Strategic Priorities for Mental Health Research

Final Report

Prepared for the National Mental Health Commission (NMHC)

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Executive Summary

Mental health research in Australia is excellent. Yet, there is a striking consensus in the available literature and among the experts interviewed for this report, that the mental health system and the community are not receiving the evidence they need to support “a contributing life” for all Australians. This situation has arisen chiefly because the research system and the broader mental health system are poorly connected and have disparate goals and drivers:

- The mental health research system is largely investigator-driven, with incentives, including funding, oriented primarily around peer-regard
- The broader mental health system, incorporating services and programmes, has multiple, complex drivers and faces a range of significant challenges, including issues with evaluation and the application of research evidence

Furthermore, there are underlying scale and capacity constraints. Mental health research in Australia has been described as “a cottage industry”. National Health and Medical Research Council (NHMRC) funding of mental health research rose tenfold over the last decade or so to reach $70 million in 2013; yet this remains a small amount when compared to the direct cost to government of running mental health-related services, which exceeds $7 billion – and previous analysis suggests that the total (direct and indirect) cost to government could be twice as high.

A balanced research system, appropriately connected to and internalising drivers from the mental health service system and the community, has the potential to underpin a “virtuous cycle”, including:

- Generating evidence for reform
- Supporting monitoring and evaluation of the impact of reform interventions
- Using ongoing data to generate further evidence for system improvement

At the same time, a broader mental health system that can make better use of the evidence and capacity provided by the research system is central to ensuring improvements in mental health and mental health care.

An imbalance between stakeholder priorities and the focus of mental health research has long been recognised. There have been multiple efforts to address this, predominantly through the application of “soft” levers, including highlighting priorities as part of investigator-driven research and a broad push for “translational” research.

Despite evidence for recent shifts in research focus, policy makers, practitioners and those living with mental illness continue to experience a lack of useable evidence relevant to the challenges they face. This suggests that previous approaches have met with limited success in these terms and continuing reliance on them as the translational mechanisms is unlikely to result in significant change.

Previous attempts to improve the situation have tended to locate the problems within the research sector and to focus on re-aligning research. A greater emphasis on priority-driven research remains an important part of system reform. However, if this is
undertaken in isolation it will not be sufficient to bring about the optimal generation and application of evidence to improve mental health and mental health care.

A systems approach, which considers research and the broader mental health system together, is likely to produce more effective reform. This approach suggests two synergistic strategies to guide change:

1) To increase the **connectedness** of the research and broader mental health systems

2) To increase the ability of the broader mental health system, including the community, to **leverage** local and international research.

The following **principles** should apply to the rebalancing of the mental health research portfolio, to ensure it optimally improves mental health services and outcomes:

- **Excellence** – the overall excellence and diversity of mental health research in Australia should be maintained, within a system that balances investigator- and priority-driven research
- **Responsiveness** – research should deliver outputs that mental health services and programmes and the community need, according to current priorities
- **Partnership** – priorities for mental health research should be set by a wide range of stakeholders, including people with lived experience of mental illness, carers, service providers and policymakers and research should be conducted in partnership with these groups
- **Relevance** – improving the lived experience, including experience of interventions and supports, of mental health consumers and those caring for them should be central to research
- **Connectedness** – specific measures should be put in place to connect the research and mental health service systems, including methods for translation of research into evidence-based policy and practice and the embedding of evaluation and research into service provision
- **Evidence** – measures to implement improvement should, where possible, be evidence-based and subject to monitoring and evaluation to ensure that quality and safety can be maintained and inappropriate interventions ceased
- **Accountability** – research should be accountable for the investment made in it

Also, an emerging consensus among stakeholders and a review of system needs yielded the following current **priorities** – that mental health research should increasingly:

- Be relevant to the real-world needs of those living with mental health problems, carers, the community, policy agencies and health services, including research that:
  - Provides evidence regarding complex interventions, systems of care and pathways, rather than focusing primarily on individual therapies
  - Applies to the broad population of people with mental health problems, including those with multiple complex needs
- Provides evidence to inform decision-making, including cost-effectiveness research

- Support a whole-of-life approach to management of mental health, including childhood
- Focus on prevention of and early intervention for mental health problems
- Recognise the interplay between mental and physical health
- Be cross-disciplinary, e.g., include sociologists, economists and demographers
- Go beyond the health sector, to consider the interdependencies between mental health and community wellbeing, employment, education and housing
- Be inclusive of the particular health challenges of disadvantaged groups, e.g., Aboriginal and Torres Strait Islander people, rural and remote communities, and people in the justice system
- Be scalable
- Be integrated into service delivery through development of practice-based evidence, quality improvement and evaluation

Strategic oversight and leadership is central to effective reform. It should incorporate partnership with stakeholders, including those living with mental health problems, their families and carers, policymakers and practitioners, throughout the reform process. It should also support a whole-of-system (or systems) view and the judicious and timely application of potential solutions.

Initiatives and strategies for applying these principles and priorities, within a systems approach, to support and enhance the wider process of mental health system reform, include:

1) **Processes to facilitate greater involvement** of those living with mental health problems, their families/carers and the wider community in research
2) **Embedding research, monitoring and evaluation** into the mental health service system, including the active commissioning of research
3) **Securing funding** for ongoing competitive priority-driven research schemes
4) **Widespread adoption of an outcomes framework** for mental health, and advocacy for its use in research and mental health services
5) **Data reform**, including an audit of current data systems, implementation of a minimum dataset for use in multiple services and support for data linkage
6) **A “What works” and “Best buys” resource** for accessible national and international evidence on efficacy, effectiveness and cost-effectiveness
7) **Increasing exchange and understanding** between researchers, policy makers, practitioners and the community
8) **Intensive research involvement** at key health system investment points
9) **Capacity building** in key areas, including: use of evidence in policy and practice; large scale data management and analysis; monitoring and evaluation

Options for implementation of these strategies, within a change management framework, are outlined in the report.
1 Introduction

This report was commissioned by the National Mental Health Commission (NMHC) in May 2014 as part of a series of reports feeding into the 2014 National Review of Mental Health Programmes and Services.\(^1\) The report outlines a systems-based approach to mental health research, and identifies and recommends priorities and steps for the Commission to consider. These would need to be consulted upon to test and develop/expand them for implementation.

Mental health problems are complex in nature and are a major cause of morbidity, mortality, disability and lost productivity in Australia. As noted by one leading expert:

> Despite two decades of investment in improving mental health services, the mental health of Australians has not improved.\(^2\)

During the last ten years, a number of forward-looking reports published by Mental Health Commissions, Health Departments, the Council of Australian Governments (COAG), high profile mental health researchers and other mental health experts and organisations have highlighted the need for reform of the mental health system generally.\(^1,3-11\) The NMHC has a long term vision of a mental health system that enables every Australian to lead a ‘contributing life’.\(^4\)

These reports do not focus on mental health research specifically; however the overall tone of these reports is clearly in favour of more evidence-based, people-centred, whole-of-life approaches to mental health in which mental health problems are prevented or detected early and integration across a wide range of sectors and providers is supported.

Some of the recommendations made by the above-mentioned forward-looking reports have direct relevance to research and evaluation; an example of this is the first recommendation of the South Australian Social Inclusion Board’s report on reforming the mental health system:

> People with a mental illness who are consumers of the state’s mental health services should participate at all levels of the system. This will require innovative ways of ensuring their meaningful involvement in planning, organising and evaluating services.\(^9\)

The NMHC itself has identified the need for a strategic and systems-based approach to mental health reform, within which research can play a critical, enabling role.

1.1 The McKeon Review

In late 2011, the federal government asked a panel of experts chaired by Simon McKeon to investigate the state of health and medical research in Australia and to make recommendations about the strategic direction of the sector as a whole. Panel members completed an extensive series of consultations with researchers, clinicians, hospital managers and governments in every state and territory over a period of 18 months, and considered feedback received in response to the release of a consultation paper in 2012. The panel’s final report was released in April 2013 and presented a 10-year strategic
health and medical research plan for the nation.\textsuperscript{12} In its foreword, McKeon states that:

...an overarching message that emerged during this review was the lack of a sufficiently strong connection between health and medical research and the delivery of healthcare services. There is no better means to do this than by fundamentally embedding research within healthcare delivery. That is to say, research must be routinely performed as a part of healthcare delivery and there must be greater linkage between healthcare providers and research organisations...As we face a trajectory of unsustainably increasing healthcare costs, we must use research to improve the efficiency and effectiveness of the health system.\textsuperscript{12}

This message is highly relevant in the context of mental health research. The McKeon Review also strongly supported priority-driven research, noting that:

Australian health and medical research is not sufficiently driven by a nationally coordinated set of priorities and there is currently no nationally agreed mechanism for facilitating this.\textsuperscript{12}

Unlike the UK Medical Research Council’s Review of Mental Health Research,\textsuperscript{13} the McKeon Review did not specifically focus on mental health. In a section on priority-driven research, the McKeon Review did cover four “strategic topics” in some detail: Indigenous Health Research, Rural and Remote Health Research, Global Health Research, and Advances in Genomics. The current report therefore builds upon the discussion presented in the McKeon Review.

1.2 Methods used to prepare this report

The preparation of this report involved a number of methods. Essentially the approach was one of rapid immersion in the literature by team members coupled with interviews of experts in the field in order to gain an understanding of the key issues, and then synthesis of ideas through a process of drafting report sections which were circulated within the team and revised until there was agreement across the team. The project was carried out in two stages, during each of which the NMHC was given the opportunity to comment. NMHC feedback was integrated into the brief, interim and final report. The following steps and activities were involved in preparing the report:

- Agreement on how to approach interviews, including the development of an interview template (see Appendix B)
- Interviews of acknowledged experts and leaders in mental health research (de-identified in this report)
- Rapid literature reviews by different team members, using a variety of online searches (notably PubMed)
- Consideration of a systematic review on how the use of evidence in mental health policy can be increased (provided to NMHC in confidence)
- Analysis by the consulting team which included five members with high level experience in health research and evaluation, translational research and policy, public health administration, and health economics.

Where the report refers to a ‘consensus’ view, this reflects the team’s subjective assessment drawing on, and subject to the limitations of, the steps outlined above.
2 Goals

2.1 The best possible mental health for everyone

The vision of the NMHC is that “all Australians achieve the best possible mental health and wellbeing”.\(^4\) This statement leads naturally to a questioning of the processes, technologies, relationships, institutions, work practices, knowledge, and so on, which affect mental health. There are uncertainties around all of these factors.

In the face of uncertainty any strategy can only be effective if it remains adaptable at the highest level, so that it can respond to new knowledge and experience. This provides a rationale for firmly embedding mental health research in the overarching strategy: generating new knowledge, interpreting it, and then translating it into practice, moving ever closer to the longer term goal, testing and evaluating along the way. This points to a critical, enabling role that research can play, providing evidence to underpin the move towards the best mental health for everyone.

2.1.1 A contributing life

The work by the NMHC suggests that central to the overall vision is the goal of maximising the ability for Australians to live “a contributing life”, defined as “a fulfilling life enriched with close connections to family and friends, and experiencing good health and wellbeing to allow those connections to be enjoyed”.\(^4\)

The notion of a contributing life is more concrete than “the best possible mental health for all Australians”; it focusses attention on factors such as respect, good relationships, having a job, and affordable housing, which are outside the traditional domain of mental health services, programmes and research. A useful way of considering these factors is in relation to Maslow’s hierarchy of needs (see Figure 1 below).

