National Health Literacy Strategy Framework Consultation

Overview

The **National Preventive Health Strategy 2021-2030** outlines Australia's overarching, long-term approach to prevention. The aim of the National Preventive Health Strategy is to create a sustainable prevention system for all Australians, with a particular focus on the wider determinants of health, reducing health inequity and addressing the increasing burden of disease. This will help all Australians live in good health and wellbeing for as long as possible.

The development of the **National Health Literacy Strategy** is one of eight immediate priorities under the National Preventive Health Strategy. Health literacy refers to how people understand information about health and health care, and how they apply that information to their lives, use it to make decisions and act on it. It is determined both by the skills and abilities of individuals as well as the demands and complexity of the environment.

The objective of the National Health Literacy Strategy is to provide an evidence-based health literacy environment, where health information is person-centred, accessible and culturally and linguistically appropriate, and to improve health literacy skills of all Australians.

Improving the health literacy environment for all Australians will offer a critical platform for the long-term success of the National Preventive Health Strategy. It will lead to improved navigation of the preventive health system, improved service delivery and a reduced burden on the health system.

Purpose and scope of this Consultation Paper: This paper describes a draft framework that will form the building blocks for the National Health Literacy Strategy. This framework has been developed based on feedback gathered through consultations with a diverse range of stakeholders and consumers, and reviews of national and international evidence of what works.

PLEASE NOTE: The Consultation Paper can be found at the bottom of the page under the 'Related' heading. Please ensure you have read the paper in full before you provide feedback.

Why your views matter

The purpose of this consultation is to seek stakeholder and community feedback on the draft framework for the National Health Literacy Strategy. The diverse perspectives, experiences and knowledge of all stakeholders and interested members of the community are valued and respected and will contribute to the final strategy.

Introduction

1 What is your name?

2 What is your email address?

3 Are you responding on behalf of an organisation, or as a consumer/individual?

(Required)

Please select only one item

On behalf of an organisation
On behalf of a section/team within in a organisation
As a consumer/individual
Unsure

4 What is your organisation and/or field of expertise?

Health genomics

5If representing an organisation, which sector does your organisation belong to?

Please select only one item

State or Territory Government Department/Agency
Commonwealth Government Department/Agency
Local Council
Primary Health Network
Local Health District
Professional body/Peak organisation
University/Education/Research Institution
Health service delivery organisation
Not-for-profit/Community organisation
Industry/Business
I am a consumer/individual
Other: Please specify

Consultation Questions

These questions relate to the National Health Literacy Strategy Framework paper which can be found as an attachment to the homepage of this consultation.

6 Does the Framework capture the important components? If not, please describe what else is needed. (See diagram page 6)

Please select only one item

Yes
No, and I recommend changes. Please specify.
Other. Please specify.
Not my area of expertise/experience.

The framework is high-level but captures the important components.

7 Is the proposed vision appropriate for the National Health Literacy Strategy (see page 7)

Vision: All Australians are enabled to make informed decisions about their health

Please select only one item

Yes
No, and I recommend changes. Please specify.
Other. Please specify.
Not my area of expertise/experience.

The proposed vision is appropriate. However, we have noted the inclusion of the word “enabled”. This perhaps implies that the role of the Health Literacy Framework is to provide the tools that enable people to make informed decisions about their health but takes less responsibility for their uptake and the success of their outcomes. Whether the tools developed under the framework are successful in enabling communities should be the subject of detailed evaluation which can inform ongoing development and refinement of enabling tools and resources.

8 Are the key principles captured? If not, what is missing? (See pages8-9)

Principles for Action:
Apply an equity lens
Address cultural and linguistic diversity
Be people and community centred
Address needs across the life-course
Be evidenced-based
Be practical and implementable

Please select only one item
Yes
No, and I recommend changes. Please specify.
Other. Please specify.
Not my area of expertise/experience.

