

Teaching shared decision-making to adults with low literacy as part of a health literacy program:

Findings from a randomised controlled trial

SYDNEY MEDICAL SCHOOL

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THE UNIVERSITY OF
SYDNEY

Health Literacy Research Conference
2nd-3rd November, 2015

- › University of Sydney
- › TAFE Social Inclusion and Vocational Access Unit
- › NSW Clinical Excellence Commission
- › NSW Health
- › National Prescribing Service
- › University of NSW
- › University of Southampton
- › World Education Boston, US



- Brief background
- Shared Decision Making module
 - Development and formative evaluation
 - Module overview
 - Trial design
 - Results
- Limitations
- Conclusions and future directions



Health literacy and adult education

- › National reach
- › Socially-disadvantaged learners with low literacy and numeracy express a desire to learn about health
- › Trained adult educators create a 'safe space' for learning and practicing
- › A natural extension on the skills that are already taught.
- › Decreases reliance on overburdened health-care systems



- › Health literacy programs have focused on *functional health literacy* skills
 - Scheduling appointments with the doctor
 - Describing symptoms
 - Interpreting the doctor's directions

- › More advanced *communicative* and *critical health literacy* skills facilitate greater autonomy and empowerment in health decision-making.



Shared Decision Making

What is shared decision making?

“...a partnership between professional and patient, in which each contributes equally to decisions about treatment or care.”

(Tattersall & Butow, 2005)

It is an important aspect of communicative and critical health literacy.





Shared Decision Making and Literacy



- Adults with low levels of literacy are overrepresented in the healthcare system
- May find it particularly challenging to participate in SDM in clinical encounters.
- However, efforts to involve consumers in SDM have primarily targeted populations with higher levels of education and literacy.

Health literacy program for adults with low levels of literacy to be delivered in adult education settings.

Shared Decision Making training included as a core topic.



*‘Being Healthy,
Staying Healthy’*

Health literacy
program outline

Week	Day	BEING HEALTHY Teacher manual 1	Day	STAYING HEALTHY Teacher manual 2
1.	1	Introduction	2	Baseline assessment part1
2.	3	Baseline assessment part 2	4	Baseline assessment part 3
3.	5	1.1 Taking temperature*	6	2.1 Getting involved
4.	7	1.2 Checking medicine labels*	8	2.2 Food groups (1)
5.	9	1.3 Prescriptions	10	2.2 Food groups (2)
6.	11	1.4 Dosage and timing	12	2.3 Food labels (1)*
7.	13	1.5 Health workers	14	2.3 Food labels (2)*
8.	15	1.6 Telling your doctor what is wrong*	16	2.4 Nutritional information*
9.	17	1.7 Talking to your doctor*	18	2.5 Food temperature safety
10.	19	1.8 Answering your doctor’s questions*	20	2.6 Food date safety
11.	21	1.9 Immunisation and health screening	22	2.7 What is a serve?*
12.	23	1.10 Asking questions*	24	2.8 Budgeting
13.	25	1.11 Shared decision-making (1)*	26	2.9 Understanding a diet
14.	27	1.11 Shared decision-making (2) *	28	2.10 Drinking enough fluids
15.	29	1.12 Completing medical forms	30	2.11 Heart Rate and Pulse
16.	31	1.13 Emergency services	32	2.12 Being Active
17.	33	1.14 Advice from pharmacist	34	2.13 Watch First Aid demonstrations
18.	35	1.15 Saving lives	36	2.14 Follow written instructions
		1.16 Follow emergency instructions		2.15 Talking on the telephone
		Post assessment		Revision
		Post assessment/ Course evaluation		Post assessment
				Goal setting for future learning

SDM module developed with formative evaluation

1. Reviewing the problem and previous efforts to address it

2. Formative evaluation to understand the target population

3. Program planning

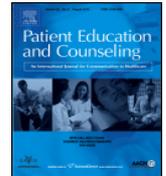
4. Pretesting intervention methods and materials

