

Adapting colorectal cancer screening for ethnic minority groups

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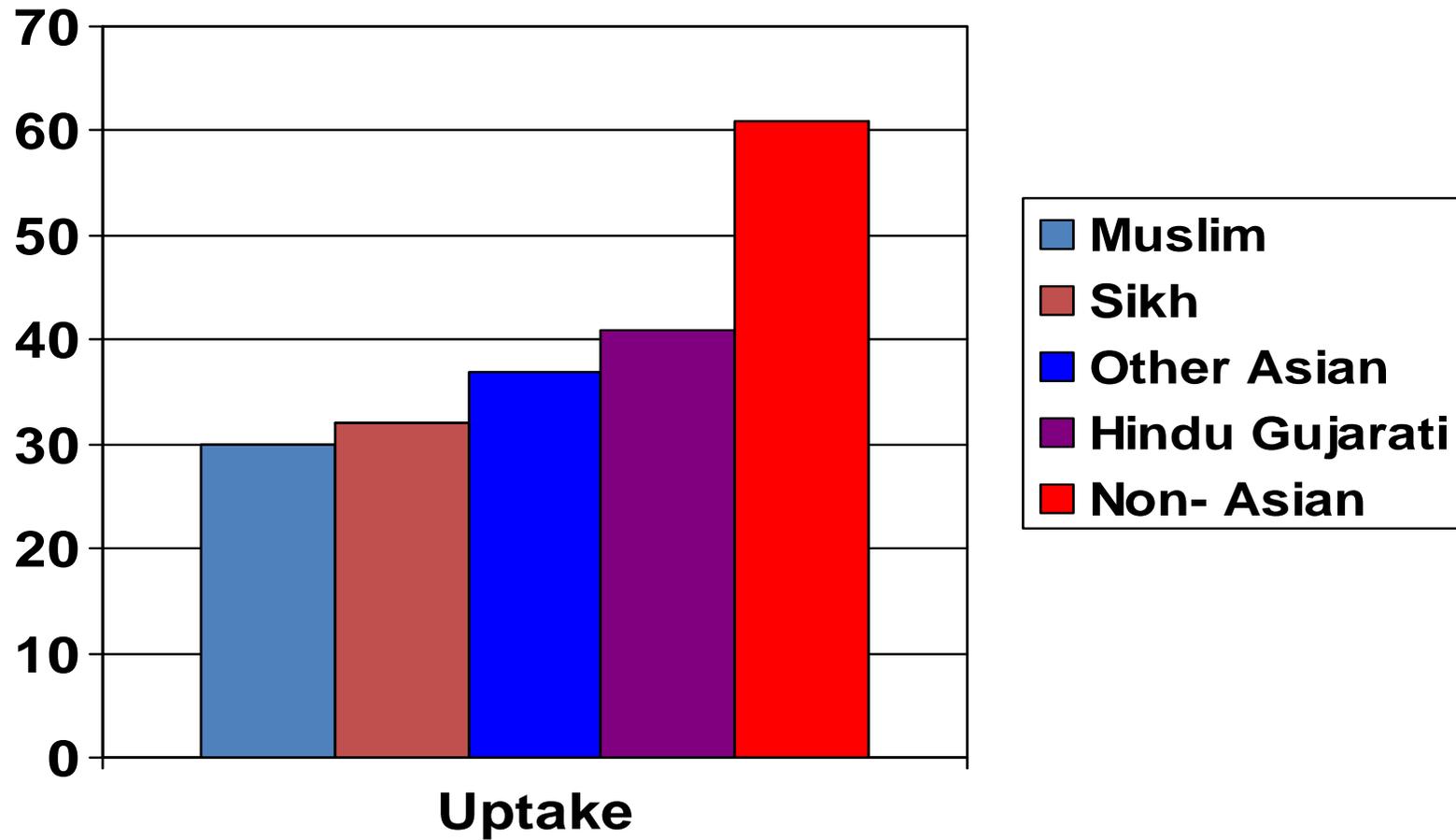
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Conference
Glasgow, Scotland, UK



