

Health Consumer Engagement Strategy

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1. Background

The Australian Primary Care Collaboratives (APCC) Program encourages and supports Primary Care Health Services throughout Australia in delivering rapid, measurable, systematic and sustainable improvements in the care they provide to patients, through the sound understanding and effective application of quality improvement methods and skills. At the core of the APCC Program has been a focus on ensuring systems change is for the benefit of health consumers and patients, including improving access to care and improving health outcomes.

Improvement Foundation (IF) recognises that health consumers (including patients) have been effectively engaged in quality improvement initiatives overseas, and the important role that health consumers can play in the improvement of healthcare delivery. In the APCC Program, IF included health consumer engagement for the first time in the Chronic Obstructive Pulmonary Disease (COPD) and Chronic Disease Prevention and Self-Management (CDPSM) Wave. In this Wave, health consumers were invited to attend and actively participate in learning workshop events, playing an integral role as part of the Division of General Practice (Division) team. At the learning workshops, the health consumers actively contributed to practice team discussions, attended breakout sessions, supported practices to develop ideas to test, and had the opportunity to network with other health consumers. Based on their experience navigating the system of care, the health consumers were able to contribute ideas for improvement to their Division team. Primary Care Health Service participants were largely very positive and accepting of the introduction of health consumers to the Program; however, some clinical staff were hesitant to receive feedback from health consumers.

To better understand the value-add for health consumer engagement in the APCC Program, IF conducted a patient engagement workshop following the COPD and CDPSM Wave with a selected number of health consumers, clinicians and Division staff that participated in the Wave. The purpose of this workshop was to discuss key strategies and recommend improvements for involving health consumers in future waves of the APCC Program.

In addition to the COPD and CDPSM Wave, IF worked with Primary Care Health Services to engage health consumers as part of the eCollaborative – 21st Century Patient Care and Self-Management Wave (eCollaborative Wave). The eCollaborative Wave, which was funded by the National E-Health Transition Authority and delivered by IF, focussed on improving chronic disease care and self-management using technology. Each Primary Care Health Service participating in the eCollaborative Wave was required to engage health consumers; an important element of this activity was to engage consumers that have a chronic disease to attain an understanding of their knowledge and experience with consenting to register and use a Shared Electronic Health Record (SEHR).

At learning workshop five (a national level face-to-face workshop) of the eCollaborative Wave, three health consumers presented during a plenary session about their experience with using a SEHR. These health consumers discussed the benefits of using a SEHR, in particular the feeling of empowerment experienced through this process. This empowerment related to having access to their health records and, more importantly, to being consulted in a meaningful way with their healthcare provider in decisions that affected their wellbeing.

The learnings and insight acquired by IF through the health consumer engagement process in the first eCollaborative Wave, as well as previous APCC Waves and the patient engagement workshop have been used to develop this Health Consumer Engagement Strategy, which provides a recommendation for health consumer engagement in Phase Four of the APCC Program.

2. Methodology

This document builds upon the 'APCC Health Consumer Engagement Strategy' that was submitted to the Department in October 2011. Further refinement of the strategy has occurred following a comprehensive consultation process, which involved input from:

- IF clinical and senior staff
- Clinical lead for the eCollaborative Wave
- eHealth Program Manager and a Collaborative Program Manager based at a Medicare Local participating in the eCollaborative Wave; and
- Input and review by a Primary Care Health Service and health consumer involved in the COPD and CDPSM Wave and eCollaborative Wave.

IF has also undertaken internal research and review of feedback received from previous health consumer engagement, as well as considering changes that have occurred in the environment. Of particular note is the formation of Medicare Locals and the culture shift in primary healthcare with a greater focus on the provision of patient-centred care, and engagement of empowered health consumers.

3. Introduction

The APCC Health Consumer Engagement Strategy seeks to strengthen health consumer representation as part of the overall approach to Program planning and delivery. Research and practical experience in North America and the United Kingdom indicates that patients can become key decision-makers in the care process. By ensuring that knowledge of their condition is developed to a point where they are empowered to take some responsibility for its management and work in partnership with their health and social care providers, patients can be given greater control over their lives.¹ By integrating health consumer engagement in the Collaborative methodology, the ability for the Program to ensure that systems change is consumer-centred can be strengthened, helping to further improve health outcomes.

