schizophrenia
and other psychoses

Translating research into policy and action

Australian Academy of Science

The symposium, *Schizophrenia – and other psychoses*, was held on 20 October 2000 at the Hyatt Hotel, Canberra. It was organised by the Australian Academy of Science with the support of several generous sponsors. This report is a summary of the papers and discussion. It is also available at **www.science.org.au**.

Introduction

Schizophrenia affects 1 per cent of the population. One-third of sufferers have a life time of chronic illness; one in ten commit suicide. Schizophrenia is indiscriminate; everyone is vulnerable.

Treatment costs Australia more than $1.2 billion a year. These costs arise from medical, hospital and after-care services and the indirect costs of family members dropping out of the workforce to take on a carer's role.

Though schizophrenia is a very serious illness, there is ignorance about the research that has produced effective treatments and the services that can help people manage the problem. Too many sufferers miss out on the medicines and support that can dramatically improve their lives.

Even with the best treatment, there is still substantial disability and cost associated with the disorder. This more than anything highlights the need for more research.

On 20 October 2000 the Australian Academy of Science held a symposium in Canberra called Schizophrenia and other psychoses: translating research into policy and action. This was not just another schizophrenia research conference, because its emphasis was not on the research itself but on the applicability of the research, as well as on the vital nexus between research findings and policy development.

Commonwealth and state governments are the primary providers of funds for schizophrenia research in our country, yet this was the first national conference to focus on giving feedback to and seeking input from mental health policy makers in relation to such research. This integrated not only the perspectives of the researcher and the bureaucrat but also the perspectives of consumers, carers and non-government funding providers. The keynote speaker, Professor Graham Thornicroft, an expert on British mental health care needs and how to meet them in the most effective and efficient manner, presented a broader international perspective.

The conference resulted in a robust exchange of information and a deepening and extension of partnerships which I hope will assist in improving the outcomes for people who live with the realities of psychotic disorders. This report is a summary of the papers and the discussion.

The catalyst for the conference was an anonymous donor. The Academy established an organising committee consisting of Barbara Hocking, the two John McGraths, Ted Atkinson, George Lipton and myself. We appreciate the Academy's imprimatur for the airing of this relevant and timely topic.

On behalf of the organising committee I would like to thank our sponsors: the Commonwealth Department of Health and Aged Care, the New South Wales Department of Health, the Department of Human Services Victoria, AstraZeneca, Eli Lilly, Janssen Cilag and Pfizer.

The bandwagon of mental health policy development moves on, appropriately taking on board issues such as the management of more prevalent and more treatment-responsive disorders such as anxiety and depression, as well as mental health promotion and prevention. This broadening of Australia's mental health strategy reflects a need to ensure an adequate balance of priority areas. It does not imply that the critical issues surrounding schizophrenia and other psychotic illnesses have been 'stitched up'. As this report shows, this is very far from the truth.

David Copolov
Director
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Living life as an experiment

Simon Champ is a consumer of mental health services and a Director of SANE Australia.

I'd like to bear witness to a life lived for over 20 years with a psychiatric illness, or form of schizophrenia. I recall the catchcry of the overseas consumer movement, 'Nothing about us without us.'

I have listened to many others affected by psychosis in my work as a consumer activist. It seems that central to all our struggles to live to our full potential is the recovery of hope in our lives after our initial diagnosis. One of the resources that give hope is the knowledge of ongoing research.

I was first diagnosed over 20 years ago. I went to libraries to find books on schizophrenia. The lack of hope in the literature and the impersonal objectifying of the person with the illness offered a bleak picture of my future. I contemplated whether life was worth living with this illness.

In the end I resolved that I would live life as an experiment. While I accepted that I had an illness, its effect and meaning in my life were for me to discover. That decision has carried me through for 20 years. For all the hardship, disappointment and heartbreak of facing psychotic illness daily, it has led me on a path of discovery that has enabled me to explore my full potential. While I still encounter daily limitations, I have surprised myself with the possible, beyond the limiting views in the literature of 20 years ago.

A lot of material in my life seems to be neglected by other researchers. The subtle relationship between having a condition like schizophrenia and the attitudinal approaches one has to living with it, the psychology and empowering effects of hope and the nature of resilience to the ravages of illness have all been part of my own researches.

My illness has never given me more than 10 months in remission. I am daily experimenting to improve the quality of life with a major disability. I now have better medication as a result of research. But there is still no cure.

Is there enough research and enough of the right kind of research? Technological innovations and new tools enable us to probe ever deeper into cellular and molecular aspects of psychosis, but there are still many areas of understanding of the lived experience that concern consumers and are not researched adequately.

Research has found treatments that can benefit consumers, yet there is a lack of will to reform service delivery and resource allocation to make better use of these.

Research gives hope

For a young person newly diagnosed with an episode of psychosis, there is now a more optimistic attitude to treatment; new medications offer new choices.

Research is a product of its times, influenced by intellectual fashions and the vagaries of economics and politics. How much does policy determine the nature and scope of research being done? Do we sometimes create research to support directions in policy rather than have research create better directions in our policies?

To what extent are the findings of research that could benefit consumers given a biased reading when they have implications for policies driven by economic rationalist concerns? Government does place an economic value on human worth by limiting how much per head we spend on services or research. Of particular interest is research that might suggest the injection of significant funds into earlier intervention for better long-term prognosis.

Many consumers question the nature of research being done and the means and methods of doing it. Research subjects need information about the aims and results of research. Payment of subjects is another issue.

A concern for many consumers is how research gets disseminated through the health care system and the policy-making arms of bureaucracy. It is essential that mental health workers, including psychiatrists, keep updating their knowledge of research findings and new medications. For drug companies, there is a fine line between good marketing and disseminating new knowledge of psychosis and its treatment.

One would hope that policy would encourage consumer participation in research. Consumer-driven research and consumer-focused outcomes in research are always our hopes.

The scope of the problem in Australia

Professor Assen Jablensky is Professor of Psychiatry at the University of Western Australia.

We need good data for a number of reasons. Schizophrenia and related illnesses constitute a worldwide public health problem. In the established market economies they make up 25 per cent of the total burden of disease, measured in disability-adjusted life-years lost. By 2020 this could be 30 per cent.

Leading causes of disability world, 1990

Per cent of total disability-adjusted life-years lost:

1. Unipolar major depression	10.7
2. Iron deficiency anemia	4.7
3. Falls	4.6
4. Alcohol use	3.3
5. Chronic obstructive lung disease	3.1
6. Bipolar disorder	3.0
7. Congenital anomalies	2.9
8. Osteoarthritis	2.8
9. Schizophrenia	2.6

Schizophrenia inflicts losses comparable to cancer and greater than heart disease. But it is lifelong and recurrent.

The clinical and public health significance of the psychotic disorders is greater at a time of transition from institutional to community-based care. Australian health services and society face the gamut of problems associated with changes in values, attitudes, professional skills and principles guiding resource allocation.

National survey

While the risk of schizophrenia varies little across diverse populations and cultures, extrapolations from other parts of the world lack Australia's socioeconomic, clinical and service provision context and so have limited use for policy and planning decisions. To generate up-to-date information on psychotic disorders in Australia, researchers from a number of universities conducted a study within the framework of the National Survey of Mental Health and Wellbeing.

The study initially screened 5710 people who visited hospitals, doctors, carers and homeless services in Canberra, Brisbane, Melbourne and Perth during one month in 1997. It followed up 980 people with a diagnostic interview for psychosis.

Survey results

The study found that of every 1000 adults, about 4 sought treatment for psychotic disorders. Of these, about 60 per cent were male.
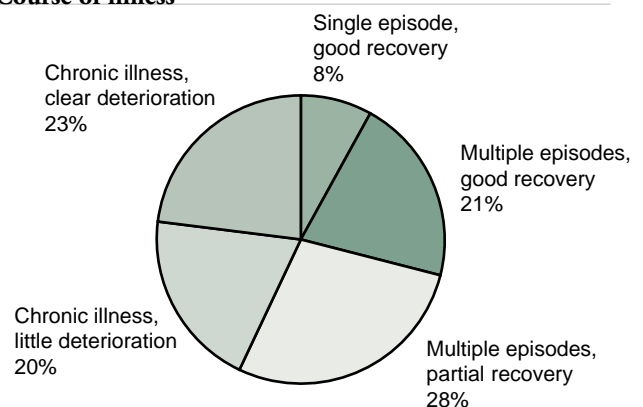
Highest educational qualification
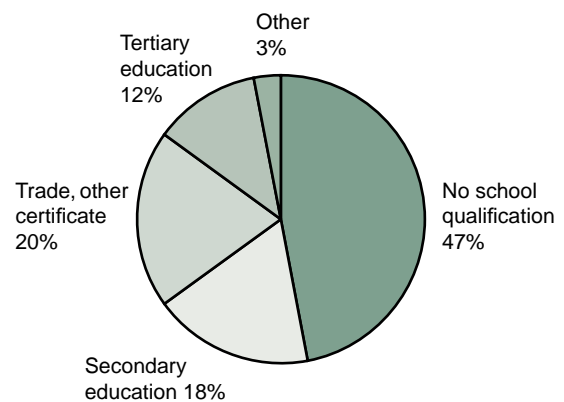
Nearly half the people interviewed had no school qualification, while for the Australian population as a whole this figure is about 13 per cent.

The age at onset of the disorder was about 24 for males and slightly older for females. The mean duration of the illness for those interviewed was 15 years.

Course of illness

The most common symptoms were hallucinations and delusions (96 per cent had experienced these), depressed mood and loss of pleasure (73 per cent), and thoughts of suicide (68 per cent).

The daily lives of people with psychotic disorders are impaired by self-neglect, difficulty maintaining an interest in the world and problems with relationships and sex. About 30 per cent said they had trouble caring for themselves.

Accommodation

Own home	14.5%
Family home	14.9%
Rented accommodation	31.4%
Lodge or hospital	19.6%
Hostel or group home	16.4%
Supported housing	2.6%
Rooming houses, hotels, crisis shelters, no fixed address	8.8%

Many sufferers were never married or divorced. About 9 per cent had a carer available at home. Of the carers, 42 per cent were the mothers of the sufferers, 24 per cent were partners.

Social isolation in psychosis

Living alone	31%
Impaired ability to socialise	59%
No frequent face to face contact with a close relative	35%
No best friend with whom to share thoughts, feelings	39%
No friends at all	12%

The great majority (72 per cent) were unemployed. Employment creates a meaningful social role and affects the outcome of psychiatric illness. The lack of employment opportunities limits rehabilitation.

Substance abuse is a major related problem, possibly contributing to relapse. Rates of smoking and alcohol abuse were much higher than the general population. Cannabis smoking and other drug use were also common.

Violence is another problem in sufferers' lives. About 18 per cent of the people interviewed had been victims of violence in the last year, 10 per cent had been arrested and 16.5 per cent had taken a deliberate overdose or inflicted harm on themselves.

Nearly all the respondents found medication useful, but the majority reported side effects that impaired daily life.

