Options for Supported Decision-Making to Enhance the Recovery of People Experiencing Severe Mental Health Problems

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1. Executive Summary

People experiencing severe mental health problems may experience a loss of autonomy in decision-making under laws that enable others to make decisions for them or because of pre-conceived notions about their decision-making abilities. The United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2008), which Australia has ratified, is driving changes to ensure the integration of a human rights perspective into mental health and community services. Mental health laws, policies and practice are moving towards a stronger focus on personal recovery and human rights. The personal recovery model values autonomy and the right of people experiencing severe mental health problems to have choice and control over important decisions. Ensuring people's views and preferences in decision-making are respected on an equal basis with others is a cornerstone of these developments. Supported decision-making means that those assisted retain legal authority to make decisions. It involves individuals receiving support from others to consider alternatives and make specific decisions.

This report summarises the findings of an Australian Research Council Linkage project which sought to document the experiences, views and preferences of people experiencing severe mental health problems, family members and other informal supporters, and mental health practitioners about supported decision-making, treatment and recovery in Australia. The research team interviewed 90 people across Victoria. This report documents the analysis of those experiences and the project's findings. It also includes an international comparative analysis of supported decision-making laws, policies and programs. The project findings have informed recommendations for improvements to mental health service delivery.

Language and Terminology

In writing this report, the authors acknowledge that there are many different opinions about the respectful use of language in the context of mental health experiences and systems. Some people are quite satisfied with the kinds of words and phrases commonly used within mental health settings, while others find this language inaccurate and offensive. The term 'people experiencing severe mental health problems' is used in this report because it was recommended in initial consultations about this project with leaders in the consumer movement in Victoria.

The term 'family members and other informal supporters' has also been selected for use throughout this report to encompass families, partners and friends who provide support and care, through a diverse range of

supportive behaviours and actions, to people experiencing severe mental health problems.

Main Findings

1. People experiencing severe mental health problems, families and other informal supporters and mental health practitioners emphasised the importance of developing enduring relationships with mental health practitioners and other health service providers (such as General Practitioners) that are based on safety, trust, choice, collaboration and empowerment. Interpersonal strategies to support decision-making were viewed as particularly important in working with people who have experienced trauma (Blueknot Foundation (formerly known as ASCA), 2016).

Managers and leaders of mental health services and mental health practitioners are encouraged to adopt strategies that focus on providing personalised, continuous care, sensitive use of language and sharing information with families and other informal supporters, and adopting a person-centred approach.

2. People in contact with mental health services can feel that legal or administrative procedures take priority over care and good communication (Bee et al., 2015). An accumulation of these experiences can result in feelings of disempowerment and hopelessness that undermine supported decision-making (Healthtalk Australia, 2016). Participants experiencing severe mental health problems described how feeling empowered by their General Practitioner or mental health practitioner helped restore their confidence to make decisions. Psychiatrists and other practitioners also emphasised the value of practices and attitudes that communicated belief in the person's capacity to make decisions.

Mental health practitioners can support people to express their views and preferences, can ensure people have access to genuine choices and support people to take responsibility for

the consequences of their choices. Other helpful interventions include assisting people to:

- access credible online information that will help with decision-making;
- access peer support and other mechanisms for normalising and sharing experiences of mental health problems; and
- encourage self-advocacy.

3. Management and leadership practices can lead change and support and motivate staff to embed supported decision-making into practice.

Psychiatrists and senior clinicians are encouraged to champion supported decision-making. Mental health services can recognise and support 'pockets of excellence' that already occur in services. Staff supervision, support and training are needed to increase knowledge of the different types of decision-making and to ensure that preferences in advance statements are followed where possible. Resources will be required to adequately support these activities.

4. Barriers to supported decision-making practice in mental health services include concerns about risk and duty of care, stigma and discrimination and the need for system transformation. Youth, aged and rural services may face difficulties in offering real choice to people so that their preferences for treatment can be respected.

Assisting staff to deal with their concerns about risk and meeting their duty of care is important to supported decision-making. This needs to be balanced with respecting the 'dignity of risk' in the decision-making of people experiencing severe mental health problems. Tailoring strategies to overcome obstacles to supported decision-making to meet location and service needs is required. Facilitating access to online support, advocacy and encouraging the involvement of family and other informal supporters are examples of useful strategies to overcome these barriers.

5. Engaging family members and other informal supporters is valuable but needs to be more than being invited to meetings and discussions. Families and other informal supporters need to be informed and involved and have their difficulties in the process acknowledged.

Involving families and other informal supporters in decision-making includes and extends to recognising their expertise and engaging with them as key sources of support for people's treatment decision-making. Families and other informal supporters can support decision-making if practitioners gain agreement from consumers to include them in the information sharing process. Mental health practitioners should be encouraged to consult with and involve families and other informal supporters in treatment decisions rather than 'informing' or 'telling' them about such decisions.

6. Legal and rights-based supported decision-making mechanisms help participation in decision-making. These mechanisms include advance statements, nominated persons, second opinions and advocacy. There is some evidence that appropriate use of advance directives or statements leads to clinically significant reductions in compulsory admissions (de Jong et al., 2016). People experiencing severe mental health problems want to use advance statements to ensure their preferences are incorporated into treatment decisions (Pathare and Shields, 2012).

Information about advance statements, nominated persons, advocacy and second opinions should be promoted throughout mental health services. Further education and support for mental health practitioners is needed to ensure that legal and rights-based mechanisms are available and used.

As well as this Report, an important outcome of this research project is the development of online resources at http://research.healthtalkaustralia.org/supported-decision-making/overview and http://research.healthtalkaustralia.org/carers/overview.

Guidelines and Fact Sheets are also available to enable a better understanding of supported decision-making and personal recovery. The Guidelines and Fact Sheets are linked to the online narratives and interviews and can be used in training programs, as an aid to policy development and as communication materials to improve supported decision-making practices. They can be obtained by contacting the Melbourne Social Equity Institute at the address on the inside cover and online at http://socialequity.unimelb.edu.au/.

2. Overview of Supported Decision-Making

People experiencing severe mental health problems may face discrimination and exclusion (Thornicroft, 2006; World Health Organization, 2013) as well as infringements of their human rights (United Nations Human Rights Council, 2016). They may experience a loss of autonomy in decision-making under laws that enable others to make decisions for them or because of pre-conceived notions about their decision-making abilities. This section of the report discusses the recent move in Australian mental health policy and legislation toward a recovery and human rights focus.

The framework for the delivery of mental health services is set out under legislation. In Victoria, specialist mental health services are delivered through government-funded, area-based clinical services. These services are delivered through a range of in-patient units and community-based continuing care and treatment teams. Mental Health Community Support Services (MHCSS) provide residential and outreach support. Each Australian state and territory has mental health legislation that enables the detention and treatment of a person without their consent, providing certain criteria are met.

The Policy and Legal Context

Mental health policy throughout Australia has become increasingly influenced by what is generally termed "recovery" (State of Victoria, 2011; Commonwealth of Australia, 2013). Roberts and Boardman (2013) define this as "a set of values, ideas and principles" derived from the lives of people experiencing mental health problems. Deegan (1992) refers to the "dignity of risk" and the "right to failure" as central to recovery and Parsons (2008) points out that autonomy can involve "risky and potentially self-defeating choices." The move to recovery-oriented practice redirects the focus in mental health services from alleviating symptoms to working with strengths, capacities and opportunities for personal recovery.

Members of the World Psychiatric Association's Task Force on Best Practice in Working with Service Users and Carers chaired by Helen Herrman developed ten recommendations for mental health experts (Wallcraft et al., 2011). One of the key recommendations was that "education, research and quality improvement in mental health care require collaboration between users, carers and clinicians." This was noted as particularly important by service user and carer respondents in the

consultation process due to the growing emphasis on recovery (2011: 233).

An emphasis on human rights is also shaping mental health law reform (McSherry and Weller, 2010; McSherry and Freckelton, 2013). The United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2008), which Australia has ratified, sets out as its first guiding principle, "[r]espect for inherent dignity, individual autonomy including the freedom to make one's own choices" (Article 3) (CRPD). This Convention applies to those with "mental impairments" as well as intellectual, sensory and physical impairments (Article 1). The United Nations Human Rights Council (2016) has also formally recognised "the need for States to take active steps to fully integrate a human rights perspective into mental health and community services."

The move toward a recovery and human rights focus in the mental health sector has contributed to policies and law aimed at ensuring individuals with lived experience who may be subject to compulsory treatment have their views and preferences respected. For example, section 11(1)(c) of the *Mental Health Act 2014* (Vic) states that:

> persons receiving mental health services should be involved in all decisions about their assessment, treatment and recovery and be supported to make, or participate in, those decisions, and their views and preferences should be respected.

Supported Decision-Making

This notion of the centrality of supporting people in decision-making about their treatment stems from one interpretation of Article 12 of the CRPD which deals with equal recognition before the law. Article 12(3) declares:

> States Parties [that is, countries that have ratified the CRPD] shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

The United Nations Committee on the Rights of Persons with Disabilities, which is responsible for overseeing the implementation of the CRPD, has issued a General Comment (2014) which defines "legal capacity" as the ability to hold rights and duties (for example being able to have a birth certificate, being registered to vote, owning property or seeking medical assistance) as well as to exercise those rights and duties. It is this second component which is sometimes taken away from persons with disabilities. It is sometimes presumed, for example, that just because a

person has been diagnosed with psychosis, schizophrenia, bipolar disorder or severe depression, he or she can no longer make any decisions about his or her treatment. The Committee on the Rights of Persons with Disabilities (2014) has stated that taking away a person's legal capacity because he or she is thought to have impaired decision-making skills is discriminatory and Article 12 of the CRPD requires support to be provided so that persons with disabilities can exercise their legal capacity.

Supported decision-making means that those assisted retain legal authority to make decisions (this can be dependent on the type of treatment, with some retention of legal authority by services for forensic or compulsory patients). It involves individuals receiving support from others to consider alternatives and make specific decisions. Supported decision-making thus differs from substituted decision-making where specific persons, such as guardians or administrators, are granted responsibility to make decisions for them. It also differs from shared decision-making which is sometimes used in medical settings to describe patients and service providers making decisions together about treatment (Kaminskiy et al., 2013). Shared decision-making has also been linked to recovery-oriented practice and is well supported internationally, with clinical and ethical justifications for involving clinical expertise with lived-experience expertise to achieve the best outcomes for people (Slade, 2017). There is some evidence from studies of shared decision-making that orienting practice towards supported decision-making would reduce dissatisfaction and improve patient involvement in decision-making. However, current mental health treatment systems would require significant changes (Slade, 2017; Clarke et al., 2015)

Types of Support

Soumitra Pathare and Laura Shields (2012: 4) have pointed out that in supported decision-making, the person concerned is always the primary decision-maker. There may, however, be different forms of support offered. These can either be informal or formal in the sense of being found in legislation. Examples of support include:

- Networks made up of peers, family members, partners, other informal supporters and so on
- Mental health advance directives
- Informal or formal peer support
- Formally nominated support persons

Piers Gooding (2013) has explored a number of these schemes including the use of networks of support in Canada, the 'Open Dialogue' approach in Finland which facilitates discussions between individuals with mental

health problems, their family members and friends and personal 'ombudsmen' in Sweden.

