

Development and introduction of a consumer-designed advance statement for mental health care in the Nepean Blue Mountains Local Health District: Findings from a pilot study

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Local Health District

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Glossary

ACD	Advance Care Directives
ACP	Advance Care Planning
ACT	Australian Capital Territory
AD	Advance Directive
AS	Advance Statement(s)
CRG	Critical Reference Group
CRPD	Convention of the Rights of Persons with Disabilities
ECT	Electroconvulsive treatment
eMR	Electronic Medical Record
F-PADs	Facilitated PADs
LGA	Local Government Area
MHRT	Mental Health Review Tribunal
NBM AS	Nepean Blue Mountains Advance Statement
NBMLHD MHS	Nepean Blue Mountains Local Health District Mental Health Services
NSW	New South Wales
PAD	Psychiatric Advance Directive
QLD	Queensland
SCMH	Senate Select Committee on Mental Health
SDM	Substitute decision-making
SPRC	Social Policy Research Centre
UN	United Nations
US	United States
Vic	Victoria
WA	Western Australia

Executive Summary

The Social Policy Research Centre (SPRC) at UNSW Sydney was commissioned by the Nepean Blue Mountains Local Health District (NBMLHD) to conduct a pilot study on the development and use of a consumer-designed advance statement form for mental health care in the Nepean Blue Mountains area. Advance Statements (ASs) are a tool that mental health consumers can choose to use to provide information on treatment preferences and other instructions for those times when their capacity to make decisions about their care and treatment are hindered by acute mental illness or distress.

The project was conducted in collaboration with the NBMLHD Mental Health Service, Aftercare NSW and a Critical Reference Group (CRG) of mental health consumers, carers and staff, and mental health consumers and their families/carers. The consumer-designed advance statement form - here referred to as the Nepean Blue Mountains Advance Statement (NBM AS) - was developed with a view to extend its use to the rest of the NBMLHD after the completion of the pilot project.

This document reports the participants' views on the function, format, content, preparation, storage, use and impact of the NBM AS and ASs in general.

Research design and methods

The study was conducted in two phases. Phase 1 (April 2016 - December 2016) included a literature review on the characteristics and use of ASs in Australia and internationally, seven interviews with stakeholders with an expertise on AS, two focus groups with mental health consumers (attended by a total of three men and three women), one focus group with family and carers (two women and one man), one focus group with health and non-government organisation workers who had experience working with mental health consumers under involuntary treatment, and the development and launch of the NBM AS. Phase 2 (January 2017- June 2018) consisted of the piloting of the NBM AS form in two locations (here referred to as Pilot location A and Pilot location B), interviews with eight mental health consumers who completed an NBM AS, one carer whose relative completed an NBM AS, and four mental health workers who were involved in piloting the NBM AS. Recruitment of mental health consumers who completed an NBM AS was possible only at Pilot location A. Overall, the study recruited a total of 36 participants, of whom fourteen were consumers (ten men and four women), four were carers (three women and one man), seven were expert stakeholders (five women and two men), and eleven were service providers (eight men and three women). All the focus groups and interviews were professionally transcribed and analysed thematically using the Computer Assisted Qualitative Data Analysis Software NVIVO 12.

Study limitations

The study was conducted using a purposive sampling method, which allowed the research team to be inclusive of participants with different experiences and a diversity of backgrounds, culture, and education. However, non-random sampling methods generate the risk that the study sample is not representative of the population being studied. Differences may exist between those who volunteered and those who declined participation in the interviews which are difficult to predict and

quantify. Although this study's findings may not be generalisable to the wider population of people completing ASs, the experiences and views of each single person about accessing tools aimed at promoting their autonomy, such as ASs, are valuable and important, regardless of whether they are typical of a large or small number of people.

Literature review

In Australia, ASs have been incorporated, to varying degrees, into mental health legislation in the Australian Capital Territory (ACT), Queensland (QLD), Victoria (Vic), and Western Australian (WA) (Ouliaris & Kealy-Bateman, 2017). Some states and territories have limited or no legislative provisions in their Mental Health Acts for ASs including New South Wales (NSW), Tasmania, South Australia, and the Northern Territory (Ouliaris & Kealy-Bateman, 2017). Recent reviews found that mental health ASs are currently legally binding only in the ACT and, with limits, in QLD (Callaghan & Ryan, 2016; Ouliaris & Kealy-Bateman, 2017). In both these legislations clinicians "must take reasonable steps" to establish the existence of an AS (Section 28, *ACT Mental Health Act 2015*; Section 43, *QLD Mental Health Act 2016*). However, only the *ACT Mental Health Act 2015* specifically calls on a tribunal – the ACT Civil and Administrative Tribunal (ACAT) – to make an independent assessment in complex cases where there is an objection to the AS from any party, thus providing greater protection of patient rights (Ouliaris & Kealy-Bateman, 2017). When legally binding, ASs require that the mental health care preferences consumers include in their AS have legal authority and allow them to receive treatment as a voluntary patient, in accordance with their wishes, instead of receiving involuntary treatment.

In NSW, ASs have limited legal force (MHCC, 2015). In NSW, mental health consumers can make an AS when they are considered, at law, to have legal capacity to make their own healthcare decisions. The AS then functions as an extension of the consumer's common law right to determine their own health care when they lose capacity to make decisions due to age, illness or injury. However, the making or enforcement of ASs are not described in the Mental Health Act; they are dealt with in the common law. If a consumer who has an AS becomes an involuntary patient under the Mental Health Act 2007 (NSW), it will be up to the treating team to decide if they will follow their AS. They may take it into account, but they don't have to (MHCC, 2015).

Research evidence from randomised controlled trials (RCTs) is contradictory about the benefits and outcomes of ASs. Some studies found that ASs were not significantly more effective in reducing hospitalisation and levels of coercion, whereas other RCTs found some evidence that ASs might reduce compulsory treatment, improve the therapeutic relationship between consumers and clinicians, and help consumers to feel more satisfied and involved in their mental health care.

Overall, research shows a low uptake of ASs in different contexts, highlighting the need for further investigation on barriers to the uptake and use of ASs. The 2017-18 report on mental health service use in Victoria (DHHS, 2018) shows that only 2.59% of adults in Victorian public mental health services (n=72,859) had an AS on record.

Study findings

The study explored the participants' views on the function, format, content, preparation, storage, use and impact of ASs.

Function of ASs. Most consumers and carers and all the mental health workers who participated in training sessions were able to describe the function of an AS. However, some mental health workers who had not participated in the training session gave a generic description of what ASs are and of their function. When talking about the function of ASs, participants discussed two main themes: the binding nature of ASs and consumers' trust in the health system and ASs. As highlighted in the literature review section, the protocols that regulate ASs differ by state in Australia. In NSW, ASs are not included in the Mental Health Act and have limited legal force. Most consumer participants expressed the view that ASs should have legal force so that consumers' wishes are respected. However, most consumer participants had challenging experiences that affected their trust in the capacity or willingness of the health system to listen to their concerns and wishes, including when reported in an AS.

Format of ASs. With regard to the format of the AS form, the study generated two themes summarising the views of consumers and carers: owning the form, and accessibility. Owning the form referred to the participants' view that ASs should look different from other NSW Health forms. This would help to avoid the risk that ASs are perceived as a bureaucratic task and give them some flexibility with regard to how consumers can express their wishes and needs in them. Overall, most consumer participants reported preferring having a template to use to write an AS, however, two consumers who had written their own ASs prior to the pilot project expressed a preference for writing their own without following a template. The theme of accessibility referred to potential literacy difficulties, challenging language, and complex questions in the form. Both consumer and service provider participants acknowledged that some consumers may have literacy difficulties, which would represent a significant barrier for them to generate their own AS. Similarly, service provider participants reported that some consumers found some of the terms and expressions in the NBM AS, for example 'acute distress', or some of the questions regarding emergency contacts as challenging. These issues showed that ASs need to be offered in a context of support for them to be accessible to all consumers from a diversity of background, culture, education and experience.

Service provider participants discussed the accessibility of AS forms also in relation to their use in clinical or emergency situations. With regard to this, they reported that having a summary of the consumers' preferences at the start of AS forms could be a desirable characteristic to help treating team to quickly access relevant information when needed. Nevertheless, they stressed the importance of starting the conversation with consumers with open questions about their daily life, rather than with a summary question, which entails consumers having to think immediately about a situation in which they are unwell and lead them to perceive the AS as yet another medical form to complete.

Content of ASs. The participants' views about the content of ASs was summarised into three main themes around the length, the topics addressed, and the need to update ASs. The majority of the consumer participants completed most sections of the NBM AS, however, the length of what they wrote in their ASs varied considerably, with some answers consisting of a simple 'none' or 'n/a', some of one line, and others of several lines. Consumers brought several examples of issues that could be stated in ASs, including medication and everyday life matters, such as their parental responsibilities, pets that need to be looked after and rent that needs to be paid. The interviews showed that some of the NBM ASs contained information that needed to be updated, however, neither the consumers nor the service providers reported plans to amend it. This indicates that

more consideration needs to be given to processes for reminding consumers to update their AS as these should, where possible, be as consumer-driven/controlled as possible.

Preparation of ASs. The study explored the preparation of ASs, reporting on the main characteristics of the participants who completed an NBM AS, and the participants views on the best time to complete an AS, the support that consumers might need, and the preferred places and contexts (e.g. face-to-face or remotely) to complete an AS.

All the consumer participants who completed an NBM AS did so assisted by a mental health worker during a routine visit at the mental health centre. Service providers reported several barriers that can prevent some consumers from completing an AS, showing value in better understanding the factors that can influence consumers to choose to have an AS, or not. People who are homeless or hard to reach might face additional barriers to completing an AS, showing the need to generate awareness and understanding of ASs not only among mental health service providers, but also other social services and agencies, and the broader community. Service providers pointed out that certain existing tools, such as the Wellness Recovery Action Plan, Relapse Prevention Plans, or the Wellness Plan, would help to lead to a discussion of the issues addressed in the AS.

Participants stressed the importance of the timing of offering and completing an AS for its successful uptake and use. Participants suggested that the best time to complete an AS depends on the specific circumstances of each consumer. It was pointed out that, although for many consumers the time of hospitalisation might not be the best time to introduce ASs, in some cases it might be the only time in which a consumer can be informed about the existence of ASs and be receptive to how it can help.

Consumers and carers stressed the importance of having trust in the person who suggests they complete an AS and, even more so, in the person who offers support to complete it. The level of support needed by consumer participants varied, with some not needing any support and others requiring someone to write the AS on their behalf. A comfortable environment was also identified as important to writing an AS, although what was considered comfortable varied depending on the personal preferences of each consumer participant. Some preferred a public place such as a coffee shop, other mentioned their home.

Storage and use of ASs. None of the participants who completed an NBM AS reported having a copy of their AS or having given a copy to family members, carers, general practitioners, psychiatrist or psychologist; only the mental health centre had a copy of the consumer participants' AS.

Service providers expressed concern that treating teams might not look for or read an AS at a time of crisis. They reported the need for a change of culture in emergency departments regarding the support provided to people with mental health challenges and saw ASs as having a positive role to provide better responses in those contexts. Service provider participants also stressed the need to better integrate the NBM AS within the electronic Medical Record (eMR) for ease of access at times of crisis. It was mentioned that having access to a consumer's AS, both in hospital and in the community, in order to better support the person's decisions and preferences, could potentially lead to shorter hospital stays. It was suggested that currently it is difficult to retrieve people's ASs.

Table 1 provides a summary of the views and experiences of the consumers and providers participants regarding the factors that promoted and limited the implementation and use of the NBM AS pilot form.

Conclusions

The findings of this pilot study will be used to improve the processes of educating and supporting consumers, carers and staff in relation to ASs in NBMLHD. Improvements will focus on the language and design of the form itself, educational activities and other resources designed to support consumers to make decisions relating to ASs, staff capability to talk with people about ASs and support the process of making an AS, and the system's capacity to identify when a person has an ASs (storage and retrieval issues) and respond appropriately (supporting treatment preferences where possible and responding appropriately if an AS is overridden, providing explanations and working with the person around any issues that arise as a result of this). A working group, established by the NBM MH Consumer and Carer Council, will play a key role in the application of the project findings to the process of expanding the use of ASs beyond the pilot sites and across the local health district, ensuring that all consumers have the option of using an AS to communicate their treatment preferences and other needs during crisis.

Table 1. Summary of the study findings on the consumers' and service providers' views and experiences regarding the function, format, content, preparation, and storage and use of ASs.

