



REPORT OF THE HUME PIR CONSUMER AND CARER ENGAGEMENT WORKING GROUP:

**OUTCOMES OF CONSUMER AND CARER FORUM HELD ON WEDNESDAY THE 18TH OF
MARCH 2015**

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Introduction and Context

PIR aims to support people with severe and persistent mental illness with complex needs and their carers and families, by getting multiple sectors, services and supports they may come into contact with (and could benefit from) to work in a more collaborative, coordinated and integrated way.

The ultimate objective of PIR is to improve the system response to, and outcomes for, people with severe and persistent mental illness who have complex needs by:

- facilitating better coordination of clinical and other supports and services to deliver 'wrap-around' care individually tailored to the person's needs
- strengthening partnerships and building better links between various clinical and community support organisations responsible for delivering services to the PIR target group
- improving referral pathways that facilitate access to the range of services and supports needed by the PIR target group and
- promoting a community-based recovery model to underpin all clinical and community support services delivered to people experiencing severe and persistent mental illness with complex needs.

In addressing these objectives it is imperative that PIR draw directly upon the expertise of consumers and carers. We defined consumer and carer engagement as “engaging consumers and carers as true partners in the PIR program and their wider health and community support systems”. Hence the Hume PIR Consumer and Carer Engagement Working Group was formed in July 2014 and went on to plan a forum to identify systems issues and potential solutions from a consumer and carer perspective.

PIR participants, their carers and people with a lived experience from the wider community were invited to participate in a Word Café style forum designed to address the following objectives:

1. To provide a safe environment for consumers and carers using the mental health system, to discuss issues that affect them.
2. To identify key mental health systems issues and solutions from the consumer and carer perspective.
3. To report back to the PIR Consumer and Carer Working Group for further action.

Thirty four (34) consumers and carers attended. The Café Style forum was set up with six round tables, each with a topic to be discussed. Each table was hosted by a PIR Support Facilitator whose role was to facilitate the conversation and assist with transcribing. The day progressed through three stages, firstly the identification of system issues, prioritisation of these issues and identification of potential solutions.

The topics discussed were:

- 1 Inpatient Facilities (including interface with community services)
- 2 Emergency Departments
- 3 Housing and Accommodation
- 4 Medication
- 5 Physical Health
- 6 Education and Training
- 7 Transport

Responses were initially grouped into common categories; and then more broadly into the common themes occurring across all areas.

Evaluation of the day was positive in that participants felt they were able to influence change through their contribution of experiences and ideas, and that the format and delivery of the session facilitated this process.

Outcomes and Opportunities

1. Inpatient Services and Community Interface	
<i>Consumers and carers were asked to identify issues they had experienced when accessing acute mental health inpatient facilities.</i>	
<p>It stands to reason that mental health consumers are at an extremely vulnerable point in their journey when accessing acute services. Participants described the experience at times to be very challenging, and particularly distressing during and post the discharge process. Research has shown that the first fourteen days post discharge are extremely important in ensuring that consumers stay well and avoid re-admission and in preventing suicide. One of the key issues reported by participants was stigma. The Report of the National Review of Mental Health Programmes and Services (National Mental Health Commission, Nov 2014) confirms the view held here that stigma persists in the mental health system and that people's needs are not prioritised.</p>	
Key Issues	Solutions and Opportunities
Stigma , including not being heard or believed and being actively discriminated against	Organisational commitment to end to stigma and discrimination in inpatient units involving clear leadership and policies and effective training which includes consumer input
Inadequate discharge planning with little or no consultation with consumers and carers resulting in high stress levels for consumers on discharge	<p>Active encouragement and training in best use of eHealth records with mental health consumers and GPs</p> <p>Implementation of a 'recovery oriented discharge process' which looks at all life issues and which is planned with consumers</p> <p>Consumer led teams to undertake discharge follow up peer support in first fourteen days as a minimum eg check-in phone calls, peer support; minor problem solving;</p>
Lack of advocacy channels to access including difficulty making complaints and getting feedback	<p>More direct peer support/consumer advocacy workers in mental health facilities who would be able to provide:</p> <ul style="list-style-type: none"> • Support and advocacy to help consumers understand choices and navigate the system • Support with discharge planning from admission through to getting home including re-connecting with families, transport, safe accommodation etc.
Low levels of mental health consumer literacy around systems processes eg information overload; lack of understanding around inpatient system processes including discharge	

	User friendly, transparent and effective complaints process where consumers are informed of the outcome in a timely manner.
Inconsistent communication and referral processes between a range of services, eg. housing and accommodation, transport, timely community follow up	Improved communications and follow up processes between inpatient services and the community

