

## **VOLUME 2**

# **IDENTIFYING HARD-TO-REACH GROUPS: A REVIEW OF THE FACTORS (INCLUDING BARRIERS) ASSOCIATED WITH CANCER SCREENING**

**Prepared for the Victorian Cytology Service  
by**

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# TABLE OF CONTENTS

<b>TABLE OF CONTENTS .....</b>	<b>2</b>
<b>LIST OF TABLES.....</b>	<b>4</b>
<b>LIST OF FIGURES .....</b>	<b>5</b>
<b>1. INTRODUCTION .....</b>	<b>6</b>
<b>2 METHODOLOGY.....</b>	<b>8</b>
2.1 LOCATING THE LITERATURE .....	8
2.2 REVIEW STRATEGY.....	8
<b>3 DEMOGRAPHIC FACTORS.....</b>	<b>10</b>
3.1 AGE .....	10
3.2 GENDER .....	16
3.3 ETHNICITY .....	18
3.4 SOCIOECONOMIC STATUS .....	22
3.5 EDUCATION .....	27
<b>4 COGNITIVE FACTORS.....</b>	<b>30</b>
4.1 LITERACY .....	31
4.2 HEALTH LITERACY .....	33
4.3 CANCER-RELATED KNOWLEDGE.....	36
4.4 PERCEIVED RISK .....	38
4.5 PERCEIVED AMBIGUITY .....	40
<b>5 PSYCHOSOCIAL FACTORS .....</b>	<b>44</b>
5.1 FEAR/ANXIETY/WORRY .....	45
5.2 COPING STYLE (EMOTION REGULATION).....	46
5.3 SOCIAL NETWORKS .....	46
<b>6 HEALTH AND LIFESTYLE.....</b>	<b>51</b>
6.1 PHYSICAL/MENTAL HEALTH .....	51
6.1 DRUG USE: ALCOHOL AND TOBACCO CONSUMPTION .....	54
6.3 PREVIOUS PARTICIPATION IN SCREENING.....	54
<b>7 Cultural FACTORS.....</b>	<b>59</b>
7.1 ACCULTURATION.....	59
7.2 FATALISM.....	61
7.3 MODESTY/EMBARRASSMENT/SHAME .....	62
7.4 MEDICAL MISTRUST.....	63
7.5 COLLECTIVISM/COMMUNALISM .....	64
7.6 SPIRITUALITY/RELIGIOSITY.....	64
<b>8 HEALTH SYSTEM FACTORS .....</b>	<b>66</b>
8.1 AVAILABILITY.....	66
8.2 ACCESSIBILITY.....	70
8.3 AFFORDABILITY.....	72
8.3 ACCEPTABILITY .....	74
<b>9. DISCUSSION AND IMPLICATIONS.....</b>	<b>77</b>

9.1	DISCUSSION .....	77
9.2	IMPLICATIONS .....	81
	<b>REFERENCES .....</b>	<b>84</b>
	<b>APPENDIX: CANCER SCREENING LITERATURE REVIEWS .....</b>	<b>90</b>

## LIST OF TABLES

TABLE 1	INITIAL NUMBER OF CITATIONS JUDGED PERTINENT TO THE THREE REVIEWS .....	8
TABLE 2	CLASSIFICATION OF FACTORS ASSOCIATED WITH CANCER SCREENING UPTAKE .....	9
TABLE 3	UPTAKE OF CANCER SCREENING TESTS AND AGE: JEPSON <i>ET AL.</i> (2000) REVIEW .....	10
TABLE 4	UK: UPTAKE OF FOBT SCREENING (FEB 2003 – NOV 2004) BY AGE IN THE SECOND ROUND OF THE ENGLISH PILOT OF BOWEL CANCER SCREENING .....	15
TABLE 5	AUSTRALIA: ESTIMATED PARTICIPATION RATES FOR FOBT SCREENING BY AGE (2008) .....	16
TABLE 6	DIFFERENCES IN MALE AND FEMALE FOBT PARTICIPATION RATES: USA, UK AND AUS .....	17
TABLE 7	FEMALE–MALE DIFFERENCES IN UPTAKE OF FOBT SCREENING IN THE SECOND ROUND OF THE ENGLISH PILOT OF BOWEL CANCER SCREENING (FEB 2003–NOV 2004).....	17
TABLE 8	CANCER SCREENING RATES BY ETHNICITY: USA (2005).....	18
TABLE 9	UPTAKE OF CANCER SCREENING TESTS AND RACE/ETHNICITY: JEPSON <i>ET AL.</i> (2000) REVIEW .....	19
TABLE 10	AGE STANDARDISED PARTICIPATION RATES IN BREASTSCREEN AUSTRALIA: VICTORIAN WOMEN AGED 50–69 YEARS .....	20
TABLE 11	MAMMOGRAM UPTAKE BY ETHNIC AND NON-HISPANIC WHITE PARTICIPANTS: PURC-STEPHENSON <i>ET AL.</i> (2008) REVIEW .....	20
TABLE 12	PARTICIPATION RATES IN BREASTSCREEN SOUTH AUSTRALIA BY ETHNIC GROUPS .....	21
TABLE 13	UPTAKE OF CANCER SCREENING TESTS AND SOCIOECONOMIC STATUS: JEPSON <i>ET AL.</i> (2000) REVIEW .....	23
TABLE 14	RELATIONSHIP BETWEEN FINANCIAL FACTORS AND UPTAKE OF SCREENING MAMMOGRAPHY: SCHUELER <i>ET AL.</i> (2008) REVIEW .....	23
TABLE 15	AGE STANDARDIZED PARTICIPATION RATES IN BREASTSCREEN AUSTRALIA BY SOCIOECONOMIC STATUS OF AREA OF RESIDENCE (2005-2006) .....	24
TABLE 16	AGE STANDARDIZED PARTICIPATION RATES OF WOMEN AGED 20–69 YEARS IN THE AUSTRALIAN NATIONAL CERVICAL SCREENING PROGRAM, BY SOCIOECONOMIC STATUS OF AREA OF RESIDENCE (2005–2006).....	25
TABLE 17	CRUDE PARTICIPATION IN AUSTRALIAN NBCSP BY SOCIOECONOMIC STATUS OF AREA OF RESIDENCE (2008).....	25
TABLE 18	SECOND ROUND OF THE ENGLISH PILOT OF BOWEL CANCER SCREENING: UPTAKE OF FOBT SCREENING BY DEPRIVATION CATEGORY OF AREA OF RESIDENCE (FEB 2003–NOV 2004) .....	26
TABLE 19	SCREENING RATES AND EDUCATION: USA (2005) .....	27
TABLE 20	RELATIONSHIP BETWEEN EDUCATION AND SCREENING UPTAKE: JEPSON <i>ET AL.</i> (2000) REVIEW .....	27
TABLE 21	PERCENTAGE OF VARIANCE (R <sup>2</sup> ) IN LITERACY PROFICIENCY ACCOUNTED FOR BY 12 PREDICATOR VARIABLES: AUSTRALIA AND FINLAND .....	31
TABLE 22	MULTIPLE REGRESSION MODELLING OF COMPREHENSION OF INTERNET-BASED COLORECTAL CANCER INFORMATION 34	
TABLE 23	ASSOCIATION BETWEEN FUNCTIONAL HEALTH LITERACY AND CANCER-RELATED KNOWLEDGE.....	35
TABLE 24	RELATIONSHIP BETWEEN HEALTH LITERACY AND UNDERSTANDING OF MEDICAL LEAFLETS (N = 321) .....	35
TABLE 25	RELATIONSHIP BETWEEN CANCER RELATED KNOWLEDGE AND SCREENING UPTAKE: JEPSON <i>ET AL.</i> (2000) REVIEW .....	36
TABLE 26	RELATIONSHIP BETWEEN BREAST CANCER KNOWLEDGE ON SCREENING MAMMOGRAPHY UPTAKE: SCHUELER <i>ET AL.</i> (2008) REVIEW .....	37
TABLE 27	RELATIONSHIP BETWEEN PERCEPTIONS OF RISK AND SCREENING UPTAKE: JEPSON <i>ET AL.</i> (2000) REVIEW .....	38
TABLE 28	RELATIONSHIP BETWEEN MARITAL STATUS AND SCREENING UPTAKE: JEPSON <i>ET AL.</i> (2000) REVIEW .....	48
TABLE 29	ASSOCIATION BETWEEN PERCEIVED HEALTH STATUS AND THE UPTAKE OF SCREENING: JEPSON <i>ET AL.</i> (2000) REVIEW .....	51
TABLE 30	IMPACT OF BREAST DISEASE ON SCREENING MAMMOGRAPHY UPTAKE: SCHUELER <i>ET AL.</i> (2008) REVIEW .....	52
TABLE 31	HEALTH FACTORS ASSOCIATED WITH LOWER UPTAKE OF COLORECTAL CANCER SCREENING TESTS: PETERSEN (2002) REVIEW .....	53
TABLE 32	AUSTRALIAN NATIONAL BOWEL CANCER SCREENING PROGRAM (NBCSP): CRUDE PARTICIPATION RATE BY DISABILITY STATUS (2008) .....	54
TABLE 33	ASSOCIATION BETWEEN PREVIOUS SCREENING BEHAVIOUR AND THE UPTAKE OF SCREENING: JEPSON <i>ET AL.</i> (2000) REVIEW .....	55
TABLE 34	CANCER SCREENING RATES BY IMMIGRATION STATUS: USA (2005).....	60
TABLE 35	IMPACT OF ACCULTURATION ON THE MAMMOGRAM UPTAKE: SCHUELER <i>ET AL.</i> (2008) REVIEW .....	61

TABLE 36	GEOGRAPHIC VARIATIONS IN SCREENING RATES IN AUSTRALIA .....	67
TABLE 37	GEOGRAPHIC VARIATION IN SCREENING RATES IN THE USA .....	67
TABLE 38	FIVE-YEAR SCREENING RATES FOR NHS BREAST SCREENING PROGRAMME: UPTAKE OF INVITATIONS TO SCREEN FOR WOMEN AGED 50–70 YEARS IN SELECTED GEOGRAPHIC AREAS .....	68
TABLE 39	GEOGRAPHIC VARIATION IN BREASTSCREEN VICTORIA 2-YEAR PARTICIPATION RATES (50–69 AGE STANDARDISED RATES) .....	68
TABLE 40	RELATIONSHIP BETWEEN AVAILABILITY AND THE UPTAKE OF MAMMOGRAMS: SCHUELER <i>ET AL.</i> (2008) REVIEW ...	69
TABLE 41	COMPARISON OF DIFFICULTY IN THE STEPS NECESSARY TO OBTAIN A PAP TEST WITH WELL-SCREENED WOMEN .....	70
TABLE 42	RELATIONSHIP BETWEEN ACCESSIBILITY FACTORS AND UPTAKE OF SCREENING MAMMOGRAPHY: SCHUELER <i>ET AL.</i> (2008) REVIEW .....	71
TABLE 43	UPTAKE OF CANCER SCREENING TESTS AND INSURANCE STATUS: JEPSON <i>ET AL.</i> (2000) REVIEW .....	72
TABLE 44	ASSOCIATION BETWEEN HEALTH INSURANCE AND THE UPTAKE OF CANCER SCREENING IN THE USA (2005) .....	73
TABLE 45	RELATIONSHIP BETWEEN FINANCIAL FACTORS AND UPTAKE OF SCREENING MAMMOGRAPHY: SCHUELER <i>ET AL.</i> (2008) REVIEW .....	73
TABLE 46	EFFECT OF COST ON WILLINGNESS TO JOIN A COLORECTAL CANCER SCREENING PROGRAM IN HONG KONG (YOUNG AND OLD AGE GROUPS ONLY).....	74
TABLE 47	SUMMARY OF THE EVIDENCE .....	78

## LIST OF FIGURES

FIGURE 1	PARTICIPATION IN THE BREASTSCREEN AUSTRALIA PROGRAM (FEMALES 2005-2006) .....	11
FIGURE 2	SCREENING MAMMOGRAPHY RATES BY AGE: VIC (2006–07), USA (2005), AND UK (2009) .....	12
FIGURE 3	LONG-TERM SCREENING MAMMOGRAPHY AND PAP TEST MONITORING DATA FOR VICTORIA.....	12
FIGURE 4	PAP TEST SCREENING RATES BY AGE: VICTORIA (2006–07), USA (2005), AND UK (2009).....	14
FIGURE 5	MODEL OF THE RELATIONSHIP BETWEEN FEAR AND BREAST CANCER SCREENING BEHAVIOUR: CONSEDINE <i>ET AL.</i> (2004) REVIEW .....	45
FIGURE 6	ASSOCIATION BETWEEN SOCIAL NETWORK SIZE AND SCREENING MAMMOGRAM STATUS .....	47
FIGURE 7	ASSOCIATION BETWEEN PREVIOUS CANCER SCREENING ACTIVITIES AND THE UPTAKE OF FAECAL OCCULT BLOOD TESTING .....	57

# 1. INTRODUCTION

The Victorian Cytology Service (VCS) was commissioned by the Victorian Department of Health to undertake a review of international literature (peer-reviewed and grey literature) focusing on key areas that inform thinking, knowledge and approaches to engaging individuals, groups and communities to participate in organised programs, including population-based screening programs.

The aim of the review was to consider:

- factors that enhance or hinder engagement in health screening and other preventative programs, including perceptions held by participants
- needs of specific groups (e.g. information needs of specific groups, such as those with low literacy skills)
- health beliefs and their impact on cognitive constructs and behaviour in relation to screening and engagement in positive health behaviours
- structural and environmental barriers to participation
- key work in other disciplines or settings that provide insight into innovative thinking and practice in engaging individuals and communities; especially within organised, voluntary programs or initiatives
- work completed in health and other disciplines on translating research findings into action.

The VCS contracted the Centre for Health Policy, Programs and Economics (CHPPE) to undertake the identification, synthesis and summary of the evidence.

The review is presented as three stand-alone documents. Each volume has a specific focus:

- volume 1 provides an overview of the theoretical models underpinning thinking in relation to participation in screening programs.
- volume 2 focuses on the factors and barriers to participation in screening programs
- volume 3 focuses on the impact of interventions designed to increase participation in organised screening/health programs.

According to Consedine *et al.* (2004), screening rates have been linked to a wide range of factors, including background variables such as age, socioeconomic status, and education. Despite the large amount of research that has been generated in the consideration of these background variables, Consedine *et al.* (2004) believe that it is important to undertake research into other factors that may have an impact on screening. In part, this is because the research into these background factors helps to identify those at risk for a poor screening profile. However, they offer little direction in terms of viable interventions. Consedine *et al.* (2004) believe that improvements in screening will require interventions that target factors that are amenable to change.<sup>1</sup> For this reason, this volume looks at a range of factors that have been found to be associated (either positively or negatively) with the uptake of screening for breast, cervical and colorectal cancer.

Section 2 of this report provides an overview of the methodology, including a typology of the factors developed to structure the report. Sections 3 to 8 contain the analysis in relation to socio-demographic factors, cognitive factors, psychosocial factors, health and lifestyle factors, cultural factors and, finally, health system factors. The report concludes with a summary of the evidence and a discussion of the results (Section 9).

## 2 METHODOLOGY

### 2.1 Locating the literature

A range of databases and indexes available through the University of Melbourne library were investigated to determine search terms for the literature review that would give a broad, multi-disciplinary coverage, coupled with the most efficient search and retrieval capabilities.

The five databases included in the search were:

1. **Medline:** medical research literature
2. **ISI Web of Science/ISI Web of Knowledge:** Science Citation Expanded<sup>®</sup>, Social Sciences Citation Index<sup>®</sup>, and Arts & Humanities Citation Index<sup>™</sup>
3. **CINAHL:** nursing, biomedicine, health sciences, consumer health and seventeen allied health disciplines in journals, books and book chapters, dissertations, selected conference proceedings, standards of practice, pamphlets, educational software packages and audiovisual material
4. **SCOPUS:** medical and social science literature
5. **Cochrane Library:** systematic reviews of health care treatments and interventions.

Broad search terms used to locate the screening literature included combinations of the following: (breast cancer OR cervical cancer OR colorectal cancer OR bowel cancer OR colon cancer); screen\*; (participation OR engagement).

Articles were also located by a scrutiny of reference lists and grey literature databases identified by the Steering Committee and through an environmental survey undertaken by the VCS.

Only articles in English and published in the period 1999–2009 were included. The original database comprised just over 1700 articles (Table 1). During the preparation of the first two reviews, the database grew to over 2000 references, over 1500 of which were pertinent to a review of factors associated with the uptake of screening mammography, Pap tests and faecal occult blood testing (FOBT).

**Table 1 Initial number of citations judged pertinent to the three reviews**

	<b>Strategy</b>	<b>Number</b>	<b>%</b>
Peer-reviewed literature:	Database search	1491	86%
	Scrutiny of reference lists and Steering Committee	165	10%
Grey literature	Database searches and Steering Committee	69	4%
Total		1725	100%

### 2.2 Review strategy

Because of time and resource constraints it was not possible to base this volume of the review for the VCS on over 1500 primary studies. Therefore, it was based primarily on monitoring data and literature reviews published between 1999 and 2009 inclusive. The reviews were of factors associated with uptake of screening for breast, cervical or colorectal cancer and/or cancer

screening in general. Because of the lack of reviews relating to FOBT, two reviews published outside this timeframe were included; one by Vernon published in 1997 and one by Guessous *et al.* published in 2010.<sup>2,3</sup> A review published in 1996 relating to screening mammography has also been included. It was referred to in a review published within the given timeframe and was pertinent to the analysis.<sup>4</sup>

A total of 26 cancer screening reviews were included (see Appendix for details). The search strategies used to locate the primary studies contained in the 26 reviews included citations published from 1872 to 2009. The focus of the reviews was as follows.

- 46% (12) related to breast cancer only
- 4% (1) related to cervical cancer only
- 12% (3) related to breast and cervical cancer
- 12% (3) related to colorectal cancer only,
- 19% (5) related to breast, cervical and colorectal cancer
- 8% (2) to cancer in general.

One of the reviews relating to colorectal cancer published in 1997 focused exclusively on FOBT.<sup>2</sup> The other two (one published in 2002 and the other in 2010) focused on factors associated with colorectal cancer screening and not exclusively on FOBT.<sup>3,5</sup> However, in the review by Guessous *et al.* (2010), 71% of the primary studies reported on FOBT alone or in combination with other screening.<sup>3</sup>

Most, but not all, the reviews were based on empirical studies – those that contained univariate and multivariate analyses of the relationships between particular factors and screening rates. For this reason, the VCS review has not explored qualitative data in great depth. The reliance on literature reviews and the plethora of factors included in the reviews also means that the review provides a broad overview of all factors rather than an in-depth analysis of each.

### **Categorising the factors associated with cancer screening uptake**

For the VCS review, the actors associated either positively or negatively with cancer screening have been classified under six domains: demographic, cognitive, psychosocial, health and lifestyle, cultural and health system factors (Table 2).