**Figure 1: Maslow’s hierarchy of needs**

```
Self-actualization

Esteem

Love/Belonging

Safety

Physiological

breathing, food, water, sex, sleep, homeostasis, excretion

friendship, family, sexual intimacy

security of body, of employment, of resources, of morality, of the family, of health, of property

self-esteem, confidence, achievement, respect of others, respect by others

morality, creativity, spontaneity, problem solving, lack of prejudice, acceptance of facts
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...
One of the key themes to emerge from the work undertaken in the preparation of this report is that currently mental health services, and the research and evaluation efforts that influence and underpin them, do not appear to respond adequately to the complexity and inter-connectedness of the range of human needs that need to be met so that an individual can live a contributing life.

A recognition of this complexity affects the way in which a discussion of the mental health research portfolio is shaped, and will assist with identifying new and potentially challenging directions for mental health research – moving beyond narrowly focussed clinical research, for example to include sectors beyond health, and responding to the priorities and strategies that are identified in this report.

In this context, it is perhaps also worthwhile noting recent ‘lessons learned’ which emerged from an in-depth retrospective analysis of schizophrenia research overseas (see Box 1 below).

**Box 1: Mental Health Retrosight**

The Mental Health Retrosight project (*Investigation of the translation payback from mental health and neuroscience research with a particular focus on schizophrenia*) examined the development of schizophrenia research over a 20-year period in Canada, the USA and the UK.14

Key observations from the Retrosight project report which may be of relevance to the development of a research strategy in Australia are as follows:

- **Mental health research conducted by researchers who work across boundaries resulted in greater academic and wider societal impacts.** This includes individual researchers and teams whose work spans stages in a translational pathway or more than one discipline

- **Researcher motivation to address patient need seems to be a key driver in determining whether mental health research has an impact.** Motivation may be more important than funding characteristics or research setting

- **Clinical research has had a larger impact on patient care than more basic research over the 20 years since the research was undertaken.** This relationship holds regardless of the approach used to classify ‘clinical’ and ‘basic’ research

- The case studies support the view that **mental health research has led to a diverse and beneficial range of academic, health, social and economic impacts** over the 20 years since the research was undertaken. Wider societal impacts were less common but had a stronger correlation with academic impact than observed in other disease areas
3 Funding of mental health research

Mental health research funding is spread across a range of potential sources. These include the National Health and Medical Research Council (NHMRC) and the Australian Research Council (ARC), as well as a variety of other funding bodies including non-government organisations such as beyondblue and Australian Rotary Health, health departments, Universities, and others also independently fund mental health research projects.

The variety of funding sources, and differences in reporting, mean that the overall picture of funding for mental health research in Australia remains opaque. In this section, in the interest of brevity, only the key findings and conclusions of the team’s analysis of mental health research funding in Australia are presented. Appendix A of this report provides a more detailed discussion including additional information on the activities of a number of funding bodies which were identified during the preparation of this report.

Difficulties with collecting data on mental health research funding are not unique to Australia. In a major exercise, the UK’s Medical Research Council, for example, recently attempted to consolidate data on UK funding of mental health-related research, concluding that:

There was insufficient data available to accurately measure the total investment on mental research each year.¹³

Box 2: Key findings on mental health research funding in Australia

The analysis presented in this section of the report, when combined with the findings summarised in Appendix A, suggest the following key findings:

- Funding of mental health research comes from a variety of sources, notably the NHMRC
- At an average rate of around 19% p.a., NHMRC total funding of mental health research has grown rapidly over the last 15 years
- It is difficult however to reliably quantify where the major research spending in mental health has been occurring (portfolio analysis)
- There is an urgent need to pool knowledge and data about the nature of and investment in mental health-related research nationally
- Mismatches between stakeholder priorities and research funding continue to persist

3.1 Published reviews of funding

Two formal reviews of mental health research funding and outputs in Australia in relation to research priorities have been conducted, using data from 1998-2000⁵ and 2008;¹⁵ these are among the most comprehensive reviews of this nature internationally. They involved rigorous review of funded grants and of publications, along with formal large-scale stakeholder consultation and quantitative data on their stated priorities.
Importantly, each grant was reviewed by content experts according to the information provided to NHMRC and other agencies and was assigned to a single category for each attribute, including the mental disorder investigated and the research goal. This should be considered the “gold standard” for the categorisation and attribution of grant funding, based on the available data. For the data relating to 2008, which is the more relevant of the two to this report, the investigators found that:

- The NHMRC was the major funder of mental health research in Australia
- The proportion of NHMRC project grant funding assigned to mental health research was similar from 2000 to 2008, although it increased in absolute terms over this time
- The top three priority goals among the 570 stakeholders surveyed (including health professionals, consumers, carers and researchers) were: prevention of mental disorders (44% of respondents ranked this in their top three); psychological and social treatments (30%); and evaluation of services (28%)
- The stakeholders’ top three priorities for research on specific mental disorders were: affective disorders (56%); schizophrenia/psychosis (50%); and childhood disorders (39%)
- Prevention and health promotion received the lowest proportion of grant funding among the research goals assessed, and decreased significantly between 2000 and 2008 (from around 7% to <5%).
- Prevention and promotion also accounted to <10% of publications in 2008
- Research funding for affective disorders, dementia and psychosis increased, remained fairly stable for anxiety disorders and suicide, and decreased for childhood disorders

The investigators concluded that despite the mental health policy reforms over the previous decade, there was little change in the focus of research funding or publication output. Moreover, the majority of mismatches between stakeholder priorities and research funding and outputs remained.

Given the acknowledged role of the NHMRC in the funding of mental health-related research, the following section discusses NHMRC funding in some detail – however, a lengthier discussion of data provided online by the NHMRC, as well as information obtained directly from the ARC and from the websites of a number of other organisations that fund mental health-related research in Australia, is included in Appendix A of this report.

3.2 National Health and Medical Research Council (NHMRC)

The major competitive funding body for mental health research in Australia continues to be the NHMRC. The NHMRC consults and interacts with a broad variety of organisations in the health system, however the process of allocating funds to specific research projects is driven by peer review. The main way in which the NHMRC disburses funds is through its annual grants round; however, at a high level, and influenced by National Health Priority Areas such as identified by Australian Health Ministers, the NHMRC can set aside or earmark funds, and issue targeted calls for research, as it has done for mental health in the past five years.
In 2011, the NHMRC committed $26.2 million over five years for research delivering greater evidence-based policies and practices aiming to improve mental health care and the provision of mental health services in Australia. To identify target research areas and to allocate these funds, the NHMRC set up and utilised an expert working group.

### 3.2.1 Total funding

Datasets on the NHMRC’s funding of research, including mental health research, are available for download from the NHMRC website. These datasets show that:

1. **Since 2000-01, NHMRC funding of mental health research has grown ten-fold**, from $7 million to $70 million (see Figure 5); the average annual rate of increase was 19%

2. In the most recent decade for which data are available, **the proportion of all NHMRC funded research which was attributed to mental health has risen steadily from 5.4% to 8.7%** (from $18 million out of $341 million in 2004, to $70 million out of a total of $805 million in 2013)

   - Note that this contrasts with the finding of the formal review to 2008; however, the major reason for this is likely to be that the formal review surveyed project grants, whereas the data in the spreadsheet from the NHMRC website cover all types of funds disbursed (including Strategic Awards, Fellowships, etc.)

### 3.2.2 Funding by Broad Research Area

The NHMRC dataset lists grants by four Broad Research Areas (see Figure 2); as these are mutually exclusive there is no double counting involved with this breakdown of total funding of mental health-related research:

1. Around 40% and 35% of NHMRC mental health research funds go to clinical research and public health, respectively, and around 15% and 10% are attributed to basic science and health services research, respectively.

2. Perhaps the most important finding here is that there has been little change in the shares of Broad Research Areas over the last ten years or so – for example, Health Services Research reached 10% in 2004 and has stagnated there, and Public Health has not returned to the earlier high shares of 39% seen in 2000 and 2007

The NHMRC datasets also present data on funding of mental health research for a number of other classifications (e.g., by type of mental health problem, or by other descriptors such as “Intersection with neuroscience” or “Epidemiology”).

Unlike the Broad Research Areas shown in Figure 2 below, however, these categories are not mutually exclusive, leading to significant double counting. This makes it virtually impossible to reliably ascertain changes in the composition of the NHMRC’s portfolio of mental health research projects using the spreadsheet data in their current form (see Appendix A).
3.3 Analysis of research funding and conclusions

Data on funding of mental health research from the NHMRC, beyondblue and Australian Rotary Health were included in two formal reviews.\(^5\),\(^15\) These do not capture a sizeable proportion of mental health research funding from government and non-government sources.\(^5\) Considering the wide range of funding bodies, and depending on how mental health research is defined and measured, it is likely that NHMRC funding of mental health research is not quite as predominant as may previously have been thought.

As indicated in Appendix A, the NHMRC data that are routinely available on research funding are difficult to interpret, primarily because the focus of research is categorised according to five or more keywords that are chosen by the applicants, which are subject to double- (or quintuple) counting and to gaming.

Where it was possible to compare the publicly-available data to expert review and categorisation, we found that there were material differences between the two, which would lead to different conclusions if the routine data had been used to monitor the effectiveness of interventions to change the emphasis of research efforts. Specifically:

- Investigators using expert review methods concluded that there had been a significant drop in the proportion of NHMRC project grant funding for prevention of/health promotion for mental health problems for project grants starting in 2000 and in 2008 (from around 7% to <5%)\(^15\)
- Following the Christensen et al methods as closely as possible, the publicly available data indicate a decrease of 58% in the proportion of mental health
NHMRC project grants using the keywords “prevention” or “health promotion” starting in 2000 and in 2008, from 12.9% to 5.4% of the total NHMRC mental health related project grant funding for grants starting in those years.\(^{17}\)

- However, the publicly available data also indicate a 43% increase in the proportion of total mental health funding to all NHMRC grants (incorporating project grants, fellowships, strategic awards, programme grants and capacity building grants) with the keyword “prevention”, during 2000 and during 2008 (from 11% to 16%)\(^{17}\)

Acknowledging that the scope covered by these methods differs, the sensitivity of the conclusions to the method used is problematic.

These issues indicate that if the large investment in mental health research is to be monitored properly, it will be necessary to investigate and validate sources of data for such monitoring, and to be clear about what needs to be measured.

Moreover, even if the accuracy and completeness of the available data sources could be assured, the data provided do not allow monitoring against some of the key goals of research reform, including consumer involvement, testing of complex interventions and usefulness for translation into policy and practice.

Caveats aside, the data provide evidence that:

- Mental health research funding through NHMRC has increased rapidly, in line with, and more recently in excess of the general growth in NHMRC funding
- The most commonly used keywords regarding types of research are: public health; intersection with neuroscience; therapies and treatment; interventions; and prevention. Funding to grants attributable to these areas has increased rapidly in recent years
- The most commonly used keywords regarding specific disorders are: affective/depressive disorders; anxiety disorders; schizophrenia/psychosis; and adolescent and childhood mental health issues
- Grants using keywords relating to Indigenous mental health grew rapidly from 2000 to 2009, but have either fallen or remained constant since then

At face value, the data suggest that there may have been some progress towards addressing stakeholder priorities, however it is difficult to come to firm conclusions without additional data and more detailed review of individual grants.

There are persistent gaps between stakeholder priorities and research that is funded, particularly in the areas of health promotion, evaluation and research relevant to disadvantaged groups.

It is important to acknowledge the recent NHMRC $26.2 million priority-driven funding for mental health research over five years, which is significant in being targeted both at mental health and at research that is relevant to policy and practice. This type of priority-driven funding is in line with the recommendations of the McKeon and other reviews, as well as stakeholder perspectives on the needs of the mental health system.
4 Key findings on the status quo

4.1 Excellent performance by international research standards

Australian mental health research punches above its weight. It is important to recognise this, so that changes that are mooted do not undermine the excellent research effort that emanates from Australian initiatives and organisations.

A recent formal review of the overall levels of funding and performance of mental health research in Australia concluded that it received a lower proportion of health funding than other National Health Priority Areas, including cancer, diabetes and cardiovascular disease. Despite this, in psychiatry and psychology, and social sciences, Australia’s performance was in the top five internationally, in terms of both quantity and quality of research publications, outperforming immunology, clinical medicine and microbiology. After adjusting for population size, Australia’s performance in mental health research was excellent in relation to the rest of the world.

The sentiment that Australia’s mental health research is world leading is reflected in other articles such as a paper on the Australian and New Zealand contribution to mental health research publications in high-impact journals, as well as claims made by key research organisations themselves (as evidenced by statements on their websites; some of these are highlighted in Appendix A of this report).

4.2 Questions around overall strategic direction

There is currently no ‘system-wide’ view and/or coordination of the mental health research portfolio for the country as a whole, and hence no overall strategic direction of research.

- The primary drivers of mental health research appear to come from the research community itself, i.e., the field is primarily investigator-driven
- As a consequence, there appears to be a gap between the research that is currently undertaken for very valid academic (and financial) reasons, and the research that might have more direct impact on the individuals and communities living with mental health issues

The creation of Mental Health Commissions at the state and federal levels reflects the need for oversight and coordination functions generally; however, these Commissions currently have little power to directly influence the direction of research.

4.2.1 Mental health research priorities overseas

Several governments internationally have outlined their strategic priorities for mental health research. In reviewing the priorities of countries such as the United Kingdom, USA and Canada, a number of common themes emerge. In particular, these advanced industrialised countries with a number of social and cultural attributes similar to Australia, are seeking to prioritise mental health research focussed on:
- Patient-centred or personalised mental health care
- Identifying efficacious new mental health treatments and interventions
- ‘Outcomes’ that extend beyond symptomology and into functioning, general health and quality of life
- Evaluating the impact of changes in the mental health service delivery system on outcomes
- Opportunities for prevention or early intervention
- Closing the evidence/practice gap

