Supporting informed-decision making in efforts to improve screening participation: implications for 'hard to reach' recruitment strategies

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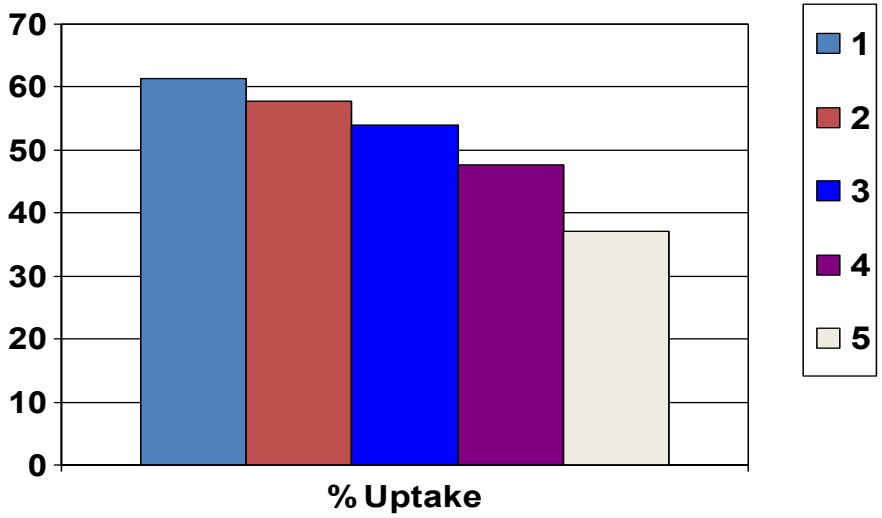
Overview of this presentation

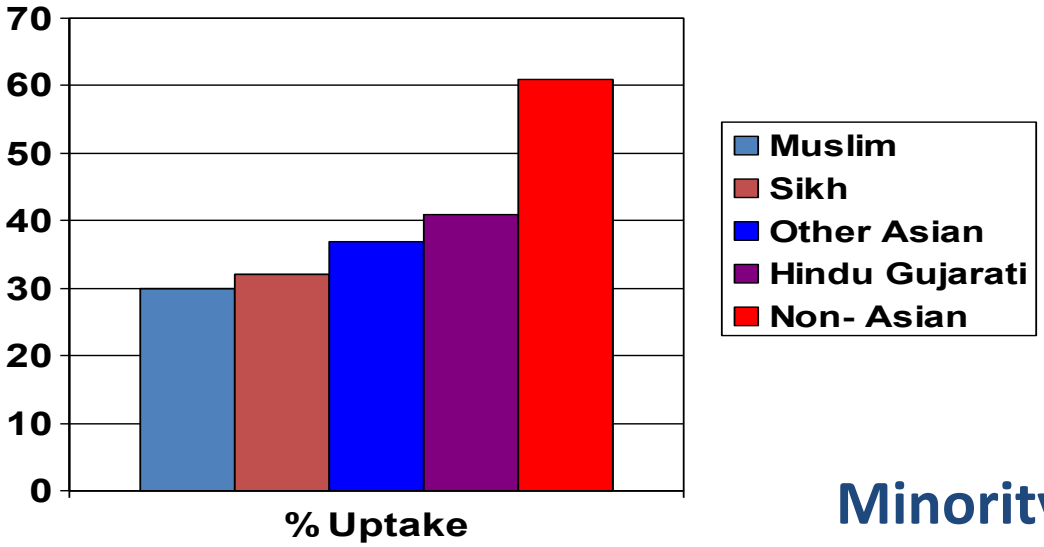
1. The challenge of inequitable participation in cancer screening programmes
2. Informed choice & use of decision aids in cancer screening
3. Public preferences regarding level of recommendation – result from a UK survey
4. Concluding thoughts

(my focus will be on bowel cancer screening, and wrt population screening: the issues are just as pertinent for cervical and breast screening, and other screening contexts)

UK Bowel Screening Pilots

Socio-economic gradient
1 least deprived
5 most deprived





Minority ethnic populations

Barriers to participation in bowel screening

Generic

- Lack of clinical support (esp primary care provider)
- Fear (of cancer, treatment, colostomy)
- Lack of understanding of nature of screening
- Shame (embarrassment)
- Perception of personal risk
- Screening in absence of symptoms
- Conflicting priorities

Cultural

- Taboo around faecal matter
- Fatalism

Process

- Understanding of process
- Storage & Hygiene
- Use of medical terms
- Health literacy

