



## **Community Health Literacy in the ACT:**

### **Environmental Scan**

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.

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- 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

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- 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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## Section 1. Executive Summary

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.<sup>1</sup>

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

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.<sup>3</sup>

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.<sup>4</sup> 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.<sup>5</sup>

Health literacy is a “state, not a trait”.<sup>6</sup> 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.<sup>7</sup> 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.<sup>8</sup>

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.

This report identifies key gaps in the ACT's response to community 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.

In response to these gaps, this report makes 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.<sup>9</sup>
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.

## Section 2. Background

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### *About this report*

This report shares learning from research and consultation on the topic of community health literacy in the ACT and region. Between February and July 2019 HCCA consulted 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.

This report:

- documents community health literacy strengths and barriers in the ACT and surrounding NSW region
- maps existing initiatives and services that support health literacy
- identifies initiatives in other jurisdictions that could be adapted for the ACT, and
- recommends actions to improve community health literacy, including work for implementation in 2019-21.

Consistent with the requirements of Schedule 2 of the contract between HCCA and the ACT Health Directorate for the Community Health Literacy Project, this document is **an environmental scan and report on the health literacy context in the ACT.**

The report's findings are relevant to people who work for health care services, or are involved with consumer organisations. The findings are also relevant to volunteers and staff of community services that assist vulnerable people who may face health literacy challenges.

The findings will inform a Health Literacy Framework for the ACT Health Directorate, the Health Directorate's ongoing policy development related to health literacy and HCCA's work in support of community health literacy.

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### *Report structure*

Sections 2 to 4 of this report provide a general background on health literacy. Section 5 to 8 provide ACT specific information and Section 9 provides conclusions and recommendations

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### *Methods*

Research and consultation for this project involved:

- Review of organisational and jurisdictional health literacy plans developed by other Australian jurisdictions and by overseas jurisdictions with comparable health systems,
- Identification and review of key data relating to health literacy in the ACT,

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- A survey for health and community services, to map existing work in support of health literacy in the ACT and region,
- Semi-structured interviews with representatives of health care organisations consumer organisations and community sector organisations, and
- Two workshops with representatives of consumer and community organisations.

Data gathered in workshops, interviews and the survey were analysed to identify key themes relating to community health literacy strengths and challenges, factors enabling improvement in levels of health literacy, and gaps and priorities for future work.

Findings from consultation with consumer and community organisations were shared with participating organisations with the invitation to make corrections, additions and other suggestions. Minor changes have been made in response to feedback received.

The project was overseen by a Reference Group that advised on methods, findings and recommendations. It brought together representatives of the Mental Health Consumer Network, ACT Health Directorate, Canberra Health Services, Calvary Public Hospital Bruce, Capital Health Network and HCCA.

## Section 3. Health literacy

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### *Defining health literacy*

The National Statement on Health Literacy, to which all Australian governments have agreed, recognises that action is needed to build *the health literacy of individuals*, and to improve the *health literacy environment*.

*Individual health literacy* refers to the knowledge, skills, motivation, confidence, capabilities and personal networks that people draw on to get, understand and act on health information and make decisions about their health in everyday life.<sup>10</sup>

The *health literacy environment* refers to the settings in which people seek health information and receive health care. This includes buildings, signage and maps, policies and processes, information resources such as websites and brochures, and interpersonal communication with clinical and non-clinical staff in health care services.<sup>11</sup>

Health literacy is central to good health and to safe, high quality care. It helps people to stay well, recover from injury or illness, and live well with an ongoing condition or disability. Having low health literacy puts people at risk of poor health, going to hospital more often, poor recovery after being in hospital, making mistakes when taking medication, and needing health procedures or treatments that may have risks or financial costs.<sup>12</sup> People with lower health literacy are more likely than others to face difficulty accessing health services, and to have poor control of ongoing conditions such as Type 2 Diabetes or heart disease, which can impact negatively on their quality of life.<sup>13</sup> They are also more likely to have poor health in later life, and to experience an adverse event while receiving care.<sup>14</sup> Having low health literacy and being cared for in a complex health literacy environment increase the risk of avoidable patient harm - including emotional, financial and physical harm.<sup>15</sup>

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### *Individual health literacy: skills, confidence and knowledge*

Individual health literacy includes the *basic skills* that people need to understand health information, for example literacy, numeracy and problem-solving. Health literacy also includes *interactive and communication skills* such as expressing ideas, listening, asking questions, assessing information and applying it to changing circumstances. These skills make it possible for people to make informed decisions about their health, and decide between health care options. It can take time, support and practice as well as motivation and confidence to develop and use these skills.<sup>16</sup> For many people, supportive personal networks - for example of family, peers or colleagues - are essential to developing and using health literacy skills.<sup>17</sup> Health literacy also includes *critical literacy skills*. These are the conceptual and social skills that allow people to gain greater control over their circumstances, including by participating in health care improvement processes and collective action to address health care issues.<sup>18</sup>

Many definitions of health literacy emphasise that it involves a *process of consumer empowerment* in which people develop skills, confidence, knowledge and networks

that allow them to participate in decisions about their own health, and take part in decisions about how health services are delivered.<sup>19</sup>

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*A community, professional, organisational and system asset*

Health literacy is not only about individuals. It is also an asset for families and communities, health professionals, health care organisations and health systems. *Communities* with high health literacy are better able to thrive despite challenges such as pressure on health services and the growing number of people of living with long-term conditions.<sup>20</sup> *Health literate professionals* present information in ways that improve people's understanding and ability to act on information. Professionals who do this are better able to partner with consumers in decision-making, which has demonstrated benefits not only for patient outcomes but also for staff satisfaction and retention.<sup>21</sup> *Health literate organisations* understand the health literacy issues affecting people who use their services, and take action to improve the health literacy environment.<sup>22</sup>

**Box 1: Attributes of health literate organisations**

A health literate organisation:

1. Makes health literacy integral to its mission, structure, and operations.
2. Integrates health literacy into planning, evaluation measures, patient safety, and quality improvement.
3. Prepares the workforce to be health literate and monitors progress.
4. Includes populations served in the design, implementation, and evaluation of health information and services.
5. Meets the needs of populations with a range of health literacy skills while avoiding stigmatisation.
6. Uses health literacy strategies in interpersonal communications and confirms understanding at all points of contact.
7. Provides easy access to health information and services and navigation assistance.
8. Designs and distributes print, audiovisual, and social media content that is easy to understand and act on.
9. Addresses health literacy in high-risk situations, including care transitions and communications about medicines.
10. Communicates clearly what health plans cover and what individuals will have to pay for services.<sup>23</sup>

*Health literate health care systems* provide “equal, easy and shame-free access to and delivery of health care and health information”, and are better placed to reduce preventable illness and provide high quality and safe care.<sup>24</sup> They are also better able to reduce unnecessary health care costs associated with low health literacy,

which are estimated to account for between 2 per cent and 5 per cent of national health budgets.<sup>25</sup>

Building health literacy is a shared responsibility of health service leaders, health care professionals and other health care staff, consumers and carers, community services and other agencies including libraries, schools and higher education and training providers.<sup>26</sup>

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### *Conclusion*

There is a clear case for action to improve individual health literacy, and the health literacy environment. When community health literacy is strong and the health literacy environment is positive, communities are healthier and more resilient, and health care is safer for people. Health professionals are more satisfied in their work, and health care organisations are more efficient. Consumers and carers are better able to act on health information, make decisions about their care and look after their health.