The United Kingdom and Canada are also seeking to prioritise research on:

- Marginalised groups (ethnic minorities, dual diagnosis, people in contact with the criminal justice system, and people with a physical or psychosocial disability)
- Increasing the participation of consumers and carers in mental health research

### 4.3 Consumers and their supporters are insufficiently involved

The literature surveyed during the preparation of this report, as well as interviews with experts, make it clear that listening to people and increasing the capacity for people who live with mental health problems to contribute is a well-accepted goal of mental health system reform generally. For example, the Government of Western Australia’s Mental Health Commission promotes the aim that:

> People with mental health problems and/or mental illness are empowered to have a central role in determining their own relationships and directing their own supports and services wherever possible.³

Similarly, the first priority of the Council of Australian Governments (COAG) vision for reform is to “promote person-centred approaches”.²¹ Last year, the Mental Health Coalition of South Australia published the results of a series of consumer, carer and service provider consultations held in late 2012.²² One of the six key areas which were identified by consumers as areas in which things could work better for them was “Greater respect for the consumer voice”. One of the experts consulted commented that:

> Often it was seen by consumers and carers that research did not have consumers and carers in mind – was the research going to be of value to consumers and carers? If not, why is it being done? Mental health research is often seen as an academic adventure rather than gaining practical and useful change for consumers and carers...

There is a rights-based argument for consumers and their support people being involved in research, but there is also a research effectiveness based argument for making consumers more central to the research process. If research and service sectors are to mesh more effectively, and considering the complexity of mental health issues (genesis, diagnosis, pathways, expression, etc.), there are opportunities for the person living with a mental health problem to become more than just an object of study – he or she can be a repository of valuable information including, of course, being a member of a research team or offering feedback on the outcomes of any interventions or other research that is aimed at them.
4.4 Disconnect between research, policy and practice

Previous reviews of health and medical research in Australia have highlighted a general disconnect between Australian research (which is considered excellent by academic standards) and its implementation, whether for product development, clinical application or system and policy improvement.

The input considered in this report indicates that this situation applies to mental health research in Australia. Interviews with stakeholders indicated difficulties finding appropriate evidence to support policy and practice decision making, an inability of policymakers, practitioners and consumers to directly influence the research agenda and a lack of capacity within policy agencies and health services to evaluate and apply research evidence. One of the interviewees stated that:

- There is a lack of implementation research and evaluation of existing programs; money is handed out for activity, not for outcomes. You wouldn’t do that for physical programs.

Practitioners and policymakers should be able to readily access and use research evidence which is relevant to their work. There is much evidence (e.g. Campbell 2009; Lavis 2004; Lomas 1997) from a range of fields that this is often difficult, if not impossible, to do easily or well: research may not be relevant; research evidence is not presented in a format that is readily accessible; staff do not have time to read through the large amount of material which may be relevant; and staff may not have capacity to appraise and determine applicability of research evidence to their own setting.

This disconnect is extremely important, in terms of its effect on the whole system. First, it means that policy and practice are not included as key drivers of the research agenda. Second, it means that research evidence is not being applied appropriately. Although rebalancing of the research portfolio is important for system reform, this alone will not be sufficient to bring about the optimal generation and application of evidence to improve mental health and mental health care. At this point in time, improvements in the capacity of the whole system to use evidence has the potential to bring about a greater magnitude of benefit – as evidenced by estimates of the substantial disease burden that would be avoided if what is already known were to be applied systematically.

4.5 Under-representation of research addressing real-world problems

The following are seen to be under-represented:

- Action/intervention oriented research
- Complex community level interventions
- Qualitative exploration of the lived experience
- Cost-effectiveness research

Research on prevention, early detection, and whole-of-life support for complex, ramifying problems have the potential to be closer to the consumer experience, but appear comparatively under-funded. Inter-sectoral research, incorporating basic needs such as
housing, employment and education (see Figure 1) also appears under-represented.

Over-represented research methods appear to be:

- Single rather than whole-of-life / complex interventions
- Clinical trials

Basic science and neuroscience projects, and single therapeutic clinical interventions, are considered by some to be over-represented. Many of these lie clearly within the investigator-driven spectrum, are distant from point of impact, and lack ‘scalability’.

Many interventions are researched that would never be scalable. Things that are going to be funded should be asked about whether they would ever truly be applicable in humans, whether they would be scalable and what their likely cost-effectiveness would be.

Research needs to apply to a broader base of the population and relate to earlier and/or wider stages of intervention:

- Within the health system
- The broader community
- Within the criminal justice system
- Disadvantaged or underserved communities including Aboriginal and Torres Strait Islander Peoples, refugees and people of CALD background.

There is a dearth of research drawing together the social, system, and clinical measures along with family, carer and community supports to bring about measurable and sustainable reductions in the burden of mental health conditions.

Innovative trials in ‘real-world’ settings and involving people who would typically be excluded from participating in clinical trials should be encouraged.

### 4.6 Some conditions appear under-researched

Bearing in mind caveats about the issues with focusing on single conditions, the Black Dog Institute’s review of mental health research for the Obsessive Hope Disorder Report, the review of research priorities by Christensen et al, and a number of other publications indicate that the following mental health conditions are under-researched:

- Suicide
- Anxiety
- Dementia
- Personality disorders
- Childhood/youth conditions

It is important to note that certain recent investments in mental health research, such as the NHMRC package referred to in Section A.1 above, are attempting to address some of these gaps in the Australian context. It may be that there is simply a lag in time before this will start to make an impact both in terms of research publications but also in terms of the lived experience.
As argued elsewhere in this report, it is extremely difficult to tell whether or not an
impact has been made without a more rigorous evaluation framework that includes
feedback from those living with mental health problems.

In line with other fields of health research, there are also particular difficulties with
researching complex conditions and multi-morbidity (so-called ‘trimorbid illness’\textsuperscript{35}). Low
level mental illnesses which can impair quality of life and progress to more serious
morbidity may currently also be under-researched.

4.7 **Data infrastructure, workforce, and other gaps**

At present, there is no national ‘data system’ for mental health, in that there are multiple
distinct datasets, with limited ability to coordinate and link data and to collect data on
specific measures to meet stakeholder needs (WA data linkage in mental health is an
exception); nor is there clear oversight of how to create and sustain an appropriate
system in the future. This is in contrast to established and emerging systems that allow
monitoring of system performance (e.g., cancer registrations, adverse events following
immunisation, infectious diseases notifications).

Information provided to this review indicates that many programmes in mental health are
not subject to rigorous evaluation and hence do not provide solid accountability for
investment or evidence to guide future decision-making. Those evaluations that do occur
are almost always based on process rather than outcome measures. At the same time,
in the experience of the consultants having had the opportunity to act as observers in a
variety of settings, staff at many services feel burdened by paperwork and data collection.

Other important gaps identified during reviews of evidence and in interviews include a
lack of capacity in:

- Mental health research workforce, including clinician and consumer researchers,
  with the need to retain mid-career women mentioned as a priority
- Large scale data management and analysis
- Biostatistics
- Evaluation
- Knowledge translation
- Implementation research
5 A systems view and approach

The need to take a systems view and approach to mental health research in Australia is a central finding of this report – many of the solutions to the system as a whole lie beyond re-alignment of the Australian research sector alone. Instead, these solutions are likely to be found in maximising the ability of the health service system to leverage the research sector, by conducting research in partnership, incorporating international research, and in embedding research, monitoring and evaluation into the larger service- and community-based elements of the system.

5.1 What is mental health research not delivering, and why?

Reviews of the available evidence and interviews with relevant experts suggest that mental health research in Australia is considered excellent, by international standards. At the same time, there is a striking consensus that, in keeping with findings regarding health and medical research more generally, that the mental health system and the community are not receiving the evidence they need to support “a contributing life” for all Australians.

There is also general agreement that what the mental health system needs primarily from research is evidence to make appropriate choices and to drive system improvement and innovation. If monitoring and evaluation are considered to be part of the research spectrum, then research has a further role in ensuring system accountability.

The strengths and limitations of data from the research or “supply” side have been outlined in this report in Section 3 and in Appendix A. Data from the mental health service or “demand” side are generally lacking and, when available are mostly small-scale surveys of policy makers and practitioners (e.g., Milat et al 201436). They are not currently available in a form that can quantify the issues across the sector or be monitored to assess progress.

Applying a systems perspective and bringing together the available evidence, a number of things can be considered to be contributing to the current situation, whereby research is of a high standard, but the health system is not receiving and able to apply appropriate evidence:

- The research system and the broader mental health system are poorly connected and have disparate goals and drivers. The mental health research system is largely investigator-driven, with incentives, including funding, oriented primarily around peer-regard.
- The mental health system, incorporating services and programmes, has multiple, complex drivers and faces a range of significant challenges, including a lack of capacity in evaluation and the use of research evidence.
- Although all researchers in mental health would ultimately aspire to reduce the suffering caused by mental health problems, this is not what their performance is measured against, nor is it the key driver of what they focus on. Research performance and academic success are largely measured according to publications, citations, acquisition of competitive funding, prizes, committee membership and
other measures of peer-regard

- Even if it were more appropriately aligned, there is a general lack of capacity within the current Australian research system to meet the needs of the broader mental health system
- The mental health service system is not well placed to maximise leverage capacity and outputs of the research sector

In general, previous approaches have tended to locate the problems within the research sector and to focus on re-aligning research. Clearly, greater emphasis on priority-driven research remains an important part of system reform. However, if this is undertaken in isolation it will not be sufficient to bring about the optimal generation and application of evidence to improve mental health and mental health care. Improvements in the capacity of the whole system (research, policy and service delivery) to use evidence have the potential to bring about an even greater magnitude of benefit.26

The underlying scale and capacity constraints of the research sector need to be taken into account here – there was a general view among interviewees that the mental health research sector in Australia is small, with one of the interviewees describing it as “a cottage industry”. As discussed in Section 3.2.1, NHMRC funding of mental health research rose tenfold over the last decade or so to reach $70 million in 2013; yet this remains a small amount when compared to the direct cost to government of running mental health-related services, which exceeds $7 billion – and previous analysis suggests that the total (direct and indirect) cost to government could be twice as high.37,38

Interviewees also noted that certain types of research that are vital for improving population-level mental health, such as large-scale complex pragmatic community-based interventions, have resource requirements that exceed those provided through traditional funding agencies. At the same time, data from this type of research are required to underpin large investments in programmes and services.

Hence, although the rebalancing of the mental health research portfolio is important and is inextricable from research-service system reform, it is likely that the difficulties experienced by mental health services and programmes in accessing and using evidence are large contributors to the current problems. Moreover, issues with implementation are extremely common, even when evidence-based guidelines exist, as it depends heavily on the functionality of the health system.27 Hence, the wider issues already identified with the functioning of mental health services and programmes are likely to influence their ability to uptake research evidence. More detailed quantitative analysis by experts in the field around these issues may be warranted prior to embarking on reform initiatives, as they may indicate the need to focus on different elements of the system.

5.2 What is a useful systems-based approach?

All of the potential options for addressing the issues in mental health research proposed at the end of this report assume accountable strategic oversight and a set of guiding principles and priorities, to be agreed by key stakeholders, including those living with mental health problems, their families and carers. These are outlined in more detail in Sections 5.3 and 5.4 below.
Further to this, options that incorporate system change and affect multiple parts of the system are likely to have more substantive, multiplicative effects than interventions affecting single points. Such options should therefore be prioritised. Incentives and positive measures, accompanied by a sense of shared goals are among the most effective drivers of change.

The options should focus on:

- Increasing the connectedness and interdependency of the research system and the mental health service system, including: greater internalisation of the needs of the mental health service system into the research system; enhancing elements and infrastructure that support the two systems, such as data; encouraging partnership, interaction and exchange between people operating within the two systems; and emphasising shared drivers, including the need to support a continuing life and to improve the lived experience of mental health problems
- Increasing the overall capacity to generate and obtain evidence to support improved mental health and mental health services
- Increasing the capacity of the mental health service system to leverage research

Figure 3: The research system and the service system in mental health
These approaches are likely to be synergistic. Together, they would be applied with the aim of:

- Increasing the generation of research evidence that is relevant and applicable to the mental health service system and the community
- Maximising the use of research to improve prevention of mental health problems, care and outcomes
- Improving system accountability, sustainability and efficiency

### 5.3 Leadership with strategic oversight

Implementing change effectively requires leadership and strategic oversight. There are a number of existing organisations and processes which provide options for the provision of national leadership and oversight. These include:

- NHMRC (Research Translation Faculty)
- COAG process
- The NMHC

The creation of new bodies / entities or processes is also a possibility, including statutory mechanisms:

- Ministerial portfolio for Mental Health (Commonwealth and State)
- A Cancer Australia equivalent for mental health
- A national Institute for Translational Research in Mental Health

Strategic oversight and leadership is central to effective reform. It should incorporate partnership with key stakeholders, including those living with mental health problems, their families and support people, policymakers and practitioners, at all stages of the reform process.

Strategic oversight should support a whole-of-system (or systems) view and the judicious and timely application of potential solutions. Important additional functions of such oversight include: leadership and vision; priority setting; high-level decision making relating to initiatives and implementation; ensuring rigorous monitoring and evaluation of initiatives and their effects; and risk management.

