Institution: University of Essex

Unit of Assessment: 4 – Psychology, Psychiatry and Neuroscience

Title of case study: The NHS Bowel Cancer Screening Programme: Psychological aspects of development and implementation

1. Summary of the impact

Essex contributed to the independent evaluation of the UK NHS Bowel Cancer Screening Pilot programme by conducting the psychosocial aspects of this research. The evaluation recommended full roll-out, and was used to inform the programme's subsequent development and implementation. Nationwide screening for 60-69 year olds, using the Faecal Occult Blood test, began in 2006 and in 2010 the programme was extended to include adults up to their 75th birthday. Since July 2006 over 17 million screening episodes have been completed and 15,000 cancers detected. It is estimated that the programme is on track to cut deaths by 16%.

2. Underpinning research

Background: Bowel (colorectal) cancer is the third most common cancer in the UK and the second leading cause of cancer mortality, accounting for 16,013 deaths in 2010 (http://www.bowelcancerwest.org.uk/information.php?t=Bowel-Cancer-Statistics&s=About-Bowel-Cancer&id=69). It is intended that screening can lead to detection at an early stage (in people with no symptoms), when treatment is more likely to be effective. Such screening can also detect polyps, which may develop into cancers over time. In 2000 the Department of Health (DoH) set up a National Bowel Screening Pilot based on faecal occult blood testing (FOBt). This involved two English Health Authorities and three Scottish Health Boards, with male and female participants aged 50-69 years. The pilot ran from 2000 to 2007 involving 478,250 residents in England and Scotland (www.cancerscreening.nhs.uk/bowel/pilot.html).

Evaluation Research: The DoH commissioned an independent evaluation of the UK pilot (grant 1). This had the aim of assessing screening uptake as well as establishing whether the results of earlier trials would be reproducible on a larger scale. It was also intended to guide and inform the potential roll-out of the screening programme to a much wider audience. The evaluation ran from 2000-2002 (reporting in July 2003) and comprised a single study of both the English and Scottish sites, conducted by a multi-disciplinary team. Psychological research was conducted at the University of Essex (Professor Sheina Orbell); Epidemiological, Economic and Primary Care research was conducted at the University of Edinburgh (Professor David Weller and Professor Freda Alexander); and Management research was conducted at the University of Warwick (Professor Ala Szczepura).

Contribution of Essex Research: The research conducted at Essex for the psychological part of the pilot evaluation specifically focused on measurement of the acceptability of screening and the influence of socio-demographic and psychological variables on uptake of the screening test. This was particularly important as the screening programme itself had two unique aspects. It would be the first UK screening programme to involve both men and women. It would also take the form of a self-sampling (FOBt) kit, which meant people had to take stool samples themselves and post them to the laboratory for testing. This introduced a number of additional factors to be considered when evaluating the psychological aspects of the pilot's uptake. The research focused on a sample of 2292 people invited for screening as a part of the pilot, and assessed:

a) psychological distress associated with the screening process as well as with colonoscopy, (which was being offered in those cases where abnormal results were returned);
b) beliefs and attitudes associated with uptake versus non-uptake of screening;
c) association of behavioural risk indices such as diet and exercise, with uptake-non-uptake of screening;
d) the impact of an abnormal screening result on subsequent health behaviour change.

Research Findings and Outcomes: The research demonstrated that the self-sampling kit and instructions appeared to pose a number of (self-efficacy and negative outcome-expectancy) challenges to participation, and prompted a subsequent study of 500 people (grant 2), which investigated strategies for completion in some detail. This also instigated a pilot intervention study funded by the National Institutes of Health (grant 3), concerning the development of a leaflet intervention based upon implementation intentions. This proved to be very successful in increasing uptake (by nearly 10%) amongst low socio-economic status population groups. Another early insight showed that screening uptake was significantly lower amongst ethnic minorities. Following the Race Relations Amendment Act 2000, the DoH commissioned Essex, in partnership with Warwick, to conduct an additional evaluation (grant 4) to focus exclusively on social, cultural and psychological factors associated with this low uptake. The psychological research conducted at Essex involved a survey of 1000 Indian, Pakistani and Bangladeshi invitees, and identified specific psychological belief-processes differentiating these groups from the British white population sample in the main evaluation.

