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Health Consumers Queensland Impact Evaluation Project

Executive Summary

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Table of Contents

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Acronyms and definitions

Carer	A person who provides care and support to someone with health issues. They could be family, friends or community members.
Consumer	A person with a lived experience of health issues and who uses, or has used, health services.
Consumer and carer representative	A person who has taken up a formal, specific role to advocate on behalf of other consumers.
CAG	Consumer Advisory Council
DoH	Department of Health
HCQ	Health Consumers Queensland
HHS	Hospital and Health Service
HREC	Human Research Ethics Committee

Executive summary

This report details the approach, activities and results of evaluation activities undertaken by researchers in the Hopkins Centre at Griffith University on behalf of Health Consumers Queensland (HCQ). The research team conducted a Human Research Ethics Committee (HREC) approved multi-site and mixed methods evaluation of consumer engagement activity across health services in Queensland with the purpose of discerning the impact that HCQ has had in the consumer engagement space in Queensland between 2016 and 2018. We worked in consultation with staff at HCQ to develop a logic of their work and then undertook a pragmatic and reflexive approach to understanding consumer engagement in Queensland.

Evaluation aims

The following short-term outcomes, long-term outcomes and impacts were identified by HCQ staff as relevant to their program of work (refer program logic Appendix 8.1).

1. Short-term outcomes:
    a. Increase in consumer confidence to engage with health services.
    b. Increase in requests for HCQ services.
    c. Increase in expressed value of consumer engagement in health organisations.
    d. Authentic, meaningful engagement (eliminating tokenistic engagement).
2. Long-term outcomes:
    a. Increase in consumer expertise, capacity, health literacy, and numbers of skilled consumers.
    b. Increased knowledge and use of consumer engagement in health services.
    c. Development of consumer engagement policy, incorporation of consumer involvement as standard and ongoing in services.
3. Impact:
    a. Power diffusion within health services – power redistribution toward consumers.
    b. Consumer engagement becomes business as usual: thoroughly embedded and inextricably linked with all aspects of health and community service operations.
    c. Consumers always included in service design.

Therefore, in this study, we used mixed methods to explore the following from the perspective of HCQ board members and staff, consumer and carer representatives, and health services staff:

1. What are existing perceptions about the engagement role that consumer and carer representatives currently have with health services?
2. What is the impact of relationships and interactions between:
    a. Consumer and carer representatives and health services?
    b. HCQ and health services?
    c. HCQ and consumer and carer representatives?

A number of data collection activities were used. These included: (1) semi-structured interviews with HCQ staff, board and consumer advisory group (CAG) members (2) surveys of consumer and carer representatives across Queensland; (3) semi-structured interviews with consumer and carer representatives across Queensland; (4) surveys with health services staff across Queensland; (5) semi-structured interviews with health services staff across Queensland; and (6) analysis of publicly available consumer engagement information from each Hospital and Health Service (HHS) in Queensland and the Queensland Department of Health (DoH).

Data collection approaches and participant groups

Semi-structured interviews with HCQ staff, board and Consumer Advisory Group members

Key HCQ staff (n=7), board members (n=4) and CAG members (n=5) were invited, and consented, to participate in individual semi-structured interviews. The interviews requested information about the nature of their role, who they were working with, how often they worked with these people/health services and the direction of those interactions. Twelve months after the first round of interviews, staff (n=7)also participated in a second follow-up interview with researchers, which focused on any changes in the work they were doing to support consumer engagement during the preceding period.

Consumer and carer representative interviews

Consumers and carers were invited to participate in one-on-one telephone interviews with research team members. The aim of the interviews was to gain in depth understanding of their role in health services and their interactions with HCQ. Thirty-eight consumer and carer representatives consented and were interviewed over a six-month period. Of those 38 people, 23 were contacted six months after their initial interview to determine if, and what, changes had occurred with their consumer engagement role in the preceding period. Sixteen consumer and carer representatives who were able to be contacted reported changes in their role.