Other considerations include the following:

- Ideally, an oversight entity would independently and publicly report to parliament on progress against goals, for example in a manner similar to the now abolished COAG reform council
- The oversight of research reform must be integrated effectively into that planned for the reform of the mental health system more generally
- The oversight entity should have “teeth”, that is effective means of implementing and monitoring change

The Review of Mental Health Programmes and Services by the NMHC that is currently underway forms important groundwork for the establishment of leadership and for stakeholder engagement.
5.4 Principles and priorities

The following principles should apply to the rebalancing of the mental health research portfolio, to ensure it optimally improves mental health services and outcomes:

- **Excellence** – the overall excellence and diversity of mental health research in Australia should be maintained, within a system that balances investigator- and priority-driven research
- **Responsiveness** – research should deliver outputs that mental health services and programmes and the community need, according to current priorities
- **Partnership** – priorities for mental health research should be set by a wide range of stakeholders, including people with lived experience of mental illness, carers, service providers and policymakers and research should be conducted in partnership with these groups
- **Relevance** – improving the lived experience, including experience of interventions and supports, of mental health consumers and those caring for them should be central to research
- **Connectedness** – specific measures should be put in place to connect the research and mental health service systems, including methods for translation of research into evidence-based policy and practice and the embedding of evaluation and research into service provision
- **Evidence** – measures to implement improvement should, where possible, be evidence-based and subject to close monitoring and evaluation, to ensure that quality and safety can be maintained and ineffective interventions ceased
- **Accountability** – research should be accountable for the investment made in it

An emerging consensus among stakeholders and a review of system needs yielded the following current priorities – that mental health research should increasingly:

- Be relevant to the real-world needs of those living with mental health problems, carers, the community, policy agencies and health services, including research that:
  - Provides evidence regarding complex interventions, systems of care and pathways, rather than focusing primarily on individual therapies
  - Applies to the broad population of people with mental health problems, including those with multiple complex needs
  - Provides evidence to inform decision-making, including cost-effectiveness research
- Support a whole-of-life approach to management of mental health, including childhood
- Focus on prevention of and early intervention for mental health problems.
- Recognise the interplay between mental and physical health
- Be cross-disciplinary, e.g., include sociologists, economists and demographers
- Go beyond the health sector, to consider the interdependencies between mental health and community wellbeing, employment, education and housing
- Be inclusive of the particular health challenges of disadvantaged groups, e.g., Aboriginal and Torres Strait Islander people, rural and remote communities, and people in the justice system
- Be scalable
Be integrated into service delivery through development of practice-based evidence, quality improvement and evaluation

The systems view which has been identified and emphasised in this report indicates that change needs to happen in the research sector as well as in the service sector. The need for a balance of priority- and investigator-driven research has long been recognised throughout the health and medical research sector, as outlined in the 1998 Wills report and reiterated in subsequent reviews:

Australia needs a well managed, priority-driven programme of research. This programme requires explicit funding, national coordination, and a rigorous priority-setting process. Capacity must be built to undertake this research and to facilitate the transfer of research results into policy and practice.³⁹

Figure 4 summarises the desired change in the focus of the research sector. While Figure 4 clearly does not capture all of the issues discussed above, it reveals the consultants’ assessment that Australian research in mental health needs to be re-balanced away from investigator-driven research and towards priority-driven research (the y-axis on Figure 4).

The balance also needs to move further away from research carried out under controlled conditions (e.g., clinical trials which exclude a significant proportion of the potential cohort) or research that is not realistically scaleable, and towards practical, realistic interventions, drawing on the input from people living with mental health problems and their support groups in the community (the x-axis on Figure 4).

Figure 4: Current and desired focus of research effort in mental health
6 Strategies for bringing about change

This chapter proposes a number of strategies for bringing about change – these strategies are considered to have particular potential to add value and generate yields across the research system as well as through explicit linkages with mental health service delivery. They are also consistent with the systems approach proposed.

Each of the strategies involve an element of capacity building and would benefit from demonstration projects; where the team was able to identify potential ‘lighthouses’ in Australia and from overseas, these have been identified in the text.

6.1 Engagement of people living with mental health problems

Better engagement with, and inclusion of, people living with mental health problems and their support networks, should be a critical part of the overall strategy going forward. Putting them centre stage will challenge researchers to respond innovatively. The following are recommended for consideration as options:

- Inviting people who live with mental health problems, their families and supporters with research experience into research teams
  - Consider paid participation
- Providing, where needed, training in how to work with researchers
  - The Cancer Council offers training for consumers to engage with research
- Including people living with mental health problems in the strategic oversight of the reform process and support novel research methods involving greater empowerment (see Section 6.1.1 below)
- Pushing for the routine incorporation of consumer-based outcome measures in the mental health research and service system
- Championing the case for funding agencies to include consumer involvement as a criterion for funding
  - Consumer participation is already one of the funding criteria for all projects, including those in basic science, funded by the Cancer Council, National Breast Cancer Foundation, and Cancer Australia
- Supporting community based research into “what works”, such as the Arts on Prescription (AoP) models trialled in the UK\textsuperscript{40,41} which by their very nature involve and focus on the lived experience
- Trialling ‘researcher-in-residence’ exercises, along the lines of the following three examples, which are drawn from a recent paper\textsuperscript{21}
  - Operational researchers in front-line delivery teams
  - Anthropologists working as members of an executive team
  - Health Services Researchers working across an integrated care organisation

The aim for the research sector should be to foster true, genuine and respectful participation, with the expectation that this would generate a stream of new and valuable research perspectives and projects, as well as helping deliver and account for improved outcomes. Bradley Foxlewin, the Deputy Commissioner of the Mental Health Commission of NSW, has emphasised the importance of building relationships.\textsuperscript{42} An example of strong
consumer involvement is the UK’s National Health Service (NHS) Clinical Research Network for mental health, with a strong focus on easy access to research (see Section 6.7.1).

### 6.1.1 Expanding user-controlled research

This section has been adapted from the UK’s NHS Good Practice Guidance for Involving People with Experience of Mental Health Problems in Research. The guidance document notes that:

> Over recent years there has been an increase in the number of people with experience of mental health problems carrying out research themselves. In the majority of cases such people work within and alongside existing research teams. Most commonly such people identify themselves as ‘service user researchers’.

In the UK, well known research groups that include service user researchers are the Spectrum Centre at Lancaster University and the Service User Research Enterprise (SURE) at the Institute of Psychiatry (see Section 6.1.4 below).

In 2010 INVOLVE, which is an initiative funded by the UK’s National Institute of Health Research (NIHR) to support public involvement in research, produced a publication showcasing seven user-controlled research studies. This identified three broad reasons for why user-controlled research projects were conducted:

- To make change happen
- To highlight the needs of marginalised people
- Because ‘No-one else will do it’

The benefits of such user-controlled research projects were identified in the same report as being:

- Making change happen
- Access and trust
- Improved research quality
- Empowerment
- Credibility

### 6.1.2 Lighthouse 1 – The National Empowerment Project

The National Empowerment Project (NEP) is Aboriginal and Torres Strait Islander-designed and led. It utilises a Participatory Action Research model in order to give a ‘voice’ to participating communities and adapt all work to local needs. The NEP emphasises self-determination, a community-based approach, holistic perspectives, Aboriginal and Torres Strait Islander diversity and acknowledging a history of colonisation. The NEP website indicates that research projects may already be planned or underway (the website link on research simply states ‘coming soon’) and it may be possible to pursue opportunities for mental health research in collaboration with the NEP team.
6.1.3  Lighthouse 2 – Families/Friends and Carers Together in Research

Family members and friends who support people with mental health problems have extensive knowledge and experience that can really make a difference to research projects. Families/Friends and Carers Together in Research (FACTOR) is a network of family members and friends of people with lived experience of mental health problems which facilitates opportunities to get involved in research. This involvement may constitute attending a one-off meeting to give advice on a specific proposal, joining a research project steering committee that meets regularly, or going to meetings of a group of researchers planning future studies. The Network also publishes a bulletin that is sent out to carers with an interest in research.46

6.1.4  Lighthouse 3 – The Service Users Research Enterprise

This British initiative relates to testing the effectiveness of services and treatments from the perspective of people with mental health problems and their carers. The Service Users Research Enterprise (SURE) is the largest university unit in the world which employs people who have both research skills and first-hand experience of mental health services and treatments.47 They carry out service user led studies, such as developing Patient-Generated Patient Reported Outcome Measures (PG-PROMs) on neuroleptic side effects, as well as collaborating with academics on all aspects of mental health research.

6.2  Embedding research and evaluation in service provision

6.2.1  Commissioning of research by health services

There is a need to shift the balance of the research-health system relationship from a predominantly supply-driven one to increase the amount of demand-driven research. A fundamental change would be the effective use of a proportion of health service budgets for monitoring, evaluation and research, and to put structures in place to allow services to commission research and to partner in collaborative research projects.

Under the National Health Reform Agreement (NHRA) agreed in 2011, teaching, training and research (TTR) functions undertaken in public hospitals are block funded as per bilateral arrangements between the Commonwealth and each state and territory. The McKeon Review strongly supported the use of the allocation to drive research from within the health care system, but noted the range of difficulties in doing so, including strong competition for resources.12

The commissioning of research by health service and policy agencies and its collaborative conduct and implementation should ensure that their priorities are served by research. Moreover, the partnership of research and service should allow the efficient support of larger scale research, for example by embedding research into the roll out of programmes. The partnerships formed should also build relationships and understanding between disciplinary groups.

One interviewee noted that working with people from different disciplines is a major factor in innovation – the system of commissioning should promote this:
Innovation often comes from analogies from other areas and from working across disciplines...it is important not to do research only with your friends – forge new relationships.

The agencies able to commission research should reflect the diversity of services in the mental health care system, including community services and primary care.

The commissioning of research should be part of a broader initiative to embed monitoring, evaluation and research into health services. Substantial capacity building will need to occur to support this process, including support to identify and articulate research questions of importance to the service, to work effectively with researchers, to interpret research findings and implement interventions flowing from research findings (see Section 6.7.1). These should form part of general capacity building on the research-policy-practice interface (see Section 6.6).

### 6.2.2 Monitoring and evaluation

Monitoring and evaluation are essential to quality improvement and a number of issues with these in the mental health area have been identified in this report (see, for example, Section 4.7).

Reform of the research and broader mental health system will require careful attention to monitoring and evaluation within health services, including in the context of data and data systems (see Section 0). Specific areas requiring attention include the need to:

- Clarify performance measures, including the proposed outcomes framework (see Section 6.3.5). Performance measures should include genuine person-centred outcomes
- Streamline data collection including:
  - Reducing collection of data that are not used or under-used
  - Using data systems that ensure data are “collected once and used many times”
  - Build capacity in collection, analysis and interpretation of data
  - Build capacity in evaluation
  - Pool and link data for large scale analyses and monitoring of variations in care
  - Optimise use of new technologies, including consumer-controlled data collection mechanisms
  - Partner with researchers to optimise development and use of indicators
  - Create peer-support networks around monitoring and evaluation

### 6.2.3 Lighthouse 4 – Evaluation of Improved Access to Psychological Therapies

This is a large scale evaluation of a government mental health initiative. The *Improving Access to Psychological Therapies* (IAPT) programme is one of the largest-scale examples internationally of an evidence-informed mental health policy. Launched in the UK in 2008, this programme aims to substantially increase access to the psychological treatments judged by the National Institute for Health and Clinical Excellence to be evidence-based, primarily cognitive-behavioural therapy for depression and anxiety.
In the first three years of the programme more than 1 million people were treated in IAPT services and more than 680,000 of these completed a course of treatment. Recovery rates have consistently exceeded 45%.

Working with and within mental health services is often difficult or impossible for mental health researchers in Australia. Few services have the infrastructure, time or incentive to participate heavily in research. In addition, there are few clinician/researchers available to champion research and provide leadership and support. These factors have led to a major deficit in the type of translational research needed to underpin the reform of Australia’s mental health service system. The UK National Institute for Health Research has established programmes which address these issues.

6.2.4 **Lighthouse 5 – The At Home/Chez Soi demonstration project**

This Lighthouse is an exemplar of ‘real life’ research that looks beyond the traditional health sector and measures of treatment efficacy. At Home/Chez Soi was a research project funded by the Mental Health Commission of Canada involving 2,825 homeless Canadians living with moderate to severe mental illness. It was designed to deliver and evaluate the “Housing First” approach to ending homelessness compared to treatment as usual.

Participants in the “Housing First” group were offered the opportunity to live in permanent housing and to access Assertive Community Treatment over the study period. Participants in the treatment as usual group were able to access the services generally available in their city. Results to date indicate that “Housing First” reduced reoffending amongst formerly homeless adults with mental disorders, improved subjective quality of life and was associated with positive recovery trajectories.

6.3 **Competitive funding schemes for priority-driven research**

Traditional funding agencies, such as the NHMRC and ARC remain important sources of support for mental health research. Continuing initiatives to ensure priority-driven mental health research through these agencies are important for increasing priority-driven research. From our review of the available information, although broad priority areas are often named, these and other organisations have had difficulty incorporating priorities into funding decisions in an ongoing, systematic and transparent way.

“Soft” levers, such as naming and publicising of priorities, appear to have had a limited effect on funding profiles over the past two decades (see the discussion in Section 3 of this report). The application of “hard” funding levers or incentives is likely to result in more rapid and specific changes in the balance of funding through traditional funding agencies.

