



Mental Health Commission
of New South Wales



Medication and mental illness

PERSPECTIVES

Preferred citation:

Mental Health Commission of NSW (2015). *Medication and Mental Illness: Perspectives*.
Sydney, Mental Health Commission of NSW

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ISBN: 978-0-9923065-7-1

Foreword



This paper tells the story of medication as a treatment for mental illness from the perspective of consumers, carers, families and people who work within the mental health system.

All the people who responded to the call for submissions, issued by the Mental Health Commission of NSW in November 2014, want a good life for themselves, their loved ones, or the people they support professionally. Mental health and wellbeing are critical to building and maintaining a good life, and medication, people told us, sometimes assists in this aim, and sometimes detracts from it.

The experiences we heard were varied. Some were nothing short of heartbreaking, while others, which told of inspiring people and innovative practice, were uplifting and hopeful. These perspectives on medication reflect what the Commission knows about the mental health system more broadly: that it too often lets people down, and that change is necessary.

The Commission exists to promote this change and to guide and to monitor it. I want to sincerely thank those people who have shown courage and honesty by sharing their experiences with us. Your perspectives are invaluable, as they demonstrate the diverging roles medication can play in recovery, and they make a clear case for the quality use of medicines.

I also express my gratitude to the Commission's Pharmacotherapy in Mental Health Advisory Group whose expertise has guided this paper. Their wealth of experience and their dedication to positive change have also been invaluable.

People with a lived experience of mental illness deserve to be supported by a system that is safe, puts them at the helm, and holds high expectations for their recovery. And this vision should be no different when medication is a part of treatment and recovery.

This paper is a unique resource that exposes both the challenges and opportunities for medication as a treatment for mental illness. The Commission will advocate for the changes it outlines, and I urge others to join with us in doing so.

A handwritten signature in black ink, appearing to read 'John Feneley'.

John Feneley

NSW Mental Health Commissioner

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Executive summary

The Commission was established in 2012, and during the early development phase the Commissioner and staff travelled widely across NSW to meet with consumers and carers to learn from those with a lived experience of mental illness.

On these travels people described a mental health system that didn't always adhere to the quality use of medicines. At the same time there was clearly an increasing reliance on the use of medication as a treatment for mental illness.

These two simultaneous trends presented a convincing case for the Commission's attention.

Initial investigation showed that conversations about medication were largely initiated by researchers and clinicians, and that there was little evidence of participation by the people who take the medication or those who care for them. It then became the Commission's objective to seek out the voice of consumers and carers so they could help influence policy and practice.

In February 2014 the Commission established an expert Pharmacotherapy in Mental Health Advisory Group. In November 2014 the Commission published an issues paper on Medication and Mental Illness, which opened a month-long call for submissions about using medication to treat mental illness. More than 200 submissions were received.

In early 2015 the Commission held consultations with Aboriginal health workers, young people, older people, and culturally and linguistically diverse (CALD) community representatives.

Analysis of the submissions and consultations revealed six key themes:

Medication is one treatment option

People want medication to be prescribed in conjunction with non-pharmacological therapies, or only after all non-pharmacological options have been exhausted. Medication is not always the answer. For some it will bring relief from symptoms, but if mental illness is the result of trauma, people said medication on its own did little to resolve this. People asked for other therapies, such as counselling, psychotherapy or mindfulness, to be explained before a prescription was offered, or for practical support with housing or employment to be discussed.

Health systems, practices and recovery

Prescribing takes place within a health system experiencing challenges. These include time pressures, stretched resources, and consumers presenting with a variety of complex social issues. The effect of these challenges is sometimes borne by consumers in the form of practices that work contrary to recovery. These practices include; inappropriate polypharmacy, consumers not being informed about side effects, carers excluded from discussions about treatments, and the lack of regular medication reviews.

Taking medication

Many consumers and carers said their concerns about medications were either ignored or dismissed. People repeatedly said the views of clinicians took precedence over their own, and that the lived experience of medication was rarely valued. People used words such as 'powerless' and 'demeaned'; they felt they were disapproved of and rarely listened to. People said that when their concerns were not taken seriously there was a high risk of disengaging from treatment.

Medication costs

People reported that the high cost of medication could be a barrier to access. They also raised the indirect costs associated with medication, including psychiatric fees, time off work to attend medical appointments, travel costs, and blood tests. People said they often had to choose between paying life's expenses or buying medication. Many consumers, particularly those with children, told of placing the needs of others above theirs.

Medication side effects

People spoke of the unwanted side effects of medication. For some these were temporary, or were bearable, given the benefits of the medication on their lives. However, for some people the side effects were debilitating, and worse than the symptoms of the mental illness. For some who had been on medication for long periods, the side effects were permanent, and sometimes life threatening.

Medication supported my recovery

People also highlighted positive experiences and outcomes. They told of caring, compassionate and innovative clinicians and said medication had helped them to return to work or study, and to contribute to their family and community. They said medication could help them become well and stay well when it was part of broader treatment - and when they were involved in meaningful discussions about personal recovery goals.

This paper makes it clear that change is needed on several fronts, and, to be effective, change must include consumers, carers, families, clinicians, including general practitioners, psychiatrists, and pharmacists.

Introduction

While psychological and social interventions are available for people experiencing mental illness, too often the first-line treatment is medication.

The early 1950s marked the introduction of medication as a treatment for mental illness, and in the 1990s this treatment expanded enormously. New classes of antidepressants, the development of second generation antipsychotic medication, and the use of medication not traditionally regarded as psychiatric, profoundly influenced the treatment of mental illness.

In the past decade the use of medication to treat mental illness has risen 58 per cent in Australia¹ which has the second-highest, per capita antidepressant consumption of all OECD countries².

In 2011 more than 2.3 million people in Australia accessed mental health-related medications subsidised by the Pharmaceutical Benefits Scheme (PBS)³. The most rapid percentage rise in antidepressant and antipsychotic dispensing has occurred in the treatment of children and young people⁴.

The use of antipsychotics has also increased for older people. A person in their 80s is three times more likely to be taking antipsychotic medication than if they were in their 30s, 40s, or 50s⁵.

The majority - 86 per cent - of mental health-related prescriptions⁶ in Australia were issued by GPs, eight per cent were prescribed by psychiatrists and six per cent by non-psychiatric specialists.

There were 34 million prescriptions for mental health-related medications dispensed in Australia in a twelve month period in 2013–14, accounting for 12 per cent of all prescriptions⁷.

Antidepressant medications accounted for 67 per cent of total mental health-related prescriptions in Australia in the same period⁸.

The NSW Mental Health Commission is an independent statutory agency responsible for monitoring, reviewing and improving mental health and wellbeing in NSW. The Commission is guided by the lived experience of mental illness, and medication is part of the lived experience for many people.

The role of medication in recovery from mental illness is complex and often polarising. Its effectiveness is the result of interactions between clinical practice, biological determinants, social factors, and personal relationships. For these reasons medication can be associated with health risks ranging from the mild to the significant, and it can also improve people's quality of life and prevent complications.

The Commission, with the support of its Pharmacotherapy in Mental Health Advisory Group, sought to explore this complexity via the perspectives of consumers, carers, and clinicians.

- In February 2014 the Commission established an expert Pharmacotherapy in Mental Health Advisory Group
- In November 2014 the Commission published the Medication and Mental Illness issues paper
- Submissions were received during the calendar month of November 2014 from consumers, carers, and clinicians. They were accepted online, by mail, email and to a dedicated 1800 phone number.
- Group consultations with Aboriginal mental health workers, young people, older people and representatives from culturally and linguistically diverse communities were held from January to March 2015.

Submissions

The Commission acknowledges the people and organisations who took the time to provide a submission or attend a focused consultation.

The Commission received more than 200 submissions, as follows:

- 60% consumers
- 21% carers
- 28% clinicians
- 62% metro
- 15% rural and regional
- 12% Aboriginal and Torres Strait Islander
- 18% young people

Nine submissions were received from states other than NSW

The following organisations provided submissions:

- The Aboriginal Health & Medical Research Council
- Carers NSW
- Illawarra Suicide Prevention & Awareness Network Inc
- Mental Health Carers ARAFMI NSW
- NSW Official Visitors Program
- Pharmacy Guild of Australia (NSW branch)
- Pharmaceutical Society of Australia (NSW branch)
- Royal Australian and New Zealand College of Psychiatrists
- Transcultural Mental Health Centre of NSW

A pragmatic approach

The Commission recognises that an open call for submissions, like any methodology, has its limitations. People who are dissatisfied are often more motivated to respond, and these perspectives may not be representative of the average experience. However, most of the submissions, while outlining challenges, also told of positive experiences.

Consumers, carers and their families were the main respondents but the Commission also made efforts to hear from others who play a role in the use of medication to treat mental illness. The views of GPs, psychiatrists and allied health workers were sought.

This paper is a unique resource. It is not a literature scan, or a critical review of science or guidelines. Instead, it provides an opportunity for consumers, carers and people who work within the system to use their own words to advocate for change.

A note on language

The Commission recognises that words and terms can have a profound impact on people. The use of inclusive and contemporary language empowers people and allows important issues, such as medication and mental illness, to be aired with sensitivity while minimising stigma. The Commission also recognises that words and terms are sometimes contested and are subject to change.

People with a lived experience of mental illness, their families and carers, and the clinicians who support them, advised the Commission that the terms used in this paper, and listed below, were appropriate.

Carer

A person of any age who provides personal care, support and assistance to another person because the other person has a disability, a medical condition, a mental illness or is frail.⁹

Clinician

A health professional, such as a GP, psychiatrist, psychologist, nurse, or occupational therapist, who is directly involved in patient care.

Lived experience

The experience people have of their own or other's mental health issues, emotional distress or mental illness, and of living with, and recovering from, the impacts and consequences of their own or other's mental health issues, emotional distress or mental illness¹⁰.

Mental health consumers (or consumers)

Refers to people who are using, or have used, a mental health service and includes people who have accessed general health

services for a mental health problem. For the purposes of this paper, this term includes those with emerging or established mental illness for which they have not yet sought treatment, or for whom treatment has not yet been provided¹¹.

Medication (or medicines)

Prescription drug/s used to treat illness, including mental illness.

Non pharmacological

Treatment that does not use pharmaceutical/prescription medication.

Pharmacotherapy

Treatment using pharmaceutical/prescription medication.