Function	
Consumers	<ul style="list-style-type: none"> • Participants gave examples of how ASs could be helpful to them, however, the lack of clarity regarding their binding nature was discussed as an obstacle to their uptake • Lack of trust in the health system due to previous negative experiences was also discussed as an obstacle to the uptake of ASs
Providers	<ul style="list-style-type: none"> • Staff who were not trained had only a general idea of what the AS was but no depth of knowledge
Format	
Consumers	<ul style="list-style-type: none"> • Need to 'own' the AS form and thus want its format to visually, and format wise, differ from other health department forms • Most consumers preferred a format to follow, although two consumers who had an AS in place for themselves prior to the pilot of the NBM AS preferred to 'free flow' their AS
Providers	<ul style="list-style-type: none"> • Support is need for those with low literacy who may not be able to complete an AS • A summary of the consumers' preferences at the start of AS forms could be a desirable characteristic to help treating team to quickly access relevant information when needed.
Content	
Consumers	<ul style="list-style-type: none"> • Consumers reported several examples of issues that could be stated in ASs, including medication and everyday life matters, such as their parental responsibilities, pets that need to be looked after and rent that needs to be paid. • Length of answered provided in the different sections of the ASs varied considerably, with some answers consisting of a simple 'none' or 'n/a', some of one line, and others of several lines. • Questions asking multiple things at once were answered only partially • Some information in the ASs needed updating, however, there were no plans in place to update it, showing that more consideration needs to be given to processes for reminding consumers to update their AS as these should, where possible, be as consumer-driven/controlled as possible.
Providers	<ul style="list-style-type: none"> • Some of the language was reported to be confronting for consumers and some questions complex, indicating the importance of offering support to complete ASs, especially for those with low literacy • There were no methods in place to promote adding or updating the information in the ASs
Preparation	
Consumers	<ul style="list-style-type: none"> • Stressed the importance of trusting the person who suggests or helps them complete an AS. • Preferred to have control over the place/context in completing the form, so they are feeling comfortable and safe • Not all participants needed support to complete their AS, however, they all stressed the importance of being offered and being able to access support if needed. • Time of offering was stressed as important, with time of crisis being the least helpful. • A comfortable environment was also identified as important to writing an AS, although what was considered comfortable varied from public places such as a coffee shop to the consumers' home.
Providers	<ul style="list-style-type: none"> • Several barriers to completing ASs were identified: homelessness, consumers hard to reach or engage, and literacy, showing the need to extend knowledge of ASs beyond mental health service providers to other social services and agencies. • Although hospitalisation was discussed as a challenging time to introduce ASs, it was mentioned that for some consumers it might be the only opportunity to become aware of ASs. • It was suggested that ASs could be promoted by better integrating their use with that of other existing tools and forms, such as the Wellness Recovery Plan, the Relapse Prevention, and the Wellness Plan.
Storage and use	
Consumers	<ul style="list-style-type: none"> • At the six-month review, no participant in the pilot who completed an AS had yet a copy or had given a copy to carers or other mental health personnel, including their GP.
Providers	<ul style="list-style-type: none"> • There was concern that treating teams might not look for or read an AS at a time of crisis. • The need for a change of culture in emergency departments regarding the support provided to people with mental health challenges was stressed. ASs were seen as having a positive role to provide better responses in those contexts. • It was suggested that currently it is difficult to retrieve people's ASs. There is a need to better integrate the AS within the electronic Medical Record (eMR) for ease of access at times of crisis, improving support and therefore potentially leading to shorter hospital stays.

1. Introduction

Advance Statements (ASs) are a tool for communicating treatment preferences and other instructions in times of acute mental illness/distress when capacity to make decisions may be limited. They provide a framework for crisis planning, where the consumer's treatment preferences can be communicated, respected and upheld. Advance Statements embody key principles of the United Nations (UN) Convention on the Rights of Persons with Disabilities (CRPD) and their use is consistent with recovery-oriented and trauma-informed approaches. Advance Statements have the potential to reduce coercion, promote autonomy and improve relationships between service user, mental health professional, family/carers and other supports. These are all critical factors influencing consumer outcomes in mental health (Jankovic, Richards, & Priebe, 2010):

1. *Promote choice and autonomy*

People with mental illness/distress experiences often experience a loss of autonomy with regard to their treatment during times of crisis and/or admission to hospital. ASs enable consumers to have a say about their treatment and support preferences. Research shows that consumers who feel their choices have been respected, and who have greater sense of control regarding treatment have higher levels of satisfaction with care, shorter admissions and less readmissions (Katsakou et al., 2011).

2. *Reduce coercion*

The NSW Government is committed to preventing the use of seclusion and restraint in NSW Health acute mental health units and emergency departments (NSW Government, 2018). The CRPD advocates elimination of coercion. As a practice that can reduce and even avoid coercion, there is a strong argument for supporting the use of ASs.

3. *Improve therapeutic alliance and consumers' experience of services*

Advance Statements have been demonstrated to improve the therapeutic alliance and experience of care (Jankovic et al., 2010). The benefits of a positive therapeutic relationship for consumer outcomes is one of the most robust findings in the psychotherapeutic literature (Wampold, 2015).

At the time of this project, ASs are not recognised in NSW mental health legislation. However, local and international developments reflect a general shift towards the recognition and promotion of ASs as a tool for consumer self-determination and supported decision-making. These include the CRPD (UN General Assembly, 2006), which emphasises self-determination, supported decision-making, and recovery as a framework for state, national and international mental health policy (Australian Government, 2010). In Australia, ASs have been incorporated, to varying degrees, into mental health legislation in the Australian Capital Territory (ACT), Queensland (QLD), Victoria (Vic), and Western Australian (WA).

1.1 Aims and objectives

The project aim was twofold: to ensure that people residing in the Nepean Blue Mountains Local Health District (NBMLHD) who experience mental illness/distress have the opportunity to develop

their own AS; and to promote ASs among service providers, families and other supports as a tool for informing care and communicating treatment preferences during times of crisis.

The objectives of this project were to:

- Conduct a review of the current literature on ASs.
- Develop an AS form to be trialled in two areas of the NBMLHD.
- Develop a service policy and procedure for working with consumers in relation to ASs, including recording and documentation of ASs, upholding ASs when a person is in crisis, and reviewing ASs after a crisis.
- Raise awareness of the use of ASs among consumers, families/carers, community agencies, and staff of NBMLHD.
- Attain the above objectives through a process of co-production. In co-production, every component of a project or program is informed by the combination of lived and professional perspectives both of which are valued equally. This is consistent with the recovery-oriented, trauma-informed, rights-based approach on which ASs (and this project) are based.

The Advance Statements Project was overseen by the Advance Statements Project Critical Reference Group (AS CRG) representing key stakeholders from across the LHD with 50% lived experience membership. The purpose of the AS CRG was to:

- Guide the direction of the research project.
- Develop and advise NBMLHD and key stakeholders regarding the best way to use the ASs to support self-determination.
- Advise and consult on all areas of the project, according to specific experience and skills.
- Promote the project at all stages and to a range of stakeholders, services and departments and to consumers and carers.

1.2 Methodology

The research study consisted of two phases. Phase 1 was conducted between April and December 2016 and involved:

- A literature review of national and international literature on ASs' typologies, characteristics, legal implications, typical content, typical formats, and potential benefits for consumers and mental health service delivery.
- Six individual interviews with stakeholders who have a specific interest and experience with ASs.
- Four focus groups, of which two involved mental health consumers, one involved families and carers, and one involved service providers.
- Generation of an AS form based on the learning from the literature review, individual interviews, focus groups and input from the NBMLHD MHS and CRG.

Phase 2 was conducted between January 2017 and August 2018 and involved:

- Individual interviews with mental health consumers, family and carers, and mental health workers involved in piloting the NBM AS form.
- Final report.

As part of Phase 1 and 2 of the project, NBM MHS also organised a project launch event and education workshops (Section 0).

The study received ethics and governance approval from the Nepean Blue Mountains Local Health District Human Ethics Research Committees (HREC reference number: Study 16/4- HREC/16/NEPEAN /43).

1.2.1 Literature review

The literature review was informed by a purposive review methodology, which aimed to offer a comprehensive panorama of the typologies, characteristics, impact, and experiences of completing and using advance statements. The review included national and international literature published from January 2006 to January 2016. Electronic searches were performed using combinations of keywords related to advance statements and mental health in four databases: Medline, PsycINFO, and Web of Knowledge, inclusive of Social Sciences Citation Index, and Google Scholar. A detailed methodology can be found in Gendera and Giuntoli (2016).

1.2.2 Focus groups and interviews

Participants

In Phase 1, the study aimed to explore the views and expectations on ASs of the following four groups of participants (Appendix C):

- Mental health consumers who had experiences of involuntary treatment and who may or may not have known about ASs. They were invited to participate in either of two focus groups.
- Family members and carers of mental health consumers. They were invited to participate in one focus group.
- Expert stakeholders who had knowledge of ASs. They were invited to participate in semi-structured telephone interviews.
- Health and NGO workers who were likely to be involved in the implementation of ASs, regardless of their specific knowledge about them. They were invited to participate in one focus group.

In Phase 2, the study aimed to explore the views and experiences of completing the NBM AS of the following three groups of participants (Appendix C):

- Mental health consumers who completed an NBM AS. They were invited to participate in face-to-face semi-structured interviews.

- Family members and carers of mental health consumers of mental health consumers who completed an NBM AS. They were invited to participate in face-to-face semi-structured interviews.
- Mental health workers who were involved in the NBM AS pilot. They were invited to participate in face-to-face semi-structured interviews.

Sampling and recruitment

The study adopted a criterion sampling approach. In Phase 1, mental health consumers and carers were invited to participate in focus groups based on their previous experiences of involuntary treatment. Similarly, health workers were invited in a focus group based on their role and potential involvement in the implementation of ASs. In Phase 2, mental health consumers and carers were invited to participate in individual, semi-structured interviews based on whether they had completed an NBM AS. Mental health workers were also recruited based on their involvement in piloting the NBM AS.

The study recruited a total of 36 participants, 23 in Phase 1 and 13 in Phase 2 (Table 1). The age of the mental health consumers in Phase 1 ranged from 22 to 65; the median was 43. In Phase 2, the age of mental health consumers ranged from 22 to 62; the median was 54. Seven of the eight mental health consumer participants in Phase 2 were men (Table 2), which represents a limit of this study.

Table 1. Study participants in Phase 1 and Phase 2 of the study

	Phase 1 (Method)	Phase 2 (Method)	Total
Consumers	6 (FG)	8 (FFI)	14
Carers	3 (FG)	1 (FFI)	4
Expert stakeholders	7 (TI)	-	7
Service providers	7 (FG)	4 (FFI)	11
Total	23	13	36

Notes. FG = Focus group. TI = Telephone interview. FFI = Face-to-face interview.

Table 2. Participants by gender

	Phase 1		Phase 2		Total	
	M	F	M	F	M	F
Consumers	3	3	7	1	10	4
Carers	1	2	0	1	1	3
Expert stakeholders	2	5	0	0	2	5
Service providers	5	2	3	1	8	3
Total	11	12	10	3	21	15

Consumer and carer participants were recruited using an arm's-length approach where their consent to pass on their contact details to researchers was first sought by the mental health service. All participants received a study information sheet and were able to ask any questions about the study before signing a written consent to participate in the research.

Following a similar approach, expert stakeholders in Phase 1 and service providers in Phase 2 were invited to participate in a telephone interview (Phase 1) or face-to-face interview (Phase 2) and were able to ask any questions about the study before signing a written consent to participate in the research.

Data analysis

All interviews were audio recorded, transcribed verbatim and imported in the Computer Assisted Qualitative Data Analysis Software NVIVO 12, which was used to assist with the coding of the transcripts and their thematic analysis (Braun & Clarke, 2006). A thematic approach entails three main phases: 'coding' of the transcripts; inductive identification of recurring themes; generation of connections between themes and their grouping under more abstract, descriptive concepts.

The transcripts were first read in full in order to obtain an overall picture of the contents and, where needed, the audio files of the recorded interviews listened to twice. Statements and discussions that expressed ideas related to participants' views on ASs were coded, that is highlighted and stored as retrievable text in a 'node' (that is a category) created in NVIVO. Following Miles' and Huberman's (1994) suggestion, a preliminary list of relevant categories (i.e. nodes) – including the function, format, content, preparation, storage, use and impact of ASs – was generated prior to commencement of the analysis. This was then enriched during the coding phase.

The transcript extracts contained in each 'node' in NVIVO were then retrieved and analysed to refine the list of nodes by merging redundant ones and pulling them together under common 'themes'. Themes represented overarching personal, emotional and social experiences that cut through several nodes. Finally, the themes generated by the analyses were re-analysed to explore possible connections among them.

1.2.3 Study limitations

The study was conducted using a purposive sampling method, which allowed the research team to be inclusive of participants with different experiences and a diversity of backgrounds, culture, and education. However, non-random sampling methods generate the risk that the study sample is not representative of the population being studied. Differences may exist between those who volunteered and those who declined participation in the interviews which are difficult to predict and quantify. Although this study's findings may not be generalisable to the wider population of people completing ASs, the experiences and views of each single person about accessing tools aimed at promoting their autonomy, such as ASs, are valuable and important, regardless of whether they are typical of a large or small number of people.

2. Project development

This section reports on the different phases which lead to the development and piloting of the consumer and carer co-produced Advance Statement form used for this study, which we refer to as the Nepean Blue Mountain Advance Statement (NBM AS)¹ form (Appendix A).

2.1 Project launch

The Advance Statement Project launch was held on 4 March 2016 at the Blue Mountains Cultural Centre in Katoomba. As the first major project activity it aimed to:

- raise awareness of the use and benefits of ASs,
- promote awareness of and interest in the Advance Statements Project, and
- gain support and input from consumers, families and workers.

Fifty-nine people attended the launch. Consumers, families, community and NGO staff, and public mental health staff were represented. The launch included presentations from guest speakers, members of the Critical Reference Group (CRG) and consultants to the project:

- Wanda Bennetts, a consumer representative from Victoria, gave a lived perspective of ASs as well as an overview of the Victorian experience.
- Sascha Callaghan, a lawyer from the University of Sydney, provided a legal perspective as well as words of encouragement for the project.
- Members of the CRG provided an overview of the project itself, progress to date and plans for the coming months.

The response to the project was observed to be positive. After the launch a number of people (consumers, family members and workers) put their names forward indicating willingness to be contacted about project related activities and to be involved in the research.

2.2 Advance Statement Form

An Advance Statement form (NBM AS) was designed to be used for the project pilot (phase 2). The form was developed through a consultative process which involved:

- Focus groups with consumers, families/carers and workers,
- A focus group with the Critical Reference Group (CRG),
- Consultation with expert advisors - Wanda Bennetts (Lived Experience Advisor, Vic), Penny Weller (Lawyer, Vic) Sascha Callaghan (Lawyer, NSW), and Dr Christopher Ryan (Psychiatrist, NSW)
- Review of the literature and existing AS forms both in Australia and overseas.