The mechanisms for deriving and applying appropriate priorities to research are likely to be specific to each funding scheme, but should interface with the process of strategic oversight and priority-setting discussed in this report.
6.3.1 Dedicated funding for priority-driven research

Dedicated funding for priority-driven mental health research is required and should be ongoing; existing, applicable models include:

- The creation of new schemes to fund priority-driven mental health research. This could include stand-alone dedicated funding through a new scheme and/or variations on existing models, e.g.:
  - Application of priorities to and additional funding for grants in mental health – for example, the model used by Cancer Australia in their Priority Driven Collaborative Cancer Research Scheme, whereby additional research funding is disbursed by Cancer Australia. Project grant applications in cancer that are designated “fundable” following the NHMRC process are assessed by a panel that includes consumers and have priority criteria applied to their initial NHMRC scores. This tends to result in selection of more applied and consumer-oriented research from the general pool of investigator-driven research
  - Calls for research to answer specific research questions or smaller priority areas. This is the model used by the Heart Foundation Focus Grant scheme which provides funding to researchers to answer specific research questions, derived from priority-setting within the Heart Foundation

- Strategic initiatives within the traditional funding agencies. For example, the 2012 NHMRC $26.2 million priority-driven funding to support research delivering greater evidence-based policies and practices aiming to improve mental health care and provision of mental health services provides an exemplar of how identified priorities can be implemented in practice. The initiatives that were funded through this scheme align well with the priorities elicited as part of this review, and also demonstrated a broad portfolio of funding, including projects, fellowships and Centres of Research Excellence. beyondblue’s National Priority Driven Research Program and its Victorian Centre of Excellence in Depression and Anxiety are additional examples of this approach.

- Fellowships to support individuals working on mental health in priority-related areas and/or using priority methods. The one-off NHMRC John Cade Fellowship in Mental Health Research is an example of this

6.3.2 Research funding based on partnerships

Facilitation of research funding based on partnerships between researchers, policy makers, practitioners, consumers and other groups, such as industry. This model could include:

- Structured competitive calls for partnership similar to the Heart Foundation Partnership Engagement Grants (e.g. for ARC Linkage and NHMRC partnership project grants)

- Participation in and allocation of funding to large scale projects based on multiple funding partners, including NHMRC Partnership Centres and Cooperative Research Centres
6.3.3 Preferencing through application of criteria

Application of criteria allowing mental health research or sub-categories of mental health an advantage within competitive funding agencies, for example by applying a lower cut off for funding or weighting of scores. This has been the approach used within the NHMRC for increasing funding to Indigenous Health. This option is included here for completeness but is unlikely to be acceptable to existing competitive funding agencies (i) because the NHMRC and ARC fund research in general annual grant rounds according to quality determined by peer review, rather than research topic, and this would not be in keeping with the “level playing field” they are committed to and (ii) this approach would potentially increase funding to mental health and broad areas but would not allow the complex application of priorities.

6.3.4 Accessing other sources of funding

A suggestion from one of the researchers interviewed was the earmarking of funding from specific sources to mental health research relating to outcomes known to be related to that source. For example, a proportion of alcohol or tobacco taxes could be allocated to mental health research relevant to these exposures, with the incorporation of appropriate priorities.

Increasing philanthropic funding for priority-driven mental health research was also mentioned as having considerable potential.

6.3.5 Widespread adoption of a more person-centred outcomes framework

At present, services and programmes are not consistently monitored and/or evaluated. When they are, it is often in terms of process rather than outcome indicators. There is a need to:

- Measure outcome as well as process indicators
- Ensure the consumer and carer experience are prioritised
- Embed evaluation and research into all services
- Ensure accountability for mental health investments
- Drive quality improvement in relation to outcomes that matter to stakeholders

An important element of mental health system reform is collecting data to serve these aims, incorporating data on defined outcomes of service, including functioning, key symptoms, and mental health measures, ensuring that how consumers are functioning and feeling is adequately reflected. Moreover, incorporating the experiences of those living with mental illness into real-world data systems will ensure that optimising these outcomes is a key driver of the mental health system.

In keeping with the emphasis on early intervention, being person-centred, acknowledging complexity and heterogeneity of experiences and need, areas that could be included in an outcomes framework should focus on functioning and broader indicators of wellbeing, rather than emphasising syndrome progression. This has the added advantage in allowing common data elements regardless of an individual’s underlying condition, which is often
complex and difficult to classify. Such an approach has been found to be practical in extreme settings, including conflict zones (de Jong 2011, Lokuge et al. 2013). Potential elements of an outcomes framework include:

- Functional status [self-rated functioning, wellbeing, relationships, social and economic participation]
- Physical health
- Alcohol and other substance abuse
- Self-harm and suicidal behaviour (including unexplained accidental death)
- Syndromal progression/course of illness

The outcome framework could contain data elements gathered via a number of sources, with the key one being the patient themselves. It also has the potential to be incorporated into electronic media, including those that are controlled by the consumer. It is also important that the framework be brief and simple to administer, and where possible, to be integrated into existing data collection systems. As has been highlighted, the efficient use of outcomes data will also help improve the consumer experience, as one consumer requested:

All services [should be] linked and in communication with each other and with support workers. [There should be a] National access/database for medical and mental health related organisations so I don’t have to repeat my story over and over again!

An outcomes framework incorporating person-centred outcomes, including functional status and psychological measures, has already been developed for reporting on State and Territory services. The development of national outcome standards for mental health services was an agreed objective of the 1992 National Mental Health Strategy. The need to measure “consumer” outcomes was identified early in the process and field tested, with implementation commencing from 1998-2003; this innovative move placed Australia at the forefront internationally as no other country had incorporated these types of measures across publicly funded services.

The Australian Mental Health Outcomes and Classification Network (AMHOCN) was established by the Australian Government in December 2003 to lead and support the sustainable implementation of the outcomes and casemix collection as part of routine clinical practice. It aims to support states and territories and to work collaboratively with the mental health sector “to achieve the vision of the introduction of outcomes and casemix measures”. In 2005, AMHOCN produced an initial reporting framework stating that:

The reporting framework is based on the extensive work undertaken by many people working in Australia’s public mental health services, including consumers, carers, clinicians, service managers, who are implementing an outcomes focus within their local services.

By 2009, over 95% of State and Territory mental health services were estimated to be involved in routine collection and use of consumer outcomes data. In November 2013, AMHOCN released a paper summarising current state and territory reporting requirements for the Mental Health National Outcomes and Casemix Collection. This document was endorsed by the Mental Health Information Strategy Standing Committee.
(MHISSC), which in turn considers input from the National Minimum Data Set Subcommittee. The paper also states that expert advisory groups have been set up to provide input from clinicians, those living with mental health problems and their support people.\textsuperscript{60}

From the information reviewed, Australia is considered among the world leaders in incorporating consumer information in assessment of services.\textsuperscript{60} At the same time, there is a consensus that most services and programmes do not undergo appropriate review from this perspective. Bringing the evidence together, it is the view of the consulting team that:

- Considerable resources and decades of work have gone into developing and harmonising mental health outcome measures, including consumer-oriented outcome measures, designed to cover health services managed by or in receipt of funds from State or Territory health authorities.
- It is unclear how advanced these efforts are in terms of their practical implementation.
- These types of measures do not appear to be in widespread across the full mental health service sector, i.e. including services beyond those specifically covered by the AMHOCN.
- Although these outcome measures are considered brief by standards of the discipline, they are relatively long in general terms, with over 40 items in the briefest measure identified\textsuperscript{60}
- It is unclear at this stage whether the currently available data are able to inform the type of research and evaluation efforts that have been outlined as being of critical importance in this report.

It is important at this stage to support and build on the existing efforts with a view to: (a) gaining coverage of the broader mental health services sector; (b) making data more accessible; (c) supporting an explicit effort to involve researchers and people living with mental health problems and their supporters in the refinement of the outcomes framework.

\textbf{6.4 Data and data systems}

A high quality data system is crucial to the future of mental health services and research and is highlighted as a priority of the McKeon review.\textsuperscript{12} The evidence reviewed to date shows that a functional data system is among the most important tools to bring about improvement, in that it can:

- Allow monitoring of, and accountability against agreed key performance measures.
- Underpin the integration of key performance drivers and measures into the broader mental health system, including outcomes of service and the lived experience of consumers and carers.

Provide a major means of connecting the research system and the mental health service system (see
Without appropriate data systems, the mental health system will not only be ‘flying blind’, it will also be deprived of the main means of learning from experience and of ensuring accountability for the very large investment made. Data allow us to understand how we are travelling, where we should go next, what has worked and what hasn’t; data are also essential in maintaining the cohesiveness and sustainability of efforts to bring about reform.

6.4.1 Audit of existing data and data systems

Where possible, data systems should use and build on existing data and data linkage platforms. An audit of existing mental health data collections and frameworks, building on what is known, would be important prior to system development.

The items on which data are collected play a key role in defining how performance is measured and consequently how a system functions. The ability to link data adds an important dimension to monitoring, evaluation and research, and offers the possibility of tracking the consumer journey.

The large-scale data currently collected on mental health through the mental health system are largely driven by administrative requirements particularly relating to payment for services. These include mental health relevant data on MBS and PBS items, hospitalisations, deaths, workforce and State-specific services. Other sources of information include: survey data (e.g. the Australian Bureau of Statistics periodic surveys of mental health and wellbeing) research study data (e.g. PATH through life, the 45 and Up Study, Women’s Health Australia), data from specific mental health programmes and related research (e.g. data from individual Aboriginal community controlled health services, mental health initiatives, Black Dog Institute) and other data (e.g. primary care data from MedicineInsight).

6.4.2 A minimum data set for monitoring and evaluation

A fully functional minimum data set, able to cover a large portion of mental health services, including those provided by the Commonwealth and reflecting the person-centred approach suggested in Section 6.3.5, has the potential to underpin monitoring and evaluation efforts and would be a highly useful tool for system reform.

The perceived benefits of having a minimum dataset include its enabling functions in:

- Large scale monitoring
- Evaluation and research
- The understanding of change over time
- Genuine incorporation of and hence prioritisation of consumer experiences
- Measurement of effectiveness and efficiency

As discussed in Section 6.3.5, work on collecting and harmonising data for a National Minimum Data Set for service monitoring of State and Territory mental health services is
already underway, however the coverage of this data set is limited. The Australian Institute of Health and Welfare website indicates that the MHISSC provides advice and currently leads work on the establishment of new mental health National Minimum Data Sets. None of the interviewees mentioned the current efforts that have been identified in Section 6.3.5, suggesting some barriers to awareness.

Characteristics of measures suitable for a minimum dataset include those that apply broadly, regardless of underlying mental health problem. The agreement on an outcomes framework and minimum dataset could improve monitoring and programme efficiency by allowing services to build on an agreed template. Other elements of a minimum dataset could include information permitting tracking and linkage, and the characteristics considered material to services and outcomes.

It should be acknowledged that it is much more difficult to agree indicators and items for a minimum dataset for mental health than for conditions such as cancer and other notifiable diseases. The heterogeneity of mental health conditions and the lack of agreement on various scales and metrics play a role in this. However, the social and economic costs of not having a useable minimum dataset are also likely to be high, in terms of reduced efficiency.

6.4.3 Systems for making appropriate use of data

Data take many forms and appropriate infrastructure is required for the optimal use of all data types, including qualitative and quantitative data. The use of large scale data underpins many of the recent public health advances, increasing statistical reliability, as well as the scope, timeliness and efficiency of research. Data collected relevant to mental health should ideally be scalable, such that they can be applied for monitoring and evaluation of individual services, service groups/sectors/regions and on a larger scale.

Several interviewees commented on the importance of linked data. Highly functional data linkage systems provide valuable infrastructure to support and encourage health services and other practice-relevant research. The general experience has shown that they attract researchers with high-level quantitative skills to conduct research that is readily translatable and real-world, not least because it builds directly on elements of the health service itself. It is efficient, in that data are collected once, but are used for multiple purposes.

Data linkage is important to underpin monitoring, evaluation and research. Frequently, elements of service and evidence regarding outcomes exist in different datasets. For example, data regarding suicide are in State and national death datasets, while data regarding services and other relevant data (e.g., contact with the justice system) are held elsewhere. Although there are notable examples of work in this area, including the Western Australian Data Linkage Service, data linkage relating to mental health is relatively limited.

Efforts to improve data linkage relevant to mental health should involve building on existing initiatives such as NCRIS and PHRN, and state-based data linkage units:

- Harnessing existing mechanisms through the Commonwealth and recognised
integrating authorities
➢ Working to facilitate access to shared large-scale linked resources for researchers and service providers

Systems for the synthesis and integration of qualitative information are also in place and others are being developed. Examples are the University of Oxford’s HealthTalkOnline63 and the Consumers Health Forum of Australia’s ‘Real data, real people’ initiative.64 The approaches to “big data” are constantly evolving and hold great promise for innovation. However, to harness this potential, the data have to be collected and in a form capable of being used.

6.5 A “What Works” and “Best Buys” resource

A range of issues regarding the disconnect between research, policy and practice have been identified and are discussed in Section 4.4. Additional related issues include:
➢ The relatively small size of the Australian mental health sector
➢ The imperative that policy and practice should be based on the sum total of the best national and international evidence
➢ The difficulties researchers have in ensuring their finding reach the appropriate policy and practice audience

These issues point to the need for a service that integrates evidence on the efficacy, effectiveness and cost-effectiveness of mental health interventions, including systems of care, and which provides it in a form that can be used by practitioners, policymakers and the broader community. This initiative would provide high value to the health service, policymakers and researchers.

