Family and carer participation and involvement in Victorian public mental health services.

Progress report against *Caring together: An action plan for involvement in Victorian public mental health and carer participation in mental health services implementation framework.*
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Progress report against Caring together: An action plan for involvement in Victorian public mental health and carer participation in mental health services implementation framework.
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Part 1: Introduction

Purpose of the report

The Victorian Government released *Caring together: an action plan for carer involvement in Victorian public mental health services* to strengthen the role of carers and the support provided to assist them in their caring relationships across the domains of individual treatment and care, planning, the development and evaluation of mental health services and broad systemic or whole-of-system policy development. The action plan was developed in consultation with mental health stakeholders, carer support organisations and carers of people with mental illness.

Shortly after the release of the action plan, the Victorian Government funded each Victorian public mental health service to develop and implement a service-specific carer participation plan. Services were to use the three-year participation plan to inform their service planning and delivery to strengthen mechanisms for the participation and involvement of carers of people with mental illness. The aims set within the plan support carer participation as an ongoing component of the quality improvement cycle.

The purpose of this paper is to provide a progress report on *Caring together* and the implementation of mental health service carer participation plans.

Between March and October 2011, carer consultants, participation coordinators, quality managers and general managers in Victorian public mental health services completed an online survey developed by the Victorian Government. The purpose of the report is to provide an overview of progress made by public mental health services to increase the participation of carers in service delivery and identify opportunities to strengthen carers’ involvement and act on their recommendations.

The findings will inform future directions for carer participation programs and carer involvement strategies within Victorian Government policy and sector practice. The report also informs the evaluation and monitoring responsibilities of the Victorian Department of Health. The report provides an opportunity for services to identify continuous quality-improvement activities at individual, service and system levels that relate to *Caring together*.

Mental Health Drugs and Regions Division, Victorian Department of Health

The Mental Health and Drugs Regions Division (the division) encompasses public sector policy, program, service and workforce development for mental health services and alcohol and other drug treatment teams and related services.

The division has consistently reinforced the importance of carer participation within mental health services since 1996, with the introduction of guidelines and funding for carer consultant positions. The division has a critical role in continuing to articulate government and departmental policy and practice expectations for carer participation.

Public mental health services

Public mental health services in Victoria service those people severely affected by mental illness. Each service is area-based to service a geographically defined population. There are separate services for adults, aged persons, and children and young people. Each area mental health service provides a range of community-based mental health services and inpatient facilities.

Public mental health services are responsible for delivering services in accordance with relevant government policy and legislation and for meeting reporting and accountability requirements. Since
deinstitutionalisation, government policy has strongly emphasised and strengthened concepts such as consumer-centred care, partnerships with families and carers, linkages with other services and community organisations, and more recently an orientation towards recovery from mental illness.
Part 2: Carer participation

Caring relationships

Family members and friends are widely acknowledged as having a legitimate and critical role in supporting a person with mental illness during setbacks and towards recovery. Governments and many services use the term ‘carer’ to identify the family members and friends of someone with a mental illness whose lives are also affected by the mental illness.

Many carers never think of themselves as a ‘carer’. They may be a parent of someone with mental illness or an adult caring for a partner, parent or friend. A child who contributes to caregiving for family members can also be a carer. The role of carers often changes over time in response to changing needs and circumstances. Many people take on the role of carer as they see it as a natural extension of their responsibilities within the relationship they have with the person who is ill, although the care provided often exceeds the usual expectations of a close family or personal relationship. The element of ‘carer choice’ in undertaking the role can also vary, with some carers actively choosing the role, while others feel compelled to be a carer due to specific circumstances. The psychological impacts of stigma, guilt and isolation sometimes associated with mental illness, as well as intermittent nature of illness due to fluctuating or episodic symptoms, influence the caring role.

Carers of children have a legal responsibility to provide care and are required to be active decision makers in all aspects of the child’s life. Carers of older people may also have involvement in decision making. Depending on the legal guardianship status of the person with a mental illness, their capacity to make decisions and the nature of consent provided, the carer will have varying degrees of involvement in that person’s treatment and support.

Carers may be involved in monitoring symptoms, ensuring medication compliance, obtaining or coordinating services, and requesting professional intervention for the person with mental illness. Caring for someone who experiences mental illness will vary according to the individuals and their relationship. It may include ‘hands-on’ personal care and household assistance, offering moral support, motivation, supervision and encouragement, or dealing with behavioural changes, providing companionship, and supporting participation in the community. This informal care can enable people with mental illness to function more independently in the longer term and manage their own illness more effectively than may otherwise be possible.

Caring involves many demands and challenges, including balancing the caring role with the carer’s other family and work responsibilities and the carer’s own needs. The caring role also changes across the life span, depending on the age of the carer and the person with mental illness. Caring for someone with mental illness is a complex experience that requires significant commitment and understanding. The impact on carers varies according to the severity, course and outcomes of the illness as well as the circumstances of individuals and their families and friends.

Carer perspective in systemic participation

Carer participation refers to either voluntary or position-based remunerated involvement across a broad range of program and service development and delivery including policy, service delivery, staff training and support to carers. Encouraging and supporting carer participation offers formal and informal opportunities to consider processes that affect the lives of consumers and carers through sharing of information, opinions and decision-making power.