## Section 4. What builds health literacy? Evidence and practice review

### Key messages

Health services and other agencies can take many practical steps to make it simpler for people to:

- get, understand and act on health information that is relevant, recent, reliable and trustworthy,
- communicate well and be understood by health professionals, so their needs are met,
- access health services and navigate the health system and
- change organisational culture and systems so these support health literacy.

There are many initiatives in each of these areas that organisations in the ACT can learn from, including initiatives that promote health literacy as a patient safety issue.

### Areas for action

Health literacy strategies, frameworks and initiatives in Australian jurisdictions and comparable overseas countries consistently focus on the areas detailed in tables 1 and 2 below. Section 10 provides links to the initiatives in this table.

**Table 1: Health literacy action areas and example actions**

| Action area                              | Example actions  |
|--|--|
| Improving consumer information resources | <ul style="list-style-type: none"><li>• Use guidelines when developing consumer resources or choosing existing material (for example the <i>ACT Health Directorate Consumer Handouts Policy</i> or the <i>Guide to Producing and Sourcing Quality Health Information</i> developed for Safer Care Victoria)<sup>27</sup>.</li><li>• Provide trustworthy consumer information in non-clinical settings (for example the <i>Words for Wellbeing</i> program in public libraries).<sup>28</sup></li><li>• Provide consumer information in a variety of ways to meet needs and preferences of different audiences, including but not limited to online via internet-connected mobile devices (for example Illawarra Shoalhaven Primary Health Network's <i>MySurgery</i> app and magazine).<sup>29</sup></li></ul> |

|  |   |
|--|---|
| <p>Improving interpersonal communication between consumers and health professionals</p>  | <ul style="list-style-type: none"> <li>• Train and support staff to use approaches that improve patient understanding (for example <i>Teach Back.</i>)<sup>30</sup></li> <li>• Train and support staff to use communication techniques that build empathy and help ensure care responds to patient priorities (for example <i>What Matters to You?</i> conversations).<sup>31</sup></li> <li>• Train and support staff to provide culturally competent care.<sup>32</sup></li> <li>• Promote use of interpreters.</li> <li>• Promote use of consumer-controlled communication resources (for example <i>Health Passports.</i>)<sup>33</sup></li> </ul>  |
| <p>Making health services and the health system easier to access and navigate</p>        | <ul style="list-style-type: none"> <li>• Create cross-service networks to identify people who cannot access services due to cost issues, and fund free service access.<sup>34</sup></li> <li>• Introduce and evaluate patient navigator and care coordination roles.<sup>35</sup></li> <li>• Use the <i>First Impressions</i> or <i>Walking Interview</i> methods to identify wayfinding improvements.<sup>36</sup></li> </ul>  |
| <p>Changing organisational culture and systems so that these support health literacy</p> | <ul style="list-style-type: none"> <li>• Use validated organisational self-assessment tools to set a benchmark for performance and to measure change.</li> <li>• Ensure quality improvement processes address health literacy.</li> <li>• Report to the public on organisational health literacy aims and achievements at regular intervals.</li> <li>• Make an organisational commitment to improving health literacy.</li> <li>• Identify organisational leaders and champions of health literacy.</li> <li>• Raise the profile of health literacy issues (for example by observing Drop the Jargon Day or Health Literacy Week).</li> <li>• Improve information management systems so that health professionals are less reliant on consumers and carers to coordinate information and repeat their story.<sup>37</sup></li> </ul> |



Some jurisdiction-level plans also focus on the following additional areas for change.

**Table 2: Additional action areas and example actions**

| Action area   | Example actions   |
|---|---|
| Prioritise health literacy in higher risk situations                | <ul style="list-style-type: none"> <li>• Review and improve correspondence with consumers, for example discharge notes and outpatient appointment letters, to identify opportunities for these to support health literacy including by providing clear information about self-care and self-management.<sup>38</sup></li> <li>• Develop consumer information resources that support consumer understanding of patient safety risks and ways to promote safety. Examples include the Western Australian Government's <i>Patient First</i> initiative<sup>39</sup>, the Health Consumers' Council of Western Australia's <i>Going to Hospital, a consumer guide</i> and <i>Staying safe when using health services</i> publications<sup>40</sup>, and United States Joint Commission's <i>Speak Up</i> program.<sup>41</sup></li> </ul> |
| Support health professionals and consumers to make informed choices | <ul style="list-style-type: none"> <li>• NPS MedicineWise's <i>Choosing Wisely</i> initiative<sup>42</sup> promotes conversations about the risks and benefits of tests and treatments, and encourages health professionals, consumers and systems to move away from low-value care.</li> </ul>   |
| Community and human services systems support health literacy        | <ul style="list-style-type: none"> <li>• Train and support community sector workers to help their clients navigate the health system and build health literacy, for example the Scottish NHS <i>Link Worker</i> program.<sup>43</sup></li> </ul>  |
| Education system supports health literacy                           | <ul style="list-style-type: none"> <li>• Expand the role of school nurses in health literacy.</li> <li>• Integrate health literacy into higher education and training of future health professionals.</li> <li>• Incorporate health literacy skills training in adult literacy and numeracy education, and English language education for recent migrants and refugees.<sup>44</sup></li> </ul>   |

### *Conclusions*

While there is a strong case for action in these areas, the evidence about which specific actions or interventions are most effective is less clear. A good practice principle in this area is that community members, consumers and representatives of services hold valuable knowledge about what is necessary, possible and best in local settings.<sup>45</sup> The next sections describe the community health literacy context in the ACT, and findings from consultation with representatives of health care providers, community services and consumer groups.

