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## **Reasons for endorsing or rejecting ‘self-binding directives’ in bipolar disorder: a qualitative study of survey responses from UK service users.**

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## Summary

**Background** Self-binding directives instruct clinicians to overrule treatment refusal during future severe episodes of illness. These directives are promoted as having potential to increase autonomy for individuals with severe episodic mental illness. Although lived experience is central to their creation, service users' views on self-binding directives have not been investigated substantially. This study aimed to explore whether reasons for endorsement, ambivalence, or rejection given by service users with bipolar disorder can address concerns regarding self-binding directives, decision-making capacity, and human rights.

**Methods** This study used qualitative data from an internet-based survey distributed to the mailing list of the UK charity Bipolar UK, which contained multiple closed and open questions on advance decision-making in bipolar disorder. Quantitative analysis of a closed question about self-binding directives had already demonstrated endorsement amongst a very high proportion of participants with bipolar disorder who completed the survey. We conducted thematic analysis of responses from those participants who answered a subsequent open question about reasons for their view. Research was co-produced within a multi-disciplinary team, with clinical, legal, and ethical expertise, and lived experience of bipolar disorder. Ideas and methodologies associated with all these areas of expertise were used in the analysis of these reasons and to gain insight into the thoughts of individuals with bipolar disorder about self-binding directives and associated issues.

**Findings** Between Oct 23 and Dec 5, 2017, 932 individuals with a self-reported clinical diagnosis of bipolar disorder completed the internet survey, with 565 (154 men; 400 women; 11 transgender or other) providing free text answers to the open question. A large majority of respondents endorsed self-binding directives, nearly all describing a determinate shift to types of distorted thinking and decision-making when unwell as their key justification. Responses indicating ambivalence were dominated by logistical concerns about the drafting and implementation of self-binding directives, while those who rejected self-binding directives also cited logistical concerns, validity of their thinking when unwell, and potential contravention of human rights.

**Interpretation** This study is, to our knowledge, the first large study of reasons why mental health service users might endorse or reject the use of self-binding directives. The findings provide empirical support for introducing self-binding directives into mental health advance decision-making practice and policy and may help to address enduring ethical concerns surrounding possible implementation of the directive while a person retains decision-making capacity. The opinions expressed here in responses given by multiple service users with bipolar disorder challenge a prominent view within international disability rights debates that involuntary treatment and recognition of impaired mental capacity constitute inherent human rights violations.

**Funding** The Wellcome Trust

## Research in context

### Evidence before this study

We searched PubMed and SCOPUS from database inception to February 4, 2020, with the broad terms (“self-binding directive” OR “Ulysses” OR “self-binding”) AND (“psychiatric” OR “mental disorder” OR “mental illness” OR “bipolar” OR “mental health”), setting no language restrictions. We supplemented the search by reviewing reference lists and forward citations, until no additional relevant articles could be identified. We updated our searches on 2 November, 2020, to check for new publications. With the exception of three very small interview-based surveys, all of which included clinicians and service users, research found on self-binding directives as a form of mental health advance decision making is restricted to medico-ethical and legal analysis, despite calls from researchers for empirical work. We found no large studies investigating service user views of self-binding directives. There is also a paucity of research investigating views of service users with bipolar disorder on advance decision-making in general.

### Added value of this study

This is, to our knowledge, the first large study to provide empirical evidence about mental health service users' views on self-binding directives. We found that the majority of service user participants endorsed self-binding directives on the basis that the participants viewed severe episodes of illness as involving a determinate shift and impairment of their thinking and decision-making. At the same time, the study includes respondents who reject this view, demonstrating diversity of opinion amongst service users with bipolar disorder. This study counters key ethical concerns which have so far prevented the introduction of workable self-binding directives into psychiatric practice and mental health legislation. It also contributes to research on advance decision-making in people with bipolar disorder, by supporting the need to consider diverse outcomes and to incorporate empirical studies of stakeholder views.