There are four proposed levels of participation to define how carers can be involved to participate. Mental health services are encouraged to aim towards participation level four to fully draw on the knowledge and expertise of carers and carer consultants to ensure genuine carer participation. The four carer participation levels are described in Figure 1.
Carer perspective in individual participation

Carer-inclusive practice is defined as providing opportunities for individual carers to be involved and engaged in individual care planning, treatment and decision making in aspects of treatment and care provided to the person with mental illness with whom they have a caring relationship. It also includes supporting carers' needs to assist them in their caring role.
Part 3: Policy context

Fourth National Mental Health Plan

In 2009, the Australian Government released the *Fourth national mental health plan: an agenda for collaborative government action in mental health 2009–2014*. It sets an agenda for collaborative government action in mental health for five years from 2009. It offers a framework to develop a system of care that is able to intervene early and provide integrated services across health and social domains, and provides guidance to governments in considering future funding priorities for mental health.

National Standards for Mental Health Services

In 2010, the Australian Government released the National Standards for Mental Health Services. These standards outline a revised set of mental health service standards that can be applied to all mental health services, including government, non-government and private sectors across Australia. Standard 3 sets out criteria for consumer and carer participation: ‘Consumers and carers are actively involved in the development, planning, delivery and evaluation of services’. The revised standards also contain Standard 7, a new carer standard to recognise the significance of the role carers contribute to support individual recovery: ‘The MHS recognises, respects, values and supports the importance of carers to the wellbeing, treatment, and recovery of people with a mental illness’.

Mental Health Council of Australia – National Mental Health Consumer and Carer Forum

Through its membership, the National Mental Health Consumer and Carer Forum gives mental health consumers and carers the opportunity to meet, form partnerships and be involved in the development and implementation of mental health reform.

Victorian Carers Recognition Act 2012

The Carers Recognition Act recognises people in care relationships, and supports the role of carers in the community. The *Victorian charter supporting people in care relationships* supports the Act and states that carers can expect to:

- be recognised and respected as an individual, including their cultural identity
- be recognised and respected as part of the care relationship
- have a say in decisions about care planning and care
- have their needs understood and met
- receive support now and as their needs change
- be able to use what the Act and charter say to support their relationship and use of services.

The principles outline the following obligations of care organisations and agencies which must:

- be staffed by people who understand and comply with the legislation
- inform those in care relationships about their rights
- treat those in care relationships respectfully
- reflect the Act’s principles in their planning and how they support people
- report publicly about how they are meeting their obligations.
Supporting consumer participation

The Victorian Government is focused on involving people in decision making about the treatment and care that they receive from Victorian healthcare services. This includes a collection of participation standards and indicators that apply across the entire Victorian public health service system.

Participation is valued because it is:

- an aid to improve health outcomes and the quality of healthcare
- an important democratic right
- a mechanism to ensure accountability.

Framework for recovery-oriented practice

In 2010, the Victorian Government released the *Framework for recovery-oriented practice*, which acknowledges the importance of consumer participation in improving individual outcomes and strengthening recovery pathways. As part of recovery-oriented practice, the framework requires mental health professionals to know about relevant legislation and policies on consumer rights and consumer and carer participation across a range of processes.

Review of the Victorian Mental Health Act 1986

New mental health legislation is a central element in the Victorian Government’s agenda for mental health reform.

The government has undertaken extensive public consultations to understand the strengths and weaknesses of the *Mental Health Act 1986* and to find out the things that people with a mental illness, families, carers, clinicians and service providers expect of mental health legislation in Victoria. These consultations were extremely useful, with the community and government working in partnership to shape what a new Mental Health Act in Victoria could look like.

The Minister for Mental Health, the Hon. Mary Wooldridge MP, released the document *A new Mental Health Act for Victoria: summary of proposed reforms* on 8 October 2012, which outlines the government’s key reform objectives and policy intentions.

The legislative reforms will promote recovery-oriented practice, minimise the duration of compulsory treatment, safeguard the rights and dignity of people with mental illness and enhance oversight while encouraging innovation and service improvement. These reforms will result in significant improvements to Victoria’s mental health system.

The new legislation will embed supported decision making by facilitating strong partnerships between patients, carers and practitioners. At the same time there will be greater focus on supporting public-sector clinicians and public mental health service providers to deliver high-quality mental healthcare.

Caring together action plan

The Victorian Government developed *Caring together* (2006) and the Carer Participation in Mental Health Services Implementation Project 2007–2010 to delineate the carer role and needs of carers involved with mental health services. The action plan drew on the experiences of the previous decade in terms of achievements and areas for improvement, and provided strategies for implementation over the following five years. The objectives formed the structure for the implementation plan project. Both the action plan and implementation plan identified key priorities to improve the involvement of carers of people with a mental illness in individual care as well as the planning, development, implementation, delivery and evaluation of mental health services in Victoria, including clinical mental health services and the psychiatric disability rehabilitation and support services (PDRSS) sector.
The following key directions identified in *Caring together* aimed to increase participation and achieve improved support for families and carers at the individual, local service and systemic levels:

- **individual level**
  - enhanced involvement of carers in the treatment of a person with a mental illness, including assessment, service delivery, discharge planning and monitoring
  - improved information about mental illness
  - improved access to carer support services and education programs

- **local service level**
  - enhanced involvement of carers in local service planning delivery and evaluation
  - improved information about mental health services
  - enhanced access to carer peer support services and education

- **systemic level**
  - enhanced involvement of carers in systemic service planning, delivery and evaluation
  - improved statewide information about mental health services.

**Carer Participation in Mental Health Services Implementation Project 2007–2010**

All Victorian public mental health services have developed local three-year (2008–10) strategic carer participation plans for their specific age-range programs: child and adolescent, adult, and aged persons mental health.

The key objectives and priorities outlined in *Caring together* are the basis of participation plans. The aim of the Carer Participation in Mental Health Services Implementation Project 2007–10 was to ensure that the integrity and practice of carer participation was maintained and where possible extended beyond the established commitment.

