

A health system that meets everyone's needs

Policy proposals for public involvement in the
South Australian health system

A health system that meets everyone's needs: Policy proposals for public involvement in the South Australian health system

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About SACOSS

The South Australian Council of Social Service (SACOSS) is the peak non-government representative body for health and community services in South Australia, and has a vision of justice, opportunity and shared wealth for all South Australians.

Our mission is to be a powerful and representative voice that leads and supports our community to take actions that achieve our vision, and to hold to account governments, businesses, and communities for actions that disadvantage vulnerable South Australians.

SACOSS aims to influence public policy in a way that promotes fair and just access to the goods and services required to live a decent life. We undertake research to help inform community service practice, advocacy and campaigning. We have more than 80 years' experience of social and economic policy and advocacy work that addresses issues impacting people living with poverty and disadvantage.

SACOSS led the establishment of the Health Consumers Alliance of South Australia after receiving funding from the state government for the Healthy Voices project, and auspiced the Alliance in its early days.

SACOSS has a membership base of around 200 people and organisations from a broad cross section of the social services arena. Members of our organisation span both small and large agencies, peak bodies, service providers, individuals, and some government departments.

SACOSS is part of a national network, consisting of the Australian Council of Social Service and other State and Territory Councils of Social Service.

Acknowledgements

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Summary

This paper on policy proposals for public involvement in the South Australian health system follows on from the SACOSS discussion paper on the topic ([pre-release copy available here](#)).

In this paper we argue for the following 10 policy proposals.

Regarding funding:

1. The establishment of an independent organisation for public involvement in health funded by the state government.
2. The funding needs to match the mandate of the organisation, and be sufficient to allow prioritisation of equity.
3. The organisation may benefit from an agreement with a suitable auspicing body for some organisational functions and resources, including premises; but its independence should be maintained.
4. Federal funding should also be sought to complement the state funding, potentially through the two South Australian Primary Health Networks.

Regarding governance:

1. SACOSS proposes that community groups that represent populations with inequitable health are embedded in the governance of the new body.
2. The constitution and aims of the organisation need to prioritise a focus on equity.

Regarding areas of work:

1. The organisation would focus on systemic advocacy, building the health system's capacity for public involvement and equity, and training, mentoring, and supporting consumer advocates in the health system.
2. The organisation is provided with additional funding to provide an individual advocacy service.
3. The organisation's funding agreement and ways of working need to support working with sectors outside the state health care system.

SACOSS also argues that the public health system should be mandated to enhance the value of public involvement in their operations, with a focus on equity.

The paper concludes by making the case for the urgent re-establishment of an independent, statewide public involvement in health body that has an emphasis on equitable public involvement.

Introduction

Public involvement in the health system, through community and consumer engagement and participation, is vital for safe, accessible, appropriate and effective health care that meets the needs of all South Australians.

Consumer and community participation is when members of the community are able to contribute their perspective to health planning and delivery – ranging from consulting community members when designing a new program, through to structural opportunities for participation that gives communities the power to shape health services to ensure they meet the needs of the community (Baum et al., 2016).

There is evidence that public involvement can improve access to care, quality of care, and health outcomes (Bath & Wakerman, 2015). Public involvement has been argued to be crucial during the COVID-19 pandemic (Marston et al., 2020), to improve acceptability and effectiveness of public health measures, reach communities experiencing marginalisation, mitigate harms from lockdowns, and ensure equity and cultural sensitivity are considered in public health responses (Mahmood et al., 2021; Marston et al., 2020).

The health system is a critical sector that people rely upon to live healthy lives – for health care, disease prevention, and health promotion. SACOSS sees it as vital to the wellbeing of South Australians living in poverty or disadvantage that the health system is accessible, high quality, and responsive to their needs. Robust public involvement opportunities that are inclusive of people with lived experience of disadvantage are necessary to achieve this.

