Human Rights protection frameworks for people being treated involuntarily for a mental illness: Study findings

Prepared for: The Queensland Mental Health Commission

May 2019

Authors

Gianfranco Giuntoli, Victoria Stewart, Amanda Wheeler, Sandra Gendera, Christopher Ryan, Donna McAuliffe, Karen R. Fisher

Acknowledgements

We would like to thank all the study participants, the Project Advisory Group members, and the Commission for their suggestions about the research project.

Research Team

Dr Gianfranco Giuntoli, Professor Amanda Wheeler, Mr Andrew Blythe, Dr Sascha Callaghan, Professor Karen R Fisher, Ms Sandra Gendera, Ms Rosemary Kayess, Professor Donna McAuliffe, Ms Helena Roennfeldt, Clinical Associate Professor Christopher Ryan, Ms Victoria Stewart.

For further information:
Gianfranco Giuntoli (g.giuntoli@unsw.edu.au) +61 2 9385 7800

Social Policy Research Centre

UNSW Sydney NSW 2052 Australia
T +61 2 9385 7800
F +61 2 9385 7838
E sprc@unsw.edu.au
W www.sprc.unsw.edu.au

The Social Policy Research Centre is based in the Faculty of Arts & Social Sciences at UNSW Sydney. This report is an output of the <project name> research project, funded by <funder name>.

Suggested citation:

Giuntoli, G., Stewart, V., Wheeler, A., Gendera, S., Ryan, C., McAuliffe, D., Fisher, K.R. (2019). *Human Rights protection frameworks for people being treated involuntarily for a mental illness: Study findings (SPRC Report [to follow/19)*. Sydney: Social Policy Research Centre, UNSW Sydney.

Contents

Tables

Glossary

ACT	Australian Capital Territory
ACAT	ACT Civil and Administrative Tribunal
AD	Advance Directive
AG	Attorney General
AHD	Advance Health Directive
AMHS	Authorised Mental Health Service
Carer	Family member and carer participant
CIMHA	Consumer Integrated Mental Health Application
Consumer	Participant with lived experience of mental health challenges
CRPD	Convention of the Rights of Persons with Disabilities
CTO	Community Treatment Order
DBT	Dialectical Behaviour Therapy
ECT	Electroconvulsive therapy
f-PAD	Facilitated Psychiatric Advance Directive
HHS	Health and Hospital Services
ieMR	Integrated electronic Medical Record
IPRA	Independent Patient Rights Advisers

HDU	High Dependency Unit
JCP	Joint Crisis Plan
JP	Justice of the Peace
MH	Mental Health
MHEA	Mental health experts and advocates
MHP	Mental health practitioners
MHRT	Mental Health Review Tribunal
NGO	Non-Governmental Organisation
NSP	Nominated Support Person
NSW	New South Wales
OPG	Office of the Public Guardian
PAD	Psychiatric Advance Directive
PICU	Psychiatric Intensive Care Unit
QCAT	Queensland Civil and Administrative Tribunal
QLD	Queensland
RCT	Randomised Controlled Trials
TA	Treatment Authority
TSO	Treatment Support Order
UN	United Nations
Vic	Victoria
WA	Western Australia
WHO	World Health Organisation

Executive Summary

A consortium comprising the University of New South Wales (UNSW Sydney), Griffith University, and the University of Sydney has been commissioned by the Queensland Mental Health Commission (the Commission) to undertake research into the processes provided in the new Queensland Mental Health Act 2016 (*Mental Health Act 2016*) to protect the human rights, as currently expressed in the *Mental Health Act 2016*, of adults who receive involuntary treatment for a mental illness in hospital and community settings. The consortium is co-led by the Social Policy Research Centre (SPRC) at UNSW Sydney and the Menzies Health Institute at Griffith University, also involving Sydney Law School and The Centre for Values, Ethics and the Law in Medicine at the University of Sydney.

1. Project objectives and scope

The project's objectives were to investigate:

1) the experiences of the protection of human rights, as currently expressed in the *Mental Health Act 2016*, of adults who receive involuntary treatment in hospital and community settings under the *Mental Health Act 2016*, including the views and experiences of their families and carers and a wide range of other stakeholders, including service providers, experts and advocates (Project Objective 1)

2) how the processes to protect the human rights of people who receive involuntary treatment in hospital and community settings as provided in the *Mental Health Act 2016* compare to other Australian States and Territories (Project Objective 2)

The study focused on the following five areas of investigation (referred to as focus areas):

- rights and information for inpatients within mental health wards
- the role of Independent Patient Rights Advisers (IPRAs)
- Advance Health Directives (AHDs)
- the operation of the Mental Health Review Tribunal (MHRT)
- rights and information regarding involuntary treatment in the community;

The project did not aim to evaluate the five focus areas but investigated them to identify common factors that helped or hindered the implementation of the human rights of people treated involuntarily for a mental illness under the *Mental Health Act 2016*.

2. Research design and methods

The research project consisted of a qualitative study with Phase 1 and Phase 2 over 18 months: from June 2017 to March 2019.

Phase 1 (June 2017-February 2018) consisted of a scoping literature review and telephone interviews with six selected stakeholders from NGOs, for which we received Low Risk ethics approval from UNSW HREC (approval number HC17577, attached) and Griffith University (HREC/2018/185).

Phase 2 (March 2018-March 2019) explored the experiences of human rights and their protection, across the five study focus areas, with a total of 32 interviewees:

- Ten people with lived experience of mental health challenges who received involuntary treatment under the *Mental Health Act 2016* (here referred to as people/participants with lived experience) (6 men and 4 women)
- Five family members and carers of people with lived experience (all women)
- Seventeen service provider stakeholders (referred to as service provider participants), including practitioners, experts, and advocates.

Ethics approval was received from UNSW Sydney HREC (HC17990), Griffith University (2018/033) and Metro South HREC (HREC/18/QPAH/86) for the Phase 2 interviews.

A total of 38 participants took part in the study.

Literature review. The review adopted a scoping approach, which helps to explore topics that have not yet been extensively reviewed or are of a complex or heterogeneous nature, as in the case of this study.

Relevant keywords related to involuntary treatment and the five study focus areas were searched in the following electronic databases: PsycINFO, MEDLINE, SCOPUS, Google Scholar, Westlaw AU, APAFT: Australian public affairs. The keywords were combined using Boolean operators to identify relevant literature and research evidence on the views and experiences of people with lived experience of mental health challenges.

The retrieved literature was analysed with the aim to describe the characteristics and functioning of each of the five focus areas within the *Mental Health Act 2016* and in other relevant Australian and international frameworks (Project Objective 2), with a particular focus on their efficacy in meeting the needs and protecting the human rights of people with mental illness being treated involuntarily (Project Objective 1).

Interviews. The interviews with service provider participants were conducted from January 2018 to September 2018. Those with people with lived experience, their family and carers were conducted from end of May 2018 to October 2018.

All the interviews were conducted at two study sites – Brisbane and Townsville – which allowed the research team to include participants from a range of backgrounds and settings and disadvantaged groups, wherever possible, whilst remaining within the limited scope of the project.

Data analysis. The qualitative data from the interviews with all study participants were transcribed and thematically analysed using the qualitative data analysis software NVIVO.

The experiences of the protection of human rights of adults who receive involuntary treatment in hospital and community settings under the *Mental Health Act 2016* (Project Objective 1) were analysed using the framework of patients' rights provided in the *Mental Health Act 2016,* including the right of patients to:

1) be visited by the nominated support persons, family, carers and other support persons (Section 281);
2) be visited by a health practitioner (Section 282)
3) be visited by legal or other advisers (Section 283),
4) communicate with other persons (Section 284);
5) be given information about treatment and care (Section 285) and to ensure that the person understands the information (Section 286)
6) to obtain a second opinion about one's treatment and care (Section 290).

Where possible, the study participants' experiences of protection of human rights under the *Mental Health Act 2016* in each of the five study focus areas were also summarised using as a framework the five themes that the World Health Organisation (WHO) drew from the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD) for mental health and social care facilities (WHO, 2012). For ease of reference, these five themes are here referred to as the participants' rights to: 1) social protection; 2) health, including access to health care services and information; 3) equal justice and presumption of capacity; 4) autonomy, including freedom of movement, freedom from interference, and bodily integrity; 5) family and community participation.

Study limitations. The study was conducted using a purposive, maximum variation sampling method, which allowed the research team to be inclusive of a wide range of experiences about the protection of human rights of adults who receive involuntary treatment under the *Mental Health Act 2016*. However, non-random sampling methods generate the risk that the study sample is not representative of the population being studied. Differences may exist between those who volunteered and those who declined participation in the interviews which are difficult to predict and quantify. Although this study's findings may not be generalisable to the wider

population of people receiving involuntary treatment under the *Mental Health Act 2016*, the experiences and views of each single person about the protection of their human rights are valuable and important, regardless of whether they are typical of a large or small number of people.

3. Literature review - Findings

The *Mental Health Act 2016* has introduced some important changes, for example treating persons in a less restrictive way, the role of Independent Patient Rights Advisers (IPRAs), and promoting the use of Advance Health Directives (AHDs). These changes make the *Mental Health Act 2016* more closely realise the requirements of the CRPD comparatively to the previous legislation.

Rights and information for inpatients within mental health wards. The rights and information of inpatients, family and carers within mental health wards are regulated by both national documents and laws – the Australian Charter of Healthcare Rights, the National Safety and Quality Health Service Standards, and the National Standards for Mental Health Services – and state documents and laws, including the *Mental Health Act 2016*, the Guardianship and Administration Act 2000, the Carers (Recognition) Act 2008, and the Audit Tools for National Safety and Quality Health Service Standards.

These laws and frameworks recognise the right of all persons to the same basic human rights, including the right to have the highest possible standard of physical and mental health. The rights to safety, respect, receiving information in a clear and open way, participating in decisions and choices about care, privacy and confidentiality, and commenting on care and having concerns addressed are listed by the Australian Charter of Healthcare Rights, and included in the National Safety and Quality Health Service Standards, the National Standards for Mental Health Services, as well as the *Mental Health Act 2016*.

Chapter 9 of the *Mental Health Act 2016* provides for a statement of rights and the rights of patients and relevant others, including the right of a patient to:

1) be visited by the patient's nominated support persons, family, carers and other support persons (Section 280);
2) be visited by a health practitioner (Section 282), legal or other advisers (Section 283);
3) communicate with other persons by post, a fixed line telephone in the authorised mental health service, a mobile telephone or other electronic communication (Section 284). However, this does not apply if the other person asks that the communication does not take place, if there is a 'non-contact' condition of an order in place under the *Mental Health Act 2016*, or if communication by phone or electronic device is likely to be detrimental to the health and wellbeing of the patient or others. (Section 284);

4) be given information about treatment and care (Section 285);
5) ensure that the patient understands the information (Section 286);
6) a second opinion to be obtained about a patient's treatment and care (Section 290).

Section 5 of the *Mental Health Act 2016* recognises and acknowledges Aboriginal and Torres Strait Islander people. It states that 'the unique cultural, communication and other needs of Aboriginal and Torres Strait Islanders must be recognised and taken into account. Similarly, Section 5 recognises and acknowledges persons from culturally and linguistically diverse backgrounds. It states that 'services provided to persons from culturally and linguistically diverse backgrounds must have regard to the person's cultural, religious and spiritual beliefs and practices', including using interpreters 'to the extent practicable and appropriate in the circumstances'.

Section 278 of the Act establishes that after admission of a patient to an authorised mental health service, the administrator of the authorised mental health service must: 1) explain the statement of rights prepared by the Chief Psychiatrist under the Act to the patient, ensuring that the patient understands the information given; 2) if requested, give a copy of the statement of rights to the patient and to the patient's nominated support persons, family, carers or other support persons. The administrator of an authorised mental health service must also display signs in prominent positions in the service stating that a copy of the statement of rights is available on request (Section 279).

Independent Patient Rights Advisers. The *Mental Health Act 2016* for the first time establishes the positions of Independent Patient Rights Advisers (IPRAs). IPRAs have an important role in informing people with lived experience of their rights under the *Mental Health Act 2016* and in liaising between clinical teams, patients and support persons. IPRAs must act independently and impartially, and they are not subject to the direction of any person in relation to the advice given to a patient or a patient's nominated support persons, family, carers or other support persons (Section 295).

The *Mental Health Act 2016* does not use the word advocacy in relation to IPRAs. However, Section 294(b) states that the functions of IPRAs include to 'help the patient and a patient's nominated support persons, family, carers and other support persons to communicate to health practitioners the patient's views, wishes and preferences about the patient's treatment and care', which seems to entail elements of an advocacy role. The advocacy role is more prominent in other patient advisory roles in Australia and internationally, such as for example the Independent Mental Health Advocates (IMHA) in Victoria and in England.

Advance Directives. Advance Directives (ADs) are a tool that people with lived experience of mental health challenges can choose to use to provide information on treatment preferences and other instructions for those times when their capacity to

make decisions about their care and treatment are hampered by acute mental illness or distress.

In the *Mental Health Act 2016*, ADs are referred to as Advance Health Directives. Part 8, Division 1 of the *Mental Health Act 2016* states that 'the advance health directive may include the principal's[1] views, wishes and preferences about the principal's future treatment and care for a mental illness'. In deciding the nature and extent of treatment and care to be provided to a person under a treatment authority, the authorised doctor needs to: 'a) discuss the treatment and care to be provided with the person; and b) have regard to the views, wishes and preferences of the person, to the extent they can be expressed, including, for example, in an advance health directive' (*Mental Health Act 2016*, Section 53).

ADs[2] are characterised by low take up rates and similar barriers to implementation, such as low engagement with the process from people with lived experience and mental health professionals alike. Research shows that key barriers to the implementation of mental health ADs are lack of ready access to the documents in crisis, a lack of clinician familiarity, and legal uncertainty about their application. At the service and policy level, researchers have argued that the introduction of supported-decision making regimes can help the successful implementation of mental health ADs as well as greater recognition of the intentions of the CRPD in compulsory treatment in Australia.

Mental Health Review Tribunal. The Mental Health Review Tribunal (MHRT) is an independent decision-making body under the *Mental Health Act 2016* (Qld Health, 2018). Section 28 of the *Mental Health Act 2016* states that the Mental Health Review Tribunal reviews: (a) treatment authorities; (b) forensic orders; (c) treatment support orders; (d) the fitness for trial of particular persons; (e) the detention of minors in high security units. The MHRT also hears applications for: (a) examination authorities; (b) the approval of regulated treatment; (c) the transfer of particular patients into and out of Queensland. In addition, the MHRT has further powers in relation to appealing a limited number of decisions made by the chief psychiatrist or administrator (Sections 705(1)(c) and 533) (Qld Health, 2017).

The reviewed national and international literature showed that Mental Health Tribunals' (MHTs)[3] role of protecting the rights of people with mental illness of unjustified detention or treatment can be hampered by factors such as an over-reliance on medical opinion, the quality of the health reports provided by medical

---

[1] The Powers of Attorney Act 1998 (current as at 5 March 2017) states that in the context of advance health directive and power of attorney, principal means the person who made the advance health directive or appointed the attorney.
[2] The expression ADs is used to refer to the literature findings across different contexts, whereas the expression AHDs is used to refer to findings specific to the Queensland context.
[3] The expression Mental Health Tribunals (MHTs) is used to refer to the findings of the literature across different contexts. The expression Mental Health Review Tribunal (MHRT) is used to specifically refer to the tribunal in Queensland as regulated under the *Mental Health Act 2016*.

staff, and a primary focus on risk and dangerousness assessments. The reviewed literature has also identified several limits in the implementation of MHT processes, including lack of training for clinicians on how to report to MHTs, clinicians' reliance on personal views rather than the specific circumstances of each consumer, lack of resources (MHTs in Ireland devote 16 to 18 times the Australian expenditure per case), the number of virtual hearings, the timing of tribunal reviews, and limited legal representation before tribunals.

Overall, there is agreement in the reviewed literature that there is a need for more support for people with lived experience attending MHTs, including advocacy from lawyers, carers and peers.

Community Treatment Orders. Section 18 of the *Mental Health Act 2016* defines a treatment authority as 'a lawful authority to provide treatment and care to a person who has a mental illness who does not have capacity to consent to be treated'. It further states that: 'a treatment authority may be made for a person if an authorised doctor considers the treatment criteria apply to the person and there is no less restrictive way for the person to receive treatment and care for the person's mental illness, including, for example, under an advance health directive'. The category of a treatment authority is community, 'if the person's treatment and care needs can be met in the community', or inpatient 'if the person's treatment and care needs can be met only by being an inpatient'.

Here, the expression Community Treatment Order (CTO) is used to report literature findings across different contexts. The expression Treatment Authorities – Community Category will be used to refer to findings specific to the Queensland experience under the *Mental Health Act 2016*.

The evidence in qualitative studies about CTOs remains mixed. CTOs appear to be the preferred choice of people with lived experience and to increase some freedoms, in particular if the alternative is involuntary inpatient treatment. However, there is strong qualitative evidence that many people with lived experience, family members and carers in Australia and overseas complain about not having access, received, or been provided with the necessary support to fully access, comprehend, and act on information about involuntary treatment, CTOs and their legal implications, and mental health consumer rights more broadly (i.e. review process). Recent research on CTOs has highlighted that legislation needs to improve the mechanisms by which people with lived experience, family members and carers receive mental health information and support to understand the information and manage their pathways through the mental health system.

Overall, CTOs as a treatment or procedural tool in community mental health remain controversial regarding their efficacy and outcomes and pose some risks to the rights of people with mental illnesses.

4. Interviews - Findings

General comments about the *Mental Health Act 2016.* Most study participants welcomed the changes brought by the *Mental Health Act 2016,* which they believed improved the protection of the human rights of people with lived experience who receive involuntary treatment. However, many commented on the very limited changes they had observed in mental health practice. The main factors that were discussed as affecting the protection of human rights under the *Mental Health Act 2016* were:

1) a pervasive paternalistic culture in mental health services;

2) lack of consistency in the practices and approaches to information giving and communication with people with lived experience among clinicians, teams, and locations;

3) lack of understanding of and training on the rights introduced by the *Mental Health Act 2016*;

4) some perceived gaps in the *Mental Health Act 2016* , such as a lack of safeguard mechanisms for the 72-hour assessment period, limited mechanisms to challenge seclusion and restraint, particularly for people with an intellectual disability and a mental health challenge, and the fact that, for certain groups of people on forensic orders, a *non-revocation period* of up to 10 years may not allow a more dynamic consideration of the person's response to treatment and right to recovery.

Focus area 1: Rights and information for inpatients within mental health wards. Participants with lived experience described the experience of being hospitalised as scary and confusing. The following experiences were discussed as affecting the protection of human rights in mental health wards under the *Mental Health Act 2016*:

1) The difficulties of some participants to maintain communication with their family and friends (Section 284). It was reported that in some units there was still the practice of locking away patients' mobile phones regardless of any specific assessment of whether they were going to be detrimental to the health or wellbeing of the person or others.

2) The need for more training aimed at educating clinicians about the importance of IPRAs and of supporting their role.

3) Limited access of people with lived experience, family and carers to appropriate, linguistically and culturally relevant information about their rights, treatment (Section 285), and the services they can access, including social benefits. The importance that this information is offered at different times during hospitalisation was stressed.

4) Negative experiences of people with lived experience, family and carers were

reported when requesting information about medication or providing feedback to treating professionals about what had worked for them in the past (Section 285). Some participants reported difficulties having their concerns or wishes heard and were concerned that if they did complain the treatment would get worse rather than better. Participants also identified that general health care was not always managed appropriately in the mental health setting.

5) Access to a second opinion (Section 290) was identified as a positive addition to the *Mental Health Act 2016*, which supported the rights of those being treated involuntarily. However, service provider participants raised concerns regarding how this second opinion was arranged by Health and Hospital Services (HHS), questioning the independence of the reviews.

6) The fact that the *Mental Health Act 2016* requires authorised mental health services to provide data on the use of restraint on children and young people to the Office of the Public Guardian (Section 274) was discussed as an important improvement. Nevertheless, the lack of written informed consent to the use of restraint or seclusion on children by parents, guardians and carers as well as the lack of mechanisms to monitor provision of information on these practices by doctors to the children's parents, guardians and carers was seen as limiting their rights and choice. The fact that the *Mental Health Act 2016* does not require authorised mental health services to communicate the use of restraint or seclusion on adults to the Office of the Public Guardian (OPG) was also seen as a limitation to safeguard people's right to bodily integrity and autonomy. Concerns were also raised for the lack of safeguard mechanisms to question the use of medication by advocates, particularly in the case of forensic orders.

7) Over half the participants with lived experience, family and carers reported experiencing trauma when security guards were involved in restraining practices, with resulting physical pain and injury, fear and distress. Participants asked that mental health staff put more effort into de-escalation techniques before security were called.

8) People with a dual diagnosis (i.e. an intellectual disability and a mental health challenge) were at risk of prolonged hospitalisation or detention because of the shortage of disability services in place to transition back to community. There are only 10 beds at the Forensic Disability Service provided under the *Forensic Disability Act* 2011.

9) There was also high concern for the problem of sexual assault in wards and concerns were expressed about mixed gender wards.

10) Whilst it was acknowledged that smoking was not good for a person's health, for those who smoked, being prevented from smoking on the inpatient ward was reported by participants with lived experience, family and carers to have a negative impact on their wellbeing and recovery.

Focus area 2: The role of Independent Patient Rights Advisers (IPRAs). The addition of the Independent Patient Rights Adviser (IPRA) role within the *Mental Health Act 2016* was considered important in protecting the rights of those being treated involuntarily under the Act. However, most participants with lived experience, family, and carer participants had no knowledge of the IPRA role, although they felt that the addition of IPRA support in both the inpatient and community settings was a positive inclusion in the Act. Only two of the ten participants with lived experienced and one of the five family members and carer participants had experienced accessing an IPRA; they described the experience as positive and reported that they would access the IPRA again in the future if needed.

The following experiences were discussed as affecting the IPRAs' role and therefore their capacity to inform patients, family and carers about their rights under the *Mental Health Act 2016*:

1) A lack of guidelines and direction to assist the development of the IPRA role. As a result, each HHS implemented the role and governance structure differently.

2) Lack of clarity regarding the IPRAs' role, including in relation to whether they provide advice rather than advocacy, in some instances generated tensions with some treatment teams resulting in the IPRAs' role being viewed with suspicion and difficulties in establishing positive working relationships. A collegial relationship with treatment teams was seen as important to allow IPRAs access to information and referrals. Most IPRAs described their roles as advisers or facilitators, but not as advocates.

3) Some service provider stakeholders questioned the independence of the IPRA role due to the current governance and management structures which exist within the HHS, with recommendations that the IPRA role governance be from outside the HHS, with direct reporting requirements to the Chief Psychiatrist's office. Further resourcing to expand access to IPRAs across a number of sectors including community-based services and prisons was also recommended by service provider participants.

4) Current lack of resources for IPRAs in community-based services and prisons was identified as a limit that needed to be addressed to help people with lived experience, their family and carers to access information on their rights also in those settings (Sections 285 and 286 of the *Mental Health Act 2016*).

Focus area 3: Advance Health Directives (AHDs). Most service provider participants saw AHDs as a welcome addition in the *Mental Health Act 2016*. AHDs were seen as an option that would promote less restrictive treatment practices and so support the rights to autonomy and bodily integrity of people with lived experience. Nevertheless, very few of the consumer, family member and carer participants had heard of AHDs. The only participant with lived experience who had completed an AHD described the process as complicated, requiring several steps

and visits to different people, including a solicitor and a GP. This participant was assisted by an IPRA, who they visited twice. The IPRA offered help with information and with writing the participants' wishes in a way that was clear and suitable to the AHD form. The type of help that people with lived experience might require to complete their AHD and to keep it up to date raises the question of whether IPRAs are the best people to offer that support.

The following experiences and factors were discussed as affecting the availability, accessibility and potentially use at times of need of AHDs both for people with lived experience, family, carers, and treatment teams:

1) Keeping AHDs up to date. It was flagged that the way AHDs are currently used is not conducive to regular updates and so there is a risk that AHDs in place quickly become out of date.

2) More consumer accessible and appropriate documents and process for completing AHDs is needed to increase their accessibility to different groups of consumers.

3) Access to support for people with lived experience in the community or in prison, who do not have access to IPRAs and therefore might not know or have the necessary help to complete an AHD, is needed.

4) Further training and information about AHDs for clinical staff to better understand the concept and how to work with people with lived experience to use them effectively. It was suggested that the training needed to target medical practitioners as well as mental health workers to ensure integration of the AHD across acute and community settings, as well as provide practical resources to support current training options.

5) Small and slow uptake of AHDs state-wide. Among the three people with lived experience and two carers who were aware of the AHD, the main reason for not completing an AHD was a belief that it would not make any difference to how they would be treated on admission to hospital. Service provider participants also reported that they had received feedback from people with lived experience that they were unsure if the AHD would be followed by the treating team and had concerns that even after completing an AHD their wishes would not be respected.

6) The current ways and procedures to upload and store AHDs in the health service information systems, with these automatically highlighted on the public mental health consumer record, but not for emergency, other health areas, and in private hospitals; the upload of AHDs into the electronic health record was described as requiring a different process. Concerns were raised that in a fast-paced health system, information about a consumer's AHD would not be accessed.

Focus area 4: Mental Health Review Tribunal (MHRT). Participants reported that the *Mental Health Act 2016* brought significant improvements for supporting the

human rights of people with lived experience in MHRT hearings. Participants with lived experience, family and carers stressed the importance of receiving more accessible and 'stepped' information on the MHRT processes prior to their first appearance. Similarly, service provider participants stressed the need for more information regarding the MHRT decision making processes, including recording of MHRT proceedings as other tribunals and courts do. Transparency in the decision-making processes of the MHRT was identified as necessary to improve the right to information and support to people with lived experience.

The addition of representation for people with lived experience within the MHRT process was overwhelmingly seen as a positive addition to the Act. Although service provider participants agreed that representation supported the human rights of people with lived experience, the introduction of advocates and representatives in the MHRT process did not always proceed smoothly. All parties involved were required to learn about individuals' roles, which took time, and some participants described negative experiences of this process. Service provider participants reported two major limits of the advocacy system, the fact that: 1) there was no training in place for advocates and lawyers and, 2) support was offered only at the hearing, leaving people with lived experience with no help between hearings, when help would often be most needed.

Participants also believed that, despite the improvements brought by the *Mental Health Act 2016*, the MHRT tended still to focus on risk rather than recovery. This was particularly evident for people on forensic orders and in relation to stepping people down to a Treatment Support Order (TSO). One opinion was that the MHRT had a risk adverse attitude towards accepting existing procedures to assess the risk of stepping people down to a TSO. This had led in some instances to delaying people's hearings, so compromising their right to autonomy and family and community participation.

The following factors were discussed as affecting the experiences of MHRT hearings for people with lived experience, family and carers, and its implementation:

1) Appointing assistants with expertise in the support of persons with an intellectual disability and with appropriate cultural or social knowledge when presiding forensic orders disability and supporting with people from Aboriginal or cultural and linguistic background. Section 750 of the *Mental Health Act 2016* states that the tribunal may appoint a person with appropriate knowledge or experience to assist it in these proceedings, but it is not obliged to.

2) The difficulties associated with learning to manage new administration processes introduced by the *Mental Health Act 2016* had generated the need for adjournments. The addition of an MHRT Registrar was suggested to support the administration processes.

3) The timely delivery of reports before the hearings. Although provision of information before the hearings was considered important, participants with lived experience reported that the detailed content of the clinical reports could generate a lot of stress and anxiety to them, highlighting the importance of support to go through them. There was also concern that the volume of long-standing history detailed in medical reports could often unfairly influence Tribunal decisions, which would focus on past behaviour often from many years ago rather than on current risk.

Focus area 5: Rights and information regarding involuntary treatment in the community. Given the new protections in the *Mental Health Act 2016*, service provider participants saw people with lived experience living in the community as ideally suited to receive information aimed at strengthening the protection of their human rights. Participants with lived experience, family and carers reported having good relationships with their case managers and saw them as their primary source of information on the new Act.

Nevertheless, there seemed to be a limited structured approach from the health services on providing rights-based information. There was general consensus that ensuring people are provided with information about the *Mental Health Act 2016* and human rights protections had not necessarily been a priority for community-based service providers. There was not a way of tracking who had been provided with information and it was unknown how many of the people being treated involuntarily in the community had been informed of the changes to the Act and additional protections.

The introduction of more IPRA services to the community was identified as an option for increasing access to information and support, which would lead to an increased uptake of NSP and AHD applications.

5. Conclusions

This study reported the views of the participants on some strengths and challenges still existing in the *Mental Health Act 2016* as well as about some factors that they perceived as either hindering or promoting the protection of human rights of people being treated involuntarily in hospitals and in the community. Some of these factors concerned systemic issues, whereas other concerned implementation and cultural ones.

