Shared decision making as the basic approach to patient centred care: opportunities and limitations

SYDNEY MEDICAL SCHOOL

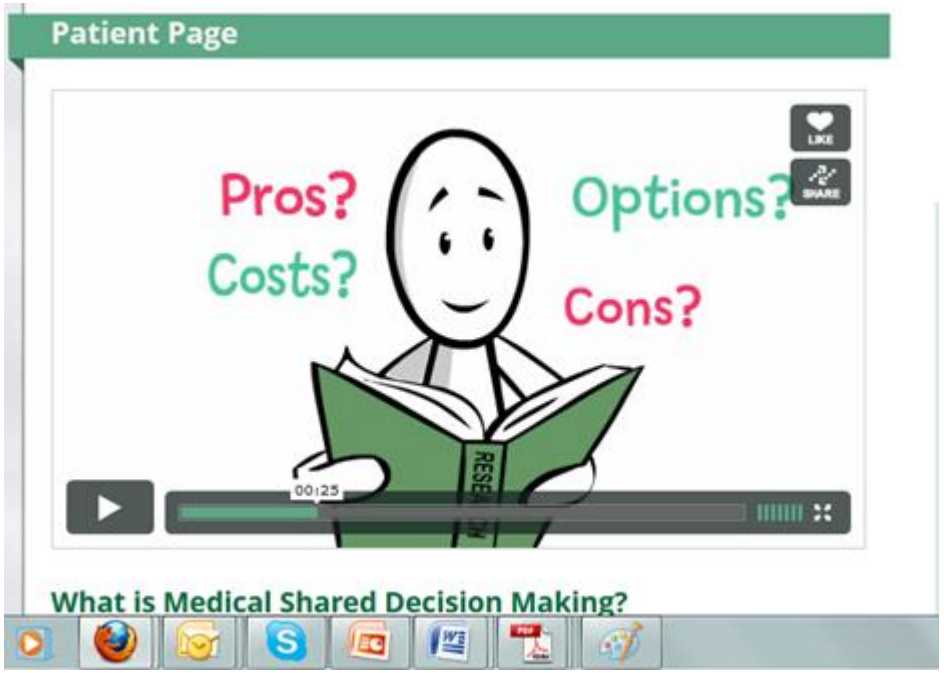
Alexandra Barratt, Professor of Public Health, University of Sydney

THE UNIVERSITY OF SYDNEY

Shared Decision Making should be our basic approach

SDM – decision making with:

- At a minimum physician and patient being involved in decision making
- Both sharing information and preferences
- Both deliberating
- Both making a decision and agreeing on the treatment to be implemented



EBM and SDM

SDM – decision making with:

- At a minimum physician and patient being involved in decision making
- Both sharing information and preferences
- Both deliberating
- Both making a decision and agreeing on the treatment to be implemented

EBM – clinical decision making based on:

- Current best research evidence
- Clinical expertise
- Patient values and preferences

Ten steps to make SDM the norm in clinical practice

1. Recognition that health care involves choices and of patients' autonomy
2. Evidence of clinical effectiveness and cost-effectiveness
3. Favourable policy climate with supporting regulation and professional and legal standards
4. National implementation plan
5. Supportive health system with financial incentives
6. Rapid synthesis of latest evidence (2 week systematic review) and link to decision support intervention development and certification
7. Readily accessible decision support interventions
8. Clinical champions and clinician training
9. Consumer champions and consumer training
10. Metrics to monitor progress

	Germany	UK	USA	Canada
Evidence of C-E				
Favourable policy climate	✓✓✓	✓✓✓	✓✓	✓✓
National implementation plan				
Supportive health system	✓			
Rapid SR – DESI production				
Accessible DESIs	✓	✓✓	✓✓	✓
Clinical training	✓	Research only	Demonstration projects	
Consumer training	✓	Research only		
Metrics to monitor progress				

Ten steps to make SDM the norm in clinical practice

1. *Recognition that health care involves choices and of patients' autonomy*

25 October 2011 Last updated at 23:01 GMT

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Breast cancer screening under review

COMMENTS (55)

By James Gallagher
Health reporter, BBC News

The evidence for breast cancer screening in the UK is being reviewed amid controversy about the measure's effectiveness.

The NHS says screening saves lives, but other researchers have argued that it may cause more harm than good.

The national cancer director for England, Prof Mike Richards, announced in the **British Medical Journal** that he will lead a review.

He said he was taking the "current controversy very seriously".

When it comes to cancer treatment, earlier is better. Screening

Professor Mike Richards: 'Screening can diagnose cases that would never have caused trouble during a woman's lifetime'

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November 20, 2009, 7:49 AM

The Uproar Over Mammography

By UWE E. REINHARDT

TODAY'S ECONOMIST

Uwe E. Reinhardt is an economics professor at Princeton.

In a report on routine screening for breast cancer summarized on Tuesday in Annals of Internal Medicine, the United States Preventive Services Task Force recommended against routine screening mammography in women under age 50.

But in its summary the task force also takes pains to point out that

> [t]he decision to start regular, biennial screening mammography before the age of 50 years should be an individual one and take into account patient context, including the patient's values regarding specific benefits and harms. (Grade C recommendation)

Jobs and the Election: A Weekly Tracker

Updated May 24, 2012

+184,000
Forecast monthly job growth in six months before election

+197,000
Pace in previous six months

7.9%
Forecast unemployment rate for October 2012

8.1%
Most recent rate (April 2012)

History suggests that monthly job growth of 100,000 to 175,000 would lead to a close presidential election, with anything more favoring the incumbent and anything less favoring the challenger.

Forecasts by Moody's Analytics and updated weekly.

New Data on Harms of Prostate Cancer Screening

CANCER | By TARA PARKER-POPE | May 21, 2012, 5:00 PM | 330 Comments

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In a controversial finding that will affect at least 44 million American men, a government task force published its final recommendations against regular prostate cancer screening, concluding that the harms of the simple blood test far outweigh any potential benefit.