### Implications of all the available evidence

The endorsement, by the majority of service user respondents, of involuntary treatment on the basis of impaired decision-making abilities, counters a widespread view, upheld by the United Nations Committee on the Rights of Persons with Disabilities, that psychiatric use of capacity assessment and involuntary treatment necessarily violate fundamental human rights. Researchers, clinicians, and policy-makers should consider that some service users with severe mental health conditions wish to request their own future involuntary treatment, using self-binding directives as a way to self-manage their illness and increase autonomy. When assessing the ethical viability of self-binding directives, mental capacity, and involuntary treatment, human rights advocates need to take a broad range of service user views into account.

## **Introduction**

So-called self-binding directives, sometimes known as Ulysses contracts, have been promoted since the 1970s as a means of damage limitation for people with severe episodic mental illness. These directives, based on lived experience of harms occurring when treatment is accessed too late, instruct clinicians to overrule treatment refusal during future severe episodes by using involuntary treatment. Following extensive legal and ethical discussion, mental health laws have started to provide for self-binding directives in some jurisdictions in Europe, North America, and Australasia. However, enduring concerns have hindered construction of a widely accepted self-binding directive model that is clinically and legally practicable.<sup>1-3</sup> The main concern is how to ensure that an individual's decision-making capacity for treatment is definitely impaired when a self-binding directive is implemented as a form of early intervention. Although lived experience is central to creating a self-binding directive, evidence regarding service user views about their use is scarce.<sup>4,5</sup>

Service users drafting self-binding directives usually accept that: severe illness impairs decision-making capacity for treatment; future treatment refusal might cause them harm; and involuntary treatment potentially offers protection, control, and increased autonomy.<sup>1</sup> While a small body of research examining service users' retrospective views of involuntary treatment found that a substantial proportion thought it justified,<sup>6-8</sup> involuntary treatment and substitute decision-making, where decisions relating to a person whose decision-making capacity is judged to be impaired are made by another person, are generally seen as deeply controversial.<sup>9</sup> In particular, the UN Committee on the Rights of Persons with Disabilities rejects the notion of impaired decision-making capacity and has called for complete abolition of involuntary treatment.<sup>10</sup>

The study aims to understand how these ideas relate to highly influential human rights and ethical assumptions surrounding autonomy and psychiatry. We examine whether reasons given by service users with bipolar disorder for endorsing or rejecting self-binding directives provide empirical support for the use of such directives and address both concerns both specific to self-binding directives, such as worries about implementation prior to loss of decision-making capacity, and broader human rights concerns. We focused on people with bipolar disorder, because severe periods of bipolar illness are typically episodic and repetitive, often feature a loss of decision-making capacity for treatment that is regained during recovery, and there is a paucity of research on advance decision-making for this condition.<sup>11,12</sup>

## **Methodology:**

### **Study design, participants, and procedures**

Our target population comprised 20,134 people on the mailing list of Bipolar UK, the UK's largest charity dedicated to bipolar disorder, who had registered their email and provided consent to be contacted by the charity at the time of distribution. On 23 Oct, 2017, a dedicated email containing the URL to the online questionnaire with a description of the project and a request for participants was sent. The survey remained open until 5 Dec, 2017. Bipolar UK 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. Respondents were able to revisit pages already completed and edit responses, and only completed questionnaires could be accessed for analysis by the research team. The internet survey medium was helpful for ensuring wide distribution and facilitating privacy and full anonymity when answering questions concerning such sensitive subject matter. Inclusion criteria were having provided informed consent and having or being a carer for a person having a self-reported diagnosis of bipolar disorder by an appropriate professional (doctor or psychologist).

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.