Recovery

A personal process of changing one's attitude, values, feelings, goals, skills and/or roles. It involves developing new meaning and purpose as the person grows beyond the effects of psychiatric disability.¹²

Medication is one treatment option

The call for holistic care

Treatment and support that is other than medication plays an essential role in recovery-oriented mental health practice.

The Royal Australian & New Zealand College of Psychiatrists wrote in its submission that psychotropic medication was an important part of treatment for people with some mental illnesses, but

“they should be provided in conjunction with appropriate, evidence-based psycho-social treatments to ensure holistic consumer care.”

And while this is increasingly recognised by mental health practitioners, submissions indicate there is still some way to go before holistic mental health care plans become a broad reality.

Submissions from GPs, nurses, and psychiatrists, also expressed the need for comprehensive care, with one clinician saying:

“[Non-pharmacological] approaches need to be given equal weight, as part of the treatment plan, and not as an after-thought... If we used the same level of assertiveness with non-pharmacological approaches as we do with making sure people are compliant with medications, I think we might actually get some balance.”

One clinician suggested there is a schism between psychological therapies and medication.

“Medication treatments sit in one corner, almost in opposition to the psychology treatments. Such a dichotomy is also promoted between the scientific, evidence-based approach and the recovery model. The use of medication in mental illness is an important part of recovery and its intelligent use involves a working relationship between a skilled practitioner and the individual with mental illness.”

Consumer experiences

Consumers reported positive experiences with a range of non-pharmacological therapies ranging from acceptance and commitment therapy (ACT) to mindfulness to dialectical behaviour therapy (DBT), particularly for reducing the levels of medication taken and the side effects. Several noted that these therapies were offered only years into their treatment or were difficult to access.

One consumer said:

“I have recently been able to reduce some of my Seroquel. This was as a result of attending group therapy doing the acceptance and commitment therapy (ACT) modules. Group training is more effective than one-on-one training for me. You get to hear about other experiences and understand that you can improve. This training gave me many light-bulb moments and many skills to use to manage my anxiety.”

A consumer who reported benefit from DBT said she wished it had been offered first rather than *“immediately being placed on a variety of drugs that mask the symptoms.”*

Another consumer said:

“Talking to a counsellor helped me to understand that I did have a choice and I did have control... When I do need drugs again, I’ll know I need something extra, but that it’s mostly me. What a shame that talking therapies are so expensive and hard to access.”

A consumer admitted to hospital during an acute episode of mental illness said:

“[Medication] helped me a bit when I was very unwell but when I left hospital, I was kept on medication... for many years but the rest of my life was a mess. I only started to actually recover when I stopped medication and got help from a brilliant and caring psychologist at my local hospital. I have since had the confidence to complete a uni degree... Please don’t put us on medication until all the other stuff that actually works has been tried properly.”

A consumer who contacted the Commission by telephone said:

“It is concerning that medication is prescribed as a first line of response to young people, instead of asking what is happening to this young person and trying to provide psychological counselling... My local general counselling service had to close down because of lack of funding. This type of counselling is valuable to clients who don’t necessarily tick the boxes to be eligible for help under the mental health plan.”

“It is concerning that medication is prescribed as a first line of response to young people, instead of asking what is happening to this young person and trying to provide psychological counselling.”

The same consumer also said:

“Medication is certainly helpful in treating some physical symptoms but not in treating the illness. For me, medication was helpful in treating severe anxiety but at the root of it was trauma.”

A consumer from a CALD background said:

“I had counselling. It saved my life. Also, expressive therapies, like art therapy, it’s good because you don’t have to talk. Sometimes you are unable to talk, but you can express.”

Mostly people said that medication was most effective when combined with non-pharmacological approaches. In these cases, medication reduced the symptoms, and talking therapies and the like helped change negative patterns of thinking.

Sometimes though, consumers felt non-pharmacological interventions were enough on their own. An emphasis on learning skills of self-care and self-management was needed they said. This is where people with mild to moderate mental illness may be able to manage symptoms with the use of mindfulness of thought and action, early warning sign recognition and management, or cognitive skills. People said these skills could improve their daily lives, enable a return to regular routine, and prevent the need for medication.

Inpatient experiences

One consumer describing her hospital experiences said there was an emphasis on medication at the expense of other approaches.

The consumer explained:

“Access to prescription medication appears to be the default position when people express distress, rather than offering opportunities to talk, to access other resources (e.g. art, exercise, sensory modulation rooms etc.). When behaviour or distress escalates and sedation and seclusion are the outcome, this may have been averted by offering a more spacious area, low stimulus environment or other self-soothing opportunities. However training and support for staff in using these resources and options is often lacking.”

Some inpatient experiences were more positive, with one young consumer comparing a current experience with previous ones:

“Here they actually try to calm you down before they give [a sedative injection] to you, which is a great relief.”

“Access to prescription medication appears to be the default position when people express distress, rather than offering opportunities to talk, to access other resources...”

Children and young people

A child psychiatrist wrote to the Commission about the importance of non-pharmacological therapies for children and young people, as well as education for parents, some of whom have:

“...expectations that there is a tablet to ‘fix’ childhood mental health issues such as low mood, oppositional behaviour, anger, poor sleep etc.”

“In childhood mental health problems, medication can allow psychological and behavioural therapies to have a greater impact ... but over time, and in most cases, I have to say, over-reliance on drug intervention can worsen a child’s prognosis because of the unrealistic expectations placed on the [medication].”

Good practice: Open Dialogue

In the 1980s the far north of Finland had some of Europe's poorest outcomes for people with schizophrenia. But the area has now transformed its mental health system to one that achieves the world's best documented results for first episode psychosis.

The Open Dialogue approach meets with people in crisis immediately and often daily until there is resolution. Everyone's voice is valued, particularly that of the person experiencing mental illness. Early conclusions or decisions about treatment are discouraged, which means medication is not generally discussed in a first meeting, and is usually discussed in at least three meetings before any prescribing decision is made.

Carer experiences

A carer whose young son responded poorly to a range of medications said she wished there had been more collaboration with the family and more support for them in the form of respite care, behaviour management strategies and counselling. This could have increased the family's capacity to support their son, who might then have needed less medication to “control” his behaviour.

Another carer said:

“...medication is often seen as the first and only treatment. It appears that once someone is on medication it is not properly reviewed, there is no investigation to see if the person can function without the medication, so they are on it for life. If they become mentally unwell whilst taking medication they are just prescribed more medication.”

A carer of a young adult with a psychotic illness said her son needed more rehabilitation, symptom management skills and general life skills, and less sedation to be able to move forward in his life. She commended the approach of the Hearing Voices Network, which says hearing voices is a relatively common human experience that needs to be accepted and supported rather than feared.

Experiences of Aboriginal people

The Aboriginal people the Commission spoke with said the Aboriginal concept of health was generally holistic and not always aligned with medical models. Health, for some Aboriginal people, they said, encompassed mental, physical, cultural and spiritual health. For some Aboriginal people, opportunities to “yarn” and to communicate “on a spiritual level” were crucial to their wellbeing:

“I went to the doctor. I was given medication, but he said I wasn't ill enough to see a counsellor. I thought it should be the other way round.”

Other suggested non-pharmacological therapies included taking women 'out on country' and cultural programs that support women to visit sacred sites and share their knowledge. Positive mention was made of Waminda's Aboriginal Women's Respite Healing House Project, where Aboriginal women living with a mental illness or their Aboriginal carer can access respite from the pressures of daily life.

System pressures on clinicians

Clinicians said they struggled with the provision of holistic mental health. Care, which requires the engagement of different tiers of government and a mixture of clinician and allied worker support. Yet the system is fragmented.

Clinicians said they felt pressured for time and resources. One explained:

"I find that due to extremely stretched resources within NSW Health and community mental health settings, that most client contact is phone based and governed by medical models of care provision ... The time a clinician can take with a client to provide psychotherapy-based counselling, brief interventions, social planning and supports has become sorely limited, hence care provision consists primarily of mental health review, medication prescription and review ..."

A GP said:

"The implementation of effective non-pharmacological management ... comes up against a number of barriers. These include time, practitioner skill, access to psychologists, psychiatrists and other mental health professionals, and finance, to mention a few. Hence, medication can seem an easier option."

He added:

"The key resources needed to further improve the use of psychotropic medication in general practice are time, communication skills, expertise in mental health, and improved knowledge of communication with and ease of referral to specialist and allied mental health services. This may require GP education and training, changes to the Medicare [Benefits] Schedule and further investment in mental health services."

A clinician working in primary care in a regional area said:

"Psychosocial interventions have important roles to play ... The problem with making these choices at the front line of health care is that social supports and psychological interventions are not readily accessible, certainly in outer metropolitan and rural areas. In many cases, despite the ability to use Medicare reimbursements when referred by a ... GP, the fees charged for psychology are prohibitive for poor patients. Access to psychiatric assessment and follow-up is extremely difficult for similar reasons in these areas although the ability to conduct psychiatric consultation by video link is helping where it is available."

“The fall-back position becomes then the prescription pad, for the general practitioner who is unable to readily access these other services for patients. An action they take to help the patient using the most pragmatic means at their disposal.”

“The fall-back position becomes then the prescription pad, for the general practitioner who is unable to readily access... services for patients.”

Clinicians said they often operate within challenging environments and change was needed from the system so that practice which is person centred and recovery oriented is supported rather than constrained.

Good practice: Choosing Wisely Australia

Choosing Wisely Australia, an initiative of NPS MedicineWise, is helping clinicians and consumers start an important conversation about improving the quality of care, for both physical and mental health, by eliminating unnecessary and sometimes harmful tests, treatments and procedures. The program encourages people to consider what care is truly needed - conversations between consumers and clinicians can help identify which treatments are helpful and which are not.

<http://www.choosingwisely.org.au/>

Broader than health

People also said that non-pharmacological interventions needed to be much broader than the health system.

“If every person with a mental illness could have the appropriate medical assistance along with housing assistance, if required, we as a society would be a lot better off.”

People said mental health care plans needed to include community support, which might be in the form of accommodation, help with finding suitable work, or training and education.

