication for mental disorder (including bipolar disorder) if the patient is subject to detention under the Act. For a period of three months following detention, the MHA provides that the patient may simply be treated without consent; after that period, the patient may be treated either on his or her competent consent, or with the certification of an authorised doctor ('SOAD') that 'it is appropriate for the treatment to be given' (MHA, s 58, 63). The decision of the SOAD is certainly judicially reviewable (see, eg., *R (Wooder) v Feggetter* [2002] EWCA Civ 554. The original decision of the responsible clinician presumably involves the exercise of a statutory power of decision, and would therefore be judicially reviewable (although this appears not to have been attempted in these terms). If that decision engages rights under the European Convention on Human Rights, however, it is clearly judicially reviewable (see *R (Wilkinson) v Responsible Medical Officer Broadmoor Hospital* [2001] EWCA Civ 1545, and subsequent cases; discussed in Bartlett 2011). No judicial review cases have overruled the decision of the treating physician on a decision to enforce treatment over a patient's objection. This suggests that, while none of that jurisprudence concerns advance planning, the prospect for legal enforceability of advance plans in this context may be minimal.

That said, the relevant judicial review jurisprudence pre-dates the MHA Code of Practice, published in 2008. The 2008 Code, unlike its predecessors, contained specific advice and detailed to clinicians as to how to approach wishes and decisions expressed in advance when the decision involves treatment within the scope of MHA compulsion. The relevant elements were reiterated in the current Code of Practice, published in 2015. The advice runs to an entire chapter of the Codes (Department of Health 2008, chapter 17, Department of Health 2015, chapter 9). While the Code stops short of saying that an ADRT or previously expressed wishes must be followed, it does encourage clinicians to engage with patients in making such advance plans, and suggest that plans be given serious regard. Thus regarding ADRTs, the current Code states:

Even where clinicians may lawfully treat a patient compulsorily under the Act, they should, where practicable, try to comply with the patient's wishes as expressed in an advance decision. They should, for example, consider whether it is possible to use a different form of treatment not refused by the advance decision. If it is not, they should explain why to the patient. (Department of Health, 2015, para 9.9)

Regarding statements of wishes and feelings, the Code states:

Encouraging patients to set out their wishes in advance will often be a helpful therapeutic tool, promoting collaboration and trust between patients and professionals. It is also a way in which effective use can be made of patients' expertise in the management of crises in their own conditions. (Department of Health 2015, para 19.15; see also Department of Health 2008, para 17.14)

At least since 2008, therefore, it has been good practice for clinicians to take the advance decision-making seriously even for people detained under the MHA. The legal effect of these Code provisions is not yet clear. The Code of Practice is not binding, (*R (Munjaz) v. Mersey Care National Health Service Trust* [2005] UKHL 58) but again since 2007, the MHA requires practitioners to 'have regard' to it (MHA, s 118(2D)). This presumably means that it has some legal force.

Two specific situations relating to treatment for mental disorder warrant particular note.

The first concerns the provision of electro-convulsive therapy (ECT). Amendments to the MHA in 2007 now mean that an ADRT that prospectively refuses the provision of ECT, and the refusal of the donee of an LPOA to ECT, is enforceable, and cannot be overruled (MHA, s 58A(5)(c)). This is relevant to people with bipolar disorder, since ECT is still an approved treatment in some circumstances for patients experiencing severely depressive symptoms (National Institute for Health and Clinical Excellence 2006). They can if they wish, through an ADRT, ensure that they do not receive ECT, except in emergency situations.

The second concerns people subject to community treatment orders. These introduce some coercive mechanisms into treatment programmes in the community, for some patients, following a release from MHA detention. Treatment cannot be given to an individual lacking capacity under these orders if the provision of such treatment would conflict with either a valid and applicable ADRT or the refusal of a donee of an LPOA (MHA, s 64D(6)-(7)). This does not provide as much protection as might appear, since a clinician can still recall the individual to hospital for enforcement of treatment in the order, either in the first three months following the initial detention giving rise to the community treatment order or if an independent doctor provided through a statutory scheme (a 'SOAD') has permitted such a recall. The protection is usually thus that the treatment cannot be given by force in the community, rather than in hospital.

### III. THE PRESENT STUDY

#### 1. Methodology and Participants

The present study was designed to build a representative picture of the use, experience and understanding of advance planning under the MCA by adults with bipolar disorder, and the barriers and drivers to advance planning in this group. For the quantitative element, 549 adults in England who had a (self-reported) diagnosis of bipolar disorder were recruited, in part through an online survey hosted at the University of Nottingham and promoted through service user organisations, and in part through substantively identical paper-based survey distributed and collected by the Mental Health Research Network. Participation was restricted to English-speakers. Participants were further required to complete the MDQ screening tool for bipolar disorder, (Hirschfeld et al 2000) and those not meeting its criteria were excluded from the study.

Advance planning under the MCA is not limited to planning in matters of medical treatment, but it was (correctly) anticipated that this would be a matter of significant concern to the service users. For this reason, and because psychiatrists were expected to have relevant insights into the barriers and drivers for take-up by service users, they too were surveyed, again with recruitment both through electronic means and through the Mental Health Research Network. In all, 650 psychiatrists took part in the quantitative element of the study.

The questionnaires were developed following interviews with five service users with bipolar disorder, four lawyers, two psychiatrists, a general practitioner, three social workers, and an MCA lead for a major mental health trust. In addition, the project benefitted from the involvement of a

service user advisory group based at the Spectrum Centre for Mental Health Research at the University of Lancaster and discussions among the key staff on the larger PARADES project.

From among the respondents to the quantitative survey, 14 service users and 8 psychiatrists were selected for semi-structured interviews. In addition to an indication of willingness to be interviewed in their responses to the quantitative questionnaire, the selection for involvement in the qualitative arm was based on geographic location, and, most significant, level of experience of advance planning.

