Commentary on consumer and carer participation in a national mental health promotion initiative.

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Current Australian government policy acknowledges that consumers and carers are an integral component of improving all aspects of mental health, from individual service provision to policy development.

However, although the ability of consumers and carers to influence mental health programs and services in Australia has increased over the past decade, the theory of partnership for consumer and carer participation has many challenges when put into practice.

The Children of Parents with Mental Illness (COPMI) national initiative has endeavoured to overcome these challenges and integrate consumer and carer participation across the initiative through a range of strategies. This paper will explore and describe how consumers and carers have engaged with the initiative and overcome barriers or worked through ways to negotiate them. Examples and consumer and carer reflections are provided specifically in relation to the development of both public information and workforce development resources.

The COPMI national initiative’s experience adds to the body of knowledge that is increasing as consumer and carer participation becomes more integrated across the mental health sector.

Key words

Consumer, carer, parents, children, mental health, partnership,
**Introduction and Context**

Current Australian government policy acknowledges that consumers and carers are an integral component of improving all aspects of mental health, from individual service provision to policy development (need a reference here because the documents listed in the next paragraph are plans and standards, not policy documents – I suggest Gregory, 2007).

There are many examples of national plans and standards documents identifying and requiring that consumer and carer participation is included as a matter of good practice in mental health service provision and worker training. The National Mental Health Plan 2003-2008 (2003) states that ‘consumers, families and carers should be able to genuinely participate as equal partners in national, State/Territory and local decision making that affects their quality of life’ (p.5). The Mental Health Services Strategic Plan 2006-2011 (2006) identifies a framework for consumer and carer participation and The National Practice Standards for the Mental Health Workforce (2002) identifies consumer and carer participation as a key principle. In addition, ‘international literature is now strongly supporting the view that children, young people and their families should be involved in mental health service planning and delivery at all levels’ (Australian Infant, Child, Adolescent and Family Mental Health Association, 2008 p.14).

However, although the ability of consumers and carers to influence mental health programs and services in Australia has increased over the past decade, partnership in consumer and carer participation has many practical challenges. Barriers identified include inadequate resourcing and time, lack of planning and processes, inflexible options for participation, and organisational cultures that are indifferent or hostile to the concept of consumer and carer participation (Epstein, 2005; Horsefall et al., 2007; McInerney, 2008; Oliver,S et al 2001; Stacey & Herron, 2002).
The Australian Infant Child Adolescent and Family Mental Health Association (AICAFMHA) has undertaken the Children of Parents with a Mental Illness (COPMI) national initiative with funding from the Australian Government since 2002 with the goal of ‘improving mental health outcomes of children of parents with a mental illness’. Aims of the current phase of the initiative (2007-2010) include the development of quality information for families where a parent experiences mental illness are raising children in the 2-7 year age range and associated information for the early childhood workforce; the development of quality workforce development resources, principally targeting the mental health workforce but also accessible for other workers; and the development of information regarding the efficacy of relevant programs, services and approaches and greater access to research literature and evaluation models.

AICAFMHA and COPMI initiative staff members are committed to consumer and carer participation, however they are also aware (through the literature and from personal experience) of the barriers to effective consumer and carer participation and have actively sought to address these.

This commentary aims to do three things. It briefly summarises the information that was used to guide efforts to enhance consumer and carer participation within the initiative. It provides information about the measures that were subsequently taken, plus examples of these activities and approaches, supplemented by quotes from participants. It concludes by sharing insights and recommendations from the authors (three ‘participant observers’ in the process).

The term ‘participants’ is used throughout this article to refer to people who actively participate in the COPMI initiative and who are a parent-consumer of mental health services and, or, a carer of a parent-consumer. Many of the participants are both ‘carers’ and
‘consumers’. For example, some participants are parent-consumers who also provide care for their parent with mental illness; other participants are parent-consumers who also provide care for their adult child and that person’s offspring, due to the adult child’s mental health problems.

A Brief Overview of Known Challenges Associated with Consumer and Carer Participation

- **Resourcing - Time and money**

‘True involvement, discussion, detailed planning, development of trust, and a collaborative relationship all take time - which means funds’ (Hanley et al., 2001; Trivedi & Wykes, 2002 as cited in Horsefall et al. 2007, p. 1208).