Contact with health services in past year

Inpatient services	51.6%
Outpatient services	60.1%
Emergency services	43.9%
Psychiatric emergency services only	23.7%
General practitioner	81.3%
Private psychiatrist	24.4%
Private psychologist	6.6%

Length of stay in hospital

Up to 2 weeks	30%
2 weeks to 3 months	44%
3 to 12 months	16%
Over 12 months	10%

Over 75 per cent were satisfied with mental health services. However, nearly half had felt a need for a particular service but had been unable to gain access to it. The main concerns were access to care, continuity of care and mental health information. Half the respondents said that the service they needed was available but not affordable.

There is a serious lack of community-based rehabilitation services; only 19 per cent had participated in rehabilitation programs.

Increasing wellbeing

Some people with psychotic disorders function well. This was linked to more education, work, social adjustment, being married, being older at the age of onset, less substance abuse, and symptoms that responded well to medication.

The majority of people with persisting psychotic disorders now live in the community, but only a minority attain a satisfactory level of functioning and wellbeing. The services available to them tend to be on a crisis-response basis. Their need for therapy, housing, rehabilitation and support remains largely unsatisfied.

How research can improve service provision

Professor Graham Thornicroft is Professor of Community Psychiatry at Kings College, London, and an adviser to the British Government on mental health.

In the more economically developed countries we are now in the post-institutional era. But though the institutions are largely behind us, there is still considerable discrimination against people with mental health problems, particularly people with psychotic and schizophrenic disorders.

I want to look at three aspects of driving up the quality of services and improving outcomes for people with mental health problems:

- conducting primary research
- gathering and summarising research findings into meta-analyses which review our current state of knowledge
- using the evidence to help governments formulate policy.

Last year I published a book called *The mental health matrix*, with Professor Michaela Tansella. This established a framework for thinking about mental health in terms of two dimensions: time and geography.

The mental health matrix

Geographical level	Time		
	A input	*B process*	*C outcome*
1 country/region	1A expenditure	1B performance indicators	1C suicide rates
2 local/catchment	2A population needs assessment	2B pathways to care	2C better access
3 patient	3A individual needs assessment	3B quality of care	3C satisfaction

The outcome for individual consumers or patients (3C) is the most important cell in the matrix. Formulating policies and delivering services is only important in so far as it improves outcomes for consumers.

Primary research – community care in London

In the last couple of years, some colleagues and I have done a study on community-oriented models of treatment. It relates to the effectiveness of a service rather than the efficacy. The efficacy of a treatment is whether it works under ideal or experimental conditions. Effectiveness has to be measured in real-life conditions, taking into account the costs.

We knew from previous studies that community mental health teams could produce gains under experimental conditions. But do you still get the gains in ordinary practice? If so, are they diluted? Is it cost-effective?

The PRiSM psychosis study was based around South London's Maudsley Hospital, taking in two catchment areas, Nunhead and Norwood. Both of these areas received 1970s-style hospital-based care, inpatient and outpatient services. We called one catchment experimental and the other the control. In the experimental area we introduced an acute treatment team and a long-term treatment team. In the control area we had a generic community treatment team; we moved most of the services away from hospital wards, buying up old shops and offices in ordinary streets and converting them into community mental health centres.

We also developed a new, short method of assessing needs: a questionnaire called the *Camberwell Assessment of Needs* (CAN), which was published as a book in 1999. This assessed needs from the perspectives of staff, carers and consumers.

We followed up 514 patients two years later. There were many improvements in both sectors. On none of the variables – quality of life, disability needs, symptoms, satisfaction and carer burden – was the community-based service worse than the hospital-based service. Having the community mental health teams reduced costs more quickly, cut down the need for inpatient beds, improved social networks and improved consumer satisfaction, particularly among black consumers.

But the family burden didn't change, nor did symptoms or social behaviour. Among staff, there were very high rates of burnout and low morale.

Another research project, called the Team for the Assessment of Psychiatric Services (TAPS) study, ran from 1985 to 1998 in North London. It followed up about 600 long-stay, non-demented patients five years after discharge from two large Victorian psychiatric institutions – the Free and Barnett, and the Claybury. The quality of care in some of these large institutions was dreadful. Some of the patients had been in these hospitals for 20 or 30 years.

After five years in the community, the patients' death and suicide rates were unchanged, contrary to some previous findings of a catastrophic response to discharge. About the same number were homeless before admission and after discharge. Patients' quality of life greatly improved when they moved to community care but there were deficiencies due to the nature of their conditions. The overall costs were the same but, coupled with improved outcomes, this suggests that community care is more cost-effective.

But you can't simply relocate people outside hospitals. They have relapses. About one-third of the patients were readmitted to hospital during follow-up. About 10 per cent were in hospital at follow-up five years later. This allows us to plan the number of acute beds needed for people with long-term psychotic disorders.

Meta-analysis of different treatments

How can we balance projects when they produce conflicting results? How can we make sense of better and worse designed studies? Fortunately there is a huge industry dedicated to this.

The National Health Service Centre for Reviews and Disseminations in York produces scholarly reviews of these studies and reviews of reviews. This is the state of the art, boiling down current knowledge to the basics. The October 2000 issue of the journal, *Effective Health Care*, summarises research findings for different types of psychosocial treatments of schizophrenia.

About 2500 people in Britain have been through various randomised controlled trials of **assertive community treatment**. The review showed that patients receiving this treatment were more likely to remain in contact with services, less likely to be admitted to hospital and, if admitted, the time spent there was reduced by nearly 50 per cent. These are significant advantages but there was no difference in clinical outcomes. So it manages

where contact takes place, but does not provide benefits for individuals. A similar review has come from Baltimore, where this treatment also reduced hospitalisation. It seems the closer you are to true assertive community treatment, the better the outcomes.

There are a number of randomised controlled trials of **acute day hospitalisation**. These showed that between 10 and 30 per cent of patients could be diverted from inpatient care to acute day hospitals. This has not filtered into policy and practice.

Cognitive behavioural therapy is one of the most exciting areas of current research. It started with depression and affective disorders but is now applied widely to anxiety-related disorders. Applied to psychotic disorders, there is solid evidence that cognitive behavioural therapy can improve the patient's symptoms and decrease the risk of relapse. It is acceptable to patients, reduces readmission rates and improves mental states.

Individual psycho-educational interventions can also decrease the risk of relapse. The active ingredient in the package is not clear.

A couple of years ago I produced a video, *Living with schizophrenia: The carer's story*, about what it means to be very closely associated with someone with a psychotic disorder. **Family intervention** trials again show a decreased risk of relapse. But the benefits of this intervention were most marked in the studies done by pioneers of this work; they tended to reduce over time. This is an effect of going from experimental efficacy to real-world effectiveness. It is quite common to see the benefits dilute as others get their hands on new techniques.

There is hardly any good evidence of beneficial effects arising from **psychoanalytic therapy** for schizophrenia. It does not help people leave hospital. Other effects are essentially unknown.

The evidence for **social interventions** and **training in life skills** is poor. There have been no randomised controlled trials in this area.

The York Centre for Reviews and Disseminations concluded that non-pharmacological treatments for people with schizophrenia are under-researched. More randomised trials are needed of accessible interventions in everyday practice. And they should include outcomes which have meaning for consumers.

Formulating policy

Having developed and summarised evidence, how can we use it to formulate policy designed to improve care?

Two years ago the British government decided to set up blueprints for specific areas of care and health. The first was called the National Service Framework for Mental Health. The framework aims to drive up the quality and reduce variation in the provision of mental health services.

I chaired a group offering advice to the government. We found out the views of service users, carers, professionals and non-government organisations. We also summarised what we could find in the world research literature. Much of the best, most relevant literature came from Australia.

We established fundamental values and principles and priorities which were accepted by the government:

- choices for independence
- empower and support staff
- continuity of care only as long as needed
- accountability
- involvement of users
- high quality care
- non-discriminatory service
- accessibility.

The framework is not only based on evidence but the evidence supporting each standard is spelt out line by line. Each study is given a weight, depending on the type of evidence used. There are five types of evidence, with type I as the gold standard:

I   at least one good, systematic review or meta-analysis

II   at least one good randomised controlled trial

III more than one intervention study (with no randomisation)

IV   more than one well designed observational study

V   expert opinion, including the opinions of service users and carers.

Type V is a controversial standard of evidence. For the first time it brings into the frame of reference the views of carers and users as experts being able to contribute valid evidence. But it relegates them to the fifth grade, below the scientific evidence.

The framework sets national standards for the next 10 years and defines service models for promoting mental health and treating mental illness in adults of working age. Implementation teams will work at local, regional and national levels. There are performance indicators and milestones with time scales.

The seven standards cover the areas of mental health promotion, primary care, service access, effective services for severe mental illness, caring about carers and preventing suicide. They aim to form a balance between common mental disorders and severe mental illness.

The first standard states that health and social services should promote mental health, combat discrimination and promote social inclusion. A whole range of actions under this heading is permissible.

Any service user who contacts their primary health care team with a common mental health problem should have their needs identified and be offered effective treatments, including referral to specialist services.

A health service should be as accessible as 24-hour banking. The access standard requires that a person with a common mental health problem should be able to make contact around the clock with the local services necessary to meet their needs. A new 24-hour telephone help service, NHS Direct, has nurses offering first-level advice and referral.

Anticipating crises reduces disability in the short term and improves the longer term course of the condition. The standard for severe mental illness states that service users should receive care which prevents crises and reduces risk.

They will be given a written care plan which spells out action to be taken in a crisis by the service user, their carer and their case manager, which advises their general practitioner how they should respond and which is reviewed regularly. The care plan means that the consumer is much better informed and able to participate in and change the plan to reflect their own aspirations. This shows how the issues of information and participation, which come up again and again in consumer and carer surveys, are being enacted in national policies.

People with severe mental illness will also be given timely access to an appropriate hospital bed or alternative bed or place as close to home as possible. This is the least restrictive environment consistent with the need to protect them and the public. Alternatives to hospital inpatient beds – women's houses, safe houses, respite care houses and acute short-stay hospitals – are being evaluated for cost-effectiveness. On discharge they will be given a copy of their written plan for care and rehabilitation.

Thanks to intensive lobbying, carers have been explicitly recognised in one of the seven standards, called Caring about Carers. This requires that all those who provide regular and substantial care for a person with severe mental illness should have an annual assessment of their health and other needs and their own written care plan. These carers have to have the ability to continue to care. This is a considerable leap forward in our thinking about the wider network of the recipients of services.

There is evidence for this standard even though some of it is quite weak in terms of the types of evidence listed above (it is based on statements from carer groups). In Britain, about half of the people with mental illness live with the family or a friend. Women are more likely to be carers than men. Families have to contend with demanding behaviour, financial burdens, restrictions on their lives and occasional risks to safety. They feel a sense of loss of the young person and their imagined future. The carers ask: what will happen when I'm frail or when I die? Who will support my family member then?

In Britain, the rate of suicide is falling. The standard for preventing suicide restates the other standards as the building blocks for delivering good quality care.