1. Introduction to SDM and the rights of patients to be involved in decision-making
2. Introduction to question-asking as a means to participate in SDM (specifically, the AskShareKnow questions)
3. Definition and interpretation of each question
4. Provision of relevant examples of the type of information each question may elicit
5. Develop self-efficacy to ask the questions and address barriers to
USE (Bandura, 1986)



Contents lists available at ScienceDirect

Patient Education and Counseling



Three questions people can ask to improve the quality of information people give about treatment options: A cross-over trial

Heather L. Shepherd ^{a,b,*}, Alexandra Barratt ^a, Lyndal J. Trevena ^a, Kevin McGeechan ^a, Karen Carey ^f, Ronald M. Epstein ^g, Phyllis N. Butow ^c, Chris B. Del Mar ^e, Vikki Entwistle ^h, Martin H.N. Tattersall ^d

1. What are my options? (One option will always be to wait and watch)
2. What are the benefits and harms of these options?
3. How likely are these benefits and harms to happen to me?

- › Increase the amount and quality of information about treatment options provided by family physicians.

- › Acceptable to patients and practical to implement
 - 68% of patients asked at least one of the questions during their consultation after watching a 4-minute video-clip.

- › Used widely
 - From 2010 to 2013 the UK Health Foundation used the three questions as one of its tools to promote SDM within the MAGIC (MAking Good decisions In Collaboration) program.

1. Introduction to SDM and the rights of patients to be involved in decision-making
2. Introduction to question-asking as a means to participate in SDM (specifically, the AskShareKnow questions)
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SHARED DECISION-MAKING

RESOURCE 2

What is Shared Decision Making?

Shared decision making is when patients and doctors work

_____ to make decisions about the patient's health.

_____ decision making happens when doctors and patients share information and _____ about all of the different things that can be done. Sharing information _____ doctors and patients make decisions that they are both happy with and can improve the care that patients receive.

It is important that _____ and patients work together to make decisions about health. The doctor should not decide what is best for the patient without talking to them: the patient and the doctor should _____ together.

Word bank:

helps	doctors	Shared
talk	together	decide

Discussion Questions

- Q1. Have you ever heard of Shared Decision Making before?
- Q2. What is good about sharing decisions with your doctor?

SHARED DECISION-MAKING

RESOURCE 3

It is important for the doctor and the patient to share information with each other. Choose which information might be given to the doctor, and which information might be given by the patient.

<u>DOCTOR</u>	<u>PATIENT</u>

1. Diagnose the problem	5. Express feelings about risks
2. Describe lifestyle (e.g. smoking, exercise, work)	6. Identify the cause of the condition
3. Suggest treatment options	7. Explain preference/feelings (e.g. you would prefer to wait and see what happens, or would you prefer to take medicine?)
4. Describe symptoms and history of the condition	8. Predict what might happen. For example, will the condition get worse?

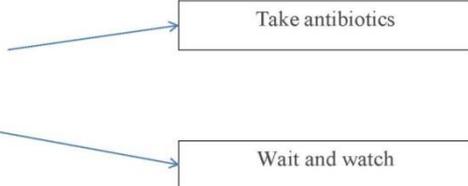


SHARED DECISION-MAKING

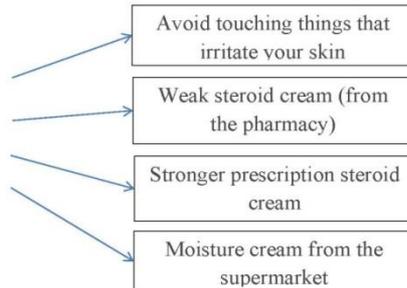
RESOURCE 5

The examples below have different options for treatment. Read through the examples as a class and talk about the options.

Example 1: You have pain in your ear and a fever for two days.



Example 2: You have an itchy rash on your hands due to a skin allergy for a week.



SHARED DECISION-MAKING

RESOURCE 7

Why should I ask about my options?

Write down three reasons why you might ask your doctor: "What are my options?"

1. _____

2. _____

3. _____



What are the possible benefits and harms of these options?

