Partnering with Consumers in Governance

Health Consumer Advocacy Network of South Australia

The Health Consumer Advocacy Network of South Australia (Health CAN SA- the Network) is a group of health consumers who believe the people, who pay for, fund and use health services in South Australia should be able to inform and influence how those services are designed and delivered.

The Network provides an independent health consumer voice in South Australia to inform government, service providers and policy makers about the experiences, issues and concerns of health consumers and contributes to shared planning and problem solving. Since the closure of HCASA in October 2020 the Network is committed to ensuring independent health consumer advocacy continues in South Australia.

Heath CAN SA acknowledges and supports the Position Statement Working with Consumer Advocates and Representatives originally developed by Health Consumer Alliance of SA and endorses this updated Statement.

Our Position

Health CAN SA calls on health services, policy-makers and researchers to ensure health consumers are recruited, trained, engaged and supported in a structured, inclusive, experience and skills-based process that respects the value health consumers bring to health care decision-making for all South Australians.

This position statement outlines the imperative for health, research and other organisations/services to effectively and efficiently partner with health consumers in the codesign, decision-making, monitoring and evaluation and accountability of health and community services.

A **Consumer** is recognised as a user or potential user of health services and is used broadly to recognise and includes as person's carers, their family, and other members of their support network (as identified by the person) who have an important role in the person's health care decision making, care giving and advocacy. A consumer is recognised as any person who is impacted by the health care and/or health service decision-making and therefore has a right to be involved in this decision-making.

It is recognised that this language is ever changing and evolving. Consumer has been used actively as a shift away from *patient* as a concept of passive receiver of health care, towards an active user and partner in shared decision-making.

A **Consumer Advocate** is a person with lived experience who supports, promotes and defends the interests of consumers, carers and/or the community. They may support an individual or stand up for a just cause or a specific position. A consumer advocate is independent of the health service and is able to provide a unique perspective and experience of the needs, goals and expectations of the person or cause for which they advocate.

A consumer advocate may also represent the collective values, perspectives and views of a community of interest or group. As a representative, they may be nominated and given authority by an organisation or group to speak on their behalf. As a representative, they have a responsibility to remain informed by and inform the organisation or group of discussions and issues arising from the representation.

Recruitment of health consumers to governance roles should include:

1. **A transparent expression of interest and selection process** with clear selection criteria including;
    a. Level of experience, knowledge and skill required of the consumer to contribute effectively
    b. Expected contribution, value and benefit of consumer participation
    c. A role description outlining the scope of the consumer role consumer co-design, co-decision-making
    d. A statement of payment and reimbursement (or other recognition)
    e. What the consumer can expect as outcomes from their participation

2. **Recruitment for diversity and inclusion** to reflect the diversity of the broadest range of consumers that reflect the service users and the community to ensure they are able to contribute to the planning and design of health services that will directly impact them. This ensures a broad range of experience, needs, preferences and values (including cultural) and ensures inclusion of the voices and experiences of people living with health disadvantaged and hard to reach consumers and community groups and provides opportunities for them to engage.

3. **Consumer Advocacy Training** as a fundamental requirement to appropriately prepare health consumers for the role and a standard in supporting consumers to participate as partners in health policy and governance. (eg Health Consumer CoLab Training Programs https://healthconsumercolab.com.au/training *Introduction to Consumer Advocacy* and/or *Consumer Leadership* or equivalent

4. **A Consumer Advocate Role Description** to support greater understanding of the scope and limitations of the role, recognition of lived experience and support for diversity. This ensures role clarity and recognises that consumer members are often the only external (non-staff) members of committees and do not have a clear role/job description other than the Terms of Reference.

5. **Terms of Reference,** which outline as a minimum; scope, role and responsibility, reporting and output/outcome requirements for all members of the group and the anticipated impact and influence of consumer recommendations and advice. Key Performance Indicators include outcomes and measures consistent with NSQHSS Standard 2 Partnering with Consumers or other relevant standards.

6. **Confidentiality and Conflict of Interest Agreements** to ensure consumers have clear parameters and understanding to meet their obligations.

7. **Sitting fees and Reimbursement Entitlements** that provides a measure of recognition of the time, effort and positive contribution that consumers make, and ensures that costs incurred by consumers do not create financial barriers that may prohibit consumer participation.

Consideration should be given to collaborative leadership of any work with/for consumers:

- Explicit induction processes (that include the chairperson as well as the consumers and other committee members) and

- Routine (at least annual) review of efficiency and effectiveness including consumer-centred measures of value.

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