



To whom it may concern

The Schizophrenia Fellowship of New South Wales Incorporated (the Fellowship) is the largest by membership non government charitable mental health organisation in the State with approximately 4,500 memberships, many being family and organisation membership. We provide services to people with a mental illness, and to their families and carers.

The Fellowship was commissioned in 1997 by NSW Health to develop a clinical practice guideline for the treatment of schizophrenia which was launched in 2000, "The Schizophrenias: guidelines for a holistic approach to clinical practice". This obviously included reviewing the evidence base regarding anti psychotic medication. It was and is internationally recognised that medication provides the platform on which rehabilitation and recovery can be achieved for people with mental illness. It is estimated that this is the 20% platform on which other services can be built to help people on their recovery journeys. It was also clear that there is no "magic bullet" for treating any mental illness, we need a range, indeed the broadest range possible.

For these reasons the Fellowship has provided submissions regarding medication listing to Ministers and more recently to the PBAC. As an active participant in the approval process it is disappointing to find that this review of PBAC guidelines is occurring and to have only one day to respond. Our comments by necessity will be brief to ensure that this is submitted by 1 April.

The review of the guidelines is welcome. Our system has developed over the years and has much that is good about it. There are also concerns, or possible improvements that can be achieved to be the world leader.

Our reading of the data would suggest that PBS expenditure as a percentage of government expenditure and GDP has shrunk, not grown. This should provide more flexibility for approvals of new treatments rather than a more restrictive environment. In the area of mental illness, there are few advances that need to be considered which should provide a more accepting process for new, novel treatments. We know there is no magic bullet. We know that with the advent of each new medication a group of people, sometimes a small group, will have maximum benefit with minimum side effects. This should strongly suggest that we need the broadest possible range of medications available. However the experience in 2014 with an antipsychotic medication which had been approved in other jurisdictions and that had promise for some people being rejected was greatly disappointing. The Fellowship sent a submission regarding this medication.

Schizophrenia Fellowship of NSW Inc.
Locked Bag 5014 Gladesville 1675
Tel: +61 2 9879 2600 Fax: +61 2 9879 2699
1800 985 944
E-mail: admin@sfnsw.org.au Web Site: www.sfnsw.org.au

ABN 58 903 786 913

Patron: His Excellency General The Honourable David Hurley AC DSC (Retd)

Supported by the
Commonwealth Department of Social Services
Commonwealth Department of Health
NSW Department of Health

We note that the draft guidelines focus very heavily on the approval process, the various steps and requirements, which makes some sense. However in reviewing the document we had to reach page 167 before the first, and relatively meaningless, reference to consumers. The only mention of consultation relates to a future document and sits outside the body of these guidelines.

We would strongly suggest that there is benefit to the process of assessment and approval through the engagement of the end user, the consumer. Further in the psychiatric area, the view of the carer can be critical. There appears little or no consideration given to this in the guideline document.

We are aware that other jurisdictions such as Scotland not only have a method for input, they seem to have established consultation panels of consumers and carers. Whilst the PBAC is an instrument of government decision making, the value of medicines is of importance to all Australian citizens, no more so than those directly involved. A medicine that relieves some symptoms of schizophrenia has health benefits beyond the person with the illness. The daily stress and anxiety of the carer and the family also has long term health implications and must be taken into account. The potential for growth in the common wealth of our nation through a person's mental illness being controlled is enormous and should also be a consideration when assessing an antipsychotic medication.

The section dealing with comparator medication raises a significant issue in the area of mental illness. Prescribing for a person with schizophrenia, bipolar disorder or depression is a matter of trial and error. The individual's responses vary dramatically, suggesting a much broader range of illnesses than is currently known. It is impossible to predict which medication will work and which will not for the individual. Again this suggests that the broadest possible range be available and we should not be looking at the cheapest alternative that alleviates symptoms.

When cost effectiveness is based purely on the price of the comparator we run a very high risk of denying Australians access to the medication that will work for them and long term may prove to be the most cost effective by allowing control of symptoms and tax paying employment. A further consideration in considering comparators and cost must be the issue of quality of life. Some low cost comparators are known to cause extrapyramidal and parkinsonian side effects. A person whose tremor is so severe that half of their cup of coffee ends up on the front of their clothes is clearly being denied access to quality and respectful life.

Over 40 years of working with people with mental illness I have personally observed a small number of people who do well with Largactil (Chlorpromazine), generally considered a brutal medication for its side effects. I have also seen a small number who have done very well on Orap (Pimozide) which has never been approved for use in Australia. The dramatic difference has been that Largactil is cheap and Orap, not being on the PBS, is very expensive. The consequence being that the consumer had to switch

from a medication that was working to one that did not have the same benefit and had terrible side effects.

This is a very brief submission made at the literal eleventh hour. I would be pleased to provide further comment should there be the opportunity. Finally we restate that the review is welcome. Australia should have a world leading system for pharmaceutical approvals that is safe, effective and considerate of the needs of the population.

Yours sincerely,

A handwritten signature in black ink, appearing to read 'Rob Ramjan', written in a cursive style.

Rob Ramjan AM
CEO
1 April 2016