

Consumer Survey Results



ADVANCE STATEMENTS AND NOMINATED PERSONS

A survey exploring consumer attitudes, experiences and perspectives, conducted by VMIAC, commissioned by the Department of Health and Human Services, 2018.

VMIAC. (2018). *Consumer survey results: Advance statements and nominated persons*.



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This survey was conducted by VMIAC, the Victorian peak body for consumers of mental health services. It was commissioned by the Victorian Department of Health and Human Services.

This document can be downloaded from the VMIAC website: www.vmiac.org.au

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VMIAC extends grateful thanks to all the consumers who completed this survey, and we acknowledge all consumer/patient/survivor experiences in mental health systems.



VMIAC is located on the lands of the Wurundjeri people of the Kulin Nation. We acknowledge the traditional custodians of the land on which we work, and pay our respects to elders past, present and emerging.

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BACKGROUND

Advance statements and nominated persons were introduced in Victoria in the Mental Health Act 2014, in Part (3): *Protection of rights*.

In the four years since the introduction of the new Act, the uptake of advance statements and nominated persons has been very low, sitting at about 2% of all admitted mental health consumers. This survey was commissioned by the Department of Health and Human Services, to help better understand why so few consumers have been utilising these protections. The survey was conducted by VMIAC, Victoria's peak body for mental health consumers.

Supported decision making: The context for advance statements and nominated persons

The new 2014 Mental Health Act aimed to introduce a stronger rights-based approach to mental health, incorporating supported decision making as the preferred alternative to substitute decision making. The Act still allows for substitute decision making, but the Act's objectives express a clear preference towards less restrictive practice. Advance statements and nominated persons are both types of supported decision making.

Substitute decision making occurs when a psychiatrist makes treatment decisions on behalf of the consumer, usually through a compulsory treatment order.

Currently, more than half of all mental health patients are treated against their will under these orders¹. This approach breaches human rights, including (at least) the right to health (which includes the right to informed consent), bodily integrity, liberty, and potentially other rights.

Supported decision making recognises that decision-making is an area where some people require assistance or support. It aims to support every person to uphold their right to legal capacity, by providing flexible supports to help people continue to make their own decisions. This can include giving informed consent, withholding consent, and leaving services.

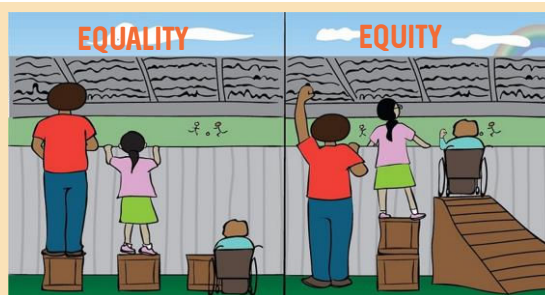


Image credit : Maryam Abdul-Kareem www.muslimgirl.com

Advance statements and nominated persons can create increased equity in mental health service provision.

People increasingly understand the concept of equity versus equality, as illustrated in the image above. This image demonstrates equity for people who live with mobility-related disability. Equity isn't about giving everyone the same supports, but about giving different supports so everyone is able to access the same outcome.

For people living with mental health-related disability, supported decision making is our version of a wheelchair ramp. It is a tool that can enable us to make our own decisions and participate fully in our lives.

¹ Department of Health and Human Services. (2017). *Victoria's mental health services annual report 2016-17*. Victorian government.

About nominated persons and advance statements



Nominated persons are a form of supported decision making that may assist consumers to uphold their human rights.

- Consumers select their own nominated person, and ensure the person understands their treatment and care preferences
- The service has to provide information to the nominated person, consult with them about treatment, and provide them access to meet with the consumer.
- A nominated person can support consumers to understand, make and communicate their own decisions, if required.
- A nominated person can speak on the consumer's behalf, if required, to communicate their treatment and care preferences.



Advance statements are a form of supported decision making where consumers can document their treatment and care preferences in advance. In relation to advance statements, the Mental Health Act only specifies that they are used to document treatment preferences—however some people find these statements useful for documenting other needs like care, support and practical needs.

- Hospitals and the Mental Health Tribunal are required to read and consider advance statements at times where they may not feel able to gain informed consent from the consumer. They must have a good reason for not following the preferences expressed in an advance statement.
- Advance statements are a mechanism for consumers to consent, or withhold consent, in advance of treatment. Consumers can outline what is helpful, and not helpful, for their treatment. They may outline potential triggers, coping skills and emotional needs.
- Advance statements can communicate practical information about treatment and care, such as allergies, dependents or pets requiring care, financial needs, people to contact, people not to contact, dietary needs and more.

Common misunderstandings

Misunderstanding (1):

Nominated persons protect the rights of carers and family to be involved and have a say.

Fact: *The intent of a 'nominated person' is to protect the rights of consumers. They are not a mechanism for carer/family inclusion.*

This is commonly misunderstood, including by services. The main role of a nominated person is to express the will and preferences of the consumer—which may not

always be the same as the will and preferences of a carer or family.

A consumer can choose anyone to be their nominated person. While consumers may choose a carer or family member, this is not everyone's preference: many consumers do not have carers or close family members, and others may have good reasons for wanting a different person to be their nominated person, such as the carer/family member having conflicting views about treatment.

Misunderstanding (2)

An advance statement is the same as an advance directive.

Fact: *Advance statements are different to advance directives.*

Statements do not have to be upheld by services, whereas directives must always be upheld.

Despite much advocacy by consumers, the current Act only allows for advance statements.

The hospital told me my 'carer' was my nominated person and I said I didn't have a carer and had not nominated anyone to be my nominated person so they couldn't be.

(Survey respondent)

SURVEY METHODS

This survey was part of broader consultation process with the aim of understanding why so few consumers have used advance statements or nominated persons.

The project was initiated by the Office of the Chief Mental Health Nurse, within the Department of Health and Human Services (DHHS).

The Office of the Chief Mental Health Nurse provided an initial list of proposed survey questions. These were adapted and expanded by VMIAC to ensure clear and consistent questions, inclusion of consumer perspective, and questions about human rights.

A set of 27 survey questions was included for the final survey (see complete survey in attachment 1), and established on the online platform, Survey Monkey.

The survey was promoted via:

- An email to VMIAC information distribution list (more than 1000 people)
- Promotion via Twitter and Facebook

The survey was open to any person who has been a consumer of Victorian public, clinical mental health services.

The survey remained open from 8 June until 22 June 2018 (15 days) and received 50 responses.

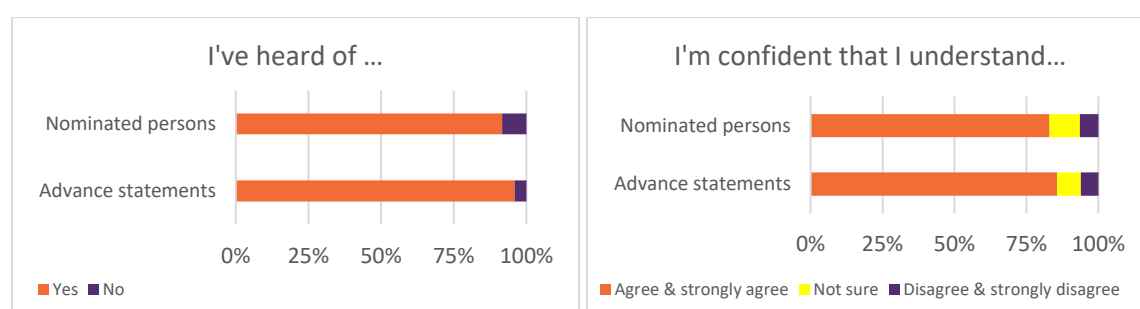
SUMMARY OF KEY FINDINGS

Awareness and understanding

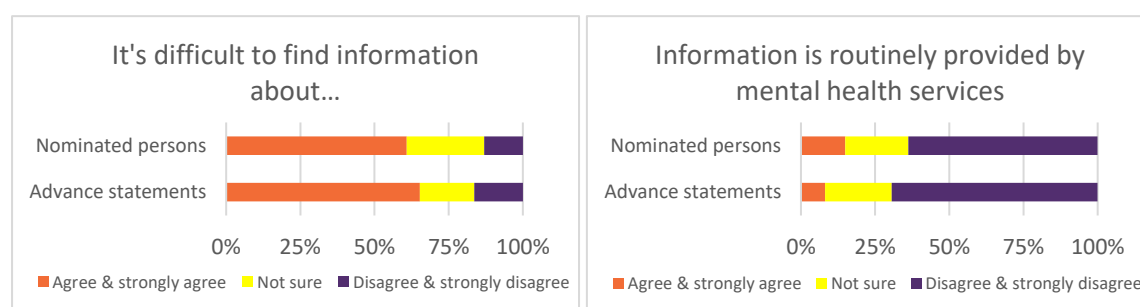
Most respondents reported a high level of awareness (over 90%) and understanding (over 80%) about advance statements and nominated persons.

However, even amongst those consumers who said they understand these mechanisms, some of the responses indicated gaps in knowledge or misunderstandings, e.g.:

- Several consumers referred to advance statements as 'directives'
- One consumer said they would only set these up if they get readmitted to hospital (which would be too late)
- Another consumer seemed to expect that these are available at private hospitals



Responses indicated opportunities to improve information promotion. Mental health services, in particular, have significant opportunities for improvement. More than 60% of consumers agreed it was difficult to find information, and only 8-15% of consumers reported that mental health services routinely provide information about advance statements and nominated persons.



Too many bits all over the place and not easy if you are not a technology person.

Plain English info is hard to come by

Case managers and consultants don't consider them important

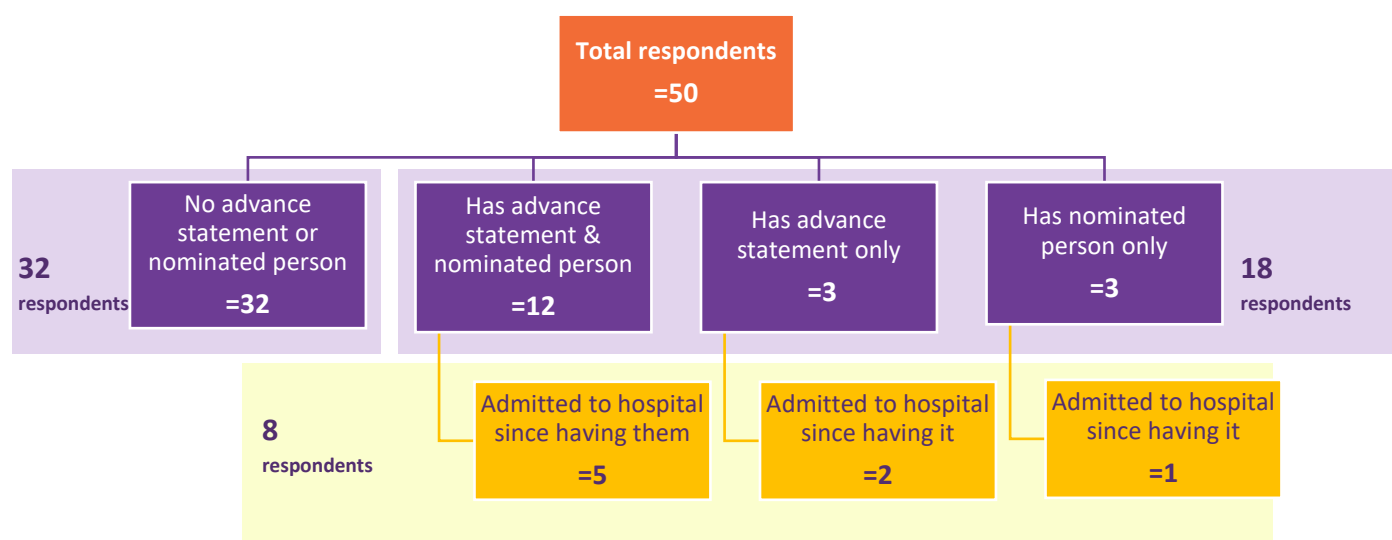
My case manager didn't know what they were

Services need to regularly remind consumers of this option, not just once.

There is information about patient feedback and other flyers on mental health and the tribunal and the NDIS yet there is nothing specific in regards to flyers on advanced statements or nominated persons

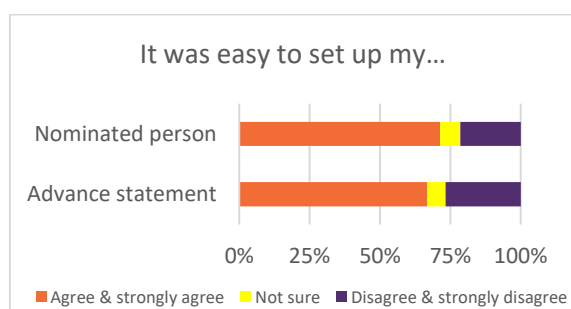
Experience of setting up advance statements & nominated persons

Thirty-six percent of respondents had an advance statement and/or nominated person. Of those respondents with an advance statement and/or nominated person, 44% (n=8) have since been admitted to hospital and could speak about the experience of using them.



Easy to set up?

Most respondents agreed that it was easy to set up their advance statement and/or nominated person, however 21-27% disagreed. Themes about challenges in getting an advance statement or nominated person included: *What should I include? A lot of thinking and planning. Not sure how to alert hospital. Who can sign? What if a clinician refuses to sign it? Can I have another consumer as my nominated person?*

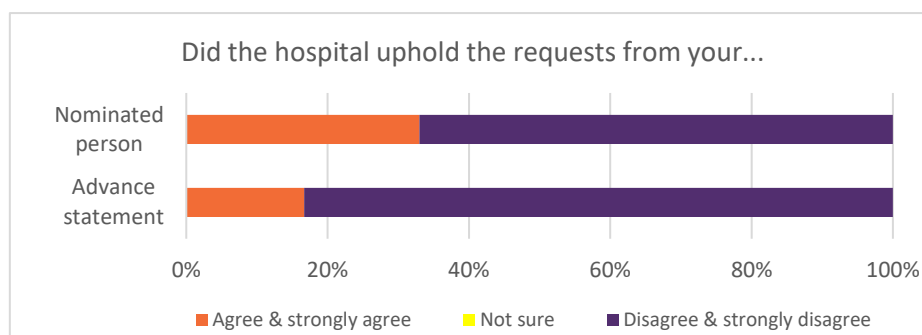


I asked my case manager to sign it and she wouldn't because she didn't know what it was for.

Experience of using advance statements and nominated persons in hospital

Respondents reported very poor experiences of trying to use advance statements or nominated persons while in hospital.

A high proportion of respondents said that the hospital did not uphold requests in their advance statements (83%), or uphold requests made by their nominated person (67%).



This reinforced concerns by consumers who don't yet have advance statements or nominated persons, such as fears that the hospital would not respect or uphold them.

Comments by consumers about trying to use advance statements and nominated persons varied from very positive to extremely negative.

They couldn't find it, although I gave a copy to my case manager and to the nurse in ED.

It varied as to whether staff looking after me read my advance directive - I would say maybe 1 in 5 did. The staff could not help me feel safe because they could not place me in an area that was separate to unwell men.

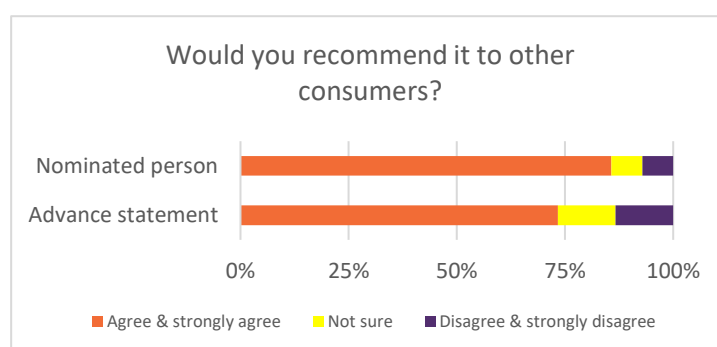
My nominated person helped when I became unwell in the community, which meant I didn't need to be admitted to hospital and got the support I needed through CATT

I think most people think there's no point in having an advance statement if it's just going to be ignored. Also, I don't think mental health services promote or encourage either advance statements or nominated persons. I think it's difficult to organise it all, and a lot of consumers don't have anyone they would want to be their nominated person. I would like to have another consumer act as my nominated person, but I do not have confidence that a nominated person who was a consumer would be respected and listened to by treating teams.