## Section 5. Community health literacy in the ACT

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### Key points

- Health literacy challenges in the ACT are consistent with those faced nationally.
- Some groups of people are more likely than the general population to face health literacy challenges. This includes people with limited formal education and people working in low-income employment, people of culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander people, people with disabilities, and people with one or more chronic condition.
- People's health literacy strengths and challenges, their health information needs, and their preferences for how information is delivered, may change over the course of their life.

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### Population data about health literacy

In 2006, the Australian Bureau of Statistics (ABS) released national data that measured health literacy as a component of adult literacy, numeracy and problem-solving skills. This survey found that 44% of people in the ACT had a level of health literacy which meant they could face difficulty completing every day health-related tasks, for example calculating the dose of an over the counter medication.<sup>46</sup>

Nationally, this survey found that 60% of people in Australia had a level of health literacy inadequate to daily health-related challenges. The ACT's comparatively strong result may have reflected the jurisdiction's relative proportion of residents with higher education qualifications and incomes above the national average, both factors associated with better individual health literacy.<sup>47</sup>

More recent ABS health literacy data released in April 2019, which used a different methodology to measure nine health literacy competencies,<sup>1</sup> does *not* suggest significant differences between the ACT residents and people in other urban parts of Australia. This data indicates that most ACT residents feel positive about their health literacy, particularly about their relationship with health care providers, their access to information to manage their own health, and social support for health. However, a significant minority of ACT survey respondents reported facing health literacy challenges. Of these respondents:

- Almost 20 per cent reported difficulty appraising information.
- Just over 15 per cent reported difficulty navigating the health care system.
- More than 10% reported difficulty "actively engaging" with their health care providers.<sup>48</sup>

Reflecting the situation nationally, some communities and groups of people in the ACT are more likely to have lower health literacy and to face significant demands on

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<sup>1</sup>For example, feeling understood and supported by health care providers, social support for health and ability to find good health information.

their health literacy. There is a close association between lower socioeconomic status, and lower health literacy. Adults with limited literacy and numeracy skills, people working in low-paid and low-skilled jobs, and people without a post-school qualification in the ACT and region are more likely to have lower health literacy.<sup>49</sup> People who live outside metropolitan areas are also more likely to be affected by health literacy challenges.

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### *People with one or more chronic conditions*

People with multiple chronic conditions are more likely to feel negative about their ability to manage their own health and are less likely to have social support for health than other people.<sup>50</sup> By necessity, people with two or more ongoing health conditions often develop a range of health literacy skills, and strategies to protect their safety while receiving care - for example, carrying documentation about their care preferences and medical history. However even people with high health literacy can face challenges when their circumstances change, for example when diagnosed with a new condition.<sup>51</sup> People with multiple chronic conditions who participated in consultation for this project indicated that it can be difficult to get health information that reflects the interplay of their different health conditions.

Many people in the ACT have one or more chronic condition. The most recent ACT Chief Health Officer's Report observes that:

*"More than half of all adults in the ACT had at least one of the following: arthritis, asthma, back problems, cancer, chronic obstructive pulmonary disease, cardiovascular disease, diabetes and mental health conditions. Of all adults, 23.2% had at least two of these chronic diseases. Of those aged 45 years and over, 44.8% had at least two of these conditions."*<sup>52</sup>

Supporting people to build their health literacy skills, confidence and motivation is recognised as part of safe, high quality care for people who have one or more chronic condition.<sup>53</sup>

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### *Culturally and linguistically diverse communities*

People of culturally and linguistically diverse backgrounds are more likely than the rest of the population to face health literacy challenges. Migrants to Australia can experience tensions between their cultural understandings of health and illness, and the biomedical model of Australian health care.<sup>54</sup> In addition, migrants' experiences of health care in their countries of origin shapes their expectations of care in Australia, and this can affect patterns of service use and under-use.<sup>55</sup> For example, refugees and migrants from countries with poor health systems may lack trust in public-funded health services. Lack of familiarity with the Australian and ACT health and human services systems means that people of culturally and linguistically diverse backgrounds may not know where to go for health information or services.<sup>56</sup>

People with limited English language proficiency can face significant barriers to good communication about their health care needs.<sup>57</sup> Participants in consultation for this project have suggested that health professionals do not always recognise when a patient requires an interpreter. Even when interpreters are engaged, people may feel that their understanding of the situation is brushed aside or overlooked.<sup>58</sup> Refugees

may have past experiences of trauma, placing an onus on services and professionals to deliver trauma-informed care.<sup>59</sup>

The ACT and region's culturally and linguistically diverse population is growing, and is expected to continue to grow in coming years. At present, approximately 28 per cent of the ACT population was born overseas, and the ACT's largest migrant populations are from England (13,300 people), China (11,900 people) and India (10,900 people). The Philippines, Vietnam, Malaysia, Sri Lanka, South Korea, Italy, and Germany are among the top 20 countries of origin for international migrants to the ACT.<sup>60</sup>

Data consistently indicates that people born outside of Australia have lower health literacy than the Australian-born population. However, published data for the ACT and surrounding NSW region reveals little about the specific health literacy strengths and barriers of either emerging migrant or refugee communities, or well-established communities that now include an ageing population.

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### *Aboriginal and Torres Strait Islander people*

Aboriginal and Torres Strait Islander people in the ACT and region experience a greater incidence of chronic conditions than the general population, and are over-represented among people living with poverty.<sup>61</sup> In the ACT, Aboriginal and Torres Strait Islander people report having a level of psychological distress more than three times higher than non-Indigenous people.<sup>62</sup> The National Aboriginal and Torres Strait Islander Health Plan (2012-2023) recognises that a focus on health literacy is one part of an approach to improving the health and wellbeing of Indigenous Australians.<sup>63</sup>

Aboriginal and Torres Strait Islander people often report feeling culturally unsafe in hospitals.<sup>64</sup> Representatives of Aboriginal and Torres Strait Islander community and health services who took part in this project reported that this can compound the stress and anxiety that is often associated with hospital, particularly with in-patient care in emergency circumstances. The Capital Health Network reports that "some Aboriginal and Torres Strait Islander patients and families experience barriers" to mainstream primary health care services.<sup>65</sup> Participants in consultation for this project reported that general practitioners and practices have a varied awareness of health issues affecting Aboriginal and Torres Strait Islander people.