The recommendations, from the United States Preventive Services Task Force, offer the most detailed breakdown to date of the potential risks and benefits of the prostate specific antigen blood test, commonly known as the P.S.A. test. Most important, the task force found that, at best, one man in every 1,000 given the P.S.A. test may avoid death as a result of the screening, while another man for every 3,000 tested will die prematurely as a result of complications from prostate cancer treatment and dozens more will be seriously harmed.

Even so, the suggestion that men should give up annual prostate cancer screening has met with resistance, particularly from prostate cancer advocacy groups as well as some medical groups, including the American Urological Association.

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The Doctor's Remedy: Biofeedback for Stress

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New Data on Harms of Prostate Cancer Screening: What's your experience been with P.S.A. testing?

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A Richer Life by Seeing the Glass Half Full: Share your thoughts.

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Touche pas à ma prostate !

Manifeste pour un moratoire sur le dépistage du cancer de la prostate

Publié le 4 avril 2012
Publication antérieure : 7 septembre 2008

Imprimer

Lire sur grand écran

Auteur : Dominique Dupagne

Je republie cet article de 2008 à l'occasion de la mise au point de la Haute Autorité de Santé du 4 avril 2012, qui confirme l'absence d'intérêt du dépistage du cancer de la prostate, y compris chez les sujets à risque.

Ajout du 22 mai 2011 **: pour des données à jour, écoutez plutôt l'émission du 20 mai 2011 : la Tête au Carré sur France-Inter. L'USPSTFa confirmé son avis le 21 mai 2012**

Le dépistage systématique du cancer de la prostate n'est pas une bonne stratégie de santé.

Ce dépistage aboutit dans de nombreux cas à découvrir dans la prostate des cellules cancéreuses qui n'auraient jamais provoqué de cancer. La moitié des hommes de 60 ans ont des cellules cancéreuses dans leur prostate, c'est un phénomène quasi normal et c'est le cas de près de [illegible]

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Should I Continue Having Mammograms to Screen for Breast Cancer?

A decision aid for women aged 70 and older at their next screening mammogram.

AUSTRALIAN SCREENING MAMMOGRAPHY DECISION AID TRIAL

THE UNIVERSITY OF SYDNEY

Should I continue or stop having mammograms to screen for breast cancer?

Many people think mammograms are always a good thing. But there are reasons why you might choose not to have another screening mammogram if you are aged 70 or older. The following pages outline some issues you may want to consider in making your decision.

There is no right or wrong answer about whether to continue or stop having screening mammograms.

It is your decision to make.

Screening is for women with no breast symptoms.
If you have any breast symptoms, you should see your doctor.

AUSTRALIAN SCREENING MAMMOGRAPHY DECISION AID TRIAL

A decision aid for women aged 40 thinking about starting mammography screening

Should I Start Having Mammograms to Screen for Breast Cancer?

Some 40 year old women start thinking about whether they should attend mammography screening now or wait until they are 50. If you are in this situation, you might find this website helpful.

Researchers from the University of Sydney have compiled the best available evidence regarding mammography screening and created what we call a decision aid. A decision aid is intended to provide you with unbiased information so that you can make a decision after considering the evidence.

We invite you to spend approximately 30 minutes reading the decision aid and completing some questions. All of your responses remain confidential, and at no time do we ask your name or an email address.

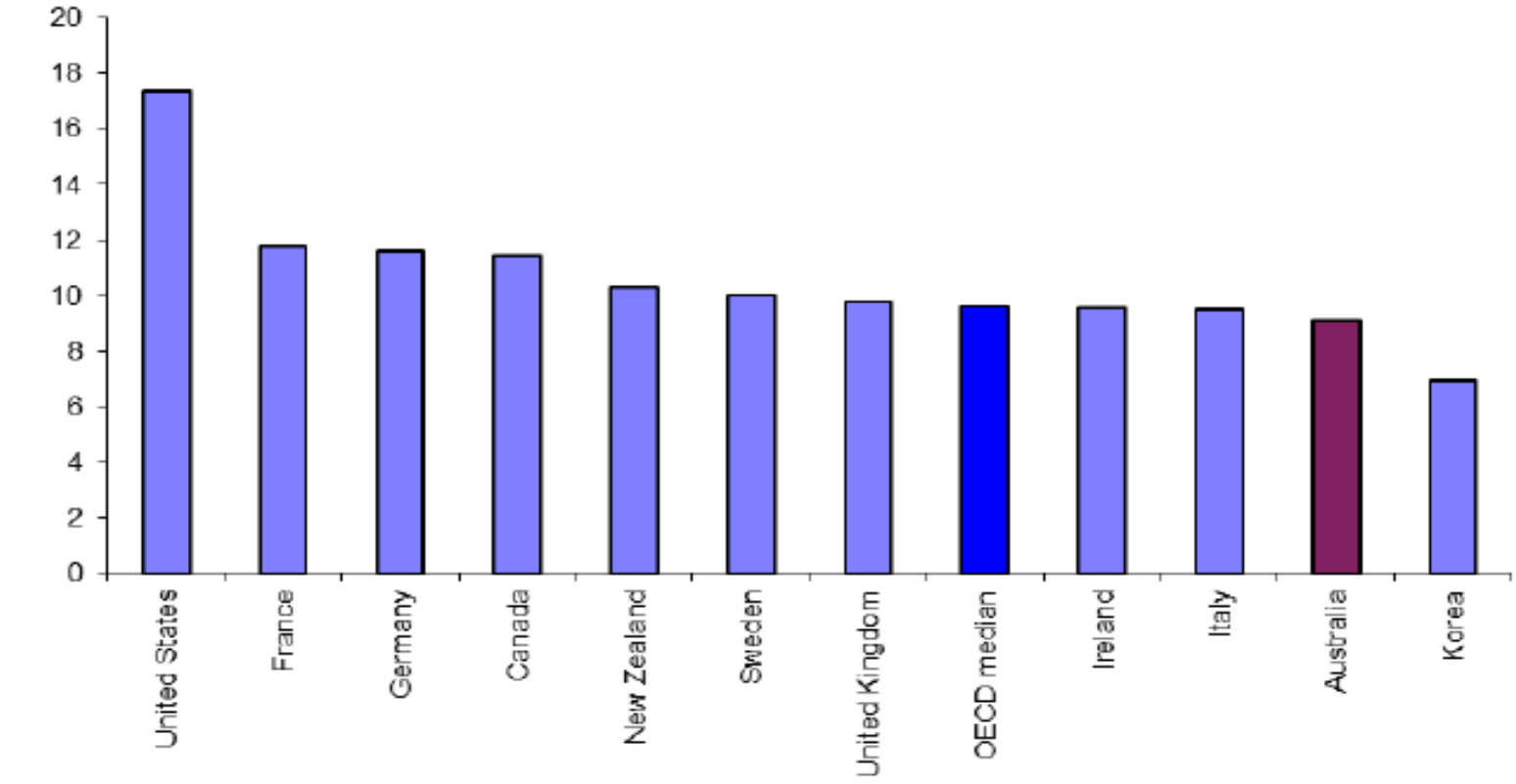
If you are interested, click 'next' to find out more.