**Table 2 Classification of factors associated with cancer screening uptake**

<b>Domain</b>	<b>Factors</b>
Demographic factors	Age, gender, ethnicity, socioeconomic status, education
Cognitive factors	Literacy, health literacy, cancer-related knowledge, perceived risk, perceived ambiguity
Psychosocial factors	Fear/anxiety/worry, coping style (emotion regulation), social networks
Health and lifestyle factors	Physical/mental health, drug use, previous participation in screening
Cultural factors	Acculturation, fatalism, modesty/embarrassment/shame, medical mistrust, collectivism/communalism, spirituality/religiosity
Health system factors	Availability, accessibility, affordability, acceptability

### 3 DEMOGRAPHIC FACTORS

Demographic data relate to the characteristics of a population. Commonly used demographics include sex, race, age, income, disability, mobility (in terms of travel time to work or number of vehicles available), educational attainment, home ownership, employment status and location.<sup>1</sup>

The demographic factors included in this review were: age, gender, ethnicity (including Indigenous status), socioeconomic status and education. Data relating to these factors come from two sources:

- monitoring data for population-based screening programs published on the internet in the form of Excel spreadsheets and in grey literature reports
- systematic reviews included in the peer-reviewed literature, supplemented, where appropriate, with a small number of recently published primary studies.

#### 3.1 Age

As shown in Table 3, just under two-thirds (61%) of the 31 studies relating to screening mammography included in the Jepson *et al.* (2000) review did not find an association between mammogram uptake and age. However, over three-quarters of the studies relating to Pap tests and the studies relating to FOBT reported a significant association.<sup>2</sup> The authors stated that the results relating to Pap tests were difficult to interpret. However, for FOBT, ‘many’ studies showed that uptake increased with age.<sup>6</sup> The evidence in relation to each of the screening tests is considered in more detail below.

**Table 3 Uptake of cancer screening tests and age: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	12/31 studies (39%)	7/9 studies (78%)	7/9 studies (78%)
Authors’ conclusion	The majority of studies did not find an association between uptake and age, and those that did reported conflicting results. It was not clear whether older or younger women were more likely to attend	The majority of studies found an association between uptake and age. However, they reported conflicting effects. It was not clear whether older or younger women were more likely to attend	The majority of studies found a significant association between uptake of colorectal cancer screening and age. In many the return of FOBT was highest among participants aged $\geq 65$ years

Source: Jepson *et al.* (2000)<sup>6</sup>

Notes:

FOBT: Faecal occult blood testing

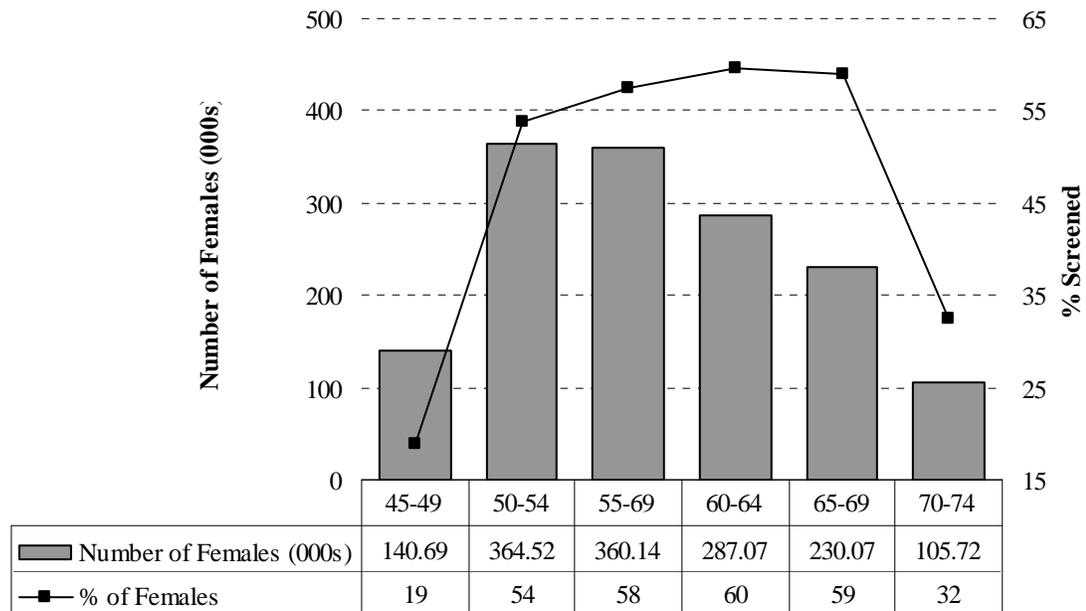
<sup>1</sup> <http://en.wikipedia.org/wiki/Demographics>

<sup>2</sup> See the Appendix for an overview of the 26 original literature reviews.

- **Screening mammography**

BreastScreen Australia actively recruits women between the ages of 50 and 69 (inclusive). As shown in Figure 1, there were relatively high participation rates for the target group in the period 2005-2006. – 54% to 59% compared to 19% for 45-49 year old women and 32% for 70-74 year olds.

**Figure 1 Participation in the BreastScreen Australia Program (females 2005-2006)**

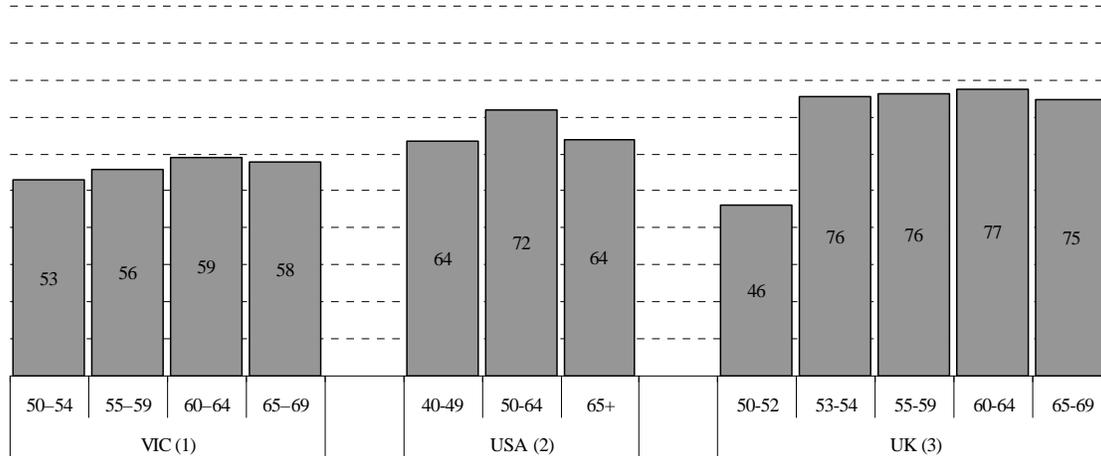


Source: Australian Institute of Health and Welfare (2009) <sup>7</sup>

USA monitoring data are highly aggregated and indicate that screening is highest among the 50–64 year age group. UK and Victorian monitoring data are more disaggregated. These data indicate that screening rates are lowest for those who become eligible to enter screening programs (i.e. women in their early 50s) with a slight diminution for 65–69 year olds as women move out of the target group (Figure 2).<sup>3</sup> Long-term Victorian data indicate that, although there has been some variation in uptake by different age groups over time, uptake across the age groups has remained relatively stable (Figure 3).

<sup>3</sup> There is no centrally organized screening program in the USA, but the American Cancer Society indicates that it is important women age 40 years of age and older have annual mammograms at an accredited mammography screening facility.<sup>8</sup> In the UK, the NHS Breast Screening Programme provides free breast screening for all women in the UK aged 50 and over. Women aged between 50 and 70 are routinely invited. (<http://www.cancerscreening.nhs.uk/breastscreen/#whatdoes>)

**Figure 2 Screening mammography rates by age: VIC (2006–07), USA (2005), and UK (2009)**

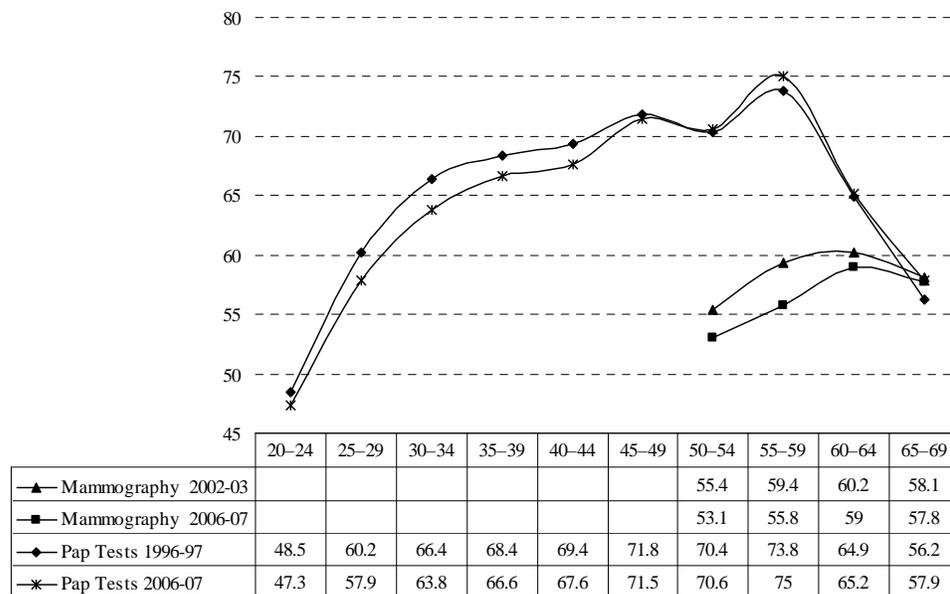


Sources: VIC (Victoria): Productivity Commission Excel spreadsheet downloaded 15 October 2009 from [http://www.pc.gov.au/data/assets/excel\\_doc/0004/85414/53-chapter12-attachment-only.xls](http://www.pc.gov.au/data/assets/excel_doc/0004/85414/53-chapter12-attachment-only.xls); USA: Cokkinides *et al.* (2007)<sup>8</sup>; UK: Table 2 of National Health Service Excel spreadsheet downloaded on 24 Dec 2009 from [http://www.ic.nhs.uk/webfiles/publications/breastscreening0708/2007-08 Breast Screening Tables.xls](http://www.ic.nhs.uk/webfiles/publications/breastscreening0708/2007-08%20Breast%20Screening%20Tables.xls)

Notes:

(1) Participation in BreastScreen Australia program over a 24-month period; (2) Mammogram in past 2 years; (3) Less than 3 years since last test

**Figure 3 Long-term screening mammography and Pap test monitoring data for Victoria**



Sources: Mammography - Productivity Commission Excel spreadsheet downloaded 15<sup>th</sup> October 2009, available at [http://www.pc.gov.au/data/assets/excel\\_doc/0004/85414/53-chapter12-attachment-only.xls](http://www.pc.gov.au/data/assets/excel_doc/0004/85414/53-chapter12-attachment-only.xls), Pap tests – AIHW (2009)<sup>9</sup>

Notes: Residents of Victorian postcodes allocated to the Albury/Wodonga catchment (NSW jurisdiction) are included in Victoria’s population estimate, accounting for the slight decrease in participation rates compared to those published by BreastScreen Victoria

In the Wells *et al.* review of factors associated with mammogram uptake by Latin American women in the USA published in 2007:

- 57% of studies (8/14) reported that age was a significant predictor of screening mammography in multiple logistic regression analysis
- 43% of studies (6/14) did not find an association between the uptake of mammograms and age.

The authors indicated that it was difficult to interpret the results because the studies used different age ranges in the regression analyses.<sup>10</sup>

- **Pap tests**

In Australia, the National Cervical Screening Program promotes screening for women between 18 (or two years after first sexual intercourse, whichever is later) and 69 years.<sup>4</sup> Victorian monitoring data indicate that Pap test participation rates peak in the 45–59 age group and then decrease (Figure 4). Although some variations have been seen over time, differences across age groups are relatively consistent (Figure 3).

In the USA, there is no centrally organised program and the most recent American Cancer Society cervical cancer screening guidelines are shown in Box 1. USA survey data published in 2007 (before the new guidelines were issued) indicate that the uptake of Pap tests appeared to peak in the 30–39 year age group, followed by a decline in participation (Figure 4).

**Box 1 Current American Cancer Society cervical cancer screening guidelines (2010)**

All women should begin cervical cancer screening about 3 years after they begin having vaginal intercourse, but no later than 21 years old. Screening should be done every year with the regular Pap test or every 2 years using the newer liquid-based Pap test.

Beginning at age 30, women who have had 3 normal Pap test results in a row may get screened every 2 to 3 years. Women older than 30 may also get screened every 3 years with either the conventional or liquid-based Pap test, plus the human papilloma virus (HPV) test.

Women 70 years of age or older who have had 3 or more normal Pap tests in a row and no abnormal Pap test results in the last 10 years may choose to stop having Pap tests.

Source:

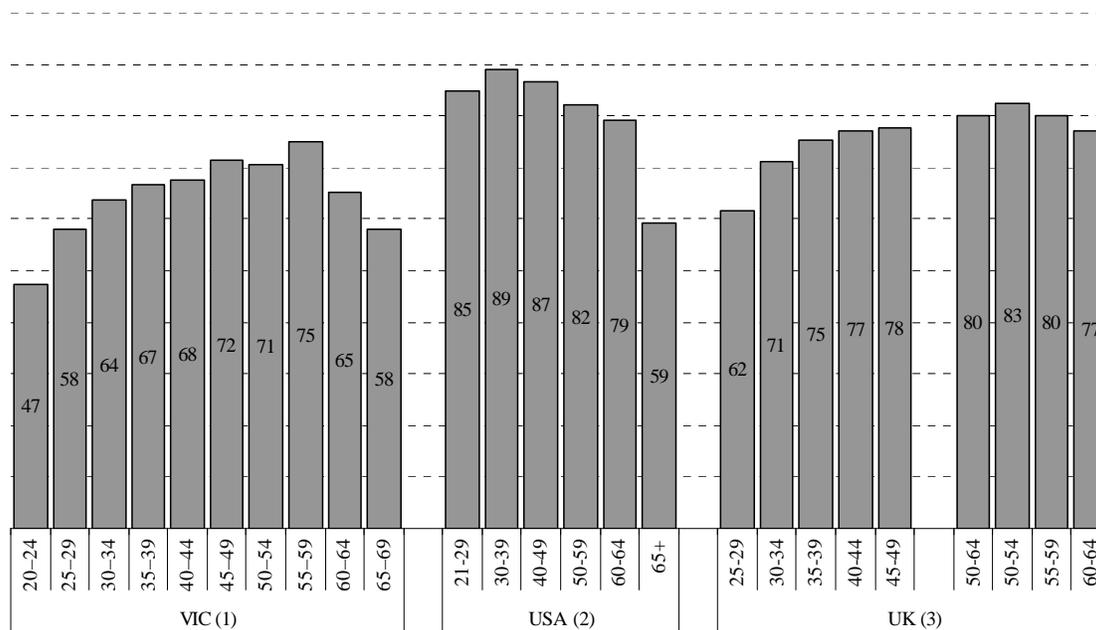
[http://www.cancer.org/docroot/ped/content/ped\\_2\\_3x\\_acs\\_cancer\\_detection\\_guidelines\\_36.asp](http://www.cancer.org/docroot/ped/content/ped_2_3x_acs_cancer_detection_guidelines_36.asp)

In the UK all women between the ages of 25 and 64 are eligible for a free Pap test every three to five years, depending in their age.<sup>5</sup> The data indicate that Pap test participation rates increase up to the 40–59 year age group. However, because the recommended screening interval differs for the 25–49 group and the 50–64 year age groups, rates across the whole range cannot be compared (Figure 4).

<sup>4</sup> <http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/cervical-about>

<sup>5</sup> <http://www.cancerscreening.nhs.uk/cervical/index.html>

**Figure 4 Pap test screening rates by age: Victoria (2006–07), USA (2005), and UK (2009)**



Sources: VIC: AIHW (2009)<sup>9</sup>

USA: Cokkinides *et al.* (2007)<sup>8</sup>

UK: Table 1 of National Health Service Excel spreadsheet downloaded on 25 Nov 2009 from [http://www.ic.nhs.uk/webfiles/publications/cervscreen0809/Cervical Screening Programme 2008 09 Data Tables.xls](http://www.ic.nhs.uk/webfiles/publications/cervscreen0809/Cervical%20Screening%20Programme%202008%2009%20Data%20Tables.xls)

Notes:

(1) Victorian 2-year participation rates by age in the National Cervical Screening Program

(2) In 2005, proportion of women who had a Pap test within the previous 3 years

(3) Coverage of the NHS Cervical Screening Programme in England as at 31st March 2009. For ages 25–48, coverage represents the proportion of women with an adequate test result who have had a test within the last 3 years and for ages 50–64, coverage represents the proportion within the last 5 years

### Faecal occult blood testing

A review of the factors associated with the uptake of FOBT published in 1997 contained thirteen studies that reported the relationship between age and uptake. Seven (54%) measured prospective behaviour and reported that uptake was lowest among persons aged 70 years and over. Three studies (23%) found that completion was higher in younger groups and three (23%) found no consistent pattern.<sup>2</sup>

In 2005 in the USA, the rate of having an FOBT within the past year was 10.6% for those aged 50–64 and 13.8% for those aged 65 years and over.<sup>8</sup> The relatively low FOBT screening rates in the USA are due to the fact that there is no centrally organised screening program, and the current American Cancer Society screening guidelines do not unequivocally state that people aged 50 and over should have yearly FOBT (Box 2).

## Box 2 Current American Cancer Society colorectal cancer screening guidelines

Beginning at age 50, both men and women should follow one of these testing schedules:

- (i) Tests that find polyps and cancer  
 Flexible sigmoidoscopy every 5 years\*, or  
 Colonoscopy every 10 years, or  
 Double-contrast barium enema every 5 years\*, or  
 CT colonography (virtual colonoscopy) every 5 years\*
- (ii) Tests that primarily find cancer  
 Yearly faecal occult blood test (gFOBT)\*\*, or  
 Yearly faecal immunochemical test (FIT) every year\*\*, or  
 Stool DNA test (sDNA), interval uncertain\*\*

\* If the test is positive, a colonoscopy should be done.

\*\* The multiple stool take-home test should be used. One test done by the doctor in the office is not adequate for testing. A colonoscopy should be done if the test is positive.

The tests that are designed to find both early cancer and polyps are preferred if these tests are available to you and you are willing to have one of these more invasive tests.

Source:

[http://www.cancer.org/docroot/ped/content/ped\\_2\\_3x\\_acs\\_cancer\\_detection\\_guidelines\\_36.asp](http://www.cancer.org/docroot/ped/content/ped_2_3x_acs_cancer_detection_guidelines_36.asp)

In the UK, FOBT uptake increased with increasing age for both women and men in the second round of the English pilot (Table 4).

**Table 4 UK: Uptake of FOBT screening (Feb 2003 – Nov 2004) by age in the second round of the English Pilot of Bowel Cancer Screening**

Age (years)	Males			Females		
	%	Adj OR	95% CI <sup>1</sup>	%	Adj OR	95% CI
<55	41.3	1		50.2	1	
55–59	46.9	1.23	1.18–1.28	56.2	1.26	1.20–1.31
60–64	51.0	1.47	1.41–1.54	60.0	1.49	1.43–1.56
65–69	56.2	1.82	1.74–1.91	60.6	1.55	1.48–1.63

Source: Weller et al (2006)<sup>11</sup> Downloaded from the NHS website on 26 November 2009

<http://www.cancerscreening.nhs.uk/bowel/pilot-2nd-round-evaluation.pdf>

Notes:

Adj OR: Adjusted odds ratio; CI: Confidence interval

The monitoring data for people invited to participate in the Australian National Bowel Cancer Screening Program (NBCSP) also indicated that participation rates increased with age – 50 years 31.8%, 55 years 38.9% and 65 years 47.7% at 26 weeks (Table 5).