Health System

- Cost – medical coverage
- Access

Techer L, Campbell C, Weller D, et al. Strategies to improve uptake of colorectal cancer screening in South Asian and lower income groups-a qualitative study. *Psychooncology* 2009; 18(3):310-311

Strategies to address low participation

- **Screening modalities** – e.g. one-sample FIT versus three-sample guaiac FOBT; HPV self-sample for cervical screening
- **Improved access** - screening facility hours, location, costs
- **Adapting recruitment materials** -targeted & tailored materials for specific populations
- '**pre-notification' letters** (improved uptake by >5%) and **reminders** (improved uptake by 8%)
- **Primary care engagement** - endorsement of invitations; 'Local Champion' role; more extensive feedback on participation status; practice-based promotion of screening

Weller D, Campbell C. Uptake in cancer screening programmes: a priority in cancer control. Br J Cancer. 2009 Dec 3;101 Suppl 2:S55-9

Informed choice in cancer screening

- In order to **maximise the public health benefits** of screening **uptake must be high**
- Current important emphasis on patient involvement in health care; **informed choice principles**
- The UK's Department of Health Improving outcomes: a strategy for cancer – '*To empower the greatest number possible from all groups and communities… to make an informed choice to participate in cancer screening*'
- **Potential tension** between personal autonomy and public health benefit.

Rapid review: informed choice & cancer screening

- Five systematic reviews of informed choice and decision–making
  - Although most people value information on the limits of screening, provision of information and education alone are not sufficient to facilitate an informed choice
  - An individual's personal experience, values and health and social contexts are equally or more important
  - Few interventions are sufficiently grounded in theoretical models or conceptual frameworks

What about decision aids for cancer screening?

- Seven systematic reviews of decision aids
  - Good evidence that **DAs incorporating knowledge and patient values are effective in increasing informed decision–making**, reducing decisional conflict, and reducing anxiety
  - DAs do result in increased informed choice and decreased PSA testing; **data inconclusive for screening for other cancers**
  - Some evidence DAs can increase patient/physician communication (USA)

Rapid review –recent RCTs of DAs

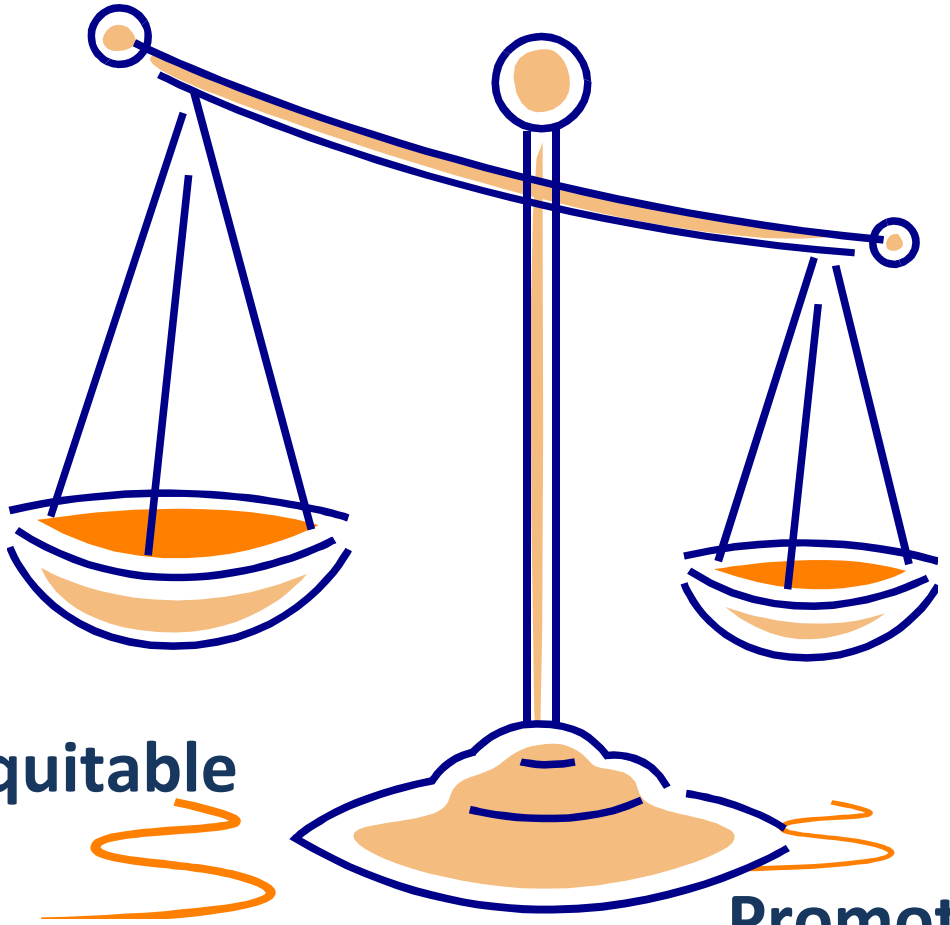
Reference	Country	Details	Key findings
Smith et al BMJ 2010	Australia	Colorectal cancer screening for **adults with low educational attainment**; extensive decision aid booklet	Increased knowledge, less positive attitude, increased proportion making an in formed choice; **significantly lower participation in bowel cancer screening in intervention arm**
Steckelberg et al BMJ 2011	Germany	Colorectal cancer screening, brochure with comprehensive evidence-based risk information	Increased the proportion who indicated an informed choice**; no difference in combined actual and planned uptake**
Miller et al Am J Prev Med 2011	USA	Colorectal cancer screening **- Web-based multi-media** patient decision aid, designed for mixed-literacy abilities, in low SES population	DA significantly increased readiness to receive screening; **non- sig increase in tests ordered and completed; results similar across literacy levels**

