

Article

# Consumers' Experiences of Mental Health Advance Statements

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**Abstract:** Mental health psychiatric advance directives, advance statements, and similar documents are designed to convey a person's treatment preferences to their treating clinicians at times when, due to their mental health, their ability to communicate or make decisions might be impaired. This paper explores the current debates in the literature and presents the findings of a small qualitative study that explored the experiences of people who had completed advance statements in Victoria, Australia. Data was collected through interviews with participants and analysis of their advance statement. Participants completed their advance statements for two main reasons; to authorise future treatment or to limit the power of their treating team. Participants also included non-treatment preferences that were linked to their recovery and pragmatic considerations, such as contact details and dietary requirements. Participants who had used their advance statement reported a lack of acceptance or inclusion from clinicians. Further consideration of the legal enforceability of advance statements is necessary, and if they are to continue to lack legal force, much work remains to be done to support acceptance by clinicians.

**Keywords:** mental health; advance statements; psychiatric advance directives; Mental Health Act 2014; Victoria; Convention on the Rights of Persons with Disabilities

## 1. Introduction

In a mental health setting, psychiatric advance directives, advance statements, and similar documents are designed to convey a person's treatment preferences to their treating clinicians at times when, due to their mental health, their ability to communicate or make decisions might be impaired. Originally developed for use in end-of-life decision-making, in a mental health setting advance directives are usually prepared in situations where a person anticipates that they will become subject to compulsory mental health treatment in the future. This paper presents the findings of a small qualitative study that explored the experiences of people who had completed an 'advance statement' since their introduction in Victoria in 2014.

This paper introduces and describes psychiatric advance directives before describing the legal framework in Victoria, Australia, where consumers are able to write an advance statement to document their treatment preferences. The paper then presents the analysis of ten interviews with people who had completed an advance statement. Drawing on the attitudes of participants and the contents of their advance statements, it became possible to group participants into those who sought to use their advance statement to limit the power of the treating team, and those who sought to use it as a tool to authorise their treating team to make treatment decisions. Finally, the paper considers the significance of other preferences that are not related to clinical treatment and the lack of acceptance of advance statements participants reported from clinicians. Overall, the findings indicate that advance statements

have significant untapped potential, but that while they lack legal enforceability, much work will be required to improve their acceptance by clinicians.

### 1.1. Psychiatric Advance Directives and Other Similar Documents

Psychiatric advance directives and similar documents have a long history. The idea was first mooted by May Ellen Redfield in 1964, in ‘Will for the living body’. Redfield described a document that appointed medical staff as her guardians, refused all medical treatment but provided consent in advance for psychotherapy (Redfield cited in [Newnes 2016](#), p. 182). Prominent psychiatrist Thomas Szasz (1982) also promoted the a ‘psychiatric will’, suggesting that such documents can be used to protect people from psychosis, by commending their future selves to psychiatric care, or to protect people from psychiatry by preventing psychiatric intervention.

Since that time, following a decade of consumer advocacy, psychiatric advance directives or similar documents have been legislated, implemented, or piloted in a number of jurisdictions. These include some states in the United States ([Appelbaum 2013](#); [Kim et al. 2007](#)), Belgium ([Nicaise et al. 2015](#)), Ireland ([Morrissey 2010](#)), Scotland ([Reilly and Atkinson 2010](#)), India ([Shields et al. 2013](#); [Kumar et al. 2013](#); [Ratnam et al. 2015](#); [Javed and Amering 2016](#)), and England, Wales, and Canada ([Weller 2012](#)). There is a wide variation in the legislative form. The documents may have no legal force, decision makers may have to ‘have regard’ to them, they may be overturned by a tribunal or other higher authority, or they may be entirely binding in certain circumstances. They may be used to offer advance consent to treatment, in effect ‘binding’ the person making them, which is sometimes described as a Ulysses clause, or they may be used to select, restrict, or refuse specific treatments, in effect ‘binding’ the treating team or other decision maker. Despite this variety, all of the models are intended to empower a person and assist in supporting their will and preferences.

This has generally been based on a traditional view of capacity, assuming that a person has capacity to make decisions when they are mentally ‘well’ and that when they become ‘unwell’ they lose this ability. This view is of binary competence and incompetence is still widely used in mental health legislation (see e.g., *Mental Health Act 2014* (Vic) s 68), but has come into question since the introduction of the *Convention on the Rights of Persons with Disabilities* (CRPD)<sup>1</sup>.

### 1.2. Psychiatric Advance Directives and the CRPD

Psychiatric advance directives and similar documents are one element of a broader shift in mental health treatment, toward a human rights based approach, where the right of people to make their own decisions is preserved ([Weller 2012](#)). A new dimension in this debate has been introduced by the CRPD, which makes a clear distinction between legal capacity—the ability to make contracts, refuse medical treatment, marry etc.—and decision-making capacity, which is the mental process of making decisions ([Maylea and Hirsch 2017](#)). Article 12 of the CRPD requires that legal capacity is not linked to decision-making capacity, so that a person is provided with adequate support to exercise their legal capacity, as detailed in the *Committee on the Rights of Persons with Disabilities General Comment No. 1* (2014) (General Comment No. 1)<sup>2</sup>. This means that a person’s legal capacity—the right to choose or to refuse treatment or to create, amend, or revoke a psychiatric advance directive—cannot be taken away on the basis of their impaired decision-making capacity. This sits uncomfortably with the notion that an advance statement or a similar document can be made when a person has decision-making capacity and be used to force a person to receive treatment when they do not. The CRPD requires a shift from substituted decision-making to supported decision-making, where a person never lacks legal capacity, but instead, requires more or less support to exercise it.