**Table 5 Australia: Estimated participation rates for FOBT screening by age (2008)**

	50 years	55 years	65 years
26 weeks			
People participating (per 100 invitations) <sup>(1)</sup>	31.8	38.9	47.7
95% CI	31.6–32.0	38.7–39.1	47.5–48.0
52 weeks <sup>(1) (2)</sup>			
People participating (per 100 invitations)		39.3	48.1
95% CI		39.1–39.5	47.8–48.3

Source: Australian Institute of Health and Welfare and Department of Health and Ageing (2009) <sup>12</sup>

Notes:

(1) Participation rates equal the estimated Kaplan-Meier participation rate of people who returned a completed FOBT kit as a proportion of the total number of the eligible population who were invited to screen, excluding people who suspended or opted off the Program.

(2) People aged 50 years were invited to screen from 1 July 2008, so no 52-week data were available..

## 3.2 Gender

### Faecal occult blood testing

In 1997, Vernon’s review of factors associated with the uptake of FOBT indicated that the impact of gender differed across different methodologies:

- prospective studies (15 studies): participation was higher for women in 13 studies (87%), and for men in 2 studies (13%)
- experimental interventions (11 studies): women were more likely than men to complete FOBT, although the differences were not pronounced and, when tested, were not always statistically significant
- other studies (5 studies): data from these studies, including national surveys of recent past behaviour, showed inconsistent patterns by gender.<sup>2</sup>

In the 2000 review of factors associated with FOBT screening, Jepson *et al.* (2000) found that the majority of studies (6 of 7 studies; 86%) did not find an association between uptake and gender.<sup>6</sup>

In a review of factors associated with participation in colorectal cancer screening published in 2002, Petersen stated that males generally had lower adherence to colorectal cancer screening.<sup>5</sup> In their 2010 review of factors associated with colorectal cancer screening in people aged 65 years of age and over, Guessous *et al.* reported that in 14 of 26 studies (54%) ‘female sex’ was a significant barrier to participation, while two studies (8%) reported it to be a significant facilitator. Although not stated, it is assumed that the remaining 10 studies (38%) found no association between gender and the uptake of colorectal cancer screening.<sup>3</sup>

As shown in Table 6, very small gender differences in the uptake of FOBT were reported in the USA for 2005; the rate for females was slightly lower than for males. In the second round of the English pilot of bowel cancer screening, uptake was higher among females than males (OR 1.42, 95% CI 1.36–2.48) (Table 6). The gender differences in the UK appeared to be greater in the younger age groups (Table 7). There was also a statistically significant difference in participation

between the sexes in the National Bowel Cancer Screening Program in Australia – males 36.0% (95% CI 35.5-35.8), females 42.6% (95% CI 42.0-42.4) (Table 6).

**Table 6 Differences in male and female FOBT participation rates: USA, UK and AUS**

Country	FOBT participation	Male	Female	Female – male difference
USA	FOBT within past year (2005)	12.7%	11.7%	-1.0%
UK	Uptake in second round of English Pilot of Bowel Cancer Screening (Feb 2003–Nov 2004)	47.7%	56.1%	+8.4% <sup>(1)</sup>
AUST	Uptake by people invited to participate in NBCSP (2008)	36.0%	42.6%	+6.6% <sup>(2)</sup>

Sources: USA Cokkinides *et al.* (2007)<sup>8</sup>

UK Source: Weller *et al.* (2006)<sup>11</sup> Downloaded from the NHS website on 26 November 2009

<http://www.cancerscreening.nhs.uk/bowel/pilot-2nd-round-evaluation.pdf>

Notes:

FOBT: Faecal occult blood testing

(1) Difference between female and male participation rates was statistically significant: OR 1.42, 95% CI 1.36 – 1.48, p < 0.001

(2) At 52 weeks since invitation.

**Table 7 Female–male differences in uptake of FOBT screening in the second round of the English Pilot of Bowel Cancer Screening (Feb 2003–Nov 2004)**

Age (years)	Males	Females	Female–male difference
<55	41.3	50.2	+8.9%
55–59	46.9	56.2	+9.3%
60–64	51.0	60.0	+9.0%
65–69	56.2	60.6	+4.4%

Source: Weller *et al.* (2006)<sup>11</sup> Downloaded from the NHS website on 26 November 2009

<http://www.cancerscreening.nhs.uk/bowel/pilot-2nd-round-evaluation.pdf>

### Gender differences in other health-seeking behaviour

A review of 124 key gender-comparative health-seeking studies published between 1966 and 2004 did not fully support the hypothesis that men are less likely than women to seek help when they experience ill health. Many studies noted the relative under-use of health services and symptom reporting by men compared with women, while others found an increase in help-seeking in men compared with women, or no significant difference in help-seeking behaviour between genders.<sup>13</sup>

According to Galdas *et al.* (2005), the contradictory nature of the findings and the ‘sex-differences’ approach in these investigations fail to provide an explanation for the actual differences between men and women in help-seeking patterns. Neither do they address the issue of within-group variability. The authors identified one review of gender-specific research that revealed a clearer picture of potential factors influencing help-seeking behaviour in men that supported the proposition that males delay seeking help.<sup>13</sup>

Galdas *et al.* (2005) also identified an increasing body of research literature pointing towards cultural stereotypes (e.g. ‘traditional masculinity’ and/or ‘masculinity beliefs’) as a significant variable influencing the help-seeking behaviour and health-risk appraisal of men when they become ill. Theories prevalent in the international men’s health literature contend that men: (i) are not permitted to be expressive in their illness behaviour; or (ii) are unable to be expressive because of the ‘construction of traditional masculinity’ and efforts to conform to a ‘socially prescribed male role’ where weakness and need for help are not believed to be masculine. As a result of these beliefs it is likely that men will react differently to health care services and health promotion messages, both in comparison with women and between men of differing age, social and ethnic groups.<sup>13</sup>

The role of cultural factors influencing men’s utilisation of health care services was espoused by Woods (2001) as one of the explanations accounting for the lower usage rate of GP services by Australian men. This explanation suggests that our culture conveys different values regarding health to each gender, and that men have not been encouraged to place the same premium on health than women do. To support this explanation, Woods (2001) quoted a study of men in rural Queensland which indicated that health only becomes a priority for men once it is under threat from illness or injury. These men equated health with ‘being able to work’.<sup>14</sup>

An alternative hypothesis locates the problem of under-utilisation of health services by men in the structure of the health care system including: the location (availability), convenience (accessibility), ‘male friendliness’ (appropriateness) and affordability of health care services. A survey of men in Western Australia regarding the factors that militated against their use of GP services indicated that the main reason why men were reluctant to access GP services was the amount of time spent in waiting rooms. Lesser reasons included: negative perceptions of GP knowledge and skills; feeling ‘uncomfortable’; cost; and restricted surgery hours. These findings are supported in a further Australian study by Aoun and Johnson (2000).<sup>14-16</sup>

Finally, Smith *et al.* (2006) have pointed out that it is the pattern of help-seeking and health service utilisation by men that differs; for men the initial approach tends to be indirect. Men tend to see their partners and friends as primary resources for help.<sup>17</sup>

### 3.3 Ethnicity

Monitoring data from the USA indicate that there are differences in participation in cancer screening by ethnicity. White (non-Hispanic) groups are more likely to participate in screening than other ethnic and Indigenous groups (Table 8).

**Table 8 Cancer screening rates by ethnicity: USA (2005)**

Ethnicity	Mammogram past 2 years	Pap test past 3 years	FOBT within past year
White (non-Hispanic)	68.1%	81.4%	12.6%
American Indian, Alaskan Native	66.6%	75.8%	5.8%
African American (non-Hispanic)	64.9%	80.2%	10.3%
Hispanic/Latin American	59.6%	74.5%	9.4%
Asian	54.2%	65.8%	10.8%

Source: Cokkinides *et al.* (2007)<sup>8</sup>

As shown in Table 9, very few of the studies included in the Jepson *et al.* review published in 2000 indicated a significant association between race or ethnicity and the uptake of mammograms, Pap tests and FOBT.<sup>6</sup> The evidence in relation to each of these screening tests is considered in more detail below.

**Table 9 Uptake of cancer screening tests and race/ethnicity: Jepson *et al.* (2000) review**

Factor	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	Black: 3/15 studies (20%) African American: 1/15 studies (7%) White: 1/15 studies (7%) Native American: 1/15 (7%)	Race: 0/2 Nationality: 0/1	0/5 studies
Authors' conclusions	The majority of studies did not find a significant association between uptake and ethnic origin but several studies reported higher uptake among black women.	Insufficient studies (i.e. determinants not investigated in three or more studies) to draw a conclusion	None of the studies found a significant association between uptake and ethnicity.

Source: Jepson *et al.* (2000)<sup>6</sup>

Notes:

FOBT = Faecal occult blood testing

- **Screening mammography**

Monitoring data indicate that the age-standardised participation rate in the BreastScreen Australia program for non-Indigenous women aged 50 to 69 years was 57% (95% CI 56.6-56.8) in the 2005/2006 compared with 38% (95% CI 37.3-38.9) for Indigenous women. Women who mainly spoke English at home were more likely than other women to have participated in the BreastScreen Australia program in the 2005-2006 period (59.1%, 95% CI 59.0-59.2 vs 44.8, 95% CI 44.6-45.0).<sup>7</sup>

Table 10 shows the participation rates for Victorian women aged 50–69 years in BreastScreen Australia program for the period 2002-2003 to 2006-2007. A number of observations can be made about these data:

- participation rates for Indigenous women and those from non-English speaking backgrounds (NESBs) are lower than the rate for all women
- during the period rates declined across all groups
- the decline for Indigenous women (–14.8%) was more marked than for women from NESBs (–3.3%); the reasons for the marked decrease among Indigenous women are not clear.

**Table 10 Age standardised participation rates in BreastScreen Australia: Victorian women aged 50–69 years**

Period	All	Indigenous	NESB
2002–2003	58.0%	50.9%	39.8%
2003–2004	58.6%	45.1%	39.7%
2004–2005	57.7%	37.3%	38.4%
2005–2006	56.8%	35.9%	37.5%
2006–2007	55.9%	36.1%	36.5%
Change: 2002–03 to 2006–07	–2.1%	–14.8%	–3.3%

Source: Productivity Commission Excel spreadsheet downloaded 15<sup>th</sup> October 2009, available at [http://www.pc.gov.au/data/assets/excel\\_doc/0004/85414/53-chapter12-attachment-only.xls](http://www.pc.gov.au/data/assets/excel_doc/0004/85414/53-chapter12-attachment-only.xls)

Notes:

Residents of Victorian postcodes allocated to the Albury/Wodonga catchment (NSW jurisdiction) are included in Victoria's population estimate, accounting for the slight decrease in participation rates compared to those published by BreastScreen Victoria

NESB = Non-English speaking background

Lower screening mammography participation rates for Indigenous populations are also evident in the monitoring data for New Zealand. Information supplied by BreastScreen Aotearoa, indicated that coverage for the 24 months to the end of April 2009 for eligible women aged 50–69 was: (i) 51.5% for Māori women; (ii) 54.7% for Pacific women; and (iii) 67.0% for 'other' women.<sup>18</sup>

In a review of Canadian and US studies, Purc-Stephenson *et al.* (2008) found evidence that ethnic minority-screening differences exist but the differences were 'impacted' by socioeconomic status. As shown in Table 11, when the odds ratios (ORs) were adjusted for socioeconomic status, African Americans, Hispanic and Asian/Pacific Islander women were just as likely as non-Hispanic White women to obtain a mammogram.<sup>19</sup>

**Table 11 Mammogram uptake by ethnic and non-Hispanic White participants: Purc-Stephenson *et al.* (2008) review**

	Unadjusted OR			Adjusted OR <sup>(1)</sup>		
	Number of studies	OR	95% CI	Number of Studies	OR	95% CI
African Americans	28	0.87	0.75–1.00	7	1.05	0.71–1.76
Hispanic	18	0.65	0.50–0.85	7	1.08	0.64–1.93
Asian/Pacific Islander	10	0.63	0.40–0.99	8	0.57	0.31–1.27

Source: Purc-Stephenson and Gorey (2008)<sup>19</sup>

Notes:

(1) Adjusted for socioeconomic status;

OR: Odds ratio

These results confirm the conclusion of the review by Sadler *et al.* (2001), which identified several studies reporting that when confounding factors are taken into account, ethnicity was not a significant factor in determining screening behaviour. However, other factors that

are thought to predict low screening adherence, such as not having an identified medical provider, having limited education and having a low income level, are closely aligned with many minority groups. Therefore a focus on ethnic groupings will reach groups most likely to experience those other factors. The authors also cautioned that it was important to be mindful of the diversity within diversity and, that it was not always possible to generalise results from one ethnic or Indigenous groups to another.<sup>20</sup>

Australians from culturally and linguistically diverse (CALD) backgrounds make up approximately 13% of the population and are from more than one hundred countries of origin.<sup>21</sup> Data from BreastScreen South Australia show that participation rates differ by ethnic group (Table 12).<sup>22</sup>

**Table 12 Participation rates in BreastScreen South Australia by ethnic groups**

Ethnic group	BreastScreen South Australia participation rate (%)
Greek	58%
Chinese	58%
Spanish-speaking	57%
Italian	54%
Polish	53%
German	52%
Former Yugoslavia (Bosnia, Croatia, Herzegovina, Serbia)	50%
Dutch	48%
Filipino	45%
Khmer	41%
Russian	40%
Pacific Islander: Melanesia (Age-standardised rate) <sup>(1)</sup>	36%
Pacific Islander: Polynesia (Age-standardized rate) <sup>(1)</sup>	28%

Source: Cancer Council SA, SA Cervix Screening Program, BreastScreen SA (2008)<sup>22</sup>

Notes:

(1) The data in this table are presented as they appeared in the original reference. It is unclear if all the rates shown are age-standardised or only these two.

- **Pap tests**

According to Mullins (2006), 'the Victorian Cervical Cytology Registry (VCCR) does not have information about the country of birth or the language spoken by women who have Pap tests. However, data from the National Health Survey (ABS 2001) indicated that women who speak a language other than English at home are less likely to have regular Pap tests (43%) than women who speak English at home (57%)'.<sup>23</sup>

Akers *et al.* (2007), state that studies have 'consistently shown' that screening rates are lower among immigrant groups compared with the general population in the USA. They concluded that for cervical cancer specifically, women from immigrant groups appear to be less likely to undergo screening.<sup>24</sup>

- **Faecal occult blood testing**

In the Vernon (1997) review, three studies reported associations between race or ethnicity and adherence. However, data from national surveys of self-reported past screening behaviour showed minimal or no differences between Whites and African Americans, as did data from four other studies. The conclusion in the Vernon (1997) review was that the majority of studies did not find an association between ethnicity and FOBT uptake.<sup>2</sup>

The 2009 report of the Australian NBCSP indicated that the crude participation rate for FOBT was 2.2 times higher for non-Indigenous invitees compared to Indigenous invitees and the result was statistically significant (23.5%, 95% CI 23.4-23.6 vs 10.5%, 95% CI 9.9-11.2). However, a close reading of the data tables on which this result was based indicated that the 'data in the table ... is considered unreliable'. The crude participation rate for people speaking English at home was 41.1% (95% CI 40.9-41.2) and for those who speak a language other than English at home the crude participation rate was 14.0% (95%CI 13.8-14.2). There are no cautions attached to these data.<sup>12</sup>

In 2002, Petersen (2002) stated that lower colorectal cancer screening adherence was generally seen among minority race or ethnic groups.<sup>5</sup> The latest review of colorectal cancer screening published in 2010, reported that among people aged 65 years and over:

- African American race was a significant barrier to screening in 14 of 26 (54%) studies, while 2 studies (8%) reported it to be a facilitator; although unstated, it appears that 10 studies (38%) found no association
- Hispanic ethnicity was reported to be a barrier in 13 of 19 studies (68%); no studies found it to be a facilitator and, presumably, 6 studies (32%) found no association between Hispanic ethnicity and colorectal cancer screening uptake.<sup>3</sup>

The conclusion from the 2010 review was that the majority of studies found that ethnicity decreased the uptake of colorectal cancer screening among people aged 65 years of age and over.<sup>3</sup>

### **3.4 Socioeconomic status**

According to Fiscella *et al.* (2000) race/ethnicity and socioeconomic position in the United States are closely intertwined, and it is difficult to isolate racial/ethnic disparities in health care due primarily to socioeconomic disparities. They did however conclude that socioeconomic position appears to be the more powerful determinant of primary health care use in the United States.<sup>25</sup>

As shown in

Table 13, Jepson *et al.* (2000) concluded that there were no significant associations between markers of socioeconomic status and the uptake of mammograms and FOBT, and the association with the uptake of Pap tests was not clear.<sup>6</sup> The evidence for each test is considered in more detail below.

