

# Shared decision-making in Australia: Improving evidence-based decision-making between clinicians and their patients

SYDNEY MEDICAL SCHOOL

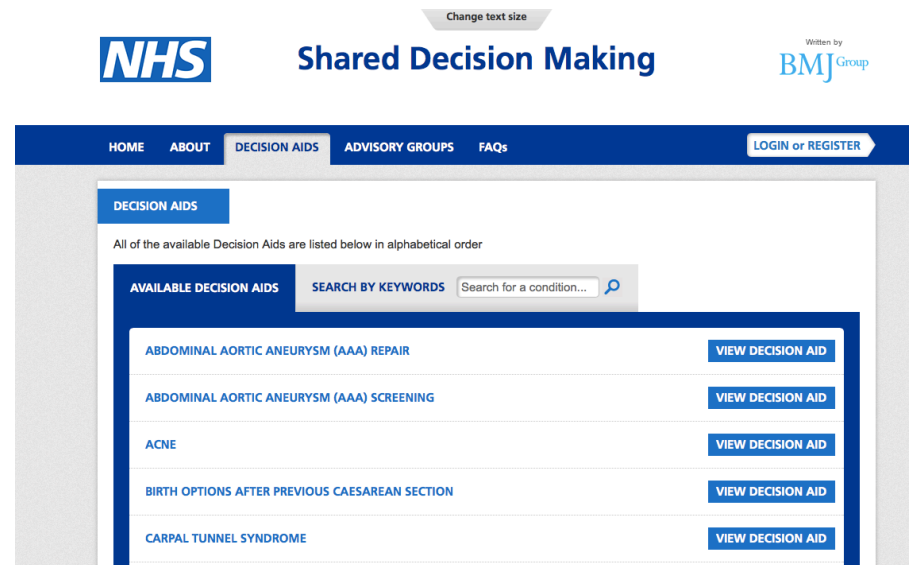
Lyndal Trevena



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# SDM in Australia: Lessons from the past decade

- › Australian researchers have been leaders in the field over the past decade
- › Most tools have been investigator-driven but more recently responding to sector needs
- › Australia has only recently started to consider a coordinated national approach to SDM
- › UK, Canada, US, Germany and Netherlands are well ahead
- › The Commission's program is the first national approach to this important issue



The screenshot shows the NHS Shared Decision Making website. At the top, there is a navigation bar with the NHS logo, the text "Shared Decision Making", and the BMJ Group logo. Below the navigation bar, there is a "DECISION AIDS" section. A search bar is present with the text "SEARCH BY KEYWORDS" and a search icon. Below the search bar, there is a list of available decision aids, each with a "VIEW DECISION AID" button. The list includes:

AVAILABLE DECISION AIDS	SEARCH BY KEYWORDS
ABDOMINAL AORTIC ANEURYSM (AAA) REPAIR	Search for a condition...
ABDOMINAL AORTIC ANEURYSM (AAA) SCREENING	
ACNE	
BIRTH OPTIONS AFTER PREVIOUS CAESAREAN SECTION	
CARPAL TUNNEL SYNDROME	

<http://sdm.rightcare.nhs.uk/pda/>

# Case study One: The RACGP requests an SDM tool for men asking for a PSA screening test

## *Guidelines for preventive activities in general practice* 8th edition



### 9.8 Prostate cancer

Age	0-9	10-14	15-19	20-24	25-29	30-34	35-39	40-44	45-49	50-54	55-59	60-64	65-69	70-79	≥80
	Screening for prostate cancer is not recommended unless: <ol style="list-style-type: none"> <li>1. the man specifically asks for it; and</li> <li>2. he is fully counselled on the pros and cons</li> </ol>														

Routine screening for prostate cancer with DRE, PSA or transabdominal ultrasound is not recommended.<sup>548-550</sup> DRE has poor ability to detect prostate disease.<sup>551</sup> Yet some cancers missed by PSA testing alone are detected by DRE,<sup>551</sup> which is why those recommending screening advocate DRE as well as PSA.

The recommendation is contentious. Two large RCTs<sup>552,553</sup> found none or marginal benefit. However, analysis of the data from one centre contributing to one of these<sup>554</sup> showed an increased survival from prostate cancer (but not mortality from any cause) beyond 10 years. Two recent systematic reviews concluded that screening is not effective.<sup>555,556</sup>

Even if we were to conclude there was a survival benefit (from current or future trial data), this survival would need to be balanced against the harms of cancer overdiagnosis and treatment.

GPs need not raise this issue, but if men ask about prostate screening they need to be fully informed of the potential benefits, risks and uncertainties of prostate cancer testing.<sup>556</sup> When a patient chooses screening, both PSA and DRE should be performed.



## PSA Testing for Prostate Cancer in Asymptomatic Men Information for Health Practitioners

This information has been developed for health practitioners\* to read before they discuss the prostate-specific antigen (PSA) test as part of a medical consultation. It provides a summary of the evidence on the benefits and harms of PSA testing, with or without digital rectal examination (DRE), for prostate cancer in asymptomatic men.

For the purposes of this document, asymptomatic men include those with stable lower urinary tract symptoms, because these symptoms are very common in ageing men and are not clearly associated with an increased risk for prostate cancer.

### What are the potential benefits of PSA testing?

- **Reassurance:** If the PSA test result is normal or very low, this can provide reassurance.
- **Early detection:** If prostate cancer is detected at an early stage, when it is still confined to the prostate gland, there is an opportunity to commence early treatment.
- **Early treatment:** Early treatment may cure the disease, and thus avoid loss of quality of life due to advanced prostate cancer, and death from prostate cancer.

### What are the potential harms of PSA testing?

- **False positive results:** If no cancer is present, a positive test may cause psychological distress and unnecessary prostate biopsies.
- **False negative results:** If prostate cancer is present, a normal or low PSA may provide false reassurance and may delay cancer diagnosis.
- **Overdiagnosis:** A positive PSA result may lead to diagnosis of a cancer that is progressing so slowly it would not have caused any health problems had it been left undetected and untreated.
- **Overtreatment:** Unnecessary treatment of slowly progressing cancer may result in harmful effects without any health benefit.