Would you recommend them to other consumers?

Despite reported concerns and issues, 86% of consumers would recommend getting a nominated person and 73% would recommend getting an advance statement.

To some extent it's made me feel less powerless. However, not all staff read them or take them seriously, so don't hope for respectful care.

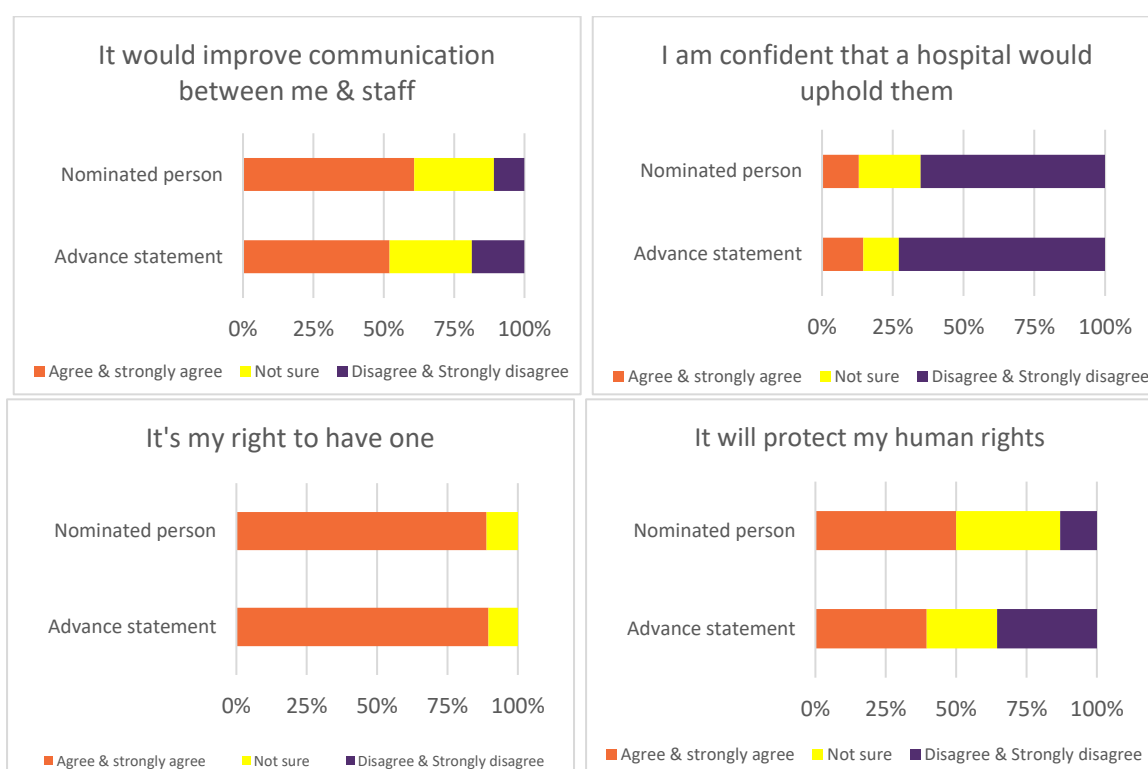
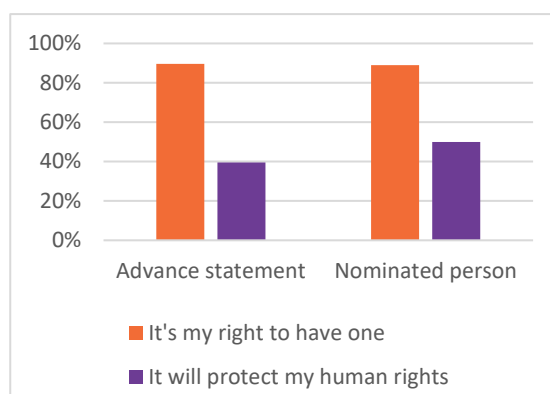


Consumer confidence and views

Rights: Most respondents (around 90%) were correct in their understanding that they have a right to an advance statement and nominated person, but this percentage decreased by half when we asked if they thought having an advance statement or nominated person would actually protect their human rights.

Communication: More than half of the respondents thought that an advance statement or nominated person would improve communication.

Upheld by hospital: The most negative opinion by respondents was in relation to whether a hospital would respect and uphold requests in an advance statement, or those made by a nominated person: 65-73% of respondents were not confident that a hospital would do so. This seems to indicate a serious lack of confidence by consumers in the effectiveness of these mechanisms.



My nominated person would be a friend who is also a fellow consumer. I would like to have someone in my corner who understand MI, the system and is a bit further removed from the situation so as to have more perspective if I became unwell again.

Some clinicians actually rolled their eyes when I asked them to read my advance directive.

It wouldn't protect my human rights because my doctor can just ignore it if he wants to, and I think he would.

It's difficult, as I know they'd [nominated person] be heavily influenced by the treating team, especially if I'm in hospital. How can you know what they'd agree to do under that kind of stress?

Perceived benefits

Most respondents commented about perceived benefits. Themes included:

1. **Protecting human rights:** Having a voice in my treatment, having a voice when I can't speak for myself, my voice instead of my carer
2. **Improved experiences:** Better treatment and outcomes, better planning and communication
3. **No benefits:** Not respected or upheld by services

Themes with the most comments (in order of magnitude) included:

- | | |
|---|---|
| 1. Having a voice in my treatment | 3. Better treatment and outcomes |
| 2. Having a voice when I can't speak for myself | 4. No benefits: not respected or upheld by services |

Perceived barriers

Respondents identified many different barriers to the uptake of advance statements and nominated persons. Broad themes included:

1. **Information barriers:** Lack of awareness, lack of necessary information
2. **Service barriers:** They won't be used or respected by services, lack of support to complete them, services don't make an effort, services don't understand them
3. **Negative impacts:** Emotional challenges, big effort/too hard, fear of negative consequences
4. **Language and literacy**
5. **Challenges to findings a nominated person**

Themes with the most comments (in order of magnitude) included:

- | | |
|--|-------------------------|
| 1. They won't be respected by services | 3. Big effort/too hard |
| 2. Lack of information | 4. Emotional challenges |

Nominated persons

Respondents indicated a wide variety of people they have chosen, or would choose, as their nominated person. The two most common groups included carers/family (45%) and friends (30%). While most people knew someone they would trust to be their nominated person, a sizeable minority of 18% did not. For this group of consumers, this translates to 1 in 5 people not being able to utilise nominated persons as a protection.

RECOMMENDATIONS

This survey's aim was to understand why the uptake of advance statements and nominated persons in Victoria is so low. The results provide rich information to help understand the issue, and includes many opportunities for further action by the Department of Health and Human Services.

Information and promotion is not enough. Clinicians need to get on board.

The findings make it clear that better promotion and resources will not necessarily increase the uptake of advance statements and nominated persons (although they are clearly needed).

Throughout most of the survey questions, there was a clear and repeated message that many consumers do not trust clinicians or mental health services to actually do anything with their advance statements or nominated persons. This was the view of people who don't yet have these mechanisms, and of people who have them and have tried to use them. This is a serious issue which undermines the intent of the Mental Health Act to uphold rights and promote least restrictive practice.

I think the push should be towards services actually utilising the statements.... I question why consumers are being nagged to complete something that can—depending how the service responds to it—feel a little tokenistic.

But better information, resources and support are sorely needed.

Respondents were clear that information and resources are hard to find, insufficient, unclear and unhelpful. Many people also confronted barriers in setting up their advance statements and nominated persons, particularly finding the process too difficult, and facing a range of emotional challenges.

Recommended priorities for action

1. **Clinical culture & attitudes:** Improve mental health clinician attitudes and service culture regarding advance statements, nominated persons and human rights.
2. **Clinical standards & accountability:** Improve standards of practice and accountability. Establish a process for consumers to self-report whether the service is compliant with their AS or NP, mandated information distribution, better safeguards at the Mental Health Tribunal, and state-wide systems for lodging and retrieving advance statement and nominated person records.
3. **Consumer-developed resources:** Fund a comprehensive suite of consumer-developed information and resources, for a range of mediums (e.g., online, posters, booklets, templates, examples & stories, online learning modules). Provide materials in standard English, easy English, and translations. Ensure comprehensive distribution.
4. **Support staff:** Provide staffing resources to support people to complete advance statements and nominated persons, including administrative support, exploring options, and emotional support. These staff should be accessible to all. Involve services beyond the clinical sector—options include IMHA, community services, or VMIAC. Consider ways to involve the consumer workforce.
5. **Legislative change:** VMIAC strongly recommends legislative change during the 2019 Mental Health Act review: including changing from advance statements to directives, allowing the nomination of excluded people, and strengthening safeguards for human rights.

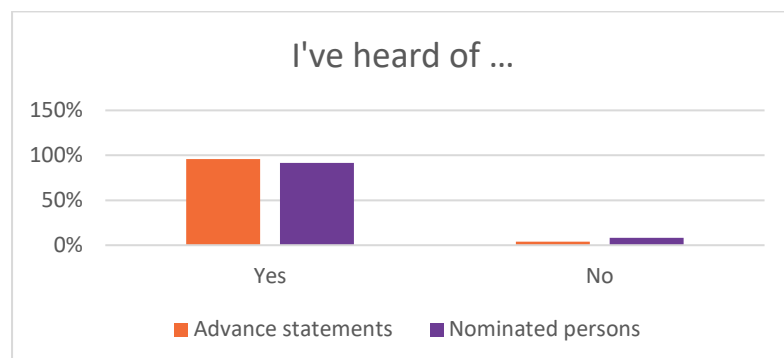
These first two priorities are critical.

There is no value in promoting mechanisms that will fail once people try to use them.

DETAILED SURVEY RESULTS

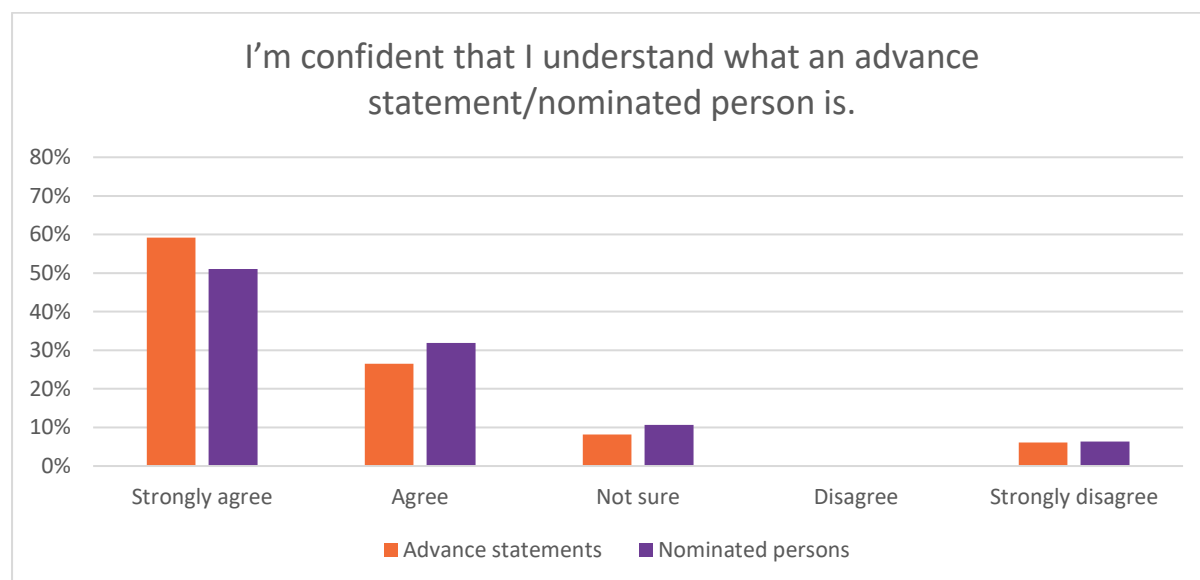
1. Consumer awareness, understanding & information

a. Awareness



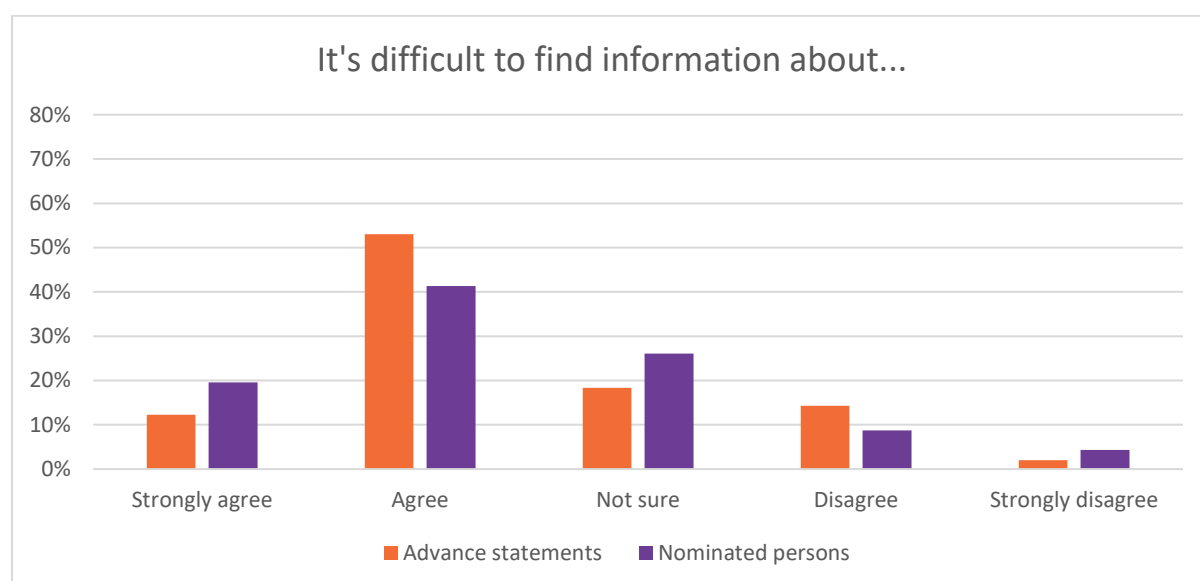
<i>'I've heard of advance statements / nominated persons'</i>	Yes	No	No. of respondents
Advance statements	96%	4%	(n=49)
Nominated persons	92%	8%	(n=48)

b. Understanding



<i>'I'm confident that I understand what an advance statement / nominated person is'</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statement	59%	27%	8%	0%	6%	(n=49)
Nominated person	51%	32%	11%	0%	6%	(n=47)

c. Accessible information



<i>'It's difficult to find information about...'</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statements	12%	53%	18%	14%	2%	(n=49)
Nominated persons	20%	41%	26%	9%	4%	(n=46)

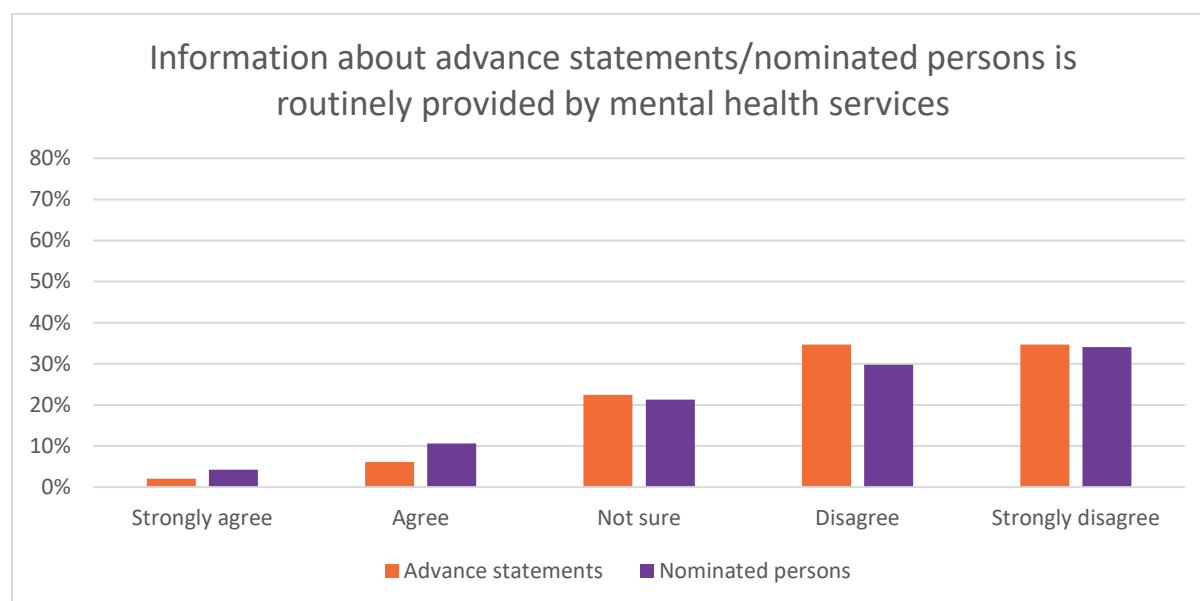
Comments (advance statements)

1. I've exited myself from the psychiatric system, and so have no use for creating a statement as I have no intention to ever use public services. Too traumatic. Why subject myself to something that is knowingly iatrogenic? I'd rather deal with my mental health in isolation than be treated with disdain and ignorance by so-called mental health professionals.
2. It's easy to find the information about advance statements on the department of health through googling, however you need to know they exist in the first place. You need to know where to look for other information about advance statements, such as where is the rights information kept at the mental health service.
3. The reason why I know is because my case manager set up a plan before it became part of the 2014 mental health act.
4. Too many bits all over the place and not easy if you are not a technology person.
5. Plain English information is lacking.

