Colorectal Cancer Screening
Why different levels of participation in Europe?

Influence of ‘population type’
How to tackle inequalities!
HAPPY COUPLES
POSH WEALTHY EDUCATED MIDDLE CLASS

HANDICAPPED DISADVANTAGED
POPULATION-BASED SCREENING
ETHNIC MINORITY
PRISONERS HOMELESS
CRC Screening Participation Rates
(60-69 year old) 2013

Table 4.14.1. Colorectal cancer screening programmes in the EU (EUROSTAT Population 2013)

<table>
<thead>
<tr>
<th>Country</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>UK Wales</td>
<td>gFOBT</td>
</tr>
<tr>
<td>UK Scotland</td>
<td>gFOBT</td>
</tr>
<tr>
<td>UK England</td>
<td>gFOBT</td>
</tr>
<tr>
<td>Sweden</td>
<td>gFOBT</td>
</tr>
<tr>
<td>France</td>
<td>gFOBT</td>
</tr>
<tr>
<td>Finland</td>
<td>gFOBT</td>
</tr>
<tr>
<td>Belgium</td>
<td>gFOBT</td>
</tr>
<tr>
<td>Spain</td>
<td>FIT</td>
</tr>
<tr>
<td>Slovenia</td>
<td>FIT</td>
</tr>
<tr>
<td>Netherlands</td>
<td>FIT</td>
</tr>
<tr>
<td>Malta</td>
<td>FIT</td>
</tr>
<tr>
<td>Italy</td>
<td>FIT</td>
</tr>
<tr>
<td>Ireland</td>
<td>FIT</td>
</tr>
<tr>
<td>Hungary</td>
<td>FIT</td>
</tr>
<tr>
<td>France Calvados</td>
<td>FIT</td>
</tr>
</tbody>
</table>
Screening Participation – primary influences

Healthcare system

- Universally accessible
- Funding arrangements
- Trust (reputation)
- Support services (inc. transport)

Programme design

- Too difficult
- Invitation material – complex /attractive
- KIT sampling - difficult
- Return of kit - ?post
- Travel – mobility and cost

On-going promotion

- National and local initiatives
- Champions
- Media support
Programme design

Starting point...

• Subjects are looking for a reason not to do the test!
  • Don’t provide them with an excuse!

• ‘Design’ to maximise uptake
  • Don’t make good participation an ‘after-thought’
  • Consulting widely - test, trial and apply
  • Repairs are difficult and expensive

• One size... does not fit all
  • Consider for personalisation!
Table 4.14.1. Colorectal cancer screening programmes in the EU (EUROSTAT Population 2013)
First evidence of population differences

- Sex
- Age
- Ethnicity

UK NHS Colorectal Cancer Screening Pilot 2000 - 2003
First evidence of population differences

- Sex
- Ethnicity

UK NHS Colorectal Cancer Screening Pilot 2000 - 2003

![Chart showing the percentage of returned FOBt kits by ethnicity and gender. The x-axis represents different ethnic groups (Muslim, Sikh, Other Asian, Hindu-others, Hindu-Gujerati, Non-Asian) and the y-axis represents different genders (Males, Females). The chart illustrates the proportion of kits returned by each group and gender, highlighting the differences in participation.]
First evidence of population differences

- Socio-economic status
- Indices of Multiple Deprivation (IMD)

UK NHS Colorectal Cancer Screening Pilot 2000 - 2003

* Trend p<0.0001
Easy access to Information

- Emphasis on reaching everyone!

