

ACT Mental Health Consumer Network Inc. The Griffin Centre, Level 2, Room 11 20 Genge Street, Canberra City, 2601 G.P.O Box 836, Canberra, ACT, 2601

Phone: 02 6230 5796

Email: research@actmhcn.org.au
Website: www.actmhcn.org.au

Submission: Canberra Health Services (CHS)

Procedure: Electroconvulsive Therapy (ECT)/Neurostimulation (NS) – Adults and

Children 12 years of age and over



Submission: CHS Procedure: ECT/NS – Adults and Children 12 years of age and over

This submission has been prepared by the ACT Mental Health Consumer Network (the Network) in response to the invitation from Canberra Health Services (CHS) Mental Health, Justice Health, Alcohol and Drugs Services (MHJHADS).

Acknowledgment of Country

We wish to acknowledge the Ngunnawal people as traditional custodians of the land upon which we sit and recognise any other people or families with connection to the lands of the ACT and region. We wish to acknowledge and respect their continuing culture and the contribution they make to the life of this city and this region. We would also like to acknowledge and welcome other Aboriginal and Torres Strait Islander people may be reading this submission, and we recognise the ongoing contributions of all Indigenous peoples to ACT society and Australia more broadly.

Recognition of lived experience

We wish to recognise people with mental health illness whose resilience and work contributes to creating a better mental health system for the Australian Capital Territory (ACT) and a more compassionate society for all.

The ACT Mental Health Consumer Network

The Network is a consumer-led peak organisation representing the interests of mental health consumers in the ACT in policy and decision-making forums. The Network is committed to social justice and the inclusion of people with experience of mental illness. Run by consumers for consumers, our aim is to advocate for services and supports for mental health consumers which better enable them to live fuller, healthier and more valued lives in the community.

A meeting of the Policy Reference Group was held, and additional feedback was sought via email in relation to the CHS Procedure: ECT/NS – Adults and Children 12 years of age and over (the ECT/NS Procedure). Verbal and written feedback received from consumers is incorporated in this submission.

General comments.

The Network welcomes this opportunity to contribute to the ECT/NS Procedure. Consumers hold concerns about the use and practice of ECT that stem from their experiences and the experiences of loved ones, as well as the problematic public

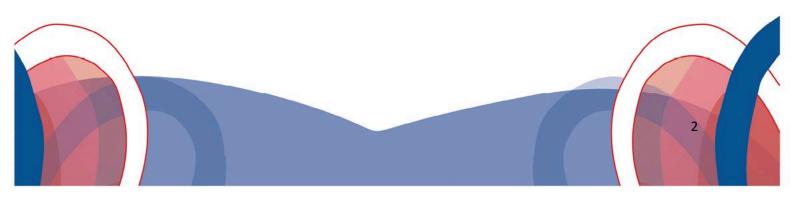


image that ECT has. During the feedback session, care was taken to clarify consumer questions regarding ECT by referring to the Royal Australian and New Zealand College of Psychiatrist's (RANZCP) guidelines for the administration of electroconvulsive therapy (the Guidelines). The Guidelines were used, for example, to distinguish contemporary ECT practices where treatment is provided while the patient is under general anaesthesia, from popularised representations of old ECT practices where the patient is conscious and not anaesthetised for the procedure. Noting this, overall consumer feedback was concerned with ensuring that the ECT/NS Procedure included appropriate checks and balances so that consumer rights are protected and informed decision making supported.

Consumer feedback can be divided into procedure-specific and practice-focused concerns. The submission addresses each in turn. The former is focused on aspects of the processes as outlined in the ECT/NS, while the latter is focused on consumer recommendations for ensuring and enhancing the safe practice and monitoring of ECT treatments. Both the consumers who provided feedback and the Network understand that these latter recommendations are not within the strict scope of this specific review process. However, they have been included in this submission as both a reflection of the consumer feedback received and with a view towards further consideration and dialogue.

Procedure focused feedback

Consumers expressed concerns about the provision of information to consumers in the ECT/NS Procedure. Two issues were identified: insufficient detail regarding the information about ECT to be provided to consumers; and neglecting to specify that persons subject to involuntary ECT should also be provided with verbal and written information about ECT treatment.