Comments (nominated persons):

1. It depends. Anybody with an internet connection and basic proficiency in google search functions can find out some information about NPs. I imagine this information is harder to come by for non-English speaking people or those from a different culture, as well as for those who are illiterate or without internet connection.
2. Easy to find information online but you have to know what they are in the first place.
3. There are no information that was given to me other than a conversation and filling in a form
4. Plain English info is hard to come by

d. Information provided by mental health services



'Information about... is routinely provided by mental health services'	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statements	2%	6%	22%	35%	35%	(n=49)
Nominated persons	4%	11%	21%	30%	34%	(n=47)

Comments (advance statements)

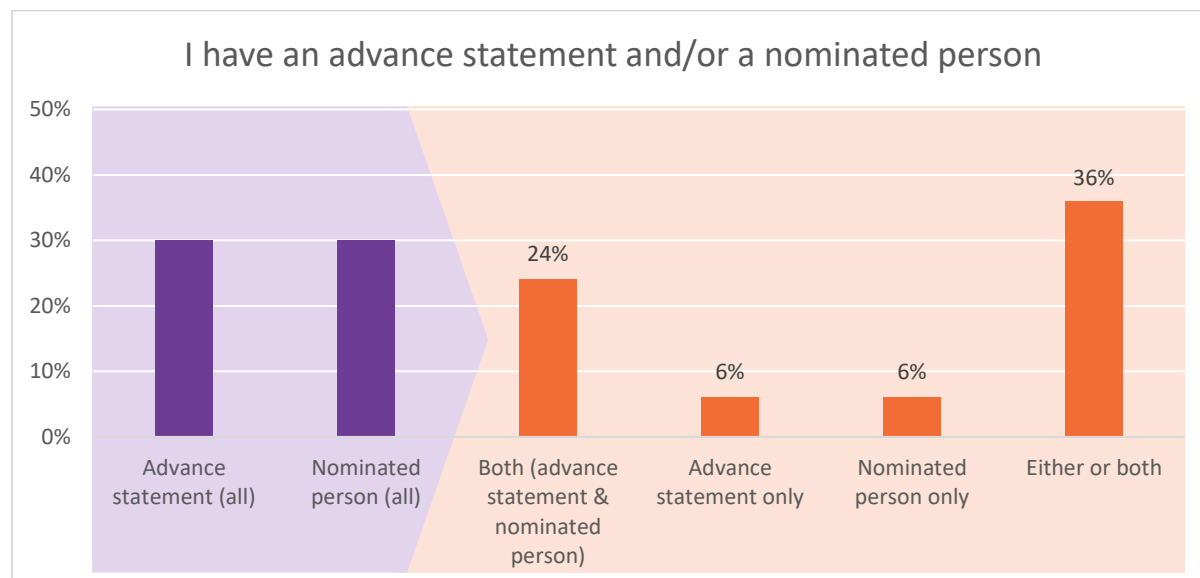
1. Not at albert road clinic!
2. Case managers and consultants don't consider them important enough because there is no KPI and the department doesn't set targets or audit the number of consumers offered to complete an advance statement. It's a consumer document, not a clinical document so services don't care
3. Nope. And I think the reason it's 'nope' is because the mental health landscape is shifting so consistently and managed so poorly by government and services that a human's rights are the last priority for services scrambling to get their funding.
4. Services need to regularly remind consumers of this option, not just once. On admission, on discharge, and every 3 months I would suggest. The conversation about them is something clinicians must do, as much as doing say a risk assessment
5. In the past there is information about patient feedback and other flyers on mental health and the tribunal and the NDIS yet there is nothing specific in regards to flyers on advanced statements or nominated persons
6. My case manager didn't know what they were

Comments (nominated persons)

1. Mental health services trust carers/nominated persons more than consumers and will therefore give more information to gain support from NPs
2. Similar to my comment about Advance Statements
3. Only in consultation
4. The hospital told me my 'carer' was my nominated person and I said I didn't have a carer and had not nominated anyone to be my nominated person so they couldn't be

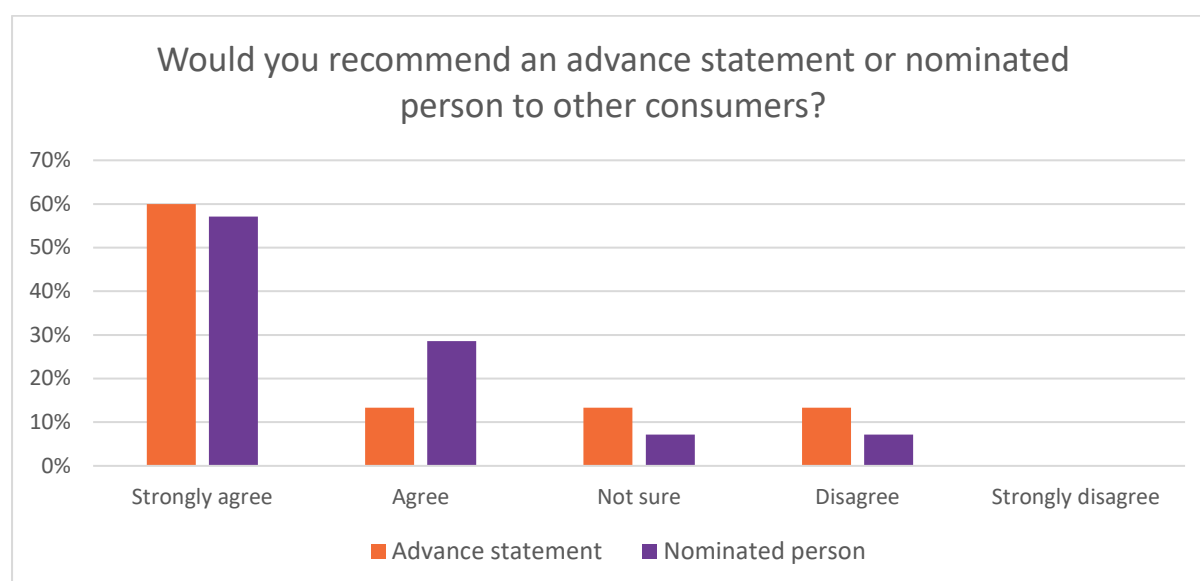
2. Experience of setting up advance statements & nominated persons

a. I have one



'I have ...'	Yes	No	No. of respondents
An advance statement	30%	70%	n=50
A nominated person	31%	69%	n=49
a. Both: advance statement and nominated person	24%	n/a	n=50
b. Advance statement only	6%		
c. Nominated person only	6%		
d. Either or both	36%		

b. Would you recommend it?



'Would you recommend it to other consumers?'	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statement	60%	13%	13%	13%	0%	n= 15
Nominated person	57%	29%	7%	7%	0%	n =14

Comments (advance statements):

1. We need them to be able to share our needs, the things that help us, the issues that trigger us and strengths we have to help us get through a crisis. It can't be just for medication, children and pets.
2. There's no guarantee that it will be followed, but there's many reasons to have one. It makes sure my preferences are considered, and will let staff know how to support me if I'm admitted or in a crisis. I won't be able to remember all my strategies in these situations so an Advance Statement could be a good reminder.
3. I struggle to understand why they are not promoted more highly, I feel that having all my supports working together will ensure that my recovery will be highly improved.
4. I have been labelled as psychosomatic in regards to some of my issues. With an advanced statement no one can say there was a lack of communication
5. it makes no difference so why would I tell anyone to have one?
6. To some extent it's made me feel less powerless. However, not all staff read them or take them seriously, so don't hope for respectful care.

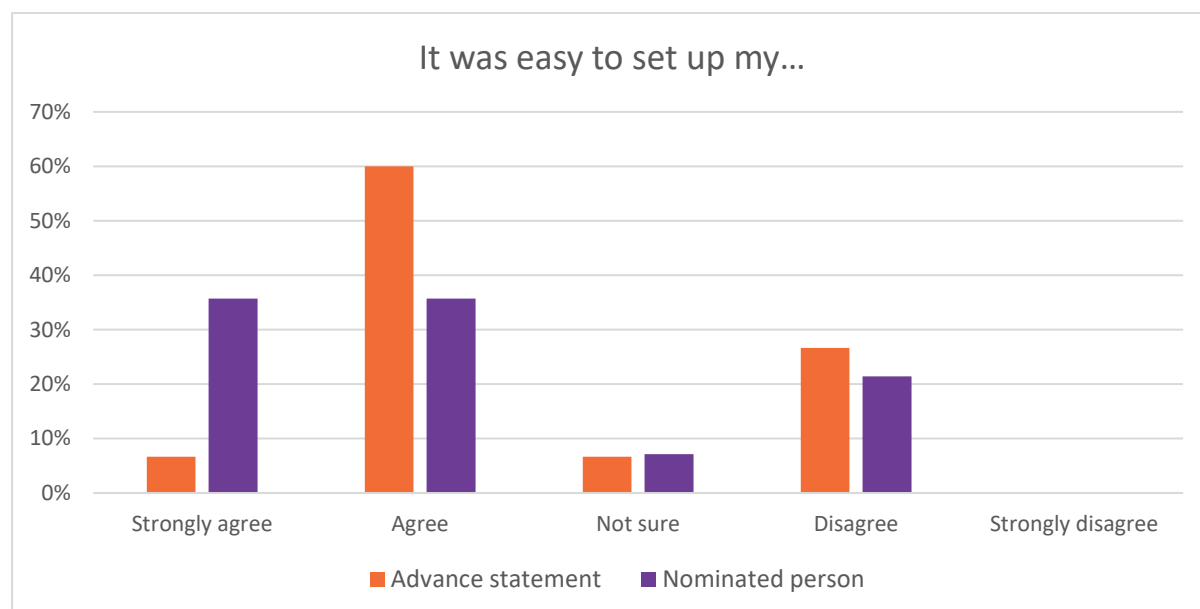
Comments (nominated persons):

1. As long as it is the consumer's choice and case managers or consultants agree that the consumer has not been pressured or coerced by the nominated person (especially in domestic violent situations).
2. It makes sure a support person of mine will be involved straight away as soon as I'm being assessed for compulsory treatment. They will hopefully be able to advocate for me in things

such as clinical reviews and Mental Health Tribunals. I just hope that they represent what I would want first, not their own opinion.

3. It avoids having multiple voices trying to speak for you. It avoids conflict when there is a difference of opinion

c. Easy to set up



<i>'It was easy to set up my...'</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statement	7%	60%	7%	27%	0%	n= 15
Nominated person	36%	36%	7%	21%	0%	n =14

Comments (advance statements)

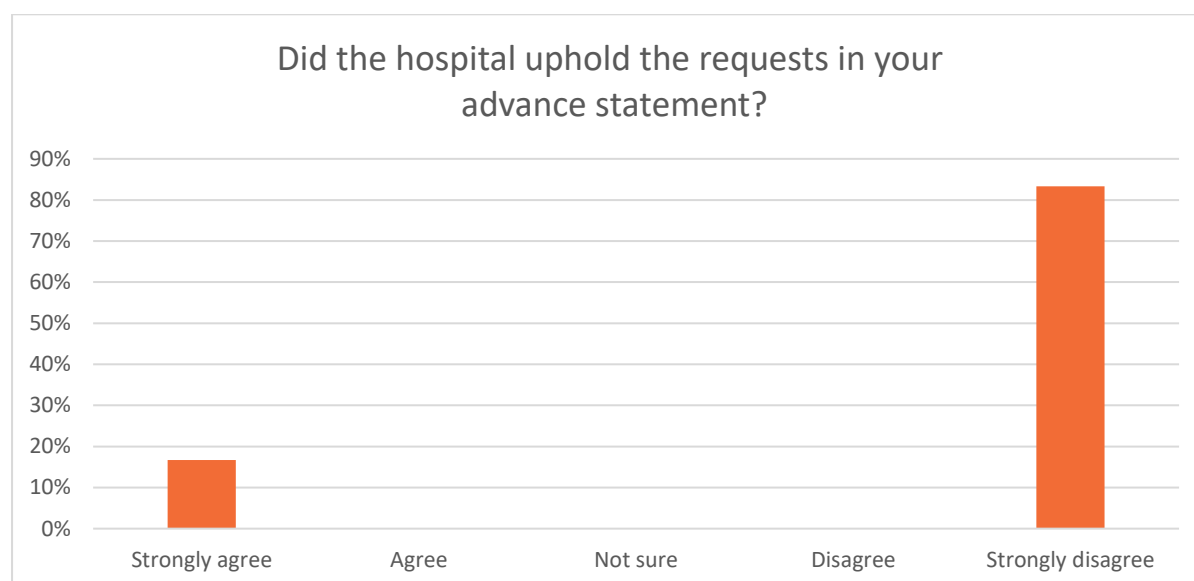
1. No one could give me consistent information about what to include and just said, "include anything you don't want in hospital"
2. I was lucky to have a good relationship with a private psychiatrist to complete mine, however I don't know how to alert public mental health services that I have one as I'm not accessing that type of service at the moment. This is important in case I'm admitted to a public mental health unit.
3. There was a lot to fill in and we had to make sure who was eligible to sign
4. It took a lot of work and thinking.
5. I asked my case manager to sign it and she wouldn't because she didn't know what it was for

Comments (nominated persons)

1. The form was quick to fill out but to be honest I haven't given it to my psychiatrist yet to witness so it's technically not completed.
2. There was a lot to do