The six-page form covers personal, medical and social information and includes a section for signing and witnessing of the statement in order to confirm and, if needed, revoke it. It is

¹ This is not to be confused with the NBM AS Project, which refers to the ongoing NBM AS Project in NBMLHD.

accompanied by a four-page Guide to Completing an Advance Statement (Appendix B) which was compiled by members of the CRG drawing on personal experience, the literature and the outcomes of the focus groups and interviews.

The design, content and utility of the Advance Statement is part of the pilot project, so changes may be made to the form subject to feedback. Once the pilot project has been completed, the form will also be made widely available through any other agencies interested in ensuring access to Advance Statements by any consumers or member of the public who wish to advance plan for a crisis.

2.3 Education strategy

An education strategy for the Advance Statements Project covering the pilot areas was developed. All education sessions were co-designed and co-delivered by consumer and clinical educators, consistent with the co-production approach that has underpinned the Advance Statements Project. Education sessions were offered between December 2016 and June 2017.

Attendees at education sessions have included consumers, families, community mental health staff, hospital mental health staff, NGO staff, and psychiatric registrars and consultants. Sessions followed a variety of formats and lengths depending on the differing needs of each group. The workshop template provided an adaptable format with content, timeframes and learning activities able to be adjusted as appropriate. At the initial phase, sessions were delivered to primarily homogenous groups and teams. For example, each of the above had a session specifically delivered to that group. Now that the initial phase of education is complete, the aim will be to offer education sessions for heterogenous (consumers, families, staff) groups wherever possible. The key benefits of a heterogenous group are the sharing of different perspectives and being able to learn from different experiences.

2.4 Policy and procedures

A procedure for ASs in NBMLHD was developed and provides guidance to staff about supporting consumers in relation to the process of developing, using, reviewing, renewing and revoking one's AS.

2.5 Piloting the Advance Statement form

Piloting of the NBM AS commenced in January 2017. Piloting the form has allowed for an initial evaluation of the use of ASs including those factors (personal and systemic) that support and/or hinder their use from the perspective of consumers, families and workers. This enables any unforeseen issues or barriers to be addressed and resolved prior to the implementation of ASs across the LHD.

2.6 Reporting

The Advance Statement Project CRG reported to:

- NBM Mental Health Services (MHS) Executive via the Manager, Allied Health, Wellbeing, Children and Families
- Aftercare Executive Team via the Regional Manager, Aftercare

In addition, regular reports on the project were provided to the NBM MHS Consumer and Carer Advisory Committee (CACAC) via members who represented on both the Advance Statements Project CRG and CACAC. CACAC (now known as the Consumer and Carer Council, CCC) reports to the NBM Mental Health Service Patient Safety and Quality Meeting for all matters relating to consumer care. The Manager, Allied Health, Wellbeing, Children and Families also sits on the NBM Mental Health Service Patient Safety and Quality Meeting.

3. Literature review – A summary

3.1 Background

To achieve the basic human right of autonomy, individuals must be able to practice decision-making (Werner, 2012). Article 12 of the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD) stresses the right of individuals with disabilities to legal capacity on an equal basis with others (Werner, 2012) and requires states to replace involuntary treatment provisions in mental health laws with a new model of 'supported decision-making' (Callaghan & Ryan, 2016). Supported decision-making entails a systemic response which implies wide networks of support, including from institutions, peers and advocate groups, who can give people a real opportunity to engage in an enabling dialogue around the issue they want to make a decision about.

The Australian Government ratified the CRPD in 2008, with the inclusion of an interpretive declaration that retains compulsory treatment of persons, including measures taken for the treatment of mental disability, where such treatment is necessary, as a last resort and subject to safeguards.

Advance Statements (ASs) are a tool that mental health consumers can choose to use to provide information on treatment preferences and other instructions for those times when their capacity to make decisions about their care and treatment are hindered by acute mental illness or distress.

3.2 Typologies and legislation

There exists a range of models and terminologies for ASs in Australia and internationally (Atkinson, 2007). The interventions differ by health settings, such as general health care (advance statements, advance directives, advance agreements) and psychiatric care (psychiatric advance directive (PAD), facilitated advance directives (f-PAD), psychiatric wills, joint crisis plans (JCP)) (Henderson, Swanson, Szmukler, Thornicroft, & Zinkler, 2008). The models can also be distinguished by the extent that they are legally binding (e.g. can the treating clinician override them); the parties involved in their completion (e.g. consumers, clinicians, informal supporters, advocates) and the support provided to consumers during the completion; the role of proxy-decision makers during crisis; the scope of decisions they cover (only health and health related preferences or also social, financial, housing etc); their implementation and accessing the protocols when changed health circumstances prevail (Nicaise, Lorant, & Dubois, 2013).

Another overarching distinction between the models used in the mental health care sector is the instructional directive (the consumer and or a number of parties work out the treatment preferences for future times) versus the proxy directive (the consumer appoints a person or 'attorney' to make treatment decision on their behalf should they lose capacity) (Campbell & Kisely, 2009).

In mental health care settings psychiatric advance directives (PADs), advance health directives (AHDs), joint crisis plans (JCPs), or facilitated psychiatric advance directives (f-PADs) are the common protocols in use. Here, the expression ASs is used to refer to the literature findings across different contexts.

ASs have been incorporated, to varying degrees, in mental health legislation in the Australian Capital Territory (ACT), Queensland (QLD), Victoria (Vic), and Western Australian (WA) (Ouliaris & Kealy-Bateman, 2017). Some states and territories have limited or no legislative provisions in their Mental Health Acts for ASs including New South Wales (NSW), Tasmania, South Australia, and the Northern Territory (Ouliaris & Kealy-Bateman, 2017). In their comparative legislative review, Ouliaris and Kealy-Bateman (2017) identify the ACT Mental Health Act 2015, and how it implements mental health ADs, as a stand out model for other Australian jurisdictions. According to the authors, the ACT makes the most extensive mental health AS provisions. First, it encourages the uptake of mental health ADs by requiring consumers be informed about this possibility. Second, both in the ACT and in QLD, clinicians “must take reasonable steps” to establish the existence of an AS (Section 28, ACT *Mental Health Act 2015*; Section 43, QLD *Mental Health Act 2016*). However, in the ACT the *Mental Health Act 2015* provides stronger safeguards for the person’s wishes compared to the QLD *Mental Health Act 2016*, requiring consent from the person and a nominated proxy-decision maker (guardian, health attorney). Alternatively, the clinician can put in an application to the Mental Health Tribunal for an order. However, the ACT Act specifically calls on a tribunal – the ACT Civil and Administrative Tribunal (ACAT) – to make an independent assessment in complex cases where there is an objection to the AS from any party, thus providing greater protection of patient rights (Ouliaris & Kealy-Bateman, 2017). When legally binding, ASs require that the mental health care wishes that consumers include in their AS have legal authority and allow them to receive treatment as a voluntary patient, in accordance with their wishes, instead of receiving involuntary treatment. Third, in the ACT Mental Health Act 2015, a mental health AS does not remain a binding agreement: the consumer does not have to accept treatment that they previously consented to in writing. The authors conclude that unless jurisdictions make ‘explicit legislative requirements, such as those in the ACT Act, the likelihood of [mental health ADs] being widely utilised is dubious at best’ (ibid.p.4).

In NSW, ASs have limited legal force (MHCC, 2015). In NSW, mental health consumers can make an AS when they are considered, at law, to have legal capacity to make their own healthcare decisions. The AS then functions as an extension of the consumer’s common law right to determine their own health care when they lose capacity to make decisions due to age, illness or injury. However, the making or enforcement of ASs are not described in the Mental Health Act; they are dealt with in the common law.

The Mental Health Coordinating Council (MHCC, 2015) suggests that in NSW, consumers can include in their AS that they want to be treated with particular drugs and not other drugs if they become unwell. They can include that they don’t want to be treated (or do want to be treated) with particular procedures such as electro-convulsive therapy (ECT). They can also identify in their AS their wishes about life management arrangements if they are admitted to hospital with a mental illness in an acute phase, including, for example, details about what they want to happen about the care of their children, the care of their pets, and who in their work place can be informed (MHCC, 2015).

However, if a consumer who has an AS becomes an involuntary patient under the Mental Health Act 2007 (NSW), it will be up to the treating team to decide if they will follow an AS. They may take it into account, but they are not legally required to do so (MHCC, 2015). It is also unlikely that the courts would allow an AS to overturn the decision about medication made by a hospital to treat an involuntary patient, a decision by the Mental Health Review Tribunal to order that a consumer have

ECT, or a decision by Community Services NSW or the Children's Court to place a consumer's children in care (MHCC, 2015). Nevertheless, these bodies can better take into account the wishes of consumers who become unwell and cannot express themselves when they are outlined in an AS (MHCC, 2015).

3.3 Effectiveness

Research evidence from randomised controlled trials (RCTs) is contradictory about the benefits and outcomes of ASs. Thornicroft et al. (2013) found that ASs were not significantly more effective in reducing hospitalisation and levels of coercion, whereas other RCTs found some evidence that AHDs might reduce compulsory treatment, improve the therapeutic relationship between consumers and clinicians, and help consumers to feel more satisfied and involved in their mental health care.

Overall, research shows a low uptake of ASs in different contexts, which highlights the need for further investigation on barriers to uptake and use of ASs. In an Australian computer-assisted telephone interview survey that included 2405 participants (50% of whom were female), 14% reported to have an Advance Statement, including physical, aged care and mental health types² (White et al., 2014). White et al. (2014) found significant state/territory differences in the prevalence of ASs, with NSW, Australia's most populous state, having a proportion of ASs (13.3%) not significantly different from the Northern Territory (9%), Victoria (13.4%), Tasmania (15.1%) and the ACT (18.5%), but lower compared to Queensland (19%) and South Australia (21%), which have a long-standing, reasonably well publicised statutory AS form allowing a person to accept or refuse treatment (White et al., 2014). The 2017-18 report on mental health service use in Victoria (DHHS, 2018) shows that only 2.59% of adults in Victorian public mental health services (n=72,859) had an AS on record. Nevertheless, this represented a small increase in the uptake of ASs compared to 2015-16 (2.02% of AS out of 67,559 registered clients of mental health services) and 2016-17 (2.37% out of 66,487 registered clients of mental health services).

Research shows that key barriers to the implementation of ASs include low engagement with the process by people with lived experience and mental health professionals alike, lack of ready access to the documents when in crisis, lack of clinician familiarity, and legal uncertainty about their application. At the service and policy level, researchers have argued that the introduction of supported-decision making regimes can help the successful implementation of mental health ASs as well as greater recognition of the intentions of the CRPD in compulsory treatment in Australia.

Although ASs can be adopted in NSW without need of any legislative changes, the international experience of New Zealand shows that an ambiguous legislation allows for informal arrangements to arise (i.e. collaborative drafting with the treating clinician), which may undermine the key intentions of self-determination upheld by the CRPD. Several commentators (Johnson, 2004;

² Survey participants were asked whether they had a 'document where you make decisions about what sort of medical treatment you want or don't want' and were then prompted with: 'In [State of participant], this would be called [the name with which advance statements are identified in the participants' state of origin was provided]'. The survey was implemented with a national sample of the Australian adult population (aged 18 and above) representative of age and state. A total of 12,110 households was randomly contacted by telephone with 40% (4846) of households falling outside the proposed sample (e.g. no one over 18 available, jurisdictional or age quotas already met), leaving a potential 7264 respondents to be interviewed. Of the 7264 respondents within the inclusion criteria, 2405 agreed to be interviewed, 50% of whom were female.

Wareham, McCallin, & Diesfeld, 2005; Weller, 2010) have pointed out that the legislation in New Zealand is ambiguous, that the validity of an AS at common law is unclear, as “consumers are presumed to be competent to make an informed choice” when the AS was made (Wareham et al., 2005, p. 352). Weller (2010) mentioned that although it is not a legal requirement to consult a clinician, in practice, ASs in New Zealand are generally drafted with a treating practitioner. This so called ‘collaborative drafting’ (Weller, 2010, p. 224) has several benefits according to the author, for example, stronger backing by the treating clinician and commitment to the treatment decisions expressed in the AS. Weller (2010) also acknowledges that there are inherent risks with this practice, as it may undermine the independence of ASs and self-direction of the person with mental illness.

3.4 Conclusions

Overall, the reviewed literature suggests the need to develop an AS form which is visually clear and accessible and that offers consumers the possibility to give directions in relation to treatment and non-treatment related issues. It also demonstrates the importance of support and investment to build the capability of health professionals and consumers in relation to supported decision-making and self-determination. These are essential to improving the uptake of ASs and aligning current practice to the CRPD.

4. Advance statements: Expectations and experiences

This section reports the main findings of the fieldwork conducted as part of the study, bringing together the views and experiences of consumers, carers, experts and service providers who participated in the study both in Phase 1 – before the development of the Nepean Blue Mountain Advance Statement form (NBM AS) – and in Phase 2, after piloting the NBM AS.