The age, race, education and employment status of the service user participants in the quantitative study are contained in tables 1 through 4. Of the sample, 251 (45.7%) were married, civilly partnered, or living with a partner, while 213 (38.8%) were single and not partnered. The age distribution and the rates of employment are broadly consistent with that found in Morgan et al's 2005 Australian epidemiological study of bipolar disorder, although the proportion of people married or civilly partnered appears somewhat higher in the present sample. Insofar as the population of people with bipolar disorder mirrors the general population, the sample under-represents people from BME communities (7.8% in the present study, as compared to 14.0 per cent in the 2011 national census (Office of National Statistics, 2012)).<sup>3</sup>

**Comment [Author1]:** Note to editors: please include these tables approximately here.

Just over one third (199; 36.2%) of the service users had heard of the MCA prior to participating in the study.

A majority of the 650 psychiatrist respondents were consultants, primarily in general adult psychiatry (283, 43.5%) or old age psychiatry (91, 14.0%). There were 111 trainees who passed examinations in psychiatry set by the Royal College of Psychiatrists namely ST4-6 (17.1%), and 130 more junior trainees working as psychiatrists CT1-3 (20%). The breakdown of the years since qualification is contained as Table 5. 595 (91.5%) had been trained in the MCA, with table 6 showing that almost half of those attending at least three training sessions on the Act. Perhaps tellingly, however, 61 per cent of those trained attended because the training was mandatory or as part of gaining approved clinician accreditation status (effectively a job requirement for psychiatrists); only 13 per cent described themselves as attending for personal interest.

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## 2. Results

### a. *Low Usage*

The most striking initial finding of the quantitative element of the project is just how rarely advance planning is used, notwithstanding overall enthusiasm for the idea. Thus of the 496 service users expressing an opinion, 408 (82.3%) thought it very important to be able to make plans about personal welfare, and an additional 61 (12.3%) thought it important. Nonetheless, of the 549 service users in the survey, only 242 (44.1%) had engaged in any form of advance planning for incapacity covered by the survey. Further, a considerable proportion of this was limited to informal conversations about property and affairs (151 or 28% respondents). The more formal advance planning arrangements of the MCA are much less frequently used: 54 (9.8%) had made an advance decision to refuse treatment (but only 27 of those in writing), 28 (5.1%) an EPOA under the 1985 legislation, 21 (3.8%) an LPOA for property and affairs, and 62 (11.3%) a statement of wishes and feelings. Of the statements of wishes and feelings, 53 were in writing. 31 (5.6%) identified themselves as having made an LPOA for personal care, although the analysis below suggests that this

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<sup>3</sup> Based on the 2011 census - <http://www.ons.gov.uk/ons/rel/census/2011-census/key-statistics-for-local-authorities-in-england-and-wales/rpt-ethnicity.html>, accessed 9/08/14.

may well be higher than is in fact the case.<sup>4</sup> Of the total sample, only 130 people (23.7%) used one or more of these mechanisms. The quantitative evidence from the psychiatrists survey is consistent with a low take-up rate. Only 94 (14.5%) had encountered a patient with bipolar disorder who had made an ADRT; 136 (20.9%) had encountered a patient who had made an oral or written statement of wishes and feelings; and 91 (14.0%) had encountered a patient who had made an LPOA relating to health or personal welfare. Each psychiatrist is likely to have treated a number of people with bipolar disorder; the relatively small numbers of psychiatrists who had encountered these mechanisms suggests they are indeed rarely used or perhaps that when used they are not coming to the attention of the psychiatrist. This latter is a distinct possibility: as will be discussed below, not all service users provided copies of their ADRTs to their psychiatrists, or indeed to other NHS contacts that would place them on the clinical file.

No doubt, this low usage at least in part reflects a lack of knowledge of the MCA provisions (see also Samsi and Manthorpe 2011a regarding elder people). Almost two thirds of the service users in the sample (63.4%) had not heard of the MCA prior to the study, and lack of knowledge was the most significant factor reported by service users in failing to make use of the specific mechanisms of advance planning. For people failing to make an ADRT, 326 (65.4%) per cent gave this as the primary reason; for persons failing to make a statement of wishes, the figure was 385 (80.2%).

This may, at least in part, reflect poor knowledge and implementation of the MCA more generally. Overall implementation of the MCA has recently been roundly criticised by an ad hoc committee of the House of Lords (House of Lords 2014). It would be surprising for advance planning to be an exception to that overall failure, and a number of the issues identified by that Committee will arise as themes in the discussion that follows, including who has responsibility for implementation of the MCA, how the MCA integrates into professional practice, the need for systemic programmes of implementation, and the need for improved and appropriate information targeted at both professionals and service users.

The nature of training received by psychiatrists may constitute part of the reason for this lack of knowledge among service users in this study, although the data are mixed on this point. As noted in table 6, the vast bulk of psychiatrists in this study received training, often considerable training. The training received tended to be viewed as of reasonably high calibre. 592 of the 595 (99.5%) psychiatrists trained provided a view on this point. Of these, 580 (98.0%) rated the training as average or better in quality; 473 (75.3%) considered it good, very good, or excellent. The training did not necessarily focus on advance planning, however: only 230 (38.8%) stated that a reasonable or a significant amount of focus was given to advance planning; 333 (56.2%) reported minimal focus on advance planning; 30 (5.1%) reported none. Nonetheless, when asked to identify which health profession was best informed of the advance planning provisions of the MCA, the psychiatrists identified themselves by a considerable margin – psychiatrists 336 (55.8% of 602 responses); social workers 206 (34.2%), GPs 26 (4.3%), other physicians 18 (3.0%); nurses 16 (2.7%). This suggests it may be simplistic to attribute the lack of information provided to service users to a lack of training of psychiatrists. Consistent with that, while numbers are small, of 22 service users who reported consulting with their psychiatrist about a statement of wishes and who provided a view as to the calibre of that advice, 19 viewed the advice given as good or very good; and of 11 service users providing a view on advice received from psychiatrists regarding ADRTs, 7 considered the advice either good or very good. While the nature of training may be relevant to the low rate of advance planning among people with bipolar disorder, it should not be understood as a complete explanation.

