

**Response to Promoting the Generation and Effective
Use of Population Health Research in NSW
A Strategy for NSW Health 2011-2015 Draft**



November 2010

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NSW Consumer Advisory Group – Mental Health Inc.
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22nd November 2010

Ms Beth Stickney
NSW Department of Health
bstic@doh.health.nsw.gov.au

Dear Ms Stickney,

Re: Comments on the Draft – Promoting the Generation and Effective Use of Population Health Research in NSW: A Strategy for NSW Health 2011-2015

Please see the attached comments on the draft strategy for *Promoting the Generation and Effective Use of Population Health Research in NSW* from the NSW Consumer Advisory Group – Mental Health Inc. (NSW CAG).

NSW CAG is the peak, independent, statewide organisation representing the views of mental health consumers at a policy level, working to achieve and support systemic change. Our vision is for all mental health consumers to experience fair access to quality services that reflect their needs.

NSW CAG thanks NSW Health for the opportunity to comment on the draft strategy for promoting the generation and effective use of population health research in NSW.

Please do not hesitate to contact me with any further enquiries you may have.

Yours sincerely,

Peri O'Shea
Policy & Operations Manager

Basis of this advice

NSW CAG exists to ensure that policy makers hear the perspectives of mental health consumers across NSW. The basis of this advice derives from information obtained through our core work. This includes regular interaction and consultation with people who use mental health services across NSW including:

- Over 1000 people on our Network who are accessible via the internet;
- Face to face consultations that NSW CAG has conducted during 2009/10 at several locations within each Area Health Service across NSW; and
- Our knowledge base derived from consulting with consumers of mental health services in NSW over the last 17 years.

General Comments on the Draft Strategy

NSW CAG is pleased to see the development of the draft strategy for ensuring the coordination of high quality and relevant research for population health. In particular we are also pleased to have the opportunity to provide input into the strategy based on the views of mental health consumers.

In order to strengthen to the strategy NSW CAG recommends the following:

- That the strategy be written in a way that is accessible to all stakeholders including consumers. At the moment the strategy is presented with very long sentences and use of language that appears to target researchers and people familiar with the context of health operations. This may make it difficult for consumers, consumer groups and consumer researchers to participate in contributing to the realisation of the strategy.
- As the document is currently written, the relationships between the centres within Population Health and the Mental Health and Drug and Alcohol Office (MHDAO) funded research is unclear. The document would be strengthened by clarifying how this strategy interlinks with the *NSW Department of Health, Mental Health Research Framework* and the research funded through the Mental Health and Drug and Alcohol Office.
- The strategy needs to be more inclusive of consumers and consumer researchers/groups. As it is currently written it refers only to policy-makers, practitioners and researchers. NSW CAG advocates that population health research needs to incorporate consumer partnerships in the design, development and implementation of research that is relevant to them. We also advocate that consumers are included on any ethics committees relevant to mental health.
- NSW CAG is concerned that examples presented within the strategy are focused predominantly on general health and do not refer to mental health specifically. In order to ensure consideration of mental health within the strategy NSW CAG recommends that some mental health related examples are used throughout the strategy.

Recommendations:

- Revisit lengthy sentences and use of jargon.
- Clarify the relationship between the centres within Population Health and the MHDAO funded research Framework.
- That some specific mental health related examples are included.
- Amend the following:

Page Number	Sentence / Section	Recommended amendment
10	<i>Principles of effective priority setting - first bullet point</i>	<i>Involve all partners (e.g. funders, researchers, policy-makers, practitioners, <u>consumer groups</u>, the public)</i>
11	<i>Criteria for identifying population health research priorities - last bullet point</i>	<i>...with academic institutions and research institutes, non-government organisations, <u>consumer groups</u> and industry)</i>
	<i>The first bullet point under <i>Priorities</i> can also be defined by:</i>	<i>include <u>people with mental illness</u> in the bracketed list of examples.</i>
	<i>Current Actions - the first sentence</i>	<i>Provide ongoing forums for discussion of research priorities between policy-makers, <u>consumer groups</u> and researchers</i>
14	<i>Current Actions – Conduct research in collaboration with local population health services and academic institutions</i>	<i>include consumer groups</i>
	<i>Current Actions – Monitor and report on the health status of the NSW population, using tools such as:</i>	<i>include a mental health tool</i>

19	Under S2.3.1 – first bullet point	to read: <i>a regular assessment of whether Population Health Division funding processes require the inclusion of strategies for use of the research results and evidence of involvement of <u>consumers</u>, policy-makers or practitioners in research and translation processes.</i>
22	2nd last paragraph	to read: <i>Long-term programmatic engagement between researchers, <u>consumer groups</u> and policy-makers and practitioners has the greatest potential for enhancing the quality and relevance of population health research in NSW.</i>
23	first sentence	to read: <i>with universities, and with non-government organisations, <u>consumer groups</u> and other research organisations.</i>
25	<i>Implementation, evaluation and reporting</i>	include a 6 th bullet point to read: <i>Increased consumer input into all research design and implementation</i>

Comments on the Framework (pages 8-9)

NSW CAG advocates that processes for encouraging partnerships between researchers, policy makers and consumers in research need to be strengthened. Consumer participation in the development, design and conducting of research has shown to be of benefit to the outcomes of research (Horsfall, Cleary, Walter, & Malins, 2007).

It has been established that consumers of mental health services can help to compliment existing services or suggest new ways of thinking about mental health (Robert et al., 2003), and hence are able to contribute in a way which may differ from health professionals and researchers (National Health & Medical Research Council & Consumers' Health Forum of Australia, 2002; Stacey & Herron, 2002). This is because mental health consumers can draw from their expertise and lived experiences (Stewart et al., 2008). Hence, NSW CAG strongly recommends that consumer participation be clearly written into this strategy.

Specific Recommendations:

- In the *Key Strategies, S3* (p. 8) add an extra point to include consumer stakeholders:
 - *S3.4 Strengthen collaboration and partnerships with those who are likely to be affected by the research.*
- In *Table 1: Strategies at a glance* (p.9). in the 2nd column, under S2.2 amend the fourth point to read “*Strengthen researcher-practitioner and consumer engagement*”

REFERENCES

- Horsfall, J., Cleary, M., Walter, G., & Malins, G. (2007). Challenging conventional practice: Placing consumers at the centre of the research enterprise, *Issues in Mental Health Nursing*, 28 (11) 1201-1213
- National Health & Medical Research Council & Consumers' Health Forum of Australia (2002). *Statement on Consumer and Community Participation in Health and Medical Research*, Canberra: Commonwealth of Australia.
- Robert, G, Hardacre, J, Locock, Bate, P & Glasby, J (2003). Redesigning mental health services: lessons on user involvement from the Mental Health Collaborative, *Health Expectations*, 6, 60-71.
- Stewart, S, Watson, S, Montague, R & Stevenson, C (2008). Set up to fail? Consumer participation in the mental health service system, *Australasian Psychiatry*, 16 (5) 348-353.