» Next

Navigation

Ten steps to make SDM the norm in clinical practice

1. Recognition that health care involves choices and of patients' autonomy
2. *Evidence of clinical effectiveness and cost-effectiveness*



(a) See definition of 'OECD financial year' in Box 5.1.

Source: Table 5.1.

Figure 5.1: Health expenditure as a proportion of GDP, selected OECD countries, 2009[(a)]

Source: Australian Institute of Health and Welfare 2011. Health expenditure Australia 2009-10. Health and welfare expenditure series no. 46. Cat. no. HWE 55. Canberra: AIHW.

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7. *Readily accessible decision support interventions*

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What is EBM?

Put simply, evidence-based medicine (EBM) means applying current best evidence to clinical decision making.

In practice, this means integrating that evidence with individual clinical expertise and the needs and values of patients.

Good health practitioners use individual clinical expertise, their dialogue with their patients, and the best available external evidence, and none of these elements alone is enough.

Without clinical expertise and the knowledge of the views of the patient, we risk becoming slaves to the evidence — because even excellent external evidence may be inapplicable to an individual patient.

Without current best evidence, practice risks becoming rapidly out of date, denying patients access to new treatments and management techniques.

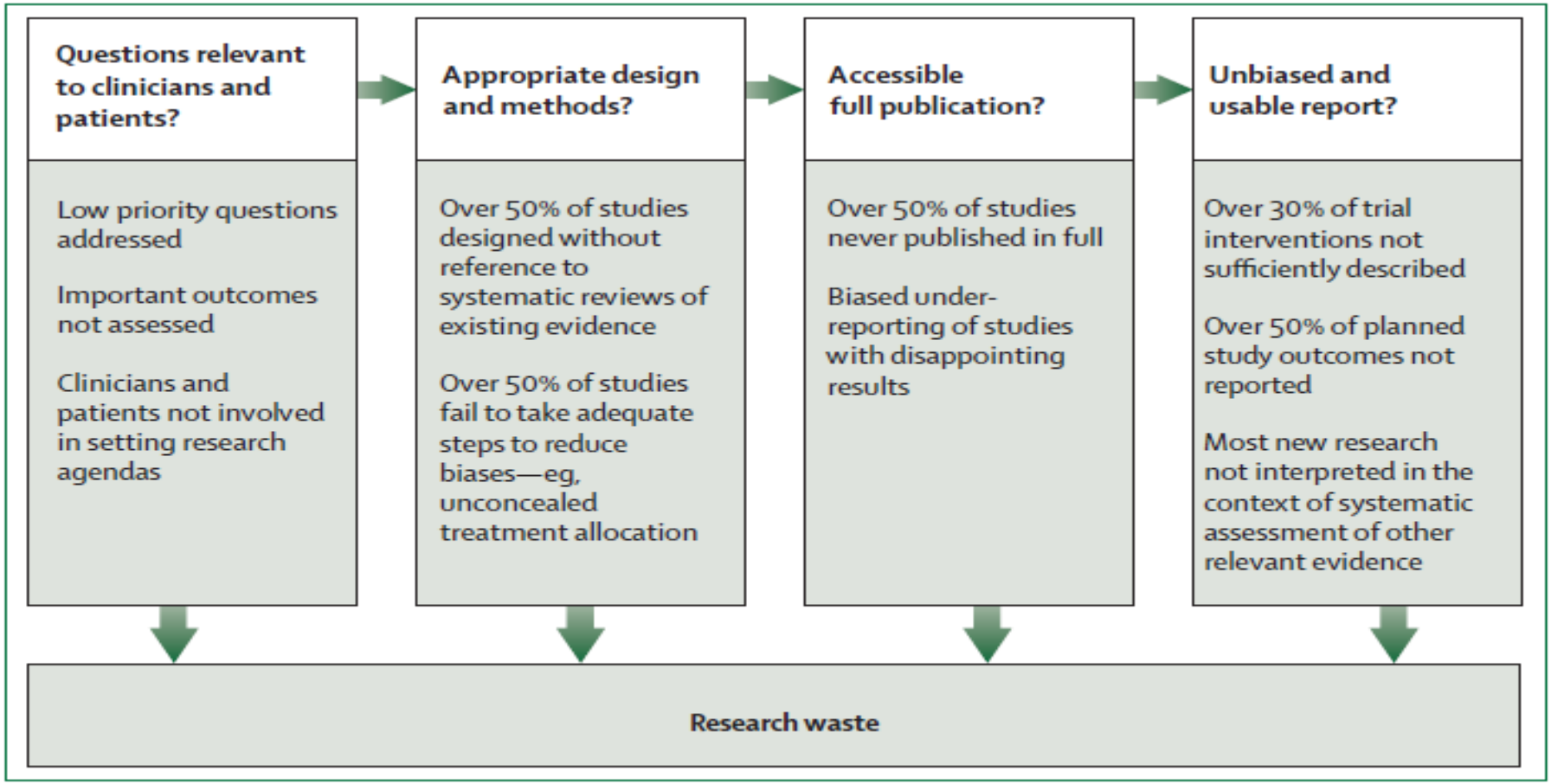

Figure: **Stages of waste in the production and reporting of research evidence relevant to clinicians and patients**

Chalmers I, Glasziou P. Avoidable waste in the production and reporting of research evidence. Lancet 2009;374:86-89.