The resourcing challenges to ensuring participation by consumers of mental health services and their carers include those that are unique to these groups, in addition to those that need to be addressed whenever anyone adds additional roles to their lives. For example, financial hardship and access to convenient and affordable transport have been noted by mental health services’ consumers as cause for trepidation about participating (Epstein & Shaw, 1997) and carers may require respite to be arranged for the person they are caring for (Carers Australia, 2009). The negative belief systems of participants who have been involved with mental health services may also result in additional time being required for development of trust, briefing and pre-briefing; ‘Self stigma is an issue for most people with lived experience and is the result of internalising messages and behaviour received from others’ (Hinton, 2009, p25).

- **Planning and Processes**
When integrating consumer and carer participation into a mental health promotion initiative, both structural and interpersonal barriers require consideration (McCann, et al., 2008). Some barriers come from within the individual (for example, lack of confidence in abilities, skills and experience) and these may need to be addressed as they arise. Potential structural barriers (e.g. procedures, processes, resourcing, shared clarity of purpose) can usually, and more appropriately, be addressed in advance. The potential for conflict between the agendas of consumers and carers is an example of the challenges that have been identified as requiring consideration in planning (Goodwin & Happel, 2006). The need for clearly identified strategies for personal support of consumers and carers is another example. Meehan and Glover (2007, p.154) note the need for follow up for consumers presenting information ‘even for those presenters that appear comfortable and confident disclosing their experiences’.

- **Flexibility of Engagement Options**

Consumer and carer participants work life balance may already be strained due to many factors including finances and time. Other challenges they may face include additional caring tasks that are not always predictable, being unwell, decreased confidence, feeling unreliable, lack of access to technology or time to use it when it is available and needing to prioritise many other commitments before participation. ‘Participation strategies should be matched to tasks and commitments...’ and ‘Often more than one participation strategy is needed’ (Stacey et al. 2002, p. 10).

In attracting young people as participants, a variety of different methods that are interchangeable may increase the level of participation and interest (Gregory J. 2006). This is particularly crucial for young carers who will have many competing needs and responsibilities. (James, A.M. 2007 NYPS 2008)
A variety of access options may also be required to decrease stress levels and increase participation when there is available time and/or motivation, for example via technology, ‘such as access to effective communication tools, such as email, internet and SMS (NYPS 2008 p.58) that allows participation through community centres, schools, libraries, workplace or home

**Organisational Culture**

The attitude of both the organisation and individuals within it has been noted to be a crucial component in building sustainable participation (Meagher, J. 2002).

‘All Participants involved in the Mental Health sector must display a high level of commitment and belief in the value of consumer and carer participation, for it to be truly effective rather than just tokenistic’(Mental Health Council of Australia, 2008, p.3).

The supportive culture of an organisation, demonstrated by ‘the nature of the working relationship, the commitment of the partners and the trust and respect accorded each other’ (Moore, 2003 p.22) is pivotal to successful participation. Genuine partnerships in participation take time, genuine and sustained communication and a clear belief that the input of consumers and carers is crucial to a valid end result (Department of Health and Human Services, 2009). The real or perceived power imbalance between consumers, carers and the professionals can strongly influence participation outcomes (Meagher, 2002) and therefore needs to be addressed with all stakeholders. A culture that is open to everyone learning, to undertaking skills development for both the workforce and for consumer and carer participants has been noted to support effective engagement with consumers, carers and community members (Department of Health and Human Services, 2009).
People who feel that their participation was not meaningful and where they are not informed of the results of their participation are less likely to continue (Stacey & Herron, 2002).

Feedback to participants as to how their participation has been useful is important to ensuring continued goodwill and future participation.

Care must be taken to ensure that participants are not perceived as ‘representatives’ of groups or sub-groups of other carers and consumers but are valued for their own personal experience and perspective. (Meagher must have a reference for this somewhere, I presume??) This requires a range of participants to be sought to inform initiatives.

**Measures Taken to Address Challenges**

Having identified the challenges outlined above (through the literature and workers’ experience) the COPMI national initiative has attempted to address them by planning for and resourcing integrated and flexible consumer and carer participation across the initiative.