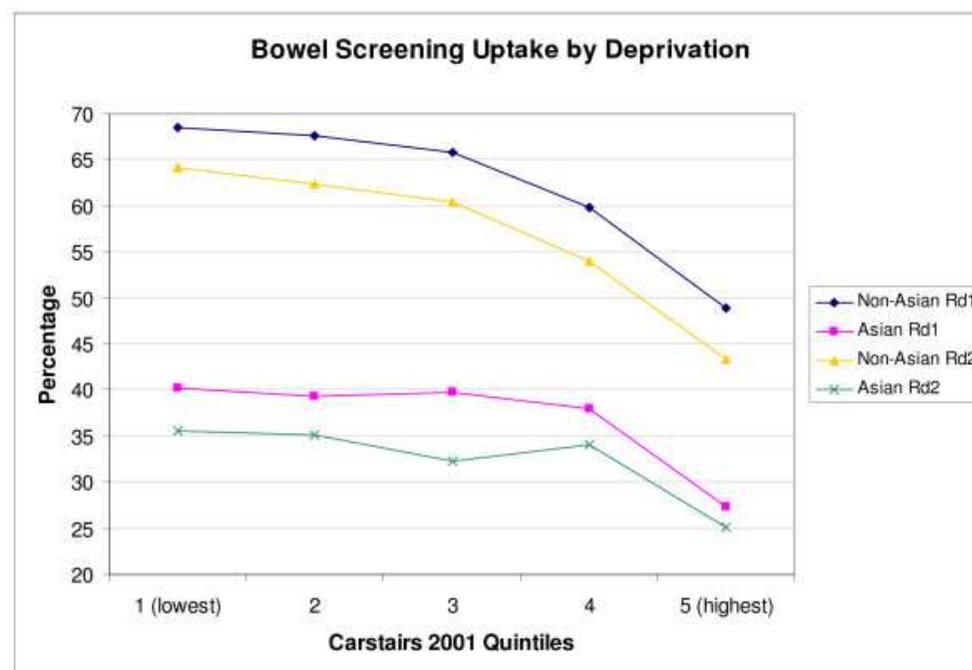
Outline of talk

- Evidence of differential uptake of colorectal cancer screening
 - What are contributing factors?
- Research evidence on effective interventions
- Guidelines and policies
 - European and UK
- Examples of ongoing initiatives and practice
 - England and Scotland

Uptake by Ethnicity (CRC Pilot 2000-2, England)