The findings are reported around five main topics about Advance Statements (ASs) that were discussed in the focus groups and interviews (Section 1.2):

1. Function
2. Format and content
3. Preparation: when, with whom, where, how
4. Implementation: storage and use at a time of crisis
5. Previous experiences and impact

4.1 Function

Most consumers and carers, both in the focus groups (who did not yet have an AS) and in the individual interviews (who had an AS), were able to describe the function of an AS when asked how they would explain what is an AS to a friend:

[An AS is] a type of contract thing so that when you do go into hospital and that, that you're able to have this, that and things done so that way you're not freaking out, which makes it easier to recover, so you're not in for as long as well (Consumer, phase 1 focus group 1)

[...An AS] reinforces that idea that a person has a right to have a say in their treatment, even if they are involuntary patient, they still have the right to at least be heard and certainly to have the information about what treatment is being proposed and what is it for. So, I think any mechanism that's going to strengthen and reinforce those rights is important and because people – that's the thing, is that people are at their – it's a low point. It's not like you're there being the best version of yourself if you've been admitted as an involuntary patient and – yeah and it gives a person – to capture when they are well, what they – what their wishes are and – yeah. (Consumer, phase 1, focus group 2)

[An AS is] to help the hospital know, to help people know if I do get hospitalised what - how to care about me (Consumer, phase 2, interviews)

[An AS is] to help me get through all the things that I need to [do...] (Consumer, phase 2, interviews)

[...] When people have to be admitted [...] to hospital [an AS allows] that they have a say in what happens to them after that point. If there are certain people they want to have with them or certain things they don't want to have happen to them during that admission that it's written down and it's documented and everybody understands the client's wishes and takes them into consideration (Carer, phase 1, focus group)

Some workers in the service provider focus groups gave generic descriptions of what ASs are and what their function is, whereas others were able to describe them more precisely, as exemplified in the extract below:

Speaker 2: My understanding is that it's a discussion and the idea is to get as much information as a precursor to further discussion papers [...]

Speaker 3: I actually thought it was how a person would prefer their treatment to go, who they wanted involved and how they wanted that to look [...] what supports are in place for that person prior to maybe a crisis (Service providers, phase 1, focus group)

All the health workers who participated in individual interviews (phase 2) had participated in training sessions about ASs and were able to provide nuanced explanations of what ASs are for. However, most of them had not heard about ASs before their training and still had doubts and questions about their function and implementation (Section Preparation: who and when, with whom, where, how). In particular, some health workers were not sure whether ASs could only be used in the context of involuntary hospitalisation or also in the community (Section 4.3).

Overall, the discussions around the function of ASs generated two main themes, which are explored in the following sub-sections:

- the binding nature of ASs
- consumers' trust in the health system and ASs

4.1.1 The binding nature of ASs

The theme of how legally binding ASs are in NSW and in other states in Australia is exemplified in the quote reported above, in which a consumer describes ASs as a 'type of contract'. The actual binding nature of ASs was an element of concern that was raised both in the focus groups with consumers and carers and in the interviews with staff members and stakeholders.

Most consumers expressed the view that the AS should have some legal power:

Speaker 1: [Speaking about ASs...] Make it a legal document [...] I mean that it's just as much important as a Will.

[...]

Speaker 1: You can't just have this plan and they just look at it and say it's just a plan. You have to have something behind it because then they'll actually believe it and they'll understand it better, but if you just write it, they're not going to do anything. They'll probably just push it aside and put it in your folder and not even look at it. (Consumers, phase 1, focus group 2)

The binding nature of ASs was discussed in depth in the interviews with the expert stakeholders, who mentioned that, in some cases, the form ASs take is guided by legislation in the Mental Health Acts (Section 3.2).

4.1.2 Consumers' trust in the health system and ASs

Consumers often discussed the binding nature of ASs in the wider context of their trust, or lack of, in the health system:

Speaker 4: [Consumers...] start to trust this [referring to ASs], and if it's not followed through by the doctors...

Speaker 3: Because it's not--it's not exactly a legal form in a lot of ways.

Speaker 4: Yeah, it's going to create a bigger--"We've tried to do this for you [referring to the category of clinicians], we've tried to come halfway, and you still haven't applied anything." So, in a sense that would make it even worse for someone trusting the process [... Trust] It's a massive part [of the process] (Consumers, phase 1, focus group 1)

Most consumers had challenging experiences which affected their trust in the health system. In particular, consumers and carers often reported frustrating experiences of not being listened to, especially in relation to their concerns or circumstances. A consumer who participated in a focus group, gave the following example:

[...] I've been in hospital before and I write down my symptoms and what's happening and I – if I have a hallucination, I draw what the hallucination looks like and I hand it to the nurses. They just put it in the folder. They don't even really look at it or anything. They don't really – yeah. Some do but usually they just put them in the folder, and they don't really take notice of it (Consumer, phase 1, focus group 2)

In the focus group with carers, the mother of a consumer who escaped from the hospital where he was an involuntary patient and who was brought back to the hospital by the police, reported this episode:

They [referring to hospital staff] actually wrestled him [referring to her son] to the ground and injected him and he said, "what's this going to do to me" and they said, "oh it'll just make you sleep." But I thought it was kind of like a punishment for him to have escaped. They wanted to bring him down. That was the only really brutal treatment that I saw, and I thought that was pretty bad and I think that in that sort of situation once he's in hospital and he's fairly safe he should be allowed some time to calm down. If that was in his advance directive, I don't want to be physically restrained... (Carer, phase 1, focus group)

The potential negative impact of the uncertain binding nature of ASs on the consumers' trust in ASs and, more generally, the health system, was also discussed by the health workers. Most health workers mentioned how the fact that ASs can be overridden can confuse consumers or make them less prone to engage in completing an AS, as exemplified in these quotes:

[...] I've come across that myself, where you know, [ASs are overridden] based on medical grounds, and it's not always explained; it's just on medical grounds, "This is the decision", and it can create a lot of dissatisfaction, to say the least, from the client and carers. So, in that way, yeah, it [referring to ASs] could have the opposite effect. Like, if people think, "Oh you know, I've gone to this trouble to put my wishes into an advance statement, and then it's just been overruled, and I was just told it was on medical grounds, but I don't know why, really. It's just the doctor's decision." (Service provider, phase 2, interviews)

[Referring to her discussions about ASs with consumers] So I had to sort of say it's not law binding. If the risk occurs, they [referring to clinicians] can still use those

things [referring to restraint and treatments that consumers state they do not want in their AS]. So, it was almost like well... [...] ...why are you asking me? [simulating a conversation with a consumer] (Service provider, phase 2, interviews)

These quotes show the complexities relating to the advantages of using ASs and the limits they are subject to in the different legislations, especially in NSW, where they are regulated by the common law.

When shown three examples of ASs forms, some consumers expressed the view that the bureaucratic look of AS forms could also trigger negative thoughts and attitudes. The issue of the format and content of AS forms is discussed in the next section.

4.2 Format and content

All participants were asked to comment on the look, format and content of ASs. Focus group participants were asked to comment on three ASs forms, which had different looks and formats: the Victorian form (Department of Health, 2014), the Victorian Mental Health Legal Centre form (MHLC, 2012), and the form included in the Queensland *Powers of Attorney Act 1998* (Queensland Government, 2004). Interview participants were asked to comment on their experience of completing the AS form developed for this project (NBM AS) (Appendix A).

This section discusses the participants' views on these topics, highlighting the tensions between the consumers' and health workers' views on some aspects.

4.2.1 Format

The views of consumers and carers around the format of AS can be summarised into two main themes, which are discussed below:

- Owning the form (the form being distinct from typical government forms and having control over the length and content of the form)
- Accessibility (considerations regarding literacy, language and choice of questions)

Owning the form

Consumers and carers expressed the view that it is important that an AS form look different from the NSW Health service forms that they regularly fill in. There were two main reasons behind this view. First, consumers would be less likely to associate ASs with yet another bureaucratic requirement and more likely to see it as a tool to express their own voice:

Yeah, that [referring to one of the three AS forms shown in the focus group] just looks like a normal form that the government gets us to fill out every couple of weeks when we're--couple of months when we're being check [sic] up upon

[...]

whereas people aren't going to, you know? They're going to go, "Oh, hang on, I'm still not going to trust this again", and throw it out. Why bother? (Consumer, phase 1, focus group 1)

Second, government-like forms tend to be quite directive regarding the information that people are asked to provide. Participants expressed the need to be able to complete the AS according to their own needs and priorities. Two consumers who participated in the focus groups had written an AS in the past but did not use any templates. They reported that not having to follow a rigid structure was an empowering experience that allowed them to write in the AS exactly what they needed.

I actually started with a blank piece of paper. So, because it's blank I can put it to the way I want to put it. I don't need to add whatever governmental bureaucracy crap, they go, 'Oh yeah, well how about this? How about...?' It's like, "No, this is mine. This is what I've done, that's it." (Consumer, phase 1, focus group 1)

I know most people say they want a template and I think that's fine and it's good and we should have a template for people. But I tried – I'd already written mine and my template doesn't fit. Mine didn't fit into a template and so that irritated me but we don't have to have a template legally. We can write it on a napkin if we want but it has to be in writing. And I think, again, people should be able to speak it, and have it recorded, you know? What if they have some issues, because some people have hidden their literacy issues [...] So I type it. Mine's narrative in style... (Consumer, phase 1, interviews)

However, other consumers thought that having a template and some standardisation would be helpful, also with regard to the implementation of ASs:

[...] I guess there has to be some level of uniformity if it's going to become familiar to workers and people are going to start presenting bits of papers. There has to be some level of recognition of standard (Consumer, phase 1, focus group 2)

Similarly, most health workers and expert stakeholder participants thought that it would be important that AS forms have some level of standardisation, although this should not prevent them from being flexible enough to allow consumers to express their own personal needs.

I think one of the things that enhances the useability of them and the uptake and the respect they're given by clinicians is actually having a single, consistent, recognised form that people know (Expert stakeholder, phase 1, interviews)

An issue strictly related to the standardisation of AS forms was their layout. Health worker participants mentioned how this could help or hinder how the form would be considered in relevant health settings as well as by consumers. In particular, health workers mentioned that a summary at the start of AS forms could help health workers and service providers to easily find all relevant information in an emergency situation:

Speaker 4: [...] Actually having something like say if it were something like on the front of this, an alert which might be a summary of – so when someone comes into hospital. Aside from the expectations around that immediate treatment, what other things – like do they have kids that have to be picked up from school. Do they have pets that need to be fed by the neighbours? Yeah perhaps they're the things that in a hospital setting people aren't going to think of immediately. But obviously for a patient in that setting they're going to be thinking of it immediately. What's going to happen to my kids? What's going to happen to my pet? Did I leave the stove on? (Service provider, phase 1, focus group)

[...] If people are going to read it then it's nice to have the information summarised so it's right there in the front, you don't have to read through a whole page if that's going to help more people read it later on and take it seriously... (Service provider, phase 2, interviews)

Although most service providers expressed the view that having a summary of the consumers' preferences at the start of AS forms was a desirable characteristic, the health worker participants who helped consumers completing the NBM AS mentioned that such a summary may not be the best place for consumers to start completing their AS. They reported that many consumers found answering the summary question "Information that I would like the people involved in my care to know about me", which is placed in the first page of the form, to be a complex task. This question also entails consumers having to think immediately about a situation in which they are unwell, which may lead them to perceive the AS as yet another medical form to complete. They suggested that starting the conversation with consumers with more open questions about their daily life could help to ease the discussion into the issues more relevant in an emergency situation, which could be included in summary answers at the start of the AS form:

Just so they get the sense that it is about them. We're not just focusing on when you become unwell, we're going to take you to hospital, and this is what it looks like for you which was on the first page. If we sort of socially made it, it is about you, tell me again about your day, then you can sort of go through okay what happened when you do become unwell and then who do you want - just a chain of events. [...] When they do see it [referring to the above question] they think it's another form. It's another medical form. You're going to ask me when I'm unwell - then it went into medications. So, it was very medically - well a medical approach to start with. But if we can start it with something friendly, casual, this is what you do, that's what you want people to know and then move through - just a suggestion. (Service provider, phase 2, interviews)

Similarly, some health workers reported how consumers who did not have any social support found the first question of the NBM AS quite confronting – 'The most important person to notify about my admission to hospital is' – to the point that most of them did not want to continue completing the AS.

The ones that sort of had to think about I actually don't have anyone I can put in my contacts their mood dropped completely and then that's why they stopped. So, it was like the ones that had more insight into this, you're sort of wrapping up my life and it's not looking very good, wouldn't do it

[...]

It would have been very confronting with the information that you know what I don't have family, I don't have friends and they didn't like that part at all. One actually rang someone in front of me to say "can I put you down as a contact" because she had no one else (Service provider, phase 2, interviews)

In this case too, although information on next of kin is important at the start of the form, the suggestion was to start from more open-ended questions, then move to more personal questions. Health workers also suggested that the information on next of kin should already be recorded in the eMR, so this information should be double checked at the time of completing an AS and then integrated into the AS.

The above discussion on the layout of AS forms has implicitly introduced the second theme that has been generated from the discussions around their format, that is, their accessibility.

Accessibility

The theme of the accessibility of ASs consisted of three main subthemes: 1) literacy difficulties, 2) challenging language, and 3) complex questions.

Literacy difficulties. Both consumer and service provider participants mentioned that some consumers may have literacy difficulties, and so may not be able to write an AS unless they receive assistance. As discussed in more depth in Section 4.3, it is important that ASs are offered within a context of support for them to be accessible to anyone. This helps reduce the risk that consumers miss the opportunity to create their own ASs because of the many different challenges that ASs can pose to them. In this section we review two specific challenges which concerned the AS form generated for this study: potentially challenging language, and potentially complex questions.

Challenging language. The health workers involved in piloting the AS form generated for this study reported that consumers found some of the expressions used in the form challenging. In particular, they mentioned the expression ‘acute distress’, which appears in the first page of the form in the question: ‘How acute distress can affect me, the reasons for this, and responses that be helpful’:

This one in particular so how acute distress can affect me. So, the first question I would always get is what does that mean? So for them to fill it out on their own they didn't know so I got a lot of phone calls about acute and I would say "look that's when you did become unwell and maybe your family were concerned or you were taken to hospital." [...] (Service provider, phase 2, interviews)

The health workers thought that the expression ‘acute distress’ was too clinical and suggested that it could be replaced with expressions such as ‘early warning signs’, which is used in the wellness plan form, or with a description in plain English, such as: ‘when I am becoming unwell, I sometimes behave and feel...’. Notwithstanding the value in avoiding clinical language as suggested, the terminology proposed might blur the distinction between an AS (which comes into play at times of crisis) and a Wellness Plan (which is a tool for identifying and addressing ‘early warning signs’ before reaching crisis level). Efforts should go into determining non-clinical language that does not blur this distinction.