<sup>1</sup> *Convention on the Rights of Persons with Disabilities: Adopted 13 December 2006*, GA Res 61/106, UN Doc A/Res/61/106, Entered into Force 3 May 2008.

<sup>2</sup> CRPD General Comment No. 1 Article 12: Equal Recognition before the Law, CRPD/C/GC/1 11th Session, 31 March–11 April 2014.

Scholten and Gather (2017) have described this as an ‘adverse consequence’ of the CRPD, arguing that the rejection of a competency model of decision-making capacity *diminishes* autonomy, as it prohibits people from making advance statements, which they cannot later override at any time because they must always be viewed as having legal capacity to do so. It is difficult to see how a binding advance directive regime that binds the person making it is compatible with a post-CRPD conceptualisation of capacity, however an advance directive regime that binds the substitute decision makers, but not the person themselves, would be. General Comment No. 1 (2014, 5) specifically requires that “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”.

### 1.3. Aiding Recovery and Improving Care

Beyond a rights-based consideration, psychiatric advance directives can serve an additional purpose in improving the quality of the care, treatment, and support that people receive, and in doing so, support their recovery. Recovery has a specific meaning in mental health parlance, referring to the lived experience of the individual—their thoughts, feelings, and experiences of ‘finding a way through the illness’—with attention being paid to the whole life experience of the individual, rather than merely their symptoms and diagnosis (Bland et al. 2015). For this paper, we adopt Deegan’s (1996) understanding of recovery as a journey of the heart, as opposed to a clinical understanding of living without symptoms. Advance statements provide an opportunity for a person to convey important personal preferences to clinicians who adopt a recovery approach, an approach that has been adopted across Australia and is mandated in Victorian mental health services (Department of Health 2011).

Psychiatric advance directives or similar documents have also been shown to improve people’s experience of crises (Ruchlewska et al. 2016), improve the quality of crisis planning (Ruchlewska et al. 2014), increase their likelihood of taking medication (Wilder et al. 2010), reduce the likelihood of coercive interventions (Swanson et al. 2008), including compulsory treatment (Morrissey 2010), and support the maintenance of human rights (Weller 2010). Their potential impact will depend on their specific nature in each jurisdiction, particularly their legal enforceability. Despite this potential, studies show that they have not had high take up rates in other jurisdictions (Zelle et al. 2015; Radenbach et al. 2014), and in the absence of enforceable legal standing, are reliant on the support of substitute decision makers (Ruchlewska et al. 2016; Radenbach and Simon 2016). This support has not always been widespread (Gooding 2015; Sellars et al. 2016; Haw et al. 2011).

### 1.4. Advance Directives in Australia

In Australia, Victoria was the first jurisdiction to introduce legislation that supported the right of mental health consumers to document their treatment preferences. Since then, Queensland, the Australian Capital Territory (ACT), and Western Australia have followed suit (Ouliaris and Kealy-Bateman 2017).

Under both the Western Australian *Mental Health Act 2014* s 8 and Queensland *Mental Health Act 2016* s 222, decision makers, including clinicians, are required to consider a person’s treatment preferences if they are made in an ‘Advance Health Directive’. These are general health directives, made under *Guardianship and Administration Act 1990* (WA) or *Powers of Attorney Act 1998* (Qld), which are not specific to mental health treatment. In a mental health context, they are not required to be followed, but rather, merely considered.

The ACT has adopted a two-pronged, mental health specific approach, allowing for consumers to either create an ‘Advance Agreement’, which is not binding, or an ‘Advance Consent Direction’ that can only be overridden with consent of the person or on application to ACT Civil and Administrative Tribunal (ACAT) (*Mental Health Act 2015* (ACT) ss 24–32). A feature of the ACT scheme is that a person may consent to treatment which is prohibited by their Advance Consent Directive, even if they are assessed as not having decision-making capacity (*Mental Health Act 2015* s 28(3)(a)). This seems to imply a post-CRPD understanding of capacity—a person can use an Advance Consent Directive to

restrict the treatment they receive so long as it is consistent with their ongoing wishes—but are able to override their document at any time.

Ouliaris and Kealy-Bateman (2017) have produced a comparative overview of the Australian frameworks, as summarised in Table 1:

**Table 1.** Legislation provisions for psychiatric advance directives in Australia (adapted from Ouliaris and Kealy-Bateman (2017, p. 576).

