

<b>Institution:</b> University of Essex		
<b>Unit of Assessment:</b> 4- Psychology, Psychiatry and Neuroscience		
<b>Title of case study:</b> Saving lives by promoting population bowel cancer screening: Psychological aspects of screening uptake and coverage.		
<b>Period when the underpinning research was undertaken:</b> July 2000 – December 2012		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Professor Sheina Orbell	Professor	July 2000-present
<b>Period when the claimed impact occurred:</b> 1 <sup>st</sup> August 2013- 31 December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> Yes. See Section 4.		
<p><b>1. Summary of the impact</b></p> <p>Bowel cancer is a major threat to life. In 2000 the NHS commenced a UK Pilot to assess the feasibility of introducing a National Bowel Cancer Screening Programme (BCSP). Essex conducted all the psychosocial aspects of the evaluation of the UK Pilot. The evaluation research underpinned the policy decision to commence roll-out of population screening across the UK in 2006 and guided the programme's subsequent development. Since August 2013 <b>screening population coverage increased to 61%</b> reaching the national target for the first time. Over 20 million more screening episodes have been completed and <b>more than 26,000 screen detected cancers have received early treatment</b>. The programme has now achieved 12% <b>reduction in colorectal cancer mortality</b>. Essex research has informed new post 2013 screening programme developments including the phased <b>introduction of an alternative test method (FIT)</b> across the UK with concomitant increases in uptake, and specific and targeted <b>programmes to increase uptake, particularly amongst the under-represented lower SES and BAME populations</b>.</p>		
<p><b>2. Underpinning research</b></p> <p><b>Bowel Cancer Screening.</b> Bowel cancer is the second leading cause of cancer mortality in the UK, yet mortality can be reduced by regular screening. Bowel cancer screening reduces mortality by detecting pre-symptomatic disease when treatment is more likely to be effective. Screening also reduces incidence by detecting and treating non-cancerous polyps (adenomas) that may otherwise develop into cancers over time. Clinical trials have shown that regular bowel cancer screening can reduce risk of dying by over 16%. Translating these potential gains to wider society, however, requires <b>adequate population participation</b>. From 2000-2007 the UK Department of Health (DoH) undertook a feasibility <b>National Bowel Screening Pilot</b> based on faecal occult blood testing (FOBT) during which 478,250 men and women aged 50-69 years resident in England and Scotland were offered screening. The UK was amongst the first countries worldwide to consider implementation of a population-wide early detection programme.</p> <p><b>Research to Evaluate the Screening Pilot:</b> The DoH separately commissioned [G1] a multi-disciplinary independent evaluation of the pilot outcomes (2000-2002, reporting in July 2003: [R1]), to inform the feasibility of a nationwide roll-out of a population bowel cancer screening programme in the UK. <b>The psychosocial research was conducted by Professor Orbell at the University of Essex</b>. Epidemiological and economic research was conducted at the University of Edinburgh (Professor David Weller and Professor Freda Alexander) and management systems research was conducted at the University of Warwick (Professor Ala Szczepura).</p> <p><b>Psychosocial Research and Insights.</b> Bowel screening had two unique aspects. It was the first UK screening programme to involve both men and women and also the first to take the form of a self-sampling (FOBT) kit, requiring people to take samples of their own stool to post to a laboratory for testing. The initial psychological research concerning a random sample of 2,292 invitees to the pilot focused upon examining acceptability, psychological side-effects, and identifying beliefs, attitudes and behavioural risk indices associated with screening uptake [R1].</p> <p>The evaluation research did not detect sustained adverse psychological side effects, whether amongst those with normal or abnormal results, contributing to <b>the conclusion that potential</b></p>		

**bowel screening benefits would not be offset by psychological harm [R1, R2].** Examination of emotional responses to abnormal results [R1, R3] identified particular patterns of illness beliefs associated with positive lifestyle impacts of screening.