Health services can improve care by understanding the culture and health needs of Aboriginal and Torres Strait Islander communities who access their services, using culturally appropriate signage and information resources, working with Aboriginal and Torres Strait Islander organisations to identify and meet information needs,<sup>66</sup> and having current knowledge about health care initiatives for Aboriginal and Torres Strait Islander people. As an example, consultation participants advised that general practitioners and community pharmacists do not always know about the Closing the Gap PBS Co-Payment measure, under which Aboriginal and Torres Strait Islander people with a chronic illness can access free or low-cost medicines.<sup>67</sup>

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### *People with disabilities*

People with disabilities can face additional health literacy barriers. People who have National Disability Insurance Scheme (NDIS) plans must have high health literacy in

order to manage their plans and negotiate NDIS requirements. People who are ineligible for the NDIS can face challenges in finding information about what services are available and accessing services.<sup>68</sup> This is also an issue for people who may be eligible for the NDIS but choose not to participate. The way health facilities are designed can make it hard for people with physical disabilities to physically access services, for example if kerbs are too high for people who use wheelchairs, scooters or walkers. People with vision or hearing impairments may require information in accessible formats. People with intellectual disabilities or cognitive impairment may require support and time to take part in supported decision-making. Some people with disabilities prefer to communicate with health care professionals by using communication tools, for example communication boards or health passports.<sup>69</sup> Participants in consultation for this project advised that health service staff are not always familiar with these tools, and services do not always have clear processes in place to support their use. Improvement in this area would support health literacy.

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### *Carers*

Unpaid carers face significant demands on their health literacy, and their health and social support needs are often overlooked.<sup>70</sup> Carers play an important role in protecting the safety of the person they care for, but this role is not always well-recognised by health care organisations or professionals.<sup>71</sup> Participants in consultation for this project advised that better identification of family carers, recognition of the needs of carers, and involvement of carers and family members in decision-making would support the role that carers play in patient safety. These issues affect many people who use health services in the ACT: approximately 44,800 ACT residents care for a family member or friend.<sup>72</sup>

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### *Older people*

People aged over 65 are recognised as a group that may require health literacy assistance.<sup>73</sup> However, recent ABS data suggests older people may also be more likely than others to have health literacy strengths including the capacity to actively manage their health and to engage with health care providers.<sup>74</sup> Older people with other risk factors for poor health literacy, for example multiple chronic conditions, cognitive decline or loss of vision, hearing or memory, are more likely to experience poor health as a result of low health literacy.<sup>75</sup>

In the ACT, there has been a reduction in recent years in the numbers of GPs attending Residential Aged Care Facilities (RACFs).<sup>76</sup> This poses a challenge for the health literacy of RACF residents as well as for their health generally, as GPs are a key source of health information. Registered Nurses employed in RACFs are often responsible for the nursing care of many residents, meaning that residents and their families are highly reliant on personal care workers and Enrolled Nurses to identify and respond to health care needs. While the significant challenges related to aged care quality, safety and workforce sustainability<sup>77</sup> are beyond the scope of this report, this situation indicates that personal care workers and Enrolled Nurses in RACFs may benefit from additional opportunities to build skills, confidence and knowledge related to health literacy.

Like the general population, older people have diverse preferences with regards to how they prefer to receive health information. Participants in this project expressed that while online delivery of information will suit some older people, this group is less likely than the general population to have strong internet search skills, or internet access. Older people on low and fixed incomes, including public housing residents, are less likely than the general population to use internet-connected mobile devices or have computers in their homes, and can face information barriers because health information is increasingly delivered online.

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### *Children and young people*

Children and young people require support and education to develop their health literacy skills, knowledge and confidence so that they can manage their own health and health care needs more independently. Young people in complex circumstances and experiencing socioeconomic disadvantage face additional health literacy barriers.<sup>78</sup>

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### *Anyone can be affected*

Anyone can be affected by low health literacy. It is not a fixed individual capacity, and can change over the life course and depending on personal circumstances. Individual health literacy tends to be lower when people are unwell, fatigued or stressed – all experiences that often accompany use of health care services.<sup>79</sup> Health experiences such as injury or illness, considering a test or treatment, diagnosis with a long-term condition, becoming a parent or taking on a caring role for a family member or friend, can also test health literacy capacity.

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### *Conclusions*

This discussion has identified that health literacy strengths and challenges in the ACT are consistent with those faced across Australia. There are opportunities for health care services in the ACT to:

- Improve identification of carers and their health and social support needs, and support carers to play a role in patient safety,
- Promote health initiatives for Aboriginal and Torres Strait Islander people, including promoting general practice and community pharmacy awareness of the Closing the Gap PBS co-payment initiative,
- Respond to the needs, preferences and circumstances of the groups of people who are most at risk of low health literacy,
- Adapt health communication strategies to meet the needs and preferences of people of different ages and stages in life, and
- Introduce policies and practices that support consumers to use communication aids where that is their preference.

Because health literacy challenges can affect anyone, health services and professionals should share information and speak in ways that everyone will find

easy to understand, and avoid pre-judging a person's level of health literacy. This is sometimes called a *universal precautions* approach to health literacy.<sup>80</sup>



## Section 6. Policy, organisational and professional frameworks in the ACT

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### Key messages

This section reviews ACT Government policy frameworks, and organisational and professional standards that apply to health care providers in the ACT. It shows that:

- The policy environment in the ACT encourages action on health literacy, and
- Organisational standards, and professional competency frameworks, support or require action on health literacy.

The aim of the review is to indicate the general state of these aspects of the health literacy environment. It does not seek to cover every professional standard or policy document related to health literacy in the ACT.

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### Policy and funding frameworks

ACT Government policy frameworks recognise the importance of health literacy. For example, the ACT Health Directorate's Digital Health Strategy commits to improving the management of digital information so that the system is less reliant on consumers and carers "telling their story" multiple times to different health professionals. The Strategy also commits to providing more information via an ACT Health Directorate digital platform, for example real time data on waiting times at health services, to help consumers make informed choices about service use.<sup>81</sup>

The ACT Health Quality Strategy recognises that health literacy is a driver and enabler of safe and high quality care.<sup>82</sup> It observes that:

*"An organisational commitment to improve health literacy is required to help people understand information about health and health care and how they apply that information to their lives, and use it to make decisions."*<sup>83</sup>

The draft Territory Wide Health Services Framework makes a commitment to support the health literacy of parents of babies, infants and young children, including families at risk of poor health outcomes.<sup>84</sup> The ACT Chronic Conditions Strategy (which ended in 2018) aimed to support health literacy by encouraging people to be involved developing their care plan.<sup>85</sup> Initiatives led by the Community Services Directorate under the ACT Human Services Blueprint are also relevant as they proceed from the principle that human and community services should be easy to navigate and should respond to the needs of service users.<sup>86</sup> The ACT Health Directorate's forthcoming Preventative Health Strategy is an opportunity to address the connections between health literacy and preventative health interventions.

