



Community Health Literacy in the ACT:

Environmental Scan – Summary of Findings

February 2020

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About the Health Care Consumers' Association

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations
- training in health rights and navigating the health system
- community forums and information sessions about health services
- research into consumer experience of human services.

Acknowledgements

This project was supported by the ACT Health Directorate. HCCA acknowledges the assistance of the ACT Health Directorate Policy and Partnerships Branch.

HCCA acknowledges with appreciation the guidance and contribution of the Community Health Literacy Project Reference Group:

- Shelley McInnis, Consumer Representative, HCCA
- Purity Goj, Policy Officer, Mental Health Consumer Network
- Nicole Kefford, Policy Partnerships and Programs, ACT Health Directorate
- Louise Botha, Acting Senior Manager Patient Experience and Quality Improvement, Canberra Health Service
- Kathryn Dwan, Policy Officer, Mental Health Consumer Network
- Karen Caldwell, Director of Clinical Governance, Calvary Public Hospital Bruce
- Belinda Yates, Clinical Governance and Quality Manager, Calvary Public Hospital Bruce
- Anais le Gall, Health Pathways Manager, Capital Health Network

HCCA thanks the individual HCCA members, and the staff and volunteers of health care services, consumer organisations and community services who participated in our consultation between February and July 2019. This included representatives of:

- ACT Council of Social Service (ACTCOSS)
- ACT Down Syndrome Association
- ACT Health Directorate
- ACT Shelter
- AIDS Action Council
- Alcohol, Tobacco and Other Drugs Association (ATODA)
- Asthma Foundation
- Bosom Buddies
- Calvary Public Hospital Bruce
- Canberra Alliance for Harm Minimisation and Advocacy (CAHMA)
- Canberra Health Services
- Canberra Multicultural Community Forum
- Cancer Council ACT
- Capital Health Network (ACT Primary Health Network)
- Carers ACT
- Companion House
- Congress of Aboriginal and Torres Strait Islander Nurses and Midwives (CATSINaM)
- Consumers Health Forum of Australia (CHF)
- COORDINARE (South East NSW Primary Health Network)
- Council on the Ageing ACT (COTA ACT)
- Heart Foundation ACT
- Hepatitis ACT
- HCCA Health of Older People Consumer Reference Group
- Mental Health Community Coalition
- Mental Health Consumer Network

- Migrant and Refugee Resettlement Service (MARRS)
- NSW Clinical Excellence Commission
- Pain Support ACT
- Palliative Care ACT
- Partners in Culturally Appropriate Care (PICAC) NSW/ACT
- People with Disabilities ACT
- Red Cross ACT
- Self-Help Organisations United Together (SHOUT)
- Sexual Health and Family Planning ACT
- Women With Disabilities ACT
- Women's Centre for Health Matters

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The ACT - like all other Australian states and territories - endorsed the National Statement on Health Literacy in 2014. The Statement makes it clear that action is needed to improve individual health literacy and the health literacy environment.

Individual health literacy is a term to describe the skills, knowledge, motivation, confidence and personal networks that people need to get, understand and act on health information in daily life.¹

The *health literacy environment* describes the settings in which people seek health information, make health decisions, and use health services.²

Good health literacy is central to good health and to safe, high quality care. Low individual health literacy, and complex health literacy environments, create risks for patient safety and contribute to poor consumer health outcomes.³

In 2019 the Health Care Consumers' Association undertook an environmental scan of health literacy strengths, challenges and existing initiatives in the ACT. This work was supported by the ACT Health Directorate. It involved discussion with more than 70 representatives of consumer organisations, community services and health care organisations in two workshops, semi-structured interviews and an online survey. HCCA also reviewed Australian and international health literacy initiatives, and relevant academic and policy literature, to identify initiatives that could meet community needs in the ACT.

The Environmental Scan found that health literacy strengths and challenges for communities in the ACT and region are consistent with those experienced in other metropolitan and urban areas of Australia. Recent data from the Australian Bureau of Statistics suggests that most people who use health services in the ACT are confident in their health literacy skills. However, a significant minority report challenges in areas including navigating the health system, and assessing the quality of health information.⁴ The only nationally representative survey of the health literacy of Australians found in 2006 that 44 per cent of ACT residents have a level of health literacy that means they would struggle with daily health-related tasks, such as calculating the right dose of a medication.⁵

Health literacy is a "state, not a trait".⁶ It is not a fixed personal characteristic. Most people who use health services in the ACT will face health literacy challenges at some point in their life.⁷ In the ACT as nationally, people facing socioeconomic disadvantage, Aboriginal and Torres Strait Islander people, people of culturally and linguistically diverse backgrounds, people with multiple chronic conditions and people with disabilities are more likely than others to experience health literacy challenges.