Special arrangements for...
- Prisoners
- Military personnel

Major challenges to reach those with...
- Dementia
- Learning difficulties
- Blindness

Over 10,000 phone calls each week

Braille for the blind
Available in 21 Languages
British Sign Language
Picture based
DVDs CDs

Large Print Version
% Uptake – Relationship to Socioeconomic Status
First 2.6 million Invitation
(BCSP - UCL Study)

% Uptake - Flexible Sigmoidoscopy

(N = 24,268 invitations since March 2013)
First 2.6 million invitations in England

% Uptake FOBT kits
First 2.6 million invitations in England

% Uptake FOBT kits
First 2.6 million invitations in England

Uptake of faecal occult blood test colorectal cancer screening by different ethnic groups in the Netherlands

M. Deutekom E J of Public Health 2009 Vol. 19, No. 4, 400–402
2007 Ethnicity in England

Geography matters

Diversity Index:
- 0.50 and above
- 0.20 to 0.49
- 0.15 to 0.19
- 0.08 to 0.14
- 0 to 0.07
Geography matters

2013 % Uptake S. Hub

Sept’ 2013
2006 - 11% Uptake S. Hub

% Uptake in 1,673 postcode areas

Affluent area

Deprived area
% Uptake - rural & city
Poor Uptake in Slough
Better Uptake in Reading

%Uptake

29%
63%
24%
% Uptake - gFOBT Screening
(Southern Hub)

% Uptake in all invited

61% Uptake

Date Sept 2006 – April 2013
% Uptake - gFOBT Screening (Southern Hub)

% Uptake following previous acceptance

% Uptake in all invited

% Uptake following previous refusal

61% Uptake

Date Sept 2006 – April 2013
NIHR Programme Grant for Applied Research

The ASCEND study:
Strategies to reduce the social gradient in bowel cancer screening uptake


ASCEND - Cluster-randomised trial (Men & women 60 – 74)


**Trial 1** - Supplementary summary leaflet with Invitation letter (n=163,525)
No effect

**Trial 2** - Supplementary narrative leaflet Invitation letter (n=150,417)
No effect

**Trial 3** - GP endorsement of programme on Invitation letter (n=265,434)
Increased uptake 0.7% but no change to SES gradient

**Trial 4** - GP endorsement of programme on Reminder letter (n=168,480)
Increased uptake 0.7% & some interaction with SES gradient
ASCEND - % Uptake after ‘Standard’ and ‘GP Endorsed’ screening ‘Reminder Letter’

<table>
<thead>
<tr>
<th>Index of Multiple Deprivation</th>
<th>Standard Letter</th>
<th>Reminder</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>34.9</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>29.7</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>25</td>
<td></td>
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<tr>
<td>4</td>
<td>20.4</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>13.3</td>
<td></td>
</tr>
</tbody>
</table>
Further reduction in inequalities in screening uptake... with written materials alone will be a challenge.


CRC Cancer Screening - Relationship between %Uptake and a Personalisation Score
CRC Cancer Screening - Relationship between %Uptake and a Personalisation Score

[Graph showing the relationship between CRC screening uptake and personalisation score across various countries.]
CRC Cancer Screening - Relationship between %Uptake and a Personalisation Score

- Personalised Opportunistic & Decentralised
- Primarily Care Test Distribution
- Population-based Centralised Invitations
Does FIT make things better... or worse?
Faecal Occult Blood Test? – *I can’t face it!*
Faecal Occult Blood Test? - Too difficult!
Faecal Occult Blood Test? - Too horrible!

‘One’... can’t possibly do that!
‘They say it is easier with FIT!’
Deprivation Index for the Pilot Hubs

(IMD – Index of Multiple Deprivation)
Prevalent Episode - Uptake

1 – 5 invitations but no previous response

11.6% Increase

11.8%

11.3%
Prevalent Episode - Uptake

1 – 5 invitations but no previous response

London

- 9.7% FIT
- 19.5% gFOBt

Increase: 9.8%

Southern

- 9.8% FIT
- 20% gFOBt

Increase: 11.8%

Mid & NW

- 11.3% FIT
- 25% gFOBt

Increase: 11.3%
Deprivation – Uptake

- IMD 1 (Posh)
- IMD 2
- IMD 3
- IMD 4
- IMD 5 (Poor)