Terminology

The varied terminology used in this field is reviewed in the companion discussion paper. Here, we use the term **public involvement** as an overarching, inclusive term to capture consumer and community engagement, participation, and systemic advocacy in the health system.

Public involvement terminology comes largely from UK literature, to differentiate community and consumer input into health system decision-making and governance, and collective advocacy, as opposed to patient involvement, which concerns where patients are involved in decision making about their own care (Florin & Dixon, 2004). Public is a more inclusive term than consumers or citizens (which excludes the voices of non-citizens, who often struggle the most to access health care), and avoids some of the fraught definitional issues of ‘community’, and locates involvement within a democratic ideal.

Brief summary of the issue

The Health Consumers Alliance of South Australia closed in 2020, leaving South Australia as the only state without a funded, independent health consumer organisation (for the two territories: ACT has a health consumer organisation, but the Northern Territory does not).

The Health Consumers Alliance was funded by the South Australian Department of Health with an initial budget of \$160,000 per annum, growing to \$440,000 by 2019, allowing it to

employ a small number of core staff. The Alliance undertook multiple roles, including consumer advocacy training and mentoring, dissemination of information resources to consumers, working with health organisations on consumer engagement projects and to build their consumer engagement capacity, recruitment of consumer advocates for health system consumer advocate positions, systemic advocacy through forums, reports, and submissions, participating in health system committees, reviews, and advisory groups, presenting consumer engagement awards to the sector, conducting and reporting on surveys on consumer issues, and contributing to multiple consumer engagement frameworks.

The reason given for the defunding was the decentralisation of governance to the Local Health Network level. The Alliance produced a discussion paper in 2020 on future models, highlighting the need for independent, statutory agency that was properly resourced, that could span individual through to systemic advocacy (Health Consumers Alliance of South Australia, 2020b). Since the closure of the Alliance, a volunteer network involving previous members of the Alliance, Health CAN SA, has been established to support consumer advocates in the system and to ensure some level of independent consumer voice in the state, without any resources to support its work.

The discussion paper mapped the current public involvement structures in the state, highlighting Aboriginal Community Controlled Health Organisations (ACCHOs), Local Health Network consumer and community engagement frameworks and structures, Wellbeing SA, the Commission for Excellence and Innovation in Health, Health Advisory Councils, Primary Health Networks, and non-government organisations. Local government and health and medical research were also noted but were not included in the scope of the research.

Methods

This project was funded by residual funds from the closure of the Health Consumers Alliance of South Australia. The money was granted to SACOSS by the outgoing executive of the Alliance. This small amount of money allowed the employment of a Policy Officer for 0.7FTE for 4 months.

National and international grey and peer reviewed literature on public involvement was collected using Google and Google Scholar searches, and reviewed. Interviews were conducted with stakeholders, consumers, and other key informants. Initial potential interviewees were identified through professional networks, and subsequently snowball sampling was used, inviting people recommended by interviewees. Fifty people participated in the project, sharing their perspectives and experiences.

Discussion Paper Findings

The discussion paper reports the main themes emerging these interviews and the literature review:

- Interviewees were clear there was an urgent need to re-establish an independent health consumer body in South Australia. The critical gaps left by the closure of the Health Consumers Alliance include systemic advocacy at a statewide level, training, support,

and networking for consumer advocates in the health system, support in developing consumer engagement frameworks and materials, and a source of information for consumers, community, and staff on consumer engagement and related issues.

- Equity and diversity in the voices of consumer and community advocates is crucial to ensure the health system meets the needs of those experiencing disadvantage or marginalisation, and contributes to reducing health inequities. There are challenges to achieving equity and diversity in public involvement organisations, and it needs to be intentionally prioritised in the way the organisation does business, and supported by the funding and funding agreement arrangements.
- Public involvement bodies typically play an advocacy role and must be able to critique the health system, while also needing to appeal to funders and the health system to which it is providing services (sometimes paid services). It needs to constantly argue for the legitimacy of its voice, and seek coalitions with other community groups.
- The health system can be difficult to interface with – there are 10 Local Health Networks to engage, as well as agencies such as Wellbeing SA and the Commission on Excellence and Innovation in Health, two Primary Health Networks, general practice, the dental sector, allied health, and private health.

