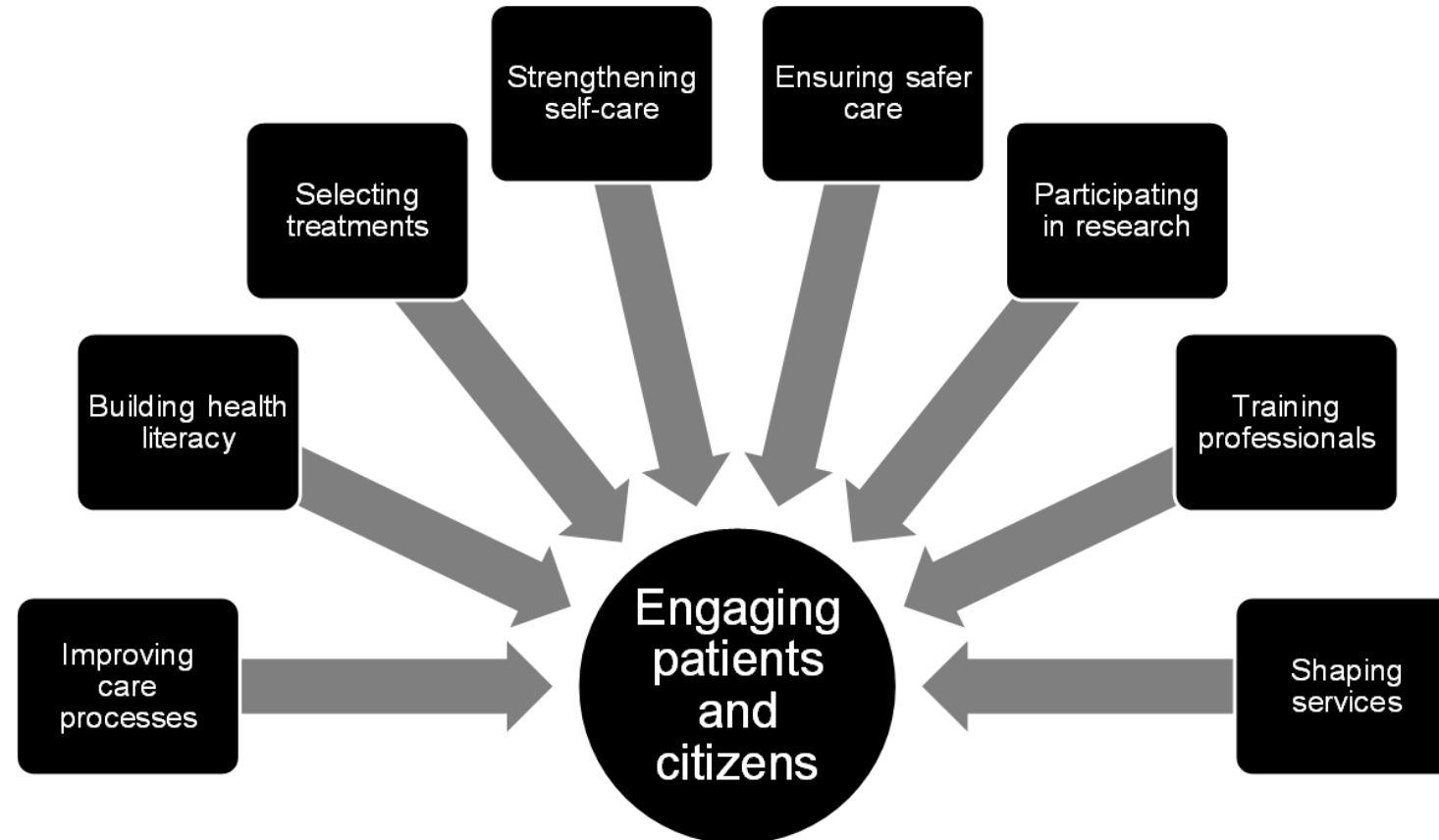
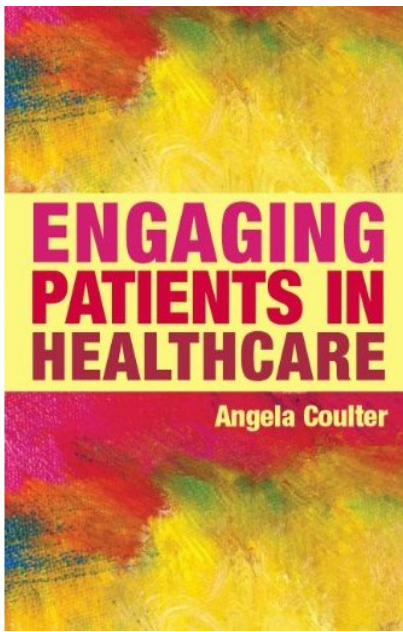