*b. Administrative and Professional Tensions*

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<sup>4</sup> See below, s III.2.e. If this analysis is correct, then the number of LPOAs for property and affairs may be slightly higher than the raw statistics suggest.

The data disclose a set of interrelated tensions as to how advance planning fits within clinical structures, whose responsibility it is to investigate advance planning with service users, and the overall enthusiasm (or lack thereof) of professionals to engage with advance planning.

The issues surrounding integration into clinical structures are of two sorts. It would seem that Trusts have abundant policies relating to the MCA in general, and to advance planning in particular. All of the psychiatrist interviewees who were asked about this affirmed the existence of Trust policies; none of them gave a coherent account of what they were, or how they worked. This applied not merely to directive policies from the Trust, but also to the ways in which relevant documents are stored in clinical files: none of the clinicians interviewed was able to identify how an advance plan, if one existed, would be located or flagged up in a clinical record. At least as it is configured in some trusts, RIO, the electronic file system used in much of the NHS, does have a sub-file for MCA documents; but it does not appear that this is well-known or well-used. Instead, MCA documents seem to be filed inconsistently, in other parts of the system. In any event, the filing of a document in the MCA sub-file does not create a flag on the top sheet of the file alerting a clinician, so the system would seem to expect a search through the file on each occasion that information might be relevant. Trusts that use paper files create additional problems, as documentation may not be moved between files.

None of this is likely to encourage clinicians to engage in processes of advance planning with service users. Perhaps as a result, when attempts are made to implement policy, the results are not always satisfactory, as the following account from SU6 shows:

SU6: Certainly Dr S presented me with a form for... I forget.. well, what you're looking into. A form which asks about your desires for what you want to happen if you are not capable of looking after your own affairs.

Interviewer: I see. And was this a pro-forma? Was it something that was standardised?

SU6: Indeed it was. Published by... I think it was [name of Trust], rather than any other area, because I have another friend who's bipolar, who had a different layout of the form, with the same questions.

Interviewer: Right, I see. Forgive me for not phrasing this well. When your doctor gave you this form, what led to him actually doing this? What was the conversation beforehand if you like?

SU6: I think it was... this is the gist... the government now require us [psychiatrists] to present to you this form... well, you don't have to do it... if you wish to you can fill this form in. you can have one form yourself, or you can give a copy to a friend, GP, or we [the psychiatrist] can have one. I can show it to you if you like...

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Interviewer: Right,. OK. Did you first raise this issue with your doctor? Did you come and say 'I've been reading about this and apparently there is a form which I can fill in...'

SU6: No. It was just that my psychiatrist handed me the form and said 'look at this'.

A very similar experience is related by SU2, where the form was provided by a support worker rather than a psychiatrist, and by SU1 whose psychiatrist was uncommunicative when a service user wished to develop a plan. Whether because of lack of training, lack of time, or lack of enthusiasm, these are

situations where the relevant policy has not been implemented in a fashion that encourages advance planning (or, certainly, not co-operative and high quality advance planning).

A second sort of administrative complications arises when the MCA policies implicitly or explicitly linked or are in potential tension with other policies, which may have somewhat different objectives or foci. This difficulty is not restricted to local implementation. The government's mental health strategy makes no reference to the MCA, notwithstanding that its stated 'guiding values and principles' require that 'people with mental health problems are able to plan their own route to recovery' supported by professional staff who 'put them and their families and carers, at the centre of their care by listening to what they want, giving them information, involving them in planning and decision-making, treating them with dignity and respect, and enabling them to have choice and control over their lives and the services they receive' (DOH 2011, para 2.3; the previous strategy of the previous government similarly contains no reference to the MCA: see DOH 2009). Little if any thought appears to have been given to the relevance of the MCA in this process, and how the MCA provisions fit (or not) with the mental health strategy.

The potential difficulties of this silence are reflected at the local level. It would seem that frequently, as anticipated by the government strategy, planning is integrated with Recovery programmes. Two of the interviewees in the qualitative study noted that their advance plans resulted from the implementation of Recovery programmes in their Trusts. A third drafted an advanced plan based on advice about Recovery from a textual source, rather than a programme provided through a Trust. 'Recovery' is in this context a term of art. Recovery programmes encourage service users to articulate in their own terms, in consultation with clinical and social services staff, how they want to live their lives, what goals they wish to set for the treatment of their condition, and how those goals should be achieved (see Shepherd et al 2008). While no doubt highly desirable, the ethos of this is not necessarily quite the same as for the MCA. At the core of Recovery Programmes is the setting of therapeutic and related goals, and the construction of a therapeutic alliance between the patient and his or her clinical and social carers. At its core is meant to be a process of ongoing reflection. That is certainly related to, but not quite the same as the making of legally meaningful (and in the case of ADRTs, potentially legally binding) statements determining future care. Where the ethos of Recovery is partnership, the ethos of advance planning under the MCA is service user empowerment – a related but not quite identical concept. While the empowerment is rarely absolute for people with bipolar disorder – as discussed above decisions can generally be over-ruled through the compulsion provisions in the MHA – that does not alter the ethos of the Act.

Whether for that reason, or because of the poor policy of implementation more generally, or because the legal technicalities of the MCA are complicated, it does seem that service users are not clear on the legal effects of what they are doing, as in the case of SU13:

SU13: The only thing I've done is when I was working on my Recovery booklet. There was a section there about your requests if you had to be sectioned again. That was supposed to be scanned and added to your care plan, but that didn't happen I don't think. Then I had a new care coordinator since... probably the end of last year.... And we've gone through a new care plan, but again that isn't anything to do with the MCA... it was a very informal... sort of my wishes were written down... I don't think anybody would even find them on the system to be perfectly honest with you (laughs)!

