

The NEMICS Consumer Reference Group (CRG) and the directorate team co-design workshop report

Background

A strategic goal of NEMICS is to work with cancer service providers in the north eastern region of Melbourne, to deliver optimal care and improve consumer experience and outcomes. For the NEMICS network to achieve its strategic goals there is a need for the directorate and key stakeholder groups to work more closely in the development of ideas, projects and initiatives.

On 18th June 2015, members of the Consumer Reference Group (CRG) and the directorate participated in a workshop aiming to enhance the contribution of the CRG to the work of NEMICS.

Objectives

The objectives of the session were to:

1. Explore the current relationship between the CRG and the directorate in order to evolve and extend the relationship in a way that better suits the needs, abilities, maturity and mandate of both groups.
2. Build common understanding of the changes that may need to happen to enable a more mature exchange of value between both groups.
3. Prototype a project planning process that enables both groups to work effectively, efficiently and collaboratively.

What do we offer to each other?

The participants agreed that consumers offer a special perspective that is distinctly different from that of health professionals. What makes the consumer perspective unique, is the first-hand existential experience of cancer and the experience of cancer service delivery with all the interactions that that entails. These experiences place the CRG members in a position to offer an authentic, genuine and credible voice to the NEMICS network. The consumer perspective is crucial as health services and the NEMICS network projects may be well intentioned in the pursuit of safe and high quality of care but also need to consider the direct impact on the consumer experience, outcomes and choice.

In addition, the CRG offers the power of a collective consumer voice which brings about a greater potential for influence. Specific skills that participants identified that CRG members offer, include: advocacy (many have received specific training in consumer advocacy), translating policy and medical jargon into plain English, and involvement and links with other consumer advocacy groups, organisations, committees (and thus a mechanism for wider consumer reach). There can also be a greater role for the CRG members to act as spokespeople for NEMICS work.

The following is what the participants identified the directorate team offers to the CRG: access to policy makers and clinicians and access to information that enables meaningful contribution, a forum for collective consumer voice to be heard, direction, education (funding opportunities to attend educational courses in consumer advocacy), opportunities to contribute to service improvement initiatives, support and encouragement. The directorate team are seen as a conduit between the CRG and a broader cancer system, to enable the group to meaningfully contribute.

Attendees agreed there are opportunities for the CRG's collective and individual skills to be utilised more than they are currently. The CRG members expressed some frustration at not being able to contribute meaningfully to the work of the Clinical Reference Group.

Ideas for change – what can we do differently?

The participants worked in mixed groups to identify what can be done differently to unlock greater value in the relationship between the two groups. Overall, the participants agreed to work on creating more opportunities for informal contact with the broader directorate team and consumer community.

Furthermore, the following ideas were identified:

- More information about current initiatives and projects including context to flow to the CRG.
- Avoid 'lost in translation' situations - make more effort to translate cancer policies into what they really mean.
- Amend CRG ToRs to improve role clarity and fit with NEMICS organisational structure
- Identify where it would be value adding to engage CRG in concept development for projects and initiatives.
- More formal involvement of consumers in projects as advisors/champions.
- Improved project planning to allow appropriate length of time for consumer input and for the directorate to provide information.
- Provide more flexible options for communication i.e. blog, workspace for project plans and different platforms for raising ideas.
- Identify ways to minimise 'tyranny of the majority' on NEMICS committees and ensure consumers are welcome and encouraged to contribute
- Directorate staff and CRG members to have greater awareness of each other's skills and areas of interest.

A number of barriers to implementing these ideas were identified including:

- Time (both for the directorate to prepare the material and for the CRG to review larger volume of information),
- Limited opportunities for interaction and limited tools to communicate,
- committee meeting culture and leadership,
- Limited opportunity to influence projects mandated by the Department of Health and Human Services (DHHS).

The participants identified NEMICS project planning as the most opportune point to increase the interaction between the two groups that would unlock a greater value in the working relationship.

Prototyping the NEMICS project process

In this last session of the workshop the participants explored NEMICS project process prototype which includes the following steps and key activities:

1. Concept proposal:
 - a. Define the problem and the evidence to support it
 - b. Gather feedback and input
 - c. Create a project proposal
 - d. Define objectives
2. Scoping:
 - a. Relevant stakeholders are identified and consulted
 - b. Local data is explored
 - c. Undertake cost / benefit analysis
3. Approval:
 - a. Argue the case to the Governance Committee
 - b. Advocate for resources
4. Project planning:
 - a. Resources and budget are made available
 - b. Identify key project stakeholders
 - c. Set-up working parties and governance
 - d. Create communication strategy
 - e. Identify project risks and measures of success
 - f. Obtain broader stakeholder buy-in
5. Managing:
 - a. Complete activities as defined by the project brief
 - b. Managing risk
 - c. Monitor progress
 - d. Engage stakeholders
6. Evaluation:
 - a. Evaluate project outcomes against the measures of success
 - b. Complete a formal post project review if required

Following a brief presentation of the project process prototype, the discussion focused on identifying questions and points of interactions that will support robust contribution from the CRG.

The key questions covered in this session were:

- When, where, how and why can the CRG contribute?
- What is the desired level of contribution for each step of the project planning process using RACI framework (responsible, accountable, consulted & informed)?
- What are the questions that the directorate should ask the CRG at each stage?

- Will these contributions be the same for every project? How can we build a project model that is adaptable?

The CRG can generate their own ideas and concepts, as any network stakeholder can do. For CRG consumer-led projects, the CRG can be responsible for all project stages with the support of a project officer. Any ideas that have funding and resource implications are referred to the NEMICS program manager. For other projects the summary below captures feedback from the participants in relation to the discussion of the above outlined questions.