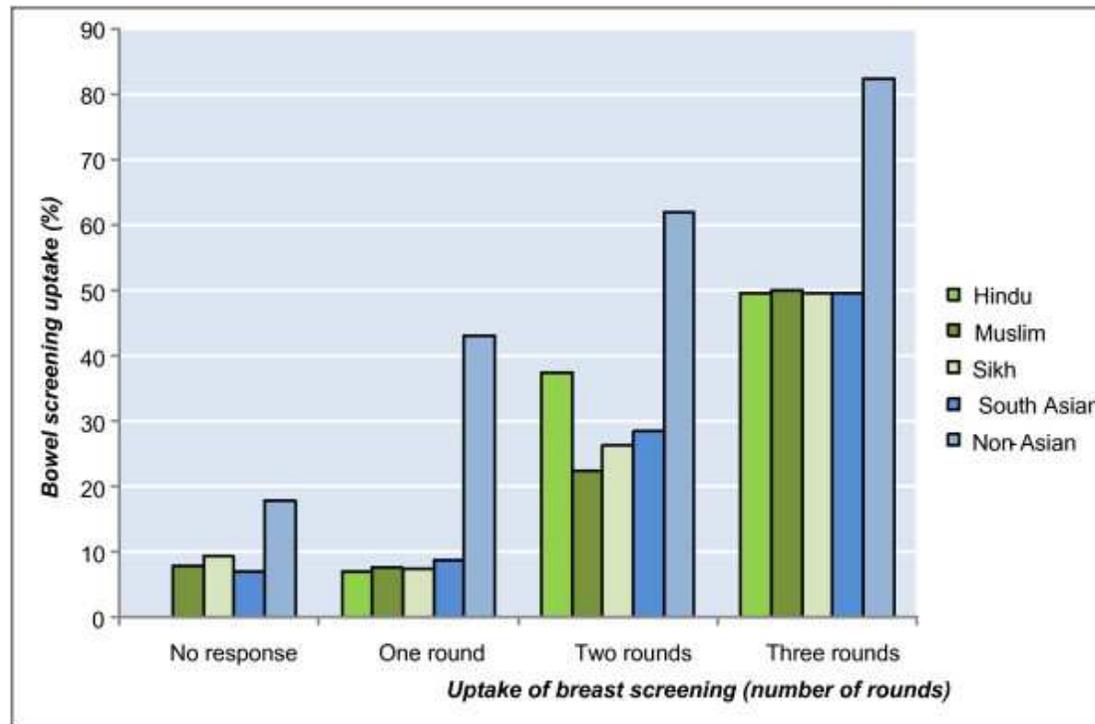


- Recognition that a variety of socio-demographic characteristics influence screening participation
- Analysed uptake in > 240,000 invitees, over 2 screening rounds in Coventry and Warwickshire
- After adjusting for age, deprivation, and gender found that bowel screening uptake remained lower for all South Asian sub-groups c.f. non-Asian)

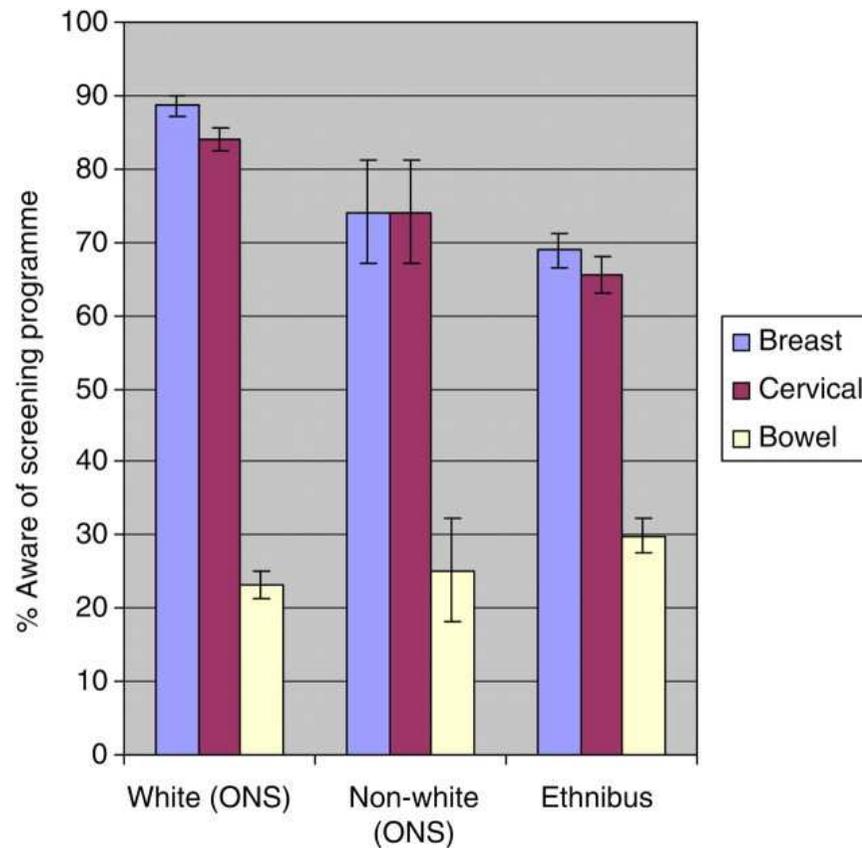


Szczepura et al. Breast and bowel cancer screening uptake patterns over 15 years for UK south Asian ethnic minority populations, corrected for differences in socio-demographic characteristics. BMC Public Health 2008 Oct 2;8:346. doi: 10.1186/1471-2458-8-346.