In light of these findings, SACOSS has developed the following 10 policy proposals.

Proposals: Funding

1. The establishment of an independent organisation for public involvement in health funded by the state government

There was widespread support for re-establishing an independent health public involvement body, with stakeholders outlining a list of critical functions that were now missing from the South Australian health system, including systemic advocacy, and training and support for consumer advocates in the health system.

2. The funding needs to match the mandate of the organisation, and be sufficient to allow prioritisation of equity.

Stakeholders were emphatic that public involvement bodies need to be resourced properly, with funding to match their remit, or else they risked being set up to fail, and poisoning the well for future attempts.

In particular, achieving more equitable public involvement requires resources, to support consumer advocates from a range of circumstances, to properly service rural and remote South Australia, and to do the work of establishing relationships with community groups and supporting the health system to ensure their community engagement structures are as accessible as possible. Failure to provide sufficient core resources to the public involvement body risks the reproduction of structural inequities, which will exacerbate the state's already increasing health inequities, rather than contribute to remediating them.

3. The organisation may benefit from an agreement with a suitable auspicing body for some organisational functions and resources, including premises; but its independence should be maintained.

Establishing a new body comes with extensive start up costs, consuming limited resources. To help with establishment, the new public involvement body could be auspiced by a peak body such as SACOSS, or sharing infrastructure and support costs with other independent bodies, such as the Health Performance Council or the planned independent preventative health agency could be considered. The benefits and risks of this location of the new body would need to be carefully weighed so that independence was not compromised.

4. Federal funding should also be sought to complement the state funding, potentially through the two South Australian Primary Health Networks.

Since health is the joint responsibility of state and federal governments, many stakeholders reasoned that Federal government funding ought to be advocated for to complement state government contributions. In Tasmania, where a health consumer organisation was recently established, this was achieved via co-funding from the Federally funded Primary Health Networks. There are two Primary Health Networks in South Australia that could be approached to make co-investments. There would also be benefits to advocating nationally for Federal government funding for state and territory public involvement organisations, which may also reduce the threat of state government defunding of these organisations, providing more stability and certainty.

Proposals: Governance

1. SACOSS proposes that community groups that represent populations with inequitable health are embedded in the governance of the new body.

Groups who may have inequitable health care access, health care quality, and/or health outcomes include:

- Aboriginal and Torres Strait Islander peoples
- Multicultural communities, including migrants and refugees
- Lesbian, gay, bisexual, trans/transgender, intersex, queer, asexual, and other sexuality, gender, and bodily diverse people (LGBTIQ+)
- People subject to gender-based violence and experiencing discrimination in health care
- People living in rural and remote South Australia
- People with a disability
- People with mental illness
- People living in poverty
- People who are homeless
- Prisoners

One mechanism that SACOSS strongly encourages would be to structure the board of the organisation so as to enable strong representation on behalf of these population groups. This representation should be drawn from community groups designed to be the voice for those communities, rather than government organisations or service providers. Such a governance model could be embedded in the constitution of the organisation without specifically naming organisations, as the landscape of community organisations is likely to be in a constant state of change.

The Health Consumers Alliance 2004 Constitution included an item that the governing body “shall aim to include representation of people from a non-English speaking background, an [I]ndigenous background and residents outside metropolitan Adelaide” (6.4, p. 4). This emphasis on equity in governance was not in subsequent constitutions.