- These examples of decision aids in colorectal
  - These examples of decision aids in colorectal
informed decision making does not facilitate increase

"If interventions that foster informed decision-making reduce uptake of bowel cancer screening, then interventions that prioritise the soundness of individual patient decisions may work at cross-purposes with the overarching programme goal of reducing population cancer burden"

JJ Fenton, *Evidence-Based Medicine*2011;16:79

A fine balance



Promoting equitable uptake

Promoting informed decision-making

What do the public want?

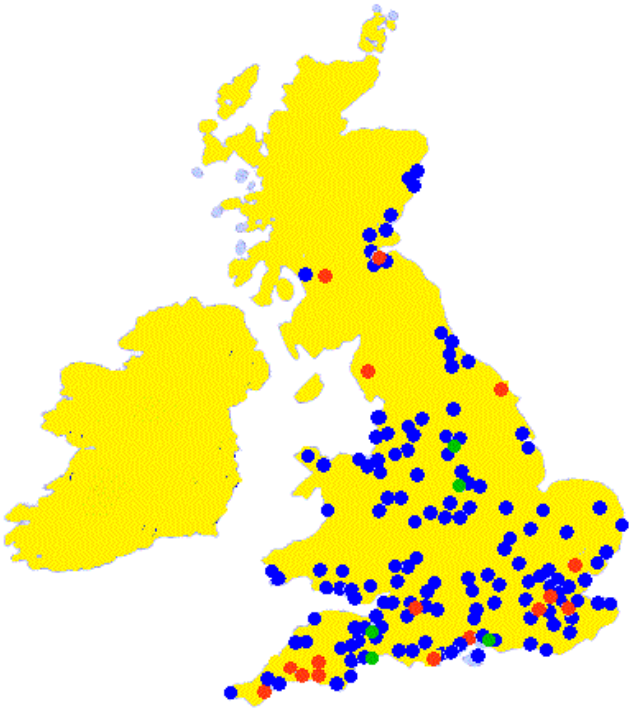
- A recent UK study examined current attitudes towards and understanding of cancer screening
- Allowed us to explore public preferences for levels of recommendation about bowel cancer screening
- Carried out in 2011, random location sampling across the UK with quotas for gender, working status

Aims and objectives

- To assess public preferences for **the level of recommendation** provided by the National Health Service for the bowel screening programme in the UK

- To measure the public's desire about **the quantity of information** about the risks and benefits of screening

- To explore differences by socio-demographic characteristics



84% England; 11% Scotland; 5% Wales

4% minority ethnic origin

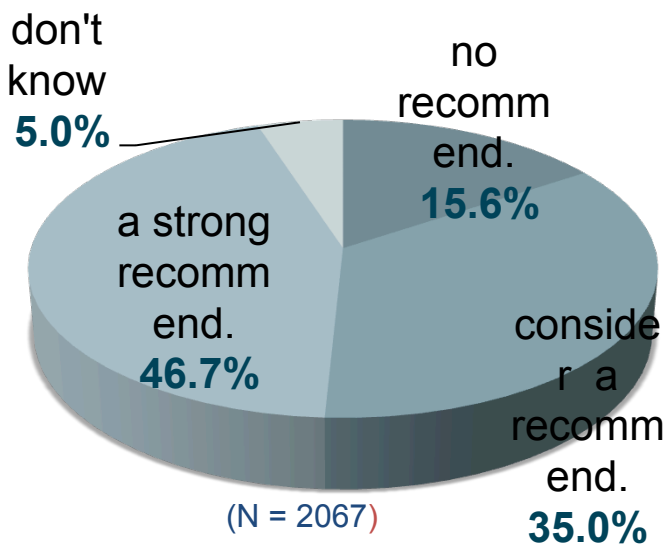
50 to 80 years (*M age*: 64.2)

