

Mental Health Experience Co-Design: A Quality Improvement Initiative

Mental Health Experience Co-Design (MH ECO) is an innovative method of identifying mental health consumers' and carers' experiences of using mental health services. The mixed design MH ECO methodology involves a data collection phase which utilises questionnaires, semi-structured interviews, and focus groups with consumers, carers, and staff to prioritise service parameters that may require improvement. This is followed by a Co-Design phase in which groups of stakeholders collaboratively design action plans relating to the identified areas for improvement. This project was implemented at the Darebin Community Mental Health Centre in Victoria, with 110 consumer participants and 98 carer participants. MH ECO was found to provide a structured way for all service stakeholders to work collaboratively, and resulted in a concrete set of action plans for service change. The methodology also supports meaningful consumer and carer involvement in service evaluation and quality improvement.

1. BACKGROUND

The participation of consumers and carers in the provision and evaluation of mental health services is enshrined as best practice across current state and federal mental health policy in Australia (Victorian Department of Human Services, 2009; Australian Health Ministers, 2003; National Standards for Mental Health Services, 2002; Tasmanian Government, 2009; ACT Health, 2006). Consumer and carer participation is identified as a means of improving the quality of mental health services, and of upholding the rights of stakeholders to influence and inform the services designed to meet their own support needs. Participation is a multi-faceted concept, encompassing a variety of roles and contexts. Examples may include participation in direct service provision (such as service and discharge planning) systemic participation in the development and application of policies and procedures, representation on, and contribution to boards and committees, participation in, and provision of staff training, and employment as consumer and carer consultants within mental health services (Hayman & Fahey, 2007).

Whilst research supports that collaborative mental health practice can positively impact consumer and carer wellbeing (associated with reduced rates of consumer relapse, fewer and shorter periods of consumer hospitalization and community case-management, and reduced levels of reported carer distress (McFarlane, Dixon, Lukens & Lucksted, 2003; Pitschel-Walz, Leucht, Baumi, Kissling & Engle, 2001; Dixon, Adams & Lucksted, 2000; Schulz & Martire, 2004) it is critical that consumers, carers and staff receive appropriate support, opportunities to translate these learnings into meaningful practice realities. Critically, collaboration and partnership with consumers and carers must be encouraged and enabled by mental health service systems and cultures through the provision of appropriate training, systems and policies, resources and leadership (Lakeman, 2008; Mottaghipour & Bickerton, 2005; Simpson & House, 2003). This may not only comprise the provision of support and training to staff, but targeted support to consumer and carer stakeholders who might otherwise lack the tools, confidence or expertise to effectively contribute to the systems and processes impacting their own support needs (Lammers & Happell, 2004; Simpson & House, 2003). In the absence of such, the language and ideals of consumer and carer participation can too easily become rhetoric (Tasmanian Government, 2009; ACT Health, 2006; Walker & Dewar, 2001; Dixon et al., 2001).

Minogue, Boness and Girdlestone (2005) further contend that the systemic participation of consumers and carers is most meaningfully realised when it extends to the practice of research and service evaluation within health settings. Ideally this should include participation in the development of research priorities, the design and delivery of research methods, the analysis of research outcomes and applications to practice. Such inclusion not only acknowledges the invaluable expertise and alternative perspectives consumer and carers bring to research undertaken to support their own health needs, but is consistent with the rights of consumers and carers to inform and influence their own mental health support needs and pathways to recovery.

Enabling systematic consumer and carer involvement across mental health service quality improvement and research has been central to a recent initiative undertaken in Australia between the Victorian Department of Health (DH), the Victorian Mental Illness Awareness Council (VMIAC), the Victorian Mental Health Carers Network (VMHCN) and participating mental health services. The initiative comprised the *Consumer and Carer Experience of Care and Support (C&C Experience)* pilot project, and the associated *Mental Health Experience Co-Design (MH ECO)* process. A central feature was the appointment of both a consumer and carer research team, based at VMIAC and VMHCN respectively, with each team comprising three workers with the lived experience of being consumers or carers. Their responsibilities included involvement at the planning, implementation, analysis, reporting and evaluation stages.