Towards change

People told the Commission:

- the first, and only option should not be a prescription.
- psychological and social interventions such as counselling, cognitive behaviour therapy and exercise should be considered at the same time as medication.
- sometimes non-pharmacological options on their own are enough, particularly in cases of mild to moderate depression.
- mental illness may be the result of surviving a trauma, and when this is the case clinicians should look to address the root cause of mental distress.
- access to and the cost of non-pharmacological interventions is problematic.
- medical interventions may be of limited effectiveness if the broad and complex factors that affect health and wellbeing are not addressed. These factors include; housing, education, and employment.

Mental health systems, practices and recovery

Information and communication

People said that information enabled informed decisions. This means that treatments can be tailored to individual recovery goals, personal circumstances and preferences.

The Royal Australian and New Zealand College of Psychiatrists' (RANZCP) submission highlighted the duty of medical professionals to provide information so consumers use medication correctly and safely, and to take an active role in their recovery. It also emphasised the need for this information to be provided in writing.

Many consumers told the Commission they would like more information about medications, particularly potential side effects, adverse interactions with other medications, and how any side effects are likely to unfold over time. And while information is a requirement of any new prescription, people said they did not always receive it.

Good practice: medicines information

Consumer Medicines Information Group, Manly Hospital

Aoife Davis, a mental health pharmacist, believes that when people have knowledge and understanding about their medications, they can make informed decisions about their mental health, and that this is key to recovery.

In collaboration with the occupational therapist and clinical nurse educator, Ms Davis established a fortnightly Medicines Information Group at the in-patient unit at Manly Hospital. The group is informal, discussion based and consumer led. Consumers raise concerns, ask questions or obtain written information about their medications and side effects.

Braeside Hospital, Fairfield, Specialist Older People's Mental Health Service

The pharmacists at Braeside Hospital know that information about medication is critical to ensuring its safe and effective use. Consumers and carers can be referred to the pharmacist for a detailed and personal discussion about the medication that has been prescribed whilst they are an in-patient. Additionally on discharge, every consumer receives a printed medication list which includes indications and clear instructions for use. This same medication list is provided to the community mental health team so that they can support the person when they have returned home.

Hospitals and in-patient facilities

One mother – whose son has a complex mental illness, an intellectual disability, has had repeated hospital admissions and tried numerous medications – said the information she had received from hospitals had been poor. She had taken to checking the internet for information about her son's prescriptions, in lieu of information from clinicians.

Another submission about in-patient experiences said:

“Consumers commonly report that the potential side effects, and ways the ... side effects can be monitored or mitigated, are not explained to them. There is no discussion about alternative medications or treatment protocols, dosage rates, ongoing monitoring with a view to reducing the medication to the lowest dose achieving efficacy etc. There is little explanation provided to families and carers about how the medications work.”

Young people's experiences

Some of the submissions from young people highlighted the challenges of pitching information at the right level to meet the needs of consumers and carers.

Several young people said they had been scared by the information given them about medication. A number felt the information was inadequate or that they did not understand it. One young person who had experience anger issues while taking a particular medication said:

“I wish I was given information on what to expect or look out for to see if it was working correctly...”

She was unaware at the time that heightened aggression was a potential side effect and found out only much later when she started a different medication and the anger dissipated.

One young person who was an inpatient was satisfied with the information provided by hospital psychiatrists:

“They gave like a list of all the normal side effects, so I guess it kind of helps cause I didn't get that worried cause I knew that it was normal.”

Several young consumers described experiences where they felt their parents' views and feelings were prioritised over their own. One said:

“[The psychiatrist] wasn't explaining it well and he was scaring me and he wasn't listening to me, he was just listening to my family instead of actually talking to me, and he said what I was saying wasn't true and stuff, which made me really angry.”

Language and literacy

Several submissions called for clinicians to be mindful of the varying levels of literacy amongst the population, asking for medication information that is simple and clear and free from jargon.

The call for straightforwardness is particularly important for people whose first language is not English. The Transcultural Mental Health Centre said:

“Complicated combinations of medication and doses that need to be taken at different times of day can be confusing for those whose first language is not English. Prescriptions are usually provided in English, as are many educational materials.”

In its submission, Carers NSW also drew attention to language barriers:

“Carers from culturally and linguistically diverse backgrounds may find communications with health professionals particularly challenging, especially when multiple professionals are involved in their loved one’s care, and information about medication is provided in English.”

Cultural differences

A quarter of all Australians were born overseas, many in countries whose languages, cultures, beliefs and health systems are different from those in Australia. These diverse experiences can affect the way medication is viewed and used.

The Transcultural Mental Health Centre explains:

“Recent migrants, especially those from refugee backgrounds, may be unfamiliar with western medical system in general and distrust medical professionals. In some migrant countries of origin psychiatry and psychiatric medication may be viewed with suspicion and associated with fears of social control.”

“Cultural issues such as taking pills orally during religious festivities ... may also influence when and how people take medication.”

The Transcultural Mental Health Centre says the Australian health system could take better account of culture and beliefs, and gives fasting, which is important in many faiths, as an example.

“Cultural issues such as taking pills orally during religious festivities such as Ramadan or the impact of fasting on meal consumption may also influence when and how people take medication.”

Carer experiences

In its submission, Carers NSW reported:

“Many carers accumulate considerable knowledge and expertise around medication ... and may find themselves not just supervising the consumer but also other professionals who may be administering medication for mental illness in community, hospital or aged care settings.”

However, the submission goes on to say:

“Carers still describe hit and miss experiences with health professionals communicating with them in regards to medication for the person they care for, with one carer describing it as ‘a lucky dip’. Many carers experience uncertainty about medication issues, and carers continue to report that they are not given adequate information about medication from health care professionals.”

Good practice: Quality Use of Medicines

The quality use of medicines (QUM) indicators recognise that the use of medication is complex. From the decision to prescribe a medication through to its administration, there are numerous steps and people involved which allows opportunities for error. The QUM indicators seek to minimise these errors through safer systems for managing medication, using information to drive improvement, and importantly by making care centre on the person. In 2014 the QUM indicators were revised and now include specific indicators for acute mental health services.

<http://www.ciap.health.nsw.gov.au/nswtag/documents/publications/indicators/manual.pdf>

The challenges of multiple medications

A nurse working in aged care wrote:

“One of the challenges is the co-morbidities of old age - which can include cardiac, metabolic, skeletal and psychiatric issues - and the arsenal of prescription medications that comes with them. This is often accompanied by specialists working on the left hand and not interacting with or knowing what the prescribing specialist on the right hand is doing. They are not aware of or mindful of the possible contraindications, drug reactions or the testing that may be required.”

A carer explained her struggle with the multiple medications prescribed for her young son:

“My son has been heavily medicated since the age of 6-7 until 11 months ago (he is now 12). At one stage he was on 900 mg of Seroquel, including 3-4 other. He developed metabolic symptoms, excessive weight gain, mouth tremors, neutropenia, issues with his thyroid levels.”

Good practice: Home Medicines Review

A home medicines review (HMR) is a comprehensive review of a consumer's medication in their home by an accredited pharmacist on referral from the person's GP.

The service involves cooperation between the GP, pharmacist, other clinicians and the consumer and/or carer. An HMR improves the consumer's and clinician's knowledge and understanding about medication, facilitates cooperative working relationships among members of the care team, and provides medication information to the consumer and other clinicians involved in care.

Over-medication of older consumers

The Older Persons Mental Health Peak Advisory Committee (OP committee) of ARAFMI NSW¹³, noted that psychotropic medication could have benefits for some older consumers. But it also noted that the over-use of antipsychotics and sedatives was a significant problem, particularly where dementia was present.

Risk of over-medication with older people is also increased because doses are usually based on research with younger adults. A member of the OP committee described the result as “*elephant doses for a gazelle*.”

The OP committee said the use of psychotropic medication to control behaviour was an issue in some aged-care residences. It said antipsychotics and sedatives could be used to “*keep older people quiet*”. The committee explained that these practices were often the result of a system was under-resourced and under-recognised because of the stigma associated with ageing.

Treatment or control?

Consumers, and indeed carers and advocates, viewed medication not always as a treatment but sometimes as a form of behaviour control.

A consumer said:

“...in hospital the more unstable I was the more they increased the unsuitable medications to try to settle me rather than talk to me about what was happening and what was causing me distress.... It was like chemical restraint.”

A carer commented:

“All psychotropic medications are used for behaviour control, be that for the benefit of the patient or their medical minders ... [in locked wards] benzodiazepines ... are used to calm the patient and make everyone's job easier.”

Medical records and record-keeping practices

A number of requests came from consumers, carers and clinicians for a centralised medical records system. People said the regular recording of medications would help to:

- minimise the chances of adverse medication interactions, particularly among older people who are more likely to be taking medication for a range of health conditions
- keep track of allergic or other adverse reactions to particular medications
- make people alert to variability in responses to medication as a result of genetics
- ensure all professional members of a person's mental health care team had access to all the information needed to prescribe safely and sensitively at all times
- help prevent "doctor shopping"¹⁴, by consumers who also have issues with drug and alcohol abuse.

One consumer with an enduring mental illness told of a near fatal allergic response to medication. She said this occurred because while many of the services she attended were aware of the long-standing allergy, the service helping her at that time was not.

GPs and private psychiatrists said they were often not consulted when their patients were admitted to hospital, so the medication history they recorded was not shared with the new clinicians, and vice versa.

A young consumer commented on the discomfort she experienced when questioned by a pharmacist about a prescription, highlighting the importance of communication among all those involved in a patient's care:

"On one or two occasions ... my pharmacist refused to give me the medication because of the extremely high dosage my doctor had prescribed. This was traumatic and very distressing for me and I had to navigate between both of them in order to get this sorted out."

"...my pharmacist refused to give me the medication because of the extremely high dosage my doctor had prescribed. This was traumatic and very distressing for me..."

Monitoring, review and continuity of care

Many of the submissions said that achieving the best outcome for individual consumers on psychotropic medication took fine-tuning, sometimes over long periods, and that regular monitoring and review were essential.

A clinician working in aged care said:

"We find [older] consumers having been on the same medication for years with no clear recollection of when they started or why."

In laying out some of the challenges of managing mental illness in general practice, one clinician noted:

"There are no clear cut guidelines to suggest how long an episode of depression, anxiety or psychosis should be treated. Clinical skill, regular follow up and good communication are needed to make decisions about when to withdraw treatment. People often remain on

antidepressants for long periods of time because no one is reviewing their treatment and engaging in shared decision making about a trial of cessation. Likewise in general practice, patients may be on antipsychotics but no longer under regular review by psychiatrists or mental health teams. These people often lack a regular GP, and hence their medications are often renewed almost endlessly without proper review.”