Health service staff interviews

Health service staff were invited to participate in one-on-one telephone interviews with research team members. The aim of the interviews was to gain an in depth understanding of how they engaged with consumers and carers in their health service and their interactions with HCQ. In total nine staff consented and were interviewed.

Consumer and carer representative surveys

Consumer and carer representatives were invited to complete a brief online survey which sought their perceptions about how they were engaged in health services, their confidence in undertaking their role, and their interactions with HCQ. In total 128 consumer and carer representatives completed the survey.

Health service staff surveys

Health services staff were invited to complete an online survey which sought their perception about their organisation's capacity for consumer and community engagement. In particular, the level of support for evaluating consumer and carer engagement, partnership effectiveness, planning and implementation strategies, resources and supports were explored. One hundred and fourteen staff completed the online survey.

Analysis of health services websites and associated consumer and carer engagement policies

An examination of HHS and the DoH websites and publicly available consumer and community engagement policy was conducted in order to: (1) identify the types of consumer and community engagement documents that were available; (2) understand how these health services communicated information about consumer and carer engagement roles within their organisations; (3) examine the standards, frameworks, or spectrums that were used to educate consumer and carer representatives about their engagement role; and (4) determine the types of opportunities and accompanying level of involvement that were available to consumers. All 16 HHS and the DoH websites were included in this component of the evaluation.

Results

Semi-structured interviews with HCQ board, staff and consumer advisory group members

HCQ staff provided practical and strategic support to consumer and carer representatives as well as health services staff across Queensland. They actively provided fee-exempt training to consumer and carer representatives and staff from public health services across Queensland. They provided fee-for-service training for consumer and carer representatives and staff from private and non-Government health services across Queensland.

Building and maintaining networks that included consumer and carer representatives and health services staff was an important function of HCQ. They had established a membership database and regularly communicated with members via e-alerts and e-news. Despite a growing number of consumer and carer representatives across the state, there were some concerns that these representatives were not entirely representative of the population of Queensland. HCQ staff recognised that there was a need to continue to grow an ethnically diverse and socio-demographically representative membership base.

HCQ hosted an annual forum, which was well-regarded and was growing in size and esteem. In 2018, for the first time, all 16 HHSs were represented by both a consumer or carer representative and a health services staff member.

HCQ staff were actively engaged in bespoke programs of work. They worked closely with consumer and carer representatives to engage with health services around sensitive topics such as the Youth Mental Health Project and the Maternity Hub in Logan.

HCQ staff anecdotally reported that consumer and carer representatives were being engaged in areas within health services that were previously inaccessible.

In light of the breadth of work that HCQ staff were engaged in, and an identified need to ensure that there was equitable distribution of their resources across the State, there had been a recent internal restructure within HCQ. Staff reported that they felt re-invigorated by the restructure and believed that they would be better able to develop relationships with consumer and carer representatives and health services staff, which in turn would assist them to deliver customised and high quality consumer engagement services and support. Staff also reported that HCQ was exceptionally well-led.

Consumer and carer representative interviews

Consumer and carer representatives were engaged in multiple levels and in multiple ways across Queensland. Some consumer and carer representatives were engaged in single pieces of work while others were engaged more consistently and strategically. Consumer and carer representatives were passionate and engaged in their roles, with some committing almost full-time hours to their engagement work. Although some consumer and carer representatives were engaged in service planning and design, the majority were involved in document reviews, undertaking surveys, and providing input into advisory group meetings.

A greater number of consumer and carer representatives were maturing in their capacity to engage with health services and to more broadly represent consumer issues in ways that were commanding attention from health services staff. As their capacity to engage with health services matured, consumer and carer representatives would sometimes change the type of roles that they were engaging in, with some representatives reporting that they were engaging in more strategic roles. Other consumer and carer representatives reported that they were moving away from some roles, often because of illness or other life priorities, but sometimes because of conflict within committees.