Consumers interviewed did not indicate any specific concerns about the language used in the AS form. However, they did mention that when they needed a clarification on the meaning of the AS sections, they were answered by the case worker with whom they completed the AS.

Complex questions. The discussions with the consumers who completed the NBM AS form (Appendix A) and the feedback from the health workers who were involved in the pilot showed that consumers found some questions on the form challenging. The third question on the front page of the NBM AS, which had the expression ‘acute distress’ discussed above, was also found challenging because it asked three different things: 1) ‘how acute distress can affect me’, 2) ‘the reasons for this’, and 3) ‘responses that can be helpful’. The interviews with consumers showed that people ended up answering only one, or maximum two of the three questions, usually the one that struck them most. The suggestion from both consumers and health workers was to break down this question into its different components.

The health workers also mentioned that not all consumers would be able to provide an explanation of the reasons behind their behaviour:

They know they become distressed; they know that they might understand how they feel, and what they do; they may not understand what's behind all of that. That's part of what's worked through in therapeutic process, which everyone doesn't get to. But some of them do. They know it's because of something that happened in my life before, that's why I feel like this. But for some of them, it's just they haven't gotten to that yet (Service provider, phase 2, interviews)

Consumer participants did not specifically speak of this issue, however, some of them described the experiences and events that led them to be diagnosed with a mental illness/mental health challenge.

Despite the complexity of the question, some health workers mentioned the importance of keeping that information on the front page of the AS, because it can help treating teams to understand the consumers' behaviour in an emergency situation. At the same time, they stressed the importance that health workers receive training in complex trauma to be able to better respond to the needs of mental health consumers.

I think that's one of the most important things for the clinician to understand [referring to the information about distress], because frequently what happens is, the staff member or the clinician sees the behaviour, and there's really very little understanding about what's under the behaviour, and that's what makes the whole treatment process so difficult. So many of the staff haven't had training in mental health, if they're in emergency; but even clinicians in mental health, they haven't had training in the sorts of conditions that the clients experience, and particularly trauma. So that's why there's a big emphasis on trying to train more staff in complex trauma. So that's really important (Service provider, phase 2, interviews)

As discussed, in Section 4.1.2, consumer participants reported examples of challenging experiences that affected their trust in the health system. Most participants reported having to wait long times without being seen by a doctor in emergency departments. One participant reported this experience:

People [referring to staff at the emergency department] don't ask you [about preferences]. They just give you tablets all the time and if you ask them what's it for, they say it's just to keep you – so they just keep on giving you tablets. Yeah. Half the time – nearly all the time they don't tell you what it is, or they say it's just a little bit, it won't do anything and then you get zonked out [...]

If you say you don't want it, they say you're noncompliant and stick a needle in your bum. Not in your bum but in your side. (Consumer, phase 2, interviews)

4.2.2 Content

The participants' discussions about the content of ASs are summarised into three main subthemes: 1) length, 2) topics addressed, and 3) need to update.

Length

As one of the expert stakeholder participants pointed out, the length of ASs, that is the amount of information included in them, can affect how treatment teams may evaluate an AS:

...The shorter [an AS is] the more likely people are to read it, the shorter the less convincing they're likely to be. So, you're going to have to find some sort of happy medium. (Expert stakeholder, Phase 1, interviews)

Most AS templates, including the NBM AS form, are organised into sections with dedicated text boxes in which people can write their answers and preferences. The size of the text boxes can be taken as a suggestion of the length of the answer that is expected from people, although the amount of text that can be included in them can change significantly depending on whether the forms have a digital version that allows people to type in them or whether people fill them in by hand. In this latter case, people's writing style can have a major role in determining the amount of text that can actually fit in each text box.

The NBM AS form was given to the pilot sites as a PDF document. As such, it could be completed either electronically, by typing text in the PDF document using a PDF editor such as Adobe Acrobat Reader DC®, or by hand after printing the form. All the participants involved in this study had handwritten their AS. Most of them had completed the form using short sentences presented in a list form. However, the length of what they wrote changed considerably, with some answers consisting of a simple 'none' or 'n/a', some of one line, and others of several lines which took up an entire text box.

In most cases, the participants' writing was clear, however, for one participant the health worker had enclosed a transcription of their handwriting. This was added as a last page and signed by the consumer. However, there was no reference in the form to the typed version of the consumer's answers, so unless this page was found by the treating team, there was a risk that it would not be seen.

Table 3 shows that the majority of the consumer participants completed most sections of the NBM AS. Only one participant had completed less than half of the form, mostly filling in the questions on contact persons. In cases like this one, treating teams can probably use the AS to contact a next of kin, but not to address the consumer's wishes in terms of treatment or other aspects of their life because these were not reported in the AS.

Table 3. Sections of the NBM AS completed by study participants

Advance Statement page and section	C1	C2	C3	C4	C5	C6	C7	C8
Page 1								
Name	✓	✓	✓	✓	✓	✓	✓	✓
Primary contact person for hospitalisation	✓		✓	✓	✓	✓	✓	✓
Optional: further contact for hospitalisation			✓	✓	✓	✓	✓	✓
Information about the consumer			✓	✓	✓	✓	✓	✓
Effects of acute distress, reasons, and helpful responses		✓	✓	✓	✓	✓	✓	✓
Page 2 – My supports								
People to contact	✓	✓		✓	✓	✓	✓	✓
People not to contact		✓						
Mental health support worker	✓		✓	✓	✓	✓	✓	✓
Other support worker			✓			✓		✓
General Practitioner	✓		✓	✓	✓	✓	✓	✓
Psychiatrist	✓		✓		✓	✓	✓	✓
Page 3 – My treatment and care preferences								
Preferred medications and treatments	✓	✓	✓	✓	✓	✓	✓	✓
Unwanted medications and treatments			✓	✓	✓	✓	✓	
Other medical information (e.g. other medical conditions)	✓		✓	✓	✓		✓	
Other helpful things (e.g. strategies and supports)		✓	✓		✓	✓	✓	✓
Page 4 – Everyday matters	✓		✓	✓	✓	✓	✓	
Page 5 – Signature and witnessing	✓	✓	✓	✓	✓	✓	✓	✓
Page 6 – Withdrawal								
Sections completed	10/17	7/17	16/17	15/17	17/17	16/17	17/17	14/17

Topics addressed

Consumers who participated in the focus groups volunteered several examples of issues that could be stated in ASs (Section 3.2), including both medication and everyday life matters, such as their parental responsibilities, pets that need to be looked after and rent that needed to be paid.

I've got a pet ferret. He'll be sitting there in the cage, waiting for me to come home, if anything happened to me. And I've got bonsais. (Consumer, phase 2, interviews)

This [referring to ASs] would be so useful for somebody - for a single parent or parent. It would be very, very useful because they could say who they wanted to have look after their children. They could talk about the access of their children to visiting them at the hospital, how they would want. (Carer, phase 1, focus group)

One consumer participant reported his distressing experience of being brought to hospital and leaving his dog behind:

I had to leave the dog, the phone they took and then I tried to get them to phone up the RSPCA to come out and get the dog and then they had to give keys to my property to someone to get in and get the dog. The dog was taken to the RSPCA. That's fine.

[...]

You can't not feed and water a dog. They are living animals [...] They had to do all that. They delayed and didn't realise the necessity of the situation. (Consumer, phase 2, interviews)

Similar topics were included in the NBM AS completed by the study participants and acknowledged in the discussions with the health workers:

A lot of our clients are on their own. They have pets. They have bills. So, somebody needs to know about these things. But then it's more just will someone read it, and will they be acted upon? So, I think there is definitely value in having them and for allowing the client to sort of put through what they think is important and what they actually go through. Some are privately renting so their rent needs to come out each week and all of that - they would lose their housing, and no one would know. (Service provider, Phase 2, interviews)

The two participants who had an AS before the NBM AS project commenced, and who did not follow a template, used it to express their wishes in relation to their personal and family matters. They did not need it in relation to medication. In fact, one of them had two ASs, one from their psychiatrist and one for their work. This latter one was more an agreement with the participant's employer on what to do and not to do in case she had symptoms of her mental illness/mental health challenge while at work. However, it was described as exceeding the remit of a typical mental health AS.

Need to update

The discussions with the participants who completed an NMB AS showed that some of the contact details and information in the medication and treatment sections were not up to date. However, consumers and service providers did not mention any plan to update their AS. Although there is no rule on the frequency with which an AS should be updated, an AS that is up to date avoids the risk that it is not current at the time of need and, therefore, overlooked by treating teams. To this end, some service providers suggested that integrating ASs into the eMR could help to review and update the clients' ASs on a regular basis.

Oh yeah [...] If they put it on document launcher, and the system, with the [eMR] they're still trying to fine tune it, but if it was put on there and said that once it starts six months, a flag then would come up that it needs to be reviewed at six months, so there'd be an automatic trigger for the clinician to go and say "Ah, this is up, next time the person comes in, need to have a chat about it" [referring to reviewing the AS]. That wouldn't be that hard to do. (Service provider, phase 2, interviews)

Further consideration needs to be given to processes for reminding consumers to update their AS as these should, where possible, be as consumer-driven/controlled as possible.

4.3 Preparation: who and when, with whom, where, how

The participants' discussions about the writing of AS are summarised into five main subthemes:

1. who, which reports who completed an NBM AS;
2. when, which explores the issue of the best time to complete an AS;
3. with whom, which explores the issue of the support consumers might need to complete an AS;
4. where, which explores the issue of the context in which ASs can be completed; and
5. how, which explores the participants' views about whether an ASs need to be completed in face to face meetings, whether they require multiple sessions to be written up, and service providers' views on best practice and procedures.

Who

All the consumer participants who completed an NBM AS did so assisted by a mental health worker during a routine visit at the mental health centre. The mental health workers reported the challenges that they faced in offering the AS to consumers, including that some consumers were hard to engage and that offering to assist them to complete an AS was difficult.

So even today, you know, it's issues to do about the community treatment orders. So, some of those people, who are people that I see, they're hostile to all contact and they just agree for - to have medication. So if, I mean, you can ask them even, like, for the [routine] mental health measures, they don't want to do it. And this, yeah - and then you've got the other people who are cognitively challenged in some respects and - or there's a cultural barrier and they think that you're planning for them to be admitted to hospital. So, you have to get through those barriers. (Service provider, phase 2, interviews)

The following statement suggests that people who are homeless or hard to reach might face additional barriers to completing an AS, and that an awareness and understanding of ASs needs to extend beyond mental health service providers to other social services and agencies, and the broader community:

[Referring to clients who are homeless or hard to reach...] We wouldn't even get the opportunity to do it [referring to the AS] with them, because the only times that we would see them often is probably when they first come to the service, when you're trying to get some general rapport and get all the legal paperwork and that done, and then the next time we probably see them is when they're acutely unwell in hospital,

when it's probably not appropriate doing this either [still referring to the AS]. (Service provider, phase 2, interviews)

One mental health worker pointed out how completing an AS is intrinsically an activity that can be very challenging for some consumers. In her experience, consumers who were experiencing good mental health were more likely to decline to complete an AS compared to consumers who were currently experiencing mental illness/mental health challenges.

So, we have him at a well stage but he's not 100 per cent [referring to the consumer who completed an AS]. The ones that actually didn't complete it [referring to an AS] were quite well and they were the ones that were more with that acute distress they're like "I don't want to go back there. I can't remember what I was like" or they were embarrassed of what happened when they were unwell. So, the ones that were actually less hesitant [to refuse completing an AS] were the really, really well ones.

This suggests that there would be value in finding out more about the factors that influence a person to choose to have an AS, or not. One possible explanation for the above is that a person experiencing current or recent mental health difficulties is more likely to see the value in having an AS, because they are aware that an admission to hospital remains a possibility, and/or because a reduced sense of personal control in relation to treatment is a current or recent experience. On the other hand, someone who is experiencing good mental health may determine that they do not have the need for an AS. Ultimately, in line with the AS philosophy that people have the right to make decisions relating to their own treatment, the decision to have an AS also lies with the consumer and must be respected.

Overall, the uptake of the NBM AS was low, with a notable difference in rates of uptake between case workers. Some workers reported that only one out of the fifteen consumers with whom they worked completed an AS, whereas others estimated that about one in four consumers with whom they worked completed one.

When

Consumers, carers and service provider participants discussed how important the timing of offering and completing an AS is to its successful uptake and use. Most participants agreed that offering to complete an AS at a time of crisis is not going to be helpful, as one consumer put it:

Because I mean, I'm going in [referring to the hospital] because I'm trying to kill myself, why would I care about anything else, you know, in this? [referring to the AS] That is just so much, "Oh yeah, don't do this, don't do that", and it's like, "Hang on, I was just trying to kill myself, what's the point?" (Consumer, phase 1, focus group 1)

However, an expert stakeholder participant pointed out that some mental health consumers might become aware of the existence of ASs only once hospitalised. So, although that is a challenging time to introduce ASs to consumers, it might still be important to do so, even if it's a matter of just letting the person know such a tool exists and that this might help the person to have a say in the treatment should a similar situation arise in future.

I still think that we should be respectful though in that moment and if the person does want to express their wishes in that way, then that would be important, but I think it just increases the potential for that advance statement to be overridden, but not necessarily, not necessarily. I wouldn't say that we should not have people doing advance statements when they've just come into the in-patient unit, because it might be the only time that they've ever been told about them and it might be a very

important time for them to do them. I think it's a 'case by case' situation. (Service provider, phase 1 interviews)

Some participants referred to the need to be in the 'right frame of mind' to complete an AS. To this end, the help and support that consumers receive when completing an AS can be fundamental.