The plans developed by each public mental health service provide a framework for participation at the service level. The survey aimed to measure progress against the key strategies and objectives of the participation plans.

Mental health services were to use the participation plans to:

- assist with strengthening their framework for carer participation and carer-inclusive practice
- enhance the link between organisational governance, participation and involvement at all levels of the service
- serve as a valuable tool for demonstrating evidence of compliance with the National Standards for Mental Health Services
- facilitate discussion with the Department of Health about the integration of future carer initiatives.

Key strategies to achieve these objectives included:

- reviewing and improving structures and mechanisms for ensuring consumer, family and carer participation across all levels of the service
- improving consumer, family and carer participation in individual care and recovery plans
- identifying locally improved service quality and consumer outcomes to be achieved by consumer, family and carer participation at all levels
- reviewing and improving current structures for ensuring meaningful consumer, family and carer participation in policy and service planning, development and evaluation, including participation of consumer and carer consultants
- ensuring governance structures support consumer and carer participation in mental health services.
Part 4: The carer workforce

Carer consultants

Carer consultant positions emerged through advocacy in recognition of the need for greater responsiveness to families within area mental health services. Carer consultants bring a lived experience of mental health services through the carer’s lens. They provide support, information and referral for families/carers, and work collaboratively with area mental health services to develop service responsiveness to the needs of families and carers. The development of carer consultant positions has further strengthened the range of support available to carers through Victoria’s public mental health service system. Being within mental health services, these roles add value to the service development and direct support available to carers across the public mental health system. Their development further complements the pre-existing carer support and resource workers located within generalist carer services.

The Victorian Government has funded the employment of carer consultants in clinical mental health services. Initially a capped sum of existing carer brokerage funds, provided as part of the Carer Support Program, could be used to employ a part-time carer consultant. The Carer support program review report 2008 identified 24 carer consultants employed in predominantly adult public mental health services. Informed by the review findings, the Victorian Government provided 21.2 EFT of recurrent dedicated Carer Support Program funding to employ carer consultants. The funding enabled public mental health services to uniformly employ part-time carer consultants across all child and adolescent, adult and aged mental health programs.

Carer peer support workers

Carer peer support workers use ‘carers lived experience’ to empathise with and normalise the impacts of mental illness on those in caring relationships. Peer work often sits alongside clinical treatment and care provided by mental health services by offering a supportive, holistic and non-clinical focus. Peer workers are an emerging workforce across various health domains and a growing evidence base suggests they can provide cost-effective benefits to complement clinical work and lead to improved outcomes for individuals.

Carer Advisory Groups

Carer Advisory Groups (CAGs) provide a forum for carers linked to a particular mental health service, through the person they care for, to work in partnership with mental health service providers to plan, develop, implement, educate and evaluate services.
Part 5: Measuring carer participation in Victorian mental health services

Overview
The Victorian Government has developed a mixed-method online survey tool based on the individual and local service priorities and objectives outlined in Caring together. The survey was developed in consultation with the peak body for carers (the Victorian Mental Health Carers Network), and the professional carer workforce body (the Carer Consultant Network of Victoria). The survey sought to ascertain the progress towards service-level implementation of carer participation policy and practice.

Survey tool
The survey consisted of 28 multiple choice items and 23 open-ended response items. It provided quantitative and qualitative data to report how mental health services used their carer participation plan to consider new and enhance existing carer participation and carer-inclusive initiatives in mental health services.

The survey questions reflect the general objectives for the policy and implementation project, but there are notable limitations. The survey was developed in conjunction with a corresponding consumer participation survey. The two surveys cover commonalities across consumer and carer action plans. Notably, Caring together does not include specific performance indicators, whereas the equivalent plan for consumers, Strengthening consumer participation in Victoria’s public mental health services, does. A limitation of the carer survey is that not all quantitative items directly measure the existing objectives. In these instances the results reflect the qualitative data.

The results are organised to reflect the objectives stated in Caring together.

Conducting the survey
In March 2011, the Department of Health invited all Victorian public mental health services to complete the survey online. Each child, youth and adolescent, adult, and aged mental health program was required to complete a separate survey. The carer consultant, quality manager and general manager of mental health or equivalent staff were asked to complete the survey as a group task.

Survey respondents
Survey respondents included:

- nine of the 13 public child, youth and adolescent mental health services in Victoria
- seventeen of the 21 public adult mental health services in Victoria
- six of the 17 public aged mental health services in Victoria.

A total of 32 online surveys were completed. The 32 surveys involved 91 mental health service employees to represent the perspectives of their service. This consisted of 28 carer consultants (also called family consultants, family advocates or peer workers), 12 quality managers and 51 service or carer portfolio managers. The results are based on the total combined sample comprising all three age ranges.

Although the respondents included a cross-sample of mental health services and staff, it is worth noting the majority of respondents represent adult services. This may be attributable to the differences in duration of
carer participation in each age range. While adult programs have recognised the role of carer consultants for a number of years, both child, youth and adolescent and aged mental health services commenced dedicated funding in July 2009. Reportedly, some of those services were still in the establishment phase of introducing carer participation or yet to recruit to carer consultant positions.
Part 6: Survey findings – carer participation at the local mental health service level

The first section of the survey reviewed how mental health services are supporting carer participation at a system level, for example policy development. Carer participation is defined as: opportunities for carers to use their lived experience to inform policy and practice.

Carer participants may volunteer or be employed to have input into systemic organisational program and policy development and/or delivery. There are numerous ways carer participation may be sought including: committee membership, strategic planning, or delivering professional development and/or training to staff.