Concept proposal stage- “An idea is born”

The desired level of the CRG involvement at this stage was to be consulted and informed. It was suggested that this is an important stage of the project to have consumer input in a more formal way and that this is the stage that is currently most lacking the CRG input.

The questions that the directorate team should consider when presenting the project concept to the CRG are:

- What is the potential impact of this initiative on the consumer?
- What is the need for this initiative?
- Does this initiative resonate with an experience you (*consumers*) are aware of?
- Does this relate to anything else you (*consumers*) are aware of?

The following actions were recommended to the team to implement:

- Project officers to present the project concept to the CRG for discussion and input
- Introduce a *consumer project advisor* role. Consumers nominated to this role would become conduits between the project officer and the CRG for information and updates and would be asked to be present at any directorate project meetings where the project is discussed. More than one consumer may be involved depending on the project and time commitment required.

Scoping stage - “We get clear on the value of the idea”

The desired level of consumer involvement at this stage was to be consulted and informed. Scoping and concept proposal steps are often completed simultaneously. It is not expected that the project officer will do a formal presentation to the CRG at this stage, but rather work with consumer project advisors who will relay any important project information to the CRG.

The following questions identified as important to address from the consumer perspective:

- Can you (*project officer*) provide examples / stories to illustrate that this project / initiative addresses a true consumer need?
- Why is this project valuable to the consumer?
- What is the benefit and impact of this to the consumer?
- What are the important aspects of the project to consult the consumers for?

Approval stage- “We seek formal approval”

The desired level of consumer involvement at this level is to be informed. For the CRG Chair and delegate member who sit on the NEMICS Governance Committee, the level of involvement for them at this stage is accountable. The CRG identified that at this stage they can however help build arguments for the initiative if required.

Project planning stage - “Setting up for success”

The desired levels of consumer involvement in the project planning stage are for the CRG to be consulted and informed. The consultation could occur via the consumer project advisor role attending any formal meetings where the project is discussed. In addition, the CRG is seeking more opportunities for informal exchange of information about projects at this stage using different modes of communication. The CRG would also like to be informed if any projects or initiatives that were not successful in progressing to this stage.

The following questions could be considered when planning the project:

- What are project risks / measures of success?
- Who are project stakeholders?
- What level of involvement does the CRG want?
- How do they want to be kept informed?
- Who do you think would be interested in knowing about the project / being involved?

Managing stage - “Turning our idea into a reality”

The desired level of consumer involvement at this level is for the CRG to be informed and the mechanisms for this are the same as for the project planning stage.

The questions of interest in this managing stage are:

- How is the initiative progressing against its success measures?
- Are there any risks to the project that are creating problems?

Evaluation stage - “Measuring success”

The desired levels of consumer involvement in the evaluation stage are for the CRG to be consulted and informed.

The key questions suggested as being important to ask at this stage include:

- What has worked well in the project?
- Is there anything that could have been improved in the consumer engagement aspects of the project / initiative?

Actions following the co-design workshop

The following actions have been proposed as a result of the workshop:

1. Create more opportunities for informing and consulting the CRG via:
 - a. Enabling a workspace on the NEMICS website for consumers that will be accessible to the directorate team and vice versa. Project information

- can be posted on the workspace and consumers can use it to post their ideas and have conversations about topical issues outside the quarterly CRG meeting.
- b. Schedule informal but regular opportunities for the CRG and the directorate team to interact i.e. standing invitation to the CRG members to drop in the directorate office and the team to meet with the CRG members post their quarterly meetings.
 - c. NEMICS program manager to be invited to attend the CRG meetings and provide updates on broader NEMICS business.
 - d. Consumer engagement portfolio within the Directorate to continue being a primary conduit for information sharing between the two groups.
2. The directorate team to utilise consumer expertise and skills in plain language when writing materials for publication. Due to a potential volume of work for the CRG, the directorate team is asked to forward any requests via a single point of contact.
 3. Where appropriate, projects will be presented to the CRG at the concept / scoping stages. The following points explain the steps in the process and rationale:
 - a. This new process will provide a formal opportunity for the CRG to provide input into the project development.
 - b. Presentations should include appropriate background information including the history of the idea.
 - c. The directorate team will be asked to refer to the list of identified questions that are important to consider when developing any project.
 - d. Due to the potential volume of initiatives and projects it will not be feasible to have all work presented in this formal way.
 - e. With an increased flow of information about NEMICS initiatives between the CRG and the directorate team, consumers will be encouraged to be proactive in requesting projects to be presented to the group.
 4. Develop the role of the consumer project advisor. This role would:
 - a. Act as a consumer advisor to the project
 - b. Be an advocate for the project if required
 - c. Act as a conduit for information about the project between the CRG and the directorate team.
 - d. Attend meetings where the project is formally discussed throughout the life of the project.
 5. All NEMICS meetings where consumers are present ensure that:
 - a. For new committees or when consumers are present for the first time, the Chair introduces and welcomes consumers at the start of the meeting and that other members introduce themselves. This will signify to other committee members the importance of consumer contribution to ensuring NEMICS initiatives are creating positive impact on patient care.

- b. For more established meetings where consumers are part of the membership, the Chair ensures that the consumer voice is heard and that they have been asked for the view before discussion is finalised.
 - c. In addition, a list of instructions outlining best practice to support consumer participation in committees will be made available to the directorate team.
6. Create profiles of the CRG members and use this to inform the directorate team of specific experiences, skills and interests that consumers offer. This will support a targeted involvement of the CRG members into different initiatives depending on their skills and interests.
 7. Create a list of projects, portfolios and contact details that each member of the directorate is responsible for, to inform the CRG members and facilitate communication.

It is proposed that the implementation of these actions be evaluated with members of the CRG and the directorate team in September 2016.

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