With regard to this, a service provider pointed out that it might be appropriate and helpful to propose to complete an AS after a consumer has experienced a crisis, but when they are still in hospital and may be more receptive of the value of an AS:

And that's where I'm thinking for me in the community with a first episode of psychosis as an example, 'I'm not going back there, I'm good now.' So, whilst they are in hospital it can be a better chance because they're thinking about, 'I don't want this to happen again'. (Service provider, phase 1 interviews)

With whom

Consumers and carers stressed how important it is to know and have trust in the person who suggests they complete an AS and, even more so, in the person who offers support to the consumer in completing one. With regard to this, the study participants who completed an NBM AS stressed how they had felt at ease when completing their AS together with their mental health worker.

Speaker 2: I think it would help if he was my caseworker, and something to do with mental health [...] he's got a bit more knowledge of me than someone else.

Speaker 1: And do you think a relationship of trust is important?

Speaker 2: Yeah. It comes down to that, too. (Consumer, phase 2, interviews)

Not all participants who completed an NBM AS needed help to complete one and consumers and carers in the focus groups also pointed out that not everyone would ask or need help to complete an AS. However, most participants acknowledged the importance of the possibility for consumers to be offered and to access support when needed.

Having the support there I even found valuable because they go through a few things and it's hard for them to explain it. It's hard for them to call it important or to see it as valuable. So, it's like well no that's good that you do that. That's something that only you can do. That needs to go down. So, it's almost picking apart what's important and what's worthwhile. Definitely having a support, I would agree with. (Service provider, phase 2, interviews)

When asked about the potential role of peers in providing support to complete an AS, consumer participants mentioned how they may at first not feel comfortable to open up with someone they do not know. (It is important to note here that peer work is relatively new in NBM MH and consumers at the pilot services have had little to no exposure to peer workers within this service.)

No, I wouldn't feel comfortable, if someone come up to me [referring to the scenario of a worker they do not know ...] Yeah, I don't want to tell them what's on my mind, and all that kind of thing. [...] It would have to be a health worker or something like that. [...] Not a stranger. (Consumer, phase 2, interviews)

One of the consumer participants had completed her AS with the help of a student (probably an intern). She mentioned how her presence made her feel a bit wary because she did not know her.

It took a while for me to trust and to open up to him [referring to her mental health worker...] Yeah, [I felt] a bit wary.

[...]

Like, with me it takes a while for me to trust a person; a very long time. Well, it took me - I don't really trust [mental health workers] really [...] Not 100 per cent.
(Consumer, phase 2, interviews)

Where

Consumers and carers talked about the need for a comfortable environment to write their AS. There was acknowledgment that what is perceived as comfortable would change from person to person:

Just where the person is more comfortable, because some people – like, you work with some, they don't want to go in public places or they feel that when they [are] in public places something is going to happen to them or – so I guess it's all about where that person is comfortable, but definitely, if you can have it over food...
(Service provider, phase 1, focus group)

The consumer participant who had completed her AS before piloting the NMB AS had done her own in a coffee shop and found that appropriate and relaxing, more than in a home environment.

We went out and had a cuppa [referring to the time of completing her AS]

[...]

It's easy, because you're more relaxed, you're settle down, whereas like if it was done at home I'd be there, "Yeah, hang on I don't really want my kids involved in this and I've got the animals running around like anything", you know? So, they're sort of in the way in one area and then her somewhere else, so it was just easier to go out, have a cuppa, talk about what we wanted, write it down and then do it straight out.

However, other consumers reported that they would choose to receive help and write their AS in their home environment.

How

Service providers discussed the different strategies that they used to introduce the NBM AS to their clients. They discussed how handing out the form and asking the clients to have a look at it at home was not a successful strategy, because hardly any of the clients brought it back or raised the issue again. Similarly, offering support over the phone was not a successful strategy.

The first time I tried I explained in a session. I did tell them there would be a bit of sensitive information, we could do it together if they chose or they could take it home and read it. The first one that took it home said they didn't want to complete it after reading it. [...] The one that was completed, we did do it together and it took about an hour just to sort of discuss things, do you understand the question, think about what you do during your day. But I was the support to sort of prompt it along a little bit. When people said they would take it home and read it they never returned it. It was pointless [...] So, I did try a few options. [...] I tried over the phone. We can complete it over the phone, and they were just like no [...] This one [referring to the client who completed an NBM AS] was the only one who allowed me to do it in a session with him. It did take quite a long time. Phone numbers he wouldn't remember so he's like "I'll have to get back to you." So, it was quite challenging. (Service provider, phase 2, interviews)

As mentioned, all of the participants who completed an NBM AS did so in an office at the mental health centre with their mental health worker. It is unclear whether that would have been their preferred choice, however, the trust they had in their mental health worker probably helped to overcome any possible issue with the location.

Service provider participants discussed how it would be beneficial to integrate the offering and completion of ASs with already existing tools, such as the Wellness Recovery Action Plan, Relapse Prevention Plans, or the Wellness Plan, which would help to lead to a discussion of the issues addressed in the AS.

This is just an idea I was thinking of, that we do relapse prevention plans with clients. Like, early intervention plans, as part of our case work. So, we talk about, “Okay, what happened before, when you became unwell? What was going on? Then what happened? What were the signs and symptoms you noticed? What was going on around you? What was the process like, going into hospital, or coming into care? What happened?” Then you find out about the things that were not so positive, and the things that worked. So, it’s getting them to identify what’s happened in the past, and what’s worked for them, and how to identify that they might be becoming unwell, and those sorts of things. So, I thought if you sort of do that around this, or prior to doing this, then they’ll already be thinking about those circumstances, and then they’d have their ideas about what they would like to happen if they become unwell. (Service provider, phase 2, interviews)

One of the things I used to love doing with people I worked with was – have you guys heard of the wellness recovery action plan? – it’s doing that. Because it gives you so much insight, you’re talking triggers and early warning signs. It’s very recovery focused. Who they want involved with their care, it’s like everything that they’re talking about that would go on an advanced statement is everything that’s discussed within a wellness recovery action plan, and perhaps it comes down to preventative medicine. (Service provider, phase 1, focus group)

Education/training about ASs may benefit from more time spent exploring the different wellness tools available and how these complement each other in terms of their use.

4.4 Implementation: Storage and use at a time of crisis

The participants who completed an NBM AS reported that they did not have a copy of their AS, nor had a copy been given to family members, carers, general practitioners, psychiatrist or psychologist. Only the mental health centre had a copy of their AS. This raises concerns regarding the accessibility of the AS at a time of crisis.

Service provider participants were concerned that treating teams would not look for or read an AS at a time of crisis. To this end, it was stressed the need for a change of culture in emergency departments regarding the support provided to people with mental health challenges, and that an AS could help to provide better responses in emergency departments.

This sort of thing of like there is a life and death [referring to an emergency department] – like, you know, that level of seriousness obviously in hospital. But also, I guess as health practitioners not doing harm as well. And like it makes me think of a fellow that I worked with a few years ago who admitted himself to hospital and obviously because he didn’t have a head wound spitting blood out everywhere. As far as that triage went, he was low priority. In terms of looking at life or death situations, physical injury, he was really low priority. Like he’d been left there for

hours in a hyper anxious mood, set him right off. Like it just – no more from there... (Service provider, focus group worker)

Then because he wasn't getting the support, he also felt that he was on show, sitting in the waiting room in the emergency department. Everyone could see him, he's saying 'everyone could see me going psycho'. He really needed to be taken away somewhere else and reassured that he is okay, and someone is with him. And it ended up because he got aggressive he was angry because he was waiting for so long. Security guards were called, security respond in a certain way, which is what all sort of security emergency services tend to get, which is if you don't know what a situation is, take control of it. (Carer, phase 1, focus group),

For someone who's quite ill at the time, if it was flagged – if ... there was a section that – it doesn't necessarily have to be check boxes but it could be alerts of what is really important to this person, be it the dog, be it medications, be it – you know, don't leave me sitting here feeling ignored. ... So, I mean it so can realistically go from the moment someone steps foot into a hospital or gets picked up by an ambulance or something like that too. (Service provider, focus group worker)

With regard to this, another service provider mentioned how the main problem is at a systemic level and goes beyond the treating team's culture:

I don't think in that situation they will, because if you've got someone being really aggressive you've got to do all that and a piece of paper, someone's not going to go, 'Oh hang on a minute...', They don't have time for that and I think it's a system thing. So ... it does come down, in that emergency situation, it does come down to it's a systems thing and a piece of paper is not going to make any difference to that unfortunately. (Service provider, focus group worker)

Service provider participants discussed the different roles involved in the implementation of the NBM AS form. For example, acting on the content in the section of the NBM AS titled 'everyday matters' was clearly seen as the responsibility of social workers. On the other hand, treating teams were seen as having direct responsibility in acting upon the section on medication and treatment.

Service provider participants also stressed the need to integrate the NBM AS within the eMR for treating teams to be able to easily access it at a time of crisis.

So, I do think these [referring to ASs] are very valuable. I guess it's just going to be a way to get everyone on board and to get them - I think it needs more of a flagging system, the importance, right at the top of the file or something that jumps up straight at inpatient that this is what the person needs. (Service provider, phase 2, interviews)

Overall, service provider participants expressed concern about the difficulty of accessing clients' ASs in the eMR.

It's an awful system. It [referring to an AS] gets put into, at the moment, into the progress notes, right, on CHOC [Community Health and Outpatient Care], which is the eMR, which is our computer system we use. It goes underneath where you put the documentation in, so where the progress notes go into. You're often having to scroll through up to 10 pages worth of notes until you can find it, and that's the issue. Now, we struggle sometimes to find them ourselves, and we're the ones who have uploaded and put them into the system, you know what I mean? (Service provider, phase 2 interviews)

4.5 Previous experiences and impact

None of the participants who completed an NBM AS had used it at the time of the interviews. However, both the consumer participants who had completed an AS before the piloting of the NBM AS reported that, despite the challenges they faced, they felt benefits from having an AS, particularly in terms of feeling in control of their lives:

It helped me [referring to her AS], it gave me a sense of feeling in control and it turned my life around, but I was naive about the value of them if it came down to the crunch at first. And then by the time I worked all that out, I sort of got myself hopefully sorted out enough that I'm not going to ever need but every time I have a new psychiatrist, that they move on or have a new job when I use it and that's very helpful. (Consumer, phase 1 interviews)

Most of it was to do with family and stuff because I did have underage children at the time and I was pretty much just being a single mother, so being a single mother and not really having anyone else made it difficult when something did happen. Having that, it was able to be passed around where everyone sorts of knew what was going on. The only problem was, when you do get scheduled and you can't use a phone and you can't really get in contact with people that actually have it until whenever they decide they're going to let you get in contact and that's where the problem is. Because not everything can be done because nobody's bothering to look at your records or anything to see what's actually there. (Consumer, focus group 1)

Service providers also stressed the advantages of having access to a client's AS, both in hospital and in the community, particularly in relation to knowing their previous medical and personal history, including what works well with them. One service provider mentioned how, potentially, this could lead to shorter hospital stays.

I think it would definitely for inpatient stay because you're not starting from the beginning again. You know what works for them. They're telling you what has worked in the past so it's almost like you can cheat. You can take what has worked in the past and see if it happens again without having then to put them through all of the trials of medication, all of the trials of therapy if it hasn't worked in the past. So I think this is a good point to start engaging with someone when they are unwell to get that moving along and then once they come out into the community we can look at replicating what's worked and then have a look at different groups, different services that can continue with that. So, it's a good starting point. So sometimes it's like the middle of their treatment where you can start rather than again at the beginning, just give them meds, just give them meds. If we know this works why wouldn't we use it? It would improve their - hopefully shorter days in hospital because they would recover quicker. (Service provider, phase 2 interviews)

5. Conclusions

This document reported the findings of a study on the pilot phase of the Nepean Blue Mountains Advance Statements Project. The study was conducted in two phases. Phase one included a literature review on the characteristics and use of Advance Statements (ASs) in Australia and internationally (Section 3), interviews with stakeholders with an expertise on AS, and the development and launch of a consumer-designed AS form. Phase 2 consisted of piloting the consumer-designed AS form, here referred to as the Nepean Blue Mountains Advance Statement (NBM AS) form, in two locations. Training sessions about ASs and, specifically, the NBM AS form were conducted with staff members at both locations. Overall, the study included a total of 36 participants, of whom fourteen identified as consumers, four as carers, seven were expert stakeholders, and eleven were service providers.

The study explored the participants' views on the function, format, content, preparation, storage, use and impact of ASs.

Function of ASs. Most consumers and carers and all the mental health workers who participated in training sessions were able to describe the function of an AS. However, some mental health workers who had not participated in the training session gave generic description of what ASs are and of their function. When talking about the function of ASs, participants discussed two main themes: the binding nature of ASs and consumers' trust in the health system and ASs. The protocols that regulate ASs differ by state in Australia. In some states, such as the ACT and, with more limits, in Queensland, ASs are legally binding, however, in NSW ASs are not included in the Mental Health Act and have limited legal force. Most consumer participants expressed the view that ASs should have legal force so that consumers' wishes are respected. However, most consumer participants had challenging experiences that affected their trust in the capacity or willingness of the health system to listen to their concerns and wishes, including when reported in an AS.

Format of ASs. With regard to the format of ASs, the study generated two themes that summarise the views of consumers and carers: owning the form, and accessibility. Owning the form referred to the participants' view that ASs should look different from other NSW Health forms. This would help to avoid the risk that ASs are perceived as a bureaucratic task and to give them some flexibility with regard to how consumers can express their wishes and needs in them. Overall, most consumer participants reported preferring having a template to use to write an AS, however, two consumers who had written their own ASs prior to the pilot expressed a preference for writing their own without following a template. The theme of accessibility referred to potential literacy difficulties, challenging language, and complex questions in the form. Both consumer and service provider participants acknowledged that some consumers may have literacy difficulties, which would represent a significant barrier for them to generate their own AS. Similarly, service provider participants reported that some consumers found some of the terms and expressions in the NBM AS, for example 'acute distress', or some of the questions as challenging. These issues showed that ASs need to be offered in a context of support for them to be accessible to all consumers from a diversity of background, culture, education and experience.

