Supported decision-making under the Mental Health Act 2014: What consumers want

Consultation report

May 2016

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May 2016

Published by Independent Mental Health Advocacy, Victoria Legal Aid

IMHA acknowledges the support of the Victorian Government.



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# Executive summary

The project was undertaken to enhance Independent Mental Health Advocate’s (IMHA’s) understanding of consumers’ needs in the context of compulsory mental health treatment and what they want from an advocacy service. Consultation sessions were undertaken with consumers and focused on key elements of the *Mental Health Act 2014* (Vic), in particular on the change from substituted decision-making to a Supported Decision-Making model.

There were 49 participants in total across six consultation sessions run between February and March 2016, with four of the sessions targeting some of the IMHA priority groups (including young people, people experiencing homelessness, consumers from diverse cultural backgrounds and consumers receiving treatment in secure extended care units). In these sessions, there was a strong focus on consumers’ requirements from advocacy, and the tools, information and resources which may be utilised to build and support consumers’ abilities to exercise their decision-making capacity and to self-advocate.

The information gathered throughout the consultations identified common themes in decision-making when receiving compulsory treatment: supported decision-making under the Mental Health Act 2014, consumer requirements of an advocate, support to build consumer’s capacity to self-advocate and consumer information and resource preferences. The consultations have resulted in the following set of recommendations for IMHA:

1. Consumers identified the following priorities for information to support their decisions:
* IMHA advocates exploring consumers’ information preferences to enable the timely provision of suitable information in accessible formats.
* Ensuring that information about IMHA and people’s rights is provided using a range of methods, including a website that is accessible by smartphone or tablet with inclusion of audio and video guides and the development of a free telephone service with a voice recording to provide information.
1. Consumers identified the following requirements when being provided an advocate:
* Choice of an advocate based on requirements for gender, cultural competence, lived experience, or non-lived experience.
* Advocates who hold a certain set of personal qualities such as empathy, open mindedness, knowledge of consumer perspective and historical context of consumer recovery movement.
* An advocate who takes the time to build trusting relationships with consumers through ongoing presence in clinical settings.
* An advocate who is able to work with consumers to define, develop and work towards meaningful outcomes which meet the needs of the consumer in relation to their lived experience and recovery journey.
* An advocate who supports decision-making through collaboration with other key people whom the consumer chooses (i.e. nominated persons), to ensure that context of the consumer’s life experience can be accurately and collaboratively represented in decisions made.
1. Advocates working to build collaborative relationships with the consumer’s clinical treating team to understand the stance on the treatment of the consumer in order to build an effective strategy to work with the consumer towards their goals and preferences.
2. IMHA to ensure that advocates continue to build public awareness of the role and nature of the service to ensure that consumers know how to access advocacy, who the advocate is and availability of advocacy as soon as a person is placed on treatment orders i.e. using various database and support networks.
3. Advocates to work with consumers to build capacity to self-advocate through a range of activities including coaching or mentoring through role-plays, as well as the development of an advocacy plan to be utilised in meetings with clinicians or others.
4. IMHA developing comprehensive guide to advance statements and supporting consumers through the process of developing an advance statement and how to use advance statements.

IMHA will use the consultations to inform a range of activities including the development of a plan to produce self-advocacy resources, with input from a range of key stakeholders, including Victoria Legal Aid’s (VLA’s) Speaking from Experience group, the IMHA Reference Group, and VMIAC.

# Purpose, aims and scope

The purpose of the consultation project was to understand what consumers want from an advocacy service and what resources, information and tools they require to make decisions about their treatment and recovery as well as to self-advocate.

The aim of the consultation project was to:

* produce evidence for what resources IMHA should develop to help inform people of their rights under the *Mental Health Act 2014*
* scope the need for further training and professional development for IMHA advocates based on consumers’ requirements for advocacy and self-advocacy
* produce information about how consumers of different community groups can build their capacity to self-advocate.

Consistent with the focus of IMHA on providing services to people subject to compulsory treatment, the scopeof the consultations involved speaking with people who have a lived experience of compulsory treatment and those who identified as being part of the IMHA priority groups (as set out in [Appendix A](#_Appendix_A:_IMHA)).

Areas of mental health that are not covered by the *Mental Health Act 2014* were not within scope. These areas include non-coercive, voluntary mental health support and treatment, or mental health/other support service-types that are voluntary in nature.

# IMHA background

The *Mental Health Act 2014*, which commenced on 1 July 2014, seeks to ensure consumers receiving compulsory mental health treatment are supported to make, or participate in, decisions about their assessment, treatment and recovery. [Advocacy](#_Appendix_B:_Glossary) is a key mechanism to promote consumer supported decision-making.

IMHA commenced on 31 August 2015. IMHA’s vision is to support and promote the human rights of people subject to compulsory treatment. Its main function is to work with consumers, mental health services and the mental health system in order to embed supported decision-making and recovery orientated service delivery (as defined in [Appendix B](#_Appendix_B:_Glossary)).

IMHA provides a free, confidential and independent state-wide serviceto people receiving compulsory treatment and aims to support people to express their views and preferences regarding their assessment, treatment and recovery. The IMHA service provides people with information, coaching for self-advocacy, referral and advocacy, as well as community education. IMHA also participates in systemic advocacy activities that aim to promote and support the human rights of people subject to compulsory treatment.