**Table 13 Uptake of cancer screening tests and socioeconomic status: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	No studies	No studies reported	No studies reported
Authors' conclusions	No significant association with uptake: <ul style="list-style-type: none"> <li>• income</li> <li>• home ownership</li> <li>• employment status</li> <li>• occupation</li> <li>• partner's occupation</li> </ul>	Association with uptake unclear: <ul style="list-style-type: none"> <li>• employment status</li> <li>• level of income</li> </ul> No significant association with uptake: <ul style="list-style-type: none"> <li>• occupation</li> </ul>	No significant association with uptake: <ul style="list-style-type: none"> <li>• employment status</li> <li>• income</li> </ul>

Source: Jepson *et al.* (2000)<sup>6</sup>

- **Screening mammography**

In a review published in 2007, of the factors associated with the uptake of screening mammography among Latin American women in the USA, 4 studies reported that income was a significant predictor of screening mammography in multiple logistic regression analysis (adjusted OR 1.02–1.69). However, another 4 studies did not find this association.<sup>10</sup>

In the same review 5 studies evaluated the association between employment and the uptake of mammograms, but only 3 reported adjusted ORs. One of the three (33%) found that full-time employment was associated with higher odds of screening mammography (adjusted OR 1.27). The other two (66%) did not find a statistically significant association.<sup>10</sup>

As shown in Table 14, a meta-analysis by Schueler *et al.* (2008) found that having a low income or money worries reduced the likelihood of having a mammogram, but employment status did not have a statistically significant effect.<sup>26</sup>

**Table 14 Relationship between financial factors and uptake of screening mammography: Schueler *et al.* (2008) review**

	Number of studies	Adjusted OR	95% CI
Low income/money concerns	49	0.74	0.67–0.82
Not employed	17	0.89	0.77–1.03

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

OR: Odds ratio; CI: Confidence interval

In Australia, monitoring data for BreastScreen Australia for the 2005-2006 period indicated that women living in 'middle' socioeconomic status areas (59.4%) were more likely to participate than those living in low (57.1%-57.6%) and high socioeconomic status areas (55.0%-55.4%) (Table 15).<sup>7</sup>

**Table 15 Age-standardised participation rates in BreastScreen Australia by socioeconomic status of area of residence (2005-2006)**

Socioeconomic Status of Area	Age Standardised Rate	95% CI
1 (Lowest)	57.1%	56.9-57.4(b)
2	57.6%	57.4-57.8(b)
3	59.4%	59.2-59.6(a)
4	55.4%	55.2-55.7(c)
5 (Highest)	55.0%	54.8-55.2(c)

Source: Australian Institute of Health and Welfare and Department of Health and Ageing (2009)<sup>7</sup>

Notes:

CI: Confidence interval

(a), (b), (c) indicate overlapping confidence intervals

- **Pap tests**

According to Akers *et al.* (2007), the most common measures of socioeconomic position that have been examined for their association with cervical cancer screening rates include income, poverty level, educational status, and residence in socioeconomically disadvantaged areas. The authors state that ‘in general, these studies have found that higher socioeconomic status correlates with higher cervical cancer screening rates’. They also state that, in a ‘number’ of the studies, it has been noted that socioeconomic position explained differences in cervical cancer screening rates better than race/ethnicity.<sup>24</sup>

In a review of the factors associated with regular cervical screening among African American and Hispanic women it was noted that ‘several’ studies reported that the lower the income, the less likely it was that a woman would obtain a Pap test.<sup>27</sup>

Monitoring data for the Australian National Cervical Screening Program for the 2005-2006 period indicated that women living in the highest socioeconomic areas were more likely to obtain a Pap test than those living in other areas. Women living in the lowest socioeconomic status areas were the least likely to obtain a Pap test (Table 16).<sup>28</sup>

**Table 16 Age standardized participation rates of women aged 20–69 years in the Australian National Cervical Screening Program, by socioeconomic status of area of residence (2005–2006)**

Socioeconomic Status of Area	Age Standardised Rate <sup>(1)</sup>	95% CI
5 (Lowest)	57.3 %	57.1–57.4
4	60.2 %	60.0–60.3
3	61.8 %	61.7–62.0
2	68.3 %	68.2–68.5
1 (Highest)	71.5 %	71.3–71.7

Source: Australian Institute of Health and Welfare and Department of Health and Ageing (2008)<sup>28</sup>

Notes:

CI: Confidence interval

(1) Tasmanian data were not included in the report

- **Faecal occult blood testing**

Data from the Australian NBCSP indicated that people living in the lowest socioeconomic status areas were less likely than those living in other areas to participate in the program. But there did not appear to be a consistent pattern in the association between uptake of FOBT and the socioeconomic status of the area in which the invitees lived (Table 17).<sup>7</sup>

**Table 17 Crude participation in Australian NBCSP by socioeconomic status of area of residence (2008)**

Socioeconomic Status of Area	Crude Participation Rate	95% CI
1 (Lowest)	34.6%	34.3-34.8(a)
2	37.4%	37.1-37.6(b)
3	36.8%	36.5-37.0(c)
4	37.3%	37.1-37.6(b)
5 (Highest)	37.4%	37.1-37.7(b)

Source: Australian Institute of Health and Welfare (2009)<sup>7</sup>

Notes:

(a), (b), (c) indicate overlapping confidence intervals

The evaluation of the first round of the UK Pilot reported that the uptake of the FOBT was close to its target of 60%. However, people living in the most deprived areas were less than half as likely to participate as those living in the least deprived areas (Table 18).

**Table 18 Second round of the English Pilot of Bowel Cancer Screening: Uptake of FOBT screening by deprivation category of area of residence (Feb 2003–Nov 2004)**

Deprivation category (IMD) <sup>(1)</sup>	Adjusted OR (95% CI)
5 Most deprived	0.41 (0.39–0.43)
4	0.60 (0.57–0.62)
3	0.74 (0.72–0.77)
2	0.86 (0.83–0.90)
1 Least deprived	1

Source: Weller et al (2006)<sup>11</sup> Downloaded from the NHS website on 26 November 2009

<http://www.cancerscreening.nhs.uk/bowel/pilot-2nd-round-evaluation.pdf>

Notes:

OR: Odds ratio; CI: Confidence interval; Adjusted for all other factors

(2) IMD – The Index of Multiple Deprivation (IMD) 2004 is a measure of multiple deprivations at the small area level.

The index contains seven domains of deprivation: income, employment, health and disability, education, skills and training, barriers to housing and service, living environment and crime. The overall IMD is conceptualised as a weighted area level aggregation of these specific dimensions of deprivation.

In the Vernon review published in 1997, 5 of the 7 studies (71%) found a positive association between income and FOBT completion; higher income was associated with higher completion rates. Vernon (1997) noted that in the 2 studies that did not report an association, the income range was 'truncated'.<sup>2</sup>

In 2002, Petersen concluded that lower adherence to colorectal cancer screening was generally associated with lower income.<sup>5</sup> In the latest review published in 2010 of the factors associated with colorectal cancer screening among older people (≥65), low socioeconomic status was reported as a significant barrier in only 7 of the 19 studies (37%). Socioeconomic status was not reported as a facilitator in any studies and, presumably, in the other 63% of studies there was no association.<sup>3</sup>

### Time orientation

According to Fiscella *et al.* (2000), the 'pathways through which socioeconomic position and race/ethnicity affect health care are complex'. The authors indicate that the pathways are likely to include health care affordability, geographic access, transportation, education, knowledge, literacy, health beliefs, racial concordance between physician and patient, patient attitudes and preferences, competing demands including work and child care, and provider bias. The significance of any one of these factors is seen as varying by patient and physician.<sup>25</sup>

One of the factors that appears to have received some attention is the time orientation of low socioeconomic status groups. According to Deshpande *et al.* (2009), time orientation reflects a person's tendency to think and act according to consequences that are primarily immediate (i.e. present) or more distal (i.e. future). Deshpande *et al.* (2009) state that, by circumstance and necessity, people living in poverty tend to be present rather than future-oriented.<sup>29</sup>

According to Wolff *et al.* (2003) African American underserved patients have difficulty prioritising preventive and screening activities in the context of more immediate survival needs such as food, shelter, safety and clothing. The stress associated with living in less-than-secure environments and existing on insufficient and unreliable resources makes focusing on preventive health care difficult. They state that 'many' underserved patients report feeling

isolated and alone, and heightened concerns about daily safety and well-being are perceived as more prominent needs than worries about a disease they do not believe they have.<sup>30</sup>

In their review Deshpande *et al.* (2009) concluded that present time orientation was negatively associated with uptake of mammograms. One study reported that, overall, lower income black women tended to be more future- than present-oriented, but high present-orientation scores were negatively associated with the use of screening mammography even after adjusting for education and income.<sup>29</sup>

In the Australian context, Newman *et al.* (2008) have also pointed out the importance of looking at the context of people's lives in understanding Australian Aboriginal experiences of cancer. The authors state that 'health is often of little importance to those living with more immediate issues such as poverty, unemployment, poor housing, or violence'.<sup>31</sup>

### 3.5 Education

As shown in Table 19, monitoring data indicate higher levels of education appear to be related to higher levels of participation in cancer screening activities in the USA.<sup>8</sup>

**Table 19 Screening rates and education: USA (2005)**

Years of education	Mammogram past 2 years	Pap test past 3 years	FOBT within past year
11 or fewer	53.0	68.0	8.9
12	64.4	77.0	11.2
13–15	69.1	83.7	13.8
≥ 16	76.8	88.1	15.3

Source: Cokkinides *et al.* (2007)<sup>8</sup>

Notes:

FOBT: Faecal occult blood testing

Although the review by Jepson *et al.* (2000) concluded that the majority of studies did not find a significant association between education and uptake of screening tests (Table 20), later reviews have come to a different conclusion and these are discussed in more detail.

**Table 20 Relationship between education and screening uptake: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	3/18 (17%)	1/7 (14%)	1/4 (25%) <sup>(1)</sup>
Authors' conclusions	The majority of studies did not find a significant association between uptake and level of education	The majority of studies did not find a significant association between uptake and level of education	The majority of studies did not find a significant association between uptake and the level of education

Source: Jepson *et al.* (2000)<sup>6</sup>

Notes:

(1) Only found to be significant in older women (> 65 years)

FOBT: Faecal occult blood testing

- **Screening mammography**

In a review of studies involving Latin American women, Wells *et al.* (2007) concluded that ‘for the most part’, the studies reviewed reported that Latin American women with at least some college education were more likely to receive a screening mammogram (adjusted OR range 1.36–3.69). However, the authors noted that the evidence for the relationship between high school education and the uptake of mammograms was equivocal. Two studies found that a high school education was associated with higher odds of screening mammography compared with less than a high school education, but two other studies did not find that relationship.<sup>10</sup>

In the studies included in the Wells *et al.* (2007) review that reported an association between education and uptake of mammograms, education was entered into the multiple logistic regressions as a continuous variable or was categorised across several categories. In the studies that did not report an association, 4 did not report the adjusted OR, 3 dichotomised education near or at the completion of high school, and the remaining study sampled an immigrant population.<sup>10</sup>

The Scheuler *et al.* meta-analysis published in 2008 included 52 studies that examined the relationship between education and the uptake of mammograms. Schueler *et al.* (2008) reported that, despite variability in the magnitude of effects, studies consistently demonstrated that low education levels correlated with a low uptake of mammograms (adjusted OR 0.78, 95% CI 0.73–0.83).<sup>26</sup>

- **Pap tests**

In the Ackerson *et al.* review published in 2007, it was concluded that ‘most’ studies found that lower levels of education were associated with decreased likelihood of Pap testing.<sup>27</sup>

- **Faecal occult blood testing**

In a review of the factors associated with the uptake of FOBT published in 1997, Vernon *et al.* reported that, with one exception, both prospective and retrospective studies found a positive association between higher education and completion of FOBT.<sup>2</sup>

In 2002, Petersen reported that lower participation in colorectal cancer screening tests were associated with less educational attainment.<sup>5</sup> In the latest review of factors associated with colorectal cancer screening in older adults ( $\geq 65$  years), published in 2010, 19 of 27 studies (70%) found that low education was a significant barrier to screening uptake and none found it was a significant facilitator.<sup>3</sup> Presumably the other 30% of studies did not find an association

## Summary

- **Age**

There is evidence to suggest that age is associated with the uptake of screening but the patterns vary by screening type. For screening mammography and Pap tests, it appears that participation is lower in younger age groups (i.e. among those who become eligible to join population-based programs). Participation in Pap testing appears to decline as women move towards the upper age limits for population-based screening. Available

evidence indicates that the uptake of FOBT will increase with age up until about 70 years of age.

- **Gender**

The strongest evidence in relation to uptake of FOBT comes from an evaluation of the second phase of the UK pilot program. This study indicated that uptake was higher among women than men, particularly in younger age groups. Findings from peer-reviewed literature and a brief review of health-seeking behaviour are less consistent. However, this literature did warn against treating men as a homogeneous group. On balance, it seems likely that the uptake of FOBT will be higher among women than among men, although the differences may be smaller among older age groups.

- **Ethnicity**

Monitoring data clearly indicate lower participation among ethnic and Indigenous groups compared with other groups. However, the reviews indicate that when the analyses control for other factors (e.g. socioeconomic status), ethnicity may not be a significant factor in the uptake of screening.

- **Socioeconomic status**

When socioeconomic status is operationalised in terms of income, there appears to be sufficient evidence to conclude that lower income is associated with lower screening rates. There is some research to indicate that the underlying issue with low socioeconomic status may not be a lack of money as such but a focus on the more pressing problems of everyday life which works against the uptake of screening. The Australian monitoring data indicate lower uptake in the areas ranked lowest on a socioeconomic area index. The relationship between uptake and area of residence socioeconomic status for other rankings varies across tests.

- **Education**

On balance, the evidence indicates that low levels of education are associated with lower uptake of mammographic screening, Pap tests and FOBT.

## 4 COGNITIVE FACTORS

The term cognition (Latin: *cognoscere*, to know or to recognise) refers to the processing of information, applying of knowledge, and changing of preferences. Within psychology the concept is closely related to concepts such as the mind, reasoning, perception, intelligence, learning, and other concepts describing ‘capabilities of the mind’.<sup>6</sup> Cognition can therefore be regarded as a term referring to the mental processes involved in gaining knowledge and understanding.<sup>7</sup>

Five factors have been included under the umbrella of cognitive factors: literacy, health literacy (HL), cancer related knowledge, perceived risk and the perceived ambiguity of messages relating to cancer screening.

- **Literacy**

In 1991, the US Congress defined literacy as ‘the ability to read, write and speak the language in order to compute and solve problems at levels of required to function on the job and in society, achieve one’s goals and develop one’s knowledge and potential’.<sup>32, 33</sup>

- **Health literacy (HL)**

According to Ishikawa *et al.* (2008) there are numerous HL definitions. For example:

- the American Medical Association (AMA) defines HL as a constellation of skills required for functioning in the health environment
- the National Library of Medicine (NLM) defines HL as the degree which a person has the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions
- the World Health Organization (WHO) defines HL as the cognitive and social skills which determine the motivation and ability of individual to gain access to, understand and use information in ways that promote and maintain good health.<sup>33</sup>

Regardless of how it is defined, HL affects: (i) a person’s knowledge about health and health care; (ii) the ability to find and communicate health information; and (iii) the skills required for making health decisions.<sup>34</sup>

- **Cancer-related knowledge**

In the literature, cancer-related knowledge covers a range of issues related to screening: (i) knowledge of the risk factors; (ii) knowledge of the screening process itself; and (iii) knowledge of screening guidelines.

- **Perceived risk**

According to Katapodi *et al.* (2004), education interventions that aim to improve the uptake of mammograms have generally been based on theoretical models that attempt to explain how and why individuals adopt health-protective behaviours. The majority of these models adopt a decision-making perspective focused on a cost–benefit analysis of outcomes (e.g. Health Belief Model, Theory of Planned Behaviour).<sup>8</sup> In these models one

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<sup>6</sup> <http://en.wikipedia.org/wiki/Cognition>

<sup>7</sup> [http://psychology.about.com/od/cindex/g/def\\_cognition.htm](http://psychology.about.com/od/cindex/g/def_cognition.htm)

<sup>8</sup> An overview of these models is contained in Vol 3.

of the major components of the cost–benefit analysis is a person’s perceived susceptibility to the disease. Perceived susceptibility or perceived risk refers to a person's belief about the likelihood that a health problem will be experienced if no precautions or behavioural changes are undertaken.<sup>35</sup>

- **Perceived ambiguity**

Han *et al.* (2006) have defined ambiguity as uncertainty about the ‘reliability, credibility, or adequacy’ of one's information concerning the likelihood of outcomes. Ambiguity arises from incomplete or conflicting evidence or expert opinion and is high when ‘expert knowledge’ is contested.<sup>36</sup>

## 4.1 Literacy

The Federation of Ethnic Communities' Councils of Australia (2006) has pointed out that low literacy levels among some national groups in Australia have implications for the success of health promotion programs with new and emerging communities.<sup>37</sup> The relationships between the host country's language and literacy is shown in two reports from the Organisation of Economic Co-operation and Development (OECD).

In one report, non-native language status is a significant predictor of literacy in all English-speaking countries (including Australia, Canada, New Zealand, the United Kingdom and the United States) and exerts an effect in the smaller European countries with large immigrant populations such as Finland (Table 21). As shown in Table 21, there is a negative relationship between age and literacy; in both Australia and Finland, older age is associated with lower literacy levels.<sup>38</sup>

**Table 21 Percentage of variance (R sq) in literacy proficiency accounted for by 12 predictor variables: Australia and Finland**

Variable	Australia	Variable	Finland
Native vs foreign language	0.299	Respondent's education	0.318
Respondent's education	0.294	Parents' education	0.159
Occupational category	0.164	Occupational category	0.138
Labour force participation	0.112	Native vs foreign language	0.113
Reading at home	0.093	Labour force participation	0.103
Participation in adult education	0.090	Participation in adult education	0.091
Participation in voluntary activities	0.083	Reading at work	-0.042
Parents' education	0.052	Participation in voluntary activities	0.038
Industrial sector	0.033	Reading at home	0.019
Reading at work	0.033	Industrial sector	0.019
Gender	0.017	Gender	0.007
Age	-0.133	Age	-0.175
Explained variance	0.488	Explained variance	0.454

Source: Organisation for Economic Co-operation and Development (2000)<sup>38</sup>

The second OECD report related to the International Adult Literacy Survey (IALS), which measured literacy proficiency in the domains of prose literacy, document literacy and quantitative literacy.<sup>38</sup> Each domain is divided into five levels.

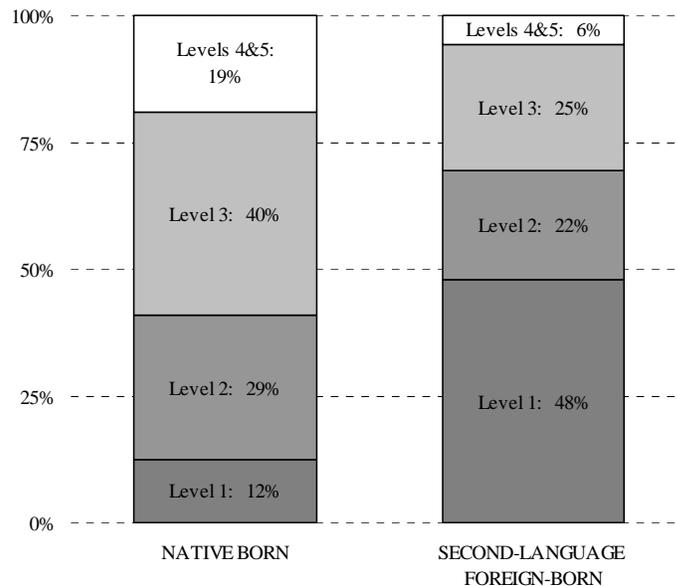
- **Level 1**  
Persons at this literacy level have very poor literacy skills. For example, a person at this level may be unable to determine the correct amount of medicine to give a child from information printed on the package.
- **Level 2**  
People at this level can deal only with material that is simple, clearly laid out, and in which the tasks involved are not too complex. It identifies people who can read and they may have developed coping skills to manage everyday literacy demands, but their low level of proficiency makes it difficult for them to face novel demands.
- **Level 3**  
This is considered a suitable minimum for coping with the demands of everyday life and work in a complex, advanced society. It corresponds roughly to the skill level required for successful secondary school completion and college entry. It requires the ability to integrate several sources of information and solve more complex problems.
- **Levels 4 and 5**  
People at these levels demonstrate command of higher-order information processing skills.<sup>39</sup>

Document literacy is described as ‘the knowledge and skills required to locate and use information contained in various formats’.<sup>38</sup> It has been found that, compared to people born in Australia (native-born), those born in a foreign country and whose ‘mother tongue’ is not English (second-language, foreign-born) are four times more likely to be in the lowest document literacy level (Figure 4).

A review of studies conducted in the ‘developed world’ which was published in 2004, contained two studies which evaluated the relationship between reading ability and health promotion.

