

Response to the draft South Australian Clinical Genomics Plan 2022

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HCA acknowledges the Traditional Custodians of Country. We pay respect to Elders past and present, and recognise that their cultural heritage, beliefs and relationship to Country are important for sustaining health and wellbeing.

Health Consumers Alliance of South Australia Inc (HCASA)

HCASA is the peak body for health consumers in South Australia. We are a member-based, independent, not-for-profit organisation. We work with consumers and health services to position consumers at the centre of care. Health consumers are people who use, or are potential users of health services, including their family and carers.

HCASA'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. This includes public, private and non-government health service providers.

Consumer engagement results in better planning and policy-making and leads to better health outcomes and community wellbeing.

HCASA has recommendations for the SA Clinical Genomics Plan relating to the importance of considering the impact of genomics on health consumers with a focus on equity.

Recommendations

1. A strong overt statement about the importance of considering the impact of genomics on health consumers be included in the SA Clinical Genomics Plan 2022.
2. The SA Clinical Genomics Plan have a commitment to a focus on equity for health consumers that is evident throughout the priority areas for action.

In relation to the specific priority areas and actions HCASA seek the following inclusions:

1. Person-centred approach

HCASA seeks the inclusion of a statement that a person-centred approach to genomics in South Australia will be aware of different needs/expectations of cultural needs.

2. Workforce

HCASA seeks the addition of the need to not only build a workforce that is literate in genomics but one that understands the importance / impact of genomics on consumers.

3. Financing

HCASA seeks an overt statement that financing needs to ensure a focus on equity.

4. Services

HCASA seeks the commitment that the use of genomics in health care should be based on the best available knowledge, evidence and research and the outcomes of treatment should be used to help improve care *for all with a specific focus on equity*.

4.1 HCASA seeks a commitment that genomics applications also refer to ensuring accessibility for all and include culturally appropriate approaches.

4.2 HCASA seeks that sharing of data and information is undertaken with respect to differing cultural beliefs.

4.3 HCASA seeks that genomics research opportunities aim to resolve both clinical and consumer uncertainty.

5. Data

HCASA seeks a commitment to clear and transparent information for health consumers regarding the extent of genomic data that will be collected, stored and shared.

Conclusion

Health consumers will be directly impacted by the advances in research and increased utilisation of genomics services. The commitment in the SA Clinical Genomics Plan to establish a Clinical Genomics Consumer Advisory Committee will help support SA Health to implement the Plan being mindful of the needs of consumers through all aspects of the implementation.