Measuring a Contributing Life

MHCA consultations on targets and indicators to drive mental health reform

Final Report Prepared for the National Mental Health Commission, June 2013
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1. Introduction

Following the inaugural Council of Non Government Organisation on Mental health (CONGO), the National Mental Health Commission (NMHC) asked the Mental Health Council of Australia (MHCA) to undertake a series of consultations across the mental health and social services sectors to gather views on the most appropriate targets and indicators to drive long-term reform to the benefit of mental health consumers and carers. Consultations were held in April and May 2013.

This Final Report:

- Explains the background to and rationale for the consultations
- Describes the consultation process
- Presents key consultation outcomes, particularly where consensus emerged regarding the best targets and indicators to drive change
- Sets out in detail the range of candidate indicators proposed by stakeholders
- Reflects on key themes to emerge from the consultations and issues which remain contested or unresolved
- Provides feedback on COAG’s preliminary indicators for monitoring progress (as set out in the Roadmap for National Mental Health Reform)
- Makes recommendations to the NMHC on the basis of feedback gathered by the MHCA.
2. Background and rationale

Accessible and reliable indicators provide a powerful way of communicating the collective experiences of mental health consumers and carers and for conveying the state of the ‘mental health system’. The right set of national indicators and targets, reported regularly, will provide a clear picture to the community of how we are doing as a nation to support people and families affected by mental health problems. They will also provide a way to hold governments at state and federal levels accountable for progress, and to guide the work of the whole community.

The NMHC’s 2012 *A Contributing Life: The National Report Card on Mental Health and Suicide Prevention* called for the Council of Australian Governments (COAG) to agree on targets and indicators in mental health at the national level, to bind all governments to work co-operatively and drive results. In December 2012, an open letter to was co-signed by 70 leading non-government organisations and mental health advocates, urging governments to develop whole-of-life targets to guide Australia’s mental health response. Soon after, COAG released the *Roadmap for National Mental Health Reform 2012-2022*, which reaffirmed COAG’s commitment to ongoing mental health reform and announced two new consultative structures to progress reform:

- A Working Group on Mental Health Reform, a national high level, inter-jurisdictional, cross-portfolio body tasked with ensuring that mental health reform remains a priority across governments.
- An Expert Reference Group (ERG) to provide independent advice to the Working Group on the most appropriate set of national, whole-of-life, outcome-based targets and indicators for mental health. Importantly, the ERG has been established to provide advice that reflects a broader community perspective, especially taking into account the views of those with lived experience of mental health issues, their families and support people.

The NMHC is secretariat to the ERG and retains a strong interest in identifying the best mix of targets and indicators to drive long-term reform. The NMHC is keen to ensure that the ERG’s recommendations, as well as its own independent thinking, are informed by broad consultation, and that the views of consumers and carers are a primary consideration in developing recommendations for government. The NHMC is therefore working in partnership with the MHCA to ensure that the views of the broader mental health sector, including consumers and carers, are conveyed to the ERG.
3. Consultation process

With support from the NMHC, the MHCA conducted a series of consultations between 2 April and 21 May 2013. The consultations sought input from consumers, carers, mental health practitioners, allied service providers, the non-government sector, thought leaders and academics about targets and indicators that, if adopted, would drive real and lasting change for the benefit of people living with mental illness and their carers.

Stakeholders were asked to determine which targets and indicators should be given the highest priority based on the following criteria, which reflect the ERG’s terms of reference:

- Ambitious
- Achievable
- National
- Whole-of-life
- Outcome-based
- Understood by the community.

The process described below reflects the shared understanding of the MHCA and the NMHC that the aspirations of consumers and carers should be fundamental in any decisions about targets and indicators. With this in mind, the MHCA sought in the first instance to promote discussion about what kinds of change would most benefit the lives of consumer and carers, prior to any detailed discussion about how to measure that change. The MHCA also sought stakeholder feedback on the list of preliminary indicators nominated in the Roadmap, taking into account the views of consumers and carers on what would make most difference in their lives.