Focus on patient outcomes

Mental illness makes up a large and growing proportion of the global burden of disease. People with schizophrenia have a mortality rate 1.6 times higher than the rest of the population. In many cases this is associated with cardiovascular diseases, smoking, lack of exercise, diet and poor access to physical health care. The risk of suicide is 9 times higher than the general population. Death from violence is twice as high. People with severe mental illness are much more likely to be victims of violence. They suffer social isolation, drug and alcohol problems, and exclusion from the job market. Of the people with psychotic disorders, about one-third have at least one severe physical health problem.

We must improve the outcomes for individual consumers. The mental health matrix provides a way to close the gaps between evidence and practice. With our eyes firmly focused on patient outcomes (3C), we want to strengthen the links between that and every other cell in the matrix.

At the national level we want policy based on evidence of things that work. At the local level, there is no point doing things unless they improve outcomes for individuals. A lot of service innovations at the local level are only delivery systems, creating opportunities to deliver effective treatments direct to individuals. They are necessary but not sufficient. What really matters is the processes which take place between care-givers, providers, professionals and people with mental health problems. If these treatments are based on evidence which shows they are effective, then outcomes will improve.

Discussion

Nicholas Marlowe (The Sydney Clinic). *Why are non-pharmacological treatments for mental illness under-researched?*

Graham Thornicroft. They don't have the pharmaceutical industry funding them. These are labour-intensive and complex human interventions. We don't have good methods of disaggregating the effective parts. We haven't had a strong mental health lobby in this field until recently and we are still in a research ghetto which we are gradually breaking out of.

Anthony Duncan (Ministry of Health, New Zealand). *There is a lack of morale among mental health care workers. People in the field are resisting change. How do we keep mental health professionals up with things?*

Assen Jablensky. Our survey did not focus on staff morale. But we know that the stigma attached to a mental health disorder also attaches to staff and services.

Graham Thornicroft. Research among staff in London showed that morale was reasonably low among groups in transition to a new type of service. Staff said that their satisfaction levels were high but exhaustion levels were also high. The new methods are challenging and tough. They are less cosy and there is less reassurance. Having change forced upon you makes it worse. Most staff want to help. When governments introduce policy they need to emphasise that it is based upon evidence; this gives a more favourable uptake.

Anthony Harris (Westmead Hospital, Sydney). *Only one per cent of people with mental illness attended a drug and alcohol clinic. How do English services approach comorbidity?*

Graham Thornicroft. Those with dual diagnosis – severe mental illness and substance abuse – make up about 30 per cent of the mentally ill. Services fail them. They have much worse long-term outcomes – more violence and suicide. They stay twice as long in hospital. What is the best treatment? Set up a special team with special skills: there is little evidence that this works. Skill up case managers: there is mild evidence of usefulness. Improve system linkages with nurses to break down organisational boundaries: there is no evidence for this. We are right at the beginning of research.

Assen Jablensky. We need more intensive epidemiological and biological research in this area. It may be related to genetic risk factors. We need more knowledge before suggesting specific measures.

Sadanand Rajkumar (Newcastle Health Centre). *Can we draw lessons for rural Australia?*

Assen Jablensky. I would be cautious. It must be put into socioeconomic context. It would be surprising if the rural incidence of schizophrenia were different from urban Australia. The point prevalence is likely to be higher in urban areas. Rural areas have special problems and higher Aboriginal populations. A special research program is needed for rural Aboriginal people.

Simon Champ. Regarding the rural community, research does not often address the quality of life. The lives of urban consumers of mental health services are improving but in rural areas there is a lag. The stigma is different. Few consumers have cars, they can't get around. Better measures of quality of life are needed. This will affect other studies; meeting consumers has interesting effects.

David Copolov. How do the news media affect mental health policy? For example, has there been a move of patients back to institutions following media and community concerns about safety?

Graham Thornicroft. There is widespread misunderstanding in the community about mental health problems and social anxiety about mental health. Traditional belief structures have broken down and so there is a mass free-floating anxiety that can attach to certain groups in society, for example, paedophiles. On the scale of moral outrage, some is attached to people with mental health problems. The British Government has been holding public inquiries into crimes with a mental health link, but following adverse public reactions, it is reconsidering the holding of such inquiries. There has been a change of the government and public mood towards safety and risk aversion.

Trevor Jacobs (Canberra). Travelling around Australia I have found that interstate borders affect care. We need a national approach. Is there a similar problem in the UK?

Graham Thornicroft. There is the postcode lottery; different areas have variable services. One reason to set national standards is to raise the floor. There will still be variations but I would like to feel that everyone is getting the minimum level of care they need.

What has fundamental research taught us about schizophrenia?

Professor David Copolov is Director of the Mental Health Research Institute of Victoria.

Mental health policy makers have a cautious attitude to fundamental research because its highly technical nature makes it difficult to understand and because its primary considerations do not relate to the immediate and practical issues facing the mental health service sector.

Types of research

Fundamental research is curiosity-driven, rather than being the result of some administrative master plan. Results are unpredictable and any benefits are long term.

Strategic research is more focused on specific needs and problems. Most research in our field is strategic, because it is focused on understanding the neurobiology of schizophrenia, often with therapeutic intent.

When unplanned practical benefits do arise from fundamental research, they are often of much greater significance than benefits from research aimed at practical outcomes. For example, Howard Florey and Ernst Chain investigated the Penicillium fungus not because of its potential use in clinical medicine but to examine basic questions about the production and secretion of antimicrobial enzymes.

So fundamental research not only enriches our understanding of ourselves and our world, it also may give birth to unplanned therapeutic spin-offs of profound importance. It also provides a training ground for young scientists.

Finding the causes of schizophrenia

Fundamental and strategic research are crucial for the understanding of schizophrenia because the specific causes of the disorder remain a mystery and there are no objective measures to determine the diagnosis, prognosis or best treatment for patients. Without fundamental research, the 10 to 40 per cent of patients who respond poorly to antipsychotic medications will probably remain beyond effective treatment.

One of the pioneers of fundamental work that became highly relevant to psychiatry and neurology, Arvid Carlsson, from the University of Göteborg in Sweden, recently won the Nobel prize in physiology or medicine. In the late 1950s, Carlsson conducted pivotal animal studies which showed that dopamine was an important neurotransmitter (a chemical messenger between nerve cells in the brain). He also characterised the major dopamine-containing pathways. This work has proven to be of immense practical value in the understanding and discovery of antipsychotic drugs.

Carlsson's research directions could not have been predetermined by those seeking to develop new treatments for schizophrenia. They were curiosity-driven. Now he is encouraging researchers to look beyond dopamine and to study the role of glutamate in schizophrenia.

In the 1980s researchers emphasised dopamine overactivity and static brain lesions caused during pregnancy and early childhood. More recent research has addressed the subtle and complex interactions between different neurotransmitters which may be involved in the disorder and in responses to medication. Understanding the role of serotonin and its interactions with dopamine has proven to be useful in the development of antipsychotic drugs with improved side-effect profiles. Brain imaging has helped demonstrate the changes which occur in the brain during later childhood and adolescence, much closer to the onset of symptoms. This contrasts with the 'doomed from the womb' pessimism of earlier hypotheses.

Molecular genetics

A great deal of research is also being carried out in the molecular genetics of schizophrenia. The main effort has been the search for genetic markers of the disorder. There have been no clear findings so far.

Another approach is to look at which genes are turned on in the brains of people with schizophrenia and comparing that repertoire with others. This method has shown value in animal studies, with possible applications to the treatment of epilepsy. If a limited number of gene differences can be identified for schizophrenia, drugs could be designed which affect the products of these genes.

Following the introduction of the second wave of antipsychotic drugs – olanzapine, risperidone and clozapine – drug treatments have reached a plateau. Research into neurotransmitters has indicated promising leads, but no new antipsychotic drugs whose effects are unrelated to dopamine and serotonin have been introduced into clinical practice. Effective drugs which operate on different principles are needed. Genetic studies may also help predict drug side-effects and tailor treatment to suit individual patients.

Fundamental research underpins our hopes for therapy beyond the horizon. It should neither be played down nor dominate the priority setting or policy makers. It should be strongly supported, along with other research approaches.
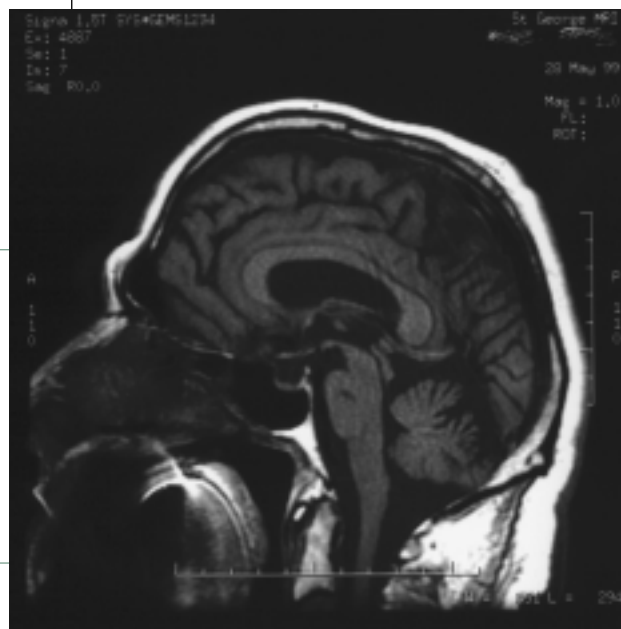
A magnetic resonance image of a human brain

Bridging the gap between clinical research and treatment

Associate Professor John McGrath is Director of the Queensland Centre for Schizophrenia Research in Brisbane.

The last quarter of the 20th century saw improvements in the diagnosis of schizophrenia. For a caring civil society the goal is immediate, complete and sustained recovery for affected individuals. But there is a gap between clinical research and treatment.

Different perspectives identify different gaps in treatment. Clinicians look for remission. Consumers want recovery. Health planners strive for efficiency. Governments want to reduce death and disability. The community wants to maintain social and human capital.

There are different sorts of exchanges across the gap. The translation of research into clinical practice is often seen as a one-way technology transfer. But technology transfer can backfire if we continue to expect busy clinicians to take on added responsibilities without providing the supports needed to deliver the service. In addition to the flow of information from the researcher to the clinician, there needs to be an opportunity for clinical knowledge to influence research. In other words, the exchange across the gap has to be a two-way flow. What factors influence the flow of information across this gap?

Effective treatments

The evidence base – randomised controlled trials, expert opinion and so on – is quite large. Effective treatments exist – antipsychotic medication, cognitive behavioural treatment and cognitive remediation. Psycho-education also helps to reduce the risk of relapse.

There is less evidence available to guide clinicians about the best rehabilitation techniques, although the literature suggests that interventions related to cognitive behavioural and cognitive remediation treatments may improve outcomes for some clients. There is a need for more research about vocational rehabilitation for those with schizophrenia. In the light of the substantial disability

associated with schizophrenia, it is surprising that more effort has not gone into this area. For those who do not respond to treatment, there is a paucity of information about how we can best deliver disability support services.

How do we rate?