Supported decision-making schemes are currently being trialled in Australia, primarily for those who have been diagnosed with cognitive or intellectual disabilities. However, there have been attempts to provide supports in a broad sense for individuals experiencing severe mental health problems to make decisions about their treatment. For example, under the Victorian *Mental Health Act 2014,* individuals can make advance statements as to preferred treatment options, based on their values and preferences, and nominate others to support them. This may be particularly valuable in the event they become subject to compulsory treatment or to help avoid compulsory treatment.

Exploration of supported decision-making schemes and factors that influence, support and hinder supported decision-making have been the subject of research within a range of forums, including medical, health and welfare, legal and policy fields.

Literature Reviews

In order to understand the current state of knowledge about supported decision-making in health and welfare research, a systematic review of the academic health and welfare literature on mental health decision-making since 2000 was conducted. Rigorous assessment of the research involved first conducting a review of reviews. Reviews were found addressing the domains of supported decision-making, decision-making tools and user-involved care planning. The qualitative literature on involvement in mental health decision-making is then summarised. Studies that focused on shared decision-making were excluded due to reporting constraints. Five reviews of studies of decision-making relating to mental health were identified (see below and Appendix One for details). No reviews or studies were found in the health and welfare literature addressing other elements of supported decision-making, such as implementation of the CRPD.

A separate review of the international legal literature was also undertaken, using legal indexing/abstracting and full text databases including:

- AustLII journals
- All Databases on the INFORMIT platform (including AGIS)
- LexisNexis AU
- HeinOnline
- Social Sciences Research Network (SSRN)

- Index to Legal Periodicals
- Westlaw
- Google Scholar

Combinations and variations of the following search terms were used in keyword searches:

'Decision-making'; 'Decision-Making'; 'Supported'; 'Supporting'; 'Substituted'; 'Assisted'; 'Mental Health'; 'Mental Disability'; 'Mental Impairment'; 'Mental Health Law'; 'Disability'; 'Disability Law' 'Convention on the Rights of Persons with Disabilities'; 'CRPD'; 'Guardian'; 'Guardianship'; 'Personal Ombudsman'; 'Personal Ombudsmen'; 'Personaligt Ombud'; 'Personaliga Ombud'; 'Sweden'; 'Swedish'; 'Finland'; 'Finnish'; 'Capacity'; 'Legal Capacity'.

Forty-three journal articles and 28 other sources were identified, some of which overlapped with the general literature review. The most relevant items were then analysed for reference to international treaties and comparative legislation and case law. Overviews of this literature informed two publications (McSherry and Butler, 2015; McSherry, 2014).

Review of health and welfare research reviews

Pathare and Shields (2012) assessed the legal and health literature on supported decision-making internationally. They reported that people experiencing severe mental health problems varied in their desire for support depending on the health issue. For example, autonomous decision-making was preferred for psychosocial treatments, whereas shared decision-making was preferred for medication decisions and substitute decision-making was preferred for general health. Treatment settings influenced desire for involvement in decision-making, with people in involuntary treatment experiencing less autonomy and less decision-making confidence than those in voluntary settings. Factors that prevented individuals from making decisions included feeling uninformed and unsupported, traumatic past experiences of health care and previous assessment as incompetent due to severe mental health problems, cultural differences in relating with health practitioners, and the role of social exclusion where those with limited social networks lacked friends or supporters with whom they could discuss decisions. Professional barriers included perceptions by psychiatrists that patients who sought involvement in decisions were more difficult to treat, extra stress associated with involving patients in decisions, lack of time and system support, and difficulties managing involvement in decision-making during mental health crises.

The effectiveness of advance directives was reviewed by Campbell and Kisely (2009). They conducted a Cochrane review of randomised controlled trials of psychiatric advance directives finding two trials involving 321 people and concluded that there was no evidence for the effect of advance directives on improvements in psychiatric admissions, number of bed days, adherence to treatment, self-harm, violence or service use. A randomised controlled trial of a type of advance directive known as a Joint Crisis Plan (a statement of treatment preferences developed in collaboration with service providers) also demonstrated no difference in subsequent compulsory treatments compared to treatment as usual (Thornicroft et al., 2013). However, the most recent systematic review and meta-analysis of interventions to reduce compulsory psychiatric admissions found that advance statements were more effective than community treatment orders in reducing the risk of compulsory admission. As subsequently recommended by de Jong et al (2016), advance statements should be utilised in psychiatric treatment for patients who are most at risk of being compulsorily admitted.

Bee et al (2015) synthesised the evidence in relation to the involvement of service users in care planning in secondary mental health services. They concluded that health practitioners often take an outcomes-focused approach whereas service users take a relational approach to care-planning. They proposed that health practitioners focus on the quality of engagement and relationships to optimise outcomes. Measurements of success should also focus on indicators of engagement rather than numbers of care plans signed to assess genuine involvement.

Davidson et al (2015) reviewed supported decision-making in psychiatric and other medical contexts. Most psychiatric staff and patients did not believe that using advance directives was useful. Staff were often not aware of advance directives, advance directives were not integrated into care, or they believed that patients would make 'unrealistic' treatment requests in them. Patients also reported that staff were often unaware of advance directives or they did not act on requests. Patient resuscitation preferences were not considered in the majority of cases (91%) with older psychiatric patients. Davidson and colleagues concluded that staff training is effective but not sufficiently utilised. They recommended that clear information on advance directives be available and that decision-making components should be simplified. All patients should be offered support to make decisions and utilise decision-making tools, and that this support should be adapted to individual capacity and needs, acknowledging that some patients did not want to be involved in making treatment decisions at times.

Nicaise et al (2012) reviewed advance directives using a realist systematic review method (Greenhalgh et al, 2011). They found important discrepancies in expectations about the use and outcomes of advance directives. People experiencing severe mental health problems hoped that advance directives would create more equality in their relationships with health care practitioners and persuade them of their treatment preferences, along with reducing conflict. Health practitioners endorsed the concept of advance directives, but psychiatrists were the professional group least likely to describe them as beneficial. Psychiatrists were concerned with the burdens of administrating advance directives, conflicts with patients, and the redundancy of advance directives, with healthy, stable patients least in need utilising them, and unwell patients with few resources less likely to utilise advance directives (Nicaise et al., 2013). A key gap in the literature was the lack of implementation studies.

In summary, there are several key areas for development in both practice and research. Staff training is needed to improve communication and negotiation with people experiencing severe mental health problems so that practitioners improve their skills in ensuring supported decision-making. Studies that focus on simple outcomes such as completion of advance directives or number of days in hospital have not shown effectiveness, leading to calls for trials of complex interventions (Coulter, 2017).

Psychiatrists have a range of concerns about supported decision-making which must be addressed, as these concerns may undermine the uptake and adherence to requests in advance directives, particularly during mental health crises. These concerns include administrative barriers, conflicts with patients and workload. Those psychiatrists who prioritise the autonomy of patients are more likely to utilise advance directives (Sellars et al., 2017) and could 'champion' or assist to develop education and support mechanisms for other psychiatrists. People experiencing severe mental health problems can range in their desire for involvement in decision-making and support should be tailored to that preference. Overall, people experiencing severe mental health problems are more likely to want involvement in treatment decision-making, but may have had negative past experiences and be wary of the utility of future involvement (Nicaise et al., 2013). Future research on supported decision-making should focus on processes such as communication and negotiation skills, implementation studies and consult people experiencing severe mental health problems in the best measurement of outcomes.

Review of qualitative studies of decision-making

A review of qualitative studies of decision-making was conducted from July 2015 to August 2016 using a formula from evidence-based medicine

to define research questions, known as PICO. In this context, PICO stands for; **P**atient: People experiencing severe mental health problems and their carers, all types of mental health practitioners; **I**ntervention: Decision-making; **C**omparator: None required for qualitative studies; **O**utcome: Perceptions or experiences of decision-making.

A systematic review of the literature was conducted using the following electronic databases; Web of Science, Scopus, Cinahl, Ovid, PsycINFO, Social Science Research Network (SSRN), EBSCO Host, and Discovery. The search dates were confined to 2000 until 2016 in order to assess literature relevant to the current context.

The search terms used were: 'Psychiatr*'; 'Treatment'; 'Social work'; 'Psycholog*'; 'Occupational Therapy'; 'Supported Decision-Making'; 'Mental'; 'Persons With Mental Illness'; 'Care'. Reference lists of retrieved articles were hand searched for additional studies and grey literature was reviewed. Finally the following served as exclusion criteria in this review of previous qualitative studies: Articles or studies before 2000 and that focused exclusively on legal arguments; and studies that focused on supported decision-making in other populations such as intellectual disability, medical decisions, and palliative care.

Twenty-four individual studies were then reviewed using the Mixed Methods Assessment Tool (Pluye et al., 2009) to address the inclusion of both qualitative and mixed method studies and a hierarchy of evidence for assessing qualitative research (Daly et al., 2007: See Appendix). Four studies produced high quality evidence. A Danish ethnographic study of illness discourses in in- and out-patient settings found that patients need to develop a precise sense of the discourse required to have a say in their treatment (Ringer and Holen, 2016). Three discourses were identified – the instability discourse, the 'really ill' discourse and the lack of insight discourse. Patients who demonstrated too much volition risked having much-needed treatment withdrawn, whereas patients who presented as 'lacking insight' had their preferences discounted (Ringer and Holen, 2016). Two studies explored decision-making options for young people diagnosed with depression, their family members and other informal supporters and clinicians. Young people reported varying levels of desire for involvement in decision-making depending on the setting. Less involvement was desired by people in in-patient, detox units and forensic settings. Both young people and family members and other informal supporters wanted more information than they received. Clinicians believed that decisions ultimately belonged to the patient, however four circumstances justified paternalism – severity of symptoms, risk, client preference for involvement and the age/developmental stage of the client (Simmons et al., 2010; Simmons et al., 2011). A UK study of Joint

Crisis Planning (JCPs) found that clinicians prioritised compliance with organisational and professional requirements over service user autonomy. JCPs helped to reduce organisational influences and facilitated communication (Thornicroft et al., 2013).

