New Zealand Guidelines Group

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GUIDELINES
GROUP

National Women's Hospital, Auckland, NZ

CPG 2002: how to (better) include patient's preferences for better outcomes

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New Zealand Guidelines Group
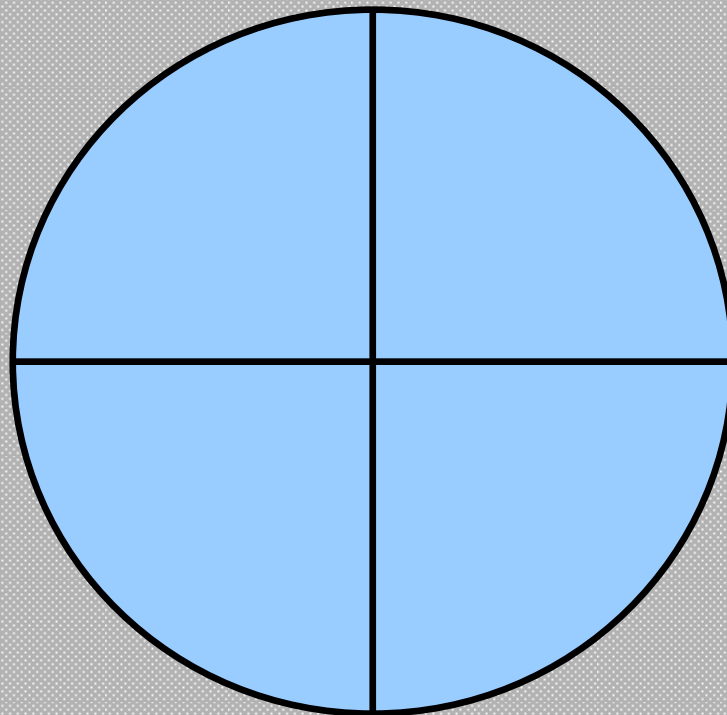
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Evidence Based Decisions

Clinician skills

Resources

Evidence

Patient preferences

Improving outcomes for patients

- The major focus of guideline developers
- The challenge is to design guidelines with endpoints that are relevant to patients, and not just health care providers.
- An implementation issue

AGREE Instrument: Item 5

- Seeking the views and preferences of patients' as one of the criteria for assessing the quality of a clinical practice guideline

AGREE Instrument: Item 5

5. The patient's views and preferences have been sought.

4	3	3	1

Strongly agree   **Strongly disagree**

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AGREE Item 5: User guide

- Information about patients' experiences and expectations of health care should inform the development of clinical guidelines
- There are various methods for ensuring that patients' perspectives inform guideline development
- There should be evidence that this process has taken place.

Better patient outcomes

Research into barriers to successful guideline implementation:

- Patients don't want the recommended treatments

OR

- Patients want treatments not recommended by guidelines

Respondents view of barriers to the use of guidelines

	Not a barrier	Midpoint	A major barrier
The patient requests different procedures than the guideline	39.8%	30.8%	29.4%

ACOG survey 2000

Another example

- Of 39 patients with Atrial Fibrillation who were recommended to take warfarin to reduce stroke risk, ….

  33 did not want warfarin treatment when presented with choice of premature death or the inconvenience and morbidity of taking warfarin for the rest of their lives…

How to get to better patient outcomes?

- Inclusion of consumer representatives on guideline development teams
- Formal surveys of patients opinions
- Focus groups to seek patient opinions on the clinical questions and implementation strategy
- Decision analytic methods
- Consumer resources
- Qualitative approach

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Inclusion of patients/consumers on guideline development teams

11 of 19 guideline development programmes:

- included patients on teams
- developed patient information to accompany guidelines

(Burgers et al 2002)

Patient representation

New Zealand Guidelines Group:

- Recommends a minimum of two consumers for each guideline development group

- Ethnic representation

- Training programmes designed for consumer participants on guideline teams

- Guidelines for consumer involvement

NZ Guidelines for Consumers on Representation on Working Parties

- Partnership and collaboration
- Democratic participation
- Equity and fairness
- Accountability
- Acceptability
- Ensure the rights of consumers are upheld
- Ensure that consumer input is valued
- Wholistic approach

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Examples of formal surveys of patients views

- Caesarean section: obstetricians report that pregnant women are asking for elective caesarean sections

- Survey data of women who had just given birth:
  - 50% of women felt that c-section was more convenient that normal birth
  - 30% felt that c-section was safer than normal birth
  - 15% were planning to ask for c-section in the future

  (Australian data)

Surveys of acceptability of recommendations

- Example: in guideline for management of heavy menstrual bleeding recommendation was for transvaginal ultrasound as initial investigation

- Survey of Maori, Pacific and European women found that 80% would find this acceptable if their doctor recommended it

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Focus groups of consumers

- Seeking the outcomes that serve patients needs
  - Not intermediate or surrogate outcomes
- Clinical question development
- Useful for assessing implementation strategies also
- Provides a supportive environment

Shortcomings in clinical research for patient outcomes?