MHCA State and Territory Workshops

The MHCA hosted 8 State and Territory consultation workshops between 2 April and 18 April 2013. A total of 401 people attended the workshops in the following locations:

- Brisbane - 2 April (45 attendees)
- Sydney - 3 April (69 attendees)
- Canberra – 8 April (53 attendees)
- Melbourne 10 April (63 attendees)
- Hobart 11 April (35 attendees)
- Adelaide 15 April (62 attendees)
- Mandurah (45 attendees)
- Alice Springs (29 attendees)

The State and Territory workshops were attended by a broad cross-section of stakeholders from the mental health sector including consumers and carers, community mental health workers, clinicians, mental health nurses, academics and policy officers/program managers from both within and outside government.

Each workshop included a dedicated session on targets and indicators, although these consultations also canvassed a broader range of issues and provided an opportunity for the
Mental Health Council of Australia to get a sense of the key issues affecting the mental health sector and consumers and carers at that time.

The process for seeking input about targets and indicators was two-fold. In addition to the dedicated session in which stakeholders were invited to provide broad feedback in groups, paper surveys designed by the MHCA were distributed and participants were invited to fill them in during the workshops. Of the 401 participants in the MHCA state and territory consultation workshops, approximately 300 returned completed surveys on targets and indicators the results of which were analysed by the Nous consulting group and incorporated into the Discussion Paper presented to delegates at the CONGO meeting.

After the first couple of consultations the process of seeking participant input on targets and indicators was refined. Participants were presented with the domains covered in the Report Card, otherwise known as the Contributing Life Framework. The Framework was used to bring some structure to the discussions without leading participants to select from a predetermined set of indicators. Most participants agreed that the domains covered in the A Contributing Life Report Card were sufficiently broad to facilitate discussions on indicators and target across a broad range of areas in a person’s life.

- **Consumer and carer consultation**

On 6 May 2013, 38 representatives from the National Mental Health Consumer and Carer Forum and the National Mental Health Consumer and Carer Register, along with some additional consumers and carers, attended a two day workshop in Sydney. The first day was dedicated to gathering their views on targets and indicators. Participants were provided with a background paper in advance of the workshop so they could think about their feedback in advance.

The workshop concluded with a list of fifteen indicators that consumer and carer representatives believed would, if adopted, drive improvements across the mental health sector that would lead to measurable changes in consumer and carer outcomes. These are documented below.

- **CONGO consultation**

On 21 May 2013, the MHCA convened a gathering of the Council of Non-Government Organisations for Mental Health (CONGO) in Canberra. The sole purpose of the gathering was to gather the views of the non-government mental health sector on the best mix of indicators and targets to drive reform. The CONGO meeting was attended by more than 110 delegates from academia, national NGOs and peak bodies, including representation from the broader social services sector.

In advance of the gathering, delegates were provided with a detailed discussion paper explaining the rationale for the consultation and setting out various options for deciding from a huge range of possible indicators. In addition, delegates were presented with a preliminary set of thirteen indicators developed by the Mental Health Council of Australia, based on the feedback received in prior consultations, to prompt discussion.

CONGO delegates were asked to identify up to ten targets, and related indicators, that would:
• Take a whole of life perspective
• Respond to the issues identified as important to consumers and carers
• Address other critical issues and;
• Drive long-term improvements in consumer and carer outcomes
• Be both ambitious and achievable and;
• Be able to be stratified for particular population groups

Delegates were also asked to consider:

• What issues might be missing; and
• Any unintended consequences of the indicators and/or targets recommended for adoption by the ERG.

To help the CONGO reach definitive conclusions, twenty delegates were invited to facilitate discussions on particular issues, as expert chairs. The chairs were tasked with leading discussions about a particular domain and documenting the conclusions reached on specific targets and indicators.

