Suzanne Eastwood Project Consultant
Health Care Consumers’ Association ACT
What do you want to get out of this session today?

What is consumer led health literacy?

How understanding the social determinants of health can help you work better with disadvantaged and marginalised consumers

Consumer representation and empowerment – the new challenge in health care

Examples of topics for consumer led health literacy modules from HCCA

Planning a delivery strategy for a health literacy module and designing content that you could run in your own agency, service or region
CONSUMER ORGANISATIONS IN AUSTRALIA

Consumers Health Forum of Australia

The Health Consumers’ Council

Health Consumers Alliance of SA Inc.

Queensland Government Health Consumers Queensland

HEALTH CONSUMERS NSW

HEALTH ISSUES CENTRE
We make political space for lived experience with forums & policy submissions.

We get consumer participation into planning & decision-making.

We are a small grassroots, government funded, community sector organisation with ~ 7 full-time staff.

Our mission is to drive better health outcomes through consumer empowerment.

HEALTH CARE CONSUMERS ASSOCIATION
CANBERRA

We are a small grassroots, government funded, community sector organisation with ~ 7 full-time staff.

Our mission is to drive better health outcomes through consumer empowerment.

We get consumer participation into planning & decision-making.

We make political space for lived experience with forums & policy submissions.
Consumers seeking health information have the skills, knowledge, understanding & confidence to access relevant quality resources pitched at the right level.

Consumers have opportunities to build their skills & capacity so they can fully participate in their own healthcare and are able to pass on knowledge and support their families & friends.

Consumer led HL uses a strengths based approach and an opportunity to build personal communication skills and to know where & when to seek help.

Higher levels of Health Literacy in the community could play a significant role in delivering better health outcomes for consumers and for the Health System and can assist in reducing the cost of healthcare.

Consumers able to generate ideas & requests for topics. Consumer led HL is one of the cornerstone of health consumer empowerment.
RELEVANCE TO ENHANCING THE PATIENT EXPERIENCE?

- Able to be responsive to an issue/need as it emerges
- Health staff are confident information is understood by the Consumer in a way that is relevant for the consumer's own life
- Improved consumer action in their own lives
- Strengths based
- No shame, no judgment & no questions are stupid
- Consumers and families are better informed with directly relevant information
- No down time for the patient/consumer & family - there can be a lot of waiting around in a health care setting - why not have the Orthopaedic Colouring book & word search or the “How the body works” resources available at different levels of literacy
YOU DON’T NEED TO REINVENT THE WHEEL.
THERE ARE EXCELLENT RESOURCES LIKE THIS PAMPHLET FROM NACCHO
HIGH BLOOD PRESSURE [ HYPERTENSION ]
PRESENTED IN A CULTURALLY APPROPRIATE WAY

About high blood pressure:
• It usually has no symptoms.
• It can speed up blocking of the arteries, which can damage the:
  • Heart – leading to heart attacks
  • Brain – leading to stroke
  • Kidneys – leading to kidney trouble and dialysis
  • Eyes – leading to eye trouble and blindness

People with a family history of high blood pressure are at increased risk.

©2010 National Heart Foundation of Australia, National Prescribing Service Limited, National Aboriginal Community Controlled Health Organisation and Aboriginal Health Council of SA Inc.
The human body jigsaw. Why not have simple resources that people can use while they are waiting? Or while they are in the ward with family & friends.
THE HUMAN BODY EXHIBITION
AT THE MELBOURNE MUSEUM
CREATING AN ADULT LEARNING ENVIRONMENT

- Comfortable learning environment
- Accessible. Welcoming
- Inclusive activities. Fun
- No question is stupid zone
- Sharing experiences
- Learning new things
- Supporting each other
- Challenging each other
- Providing access to accurate up to date information
COMMUNITY DEVELOPMENT

- Being able to respond to a community need as you are seeing it develop.
- Ordinary people can do extraordinary things
- Ensure cultural competency within organisations
- Listen, Ask, Listen, Ask, take advise freely offered from stakeholders and key informants.
- Don’t be an org. where people say- “They never listen- I tried to tell them”
Be aware of health justice/social justice issues in your local area. Have a plan to address them.

Recognising people are experts in their own lives. Use a strengths based model.

Be aware of and address the SOCIAL DETERMINANTS OF HEALTH.

Have strategies to address Social Exclusion.

Find out where consumers/patients are at and start there.

Challenge yourself & your service to work with the difficult people.
1. Understanding the Pharmaceutical Benefits Scheme (PBS).

Including hands-on exercises using sample medicine packaging. What the labelling means, warning stickers and pricing. The Safety Net. Adverse events reporting. How are medicines listed on the PBS and how are they priced. A Generic or a brand? How is Australia different from other countries?
TOPICS FOR THE HEALTH LITERACY MODULES

2. Quit Smoking + (Multicultural). – Training facilitators to work with communities on QUIT strategies in their own language. Ensuring QUIT resources are available in community languages. Offering community information workshops.