The IMHA service model was developed in partnership with the IMHA Reference Group, which includes a wide range of stakeholders, including consumers. Under the IMHA service model, identified priority groups receive more intensive services, due to experiencing marginalisation, barriers to enacting their rights and those who are over-represented on compulsory treatment orders. A list of the IMHA priority groupstogether with more detailed IMHA background information is set out in [Appendix A](#_Appendix_A:_IMHA).

# Methodology

## Consultation process

Consultations with consumers was the primary methodology for the project. These consultations were predominantly held in group settings. The following provides an overview of the consultation process:

* Email, phone and face-to-face contact with mental health services and representative bodies to recruit people from various community groups. This process was undertaken over a four-month period.
* A total of six consultation sessions, in various venues including a meeting room located at Victoria Legal Aid, as well as some mental health services and community venues.
* Each consultation involved IMHA priority target groups (as detailed in [Appendix A](#_Appendix_A:_IMHA)).
* The consultation sessions ran for approximately two to three hours.
* Each session was facilitated by the seconded VMIAC Consumer Consultant, with scribe (to type or write responses), and a support person who could be utilised to clarify content, or offer support for participants, if there were concerns, difficulties, or distress experienced during the sessions.
* Participants were reimbursed for their time and travel.
* Participants were provided a demographic information form to submit, which did not require identifying information. Due to the personal nature of the questions, participants were provided the option to leave questions blank, or otherwise to not submit the form if they did not wish to.
* Participants were also provided an information statement about the consultation session and their rights in participating. This was accompanied by a consent form to be signed for participation (Please refer to [Appendix C](#_Appendix_C:Informed_consent)).

## Key consultation questions

Each session covered three key areas: (i) supported decision-making, (ii) advocacy and self-advocacy, and (iii) information requirements. The key consultation questions covered were:

1. What makes it difficult to make decisions when you have been on compulsory treatment?
2. What makes it easier to make decisions?
3. What are some circumstances when you have been involuntary, or on compulsory treatment where you needed an advocate?
4. What would you need from an advocate/advocacy in the circumstances?
5. What would help you to self-advocate in the context of compulsory/involuntary treatment?
6. How have you received information about your rights in the past? What made it helpful, or unhelpful?
7. What type of information is best for you?
8. What information would you like from IMHA?

## Limitations

There was some difficulty in gaining participation from various IMHA priority areas such as those of Aboriginal and/or Torres Strait Island descent, people requiring communication assistance i.e. interpreter and people who identify as having dual disability diagnoses. This was despite numerous attempts to recruit from these communities.

The information gathered and developed represents the perspectives and specific requirements of the participants who attended the sessions, but may not reflect those of broader consumer communities in Victoria.

# Findings

## Participants

There were 49 participants in total, across six consultation sessions. Not all participants completed demographic and background information. Of the participants who completed the demographic and background form, twenty were male and twenty-five were female. Four people reported they were LGBTI. Participants were aged between nineteen and eighty-two years old. Over half the participants were from regional areas (n=29) with the remaining from metropolitan Melbourne (n=18). The majority of people identified as Australian (n=40), there was one person who identified as Aboriginal and six people who reported being from a culturally and linguistically diverse background. Finally, twenty-five participants had experienced restrictive interventions and six had been subject to ECT.

The six consultation sessions were run with representation from the following groups:

* 1. General group – consumers invited not based on whether they fit IMHA priority groups
	2. Regional group – Maine Connection
	3. Younger persons group – consumers recruited from Orygen youth mental health service
	4. Homeless group – consumers recruited from Launch Housing
	5. CALD group – consumers who identified as being from diverse cultural backgrounds
	6. SECU group – consumers who were receiving treatment and residing in a Secure Extended Care Unit.

## Themes identified through consultations

The following were the key areas identified by participants and themes:

* Common decision-making difficulties – covering the themes of power differentials; lack of information and education; and impact of circumstances and environment.
* Making decision-making easier – covering the themes of information provision; support from independent people to make decisions; collaboration, continuity and support linkages; and structures and tools to build capacity to make decisions.
* Advocacy requirements – covering the themes of personal qualities of an advocate; determining meaningful outcomes; providing information; and building relationships to understand consumers.
* What consumers need to self-advocate – covering the themes of having access to the right information; building skills, knowledge and capacity; helpful tools and techniques; and knowledge of treating team.
* Suggestions for IMHA to build information and resources for consumers – covering the themes of IMHA raising public awareness; continued availability and presence of advocacy support; information that is user friendly/reader friendly; verbal information; content of information and IMHA postcard critiques.

Within each of the above key areas and themes there were sub themes identified and these are detailed in [Appendix D](#_Appendix_D:_Common).

# Discussion

## Common difficulties in decision-making when on treatment orders

For consumers, there are several aspects of compulsory treatment and clinical mental health environments that create difficulty or hinder the decision-making process. Consumers throughout all of the consultation sessions discussed the difficulty imposed by power imbalances within clinical settings. More specifically, consumers identified that their decisions were often ignored or not listened to, and made by clinical mental health staff who may enforce conditions (i.e. mental health treatment preferences) upon them. Often, consumers’ decision-making difficulties were a result of not being included, or involved in meetings about their assessment and treatment, which is a resemblance of the power differentials surrounding the circumstances of compulsory treatment.