Uptake:
- gFOBt
- FIT

Location: London
Deprivation – Uptake

<table>
<thead>
<tr>
<th>IMD Level</th>
<th>gFOBt</th>
<th>FIT</th>
</tr>
</thead>
<tbody>
<tr>
<td>IMD 1 (Posh)</td>
<td>6.7%</td>
<td></td>
</tr>
<tr>
<td>IMD 2</td>
<td>6.0%</td>
<td></td>
</tr>
<tr>
<td>IMD 3</td>
<td>6.8%</td>
<td></td>
</tr>
<tr>
<td>IMD 4</td>
<td>8.0%</td>
<td></td>
</tr>
<tr>
<td>IMD 5 (Poor)</td>
<td>7.9%</td>
<td></td>
</tr>
</tbody>
</table>
Deprivation – Uptake

London

IMD 1 (Posh)  IMD 2  IMD 3  IMD 4  IMD 5 (Poor)
gFOBt in London

40%  45%  50%  55%  60%  65%  70%  75%

40%  45%  50%  55%  60%  65%  70%  75%

8.3%  7.7%  10.0%  7.4%  9.8%
Bowel cancer screening

Nationwide advertising campaign…
…to reach the ‘deprived’
…designed specifically to address barriers!

Cologuard Fecal Immunotherapy Test
‘More than just a screening test!’
‘Identifies… early-stage and pre-cancers’

- Patient compliance program
  - 24/7 support
    - 70 languages

Personalising Screening

I want more information...

• I want to read it in **Swahili**, Polish, Cornish!
• I’m **partially blind** and want audio details
• A **video** would help me understand better
• What does **abnormal result** mean?
• I want to know more about colonoscopy

Quick Response (QR) Code

*Designed for this purpose*

http://www.cancerscreening.nhs.uk/bowel/faqs.html
Personal Bowel Screening Account

Mrs Dawn P. Harlequin
BCSP No. **** *** 7843
Preferred Language? English

Your Personal Screening Record

1. Next Screen: March/April 2016
2. Last Screen: 18/03/2014 – Normal Result
3. Previous Screen: 14/02/2012 – Not Received
4. Previous Screen: 14/02/2010 – Normal Result

Screening Information Kiosk

- Why screen for colon cancer?
- How to collecting your sample
- Understanding your result
- What happens at clinic appointments?
- What is colonoscopy?
- More questions?

Context sensitive answers

0800 707 60 60

Cancer Screening Programmes
Личный учет скрининга кишечника

Mrs Dawn P. Harlequin
BCSP No. **** *** 7843
Preferred Language? Russian

Ваш личный показатель скрининга

1. Следующий экран март апрель 2016
2. Последний экран 18/03/2014
3. Предыдущий не полученный экран 14/2/2012
4. Предыдущий экран 14/02/2010

Киоск данным по скрининга

- Почему экран?
- Собирать ваш образец
- Понимать ваш результат
- Что случается на назначениях клиники?
- Что колоноскопия?
- Больше вопросов?
Personalising Screening

Track my screening sample...

• Have they got my test sample yet?
• Have they tested my sample yet?
• When will I get my results?
• What was my last result?
• When will I be screened next?

Quick Response (QR) Code

http://www.cancerscreening.nhs.uk/bowel/faq.html
Track Your Package

Mrs Dawn P. Harlequin
Accont No. **** *** 7843

Order Received: 02/01/2015
Ready for Dispatch: 04/01/2015
Heathrow Airport: 05/01/2015
Out for Delivery: 15/01/2015

Contact amazon
0800 777 1111
Personal Bowel Screening Account

Mrs Dawn P. Harlequin  
BCSP No. **** *** 7843  
Preferred Language? English

Call the HELPLINE
0800 707 60 60

Sample Received By the Hub: 02/01/2015  
Sample Tested By the Hub: 04/01/2015  
Result in the Post: 05/01/2015  
15/01/2015

Click for Details  
SSP Clinic Appointment
Personal Bowel Screening Account

Mrs Dawn P. Harlequin
BCSP No. **** *** 7843
Preferred Language?  *English*

Two way communication as well?