- May not answer the questions that need answering
- Clinical trials often focus on irrelevant, intermediate or surrogate outcomes
- Using a surrogate or intermediate outcome may mislead the interpretation of the results
  - Surrogate outcomes: blood pressure, T-cell counts, lab tests, scoring systems, fertilization
  - Patient outcomes: mortality, pain, recurrence of disease, satisfaction, livebirth

Example of Focus Group

- Atrial fibrillation and warfarin decision model
  - Iterative approach
  - Explores patients need for information
  - How to best present information
  - Assess acceptability

  Thomson et al Qual Saf Health Care 2002

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Decision Analysis as a method of getting at patients views

A quantitative approach that assesses the relative value (trade offs) of different decision options:

Effectiveness (trials)

Adverse events (trials, case control)

Utility scores (patients)

Examples of decision analysis

Aiding decision making:

– Prostatic disease

– Bone marrow transplantation in Chronic Myeloid Leukemia

– Warfarin and atrial fibrillation

– Fertility treatments

– Management of heavy menstrual bleeding

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Ranking by effectiveness data

	Mean reduction in blood (%)	Ranking by effectiveness data
Levonorgestrel IUS	94	1
Progestagen (long course)	86	2
Danazol	50	3
Tranexamic acid	47	4
OC pill	43	5
NSAIDs	29	6

Medical therapy for heavy menstrual bleeding: Derivation of utility values interview process

- 20 women volunteers with heavy menstrual bleeding

- For each treatment, the treatment length, dosage and adverse events were described but no treatment name given

- Access and convenience issues such as need for specialist consultation or over the counter purchasing were described

Assigning utility values

The patient was given 2 different scenarios:

1. asked to assume the Rx had 100% efficacy but they experienced at least I adverse event

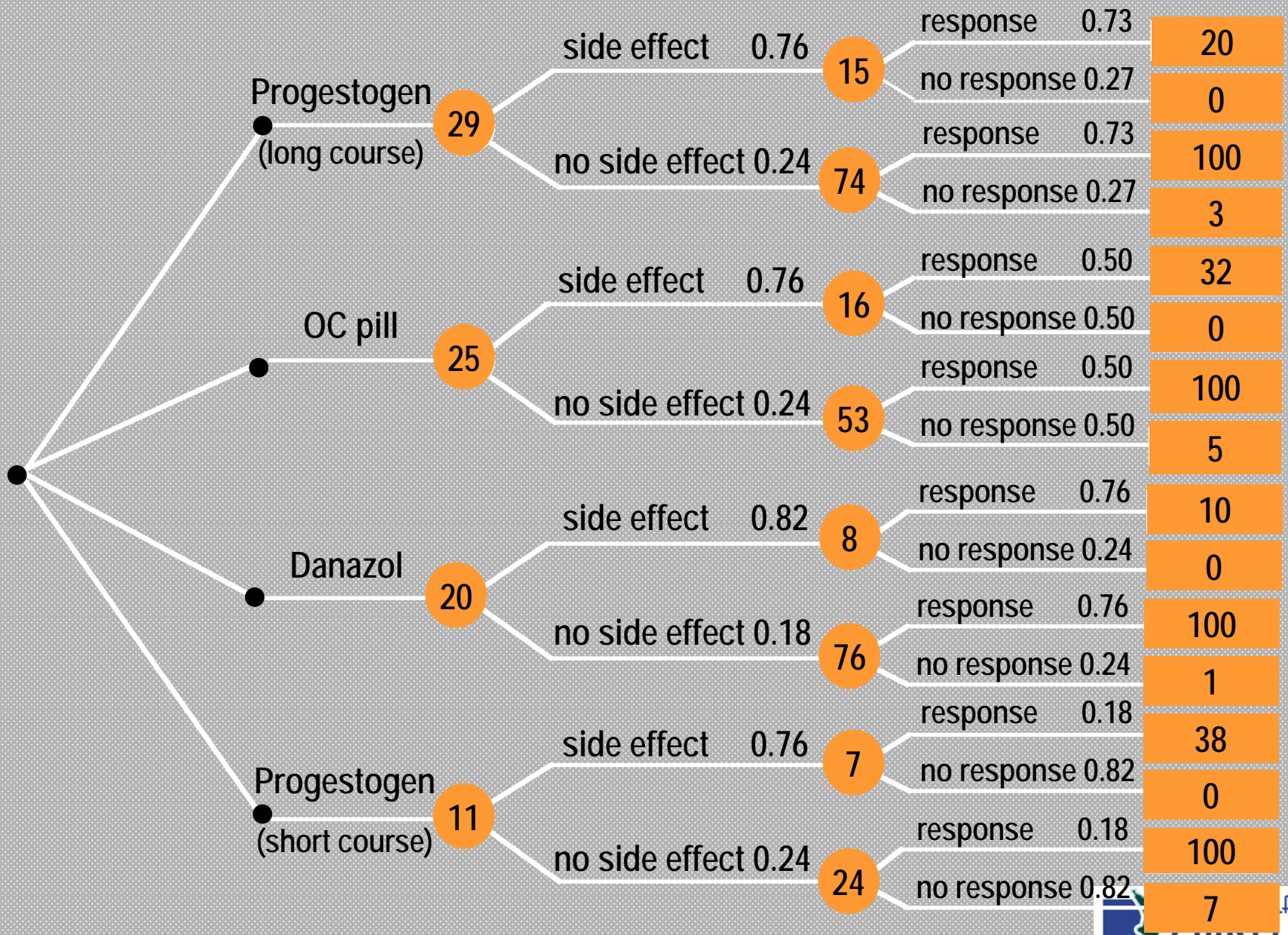2. asked to assume they experienced no benefit or no adverse events

