## Aiding Better Decisions Informed consent in prostate screening

#### Sacha Dylan

Connectos Consulting Ltd Member, National Screening Advisory Committee (NSAC)

*Aiding Better Decisions – Informed consent in prostate screening* NatiOnal Screening Advisory Committee *at* The Royal New Zealand College of General Practitioners Conference, Christchurch, 3 September 2010

## Outline

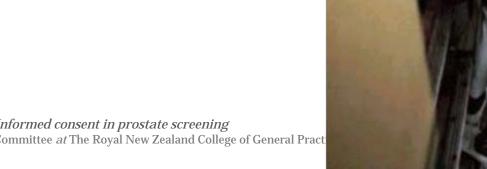
- Themes, not answers
- Improving informed consent
  - Discussion document
  - Making information understandable
  - Outlining the full screening pathway
- Prostate cancer decision aids
  - Describing natural course without screening
  - Reporting both survival and death rates
  - Reflecting cultural considerations, personal values and varying health literacy

#### **Informed Consent discussion document**

- Key themes from the literature
- Relevant decisions by the Health and Disability Commissioner
  - Consumer-oriented medico-legal framework
  - Practitioners also bound by duties of care, professional compliance
  - Clause 3 allows flexibility, "reasonable actions"
- Gaps in our knowledge
  - Consumer perspectives and needs
  - Local cultural factors

## **Discussion document**

- There's always a way
- Practical implications in the New Zealand context
  - Trustworthy and understandable information, communication options
  - Resourcing contact time
  - Incentivising consent alongside coverage
  - Seeing consent as an ongoing process, not an event



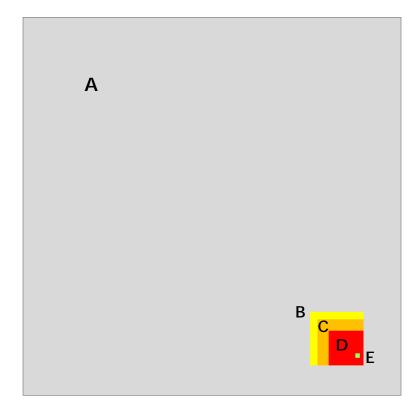


#### Making information understandable

- HDC Code right 5 Effective communication
  - In a form, language and manner that enables the consumer to understand the information provided.
  - In an environment that enables both consumer and provider to communicate "openly, honestly and effectively".
- HDC Code right 6 Fully informed
  - Ensure consumer has adequate information to make an informed choice.
  - Consumer has a right "to be fully informed".
- How do we deliver on that?
- Especially risks and benefits

#### Chances of harms/benefits 9 years after PSA screening

from ERSPC trial 2009, screened 1.7 times over 9 years



A. Asymptomatic population – 1410 men

- B. Positive PSA test 228 men
- C. Biopsy 193 men
- D. Cancer diagnosed 80 men
- E. Lives saved 1 man

Sacha Dylan, Connectos Consulting Ltd, 2010 adapted from Jim Vause presentation to NZRCGP conference 2009

*Aiding Better Decisions – Informed consent in prostate screening* NatiOnal Screening Advisory Committee *at* The Royal New Zealand College of General Practitioners Conference, Christchurch, 3 September 2010

## **Outlining the full screening pathway**

- Screening test  $\rightarrow$  Diagnosis  $\rightarrow$  Treatment  $\rightarrow$  Follow-up
- Full implications of consent decision
  - Extra ethical considerations asymptomatic
  - Especially relevant for conditions with strong social factors

#### **Prostate cancer decision aids**

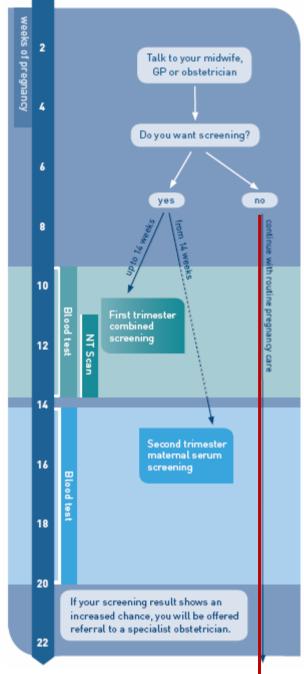
- Practical solution
- International Patient Decision Aid Standards (IPDAS) Collaboration
- Developing local criteria for informed decision tools

#### **Describing natural course without screening**

- IPDAS criteria 2.4
  - "The patient decision aid describes what happens in the natural course of a health condition if none of the health care options is chosen."

#### "Second Trimester Maternal Serum Screening - Screening for Down Syndrome and other conditions" brochure

National Screening Unit, Ministry of Health, 2009



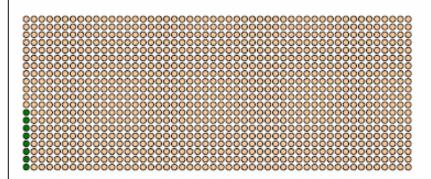
Aiding Better Decisions – Informed consent in prostate screening

NatiOnal Screening Advisory Committee *at* The Royal New Zealand College of General Practitioners Conference, Christchurch, 3 September 2010

#### **Reporting both survival and death rates**

- IPDAS criteria 3.13
  - "The patient decision aid presents probabilities using both positive and negative frames (e.g. showing both survival and death rates)."
- How risks and benefits are framed
- Paling charts

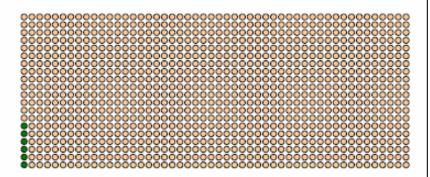
How many women aged 70 who stop having screening mammograms will die from breast cancer in the next 10 years?



Out of 1000 women aged 70 who stop screening mammograms, over the next 10 years:

8 women will die of breast cancer

How many women aged 70 who continue having screening mammograms every 2 years for the next 10 years will die from breast cancer?



Out of 1000 women aged 70 who continue screening mammogram every 2 years for the next 10 years:

<u>6 women</u> will die of breast cancer

Putting it into perspective for women 70 years old Out of 1000 women who continue screening mammograms, 204 will die from any cause of death (including breast cancer) over the next 10 years. Out of 1000 women who stop having screening mammograms, 206 will die from any cause of death (including breast cancer) over the next 10 years.<sup>2</sup>

6

Alexandra Barrett, University of Sydney, Australian Mammography Screening Decision Aid Trial materials presented to NZ Prostate Screening Decision Aids workshop 2009

*Aiding Better Decisions – Informed consent in prostate screening* NatiOnal Screening Advisory Committee *at* The Royal New Zealand College of General Practitioners Conference, Christchurch, 3 September 2010

# Cultural considerations, personal values, health literacy

- Personal values
  - Big impact on decisions
  - Practitioners and consumers may differ
- Diverse cultures, different practices
  - Affects whole process, not just "values"
  - Relationship-based; collective decisions; holistic models
  - Face-to-face and group communication; not brochures
- Health Literacy
  - How to ground decisions in broader health knowledge
  - Layering and phasing of information; who delivers it