Ten steps to make SDM the norm in clinical practice

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8. Clinical champions and clinician training
9. *Consumer champions and consumer training*

Three simple questions to improve healthcare consultations

Research team

HL Shepherd[1,8] , A Barratt[1] , LJ Trevena[1] , PN Butow[2], MHN Tattersall[3], RM Epstein[4], CB Del Mar[5], K McGeechan[1] , V Entwistle[6], K Carey[7]

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Acknowledgements

Three simple questions to improve health care consultations

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Heather Shepherd
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Ron Epstein
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Karen Carey

The Actors
Jennie Dibley
Jan Langford Penny
Sandy Velini
Syann Williams

The Doctors & their clinic staff

This study was funded through an investigator initiated grant from the Foundation of Informed Medical Decision Making and through supporting funds from *Beyond Blue: the National Depression Initiative.*

STUDY AIM

- To test the effect of a brief, consumer-led intervention consisting of three questions on
  - Information provided to patients about their treatment options
  - Patient involvement in the consultation (shared decision making)


www.abc.net.au/austory/specials/heartofmatter/default.htm
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The Heart Of The Matter
09/11/2009
Karen Carey is a Perth woman who grew up with a relatively simple heart problem.
But when it came time for an operation to install an artificial heart valve, everything that could go wrong did.
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Intervention: Ask 3 questions

The Intervention: Treatment Decision Questions

A set of questions which represent the minimum dataset required to make an informed choice under conditions of uncertainty:

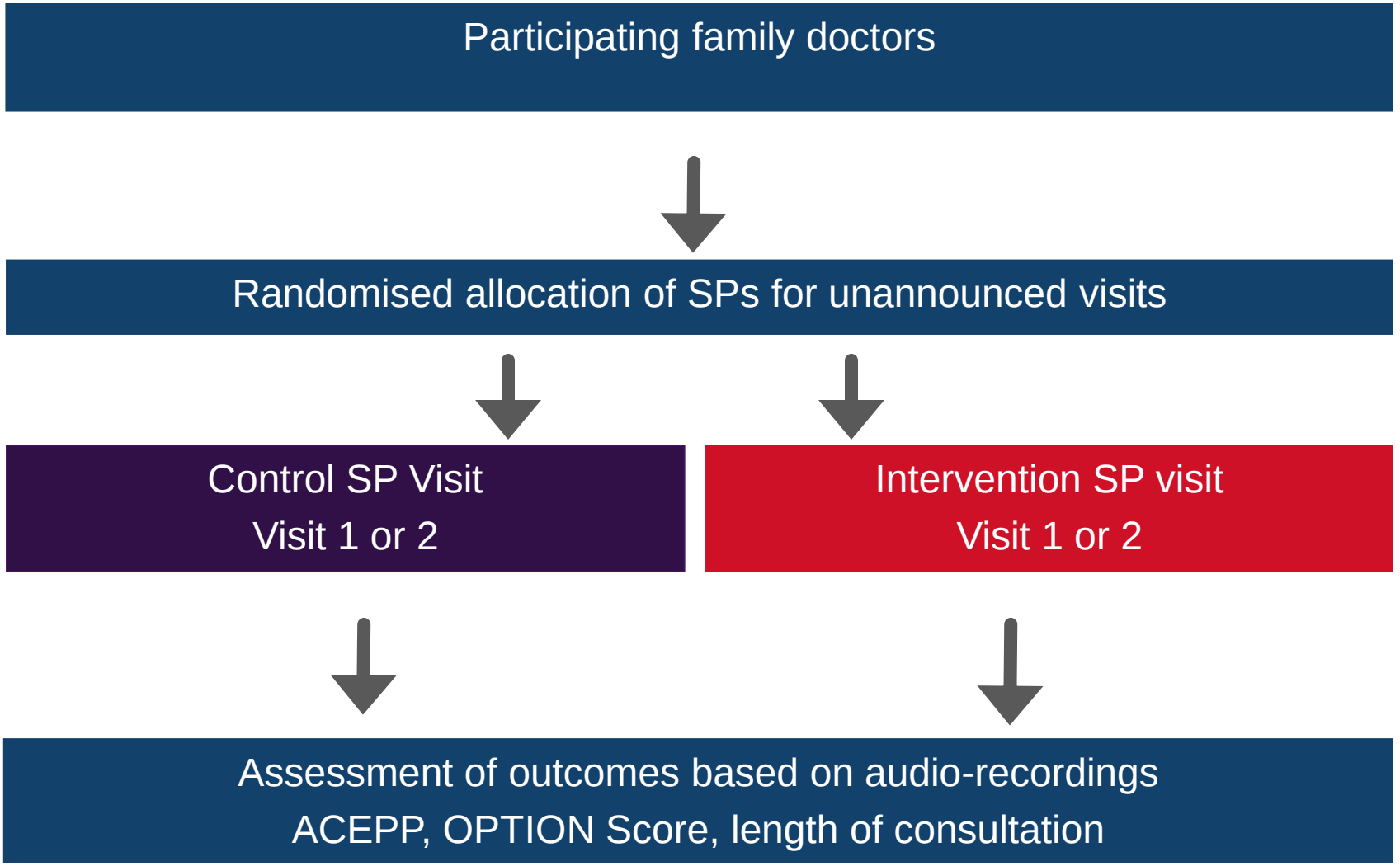
1. What are my options?