SHARED DECISION-MAKING

RESOURCE 8

The Second Question

Another important question to ask your doctor is:

What are the possible benefits and harms of these options?

1. What does the word benefit mean? Write down your definition.

2. What does the word harm mean? Write down your definition.

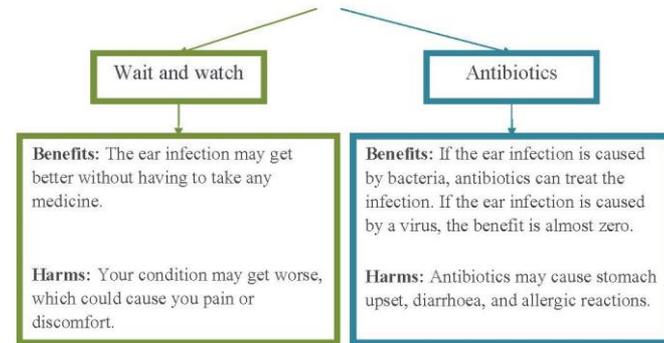
3. In the table below, colour in all of the words that mean 'benefit' in green. Colour all of the words that mean 'harms' in red. Write in any other words you can think of.

Advantage	Problem	Positive	Help
Cons	Pros	Hurt	Bad
Damage	Good	Negative	Injure
Disadvantage	Danger		

SHARED DECISION-MAKING

RESOURCE 9

Ear Infection



Think about a medical treatment decision that you (or a relative or friend) had to make. Did you know the benefits and harms?

Write down the benefits and harms of this treatment on the lines below.

- a) What were some benefits of the treatment?

- b) What were some harms of the treatment?



How likely are each of these benefits and harms to happen to me?

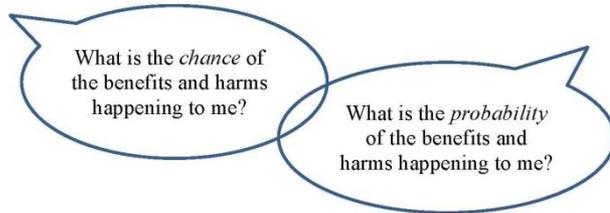
SHARED DECISION-MAKING

RESOURCE 11

The Third Question

Another important question to ask your doctor is:

How likely are each of these benefits and harms to happen to me?



Write down your own definition of the word 'likely'.

Some things are more likely to happen than others:

- It is more likely that your headache will go away if you take paracetamol than if you do not.
- It is more likely to get some diseases, such as cancer, as you get older.

Write down two more examples:

- _____
- _____

SHARED DECISION-MAKING

RESOURCE 12

Word bank:

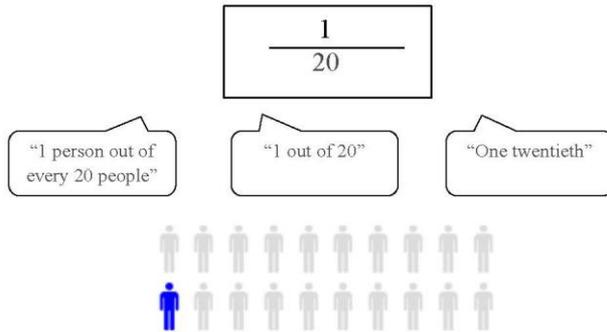
Certain	%
Very Likely	_____
Likely	_____
Possible	%
Unlikely	_____
Very Unlikely	_____
Impossible	%



How likely are each of these benefits and harms to happen to me?

SHARED DECISION-MAKING

RESOURCE 15



Doctors can use different ways to tell you about risk (how likely something will happen to you). Some of the different ways are shown below.

Example:

"1 child out of every 20 children will have an allergic reaction after taking medication X".

Read the sentences below and highlight the parts of the sentence that give the risk (how likely something will happen).

- One tenth of all people who take medication X will have an allergic reaction
- Serious side-effects will happen to 1 person out of every 100 people
- 7 people out of every 10,000 people will have serious bleeding during the operation

SHARED DECISION-MAKING

RESOURCE 20

Fractions and percentages

Change the following fractions into percentages. Which is the biggest risk?