Summary: Based on the psychological aspects of the pilot evaluation research, Essex drew conclusions and made recommendations relating to the uptake and acceptability of both screening and colonoscopy. These were useful in informing timely and effective implementations, as well as providing insight into the uptake and acceptability of the pilot. In general, good levels of uptake and acceptability were found and the research was unable to detect sustained adverse psychological side-effects. Orbell's research also highlighted a number of challenges that had been experienced, identified possible causes, and outlined means by which they could be avoided e.g. through the recommendation of greater use of tailored recruitment strategies towards groups having low engagement with the pilot.

3. References to the research [can be supplied by HEI on request]

The UK CRC Screening Pilot Evaluation Team (2003) *Evaluation of the UK Colorectal Cancer Screening Pilot: Final Report*. Available from: www.cancerscreening.nhs.uk/bowel/finalreport.pdf [Accessed 30 October 2013]

The UK CRC Screening Pilot Evaluation (Ethnicity) Team (2003) *Ethnicity: UK Colorectal Cancer Screening Pilot: Final Report.* Available from: www.cancerscreening.nhs.uk/bowel/ethnicity-finalreport.pdf [Accessed 30 October 2013]

O'Sullivan, I. and S. Orbell (2004) Self-sampling to reduce mortality from colorectal cancer: A qualitative exploration of the decision to complete a Faecal Occult Blood Test (FOBT). *Journal of Medical Screening*, 11(1), 16-22. DOI:10.1177/096914130301100105

O'Sullivan, I., S. Orbell, T. Rakow and R. Parker (2004) Prospective research in health service settings: Psychology, science and the 'Hawthorne effect'. *Journal of Health Psychology*, 9(3), 355-359. DOI:10.1177/1359105304042345

Orbell, S., M. Perugini and T. Rakow (2004) Individual differences in sensitivity to health communications: Consideration of future consequences. *Health Psychology*, 23, 388-396. DOI:10.1037/0278-6133.23.4.388

Hagger, M.S. and S. Orbell (2006) Illness representations and emotion in people with abnormal screening results. *Psychology and Health,* 21(2), 183-209. DOI:10.1080/14768320500223339

Orbell, S., I. O'Sullivan, R. Parker, B. Steele, C. Campbell and D. Weller (2008) Illness representations and coping following an abnormal colorectal cancer screening result. *Social Science and Medicine*, 67(9), 1465-1474. DOI:10.1016/j.socscimed.2008.06.039

Techer, L., C. Campbell, D. Weller, S. Orbell, A. Szczepura and A. Gumber (2009) Strategies to improve uptake of colorectal cancer screening in South Asian and lower income groups – a qualitative study. In: *British Psycho-Social Oncology Society 2008 Conference, Leeds, England, December 04-05, 2008*. Published in: *Psycho-Oncology*, 18(3), 310-311. DOI:10.1002/pon.1549

Research funding:

(1) Weller, Alexander, Orbell, Szczepura, *Evaluation of colorectal cancer screening pilots (Psychosocial determinants of uptake)*, UK Department of Health (DoH), 2000 – 2003, total: £319,000, Essex portion: £83,895

(2) Orbell, *A pilot study to develop a self-efficacy enhancing intervention for use of faecal occult blood screening kits used in prevention of colorectal cancer*, University of Essex Research Promotion Fund, 2005, £4,506

(3) Weller, Campbell, Orbell, Szczepura, *Colorectal cancer screening – Primary care strategies*, National Institutes of Health (NIH) (US), 2006 – 2008, total: $232,000, Essex portion: £11,000