Jurisdiction	Legislation	PAD	Binding?	May Be Overridden?	Considered in Involuntary Treatment Orders?
Australian Capital Territory	<i>Mental Health Act</i> (2015)	Advance agreement (AA) and advance consent direction (ACD)	AA; no ACD; yes	AA; yes. ACD; on application to ACAT or with consent	AA; yes ACD; yes
Queensland	<i>Mental Health Act</i> (2016)	Advance health directive (AHD)	Yes	Yes	Yes
Victoria	<i>Mental Health Act</i> (2014)	Advance statement (AS)	No	Yes	Yes
Western Australia	<i>Mental Health Act</i> (2014)	AHD	No	Yes	Yes

Ouliaris and Kealy-Bateman (2017) praise the ACT legislation, writing that, '[i]ts careful balancing of self-determination and harm minimisation creates a unique safe space in which clinicians and consumers may engage, build therapeutic alliances and develop appropriate frameworks for further change.' While they note that this still allows for compulsory treatment, even for people who can be assessed as having decision-making capacity, it goes the furthest amongst Australian jurisdictions to give force to a person's will and preferences. In Victoria, however, consumers do not have the option of making any kind of document which would be binding on clinical decision makers.

### 1.5. Advance Statements in Victoria

In 2014, Victoria introduced 'advance statements'. These documents are not binding on either the person or decision makers, but must be considered by decision makers exercising powers under the Act. They were intended to be a key feature of mental health care reform, particularly in improving "patient experience and recovery" (Rich-Phillips 2014), and featured prominently in the passage of the *Mental Health Bill 2014*, mentioned 174 times in 18 separate parliamentary speeches during the passage of the Bill (Parliament of Victoria 2017) and in 23 distinct sections of the Act.

Advance statements are detailed in pt 3 div 3 of the Act. They are defined in s 19 as 'a document that sets out a person's preferences in relation to treatment in the event that the person becomes a patient.' Under the Act, a person becomes a patient when they are subject to compulsory treatment.

Advance statements may be made at any time and must be in writing, signed and dated by both the person making the statement and an authorised witness. They must include a statement by the witness stating that the person understands the nature and purpose of an advance statement. This need to 'understand' the nature and the purpose of the document is not a test of the person's decision-making capacity regarding their treatment decisions—they must understand what an advance statement does and what it is for, but this falls short of the definition of capacity to give informed consent to treatment under the Act.<sup>3</sup> An advance statement cannot be altered, but it can be revoked in writing at any time, and a new advance statement can be written at any time.

<sup>3</sup> This test, in s 68, requires a person be able to understand, remember and use or weigh information relevant to the decision and communicate the decision.

Authorised psychiatrists are responsible for making decisions about a person's treatment if they are subject to a treatment order under the Act (*Mental Health Act 2014* s 71). When making decisions, an authorised psychiatrist 'must have regard, to the extent that is reasonable in the circumstances, to . . . the views and preferences of the patient expressed in his or her advance statement' (*Mental Health Act 2014* s 71(4)(b)). While making treatment decisions under the Act, they are able to override the preferences in a person's advance statement if they are satisfied that the treatment is not clinically appropriate or not ordinarily provided by the service (*Mental Health Act 2014* s 73(1)). If an authorised psychiatrist does override a person's preferences, then they must explain why and advise the person that they have the right to request written reasons for the decision (*Mental Health Act 2014* s 73(2)).

Authorised psychiatrists can make Temporary Treatment Orders for up to 28 days, but for longer orders, up to 6 or 12 months, must make an application to the Mental Health Tribunal (the Tribunal). The Tribunal must also 'have regard' to a person's advance statement, but similarly, are not bound to follow it (*Mental Health Act 2014* s 55(2)(b)).

Despite clear parliamentary support, in 2016/17, only 2.34% of adults in Victorian public mental health services had an advance statement on record (DHHS 2017), which is a marginal increase from 2% in the previous year. This low and stagnating take up rate prompted the Mental Health Legal Centre (MHLC) to partner with RMIT's Social and Global Studies Centre to explore the experience of people who had developed advance statements through the MHLC's Advance Statements Project, a non-government funded project aimed at maximizing autonomy, dignity, and control for people who are subject to compulsory treatment (Helen Macpherson Smith Trust 2015).

## 2. Method

This study employed qualitative semi-structured interviews to collect data with 10 participants, all being recruited through the MHLC Advance Statements Project. The MHLC Advance Statements Project was funded in 2015, by the Helen Macpherson Smith Trust, to '[h]elp Victorians to assert their legal rights and effectively engage in the Recovery Orientated Framework exercising these rights' (Helen Macpherson Smith Trust 2015). The project provides a lawyer to assist consumers to develop advance statements, on a fortnightly or monthly basis at Saltwater Clinic Community Mental Health, Thomas Embling Forensic Mental Health Hospital and Orygen Youth Health. Consumers are usually referred by their treating team, by a mental health lawyer, mental health advocate, or other professional. They may also be approached directly by the lawyer or self-refer.

All consumers who had completed an advance statement since the inception of the project ( $n =$  undisclosed) were sent letters inviting them to participate in the research, with MHLC contacting consumers via telephone with follow up invitations. Participants were compensated with \$50 gift vouchers.

Participants were not asked to identify a gender that they identified with, or any other demographic data. Where they identified relevant demographic information (such as diagnosis, number of admissions, current involuntary status, or that they were parents of young children), this was included in the analysis. Nearly all ( $n = 9$ ) indicated that they had been compulsorily treated under the Act and/or its predecessor, the *Mental Health Act 1986* (Vic), and had been referred by case managers or mental health lawyers to the MHLC Advance Statements Project. Those who had been compulsorily treated under the Act would have had to have been assessed by a psychiatrist to have a mental illness, as defined in s 5 of the Act, 'a medical condition that is characterised by a significant disturbance of thought, mood, perception or memory'. Participants were not asked if they agreed that they had a mental illness or what diagnoses they had been given.