- Examined uptake of both breast and bowel screening on cohort of South Asian and non-Asian women
- South Asian women were significantly less likely to undertake both breast and bowel screening (29.9% vs 59.4%)
- Participation in more than one round of breast screening increased the likelihood of participating in bowel screening



Price et al Comparison of breast and bowel cancer screening uptake patterns in a common cohort of South Asian women in England. BMC Health Serv Res. 2010; 10: 103.



- Data from 2 surveys – ONS Opinions Survey (2216) and Ethnibus (1500 from six largest ethnic minority groups in England)
- Awareness of cancer screening using CAM in home-based, face-to-face interviews
- At the time of the surveys (Oct & Nov 2008) knowledge of bowle screening was less than 30% of in both white and ethnic minority groups

[Figure 1. From: Ethnic disparities in knowledge of cancer screening programmes in the UK.](#)

Awareness of cancer screening programmes in the Office of National Statistics (ONS) and Ethnibus™ samples (95% CI). Robb K, et al. J Med Screen. 2010 September;17(3):125-131.

**Irish
in Britain**

Cancer Awareness

A factsheet looking at the causal factors and implications of the high mortality rates for cancer within the Irish community.

Qualitative - focus groups in low-uptake communities

Aims:

- Gain a deeper understanding of barriers to/facilitators of bowel cancer screening in low-uptake groups
- Explore views around the bowel screening information leaflets

Method:

- Qualitative (Focus groups)

Settings:

- West Midlands in England (*South Asian communities*)
- Tayside & Lothian in Scotland (*Lower-income*)

Topic guide:

- Informed by previous psychosocial data, and literature
- Knowledge and attitudes; feedback on information leaflets; experiences; recommendations

Focus groups - South Asian communities

ETHNICITY	GENDER	NO. GROUPS	AGE RANGE	LOCATION
Hindu Gujerati	Male	1	56-66	Focus groups were conducted in Leicester, Coventry, Birmingham, and one group (male, Urdu) in North Manchester.
	Female	1		
Sikh Punjabi	Male	1	58-69	
	Female	1		
Muslim (Bengali)	Male	1	56-66 (1 = 77)	
	Female	1		
Muslim (Urdu)	Male	1	50-69 (1 = 49)	
	Female	1		

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

Process

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

Additional themes from South Asian focus groups

- Shame / Taboo re cancer diagnosis

It is also observed that once a person is diagnosed with cancer other people get scared as well and start hating him. That is why a person is afraid of taking this screening so that he should not be hated by his family. (Male, Urdu)

A lot of people have worries that if I had cancer, just say if people find out about it my three daughters' futures because of hereditary some people will be scared that my son and daughter will suffer. (Male, Gujarati)

- Religion and responsibility for health

Frequent reference to Allah's will regarding onset of illness and life/death: this 'fatalism' did not appear to translate into having a reduced sense of responsibility for one's health.

This is the duty of every human being that he should look after his healthThis is what God has commanded to look after his health and take necessary action (Male, Urdu)

- Seeking assistance from others viewed positively

Systematic review evidence on interventions for ethnic minority populations

Naylor et al. Interventions to Improve Care Related to Colorectal Cancer Among Racial and Ethnic Minorities: A Systematic Review. *J Gen Intern Med* 27(8):1033–46

- Exclusively US populations, interventions $\geq 50\%$ racial/ethnic minorities (most studies Hispanic or African American) MEDLINE, PsycINFO, CINAHL, and Cochrane databases, from 1950 to 2010.
- Thirty-three studies included in the final analysis
- Patient education involving phone or in-person contact combined with navigation can lead to up to 15% increase in participation
- Interventions for the health care provider and practice (e.g. education sessions and system reminders) also effective

