

Communicating risk information to consumers

Professor Jeanette Ward & Dr Melina Gattellari

Division of Population Health
South Western Sydney Area Health Service
& School of Public Health and Community Medicine, UNSW

Overview

- *Emerging insights about consumer perspectives*
 - Mammography screening
- *Evaluations of decision-aids for risk communication*
 - Community-based trial ('head-to-head' comparison of three PSA resources)
- *Development of professional workforce skills*
 - Trial of an educational strategy to develop GP capacity to facilitate informed choice about PSA screening

Evidence-based informed choice

- *Informed choice:*
 - ‘where all the available information about health alternatives is weighed up and used to inform the final decision’
 - ‘one where a reasoned choice is made by a reasonable individual using relevant information, in accord with the individual’s belief’
- *Evidence-based informed choice:*
 - ‘individuals are given research-based information on two or more options’
 - ‘the provision of research evidence on the pros and cons of one or more healthcare options along with the promotion of active patient involvement in clinical decisions’

(Bekker et al; Marteau et al 2001; Trevena & Barratt 2003)

Consumer perspectives

Making a decision about mammographic screening

Davey et al (*ANZJPH* in press)

- GP-based sample, n=106 women, 45-70 yrs
- Scenario 1: Relative risk reduction (RRR)

'Having this test every 2 years will reduce your chance of dying from breast cancer by about 34% over a ten year period'

88% definitely interested

- Scenario 2: Absolute risk reduction (ARR).

'If we imagine 1000 women aged between 50-69 years, the chances are that 6 of these women will die from breast cancer. This means that the odds of dying from breast cancer are 6 in a 1000. With this new screening test, the odds change. Of 1,000 women all having this new test every two years, instead of 6 women dying, the chances are that 4 women will die from breast cancer. This means the odds have been reduced to 4 in a 1000. This means 2 fewer women will die from breast cancer for every 1000 women who have this test.'

78% definitely interested

- Scenario 3: non-significant impact on *all-cause* mortality.

‘Having this test reduces the chances of dying from breast cancer. However, having this test will not increase the absolute chance of living a longer life. This means that the test changes the cause of death from breast cancer to something else.’

53% definitely interested

- Scenario 4: Limitations (full narrative)

'Imagine 1000 women aged 50-69 years who regularly have this screening test for breast cancer before any signs can be felt or noticed... the vast majority of women, (about 940) they will be correctly told that their test is normal...However, about 2 women who really do have breast cancer will be wrongly told that their result is normal....Also, because the test is not 100% accurate, about 50 women out of the 1000 women will be asked to come back for further tests because their screening test was not normal. These 50 women will eventually be shown through further tests that they do not have breast cancer. However, these women might experience worry, possible discomfort and inconvenience.

So, for these 1000 women, we've talked about the vast majority of women (940) who don't have breast cancer, who get a normal result. Those who don't have breast cancer, but need further tests before they get clearance (about 50 women). And we've talked about women with breast cancer who are missed (about 2 out of 1000 women)....'

79% definitely interested

Consumer perspectives

Framing effect in personal decision-making

RRR	88% definitely interested
ARR	78% definitely interested
Unchanged all-cause mortality	53% definitely interested
Limitations	79% definitely interested

RRR v ARR $p < 0.013$; RRR v ACM $p < 0.01$; RRR v Limitations $p < 0.06$)

46% did not alter their response for all four scenarios. These women were significantly more likely to be positively inclined to the first scenario ($p < 0.04$)(no other predictors).

