

Select Committee Inquiry into Health Services in South Australia

Health Consumers Alliance SA Submission

Health Consumers Alliance SA

Health Consumers Alliance of SA Inc (HCA) was established in 2002 as the peak health consumer organisation in South Australia as a direct result of grass roots community lobbying. We are a member-based, independent, not-for-profit organisation. We work with our members and supporters to achieve our vision: **Consumers at the centre of health in South Australia.**

Health consumers are people who use, or are potential users of health services, including their family and carers.

HCA's mission is to engage consumers and health services to achieve high quality, safe, consumer-centred care for all South Australians. We seek to promote and strengthen the voices, wellbeing, rights and leadership of health consumers. We advocate that consumer engagement policy and practice is embedded across the SA health care system.

We believe that consumer engagement results in better planning and policy-making. This leads to better health outcomes and community wellbeing.

HCA is currently part of a network of state/territory funded peak consumer organisations that promote and facilitate consumer voice to the health systems across Australia.

HCA submission

Health Consumers Alliance (HCA) was invited to provide a written and/or oral submission. As the peak health consumer group in this state, we are well placed to work with our consumer, community and organisational partners to respond to more detailed questions from the Committee and welcome any Committee request to do so.

This document provides an initial consumer perspective to the Committee's deliberations. It has been informed by:

- A consumer focus group comprising consumers and representatives experienced in safety, quality and governance in South Australian health services
- Ongoing advice from the HCA Consumer Advocates Network, a state-wide group of 200 consumers trained and supported to represent the views of their lived experience and community constituencies
- HCA's long-standing role in consumer representation in a wide range of health system inquiries and health service improvement activities.
- HCA's contracted work with local health networks in the development and implementation of consumer and community engagement frameworks to ensure services meet the requirements

of the National Safety and Quality Health Care Service Standards, particularly Standard 1, Governance and Standard 2, Partnering with Consumers

- Our experience, and that of consumers, of EPAS - from inception and including our current role on the EPAS Reference Group
- Our experience of Transforming Health, including HCA's convening and facilitation of an independent non-government representational reference group, and consumer contributions to the South Australian Health and Medical Research Institute (SAHMRI) evaluation.
- Our everyday work, which sees us interacting with consumers with lived experience and their representatives, and community leaders and representatives, regarding their needs, values and preferences in the delivery of safe, quality health care for all South Australians.
- National and international evidence.

Introduction

HCA welcomes the opportunity to contribute to measures to improve the health service quality, accessibility and affordability for all South Australians.

We note mention of an increased focus on preventative and primary care, a high priority for South Australian consumers as noted in our past two state election and in multiple submissions to government – including submissions to the Transforming Health team.

We welcome interrogation of the South Australian experience in health reform and note the crucial importance of ensuring the lived experience of South Australian health consumers informs decision-making in a systematic and evidence-based manner, in accordance with National Safety and Quality Health Care Standards.

We note our recent pre-election priority, confirmed in all our consumer consultations, of the need for health and social care services to which may be provided or funded by state or federal governments to provide holistic, integrated, consumer-centred care.

We provide the following comments, informed by consumers with lived experience of health services and their communities. We reiterate their high priority for equity of health service access and outcome and services that provide value as defined by the people who use and fund them and measure success in terms of outcomes for people rather than a dollar value for service products and outputs.

Recommendations

1. Increase the focus on preventive and primary health strategies, including (re)establishment of contemporary preventive health and wellness hubs in each local health network that address physical (including dental) health, mental health and social and emotional wellbeing
2. Implement measures to embed consumer and community engagement structures and practices in the design, development, implementation, monitoring and evaluation of health and wellness services.
3. Engage with consumers and communities to determine needs and priorities and work with consumers, clinicians, other front facing staff, managers, policy makers and other decision makers to design and implement evidenced based strategies to meet those needs.

4. Commit to continuous improvement, informed by evidence and driven in partnership between consumers, a broad base of clinicians (including emerging clinicians) and other staff across the health system.
5. Take into account the contribution of other health and social care services in any review of health services, for example, the poor models of general practice within aged care services leads to unnecessary hospitalisations and lack of dignity and self-determination for aged care clients.
6. Implement the use of patient reported outcome measures (PROMs) and patient reported experience measures (PREMs) to ensure consumers expectation of the health system are being recorded and reported on.
7. Establish an individual advocacy service across the health system for consumers and carers.
8. Reinstate centralised funding for the consumer peak body to enable genuine, evidence-informed systemic, state-wide consumer and community engagement.
9. Develop strong accountability for collaboration between LHN's and the development of state-wide plans and approaches to ensure equity of service access and address the needs of vulnerable population groups.

Response to Terms of Reference

The opportunities to improve the quality, accessibility and affordability of health services including through an increased focus on preventative health and primary health care.

Locally, nationally and internationally, consumers have been passionate advocates for preventive and primary health services for many generations. This was evident in the strong community response to the drastic reduction in funding of preventive health programs across South Australia in 2013. South Australia is behind most other Australian states and international jurisdictions in preventive health investment.