2. What are the possible benefits and harms of those options?

3. How likely are the benefits and harms of each option to occur?

(and, if not offered by physician) What will happen if I do nothing?

Study Design



Outcome measures

- ACEPP, Assessing Communication about Evidence and Patient Preferences
  - Detailed coding scheme applied to transcripts of audio-recorded consultations
  - Four subscales assessing information/evidence about treatment options, expression of patient preferences and information about patient circumstances
  - Assesses amount and quality of information about treatment options and outcomes, eg distinguishes between qualitative and quantitative information about treatment effects and nature of any quantitative information such as RR, RRR, ARR, event rates.
  - Each scale generates a score out of 10, giving a total score range 0-40

- OPTION (Elwyn 2003, 2005)
  - a 12-item, validated coding system of physician behaviors that facilitate patient involvement.
  - Items are rated on a 0-4 scale, scores are transformed to give a total out of 100

- Additional outcomes
  - Length of consultation

Analysis

Consultations were audio-recorded and transcribed verbatim

- Two coders coded all audio-recordings, one coder coded using OPTION and the other coded using ACEPP.
- These coders were kept blind to study hypothesis and intervention
- A third coder dual coded 36% of the transcripts (13) using the ACEPP scale to assess inter-rater agreement; intra-class correlation co-efficient was 0.8 (0.48-0.94).

Paired *t* tests used to compare intervention and control consultations

- ACEPP score
- OPTION score
- Consultation duration

ACEPP scores

	Mean scores		Paired Samples Test – Paired Differences		
	Intervention	Control	Mean	95% CI (Lower-Upper)	p
ACEPP score	21.4	16.6	4.7	2.3-7.0	<0.001
OPTION score	35.6	25	11.6	5.5-17.7	0.001
Consultation time	26	26	0		0.83

Shepherd HL, Barratt A, Trevena LJ et al. Three questions that patients can ask to improve the quality of information physicians give about treatment options: A cross-over trial. Patient Education and Counseling 2011;84:379-385.

CONCLUSIONS

A brief consumer-led intervention consisting of three questions:

- Increased the amount and quality of information given about treatment options and possible outcomes
- Improved communication behaviours that encourage patient involvement in decision-making
- Did not increase consultation time in family practice.

Implications for practice

- These 3 simple questions appear to have potentially important effects on decision quality in clinical consultations.
- However, this study trained actors to serve as SPs and ask the questions.
- Next steps involve testing how ordinary patients would learn and ask the questions in routine healthcare situations.

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Home > Resources Ask Three Questions

Search Go

Resources Ask Three Questions

As part of the work of the MAGIC programme and the Ask 3 Questions campaign new resources have been developed to help.

Here are a selection of related resources and links to tools for both the public and medical staff.

New resources will be available here as they are approved.

Click here for a printable booklet about the Ask 3 Questions campaign.

Click here for Ask 3 Questions posters.

Share:

Find Out More

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

Ask 3 Questions

Sometimes there will be choices to make about your healthcare. If you are asked to make a choice, make sure you get the answers to these 3 questions:

what are my **options?**

what are the possible **benefits and risks** of those options?

how **likely** are the benefits and risks of each option to occur?

We want to know what's important to you

www.ask3questions.co.uk

Australian Cancer Trials Online

- Australian consumers identified a need for a national consumer friendly website about cancer clinical trials
- In Australia, most trials are registered with ANZCTR & ClinicalTrials.gov
- These trial registries are a useful source of data about cancer trials for the **Australian Cancer Trials website** which was developed in 2008 by The University of Sydney, ANZCTR, Cancer Voices NSW & Cancer Australia
- www.australiancancertrials.gov.au

www.australiancancertrials.gov.au

Australian Cancer trials online

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Australian Cancer Trials

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Quick Links

- About Cancer
- Advanced search
- Glossary of terms
- Other useful websites

Highlights

- What is a clinical trial?
- Question prompt lists
- Tell us what you think

Project partners

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Welcome to Australian Cancer Trials

This is a free information service that displays the latest **clinical trials in cancer care, including trials that are currently recruiting new participants**. We believe that this information should be freely available to all, and written in a way that is easy to understand.

This website is for anyone affected by cancer ... whether you, your friend or family member. Cancer specialists too will find this an invaluable resource to use with their patients. Australian Cancer Trials aims to assist you, with your cancer specialist, make decisions about your cancer care options, including clinical trials.

The website is updated each day with new information from the Australian New Zealand Clinical Trials Registry and ClinicalTrials.gov from the United States.

Search Clinical Trials

View details of cancer clinical trials in Australia, including those that are currently recruiting participants. You can conduct a simple or advanced search, and find out if you are eligible to join a trial.

Clinical Trials Search Tips

- Simple Search
  To search by keyword (name any word contained in the trial information, such as a particular drug or treatment) or by cancer type (name the place where the cancer started in the body).
- Advanced Search