Somewhat similarly, one of the options canvassed in the Health Consumer Alliance’s 2020 discussion paper on possible future models of consumer engagement was a consortium, or “platform model”:

“A platform model would act to bring together like-minded and supportive organisations and individuals as a collective voice, to improve the health system with a focus on quality improvement.” (Health Consumers Alliance of South Australia, 2020b, p. 11)

There are multiple intended benefits from this model:

- a) Equity and diversity would be front and centre, bringing community voices to the table with power to shape the organisation’s ways of working and decision-making in a way that being a member of an organisation does not allow to the same extent. This would ensure the needs of these equity groups are foregrounded and are the priority for health system change.
- b) It would allow the body to act as a conduit between community groups and the often messy, fragmented health system, and conversely, be available as a conduit to a wide range of community groups for health system actors seeking to engage them. Community groups are often operating on extremely scant resources, and efficiency is needed in how they interact with the large, disparate health sector to support the ability for them to have their voice heard.
- c) It would embed the public involvement body in the community, with strong ties to multiple community groups, allowing the body to be constantly refreshing, learning, and avoid becoming insular or stale, as stakeholders often commented is possible for any longstanding public involvement body.
- d) Being embedded strongly in the landscape of community groups would enhance the organisation’s legitimacy, making it more difficult for others to critique their representativeness, or validity of their advocacy.
- e) It would ensure the body could support consumer advocates and staff in the health system around equity issues, and be a safe place for all consumer advocates in the system to seek help. It would allow the body to have a wealth of shared knowledge around equity, consumer engagement, and the experiences of people from groups with inequitable health and access to health care.

Interviewees generally endorsed this model, though it was not unanimous. People noted that it would require a skilled facilitator. Some interviewees were concerned with conflict between the groups, especially if there were ‘bidding wars’ that threw these groups into competition. Others felt the interactions would be beneficial, as they could learn from each other, and because there were common barriers experienced by many groups, such as around the need to be treated with respect, affordability, and transport.

Some interviewees felt that it may still be beneficial to have some level of competitive appointment to the board, or some means of ensuring a standard of representativeness for board candidates, and of ensuring the board had the required skills base, but that the benefits could be extensive. Others felt it was important to have “skills on the board”, rather than a skills-based board, and that training and structures could be placed around the board members as needed to support the development of required skills, which would have benefits for the wider community organisation sector. Other interviewees felt there may be more innovative governance solutions than a board structure to pursue this goal of embedding equity into governance. Some felt a platform to bring together excluded groups could be central to the organisation without it being part of how the organisation governs itself.

In terms of representativeness, people who have links back to community organisations was seen as a necessity, and that organisations that provided services sometimes had conflicts of interest and did not always as directly represent the interests of the community. One interviewee advised “recruiting from the movement, not the community”, meaning selecting active members of the community with the confidence and skills to see the big picture, and have conversations with decision-makers in ways that could shape decisions. This link to decision-makers was seen as critical to avoid the process becoming tokenistic or failing to achieve change, which can be disheartening and disempowering. The need to resource the involvement of people from community organisations was raised as critical, given the extremely limited funds and staff time available for most community organisations.

To ensure a supportive, fit for purpose public involvement body, governance and how to bring organisations together should be workshopped with community organisations and the health sector to ensure the goals of equity of participation, and influence on decision making can be achieved.

2. The constitution and aims of the organisation need to prioritise a focus on equity.

Achieving equity in public involvement requires intentional prioritisation of time and resources. There are institutional and societal forces and inertia that act against the achievement of equity and diversity. To safeguard equity as the core mission of a new public involvement body, it needs to be baked into the body’s constitution and terms of reference, so that it shapes the body’s ways of doing business. The organisation’s service funding agreement also has to support pursuit of equity in public involvement rather than act as a constraint.

Proposals: Areas of Work

1. The organisation would focus on systemic advocacy, building the health system’s capacity for public involvement and equity, and training, mentoring, and supporting consumer advocates in the health system.

These three areas were the key gaps identified by a wide range of interviewees, and is commensurate with literature on public involvement in health care. It would fall to the

different areas of the health system to recruit members of the public for their consumer engagement structures, with support and guidance from the public involvement body.