Interviewer: That's really interesting. So just so I have it correct – this is a Recovery 'booklet'?

SU13: Yes, it was one that was produced by [xxx] Trust. They're quite big on recovery and they have recovery packs that the care coordinator works through with clients. Part of that

is, you know, write it down with us... when you're high or low and then... it's the whole thing really... you just write about your illness.

There is no suggestion in this that the service user understands that this may well have legal significance in determining what treatment may or may not be provided. Similarly SU 12 stated:

Interviewer: Ah, I was going to ask about this – when you completed the advance directive, was there a template that you'd used or anything...

SU12: Yes there was [provided through the Trust]. I used that, but just added in my own personal needs and what I wanted. Obviously it's not a legal document and the doctors can override that as far as I am aware, but at least there's a lot of information in there that could be quite useful to a new doctor. I think probably one of the reasons which prompted me to do it was because I was moving areas, I was losing the doctor I'd had for years. It was as if you'd been thrown out into the world, and no-one knows who you are. So it was a bit of reassurance for me really.

Notwithstanding the view of the service user, it may well be a legal document; certainly it is a document with legal meaning in determination of best interests. Similarly, the qualitative data showed considerable confusion among service users as to the actual effects of the various MCA planning mechanisms. There was considerable confusion for example in the distinction between a statement of wishes and feelings and an ADRT. The failure of the service user to understand this is a matter of concern.

If the status quo is problematic, it is fair to ask who should take responsibility to ensure that appropriate advance planning occurs. If it is expected that for people with bipolar disorder this will happen through the mental health system (either through clinicians or social services staff based in health environments), it is unsurprising that the MCA provisions will be reinterpreted through a therapeutic or clinical lens: that does after all reflect clinicians' training and professional culture. At the same time, the implied focus on therapeutic matters leaves other aspects of advance planning outside consideration. Few service users in the survey were aware of LPAs for property and affairs, for example, even though the financial problems that can result from behaviour of people with bipolar disorder when in a manic state are well known. These can be articulated in therapeutic terms – the incursion of massive debts can contribute significantly to depression – but as with ADRTs and statements of wishes relating to health care, the lack of knowledge suggests that psychiatrists do not see themselves as having a role proactively to draw these to the attention of service users.

The empowerment ethos of the MCA provisions can also come into perceived conflict with the clinical role. One administrator and former clinician commented in the pilot interviews for the design of this study:

There is a difficulty when talking about advance decisions and patients with mental disorder, you can see where the Trust might have a bit of a conflict of interests perhaps. If you're thinking about patients with a mental disorder making advance decisions to refuse treatment, and yet when the core business of the Trust is to treat mental disorder, you can see where there might be a certain amount of conflict of interest. Now I'm not saying that there shouldn't be any advice given at all, but I can see why the Trust might be a little bit careful about advice they may give about decisions to refuse treatment, whereas I can see why they might be happier to talk about statements of wishes and feelings – non-binding, persuasive, have to be taken into account, and of course the trust does look into that in terms of recovery. Refusal of treatment I think is perhaps a little bit different.

Perhaps consistent with this, of the 186 psychiatrists who stated they had experience of people with bipolar disorder making oral ADRTs, 125 (67.2%) stated they made a record of the decision and 74 (39.7%) said they provided an ADRT form for the service user to complete, but 36 (19.3%) said they

did neither of these, presumably not seeing it as appropriate to ensure that the decision was recorded.

Other clinicians were doubtful as to the reality of the conflict, but did not dispute that there was a perceived tension among some colleagues between advanced planning, and particular ADRTs, and the best therapeutic care. In the view of one of the psychiatrist interviewees, this resulted in a focus away from core issues of treatment and consent, towards less controversial matters:

But in general, most advance directives I see are done with care coordinators – I think they are encouraged to do them with patients – they’re biased towards things like ‘who’s going to look after the dog’. You know, the format they use has those kind of things – ‘who can know about the condition’. I think we’re probably not doing enough with people on discussing what their wishes are about treatment in certain scenarios.

Interestingly, none of the psychiatrists interviewed as part of the qualitative study mentioned the provisions in the MHA Code of Practice that encourage clinicians to engage with service users in the development of plans for future care, and while interviewees tended to view the MCA provisions as a very positive innovation in mental health services, they also acknowledged that discussions regarding advance planning were not occurring as frequently as they might. The quantitative survey asked psychiatrists what would increase the amount of time they spent discussing ADRTs with patients, and the results are in table 7. That suggests that it is not time or information that is the key barrier, but whether the service user presses the issue. Along with the qualitative material noted above, this reinforces the image of the psychiatrist as passive on advance planning issues (and ADRTs in particular) – content perhaps to discuss the issues raised by service users, but not generally viewing themselves as the instigators of the process. As an implementation strategy for MCA advance planning, this is of course problematic. The evidence from the present study and elsewhere is that service users do not routinely find out about their options under the MCA from other sources; and if they do not know, it cannot be assumed that they will ask.

**Comment [Author3]:** Note to editors: place table 7 roughly here.

### c. *Factors related to Service Users*

While there are thus systematic impediments to the full implementation of the MCA provisions regarding advanced planning, the data also suggest that the enthusiasm of service users to engage with planning processes should not be read simplistically. Certainly, the service users interviewed for the qualitative element of this project were generally extremely enthusiastic about the possibilities afforded by the MCA, and lack of knowledge was identified as a major factor in failure to engage with those possibilities, but for all their enthusiasm, not all had taken advantage of the mechanisms which might well have been relevant to them even when they did know about them. The case of SU12 provides an example:

I do know about Powers of Attorney. We should all have one. I’ve got a will and every year, the people who made our will whom we store it with put a little note about powers of attorney. [...] So I am aware of it but haven’t got one.

That service user provided no particularly clear reason as to the decision not to make an LPA, but other data does provide some indication.