Other people making decisions for you – things are already determined before you have even been asked.

(Consumer)

Another aspect that often reinforces the power imbalance and lack of control over decisions is the way consumers often feel due to the treatment they receive from clinical mental health staff; feeling judged, coerced, or fearful of punishment are common experiences for consumers undergoing compulsory treatment in clinical mental health settings.

Throughout the consultation sessions, consumers also raised the difficulty of not receiving informationto support and inform their decisions. Consumers identified difficulties due to a lack of specific information about their rights and treatment orders. In addition, for consumers experiencing mental health treatment in a secure extended care unit (SECU), not knowing how to access an advocate was identified as a further barrier.

Also in relation to information, services not having enough and/or accurate information about the consumer, was revealed as a further obstacle to consumers feeling understood and supported by clinical services in making decisions.

Consumers identified clinical mental health circumstances and environments as being a further hindrance to decision-making. Consumers throughout nearly all of the sessions described clinical inpatient environments as often being ‘scary’, or ‘intimidating’ places, which felt ‘unsafe’.

In addition to the inpatient environment, consumers identified their personal circumstances as being an additional limitation to their decision-making. Common experiences of being cognitively impaired due to medication, as well as being emotionally distressed due to being in crisis or in other difficult circumstances (i.e. unstable housing) created further difficulty in decision-making.

Other common circumstances such as guardianship (see definition in [Appendix B](#_Appendix_B:_Glossary)), experiencing aggression from others and problems associated with not being allowed to smoke in inpatient settings also created further difficulty to consumers’ decision-making.

## Supporting decision-making under the Mental Health Act

The findings through the consultation sessions identify several key areas which would help support decision-making in the *Mental Health Act 2014*.

Provision of information in consumer-friendly language and suitable formats is an essential part of enabling consumers to be informed of their rights and their options (i.e. treatment and other decisions) in the context of compulsory treatment. Consumers require useful and timely information to ensure that it is applicable to the immediacy and specific nature of their circumstances. Of particular importance is ensuring that information is provided in suitable community languages to support decision-making.

Consumers identified having support from others as a key part of supporting decision-making. Specifically, consumers spoke of being able to trust those who can support decision-making and honesty, empathy and listening skills as part of building a relationship to support decision-making.
In addition, there was a requirement for the person to be independent and acknowledge the expertise of one’s own lived experience.

Collaboration between people involved in different areas of a person’s life was identified as being a key part of supporting consumers’ decision-making. Ensuring that consumers are well informed about the individual’s life and continuity in relationships throughout consumers’ lives were seen as key in supporting decision-making

Consumers spoke of the important role of supportive structures and tools to support their decision-making capacity. Specifically, feeling safe in a non-coercive environment was an important part of supporting decision-making. Further, consumers identified the requirement for an advocate who is able to provide emotional support to assist a logical decision-making process. Decisions could also be supported through the development of advance statements.

Information about options, steps you can take to speak up about your situation.

(Consumer)

## Consumers’ requirements of an advocate

Consumers identified various qualities, perspectives and expertise as fundamental to constructing an effective relationship where trust is built on the advocate’s ability to present the consumer’s preferences and views.

Personal qualities such as empathy, non-judgemental and someone who can relate as ‘a friend or peer’ were a priority for consumers. In addition, consumers identified the importance of being able to choose an advocate who is a good match, gender wise and a willingness to understand the consumer’s cultural background. Other personal qualities such as passion, strength and determination were also important to consumers.

Consumers prioritised the need for an advocate who is skilled in assisting the interpretation and identification of outcomes and goals, which are meaningful to the consumer. Some consumers also outlined the preference for an advocate who is also a consumer, to enable shared understandings through experiences of common threads such as stigma, discrimination and individual recovery journeys. Consumers also spoke of the need for an advocate who provides clear information in a suitable way that allows an understanding of options. Consumers require an advocate who takes the time to build effective relationships with them by being regularly available through ongoing presence in clinical settings.

The advocate needs enough time to build a relationship prior to a meeting – time to find out about the consumer’s perspective and walk consumer through options.

(Consumer)

## Helping consumers build the capacity to self-advocate

Several of the groups identified that information was a key part of building consumers’ capacity to self-advocate. Consumers spoke of the necessity in being able to access information to support them to understand and seek to rely on their human rights and to support their decisions on treatment. Consumers identified the preference for verbal information provided by an advocate to support the ability to self-advocate.

Consumers raised the importance of building skills, knowledge and capacity to self-advocate through encouragement and support from an advocate. Through encouragement and reassurance from an advocate, consumers may increase their confidence and self-esteem, which would also help build the capacity to self-advocate. Self-advocacy training and education were also seen as important. Specific tools and techniques should be used to support self-advocacy including coaching, role-play, and development of a plan.

Consumers may also need an advocate to support the development of an advance statement that can be utilised as a tool to communicate their wishes in difficult circumstances. Knowledge of the treating team and their stance on the treatment of the person may also provide consumers a realistic picture of the boundaries and opposing positions as a guide to consumers developing a strong argument for their own rights.