Consumers observed that in the public system in particular you are less likely to experience continuity of care or be able to see the doctor of your choice. This makes it difficult to get the right balance of medication.

One consumer said:

“My mental health doctors keep changing and that makes it difficult at times to review if dosages could be adjusted as the doctors don’t have a baseline and each time one gets an idea, they move on.”

A consumer who cares for a parent with mental illness described the difficulties her mother experienced through lack of continuity of care as an older person within the public health system in NSW.

“My mum has multiple health problems ... There are so many contraindications between medications and with no constant treating psychiatrist to manage her overall care she seems to get a trial-and-error approach from interns which has seen her almost die ... on three occasions.”

Good practice: Consumer-centred medical home

In 2015 the Royal Australian College of General Practitioners (RACGP) published a vision for general practice and a sustainable healthcare system, which is based on the consumer-centred medical home model. This facilitates a partnership between a consumer, their GP and the extended healthcare team.

The medical home provides GPs with a more complete view of the consumer, strengthens their role in the health system, and delivers better outcomes for consumers by encouraging coordinated and integrated care across the health system.

The consumer-centred medical home model has been implemented in the United States where it has shown a reduction in avoidable hospital admissions, length of stay in hospital and use of the emergency department.

Risk of suicide

The Illawarra Suicide Prevention and Awareness Network (iSPAN) raised concerns about the increased risk of suicidal ideation and behaviour when new medication is started and the way this is managed:

“The greatest risk period for increased suicidal ideation and suicidal behaviour appears to be in the first two to three weeks after commencing a new medication. However, patients starting a new medication are not systematically provided with a clear monitoring plan that would cover the initial high-risk period. More typically, they are told to return in a few weeks for a follow-up consultation.”

iSPAN also said carers need to be informed about the risks of new medication and how best to respond. This issue was typically raised, the group said, by people whose loved ones have died by suicide:

“Carers, responsible for the welfare of their loved ones, are often disempowered and excluded, particularly when the patient is over 18.”

In another submission, a person who had been caring for a young woman who died by suicide while on a new medication described a complex set of circumstances in which the young woman was left alone between medical appointments and in a grey area of duty of care by two clinicians. This carer highlighted the need for continuity of professional care and for carers to be informed of the risks during this period.

Primary care and mental health expertise

Consumers and carers expressed their frustrations at the ‘luck of the draw’ scenario they sometimes faced when accessing primary care. GPs are usually the first and often sole point of entry to mental health support, but the quality of support can be depend on the GP’s training and knowledge in identifying and treating mental illness.

One consumer said:

“I am concerned at the lack of skill by some general practitioners in prescribing for other [non mental-health related] conditions without proper thought about potential interactions with your medication for mental illness. GPs don’t seem to know enough about anti-depressants, mood stabilisers and antipsychotic drugs. Perhaps [there should be] more training in this area or perhaps some GPs could specialise in mental illness?”

A clinician working in primary health care noted that the role of the GP was extremely challenging and poorly understood.

“There are many demands in general practice which, compared with other areas of health care, is under-resourced and undervalued. Primary health care and general practitioners need stronger recognition of the roles they fulfil and to receive support from specialised services and government in carrying out these tasks.”

A carer observed:

“Surely every GP practice should have at least one nurse with experience in mental health. That way, any patient with mental health issues could be seen first by the nurse, who may be able to spend sufficient time with the patient to determine an appropriate intervention strategy.”

Towards change

People told the Commission:

- they want comprehensive, yet accessible and readable information about what they are prescribed, the benefits and risks of treatment and non-treatment, and other treatment options.
- they benefit from established relationships with clinicians and when all members of the care team, irrespective of the health care system they work within, communicate with one another.
- they are concerned about the high level of prescribing of antipsychotics for older people in residential aged care facilities, and in particular that medication may be used as a means of behaviour control for people with dementia.
- GPs have unrealised potential in the treatment of mental illness; they are specialists in whole person care, often have established relationships with consumers, and are uniquely placed to identify and treat co-morbidity.

Taking medication

Pressure to avoid medication

Some respondents said the stigma surrounding mental illness included the medication used to treat it. Some also said that stigma prevented people seeking help, and the prejudice experienced could be as debilitating as the illness itself.

Consumers described being judged as ‘weak’ and being given advice such as ‘you just need to snap out of it’, and ‘pull yourself together’. The respondents pointed out that these attitudes did not necessarily apply to the medications that treat physical illness:

“The main problem is generally people think you shouldn’t need medication because you should just be able to ‘get over it’.”

One clinician said the general community’s awareness of the milder forms of depression had increased considerably, but this had not been matched by awareness and understanding of the more severe and enduring forms of mental illness. As a result, the community might underestimate the level of support, including medication, needed to treat severe mental illness.

“The main problem is generally people think you shouldn’t need medication because you should just be able to ‘get over it’.”

One consumer, who finds an antidepressant significantly improves her quality of life, said she stopped using her medication several times, in response to comments such as, “Are you still dealing with that depression? Thought you were over that” or “You don’t really need those [drugs]”. This consumer, who is now a peer-support worker, said she had overcome the self-doubt and was confident she knew how to stay well:

“I’m okay and it is okay to take medication.”

Psychotropic medication is stigmatised

Several submissions from clinicians observed that psychotropic medications were sometimes seen as especially fearsome, and might be subject to more suspicion than other types of medication. As a result, consumers who might benefit from medication might resist it, as might their families and carers.

One consumer with complex mental illness who has benefited greatly from medication said that for some years she took it in secret:

“because my parents were very anti-medication ... and remained very against the use of medication in my recovery for years.”

A GP summed up a range of concerns and beliefs he has encountered about psychotropic medication:

“There are practical concerns, such as the fear of side effects and the possibility of a fundamental change in personality. There is the belief that medications represent poor treatment – that even if effective they are a purely symptomatic or Band Aid treatment. There can be a feeling of failure associated with taking medications; patients can feel that if suffering from an illness such as depression I ‘ought’ to be able to get over it without medication. There may be a political dimension, distrust [of the motives of big pharmaceutical companies]. And there is often a more philosophical sense that it is plain wrong to treat sufferings of the mind, soul or spirit with chemical agents, or that mental illness is itself a false concept born out of repressive intolerance of difference.”

Fear of dependence on medication and the idea that relying on medication is a form of weakness were prominent themes among the submissions from young people.

One said:

“I wonder if I’ve become dependent on antidepressants and worry they’ll be something I’ll be forever taking. I remember when at first I was still in the full depths of depression hating the idea of having to take a tablet every day simply so I could be happy. However, now I’ve come to realise that it’s simply something I must do to live a normal life. It still depresses me at times and I get sad at the fact that happiness does not come normally to me.”

Another who refused medication the first time it was offered by a GP said:

“I refused because of thoughts that it meant that I wasn’t strong enough to deal with my problems myself.”

The right to risk withdrawing from medication

A consumer who uses antidepressant medication said that accepting that you might need to take medication indefinitely could take time and might include a number of attempts at withdrawal. She would like this right of risk to be respected:

“It would be good if people did not freak out when [consumers] go off the medication ... I feel going off the medication is part of the journey. My GP was not happy when I told her about the experiment of going off meds when I went back to [see her about starting] again. Kindness and understanding is what is important for a person to learn from their mistakes and journey in life. Not being made to feel like a kid who doesn’t know what they are doing.”

A pharmacist made similar comments:

"Another vital ... aspect of [treating people with mental illness with respect and understanding] is the realisation of the importance of dignity of risk in mental health practice: the necessity for [consumers] to have the right to make their own decisions even where those decisions might be risky to themselves, and to not be patronised by healthcare workers, carers and even family."

"Whereas dignity of risk is now well accepted for people with physical disabilities, it is recognised that many in the mental health sector still struggle with implementing the concept and in so doing fail to treat patients in a way that allows them to learn and which fosters and promotes healing."

"...dignity of risk is now well accepted for people with physical disabilities, it is recognised that many in the mental health sector still struggle with implementing the concept..."

The battle to be heard

The submissions of consumers and carers made it clear that they feel their concerns and experiences are frequently ignored or dismissed.

One consumer asks:

"Most of all, listen, listen, listen, listen to what the person with the mental illness is telling you about the medication. It is their feelings. It is their experience that really needs to be heard."

Clinicians also emphasised the importance of respectful listening and consultation. One clinician from an aged care setting said:

"We can make medications part of the solution rather than the problem by having meaningful discussions with consumers about medications before they are prescribed (and addressing any underlying concerns)."

When these steps are not taken, he said, consumers might wind up being charged with 'non-compliance' – *"a dreadful word best used for totalitarian regimes not modern health care."*

Perceptions about the efficacy of particular medications and the severity of side effects can vary between consumers and clinicians. Some consumers feel the views of clinicians take precedence over their own.

One consumer described her experience:

"It's hard when professionals are telling you that you are better on some medication but you personally don't feel like you are. I was given [an antipsychotic medication] and it made me completely manic, but apparently I was better according to the psychiatrist. I stopped taking it as soon as I left hospital..."

"Most of all, listen, listen, listen, listen to what the person with the mental illness is telling you about the medication."

Another consumer who had a poor experience with a number of medications said:

“Treating doctors appeared not to believe what I was telling them and consequently not only lost interest in me but were openly critical about my personality and blamed me for what was occurring.

“There is no universal response to medication and consumers are often very aware of what is happening. As a consumer I felt demeaned, powerless and desperate to feel better when none of the drugs helped at all and I was made to feel at fault.”

Another consumer said:

“Doctors minimise the side effects of medication. They say that people are lying or exaggerating their symptoms. They don’t see the struggle people go through ... they think it’s good and it is helping clients.”

In its submission, the NSW Official Visitors Program¹⁵ said disregard for consumer experiences and stigmatisation of mental illness are demonstrated in in-patient settings when treatable side effects are ignored:

“Patients with a dry mouth or excessive salivation can receive treatment to reduce the side effects or the impact on the patient. This is routinely done for cancer patients with a dry mouth but the OV’s do not see this occurring routinely for consumers.”