3. Experience of people admitted to hospital

a. Using an advance statement in hospital

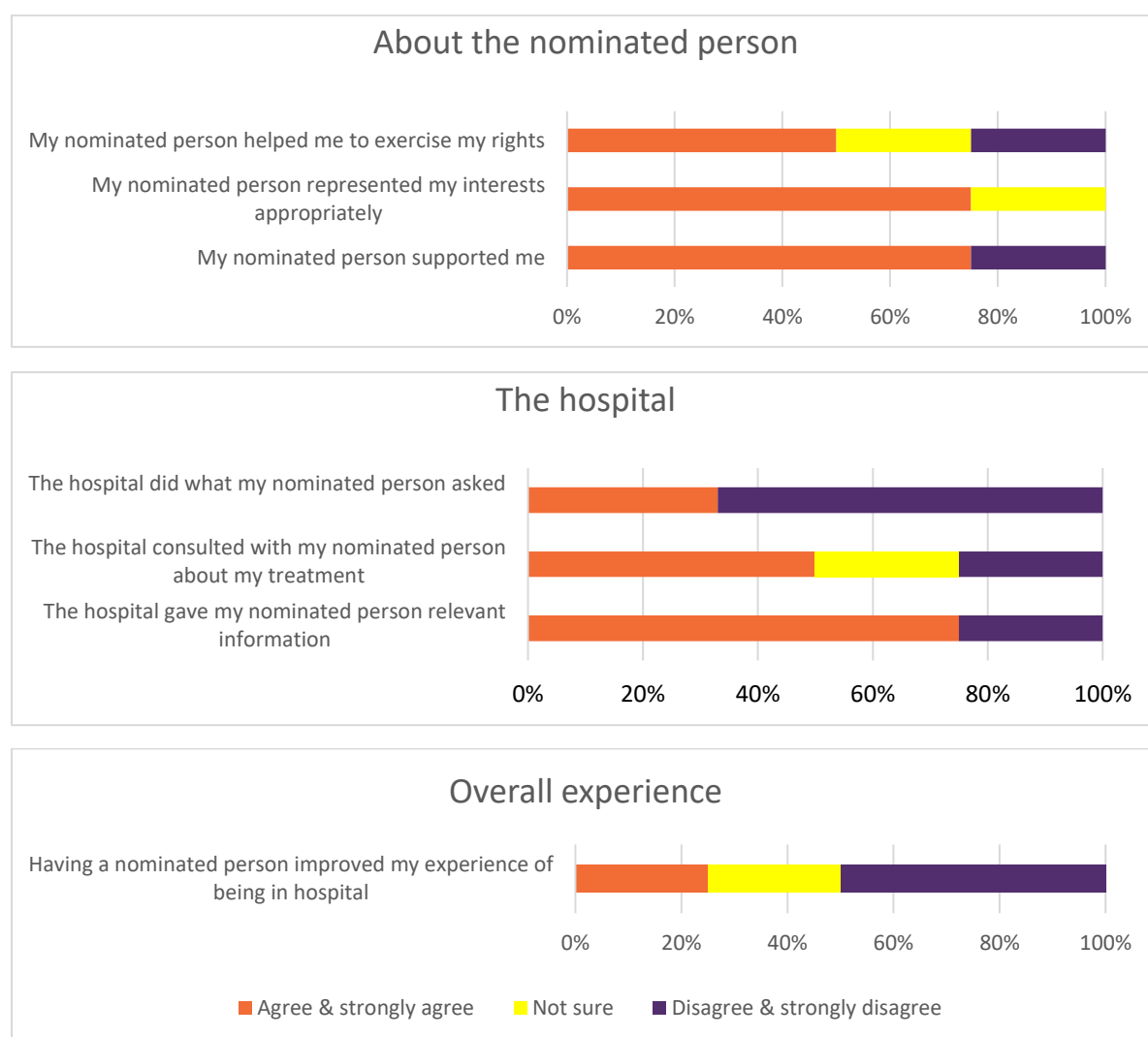


<i>'Did the hospital uphold the requests in your advance statement?'</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statement	17%	0%	0%	0%	83%	n=6

Comments:

1. I have not been admitted since I completed one, the way both myself and my carer were treated is why I have one now. Everyone in my support network has a copy of it
2. They couldn't find it, although I gave a copy to my case manager and to the nurse in ed
3. It varied as to whether staff looking after me read my advance directive - I would say maybe 1 in 5 did. The staff could not help me feel safe because they could not place me in an area that was separate to unwell men.

b. Using a nominated person in hospital



<i>Experience of using a nominated person in hospital</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
The nominated person						
My nominated person supported me	75%	0%	0%	25%	0%	n=4
My nominated person represented my interests appropriately	75%	0%	25%	0%	0%	n=4
My nominated person helped me to exercise my rights	50%	0%	25%	25%	0%	n=4
The hospital						
The hospital gave my nominated person relevant information	25%	50%	0%	25%	0%	n=4
The hospital consulted with my nominated person about my treatment	25%	25%	25%	25%	0%	n=4
The hospital did what my nominated person asked	33%	0%	0%	67%	0%	n=3
Overall experience						
Having a nominated person improved my experience of being in hospital	25%	0%	25%	50%	0%	n=4

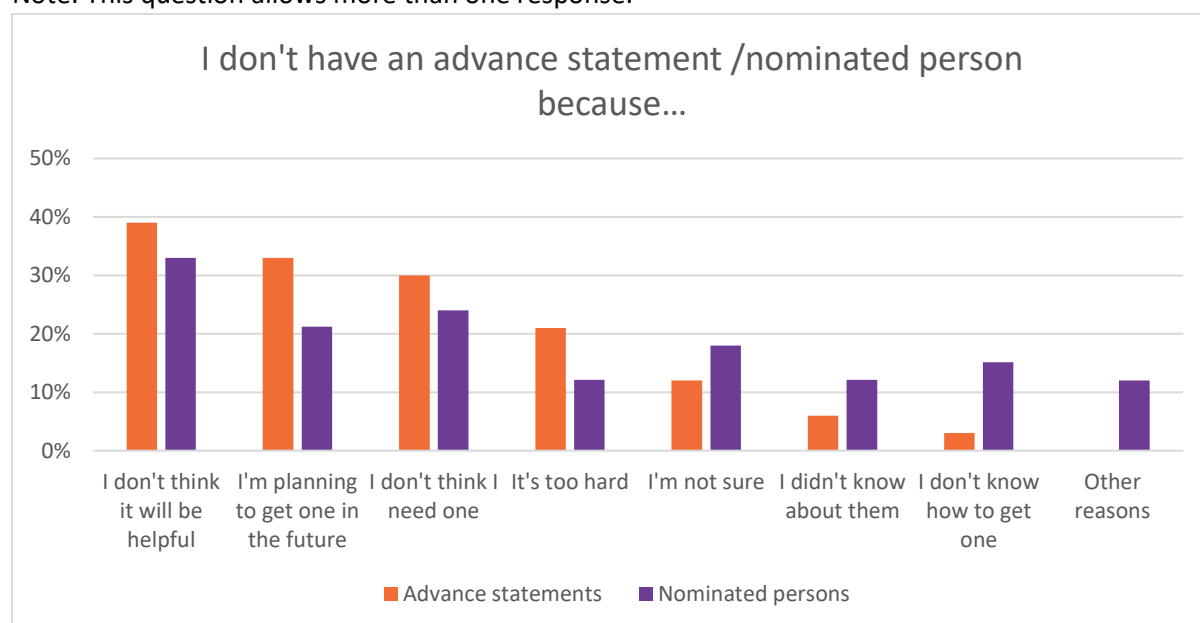
Comments:

- My nominated person helped when I became unwell in the community, which meant I didn't need to be admitted to hospital and got the support I needed through CATT
- I have not been admitted to hospital as part of advance statement I spent some time in a PARC to stop an admission. Which has worked on 2 occasions.

4. Consumer confidence & views

a. I don't have one because...

Note: This question allows more than one response.



Reasons for not having...	Advance statements	Nominated persons
I don't think it will be helpful	39%	33%
I'm planning to get one in the future	33%	21%
I don't think I need one	30%	24%
It's too hard	21%	12%
I'm not sure	12%	18%
I didn't know about them	6%	12%
I don't know how to get one	3%	15%
Other reasons	0%	12%
No. of respondents	n=33	n=33

Note: 18 responses (from the 'other' category) were redistributed into existing categories based on the comments provided.

Comments from 'other' category (grouped by theme)

Theme: I don't think it will be helpful

Advance statements	Nominated persons
<ul style="list-style-type: none"> • Unsure how seriously services take them. Not sure if they're even read to be honest • There is no compulsion for psychiatrists or services to honour them. Tribunal can overrule them also. Waste of time till the Act gives them 'teeth' • I don't believe my thoughts on preferred treatment will be properly listened to • No weight • I don't trust the doctors at my hospital for one second. There's no way they would do what I'd ask in an advance statement! They just want to shoot me up with pills, treat me like I'm subhuman, and chuck me out the door for the next poor soul. Make them advance directives and I'll do one tomorrow but until then advance statements are a joke. • I'm concerned about being unable to change it if I become unwell 	<ul style="list-style-type: none"> • My understanding is that although NP is there to present the person's wishes, they may also be asked their opinion and I do not want that. I want it to be my opinion as per my AS. • because the hospital will just ignore it anyway • Services don't comply with the regulations and complaints commission fails to enforce patients' rights in this regard. • I had one and I revoked them. The hospital staff listened to what my nominated person wanted in preference to what my treating private psychiatrist wanted.

Theme: I don't think I need one

Advance statements	Nominated persons
<ul style="list-style-type: none"> • I don't engage with the mainstream public mental health system or services; too archaic, too broad a sword to do any good for me. I thus can't envision a scenario in which I would need an AS. • I think it's something that is of use, but I also see it as something that says 'I will become unwell and can't think for myself', which is something I don't believe will occur. It's like I'm admitting defeat, or planning for a loss, which don't want to do. I do at times become unwell, but I'm able to manage this and I'm not likely to become hospitalised and so I see it also as unnecessary. It's complicated, as my opinion varies, as overall I think it's not a bad thing to have, it's just for me I see it as a sign of not being able to cope and I won't admit that. 	<ul style="list-style-type: none"> • I've not gotten that far in my planning and have to admit not thinking I'd need one at present. • As with the Advanced Statement, I see it as a negative sign, that I can't help myself or seek help. I'll do it if I become hospitalised, otherwise I don't see it as necessary.

Theme: Not sure

Advance statements	Nominated persons
<ul style="list-style-type: none"> • I should have done one. it might have given loved ones some assistance. instead, they were lost n supported me in bad ways or not at all 	<ul style="list-style-type: none"> • I don't know. this survey is making me wonder why I don't have all this!

Other reasons

Advance statements	Nominated persons
<ul style="list-style-type: none"> I'm in the process but finding it difficult to get my health practitioners - GP and psych to do it with me as they don't have a lot of experience with them. Need someone else who knows more about them to help me with it. I want to know as many options and alternatives as possible. My psychiatrist has not mentioned it (I've been seeing him since 2013) so I assume it's unimportant. 	<ul style="list-style-type: none"> Retired MH Peer Support Worker (Mental Health Advocate). I don't have an advanced statement There's no one I can fully trust with something this important. I would probably get a lawyer if I could afford one.

b. Perceived impacts on communication, rights and hospital actions

Survey question: How strongly do you believe these statements?



How strongly do you believe each of these statements?	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
Advance statements						
An advance statement would improve communication between me and staff.	25%	27%	29%	10%	8%	n=48
I am not confident that a hospital would respect and uphold an advance statement.	35%	38%	13%	8%	6%	n=48
It's my right to have an advance statement.	79%	10%	10%	0%	0%	n=48
An advance statement will protect my human rights.	17%	23%	25%	15%	21%	n=48
Nominated persons						
A nominated person would improve communication between me and staff	26%	35%	28%	9%	2%	n=46
I am not confident that a hospital would respect and involve a nominated person.	26%	39%	22%	7%	7%	n=46
It's my right to have a nominated person.	67%	22%	11%	0%	0%	n=45
A nominated person will protect my human rights.	20%	30%	37%	4%	9%	n=46

Comments (advance statements):

1. When I'm unwell I can hardly talk. Advance statements should be well known, encouraged, followed and respected.
2. To enable more confidence in hospitals upholding consumer requirements, we should be able to meet with a consultant to discuss what is available, what are reasonable requests and how do we negotiate shared mutual expectations
3. First statement: It could inflame relationship with staff and retard communication. In my experience many staff don't care to consider a patient's treatment preferences. Last statement: This is naive. It can do, but by their very nature, as I understand them, they can't protect my human rights, just delay their violation, or reinstate them post hoc, once the damage has already been done and a person's been made to feel powerless before the system.
4. I have been saying for many years that organisations like VMIAC should be promoting and empowering both consumers and support networks to complete one together. I promote the one you have in your resources.
5. The treating team only has to look at it, they can decide to do as they please and simply say 'we thought a, b and c was more important than what is written.
6. It can still be overridden too easily and explained away.
7. You shouldn't need an advance statement to have your human rights protected. In any patient care situation, you have rights anyhow
8. Lack of enforceability.

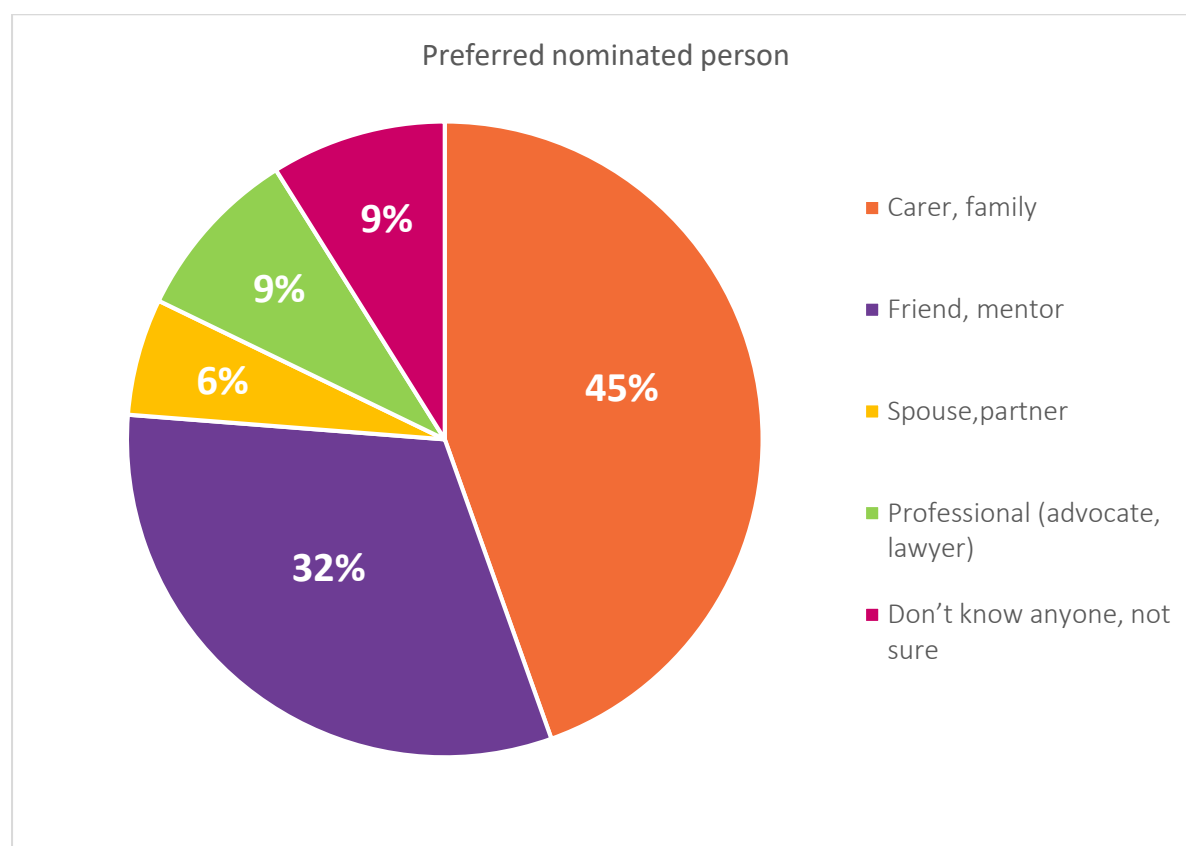
9. In my experience hospitals were too under resourced to protect my human rights or keep me safe, and I was harassed and assaulted by male patients in all of my compulsory admissions.
10. It wouldn't protect my human rights because my doctor can just ignore it if he wants to, and I think he would.