The C&C Experience pilot project was initially developed in response to the recommendations of a 2003-04 review of the use of consumer and carer evaluation surveys across Victorian mental health services (Victorian Department of Human Services, 2005). This evaluation found that the 'satisfaction' surveys used by services had been developed without consumer input, yielded very low response rates (below 10%) and failed to provide adequate opportunity for respondents to explore the issues most important to them. It was also found that no survey had been developed to target or capture the experiences of mental health carers. The evaluation ultimately concluded that the use of satisfaction surveys had resulted in marginal service improvements, demonstrating the need for improved systematic processes to translate the results of service evaluations into actual service change.

Aware of the limitations of past satisfaction surveys, the combined C&C Experience and MH ECO projects developed methods of exploring and identifying consumers' and carers' *experiences* of

service delivery, and of utilising these experiences to direct service improvement. The core of this shared approach was to engage consumers, carers and service providers to collaboratively re-design key aspects of service delivery. This process of collaborative redesign strongly parallels Bate and Robert's (2007) model of 'Experience Based Design', which similarly comprises a method of consumer, carer and service provider collaborative service 'redesign' to drive service improvement.

The project carried out at the Darebin Community Mental Health Centre (DCMHC) marked the transition from the *separate* C & C Experience and MH ECO piloted methodologies to the implementation of the *combined* MH ECO initiative and was a joint undertaking between DCMHC , the research teams from VMIAC and VMHCN, and the DH. DCMHC is one of two continuing care teams operating within the Northern Area Mental Health Service (a service of NorthWestern Mental Health in Victoria, Australia). It provides an outpatient service to clients with low prevalence disorders (primarily schizophrenia and bipolar affective disorder) residing in the inner-northern suburbs of Melbourne. The objectives of the project were as follows:

- To facilitate the participation of consumers, carers and staff in the redesign of key aspects of care identified in the collection of experiences
- To improve the systematic collection, analysis and use of information about consumer and carer experience of DCMHC.
- To use MH ECO to respond to the information about consumer, carer and staff experience to contribute to service planning and continuous quality improvement.

The remainder of this paper presents the project's methodology, findings and implications, broken down according to two phases: an initial data collection phase and an associated phase of co-design.

2. METHOD

Management of the project was undertaken by a liaison group of key stakeholders. The group met on a monthly basis and consisted of representatives from Northern Mental Health, the DH, and the consumer and carer research teams. The liaison group ensured fidelity to the piloted C&C

Experience and MH ECO methodologies, developed project guidelines and strategies, monitored project progress and implementation, and assisted in the evaluation of project outcomes.

2.1 Phase one: Exploring consumer and carer experiences of service delivery

Both quantitative and qualitative methods were used for data collection: a quantitative survey and a series of one-to-one interviews and focus groups. This data was later utilised to inform the service co-design component of the project.

2.1.1 Quantitative data collection

2.1.1.1 Survey Design

A consumer and carer survey methodology was developed as part of the piloted C&C Experience project. This methodology was developed through wide consultation with consumers and carers, and enabled the exploration and identification of consumers' and carers' experiences of service delivery. The methodology ultimately led to the development of separate consumer and carer questionnaires which were then extended to suit the specifications of the current project by the research teams.

2.1.1.2 Sample

The main consumer sample (n= 319) was derived from information drawn from the service's electronic consumer database. As separate carer information was not maintained by the service, a subset carer sample (n=233) was drawn from the main consumer listing, limiting the carer sample to those whose details had been successfully recorded within consumer records. Both were convenience samples.

2.1.1.3 Implementation

Due to the combined sample size (consumer (n)=319, carer (n)=233) the research teams worked collaboratively with a market research company to manage the collection of data. The consumer and carer research teams trained for, supervised and conducted the telephone interviews, whilst the market research company tracked the sample and produced the raw data and survey response outcomes.