\*This document is not a substitute for relevant clinical practice guidelines and therefore does not contain recommendations.

### How frequent are these benefits and harms?

To help men make a decision, they should be informed of both the potential benefits and harms of PSA testing. These vary with age and familial risk. The following rates are estimates for men aged 60 years who have no first-degree relatives affected by prostate cancer and who, for the next 10 years, have an annual PSA test. Ideally, they would be based on current Australian active surveillance and treatment rates. However, since these figures are unavailable, the most recent relevant figures have been used, including evidence-based estimates of benefit.

#### Possible benefit of PSA testing

- For every 1000 men tested, 2 men will avoid death from prostate cancer before 65 years of age because of PSA testing<sup>1</sup>. This benefit might be greater for men at high risk of prostate cancer, such as those with a strong family history of the disease.
- For every 1000 men tested, 2 men will avoid metastatic prostate cancer before 85 years of age because of PSA testing<sup>2</sup>.

#### Expected harms of PSA testing

##### False-positive results:

- For every 1000 men tested:
  - 87 men who do not have prostate cancer will have a false positive PSA test that will lead to a biopsy<sup>1</sup>.
  - 28 men will experience a side effect from the biopsy that they consider to be a moderate/major problem that may require healthcare, and 1 will require hospitalisation<sup>3</sup>.

##### Overdiagnosis:

- For every 1000 men tested, 28 men will have prostate cancer diagnosed as a result of the PSA test<sup>1</sup>, many of whom would have remained asymptomatic for life (i.e. are overdiagnosed).

##### Overtreatment:

- For every 1000 men tested,
  - 25 men will choose to undergo treatment (surgery or radiation) because of uncertainty about which cancers need to be treated, many of whom would do well without treatment (i.e. are overtreated)<sup>4</sup>.
  - 7-10 of these 25 men will develop persistent impotence and/or urinary incontinence, and some will develop persistent bowel problems, due to treatment<sup>4</sup>.
- For every 2000 men tested, 1 man will experience a serious cardiovascular event, such as myocardial infarction, due to treatment<sup>5</sup>.

Continued on page 2

[https://www.nhmrc.gov.au/\\_files\\_nhmrc/publications/attachments/men4d\\_psa\\_testing\\_asymptomatic\\_men\\_140304.pdf](https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/men4d_psa_testing_asymptomatic_men_140304.pdf)

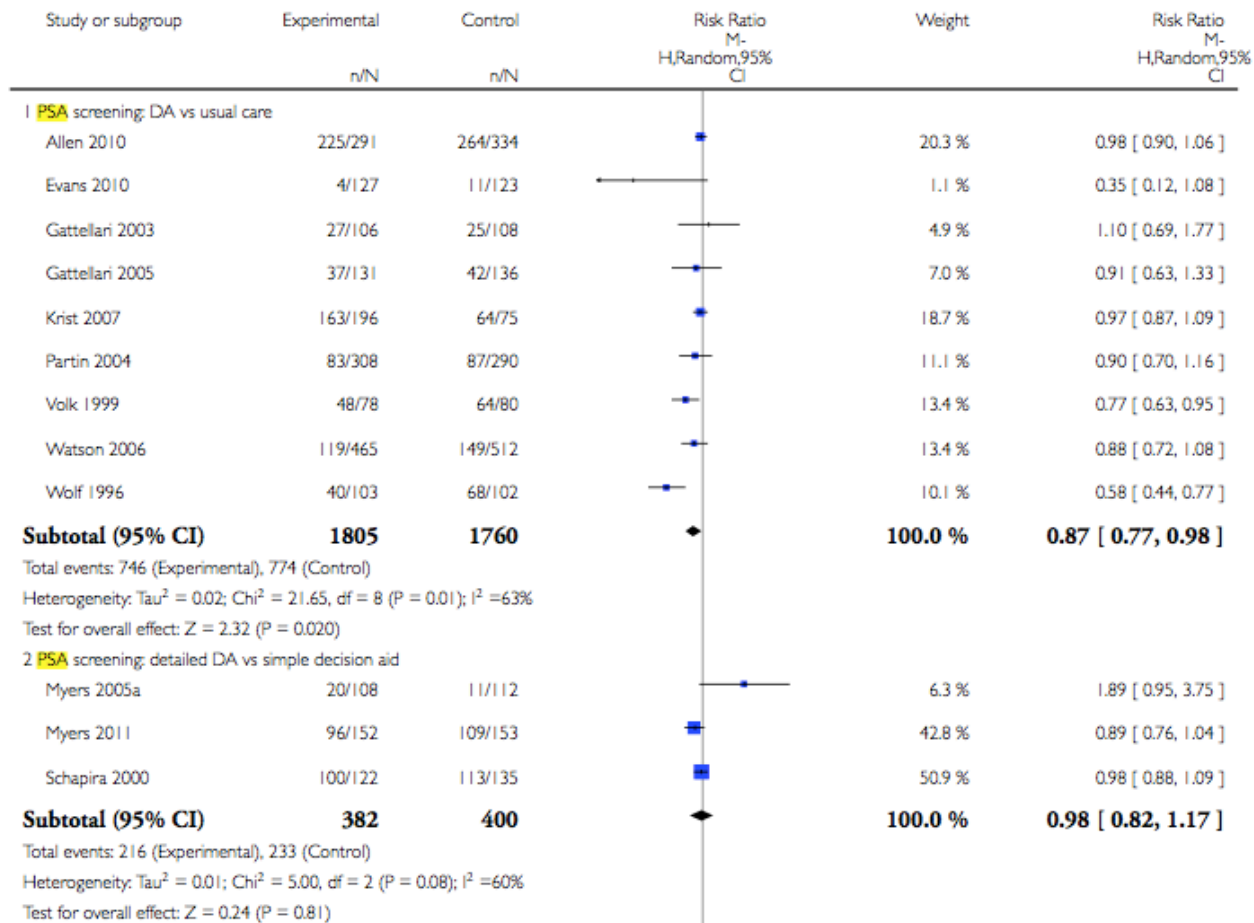
# There have been at least 12 RCTs of PSA decision aids (Stacey et. al. Cochrane review 2014)

## Analysis 8.3. Comparison 8 Choice, Outcome 3 Choice for screening.

Review: Decision aids for people facing health treatment or screening decisions

Comparison: 8 Choice

Outcome: 3 Choice for screening



[Intervention Review]

## Screening for prostate cancer

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**Editorial group:** Cochrane Prostatic Diseases and Urologic Cancers Group.