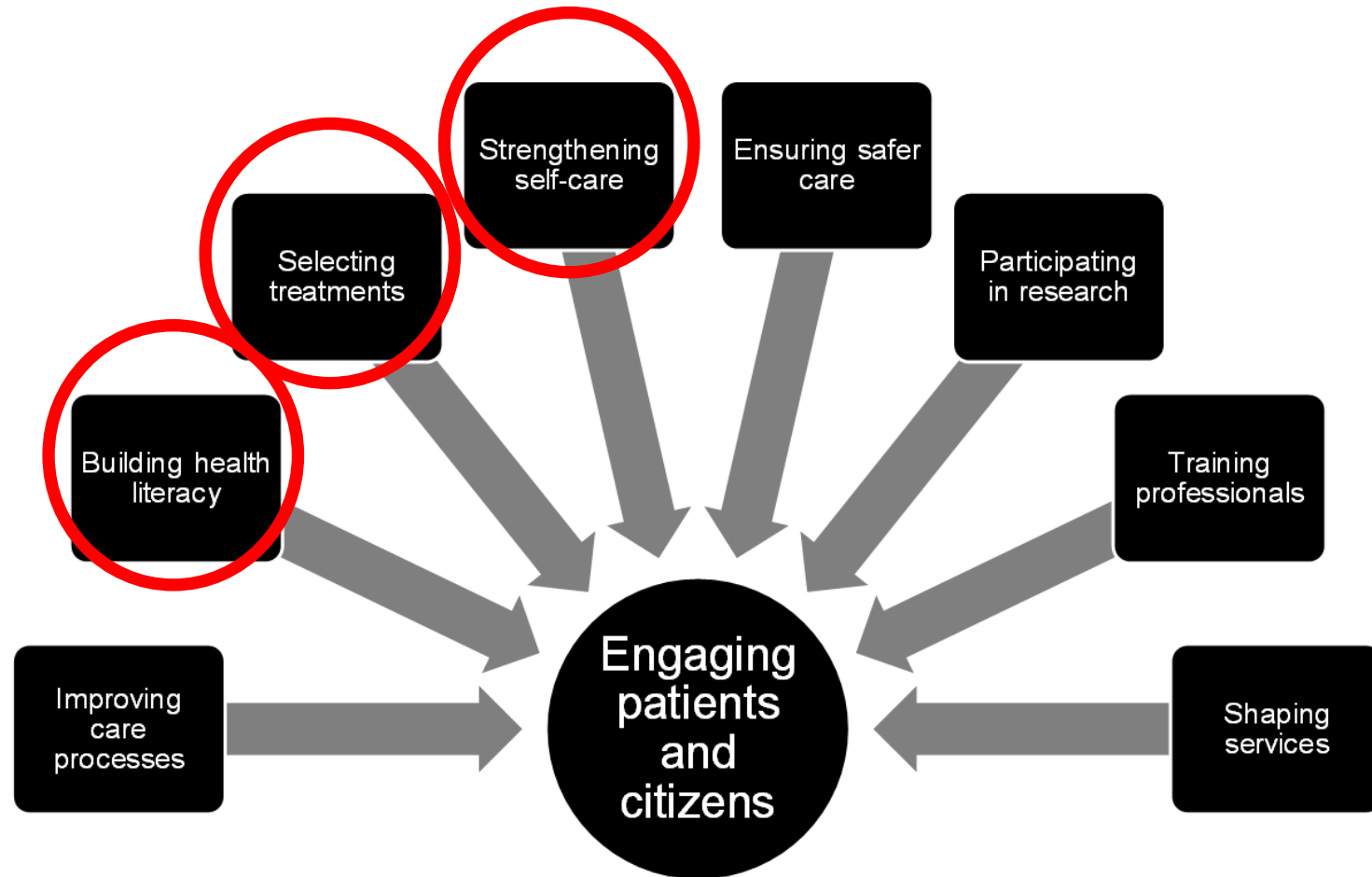
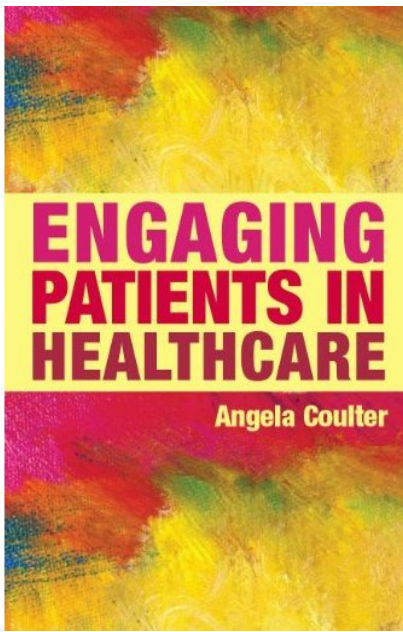
# The Case for Patient Empowerment

Angela Coulter

Nuffield Department of Population Health, University of Oxford  
and Informed Medical Decisions Foundation

