Health Consumers Queensland Impact Evaluation Project

Interim Report

Carolyn Ehrlich
Maddy Slattery
Kelsey Chapman
Elizabeth Kendall

January, 2018

Table of Contents

EXECUTIVE SUMMARY **5**
Qualitative interviews with HCQ staff and board **6**
Method 6
Summary of key findings 6
Qualitative analysis of accessibility of consumer engagement activities on publically available Hospital and Health Services Websites **7**
Method 7
Summary of key findings 7
Qualitative analysis of publically available consumer engagement policies **8**
Method 8
Summary of key findings 8
Preliminary qualitative analysis of consumer interviews **9**
Methods 9
Summary of key findings 9
Quantitative analysis consumer and staff surveys from PHNs and NGO **10**
Method 10
Summary of key findings for PHNs & NGO 10
Quotes that support the impact that HCQ is having across Queensland **11**
Interpretation of key findings with regard to the impact that HCQ is having on consumer and community engagement **12**
Next steps **13**
REFERENCES **14**

Abbreviations used in this document

CBD	Central Business District
DoH	Department of Health
GU	Griffith University
HCQ	Health Consumers Queensland
HHS	Hospital and Health Service
IAP2	International Association for Public Participation Spectrum of Engagement
NGO	Non-Government Organisation
PHN	Primary Health Network

EXECUTIVE SUMMARY

Health Consumers Queensland (HCQ) and Griffith University (GU) entered a contract in May 2017 to evaluate the impact that HCQ is having on consumer engagement in Queensland. However, data collection for this interim report has been delayed because of exceedingly complex ethics and governance approvals required before research and evaluation activities can be conducted. These approvals are mostly completed now, but despite best efforts were unable to be obtained in time to inform the current report. Therefore, additional information that assesses the impact of the work of HCQ in Queensland will be available in the next report.

Never-the-less, this interim report contains details from the following evaluation activities:

1. Qualitative interviews with HCQ staff, board members and consumers
2. Website review of publically available consumer engagement information on Hospital and Health Service websites throughout Queensland
3. Policy analysis of publically available policy documents from Hospital and Health Service websites throughout Queensland
4. Qualitative interviews with health consumers throughout Queensland
5. Quantitative surveys of consumers and staff from three NGOs in Queensland

Qualitative interviews with HCQ staff and board

Method

Existing board members were invited to participate in a telephone interview. Staff were invited to participate in either a face-to-face or telephone interview, whichever option was the most convenient for them. Interviews were conducted at a time, and if relevant, a place that was mutually suitable.

A semi-structured interview guide was used during data collection. Board members and HCQ staff were asked questions including details about: which organisations they had contact with in regard to consumer and community engagement over the preceding 18 months; who they had worked with; what the role of those people was; how they worked with these identified people around consumer and community engagement; how contact with these people occurred; and the frequency of the interaction. Interviews were digitally recorded and transcribed verbatim by an external transcription agency. Data were then coded and categorised using standard thematic analysis processes (Bazely, 2009; De Santis & Ugarizza, 2000; Ryan & Bernard, 2003).

Summary of key findings

HCQ performs two key and interdependent consumer and community engagement roles. It holds both a ***capacity building*** and a ***change agency*** role. By achieving these key roles, HCQ supports the consumer voice to be identified, heard, engaged with and acted on to improve health services throughout Queensland.

Two primary and interdependent mechanisms are used by HCQ staff to achieve capacity building and change agency. They are ***advocacy*** and ***knowledge mobilisation***. Advocacy occurs at all levels of the health system and requires strategic and political astuteness. Thus, the work of HCQ involves cutting across boundaries and barriers to address consumer and community engagement at individual, service, network and system levels. Achieving the advocacy role of HCQ is supported by staff and board members who have lengthy experience in advocating for consumers in various ways. Knowledge is mobilised in both formal (i.e., mandated deliverable of training) and informal ways (e.g., responding to questions about meeting Standard 2 requirements). Although training is the most measurable of the knowledge mobilisation work performed by HCQ, informal and largely intangible knowledge mobilisation processes are likely to be the most impactful and are best captured through consumer and organisational narratives.

