

CMHDARN Research Forum Presentation 19 November 2013

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Deb has asked me to talk about a few things today regarding consumer involvement in research at Neami and to also provide an example demonstrating the importance of routine data analysis and how it can help to inform the practice of staff and outcomes for consumers.

What has Neami done to build consumer voice into research work?

Neami aims to ensure the research and evaluation projects we complete and those that are completed by external researchers within Neami are aligned with the values of consumer participation, i.e. have a strong emphasis on the voice of consumers informing all aspects of a particular project. We have a number of structures and processes to help ensure this is the case including:

- Research & Evaluation Framework
- Research & Evaluation Committee
- A Manager of Consumer Participation
- Completing projects initiated by consumer priorities
- Employing staff with a lived experience to work on projects

Research & Evaluation Framework

Neami's Research and Evaluation Framework is the organisation's key guiding document for all research and evaluation activity conducted within. The document discusses things like research directions, key priorities, decision making processes, outlines the process for reviewing external research requests and reinforces the importance of consumer participation being a key feature of all components of any study completed.

The Research Framework is reviewed and discussed at most meetings and is always evolving to ensure it remains relevant and current for the organisation and reflects current best practice for consumer participation in research. A key set of revisions that occurred recently was to strengthen the consumer voice in the document by further developing sections about consumer participation, reviewing the language throughout the document and getting detailed feedback from the consumer members on the committee. The NHMRC statement on consumer participation in research was the key reference which informed how the document could be improved. The document also outlines the key functions and role of the Neami Research and Evaluation Committee, of which I will speak about in detail now.

Research & Evaluation Committee

The Neami Research and Evaluation Committee is comprised of Neami staff, external academics (of which one member has a lived experience of mental illness) and consumers. Two positions on the committee must be filled by individuals with a lived experience and a meeting will not proceed unless consumer members are present. In instances where a consumer has left Neami this has not meant that they also have to leave the committee.

Consumer members sit on Neami's Research and Evaluation Committee and are provided additional mentoring and support to ensure they are able to actively participate and contribute to discussions. I meet with a new member prior to their first meeting, discuss the meeting with them after it finishes and provide other advice and support where necessary. Consumer members are paid for their time preparing for and attending the meetings.

The committee meets up to 4 times per year and acts as an advisory committee on Neami's research and evaluation work by helping to review external requests to conduct research, discussing the design of proposed internal studies, discussing processes associated with research, i.e. how to communicate the findings of studies, etc.

Objective four of the Committee is to promote the importance of consumer participation in research and evaluation by actioning the following tasks:

- Ensuring opportunities for consumer participation in the implementation of existing and proposed projects
- Reviewing research proposals to ensure they are aligned with the values of consumer participation
- Identifying potential research projects of importance to consumers

We have also developed an application form external researchers must complete before they can conduct research at Neami and a checklist for committee members to use when assessing projects. If there is no evidence of consumer involvement in the study design or consultation with consumers (where relevant) the committee is not likely to approve the research request.

Consumer Participation Manager and project worker positions

We have recently employed a Consumer Participation Manager to guide our approach to consumer participation across the organisation. Luckily for us she has an active interest in research so we will be actively consulting to ensure we have considered all potential options of embedding the consumer voice in research Neami undertakes.

In an upcoming research project 3 positions on the research team are for consumer researchers. They will play a key role in going through the informed consent process with consumers and administering a questionnaire which is reviewing the support provided to them by their support worker. The project will also include a consumer expert working group who will meet to review the study design, interview questions, etc, prior to the study beginning.

General

We recently surveyed 168 randomly selected consumers about their communication preferences for receiving information from the organisation. As part of the project we asked them if they would be interested in being involved more in projects and research undertaken by the organisation. We found that about 40% expressed an interest in being involved in research and project work either as a participant or as a member of the team. This demonstrates that consumer involvement is a priority for a

number of consumers and we need to ensure as many opportunities are provided as possible to ensure they remain engaged and interested.

