Consumer involvement in the design, delivery and efficacy of a HIV clinical service

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Introduction

The involvement of consumers in the self-management of chronic illness has been identified as leading to better health outcomes and result in significant cost savings on the health system [1]. These findings have led to the adoption of consumer involvement as an essential strategy for programs in the NSW Department of Health South East Sydney Local Health District (SESLHD) [2].

The HIV Outreach Team (HOT) is a community-based team located in SESLHD which provides case management services to people living with HIV with complex health and social needs. HOT has facilitated a consumer reference group (CRG) since 2008 to inform service delivery, this has recently been enhanced with the employment of a part-time consumer representative (CR). Paid CRs have been a feature in mental health services; this is now extending to HIV Clinical Services within the NSW Department of Health. The employment of a CR coincides with a much greater role and development for the CRG.

Methods

The HOT has facilitated a CRG since 2008 with varying levels of client interest and participation, with no more that 4 to 6 regular attendees who were mostly gay men. Ultimately HOT envisaged a core group to be 12 consumers (approx. 10% of HOT consumer population group) from a broad spectrum of clients.

In line with the SESLHD Equity Strategy[3] HOT team sought to enhance a partnership with consumers to develop healthy communities. Annual consumer satisfaction surveys of HOT consumers revealed a need for **peer led** consumer participation in the design and delivery of services, this was recognised as an important indicator for moving beyond a top-down approach consultative approach towards a genuine and equal partnership [2].

Extract from SESLHD Consumer Partnership Strategy 2015

HOT reviewed CRG strategies and consulted other health services with consumer involvement to facilitate the shift in CRG towards the ultimate aim of providing a service that is population driven and tailored to suit the needs of HOT consumers [4].

The identified areas for change in the CRG:

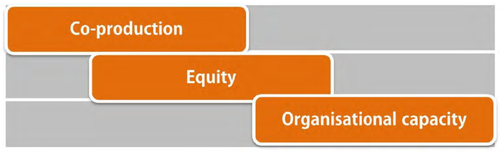
- Increased participation
- Broader representation
- Enhanced co-production mechanisms between HOT & CRG

As a result:

- HOT piloted employment of a part-time Consumer Representative position in January 2016, this was a key component of meeting National Standard 2[5] and was supported by executive sponsorship.
- HOT supported training for CRG members at Consumers NSW in 2015.

Results

For the purposes of evaluating changes in CRG since implementation of these strategies this poster will focus on the three key concepts outlined in the SESLHD Consumer Participation Strategy 2015 [2]:



Co-production

Consumer participation shifted from *informing*, *consulting* and *engaging* towards the beginning of *co-designing* (see table below).. As displayed in the table below a change in co-production occurred during the time a CR was employed. This has significantly increased salience about the importance of consumer input in processes and a voice for consumer involvement in team activities or projects.

Timeline	Consumer Participation Activities in HOT	Phase of Co-production
2008	Commencement of CRG in HOT	Informing
2008 - 2014	Ongoing CRG meetings 4 core members Facilitated by HOT staff	Informing
2014-2015	Consulting CRG on NSQHS Standard 2 for Accreditation Consultation and input for HOT promotional materials Engaging in discussion of Annual survey results Consumer NSW training provided to CRG HOT implementation of Flinders Self Management	Consulting and engaging
2016	Employment of CR on HOT CR facilitating CRG meetings Co-development of HOT projects such as: - Employment project - Social isolation - Aging Co-design of Annual Survey Co-authoring of AHSM poster	Engaging and co-designing
Future plans	Community conversation series with CRG to gain greater understanding of community aspirations CRG reviewing HOT models of care Annual meeting for all HOT consumers arranged by CRG Review and continued advocacy to retain CR position in the team CRG led HOT consumer picnics	Co-designing and co-producing

Equity

The CRG has a broader and more diverse membership, it has progressed from 4 core members in 2008 to 7 core members in 2016. The CRG is now representative of the following key groups: people from low socioeconomic backgrounds, aboriginal people, carers representing women and single parents, people from CALD backgrounds, people with disabilities, people with mental health issues, socially isolated people, people affected by long term conditions, LGBTI and heterosexual people.

Organisational Capacity

Health Consumers NSW provided training to CRG received g on being a consumer and HOT were trained on working with consumers. CRG found this training invaluable. It led to a re-evaluation of the role consumers played as a group, and increased the scope of interest of the consumers into areas of core business of the team and providing input on practices and policies that materially affected consumers' lives and well-being.

Discussion

Over the course of 8 years the CRG has evolved from a mechanism for limited information exchange, personal support and limited input into relevant policy. It is now evolving into a team of more 'expert' consumers who are having much more input into policy and practice and are assisting the team in ongoing strategies to improve their ability in assisting their clients to self-manage (where possible and/or appropriate) their major health and living issues. This shift has occurred with increased the employment of a CR creating changes in communication and ownership of the CRG.

As the CRG and HOT continue to evolve towards co-designing and co-producing they continue to identify key challenges :

- Selection of CRG members. Members are invited by HOT case managers. The CRG is seeking a wider invitation and interaction with consumers by holding an annual HOT consumer meeting.
- Scope and goal of consumer involvement has been an ongoing discussion. Training, effective communication, and opening up consumer meetings for staff members have been effective ways to improve mutual understandings.
- Resourcing. A consumer reference group has some (small) costs – and without which their ability to work is constrained. Consumer advocacy groups argue that paying consumer and community representatives for their work is the most equitable and sustainable way to ensure they are committed to their representative activities, and deem such a model as 'best practice'[6]
- Evaluation and reflection through annual consumer survey . The 2015 survey highlighted issues included social isolation and social activities, employment, ageing, housing and dental care. Initiatives addressing or further exploring some of these issues have been developed by both HOT and the Consumer Reference Group.
- Future mapping of CRG focus**.** HOT and CRG plan to hold 'community conversations' based on Harwood[7], as well as the 2016 annual survey which it is hoped will define future projects will be developed.

Conclusion

HOT partnership with CRG has been enduring and the team has taken steps towards enhancing the effectiveness of the partnership. An important step towards maintaining the shift towards a co-productive partnership has been the employment of a Consumer Representative on the team.

The results indicate that when a clinical team listens to the needs of it's consumers and in turn becomes intentional about tailoring the service towards these needs it can then implement strategies that create shifts towards a genuine and equal partnership with consumers.

Acknowledgements

Consumer Reference Group and the HIV Outreach Team, SESLHD

References

1. Greenhalgh, 2009. BMJ;338:b49
2. SESLHD, Nov 2015. *Community Partnerships Strategy*
3. SESLHD, Dec 2015. *Equity Strategy*
4. HIV Outreach Team, 2015-2016. *HOT operational plan*
5. ASQHC, 2012. *Safety & Quality Improvement Guide Standard 2.*
6. HCASA, Nov 2015. *Remuneration and Reimbursement of Consumers*
7. Harwood Institute for Public Innovation, 2016. *Public Innovators*