(4) Szczepura, Orbell, Johnson, *Colorectal cancer screening evaluation: Ethnicity (Psychosocial determinants of uptake)*, UK Department of Health (DoH), 2001 – 2003, total: £76,599, Essex portion: £34,083

4. Details of the impact

Essex undertook the psychosocial research aspects of the screening pilot evaluation. This work has primarily had impact in two ways. Firstly, the conclusion that there was no evidence to suggest adverse psychological effects from screening was an important influencing factor in the decision to roll-out the screening on a national scale. Secondly, research focussing on the psychological aspects of the pilot also identified psychologically-informed strategies by which the level of screening test uptake, and hence its associated benefits, could be maximised. As an example, results concerning uptake and acceptability proved to be useful in informing strategies to overcome limiting factors for underrepresented groups. Both main impacts are recognised in a letter of support from the Director of NHS Cancer Screening Programmes, who oversaw the pilot and subsequent roll-out on behalf of the NHS [see corroborating source 1]. In this letter, the Director explains how:

> "Professor Orbell's research made an important contribution to inform the decision that the screening should be rolled out in a national programme. Given that this was the first programme of its kind to use the self-sampling FOBT kit and the first cancer screening programme to involve men as well as women, understanding the uptake and acceptability of the pilot programme was particularly important".
>
> *Director, NHS Cancer Screening Programmes*

Drawing on the conclusions and recommendations of the pilot evaluation, full roll-out of the NHS Bowel Cancer Screening Programme (BCSP) using the FOBt was completed in July 2010. This achieved 100% coverage of PCT populations and in the first instance focussed on 60-69 year olds, as detailed in the 2011 DoH report *Improving Outcomes: A Strategy for Cancer* [2, p.40]. The impact of the BCSP is extensive and unprecedented. Between July 2006 and July 2013, over 17 million screening episodes had been completed and 15,000 cancers had been detected [1]. *Improving Outcomes* also reports that as of December 2010, 40,000 patients had also undergone polyp removal [2, p.40]. The use of the self-sampling FOBt kit was important in making screening widely accessible, and it provided a good balance of ease of use and efficiency. The pilot evaluation had highlighted, in 2003, that the ability to undergo a self-test in the privacy of one's own home imbued a sense of personal autonomy, and that patients often perceived less embarrassment from this means of testing. As screening was subsequently rolled-out, amongst a sample of people interviewed it was reported how most were finding it straightforward to undertake the test [3].

In December 2007 the NHS Cancer Reform Strategy stated that, from April 2010, the screening programme would be extended to invite men and women up to the age of 75 [4, p.8]. This was reaffirmed by the Coalition Government in January 2011 [2, p.40]. The NHS Operating Framework of 2011/12 also asserts the intention to continue to screen adults in the target age range every 2 years [5, p.39]. Whilst it is too soon to measure the effective decline in bowel cancer mortality that will accrue from the 2006 roll-out of screening, there is strong evidence to suggest that screening is indeed enabling a reduction. A statistical analysis of figures in Scotland, that compares the mortality rates amongst those who were invited to take part in the screening *pilot* between 2000 and 2007 and those who were not, shows a dramatic impact of screening, suggesting that the full roll-out will have the same positive effect. This analysis was published in the *BMJ* in 2011 [6]. The study shows that people who were invited to take part in the screening pilot had a 10% lower mortality rate than people who were not invited (intention to treat analysis). Furthermore, when comparing those who were invited and *actually participated* in screening with those who were not invited, the benefit was a 27% decline in bowel cancer mortality. Hence, it is suggested that the screening programme has the potential to save more than 1000 lives every year as it continues. In

2011, following the return of the first million kits, the Programme's Director indicated that it was on track to cut deaths by 16% [1] [7].