Participant assigned her own value between 0 and 100 for these scenarios on a direct rating scale

Example: Tranexamic acid

Adverse Effects *Effectiveness* *Utility Values*
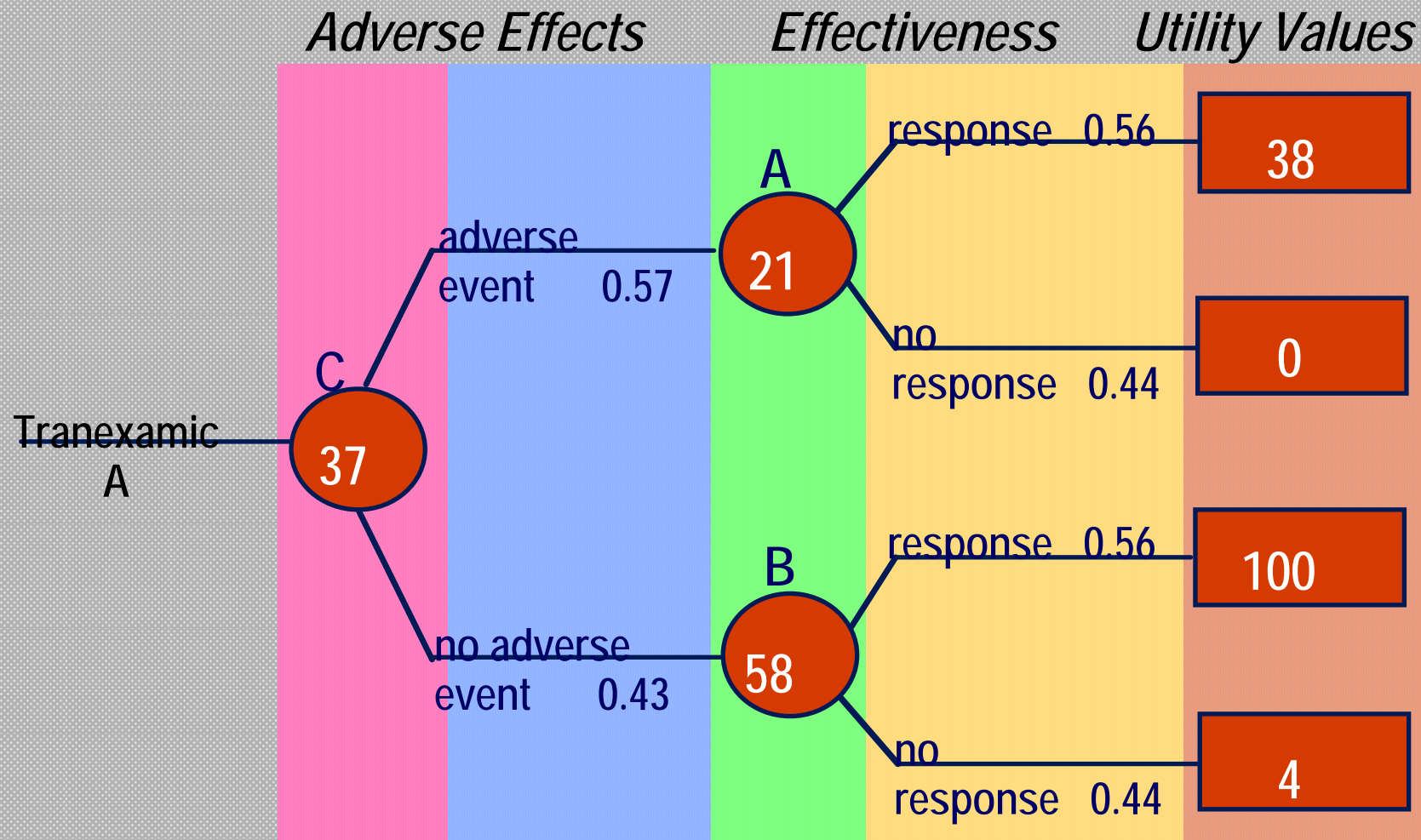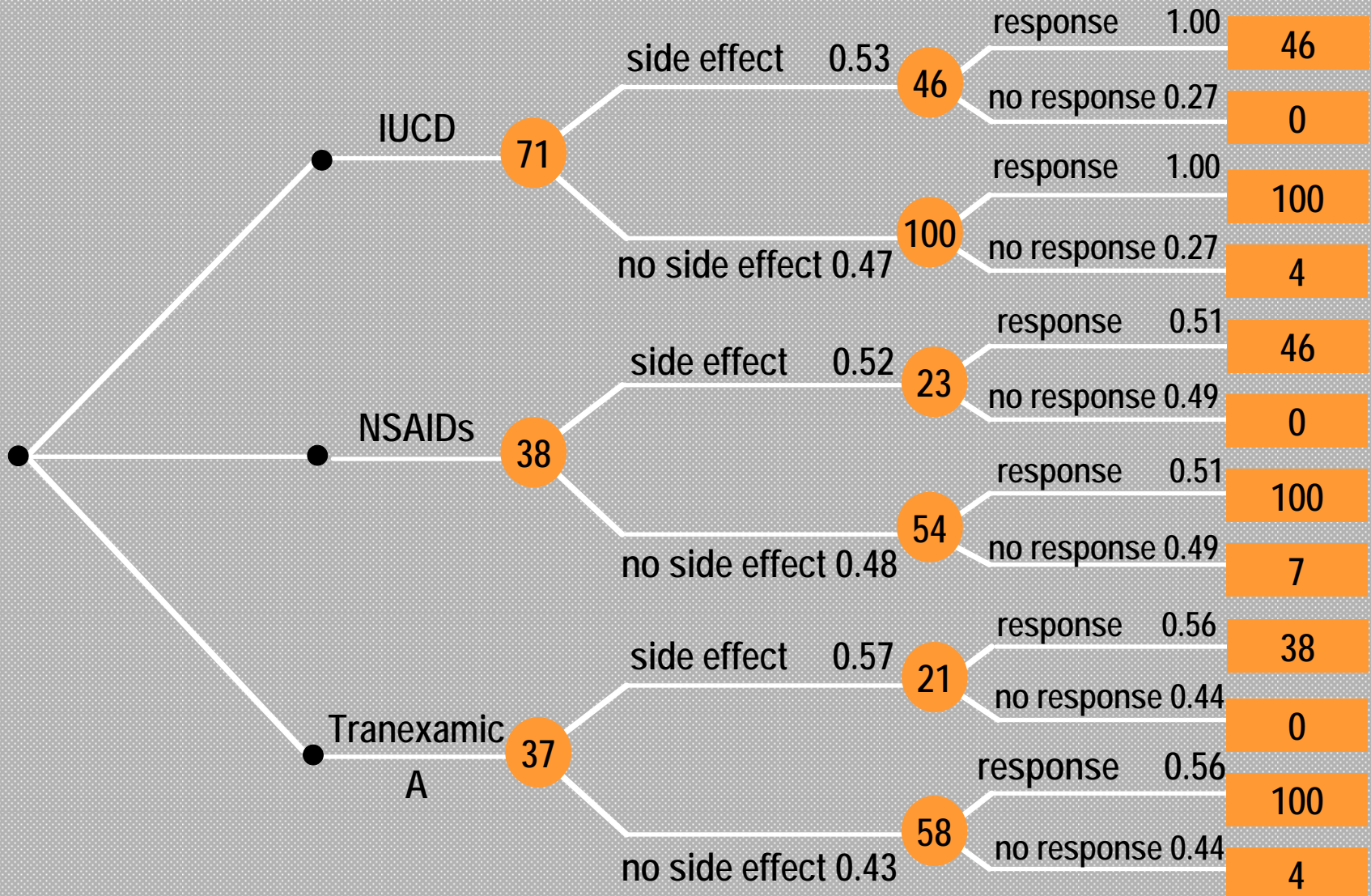
Ranking by evidence or decision analysis scores