The main systemic factors that were identified as promoting and protecting the human rights of patients, family and carers in the five study focus areas were changes introduced by the *Mental Health Act 2016* that offer more opportunities to enact specific rights as well as more safeguard mechanisms to protect them, including:

- the right to health, access to health care services and information, for example through the introduction of IPRAs, provision of information regarding treatment, and access to a second opinion;

- the right to autonomy, including freedom of movement, freedom from interference, and bodily integrity, for example through a more prominent role of AHDs, and the requirement that authorised mental health services provide data on the use of restraint on children and young people to the OPG (Section 274);

- the right to family and community participation, for example through acknowledging patients' rights to communicate with family and friends using different communication means, including mobile phone and other electronic devices (Section 284);

- the right to equal justice and presumption of capacity, for example through the addition of representation for people with lived experience within the MHRT process.

The main systemic factors that hindered the promotion and protection of human rights of patients, family and carers in the five study focus areas, can be summarised into two groups: 1) what participants perceived as current shortcomings in the *Mental Health Act 2016,* and 2) cultural barriers and implementation issues.

The main perceived shortcomings in the *Mental Health Act 2016* regarding the five study focus areas were:

- a lack of safeguard mechanisms for the 72-hour assessment period;

- limited mechanisms to challenge seclusion and restraint, particularly for people with intellectual disability and a mental health challenge;

- the fact that, for certain groups of people on forensic orders, a *non-revocation period* of up to 10 years may not allow a more dynamic consideration of the person's response to treatment and right to recovery;

- the fact that the *Mental Health Act 2016* does not require authorised mental health services to communicate the use of restraint or seclusion on adults to the OPG;

- the lack of safeguard mechanisms to question the use of medication by advocates, particularly in the case of forensic orders.

The main cultural barriers and implementation issues were:

- a long-standing paternalistic culture;

- a risk-adverse rather than recovery focused culture;

- a lack of understanding of and training on the rights introduced by the *Mental Health Act 2016* – including the role of IPRAs, AHDs, and the right to communication, with some AMHSs still locking away patients' mobile phones regardless of any specific assessment of whether they can be detrimental to the patient's or others' health and wellbeing (Section 284 of the *Mental Health Act 2016*);

- limited access of people with lived experience, family and carers to accessible, appropriate, 'stepped', linguistically and culturally relevant information about their rights, treatment (Section 285), and the services they can access, including social benefits;

- people with a dual diagnosis (i.e. intellectual disability and a mental health challenge) experiencing prolonged hospitalisation or detention because of the shortage of disability services in place to transition them back to community. There are only 10 beds at the Forensic Disability Service provided under the *Forensic Disability Act* 2011;

- inadequate resourcing to expand the role of IPRAs from inpatient units to people with lived experience, family and carers in the community and in prisons, who do not currently have access to them.

Table 1 provides an overarching conceptual framework that summarises the study findings on the factors that promoted and limited the protection of the five human rights stated in the WHO (2012) Quality Rights Toolkit to assess and improve quality and human rights in mental health and social care.

Table 1. Conceptual framework summarising the study findings on the factors promoting and limiting the protection of the five human rights stated in the WHO (2012) *Quality Rights Toolkit* to assess and improve quality and human rights in mental health and social care.

Rights[1] and domains	Study focus areas: rights promoting and limiting factors[2]
Right to health, including access to health care services and information	
Promoting factors	• **IPRAs[2] and AHDs[2]:** o Training to educate clinicians, medical practitioners and mental health workers about the role and importance of IPRAs and AHDs. • **Rights in the ward and community:** o Access to a second opinion (Section 290 of the MH Act).
Limiting factors	• **Rights in the ward and community:** o Lack of communication on consumers' treatment preferences. o Lack of attention on general health in mental health settings. o Lack of transparency by HHS in arranging a second opinion.
Right to family and community participation	
Promoting factors	• **Rights in the ward and community:** o Providing access to information on the consumers' rights and treatment at different times during their hospitalisation and in ways which are accessible and appropriate to consumers as well as linguistically and culturally relevant (Section 285). o Expanding disability services to support the transition of people with a dual diagnosis (i.e. an intellectual disability and a mental health challenge) back to community.
Limiting factors	• **Rights in the ward and community:** o Locking away patients' mobile phones regardless of any specific assessment of whether they were going to be detrimental to the health or wellbeing of the person or others.
Right to autonomy, including freedom of movement, freedom from interference, and bodily integrity	
Promoting factors	• **AHD:** o Promoting the implementation and uptake of AHDs. o Upload of AHDs into the electronic health record was described as requiring a different process. Concerns were raised that, in a fast-paced health system, information about a consumer's AHD would not be accessed. • **Rights in the ward and community:** o Provision of data on the use of restraint on children and young people to the OPG[2] (Section 274 of the MH Act). o Use of de-escalation techniques before security guards are called. o Recovery approach, including to smoking in the wards.
Limiting factors	• **Rights in the ward and community:** o Lack of written informed consent to the use of restraint or seclusion on children by parents, guardians and carers. o Lack of mechanisms to monitor provision of information on use of restraint or seclusion by doctors to children's parents, guardians and carers. o No requirement for mental health services to communicate the use of restraint or seclusion on adults to the OPG. o Shortage of disability services to support the transition of people with a dual diagnosis (i.e. an intellectual disability and a mental health challenge) back to community. o Lack of safeguard mechanisms to question the use of medication by advocates, particularly in the case of forensic orders. o Involvement of security guards in restraining practices. o Risk of sexual assault in wards.

Right to equal justice and presumption of capacity	
Promoting factors	• **IPRAs:** o The implementation of IPRAs. o Training to educate clinicians, medical practitioners and mental health workers about the role and importance of IPRAs. o Informing consumers about IPRAs and their limitations. o Having the IPRA role governance from outside the HHS. o Having IPRAs reporting directly to the Chief Psychiatrist office. o Expanding access to IPRAs across community-based services and prisons. • **AHDs:** o The implementation of AHDs. o Training to educate clinicians, medical practitioners and mental health workers about the role and importance of AHDs. o Simplifying storage and access of AHDs in the health service information systems and electronic health record. o Informing consumers about AHDs and their limitations. • **MHRT:** o The implementation of advocates and representatives in the MHRT[2] process. o Appointing assistants with expertise in the support of persons with an intellectual disability, Aboriginal people or Torres Strait Islanders, and people from other cultural and linguistic diverse backgrounds.
Limiting factors	• **IPRAs:** o Lack of guidelines and direction to assist the development of the IPRA role. o Lack of clarity regarding whether IPRAs provide advice or advocacy. • **AHDs:** o Lack of consumer accessible and appropriate AHD forms and guidelines. • **MHRT:** o Lack of training for advocates and lawyers. o Lack of support for consumers in accessing the reports before the hearings. o Lack of legal support for consumers between hearings. o A focus on risk and consumers' past behaviour rather than current risk and behaviour.
Right to social protection	
Promoting factors	• **Rights in the ward and community:** Promoting information on the social security services that hospitalised consumers can access.
Limiting factors	• **Rights in the ward and community:** Lack of information and communication on social security when hospitalised.

Notes. [1] The rights consist of the five themes reported in the *Quality Rights Toolkit. Assessing and improving quality and human rights in mental health and social care facilities*, which the World Health Organisation (WHO) drew from the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD) (WHO, 2012). [2] The promoting and limiting factors are the findings of the Human Rights framework study by Giuntoli, Stewart, Wheeler, Gendera, Ryan, McAuliffe, Fisher (2019). [2] IPRA: Independent Patient Rights Advisers; AHD: Advance Health Directive; OPG: Office of the Public Guardian; MHRT: Mental Health Review Tribunal.

1. Introduction

This study investigated the experiences of the protection of human rights of adults who receive involuntary treatment in hospital and community settings under the *Mental Health Act 2016*, including the views and experiences of their families and carers and a wide range of service providers and other stakeholders, with a specific focus on five areas: rights and information for inpatients within mental health wards; the role of Independent Patient Rights Advisers; Advance Health Directives; the operation of the Mental Health Review Tribunal; rights and information regarding involuntary treatment in the community.

The project's objectives were to investigate:

1) the experiences of the protection of human rights, as currently expressed in the *Mental Health Act 2016*, of adults who receive involuntary treatment in hospital and community settings under the *Mental Health Act 2016*, including the views and experiences of their families and carers and a wide range of other stakeholders, including service providers, experts and advocates (Project Objective 1)

2) how the processes to protect the human rights of people who receive involuntary treatment in hospital and community settings as provided in the *Mental Health Act 2016* compare to other Australian States and Territories (Project Objective 2)

The project did not aim to evaluate the five focus areas but investigated them to identify common factors that helped or hindered the implementation of the human rights of people treated involuntarily for a mental illness under the *Mental Health Act 2016*.

1.1. Research study and methods

The research project consisted of a qualitative study that comprised two phases (Phase 1 and Phase 2) over 18 months: from June 2017 to December 2018.

Phase 1 (June 2017-February 2018) consisted of a scoping literature review and telephone interviews with six selected stakeholders from NGOs, for which we received Low Risk ethics approval from UNSW HREC (approval number HC17577), and Griffith University HREC (HREC/2018/185).

Phase 2 (March 2018-December 2018) explored the experiences of human rights and their protection, across the five study focus areas, of a total of 32 interviewees:

- ten people with lived experience of mental health challenges who received involuntary treatment under the *Mental Health Act 2016* (here referred to as people/participants with lived experience or consumers)
- five family members and carers of people with lived experience
- Seventeen service provider stakeholders (referred to as service provider participants), including practitioners, experts, and advocates.

1.1.1. Literature review

The review adopted a scoping approach, which helps to explore topics that have not yet been extensively reviewed or are of a complex or heterogeneous nature, as in the case of this study.

Relevant keywords related to involuntary treatment and the five study focus areas were searched in the following electronic databases: PsycINFO, MEDLINE, SCOPUS, Google Scholar, Westlaw AU, APAFT: Australian public affairs. The keywords were combined using Boolean operators to identify relevant literature and research evidence on the views and experiences of mental health consumers.

The retrieved literature was analysed with the aim to describe the characteristics and functioning of each of the five focus areas within the *Mental Health Act 2016* and in other relevant Australian and international frameworks (Project Objectives 2), with a particular focus on their efficacy in meeting the needs and protecting the human rights of people with mental illness treated involuntarily (Project Objective 1).

1.1.2. Interviews

The interviews with people with lived experience, their family and carers were conducted from end of May 2018 to October 2018. Those with service provider participants were conducted from January 2018 to September 2018.

All the interviews were conducted at two study sites – Brisbane and Townsville – which allowed the research team to include participants from a range of backgrounds and settings and vulnerable groups, wherever possible, whilst remaining within the limited scope of the project.

1.1.3. Data analysis

The qualitative data from the interviews with all study participants were professionally transcribed and thematically analysed using the qualitative data analysis software NVIVO.

The experiences of the protection of human rights of adults who receive involuntary treatment in hospital and community settings under the *Mental Health Act 2016*

(Project Objective 1) were analysed using as a framework the rights provided by the *Mental Health Act 2016,* including the right of patients to:

1) be visited by the nominated support persons, family, carers and other support persons (Section 281);
2) be visited by a health practitioner (Section 282)
3) be visited by legal or other advisers (Section 283),
4) communicate with other persons (Section 284);
5) be given information about treatment and care (Section 285) and to ensure that the patient understands the information (Section 286)
6) to obtain a second opinion about one's treatment and care (Section 290).

Considering the Australian Government's commitment to improve the lives of people with disability, their families and carers and to assist in realising their rights under the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD), the research team also referred to the five themes that the World Health Organisation (WHO) drew from the CRPD for mental health and social care facilities (WHO, 2012):

1) The right to an adequate standard of living and social protection (Article 28 of the CRPD).
2) The right to enjoyment of the highest attainable standard of physical and mental health (Article 25 of the CRPD).
3) The right to exercise legal capacity and the right to personal liberty and the security of person (Articles 12 and 14 of the CRPD).
4) Freedom from torture or cruel, inhuman or degrading treatment or punishment and from exploitation, violence and abuse (Articles 15 and 16 of the CRPD).
5) The right to live independently and be included in the community (Article 19 of the CRPD).

For ease of reference, these five themes are here referred to as the participants' rights to: 1) social protection; 2) health, including access to health care services and information; 3) equal justice and presumption of capacity; 4) autonomy, including freedom of movement, freedom from interference, and bodily integrity; 5) family and community participation.

Where possible, the study participants' experiences of protection of human rights under the *Mental Health Act 2016* in each of the five study focus areas were also summarised in relation to the above five human rights.

1.2. Reporting

The study findings are reported in six chapters, starting with the participants' general views on the *Mental Health Act 2016*, to then explore their views on the five study focus areas in the following sections.

Findings are reported from all the interviews conducted in the study and referring to three main groups of study participants:

1) people with lived experience of mental health challenges, referred to as participants with lived experience or consumers;

2) their family and carers;

3) service provider stakeholders (referred to as service provider participants), by which we mean all the service providers, practitioners, experts, and advocates who participated in the interviews in both Phase 1 and Phase 2 of the study.

The general expression 'participants' is used to refer to all three groups of study participants.

The views of participants with lived experience, their family and carers are reported in every section of the report together with those of the other stakeholders. Results of the data analysis are presented supported with verbatim quotes from the participants. The following codes are used to identify the data source:

- MHP (1-6): Mental health practitioners
- MHEA (1-17): Mental health experts and advocates
- Consumer (1-10): Consumer participants
- Carer (1-5): Carer participants

1.3. Study limitations

The study was conducted using a purposive, maximum variation sampling method, which allowed the research team to be inclusive of a wide range of experiences about the protection of human rights of adults who receive involuntary treatment under the *Mental Health Act 2016*. However, non-random sampling methods generate the risk that the study sample is not representative of the population being studied. Differences may exist between those who volunteered and those who declined participation in the interviews which are difficult to predict and quantify. Although this study's findings may not be generalisable to the wider population of people receiving involuntary treatment under the *Mental Health Act 2016*, the experiences and views of each single person about the protection of their human rights are valuable and important, regardless of whether they are typical of a large or small number of people.

2. Literature review – A summary

This section reports a summary of the findings of a scoping literature review which explored national and international literature on the five study focus areas:

- rights and information for inpatients within mental health wards;
- the role of Independent Patient Rights Advisers (IPRAs);
- Advance Health Directives (AHDs);
- the operation of the Mental Health Review Tribunal (MHRT);
- rights and information regarding involuntary treatment in the community.

A scoping review approach is best suited to explore topics that have not yet been extensively reviewed or are of a complex or heterogeneous nature, as in the case of this study (Appendix A).

The full findings of the literature review are published in Gendera, Giuntoli, Fisher and Kayess (2019).

2.1. Rights and information for inpatients within mental health wards

The rights and information of inpatients, family and carers within mental health wards are regulated by national documents – the Australian Charter of Healthcare Rights (ACSQHC, 2008), the National Safety and Quality Health Service Standards (ACSQHC, 2017), and the National Standards for Mental Health Services (Australian Government, 2010) – and state documents and laws, including the *Mental Health Act 2016*, the *Guardianship and Administration Act 2000*, the *Carers (Recognition) Act 2008*, and the Audit tools for National Safety and Quality Health Service Standards (Queensland Government, 2017).

These laws and frameworks recognise the right of all persons to the same basic human rights, including the right to have the highest possible standard of physical and mental health. The rights to safety, respect, receiving information in a clear and open way, participating in decisions and choices about care, privacy and confidentiality, and commenting on care and having concerns addressed are listed by the Australian Charter of Healthcare Rights (ACSQHC, 2008), and included in the National Safety and Quality Health Service Standards, the National Standards for Mental Health Services, as well as the *Mental Health Act 2016*.

Chapter 9 of the *Mental Health Act 2016* provides for a statement of rights and the rights of patients and relevant others, including the right of a patient to: 1) be visited

by the patient's nominated support persons, family, carers and other support persons (Section 280); 2) be visited by a health practitioner (Section 282), legal or other advisers (Section 283), 3) communicate with other persons (Section 284); 4) be given information about treatment and care (Section 285); 5) ensure that the patient understands the information (Section 286); 6) a second opinion to be obtained about a patient's treatment and care (Section 290).

Section 5 of the *Mental Health Act 2016* recognises and acknowledges Aboriginal people and Torres Strait Islander people. It states that 'the unique cultural, communication and other needs of Aboriginal people and Torres Strait Islanders must be recognised and taken into account. Similarly, Section 5 recognises and acknowledges persons from culturally and linguistically diverse backgrounds. It states that 'services provided to persons from culturally and linguistically diverse backgrounds must have regard to the person's cultural, religious and spiritual beliefs and practices', including using interpreters 'to the extent practicable and appropriate in the circumstances'.

Section 278 of the Act establishes that after admission of a patient to an authorised mental health service, the administrator of the authorised mental health service must: 1) explain the statement of rights prepared by the Chief Psychiatrist under the Act to the patient, ensuring that the patient understands the information given; 2) if requested, give a copy of the statement of rights to the patient and to the patient's nominated support persons, family, carers or other support persons. The administrator of an authorised mental health service must also display signs in prominent positions in the service stating that a copy of the statement of rights is available on request (Section 279).

2.2. Independent Patient Rights Advisers (IPRAs)

The *Mental Health Act 2016* for the first time in Queensland establishes the positions of Independent Patient Rights Advisers (IPRAs). IPRAs have an important role in informing people with lived experience of their rights under the *Mental Health Act 2016* and in liaising between clinical teams, patients and support persons. IPRAs must act independently and impartially, and they are not subject to the direction of any person in relation to the advice given to a patient or a patient's nominated support persons, family, carers or other support persons (Section 295).

Section 294 of the *Mental Health Act 2016* establishes the functions of IPRAs, including to:

a) ensure that a patient, and the patient's nominated support persons, family, carers and other support persons are advised of their rights and responsibilities under the *Mental Health Act 2016*;
b) help the patient, and the patient's nominated support persons, family, carers and other support persons to communicate to health practitioners the

patient's views, wishes and preferences about the patient's treatment and care;

c) work cooperatively with community visitors performing functions under the *Public Guardian Act 2014*;
d) consult with authorised mental health practitioners, authorised doctors, administrators of authorised mental health services, and the Chief Psychiatrist on the rights of patients under the *Mental Health Act 2016*, the *Guardianship and Administration Act 2000*, the *Powers of Attorney Act 1998* and other laws;
e) in relation to Tribunal hearings - (i) advise the patient, and the patient's nominated support persons, family, carers and other support persons of the patient's rights at the hearings; and (ii) if requested, help the patient engage a representative for the hearings;
f) identify whether the patient has a personal guardian or attorney and, if the patient has a personal guardian or attorney, work cooperatively with the personal guardian or attorney to further the patient's interests;
g) if appropriate, advise the patient of the benefits of an advance health directive or enduring power of attorney for a personal matter.

The *Mental Health Act 2016* does not make use of the word advocacy in relation to IPRAs. However, Section 294(b) states that the functions of IPRAs include to 'help the patient and a patient's nominated support persons, family, carers and other support persons to communicate to health practitioners the patient's views, wishes and preferences about the patient's treatment and care', which seems to entail elements of an advocacy role. The advocacy role is more prominent in other patients advisory roles in Australia and internationally, such as for example the Independent Mental Health Advocates (IMHA) in Victoria and in England.

2.3. Advance Directives

Advance Directives (ADs) are a tool that people with lived experience can choose to use to provide information on treatment preferences and other instructions for those times when their capacity to make decisions about their care and treatment are hampered by acute mental illness or distress.

ADs have been incorporated to varying degrees in the Australian Capital Territory (ACT), Queensland (Qld), Victoria (Vic), and Western Australia (WA) (Ouliaris & Kealy-Bateman, 2017). Some states and territories have limited or no legislative provisions in their Mental Health Acts for ADs including New South Wales (NSW), Tasmania, South Australia, and the Northern Territory (Ouliaris & Kealy-Bateman, 2017).

In the *Mental Health Act 2016*, ADs are referred to as Advance Health Directives (AHDs), therefore here the expression mental health ADs is used to refer to the literature findings across different contexts, whereas the expression AHD is used to

refer to findings specific to the Queensland context. Part 8, Division 1 of the *Mental Health Act 2016* states that 'the advance health directive may include the principal's[4] views, wishes and preferences about the principal's future treatment and care for a mental illness'. In deciding the nature and extent of treatment and care to be provided to a person under a treatment authority, the authorised doctor needs to: 'a) discuss the treatment and care to be provided with the person; and b) have regard to the views, wishes and preferences of the person, to the extent they can be expressed, including, for example, in an advance health directive' (*Mental Health Act 2016*, Section 53). This provision in the *Mental Health Act 2016* establishes an obligation for clinicians to determine the existence of an AD (Ouliaris & Kealy-Bateman, 2017). However, only the *ACT Mental Health Act 2015* specifically calls on a tribunal – the ACT Civil and Administrative Tribunal (ACAT) – to make an independent assessment in complex cases where there is an objection to the AD from any party, thus providing greater protection of patient rights (Section 28, *ACT Mental Health Act 2015*). When legally binding, ADs entail that the wishes that consumers state in their AD have legal authority and allow them to receive treatment as a voluntary patient, in accordance with their wishes, instead of receiving involuntary treatment. With regard to this, in the *ACT Mental Health Act 2015*, the consumer does not have to accept treatment that they previously consented to in writing (Section 28, *ACT Mental Health Act 2015*).

Research evidence from randomised controlled trials (RCT) are contradictory about the benefits and outcomes of ADs. Thornicroft et al. (2013) found that ADs were not significantly more effective in reducing hospitalisation and levels of coercion , whereas other RCTs found some evidence that AHDs might reduce compulsory treatment, improve the therapeutic relationship between people with lived experience and clinicians, and help people with lived experience to feel more satisfied and involved in their mental health care (Henderson et al., 2004; Sutherby et al., 1999; Swanson et al., 2006).

Overall, research shows a low uptake of ADs in different contexts. In an Australian computer-assisted telephone interview survey that included 2405 participants (50% of whom were female), 14 per cent reported to have an Advance Statement, including physical, age care and mental health ones[5] (White et al., 2014). White et al. (2014) found significant state/territory differences in the prevalence of ASs, with

[4] The Powers of Attorney Act 1998 (current as at 5 March 2017) states that in the context of advance health directive and power of attorney, principal means the person who made the advance health directive or appointed the attorney.

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

NSW, Australia's most populous state, having a proportion of ASs (13.3%) not significantly different from the Northern Territory (9%), Victoria (13.4%), Tasmania (15.1%) and the ACT (18.5%), but lower compared to Queensland (19%) and South Australia (21%) (White et al., 2014). The 2017-18 report on mental health service use in Victoria (DHHS, 2018) shows that only 2.59% of adults in Victorian public mental health services (n=72,859) had an AS on record.

Research shows that key barriers to the implementation of ADs include low engagement with the process from people with lived experience and mental health professionals alike, lack of ready access to the documents in crisis, a lack of clinician familiarity, and legal uncertainty about their application (NSW Health, 2005; Weller, 2010; White et al., 2014).

2.4. Mental Health Review Tribunal

The Mental Health Review Tribunal (MHRT) is an independent decision-making body under the *Mental Health Act 2016*. Section 28 of the *Mental Health Act 2016* states that the MHRT reviews: (a) treatment authorities; (b) forensic orders; (c) treatment support orders; (d) the fitness for trial of particular persons; (e) the detention of minors in high security units. The MHRT also hears applications for: (a) examination authorities; (b) the approval of regulated treatment; (c) the transfer of particular patients into and out of Queensland.

In addition, the MHRT has further powers in relation to appealing a limited number of decisions made by the chief psychiatrist or administrator (Sections 705(1)(c) and 533) (Qld Health, 2017).

Here, the expression MHRT is used to refer to research findings specific to the Queensland context, whereas the expression MHT (Mental Health Tribunal) is used to refer to the literature findings across different contexts.

The reviewed literature showed that MHTs' role of protecting the rights of people with mental illness of unjustified detention or treatment can be hampered by factors such as an over-reliance on medical opinion, the quality of the health reports provided by medical staff, and a primary focus on risk and dangerousness assessments (Thom & Nakarada-Kordic, 2014). The reviewed literature has also identified several limits in the implementation of MHT processes, including lack of training for clinicians on how to report to MHTs, clinicians' reliance on personal views rather than the specific circumstances of each consumer, lack of resources (MHTs in Ireland devote 16 to 18 times the Australian expenditure per case), the number of virtual hearings, the timing of tribunal reviews, and limited legal representation before tribunals (Carney, 2011; Carney & Tait, 2011; Thom & Nakarada-Kordic, 2014).

Overall, there is agreement in the reviewed literature that there is a need for more support for people with lived experience attending MHTs, including advocacy from lawyers, carers and peers (Carney, 2011; Weller, 2011).

The *Mental Health Act 2016* strengthened the rights of mental health consumers in relation to attending MHRT hearings by addressing many of the issues raised in the literature, including:

- The possibility for the MHRT to appoint a lawyer at no cost for the consumer, if the consumer is not represented by a lawyer or another person and if the Tribunal considers it to be in the person's best interest. The MHRT must appoint a lawyer if the person is a minor, the Attorney-General is to appear or be represented at the hearing, and if the hearing is for a review of the person's fitness for trial, for an application for approval to perform electroconvulsive therapy on the person, or another hearing prescribed by regulation. The possibility for people with lived experience who become involuntary patients to nominate up to two support persons, who can: receive notices for the appointing person under the Act; receive confidential information, under the *Hospital and Health Boards Act 2011*, relating to the appointing person; request a psychiatrist report under Section 90 of the Act; act as the appointing person's support person in the Tribunal; or represent the appointing person in the Tribunal (to the extent permitted under Chapter 12 or 16).

- Introducing the role of IPRAs (Section 5), who can advise the patient, and the patient's support persons of the patient's rights at the hearings, and, if requested, help the patient engage a representative for the hearings.

- Strengthening the use of AHDs (Section 6), which also support people with mental illness to make their own decisions.

- Regulating the possibility for patients to ask for a second opinion (Section 290) and allowing the MHRT to order a relevant person to submit to an examination by a stated examining practitioner when a patient is already before the Tribunal for a matter over which the Tribunal has jurisdiction (Section 721). In Queensland, patients, their families and carers, can also use the Ryan's Rule to raise concerns if a patient's health condition is getting worse or not improving as well as expected, or start a complaint process with the hospital/mental health service or the Office of the Health Ombudsman.

2.5. Community Treatment Orders

Section 18 of the *Mental Health Act 2016* defines a treatment authority as 'a lawful authority to provide treatment and care to a person who has a mental illness who does not have capacity to consent to be treated'. It further states that: 'a treatment

authority may be made for a person if an authorised doctor considers the treatment criteria apply to the person and there is no less restrictive way for the person to receive treatment and care for the person's mental illness, including, for example, under an advance health directive'. The category of a treatment authority is community, 'if the person's treatment and care needs can be met in the community', or inpatient 'if the person's treatment and care needs can be met only by being an inpatient' (*Mental Health Act 2016*).

Here, the expression community treatment order (CTO) is used to report literature findings across different contexts. The expression Treatment Authorities – Community Category will be used to refer to findings specific to the Queensland experience under the *Mental Health Act 2016*.

Section 51 of the *Mental Health Act 2016* establishes that the category of a treatment authority can be inpatient only if the authorised doctor considers, after having regard to the relevant circumstances of the person, that one or more of the following cannot reasonably be met if the category of the authority is community: (a) the person's treatment and care needs; (b) the safety and welfare of the person; (c) the safety of others.

Section 140 regulates Community Category for Forensic Orders and Section 145 regulates Community Category for Treatment Support Orders. A forensic order (mental health) operates in a way that is more restrictive of a person's rights and liberties than a treatment support order (Section 130).The main difference between Forensic Orders and Treatment Support Orders is that similarly to treatment authorities, the category for Treatment Support Orders must be a Community Category unless it is necessary for the person to be an inpatient, having regard to the person's treatment and care needs, the safety and welfare of the person and the safety of others. On the other hand, Sections 138 establishes that the Mental Health Court can decide that the category of a forensic order is community only if the court considers there is not an unacceptable risk to the safety of the community, because of the person's mental condition, including the risk of serious harm to other persons or property.

The evidence in qualitative studies about CTOs remains mixed (Corring, O'Reilly, & Sommerdyck, 2017; Dunn, Canvin, Rugkåsa, Sinclair, & Burns, 2016; Floyd, 2013; Light et al., 2014). CTOs appear to be the preferred choice of people with lived experience and to increase some freedoms, in particular if the alternative is involuntary inpatient treatment (Banks, Stroud, & Doughty, 2016; Davis, Doyle, Quayle, & O'Rourke, 2015; Newton-Howes, Lacey, & Banks, 2014). However, there is strong qualitative evidence that many people with lived experience, family members and carers in Australia and overseas complain about not having access, received, or been provided with the necessary support to fully access, comprehend, and act on information about involuntary treatment, CTOs and their legal implications, and mental health consumer rights more broadly (i.e. review process) (Corring et al., 2017). According to Corring et al. (2017), legislation needs to

improve the mechanisms by which people with lived experience, family members and carers receive mental health information and support to understand the information and manage their pathways through the mental health system.

Overall, CTOs as a treatment or procedural tool in community mental health remain controversial regarding their efficacy and outcomes and pose some risks to the rights of people with mental illnesses.

2.6. Conclusions

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

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

The *Mental Health Act 2016* has introduced some important changes, for example treating persons in a less restrictive way, the role of IPRAs, and promoting the use of AHDs. These changes make the *Mental Health Act 2016* more closely realise the requirements of the CRPD comparatively to the previous legislation.