The telephone interviews were conducted over a two week time frame, and hard copies of the questionnaire were posted to consumer participants if preferred.

2.1.1.4 Analysis

Statistical analysis (using SPSS) enabled the identification of key aspects of care by summing participants 'yes' and 'no' responses to the questionnaire items. The three items that obtained the lowest percentage of 'yes' scores and the three items that obtained the highest percentage of 'no' scores were then designated as the 'touch points' for consideration within the co-design phase of the initiative.

2.1.2 *Qualitative data collection*

2.1.2.1 Consumer and Carer Interviews

Six individual interviews were conducted, split evenly between consumers and carers. The interviews focused on participants' direct experiences of the service within the previous year were structured in a way that invited participants to 'tell their story' and explain their experiences of care and support in detail. The majority of interviews were held at a mutually convenient, neutral venue as a way of protecting the privacy and confidentiality of participants, and of supporting consumer and carer confidence by separating the process from a clinical setting. Each interview was recorded and transcribed.

2.1.2.2 Consumer and Carer Focus Groups

Two focus groups were held; one with consumers, one with carers. Participants were required to have direct experience of the service within the previous year. As per the individual interviews, the focus groups were held at a mutually convenient, neutral venue. The focus groups were conducted to generate deeper discussion of the consumer and carer survey data. To achieve this aim, focus group participants were asked to discuss statements that had been derived from the CATI questionnaire results; specifically the three items with the lowest percentage of 'yes' scores and the three items with the highest percentage of 'yes' scores. The discussions from each group were recorded and transcribed. The focus groups resulted in a substantial amount of complementary qualitative data which provided a comprehensive picture of consumers' and carers' experiences of service delivery.

2.1.2.3 Staff Focus Group

Consistent with the project's collaborative approach, staff member perspectives on the CATI survey results were sought. The aim of the group (n=8) was to give staff representatives the opportunity to respond to the key survey results, and share their perspectives on the emergent issues. The group's discussion was recorded and transcribed and key points were recorded on butcher's paper by participants.

2.1.2.4 Analysis

Transcripts of the interviews were independently coded for themes by two members of each team to identify significant themes. In addition, transcripts and butcher's paper records from the consumer, carer and staff focus groups were analysed to identify key themes within the data.

2.2 Phase Two: The Co-Design Process

The data collection phase of the project informed a co-design process, or the service 're-design' component of the MH ECO methodology. The co-design process was designed to engage consumers, carers and staff in working together to re-design key aspects of service delivery. The co-design process involved setting up a collaboration group and three co-design groups, enabled by the provision of training and support to all stakeholders to support their effective and equal participation in the process. Two members from each of the consumer and carer research teams attended meetings of the collaboration group and one from each team participated in the co-design groups to support the process.

2.2.1 *Training*

The purpose of the training workshops was to provide an opportunity for socialization, confidence building, and the skilling of participants in the co-design method, particularly in working together effectively and co-operatively in groups. They were facilitated by a member from each of the research teams. The first workshop provided consumers and carers with baseline information about the entire project methodology and the outcomes achieved via the data collection phase. Staff members had previously received similar information in a presentation delivered by research team personnel. The second workshop was held for staff, consumers and carers with the main purpose of familiarising attendees with the details of the co-design methodology. At the

conclusion of the training, participants nominated whether they wished to take part in either the collaboration group, a co-design group or both. An evaluation was performed at the conclusion of the training sessions. A total of nineteen participants provided evaluation feedback from the workshops with over 90% rating them as useful, informative and well planned.

2.2.2 Collaboration group

The collaboration group comprised senior staff from the service, consumers, carers, and consumer/carer consultants. The collaboration group met four times; prior to, and at the completion of the co-design groups, and at three and six month post-project intervals to assess the impact of the quality improvement action plans.