Ethical approval was provided by the London – Surrey Borders Research Ethics Committee and Health Research Authority (REC reference number 17/LO/1071). The exploratory survey asked about experiences and attitudes towards advance decision-making. The survey included closed and open (free-text) questions. A brief introductory section included a simple explanation of advance

care planning and existing provision within the Mental Capacity Act 2005 (England and Wales) for formal advance decision-making. No other background information was included. The questionnaire can be accessed at: <https://dataverse.harvard.edu/dataset.xhtml?persistentId=doi:10.7910/DVN/WHUYQR>. Quantitative analysis of all service user answers to closed questions and a detailed description of the survey's rationale and methods have been published.<sup>11</sup>

The survey was designed following a review of the literature. First, a pilot questionnaire was formulated and reviewed by the research team. The revised questionnaire was then reviewed by two experienced Bipolar UK employees before being piloted on 8 people with bipolar disorder and 5 carers who provided written feedback. Follow-up interviews were conducted with one of these service users and one carer to discuss the feedback in detail and trial possible alterations. The questionnaire was revised a second time by the original research team (GH, TG, LS, GO, LR, ARK). Both the original survey research team and extended research team (all authors) for the current study include expertise in psychiatry, medical ethics, law, psychotherapy, and lived experience of advance decision-making in bipolar, allowing multidisciplinary and co-produced study design and analysis throughout.

One closed question was: "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 during an episode of illness. Do you think this is a good idea?". The wording "Some people think a 'self-binding statement' is a good idea" was chosen as a means to stimulate critical thinking and is indicative of the positive general consensus amongst available discussions about the idea of self-binding directives, despite various concerns. Answers used a Likert-type scale from 1-5, with options "definitely yes; probably yes; neither yes nor no; probably no; definitely no". The results showed high levels of endorsement, with 719 (77%) of participants answering 1 or 2, 120 (13%) answering 3, 90 (10%) answering 4 or 5, and only three participants failing to answer.<sup>11</sup> For the current study, we classified closed answers as: 1 and 2 indicating endorsement (**Yes**); 3 - ambivalence (**A**); 4 and 5 - rejection (**No**).

A further open question, 'Why do you think this is?', invited free-text responses, without a fixed word limit. The aim of the current study was to understand more about reasons for endorsement, rejection, or ambivalence, by analysing the free-text answers.

### **Data analysis**

Given the complexity of the self-binding directive concept, we excluded free-text responses where factors such as brevity or apparent incongruity between quantitative and qualitative responses made it unclear whether the concept had been understood. Qualitative free-text answers were assessed both separately and then through correlation with the classification of the quantitative answers. PD and TG conducted initial independent checks of all answers and their initial analysis correlated almost completely. PD and TG then discussed together and reached agreement concerning the small number of cases which remained uncertain, and the classification of all answers was circulated amongst LS, GO, ARK, and LR, to check until final agreement was reached.

Although usually short, the free text answers, linked directly to the quantitative 'endorsement' question, provided a conceptually rich and varied dataset, and we used thematic analysis to identify themes within it.<sup>13</sup> To emphasise distinct patterns emerging from the data, we combined in-depth conceptual analysis of inductively derived themes with quantitative analysis of theme distribution, following established methods for analysing open survey responses.<sup>14,15</sup>

Data were entered into coding Software (NVivo12). PD and TG read the raw data independently, discussed initial reflections, then developed a preliminary coding framework. An inductive approach was used and both coding framework and themes were refined through an iterative process, including regular consultation with all authors, until saturation was reached. The data for each theme were then checked a number of times by both PD and TG to ensure conceptual coherence, and final percentages for distribution of each theme within the Y, A, and N groups were calculated.

### **Role of the funding source**

The funder of this study had no role in study design, data collection, data analysis, or data interpretation. The corresponding author had full access to all of the data and the final responsibility to submit for publication.