Through previous Collaborative waves and health consumer engagement workshops, IF is aware that a considered approach is needed to develop an approach to health consumer engagement that overcomes the barriers of patient/doctor relationships and engages health consumers effectively in the quality improvement journey.

In the APCC Program, health consumer engagement serves a number of purposes:

- Ensures a health consumer-centred Program
- Involves health consumers as key decision-makers in the care process through a greater focus on empowering consumers to support self-management of chronic disease in Program topics; and
- Adds a health consumer perspective to change ideas and innovation.

The focus of this strategy is the role of health consumers in the Collaborative methodology. This strategy does not seek to describe the role of health consumer engagement in the wider primary healthcare sector, including the role of health consumers in the clinical encounter or as part of consumer advisory groups.

¹ Magura, C. (2009). *Chronic Disease Management – The Expert Patient*. Disabled World. Retrieved 11 December 2012, from <http://www.disabled-world.com/health/chronic-disease-management.php#ixzz2EdUBxvAE>.

In the APCC Program, the successful engagement of health consumers is based on the following principles:

- A clearly defined scope for health consumer engagement that fits within the framework of the Collaborative methodology
- A flexible approach to health consumer engagement that works in partnership with local support structures, including Medicare Locals, National Aboriginal Community Controlled Health Organisation (NACCHO) State and Territory Affiliates, and Primary Care Health Services
- A commitment to working in partnership with health consumers, using a supportive approach based on open and transparent communication, and ensuring their individual opinions and needs are respected; and
- The active participation of health consumers as an integral component of system improvement in primary health care.

This strategy will include the following elements:

- Identification of the role of health consumers in the Collaborative methodology
- Discussion of the key considerations that need to be taken into account when involving health consumers in future Collaborative waves, including health consumer selection and the influence of wave design on consumer involvement
- Consideration of the role of health consumers in Medicare Local level quality improvement initiatives; and
- Recommendations for health consumer engagement in Phase four of the APCC Program.

4. Role of Health Consumers in the Collaborative Methodology

The following sections will consider the role of health consumers in the various aspects of the Collaborative methodology, including:

- Topic development
- Learning workshops
- Activity periods.

Additionally, this section will outline the key considerations that need to occur from a design perspective if health consumers are to be effectively engaged in the Collaborative methodology, including:

- Health consumer selection
- Training and support
- The influence of wave design (on consumer involvement).

2.1 Topic Development

The Collaborative methodology uses a complex learning and change management process, which is based on a robust framework that is developed using an Expert Reference Panel (ERP) approach. Once a topic is selected for the Program, an ERP is formed to consider available evidence in the relevant topic area and ensure that such evidence is appropriately translated for the implementation environment.

An ERP consists of committee members with content expertise and application expertise. Content expert committee members are people with expert knowledge in the area of the topic, possibly through research related experience. Application expert committee members are people with expert

knowledge in the application of evidence related to the topic area, such as general practitioners, practice nurses and practice managers.

Under the leadership of the ERP Chair and the Program Clinical Director, the ERP recommends the aims, measures, change principles and change ideas for each topic. This work is then compiled into the Program handbook.

Based on their unique view of the health system, health consumers could offer substantial value to the ERP process. Health consumers generally have expertise navigating the system of care and those with a disease condition(s) are often experts in the self-management of their condition(s). Consequently, health consumers could contribute to shaping the design of the relevant topic area, including the change principles and ideas, and adding practical content (such as examples and resources) to the handbook.

The role of the health consumer could commence at the start of the planning phase of any wave. Identifying and inviting a suitable health consumer(s) to contribute at the ERP is acknowledging the value of the consumer from the onset. At the ERP meeting, where panel members discuss and agree on recommendations for the topic aim, change principles and measures, health consumers would have an ideal opportunity to represent the 'consumer view'.

In addition to the topic aim, the ERP could also consider the development of a collective aim for health consumers participating in the Program, as well as measures that can be used to monitor and evaluate health consumer participation and outcomes.

2.2 Learning Workshops

The ability for health consumers to assist Primary Care Health Services with understanding the impact of their planned changes from a consumer point of view and to contribute ideas and examples is most clearly evident at learning workshops. As mentioned earlier, the COPD and CDPSM Wave included the involvement of health consumers at learning workshops as part of the Division team. Additionally, the eCollaborative Wave involved health consumers in local engagement activities and some health consumers also participated in the workshops as presenters. In IF's experience, where health consumers are engaged in the Collaborative methodology, their active involvement at learning workshops is considered to be valuable and supports the inclusion of the consumer as part of the team.