This evidence suggests that there is an unmet need for involvement in treatment decision-making among people experiencing severe mental health problems. Advance statements and other related tools, such as safety plans, have also been recommended as mechanisms to prevent seclusion and restraint during admissions, alongside the further development of peer support roles (Huckshorn, 2004).

Current institutional practices may inhibit the efforts of health practitioners to ensure autonomy and legal capacity are respected, by focusing on risk and the accountability of practitioners for the actions of their clients/patients. There is a lack of high quality research that explores the implementation of supported decision-making schemes. There is a need to better understand current stakeholder perspectives of attitudes, knowledge and practices regarding supported decision-making so that practices can be brought into line with legal developments. This Australian Research Council Linkage Project study on supported decision-making adopted evidence-based methods to address the question of how people experiencing severe mental health problems and other stakeholders experience decision-making. These methods are detailed in the following section.

3. The Supported Decision-Making Project: Aims and Methodology

The supported decision-making project which was funded by the Australian Research Council examined the experiences, views and preferences of people experiencing severe mental health problems, their families and other informal supporters, and mental health practitioners in relation to enabling decision-making about care and treatment in mental health service delivery.

The specific aims of the project were to:

(1) For the first time in Australia, systematically document the experiences, views and preferences of people experiencing severe mental health problems (this included those with lived experience of being diagnosed with psychosis, schizophrenia, bipolar disorder and severe depression; see Language and Terminology note), family members and other informal supporters and mental health practitioners about supported decision-making, treatment and recovery;

(2) Conduct an international comparative analysis of supported decision-making laws, research and programs;

(3) Analyse and synthesise these datasets to inform the development of options for supported decision-making and the design of tools for the implementation of supported decision-making schemes; and

(4) Engage in collaboration and partnerships across the full spectrum of services for people experiencing severe mental health problems in all aspects of the research.

The research and production of online resources were informed by the qualitative research methodology developed by the University of Oxford Health Experiences Research Group (HERG, 2014) that Chief Investigator, Professor Renata Kokanovic, has been trained and licenced to use in the Australian context.
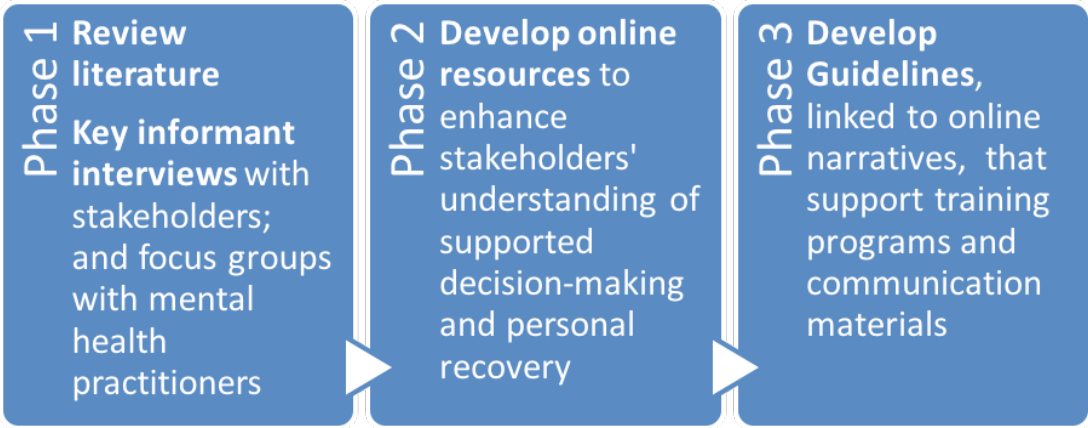
The project was conducted by an interdisciplinary group of researchers (with backgrounds in law, the sociology of health and illness, psychiatry, psychology, social work and population health) from three universities, and supported by research staff trained in qualitative research and in

the production of online health resources. The project was guided by an Advisory Group that met twice over the life of the project, the members of which were available for consultation during data collection, data analysis and production of online resources. Most importantly, members of the Advisory Group included representatives from people experiencing severe mental health problems and family members and other informal supporters, and their involvement was invaluable.

Research Phases

The research was conducted in three successive phases (see Figure 1 below). Phase one involved key informant interviews and focus groups to examine the treatment and recovery experiences of people experiencing severe mental health problems and other stakeholders. The policy, legal, mental health and welfare literature was reviewed (reported above) to establish what is currently known about supported decision-making. Analysis of these materials led to the development of two online resources to assist both people experiencing severe mental health problems, families and other informal supporters, and improve practitioners' understanding of supported decision-making, as well as informing mental health policy development (phase two). Phase three involved the development of tools linked to online narratives to aid implementation of supported decision-making schemes, including Guidelines and Factsheets, for use in training.

Figure 1. Research phases

Phase 1	Phase 2	Phase 3
Review literature	**Develop online resources** to enhance stakeholders' understanding of supported decision-making and personal recovery	**Develop Guidelines**, linked to online narratives, that support training programs and communication materials
Key informant interviews with stakeholders; and focus groups with mental health practitioners		

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Ethics

Monash University ethics approval was received prior to the commencement of research (reference CF13/2980 – 2013001607 – Supported decision-making for people experiencing severe mental health problems).

Participants

To be eligible for the study, participants needed to have lived experience of being diagnosed with psychosis, schizophrenia, bipolar disorder or severe depression at some stage of their life and to feel sufficiently well to participate in the interview. Family members and other informal supporters were eligible if they were supporting one or more persons experiencing severe mental health problems. Mental health practitioners currently or previously working with people experiencing severe mental health problems were qualified for inclusion in the study.

People experiencing severe mental health problems, families and other informal supporters were predominantly recruited through participating partner organisations. Strategies included: distributing flyers and information sessions about the research, via email networks, staff members passing flyers to potential participants, by displaying flyers in public spaces in the organisations (for example, on noticeboards and in waiting rooms), and by researchers attending relevant meetings and workshops discussing the research project. Potential participants were asked to contact researchers directly if/when they chose to participate in the research to gain more information and arrange a time and place for the interview. This approach was used to ensure that users of the service were able to make informed decisions about participation in the research without feeling obligated to take part. Psychiatrists and other mental health practitioners were recruited through distribution of information through researchers, staff and professional development events at participating organisations.

People experiencing severe mental health problems

Thirty people experiencing severe mental health problems were interviewed. One participant withdrew their participation before the production of the online resources began. Table 1 sets out the characteristics of participants experiencing severe mental health problems.

Table 1: Characteristics of participants experiencing severe mental health problems

Characteristics	Number of participants (n=29)
Gender	
Male	10 (34%)
Female	18 (62%)
Transgender	1 (3%)
Age range	
aged 18-39	13 (45%)
aged 40-65	16 (55%)
Ethnicity/cultural background	
Anglo-Australian	17 (59%)
Diverse ethno-cultural background	8 (28%)
Not stated	4 (14%)
Main diagnosis – self-reported	
Psychotic disorders all types (schizophrenia, schizoaffective disorder, Reactive psychosis, Paranoid psychosis)	16 (55%)
Bipolar disorders all types (bipolar I, bipolar II, bipolar rapid cycling, manic depression)	8 (27%)
Borderline personality disorder	2 (7%)
Anxiety and depression	3 (10%)
- Multiple lifetime diagnoses reported	16 (55%)
- One diagnosis reported	13 (45%)

Note: percentages may not add up to 100 due to rounding

The age of participants experiencing severe mental health problems ranged from 18 to 65 years. Most participants experiencing severe mental health problems were female (62%), aged between 40-49 years (37%), and of Anglo-Australian background (59%). More than half had received more than one diagnosis over their lifetime (55%). The majority (75%) had experienced involuntary treatment. Almost half of participants were employed (48%), predominantly in mental health, peer support or community sector roles. The largest group (45%) were single, with 38% in partner relationships (married, defacto) and a further 17% of participants were divorced. Participants were assigned pseudonyms for reporting purposes.

Family members and other informal supporters

Thirty family members and other informal supporters, ages ranging from 18 to 87 years, were interviewed. One member from this family and other informal supporter interview group later withdrew their participation. Family members and other informal supporters were supporting family members who had been diagnosed with psychosis, schizophrenia, schizoaffective disorder, bipolar disorder, borderline personality disorder and/or severe depression. Their characteristics are set out in Table 2.

Table 2. Characteristics of family member and other informal supporter participants

Family member and other informal supporter characteristics	Number of participants (n=29)
Gender	
Male	6 (21%)
Female	23 (79%)
Age range	
aged 18-59	13 (45%)
aged 60-87	16 (55%)
Ethnicity/cultural background	
Anglo-Australian	23 (79%)
Diverse ethno-cultural background	6 (21%)
Employment	
Full time	6 (20%)
Part time/Casual	8 (27%)
Full time carer	6 (20%)
Other (incl. Homemaker, study, retired)	9 (30%)
Location	
Inner-city	10 (34%)
Outer-city	12 (41%)
Regional	7 (24%)
Relationship of family member or informal supporter to person supported	
Parent caring for adult child/ren	20 (69%)
Partner	5 (17%)
Sister caring for adult sibling	4 (14%)
Living Arrangements	
Lived with person supported	18 (62%)
Lived separately from person supported	11 (38%)

Experience of CTO or Involuntary treatment (person cared for)	
CTO	11 (38%)
Involuntary treatment	16 (55%)

Just over half of family members and other informal supporters (38%) lived separately from a person they supported. Many (55%) had supported a family member who had experienced involuntary treatment, while 38% had supported a family member receiving treatment under a Community Treatment Order (CTO).

Mental health practitioners

Twenty mental health practitioners and twelve psychiatrists ranging in age from 22 to 65 years participated in the interviews. Their characteristics are set out in Table 3.

Table 3. Characteristics of mental health practitioner participants

Characteristics of mental health practitioners	Number of participants (n=32)
Gender	
Male	14 (44%)
Female	18 (56%)
Age range	
20-30 years	6 (19%)
31-40 years	8 (25%)
41-50 years	6 (19%)
51-60 years	10 (31%)
61-65 years	2 (6%)

Practitioner background/role	
Psychiatrists	12 (37.5%)
Peer workers	2 (6%)
Community mental health support service practitioner	6 (19%)
Nursing	5 (16%)
Social worker	4 (12.5%)
Occupational therapist	2 (6%)
Clinical psychologist	1 (3%)
Primary Work Setting	
Youth mental health services	2 (6%)
Mental Health Community Support Services (MHCSS) (or NGOs)	7 (22%)
Clinical services	19 (59%)
Private practice	2 (6%)
Commercial providers	2 (6%)

Psychiatrists made up the largest practitioner group. Most mental health practitioners were currently employed in specialist mental health services that are delivered through government-funded, area-based clinical services, including in-patient and community treatment settings. Others were employed in Mental Health Community Support Services (MHCSS) that provide residential and outreach support.