A web-based resource or portal with information on “what works” and “best buys” is an option worth considering. Such a resource or portal should be designed specifically around the needs of policy makers and those working in the mental health system, and with a section dedicated to providing information for the general community, including those living with mental health problems and their support people. By incorporating international evidence, this service would allow the Australian mental health care system to leverage international investments in research.

The Australian “what works” and “best buys” portal could build on other evidence integration initiatives internationally, including the mental health elements of the UK “what works” network65 and the Cochrane Library.66 It could be part of a Centre of Research Excellence focusing on the use of research evidence to underpin mental health care, or equivalent. Moreover, it could become an expectation that researchers in mental health, especially those funded through NHMRC, ARC and NGOs would actively contribute to the resource and that inclusion of work on the “what works” portal would be something to aspire to.

6.6 Improving the research, policy and practice interface

Improving the research-policy-practice interface is a key area that will drive change. To design and undertake research that will have real-world applicability, and for relevant
research findings to be taken up by policy makers and practitioners there needs to be a two way exchange of information and learnings. Researchers need to understand how mental health services and practitioners work and what policy makers and practitioners see as important areas for research. Policy makers and practitioners need to be able to readily access information from research that will inform the development of policies and practice.

The gap between the worlds of research and those of policy and practice and service use is generally acknowledged.67,68 A number of strategies have been employed to bridge this gap generally as well as specifically in the mental health sphere.

Some strategies already in place and other suggestions to improve the research-policy/practice interface include those driven or supported at the level of funder, research/academic institution, health service, researcher or policy maker/practitioner. These include:

- NHMRC Centres of Research Excellence which support collaborative approaches to research. The CREs for mental health and substance use and for suicide prevention (others) are examples
- Changing drivers for academics/researchers from publication as a benchmark of success to those that reward engagement with policy makers and practitioners and where there is an impact on the delivery of health services and/or health outcomes
- Ensuring that research addresses real-world problems by including practitioners and consumers from the outset of the research process. This may involve embedding researchers into service delivery as part of their training, and building an understanding of translational strategies into researcher training from the beginning of their careers
- Holding forums for exchange between researchers and policy makers and practitioners to discuss and progress common understanding and goals, and identify areas where more research is needed
- Developing working relationships between researchers and practitioners, and networks

The Sax Institute identified learnings from Australian and overseas experiences indicating the need for:

- A more coherent approach from policy and service agencies in setting priorities for areas where research evidence is required so that research priorities can be better aligned with the system priorities
- More flexible research funding approaches that recognise the benefit of both the community and policy/service/clinical experts in the setting of research priorities and in the framing of research questions, study design and conduct and reporting and dissemination
- Research funding arrangements that are more diverse than investigator-initiated models, e.g. proposals involving joint researcher/policy or service or clinical; and research that is undertaken through commissioning around particular issues and is academically rigorous
- Developing incentives for researchers to be able to pursue research careers that
are largely built around priority-driven research and that recognise a mix of research, policy management and/or clinical skills rather than just a high degree of excellence in a particular discipline.

The evidence to date indicates that improving the research-policy-practice interface requires multiple integrated strategies, incorporating the components outlined above. The Centre for Informing Policy in Health with Evidence from Research (an NHMRC Centre for Research Excellence headed by the Sax Institute) is investigating the tools, skills and systems that might contribute to an increased use of research evidence in policy. Its tools are also being adapted for the practice setting. A major goal is to identify scalable solutions to the issue, with an emphasis on systematic capacity building relevant to the use of evidence in policy and practice, and on increasing exchange and partnership between researchers, policy makers and practitioners.

6.6.1 Lighthouse 6 – Penn State University and the Pennsylvania Commission on Crime and Delinquency

This partnership between the Prevention Research Centre at Penn State University and the Pennsylvania Commission on Crime and Delinquency (PCCD) promotes the dissemination of evidence-based practices, and supports the effectiveness and sustainability of their implementation through the provision of practical, technical assistance. The PCCD funded a technical assistance centre to support ‘Communities That Care’ coalitions throughout Pennsylvania and established an additional state-funded initiative to provide grants for the adoption and implementation of a set of specific research-based prevention and intervention programmes for children and youth.

Over a ten year period more than 100 community prevention coalitions have been created as a result of these two initiatives and nearly 200 replications of evidence-based practices have been funded. Population level rates of delinquency and substance abuse have been shown to be significantly lower in areas where the combination of ‘Communities That Care’ and specific evidence-based practices have been adopted, and adolescent developmental trajectories have shown sustained improvement.

An important lesson from the programme has been that structured, ongoing support and technical assistance is required to assist sites in overcoming the barriers to implementation quality and sustainability. Seed funding and support is not enough.

6.6.2 Lighthouse 7 – Center for Psychiatric Rehabilitation at Boston University

The Center is funded through a cooperative between the National Institute of Mental Health and the Rehabilitation Services Administration. Unlike most university/policy partnerships, its funding agreement stipulates that both time and money be invested in the translation and dissemination of research-based knowledge to policy makers and practitioners. They have developed a set of principles for evidence-based messaging that they employ in all their programmes:
- Develop evidence-based messages from a body of research not a single data set
- Build credibility with decision makers as legitimate developer of evidence-based messages
- Develop knowledge transfer expertise and infrastructure within research organisations
- Convey evidence-based messages using organised approaches to achieve targeted outcomes
- Routinely evaluate evidence-based messaging efforts

6.6.3 **Lighthouse 8 – The Provincial Centre at the Children’s Hospital of Eastern Ontario**

The Provincial Centre of Excellence for Child and Youth Mental Health at the Children’s Hospital of Eastern Ontario is funded by the Ontario Ministry of Children and Youth Services. The strategic goals of the centre are to: 1) support the use of evidence-based knowledge and practice; 2) maximise capacity in training, research and evaluation; and 3) collaborate with stakeholders to make child and youth mental health matter across Ontario. The Centre provides grants and awards to organisations and individuals and is involved in initiatives including information networks and communities of practice, family mental health in the work place, credible evidence reviews, toolkits on knowledge mobilisation and programme evaluation, interactive online health programmes for youth and mental health screening in primary care. The centre also provides free consultation services on evaluation and offers programme evaluation grants.

6.7 **Intensive research engagement at points of significant investment**

There are critical points in the development of the mental health service system where the involvement of researchers is likely to be of particular importance. These include times when decisions are being made about the adoption of new programmes and when such programmes are being rolled out. A useful resource at these times would be a multidisciplinary research ‘flying squad’ that would be able to assist in areas such as: evidence-based decision making; cost-effectiveness analyses; design of programme evaluation including embedding of evaluation in programme rollout; data collection systems; analysis methods; interpretation of findings and dissemination of results. The ‘flying squad’ would help to ensure that the knowledge generated by the evaluation is able to contribute to the system as a whole.

The targeted use of the ‘flying squad’ at points of significant investment in the mental health system will help to ensure evidence-based decision making, efficiency and appropriate evaluation.

6.7.1 **Lighthouse 9 – The Clinical Research Network**

The Clinical Research Network (CRN) provides the infrastructure that allows high-quality clinical research to take place in the National Health Service (UK). The CRN enables researchers to set up clinical studies quickly and effectively; supports the life-sciences industry to deliver their research programmes; provides health professionals with
research training; and works with people living with mental health problems to ensure their needs are at the very centre of all research activity.

6.8 Capacity building

All of the initiatives outlined above require significant capacity building. Specific areas of identified need are:

- Workforce for monitoring, evaluation and generally dealing with data, particularly large scale quantitative data
- Skills in developing and articulating research questions and issues that can be addressed through research, monitoring and evaluation
- Skills in the use of research evidence in policy and practice
- Skills for practitioners in partnering with research, and for researchers in partnering with practitioners
- Individuals who are able to bridge interdisciplinary and inter-sectoral gaps, including clinician-researchers

It will be important to create specific initiatives around capacity building and/or include it within each area of the strategy. Capacity building will need to be appropriately resourced.

Sources of expertise for capacity building include Centres of Research Excellence in translation, and such centres could serve as ‘hubs’ for training. Such training could include the development of scalable systems for capacity building in monitoring and evaluation and in the use of evidence for policy, planning and service improvement. The CIPHER CRE is developing and trialling such methods.

Other possibilities include adding mental health components to existing data-related training programmes such as the Biostatistical Collaboration of Australia and the NSW biostatistical training programme. Scholarships and fellowships in priority areas of mental health research will build capacity in the mental health (research) workforce as well as build the body of evidence.

6.8.1 Lighthouse 10 – NIHR Integrated Academic Training Programme

The National Institute for Health Research (NIHR) Academic Clinical Fellowships allow medical and dental trainees to undertake 25% research and 75% clinical training over 3 years (4 years for GPs) and Clinical Lectureships (CLs) allow trainees to undertake 50% research and 50% clinical training over 4 years. The posts are allocated to institutional partnerships of University, NHS Organisations/ Trusts and Local Education Training Boards (LETBs), the latter having taken over the functions of Postgraduate Deaneleries from April 2013 onwards. Academic trainees are recruited by the LETBs through open competition via a nationally developed process for academic recruitment run by NIHR TCC.

The schemes were initially developed through an Implementation Group, then maintained by a Task and Finish Group and now continued support is offered by an Advisory Panel that works with the Dean for NIHR Faculty Trainees, Professor Jim Neilson.
The Advisory Panel is supported by NIHR TCC as secretariat, and has advised NIHR on arrangements for ensuring the success of schemes within the Integrated Academic Training Pathway.
6.9 Risk management

Any action or indeed, inaction, entails risk. There are a range of unintended adverse consequences that could potentially result from the initiatives proposed here. For example, Australian researchers conduct outstanding mental health research. It is important that efforts to redress the identified imbalances do not jeopardise this. Similarly, efforts to increase research should not compromise front-line mental health services.

Risk management is essential to any strategy, with goals and performance measures identified clearly, monitoring of both outcomes and adverse events and action on feedback to mitigate risks. Risk management needs to be incorporated within each element of implementation, with mechanisms for overarching risk management, which could be the remit of the strategic oversight entity.
7  A change management strategy

7.1  Who or what needs to change?

A strategy links action with long term goals. The long term goal of a contributing life for every Australian relies on significant change occurring in a number of areas, notably mental health services and research.

Australian mental health research is excellent and, as evidenced during the interviews carried out for this report, the leaders in the field have a passion for the cause. Innovative and acclaimed research initiatives driven by these leaders are beginning to align with the principles and priorities discussed in this report.

Although change appears to be happening slowly, it would be a premature to blame the research sector for a slow rate of change in general. There is always a lag between innovation and widespread adoption.

A major issue identified in this report is related to scale and connectedness. The mental health research sector, even though growing rapidly in recent years, is in turnover terms miniscule when compared to mental health services as a whole – probably less than half of one percent in size.

The question arises therefore how any change in the way research is done could show up in the bigger picture. The only way in which this would be possible clearly is if research produces scalable solutions and if there is a high degree of leverage on research by the broader mental health sector. This depends, to a significant degree, on capacity outside the research sector itself.

It follows that effective change must involve the research and the mental health service systems and other stakeholders such as people living with mental health problems. This affects the target audience for the change management strategy.

The consulting team carried out a rapid online review of change management models and theories. It quickly became apparent that Dr John Kotter’s 8-step process for leading change is the dominant model and should indeed be considered in this context. For clarity, this Section uses the eight steps of the Kotter model as the next eight headings.

7.2  Establishing a sense of urgency

The starting point of the journey is critical in Dr Kotter’s view; he claims that nearly half of the organisations that fail to make needed change make their mistakes at the very beginning.

True urgency involves people being clearly focussed on making real progress every single day and, according to Kotter, urgent behaviour is driven by a belief that the world contains great opportunities and great hazards. Furthermore, according to Kotter, the problem in failed change initiatives is rarely that the case for change is poorly thought out (or not supported with sufficient facts), but that these initiatives engage only the head and not the heart.
While a broad vision for the future of mental health research may be generally agreed upon – see Section 7.4 below – from the interviews and our reading of the literature, it is our impression that there is no particular sense of urgency among mental health researchers to change the way they do things right now (and there are good reasons for this too – such as the high regard in which Australian mental health research is held internationally). If anything, due to workforce shortages and for a variety of other reasons, mental health researchers are likely to be hard pressed for time to even begin to think about serious change, being pre-occupied as they are by (i) running large projects, (ii) the need to publish, and (iii) securing ongoing funding. One of the interviewees went so far as to state the following, somewhat tongue-in-cheek:

> There is nothing wrong with mental health research. Being a researcher is a fantastic job. I have loads of citations and I can spend the whole day playing with my “Lego”.

As has been noted in Section 5 of this report, meaningful change needs to include both the research and service sector. Although not specifically the subject of this report, it is not clear that there is a unified sense of urgency for reform relating to research, within mental health services and programmes.

The questions at this critical stage therefore are: who will drive change? Who is the target audience? And will the case for change in research capture their hearts?

### Step 1: Establish strategic oversight – start with core group before creating coalition

### Step 2: Identify target audience for change

At this stage, the target audience appears to be:

- Mental health research leaders
- People in leadership positions in mental health services, programmes and policy

However, we would strongly recommend that prior to any implementation, the NMHC consider this carefully, particularly in the context of the review as a whole. The organisations and individuals who have made submissions for the NMHC’s Review should be considered as potential target audience members.

Kotter claims that leaders who know what they are doing will “aim for the heart”:

> They will connect to the deepest values of their people and inspire them to greatness. They will make the business case come alive with human experience, engage the senses, create messages that are simple and imaginative, and call people to aspire.  