Sometimes, it is fairly clear that the administrative complexity of advance planning is a barrier. The qualitative data suggests that this in part flows from the lack of support provided by professional staff noted above, but it is also that the forms themselves can be complex. LPOAs are notorious in this regard, (see House of Lords 2014 para 182). The data from the quantitative survey suggest that service users want help and advice in how to complete ADRTs, LPAs and statements of wishes, but do not know who to ask or are unsure how to fill in the relevant documents. While there are

occasional comments in qualitative and quantitative data to suggest a desire not to be seen to disagree with one's doctor, it also needs to be noted that a significant deterrent to completion of an LPOA is a feeling of intimidation by involvement with lawyers.

Sometimes, reluctance would appear to flow from a desire not to foreclose treatment options. Of the 96 service user respondents who had heard of statements of wishes and feelings but not made one, exactly half stated that there was no treatment about which they had sufficiently strong views that they would wish to make a statement. For SU10 and SU7, the failure to make an advance plan would appear to be the result of a good relationship with the treatment team:

SU10: Well, psychiatrists are very good at listening to you and trying out things that will both work and be acceptable to you. I've never had any problem with feeling that medication has been imposed on me. I've been occasionally, not with my current psychiatrist, but occasionally been under pressure to take a certain type of medication that I didn't want, like Lithium – but I've never felt like I didn't have any choice in the matter.

Consistent with this, 63 of the 171 respondents (36.8 %) who were aware of ADRTs but had not made one, did so on the basis that 'I am confident that my doctor will make the right decisions for me.'

While one can only be pleased at such successful clinical relationships, a note of warning is appropriate. As noted above, the data suggests that service users are not always correct in their understanding of the effects of the advance planning mechanisms. In particular, the qualitative data in the present study suggests that some service users believe that family members have a residual right to make decisions on behalf of adults lacking capacity, in both personal and at least some financial matters. Absent an LPOA or a court order, this is simply not correct. It is perhaps appropriate to keep some critical eye on the view that advance planning is not done because it is not thought to be required.

It is worth noting that the process of advance planning can itself have problems associated with it, albeit sometimes with related benefits:

Interviewer: Right. And how did you find the process of completing the document?

SU13: Quite difficult. I mean, it's quite upsetting to remember times when you were in a state that you had to be sectioned or go into hospital. I mean, it did bring up quite a few memories that weren't so great. There was quite a lot of planning when I was pregnant because there was a one in two to one in four chance of me going high after the birth of my son, so we had planning meetings for two weeks where my wishes were known about – what mum and baby unit I'd want to be admitted into in London. That was quite upsetting.

Interviewer: Yes, I can imagine that the process of filling in that sort of information would trigger a lot of memories. Did you find it a worthwhile thing to do overall? Did you have any feelings that you were more in control or empowered.

SU13: It did make me realise how much better I am now than I have been previously. Within the last four or five years, I've had minor ups and downs, but nothing compared to how I was before.

Consistent with this, a respondent to in the quantitative survey responded when asked why an ADRT was not made with a discursive comment, 'cannot face doing it'. While SU13 saw benefits as well as detriments to the experience of revisiting her illness, the experience of different individuals may be different. How far it is appropriate to encourage service users to revisit their past in this way is an ethical question, contingent on the individual service user and situation; but it is appropriate to note that there may be emotional costs attached, a matter to be considered by anyone offering advice in this area.

Finally, a fairly small number of service users said that they had not made an ADRT because it could be overridden in any event if they were sectioned under the MHA. That concern would apply equally to other forms of advance planning relating to detention or treatment for mental illness.

The data suggests that service users are in general enthusiastic about advance planning. It would also appear that they find the process of making advance plans administratively complicated, that it is not clear to them that the advance plans will be readily located by clinicians when they are required, that they may be overruled anyway, and that there may be emotional costs to revisiting the period of illness. Many of these views are consistent with those provided in the psychiatrists' data. It is perhaps therefore unsurprising that some service users take the view that the benefits are not worth the effort, even if they are aware of the options available to them (which most are not).

One of the findings from the above data is that the differences between the various advance planning mechanisms is not well understood, either by service users or psychiatrists. The data nonetheless also provide some interesting insights into the use of the specific planning mechanisms under the MCA. The paper now turns to that analysis.

#### *d. ADRTs*

As noted above, 54 (9.8%) of the service users in the quantitative study had made ADRTs, of which 50 indicated where they had first heard of them. Unsurprisingly given the data described above, only one in five of these found out about the ADRT from a psychiatrist, and one in ten from a care co-ordinator. Indeed, the largest source of information was contained within 'other, please specify', where service users typed in 'myself' (n=12, plus 2 who knew about ADRTs from employment unrelated to their treatment and an additional 4 who found out through their own research, for example on the internet or in the library). The other sources of initial information are vanishingly small. Consistent with the comments above, there appears to be no consistent or systematic way in which people are to be notified of ADRTs.

27 of the ADRTs were in writing. Table 8 indicates what treatment was refused. While the numbers are small, it is notable that no one refused all medication. It would appear instead that most of the refusals refer to fairly specific medications or types of medication. This seems consistent with the experience of the psychiatrists interviewed, suggesting that there may be considerable potential common ground between service user and clinician, or at least that reasonable compromise by the clinician may allow a good standard of care to continue. The fears of full-scale conflict of interest, noted above, may overstate the actual tensions likely to arise. Nonetheless, there was no suggestion from the psychiatrists that the enforceability of ADRTs should be extended. Instead, the view of psychiatrists was that the MHA override provisions should be retained for situations of real necessity, as in the following comment:

Psychiatrist: She'd made an advance directive which was not very official looking, but was probably OK. I don't think they need to be quite officially. Something written, signed and dated is OK. They don't need to be with solicitors and things. Essentially, she pretty much scribbled it when she became unwell. Unfortunately it was quite an unrealistic one – it hadn't been discussed properly with her because she was becoming unwell. It pretty much said no medication except carbamazepine. The difficulty was, to be fair to my colleague who was managing her, she [patient] was there on a section 3 on the ward, and clearly what he [colleague] had tried to do, and his way of negotiating this, was he said 'OK I'll TRY and manage you on carbamazepine first. But you are pretty unwell and I'm not sure that'll be very effective. Sure enough, two weeks on and she was no better. He said 'Sorry but I'm going to have to move your treatment on and give you medication that you don't want. You're under a section 3 and I have to get on and do that.' That was when he has to introduce something else. I think she was on a depot in the end because she wouldn't even swallow the tablets.