The initial role of the collaboration group was to examine the emergent touch points from the data collection phase of the project, and from these formulate a set of objectives appropriate for the co-design process. The secondary role of the collaboration group was to prioritise these objectives, allocating one separate objective for each of the three co-design groups. Underpinning the process was an understanding that the objectives should be realistic, achievable and measurable over time. The two final roles of the collaboration group were to critique the emergent action plans (following the co-design process) prior to their presentation to the service, and to perform some initial assessments of their impact upon service delivery. In support of sustained implementation of the action plans, the service was advised to undertake a staggered approach (eg. with short, medium and longer term goals) as simultaneous implementation of multiple tasks may have become unmanageable and burdensome for all stakeholders.

2.2.3 Co-design groups

Three co-design groups were established with each group meeting on three occasions over a period of six weeks. Each co-design group was assigned a service aspect to redesign with the intention of producing a focused action plan at the conclusion of the six week period. The co-design groups were comprised of staff from the service, consumers, carers, and consumer/carer consultants. An evaluation was performed at the conclusion of the third meeting of each co-design group.

3. RESULTS

3.1 Phase I: consumer and carer experiences of service delivery

3.1.1 *Quantitative data*

3.1.1.1 Demographic information

As illustrated in Table 1, the majority of participants in both the consumer and carer groups were between the ages of 35-64 years, with a greater number of males than females. The majority of consumers had started receiving service from Darebin Community Mental Health Centre more than six months ago, while the majority of carers had last had contact with the Centre during the past month.

3.1.1.2 Survey Response Rates

A total consumer sample of n=319 was derived from records held by the participating mental health service. From this sample, n=230 consumers were successfully contacted to complete the survey, with n=110 final survey completions. Eight surveys were completed via mail-out. The consumer survey completion rate of 47.8% was affected by difficulty contacting consumers (n=89) and the number of survey refusals (n=119). Such problems may be in part attributable to incorrect contact information in the case of the uncontactable sample. Other viable explanations include ambivalence due to previous exposure to multiple 'satisfaction' type surveys, and the negative impact of medication side effects and illness.

A total carer sample of n=233 was drawn from information attached to consumer records (n=319). From this sample, n=123 carers were successfully contacted, with n=98 completed surveys. The completion rate for the carer survey was 79.7%. The uncontactable carer sample of n=110 was affected by incorrect contact information, and carer unavailability following multiple attempts at contact.

3.1.1.3 Survey (CATI) Data

Overall, the consumer and carer survey participants reported positive experiences of service provision, indicating that staff were respectful, collaborative and provided a high quality of service. Due to the length of the consumer and carer questionnaires this paper will only report the three items that obtained the lowest percentage of 'yes' scores and the three items that obtained the

highest percentage of 'yes' scores (see Tables 2 and 3). This subset of survey data is also particularly relevant as it was used within the methodology to inform the co-design process.

3.1.2 Qualitative data

3.1.2.1 Personal Interviews

The consumer interviewees (n=3) provided information consistent with many of the findings from the CATI survey questionnaire. All felt that the service had helped them in their recovery journeys in some way. Two of the interviewees felt that their case workers had been a key element in their care. Being treated with respect and being listened to by staff were important issues for all of the interviewees. Medication was a common discussion point, with two interviewees indicating that their lives had been changed by the medication they had received. All interviewees stated that they would have liked more information about services that were available in their wider community, with particular regard to when they left the service. In line with the CATI survey findings, the interviewees indicated that they were unfamiliar with the Basis-32 outcome measure tool, even after the tool had been described to them by the interviewer. The interviewees all concluded their interviews with positive statements about their experiences of the service.

All carer interviewees (n=3) indicated that they valued the service provided by the service, but described mixed experiences of communication with staff. Two interviewees described inadequacies in the response of the service to requests for help in urgent situations, and the perceived devaluing of their knowledge and experience. Two of the carers also indicated that they would have liked information from the service about support options for carers.