ttp://www.australiancancertrials.gov.au/

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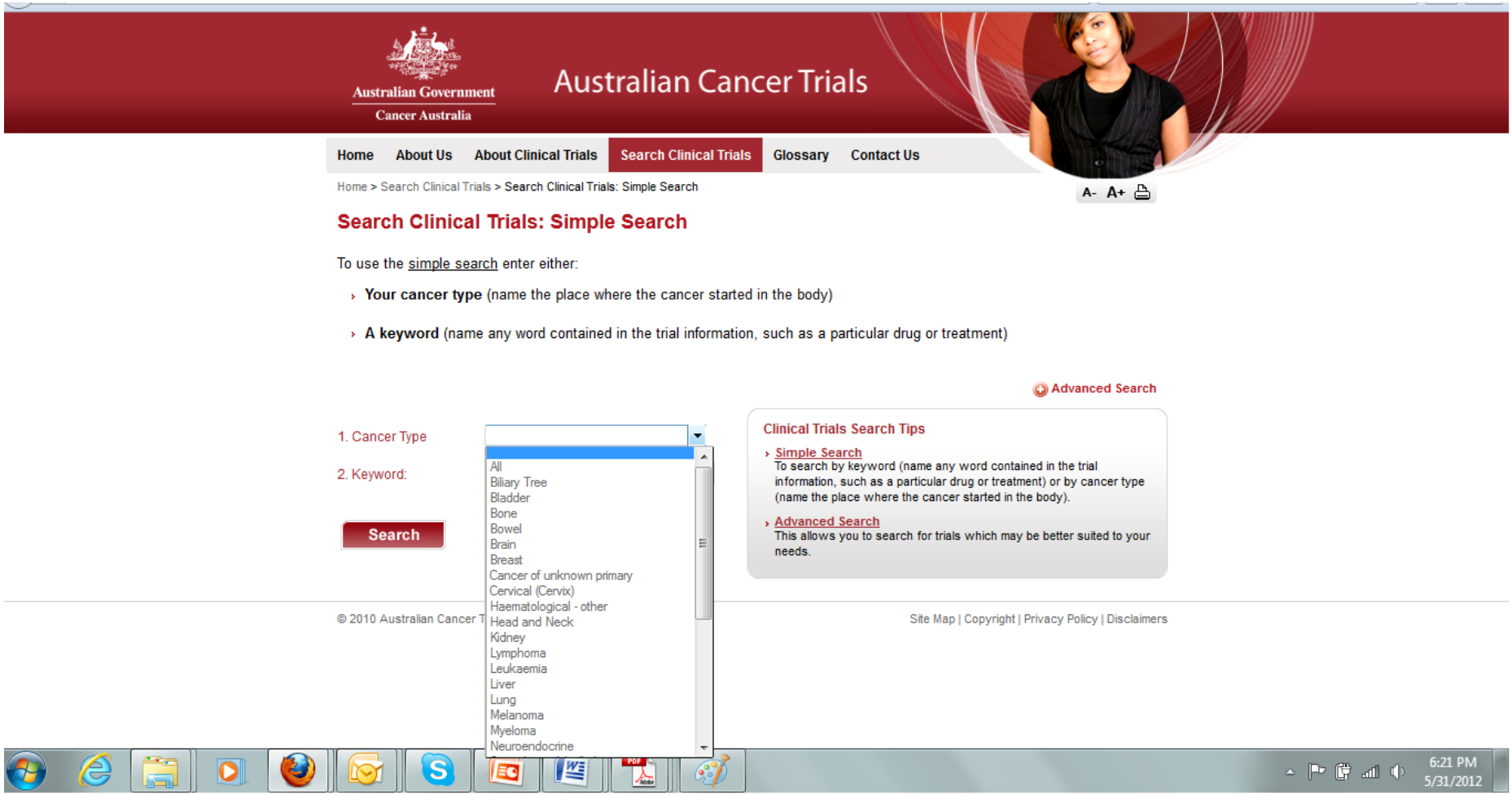
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To use the simple search enter either:
Your cancer type (name the place where the cancer started in the body)
A keyword (name any word contained in the trial information, such as a particular drug or treatment)
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1. Cancer Type
2. Keyword:
Search
All
Biliary Tree
Bladder
Bone
Bowel
Brain
Breast
Cancer of unknown primary
Cervical (Cervix)
Haematological - other
Head and Neck
Kidney
Lymphoma
Leukaemia
Liver
Lung
Melanoma
Myeloma
Neuroendocrine
Clinical Trials Search Tips
Simple Search
To search by keyword (name any word contained in the trial information, such as a particular drug or treatment) or by cancer type (name the place where the cancer started in the body).
Advanced Search
This allows you to search for trials which may be better suited to your needs.
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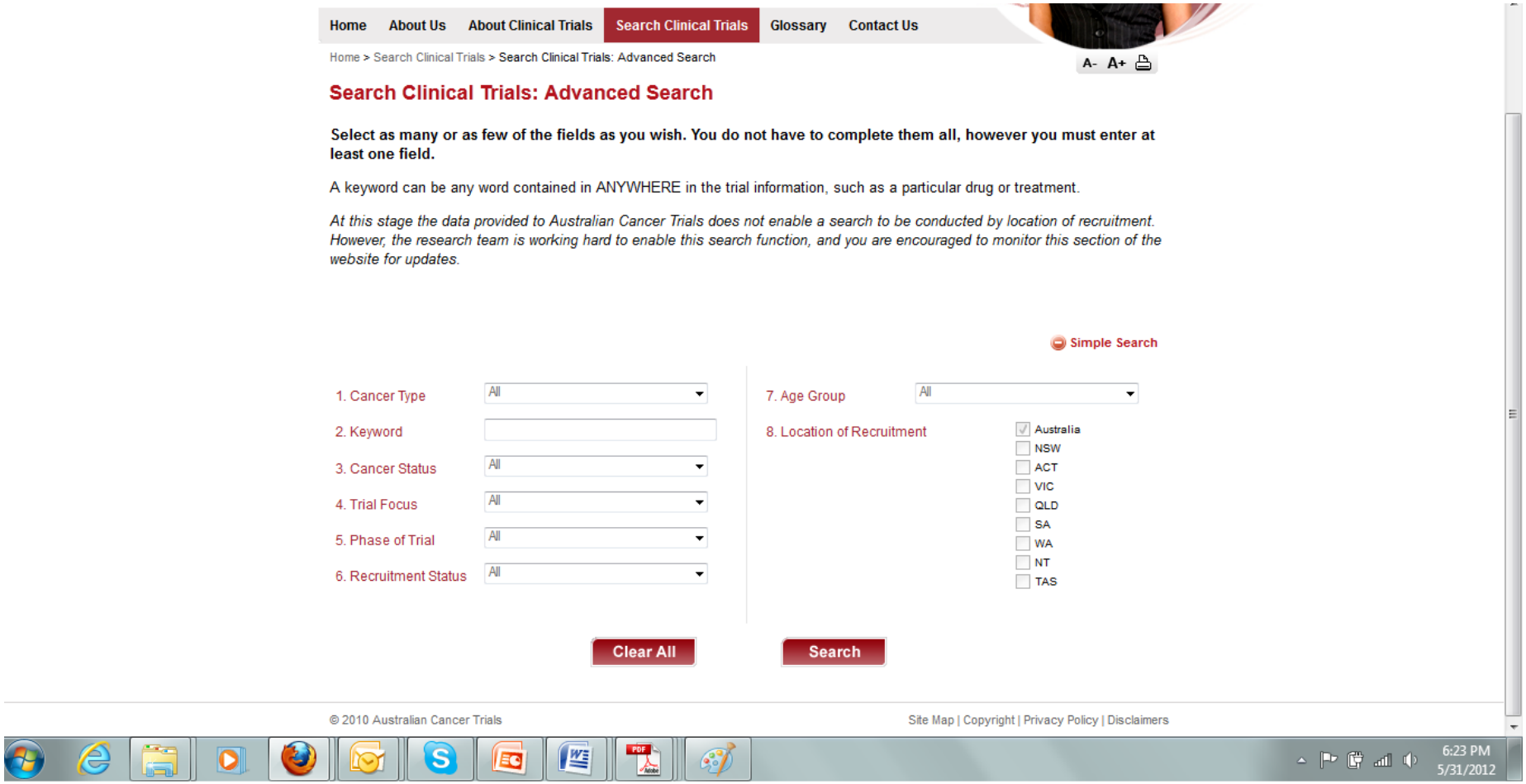
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Search Clinical Trials: Advanced Search
Select as many or as few of the fields as you wish. You do not have to complete them all, however you must enter at least one field.
A keyword can be any word contained in ANYWHERE in the trial information, such as a particular drug or treatment.
At this stage the data provided to Australian Cancer Trials does not enable a search to be conducted by location of recruitment. However, the research team is working hard to enable this search function, and you are encouraged to monitor this section of the website for updates.
Simple Search
1. Cancer Type
All
2. Keyword
3. Cancer Status
All
4. Trial Focus
All
5. Phase of Trial
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- Brain
- Breast
- Cancer of unknown primary
- Cervical (Cervix)
- Children's cancers
- Haematological - other
- Head and Neck
- Kidney
- Lymphoma
- Leukaemia
- Liver
- Lung
- Melanoma
- Myeloma
- Neuroendocrine
- Oesophageal (gullet)