Good practice: Deprescribing

People want to be involved in discussions about the possibility of withdrawing from medication or ceasing a regime altogether if symptoms are now controlled.

Contemporary medication guidelines are mostly focused on starting treatments rather than withdrawing from them. There is, however, a promising push to develop an evidence base for ‘deprescribing’. This is where the skill and diligence of the prescriber identifies side effects or a lack of efficacy and under supervision a withdrawal from medication can take place.

Challenges of cross-cultural communication

One person who attended a CALD focus group mentioned a young consumer with mental illness whose mother would not allow her to take Western medicine. The mother viewed Western medicine as “poison” and would allow the daughter to use only traditional medicine from her country of origin. This proved highly ineffective.

Another person said clinicians might benefit from knowing more about the diverse range of cultures represented in NSW, including their sensitivities and strengths. This person also noted that Australian clinicians can seem very pragmatic and impersonal:

“They work automatically, not with their heart and compassion. They try to hurry you up. They are rushing you and you feel embarrassed.”

The Transcultural Mental Health Centre also reports that people from CALD communities who also experience mental illness may be less likely to follow medication regimes. A complex range of cultural and linguistic factors leads to stopping medication: altering the dosage/frequency; use of potent herbal medicine at the same time as prescription medication; and the sharing of medication between people who appear to have similar symptoms.

Stigma and prejudice experienced by people from CALD backgrounds

The Transcultural Mental Health Centre said stigma affects the way people from CALD communities use medication:

“Fear of social isolation associated with stigma towards mental illness and taking medications such as antidepressants can discourage people from seeking help to begin with. This can result in delays in diagnosis, increased severity of symptoms and reluctance to take medication once diagnosed.”

Several people who attended the Commission’s CALD focus groups also said mental illness and medications were highly stigmatised in their cultures, and this results in secrecy and suffering for carers and consumers:

“In Chinese culture there is stigma. Children don’t want to seek help. [Mental illness is viewed as] our family business.”

Another person said men from some backgrounds were particularly embarrassed about the effects medications could have on sexual function and found it hard to broach this subject with doctors. This person suggested culturally-based men’s support groups were a possible solution.

One carer described the good fortune of discovering a culturally sensitive liaison officer at TAFE NSW:

“My daughter feels such embarrassment. She kept dropping out of TAFE. Then we learnt there is a liaison officer who is discreet. It encouraged her to seek help.”

Stigma, it was noted, can also interfere when a translator is available, particularly for older consumers and carers.

“Fear of social isolation associated with stigma toward mental illness and taking medications such as antidepressants can discourage people from seeking help to begin with.”

One participant said:

“There is a lot of suffering for older people. They do not feel confident with the translator as they do not know them. There is too much stigma in the community.”

Several people from CALD backgrounds, both carers and consumers, said they had difficulty asserting themselves and asking questions about medication. Several reported being ignored. One consumer explained:

“My mother was my carer. She sat next to me. No one ever spoke to her. It was like she was invisible ... it’s a lack of respect.”

Inpatient experiences

Informed consent is a particularly fraught issue in inpatient settings, and consumers reported that in hospital it can be a struggle to be heard.

One consumer who has been hospitalised a number of times said:

“I believe that taking medication should be on a voluntary basis and all treatment should be on a voluntary basis. When you are in hospital you don’t really have much of a choice. If you don’t take the medication, they make you take it against your will and if you fight, then they think this is part of your ‘mental illness’.”

Disregard for patient experiences of medication, the presumption that all unwanted consumer behaviour is a reflection of mental illness and administering medication as the first response, were also noted by the Official Visitors Program:

“The opinions and preferences of the consumer are often ignored and rejected, and their views attributed to ‘part of the illness’ ...deterioration in a person’s condition that leads to an admission is frequently assumed to be due to “non-compliance” with prescribed medication. Consumers will report to OVs that significant life events and stressors preceded their admission and non-compliance is not the major factor (or sometimes any factor) in their deterioration.”

One young consumer with enduring mental illness reported feeling traumatised by the forcible administration of antipsychotic medication via injection while she was an inpatient. She recalled being held down and having clothing removed:

“...my arms and body would also be so heavy from the sedation, I would be unable to move, and therefore completely disempowered and vulnerable and in terror ... ”

“[These experiences] only increased my distress and paranoia and fear of hospitals and medication... and became a further barrier to seeking help long term ... my arms and body would also be so heavy from the sedation, I would be unable to move, and therefore completely disempowered and vulnerable and in terror...”

This consumer underlined the importance of respectfully informing consumers about what is happening, even when they are experiencing acute psychosis and even if informed consent is not possible at the time. Sometimes, she said, consumers experiencing psychosis understand more than they appear to and being informed about what is happening can help to make the experience of forced treatment less distressing when you're *"piecing it together later... because you can recall being informed."*

Some consumers and carers have questioned the right of in-patient mental health services to administer psychotropic medication without informed consent.

A carer of many decades said:

[When consumers with mental illness are] "incarcerated in locked public hospital wards, the treating team can apply any medications they please without consent from either the patient or the patient's family and advocates. Given the dubious outcomes of many polypharmacy regimes, this legal nightmare is a serious violation of an ill person's human rights. It is particularly confronting for carers and family."

Older people, information and consent

ARAFMI NSW's OP Committee reports that older carers and consumers may be reluctant to challenge medical staff or to be assertive about requesting information. In some instances this may be because their generation viewed medical professionals as all-knowing authorities. Importantly, consumers also fear loss of autonomy if they lay out their concerns in full to a doctor or challenge medical authority.

Informed consent for older consumers can also be fraught. Carers, the OP Committee noted, do not always act in the best interests of consumers. Sometimes family tensions influence decision-making and consent, and this can be difficult for non-family members to discern.

Carers' experiences

Carers can play a vital role when it comes to the safe and effective use of medication. In their submissions carers explained their involvement in making and keeping track of medical appointments, transportation for consumers, buying medication, supervising its use, and monitoring its effects. Carers NSW said they might face particular challenges in doing so:

"Carers are often keen to reiterate their respect for consumers' autonomy, empowerment and right to privacy and confidentiality but they also report frustration when they are excluded."

The mother of a young boy with mental illness who has been heavily medicated said:

"Carers are not listened to or respected when they say the meds are not working or to please stop them. They are made to feel stupid or interfering as this is not the carer's area of expertise."

Carers NSW also reported that:

“Carers’ health and wellbeing is often challenged by having to understand and perform tasks relating to managing medicines [for consumers] and may be particularly challenged by difficult negotiations with health professionals. Carers NSW asserts that this stress can be minimised through appropriate recognition and inclusion of carers.”

Good practice: Top 5 model

TOP 5 model Central Coast Local Health District and Clinical Excellence Commission

TOP 5 is a model that encourages health professionals to engage with carers to gain non-clinical information to personalise the care provided. It is used for consumers with dementia and other types of cognitive impairment in hospital settings. The information provided by carers is documented on a TOP 5 form and made available to every member of the care team to improve communication between the consumer, the carer and the team. The consumer’s care can then be personalised using agreed strategies, which aim to lessen anxiety, distress and provide a safer environment.

This partnership approach to care has in one hospital brought a 68 per cent reduction a month in the average cost of anti-psychotic medications¹⁶.

Young people’s experiences

Children and young people can be particularly susceptible to feeling shame. At a time when fitting in is important the stigma that surrounds mental illness, including the medications used to treat it, can bite particularly hard. Several submissions from young consumers described being bullied. One said:

“I have had to deal with people calling [my medication] my crazy pills etc. and being told maybe I need to take my meds if I’m upset about something. I think a huge problem I had was being afraid of [being judged for] having to take medications...”

Another reported that while on a high school camp a teacher had brought her medication to her while she was with her peers. They then questioned her and she felt judged:

“I feel like [taking medication to treat mental illness] makes me stereotyped. People judge you as soon as they know you’re on medication.”

Pharmacy and privacy

Community pharmacies are located where people live and work, and at times they can be the most frequently visited medical service for people with a mental illness. However people also told of the challenges this presents.

“Everyone knows everyone else, especially in [rural CALD] communities. If you go to the chemist, they know.”

A consumer now in her 40s said:

“I am not worried about this now, but as a young person I found it confronting to fill scripts. It was a reminder that I had the illness. [I was] concerned about the pharmacists and assistants knowing my secret, judging me and how I acted in the pharmacy; concerned that someone I knew might see me filling my scripts.”

“[I was] concerned about the pharmacists and assistants knowing my secret, judging me and how I acted...”

A young consumer said:

“My biggest problem is the constant judgement and condescension from pharmacy workers dealing with my script. It is a constant battle and usually now my mum gets my script for me because I can’t handle the treatment ... by pharmacists.”

A pharmacist in rural NSW highlighted the importance of privacy and good communication. He noted that while the physical layout of a pharmacy - including the availability of private spaces - could play a vital role, professional, understanding staff who are nuanced communicators and sensitive to the unspoken word are equally important in making consumers and carers feel comfortable.

Towards change

People told the Commission:

- rather than being demonised, medication - for those who choose to take it - should be seen as a potentially effective treatment to help people achieve their goals
- that consumers who take medication know better than anyone else what it feels like; clinicians should take the time to ask about the effect of medication and take seriously any issues raised
- when the use of medication is involuntary its administration must adhere to the principles of care and treatment in the NSW Mental Health Act and the views of the person should still be taken into account
- carers can help in informing consumers and supporting medication regimes, and play a critical role in recovery
- pharmacists can be partners in the safe and effective use of medication.

Medication costs

Financial assistance

Many consumers were grateful for the Pharmaceutical Benefits Scheme and the Health Care Card. A significant number also made more qualified comments, typically that the costs of medications are manageable or reasonable but that they compound over time, particularly with severe and enduring mental illness and where the side effects of psychotropic medications lead to more prescriptions for additional illnesses.

Some consumers find medication expensive or even exorbitant:

“It is quite costly and not something I have a choice about taking. If I don’t take it I will become very unwell and therefore I think it should be a lot cheaper, if not free.”

A number of employed consumers ineligible for a Health Care Card said they found the cost of medication challenging, either because they were not earning a great deal or were intermittently unable to work because of the relapse in their illness.

A consumer who has been taking a number of medications for bipolar disorder for 20 years said:

“The cost is a big issue. I am not on a Health Care Card but my illness has affected my capacity to work and at times I have left scripts unfilled because I need to wait for the next pay day.”