In addition to the use of Orbell's research in informing the decision to roll-out the programme, the psychological aspects of the evaluation have also been used to guide and inform recruitment campaigns. Part of the pilot evaluation exercise had identified beliefs and attitudes amongst underrepresented groups. These findings were then used to inform the use of targeted recruitment campaigns intended to increase uptake. For example, the 2007-11 Men's Health Forum (MHF) *Bowel Cancer Project* targeted greater male participation in the Bowel Cancer Screening Programme. The MHF's 2011 final report referenced the research of Orbell, using insight provided by the focus groups from the bowel cancer screening programme evaluation. In particular, it highlighted how factors from the pilot which were seen as positive could be used to increase male uptake [8, p.22]. In another example, again using knowledge gained from the psychological aspects of the pilot evaluation, Orbell consulted on the *healthtalkonline* website. Since May 2007 this has provided extensive advice and resources, as well as encouraging discussion, designed to help people decide whether to take part in bowel cancer screening, and also to help them complete the sampling kits [9]. In a wider context, at governmental level, Orbell's work is recognised in the 2008 *Gender and Access to Health Services Study* [10, p.80], as well as a report written for the US Agency for Healthcare Research and Quality, *Enhancing the Use and Quality of Colorectal Cancer Screening*, AHRQ Publication No. 10-E002, February 2010 [11, p.32].

5. Sources to corroborate the impact [All sources saved on file with HEI, available on request]

[1] Director, NHS Cancer Screening Programmes, Directorate of Health and Wellbeing, Public Health England

[2] Department of Health, 2011. *Improving Outcomes: A Strategy for Cancer* [pdf] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213785/dh_123394.pdf [Accessed 14 June 2013]

[3] healthtalkonline.org, 2010. *The Faecal Occult Blood test for bowel cancer: Doing the Faecal Occult Blood test at home* [online] Available at: http://www.healthtalkonline.org/cancer/Bowel_screening/Topic/1392/ [Accessed 17 September 2013]

[4] NHS, 2007. *Cancer Reform Strategy* [pdf] Available at: http://www.cancerscreening.nhs.uk/cervical/cancer-reform-strategy.pdf [Accessed 14 June 2013]

[5] NHS, 2010. *The Operating Framework for the NHS in England 2011/12* [pdf] Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216187/dh_122736.pdf [Accessed 14 June 2013]

[6] *Population based screening in Scotland reduces bowel cancer deaths*, Wise, BMJ, 2011;343:d7304. DOI: 10.1136/bmj.d7304 (Available at: http://www.bmj.com/content/343/bmj.d7304.pdf%2Bhtml) [Accessed 14 June 2013]

[7] Department of Health, 2011. *The NHSBCSP in England is on track to cut bowel cancer deaths by 16 per cent* [online] Available at: http://www.cancerscreening.nhs.uk/bowel/news/010.html [Accessed 14 June 2013]

[8] Men's Health Forum, 2011. *Slow on the uptake? Encouraging male participation in the NHS Bowel Cancer Screening Programme* [pdf] Available at: http://www.menshealthforum.org.uk/content/slow-uptake-encouraging-male-participation-nhs-bowel-cancer-screening-programme [Accessed 14 June 2013]

[9] healthtalkonline.org, 2007. *Bowel screening, Credits* [online] Available at: http://www.healthtalkonline.org/cancer/Bowel_screening/Credit [Accessed 14 June 2013]

[10] Department of Health, 2008. *Gender and Access to Health Services Study* [pdf] Available at: http://www.sfhtr.nhs.uk/attachments/article/41/The%20gender%20and%20access%20to%20health%20services%20study.pdf [Accessed 14 June 2013]

[11] RTI International-University of North Carolina Evidence-based Practice Center, 2010. *Enhancing the Use and Quality of Colorectal Cancer Screening* [pdf] Available at: http://www.ncbi.nlm.nih.gov/books/NBK44526/pdf/TOC.pdf [Accessed 14 June 2013]