Optimising health information to reduce inequalities in screening uptake: The ASCEND study

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NHS Bowel Cancer Screening Programme

- Fully rolled out 2008
- Aged 60-74
- Biennial Faecal Occult Blood Testing
  - Small sample of faeces onto test card
  - 3 times over two weeks
  - 16% RRR (population level)
NHS BCSP and health information

• Complex programme
• No HCP involvement at invitation stage
• Reliance on health information:
  – Invitation & reminder letters
  – Bowel Cancer Screening: The Facts
  – Instruction leaflet
  – Results
  – Follow-up instructions
Readability

• Based on sentence and word length

• Flesch-Kincaid: (hard) 0-100 (easy)

• Harvard law review = 30

• Sun newspaper = 76

• The NHS BCSP ‘Facts’ booklet = 62
Communication Inequalities

- 5.1M English adults ≤ age 9-11 literacy level

- Is the information used in the NHS BCSP creating ‘communication inequalities’?
FOBT kit return by IMD score

54% uptake overall
61% in least deprived
35% in most deprived

von Wagner et al., 2012
The ASCEND Project

ASCEND

Design, evaluation and pilot stages

Nationwide RCT of enhanced reminder letter

Nationwide RCT of GP endorsed invitation letter

Nationwide RCT of ‘gist’ based information leaflet

Nationwide RCT of narrative information leaflet
Study 1: Testing ‘The Facts’ booklet

- Aim: To investigate how people process the NHS BCSP information booklet

Smith et al., 2015. HEX
‘Think-Aloud’ methodology

- Records utterances which represent content of short-term memory
- 18 participants
- Deprived sites in London and Midlands
- Mean age = 55 years [range 48-60]
Analysis

• Interviews transcribed
• Content analysis
  – Counting mistakes
• Thematic analysis
  – Coding utterances into framework
Results

- 776 coded utterances
- Mean = 43 per person [range 8-95]
- 270 reading mistakes
- Mean = 15 per person [range 0-59]
- Substantial variation in type of utterance
Background to NHS BCSP

Introduction to bowel cancer

The FOBt and possible outcomes

After the FOBt
Is screening for bowel cancer important?

About one in 20 people in the UK will develop bowel cancer during their lifetime.

over 16,000 people dying from it each year (Cancer Research UK, 2005. Cancerstats).

Regular bowel cancer screening has been shown to reduce the risk of dying from bowel cancer by 16% (Cochrane Database of Systematic Reviews, 2006. Screening for colorectal cancer using the faecal occult blood test: an update).

Numerical information:

“That’s about, yea, that’s one in 4 of the population isn’t it?” (IT, 51 years, Male, higher education).
Background to NHS BCSP

Introduction to bowel cancer

The FOBT and possible outcomes

After the FOBT
What does the bowel do?

The bowel is part divided into the small bowel and the colon and rectum. Food passes from the stomach to the small bowel. After the small bowel takes nutrients in, any undigested food passes through the colon, where it is converted into waste.

Scientific terminology:

‘Ok, I’m sure that’s correct but doesn’t strike me as particularly meaningful or enlightening in this context. I would prefer a more high level definition of what the bowel is actually. This just seems to provide too much detail…’ (SM, 51 years, Male, higher education).
Background to NHS BCSP

Introduction to bowel cancer

The FOBt and possible outcomes

After the FOBt
A **normal result** means that blood was not found in your test sample. Most people (about 98 out of 100) will receive a normal result. A small number of these people will have repeated the test due to an unclear result beforehand.

About **four people** out of every 100 will initially receive an unclear result.

About **two** in every 100 people doing the test will have an abnormal result.

**Miscomprehension:**

‘Does that equate with the 98 out of 100 in the previous paragraph? Something, somewhere doesn’t seem quite. 4 people out of 100 and then we had 98 out of 100, anyway, not quite sure about that’ (WW, 56 years, Female, higher education).
Background to NHS BCSP

Introduction to bowel cancer

The FOBt and possible outcomes

After the FOBt
Emotional reactions:

‘Oh, oh that is shocking…what on earth would they have had to do for that to happen – whether a heart attack…or you perforate the liver or something…’ (CW, 56 years, Female, higher education).