Consumers noted that Section 5 specifies that "written material about the treatment, its reasons for use, its course and potential benefits and side effects" (p. 18) are to be provided to the consumer. However, the procedure does not include these materials as attachments or give reference to a specific set of written materials that are to be provided. Consumers' concern here is to ensure that the written materials provided to consumers to inform them about the ECT procedure are consistent and contain all relevant information needed for the purposes informed decision making. Consumers therefore recommend that, if there is a standardised or core set of

¹ Weiss, A., Husain, S., Ng, B., Sarma, S., Tiller, J., Waite, S., and Loo, C. (2019). Royal Australian and New Zealand College of Psychiatrists professional practice guidelines for the administration of electroconvulsive therapy. *Australian and New Zealand Journal of Psychiatry*, pp. 1-15. doi: 10.1177/0004867419839139

written materials that are provided (e.g. a booklet), this set of materials should be specified and referenced in the ECT/NS Procedure. If there is no standardised or core set of written materials that are provided to consumers about ECT, then consumers recommend the development of a standardised information pack for this purpose.

Consumers highlighted that Section 5 outlines the requirements for clinicians to provide both verbal and written information about ECT to consumers for whom informed consent must be sought. However, no such requirement is specified in Section 6 for consumers for whom consent is not required. While consumers understood that it is not necessary to obtain a consumers' consent for ECT treatment if an order for ECT treatment has been granted, they nevertheless noted that providing information to consumers has both ethical and clinical utility. Consumers argued that although consumers subject to an order may not have the right to refuse ECT treatment, they still have the right to understand the intended benefits and possible risks of the treatment that they have been ordered to receive. Following from this, consumers also argued that providing such information – verbal and written – can support consumers during the treatment process by equipping them with the information they need to be able to communicate with their clinicians about the efficacy of their treatment, for example, what side effects they need to be attentive for and report on. Consumers therefore recommend that Section 6 include as a stipulation that clinicians must provide consumers on an order with verbal and written information about the ECT treatment that they will receive.

Practice focused feedback arising from the ECT/NS Procedure

In the course of considering the ECT/NS Procedure, consumers outlined several recommendations for reinforcing the safe practice of ECT. To reflect consumer feedback while acknowledging the scope of the review process, this section details these recommendations for further consideration and dialogue. Consumers expressed concerns about:

- 1. Improving protections for young people;
- 2. Establishing long-term post-treatment outcomes tracking;
- 3. Introducing a set period for clinical review of latest ECT practice and outcomes literature; and.
- 4. Exploring appropriate avenues for incorporating consumer representation into ECT governance.

Each will be discussed in turn.



Consumers acknowledged that ECT treatment for young people is rare. They also noted that if ECT treatment for a young person is being actively considered, then the young person is highly vulnerable and may feel, or be, pressured to consent to treatment by clinicians and/or persons with parental responsibility. Because this is a readily appreciable risk that could occur in the context of rare circumstances, consumers argued that additional support and protection for a young person is merited. Consumers therefore proposed that consideration be given to developing a process to provide young people access to independent support in such circumstances to protect against the possibility of coerced consent.

Additionally, consumers noted that Western Australia passed legislation in 2013 to set the minimum age for ECT treatment at 14 years old. In view of this, and the noted rarity of the use of ECT for young people, consumers proposed that consideration be given to raising the minimum age for ECT treatment in the ACT. Given that a review of the *Mental Health Act 2015* (ACT) is scheduled to be undertaken by the ACT Chief Psychiatrist in August 2025, consumers proposed that this could be included in this review with consideration to be given to raising the minimum age from 12 years old to at least 14, if not 16 years old.

Consumers highlighted that, while the short-term efficacy of contemporary ECT treatment practice has a strong evidence base, there is ongoing scientific discussion about the long-term efficacy of ECT treatments for different mental illnesses.² In particular, there are markedly fewer studies that examine the long-term efficacy of ECT treatments efficacy alongside other therapeutic options while controlling for socio-economic variables.³ Given that ECT treatment bears the risk of autobiographical memory loss, consumers emphasised that the gravity of such possible side effects merits additional longer-term monitoring. Consumers also stressed that the public health system is likely best placed to implement and undertake such monitoring due to established governance systems, accountability mechanisms and routine documentation practices. To this end, consumers proposed that consideration be given to developing a longer-term outcome