How well do Australian clinicians comply with evidence-based treatments? There are high rates of persisting psychosis, high rates of side-effects, high levels of disability and needs for more access to services, information and companionship. A number of effective treatments appear to be under-utilised – psycho-education, cognitive behavioural treatment, the best medication at the right dose, rehabilitation programs and other services. Even if the services are there, the patients are not referred.

According to the National Survey of Mental Health and Wellbeing, between a third and a half of people with psychotic disorders had hallucinations and delusions during the month of interview. This suggests that these individuals may be receiving inappropriate doses or types of medication. Patients who do not respond to traditional antipsychotic medication should be given a trial of newer medications.

Many patients in the survey had disabling side effects, such as dry mouth and problems coordinating movement. This suggests either that traditional drugs are being used at too high a dose or that newer drugs are under-utilised.

A small fraction of sufferers (19 per cent) receive rehabilitation. For those with access to psychiatric rehabilitation, the frequency and intensity of this rehabilitation is less than optimal. There is no association between the degree of disability and access to rehabilitation. This raises concerns about the equitable distribution of resources among this disadvantaged population.

Putting research into practice

What factors impede the application of research to clinical practice? There can be a time lag between research design and publication. Research design or choice of subjects may not be enough like the real world.

Lack of access to knowledge is a factor delaying the use of effective treatments. However, there may be more pragmatic problems: services may have insufficient staff to deliver the full range of effective treatments.

Ways to encourage the application of research-based treatments in clinical practice include education, guidelines, audits, standards and financial incentives.

Not providing the best interventions has costs. In one scenario, the burden of acute care and crisis work soaks up all the time and budgets of service providers. As a result, the medium-term gains from funding rehabilitation and disability support services cannot be realised.

Putting practice into research

Some clinical practices have not been adequately examined by researchers. Clinicians often combine medication in bewildering combinations. This practice could increase adverse events; it may also provide wider receptor blockage. The practice lacks a research base.

Clinical practice leads research in the use of alternative treatments. Homeopathy, vitamins, fish oil, acupuncture and other natural treatments are widely used. Some are biologically plausible. They should all be thoroughly assessed. Clinicians are also more aware of shared care opportunities and cohesion between consumers, which offer hope and build social capital.

Even when the best treatment is delivered, a substantial group of people with schizophrenia will have persisting illness and disability. How we can best improve the quality of life for this group is an under-researched area. Collaboration between mental health, accommodation and disability support agencies and vocational rehabilitation is required.

The National Survey of Mental Health and Wellbeing found that about 40 per cent of those with psychosis also had a lifetime diagnosis of alcohol or marijuana abuse or dependence. Caregivers rank the issue of substance abuse highly, whether it is smoking, alcohol or illicit drugs. This is a major clinical issue that lacks effective treatment and

is not attracting as much research as it deserves. Substance abuse also shows how the structure of services may impede care; programs that split drugs and alcohol from mental health allow many people to fall between the cracks.

We also don't know how best to reduce smoking in those with psychosis. Modifications of standard stop-smoking treatments may be of some benefit. However we cannot be sure in the absence of good research.

When do we stop medication? We don't know that either.

Ten years ago psychosis treatment programs lacked a strong base of evidence. The gap between treatment and research has been substantially narrowed in recent years. Clinicians and researchers often leap-frog each other. However, clinicians need to remember that treatments that appear humane and plausible still require well controlled research. Only after conducting randomised controlled trials did we find that the use of low dose and intermittent medication was not effective.

Improving outcomes

A measure of how well we are treating schizophrenia is the proportion of disability-adjusted life-years averted, that is, how many years of life without disability can be added to patients' lives. Current practice averts 13 to 21 per cent of disability-adjusted life-years. The application of best practice within the constraint of current resources could avert 29 per cent. But what if we had unlimited funding? There would still be a substantial amount of disability that could not be prevented. So we need more research to find better treatments.

We can improve clinical outcomes by the careful application of proven treatments. We need to look for creative solutions to redesign services, using resources more effectively. We need more funds. We need to encourage the exchange of ideas across the gap between research and clinical practice. We can do better.

Professor Harvey Whiteford is the Kratzmann Professor of Psychiatry at the University of Queensland. He has been Director of Mental Health in the Queensland and Commonwealth governments.

Government policy is influenced much more by the political process than it is by scientific research. The most influential form of research in the political arena is market research – ascertaining public opinion about an issue which has reached the threshold for political attention. Explanations for the decisions that we are exposed to must be sought in the realm of political science, not psychiatry.

The process of policy development, implementation and evaluation has five steps:

1. problem identification
2. option development
3. political decision
4. implementation
5. evaluation.

Problem identification

This occurs within the context of larger social, cultural, historical and political factors. For example, a decision to balance the budget can have major impact on spending portfolios such as health and education.

Cultural norms and social attitudes can selectively focus or divert public attention. Human rights abuses existed in asylums for decades before they were seen as a problem. This perception took a change in social attitudes.

Issue entrepreneurs are individuals or groups who gain attention, advocate an issue and get it to be seen as a problem. Having mentally ill people in the community has produced two groups: one that says they need better care, and another that says they are a risk to public safety. Both groups raise awareness that could put these people back into psychiatric hospitals.

AIDS issue advocates are extremely effective. But the intentions of issue entrepreneurs are not always transparent. Their motives may be to use an issue to change the power balance in governments, political parties or the community.

The mass media are critical players in gaining selective attention for an issue. Tabloid journalism focuses on sensationalism, trying to get a gasp from the audience. News combines entertainment and information because revenues depend on circulation and audience. Stories become stale and new stories are always wanted. Because of a herd mentality, reporters give an issue a high profile, then quickly move on.

Objective information pales into insignificance. In the case of the Port Arthur shootings, there was a period when the issue could have been either gun control or mentally ill people in the community. Partly as a result of the presentation of a paper on crime, guns and mental health at a critical moment, the debate turned to gun control and resulted in new legislation.

In the burden of disease research, complex and controversial science underlies the concept of disability-adjusted life-years. But it produces a nice number that is easy to grasp. This has gained the attention of the news media and allowed us to show the burden of mental illness.

Option development

At a certain point policy makers decide that an issue is a problem they have to fix. Then begins the process of stakeholder analysis and option development.

Stakeholders include producer groups (health professionals, pharmaceutical companies), consumer groups (which could be based on disease, geography, gender or age), economic groups (business, health funds, unions) and ideological groups (political parties, reform organisations or issue advocates).

When options are considered, the overriding question is whether a given policy is politically feasible. Usually it isn't. There has to be a great degree of consensus to pull it off, as there was for a short time after the Port Arthur shootings.

The view that governments are all-powerful is not true. Governments can't change people's behaviour or how they think, despite expensive publicity campaigns. They have only a few levers available of which the biggest is finance. But rarely does throwing money at a problem actually solve it. And the ministers then have to suffer the political cost of cutting other spending or raising taxes.

The government can put regulations on the market, as it does for doctor registration, the Pharmaceutical Benefit Scheme, health insurance and hospitals. But economists don't like regulation because it reduces the efficiency of the market.

Another lever is the organisation of the health system; this has been a major thrust of the National Mental Health Strategy.

Political decision

The adoption of a particular option as policy requires a political decision. This is like a game of chess, with no set rules. Like chess, different pieces in the game have different powers. Trade-offs are considered – who will win and lose from a possible decision. The stakeholder analysis may have been forgotten. Manoeuvring – which is rarely explicit – decides the policy outcome.

The decision may be technically complex, with changes made to a number of parts of the system at the same time. A policy of closing psychiatric hospitals requires support from the public housing system.

The costs may be concentrated on well organised groups, while the beneficiaries (often consumers) may be less organised and widely dispersed. Those who lose a lot scream loudly compared to those who are gaining smaller benefits.

There are a number of strategies for gaining a favourable political decision. Build a coalition of support. Be willing to bargain. Disrupt the alliances of those opposing the policy.

Use symbols which are hard to challenge. For example, health is a basic human right! But is it? Equity demands this action!

Reframing a policy can make it more acceptable, changing the symbols and evoking public sympathy. Political decision-making is about emotion as well as data.

Implementation

This is where the hard work really begins. Implementation requires the continuing support of the coalition built to ensure the policy was adopted. Incentives are required, tying dollars to outcomes. For example, Commonwealth funding to the states and territories was tied to the implementation of the National Mental Health Policy and the release of data.

Evaluation

This is the most neglected area of the policy process. By the time a policy is implemented, the originators have often left the bureaucracy or become consultants. The stakeholder analysis has been forgotten.

But we must learn the lessons from applying the policy. There must be a transparent and objective review conducted by people who are independent of the original decision and its implementation. The results must feed into revision of the policy.

The second National Mental Health Plan is better than the first because an independent review was conducted using data collected along the way.

In conclusion, research can guide policy, but only if it is suitably packaged and presented. Scientific information must be converted to politically consumable nuggets delivered to the right person in the right place at the right time. Translators who understand agendas and processes can make the message understood in political terms.

Discussion

Nicholas Marlowe. The potency of emotion and the media are driving policy. Psychiatry is more humane and person-centred than it was 40 years ago. In the 1960s RD Laing validated the patient's experience. He was picked up by the British media, gaining power and money. This affected attitudes to hospitalisation. Have we missed the boat or could we learn from Laing's experience with British media?

Harvey Whiteford. That is one example of how the media pick a charismatic and controversial personality to focus on.

Max Bennett (University of Sydney). With current methods, an infinite amount of expenditure could reduce disability and death in only about 30 per cent of those suffering from a mental illness. That leaves 70 per cent of sufferers dependent on the results of basic research in the future. Arvid Carlsson went from Sweden to the National Institute of Mental Health in the USA. The previous Nobel prize also went to a scientist from that institute. In the 1950s Australia led the world in brain research, but this lead was taken over by the National Institute of Mental Health. We need such an institute to help the 70 per cent without an effective treatment.

David Copolov. Funding is the difficulty. The Commonwealth Minister for Health has doubled funding for the National Health and Medical Research Council over five years, for which we are grateful. But we are still very much behind the USA. The USA has what I think is required in terms of funding, but lobby groups such as Research!America think it is very much under-funded.

As for a national institute of mental health, we could start with a coalition of existing mental health and psychiatric research institutes. There is a lot of underlying activity; increased collaboration would enhance this.

John McGrath. We need a broad spectrum of research, with a balance between basic neuroscience and clinical and service-related research. However, we also need funding agencies that can incubate new, more speculative ideas. We need to put money into high-risk but woolly ideas that don't get National Health and Medical Research Council funding. We also need to study the outcomes of human services.

Alan Rosen (Royal North Shore Mental Health Services, Sydney). In comparison with the USA, Australia has done better at gun control. Also, we have done better than it appears at research, involving it in social and political issues.

Research that benefits consumers and carers

Barbara Hocking is Executive Director of SANE Australia.

SANE Australia is a national charity that helps people affected by mental illness, their families and friends. It does this through campaigning for improved services, community education and applied research. SANE works in partnership with groups such as national peak bodies, professional colleges, universities, government departments and health promotion agencies.