3.1.2.2 Focus groups

The consumer focus group participants (n=5) confirmed the relevance of the key items that had emerged from the CATI survey data. In particular, the focus group participants felt that staff had demonstrated respectful treatment towards them and that the service had provided a safe environment. Confusion over the Basis-32 was further highlighted, as most participants did not know what the tool was even after the facilitators gave an explanation of the instrument. The participants indicated that overall they had had positive experiences with the service although several related experiences commensurate with the least positively rated items arising from the CATI survey.

The carer focus group participants (n=11) confirmed the importance of most of the six key items emerging from the survey data, especially that staff had taken time to listen to their experiences as carers. The participants indicated that the effects of both positive and negative experiences of service delivery had been quite profound. A comparison of the qualitative (focus group/personal interviews) and quantitative (survey) findings revealed some wide disparities. Namely, whereas the focus group participants reported quite mixed experiences of service provision, the survey findings indicated that a large majority of carers had experienced very positive experiences of service provision, particularly in relation to staff listening to their opinions, and the provision of a safe environment for the consumer.

The staff member participants (n=8) indicated they had developed a deeper understanding of the perspectives of consumers and carers in regard to the six issues discussed. They stated that the discussions had helped them to obtain new perspectives on critical issues relating to their practice, particularly associated with use the Basis-32, the information needs of carers and the concerns of consumers at discharge from the service. Several of the staff participants went on to become members of the MH ECO collaboration and co-design groups.

3.2 Phase Two: The Co-Design Process

3.2.1 Collaboration group: Which touch points were selected?

'Touch points' were identified in the data collection phase of the project, representing the elements of service provision that consumers and carers experienced as most positive and as least positive (via the CATI survey results). Following an examination of these touch points, those considered least positive were identified of highest priority for redesign purposes. The service aspects allocated for redesign by the co-design groups were as follows:

- Review and redesign information delivery pathways to more effectively engage consumers and carers, including information about rights, complaints, legal issues and supports.
- Review and redesign discharge planning to reflect more opportunities for consumers' and carers' involvement within transparent timelines.
- To improve the participation of consumers completing the Basis 32 Outcome Measure.

3.2.2 Action Plan Examples

Information Delivery

The overall objective of this action plan was to review and revise information delivery to more effectively engage consumers and carers. A number of specific goals were developed, including information nights catering for the needs of carers and consumers.

The Basis-32 Outcome Measure

The overall objective of this action plan was to improve participation of consumers completing the standard Basis 32 outcome measure, including consideration of staff motivation and the carer's role. One specific goal was to embed the Basis 32 more effectively in treatment planning and clinical practice. A second goal was to increase staff awareness of the value of the Basis-32 and build capacity for effective utilization of the tool. Strategies for meeting these goals were planned and prioritised for implementation.

3.2.3 *The co-design group evaluation*

After the final meeting of each of the three co-design groups, participants were asked to provide feedback about the groups through an evaluation form. This consisted of a set of statements relating to features of the groups including the organisation of the groups, punctuality, opportunity to express opinion and the valuing of opinion, objectives of the group and usefulness of the process. Nineteen co-design participants completed evaluation forms. 79% indicated that the co-design groups had been useful, fulfilled their objectives and had provided opportunities for participants to express their opinions and have those opinions valued. Echoing the opinions of many group members, one participant remarked:

'It was a meaningful process to reflect on the practices currently available. Great experience to work with staff, consumers and carers in a common forum'

Another further remarked that it had been:

'An extremely valuable experience, powerful and positive with a great respect for everyone's point of view. This model of working should be much more widely implemented'

4. DISCUSSION

The findings of this project demonstrate that the piloted C&C Experience and MH ECO methodologies can be together implemented to support consumers, carers and service providers to work together in partnership in the design, delivery and improvement of mental health services. The findings indicate that the project yielded many positive outcomes for all stakeholders, lending support for the methodology, and its role as an inclusive, efficient and useful service evaluation and quality improvement measure.

