

Submission

Consultation on the NHMRC draft 'Consumer involvement' module for 'Guidelines for Guidelines'

15 June 2018

Orygen, The National Centre of Excellence in Youth Mental Health (Orygen) welcomes the opportunity to provide a submission to the National Health and Medical Research Council (NHMRC) on the draft 'Consumer involvement' module for 'Guidelines for Guidelines'. Orygen has responded to questions 1 and 3 in this submission.

About Orygen

Orygen, The National Centre of Excellence in Youth Mental Health is the world's leading research and knowledge translation organisation focusing on mental ill-health in young people. At Orygen, our leadership and staff work to deliver cutting-edge research, policy development, innovative clinical services, and evidence-based training and education to ensure that there is continuous improvement in the treatments and care provided to young people experiencing mental ill-health. Orygen is committed to partnering with young people and ensuring they remain at the forefront of everything we do. We recognise that young people, families and the community are key partners in improving young people's mental health.

Use of the term 'consumer'

Orygen notes that the module utilises the term 'consumer' throughout. In the context of working with young people and mental ill-health, Orygen prefers the terms 'young people' and 'people with a lived experience'. While 'consumer' is used in some areas of health, it tends to imply a choice in whether care is needed. It also implies that a person is already engaged with the health system, potentially in the long term. In relation to youth mental health, barriers to accessing care have resulted in a significant proportion of young people with mental ill-health not being in contact with mental health services (1, 2). Further, mental ill-health for young people can also be episodic, further removing a young person from identification with the term 'consumer' (3). It is important that guidelines take into consideration the needs of both existing service users, future service users, as well as, individuals who are experiencing barriers to service access.

Orygen has used the term 'consumer' here to reflect the current draft module but recommends the module include a statement that consideration should be given to whether the term is the most appropriate for each guideline developed. In relation to young people with a lived experience of mental ill-health, Orygen does not consider 'consumer' to be the most appropriate choice.

1. The aim of updating ‘Guidelines for Guidelines’ is to provide current, relevant and practical advice to Australian guideline developers. Has this goal been achieved in the ‘Consumer involvement’ module?

Yes. Orygen has found the draft module to thoroughly address consumer participation in the development of a guideline. In particular, Orygen is pleased to see that the module:

- highlights the need to reduce barriers to engagement
- directs guideline developers to work with consumers to identify the best form of communication to suit them
- discusses the need for multiple and diverse consumers
- stresses that consumers should not have any out-of-pocket expenses or need to forego paid work to be involved
- suggests the ongoing engagement of consumers in co-presenting guidelines or co-authorship.

Orygen offers the following advice to help further achieve the aims of the module.

In its work in youth mental health, Orygen generally recommends that a partnership level of engagement with young people is preferred to simple consultation. A partnership with the relevant consumers, starting with early planning measures, helps to ensure guidelines are developed that are both highly appropriate and acceptable to consumers (3). Orygen suggests that the NHMRC consider highlighting the benefits of higher levels of participation in relation to the different options in Figure 1.

The module could benefit from a greater focus on allowing different people to engage via multiple and individual ways throughout their participation. Table 2 (Examples of consumer involvement in guideline development) is a start by highlighting different types of consumer engagement activities. However, there could be further detail on adapting engagement activities and styles to suit relevant consumers throughout the engagement process. The module states on page 3 that ‘not all consumers can contribute to each stage’ and discusses their ‘capacity to contribute’. Orygen suggests refocusing this to acknowledge that tasks can and should be adapted to the consumers to maximise engagement.

Where guidelines are meant to address the needs of subgroups of populations, these particular consumers must be engaged meaningfully throughout the development of the guidelines. For example, young men are best-placed to discuss the impact of traditional masculine norms in health care on young men. Orygen suggests stating the necessity of engaging consumers from the specific population subgroup(s) affected by the guideline and that consideration should be given to understanding and utilising mechanisms for engagement that will maximise the participation of these groups.

The module refers to ‘disadvantaged populations’ on page 4. Orygen recommends changing this to ‘vulnerable populations’ to reflect more inclusive language.

3. Do you know of any useful resources that have not been included that should be referred to in these draft modules? (refer to the attached Principles for selecting resources):

Orygen developed a Supporting Youth Partnerships in Research Toolkit to help engage young people in research. It was developed in partnership with Orygen’s Youth Advisory and Youth Research Councils and is freely available at:

<https://www.orygen.org.au/Education-Training/Resources-Training/Resources/Free/Toolkits/Supporting-Youth-Partnerships>.

This Toolkit would add value to the resources section as it helps to address specifics in engaging with young people (aged 12 – 25) as opposed to general consumer engagement. Young people have a range of needs and preferences that differ from the general population (3); therefore, it is important to capture their perspectives by appropriately engaging them as partners in guideline development. In particular, young people need to be engaged in the design, delivery and evaluation of mental health care to better understand and address youth attitudes and potential barriers and facilitators to access, which should help to create more acceptable services for young people.

In addition to being developed in partnership with young people, the Toolkit was based on an unpublished, non-systematic review of the academic and grey literature.

An academic paper by authors including the lead creator of the Toolkit (MB Simmons) has also recently been accepted for publishing:

Faithful S, Brophy L, Pennell K, Simmons MB. Barriers and enablers to meaningful youth participation in mental health research: Qualitative interviews with youth mental health researchers. In Press. *Journal of Mental Health*. (Accepted 19th May 2018).

References

1. Lawrence D, Johnson S, Hafekost J, Boterhoven de Haan K, Sawyer M, Ainley J, et al. The Mental Health of Children and Adolescents: Report on the second Australian Child and Adolescent Survey of Mental Health and Wellbeing (Young Minds Matter). Canberra: Department of Health; 2015 August 2015.
2. Australian Bureau of Statistics. Mental Health of Young People, 2007. Canberra; 2010 19 July 2010. Contract No.: 4840.0.55.001.
3. James AM. Principles of youth participation in mental health services. *Medical Journal of Australia*. 2007;187(7):S57.

Further information

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