2. Emergency Departments <i>Consumers and carers were asked to identify issues they had experienced when accessing Emergency Departments (EDs).</i>	
Key Issues	Solutions and Opportunities
The triage system did not meet the needs of mental health consumers due being assessed as low priority and experiencing long waiting times	A Headspace type environment for mental health emergencies or separate mental health assessment service attached to a mental health unit
The ED physical environment presented additional challenges to already distressed consumers particularly in relation to lack of privacy and noise. Consumers used words like “horrifying”, “stressful” and “intimidating”	Private/quiet area for people to wait/be seen that is staffed by peer workers
Lack of range of appropriate information, support and advocacy channels to access, including ED system processes, and difficulty making complaints and getting feedback	More direct peer support/consumer advocacy workers in mental health facilities who would be able to provide: <ul style="list-style-type: none"> • Support and advocacy to help consumers understand choices and navigate the system • Support with discharge planning from admission through to getting home including re-connecting with families, transport, safe accommodation etc. User friendly, transparent and effective complaints process where consumers are informed of the outcome in a timely manner.
Overwhelmingly consumers reported experiencing high levels of stigma and discrimination from staff including intimidation, lack of respect, physical health symptoms ignored and poor levels of understanding about mental ill health and trauma	Organisational commitment to end to stigma and discrimination in inpatient units involving clear leadership and policies and effective training which includes consumer input Mental health trained staff/specialists available at all times Recovery oriented training for all staff

Discharged without adequate transport or follow up	ED discharge and follow-up policies for mental health consumers in place
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3. Medication

Consumers and carers were asked to identify medication issues they have experienced.

It is understood that whilst some people who experience mental illness are able to live well without the use of prescription medicines at all, for others, medication is often necessary to keep people well even though it brings with it unwanted and sometimes very unpleasant side effects. It is also recognised that due to the lack of alternatives to certain drugs on the market, on some occasions prescribing doctors have limited prescription options.

Key Issues	Solutions and Opportunities
Consumers and carers experience difficulty when having conversations about side effects, trying different medications and other therapeutic alternatives	<p>More time taken by GPs in appointments with mental health consumers</p> <p>Provide straightforward, accessible, 'lay person' information about medication and side effects – improved health literacy</p> <p>Regular discussion about potential alternative medication or additional therapies to support/reduce medication side effects</p>
Lack of clear information about medication side effects and alternatives	<p>Training for GPs in mental illness medication and recovery oriented practice</p> <p>Offer family consultation about medication and side effects (with consumer consent) - improved health literacy</p>
Lack of understanding of the impact of physical distress caused to consumers by medication side effect	Medication information day for GPs and consumers together
Cost of medication, additional costs of Webster packs – leads to financial stress sometimes resulting in consumers making impossible choices: going hungry or not taking meds	Lower costs associated with necessary medication
Reports of physical health misdiagnosis due to it being seen as part of the mental illness	Support provided to improve uptake of Personally Controlled EHealth Records
Range of levels of understanding amongst GPs about mental illness and appropriate prescribing	Closer working relationships between GPs and psychiatrists

4. Physical Health

Consumers and carers were asked to identify physical health issues they had experienced.

Consumers understand how important it is to maintain good physical health, but reported experiencing a high level of physical health problems associated with their mental ill health and particularly as a direct result of the unwanted side effects of medication. There is a substantial amount of research that confirms that physical health and mental health are critically linked (NSW Health Mental Health Drug and Alcohol). Poor mental health is a risk factor for chronic physical conditions and people with serious mental health conditions are at a high risk of experiencing chronic physical conditions (Canadian Mental Health Association).

Key Issues	Solutions and Opportunities
Physical health problems which develop as a direct result of unwanted side effects of medication are often disregarded by clinicians as unavoidable and low priority	More in depth and broader assessment and diagnosis - ruling out or taking account of any physical causes for mental illness or disorder first More careful consideration about how any treatment the consumer receives for their mental illness will affect their physical health and vice versa
Physical health issues which arise separately from mental health problems can be ignored as 'imagined' or linked to mental illness	More physical health screening eg. metabolic testing
Social isolation and costs of accessing physical activity are contributing barriers to improving physical health	Mental health plans that are recovery focused and address physical health issues are developed alongside the consumer
Services that focus on one or two core issues as opposed to taking a holistic	Holistic approach to service provision where support mechanisms are built in for consumers to improve their physical health More opportunities for consumers to improve physical health and attend activities Improved health literacy ie. promote improved understanding of relationship between positive mental health and physical health through accessible consumer friendly information sources

5. Understanding Recovery

Consumers and carers were asked to discuss their experiences of recovery oriented practice

The principles of recovery oriented mental health practice are relevant to all of the 10 National Standards and apply to the whole mental health service system, including the non-government community mental health service sector.