@acpatient

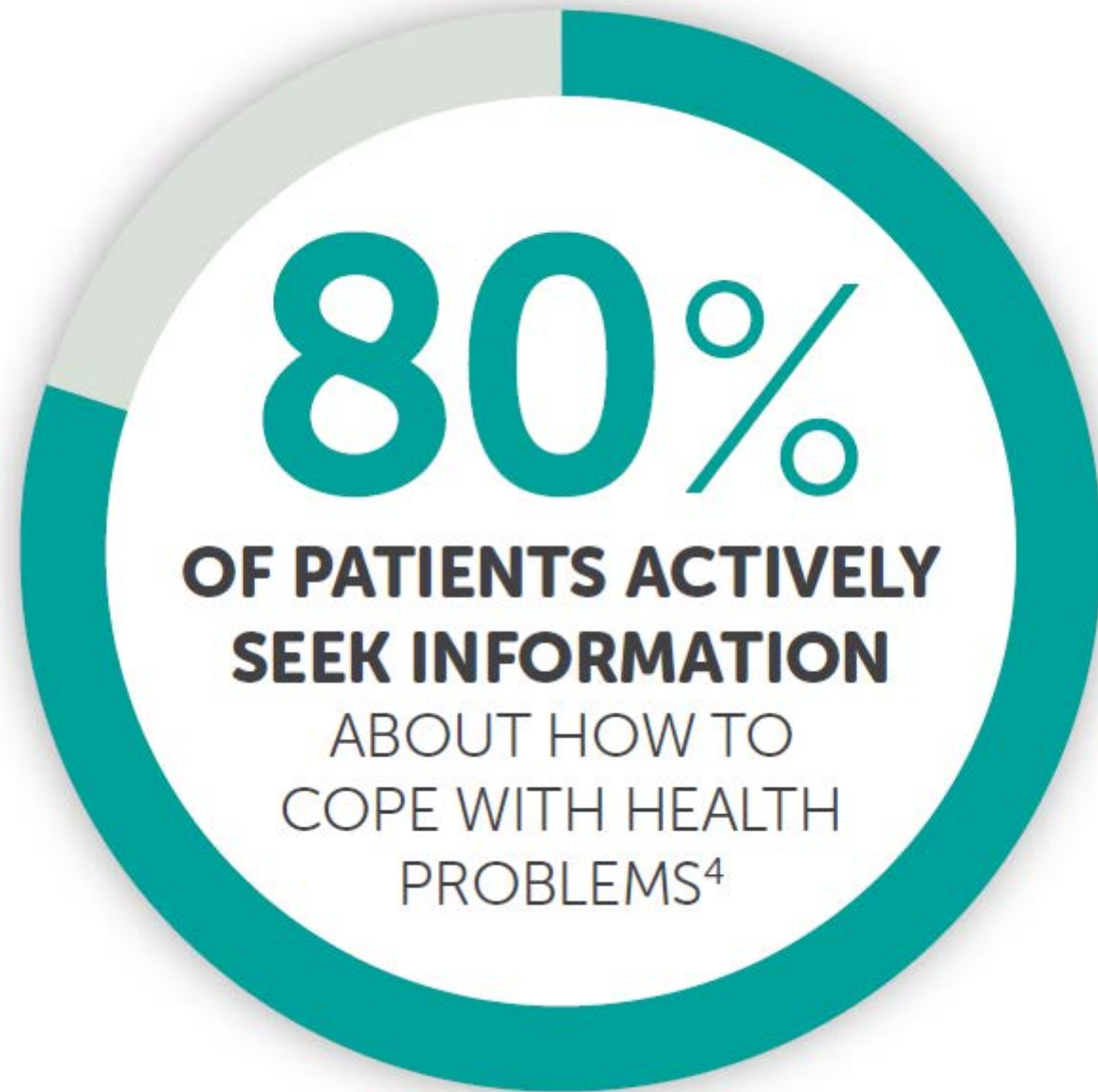




# The Passive Patient

Healthcare can be profoundly disempowering





**80%**

**OF PATIENTS ACTIVELY  
SEEK INFORMATION**

ABOUT HOW TO  
COPE WITH HEALTH  
PROBLEMS<sup>4</sup>



**8 in 10**  
PEOPLE WANT  
THEIR HEALTH  
CARE PROVIDER  
TO **LISTEN TO**  
**THEM...**

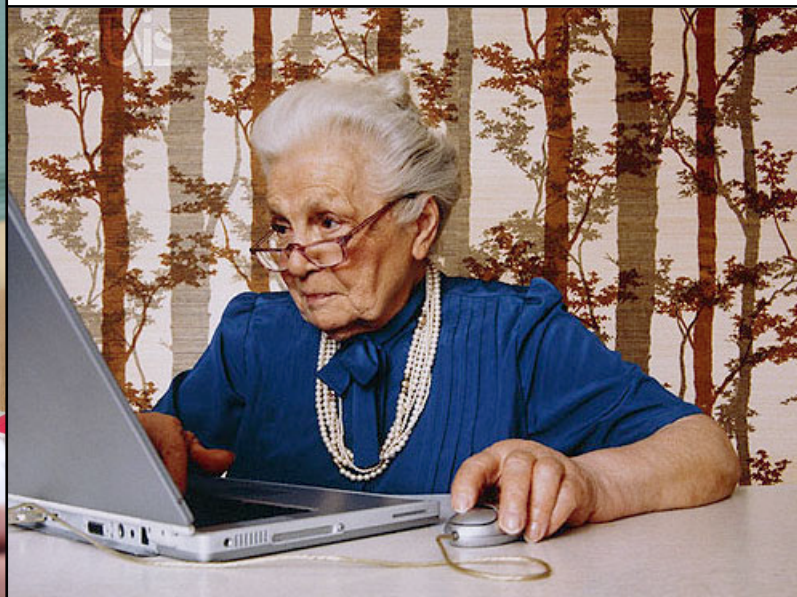
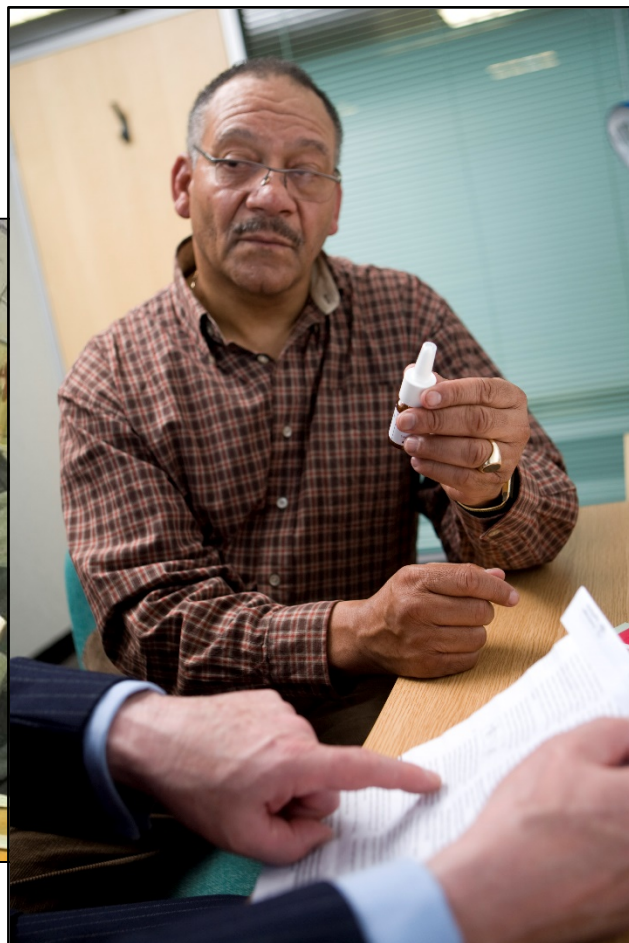
BUT ONLY  
**6 in 10**  
SAY IT  
**ACTUALLY**  
**HAPPENS**<sup>1</sup>

# What Patients Need to Know

- What are my options?
- What are the benefits and possible harms?
- How likely are these benefits and harms?
- What are your treatment goals? Do they match mine?
- What can I do to help myself?
- What can you do to support me?