However, as with most medical procedures, there is the possibility of complications. These can include heavy bleeding (about a one in 150 chance) that needs further investigation or medical advice. The colonoscope can cause a hole (perforation) in the wall of the bowel (about a one in 1,500 chance). In extremely rare cases, colonoscopy may result in death. Current evidence suggests that this may only happen in about one in 10,000 cases.
Conclusion

- Difficulties processing complex information
- Sections miscomprehended (e.g. results)
- Difficulties extracting underlying meaning i.e. ‘gist’
Study 2: Designing the ‘Gist’ leaflet

• Aim:
  i) To design an information leaflet using principles of Fuzzy-Trace Theory
  
  ii) To evaluate the readability and comprehensibility of the leaflet

Smith et al., 2014 Patient Educ Couns
Fuzzy-Trace Theory (Reyna et al., 2008)

- **Gist**
  - Vague and qualitative
  - E.g. ‘My risk of CRC is high'

- **Verbatim**
  - Precise and quantitative
  - E.g. ‘I have a 1 in 20 chance of getting CRC’

- **Core values and background knowledge**

- **Judgements and decisions**

- **World views**
- **Basic skills**
- **Emotional state**

- Parallel processing model
- Preference for most simple gist
- Providing gist reduces cognitive burden
User-testing approach

- Design phase
  - Expert groups
  - Threshold of knowledge items not reached
    - Rounds of 6-10 people
    - 8 items had to be answered correctly by 80% of participants
- Structured interviews
- Threshold of knowledge items reached
- Comprehensible leaflet
Participants

• 28 participants (3 rounds)

• Recruited from community organisations

• Mean age = 53 years [range 41-60]
  – Naïve to screening process and information
Design process

• ‘Gist’ used (where possible)
• ‘Sign-posting’ to improve navigation
• Vernacular language (e.g. colorectal=bowel)
• Numerical information removed / reduced
• Concepts reduced (e.g. unclear results)
Round 1

- The FOB test lowers the risk of dying from bowel cancer
- Most people (98 out of 100) have a normal result

Flesch-Kincaid Reading Ease (out of 100) = 82.1
### Round 1

<table>
<thead>
<tr>
<th></th>
<th>Round</th>
<th>Correct n (%)</th>
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</tr>
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<td>6 (100)</td>
<td></td>
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</table>
Qualitative data

Language

‘...a couple of words in it that I thought might need thinking about...‘discuss’, I wonder whether ‘talk about’ would be more appropriate?’ (JP)

Abnormal results [not always cancer]

‘That’s inferred but it doesn’t necessarily say that’ (JP)
The NHS Bowel Cancer Screening Programme: A Two Minute Guide

An abnormal result does not always mean cancer has been found.

- The FOB test checks for tiny amounts of blood in stools (poo) that cannot be seen by
- A small number of people (2 out of 100) have
- until they are 70

What happens after the FOB test is done?

- The test kit is sent back to a laboratory in a freepost envelope
- The FOB test result is sent to the home within two weeks
- Most people (98 out of 100) have a normal result
- The FOB test lowers the risk of dying from bowel cancer
- Like all screening tests, the FOB test is not 100% accurate
- Bowel cancer that is not bleeding at the time of testing can be missed

To find out where you can get more information, see the back page.

Flesch-Kincaid Reading Ease (out of 100) = 79.4
### Round 2

<table>
<thead>
<tr>
<th>Statement</th>
<th>Round 1</th>
<th>Round 2</th>
<th>Round 3</th>
</tr>
</thead>
<tbody>
<tr>
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Qualitative data

Age extension

‘That’s all clear and it’s explained further, all very simple. But this I couldn’t get [age extension]. That’s like a random statement. It’s not really backed up or [explained] why’ (GE)

Title

‘This is meant to be a two minute guide. Well people read at their own pace and you know they might think well, oh. A simple guide? Or is that being patronising…or the essentials?’
Round 3

- Bowel cancer is a common cancer in people aged 60 and over
- The Faecal Occult Blood (FOB) test can spot signs of bowel cancer early
- The FOB test is for men and women, even if they do not have bowel problems
- Doing the FOB test lowers the risk of dying from bowel cancer
- Everyone aged 60-69 is sent the FOB test to do at home every 2 years
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Conclusion

• Successful method

• Good readability (11-12 years)

• Comprehensible (80% threshold passed)
Evaluating the gist-based leaflet

- Regional randomised controlled trial\(^1\)
  - Improved knowledge but no influence on intentions

- National cluster randomised controlled trial\(^2\)
  - No difference in uptake

1. Smith et al., 2014 Behav Med; 2. Wardle et al., 2015 Lancet
Conclusion

- NHS BCSP information materials are complex and can lead to miscomprehension
- FTT useful model for designing information
- User-testing can optimise information
- Would like to test the gist-based leaflet as a standalone document…
DEDICATED TO THE MEMORY OF
PROFESSOR JANE WARDLE PhD, FBA, FMedSci

OCTOBER 30TH 1950 – OCTOBER 20TH 2015
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Wider study team
ASCEND collaborators

Recruitment
SAfH
ContinYou
Thank you for listening

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