**Publication status and date:** New search for studies and content updated (no change to conclusions), published in Issue 1, 2013.

**Review content assessed as up-to-date:** 20 November 2012.

**Citation:** Ilic D, Neuberger MM, Djulbegovic M, Dahm P. Screening for prostate cancer. *Cochrane Database of Systematic Reviews* 2013, Issue 1. Art. No.: CD004720. DOI: 10.1002/14651858.CD004720.pub3.

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## Patient Decision Aids



Français

### Search Results - A to Z Inventory of Decision Aids

Your search: **PSA** found the following decision aids (see list below).

Click on a **title** to view a brief description that will help you decide if the decision aid will meet your needs, or try another keyword search to look for other decision aids.

#### Search again:

PSA

Found 7 matches.

#### Prostate Cancer

- [Prostate Cancer Screening with PSA Testing](#) American Society of Clinical Oncology
- [Prostate Cancer Screening: Should I Have a PSA Test?](#) Healthwise
- [Prostate cancer screening: Should you get a PSA test?](#) Mayo Clinic
- [Prostate specific antigen \(PSA\) test](#) Option Grid Collaborative
- [PSA \(prostate specific antigen\) testing for prostate cancer: An information sheet for men considering a PSA test.](#) University of Oxford
- [Should I Have a PSA Test?](#) University of Sydney
- [Should You Get a PSA Test? A Patient-Doctor Decision.](#) Virginia Commonwealth University

- › ASCO – 2012
- › Healthwise – 2013
- › Mayo clinic – 2008
- › Option Grid – 2013
- › University of Oxford – 2008
- › University of Sydney – 2003
- › Virginia Commonwealth University - 2007

- › 12-page document
- › A high quality current resource but too long for GPs to use in the consultation

ASCO Guidelines  
Clinical Tools and Resources

## DECISION AID TOOL PROSTATE CANCER SCREENING WITH PSA TESTING

This booklet is what is often called a decision aid. The goals of a decision aid are to help people better understand their medical choices and to help them make the best medical decision possible for their situation.

This decision aid is for men who are concerned about prostate cancer and are trying to decide whether or not to receive a blood test, known as the prostate-specific antigen (PSA) test that is used to screen for prostate cancer. PSA-based screening is often used to screen healthy men for prostate cancer, and may be included as part of a routine check-up. The PSA test can be done with or without other tests such as a digital rectal exam. Visit [www.cancer.net](http://www.cancer.net) and/or ask your doctor for more information about other tests to screen for prostate cancer.

The goal of this decision aid is to help men and doctors make shared and informed decisions about prostate cancer screening. It is based on recommendations from Screening for Prostate Cancer with Prostate-Specific Antigen Testing: American Society of Clinical Oncology Provisional Clinical Opinion. Use of this decision aid is voluntary.

The decision aid is divided into two sections:



- › Does not contain all the information that the NHMRC has included
- › Risk representation is not best practice (variable denominators)
- › Web-based and may not be useful in consultation
- › Current as of May 2014



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### Decision Point

You may want to have a say in this decision, or you may simply want to follow your doctor's recommendation. Either way, this information will help you understand what your choices are so that you can talk to your doctor about them.

Non-Interactive Decision Point

### Prostate Cancer Screening: Should I Have a PSA Test?

Please answer every question

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

Please answer every question

#### Your options

- Have a PSA test to check for prostate cancer.
- Do not have a PSA test to check for prostate cancer.

#### Key points to remember

- Experts disagree on whether PSA testing should be used to routinely screen men for prostate cancer. Talk with your doctor about your age, your health, and the pros and cons of PSA testing. He or she can help you decide.
- A high level of PSA may mean cancer. But usually it isn't cancer. It's often something else, like an enlarged prostate or an infection.
- A PSA test cannot show if you have cancer. You will need a prostate biopsy to find out if your high level of PSA is from cancer or something else.
- A PSA test may help find cancer early, when it can be cured. But many PSA tests also find cancers that

- › Information not consistent with NHMRC
- › Risk presentation not c/w best practice (variable denominators)
- › Does not have graphical representation (which RACGP wanted)



**Prostate Specific Antigen (PSA) Test**

Use this Grid to help you and your healthcare professional decide whether or not you will have a prostate specific antigen (PSA) test. This test measures the amount of activity in your prostate. Men usually consider this test when they are aged 50 or older.

Frequently asked questions	Having a PSA test	Not having a PSA test
If my PSA level is high, what are the chances that I have prostate cancer?	30 out of every 100 men with a high PSA level (30%) have prostate cancer. Other causes of a high PSA level are inflammation and infection.	If you choose not to get the PSA test then you will not know your PSA level.
If my PSA level is normal, can I be sure that I don't have prostate cancer?	No, you cannot be sure. About 15 out of every 100 men (15%) with a normal PSA level do have prostate cancer.	If you choose not to get the PSA test then you will not know your PSA level.
Will getting the PSA test reduce my risk of dying from prostate cancer?	At most, 1 death is prevented for every 1000 men who get the PSA test (0.1%). 4 out of every 1000 men who get the PSA test (0.4%) will still die from prostate cancer.	5 out of every 1000 men who do not get the PSA test (0.5%) will die from prostate cancer.
What are the advantages?	33 out of every 100 prostate cancers found (33%) are aggressive. 10 out of every 100 aggressive cancers treated (10%) will benefit from early treatment.	You will avoid the risks associated with the biopsies and treatments that could follow an abnormal PSA test.
What are the risks?	Because it is difficult to tell if a cancer is aggressive, you may have unnecessary biopsies and/or treatments. 67 out of every 100 prostate cancers (67%) are not aggressive and do not	You lose the small chance of catching an aggressive cancer that would be found with a PSA test and would benefit from early diagnosis and treatment.

