

Health literacy in New Zealand: A tale of serendipity and indigenous health

Susan Reid and Carla White

Introduction

This chapter discusses the emergence of health literacy, including policy development, in New Zealand (NZ), through the lens of the authors' involvement in the initial health literacy development projects, and in light of international perspectives. New Zealand has a small population, centralised government and a single Ministry of Health responsible for health outcomes. A lucky series of chance encounters generated interest in the relationship between recently published adult literacy data about New Zealanders, including the indigenous Māori population, and poor health outcomes for Māori. This resulted in the publication of NZ's first health literacy research report for the adult population (Ministry of Health, 2010), showing the widespread need to address health literacy as a nation.

Health literacy in NZ over the past 10 years has been driven by the need to reduce health inequalities and inequities for Māori, NZ's indigenous population. In beginning work in the health literacy field more recently than other nations, NZ has been able to take advantage of research and experiences generated by others who have worked in this area for much longer, in particular, the US. This supported health literacy to be positioned as a system and health equity issue, rather than as a problem of patient-deficit.

The Ministry of Health's *He Korowai Oranga – Māori health strategy* (Ministry of Health, 2014b) supported a systemic approach to improving health outcomes for Māori, with health literacy identified as a key enabler to improving health outcomes. The Strategy supported the creation of NZ's *A framework for health literacy* (Ministry of Health, 2015a), outlining expectations for the health system, health organisations, health professionals and consumers in addressing health literacy. The Framework and other health literacy initiatives reflect the contribution and engagement of indigenous communities in actively managing their health and wellbeing.

1 **New Zealand context**

3 *How government operates*

5 New Zealand is a small country of 4.75 million people. As a member of the
6 British Commonwealth, NZ operates a stable, democratic system with national
7 parliamentary elections every three years. Government ministers are selected
8 from the elected members of Parliament. New Zealand has no states or federal
9 government structure.

10 The relatively small population of NZ enables the vast majority of social,
11 education, health, infrastructure, environment and economic policy to be
12 managed by centralised government departments (also known as the public
13 sector). Schools, hospitals, welfare, roads, conservation and so on are designed
14 and funded by government departments. The departments are politically neutral
15 while being answerable to a minister, the Government and the public. Ministers
16 with high-profile portfolios such as health, social welfare, education and finance,
17 are well known and accessible to the public. By international standards, the NZ
18 public sector is seen to be transparent and free of corruption.

19 The policies and decisions of the Government and public sector affect the
20 daily lives of New Zealanders, directly influencing their access to health services,
21 education and social and income support if needed. By design, and partly due
22 to population size, policy-writers, planners, decision-makers and funders can be
23 accessed in both formal and informal ways through official channels and personal
24 networks. Back in 2008, when NZ's health literacy journey started, NZ had
25 recently elected a new right-of-centre coalition government, following a nine-
26 year term of a left-of-centre coalition.

28 *New Zealand recognises the rights of the indigenous population*

30 The Treaty of Waitangi signed in 1840 is the founding document of NZ. The
31 Treaty is an agreement entered into by representatives of the British Crown and
32 the indigenous Māori people. The Treaty is a broad statement of principles on
33 which a government could be built, a legal system introduced and the settlement
34 of the British could be managed. The Treaty is not a constitution or stand-alone
35 statute, and while the principles of the Treaty are referred to in some statutes,
36 the interpretation of the Treaty continues to be a topic of debate.

37 Despite the Treaty, from 1840 onwards laws and regulatory decisions saw Māori
38 dispossessed of land and other natural resources. Since the 1970s, successive
39 governments have recognised the unjust nature of the treatment of Māori and
40 have tried to address past and current grievances, as well as remove prejudice
41 from the system of government. There has also been acknowledgement of the
42 right of Māori to be provided with the conditions that create equitable outcomes.
43 Exactly how this might be achieved remains a challenge. It does mean that in
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key government portfolios, such as health, expertise, resources and policies are focused on improving equity and outcomes for Māori.