### **Results**

Between Oct 23 and Dec 5, 2017, the questionnaire was accessed by 3418 people, with a total of 1131 people completing it or a parallel carer's questionnaire constituting a response rate of 5.61%. This was the combined response rate for both service users and carers, given that the total number of each group amongst the target population is unknown. 50 completed service user questionnaires were excluded due either to lack of consent, or failure to meet the diagnostic inclusion criteria. This left a study population of 932 service users with bipolar disorder, 621 of whom answered the free-text question about self-binding directives. After data quality checks, 56 (9%) of the responses were excluded, leaving a data set of 565 service user responses, divided into Y (endorsement), A (ambivalence), and N (rejection) groups. Response rates for the free text question were high amongst those who endorsed (463/64%) and rejected (65/72%), but lower amongst those who were ambivalent (37/31%).

565 participants provided reasons behind their answers to the closed question about endorsement of the self-binding directives concept. These participants had self-identified as having a diagnosis of bipolar disorder and were predominantly white British, female, and well-educated (Table 1). Many respondents had lived experience of severe illness and treatment where self-binding directives would apply. A majority (63%) reported at least one episode of hospitalisation, one third reported at least one experience of formal involuntary detention (34%), and many mentioned experiences of mania, psychosis, and suicidality. The proportion of respondents reporting hospitalisation experiences within the Y, A, and N groups was similar, with slightly higher rates of previous detention amongst those who endorsed or were ambivalent than amongst those who rejected. The distribution of hospitalisation rates was: 291/64% (Y); 24/67% (A); 37/64% (N). For detention rates it was: 165/36% (Y); 12/24% (A); 16/25% (Y).

While 463 (82%) of participants endorsed 'self-binding directives', support was not unanimous, with 37 (6.5%) ambivalent and 65 (11.5%) rejecting (Table 2). Five clear themes concerning reasons for endorsement, ambivalence, or rejection emerged. Reasons for endorsing self-binding directives were classified into two themes: distorted thinking when unwell and benefits. Reasons for rejecting or questioning self-binding directives were classified into three themes: logistical concerns relating to drafting and implementation; valid thinking when unwell; and harms. Both the benefits and harms themes were subdivided into conceptual and practical subthemes, to differentiate between outcomes such as increased or decreased empowerment (conceptual) and reduced suicide risk (practical).

The most striking result was the predominance of the distorted thinking when unwell theme (Table 2) and the remarkably varied articulations of this idea (panel; see appendix p xx for full dataset).

A key reason for endorsing self-binding directives was the theme of distorted thinking when unwell. This theme appeared in nearly all endorsements (411/89%) and, interestingly, even within some rejection and ambivalence responses. The term "distorted", used by a few participants, was chosen for this theme's name, to capture the central idea of adverse change in thought processes, without the distinct judgement conveyed by terms such as invalidity. This adverse change was presented as a dramatic alteration from valid thinking when well and was generally described as a determinate shift that substantially compromised decision-making abilities. An example is: *'A person going through a manic episode has, by definition, seriously distorted thinking. If a person is manic to the extent that they cannot make their own decisions then again, by definition, they are not in a right mind to refute their advance care plan - otherwise it's basically worthless.'* (Y)

Thought processes when well were presented as valid or authentic, either explicitly or implicitly. Participants linked this idea to using lived experience of previous episodes of severe illness to understand both the impact of distorted thinking when unwell on decision-making abilities and how to manage future episodes. Many respondents stated explicitly that the breakdown of decision-making abilities justifies overruling their treatment decisions "during an episode of illness". Some of the free-text answers referred to outcomes of decision-making, rather than simply the process, and used language clearly implying value judgements, such as best, right, good, or wise decision. The impact on decision-making ability and outcomes was expressed with great variety, ranging from the appearance of directly evoking medico-legal terminology associated with decision-making capacity to using far less technical language.

Many participants used diagnostic terms like mania, psychosis, and depression when explaining the distorted thinking and shift from valid to distorted thinking when becoming unwell' while others used the concept from psychiatry of lack of insight into one's illness. Many responses conveyed distortion through stark descriptions of so-called irrationality, using highly emotive and even stigmatising language. This might represent a deliberately hyperbolic attempt to distance themselves from their so-called ill self—a distancing also expressed by presenting distortion as a fundamental change of identity.

