

What consumers think about health genomics information

Key findings from consumer research, 2026



Background

Having accurate information about genomic health care helps people to make informed decisions. Genomics Australia engaged ORIMA Research to better understand the public's information needs regarding genomic health care. The purpose of the study was to identify pre-existing, high-quality resources about genomic health care and assess how well they met consumers needs and preferences.

Methodology

The research took place in April - June 2026 and had three parts:

1. Researchers found publicly available resources about genomic health care and reviewed their quality. They identified 405 resources.
2. Researchers talked with 187 people to hear about their information needs and get detailed feedback about some of the resources (qualitative research).
3. 1,501 people were then surveyed about genomic health care information (quantitative research).

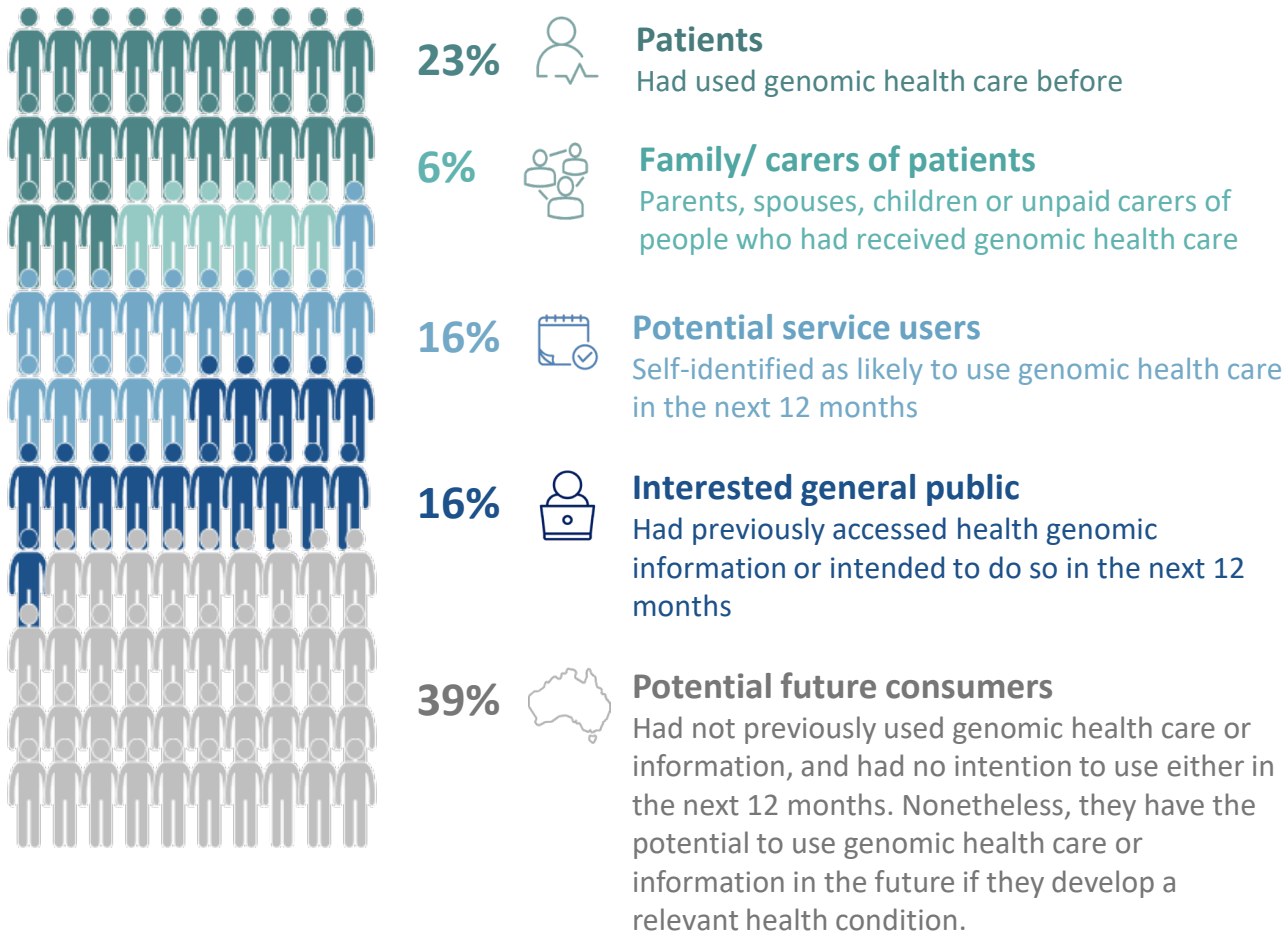
Qualitative and quantitative research was conducted with **those who had engaged with, or were likely to engage, with genomics information**. The qualitative research included priority groups with potentially unique information needs and preferences in relation to genomics including **people with disability, First Nations peoples and culturally and linguistically diverse communities**.