Healthcare funding arrangements also support action on health literacy. In particular, the bilateral funding agreement between the Commonwealth and ACT governments for *Co-ordinated care reforms to improve patient health outcomes and reduce avoidable demand for health services*, which concludes in December 2019, commits ACT Health to work in partnership with other agencies to improve consumer and organisational health literacy by:

- Providing information to consumers through a range of mediums,
- Supporting consumers to self-manage chronic conditions, and
- Ensuring that clinicians and other relevant staff incorporate health literacy principles in all communication with consumers.<sup>87</sup>

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### *Organisational and professional frameworks*

Key health service quality frameworks, including the National Quality and Safety Health Service (NQS) Standards and the Royal Australian College of General Practitioner's Standards for General Practice, require action to address health literacy.

NQS accredited health services must demonstrate that they “communicate with patients in a way that supports effective partnerships”. Standard 2, Partnering with Consumers, includes three Standards that are directly relevant to health literacy. These are:

*Standard 2.8: The health service organisation uses communication mechanisms that are tailored to the diversity of the consumers who use its services and, where relevant, the diversity of the local community.*

*Standard 2.9: Where information for patients, consumers, carers, families and consumers about health and health services is developed internally, the organisation involves consumer sin its development and review*

*Standard 2.10: The health service organisation supports clinicians to communicate with patients, carers, families and consumers about health and health care so that:*

- a. Information is provided in a way that meets the needs of patients, carers, families and consumers*
- b. Information is easy to understand and use*
- c. The clinical needs of patients are addressed while they are in the health service organisation and*
- d. Information needs for ongoing care are provided on discharge.<sup>88</sup>*

The RACGP's *Standards for General Practice* Criterion C1.3, *Informed Patient Decisions*, includes a statement that health literacy is important to shared decision-making and informed patient decision-making. This standard encourages general practitioners to consider the health literacy level of their patients, and tailor their information and communication accordingly. It also suggests action that general practitioners could take, for example, using flipcharts and diagrams to explain health concepts and processes to patients.<sup>89</sup>

Professional standards and codes of conduct for health professionals vary in terms of how directly they address health literacy. For example, the Code of Conduct for Medical Practitioners does not include the term 'health literacy', but its Standard 3, Working with Patients, recognises the importance of doctor-patient partnerships based on respect, openness, trust and good communication (3.2). The Code of Conduct for Surgeons doesn't mention health literacy but does commit surgeons to

using interpreters where required by people of culturally and linguistically diverse backgrounds. The Standards for Registered Nurses do not mention health literacy explicitly but include the following closely associated competencies:

- Standard 2.4: Provides support and directs people to resources to optimise health related decisions, and
- Standard 3.2: Provides the information and education required to enhance people's control over health.<sup>90</sup>

Other standards do use the term 'health literacy' to articulate key professional competencies. For example, the Standards for Nurse Practitioners commit nurse practitioners to "contribute... to health literacy by sharing knowledge with the person receiving care to achieve evidence-informed management plan". The Professional Practice Standards for Pharmacists includes a focus on health literacy in the context of medicines information. Standard 6 commits pharmacists to:

*"develop resources and skills to provide services and education consistent with health literacy principles and empower patients by providing appropriate information and resources so that they can actively participate to achieve their own healthcare goals."*

This Standard also requires pharmacists to respond to the digital literacy needs of patients and the community.

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## *Conclusions*

There is a strongly enabling environment for action to improve health literacy in the ACT. There is an opportunity for professional standards and codes of conduct for health professionals to more consistently address health literacy competencies.

## Section 7. Existing health literacy initiatives in the ACT

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### Key messages

- A range of work in support of health literacy is occurring in the ACT. This work is led by ACT Government Directorates, health services and other agencies including ACT schools. Community services and consumer organisations also have established programs of work that relate to health literacy.
- There is a concentration of work that aims to improve individual health literacy by providing consumer information and education in areas including healthy lifestyles, chronic conditions self-management, and understanding what health services are available in the ACT.
- Fewer initiatives aim to build the confidence, motivation, skills and social networks that consumers often need in order to put health literacy knowledge into practice. Community and consumer organisations hold expertise in this area.

This section indicates the scope of work occurring in the ACT. It does not aim to provide an exhaustive list of all relevant work occurring in the ACT.

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### Work led by health care organisations

Within ACT health care organisations there is a concentration of work that aims to build *individual health literacy* by providing consumers with health information and education. This is consistent with experiences in other Australian jurisdictions.<sup>91</sup> A majority of health professionals who responded to the survey for this project reported that they address health literacy by:

- Educating or supporting consumers, carers or patients to become more health literate
- Providing health or medical care in a way that is health literate, or
- Developing health information material for consumers, carers or patients.

Examples of organisational initiatives designed to build individual health literacy include:

- Canberra Health Services' *Living a healthy life with a long-term conditions* program, which aims to enhance people's ability to live with an ongoing condition and is delivered in partnership with consumer organisations.<sup>92</sup>
- The publication *Using Health Services in the ACT*, which provides information about how to access services for recent arrivals to the ACT.<sup>93</sup>
- The ACT Health *Consumer Handouts Policy*, which guides the development of new consumer information resources used within Canberra Health Services, and includes a focus on plain English expression and consumer involvement.<sup>94</sup>

While there is a focus on individual health literacy, work to improve the *health literacy environment* is also occurring. For example, Canberra Health Services and Calvary Public Hospital Bruce have partnered with HCCA to use the *First Impressions* methodology to identify necessary changes to the built environment in health facilities.<sup>95</sup> Health care services also offer staff training related to health literacy:

*“Health literacy is a particular focus in staff education to ensure a solid understanding and application in the messaging to consumers.” – Calvary Public Hospital Bruce survey respondent.*

*“Education for staff... is included in cultural competence education and weaved into other forms of education.” - CHS survey respondent.*

ACT Government service reform processes that aim to make health and human services easier to navigate are also relevant. In addition to the *Human Services Blueprint*<sup>96</sup> reforms described in Section 6, the ACT Office for Mental Health has developed a territory-wide vision for mental health and wellbeing in consultation with consumers and carers.<sup>97</sup> Agencies including the ACT Education Directorate, Community Services Directorate and Health Directorate lead work under the ACT *Healthy Weight Initiative*, which aims to make it easier for people to eat healthy food and to exercise, including by improving the “active living environment”.<sup>98</sup> Capital Health Network leads work to improve coordination of care including across hospital and primary care services, with the aim of making transitions in care easier for consumers to navigate. Examples of Capital Health Network’s work in this area include the *Heart Failure Care*<sup>99</sup> and *Transitions of Care*<sup>100</sup> projects.