3. Communicating with the health system. Opportunity to learn new ways of communicating in the health system, including how to find trustworthy sources of health information.

4. Choosing a service (customised for geographic areas). Assisting consumers to make an informed choice. When would/wouldn’t you go to the Emergency Department? Could you use The Walk In Centre? Accessing after hour’s services.
5. Understanding Medicare. What is a ‘gap payment’? What does ‘bulk billing’ mean? Why do we have Medicare? How is it paid for? How can Medicare work best for me? Am I claiming everything I am entitled to from Medicare?

7. Giving feedback and Making a Complaint. How to give positive feedback. How to let the system know when things are going wrong so they can be fixed at the time. Identifying services to support you if you need it. How you can make a health services complaint.

8. The role of the GP. The GP is key to a consumer’s primary health care. How can a consumer work with GP to improve their healthcare? Ask me 3
9. ‘Respecting Patient Choices’. Advanced Care Directives. Providing education and information about decision making for you and your family and friends, and referral to complete the paperwork for an Advanced Care Directive.

10. Answering Consumers’ Questions. What do you want to know about the health system. How can you find out?


12. Building skills to pass on what you have learnt about health literacy to others- Creating Peer Educators
To improve a patient's experience:

1. Find out about and address an emerging issue at the time.

2. Have an accessible feedback & complaints process that all consumers can access.

3. Operate a no blame culture so staff do not feel threatened by consumers giving feedback or making a complaint so staff will inform consumers about the process.

4. Give appropriate information on the actions resulting from the feedback or complaint to the consumer, the service & the staff involved.
NEW TOPICS AFTER CONSULTATIONS WITH OUR PARTNERS IN THE 2ND YEAR

- Safely using over the Counter Medications for adults & children
- Safe use of Alcohol
- Contraception & sexual health in partnership with SHFPACT
ASK ME 3

Good questions for your good health

1. What is my main problem?
2. What do I need to do?
3. Why is it important for me to do this?

- When To Ask?
- Who Needs to Ask?
- What If I Still Do Not Understand?
- Your Doctor Wants to Answer
- Tips for Clear Health Communication

http://www.npsf.org/askme3/
Not your typical bunch of political activists
The Australian Charter of Healthcare Rights

The Charter summarises the basic rights that patients and consumers are entitled to receive when accessing health care services.

<table>
<thead>
<tr>
<th>Access</th>
<th>Safety</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respect</td>
<td>Communication</td>
</tr>
<tr>
<td>Participation</td>
<td>Privacy</td>
</tr>
<tr>
<td>Comment</td>
<td></td>
</tr>
</tbody>
</table>
8 Dimensions of Patient-Centered Care

- Patients’ Preferences
- Emotional Support
- Physical Comfort
- Information & Education
- Continuity & Transition
- Coordination of Care
- Access To Care
- Family & Friends
1. Respect
2. Choice and empowerment
3. Patient involvement in health policy
4. Access and support
5. Information
Figure 3: Dahlgren and Whitehead's Social Determinants of Health Rainbow
Source: Dahlgren and Whitehead (1991) cited in Leeds NHS Primary Care Trust, Date ?)
NEVER GIVE UP ON THE QUIT MESSAGE

Monitoring Inequality in Australia: Australia  Public Health Information Development Unit
Suzanne Eastwood
Project Consultant
Health Care Consumers’ Association

If you intend to use any of this material please request permission from
HCCA 100 Maitland st Hackett 02 62307800
REDUCING HEALTH INEQUALITIES WILL REQUIRE ACTION ON SIX POLICY OBJECTIVES:

- Give every child the best start in life
- Enable all children, young people and adults to maximise their capabilities and have control over their lives
- Create fair employment and good work for all
- Ensure healthy standard of living for all
- Create and develop healthy and sustainable places and communities
- Strengthen the role and impact of ill-health prevention.
What do consumer organisations do?

- Build opportunities to work with health care organisations
- Support and train consumers to participate in service planning
- Create opportunities for consumer representatives to tap into community views
- Complete research into consumer experiences and expectations
WHAT CONSUMERS VALUE

- We value our universal access to health care
- We value safe, good quality care.
- We want to be in control of our health care but some of us need more support than others to achieve that.
- We want care that is integrated
- We value being able to give feedback so if things go wrong they can be fixed at the time.
- We want to be able to make a complaint if necessary in a no blame culture
WHAT CONSUMERS WANT

- To contain out of pocket costs.
- An Integrated care model that works
- Emphasis on prevention & early diagnosis
- To have access to our own records
- A health system that provides safe quality care
- Seamless access to multidisciplinary care
- Proper discharge planning
- Competent, professional health care
- To understand health information so we can participate equally in our own care.
WHAT CONSUMERS WANT FROM HEALTH PROFESSIONALS

- listens to me
- talk and explain things to me in a way I can understand
- encourages me to ask questions and does their best to answer them
- Gives me enough information about my treatment options
- Involves me in decisions about my treatment options
- explains the purpose of tests and treatment in a way that I understand
- Supports me to self manage my health