Remuneration was contested, with some consumer and carer representatives willing to volunteer their time to support health services and others seeking remunerated consumer engagement opportunities. Although some consumer and carer representatives were willing to volunteer their time, they did expect that they would be appropriately remunerated for out-of-pocket expenses.

Consumer and carer representatives reported that they sometimes experienced subtle but impenetrable barriers to engaging with health services. These barriers politely but effectively excluded consumer and carer representatives by actions or inactions that included: not having continuity of support staff; lengthy time lapses between meetings; failing to adequately remunerate consumer and carer representatives; limiting the number of people invited to participate in engagement activities; using expression of interest recruitment processes; labelling consumer experiences in clinically defined ways; openly discounting and disparaging consumer experiences of the service system; assuming that processes in one service location would be transferrable to other service locations; and communicating verbally and in writing using language that was not easily understood.

Not all consumer and carer representatives were familiar with HCQ. However, those who were most familiar with HCQ appreciated the opportunity to grow their understanding about consumer engagement and increase their capacity to effectively and efficiently engage with health services.

Health services staff interviews

Health services staff who participated in the evaluation were mostly familiar with the concept of consumer engagement, and many were employed in roles with a specific consumer engagement focus. Participants brokered consumer engagement across health services by providing consumer feedback to clinicians and executive. They also supported consumer and carer representatives to effectively engage with internal health services processes.

Health services staff also acknowledged that there were different levels of maturity regarding consumer engagement within individual services. The importance of consumer engagement in health services was described on a range between ‘nice to have’ to ‘the next frontier’.

Many participants were familiar with HCQ. Some interacted regularly with HCQ staff. The HCQ activities with which health services staff were most familiar included the annual forum, training, assistance with recruiting consumers, and personal relationships whereby health services staff relied on HCQ staff as a sounding board for consumer engagement direction and work.

Consumer and carer representative surveys

The majority of consumer and carer representatives engaged with their health service regularly. They felt satisfied about their interactions with health services; trusted their health service and believed consumer and carer representative views were being heard. The majority of consumer and carer representatives reported feeling confident to meet the demands of their consumer engagement role. Consumer and carer representatives’ confidence in performing their role was associated with them having at least monthly contact with HCQ and receiving help from HCQ to prepare for their role. Over 30% of participants did not believe that remuneration for their role was applicable to them.

More than half the consumer and carer representatives reported that they had engaged with HCQ. A high proportion of consumer and carer representatives had attended training or received e-news compared to networking sessions/webinars or the annual forum. However, the networking sessions/webinars and annual forum were reported to be the most useful. With respect to how HCQ could support consumer and carer representatives more, suggestions included holding more activities outside of Brisbane; providing more information about the consumer and carer representative role; making individuals more aware of HCQ when they first commenced a consumer and carer representative role and providing a HCQ buddy; having more formally recognised training programs and offering online training options; advocating more strongly on behalf of consumer and carer representatives in health services, to provide more support when individuals were facing tricky situations; and for HCQ to be more engaged at multiple levels within health services.

Health services staff surveys

Approximately half of the staff believed there was a real commitment to consumer engagement in their health service and that consumer engagement was understood and valued by staff and management. However, a high proportion of staff were either unsure about, or believed that consumer engagement was tokenistic in their health service. The majority of staff agreed that consumer engagement was increasing and that partnerships with consumer and carer representatives had brought new ideas to service delivery.

More than half of staff who responded to the survey said there were written monitoring and evaluation policies regarding consumer engagement in place, however, these policies did not appear to be easily accessible. Approximately half thought that lessons learned from monitoring and evaluating consumer engagement were being used to make changes in their organisation. The majority of staff thought management were accessible regarding consumer engagement activities, however, the majority also disagreed that management was providing leadership and effectively communicating around consumer engagement, were making timely decisions, were receptive to new ideas or were responsive to consumer engagement issues. With respect to resourcing consumer engagement, the majority of staff thought there was inadequate staffing levels to carry out consumer engagement activities and that there was not adequate resourcing and administrative support.