Many of those who work in mental health and mental health research are likely to have a deep connection to the subject matter on one level or another – whether they are conscious of it or not. It would therefore appear that before rushing into any major initiatives, the target audience (once identified) needs to be reminded of why they are doing the job they are doing. Some of the research innovations that have been discussed in this report, such as the researchers-in-residence model, are inherently valuable in this respect, and rather than being seen as ‘nice to have’ add-ons to the research portfolio, these types of endeavours should be highlighted and encouraged early in the process.
Researchers who have established careers may not feel so hard pressed by the “publish-or-perish” imperative, and may be willing to try out a new approach if offered the opportunity. Suitable “champions” may be drawn from this pool of researchers.

It is our view that from the very outset, the person with the lived experience needs to be brought into the picture. The NMHC may be well placed at a high level to lead an Initiative to Reconnect specifically designed to create the heartfelt sense of urgency that is necessary. Such an initiative could, for example, disseminate case studies, such as the short Hearing Voices TED video that was circulated to the NMHC by the consultants.74

**Step 3: Create a case for change that engages the target audience on multiple levels, including an emotional one.**

### 7.3 Creating the guiding coalition

The rationale and requirements for this coalition are set out in Section 5.3. The guiding coalition for the mental health research component of the target audience is probably easily identified; however, restricting the guiding coalition to a set of well-known individuals means not engaging or reaching out to the wider community of concern, and would not reflect the intention of the priorities identified in this report. Certainly, there should be representation of those living with mental health problems and their support networks (see Section 6.1).

It would also appear that there is scope to involve those who have recently made submissions to the NMHC. One of the steps to engage these bodies would be to tailor specific responses to their submissions at the same time as inviting them to join a guiding coalition of some sort.

To create a sense of shared purpose it would also be advisable to create an entity that people could identify with, for example, the National Mental Health Research Reform Partnership (or similar). “Foundation Members” could sign a Charter endorsing agreed principles and priorities and could also serve as a source of expertise for the strategic oversight of change.

**Step 4: Create a Partnership & sign Charter of Intent**

### 7.4 Developing a change vision

It is our feeling that there is a solid support base for the vision of mental health research outlined in this report, including its ideal integration into health services and the community more generally.

This report, including the NMHC response to it, could feed into a brief document outlining the vision for reform. It would need to be integrated with the change management planned for the reform of the mental health system as a whole.

**Step 5: Produce a draft document outlining the change vision with the initial partnership group**
Working on a draft document may not be the only way to develop a change vision – the NMHC may have other methods; however, it is important to recognise that developing a change vision is an opportunity to empower those who may to date have felt most left out, or who have not had an opportunity to contribute.

These groups are indeed potential agents of change – they are most likely to feel rewarded through inclusion in the vision development process, and will consequently also be more passionate about ‘spreading the vision’. It may also be worthwhile noting that the Kotter process need not be a ‘linear’ one, and some of the steps in the sequence outlined here may run contemporaneously and/or overlap in other ways.

7.5 Communicating the vision for buy-in

In the first instance, the draft document will need to be circulated to a wider audience as part of a formal consultation process. As part of this, comments should be invited and incorporated to produce a final document which includes buy-in from the broader audience. If the change vision manifests differently, e.g., a presentation, conference, meeting, or even a film – in other words a process other than the drafting of a document – then ways and means of collecting feedback from a wider audience must be considered.

**Step 6: Formal consultation process regarding the draft vision document (or process)**

The next part of the process will require a comprehensive communication plan, developed in partnership with communication experts. Multimedia components, roadshows, focus groups, consumer engagement, and targeted messaging incorporating social media, would appear to be key elements of this part of the process for leading change.

**Step 7: Develop and implement communication plan regarding vision for change**

7.6 Empowering broad-based action

This step is aimed at transferring initiative from the guiding coalition, or the limited number of leaders involved in kick-starting the process, to for example front-line staff involved in service delivery, early or mid-career mental health researchers, or anyone else with an interest in change – this could include a wide variety of stakeholders.

Inherent in the proposed vision for mental health research reform presented in this report is the empowerment and prioritisation of the needs of stakeholders, including those living with mental health problems, their families/carers, healthcare providers, and the broader community. Hence the vision itself, if communicated effectively, should encourage broad-based action.

Although empowering broad based action in the case of mental health research includes a number of the initiatives that have been mooted in this report, many of these will take a considerable time to implement. At this stage of the change management process, elements that enable broad-based and inclusive action, that can be started early are required. The identification of these elements would require review and prioritisation by the NMHC. Suggestions include: commencing initiatives for greater engagement of those...
living with mental health problems (Section 6.1); scoping work for pilot projects for health services to commission research; and engaging with the NHMRC Research Translation Faculty in lead up to the mental health “Case for Action” which is to be considered in the first half of 2015.

**Step 8: Begin implementing the vision**

- convene strategic oversight group
  - agree terms of reference
  - develop a project plan
- draft a risk management plan
  - engage stakeholders
- monitor and report against goals

The change management strategy for mental health research here would once again diverge somewhat from the steps of the Kotter model if interpreted sequentially, as some of the means by which the empowerment of broad based action could be achieved will clearly take time to build. Some of this may therefore have to run alongside the next step of the Kotter process, which is focussed on generating short-term wins.

### 7.7 Generating short-term wins

A number of the steps listed above have the potential to become short-term wins (e.g., launching the guiding coalition, signing the Charter, etc.). A useful strategy would be to identify and support demonstration projects within each strategic domain that exemplify approaches consistent with the vision for reform e.g. demonstration projects for: involvement of people with a lived experience of mental health problems; embedding research in service provision; and large-scale mental health research using data linkage. The process of monitoring and evaluation is extremely important throughout, as it provides the evidence that wins are occurring, as well as those initiatives that should not be pursued further.

Using the strategies identified in this report, it would appear that the following are substantive areas in which a number of short-term wins could be targeted:

- A successfully completed Review (process currently underway)
- Evidence of greater inclusivity of people with lived experience of mental health problems (Section 6.1)
- An Australian researcher-in-residence project is commissioned and commenced (Section 6.1)
- COAG incorporates vision as part of National Mental Health Reform (Section 5.3)
- Champions are identified and rewarded (the NMHC may wish to consider prizes or other forms of recognition for this)
- Audit of current mental health data collection, frameworks and data linkage, including data linkage potential, along with a ‘gap’ analysis of data requirements (Section 6.4).
- Enhancing data linkage for mental health evaluation and research (Section 6.4.3)
Working with data linkage units to identify mental health datasets that could be added to existing data linkage platforms
Working with Commonwealth agencies and integrating authorities to create mechanisms to facilitate mental health related linkage
Commencement of demonstration linkage projects

Step 9: Identify feasible short-term wins and options to pursue these
Step 10: Publicise / disseminate information about these types of wins

7.8 Never letting up (medium term)

This step in the Kotter process is about consolidating gains and producing more change. The danger of ‘letting up’ in mental health and mental health research reform would be that critical momentum is lost and researchers and other fall back into old habits (‘regression’). According to Kotter, at this stage of a successful major change initiative one would expect to see:

- More projects being added
- Additional people being brought in to help with the changes
- Senior leadership focused on giving clarity to an aligned vision and shared purpose
- Employees empowered at all levels to lead projects
- Reduced interdependencies between areas
- Constant effort to keep urgency high
- Consistent show of proof that the new way is working

Kotter emphasises the continued need of leadership to survive this stage. Effective leaders will continue to push for more projects and not let up pressure for change. Some of the projects/innovations covered in this report that would ideally begin to be implemented and/or seen at this stage are:

- Demonstration projects on complex community based interventions – this type of large-scale research would engage a range of strategies suggested, as it would generally need large-scale funding, would be cross-sectorial and would require large-scale data functionality
- Funding bodies recognise / incorporate priorities into research funding agendas and there are specific funding schemes for priority-driven research
- An outcomes framework is agreed and expanded to a greater range of mental health services
- Agreement or at least advanced work on the minimum dataset with documented and well publicised trial or demonstration projects showing how the dataset works in practice
- “What Works” and “Best Buys” resources are functioning (Section 6.5)
- Health services are able to commission research and are increasingly embedding monitoring and evaluation into service provision (Section 6.2)
- Multiple data linkage projects are underway (Section 6.4.3)
- Intensive research engagement – the Flying Squad at work (see Section 6.6.1)
- Workforce initiatives/capacity building are part of business as usual (Section 6.6)
7.9 Incorporating changes into the culture (long term)

Kotter’s 8th and final step is about ingraining change. The new research and service practices must grow deep roots in order to remain firmly planted in the research and service culture. In order to achieve this, one must be able to prove that the new way is superior to the old, and the success must be visible and well communicated. The aim would be that:

- Priority-driven research becomes ‘business as usual’
- Change in research, practitioner and policy maker culture – research evidence is relevant and is used routinely to inform services and policies
- Health services are empowered to commission and effectively utilise research (the right research project at the right time)
- Success for researchers is measured in terms of policy and practice impact, and this is appropriately factored into the incentive system for researchers
8  Concluding remarks

The purpose of science is not to open the door to infinite wisdom, but to set a limit to infinite error.

*Bertolt Brecht*

Mental health problems are complex in nature and are a major cause of morbidity, mortality, disability and lost productivity in Australia. Despite concerted efforts, limited progress has been made in recent decades.

Research is critical to taking effective action to improve the current situation, in terms of mental health policy, services, programmes and, ultimately, outcomes. If it is used appropriately, research has the potential to serve as both a guide and a conscience for the process of reform. A systems view indicates that to do this research must be rebalanced to better serve the needs of the community; the mental health service sector must be in a better position to use evidence; and the connection between the research and service sectors must be increased.

Meaningful change requires direction and strategy. As has been emphasised throughout this report, people who live with mental health problems, and their supporters, should be much more involved in shaping and implementing the mental health research agenda for the future. Greater attention needs to be given to current priorities, including prevention and early intervention.

There are many options to bring about improvement; choices must be based on the best available evidence, and strategies planned and implemented judiciously, with rigorous monitoring and evaluation – to identify those that bring us closer to the ultimate goal of a contributing life for all, and those that take us further away.
Appendix A  Funding of mental health research

Mental health research funding is spread across a range of potential sources. These include traditional competitive funding agencies, the National Health and Medical Research Council (NHMRC) and the Australian Research Council (ARC), as well as non-government organisations such as beyondblue and Australian Rotary Health.

If the scope of research affecting mental health is considered more broadly and embraces that relating to housing, social welfare, and physical health and elements of service evaluation, then the sources and amounts of funding included are commensurately expanded to include other Commonwealth and state government sources (e.g., Commonwealth Department of Health, Australian Primary Care Research Institutes, National Institutes Funding, Departments of Human Services, State Health Departments), charities, philanthropic and commercial sectors. Administrative arrangements relating to the application for, and disbursement of grants, vary by funding body.

At a high level, some key findings relating to funding and the available funding data are:

- No comprehensive ‘market scoping’ exercise, covering all potential sources of mental health research funding, has been undertaken to date (public and private sources).
  - At this stage it is not possible to ascertain whether an accurate survey of all such funding is indeed a feasible proposition.

- Data sources which were reviewed, some of which were in the public domain, are inconsistent and difficult to interpret.
  - There are variations in classifications / data extraction methods across funders, e.g., ARC and NHMRC.
  - In the absence of a rigorous validation process, reliance on keywords supplied by researchers is problematic.

There is clearly a need to overcome organisational silos to pool knowledge and data about the nature of and investment in mental health-related research nationally.

A.1  National Health and Medical Research Council (NHMRC)

As discussed in Section 3.2 of this report, the major competitive funding body for mental health research in Australia continues to be the NHMRC. Section 3.2.1 discussed total funding of mental health-related research by the NHMRC, and Section 0 examined the funding breakdown by Broad Research Area.

A.1.1  Other research categories

The key NHMRC dataset relevant to mental health, which is published online, also presents a number of different funding categories; however, unlike with the Broad Research Areas, a grant may show up under several of these categories. In fact, when all the sub-categories listed in the NHMRC dataset are added together, the total amount is 5.5 times the amount of total funding.
Exceptional care must therefore be taken in interpreting these data. To reiterate, total funding shown in Figure 5 below is not an ‘aggregate’ of the other categories shown in the diagram – in the text that follows, the reader is therefore advised to pay more attention to the trends that have been identified rather than the nominal dollar values that are referred to.

Figure 5 includes four major categories of funding identified in the NHMRC dataset, all of which have grown from relatively small initial amounts to exceed $10 million p.a. in recent years:

- ‘Adolescent mental health issues’: starting at $0.9 million in 2000-01 and reaching $13.7 million in 2013-14, this was the fastest growing category shown in Figure 2 (average annual growth rate = 36%)
  - Steady growth over the last ten years in this category came after a major jump of $4.5 million in 2005-06 (of which a major portion was $3.1 million in two programme grants awarded to Professors Patrick McGorry and Fiona Stanley respectively)
- ‘Affective/Depressive disorders’: growing from $2.1 million to $23.3 million, at a rate of 24% p.a. this also rose faster than total funding, with slower but steady growth continuing in recent years
  - This may support the shift in research emphasis towards affective/depressive disorders noted elsewhere in the literature
- ‘All Anxiety disorders’: from $2.3 million to $17.7 million equalling the annual growth rates of total funding at 19%; however, this category appears to have plateaued during the last five years
- ‘Schizophrenia and other Psychoses’: growing from $1.6 million to $12.1 million in the period, implying an annual growth rate of 18%, but may also have plateaued in recent years

As has already been mentioned, there will be many grants that cut across categories, for example, a good number of grants will have been included under ‘Affective / Depressive disorders’ as well as ‘All Anxiety disorders’ because anxiety and depression often feature as keywords in tandem. This is why the above analysis has focussed on rates of change over time rather than nominal amounts.