Mammographic screening (continued)

Framing effect in personal decision-making

	<i>'New?'</i>	<i>'Necessary?'</i>
	Yes	Yes
RRR	30%	68%
ARR	65%	73%
Unchanged all-cause mortality	41%	16%
Limitations	40%	76%
	p<0.01	p<0.01

Consumer perspectives

Women's expectations of the process to facilitate 'informed choice'

Strongly agree

GPs should spend as much time as necessary to explain the benefits and limitations of the test	75%
GP should ask questions to ensure a woman's understanding	60%
GP should use a 'decision aid' when explaining the test	59%
Before having the test, GP should explain the risks	51%
A woman should read information before having the test	46%
A woman sign a written consent form	22%

- Prostate cancer screening

- ‘men being offered, or requesting, the PSA test must be fully informed of the limitations of the available tests and the possible further diagnostic and treatment choices with which they may be faced should they decide to proceed with the tests’ *Australian Health Technology Advisory Committee 1996*

- ‘Individual men aged 50 to 70 years with at least a 10 year life expectancy should be able to be screened by annual DRE and PSA testing, after appropriate counselling regarding the potential risks and benefits of investigations and the controversies of treatment. *Urological Society of Australia* (<http://www.urosoc.org.au/info/ainfo.html>)

Decision-aids

Do we need decision-aids for PSA screening? YES!

PROCESS:

- 38% recalled *no* discussion about pros and cons of screening
- 39% recalled <5 *minutes* discussion
- 17% given printed information before their first test *Slevin et al (1999)*

CONTENT

- 34% did not know consequences of a positive PSA result (*Pinnock et al 1998*)
- 74.3% agreed that prostate cancer was cured if treated early (*Weller et al 1998*)

Decision aids

- *'help people make specific and deliberative choices among options (including the status quo) by providing (at the minimum) information on the options and outcomes relevant to a person's health'*

O'Connor et al 2003

Head-to-head comparison in a community trial

AIMS

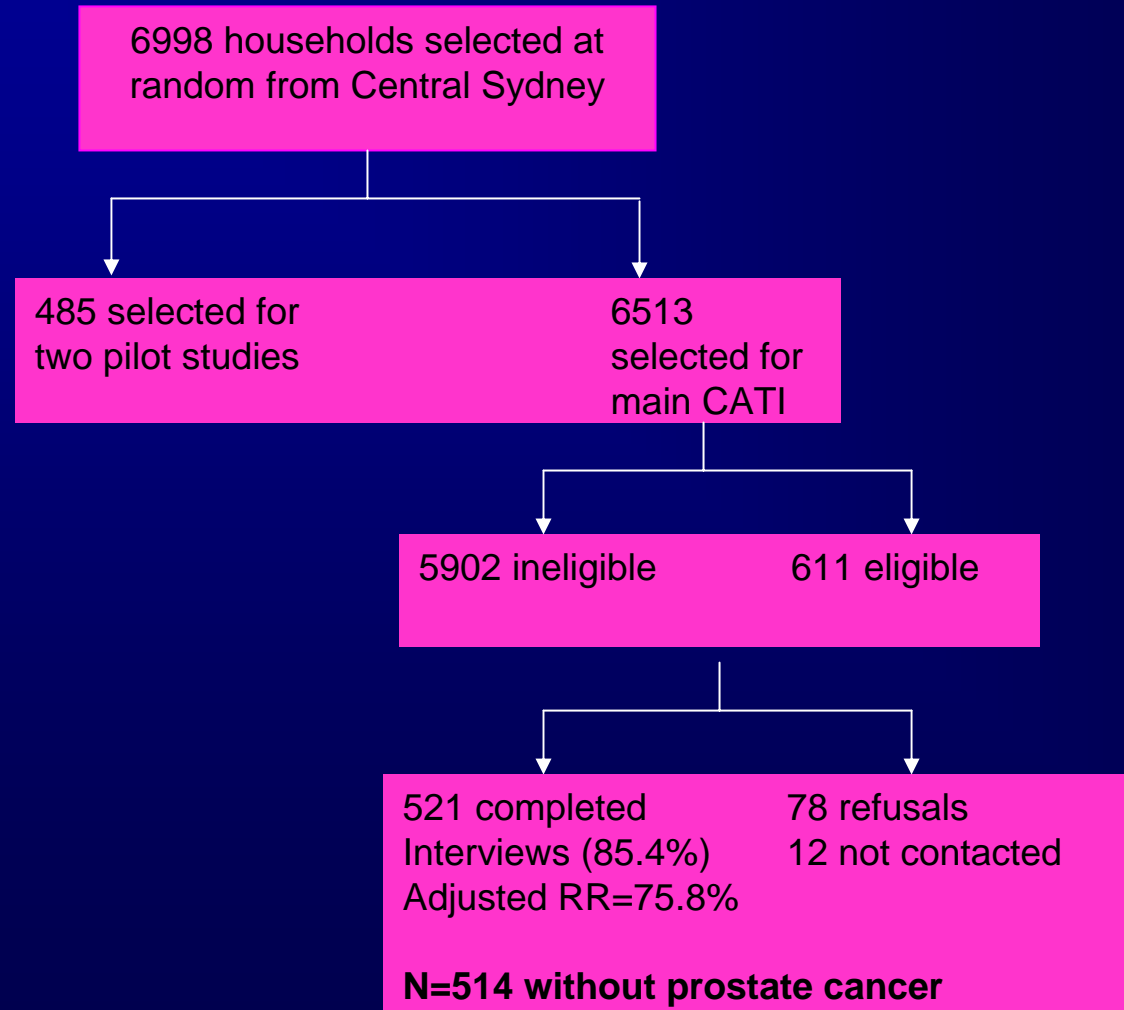
To assess the effect of the three Australian resources about PSA screening on men's