Table 3 below indicates the range of work occurring within ACT health care organisations, including ACT Government Directorates with responsibilities for health.

**Table 3: Health literacy initiatives in ACT health care organisations**

| Type of initiative                           | Example  |
|--|--|
| Health promotion                             | The ACT Government’s <i>Healthy Weight</i> program supports initiatives to prevent and reduce obesity and overweight, including nutrition education and active travel initiatives in schools and workplace. It also improves urban planning and the food environment. <sup>101</sup>   |
| Consumer information resources and education | <p>ACT Health Directorate’s <i>Beyond Today, it’s up to you</i> social media campaign supports smoking cessation among Aboriginal communities in the ACT, and was developed in partnership with Aboriginal community champions.<sup>102</sup></p> <p>The <i>Using Health Services in the ACT</i> publication provides information about how to access services for recent arrivals to the ACT. It was adapted from a Northern Territory Health publication by ACT Health.<sup>103</sup></p> <p>ACT Health Directorate’s <i>Your Health Options</i> campaign provides information about when to use GP and after-hours GP services, Walk-in Centres, the <i>healthdirect</i> website and telephone line and hospital emergency departments.<sup>104</sup></p> |

|   |   |
|---|---|
|   | <p>Canberra Health Service delivers <i>Living a healthy life with a long-term conditions</i> courses in partnership with consumer organisations SHOUT and Arthritis ACT<sup>105</sup>.</p> <p>The Canberra Health Services <i>Advance Care Planning Program</i> promotes Advance Care Planning (ACP) including assisting people to complete ACP documentation.<sup>106</sup></p>  |
| <p>Service and system access and navigation</p> | <p>ACT Health mobile app provides information including about current wait times at public emergency departments and walk-in centres and preparing for a visit to a public hospital in the ACT.<sup>107</sup></p> <p>Capital Health Network, ACT Health Directorate and the National Health Services Directorate collaborate on the <i>Live Healthy Canberra</i> directory of social participation, healthy living and physical activity services<sup>108</sup></p> <p><i>Health Pathways</i> provides primary care professionals with up-to-date information about care pathways for diverse health care conditions and consumer information resources that practitioners can provide to patients. It is coordinated by the Primary Health Networks for the ACT and South East NSW (Capital Health Network and COORDINARE).<sup>109</sup></p> <p>In partnership with the Health Care Consumers' Association, areas within Canberra Health Service and Calvary Public Hospital Bruce use the <i>First Impressions</i> walking audit method to identify improvements to the health literacy environment.</p> |
| <p>Organisational culture and systems</p>       | <p>Canberra Health Services staff can access online training related to cultural competency, which includes a component on health literacy and effective communication.</p> <p>All ACT hospitals are required to meet the health literacy-related standards in the NQSHS Standards (see Section 6 for detail).</p> <p>Canberra Health Service Consumer Handouts Policy sets out processes for developing consumer information, including consumer involvement and plain English.</p>  |

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*Initiatives in ACT schools and early childhood education and care*

ACT schools and early childhood education centres, with support from the ACT Health Directorate's Health Improvement Branch, undertake initiatives to promote healthy behaviours including active travel and active play, and to make healthy food available and attractive for children and young people. The ACT Health Directorate provides a School Youth Health Nurse Program that "supports high school communities to adopt a whole-of-school approach to address contemporary health and social issues that face young people and their families".<sup>110</sup>

Some ACT community and consumer organisations work in partnership with ACT schools to support teachers to build students' health literacy. For example, Hepatitis ACT's *Be Smart About Body Art* resource on blood borne virus transmission risks for upper high school students and accompanying teaching resources for teachers maps to the national curriculum.<sup>111</sup> Sexual Health and Family Planning ACT provides program and curriculum development support related to relationships and sexuality education, and delivers sessions and workshops for students, teachers and parents.<sup>112</sup>

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### *Work led by consumer and community organisations*

Community and consumer organisations in the ACT work in a variety of areas related to health literacy. They develop and disseminate consumer information resources, provide peer support and peer-led services, conduct individual and systemic advocacy, and offer training and professional development for health professionals. Some consumer and community organisations provide clinical services, often to people who face barriers to mainstream health services.

Consumer and community organisations have led the recent development of innovative resources that support better communication with health professionals. For example, the Mental Health Consumer Network's *My Rights, My Decision* resources, developed in cooperation with ACT Human Rights Commission and Canberra Health Services, support mental health consumers to record their "views, wishes and preferences for care in advance" so that these can be taken into account if they have reduced decision-making capacity in the future.<sup>113</sup> The *Respect, Know, Act* project led by the ACT Disability Aged Carer Advocacy Services (ADACAS) uses a Supported Decision-Making approach to assist people – for example people with intellectual impairment, dementia, acquired brain injury - to be involved in decision-making when using mainstream health services.<sup>114</sup>

ACT consumer organisations have well-established peer education programs that support health literacy. For example, Mental Illness Education ACT supports and trains people with lived experiences of mental health recovery to share their experiences in schools and workplaces in order to increase awareness of mental health illness and recovery.<sup>115</sup> The Canberra Alliance for Harm Minimisation and Advocacy (CAHMA) provides the *Treatment Support Service*, a peer-led model that helps people to navigate drug treatment services in the ACT including education, support and referral to pharmacotherapy and support services. This includes peer assistance to understand treatment and support options, and make informed choices.<sup>116</sup>

Community-based organisations also have expertise in the provision of health information and support for culturally and linguistically diverse communities. Organisations including the Migrant and Refugee Resettlement Service (MARSS), Companion House and Red Cross provide information, education and support to assist migrants and refugees to access health services and navigate the health system. HCCA, with support from the Canberra Health Services Advance Care Planning Program provides information about Advanced Care Planning to a wide variety of community audiences including culturally and linguistically diverse groups.