The majority of staff had heard of HCQ and had interacted with them by attending training or workshops, receiving assistance to recruit consumers, receiving advice on how to design and deliver effective consumer engagement programs, attending networking sessions/webinars, receiving e-news or attending the annual forum. The majority of staff believed that these activities were useful and reported having positive and satisfying interactions with HCQ. However, the majority of staff also wanted increased access to professional development opportunities. Staff believed HCQ was a valuable organisation which helped build health services' capacity to engage more effectively with consumer and carer representatives.

With respect to how HCQ could support staff to more effectively partner with consumer and carer representatives, staff wanted increased contact with HCQ (especially services outside of Brisbane), greater understanding of HCQ's role, more training opportunities for both staff and consumer and carer representatives including development of short skills based training programs (possibly using a train-the-trainer model), access to online modules and webinars, feedback from HCQ on how their health service was progressing with consumer engagement initiatives, and for HCQ to drive and coordinate the consumer engagement agenda for Queensland.

Analysis of health services websites and associated consumer and carer engagement policies

Organisations presented different information in different formats on their websites. Without standardization or guidelines for creating an engaging and accessible online presence, organisations were not effectively utilising the full potential of websites as an engagement medium.

In general, organisations were using websites as a mechanism for disseminating information ***to*** consumers rather than using them to receive information ***from*** consumers, unless it was specifically solicited for a pre-determined purpose. There was no apparent mechanism available that gave consumers any indication of what happened to their feedback when it was provided.

A review of publicly available consumer engagement policy revealed that none of the policy documents provided by HHSs or the DoH clearly or concisely listed or displayed the full breadth of opportunities that were available to consumers. 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 appeared to leave the average consumer with clarity or transparency about how they could engage with the HHS.

Key findings with regard to the program logic

Role of HCQ in the consumer engagement landscape

Within the consumer engagement landscape across Queensland, HCQ is positioned in a space that is sometimes clearly and congruently aligned with health services functioning, sometimes clearly and congruently aligned with consumers, and sometimes spanning a divide between health services and consumers and carers. Thus, HCQ is required to effectively partner with both consumers and health services. This partnering work is essential, complex, and sometimes at odds with either consumer or health services understanding of consumer engagement. Shared understandings of the meaning and operationalisation of consumer engagement is not always assured in these circumstances.

Consumer confidence:

Consumer and carer representatives reported that they more confidently engaged with health services staff as they became more familiar with expectations of their role, and when they received feedback from health services staff that made them feel valued and validated. The majority of consumer and carer representatives rated themselves as being confident to meet the demands of their consumer engagement role. They felt secure in their ability to remain calm when facing difficult situations and believed they were able to problem solve when faced with unexpected situations. Confidence to perform their role was associated with having at least monthly contact with HCQ and receiving help from HCQ to prepare for their role. Consumer and carer representatives were also more positive about their role when they were female and having at least monthly contact with the health service.

Despite the confidence that consumer and carer representatives reported when engaging with health services staff, there was evidence that significant and important groups within the population were under-represented in consumer engagement activities. Specifically, vulnerable and marginalised groups of people were largely missing. Many participants recognised a need to include more people from Indigenous and culturally diverse populations. They also acknowledged that males were under-represented in consumer engagement activities.

Requests for HCQ services:

HCQ staff reported increasing requests for their services. The majority of consumers and health service staff had heard of HCQ and had interacted with HCQ through attending training or workshops, receiving assistance with recruitment of consumers, receiving advice on how to design and deliver effective consumer engagement programs, attending networking sessions/webinars, receiving e-news or attending the annual forum. However, contact with HCQ was infrequent for a large number of participants and, particularly for those in rural and regional areas.

Value of consumer engagement:

Consumer and carer representatives reported feeling valued and validated by health service organisations. Over half of the health services staff agreed that they understood the benefits of consumer engagement and that there was a genuine commitment to consumer engagement in their organisation. However, just less than half agreed that consumer engagement was valued and one quarter agreed that engagement was often tokenistic. Only one third disagreed that engagement was tokenistic and the majority were unsure.