The way responsibilities were shared within the co-design and collaboration groups was a key marker of the project's success, with the provision of training vital to ensuring all stakeholders collaborated and contributed to the process equally. This involved training in the concepts of collaboration and co-design, and training and support to work effectively in groups. The latter was especially critical to the effectiveness of the process, providing a means of breaking-down any normalized consumer-carer-service provider relationships which might otherwise privilege staff member authority and their clinical knowledge. Without such targeted training to all stakeholders, unequal power-differentials may have remained. This involved a significant mind shift for many of the participants. Importantly, all training was practical, collaborative and structured, allowing opportunity for different learning styles, socialization and the creation of a common purpose. The facilitation provided by the research teams was also critical to the success of the groups, with the researchers providing both modeling of the co-design process and support to the consumer and carer participants where necessary to maximize their participation.

Establishing committed 'champions' at the service level was also integral to the project's successful implementation. Such champions (in this case, the DCMHC manager and three senior staff) ensured the project was given priority within the service, with responsibility taken by nominated staff members for the management of key aspects of the project's implementation (i.e. organization of meeting times and venues, recruitment of, and contact with consumer and carer participants, and attendance at all the meetings). Ensuring that the service took some ownership of the project was a means of keeping it on track, and investing it with relevance and meaningfulness. These factors were not only critical enablers of participant enthusiasm, commitment and belief in the process, but of the service's readiness to accept, prioritise and implement the co-design groups' action plans for change.

Participant feedback and researcher observations of the group processes indicate that the MH ECO methodology encouraged the development of positive, collaborative relationships between consumers, carers and staff. The strength of the methodology was not only that it provided a structured and inclusive opportunity for quality improvement (via service redesign and concrete action plans), but that it also supported staff members, consumers and carers to develop a collaborative way of engaging with one another that could benefit clinical relationships. For example, the experience of working together as peers enabled participants to develop improved understanding of each others' experiences and perspectives; to develop improved self- confidence and advocacy skills; to identify shared concerns (a critical aspect to grounding the project); to identify and share opportunities for validation, and to positively utilize past experiences. For consumers, carers and staff alike, being part of this experience resulted in increased confidence in more collaborative ways of working and relating to one another; outcomes consistent with the principles and findings of Bate and Robert's (2007) methodology of Experience Based Design. Reflecting the feedback of multiple respondents, one staff member wrote that the process had *"(i)ncreased my confidence and commitment to working collaboratively with consumers and carers"*.

Due to the shared development of the action plans and the structured nature of project, the methodology enabled the service to implement changes more quickly than may have otherwise been possible (i.e. if only a satisfaction-type survey had been conducted without an experienced-based survey and the process of co-design). By collaborating with all stakeholders, the changes proposed through the action plans were more easily adopted, as they reflected consumers', carers' and staff members' shared concerns and experiences, and harnessed their collective commitment to change. This is evident via changes already implemented at the service only six months following the completion of the co-design process. These include: making complaints information more secure and accessible; the design and implementation of procedures governing the use of the Basis-32; provision of staff training to improve their collaborative work with consumers and carers and the establishment of a consumer and carer advisory group. From this initial implementation the action plans, some particularly positive results have been welcomed, with staff indicating an increased confidence when working with consumers and carers, and with the Basis-32 completion rate of consumers increasing by 50% six months following project completion. In addition to the direct implementation of components of the action plans, the MH ECO experience

has influenced wider initiatives implemented by the service. For example, a scheduled five-session psychoeducation group was modified to include consumers as well as carers (for the first time), and to cover topics specified in the action plans. These changes are reflective of the service's strengthened commitment to consumer and carer representation across all aspects of service provision, and its strengthened confidence in shared decision making practices.

The consumer and carer surveys alone also provided useful information to the service. The use of interviewers external to the clinic allowed for open, unbiased feedback, and the addition of service-specific questions to the questionnaire (eg. with regard to the Basis-32) ensured that the service was able to receive information particular to its population and service needs. In terms of the service's communication with carers, the survey was critical in developing a separate and up-to-date carer database for the service, and in assisting the service's carer consultant to establish regular contact with carers via a monthly newsletter.