Indirect costs and fees

The indirect costs associated with psychotropic medications, such as psychiatrist fees and blood tests, plus non-pharmacological therapies, came up repeatedly as the most expensive aspects of managing mental illness.

Another carer explained:

“It’s not so much the medications themselves that are expensive, but the practitioner fees and associated psychological services.”

A consumer who also cares for an elderly parent with a mental illness said:

“It’s too expensive if you need to take a variety of medications. Even if you are working full time it can be hundreds each month with psychiatrist, psychologist and medications ...”

A number of consumers mentioned the time and inconvenience involved with managing a long-term medication regime. Several using lithium mentioned the need for regular blood tests, appointments and referrals - all with time and costs attached.

One consumer said:

“Blood tests can cost hundreds of dollars each and lithium is \$20 for a small bottle which runs out very quickly.”

Some consumers and carers with stable, ongoing relationships with a psychiatrist were frustrated by the need to obtain new referrals from a GP. They also would like more repeats on a single prescription:

"[Medication] gave me back my son ... and kept my family from disintegrating," said the mother of a school age boy with a mental illness. However, she added, getting that help required *"jumping through so many [administrative] hoops"* including sitting on waiting lists to obtain referrals and lots of paperwork.

A rural consumer called for more psychiatrists to bulk bill:

"There is one bulk-billing service where I live, without it I would be lost."

The Pharmaceutical Benefits Scheme and psychotropic medication

A significant number of submissions from consumers, carers and clinicians concern the cost of effective psychotropic medications that do not qualify for a subsidy under the PBS or do not attract the subsidy in particular circumstances. A carer said:

"[The cost of non-PBS medications] can be enormous, which is prohibitive if, like my brother, you are on a pension. This may mean some people cannot take the best drug for them which would limit their outcomes."

A number of clinicians were concerned that the PBS was not keeping up with the medications available. One said:

"The PBS listings do not equate with the evidence base. Some medications are either not listed or are listed for limited conditions only, despite a literature base for their efficacy."

Off-label concerns¹⁷

Medical authorities including the Pharmaceutical Benefits Advisory Committee have raised concerns about off-label prescribing of quetiapine¹⁸ for mental illness that does not involve psychosis, but consumers who do not have psychosis report that they benefit from it.

One consumer who has been given a prescription for quetiapine though she does not technically qualify for it, says the drug mitigated her insomnia. But she is concerned about the potential health consequences of using an off label drug.

Another consumer said:

"While quetiapine has, temporarily at least, mitigated my [symptoms], this has come at a price. I am concerned by the fact that I have been prescribed an 'off-label' medication for my mental health because I don't know what the long-term efficacy or impact of this will be - especially given the weight gain I have experienced."

Other consumers who have been prescribed psychotropic medication off label expressed concern about the lack of information or research into the longer-term effects of those choices, even if the medication was proving helpful in managing their illness.

Good practice: Pharmaceutical Benefits Scheme Co-payment Measure

The Australian government has recognised that the cost of medication is a significant barrier to improving access to medication for Aboriginal and Torres Strait Islander people. For this reason the government introduced the Close the Gap PBS Co-Payment Measure in July 2010. It improves access to PBS medicines for eligible Aboriginal and Torres Strait Islander people who are living with, or at risk of, chronic disease. Closing the Gap prescriptions require a lower or nil patient co-payment for PBS medicines.

Questionable diagnosis and the PBS

There is concern about clinicians labelling consumers with questionable diagnoses so they can access PBS-subsidised antipsychotic medication for which they would not otherwise qualify.

This practice is viewed in several ways: as a reasonable response to the inadequacies of the PBS; as fraudulent; as concerning because a diagnosis of a psychotic illness is a serious label for a consumer to have on his or her medical records; or concerning because a false diagnosis can lead to inappropriate treatment paths.

A nurse who works in an emergency department noted that clinicians increasingly seem to label consumers with psychotic illness or schizophrenia when they are experiencing substance intoxication or withdrawal, so they can obtain the PBS subsidy for antipsychotic medications to ease their symptoms:

"I feel that people with substance dependence disorder should be able to access PBS-funded antipsychotic medication without having to be given a bogus diagnosis of psychotic illness. Providing them with safer means to 'come down' from a drug is safer not only for them but also the community. Behaviour during amphetamine/methamphetamine withdrawal can be violent."

Overall, she said, expanding the PBS cover to other conditions might:

"Reduce inappropriate diagnosis of psychotic illness, benefitting mental health care provision, planning and formulation while also reducing the impact of labelling/stigma for clients falsely diagnosed."

“[It might also] reduce black market distribution of antipsychotic medications and dangerous misuse of antipsychotic medication which is not under the observation of medical professionals.”

Towards change

People told the Commission:

- clinicians should engage in discussions about the costs of medication with consumers and carers and this information should be considered in decisions about treatment options
- discussions between clinicians and consumers or their carers should take account of the many indirect costs, both financial and in time, associated with a medication
- clinicians should be supported with alternatives to off-label prescribing, such as non-pharmacological treatments that have a good evidence base and safety records
- consumers should be told if a prescription is off-label, and why their medication is being prescribed this way - and asked if they consent to this.

Medication side effects

Medication causes side effects

The overwhelming majority of submissions raised concerns about the unwanted side effects of psychotropic medications. The responses from consumers and carers in particular were often passionately expressed and painted a disturbing picture of how side effects could adversely affect the quality of people's lives, even if the symptoms of mental illness improved.

One consumer said:

"Dribbling, lethargy, massive weight gain and depression are just some of the dehumanising side effects of antipsychotic medications. The mania may be bought under control short term, but in my experience they did little to treat the illness long term."

Another consumer, who said it took almost a decade to find the right balance of antipsychotics, antidepressants and mood stabilisers to treat her complex mental illness, reported that the various regimes she has followed have left her with tardive dyskinesia, Type 2 diabetes, high cholesterol and uric acid levels, tooth damage as a result of grinding, and high blood pressure:

"Medication saved my life, but at the worst of my illness I was taking 32 tablets a day because I needed to be on other medications to [treat] conditions caused by mental health medications."

Excess saliva production, a side effect of clozapine, was raised repeatedly. Consumers reported finding it humiliating and disruptive, particularly at night. A consumer from the Elouera rehabilitation unit at the Forensic Hospital wrote:

"I do suffer from the side effects from clozapine. These include sweating and excess saliva at night. The effect is that I wake up throughout the night."

Another said:

"Some side effects could be really severe. With my antidepressants, the side effects were bad, but manageable. However, with my antipsychotic medication the side effects were really severe. I gained a lot of weight, which I lost later. Sedation was a big part as well. It affected me a lot. I was sleeping 20 hours per day. I couldn't function."

"I gained a lot of weight... Sedation was a big part as well. It affected me a lot. I was sleeping 20 hours per day. I couldn't function."

"However, I am aware that some people prefer medication and then, if it is the right dose, at the right time, and supported with the right psychological counselling, it could be beneficial."

Balancing the treatment and the illness

Side effects clearly contribute to consumer reluctance to take medication, particularly long term. Quite a few consumers found the side effects overwhelming and intolerable, and stopped taking it, sometimes with dire consequences. Occasionally individuals have damaged important relationships and caused harm to themselves and others during periods without medication.

The mother of a young man prescribed medication for bipolar disorder, described the pain of seeing her fit, active son subsumed by lethargy and looking “*like a stroke victim*”. The 17-year-old gained 25 kilograms in three months, she said, which was hugely distressing for him. He goes on and off his medication to escape the side effects and this has resulted in a number of traumatic episodes of mania, hospitalisations and encounters with law enforcement.

Other consumers said they found the unwanted effects of psychotropic medication unpleasant and distressing, but felt they had no choice. They felt stuck between two unpalatable options.

One said:

“[Medication] has saved me from the deep deep depression where the best option seems to be non-existent. However medication has helped me become overweight, my thinking is dulled, it has changed my personality... to being someone who just feels flat. I feel... slower and as though I live in a different reality to others.”

“...medication has helped me become overweight, my thinking is dulled, it has changed my personality...to being someone who just feels flat.”

A consumer with bipolar disorder said it took several years for him to accept that he needed to keep taking medication to stay well:

“The initial side effects of lithium are unpleasant: nausea, upset tummy and pain and a general feeling of being unwell. Once the initial side effects pass, the ongoing side effects for me are hand tremors, [problems with] co-ordination and balance, thirst, frequent urination and weight gain.”

Weight gain and metabolic syndrome

The issue of significant weight gain arises repeatedly in the submissions, most commonly associated with particular antidepressant and antipsychotic agents.

Consumers, carers, and clinicians variously describe the distress that gaining 10, 20, 30 or more kilograms can cause. In a society that fears and scorns both obesity and mental illness, weight gain can damage self-confidence and self-esteem. Additionally, weight gain brings significant increase in risks for physical health such as Type 2 diabetes, heart disease, and high blood pressure.

A consumer said:

"The guaranteed, unavoidable weight gain is the most depressing part of the treatment for [psychotic illness]. And the realisation that even though the symptoms of mania may be under control, you will probably die an early death from the effects of the cure, through heart attack, stroke, diabetes, kidney failure and thyroid disease. I have been perplexed by psychiatrists playing down of these dangers."

Another said:

"After I left hospital my self-esteem was very low due to stigma to do with my mental illness but also to do with weight gain."

"...the realisation that even though the symptoms of mania may be under control, you will probably die an early death from the effects of the cure..."

A number of consumers felt they were not adequately informed about the likelihood of weight gain with the medication they were prescribed. One woman said:

"Had I known that [antipsychotic medication] has massive weight gain and metabolic syndrome as a side effect, I would never have taken them. The hell I live in now because of my size ... is not worth it."

Some consumers say that when they have raised the issue of weight gain with clinicians, it has been dismissed, and has usually been overshadowed by a focus on containing the symptoms of their mental illness.

A consumer said:

"I have seen a terrific psychiatrist for three years ... she was the first health professional who [made helpful suggestions] when I said I was worried about weight gain. Mostly they just nodded sympathetically and told me to take them regardless of [my] concerns."

A number of clinicians raised concerns about medication-related weight gain among their patients. One said it was very difficult to find appropriate, public health services to which they could refer consumers for advice on diet, exercise, weight loss and lifestyle management.