Summary of evidence of effective interventions

	Breast	Cervical	Colorectal
Deprived communities	<ul style="list-style-type: none"> - Lay worker/patient navigator - Telephone counselling - Tailored interventions (print and telephone) 	<ul style="list-style-type: none"> - Primary care endorsement - Workplace initiatives 	<ul style="list-style-type: none"> - Largely organisational approaches (in the US) - simpler tests - telephone support - patient navigators
Ethnic minority communities	<ul style="list-style-type: none"> - Translation services - Community based interventions (e.g. health educator in a group setting) 	<ul style="list-style-type: none"> - Translation services - Lay workers - Psycho-educational counselling - Culturally sensitive materials - Home visits 	<ul style="list-style-type: none"> - Video and culturally sensitive educational materials - telephone support - Community engagement
Gender	N/A	N/A	Little available of proven effectiveness specifically for men

Limited evidence to distinguish between community-level and individual-level interventions

Adapted from 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.

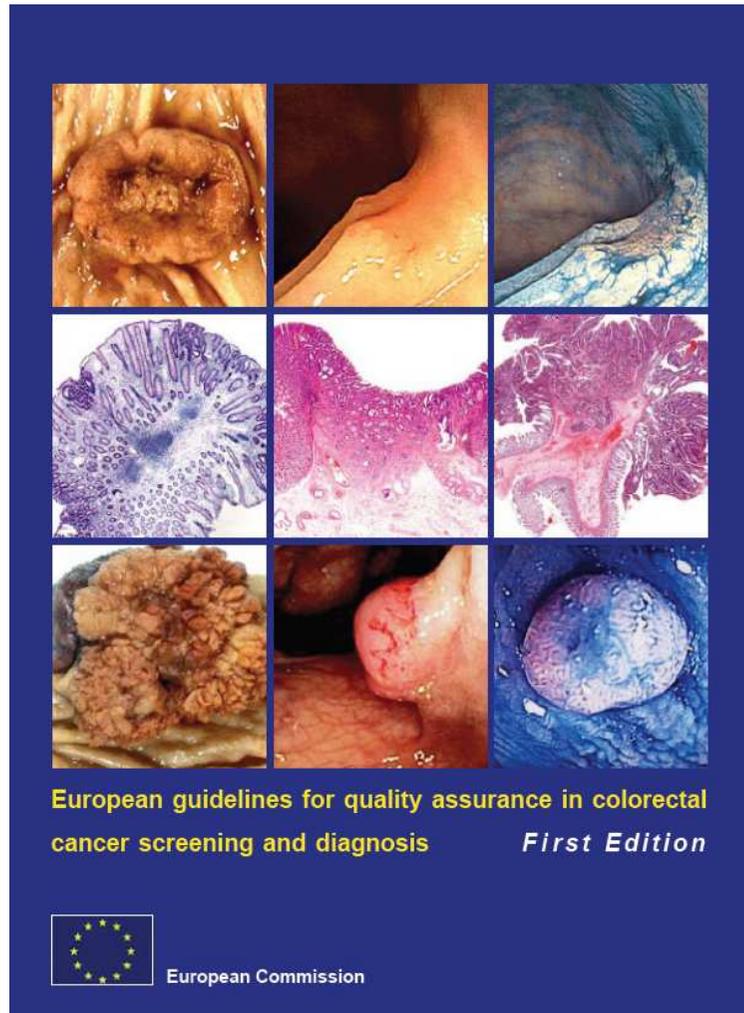
Keywords: bowel cancer; screening; faecal blood test (gFOBt); London; ethnicity

Evaluation of a service intervention to improve awareness and uptake of bowel cancer screening in ethnically-diverse areas

J Shankleman¹, N J Massat², L Khagram³, S Ariyanayagam⁴, A Garner⁵, S Khatoun⁶, S Rainbow⁷, S Rangrez⁸, Z Colorado⁹, W Hu⁹, D Parmar² and S W Duffy^{*,2}

- Uptake of bowel cancer screening is low in London, especially in populations of lower socio-economic status, and in particular ethnic or religious groups.
- General practices randomly assigned to either **face-to-face health promotion** at invitees' general practice, or health promotion delivered by **telephone only**.
- Median gFOBt kit uptake was 46.7% in the telephone practices, 43.8% in the face-to-face practices and 39.1% in the comparison practices.
- Practice-level data, not individual: not possible to tease out impact by ethnicity c.f. deprivation

European guidelines



“Providers of screening programmes frequently have to cater to multicultural and multi-linguistic populations with all the related communication problems. Overcoming these problems requires more than just translating the information material. An understanding should be gained of ethno-cultural values, beliefs, health practices and communication styles of these varied groups, and the information materials produced must conform to these identified needs.”