- **Dedicated Staffing and Financial Resources**

  Increased support for consumer and carer participation was a strong recommendation arising from the planning processes undertaken prior to the 2007-2010 phase of the COPMI national initiative and this was progressed by the resourcing and employment of a full-time Consumer and Carer Participation Officer. It was considered that a designated contact person was necessary to support and build the culture of participation within the initiative, reduce barriers to engagement, enhance communication with consumers and carers and to further build trusting relationships between participants and the COPMI team. The Consumer and Carer Participation Officer’s connection with participants needed an investment of time in order that each participant felt valued and comfortable in the COPMI environment. Financial resources were also required to facilitate initial face-to-face meetings between the Consumer
and Carer Participation Officer and individual participants and bi-annual face-to-face meetings of the COPMI National Family Forum (a consultative group of consumers and carers)

A dedicated budget and the services of a part time (0.4) Project Officer were assigned to support the Consumer and Carer Participation Officer position.

A culture of respect and trust was built in partnership with the COPMI staff and this took varying amounts of time, according to the individual participants’ circumstances, experience, skills and confidence levels. It was crucial that participants were given time to tell their stories, talk over their concerns and resolve particular challenges to their participation.

_The whole COPMI team are very supportive and approachable with all the consumers and this makes a big difference. COPMI offers many supportive tools to the consumers that I think really help in the participation. The other group members and consumers are a great inspiration and I always feel very welcomed and valued. The COPMI team are very focused on the cause and I am very looking forward to the end result_ (Participant, 2009).

A range of options for follow up and debriefing were put in place after meetings and other interactions associated with participation. Teleconferences, email, one-to-one phone contact and sometimes face-to-face meetings were used to ensure that people felt supported and their chosen level of participation was accommodated. Short ‘consumer and carer only’ debriefing sessions were held after each teleconference to allow consumers and carer the opportunity to talk with the Consumer and Carer Participation Officer and others in the group and raise any concerns. These sessions gave participants a chance to raise points that they may have omitted at the meeting and alerted the Consumer and Carer Participation Officer to any support issues that needed to be addressed.
Follow up by email and phone calls also occurred if a participant felt that they were vulnerable or if it was perceived that interactions had triggered some discomfort for them.

*All the meetings for me as a consumer do stir up many emotions and strong feelings and it can be hard to communicate your point at times, but over time this has become for me much easier. After each teleconference all the consumers and carers stay on line and, with the Consumer and Carer Participation Officer, are able to freely chat and discuss how we feel, make any points that we didn’t get a chance to express and just talk. I have found this to be an extremely valuable exercise and I know all the consumers feel the same* (Participant, 2008).

- **Planning and Process Documentation**

A participation plan including practical measures and strategies was put in place to ensure that once consumers and carers had initially engaged with the COPMI initiative there was a smooth transition to practical participation.

Potential participants were sought and contacted through state and territory peak consumer and carer groups, through email lists, by spoken word, newsletters and through face-to-face meetings. Invitations to contribute were extended through the COPMI website, electronic discussion list and at conferences and were also distributed through organisational networks, peak bodies such as the state and territory Carer Associations, Consumer Advisory Groups and their websites.

Once potential participants expressed an interest in being involved in the initiative they were contacted by the Consumer and Carer Participation Officer and their interests and needs discussed. They were given written information including the COPMI Consumer and Carer Participation Strategy and the COPMI Remuneration Guidelines. Written information helped
to ensure that all parties were clear about their roles and responsibilities and had relevant documentation available to refer back to should the need arise.

Guidelines regarding remuneration and reimbursement of expenses were clearly outlined in procedural documents to ensure that participants knew that they would not be worse off financially if they choose to engage with the initiative. Remuneration in the form of sitting fees is offered as a matter of course. Expenses such as child care, parking fees and travel costs are reimbursed.

Procedures were put in place to ensure COPMI staff members notify participants well in advance of meeting times, allowing participants time to make arrangements for their other commitments. Participants have since reported that receiving agendas and meeting notes early assisted them in their preparation and this increased their confidence. This also made it possible for them to clarify points or to discuss their perspective and ways to communicate their point of view with a COPMI team member prior to the meeting or interaction.

_The meetings are always planned well in advance, which helps a great deal with babysitting and school. This also gives you a chance to read any new material, the Actions and Outcomes from the last meeting and have comments ready for the new meeting_ (Participant, 2009)

- **Flexible Options for Engagement**

A diverse range of consumers and carers (including young carers) have been engaged across the initiative. They participate through the COPMI National Reference Group (an advisory body consisting of policy makers, academics, consumers, carers, and experienced practitioners in this field), the COPMI National Family Forum (an advisory body consisting of consumers and carers only), and they contribute to the focus groups and the COPMI electronic discussion list. Consumers and carers have also been included in all consultation groups for specific resource development areas of the COPMI initiative. COPMI staff
encouraged a diverse range of consumers and carers to participate in the consultation groups and associated consultation strategies (e.g. focus groups and surveys) to ensure that the development of resources and materials was influenced by many perspectives.