Currently, Australia is ranked 16th out of 31 OECD countries on per capita expenditure for preventive health, falling well behind Canada, New Zealand and the United Kingdom at just 1.34% of healthcare expenditure. This equates to an estimated \$2 billion each year or \$89 per person on prevention, compared to \$27 billion annually spent on treating chronic disease.¹

The experience of South Australian consumers confirms the evidence that increased investment in preventive and primary health strategies (including dental) leads to:

- Cost savings in tertiary health and hospital sector ²
- Improvements in Aboriginal health outcomes ³
- Improvements in rural and remote health outcomes
- Reduced pressure and wait times for emergency departments and hospitals in general ⁴
- More effective self-management of chronic conditions
- People living with good health and for longer

Examples of successful prevention and primary health strategies are those that have addressed smoking (lung cancer and COPD); breast cancer; skin cancer; and many diseases that are now prevented through immunisation.

Consumers and community members need a range of preventive and primary health strategies that are accessible close to home to enable healthy eating, active lifestyles, positive mental health and strong and supportive communities so that all South Australians can maximise their health and wellbeing, including those with health issues. These services could be delivered through health and wellness hubs in each LHN.

Consumers and communities confirm the long-standing international evidence that prevention and harm-minimisation approaches in health care require a holistic approach in partnership with individuals and communities. Preventative and primary health strategies must be guided by local consumer needs, values and preferences (consumer-centred); community priorities and evidence-informed principles that include the following:

- Consumers are at the centre of decision making regarding their own health through partnering with clinicians to develop and address personal health goals – including timely discussions regarding wishes towards the end of life
- Consumers are at the centre of health service planning and governance to ensure services reflect the needs, values and preferences of the people using them and value as determined by the communities that fund those services
- Collection and analysis of data includes patient reported experience and outcomes measures, developed (PREMs and PROMs)
- Use collaborative leadership approaches; remove the power imbalance and ‘expert’ views and replace them with respectful health and consumer partnerships for mutual benefit
- Health services measure their success in terms of health outcomes for everyone, including vulnerable groups who might otherwise be overlooked
- Build health literacy, noting that this requires health literate services that fulfil their role in developing consumer and community health literacy
- Remove institutional barriers including systemic racism
- Approaches are positive, focusing on wellness for all and its benefits, rather than illness and risk factors
- Services are holistic- addressing physical, mental, cultural, social and emotional wellbeing
- No blaming or shaming people for ‘poor decision making’ or ‘poor health status’
- Address the social determinants alongside any clinical strategies
- Build capacity and self-determination within communities and individuals
- Recognize that health outcomes will be improved through action on a range of issues outside of the health sector, including housing, education, crime prevention, infrastructure and social care.

The South Australian experience around health reform in the state, specifically Transforming Health, EPAS, the reactivation of the Daw Park Repatriation Hospital and other related projects and or programs.

The South Australian health system has been continuously 'reformed' by successive state and federal governments. Reforms are often led by political ideology, agenda driven clinicians, and unrepresentative vocal community members, rather than evidence-based consumer and community need. The scope for reforms/improvements should be informed by people with experience and knowledge of the service, either as consumers, carers or staff, and the timelines need to allow for proper engagement with each of these groups. Failure to do so frequently results in reforms being unsuccessful, incomplete or reversed by later governments without proper evaluation.

HCA calls for a bi-partisan commitment to engaging with consumers and communities to determine needs and priorities and work with consumers, clinicians, other front facing staff, managers, policy makers and other decision makers to design and implement evidenced based strategies to meet those needs. What our health system needs is a commitment to continuous improvement driven in partnership between an appropriate, representative cross-section of consumers, clinicians and other staff across the health system.

There has been some local success in using these approaches. Notably, the Women's and Children's Health Network worked with HCA to develop and implement a consumer and community engagement framework which is now demonstrating collaborative leadership and quality-improvement approaches to consumer-centred health services. In the recent reforms, some of the Transforming Health Models of Care working groups (such as stroke and rehabilitation) worked collaboratively with consumers to drive evidence informed improvement of these conditions.⁵ Aspects of Transforming Health that are considered by consumers to have been less successful were those where consumers, community members and clinicians were provided with inadequate communications and completely inadequate opportunity to engage in the decision-making process, such as service closures and some of the infrastructure developments.⁶

The *engagement of consumers* should be guided by the work of the Australian Commission on Safety and Quality in Health Care which is supported by all Australian governments.⁷ *Engagement of communities* should be guided by the work of the International Alliance of Public Participation (IAP2) in which consumers, clinicians and health professionals are recognized for their expertise and experience and which outlines the social contract associated with different levels of engagement.⁸ This will ensure that reforms are informed by people with lived experience of the health system being reformed, either as consumers, carers or as employees of the system, and that the voices of communities experiencing poorer health outcomes are sought and heard. Putting a notice in the paper or conducting an online survey provides an opportunity for articulate, opinionated people to provide input, but if they have not used the system, or experienced the service being changed, then their opinion is not informed by either evidence or experience.