The survey results are organised to reflect the objectives stated in *Caring together*.

**Enhanced involvement of carers in local service planning, delivery and evaluation**

**Develop and implement a formal carer participation policy**

A formal carer participation policy exists in 81 per cent of responding mental health services. Some services have adopted broader health service participation policy whereas others have developed their policy in consultation with local carers as part of a CAG committee function to address specific issues identified by carers at the local level.

The majority of responding mental health services (88 per cent) reported having a current strategic plan for carer participation, and those without one were in the process of reviewing and updating their previous plans that expired in 2010. Governance for carer participation policy is an important component to support implementing the policy. Results indicate regular monitoring and reporting of participation initiatives occur through a range of structures including: carer working groups, CAG committees, team management meetings, and executive function or quality committees.

‘Our carers were involved in the development of the carer policies. More specifically we have developed guidelines for the family support role.’ Survey respondent

**Attend family-sensitive training**

Originally The Bouverie Centre provided statewide family-sensitive training to mental health services. Feedback indicates it is common for services to use a range of awareness raising strategies to strengthen family and carer sensitive approaches to mental health service delivery. There is an emphasis on training new and graduate staff with a carer-focused component of orientation training. In some instances carer perspective modules are integrated into staff refresher training at some services or as part of the funded statewide cluster training program.

**Develop and operate formal internal complaints mechanisms**

Formal internal complaints mechanisms exist across 91 per cent of responding mental health services. Of these, feedback shows approximately two-thirds of services have a committee including carer representation to review complaints. Some services reported that they use a whole-of-health service approach to manage complaints. In other instances, complaints officers liaise with carer consultants to address concerns initiated by carers.

‘We have the Speakout system which the family peer-support workers will encourage carers to use. A specific family-oriented flyer has been developed.’ Survey respondent

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1 Only qualitative data was collected to address this strategy focus area.
Ensure carer input into staff in-service training from planning, delivery through to evaluation

It is important to include carer perspectives and lived expertise in training by involving carers in delivering training. At this stage, results show there is a lack of uniformity in the nature of carer-delivered staff training. However, a range of initiatives demonstrate carer input in the development and delivery of staff in-service training across various mental health services. Examples include training to support service redesign, the introduction of recovery-oriented practice, working on inpatient wards, medical student placement, psychiatric registrar placement, and staff orientation. In some instances carer consultants or carer representatives are involved in evaluating the effectiveness of staff training on working groups or training committees. The type of carer input is summarised in Table 1.

‘Carer perspective is part of monthly education sessions for unit and allied health staff, orientation program for medical staff, individual requests from case managers, external education sessions and conference deliveries.’ Survey respondent

Table 1: Type of carer input into staff training

<table>
<thead>
<tr>
<th>Carer Consultants</th>
<th>Carer Representatives from CAG</th>
<th>Carer Peer Workers</th>
<th>Participation Coordinator</th>
</tr>
</thead>
<tbody>
<tr>
<td>Response options</td>
<td>All the time</td>
<td>Most of the time</td>
<td>Sometimes</td>
</tr>
<tr>
<td>Percentage of Training Participation</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Appoint carer representatives to relevant committees, such as quality committees

The prevalence of carer representation on committees varies across mental health services. According to results, mental health quality committees have the highest rate of carer representation, followed by management committees. Approximately half of services include carer representation in their mental health service alliance networks or health service advisory councils.

Carer representation on governance committees provides opportunities for meaningful carer participation to inform and influence program development, service delivery and quality improvements.

Almost 90 per cent of carer consultants from responding services are members of the Victorian Carer Consultant Network of Victoria, a professional network that meet every two months to provide professional development, networking, strategic planning and peer-support opportunities specifically targeting the professional demands of this specialist workforce. About 70 per cent of those carer consultants are also members of the Victorian Mental Health Carers Network, the peak body for carers of people with mental illness. Feedback indicated membership with the peak body provides an opportunity to influence statewide advocacy to enhance mental health services and other organisations that support carers. Rates of membership are summarised in Table 2.
Table 2: Rates of carer representation on committees

<table>
<thead>
<tr>
<th>Committee</th>
<th>Percentage of Services with Carer Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quality Improvement</td>
<td>80.0%</td>
</tr>
<tr>
<td>Management</td>
<td>60.0%</td>
</tr>
<tr>
<td>Alliance Network</td>
<td>40.0%</td>
</tr>
<tr>
<td>Health Service Advisory Council</td>
<td>20.0%</td>
</tr>
<tr>
<td>Carer Consultant Network of Victoria</td>
<td>0.0%</td>
</tr>
<tr>
<td>Victorian Mental Health Carers Network</td>
<td>100.0%</td>
</tr>
</tbody>
</table>

Conduct regular discussion groups to seek the views of carers

In approximately 75 per cent of responding mental health services, CAG committees bring carers together on a regular basis to seek their views to inform the quality of program and service delivery. Committees comprise between three and 30 carer representatives. Results suggest a number of mental health services seek additional carer perspectives to complement the carer consultant role via CAGs to further inform their systemic work. Carer consultants generally oversee CAG management and then convey the issues raised on behalf of the members to the appropriate governance committee.

According to feedback, in many services, members of the CAG reportedly propose or initiate service enhancement or redesign innovations based on their lived experiences to better respond to the needs of those accessing the mental health service. Services have demonstrated CAG participation across a range of service improvement initiatives including the Mental Health Experience Based Co-Design (MH ECO), the use of carer satisfaction surveys, the Productive Ward Project, the Complaints Project, Creating Safety Project, Carer Peer Support Projects, and improving the use of outcome measurements.