- Scott *et al.* (2002) found that after controlling for age, gender, race, education and income, Medicare enrollees in the USA with lower literacy had greater odds of never having had a Pap test (OR 1.7, 95% CI 1.0–3.1) and not having had a mammogram in the past 2 years (OR 1.5, 95% CI 1.0–2.2).<sup>40, 41</sup>
- In a study of cervical cancer screening in India, researchers interviewed women residing in rural areas and urban indigent areas who had been invited to a cervical screening program. They found that there were no statistically significant differences in the age distribution, marital status and socioeconomic status of the women who did and did not attend screening. However, there was a lower literacy rate among the non-attenders (49.0%) compared with attenders (59.5%), and the difference was statistically significant (OR 2.25; 95% CI 1.23–41.3).<sup>42</sup>

**Figure 4 Document literacy: percentage of Australian-born (native-born) and second language, foreign-born Australians aged 16–65 years in each literacy level**



Source: Organisation for Economic Co-operation and Development (2000)<sup>38</sup>

## 4.2 Health literacy

HL has been described as ‘literacy in the context of health and health care’. According to Ishikawa *et al.* (2008), some studies have reported significant associations between measure of literacy and measures of functional HL. However, it has also been noted that even individuals with adequate literacy might not have adequate HL.<sup>33</sup>

According to Ackerson *et al.* (2007), people with poor HL skills have difficulty understanding information containing unfamiliar vocabulary and concepts. They point out that low HL rates are more common in certain populations, such as the elderly, ethnic minorities, immigrants, non-active English speakers, and those with limited education and low income. Low HL has consistently been associated with inadequate knowledge about disease and reduced health screening behaviours.<sup>24</sup>

- **Pap tests**

According to Giordano *et al.* (2008), HL is recognised as a critical factor affecting the individual’s ability to understand the importance of health care and the risks and benefits of cervical cancer screening.<sup>43</sup> One study published in 1991 found that HL (in English) was the only factor independently associated with cervical cancer screening knowledge. A second study published in 2004 found that low HL among Spanish speakers in the USA also correlated with low cervical cancer screening rates.<sup>24</sup>

- **Faecal occult blood testing**

According to Friedman *et al.* (2008), the majority of cancer studies relating to HL involve people with breast cancer, even though information for other cancers (e.g. colorectal cancer) is more difficult for people to understand. For example, interviews with older

adults on their comprehension of breast, prostate and colorectal cancer information found that individuals had significantly greater difficulty comprehending resources about colorectal cancer compared to other cancers, especially regarding screening procedures such as flexible sigmoidoscopy, colonoscopy and FOBT. Friedman *et al.* (2008) state that both printed and web-based colorectal cancer material materials are written at difficult readability levels.<sup>34</sup>

Donelle *et al.* (2008) undertook a study to describe the impact of HL and level of education on participants' understanding of 'common' and 'uncommon' internet-based colorectal cancer prevention information. As shown in Table 22, education was not a statistically significant predictor, but HL and particularly health numeracy were significant.<sup>44</sup>

**Table 22 Multiple regression modelling of comprehension of internet-based colorectal cancer information**

Explanatory variable	Common internet information	Uncommon internet information	Combined information
	Beta coefficient	Beta coefficient	Beta coefficient
Gender	0.118	0.30	0.00
Age	-0.26*	-0.32	-0.678*
Education	0.15	0.21	0.363
STOFHLA prose	0.014	0.007**	0.067**
STOFHLA numeracy	0.087**	0.043	0.10
Health numeracy	0.401**	0.38**	0.838**
General numeracy	-0.13	0.58**	0.466
Math anxiety	-0.004	-0.006	-0.01
Model Statistics			
R sq	0.377**	0.562**	0.598**

Source: Donnelle *et al.* (2008)<sup>44</sup>

Notes:

STOFHLA: Short Test of Functional Health Literacy for Adults

\* & \*\* represent statistically significant coefficients

Univariate analyses in a study undertaken by Guerra *et al.* and published in 2005 indicated that HL was associated with awareness of colorectal cancer and FOBT but not with knowledge of the screening guidelines for FOBT. However, in the multivariate analyses there was no statistically significant relationship between awareness and HL (Table 23).

**Table 23 Association between functional health literacy and cancer-related knowledge**

	Inadequate/marginal HL		Adequate HL		p value	
	Number	Percent	Number	Percent	Un-adjusted	Adjusted <sup>(1)</sup>
(a) Yes: Heard of colorectal cancer	34	61%	75	95%	0.00	0.87
(b) Yes: Heard of FOBT	28	50%	66	84%	0.00	0.10
If Yes to (b) asked How often should a person be tested?						
Correct response	16	59%	46	72%	0.24	

Source: Guerra *et al.* (2005)<sup>45</sup>

Notes:

(1) Adjusted for ethnicity, Medicaid status, insurance status, education and income

HL: Health literacy; FOBT: Faecal occult blood testing

### Reading and information-seeking

According to von Wagner *et al.* (2009), the evidence indicates that adults with limited HL are less likely to seek out or engage with printed health communication material and that limited HL also causes difficulties once information has been accessed. This has implications for cancer awareness and knowledge. For example, limited HL has been associated with lower knowledge about, and more negative attitudes towards, colorectal cancer screening. Participants with limited HL have expressed more negative attitudes towards colorectal cancer screening using FOBT, including worries that FOBT may be messy and inconvenient. Men with lower HL skills were found to be four times more likely to refuse the offer for FOBT screening, even if it was recommended by their doctor.<sup>46</sup>

In the review published in 2002 of the factors associated with colorectal cancer screening, Petersen concluded that lower adherence with colorectal cancer screening guidelines was generally associated with lower tendency to be an information seeker.<sup>5</sup>

However, it has also been found that ‘many’ patients, regardless of their HL levels, have reported difficulties with health information leaflets. For example, in a study undertaken by Shaw *et al.* (2009), 8% of the participants with adequate HL indicated they had some difficulty understanding the medical leaflets used in the study (Table 24).<sup>46, 47</sup>

**Table 24 Relationship between health literacy and understanding of medical leaflets (n = 321)**

	Adequate level of HL <sup>(1)</sup>		Low level of HL	
	Number	Percent	Number	Percent
Difficulty	19	8%	26	37%
No difficulty	232	92%	44	63%
Total	251	100%	70	100%

Source: Shaw *et al.* (2009)<sup>47</sup>

Notes:

HL = Health literacy

## Self-efficacy

Wolf *et al.* (2007) have pointed out that, although the association between HL, health-related knowledge and attitudes are significant, studies have found that these associations only partially account for the link between HL and health outcomes. These authors believe that it is important to establish connections between HL and variables that are 'proximal' to behaviour such as self-efficacy.<sup>48</sup>

Self-efficacy is an individual's perception of his/her ability to perform a specified behaviour/set of behaviours.<sup>49</sup> It has been used extensively to predict the likelihood of enacting behaviours in various contexts including colorectal cancer screening.<sup>48</sup> In a workplace study of employees aged 40 years and older, self-efficacy was a significant and independent predictor of colonoscopy attendance.<sup>50</sup>

In their review published in 1997, Vernon *et al.* found that self-efficacy was positively associated with adherence to FOBT in 3 of 3 studies.<sup>2</sup> However in a 2007 study, there were no differences in reported self-efficacy to complete FOBT between participants with adequate HL and those with limited HL (3.93 vs 3.87,  $p = 0.44$ , adjusted for age, sex, race, insurance status).<sup>51</sup>

## 4.3 Cancer-related knowledge

In their systematic review published in 2000, Jepson *et al.* concluded that there was little evidence of a statistically significant positive relationship between mammogram uptake and breast cancer-related knowledge. They did not include any studies relating to the relationship between knowledge and Pap tests or FOBT (Table 25).

**Table 25 Relationship between cancer related knowledge and screening uptake: Jepson *et al.* (2000) review**

	Screening mammograms
Studies with statistically significant effects ( $p \leq 0.05$ )	Breast cancer: 0% (0/4) Mammography and screening guidelines: 20% (1/5)
Authors' conclusions	The majority of studies did not find a significant association between the uptake of mammograms and knowledge about breast cancer or screening mammography

Source: Jepson *et al.* (2000)<sup>6</sup>

- **Screening mammography**

In 2006, Parsa *et al.* published a review that included several studies examining the factors affecting screening practices among women of Asian descent. According to the authors, these studies demonstrated that lower screening rates are associated with lower levels of cancer-related knowledge. Studies in Korea and Turkey showed knowledge of breast cancer screening guidelines was a major predictor of regular screening women; women who had knowledge of mammography guidelines were ten times more likely to have regular mammograms.<sup>52</sup>

A study in Hong Kong that was included in the Parsa *et al.* (2006) review reported that 42% of the surveyed population had heard of screening mammography. In this study, education level had no impact on the awareness. Full-time housewives were significantly more likely to have heard of screening mammography compared to non-housewives (49%

vs 73%,  $p = 0.0001$ ).<sup>52</sup>

In the Wells *et al.* (2007) review of factors associated with the uptake of screening among Latin American women in the USA, 2 studies evaluated knowledge of breast cancer and attitudes towards breast cancer and participation in breast cancer screening. One found that a higher level of knowledge about breast cancer was related to higher odds of ever having a mammogram (adjusted OR 2.8) but another found that knowledge about risk factors for breast cancer and symptoms of breast cancer was not related to screening mammography.<sup>10</sup>

As shown in Table 26, the Schueler *et al.* (2008) meta-analysis of factors associated with screening mammography uptake indicated a statistically significant association between poor screening knowledge and lower levels of uptake. Moreover, beliefs that mammograms are harmful and are only needed if symptoms are present were associated with reduced uptake.<sup>26</sup>

**Table 26 Relationship between breast cancer knowledge on screening mammography uptake: Schueler *et al.* (2008) review**

	Number of studies	Adj OR	95% CI
Poor knowledge of:			
screening	11	0.46	0.35–0.60
risk factors	6	0.76	Not available
Mammogram ineffective/ inaccurate	6	0.48	Not available
Mammogram harmful	6	0.54	0.43–0.67
Mammogram only needed if symptoms present	5	0.56	0.43–0.72

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

Adj OR: Adjusted odds ratio; CI: Confidence interval

- **Pap tests**

According to Ackers *et al.* (2007) lack of knowledge about the importance of cervical cancer screening, early detection, and treatment has been extensively studied, particularly among ethnic minorities and women from low socioeconomic groups. These studies have shown that women who are younger, non-white, and those with low educational attainment or low income are more likely to be unaware of the purpose of Pap testing.<sup>24</sup>

According to Ackerson *et al.* (2007), few studies have been published that describe the beliefs and perceptions of African-American women regarding cervical cancer and the impact these have upon screening uptake.<sup>27</sup>

- **Faecal occult blood testing**

In 1995, a population study was conducted of Australians' colorectal screening attitudes, intentions, beliefs and knowledge. Based on a sample of 1776 people, the study found that although community awareness of FOBT screening was 'reasonable' there was a lack of uptake of FOBT. The potential barriers to screening on a mass scale identified included a lack of knowledge about the causes and disease trajectory of colorectal cancer. The study noted that participants born in Australia, the UK and Ireland were more likely to be

aware of colorectal cancer screening tests.<sup>21</sup>

In the 1997 Vernon review, 3 of 4 studies (75%) reported a positive association between knowledge of cancer risk factors and the uptake of FOBT. The other study reported no association.<sup>2</sup> In 2002, Petersen reported that having ‘less knowledge of colorectal cancer and cancer screening’ was generally associated with lower adherence to colorectal cancer screening guidelines.<sup>5</sup>

According to Wolff *et al.* (2003), African-American underserved populations are not as likely to be informed about the current guidelines recommended for cancer and screening.<sup>30</sup> One study found that the American Cancer Society recommendations for early detection in asymptomatic people were not well known by a study sample of African-Americans. Although 75% of the men participating in the study knew that annual physical examinations were recommended for cancer detection in men over 40 years of age, only 25% of the men identified colorectal examinations as part of this annual examination.<sup>30</sup>

In 2004, the baseline knowledge, attitudes and practices survey conducted at the commencement of the Australian Pilot Program for colorectal cancer screening showed that awareness among Australians of FOBT screening was ‘relatively low’. Only 41% of those surveyed had heard of FOBT and only 26% had ever been tested. In the follow-up survey undertaken near the completion of the pilot, 81% of those surveyed had heard of FOBT with 43% having undertaken a test in the last 12 months. However, in these surveys, people from CALD backgrounds were under-represented; people were excluded from participating if their English language skills were not adequate for them to participate in the survey.<sup>21</sup>

In the 2010 review by Guessous *et al.*, of the factors associated with colorectal cancer screening among people aged 65 years of age and over, a lack of awareness of colorectal cancer screening was reported as a significant barrier in 100% of studies (11 of 11).<sup>3</sup>

#### 4.4 Perceived risk

In the Jepson *et al.* review published in 2000, the majority of studies failed to find an association between perceived risk or susceptibility and the uptake of mammograms and FOBT (Table 27). There were no studies in this review that examined the relationship between perceived risk and the uptake of Pap tests.

**Table 27 Relationship between perceptions of risk and screening uptake: Jepson *et al.* (2000) review**

	Screening mammograms	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	1/8 (12.5%)	1/3 (33%)
Authors’ conclusions	The majority of studies did not find an association between the uptake of mammograms and perceived vulnerability or susceptibility (risk)	The majority of studies did not find an association between the uptake of FOBT and perceived vulnerability or susceptibility (risk)

Source: Jepson *et al.* (2000)<sup>6</sup>

Notes:

FOBT: Faecal occult blood testing

- **Screening mammography**

In an analysis of the 1990 US National Health Interview Survey data, Austin *et al.* (2002) found that the response 'not needed' was the largest barrier to screening mammography among older Hispanic women. According to Austin *et al.* (2002), it appears that many women understand that mammography successfully detects breast cancer early, but they do not perceive their own vulnerability to breast cancer and do not see themselves at risk if they asymptomatic or have no family history of the disease.<sup>53</sup>

In 1996, McCaul *et al.* undertook a meta-analysis of the relationship between perceived breast cancer risk and the uptake of mammograms. Their results showed that perceived risk was positively associated with screening mammography in 95% of studies (18 of 19). Most, but not all, of these studies were of women at average risk of breast cancer. The average effect size (adjusted for sample size) was  $r = 0.16$ , and was smaller for prospective ( $r = 0.10$ ) compared with cross-sectional studies ( $r = 0.19$ ). The authors concluded that there was no support for the hypothesis of a curvilinear relationship between perceived risk and screening (i.e. that high and low perceived risks are negatively associated with screening).<sup>4</sup>

In 1999, Vernon *et al.* concluded that studies had consistently found a positive association between perceived risk and screening mammography in women at average risk of breast cancer although the magnitude of the overall effect size was small.<sup>54</sup>

Katapodi *et al.* (2004) built on the McCaul *et al.* (1996) meta-analysis and included 13 extra studies published between 1993 and 2002. Four of the extra 13 studies (31%) did not demonstrate a positive association between perceived risk and screening mammography. The average effect size for the extra studies weighted by sample size was 0.20 (95% CI 0.18–0.23). When the 13 studies were added to the McCaul *et al.* (1996) data, the average effect size was 0.19. The authors concluded that the results suggest that perceived risk has a small but significant positive effect on adherence to screening mammography.<sup>35</sup>

Overall, 42% of the 42 studies included in Katapodi *et al.* (2004) meta-analysis included women of diverse racial/cultural backgrounds in percentages ranging from 14% to 100%. The remaining 58% of the studies reviewed included mostly, or exclusively, white women. Five studies examined the relationship between race/culture and perceived risk of breast cancer in samples consisting of 14–49% minority women. In these studies, white women were more likely to perceive themselves as being at increased risk for developing breast cancer compared with other women. Black women were more likely to be unaware that diagnosis of a first-degree relative with breast cancer increased their risk of developing the disease (ES = 0.38, 95% CI 0.28–0.47). However, two studies with an over-representation (> 60%) of women from diverse racial/cultural backgrounds reported no significant differences perceived risk of breast cancer among women of diverse ethnic/cultural groups and white women but there were 'insufficient data to calculate effect sizes'.<sup>35</sup>

In 2007, Magai *et al.* concluded that it appears that perceptions of risk do have an impact on screening adherence but effect sizes appear to be 'comparatively' small.<sup>55</sup> In a meta-analysis published in 2008, Schueler *et al.* concluded that the belief one was less

personally susceptible did not have a statistically significant impact on the uptake of mammograms (6 studies, Adj OR=0.75, 95% CI 0.45–1.24).<sup>26</sup>

- **Pap tests**

The Vernon *et al.* (1999) review contained 3 studies with a multivariate analysis of a number of cognitive and attitudinal variables, including perceived risk, and cervical cancer screening. After controlling for other variables, 1 study found a positive association with cervical cancer screening and 2 studies found no association.<sup>54</sup>

According to Ackerson *et al.* (2007) minority women were less likely to participate in Pap tests if they did not perceive cervical cancer as a possibility. Hispanic women believed that physical trauma related to abortion and rough sex, an infected partner, and lack of feminine hygiene made an individual vulnerable to cervical cancer. If Hispanic women did not feel that they were personally vulnerable, they were less likely to obtain testing.<sup>27</sup>

- **Faecal occult blood testing**

In a review of the literature on colorectal cancer screening adherence, Vernon *et al.* found that 2 of 8 studies (25%) reported a positive association between perceived risk and completion of FOBT while 6 studies (75%) reported no association. The authors concluded that, at that time, there were insufficient data to draw firm conclusions about the pattern or magnitude of the association between perceived risk and uptake of FOBT.<sup>2</sup>

In 2002 Petersen concluded that lower perceived risk of colorectal cancer and lower perceived susceptibility to colorectal cancer were associated with lower screening adherence.<sup>5</sup>

In a 2009 study, Weinberg *et al.* found that, in a population of ‘average-risk, non-compliant women’ for whom the barriers regarding access and insurance were almost eliminated, inaccurate risk perception about colorectal cancer and the belief that screening might be painful were among the key factors that contributed to reduced intention to participate in colorectal cancer screening.<sup>56</sup>

## 4.5 Perceived ambiguity

Perceived ambiguity appears to be a relatively ‘new’ line of research in relation to screening behaviour. It has been included because, as Han *et al.* (2007) state, there are ‘conflicting expert recommendations regarding cancer screening and prevention’ that are ‘growing in number, visibility and importance’.<sup>57</sup> Mullins (2005) has also pointed out that ‘recommendations on the frequency of cervical cancer screening vary from country to country’.<sup>58</sup> Moreover, a country’s recommendations may change over time and these changes are often highlighted in the media (Box 3).

According to Han *et al.* (2006) one of the consequences of publicity about health care (including cancer screening) is a belief among the scientific community that it leads to an increase in ‘public confusion and scepticism about health recommendations’. Added to this publicity, the promotion of ‘informed consent’ and ‘shared decision making’ as normative ideals in health care has meant that doctors have an obligation to increase patients’ awareness of scientific uncertainties so that they can understand the implications of their decisions in relation to health care.<sup>36</sup>

### Box 3 USA: Changes in screening mammography and Pap testing guidelines

#### New cervical cancer screening guidelines released

By Sandra Young, CNN Medical Producer November 20, 2009 10:51 a.m. EST

The new mammogram recommendations out earlier this week caused quite an uproar. Now comes another change in screening tests for women -- this one for cervical cancer.

The American College of Obstetricians and Gynecologists (ACOG) releases new guidelines Friday, saying women don't need their first cervical cancer screening -- or Pap test -- until they're 21 years old. And, they don't need follow-up examinations as often as previously recommended.

According to the guidelines, women younger than 30 should be screened every two years, instead of annually. Women 30 or older can be examined once every three years.

"The tradition of doing a Pap test every year has not been supported by recent scientific evidence," said Dr. Alan G. Waxman, who developed the document for ACOG's Committee on Practice Bulletins-Gynecology. "A review of the evidence to date shows that screening at less frequent intervals prevents cervical cancer just as well, has decreased costs, and avoids unnecessary interventions that could be harmful."