Key Issues	Solutions and Opportunities
Stigma still persists across all areas of the mental health system as well as in the community.	<p>Organisational commitment to end stigma and discrimination in inpatient units involving clear leadership and policies, and effective training which includes consumer input</p> <p>Targeted campaign at organisations and employers to demonstrate that people with mental illness can hold productive jobs and the positive impact this has on their recovery</p> <p>Encouragement for mental health consumers to let go of own stigmatising attitudes – “the diagnosis does not define you – you are a person first”</p>
Reluctance amongst some professionals and services to embrace the notion of recovery and let go of the traditional ‘medical’ model of care – resulting in clinicians and services continuing to provide inappropriate care and support	<p>Recovery focused mental health plans</p> <p>Recovery focused clinicians to actively co-champion recovery oriented practice alongside consumers and non-clinical recovery workers</p> <p>Consumer advocates with appropriate levels of autonomy embedded in all services</p> <p>Independent advocacy support services for consumers</p>
Ignorance across all sectors of the community about mental illness and recovery	<p>Funding to train and support consumer educators to carryout/deliver training</p> <p>Mental health awareness and recovery to be included in school curriculum – improved health literacy</p>
Lack of understanding that recovery is consumer centred and ‘not a model’ which is ‘done by’ services	<p>Increased consumer participation and representation within organisations</p> <p>Mandatory recovery training involving consumer educators, for all clinical and non-clinical staff and services including public and private</p> <p>Education for carers and families about recovery</p>

6. Training and Education

Consumers and carers were asked to identify issues they had experienced when accessing training and education.

Mental illness can impact negatively on education and training, due to the effects of medication or an episode causing a loss of attendance or inability to complete coursework (Mental Health Council of Australia. Let's get to work: A National Mental Health Employment Strategy for Australia, 2007).

Some people with a psychiatric disorder are unable to commence or complete studies or training courses due to the compounding issues their condition brings. For sufferers of a mental illness the extra stress placed on them having to cope with study can have negative consequences (Home Truths: Mental Health, Housing and Homelessness in Australia; Mental Health Council of Australia, 2009).

Key Issues	Solutions and Opportunities
Costs of retraining/accessing education opportunities prohibitive for consumers due to low income and/or due to holding previous qualifications at a higher level, therefore not eligible for concessions/loans	Education advocacy services which are recurrently funded Ability to pre plan for times of unwellness
Few support and advocacy services for consumers re-entering education or undertaking training	Proactivity by staff in support of learning and wellness plans in the workplace as well as in educational establishments to prevent crisis
Few alternatives to help with transition to learning eg. bridging courses	Mental health literacy (impact of mental ill health on education and learning) training for lecturers
Effect of medication on ability to keep pace with learning	"Reasonable adjustment" tailored solutions from education providers eg. later start times, and more time for exercises and assessments for all subjects without having to negotiate this individually with each trainer
Difficulty accessing training in rural areas or issues with transport and lack of public transport at night	Access to affordable training for people with higher qualifications

7. Transport

Consumers and carers were asked to discuss their experiences of accessing transport.

It is commonly accepted that people living with mental illness often face significant challenges travelling to and from health services due to either individual experience of mental illness or the side effects of medication. This is particularly problematic in remote and rural areas where transport is costly due to high fuel costs, and public transport is limited or unavailable. This affects access, not just to capital cities, but also to local towns and the larger rural centres. Research demonstrates that rural isolation increases the levels of inequity of access to appropriate health care.

Key Issues	Solutions and Opportunities
Transport from hospital identified as a key issue – always support to get to hospital but	Flexible transport solutions from services to get to and from appointments/ED/acute units eg. taxi vouchers; service vehicles; timely discharge etc.

left with responsibility to get home with no assistance on discharge	
Transport in rural and remote areas tends to be costly due to higher fuel prices and longer distances leading to increased social isolation for those living out of the main towns	Subsidised public transport and vouchers for private transport (where there are no public transport options)
Accessibility issues (to and from appointments and services) arise due to lack of transport options and lack of coordination between transport services	Networking and coordination of transport services
Transport often falls to family or carers necessitating additional time off work either with no pay, or using up valuable holiday/respice time	More funding and support for community transport services Support for carers/families when providing transport
Lack of services within reasonable distance	Outreach services to the home

Recommendations

This report highlights a number of opportunities for reform that will address the objectives of Partners in Recovery to improve the system response to, and outcomes for, people with severe and persistent mental illness. It is the view of participants that any reforms should be consumer led and that commitment and leadership is required at an organisation level. Addressing stigma in the community and service system, particularly mental health services, is also key to the success of the reforms identified in this report.

Since the Forum was held Hume Partners in Recovery released its Systems Change Framework which has informed over ten local projects addressing the objectives of PIR. The Framework ensures the involvement of consumers and carers in all projects funded by PIR. (The progress of these projects can be followed through our monthly newsletter the PIR Connection).

More recently a review of data collected by PIR, from a range of sources including the Consumer and Carer Forum, resulted in the identification of two key areas of concern for the Consortium – they are stigma and the interface between clinical services and community. Hume PIR in partnership with Loddon Mallee Murray PIR have developed a Stigma Action Plan which will utilise a range of strategies to address stigma at a local level. Currently reforms addressing the interface of between clinical services and the community are being identified.

The Consumer and Carer Engagement Working Group has identified building the capacity for consumer driven system reform and contributing to reforms concerning peer support in hospital settings as priorities for their activities in the period leading up to June 30th 2016.

This report will be distributed to existing system reform working groups funded by PIR to inform their planning and contribute to a consumer and carer driven approach. Other potential uses of the report will be identified by the Consortium.

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