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## Health

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# Prostate Cancer Screening

Decisions for men with a family history of prostate cancer

**You are here:** [Home](#) > [Individuals and Families](#) > [Prostate Cancer Screening](#)

### Prostate Cancer Screening

- [Welcome](#)
- [What is prostate cancer?](#)
- [Family history](#)
- [Prostate cancer screening](#)
- [Statistics](#) 
- [Side-effects of prostate cancer treatment](#)

## Prostate Cancer Screening

### Welcome

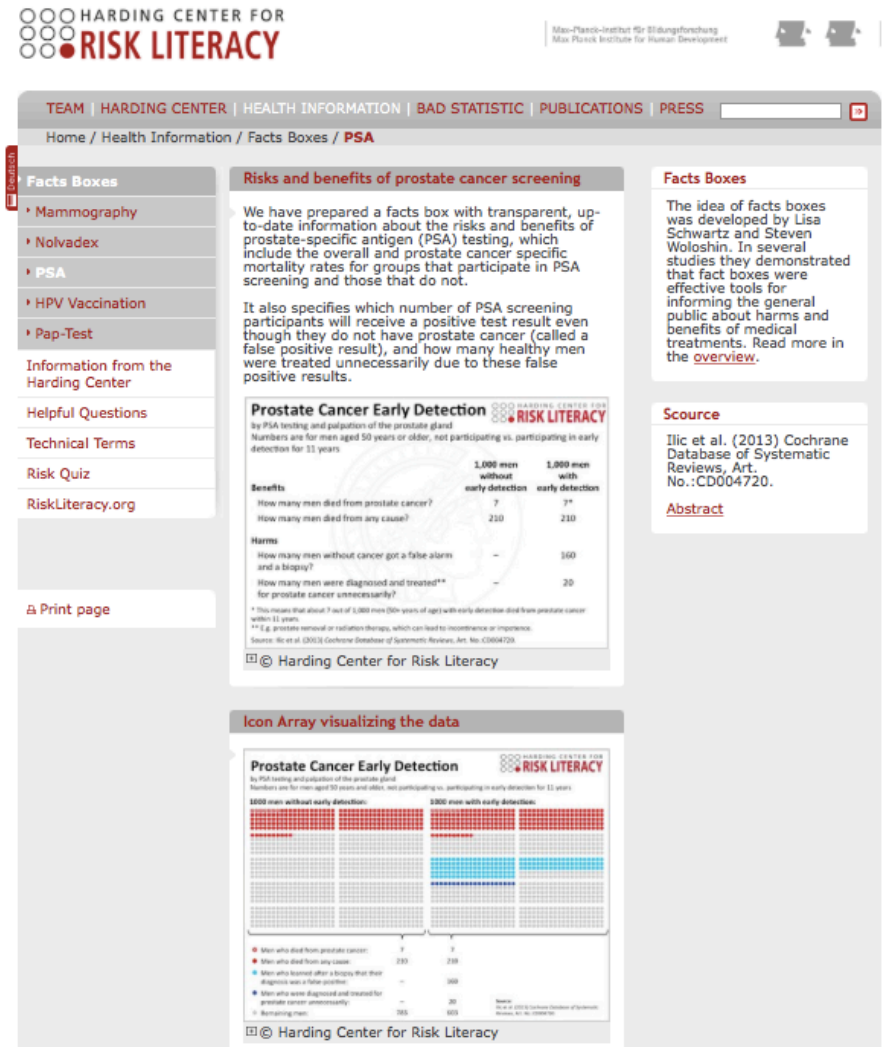
This website is for men who are thinking about *prostate* cancer screening because they have a *family history of prostate cancer*. It is not designed to either encourage or discourage screening for prostate cancer. The decision about screening is yours and there is no right or wrong decision. The purpose of this website is to help you to make an informed choice about prostate cancer screening.

Using this website will help

- Learn about the possible benefits and harms of prostate cancer screening in your situation
- Make a decision about prostate cancer screening
- Clarify what is important to you in making a decision about prostate cancer screening



- > A short tool suitable for GP use
- > Current evidence
- > Does not include all the information that the NHMRC document wants



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**Facts Boxes**

- Mammography
- Nolvadex
- PSA
- HPV Vaccination
- Pap-Test

Information from the Harding Center

Helpful Questions

Technical Terms

Risk Quiz

RiskLiteracy.org

Print page

**Risks and benefits of prostate cancer screening**

We have prepared a facts box with transparent, up-to-date information about the risks and benefits of prostate-specific antigen (PSA) testing, which include the overall and prostate cancer specific mortality rates for groups that participate in PSA screening and those that do not.

It also specifies which number of PSA screening participants will receive a positive test result even though they do not have prostate cancer (called a false positive result), and how many healthy men were treated unnecessarily due to these false positive results.

**Prostate Cancer Early Detection**

by PSA testing and palpation of the prostate gland  
Numbers are for men aged 50 years or older, not participating vs. participating in early detection for 11 years.

	1,000 men without early detection	1,000 men with early detection
<b>Benefits</b>		
How many men died from prostate cancer?	7	7*
How many men died from any cause?	210	210
<b>Harms</b>		
How many men without cancer got a false alarm and a biopsy?	—	160
How many men were diagnosed and treated** for prostate cancer unnecessarily?	—	20

\* This means that about 7 out of 1,000 men (50+ years of age) with early detection died from prostate cancer within 11 years.  
\*\* E.g. prostate removal or radiation therapy, which can lead to incontinence or impotence.  
Source: Ilic et al. (2013) Cochrane Database of Systematic Reviews, Art. No. CD004720.