The kit proved broadly acceptable and achieved adequate uptake to make screening cost effective. It was established that on roll out, a 60% uptake standard should be achievable. However, uptake was substantially lower amongst socioeconomically deprived individuals. The research demonstrated that **the self-sampling kit and instructions appeared to pose a number of challenges to participation.** In particular, **people who did not complete the kit in the pilot study had very low self-efficacy with regard to their ability to complete and store the 3 samples required by the kit, doubted their need for screening in view of being asymptomatic, and perceived possible negative consequences of taking part [R1, R4, R5].** Findings prompted a subsequent study of 500 people [G2], which investigated strategies for kit completion in more detail. This also instigated a pilot intervention study funded by the National Institute of Health (NIH) (US) [G3, R7], to develop a leaflet based upon implementation intentions that proved successful in increasing uptake (by nearly 10%) amongst under-represented low socio-economic population groups.

Another early insight was that **screening uptake appeared lower amongst BAME** individuals yet could not be definitively evidenced from [G1] because ethnicity was not adequately recorded on medical records [R1]. Following the Race Relations Amendment Act 2000, the DoH commissioned Essex, in partnership with Warwick, to **conduct an additional research project [G4, R6, R7]** to focus exclusively on social, cultural and psychological factors associated with the low uptake amongst South Asian Britons. The results [R6] provided, for the first time, definitive evidence that uptake varied by ethnicity and consequently was a source of health inequality. The psychological research conducted at Essex involved a survey of 1000 British-Indian, Pakistani and Bangladeshi invitees identified and sampled by means of specialist name identification software. Results identified specific psychological belief-processes differentiating Asian Britons from the British white population sample in the main evaluation, and showed that **these groups experience higher psychological costs associated with screening** (e.g. greater concerns about negative outcomes on family) and **lower self-efficacy**. This research, having identified possible causes, made recommendations for use of tailored recruitment strategies towards groups having low engagement with the pilot.

**3. References to the research (Publications and grants listed in the 2014 case)** Competitively awarded grants, reports to DoH, and peer reviewed publications in established Q1 and Q2 international journals in the field (Mean IF = 2.82). PDFs available from the HEI.

**R1** UK CRC Screening Pilot Evaluation Team (members/authors shown on p.5). (2003). *Evaluation of the UK Colorectal Cancer Screening Pilot: Final report*. PHE:

[https://legacyscreening.phe.org.uk/policydb\\_download.php?doc=384](https://legacyscreening.phe.org.uk/policydb_download.php?doc=384). Scotland:  
<https://www.sehd.scot.nhs.uk/publications/ColorectalCaScreenPilotEval2003.pdf>

**R2** Hagger, M. S., & Orbell, S. (2006). Illness representations and emotion in people with abnormal screening results. *Psychology and Health*, 21, 183-209. doi: 10.1080/14768320500223339. (IF = 2.528)

**R3** Orbell, S., O'Sullivan, I., Parker, R., Steele, R. J. C., Campbell, C., & Weller, D. (2008). Illness representations and coping following an abnormal colorectal cancer screening result. *Social Science and Medicine*, 67, 1465-1474. doi: 10.1016/j.socscimed.2008.06.039 (IF = 3.616)

**R4** O'Sullivan, I., & Orbell, S. (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, 16-22. doi: 10.1177/096914130301100105. (IF = 1.897)

**R5** Orbell, S., Perugini, M., & Rakow, T. (2004). Individual differences in sensitivity to health communications: Consideration of future consequences. *Health Psychology*, 23, 388-396. <http://doi.org/10.1037/0278-6133.23.4.388>. (IF = 3.052, 203 cites GS).

**R6** UK CRC Screening Pilot Evaluation (Ethnicity) Team (members/authors shown on p.3) (2004). *Ethnicity: UK Colorectal Cancer Screening Pilot: Final Report* (available on request).