Positively, the CONGO was able to reach consensus on a range of specific long-term targets. There was less consensus on which specific indicators would best reflect progress towards those targets. These outcomes are described in detail below.
4. Key consultation outcomes

This section presents the key outcomes of the MHCA’s consultations: namely, a small number of specific targets and indicators for which there was clear consensus among and across stakeholder groups, as informed by the MHCA’s consultations.

The aspirations of consumers and carers, as articulated by consumer and carer representatives through the MHCA’s consultations, are the starting point for the conclusions drawn below; consumer and carer views are reported in detail in the next section. Consumer and carer feedback did not always cover technical measurement issues (with some notable exceptions), but instead provided direction about what kinds of issues need to be captured through targets and indicators.

Building on this feedback, the MHCA and CONGO delegates (including consumer and carer representatives) considered which targets and indicators would be most likely to drive the kinds of change that consumers and carers said they hoped to see, both immediately and over the long term. For some issues (e.g., seclusion and restraint) a target was immediately apparent, while for other issues (such as access to services) stakeholders discussed a range of technical and policy issues in weighing up various options, and did not always arrive at a firm consensus on a particular target/indicator in favour of another.

For some issues (or ‘domains’), there was stakeholder consensus on both targets and related indicators, with a natural hierarchy incorporating several shorter-term indicators to signal progress towards longer-term targets. For other issues, consensus emerged on a specific target or a specific indicator, but not both; however, the issue itself was deemed critical enough to capture in a suite of targets and indicators.

Despite the MHCA and the NMHC consistently drawing attention to the need to focus on outcomes, stakeholder feedback strongly indicated that at least some indicators need to be process-based, because they would drive the right kinds of change to contribute to a long-term, outcome-based target.

Table 1 (below) sets out targets and indicators for which there was a clear consensus. Table 2 (in Appendix A) presents a more detailed list, including both the targets and indicators in Table 1 and other targets and indicators which generated additional discussion and debate. Table 2 also includes the MHCA’s analysis of the degree of consensus associated with various indicators and the issues that were raised in relation to those indicators.
Table 1: Targets and indicators with strong support from stakeholders consulted by the MHCA

<table>
<thead>
<tr>
<th>Domain</th>
<th>Target</th>
<th>Related indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical health</td>
<td>Reduce the gap in mortality rates between people with severe mental illness and the rest of the population by 30-40% within 5 years and 80% within 10 years</td>
<td>Improvements in the physical health of people with mental illness in relation to comorbid health problems, alcohol misuse, metabolic syndrome and smoking rates</td>
</tr>
<tr>
<td>Access to services</td>
<td>No clear consensus on target</td>
<td>Proportion of consumers and carers who receive timely access to quality services that meet their self-assessed needs</td>
</tr>
<tr>
<td>Economic Participation</td>
<td>Increase the employment participation rate for people with mental illness to 35% within 4 years. Within ten years, increase the employment participation rate for people with mental illness to 80% of the national rate</td>
<td>Year 12/VET completion rates</td>
</tr>
<tr>
<td>Housing</td>
<td>Decrease the proportion of people who do not have access to affordable, appropriate, safe, secure and lasting accommodation (including people in hospital) by 20% within four years and 50% within 10 years</td>
<td>Proportion of people in mental health and justice settings who are in insecure or unstable housing</td>
</tr>
<tr>
<td>Suicide</td>
<td>Reduce rates of completed suicide among at risk groups by 25% with four years</td>
<td>Rates of attempted suicide</td>
</tr>
<tr>
<td></td>
<td>Halve the rate of completed suicides population-wide within ten years</td>
<td></td>
</tr>
<tr>
<td>Domain</td>
<td>Target</td>
<td>Related indicators</td>
</tr>
<tr>
<td>----------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Peer workforce</td>
<td>No clear consensus on target</td>
<td>Size and qualifications of the peer workforce</td>
</tr>
<tr>
<td>Community wellbeing</td>
<td>No clear consensus on target</td>
<td>Population awareness of mental health issues &lt;br&gt;Levels of stigma in community</td>
</tr>
<tr>
<td>Safety</td>
<td>Eliminate all instances of seclusion and (physical and chemical) restraint in mental health and justice settings within four years</td>
<td>Reporting of seclusion and restraint by every jurisdiction</td>
</tr>
<tr>
<td>Government spending</td>
<td>Growth in national spending on community based mental health services exceeds growth in the national health budget</td>
<td>No related indicators</td>
</tr>
<tr>
<td>Consumer and carer involvement</td>
<td>No clear target was adopted for this domain.</td>
<td>Experiences of discrimination against people with mental illness in the general population and among health professionals &lt;br&gt;People experiencing mental illness and their carers report ‘having a voice’ and being able to participate in community life and social activities as desired</td>
</tr>
</tbody>
</table>
5. Consumer and carer aspirations