Harding Center for Risk Literacy

**Icon Array visualizing the data**

**Prostate Cancer Early Detection**

by PSA testing and palpation of the prostate gland  
Numbers are for men aged 50 years or older, not participating vs. participating in early detection for 11 years.

1,000 men without early detection | 1,000 men with early detection

	1,000 men without early detection	1,000 men with early detection
<b>Benefits</b>		
How many men died from prostate cancer?	7	7*
How many men died from any cause?	210	210
<b>Harms</b>		
How many men without cancer got a false alarm and a biopsy?	—	160
How many men were diagnosed and treated** for prostate cancer unnecessarily?	—	20
Remaining men	265	603

\* This means that about 7 out of 1,000 men (50+ years of age) with early detection died from prostate cancer within 11 years.  
\*\* E.g. prostate removal or radiation therapy, which can lead to incontinence or impotence.  
Source: Ilic et al. (2013) Cochrane Database of Systematic Reviews, Art. No. CD004720.

Harding Center for Risk Literacy

**Facts Boxes**

The idea of facts boxes was developed by Lisa Schwartz and Steven Woloshin. In several studies they demonstrated that fact boxes were effective tools for informing the general public about harms and benefits of medical treatments. Read more in the [overview](#).

**Source**

Ilic et al. (2013) Cochrane Database of Systematic Reviews, Art. No.:CD004720.

[Abstract](#)

# What actually are the information requirements for Australian men and their GPs?

- › Background information about who the tool is for, prostate cancer and risk factors, test and follow-up
- › The options
- › The population
- › Effect on prostate cancer mortality
- › Mortality risk in context (all cause)
- › Diagnosis and over-diagnosis of prostate cancer
- › Benefits of early treatment
- › False positive rate
- › False negative rate
- › Treatment of inconsequential disease
- › Complications from testing
- › Complications from treatment



› Slide containing unpublished work removed

- › Australia was slow to implement early work in PSA SDM despite a locally developed and validated tool. Why?
- › There are significant challenges in keeping tools up-to-date
- › There are challenges for Australian consumers and clinicians in finding good quality evidence-based tools
- › Despite this being one of the most decision-tool-rich clinical problems there were none that really fitted the Australian information requirements and the clinical context for the GP consultation

# Case study 2: Pregnancy-related decision-making (Ottawa inventory results 'pregnancy')

- › Numerous Australian tools developed
- › Several funded through NHMRC project grants
- › Include decisions about antenatal screening, trial of labour after LSCS, analgesia in labour, ECV for breech presentation

## Childbirth

- [Do you want a water birth?](#) MIDIRS
- [Epidural pain relief in labour](#) MIDIRS
- [Making Choices: options for a pregnancy woman with a breech baby.](#) Centre for Perinatal Health Services Research
- [Pregnancy: Should I Have an Epidural During Childbirth?](#) Healthwise
- [Pregnancy: Should I Try Vaginal Birth After a Past C-Section \(VBAC\)?](#) Healthwise

## Depression

- [Depression: Should I take antidepressants while I'm pregnant?](#) Healthwise

## Diabetes

- [Diabetes: Should I Get Pregnant?](#) Healthwise

## Epilepsy; Pregnancy

- [Epilepsy treatment when considering pregnancy.](#) Option Grid Collaborative

## Infertility

- [Infertility: Should I Have Treatment?](#) Healthwise

## Pregnancy

- [Miscarriage: Should I have treatment to complete a miscarriage?](#) Healthwise
- [Multiple Pregnancy: Should I Consider a Multifetal Pregnancy Reduction?](#) Healthwise

## Prenatal Testing

- [A Decision Aid: Testing in Pregnancy for Foetal Abnormalities.](#) Murdoch Children's Research Institute
- [Amniocentesis](#) Option Grid Collaborative
- [Is my baby alright? Screening in pregnancy](#) MIDIRS
- [Pregnancy: Should I Have Amniocentesis?](#) Healthwise
- [Pregnancy: Should I have an early fetal ultrasound?](#) Healthwise
- [Pregnancy: Should I Have CVS \(Chorionic Villus Sampling\)?](#) Healthwise
- [Pregnancy: Should I Have Screening Tests for Birth Defects?](#) Healthwise
- [Ultrasound scans -- what you need to know](#) MIDIRS

## Stem cells

- [Pregnancy: Should I Bank My Baby's Umbilical Cord Blood?](#) Healthwise





## Your choice

screening and diagnostic tests  
in pregnancy



**Making choices:  
options for a pregnant  
woman with a breech baby**



A decision aid for women



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Queensland Centre for Mothers & Babies

*Having a Baby in Queensland*

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## Having a Baby in Queensland Website

Welcome to the Having a Baby in Queensland website.

This website:



## *pregnancy decision aids*

General Information

Pregnancy

Labour & Birth

After Birth

Sharing Your Story



Pregnancy > Pregnancy Decision Aids >

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## Pregnancy Decision Aids

Decision aids are tools that give you information and support you to make decisions. The following decision aids about pregnancy are now available:



### [Choosing your model of care: A decision aid for pregnant women choosing their maternity care provider](#)

This decision aid has been written to support women to know what to expect and to have a say in making decisions about their **model of maternity care**. To download this decision aid, click on the button to the left.



### [Choices about first trimester ultrasound scans: A decision aid for pregnant women](#)

This decision aid has been written to support pregnant women to know what to expect and to have a say in making decisions about **first trimester ultrasound scans**. An **ultrasound scan** is when a small handheld device is used to create a picture of a woman's **uterus** (womb) and baby during pregnancy. A **first trimester** ultrasound scan is an ultrasound scan done in a woman's first trimester of pregnancy (the first 14 weeks of a woman's pregnancy). To download this decision aid, click on the button to the left.



## What are my options for my maternity care?

There are four options for how to be cared for during pregnancy:

This decision aid is not designed to help you make decisions as to whether or not to choose a maternity care provider. The option not to have a care provider at all during pregnancy and/or birth is referred to as a free birth.