2. The organisation is provided with additional funding to provide an individual advocacy service.

There is no individual health advocacy service in the state. Several interviewees identified this gap. The only advocacy services identified in the state were disability advocacy services, which were regarded as very hit or miss, and have extremely long wait times, and the Aged Rights Advocacy Service, which also has a very long wait time for services. The Health Consumers Alliance of South Australia produced a report highlighting this gap (Health Consumers Alliance of South Australia, 2020a), and SACOSS unsuccessfully lobbying for the establishment of such a service in 2020.

Further funding a new public involvement body to provide an individual advocacy service would fill this gap. It would also further strengthen their capacity for and their ability to cement the legitimacy of their systemic advocacy. The Western Australian Health Consumers Council is one successful model that combines systemic advocacy and individual advocacy, as well as consumer and health system staff training and support, and other work with the health system.

3. The organisation's funding agreement and ways of working need to support working with sectors outside the state health care system.

There are opportunities to collaborate with the whole health system. In particular, for a large proportion of people, general practice, allied health, and dental care will be where the bulk of their interaction with the health system takes place. However, these sectors can be difficult to influence because they largely comprise individual private practices.

Public involvement is also critical to health promotion. A number of people advocated for a public involvement body that has the capacity to look outside of the health care system, to raise issues and ideas around the social determinants of health – how our living conditions, including education, employment, housing, neighbourhoods, and the way we structure our society affects people's health (Commission on Social Determinants of Health, 2008). The importance of sectors outside of health was very evident during the COVID-19 pandemic, and highlights the potential of a public involvement in health body that could work with sectors outside of health. To avoid the body's remit far exceeding their resourcing, the body could take on an ally role, amplifying arguments for healthier public policy and healthier environments. One avenue for the public involvement body to address social determinants of health would be to contribute to Wellbeing SA's Health in All Policies initiative.

A number of stakeholders also expressed the importance that the new public involvement in health body could also contribute to public involvement in health and medical research.

Change in the Health System

In order to achieve equitable public involvement in health, considerable work needs to be undertaken in the health system to make consumer engagement structures less ableist,

more inclusive and more accessible. A public involvement in health organisation with a strong focus on equity would be well placed to support this work, but change and vision is needed from within the state health system. This includes providing training to staff, embracing the second National Standard around “Partnering with Consumers”, and developing a culture where community and consumer input is valued, the need to address health inequities is recognised, and health system actors are comfortable and know how to work with the public to ensure the health system meets everyone’s needs.

A statewide public involvement in health body is urgently needed

A statewide, independent body focused on equitable public involvement in the health system would bring wide ranging benefits. Systemic advocacy, informed by the needs of communities with inequitable health and access to health care, would support policy making and health system decision-making that reduces health and health care inequities in the state, and fosters the development of a health system that meets everyone needs.