Alongside evidence that consumer engagement was valued on a continuum from tokenistic engagement to highly valued input, evidence that there were invisible and impenetrable barriers within health service systems beyond which consumers could not progress indicates that consumer engagement activities are not always valued by health services staff, policies or practices. Additionally, there were some reports that consumer engagement activities and coordination of those activities were under-resourced in some HHSs.

Type of consumer engagement:

Consumer engagement occurred on a continuum from simple passive activities to more meaningful and influential activities. Consumer and carer representatives were included in service planning and design (e.g., refurbishing a ward in a hospital, designing a new model of service/care); service monitoring and evaluation (e.g., consumer surveys, identifying measures that need to be evaluated), service delivery (e.g., peer workers). However, health services staff tended to report slightly higher levels of engagement in all categories than reported by consumers/carers, and particularly in the deeper levels of engagement. Passive engagement activities (e.g., inform, consult, involve) were more frequent than active partnering with consumer and carer representatives (e.g., collaboration and consumer-led opportunities).

Depth of consumer engagement:

Some qualitative evidence suggested that consumer and carer representatives' expertise, capacity, health literacy and skills were shifting in a positive direction. Some consumer and carer representatives reported that they were moving to more strategic consumer engagement roles in health services. Health services staff and HCQ staff also reported that consumer and carer representatives were engaging in more complex engagement roles and becoming more skilled. Some consumer and carer representatives expressed concern about the health literacy of consumers more generally.

Commitment to consumer engagement:

Some qualitative evidence suggested that there were positive shifts in knowledge and use of consumer engagement in health services. Surveys showed that the majority of staff (>70%) assessed their organisation's priority for consumer engagement as being moderate, good or very good. The majority (>55%) believed that support for consumer engagement from senior management and HHS boards was moderate, good or very good as were staff attitudes about consumer engagement. More than half of the staff (>55%) thought the structures in place to support consumer engagement were moderate, good or very good. However, only a minority of staff (<40%) thought that funding and resourcing for consumer engagement was moderate, good or very good.

Accessibility of consumer engagement:

The website analysis confirmed that consumer engagement policy existed in health services, but also that policy was inaccessible and often not yet translated into practice. There was inconsistency with regard to the content and presentation of consumer engagement policy across the state. Qualitative evidence showed that remuneration of consumer and carer representatives was one policy area that was inconsistent and contested. Health services staff also believed that consumer engagement policy was inaccessible.

Embedded consumer engagement:

Qualitative data showed that there were pockets of change occurring throughout Queensland, but there was no consistent evidence to conclude that authentic consumer engagement was embedded as standard practice in the health service system. Additionally, it was evident from the data that change required to embed consumer engagement as usual practice was slow.

Recommendations

1. *HCQ work with the DoH to develop a state-wide policy regarding remuneration for consumer and carer representatives.*
2. *HCQ broker ongoing support for vulnerable and marginalised populations in Queensland by taking action to attract, support and retain a diverse network of consumer and carer representatives with a special focus on mobilising males who are engaged consumers.*
3. *A clear future focussed vision for HCQ is recommended to address multiple, complex and competing tensions that co-exist at the interface between health care consumers and carers and health care organisations.*
4. *Ongoing attention is given to the strategic positioning of HCQ within the health services landscape, especially with regard to competing tensions when working with consumers and health services who sometimes have different understanding about the meaning and methods of operationalising consumer engagement within services.*
5. *Monitoring change in consumer engagement practices by regularly evaluating the depth and type of consumer engagement occurring in health services across Queensland is necessary.*
6. *Consideration be given to developing consumer and carer peer mentoring and support processes.*
7. *Unlocking consumer potential to develop self-organised support systems in geographically diverse locations will enhance the development of skilled representatives across the state.*
8. *The annual forums are a unique and valued networking opportunity and need to be protected in a 2-day format*