**R7** Techer, L., Campbell, C., Weller, D., Orbell, S., Szczepura, A., & Gumber, A. (2009). Strategies to improve uptake of colorectal cancer screening in South Asian and lower income groups – a qualitative study. *Psycho-Oncology*, 18, 310-311. doi: 10.1002/pon.1549. (IF = 3.006).

**Competitively Awarded Bowel Cancer Screening Research Grants, UK & USA**

**G1** Weller,D. Alexander,F. Orbell,S. Szczepura,A. *Evaluation of colorectal cancer screening pilots* (Psychosocial determinants of uptake), UK Department of Health, 2000 – 2003, total: £319,000

**G2** Orbell,S. *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

**G3** Weller,D. Campbell,C. Orbell,S. Szczepura,A. *Colorectal cancer screening – Primary care strategies*, National Institutes of Health (US), 2006 – 2008, total: \$232,000 (£126,086).

**G4** Szczepura,A. Orbell,S. Johnson,M *Colorectal cancer screening evaluation: Ethnicity* (Psychosocial determinants of uptake), UK Department of Health, 2001 – 2003, total: £76,599

**4. Details of the impact**

**Impact Continuation Statement:** The REF2014 case demonstrated that the underpinning research described in Section 2 informed the decision by the NHS to commence UK roll out of the BCSP in 2006. Orbell's evaluation confirmed that adverse psychological effects of screening would not outweigh benefits, that the test was broadly acceptable, and identified psychologically informed strategies by which the level of screening test uptake, and hence its associated benefits, could be improved. The Director of NHS Screening Programmes confirmed: "**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". (See REF2014 case: *The NHS Bowel Cancer Screening Programme: Psychological aspects of development and implementation*).

**Since August 2013** the decision to roll-out screening that was informed by Essex research has led to **increases in population screening coverage with associated benefits for detection and treatment of cancers and adenomas, and decline in cancer incidence and mortality** that could not be evaluated so soon after roll out in 2013. The research outlined in Section 2 has also led to **important post 2013 improvements to programme delivery across the UK, in particular the introduction of a simpler self-sampling kit (FIT) with further benefits for uptake especially amongst under represented populations.** The research continues to **inform public health activities that increase uptake** in parts of the UK where uptake is suboptimal.

Drawing upon the recommendations of the pilot evaluation [**G1, R1**], roll out of the Bowel Cancer Screening Programme across the UK to adults aged 60-69 years commenced in 2006 and in 2010 the programme was extended to include people aged 70-74 years of age. **Throughout 01/08/2013 – 31/12/2020, the UK National Screening Committee annual review has continued to recommend bowel screening as UK Public Health Policy [S1]** and bowel screening has continued to be offered every two years to men and women aged 60-74 in England, Wales and Northern Ireland and to men and women aged 50-74 in Scotland.

**Increases in Population Screening Coverage and Associated Detection and Treatment Benefits since August 2013**

Since changes to the NHS in 2013, data are independently reported by four separate public health administrations collectively representing the UK. **Increases in coverage and uptake since 2013 have been observed in all four countries.** Coverage, defined as the proportion of the population eligible for screening who were screened adequately within the preceding two and a half years (i.e. 'took up an invitation and have an up to date screening record') increased in England from 35% in 2009/10 when roll out was first completed, to 56% in 2013/14. From 2013/14 coverage increased to 60.5% in 2018/19, meeting and exceeding the programme target of 60% for the first time [**S2a**]. Promising improvements in coverage since 2013/2014 have also been observed in Wales (from 50.0% in 2013/14 to 55.7% in 2019) [**S2b**]. Uptake (i.e. response to a given invitation) in Scotland reached 61.6% in 2017-2019 [**S2c**] and in Northern Ireland the national target was exceeded for the first time in 2017/18 (61.34%) [**S2d**].

During 2013-2020 more than 33 million people were invited to complete a bowel screening test kit,

over 20 million new screening episodes were successfully completed and more than 26,000 screen detected cancers were treated across the UK [S3].