Summary of key findings

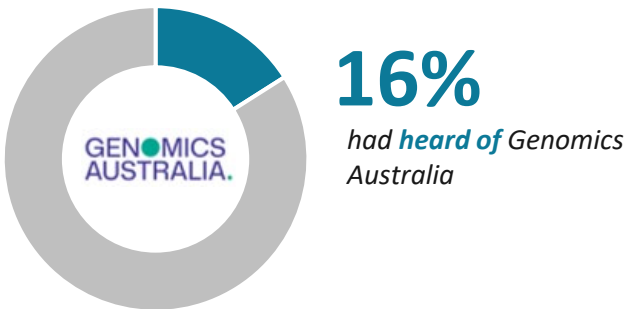
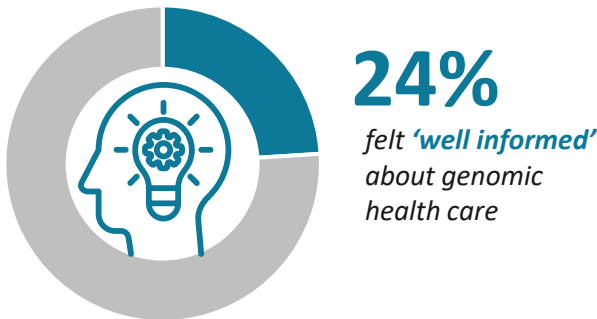
- › Most survey respondents felt they knew very little about genomic health care.
- › Among respondents who had accessed genomic health information, most did so in response to a specific health need, particularly in relation to planning a pregnancy or for other familial health conditions.
- › Respondents used a wide range of sources when accessing information on the topic, including informal sources such as social media and family or friends. The variety of sources used suggests there is currently no clear 'go to' source on the topic.
- › Respondents had a clear preference to access genomic health information from credible sources, including healthcare professionals and a government health department.
- › Information that was currently available in relation to genomic health was not fully meeting respondents' needs, with challenges noted in relation to ease of finding, understanding, and applying it to their situation.
- › Respondents preferred information that used plain language, avoided technical terms, provided the basics of health genomics, and was presented in a variety of formats.
- › There were gaps noted in the information that was currently available, particularly in relation to: risks, privacy and ethics; genomic medicines and therapies; getting access to genetic services; information tailored for culturally and linguistically diverse communities; and information tailored for people with disability.

What consumers think about health genomics information (continued)

Current and potential consumers of genomics health information are a broad and highly diverse group