- Knowledge
- Views
- Decisional conflict
- Propensity to litigate and perceptions of GP role

Gattellari & Ward *Patient Educ & Couns* 2004 (in press)

Gattellari & Ward *Health Expectations* 2004 (in press)

Recruitment



Baseline findings

Preferences for involvement in PSA screening decisions

- The doctor should decide using all that's known about the test (*'passive'*)
- The doctor should decide but seriously consider my opinion (*'passive'*)
- The doctor and I should decide together on an equal basis (*'shared'*)
- I should decide but seriously consider the doctor's opinion (*'active'*)
- I should decide using all that I learn about the test (*'active'*)

Adapted measure from Degner and Sloan 1992

Baseline findings

Passive	25%
Shared	50%
Active	25%

Independent predictors of 'passive role'	AOR (95%CI)
<i>Age</i>	
50-59 yrs	1.00
60-70 yrs	1.78 (1.14-2.78)
<i>Occupational skill level (ABS classification)</i>	
1 and 2 (prof/paraprof/managers)	1.00
3-5	1.95 (1.26-3.01)

Men's intention to screen

Intention to screen for an unspecified cancer ('probably' or 'definitely want' screening test) in response to:

<i>Scenario 1:</i> Lack of definitive evidence for the efficacy of screening	61.3%
<i>Scenario 2:</i> Risk of detecting indolent cancer	61.9%
<i>Scenario 3:</i> Life-time risk of dying from cancer	72.9%
<i>Scenario 4:</i> Scientific and expert equipoise	62.8%
<i>Scenario 5:</i> Risks of side-effects of treatment and its unproven efficacy	46.1%
Intention to undergo PSA screening in the next 12 months	68.1%

Decision-aids and informed choice about PSA screening

- 421 men randomised as follows:
 - LEAFLET (Cancer Foundation of WA) (n=140)
 - VIDEO (Cancer Foundation of WA) (n=141)
 - EB BOOKLET (n=140)

- 405 completed post-test CATI (~ 20 minutes)
 - LEAFLET (n=136; 96.5%)
 - VIDEO (n=138; 97.9%)
 - EB BOOKLET (n=131; 93.4%)

	Leaflet	Evidence-based Booklet	Video
Flesch Reading Ease Score	57.9%	67.3%	NA
Kincaid Reading Age	14.6 years	11.8 years	NA
SMOG Reading Age	15.9 years	11 years	NA
Length	856 words	2,407 words	22 minutes
Met criteria of decision-aid	No	Yes	Yes
Developers	CFWA	Update of GP booklet	CFWA