A principle for action relating to timeliness should be considered: framework actions and specific health literacy initiatives should be rolled out based on the urgency of need. This would also include health literacy actions being targeted toward the parts of the community who are most in need at a given time. Sustainability should also be addressed as a principle, as there needs to be a long-term plan to keep of information current, incorporate new information, and keep pace with the best methods of delivery (e.g. multi-media approaches). One example of an immediate need for public education and good health literacy relates to the increased availability of genetic screening using genome sequencing. Genome sequencing has powerful potential to predict, prevent, and inform management and treatment of disease throughout the life course. Genomic information impacts families and communities with shared ancestry. Genomic tests are already available for people with increased risk of developing hereditary conditions, including cancers. However, genomic sequencing will also enable expanded reproductive carrier screening to identify reproductive couples who have an increased chance of having a child affected by a rare genetic condition but are not affected themselves. This has recently been trialled through the Australian Reproductive Carrier Screening study, Mackenzie’s Mission (funded by the MRFF) with 10,000 couples. An application to MSAC to sustainably fund this program was recently not recommended for funding. Some of the main reasons funding was not recommended related to unknowns about public acceptance, and equity of access. Equity concerns include the likelihood that there are different levels of knowledge (health literacy) about genomics across the population. Australian studies (PMID: 30808825, PMID: 19039252) suggest that public knowledge of genetics and genomics is increasing but is generally perceived to be low. Health genomics implementation also relies on digital health infrastructure, so is also affected by digital health literacy. Although familiarity with the term ‘genomics’ may have increased during the COVID-19 pandemic, public perceptions of genomics remain highly diverse (PMID: 36257982). This example demonstrates how important health literacy, education and public partnerships, are for Australians to be able to share in the health benefits afforded by new health-related technologies. This means that reproductive genetics and genomic testing/screening options are an example of an area where there is urgent need to assess current health literacy,and develop ways to enable Australian communities to build their knowledge and make appropriate health decisions for themselves and their families. It is important to note that a component of health literacy in genetics and genomics is recognition of both genetic and environmental involvement in disease. Therefore, increased public genetic health literacy would also support identified focus areas in the National Health Prevention Strategy including increased cancer screening and prevention.

Australian Genomics is in support of a national approach and platform for credible, evidence-based, health-related information, including genomic information.

9Are the aims the right ones for achieving the vision of the National Health Literacy Strategy? (See pages 10-13)

Aim 1: Systems, policies and practices within and across sectors support an effective health literacy environment
Aim 2: All Australians can access health information that is easy to understand, trustworthy and culturally appropriate
Aim 3: All Australians have the skills to find and use reliable health information across the varied media they use

Please select only one item
Yes
No, and I recommend changes. Please specify.
Other. Please specify.
Not my area of expertise/experience.

10Do you have any example actions that could be considered under each aim? (See pages 11, 13 & 14)

Aim 1: Systems, policies and practices within and across sectors support an effective health literacy environment

A sustainably resourced, coordinated, multi-sector approach to health literacy will encourage alignment of existing materials, use of existing channels and the emerging evidence base for enabling health literacy.

Mechanisms will be in place to manage the removal of incorrect information, to support an effective and accurate health literacy environment. This may include review of how fake news can be regulated, and monitoring systems for social media platforms.

Aim 2: All Australians can access health information that is easy to understand, trustworthy and culturally appropriate

A national approach to making credible, evidence-based health information will be established, partnering with publics and integrating existing local and state providers’ existing channels and capabilities.

This will be complemented by a national approach to workforce education and health literacy in current and emerging areas such as genomics, including universities, professional societies and Colleges

Health literacy information development will be resourced to include evaluation with consumers and/or coproduction, together with assessment of short, medium and long-term outcomes to continue to contribute to the evidence base

Please also see response to Q12

Aim 3: All Australians have the skills to find and use reliable health information across the varied media they use

Cross-sector collaborations and alignment, such as health and school education, enable consumers to develop health and digital literacy skills and further inform information provision through cross-sector research into preferences and accessibility.

