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# Health literacy 101 – Going back to basics to move diabetes practice forward

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life-skills

online education

self-management

## Introduction

Since diabetes self-management primarily involves health behaviour changes, knowledge and skills for self-management are fundamental for people living with diabetes. Diabetes self-management education aims to promote relevant changes and improve knowledge and skills to support diabetes self-care. The American Diabetes Association, Association of Diabetes Care and Education Specialists and Academy of Nutrition and Dietetics define diabetes self-management education as the process of facilitating knowledge, skills and ability necessary for diabetes self-care, which incorporates the person's own needs, goals and life experiences and guided by evidence-based practices to improve their own health outcomes.<sup>1</sup> This definition positions diabetes self-management education as key to helping people with diabetes to navigate their daily decision-making and activities to support better health outcomes. Most importantly, it also aligns diabetes self-management education with an emerging health promotion concept, health literacy.

Health literacy plays a vital role in chronic conditions management, and has become increasingly prominent in literature and diabetes education practices in the past decade in Australia. In this article, we are going to discuss the concept of health literacy, including relevant facts and policies, and explore why it matters in diabetes practice. In future editions of *Australian Diabetes Educator*, we will address a range of health literacy topics related to diabetes self-management education including effective verbal and written communication and priority population groups.

# What is health literacy?

Health literacy is concerned with people's ability to appropriately implement and act on health information to make good health and wellbeing decisions. While there are now more than 20 definitions of health literacy, an integrated definition published in 2012 referred to '*people's knowledge, motivation and competences to access, understand, appraise, and apply health information in order to make judgements and take decisions in everyday life concerning healthcare, disease prevention and health promotion to maintain or improve quality of life during the life course*'.<sup>2</sup> This definition incorporates a person's ability to know where to access health information (e.g. online, printed, via telehealth or from health professionals), understand and critically evaluate the information, including making judgements about whether it is reliable and how well it applies to the person's circumstances.

Nutbeam<sup>3,4</sup> has proposed a three-level hierarchy model of individual health literacy:

1. **Functional health literacy:** the basic skills in reading and writing as well as knowledge of health conditions and health systems needed to obtain health information, and comply with this information.
2. **Communicative health literacy:** more advanced literacy and skills required to access, understand and discriminate between health information from different sources, and independently apply new information to changing circumstances.
3. **Critical health literacy:** the most advanced cognitive and social skills which enable people to critically analyse health information from a variety of sources and use this information to exert greater control over personal health decisions and the wider influences on those decisions.

Table 1 provides an example of applying these three levels of health literacy for a person with diabetes.

## Health literacy and the health environment

While these early definitions and models of health literacy are fundamentally important, the concept of health literacy has also evolved to encompass the health literacy environment. The health literacy environment includes the infrastructure, policies, processes and materials that impact people's ability to access, understand, appraise and apply health information.<sup>5</sup> This positions health literacy as a multifactorial outcome that typically arises from a convergence of an individual's education, language, social and cultural factors together with available healthcare systems and services to the individual.<sup>6</sup> Reflecting on such changes, the World Health Organization revised its definition of health literacy in 2021 to emphasise the key role of "available organisational structures and resources" in promoting health literacy.<sup>7</sup>

## Statistics on health literacy

Low health literacy is common in many countries, with estimates ranging from 36 – 60% of Australian, European and the United States of America populations.<sup>8-10</sup> The Australian national health literacy survey conducted in 2006 used the Adult Literacy and Life Skills Survey (ALLS) to measure health literacy skills in five health-related activities: (1) health promotion; (2) health protection; (3) health condition prevention; (4) health care maintenance; and (5) systems navigation.<sup>11</sup> The responses from the survey were scored across five levels, where Level 1 was the lowest and Level 5 was the highest, with the minimum target

level set at Level 3. Data from the ALLS national survey showed that only 41% of adults aged 17 to 74 years had 'adequate' or better health literacy skills, scoring Level 3 or above. These individuals could perform tasks such as combining information in text and a graph to assess the safety of a product like a medication correctly. One-fifth (19%) of adults had Level 1 health literacy skills and a further 40% had Level 2, indicating these adults had difficulties with simple tasks such as locating information on a medication label about the maximum number of times the medicine could be taken or correct dosage information.<sup>8</sup> Overall, the results suggested that three in five (60%) of Australian adults had low health literacy.<sup>8</sup>