The inclusion of health consumers at learning workshops requires a considered approach and additional training and support for the health consumer, the Support Organisation (Medicare Local and NACCHO State Affiliate), and the Primary Care Health Services participating in the wave. The following list presents a range of ideas that support the involvement of health consumers at learning workshops and is not intended to be exhaustive:

- Orientation to the purpose of health consumer engagement and the role of consumers at workshops for the participating health consumers, Support Organisation staff and Primary Care Health Services.
- Dedicated training for health consumers prior to each learning workshop to outline expectations, roles and responsibilities, and provide them with the knowledge and skills to effectively undertake their role. This training can include information on the Program fundamentals, such as the Collaborative methodology and the Model for Improvement.
- Provision of pre-workshop materials, training and teleconferences to equip health consumer with the appropriate knowledge.
- Availability of dedicated Program staff at workshops to support health consumers.

- Involvement of health consumers in the development of the workshop agenda and the development of 'health consumer friendly' agendas that provide consumers with further information on the content of each session and suitable times to take breaks, if required.
- Additional team time for health consumers to discuss issues and provide feedback on their involvement. This also an opportunity for health consumers to come together as a 'consumer team' to share ideas and experiences, work on their own improvement journey and form a community.
- Involvement of health consumers in plenary and breakout sessions focused on exploring their experiences and gaining an understanding of the topic from a consumer's perspective. This could include health consumer led breakout sessions and the involvement of consumers as keynote speakers.
- Availability of a lounge to enable health consumers to rest during the workshops and provide an opportunity to network.

2.3 Activity Periods

Activity periods are the episodes of time between and after learning workshops, which enable Primary Care Health Services to test change ideas and submit data to monitor the impact of their changes. The role of health consumers during activity periods requires a flexible approach that is determined in partnership with the health consumer, local Support Organisation and Primary Care Health Services based on their capacity and capability. Medicare Locals, for example, will be required to establish processes to effectively engage with health consumers. The role of health consumers during activity periods could fit within the framework of this local engagement.

In the COPD and CDPSM Wave, health consumers had varying levels of involvement during the activity periods, which depended on the needs and capabilities of the individual consumer, Division and participating Primary Care Health Services. Some of the mechanisms used to engage health consumers during the activity periods included:

- Involvement in local activity period meetings where they had further opportunities to contribute to the Primary Care Health Services' ideas for change and learn about the results of their change efforts.
- Engaging health consumers as advisors by allowing them to provide their perspective through talks and presentations to Primary Care Health Service staff, Support Organisations and consumer groups.
- Enabling health consumers to provide feedback and act as a sounding board for change ideas and processes designed by Primary Care Health Services.
- Engaging health consumers to assist with the development of resources, including Support Organisation newsletters and health literacy material.

2.4 Health Consumer Selection

Involving health consumers in the Collaborative methodology will require them to participate in a variety of activities, including attending learning workshops where they could be engaged by clinicians to develop change ideas that would impact on service systems or workflow. Consequently, the selection of appropriate health consumers is an important consideration.

In the COPD and CDPSM Wave, participating Divisions recruited one health consumer per Divisional group of up to seven Primary Care Health Services, and two health consumers (or a patient and their carer) for Divisional groups greater than seven Primary Care Health Services. Although IF provided supporting material for health consumer recruitment, including guidelines and interview questions to determine suitability for participation, the Division made the actual selection. Additionally, the

criteria to determine suitability was broad, and some Divisions recruited health consumers that had been involved in consumer groups, whereas other Divisions recruited consumers with no prior experience. The selection of health consumers influenced the ability for some consumers to engage with the Divisional group and provide input.

Health consumers engaged in the eCollaborative Wave were recruited via the participating Primary Care Health Services. Health consumers were invited to participate in health consumer engagement activities, in many instances by their general practitioner or the practice nurse. This strategy proved successful, possibly due to the established relationship and foundation of trust between the health consumer and the service.