National consultation

In October 2000 SANE conducted a national consultation, inviting people to have their say about how life could be improved for people with a mental illness, their families and other carers. In one week 500 people responded with phone calls, letter and emails.

Many respondents simply appreciated that someone was asking for their views. People didn't ask for the cure, they are not expecting it soon. They just want to improve their day-to-day lives. The results have not yet been analysed, but some quotes are revealing.

A consumer of mental health services from Queensland said, 'If people around me – family and friends and the community in general I suppose – would understand that I am not lazy and I'm not weak.'

A consumer from South Australia said, 'By providing rehab support, social and sporting outlets and by reducing the isolation of people experiencing mental illness, many of the reasons for desperate acts like suicide can be avoided. The link between drug taking (marijuana and heroin) and psychosis should be advertised on telly, like drink driving.'

Two consumers from rural New South Wales said, 'The structure of services in our area has changed and acute care now gets all the resources and funding.' They also said 'much stigma is generated by health professionals'.

A carer in Victoria said, 'I have been a carer for 25 years and am actively engaged in the mental health field, but I become increasingly confused, tired and disillusioned as I listen endlessly to newer carers expressing, with despair, the same feelings of isolation and frustration that I still feel.'

Research and policy needs

People with schizophrenia face social as well as clinical issues. Yet current research funding concentrates on clinical issues, especially pharmacological therapies.

People living with psychotic illness would like:

- early, effective clinical and pharmacological treatment
- a safe place to live, with support
- help to learn skills
- a job or something meaningful to do
- friends to do things with
- help with drug problems, including tobacco
- a doctor or health worker who will listen and explain
- understanding instead of discrimination.

People caring for someone with psychotic illness would like:

- effective treatment and support for their relatives
- involvement in treatment plans
- education and training in their role
- the opportunity to talk to others in the same situation
- a break from the responsibility of caring
- acknowledgment
- understanding and support from the community.

Medication has enabled people to see the need for and to ask for other treatments and community support. While research is needed to improve our understanding of psychosis and to develop improved medication, we must research social issues more equitably. We need to support research that improves lives today as well as trying to improve lives tomorrow.

Researchers and funding bodies must heed the concerns of consumers and carers. For example, we need rigorous research into strategies to improve community understanding and reduce stigma and discrimination, and into community services and supports for day to-day living.

Policy makers must learn from research evidence. Research demonstrates the value of family education and training, case management and community rehabilitation programs, and newer antipsychotic medications. Yet there are no funded systematic programs for family education and training, few rehabilitation programs, and access to medications seems to be based on economic rather than quality of life indicators.

Directing research

There is enormous goodwill in the area of mental health yet consumers and carers are not benefiting as much as they could.

How can we ensure that the most useful research is conducted, and that the most effective policies are set and adopted? Consumer and carer views must be represented when research and policy decisions are made which will influence their lives. This is already happening in a limited way but meaningful representation should be expanded and supported.

There is a lot of evidence-based rhetoric at the moment but it is not always meaningful. It may have provided opportunities for researchers to indulge in over-researching and for policy makers to do nothing because there is not enough evidence. How much research evidence is enough? And whose evidence is considered worthy?

Research and policy:
A Commonwealth perspective

Dermot Casey is Head of the Mental Health and Special Programs Branch of the Commonwealth Department of Health and Aged Care.

Let us take a broad view of the relationship between research and policy. Disciplined enquiry is based on empiricism but doesn't necessarily follow a strict methodology. Not all change arises from incremental learning; some is more revolutionary in nature. While the search for answers is important, the greatest challenge is to put into practice what we already know.

My key theme is that researchers need to grapple with the politics of change as much as with the science of discovery.

The National Mental Health Strategy commenced in 1992, giving the Commonwealth a new role – to improve the mental health of the Australian community. At the time, we felt that the resources we had were not meeting the needs of the severely mentally ill, let alone the mental health needs of the broader community. We knew that the standard of mental health care had to improve to achieve the best possible outcomes. And we believed that more effort should be directed to learning new things.

One of the most critical information 'black holes' was that we didn't know how many Australians needed mental health care. We didn't know the nature or consequences of their disorders, or whether the services we provided had sufficient resources to be effective.

Research and development activities

Over the first five years, the strategy funded a range of research and development activities, including formal research studies, major consultancies, and a mix of qualitative and quantitative research. We aimed to fill the major knowledge gaps and accumulate evidence to serve as a foundation for future policy.

One of the key findings from this research was a substantial inequity across Australia in the level of resources available for mental health care. There was a 40 per cent difference between the funding for public mental health services in Western Australia and the Australian Capital Territory,

respectively the highest and lowest spenders. Over the course of the strategy, there has been a 25 per cent increase in spending in all jurisdictions but the funding disparities have not decreased.

### Inequity in public mental health services available

Spending on mental health in the states and territories, 1997–98
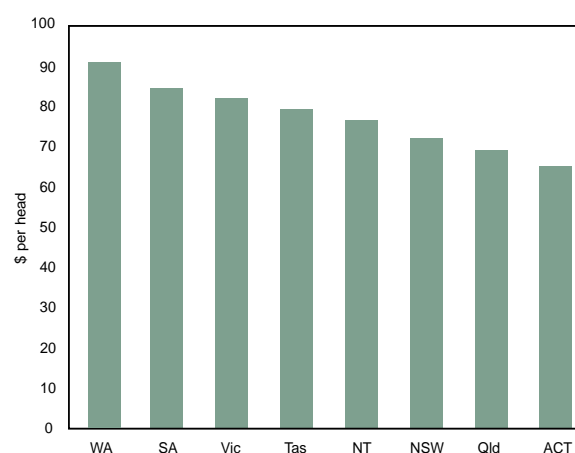
There is even greater inequity in private sector resources dedicated to mental health services delivery. Generally, private psychiatrists direct a much greater proportion of their time to metropolitan clients, particularly those living in more affluent suburbs.

The second research finding concerns the prevalence of mental health disorders in the community. The National Survey of Mental Health and Wellbeing found that 18 per cent of the general population experience a mental health disorder over a 12-month period. Moreover, only 38 per cent of people with treatable disorders such as anxiety and depression received some form of care. Nearly two thirds of those with a mental health disorder receive no treatment.

Need greatly exceeds supply
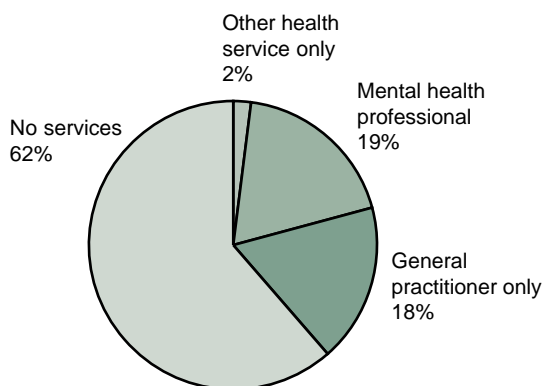
It is unrealistic to expect that policy change will inject sufficient funds to enable the specialist sector to meet the needs of the 18 per cent. Rather, we need to broaden the horizons of the wider human services sector to contribute to the mental health of the community.

The third research finding indicates that service providers drive costs, not patients. The treatment that a patient receives depends very much on who they see. The finding supports what has long been suspected in the mental health industry – that there is insufficient consistency in service delivery and quality.

Other research findings concern people with psychotic conditions, consumer opinions about the services they receive and the burden of mental health disorders in the Australian community. The needs of people with psychotic conditions raise questions about the policy changes required to balance medical and social intervention approaches. Consumers report dissatisfaction with access to services, poor service quality and stigmatising staff attitudes. An Australian Institute of Health and Welfare report found that mental health is the third leading cause of disease burden in Australia.

These findings have substantially increased the profile of mental health in the health sector and the wider community.

A new paradigm

Mental health is firmly positioned on the public agenda. The next step is to convert the research evidence into policy action. The second National Mental Health Plan, which began in 1998, attempts to move from specialist mental health services to mental health in the community, balance treatment with prevention, address the social and economic consequences of illness as well as its individual impact, and focus on value for money in services.

For many areas of the specialist sector the first mental health plan still remains continuing or unfinished business as we move towards expanding from a focus of specialist services to the broader social concerns. This is a paradigm shift that will require major political and cultural change. It will take mental health into new forums.

The second National Mental Health Plan has added three new themes to the existing objectives: prevention and promotion, partnerships in service reform and delivery, and quality and effectiveness. Over five years the Commonwealth is spending $340 million on the plan, with about 85 per cent going to states and territories and the remainder to national projects.

Mental health is everybody's business. A modern nation must widen its concern to population health and the social, political and economic forces that produce mental health disorders. A whole of community approach must be promoted to build resilience and reduce future illness. Two recent responses to the call are Rotary International committing $5 million to research and awareness, and the ACTU campaign against bullying in the workplace.

I would suggest six areas of inquiry for the future research agenda:

- understanding the causes of mental illness, including biological and social factors
- informing value for money in resource allocation
- enhancing the role of primary care
- developing effective promotion and prevention initiatives for the whole population
- balancing the emphasis on treatment of illness with a concern for improving quality of life
- understanding the impact of mental health on social and economic development.

A state government perspective

Professor George Lipton is General Manager and Chief Psychiatrist of the Mental Health Division of the Health Department of Western Australia.

The development of policy should be one of the natural outcomes of research to which a state director and all other stakeholders have access. The work of the director is in itself action research. It takes into account the streams of data that flow from a wide variety of fields and somehow integrates that into what is called policy but which is, in effect, a working hypothesis to be tested in the field.

The basic paradigm that confronts us in the treatment of schizophrenia is the microcosm that incorporates the patient, his or her carers and community, and the providers of service. This takes place within an environment that is considerably influenced by the nature of current knowledge and current policy.

Belief systems

As in all political systems, perceptions may overcome reality. The existence of research findings is not enough. They must be understood and incorporated into the current belief systems. If the research is only partly acknowledged, so will practices be distorted.

The state administrator knows how important it is to use the best methods as 25 per cent of resources are spent on the care of less than 1 per cent of the population. He or she also shares in the knowledge of the anguish and tragedy of disrupted lives.

Structure of system

The factors above the patient – system structure, resources, epidemiology – influence the overall treatment environment and limit the possibilities available to the clinician and patient. These are the drivers of policy. The factors below the patient – biology, society, personal psychology – influence the nature of the illness and its treatment.

All the factors interact and all are overshadowed by current belief systems. No amount of research-based policy will prevail if these belief systems cannot be changed.