Evidence Based (EB) Booklet

- 32-page
- Statistics on life-time and age-specific incidence and mortality
- Information on LUTS
- Test characteristics (test positivity, PPV, NPV)
- Reasons for having a PSA test
- Detection of indolent disease, risk of treatment-related side-effects presented
- Values-clarification exercise

J Med Screening 2003; 10: 27-39

Before the age of 75, for every 100 men from NSW, around:



ONE will die from prostate cancer



TWO will die from bowel cancer



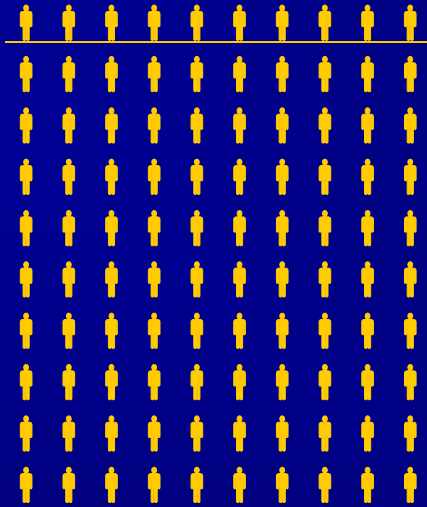
TWO will die from strokes



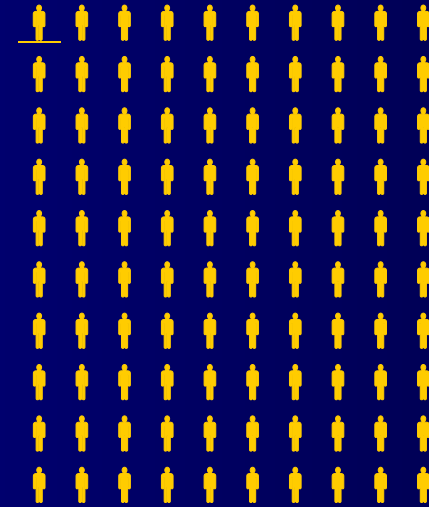
FOUR will die from lung cancer



NINE will die from Coronary Heart Disease (CHD)