"[There is a need for more] programs in the community for managing side effects such as metabolic syndrome. I can access exercise physiologists and dietitians for people while they are in hospital but [in the community] these services are either not available, involve a cost, even with GP mental health plans, or are not catering to those with mental illness."

Good practice: preventing premature deaths

Preventing premature deaths of people living with severe mental illness is possible but it requires a concerted effort to ensure that both the physical and mental health of the person is treated and monitored. NSW has two examples of innovative practice in this regard.

Collaborative Centre for Cardio metabolic Health in Psychosis

This is the work of Professor Tim Lambert and his team at ccChip, the Collaborative Centre for Cardio metabolic Health in Psychosis, in the Sydney Local Health District. The team focuses on the physical health needs of people with severe and persistent mental illness. This work is directly supported by the local health district chief executive who has established a multidisciplinary mental health /physical health clinical committee which she chairs.

Keeping the Body in Mind

This is the work of Dr Jackie Curtis and her team at Bondi Junction in eastern Sydney, working with young people who experience first episode psychosis. They are committed to ensuring that a young person who experiences a first episode of psychosis will never develop metabolic syndrome. This program is supported by the South Eastern Sydney Local Health District and rolled out across the whole district. This ground-breaking work has led to the HeAL (Healthy Active Lives) declaration, which has now been adopted in Britain and many other countries.

Genetic factors

The Transcultural Mental Health Centre said genetics influenced the way psychotropic medications were metabolised and that medical professionals are not always aware of these differences. Genetics can cause a medication to accumulate in the body which results in toxicity. Or the opposite can happen where a medication is metabolised so quickly it doesn't have the chance to become effective.

One carer described her daughter as having been *"an intelligent person who loved learning and a successful sportswoman"*. After an adverse reaction to medication due to a genetic deficiency she described her as *"...requiring 24/7 care."*

The daughter has a CYP450 deficiency. The CYP450 enzymes are responsible for metabolising most psychotropic medications, and, where a CYP450 deficiency exists and psychotropic medications are prescribed, toxicity can occur. This can have anything from mild to devastating consequences.

The carer said:

“cruel health outcomes now dominate my daughter and my life.” She asks that “the NSW mental health system adequately flag medical records to accept that some drugs are toxic for some people.”

Heavy sedation

The term “zombie” was used frequently to describe either one’s self or a loved one taking antipsychotic medication.

One carer wrote:

“My 22-year old son has had 9 different medications in 5 years. Each medication brings side effects to the point of his being unable to function daily because of lethargy... I have seen an otherwise healthy young man shuffle as if he were old. He sleeps for hours daily, is unable to work or study... He turns into a zombie, stops all daily activity and has no emotion or expression.”

One consumer in her early 20s, who has been hospitalised several times, said the medication she was prescribed left her:

“just a shambling shell, existing, and unable to read, write or concentrate or really function at all other than to sleep. While I was no longer disorganised, paranoid, catatonic or experiencing psychotic symptoms, I was rendered completely, hopelessly dependent on my parents and family, and had no real autonomy ... I would rather be a person than a zombie ...”

“While I was no longer disorganised, paranoid, catatonic or experiencing psychotic symptoms, I was rendered completely, hopelessly dependent on my parents and family, and had no real autonomy...”

The same woman has also experienced weight gain, weight loss, hair loss, facial spasms, jaw hanging open, bleeding gums, headaches, nausea, light sensitivity, dry mouth and tremors.

Sexual health

Sexual dysfunction can be a side effect of psychotropic medications. A mental health nurse working in an acute mental health facility, said sexuality was taboo in the mental health arena or viewed as trivial compared to the symptoms of mental illness. People are embarrassed to talk about sexual health, but it is important, he said. Others may be too unwell during a hospital stay to raise the issue:

“A significant percentage of the male clients between 18 and 35 that I have worked with have stopped taking prescribed medications or refuse to comply with a depot¹⁹ simply because it affects their sexual performance. This can range from total erectile dysfunction to being unable to ejaculate. This has a cascading effect on many aspects of a client’s life, affecting their self-image, relationships and quality of life...”

Female consumers, he said:

“voice concerns about antipsychotic medications interrupting their menstrual cycle [which raises] questions in their minds about being able to have children in the future.”

Trial and error

Among the submissions are reports of individuals enduring months and years of debilitating side effects, mood shifts and ongoing illness while trialling different types and doses of medications. Some consumers have felt alone and afraid, sent home with a prescription to “see how it goes”. Some still have not found the right balance and continue to suffer. Some do not believe the right combination exists and have no faith in medication. A consumer explains:

“It took about two years to get the mix right for my bipolar medication as it is not just a matter of taking one medication. Some medications didn’t work, some were too sedating, some put on too much weight, some caused an allergic response. Once my doctor got it right, my mood has been stable. Before this I was see-sawing between hypomania and deep depression. It was making a mess of my life.”

“Once my doctor got it right, my mood has been stable. Before this I was see-sawing between hypomania and deep depression.”

Several consumers also pointed out how challenging it can be to hold down a job while trialling new medication and experiencing the mood shifts, loss of concentration and anxiety that can come with the process.

A consumer diagnosed with bipolar disorder, who has also withdrawn himself from all medications, said:

“The biggest challenge is that you have no idea if its working and most doctors freely admit there are no guarantees you are on the right medication as even diagnosing most conditions takes years.

“There is no real way to improve the treatment of mental illness using medication. It has far too many side effects and rarely does much good. Yet it is convenient, highly profitable and suits the delivery method of doctors.”

One consumer with severe and complex mental illness, including an eating disorder, wished she had had much more support while trialling new medication as she felt she was a danger to herself and to others:

“I was placed on a multitude of various medications and I was suffering all sorts of side effects... I do not believe these changes of medications should have been done in the community ... I was unsafe to be driving. I was suicidal and self-harming. By the end of the year I had a huge variety of leftover pills from the false trials on meds, and I took an overdose... ”

Diagnosis

The prevalence of trial and error in medications may also reflect challenges and uncertainty in diagnosis. A consumer said:

"I was diagnosed with having a mental illness in 1998 [but] I was not correctly diagnosed until 2004. I was basically a guinea pig during that time, trying various medications, and suffering all their side effects."

Another consumer said her negative experiences of medication related to:

"...years of misdiagnoses and therefore inappropriate medication for years until I was finally diagnosed with a severe dissociative disorder about 10 years ago and even then I was prescribed all types of medication which had limited effect."

One clinician explained the challenges of treating mental illness in general practice, noting that:

"To use any medication well you need to have a good idea of what you are treating. Assessing mental health symptoms thoroughly is time consuming and requires good communication skills, and time particularly is often at a premium in general practice. As such, many patients with low mood may be diagnosed with depression and treated with an antidepressant when they may have some other species of low mood, such as bipolar disorder or borderline personality disorder."

"I was diagnosed with having a mental illness in 1998 [but] I was not correctly diagnosed until 2004. I was basically a guinea pig during that time, trying various medications, and suffering all their side effects."

Withdrawal

Finding the right antidepressant has been a challenge for many consumers, a process that can involve a great deal of trial and error plus the need for wash-out periods between different types. One said:

"I had a terrible time with mood and anxiety while trying to find something else that worked. It was extremely difficult to get off. It took six months and almost made me psychotic. I would never recommend it to anyone unless it was a last resort."

Another said:

"It is laborious finding the 'right' medication. Meanwhile, suffering continues. There is no support for the horrific side effects of stopping antidepressants. As part of their training, all psychiatrists should wean themselves off antidepressants to understand the agonising severity of the process."

A consumer with bipolar disorder, who has tried a range of medications in the past 20 years, said:

“Withdrawal from SSRIs is horrendous. I have had to take time off work or work at very low capacity to do this. Effects (severe anxiety and brain zaps) last for months.”

The carer experience

Some carers reported feeling uninformed and shut out, even though they were carrying the responsibility for administering the medications and supporting consumers day-to-day.

One said:

“Medication is very hit and miss. The trial and error to see what works best is frustrating and as a carer is even more frustrating when doctors won’t speak to you to discuss medication and medication changes.”

In its submission Carers NSW said:

“It is clear that outcomes of using medication as a treatment for mental illness impact the quality of life of carers as well as consumers. This impact can be brought into particularly sharp relief when medication is mismanaged, or when consumers cease or change their medication regime.

“Carers deal with the fallout of medication changes” [and their own] “health and wellbeing may be directly compromised.”

Scientific research and young people

A number of submissions raised concerns about the lack of scientific research into the long-term use of psychotropic medications, particularly for young people and children. According to one:

“Some [children] are diagnosed as bipolar disorder – with very little scientific basis for such a diagnosis in childhood – and then they are prescribed powerful medications such as antipsychotics.”

A number of carers and health care workers noted that children and young people seemed to be subject to a great deal of traumatic trial and error with medications because the evidence base for their use in this age group is limited. A psychiatrist noted that diagnosis in young people can be challenging because normal developmental stages and behavioural issues can be hard to distinguish from symptoms of mental illness.

This psychiatrist said:

“Children [are] medicated for so called ADHD [attention deficit hyperactivity disorder] when the diagnosis is not well established and other causes of hyperactivity such as anxiety and abuse have not been excluded.”

Towards change

People told the Commission:

- it is an urgent challenge that people living with severe mental illness die 15 to 25 years earlier than the rest of the population
- a balance needs to be achieved between managing the symptoms of mental illness and protecting overall physical health, via the careful monitoring and managing of medication
- side effects must be part of up front discussions about treatment options between clinicians, consumers and carers
- side effects of medication for mental illness must not be viewed by prescribers as normal, or an expected part of the treatment
- medication for mental illness can affect sexual function - normalising discussion about sexual health and these side effects will help alleviate unnecessary shame.

Medication supported my recovery

Many submissions recounted positive experiences of innovative practice and support. These include relief from distressing symptoms which enabled a return to work, study, and family life, and interactions with highly capable, sensitive, and compassionate clinicians.

One consumer said:

"I have improved my health where I can work part time. Without the 'magic' of tablets I would still be a serious wreck".

There is much gratitude in the community for the Pharmaceutical Benefits Scheme and the Disability Support Pension, and the way they assist timely, reliable and affordable access to medication:

"I am on a Disability Support Pension. Without this the financial cost would seriously impact other areas of my family life. I have always appreciated that I live in a country with a great social safety net."