Interviews were between 26 and 46 min in length and were all conducted by the chief investigator. Participants were asked why they completed an advance statement, how they found the process, how they thought they should be used, how they thought they should be distributed, and if they would change anything about the process. Participants were asked to provide consent to access their advance statement. Interview recordings were transcribed before being analysed.

Using well-rehearsed coding conventions of thematic analysis in NVivo, two members of the research team independently coded the data according to research questions and responses. This coding was presented to other members of the research team and discussed, refined, and combined. The chief investigator conducted an independent thematic analysis, and then compared this with the initial coding. Themes consistently agreed, and where they did not this was further discussed with other members of the research team. The axial themes were identified through a process of mapping group distinction in answers to the interview questions using Nvivo's maps tool to facilitate insight into the data.

Quotes from interviews are indicated with (#I) and the participant number and quotes from advance statements are indicated with (#AS) and the participant number.

Ethics approval for this project was granted by RMIT University's Human Research Ethics Committee (#20891/2017).

### 3. Results

#### 3.1. Authorise and Limit

Overall, participants found the process of having completed an advance statement positive, albeit often for quite different reasons. These reasons can be loosely grouped around a desire to *authorise* the treatment team to make decisions ( $n = 6$ ), and a desire to *limit* the power of the treating team ( $n = 7$ ). These concepts are not diametrically opposed—advance statements can be used to limit some areas of treatment and authorise others, with some ( $n = 3$ ) participants expressing both themes.

Despite this, the themes were quite distinct, and they were clearly linked to opposing understandings of the purpose of advance statements, their operation, and mental health more generally. Most clearly distinct are the reasons participants gave for creating advance statements. All the participants who related a negative experience of receiving mental health treatment ( $n = 6$ ) sought to limit their treatment or the potential for harm in the future. Those who thought that they made unsound decisions while unwell ( $n = 4$ ), all used their advance statements to authorise future involuntary treatment. This indicates two nearly distinct groups; one group deferring to the decisions of the treating team, who accept that they make 'poor' decisions while unwell, and another group who do not accept this narrative, and who wish to make their own decisions at all times.

The clearest difference between the two groups is in their attitudes to questions about legal enforceability. When asked if they thought advance statements should be legally binding on the treating team, six participants thought they should be, only one of whom did not express a desire to limit their treatment. Conversely, all of those who said that they should not be binding ( $n = 5$ ) expressed the theme of authorisation. Those ( $n = 3$ ) who expressed both themes were evenly divided on the question.

Less clear, but also linked, was the way these that two groups wanted to create an advance statement. All of those ( $n = 4$ ) who wanted to create it alone with a lawyer also expressed a desire to limit treatment. Conversely, all but one of those ( $n = 5$ ) who wanted to create their advance statement with a broader group including clinicians, family, and friends, expressed the theme of authorisation.

One way in which the two groups were not consistently divided was in the way they thought advance statements could be changed. All of those asked ( $n = 9$ ) agreed that they should be able to be changed, with six participants indicating that a capacity test or a test of 'wellness' should be undertaken prior to any changes. These six were not aligned along themes of limitation or authorisation, and they did not agree on who should conduct this test, with case managers ( $n = 1$ ), treating psychiatrists ( $n = 2$ ) and an independent third party ( $n = 1$ ) all suggested. One participant thought that there should be a best interests test, and another did not anticipate needing to change it.

As with any qualitative research, this is only one of many ways in which the data can be interpreted, however the way the two groups were consistently divided on nearly all points of contention strongly supports the distinction between the two main themes. Despite these

differences between the two groups, there were other, overarching themes that are common to all participants, including treatment preferences, non-medical recovery preferences, and the consideration of pragmatic factors.

The remainder of this section explores the two main themes of authorisation and limitation, before describing the integration of recovery goals and practical elements that are described by the participants or revealed by analysis of their advance statements. This section concludes with the experiences portrayed by the participants regarding the acceptance of their advance statements by clinicians.

### 3.2. Limitation

All but one of the participants who sought to limit the power of the treating team generally linked this to some negative experience in the mental health system, be it a single significant event, or an experience of not being listened to or respected. This participant, who had made a formal complaint about a violation of their rights while an inpatient, articulated this experience of powerlessness:

*I came to doing an advance statement because I had a really bad experience where I was involuntary admitted into hospital and I obviously didn't want to be there. I felt at the time that I could express what I wanted but I didn't feel that I was listened to. So, when I came out of hospital I did a lot of research . . . and I found out about advance statements and thought that maybe next time I'd be listened to more if it was in writing.*

*. . . I do get quite uncomfortable and anxious when I am not in control, and so situations like that of course I am going to lose it and yeah have a bit of a breakdown and not be able to communicate properly. So I put that in there as well. (I#3)*

This participant clearly linked this experience to a need for dignity, identifying how crucial this would be to their recovery, writing in their advance statement:

*I am a person, just like you. Please do not treat me like I have done something wrong, or will not understand. I have suffered traumas in my past, which have affected my mental health but I am committed to my recovery. I am currently having weekly psychotherapy sessions, I am starting with EMDR therapy, and I have strong family and social supports. If I am in hospital again, I need my wishes respected and to be treated with compassion and empathy, and not control. (AS#3)*

This was a consistent subject for those that were seeking to limit the power of the treating team, who emphasised the importance of autonomy and respect in their recovery journey. This was clearly articulated in this participant's advance statement:

*Losing control over decisions is the single most threatening thing for me and is therefore extremely unhelpful for my recovery. (AS#1)*

This participant based this position on decades of experience, resulting in an understanding into what would be most useful for themselves into the future, and was clearly linked by this participant to personal frustrations with the mental health system. In this way, those using advance statements to limit treatment were seeking to wrest control back from the mental health system that had taken it away from them:

*. . . unfortunately I don't think the mental health system or the hospitals want the control taken away from them. . . you go there, they force you to take medication—they never give you an end date—they never say you're gonna get better from this. Every time I enter the hospital they tell me this is your life you just gotta learn to manage it—they never tell me that I'm gonna get well. (I#9)*

This group of participants, who focused on limiting their treatment, were not denying their need for treatment or support, they just wanted to dictate that treatment or support themselves. Only one participant expressed a desire to refuse medical treatment entirely, however, their statement also

included a variety of other, non-medical supports, which should be employed instead. Those who sought to authorise treatment, on the other hand, focused instead on improving communication so that the treatment they received was of a higher quality.

### 3.3. Authorisation

Those who expressed themes of authorisation sought to engage with and influence the treating team, while trusting the treating team to make the best decision for them if provided with the right information. This group still identified treatment preferences, but sought to exercise power with, rather than power over, the treating team. When asked about the idea of legally binding advance statements, participant #2 was quick to dismiss this idea:

*Well that wouldn't work either because . . . a qualified treating practitioner is going to have better idea of what I need when I am unwell. So as much as I would have thoughts and views on it, if I am not well I can't make that call anyway. (I#2)*

The same participant clearly articulated this in their advance statement:

*I acknowledge the need to take medication to avoid manic episodes and I am willingly to comply voluntarily with the directions of my treating psychiatric team. (AS#2)*

For this group, advance statements were not so much about limiting treatment, as ceding control to the treating team so that they would receive the most appropriate care. They were willing to accept that their mental illnesses had on their decision-making capacity and viewed their insight as important to their recovery journey. Three participants in this group were the only ones to identify insight or understanding of their diagnosis as necessary for a useful advance statement.

An example of authorisation was from participant #10, who used an advance statement to request electroconvulsive treatment (ECT), on the basis that the medications they had previously tried had not been effective:

*When admitted, my treatment preference is ECT and at a minimum 4 rounds of treatment. I have found in the past that it has taken 4 rounds before I feel and appear to my friends to be myself again. My need for treatment is infrequent, but I have found that when treatment has been required ECT works the best in 'bringing me back'. I do get short term memory loss, but I am ok with this. (AS#10)*

This participant's authorisation of treatment, attempting to provide consent in advance, acceptance of side effects, and the justification of this decision is characteristic of an authorisation approach to advance statements.

Those who sought to authorise treatment focused on communicating their preferences clearly, while ceding control to the treating team:

*I tend to believe that the team, the treating team psychiatrist, psychologist, nurse whatever, social worker, OT, everyone is, has my best interest at heart . . . even though I outlaid everything that I would prefer to have implemented, I don't think I am in a position. as I say I am not psychiatrically trained, they would have insights into the treatment that I am not privy to or aware of. I had my history I know a lot of about my own history. So I do know what works well for me and that sort of thing, and that's what I sort of expressed. But if they were of the opinion for example that they couldn't treat me without giving me injections, perhaps I was not being compliant or something, I don't think that its really my legal right to say what they can and can not do. I thinks it's more a guide for me, for them. (I#4)*

This concept of the advance statement as a guide was also characteristic of this group, with participants viewing the advance statement as a letter to their treating team. Not all of those who wanted to authorise treatment had this kind of confidence in the treating team, but still sought to put them in the best position to provide care by communicating preferences and experiences:



*You don't have a lot of hope in the team and that's the thing . . . it's hard because they have to go from nothing to all this ground work of where you're at psychologically, of where you're at emotionally, physically, and there's a lot of work that needs to be done for you to be able to come through that and . . . all sorts of communicated skills and that you learn a lot along the way. But it's important to have a solid foundation to work on because I think it would make the whole process a lot quicker and easier for everybody involved. (I#7)*

This process of authorisation through communication, of explanation and justification, was typical of those who sought to authorise treatment. For participant #7, this was based on the potential that the treating team would have no background unless it was provided in their advance statement:

*If you do find yourself caught out and becoming unwell and there's not the supports in place and you don't have the advance statement you're leaving it up to someone who doesn't even know you and never met you before and hoping that they know what's best for you. (I#7)*

Another feature common to those who sought to authorise treatment was a tendency to use their advance statements to override decisions they might make later ( $n = 5$ ). One participant (#10) requested that their phone be taken from them, so that they did not contact people and cause embarrassment, and others generally identified that their thinking would be disordered while unwell.