The health system

The Ministry of Health has overall responsibility for the management and development of New Zealand's health and disability system (Ministry of Health, nd, a). The Ministry develops national health policy, plans and strategies such as government health targets and the Māori Health Strategy, as well as designs and funds the majority of health delivery in NZ. The Ministry of Health has approximately 800 staff and is led by the Director General of Health.

The provision and funding of health services is geographically divided across 20 district health boards (DHBs). Funding is provided to the DHBs by the Ministry, and performance is measured against government health targets and other output measures. The DHBs are expected to show a sense of social responsibility, to foster community participation in health improvement, and to uphold the ethical and quality standards (Ministry of Health, nd, c). Public hospitals are owned and funded by DHBs in each district and are the main providers of secondary care in NZ, with care being free for NZ citizens and residents.

Primary health organisations (PHOs) are funded by DHBs, and occasionally directly by the Ministry of Health. PHOs arrange or provide primary healthcare services through general practices to NZ citizens and residents. PHOs are not-for-profit organisations and vary widely in size and structure. Visits to primary care are free for children up to age 13. After this age people pay to visit primary care; however, these charges are subsidised by DHB funding and vary significantly by practice, with greater subsidy directed to unemployed people and older people and those living in low socioeconomic communities.

Statistics and the adult literacy sector

In 2008, the full results of the Organisation for Economic Co-operation and Development (OECD) Adult Literacy and Lifeskills (ALL) Survey were published by the Ministry of Education following the Survey's administration in NZ households in 2006 (Satherley et al, 2008). The results showed that 42 per cent of adult New Zealanders aged 16–65 had inadequate literacy and numeracy to manage the daily demands they were likely to face. The results also showed some improvement has been achieved in adult literacy and numeracy since the 1996 International Adult Literacy Survey (IALS). In the Survey appropriate sampling of smaller population groups, including Māori, was undertaken to produce valid and representative results for these groups. These results showed Māori, Pacific and Asian groups had lower literacy and numeracy skills than people of European ancestry. This caused a misconception that Māori and Pacific and Asian groups were the largest populations with low literacy and numeracy skills in NZ, when, in fact, the issue was much more widespread, with the largest single group being

1 NZ Europeans as they made up 68 per cent of the adult population (Satherley
2 and Lawes, 2009).

3 At the time of publication of the ALL Survey results, the authors of this article
4 were both working in the adult literacy sector at Workbase, a not-for-profit
5 trust, based in Auckland. Workbase provided long-term workplace literacy and
6 numeracy programmes within companies, funded by the companies themselves,
7 and later by government subsidies. Workbase's programmes used a system analysis
8 approach to identify training needs. This involved initially identifying and
9 resolving business issues that create unnecessary literacy and numeracy 'demands',
10 such as unclear processes, poor quality instructions and unneeded complexity, in
11 order that the eventual literacy and numeracy training programme could focus
12 on both reducing these demands as well as building the skills and knowledge
13 essential to a workplace.

14 As a result of using the system analysis approach with a large number of
15 companies, we found employees were often unable to apply to work environments
16 the literacy and numeracy skills they already possessed, mainly due to overly
17 complex workplace systems, and poorly communicated, incomplete or incorrect
18 instructions and documents creating unnecessary literacy and numeracy demands.
19 We later used a similar approach to inform our work with the health literacy
20 and health sector.

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22 **The health literacy picture emerges from adult literacy research**

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24 As part of managing the New Zealand Literacy Portal and specialist literacy library
25 for the sector (while at Workbase), we actively identified and disseminated new
26 international research and information about literacy, language and numeracy. This
27 included research and articles about health literacy and health literacy statistics.