Some respondents presented the benefits (theme) of self-binding directives as a reason for endorsing their use and suggest potential positive outcomes: 36 (8%) of participants who endorsed the use of such directives mentioned conceptual benefits (subtheme) as a justification, such as increased empowerment, autonomy, authenticity, and rights, and there was substantial overlap with the theme of distorted thinking when unwell. For example, *'I use it myself. I give mental health staff permission to section me if needed. It gives back the power to me.'* (Y)

58 (13%) of participants who endorsed the use of self-binding directives suggested that these might bring them potential practical benefits (subtheme of benefits), including ensuring treatment, minimising risk, and collaboration in, and continuity of, care. For example, *'When you are in either a manic or depressive episode you are more likely to stop people helping and just want to push away any help'* (Y). Some (Panel and Appendix x) described the cost-benefit analysis of weighing the consequences of not receiving treatment against the likely trauma of experiencing involuntary treatment. Eight participants explicitly presented self-binding directives as a way to reduce suicide risk. Some free-text answers were quite closely connected to the theme of distorted thinking when unwell.

A small group of participants rejected self-binding directives (65/11.5%) or were ambivalent about their use (37/6.5%), expressing doubts about the viability of such directives and the prospect of potential harms, which often directly conflicted reasons given for endorsement.

The theme of logistical concerns about the drafting and implementation of self-binding directives was the most prevalent among participants who gave ambivalent (36/98%) and rejection responses (33/51%), and also appeared in responses of participants who endorsed the use of self-binding directives (63/14%). Many participants expressed concerns about the criteria for valid advance decision-making, such as being properly informed. A common concern was that the self-binding directive would become out-of-date, as illustrated in the response: *'A plan that is written when I am well is a good idea BUT I may have changed my mind about things and not updated the original plan.'* (N). Some respondents worried about the applicability of the self-binding directive to later circumstances, when unwell. Seven worried about ensuring decision-making capacity at the time the directive was completed. Six participants who said they were ambivalent or rejected the use of self-binding directives, along with six participants who endorsed their use, voiced concerns about ensuring that decision-making capacity for treatment was definitely impaired at the time of implementation. Four participants expressed concern about undue influence from family, clinicians, or others.

The theme of valid thinking when unwell was given as a reason for rejecting self-binding directives by 26 (40%) of those who rejected the use of such directives, with the theme name based on the term "valid", which was used in a number of responses. The idea of valid thinking when unwell seemed to challenge directly the theme of distortion of thinking when unwell. An example was, *'I think how a person is feeling in a crisis is valid. As it's valid at the time, the advanced statement might be temporarily invalid.'* (N) One powerful statement presented mania as a valid and positive dimension of the participant's life, contrary to the usual psychiatric evaluation. Another concern was that valid thinking might persist through some severe illness states, but not others, whereas the self-binding directive would apply during all. A small proportion (5/14%) of participants who gave ambivalent responses and even a few of those who endorsed the use of self-binding directives (7/2%) shared these valid thinking reservations, without being convinced by them, illustrating the complexities of the cost-benefit analysis.

Some respondents presented the potential harms (theme) of self-binding directives as a reason for rejection or ambivalence regarding the use of self-binding directives, suggesting that the use of such directives could have damaging outcomes. 26 (40%) of participants who rejected the use and 7 (19%) of participants who were ambivalent raised concerns about conceptual harms (subtheme), presenting a distinct idea: that, although thought processes might change when a person is unwell, this does not necessarily render the thought processes invalid; therefore, to overrule decisions at this point risks contravening human rights. Many participants connected this idea with that of valid thinking, inverting the distorted thinking and conceptual benefits theme. Some participants used terms such as mad almost ironically, suggesting that decisions made when unwell might be contrary to an individual's best interests, but still valid and worthy of respect. Others presented self-binding directives as threatening autonomy, self-respect, and civil liberties, in direct opposition to those who endorsed them as having the potential to enhance these very values. An example was: *"Being unwell does not necessarily mean that you are unable to make a decision that is not right for you. Considering what is best for someone is subjective and it would be against one's human rights to not allow someone to change their mind about what is happening in a specific situation when a plan is made on what to do in a hypothetical one."* (N)