**Comment [Author4]:** Note to editors: print table 8 approximately here.

Interviewer: It's fascinating. I'm not a clinician so I always imagined that in those sorts of scenarios, rather than being in the context of not wanting any medication other than this, I expected that it'd be 'I don't mind other medications APART from this.'

Psychiatrist: That's right. That is what other cases I've been involved with say. They just exclude one or two treatments. They consult me in the CPA and ask if that was reasonable. This lady had gone off and done it whilst becoming unwell and off her own back. It just didn't make sense really. I felt for my colleague because on the one hand, he wanted to keep a relationship with the patient.

This quote raises not merely the question of the scope of ADRTs, but also their enforceability. There is no formal requirement in the MCA that an ADRT be discussed with anyone prior to it taking effect nor that it be in writing unless it is a refusal of life-sustaining treatment. At the same time, when the psychiatrist can often overrule the ADRT by the compulsory powers under the MHA, it seems strategically wise to make the ADRT in writing and discuss it with the psychiatrist or allied professional. In this study, almost half of the ADRTs were not in writing. Of service users who did make their ADRTs in writing, only 17 (62.9%) discussed their ADHT with a psychiatrist, and 17 with a Care Co-Ordinator. Service users making 13 of the 17 ADRTs consulted neither of these people, leaving some doubt as to how their refusals will be dealt with, whatever the law says.

People making ADRTs did, generally, seek out advice. The quantitative survey asked about consulting care coordinators, psychiatrists, lawyers, service user groups within and outside the NHS, family members, friends, text-based materials and other sources. Only two of the 27 service users consulted none of these. Of the six people consulting only one of these, four considered the advice received to be good or very good. Of the remaining 19 people who consulted at least two of these, all but one received at least one set of advice that was viewed as good or very good. Consistent again with the view that the problems are not just about training, it does seem that good advice is to be had, if the service user is prepared to look for it.

Table 9 describes the places written ADRTs are lodged for safekeeping. A problem with the data arose in this question. 12 of the 29 people indicating that 'I just keep a copy for myself', but 11 of these went on to identify others with whom the document was kept. This presumably means that these respondents read the response as 'I kept a copy for myself' – although this is not a good measure for the numbers of respondents keeping a copy of their ADRT, since the other respondents presumably did not read the question in that way. It does not follow from this, however, that NHS staff were routinely informed of the ADRTs. Of the 29 responses, 8 did not provide a copy of the ADRT to their psychiatrist, care co-ordinator, or had it placed in their notes, (although one of these provided a copy to his or her GP). This is a questionable strategy, as it is not obvious how the professional will be made aware of the ADRT, in the event that it is needed. That said, the qualitative data from the psychiatrists and, to a lesser degree, from the service users suggests that placement of the ADRT on the clinical file may also be of doubtful efficacy, since as noted above there is generally nothing on the top page of the file to alert the clinician to the existence of the ADRT within the file. It seems therefore a good strategy in addition to give a copy to a friend or family carer; but only 14 of the service users had done this.

**Comment [Author5]:** Note to editors: print table 9 roughly here.

*e. LPOAs*

The raw statistics on LPOAs from the quantitative study of service users would suggest that 31 (5.7%) made an LPOA for personal welfare, 28 (5.1%) an EPOA under the 1985 legislation, and 21 (3.8%) an LPOA for property and affairs. Those making LPOAs for personal welfare were however invited to write in the primary reason for doing so, and 27 did so. The reasons provided make it

clear that there is no understanding of the difference between powers of attorney for personal welfare, and those for property and affairs: in 10 of these cases, the motivation for making the document was stated unambiguously to be for financial matters, rather than personal matters, notwithstanding the introduction to the question stating that 'an LPA for Personal Welfare allows you to appoint a person of your choice to make decisions on your behalf in matters relating to your health and welfare.' It is at best doubtful that these people in fact made LPOAs for personal welfare, rather than for property and affairs. In that event, the number of LPOAs for personal welfare would reduce to 21 (3.8%). Taking into account the number of those people who also said they had made property and affairs powers of attorney, the total number of EPOA/property LPOAs would rise to 53 (9.7%).

Certainly some of the motivations listed for the personal welfare LPOAs is entirely consistent with what the MCA might be taken to envisage: 'I trust my attorney will make right decisions for me. Knows me well'; 'I feel that there are periods when I am not capable of making decisions and I need other people to step in at these times.'. Other reasons again make it clear that there is considerable lack of understanding about LPOAs for personal care. Thus one respondent comments that 'I was grateful for the opportunity to register my long-held request for palliative intervention only.' While it may be the case that a donee of an LPOA for personal welfare may be particularly sympathetic to the views of the donor, the LPOA itself merely designates a decision-maker; the decision is still taken under the general best interests test of the MCA. If the individual wished to preclude other than palliative treatment, the appropriate mechanism is an ADRT.

By comparison, the motivations for LPOAs for property and affairs and EPOA do not seem to suggest motives relating to personal welfare. They are instead related to financial transactions such as the need to pay rent or control spending.

The qualitative data for LPOAs, both for property and affairs and for personal care decisions, does suggest that those not making them may be under misapprehensions as to the ability of family members and similar carers to make decisions absent the LPOA:

SU13: well I would want my partner to take over my account to pay my bills, but I've got nothing... if I was in hospital, I've got no power of attorney or anything formally documented with the banks specifying who should take over my account. It's all rather informal.