4.1 Limitations

Despite the strengths associated with the project, this experience nonetheless raised challenges for the service and the research team. With regard to the equal participation of all stakeholders, the number of consumer and carer participants would have ideally been greater (and their attendance more consistent), particularly in the collaboration group where staff members outnumbered consumers and carers, potentially undermining the intent of the process. Moreover, despite the training provided, it was often challenging to ensure equal participation in a context where staff were accustomed to taking initiative and managing the process, and consumers and carers to being more passive 'receivers' of care. In this instance, having members of the consumer and carer research teams in attendance at all of the groups was particularly critical in equalising the process, providing opportunities to strengthen consumer and carer participation where necessary. The effects of medication and illness were also an issue for some consumers (in terms of their ability to attend the groups or contribute when in attendance), highlighting the importance of providing support to all stakeholders to ensure equal participation. Such support may involve the provision of transport and reminders to consumers, or consideration of when meetings are best scheduled to meet all participants' needs (amongst other factors).

The need for staff training to implement aspects of the action plans is a further factor to be considered for future implementation of the methodology. The MH ECO process presented a

considerable commitment for the participating service, increasing staff work load during its implementation, particularly during the co-design phase, and requiring the allocation of extra resources. The service felt that the question of additional resources or support would need to be considered if replication of the process were to occur in their service in the future.

4.2 Conclusion

The project at DCMHC has demonstrated that MH ECO is an innovative and inclusive service quality improvement methodology for use in mental health services, consistent with the original objectives set out in the project brief. Whilst DCMHC had previously established a commitment to working inclusively with consumers and carers, MH ECO provided a methodology for implementing these values in a structured way, strengthening the commitment and confidence of all service stakeholders to work collaboratively, and providing the service with a concrete set of action plans for service change. The project achieved the goal of building capacity in the service for ongoing collaborative quality improvement activities, and demonstrates that the methodology offers a viable way forward for meaningful consumer and carer involvement in service evaluation and quality improvement in a wider service context.

Competing Interest Declaration

The co-authors of this paper declare that they do not stand to gain any financial benefit from any third parties resulting from the publication of this paper. The co-authors declare that they have no competing interests.

Funding

This work was supported by the Victorian Government Department of Health, Australia.

5. References

- Australian Health Ministers (2003). *National Mental Health Plan 2003-2008*. Canberra: Commonwealth Government of Australia.
- ACT Health (2006). *Come to the table: A proposed model for effective and genuine participation of consumers and carers cross mental health* (unpublished discussion paper). Canberra: ACT Health.
- Bate, P., & Robert, G. (2007). *Bringing user experience to healthcare improvement: The concepts, methods and practices of experience-based design*. Abingdon, UK: Radcliffe Publishing Ltd.
- Dixon, L., Adams, C. & Lucksted, A. (2000). Update on family psychoeducation for Schizophrenia. *Schizophrenia Bulletin*, 26, 5-20.
- Dixon, L., McFarlane, W.R., Lefley, H., Lucksted, A., Cohen, M., Falloon, I., Mueser, K., & Miklowitz, D., Solomon, P., & Sondheim, D. (2001). Evidence-based practices for services to families of people with psychiatric disabilities. *Psychiatric Services*, 52(7), 903-910.
- Hayman, F., & Fahey, A. (2007). Involving carers in mental health service development. *Australasian Psychiatry*, 15(3), 191-194.
- Lakeman, R. (2008) Family and carer participation in mental health care: perspectives of consumers and carers in hospital and home care settings. *Journal of Psychiatric and Mental Health Nursing*, 15, 203-211
- Lammers, J., & Happell, B. (2004). Research involving mental health consumers and carers: A reference group approach. *International Journal of Mental Health Nursing*, 13, 262-266.
- McFarlane, W., Dixon, L., Lukens, E., & Lucksted, A. (2003). Family Psycho education and Schizophrenia: A Review of the Literature. *Journal of Marital and Family Therapy*, 29(2), 223-245.