The small number of participants who rejected the use of self-binding directives on the basis of concerns about potential practical harms (subtheme) provided an interesting contrast to those who gave responses in the conceptual harm (subtheme), insofar as most supported clinical judgement taking precedence when a person was unwell. These participants worried that treatment instructions in self-binding directives might be misguided, inappropriate for the circumstances, or even directly harmful, and might then hamper clinical decision-making. Similar concerns were found within the responses of participants who were ambivalent about the use of self-binding directives, where practical harm concerns marginally outweighed conceptual harm. Nevertheless, one response clearly questioned psychiatric viewpoints and rejected self-binding directives as potentially removing the benefits of mania. A typical example from the practical harms subtheme was *"I trust clinicians to be bound by their duty to treat me according to the immediate and presenting symptoms, not some guess made the previous year. They medicate, care, and where possible seek insight from friends and family. Sad fact, bipolar disorder can smash up the world and leave one picking up the pieces at a later time. So too can a broken back or shattered knees. Help me face the daunting haul back to autonomy following an episode, not shackle and fetter me with red tape."* (N).

## Discussion

People with bipolar disorder gave clear, rich, and varied responses describing their opinions regarding the use of self-binding directives. This empirical evidence supports the view that mental health law and practice should be adapted to accommodate a feasible self-binding directive model<sup>1-3</sup> and, more generally, that we cannot define the successful outcomes of mental health advance decision-making purely in terms of avoidance of involuntary and inpatient treatment.<sup>12,16</sup> Yet, despite overall predominance of endorsement of the use of self-binding directives, the presence of clear rejections and ambivalence based on varied concerns, such as logistics, or endangering autonomy, capacity, and clinical judgement, emphasise the need to take individual values and opinions into account. Such rejections and ambivalence certainly show that endorsement of the use of self-binding directives is not unanimous among people with bipolar disorder and that there are concerns which need to be addressed.

Self-binding directives are conventionally justified in terms of minimising risk by ensuring swifter access to treatment.<sup>1-3,5,17-19</sup> However, surprisingly perhaps, the dominant justification given for the use of self-binding directives was the theme of distorted thinking when unwell and the resultant impairments of decision-making abilities, rather than risk avoidance. This dominance is all the more striking, given that all survey participants resided in countries where mental health laws are based on assessment of mental disorder and risk, rather than decision-making capacity. This might provide support for the enactment of so-called fusion proposals, where mental health laws are based on impairments of decision-making capacity, rather than risk.<sup>20</sup> Some statements supporting the use of self-binding directives did present minimisation of risk as a justification, particularly suicide risk. The possibility of such risk reduction may be a powerful argument for the use of self-binding directives, given that it is estimated that “about one-third to one-half of bipolar patients attempt suicide at least once in their lifetime and approximately 15–20% die due to suicide”.<sup>21</sup>

Participants presented distorted thinking when unwell as a determinate, unwelcome, and uncontrollable shift from healthy, authentic, and rational cognitive processes of decision-making. This description contrasts with the commonly expressed fear that a self-binding directive might be implemented before the individual’s decision-making capacity for treatment is sufficiently impaired. This fear has been a primary factor hindering clinical and legal introduction of self-binding directives, insofar as it has led either to rejection of self-binding directives or the imposition of impracticable legal safeguards.<sup>1-3</sup> Survey responses within the distorted thinking theme appeared to indicate widespread confidence that the transition to a severe state of illness would be accompanied by clear impairment of decision-making abilities concerning treatment. Concerns about early implementation of self-binding directives were presented as a reason for overall ambivalence or rejection of their use in only six responses.