The most recent Australian national survey of health literacy conducted in 2018 adopted a different methodological approach, through a self-reported measure of health literacy.<sup>12</sup> The Health Literacy Questionnaire used covers nine domains, including health information adequacy, seeking, understanding and appraisal, self-management, social support, healthcare provider engagement, and healthcare service navigation.<sup>13</sup> Key findings from the 2018 survey showed the majority of adults thought they had sufficient information to manage their health (97%), felt they were understood and supported by health care providers (96%); believed they were actively managing their health (92%), and reported they were able to appraise health information (83%).<sup>13</sup> However, findings should be interpreted in light of the self-report methodologies used.

Both national surveys have consistently shown within-country disparities in health literacy for different priority population groups, including people from culturally and linguistically diverse (CALD) backgrounds. However, much less is known about specific cultural and language groups, mostly due to the scarcity of health literacy instruments available non-English languages. In the 2006 survey, a disproportionate number of people with lower health literacy (44%) were from CALD backgrounds being overseas-born and having English as the second language compared to the Australian-born population (26%) where English was the first language.<sup>8, 14</sup> The disparity among people who spoke a language other than English was consistent across all nine domains of the Health Literacy Questionnaire in 2018.<sup>15</sup>

## Why it matters for diabetes self-management education?

Low health literacy impacts several health outcomes, especially in diabetes. Strong evidence suggests that lower health literacy is associated with suboptimal diabetes knowledge, reduced self-care practices, and more diabetes-related complications.<sup>16-19</sup> The most recent systematic review included 34 publications exploring the impact of health literacy on health outcomes in diabetes<sup>17</sup> and the meta-analysis of 61 studies with 18,905 people with diabetes<sup>21</sup> have collectively pointed out lower health literacy was associated with less participation in prevention activities, less likely to take medication as prescribed and increased adverse medication events, increased hospital admissions and readmissions, increased healthcare costs and poorer overall health status including increased mortality. A recent meta-analysis, including 33 studies and a sample size of 10,259 people with diabetes, explored the relationship between health literacy and five diabetes self-management variables.<sup>20</sup> The authors found positive correlations between higher health literacy and increased levels of self-monitoring (correlation coefficients [ $r$ ]=0.19; 95% CI 0.11, 0.27;  $P<0.00001$ ), dietary and physical care ( $r=0.12$ ; 95% CI 0.07, 0.18;  $P=0.009$ ), diabetes knowledge ( $r=0.29$ ; 95% CI 0.09, 0.45;  $P<0.001$ ), self-efficacy ( $r=0.28$ ; 95% CI 0.15, 0.41;  $P<0.00001$ ) and self-care ( $r=0.24$ ; 95% CI 0.16, 0.31;  $P<0.00001$ ).<sup>20</sup> These outcomes are supported by another meta-analysis of 61 studies with 18,905 people with diabetes, which similarly found that higher health literacy was associated with improved glycaemic management, measured by lower HbA1c levels ( $n=36$ ,  $r=-0.048$ ,  $p=0.027$ ,  $I^2=71\%$ ).<sup>21</sup>