28 In 2008 NZ had no health literacy data but we were aware that nearly
29 200 questions in the recently released ALL Survey results related to using literacy
30 and numeracy in health contexts. This health context data had not been separately
31 analysed as the Ministry of Education did not have the mandate or budget to
32 do so, and was not intending to seek further funding for such an analysis. The
33 lead author Susan Reid casually mentioned this matter at a family gathering to
34 a family member who is a highly regarded indigenous public health researcher.
35 As a result, Susan was introduced to the Director of Te Kete Hauora, the Māori
36 Health Directorate in the Ministry of Health. The role of Te Kete Hauora was
37 to undertake and fund research, develop policy and help design and deliver
38 a health system that better responds to the needs of Māori and addresses the
39 significant health inequalities and inequities experienced by Māori. The Director
40 immediately recognised the strong alignment between health literacy, health
41 equity and health outcomes for Māori.

42 As a result, Te Kete Hauora funded the analysis of the ALL Survey health literacy
43 data, and subsequently published the research report, *Kōrero Mārama: Health literacy
44 and Māori* (Ministry of Health, 2010), describing the health literacy skills of adult

Māori compared to the adult non-Māori population by gender, rural and urban location, age, level of education, labour force status and household income.

Kōrero Mārama showed that 56 per cent of the adult population in NZ had low health literacy, equating to 1.8 million people. As non-Māori make up 85 per cent of the population, the report provided evidence of health literacy needs across the whole population, as well as specifically for Māori (who make up 15 per cent of the population).

Within the adult Māori population, 72 per cent had low health literacy. Very low health literacy for Māori in the 50–65 and 16–24 years age groups was particularly concerning because Māori have lower life expectancy than non-Māori, older age groups have higher levels of health need, and over half of the Māori population is under 25 years of age.

The publication of *Kōrero Mārama* was a defining moment for health literacy in NZ. *Kōrero Mārama* gave the Ministry of Health and health providers an idea of the size and scale of the health literacy challenge. The results suggested health literacy needed to be taken into account in every decision about service design, delivery, access and communication. *Kōrero Mārama* also included a definition of health literacy for NZ, taken from international literature:

Health literacy is the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions. (Ministry of Health, 2010, p iii)

This broad definition of health literacy includes many aspects of information gathering and use for decision-making. However, on the face of it, the definition emphasises health literacy as an individual skill or capacity that does not reflect the system-wide aspects of health literacy. Like adult literacy, the adequacy of a person or population’s health literacy is determined by the health literacy ‘demands’ faced by a person or population. Health literacy demands are created by health information, services and systems. Providing accessible information, services and health systems is an important system response to improving health literacy, as is supporting the upskilling of patients, families and communities. Other definitions of health literacy describe health literacy as having both system and individual components rather than as a personal (patient) skill set, for example:

Health literacy is an interaction between the skills of the patient, and the demands of the health system. (Institute of Medicine, 2004)

Exploratory research

Following the publication of *Kōrero Mārama*, the Ministry, through Te Kete Hauora, contracted three exploratory research projects to determine whether and how health literacy affects health outcomes for three health conditions where

1 Māori had historically poor health outcomes as well as at the present time. These
2 three projects were:

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- 4 • Skin infections in children: Māori children have high numbers of hospitalisations
5 for skin infections and associated illnesses that could be prevented by timely
6 treatment in primary care.
- 7 • Prevention and effective management of gout: Gout affects Māori at a much
8 earlier age than the general population, and Māori are far less likely to be
9 prescribed urate-lowering medicines to prevent and manage gout.
- 10 • Timely identification of gestational diabetes mellitus (GDM): Māori women
11 were less likely to be tested for GDM, despite free testing for the diagnosis of
12 GDM being offered to all pregnant women, and Māori women being more
13 likely to develop GDM.
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15 The research methodology for all three projects focused on talking with health
16 professionals and families about these conditions, what was important to them,
17 how and why families access health services, what and who helped, what was
18 difficult, and what might assist with the prevention and management of these
19 conditions.

20 At the time Workbase was growing consulting services in health literacy, building
21 on experience advising workplaces, organisations and government agencies on
22 adult literacy. We submitted tenders to carry out each of the three research projects
23 and were selected to undertake the projects. Each of the research projects found
24 different health literacy facilitators and barriers, and identified potential solutions
25 to improve health outcomes for Māori.