Photo courtesy of Deirdre Cullen

### Public care

#### Option 1

Shared care

#### Option 2

Midwifery models of care

### Private care

#### Option 3

Private obstetric care

#### Option 4

Private midwifery care

## Labour & Birth Decision Aids

Decision aids are tools that give you information and support you to make decisions. The following decision aids about labour and birth are now available:



### Choosing how to birth your baby: A decision aid for women without a previous caesarean section

This decision aid has been written to support women to know what to expect and have a say in making decisions about how to birth. To download this decision aid, click on the button to the left.



### Choosing how to birth your baby: A decision aid for women with a previous caesarean section

This decision aid has been written to support women who have had one or more previous caesarean sections to know what to expect and have a say in making decisions about how to birth. To download this decision aid, click on the button to the left.



### Choosing how your labour will start: A decision aid for women with a prolonged pregnancy

This decision aid has been written to support women who might have a prolonged pregnancy (a pregnancy that continues beyond 42 weeks) to know what to expect and to have a say in making decisions about how labour will start. To download this decision aid, click on the button to the left.

*Note: This decision aid is currently being updated and a revised version will be made available shortly. If you would like to be notified when this is available, please send us a message on the 'Contact Us' page.*



### Monitoring your baby during labour: A decision aid for women having a vaginal birth

This decision aid has been written to support women planning to have their babies monitored during labour and birth to know what to expect, and to have a say in making decisions about how their baby will be monitored. To download this decision aid, click on the button to the left.



### Choosing your positions during labour and birth: A decision aid for women having a vaginal birth

This decision aid has been written to support women planning a vaginal birth to know what to expect and to have a say in making decisions about positions in labour and birth. To download this decision aid, click on the button to the left.



### Choices about epidural: A decision aid for women having a vaginal birth

This decision aid has been written to support women planning a vaginal birth to know what to expect and to have a say in making decisions about having an epidural. To download this decision aid, click on the button to the left.



### Choices about episiotomy: A decision aid for women having a vaginal birth

This decision aid has been written to support women planning a vaginal birth to know what to expect and to have a say in making decisions about episiotomy (when a care provider uses scissors to make a cut to increase the size of the opening of the vagina). To download this decision aid, click on the button to the left.



### Choosing how to birth your placenta: A decision aid for women having a vaginal birth

This decision aid has been written to support women planning a vaginal birth to know what to expect and to have a say in making decisions about the third stage of labour. The third stage of labour is the time from when a woman births her baby to when she births her placenta (the afterbirth). To download this decision aid, click on the button to the left.



### Using a bath or pool during first stage labour: A decision aid for women having a vaginal birth

This decision aid has been written to support women who are wanting to have a vaginal birth to know what to expect and to have a say in making decisions about using a bath or pool during the first stage of labour. To download this decision aid, click on the button to the left.



### Choices about clamping your baby's umbilical cord: A decision aid for women having a vaginal birth

This decision aid has been written to support women planning to have a vaginal birth to know what to expect and have a say in making decisions about clamping their baby's umbilical cord. To download this decision aid, click on the button to the left.

- › Many Australian decision aids are potential ‘orphans’ after funding ends
- › The ‘Having a Baby in Queensland’ innovation was an attempt to package resources for the pregnant woman
- › Evaluations of the tools were extremely positive with a preference for hard copy which was not funded or resourced
- › Pregnant women and providers continue to request copies of the resource but it is no longer funded or supported since change of govt in Qld
- › Other relevant decision aids appear to be disconnected from this package

## Case study 3: HRT for menopausal symptoms

- › Following the publication of the WHI trial
- › First NHMRC-funded decision aid was produced
- › 75,000 copies requested over 2 years (personal communication)
- › Intellectual Property lies with NHMRC
- › No plan for updates
- › Continues to be used in clinical practice

### Making Decisions:

**Should I use hormone replacement therapy?  
(HRT)**





- › There was enormous interest and uptake for this tool despite NO dissemination or implementation strategy
- › There is currently no ownership of the tool and no commitment to updating the evidence
- › Intellectual Property sits with NHMRC
- › Need for oestrogen-only version. Who decides on this?
- › GPs and hospital clinics have used this tool extensively

# Case study 4: Teaching SDM to consumers

## Ask, Share, Know



Shepherd HL, Barratt A, Trevena LJ, McGeechan K, Carey K, Epstein RM, et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. *Patient Educ Couns.* 2011;84(3):379-85

Funded by Foundation for Informed Medical Decisions



The screenshot shows the homepage of the 'ask share know' website. The header features the 'ask | share | know' logo and navigation links for HOME, ASK, SHARE, and KNOW. The main content area is green and includes a section titled 'WHAT IS ASK SHARE KNOW?' with introductory text and a graphic highlighting '3 Questions to ask your health professional'. Below this, there are sections for 'ABOUT THE ASK SHARE KNOW PROJECT:' and 'WATCH THE ASK FILM CLIP:', each with descriptive text and video player thumbnails. The first question is highlighted in a green box: '1. What are my options? (One option will always be wait and watch)'.

## WHAT IS ASK SHARE KNOW?

ASK SHARE KNOW aims to encourage and empower people to be involved in decisions about their health.

Making decisions about our health is important. However, sometimes the decisions we face involve a lot of information that is new, and can seem difficult to understand.

Deciding about medical tests and treatments are some of the most stressful decisions we will have to make. BUT they are usually no more complex than other decisions we are used to making.

Provided we get the right information, we can all be involved in medical decision-making, and the good thing is, health professionals will share the decision making with you.

**3**  
Questions to ask  
your  
health professional

ASK more  
SHARE more  
KNOW more

### ABOUT THE ASK SHARE KNOW PROJECT:

The ASK SHARE KNOW project wants to help people to get the information they need, to share making medical decisions with health professionals.

To do this, we are suggesting that people ask health professionals three key questions. These questions give you the words to use when you are talking with a doctor or nurse. We also suggest you share important information about your life and preferences with your doctor or nurse.

And finally we suggest you use what you learn from these discussions to help you make decisions.