Comments (nominated persons):

1. It's hard. I don't want my carer/my mother to make bad decisions for me
2. My nominated person would be a friend who is also a fellow consumer. I would like to have someone in my corner who understand MI, the system and is a bit further removed from the situation so as to have more perspective if I became unwell again.
3. It's difficult, as I know they'd be heavily influenced by the treating team, especially if I'm in hospital. How can you know what they'd agree to do under that kind of stress?
4. My father was my nominated person. He was also a perpetrator of violence in my family - having him involved in my care is painful and complex. There is no one else I trust to ask.
5. I guess a family member is the obvious choice for lots of people but when you've been abused by your family then you really don't want anything to do with them. And even the ones that were OK still don't really put my interests over their own. They'd rather have me doped up so they can sleep at night, than trust that I know what I need for myself.

5. Choosing a nominated person

a. Who do consumers prefer to have as their nominated person?



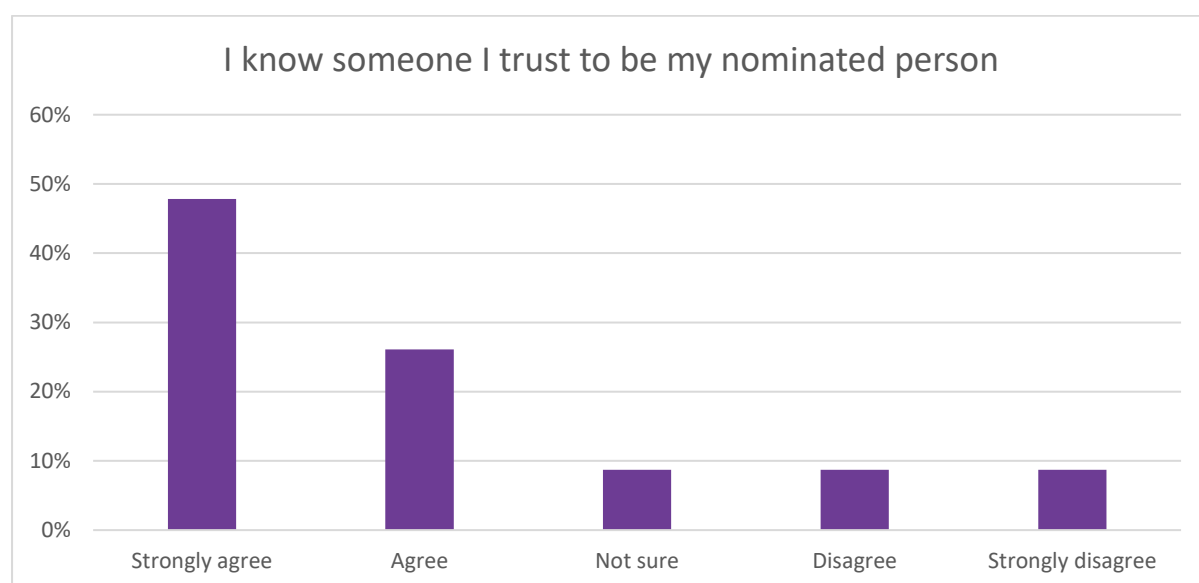
Consumer respondents considered a variety of different types of people for nominated persons, with either friends/mentors (32%) or carers/family (45%) as the most preferred people.

	Carer or family	Friend	Support worker	Advocate	Lawyer	Spouse/partner	Mentor	Don't know anyone	Not sure	Total
Actual nominated person	7	4	0	0	0	2	1	0	0	14
If I did get a nominated person I'd choose	14	10	0	3	1	1	0	1	3	33
Total (n)	21	14	0	3	1	3	1	1	3	47
Total (%)	45%	30%	0%	6%	2%	6%	2%	2%	6%	100%

Summarised preferences:

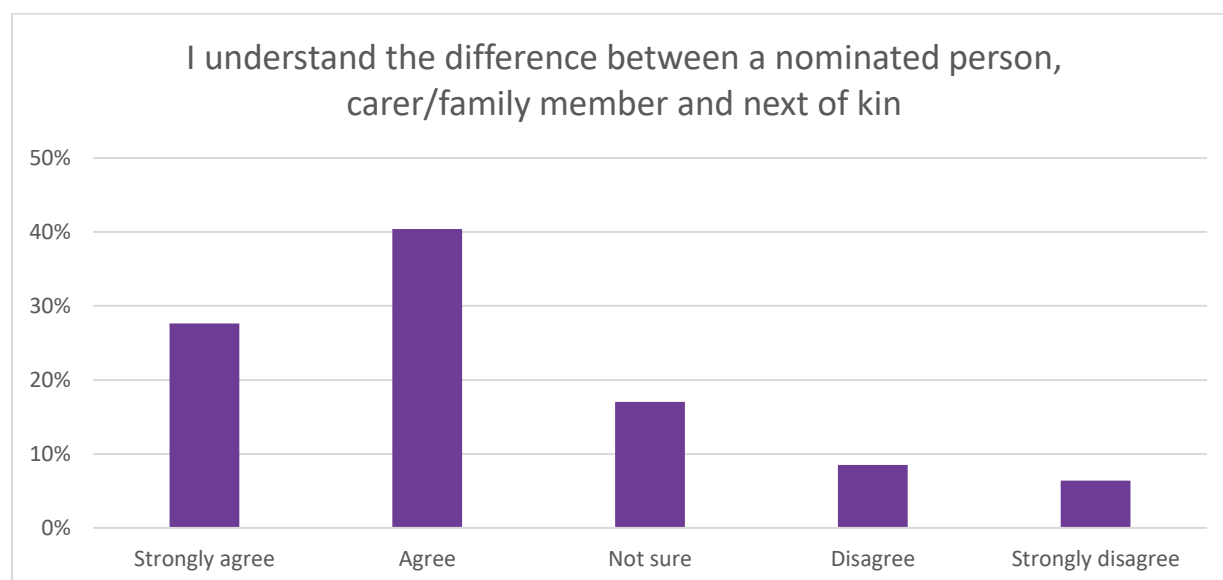
	Carer, family	Spouse, partner	Friend, mentor	Professional (advocate, lawyer)	Don't know anyone, not sure
<i>n</i>	21	3	15	4	4
<i>%</i>	45%	6%	32%	8.5%	8.5%

b. I know someone I trust to be my nominated person



<i>I know someone I would trust to be my nominated person</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
	48%	26%	9%	9%	9%	n=46

c. Nominated person VS carer/family VS next of kin



<i>I understand the difference between a 'nominated person', a 'carer/family member' and 'next of kin'.</i>	Strongly agree	Agree	Not sure	Disagree	Strongly disagree	No. of respondents
	28%	40%	17%	9%	6%	n=47

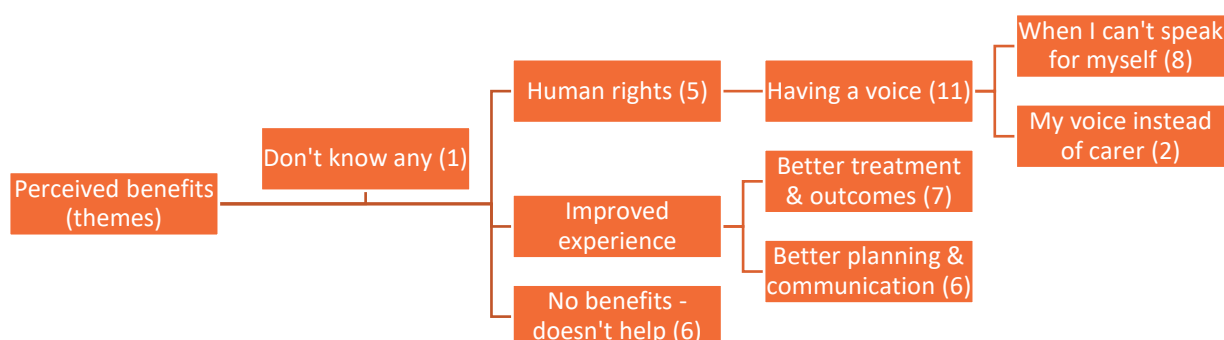
Comments:

1. its complex but someone could make it simple I'm sure!
2. Is it a legal thing? I suppose a NP is someone explicitly nominated in an AS, who may be different from (or the same as) a carer, NOK.
3. I suppose carers and nominated persons have very similar rights and role under the Mental Health Act, the difference being nominated persons would automatically be granted this, whereas it would need to be assessed if a carer is definitely someone's carer as defined under the Mental Health Act.
4. I'd hope that a nominated person has a larger role than another carer in being involved in someone's treatment.
5. I think 'next of kin' is more related to physical health if someone is on life support for example, and they make the decisions for them. Whereas nominated person is more working with the person by advocating and explaining information instead of making all the decisions.
6. A nominated person can act on my behalf and make decisions
7. I think so, as basically they can be anyone and they have a say in my treatment. They don't have to be a family member or partner. The latter only have limited rights, whereas the nominated person can have a say in how I'm treated.
8. But the hospital doesn't!!
9. I know the difference between nominated person and family, but I don't get how next of kin is different to family. I don't have a 'carer' and don't want one I can't trust my family to make treatment decisions because they're too easily influenced by the doctors and they don't realize how much compulsory treatment hurts me.
10. I learned about this through work.

6. Perceived benefits

Survey question: What do you think are the most important benefits of having an advance statement and/or a nominated person?

Forty-two responses were received and have been grouped by theme. The different themes are outlined below, with the number of related comments in brackets.



Theme	Respondent comments (grouped by theme)
Uphold human rights	<ul style="list-style-type: none"> Human rights respected!!!! People won't feel adrift with what to do with me! it might help my recovery! Having human rights upheld. Provides my rights to determine the treatment I receive Respect for my wishes That my rights & how I wish to have these adhered to has been already decided and can easily be accounted on by the mental health people involved in my care. My wishes have already been recorded.
Having a voice	<ul style="list-style-type: none"> Having a say in your treatment and care Can give an idea of treatment preferences. In theory they should ensure people are more heard when it comes to the support they receive in hospital. That you can put your wishes in writing and they must be considered - having it in place early can open up conversations that may be better heard at certain times. In case of the worst happening, you have your wishes clearly stated for that circumstance on how you wish to be treated. Any action taken against you contrary to those wishes should be considered medical trespass Having a say in what might happen To have my treatment wishes put in place Having an advocate who is "well" gives legitimacy to my views about hospitalisation and treatment. Your preferences (and maybe expectations) for treatment are clearly outlined in a written document. This can increase your chances of receiving your favoured treatment. Ensuring that medication / treatment requests are adhered to in hospitals, children are considered - avoiding unnecessary involuntary treatment requirements Improved communication and my wants being respected at times of unwellness.

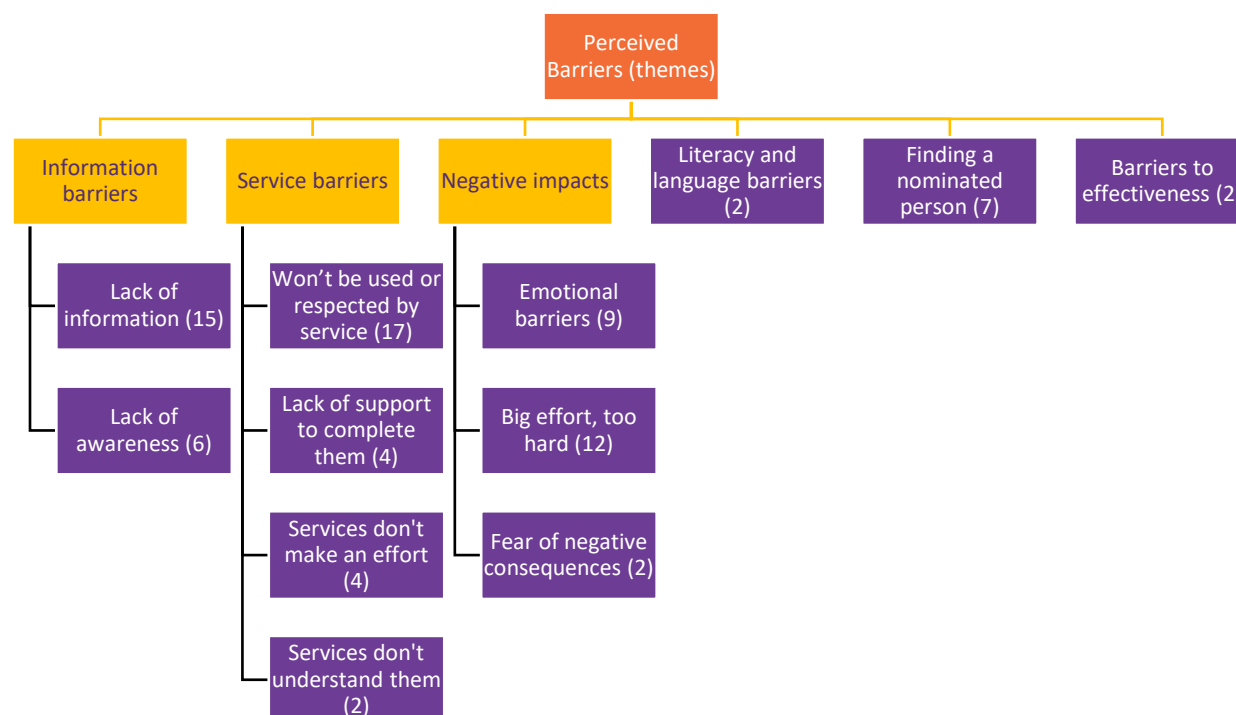
To voice my choices when I can't	<ul style="list-style-type: none"> • To 'speak' for you when you can't • Consumers can provide any information we see as being relevant and important when we are unwell and unable to communicate as clearly as we would like to. If we have the right NP and the service is aware of the relationship between the consumer and our NP, there is a stronger sense of collaboration between the consumer and the service • Having an advocate - be it the document, the person or both - to voice my choices when I can't. • Someone is there to look after your interests in the event you're unable to do it for yourself. • Giving the consumer a voice in acute or inpatient settings in their treatment choices, even while they are unwell and their judgement and consent at the time is considered invalid • Having a voice when unwell • If you're admitted and can't clearly indicate your treatment preferences the nominated person can hopefully advocate on your behalf " • My AS and my nominated person are my voice to express my preferred treatments when I am unable to do so. My carer will also be expressing my views about treatment (increasing the odds my views will be respected one hopes)
My voice instead of carer's voice	<ul style="list-style-type: none"> • To get the doctor to listen to what I want instead of my mum. • Removes so-called 'carers' - allows personal treatment preferences to occur, services are keen from my experience to place me at the centre of care rather than having 'carers' wishes and preferences acted upon.
Better treatment and outcomes	<ul style="list-style-type: none"> • Will have correct meds and help if have dual diagnosis • Improved MH Care AND outcome for consumer, family, and other carers. • Both I and my support network have a clear plan of what has worked and what has not worked in the past. My nominated person is clear about what treatment options I would like or not and is empowered to act on behalf. • Also, with an advanced statement the focus shifts from clinicians and others making decisions to clinicians and others delivering preferences and treatment that have been clearly articulated by me. I know my illness best, I know what works best, I've taken steps to ensure this happens in a clinical setting. • It gives you some peace of mind that your wishes have to be taken into account. It allows you to state what has or will help your recovery and hopefully fast tracks you getting the treatment you need. • don't know what an advance statement is but a nominated person would help make sure I get the mental health services that I need • Support around important aspects of my care
Better planning & communication	<ul style="list-style-type: none"> • Having a plan if you're admitted makes it easier to get your point across because hopefully you're well and thinking clearly when it's written. • Provides the treating team with an understanding of the way I want to receive treatment
Prevention of harm	<ul style="list-style-type: none"> • It can also hold treating professionals to account, at least hypothetically, and therefore serve to highlight abuses of power, or discrepancies between what a person has opted in terms of treatment, versus what they've been prescribed. • it possibly helps to identify triggering and traumatic situations, and can identify medication intolerance/ allergies that the treatment team is not aware of. • To receive care that is not detrimental to me

	<ul style="list-style-type: none"> To prevent staff at psychiatric facilities from being negligent, mostly due to the stigma of mental illness.
No benefits	<ul style="list-style-type: none"> None really, because advance statements are not legally binding, and because having a nominated person does not stop other family members that I trust even less being involved in decisions about my treatment. Having my say, but it makes no difference If they had the same weight as medical directives and next of kin in other areas of health care then they would up hold my rights but they don't so I'm not sure if they are worth that 'paper' They are written on... trimming around the edges Theoretically, it would help me access safe, respectful care. This hasn't been the case in practice. They could help to make sure you only get the treatment you want BUT only if you've got doctors with principles and kind hearts (I haven't met them yet but I guess there must be some out there) and only if you have someone you trust who will always be true to your wishes.
Don't know	<ul style="list-style-type: none"> Don't know as no-one has spoken to me about them or given me information about them. I saw some information online but as no-one has said anything, I've not done anything about it.