The survey responses also challenge various alternative models of self-binding directives that have been proposed by researchers to address this early implementation problem and have been summarised by Gergel and Owen.<sup>1</sup> Most controversial is a competence insensitivity model, that would allow implementation of a self-binding directive regardless of the individual’s decision-making capacity for treatment.<sup>1</sup> Other models de-emphasise decision-making capacity in various ways. Some view the self-binding directive as prioritising an individual’s long-term values over those they hold when unwell;<sup>1</sup> some propose risk, not decision-making capacity, as the criterion for implementation;<sup>22</sup> and some adopt the idea that decision-making capacity varies by degrees, rather than as establishing a determinate threshold for implementation.<sup>19</sup> By contrast, most responses in our survey from service users with bipolar disorder, whether they individual endorsed or rejected the use of self-binding directives, appeared to assume that impaired decision-making capacity for treatment was a prerequisite and the reason for implementation of a self-binding directive. Moreover, most of these responses appeared to imply the acceptance of the medico-legal notion of decision-making capacity as a threshold concept, when they presented distorted thinking as a distinct, determinate shift from healthy and unimpaired decision-making.

Concerns about vulnerability, often raised with respect to self-binding directives,<sup>1,2</sup> do not feature in the survey responses. Such concerns might reflect status-based assumptions about the inherent psychological and epistemic vulnerabilities of people with mental illness and intellectual disabilities by those without lived experience of such conditions.<sup>23,24</sup> For instance, respondents did not express any concerns about potential emotional distress from discussing disturbing memories and topics while drafting a self-binding directive, while concerns about undue influence, or about self-binding directives hampering clinical judgement, were raised in only 12 responses. Respondents appeared ready and able to articulate details about their illness and its effects on their thinking and decision-making, and to understand these effects with great insight and clarity. Similar findings about the inapplicability of such concerns about vulnerability were reached in a more general study of mental health advance decision-making,<sup>8</sup> and in studies suggesting that people with bipolar disorder tend to have good insight and understanding into illness when in remission.<sup>25,26</sup> The degree of understanding shown in responses in our survey challenges the view that poor insight, or inability or refusal to acknowledge and understand one’s condition, and even lack of decision-making capacity for treatment, persist during remission in bipolar, and could impede shared decision-making.<sup>27,28</sup> Such a view is reflected, for example, in a Louisiana law requiring decision-making capacity to be formally certified by a clinician when a service user drafts an advance directive for treatment of mental, but not physical, health.<sup>2</sup>

Many survey respondents appeared to accept and articulate, either explicitly or implicitly, the experience of impaired decision-making capacity for treatment during severe episodes of bipolar disorder, with many including other psychiatric diagnostic categories and concepts sometimes considered controversial, including, psychosis, delusions, and loss of insight. They presented these experiences as constituting justifications for others to impose treatment decisions which can override their own treatment decisions while severely unwell. Such views could be seen to challenge human rights-based rejection of mental capacity assessment and involuntary treatment, and to help address some of the difficulties associated with the need to provide protection, while also respecting agency and autonomy. In particular, the UN Committee on the Rights of Persons with Disabilities (the UN Committee) has, in its General Comment No 1 (GC1), called for the abolition of both mental capacity assessment and involuntary treatment.<sup>10</sup> However, the Committee also clearly supports advance decision-making in its GC1, stating “all persons with disabilities have the right to engage in advance planning”,<sup>10</sup> which has led countries such as India<sup>29</sup> and Australia (in some states and territories including the Australian Capital Territory)<sup>30</sup> to incorporate advance decision-making into their mental health laws.<sup>3,31</sup> In its commitment to promoting “individual autonomy”, the UN Committee presents mental capacity, defined as “the decision-making skills of a person”, as a flawed, “highly controversial” concept, which is “contingent on social and political contexts”, and argues that to deny any type of legal capacity, on the basis of impaired decision-making capacity, is inherently discriminatory and contravenes the individual’s core right to “equal recognition before the law”.<sup>10</sup>