#### **Advances in Saving Lives by Reduced Bowel Cancer Incidence and Mortality**

The impact of bowel screening is extensive and unprecedented in its ability to detect and treat benign adenomas in order to reduce cancer incidence, and in detecting cancers early so as to benefit from advances in treatment that increase survival. **During 01/08/2013 – 31/12/2020, declines in incidence and mortality have been documented [S4a-b].**

**Incidence of newly diagnosed colorectal cancer per 100,000 population for the UK as a whole decreased [S4a]** from 75 per 100,000 at the end of roll out in 2010, to 72 per 100,000 in 2013, with a further decline to 68 per 100,000 in 2017. **Evidence of reduced incidence is particularly noteworthy amongst men across the UK (from 90 per 100,000 in 2013 to 83 per 100,000 in 2017; a decline of 8% [S4a]) and in specific areas of high cancer incidence.** For example, an analysis published in 'BMJ' in 2020 by the Independent Chair of the NHS Screening Committee showed that **incidence of bowel cancer amongst 50-74 year olds in Scotland has fallen from 156.5 cases per 100,000 in 2010 to 123.9 cases per 100,000 in 2017, a decrease of approximately 21% [S4b].**

**Mortality from colorectal cancer has also declined across the UK.** From the introduction of population screening (figures for 2006-2008 period) to 2016-2018, **age standardized mortality has decreased by 12% for men and women combined**, 14% for men and 11% for women. **Gains in lives saved since 2013** are particularly apparent for 75 -79 year olds for whom mortality per 100,000 declined from 122 per 100,000 in the 2011-13 reporting period to 111 per 100,000 in 2016-2018 and for 60-74 year olds (from 54 per 100,000 in 2011-13 to 49 per 100,000 in 2016-2018) [S4a].

#### **Improvements to the Screening Programme Delivery to Extend Uptake and Benefits, Particularly to Under-represented Population Groups (Low SES and BAME).**

The pilot evaluation research [R1, R4, R5, R6, R7] reported that people who did not complete the FOBt self-sampling kit found it difficult, lacked self-efficacy, and perceived psychological costs such as distaste in storing 3 samples [Section 2]. The evaluation team recommended in 2003 [R1: p.6, p.66, p.68, p.91, p.188], that the DoH consider the use of an alternative simpler self-sampling kit, known as the Faecal Immunochemical Test (FIT) ([cf. [S5] p.113 "*The evaluation of the pilot also recommended that consideration should be given to the use of immunochemical tests*"). **A decision to implement this 2003 recommendation from the Pilot Research Evaluation Team and to adopt FIT was made by the National Screening Committee in 2016 [S6a].** FIT was implemented in Scotland in November 2017 (England; June 2019; Wales; September 2019; Northern Ireland; January 2021 [S6b, p.2]. Recognising the psychological barriers identified by Essex research, PHE note that "*the FIT test requires just one sample rather than 3 and will make it easier to take part*" [S6c, p.5].

In Scotland, **introduction of FIT in 2017 has increased bowel screening uptake by 8.5%** (from 56.2% (2015-17 reporting period) to 64.1% (2017-2019 reporting period). Prior to the introduction of FIT, screening in Scotland had never previously reached the nationally set achievable standard of 60% uptake. Of particular importance, **the greatest increase in uptake after FIT was observed among people from the most socioeconomically deprived areas** (from 42.0% to 51.8%) [S7a] thereby reducing health inequality. KPI reports for screening in England released in February 2020 [S7b, p. 34] show a remarkable increase in uptake from 62.1% in the first quarter of 19/20 to 67.5% in the second quarter following the introduction of FIT. There are promising signs from Wales [S7c] that FIT (rolled out September 2019) is improving uptake. The 18/19 uptake was the highest ever achieved in Wales to date, at 57.3% (vs. 55.7% in 17/18) [S7c].