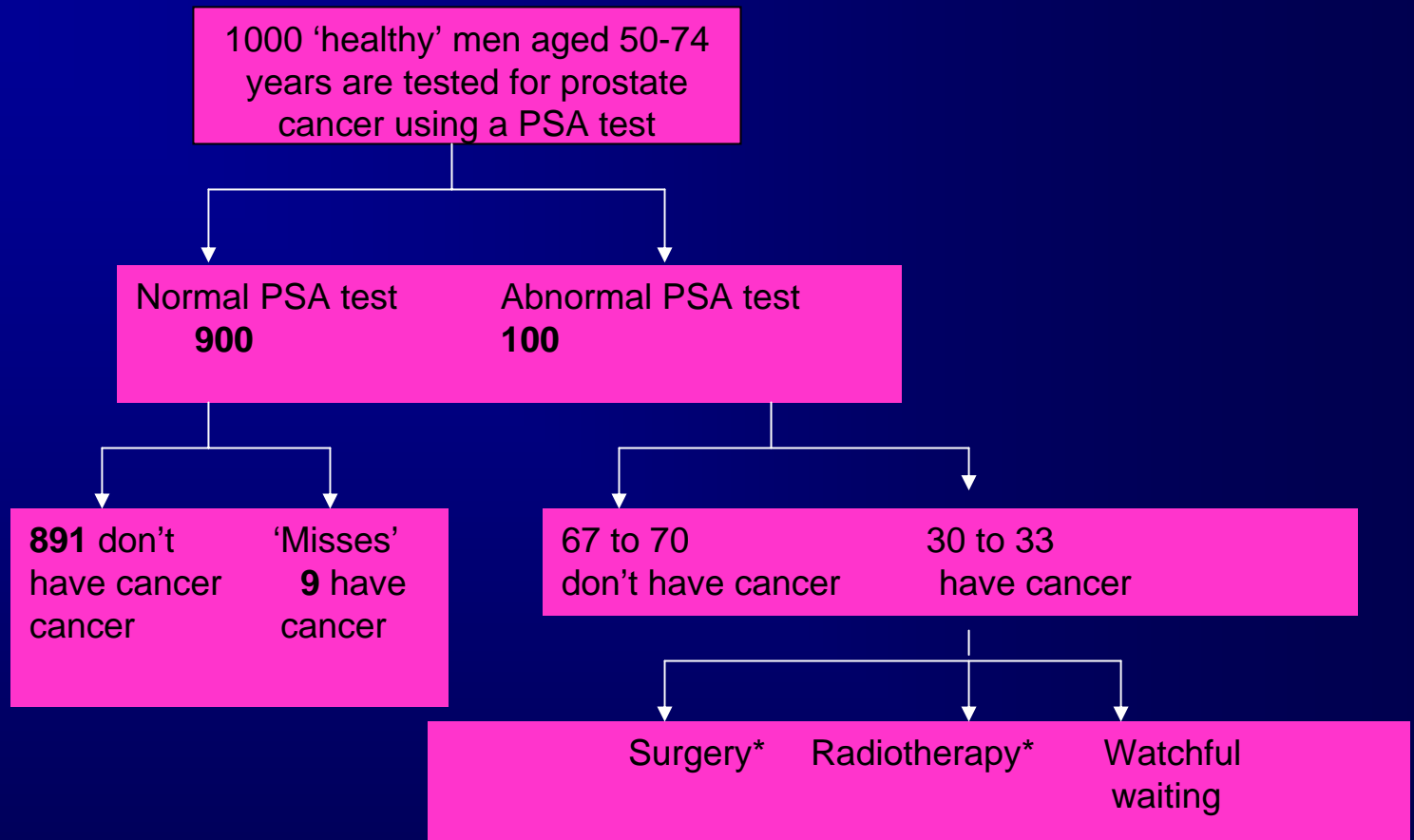
For every 100 men up to age of 75 years, around TEN will develop prostate Cancer



For every 100 men up to the age of 75 years, around ONE (1.2%) will die from prostate cancer

*Source: adapted from NSW Cancer Council, 2003
Cancer in NSW: Incidence and Mortality, 2001*

Possible outcomes of having a PSA test



Sexual dysfunction:	~20-70%	~20-45%
'Severe' incontinence:	~10%	~3%
'Mild' incontinence:	~40%	~2-16%
Improved survival:	Uncertain	Uncertain