27 *Skin infections and health literacy*

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29 While Māori make up 15 per cent of the general population, Māori under the
30 age of 15 make up 26 per cent of children in this age group. This research project
31 found parents and families were confused about skin conditions in children
32 because many skin conditions seemed to be harmless and often resolved with
33 no primary care intervention, while others with similar symptoms quickly led
34 to hospitalisation if not treated in primary care. Parents wanted to build health
35 literacy in order to know what to do before seeing a health professional, as well
36 as identify the circumstances under which to seek treatment in primary care.

37 Families' experiences in primary care were not frequent enough or sufficient to
38 build a wide understanding of what to do if similar or other types of skin infections
39 developed. Families wanted credible, clear, easily accessible photographic
40 information to help them identify *why* and *when* a child needed to be taken to
41 primary care. Parents had found online material of little value as it often showed
42 advanced cases of a disease, used drawings rather than photographs, relied on
43 parents knowing appropriate search terms or was focused on promoting and selling
44 remedies or services. Parents also described informal, but highly regarded, sources

of health advice, such as friends and grandparents, as being unsure or out of date about managing infections especially in light of confusing public health messages about antibiotic overuse and resistance (White et al, 2013). From a health literacy perspective, this meant there were difficulties accessing information, including people to talk to for reliable up-to-date advice prior to visiting primary care, as well as issues with the accuracy and relevance of information available at the early stages of a skin infection.

As part of the research, resources were developed and trialled with families to use at home, with photographs of the warning signs and progression of common skin conditions, identifying when and why to seek treatment in primary care, as well as how to prevent and treat various types of skin infections. The resources were designed for people to access before seeing a health professional as this is when crucial decisions need to be made within families. Parents identified that the resources were very helpful, as did health professionals who used them with families to build understanding of managing infections. The resources are freely available for download on the Ministry of Health website (Ministry of Health, nd, b) and other credible websites, and are often used in primary care as the basis of discussion with parents about what they can do. Ideally, access to these or similar resources would be available at schools and early childhood centres, in primary care waiting rooms and in public places such as supermarkets and pharmacies.

Gout and health literacy

Gout is much more prevalent amongst Māori, particularly Māori men, and affects Māori at a much earlier age. This leads to a loss of employment and income. In the gout project the researchers identified that men with gout believed their gout was caused by eating too many purine-rich foods and beverages rather than understanding that for a large number of Māori men, high uric acid levels are caused by genetic factors that stop the kidneys excreting uric acid. Little was understood about the long-term implications for joints and kidneys of repeated gout attacks and long-term use of pain relief medicines. Primary care health professionals were aware of the genetic link, but did not discuss this or gout prevention with patients as they thought men with gout would neither comply with the titration of uric acid medicines nor reduce their consumption of purine-rich food and beverages (Reid et al, 2014). With little discussion about gout prevention or long-term management in primary care, and with patients feeling ashamed or blamed for having gout, discussion usually focused on pain management for gout attacks. From a health literacy perspective, people were not involved in discussions with a health professional which, over time, can build a comprehensive understanding of gout and the long-term implications of the condition. In light of this, it was understandable that patients preferred to manage gout attacks with short-term pain medication rather than use urate-lowering medicine, which was complicated and at times painful to introduce as well as being a long-term or permanent regime.

1 As part of the research, researchers co-designed gout resources that explained
2 the importance of reducing uric acid levels, how genes prevent the clearance of
3 uric acid for many Māori, that urate-lowering medicines were the most effective
4 and efficient way to reduce uric acid levels and how different urate-lowering
5 medicines work. Researchers also developed guidance for health professionals
6 about how to use the resources with patients as a way of addressing the biases
7 health professionals had about people with gout. The resources focus on discussing
8 gout in primary care settings as gout is a long-term condition that benefits from
9 expert advice and ongoing monitoring. The resources are used in primary and
10 secondary care and are freely available on the Ministry of Health and other health
11 websites (Ministry of Health, nd, d).