Figure 6 illustrates changes over time in some of the minor categories included in the NHMRC dataset (where minor is defined as less than $5 million in 2013). On account of the smaller base from which these values start, more variation is apparent – but certain elements such as a spike in the category ‘Psychosocial issues’ in 2008-09, are clearly discernible.

- Particularly rapid growth was observed in Maternal Mental Health (32% p.a.) and Indigenous Mental Health (50% p.a.). Indigenous Mental Health in fact rose from zero in 2000 to $5.6 million in 2009, after which it fell back before recovering to $4.9 million in 2013.
The NHMRC dataset also lists funding data by other categories, a selection of which are presented in Figure 7 below. As with all the other categories analysed above, there has been substantial growth in the amount of funding attributed to each of these categories if
one compares the beginning of the period with the end of the period covered; however, there are some notable differences:

- Funding of mental health research in the categories of neuroscience, interventions, therapies / treatments, and prevention has grown rapidly and appears to continue to be on the increase
- Funding in the categories of epidemiology, genetics and (in particular) evaluations appears to have flat-lined to a greater or lesser degree in the last five years
- Funding for research in the category of ‘promotion’ has grown steadily and consistently but is still at a relatively low level when compared to some of the other categories which also started out at comparatively low levels in 2000-01

**Figure 7:** NHMRC funding of mental health research, other categories ($ million)

![NHMRC funding of mental health research, other categories ($ million)](image)

**A.1.2 Methodological note**

The NHMRC research funding datasets which are available for download on its website, rely predominantly on the information provided by the Chief Investigators through the
application process. Decisions on allocation to particular disease and health issue datasets are made subjectively by the NHMRC Evaluation and Reporting Section (supported by other internal review mechanisms) based on the information provided.\textsuperscript{17}

It is quite possible that a research project in which mental health is only a minor component is listed as a mental health research project, because Chief Investigators have included mental health associated keywords in their grant applications.

As the ‘basket’ of research projects changes over time, it is possible that the mental health component could become ‘thinner’ over time (the opposite is also possible). Such changes in the degree of relevance would not have been reflected in any of the data shown in this Section.

**Figure 8:** Share of grants in which mental health was assessed as not being the primary component, NHMRC grants commencing 2013 (%; by Broad Research Category)

![Bar chart showing share of grants in which mental health was assessed as not being the primary component by Broad Research Category]

Source: Authors' calculations, based on NHMRC.\textsuperscript{17}

As a subjective ‘spot check’, one of the team members read all of the scientific and lay titles, research keywords, and media summaries for NHMRC mental health grants for which funding commenced in 2013, and highlighted grants for which mental health did not appear to be the primary component. The results of this rapid assessment are shown in Figure 8 above, revealing important differences by Broad Research Area.

In particular, this analysis suggested that there was more significant doubt about the degree to which mental health was the predominant target of the Basic Science projects when compared to, for example, Health Services Research. This (admittedly rudimentary) analysis does suggest that the type of analysis such as has been presented in this section should be considered indicative, at best.
A.2 Australian Research Council (ARC)

The ARC is a statutory agency within the Australian government. Its mission is to deliver policy and programmes that advance Australian research and innovation globally and benefit the community.\textsuperscript{75} It awards a range of grants, including multi-year grants for mental health research projects.

In May 2014, the NMHC wrote to the ARC seeking data on mental health research funded by the ARC, attaching a template for the data request. In response, a list of projects with funding allocated in the years identified in the template was provided to NMHC, which was forwarded to the consulting team. The ARC’s response noted that:

- there is no single Field of Research (FoR code) that relates to mental health research. Consequently to extract a list of possible relevant projects we have conducted an extraction using possible relevant FoR codes and then conducted a subsequent extraction using relevant keywords. The resulting list has not been further vetted and some projects may be less relevant to your request than others.
- data are reported by calendar year, rather than financial year.
- funding figures are reported in current prices.
- we are not able to provide project title information.\textsuperscript{76}

A table of ARC funded projects which were classified as mental health research was made available to the consultants. It included financial information and a column with a completed ‘Summary/Abstract’ (but not project titles). The table showed that in the five years from 2010 to 2014, a total of $75,906,446 was awarded – equivalent to $15.2 million per year.

To analyse the data in the ARC table, one of the team members read the abstracts of the first 25 and last 25 projects included in the table (meaning a 50 out of 257, or roughly one-fifth of the projects were included). The team member then considered whether mental health was the primary driver of the project listed. The following Abstract is an example of the type of project for which mental health was not considered the primary driver:

Great advancements in the science of genetics are accompanied by increased public propensity to attribute causality to the genes for diverse outcomes such as abilities, social group differences, attitudes, and diseases. These genetic attributions activate cognitive biases termed Genetic Essentialist Biases, which have been shown to instigate a variety of deleterious outcomes. The project will evaluate hypothesised detrimental effects of genetic attributions on actual health behaviours, endorsement of health policies, and disease related stigma. Furthermore, it will test interventions designed to reduce the negative effects of such attributions on attitudes, beliefs, intentions, and behaviours related to a common disease.\textsuperscript{77}

Clearly, this type of analysis is subjective and limited, particularly given that titles were not provided. Nevertheless, it is interesting to note that there was little difference in the outcome of the analysis when comparing the first 25 with the last 25 project descriptions – in the first case, 16 out of 25 projects were considered in scope, while in the second case 15 out of 25 were seen as in scope (see Figure 9).
This may be an indication that the annual funding of mental health projects by the ARC is lower than the $15.2 million cited above; however, the nature of the available data meant it was not possible to analyse them further, within the scope of this report.

Figure 9: The proportion of projects in the ARC table for which mental health was considered a ‘primary’ driver (first 25 and last 25 projects listed)

Source: Authors’ calculations, based on ARC data. Note that this percentage refers to the dollar amount allocated to these projects as a proportion of the total dollar amount (rather than the number of projects).

A.3 beyondblue

Since 2001, beyondblue has distributed more than $55 million in research and evaluation funding across more than 250 projects Australia-wide, through a range of competitive grant programmes as well as funding studies that have relevance to beyondblue’s strategic directions and priorities. This is equivalent to around $4.2 million annually.

During the 2012-13 financial year, beyondblue received $8.7 million in core funding from the federal government’s Department of Health and Ageing, and an additional $6.4 million from the States and Territories. During the same year, beyondblue also received $22.2 million of tied funding from the Australian government to deliver a range of specific projects over a number of years, and $3.5 million in donations from individuals and businesses. These figures are noted here to provide an indication of beyondblue’s overall budget envelope – but the exact proportion of this budget which is going towards research projects is unknown.

These figures could indicate that there is scope for beyondblue to expand funding of mental health research; however, the figures also highlight the fact that beyondblue is in fact a major mental health service provider. It is therefore not inconceivable that beyondblue might step away from research in the future; however, given the thrust of the
argument presented in this report, it is precisely organisations like this which may be able to act as conduits for forward and backward linkages across the research sector and the service sector.

### A.4 Black Dog Institute

The Black Dog Institute undertakes research into the prevention, early intervention, treatment and recovery of depression and bipolar disorder. The Institute’s annual budget in 2011-12 was $6.7 million, of which $1.5 million came from a recurrent grant from the NSW Department of Health, and another $1.4 million from donations. Not all of this money is spent on research. The Black Dog Institute’s website states that:

- As an organisation, we place focus on the rapid translation of quality research into improved clinical practice, increased accessibility for consumers, and delivery of long-term public health solutions. This unique model incorporates expertise in clinical management with cutting edge research, health professional training and community education to ensure we are having a positive impact at all stages from prevention and early intervention through to treatment and recovery.

This suggests that the Institute is involved in research that is filling gaps in areas such as engagement with people living with mental illness, perhaps partly due to the influence of its Chief Scientist Professor Helen Christensen, whose reports on the direction of mental health research and research funding have been influential.

### A.5 Rotary Mental Health Research Grants

Since 2000, Australian Rotary Health has provided research project grants related to mental health. In 2012, the focus narrowed to the mental health of young Australians (0-25 years), and in 2013 research projects focusing on prevention of mental health disorders were included.

Funding of $772,793 was allocated in 2014 for Mental Health Research Grants, $250,925 of which was within the area of “prevention”. Applications for funding are assessed by the Research Committee, with the final selection being made by Australian Rotary Health. The conscious choice of targeting funding to areas such as youth mental health and prevention does appear to suggest that research priorities are changing.

### A.6 The Florey Institute of Neuroscience and Mental Health

On the 1 August 2012 the Mental Health Research Institute joined the Florey Neuroscience Institutes to become The Florey Institute of Neuroscience and Mental Health (the ‘Florey’). The Florey has a combined operating budget in excess of $60 million and with over 700 staff, students and honoraries it is one of the largest independent medical research institutes in Australia. Its scientific output, measured by citations and impact, places it amongst the top half a dozen neuroscience and mental health research institutes in the world.

The Florey raises funds from a variety of sources (e.g., $1.1 million from fundraising events, appeals, grants, trusts and bequests in 2011), and in turn the Institute funds a
significant stream of mental health research projects. However, is not known exactly how much of the Florey’s annual income is spent on mental health research.

The following may appear somewhat ‘granular’ or ‘micro-level’ in the context of this report; however, the Florey’s crowdfunding initiative using the Pozible.com platform did illustrate that new approaches can potentially link mental health research with a broader funding base and audience while allowing people to have a direct voice in funding decisions. Although at $72,389 this was only a small stream of income for the Florey in 2013, it is interesting to note the types of projects that met their targets and those which fell short:

- Touchscreen Training in Mice: pozible.com/imice ($23,452 pledged by 9/12/2013, meeting target of $23,000)
- No Pills Brain Treatments: pozible.com/nopills ($20,522 pledged by 9/12/2013, meeting target of $20,000)
- DNA and Autism: pozible.com/boonians ($15,490 pledged by 9/12/2013, meeting target of $15,000)
- Viral Vectors - Name the Virus! pozible.com/namethivirus ($12,925 pledged by 9/12/2013, well exceeding target of $10,000)
- Bone Density Rehabilitation After Stroke: pozible.com/strokeandbone ($1,441 pledged of $15,258 target; closed)
- Depression After Stroke: pozible.com/depressionafterstroke ($770 of $20,000 target pledged; closed)
- Fatigue After Stroke: pozible.com/strokealert ($185 of $32,000 target pledged; closed)

The mental health research projects relating to the effects of stroke were unsuccessful, while the four other projects, which were quite eclectic in their coverage, did meet their targets and got off the ground. This information is included here as a small example of how public preferences may surprise researchers and policy makers.

A.7 Orygen Youth Health Research Centre

The Orygen Youth Health Research Centre was created in 2002 with funding support from the Colonial Foundation through a partnership between the University of Melbourne, Melbourne Health and the Colonial Foundation. It claims to be “a world leading youth mental health organisation” and is Australia’s largest youth mental health research centre. The centre accommodates all of the staff based in the University of Melbourne Medicine, Dentistry and Health Sciences Faculty Centre for Youth Mental Health:

...we have grown through a series of reinventions to become Australia’s premier youth mental health translational research institute, with over 300 dedicated researchers, clinicians and support staff.

The composition and nature of the Centre’s staff is not clear from the Annual Report (which also does not present any budget data), but it does suggest an annual spend of several million dollars on mental health research funded from a variety of sources, notably including private and philanthropic sources.
A.8 Other funders

As indicated at the beginning of this Section, there are a number of potential funders of mental health research. The Australian National University’s recurrent operating budget, for example, which is primarily funded from the Commonwealth Department of Education, Employment and Workplace Relations (DEEWR), delivers so-called National Institutes Funding, which supports ANU initiatives such as the National Institute for Mental Health Research, and the Centre for Ageing, Health and Wellbeing.

A comprehensive assessment of mental health research funding would have to include all of the above sources and a variety of other sources as well. As an example of the range of these, Granting Bodies named in the Black Dog Institute’s 2012 Annual report relating to research undertaken in partnership with the Black Dog Institute included:

- Australian Department of Health and Ageing (DOHA)
- Australian Government Department of Innovation, Industry, Science & Research (Cooperative Research Centres)
- Bupa Health Foundation (formally the MBF Foundation)
- CSIRO Prevention Flagship
- Lansdowne Foundation
- NSW Department of Ageing, Disabilities & Home Care (Applied Research Grant)
- NSW Institute of Psychiatry (Research Fellowship)
- Other Australian academic institutions (e.g., UNSW)
- Overseas funders (Alberta University, Canadian Institutes of Health, Norlien Foundation)
- RANZCP
- St George Medical Research Foundation
- Stanley Medical Research Foundation
- The Heart Foundation (e.g., Cardiovascular Disease and Depression Strategic Research Program co-funded with beyondblue)

This is by no means an exhaustive list but it begins to illustrate the challenge of fully capturing mental health research funding in Australia.
Appendix B  Template for interviews

Structure for National Mental Health Commission interviews

Thank you for agreeing to be interviewed today. As discussed by phone/email we have been engaged by the National Mental Health Commission to assist them with the development of strategic priorities for mental health research. You are one of a small number of key people working in mental health and mental health research that are being interviewed for this purpose. The purpose of these interviews is to gather strategic views on mental health research in Australia. We are interested in your thoughts on all aspects of mental health research – from questions around national oversight for, or coordination of, mental health research, how it is funded, the structure of the workforce, and so on, to more specific ideas about the types of conditions or the typical settings of research, topics that are over- or under-researched, and so on. So...

What do you think are the major issues in mental health research in Australia right now – what are the problems that need fixing?

What do you think needs to be done to fix these issues? How would you approach this?

Do you think mental health research needs to be more relevant to address real world problems? (If so, again, how can this be done?)

What sort of practical steps or strategies do you think need to be developed / taken to make improvements in how mental health research is carried out?

Can you think of any leaders in the field, or exemplar projects, either nationally or internationally from which Australia could learn?

If the interviewee is not giving much by way of feedback, or is struggling to contextualise their answer, we could offer to read out the draft principles

- Be relevant to practitioners and consumers
- Take a real world approach
- Be needs based and practice led, rather than investigator driven
- Support a whole of life approach to management of mental health, including childhood
- Recognise the interplay between mental and physical health
- Build or support strong partnerships between researchers and practitioners and policy makers
- Be cross disciplinary, e.g., include sociologists, economists and demographers
- Be cross sectoral – consumers, families, communities, employment, housing
- Include a focus on highly disadvantaged groups – Aboriginal and Torres Strait Islander people, rural and remote communities, people in the justice system
- Build in quality improvement and evaluation

They could speak to each of those, you can stop and start.
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