Advocacy and knowledge mobilisation are operationalised through ***extensive networks***. These networks are relationship based and require ongoing nurturing and management. Through active management of relational networks, opportunities for all types of consumer and community engagement (consultation, collaboration etc.) can be identified and acted upon. An important part of the work of HCQ staff, therefore, is to build ***relational trust*** so that health services can progress towards embedding consumer and community engagement in practice. The outcome of this relational work is that HCQ are often involved in ***tailored programs of work***. Through these tailored activities, *gaps in consumer and community engagement are closed*, *value is added to the healthcare system and strategies are developed to improve the quality of healthcare.*

Qualitative analysis of accessibility of consumer engagement activities on publically available Hospital and Health Services Websites

Method

Each of the 16 Queensland HHS websites was visited on two occasions for examination, first in May/June 2017 and then again in October/November 2017. The two time points were used in the event that any HHS updated or changed the content available on the website. The review examined what types of information were available on the HHS websites, how accessible that information was from a simple navigation perspective, and the types of consumer and community engagement opportunities a person could find within the content. In order to gather this data, one member of the research team visited each websites' homepage and then proceeded to navigate to the consumer and community engagement information either via direct clicks, or a keyword search for "consumer and community engagement" or "community engagement" when there was no obvious related consumer and community engagement information on the homepage or contained within the navigation menu. The reviewer then thematically analysed all consumer and community engagement information contained within each website (Bazely, 2009; De Santis & Ugarizza, 2000; Ryan & Bernard, 2003). A further list of the types of consumer and community engagement opportunities available was created and then analysed using the HCQ Consumer Engagement Spectrum and the IAP2 to determine the level of influence that each engagement activity provided.

Summary of key findings

HHSs individually present different information in different formats on their websites. Without standardization or guidelines for creating an engaging online presence that is accessible for all consumers (including culturally and linguistically diverse populations and visually and hearing impaired people), HHSs are not effectively utilizing the full potential of websites as an engagement medium.

In general, HHSs are using websites as a mechanism for disseminating information ***to*** consumers about the HHS. They are rarely using websites to receive information ***from*** consumers, unless it is specifically solicited for a pre-determined purpose. Additionally, there is no apparent mechanism available on websites that give consumers any indication of what happens to their feedback when it is provided. Failure to close this information feedback loop with consumers is also evident in direct consumer feedback.

Websites with direct links to participate or register for participation in engagement activities are maximizing the opportunity for converting consumers looking at a website and searching for information into engaged consumers. This is especially true with regard to the Consultation Hubs.

Qualitative analysis of publically available consumer engagement policies

Method

The 16 Queensland HHSs websites were visited on two time points, once in May/June 2017 and again in October/November 2017. A search was conducted on each website for the available policy documents related to consumer or community engagement. The policy documents or strategies that featured "consumer engagement" or "community engagement" within the titles were then downloaded, read, and analysed. Using thematic analysis (Bazely, 2009; De Santis & Ugarizza, 2000; Ryan & Bernard, 2003), categories were developed for the types of information disseminated in each policy document. Particular attention was paid to the language, graphs/figures, and description of the different frameworks, spectrums, and guidelines that were employed or embedded within each of the policies. A list of all types of consumer and community engagement opportunities presented within the documents was then created. The area of engagement and the level of impact or influence an opportunity may generate were analysed using the HCQ Engagement Spectrum (2017) and the IAP2.

Summary of key findings

A review of publically available (i.e., accessible via internet) consumer and community engagement policy revealed that none of the policy documents provided by HHSs clearly or concisely listed or displayed the full breadth of opportunities that were available to consumers.

Without a standardized target audience or guideline for policy, each policy addressed different levels of information, included different opportunities, and often created more ambiguity about consumer roles and the meaning and interpretation of consumer and community engagement in practice.

No policy appears to leave the average consumer with clarity or transparency about how they can engage with the HHS. Monitoring of, and progress towards achieving, consumer and community engagement activities outlined in policy are notably absent in publically available information.

Preliminary qualitative analysis of consumer interviews

Methods

Consumers were recruited via an e-alert, which is distributed by HCQ on a regular basis to the entire network. People who were interested in being involved in the research contacted research staff by email or telephone. A telephone interview at a mutually agreed time was then arranged with each consenting participant. All potential participants were provided with written information about the research. A semi-structured interview guide was used that included questions such as: How are you engaged as a consumer in your health service?; How did you come to be involved?; What type of things do you do?; How often do you do something in your consumer role?; How difficult or easy is it for you to do the things that you are required to do?; Do you get any support to do those things?; Have you had any interaction with HCQ?; Who have you worked with?; Did they contact you, or did you contact them?; How often have you interacted with them?; How useful has HCQ been to you?; Would you recommend HCQ to your friends / colleagues?; How satisfied are you with your interaction with HCQ?; Were there some things that you would have liked HCQ to help with, but that didn't happen?. Interviews were digitally recorded and transcribed verbatim by an external transcription agency. Data were then coded and categorised using standard thematic analysis processes (Bazely, 2009; De Santis & Ugarizza, 2000; Ryan & Bernard, 2003).

Summary of key findings

HCQ have a key role in increasing the ***capability*** of consumers to engage effectively with the health system. They achieve this role through targeted and generic training, as well as by offering individualised support for consumers to participate in health service engagement activities as and when needed.