13 *Gestational diabetes mellitus and health literacy*

15 Māori women have more children, and start having children earlier, than the
16 non-Māori. Researchers in this project found the majority of Māori women who
17 had not been tested for GDM during pregnancy had agreed in principle to be
18 tested, and intended to have a test but had not prioritised the test and ‘ran out
19 of time’ as they did not think the test was very important or of themselves as at
20 high-risk of developing GDM. These women had been offered the test and no
21 objections to testing, other than it being time-consuming (taking approximately
22 three hours) and therefore inconvenient. This reflects that some women need
23 to understand why testing is important (for them) in order to prioritise the
24 testing process. A few women who had been diagnosed with GDM in previous
25 pregnancies attributed not being tested during subsequent pregnancies to not
26 liking the diabetes services provided after diagnosis. A small number of women
27 disagreed with medical tests being carried out during pregnancy.

28 Significantly, the health professionals offering the test to women had mixed
29 views about how to offer testing, as well as the value of testing. A small group saw
30 this as over-medicalising pregnancy. Most often, women were told the purpose of
31 the test (to identify diabetes that can develop during pregnancy) and where the
32 test could be taken, with little discussion involved. Some health professionals did
33 not want to jeopardise their relationship with women by ‘nagging’ them if they
34 did not carry out the test as initially agreed. There was also a view that having
35 all women receive the same offer of testing, in the same way, was providing an
36 equitable service. This view did not recognise that in order to prioritise testing
37 for GDM (rather than just agree in principle), some women may need more or
38 different information than others (and assistance with transport and childcare).
39 Some health professionals had very high rates of GDM testing among the Māori
40 women they worked with. They described using more in-depth discussion to
41 support the testing decision, particularly explaining the risks of GDM to women
42 and babies and benefits of managing GDM if present, as well as giving timely
43 reminders if a woman agreed to testing but had not completed the process (White
44 et al, 2014).

It became clear that how GDM and testing were discussed with women, and encouraging completion with those who agreed to be tested, affected testing rates. A booklet explaining gestational diabetes and reasons for testing was developed for women and health professionals to support more discussion about GDM. However, this was sometimes added to the information pack for women rather than being discussed and as such, had little impact on testing rates. In addition, there were complex reasons why organisations were not often able to deal with access (to testing) issues such as transport and childcare.

Research results

The three exploratory research projects demonstrated the complexity of health literacy and that health literacy was relevant to health outcomes for Māori. The projects highlighted that health literacy issues can stem from difficulty accessing people with knowledge and expertise, to a lack of credible, appropriate information being available at the right time, to assumptions being made by patients and health professionals that ultimately lead to poor health outcomes.

The differences between the information needs and sector responses in each project helped highlight that health literacy skills are not a fixed skill set that can be pre-learned by a child or adult, and are not the same as general literacy and numeracy. For example, someone with strong literacy and numeracy skills can have low health literacy in relation to gout. The health literacy relevant to a health condition is often detailed and involves specific knowledge about how the body functions and responds to particular medicines and how health conditions progress and can be managed. Until a health condition becomes relevant to a person or family, there is little need or reason to learn about it.

The projects also identified a commonly held belief that health literacy is an individual or patient issue, with little recognition that health services and systems often create health literacy barriers and do not support people to build health literacy when opportunities arise. The need to address the health literacy demands created by the complexity, culture and accessibility of the health system, services and information was identified in each project, with the answer often involving both working differently in health service provision, as well as health professionals identifying appropriate opportunities with patients and families to build skills and knowledge.

Growing interest (and popularity)

For the Ministry of Health, the exploratory projects demonstrated how health literacy was integral to achieving the outcomes sought in the Māori Health Strategy, *He Korowai Oranga* (Ministry of Health, 2014b), and aligned with other frameworks in Māori health such as health equity (Ministry of Health, 2014a), person and family-centred care and cultural competence. The challenge became how to get the wider health sector to build awareness of and capability in health

1 literacy and make changes accordingly. Te Kete Hauora and other Ministry teams
 2 funded further health literacy projects in relation to key health issues for Māori,
 3 such as childhood asthma (Māori children are more likely to be hospitalised with
 4 poorly managed asthma) and palliative care; (Māori, like all indigenous peoples, are
 5 far more likely to provide palliative care services at home to extended family but
 6 are far less likely to be offered access to or seek assistance from funded palliative
 7 care providers).