The tradition of doing a Pap test every year has not been supported by recent scientific evidence.

The current guidelines, from 2003, recommend that women get a Pap test three years after they begin having sexual intercourse, but no later than age 21. And that women younger than 30 have an annual exam. For women 30 or older, the recommendation was every two to three years, if they'd had three consecutive negative Pap tests.

The American Cancer Society (ACS) supports the guidelines and said it is reviewing new data and updating its own recommendations.

"There's good data since the last guidelines in 2003 that show that screening teens or before age 21 is not having an impact on reducing cervical cancer," said Debbie Saslow of the Cancer Society.

And, Saslow added, this is completely different from the new, hotly debated mammogram recommendations.

"Getting an annual Pap test is the equivalent to getting a mammogram every four months. Breast cancer on average is growing at a point where, if you get a mammogram every two years, you will miss a lot of deadly cancers that you would have caught if you're having them every year. This is not true for cervical cancer; we are detecting pre-cancers that are taking 10 to 20 years to develop into cancer."

According to the ACS, there are about 10,000 new cases of cervical cancer each year, and more than 4,000 deaths. Over half were found in women who never had a Pap test. Most cases are in women younger than 50, and rarely occur in females younger than 20.

The risk simply is not there, though the human papillomavirus (HPV), which is responsible for 70 percent or more cervical cancers, is high among sexually active teens, said Dr. David Soper of the Medical University of South Carolina.

The vast majority of those infections will resolve and not cause any significant pre-cancerous lesions, according to Soper. Females, particularly adolescents, develop immunity to HPV and can resolve the infection without treatment.

Source: Downloaded on 14<sup>th</sup> January 2009 from  
<http://www.cnn.com/2009/HEALTH/11/20/cervical.cancer.guidelines/index.html>

Han *et al.* (2006) reported that studies have provided 'strong' support for the proposition that cancer worry will 'predispose' people to interpret ambiguity relating to cancer prevention recommendations more pessimistically; it is likely to reduce people's beliefs that cancer can be prevented.

In a 2006 study, Han *et al.* found increased perceived ambiguity was associated with an increase in:

- perceived cancer risk (Adj OR 1.46, 95% CI 1.18–1.80,  $p < 0.01$ )
- cancer-related worry (Adj OR 1.53, 95% CI 1.01–2.32,  $p = 0.04$ ).<sup>36</sup>

In a study reported in 2007, Han *et al.* conducted a secondary analysis of longitudinal data from the 1995 Maximizing Mammography Participation Trial in the USA.<sup>57</sup> The results indicated that, compared with women reporting the lowest level of perceived ambiguity, women with higher levels of perceived ambiguity had progressively:

- lower odds of intending to obtain a future mammogram; for women indicating the highest level of perceived ambiguity OR = 0.34 (95% CI 0.20–0.55);
- lower odds of actually obtaining a subsequent mammogram; for women indicating the highest level of perceived ambiguity (OR 0.43, 95% CI 0.22–0.84).

Contrary to predictions arising from the earlier research, no significant relationship was found between baseline perceived ambiguity and perceived breast cancer risk at the 12-month follow-up, controlling for demographic variables and baseline perceived risk.

The authors concluded that, among women aged 50–79 years, high perceived ambiguity about mammography recommendations is associated with both diminished uptake of screening mammography over time, and lower intentions for future mammography. High perceived ambiguity also predicted greater mammography-related worry.

## Summary

- **Literacy**  
There is evidence to indicate lower literacy levels among Australians for whom English is not their 'native' language. However, there is very little evidence relating to the association between literacy and screening uptake. Two studies indicated that lower literacy was associated with lower uptake of mammograms among Medicare enrollees in the USA and Pap tests among women residing in rural and urban indigent areas in India. However, it is not clear that these results would generalise to other groups.
- **Health literacy**  
HL is, to some extent, associated with literacy but not entirely. HL has been found to be lower among the elderly, ethnic minorities, immigrants, non-active English speakers and those with limited education and low incomes. Low HL has been associated with lower uptake of Pap tests when other factors are controlled. There is some evidence that low HL is associated with proximal measures of participation in colorectal cancer screening (e.g. knowledge, comprehension, information seeking, and difficulty in understanding information) and negative attitudes towards colorectal cancer screening and refusal to participate in FOBT screening.
- **Cancer-related knowledge**  
The evidence for the relationship between breast cancer knowledge and uptake of screening mammograms is conflicted. However, the latest review published in 2008 indicates that poor knowledge of screening, the belief that mammograms are harmful and that mammograms are not needed unless symptoms are present are associated with a

reduction in the uptake of mammograms. There is insufficient evidence to draw any conclusions about the relationship between cancer-related knowledge and Pap tests. The evidence for FOBT indicates that knowledge may be lower in ethnic groups, and there is some evidence that poorer knowledge of colorectal cancer is associated with a lower uptake in colorectal cancer screening.

- **Perceived risk**

On balance, the evidence indicates that perceiving oneself to be at a heightened risk of breast cancer is likely to increase the uptake of mammograms; however, the effect is small. There is little evidence to support this association in relation of Pap tests and FOBT.

- **Perceived ambiguity**

There was some evidence that higher levels of perceived ambiguity are related to lower participation in the uptake of mammograms. There was no evidence for the impact of this factor on the uptake of Pap tests and FOBT.

## 5 PSYCHOSOCIAL FACTORS

In 2003, Magai *et al.* wrote that the literature on screening adherence had moved away from emphasising demographic and structural variables as predictors to include cognitive and emotion variables. At that time, the authors indicated that studies suggested that emotion variables could add 'significant' variance to the prediction of screening in multiple regression and regression models. They used the example of the Bowen *et al.* (2003) study, in which emotion variables (cancer worry, anxiety, and depression) added an additional 4% of the variance to screening mammography.<sup>55, 59</sup> This section of the VCS review examines the relationship between screening and the three following psychosocial factors.

- **Fear/anxiety/worry**

Definitions of cancer worry and anxiety are conceptually and empirically distinct from perceived cancer risk. Perceived risk and cancer worry are only moderately correlated (0.30–0.40) and both factors have been found to be independently related to cancer screening.<sup>60</sup>

A clinical diagnosis of anxiety disorder also differs from the measurement of anxiety symptoms.<sup>61</sup> Spielberger (1996) differentiated between state and trait anxiety. Trait anxiety was defined as a person's predisposition to experience anxiety in a stressful situation and tends to be stable over time; its test–retest reliability is high (range 0.73–0.86). State anxiety was defined as a short-lived emotional response characterised by unpleasant feelings of tension and apprehensive thoughts<sup>61-63</sup>

In the cancer prevention literature, there does not appear to be a distinction between these two types of anxiety. However, the small amount of literature relating to trait anxiety has been included in the section of the review that focuses on health and lifestyle factors rather than in this section.

- **Emotion regulation (coping styles)**

Emotion, such as fear, anxiety and worry, have well-documented, strong motivational properties, and people often feel impelled to regulate them. It has been hypothesised that the manner in which the individual regulates, or fails to regulate, these emotions is likely to exert an important influence on health behaviour.<sup>1, 55</sup> According to Magai *et al.* (2007), people engage in a range of regulatory strategies, including active problem solving and seeking social support, as well as by activating more defensive coping styles, such as repression and denial.<sup>55</sup>

- **Social networks**

According to Kinney *et al.* (2005), research and theory suggest that social networks play a role in a range of health-related outcomes. In the literature, social networks and social support have been operationalised in two ways:

- the structural approach focuses upon the aspects of social networks such as social integration, group membership, marital status and the number of social contacts
- the functional approach focuses on the nature of the support provided, such as emotional support, the provision of tangible support (e.g. the provision of material and

financial support) or the provision of information (e.g. contact with someone who has experienced something similar).<sup>64</sup>

## 5.1 Fear/anxiety/worry

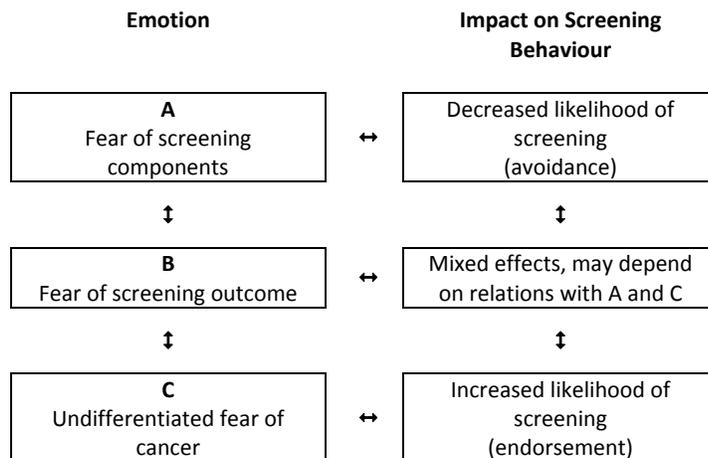
In 2005, Hay *et al.* wrote that ‘the question of whether cancer worry ... facilitates or deters cancer screening has been pursued for over 30 years. Yet ... we currently lack consensus concerning whether cancer worry motivates or inhibits screening’.<sup>60</sup> This review was accepted for publication in 2004, the same year in which a review by Consedine *et al.* was published.<sup>1</sup>

Consedine *et al.* (2004) also noted that the relationship between screening behaviour and ‘the construct variously called anxiety, fear, or worry’ had been studied extensively, but it was unclear whether fear was positively or negatively associated with screening behaviour. The authors noted that part of the difficulty was due to the fact that ‘fear’ had been operationalised in a variety of ways: fear of cancer, fear of the screening process, or fear of the outcome. Consedine *et al.* (2004) proposed a model in which:

- fear of the screening components is likely to result in a decrease in screening behaviour,
- an undifferentiated fear of cancer is likely to lead to an increase in screening behaviour, and
- the result for a fear of the screening outcome was not clear (Figure 5).<sup>1</sup>

Magai *et al.* (2007) in their review of the psychosocial and cognitive variables associated with breast cancer screening indicated that the few papers that had been published on this subject since the Consedine *et al.* (2004) review were ‘not inconsistent’ with the model.<sup>55</sup>

**Figure 5 Model of the relationship between fear and breast cancer screening behaviour: Consedine *et al.* (2004) review**



Source: Consedine *et al.* (2004)<sup>1</sup>

Hay *et al.* (2006), in their review of the role of worry in breast cervical and colorectal cancer screening, pointed out that the conflicting empirical findings prior to the production of the Consedine *et al.* (2004) model could have been due to factors including:

- the ‘multiple, un-reconciled methods of defining and measuring cancer worry’

- the preponderance of cross-sectional studies that measured cancer fear/worry/anxiety and screening adherence simultaneously.

Hay *et al.* (2006) limited their review to studies in which worry assessment preceded measures of screening uptake. They found that 92% of the prospective studies (11 of 12) reported a positive relationship between cancer worry and screening behaviour. The un-weighted effect size for screening mammography was 0.10 ( $p < 0.001$ ). The authors also concluded that the data suggested that high levels of cancer worry were not common and that higher worry levels were not associated with reduced screening.<sup>65</sup>

## 5.2 Coping style (emotion regulation)

In 2007, Magai *et al.* pointed out that there was 'slim but important literature' on how coping styles relate to breast cancer screening.<sup>55</sup> The two styles that appear to have been researched are 'denial' and 'repression'.<sup>9</sup> These are psychological mechanisms that people use to protect themselves from anxiety and are generally regarded as maladaptive from a psychoanalytical perspective. However, more recent and everyday understandings of the concepts indicate that whether or not they are maladaptive will depend on the costs and benefits associated with their use.<sup>66</sup>

Based on one study, Consedine *et al.* (2004) stated that research has shown that beliefs indicative of realism and willingness to directly face breast problems – attributes that appear antithetical to denial – were more prominent in women who screened compared with those who did not. They also reported that 2 studies showed that the emotion regulatory style of repression may be associated with increases in screening.<sup>1</sup> One study compared 210 women who self-referred for screening with 210 non-attenders and found that those who self-referred evinced higher repressiveness than non-attenders.<sup>67</sup> The other study, involving 1364 women in six ethnic groups, reported that greater repression was associated with increased uptake of screening mammography even when demographics and background characteristics were controlled.<sup>68</sup>

Magai *et al.* (2007) have also pointed out the different effects of denial and repression. In an attempt to reconcile these contradictory results, the authors speculated that: (i) repression operates more broadly, such that cancer threat is pre-emptively excluded from consciousness; whereas (ii) denial comes into play after threat has entered consciousness and generates avoidance behaviours aimed at reducing anxiety.<sup>55</sup>

## 5.3 Social networks

### Structural approach

#### *Social integration*

There was little evidence in the reviews of the impact of social integration on the uptake of mammograms, Pap tests and FOBT. However, the database used for the review contained 2

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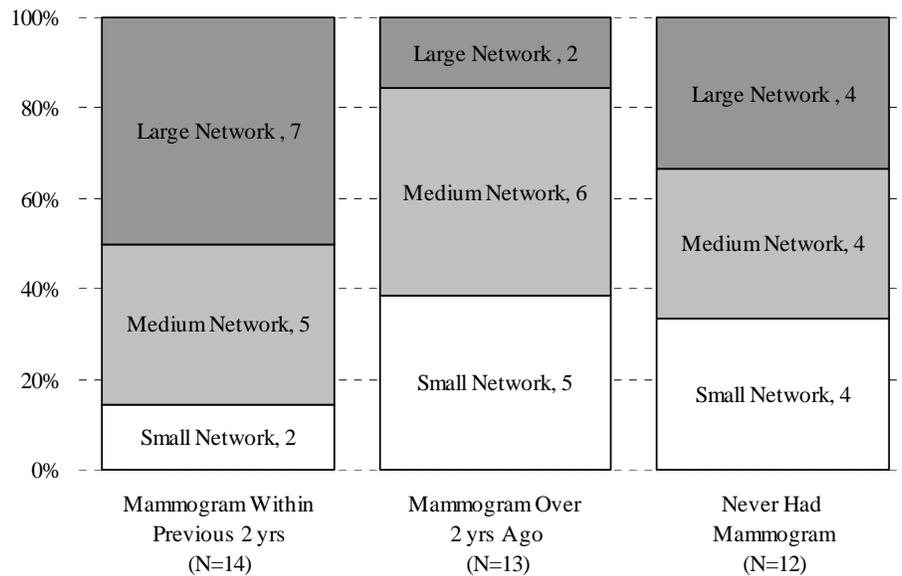
<sup>9</sup> Denial occurs when a person is faced with a fact that is too uncomfortable to accept and rejects it instead, insisting that it is not true despite what may be overwhelming evidence to the contrary. <http://en.wikipedia.org/wiki/Denial> Repression occurs when a person excludes thoughts which may cause fear and anxiety from consciousness. [http://en.wikipedia.org/wiki/Psychological\\_repression](http://en.wikipedia.org/wiki/Psychological_repression)

primary studies showing the impact of the size of the participants' networks on screening uptake; these studies have been included.

- **Screening mammography**

Tejeda *et al.* (2009) used the Social Network Index (SNI) to determine the size of the social network of the participants. The results of the study found few differences between the size of the network and the uptake of mammograms, although a greater proportion of women who reported having a recent mammogram were categorised as having large or medium social networks (Figure 6).<sup>69</sup> However, the small number of participants in each group precluded the use of tests of statistical significance (e.g. Chi<sup>2</sup>).

**Figure 6 Association between social network size and screening mammogram status**



Source: Tejeda *et al.* (2009)<sup>69</sup>

- **Faecal occult blood testing**

The Jepson *et al.* (2000) review included 4 studies relating to social influences on the uptake of FOBT. One used a version of the SNI to measure network characteristics. This study did not find any significant relationship between network characteristics and the uptake of FOBT.<sup>6</sup>

A primary study undertaken by Kinney *et al.* (2005) suggests that the impact of social integration may differ across ethnic groups. The results of this study indicated that participants who were 'most socially connected' (measured using the SNI) were more likely to report recent use of colorectal cancer screening tests<sup>10</sup> (OR 3.2, 95% CI 1.7–6.2) and that this association was stronger among blacks (OR 3.8, 95% CI 1.3–10.7) than whites (OR 2.9, 95% CI 1.2–6.9; p value for the interaction –0.006).<sup>64</sup>

<sup>10</sup> Recent use was indicated by having at least one of: (i) FOBT within previous 12 months, (b) sigmoidoscopy within the past 5 years, colonoscopy within the past 10 years, or (iii) double contrast barium enema within the previous 5 years.

### Source of social support

- **Screening mammography**

Jepson *et al.* (2000) reviewed studies relating to the sources of social influence that might have affected women’s decisions to have a screening mammogram. They included health care professionals (2 studies), other household members (1 study), significant others (2 studies), family and friends (3 studies) and general social support (1 study). None of the studies found social support from any of these sources to be significantly associated with the uptake of mammograms. However, Jepson *et al.* (2000) reported that the studies involved primarily Caucasian populations and did not investigate women from ethnic minorities or low socioeconomic areas.<sup>6</sup>

Wu *et al.* (2005) reviewed the factors associated with breast screening practices among Chinese, Korean, Filipino, and Asian Indian American women and concluded that women whose friends and relatives favoured mammogram screening were more likely to be screened.<sup>70</sup>

Similarly in a study of the factors associated with the uptake of mammograms among Hispanic and non-Hispanic white women living in a rural area, Tejada *et al.* (2009) found that women who reported having a recent mammogram were more likely to mention female friends and daughters as people they trusted with their personal issues was positively associated with participation.<sup>69</sup>

- **Faecal occult blood testing**

The Jepson *et al.* (2000) review included 1 study that examined the impact of having two members of the same household taking part in the study. There was a significantly higher rate of FOBT uptake among study participants who lived with other participants.<sup>6</sup>

### Marital status

As shown in Table 28, Jepson *et al.* (2000) concluded that the majority of studies in their review did not find a significant relationship between marital status and the uptake of mammograms or Pap tests. The review also concluded that marital status was not found to be significantly associated with FOBT uptake, although the basis for this conclusion is not clear.<sup>6</sup>

**Table 28 Relationship between marital status and screening uptake: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	3/11 (27%)	2/5 studies (40%)	Not included
Authors’ conclusions	The majority of studies did not find a significant association between marital status and the uptake of mammograms	The majority of studies did not find a significant association between the uptake of Pap tests and marital status. However, there was some evidence to suggest that being single was associated with non-attendance	Marital status was not found to be significantly associated with the uptake of FOBT

Source: Jepson *et al.* (2000)<sup>6</sup>

- **Screening mammography**

In a review published in 2007 of the factors associated with the uptake of mammograms among Latin American women in the USA, Wells *et al.* found that marital status was not consistently related to the uptake of mammograms in multiple logistic regression analyses. Two studies reported a relationship between being widowed (adj OR 0.66) or unmarried (adj OR 0.74) and the lack of recent screening mammography. Four studies reported no association between marital status and uptake of screening mammography based on multiple logistic regression analysis.<sup>10</sup>

In the Australian context, the Blue Moon Research and Planning (2008) review included 4 studies that indicated lower uptake of mammograms among single, widowed, or divorced women than among women in long-term relationships.<sup>71</sup>

- **Faecal occult blood testing**

In their 1997 review, Vernon *et al.* reported that there were few studies of the associations between marital status and uptake of FOBT and that among those studies, results were inconsistent. Four studies reported that married persons were more likely to complete FOBT and 3 reported no relationship.<sup>2</sup>

## **Functional approach**

In the introduction to their study, Kinney *et al.* (2005) stated that most of the literature on the association between social networks and health has been concerned with structural analyses. However, researchers have hypothesised that it may be the type of support that influences health outcomes. Types of support have been classified as emotional (e.g. offering reassurance that one is loved and cared for), tangible (e.g. giving material or financial assistance), or informative (e.g. someone who has experienced something similar providing information).