Procedures

Interviews

Narrative interviews were structured in two parts, with the focus in the first part on an uninterrupted account of lived experiences of severe mental health problems, or supporting someone thus diagnosed. Following the narrative account, more detailed accounts were sought about experiences of being diagnosed with severe mental health problems; how treatment decisions were made; how personal recovery was conceptualised; and how people would like to be best supported when making important decisions about their mental health and general wellbeing.

Following the narrative account of supporting a family member experiencing severe mental health problems, more detailed accounts were sought about the impact of supporting and caregiving; experiences of navigating the mental health system; and the role of family members and other informal supporters in supporting the person cared for to make his/her own decisions about treatment and life choices.

Mental health practitioners were asked to provide an account of their experience of working with both people experiencing severe mental health problems and family members and other informal supporters, focusing on views and processes related to supported decision-making; the perceived impact of supported decision-making on personal recovery; major opportunities and concerns around participating in supported decision-making that involves both people experiencing severe mental health problems and family members and other informal supporters; and the potential role for people in their profession to assist in developing supported decision-making processes and mechanisms. They were also asked how they would describe the benefits of supported decision-making to both people experiencing severe mental health problems and family members and other informal supporters.

Interviews took place at locations chosen by participants. For people experiencing severe mental health problems and family members and other informal supporters this was mostly in interview rooms at partner organisations (Mind Australia Limited, Neami National, Victorian Mental Illness Awareness Council (VMIAC), Wellways and Tandem Carers) or participating universities. Mental health practitioner interviews were predominantly conducted at the participant's workplace.

With the consent of participants experiencing severe mental health problems, 14 interviews were video-recorded and 16 interviews were audio-recorded. Interviews were conducted between June 2014 and June 2015, and most lasted between 60 – 90 minutes. Fourteen participants agreed to have their interviews presented on the online resources in video format, 11 in audio format, and four in written format.

With family members and other informal supporters' consent, 19 interviews were video-recorded and 11 were audio-recorded. Interviews were conducted between June 2014 and May 2015, and most lasted about 2 hours. Mental health practitioner interviews lasted approximately one hour and all were audio recorded.

Based on interview analysis, the project team prepared 26 thematic summaries for an online resource detailing experiences of people experiencing severe mental health problems and 24 thematic summaries for

an online resource detailing experiences of family members and other informal supporters. Thematic summaries were between 800-1000 words and were illustrated by video, audio and written quotes selected from participants' interviews. Summaries drafted by members of the project team were reviewed and approved by Chief and Partner Investigators and members of the Advisory Group. Content for online resources development (thematic summaries and biographies) was delivered for website production to Healthdirect Australia. Launched in June 2016, these resources can be found on the Healthtalk Australia website ([http://health-talkaustralia.org/](http://healthtalkaustralia.org/)),with both a 'Lived experience perspectives'([http://re-search.healthtalkaustralia.org/supported-decision-making/overview](http://research.healthtalkaustralia.org/supported-decision-making/overview)) and a 'Carers' perspectives'(http://research.healthtalkaustralia.org/carers/overview) overview pages.

Both of the overview landing pages offer detailed resources relevant to severe mental health problems, mental wellbeing, recovery and supported decision-making (the overview page on the carers' website is tailored for family members and other informal supporters). These resources include telephone helplines, websites of mental health organisations, recovery-related material and other relevant information (most of the resources listed are specific to Victoria).

Focus groups – Australian and New Zealand Association of Psychiatry, Psychology and Law (ANZAPPL) Annual Congress, 2015

Recruitment of practitioner participants to the focus groups took place at the Australian and New Zealand Association of Psychiatry, Psychology and Law Annual Congress which was held in Canberra from November 25th to the 28th, 2015. The Congress was attended by mental health practitioners, legal experts and other relevant stakeholders. Potential practitioner participants were informed at the start of the conference about the focus groups with each conference delegate receiving an invitation and explanatory statement in their conference pack.

Fifteen conference participants took part in three focus groups which lasted approximately one and a half hours. Table 4 sets out the characteristics of focus group participants.

Table 4. Focus group participant characteristics

Characteristics of focus group participants	Number of participants (n=15)
Gender	
Male	10 (67%)
Female	5 (33%)
Age range	
30-39 years	2 (13%)
40-49 years	2 (13%)
50-59 years	6 (40%)
60-69 years	4 (26%)
70-79 years	1 (7%)
Practitioner background/role	
Legal practitioners (academic, other)	4 (26%)
Psychiatry (private practice, public sector, policy)	7 (47%)
Social work (management)	1 (7%)
Psychologist (private practice, forensic, policy)	3 (20%)
Location	
New South Wales	5 (33%)
Victoria	4 (26%)
South Australia	1 (7%)
Australian Capital Territory	1 (7%)
Northern Territory	1 (7%)
New Zealand	3 (20%)

The focus groups were facilitated by the project's Chief Investigators and were audio-recorded. The major topics that were discussed included how practitioner participants viewed supported decision-making occurring in practice, and the challenges and advantages for implementing supported decision-making in mental health settings.

Data analysis

All interviews were professionally transcribed and interview transcripts were returned to the participants for review. Participants with lived experience and family members and other informed supporter participants were asked if they wished for anything to be amended or sections to be removed from the transcript and to confirm their written short biography. They were asked to return revised transcripts and biographies along with a signed copyright form authorising the publication of the biography and other interview data as a part of online resources. Coding frameworks for both the lived experience and family member and other informal supporter data were developed by the research team and confirmed at a meeting of the Advisory Group. Interview transcripts were imported into Nvivo 10 software for qualitative data management and were thematically analysed. The analysis used an experience-centred approach based on a socially and culturally-directed research framework (Squire et al., 2008). Common and divergent themes amongst participant groups were identified in the analysis. Analysis of mental health practitioner interview transcripts followed the same procedure described for the other groups, but because their accounts were not included on the online resources, biographies were not written for this group. The mental health practitioner interviews and transcripts of the focus groups were an important resource for the development of the Guidelines and Fact Sheets. The next section sets out the major findings from the project.

4. The Supported Decision-Making Project: Main Findings

The findings for each of the groups interviewed for the project are presented in separate sections below, beginning with the results for people experiencing severe mental health problems, followed by family members and other informal supporters, then mental health practitioners. An overarching finding of this study is the commonality of themes across all three groups. There is substantial agreement among all participants about the enablers of supported decision-making, and conversely, the barriers to care that facilitates involvement. All groups agreed that discrimination and stigma reduced autonomy for people experiencing severe mental health problems. Supported decision-making was seen as a mechanism and indicator of recovery-oriented practice.

Experiences of People Experiencing Severe Mental Health Problems of Enablers of and Barriers to Supported Decision-Making

This section sets out the findings that focus on the views and experiences of participants experiencing severe mental health problems of being supported, and occasions when they were not supported to access resources they needed to make decisions about treatments and day-to-day life. Further findings can be found at http://research.healthtalkaustralia. org/supported-decision-making.

Enablers of supported decision-making

People experiencing severe mental health problems described the important role that supportive mental health practitioners played in enabling their involvement in decision-making. Clinicians were seen as having good communication skills when they were attentive to their patients' needs and tailored interventions to the patient, rather than delivering what was perceived as 'standard advice'. This was seen as evidence that the clinician was engaged and trustworthy.

> I don't think [the medication] had really worked … My psychiatrist currently, she's happy to work with me actually on that, and say, "Okay, well if it's not working, why are you on it?" And I said, "Well because everyone says I should remain on it." And she's like, "Well if it's not doing anything, and in some cases it doesn't, then there's no

point, and we need to start weaning you off it and look at psychosocial issues that might be impacting instead." (Ella, 47)

General Practitioners who were interested in, specialised in, or had personal experience of relatives who had lived experience of mental illness were seen as effective supporters. Many participants said that they had been empowered to make their own decisions through their good relationships with General Practitioners. Qualities of General Practitioners that were appreciated by people and crucial for positive clinical experiences included flexibility, honesty, friendliness, empathy, communication skills and advocacy skills:

> Oh, probably 13 years [of contact with the same General Practitioner]. He's been a fantastic advocate … He's been really with me every step of the way … He's been a really, really empowering part of the process in what otherwise could have been totally disempowering. I could have had someone who was very high-handed and just wanted me in and out. And, you know, just another patient, part of the numbers. I think I'm a real person with my doctor. (Joseph, 37)

Supported decision-making mechanisms: advance statements and nominated persons

Some people were aware of formal supported decision-making mechanisms available to them, including advance statements and nominated persons. All participants easised the value of having their own views and preferences represented should they experience compulsory treatment. They particularly valued incorporating aspects of their daily lives that were important to them, such as care for pets, while hospitalised.

> I just heard someone mention [the advance statement] and then I followed up on it on my own … it's not just about my medical treatment that I've got in there. I've got things in there about the fact that if I need to go to hospital then I need to be reassured that someone's looking after my dogs, like that has to be in there because that's critical for me … so I've written quite a lengthy advance statement but it's quite broad and it covers a lot of things …. I'm not consenting to ECT … and not consenting to a few different medications (Allison, 36)

Barriers to supported decision-making

A major barrier to participating in decision-making was the effect of 'stigma'. Negative attitudes from self, family and community towards mental health problems often led to feelings of shame and avoiding others. Negative attitudes limited sources of support which is an important aid when tackling complex decisions. Struggling to think through the problems and unable to talk about potential options with friends or family, some participants described feeling unable to get support from their internal and external social networks.

> When things go badly … I don't really feel that I'm able to talk to people about it. I think that it's a real sense of shame that these are the things that I should be able to manage myself, and guilt … that I'm letting people down. Or letting myself down … I've got these expectations about what I wanted to achieve and what I want to do, and if I can't deal with life … I'm not going to be able to reach these goals. Or I'm not successful. That I'm this person who maybe can't even handle life. So there's no worth to me. (Daniel, 39)

Clinicians played an important role as they were among the few people with whom participants could talk about severe mental health problems. Yet many participants recounted examples of feeling unsupported by clinicians. This was communicated through the structures of appointment making, like long waiting times to see psychiatrists and psychologists; long gaps between appointments; and lack of continuity of care preventing them from establishing trustworthy relationship with clinicians. While such barriers were seen as largely due to the underfunding and understaffing of the mental health system, many believed that within the current constraints clinicians should still be able to engage sensitively with patients. Participants were critical of those clinicians who they felt, neglected to create a positive therapeutic relationship that enabled them to express their treatment preferences. Most participants named experiences with clinicians in which they did not feel an equal participant in their own care, listened to, or offered clear treatment options.