The following is a list of considerations that need to be taken into account during the selection process:

- Previous experience held by the health consumer and its influence on the consumer's ability to understand the role and contribute to the team.
- Previous experiences held by the participating Primary Care Health Services with regards to consumer engagement and any influence this has on the process. Primary Care Health Services need to understand the benefits of engaging health consumers and the contribution they can make to the Program.
- The impact that health consumer engagement can have on the team dynamics at workshops and during activity periods. Engaging participating Primary Care Health Services in the selection process may be an appropriate way of addressing this impact.
- The ability for the health consumer to contribute ideas and act as a sounding board, and their availability to be involved for the duration of the wave.
- The availability of health consumer advisory groups at the Medicare Local level. Where these exist, it may be useful to utilise their expertise and understanding of the local environment, as this can contribute to local level quality improvement work.
- The inclusion of health consumers from marginalised groups, which can provide a more holistic perspective when identifying barriers and developing ideas for change.

Another important consideration is payment for health consumers' time to participate in the Program. In the COPD and CDPSM Wave and eCollaborative Wave, travel and accommodation for health consumers was funded, but consumers were not paid for their time. The payment for consumers that are involved in a given wave needs to be identified as part of the wave design, taking into consideration their role in the wave.

2.5 Training and Support

Health consumers need to receive appropriate training and support to enable them to contribute effectively to the APCC Program. Additionally, participating Support Organisations and Primary Care Health Services also require training to ensure they understand the role of the health consumer and see their involvement as being beneficial to the quality improvement process. The following list presents some ideas for training and support:

- Orientation sessions for Support Organisations and Primary Care Health Services to include information on the role and scope of health consumer engagement.
- Training for health consumers to equip them with knowledge and skills to actively share ideas and provide input to the development of change ideas during team time. This training could include, but is not limited to, the Collaborative methodology and the health consumer's role within it, the Model for Improvement and other quality improvement tools, introduction to general practice and its systems, and practical approaches to providing ideas for change.

- Development and training of a health consumer network to offer peer support.
- Involvement of health consumers that have previously been involved in the Program to share their journey and offer peer support to new health consumers and Support Organisations.
- Development of an engagement change principle that includes ideas and examples focused on engaging health consumers in service redesign. Alternatively engagement ideas could be included within an existing change principle.
- Providing training and access to the IF Web Portal for health consumers. This would enable consumers to view resources, access appropriate discussion boards and contribute their own PDSAs. Where appropriate, consideration can also be given to providing access for health consumers to view their Primary Care Health Services' PDSAs, enabling them to provide input and feedback, and contribute further ideas.
- Training on social media forums such as Twitter so health consumers can contribute to discussions incorporating their perspective.

2.6 Influence of Wave Design

The design of the wave can have an impact on the level and role of health consumer engagement. In the COPD and CDPSM Wave, for example, health consumers were principally engaged during the three learning workshops, which were of two days duration each. This enabled the consumers to develop as part of the Divisional team. In other Collaborative waves (such as hybrid waves) there is less direct contact time and this may have an impact on the ability for health consumers to form relationships with the participating Primary Care Health Services, influencing their confidence and comfort with contributing ideas.

There are a number of considerations when engaging health consumers in different types of Collaborative waves, and strategies to foster engagement including:

- The availability of sufficient contact time to develop relationships. Where there is less formal contact time (e.g. during the one day learning workshops used in the hybrid wave), relationship building may need to be fostered at a local level with all parties committed to the process.
- Incorporating feedback mechanisms for health consumers that participate in a wave to provide these consumers with the outcomes of their participation. This will give health consumers a tangible outcome, and a sense of purpose and achievement in their contribution.
- Linking with local structures at the Support Organisation level to foster ongoing engagement after the completion of a wave. For example, Support Organisations can consider the ongoing involvement of health consumers in line with their local health consumer engagement framework and articulate the possibilities for continuing engagement clearly with the consumers.

5. The Role of Health Consumers in Medicare Local Quality Improvement Initiatives

Medicare Local Waves provide an opportunity for Medicare Locals to engage with their Primary Care Health Service professionals to identify health priorities of the community through examination of local demographic and clinical data, and develop a Quality Improvement Plan to address these priorities. IF considers that there may be scope in these waves to engage health consumers at a local level to support the development of locally focused and responsive services that improve care in the management and prevention of chronic disease. Health consumer input would contribute towards

the aim of these waves, which is to 'Achieve better outcomes in local primary healthcare through the use of quality improvement'.

The above considerations around the role of health consumers during topic development, and at workshops and activity periods should be considered as part of a Quality Improvement Plan that engages health consumers. Medicare Locals may be able to link with existing health consumer groups, which may have a good understanding of the local health environment, to identify health consumers that can contribute to the development of Quality Improvement Plans and engage in the activities outlined in the plan.