7. Perceived barriers

Survey question: What do you think are the main barriers to people having an advance statement or a nominated person?

Forty-three respondents answered this question, and responses have been grouped by theme. Note that many respondents included more than one suggestion within their comments—where these apply to different themes, the comments have been split up and allocated to the appropriate theme.



Theme	Respondent comments (grouped by theme)
Lack of awareness	<ul style="list-style-type: none"> • Not knowing about them • Awareness • Not knowing they are available. • Don't know about them • Lots of people aren't aware of them • Don't know they exist
Lack of information	<ul style="list-style-type: none"> • Confusion. not knowing where to get a form • Don't how to get them • Lack of knowledge around an A.S • Understanding the functions and benefits of both • there isn't enough information • Lack of information • There is little knowledge in the greater community about nominated person/s and advance statements. • people may not understand them, may not have enough insight into the benefit of having them. • They seem overly legal, difficult to find templates and information on, not offered by hospital staff, the explanation of them sit in a

	<p>mental health act that not many people seem to know anything about.</p> <ul style="list-style-type: none"> • Also lack of information about what they are • knowledge about it • Not enough information and support to assist people create one. • Education and lack of understanding about advance statements. • a barrier for myself having an advanced statement is not knowing who I can get to sign off on it • lack of information
No perceived benefit – won't be used or respected by hospital	<ul style="list-style-type: none"> • Can't trust the doctors to pay any attention to us, they always think their right • Services actually taking them into consideration (e.g. asking for one or reading what's provided) • I think most people think there's no point in having an advance statement if it's just going to be ignored • Concerns that they may not be valued by hospitals. • Them being listened too by mental health professionals. Especially if the person nominated isn't a strong willed person who has the mental health professional walk all over them. • Feeling a lack of trust towards the honouring of an advance statement. • I'm not confident it would be useful if I become unwell again. • Perhaps a disbelief that it will make any difference. • Don't believe they will be upheld • The doctors and hospitals, they don't care what you want they just do whatever they like • Lack of mental health system interest. • They are ignored during inpatient treatment • Hospital staff who think they know better. • The treating clinician's failure to observe what is in an advanced statement. • They are not legally binding, the doctors can still do whatever they like • The routine and casual disregard of both by the clinical staff in psych facility. If on the small chance your statement is even looked at, it's unlikely to be followed • This makes me so angry. I shouldn't have to get these things. We should get rid of the mental health act instead, so I can just make my own choices like any other person. Plus advance statements are totally weak. Why can't we have advance directives??
Emotionally difficult	<ul style="list-style-type: none"> • Confronting - not wanting to reconsider hospitalization. • It can be hard filling out an Advance Statement as you may be reflecting on past traumatic memories • People may not want to pre-empt another hospitalisation • People don't want to face the reality of treatment that is so often coercive, unnecessary, not conducive to good outcomes, in other words people most likely just want to get the hell out of hospital and never see one again.

	<ul style="list-style-type: none"> • People may pre-suppose further hospitalisations, why would anyone want to ever to go back to an acute in-patient unit and experience the trauma so many people experience, and further, spend time putting in place a document and a nominated person that sets you up to face a trauma based, rights deficient, coercive, medical focussed, pharmaceutical based institutionalised system that causes more trauma and longer recovery. Why would anyone want to face that reality by putting in place a person and a document that may or may not alleviate trauma psychiatric hospitals generate purely by the way they deal with patients? • It's confronting to think about • Many others prefer to think I will not need one that is until you are in crisis • A barrier for myself having an advanced statement is being ashamed to express my treatment desires because I know they're different to what the public mental health system usually suggests. • Mental state
Big effort, too hard	<ul style="list-style-type: none"> • Effort • Paperwork • Putting the information together on my end • I think it's difficult to organise it all. • Deciding what to include in the advanced statement • Choosing the nominated person and discussing their preferences with them • Getting the documents notarised • Advanced statements seem hard to produce • The forms are lengthy • Apathy • Takes too much time an energy • The fact you have to fill in a form and have it witnessed. I also keep copies with trusted family and friends and on my phone. I review it annually just to check I still hold same treatment preferences. I discuss my AS with my nominated person, my spouse and my family and friends.
Literacy and language barriers	<ul style="list-style-type: none"> • The usual: lower income, lower or non-existent education, culturally and linguistically different peoples, non-English speakers. Those sorts of things. • Literacy
Challenges in finding nominated person	<ul style="list-style-type: none"> • A lot of consumers don't have anyone they would want to be their nominated person. I would like to have another consumer act as my nominated person, but I do not have confidence that a nominated person who was a consumer would be respected and listened to by treating teams. • Not wishing to ask nominated person - giving somebody responsibility to take on this role. • patient may feel they do not want to burden friends and family members with nominating them.

	<ul style="list-style-type: none"> • hard to find info on nominated persons • Also some clients may not have someone they trust to be a nominated person. This might be something to consider for the community visitors • Not having anyone to trust. • Nominated person - having a person to entrust to do this.
Services don't make an effort	<ul style="list-style-type: none"> • Services don't recognise the importance or how AS relate to Safewards. No one explains to consumers that even though they believe they will never go to hospital again, an AS is like an insurance policy. Services offer an AS once, which the consumer doesn't want to do out of fear, and it's never mentioned again. Services need to have a set KPI at 80% offered to complete an advance statement at each 91 day clinical review and show it through auditing of management plans signed by consumers. • I don't think mental health services promote or encourage either advance statements or nominated persons. • Psych services rarely advise that you can make an advance statement. I think they just see it as extra work.
Services don't understand them	<ul style="list-style-type: none"> • Lack of knowledge, understanding and validation by health services regarding their existence, how they work, how to create one or implement one. No-one seems to know of them. • Services lack of 'real' understanding of them
Lack of support to complete	<ul style="list-style-type: none"> • Time Available to Staff (Incl Peer Workers) to Help Complete. • Perhaps lack of support to ensure the document is completed. • A good trusted support • Lack of support for consumers to complete an advanced statement
Barriers to effectiveness	<ul style="list-style-type: none"> • The nominated person may be away or unavailable at the time. • Advance statement - actually being able to get it to hospital staff when you're admitted.
Fear of negative consequences	<ul style="list-style-type: none"> • Being seen as trouble • They can remove carers, family, concerned others from people's lives.

8. Suggestions for raising awareness & knowledge

Survey question: What are the best ways to let more consumers know about advance statements and nominated persons:

Forty-two respondents answered this question.

Themes emerging from the comments included:

People and services who can promote them <ul style="list-style-type: none"> • Advocates and lawyers • Mental health clinicians: psychiatrists, nurses, psychologists, social workers, case managers • Clinical mental health services • Community mental health workers, community services • Consumer workforce • Consumer networks, VMIAC • GPs • Pharmacists • Schools • Clinics • Support groups 	Suggested promotional tools <ul style="list-style-type: none"> • Booklets, flyers, posters • Online learning modules • Online information • Mass media advertising • Advertising, mass media • Health promotion campaigns • Social media • Direct mail • Workshops • Groups • Weekly info sessions at hospitals
Adapting current practices <ul style="list-style-type: none"> • Promote them as part of practice 	Supportive services that could help <ul style="list-style-type: none"> • Staff to provide support for consumers to complete them • Templates
Accountability <ul style="list-style-type: none"> • Document that advance statements and nominated persons were offered to consumers at regular reviews 	
Promotional content ideas: <ul style="list-style-type: none"> • Provide information about them • Examples of advance statements and nominated persons • Examples of when they've been useful, stories from people who've used them 	Key tips <ul style="list-style-type: none"> • Consumer-led, consumer written materials • Different languages • Don't rely only on the hospitals to do it • Services need to be respecting & using them before promoting them

Detailed comments are sorted by theme below.

Theme	Respondent comments (grouped by theme)
What mental health clinicians can do	<ul style="list-style-type: none"> • Every MH service and hospital and psychiatrist psychologist social worker-should ALL be pushing these. It seems basic. • Consultants to discuss and offer AS at every 91 day review, evidenced by consumer signature of being offered and either refusing or accepting. • Making them part of the everyday training of health professional • Clearly explained by staff regularly, doesn't matter if the information has to be repeated.

	<ul style="list-style-type: none"> • Via health professionals. Perhaps GP when diagnose mental health issues with a patient. • Full time people in services letting people know about them. Showing examples of where they have been useful • To have nurses and case managers and GPs etc inform people about them and offer to support them to fill the forms out. • It makes sense to me to also publicise AS to pharmacists and GPs and private psychologists and psychiatrists as everyone should know these are your rights under the mental health act.
Consumer workforce, consumer networks	<ul style="list-style-type: none"> • More funding for Consumer peer support workers in inpatient units (separate to post-discharge) and in each of the community teams. • Funding for clinical-service based Consumer and Carer Consultants to develop information packs for all consumers and carers entering a clinical service. • Spreading the word via consumer based networks • Consumer advocacy • Have a workshop at VMIAC so that consumers are aware of their rights.
Existing support groups	<ul style="list-style-type: none"> • Support groups, networking, hearing stories from those who have used them successfully and had them respected
Advocates and lawyers	<ul style="list-style-type: none"> • Through advocates, support workers and legal representatives.
Mental health services	<ul style="list-style-type: none"> • Regular information sessions (weekly) inside psychiatric hospitals • All services should be required to provide information and support. • Organisations having a dedicated person/s who can work with consumers in regards to advanced statements. • SIGNAGE. also making it mandatory for clinical staff to make clients aware. It should also be addressed in psychiatric review • Advertise more in inpatient and community settings to get the word out
Booklets	<ul style="list-style-type: none"> • Information in the rights and responsibilities booklet on inpatient units. • Flyers in hospitals. Information in consumer packs and carer packs
Advertising	<ul style="list-style-type: none"> • Advertising-literally via MH campaigns and personal accounts of how helpful an AS has been • As much public awareness raising as other important medical decisions get, like being an organ donor - TV, newspaper, in waiting rooms, on the back of toilet doors. • Paid advertisements during prime time on radio and TV. • Social media. • Raise awareness. Social media seems to get the word out, use good news stories. Ensure it is Peer Led

	<ul style="list-style-type: none"> • Developing a template for an advance statement, and advertising it on social media, with a list of places it can be notarised • Direct mail. Anyone taking anti-depressant or anti-psychotic medication has to be given an info sheet by their GP or pharmacist. • Ads on TV
Templates	<ul style="list-style-type: none"> • Developing a template for an advance statement
Include in treatment plans	<ul style="list-style-type: none"> • Included and integrated as part of the treatment plans when in hospital, regardless of Advanced Statements being acted upon.
Workshops, groups	<ul style="list-style-type: none"> • Hold workshops both within services and in the community • Groups run by peer workers on MH units; at rehab services; and in the community. • Area mental health services should run workshops on advance statements and nominated persons. • Run workshops for consumers to support them to understand their rights.
Online	<ul style="list-style-type: none"> • More in depth learning what about a really thorough online learning module that takes people through the steps that's very achievable surely • Have a website with videos, and or subtitles and/or in different languages.
Tips	<ul style="list-style-type: none"> • Would be good to present an example of a success story with these initiatives. • Don't leave it to the hospital they don't want us to know • Importance in case of crisis • Don't get the hospitals to do it, because they don't really want us to have them, and it's already too late anyway once we get to a hospital. Get the community services to promote them, and GPs, and VMIAC. And don't make it sound like government talk, use consumers to write about it. And be honest that these things are not perfect. • By not naming patients as 'consumers'. • More information provided
Criticism	<ul style="list-style-type: none"> • I don't see the point in letting them know. • don't bother until they can't ignore them • The mental health system is a disaster. If there was a union representing those with a diagnosis there would be better communication and consumers would be better informed. • I don't think this is an issue of whether or not consumers know about them - I think it's about hospitals having the resources, including staffing time, to read and actually action advance directives

9. Other feedback

Survey question: Please tell us any other feedback you might have about advance statements and nominated persons:

Twenty-two respondents provided other feedback. These comments have been grouped into themes in the table below.

Theme	Respondent comments (grouped by theme)
Prioritise services using AS & NP, rather than increasing uptake	<ul style="list-style-type: none"> I think the push should be towards services actually utilising the statements rather than heaping more shame on consumers that don't have one. That's heavy language, but considering how often they seem to go unnoticed I question why consumers are being nagged to complete something that can - depending how the service responds to it - feel a little tokenistic.
Good practice	<ul style="list-style-type: none"> IMHA was very helpful in giving me information regarding advanced statements and nominated person/s, through leaflets and booklets that were posted out to me.
Challenges: administrative	<ul style="list-style-type: none"> Any change at all with nominees or addresses you have to rescind old one and redo new one going to doctors to get it signed They have to made easier to understand, create and implement. If health professionals have difficult supporting a person to create them, then perhaps the how needs to made as equal a priority of why.
Challenges: service attitudes & culture	<ul style="list-style-type: none"> My only other concern is a consumer might nominate another consumer who might not be considered a suitable nominee. I found that none of the clinicians were giving me this information, even though I had complained about my treatment. It is almost like the clinicians fear that the patient would know how to navigate their way around this. Hospitals, especially hospitals should be proactive in informing consumers about their rights. People need to realise that they don't have to agree with the person's AS to respect their wishes. I feel sad thinking about this. Some clinicians actually rolled their eyes when I asked them to read my advance directive.
Challenges: other	<ul style="list-style-type: none"> the consumer doesn't have a suitable nominee at all. What then? Stop assuming all families are all-knowing and all-good. Some of them are really awful.
Legislative improvement: directives and accountability	<ul style="list-style-type: none"> Nothing else I can think of. I guess my general feel is that they're a 'toothless tiger' document. You can have 'em, but they don't protect you against abuse or rights' violations. What legal recourse do we have when a registrar disregards advance statement? I still think they allow too much opportunity to be ignored, until clinical staff are held more accountable it will remain just a 'wish list' rather than a care plan. Nice try, but they're not good enough. Give us advance directives!

Legislative improvement: other	<ul style="list-style-type: none"> Concerns that advance statements / nominated persons have limited impact in changing treatment of consumers in Emergency departments (restraints, sitting for long waiting periods in cubicles under observation) and in using seclusion to manage clients on wards - all of which are likely to cause deterioration of condition and trauma. If I have a nominated person, I do not want any other family member to be able to be involved in my treatment, or to have rights to information about me. Change the law
Value of consumer peers in promoting and supporting	<ul style="list-style-type: none"> Please ask Consumer Consultant employed in clinical services to help develop a better advance statement document that will cover all the issues present in clinical services for consumers and staff. As soon as staff see "no medication" it is very difficult to have the conversation that the preference as valid as the next preference, which may be "no meat - vegetarian" Make training consumer led and run I think having conversations with peers and people you trust helps assist in producing an AS. It took me a while to decide what my treatment preferences were. And why I don't want and why. As well as including important info like allergies as I think they might be overlooked.
Importance of mechanisms	<ul style="list-style-type: none"> I want one where do I do it?! Please. Push this issue. I regret not having one. No one respects you when you're unwell. Very important to empower the care of MH clients ?!
Awareness	<ul style="list-style-type: none"> I've been sick for decades and never heard of these terms maybe they are newish
Other	<ul style="list-style-type: none"> Another example of how ineffective the mental health system is that the Department of Health and Human Services can't even enact its own legislation.

