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## 2 Consumer engagement and information

### Goal

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*To improve health outcomes by promoting the role of consumers in managing their health in partnership with health care providers and in helping to shape services to be better targeted to consumers' needs.*

### Rationale

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#### Magnitude of the problem

Heart, stroke and vascular disease is a chronic condition, and prevention of acute events requires people with the disease or at risk of developing it to work in partnership with their health care providers. Engaging consumers in managing their health can improve concordance with medication regimes and with lifestyle counselling. Services also need to be organised to address the geographic, cultural and socioeconomic diversity of consumer needs.

The evidence base underpinning consumer participation in health supports:

- a link between structured approaches to self-management education and better patient outcomes in relation to chronic disease (Lorig et al 1999);
- the importance of having a written action or care plan, prepared through partnership between the consumer and health care provider, with the consumer able to self-monitor between health care visits; and
- the importance of access to quality health information in raising the confidence of patients to deal with their condition (Consumer Focus Collaboration 2001).

#### Opportunities

Broad approaches to self-management of chronic and complex conditions are under development at a national level such as the Sharing Health Care Initiative and specific initiatives are underway in relation to conditions such as arthritis and asthma. Through building on these programs there are opportunities to develop self-management education approaches and resources that are targeted to heart, stroke and vascular disease.

There also appears to be substantial potential for gain through the development of information for people at risk or with existing heart, stroke and vascular disease, as long as the information is accessible for diverse groups of consumers.

As well as contributing to their own health, people with heart, stroke and vascular disease and those who are at risk of developing it, can offer a particular expertise and perspective on the safety and quality of the services they receive. Consumers and consumer networks need to be at the centre of service development and delivery. This can be used to enhance service improvements and increase the likelihood of concordance in others.

## Strategies

- Improve the availability of high quality, accessible and culturally appropriate information to consumers on:
  - preventing heart, stroke and vascular disease;
  - warning signs of acute heart and stroke events;
  - the benefits and risks of treatments, to facilitate decision-making; and
  - medications and their side effects and alternatives.
- Support the development of appropriately structured care plans, developed in partnership with individual patients in order to meet their needs, including discharge plans, to increase consumers' understanding of their treatment regimes.
- Strengthen the capacity and confidence of consumers to self-manage their condition(s).
- Use the experiences of and work with consumers and their carers through the patient journey along the continuum of care to facilitate continuous quality improvement.
- Increase support for community-based consumer networks for people with heart, stroke and vascular disease and their carers.
- Design activities to take into account the diverse needs of consumers from disadvantaged groups including Aboriginal and Torres Strait Islander peoples, people who are socio-economically disadvantaged and people from culturally and linguistically diverse backgrounds.
- Increase support and information for carers of people with chronic heart, stroke and vascular conditions and support for existing community-based consumer networks for people from the at risk groups, such as Aboriginal and Torres Strait Islander people, older people, and people affected by mental illness to enable them to develop appropriate strategies for improving the heart, stroke and vascular health of their members.
- Develop information to consumers that will increase their understanding and acceptance (destigmatisation) of the role of depression, lack of quality social support and social isolation as independent and significant risk factors in heart, stroke and vascular disease.
- Consumer representatives for people from at risk groups should be included in the development stage for any projects, information and resources, dissemination, other strategies aimed at the consumers.

## Priorities for national action

- *Improve the availability of high quality, accessible and culturally appropriate information for consumers on prevention, treatment and management of heart, stroke and vascular disease.*
- *Support the development and effective use of written action plans.*
- *Strengthen the capacity of consumers to self-manage their condition and adhere to care plans and treatment regimes through a team approach.*
- *Increase support for community-based consumer networks for people with heart, stroke and vascular disease and their carers.*