Service provider participants discussed the accessibility of AS forms also in relation to their use in clinical or emergency situations. With regard to this, they reported that having a summary of the consumers' preferences at the start of AS forms could be a desirable characteristic to help treating team to quickly access relevant information when needed. Nevertheless, they stressed the importance of starting the conversation with consumers with open questions about their daily life, rather than with a summary question, which entails consumers having to think immediately about a situation in which they are unwell and lead them to perceive the AS as yet another medical form to complete.

Content of ASs. The participants' views about the content of ASs was summarised into three main themes around the length, the topics addressed, and the need to update ASs. The majority of the consumer participants completed most sections of the NBM AS, however, the length of what they wrote in their ASs varied considerably, with some answers consisting of a simple 'none' or 'n/a', some of one line, and others of several lines. Consumers identified several examples of issues that could be stated in ASs, including medication and everyday life matters, such as their parental responsibilities, pets that need to be looked after and rent that needed to be paid. The interviews showed that some of the NBM ASs contained information that needed to be updated, however, neither the consumers nor the service providers reported plans to amend it. This indicates that more consideration needs to be given to processes for reminding consumers to update their AS as these should, where possible, be as consumer-driven/controlled as possible.

Preparation of ASs. The study explored the preparation of ASs, reporting on the main characteristics of the participants who completed an NBM AS, and the participants' views on the best time to complete an AS, the support that consumers might need, and the preferred places and contexts (e.g. face-to-face or remotely) to complete an AS. All the consumer participants who completed an NBM AS did so assisted by a mental health worker during a routine visit at the mental health centre. Service providers reported several barriers that can prevent some consumers from completing an AS, showing value in better understanding the factors that can influence consumers to choose to have an AS, or not. People who are homeless or hard to reach might face additional barriers to completing an AS, showing the need to generate awareness and understanding of ASs not only among mental health service providers, but also other social services and agencies, and the broader community. Service providers pointed out already existing tools, such as the Wellness Recovery Action Plan, Relapse Prevention Plans, or the Wellness Plan, which would help to lead to a discussion of the issues addressed in the AS.

Participants stressed the importance of the timing of offering and completing an AS for its successful uptake and use. Their discussions on this topic suggest that the best time to complete an AS may depend on specific circumstances of each consumer. It was pointed out that, while hospitalisation might not be the best time to introduce ASs to consumers, in some instances it might be the only time a consumer can be informed about the existence of ASs and be receptive to its benefits. Further, consumers and carers stressed the importance of having trust in the person who suggests they complete an AS and, even more so, in the person who offers support to complete it. The level of support needed by the consumers varied, with some not needing any support and others requiring someone to fill in the AS on their instruction. A comfortable environment was also identified as important for writing an AS, although what was considered comfortable varied depending on the personal preferences of each consumer participant. Some preferred a public place such as a coffee shop, other mentioned their house.

Storage and use of ASs. None of the participants who completed an NBM AS reported having a copy of their AS or having given a copy to family members, carers, general practitioners, psychiatrist or psychologist; only the mental health centre had a copy of the consumer participants' AS. Service providers expressed concern that treating teams might not look for or read an AS at a time of crisis. They reported the need for a change of culture in emergency departments regarding the support provided to people with mental health challenges and saw ASs as having a positive role to provide better responses in those contexts. Service provider participants also stressed the need to better integrate the NBM AS within the eMR for ease of access at times of crisis. It was mentioned that having access to a consumer's AS, both in hospital and in the community, in order to better support the person's decisions and preferences.

Table 4 provides a summary of the views and experiences of the consumers and providers participants regarding the factors that promoted and limited the implementation and use of the NBM AS pilot form.

The information obtained through this pilot study will be used to improve the processes of educating and supporting consumers, carers and staff in relation to ASs in NBMLHD. Improvements will focus on: language and design of the form itself; educational activities and resources designed to support consumers to use ASs; staff capability to talk with people about ASs and to support the process of making an AS; and the system's capacity to identify when a person has an AS (storage and retrieval issues) and respond appropriately (supporting treatment preferences where possible and responding appropriately if an AS is overridden,). A working group, established by the NBM MH Consumer and Carer Council, will play a key role in the application of the project findings to the process of expanding the use of ASs beyond the pilot sites and across the local health district, ensuring that all consumers have the option of using an AS to communicate their treatment preferences and other needs during crisis.

Table 4. Summary of the study findings on the consumers' and service providers' views and experiences regarding the function, format, content, preparation, and storage and use of ASs.


Function	
Consumers	<ul style="list-style-type: none"> • Participants gave examples of how ASs could be helpful to them, however, the lack of clarity regarding their binding nature was discussed as an obstacle to their uptake • Lack of trust in the health system due to previous negative experiences was also discussed as an obstacle to the uptake of ASs
Providers	<ul style="list-style-type: none"> • Staff who were not trained had only a general idea of what the AS was but no depth of knowledge
Format	
Consumers	<ul style="list-style-type: none"> • Need to 'own' the AS form and thus want its format to visually, and format wise, differ from other health department forms • Most consumers preferred a format to follow, although two consumers who had an AS in place for themselves prior to the pilot of the NBM AS preferred to 'free flow' their AS
Providers	<ul style="list-style-type: none"> • Support is need for those with low literacy who may not be able to complete an AS • A summary of the consumers' preferences at the start of AS forms could be a desirable characteristic to help treating team to quickly access relevant information when needed.
Content	
Consumers	<ul style="list-style-type: none"> • Consumers reported several examples of issues that could be stated in ASs, including medication and everyday life matters, such as their parental responsibilities, pets that need to be looked after and rent that needs to be paid. • Length of answered provided in the different sections of the ASs varied considerably, with some answers consisting of a simple 'none' or 'n/a', some of one line, and others of several lines. • Questions asking multiple things at once were answered only partially • Some information in the ASs needed updating, however, there were no plans in place to update it, showing that more consideration needs to be given to processes for reminding consumers to update their AS as these should, where possible, be as consumer-driven/controlled as possible.
Providers	<ul style="list-style-type: none"> • Some of the language was reported to be confronting for consumers and some questions complex, indicating the importance of offering support to complete ASs, especially for those with low literacy • There were no methods in place to promote adding or updating the information in the ASs
Preparation	
Consumers	<ul style="list-style-type: none"> • Stressed the importance of trusting the person who suggests or helps them complete an AS. • Preferred to have control over the place/context in completing the form, so they are feeling comfortable and safe • Not all participants needed support to complete their AS, however, they all stressed the importance of being offered and being able to access support if needed. • Time of offering was stressed as important, with time of crisis being the least helpful. • A comfortable environment was also identified as important to writing an AS, although what was considered comfortable varied from public places such as a coffee shop to the consumers' home.
Providers	<ul style="list-style-type: none"> • Several barriers to completing ASs were identified: homelessness, consumers hard to reach or engage, and literacy, showing the need to extend knowledge of ASs beyond mental health service providers to other social services and agencies. • Although hospitalisation was discussed as a challenging time to introduce ASs, it was mentioned that for some consumers it might be the only opportunity to become aware of ASs. • It was suggested that ASs could be promoted by better integrating their use with that of other existing tools and forms, such as the Wellness Recovery Plan, the Relapse Prevention, and the Wellness Plan.
Storage and use	
Consumers	<ul style="list-style-type: none"> • At the six-month review, no participant in the pilot who completed an AS had yet a copy or had given a copy to carers or other mental health personnel, including their GP.
Providers	<ul style="list-style-type: none"> • There was concern that treating teams might not look for or read an AS at a time of crisis. • The need for a change of culture in emergency departments regarding the support provided to people with mental health challenges was stressed. ASs were seen as having a positive role to provide better responses in those contexts. • It was suggested that currently it is difficult to retrieve people's ASs. There is a need to better integrate the AS within the electronic Medical Record (eMR) for ease of access at times of crisis, improving support and therefore potentially leading to shorter hospital stays.

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Appendix A. Nepean Blue Mountains Advance Statement

This is the ADVANCE STATEMENT of: 

_____ (name)

The most important person to notify about my admission to hospital is:


Name:	Relationship:
Contact number(s):	

(optional) If this person is unavailable, please contact:

Name:	Relationship:
Contact number(s):	

Information that I would like the people involved in my care to know about me:

How acute distress can affect me, the reasons for this, and responses that can be helpful:



My Supports



People (family/friends) to contact:

Name: dkfnaksdnfakdnf	Ph. number/s:
Name:	Ph. number/s:
Name:	Ph. number/s:

People who should NOT be contacted:

Name:	Relationship (optional):
Name:	Relationship (optional):

Health and other service providers to contact:

Mental health support worker

Name:	Organisation:
Ph. number/s:	

Other support worker

Name:	Organisation:
Ph. number/s:	

General Practitioner

Name:	Organisation:
Ph. number/s:	

Psychiatrist

Name:	Organisation:
Ph. number/s:	

2 of 6

My Treatment & Care Preferences



Medications and treatments that I prefer and the reasons I prefer them (e.g. more helpful, more effective, less harmful)

Medications and treatments that I do NOT want to be treated with and the reasons I do not want them (e.g. unwanted effects, drug interactions, not effective).

Other medical information that is important (i.e. allergies, other medical conditions and treatments).

Other things that have been helpful for me (i.e. strategies, environments, approaches, supports) and any reasons for this.

Not enough space to write all your information? Additional pages can be affixed to this form. Please make sure they are clearly identified.

3 of 6

Everyday Matters



Personal roles and responsibilities that may need follow up while I am in hospital (i.e. children and other dependants, pets, work, accommodation, garden, deliveries) and the name and contact details of those who will attend to these matters.



This is my Advance Statement which outlines my needs and preferences should I lose the ability to make decisions for myself as a result of acute mental distress/mental illness.



- I understand the nature and implications of making this statement.
- I understand that this statement operates only when my capacity to make decisions is impaired.

Signature:	Date:
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(Note: sign in the presence of the witness)

First name:	Surname:	
Date of birth:		
Address:		
Telephone:	(home)	(mobile)

Witness

My opinion is that _____ (name) understands the nature and implications of the information and directions contained in this Advance Statement.

- I am not a relative of the person who is making this statement.
- I understand the implications of being a witness to this statement.

Signature:	Date:
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First name:	Surname:	
Position:		
Address:		
Telephone:	(home)	(mobile)



Withdrawing my Advance Statement



I withdraw the advance statement I made on: _____ (date)

Signature:	Date:
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(Note: sign in the presence of the witness)

First name:	Surname:	
Date of birth:		
Address:		
Telephone:	(home)	(mobile)

Witness

My opinion is that _____ (name) understands the nature and implications of the withdrawing/revoking this Advance Statement.

- I am not a relative of the person who is withdrawing their advance statement.
- I understand the implications of being a witness to this withdrawal.

Signature:	Date:
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First name:	Surname:	
Position:		
Address:		
Telephone:	(home)	(mobile)



Appendix B. Nepean Blue Mountains Advance Statement guidelines

A guide to completing an Advance Statement

What is it?

An advance statement is a document you can use to convey your needs and wishes relating to your mental health care if you become unwell and it is difficult for you to make decisions. Health workers and others can then be informed by your advance statement when making decisions about your care.

*Please note the people making decisions do not **have** to do what you outline in your advance statement. Although workers will do their best to honour an advance statement certain factors may require professional discretion e.g. a unique situation not predicted in an advance statement.

How to use it?


First complete the form, then sign it to confirm that the information and preferences expressed are yours.

Then provide a copy to the people you think should have it (e.g. partner, family member, support worker, case manager, GP, psychiatrist). You will need to carry a copy yourself so it is easily accessed in an emergency. Think about the best place to keep it i.e. in your bag, in your wallet, in a smartphone or tablet.

Note that these instructions provide some helpful tips and examples of how others might fill out the form.

Frequently Asked Questions

As we understand there can be a lot of FAQs, please visit www.health.nsw.gov.au/mentalhealth/advancestatements/faq or use the QR Code by following the instructions below:



- 1) If you have an iPhone/Android/Windows/other smartphone download a 'QR Reader App' from either the App Store or Google Play Store.
- 2) Open the app and scan the code on the left for further help/information.

Completing your Advance Statement – General Tips

- Think about your own personal story and the information you feel is most important for others to know about you.
- It may help to speak to a trusted family member and/or friend who knows you well and can help to identify supports, strategies and treatments that have or have not helped in the past.
- Use the sample answers provided for some guidance on how to fill in your Advance Statement
- Note that each section is optional. You only need to complete the sections most important/useful to you
- Feel comfortable writing whatever you want as this is YOUR advance statement for your own personal needs and wishes.

Testimonials

When I present to ED, I am always worried that they will medicate me with 'X' medication which triggers my allergies. Knowing I have made clear what medications not to give me by listing them on the form helps to put my mind at ease.

Jian

If I need to go to hospital I'm usually too unwell to organise everything, and having an Advance Statement gives me peace of mind that my dog will be taken care of.

Amy

Advance Statement - Instructions

Advance Statement - Sample Responses

Information I would like the people involved in my care to know about me (page 1)

Knowing that health workers have some sense of who you are as a person can help during times of crisis when you may not be your usual self.

Sample Response 1:

I am a 30 year old recently diagnosed Bipolar entrepreneur who has 2 brothers, am driven, passionate and ambitious. Currently studying my MBA I will achieve all my dreams regardless of diagnosis or obstacles life has in front of me. I am resistant to mandatory medication and feel I am capable of self-care provided a calm caring environment for me to communicate my wishes. A social drinker, I don't smoke and I am an active soccer player.