*assuming cancer is early-stage

Reasons for having a PSA test

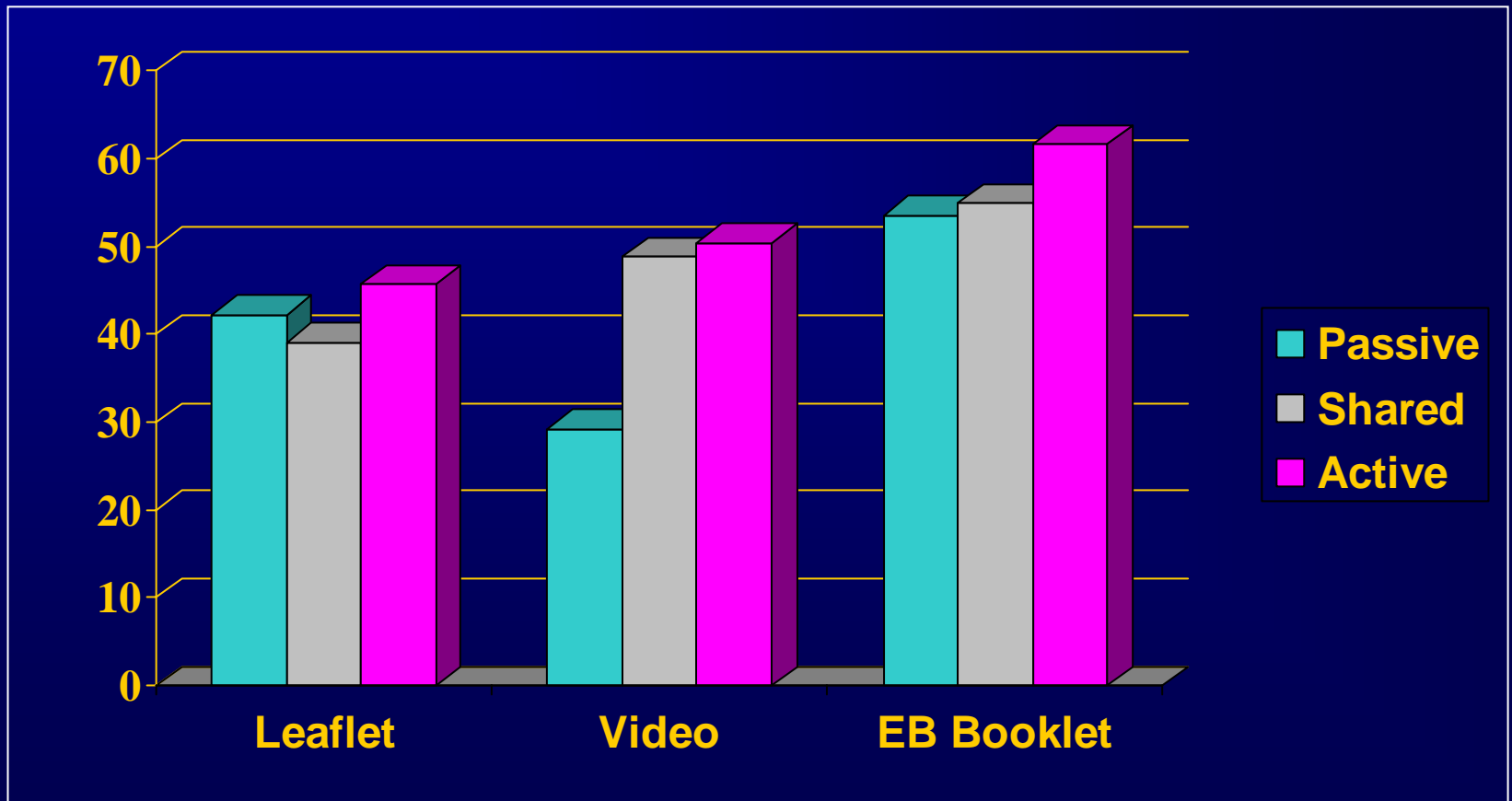
- Unlike lung cancer and heart disease, doctors are unsure how to prevent prostate cancer
- Early prostate cancer does not cause symptoms
- PSA tests can help find cancer early
- Men diagnosed with early stage prostate cancer tend to live longer than those with cancers that have spread outside the prostate
- Prostate cancer that has spread outside the prostate cancer generally cannot be cured

Values clarification exercise

Does this sound like you?

- You are worried about prostate cancer. Having a PSA test will reassure you 'everything is ok.
- You have a family history of prostate cancer.
- You are prepared to accept the chance that a PSA test might find a cancer that may never have caused you problems. You would rather know if you had cancer.
- PSA tests are not yet proven to save lives. But in the future we may find out that they do. You think it is better to be 'safe than sorry'.
- If you were diagnosed with prostate cancer, you would be prepared to accept the side-effects of treatment OR You could live with knowing you had cancer even if you chose not have treatment.
- You are not worried about prostate cancer.
- You do not want to risk finding out you had cancer when it may never bother you.
- If you found out you had cancer, you would not want treatment that could affect your quality of life.
- PSA tests are not yet proven to save lives. You do not want to risk a good quality of life for a possible but unproven chance of a longer one.
- You are prepared to accept the possibility that researchers may later find out that PSA tests benefit men's health.