This distinctly separates the authorisation group from the group seeking to limit treatment, none of whom expressed a desire to bind their future selves or to offer explicit consent to future treatment. The authorisation group were also more likely ( $n = 4$ ) than the limitation group ( $n = 0$ ) to identify a preferred hospital to be treated in.

#### 3.4. Medication Preferences, Recovery Preferences and Pragmatic Factors

Advance statements, as defined in s 19 of the Act, are documents that 'set out a person's preferences in relation to treatment'. Participants did identify treatment preferences; all of the participants identified medication preferences of some description, with only one participant (#1) rejecting medication entirely, and another (#5) identifying a preference for medication to be a treatment of last resort. Five participants used their advance statement to deny consent for ECT, although this did not correlate with either of the two groups that are identified above. Seven participants also communicated medication side effects, allergies, and dosages, with one (#10) identifying side effects that they were prepared to accept. As the purpose of these documents is to document treatment preferences, the inclusion of these aspects is unremarkable.

In addition to clinical treatment preferences, however, all of the participants included requests or statements in their advance statement that related to their recovery, but were not treatment preferences. These included requests that they be treated with humanity, dignity and respect, or factors which they identified as important to them, which might not be immediately known to the treating team. These included requests to contact specific people, such as friends or family, or not contact others, such as ex partners. Participants also requested specific clinicians by name ( $n = 3$ ), or a preference for staff of specific gender ( $n = 2$ ), pastoral care ( $n = 1$ ), lawyers or advocates ( $n = 1$ ), and access to music, art, or writing materials ( $n = 4$ ). Participants also spoke of how their treatment would be most effective—the importance of their daily routine ( $n = 1$ ), the importance of explaining treatment decisions ( $n = 4$ ), and the importance of retaining connections to support networks ( $n = 5$ ). All of the participants identified at least one preference that would not be considered 'treatment' under the Act, but that was important to their own recovery.

The inclusion of these aspects speaks to the potential of advance statements to be used as a key tool of a recovery approach, which requires clinicians to be responsive to what is important to the person. Participants viewed these aspects as crucial to their recovery and wellbeing:

*. . . it doesn't matter if I'm incarcerated or not I understand how I'm feeling. I understand what things actually are true to me getting well quicker and keeping me calm as well. Take the example*

*of being in a high dependency unit that's the worst part, one of the worst parts of being inside a psychiatric ward . . . and half the time you're worried about your own safety. Having some music just allows you to tune out just for a little bit—just keeps you in a calm spot—and maybe your calmness will sort of flow onto the other people as well. (I#6)*

Linked to these non-treatment preferences, participants included other simply pragmatic information that was not related to their treatment, such as care for dependent children, pets or plants, dietary requirements, information regarding breastfeeding and breast pumps, and details of previous trauma and triggers. Participants placed great importance on these practical aspects, with this participant requesting that their houseplants be cared for while they were in hospital:

*Watering and feeding and pruning and looking after and you know it might sound insignificant but they're part of my life and part of my day to day, of what I do. I water my plants every day and I feed them every couple of weeks and I make sure they're healthy and happy, and if I was to become unwell and not have them looked after—then that's part of me that's not getting looked after either. (I#7)*

Responding to these issues while detaining a person for treatment is obviously crucial, not only regarding the practical consequences, but also the indirect impact on a person's recovery. A person who is confident that their children, pets, or houseplants are being cared for could be expected to experience less mental distress, and a less traumatic experience of compulsory treatment. Despite this potential, in this study, participants identified that clinicians had not been consistently receptive to their advance statement.

### 3.5. Clinician Acceptance

No participants could say that their advance statement had been followed by clinical staff, with four not having been treated compulsorily since drafting it, three having had their statement overridden, and three unsure if their treating team had considered them:

*I don't know whether they read my advance statement, but I was already in there for four or five days and I brought it to their attention, so I don't know whether then they looked up my file. I thought they should've done that beforehand. (I#2)*

One was told by clinicians that their advance statement would not be followed:

*I think it helped my psychiatrist realise... because I told her what I want. That I don't want to be back in the public health system, it helped her to realise why. She was bit sceptical on it. Her reaction was 'ohh thanks for sending it to me but I don't think they are going to listen to it'. (I#3)*

This experience was the same for all three participants who had attempted to use their advance statement:

*I went and seen my psych and my psych's like this is useless . . . I spent three days in the ED unit . . . their words were similar to the lines of "we acknowledge that it's there, but we don't necessarily have to comply with it—so good luck with that". So, I was like ok cool. . . . it was really a struggle because they wanted to change all the medications and a lot of the medications they've given me in the past I haven't reacted well to. . . . They didn't really pay attention to the advance statement, how it was written or respect it in any sense.*

*. . . they just sorta went (sound of paper being ripped up)—oh yeah—yep it's like (more paper being ripped up)—you're going to be taking this medication, you're going to be doing this and if you don't get better you're going to be doing ECT. (I#9)*

This participant's (#9) advance statement clearly articulated alternative treatments and requests for early intervention that were not followed and included statements, such as 'Please understand that I have given significant thought to my treatment decisions' and 'I have had three previous

inpatient admissions and have a very clear understanding of what works best to facilitate my recovery'. The requests included a preference for vegetarian food, female only staff (following a prior sexual assault), and darkness to reduce her stress. This response from the treating team highlights the reliance on clinician acceptance for the advance statements regime to function properly.