There are multiple ***opportunities*** for consumers to engage with health services. HCQ have an active role in distributing information about these opportunities to consumers, most frequently through regular e-alerts and e-newsletters. Most consumers that we spoke to initially engaged directly through health services, but subsequently engaged with HCQ, which widened their perspective and the scope of consumer engagement work they performed. A number of consumers spoke about the difficulty they experienced attending workshops and other events that are held in South-East Queensland, but particularly in Brisbane CBD.

A number of factors ***motivate*** consumers to engage with health services. When consumers are intrinsically motivated they are often heavily engaged with health services, sometimes in an almost full-time capacity. Others are motivated to engage with health services because of relationships they have developed with clinical staff, which gives them the impetus to begin a journey of consumer engagement activities. Still others dip in and out of consumer engagement activities as opportunities periodically arise that interests them. Thus, there is a breadth and depth of consumer engagement activities that is not standardised.

Quantitative analysis consumer and staff surveys from PHNs and NGO

Method

Staff who have a consumer engagement role and consumers who act as consumer/carer representatives were sent an email asking them to volunteer to complete a brief online survey.

The survey asked questions about how consumers were engaged with their PHN/NGO, what their consumer engagement experience was like with the service, the level of confidence they had in performing their consumer engagement role, the level and type of contact they had with HCQ and their satisfaction with this interaction.

The staff survey asked about staff perceptions of consumer engagement in their organisation, the level and type of contact they had with HCQ and their satisfaction with this interaction. Demographic information was also collected from participants. Due to the small number of participants who have completed the survey to date, data analysis is limited to frequencies and percentages for question responses.

Summary of key findings for PHNs & NGO

It should be noted that the survey findings are based on a very small number of participants and therefore the key messages may change as additional data is collected.

According to consumers and staff, consumer engagement is occurring across all the International Association of Public Participation Spectrums of Engagement (IAP2) (i.e., informed, consulted, involved, collaborated with and empowered). Consumers reported feeling positive and somewhat confident about their consumer engagement role.

Staff believed there is a real commitment to consumer engagement in their organisation and that in the past few years consumer engagement has been increasing. Most staff considered board members and management as being supportive of consumer engagement activities. Consumer engagement policies did not appear to be available and/or accessible for some staff. With respect to decision making around consumer engagement and being involved in developing the organisation's consumer and community engagement strategies, staff were more involved than consumers.

Staff and consumers reported having positive and satisfying interactions with HCQ. The training HCQ delivered is highly valued; however, some staff and consumers would like to see more diversity in the training curriculum (e.g., content covered for more experienced consumer and carer representatives). While staff acknowledged that there are training opportunities available to them, finding the time to attend training and/or access the information they need about consumer engagement is difficult.

Staff and consumers would like to have more opportunities (e.g., training, forums, meetings) to interact with HCQ outside of the Brisbane area or via an online format (e.g., webinars, recordings). All staff and consumers stated they would recommend HCQ to their friends/colleagues.

Quotes that support the impact that HCQ is having across Queensland

"Great advocates for consumers, as well as the ongoing work to try and build capacity of our organisation to better engage with consumers".

"The team are fabulous, very approachable and always willing to help with queries. They are a very hardworking team and do so much with a shoe string. I feel they are making a difference for health culture in Queensland and I hope they get a big fat funding boost!"

"Having worked in this field for a number of years, I do believe that in the last few years there has been a real acknowledgement and understanding of the importance of consumers in planning, design, delivery, monitoring and evaluation across health services in Queensland. Before it was more of a tick box but I think it has in recent years become a lot more widely accepted and fully embraced. There are probably a number of factors contributing to this but I think the role of HCQ is probably one of them".

"Lovely staff who are knowledgeable, enthusiastic and always bring a positive attitude".

"I would say that if you've got access or have been approached for engagement as a consumer by an organisation such as Health Consumers Queensland, that we're incredibly well supported in that role. But, if engaged outside of some of those consumer representative groups, that it can be incredibly difficult to seek that training or that guidance otherwise".

"It's really good to have that support organisation [HCQ] available to us… It's good to have people that are proactive about actually making health services accountable, and making them bring us [consumer] to the table like they should".

"Health Consumers Queensland has been incredibly valuable [to me]. I think not just valuable in validating consumer experience for sitting at the table—there's something so incredibly valuable in having someone to support you use your voice and to acknowledge that voice—but also valuable in providing additional opportunities to use my voice as a consumer. If anything, they provided greater networking opportunities but also greater confidence to take those advocacy or opportunities that arise… To be honest, I've actually begun to value the voice of consumers and perhaps more so than I even understood the value of my voice to be; a deepening understanding of the reach of our consumer voice where used and accepted and supported appropriately."