- $20 / 100 = \underline{\hspace{2cm}} \%$
- $35 / 100 = \underline{\hspace{2cm}} \%$
- $72 / 100 = \underline{\hspace{2cm}} \%$
- $98 / 100 = \underline{\hspace{2cm}} \%$

Change the following percentages into numbers out of 100. Which is the biggest risk?

- $2\% = \underline{\hspace{2cm}}$ out of 100 people
- $30\% = \underline{\hspace{2cm}}$ out of 100 people
- $85\% = \underline{\hspace{2cm}}$ out of 100 people
- $95\% = \underline{\hspace{2cm}}$ out of 100 people

Increasing self efficacy and addressing barriers to use

SHARED DECISION-MAKING

RESOURCE 23

Role play – Asking all three questions

You have symptoms of an ear infection and are going to the doctor to see what you can do about it. Paste the three questions you would ask in order on the next page and glue to doctor's answers next to each question. When you are done, use the worksheet to do a role play.

How likely are each of these benefits and harms to happen to me?

What are my options?

What are the possible benefits and harms of these options?

"10 per cent of people who take antibiotics experience stomach upset and diarrhea. You might be someone who experiences this or you might not.

The benefits of antibiotics will only occur if it is caused by bacteria (not a virus), but we can't always tell if it is caused by bacteria. If it is not caused by bacteria, the antibiotics will not help. The benefits of antibiotics are also much more likely to happen if you remember to take the medicine and complete the course. These are things that you have to think about before you choose antibiotics."

"If your ear infection is caused by bacteria, antibiotics will treat the ear infection, and help the pain to go away. But antibiotics may cause an upset stomach, diarrhea, and allergic reactions.

If you wait and watch, the ear infection could go away without having to take medication. But it may not."

"There are two main options that we can talk about. The first one is to wait and watch. The second option that you have is to treat the ear infection with antibiotics"

ask
ask | share | know

1. What are my options? (Including wait and watch)
2. What are the possible benefits and harms of those options?
3. How likely are each of those benefits and harms to happen to me?

askshareknow.com.au

WATCH THE ASK FILM CLIP:



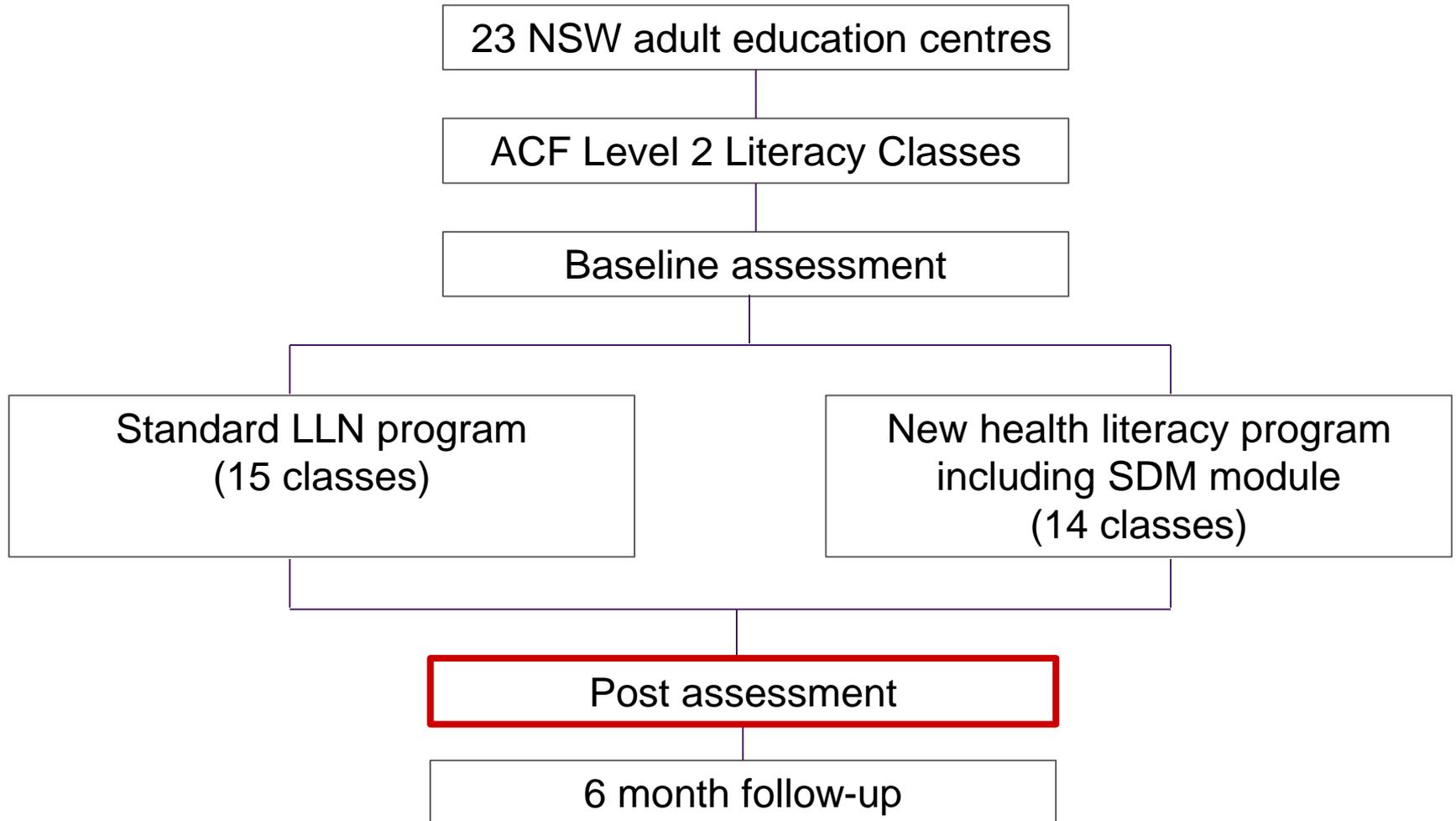
Condensed Version - 1 minute



Brief Version - 4 minutes



Full Length Version - 9 minutes



n=319

Health literacy program – Primary Outcomes

Table 1
Health literacy course primary outcomes

	Randomised			All (adjusted)		
	OR	CI	p	OR	CI	p
Functional health skills						
Temperature	0.80	0.222,2.905	0.74	0.61	0.199,1.898	0.39
Medicine labels	2.57	1.023,6.461	0.04	4.57	1.167,17.875	0.03
Nutrition labels	0.58	0.196,1.717	0.32	0.42	0.154,1.190	0.10
	Mean Difference	CI	p	Mean Difference	CI	p
Confidence	0.324	0.0005,0.648	0.05	0.141	-0.112,0.395	0.26

Table 2

Shared decision making data collection schedule

	Baseline		Post	
	Health Literacy	Standard LLN	Health Literacy	Standard LLN
SDM Knowledge			X	X
SDM important questions			X	X
AskShareKnow recall			X	

14 knowledge items (for a score out of 15)

Purpose designed, including;

- Terminology (4)
- Graphical literacy (8)
- Numeracy (3; Lipkus 2000)

Please put a cross in the box that you think has the right answer.

1. What is shared decision making?

- Doctor decides
- Doctor and patient decide together
- Patient decides
- Doctor and nurse decide together



2. Which word is most like the word 'options'?

- | | |
|--|--|
| <input type="checkbox"/> Advantages (something good) | <input type="checkbox"/> Total |
| <input type="checkbox"/> Lists | <input type="checkbox"/> Treatment |
| <input type="checkbox"/> Choices | <input type="checkbox"/> Disadvantages or Problems |

3. Which word is most like the word 'benefit'?

- | | |
|--|--|
| <input type="checkbox"/> Advantages (something good) | <input type="checkbox"/> Total |
| <input type="checkbox"/> Lists | <input type="checkbox"/> Treatment |
| <input type="checkbox"/> Choices | <input type="checkbox"/> Disadvantages or Problems |