However, there is a need to investigate the experiences of protection of human rights of people with lived experience under the *Mental Health Act 2016*. The findings of the literature review provide a background for the discussion of the findings of the interviews on the experiences of people with lived experience, family members and carers, and other stakeholders of the implementation of the *Mental Health Act 2016* across the five study focus areas.

3. General comments about the *Mental Health Act 2016*

3.1. Summary

Although there was initial excitement when the Act was first introduced, many participants commented on the limited changes they had observed in mental health practice so far. Changing the culture of mental health services as well as that of individual teams and practitioners, which often differed from place to place and which was described as characterised by paternalism, was seen as an important element in promoting the human rights of people with lived experience. To this end, the need for further leadership and time to effect these cultural changes was noted. Further resourcing, training, guidelines and administrative assistance were identified as crucial supports to strengthen the capacity of mental health teams to fully implement the *Mental Health Act 2016*. The need to clarify aspects of the Act that were unclear, standardise health services responses and monitor adherence were also identified.

The following aspects of the *Mental Health Act 2016* were discussed as still presenting some gaps in relation to the protection of human rights of patients, family and carers: 1) a lack of safeguard mechanisms for the 72-hour assessment period; 2) limited mechanisms to challenge seclusion and restraint; 3) people who have a dual diagnosis (intellectual disability and mental health challenge) do not have the same level of protection in relation seclusion and restraint when they find themselves in an authorised mental health service or with a forensic order under the MHRT; 4) the *non-revocation period*, which can be up to 10 years for certain offences, may not allow a more dynamic consideration of the person's response to treatment and whether the ongoing forensic order should be withdrawn based on how a patient is actually progressing.

3.2. Introduction

Participants' general views on the *Mental Health Act 2016* are here summarised under two main headings and discussed below:

1) Expectations

2) Factors influencing change

Most participants with lived experience, family and carers did not make general comments on the *Mental Health Act 2016*. However, they often reported comments in line with the feedback from service provider participants

3.3. Expectations

Generally, service provider stakeholders reported that, at the introduction of the *Mental Health Act 2016*, there was widespread expectation that the Act would strengthen human rights for consumers, focus more on recovery, include family and significant others in treatment, and ensure that decisions were more transparent. The role of the IPRAs and the focus on a 'less restrictive way' were identified as strong examples of how people could view the Act as ensuring people with lived experience of mental health challenges had their human rights protected.

> There was a lot of excitement, there was a lot of buzz about how it was going to significantly enhance patient rights, that it was a patient rights-based legislation, that there was a lot of talk about the important role of the IPRAs that came through from the Minister and from the Director General. (MHEA 7)

One participant expressed their surprise at the extent of the changes made to the Act.

> It was really interesting because initially I was like... There were changes, but I wasn't quite clear that they were significant changes, but the more and more I've looked at it, it's almost like Queensland's had to go vroom … we've had to progress very quickly with this Act. (HP 1)

Others were concerned about the impact of the new Act on current practices and team culture (Section 3.4.2):

> So, my expectation wasn't based on me knowing anything more about the previous Act, but when I did read it and thought about the culture, I was concerned how it would be received and how it would work. So, I was I guess dubious, I wasn't excited at all, I thought this was going to be a very hard task. (MHEA 8)

Whilst most service provider participants were initially excited about the changes in the legislation, some were unsure to what degree the changes actually influenced mental health practice.

> I was hopeful of a more rights-based approach and I've been disappointed. (MHEA 10)

Participants with lived experience, family and carers were concerned about the limited changes to practice, particularly in relation to their experience of receiving care in both hospital and community.

> Well, obviously [the Act] is more consumer focused, more on recovery. To be quite honest, I don't know if it's working … I think it's documented in there that their human rights are protected. But I don't see a lot of that happening. (Carer 1)

One consumer was able to identify contact with an IPRA and receiving information about the AHDs, as the only changes they had noticed since the introduction of the Act 18 months prior (March, 2017).

> I didn't notice any difference, no. The only difference I noticed was that I've got IPRA and the advance health directive, that's what I have noticed. (Consumer 1)

3.4. Factors influencing change

Participants identified factors that they believed had influenced how changes to the Act had been adopted in mental health practices, which are here grouped under the eight headings discussed below:

1) Paternalism in mental health care

2) Treating teams' culture

3) Need for training and information

4) Lack of practical guidance for practitioners

5) A focus on administration and form filling

6) Lack of resources to make substantial changes

7) Health services interpreting the Act differently

8) Lack of consequences for non-adherence to the Act

9) Perceived limits in the new Act

3.4.1. Paternalism in mental health care

The concept of paternalism is defined as the restriction in a person's choice or opportunity to choose without their consent with the objective of furthering the person's perceived welfare (New, 2008). Participants discussed a long-standing history of mental health practitioners and systems reportedly protecting consumers, whereby beliefs that consumers were unable to participate in treatment decisions were common. This history of 'care' and 'protection' has resulted in paternalistic attitudes towards consumers, and a focus on risk rather than rights.

> I think there's a long history though, of just believing you know what's best for people. That real paternalistic idea. And that is difficult to then afford people human rights because they might make decisions that you don't think are the right decisions. (MHEA 1)

> Mental health is so patronising, in a way. It's so overarchingly, you know, we will tell you what's good for you. That's what it's been for a long time, and this is a massive shift to try to get people to recognise that we'll work with you to find out what's going to work for you. (HP 1)

In referring to the effects of the paternalistic culture in mental health practice, one service provider participant reported the view that there are more treatment authorities under the *Mental Health Act 2016*, despite its less restrictive approach.

> I just think it's still a very paternalistic culture, that's the difficulty, you know, when people say, "We've got this new Mental Health Act that's meant to be less restrictive, but the treatment authorities are more now than they were before, under the [previous Involuntary Treatment Orders]." I don't understand why that is. Sometimes I just worry that treatment authorities aren't sometimes used in, for more risk averse way than a clinical way. (MHEA 4)

3.4.2. Treating teams' culture

In addition to a paternalistic view of care, service provider participants explained that each treating team had a particular team and working culture. Changing team culture was seen as a difficult task and one that would require time and leadership to achieve. The underlying beliefs and attitudes of staff were described as the main driver in changing staff behaviour towards consumers, and how staff implemented aspects of the Act.

> I find it depends more on the staff who are on [the inpatient unit] than the Act itself. (Con 4)

> …about relationships. It really comes down to… it really has very little to do with the content, and even with the legislation. It comes down to how it's all managed with the people…. I think our good staff, our good, consistent staff, are still good and consistent. And our less good and consistent staff are possibly doing things because they have to, but I don't think deep down they've consistently changed their attitude. Possibly. (HP 4)

> Yes, yes, I think it's the team leader makes all the difference in the world, because it starts from the top and works its way down. So, if there's an issue and it's brought to one of the staff member's - more junior staff members - if you like, if it's brought to their attention and they pass that onto the team leader, quite often it will depend on what the team leader does as to what actually filters through to the patient. (Carer 5)

3.4.3. Need for training and information

Service provider participants identified that confusion and misunderstandings about the Act remained for most practitioners. While many had attended some training, there was still concern and a lack of clarity about how best to apply changes in the Act in practice. Further mentoring and different forms of training were recognised as essential to assist a better understanding of the human rights aspects of the Act,

how to support this in everyday professional practice and, therefore, change teams' culture regarding using a less restrictive way approach.

> So, there's a whole lot of education that hasn't sort of happened around in this sort of space. There was lots of education online, and I did all of the training for the doctors and the psychiatrists, because we could access that, but it doesn't appear to have changed the culture of how things are done. On the ground, in the wards, there's not … there just hasn't been a change. (MHEA 1)

> There was actually a lot of feedback from teams, I would say nursing staff, who actually would often say, "There's nothing much changed between the old Act and this Act." They really completely missed that the legislation had a far more patient rights focus. And come fifth of March [2017, introduction of the Act] there was no change really, like on the ground, and I was quite stunned about how naïve they were about that, even though they had done the mandatory online Mental Health Act training. They really didn't quite get it, for a lot of staff. (MHEA 7)

> Yeah, and that's, I think, a barrier to a clinician, you know, to - about informing people of their choices and their rights and all that sort of stuff. Because if they don't really - not really sure themselves - and it's, like, happening right now in front of you in assessments, you know what I mean, they're not going to have those more in depth conversations with the consumer. So, I think that's a bit of a - it makes it hard for a clinician to inform someone of their rights if they're not really sure of what the person's entitled to. (MHEA 3)

3.4.4. Lack of practical guidance

In addition to a widespread lack of understanding of some aspects of the Act, service provider participants also described receiving limited practical guidance and few examples that provided an overview of the processes supporting the changes in practice.

> I think my biggest issue when I read the Mental Health Act or was going through it - I don't think anyone's read the whole thing, but my biggest issue is that a lot of it was built on more this ideal sort of thing. And in terms of actual practicalities the old Act was better, because the old Act was a bit like it's A, B, C, D, E. Whereas with the new one it was a little bit airy fairy in some ways and even when I was doing the training, it wasn't clear in terms of okay this ... Yeah, the actual process. It was all geared towards how to be less restrictive. And that's fine, but at the same time on a practical level … How do we do it? People need yeah better guidelines. It took them a very long time to come out with things like a simple flow chart. (HP 6)

> I think another thing that is a barrier to us giving people more tools and more empowerment is the Chief Psychiatrist's website - I don't know if you've had a look at - it's very not clear. Back in the day we had a clinician guide. It was called a resource guide. It was massive; 130 pages. But it was the one document where clinically, you could go if you wanted to detain someone under the Act. Step one, here's what you should be doing. (MHEA 3)

3.4.5. Administration and form filling focus

The majority of service provider participants commented on the additional documentation and administrative processes generated by the Act. Changes to reporting requirements and the need to complete on-line forms increased the workload of practitioners.

> No, not so much. It's just like, that's another form, and the whole thing about this act is linking to something with five million forms. So, we've increased the burden of documentation as opposed to being able to talk to people. (HP 4)

> I worry as well that because the focus of the new Act, in being more – some doctors might describe as more legal I hear but also more administrative, like you need to produce all these reports in time and they're very strict on the administrative requirements. Everything is to be recorded, documented, that might erode the goodwill in implementing the positive changes ... I worry that it's going to just be seen as something that's in the too-hard basket there appears to be more focus on administrative compliance rather than balanced decision-making, a balance between both risk and rights. (MHEA 9)

However, advocate participants stressed the importance of reporting both in relation to informing patients and to safeguard their rights:

> Under the new Mental Health Act, I think the provision of information has vastly improved, especially when you go to a tribunal hearing. You're supposed to receive a report from the doctor saying why they think you should remain under an order seven clear days before the hearing. Before the new Mental Health Act, people were variously getting that report late or not at all before a hearing and hearings were still progressing as normal. But now the tribunal from the very beginning of the Act has taken a really robust view of that. They're not going to proceed with a hearing unless that client has had seven clear days to consider that report. So that's been a real positive outcome and we've seen a much better response from clinicians in making sure that the client has access to that report within the required timeframe. (MHEA 12)

In some cases, confusion remained about how best to complete the paperwork to ensure they were compliant with the new requirements

> Also, the paperwork that needs to happen - paperwork in terms of how we complete the paperwork. You'll do those things with the patient and then will fill the paperwork. Or someone else might start the paperwork. … So, the starting time and the signing time is different and there are two places where you can enter it and then you need to start a treatment authority. There's confusion about whether you should go by the starting time or the time you signed the document. (HP 3)

3.4.6. Lack of resources

Service provider participants and family and carer participants identified that to make changes, resources were needed - particularly for education, mentoring and

supervision. Treating teams were already seen to be stretched and overworked, leaving limited time to incorporate new practices to support the human rights of consumers.

> We kept saying the implementation of the Act is going to cost money. Because if it is about rights, we actually need access to more supervisors. We need more educators. We need people with time to do their job. We were told it was an essentially… required to be pretty much cost-neutral. So, you've got the same number of staff, with the old habits that they had before, trying to embed a new thing which is about human rights, which they did in nine hours online, with no increased access to supervision, training, or whatever, or capacity to have conversations about how to change this. And expect us all to just change. It's not going to happen. (MHEA 11)

Referring to an education talk that a carer gave in the past to an audience of doctors, a carer said:

> I really admire the fact that they stood up and they actually said, "Yeah, we get what you're saying, but our hands are tied. We have a certain number of hours a day, and half of that day we are on our computers doing our paperwork. We can't have consumer focus." Now that's a big problem too for them. They get 10 minutes, then they've got to move on, move on, move on. How much are you going to be able to help somebody in that time? So that's what I mean, I can really always see both sides of the coin. (Carer 4)

3.4.7. Different interpretations of the Act

As the *Mental Health Act 2016* was rolled out across the State, it became clear that different Health and Hospital Services (HHS) were doing things differently. Variety in the interpretations of the Act was reported and service provider stakeholders identified difficulty obtaining clarification to inform their practice.

> … but more to the point is that every HHS is interpreting patient rights, extraordinarily differently. How can that be? How can this be a patient rights-based legislation and every HHS interprets it differently? ... But when it comes to patient rights, its hotchpotch whatever is that HHS culture, how they've always done it, is going to lead how that patient's right is going to be implemented in that HHS … which is wrong. (MHEA 7)

> Okay, in the old Act, you know, people were left to do, you know, different things, and, you know, we're going to stop that. And, you know, so you're all going to be doing the same thing and we'll be comparing apples and apples ... and it has become clear that we've just slipped straight back into the, you know, people are just doing different things. (MHEA 3)

3.4.8. Lack of consequences for non-adherence to the Act

The majority of service provider stakeholders identified that the human rights of people with lived experience under the Act would be strengthened with better

monitoring and sanctions for health services not adhering to the guidelines. Whilst administrative compliance was monitored and reviewed, there was no review of the quality of the reporting or the changes to practice, particularly responses to complaints or identified human rights issues. A major concern was that individual health services were responsible for responding to concerns and there was no independent oversight.

> No, no, and I think that's a lot of the times, no teeth. If no one abides by [the Act], like there could be multiple instances of people not engaging in the rights of people, but nothing happens. It's like, okay, we've got all these human rights in the Act but if no one abides by them, nothing happens anyway. It's like, well, that's what it is. (MHEA 4)

> There's a real problem with some of those sorts of things, which I would really like for there to be some sort of consequences. Or even someone keeping a record that we could say, "This has happened many times.", just so that it could be perhaps looked at. Like I would hope that someone's keeping track of the hospitals and health services that aren't getting the clinical reports done if it's a common regular thing because we notice that there are certain services that are never ready. Is someone monitoring that? And really sad a lot of the time, because you know, we all go home to our families, to our beds, and they're stuck in a hospital, without lots of answers a lot of the time. It's really hard. (MHEA 1)

> I'm going to be very diplomatic and say that [the Act] tries to understand the business of a modern hospital but in doing so it doesn't provide any accountability for decisions. It does allow for accountability, but it doesn't push it back onto doctors or treating teams to be able to do these things. (MHEA 10)

> Oh, I just think there's too many loopholes for me. In the Act - I don't know - when you look at it you kind of notice. Because I've used it to my advantage over the years; there's shoulds and there's musts. I think the shoulds are a little bit, you know, loose and I think there's too many kind of loopholes, you know, for people to kind of get around. I think one of the big things that the branch have gone away from is they're not doing standard audits anymore. (MHEA 3)

3.4.9. Perceived limitations of the *Mental Health Act 2016*

Service provider participants discussed the following limits in the *Mental Health Act 2016* which they believed limited the human rights of people with lived experience, family and carers:

- A lack of safeguard mechanisms for the 72-hour assessment period;
- Limited mechanisms to challenge seclusion and restraint. In particular, people who have a dual diagnosis (intellectual disability and mental health challenge) do not have the same level of protection in relation seclusion and restrain when they find themselves in an AMHS or with a forensic order under the MHRT.

- Length of forensic orders

72-hour assessment period. Participants identified that the human rights protections embedded in the Mental Health Act did not cover the 72-hour assessment period. This was particularly confusing for people with lived experience who had attended the hospital voluntarily and then found themselves detained under the Act.

> There seems to be a lot of safeguards for people once they're under a treatment authority but the assessment phase, there doesn't appear to be a lot of "you must get this information," or, "you have access to an IPRA," or whatever within that kind of part of it … and unless you know to ask the questions then you don't know … they're not being told what they're options are and where they are at ... and it's scary. (HP 1)

Mechanisms to challenge seclusion and restraint. Some service provider participants reported that there are a lot of rules and procedures that clinicians must follow before they can place somebody under seclusion and restraint, which was seen as positive. However, they also flagged that there are limited ways to challenge the use of seclusion and restraint in the *Mental Health Act* 2016, and that the MHRT does not get involved in decisions regarding seclusion and restraint. Some service provider participants mentioned two mechanisms to challenge seclusion and restrain in the Act: for everyone, through injunctive relief through a Supreme Court; for people under a forensic order, the possibility for the Mental Health Court to enquire into somebody's detention. However, it was pointed out that these mechanisms can be quite inaccessible to patients.

The issue of the limited number of mechanisms through which seclusion and restraint can be challenged was reported as particularly significant for people with a dual diagnosis, that is people who have an intellectual disability and a mental health challenge. It was pointed out that, in Queensland, the *Disability Services Act* and the *Guardianship and Administration Act* have stringent safeguard mechanisms to protect the rights of people with an intellectual disability in seclusion and restraint. Any plan to use seclusion and restraint on a person with intellectual disability is reviewed by the Queensland Civil and Administrative Tribunal (QCAT) and those decisions can be appealed. However, because of the limited mechanisms to challenge seclusion in the *Mental Health Act 2016,* people with a dual diagnosis who are treated in an authorised mental health service (AMHS) rather than in a disability service (for example those on a forensic order) run the risk of having a lesser tier of rights in relation to seclusion and restrain. With regard to this, some service provider participants stressed the need for more training, understanding and knowledge regarding limiting restrain and seclusion practices amongst clinicians.

Length of forensic orders. Some service provider participants feared that the minimum time that the Mental Health Court can give for a forensic order to be in place (the *non-revocation period*, which can be up to 10 years for certain offences), may not allow a more dynamic consideration of the person's response to treatment

and whether the ongoing forensic order should be withdrawn based on how a patient is actually progressing. It was discussed how the minimum length of the forensic order was introduced to increase certainty for the public. Considering that the *Mental Health Act 2016* had only been in place for one year at the time of the interviews, the participants who raised this issue had not come across it a lot yet, but they feared that certain groups of people on forensic orders might experience this issue more and more in the future.

4. Focus area 1: Rights and information for inpatients within mental health wards

4.1. Summary

Participants with lived experience described the experience of being hospitalised as scary and confusing. No participants with lived experience, family members and carers reported that they had been denied the right to be visited or to visit a patient (Section 280 of the *Mental Health Act 2016*). However, some participants with lived experience reported that maintaining communication with their family and friends (Section 284) was challenging at times, either because they had to ask to be able to contact them, or because their mobile phones had been taken away. One patients' advocate reported that in some units there was still the practice of locking away patients' mobile phones regardless of any specific assessment of whether they were going to be detrimental to the health or wellbeing of the person or others.

No participants with lived experience, family members and carers reported that they had invited a legal or other adviser to visit when hospitalised (Section 283). However, a service provider participant reported that some clinicians are not willing to engage with IPRAs and lawyers who provide support to patients within the hospital. This participant mentioned that relationships need to be established to break down these barriers and that there is a need for more training aimed at educating clinicians about the importance of IPRAs and of supporting their role.

Similarly, no participants with lived experience, family members and carers reported that they had invited an outside health practitioner to visit when hospitalised (Section 282). However, participants spoke at length of the importance of accessing information in protecting the human rights of people being treated involuntarily in hospital (Section 285). There was acknowledgement that on admission often patients are unable to read and comprehend information, but it was stressed that it is important that the information continue to be made available again as people become well. It was recommended that information be provided in an accessible and appropriate written format as well as through discussion and having questions answered by staff.

The importance of communication with treating professionals was also identified as important when discussing treatment plans (Section 286). Some participants with lived experience reported negative experiences when requesting information about medication or providing feedback to treating professionals about what had worked for them in the past. Some also reported difficulties having their concerns or wishes heard and were concerned that if they did complain the treatment would get worse rather than better. Participants also identified that general health care was not always managed appropriately in the mental health setting. A few participants had

experienced negative responses to their healthcare needs. Overall, participants highlighted the importance of inclusion in decision making on their treatment.

Access for appropriate information for people from culturally and linguistically diverse backgrounds was also seen as important, as was support for carers to access information and participate in decision making. Some IPRAs reported instances in which information was not offered in a linguistically or culturally appropriate ways to patients.

Access to a second opinion (Section 290) was identified as a positive addition to the *Mental Health Act 2016*, which supported the rights of those being treated involuntarily. Concerns were raised by service provider participants regarding how this second opinion was arranged by HHs, questioning the independence of these reviews.

The fact that the *Mental Health Act 2016* requires authorised mental health services to provide data on the use of restraint on children and young people to the Office of the Public Guardian (Section 274) was discussed as an important improvement. Nevertheless, the lack of written consent to the use of restraint or seclusion on children by parents, guardians and carers as well as the lack of mechanisms to monitor provision of information on these practices by doctors to the children's parents, guardians and carers was seen as limiting their rights and choice. The fact that the *Mental Health Act 2016* does not require authorised mental health services to communicate the use of restraint or seclusion on adults to the Office of the Public Guardian was also seen as a limitation to safeguard people's right to bodily integrity and autonomy. Concern were also raised for the lack of safeguard mechanisms to question the use of medication by advocates, particularly in the case of forensic orders.

Over half the participants with lived experience, family and carers reported experiencing trauma when security guards were involved in restraint practices, with resulting physical pain and injury, fear and distress. Participants asked that mental health staff put more effort into de-escalation techniques before security personnel were called.

There was also high concern for the problem of sexual assault in AHMS wards and concerns were expressed about mixed gender wards.

Whilst it was acknowledged that smoking was not good for a person's health, for those who smoked, being prevented from smoking on the inpatient ward impacted negatively on their wellbeing and recovery.

Finally, some family members and carers reported not knowing who to contact to ask for information and experiencing difficulties in accessing information necessary for managing their loved one's affairs, such as for example Centrelink or social workers. One family member reported that although she learnt that a Centrelink

officer was supposed to once a week visit the hospital where her loved one was recovered, she did not know any other details and so was never able to meet the Centrelink officer. After the hospitalisation, this family member also learnt that at the hospital there was a social worker whom she could have asked information to, but she was not informed about this by the health staff.

4.2. Introduction

Participants' discussions about rights and information in the mental health wards are here summarised under four main headings and discussed below:

1) Hospitalisation – Availability of information and support
2) Information accessibility
3) Obstacles to information access and information
4) Communication about treatment and symptoms

4.3. Hospitalisation – Availability of information and support

Participants with lived experience, their family and carers discussed their recent experiences of hospitalisation. The experience of hospitalisation, particularly for the first time, was described as scary and confusing.

> The first time I was petrified. I didn't trust any of them [referring to health workers] and I would have come across really paranoid. No, it was just dark, cold and dingy. I don't know, just horrible ... It's a different world and it's not a normal world. I'm not saying that because of who's in there, it's just the clinical setup is very … It's not a real environment. (Consumer 1)

> Like I think it's a very traumatic experience to be put somewhere when you're unwell and you don't really know how long are you going to be there. And your mind just, I could see for her particularly, her mind was kind of just going, shutting down because she just thought well … What's the point? Yeah, it's a trauma in itself. I guess that's the way I can express that. (Carer 2)

The majority of consumer and carer participants described experiencing negative interactions with mental health staff, increasing their feelings of powerlessness. Whilst these experiences were not attributed to all staff interactions, when they occurred, they had a powerful impact on people with lived experience, family and carers.

> When you're sitting in a ward for six hours – like, we'd just be in the lounge and I'd just be brushing her hair and we'd be watching TV – I think they forget you're there, sometimes, and I could hear how they were talking to

> some of the patients, which I thought – that's not right, and no wonder this person is getting agitated, because the way you're talking – and I could see dynamics that were going on and I'd think, yeah, they just forgot that I was there. (Carer 5)

> Even while I was sort of outside, every time I used run away – run away because of the way they treat us, treat me, and I just couldn't handle it any longer, and I just don't know what to do, like, I have to keep my health together, I just can't, because of the way they treat me. Not just me, but other patients as well, you see how everyone else experiences, from what I see. But I do my best to, you know, do the right thing by the nurses. Sometimes they don't listen to us, they take advantage of us, and you know, ignore every bit of word we say to them. We've got to beg when we ask for something. (Consumer 10)

> I stopped digging my heels in, and arguing with them, and just doing exactly what they told me. Jump. How high? Three bags full sir. And that's part of the reason I'm so disgruntled with the whole system. That there's no personal care. (Consumer 8)

Issues such as a lack of respect, insufficient acknowledgement of all aspects of a person's life and experiencing arrogance were identified as impacting negatively on relationships with staff.

> And it's just like, well, that's not taking into the complete scenario of who I really am, and the way that I've been questioned by doctors has been quite atrocious. Just throwing out questions. That's really big for me. If someone's going to use a condescending tone, negative words, body language like stiff, rigid, and like towering over you … (Consumer 1)

> Just be spoken to properly, instead of treated the way that I was, treated badly, instead of, like I said, you know, the other day, the ambulance staff and the police all treated you fine and you know, spoke to you normally. You're in psychosis of course, but you can still acknowledge that you're being spoken to, asked nicely and everything like that and then when you get to [hospital] and you get treated like I was treated it was absolutely shocking. Yeah. (Consumer 2)

> That's your ego talking here. This has got nothing to do with what we're doing here. So, this is what I see a lot of, is power ego. I'm stronger and bigger than you, and I have a degree and you don't. You're unwell. I mean that the whole thing that they keep conveying to these people. (Carer 4)

The introduction of the role of the IPRA was seen as an important new support which facilitated access to information about rights and promoted access to independent advice and information.

> If they feel they haven't had a proper explanation, well does it hurt to ask an IPRA or someone else to give that explanation? Sometimes coming from another party can help because we communicate in a different way. (MHEA 4)

> I don’t think that’s going to be necessarily efficient but the IPRA’s are a really, really critical role to support patients to understand their rights, to understand decisions that are made, to be able to facilitate constructive conversations, to be able to sort of mediate as well. (MHEA 9)

Some participants with lived experience did not know about the role of IPRAs, neither were they told about them, as shown in the first quote below.

> I felt like I was annoying them [referring to nurses], like if I wanted to know more, it was just like, "Oh, I'm busy." Not that they would say I'm busy, but it was just the attitude of the nursing staff was we don't have time for this …Yeah, take your medication and go find something to do. I would think that they really weren't there for answering questions, I almost think it should be another role, there should be another person on the ward who's like a patient information someone. Like a communication person or that's their role, because the nurses just can't do it. (Consumer 5)

> I think it's really important just to be honest. Just to be honest with the patient …Yeah. We're concerned for you, so where are you going to put you somewhere where we feel you’re going to be safe, not we're locking you away. I mean there's ways of explaining things. You could say we don't expect you to be here for very long … The doctor will come around to see you ... you can go and get yourself a cup of tea, well you're welcome to do that. It shouldn't be like, no one can get out those doors no matter how hard you kick and scream. (Carer 2)

Participants acknowledged that many consumers struggled to read, hear or understand the information about their rights on admission due to acute illness, but it was recognised that it was still important for people to receive this information. Equally important was the need to ensure that the information was repeated and further explained throughout a person’s stay in hospital, in a format that could be understood by the consumer.

> I don't remember receiving it. I remember gathering it from the brochures on the wall and being very curious about all of it. Well, mostly... most of them and at that stage I sort of, I didn't know what my diagnosis was so I took a few brochures on different diagnoses and trying and understand it better. I think that I was comforted that the information was there even though I wasn't, at the time probably able to process it in the best way. I sort of gathered it for later use, and it turned out to be pretty helpful. (Consumer 5)

> I know that he got copies of everything, but that was when he was first admitted. There’s no point in giving him a comic book when he’s first admitted, because he won’t take it in. These things need to be offered when somebody’s first admitted, a week later, 10 days later, they need to be followed through. (Carer 1)

IPRA participants stressed the importance of having time and resources to ensure that patients understand the information provided:

> You’ve got to realise that you are going to have to fund systems that allow people enough time to not just say – here’s your rights. Not just say – this is

> your piece of paper, oh you're an 80 year old Muslim woman who can't read or can't even read English. That's not a problem, you've still got your rights. No, this is about making sure that someone is in a state to hear their rights and understands those rights. So it's about timing, it's about maybe going back a few times to talk to someone. (MHEA 10)

Other IPRA participants mentioned that, at times, some treating teams were worried about giving the statement of rights to patients in fear that it might aggravate them:

> Then the statement of rights. There's a fear that if you give them a statement of rights, if they're too unwell... I can see that at times, that they feel that that can aggravate them, but I understand that from their point of view. However, from my point of view is that it just doesn't matter. It doesn't matter if a person's unwell or not. (MHEA 4)

Participants discussed the importance of having information in the early phases of the processes of assessment, treatment and hospitalisation to assist consumers manage anxiety and feel like they have a say in how things happen. Access to information was seen as essential in facilitating a person's participation in decisions and treatment options.