I hope these examples give a bit of a picture of the type of work Neami has been doing to strengthen consumer participation in research and evaluation. We are not there yet in terms all aspects of our research including consumer participation at all levels but we have made significant progress in recent years and I can only see these initiatives being strengthened and new ones developed in coming years.

How does organisational approach to engaging consumer voice affect research and data collection?

So I'm sure we are all very aware of the benefits of consumer involvement in research, but I thought I would also share with you some of our experiences of how this approach can affect research and data collection. From our perspective the organisational approach to engaging the consumer voice in research and evaluation has achieved the following:

- Made research more meaningful and relevant to staff and consumers, which has resulted in CRSWs becoming more engaged in projects. If support workers feel that the consumer voice has been incorporated they are more likely to be supportive of a project and engage in the required tasks.
- The discussions at the Research Committee meetings, influence of NHMRC consumer participation guidelines and tools used to assess projects (approval form and checklist) has meant that the consumer voice is a key influence in deciding whether or not to approve or commence a particular research/evaluation project
- Can impact on designs of external researchers looking to conduct studies within Neami as we have given feedback in the past about research designs which have had to change due to not incorporating consumer voice. One example of this was related to numerous evaluations being conducted of a program involving consumers of Neami in Sydney. As a result of the feedback provided by the Research Committee we were able to influence the study design to ensure they methodology was more in alignment with actually answering the research questions and protecting consumers from having to complete a very intensive and somewhat invasive battery of assessment items. Were able to get researchers to incorporate more qualitative interviewing so the effectiveness of the program could be determined in a more meaningful way.

Linking between data analysis and informing practice

As far as the link between data analysis informing the practice of staff I have two examples I will provide. The first is very brief and related to the caffeine research project we recently completed. As part of the study we asked consumers how much they knew about the potential impact that caffeine can have on their medication. An overwhelming (70%) of the small sample of 59 people stated that they had no awareness of any impact that caffeine can have on the effectiveness of their medication. The response to this question has since informed the development of numerous resources and prompts for staff to refer to and guide their conversations with consumers regarding the potential risks of consuming too much caffeine.

A more detailed example (also related to consumer general health) that demonstrated the importance of regular data analysis informing organisational

priorities and staff practice was when valued life directions developed as part of the Compass (CRM Protocol) were analysed.

Feedback received from direct support staff revealed that a large proportion of their work with consumers was about supporting them to achieve goals made about improving their general and physical health. A detailed analysis of information collected through the Compass was required to determine the scale of this feedback across Neami.

- What we did:
 - Extracted data from consumer database
 - Categorised valued directions developed by consumers undertaken by two staff to ensure consistency in analysis
- What we found:
 - Analysed 3356 valued directions from 899 unique consumers (life priority areas which inform the development of tailored 3 monthly goals) collected between July 2011 and May 2013
 - Analysis revealed that 24% of all valued directions developed by consumers were related to general and physical health, things like: joining a gym, eating healthy, losing weight, quitting smoking, etc.
 - 2nd was daily living activities (19%) and 3rd mental health and well-being (18%).
 - The fact that the top rated goals were related to general and physical health is very meaningful considering the increased morbidity and mortality experienced by people with a serious mental illness are largely due to higher prevalence of modifiable risk factors, many of which are related to individual lifestyle choices, such as smoking, poor diet and exercise
- Next steps:
 - Information was presented back to staff teams and disseminated across the organisation.
 - The results further reinforced the organisations commitment to our health promotion strategy and the information gathered was particularly relevant for two initiatives including Peer Health Coaching and the use of the Health Prompt.
 - Peer health coaching involves a consumer who develops a health related goal receiving structured mentoring from a peer worker to help them achieve their desired health outcome. (pilot is currently being evaluated)
 - Health prompt is a discussion tool used between workers and consumers designed to keep people up to date with potential health issues, includes a series of yes/no questions. E.g. have you had your cholesterol checked? Is your waist measurement in the recommended guidelines? etc.
- The project ultimately reinforced that consumers have an interest in improving their general health and community based mental health organisations are ideally placed to support consumers in achieving these goals. It demonstrated that there is a need for organisations to ensure consumers interested in

improving their general and physical health have the necessary resources available to them so they can make improvements.