Post-test knowledge by group by decisional preference



($F_{4,395}=4.29$) ($p=0.002$)

Additional outcomes

- Decisional uncertainty
- Factors contributing to uncertainty
- Views (*negative score views weighted against, positive score views weighted for*)
- Interest in PSA screening in next 12 months (non-GP recommended) (*Very unlikely to very likely*)
- Likelihood of agreeing to have a PSA test on the recommendation of a GP (*Very unlikely to very likely*)

Post-test comparisons between groups (ex knowledge)

Significant differences between groups

	Leaflet	Video	EB Booklet
Views (-5 to 5)	1.7 (1.6-1.9)	1.7 (1.5-1.8)	1.3 (1.1-1.5) *
Factors contributing to uncertainty	6.6 (6.3-6.8)	6.4 (6.2-6.6)	6.2 (5.9-6.5) *
PSA if GP advised	63.2%	65.2%	49.6% *

*Post-test differences between groups significant

Post-test comparisons between groups

No significant differences between groups:

- Worry about prostate cancer
- Decisional uncertainty (Degner and Sloan 1992)
- Perceived ability to make an informed choice about PSA screening
- Interest in PSA screening in the next 12 months (non-GP recommended)
- Scenario 1 (disclosed opportunistic screening)
- Scenario 2 (undisclosed opportunistic screening)

Evaluation of information

	Leaflet	Video	EB Booklet
Men over 50 should be tested	63.2%	44.6%	48.1%
Men over 50 should not be tested	2.2%	1.4%	1.5%
Neither	22.1%	42.8%	41.2%
			<i>P=0.007</i>
Information easy to understand	85.3%	87.7%	90.1%
			<i>P=0.31</i>
Information about the disadvantages 'about right'	67.6%	64.9%	76.3%
			<i>P=0.008</i>
Information about the benefits 'about right'	80.1%	73.9%	81.7%
			<i>P=0.70</i>

Enhancing GP capacity to promote informed choice about PSA

To improve outcomes such as:

- GP knowledge of evidence
- GP understanding of the medicolegal dimensions of ‘informed choice’
- use of EB resources with male patients
- uptake of counselling techniques to engage men in a process of ‘informed choice’

Study variables included

- Provider conflict (decision-making process)
- Risk preferences (risk-seeking / risk-averse)
- Uncertainty scale
 - Reluctance to disclose uncertainty
 - Anxiety due to state of uncertainty
 - Implications of uncertainty for outcomes

A cluster RCT of 'peer coaching'

- 277 GPs in NSW recruited through private pathology laboratory
- Three month education programme:
 - Written education materials
 - Audio-visual resources
 - Three 'peer coaching' sessions delivered by one of five GP academic detailers
 - Theoretical approach:
 - 'motivational interviewing' (*Miller and Rollnick 2002*)
 - 'transtheoretical stages of Change model stage of change' (*Prochaska and DiClemente 1986*)

Baseline data

Self-reported counselling techniques re PSA	% 'rarely'
Advising men to take the time to think about benefits and risks	50.0%
Give men written information	80.0%

Baseline data

Self-reported confidence	%
Not confident in eliciting men's concerns	35%
Not confident in ensuring men understanding benefits and risks	20%

Baseline data

<u>Self-reported disclosure of facts about PSA</u>	<u>% 'always' disclosed</u>
Chances of having a prostate cancer if PSA test is positive	17.8%
Chances of having prostate cancer if PSA test is negative	15.5%
Treatment options for prostate cancer	15.5%
Age-specific risk of developing and dying from prostate cancer	13.4%
Scientific controversies about PSA testing	13.0%

GP perspectives (pre-test)

Patient Passive	21%
Shared	40%
Patient Active	38%

Multivariate predictors of preferring patient 'passive role'	AOR (95%CI)
Provider conflict (decision process)	0.91 (0.85-0.96)
Knowledge score	0.98 (0.96-1.00)
Reluctance to disclose uncertainty subscore	1.13 (1.04-1.22)
GP sex (male)	2.66 (1.07-6.59)
Education in EBM	2.46 (1.17-5.22)