The conclusions drawn regarding the broader mental health sector’s priorities for targets and indicators, described in the previous section, were formed with the aspirations of consumers and carers as primary considerations. Consumer and carer views were sought through multiple consultation events, most notably a one-day gathering of the National Mental Health Consumer and Carer Forum, the National Mental Health Consumer and Carer Register and selected additional consumer and carer representatives. The key outcomes from that event are reported below. More detailed findings from the MHCA’s consumer and carer consultations can be found in Appendix C.

- Broad themes

Consumers and carers raised four major themes as most critical in thinking about mental health reform and selecting the right mix of targets and indicators.

  o 1. Nothing about us without us

Consumers and carers described experiences of marginalisation and dismissal by current systems, and reported routinely being treated with a lack of dignity and respect. They felt that these problems were inherent in the way that the current system understands and treats mental health issues.

Representatives suggested that the only way to overcome these problems is for consumers and carers to be ‘co-creators in the process of designing, delivering and evaluating mental health services. Consumers and carers should be involved in all dimensions of service, from academic and non-academic research underlying service design, to delivering services as peer workers, to involving carers and consumer consultants in treatment decisions, to the audit of seclusion and restraint decisions.

  o 2. Achieving equity in funding

To meet the aspirations of consumers and carers, it is necessary in the first instance to properly resource the mental health system (as broadly conceived). There was strong consensus that budget allocations for mental health should reflect the overall burden of disease; mental health receives a disproportionately low level of funding compared with physical health, despite the fact that mental illness can increase the likelihood of, exacerbate the effects of, and reduce the chance of recovery from, physical illness. Mental health services are often more effective when delivered in the community rather than in a clinical setting, and it is important that community-based services benefit from any growth in funding for mental health.

  o 3. Identifying and supporting people who have fallen through the gaps

Consumers and carers emphasised the importance of paying particular attention to people with severe and enduring mental illness and psychosocial disability who are socially excluded and not in appropriately supported accommodation. Aside from the need to protect their human rights, governments need to reach out to these individuals and better understand (and attempt to correct) current service limitations that allow social exclusion to occur.
4. Promoting wellbeing and recovery, beyond the absence of physical and mental illness

Consumers and carers emphasised that wellbeing is about more than the absence of illness. For recovery to be meaningful and lasting, consumers need to have a control over their lives. An emphasis on wellbeing (as understood broadly, from the individual and the community perspective) is beneficial both for people with a diagnosis of mental illness and for people who are at risk of psychological distress.

- Consumer and carer priorities for targets and indicators

After discussing the issues and candidate indicators that were seen to be critical, consumer and carer participants were asked to come to a consensus on a small number of indicators that could drive mental health reform in the interests of consumers and carers. This list of indicators is reproduced below, in no specific order; in many cases these reflect the four major themes discussed above.