- Can I have a replacement FIT kit?
- My FIT kit will be delayed because I’m going on holiday?
- Can I change my appointment date?
- I have decided not to do ‘bowel scope’ screening?
FUTURE OF PERSONALIZED MEDICINE

NEED MORE AGILE REGULATORY SYSTEM
GENETIC COUNSEL + DECISION SUPPORT GENETIC LITERACY

BETTER EVIDENCE FOR DIAGNOSTICS AND THERAPIES

TRANSLATE RESEARCH

EMPOWER PATIENTS!

TAKE CARE OF YOUR OWN HEALTH!

MAKE MY SCREEN THE BEST FOR ME

TEST BEFORE YOU TREAT

GIANT LEAPS IN MEDICINE ARE JUST AROUND THE CORNER!

GET TO THE RIGHT DRUG THE FIRST TIME!

ALL OF THE DATA FROM THE INTERNET CAN BE STORED IN DNA IN A SMALL TEST TUBE.
Screening needs to join the ‘Personalised Medicine’ band wagon.

Make MY screen the best for ME.

Test before you treat.

Giant leaps in screening are just around the corner!

Get to the right screen the first time.

Better evidence for diagnostics and therapies.

Empower patients.

Take care of your own health.

MED

GENETIC COUNSEL
DECISION SUPPORT
GENETIC LITERACY

NEED MORE AGILE

FIT 4 Me

Cancer Screening Programmes

Screening Systems

ALL
OF THE DATA
FROM THE INTERNET
CAN BE STORED IN DNA
IN A SMALL TEST TUBE
EU - Variation in Screening Participation

Population differences

- Age
- Sex

Ethnicity /Culture
- Religious /cultural taboos
- Gender roles and taboos

Competing priorities
- Family
- Work (?retired)
- Health

Financial
- Expensive
- Travel to pickup (GP) or return (post)

Ease of access
- Geography
- Health
- Support

Deprivation
- Disengaged from healthcare
Population Type?

• Age
• Sex
• Deprivation
• Ethnicity
• Language (written)
• Rural v Urban (city)
• Well v unwell
• Single v partner /family
• Working v retired
• Wealthy v poor
• Health v unhealthy
• Traveller v home-based
• Learning ability /
• Cognisance –
• Reading ability (learning difficulties)
• Manipulation ability (arthritic, Parkinson's etc)
Tackling social inequalities in cancer prevention and control for the European population

• Recommendation 1: Embed equity in all aspects of cancer control and prevention strategies.

• Recommendation 2: Adopt a Health Equity Impact Assessment (HEIA) Approach

• Recommendation 3: Align the cancer control and prevention strategy with a ‘Health in all Policies’- approach.

• Recommendation 4: Engage and empower communities and patients in cancer control and prevention activities.

• Recommendation 5: Promote the exchange of experiences of good practices and support development of professional expertise on social inequalities in cancer.

• Recommendation 6: Support the development of European research programmes on equity in cancer.
Tackling social inequalities in cancer prevention and control for the European population

• **Recommendation 1:** Embed equity in all aspects of cancer control and prevention strategies.

  • **Specific recommendation 1.1:** Formulate specific objectives directed to tackle social inequalities in cancer, with a focus on cancer intervention, prevention and control strategies, for the whole social scale within a population and targeted to socially vulnerable groups.

  • **Specific recommendation 1.2:** Include indicators of social cancer inequality in the quality criteria established for cancer prevention and control programmes and services.

• **Recommendation 2:** Adopt a Health Equity Impact Assessment (HEIA) Approach

  • **Specific recommendation 2.1:** Assess the evidence on social inequalities in cancer and identify any gaps in knowledge.

  • **Specific recommendation 2.2:** Introduce a unique identifier to facilitate safe record linkage between different databases in each European country in order to monitor social inequalities in cancer.

  • **Specific recommendation 2.3:** Collect information on patients’ reported outcome measures (PROM) and link this information with cancer registry data.

  • **Specific Recommendation 2.4:** Assess the impact of current and new cancer programmes and services on social inequalities in cancer.

  • **Specific recommendation 2.5:** Periodically develop a report on the situation on social inequalities in cancer.

• **Recommendation 3:** Align the Cancer Prevention and Control Strategy with a “Health in all Policies” approach.