The difficulty is, of course, that absent the LPOA, the partner has no formal authority to make the relevant decision.

#### *f. Statements of Wishes and Feelings*

As noted above, statements of wishes and feelings are a rather more amorphous mechanism of advance planning. While written statements made when competent have a particularly high status under the MCA, oral statements and statements of incapacitous wishes and feelings are also to be taken into account in determination of the individual's best interests. As noted above, these may therefore merge into other information-gathering systems, such as Recovery programmes, that may or may not precisely coincide with the ethos of advance planning under the MCA. Thus while 62 service users in the quantitative survey (11.5%) stated that they had made statements of wishes and feelings relating to personal care, it may well be the case (and it is to be hoped that it is the case) that considerably more have discussed their care and treatment with their medical and social care advisors: this is, after all a key element of good care. The service users may well not have understood that the discussion could have legal meaning, but that is a slightly different issue. Presumably, they would have wanted their wishes taken into consideration in decisions related to future treatment, and that is what is envisaged by the MCA.

Of the statements, 52 were in writing, and the place in which they are lodged is detailed in Table 9, above. 17 of the 53 respondents did not provide a copy to their psychiatrist, care co-ordinator, or placed a copy in their NHS notes (although of these, 4 provided copies to their GP and 1 to a CPN). Where the ADRT of course refers only to medical treatment, 33 of the written statements concerned matters extending into the broader social or domestic sphere, making it less obvious that disclosure to medical staff was necessary.

The subjects covered in statements of wishes and feelings for personal care and treatment are contained in Table 10. Of those identifying themselves as making such statements relating to personal care and treatment, however, 51 included provisions either favouring or expressing reservations about medical treatment or identifying people who should or should not be contacted in the event of illness or which 44 were in writing. Here, too, not all provided copies to the treatment team: 16 provided a copy to their psychiatrist; an additional 16 people give a copy to care co-ordinator or stated that a copy had been placed in their NHS notes, one more had given a copy to his or her GPs and one to a CPN. Thus 8 had not lodged it with an NHS source. While numbers are small, this also applies to oral statements of wishes, of which there were 7: only one had been communicated to the psychiatrist, and an additional one to the GP. This does seem a matter of concern: it seems likely that oral wishes regarding treatment issues will carry considerably more weight if discussed with the relevant clinician directly.

**Comment [Author6]:** NOTE TO EDITORS: Insert table 10 approximately here.

The patterns surrounding statements of wishes in property and affairs matters are different. 151(27.5%) of the service users indicated that they had made such statements, either orally or in writing – by far the highest participation rate for advance planning mechanisms in the survey, and two thirds of these people indicated that the statement was made to family members. Again, this is a perplexing statistic. It is unsurprising that people with bipolar disorder discuss financial matters with their families; but is it really the case that they do so to such a greater degree than matters of personal care and treatment? It seems much more likely that statements of wishes regarding property and affairs in the survey were not recognised as parallel questions to those concerning statements regarding personal care. That again reinforces that the legal mechanisms are not well-understood.

#### IV. CONCLUSION: THE IMPACT OF PLANNING UNDER THE MCA, AND THE POSSIBILITY OF IMPROVED IMPLEMENTATION

The obvious remaining question is whether all the MCA amendments that provide new and clarified opportunities for advance planning make any difference. As noted in the introduction to this paper, treatments for mental disorder, unlike treatments for other disorders, can be provided under compulsion if the relevant requirements of the MHA are met. It is clear from the qualitative interviews and the discursive entries on the quantitative surveys that the MHA power to 'trump' is well-known by service users and clinicians alike. In principle, decisions by clinicians to treat involuntarily can be subject to judicial review, but there is as yet no case where a doctor's decision to provide such treatment has been overturned by the courts. In terms of the formal legal process, advance planning under the MCA appears to be rather a paper tiger.

What happens in court, of course, does not necessarily reflect what happens in the consulting room. Here, the evidence from the survey is mixed and inconclusive. As noted above, the usage rates are generally poor, and it would seem from the psychiatrists' data, not improving. Of the 259 psychiatrists expressing an opinion, 208 (80.3%) considered that the number of people with bipolar disorder making ADRTs had remained the same since the implementation of the MCA in 2007, and 41 (15.8%) considered that it had increased by less than 10 per cent. Of the 252 psychiatrists expressing a view regarding statements of wishes and feelings by people with bipolar disorder, 187

(74.2%) thought that frequency remained the same since the MCA came into force, and 46 (18.3%) that it had increased by less than 10 per cent. These are not encouraging numbers.

Certainly, there is evidence in the data of some very good practice among clinicians (as well, of course, of some considerably less good practice). It is difficult to isolate however how far the good practice identified is directly related to the advance planning provisions of the MCA. Thus a number of the service user interviewees speak of how good their doctor is at listening to them. This is of course good; but it is not clear how it relates to the MCA specifically. Psychiatrists gave examples of where they had made real attempts to comply with advance plans; but often were unsuccessful and reverted to compulsion under the MHA. There are jurisdictions where ADRTs in mental health care are enforceable and cannot be overruled (See, eg., Ontario Health Care Consent Act, SO 1996, c 2, Sch A, s 42). It is perhaps notable that not even the most enthusiastic of the psychiatrist interviewees proposed a similar system here. For those that knew of patients with bipolar who had ADRTs and were sectioned, more than a third of psychiatrists said that the detentions were motivated at least to some extent by the need to override the ADRT. Again, this is an ambiguous statistic: 65% of the psychiatrists said that the ADRT was not a factor in the detention. Nonetheless, it is clear that there is a limit in clinical practice to the scope of advance planning permitted.

If advance planning under the MCA is to be successful however among people with bipolar disorder (and, quite possibly, other conditions within the scope of the MHA), there must be some evident benefit to the service user. Even within the scope of the existing compulsion provisions of the MHA, that may well be possible, if it becomes clear to service users that the ADRTs, LPOAs and statements of wishes are taken seriously by clinical and care staff. It is not clear from the data in the present study how much that is happening.