**Research insights from the psychosocial evaluation have continued to inform public health activities to promote uptake across the UK.** For example: Cancer Research UK's Guide for Health Professionals to help reduce inequalities under 'What can you do to support your practice patients? [S8] refers to barriers identified in [R4]: 'A misconception that the test is not applicable if



you don't have any apparent symptoms of bowel cancer' and 'Concerns around the practicalities and cleanliness of the test' in its summary of identified barriers [S8].

Results from [G4, R6] informed the Director of Public Health for Newham, London's strategy to improve uptake, Newham is an area with some of the lowest bowel cancer screening coverage in the UK: below 40%: S9 p.16). The report [S9] notes that uptake in Newham was likely to reflect unique evidence from [G4, R6] [cf. 13 in source S9] that uptake varies by ethnicity *'It does appear that there are particular ethnic and religious groups with low uptake of bowel screening. In a pilot study of FOB screening in England, there was a lower uptake in Asian groups: 44% in those who identified themselves as Hindus, and as low as 32% in those who identified themselves as Muslims'*. Newham consequently implemented strategies that were culturally responsive, for example telephone contact by *'Paid bilingual facilitators who understand the socio-cultural nuances of different Newham communities.'* (p.20, [S9]), in line with the greater use of tailored recruitment strategies towards groups having low engagement with the pilot as advocated in [R6]. Screening coverage in Newham subsequently increased from 35.5% in 2015 to 47.7% in 2018/19 [S9b].

Similarly, the research has informed Public Health Wales' 2016 campaign [S10] to improve a 51% 2013 participation rate via strategies such as the provision of rubber gloves in postal kits that addressed acceptability and storage barriers identified by Orbell's research [R1, R4].

## 5. Sources to corroborate the impact

**S1** National Screening Committee Recommendation to continue biennial screening across UK (accessed 01.07.20).

**S2 (a-d)** **a:** Bowel screening coverage in England 2009-2019 accessed 22.05.20 and Public Health England 2020 KPI Factsheet, p.35. **b:** Public Health Wales Annual Statistical Reports 2013-14 p.7 and 2018-19 p.11. **c:** Public Health Scotland KPI One, Table 1.1. **d:** Northern Ireland Neighbourhood Information Service accessed 17.02.2021 2017-18 uptake.

**S3** Email communication from Independent Chair, NHS Screening Programme confirming number of screens and screen detected cancers from 2013-2020. 09.02.2021.

**S4 (a-b)** **a:** Data confirming declines in Bowel Cancer Incidence and Mortality since 2013 from Cancer Research UK. **b:** Published article pdf from BMJ.

**S5** "Independent review of screening programmes in England" reporting the recommendation made in [R1] to introduce FIT (on page 113 referring back to recommendation made in [R1])

**S6 (a-c)** **a:** UK National Screening Committee decision to implement FIT in 2016: "UKNSC Screening in the UK: Making Effective Recommendations 2015-2016" (p.9) **b:** CRUK implementation of FIT in different countries across the UK accessed 17.02.2021 (p.2) **c:** PHE 2016-2017 report, quote p.5 on easier use of FIT.

**S7(a-c)** **a:** Public Health Scotland Data and Intelligence and KPI report Nov. 2019 (FOBT vs. FIT tables C1 and C3) **b:** Public Health England Screening KPI fact-sheet, February 2020 (p. 34) **c:** Public Health Wales Annual Statistics 18/19 (Table 1c, p. 15) and 17/18 (Table 1c, p.14)

**S8** Cancer research UK Guide for Health Professionals to increase uptake citing [R4]. (accessed 19.03.2020)

**S9** Director of Public Health, Newham, London, Annual Report "Improving uptake of bowel cancer screening in Newham (2015-2016) citing [R6]

**S10** Wales Bowel Cancer Screening Pilot Evaluation Report, August 2016