UK policy interventions (England)

- Since 2008 NAEDI (**National Awareness and Early Diagnosis Initiative**) has aimed to improve public awareness of signs and symptoms of cancer, and promote early diagnosis – including addressing low uptake of screening programmes
- NAEDI and NCAT (**National Cancer Action Team**) have worked with the Bowel Cancer Screening Advisory Group to devise strategies to increase awareness of bowel cancer and participation in the screening programme
- Methods were developed with **BME charities and organisations**
- Emphasis on **engagement** with local community leaders and faith communities, **partnerships** with local radio stations, development of targeted and tailored information, and direct awareness raising at cultural and religious events, festivals, carnivals, etc.



- [Home](#)
- [Sylheti](#)
- [Urdu](#)
- [Hindi](#)
- [Punjabi](#)
- [English](#)

Sylheti language information

Films

(Click on the image to play the video.)



Posters

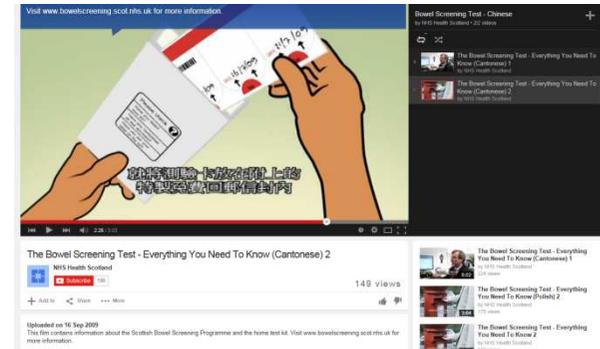
(Click on the links to open/download)

- [Bowel Cancer](#)
- [Bowel Cancer Screening](#)
- [Breast Cancer](#)
- [Breast Cancer Screening](#)
- [Lung Cancer](#)

<https://www.detectcancerearly.org/sylheti.html>

What are we doing in Scotland?

- NHS Health Scotland and the Scottish Bowel Screening Programme have developed a DVD resource to support health boards in conveying key messages about bowel cancer and the screening test.
- DVD available (via voiceover and subtitles) in Polish, Urdu, Cantonese, Punjabi, Sylheti, and British Sign Language