8 In addition, some academic institutions were carrying out health literacy research
 9 projects, for example, the University of Auckland's project on cardiovascular
 10 disease medicines and the University of Otago's follow-up project on asthma for
 11 Māori children and their families. A number of students were also completing
 12 doctoral studies in health literacy.

13 In 2012 the Ministry published *Rauemi Atawhai: A guide to developing health*
 14 *education resources in New Zealand* (Ministry of Health, 2012), setting out the main
 15 steps for developing health education resources, including understanding the
 16 health literacy demands placed on audiences and the health literacy skill needs
 17 of those audiences. In 2012 another government agency, the Health Quality and
 18 Safety Commission, undertook a health literacy project as part of the Partners
 19 in Care initiative about engaging consumers in decision-making, particularly
 20 around medicine use. The Commission contracted Workbase to work with health
 21 professionals, initially community pharmacists, to develop workforce development
 22 material that could be used by pharmacists working directly with patients and
 23 families to build the health literacy of those patients and families.

24 The workforce development materials were based on applying the universal
 25 precautions approach to health literacy (AHRQ, 2010) and employed a strengths-
 26 based approach. Along with background information on health literacy, a training
 27 resource was developed called the *Three steps to better health literacy*, centred on
 28 a community pharmacy context. The authors used reading and schema theory
 29 and other knowledge developed in the context of adult literacy to inform the
 30 content of the resource. The three steps described were:

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- 32 1. Ask – focused on eliciting a person's existing knowledge and beliefs.
- 33 2. Build – focused on building new knowledge by linking to what had been
 34 uncovered in Step 1 and using a mix of teaching and learning strategies
- 35 3. Check – focused on checking whether the health professional has helped a
 36 person build new understanding, incorporating the teach-back method (Health
 37 Quality and Safety Commission New Zealand, 2014).

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39 The project also identified the health literacy demands placed on patients and
 40 families. For example, pharmacists used a considerable amount of unfamiliar
 41 language and abbreviations that had an impact on patients and families'
 42 understanding of medicines. The three steps were designed to help pharmacists
 43 think more about the way they provided information to patients and families

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as well as to check whether a pharmacist had been clear and effective in their communication. 1
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In 2014 the Commission asked Workbase to redevelop the workforce development material, so it was applicable to all health professionals, and not specifically community pharmacists (Health Quality and Safety Commission, 2014). At the same time, other Ministry of Health-commissioned projects required health literacy demands to be identified and addressed, such as in the Ministry's Rheumatic Fever Prevention Programme. Rheumatic fever is still present in Māori and Pacific youth populations and those living in areas of high deprivation. Significant government investment had been made in producing national media campaigns to build awareness of rheumatic fever risks, as well as providing additional free health services in schools and communities to encourage the identification and treatment of streptococcus bacteria sore throats. 3
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When looking at the issues of timely access to healthcare and medicine adherence from a health literacy perspective, it was identified that families were sometimes unsure of the connection between sore throats and rheumatic fever, the consequences of rheumatic fever and the rationale for continuing to administer antibiotics for a sore throat after a child appeared to be symptom-free. 14
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Rheumatic fever is a complex condition requiring parents to understand the role of the immune system and how it can attack the heart and joints. There is no obvious connection between heart damage and a sore throat, and parents were also receiving conflicting messages about antibiotic use. Parents were hearing messages about antibiotic over-use and resistance, while being told to immediately start children on antibiotics for sore throats (and not wait until a streptococcus infection is confirmed), and to continue antibiotics after the symptoms had cleared up. This reinforced the need for the health workforce and media campaigns to engage with families about their understanding of sore throats, discussing *why* antibiotics are needed in this situation as well as *what* to do, in order to support healthy behaviours and good outcomes from improved access to health services. 19
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Associated initiatives, such as work in the public housing sector, also needed to take a health literacy approach when discussing healthy home environments in order to make the link to and support prevention and management of streptococcus throat infections and rheumatic fever. 30
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Other health literacy projects funded by the Ministry included resources for people considering live kidney donation, as well as resources for recipients of live donor transplants and resources to support people's enrolment in national screening programmes, for example, bowel screening, breast screening and cervical screening. 34
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Big-picture thinking 40