**Table 4: Community and consumer-led initiatives that support health literacy<sup>117</sup>**

| Type of initiative   | Example  |
|--|--|
| Peer education   | MIEACT peer educators share lived experience in supported face-to-face forms to raise awareness of mental health issues <sup>118</sup>   |
| Peer support   | Consumer and self-help organisations provide peer support and networks that validate and normalise consumers' experiences, and provide information and support to help people navigate the health care system.   |
| Peer navigation  | CAHMA provides the Treatment Support Service, a peer navigation service for people seeking treatment and support related to problematic drug use. <sup>119</sup>   |
| Consumer health information resources  | The Cancer Council produces information sheets on various impacts of cancer on daily life in A4 Easy Read format. <sup>120</sup>   |
| Community health promotion and education that support health literacy skills, knowledge and confidence | People with Disabilities ACT has developed resources to assist people with disabilities to consider their options for making a complaint in relation to health care or disability services. <sup>121</sup>   |
| Education for health professionals   | The Heart Foundation provides ongoing professional development for health professionals in relation to heart disease, and supports them to undertake small quality improvement projects in their workplaces. <sup>122</sup>  |
| Workplace health promotion   | Bosom Buddies, with support from Healthy Work ACT, has provided workplace education session on breast cancer risks, as part of the organisation's work to raise community awareness of breast cancer and the importance of early detection. <sup>123</sup><br><br>Palliative Care ACT has recently produced a resource for human resource professionals on good practice support for workers who are palliative carers. <sup>124</sup> |



|  |   |
|--|---|
| Consumer resources that support better communication | People with Disabilities ACT, with support from the ACT Office for Disability, is developing a Health Passport to assist people to communicate information about their care preferences and needs. <sup>125</sup>   |
| Individual advocacy                                  | ADACAS provides individual advocacy services, including to help people access services, communicate their needs and preferences, and provide feedback or pursue health care complaints. <sup>126</sup>  |
| Community-based health services                      | Some community services provide medical and other health care services for people who face barriers to care or who have specific experiences including experiences of trauma. For example, Companion House provides medical services for refugees. <sup>127</sup> |

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### Conclusions

While innovative work in support of health literacy is occurring in the ACT, this scan indicates that it is widely distributed across diverse organisations. The people and organisations involved have few opportunities to share learning and experiences, or to develop shared knowledge and skills related to supporting health literacy.

In contrast to many jurisdictions, the ACT does not have a Health Literacy Framework or Action Plan. Experience in other jurisdictions indicates that this can provide visibility to health literacy challenges and strengthen work in response.<sup>128</sup>

Health literacy initiatives in the ACT address a wide variety of consumer health information needs. A number of these indirectly address the link between health literacy and patient safety. For example, resources that support interpersonal communication aim to reduce miscommunication - a leading cause of preventable patient harm.<sup>129</sup> However, this scan has not identified any existing ACT work that focuses *directly* on health literacy as a patient safety issue, for example by raising consumer awareness of risks when using health care, and strategies to promote safety. There are interstate examples of work of this kind, including the Western Australian Government's *Patient First* initiative, and the Health Consumers' Council of Western Australia's *Going to Hospital, a consumer guide* and *Staying safe when using health services* publications. International examples include the United States Joint Commission's *Speak Up* program.<sup>130</sup>

Public libraries play a recognised role in promoting health literacy, including by providing trustworthy and reliable health information material. This scan has identified that there may be opportunities to promote and strengthen the role that the ACT Public Library service plays in supporting health literacy. For example, public library services in other Australian jurisdictions have adopted the *Words for Wellbeing* program.<sup>131</sup>

*Health Care Consumers' Association*  
*Community Health Literacy in the ACT: Environmental Scan*

These projects and resources could be adapted for the ACT context to meet gaps identified by this scan.

## Section 8. Consultation findings

This section presents key learning from consultation with representatives of consumer organisations, community services, and health professionals.

### 8.1. Learning from consumer and community organisations

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#### *Key points*

The key health literacy challenges that community and consumer organisations report are that:

- Navigating the health system can be very challenging, particularly for people experiencing or at risk of poverty, stigma and/or discrimination.
- Consumer information gaps persist, at the same time as consumers face what can feel like an overload of health information.
- Communicating well with health professionals and participating in shared-decision making takes time, skills and confidence.
- People can face barriers to health service access due to cost, lack of transport, stigma and discrimination, inflexible eligibility criteria, and long waiting times.

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#### *Knowledge of health literacy*

While consumer and community organisations in the ACT report that health literacy issues matter to the people who use their services, not all organisations use this term to describe this work. Some consultation participants reported that health literacy is an abstract term that:

- is not used by members of the communities they work with
- is not easily understood by most people, and
- lacks clarity because it relates to a wide range of consumer concerns.

Nonetheless, representatives of consumer and community organisations that participated in consultation regard health literacy as an area requiring action. Section 7 provides examples of the practical ways in which consumer groups and community services support individual health literacy and work to improve the health literacy environment.

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#### *Service and system access and navigation*

Consultation participants indicated that from the perspectives of consumers, navigating the health system means:

- **knowing where to go for health care services**
- **being able to access these services:** this includes easy physical access to buildings, good public transport access, being able to afford services, reasonable waiting times, and a sense of welcome and safety on arrival and while receiving care.

- **being able to find your way within health services easily**, including signage and wayfinding assistance.
- **receiving care that is coordinated and offers continuity** across the services and professionals caring for a person. This issue can be more pronounced for people who have multiple chronic conditions, or who access services in both the ACT and NSW.
- **being assisted and feeling welcomed by** health service staff who are respectful, helpful and listen. This includes clinical and non-clinical staff, for example people working in administrative roles that involve communication with consumers.

Navigating the health care system presents particular challenges for people with complex health and social circumstances, or health care needs that may cause them to experience stigma, discrimination or unequal care (for example care needs associated with alcohol or other drug use, mental illness or conditions including HIV and Hepatitis B and C), and for carers of people in these circumstances. These situations demand high levels of health literacy from people who may already be under significant stress.

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### *Information and communication*

Consultation participants reported that consumers can face information overload. It can be very difficult to sift through the information that is available on any health topic, particularly on the internet. Sometimes in an informal way, consumer and community organisations help people in their networks to assess whether health information is trustworthy, accurate and relevant. For example, a peer support group leader reported encouraging other members of the group to think carefully about the risks and benefits of alternative therapies they had heard about.

While there is no shortage of health information for consumers, consultation participants report that information gaps persist. In particular, consumers and carers often do not have access to information and support that will help them to:

- understand the possible impacts of recommended diagnoses, tests, treatments and procedures on their everyday life, and the potential benefits and risks resulting from these,
- understand and consider their options for care and treatment, particularly when there are options in different parts of the health system, for example in public and private health care services, across primary, secondary and tertiary care, or in the ACT and NSW,
- form an understanding of care pathways, possible impacts and self-management after a new diagnosis, particularly with a chronic condition,
- communicate well with health professionals,
- connect to peer networks and social support in a timely way, and
- understand and consider options for providing feedback and complaints.

Consultation participants also reported that:

- people of culturally and linguistically diverse backgrounds often are not provided with culturally appropriate information or offered an accredited interpreter, and
- constraints on clinicians' time limit opportunities for consumers and carers to participate in health decision-making and give informed consent.