1. Equal partners in the co-design, delivery, evaluation and [academic and non-academic] research of social and emotional wellbeing services led by consumers and carers [and consumer and carer organisations]

2. Proportion of health budget allocated to mental health

3. Seclusion and restraint

4. People with severe and enduring mental illness and psychosocial disabilities who are socially excluded and not in appropriately supported accommodation

5. Community awareness of mental health issues (including stigma and discrimination)

6. Carer support

7. Rates of mental illness in the criminal justice system

8. Workplace support for people living with mental health difficulties

9. [Stigma and] Discrimination by health workers and clinicians

10. Wellbeing and recovery, going beyond good mental and physical health

11. Peer workforce

12. Access to mental health services across various parts of the community

13. Cultural connections

14. Rates of suicide

15. Rates of mental illness.
6. Other feedback and reflections

In addition to findings relating to specific targets and indicators, the MHCA heard stakeholder views on a range of related issues, including feedback on COAG’s stated ambition to identify a small number of targets and indicators that will drive change. This section provides some commentary on:

- Stakeholder views on the need for targets
- The Contributing Life Framework
- Preliminary indicators in the Roadmap
- National coordination in prioritising data collection

- Stakeholder views on the need for targets

The non-government mental health sector has already voiced its support for ambitious targets in mental health. In December 2012, 70 leading mental health advocates (including consumer and carer representatives) signed an open letter to COAG urging governments to include concrete targets in the Roadmap for National Mental Health Reform. It is not surprising, then, that the MHCA consistently heard support for the goal that the ERG and the NMHC are working towards: to identify a relatively small number of targets, and related indicators, that will drive the kinds of change that consumers and carers say they hope to see from a whole-of-life perspective.

It was clear from our discussions with stakeholders that the broader mental health sector understands the importance of, and wishes to embrace, this rare opportunity to align government and NGO ambitions with consumer and carer aspirations. The sector also hopes to see governments endorse targets that are as ambitious as possible while still being realistic.

Consumer and carer representatives agreed that distilling candidate indicators into small number of cohesive indicators is a daunting challenge, given the number of issues that (rightly) deserve attention. Consumers and carers are concerned that indicators properly capture the experiences of different population groups. The MHCA will therefore work with the NMHC to communicate the results of our consultations and of the ERG’s deliberations to consumers and carers, making the link between consumer and carer feedback and specific targets and indicators where possible.

- The Contributing Life Framework

There was much discussion in all our consultations about the best way to structure a set of targets and indicators. As noted in Section 2, the NMHC’s Contributing Life Framework (described in the first Report Card) was used as a tool to organise and structure candidate indicators and prompt stakeholder feedback, particularly in preparing the discussion paper (see Appendix F). Despite broad support for the Contributing Life Framework, this proved to be somewhat problematic, because some of those consulted (particularly consumers and carers) felt that the Framework constrained their choices, while others (particularly CONGO delegates) believed that there was a need for additional domains to supplement the Framework in order to do justice to the broad range of issues. It also became clear that the six elements of the Framework are not ‘domains’ in the same sense that (say) housing or
employment are ‘domains’, with the latter being easier to associate with specific, measurable indicators. Ultimately the CONGO decided to adopt the six elements of the Framework to guide discussion, and supplemented them with three additional domains:

- Community wellbeing
- Workforce
- Promotion, prevention and early intervention

At the consumer and carer workshop, there was lively debate about the best ways to structure candidate targets and indicators, with reference to the Contributing Life Framework and other approaches. There were also spirited discussions about the definition of domains such as ‘thriving, not just surviving’ and about what constitutes ‘effective care, support and treatment’. Consumers and carers also discussed how we might think about the interaction between mental illness and the forensic space, the level of autonomy consumers and carers have over decisions that affect them, and the need to ensure that targets and indicators developed are well understood by the community and in particular consumers and carers. These issues all have implications for the way that any targets and indicators adopted by COAG are explained to stakeholders, both initially and over time.