> Because with a mental illness, we go through so much discrimination and inequality. And doctors have put themselves up on such a high pedestal, and they impose their structures on us, from the outside. And they don't know or care what we are going through … Most of them don't listen to us … We would probably see a psychiatrist for about 15 minutes once every three months … You have to have emotion. You have to care about someone and if you don't care about them enough to dispute something with them, then you're not doing your job. (Simon, 54)

Hospitals were experienced as the most difficult environments within which to participate in treatment discussions. Participants who had experienced closed wards and seclusion described it as akin to 'being imprisoned'. In response, they explained that occasionally adopting a submissive approach was a strategy that they hoped would lead to staff allowing them to be released from hospital. Hospital staff who did not take the time to explain procedures added to feelings of powerlessness.

> From the admission process for example, why do I have to sign all these forms? And I told them, I was petrified. I didn't even know why I was there and what was happening and yet I had to sign all these forms to say I was going to be there for 60 days. I mean that … put that fear into me that, "Shit I'm going to be here like for ages." (Lucca, 40)

Some participants said that spending time in hospital with other people who had had similar experiences to them was an opportunity to make friendships that enhanced their ability to make decisions. Others experienced the company of other - particularly acutely unwell - patients as making it harder to think clearly.

> For me, my first admission into hospital was trauma enough, because patients were on different levels of recovery and some [were] really sick compared to how I was … When my parents would come and visit, I would just say, "I want to come home, … I don't want to be here." (Sophie, 46)

Family Members and Other Informal Supporters' Experiences of Barriers to and Enablers of Support for Carers' Role in Supported Decision-Making

This section summarises the views and experiences of family members and other informal supporters in decision-making for their loved ones. Further findings can be found at http://research.healthtalkaustralia.org/supported-decision-making.

In Australia, the *Carer Recognition Act 2010* (Cth) gave formal recognition to the role of carers. The Act aims to increase awareness of family members and other informal supporters, to acknowledge the important part that such persons in general play in the day-to-day lives of those whom they support and the valuable contribution they make to society. However, family members and other informal supporters need support if they are to fulfil their role in supported decision-making as defined by the CRPD and the Victorian *Mental Health Act 2014*. Most of the family

members and other informal supporters interviewed for this study felt that clinicians were unwilling to collaborate with them, share information, recognise their expertise, or provide referrals for support to them, and this undermined their role in supported decision-making. Nearly all family members and other informal supporters described stigma as a factor that led to them becoming socially isolated from the wider community and this undermined their own well-being and health.

Enablers of support for family members and other informal supporters' role in supported decision-making

Family members and other informal supporters also described factors that helped fulfil their role in supported decision-making. The majority described advance statements and nominated persons as important enablers of their role. Many proposed that General Practitioners could provide more systematic support than they currently do. They recommended that education programs be developed to improve understanding of family members and other informal supporters' role in supported decision-making.

Supported decision-making mechanisms: advance statements and nominated persons

Many participants said that in order for formal supported decision-making mechanisms to be supportive of family members and other informal supporters, the person that was supported would need: a) to be comfortable with involving the family member or other informal supporter in treatment discussions; and b) understand the process of preparing an advance statement or appointing a nominated person to be one that enabled him/her to exercise control. Advance statements could give them confidence that if the person who is supported became unwell then family members and other informal supporters could act on the wishes and preferences specified in the advance statement.

> I think the advance statement's terrific because it gets the person when they're well, thinking about what they want. And so for [family members and other informal supporters] who have some reluctance … it gives them the confidence to do what they've discussed with that person (Anita, 63)

The role of the nominated person was seen as a way to overcome the frustrations associated with current treatment systems and validate and

formalise recognition of the importance of family members and other informal supporters in mental health settings.[1]

> I feel that carers won't be hanging around to care if they're unable to liaise in a productive manner with the medical staff, because they'll be throwing their hands up in the air going, "Okay, well you want to deal with it … you have it all then. I'm trying to help you in your job and have this person at home and not in the hospital system. If you want it, take it." I feel it's very important for the carer or the nominated person to have access and liaise with medical staff. (Rachel, 40)

Role of General Practitioners

Many family members and other informal supporters described General Practitioners as major sources of support for carers to fulfil their role in supported decision-making. They recommended that General Practitioners ought to provide a pathway through all aspects of mental health support:

> I would like to think that the GPs were able to direct you to one particular spot … say, "This is where you go and this is where you will start your journey with what treatment, what medications, what doctors you need to see" … When my son was diagnosed, we [went] just here, there and everywhere. Because I didn't know anything about mental illness, that's why I trusted the professionals. (Leah, 68)

Education about family members and other informal supporters' role in supported decision-making

Most family members and other informal supporters felt that there was a need for greater clarity about disclosure of health information by health practitioners to them.[2] A few participants also recommended training

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1   While the nominated person and the carer are distinct roles, they can also overlap if a person with lived experience of being diagnosed with severe mental health problems decides to appoint his/her carer as his/her nominated person.

2   Section 346(g) of the *Mental Health Act 2014* (Vic) enables disclosure of information "in general terms to a friend, family member or carer", provided this is not contrary to the views and preferences of the person concerned. Section 346(h)(i) enables disclosure of information to carers where this is reasonably required "to determine the nature and scope of the care to be provided." Wider dissemination of these relevant sections of the Act regarding disclosure of health information would

programs that would support family members and other informal supporters to help foster the independence of the person cared for:

> Are [the person cared for] doing any of those things like self-support for themselves like cleaning, cooking, budgeting … If they haven't been … for a long time, how do you change that? … So … teaching people to become independent [rather than] co-dependent at home. (Natalia, 65)

Participants recognised the array of skills and knowledge needed to effectively support decision-making. They suggested education programs as a way to assist family members and other informal supporters and link them to resources available that would enable them to provide better support for decision-making.

> I think it is … absolutely mandatory for carers or whoever the primary support person is to be involved in the decision-making, if the consumer consents to that … they have that familiarity with the person and hopefully with the person's condition. I think it just needs to be a bit more collaborative. If clinicians don't feel that the consumer or the carer have the right end of the stick, then … there should be a place to educate them and give them the resources they need to help inform their decision-making. I think that's a big thing that's lacking currently. So where they might discard someone's preference, because they don't see it as … being conducive with the therapeutic aims, then … rather than doing what clinicians feel like anyway, there should be a place for providing educative materials. (Nicole, 29)

Hospital environment and staff attitudes towards family members and other informal supporters

While they understood the challenging nature of working in hospitals and mental health units, many family members and other informal supporters felt unwelcome at times. They described encounters with mental health staff who appeared guarded and wary of dealing with them. Such environments and attitudes were experienced as disrespectful of their support role. They felt that the treatment system needs family members

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contribute to increased recognition of family members and other informal supporters' role of facilitating supported decision-making.

and other informal supporters to provide care, yet seems unwilling to treat them as part of the team of people involved in this task.

> They took [wife] to the local psych hospital … and that was a … pretty demeaning experience … because. I felt that they were looking at me like I was the local drug supplier that was coming in for a junkie … You're searched when you go in and I'm talking about a pretty full on search too, checking through all your bags … because you're automatically suspected of taking in medications and drugs and all manner of things and here I am, just coming to a hospital to visit my wife and I'm being treated like a … pat-down at a prison. (Ben, 55)

Clinician attitudes towards family members and other informal supporters

Compassion, empathy and a willingness to listen were qualities that family members and other informal supporters valued highly in mental health practitioners. They understood that mental health practitioners were busy and overworked, but by not giving them the support they needed, practitioners were undermining family members and other informal supporters' role. Supporting decision-making was made difficult by practitioners who were reluctant to share treatment information with or who overlooked family members and other informal supporters, and did not value their experiential knowledge.

> I just think [family members] know more about the illness than what a doctor does … They know what they're taught, and all that sort of thing, but there's varying degrees of the illness that they don't see … Because they [family members] see it daily and a doctor only sees the patient once a month, once every few months. (Wendy, 67)

Discrimination

Nearly all the family members and other informal supporters described how ongoing discrimination against mental health problems had led them also to becoming socially isolated. This left many family members and other informal supporters uncertain about the support role.

> As I get older, I really worry … because his [older siblings] take not much notice. I think there is an enormous fear of mental illness generally in the community, and … that I have been receiving from them. They've just got on with their own lives … and they were certainly concerned when he was in hospital, but it's not an ongoing supportive concern, either for him or for me. (Larissa, 73)

Mental Health Practitioner and Psychiatrist Perspectives

"Everyone can [make decisions] to some extent, you've just got to find and support the maximum extent."

This section summarises the themes raised in interviews with psychiatrists and other mental health practitioners. While there was agreement amongst the majority of practitioners about the value of supported decision-making, many also expressed reservations and were acutely aware of a range of barriers. These included attitudes and lack of skills, as well as problems in the systems they work in.

Experience in the practice of psychiatry or mental health care

Mental health practitioners were purposefully recruited from diverse workplaces and from a range of professional backgrounds. They ranged in their experiences of working with other mental health providers, people diagnosed with mental illness and family and other informal supporters.

Psychiatrists were the largest single professional group interviewed and the themes that particularly featured in the interviews with psychiatrists related to specific aspects of their role. For example, three psychiatrists raised the issue of diagnosis and the opportunities and problems that are associated with providing a diagnosis. While a diagnosis could offer clarity for some people, it could also raise problems, such as labelling, increasing the power imbalance and contributing to a narrow focus for treatment options. However, other issues raised specifically by psychiatrists related to more generic aspects of their role such as valuing continuity of care in facilitating supported decision-making. Psychiatrists were more likely to comment on the importance of management and leadership in facilitating supported decision-making than other practitioner participants. More than half of the psychiatrists identified service design and teamwork as factors that can enhance supported decision-making in practice.

Most of the practitioner participants identified several challenges preventing exemplary mental health care delivery that they were aspiring to provide. Half mentioned experiences of disempowerment and paternalism featured in service delivery. These included observing people losing control over their everyday lives, particularly in in-patient units. Many practitioner participants described people experiencing severe mental health problems frequently having decisions being made for them, especially when there is a perception that this needs to be done quickly or

that the person is not seen to be capable of making good decisions for themselves. For example:

> I find that if somebody has a diagnosis of a low prevalence disorder like schizophrenia or bipolar disorder or the more severe end of mental health issues that it seems to me that those folks are a lot more prone to becoming unwell more severely and perhaps more quickly. And the notion or the ability of someone to manage, control and make decisions at those times really gets diminished and therefore they're quite prone to other people coming in over the top … so the person becomes very quickly a passenger in the whole process. (Mental Health Community Support Service worker)

Less experienced or qualified staff, especially those in Community Mental Health Support Service or NGO roles, also sometimes felt disempowered in connection with how they were treated by senior or clinical staff. Examples included being told not to help their clients answer questions in interviews, being spoken to 'rudely' and experiencing negative attitudes.