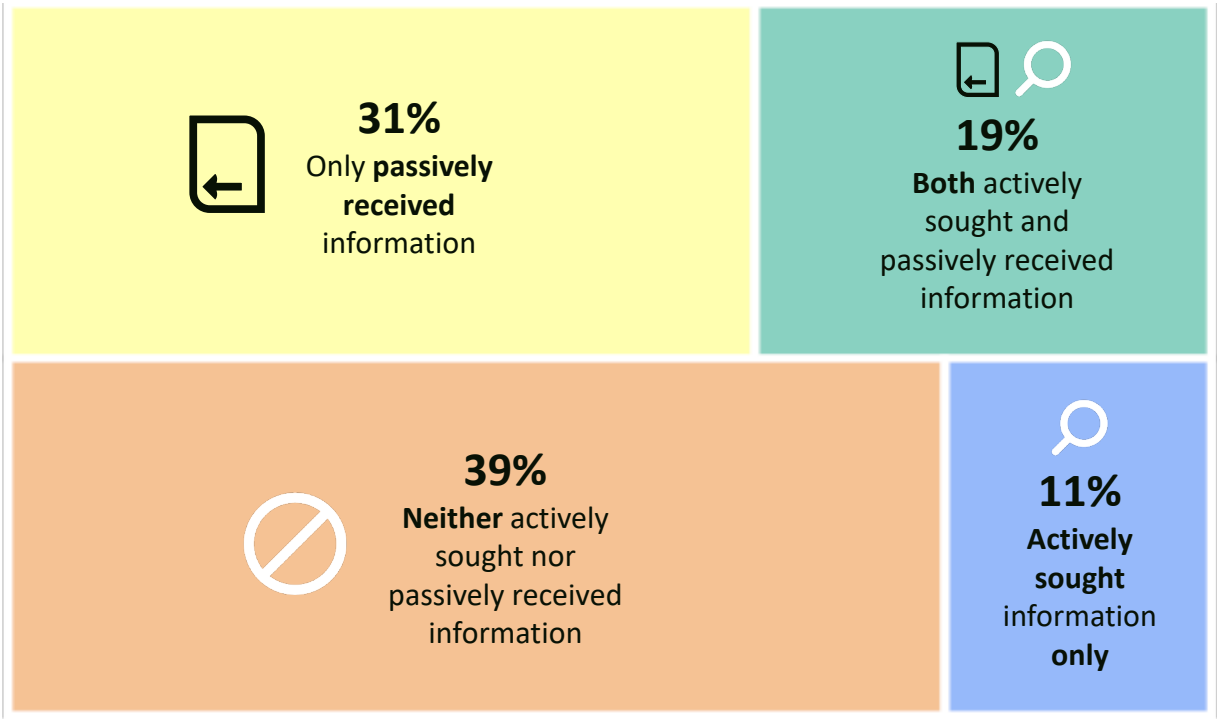


Most felt they knew very little about genomic health care and Genomics Australia

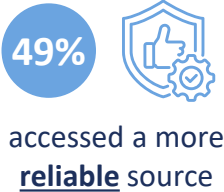


What consumers think about health genomics information (continued)

Many had not actively sought out information about genomics, and among those who had, a significant proportion used sources that may be less reliable



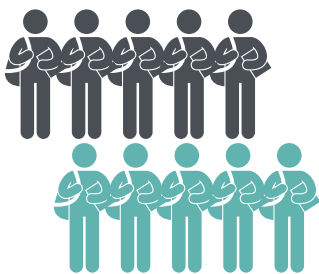
e.g. social media (28%), family and friends (25%), online news articles (24%), online search (24%).



e.g. doctors/ medical professionals/ health services/ hospitals (21%), scientific research articles (16%), government health department (11%).

(Multiple response question).

Confidence in making health decisions based on accessed information was only moderate



53% ...of those who had used health genomic information/ resources, felt **confident in making health decisions** based on the information accessed

Reliable information led to greater confidence and more positive feelings about health genomics



62%  of respondents
who accessed information
from a more **reliable source**
had high confidence in
making health decisions
based on the accessed
information



...compared to

53% of those who accessed information from a **potentially unreliable source**



There was a desire for more information about health genomics through a government website

39%

would seek out
more information

43%

prefer government
health sources

47%

prefer a
website format

51%

would use the
Genomics Australia
website

In response to these findings...

The research identified existing resources that can be linked via the Genomics Australia website to provide accessible information to support individuals in making informed health decisions. It also highlighted gaps in available resources that may be addressed over time. These gaps could be addressed either by other organisations or by Genomics Australia as part of a phased approach to expand and/ or enhance the available resources.