The UN Committee's position would seem to remove the medico-legal foundations for both self-binding directives and advance decision-making in general.<sup>32</sup> More broadly, disagreements over whether coercive care can ever be justified have led to an impasse in the UN human rights system.<sup>33</sup> The results from our survey might help to circumvent such difficulties, if we view self-binding directives as a means to support, rather than prohibit, the exercise of legal capacity. Clearly, many service users with bipolar disorder have found that severe illness distorts their thinking and thereby renders them temporarily unable to exercise legal agency and autonomy. They wish, therefore, to exercise their autonomy and manage their condition through advance treatment decisions which can be followed during future severe episodes.

A limitation of our study is generalisability, given that the survey was available only in English and the participants were predominantly white British, female, and well-educated. The use of the UK mailing list as the sampling frame and a low response rate introduced further selection bias, as people with a prior awareness of or interest in advance decision-making are likely to be over-represented and the survey was only accessible to those with the necessary digital resources.<sup>11</sup>

The use of self-binding directives has also been discussed with regard to other types of episodic mental health condition. It would be useful to explore the idea with a broader range of participants, in a broader range of contexts and disorders. An implementation study on self-binding directives for people with bipolar disorder, led by LS, and being conducted by LS, TG, GO, LR, and ARK, uses purposive sampling and actively attempts to engage those who have experience of compulsory treatment. Participants have been recruited to this study from a range of clinical services and belong to groups which might be less actively involved in third sector groups such as Bipolar UK and include a broader demographic range.

The most striking aspect of our results is the number and variety of endorsements by service users with bipolar disorder justifying the use of self-binding directives on the grounds of a major determinate shift and distortion of thinking and decision-making abilities occurring when unwell. The ethical, policy, and practical implications of these findings for advance decision-making and decision-making capacity need further exploration. TG has been working on a more detailed analysis of answers from the distorted thinking theme and further interviewing of service users with bipolar disorder or other mental health conditions could be valuable. The variety of responses suggests a need for a more personalised understanding of decision-making capacity,<sup>1,16</sup> a particularly important point given the increasing significance of capacity assessment in mental health law and practice. While the focus of the current study was on service user responses, TG and PD also analysed the dataset of 110 free-text carer responses, finding quite a strong correlation with the service user results. It would be valuable to consider these results in more detail, to obtain perspectives from another key group of stakeholders.

To conclude, these results highlight both a need to recognise the rights of people with bipolar disorder who want to use self-binding directives to manage their health and advance their autonomy, and the difficulties of trying to find a single approach to maximising autonomy within human rights in psychiatry.

## **Contributors**

TG and PD were joint first authors and wrote, reviewed, and edited the manuscript together. They conceived the study and conducted selection, analysis, and verification of the data, with all other members (ARK, GO, LS, LR, JD, GH) of the team reviewing throughout the process. GH conceived and conducted the original survey, with the help of TG, GO, LS, LR and ARK, and assisted with demographic analysis and data selection for the current dataset. All authors reviewed and approved the final version. GO, ARK, and TG contributed towards acquisition of the financial support for the project leading to this publication.

## **Declaration of interests**

We declare no competing interests.

## **Data sharing**

All survey participants gave permission for their anonymised answers, including quotations, to be used in publications. We have therefore included the full dataset as supplementary material with this publication.

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Table 1: Demographic details of the survey population.

Table 2: Distribution of themes and subthemes within responses. Given that many individual responses contained multiple themes, the total percentages for distribution of themes within each group exceed 100%.

Panel: Quotations supporting themes and subthemes