Post-test data

GP counselling techniques re PSA (self-report)	% 'always'	
	Intervention	Control
Advising men to take the time to think about benefits and risks	52.6%	5.0%
Give men written information	44.4%	0.7%
Ask men for their opinion about PSA	27.4%	5.0%
Tell men it is their decision	59.3%	21.6%

Post-test data

GP self-reported confidence	Intervention	Control
Communicating benefits	87%	72%*
Communicating harms	94%	65%*
Eliciting men's opinions	88%	50%*
Ensuring men understand benefits & risks	93%	66%*

*p<0.001

Post-test data

Self-reported disclosure of facts about PSA % 'always' disclosed

	Intervention	Control
Chances of having prostate cancer if PSA test is positive	45.2%	19.3%*
Chances of having prostate cancer if PSA test is negative	43.7%	20.7%*
Treatment options for prostate cancer	41.5%	20.7%*
Age-specific risk of developing and dying from prostate cancer	37.0%	15.7%*
Scientific controversies about PSA testing	47.4%	20.0%*

*p<0.001

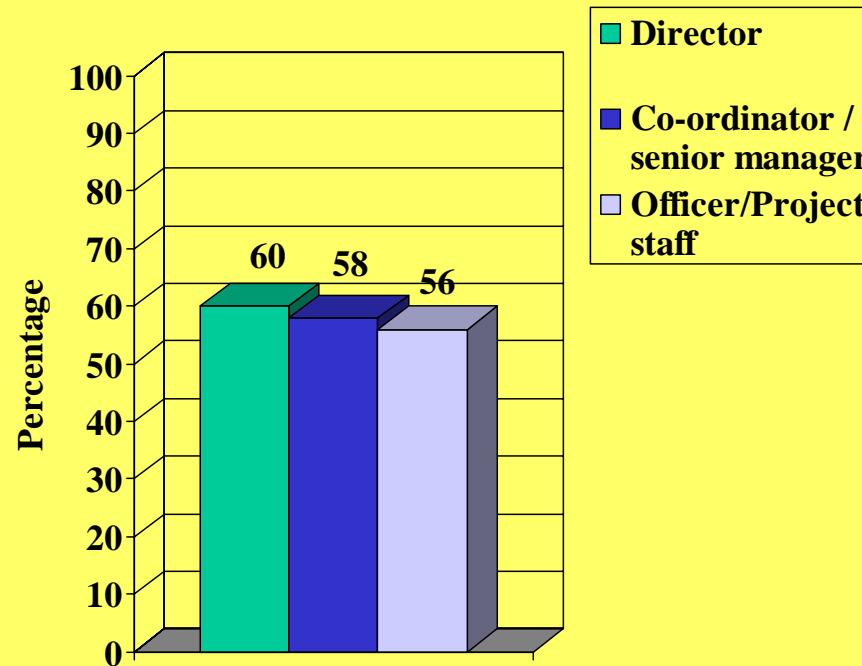
Promoting capacity among professionals

Surveys of EBM terms and tools

'I understand and could explain to others' / 'very confident'

	GPs n=60	Physicians n=244	Radiation oncologists n=191	PH staff n=76
	%	%	%	%
RCT	38	76	NA	26
RR	23	48	65	17
AR	28	45	65	13
NNT	15	40	58	12
95% CI	12	44	64	21
P value	18	55	NA	22

Need to increase capacity in EBP by occupation category



$\chi^2=0.08, 2df, p=0.96$

Where to from here?

- *Conceptual and empirical research agenda*
 - CONTENT less of an issue now for risk communication research than the PROCESS and, therefore, the DYNAMIC between consumer and provider
 - Priority: Interventional research of risk communication process and standards
- *Partnerships between policy – practice - research*
- *Our own ‘values clarification’ exercise: individualism v social goals ??*