Any future reform of our health system should be guided by consumer-informed and evidence-based principles which include the following:

- Focus on bi-partisan sustainable continuous improvement

- Engaging consumers, clinicians and other health service staff in design, development, implementation and evaluation
- Transparency, including open disclosure
- Evidence of accountability to consumers through co-design processes and consumer experience and outcome measures
- Investment in consumer driven research
- Cultural respect and inclusion
- Equity of access and outcome
- Consideration of impacts of reform on the health of Aboriginal people, rural and remote communities and other vulnerable and emerging communities experiencing health inequality.
- Integrated, coordinated care that focusses on achievement of priority consumer and community goals
- Resourcing monitoring and evaluation for safety and quality
- Commitment to effective and efficient use of funds
- Supporting consumers to be self-determining and self-managing to the extent that they choose.

The Federal Government's funding of State Government services and the linking of other federally funded services in South Australia, such as Medicare funded GP services and the Adelaide Primary Health Networks and Country SA Primary Health Network.

When federal and state leaders, bureaucracies and funders do not work together, taxpayer's money is wasted, and the community's health and economic goals are not met at an individual, service or community level. There are many examples of this such as the former government cutting preventive and population health strategies, partly based on the assumption that federally funded Medicare Locals should deliver this work. South Australian consumers and people who work in our overstretched primary care and hospital systems continue to feel the effects of this decision six years later.

The National Disability Insurance Scheme (NDIS) is another current example. This national program has impacted on the funding and provision of state services. While some consumers have benefitted from the program, many others are worse off, or are struggling in a self-directed care environment without adequate support or skills to take sole responsibility for managing their own healthcare needs. In the Riverland, for example, of the 505 individuals approved for NDIS, there are 241 (48%) who are receiving either no services because they are still awaiting a plan or receiving less than 25% of their approved services.⁹

The impacts of lack of access to NDIS, aged care and other social care services can flow on to cause increased emergency department attendance, increased hospital admissions, and longer waiting lists for specialist services.

It is worth noting here that any review of health services should take into account the contribution of other health and social care services, for example, the poor models of general practice within aged care services leads to unnecessary hospitalisations and lack of dignity and self-determination for aged care clients. Similarly, ready access by consumers to primary care services with whom they partner in their health care plans means people's concerns can be quickly answered and unnecessary hospitalisations are avoided.

HCA calls on SA Health and the local health networks to work in partnership with federal health systems and services, including primary health networks and General Practice to ensure that our health system works to support people to maintain their health and wellbeing through early intervention and treatment, and efficient and responsive health services and systems. We must ensure that services are accessible and easy to navigate, so that everyone gets the treatment they need, regardless of their culture, location, age, life circumstances and financial capacity.

Any related matters

South Australian consumers with lived experience of illness, and their carers, possess valuable knowledge and perspectives about health conditions and services that are invaluable and directly relevant to government and policy makers.

The Australian Commission on Safety and Quality in Health Care cites a body of evidence illustrating linkages between consumer-centred care – through strategies such as consumer engagement – and decreased readmission rates, lower healthcare-acquired infections, improved delivery of preventative care services, better functional status, reduced hospital stays and enhanced compliance with treatment regimens.¹⁰ National and international experience suggests this can best be achieved with the continued support of a centrally funded health consumer peak body that can provide training and support to consumers to engage positively, constructively and strategically in health services and systems while also building the capacity of health services to involve consumers in decision making processes.

Further, consumers and carers have consistently identified a need for independent professional support and advocacy whilst they personally attempt to navigate our complex health care system. Making available independent advocacy for consumers experiencing difficulties within the health system would reduce failures in communication, improve access to appropriate services and ensure the voice of consumers is heard by health professionals. As such it would have positive results for both consumer outcomes and public health resources. Increasing public accountability would reduce the risk of situations like Oakden, chemotherapy under-dosing and privacy breaches ever being repeated. This service would recognise and protect the rights of consumers, carers and their families. The effectiveness of advocacy on outcomes is supported by research. For example, it was found that the presence of an effective family advocate increased the chance of referral to rehabilitation for stroke patients.¹¹ The important role of consumer advocates has grown out of this need and is increasingly recognised in health policy and practice locally, nationally and internationally. HCA is appropriately placed, as the peak health consumer body in South Australia, to implement and manage an independent individual consumer advocacy service as an expanded role with ongoing centralised funding.

Decentralising of the South Australian health system will have the positive impact of bringing local health network decision making closer to the consumers and communities they serve, however there is an inherent risk of creating silos and disparities in service access across regions and population groups. HCA calls for strong accountability for collaboration between LHN's and the development of state-wide plans and approaches to ensure equity of service access and address the needs of vulnerable population groups.

Recommendations

1. Increase the focus on preventive and primary health strategies, including (re)establishment of contemporary preventive health and wellness hubs in each local health network that address physical (including dental) health, mental health and social and emotional wellbeing
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