In 2011 Dr Rima Rudd, an internationally renowned health literacy researcher from the Harvard School of Public Health in the US, visited New Zealand to speak at our first (and only) health literacy conference, and was asked to meet 41
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1 with the Ministry of Health and DHBs to discuss health literacy. Her visit was
2 influential, particularly as her description of health literacy as a system issue rather
3 than an issue of patient-deficit resonated with the Ministry, as their analysis of
4 health disparity had led to a very similar perspective for achieving health equity
5 in New Zealand. For those DHBs working with populations living in significant
6 socioeconomic deprivation, this framing of health literacy matched the DHBs'
7 concerns that the inequities and poor health outcomes experienced by these
8 populations were due to far more complex issues than the individual efforts of
9 patients and families.

10 In 2013 and 2014 the Ministry decided to develop guidance for healthcare
11 organisations, particularly DHBs, about reviewing services from a health literacy
12 perspective, and again sought contestable bids for the project. Workbase was the
13 successful bidder working with three DHBs and Dr Rima Rudd as an expert
14 reviewer.

15 The project involved developing a process by which large healthcare
16 organisations could self-review their services and models-of-care from a health
17 literacy perspective. Following the review process a healthcare organisation would
18 develop an action plan for providing health-literate services, becoming a health-
19 literate organisation and providing health literacy leadership to the sector in NZ
20 (see Chapters 31 and 35, this volume). The guide, *Health literacy review: A guide*,
21 and supporting website were made available by the Ministry at the end of 2015
22 (Ministry of Health, 2015b).

23 A critical foundation document for the Guide was the Institute of Medicine's
24 discussion paper, *Ten attributes of a health literate health care organization* (Brach et al,
25 2012). This described what healthcare organisations could do to reduce the
26 barriers to accessing and using health information and services. Many of these
27 attributes seemed relevant to the NZ health system.

28 Eventually, six dimensions of a health-literate organisation were found to
29 be significant and relevant to NZ and the self-review process, and these were:
30 governance and management; access and navigation; consumer involvement;
31 meeting the needs of the population; the health workforce; and communication.
32 These dimensions helped to reinforce the system and service design aspects of
33 delivering health literate-healthcare, reducing unnecessary complexity and finding
34 opportunities to build patient and public understanding of health and healthcare.

35 The Guide was also informed by health literacy toolkits, guides and projects
36 that had been developed in the US, for example, the *Pharmacy health literacy*
37 *assessment tool* (Jacobson et al, 2007); AHRQ *Health literacy universal precautions*
38 *toolkit* (AHRQ, 2010); and *The health literacy environment of hospitals and health*
39 *centers – Partners for action: Making your healthcare facility literacy-friendly* (Rudd and
40 Anderson, 2006).

41 As health literacy was very much an emerging concept in NZ, the Guide needed
42 to help reviewers and their organisations understand and support the concept of
43 health-literate healthcare organisations, as well as provide a straightforward process
44 for undertaking a review. A balance needed to be struck between providing

standardised, reusable review tools, such as an exemplar review plans, observation checklists and interview questions, and ensuring a review team would be able to design and adapt the review process to best suit the services, issues and parties involved in a review.

An extra challenge in NZ was the self-administered nature of the review, given that health literacy experience and expertise was not widespread within the sector. The expert feedback from Dr Rudd and advice from Cindy Brach focused on what could reasonably be expected of healthcare organisations and their understanding of health literacy, when carrying out a review would be the start of the health literacy journey for most organisations.