## Consumers’ information and resource preferences

Throughout the consultation sessions, consumers identified the necessity for IMHA to promote the service and therefore make it more accessible to consumers throughout Victoria. Consumers suggested information about IMHA be displayed in public locations and support service listings, i.e. the Melbourne City Council smartphone application for people experiencing homelessness ([www.askizzy.org.au](file:///C%3A%5CUsers%5Cma8116%5CAppData%5CRoaming%5CMicrosoft%5CWord%5Cwww.askizzy.org.au)). Consumers also wanted to know how to contact an advocate and when an advocate would be available at an inpatient unit.

Consumers throughout the consultation sessions prioritised user-friendly information as a requirement. Several consumer groups discussed the need for easy to understand information in plain language, while some also identified the requirement for culturally specific information.
One group identified the preference for use of whole words rather than abbreviations.

In addition, consumers identified several key preferences for:

* information that is readily accessible (i.e. a fold out wallet-sized card, or a fridge magnet), with recognisable graphics and catchy designs
* online websites and applications that are smartphone friendly, which may include audio/or video guides
* the need for an information/orientation pack about IMHA and how to access an advocate, and consumers’ human rights in the Mental Health Act.

Throughout various consultation sessions, consumers raised the preference for verbal information to support ease of understanding when other types of information may be difficult to comprehend. An independent person such as an advocate would be preferred in explaining information through meeting with the consumer, or over the telephone. Consumers in some groups also spoke of the value in having access to information through a phone voice recording.

Consumers in several groups identified the importance of receiving information about the specific roles and functions of crisis and support services. Consumers also wanted more information about IMHA such as the differentiation between IMHA and VLA. Consumers also deemed it important for IMHA to ensure there is provision of clear information about IMHA’s accessibility and it being a free service.

Consumers also spoke of the need for specific information about advance statements including the purpose, duration, as well as when and how to make an advance statement so that it is most effective. Consumers also requested more specific information about how nominated persons may represent their interests.

# Conclusion

Throughout the consultation project, consumers identified a number of key areas which may be acted upon by IMHA to support people receiving compulsory treatment to express their views and preferences.

The context of being on compulsory treatment under the Mental Health Act 2014 raised the theme of power differentials and common consumer experiences of disempowerment due to circumstances in clinical mental health settings in Victoria.

The power imbalances associated with compulsory treatment may be somewhat addressed through the development of tools and resources to be utilised in supporting consumers’ decision-making capacity in clinical settings.

The way advocates work to support consumers to make decisions and express their views and preferences, may be informed by the recommendations made about advocate personal qualities; experience; approach to building relationships and working with people; location in services; and training. The development of these requirements may foster an advocate-consumer relationship that is an enabler to supporting and encouraging self-advocacy.

IMHA will develop an implementation plan in consultation with a range of key stakeholders and groups, including VLA’s Speaking from Experience group, the IMHA Reference Group and VMIAC.

# Appendix A: IMHA background and IMHA priority groups

The *Mental Health Act 2014*, which commenced on 1 July 2014, seeks to ensure consumers receiving compulsory mental health treatment are supported to make, or participate in, decisions about their assessment, treatment and recovery. Importantly, the legislation introduced the Mental Health Principles which provide, in part, for:

* mental health services being delivered in the least restrictive way possible and promoting recovery and full participation in community life
* consumer supported and participatory decision-making regarding assessment, treatment and recovery, which decisions may involve a degree of risk
* respecting and promoting consumers’ rights, dignity and autonomy and responding to individual needs (whether as to culture, language, communication, age, disability, religion, gender, sexuality or other matters).

Advocacy is a key mechanism to promote consumer supported and participatory decision-making. In November 2014, DHHS announced that Victoria Legal Aid (VLA) had agreed to deliver the IMHA service – the first of its kind in Victoria and Australia.

VLA is a government-funded statutory authority that helps people with a range of civil, criminal and family law legal problems. The IMHA service goals align closely with VLA’s objectives to support people who are experiencing disadvantage, give early and timely help, ensure people know about their rights and options and support people if they need to access other services.

The IMHA non-legal service commenced on 31 August 2015. IMHA’s vision is to support and promote the human rights of people subject to compulsory treatment. Its main goal is to work with consumers, mental health services and the mental health system to embed supported decision-making and recovery orientated service delivery.

IMHA provides a free, confidential and independent service to people subject to compulsory treatment and aims to support people to express their views and preferences regarding their assessment, treatment and recovery. The IMHA service provides people with information, coaching for self-advocacy, referral and advocacy, as well as community education. IMHA also participates in strategic advocacy activities that aim to promote and support the human rights of people subject to compulsory treatment.

The IMHA state-wide program operates from four offices across Victoria, located in the Melbourne CBD, Dandenong, Geelong and Bendigo. IMHA services are delivered via phone and in person from outreach locations.

The IMHA service model was developed in partnership with the IMHA Reference Group, which includes consumer and other stakeholder representatives. Under this service model, identified priority groups receive more intensive advocacy and self-advocacy services, due to experiencing marginalisation, barriers to enacting their rights or being over-represented on compulsory treatment in clinical mental health settings.