Despite participant #5 sharing this expectation that the clinicians would not accept the advance statement, merely having an advance statement gave them more confidence, even though they were wary of standing up for their rights:

*Participant: [My advance statement] just me feel like I had more confidence. So on the last one they gave me 12 weeks, but at the [MH service] they took the order off earlier.*

*Interviewer: And you think that was to do with the advance statement?*

*Participant: I am not sure, I think its because I did everything they asked and agreed with them. That's how I got out . . . . Because if you stand up for your rights that goes against you. (I#5)*

Another participant (#9) was also wary of what they put in their advance statement that was being used against them. When asked if they would document preferences relating to their voices, such as if clinicians should interact with them or not, they replied:

*. . . if I ever said that—you know—when I'm unwell— . . . —one of my voices does x, y, z—and then it meant that I was in hospital and then they looked at that and go, "Oh Ok this person's unwell and they've got a tendency to when they're unwell to do this—I just don't ever see a release date from that prison—from that hospital. (I#9)*

This fear of consequences arising from unintended disclosure via an advance statement was not raised by other participants.

Another implementation issue that was discussed with participants was the way advance statements were stored. Currently, participants are responsible for conveying advance statements to clinicians, which would not necessarily be ideal if a person was compulsorily treated outside of their usual hospital catchment area. Eight participants supported the notion of a central register to address this issue, with two opposing this idea on privacy grounds.

The participants were unable to provide any specific examples of advance statements being used by mental health staff in supporting their recovery, although with the small number of participants that may be a function of sample bias. Although difficult to quantify, participants generally expressed sense of the possibilities for advance statements, positive attitudes to the process of creating one, and hopefulness that their preferences would be respected into the future. This sense of hope may be seen in itself as supporting recovery.

#### 4. Discussion

This dichotomy between authorisation and limitation is largely consistent with the notion of documents that can be used to protect people from psychosis, by commending their future selves to psychiatric care, or to protect people from psychiatry, by preventing psychiatric intervention. They also correlate roughly with other contemporary research on supported decision making, such as Knight et al.'s (2018) four groups; Inward Expert, Outward Entrustor, Self-Aware Observer, and Social Integrator. Their much larger study was able to describe more nuance in the approaches that participants took to decision making, however the 'inward expert' and 'social interrogator' is closely aligned with the theme of limitation, and their 'outward entrustor' and 'self-aware observer' can be seen as expressing the theme of authorisation.

Similarly, the diversity of content in advance statements and the inclusion of preferences that are not related to treatment are consistent with other studies. A content analysis of advance statements in Scotland found that more than half contained preferences that did not fall under the definition

of treatment, such as requests for regular walks, access to open air, use of a gym, or care of pets (Reilly and Atkinson 2010).

For policy makers and practitioners that were working with advance statements, understanding the diverse motivations behind advance statements is essential. As Knight et al.'s (2018, p. 1012) note 'recognition that people may view decision-making in different ways, and that their preferences may change over time, enables a more nuanced approach to practice, which might facilitate more positive and empathetic clinician and service user interactions'. Unfortunately, this nuanced approach to practice was not described by the participants in this study.

#### *4.1. Relationships with the Mental Health System*

The two main themes of authorisation and limitation have significant implications for the way that the mental health system works with people who are subject to compulsory treatment. While the study did not seek to demonstrate a correlation between harm that is caused by the mental health system or other past trauma and a willingness to cooperate with the mental health system, this was clearly present. Good relationships and communication are vital for good mental health treatment and support, and this study clearly illustrates that people who had experienced harm in the mental health system used their advance statements as a kind of shield to protect them from harm in the future. Given the consistent turnover of all mental health staff, but particularly psychiatric registrars, in the public mental health system, there is an opportunity for advance statements to provide a continuity of care that would otherwise not be achievable.

Clinicians and mental health policy makers should ensure that compulsory treatment does not inflict harm, or that it is not used when it will do so (Maylea 2016, 2017). This may be a difficult task in resource poor mental health systems, but it should be the ultimate goal of all clinicians exercising coercive powers under mental health legislation. Conversely, participants who had positive relationships with their treating team and the mental health system more broadly expressed a preference to be treated in therapeutic ways and had clear strategies for authorisation. Well-constructed advance statements can facilitate good therapeutic relationships through communication, and even the process of completing an advance statement may assist in promoting a sense of autonomy, which may facilitate wellbeing.

#### *4.2. A Diversity of Needs, Wants and Preferences*

A second key finding is that while there are a number of ways to group participants' approaches to advance statements, each was a unique document and reflected each person's personal recovery journey. Professionals assisting consumers in drafting advance statements as well as clinicians using advance statements should note this diversity and shape their approach and practice accordingly.

As noted above, participants nominated a range of ways in which they thought that advance statements should be drafted, with some participants preferring one-on-one with lawyers, and others wishing to include their treating team, friends, and family. Similarly, participants identified a range of ways in which they thought advance statements should be able to be changed, with some preferring a capacity assessment and others wanting to be free to change it at any time. This variety is good data in itself, signalling the importance of flexibility to suit those who want their capacity to be assessed before any changes are made, and those who wish to be able to make changes at any time. This seems to be more consistent with current thinking regarding capacity in the wake of the CRPD—if a person is allowed to choose to bind their future selves, but is not required to, then this seems closer to a supported decision-making approach than if they are not offered this opportunity. In any case, a flexible advance statements regime that responded to the needs of individuals making advance statements would be expected to both increase the uptake and the usefulness of the scheme.