While this study is, as far as we are aware, the largest empirical study of advance decision-making yet conducted regarding the MCA, it is not of course definitive. While the quantitative elements of the study are composed of reasonable sample sizes, they are to a considerable degree independent samples: the service users sampled were not necessarily the patients of the psychiatrists sampled. Even with the large numbers in the initial samples, the numbers engaged in advance planning directly was small. While that is itself a highly important finding – the MCA advance planning mechanisms are not being used to any great extent by people with bipolar disorder – it does mean that the quantitative inferences relating to the individual planning mechanisms is based on relatively small sample sizes, and it is much less obvious that these conclusions can simply be generalized uncritically. In the extreme, only two of the service users who had made ADRTs had been subject to MHA admission afterwards. That is, of course, an insufficient number to produce relevant quantitative findings. The limitations of the statistical data are addressed in part through the use of the qualitative data: the quantitative conclusions received support through the interviews.

The value of the quantitative evidence will also be contingent on the representativeness of the samples. If service users with bipolar match the general population – a matter not entirely free from doubt – the sample in this study was somewhat overeducated, and BME people were under-represented. It is not obvious how the racial disparity would affect the results. The educational disparity might perhaps suggest that the situation is in fact more extreme on key findings than the statistics would suggest. It is hard to believe that more highly educated people are less informed about their rights than the general population, and hard to believe they are less willing to press for those rights and engage with service providers in ensuring that those rights are respected. If the problems are a lack of knowledge and limited engagement with professionals, it is hard to believe a sample with fewer educated people would result in findings of greater usage of the MCA or greater engagement with professionals about advance planning.

The result remains problematic, however. The study remains essentially a study of service users and psychiatrists. Apart from the initial interviews upon which the survey was developed, no social care

professionals, other health professionals, legal professionals or non-professional carers were surveyed or interviewed. One might reasonably expect such groups to have a rather different perspective on the MCA. As a clear example to make the point, as noted above, only 2.7% of psychiatrists thought nurses were the best informed health profession on advance planning and the MCA. One might reasonably expect that if nurses were surveyed, they might well have a different view. While that is a particularly clear example, the issue of perspective is pervasive: this is a study of psychiatrists and service users.

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**Tables**

**TABLE 1: Age of service user participants**

	Frequency	Percent
18-25	32	5.8
26-34	74	13.5
35-44	125	22.8
45-54	168	30.6
55-64	107	19.5
65+	38	6.9
Missing	5	.9
Total	549	100.0

**TABLE 2: Ethnicity of service user participants**

	White	Mixed	Asian/ Asian British	Black/ Black British	Chinese/ Other
N	506	14	12	12	1
Percent	92.2	2.6	2.2	2.2	0.2

**Table 3: Highest education level reached by service user participants**

	Frequency	Percent
GCSE	95	17.3
A-Level	48	8.7
N.V.Q	59	10.7
College/ University Diploma	109	19.9
University Undergraduate Degree	103	18.8
University Postgraduate Degree	53	9.7
PhD	9	1.6
None of the above	63	11.5
Missing	10	1.8
Total	549	100.0

**Table 4: Employment status of service user participants**

	Frequency	Percent
Employed (Full Time)	85	15.5
Employed (Part Time)	69	12.6
Employed (Voluntary)	21	3.8
Self-employed	26	4.7
Unemployed	90	16.4
Sick/Disability	140	25.5
Retired	79	14.4
Student	18	3.3
None of the above	10	1.8
Missing	11	2.0
Total	549	100.0

**Table 5: Psychiatrist Respondents' Years since Qualification**

Years since Qualification	Frequency	Percent
0 - 10	210	32.3
11 - 20	241	37.1
21 - 30	146	22.5
30+	51	7.8
Total	648	99.7
Missing	2	.3
Total	650	100.0

**Table 6: Number of Training Sessions attended by Psychiatrists**

	Frequency	Percent
1	128	19.7
2	183	28.2
3	113	17.4
More than 3	169	26.0
Trained, but data missing	2	.3
Not trained	55	8.5
Total	650	100.0

**Table 7: I [Psychiatrist] would discuss ADRTs more if...**

	Number	Percent
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		[n=650]
There was more time	227	34.9
There was more information on the subject	245	37.7
The patient had requested this	457	70.3
A Care Co-Ordinator/Carer requested this	294	45.2
[Other reasons]	115	17.7

**Table 8: Treatments Refused in ADRTs (n=29)**

All medication	0 (0%)
A particular brand of medication	15 (51.7%)
Electro-Convulsive Therapy (ECT)	9 (31.0%)
Depot Injections	4 (13.8%)
A particular type of medication (eg., anti-depressants)	12 (41.3%)
Not stated	2 (6.7%)

**Table 9: Places where ADRTs and Statements of Wishes Kept**

	Written ADRTs (n=29)	Written Statements of Wishes (n=53)
Self alone	125	0
Care Co-Ordinator	5	17
General Practitioner	10	15
Psychiatrist	12	17
Lawyer	2	3
Carer	2	7
NHS Notes	12	13
NHS Service User Group	0	0
Non-NHS Service User Group	1	3
Family Member	12	15
Friend	3	6
Other	5	13
Not stated	2	

**Table 10: Subjects of Statements of Wishes and Feelings (n=62)**

in favour of a particular medical treatment	30 (48.3%)
against a particular medical treatment	32 (51.6%)
Wishes regarding accommodation	19 (30.1%)
Whom to be notified in the event of illness	38 (61.3%)
Whom not to be notified in the event of illness	17 (27.4%)
childcare	6 (9.7%)
Dependant care	4 (6.5%)
Pet care	15 (24.2%)

<sup>5</sup> This is almost certainly an unreliable number: see discussion in text.

General domestic affairs	23 (37.1%)
Other	15 (24.2%)