In addition, the considerations of health consumer selection, training and support, and design of the quality improvement initiative are equally pertinent.

6. Recommendations

Based on the methodology described earlier in this strategy, IF has developed a number of recommendations to enhance the role of health consumers in the Collaborative methodology and Medicare Local quality improvement initiatives. These recommendations cover the areas of:

- Topic development
- Learning workshops
- Activity periods
- Health consumer selection
- Training and support; and
- The influence of wave design on consumer engagement.

3.1 Topic Development

IF considers that health consumers can be engaged in the topic development component of a wave using the following approaches:

- Include health consumer representation on an ERP
- Encourage active contribution of ideas and examples to shape the design of the relevant topic area and add practical content to the handbook
- Develop aims related to health consumer engagement, as well as measures to monitor engagement
- Develop an engagement change principle or include engagement ideas in an existing change principle; and
- Where relevant, include health consumers at the local level to assist with the development of Medicare Local Quality Improvement Plans as part of the Medicare Local Waves.

3.2 Learning Workshops

The following recommendations can be used to encourage health consumers to play an active role at learning workshops:

- Provide participating health consumers, Support Organisations and Primary Care Health Services with an orientation on the role of health consumers
- Have dedicated Program staff available at workshops to support health consumers
- Provide dedicated training for health consumers prior to learning workshops
- Provide opportunities for health consumers to have dedicated breakouts and team time
- Provide a health consumer lounge at workshops
- Involve health consumers in the development of workshop agendas

- Consider the inclusion of health consumer led breakout sessions and health consumers involved as keynote speakers; and
- Encourage health consumers to participate in priority workshops held as part of Medicare Locals' Quality Improvement Plans.

3.3 Activity Periods

The following recommendations can be used to engage health consumers during activity periods:

- Involve health consumers in local activity period meetings
- Utilise health consumers as advisors by encouraging them to provide their perspective through presentations and involve consumers at the practice level where they can contribute to the quality improvement process
- Develop feedback mechanisms that provide consumers with the outcomes of their contributions and wave level improvements; and
- Engage health consumers with the development of resources.

3.4 Health Consumer Selection

The selection of health consumers requires careful consideration. The following recommendations can guide the selection of consumers in the Collaborative methodology and local quality improvement initiatives:

- Consider previous experiences held by health consumers and their ability to understand their role and contribute to the team
- Consider the experiences held by Primary Care Health Services with regards to health consumer engagement, and articulate the benefits and contribution of health consumers to the quality improvement process
- Engage Primary Care Health Services in the selection process
- Consider the ability of health consumers to contribute ideas and act as a sounding board
- Ascertain the availability of health consumers to be involved for the duration of the wave
- Consider whether payment for health consumers' time to participate at workshops is appropriate
- Explore the participation of health consumers from marginalised groups; and
- Link with existing health consumer advisory groups at the Medicare Local level.

3.5 Training & Support

The following recommendations can be used to ensure health consumers have appropriate training and support:

- Ensure the health consumer perspective is intrinsic to all aspects of training for Support Organisations and Primary Care Health Services
- Develop a health consumer network to offer peer support and training to health consumers commencing a wave
- Provide information on the role and scope of health consumer engagement during the orientation sessions for Support Organisations and Primary Care Health Services
- Train health consumers in the Program, including the Collaborative methodology, Model for Improvement and other quality improvement tools
- Provide health consumers with appropriate training and access to the IF Web Portal; and
- Provide health consumers with training on social media forums such as Twitter.

3.6 Influence of Wave Design

As previously mentioned, the design of a wave can have an impact on the level and role of health consumer engagement. The following recommendations can be used to foster engagement:

- Where direct contact time is limited due to wave structure, include strategies to foster relationship building between health consumers and Primary Care Health Services at a local level.
- Assist Support Organisations with considering the ongoing involvement of health consumers in line with their local health consumer engagement framework.
- Ensure feedback mechanisms are designed to provide health consumers with the outcomes of their contribution, even after wave completion.

IF considers that health consumers can play a valuable role in the Collaborative methodology and Medicare Local quality improvement initiatives through the various recommendations described in this strategy. It is important that the engagement of health consumers in the Program follows the principles outlined in the introduction, and IF will work with the Department of Health and Ageing to identify suitable opportunities to involve health consumers in future waves of the Program.