- Minogue, V., Boness, A.B. & Girdlestone, J. (2005). The Impact of Service User Involvement in Research. *International Journal of Health Care Quality Assurance*, 18(2), 103-112.
- Mottaghipour, Y. & Bickerton, A. (2005). The Pyramid of Family Care: A framework for family involvement with adult mental health services. *Australian e-Journal for the Advancement of Mental Health*, 4(3), <http://www.auseinet.com/journal/vol4iss3/mottaghipour.pdf>
- National Standards for Mental Health Services. (2002). Canberra, Australia: Commonwealth Department of Health and Family Services.
- Pitschel-Walz, G., Leucht, S., Bauml, J., Kissling, W., & Engel, R. R. (2001). The Effect of Family Interventions on Relapse and Rehospitalisation in schizophrenia –A Meta-Analysis. *Schizophrenia Bulletin*, 21(1), 73-92.
- Schulz, R., & Martire, L. (2004). Family Caregiving of persons with dementia: Prevalence, Health effects and support strategies. *The American Journal of Geriatric Psychiatry*, 12(3), 240-249.
- Simpson, E. L., & House, A. O. (2003). User and carer involvement in mental health services: from rhetoric to science. *The British Journal of Psychiatry*, 183, 89-91.
- Tasmanian Government. (2009). *Mental Health Services Consumer and Carer Participation Review*. New Town: Department of Health and Human Services.
- Victorian Department of Human Services. (2005). *Review of the 2003-04 Victorian surveys of consumer and carer experience of the public mental health system*. Melbourne: Department of Human Services.
- Victorian Department of Human Services. (2009). *Because Mental Health Matters: Victorian Mental Health Reform Strategy 2009–2019*. Melbourne: Department of Human Services.
- Walker, E., & Dewar, J. (2001). How do we facilitate carers' involvement in decision making? *Journal of Advanced Nursing*, 34(3), 329-337.

Table 1 Consumer and Carer Demographic Information

	Consumers (n=110)		Carers (n=98)	
	n	%	n	%
Gender				
Male	63	57%	62	63%
Female	47	43%	36	37%
Age				
Under 18	1	1%	0	0
18-34	29	26%	6	6%
35-44	43	39%	10	10%
45-64	39	36%	54	55%
65-74	1	1%	23	24%
75+	0	0%	5	5%
Started receiving service from Darebin Community Mental Health Centre				
Within past month	1	1%		
Within the past 3 months	3	3%		
Within the past 6 months	11	10%		
More than 6 months ago	95	86%		
Can't remember	0	0%		
Last had contact with Darebin Community Mental Health Centre				
Within past month			39	40%
Within the past 3 months			18	18%
Within the past 6 months			8	8%

More than 6 months ago	30	31%
Don't know/Never	3	3%

Table 2. Consumer Touchpoints

	Yes %	No%	Not sure%
Most positive			
Did staff treat you with respect?	92	8	0
Do you feel that you are being treated in a safe environment?	92	6	2
Do you feel that the staff are able to help you?	92	7	1
Least positive			
Did staff explain how long you might need the service for?	46	54	0
Are you involved in decisions about what you might need when you are discharged from Darebin Community Mental Health Centre?	34	58	8
Do you find it helpful to complete the Basis 32?	34	37	29
n=110			

Table 3. Carer Touchpoints

	Yes %	No%	Not sure%
Most positive			
Did staff take time to listen to your opinion as a carer/family member/friend about what was happening?	80	18	2
Does Darebin Community Mental Health Centre provide a safe environment for your family member/friend?	80	9	11
Do you know how to help and support your family member/friend at home?	91	6	3
Least positive			
Do you understand what has to happen before your family member/friend can be discharged from Darebin Community Mental Health Centre?	35	56	9
Do staff check to see if you are confident and prepared to keep on caring for your family member/friend?	35	58	7
Have you been given information about legal issues that might affect you as a carer/family member/friend?	32	64	4
Do you have concerns about your family members /friends living arrangements?	32	66	2

n=98