Participants’ availability to attend meetings can be compromised due to a variety of circumstances. Several participants disclosed that being unwell, experiencing a decrease in confidence or having to take on additional caring responsibilities resulted in their non-participation in some meetings and activities. Individual participants required flexibility in order to accommodate changing circumstances so that they were still able to have input and influence in the decisions and the resulting practical outcomes, even if the designated meetings were sometimes not attended.

Some participants reported that the unpredictability of their availability was very frustrating because they then sometimes felt that they were not perceived as being as reliable as others in the group. Reassurance to return and re-engage was required in these situations and particularly so for parent consumers who sometimes felt that their attendance could be judged as a measure of their coping and parenting abilities.

Built into the COPMI Consumer and Carer Participation Strategy was the ability to move between levels of participation and in and out of participation according to the needs of participants. This flexibility provided a safety net so that people did not feel absolutely locked into a term of participation and it alleviated some of the stress and anxiety if circumstances prevented their attendance. People were encouraged to participate but were reassured that if circumstances prevented engagement in one form there were other options available to them to provide their input and influence decisions.

At times a consumer or carer may have been unwell personally but overcame their problems to give to the program - even if it took great effort to do so’ (Participant. 2009).
An adequate pool of participants was thought to be essential so that individuals were not asked to participate too frequently and therefore provide a guard against burnout. This also reduces any expectation that a participant ‘represents’ a group of others. One consumer mentioned that in a previous participant role she felt unable to be assertive enough to refuse a request for participation as she knew the organisation had so few willing participants. When this is the case, it is a threat to sustainable participation as participants may struggle to juggle participation along with all their other commitments and their personal needs. Adequate numbers of participants also allows and encourages peer support. It was planned to always have more than one consumer and carer participant at meetings both by teleconference and face to face.

Telephone conferencing and use of electronic discussion forums (e.g. wikis) were utilised to assist consumers and carers to participate from a range of locations across Australia and (in the case of wikis) in their own time and at their own pace. A wiki was also used in an anonymous Delphi study that sought to determine the key elements that would be incorporated into the COPMI e-learning resource for the mental health workforce. The participants in the Delphi study represented a wide range of expertise including mental health workers, consumers, carers, workforce facilitators and academics but the anonymity associated with the process was designed to assist participants to feel that their view was of equal value to others on the group (Whitham et al. 2009).

*The unique thing about it was that even after people started using their own names there was no differentiation between a worker and a consumer/carer. This allowed everyone to feel safe with no pre-conceived ideas or discrimination regarding who they were* (Participant, 2008).
Assistance with technology through clear information, one-on-one help and access to courses where necessary, value added to participation. Several COPMI staff skilled in using various methods of technology made time available to discuss particular issues with participants if they arose.

- **Culture of the organisation.**

All COPMI staff members are involved with participants to varying degrees and therefore have needed a good understanding, empathy and available support for these interactions. The culture of inclusion has been promoted by management and supported by the Consumer and Carer Participation Officer keeping all staff informed of participant’s activities and feedback. Staff members were made aware when participants’ circumstances such as their caring role may have changed as this could either decrease or increase the amount of support that they needed. Such awareness contributed to all involved feeling more comfortable and strengthened the participation partnership.

The organisational culture was also been supported by the consumer and carer participation policy that clearly outlined the extra supports that may be needed and are available particularly if someone is facing participation challenges. Staff were encouraged to work with participants from a strength based focus and this attitude has been important in assisting to lessen the power inequity that can occur between staff and participants and to avoid perceptions of both consumers and carers as ‘victims’. A strength based perspective focuses on participants’ skills and expertise and then aims to value add to these throughout the process of participation. This focus has been particularly appreciated by some of the young carers involved in the participation process.

...(in other arenas) it is (wrongly) assumed that we should feel sorry for young carers because they are ‘brave battling young people’ who need hope (Participant, 2009).
The Consumer and Carer Participation Officer had the greatest responsibility within the COPMI team for direct engagement with participants but was also responsible, in association with the Project Manager, for assisting other staff to develop and maintain a culture where everyone could learn and reflect upon their experiences of consumer and carer participation. This involved briefing of staff, development of appropriate procedures and discussions at team meetings of issues as they arose. The role of participants within the initiative was clearly articulated so that staff members were aware that participants were involved as consultants through their expertise in their role as a consumer, carer or young carer that had been earned through the hard work of personal experience.