² Yoldi-Negrete, M., Gill, L-N., Olivares, S., Lauzière, A., Désilets, M., and Tourjman, S.V. (2022). The effect of continuation and maintenance electroconvulsive therapy on cognition: A systematic review of the literature and meta-analysis. *Journal of Affective Disorders*, vol. 316, pp. 148-160. doi: 10.1016/j.jad.2022.08.005; and, Aoki, N., Tajika, A., Suwa, T., Kawashima, H., Yasuda, K., Shimizu, T., Uchinuma, N., Tominaga, H., Tan, X. W., Koh, A. H. K., Tor, P. C., Nikolin, S., Martin, D., Kato, M., Loo, C., Kinoshita, T., Furukawa, T. A., and Takekita, Y. (2024). Relapse following electroconvulsive therapy for schizophrenia: A systematic review and meta-analysis. *Schizophrenia Bulletin*. doi: 10.1093/schbul/sbae169

³ Munkholm, K., Jørgensen., K. J., and Paludun-Müller A. S. (2021). Electroconvulsive therapy for depression (Protocol). *Cochrane Database of Systematic Reviews*, 1, Art. No.: CD013843. doi: 10.1002/14651858.CD013843.

monitoring and data-collection process.

Citing similar concerns and considerations, whilst acknowledging that practice standards are led by guidelines published by the RANZCP, consumers proposed that establishing a formal ECT evidence review process will enable up-to-date information to be incorporated, in supplemental fashion, into

- the ECT governance processes;
- the education and training of psychiatric registrars; and
- the informing of consumers.

In service of this, consumers proposed the development and implementation of a formal evidence review process that surveys current research and findings relating to best ECT practice and treatment efficacy.

Lastly, consumers expressed concerns about the adequacy of protections and supports for consumers who experience adverse outcomes from ECT treatments as well as consumers who are subject to involuntary ECT treatment orders. While acknowledging that the ECT Committee reports to and is overseen by the MHJHADS governance committee, consumers noted that this committee encompasses a wide range of MHJHADS business and as such has very limited scope for meaningful consumer contributions to ECT governance. Again, citing the gravity of potential adverse outcomes, consumers proposed the incorporation of consumer representation into the oversight of ECT governance. Consumers acknowledged that identifying appropriate means and opportunities for such representation would require further dialogue and specification, but they were nonetheless clear that consumer representation has a positive role to play in this space.

Recommendations

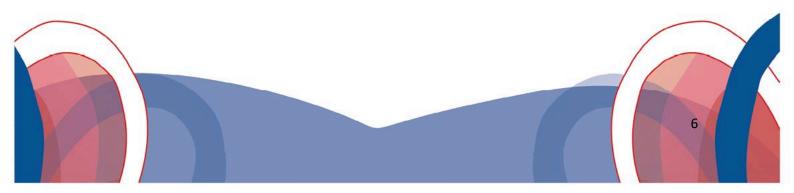
Procedure specific recommendations:

Recommendation 1:

If there is a standard set of written materials about ECT treatment that are provided to consumers, then this set of materials should be specified and referenced in the ECT/NS Procedure. However, if there is no standard set of written materials, then a standardised written information pack should be developed for this purpose.

Recommendation 2:

Section 6 should include a statement that directs clinicians to provide consumers who are subject to an order with verbal and written information about the ECT



treatment that they will be receiving.

Practice focused recommendations for further consideration:

Recommendation 1:

Develop and implement a procedure to provide young people with access to independent support for the purposes of protecting against the possibility of coerced consent to ECT treatment.

Recommendation 2:

Raise the minimum age for ECT treatments, noting that consideration of this recommendation should be included in the ACT Chief Psychiatrist's upcoming review of the *Mental Health Act 2015* in August 2025.

Recommendation 3:

Develop and implement a long-term, post-ECT treatment, outcomes monitoring and data-collection process for the purposes of building local insights into treatment efficacy and variability across cohorts.

Recommendation 4:

Develop and implement a formalised, periodic review process that surveys current research and findings regarding ECT treatments for the purposes of supporting ECT governance processes.

Recommendation 5:

Provide appropriate means and opportunities for incorporating consumer representation into ECT governance.

Editorial recommendations

The ECT/NS Procedure should be proofread to ensure that typographical errors are corrected before final approval. The References section of the ECT/NS Procedure (pp. 19-20) should use a consistent, standard referencing style such as Harvard or APA.

The following specific edit is recommended:

Section 5.5: Documentation of Consent to ECT, pp. 18-19:
 Nominated person is a legally defined position that should therefore be capitalised as 'Nominated Person'.



Conclusion

These recommendations and recommendations are based on consumer feedback and are provided for the purposes of enhancing the ECT/NS Procedure.