> Well, I think look, I think when I first went into the hospital and usually the reason people go into hospital is because they're pretty unwell. I was quite unwell and not probably able to process, or my cognitive functioning wasn't what it normally would be. So maybe in that sense for them to sit down with me and say, hey, these are some things you really need to know about your stay in the hospital maybe wouldn't have been effective, but I still think they should have given it a go rather than jump to the most restrictive option. (Consumer 5)

> [Referring to the right of information as a human right] …It helps you to make appropriate decisions, and to participate. Because if you don't have information, and for me, withholding of information, whether it's intentional or not, gives the person with the information all the power. So, I think often we unintentionally don't give people information, or we're too busy, or we don't think they're ready, or whatever. But the more information you have, the more chance I've got that you're going to take responsibility for your illness. Otherwise I have to take responsibility, because I've got all the information. (HP 4)

Participants with lived experience who had families and carers referred to them as a primary form of support to access and understand information. If families and carers were aware of the information, they often helped by reinforcing and interpreting it.

> I really didn't know like how much communication they got. Like I really, I honestly to this day don't know what they were told or not told. And I also rely on my support system, so my mum and my brothers. Maybe they could explain it in a way that I could hear it a bit better. (Consumer 5)

Nevertheless, some participants with lived experience reported that maintaining contacts with their family could be challenging.

> I think I had to fight pretty hard to keep in contact with my family and friends, whether it was using their phone. Sometimes I used the landline, sometimes I used my mobile phone, but I had to keep being my own advocate for that. No one was like, would you like to call your mum? But it was important to me, so I did it. (Consumer 5)

The importance of access to support was also evidence when participants with lived experience had been granted leave. Some reported that there was not sufficient staffing resources to ensure that leave was supported – impacting negatively on the consumer's rehabilitation and right to community participation.

> Often there's this huge under-resourcing of staff and supports to help support people on leave, so we kind of get the ones on the board if they have only a little bit of on-the-ground leave and they can't get staff to escort them and they can't demonstrate that they're invested, that they can show that they are able to take the responsibility seriously. Do you know what I mean? (MHEA 9)

4.4. Information accessibility

Most service provider participants reported that the *Mental Health Act 2016* strengthened provisions for access to information and statement of rights.

> Yep. I think it's more explicit in the new act. Whether it's being consistently done is a different thing, but the act certainly makes it more explicit, where I think the old act was more implicit that that had happened. (HP 4)

The majority of study participants described providing or receiving information in a written form. Whilst it was important for people to have information to go back to, the written information was largely seen as not accessible and appropriate for users or easy to understand.

> I think they did receive some documentation, but I think … I think it really stressed her. It was like a big book, "Here you go." I thought it was – well, I thought it wasn't really pitched at the right … it was really, probably very good heap information from a legal standpoint, but it wasn't for the benefit of a patient needing to know… (Carer 2)

> The statements of rights, the AHD [Advance Health Directive] and NSPs [Nominated Support Person] that absolutely needs to be reviewed and revised without doubt. The statement of rights is gobbledygook to consumers. It's teeny tiny font. It's very legalistic, patients read it ... I've even had staff come up to me and go, "What does this line mean? And it's because it's a double negative. It's completely not ... There is no way in the world that's gone through any consumer groups because it's completely unconsumer friendly. So, I think all three forms absolutely need to be revised. (MHEA 7)

IPRA participants expressed concern that the information was not always provided in a culturally or linguistically appropriate manner.

> Patients come in and they're not given their rights and if they are, they're given a whole booklet of about 20 magazines, which they don't read. We've been asking for Indigenous-specific rights and information for months. Nothing. We get no feedback about the stuff we send. I don't know whether it's that people are busy. I don't know. (MHEA 5)

> I've actually gone up to the hospital, and I've said, "Have they given you the statement of rights?" … And this man ferreted around in his room and came out with a beautiful shiny package, not opened … because he doesn't speak English. And we actually put in a complaint to the hospital about this because they knew he didn't speak English. I had to get an interpreter to be able to speak to him. On the website, they just had to print it out in his language so that he could read it, but no one would take responsibility for doing that. (MHEA 1)

Team culture and the skills of treating professionals were identified as important factors in how information was provided. If the treating team valued information, there was a better chance that information would be distributed. If the treating team valued relationships and talking to consumers, there was a better chance that consumers would have processes and rights explained to them.

> I felt that the nursing staff were sort of my first port of call if there was any issue, but I felt on the whole even though that I think they were quite competent and did the job well. I think they were pretty cold, and I think that's probably how they're trained to not be too warm towards you because they probably don't want you to stay for very long. I didn't sort of feel that I had a rapport with any of them enough to say, "hey, I'm really not feeling okay about this." (Consumer 5)

> Like, one of the wards has got a whole folder of patient information leaflets about medication. The other one doesn't. I'm going, "Why?" Why are two wards, when one's proactive enough to have a folder that you can go, "So, [name], I'm starting you on this medication; here's a bit of information for you", and the other one doesn't? And the Act's got nothing to do with that. (HP 4)

One service provider participant suggested a process of recording when and how information about rights was provided to consumers to better track adherence to the *Mental Health Act 2016*.

> Well, I'd make sure that the information that we're meant to give to people, like some of it was embedded into CIMHA [Consumer Integrated Mental Health Application] or there was some kind of way of ensuring that some of those really basic things, you know, that happen for people like, "These are your rights. Do you understand?", you know, in an understandable way but that's recorded somewhere that – because I think that plants that seed in people that they know they've got rights. If we can just get that bit right, we might be able to move to other things. (MHEA 6)

4.5. Obstacles to information access and communication

Although the *Mental Health Act 2016* establishes patients' right to communication, including the use of mobile phones (Section 284), some consumer participants reported that their mobile phone was taken away as soon as they were hospitalised. This was often an impediment to them exercising their right to communication and maintaining contact with families and the wider community.

> Yeah, they take your mobile phone [referring to being in hospital as a patient] (Consumer 6)

> When you're ready HDU [High Dependency Unit] you can't have your phone. If you behave, and you take your medications, then they may allow you to use it for a certain period of time. It's so important. I think they need to have little booths or something for when you're in HDU they can just go into a little technology booth or something that. Okay, so nobody else can grab your phone, but you can use it. I mean, there's got to be some way. (Carer 2)

One advocate participant reported that some treating teams were not aware that under the *Mental Health Act 2016* participants had the right to use mobile phone, or other electronic devices, to communicate with others, unless the other person asks that the communication does not take place or if communication by phone or electronic device is likely to be detrimental to the health and wellbeing of the patient or others. (Section 284).

> I think there are a couple of examples where the treating team weren't aware of their responsibilities under the Act, and where the IPRAs have said "No, enough". A very, very good example of that is use of mobile phones. And the Mental Health Act is very specific about that. It says the person has the right to communication [… Before the *Mental Health Act 2016*] you weren't allowed to have your mobile […] it was definitely an issue that came up across our network [of advocates], where I said "No, read the Act. It's very clear. You cannot put a blanket ban on mobile phones". Having said that, there's no obligation for the health service to provide [power points] (MHEA 11)

Family members and carer participants particularly struggled to access information. They reported not knowing who to contact for information and experiencing difficulty in accessing information necessary for managing their loved one's affairs, such as for example social benefits.

> When my son was in hospital that time, that was nearly four months, most of that time he was at [Hospital] and then in the last couple of weeks he was transferred down to a different Hospital to the young adults. [When] he was transferred there, somebody mentioned that there was a social worker, because I'd been trying to get him on Centrelink and other things. And people had said oh a Centrelink officer comes in to Hospital once a week, but I didn't know who he was, or I wasn't able to touch base with him. So, I found out then that there was a social worker at Hospital who I could have spoken

> to, could have done a lot of things. I had no idea - the whole time he was there I was not told there was a social worker. I wasn't told anything as I said unless I rang and rang and asked and asked and asked to have a family meeting (Carer 3).

Some individual treating practitioners were seen as more helpful than others. Carers described a need to have thick skin and a lot of perseverance to get answers to their questions.

> Well there's no, you're going up to a counter and you're going up to ... you're tapping on the glass. So, it's very difficult to ... get the time… And also, if you're going up to a counter to ask for information, it's not confidential. Anybody could be standing there and overhearing, and so they're mindful of that, I'm mindful of that. And you don't get the opportunity to meet with the whole team (Carer 2)

> They only talk to me when I really get pissed off, and make it happen. I remember walking into hospital one day, and I walked up to the nursing station, and it was one or two o'clock in the afternoon on a weekday, and I said "I'm [name]'s Mum, would any of his treating team like to talk to me?". And the nurse looked at me and she said "Why?". So, I thought, well, this is a bit of a pointless task. So, I just went and visited him. (Carer 1)

> We weren't given information about anything. And we wanted to know what was going on and he was too unwell, so I think the idea of them saying oh we told him, or we've given him the information which I don't think they did, because I was in his room and there was nothing in his room, but saying that is pretty ridiculous. When a person's very seriously unwell in intensive care and I was there every day asking for information. So, I don't know, I don't think that our rights as a family unit were really taken into consideration. (Carer 3)

Carer participants reported that treating teams and hospital staff would often provide privacy and confidentiality as the reason that they were not able to share information. Whilst all participants with lived experience and carers acknowledged the importance of privacy and confidentiality, they often felt that this was used as an excuse to not spend time providing information.

> Yeah, he was living at home and look I understand that's a tricky one because of patients. One thing they were very good at telling us was about privacy, confidentiality and all that sort of stuff, we heard that a lot. In other words, back off. (Carer 3)

All carer participants expressed concern about the lack of information and communication when it came to organising leave from hospital for their family members. There was concern that carer's concerns and information about a person's wellbeing were not taken into consideration and they were not included in the planning for discharge.

> Everyone is left in the dark as much as the patient in the high dependency unit. Basically, my mum would call up continuously, they'd give her hardly any information. About the only time they'd actually contacted my mother or

> any of my family members, was when leave was going to be granted and even then, sometimes, they didn't even do that, it was up to myself to find out what was going on, to call. Even if I was let out on say weekend leave, they'd give a whole load of tablets, 'There you go,' go out for the weekend. Well that's great. (Consumer 8)
>
> They announced that [my son] was going to get weekend leave. This was a Thursday. I said what? Oh really? You know [my son] was sitting there desperate to get out and I knew he wasn't ready. There was no way. He just got out of PICU [Psychiatric Intensive Care Unit]… anyway we were flabbergasted, so after that meeting I chased the doctors, they disappeared, scurried off. I rang and rang and rang for the rest of that day leaving messages, please can they ring me, it's urgent, that Thursday. Nothing. Friday all day nothing. And then four o'clock that afternoon that's when he was allowed to have his leave, so I had to go and pick him up, I had no choice. He was ringing me, mum when are you coming? (Carer 3)
>
> My son lives with me and I was not involved in any conversations about discharge. One day I went to visit and they had him packed, ready and standing at the door to come home. (Carer 1)
>
> I wasn't very happy that she was being discharged back into the community, because I felt as though – if they had been listening to me more and taking on board my concerns – I could actually see that her condition was deteriorating, and telling them this. (Carer 5)

No participants with lived experience, family members and carers reported that they had invited a legal or other adviser when hospitalised (Section 283). However, a service provider participant reported that some clinicians are not willing to engage with IPRAs and lawyers who provide support to patients within the hospital. This participant mentioned that relationships need to be established to break down these barriers and that a program aimed at educating clinicians about the importance of IPRAs and of supporting them in their role.

> I think one of the difficulties with the IPRA role is that I think a lot of the IPRAs are getting pushed back from clinicians, so the IPRAs will try and engage with clinicians or talk to them or try and get information from clinicians and they're not let in. The clinicians won't talk to them or won't give them the information that they need to help the person in the hospital […] Privacy laws [might be] but I think there's a lot of – I mean, even when I started in this field […] years ago and I would rock up to a hospital and say, "I'm a lawyer. I'm representing someone. Can you please give me access to this document?", people would just go, "No, I'm not…" Even if I could show a client authority, they were really unwilling to engage with a lawyer to supporting a person within the hospital and so over the years we've broken down these barriers. We've made relationships and people are now talking to us and I think similarly it's a matter of – maybe it needs to be driven from above about educating clinicians about the importance of IPRAs and how important it is that clinicians are engaged with and are supportive of the IPRA role and understand what they're there to do and achieve (MHEA 12)

4.6. Communication about treatment and symptoms

Communication was also identified as important when discussing treatment plans. A number of consumer participants described negative experiences when requesting information about medication or providing feedback to treating professionals about what had worked for them in the past.

> They put me on medication, he [referring to the psychiatrist] was putting me on Seroquel in the morning, like, 600 milligrams of Seroquel. I've never had Seroquel in the morning because it makes you way too dopey, you can't drive a car, you can't do anything. It's a good drug. Seroquel's a good drug, used in the right way, but at night before you go to bed and you wake up in the morning and you're right to go. It's not something I need in the daytime, you know? I said "I can't be on this in the morning" and he said "Well this is what I'm putting you on." And I wouldn't take it and because of that he revoked my rights as going out of the ward with my mother for the day and as getting out of the ward for an hour for a cigarette or whatever. The psychiatrist just stopped all that, would not allow me any rights like that because I wouldn't take the medication that he prescribed in the morning – I wanted to take it at night (Consumer 2)

> The nurses had asked her to take some medication and she wanted some information about that medication, and they said, “No, you just have to take it.” And I said – yeah, and it wasn’t – it wasn’t done in a kind way, and they said that she was refusing the medication, and I said, “No, she’s not, she’s just asking for some more information, can you please provide that to her?” (Carer 2)

> They didn't give me a lot of information about the medication before they started me on it. They just said, "here, take this but you know we're trying this on to see if this helps," but it wasn't like they gave me a list of side effects or anything. (Consumer 5)

Communication was also key when discussing patients’ symptoms and wellbeing.

> I think there was one admission in the PA where I was full of energy and I got up in the morning and I was just walking the halls because it was the only space available and it was just to be active. Instead of having a conversation with me the nurses have written he's agitated, he's this, he's that without even speaking to - and recommending Valium and sedatives (Consumer 4).

Consumer and carer participants reported that inpatient treatment options were often limited to medication. An increased focus on counselling and other mental health interventions was recommended by a number of consumer and carer participants.

> So is that... it's about treatment, I guess. I feel that there's not the appropriate rehabilitation and treatment there for people. They give them their medication and that's it pretty much it. (Carer 4)

> Actually, there was no therapy, there was no things – and I'd been bloody banging on all the time about, well, what about some DBT [Dialectical Behaviour Therapy] and this and that and blah blah blah. I really don't know if that was being taken on board properly (Carer 5)

> Basically, they're a glorified drug dealer. Get the patients in, get them on the medication, get them out the door. There's no background ... Looking at the background, what caused the trauma in the first place. They just get them on the pills, get them out the door. It's not humane how they treat most of the patients. Having someone that's just been traumatised, going into a mental health unit, trying to get help, and then they're immediately sedated. Okay, I understand in some cases have to be sedated, but they're already put on tablets. (Consumer 8)

> So, you know, if you come in here and you're well, you end up coming out of here unwell. It's the same with these other institutions, the acute mental health and HDU … after that experience we had to engage a private psychiatrist, cost my parents thousands of dollars, to come in and deal with me and give me coping mechanisms and things like that. (Consumer 9)

> Yes, freeing up staff to talk with patients I think that's one of my major complaints about how the system is now. Yes, not having anywhere to go and being stuck. When you are a mass of energy, there is nowhere to go to exercise. At times they've just sedated me massively to the point of dribbling. Yes. It feels damaging and like punishment rather than any sort of care. (Consumer 4)

Feelings of powerlessness were expressed by both carer and consumer participants; they reported difficulties having their concerns or wishes heard and were concerned that if they did complain the treatment would get worse rather than better.

> To have a way to communicate like to find her voice. Because you are ... when you're put in HDU, you are literally in a soundproof box, and that's how you feel. You feel as though you're cut off from the world, no one cares or hears you, and so in your own unwellness you've got to find your voice. It's hard enough when you're well. So, if you don't have advocates there with you and support … because she just couldn't do it, she couldn't do it. It's like if you can't walk, you need an aid to be able to walk, a walking stick or a wheelchair. (Carer 2)

> Or the family meetings, it would be, "I need a family meeting, and I want it this week." As a carer or a mother, whatever, you don't want to make waves, because you don't want them to be mistreated in there. So, you try to be diplomatic all the time, but there comes a point where you've got to... these guys have to be accountable for their work ethics. Just I've had many years of those things. (Carer 3)

> And if you don't take your medication then you go into another smaller room. You have an injection you go into a smaller room. It's kind of, it's almost like trial by punishment. You're punished the moment you get in there for being unwell and then you're punished more if you don't agree to the medication. (Carer 2)

Participants also identified that general health care was not always managed appropriately in the mental health setting. A few participants had experienced negative responses to their healthcare needs.

> Inside the mental health ward ... this is horrible ... I actually burned my face with one of the hot water dispensers. Yeah. I was in there for a while, they treated the best they could, but they... really, they had no idea how to treat that, they just, they had no idea. So, I was released, I obviously had burns on my face, all they had done was give me some cream for my face … I was subsequently discharged to a boarding house. The owner there actually helped me out, took me out to a GP. I was treated on a weekly basis there … they administered penicillin, they treated the wounds. (Consumer 8)

> Then there was a particular day where he was not well, and it was a Sunday. I'll never forget it. I rang up and I go, "Has anyone gone in to see him today?" "No, I don't think so." This is at lunchtime, because I had just rung him and he goes, "I can't even move. I can even move. I can't get out of bed." I go, "Why?" He goes, "I don't know." Now they tried him on this new medication, and obviously it was Clozapine. Obviously, his side effect was heart. He was having a heart problem. Because he couldn't sleep, because he wasn't well, one particular nurse went in and gave him some Valium, but then an hour later I find out another one gave him Valium. So, he was over medicated, couldn't get out of bed, and was having a heart problem. It wasn't till I said somebody better go in there now and see how he is, and they had him straight to the emergency. (Carer 4)

> Well I was given a what's it called? A clozapine on the Thursday and was supposed to be monitored every half hour for the next 24 hours, they gave it to me, monitored my vital signs once on Thursday afternoon and sent me home Friday morning and I was already having a heart attack. I came back up on the Monday when I was at mum's because she didn't want to send me home and didn't want to send me back to the hospital. And they came back on the Monday and took me back to the hospital to administer medication to get my heart rate back down (Consumer 8)

Participants reported that they did not have confidence that complaints made to the HHS would have positive outcomes. The process of making a complaint was seen as complicated and there were concerns that a complaint would have negative implications for the treatment received by people with lived experience.

> Well, there is a district policy, but we don't believe it's being adhered to within the mental health service. We believe that they have their own sort of feedback box which they go through … there seems to be a lot of patients who have been in and out for many years and they don't see any point because they've never seen any good or bad come from it really. (MHEA 5)

> I spoke to them about it, I didn't put in a complaint. At the time I was so jaded, I was so traumatised. I just didn't have - and I thought what's the point … we will say one thing, this is what actually happened, and they'll turn around and put it on black and white that this is what happened. And it's happened many times and I just think what's the point, I'm not going to win. (Carer 3)

> What happens to those complaints, or what happens once someone complains or there's a problem, or something happens that shouldn't happen, where does that go? (Carer 1)

Access to a second opinion was identified as a positive addition to the *Mental Health Act 2016*, which supported the rights of those being treated involuntarily. Concerns were raised by service provider participants regarding how this second opinion was arranged by HHSs, questioning the independence of these reviews.

> The patient has a right to an independent second opinion and there is a Chief Psychiatrist policy which is essentially meaningless because it just simply reiterates in more words without any detail. What does independent mean? What does second opinion mean? And so, we've had a number of incidences of grey areas which I've personally disagreed with how the treating team have responded to those situations. (MHEA 7)

> But things like a second opinion is in the new Act, the right to get a second opinion. It's phrased something like if there's a disagreement, if you've raised issues about treatment and care and you're not happy with the response from the treating team, that you can ask for a second opinion. That looked really good. In practise, what's happening, though, is that the second opinion is from another psychiatrist ... in the same hospital, in the same service, under the same director of mental health, so they're mates with each other. Patients aren't stupid. (MHEA 1)

4.7. Use of restraint

A few participants talked about their experiences of the use of restraint, including on children.

The fact that the *Mental Health Act 2016* requires authorised mental health services to provide data on the use of restraint on children and young people to the Office of the Public Guardian (Section 274) was discussed as an important improvement. The Chief Psychiatrist practice guidelines on child and youth: treatment and care of minors states that notice as to be given within 72 hours after the minor's admission to enable the Office of the Public Guardian to consider the need for the involvement of a Community Visitor.

Nevertheless, it was pointed out that there is no consent form for parents or guardians to sign to consent to the use of restrain, including seclusion, on their child, nor that they have been explained and understand the benefits and the negative effects that are associated with the use of restraint, including prone restraint, which is used against children in authorised mental health services. Similarly, doctors do not need to sign any document that state that they have spoken to the child or their parents about the use of restraint. The lack of informed consent and mechanisms to monitor provision of information was seen as limiting the rights and choice of patients, family and carers.

It was also pointed out that the *Mental Health Act 2016* does not require authorised mental health services to communicate the use of restraint or seclusion on adults to the Office of the Public Guardian. This was also seen as a limitation to safeguard people's right to bodily integrity and autonomy.

A service provider participant also spoke about the use of medication as a form of chemical restraint. It was pointed out that in the legislation there is a lack of safeguards to question the use of medication by advocates, particularly in the case of forensic orders. While the Office of the Public Guardian is a short-term approver of restraint for people with disability, they have no decision-making jurisdiction in the use of medication which is part of a forensic order or part of a treatment order community. This was also seen as a limitation to safeguard the right to bodily integrity and autonomy of patients under a forensic order or a treatment order community.

Over half the participants with lived experience, family and carers reported experiencing trauma when security guards were involved in restraining practices. Physical pain and injury, fear and distress were outcomes of these encounters.

> The security guards and nurse staff when I went there virtually attacked me instead of treating me like another person and the security hit me and threw me down and threw me down on the bed and they give me an injection and they hit you right in the sciatic nerve and just goes straight in hurts like all hell, like nothing else you've ever felt. (Consumer 2)

> To put me down on a mattress, like probably nurses would have been fine. And it just adds that extra element of like ... danger … And I felt like I'd done something wrong and … I hadn't done anything wrong. So that wasn't a good feeling. (Consumer 5)

These participants would like to see more effort put into de-escalation techniques by mental health staff before security personnel were called.

> I know personally with my son, and he is a very difficult patient when he's unwell. And he's been in the system for so long, he knows what to say and what to do. It probably had been over 20 years since he'd had a put down or seclusion. And talking to other carers, rather than de-escalating, or spending the time to de-escalate, it was easier to call security. (Carer 1)

> February when I was in hospital was a bad experience. I was a little elevated and venting just verbally and they had me in the HDU and I don't remember the staff trying to talk me down or offering me oral medication or anything like that. The next thing I knew there were three security guards there and I noticed that the nurse had a syringe in his hand and I've just gone and flipped out and they took me down. Sometimes in the past staff have spent a bit of time trying to deescalate me verbally and that normally works. But that last time I don't remember any of that. It was just take him down and inject him and throw him in the room. (Consumer 4)

4.8. Right to live independently

Service provider participants pointed out how the right to participate in the community of people on treatment authorities is often affected by the support they have access to. It was reported that in many cases patients have prolonged stays in hospital because they don't have any support in place for them to be discharged. People who have support from family and friends who can take them out regularly can move back into the community much faster than people who have no support and do not have a similar opportunity to show their progress into the community, which can be slower. Lack of suitable accommodation for people once they are discharged from hospital was pointed out as another main factor affecting people's capacity to return in the community after hospitalisation. It was reported that, because of the shortage of suitable accommodation, people are sent to boarding houses, or not very secure accommodation, where they have no support, running the risk of becoming unwell again and ending up back in hospital. In these cases, mental health wards were described as a catchall for people whose needs can't be met elsewhere, which was seen as not appropriate and limiting people's rights to live independently and to community participation.

This was an issue that was reported as particularly significant for people under a forensic order with a cognitive or intellectual disability, but no mental health challenge, and those with a dual diagnosis, that is with an intellectual disability and a mental health challenge. It was reported that, in many cases, although these people could be transitioned back to the community based on their mental health, they experience prolonged hospitalisation or detention because there are no disability services in place to transition them back to community. There are only 10 beds at the Forensic Disability Service provided under the *Forensic Disability Act* 2011.

> Say a person with intellectual disability is stuck in a hospital because they've got nowhere to go, and the hospital says they are medically fit for discharge. They don't have a mental illness for us to treat. It's just that they have this intellectual disability and they're on a forensic order. We're responsible for them so we can't just discharge them to the world at large. They need somewhere to go and then Disability Services Queensland are saying, "Well, we're not going to have them" or "We can't have them" or "We don't have the funding to have them" and there's no responsibility placed on Disability Services to actually support this person. It's all on the mental health treating team to organise it for this person but they're stuck because they're not in the business of supporting people with disabilities other than mental illness

It was also pointed out that the transition to the NDIS was not helping this situation. This is because people don't really get support while they are in a secure setting such as custody or secure mental health facilities. So, that can mean that support services do not offer help to these people until they are outside of these environments, which entails that it can be very challenging to organise a transition back to the community, including getting parole for those in prison.

One opinion to address this issue was that, instead of placing someone on a forensic order and under the responsibility of Mental Health Services, they could be placed under a restricted practice regime under the responsibility of Disability Services.

It was pointed out how these difficult dynamics affected the rights to living independently and to community participation of these people.

4.9. Sexual assault

There was also high concern for the problem of sexual assault in the wards and concerns were expressed about mixed gender wards. It was points out that patients in authorised mental health services often have distorted conceptions of consent because of their past history of abuse and having been taken advantage of. Because they might not necessarily have a clear concept of consenting to sexual activity, they can be vulnerable to sexual assault by others.

4.10. Smoking regulations

The smoking ban on HHS property was identified as problematic for many of the consumer and carer participants. Whilst it was acknowledged that smoking was not good for a person's health, for those who smoked, being prevented from smoking on the inpatient ward impacted negatively on their wellbeing and recovery. Increased agitation and frustration were identified as a result of the no smoking policy. Nicotine replacement was offered, but described as ineffective in managing these symptoms. Inconsistencies with how staff enforced the smoking ban was also described, adding to consumer frustration.

> I think probably people are not looking for help that they need early enough, because they can't smoke. And even that has gotten way out of hand, because when people are unwell, you might get one whole shift who turn a blind eye … inconsistent rules … and then the next shift or the next day shift that comes on is full of smoking Nazis. And people who are unwell think "Well, I could smoke out here yesterday, and now all of a sudden I'm being punished for smoking today". (Carer 1)

> It was hard because with the voluntary patients they can smoke but the involuntary patients can't and when you're involuntary you sort of stay in there. Last time I was voluntary and people would just keep coming, can you sneak me cigarettes and all that sort of thing. Just really makes things difficult when everyone's asking. (Consumer 6)

5. Focus area 2: The role of Independent Patient Rights Advisers (IPRAs)

5.1. Summary

The addition of the Independent Patient Rights Advisers (IPRA) role within the *Mental Health Act 2016* was considered important in protecting the rights of those being treated involuntarily under the Act. However, most of the participants with lived experience, family member and carer participants had no knowledge of the IPRA role, although they felt that the addition of IPRA support in both the inpatient and community settings was a positive inclusion in the Act. Only two of the ten participants with lived experienced and one of the five family members and carer participants had experienced accessing an IPRA; they described the experience as positive and reported that they would access an IPRA again in the future if needed.

Many IPRA and service provider participants reported a lack of guidelines and direction to assist the development of the IPRA role. As a result, each HHS has implemented the role and governance structure differently.

Due to the lack of clarity regarding the IPRA role, some participants reported that the IPRA role was viewed with suspicion by some treatment teams and there had been difficulties in establishing positive working relationships. Other participants reported that some treating teams had already established positive relationships with IPRAs and integrated the IPRA role well into their practices. A collegial relationship with treating teams was seen as important to allow IPRAs access to information and referrals.

Many service provider participants reported a tension within the IPRA role with regard to the provision of advice rather than advocacy when working with consumers and carers. Most IPRA participants described their roles as advisers or facilitators, but not as advocates.

Some service provider stakeholders questioned the independence of the IPRA role due to the current governance and management structures which exist within the HHS, with recommendations that the IPRA role governance be from outside the HHS, with direct reporting requirements to the Chief Psychiatrist's office. Further resourcing to expand access to IPRAs across a number of sectors including community-based services and prisons was also recommended by service provider participants.

IPRAs have a clear and potentially key role in helping people with lived experience, their family and carers to access information on their rights (Sections 285 and 286 of the *Mental Health Act 2016*). It is therefore important to address the tensions and limits (e.g. current lack of resources for IPRAs in community-based services and prisons) of the IPRAs role.