Many practitioner participants, including both psychiatrists and other mental health practitioners, described medication as often being the most important treatment and also the one that led to the most issues regarding decision-making.

> We certainly have a lot of people who are refusing treatment … and not wanting medication. Because I don't really have a mental illness, I'm just psychic or et cetera et cetera … you know and a - that - that is difficult, it's uncomfortable. You know it's - it's often conflictual … but unfortunately still quite necessary in those circumstances. (Nurse)

However the findings suggest that some practitioner participants, including psychiatrists, have doubts about the effectiveness of medication in the context of significant unpleasant side effects. As one suggested:

> Because it's like using - I mean it's like kind of - just spraying an entire jungle with fire in an attempt … to kind of hit the tiger in the middle of it. (Psychiatrist)

Some practitioner participants also expressed concern about the powers to enforce medication compliance.

> I don't think that, yeah, they [patients] really get many choice at all in what, what happens in there [hospital]. But like I said, they mostly,

the only sort of treatment that they really get is they get put on a very high dosage of medication. (Mental Health Community Support Service worker)

All the practitioner participants had some level of understanding of the new *Mental Health Act 2014* in Victoria and its link with supported decision-making and recovery-oriented practice.

Over half of the practitioner participants referred to signs of change that indicated improvement in service delivery. This included less evidence of hierarchy in services and more respectful sharing of responsibilities across and within multidisciplinary teams on in-patient units and in community based care. Specific examples of change associated with recovery and supported decision-making included an in-patient unit having a supported decision-making group, services having posters and signs encouraging people diagnosed with severe mental health problems to complete advance statements and interest in encouraging people to get a second opinion or select a nominated person.

Decision-making

Experience with substitute decision-making

All practitioner participants had a range of experiences with people diagnosed with severe mental health problems who had experienced substitute decision-making. This included involuntary admission to hospital, Community Treatment Orders, administration and guardianship orders issued by the Victorian Civil and Administrative Tribunal, decision-making regarding Electroconvulsive Therapy and issues around family members or other informal supporters becoming either formally or informally substitute decision-makers, particularly in the context of aged, and to a lesser extent, youth services.

There were some positive experiences with substitute decision-making described. Usually because substitute decision-making had enabled a positive change to the person's situation. For example:

He's on State Trustees and he wants to be on, he wants to be on it. He loves being … - having his money managed by someone else and he's got quite - like a large amount of money saved up and that's why he loves it because it's - he said to me, "Because I spend my money on rubbish." (Mental Health Community Support Service worker)

However substitute decision-making was more commonly described as distressing for people experiencing severe mental health problems.

> … in terms of getting taken to hospital or … you know, being detained under the Act, all those sorts of things that, … those times are often the most traumatising for people. (Occupational Therapist)

Substitute decision-making was also seen as sometimes inevitable because of concerns about risk of harm:

> Challenges normally sort of centre around risks and what's the risk of - you know, if somebody's decision is to have … no medication at all - they don't want to be treated with any psychotic medication, does the treatment team have [an] obligation to weigh up the risks to that person's safety - to the public safety - to everybody's safety? … And sometimes that's not a risk that the treatment team are willing to take. (Nurse)

Experience with supported decision-making

Before discussing the findings regarding supported decision-making it is important to consider that it was not always clear in the interviews that practitioner participants had a shared understanding of what supported decision-making is and, in particular, how it can be distinguished from shared decision-making. One practitioner participant articulated this from his own experiences as follows:

> But I don't think, I mean I think, the terminology that we use is probably just, I don't think nurses on the floor specifically get the difference between those three types of decision-making [Substitute, Shared, Supported]. And they're, they're doing shared decision-making when they think it's supported. Because they don't feel safe with allowing someone to make a decision that could … cause them, not, not death and not physical harm … but you know, could cause them … say financial harm or relationship … harm or something like that. (Nurse)

Most practitioner participants appeared to sometimes not see a difference between shared decision-making and supported decision-making. They valued shared decision-making because it aligns with commonly appreciated strategies for 'good practice' in person-centred approaches to mental health care (eg. information sharing, collaboration, continuity of care, listening and problem solving, taking a strengths based approach and so on) and also related shared decision-making to taking

a recovery-oriented approach. Hence much of what follows blends the comments about 'shared' and 'supported' decision-making.

Opportunities and benefits in supported decision-making

Practitioner participants identified many opportunities and benefits in supported decision-making including the opportunity to empower people, to show them greater respect and to expand their potential to have, and make, choices.

Even those who appeared to also have their doubts about whether supported decision-making could be consistently applied in practice offered support for the human rights principles behind supported decision-making.

> I think it's really helpful that people get a chance to express what they want. And even if, you know, it doesn't necessarily occur because of … situations that I've spoken about earlier … it's still good for someone to have the opportunity and to be empowered and feel that they're able to, to do things. (Nurse)

Summary of challenges, barriers and concerns in supported decision-making

The following emerged as the main themes from interviews with mental health practitioners in relation to challenges, barriers and concerns in supported decision-making.

Table 5. Challenges, barriers and concerns in supported decision-making

Theme	Sub themes	Illustrative quotes
Characteristics of people experiencing severe mental health problems	- The impact of mental illness - Vulnerability - Trauma and alienation - Lack of motivation - Concerns about capacity - People experiencing complex needs (including those who 'lack insight') - Elderly people experiencing cognitive decline - Young people who remain dependent on their parents or guardians - People being acutely unwell and a range of severity of symptoms	People experiencing the most severe illness, the most treatment resistant ongoing symptoms, difficulties in their day-to-day function, perhaps some cognitive difficulties as well, maybe substance abuse getting in the way of their understanding. All those things could come into play - um - and you might think, on the face of it, oh well, how can they participate in making complex, sophisticated decisions? But the point is: everyone can to some extent, you've just got to find and support the maximum extent that everyone can and that definitely takes skill, time, inclination, and a belief that it's possible. (Psychiatrist)
Problems in practice	- People not feeling (or being) heard - Lack of awareness about rights and supported decision-making - Lack of collaboration - Loss of a person-centred perspective - Lack of respect - Power differentials	So sometimes that can happen that, you know, you can see that people get put under pressure to kind of - ah - go along with things. (Psychiatrist)

| Features of the mental health system | - Lack of real choice
- Dominance of the medical model
- Lack of resources and time
- Lack of continuity
- Rural issues (lack of resources)
- Immediate needs come first (and supported decision-making 'sidelined')
- In-patient units have a narrowing of the lens, become crisis driven | We're not educating people yet … So you've got, you know, somebody who's - um -, who's got a severe mental illness; they're at home all day, you know, they've - no social supports. Services turn up at six o'clock on the dot to, to give them their medication. How do people know about that? [option of having medication later] Because really we'd - our service would have to be the one informing them about it and if we don't see it's an issue how are they going to know about it? (Mental Health Practitioner, Nurse) |

Overarching themes identified in the analysis

The following themes emerged as being features of much of the discussion with practitioner participants about supported decision-making.

Risk and fear

Most practitioner participants were aware of how challenging it was at times for them to tolerate risk and respect the decision-making of people experiencing severe mental health problems.

> Yes. Yes it was so hard. I worried so much. I worried so much. (Mental Health Community Support Service worker)

A sub theme of risk and fear was that of meeting expectations regarding duty of care and ongoing perceptions that, despite all the messages about support for autonomy and the "dignity of risk", staff worried that they will be blamed if a serious incident occurs that could be linked back to them.

> So it gets confusing … I mean none of it, when we let somebody go out and they, if the mistake is, is not life threatening and not, you know, homicidal or suicidal … we can get away with it sometimes, but the minute that there's a death … what were they thinking? What were these people doing? (Nurse)

Stigma and discrimination

This was a feature of many of the practitioner interviews and related to what these participants identified as structural and social barriers to people experiencing severe mental health problems having their autonomy respected. However, it was also identified as a problem located within services and how mental 'illness' is constructed.

> So we say it's about risk but I still think it's about prejudice and discrimination. That we think that people experiencing low prevalence disorders for some reason can't cope with information. (Nurse)

Mechanisms or ways of facilitating supported decision-making

The following emerged as intersecting mechanisms or domains for supporting supported decision-making in everyday practice and service delivery.

Figure 2. Domains of supported decision-making in mental health service delivery

Table 6. Mechanisms or domains for facilitating supported decision-making

Domain	Features	Illustrative quotes
Legal or rights-based mechanisms	- Advanced directives or statements - Nominated persons - Rights information and awareness - Advocacy - Second opinions	In [interviewee's role] I've become incredibly passionate about advance statements and trying to, to push those within ... our service and its, its slow ... slowly, slowly starting to see change, which we expected. But you know, every so often you know, I'm starting to hear really good stories (Nurse)
Interpersonal skills	- Connecting with the person and their values - Education and understanding - Listening and problem solving - Building trust - Peer support - Practical support - Sensitivity to cultural and linguistic issues - Early intervention - Positive environments - Intensive support - Working with the person's construction of the mental health issue - Continuity of care - Family work	Peer support groups are the most well attended groups on the in-patient unit ... I think that people can relate to the person's experiences more and they can share their own experiences. And the peer support worker that we have sort of offers information about, you know, things that he had to think about when he was writing his advance statement and things that he had to think about ... when he was ... you know, choosing a nominated person. (Occupational Therapist)

Empowering people experiencing severe mental health problems (consumers)	- Responsibility, choice and self-efficacy (including the 'Dignity of Risk') - Empowerment and hope - Internet based (credible) information and tools - Providing opportunities for comparison of people's experiences and normalising people's experiences - Self advocacy	It's around people … being supported to be human and take chances, make choices, learn from them and be part of the community in that way. (Service Manager, MHCSS)
Management and leadership	- Staff supervision and support - Training and staff development - Knowing yourself as a worker - Needing to recognise and support change (pockets of excellence) - Resourcing and education	As a consultant it's about leading it, demonstrating it, modelling it, starting the work and laying out a plan for your team members. (Psychiatrist)

Supporting families and other informal supporters

Questions related to families and other informal supporters were discussed in almost all the practitioner interviews. This included the value of assisting people to reconnect with their families and supporting them to do so with a view to this being a strategy to enable the person's recovery and self-efficacy. Also the potential for families and other informal supporters to be engaged as 'experts' in relation to the person experiencing severe mental health problems and the people who are there for the 'long haul'. Practitioner participants were also aware that family support may be an important enabler in relation to supported decision-making.