Sample Response 2:

I am a 45 year old mother of two and I experience psychotic episodes. I have learned to manage these over the past 30 years and I know my triggers and what works for me, but they still overwhelm me at times. I help out with my neighbour's garden maintenance business when they need me to and I am studying community work at TAFE. I hate to be separated from my children and when I am in hospital I worry about them a lot.

How acute distress can affect me, the reasons for this, and responses that can be helpful (page 1)

Explaining your distress experiences and reactions can help people to better understand what you need during times that it may be difficult to explain what is happening for you.

Sample Response 1:

Issue: When having a panic attack/feeling anxious, I usually get very flustered and quiet. This leads me to feel unable to communicate what the issues are for people to know how to assist.

Reasons: I feel that I don't want to be a burden on anyone so I shut down and don't speak to try to deal with it myself.

Helpful Responses: Please read my advance statement preferences and smile at me often so that I calm down knowing people aren't judging me and are there to help. This will halve the time I take to calm down and be able to speak about my issue.

Unhelpful Responses: Do not yell or shout at me, please avoid placing me in stressful situations or using stressful language that will only make me more anxious.

Sample Response 2:

When I am suffering a manic incident I feel that everyone is out to get me and I am extremely paranoid. This leads me to feel distrustful of people and act erratically. I may hide from people trying to help me, be really impatient and jump to conclusions rapidly.

I react in this manner due to deeply ingrained fears that I am working on resolving. It is helpful for people

to listen to what I have to say and respond in a caring manner. To reassure me and to try to ask me to stay calm and in one spot for 5 minutes. This is very helpful as I will start to think logically and won't run away or hide from people. At times in the past my fears have been dismissed or even scoffed at. This can increase my anxiety and my paranoia that everyone is against me. Instead, please take my concerns seriously. By responding in a kind and caring manner I will be more prone to listen and wait rather than be more paranoid and want to quickly do something else to help myself.

Sample Response 3:

I am 24 years old, and love my dog . it helps if people ask me about my dog when I am extremely depressed. This helps to make me happy and to bring me out of my depressed state. I also enjoy basketball, swimming, music and hanging out with my older brothers.



(Optional Picture of self)

(Please note that including a picture is COMPLETELY optional. If you feel it will help you can do so, but you are not obliged to in any way).

Personal roles and responsibilities that may need follow up while I am in hospital (i.e. children and other dependants, pets, work, accommodation, garden, deliveries) and the name and contact details of those who will attend to these matters (page 3)

It is often the case that a person may not be able to fulfil certain responsibilities while very unwell and in hospital. It is important to talk with the people you nominate to ensure they are clear about any arrangements that involve them.

Sample responses:

I have a dog and when I am in hospital there is no-one to feed him. My neighbour has the key to my house and my dog is used to him. My neighbour's name is Harry and his number is 0498 765 321.

I have a subscription to Technology Issues magazine and I need to collect it from outside my house. My mother who lives nearby can pick this up from me.

My 2 kids are used to me being unavailable but the youngest one needs further care. Please contact my best friend Rosalie on 0478665554 and she will be able to take care of them for a day or two.

I am growing a bamboo plant and if it isn't watered for one day in the 5 years it takes to grow it will die and all my hard work over the last 2 years will be for nothing. Please ask my neighbour Sarah to water this plant or to have someone to do it. It is in the backyard next to the rose bush and has a sign above it saying Bamboo Plant area.

I rent and manually pay for my rent/electricity each month. My account manager at ANZ knows to direct debit my account or to provide me with a months grace if my credit card bounces. Please contact Ishan on 02 9856 7788 during business hours please.

Informing health workers and others of your treatment and care preferences

Your advance statement is an important tool for informing health workers and others about the medications and treatments that are beneficial for you. It will help if you are very clear about the treatments you do and don't want and the reasons for this. Giving reasons for your treatment choices helps others to make decisions that are most likely to be in line with your preferences. If there is not enough space on the form to provide all the information you want to, additional pages can be affixed to the advance statement form. If you do add pages, please make sure they are clearly marked with your name, numbered, and securely attached to the form.

Changing or revoking your advance statement

You may decide to change and/or revoke your advance statement. You can do this at any time by completing the relevant section of the advance statement and, if you choose to, writing another one. Do make sure that the relevant people know that you have revoked and/or updated your advance statement.

Signing and witnessing an advance statement

It is important that you sign your advance statement to confirm that the information provided and the views expressed are yours and not someone else's.

Please have a witness confirm your signature. By signing the form, the witness is also confirming that you understood the nature and the intent of the advance statement and the decisions and views contained within it.

A witness may not be a close family member. It is preferable that your witness has a health or legal background e.g. doctor, nurse, allied health worker, peer worker or solicitor.

I've used my own form of an Advance Statement for the last nine years now. When I go to hospital for an episode of physical or mental illness, inevitably doctors and nurses fire questions at me. I don't have a consistent carer so, when I'm most vulnerable, I can hand my statement to hospital staff for all the information they need. This relieves the pressure and trauma of an admission and I've generally found staff relieved to have concise information which gives them the full picture of all the physical and mental conditions with which I live.

Amina

Even when I am completely well I often forget crucial information so sometimes when I am too worried or stressed I cannot clearly communicate everything I want to. This advance statement has everything nicely listed so that I do not forget to tell them important information.

Jamie

Appendix C. Focus group and interview schedules

Focus group schedule for mental health consumers (Phase 1)

1. What is your understanding of what an Advance Statement is?
2. What issues should be addressed in an Advance Statement? (show the Advance Statement example from Victoria and ask opinions on its content)
3. What should an Advance Statement look like? (show the Advance Statement example from Victoria and ask opinions on its look/format)
4. Do you think that you would need support/someone to talk to while completing an Advance Statement?
 - a. Follow up question: If so, who do you think that should be involved?
 - b. What should the role of family members/carers be?
 - c. What should the role of mental health service workers be?
5. Who do you think should have and keep a copy of your Advance Statement?
6. Who do you think should know that you have completed an Advance Statement, but perhaps not have a copy of it?
7. Where would you keep a copy of the Advance Statement?
8. Do you think that people should have the right to change their mind about what they wrote in the Advance Statement if they become unwell and need treatment?
 - a. Follow up: If so, under what circumstances? If not, why not?
9. Do you have any other comments?

Focus group schedule for family and carers (Phase 1)

1. What is your understanding of what an advance statement is?
2. What role do you think families and carers should have in them?
3. What issues should be addressed in an advance statement? (show the advance statement example from Victoria and ask opinions on its content)
4. What should an advance statement look like? (show the advance statement example from Victoria and ask opinions on its look/format)
5. Do you think that the family member/friend that you care for would need support/someone to talk to while completing an advance statement?
 - a. Follow up question: If so, who do you think should be involved?

- b. What should the role of family members/carers be?
 - c. What should the role of mental health service workers be?
6. Who do you think should have and keep a copy of the advance statement of the family member/friend that you care for?
 7. Who do you think that should know that the family member/friend that you care for have completed an advance statement, but perhaps not have a copy of it?
 8. Where do you think that the family member/friend that you care for should keep a copy of the advance statement?
 9. Prompts: At home, in their wallet/bag etc.
 10. Do you think that the family member/friend that you care for should have the right to change their mind about what they wrote in the advance statement if they become unwell and need treatment?
 - a. Follow up: If so, under what circumstances? If not, why not?
 11. Do you have any other comments?

Focus group schedule for health and NGO workers (Phase 1)

1. What is your understanding of what an Advance Statement is?
2. What role do you think families and carers should have in them?
3. What issues should be addressed in an Advance Statement? (show the Advance Statement example from Victoria and ask opinions on its content)
4. What should an Advance Statement look like? (show the Advance Statement example from Victoria and ask opinions on its look/format)
5. As the family or carer, do you think that the family member/friend that you care for would need support/someone to talk to while completing an Advance Statement?
 - a. Follow up question: If so, who do you think should be involved?
 - b. What should the role of family members/carers be?
 - c. What should the role of mental health service workers be?
6. Who do you think should have and keep a copy of the Advance Statement of your family member/carer?
7. Who do you think should know that the family member/friend that you care for has completed an Advance Statement (or that you have completed an advance statement for your friend/relative), but perhaps not have a copy of it?

8. Where do you think a copy of the Advance Statement for your friend/relative should be kept?
Prompts: At home, in their wallet/bag etc.
9. Do you think that the family member/friend that you care for should have the right to change their mind about what they wrote in the Advance Statement if they become unwell and need treatment? Follow up: If so, under what circumstances? If not, why not?
10. Do you have any other comments?

Interview schedule for expert stakeholders (Phase 1)

1. What has been your involvement with the introduction of Advance Statements in Victoria/the NBMLHD?
 - a. Prompts: At the time they were introduced/the project was first thought of and now.
2. How does the process of creating an Advance Statement occur?
 - a. Follow up questions: What is the role of peers/peer workers in developing one's Advance Statement?
 - b. What is the experience of family and friends? To what extent do they have input?
3. What processes were put in place to assist people who experience mental illness and mental distress to prepare an Advance Statement?
4. Were there any barriers to the implementation of Advance Statements at the health system level? /Do you think that there are any barriers for the introduction of Advance Statements in the NBMLHD?
 - a. Follow up question: What about barriers at the individual level, for example literacy, culture, age, experience (of system), disability?
5. Were there any factors that facilitated the implementation of Advance Statements? / Do you think that there are any factors that can facilitate the introduction of Advance Statements in the NBMLHD?
6. What is your overall perception of the effectiveness of Advance Statements in reducing coercion and improving therapeutic relationships in Victoria? /What is your expectation of the effectiveness of Advance Statements in reducing coercion and improving therapeutic relationships in the NBMLHD?
7. Has the introduction of Advance Statements had an impact on some key KPIs, such as a reduction in number of coerced admissions, the length of stay, or the satisfaction with services?/Do you expect that the introduction of Advance Statements will have an impact on some key KPIs, such as a reduction in number of coerced admissions, the length of stay, or the satisfaction with mental health services and the hospital?
8. What people put in their Advance Statements?

- a. Follow up question: How does what people put in their Advance Statements compare with clinical guidelines?
 - b. Are medical and physical health needs included in the Advance Statement?
9. What are the main outcomes of adopting Advance Statements for service users?
- a. Follow up question: What is the impact after discharge from hospital?
10. What would you say facilitates positive outcomes for service users?
11. What would you say hinders positive outcomes?
12. Do you have any recommendations about how the introduction of Advance Statements could be improved?
13. Do you have any other comments?

Interview schedule mental health consumers (Phase 2)

1. How did you know about the possibility to complete an Advance Statement?
2. What is your understanding of an Advance Statement?
3. Can you tell me about your experience of completing an Advance Statement?
 - a. Follow up questions: Who was involved in writing yours? What was the role of your family members/carers? What was the role of mental health service workers?
4. Were you able to set down your treatment preferences in the Advance Statement form?
 - a. Follow up question: Were you able to express your values, wishes and beliefs behind your treatment preferences?
5. Do you think that the form could be easier to complete?
 - a. Follow up question: What changes would you suggest for the form?
6. Did you receive support to complete the Advance Statement form? If so, who helped you?
 - a. Follow up question: Were you satisfied with the support that you received? What support do you think is needed to help people like you complete an Advance Statement?
7. Were you able to give your Advance Statement to your treating team?
 - a. Follow up questions: If so, what was their reaction? Were you satisfied with their response?
8. If you were to complete your Advance Statement again, is there anything that you wish would be different compared to this first experience?
9. Do you have any other comments?

Interview schedule family and carers (Phase 2)

1. Do you know how your family member/friend knew about the possibility to complete an Advance Statement?
2. What is your understanding of an Advance Statement?
3. Can you tell me about the experience of completing an Advance Statement for your family member/friend?
 - a. Follow up questions: Who was involved in writing it? What was your role? What was the role of mental health service workers?
4. Was your family member/friend able to set down your treatment preferences in the Advance Statement form?
 - a. Follow up question: Were they able to express their values, wishes and beliefs behind their treatment preferences?
5. Do you think that the form could be easier to complete?
 - a. Follow up question: What changes would you suggest for the form?
6. Did your family member/friend receive support to complete the Advance Statement form? If so, who helped them?
 - a. Follow up question: Were you/they satisfied with the support that they received? What support do you think is needed to help people like your family member/friend to complete an Advance Statement?
7. Was your family member/friend able to give their Advance Statement to their treating team?
 - a. Follow up questions: If so, what was their reaction? Were you/ your family member/friend satisfied with their response?
8. If you were to assist completing an Advance Statement again, is there anything that you wish would be different compared to this first experience?
9. Do you have any other comments?

Interview schedule for mental health workers (Phase 2)

1. What is your understanding of an Advance Statement?
2. Can you tell me about your experience of informing/assisting service users/clients in knowing/completing an Advance Statement?
 - a. Follow up questions: Who was involved in writing it? What was your role? What was the role of mental health service workers?
3. How does the process of creating an Advance Statement occur?

- a. Follow up questions: What is the role of peers/peer workers in developing one's Advance Statement?
 - b. What is the experience of family and friends? To what extent do they have input?
4. Do you think that the Advance Statement form enables service users/clients to write down their preferences?
 - a. Follow up question: How about their wishes, beliefs and values?
5. What processes are there to assist service users/clients to prepare an Advance Statement?
6. Were there any barriers to the implementation of Advance Statements?
 - a. Prompts: What about barriers at the individual level, for example literacy, culture, age, experience (of system), disability?
7. Were there any factors that facilitated the implementation of Advance Statements?
8. What are your views/expectations regarding the effectiveness of Advance Statements in reducing coercion and improving therapeutic relationships in the NBMLHD?
9. Is there anything about the Advance Statement form and its procedures that you would like to see changed? Follow up question: If so, what is it and why?
10. Do you have any other comments?