# quality consumer health information

The Children, Youth and Women's Health Service is committed to providing quality health information for consumers as an integral part of its clinical care and health promotion.

This guide has been developed by the Centre for Health Promotion to assist staff and other health professionals to develop quality consumer health information.

## What is consumer health information?

Consumer health information is information for patients, families and the community about their health and health care. It may be about:

- health services; eg what services are available and what they cost
- health conditions; what they are, how they can be treated and managed
- coping with long-term illness, pain and disability
- preventing illness and injury, and improving health and wellbeing
- having a voice in how health services are delivered.<sup>1</sup>

The most common forms of consumer health information are printed brochures and information published on the web. They add to advice provided in professional consultations.

## What consumers say they want

People have a right to information about their health and health care. It has been found that people want information to:

- explain what is wrong and what may happen to them
- understand tests and treatments
- assist them to manage their conditions
- learn about services and sources of help
- provide reassurance and help others to understand
- identify the 'best' health services and make the most of consultations.<sup>2</sup>



## Principles of

# quality health information

### Quality consumer health information

#### ... is clearly communicated

- clearly and simply presented
- · legible and readable
- in styles and formats consumers find acceptable.



# ... is based on quality information and expertise

- based on best available evidence and a range of expertise
- informed by current research
- presents risks, benefits and alternatives of treatment options
- acknowledges areas of uncertainty
- is clearly dated
- lists sources of information.<sup>3</sup>

# ... involves consumers throughout development

- involves consumers from the beginning
- addresses concerns that are important to consumers
- is piloted with consumers to test its appropriateness
- is evaluated with consumers.

### Why focus on quality?

Quality standards for health information are not new. The Women's and Children's Hospital was one of the first Australian hospitals to have guidelines for writing quality health information.<sup>4</sup> Since then the demands have grown as:

- the web and desktop publishing have increased the amount of information, but not always its accuracy or quality
- evidence based practice has increased our understanding of what quality information is
- health policy has affirmed the key role of information in quality, safety and consumer participation.

# Suggested process for developing consumer health information

#### Tips for getting started

## 1. A need for health information is identified by health professionals or consumers.

Good planning is essential to developing quality information. Considering these questions will help get you started.

- Why is an information resource needed?
- What are you trying to achieve, eg increased knowledge and skills, improved decision making and/or confidence? Is it intended to prepare patients for a procedure, to support self-management or prevent conditions in the first place?
- Who is the target audience? How will they use the information?
- How will they have access to it? How will it be distributed?
  Will it be accessible to people with special needs?
- Will other strategies be needed to support the information?
- What resources (eg staffing or funds) will be needed to develop and disseminate the information?
- How will it be monitored and evaluated? Ensure that consumers are involved in evaluation.

#### What information already exists?

- 2. Establish whether information related to this need has already been developed by CYWHS or others.
- Check within CYWHS eg wards, units, community services,
  Health Information Centre, Centre for Health Promotion. The
  Clinical Governance Unit has a database of information
  brochures on the intranet at
  <a href="http://cger.cywhs.sa.gov.au/cgu/clinical\_information/patient\_info\_sheets.isp">http://cger.cywhs.sa.gov.au/cgu/clinical\_information/patient\_info\_sheets.isp</a>
- Review resources from other agencies.

#### Organise a working group

#### Identify key players and organise a working group.

The group should:

- include representation from CYWHS units, disciplines or other services affected by, or with a stake in the information
- include consumers, or involve them throughout the process. Seek organisational assistance to involve consumers if necessary.
- appoint a facilitator.

#### **Develop content**

- Develop content with input from the group and consumers.
  - Determine an appropriate medium, style and layout.
  - Consider the key messages you want to convey and develop a draft. Ensure your writing is clear, simple and readable for your target audience.
  - Invite feedback from consumers and health professionals.
  - Review and modify your draft.

#### Evaluate and update

#### Monitor and evaluate your information resource and keep it up to date.

Some ways of doing this are to:

- Record the distribution.
- Seek feedback from consumers and health professionals about how they used it and any impact it had.
- Plan a time to review and update your resource. This should occur within two years, or as necessary.

## **Further information**

#### Writing quality health information

Centre for Health Care Strategies, Inc has 9 fact sheets on aspects of health literacy at <a href="https://www.chcs.org/usr\_doc/Health\_Literacy\_Fact\_Sheets.pdf">www.chcs.org/usr\_doc/Health\_Literacy\_Fact\_Sheets.pdf</a>

University of Utah, Health Sciences Centre has fact sheets for authors of health information at <a href="https://www.med.utah.edu/pated/authors/">www.med.utah.edu/pated/authors/</a>, including more about the SMOG formula at <a href="https://www.med.utah.edu/pated/authors/readability.html">www.med.utah.edu/pated/authors/readability.html</a>

#### Involving consumers in health services

Children, Youth and Women's Health Service (2006) *Bringing in the voice of the consumer*. Available from CYWHS Community Engagement Unit ph: 8161 6835.

The National Resource Centre for Consumer Participation in Health www.participateinhealth.org.au

#### Writing about treatment options

DISCERN: Quality criteria for consumer health information on treatment choices, is an internet tool and handbook with examples of communicating information about treatment options, risks and benefits. <a href="https://www.discern.org.uk">www.discern.org.uk</a>

National Health and Medical Research Council (2000). How to present evidence for consumers: Preparation of consumer publications. Canberra, AGPS. <a href="https://www.nhmrc.gov.au/publications/files/cp66.pdf">www.nhmrc.gov.au/publications/files/cp66.pdf</a>

#### Online health information

Health on the Net Foundation, an international not-for-profit initiative promotes the use of the HON code of conduct for health information published on the internet. <a href="www.hon.ch/">www.hon.ch/</a>

The Health Communication Unit (1999). The Update: Special Issue on the Internet. Canada, Centre for Health Promotion, University of Toronto. <a href="https://www.thcu.ca">www.thcu.ca</a>

#### References used in this guide

- Department of Health and Aged Care (2000) Stocktake of models and approaches to facilitating consumer access to health information.
- 2. Coulter, A., Entwistle, V. & Gilbert, D. (1998) Informing patients: An assessment of the quality of patient information materials. London, Kings Fund.
- 3. Adapted from the quality framework developed by the Centre for Health Information Quality (2000).
- 4. Johnson, A. (1994) Guidelines for the development of written health information. Women's and Children's Hospital, Adelaide.

#### Centre for Health Promotion

#### Other documents in this series available from the CHP

Making your health information clear and readable Evaluating health information with consumers

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