In some interviews, there were strong links between the overarching theme of fear and risk and supporting families and other informal supporters. Some mental health practitioners referred to situations in which family members did not appear to be in favour of supported decision-making, usually because of their fears that the person they support may not make choices that the family members considered to be in their best interests or in the family members' best interests. In addition, some family members and other informal supporters had experienced distressing situations, including violence and abuse from the person they cared

for, that may contribute to them wanting to be very cautious about taking the least restrictive approach.

> I think for carers as well as it is for everybody else, the long - the journey to recovery is long. So I think carers can get stuck in like risk and worry … and all of those same things that services get stuck in. (Nurse)

In some instances, mental health practitioners were then left with family members who were unhappy with their focus on supported decision-making and felt unsupported themselves. For example:

> But they just weren't getting it so, you know, they said, we've had years of our mother being … non-compliant and you know, having difficulties at home and - and they just didn't get that we said yes, but the neuropsychologist said that she was competent and she can decide to take risks. You know, the, she can decide to take risks bit, is the hardest thing that families - you know, it's the thing that … families often struggle to understand. (Social Worker)

The situation in aged care environments appeared to be particularly difficult in this regard and was sometimes compounded by other family interests, particularly control over finances and assets.

One practitioner participant discussed how the disempowering experiences someone may have had when acutely unwell, may then influence how family members and other informal supporters behave in relation to the person into the future.

> So I think it can happen with families and carers and professionals but I think in my experience the families and carers' area is one where it's, it's likely to bleed across into not only the unwell times but when someone's just trying to get on and live life, make their choices, make decisions, learn from making mistakes and that can be quickly taken away from them even when they're well. But it can happen obviously – it happens probably more often when the person's unwell in the professional realm. (Service Manager, Mental Health Community Support Service)

Who people consider to be family members or other informal supporters, and the complexity of choices people might make about who they want to have information shared with, and have as their nominated person, were issues discussed in many interviews. One practitioner participant described how in youth services this was also interconnected with the

young person's experiences of trauma and also the need to have a developmentally appropriate approach.

> I guess a lot of them have very disjointed families and they have family members that they connect really well with and other family members who are probably part of their trauma experience they have when they're growing up so they really wouldn't want that person to have anything to do with their health and their care … in that environment … a lot of them have, I guess, they classify friends as family and not biological parents or aunts or uncles as family … So it's a different sort of family which I guess an advance statement would be best to be able to convey that in a legal sense. (Occupational Therapist)

Many practitioner participants discussed the importance of families and other informal supporters getting support themselves in order to be able to make a positive contribution to supported decision-making. Some specific examples of support included providing information sessions for family members and other informal supporters, facilitating them taking up the role of nominated persons and also a service employing family members and other informal supporters as consultants.

Personal recovery

Several practitioner participants discussed supported decision-making as a mechanism for recovery-oriented practice. The mental health practitioners were fairly consistent in their views of personal recovery as a journey related to someone moving on from their experience of illness and living a purposeful life in the community. Themes in interviews linked to personal recovery and recovery-oriented service delivery included hope, empowerment, responsibility, choice and self-efficacy, connecting with the person and their values, listening and problem solving, education and understanding, normalising people's experiences and social dimensions. However, there was also some confusion about what recovery means for service providers and people experiencing severe mental health problems. It appears that in the context of people experiencing complex needs and particularly in the aged psychiatry domain that there were ongoing challenges in thinking through how the recovery paradigm is relevant.

> Because it's such a stupid word for what it's meant to mean … I think recovery is a good word. Not for people who have … Not for people who have chronic schizophrenia who's going to be, you know, responding and talking to themselves and doing all that stuff for the

rest of their life and have no decision-making at all because other people are making decisions for them. (Social Worker)

However, some mental health practitioners identified strong links between supported decision-making and their views of personal recovery. For example:

Well I think it's [supported decision-making] integral to recovery. I mean I think … it comes back to the notion of a person as a human being, being able to consider, think, plan and act for themselves. And to me that's what our work is about. (Service Manager, Mental Health Community Support Service)

This was also linked with supporting people experiencing severe mental health problems establish or reclaim their identity. Some practitioner participants were aware that many people experiencing severe mental health problems struggle with mental illness becoming central to how the person thinks about themselves. Practitioner participants spoke about their challenge to de-stigmatise and separating out the mental illness from the person being engaged in day-to-day decision-making and being supported to do so. However, mental health practitioners were also aware of barriers to recovery-oriented practice including similar issues to those holding back supported decision-making.

You know … we still hear of treatment plans where the consumer doesn't even know they've been drafted, let alone signed them or they've signed them but hasn't had any impact in - input into them … unless we get this basic recovery-focused things actually working on the ground, then I think the idea of supported decision-making conversations and documents are, are difficult. (Service Manager, Mental Health Community Support Service)

5. Conclusion

People experiencing severe mental health problems have the right to be involved in decisions relating to their treatment and care. This supported decision-making project sought to understand the decision-making experiences of people experiencing severe mental health problems, families and other informal supporters and mental health practitioners. It found common themes across all three participant groups. Participants largely agreed about the enablers of supported decision-making. Interactions that built trust were perceived as increasing the confidence of people experiencing severe mental health problems make decisions about their treatment and care, and everyday life.

Supported decision-making was seen as a mechanism and indicator of personal recovery-oriented practice. This suggests that interpersonal experiences of care and treatment affect the confidence of those experiencing severe mental health problems to make decisions. This confidence was needed to start conversations about mental health treatment or support, and to build on and, where necessary, to challenge mental health practice and practitioners.

Impersonal care or structures that prevented continuity of care with health practitioners eroded involvement in decision-making. Some participants experienced mental health treatment systems that seemed focused on numbers, compliance and outcomes and participants managed this by avoiding conflict. Mental health practitioners, including psychiatrists, described the challenges of working within paternalistic treatment systems that were perceived as disempowering by staff and people experiencing severe mental health problems.

Stigma and discrimination appeared to play an important role in undermining confidence about decision-making. People experiencing severe mental health problems referred to being presumed to lack cognitive capacity to be involved in treatment decisions. Stigma and discrimination also undermined the ability to utilise social supports. Being able to talk through the pros and cons of various options was perceived as helping people to clarify their thoughts and preferences and enabled them to gather new information for decision-making.

Mental health practitioners were not always clear about the differences between supported decision-making and other types of decision-making. This indicates that further education and support is needed for practitioners to clarify the key distinctions between shared and supported decision-making.

The engagement of families and other informal supporters was acknowledged as valuable, but needed to be more than being invited to meetings and discussions. Family members and other informal supporters wanted to be informed and involved in the treatment and care of those experiencing severe mental health problems, and have their experiences acknowledged. Day-to-day contact with those they were supporting allowed them to build an in-depth understanding of the situation facing the family member experiencing severe mental health problems that could support and inform treatment decisions made in consultations with mental health practitioners.

Legal mechanisms for supported decision-making, especially advance statements and nominated persons offered participants hope for increasing supported decision-making opportunities. This underlines the importance of implementation and uptake of these mechanisms. System change needs to include more resources and improved leadership to facilitate supported decision-making. Finally, the key to supported decision-making for many participants was continuity of care with General Practitioners, peer support workers and others who are seen to have high levels of trust.

Recovery and human rights frameworks generate the momentum to implement supported decision-making in mental health care and treatment. People experiencing severe mental health problems have the right to make their own decisions, with support from both informal and formal supporters. Supported decision-making enables this right.

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Appendix One: Review of Health and Welfare Studies

Results of review of decision-making in mental health research reviews

Study Name	Domain	Type of Review	Limitations	Recommendations
Campbell and Kisely. (2009) Advance treatment directives for people experiencing severe mental illness. *Cochrane Database of Systematic Reviews*.	Effects of Advance Treatment Directives on people experiencing severe mental illness.	Cochrane	Only RCTs reviewed	Little evidence for Advance Directives on improvements in admissions, bed days, compliance with treatment, self-harm, violence, service use.
Pathare and Shields. (2012) Supported decision-making for persons with mental illness: a review. *Public Health Reviews* 34.	Legislation and evidence – focus on low and middle income countries (LMICs)	'Comprehensive'	Few LMICs have legislation or research	People experiencing mental illness have higher desire for treatment decision-making than general medicine.
Nicaise, Lorant, and Dubois. (2012) Psychiatric Advance directives as a complex and multistage intervention: a realist systematic review. *Health and Social Care in the Community* 21: 1-14.	Psychiatric Advance Directives	Realist systematic review of SDM as complex intervention	No legislation reviewed	More research needed on theoretical expectations and preferences for implementation.

Davidson, Kelly, Macdonald, et al. (2015) Supported decision-making: A review of the international literature. *International Journal of Law and Psychiatry* 38: 61-67.	International review of SDM	Rapid Evidence Assessment	Only 20% of studies reviewed had a psychiatric focus.	Need for staff training – when training and information was provided, decision-making improved.
Bee, Price, Baker, et al. (2015) Systematic synthesis of barriers and facilitators to service user-led care planning. *British Journal of Psychiatry* 207: 104-114.	User-involved care planning	Systematic evidence synthesis	No meta-analysis of quantitative data. No information on carer or provider views.	User motivation and involvement depends on alignment between clinical practice and own recovery needs. Implementation studies needed.