At the same time as the Guide was being developed, Te Kete Hauora was working on developing a health literacy framework for NZ. Te Kete Hauora drew on learning from local health literacy projects and analysis, as well as current international research and responses to health literacy. Te Kete Hauora consulted widely with a large range of national healthcare organisations and health professionals. In 2015 the Ministry released *A framework for health literacy* (Ministry of Health, 2015a). The Framework identifies the leadership and management actions, knowledge and skills needed by each party, as well as system and service changes that build a health-literate health system.

New Zealand is the only country to have developed a framework that outlines expectations for the health system, health organisations and the health workforce to support health literacy being core business at all levels of the health system. The Framework identifies that effective health literacy practice contributes to improved health outcomes and reduced health costs.

The Ministry described the Framework as key to creating a health-literate health system which:

... builds health literacy skills of its workforce, and the individuals and whānau (families) who use its services. It provides high-quality services that are easy to access and navigate and gives clear and relevant health messages so that everyone living in New Zealand can effectively manage their own health, keep well and live well. (Ministry of Health, 2015a)

The current situation

At the end of 2015, Te Kete Hauora was disestablished as part of a major restructure of the Ministry of Health. The functions and responsibilities of the directorate were spread across the wider Ministry. Some DHBs and other large healthcare organisations are using the *Health literacy reviews: A guide* to understand health literacy from a service design and delivery perspective. One DHB carried out a high-level health literacy review of healthcare provision across its entire region. They were able to look at whether the health services within their region were understood and coordinated from a user perspective. Some specific projects

1 were identified that would benefit most from health literacy interventions, such
2 as access to and outcomes from bariatric surgery in order to understand what is
3 and isn't working, why and what to do. Two other DHBs have a series of health
4 literacy reviews underway and some have developed or are developing strategic-
5 level plans for health literacy.

6 New health sector initiatives, particularly those undertaken by DHBs, are
7 using the six dimensions of a health-literate organisation described in the Guide
8 to plan and introduce new services in order to build engagement with and
9 understanding of new services. This involves looking at new services from a service
10 user perspective, helping people to better understand the health journey overall
11 and a new service in particular, to anticipate the next steps in their healthcare
12 and weigh up their treatment or other options. This is not about producing
13 written information for the public, but rather focusing on the health delivery
14 and management workforce – ensuring they have skills and resources needed to
15 design, promote and discuss new services in effective ways, as well as coordinating
16 the messages provided across all of the information points. Increasingly, health
17 literacy is recognised as an essential building block in other projects, such as a
18 project about creating workforce development resources to encourage and improve
19 the provision of self-management support in primary care practices.

21 **Future challenges**

22
23 While there has been some clear leadership shown in the work carried out by
24 the Ministry, one of the ongoing challenges is moving the health sector and
25 communities framing of health literacy from being an issue of patient-deficit
26 to being an issue of system response. The health system and services, treatment
27 pathways, health conditions and anatomy and physiology are complex. Some of
28 the complexity can be removed, but a significant part of helping people manage
29 their health is helping them understand the health conditions and journeys they
30 may be facing. In an age of increasing demands on healthcare services, and where
31 self-management of complex and multiple long-term conditions is becoming
32 a necessity, it is essential that every health interaction and message is building
33 health literacy as needed.

34 Primary care practices are increasingly inviting patients to participate in patient
35 portals to improve time management for health professionals and promoting
36 the concept as giving patients greater access to information and services. This
37 increased access is a significant improvement for many, but there is the potential
38 for people unable to operate in digital environments to become even further
39 isolated unless they are upskilled, provided with equipment or offered alternative
40 ways to access their information.

41 All of these developments and changes in the health sector add to the health
42 literacy demands people face when managing their health and navigating the
43 health system. There is a continued need to consider how to reduce these demands
44 and resulting complexity, and create health organisations, services and a health

workforce that takes every opportunity to build health literacy when and where it is needed by individuals, families and communities.

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