5.2. Introduction

Participants' discussions about their views and experiences of IPRAs are here summarised under four main headings and discussed below:

1) The introduction of the IPRA role
2) Integration of IPRAs into mental health teams
3) Advice versus advocacy
4) Independence of the IPRA role

5.3. The introduction of the IPRA role

Most participants viewed the inclusion of the new IPRA role in the *Mental Health Act 2016* as a positive change. However, only two consumer and one carer participant had experienced accessing an IPRA. The other consumer and carer participants had no knowledge of the IPRA role but felt that the addition of IPRA support in both the inpatient and community settings was a positive inclusion in the Act. The consumer participants who had accessed IPRA support described the interactions with the IPRA as positive. Both consumer participants reported that they would access the IPRA again in the future if needed.

> It was quite a little way into my stay when I was on the open ward, not when I was in HDU. I had someone meet with me, and he sort of identified himself as coming from the legal perspective. He talked about my rights, and he said, "if you have any concerns you can tell me." At the time I think I was comforted by the fact that there was a person in that role, but I didn't sort of bring up any issues at the time ... so, I think he could have come a bit sooner because it was sort of like, it was just late in the piece and maybe some of the issues that I'd had initially I was sort of like, well its water under the bridge now. (Consumer 5)

> Yeah, because they didn't... they weren't untoward, they were... She actually took time to ask me good questions and she wasn't sloppy, she wasn't jumping me all over my brain, if you know what I mean. Like moving me from 2004 to 2018, to all across the timeline. She was respectful of my workings. She listened to me, yeah. (Consumer 1)

Most service provider participants saw the provision of independent advice and support to have rights recognised as benefits of the introduction of the IPRA role.

> So I had a lot of excitement and really I had an expectation that the rights that are contained in the Act were going to be, for once finally, these rights were going to be adhered to and it wasn't going to be mere rhetoric and the last thing in simply check that checkbox on a form for treating teams to do, and the fact that the IPRA's were independent from mental health services was going to help ensure that those rights were being met. (MHEA 7)

Service provider participants reported an initial confusion about the role of the IPRA. HHS had developed the IPRA role differently, with IPRA's working under different governance structures.

> There're some real systemic issues, you know, like we talk about – it's really disappointing that they made these roles with these beautiful policies, but nobody put in place any infrastructure before they started. It was never thought through. It's nice and shiny and looks good but the fact of the matter is, on the ground, people are floundering. (MHEA 6)

Service provider participants reported a lack of clarity in the IPRA role descriptions and limited guidance on how the IPRA service would be developed. There was a need to educate staff and consumers about the role of the IPRA and develop strategies to gain access to people with lived experience requiring information about their rights.

> When they started, they had no office, no phone, no computer, nothing, and they had to develop completely a service, an operational plan, work out what the model of service was ... which patients were going to see, which ones were not going to be seen? Market and promote the service. Work out what meetings to attend. They were working under the director of clinical governance, who is a director of multiple other teams, so it was really left up to them, and that was intense. Very intense … it was not okay that it was left to the HHS's to do that on their own. (MHEA 5)

IPRA participants identified the need to develop resources to support their role, with each HHS having to develop different brochures, posters, information sheets, forms and information videos.

> So, then we decided that […] we needed to up our promotion, so we developed our brochures. We made sure that when a patient gets admitted, which explains what their rights are, that it's on their bed, ready for them. We put posters up in every patient room. We had to develop the brochures, we had to develop the posters. We developed pull-up banners, so, again, in every mental health unit, in both mental health units and the community sites, they would know that there was this thing called an independent patient rights adviser. It says something about their rights, and if you want to know information, they can contact us, and it has our email and phone number, so when they can do that, we can come down and speak to them. (MHEA 7)

Some IPRA participants reported large workloads and insufficient time for them to respond to consumer needs appropriately. There was concern expressed about the capability of the current IPRA staffing to access all consumers requiring information and advice. Consumers in the community and those in the prison system were identified as specific groups which were not receiving appropriate IPRA support due to resourcing issues.

> I think it was a very poor oversight not to give us a dedicated team leader and not to give us admin support because what we are expected to do is unsustainable and too much ... I am both the advisor, I escalate issues, I have to establish meetings, I have to meet with community stakeholders, I

> have to answer all calls. I have to do extensive notes and I have to do all the data reporting, developing systems, promotion and marketing, developing this video, implementing everything. Promoting the service, training, in services. The list goes on ... (MHEA 7)

5.4. Integration of IPRAs into mental health teams

Due to the lack of clarity regarding the IPRA role, service provider participants noted that there had been issues with how the IPRAs were viewed by treating teams. A collegial relationship with treating teams was seen as important to allow IPRAs access to information and referrals. Some treating teams had established positive relationships with the IPRA and integrated the IPRA role well into their practices.

> I think in the beginning, they [referring to treating teams] weren't very receptive of it. It was the new Mental Health Act that came in and they were trying to get their head around the logistics that affected them in their day-to-day work, and they saw IPRA as something that wasn't vital to their work so, "We won't worry about that." Because they didn't have a good understanding of what our role was, they weren't able to promote it, to tell patients what it was about. Now they're sort of coming around a bit because especially in the inpatient units, we don't just tell patients, "These are all your rights", they also have responsibilities that they need to work with their treating team and what their options are if they don't believe that they need to be admitted or are on a treatment authority. (MHEA 5)

> Yeah. All my guys love our IPRA, she's great. In the beginning, there was a bit of … as she was finding what her role was, and she was sometimes overstepping what particularly the consultants thought was her job, but now they've sorted that out. (HP 4)

Other participants reported that the IPRA role was viewed with suspicion by treatment teams and there had been difficulties in establishing positive working relationships.

> But, we've tried to do everything that we can to try to avoid having a reliance on the treating teams, because their staff turnover is high, because they still don't understand what we do, because, you know, we're not part of their team, so it's easy for them to forget about us. So, we've tried to have a less of a, a reliance on those. (MHEA 9)

> The vast majority of referrals come directly from the patients. We do get a lot of referrals from the allied health members as well. We don't get a great deal from the doctors, sometimes some of the registrars, sometimes - nurses a bit too, we get a bit of nurses but once again we can have allied health staff and nurses approach us about a referral and say 'you never heard it from me' so it shows the type of environment that they're still working in. (MHEA 4)

> Yeah. Yeah. Absolutely. It, like, other services, which I won't name, they have massive issues; it's combative and it's, like, from the service perspective it's them against us. (MHEA 3)

The need for practitioner education and leadership support was identified as important in promoting the IPRA role and ensuring consumer access to IPRA support. IPRAs reported that some nurses were still confused about the role and responsibilities of IPRAs, advocates, and complaint officers.

> For example, next week, we have a meeting with the nurse unit managers to educate them on the role of the IPRA, the role of the consumer advocate, the role of the consumer complaints officer, because they call our service and say, "Oh, can I just have one of you? It doesn't matter which, whatever. The patient needs to speak to someone, whether it's the IPRA, or the complaints person, or the consumer advocate." Now, that's just not appropriate, because the IPRA has a very specific, legislative role. (MHEA7)

5.5. Advice versus advocacy

Many service provider participants reported a tension within the IPRA role with regard to the provision of advice rather than advocacy when working with consumers and carers. The *Mental Health Act 2016* defines the legislative role of the IPRA as one which provides advice to people about their rights and responsibilities under the Act. However, Section 294(b) states that the functions of IPRAs include to 'help the patient and a patient's nominated support persons, family, carers and other support persons to communicate to health practitioners the patient's views, wishes and preferences about the patient's treatment and care', which seems to entail elements of an advocacy role. However, most IPRAs described their roles as advisers, but not as advocates.

> They're advisers. So, at any point the patient or their family can, if they know they exist, get in contact with them and ask them questions where the IPRAs can advise about things under the Act. But only things under the Act, not other things. And only advise, not advocate. (MHEA 1)

> Exactly. Because you want to make the advice that you provide the patient; you provide them with general broader rights information and then you make it really specific to them, to what their complaint is, and then you can really target, "okay these are your rights with regards to the tribunal", or "your mechanisms for appeal, or how we can real this to the treating team." (MHEA 7)

> So, the question that continually comes up from the Rights Advisers is are we Rights Advisers or are we advocates? I'll be really clear saying "You are not advocates. You've really got to think about how you present information, how you ask questions, and the dialogue you're having not only with the patient and carers but with the treating team. It's really important, because the Queensland government made a decision that we aren't advocates". So within that space then how do we link with the content experts? […] So if the patient and carer or ourselves might feel it appropriate to have an advocate involved, we make the suggestion that maybe an advocate would be useful, and we support the patient to walk down that path (MHEA, 8)

Concerns were raised about whether assisting consumers and carers to act on advice would be seen as advocacy and outside of the role of the IPRA. There was no agreed definition of advocacy provided by service provider participants and each HHS appeared to have a different interpretation of what actions constituted advocacy within the IPRA role. It was identified that many people with lived experience have limited support networks and often required additional support or advocacy to have their voices heard – but it was unclear if the provision of this support was the role of the IPRA. Some IPRAs referred to their role as entailing elements of an advocate, or a facilitator.

> No, because the patient doesn't know enough about the Act. What they know is … "[name]'s come to me and said I can't have my phone, and I don't understand why, and the nurses are not telling me why". That's an invasion of a person's rights under the Act. They are unable to go the nurse unit manager. So, I've told them "well, you come and tell me, because I might be able to talk to the manager". To me, that's not an advocate; that's a facilitator. (HP 4)

> Yeah, it's been a work in progress, I think at the beginning, the Mental Health Act stipulates what our duties are but we're still - the hard thing it becomes is that if you're working with these people and - you're working with some clients and then the problem is that your role is fairly restricted about what you can do and can sometimes tip over into advocacy … which really can be your role. So, one of your roles is expressing the views and wishes of people with regard to their treatment and care including their carers and support persons. So that in a sense is advocacy, you're advocating for them. (MHEA 4)

In addition, it was noted that it was very difficult for consumers and carers to enact systemic change within health organisations without support from staff. The role of the IPRA, understanding the system and advocating for better protection of human rights across the service, was identified as an important facilitator of systemic change.

> Yeah, that's right. Having your say, that's advocacy. Supporting someone to have their say, that's advocacy … So, if an issue arises and the consumer has a certain need that isn't being met by that health service, [the IPRA] might understand, "Well, I need to go to that committee, and I need to link in with that person, and I need to advocate for this particular procedure to change because that's creating a barrier." Not all of it is direct advocacy for the person, but it's all important ... knowing the systems and being able to change so that the whole organisation can be more receptive to people's needs. Yeah. (HP 1)

5.6. Independence of the IPRA role

Service provider participants noted the importance of the IPRA being seen as independent from the mental health service. Consumers and carers trusted information provided from sources outside of the treatment team.

> We use - sometimes when we talk to the patient and they say "look I don't agree with the treatment authority, I don't agree with this" and then we say "look you're under the Mental Health Act. Under the Act you can speak to the independent patient rights adviser. This is the person. How about you speak to them" and they come and explain the process and their rights. Sometimes the patient's still angry but sometimes they understand their rights better if it comes from the independent person. (HP 3)

The employment arrangements of the IPRAs were seen as a major issue which inhibited the independence of the role. Many IPRAs were employed by the health service directly whilst others were employed by external organisations funded through health.

> Yeah and it's hard, and we've had conversations at a state-wide level with other IPRAs that our governance perhaps should go under somewhere else, instead of the health service. You know, the health providers. (MHEA 4)

> [The IPRAs] have been parachuted in, in an attempt for quasi-independence and I say quasi-independence quite deliberately. Even if they are employed by an organisation as a service to provide the IPRAs, they are still hired by Queensland Health which is a little bit tongue in cheek but it's a lot better than directly hiring the IPRAs I guess. How the hell do you have independence, how the hell is that independence. (MHEA 10)

> Personally, I do believe in the way that the service is set up; they need to be separate, yes … they can't be employed by an organisation that's administering the Act. I just don't think they can. I just think they have to be seen from a patient's perspective to be completely separate. (HP 4)

Whilst all service providers reported that IPRAs were seen as having values and behaviour congruent with their role in supporting the rights of people being treated involuntarily under the Act, there were concerns that they were open to bullying and silencing by health services under the current governance structure. The potential risk to the employment conditions of IPRAs if organisational concerns were raised was noted by the majority of service provider participants.

> In my opinion, these roles are an agitator for change. These roles are a change management role. Absolutely through and through and you cannot have a change management or a cultural change without conflict, agitation and upset and when you have a line manager within an organisation that your role is specifically designed to agitate, it is an extraordinarily precarious position for you to be in and it's a terrible position for your manager to be in. (MHEA 7)

> Because you're a health service employee, your code of conduct is to advise them of anything that could be a risk to the organisation. So, you have a moral, you know, responsibility to tell them and then you get threatened that you're going to be sacked or something. It's just very difficult. You just feel, "What difference can we make?" (MHEA 5)

> I'm part of it but I can try and make changes within it, but sometimes it's like chipping away at any iceberg, and that can be... Any IPRA I've spoken to

> around the state, the vast majority of them, it becomes emotionally taxing because you want things to happen and things to change, and you feel there's a degree of resistance there. So yeah. (MHEA 4)

In addition to independence in employment conditions, service provider participants identified that there were no independent reporting options for IPRAs. Concerns were raised regarding the practice of managing complaints about practices which impinged on the rights of consumers internally by each HHS. It was identified that there is no current requirement for independent investigation or monitoring of complaints.

> And we are so unsupported. We are dealing with major issues, we are holding all these multiple issues of legislative breaches. Very clear legislative breaches. The thing is not being done and there's no mechanism for us to report on this. Who do we tell? And when the HHS essentially is trying to protect their own skin going, "Do not raise this, quieten down." We need to have a mechanism to report on these issues and almost act unfortunately like this monitoring compliance that we have by being on the ground. (MHEA 7)

> So, then the advice we got back from the Chief Psychiatrist via S was that the Office of the Chief Psychiatrist doesn't take issues escalated by IPRAs, it only takes it through the HHS." So, we took it further through our Clinical Governance Director and it didn't go well. They spoke to management for mental health. They said they fixed it so she was happy with that. We were accused of advocating and not advising. (MHEA 5)

Service provider participants recommended stronger reporting relationships between the IPRA and the office of the Chief Psychiatrist to promote HHS adherence with provisions of the Act and enable monitoring of performance. This would allow for central collection of statistical and reporting data and assisting in understanding impacts of the *Mental Health Act 2016* on those being treated involuntarily.

> In the Act, it should have some sort of formal reporting line on that IPRA report for an HHS, a monthly IPRA report on restrictive practices or on potential human right breaches, going to the chief psychiatrist. The chief psychiatrist, then, using that report to go back to the administrators and say, please explain. (MHEA 7)

> The legislation actually provides for the chief psychiatrist, in the chief psychiatrist's functions, it does say to consult with the independent patient rights adviser. That doesn't happen. There's no mechanism for that to happen. However, I think that there should be, and I think there needs to be legislative change around that. I think there should be policy recommendations for how we do report to them. Unfortunately, this is where the conflict of interest comes up with IPRAs being under the HHS, is that our HHS has given us very clear instructions, and my line manager's given me very clear instructions that we are not to report to the chief psychiatrist, at all, until we have exhausted all avenues of internal escalation. (MHEA 8)

6. Focus area 3: Advance Health Directives (AHDs)

6.1. Summary

Most service provider participants saw Advance Health Directives (AHD) as a welcome addition in the *Mental Health Act 2016*. AHDs were seen as an option that would promote less restrictive treatment practices and so support the rights to autonomy and bodily integrity of people with lived experience.

Nevertheless, very few of the consumer and family member and carer participants had heard of AHDs. The only participant with lived experience who had completed an AHD described the process as complicated, requiring several steps and visits to different people, including a solicitor and a GP. This participant was assisted by an IPRA in completing the AHD, whom they visited twice. The IPRA offered help with information and with writing the participants' wishes in a way that was clear and suitable to the AHD form. Service provider participants flagged the importance of keeping AHDs up to date, however, they mentioned that the way AHDs are currently used is not conducive to regular updates and so there is a risk that those in place quickly become out of date.

The type of help that people with lived experience might require to complete their AHD and to keep it up to date raises the question of whether IPRAs are the best persons to offer that support. It also raises the question of what other sources of support are in place for people with lived experience in the community or in prison, who do not have access to IPRAs and therefore might not know or have the necessary help to complete an AHD. Overall, both consumer and service provider participants reported the need to simplify the documentation and process of completing AHDs to increase their accessibility to different groups of consumers.

Service provider participants reported that different health services had adopted AHDs at different rates and that there was still confusion regarding how to access and utilise AHDs in practice. Service provider participants reported the need further training and information about AHDs to better understand the concept and how to work with people with lived experience to utilise them effectively. It was suggested that the training needed to target medical practitioners as well as mental health workers to ensure integration of the AHD across acute and community settings, as well as provide practical resources to support current training options.

Service provider participants expressed concern that the numbers of completed AHDs in Queensland was quite small, indicating a slow uptake. Among the three people with lived experience and two carers who were aware of the AHD, the main reason for not completing an AHD was a belief that it would not make any difference to their treatment on admission to hospital. Service provider participants also

reported that they had received feedback from people with lived experience that they were unsure if the AHD would be followed by the treating team and had concerns that even after completing an AHD their wishes would not be respected.

Service provider participants also reported problems with how AHDs were uploaded and stored in the CIMHA (Consumer Integrated Mental Health Application) system, with AHDs being automatically highlighted on the public mental health consumer record, but not for emergency, other health areas, and in private hospitals. The upload of AHDs into the electronic health record was described as requiring yet a different process. Concerns were raised that in a fast-paced health system, information pertaining to a consumer's AHD would not be accessed.

6.2. Introduction

Participants' discussions about their views and experiences of AHDs are here summarised under four main headings and discussed below:

1) The AHD as the 'less restrictive way' option
2) The process of completing an AHD
3) How the AHD is used in practice
4) Barriers to completing AHDs
5) Nominated support persons

6.3. The AHD as the 'less restrictive way' option

Most service provider participants identified the AHD as an important and valuable addition to the *Mental Health Act 2016*. Encouraging consumers to provide prior consent along with their views, preferences and wishes was an important step in protecting their rights and dignity.

> I was very excited. Initially I thought this is an opportunity for people to be empowered to have their say and have their needs met in a stronger, legislatively embedded way. (HP 1)

> Yes, look personally I think it is a formal recognition of somebody's wishes and that can only be a good thing, because they are so powerless in so many other spheres. The fact that the Act strengthens the storage of it, that you have to look at it, that you have to review it. You have to take it into account if you're the treating team. I think all that is really good, (MHEA 2)

The addition of the AHD supported the provision of care in the less restrictive way as it promoted a discussion about options with consumers and conversations that focused on choice. The AHD also provided services with ways to reduce the number of people being treated under a Treatment Authority (TA).

> Under the new Act we have to use the AHD as this is the least restrictive option - people were not very comfortable initially … what I read was that if the patient has an advance health directive or the patient has a personal guardian or the patient had a substitute decision maker then you can use those things - we have to exhaust all those options before you consider the Mental Health Act. The Act says you should not be putting a patient under a treatment authority if you had another less restrictive option. (HP 3)

> I think that there'll be less drama for the patient. So, you know, less agitation. They'll be less distressed. Because, you know, staff will be talking to the person and - and, you know, having a conversation, "Look, you know, you've consented to this. This is, you know, you know when you get unwell, you know, this is what you want." And, you know, showing the document in our own handwriting, you know, I think it'll just be more empowering for the patients that we're not, you know, enforcing this on them and not listening to them. (MHEA 3)

6.4. The process of completing an AHD

Very few of the consumer or carer participants had heard of an AHD. The only participant with lived experience who had completed an AHD described the process as complicated, requiring a number of steps and visits to different people, as well as the need to have someone assist with ensuring their wishes were written in a way that was acceptable.

> They sent me to the IPRA, and … she made it easier for me … I saw the IPRA, then I saw the doctor, and then I saw the IPRA again then I sent it to the doctor – oh, that's right, I went to my own solicitor … and then the IPRA helped me move the wording around, it actually looked and sounded, just a little bit more legally acceptable. It was kind of more of a legal way of putting things ... Different language. Different structure, yeah, because I'm not a doctor or a lawyer. (Consumer 1)

In addition, this consumer participant reported that they were asked to make changes to their wishes by the doctor before it would be signed and accepted.

> The first time that I actually showed the doctor my advance health directive, he said “no.” You need … to put in medication … on one hand I'm given the choice of what I'm allowed to say what my rights are, what I want, but at the same time, I'm having to do what makes the doctor happy. Still, got to jump through hoops … It's my health directive as long as it's done our way. (Consumer 1)

Service provider participants also reported the process of completing an AHD to be challenging, requiring considerable time and effort from consumers. The forms were described as difficult to navigate and understand and people with lived experience faced challenges in getting appointments with their treating doctors and accessing a Justice of the Peace (JP) to finalise the process.

> She still hasn't finished it though. Because that's the other thing, is that it's freaking overwhelming. It's big. It's a lot things to think about ... So the forms

> are like, it's a chunky thing, and it's like page, after page, after page … Thinking about what it is that you actually want or don't want and putting that in writing can be just quite challenging... (HP 1)

> A lot of mental health consumers don't have transport or have money to get to places or they don't know where to go for a JP. Even getting a doctor's appointment to get the capacity part signed off and … they just couldn't be bothered going and finding a JP. (MHEA 5)

> I wouldn't say it's consumer friendly. It's probably really quite laborious. I sit down with someone, explain the document, they really need to go away, they need to talk with their family, or their friends, or their support persons, then they complete it, then they have to go to the doctors, then they complete it with a doctor, then it's got to be signed off by a JP, and then it gets stored and filed, uploaded and those sorts of things, so that's a long process. And for a lot of people who are unwell, that's just too big a thing. (MHEA 4)

Access to relevant and easy to understand information was seen as an important factor to ensure that people were aware of what they were consenting to when completing an AHD. Service provider participants reported that allowing time for conversations and opportunities to provide appropriate information and options for consumers was important to ensure that informed consent was obtained for the AHD. People with lived experience required information about treatment options, and the benefits and side effects of medications before they were able to participate in decision making. The second quote below might refer to the advance health directive form created by Queensland Health, which is different from the one provided by the Department of Justice and Attorney General.

> Not really, no. When I completed my AHD, I don't remember a conversation about different types of medications and side effects. Even though he said it shouldn't make you gain weight, but my body doesn't say the same things. (Consumer 1)

> Because not all of that's in the package, that's the other thing. The package is that stuff, but it's like you're consenting to things, but no one's checking if it's informed consent or not. So, if you're consenting to a particular medication or to ECT or to... Has anyone actually given you all of the information about that procedure? So, for me it feels a little bit, I don't know, it feels a little bit invalid if you're saying I consent or do not consent to ECT. The ECT one in there bugs me a little bit because it needs the actual information with it. People need to know what they're consenting or not consenting to it. It's not informed otherwise. Same with the restrictive practises. (HP1)

Access to information and support to complete an AHD was also raised as an issue. Often people with lived experience are informed about an AHD when they are in hospital and may not be ready or able to think about forward planning. People living in the community were identified as the most appropriate population for AHD conversations, but these people were not always receiving support from mental health services and may not be well linked to support options.

> The other thing I want to say though is in regards to AHDs, TAs and community, is that the HHS will have to change their model of care if that's the part where they go down because in terms of case managers, every person who is on a community TA gets given a case manager. If you're discharged without a TA, you do not get follow up in the community. So, if you change everyone from a TA to an AHD, then you've got no case management, have you? So, they have to change the way that they discharge patients. (MHEA 8)

> I don't think people are readily aware of where to go for that support. And I find it interesting that people are given information in the hospital, when they're not in a space to think about it. But then when they're out there's no clear, "hey go to this person to have a chat about putting one together," or, I don't think GPs are aware and they would be a lot of the people that people go to. So no, there's a big gap there, in what support do you have to make, to put one together. Who do you have that discussion with? I think they could be, I mean they could be a website, there could be an online chat forums, and things like that that could be really useful for just people going, "oh you know I've got this question, what does this mean" or "if I don't fill in this section is it legally valid," and, the stuff that could just happen, as somehow accessible support that isn't there. Yeah. (HP 1)

Service provider participants saw the AHD as a dynamic document which needed to be revisited regularly. However, they noted how the AHD form was most likely perceived as something to do once and not go back to it. In particular, they expressed concern that if the process to change an AHD was difficult, it was likely that people's AHD would quickly become out of date.

> Because certainly the way that it's been promoted, certainly the way the training has been delivered around it, is very much that you kind of sit back when you're in that quiet, contemplative space, and put it together; and it's not an iterative document at all. You do it once, and then it's done. There's no dynamism attached to it. (HP 4)

> There's a general recommendation that it's reviewed every 12 months, but again I was talking to the advance care planning office people about this and they say yeah, it doesn't happen. But a lot of people don't because there's no prompts, or there's no triggers for the clinicians to check in with them or a person goes phew I've done that and they put it away in the drawer and you get on with life because you're not thinking about it. And when you're well, you don't think about things because you're well, and it's when you're unwell that... (HP1)

6.5. How the AHD is used in practice

Whilst most service provider participants viewed the AHD positively, there was confusion from treating practitioners as to how the AHD should be implemented in practice. Whilst some health services had more experience of utilising the AHD there was concern that the numbers of completed AHDs in Queensland was actually quite small, indicating a slow uptake.

> This is our project for this year, is working out advance health directives … Because it's all new, because we've just been getting our head around the Act; now we need to look at the other parts. (HP 4)

> I have yet to use one. I have yet to work with one, to be honest … If someone said, "I want to start doing it", I'd be like, "Okay. Let me talk to someone and I'll get straight back to you about it. Yes, I know of it and the ideas of it. I understand the need for it. I think it's a brilliant idea. I think it's something we probably need to start doing to get good at. I love the concept, but yeah, it's the actual – I wouldn't even know where to get the paperwork. (HP 5)

Service provider participants identified a need for further training and information about the AHD to better understand the concept and how to work with people with lived experience to utilise the AHD effectively. It was suggested that the training needed to target medical practitioners as well as mental health workers to ensure integration of the AHD across acute and community settings, as well as provide practical resources to support current training options.

> But I'm fully aware that my lack of knowledge is… I don't know where the advance health directive fits. And I should, because I did my training, and I've got a certificate. (HP 4)

> The other thing I'll say about AHDs, the training has only now started to come out for the clinicians around how to complete an AHD. I think in this HHS there was a lot of reluctance. I think people were too embarrassed to say I don't know what an AHD is or how that will work. So, I don't think we have a single AHD in this HHS, not a single one. (MHEA 7)

> [name] then recently delivered some more training to clinicians on AHD; minimal numbers of doctors. There were case managers there and other staff but there might've been one or two doctors, which I think is very telling because they're the ones who have to sign off on capacity. (MHEA 7)

Service provider participants reported problems with how AHDs were uploaded and stored in the health service information systems. For people with lived experience with an AHD, an alert would flash up on the public mental health consumer record, although this was not automatic for emergency and other health areas. This process was not available to private hospitals and the upload of the AHD on the electronic health record required a different process. Concerns were raised that in a fast-paced health system, information pertaining to a consumer's AHD would not be accessed.

> Okay so yeah it's there, it's uploaded. We've got a copy of it. But, how do we identify when someone's being treated under the advance health directive, that's not as easy to check … It's all on CIMHA [Consumer Integrated Mental Health Application], and people are required to check that it's on CIMHA. I think this is really interesting with the Act because other things take quite a while for people to get in the habit of checking. So, I'm not sure how frequently people are checking, or how many are going to be missed. I know like looking at the research from the States and in other jurisdictions where they've used psychiatric advance directives. A lot of people like they just –

like they just weren't checked. So, people had made them in good faith like if I get sick someone's going to check and follow through. (HP 1)

We make sure [the AHD] gets loaded up to CIMHA and then up to the ieMR [integrated electronic Medical Record] and then on to the Viewer and there's a whole heap of problems, around getting them loaded up. It's an absolute nightmare around making sure …Well, the data information system – so we can get them loaded up to the mental health system, which is CIMHA, and that's a local process. So, every district will do that differently. Then in order to get it loaded to the electronic medical record for everybody, we have to walk it across to there and ask them to scan that in. Then in remote areas, for other people to be able to see it, they use something called the Viewer, where they can look in and there's no process to submit it there. (MHEA 6)

6.6. Barriers to completing AHDs

Of the three people with lived experience and two carers who were aware of the AHD, only one consumer participant had completed an AHD. The main reason for not completing an AHD was a belief that it would not make any difference to how they would be treated on admission to hospital.

Well there's not much point, they make the decisions. Basically, you're a moppet in the system. (Consumer 8)

No, well not enough for me, no. No, only the other day I was talking to someone and she hasn't been well. Now she specifically didn't want ECT. Well they override that, now she needs to do something about that, because now she's well she goes, "Why did this happen?" Why have it? What's the point? Her mother was absolutely furious. (Carer 4)

No, I haven't bothered. No. He's got no real desires or wants to fill one out. ... they need more education around it. But they often say, "What's the point of that? Nothing happens anyway". (Carer 4)

Service provider participants also reported that they had received feedback from people with lived experience that they were unsure if the AHD would be followed by the treating team and had concerns that even after completing an AHD their wishes would not be respected.