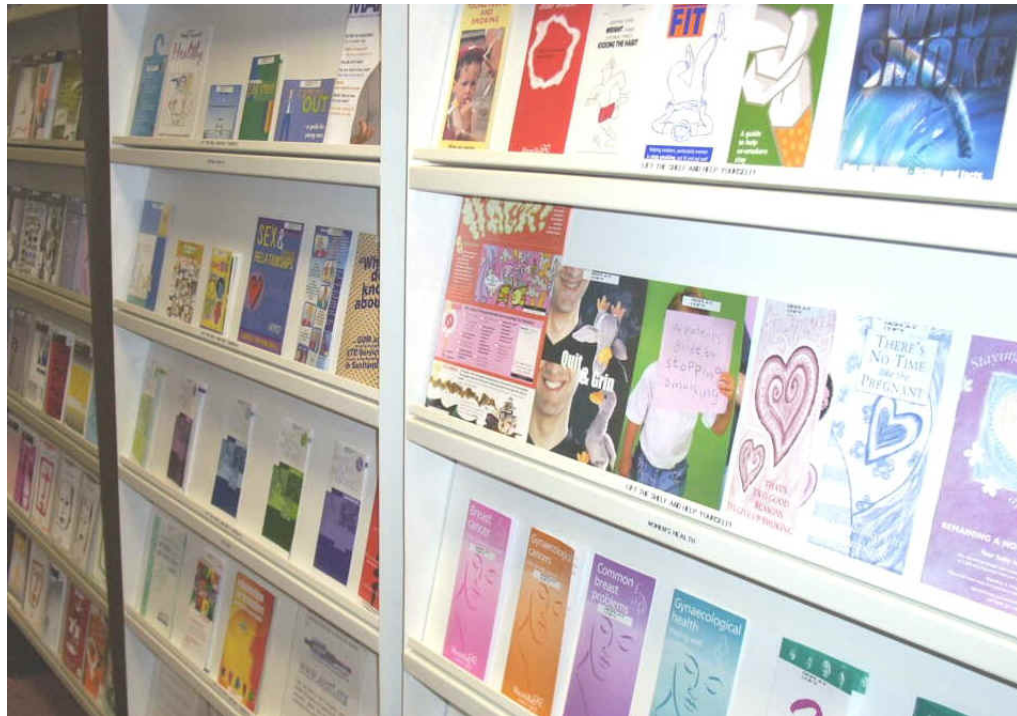


# Information is Empowering



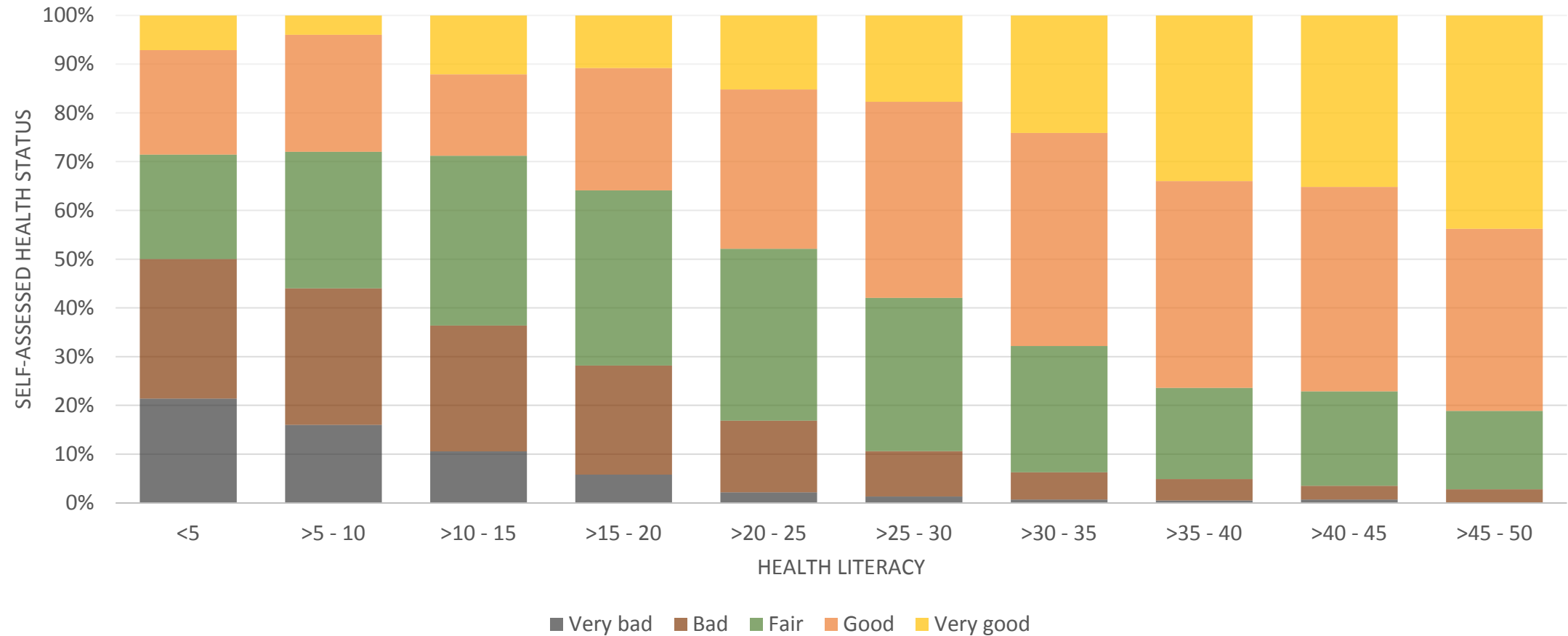


# Health Literacy



- Capacity to obtain, process and understand health information and use it to make decisions about health and healthcare

# People with better health literacy have better health



# Facts about Health Literacy

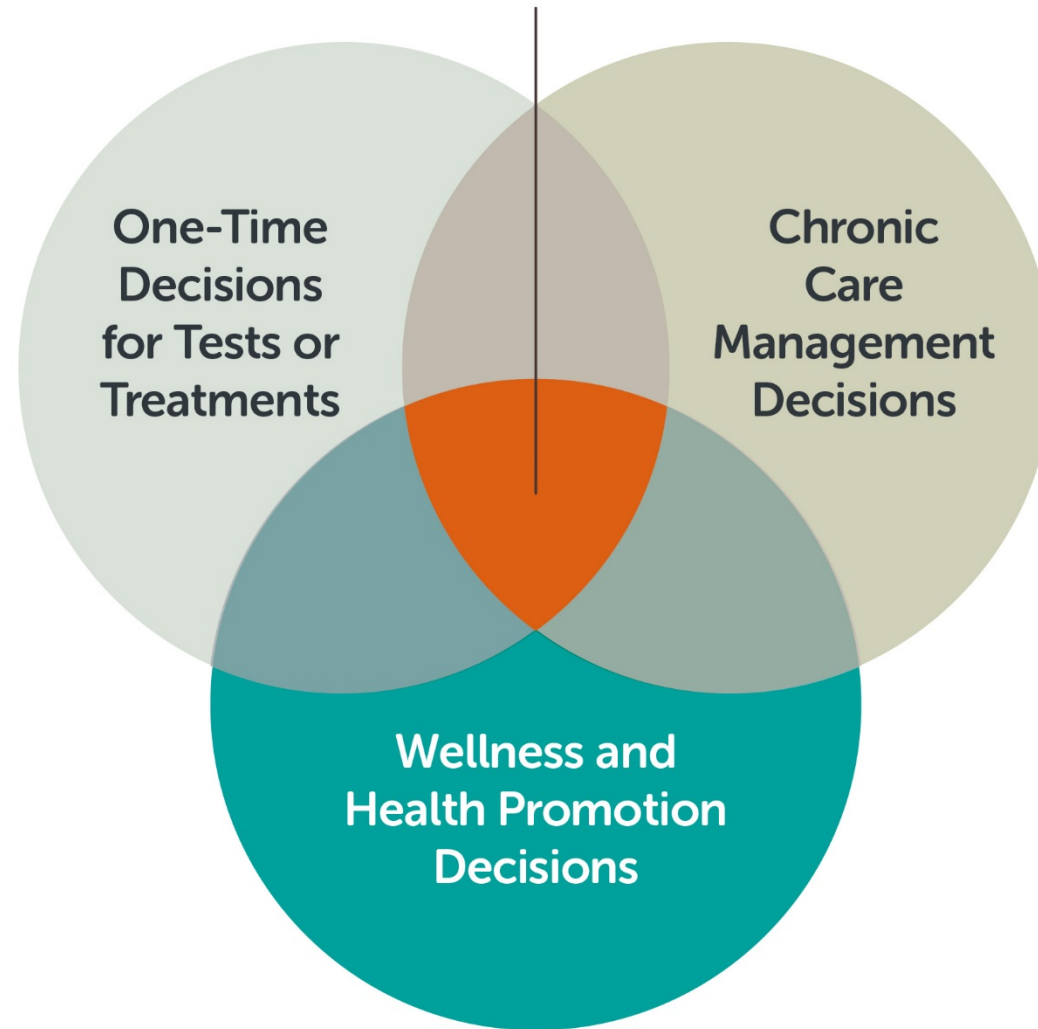
- Health literacy benefits society
- Limited health literacy affects health
- Limited health literacy reinforces health inequalities
- Health literacy is affected by context, culture and setting
- Building personal health literacy skills is a lifelong process
- Limited health literacy leads to higher health system costs