AB: 20%, C1: 23%, C2: 20%, DE: 37%

62% married, 29% wid/div/sep, 9% single

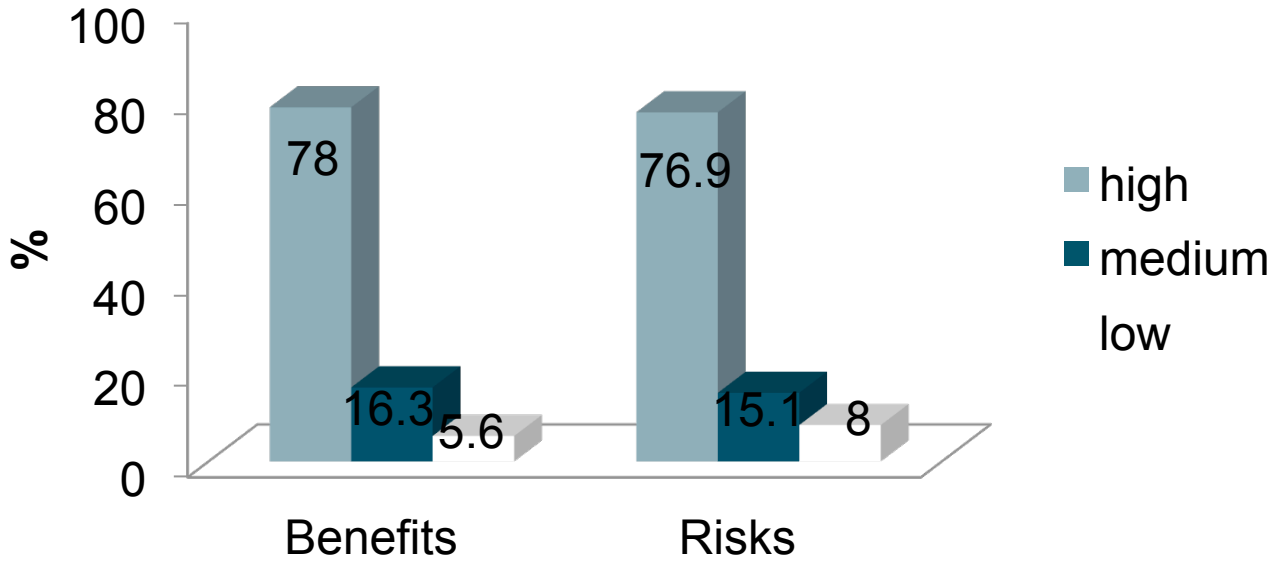
52% female and 48% male

Recommendation vs. no recommendation from the NHS



- Over 80% preferred a clear recommendation to participate from the NHS
- Only 15% wanted information with no recommendation
- **No association between SES and recommendation preference**
- Men more likely than women to want a strong recommendation

Desire for benefit and risk information



Most want to receive **all** information available: even if they report not reading previous leaflets in full

Participants with lower SES had **lower understanding of the purpose** of screening, **wanted less information on benefits and harms** of screening;

Concluding thoughts…

- Imperative that researchers and practitioners rigorously apply informed choice principles when designing and implementing interventions for 'hard to reach' groups
- Autonomous decision-making does not preclude provider input: the survey suggests that the public would welcome a recommendation –not as an alternative to information, but as an *adjunct* to it
- Consistent with 'consider an offer' approach(Entwistle ,BMJ 2009)
- Those with lower SES wanted a recommendation to the same extent as higher SES, but placed less importance on receiving full information on benefits and harms: consistent with previous findings that barriers are often elsewhere
- Role for primary care providers in supporting invitees through a decision-making process: factors such as co-morbidities can be discussed before a negotiated 'recommendation' can be reached

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Ca-PRI
The Cancer and Primary Care Research International Network

- An open, multidisciplinary network for researchers in primary care and cancer
- Promotes greater international collaboration in this field by supporting networking and arranging a yearly conference
- Focus is on the role of primary care throughout the cancer journey, from prevention to palliative care
- Website: http://www.ca-pri.com/

Ca-PRI 6th Annual Conference

will be held 15th - 16th April 2013

University of Cambridge, UK

Reserve the dates

(The conference will overlap with the UK's National Awareness and Early Diagnosis Initiative (NEADI) on the 16th/17th April)