9. *Ongoing funding for annual forums is essential to ensure that the impact of consumer and carer engagement activities across Queensland are continually highlighted and shared so that consumers, carers and health services can build consumer engagement capacity.*
10. *Avenues for contextually relevant and geographically accessible training be explored, especially beyond South East Queensland and Brisbane more specifically.*
11. *HCQ are responsive, flexible and acutely aware of ongoing consumer engagement needs across Queensland. The enthusiasm, passion, commitment and leadership within the team ought to be commended, nurtured and reinforced.*

Health Consumers Queensland program logic

Vision/ Mission: (1) Health Consumers Queensland empowers consumers to lead and drive better health outcomes (2) The health system will partner with consumers and community to get the health care we want (3) Change in engagement is able to be measured, with established measurement tools (4) Increase in diversity of networks

Assumptions: (1) Consumer and community voices are essential to planning, designing, delivering and evaluating health services and contribute to delivering better health outcomes for Queenslanders (2) Embedding consumer and community engagement in health system practice and culture are vital for building a world class health system

Stakeholders: Internal: HCQ staff and board;
Government: Health Minister (State); Queensland Department of Health
Service Providers: Hospital and Health Services; Primary Health Networks; Private Health providers **Targeted departments:** Consumer and community engagement staff, management, boards
Community specific consumer engagement groups within Service provision stakeholders: consumer/carer and community advisory groups / committees
Consumer specific organisations – health / disease specific
Other Community Organisations
Population Groups: vulnerable communities including: Indigenous Australians, Culturally and Linguistically Diverse (CALD); young people, older people, refugees, people living in rural and remote areas.
Individuals: consumers who are current, past and potential health service users, consumer representatives, carers, families, statewide network members.

PROCESS ⟶ **OUTCOMES**

INPUTS

- Funding
- HCQ Consumer and community engagement framework
- Communication, expertise, skills and knowledge
- HCQ premises, facilities and other operational locations
- Internal policies, systems and protocols for operational processes
- Time and opportunity

ACTIVITIES

- Collect data using annual surveys
- Establish a HCQ Collaborative
- Host an annual forum
- Provide consultancy for health professionals, health services and health policy makers
- Lobby for CE incentives in organisational funding requirements
- Develop and maintain fee for service
- Recruit consumers for roles in health services
- Conduct training consumers and health staff
- Establish and maintain an electronic register of all those involved with HCQ
- Provide support, advocacy and advice for consumers who are working with health services

OUTPUTS

- # of conference / grant abstracts submitted
- # of E-news, E-alerts, Brochures
- # of media and networking opportunities
- # of people attending annual forum
- # projects conducted with health services
- ↑ in consumer training participation and delivery
- ↑ in requests for HCQ services
- ↑ in numbers of consumers engaged from diverse / marginalised populations
- ↑ in overall numbers of consumers engaged in service
- # of policy submissions
- # of people who are involved with the health consumers collaborative
- Facilitate outreach between health services and consumers

SHORT-TERM OUTCOMES

- ↑ in consumer confidence to engage with health services
- ↑in requests for HCQ services
- ↑ in perceived value of CE in health organisations
- Authentic, meaningful engagement (eliminating tokenistic engagement)

LONG-TERM OUTCOMES

- Increase in consumer expertise, capacity, health literacy; increase in size of skilled consumer workforce
- Increased knowledge and use of CE in health services
- Development of CE policy, incorporation of consumer involvement as standard and ongoing in services

IMPACTS

- Power diffusion within health services – power redistributions toward consumers
- CE becomes business as usual; thoroughly embedded and inextricably linked with all aspects of health and community service operations
- Consumers always included in service design

Organisational / process goals: (1) Ongoing expansion of community networks; fostering social inclusion and increasing diversity (2) Ongoing engagement with community, private and government organisations (3) Funding for health services is determined by their ongoing commitment to embedding CE within the service (4) Expansion of HCQ to meet increased demand for CE