# Health information: the Evidence

- In 21 trials involving 2,289 stroke patients and 1,290 carers, information provision led to:
  - Increased knowledge about stroke
  - Greater satisfaction
  - Less depression
  - Active information provision with opportunities to ask questions may be better than passive information



# Shared Decision Making



# Shared Decision Making



Clinicians and patients working together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences.

# Sharing Expertise

## Clinician

- Diagnosis
- Disease aetiology
- Prognosis
- Treatment options
- Outcome probabilities

## Patient

- Experience of illness
- Social circumstances
- Attitude to risk
- Values
- Preferences

# Six Elements of Shared Decision Making



1

Invite patient  
to participate



2

Present options



3

Provide  
information on  
benefits and risks



4

Weigh options  
based on patient  
goals and concerns



5

Facilitate  
deliberation and  
decision making

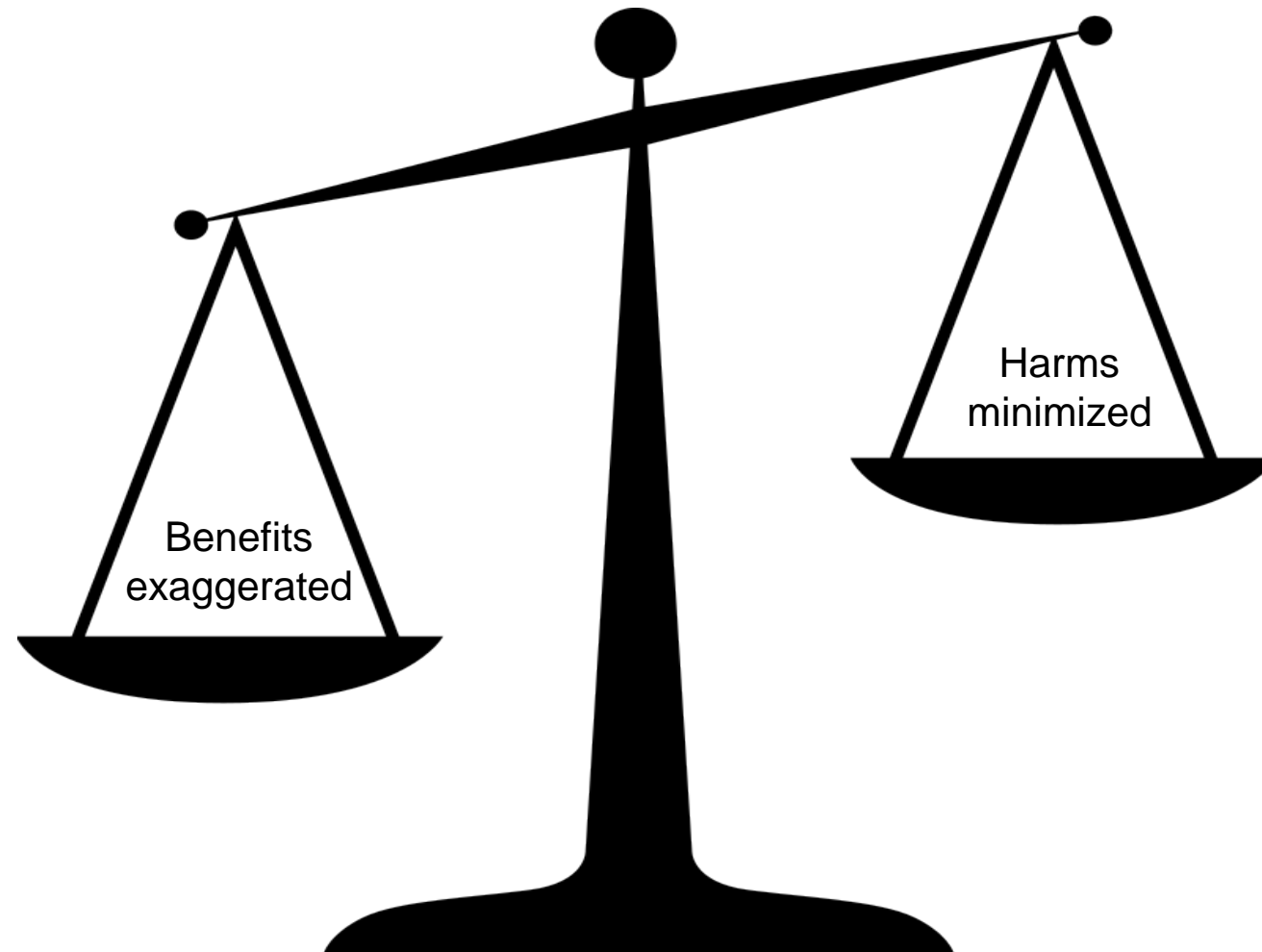


6

Assist with  
implementation



# Information About Treatments is Often Unbalanced



# Patient Decision Aids

## Arthritis: Should I Have Knee Replacement Surgery?

1 Get the Facts   2 Compare Options   3 Your Feelings   4 Your Decision   5 Quiz Yourself   6 Your Summary

### Compare your options

	Have knee replacement surgery	Try other treatment
What is usually involved?	<ul style="list-style-type: none"> <li>You may be asleep during this surgery. Or you may be awake but numb from the waist down.</li> <li>You will stay in the hospital for several days.</li> <li>You will need several weeks of physical therapy.</li> </ul>	<ul style="list-style-type: none"> <li>You can try exercise, medicines, joint injections, or, in some cases, another type of surgery.</li> <li>You can try using crutches, braces, and other types of walking support to help ease the stress on your knee.</li> </ul>