Clinical Trial Search Results

Trials are presented in the order of **the most recent first .... not the most important.** So it is important that you check **all** the results of your search carefully.

The results shown below come from two sources, the Australian New Zealand Clinical Trials Registry (ANZCTR) and the US registry, clinicaltrials.gov. Results from the ANZCTR are displayed first and are shown in red. Results from ClinicalTrials.gov are shown in purple. Trials that are closed to recruitment are shown at the end of the list.

Your search has generated 23 results

Search Results

Page: 1 | 2 | 3

1. Pilot study of Selective Internal Radiation Therapy (SIRT) with yttrium-90 resin microspheres (SIR-Spheres microspheres) in patients with Renal cell carcinoma (STX0110). | RESIRT
   20/08/2010 | Open to recruitment
2. A phase 2 trial of EVERolimus alternating with SUNitinib as first line therapy for advanced renal cell carcinoma | EVERSUN
   30/07/2009 | Open to recruitment
3. A study of pazopanib versus sunitinib in the treatment of subjects with locally advanced and/or metastatic renal cell carcinoma | COMPARZ
   01/06/2009 | Open to recruitment
4. A phase III study comparing Sorafenib with placebo in patients who have had kidney

Clinical Trial

Back to Search Results

What questions do I need to ask about this clinical trial?

Public Title

A study of pazopanib versus sunitinib in the treatment of subjects with locally advanced and/or metastatic renal cell carcinoma | COMPARZ

Recruitment Status

Open to recruitment

Focus of Trial

Treatment: Targeted and biological therapies

Phase of Trial

Phase 3

Cancer Stage

Locally Advanced or Locally Recurrent

Trial Summary

The purpose of this study is to test the safety of pazopanib and how well it works in comparison to Sunitinib in subjects with advanced Renal Cell Carcinoma (RCC) who have received no prior systemic therapy for advanced or metastatic RCC. Pazopanib will be compared with sunitinib, which is used to treat renal cell cancer. Sunitinib is also called Sutent.