Review of decision-making qualitative studies

Study name	Method	Setting	Findings	Level of evidence[*]
Perceptions of crisis care in populations who self-referred to a telephone-based mental health triage service (Sands, Elsom, Keppich-Arnold, Henderson and Thomas, 2016)	Qualitative study of 75 people who used a telephone mental health triage service. Conceptual content analysis	Telephone triage - Australia	33% were offered choices, 53% reported involvement in decision-making. Listening, caring and providing psychological support to manage distress were important. Some people experiencing severe mental health problems felt disempowered by being excluded from decisions about their care, while others were given choices and felt supported. Some people felt that triage clinicians did not recognise or acknowledge the level of crisis.	Level 3, Descriptive evidence – illustrates practical rather than theoretical issues (no discussion of recovery, limited discussion of WHO responsiveness. MMAT score 50% - no context (1.3) or reflexivity (1.4)
Australian mental health staff response to antipsychotic medication side effects – the perceptions of consumers (Morrison, Meehan and Stomski, 2016)	Brief description of shared decision-making to improve outcomes. Interviews with 10 people experiencing severe mental health problems in community care. Content analysis.	Community care - Australia	Most participants distressed by exclusion from decisions about their care.	Level 3, Descriptive study. MMAT score 75%

Understanding how clinician-patient relationships and relational continuity of care affect recovery from serious mental illness: STARS study results (Green, Polen, Janoff, Casteleton, Wisdom, Vuckovic, Perrin, Paulson and Oken, 2008)	Practical rather than theoretical based study. Mixed methods longitudinal study of 177 members of US health service.	US Health service	Clinicians who collaborated with patients to develop and evaluate plans of care, particularly regarding medication empowered patients to participate in their own care.	Mixed methods study so no qualitative description needed. MMAT score 75% (no reflexivity, unclear research question/ objective; sample not representative, no limitations)
'Hell no, they'll think you're mad as a hatter': Illness discourses and their implications for patients in mental health practice (Ringer and Holen, 2016)	Theoretically informed (conceptual) ethnographic study in 2 institutions (in-patient and out-patient). Interviews with 13 patients and 11 professionals. Discourse analysis	In-patient and out-patient in Denmark	3 discourses identified – the instability discourse, the 'really ill' discourse, and the lack of insight discourse. Patients must develop a precise sense of the discourse needed to have a say in their treatment.	Level 1 Generalisable study. MMAT score 100%
It's the talk: a study of involvement initiatives in secure mental health settings (McKeown et al., 2014)	Case study design with interviews and focus groups with 60 individuals, 6 paired interviews and 10 focus groups. (70 staff and 69 service users)	Secure mental health (forensic) in UK	Communication and relationships drove effective involvement, whereas safety and security concerns constrained communication and therefore involvement.	MMAT score 75%, Descriptive study (level 3) with good discussion of theoretical concepts

Justifying medication decisions in mental health care: Psychiatrists' accounts for treatment recommendations (Angell and Bolden, 2015)	Conversation analysis of 36 interactions between clients and one psychiatrist.	Assertive Community Treatment program (intensive case management) in US	Psychiatrist used persuasion to elicit agreement from clients – demonstrates that standard psychiatric practice is far from shared decision-making.	MMAT score 75%, Single case study (Level IV)
Promoting autonomy of the client with persistent mental illness: A challenge for occupational therapists from The Netherlands, Germany and Belgium (Granse, Kinebanian and Josephsson, 2006)	69 Occupational Therapists (OTs) – semi-structured questionnaires, constant comparative analysis of responses	Psychosocial mental health (mostly hospitals) in The Netherlands, Germany and Belgium	OTs work with client motivation to empower clients. Culture of the hospital main barrier to promoting autonomy. 10% of OTs mentioned supporting clients' choices.	MMAT score 75%, Conceptual study (Level III)
Decision-making in recovery oriented mental health care (Matthias, Salyers, Rollings and Frankel, 2012)	Observational study of medication decisions; 3 psychiatrists, 1 nurse, 40 people experiencing severe mental health problems	US Community mental health centre – ACT model	Provider preferences were reflected in the final decision in the majority of cases across all decision types. Cross-sectional study (only one visit per person)	MMAT score 75%, Descriptive study Level III. No sampling for diversity, no discussion of saturation (sample size dictated by '10 per practitioner')

Experiences of treatment decision-making for young people diagnosed with depressive disorders: a qualitative study in primary care and specialist mental health settings. (Simmons, Hetrick and Jorm, 2011)	Qualitative interviews with 10 young people, 5 carers	Australian – Orygen & Headspace (1 site)	Varied levels and desire for involvement among young people. Less involvement in in-patient, detox units and forensic. Clients and carers wanted more information.	MMAT score 75% (although only brief mention of reflexivity). Generalisable Level I. No mention of dual roles of researchers/ insider evaluation.
Making decisions about treatment for young people diagnosed with depressive disorders: a qualitative study of clinician's experiences, (Simmons, Hetrick and Jorm, 2013)	Qualitative interviews with 22 psychiatrists, general practitioners and allied health practitioners	Australian – Orygen & Headspace (1 site)	Clinicians viewed the decision as 'ultimately belonging to the client', although 4 circumstances justified paternalistic style – severity of symptoms, risk, client preference for involvement, age/ developmental stage of client.	MMAT score 75% - brief mention of reflexivity, but not in relation to 'insider evaluation'. Generalisable Level I.
Exploring the youth and parent perspective on practitioner behaviours that promote treatment engagement (Lachini, Hock, Thomas and Clone, 2015)	Focus groups with 30 youth who had received services from multiple providers, incl. Special education, juvenile justice, substance abuse; and parents	US evaluation study to improve mental and behavioural health services for youth and families. Unclear setting	Youth wanted involvement in treatment, incl. wanting to lead. Examples of non-involvement in decision-making given. Wanted more info. Parents not believed by providers, want involvement in treatment plan.	MMAT score 50% no reflexivity, no context discussion. Level III Practical rather than theoretical study. Sample not diversified.

Clinical and ethical dimensions of an innovative approach for treating mental illness: A qualitative study of health care trainee perspectives on deep brain stimulation (Bell and Racine, 2013)	Qualitative interviews with 20 health care trainees further to reading 3 general scientific articles on DBS	8 nurse trainees, 6 social work trainees, 6 OT trainees	Trainees overwhelmingly wanted to support patient autonomy in guiding choice. Saw their role (as part of their professions) to enhance autonomy, inform and counsel patients of risks and benefits of this experimental treatment.	MMAT score 75%, no reflexivity. Level IV Conceptual study, theoretical concepts guided sample, no diversified sample
Improving therapeutic relationships: Joint crisis planning for individuals with psychotic disorder (Farrelly, Lester, Rose, Birchwood, Marshall, Waheed, Henderson, Szmukler and Thornicroft, 2015)	Qualitative interviews/ focus groups with 51 service users, 29 care coordinators, and 15 psychiatrists	Community mental health settings in 4 locations in England	Clinicians comply with organisational and professional requirements over service user autonomy. JCPs helped to reduce organisation influences and facilitated communication.	MMAT score 75%, no reflexivity. Generalisable Level I study.

Australian Psychiatrists' support for psychiatric advance directives: Responses to a hypothetical vignette, (Sellars, Fullam, O'Leary, Mountjoy, Mawren, Weller, Newton, Brophy, McEwan and Silvester, 2016)	Online survey of 143 psychiatrists	Online Australian study offered through Royal Australian and New Zealand College of Psychiatrists	Fewer than 3/10 would support a patient requesting cessation of medication or remaining out of hospital or not being on IVO. 80% believed advance directives have a positive effect on mental health care. Those who would support patient preferences support autonomy under certain conditions. Those who didn't support prefs. thought that dep. is treatable. Risk to patient major reason for not supporting.	MMAT score 50%, Descriptive mixed methods study Level III. No diversified sample

Note: 14 studies excluded; six studies utilised quantitative study design and eight articles were theoretical or descriptive with no data collection.

*Refers to assessment of study quality using relevant tools; The Mixed Methods Assessment Tool (MMAT) provides a score out of 100 for studies that use qualitative and quantitative methods (Pluye et al., 2009), and Daly's hierarchy of evidence of qualitative studies from Level I (generalisable evidence) to Level IV (single case study) (Daly et al., 2007).

Appendix Two: Other Outcomes from the Australian Research Council Supported Decision-Making Project

Refereed Journal Articles

McSherry, B. and Butler, A. Support for the Exercise of Legal Capacity: The Role of the Law (2015) *Journal of Law and Medicine* 739-744.

McSherry, B. Mental Health Laws: Where to From Here? (2014) 40(1) *Monash University Law Review* 175-197.

Presentations

Brophy, L. and Moeller-Saxone, K. (2016) Options for Supported Decision Making to Enhance the Recovery of People with Severe Mental Health Problems. Royal Melbourne Hospital Department of Psychiatry Colloquium, 14 November 2016.

Brophy, L. (2016) Supported decision-making and the Mental Health Tribunal in Victoria: Are we supporting the disempowered? Early experience of Mental Health Tribunal hearings under the new Mental Health Act in Victoria Australia. Symposium, International Congress of Psychiatry, 8 to 12 May 2016, Hong Kong, China.

Brophy, L. (2016) The implications of Supported Decision-making to Social Work practice in mental health: Enhancing the Human Condition. 8th International Conference on Health and Mental Health, 19 to 23 June 2016, Singapore.

Brophy, L. (2017) The implications of Supported Decision-making to Social Work practice in mental health. Mental capacity and professional decision-making in social work, Department of Health, 22 March 2017, Templepatrick, Northern Ireland, UK (invited key note presentation via video).

Kokanovic, R. (2016) Perspectives on supported decision-making from people experiencing severe mental health problems and carers supporting them. Disability, Human Rights and Social Equity Conference. The University of Melbourne, 4 to 5 February 2016, Melbourne. [with Lisa Brophy and Audrey Statham]

Kakanovic, R. (2017) Typologies of Service User Expectations of Support in Mental Health Decisions. XXXVth International Congress on Law and Mental Health. Charles University, 9 to 14 July, Prague, Czech Republic. [with Lisa Brophy, Fauzia Knight, Damien Ridge, Nicholas Hill, Kate Johnston-Ataata and Helen Herrman]

McSherry, B. (2015) Capacity, Informed Consent and the Convention on the Rights of Persons with Disabilities. Auckland University of Technology: Public Lecture, 20 February 2015, Auckland, New Zealand.

McSherry, B. (2015) Options for Supported Decision-Making in Mental Health Care and Treatment. Joint Conference: Systems, Clients and Patients, Australian and New Zealand Association of Psychiatry, Psychology and Law (ANZAPPL) and Royal Australian and New Zealand College of Psychiatrists (RANZCP), 25 to 28 November 2015 Canberra. [with Lisa Brophy, Helen Herrman, Renata Kokanovic]

McSherry, B. (2016) Options for Supported Decision Making to Enhance the Recovery of People with Severe Mental Health Problems: Workshop. Monash University, 16 June 2016, Melbourne.

McSherry, B. (2016) Supported Decision-Making for Individuals with Severe Mental Health Problems: Findings from Focus Groups and Interviews. European Association of Psychology and Law, 5 July 2016, Toulouse, France.

McSherry, B. (2016) Support to exercise legal capacity: findings from focus groups, Disability, Human Rights and Social Equity Conference. The University of Melbourne, 4 to 5 February 2016, Melbourne.

Resources

- What is Supported Decision-Making? Fact sheet

- Supported Decision-Making Legal Mechanisms Fact sheet

- Practices to Improve Supported Decision-Making in Mental Health Services Fact Sheet

- Resources to Assist with Supported Decision-Making Fact Sheet

- Guidelines for Supported Decision-Making for Mental Health Services

- Introduction to Online Resources on Supported Decision-Making for People Experiencing Mental Health Challenges and Their Families and Other Informal Supporters

Online resources: http://research.healthtalkaustralia.org/supported-decision-making/support-in-treatment-decisions