### 4.3. Increasing Clinician Acceptance

In light of other literature highlighting low uptake rates (Zelle et al. 2015; Radenbach et al. 2014) and a lack of support from clinicians (Gooding 2015; Sellars et al. 2016; Haw et al. 2011), a key implication for policy and practice is that despite the clear intention that advance statements should feature prominently in the new legislative mental health framework, much work remains to be done to increase clinician acceptance. Other studies have highlighted a lack of awareness amongst consumers as the cause of low take up rates, but also highlighted that clinicians are responsible for informing consumers of their existence (Foy et al. 2007). For people accessing mental health services, clinical staff will be their primary source of information about advance statements, and their primary support in completing one. Without this information and support, it is difficult to see how people could exercise their right to complete an advance statement. This is not difficult to address—in the ACT, for example, the treating team is legally required to tell consumers as soon as possible that they can enter into an Advance Agreement or Advance Consent Directive, and give them an opportunity to make such a document (*Mental Health Act 2015* (ACT) s 25). This alone does not result in an increase in the understanding or in the use of the documents by clinicians or consumers, but needs to be paired with cultural change within services or legal force.

### 4.4. Legal Force

Consistent with other literature (Ruchlewska et al. 2014, 2016; Swanson et al. 2008), this study has highlighted the potential for advance statements to facilitate communication between consumers and treating teams. Without real legal force, such as that available through medical advance directives, advance statements remain reliant on decision makers valuing and incorporating them into decision-making practices. This should also be considered in light of the fact that people not subject to the Act are able to make binding directives and competent refusal regarding their physical health decisions, and denying this right to people that are diagnosed with a mental illness is fundamentally discriminatory (Maylea and Hirsch 2017).

As noted above, the notion of legally enforceable advance statements is somewhat inconsistent with a post-CRPD notion of incapacity. In the Victorian context, where a substituted decision-making regime applies, attempting to attain CRPD compliance with advance statements seems a fruitless endeavour (Maylea and Hirsch 2017). Despite this, advance statements that do not bind a person, but bind the treating team, offer a way for people to retain their right to refuse treatment, and more importantly, their right to choose treatment (Weller 2012).

The lack of legal enforceability is also a likely barrier to uptake, as consumers who have not completed an advance statement, or had it ignored, may not appreciate the subtler benefits of improved communication with their treating team. For those seeking to genuinely limit the power of the treating team, a document that can be easily dismissed by a decision maker may seem pointless—a further indignity and reminder of their powerlessness. This is compounded by public attitudes towards autonomy, with a recent study identifying only 35% of a random sample of Australian adults believed that ‘after diagnosis, the person themselves should direct the long-term management of their mental illness, rather than a medical professional’ (Byrne et al. 2018, p. 4). This is at odds with the recovery model, which places self-determination at the centre of a person’s recovery, an ongoing tension in compulsory settings (Hyde et al. 2014; Courtney and Moulding 2014). While participants in this study were split on whether they thought advance statements should be legally binding, this seems to be a strong argument for a scheme that is similar to that in the ACT, where a person can choose between a non-binding ‘Advance Agreement’ or an ‘Advance Consent Direction’ which can only be overridden with free and informed consent of the person or on application to ACAT. The very existence of the ACT scheme indicates that the public opposition to autonomy can be overcome. As that scheme is only very new, no published data is available to indicate whether the availability of binding directives has had an impact on take up rates. The ACT scheme presents an ideal case study for a comparison of the two documents and should be a focus for future research.

## 5. Limitations

Limitations of this paper include the small sample size and sample bias introduced through recruitment via the MHLC. At the MHLC, specialist mental health lawyers draft advance statements with people who are referred from a variety of sources. It should be noted that the majority of advance statements in Victoria are not drafted through the MHLC, and they are drafted either without assistance or with assistance from treating clinicians or other support people. It is not suggested that the participant group is statistically representative of the broader mental health consumer population.

## 6. Conclusions

Due to their lack of enforceability in the Victorian framework, advance statements do not immediately appear to be particularly powerful documents, either as enablers for participation in treatment decisions or as a protector from harm while receiving treatment. As this study illustrates, however, they have significant potential in both functions, and they present an opportunity to embed recovery principles in a compulsory mental health treatment environment. Their usefulness is, of course, reliant on clinician acceptance or legal force. The diversity of positions amongst participants should be interpreted as a need for a flexible model, which is in line with overarching principles of autonomy and recovery. Advance statements represent significant potential for improving consumer's experience of the mental health system, and therefore improving their mental health. Without the support of clinicians or legal enforceability this potential remains untapped.

**Author Contributions:** C.M. conceived of the study following an invitation from the MHLC. He led the research team, conducted all participant interviews and drafted the paper. S.M. and P.W., social work students on placement at the MHLC conducted literature searches, undertook preliminary data analysis and drafted preliminary reports in addition to providing administrative support. K.O. and A.J. provided advice, guidance and oversight to the project, participated in the design of the study and substantially revised the paper.

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