Previous studies have proposed causal pathways between health literacy and health outcomes. For example, based on a literature review of studies on health literacy and diabetes self-management, Fransen and colleagues developed a framework for health literacy and health outcomes. Their framework suggests that health literacy is related to psychosocial factors (e.g. knowledge, understanding, and self-efficacy), behaviour (e.g. eating patterns, physical activity levels, and taking medication regularly, which also related to the quality of client-provider communication and diabetes self-management outcomes),

and health outcomes (e.g. glycaemia measured with HbA1c and diabetes complications).<sup>22</sup> In 2019, Ueno et al. continued to use health literacy models to examine various relationships between health and wellbeing outcomes among people with type 2 diabetes based on the framework discussed above.<sup>18, 22</sup> They found that health literacy may indirectly relate to the person's health and wellbeing outcomes through psychosocial factors, communication with doctors, and self-management behaviours. The authors also found significant positive health literacy effects on understanding diabetes care, self-efficacy, communication with doctors, and taking medication as prescribed. They concluded that improving health literacy may lead to better self-management and improved health and wellbeing outcomes. However, the impact of improvements in health literacy may be determined by the relationship between a person's health literacy level and the understandability of the information provided.<sup>18</sup>

Credentialed Diabetes Educators recognise that successful diabetes self-management education requires health professionals to actively motivate and empower people living with diabetes to participate in their care.<sup>23</sup> Through personalising the person's goals, diabetes self-management education improves clinical outcomes.<sup>23</sup> This implies that supporting and improving the health literacy of people living with diabetes is a key component to incorporate for health professionals who provide in diabetes self-management education.

## What policies guide health literacy?

The high prevalence of low health literacy and the associated health behaviour consequences have made health literacy a policy priority for many countries worldwide, including Australia, the United States of America, New Zealand and Scotland.<sup>24-27</sup> In Australia, the Australian Commission for Safety and Quality in Healthcare (ACSQHC; 'the Commission' hereafter) first published the National Statement on Health Literacy in 2014, outlining three strategic areas: (1) incorporating health literacy into systems; (2) ensuring effective health communication; and (3) integrating health literacy into education.<sup>28</sup> Since then, the Commission has legislated health literacy in the National Safety and Quality Health Service Standards, which requires all public and private hospitals to take action to improve health literacy.<sup>29</sup> Health literacy is specifically mandated in Standard 2, such as through requirements for partnering with consumers in service planning, design and evaluation. Most recently, the Australian Government signed the National Health Reform Agreement for 2020-2025. Health literacy was included as one of six long-term health reforms to empower consumers in self-management and engage healthcare services through person-centred health information and support.<sup>30</sup>

Health literacy is also increasingly included in diabetes-related policies. In 2015, the Australian Government published the first health literacy white paper on diabetes to guide diabetes health professionals in providing tailored diabetes self-management education.<sup>31</sup> The white paper reinforced the importance of a shared decision-making and communication process, which not only enhances healthcare service engagement but also addresses a person's skills and capacity, for example, their health literacy. Meanwhile, a toolkit with more practical resources was developed by the Australian Diabetes Educators Association to implement health literacy principles in diabetes self-management education.<sup>32</sup> More recently, the Australian National Diabetes Strategy 2021-2030 has continued to prioritise health literacy, with goals to increase the health literacy of people with type 2 diabetes and those at risk and to improve diabetes self-management education information for people with diabetes from CALD backgrounds.<sup>33</sup> Diabetes Australia's Strategic Plan 2020-2025 also identifies people with type 2 diabetes from CALD groups as a priority group and mandates all communication from Diabetes Australia be tailored to people with diabetes considering their health literacy, linguistic and cultural needs.<sup>34</sup>

## Conclusion

Health literacy relates to how people access, understand, appraise and apply health information in ways that benefit their health. It is the convergent outcome of individual health skills, knowledge and competencies and the health literacy environment, and directly impacts health outcomes for people living with diabetes. Australian national surveys have consistently shown that low health literacy is prevalent in Australia and disproportionately affects people from CALD backgrounds. Despite strong support from health professionals at the clinical level and good intentions from peak professional organisations and the Australian Government at the policy level, lower health literacy still widely exists among people with diabetes. Continued work to ensure effective verbal and written communication that meets the health literacy needs of all, especially people with CALD backgrounds, is needed. Further discussion will be devoted to the above topics in the *Australian Diabetes Educator* in 2023, to explore ways to apply health literacy principles and guidelines to priority groups to empower them to make informed decisions about diabetes self-management and wellbeing.

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