A lot of people don't really like to know that information. You know, like the clients are like, "Well, is it not then worth the paper it's written on?" And I'm like, "No, no. You can still put in preferences and..." But the thing that they want to have some control over..., it seems very easy for the treating team to not ... Not follow it. So I guess more work needs to be done around exactly when would they ... Like, how useful are they? (MHEA 1)

The feedback we're getting from clients is that even where they're aware of the form, we've tried to fill out, there's a real apprehension as to whether the clinicians will be receptive to it and respect is as well. We've had an experience where a support worker went to complete one and then they've got the psychiatrist who said, "I can't follow this" or "I'll do what's best for you"

> or where patients haven't even completed it because they feel like, "The doctor will just do what they want to anyway." (MHEA9)

Service provider participants discussed about how and when the AHD might be over-ridden e.g., on admission to hospital. Concerns were raised that there would be few changes to practice as treating staff would develop a treatment plan and if it was not congruent with the AHD, provide involuntary treatment under the Act. As there was limited experience of this occurring in practice, service provider participants reported that the process was not clear and they would struggle to document decisions appropriately.

> I mean, it was interesting when we talked to the staff about it. They were scared. They were quite fearful, "Oh my God. What does that mean for us if people come in with AHDs? It means you've got to check CIMHA and you've got to comply with it. Unless there are reasons why you can't, you know, you can't ignore it." But it was like they were really fearful, like it was extra work for them. (MHEA 5)

> And when I had discussions with people about Advance Directives, that's one of the things I raise, "Well, the doctors have said this," or "Can the doctors override that?" I said, "Yes," but I said, "The difference with the Advance Health Directive, for me in my mind, it can hold doctors, or the reason why their liberties have been to take away from, they're more accountable. The mental health service is more accountable because they can say, well, they've got to continue to revisit that document. They're in hospital for a period of time and then they got to revisit it. They've got to always got to revisit it as part of the case review to say, can we move that person, can we move that person, back onto their Advance Health Directive. (MHEA 4)

The majority of service provider participants discussed the issue of capacity in relation to completing an AHD. There appeared to be confusion regarding how capacity to complete an AHD was assessed and how the competing legislation of the *Mental Health Act* and *Guardianship and Administration Act* impacted on practice. Service provider participants reported that they had recently received direction that people who were currently being treated under a TA did not have capacity to complete an AHD, but there was concern that people with lived experience in these circumstances would have their rights impacted by this process.

> When we first started, we were always under the impression that, this was initially, that Advance Health Directives could be treated with whilst people are on treatment authorities, but then it came out that they got legal advice and said, "No. Whilst a person's on a treatment authority, they don't have capacity to do that decision." But then it's strange because they said, "Well, okay," but then the test for capacity, especially that little bit in the middle about Power of Attorney, the test for capacity comes through guardianship, which is a different test of capacity under the *Mental Health Act*. (MHEA 4)

> The other problem is with the Advance Health Directives is that they can't be done unless the person has capacity. I think it's because it's still early days, I think eventually that will catch up. I saw somebody yesterday, it was a son,

> the mother was very involved, very supportive, did not want to be the substitute decision maker but was very keen on advocating for his particular refusal of particular kinds of medicines and stuff. He said he wanted to be on an Advance Health Directive. So, they accepted that he had a long-term relapsing condition, so wanted to be ready for it, but he didn't have capacity at this time. So, it was almost like, you've got to wait to get that window and do it then. I mean you can understand why that's the case, but I think that is going to slow it down. (MHEA 2)

6.7. Nominated support persons

A number of service provider participants saw the option of substituted decision makers as an important addition to the Act, supporting the rights for people, particularly for young people.

> Yes, I actually really like the section where you actually have considered is there a least restrictive way in using a significant other in their life that's supportive that can actually provide consent for care … a lot of our young folk have families actively involved and so we find that really helpful, that we can avoid using the Mental Health Act … So I think there's been a lot of positive changes with the new Act, that we're actually allowed now really to look at that as an option. (HP 5)

Nevertheless, there was some confusion about how to use substituted decision-making processes appropriately and a need for further education was identified.

> The whole idea of substitute decision makers getting up and going in the service … But I think what we've found when we've tried to do, not so much AHD but generally substitute decision making, is that it's not clear. It's not clear. There's no, you know, what happens if there's a disagreement? How do we record it? What exactly are they consenting to? So, there's a lack of knowledge for staff. (MHRT 3)

Other service provider participants were unsure if the use of substituted decision makers was supportive of a person's rights and had concerns about coercion from family members.

> You could look at it the other way as well, and say that's actually an insult to you, because no one else gets to have someone else cajoling them and coercing them. I think the risk of coercion from a family member is extraordinarily high with that. No one else is allowed to have a family member tell you to have an operation, so why on earth should a person with a mental illness be allowed to have that capacity to take you when you might be at your most fragile? … And I think there's a balance between are you really doing it because you genuinely believe it's the best thing for your loved one, or are you doing it because it gives you a break at home, and he'll be on a medication so he may be more sedated, or something like that? And I think for a carer, that's a very tight line to walk. (HP 4)

Issues regarding the inclusion of carers in treatment decisions through the nominated support process were noted by service provider participants. Allied

persons under the previous Act were not automatically moved to nominated persons when the Act changed, and as a result there are fewer recognised support people for people with lived experience under the 2016 Act.

> Some of the negatives have been, well first and foremost, the fact that previously patients had an allied person and now they have an NSP [Nominated Support Person] and those allied persons weren't grandfathered never. That's a major issue. We know that in our HHS we're talking about hundreds of patients who had an allied person on the third of March, come the fifth of March they no longer had that person. And for persons who are very unwell, they need to have capacity to nominate an NSP, and for a lot of them, they don't have capacity. So, they've gone without that support. They had an allied person who was there, who was attending their tribunal hearings under the old Act and now they have neither … a large proportion of patients who had an allied person who now do not have an NSP. (MHEA 7)

There was concern that carers were not always informed of the nominated support person process.

> They never actually – but nobody actually said to me, here's some forms, you'll need to sign them. They knew full well that I was up there for six hours a day, you know? (Carer 5)

Additionally, the nominated support person forms and process were described as complicated, preventing some people with lived experience from completing the process.

> And I think there's major issues with the form, it has to have a witness you know, and the forms aren't very consumer friendly. People sign in the wrong kind of area … and the person that's nominated has to sign it so if the person's an inpatient, it's just very onerous and it's not just them going "Yeah, I want this person as my NSP", and someone documenting it in the notes and then bang they're the NSP. It's a real formal process that's cumbersome. (MHEA 8)

7. Focus area 4: The Mental Health Review Tribunal (MHRT)

7.1. Summary

Participants saw the role and skills of the MHRT members as important in protecting the rights of people with lived experience and ensuring positive experiences for them. Participants reported the importance for MHRT to appoint assistants with expertise in the care of persons with intellectual disability and with appropriate cultural or social knowledge when presiding forensic orders disability and dealing with Aboriginal people or Torres Strait Islanders, or people from other cultural and linguistically diverse backgrounds. Section 750 of the *Mental Health Act 2016* states that the tribunal may appoint a person with appropriate knowledge or experience to assist it in these proceeding, but it is not obliged to.

Generally, participants had a positive view about the timing of reviews under the *Mental Health Act 2016* and felt that they supported human rights. Some service provider stakeholders pointed out that even though under the *Mental Health Act 2016* people who disagree with a TA are able to request an early review, in practice reviews rarely occur before the standard 28 days.

Whilst participants were able to understand the need to use teleconferencing or videoconferencing facilities for remote areas, often these were seen as difficult to organise and attend and not always accessible or appropriate for consumers.

Participants with lived experience, family and carers described the experience of sitting in a hearing as frightening for the possible consequences and outcomes, leading to significant anxiety. They stressed the importance of understanding the tribunal process, prior to their first appearance. Overall, participants with lived experience reported receiving more detailed information when attending hearing under the *Mental Health Act 2016* compared to the past. Nevertheless, family and carer participants requested more accessible, appropriate and ‘stepped’ information on the MHRT processes.

Service provider participants reported that understanding MHRT decision making processes was still work in progress with limited practice directions, published decisions, or information to support the treating teams and representatives in understanding how and why the tribunal made decisions, and what information and documentation were needed to inform MHRT decisions. Service provider participants pointed out that the MHRT does not record its proceedings as other tribunals and courts do and this was seen as a significant limit to inform service providers’ decision making. Further guidance and transparency in the decision-making processes of the MHRT was identified as necessary to improve the information and support provided to people with lived experience.

Learning to manage new administration processes introduced by the *Mental Health Act 2016*, in particular the need to provide patient reports to all parties seven days before the hearing, had created some difficulties and, in many instances, the need for adjournments. Nevertheless, participants saw the reports as important and mentioned that the situation with adjournments was improving over time. The addition of an MHRT Registrar was suggested to support the administration processes. Participants with lived experience reported that the detailed content of the clinical reports could generate a lot of stress and anxiety to them, highlighting the importance of support to go through them. There was concern that the volume of long-standing history detailed in medical reports could often unfairly influence Tribunal decisions, which would focus on past behaviour often from many years ago rather than on current risk.

The addition of representation for people with lived experience within the MHRT process was overwhelmingly seen as a positive addition to the Act. Although service provider participants agreed that representation supported the human rights of people with lived experience, the introduction of advocates and representatives in the MHRT process did not always proceed smoothly. All parties involved were required to learn about individuals' roles, which took time, and some participants described negative experiences of this process. Service provider participants reported two major limits of the advocacy system, the fact that: 1) there was no training in place for advocates and lawyers and, 2) support was offered only at the hearing, leaving people with lived experience with no help between hearings, when help would often be most needed.

Whilst participants were supportive of the changes brought by the *Mental Health Act 2016* to support the rights of people with lived experience, there was still a belief that the MHRT tended to focus on risk rather than recovery. The risk focus was particularly evident for people on forensic orders (see also Section 3.1 on this topic). An adverse risk attitude was also reported in relation to stepping people down to a Treatment Support Order (TSO), which was seen as a positive new element in the *Mental Health Act 2016*. Aside from the challenges brought by a common learning curve in using this new tool, it was mentioned that in some instances MHRTs postpone people's hearings (consideration of their leave or their order status) to receive specialist risk assessments to establish whether it was appropriate to step them down to a TSO. One view was that there are already procedures in place to assess the risk of stepping people down to a TSO, such as for example the ARMCs (Assessment and Risk Management Committee) and that if the MHRT evaluates that more risk assessment is needed then the onus should be on the MHRT to facilitate that assessment.

7.2. Introduction

Participants' discussions about their views and experiences of the MHRT are here summarised under four main headings and discussed below:

1) Hearings – Process and experiences
2) Advocacy and representation
3) Reporting requirements
4) Risk management

7.3. Hearings – Process and experiences

Participants' discussions about their experiences and views of MHRT hearings are summarised under four main topics: composition, timing, remote conferencing, information.

7.3.1. MHRT composition

Participants saw the role and skills of the MHRT members as important in protecting the rights of people with lived experience and ensuring positive experiences and outcomes for them. Participants often stressed that the way in which questions were asked was important.

> It depends very much who the legal member is because the legal member is the presiding member. Some legal members make the experience a really positive one, even if the client is not getting what they want, by being kind, by listening. (MHEA 2)

> It was very intrusive, from the doctor on the presiding team member on the MHRT, he was asking a lot of questions, they were very intrusive. My lawyer at the time said I didn't have to answer them, and he kept on asking more and more intrusive questions. (Consumer 9)

In particular, one service provider stressed the importance that the MHRT appoints assistants with expertise in the care of persons with an intellectual disability when presiding forensic orders disability. Section 750 of the *Mental Health Act 2016* states that the tribunal may appoint a person with appropriate knowledge or experience to assist it in these proceeding, but it is not obliged to.

> They [referring to MHRT] should be forced to have somebody with disability expertise on there if they're going to make a forensic order disability. […] How can they preside over and make decisions about somebody's ability to be on an order or not on an order or to be released into the community with disability if they have no expertise in that area whatsoever? So I think that's a failing in its implementation [referring to the implementation of the act for the

> MHRT]. But really I think the broader failing relates to what the legislation does not empower the tribunal to do.

7.3.2. Timing

Generally, participants were positive about the timing of reviews under the *Mental Health Act 2016* and felt that they supported human rights.

> I think we've got a lot of things right in relation to the timings. In some countries, the first tribunal is too soon. I think we've got that just right, where sometimes we can actually revoke before it so it gives us a bit of time to just let the dust settle so it's not too soon to have to keep artificially having too many TA's going through. (HP 5)

Whilst the option to request an early review hearing was seen as a positive addition to support the rights of people who disagree with a TA, service provider participants raised an issue with the process, because in practice reviews rarely occur before the standard 28 days.

> The first one is, obviously, patients have a right to have an early review hearing, and in my experience, the patients who are most likely to take up that opportunity are patients who are admitted to an acute mental health unit who completely oppose the fact they're under a TA. Unfortunately, though, if they don't put in that request quite early on in their admission, i.e. day one or day two of their admission, putting in a request for an applicant review is not going to be any sooner than their automatic 28-day review, which I think is a travesty. (MHEA 4)

Most service provider participants reported that through the process of regular scheduled MHRT hearings, treating teams were triggered to review the capacity and status of people with lived experience currently treated under the Act. Scheduled hearings and decision documentation were identified as vital in ensuring that people with lived experience were not treated under the *Mental Health Act 2016* unnecessarily. Nevertheless, one service provider participant reported that in many cases patients may not have their TA revoked till the eve of the Tribunal hearing, which is often when the treatment team would review cases and decide whether to keep or revoke their TA.

> The Tribunal would notice that the most revocations occur just before the hearing's due, because the treatment team have to sort of get together, they have to see the person in order to do the mental state exam and stuff like that. That's the time when they like going, "Okay, do we want to keep them on a treatment authority or not?" And if they don't believe that they strongly meet the criteria then that's an opportunity for them to revoke it. (MHEA 1)

7.3.3. Remote conferencing

Whilst participants were able to understand the need to use teleconferencing or videoconferencing facilities for remote areas, often they were seen as difficult to organise and attend and not always accessible or appropriate for consumers.

> I didn't like it and neither did the young person. I think we ended up asking for it to be deferred because he was quite paranoid and having the speaker, it was like, "Oh…" We need face-to-face so we were able to defer it. (HP 5)

7.3.4. Information

The participants' experiences about information during MHRT hearings is reported into two subsections addressing respectively the experiences of: participants with lived experience, family and carer participants, and service provider participants.

Participants with lived experience, family and carers. Participants stressed the importance of understanding the Tribunal process, prior to their first appearance. Due to the legal nature of MHRT hearings, they expressed concern such as being underprepared and frightened about the possible consequences and outcomes, leading to significant anxiety regarding the forthcoming hearing.

> This last one [referring to the hearing - was] not so bad because I've been through so many now and kind of learnt from it. But initially it was - I don't think anybody really took the time to explain it fully. To me I was going to court basically and I didn't really - didn't think I'd - I mean you've already locked me up. What else do you want…
> […]
> Yes [it is needed] somebody with patience to be able to sit with you and make sure that you understand that it's not a punishment. (Consumer 4)

> It was very intimidating going into a tribunal, because you don't... when you're sitting around a table and you've got all these people there, no one actually identifies who they are and what they do, so you go, "Do you want to tell me who you are? What's your role? How do you help?" So that's very intimidating … Really all it is, is a little room where you've got people assessing you … I'd be sitting there, "How did you come up with that assessment? Who assessed that? I don't even know if you've talked to him about it, or me." (Carer 4)

> Oh, I mean I understand it's a very formal procedure, but we were in a room at the hospital, the panel was they were on a screen, so they weren't actually in the room. Look I mean they handled, everybody handled it as respectfully as they could, you know I have no gripes about that. But the effect on a seriously unwell person and me and his father was very daunting, very daunting. And I mean he had to sit there and my son he had to listen to stuff; I don't think he really understood what was going on, but he knew that he had to try and sell himself. (Carer 3)

Family and carer participants in particular requested more accessible, appropriate and 'stepped' information. The importance of receiving clear information and the

positive change brought by giving all parties seven days to receive the reports for the hearing was particularly evident when participants with lived experience, their family and carers reported their experiences of hearings under the previous Mental Health Act.

> Well, if I didn't get things done, nothing would happen [referring to information about hearings under the previous Mental Health Act]. I wouldn't get any communication coming to me, no one would come and communicate to me what was going on, the MHRT doesn't communicate to you effectively, it just sends out a letter, it says "We're on this date", and I had to ring and make changes, and they said, "Oh, we've got good news." I said, "What's that?" "We've got your new MHRT, we brought it a week forward", from the original day, it was on the 10th and they brought it on 6 July, which was my birthday. And that's the second time that's happened in the space of five years. So that's very stressful, coming in on a day like that, and then getting intrusive questions (Consumer 9)

> Six weeks later they had to do the first review [referring to the hospitalised son]. That was the whole debacle, because we didn't know he was very, very unwell at that time. He was in intensive care. And suddenly one day a doctor said oh he's got to have this review on Thursday, that was Tuesday. We said what are you talking about, what is it? And he said what it was a little bit, so we realised it was going to be a very formal daunting process for someone who's seriously unwell. And he said oh he would have received a letter advising him. And I said he's in intensive care, he's seriously mentally unwell, he doesn't know what's going on. Oh well he would have got a letter.
> So I went into his room, no letter. Asked him, he didn't know what I was talking about. Asked the nurses. I had to more or less keep asking over 24 hours where's this letter? I wanted to know what it was all about, because I was worried about the effect on my son of this whole thing. Anyway eventually they found the letter, they'd put it in a file or something, so [family member] and I read it and realised it was going to be very formal. So I was really worried about it and the doctor said don't worry about it, we'll explain it to him. So I don't know - they explained it to him the morning that it was happening, just on the way in to the review (Carer 3)

Overall, participants with lived experience reported receiving more detailed information when attending hearing under the *Mental Health Act 2016* compared to the past.

> I think it was more detailed. Yes. I think in the past apart from receiving a copy of what they were doing there was no real other support. (Consumer 4)

Other people with lived experience reported the MHRT process was not useful and they were not hopeful that their presence at the Tribunal would influence the outcome.

> It wouldn't matter how hard I tried, what I said, how well I dressed or anything. It would be like those people sitting behind a desk, have a nice little discussion and the majority wins ... It's a no-win situation. It was pointless to me, it was just stress provoking. (Consumer 1)

> But after about the third or fourth [MHRT] there's no point. I know you're supposed to meet an independent person on the board (other than the psychiatrist) but everyone has their prejudgements and they've already decided what they're going to do before you even walk in that room, so ... (Consumer 8)

Concerns were also raised about how cultural practices were supported and how cultural considerations were taken into account when tribunal decisions were made. Whilst language interpreters were provided, questions were raised about how well differing cultural views about mental illness were taken into account. Similarly to the expertise on people with intellectual disability, Section 750 of the *Mental Health Act 2016* states that the MHRT may appoint a person with appropriate cultural or social knowledge or experience, however, it is not obliged to.

> Every time an MHRT happens, we've got to try and tell these people our stories. But none of the boys really talk to the MHRT because of who they are. They expect us to have a real good education. That's important, but the boys' lifestyles is different from the white man, but we all mentally unwell, that's what they say. All I want to do is just move on and get out of here. (Consumer 10)

Service provider participants. Understanding MHRT decision-making processes was seen as a work in progress with limited practice directions, published decisions, or information to support the treating teams and representatives in understanding how and why decisions were made, and the information and documentation needed to inform MHRT decisions. It was pointed out that the MHRT does not record its proceedings as other Tribunals and Courts do.

> None of the hearings are transcribed so you can't go back and challenge anything that was said at the hearing because they do not record or transcribe the hearings. That just would never happen in any other jurisdiction where there is a hearing about somebody's freedom. It never happened in the court (MHEA 13)

> There's a lack of published decisions both from the tribunal and the Mental Health Court that could provide valuable guidance to tribunal members, to clinicians, to lawyers, advocates, patients, families alike to help understand why the decision is made and also provide some really valuable data and promote consistency in decision-making. There's been very inconsistent decision-making at different tribunals who will want to see different kinds of documents, which can be very frustrating for clinical teams. (MHEA 9)

Confusion regarding how best to access information about relevant MHRT decision making processes and who was able to provide advice, training and support was noted.

> Because I've had that feedback from treating teams saying, "But we don't know what we need to do." … So even the treatment teams that are quite proactive, still can't get... information about what they need to do. And as a result the treatment teams gave the wrong evidence, thinking that'll be really helpful. (MHEA 1)

> There have been some very tense meetings, you know, MHRT hearings with the treating team where everyone has been incredibly frustrated and see the MHRT as being difficult - but, people just haven't been on the same page. The MHRT used to do more training; go out and give talks and stuff to the treating teams, to the services and that has stopped. (MHEA 2)

7.4. Advocacy and representation

The participants' experiences about advocacy and representation at MHRT hearings is reported in two subsections addressing the participants' perceived benefits and challenges.

7.4.1. Benefits

As discussed in Section 2.4, the *Mental Health Act* 2016 strengthens the rights to advocacy and representation of people with lived experience at a MHRT. If people with lived experience is not represented by a lawyer or another person, and if the tribunal considers it to be in the person's best interest, the MHRT can appoint a lawyer at no cost for the consumer. The MHRT must appoint a lawyer if the person is a minor, the Attorney-General is to appear or be represented at the hearing, and if the hearing is for a review of the person's fitness for trial, for an application for approval to perform electroconvulsive therapy on the person, or another hearing prescribed by regulation. Also, the *Mental Health Act 2016* introduced the possibility for people with lived experience who become involuntary patients to nominate up to two support persons (Section 2.4). Additionally, the process for advocates and supporters to attend a MHRT has been made easier.

One consumer described the importance of having an advocate present at the Tribunal, someone who understood the Act and supported their rights and to ideally achieve positive health outcomes.

> The last doctor that I had that was here, him and I clashed quite regularly and that the outcome was that he wanted all my leave revoked, so he wanted me to have no leave whatsoever, and [the advocate] put in submissions to say that, "Hang on under the new Act he's supposed to be given the less restrictive practice, and he's supposed to be able to have leave to be able to go out and do things". And they reinstated my leave. (Consumer 9)

Most service provider participants were aware of the changes brought by the *Mental Health Act 2016* to advocacy and representation rights and saw them as an important step in assisting people with lived experience to be heard and have their rights protected. It was also pointed out how the possibility for people to have a lawyer representation helped to establish better dynamics in the hearings.

> The introduction of advocates at the MHRC has been a real positive change under the new Mental Health Act. So there's a mandatory requirement that certain classifications of patients need legal representatives at the tribunal

> and I think that's made a big change for a lot of people's rights at the tribunal (MHEA 12)

> There's provisions more easily... Well, for one, from our point of view, under the old Act, advocates had to ask for leave from the tribunal to appeal. Had to. It was actually a provision that a non-legal advocate actually had to ask the tribunal, and all of our advocates had to ask the tribunal for leave. Under the new Mental Health Act, you don't have to ask for leave. They are allowed to have an advocate there. They're allowed to have a nominated support person appear with them. So those sorts of things have been strengthened. (MHEA 1)

> I think at the very least, it helps to empower people and feel they've had some sort of engagement in the process, not just, "You sit there in the corner, and the rest of us are going to make decisions about this." (MHEA 4)

> Then because there was no advocate for the patient [referring to hearings under the previous Mental Health Act] the treating team was almost forced into this position of advocating when they thought the person was ready for leave rather than being able to have that more objective role as a provider of clinical information and progress and that sort of thing. So I think that was a really problematic dynamic historically was that the MHRT almost started to view certain clinicians as well you just advocate for your patients and we can't rely on what you say because you're just going to argue for them. But there wasn't an alternative. There wasn't another real option to have an advocate in the room that was able to I guess stand up to the AG's rep in a way. So I think that that's been a really positive thing for the patients, particularly of high secure, who have access to that option. I think that's been useful.

7.4.2. Challenges

Whilst it is now easier for certain groups of people to access representation at their hearings, there are still no funding provisions for the majority of people being involuntarily detained or treated under a TA. This group of people with lived experience must rely on community organisations which fund representation through volunteer staff, private funding and donations, thus placing them at a significant disadvantage with respect to ensuring that their concerns are heard.

> Well, for starters, a lot of people are not able to access representation for the MHRT. There's only a small pool of funding and specific sort of reasons why people or how people can access funding for that. (MHEA 9)

> Whereas, and this is an issue, you can't get any, any legal representation for those patients, so I would say, more than ninety percent are either not heading to their tribunals, because they've realised what a disadvantaged situation they're in. They think, "Why would I sit there and feel intimidated by four people that aren't going to listen to me?" (MHEA 8)

In response to this identified funding gap for MHRT representation, IPRAs have provided support to people with lived experience and helped them to understand and prepare for their MHRT. IPRA participants all noted that this was an important

form of support, assisting people with lived experience prepare self-reports for their MHRT hearing and promoting attendance to help them achieve positive outcomes. Some discussion was generated about the fact that IPRAs are not allowed to attend the MHRT as a support person and while many appreciated the need to avoid conflicts of interest, there was concern that no other support options were available for many people with lived experience.

> The one thing that I think the tribunal is missing, in terms of human rights, is that they're more concerned, in my experience, about who is in the Tribunal hearing than the patient's human rights. So, for example, many, many patients, I would say the large majority of patients do not have a support person to go with to that tribunal. (MHEA 8)

> I think that's where the self-report is used to the patient's advantage. Then they have a little bit more understanding of the process, what's going to happen, what they're there for. So, they feel a little bit more empowered to at least go and speak up. Even if they don't … they can at least put their views and wishes forward. Yeah. So, I think that has really increased the uptake of, you know, you know, kind of self-access to their rights, which is good, yeah. (MHEA 3)

Although service provider participants agreed that representation supported the human rights of people with lived experience, the introduction of advocates and representatives to the MHRT process did not always proceed smoothly. All parties involved were required to learn about individuals' roles, and a number of participants described negative experiences of this process.

> I know that that's probably one of the most controversial changes for clinicians, and it's been a big learning curve for us all. ECT hearings are really challenging … the fact that the person presenting might be unwell and not have capacity and also noting that I suppose the complexity of the capacity assessment … the representative role is not there to question clinical judgement … but to help the person express their views, wishes and preferences about the treatment if they've got capacity to do so. (MHEA 9)

> I think it is good that the patient is getting a legal representation for all ECT hearings but my experience there has been at least two or three cases where the legal representative has been quite unreasonable … what I'm saying is the lawyer should get training in ECT and they should not use their personal opinion because they're not the experts in the field and ECT is already stigmatised. They should not use this provision under the Act to worsen the stigma. (HP 3)

One service provider participant pointed out that two major limits of the advocacy system were the fact that there was no training in place for advocates and that support was offered only at the hearing, leaving people with lived experience with no help between hearings.

> The drawbacks to that are the advocates who are doing this work, there's no training for them. It's just by what you learn on the job. I don't know about other states in Australia but I do know in England there's a huge

> accreditation process before you can become an advocate within this space. The other problem is that these advocates are paid through legal aid to only represent at the hearing and we see that there's a lot to be achieved between hearings for a client. The hearing is an important issue. It can unpack a lot of issues for the client and can set up a framework for where to go next but there can be a lot of other legal and non-legal issues between hearings around the client's rights that they don't get legal representation for, they don't get advocates for. So, you know…(MEAH 12)

There was a perception from a number of service provider participants that the inclusion of legal advocates and representatives had influenced the processes of the MHRT, making this process more formal and less focused on the person and their mental health challenge. One participant expressed concern about processes becoming adversarial and the potential need for clinicians to have legal representation.

> The role of the lawyer […] is more formal now than it used to be. It's hard when there are a number of lawyers in the room because then there's all that kind of competition. All that stuff about timeframes and checking things now, other legal representatives acting in the best interests versus under instruction. (MHEA 2)

> A lot of mental health people I've spoken to, like mental health service, like treating team people, and that sort of stuff feel that the Mental Health Review Tribunal now has become not about the person, that it's become more about what the best outcome is for the person. It's become more about legal arguments, but that's just their perspective. (MHEA 5)

> While it's a useful thing from a rights perspective [referring to free legal representation] I think that there have been implementation challenges in that it's created a little bit more of an adversarial dynamic in some instances where it's become a lot more of I suppose a legal argument that focuses on particular definitions of things or on some of the minutiae that perhaps previously wasn't explored as much […] I think certain HHSs and so probably certain MHRTs and certain AGs [Attorney General] reps have seemed to have made it that more - had that more adversarial experience in the MHRT compared to previously which I don't think is necessarily helpful when it's meant to be a discussion around where the patient's treatment progress is up to, what's the least restrictive approach for that patient and what's the level of risk associated with that?

> It's really kind of the general discussion rather than necessarily an adversarial approach for the sake of an adversarial approach. So that's I think been a bit of an unintended consequence again that hopefully is one of those things that as people get used to it will again settle down. (MHEA 14)

Generally, service provider participants reported that over time both legal and medical personnel had learnt to work together, understanding each other's roles and perspectives, and hence developing skills to work collegially. They thought that this should remain the common goal.