*It helped me to talk to others about my engagement with participants because my professional (clinical) training hadn’t prepared me well for it. It was obviously inappropriate to relate to participants as if they were my clients but they weren’t strictly my colleagues and neither were they my friends. Procedures put in place and discussions in the team meetings helped me with issues like how to respond appropriately to a participant that I knew was currently unwell* (COPMI staff member, 2009).

Members of the COPMI staff strive to incorporate continuous evaluation of the involvement of consumers and carers by the participants themselves, recognising evaluation as a necessary step to improving aspects of participation.

*COPMI is at the cutting edge of consumer and carer participation, however striving for continual improvement is commendable* (Participant, 2009).

**Examples of Participation**

An example of COPMI consumer and carer participation is the development of the e-Learning Resource. A diverse group of participants and professionals was involved from the outset to ensure that many perspectives were heard. This included young carers who were
engaged through the support worker of their parent or through designated young carer workers in the community. People were notified of the opportunity to participate through networks, organisations, word of mouth and the COPMI website.

Consumers and carers were involved in numerous ways including, Workforce Development Consultation Group and Information Resource Development Consultation Group meetings by teleconference, the Delphi study to determine key elements of the planned e-Learning resource, a Lived Experience Group that met face-to-face to advise the resource developers, provision of video and audio recordings, printed word and designing questionnaires for selection of trainers for the e-Learning resource.

Various groups of young carers were videoed and also engaged through focus groups for content of the resource. After discussions with Young Carer Workers, it was decided that utilising the Young Carer Workers to lead those groups would be the most suitable method of participation as young carers would then be in a familiar environment with a worker that they knew and trusted. The information gained was then more likely to be forthcoming and genuine.

Some participants contributed to one aspect of the resource such as a video or audio clip whilst others participated in several aspects or in the case of one consumer all aspects.

*In participating in this exciting new idea there has had to be voices from consumers and carers about their personal lived experience. In re-living these events or trying to explain what happens when unwell can be a big trigger for the consumer or carer. The role of the Consumer and Carer Participation Officer has been vital to assist with debriefing and reassurance in a caring way that helps the consumer or carer cope.*

*If a person who would normally attend a meeting or contribute in some way did not attend the person was contacted to ascertain they were okay and fill them in on the information that they had missed.*

*Carers and consumers were made to feel valued and important giving a boost to self-esteem and self-confidence. This included remuneration so that there were no ‘out of pocket expenses’.*
Consumers and carers were so enthusiastic and hopeful that this e-learning resource would broaden and help all workers relate to their clients and their families. At times a consumer or carer may have been unwell personally but overcame their problems to give to the program.

Throughout the whole process I have been proud to be involved. I have told many people that I have been a consultant in putting this program together and that I am excited that the whole process has included and valued my contribution. I want everyone to know that COPMI have not been tokenistic at any time they have actually been bold and insightful by including not only professionals but consumers and carers.

I can foresee many benefits for the future mental health workers after completing this e-learning resource. One of the most difficult things to cope with when having a mental health issue is that there seems to be NO HOPE but this program has the potential to help many and give hope to all involved (Thoughts from a participant involved in developing the Workforce e-learning resource development, 2009)

Benefits of the COPMI Initiative’s Participation Approach

- **Benefits To Consumers and Carers**

Some consumers and carers have reported increased confidence as a result of their engagement with the COPMI initiative and that their participation has lead to an increased hope that there will be improved and more inclusive consumer and carer participation generally across government and non-government initiatives and services. Other benefits mentioned by consumer and carer participants include having a valued role that will have practical outcomes, that promotes a sense of achievement.

There are many things that motivate me and I am inspired every time we catch up for a meeting but for me as a consumer, my main focus is to produce a really useful, practical resource for parents with a mental illness (Participant, 2009)

It was good to be able to give an opinion, to be involved in something that will help other families with mental illness and to feel useful for a change (Participant, 2009)
Participants have also been able to add their experience at the COPMI national initiative to their resumes and utilise the COPMI Consumer and Carer Participation Officer as a referee.