Many submissions include high praise for organisations and clinicians who take a holistic approach to mental illness.

One consumer said:

"I had depression and it was only after several discussions with my GP that we both decided it was best for me to have medication as well as a referral for counselling and a learning program for me to understand mental wellbeing, mindfulness and other self-help support groups".

A consumer explained the positive effect of medication in combination with non-pharmacological approaches:

"I can survive as a person. It [medication] helps me to live a normal life... Taking medication for your mental illness is only one thing to keep you well. There are also other factors to keep you well, eating healthy, sleeping well, exercise, keeping active, knowing about your triggers, the supports you have and family."

Several consumers said they owed their lives to medication:

"Without medication, I simply wouldn't be here. Medication enables me to live a steady, stable life without severe shifts in moods, without the constant rumination... and without the constant paranoia that people are out to get me. [Medication] has turned my world around, I wish I had been able to be helped 40 years ago."

"Medication enables me to live a steady, stable life without severe shifts in moods, without the constant paranoia that people are out to get me."

A young woman living with mental illness, who is in her honours year at university, described the important role medication plays in her life:

"...my ability to [study] is crucially assisted by my current medications which are the best combination I have yet experienced in treating my symptoms and disorders."

The Commission was told that some positive experiences with medication help to reduce stigma and encourage people to seek help sooner rather than later. A woman whose illness improved with the use of an antidepressant said that by drawing on that positive experience, she was able to act quickly when another episode of depression emerged for her some years later. The same consumer said she worked to alleviate people's negative views of medication by openly and honestly sharing her own experiences.

Another consumer who has found antidepressant medication effective said:

"It has aided me with facing my day-to-day life and helped me deal with problems I may face. I feel less overwhelmed. I have suffered depression for over a decade and wish I had sorted out this treatment sooner."

"...I feel less overwhelmed. I have suffered depression for over a decade and wish I had sorted out this treatment sooner."

Some consumers reported that their medication regimes had been tailored to suit their changing needs over time and that this has provided a sense of autonomy and control.

Clinicians also described the benefits of psychotropic medication for consumers and carers. One doctor said that in her experience, medication could help resolve derogatory internal voices, improve people's capacity to function and, importantly, help them reconnect with their families and friends.

Another clinician said:

"I strongly believe medication remains an essential tool in managing mental health problems in general practice, and is often used extremely skilfully and with tremendous benefit."

One young Aboriginal consumer who had a positive experience with medication expressed his gratitude for the Closing the Gap initiative. He said it had helped him find community support to take his medication consistently, eliminated the burden of cost and supported him to get on with building a contributing life:

"My voices have gone and I feel great."

Many of the young people who provided submissions also reported positive outcomes:

"My personal experience on medication has helped me through my school journey."

"I've found it a sort of good experience in its helped me with getting a lot of stuff in my life back together."

Carers NSW described a family from Iraq as an example of how including carers could facilitate positive outcomes:

“Yasmin (not her real name) has a diagnosis of schizophrenia and her daughter is her primary carer. The family are Iraqi refugees and are a close unit. They travel together to see Yasmin’s Arabic-speaking psychiatrist, who practises out of their local area. The family are not confident using public transport, so Yasmin’s son takes time off work to drive the family to see the psychiatrist. They have had difficulty finding the right medication for Yasmin as [her other] health conditions make side effects of medication, such as weight gain, very problematic.

“The psychiatrist understands the importance of including the whole family, and consults separately with mum and the family to gauge how medications are working and to get the full picture of what is going on at home. They continue to work collaboratively to find the right medication for Yasmin.”

One young woman who feels she still has some way to go in her recovery said:

“I have felt a significant difference in my mental health... My family and friends have noted an improvement in me overall, too, so I’ve kept on the medications. I feel a lot more positive in my approach to life. I no longer have suicidal thoughts and experience less anxiety... I’m less moody with my partner and son, which is appreciated.”

“I have felt a significant difference in my mental health ...My family and friends have noted an improvement in me overall, too, so I’ve kept on the medications.”

Another said:

“I think I’m one of the lucky ones who have had a good experience with medication. I found the right medication straight up.”

A young person who reported a rough time finding the right medication and who been bullied at school, said she felt her decision to take medication was right for her:

“Ultimately it is the most effective way for me to take care of myself.”

A consumer from a culturally and linguistically diverse (CALD) community said:

“I think we are lucky to have access to this medication..., we don’t have to suffer with nothing to help us. We just need to make peace with our medication.”

Towards change

People told the Commission:

- the best first line response to mental illness is prevention, through self-help, building resilience, and achieving wellbeing.
- most people find medication to be most useful when combined with non-pharmacological supports, alongside these interventions housing, employment and education requirements should be considered
- prescribing must take account of variables such as age, side effects, other medications, cost, genetic heritage, and lifestyle
- medication outcomes are improved when consumers are directly involved in designing their care
- the monitoring and review of medications is important.

The challenge to change

The Commission undertook this work with a view to hearing from all stakeholders: consumers, carers and the clinicians who support them. In particular the Commission is guided by the lived experience of mental illness and sought to elevate the voice of consumers and carers, and this voice has posed a challenge to the mental health system that it is time for change.

Some of the change that people have called for will not be easy. However some of the change is simpler and can be implemented with immediacy. These are the changes which are not costly or time-consuming, they are in line with current mental health standards and quality use of medicines indicators. They are the changes that consumers and carers have called for with particular fervour, they ask for the mental health system to treat people with respect and compassion, and they are listed here for your serious consideration.

Consumers and carers are asking for:

- **their views to be taken seriously**
- **the potential side effects of medication to be explained to them**
- **involvement in decisions about their treatment**
- **all possible treatment options to be explained to them**
- **the prescription pad not to be reached for too readily**
- **time to spend with members of the treatment team to have meaningful discussions about medications**
- **prescribing decisions to take account of personal lifestyle and recovery goals**
- **conversations about medication regimes to be regular and involve the possibility of safely reducing or ceasing.**

The Commission will use the voices in this paper as it engages with industry and the peak and professional bodies in the mental health sector, to show them that change is necessary.

The Commission will continue to draw on the expert guidance of its Pharmacotherapy in Mental Health Advisory Group in responding to the challenges and opportunities presented by the use of medication to treat mental illness.

This paper will be provided to the NSW Government and the Minister for Mental Health to assist in mental health reform.

Through monitoring, reporting, reviewing, and knowledge sharing, the Commission will advocate for systems of support that respect people, provide choice, and are of the highest quality.

Endnotes

- ¹ Roughead L. Presentation to Safety and Quality Partnership Standing Committee. 11 July 2014. (As cited in National Mental Health Commission (2014): The National Review of Mental Health Programmes and Services. Sydney: National Mental Health Commission).
- ² OECD (2011). Health at a Glance 2011: OECD Indicators, OECD Publishing. http://dx.doi.org/10.1787/health_glance-2011-en
- ³ Australian Bureau of Statistics (2014). Characteristics of people using mental health services and prescription medication, 2011. cat. no. 4329.0. Canberra, Australian Bureau of Statistics.
- ⁴ Karanges EA, Stephenson, CP & McGregor IS (2014). Longitudinal trends in the dispensing of psychotropic medications in Australia from 2009–2012: Focus on children, adolescents and prescriber specialty, Australian and New Zealand Journal Psychiatry, June 13, 2014.
- ⁵ National Mental Health Commission (2015). Fact Sheet 11. What this means for medications management. Sydney, National Mental Health Commission.
- ⁶ Department of Human Services (2015). Pharmaceutical Benefits Scheme Collection of Under Co-payment Data. Viewed 15 July 2015 <http://www.pbs.gov.au/info/statistics/under-co-payment/under-co-payment-data>
- ⁷ Department of Health (2014). Expenditure and prescriptions twelve months to 30 June 2014. Canberra, Commonwealth Government.
- ⁸ Australian Institute of Health and Welfare (2012). Mental health related prescriptions. Viewed 24 November 2015 <https://mhsa.aihw.gov.au/resources/prescriptions/>
- ⁹ Department of Health (2012). Mental health statement of rights and responsibilities. Canberra, Commonwealth Government.
- ¹⁰ Department of Health (2013). A national framework for recovery-oriented mental health services: Guide for practitioners and providers. Canberra, Commonwealth Government.
- ¹¹ Department of Health (2012). Mental health statement of rights and responsibilities. Canberra, Commonwealth Government.
- ¹² Department of Health (2012). Mental health statement of rights and responsibilities. Canberra, Commonwealth Government.
- ¹³ ARAFMI NSW is a community organisation of families and carers and friends of people living with a mental illness. ARAFMI is informed by the experience of families and carers and provides support, education and advocacy in order to help them, effectively fulfil their caring role.
- ¹⁴ Doctor shopping refers to requesting prescriptions from multiple clinicians, often simultaneously, without making efforts to coordinate care or inform the clinicians of the multiple caregivers.
- ¹⁵ Official Visitors visit people in mental health facilities in NSW and are available to assist consumers on community treatment orders. Official Visitors are independent from the health system. They make regular visits to all inpatient facilities in NSW. They aim to safeguard standards of treatment and care, and advocate for the rights and dignity of people being treated under the NSW Mental Health Act.
- ¹⁶ Clinical Excellence Commission (2014). TOP 5: Improving the care of patients with dementia 2012-2013. Sydney, Clinical Excellence Commission. Viewed 29 October 2015 http://www.cec.health.nsw.gov.au/_data/assets/pdf_file/0005/284297/TOP-5-infographic-of-Phase-1-results.pdf
- ¹⁷ Off label prescribing is where a particular medication is prescribed to treat a condition for which it has not been approved by the Therapeutic Goods Administration. It will not therefore be included in the official information document. It is a common and legal practice in all sorts of areas of health. It does not mean the TGA has rejected the indication. Off-label prescribing can also refer to a prescription for an unapproved age group, dosage or form of administration.

¹⁸ Drug Utilisation Sub Committee (2013). Review on the Utilisation of Antipsychotics - August 2013. Public Summary Document. Viewed 19 October 2015. <http://www.pbs.gov.au/info/industry/listing/elements/pbac-meetings/psd/2013-08/antipsychotics>

¹⁹ A special preparation of the medication, which is given by injection. The medication is slowly released into the body over a number of weeks.