Improved information about mental health services

Develop, implement and update a carer information kit

Carer information kits are available at 97 per cent of responding mental health services. Of these, 85 per cent have information for carers in a range of community languages. Some services provide a standard carer information pack when a consumer is admitted, while others promote awareness with notice boards or posters and provide brochures, booklets and factsheets in waiting or reception areas. Information provision includes rights and responsibilities, compliments and complaints processes, mental health service structures, local carer support organisations, financial assistance, counselling, respite and leisure activities. Feedback indicates that regular consumer and carer newsletters are produced and mailed out by some services to promote service developments, support, leisure and education opportunities.

Develop and deliver carer information sessions that are accessible to carers in the local area

Carer information sessions on mental illness and the impact on the consumer, families and friends are available through 97 per cent of responding mental health services. Some services reportedly deliver in-house sessions while others collaborate with local carer support organisations to facilitate carer information.
and education workshops and seminars. Generally mental health services appear to use carer consultants and carer peer-support workers to deliver the carer information sessions, or incorporate education into ongoing support group schedules. Because the range of local carer support organisations varies across the state, the nature of information and support opportunities differs from one service to the next.

**Make referrals to local and statewide organisations that provide relevant mental health and carer information**

Approximately 50 per cent of mental health services report informing carers of external organisations for information, support and assistance, at least most of the time. However results suggest 22 per cent of services do not routinely refer carers directly, nor record rates of uptake of local or statewide carer support organisations. This suggests some carers are missing out on opportunities to link to carer support services. Feedback suggests services are making referrals to Mental Illness Fellowship Wellways psycho-education courses, Carers Victoria or ARAFEMI support and information, Victorian Government Homewise or Utility Relief grants, the Commonwealth Carer Respite Program or Centrelink Carer Payment or Allowance. Often services provide carers with information to self-refer to their preferred choice of carer support or information.

**Enhanced access to carer support services and education programs**

**Employ and work with a carer consultant**

All but one responding mental health service have a position description for the employment of a carer consultant. At the time of the survey, carer consultants were employed in 11 child/youth, 18 adult, and seven aged of the responding mental health services. Also noteworthy is the presence of ‘participation coordinator’ roles at three mental health services, although it is unclear whether lived experience is a requirement of such roles. Services that have not recruited a carer consultant indicate a lack of clarity around funding, resources, suitable candidates or the part-time aspect of the role, have been barriers to successful recruitment to all positions.

Where services have employed a carer consultant, results indicate the proportion of individual and systemic workload varies. While some carer consultants are predominantly responsible for individual advocacy or peer support, others are involved in systemic policy or service improvement activities. For the most part, the carer consultant’s workload is distributed across a range of both individual and systemic activities.

‘The carer consultant role is embedded into quality-improvement systems. At the same time the carer consultant has been available for peer support and community linkages. This has resulted in the role being able to advocate and support carers individually and systemically. Moreover, the carer consultant has been involved in staff education and engaging volunteer carers from the region to inform and deliver training and education to staff.’ Survey respondent
Table 3: Individual and systemic work undertaken by carer consultants

<table>
<thead>
<tr>
<th>Individual Involvement</th>
<th>Percentage of staff undertaking each task</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual peer support</td>
<td>80.0%</td>
</tr>
<tr>
<td>Individual advocacy</td>
<td>80.0%</td>
</tr>
<tr>
<td>Handle complaints</td>
<td>80.0%</td>
</tr>
<tr>
<td>Group peer support</td>
<td>60.0%</td>
</tr>
<tr>
<td>Carer Support Fund applications</td>
<td>80.0%</td>
</tr>
<tr>
<td>Carer service referrals</td>
<td>80.0%</td>
</tr>
<tr>
<td>Carer respite activities</td>
<td>60.0%</td>
</tr>
<tr>
<td>Undertake research</td>
<td>40.0%</td>
</tr>
<tr>
<td>Systemic advocacy</td>
<td>80.0%</td>
</tr>
<tr>
<td>Strategic planning</td>
<td>60.0%</td>
</tr>
<tr>
<td>Staff development / training</td>
<td>80.0%</td>
</tr>
<tr>
<td>Service improvement</td>
<td>80.0%</td>
</tr>
<tr>
<td>Program development</td>
<td>70.0%</td>
</tr>
<tr>
<td>Policy development / review</td>
<td>80.0%</td>
</tr>
<tr>
<td>Facilitate carer education</td>
<td>80.0%</td>
</tr>
<tr>
<td>Conference presentation</td>
<td>80.0%</td>
</tr>
</tbody>
</table>

Provide peer-support contact information

Information about and access to peer support is generally available in 84 per cent of responding services through the carer consultant. Respondents indicated that in addition to carer consultants providing peer support, some mental health services have also initiated to working in partnership with carer support or community health organisations to provide co-located or integrated carer peer support workers. These workers consult with carers to provide peer support, offer assistance and access to additional carer support opportunities. The addition of carer peer-support workers has offered those services increased capacity to provide more extensive carer peer-support to a greater number of carers not otherwise possible within the part-time resourcing of carer consultants.

Coordinate carer input into the operation of the Carer Support Program Brokerage

The Carer Support Fund Brokerage is a government financial assistance fund available to all carers of consumers registered with Victorian public mental health services to assist carers in their caring role. Since centralising the administration of the Carer Support Fund Brokerage with the Victorian Mental Health Carers

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2 Only qualitative data was collected to address this strategy focus area.
Network in July 2009 there has been greater variation in the role of carer consultants relating to the fund operation.