Description of the Study

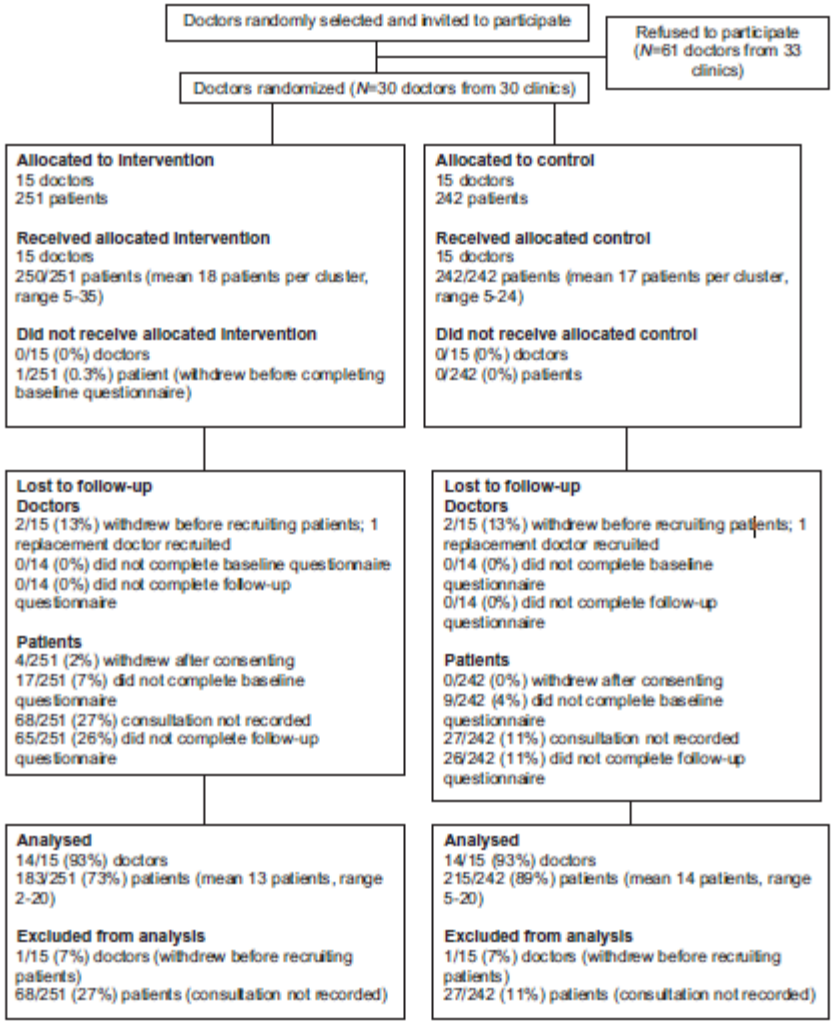

Figure 1. CONSORT flow diagram.

Outcomes

- Proportion of patients with whom the possibility of participation in any clinical trial was discussed
- Assessed by coding transcripts from audio-recordings of medical oncologist & patient consultations
- Outcome assessors blind to intervention status of transcripts
- 2nd coding of a proportion of transcripts to check inter-rater reliability
- Secondary outcomes included proportion invited to join a trial, proportion who entered a trial, nature and complexity of information given about trials, consultation duration, website acceptability to consumers.

Dear RF, Barratt AL, Askie LM et al. Impact of a cancer clinical trials website on discussions about trial participation: a cluster randomized trial. Annals of Oncology January 18 2012: doi:10.1093/annonc/mdr585

Table 3. Primary outcome from audio recordings: proportion of patients with whom the possibility of participation in a clinical trial was discussed

	Intervention group	Control group	Adjusted[a]	
			Risk difference (95% CI)	*P* value
Number of patients analyzed	183/251 (73%)	215/242 (89%)		
Number of patients with whom the possibility of participation in a clinical trial was discussed	84/183 (46%)	72/215 (34%)	10% (−1% to 22%)	0.08

Data are *N* (*N*%) or mean (SD), unless otherwise stated.
[a]Adjusted for state and urban/rural location.
CI, confidence interval.

Table 4. Secondary outcomes from audio recordings and patient follow-up questionnaires

	Intervention group	Control group	Adjusted[a]	
			Difference (95% CI)	*P* value
Secondary outcomes from audio recordings				
Patients analyzed	183/251 (73%)	215/242 (89%)		
Patients invited to join a clinical trial	3/183 (2%)	10/215 (5%)	2.86 (0.58 to 13.99)[b]	0.20[b]
Length of consultation, minutes (mean)	29	29	−1.8 (−11 to 7)	0.69
Consultations where a clinical trial was discussed	84/183 (46%)	72/215 (34%)		
Number of issues about clinical trials discussed (mean score out of 18)	5.3 (4.1)	4.9 (3.8)	0.05 (−1.7 to 1.8)	0.96
Patient (rather than physician) raised the issue of a clinical trial	11/84 (13%)	10/72 (14%)	1% (−5% to 7%)	0.81
Consultations that included extended (more complex) discussions	13/84 (16%)	9/72 (13%)	5% (−3% to 13%)	0.23
Secondary outcomes from patient follow-up questionnaires				
Patients with follow-up questionnaires and audio recordings	146/183 (80%)	194/215 (90%)		
Patients who consented to a clinical trial	14/146 (10%)	20/194 (10%)	1.20 (0.54 to 2.69)[b]	0.65
Number of patients with valid seven-item knowledge scale	146/146 (100%)	194/194 (100%)		
Seven-item knowledge scale (mean score out of 7)	3.0 (1.8)	3.3 (1.9)	−0.4 (−0.03 to −0.75)	0.03
Number of patients with a valid Decisional Conflict Scale[c]	69/84 (82%)	71/72 (99%)		
Decisional conflict score (mean score out of 100)	42 (12.4)	43 (13.0)	−0.6 (−4.7 to 5.9)	0.83

Data are *N* (*N*%) or mean (SD), unless otherwise stated.
[a]Adjusted for state and urban/rural location.
[b]Odds ratio reported as logistic model fitted. Binomial regression model failed to converge.
[c]Only patients who reported discussing a trial with their medical oncologist were asked to complete the Decisional Conflict Scale which began with the

Ten steps to make SDM the norm in clinical practice

1. Recognition that health care involves choices and of patients' autonomy
2. Evidence of clinical effectiveness and cost-effectiveness
3. Favourable policy climate with supporting regulation and professional and legal standards
4. National implementation plan
5. Supportive health system with financial incentives
6. Rapid synthesis of latest evidence (2 week systematic review) and link to decision support intervention development and certification
7. Readily accessible decision support interventions
8. Clinical champions and clinician training
9. Consumer champions and consumer training
10. *Metrics to monitor progress*

Conclusion

- SDM should be the basic and widely endorsed approach to clinical decision making, but must be based on current best evidence
- Will need widespread system reform and professional change for SDM to be the norm in clinical practice
- Consumers have an important role to play in implementing SDM
- Will need to be outspoken, persistant and innovative to achieve change
- Opportunities to accelerate change include
  - DESIs developed for and distributed by population screening programs
  - Need to contain health care costs
  - Opportunities to access DESIs and other evidence via the internet
  - Consumer pressure and consumer driven interventions