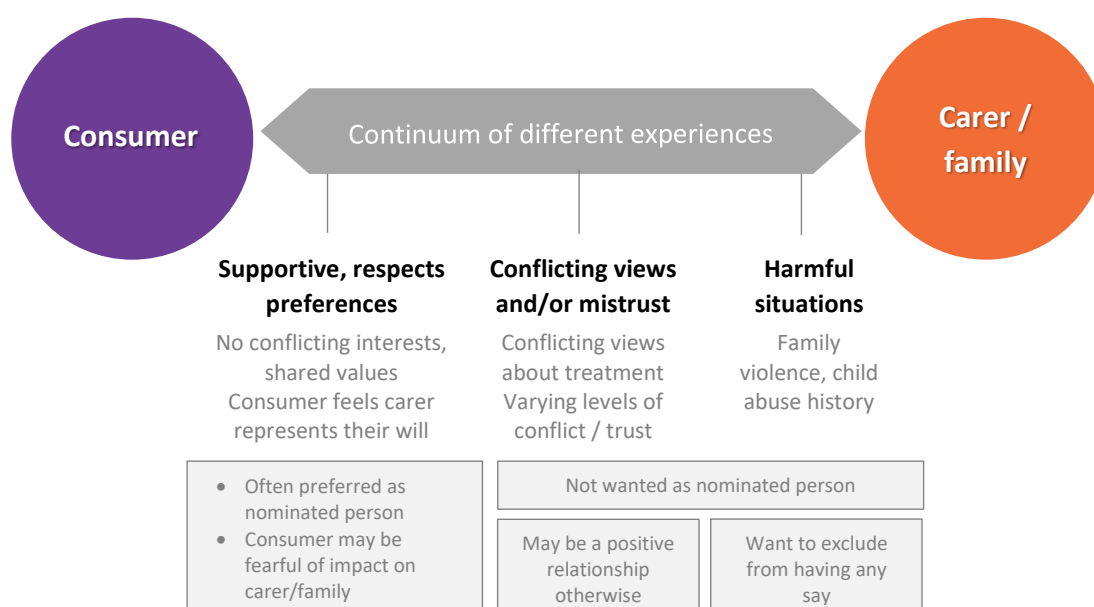
10. Additional key themes

Analysis of the survey indicated some additional themes, where related issues were mentioned throughout a range of different questions. This section consolidates views on those themes.

a. Consumer views about carers and family

Comments were made about carers and family in comments throughout the survey. These were drawn together to highlight a range of differing views and issues. These themes are illustrated in the diagrams below, and selected comments are detailed over the following page. Themes suggest a possible need for more nuanced thinking about consumer and carer/family relationships which take account of widely varying individual situations.

Consumers have different experiences with the involvement of carers and family:

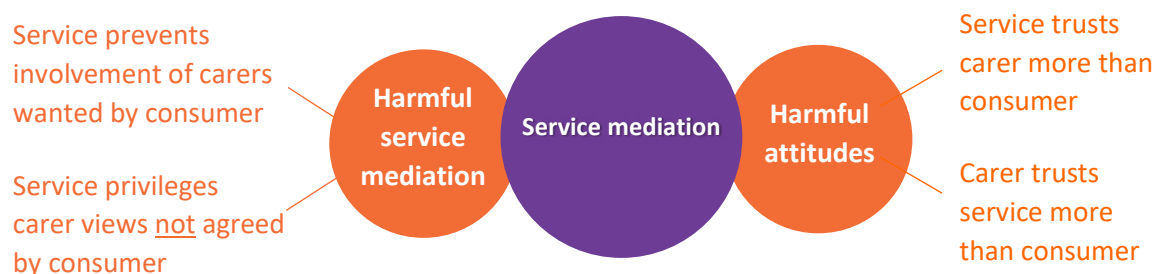


This is illustrated by the quotes below:



A further theme that emerged in relation to trust between consumers and carers/family in nominated person relationships is the mediating impact of services:

Services can contribute to trust problems in consumer-carer relationships:



Themed comments about carers & families running throughout survey responses

1. Supportive carer relationships

I also keep copies with trusted family and friends and on my phone. I review it annually just to check I still hold same treatment preferences. I discuss my AS with my nominated person, my spouse and my family and friends.

Patient may feel they do not want to burden friends and family members with nominating them.

2. Harmful situations: Conflicts of interest or values

- Recognising that consumers and carers don't always want the same things

Removes so-called 'carers' - allows personal treatment preferences to occur, services are keen from my experience to place me at the centre of care rather than having 'carers' wishes and preferences acted upon.

To get the doctor to listen to what I want instead of my mum.

- Family may be more focussed on alleviating their own anxiety than what the consumer really wants

And even the ones [family] that were OK still don't really put my interests over their own. They'd rather have me doped up so they can sleep at night, than trust that I know what I need for myself.

- Concern about carers/family making bad/unwanted decisions for consumers

It's hard. I don't want my carer/my mother to make bad decisions for me

It [having a nominated person] makes sure a support person of mine [carer or family] will be involved straight away as soon as I'm being assessed for compulsory treatment. They will

hopefully be able to advocate for me in things such as clinical reviews and Mental Health Tribunals. I just hope that they represent what I would want first, not their own opinion.

- Consumers not able to prevent untrustworthy (or abusive) family from having their say

...advance statements are not legally binding, and ... having a nominated person does not stop other family members that I trust even less being involved in decisions about my treatment.

If I have a nominated person, I do not want any other family member to be able to be involved in my treatment, or to have rights to information about me.

[Would you recommend to other consumers?] As long as it is the consumer's choice and case managers or consultants agree that the consumer has not been pressured or coerced by the nominated person (especially in domestic violent situations).

3. Harmful situations: Family violence and abuse

- Fear of abusers in family having a say

I guess a family member is the obvious choice for lots of people but when you've been abused by your family then you really don't want anything to do with them.

- Having to involve a violent family member because there is no-one in the family more trustworthy

My father was my nominated person. He was also a perpetrator of violence in my family - having him involved in my care is painful and complex. There is no one else I trust to ask.

4. Harmful service mediation

- Services preventing involvement of carers wanted by consumer

I have not been admitted since I completed one, the way both myself and my carer were treated is why I have one now. Everyone in my support network has a copy of it

They can remove carers, family, concerned others from people's lives.

5. Harmful attitudes

- Services trust carers/family more than consumers

Mental health services trust carers/nominated persons more than consumers and will therefore give more information to gain support from NPs

- Carers trust services more than consumers

I don't have a 'carer' and don't want one I can't trust my family to make treatment decisions because they're too easily influenced by the doctors and they don't realize how much compulsory treatment hurts me.

Survey respondents also made comments about carers, nominated persons & rights

1. Some respondents had a clear understanding of the difference between nominated persons and carers:

My AS [advance statement] and my [nominated] person are my voice to express my preferred treatments when I am unable to do so. My carer will also be expressing my views about treatment (increasing the odds my views will be respected one hopes)

.... they [nominated person] can be anyone and they have a say in my treatment. They don't have to be a family member or partner. The latter only have limited rights, whereas the nominated person can have a say in how I'm treated.

I'd hope that a nominated person has a larger role than another carer in being involved in someone's treatment.

2. Some respondents only had a partially correct understanding:

I suppose carers and nominated persons have very similar rights and role under the Mental Health Act, the difference being nominated persons would automatically be granted this, whereas it would need to be assessed if a carer is definitely someone's carer as defined under the Mental Health Act.

- Neither carers nor nominated persons have rights under Act, although they both have recognised roles
- The Act requires that an authorised psychiatrist must determine if it is relevant to involve or inform a carer, whereas this limitation does not exist for nominated persons.

b. Themed consumer views about poor clinician attitudes and service culture

Fifty-four percent of all respondents (n=27) commented on poor attitudes of clinicians or service culture, totalling 43 separate comments across multiple question categories. Poor attitudes and culture were attributed as barriers to people setting up advance statements and nominated persons, and in them being successfully used in practice.

These comments represent serious concerns about safety and quality that reach beyond advance statements and nominated persons. Themes of comments are outline in the chart below, and individual comments are included in the following table.



Themes	Respondent comments (grouped by theme)
They don't care about us	<p><i>I feel sad thinking about this. Some clinicians actually rolled their eyes when I asked them to read my advance directive.</i></p> <ul style="list-style-type: none"> The doctors and hospitals, they don't care what you want they just do whatever they like. Not all staff read them or take them seriously, so don't hope for respectful care. In my experience many staff don't care to consider a patient's treatment preferences. Case managers and consultants don't consider them important enough because there is no KPI and the department doesn't set targets or audit the number of consumers offered to complete an advance statement. It's a consumer document, not a clinical document so services don't care

	<ul style="list-style-type: none"> • Unsure how seriously services take them. Not sure if they're even read to be honest • They could help to make sure you only get the treatment you want BUT only if you've got doctors with principles and kind hearts (I haven't met them yet but I guess there must be some out there) and only if you have someone you trust who will always be true to your wishes. • Concerns that they may not be valued by hospitals. • Feeling a lack of trust towards the honouring of an advance statement. • People need to realise that they don't have to agree with the person's AS to respect their wishes.
They don't listen, they ignore us	<p><i>Can't trust the doctors to pay any attention to us, they always think they're right</i></p> <ul style="list-style-type: none"> • I don't believe my thoughts on preferred treatment will be properly listened to • The routine and casual disregard of both by the clinical staff in psych facility. If on the small chance your statement is even looked at, it's unlikely to be followed • They are ignored during inpatient treatment • Hospital staff who think they know better • It wouldn't protect my human rights because my doctor can just ignore it if he wants to, and I think he would. • To get the doctor to listen to what I want instead of my mum. • Services actually taking them into consideration (e.g.. asking for one or reading what's provided) • I think most people think there's no point in having an advance statement if it's just going to be ignored • Them being listened too by mental health professionals. Especially if the person nominated isn't a strong willed person who has the mental health professional walk all over them. • Lack of mental health system interest. • They are not legally binding, the doctors can still do whatever they like • the hospital will just ignore it anyway
They are coercive, judgemental, traumatising	<p><i>People don't want to face the reality of treatment that is so often coercive, unnecessary, not conducive to good outcomes, in other words people most likely just want to get the hell out of hospital and never see one again.</i></p> <ul style="list-style-type: none"> • I have no intention to ever use public services. Too traumatic. Why subject myself to something that is knowingly iatrogenic? I'd rather deal with my mental health in isolation than be treated with disdain and ignorance by so-called mental health professionals. • I don't trust the doctors at my hospital for one second. There's no way they would do what I'd ask in an advance statement! They

	<p>just want to shoot me up with pills, treat me like I'm subhuman, and chuck me out the door for the next poor soul.</p> <ul style="list-style-type: none"> • a trauma based, rights deficient, coercive, medical focussed, pharmaceutical based institutionalised system that causes more trauma and longer recovery. Why would anyone want to face that reality by putting in place a person and a document that may or may not alleviate trauma psychiatric hospitals generate purely by the way they deal with patients? • Being seen as trouble
They keep us ignorant	<p><i>Don't leave it to the hospital they don't want us to know</i></p> <ul style="list-style-type: none"> • I found that none of the clinicians were giving me this information, even though I had complained about my treatment. It is almost like the clinicians fear that the patient would know how to navigate their way around this. • Hospitals, especially hospitals should be proactive in informing consumers about their rights. • Psych services rarely advise that you can make an advance statement. I think they just see it as extra work.
They lack knowledge and due diligence	<p><i>I asked my case manager to sign it and she wouldn't because she didn't know what it was for</i></p> <ul style="list-style-type: none"> • They couldn't find it, although I gave a copy to my case manager and to the nurse in ED • It varied as to whether staff looking after me read my advance directive - I would say maybe 1 in 5 did. • My psychiatrist has not mentioned it (I've been seeing him since 2013) so I assume it's unimportant. • Lack of knowledge, understanding and validation by health services regarding their existence, how they work, how to create one or implement one. No-one seems to know of them. • Services lack of 'real' understanding of them • To prevent staff at psychiatric facilities from being negligent, mostly due to the stigma of mental illness • The treating clinician's failure to observe what is in an advanced statement.
Not accountable, they can do whatever they want	<p><i>The treating team only has to look at it, they can decide to do as they please and simply say 'we thought a, b and c was more important than what is written'.</i></p> <ul style="list-style-type: none"> • It can also hold treating professionals to account, at least hypothetically, and therefore serve to highlight abuses of power, or discrepancies between what a person has opted in terms of treatment, versus what they've been prescribed. • Services don't comply with the regulations and complaints commission fails to enforce patients' rights in this regard

SURVEY LIMITATIONS AND FUTURE RESEARCH

Sample size and selection

The survey had a reasonable sample size of 50 consumers. The total population of consumers is somewhat difficult to estimate given limited public data, however we have used the following data to evaluate our sample size.

Estimated total clinical mental health (MH) consumers since new MH Act 2014

Acute admitted MH patients (adult)	Total separations	New patients (%)	New patients (n)	Returning patients	All patients since Jul 2014 (est. running total)
Consumers 2014/15*#	21,886	36.30%	7,945	13,941	21,886
Consumers 2015/16*#	23,665	35.70%	8,448	15,217	30,334
Consumers 2016/17*#	24,314	36.60%	8,899	15,415	39,233
Consumers 2017/18**	24,981	36.20%	9,043	15,938	48,276

Estimated prevalence of advance statements and nominated persons (adult)

Consumers who have an advance statement recorded	Total (%)	Estimated total (n)
Consumers 2014/15*	1.39%	304
Consumers 2015/16*	2.02%	478
Consumers 2016/17*	2.34%	569
Consumers 2017/18**	2.71%	677

Consumers who have a nominated person recorded	Total (%)	Estimated total (n)
Consumers 2014/15*	1.41%	309
Consumers 2015/16*	1.90%	450
Consumers 2016/17*	2.43%	591
Consumers 2017/18**	3.11%	776

* Source: DHHS. (2017). *Victoria's Mental Health Services Annual Report*

** Estimate, using the same percentage increase as the previous year

*# Estimate, based on DHHS annual report. Total number of inpatients is not reported by DHHS, so we used 'separations' as an indicator. In reality, the total number of inpatients will be smaller once multiple admissions are accounted for.

Survey sample size compared to total adult consumer population

Assumption: survey respondents were users of adult services

Sample VS population	Survey sample size (n)	Est. total acute consumers (n)	% of total consumers
No. of consumers	50	48,276	0.1%
Consumers with an advance statement	15	677	2.2%
Consumers with a nominated person	15	776	1.9%

We note that the survey did not take a random sample and so we cannot speak to the representativeness of the results. It is possible that consumers who are more likely to access VMIAC communications methods (email and social media) are also consumers who have been in greater need of advocacy, and therefore may have a bias towards dissatisfaction. However, we also note

that rates of compulsory treatment and restrictive interventions are high in Victoria, suggesting that dissatisfaction with services is likely to be a common experience.

Demographic and service use data

The survey did not collect demographic or service use data. This may be useful in future research to determine sample representativeness and to narrow down whether issues are correlated with any individual, group or service factors.

Categories

The survey used a large number of open comments fields, particularly because many factors were unknown. This created significant work in thematic analysis of results, however it also provided rich data.

The resultant themes identified from these comments may be useful in streamlining data collection in future surveys.

Categories for nominated persons

We acknowledge that the nominated person relationship categories provided in this survey are not as clear as they could be. For example, some people may have included a partner or spouse under the 'carer or family' category but others recorded this relationship under the 'other' category. Further, a carer is not necessarily a family member and vice versa, and so it is not advisable to combine these factors in future research.

Comments by respondents indicated that carer-consumer relationships are complex, and can vary from extremely supportive and valued to extremely conflicted, particularly when (a) carers value or preference mental health treatments differently than consumers, and (b) when there has been violence or abuse within the family.