What are the benefits?	<ul style="list-style-type: none"> <li>Most people have much less pain and are able to do many of their daily activities more easily.</li> </ul>	<ul style="list-style-type: none"> <li>You avoid the risks and side effects of surgery.</li> <li>You avoid months of physical therapy, although exercise is still important.</li> </ul>
What are the risks and side effects?	<ul style="list-style-type: none"> <li>Risks include:                             <ul style="list-style-type: none"> <li>A blood clot.</li> <li>Infection or wound-healing</li> </ul> </li> </ul>	<ul style="list-style-type: none"> <li>The strong medicines used for severe pain may cause constipation, mental confusion, drowsiness, and nausea and</li> </ul>

## Arthritis: Should I Have Knee Replacement Surgery?

1 Get the Facts   2 Compare Options   3 Your Feelings   4 Your Decision   5 Quiz Yourself   6 Your Summary

### Where are you leaning now?

Now that you've thought about the facts and your feelings, you may have a general idea of where you stand on this decision. Show which way you are leaning right now.

Having knee replacement surgery

NOT having knee replacement

Leaning toward
Undecided
Leaning toward

# Arthritis: Should I Have Knee Replacement Surgery?



1

Get the Facts



2

Compare Options

3

Your Feelings

4

Your Decision

5

Quiz Yourself

6

Your Summary

## What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and show how you feel about the following statements.

Reasons to have knee replacement surgery

Reasons not to have knee replacement surgery

I want to be able to do low-impact activities, such as swimming and golf, as well as chores and housework.

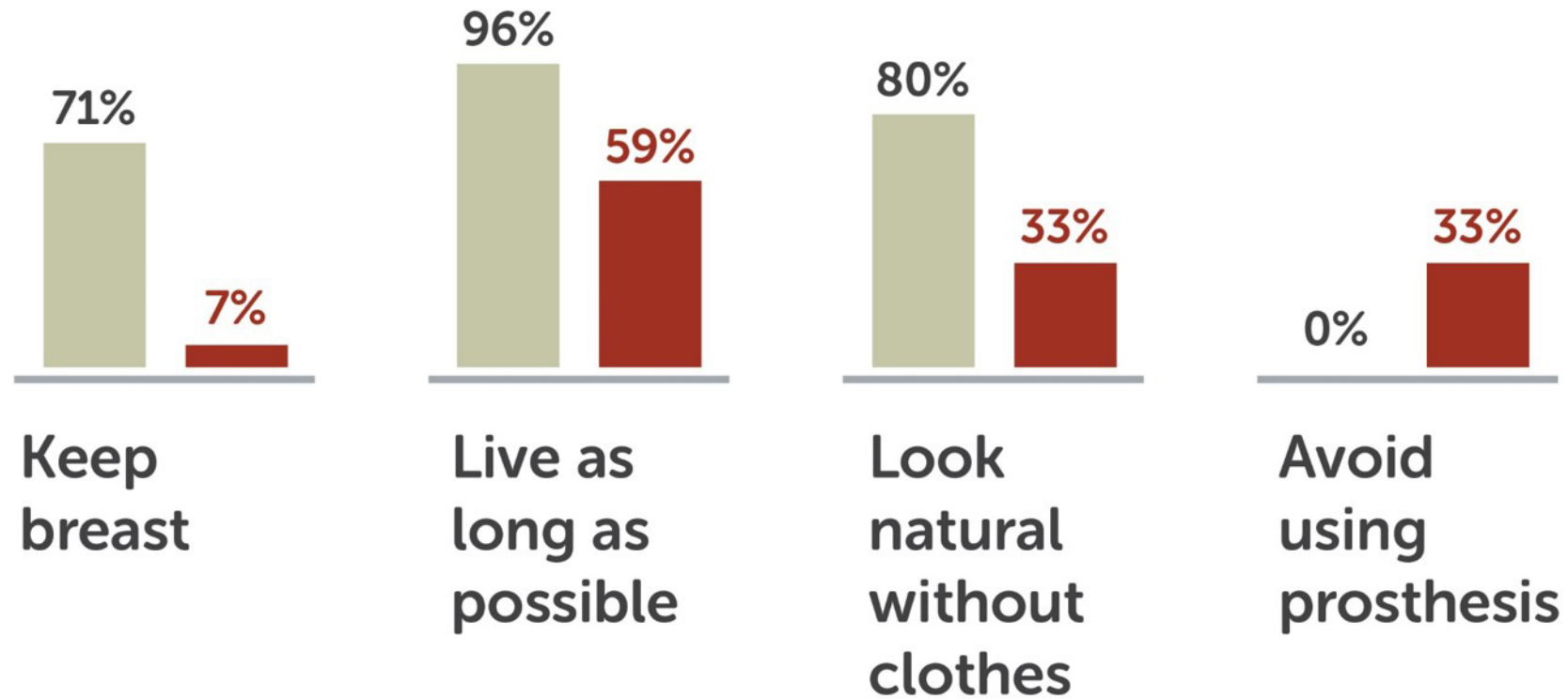
My knee doesn't really get in the way of the physical activities I like or need to do.