  • **Specific recommendation 3.1:** Convene a multi-disciplinary working group of experts on health inequalities to develop a “Health in all Policies” approach to cancer.

• **Recommendation 4:** Engage and empower communities and patients in cancer control and prevention activities.

  • **Specific recommendation 4.1:** Involve communities and patient associations in decision-making processes.

  • **Specific recommendation 4.2:** Ensure that socially vulnerable groups are involved in the design, implementation and evaluation of health policies related to cancer control and prevention.

  • **Specific recommendation 4.3:** Ensure that all patients receive up-to-date and accurate information and are proactively involved in their care.

• **Recommendation 5:** Promote the exchange of experiences of good practices and support development of professional expertise in social inequalities in cancer.

  • **Specific recommendation 5.1:** Foster European exchanges of professional experience in cancer and in tackling social inequalities in cancer.

  • **Specific recommendation 5.2:** Train cancer prevention, care, and rehabilitation professionals in tackling social inequalities in cancer.

• **Recommendation 6:** Support the development of European research programmes that help deliver equity in cancer.
4.3.2. Participation rate

- Participation rates are available for those EU Member States where subjects in the target population receive a personal invitation. Participation rate is indeed defined as the percentage of subjects screened in a particular year out of the total number of those who had received a personal invitation in that year. The observed participation rates are presented in table 4.15.

- Participation in a single invitation round is generally (but not always) higher for programmes offering faecal tests, as compared to the programmes offering flexible sigmoidoscopy (FS) or total colonoscopy (TC) screening. However, it should be considered that regular repetition of faecal tests is needed to achieve the expected protective effect, while a single FS or TC can ensure a long lasting protection to those who attend. Therefore, when considering the protective effect of screening at the individual level, a more appropriate comparison would require to estimate the proportion of regular attendees to gFOBT/FIT invitation over a time interval comparable to the duration of the protective effect of FS/TC. On the other hand, from a public health point of view as a certain proportion of non-responders will attend at least once over repeated invitations, a higher proportion of subjects in the target population will benefit to some extent from the protective effects of screening protocols using tests to be repeated at regular intervals.

- Also, while available evidence is indicating that the adoption of FIT is associated with an increase in the participation rate, the observed differences in the participation across EU countries are still showing a strong influence of cultural background, obscuring the expected impact of the adoption of the more acceptable method.

- Table 4.16 shows the participation rates separated by gender for different screening programmes and age groups. When analysing gender and age related trend in all the countries implementing gFOBT or FIT, screening participation is higher among women than among men and is higher among people aged 60 to 69 years as compared to the younger or older age groups. Men are instead showing a higher response to the invitation for FS or TC.

- Only one regional programme in Italy is offering a combination of tests - FS, once in the lifetime is offered as primary screening test and those who refuse FS are invited for biennial FIT. Such strategy results in substantial increase in the population coverage, similar among men and women.
% Uptake - IMD quintile by Hub and overall

Most Deprived

<table>
<thead>
<tr>
<th>Hub</th>
<th>1st quintile</th>
<th>2nd quintile</th>
<th>3rd quintile</th>
<th>4th quintile</th>
<th>5th quintile</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eastern Hub</td>
<td>42.7</td>
<td>47.1</td>
<td>51.6</td>
<td>55.5</td>
<td>60.1</td>
</tr>
<tr>
<td>London Hub</td>
<td>33.0</td>
<td>38.8</td>
<td>42.7</td>
<td>45.5</td>
<td>41.7</td>
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<tr>
<td>North Eastern Hub</td>
<td>50.1</td>
<td>55.5</td>
<td>60.6</td>
<td>60.8</td>
<td>59.6</td>
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<tr>
<td>North West Hub</td>
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<td>55.5</td>
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<td>60.8</td>
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<td>Southern Hub</td>
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<td>52.7</td>
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<td>60.8</td>
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<tr>
<td>National distribution</td>
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<td>55.5</td>
<td>60.6</td>
<td>60.8</td>
<td>59.6</td>
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Least Deprived