> So, look, I think there's a value. I think it is incredibly difficult. I think both lawyers and clinicians are learning and understanding each other's roles. We have managed to have some really positive relationships develop … There needs to be a focus on maintaining that therapeutic relationship and also a respect for professional colleagues as well. Sometimes we also receive professional respect back. Sometimes we don't. I'm hopeful that going forward, this is something that we can build on through more information and joint seminars and better supportive discussions with a range of professionals. (MHEA 9)

> I think it was hit and miss to start with because I think Legal Aid didn't have enough [qualified staff], so they farmed it out to whoever. Initially there were some really stupid people and people who were not knowledgeable about mental illness at all. In fact, I remember there was one hearing I was in and the lawyer was dismissed because they were so bad … so, I think now it's obviously become a bit of a speciality. So now we have people who I think are beautifully sensitive and respectful of patients and who can frame the process and the decision in a really positive way. (MHEA 2)

> I think they might need to rethink, especially with the evaluation of mental health coming up, rethink how they appoint lawyers because lawyers, you know, and especially untrained lawyers might just come to the hearing, not oppose anything and that's the end of their representation. So what real value has the person had from having that representation? And in particular really complex cases with a lot of stakeholders, representation at the hearing is clearly inadequate to support that client to eventually come out of involuntary treatment.

In addition to understanding the MHRT process, people with lived experience, family and carer participants were keen to have expert support to better prepare for the hearing. The process of receiving information and reading reports in preparation for the hearing was described as difficult and nominated support persons were not always informed or involved.

> But we weren't advised, I wasn't given the opportunity to prepare [my son]. I didn't really know what [the MHRT] was about myself. It was just not good. (Carer 3)

> [The advocate] sends me documents and stuff like that, helps me get ready. I don't get any information about [the MHRT], except the date that it's coming up, and that's it. (Consumer 9)

7.5. Reporting requirements

Improved MHRT processes such as timely access to reports for people with lived experience and advocates prior to attending a Tribunal hearing were reported to strengthen the rights of those being treated involuntarily under the Act. Timely access to relevant documents allowed for better preparation and understanding of clinical decisions.

> I think it has improved out of sight. So, I think before, and certainly there were those of us that were not comfortable about people just getting stuff on the day of the hearing, or getting stuff the day before the hearing, because they were anxious enough as it was. They'd come in – this was under the old [Act] – they'd come in, we'd say have you seen the report and they'd go – no. We'd then say; do you want to go outside and sit with the case manager or whatever and go through it. By and large they'd say yes and that's what we'd do. It really was not the best due process. So now we at least know that they've seen it. We ask questions around whether someone has gone through it with them, so it's not just a matter of we posted it to them, we left them in the letter box. We want to know if [the treating team] have gone through it with them and whether they've considered it. (MHEA 2)

Some service provider participants identified that meeting reporting deadlines had been a struggle; accessing consultant psychiatrists to complete the reports and locating people with lived experience to provide reports within the seven working day rule was a challenge.

> Yes. Having to get the reports done earlier has been a bit of a struggle, I'll be honest. Having to get the report to the person by a certain date can be tricky, given a lot of times, you know, even though we're an intensive team compared to other teams, even we sometimes can't get [the consumer]. We can't locate them and we don't like mental health paperwork in post boxes. So that's a challenge, I'll be honest. (HP 5)

> Some of the issues I've found is probably doctors not completing their reports on time, which has been quite difficult ... we get to the MHRT to say "Look, sorry. We haven't prepared enough." So, it's adjourned, adjourned, adjourned. (MHEA 4)

As a result of difficulties in meeting reporting timelines, within capacity, Tribunal adjournments had occurred regularly. Numerous adjournments were discussed by almost all service provider participants. They had been reported as a problem since the introduction of the Act, although the number was reportedly reducing. Adjournments were frustrating as they impacted on the time required to participate in the Tribunal as well as the impact on people with lived experience when decisions were delayed.

> Yeah, very frustrating. I know as soon as the new Act came in, there's been a lot of adjournments. Yeah, I've had my MHRT adjourned on four occasions - for all sorts of different reasons … all these documentations and meetings that were supposed be done weren't being done on time, so it was impacting on my rehabilitation here and getting leave and things like that. (Consumer 9)

> So the significant result of that which was in retrospect like, appalling and expensive and avoidable was that there were an enormous amount of adjournments … because of the interpretation of the seven day. The clear seven days that the patient and all parties had to have the documentation. The MHRT went from being incredibly flexible about reports to completely rigid. It had all sorts of implications for the relationship between the Tribunal and the treating teams. (MHEA 2)

> I'm not sure whether that's protecting the human rights of the patient by adjourning the matter several times for different reasons. Sometimes the treating team don't come, a report is not done on time. (HP 3)

Adding to the frustration of Tribunal adjournments, service provider participants commented on the need to attend the MHRT even if they knew that it would be adjourned. This was seen as a costly process and participants believed that it wasted time and increased anxiety of people with lived experience. The inclusion of a Registrar to make adjournment decisions and improve communication with the Tribunal was seen as an option to improve this process.

> This is my big beef with the Tribunal … within the first 28 days, they're meant to have their first hearing. What happens though is a lot of the time, if there's been lots of adjournments. So over Christmas, New Year, just this year [2017-2018] there were heaps of adjournments. The tribunal don't have the power under the act to adjourn it prior to the hearing so ... Everyone's got to turn up. Even though I've emailed and said "We will be requesting an adjournment" … and we still have to turn up, the money, the cost to tax payers. They are not allowed to, and no one can make that decision until the tribunal meets on the day. So, there's no way you could possibly have a hearing. The person who suffers is always the client. (MHEA 1)

> There's no registrar like there is with other courts and tribunals and it means that simple decisions about whether something is adjourned or could go ahead, who needs to be there, whether more reports need to be provided, decisions have to wait until the tribunal is actually convened and so there are multiple unnecessary adjournments that take up a lot of time and also require people to attend and make themselves available for maybe a matter that might run for five or 10 minutes. (MHEA 9)

Whilst the adjournment process was frustrating for participants, there was general consensus that it had improved as systems became more flexible and understanding and knowledge improved.

> I think the MRHT processes have improved. I think they have probably looked at that section of the Law and not applied as rigid an interpretation about it. The services certainly have got better at making sure that the patients receive their stuff a week in advance at least and documenting that. That is really good for the patients because it does give them time to prepare and make a decision about whether they want a legal rep or whatever. It appears that the MHRT are getting more flexible in terms of if the patient does want to proceed and there's no objection from anybody else, any other parties, then the MHRT will proceed. (MHEA 2)

Although timely access to medical reports was generally seen as important in promoting consumer's rights, the potential negative impact of report contents for people with lived experience was of concern. Study participants identified that the focus on deficits within the report including the presentation of only the clinical aspects of a consumer's narrative, could be disheartening and negatively impact on the consumer's mental health and recovery trajectory.

> Oh, it was a bit demoralising actually. Yes. It hit me pretty hard because they've just sort of listed down all the things that I've done to warrant having treatment and I felt like I was just sort of starting to get my head above water and then I had a look at my history. There was nothing good about it and it was demoralising. I sort of thought, fuck, this is the reality of my life. (Consumer 4)

> So, we are kind of quite detailed about that and I think the services are getting better at that. I mean there are some patients who don't want to have a bar of it, who don't want to go through all of that stuff again and in fact it's quite confronting. We had a patient yesterday actually who had relapsed as a result of reading the report. (MHEA 2)

Additionally, the volume of long-standing history detailed in medical reports was often seen as unfairly influencing Tribunal decisions. Rather than focusing on current risks, details of past behaviour often from many years ago, tended to influence Tribunal decisions. This increased the possibility of judgements being based on outdated information.

> Whether it means that I'm now going to keep that moment on file for the next 20 to 30 years of your life and keep referring back to it whenever you're ill and using that to help my judgement. That's not fair, that's way not fair … they were talking about something that happened 10 to 15 years ago. I thought, what the hell, that was 10 to 15 years ago, he was 18, he is nearly 32 now. Give the man a break. (MHEA 10)

> … and you tell them about your history and everything, and it keeps coming up over and over again. And then, over time a person changes, I've had to make drastic changes since that ordeal … I've had to make changes in my life to make sure that I don't go down that path again ... so when the MHRTs come up, they still hold on to past history as a prerequisite of what you're going to do in the future. (Consumer 9)

7.6. Risk management

Whilst participants were supportive of the changes to supporting the rights of people with lived experience, there was still a belief that the MHRT tended to focus on risk rather than recovery.

> But yeah, the tribunal are not very courageous … maybe it's from the terms of reference and the drafting of the criteria for their decision about unacceptable risk, you know, it's that balancing … sometimes very difficult to muster all that evidence when you've got a very busy clinical team and you've got a lack of access to second opinions and independent reports for a person. It's very difficult to push through that barrier when a person might be compliant with medication, no issues when they've accessed long term treatment but have maybe some historical issues. (MHEA 9)

The risk focus was particularly evident for people on forensic orders.

> A lot of the times they err on the side of caution, but I think it's one of those things where maybe because there is a step-down sort of type thing, they don't need to be so conservative, I guess. I think for me in my opinion having the ability to step down, it should facilitate that. (HP 6)

> Yeah. So, they can be a little bit rigid. I think there's still a little bit of that old - I'll call it the Newman Government issue where the attorney general's rep was directed to appeal every single ratification of every single forensic order, no matter what. So, there's still a little bit of that kind of coming through and they're really risk averse. (MHEA 3)

An adverse risk attitude was also reported in relation to stepping people down to a Treatment Support Order (TSO), which was seen as a positive new element in the *Mental Health Act 2016*.

> So I think the ability to have a stepdown order from a forensic order to a TSO is a useful process in terms of being able to apply a least restrictive approach. To have sort of that intermediate step gives treatment teams more flexibility to apply the right level of supervision for somebody. So I think that that has been a very useful thing.

Aside from the challenges brought by a common learning curve in using TSOs, it was mentioned that some MHRTs were delaying people's hearings to receive specialist risk assessments to establish whether it was appropriate to step them down to a TSO. It was pointed out that there are already procedures in place to assess that risk and that if the MHRT evaluates that more risk assessment is needed then the onus should be on the MHRT to facilitate that assessment.

> I think that there are still some teething problems. We're sort of getting a common understanding about what a TSO means operationally across all of the different HHSs and across all of the different MHRTs. I think some of the challenges that we have had has been in working with the MHRT to have them - they've sort of done a few things like hold off people's hearings awaiting a specialist risk assessment before they'll consider whether a treatment support order is appropriate […] They're relying on the community forensic outreach service which actually doesn't accept referrals from the MHRT. So it's sort of unnecessarily holding up people - well consideration of people's leave or their order status. Even though there are other processes in place such as the ARMCs (Assessment and Risk Management Committee) which consider risk and which CFOS (Community Forensic Outreach Services) participates in collaboratively with the treatment team and so they're already will have been kind of a review of the appropriateness of the person stepping down to a TSO. So there's a few challenges still with sort of getting the MHRT on board with the idea that risk issues are being considered appropriately. That they shouldn't be holding up somebody's progress because they want a specialist report and if they do want that report then the onus is on them really to facilitate that happening

Part of the challenge was represented by the fact that there aren't centralised directives that allow to have a consistent approach across MHRTs.

So it is a little bit challenging because the MHRT won't […] do sort of practice directions or centralised directives that go out to all of the different MHRT panels. They want to allow for the interpretation of individual panels to still operate. So it has been a challenge to get the MHRT to take a consistent approach across locations.

8. Focus area 5: Rights and information regarding involuntary treatment in the community

8.1. Summary

Given the new protections in the *Mental Health Act 2016*, service provider participants saw people with lived experience living in the community as ideally suited to receive information aimed at strengthening the protection of their human rights. Participants with lived experience, family and carers reported having good relationships with their case managers and saw them as their primary source of information on the new Act.

Nevertheless, there seemed to be a limited structured approach from health services on providing rights-based information. There was general consensus that ensuring people are provided with information about the *Mental Health Act 2016* and human rights protections was not necessarily seen as a priority for community-based service providers. There was no way of tracking who had been provided with information and it was unknown how many of the people being treated involuntarily in the community had been informed of the changes and additional protections in the *Mental Health Act 2016*.

The introduction of more IPRA services to the community was identified as an option for increasing access to information and support, which would lead to an increased uptake of NSP and AHD applications.

8.2. Introduction

Participants' discussions about their views and experiences of rights and information regarding involuntary treatment in the community are here summarised under four main headings and discussed below:

1) Relationships with case managers
2) Experiences of treatment authorities
3) Resourcing
4) Limited access to IPRAs in the community

8.3. Relationships with case managers

The majority of consumer participants were positive about their relationship with their case manager and trusted that case managers supported their access to information.

> If I felt uncomfortable or anything, then I start searching for answers, but I am very comfortable with case manager and support worker and the support is really good. (Consumer 3)

> They've been pretty good at giving me options. This last one they said we're going to recommend that we keep you on it but you're most welcome to oppose that and also gave me the options of having allied or friends or - so yes the community staff seem to be a fair bit better than the inpatient staff. (Consumer 4)

> I stay in touch with my case manager because she actually built up a good rapport with me, and she just said, "Look, she is here for me, even though I'm not on the books anymore. That if I need to just say, hey, something's happening…" You know, yeah. She has seen me go from being well to unwell and I trust that she will help me out if I need it. (Consumer 1)

> I think there was good support to live independently, because the clinic appointments were quite frequent in the beginning and pretty helpful. I felt like someone was checking in with me, I wasn't just off on my own. Rights wasn't really discussed very much but support, yeah. (Consumer 5)

A number of concerns were raised about how often case managers changed and how long support was provided to people with lived experience. This made the development of a trusting relationship difficult and people needed to retell their story a number of times to different people.

> In fact in the past, he's always been one of the first lose case management. Because they're swamped. And I understand this, but I actually said to them that when he was discharged this last time, I said "I want case management for more than a couple of months". Because of this sort of three in a row that happened. (Carer 1)

> No, I tried to and I spoke to his case managers - this is part of the issue after the hospitalisation, is the after hospital care. And under the Act the case managers and this is where it's all to do with resourcing and all the rest of it, they keep changing all the time. So there's no consistency, it's just so hard. So you've got someone who's mentally unwell having to get to know a new person and another one, another one, another one and reveal aspects of their life that they don't feel comfortable talking about to a stranger. And then that stranger is only going to be there for a short time and then they've got to do it with another stranger, it's very difficult. (Carer 3)

> I met the original case manager and we had really long discussions and I sent her heaps of information and I was going to have a meeting with her next time I came, but she had resigned and all the information that I had sent, nobody else had access to it. All the long conversations that we had,

> nobody else knew anything about it. I thought, you've got to be kidding me, because I sat there for ages talking to her, sent her all the information. It seems like it went onto her email and stayed there. It should have been printed out, in a file, or accessed for everyone. So, I had to go through the same thing again. She ended up with a new case manager who didn't know anything about any of her history, so I had to go all through that again. (Carer 5)

8.4. Experiences of treatment authorities

At least half the participants with lived experience were able to demonstrate an understanding of the TA process and what conditions were in place.

> Yeah, I take my medication, I know what I need and I take that and yeah, I just see my shrink and she says I'm going alright. Well, I'm going alright and I know I'm going alright. I don't really need to be on it, but that's what they want at the moment, they want me under, so yeah. Doesn't do anything for me or against me at the moment, it's just something that they put me on. The only thing that, you know, they can, if I'm not doing exactly what they want me to do, they can chuck me in hospital again. That's the only thing I know. (Consumer 2)

And for one participant with lived experience, being on a TA was an important factor in their recovery. The TA ensured that they monitored their own illness and attended treatment.

> There's a fear of being manic and any symptoms or anything that will trigger me I want to avoid. The TA is my safety net. (Consumer 3)

Whilst other participants with lived experience, family and carers reported receiving limited information about the TA and were not even sure if they were still being treated involuntarily.

> I think I received a form, because I had a meeting to decide whether I should be on a TA or not initially and I think I got a form in the mail saying, "yes you are on a TA." I don't know how much information was on that about what it meant. (Consumer 5)

> No, no he was taken off it a little while ago and again we weren't advised that he was taken off it. I rang his case manager one day to tell her that I had made an appointment for him in the private sector and she just happened to mention - she said oh okay well that's fine, we can transfer his records down to them, the clinic. We can transfer his records and by the way he's not on the Treatment Authority anymore. I said oh okay. My son didn't even know (Carer 3)

> No, I'm not sure if she is on a TA. See, I'm not sure. (Carer 2)

8.5. Resourcing

A number of service provider participants described the community services as being under-resourced which makes it difficult to ensure that people have been provided with the necessary information.

> So yeah in terms of inpatient versus community, I don't think we're any better at it in community in terms of providing information and support. And for a lot of community health services it's like, you know, bare minimum contact with the person. Just keep going until you have your next crisis and then we'll sort you out … I don't think community services are even equipped to be proactive enough. I think, you know, we've got a case manager who's got 35 people on their caseload, they're not really in a position to really delve into this stuff, in a lot of detail with people, which I think, I don't know is kind of blaming the system as well but... (HP 1)

> The ones that are out in the community who have been out in the community for a while, like before the new Mental Health Act for example, and haven't been an inpatient, don't even know what an IPRA is … your community people are far, far behind the eight ball with any of those things, like having an advance health directive. Because they'd be the people that are probably better placed to actually do an advance health directive. But getting information to them about that is not easy. (MHEA 1)

Participants acknowledged that initially when the Act was changed, written information was distributed to those being treated under the Act and many case managers discussed the changes with people with lived experience.

> Well with all the - it's kind of difficult, I suppose we gave people the new the information packs and things like that and particularly when the changes were happening I would verbally talk about the changes. With both the client and if family, their supports, I used to talk to them as well and try and explain what it means. But whether they actually understand exactly what it means in terms of what the differences are, it's a bit difficult to tell. (HP 6)

> My caseworker was quite good but she was good like talking me through things, but she just said, “the new Mental Health Act has come through and you've got more rights," and I'm sitting there waiting, “and they are?" … and she gave me a brochure and talked about the advance health directive. (Consumer 1)

Whilst other participants with lived experience, family and carers did not receive any information.

> I think one day I was talking to one of his case managers which they change regularly and they said something about a Treatment Authority and I said what's that? And they said oh it's now the new name for the involuntary treatment order. Oh okay. (Carer 3)

Participants identified that AHDs and nominated support person processes are best targeted to those who are living in the community.

> We are still trying to work that one out, to be honest. Obviously, their rights are less infringed in the community than what they are in an inpatient setting. Obviously, for us in the community, it's really going to rest on NSPs. Getting those NSPs and AHDs. (MHEA 7)

8.6. Limited access to IPRAs in the community

Having IPRAs based in the community was seen as an important support to assist case managers provide information and facilitate options such as AHDs. Some of the IPRAs reported providing services to community teams on a referral basis, but this was done differently in different health services and resourcing was seen as an issue to expanding this service.

> In my experience no. I have not seen IPRAs in the community or sitting with the community teams. I haven't seen anyone. Are they supposed to sit in the community team? (HP 3)

> Right now, our IPRA - even though the Act says, you know, we have to provide the service to all our patients it's really heavily for the inpatient unit. So, I think those community consumers are missing out. So, there's not much contact. The - if the community clinician is new or not rights proactive, yeah, then that person is not going to be, you know, have the discussion about nominated support person. Because those discussions aren't legislated and monitored. (MHEA 3)

9. Conclusions

This study reported the views of the participants on some strengths and challenges still existing in the *Mental Health Act 2016* as well as about some factors that they perceived either hindering or promoting the protection of human rights of people being treated involuntarily in hospitals and in the community. Some of these factors concerned systemic issues, whereas other concerned implementation and cultural ones.

The main systemic factors that were identified as promoting and protecting the human rights of patients, family and carers in the five study focus areas concerned changes introduced by the *Mental Health Act 2016*. These changes brought more opportunities to enact specific rights as well as more safeguard mechanisms to protect them, including:

- the right to health, access to health care services and information, for example through the introduction of IPRAs, provision of information regarding treatment, and access to a second opinion;
- the right to autonomy, including freedom of movement, freedom from interference, and bodily integrity, for example through a more prominent role of Advance Health Directives, and the requirement that authorised mental health services provide data on the use of restraint on children and young people to the Office of the Public Guardian (Section 274);
- the right to family and community participation, for example through acknowledging patients' rights to communicate with family and friends using different communication means, including mobile phone and other electronic devices (Section 284);
- the right to equal justice and presumption of capacity, for example through the addition of representation for people with lived experience within the MHRT process.

The main systemic factors that hindered the promotion and protection of human rights of patients, family and carers in the five study focus areas, can be summarised into two groups: 1) what participants perceived as current shortcomings in the *Mental Health Act 2016,* and 2) cultural barriers and implementation issues.

The main perceived shortcomings in the *Mental Health Act 2016* regarding the five study focus areas were:

- a lack of safeguard mechanisms for the 72-hour assessment period;
- limited mechanisms to challenge seclusion and restraint, particularly for people with intellectual disability and a mental health challenge;

- the fact that, for certain groups of people on forensic orders, a *non-revocation period* of up to 10 years may not allow a more dynamic consideration of the person's response to treatment and right to recovery;

- the fact that the *Mental Health Act 2016* does not require authorised mental health services to communicate the use of restraint or seclusion on adults to the Office of the Public Guardian;

- the lack of safeguard mechanisms to question the use of medication by advocates, particularly in the case of forensic orders.

The main cultural barriers and implementation issues were:

- a long-standing paternalistic culture;

- a risk-adverse rather than recovery focused culture;

- a lack of understanding of and training on the rights introduced by the *Mental Health Act 2016* – including the role of IPRAs, AHDs, and the right to communication, with some AMHS still locking away patients' mobile phones regardless of any specific assessment of whether they can be detrimental to the patient's or others' health and wellbeing (Section 284 of the *Mental Health Act 2016*);

- limited access of people with lived experience, family and carers to accessible, appropriate, 'stepped', linguistically and culturally relevant information about their rights, treatment (Section 285), and the services they can access, including social benefits;

- people with a dual diagnosis (i.e. intellectual disability and a mental health challenge) experiencing prolonged hospitalisation or detention because of the shortage of disability services in place to transition them back to community. There are only 10 beds at the Forensic Disability Service provided under the *Forensic Disability Act* 2011;

- inadequate resourcing to expand the role of IPRAs from inpatient units to people with lived experience, family and carers in the community and in prisons, who do not currently have access to them.

Table 1 provides an overarching conceptual framework that summarises the study findings on the factors that promoted and limited the protection of the five human rights stated in the WHO (2012) Quality Rights Toolkit to assess and improve quality and human rights in mental health and social care.

Table 1. Conceptual framework summarising the study findings on the factors promoting and limiting the protection of the five human rights stated in the WHO (2012) *Quality Rights Toolkit* to assess and improve quality and human rights in mental health and social care.

Rights[1] and domains	Study focus areas: rights promoting and limiting factors[2]
Right to health, including access to health care services and information	
Promoting factors	• **IPRAs[2] and AHDs[2]:** o Training to educate clinicians, medical practitioners and mental health workers about the role and importance of IPRAs and AHDs. • **Rights in the ward and community:** o Access to a second opinion (Section 290 of the MH Act).
Limiting factors	• **Rights in the ward and community:** o Lack of communication on consumers' treatment preferences. o Lack of attention on general health in mental health settings. o Lack of transparency by HHS in arranging a second opinion.
Right to family and community participation	
Promoting factors	• **Rights in the ward and community:** o Providing access to information on the consumers' rights and treatment at different times during their hospitalisation and in ways which are accessible and appropriate to consumers as well as linguistically and culturally relevant (Section 285). o Expanding disability services to support the transition of people with a dual diagnosis (i.e. an intellectual disability and a mental health challenge) back to community.
Limiting factors	• **Rights in the ward and community:** o Locking away patients' mobile phones regardless of any specific assessment of whether they were going to be detrimental to the health or wellbeing of the person or others.
Right to autonomy, including freedom of movement, freedom from interference, and bodily integrity	
Promoting factors	• **AHD:** o Promoting the implementation and uptake of AHDs. o Upload of AHDs into the electronic health record was described as requiring a different process. Concerns were raised that, in a fast-paced health system, information about a consumer's AHD would not be accessed. • **Rights in the ward and community:** o Provision of data on the use of restraint on children and young people to the OPG[2] (Section 274 of the MH Act). o Use of de-escalation techniques before security guards are called. o Recovery approach, including to smoking in the wards.
Limiting factors	• **Rights in the ward and community:** o Lack of written informed consent to the use of restraint or seclusion on children by parents, guardians and carers. o Lack of mechanisms to monitor provision of information on use of restraint or seclusion by doctors to children's parents, guardians and carers. o No requirement for mental health services to communicate the use of restraint or seclusion on adults to the OPG. o Shortage of disability services to support the transition of people with a dual diagnosis (i.e. an intellectual disability and a mental health challenge) back to community. o Lack of safeguard mechanisms to question the use of medication by advocates, particularly in the case of forensic orders. o Involvement of security guards in restraining practices. o Risk of sexual assault in wards.

Right to equal justice and presumption of capacity	

Promoting factors	• **IPRAs:**
	  ○ The implementation of IPRAs.
	  ○ Training to educate clinicians, medical practitioners and mental health workers about the role and importance of IPRAs.
	  ○ Informing consumers about IPRAs and their limitations.
	  ○ Having the IPRA role governance from outside the HHS.
	  ○ Having IPRAs reporting directly to the Chief Psychiatrist office.
	  ○ Expanding access to IPRAs across community-based services and prisons.
	• **AHDs:**
	  ○ The implementation of AHDs.
	  ○ Training to educate clinicians, medical practitioners and mental health workers about the role and importance of AHDs.
	  ○ Simplifying storage and access of AHDs in the health service information systems and electronic health record.
	  ○ Informing consumers about AHDs and their limitations.
	• **MHRT:**
	  ○ The implementation of advocates and representatives in the MHRT[2] process.
	  ○ Appointing assistants with expertise in the support of persons with an intellectual disability and Aboriginal people and Torres Strait Islanders, and people from other cultural and linguistic diverse backgrounds.

Limiting factors	• **IPRAs:**
	  ○ Lack of guidelines and direction to assist the development of the IPRA role.
	  ○ Lack of clarity regarding whether IPRAs provide advice or advocacy.
	• **AHDs:**
	  ○ Lack of consumer accessible and appropriate AHD forms and guidelines.
	• **MHRT:**
	  ○ Lack of training for advocates and lawyers.
	  ○ Lack of support for consumers in accessing the reports before the hearings.
	  ○ Lack of legal support for consumers between hearings.
	  ○ A focus on risk and consumers' past behaviour rather than current risk and behaviour.

Right to social protection	
Promoting factors	• **Rights in the ward and community:** Promoting information on the social security services that hospitalised consumers can access.
Limiting factors	• **Rights in the ward and community:** Lack of information and communication on social security when hospitalised.

Notes. [1] The rights consist of the five themes reported in the *Quality Rights Toolkit. Assessing and improving quality and human rights in mental health and social care facilities*, which the World Health Organisation (WHO) drew from the United Nations (UN) Convention of the Rights of Persons with Disabilities (CRPD) (WHO, 2012). [2] The promoting and limiting factors are the findings of the Human Rights framework study by Giuntoli, Stewart, Wheeler, Gendera, Ryan, McAuliffe, Fisher (2019). [2] IPRA: Independent Patient Rights Advisers; AHD: Advance Health Directive; OPG: Office of the Public Guardian; MHRT: Mental Health Review Tribunal.

References

ACSQHC. (2008). *Australian Charter of Healthcare Rights*. Sydney: Australian Commission on Safety and Quality in Health Care Retrieved from https://www.safetyandquality.gov.au/wp-content/uploads/2012/01/Charter-PDf.pdf.

ACSQHC. (2017). *National Safety and Quality Health Service Standards (2nd Ed.)*. Sydney: Australian Commission on Safety and Quality in Health Care Retrieved from https://www.safetyandquality.gov.au/wp-content/uploads/2017/12/National-Safety-and-Quality-Health-Service-Standards-second-edition.pdf.

Arksey, H., & O'Malley, L. (2005). Scoping studies: Towards a methodological framework. *International Journal of Social Research Methodology, 8*(1), 19-32. doi:10.1080/1364557032000119616

Australian Government. (2010). National Safety and Quality Health Service Standards. Retrieved from http://www.health.gov.au/internet/main/publishing.nsf/Content/CFA833CB8C1AA178CA257BF0001E7520/$File/servst10v2.pdf

Banks, L. C., Stroud, J., & Doughty, K. (2016). Community treatment orders: exploring the paradox of personalisation under compulsion. *Health and Social Care in the Community, 24*(6), e181-e190. doi:10.1111/hsc.12268

Carney, T. (2011). *Mental Health Tribunals as governance: Lessons from an Australian study?* Retrieved from

Carney, T., & Tait, D. (2011). Mental Health Tribunals - Rights, Protection, or Treatment? Lessons from the ARC Linkage Grant Study? *Psychiatry, Psychology and Law, 18*(1), 137-159. doi:10.1080/13218719.2010.544242

Corring, D., O'Reilly, R., & Sommerdyck, C. (2017). A systematic review of the views and experiences of subjects of community treatment orders. *International Journal of Law and Psychiatry, 52*, 74-80. doi:10.1016/j.ijlp.2017.03.002

Davis, A., Doyle, M., Quayle, E., & O'Rourke, S. (2015). Am I there yet? The views of people with learning disability on forensic community rehabilitation. *Journal of Intellectual Disabilities and Offending Behaviour, 6*(3-4), 148-164. doi:10.1108/JIDOB-08-2015-0024

DHHS. (2018). *Victoria's mental health services annual report 2017–18*. Retrieved from https://www2.health.vic.gov.au/mental-health/priorities-and-transformation/mental-health-annual-report

Dunn, M., Canvin, K., Rugkåsa, J., Sinclair, J., & Burns, T. (2016). An empirical ethical analysis of community treatment orders within mental health services in England. *Clinical Ethics, 11*(4), 130-139. doi:10.1177/1477750916657654

Floyd, M. R. (2013). Involuntary Mental Health Treatment: The Mental Health Consumer as Expert. *Journal of Progressive Human Services, 24*(3), 187-198. doi:10.1080/10428232.2010.538919

Henderson, C., Flood, C., Leese, M., Thornicroft, G., Sutherby, K., & Szmukler, G. (2004). Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial. *BMJ*, 329: 136.