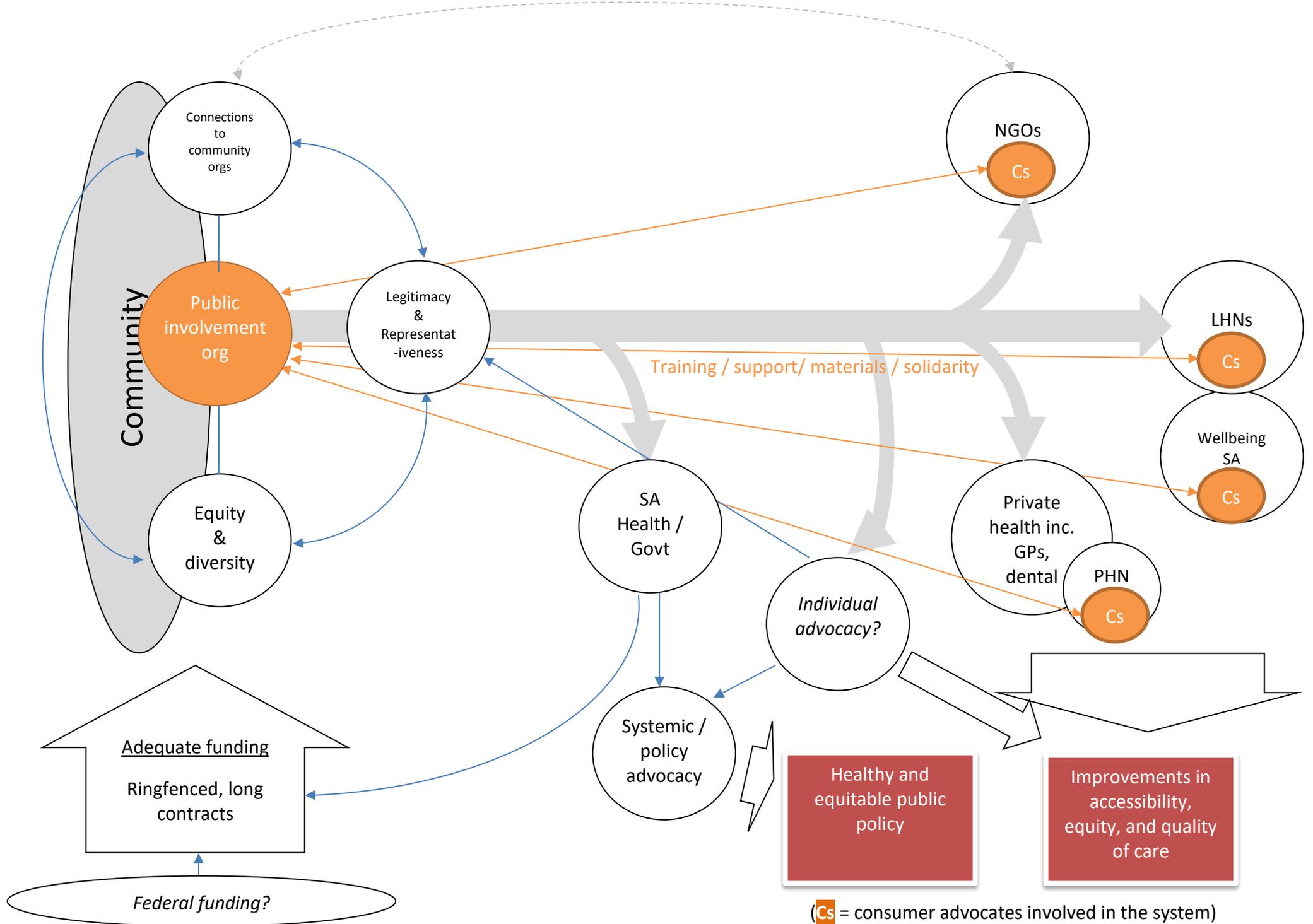
It would create a more connected system, bridging community organisations, and the various elements of the health system that are all too often siloed, and identifying gaps in the system that individual elements cannot see or address, to improve quality and continuity of care for everyone.

It would support consumer advocates and promising consumer engagement efforts in the health system, to ensure consumer advocates and staff are trained, supported, and have opportunities to learn and support each other, leading to greater innovation and better outcomes.

It would allow a greater understanding of the population health issues facing the state’s population, raising emerging issues before they hit the health system, helping promote the health and wellbeing of the population, and alleviating the ever-increasing pressures on our tertiary health systems.