The IMHA priority groups include:

* people who are subject to compulsory treatment for the first time
* Aboriginal and Torres Strait Islander people
* young people (under 18 years of age)
* older people (over 65 years of age)
* people requiring assistance with communication (e.g. culturally and linguistically diverse (CALD) people, people with a hearing or speech impairment)
* people experiencing homelessness, including:
	+ people without conventional accommodation (e.g. people living on the streets, sleeping in parks, squats, cars or makeshift dwellings for temporary shelter such as sheds or tents)
	+ people who move frequently between various forms of temporary shelter (e.g. friends or relatives, emergency accommodation or refuges, hostels and boarding houses on a short-term basis).
* people diagnosed with dual disabilities (e.g. mental illness and intellectual disability)
* people subject to bodily restraint or seclusion
* people receiving treatment in a secure extended care unit (SECU)
* people receiving electro-convulsive therapy (ECT)
* people who have been continuously subject to compulsory treatment, or subject to three or more treatment orders, over the last two or more years.

# Appendix B: Glossary of terms

**Advocacy** – the process of standing alongside an individual who is disadvantaged and speaking out on their behalf in a way that represents the best interests of that person.

**Advocates** – the professional staff who deliver IMHA services to IMHA clients.

**Compulsory mental health treatment** – mental health treatment subject to one of the following orders under the *Mental Health Act 2014* (either in a community-based setting or as an inpatient): an assessment order, a court assessment order, a temporary treatment order, or a treatment order.

**Consumer** – anyone who has received mental health services in the past, anyone who has a behavioral health diagnosis, or simply anyone who has experienced a mental or behavioral disorder.

The term was coined by people who use mental health services in an attempt to empower those with mental health issues, suggests that there is a reciprocal contract between those who provide a service and those who use a service and that individuals have a choice in their treatment.

**Consultation** – the action or process of formally consulting or discussing with others who may add value to the knowledge required and built into development of greater understanding of key topic area/s.

**Human rights** – in the context of the Mental Health Act 2014, is a set of guidelines and principles set out to define consumers’ rights in circumstances of compulsory mental health treatment.

**Legal guardianship** – a guardian is a person appointed to make personal lifestyle decisions for someone with a disability, who is unable to make these decisions themselves. A guardian may be authorised to make decisions relating to living arrangements, work arrangements, medical treatment and access to persons and services.

**Recovery** **and recovery oriented approaches** – recovery needs to be understood in a holistic way. The aim of a recovery-oriented approach to mental health service delivery is to support people to build and maintain a self-defined and self-determined meaningful and satisfying life and personal identity, regardless of whether or not there are ongoing symptoms of mental illness (Shepherd, Boardman and Slade 2008). Recovery is led by the individual and is based on consideration of their preferences, needs, experiences, aspirations and strengths. The approach emphasises self-management, personal growth, choice, hope, empowerment and social inclusion.

**Resources** – includes information and other tools to be developed for utilisation to support people in decision-making and building capacity in the context of the *Mental Health Act 2014*.

**Self-advocacy** – self-advocacy is when individuals speak up for themselves, make their own decisions about one’s own life, learn how to get information to understand things that are of interest, know of their rights and responsibilities, problem solve, listen and learn, reach out to others when seeking help and friendship, and learn about self-determination.

**Supported decision-making** – is a process in which people who need assistance with decision-making receive the help they need and want to understand the situations and choices they face, so they can make life decisions for themselves, without the need for decisions to be made by others.

**Treating team or clinical staff** – the staff employed by clinical mental health service to provide treatment and/or support to patients. May include clinical psychiatrists, clinical psychologists, mental health nurses, social workers and other/s.

# Appendix C: Informed consent and participant information sheet

## Participant information sheet

### Purpose of the consultation

To build the Independent Mental Health Advocacy’s (IMHA’s) knowledge of what consumers want from advocacy.

If you agree to take part in the consultation, we are going to ask you questions about your understanding and ideas about advocacy; your requirements for support, resources and information to best support the development of your capacity to self-advocate; and your ideas about supported decision-making. We will then use the transcription of your information in the development of a report with consumer informed recommendations for the IMHA service.

In addition to providing suggestions about what you want from advocacy, you may want to use examples for your personal experience. You do not need to share your personal lived experience but if you choose to this will be supported.

#### Why am I being consulted?

We want you to tell us about your experiences on compulsory inpatient/community treatment orders.

We will ask you some questions about your ideas of advocacy and self-advocacy.

#### How will the consultation be conducted?

If you would like to participate in the project, we will ask you to sign a consent form.

The consultation may be conducted in a group setting, or if you would prefer, in a private session. If it is not suitable for you to attend a consultation in person, provisions could be made for a written submission, however personal, group-consultation is preferable. Interviews conducted in person will be held at different community venues and may be at a venue of your choice, or the choice of your representative community group.

The consultation is expected to take approximately three hours, with a half-hour break for food and refreshments (to be provided by IMHA).

#### Who can attend the consultation?

You can have a friend, family member or other support person attend the consultation with you. IMHA will also provide another person of support during the consultation if any difficulties arise.