Three carer consultants are members of the statewide Carer Support Fund Advisory Group and provide input into the statewide guidelines and administration of the fund. In many services carer consultants are responsible for lodging individual applications for assistance on behalf of carers. Feedback indicates some mental health services have retained their local advisory committee to oversee the fund expenditure and in these instances carer representation is included within the committee structure. Many services now lodge and monitor applications via the statewide online application system. In these cases carer consultants may have the option to monitor and/or approve applications to prioritise need at the local service level. However, detailed data relating to the administration of the fund was not within the scope of this survey.
This section focuses on the survey respondents’ levels of carer participation at the individual level, such as involvement in treatment or discharge planning. Carer participation models in mental health services are expected to recognise the value of carers’ active contribution to setting the reform agenda and that active carer participation is an important component of continuous quality improvement. In doing so, mental health services must ensure that the roles and responsibilities of services and their staff to facilitate and support carer participation are defined and demonstrated.

Carer-inclusive practice is defined as opportunities for individual carers to be involved and engaged in care planning, treatment and decision making in all aspects of treatment and care provided to the person with mental illness who they care for. It also includes provision to support a carer’s needs separate from the needs of the consumer, to assist them in their caring role.

The survey results are organised to reflect the objectives stated in *Caring together*.

**Enhanced involvement of carers in treatment: assessment, service delivery, discharge planning and monitoring**

Overall, the majority of mental health services have formally integrated family inclusive practice at the policy level. Of respondents 88 per cent have developed a policy on practice and 81 per cent are expanding on this through the development of service-level carer participation plans or guidelines to uniformly identify, involve and engage with carers on an individual basis.

The approaches taken by each mental health service show a diverse range of methods and opportunities for carers to become actively involved and engaged across the treatment and care journey. Carer involvement strategies typically occur through triage, using intake assessments, referral to carer consultants, individual service planning (ISP) and discharge planning. The integration of carer involvement is strongly articulated in many key mental health service delivery policies, outlined in Table 4.

**Table 4: Rate of mental health service policies that state the role of family and carers**

<table>
<thead>
<tr>
<th>Service Level Policy</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge planning</td>
<td>96.9%</td>
</tr>
<tr>
<td>Shared care (GP/private psychiatrist)</td>
<td>71.9%</td>
</tr>
<tr>
<td>Continuum of care</td>
<td>93.8%</td>
</tr>
<tr>
<td>Clinical review</td>
<td>90.6%</td>
</tr>
<tr>
<td>Case management</td>
<td>90.6%</td>
</tr>
<tr>
<td>Intake Assessment</td>
<td>87.5%</td>
</tr>
</tbody>
</table>

**Discuss family and support networks with consumer and record carer details and relationship in consumer file**

In practice the majority (66 per cent) of responding mental health services, reported they routinely discuss family and support networks with the consumer and record carer contact and relationship details in the consumer file. The remaining mental health services, 33 per cent state they achieve this most of the time.
However feedback also highlighted two factors that determine the ability of families or other carers to be part of treatment and care. These are the willingness of consumers to identify their support networks or specific carers and the confidence of clinical staff to initiate and revisit these conversations. Results indicated these factors are at times barriers to including family and other carers and therefore possible areas of focus.

Invite carers to attend case-management meetings and discussions

Inviting carers to attend case-management meetings or the equivalent is less commonly included in routine practice, with 28 per cent of mental health services reporting they do so all the time, 34 per cent most of the time and 38 per cent only sometimes. However, carers may also be involved by other means beyond the scope of the survey such as coordinated carer-focused support services that work in partnership with mental health services. Interestingly, a number of mental health services use carer consultants to meet with carers to address their concerns and act as a conduit between carers and clinicians in place of regular meetings with clinical case management. While this works well to benefit carers, feedback from services suggests that structuring carer involvement with the carer consultant as the central point of contact has limitations due to the current level of funding, which provides for only part-time recruitment to carer consultant roles. According to services, such structures mean carer consultants’ time and resources are often overstretched. Many services reported the need to employ multiple full-time carer consultants to liaise with carers.

'We rarely see a client without parent or carer involvement. Treatment and management often requires participation of parents or other carers.’ Survey respondent

Develop a carer plan and review it regularly

Carer assistance plans or carer needs assessments are useful to identify and record opportunities for carer involvement and support needs in their own right. As yet, assessment tools are not standardised across mental health services. However, 56 per cent of responding mental health services often use carer consultants to undertake some form of carer needs assessment as part of planning appropriate carer supports. In addition to this some mental health services have recognised the key role of carers and integrated carer support planning into their recovery-oriented model of care.

‘The Strengths Model – Family Recovery Assistance Plan provides guidelines for engagement with families, relatives and other carers.’ Survey respondent

Be responsive to the complexities of the caring role and possible areas of conflict

The emerging approaches and strategies raised in the survey results by local mental health services demonstrate how services are addressing the need to be aware of, and responsive to, the complexities of the caring role and areas of potential conflict. Individual program initiatives include the use of local Working with families staff training manuals, involvement of CAGs or committees in key decision making, the promotion of carer rights, assessment processes and the availability of information packs and brochures explaining the role of carers in public waiting areas. According to feedback, adequate staff training opportunities, such as Building Family Skills Together, helps staff develop specific competencies, strategies and confidence to address the complexity and potential conflict, that may arise in caring relationships.

Train professional staff on strategies for effective collaboration with carers and families based on a partnership approach

The survey results confirm that services provide access to a range of opportunities for clinical staff to receive specialist family and carer perspective training to enhance carer collaboration. Services report carer-focused training modules are delivered at mental health services in conjunction with carers, carer peer workers, carer consultants or participation coordinators in order to draw on the lived expertise and experience of those who have accessed mental health services. In some services training also includes

3 Only qualitative data was collected to address this strategy focus area.
specialist family-sensitive training delivered by The Bouverie Centre or via the Victorian Government training clusters. The different types of carer perspective and training input are outlined in Table 5.