Climate of inquiry and change

Someone who is trying to manage and improve a state system of care has to provide information and knowledge to improve the treatment paradigm. They also have to use
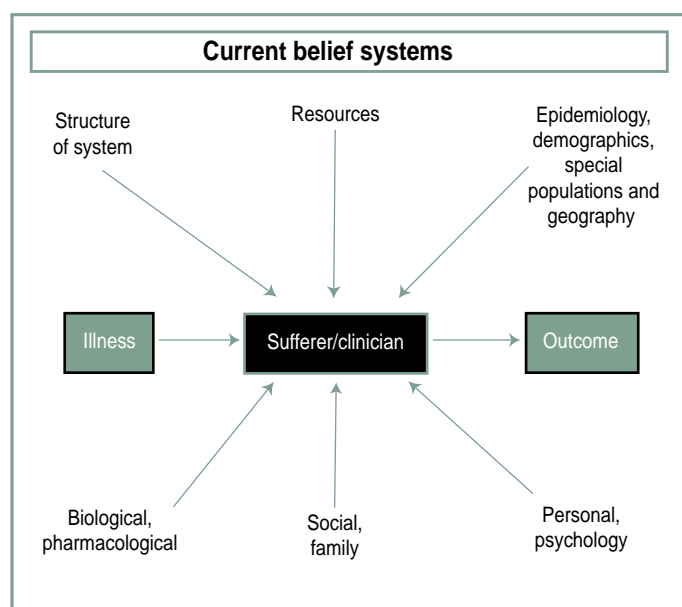
the intellectual stimulation of exciting research to engender a climate of inquiry and change.

I have always striven to encourage research. Research develops local knowledge, provides stimulation to staff and gives clinicians, consumers and carers ownership of the information that emerges. Policy is easier to formulate and apply when it is led by service providers and users.

Research in Western Australia

Western Australia has excellent data systems, including a patient-linked case register and the Western Australian Health Services Research Linked Database. The state funds academic appointments in various types of psychiatry, epidemiology and mental health nursing. It also funds two research centres: the Centre for Clinical Research in Neuropsychiatry and the Centre for Mental Health Services Research. The latter translates basic information into service development information and models that can be integrated into policy.

State government grants go to quality improvement projects, service innovation studies and mental health promotion.

Organisational structures have powerful implications for treatment. Experiments in organisational change can have major effects on policy. Research findings in telepsychiatry and rural rooming-in centres have transformed rural psychiatry in Western Australia.

Resources bear on the way services are provided. A unique casemix model in Western Australia has provided information for cost-benefit analysis, efficient resource use and effective intervention.

Epidemiology and demographics play a critical part in policy formulation. Such information adds weight to community housing policies and helps focus primary prevention programs.

Putting discoveries into action

Future discoveries in pharmacotherapies, genetics, biology and information technology will change treatment for schizophrenia. A better understanding of the inner world of a patient should also lead to better paradigms of treatment and to policies that work from within the patient and his or her relatives, rather than from the outside. SANE Australia has reported that callers to their helpline complain that all their doctors do is give them pills. We must invest considerably more research effort into the inner needs of patients and how to respond to these in a partnering and mutually acceptable way. This will require policy and resource shifts.

The biggest problem facing a state director is assessing the future, balancing discoveries and matching them with organisation, resources and demographics, while at all times dealing with resistance to change in the community and professionals. Policy may be analogous to a formulation in psychiatry: where the available facts are melded together into a conceptual framework for a plan of action.

Commonwealth-state links

Des Graham is the Chief Executive Officer of the Mental Health Council of Australia.

There is no doubt in anyone's mind of the essential importance that linkages between the Commonwealth and state have in improving the mental health outcomes of the Australian community.

Strong leadership and linkages between governments have seen Australia recognised as a world leader in research and service provision. However, beyond our success and expertise, we are increasingly aware of the significant burden that mental illness places both socially and economically on the Australian community.

Australia cannot become complacent. In the foreword to the second report of the National Survey of Mental Health and Wellbeing, the Commonwealth Minister for Health, Dr Michael Wooldridge, stated that 'The image of mental illness as a long-term costly personal burden still persists'.

Links with support services

The National Mental Health Strategy clearly stated that there was an important role to be played through links between Commonwealth and state mental health service providers and also with those outside the mental health arena. Support services such as housing, corrective services, transport, employment and general health are all vital in addressing and providing for the needs of people who experience mental illness and for the carers of people with mental illness.

In December 1997, the final evaluation report of the National Mental Health Strategy recognised the intent and achievements made through intersectoral linkages. The report also highlighted that a number of critical structural steps had been taken to better link mental health services and other support programs, both at the Commonwealth and state level.

Unfortunately, this was the area of least progress. The report observed that most mental health services did not regard the building of service linkages as core business.

Fortunately for the Australian community, these comments have not gone unheard. The renewed National Mental Health Strategy and its second National Mental Health Plan have specifically identified the importance of delivering services in partnership.

As was the case in the initial strategy, excellent linkages are occurring between the Commonwealth and state governments. Across the mental health sector, there are joint discussions and partnerships in most areas, including the implementation of standards and quality issues, funding and its models, health promotion and prevention, primary health service delivery and demonstration projects.

Clearly, partnerships are a two-way process and in many cases the mental health sector provides the invitation to other agencies without much success in return. However, these are essential links and we must persist in their establishment.

Links with the private and non-government sector

Another important area for linkage is between governments and the private and non-government sector. Private mental health providers – private hospitals, general practitioners and psychiatrists – play an essential role in the provision of mental health services. To avoid their isolation, partnerships between private and public health and welfare providers need to be further encouraged.

While funding in the non-government sector has improved, it is uncertain whether the level of funding can support the activities and roles that the non-government sector provides. The reality is that governments must further develop and appropriately fund non-government organisations to embed them as essential partners in the delivery of high-quality comprehensive services.

So where to from here? There is little sense revisiting what we already know. Our research tells us that there will be a continuing escalation in demand for mental health services. And it is clear that the mental health sector is unable to meet all of the needs of consumers and carers. The sector must develop partnerships with other sectors.

Research has clearly identified the gains made when health and welfare organisations work collaboratively towards a single goal. Let's hope that at the end of the renewed National Mental Health Strategy, the evaluation does not read as the first, and that intersectoral linkages are high on the scorecard of achievements.

Discussion

George Lipton. The state directors of mental health want to get it together. But each state has its own mental health Act. Databases are another problem; we would welcome more national information.

Dermot Casey. Federation has its downside. New South Wales and the Australian Capital Territory have cross-border legislative arrangements. The second national mental health plan aims to improve information systems across all jurisdictions. Good information is needed for clinical and administrative purposes.

Barbara Hocking. There can even be demarcations between hospitals and clinics from suburb to suburb as well as state to state. As families are often the repositories of information on behalf of the person who is ill, services need to acknowledge their importance and work with them to provide assistance.

John McGrath. *Disability disorders need more attention. In preparing for the third national mental health plan, could we put in a bigger ambit claim for $1 billion? Would it have a chance?*

Dermot Casey. I can't comment on a third plan. But there is increasing recognition of the importance of mental health. The Prime Minister has said that mental health is a bipartisan process. There are always resource issues. Health is about 8.5 per cent of gross domestic product. One achievement of the plans is that mental health is an issue for the whole community. If we get the opportunity, we will put in another ambit claim.

David Foster *(University of Adelaide). Families are an important part of treatment. Many inpatients are not voluntary. Is this because there is a lack of resources for families?*

George Lipton. As a clinician, I cannot conceive of seeing a patient without working with the family. But I would be surprised if lack of resources for families and involuntary admissions were linked. Patients have children too, at very great risk. They need to be looked after properly. I have seen eight-year-olds caring for their parents.

David Copolov. *Even though the Commonwealth is investing more funding, primary responsibility rests with the states. Psychiatric research funding comes from the Commonwealth. Are there ways of creatively looking at the formulae to boost research by the states?*

George Lipton. Research tends to be Commonwealth. States tend to be services. It is hard for states to fund research; usually the best they can do is to put up people who find funding. Some consumers are disappointed with me for funding research, feeling that the funds could have been spent on services. I get away with research by doing it under quality and promotion. The third mental health plan could look at state and Commonwealth approaches to research funding.

Dermot Casey. In another field the Commonwealth matched state funding. But that is not a universal model. Not only has there been increasing recognition of the importance of medical research, I would be surprised if mental health was not at the top. We have to engage the broader social and political context.

Des Graham. Who cares for the carers? Recommendations for broader national recognition of the role of carers are with the Commonwealth. Carers provide an average of 104 hours of care each week. That is an enormous contribution and saving to the national budget.

Influencing the political process

Peter Wills is Chairman of the Health and Medical Research Strategic Review Implementation Committee and Chairman of the Garvan Institute of Medical Research in Sydney.

There is no exact recipe for influencing the political process. The relationship between public health policy and beneficial medical outcomes is not linear; it involves constant interactions between three major stakeholders: public policy makers, the health and medical research sector, and health and medical professionals.

Direct lobbying

The first method of influencing political process is to lobby governments directly. Peak organisations can approach relevant ministers or relevant areas of government departments. Departments such as the federal Department of Health and Aged Care, and similar state government departments, set their own priorities in health research and fund projects in their own right. The six national health priority areas endorsed by health ministers are: asthma, cancer control, cardiovascular disease, diabetes mellitus, mental health, focussing on depression, and injury prevention and control.

The Strategic Research Development Committee of the National Health and Medical Research Council will consult stakeholders to determine priorities for the next triennium. Clearly, one way of increasing public sector awareness of schizophrenia as a research priority is to have input into government processes such as these.

Inquiries and reviews

The second method of influencing the political process is through submissions to specific government inquiries and reviews, such as the Strategic Review of Health and Medical Research conducted in 1998 and 1999. This review gathered over 1500 submissions which were compiled into a report containing 120 comprehensive recommendations. Those recommendations formed a compelling blueprint for change.

The Federal Government responded to this report in the May 1999 Budget by providing an additional $614 million for health and medical research, over a five-year period. This will ultimately increase the total funding to double what it was in 1999; the largest increase in medical research funding in the history of Australia.

Another method of influencing the political process is through parliamentary inquiries conducted by Senate and House of Representatives committees. In the Senate, the Standing Committee on Community Affairs deals with matters relating to health and medicine and in the House of Representatives the Standing Committee on Family and Community Affairs deals with these matters. The House of Representatives committee has recently held seminars on aspects of youth suicide. An approach to the Chair of this committee, Mr Barry Wakelin, may lead to a seminar being sponsored on schizophrenia.

Engaging the community

Another strategy for influencing public policy is to engage the community as stakeholders in medical research. A new organisation is currently being established which will provide a platform for greater public awareness of the importance of medical research in Australia.

Research!America is an organisation, funded by membership fees and in-kind support from companies, which works to raise the profile of medical science by political lobbying, advertising and building community understanding of research in the United States. This grass roots activity has doubled medical research funding.

The Health and Medical Research Strategic Review recommended that a similar body be established in Australia. The idea has gained strong support and a task force has prepared a business plan. The organisation will be called Research Australia and will be publicly launched in early 2001.

Stakeholders will be the research sector, special interest groups such as charitable foundation and peak bodies, the industry sector of pharmaceutical and biotechnology enterprises and the general business sector and the community. Stakeholders will not include any government agencies; the body will remain politically independent.

The goals of Research Australia will be to better inform the public as to the benefits of health and medical research and the organisations which perform that research; to motivate the public to actively support health and medical research; to motivate the private and corporate sectors to increase sponsorship for health and medical research; and to achieve funding for health and medical research in the public sector at a level warranted by scientific opportunity and supported by public opinion.