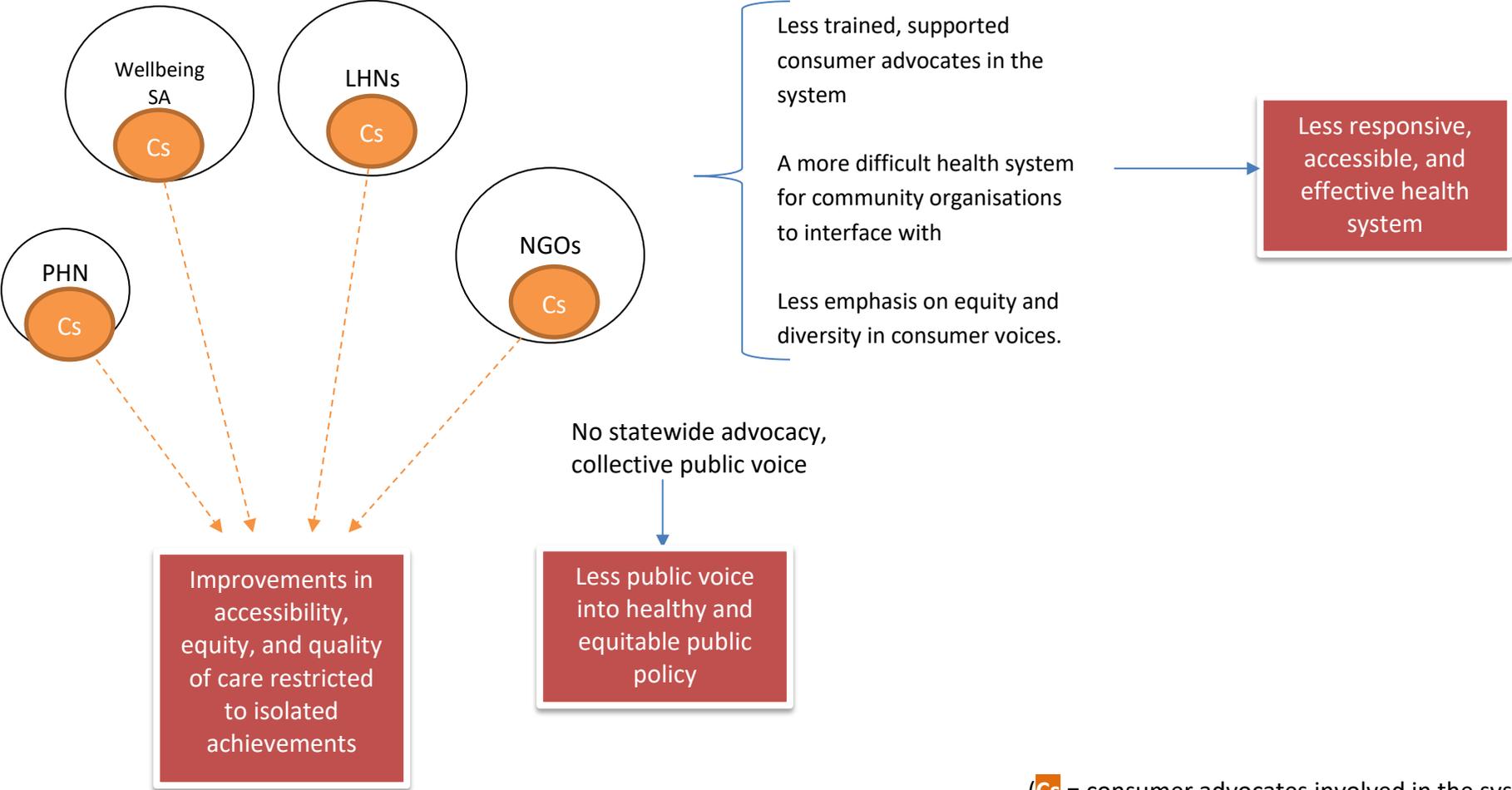
These benefits are summarised in Figure 1, while Figure 2 shows the current state of our health system without a statewide public involvement in health body.

Figure 1. Benefits of a statewide public involvement in health body



(Cs = consumer advocates involved in the system)

Figure 2. The health system without a statewide public involvement in health body



(Cs = consumer advocates involved in the system)

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SACOSS acknowledges traditional owners of country throughout South Australia, and recognises the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures, and to elders past, present and future.