There is an international research and practice consensus that better community health literacy can be achieved by action in four areas:

- Improving communication between health professionals and health care consumers and carers,
- Improving information resources for health care consumers,

- Taking action to make health services and the health system easier to access and to navigate, and
- Changing the culture and systems of health care organisations, so that these support health literacy.⁸

ACT policy frameworks and standards for health care organisations and professionals encourage and in some cases mandate action in these areas. Relevant work is being led by health care providers, community services, consumer organisations, ACT Government Directorates and other agencies including ACT schools. While this work is wide-ranging, there is a focus on supporting individual health literacy by developing and disseminating consumer information resources and educating consumers and patients. There is less focus on assisting people to develop health literacy skills (for example, assessing health information) and the confidence to use these skills (for example, by asking questions of health care providers). However, community and consumer organisations hold expertise in these areas, and some innovative work is taking place.

The Environmental Scan identified key gaps in the ACT's response to health literacy challenges. These are:

- The absence of a jurisdiction-level framework to guide health literacy improvement in the ACT.
- Limited coordination of work led by diverse organisations, and few opportunities for the organisations, staff and volunteers involved to share and learn from each other's experiences.
- Limited focus on the connection between health literacy and patient safety, and low community awareness of this connection, and
- Unmet consumer demand for health literacy skills development opportunities, including in the context of self-managing one or more chronic conditions.

In addition there is an opportunity to strengthen health and community services' awareness of the health literacy strengths and barriers for culturally and linguistically diverse communities in the ACT, and the strategies that members of these communities use to self-manage chronic health conditions.

Finally, while people who access community services can face significant health literacy challenges, the staff and volunteers of these organisations have few training or development opportunities to support them build service users' health literacy.

There are opportunities to strengthen the ACT response to health literacy. The Environmental Scan made the following recommendations for the ACT Health Directorate:

1. Develop and implement a Health Literacy Framework to guide an ACT-wide approach to health literacy. A draft Framework has been developed as part of this project.
2. Support the establishment of a Health Literacy Network for the ACT in 2019-2021, to provide opportunities for cross-agency learning and professional development.
3. Support development, pilot and delivery of health literacy training for community sector workers in 2019-21.

4. Support development of an online health literacy resource for the ACT, to raise awareness of health literacy issues and support improvement. This resource will provide practical skills-based health literacy resources for consumer organisations, community services, health professionals and consumers. This will include a focus on health literacy resources related to patient safety, self-management of chronic conditions and assessing the quality of health information.⁹
5. Support action research about the health literacy strengths and challenges for culturally and linguistically diverse groups in the ACT, particularly in relation to chronic conditions self-management.
6. Support action research to identify the factors that support consumers with multiple chronic conditions to develop health literacy skills, confidence and motivation.

The report makes the following recommendations for health services in the ACT:

7. Develop health literacy improvement plans that reflect the action areas in the ACT Health Directorate's Health Literacy Framework.
8. Partner with the NPS MedicineWise *Choosing Wisely* initiative, to support health professionals and consumers to consider the risks and benefits of tests and treatments and to make informed choices for safe, high value care.
9. Provide staff training and development in interpersonal communication techniques, and the connection between patient safety and health literacy. Other training and development opportunities identified by this project relate to culturally competent care, culturally safe care for Aboriginal and Torres Strait Islander people, and involving people with intellectual disabilities or cognitive impairment in shared decision-making. Training in these areas should be supported by organisational commitment to these areas, and ongoing quality improvement processes.
10. Ensure policies and practices support consumers to use communication aids where that is their preference.
11. Improve processes to identify carers, recognise and respond to carers' health needs, and support the role carers play in patient safety.

The report also recommends that:

12. Agencies that develop professional standards and codes of conduct for health care professionals more consistently address health literacy-related competencies in these codes and standards.
13. The ACT Public Library Service, consumer organisations and health care organisations explore opportunities to enhance the role public libraries play in support of health literacy, for example by adopting the *Words for Wellbeing* scheme.
14. Higher education and training providers in the ACT explore opportunities to strengthen the focus on health literacy knowledge and skills development for future health professionals.

Progressing these opportunities will require collaborative work between ACT Government Directorates, health services, education and training providers, community and consumer organisations and other agencies including libraries.

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