The National Mental Health Research Priorities Project

Professor Tony Jorm is Deputy Director of the Centre for Mental Health Research at the Australian National University.

We were asked by the Mental Health Branch of the Commonwealth Department of Health and Aged Care to identify gaps in mental health research in Australia. We have done this by comparing the existing state of research against various standards. This project has been carried out with colleagues at the Centre for Mental Health Research, Helen Christensen, Kathy Griffiths and Jo Medway. The project is still continuing but here are some of the results so far.

Publication analysis

The first step was to take a snapshot of existing research carried out in Australia. We decided to do a content analysis of a year of published research in mental health, where the first author had an Australian address, and a year of competitive research grants, from the National Health and Medical Research Council, the Australian Research Council and non-government sources. We have completed the analysis of published research but the analysis of grants is still going on.

We developed a classification scheme for articles and grants. This used a number of dimensions:

- type of mental disorder (for example, schizophrenia, affective, substance use, eating)
- topic of research (for example, risk factors, genetics, health service evaluation, various types of treatment)
- setting of research (community, primary care, specialist)
- inclusion of sub-groups (children, older people, non-English-speaking background, Aboriginal, rural and remote).

Standards for comparison were:

- prevalence (from the National Survey of Mental Health and Wellbeing)
- burden (Australian burden of disease and injury study)
- cost to the health system (Australian Institute of Health and Welfare)
- national policy goals (identified from Commonwealth documents)
- priorities of stakeholders.

The last standard was established by a survey of stakeholders. They included researchers, research grant committees, consumer and carer advocates, clinical service providers and administrators. In a questionnaire they rated priorities using the classification scheme for articles and grants.

Findings

These findings do not show mental health research as a proportion of published health research. The data on competitive grants will give an indication of the relative resources devoted to mental health.

The disorders covered by published mental health research in rank order were:

Substance use	25%
Anxiety	15%
Affective disorder	14%
Schizophrenia	11%
Childhood	9%
Dementia	8%
Other	18%

So schizophrenia is a small area of mental health research.

A comparison of prevalence, burden and cost showed that anxiety and substance disorders are the most prevalent. Affective disorders and dementia contribute the greatest burden and have the highest health system cost. Schizophrenia is a close third.

Affective disorders stand out in terms of high burden and cost but do not rank so highly in research. But we should not get into a competition between mental disorders; research in one area may help another. Schizophrenia often occurs with affective disorder, anxiety and substance use.

Stakeholder priorities

Stakeholder groups often differed in their highest priorities. Affective disorders and suicide were consistently high. Schizophrenia rated highly with consumers, carers, psychiatrists, nurses, research committees and administrators. But it rated less highly with researchers, general practitioners and clinical psychologists. The groups that have the most contact with schizophrenia tended to rate it most highly.

Stakeholders' priorities for research topics also differed. All agreed on the need for prevention and promotion. Psychological and social treatments ranked next, followed by evaluation of services. Consumers, carers and service providers wanted more research on training and education of health professionals.

In the current research effort, two of these priorities – prevention and promotion, and training and education – fare poorly. Each area has only 2 per cent of published papers.

For research settings, all stakeholder groups rated either primary care or the community as priorities. But two-thirds of research is carried out in a setting of lower priority – specialist care. About 30 per cent is done in the community and only 3 per cent in a primary care setting.

The high priority ratings for sub-groups were Aboriginal people, children and adolescents, and socially and economically disadvantaged people. Despite this, Aboriginal people and disadvantaged people each feature in only 1 per cent of research. Thirteen per cent of research is on children and adolescents.

Research for lives or for science

When asked about what factors should be considered in setting research priorities, there was general agreement that the following were important:

• the suffering of the individual affected

• the potential of research to make a difference to people's lives

• whether the disorder affects people for most of their lives.

The National Health and Medical Research Council panel, which has a lot of influence on what gets funded, saw research quality and the advancement of science as important. Other stakeholders did not share this view.

Assessing value for money

Associate Professor Philip Burgess is Head of the Policy and Analysis Group at the Mental Health Research Institute of Victoria.

Mental health has lagged behind other areas of health care, particularly acute hospitals, in developing indicators of performance. Over the last five years there has been increased investment in finding information to support the national mental health strategy.

Distribution of expenditure

What is the relative distribution of mental health expenditure across mental health services? The national survey of mental health services mapped psychiatry services to area health services across Australia. The Health Insurance Commission also has a rich set of data mapping medical benefits paid for psychiatry items.

Preliminary analysis of this data for area mental health services in Australia suggests a six-fold variation in public sector expenditure from the lowest to the highest area. Private sector expenditure on bills raised in the same areas showed massive variation. This indicates that rural and remote areas are poorly serviced by private psychiatrists while other areas are very well serviced.

These differentials demand explanation. They could be due to variations in population need or variations in provider practices, particularly the relative efficiency and effectiveness of services.

Designing performance indicators

The task is to design a set of key performance indicators to monitor value for money in adult mental health services. The political environment needs such indicators to inform the purchasing demands of government.

Indicators can be used for different purposes: at policy level, for monitoring the use of public funds; at service management level, for feedback on local programs; at service delivery level, for judging whether services meet consumers' needs. Indicators should be selected at a level appropriate to the decisions being made.

Another issue is defining mental health service products. Are these current purchasing inputs (beds and staff), intermediate products (bed-days and patient contacts) or final health care products (episodes of care)? The mainstream health system builds indicators around the final products.

Do we judge the performance of an area mental health service by the services it delivers, regardless of who receives those services? Or by the health status of the population served? The ideal set of performance indicators is a blend of health status indicators that point to the level of service required and health service indicators that specify what is actually delivered.

Indicators should:

- focus on outputs or products of mental health care rather than inputs or processes involved in delivering that care
- offer strategic value in actively driving change towards goals, not passively monitor the current reality
- balance information about agency performance with an understanding of population needs.

The Productivity Commission has developed a broad framework that has been applied to health monitoring. This framework measures how well the organisation meets its objectives (effectiveness) and how well it uses resources (efficiency). The diagram shows how it could be extended to mental health services in five dimensions: service volume, unit costs, access and equity, quality and appropriateness, and outcomes.

A mental health monitoring framework

What are the materials for developing robust and reliable indicators? Criteria for indicator selection are:

- definition – can the indicator be clearly defined and quantified?
- reliability – are the source data sufficiently reliable to enable the indicator to be reproduced?
- validity – does the indicator measure what is intended?
- significance – does the indicator measure the central aspects of mental health service delivery?
- clear intent – can the intent of the indicator be easily communicated and understood?
- timeliness – can the indicator be produced in time to influence decision-making?
- incentives – is the indicator likely to create positive or perverse incentives for mental health service providers?
- affordability – can the indicator be produced at a reasonable cost?

- sensitivity – is the indicator responsive to changes in service delivery?
- power to influence – is performance measured by the indicator able to be influenced by management action?

Limitations of indicators

As a demonstration project, we developed and modeled indicators using various materials including the National Survey of Mental Health Services. Preliminary findings from the modeling analyses suggested considerable variation across area mental health health services in both indicators of efficiency and effectiveness. Outcomes, such as the 28-day readmission rates, showed that the indicators have limitations as valid measures of effectiveness and efficiency.

Future priorities are to find an explanation for the variation in performance across areas, to adjust casemix measures for complexity, to invest in indicators for service managers, and to move from indicators to benchmarking. The focus on different population needs has to be strengthened and funding varied to reflect this.

Adapting the health monitoring framework for mental health
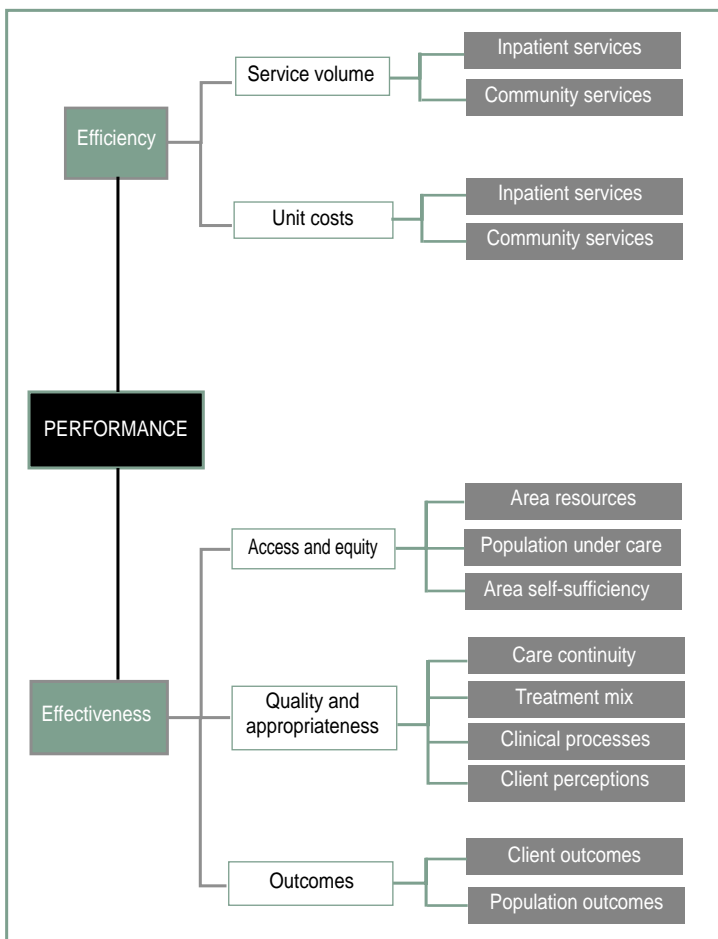
Outcomes research in schizophrenia

David Grainger is Director of Corporate Affairs and Health Economics at Eli Lilly Australia.

All research and treatment affect a range of outcomes – clinical, economic and humanistic. These should be considered together. I prefer the term 'outcomes research', which is broader than 'pharmacoeconomics'.

Why is outcomes research important for schizophrenia? Antipsychotic drugs are the second-fastest growth category in the Pharmaceutical Benefits Scheme. This reflects the disability imposed by schizophrenia and the high cost of new medications. The older 'typical' drugs, such as haloperidol, costing $0.30 a dose, are being replaced by newer 'atypical' drugs, risperidone and olanzapine, costing $4 to $8 a dose.

Economic questions

Is the increasing expenditure on new antipsychotic drugs cost-effective? Do the newer medications deliver improved outcomes? How do the newer drugs affect other costs in the health care system?

The goals for schizophrenia treatment have broadened in recent years. They include controlling symptoms, minimising the side-effects of medication, maximising the quality of life and functional ability, and avoiding the criminal justice system. We need to take account of these goals when determining cost-effectiveness.

The sources of data include randomised controlled trials, case reports and other research methods. These data may be evaluated using decision analysis, economic evaluation, non-randomised studies and budget impact modelling.

A decision analysis of direct costs in four countries over five years of treatment shows that the older and newer medications have similar total health care costs. Although the total costs are similar, the money is spent in different areas – those using typical drugs spend more time in hospital, those using atypical drugs spend more on medication.