## ask the 3 Questions:

1. What are my options?  
(One option will always be wait and watch)

### WATCH THE ASK FILM CLIP:



Condensed Version - 1 minute



Brief Version - 4 minutes



## KNOW WHAT'S BEST FOR YOU:

---

The more information you have, and the more you **know**, the better equipped you will be to make decisions, and ultimately achieve better health.

Making decisions about medical tests and treatments are some of the most stressful decisions you will have to make.

An added benefit of asking the 3 questions we recommend is that by asking the question, you are ready for the answer.

So when you ask:

“What are my **options?**”

You can expect to hear something like...

“So two things, I guess we need to talk about an anti-depressant and I’m wondering what you think about counselling”

OR

“Well what we can do for your earache is start some antibiotics or continue with good pain relief medication, such as paracetamol for example”

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?

STRATEGIES TO HELP  
REMEMBER AND UNDERSTAND  
THE INFORMATION YOU  
RECEIVE:

---

<http://www.askshareknow.com.au/know.html>



Slides containing unpublished work removed

## What's happening with this now?

- › ARC funded study includes these questions in a SDM module to improve health literacy for adults with low education (TAFE classes) – has shown the questions need refinement in this group
- › PCORI funding just received to evaluate the video vs option grid vs both vs usual care (i.e. provider vs patient vs both vs none) on SDM in Family Planning



# These 3 questions have gone 'viral' overseas



**Rachel Thompson** @ractho · Sep 25

Anouk Knops describes plans to implement Ask 3 Questions in the Netherlands  
[#radboudsdm](#) [@TriggerShep](#) [@LyndalTrevena](#) [@IQhealthcare](#)

Expand

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**France Legare** @SDM\_ULAAVAL · Sep 20


[@riyadhoneonline](#) Public awareness campaign "Ask 3 Questions" see excellent paper by [@TriggerShep](#) [@LyndalTrevena](#) [goo.gl/NHGScJ](http://goo.gl/NHGScJ)

View conversation

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**Cardiff and Vale University Health Board**  
Caring for people, keeping people well



**GIG Cymru NHS WALES**  
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro  
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Promoting Health
Our Charity
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Cymraeg

Home > Ask 3 Questions Search

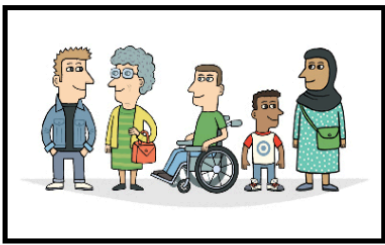
## Ask 3 Questions

Welcome to the Ask 3 Questions website - the campaign to help patients become more involved in their treatment and care.

The campaign will raise awareness of shared decision making and encourage both patients and doctors to work together in deciding on the best course of action.

We have developed the campaign based on research by [Shepherd et al at the University of Sydney](#).

A number of tools and resources have been developed to help support this but the key message is for patients to always Ask 3 Questions when discussing their treatment.



**The 3 Questions are:**

- 1. What are my options?**
- 2. What are the possible benefits and risks of those options?**
- 3. How likely are the possible benefits and risks of each option to occur?**

Cardiff & Vale University Health Board is committed to making sure that all patients receive the right care and are involved in shared decision making.

Please feel free to discover more about the Ask 3 Questions campaign by exploring this site and to [contact us](#) with any views, questions or suggestions you may have.

**Find Out More**

**Ask 3 Questions**

**What is shared decision making?**  
Learn more about shared decision making

**The 3 Questions**  
What are the 3 Questions?

**The Benefits**  
Discover the benefits behind the Ask 3 Questions campaign

**Patient Feedback**  
Hear what patients think about the Ask 3 Questions campaign

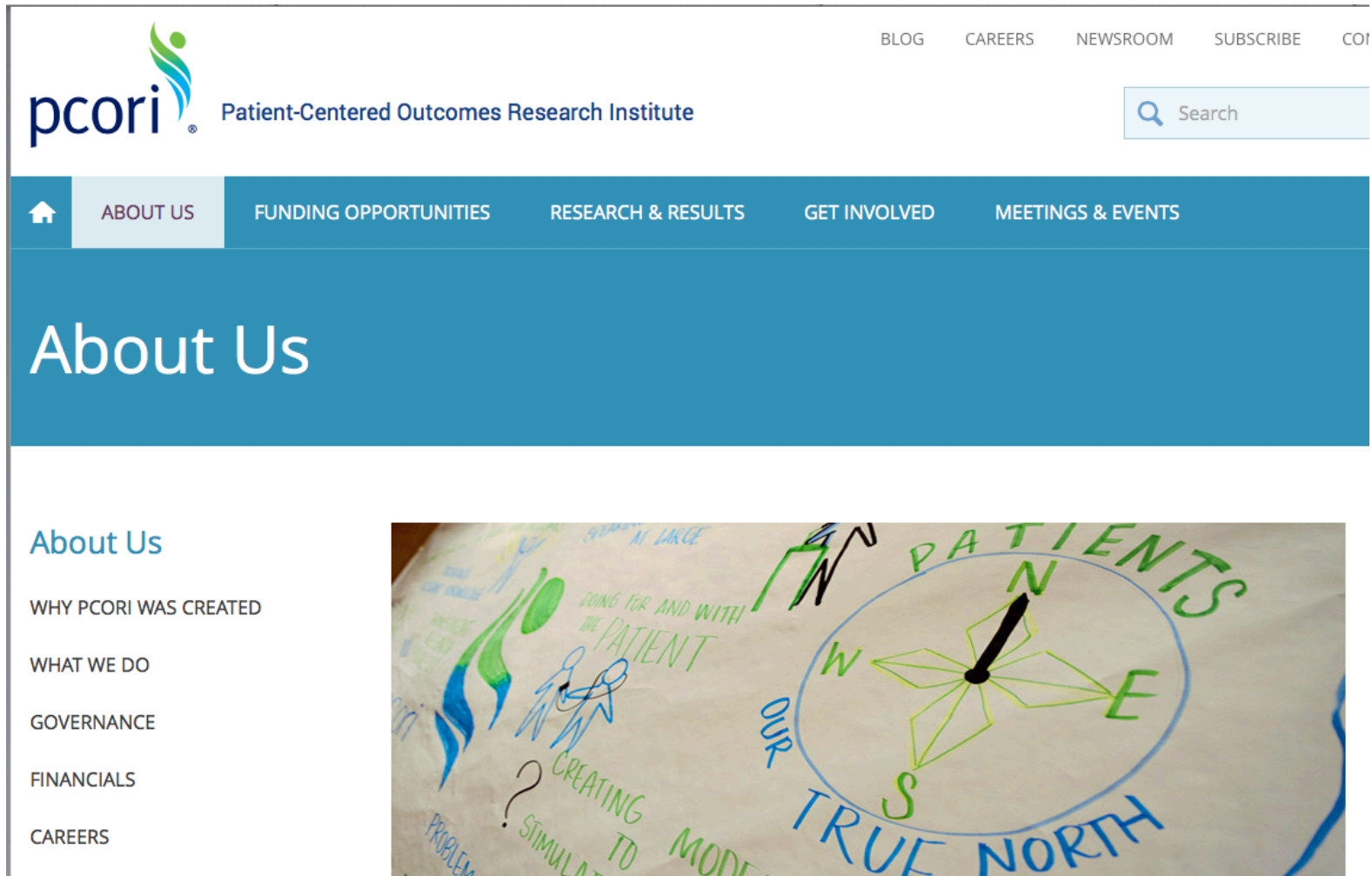
**The Nurse's View**  
Hear what medical staff think about the 3 Questions