Vernon *et al.* (1997) included 1 study that examined the relationship between 'social support' and the uptake of FOBT. That study did not find a statistically significant association between the two factors.<sup>2</sup> Similarly in their study, Kinney *et al.* (2005) found that neither emotional reassurance nor instrumental support was associated with colorectal cancer screening behaviour.<sup>64</sup>

## **Summary**

- **Fear/anxiety/worry**

The work of Consedine *et al.* (2004) has been instrumental in understanding about the impact of fear/anxiety/worry on cancer screening behaviour. The model indicates that: (i) an undifferentiated fear of cancer is associated with an increase in screening uptake; and (ii) fear of the screening process itself is associated with a decrease in screening. However, the relationship between fear of the outcome of the screening process is not definitive. Other research has indicated that, in the community, high levels of cancer worry are uncommon, and that higher levels of cancer worry do not reduce screening uptake.

- **Coping style**

There is little research on the impact of coping styles on screening uptake. The two styles that have been investigated appear to have different effects – denial leading to a

reduction in screening activity and repression leading to an increase in the uptake of mammograms.

- **Social networks**

There appears to be little evidence about the impact of different types of social support (emotional, tangible, and informative) on screening uptake. Therefore, it is not possible to draw any firm conclusions.

The structural aspects of social networks have been more thoroughly researched, but there is little firm evidence that social networks have an impact. There is some evidence that family and friends may have an influence on screening among ethnic groups. There is also some evidence to suggest that being single, widowed or divorced is associated with a decrease in the uptake of mammograms.

## 6 HEALTH AND LIFESTYLE

Three sets of factors have been considered under the heading of health and lifestyle. These are: (i) physical and mental health; (ii) tobacco smoking and alcohol consumption (drug use); and (iii) previous participation in health screening.

### 6.1 Physical/mental health

As shown in Table 29, the Jepson *et al.* (2000) review reported little evidence to support an association between health status and the uptake of screening mammography or Pap tests. However, there was some evidence to support the hypothesis of a positive association between the capacity to perform activities of daily living (ADL) and the uptake of FOBT.<sup>6</sup>

**Table 29 Association between perceived health status and the uptake of screening: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	Perceived health status: 1/4 (25%)	Chronic illness: 1/2 (50%)	Capable of performing ADL: 2/3 (67%)
Authors' conclusions	The majority of studies did not find an association between health status and the uptake of mammograms	The relationship between health status and the uptake of Pap tests is unclear	The majority of studies found that being able to perform ADL was associated with the uptake of FOBT. More able individuals were more likely to participate in screening

Source: Jepson *et al.* (2000)<sup>6</sup>

Notes:

FOBT: Faecal occult blood testing; ADL: Activities of daily living

- **Screening mammography**

In 2001 Sadler *et al.* wrote that women who are blind, deaf, have physical or mental disabilities and who are chronically ill may experience particular challenges in relation to receiving mammography services and that the 'literature is particularly silent on the issue of screening mammography among these vulnerable populations'.<sup>20</sup> This silence seems to have continued. Only the Schueler *et al.* (2008) review examined the relationship between physical health and uptake of screening mammography. As shown in Table 30, the only factor that was statistically significant was 'no personal history of benign breast disease', and this was associated with a decrease in the uptake of mammograms.<sup>26</sup>

**Table 30 Impact of breast disease on screening mammography uptake: Schueler *et al.* (2008) review**

	Number of studies	Adj OR	95% CI
Class 1 obesity <sup>(1)</sup>	4	0.96	0.89–1.94
Disability/impairment in ADL	6	0.84	0.66–1.07
Self-assessed poor health	15	0.95	0.78–1.15
No personal history of benign breast disease	13	0.51	0.42–0.62

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

(1) Class 1 obesity = body mass index of 30–34.9 kg/m<sup>2</sup>

Adj OR: Adjusted odds ratio; CI: Confidence interval; ADL: Activities of daily living

In relation to mental health:

- Consedine *et al.* (2004) reported that comparisons of screeners and non-screeners have suggested that trait anxiety<sup>11</sup> is significantly more pronounced among women who do not attend a screening in response to an invitation than among those who do. They also state that ‘other research’ has indicated no relationship between screening behaviour and trait anxiety. The two prospective studies in the review are equally conflicted. One suggested improved screening at intermediate levels of worry and the other suggested a negative relation between worry and mammography.<sup>1</sup>
- According to Magai *et al.* (2007), most studies of depression and screening mammography have failed to find an association. The single exception was based on a sample of 364 African-American women recruited from churches and low-income housing projects; but it is unclear whether this association will generalise across other groups.<sup>55</sup>
- **Pap tests**  
There were no data in the literature reviews relating to the association between health status and the uptake of cervical screening. In the grey literature Johnson *et al.* (2002) provided some evidence that women with intellectual disabilities are less likely to be screened than women without disabilities (Box 4).<sup>72</sup>

<sup>11</sup> Trait anxiety is defined as a person's predisposition to experience anxiety in a stressful situation and tends to be stable over time.<sup>62, 63</sup>

#### Box 4 Impact of intellectual disabilities on the uptake of Pap tests

Research with women with intellectual disabilities in the UK and Australia has revealed that they are less likely than women without disabilities to have regular cervical screening. For example Stein and Allen (1999) audited cervical screening for women with an intellectual disability in one English health district. Out of 389 women with an intellectual disability identified ... as eligible for cervical screening, only 13% had a record or a smear test in the previous five years<sup>73</sup> ... Similar research by Mencap<sup>(1)</sup> revealed that only 8% of women with intellectual disabilities underwent cervical screening compared with 85% of women who did not have disabilities.<sup>74</sup> A state-wide database is currently being developed by the Centre for Development Disabilities Health in Melbourne (2002 Sutherland, unpublished data). The preliminary database involved 243 women ... results ... indicated that 10% of women with an intellectual disability were involved in cervical screening during the previous 12 month period ... Only 8% of the youngest age group (18-35 years) had participated in cervical screening. 14% of women aged 36-50 and 13% of women aged over 50 years indicated that they had participated. Sutherland (2002) commented that the older subset of women was much smaller and therefore results should be viewed with caution.<sup>75</sup>

Source: Johnson *et al.* (2002)<sup>72</sup>

Notes:

(1) Mencap is a UK-based organization which is committed to 'valuing and supporting people with a learning disability and their families and carers' (<http://www.mencap.org.uk/landing.asp?id=6>)

- **Faecal occult blood testing**

As shown in Table 31, Petersen (2002) found that more anxious persons, those with no concurrent or past illness and those with no prior tumour diagnosis were less likely to adhere with colorectal cancer screening guidelines.<sup>5</sup>

**Table 31 Health factors associated with lower uptake of colorectal cancer screening tests: Petersen (2002) review**

Health factor	Lower adherence generally seen with
Anxiety	More anxious persons
Illness	No concurrent or past illness
Tumour	No prior tumour diagnosis

Source: Petersen (2002)<sup>5</sup>

In a review of the factors associated with colorectal cancer screening among people aged 65 years of age and older published in 2010, Guessous *et al.* reported that only 3 of 13 studies (23%) reported the presence of chronic/co-morbid conditions as a significant barrier to screening uptake. Seven of the 13 studies (54%) reported this factor as a significant facilitator of uptake.<sup>3</sup>

The Australian monitoring data for the NBCSP shows that males and females with severe or profound activity limitation were more likely to return FOBT kits than those who did not have a limitation (Table 32).<sup>12</sup>

**Table 32 Australian National Bowel Cancer Screening Program (NBCSP): crude participation rate by disability status (2008)**

	Severe or profound activity limitation			
	Yes		No	
	Rate	95% CI	Rate	95% CI
Females	48.0	47.2-48.9	37.2	37.0-37.4
Males	38.4	37.6-39.2	30.9	30.7-31.0
Total	43.0	42.4-43.6	34.0	33.9-34.1

Source: Australian Institute of Health and Welfare and Australian Government Department of Health and Ageing (2009)<sup>12</sup>

Notes:

CI: Confidence interval

### 6.1 Drug use: alcohol and tobacco consumption

The data about these lifestyle factors related to the uptake of mammograms. None of the reviews for Pap tests or colorectal cancer screening examined these factors.

- **Smoking**

The Jepson *et al.* (2000) review included 3 studies that investigated whether smoking was predictive of screening uptake. Only 1 study (33%) found a significant effect: women who currently smoked were less likely to adhere to screening than those who did not.<sup>6</sup> Wells *et al.* (2007) reported that among Latin American women in the USA, not being a current smoker reduced the likelihood of participating in screening mammography (Adj OR 0.71).<sup>10</sup> The 2008 review by Schueler *et al.* found that women who smoke cigarettes consistently demonstrated lower rates of mammography use (Adj OR 0.69, 95% CI 0.60–0.80).<sup>26</sup>

- **Alcohol consumption**

The Jepson *et al.* review (2000) included 2 studies that examined the relationship between alcohol consumption and the uptake of mammograms. Only 1 study found this factor to be statistically significant: within an inner city population of women in the UK, women who consumed alcohol at least once a month were more likely to obtain a mammogram than those who did not.<sup>6</sup> Schueler *et al.* (2008) concluded that drinking alcohol in any amount showed ‘consistent, modest effects’ on the uptake of mammograms (Adj OR 1.30, 95% CI 1.09–1.54).<sup>26</sup>

### 6.3 Previous participation in screening

As shown in Table 33, the Jepson *et al.* (2000) review indicated that the majority of studies indicated previous participation in screening was associated in an increase in uptake of mammograms and FOBT but not Pap tests.<sup>6</sup>

**Table 33 Association between previous screening behaviour and the uptake of screening: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	Previous mammograms: 13/20 (65%)	Previous Pap tests: 1/4 (25%)	Previous CRC screening: 4/5 (80%)
Authors' conclusions	The majority of studies found that women who had previously attended for screening (compared with those who had not) were significantly more likely to attend for further mammograms	The majority of studies found no significant association between the uptake of Pap tests and previous screening history	Participation in previous colorectal screening was found to be significantly associated with the uptake of FOBT

Source: Jepson *et al.* (2000)<sup>6</sup>

Notes:

FOBT: Faecal occult blood testing; CRC: Colorectal cancer

- **Screening mammography**

A review published by Bankhead *et al.* (2003) included 22 papers comparing breast screening behaviours in women who had or had not had a mammogram previously:

- 50% (11 studies) showed a positive relationship indicating that women who undergo screening mammography are significantly more likely to be screened in the future than women who have not been screened
- 27% (6 studies) showed no differences in screening mammography uptake between previous attenders and non-attenders
- 23% (5 studies) showed an association between lower rates of attendance and having had a mammogram previously.<sup>76</sup>

In the 2000 review by Jepson *et al.*, 5 studies examined whether previous screening behaviour (including attendance for Pap tests, clinical breast examinations and dental checks) was a significant factor in determining mammogram uptake. The authors concluded it was not clear whether attendance for other screening tests was associated with the uptake of mammograms.<sup>6</sup>

The Bankhead *et al.* review (2003) contained 26 studies investigating the effect of cervical screening on subsequent breast screening practices. Nineteen studies (73%) reported a positive association and 7 (27%) reported no association. Eight studies in the Bankhead *et al.* (2003) review examined the effect of the recency of the Pap test on screening mammography behaviour and all indicated that women with more recent Pap tests were more likely to attend for breast screening.<sup>76</sup>

In the Wells *et al.* review published in 2007, 2 studies examined the relationship between other health behaviours and uptake of screening mammography. The reported ORs

showed a significant association between screening mammography and having received a Pap test within the past 3 years (Adj OR 2.65).<sup>10</sup>

- **Pap tests**

Three studies in the Bankhead *et al.* (2003) review examined the association between attendance at previous screening and follow-up screening. Two found no association with prior use of breast or cervical screening.<sup>76</sup>

Twelve studies investigated the effects of breast screening on cervical screening. Ten of the papers (83%) showed a significant positive association between the two screening behaviours: women who had participated in breast screening were more likely also to attend for cervical screening. The remaining 2 studies (17%) showed no association.<sup>76</sup>

- **Faecal occult blood testing**

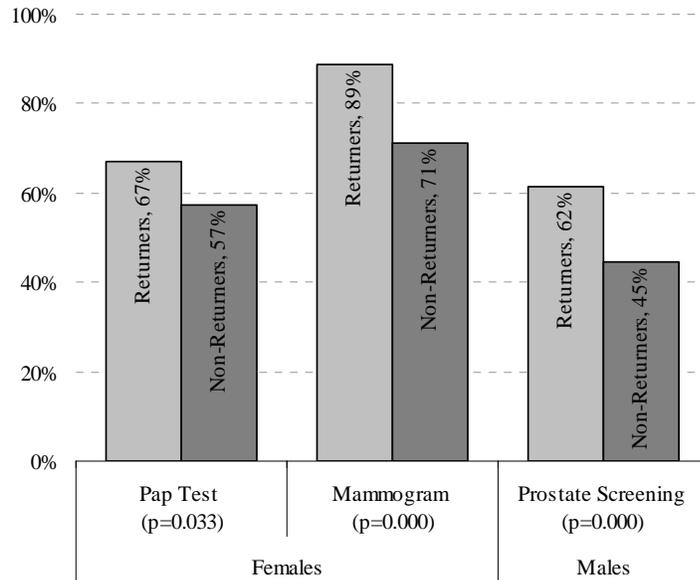
In 1997, Vernon *et al.* concluded that health motivation or a preventive health orientation (e.g. engaging in other health-promoting behaviours, such as regular medical or dental check-ups) showed the 'most consistent positive association with FOBT completion'. The authors found that this factor differentiated persistent compliers (persons who reported completing five consecutive FOBTs) from persistent refusers (persons who refused three consecutive FOBTs). Seven of 9 studies (78%) showed a positive association between health motivation/prevention orientation and FOBT uptake, while 2 studies (22%) showed no association.<sup>2</sup>

The review by Vernon *et al.* (1997) reported high rates of adherence (56% – 93%) when repeat screening was offered to those groups that had participated previously. The authors cited findings that low uptake rates (6%) characterised initial refusers who were subsequently reoffered FOBT screening.<sup>2</sup>

Petersen (2002) concluded that less participation in other screening behaviours (e.g. mammography) was associated with lower adherence to colorectal cancer screening.<sup>5</sup> The 2010 review by Guessous *et al.* did not examine this factor.<sup>3</sup>

There is some evidence in the Australian context that previous participation in other cancer screening activities is associated with an increase in the uptake of FOBT. Women who indicated that they had a Pap test or a mammogram in the past 2 years and men who had participated in prostate cancer screening were more likely to return their FOBT kits than those who had not participated (Figure 7). However, these associations are based on univariate analyses and there is no way of determining if the associations would be statistically significant in a multivariate analysis which controlled for other factors associated with the uptake of screening.

**Figure 7 Association between previous cancer screening activities and the uptake of faecal occult blood testing**



Source: Department of Health and Ageing (2004)<sup>77</sup>

Notes:

Calculation of the Pap test p value excludes respondents who indicated that they did not need to have a Pap test in the past 2 years, and therefore differs from the p value shown in the report

## Summary

- **Physical/mental health**

The assumption that people living with physical and mental health problems or disabilities would be less likely to participate in screening has face validity (i.e. seems reasonable). However, the evidence to support this assumption is not strong. In part, this appears to be due to: (i) the fact that the issue that has received very little attention in the literature; and (ii) the broad range of physical and mental health problems included under the umbrella of 'physical and mental health'. The most compelling (but not strong) evidence in the literature concerns the uptake of FOBT. For this test, increased uptake appears to be associated with: (i) the ability to perform ADL; and (ii) having a chronic/co-morbid condition. However monitoring data for the uptake of FOBT in the Australian NBCSP indicates the reverse; people with severe limitations are more likely to participate than those who do not.

- **Drug and alcohol use**

A small amount of evidence was identified relating to the association between smoking and alcohol consumption on the uptake of screening mammography, but no evidence was found in relation to Pap tests and FOBT. The evidence in relation to smoking is conflicted. However, the most recent meta-analysis indicated lower rates of uptake among women

who smoke cigarettes. The evidence in relation to alcohol consumption has consistently shown that alcohol consumption is associated with an increase in mammogram uptake.

- **Previous participation in screening**

The screening behaviours considered in this section related to: (i) previous dissimilar screening (e.g. the association between participation in prostate cancer screening on participation in FOBT, or of participation in screening mammography on having a Pap test and vice versa); and (ii) repeat screening (e.g. the impact of having a mammogram on future uptake). On balance, the evidence appears to indicate that people who participate in screening mammography, Pap test and FOBT screening are more likely to participate in repeat screenings than those who have not participated or refused to participate in earlier rounds. There is also evidence to support the proposition that participation in other types of screening is associated with the increase in the uptake of mammograms, Pap tests and FOBT.

## 7 CULTURAL FACTORS

Many of the reports and reviews included in this literature review point to the importance of considering cultural factors in relation to cancer screening.<sup>21, 31</sup> However, it is also clear that many of the factors that inhibit cancer screening among Indigenous and ethnic groups are also relevant to Caucasian groups. For example, in a review of the factors associated with cancer screening among Hispanic women in the USA published in 2002, the authors pointed out that that low socioeconomic status, poverty, low levels of education, lack of knowledge, cost of screening as well as acculturation have been established as reasons for low screening rates among this group of women.<sup>53</sup> Similarly, Condron and Fernbach (2002) undertook an evaluation of the 2001 PapScreen Victoria multicultural media campaign targeting Arabic-, Mandarin-, Polish-, Russian- and Serbian-speaking groups. They concluded that some factors that act as barriers for women from these ethnic groups to having a Pap test were also relevant for English-speaking women.<sup>78</sup>

The factors included in this section of the review are those that appear to have been most consistently associated with cancer screening among ethnic and Indigenous groups, namely: acculturation, fatalism, modesty/embarrassment/shame, medical mistrust, collectivism/communalism, and spirituality/religiosity.

In reading this section it is also important to bear in mind that there is diversity within and between Indigenous and ethnic groups.<sup>79</sup> As Newman *et al.* (2008) point out:

‘An understanding of the diversity of conceptions and beliefs about health and illness that may be held by Aboriginal people is essential for developing more effective cancer prevention ... While some issues may be broadly relevant to others of the many ethnic and cultural groups that make up the Australian population, many issues will be differently experienced or expressed by Aboriginal people.’<sup>31</sup>

### 7.1 Acculturation

Acculturation is the process by which individuals whose primary learning has been in one culture, adopt attitudes, values and behaviours from another culture.<sup>80</sup> Acculturation is often assessed by taking into account the length of residency in the host country or proficiency in the host language.<sup>24</sup> As shown in Table 34, those not born in the USA are less likely to participate in cancer screening and those who have been in the USA for less than ten years have the lowest participation rates.<sup>8</sup>

**Table 34 Cancer screening rates by immigration status: USA (2005)**

	Mammogram past 2 years	Pap test past 3 years	FOBT within past year
Immigration			
Born in USA	67.2%	81.4%	12.5%
In USA ≥ 10 years	63.3%	73.0%	9.1%
In USA < 10 years	50.0%	66.8%	2.6%

Source: Cokkinides *et al.* (2007)<sup>8</sup>

Notes:

FOBT: Faecal occult blood testing

- **Screening mammography**

Two studies included in the Tejada *et al.* (2009) citation indicate that, among Hispanic women in the USA, acculturation is negatively associated with the uptake of mammograms (2 studies: published 1999 and 2005). However, other studies described in the same citation show that the effect attenuates after adjusting for socioeconomic factors (2 studies: published in 1987 and 2005).