	Mean reduction in blood (%)	Ranking by effective-ness data	Decision analysis score	Decision analysis ranking
Levonorgestrel IUS	94	1	71	1
Progestagen (long course)	86	2	29	3
Danazol	50	3	20	3
Tranexamic acid	47	4	37	2
OC pill	43	5	25	3
NSAIDs	29	6	38	2

Medical therapies for heavy menstrual bleeding

- First choice:
  - Non steroidal antiinflammatory agents
  - Antifibrinolytic agents
  - Levonorgestrel intrauterine system

- Second choice:
  - OCpill, danazol, 21 days of progesterone
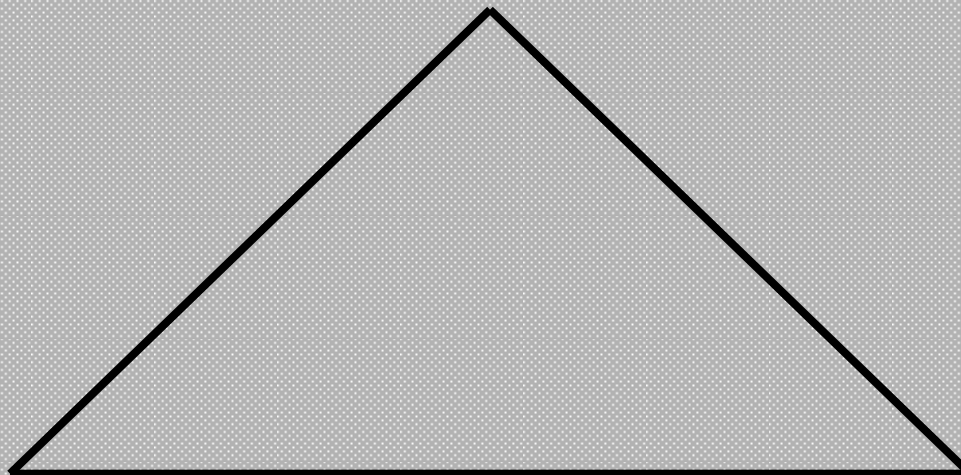
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Implementation

Need to influence the following groups:

Consumers

Practitioners   **Policy**

Patient-Centered Strategies

- Approaches or tools designed to influence patients' decision-making
- Examples:
  - Mass media
  - Videos, leaflets
  - Shared decision-making
    - eg.choice for BPH surgery, lipid lowering drugs, radical prostatectomy for localized prostate cancer

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What is Qualitative Research?

- Answers questions about meaning and how people feel about and experience situations

- Different from quantitative research in
  - how samples are chosen
  - iterative approach
  - methods of data collection & analysis
  - presentation of results

Specific Role for Using Qualitative Information in Guideline Development

- To establish which outcomes matter most to patients

- Implementation: try and establish potentially successful strategies/barriers with patients (& clinicians)

Example of qualitative research

- Asthma patients:
  - Half of asthmatics interviewed did not see themselves as asthma sufferers
  - Interpreted their "bad chests" as an acute & temporary problem, better treated with acute meds rather than daily prophylactic medications
  - The use of daily medications was seen as "stigmatising"
  - Felt that doctors assumed they want treatment
  - Concerned about becoming physically and psychologically dependent on bronchodilators and have deep seated concerns about the long term effects of inhaled corticosteroids

    (Cited by Green and Britten BMJ 1998)

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Getting better patient outcomes

- Greater involvement of patients at all stages in guideline development
- Acknowledge the complexity around decision making
- Use of different research methodologies & strategies
- Don't underestimate the degree to which patients want to be involved

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Disease/ condition	Surrogate outcome	Patient outcomes
Stroke prevention	BP control	Stroke likelihood
AIDS	T cell counts	mortality
Alzheimers	Mini mental state exam	Level of independent functioning
Heavy menstrual bleeding	Blood counts Ferritin	Improvement in periods, satisfaction
Prevention of sudden death following MI	ECG tracings	Sudden death
Prevention of hip fracture	Bone mineral density	Hip fracture rates

Patients are already involved in research and development

- National Coordinating Center for Health Technology Assessment has involved consumers in deciding which trials are needed since 1997

- Cochrane Collaboration has had a consumer network since it'sinception

- Consumers in NHS Research Support Unit

- Hanley et al, BMJ 2001

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