**The MAGIC Programme**  
Discover more about the programme that developed the campaign

**Resources Ask Three Questions**  
Find tools and resources developed for the Ask 3 Questions campaign

**Option Grids**  
View the option grids developed by the team

**The Health Foundation**



The screenshot shows the PCORI website's 'About Us' page. At the top left is the PCORI logo, which consists of a stylized human figure in green and blue above the text 'pcori' and 'Patient-Centered Outcomes Research Institute'. To the right of the logo is a search bar with a magnifying glass icon and the word 'Search'. A navigation menu below the logo includes a home icon and links for 'ABOUT US', 'FUNDING OPPORTUNITIES', 'RESEARCH & RESULTS', 'GET INVOLVED', and 'MEETINGS & EVENTS'. The main heading 'About Us' is displayed in large white text on a blue background. Below this, a list of links is provided: 'About Us', 'WHY PCORI WAS CREATED', 'WHAT WE DO', 'GOVERNANCE', 'FINANCIALS', and 'CAREERS'. On the right side of the page, there is a hand-drawn diagram on a piece of paper. The diagram features a central compass rose with a black arrow pointing towards the top, labeled 'N'. The cardinal directions are labeled 'N', 'W', 'E', and 'S'. The words 'PATIENTS' and 'TRUE NORTH' are written in green and blue around the compass. Other handwritten text includes 'OUR', 'DOING FOR AND WITH THE PATIENT', 'CREATING TO MODERN', 'SIMULATED', and 'PROBLEM'.



- › This is an example of an Australian innovation that has been adopted quickly abroad
- › Some concerns remain about lack of effectiveness research
- › Currently important work is underway looking at the role in health literacy and more vulnerable populations
- › Also some concerns about the impact on clinicians – need to evaluate and support both sides of the SDM partnership (now to be addressed in the PCORI-funded research project)
- › Limited funding sources for CER in Australia
- › Can we explore ways to evaluate and scale up interventions for the Australian public?

## Case study 5: Developing tools that reach the right people

- › Smartphone decision aid (plus) for smoking cessation
- › Feasibility study showed 1751 people downloaded in 12 months with 602 completing questions.
- › Mean age 32 years 77.2% ready to quit in next 30 days
- › More than half had downloaded smoking cessation apps before with  $\frac{3}{4}$  of these attempting to quit in the past
- › 71.7% had not contact a health professional about quitting in the past year
- › 88.7% had not contact a 'Quitline' in the past year
- › Bin Dhim et. al JMIR 2014







› Slides containing unpublished work removed

- › Many of the target population were not accessing health services for smoking cessation
- › The app appears to be effective in the short-term and appears to be cost-effective (further analysis to come)
- › Outcome data can possibly be collected from SDM tools such as these devices
- › The push notifications may be an important mechanism for supporting decisions and subsequent behaviour change



ISDM/ISEHC 2015

19-22 JULY 2015 ■ UNIVERSITY OF SYDNEY ■ AUSTRALIA  
BRINGING EVIDENCE-BASED PRACTICE AND  
SHARED DECISION-MAKING TOGETHER



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## Welcome

On behalf of the International Society for Evidence Based Health Care (ISEHC) and the International Shared Decision-Making (ISDM) group we warmly invite you to attend the joint ISDM/ISEHC Conference in Sydney, 2015. This will be a landmark event in the evolution of both evidence-based health care and shared decision making, which have much to contribute to each other and to better care for patients. This important opportunity for you to enjoy the fellowship of like-minded colleagues as well as enjoying the many pleasures of Sydney.

We look forward to seeing you there.



Professor Paul Glasziou  
Chair of ISEHC Board



Associate Professor Lyndal Trevena  
ISDM conference chair

### Expression of Interest

#### Key Dates

Call for Abstracts Opens  
29 September 2014

Registration Opens  
27 October 2014

Abstract Submission  
Deadline  
20 February 2015

Notification of Acceptance  
of Abstract  
March 2015

Early Bird Registration  
Closes  
17 April 2015

Conference Dates  
19 - 22 July 2015

#### Host Sponsor



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ON SAFETY AND QUALITY IN HEALTH CARE

- › How can we help Australian patients and clinicians find good quality decision support tools more easily?
- › How do we ensure the quality, relevance and types of tools that will be most useful for Australian clinicians and patients?
- › Who and how do we decide what tools are needed?
- › How do we ensure the sustainability of these resources?
- › What sort of clinical effectiveness research is needed and who would fund that?
- › How do we engage consumers and clinicians within and outside the healthcare consultation? What is the role of m-health in this?