4. Which word is most like the word 'harm'?

- | | |
|--|--|
| <input type="checkbox"/> Advantages (something good) | <input type="checkbox"/> Total |
| <input type="checkbox"/> Lists | <input type="checkbox"/> Treatment |
| <input type="checkbox"/> Choices | <input type="checkbox"/> Disadvantages or Problems |

Table 3

Shared decision making knowledge total (out of 15)

	Health Literacy		Standard LLN		Test statistics		
	n	Mean (SD)	n	Mean (SD)	Mean difference	p	95% CI
SDM knowledge total ^a	116	11.7 (3.1)	93	11.1 (2.8)	0.6	0.395	-0.67, 1.70

^a Adjusting for clustering only

Results remain similar after adjusting for baseline health literacy, subjective reading ability, language spoken at home and health conditions.

“Think about the next time you will visit your doctor. If your doctor tells you about a test or treatment, what are 3 important questions you might ask...?”

Table 4

Number and percentage of students who consider SDM concepts important

	Health Literacy		Standard LLN		Difference	Test statistics
	n	%	n	%	%	p
Options ^a	62	53	1	1	52	< .001
Benefits and harms ^a	57	49	3	3	46	< .001
Likelihood ^a	43	37	1	1	36	< .001

^a Adjusting for clustering only

Results remain similar after adjusting for baseline health literacy, subjective reading ability, language spoken at home and health conditions.

Intervention students asked to write down the three AskShareKnow questions

Examined % recall for:

- Individual questions
- At least one question
- All AskShareKnow questions

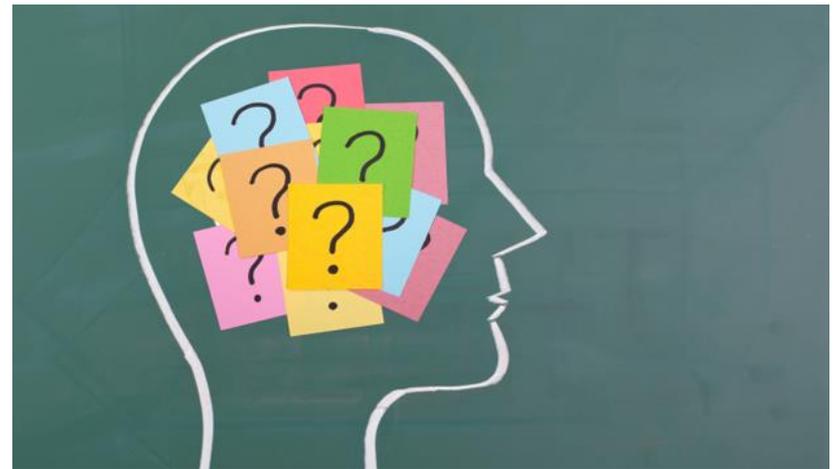


Table 5

AskShareKnow question recall at immediate follow-up

	Health Literacy	
	n	%
At least one AskShareKnow question	85	78
All 3 AskShareKnow questions	59	54
Q1: What are my options?	84	77
Q2: What are the benefits and harms of those options?	72	66
Q3: How likely are each of those benefits and harms to happen to me?	65	59

Shepherd et al; 47% of participants were able to recall all 3 questions 2 weeks after consultation.



- › Knowledge questionnaire
 - High knowledge across groups
 - Too simple?
 - Control group course content

- › Recall only, rather than use in clinical encounters
 - To be measured at 6 months

- › Incorporating SDM training into broader health literacy programs is appropriate and feasible.
- › First broad-spectrum SDM training program delivered as part of a health literacy program in adult education settings
 - › Relatively high % recall of AskShareKnow questions
 - › Significant difference in perceived importance of ASK concepts
 - › High knowledge overall, with no difference between groups



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- › The development and application of knowledge and skills required in a specific health context.
- › *The capacity to acquire, understand and use information in ways which promote and maintain good health.*
- › Health literacy skills can be developed through
 - a) Formal health education
 - b) Less formal exposure to health knowledge and practices.