Randomised controlled trials indicate that atypical drugs improve symptoms, have more tolerable side-effects and improve quality of life. Patients treated with the newer drugs were significantly more likely to stay out of hospital than those receiving older drugs. Economic evaluation as part of a large randomised trial in the USA indicated lower total health care costs in the patient group receiving the atypical drug (olanzapine).

Maintenance phase medical costs

US$ per-patient costs over 46 weeks
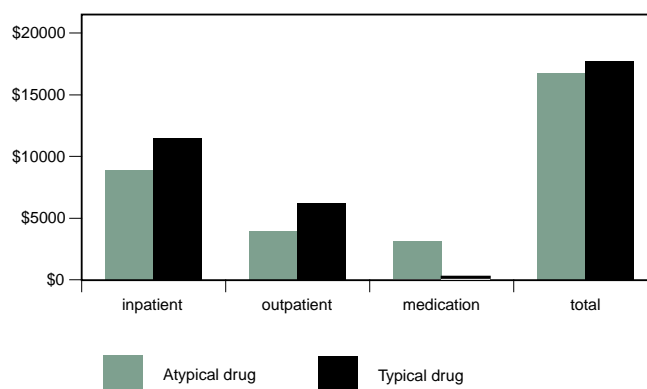
But there are limitations on these trials whereby the results may not reflect the real world.
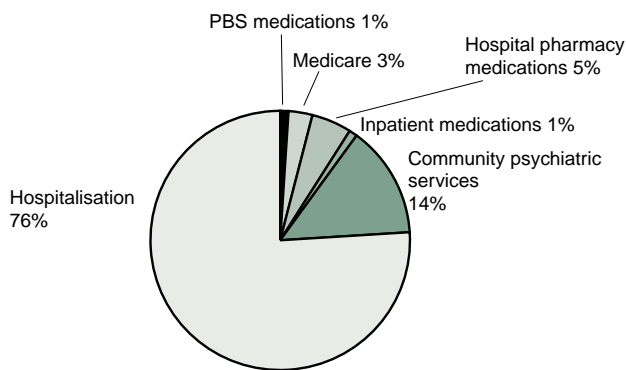
The results of randomised phase III trials have demonstrated the technical efficiency of atypical antipsychotic drugs. The Pharmaceutical Benefits Advisory Committee has judged the newer drugs to be more cost-effective, in terms of improved response rates and reduced side-effects. But it is not that simple for area health services in managing their budgets and therefore additional research approaches may be helpful.

Dandenong study

The Schizophrenia Care and Assessment Program is studying 350 patients in the Dandenong area of Victoria from 1997 to 2003. Related studies are being undertaken in the USA and UK. Patients receiving normal care are being assessed regularly over three years. This will produce a rich collection of data on clinical outcomes, quality of life and costs.

The study has shown that most community care contacts are with psychiatric nurses and most medical contacts are with general practitioners. Looking at the first 150 patients over six months, most expenditure went to stays in hospital. Medications were 7 per cent of costs and Medicare (services by doctors) was only 3 per cent.

Distribution of health care costs over six months

PBS medications 1%
Medicare 3%
Hospital pharmacy medications 5%
Inpatient medications 1%
Community psychiatric services 14%
Hospitalisation 76%

Other methodologies

Randomised naturalistic trials are an attempt to get the best of both worlds – random allocation to therapy and the real world. Patients are randomised to receive a specific drug therapy but then treatment is naturalistic. A large study of this type in the USA is comparing the effectiveness of antipsychotic drugs.

Cost-utility approaches enable comparisons to be made between different illnesses. They attempt to rate health states in terms of quality-adjusted life-years. But it is difficult to value health states in schizophrenia. Some progress is being made with video vignettes and questionnaires.

Budget models take a cohort of patients and break them up in line with the severity of the illness to more accurately portray the real world. A US model aimed to show the impact of a switch to atypical drugs on health care costs. A cohort of 300 patients was stratified by type and followed for three years. The atypical drugs reduced the total cost of their care. More was spent on drugs but hospital and residential care costs went down, more so in later years.

The newer atypical drugs are more cost-effective than the older drugs, with gains in outcomes. But it is also important to understand the impact of the drugs on other parts of health expenditure; overall the newer drugs do not appear to change total costs. New methods and more comprehensive data collection could produce a different result.

Policy implications

There is a need to plan for increases in the drug expenditure component of schizophrenia care. It is not helpful that the federal government pays for drugs and the states pay for hospitals. Expenditure on antipsychotics should not be viewed in isolation but as part of the total costs of care.

Ms Elizabeth Cham is Executive Director of Philanthropy Australia.

Philanthropy is a pervasive yet invisible sector. A lot of people don't think we have philanthropy in Australia; it's in America. Here the government does everything. We don't have the same social and cultural setting as America but we still have philanthropy.

Australian foundations and trusts have a capital base of $100 million. About 85 per cent of that is in Victoria, because of a tax incentive – the Victorian government used to give philanthropy an exemption from death duty. This has built the Parkville mile in Melbourne: the Baker, Florey and Hall medical research institutes. It has also benefited the arts and the environment.

Philanthropy is not going to make every pie bigger. It is like venture capital for community experiments: funding risks and innovation then, having shown what works, taking it to the marketplace or the government.

Corporations or foundations are not going to take on the responsibilities of governments. All the philanthropic funding in the United Kingdom would not keep the National Health Service going for a week.

Trends in philanthropy

Trusts and foundations are undergoing extraordinary change. They have had great success in increasing government funding. Though foundations only spend a tiny amount compared to government budgets, that small figure can still be very influential.

The nature of funding for philanthropy has changed. Corporations are giving more. The Prime Minister has a roundtable on philanthropy to ensure that corporations contribute to the community where they make their profits.

Companies used to see the limits of their responsibility as employing people and returning dividends to shareholders. But as the proportion of people holding shares has increased from 3 per cent to 53 per cent over the last 50 years, corporate stakeholders have come to include most of the community.

New sources of wealth

There has also been an extraordinary amount of new wealth in the rich countries, not just in growing industries but also in the hands of individuals – young e-entrepreneurs, owners of highly appreciated stock options, executives of large companies and in financial services, partners in consulting firms, celebrities and women. The largest intergenerational transfer of wealth ever is under way as the parents of the baby boomers – ordinary mums and dads – pass $50 billion on to their children.

Some of the factors influencing new donors are an ageing population, the appearance of socioeconomic extremes, change due to globalisation and new technology, and cultural shifts. One important cultural factor is the search for meaning in an age where god and the family are in decline.

Mental health and philanthropic funding

Philanthropy may not know enough about psychiatric illness. Support for research, carers and sufferers is very important.

People who are very fragile with mental illness or substance abuse, can express themselves through cultural activity – drama, writing, poetry, singing, dancing. Fragile people often have great capacity for creativity. They have the potential to see themselves and the world differently, and so they behave differently.

Victoria has earmarked funds for mental health. Trusts fund respite care for carers, volunteer coordinators for the community.

Mental health requires a different way of dealing with illness, where the extended family and friends determine what they can do for the person who has an illness. Trusts have funded research into the brothers and sisters of mentally ill people. But they don't fund the sort of research described earlier.

What do trusts and foundations fund?

Philanthropy is different from governments or companies; it doesn't have electors or shareholders. So that means it makes decisions differently.

Benefactors are energetic; they like to be hands-on. They want to help translate ideas into practice, adding value to the activity. Though they are willing to take risks, they want to know their money is being well spent.

Foundations and trusts like to fund work that is close to the source of the problem. They don't have the staff for complicated administration; trustees are busy. Many foundations fund cooperatively, they talk to each other.

How to win support

Corporations want to give. They understand the triple bottom line (financial, social, environmental). What they don't understand is why so many community organisations appear to be doing the same thing. Why can't the organisations come together? One entity should put the case for many.

How many organisations and institutes deal with schizophrenia? You need to present clearly and explain who is doing what.

International funding is also a possibility. Philanthropy Australia has a new category of international membership. Foundations from the USA, Asia and Europe fund projects around the world.

Gaining grants from trusts is different from getting government funds. It's a maze, with no centre. You need to use the tools – our resource centre, the book of foundations.

The grant makers want applications that they feel they can fund. So do some research, identify the right foundation, say why this institute is not overlapping with others that look similar, showcase examples in practice, explain any international links. Once you have won funding, establish a structure to assist donors, to keep them informed.

Discussion

Annette Atherton (Canberra Schizophrenia Fellowship). A lot of mental health consumers won't take oral medications. Is there research being done into depot antipsychotics (drugs that can be stored in the body)?

David Grainger. Yes, but they are still a long way off – a couple of years. A wafer version of olanzapine is available now.

David Copolov. We have heard about the steps for grouping and approaching trusts and foundations. What about making psychiatric illness a priority? What can we do to raise awareness?

Conclusion

Graham Thornicroft

We have had a feast of information and insight. I would like to thank the sponsors and organisers. It has been a tremendous symposium.

The scale of mental health problems is huge: two-thirds of sufferers are untreated, 60 to 70 per cent are unemployed, mental health is 25 per cent of the global burden of disease.

We are entering a new paradigm. Having moved treatment from institutions to community care, the next step is to value for money medicine. This presents positive opportunities.

Australia is taking the lead globally, in its anti-stigma work with posters, in closing the Melbourne psychopolis with three institutions together, and in its world-class epidemiology and assessments of need. Australia also leads in the setting of standards and the use of standards in the quality of care.

Mental health is making inroads into other areas of the health infrastructure, such as the World Health Organization and other international bodies. Research is moving from blue sky work to testing to large-scale studies to everyday effectiveness studies to practice.

But there are gaps – we don't yet know enough or do enough. Users must be empowered to demand that we work to the protocols that have been agreed. More training of staff is needed so that they feel validated and users are better treated. Unemployment, at 60 to 70 per cent, would be a national scandal for the sufferers of other diseases. We don't yet know what works to combat discrimination. And the mental health needs of Aboriginal people have to be met.

One theme has been partnerships – between users, carers, industry, government and philanthropists. Together we can achieve more than we can separately. Coalitions can form to achieve a common aim.

A lot depends on public understanding. This is not an area to avoid. Advocacy is needed for increased clinical services and research. We need issue entrepreneurs who wait until the time is right to press the point.

Balances are needed between severe and common mental illnesses, between acute and long-term treatment, between quick-fix and long-term research. All are important; there is no sense in robbing Peter to pay Paul.

Mental health has long been seen as a Cinderella, the last to the ball. Well ciao, Cinderella. Mental health is now leading the health sector. It pioneered user and carer involvement; now other services are becoming customer-driven. It moved away from the large hospital as the site of medical pride and prestige. Intermediate care, which has been in mental health for years, is new for other areas, such as hypertension and diabetes. And to the other symbols for mental health we can add recovery.

There are five points to remember:

1. Research does pay dividends, so invest.
2. Mental health leads the way in modern health care.
3. The needs far outstrip the care available, so invest.
4. Schizophrenia is treatable.
5. Recovery is common.