- **Indicators from the Roadmap**

Stakeholders were presented with the preliminary indicators set out in the *Roadmap for National Mental Health Reform* developed by the Council of Australian Governments, and asked to compare these with other candidate indicators and with the priorities they had nominated. While there was some support for individual targets and indicators, the general consensus across many consultation sessions was that the indicators in the Roadmap are too clinical in focus and too limited in scope. By comparison, the Contributing Life Framework was viewed as much better able to capture a whole-of-life perspective. Stakeholders agreed that it is critical to cover the social determinants of health (including housing, community participation, access to support, and participation in education, employment and training), in addition to any indicators to any targets and indicators relating solely clinical processes or outcomes.

Similarly, consumers and carers unanimously endorsed the need to look well beyond clinical mental health targets and indicators. They also emphasised that consumers and carers need to be at the centre of ongoing mental health reform and indicated that the best evidence for this would be that consumers and carers are involved at every level of decision-making.

- **Criteria for selecting indicators**

There was initially some consternation from stakeholders about the prospect of identifying up to ten targets (for this was the task that was presented to them) when there are so many issues that ought to be the focus of attention to achieve change in the interests of consumers and carers. However, participants generally recognised the political realities that led to the current consultation, and endorsed the ERG’s criteria for selecting the right targets and indicators (i.e. national, whole-of-life-, outcome-based, ambitious, achievable and likely to drive change). Positively, there was genuine commitment by many stakeholders both to making hard choices between competing alternatives and to supporting the mix of targets and indicators on which there is consensus across the broader mental health sector.
Parallel and related measurement work

The MHCA notes that there are currently many processes in train for developing, refining and collecting data that would shed light on the success or otherwise of mental health reform. This work is being carried in a variety of contexts – within, across and outside governments – and is often extremely detailed and resource-intensive. While some of the data currently collected can easily be integrated into the tracking of outcomes at a national level, other data is not useful in the context of the ERG’s task (although it is no doubt useful for other purposes).

The MHCA does not propose to describe or assess the value of the body of work currently underway. However, we do wish to emphasise the need for governments to step back and evaluate the sum total of data collection either underway or planned in the mental health space. This will enable prioritisation of those activities which are most essential to acquiring robust data relating to key national targets and indicators, and which align data collections across service systems that touch people across all stages of their ‘contributing life’.
7. Recommendations

The MHCA makes the following recommendations:

- That the ERG’s recommendations to COAG are informed in the first instance by the aspirations of consumers and carers, as described in this report.
- That the ERG and the NMHC endorse those targets and indicators on which clear consensus emerged through the MHCA’s consultations, as described in this report.
- That the ERG and the NMHC consider in their deliberations those targets and indicators on which there was considerable discussion and debate in the MHCA’s consultations, and identify the best possible approach to measure and drive change from the alternatives available.
- That the ERG and/or the NMHC communicate the outcomes of the process, including a rationale for choosing particular targets and indicators, to:
  - Consumers and carers
  - The clinical mental health sector
  - The community mental health sector
  - Service systems and other organisations that support people with mental health issues.
- Where the ERG does not ultimately recommend that COAG adopt a target or address a domain for which there was consensus support, that the ERG and/or the NMHC should work with the MHCA to explain the rationale for such decisions both to consumers and carers and to the non-government mental health sector.
- In communicating the decisions of the ERG, the Ministerial Working Group or COAG in relation to targets and indicators, that the NMHC:
  - Acknowledge the various data collection activities of the very broad number of governments, agencies and organisations involved in the design and delivery of mental health programs and services
  - Where appropriate, explain the links between these other data collection processes and any data collection associated with tracking progress towards national targets for mental health reform.
- That the ERG recommend to the Ministerial Working Group that the targets and indicators adopted by COAG inform a process of prioritising the collection of data by and across governments, in a way which is consistent with the broad direction of national mental health policy.