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### *Conclusions*

The issues raised by consumer and community organisations are closely intertwined with patient safety considerations. For example, barriers to health service access can delay necessary treatments or tests, with negative consequences for people's health. Without an understanding of the possible impacts of recommended medical procedures on daily life it is very difficult to give informed consent to these.

Consultation participants identified a number of changes that would support health literacy. These are:

- Develop information and education resources to meet the consumer information gaps identified above, including a focus on the patient safety issues inherent in these issues.
- Provide training, education and support for health professionals in areas including shared decision-making, communication tools and techniques, cross-cultural communication, and involving carers.
- Promote translated information resources and the use of interpreters.
- Address the access and navigation challenges that disproportionately affect vulnerable people, recognising that this is a long-term process involving reform of complex health and human systems.
- Increase community access to skills-based training and support related to health literacy including communicating well with health professionals, and finding and assessing health information.

## **8.2. Learning from representatives of health care organisations**

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### *Key messages*

Many health professionals in the ACT strive to respond to and support their patients' health literacy as part of delivering high quality care. While the policy, professional and organisational context in the ACT enables health professionals to act on health literacy, they face barriers including limited time to discuss issues and concerns with patients and carers.

Some health professionals use practical strategies to support health literacy including in time-constrained circumstances, for example using diagrams instead of complex explanations, avoiding medical terminology where possible and focusing on the everyday impacts of medical conditions or treatments. Specialist roles including Aboriginal Liaison Officers, hospital social workers and care coordinators, are valued in part because they support good communication and health literacy.

Participants support the introduction of initiatives to build workforce knowledge and skills related to health literacy, including education and training focused on communication techniques, and the link between health literacy and patient safety.

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### *Knowledge of and commitment to health literacy*

The ACT health workforce includes a large number of health professionals from different specialities working in diverse settings. This makes it difficult to generalise about workforce knowledge of health literacy. However, a 2015 survey of Canberra Health Service staff found that 65 per cent were familiar with the term health literacy.<sup>132</sup> Respondents to the survey for the current project reported that health literacy was either very important (26%) or important (62%) to their work. Slightly less than 10% thought health literacy was “somewhat important” or “not important”.

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### *Information and communication*

Health professionals who took part in this project stressed that they respond to patients' health literacy needs as part of their everyday efforts to deliver safe and high quality care. Survey respondents highlighted the importance of clear communication and sharing information with patients:

*“The team is encouraged to use basic language”*

*“Our patient information booklets are written in plain English, using everyday terms”*

*“[Health literacy is about] taking complex concepts and simplifying them”*

A small number of participants indicated that a focus on plain language communication can risk the unintended consequence of over-simplifying information:

*“management [do] not support the process of having different levels of information for patients that have higher as well as lower health literacy – a lot of patients do not want basic information with pictures only”.*

This reflection suggests the difficulty of expressing complex health information in plain language, and a tension that may exist between using plain language and meeting some consumers' preference for honesty about complexity.

These responses indicate that many ACT health professionals understand health literacy as primarily associated with providing good consumer information and communicating well with patients. Compared with responses from community and consumer organisations, there is less emphasis on the navigation and access aspects of health literacy.

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### *Health literate care: barriers and strategies*

Participants emphasised that they strive to deliver health literate care in the face of challenges including limited time to respond to consumers' individual circumstances. They recognised that it takes times to understand and respond to consumers' priorities and to involve them in decision-making. Survey respondents said:

*“Sometimes it is hard to translate complex medical information into language that is easily understood.”*

*“Adequate time to do the work is challenging.”*

Some participants identified strategies they use to support health literacy while managing time constraints, for example using diagrams or pictures to explain procedures, focusing on how a diagnosis or treatment will impact a person's everyday life, avoiding jargon and explaining medical terms.

Participants identified the value of specialist roles that support health literacy. These include Aboriginal Liaison Services at the Canberra Hospital and Calvary Public Hospital, hospital social workers and care coordinators. One survey respondent said:

*“Social workers are always helping patients, family and carers navigate and interpret the health systems, its language and roles, to ensure they understand what's happening, and can make full informed choices about their care and discharge.”*

These reflections suggest both the importance of specialist roles that support health literacy and good communication, and the need for ongoing education and development for all health care workers so that they are equipped to respond to health literacy challenges.

Health professionals who took part in this project identified limited access to translated consumer information and accredited interpreters as a specific challenge. Survey respondents reported:

*“Documents aren't always translated into other languages.”*

*“[There is a] lack of sufficient interpreter services for non-English speaking background patients.”*

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## Conclusions

Health professionals who took part in this project identified opportunities to improve environmental health literacy. These are:

- Provide staff training and development opportunities in areas including communication skills, and understanding and promoting digital health to consumers. Communication with patients was the single area of training and development need most often identified.
- Strengthen the focus on health literacy in the training and education of future health professionals.
- Make it easier for health professionals to access interpreters.
- Identify organisational leaders who will champion health literacy, and promote the importance of health literacy.

*“Management does not talk about it consistently therefore I suspect that not all clinicians have good awareness and practice it.” – survey respondent.*

## Section 9. Future directions

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### *Gaps and opportunities in the ACT*

This report has reviewed community health literacy strengths and barriers in the ACT and region, and has identified initiatives that currently support health literacy. While a range of work is occurring in support of health literacy in the ACT, there is limited coordination of this work, and there are few opportunities for the organisations, volunteers and professionals involved to share learning and successes. The ACT lacks a policy framework to guide health literacy improvement, and has no mechanism to recognise and support the collective efforts of health services, community services and consumer organisations in this area.

There is a specific opportunity in the ACT to raise health professionals', consumers' and community awareness of health literacy as a patient safety issue, including by developing information and education resources to support consumers and carers to understand risks and take action to promote safety.

Many consumers and carers who use services in the ACT would benefit from opportunities to develop skills, confidence, motivation and peer networks, including in relation to chronic conditions self-management, patient safety and assessing the quality and relevance health care information. There are some specific gaps in consumer health information in the ACT, including:

- access to culturally appropriate and translated health care information resources,
- information about patient safety for patients and carers, and
- information about self-managing multiple chronic conditions.

People with complex health needs, people experiencing disadvantage, and people at risk of stigma or marginalisation would benefit from support to build health literacy skills, knowledge and confidence.

Finally, existing data provides ACT services with limited information about health literacy strengths and challenges for culturally and linguistically diverse communities, including in relation to chronic conditions self-management. This makes it difficult to provide a person-centred and culturally competent response to health literacy issues for these communities.

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### *Recommendations*

In response to these gaps, this report makes 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.<sup>133</sup>
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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