#### Who will conduct the consultation?

The interview will be conducted by a consumer consultant who has been contracted by IMHA. The consultant’s name is Daniel Van der Pluym and he is employed by the Victorian Mental Illness Awareness Council (VMIAC). Daniel can be contacted on Tuesday and Wednesday at IMHA on

(03) 9093 3715, or on Thursday morning at VMIAC on (03) 9380 3900.

#### Will you be paid?

Yes. We will pay you $40 for your contribution to the project in recognition of your expertise and time commitment. If there are extra costs for travel involved (such as travel from a regional/rural location), we will make suitable arrangements for further reimbursement.

#### Why you have been asked to take part in the interviews?

Rather than just getting information from the mental health hospitals or from our advocates, we felt it was important to hear feedback and comments from people who have experienced what it’s like to deal with the mental health system.

You have been selected as you have experience on involuntary/compulsory treatment in the clinical mental health system in Victoria.

#### Do you have to participate?

No. Your participation is voluntary, and you decide whether you would like to talk to us and answer our questions.

We understand if you choose not to continue and it will not affect any current or future advocacy services you can receive from IMHA. Likewise, it is important to note that your participation in this interview does not entitle you to special access to IMHA services.

#### Will you be identified by your feedback? (confidentiality)

We will not use your name. Your feedback will be anonymous and we try to ensure you are not identified.

It may not be possible to keep every element of your feedback confidential. To help make sure people will not know who has given us the information we may change your feedback, such as where you were born, where you live, where you work, your treating hospital and details of your diagnosis.

#### What will happen with your feedback?

Once completed, you will receive a summary of the information collected through the consultation.

Your feedback will be used in a report that provides IMHA with information about what people want from advocacy in clinical mental health settings in Victoria. This includes recommendations about the information or resources required for people to better support their rights in compulsory mental health treatment settings. Through understanding your ideas about supported decision-making, the report will guide what IMHA can do to support your capacity to stand up for your rights.

The information may also be used on our website, and when we talk to a range of different people and organisations. It may also be used in the future development of information, resources and staff training development.

#### What are the disadvantages of taking part in the interview?

Talking about difficult times in your life may bring up feelings and emotions you are not expecting.

In preparation for the interview, if you think you may like some support, it would be good to think about:

* whether a friend, family member, support person or someone from your treating team can also attend the interview to provide you with support
* whether you can phone a friend, family member or support person. If you may like to do this, it’s important to make sure you have their phone number available when you attend the interview.

IMHA will also provide a person of support as someone you can communicate any difficulties to, during, or after the consultation.

We will check on how you are feeling during the consultation. However, if you are starting to feel distressed, there are a number of options including:

* tell the interviewer/support person you would like a break
* tell the interviewer/support person you would like to stop the consultation
* relying on a support person in the interview at any stage, including the support person provided by IMHA, if you choose
* calling a support person at any stage
* calling a referral service such as Lifeline on 13 11 14.

#### How can you stop being involved?

You can stop participating in the interview, and withdraw your input and feedback at any stage including after you have signed the consent form, and at any point after the consultation has been finalised.

To withdraw your consent or discuss this, you can call:

* Manager of Independent Mental Health Advocacy, Helen Makregiorgos (03) 9093 3711
* Complaints and Statutory Compliance team, (03) 9280 3789.

#### If you withdraw, what happens to your information?

At any time after the interview you can request IMHA to stop using your feedback. We will make all reasonable efforts to remove your feedback from the report, or any other material and will not use your feedback in the future.

However, if your feedback was printed in material delivered to the community outside IMHA, we will be unable to remove it from publication or control how other people may use it.

Thank you for your participation in this project. We’re very lucky to be able to work with people willing to offer their time and personal insight to help us to improve our services.

## Consent form

To confirm your participation in the interview you need to agree to the terms of involvement by providing Independent Mental Health Advocacy (IMHA) with written consent. We will keep a record of this on our files and we will give you a copy for your own records.

I [insert name], give my consent to my participation in the consultation for the Independent Mental Health Advocacy (IMHA).

In giving my consent I acknowledge that:

1. The procedures required for the consultation and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.
2. I have had the Client Information Sheet explained to me and have been given the opportunity to discuss the information and my involvement in the project with the consultant.
3. I understand that I can withdraw from the interview and process at any time without affecting my relationship with the Independent Mental Health Advocacy, now or in the future.
4. I understand that my involvement and my feedback will be kept anonymous and no information about me will be used in a way that reveals my identity.
5. I understand that this consultation is completely voluntary, and I am not under any obligation to agree to participate.
6. I consent to this consultation being transcribed.
7. I understand that I can stop the consultation at any time if I do not wish to continue, the written information will be erased and the information provided will not be used in any way.

Signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

Date:

IMHA staff signature: \_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

IMHA staff name:

# Appendix D: Common decision-making difficulties

| **Common theme** | **Sub-theme** | **Groups who identified with theme****[[1]](#footnote-1)** |
| --- | --- | --- |
| Power differentials | Decisions made by others, not being listened to, or being ignored | G1, G2, G3, G4, G5, G6 |
| Power differentials | Not having meetings or being part of discussions about choices | G3, G5, G6 |
| Power differentials | Coercion | G2, G4 |
| Power differentials | Feeling judged by clinicians | G1 |
| Power differentials | Feeling punished for previous behaviour | G6 |
| Power differentials | Not being seen as adults by the treating team, being seen as ‘little brats’. | G3 |
| Lack of information and education[[2]](#footnote-2) | Not being told of rights, or provided information about treatment order | G1, G2, G3, G4 |
| Lack of information and education2 | Consumers not having control over information that services have on them and services not having information which is informed by consumer treatment preferences  | G2, G5 |
| Lack of information and education2 | Not knowing about advocates or how to access an advocate | G6 |
| Impact of circumstances and environment | Hospital environment – feeling unsafe, scary place, intimidating | G1, G3, G4, G5, G6 |
| Impact of circumstances and environment | Difficulty making decisions when in crisis and/or distressed  | G2, G3, G4 |
| Impact of circumstances and environment | Having a legal guardian controlling/overriding decisions | G6 |
| Impact of circumstances and environment | Medication – impairing cognitive function | G1 |
| Impact of circumstances and environment | Having a Mental Health Act which imposes compulsory treatment against consumer’s wishes | G1 |
| Impact of circumstances and environment | Cigarettes – shortage, expense and other people taking them | G6 |
| Impact of circumstances and environment | Aggression from other people | G6 |

## Making decision-making easier

| **Common themes** | **Sub-themes** | **Groups who identified with theme[[3]](#footnote-3)** |
| --- | --- | --- |
| Access to and provision of information | Being informed about conditions, options, choices and consequences at the right time | G2, G3, G4, G6 |
| Access to and provision of information | Information in the right language, at the right time | G1, G2 |
| Having support from the right people to make decisions | Personal qualities (trust, empathy, compassion, listening skills, honesty) | G1, G3, G4 |
| Having support from the right people to make decisions | Helpful support staff – understand working with different groups of people | G3, G4 |
| Having support from the right people to make decisions | A nominated person | G1, G2  |
| Having support from the right people to make decisions | An independent advocate, someone who is able to recognise that consumer is the expert in own life and decisions | G1 |
| Having support from the right people to make decisions | Having someone make decisions for consumer | G4 |
| Collaboration, continuity and support linkages | Continuity of support and people who know consumer | G1, G2 |
| Collaboration, continuity and support linkages | Service integration and information sharing | G2, G3, G5 |
| Collaboration, continuity and support linkages | Being linked with support | G2, G4 |
| Collaboration, continuity and support linkages | Being part of discussions about diagnosis, rather than just being ‘rubber stamped’ | G5 |
| Structure, tools and support to build capacity to make decisions | Feeling safe, having confidentiality, non-coercive environment | G1, G4, G5 |
| Structure, tools and support to build capacity to make decisions | Managing difficult emotions, being well enough to make decisions | G4, G5 |
| Structure, tools and support to build capacity to make decisions | Having a clear mind | G6 |
| Structure, tools and support to build capacity to make decisions | Being given a voice to have a say | G4 |
| Structure, tools and support to build capacity to make decisions | Having an advance statement developed when I am well | G5 |

## Advocacy requirements

| **Common themes** | **Sub-themes** | **Groups who identified with theme[[4]](#footnote-4)** |
| --- | --- | --- |
| Personal qualities of an advocate2 | Being reliable and available – having continued presence on wards | G1, G4, G5 |
| Personal qualities of an advocate2 | Non-judgemental, trustworthy, and empathic – someone understanding what consumers are experiencing, ‘a friend or peer’ | G2, G4, G5, G6 |
| Personal qualities of an advocate2 | Having an understanding of consumer experiences, through lived experience | G4, G5 |
| Personal qualities of an advocate2 | Passionate, strong, driven | G3, G4 |
| Personal qualities of an advocate2 | Being able to choose advocate who is good match including gender of advocate | G3, G5 |
| Personal qualities of an advocate2 | A good listener | G3 |
| Personal qualities of an advocate2 | Someone who can relate to consumer culturally | G5 |
| Personal qualities of an advocate2 | Someone who looks approachable so consumer feels advocate is an equal  | G6 |
| Determining meaningful outcomes | An advocate to interpret what consumer really wants and translating information into a plan | G1, G6 |
| Determining meaningful outcomes | Helping consumer remember goals during advocacy | G2 |
| Determining meaningful outcomes | Need to know who advocate is advocating for (consumer, or carer) | G5 |
| Providing information | Provide information in a way that consumer understands and telling consumer the options | G1, G3, G4 |
| Providing information | Advocate allowing consumer the freedom to choose how their personal information is used | G2 |
| Providing information | Advocate to ensure perspective on consumer situation is not biased by medical opinion  | G1 |
| Providing information | Provide information in a way that consumer understands and telling consumer the options | G1, G3, G4 |
| Building relationships to understand consumer | Meeting with consumer before advocacy situation to understand consumer’s goals in context of life experiences | G1, G5 |
| Building relationships to understand consumer | Building trust | G5 |
| Building relationships to understand consumer | Someone who can liaise with others for consumer | G6 |