For future research we recommend:

- a. That an initial question is asked to establish whether or not there is a carer relationship for the consumer. For example:

Question: Do you have a carer in relation to your mental health?*

**Explanatory note: A carer is someone you are in a personal relationship with, who provides you with ongoing support, assistance or personal care in relation to your mental health. You do not have to live with someone for them to be your carer. (based on Carer Recognition Act)*

- b. That more accurate and detailed categories for types of nominated person are used, such as those shown below:
 - Family member (parent, sibling, child, grandparent, etc.)
 - Partner or spouse
 - Friend (not a consumer)
 - Another consumer
 - Consumer worker (peer worker, advocate, consumer consultant)
 - Community or cultural elder

- *Professional advocate (advocate, lawyer)*
- *Health professional (e.g., private psychiatrist, GP, therapist)*
- *Other (please specify)*
- *I don't know anyone I trust*
- *I'm not sure / I haven't decided*

A second-tier response should be included in relation to the carer role:

- Please indicate if the person you selected above is also your carer

We understand that partner/spouse is often automatically included within 'family', however some consumers showed a preference for having a different category which we believe should be respected.

Future research questions

1. Future research may wish to validate the findings of this survey, possibly with a larger or random sample.
2. More than half of the respondents in this survey indicated serious mistrust in clinician attitudes and service culture. There were many comments indicating that consumers felt that services don't care about them or what they want, that requests are ignored, and that some people find services more harmful than helpful. These issues are serious and warrant further exploration in future research. They may also indicate a need for researching clinicians' actual attitudes and culture – as perceived by themselves and others, or for research into accountability and expectations of clinicians in relation to respectful listening and upholding of rights.
3. There was a low proportion of survey respondents who had actually been in hospital and tried to use an advance statement or nominated person. Most of these respondents were dissatisfied with services for not upholding their requests. This survey did not draw out specific details of the content of advance statements, or the content or processes used by nominated persons. There may be value in future research examining actual advance statements or nominated person relationships in more detail, including analysis of why the consumer made the relevant requests, and analysis of how clinicians respond to those requests, and identifying whether different types of advance requests are more likely to be respected than others.
4. The experience of nominated person may also be worthy of future research, particularly exploring why they accepted the role, how they experienced the role, challenges and opportunities, and what may be helpful.

ATTACHMENT ONE: SURVEY QUESTIONS

Survey introduction text

About the survey: VMIAC is conducting this survey on behalf of the Department of Health and Human Services, as part of a project aiming to improve two of the consumer protections in the Mental Health Act (2014): advance statements and nominated persons.

The Mental Health Act has been in place since 2014, yet only about 2% of all people admitted to mental health hospital units have an advance statement or a nominated person.

This survey will provide important information to help the department improve consumer rights.

Who can complete the survey? The survey is open to any person who has been admitted to a mental health hospital service in Victoria. You don't need to have had an advance statement or nominated person to complete the survey - we are interested in the views of all consumers.

Other important information. All responses are anonymous. The survey takes 12-15 minutes to complete, on average. Your feedback is important, and we thank you for your time.

Survey questions

QUESTION	OPTIONS	COMMENTS
PART 1: ADVANCE STATEMENTS		
1. I've heard of advance statements.	Yes, No	N
2. I'm confident that I understand what an advance statement is.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
3. It's difficult to find information about advance statements.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
4. Information about advance statements is routinely provided by mental health services.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
5. I have an advance statement.	Yes, No	N
IF YES		
6. It was easy to set up my advance statement.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
7. If you've been admitted to hospital since having your advance statement, did the hospital uphold the requests in your statement?	Strongly agree, agree, not sure, disagree, strongly disagree	Y
8. Would you recommend having an advance statement to other consumers?	Strongly agree, agree, not sure, disagree, strongly disagree	Y
IF NO		
9. I don't have an advance statement because (please select all that apply):	I didn't know about them, I don't know how to get one, it's too hard, I don't think it will be helpful, I don't think I need one, I'm planning to get one in the future, I'm not sure, Other reasons (please specify)	Please specify

ALL		
10. Please tell us how strongly you believe each of these comments about advance statements:	Strongly agree, agree, not sure, disagree, strongly disagree	Y
<ul style="list-style-type: none"> An advance statement would improve communication between me and staff. I am not confident that a hospital would respect and uphold an advance statement. It's my right to have an advance statement An advance statement will protect my human rights 		
PART 2: NOMINATED PERSONS		
11. I've heard of nominated persons.	Yes, not sure, no	N
12. I'm confident that I understand what a 'nominated person' is.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
13. It's difficult to find information about nominated persons.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
14. Information about nominated persons is routinely provided by mental health services.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
15. I understand the difference between a 'nominated person', a 'carer/family member' and 'next of kin'.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
16. I have a nominated person.	Yes, no	N
IF YES		
17. Please tell us your relationship to your nominated person:	Carer or family member, Friend, Support worker, Advocate, Lawyer, Other	Please specify
18. It was easy to set up my nominated person.	Strongly agree, agree, not sure, disagree, strongly disagree	Y
19. If you've been admitted to hospital since having your nominated person, please tell us what happened:	Strongly agree, agree, not sure, disagree, strongly disagree	Y
<ul style="list-style-type: none"> My nominated person supported me The hospital gave my nominated person relevant information My nominated person represented my interests appropriately The hospital consulted with my nominated person about my treatment My nominated person helped me to exercise my rights The hospital did what my nominated person asked Having a nominated person improved my experience of being in hospital 		
20. Would you recommend having a nominated person to other consumers?	Strongly agree, agree, not sure, disagree, strongly disagree	Y
IF NO		
21. I don't have a nominated person because (please select all that apply):	I didn't know about them, I don't know how to get one, it's too hard, I don't think it will be helpful, I don't think I need one, I'm planning to get one in the future, I'm not sure, Other reasons (please specify)	Other please specify
22. If I did get a nominated person, I would probably select a:	Carer or family member, Friend, Support worker, Advocate, Lawyer, Not sure, Other (please specify)	Other (please specify)

ALL RESPONSES		
<p>23. Please tell us how strongly you believe each of these comments about advance statements:</p> <ul style="list-style-type: none"> • A nominated person would improve communication between me and staff. • I am not confident that a hospital would respect and involve a nominated person. • It's my right to have a nominated person • A nominated person will protect my human rights • I know someone I would trust to be my nominated person 	Strongly agree, agree, not sure, disagree, strongly disagree	Y
24. What do you think are the most important benefits of having an advance statement and/or a nominated person?	Open text field	
25. What do you think are the main barriers to people having an advance statement or a nominated person?	Open text field	
26. What are the best ways to let more consumers know about advance statements and nominated persons:	Open text field	
27. Please tell us any other feedback you might have about advance statements and nominated persons:	Open text field	

End of survey.

ATTACHMENT TWO: ADDRESSING INFORMATION GAPS

Throughout the survey, respondents provided information about uncertainties or concerns.

This section aims to provide some practical, consumer perspective responses to expressed concerns, for consideration in developing helpful resources about advance statements and nominated persons. It is based not just on the survey results, but also on our experience as a consumer perspective advocacy organisation.

Information for consumers

This section outlines the kinds of questions and information that may be useful to provide in **future resources**.

1. *Should I have one?* Purpose of advance statements and nominated persons
 - For example: protection of rights, support to make own decisions and avoid compulsory treatment, to minimise harms from compulsory treatment, to promote self-directed recovery
 - We advise that it's important not to over-state the benefits of an advance statement, and be upfront that they are different to advance statement. They increase the likelihood of having one's will and preferences upheld, but they cannot guarantee it.
 - One respondent said advance statements are 'like an insurance policy'. This might be a useful way to encourage uptake. Just like insurance, you hope you never have to use it, but it's there to protect you just in case.
 - Who can have one? Include age requirements.
2. Benefits of having them (draw on comments by consumers in this survey)
3. Challenges in having them
 - Advance statements and nominated persons don't guarantee that your preferences will be followed, but they make it more likely this will happen. An advance statement is not like a medical directive, that is, the service is not required to uphold your wishes. However, the service is required to consider your wishes, and to have good reasons if they don't follow them. They may also help at the Mental Health Tribunal. Provide examples.
 - Setting up an advance statement or nominated person can have some emotional challenges. Draw on examples provided in this survey, and present options for addressing these.
 - Administration and effort in setting them up. Be clear about how much work is involved to set them up. A list of steps and information sources would be useful.
 - Changing your mind. Explain how people can withdraw or change an advance statement or nominated person, including during a hospital admission.
4. Practical steps for how to set up an advance statement or nominated person:
 - Develop a range of templates. From this survey it appears that people have differing needs.
 - Template versions might include a very basic version and a more complex version. There may also be versions for people with different clusters of needs or concerns.
 - There may be value in developing a version which has fields included for the full range of areas that consumers want to identify in advance (see tips in the [VMIAC guide to advance statements](#)) – for some people this may eliminate having to think through all the ideas, and simply add a short comment against each item.

- Templates should be provided in standard English, easy English and in language translations
 - Be clear that use of a template is not required – and give minimum requirements to include if developing your own version
 - Templates should be distributed with an accompanying guide, including the kinds of information outlined in this section. The guide should also be made available in standard English, easy English and in language translations
- Provide ideas for what to include in advance statements. The VMIAC guide to advance statements include a comprehensive list of tips and ideas which can be referenced. An additional consideration is to include what helps people to feel sexually safe while in hospital.
- Selecting a nominated person
 - Who to select: Discuss different types of people that could be chosen, and some of the pros and cons.
 - Talking it over: Recommend that people meet and talk with a potential nominated person before making a decision. Tell consumers about information packs to share with potential nominated persons. Recommend having discussions to build confidence that the person will genuinely represent the consumer's interests above all else, and explore potential conflicts of interest. Ensure the person feels comfortable and confident to take on the role.
- Witnessing: What must happen, who can do it, how to do it
- How to lodge with services
- Giving copies to trusted people
- 5. Consumer stories: Share several different consumer stories about having an advance statement and/or nominated person: how they did it, why they did it, benefits, issues, recommendations. Include positive and negative stories. Consumers value hearing honest examples of pros and cons, and this is consistent with principles of supported decision making.
- 6. Examples: Share some different examples of advance statements.

Information for nominated persons

Some respondents expressed concerns about whether their nominated person would genuinely represent what the person themselves wants from treatment and care. This is perhaps a more understandable conflict in some carer-consumer relationships, however it undermines the very intent of nominated persons.

Accordingly, it may be valuable to provide resources for nominated persons which:

- a. Explain the intent of the nominated person role, particularly that it is intended to protect the rights of the consumer, rather than any rights or wishes of the person acting in the role. It may be helpful to provide clear information about a person can provide their own views and concerns and what mechanisms exist for that.
- b. Provide information to help the person understand 'conflict of interest' and how to avoid it.
- c. Suggest that the person discuss any concerns about conflict of interest with the consumer, prior to accepting the role of nominated person. Provide conversation starters to have with the consumer, for example:

What if the hospital says...

- You're at risk of harming others?

- You're at risk of suicide?
- You don't understand?
- Your health is deteriorating?
- There is no less restrictive treatment?
- You're aggressive?

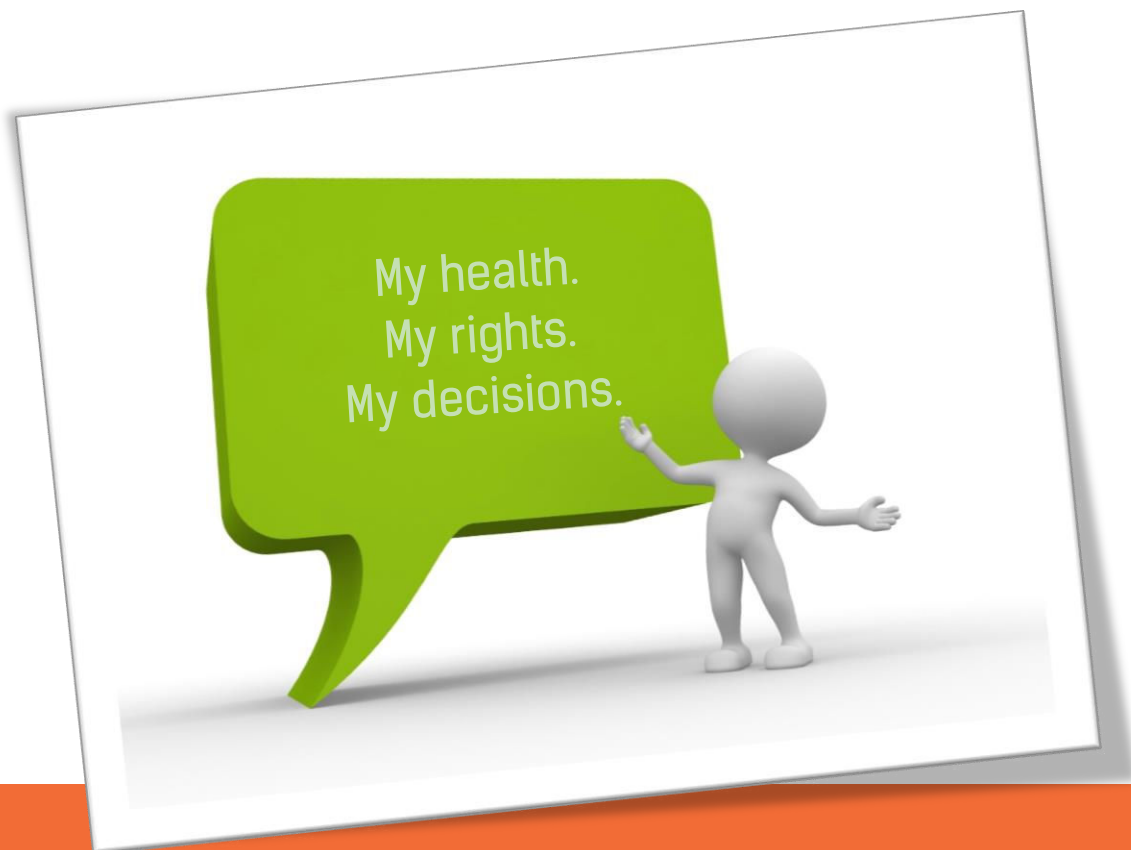
What if...

- You change your mind about what you want?
 - You do or say things you wouldn't normally do or say?
 - I feel scared?
- d. Sometimes a person's treatment wishes are related to personal values. If the nominated person prioritises different values, this can be a source of conflicting interests. For example, people's treatment wishes may vary considerably depending on whether freedom or safety is their higher priority. Provide a list of values for the nominated person and consumer to explore in conversation. These can help the nominated person to understand what matters most to the consumer in situations that may not have been discussed, for example:
- | | | |
|------------------|-----------------|-----------------|
| • Acceptance | • Freedom | • Relief |
| • Beliefs | • Friends | • Respect |
| • Body integrity | • Honesty | • Safety |
| • Choice | • Hope | • Sexuality |
| • Compassion | • Justice | • Sexual safety |
| • Confidence | • Kindness | • Spirituality |
| • Control | • Learning | • Strength |
| • Creativity | • Love | • Tranquillity |
| • Culture | • Power | • Trust |
| • Dignity | • Privacy | |
| • Family | • Relationships | |
- e. If the consumer has an advance statement, suggest the nominated person review that with the consumer to be sure that they understand the person's wishes, particularly:
- Treatments they definitely DO want, reasons why, and any exceptions
 - Treatments they definitely do NOT want, reasons why, and any exceptions
 - Treatments they will consider depending on the situation
 - What they need to feel safe, and what is frightening
 - What contributes to recovery and wellbeing, and what gets in the way

Suggest that if the nominated person has personal concerns about any of the consumer's wishes, that they explore these with the person until they feel confident that they can represent the person's wishes

Information for clinicians

The views expressed by respondents make it clear that there are gaps in clinical understanding of advance statements and nominated persons, and in how they respect and uphold them in practice. Accordingly, it is recommended that a guide be developed for clinicians which clearly outlines why these mechanisms matter and expectations of good clinical practice. Examples may be helpful. It would be ideal if this could be coproduced by a group of clinicians and consumers working together.



CONSUMER SURVEY

Advance Statements & Nominated Persons