**Table 5: Provision of carer perspective input in staff recruitment, training and development**

![Bar chart showing the percentage of respondents for different training activities.]

Educate carers, consumers and clinicians on roles, responsibilities and issues of confidentiality

Results suggest many services offer mental health staff training to build competency and strategies for effective collaboration with carers, including issues about confidentiality, within core staff training. According to respondents, carer consultants are often involved in the delivery of the training modules that cover topics such as confidentiality, carer information sharing and the Mental Health Act. In addition, many carer consultants deliver targeted professional development sessions including supporting carers to care for someone with depression, working with young carers, shared decision making, clinical presentation, family-sensitive practice, the carer’s role in youth mental health, graduate and psychiatric registrar training, cultural and equity training and grief and loss. Results indicate carers receive information about roles, rights, responsibilities and issues of confidentiality through a range of verbal and written sources at mental health services. By including carers lived expertise in staff and community training participants develop a clearer understanding of common issues that impact carers.

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4 Only qualitative data was collected to address this strategy focus area
Improved information about mental illness

Collaborate and consult with carer consultants or networks on local carers information needs
The role of a Carer Advisory Group (CAG) is to monitor, inform and influence carer involvement and responsiveness within the mental health service and local region carer support networks. Survey results show that CAGs exist at 75 per cent of responding mental health services with membership comprising between three and 30 carers in addition to the carer consultants. Members of CAGs draw on their lived experience as service users to suggest ways to improve program development and service delivery within the mental health service and broader local support organisations and groups. Services reported that CAGs function most effectively when they are linked to the mental health service’s carer participation strategic planning processes.

Provide carer information kits on first contact with service
Responses indicate information kits are available in a variety of community languages in 85 per cent of responding mental health services. These services have developed local carer information packs, booklets, brochures or posters for carers. Responses indicate mental health staff distribute the information to consumers and carers and it is also available in waiting areas, on display boards and in some cases published on organisational websites. In conjunction with the written material some mental health services also offer information and orientation sessions at acute service inpatient settings.

‘All families receive a copy of A guide for carers and families – a locally produced resource.’ Survey respondent

Address carer information needs through regular review and updating of an individual carer plan
According to feedback, at this stage only 19 per cent of responding mental health services routinely develop and maintain individual carer plans as a discrete aspect of service delivery. Results indicate 83 per cent of responding mental health services make some effort to undertake this work to varying degrees. Aside from two exceptions, services depend on the carer consultant to work with carers to develop care plans. Many services reported the barrier to doing this work systematically across their service was a lack of resources to employ full-time carer consultants. Overall feedback suggests this work has not yet been mainstreamed as part of routine case management as it is not yet recognised as a core component of clinical practice.

Although not mainstream practice, the results did highlight two innovative approaches undertaken by services to address carer support needs and the implementation of carer plans. The first showcased the use of carer peer workers as an additional complementary resource to work alongside carer consultants with an emphasis on direct individual carer support casework. The second approach has integrated carer planning into the recovery framework of treatment and care, providing carers with an opportunity to engage with the treating team to establish a family recovery assistance plan that identifies the needs of the family, as well as how they can support the consumer in their recovery.
Improved access to carer support services and education programs

Meet with carer consultants or local carer networks to discuss carer support and education needs and strategies for ensuring carer access

Routine referrals to carer consultant staff occur in the minority, in only six per cent of responding services. Although carer consultants are employed at other services, carer referrals for peer support are offered only sometimes in approximately 75 per cent of those services. Feedback indicates many factors impact on whether carers are linked to carer consultant peer support. Services confirmed the level of peer support was dependent on the configuration of the carer consultant role that may have more or less emphasis on direct carer contact and systemic advocacy. There may also be constraints due to part-time employment, or difficulties for clinical staff initiating contact with carers to refer. Feedback also suggested sometimes only limited carer involvement is provided by mutual agreement between the service, the consumer and carer.

‘We consider that many of these tasks would be assisted by increased resources as currently their capacity to impact on some of these is compromised by lack of time.’ Survey respondent

Identify the support and education needs of culturally and linguistic diverse carers

Results indicate mental health services recognise and respond to the needs of culturally and linguistically diverse (CALD) carers in a number of ways. Most often, in 97 per cent of responses, services employ the use of interpreters to assist with involving CALD carers in clinical discussions. Over 90 per cent of services employ bilingual case managers at least some of the time to support carers from CALD backgrounds. All but two responding services implement strategies aimed at improving CALD carer participation. Feedback also indicated cultural portfolio holders build CALD capacity with staff to better engage with those from diverse backgrounds. Services commonly consult with and engage the Victorian Transcultural Psychiatry Unit, The Bouverie Centre and other local community organisations to enhance and promote CALD community awareness.

‘We deliver information sessions for CALD communities using resources from transcultural mental health, local community and links with external agencies and cultural groups to pool resources.’ Survey respondent

Link carers with carer support services, regional carer support and resource workers, local mutual support and self-help groups and mental health service providers

Carer consultants establish and maintain linkages to local support external services through their membership on local carer networks. Services reported that carer-focused networks have been established in regions via the Alliance Network Project in 46 per cent of services. The Commonwealth Carer Respite Program complements the general service partnerships. It does this by coordinating regional carer-specific networks across the state with a range of local organisations to encourage collaboration to address and support carer needs. These networks comprise staff from local mutual-support and self-help organisations, PDRSS, mental health service providers, carer consultants and carer support and resource workers. The local linkages support a robust referral network to provide a broad range of support options to carers. In some instances, services indicate this has led to the establishment of local partnership in-reach or outreach carer support and education models of service delivery.
Part 8: Conclusion

This survey provides a snapshot of the overall high level of good practice being implemented across our clinical mental health service system. There are many examples of innovative quality-improvement initiatives. In many instances levels of carer participation are consistent with state and national policy directions.