<http://www.healthscotland.com/topics/health/screening/bowel.aspx>

Responsibility of health boards

Meeting the Requirements of Equality Legislation

A Fairer NHS

Greater Glasgow & Clyde

2013 – 2016

Briefing Paper:
Bowel Screening

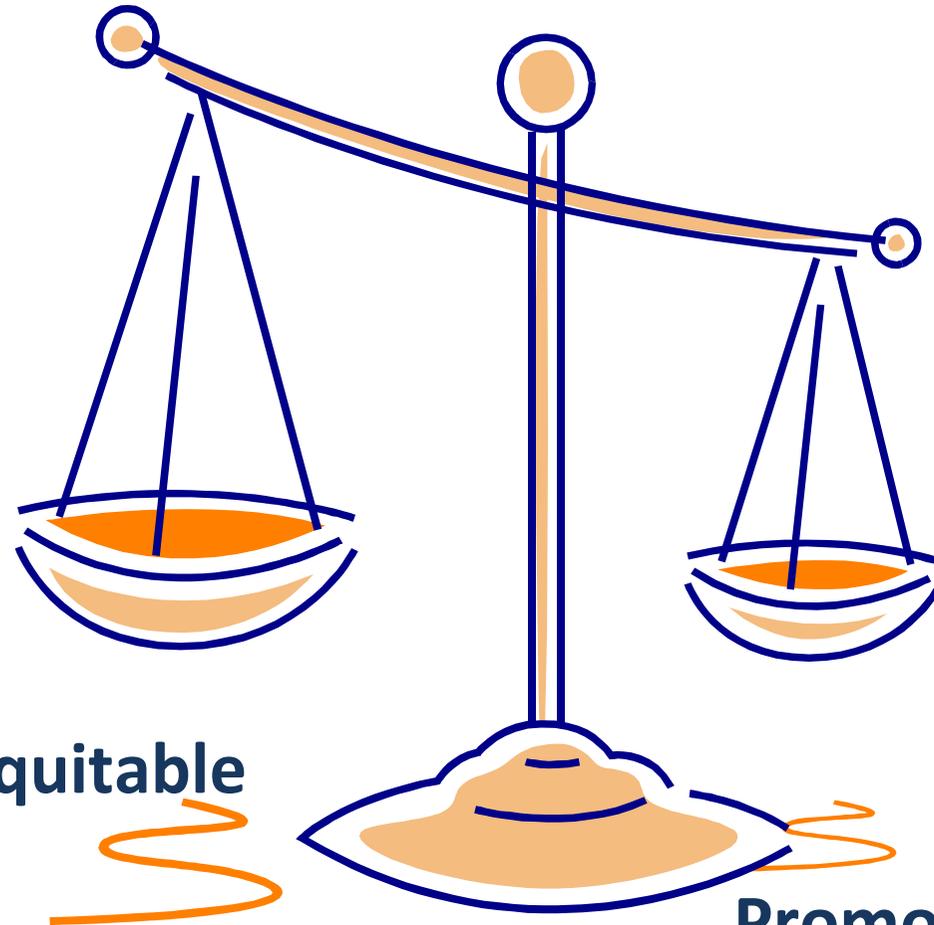
June 2013

- Each NHS health board across Scotland has a public health specialist appointed as a Bowel Screening Coordinator
- Responsibility to support bowel screening programme particularly in low-uptake populations, working with primary care and local organisations and agencies
 - identifying local priority groups and targeting them accordingly
 - Support and integrate equality and diversity issues
- Detect Cancer Early - Bowel Screening Initiative in primary care
 - *“It must also attempt to address any inequalities that might exist within the practice population in terms of screening programme participation”*
- Recognised problem: there is no system for routinely collecting uptake information on ethnicity in screening programme, nor number of non-English language leaflets downloaded

SHELS-4 bowel screening component

- Scottish Health and Ethnicity Linkage Study (SHELS)
- The Scottish Bowel Screening database does not include an ethnic code so reported estimated participation rates by ethnicity are based on census linked area-level characteristics, not on individuals.
- SHELS: linkage of the 2001 Census in Scotland, with the Community Health Index register
- Plan to link this CHI/Census database with the Scottish Bowel Screening Programme data to generate individual level information on bowel screening participation rates in minority ethnic groups in Scotland

A fine balance



Promoting equitable uptake

Promoting informed decision-making

Conclusions

- In every community the uptake of screening is affected by factors such as knowledge of screening, literacy, age, attitude, beliefs, and social and economic status.
- BME groups are less likely to participate in bowel cancer screening programmes than the white population in the UK
- There is some evidence of that targeted and tailored interventions can increase bowel screening participation: but evidence largely from non-UK populations
- There is a need for health service interventions to ethnic minority communities across the UK (including NAEDI and DCE) to be rigorously evaluated: challenge of ethnicity recording (although improving)

Are we *adapting* colorectal cancer screening programmes for ethnic minority groups?

- Efforts are increasingly being made to tailor and target information materials and models of information provision
- A national programme has limited flexibility to adapt *delivery* for different groups
- Nonetheless, there is scope to explore use of different screening kits, provision of kits through trusted health care providers, timing of invitation to avoid religious holidays, use of community champions, etc.
- Lessons learnt may benefit all communities where uptake is low

THANK YOU

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