As participants increase their skills they are more likely to move on to take up other opportunities, but if participation has been mutually beneficial it is likely that they will alert others to participation opportunities at the COPMI national initiative. Participants deciding to leave their engagement roles can be perceived as a negative outcome by some organisations. However, at the COPMI initiative it has been welcomed and recognised as a benefit as it indicates that participants may have gained more skills to contribute elsewhere in the community and this natural attrition also provides an opportunity to engage with new participants and to learn from them.

- **Benefits to the COPMI national initiative**

  The benefits of strong consumer and carer participations to the COPMI national initiative have been numerous.

  The initiative has been able to access a diverse, able and generous pool of participants to enhance the planning, implementation and evaluation of the key outcome areas of the initiative.

  Partnerships have been formed that have been mutually beneficial and that provide sustainable participation throughout the development of resources: in the case of some participants this has required participation over an eighteen month period.

  The voice of lived experience permeates throughout the COPMI information and workforce development resources, assisting in building the credibility of the COPMI initiative’s products. The consumer and carer participants have assisted with the
promotion of resources as those who have engaged well become enthusiastic ambassadors for the initiative.

Some of the participation processes in themselves also provided valuable promotion opportunities for the COPMI initiative and its resources (for example the call for participants).

The Challenges That Remain

Although males have been effectively engaged in a number of the COPMI consumer and carer participation options, females still greatly outnumber them. This could be due to a number of factors including gender role perceptions, a perceived incompatibility of consumer and carer participation with full-time work, and fathers with mental illness who have infants being less easily identifiable to service providers than mothers. However, difficulties in engaging fathers is a common feature of the childhood and parenting arena and additional strategies are required to support such involvement. (reference required - Fletcher EF to find).

The increased participation of children (under 18 years) is another challenge for any future phases of the COPMI initiative. In previous phases, much of this has been accomplished only via the goodwill of local children’s program facilitators or young carer workers who have kindly assisted with focus groups of children and who have supported several youth peer researchers.

People from CALD and indigenous backgrounds have been involved as participants in the COPMI initiative; however we would like to increase this in future.

One further challenge is how to increase many participants’ recognition of the reciprocal nature of the responsibilities of engagement. Whilst justly claiming the need for organisational cultural support, flexibility and remuneration for their valued role, some
participants still require greater assistance to recognise that these ‘rights’ come with reciprocal responsibilities to provide what they have contracted to undertake. For example, on occasion, participants have needed to be reminded that the ability to negotiate flexibility in time lines does not mean that a participant can simply choose not to undertake work that they have previously and formally agreed to.

‘Engagement goes further than participation. It conveys the idea that someone is occupied, focused and committed to an issue’ (Gregory, J, p.9).

**Conclusion**

The COPMI national initiative has sought to involve mental health service consumers and carers at all stages by providing them with flexible participation options and dedicated support within a supportive organisational culture. The resultant participation has been an influential and integrated component of the process of the development of COPMI resources. The voice of lived experience has added value and meaning to this mental health promotion initiative but has required planning, an integrated and respectful approach and a designated contact person and resources. It also required flexibility and the provision of opportunities for people to participate in a variety of valued roles that have resulted in practical outcomes and allowed for differing levels of participation to suit individual’s circumstances. Building and supporting an organisational culture that is respectful and strength focussed has also been found to be supportive, he COPMI national initiative’s experience adds to the body of knowledge that is building as consumer and carer participation becomes more integrated across the mental health sector.
It is hoped that others seeking to engage consumers and carers (including young carers) in mental health promotion initiatives that respect, remunerate and integrate participants into their structures and processes can benefit from the reflections contained within this paper and incorporate the following key points into their approach:

- A designated person resourced to specifically support participation
- An adequate pool of participants to guard against participant ‘burnout’ and to ensure that a range of perspectives are gained rather than expecting one participant to represent a range of views and experience.
- Planned consumer and carer participation across their organisations as an integrated strategy rather than an add-on component.
- Asking participants, ‘how can we do it better?’, hearing the answers and acting upon them will assist meaningful participation, as will feedback that is acknowledged, discussed and incorporated into future participation wherever possible.
- Acknowledging participants equally with other experts who have had input and keeping them informed about progress and outcomes.

Finally, it is recommended that others involved in consumer and carer participation in mental health promotion initiatives also take the time to reflect with their participants and document their successes and areas for improvement. Sharing what they have learnt and the approaches they have undertaken will assist the broader mental health promotion community to address the challenges inherent in consumer and carer participation and to help make policy become practice.
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National Service Framework for Mental Health – UK