Interpretation of key findings with regard to the impact that HCQ is having on consumer and community engagement

Ultimately, the staff at HCQ are involved in complex and often hidden consumer and community engagement work that is reliant on relational networks. There is evidence that HCQ staff have the capacity and capability to monitor, manage, support and nurture these networks. The hidden nature of the work that HCQ are doing means that assessing and measuring the impact of change agency work is likely to be tenuous and flawed, especially when legislated frameworks, accreditation mechanisms and other embedded ways of providing patient care in health services systems means that change is likely to be slow. However, it remains important to assess the impact of HCQ work. In the context of the current state of ethics and governance approval for this project, impact of HCQ will be primarily based on consumer narratives about their experience of engaging in health services and with HCQ. Consumer narratives are currently ongoing, which means that there may be additional insights regarding the impact that HCQ is having as more data becomes available.

There is evidence that the important capacity building and advocacy roles that HCQ staff and board members identified is being achieved, especially with regard to consumer voices being heard and listened to in health services. Consumers are reporting that HCQ is directly and positively impacting their confidence to speak out and be heard. However, the evidence from a website analysis and from consumers indicates that this is not consistent across HHSs. We have not yet been able to interview HHS or Department of Health staff to establish the nature of the consumer engagement work that they are doing in their routine practice.

Two consistent messages are becoming apparent from preliminary consumer interviews and staff and consumer surveys. First, several consumers reported that they have difficulty engaging as fully as they would like in training and opportunities offered by HCQ. This difficulty mostly revolves around a perception that training is frequently held in Brisbane (consumer training is held across Queensland, but consumer attendance is on invitation by HHSs). Although engaging with technology is one obvious solution to overcoming the tyranny of distance, it is possibly not the only solution for people who are geographically distant from Brisbane. Second, context specific training is being sought. This may mean that there are different levels of training required at different stages of the consumer engagement journey. It might also mean that consumers need to engage with training several times and in different formats. Given that people are able to comment about training and provide insight into ways that it could be altered to be more accessible to their geographical location and individual needs potentially means that the training is having an impact at a grassroots level. People do know that training is available and they are aware that HCQ is operating in this consumer training space.

Using electronic media to support direct consumer links to engagement opportunities was reported by consumers who frequently commented that they use the HCQ e-alert process as a mechanism for identifying opportunities that are consistent with their skill, interests and availability. Given that not all HHSs have mechanisms to support direct links between consumers and engagement opportunities, it might be important for HHSs to investigate the use of electronic media as a method for increasing consumer engagement opportunities. Alternatively, there might be an opportunity for HCQ to increase the impact that they have on consumer and community engagement by linking

directly with HHS websites that offer opportunities for consumers to be more actively engaged in health service design, planning and delivery.

There is consistent evidence that HHSs refer to the HCQ Consumer and Community Engagement Framework in their policies and website information. A small number of HHSs are embedding the language of consumer engagement in their policy documents. Thus, there is evidence that the language and strategies used by HCQ is being adopted in HHS policy language and strategies. However, the use of language is inconsistent across websites. Additionally, we did not include the Department of Health (DoH) website in the website and policy document analysis. A number of HHSs that rated amongst the most difficult websites to access and as having the least available information were linking directly to the DoH website as the host for their information. Thus, there is some evidence that there may be an opportunity for DoH to take a greater role in guiding consistency on consumer information on publically available websites and in publically available documents.

There is consistent preliminary evidence from consumers who have participated in both qualitative interviews and quantitative surveys that consumer and community engagement is occurring at various depths (i.e., inform, consult, involve, collaborate, consumer led). At a minimum, HCQ provide an avenue to inform consumers of opportunities to engage with health services. Once consumers are informed there is evidence that they are engaging in health service activities in which they are consulted and involved. Thus, there is preliminary evidence that the activities of HCQ are facilitating a shift towards deeper consumer and community engagement.

Next steps

Following this report, both quantitative and qualitative data will continue to be collected as and when governance approval is received from individual HHSs throughout the state. Based on the analysis of this data, an additional report that provides evidence regarding the activities of HCQ will be delivered in May, 2018.

REFERENCES

Bazely, P. (2009). Analysing qualitative data: more than 'identifying themes'. *The Malaysian Journal of Qualitative Research, 2*(2), 6-22

DeSantis, L. & Ugarriza, D.N., (2000). The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research 22*(3), 351-372.

Ryan, G.W., & Bernard, H.R., (2003). Techniques to identify themes. *Field Methods 15*(1), 85-109. doi: 10.1177/1525822X02239569