# Doctor-Patient Alignment

Top Three Goals and Concerns  
for Breast Cancer Decisions

**Provider view** **Patient view**



# Patient Decision Aids: the Evidence

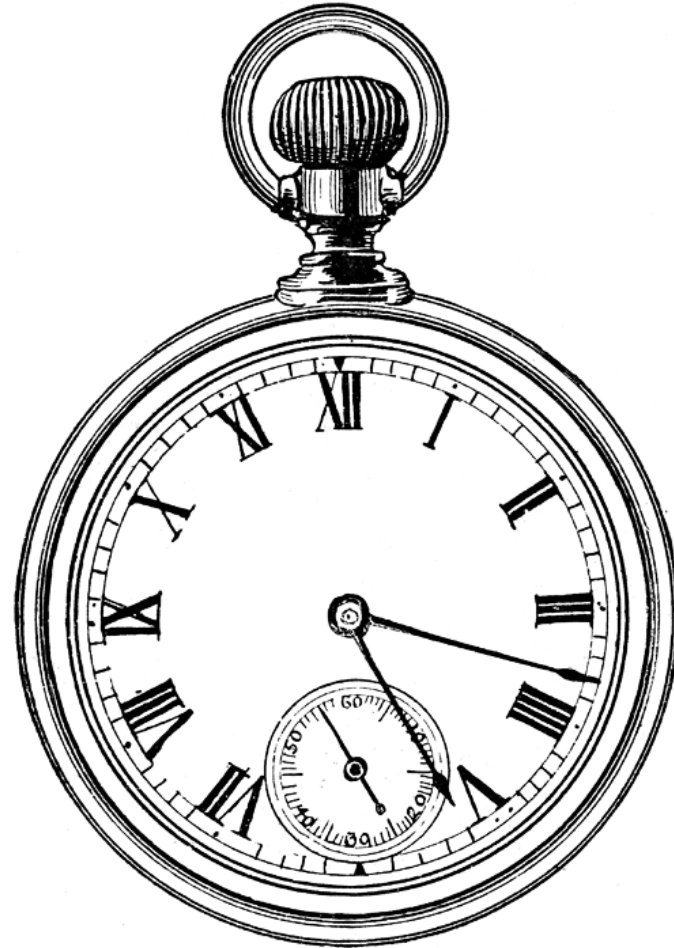
- In 115 trials involving 34,444 participants, use has led to:
  - Greater knowledge
  - More accurate risk perceptions
  - Greater comfort with decisions
  - Increased participation in decision-making
  - Better agreement between values and choice
  - Fewer patients choosing major surgery



# Managing Long Term Conditions

Professional care –  
3 hours per year (1 x 15 mins per  
month)

Self-care –  
8,757 hours per year



# Personalised care planning



Conversation between a patient and a clinician to jointly agree goals and actions for managing the patient's health problems.

- Proactive
- Targeted
- Holistic
- Anticipatory
- Collaborative
- Regularly reviewed

# Patients' Goals may be Different from Clinicians' Goals

- To better manage my pain relief so I don't wake up at night
- To stay in my house as long as possible
- To stop taking anti-depressants because I don't like the side-effects
- To learn how to cook healthy meals that the whole family will enjoy
- To have the same person caring for me from 9am to 3pm so my parents can go to work
- To meet new people in my local area so I don't have to travel into the centre of town
- To receive end of life care at the hospice close to where my sister lives





# Care Planning: the Evidence

- In 19 trials involving 10,856 participants, use has led to:
  - Better physical health (blood glucose, blood pressure)
  - Better emotional health (depression)
  - Better capabilities for self-management (self-efficacy)



# What We Have Learnt

Traditional practice styles.....

- Create dependency
- Discourage self-care
- Ignore preferences
- Undermine confidence
- Do not encourage healthy behaviours
- Lead to fragmented care



# Informed, Empowered Patients

Have the knowledge, skills and confidence to manage their own health and healthcare,

And they.....

- Make healthy lifestyle choices
- Make informed and personally relevant decisions about their treatment and care
- Adhere to treatment regimes
- Experience fewer adverse events
- Use less costly healthcare