Please also see response to Q12.

11 Are the categories for the leaders and partners who will mobilise health literacy action appropriate? (See page 14)

Key leaders and partners include:
Governments
Other organisations
Workplaces, education institutions and service providers
People and communities

Please select only one item
Yes
No, and I recommend changes. Please specify.
Other. Please specify.
Not my area of expertise/experience.

The categories of leaders and partners are very broad. It would be good to see a more detailed description of the types of organisations that will be engaged in health literacy action, and their different levels of engagement. For example, organisations involved in healthcare research and implementation organisations play roles in developing the evidence base, particularly in emerging areas. Australian Genomics would like to play a role in improving genomic health literacy under the framework. Australian Genomics also has an active genomic workforce education project which is focused on developing and implementing tools and networks to improve information provision and health workforce literacy in genomics. People and communities could also be expanded to include religious groups.

12 Please provide any other observations and advice that you have not had the opportunity to make on the Framework:

Australian Genomics recognises that health literacy and promotion are large-scale, long-term strategies that require significant investments and multi-sector partnerships best led by governments. We have been taking steps to help skill the Australian public and promote knowledge in health genomics through research and information provision. For example, the genomicsinfo.org website hosts accurate, up-to-date information resources and is designed for people currently undergoing, or considering genomic testing, or anyone who wants to learn more about genetics and genomics. Health professionals are also encouraged to also access and share the resources. Australian Genomics also collaborates and advises on a number of national programs developing information materials for people with rare disease and people with intellectual disability, contributing to the pool of accessible genetic information resources.

Australian Genomics has more recently funded several community-focussed implementation projects in 2022. These projects include:

Building genomic knowledge in partnership with Indigenous communities and health services
This public health program, led by Mrs Azure Hermes from the National Centre for Indigenous Genomics (NCIG), builds on established collaborations and programs to co-develop appropriate genetic and genomic messaging and resources for Indigenous peoples. In partnership with Aboriginal and Torres Strait Islander Organisations (ACCHOs), this project will increase genomic and genetic health knowledge within Indigenous Communities and identify what Aboriginal and Torres Strait Islander people need to know to support choices regarding genetic health and genomic research. The resources developed by this program will be adapted and utilised by ACCHOs and Indigenous Communities, empowering those communities to take ownership over their genomic information and decisions, and will also be made available, by negotiation with partners and Communities, to Australian Genomics and supported projects.

Development of culturally-aligned and language-appropriate participant information and education resources for Australian ethnic minority ancestry groups under-represented in clinical and population genomics research
One obstacle to diversity in research projects is the lack of appropriate explanatory materials. Many existing English-language explanations of genomic research are hard for lay people to understand and very few translations into other languages have been created. This project, led by Prof Daniel MacArthur from the Centre for Population Genomics (CPG) and Ms Mary-Anne Young from the Kinghorn Centre for Clinical Genomics (KCCG), will produce a core set of participant information and education materials specifically related to consent for genomic research, in plain English. The materials will subsequently be translated into ten languages (Arabic, Dari, Farsi, Fijian, Hazaragi, Samoan, Tagalog, Tongan, Urdu, and Vietnamese). The resources will be presented online in text versions with audio clips, and will be made openly available to other genomic research programs in Australia.

Genomics in schools: Resources to engage students in the translation of genomics to the real world
As genomics continues to become more important socially, legally, and ethically, public education about genomic technologies and their implications becomes increasingly necessary. To address this need, the Genetic Support Network of Victoria (GSNV) implemented a highly successful two-stage program which produced downloadable resources for students aged 10-18 in Victoria. Under the leadership of Ms Hollie Feller, the GSNV will extend their program nationally. This project will develop one national science curriculum resource focused on the everyday health utility of genomics. The curriculum will deliver a balanced genomic education program to Australian upper primary and secondary school students addressing the benefits and limitations of current and future genomic technologies, to allow for informed decision making and healthy debate.