Overall, the majority of services have integrated carer participation and carer-inclusive practice. The results of this survey provide an encouraging overview of the status of carer participation. However, it appears some services have identified challenges in meeting some of the objectives outlined in Caring together. These results inform mental health services how they can strengthen effective carer participation and meaningful carer involvement. They also suggest how the department can best implement strategies that focus on service quality-improvement initiatives to enhance current levels of carer participation and involvement.

The results suggest:

- Carer participation and carer-inclusive practice is being integrated into mental health services, but sustainable change depends on committing resources to carers as a part of core business.
- The function of carer consultants as practice and policy changers is evident through the level of systemic participation.
- Carers needs for information and support are recognised by many mental health services.
- There has been progress in linking clinical and non-clinical services and organisations to address carers’ needs for support.
- Mental health services have a growing awareness of the benefits of using carers’ perspectives to improve staff competency and good practice.
- Mental health staff are developing approaches to include carers in treatment and care.
- Carers’ needs must be assessed to they can be supported and offered appropriate assistance to offset the impacts of the caring relationship.

‘The policies related to carer participation and inclusive practice exist however implementing the relevant practice is difficult and slow. Finding resources for the carer consultant to do all this work is extremely difficult and hinders the progress of the implementation and changing of practice. Most carers in our area are much more interested in carer-inclusive practice which includes carer support needs rather than carer participation at a systemic level.’ Survey respondent

‘We have developed a different model of carer participation and support based on the needs of our families. As their contact with us is often their first experience with a mental health service they have immediate needs for direct peer support, and thus the focus of our carer interventions is there. We also utilise family peer workers in advocating.’ Survey respondent

‘Over recent time our service has made a significant commitment to carer-inclusive practice. Currently this commitment is being translated to improved services on the ground and improved experience for carers. The next step for us is creating a strategic operationalised plan to ensure services align with current mental health policies and standards.’ Survey respondent

- The survey results indicate that minimum expectations in relation to carer participation and involvement in services are not currently being met in all services. For those services that were unable to report positively against particular consumer participation indicators, reasons provided included:
• a lack of clarity on the type or purpose of participation required within carer consultant role functions.
• inadequate or ineffective communication strategies to reach and influence the practices of staff, in particular medical staff, service delivery staff and psychiatrists in relation to carer participation and involvement
• limited staff training and development to develop understanding and competency in relation to the purposes and essential behaviours needed for supporting carer participation and involvement
• scarcity or adequacy of integrated carer representation to achieve goals for organisational change.

The way forward
At this stage the carer workforce has evolved to deliver a diverse range of initiatives in an effort to address local carer needs. There is an ongoing role for the department to ensure consistent carer-led systemic advocacy meets minimum standards and to communicate the importance of this advocacy to help drive quality improvements in all Victorian mental health services. The results highlight the differences that exist within the carer workforce. Carer consultant capacity, rescourcing, reporting and measurement of individual services’ participation plans vary greatly. The variations in their responsibilities, representation, involvement on committees, their advocacy and training, as highlighted in this survey, may impact on the success of service-based carer strategy. As the interest in carer participation and meaningful carer involvement continues to grow at the policy level it will be important to consider the capacity of the carer workforce and the level of involvement required by carers to participate in the policy and practice of mental health services to deliver the identified key objectives and emerging priorities.

The survey results identify a number of opportunities for the Victorian Government to further articulate the role of carer participation.

Actions
The Victorian Government is committed to carer participation and carer-inclusive practice in Victoria’s public mental health services and will undertake the following actions to further strengthen carer involvement in mental health services:

Consumer and carer participation policy
The Victorian Government is focused on involving people in decision making about the treatment and care that they receive from Victorian health care services. This includes a collection of participation standards and indicators that apply across the entire Victorian public health service system.

The Victorian Government will develop a new policy encompassing consumer, carer and community participation in the health care system.
**Review of carer supports, including the Carer Consultant Program**

The Victorian Government is planning an integrated review of state-funded mental health consumer peer support, carer support (peer, brokerage and respite), and consumer, carer and family participation programs. It will provide advice on how current investment in a range of specific programs and activities might more effectively support consumers, their carers and families, and strengthen consumer, carer and family participation. The Department of Health is undertaking initial research and issue identification with an external reviewer expected to be engaged in the second half of 2013.

**A new Carer Partnership Dialogue**

The Victorian Government has initiated a new Carer Partnership Dialogue, which signals a new model of engagement with carers by initiating an ongoing partnership dialogue with Victorian carer representatives.

The forums will bring together the Victorian Government through the Department of Health, the Victorian Mental Health Carers Network and Victoria’s carer workforce. This includes carer consultants, peer workers, support and resource workers from across clinical and community managed Psychiatric Disability Support Services.

The partnership will facilitate open and robust dialogue between the Victorian Government and mental health carers to help inform Victorian mental health policy, planning and program implementation.

**Carer Action Agenda**

The government has committed to the implementation of a whole-of-government Carer Action Agenda to raise awareness of the importance of care relationships in the Victorian community, supports carers in their care role and helps carers achieve their personal goals.