Light, E. M., Robertson, M. D., Boyce, P., Carney, T., Rosen, A., Cleary, M., . . . Kerridge, I. H. (2014). The lived experience of involuntary community treatment: A qualitative study of mental health consumers and carers. *Australasian Psychiatry, 22*(4), 345-351. doi:10.1177/1039856214540759

Mathews, B. (2017). *Oversight and regulatory mechanisms aimed at protecting children from sexual abuse: Understanding current evidence of efficacy*. Retrieved from Sydney:

Mental Health Act 2015 (ACT). *Mental Health Act 2015. A2015-38. Republication No 9. Effective: 2 March 2019. Republication date: 2 March 2019*. Retrieved from https://www.legislation.act.gov.au/DownloadFile/a/2015-38/current/PDF/2015-38.PDF

Mental Health Act 2016 (Qld). *Mental Health Act 2016. Act No. 5 of 2016*. Retrieved from https://www.legislation.qld.gov.au/view/pdf/asmade/act-2016-005

New, B. (2008). Paternalism and public policy. *Economics and Philosophy, 15*(1), 63-83. doi:10.1017/S026626710000359X

Newton-Howes, G., Lacey, C. J., & Banks, D. (2014). Community treatment orders: The experiences of Non-Maori and Maori within mainstream and Maori mental health services. *Social Psychiatry and Psychiatric Epidemiology, 49*(2), 267-273. doi:10.1007/s00127-013-0734-7

NSW Health. (2005). *Using Advance Care Directives. New South Wales*. Retrieved from Sydney https://www1.health.nsw.gov.au/pds/ActivePDSDocuments/GL2005_056.pdf

Ouliaris, C., & Kealy-Bateman, W. (2017). Psychiatric advance directives in Australian mental-health legislation. *Australasian Psychiatry, 1-4*. doi:doi.org/10.1177/1039856217726719

Pham, M. T., Rajić, A., Greig, J. D., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: Advancing the approach and enhancing the consistency. *Research Synthesis Methods, 5*(4), 371-385. doi:10.1002/jrsm.1123

Qld Health. (2017). Mental Health Act 2016: Statement of Rights for patients of mental health services. Brisbane: Queensland Health.

Qld Health. (2018). Mental Health Review Tribunal. Retrieved from https://www.health.qld.gov.au/clinical-practice/guidelines-procedures/clinical-staff/mental-health/act/topics/review-tribunal

Sutherby, K., Szmukler, G., Halpern, A., Alexander, M., Thornicroft, G., Johnson, C., & Wright, S. (1999). A study of 'Crisis cards' in a community psychiatric service. *Acta Psychiatrica Scandinavica, 100*, 56–61.

Swanson, J. W., Swartz, M. S., Elbogen, E. B., Van Dorn, R. A., Ferron, J., Wagner, H. R., . . . Kim, M. (2006). Facilitated Psychiatric Advance Directives: A Randomized Trial of an Intervention to Foster Advance Treatment Planning Among Persons with Severe Mental Illness. *American Journal of Psychiatry, 163*(11), 1943-1951. doi:10.1176/ajp.2006.163.11.1943

Thom, K., & Nakarada-Kordic, I. (2014). Mental Health Review Tribunals in Action: A Systematic Review of the Empirical Literature. *Psychiatry, Psychology and Law, 21*(1), 112-126. doi:10.1080/13218719.2013.790004

Thornicroft, G., Farrelly, S., Szmukler, G., Birchwood, M., Waheed, W., Flach, C., . . . Marshall, M. (2013). Clinical outcomes of Joint Crisis Plans to reduce compulsory treatment for people with psychosis: a randomised controlled trial. *The Lancet, 381*(9878), 1634-1641. doi:10.1016/S0140-6736(13)60105-1

Weller, P. (2010). Psychiatric advance directives and human rights. *Psychiatry, Psychology and Law, 17*(2), 218-229.

Weller, P. (2011). Taking a Reflexive Turn: Non-Adversarial Justice and Mental Health Review Tribunals. *Monash University Law Review 81, 37*(1), 81-101.

Werner, S. (2012). Individuals with intellectual disabilities: A review of the literature on decision-making since the convention on the rights of people with disabilities (CRPD). *Public Health Reviews, 34*(2), 14. doi:10.1007/bf03391682

White, B., Tilse, C., Wilson, J., Rosenman, L., Strub, T., Feeney, R., & Silvester, W. (2014). Prevalence and predictors of advance directives in Australia. *International Medicine Journal, 44*, 975–980. doi:10.1111/imj.12549

WHO. (2012). *Quality Rights Toolkit. Assessing and improving quality and human rights in mental health and social care facilities*. Retrieved from https://apps.who.int/iris/handle/10665/70927

Appendix A. Methodology

This was a qualitative research project that run over 21 months, from June 2017 to March 2019. A qualitative research design allowed the research team to explore the experiences of human rights of adults who receive involuntary treatment in hospital and community settings under the *Mental Health Act 2016*, including the views and experiences of their families and carers and a wide range of service providers and other stakeholders, with a specific focus on five focus areas: rights and information for inpatients within mental health wards; the role of Independent Patient Rights Advisers; advance health directives; the operation of the Mental Health Review Tribunal; rights and information regarding involuntary treatment in the community.

The study consisted of two phases:

Phase 1 (June 2017-February 2018) consisted of a scoping literature review and telephone interviews with six selected stakeholders from NGOs, for which we received Low Risk ethics approval from UNSW HREC (approval number HC17577, attached).

Phase 2 (March 2018-March 2019) explored the experiences of human rights and their protection, across the five study focus areas, of a total of 32 interviewees (Section A.4):

- Ten people with lived experience of mental health challenges who received involuntary treatment under the *Mental Health Act 2016* (here referred to as people/participants with lived experience)
- Five family members and carers of people with lived experience
- Seventeen service provider stakeholders (referred to as service provider participants), including practitioners, experts, and advocates.

Ethics approval was received from UNSW Sydney HREC (HC17990), Griffith University (2018/033) and Metro South HREC (HREC/18/QPAH/86) for the Phase 2 interviews.

A total of 38 participants took part in the study.

Literature review

The review adopted a scoping approach (Arksey & O'Malley, 2005), which is particularly helpful when a topic has not yet been extensively reviewed or is of a complex or heterogeneous nature, as in the case of this study (Pham et al., 2014).

Search strategies

The keywords reported in Table 3 were searched in the following electronic

databases, which are relevant for wellbeing studies across a wide spectrum of social science and health disciplines:

- PsycINFO (Covers the professional and academic literature in psychology and related disciplines, including medicine, psychiatry, nursing, and sociology)
- MEDLINE (Premier source for bibliographic and abstract coverage of biomedical literature)
- SCOPUS (the largest abstract and citation database of peer-reviewed literature in the fields of science, technology, medicine, social sciences, and arts and humanities).
- Google Scholar (covers most disciplines and subjects)
- Westlaw AU (First Point for law reports, case citations. Commentary includes Laws of Australia and Expert Evidence. Covers Australian law journals).
- APAFT: Australian public affairs (Australian journal articles from published material on the social sciences. Also includes some international articles about Australia.)

Keywords were searched as Subject Headings (such as MeSH, Medical Subject Headings, in MEDLINE), where available, or, if not, in Titles and Abstracts. The keywords pertaining to each of the five case studies (e.g. mental health review tribunal, advance directive, independent patient right adviser, etc.) were then combined with the other keywords to identify relevant literature and research evidence on the views and experiences of people with lived experience of mental health challenges.

Table 2. Search keywords

Involuntary treatment **OR** Compulsory treatment **OR** Outpatient treatment
Community
Care planning
Advance Directives **OR** Advance Statements
Mental Health Review Tribunal
Independent patient rights adviser
Information
Inpatients **OR** Ward

User **OR** Consumer
Experiences **OR** Views
Compliance **OR** Concordance
Australia

Relevant national and international websites, such as the Commission's website, Australian Government departments, Mental Health Tribunals, the Australian Human Rights Commission, and the UN website were also searched to identify any relevant informally published material (grey literature).

Data management and inclusion/exclusion criteria

Titles and abstracts of studies identified by the searches were downloaded into the bibliographic management software EndNote and duplicates removed. The Titles and Abstracts of the retrieved literature were screened based on their relevance with regard to the research aims.

Analysis

A copy of the literature included was retrieved and analysed with the aim to describe the characteristics and functioning of each of the five focus areas within the *Mental Health Act 2016* and in other relevant Australian and international frameworks (Project Objectives 2), with a particular focus on their efficacy in meeting the needs and protecting the human rights of people with mental illness being treated involuntarily (Project Objective 1).

Adopting the framework proposed by Mathews (2017), the characteristics and efficacy of each of the five case studies were explored both in a 'narrow sense', that is focusing on their implementation, their accessibility to people with lived experience of mental illness being treated involuntarily, and the clarity and accuracy of the information provided to them, and in a 'broad sense', that is exploring the literature on the views and experiences of people who received involuntary treatment for a mental illness, their family and carers.

Limitations

The scoping nature of the literature review allowed the research team to generate a comprehensive overview of the key characteristics of each of the five case studies under the *Mental Health Act 2016* and in other relevant Australian and international frameworks. However, the literature review did not aim to systematically retrieve and analyse all existing literature on each of the five case studies, so it does not offer a comparison of the *Mental Health Act 2016* against the Mental Health Acts of all Australian states and territories or a fixed set of international countries.

Participants

The study includes three groups of study participants:

- People with lived experience of mental health challenges (also referred to as consumers) who received involuntary treatment in hospital or community settings.
- Family members and carers of people with lived experience of mental health challenges who received involuntary treatment in hospital or community settings.
- Stakeholders who have direct or indirect responsibility on the decision making regarding involuntary treatment of people with lived experience of mental health challenges.

Sample size

Overall, the project included a sample of 38 study participants (Table 4), which allowed the research team to collect a diversity of opinions and experiences regarding the current strengths and weaknesses of the implementation of the *Mental Health Act 2016* across the five study focus areas.

Inclusion and exclusion criteria

Participants with lived experience of mental health challenges who received involuntary treatment in hospital or community settings. Participants with lived experience were included in the study if aged 18 and over.

Family members and carers of people who received involuntary treatment. Similarly, to the participants with lived experience, family members and carers of people with mental illness will be included in the study if aged 18 and over.

Stakeholders. Participants included stakeholders who had an understanding of the procedures and decision making related to involuntary treatment of people with mental illness. The stakeholders were invited to participate in the study on the basis of their responsibilities in relation to each of the above mentioned five study focus areas. In other words, they were not sampled based on their involvement in the specific case of involuntary treatment of the study participants with lived experience recruited in the study. This approach minimised the study's ethical risks and maximised the chances that potential participants took part in the study.

The general expression 'participants' is used to refer to all three groups of study participants.

Research project setting

All the fieldwork will be conducted at two study sites: Brisbane and Townsville.

These two locations allowed the research team to include participants from a range of backgrounds and settings and vulnerable groups, wherever possible whilst remaining within the limited scope of the project. In particular, the Brisbane area is an urban setting where researchers have strong relationships, there is a wide range of services available, a large population to draw on, and good NGO service access and well-established consumer/carer/peer services. Townsville is a regional setting with some provision of service into rural/remote, Indigenous population (and associated services), transient population (fly-in fly-out workers, Armed Forces), good consumer/carer/peer services.

Recruitment

The six stakeholder participants in Phase 1 were selected by the research team in agreement with the Queensland Mental Commission (QMHC) based on their expertise in the five study focus areas. QMHC sent an invitation email asking the participants to contact the research team if they were interested to participate in the study.

Phase 2 interviewees were recruited from two Queensland regions (South East Queensland (SE Qld) including Gold Coast, Brisbane and Logan areas) and Townsville to reflect diversity in geography, accessibility and service availability. Service providers who were able to provide information on the five focus areas were identified from the researchers' networks and advice from the Advisory Panel and were approached by email or phone to participate in the study. Those who did not wish to participate were replaced by service providers with similar roles/backgrounds who were contacted and invited. All participants received the information sheet and consent form by email prior to the interview.

Consumer and carer recruitment was facilitated by a third party 'arms-reach' recruitment / process (i.e. NGO's, consumer and carer networks, peer support conference, word of mouth and professional networks). Research flyers and information sheets/emails were disseminated and interested participants were asked to contact the research team to express interest in taking part. On initial contact, information about the study was provided and participant's questions answered. All eligible participants who contacted the research team were included in the study. The study participant information sheet was emailed to all interested participants and a convenient time and location to undertake the interview was arranged.

Data collection

The interviews in Phase 1 were conducted over the phone by the same researcher.

In Phase 2, face-to-face interviews were conducted with all participants by the same researcher. The consumer and carer interviews were jointly conducted by a second researcher who was also a lived experience practitioner.

Service provider interviews were 34-87 minutes in length (mean of 61 minutes) and consumer/carer interviews were 14-69 minutes in length (mean of 41 minutes). An appreciation payment or gift card of $150 was provided to all consumer and carer participants.

There service provider participants recruited in Phase 2 were from a range of professional backgrounds and roles. For reporting purposes, service providers have been divided into two groups (mental health practitioners and mental health experts and advocates). Mental health practitioners (n=6) included psychiatrists and allied health staff working in a range of roles in both community and inpatient settings. Mental health experts and advocates (n=11) included lawyers, peer workers, IPRAs, mental health delegates, consumer consultants and MHRT members. Demographic details of participants can be found in Table 4.

Table 3. Phase 2 participants overview

	Location		Gender		
	SE Qld	**Townsville**	**Male**	**Female**	**Total**
Service providers	14	3	5	12	17
People with lived experience	5	5	6	4	10
Family and carers	5	0	0	5	5
Grand total	24	3	11	21	32

Note. SE = South East Queensland

Data analysis

The audio-recorded interviews were transcribed verbatim by a third-party transcription service. Identifying information was removed and data coded using NVivo© software. Following a first thorough open read, extracts of the text from each interview were analysed and condensed into ‘units of meaning’ which were stored together in different ‘nodes’, which are equivalent to folders containing text extracts pertaining to the same topic. These nodes were then clustered under the five focus areas of the study, according to common themes with supporting examples. Data that did not fit within the five focus areas of the study was clustered under the topic of general comments about the Mental Health Act. Data from all participants were collectively analysed to generate the themes.

Table 5 presents examples of how data were analysed into condensed meanings and nodes.

Table 4. Example of how data was coded

Verbatim quote	Unit of meaning	Node
You know when they brought the IPRAs, every single hospital and health service has put them in a different sort of a role ... no one was ever told they should go on the legal team, or they should go and sit with this group of people. It was just like a random we'll put them wherever.	Role of IPRA has different governance structures in each HHS.	IPRAs Roles

One criterion of trustworthiness important in this report was that of dependability. This is where the research process itself can be audited, so that future researchers can easily follow the decision trail used by the investigator of a study to arrive at similar conclusions. This criterion was met through clearly articulating the processes used to conduct this research and recording and maintaining records at each level of analysis.

Appendix B. Interview schedules

Interview guide: Consumers (Phase 2)

Background

Please note that the primary focus of the research is to examine the participants' experiences of receiving treatment under the Mental Health Act, with a focus on their views on whether and how their human rights were protected in relation to:

- their autonomy, for example their personal liberty and security;
- their freedom from cruel, inhuman or degrading treatment or punishment, violence and abuse;
- their right to exercise legal capacity;
- their right to live independently and be included in the community.
- their right to an adequate standard of living and social protection.

This interview schedule is designed to be flexible and to rely on the skills and judgement of the interviewers, who have experience interviewing people with mental illness and experiences of the use of the *Mental Health Act 2016*.

Prior preparation for participant

In the earlier stages of recruitment, researchers will have established with the participants:

- whether they would prefer a face-to-face or phone interview
- where they would like to have the interview
- whether they would like to bring a support person
- the key areas of focus
- who will be interviewing them
- support information

As part of the briefing at the start of the interview, the interviewer will remind the study participants the aims of the study, that it will take up to one hour, their right to withdraw from it, and the limits to the confidentiality of the interview. Participants will also be reminded that they can stop or take a break from the interview at any time,

although the interviewers will check during the course of the interview whether participants would like to take a break. The interviewers will suggest to the participants that they communicate their need to have a break in multiple ways, including by saying that they are going to make a cup of tea, have a smoke or stretch their legs.

Interview guide

1. Rapport building

2. Review the Participant Information Sheet together and answer any questions the participant (or support person) may have.

3. Ask the participant if they can describe their most recent experience of being placed under the *Mental Health Act 2016* – the time leading up to that and how things unfolded after that in as much detail as they feel comfortable with.

    - Prompts if not covered in the consumer's recount of their recent experience:

        - Were you given a Statement of Rights? If yes, did you understand what this was and what it meant? [The *Mental Health Act 2016* requires that a Statement of Rights (PDF) be provided for patients, containing information about the rights of patients, nominated support persons, family, carers and other support persons under the Act].

        - Was a family member or a friend of yours that you trust involved in the decisions about your treatment and care?

        - Were you able to communicate with someone you trusted or wanted to talk to?

        - How long was it before you were able to speak with a family member/community visitor/Independent Patient Rights Adviser?

        - Were you aware of/informed about Independent Patient Rights Advisers? a

        - Were you told that you, or someone on your behalf, had the right to seek an independent second opinion from a psychiatrist if there were unresolved concerns about your treatment and care?

        - Was the Mental Health Review Tribunal part of your most recent experience? If it was, then enquire further about this experience? b

        - Have you heard about/have an Advance Health Directive? c

4. Ask the participant to talk about their understanding of human rights and what protection of these personally means to them.

    - Prompts - may need to give some examples of these human rights and a range of things that these concepts might cover – but need to balance this information with not leading the participant:

        - i.e. whether their care had an impact on: their ability to live the way they wanted to, to do the things that were important to them, and to be treated in a way that they found respectful and supportive. [In plain language, this captures the areas of: their autonomy, for example their personal liberty and security; their freedom from cruel, inhuman or degrading treatment or punishment, violence and abuse; their right to exercise legal capacity; their right to live independently and be included in the community; and their right to an adequate standard of living and social protection].

5. Ask the participant to reflect on their most recent experience of being placed under the *Mental Health Act 2016* whilst thinking about their human rights and the protection of these during that experience.

    - Prompts – if not covered in the consumer's response:

        - How did you feel your human rights were protected?

        - How secure did you feel?

        - Can you describe the way decisions were made about your care and treatment?

6. Ask the participant to reflect on their most recent experience and whether the process may have been done differently in relation to protecting their human rights.

7. Ask the participant if there is anything else they would like to discuss about their experience or any questions they have before we finish the interview.

8. Further questions for particular focused areas:

    a. What could have been done differently? Their most recent experience and to describe things that they think could have been done differently regarding the Independent Patient Rights Adviser:

        - What did you learn from speaking with the IPRA?

        - Was speaking with the IPRA useful? If yes – how was it useful?

b. Mental Health Tribunal hearing:

- Who was there with you?
- Did you have an Allied Person?
- Did you get help from your case manager to prepare for the hearing? Did you find it helpful?
- Did you complete a self-report?
- Did you see and understood your clinical report? Did you get support to interpret it?
- Were you able to get to the hearing?

c. *Advance Health Directive:*

- If the participant has one: Was it used? Are you happy about the way it was used?
- If not: Have you thought to prepare an Advance Health Directive? If not, why?

Interview close and check-in

- Thank you
- Next steps (what happens with the research next, copy of interview transcription, summary of results etc)
- Support information

Interview guide: Family members and carers (Phase 2)

Please note that the primary focus of the research is to examine the participants' experiences of involuntary treatment, with a focus on their views on whether and how their human rights were protected in relation to:

- their autonomy, for example their personal liberty and security;
- their freedom from cruel, inhuman or degrading treatment or punishment, violence and abuse;
- their right to exercise legal capacity;
- their right to live independently and be included in the community.

- their right to an adequate standard of living and social protection.

This interview schedule is designed to be flexible and to rely on the skills and judgement of the interviewers, who have experience interviewing people with mental illness and experiences of involuntary treatment.

Prior preparation of participant

In the earlier stages of recruitment, researchers will have established with the participants:

- Whether he/she would prefer a face-to-face or phone interview
- Where he/she would like to have the interview
- Whether he/she would like to bring a support person
- The key areas of focus
- Who will be interviewing them
- Support information

As part of the briefing at the start of the interview, the interviewer will remind the study participants the aims of the study, that it will take up to one hour, their right to withdraw from it, and the limits to the confidentiality of the interview. Participants will also be reminded that he/she can stop or take a break from the interview at any time, although the interviewers will check during the course of the interview whether participants would like to take a break. The interviewers will suggest to the participants that he/she communicate their need to have a break in multiple ways, including by saying that he/she are going to make a cup of tea, have a smoke or stretch their legs.

Questions

Rapport building (ask about their day so far etc.)

Context

e.g. 'name of staff member at NGO' has told us what happened to 'name of family member/friend' last 'month/year' when he/she received involuntary treatment. Is there any other information he/she would like us to know about this (in as much or as little detail as he/she are comfortable with) before we talk about how the rights of 'name of family member/friend' were protected during that event?

1. Was **'name of family member/friend'** able to speak with someone about their rights after he/she received involuntary treatment?

    - Prompts:

i. Did he/she speak with an Independent Patient Rihts Advisors? If yes, was it helpful? What did he/she learnt from speaking with the Independent Patient Rights Advisor? Did something change for he/she after he/she spoke with her/him?

ii. Did he/she appoint a nominated support person? [A nominated support person can help the patient understand their rights and speak with their treating team and the Mental Health Review Tribunal]

iii. Did he/she speak with a family member?

iv. Did he/she speak with a community visitor?

2. Were he/she given a Statement of Rights? [The Mental Health Act 2016 requires that a Statement of Rights (PDF) (PDF) be provided for patients, containing information about the rights of patients, nominated support persons, family, carers and other support persons under the Act].

3. Was a family member or a friend of yours that he/she trust involved in the decisions about their treatment and care? [The Mental Health Act 2016 recognises that, to the greatest extent practicable, family, carers and other support persons of someone].

4. How long after he/she received involuntary treatment he/she were able to speak with Independent Patient Rights Advisor/family member/community visitor?

5. Were he/she told that he/she, or someone on their behalf, had the right to seek an independent second opinion if there were unresolved concerns about their treatment and care?

6. Did he/she have an Advance Health Directive?

    - Prompts:

        i. If yes: Was it used? Are he/she happy about the way it was used?

        ii. If not: Have he/she thought to write an Advance Health Directive? If not, why?

7. Did he/she have a mobile phone with he/she at the time he/she received involuntary treatment?

    - Further questions:

i. If yes: were he/she able to keep it or it was taken away from he/she? If it was taken, do he/she know why?

ii. If not: were he/she able to communicate with someone he/she trusted or wanted to talk to?

8. Did he/she feel secure during the time he/she received involuntary treatment?

- Further questions:

i. If yes: What helped to make he/she feel secure?

ii. If not: What made he/she feel not secure?

9. Did he/she feel that their right to be free from cruel, inhuman or degrading treatment was respected?

- Further questions:

i. If yes: What was helpful to this end?

ii. If not: What was not helpful to this end?

10. Did he/she go to the Mental Health Tribunal hearing?

- Further questions:

i. If yes:

1. Who was there with he/she?
2. Did he/she have an Allied Person?
3. Did he/she get help from their case manager to prepare for the hearing? Did he/she find it helpful?
4. Did he/she complete a self-report?
5. Did he/she see and understood their clinical report? Did he/she get support to interpret it?
6. Were he/she able to get to the hearing OK?
7. If not: Why not?

11. What did he/she liked/not liked about the way their right to make decisions in relation to their treatment and health was protected?

- Prompts:

i. What thoughts stood out for he/she?

12. What did he/she liked/not liked about the way their right to live independently and be included in the community was protected?

    - Prompts:

        i. What thoughts stood out for he/she?

13. What did he/she liked/not liked about the way their right to an adequate standard of living and social protection was protected?

    - Prompts:

        i. What thoughts stood out for he/she?

14. If there was one thing he/she could change about the way their experience of involuntary treatment, what would it be?

15. Do he/she have anything else he/she wanted to say about their experience of involuntary treatment before we finish?

Gentle close and check-in

- Thankyou
- Next steps (what happens with the research next)
- Support information

Interview guide: Service provider stakeholders (Phase 1)

Background

The Queensland Mental Health Commission commissioned a consortium comprising the University of New South Wales (UNSW Sydney), Griffith University, and the University of Sydney, to undertake research into the processes provided in the new Queensland Mental Health Act 2016 (*Mental Health Act 2016*) to protect the human rights of people who receive involuntary treatment for a mental illness in hospital and community settings.

The project's objectives are to investigate:

1. to what extent processes provided in the *Mental Health Act 2016* protect the human rights of people who receive involuntary treatment in hospital and community settings:

2. how these processes compare to other Australian States and Territories;

3. whether these processes are working in practice; and

4. the practical experience with the processes under the *Mental Health Act 2016* of people living with mental illness, and their family members, carers and support persons.

The study will focus on the following five areas of investigation:

- the operation of the Mental Health Review Tribunal;
- advance health directives;
- rights and information regarding involuntary treatment in the community;
- the role of Independent Patient Rights Advisors;
- rights and information for inpatients within mental health wards, e.g. community visitors.

The study includes a scoping literature review, which explores national and international literature on the above five focus areas, and fieldwork research, which explores the experiences of human rights and their protection, across the five listed case studies, of people who receive involuntary treatment under the *Mental Health Act 2016*, their family and carers, and key stakeholders.

We are seeking your advice about priorities and considerations to inform the design of our research.

Interview questions/topics

1. Did you have a role in the development/implementation of the *Mental Health Act 2016*? If so, which one?

2. What is your understanding of human rights and relationship with the mental health system?

3. What is your role in supporting the needs of people being treated under the *Mental Health Act 2016*?

    - What is your experience of operating under the *Mental Health Act 2016* so far?

    - What is your opinion about potentials and risks to its implementation in hospitals? How about in community settings?

4. In your experience, are there any specific issues that characterise the area of your competence in relation to the following five focus areas?

        - The operation of the Mental Health Review Tribunal.

- Advance Health Directives.
- Rights and information regarding involuntary treatment in the community.
- Rights and information for inpatients within mental health wards, e.g. community visitors.
- The role of Independent Patient Rights Advisors.

5. What is your overall view of the implementation of the *Mental Health Act 2016* in protecting the human rights of people with mental illness who receive involuntary treatment in hospital?
    - And in community settings?
6. Do you have any other comments about the focus area of your competence under the *Mental Health Act 2016* in relation to issues that we have not discussed so far?
    - The operation of the Mental Health Review Tribunal.
    - Advance Health Directives.
    - Rights and information regarding involuntary treatment in the community.
    - Rights and information for inpatients within mental health wards, e.g. community visitors.
    - The role of Independent Patient Rights Advisors.

Suggestions

7. What could be done differently to make the *Mental Health Act 2016* work better in your experience?
8. Do you have any other comments about priorities for our research study?

Interview guide: Service provider stakeholders (Phase 2)

Background

1. What organisation do you work for and what is your role there?
2. What activities does your organisation conduct?

Oversight mechanisms

3. Did you have any expectations about the new Mental Health Act?

4. In your experience, what are the strengths and weaknesses of the oversight mechanisms to protect the human rights of people with mental illness who receive involuntary treatment under the Queensland Mental Health Act 2016 in hospital?

    - And in Community settings?

5. In your experience, are there any specific issues that characterise the following oversight mechanisms under the new Mental Health Act?

    - The role of Independent Patient Rights Advisors.
    - The operation of the Mental Health Review Tribunal.
    - Advance Health Directives.
    - Rights and information for inpatients within mental health wards, e.g. community visitors.
    - Rights and information regarding involuntary treatment in the community.

6. What is your overall perception of the effectiveness of the Mental Health Act 2016 in protecting the human rights of people with mental illness who receive involuntary treatment in hospital?

    - And in community settings?

Suggestions

7. If there was one thing you could change about the new MH Act, what would it be?

8. Do you have anything else you wanted to say the new MH Act before we finish?