## What consumers need to self-advocate

| **Common themes** | **Sub-themes** | **Groups who identified with theme[[5]](#footnote-5)** |
| --- | --- | --- |
| Having access to the right information2 | Information on choices, rights, options and how to appeal | G1, G2, G3, G4, G6  |
| Having access to the right information2 | Information on treatment, medication and timeframes | G2  |
| Having access to the right information2 | A checklist of important information and services | G3, G5 |
| Having access to the right information2 | Someone coming in to talk about rights and choices more useful than being provided a lot of information to read | G6 |
| Building skills, knowledge and capacity | Being supported and encouraged to stand up for rights, or fight against things imposed upon us (e.g. state trustees) | G1, G3, G4, G5, G6 |
| Building skills, knowledge and capacity | Increasing confidence, self-esteem or self-worth | G4, G5 |
| Building skills, knowledge and capacity | Long term training, education, or coaching | G1, G2  |
| Building skills, knowledge and capacity | Representing the facts in a logical way by controlling emotions | G1, G4 |
| Building skills, knowledge and capacity | An advocate to allow consumer to be heard | G6 |
| Helpful tools and techniques | Coaching, mentoring or role play | G2, G4, G5 |
| Helpful tools and techniques | Advance statement | G2 |
| Helpful tools and techniques | Developing a plan for approaching meetings with treating team/others | G3 |
| Helpful tools and techniques | Religion/Praying to give consumer comfort and strength in difficult circumstances | G4 |
| Knowledge of treating team | Understanding clinician’s goals and expectations | G2, G6 |
| Knowledge of treating team | Being able to identify staff and their roles | G3 |

## Suggestion for IMHA to build information and resources for consumers

| **Common themes** | **Sub-themes** | **Groups who identified with theme[[6]](#footnote-6)** |
| --- | --- | --- |
| IMHA to raise public awareness | Making IMHA more accessible, particularly to regional/rural areas | G1 |
| IMHA to raise public awareness | Talking to people in public areas about IMHA | G4 |
| IMHA to raise public awareness | IMHA information could be added into Melbourne city council application for homeless *Ask Izzy* (<https://askizzy.org.au/>) | G4 |
| Continued availability and presence of advocacy support | Advocates based on wards, knowing when advocate is available  | G1, G5 |
| Continued availability and presence of advocacy support | Timing – Need for IMHA details as soon as on treatment order | G3 |
| Information that is user friendly/reader friendly | Information in plain language | G2, G3 |
| Information that is user friendly/reader friendly | A fold out wallet card with information on rights | G2, G3 |
| Information that is user friendly/reader friendly | Information in preferred/other languages | G3, G5 |
| Information that is user friendly/reader friendly | Recognisable graphics, catchy designs | G2, G3 |
| Information that is user friendly/reader friendly | A mobile friendly website/information | G3, G5 |
| Information that is user friendly/reader friendly  | Websites and online information | G4 |
| Information that is user friendly/reader friendly | A smartphone application | G3 |
| Information that is user friendly/reader friendly | Video clip, for people to watch and/or hear information | G5 |
| Information that is user friendly/reader friendly | Different types of information platforms (e.g. Tablet devices) need to be made more accessible in Mental Health services | G6 |
| Information that is user friendly/reader friendly | Easy to understand | G1 |
| Information that is user friendly/reader friendly | Fridge magnet | G2 |
| Information that is user friendly/reader friendly | An orientation pack | G6 |
| Information that is user friendly/reader friendly | Use of whole words rather than abbreviations | G4 |
| Verbal Information | Someone independent to explain information  | G1, G4 |
| Verbal Information | A phone recording  | G2, G4 |
| Verbal Information | Advocate to phone consumer to provide information | G2 |
| Verbal Information | An advocate to visit unit and talk to consumers about what they do | G6 |
| Content of information | Information about services (crisis or other support) | G1, G2, G4 |
| Content of information | Information on human rights | G2, G4 |
| Content of informationContent of information | Information about advocacy | G3, G6 |
| Information on advance statements – Duration? Why make one? How can it be effective? When to make one? How to make one? | G3, G5 |
| Content of information | Information about what IMHA does | G3, G4 |
| Content of information | Information on nominated persons could be more specific about how consumer’s interests are represented | G5 |
| Content of information | Information about how to access an advocate | G6 |
| Content of information | That IMHA is a free service | G5 |
| Content of information | Need to differentiate between IMHA and VLA | G5 |
| IMHA Postcard critiques | Requires more information on front about circumstances of treatment orders and how IMHA can provide assistance | G1, G4 |

1. General group = G1, Regional group = G2, Younger persons group = G3, Homeless Group = G4, CALD Group = G5,

SECU Group = G6 [↑](#footnote-ref-1)
2. Common theme identified throughout various key topic areas [↑](#footnote-ref-2)
3. General group = G1, Regional group = G2, Younger persons group = G3, Homeless Group = G4, CALD Group = G5,

SECU Group = G6 [↑](#footnote-ref-3)
4. General group = G1, Regional group = G2, Younger persons group = G3, Homeless Group = G4, CALD Group = G5,

SECU Group = G6 [↑](#footnote-ref-4)
5. General group = G1, Regional group = G2, Younger persons group = G3, Homeless Group = G4, CALD Group = G5,

SECU Group = G6 [↑](#footnote-ref-5)
6. General group = G1, Regional group = G2, Younger persons group = G3, Homeless Group = G4, CALD Group = G5,

SECU Group = G6 [↑](#footnote-ref-6)