In a review of the literature about breast screening among Chinese, Korean, Filipino, and Asian-Indian American women published in 2005, Wu *et al.* reported that:

- 40% of studies (4 of 10) showed that, among Chinese women, the inability to speak English was a significant barrier; women who spoke English fluently were about four times more likely to have had a mammogram than those with poor English fluency
- 33% of studies (1 of 3) showed that Korean American women who had resided longer in the United States were more likely to be screened
- Filipino women who had spent more time in the United States were more likely to be adherent to breast screening procedures.<sup>70</sup>

In a review of the literature relating to Latin American women in the USA, Wells *et al.* (2007) concluded that the relationship between immigration status and adherence to screening mammography is 'unclear and appears to be associated with the population sampled'. The review included five studies that evaluated the relationship between acculturation and screening status:

- 1 study found that, among immigrant women, naturalised citizens were more likely to be screened than non-citizens (adjusted OR 1.57)
- 1 study found that foreign-born Hispanic women were more likely to participate in screening mammography than non-Hispanic white women (adjusted OR 2.15)
- 1 study found that Hispanic women born in the USA were as likely to participate in screening mammography as non-Hispanic white women
- 2 studies that reported ORs did not find an association between foreign birth and screening mammography.

Schueler *et al.* (2008) found that 'poor English language skills' and 'foreign birth' showed only modest clinical relevance in the multivariate model and the results were not

statistically significant. However, being a recent immigrant did appear to have an important negative impact on the uptake of mammograms (Table 35).<sup>26</sup>

**Table 35 Impact of acculturation on the mammogram uptake: Schueler *et al.* (2008) review**

	Number of studies	Adj OR	95% CI
Recent immigrant	6	0.54	0.37–0.79
Poor English	7	0.77	0.58–1.02
Foreign born	7	0.84	0.64–1.12

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

Adj OR: Adjusted odds ratio; CI: Confidence interval

- **Pap tests**

Austin *et al.* (2002) found that in Canada and the United States: (i) the ability to speak English correlated positively with adherence to cancer screening guidelines, especially among older Hispanics; and (ii) women speaking only, or mostly, Spanish were consistently less likely to be screened for cervical cancer.<sup>53</sup>

In a single study of the factors associated with Pap testing, Ackerson *et al.* (2007) found that the inability to speak English, living in the USA for less than 5 years, preferring to speak only Spanish and filling out the questionnaire in their native language were associated with lack of cervical cancer screening in the Hispanic population.<sup>27</sup>

- **Faecal occult blood testing**

There was no information in the reviews on the impact of acculturation (however measured) on the uptake of colorectal cancer screening.

## 7.2 Fatalism

The literature includes two definitions of fatalism. The first is the belief that events (such as those related to health) are beyond the control of the individual; they depend on fate or luck.<sup>29, 81</sup> The second, which is quite common in cancer research, defines cancer fatalism as the belief that death is inevitable when cancer is present.<sup>21, 29</sup>

According to the National Bowel Cancer Screening Pilot Program’s Multicultural Working Group (2004), exploration of these concepts has ‘moved beyond anecdotal evidence that fatalism influences screening behaviour to establishing it as an independent predictor of participation in breast, cervical, colorectal and skin cancer screening’. This report indicated that fatalism is a ‘strong theme’ of Australian qualitative cancer research among ethnic communities. In the three research studies documented in the report, a common attitude among participants was the hope that cancer was not one’s personal destiny.<sup>21</sup> The report for the Department of Health and Ageing prepared by Blue Moon Research and Planning (2008) as part of the evaluation of the BreastScreen Australia program indicated that fatalism inhibited screening among Greek participants in the qualitative research but fatalism may not be a factor among other participating ethnic groups (e.g. Chinese).<sup>71</sup>

Among the literature reviews used as the basis for preparing this review, very little quantitative empirical research was presented that examined the relationship between fatalism and screening behaviour.

- **Screening mammography**

The Powe *et al.* (2003) review included 4 articles focused on breast cancer screening. Only 1 of the studies reported that women with more fatalistic beliefs were less likely to engage in screening. However, it was not clear whether this was based on screening intentions or actual participation in screening.<sup>82</sup> The Schueler *et al.* (2008) review included 14 studies containing a univariate analysis of fatalism and uptake of mammograms and 7 studies containing a multivariate analysis. Higher fatalism scores decreased the uptake of screening: univariate OR 0.74, multivariate OR 0.61 (95% CI 0.40–0.92)<sup>26</sup>

- **Pap tests**

The Powe *et al.* (2003) review included only 1 article focused on cervical cancer screening. However, the authors report that the article had methodological problems in relation to the determination of a fatalism score and that there did not appear to have been any attempt to look at the relationship between fatalism and the uptake of cervical cancer screening.<sup>82</sup>

- **Faecal occult blood testing**

In the Petersen (2002) review, the tendency to be more fatalistic and the attitude that one is not in control of one's health were reported to be associated with lower adherence to colorectal cancer screening.<sup>5</sup> The Powe *et al.* (2003) review included 3 studies that investigated the relationship between fatalism and colorectal cancer screening. However, only 1 study examined the relationship between fatalism and uptake of FOBT among African-American and Caucasian participants. The results indicated that African-American women had significantly higher levels of cancer fatalism than other participants, and cancer fatalism was 'the only statistically significant predictor of FOBT in the study'.<sup>82</sup>

### 7.3 Modesty/embarrassment/shame

According to Austin *et al.* (2002), culturally based embarrassment and similar emotions are a major barrier to breast and cervical cancer screening among Hispanic women in the USA. In one study, embarrassment was found to be a stronger predictor of screening than perceived susceptibility and perceived benefits of early detection. The authors' hypothesised that embarrassment about discussion of private body parts and embarrassment about exposing private body parts during a physical examination may pose a barrier for some Hispanics, especially if examined by a male physician.<sup>53</sup>

The review by Magai *et al.* (2007) contained 1 study that looked at the relationship between embarrassment and breast cancer screening among women from six ethnic groups. It found that greater embarrassment predicted poorer screening when other variables were controlled (i.e. age, socioeconomic status, physician recommendation, anxiety and emotion regulation style): women with high embarrassment scores were 29% less likely to screen.<sup>55</sup>

The 2008 review by Schueler *et al.* contained 4 univariate and 3 multivariate studies that examined the relationship between modesty/embarrassment and uptake of mammograms.

Modesty/embarrassment was associated with a decrease in screening rates (univariate OR 0.54; multivariate OR 0.55; 95% CI 0.39–0.76). However, there is no way of telling from the review whether or not the studies related specifically to ethnic groups. If they do not then this is a factor that is generalisable across groups.<sup>26</sup>

In the Australian context, there is some evidence from a qualitative study undertaken as part of the evaluation of the BreastScreen Australia program that ‘embarrassment may be a more difficult barrier to overcome in relation to screening mammography for some women from non-English speaking backgrounds’.<sup>71</sup> The report stated that:

‘Iraqi and Lebanese women associated mammograms with discomfort, humiliation and invasive handling of their breasts. This was most acute for one Lebanese participant, who felt that mammograms were against her Muslim religion as they required a woman to reveal her breasts to a stranger.’<sup>71</sup>

However, the report did also note that this was not an issue raised by all Muslim women.<sup>71</sup>

Shahid *et al.* (2009) noted that within Indigenous communities, there are beliefs that cancer is related to feelings of shame. No studies were cited examining the relationship between shame (either because cancer is considered a ‘white man’s disease’ or because cancer is seen as a ‘curse’ for wrongdoing) and screening uptake. However, it can be hypothesised that such shame may deter Indigenous people from accessing screening.<sup>79</sup>

## 7.4 Medical mistrust

According to Deshpande *et al.* (2009), trust in the medical profession involves the belief that individuals and institutions will act appropriately and will perform competently, responsibly, and in a manner consistent with patients’ interests.<sup>29</sup> According to Wolff *et al.* (2003), there is considerable evidence that many African-Americans believe this standard is not met regarding their care.<sup>30</sup> This mistrust has been linked to a variety of health-related decisions, behaviours, and interactions, and has been associated with negative attitudes about cancer screening and decreased use of mammography.<sup>29</sup>

This issue is also relevant to the Australian health care system. The Federation of Ethnic Communities’ Councils of Australia cite lack of trust as a major issue that may make people from ethnic communities reticent to access services, including health services. One of the antecedents for this could be experiences in a person’s country of origin and this may be a particularly important consideration when trying to engage with humanitarian entrants into Australia.<sup>3712</sup>

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<sup>12</sup> It should be noted, however, that medical mistrust is not confined to members of ethnic and Indigenous groups. Blue Moon Research and Planning (2008) classified women who never screened and who had active reasons for not participating as women who ‘tended to be from higher socioeconomic backgrounds and/or were relatively highly educated... They were most likely to be Anglo-Australians, although the literature review showed some Chinese women had similar views’. These women were ‘often sceptical about information provided by health professionals, BreastScreen Australia and the Department of Health and Ageing’.<sup>71</sup>

## 7.5 Collectivism/communalism

Collectivism is the tendency to subordinate personal goals to those of the group. In this strategy, the basic unit of society is the family, community, or tribe rather than the individual. Collectivism is expressed in values of group survival and security, concern and responsibility for others, and respect for traditions and elders. According to Deshpande *et al.* (2009), studies suggest African Americans are more likely than European-Americans to hold collectivist beliefs.<sup>29</sup>

This issue is also relevant to Indigenous communities in Australia and elsewhere.<sup>31,79</sup> Newman *et al.* (2008) pointed out that 'it is widely acknowledge that an Aboriginal conception of health encompasses the physical, social, emotional, cultural and spiritual wellbeing of not only the individual but of the community and the environment as a whole'. Such beliefs 'emphasise the capacity of Aboriginal people to perform social and domestic roles as criteria for wellness' and suggest that health-related treatments that interrupt the individual's capacity to engage in normal social activities would be viewed as 'unhealthy'.<sup>31</sup> Although this review focuses on the factors associated with cancer screening, it can be argued that, Aboriginal people may be reluctant to undergo screening for the same reasons that they are reluctant to take up cancer treatment: because of the disruption it would cause to performing daily activities and fulfilling family roles.

Deshpande *et al.* (2009) stated that no studies have clearly linked collectivist beliefs and ethnic identity to health behaviours.<sup>29</sup> Shahid *et al.* (2009) pointed out that further community-based research is needed to understand Indigenous perspectives and needs, and the way that these affect care-seeking behaviour. They also pointed out that there has been no exploration of the differences, if any, between urban, rural and remote populations.<sup>79</sup> Finally, Newman *et al.* (2008) pointed out that that they could find no research focusing on the experiences of Aboriginal men in relation to cancer.<sup>31</sup>

## 7.6 Spirituality/religiosity

In 2009, Deshpande *et al.* defined spirituality as the 'internal manifestation of belief in a higher power and the genuine, consistent commitment to its attendant values'. They pointed out that it contains, but is not limited to, adherence to doctrines, beliefs, and the ritual practices of religious institutions or a person's level of religious organisation involvement. Religiosity has been shown to be particularly high among older African-American women.<sup>29</sup> According to Lende *et al.* (2009), religiosity has been shown to have an impact on breast cancer screening among African-American women.<sup>83</sup> However, Deshpande *et al.* (2009) point out that in some studies, religiosity has been negatively associated with health-promoting behaviour, while others have found spirituality to be positively associated with health behaviours.<sup>29</sup>

## Summary

This section has focused on factors that have most often been associated with Indigenous and ethnic groups in relation to screening activity. Interpretation of the results should take account of the fact that: (i) ethnic and Indigenous groups are heterogeneous; and (ii) some of the factors examined in this section may also apply to non-ethnic and non-Indigenous groups.

- **Acculturation**

This factor has generally been operationalised as ‘length of residence in the host country’ and/or ‘ability to speak English’. No evidence was found in relation to the impact of acculturation (however defined) on the uptake of FOBT. Evidence for a relationship between acculturation and uptake of screening mammography was mixed, with the clearest evidence suggesting lower uptake among those who have most recently arrived in the host country. There is less evidence of a relationship between acculturation and uptake of Pap tests, but what evidence there was appears to point to lower uptake among those with lower English language skills and among the most recent immigrants.
- **Fatalism**

Fatalism has been defined as the belief that either there are events that are beyond the control of the individual and/or the that death is inevitable when cancer is detected. Little quantitative research was found relating to the relationship between fatalism and screening uptake. What evidence there was indicated that higher levels of fatalism (however, defined) were associated with decreases in the uptake of mammograms and FOBT. There was no evidence in relation to the association between fatalism and uptake of Pap tests.
- **Modesty/embarrassment/shame**

On balance, the evidence indicated that modesty, embarrassment and shame inhibit breast and cervical cancer screening among ethnic and Indigenous groups.
- **Medical mistrust; collectivism/communalism; spirituality/religiosity**

Whilst there is research which suggests that these factors have an impact on screening uptake, only a small amount of literature exists that specifically examines the relationships. One review concluded that medical mistrust had a negative impact on the uptake of screening mammography but there was insufficient evidence to draw any conclusions about collectivism/communalism. The evidence for spirituality/religiosity was inconclusive. There was no evidence in relation to the relationship of these factors with uptake of Pap tests and FOBT.

## 8 HEALTH SYSTEM FACTORS

According to Hausmann-Muela *et al.* (2003), it has become popular among researchers to use four categories to group key health system factors that affect health-seeking behaviour.<sup>84</sup> In this review, these four categories have been used to structure the evidence in relation to health system factors that may impact on the uptake of screening mammography, Pap tests and FOBT.

1. **Availability:** refers to the geographic distribution of health services and facilities. Having a 'usual source of care' and 'utilisation of health care services' have been included as factors relevant to this category.
2. **Accessibility:** refers to how easy or difficult it is to use the services that are available and includes such things as transport, roads and opening hours. Accessibility can be understood in terms of convenience for potential users. Included in the discussion for this category is 'provider recommendation' of a screening test.
3. **Affordability:** refers to the costs incurred by individuals, households or families in using services. Health insurance reduces out-of-pocket costs where screening services are not provided free of charge and has been included in this category.
4. **Acceptability:** refers to the cultural and social distance between services and users. The focus is mainly on the characteristics of the health providers, excessive bureaucracy, and cultural safety.

Each of these categories is discussed independently, although they are interrelated. As Wolff *et al.* (2003) state:

'Many medically underserved African-Americans lack a primary care physician and access the health care system only in an urgent or emergent care situation ... Primary care clinics and doctors may not be conveniently available in the geographic areas where these underserved population live, tend to be overburdened, and may not schedule evening and weekend hours. The underserved may also have to travel to different facilities to obtain screening tests and endure long waiting times. The cost and inconvenience of public transportation may also deter regular visits to a doctor.'<sup>30</sup>

### 8.1 Availability

In their 2008 review, Schueler *et al.* found a negative relationship between rurality and uptake of screening mammography (Adj OR 0.75, 95% CI 0.63–0.90).<sup>26</sup> However, in the 2010 review by Guessous *et al.*, only 30% of studies (3 of 10) found that rural residence was a significant barrier to the uptake of colorectal cancer screening.<sup>3</sup>

There is ample evidence in the monitoring data of geographic differences in screening rates in countries that do have population based screening programs (eg Australia and the UK) and those that do not (eg USA) (Table 36, Table 37, Table 43). In Australia, the patterns within the geographic variations differ across tests and in Victoria at least, there is evidence of marked changes in geographic participation rates over time (Table 39)

**Table 36 Geographic variations in screening rates in Australia**

	Major cities	Inner regional	Outer regional	Remote	Very remote
Mammograms					
ASR 2005-2006	54.6%	61.1%	62.2%	60.1%	49.5%
95% CI	54.5-54.7 (a)	60.9-61.3 (b)	61.9-62.5 (c)	59.2-61.0 (b)	48.3-50.8 (d)
Pap tests					
ASR 2006-2007	62.5%	61.2%	58.9%	53.6%	54.0%
95% CI	62.4-62.5 (a)	61.0-61.3 (b)	58.7-59.1 (c)	53.1-54.1 (d)	53.3-54.7 (d)
FOBT					
Crude Rate 2008	35.2%	40.1%	39.1%	34.6%	25.0%
95% CI	35.1-35.4 (a)	39.9-40.4 (b)	38.8-39.5 (c)	33.7-35.4 (a)	23.9-26.1 (e)

Sources: Mammograms: Australian Institute of Health and Welfare (2009)<sup>85</sup>; Pap tests: Australian Institute of Health and Welfare (2009)<sup>9</sup>; FOBT: Australian Institute of Health and Welfare and Australian Government Department of Health and Ageing (2009)<sup>12</sup>

Notes:

Geographic classification based on the Australian Bureau of Statistics (ABS) Australian Standard Geographic Classification (ASGC)

ASR: Age standardized rate

CI: Confidence interval

FOBT: Faecal occult blood test

(a), (b), (c), (d), (e) denote overlapping confidence intervals within each screening test.

**Table 37 Geographic variation in screening rates in the USA**

Test	Age range (years)	Uptake	
		Average	Range
Mammogram	40–64	59.7%	45.7% Utah – 71.0% Rhode island
Pap test	18–64	85.6%	74.4% Utah – 91.9% Maine
FOBT	50–64	13.4%	5.1% Utah – 19.6% District of Columbia

Source: Cokkinides *et al.* (2007)<sup>8</sup>

Notes:

FOBT: Faecal occult blood testing

**Table 38 Five-year screening rates for NHS Breast Screening Programme: uptake of invitations to screen for women aged 50–70 years in selected geographic areas**

Strategic Health Authority	2003–04		2007–08	
	Rate	Rank	Rank	Rate
East Midlands	80.2%	1	1	78.6%
South West	77.7%	4	4	75.6%
North West	74.5%	9	9	72.3%
London	62.5%	10	10	60.6%
Difference: Rank 1 – Rank 10	17.7%			18.0%

Source: Downloaded from the NHS website on 24 November 2009 from:

<http://www.ic.nhs.uk/webfiles/publications/breastscreening0708/2007-08%20Breast%20Screening%20>

**Table 39 Geographic variation in BreastScreen Victoria 2-year participation rates (50–69 age standardised rates)**

	Major cities	Inner regional	Outer regional	Remote
2004–2005	58.0%	56.2%	59.9%	72.5%
2005–2006	56.9%	56.5%	60.9%	49.7%

Source: Productivity Commission Excel spreadsheet downloaded 15<sup>th</sup> October 2009, available at

[http://www.pc.gov.au/data/assets/excel\\_doc/0004/85414/53-chapter12-attachment-only.xls](http://www.pc.gov.au/data/assets/excel_doc/0004/85414/53-chapter12-attachment-only.xls) Table 12A.12

Notes:

Residents of Victorian postcodes allocated to the Albury/Wodonga catchment (NSW jurisdiction) are included in Victoria's population estimate, accounting for the slight decrease in participation rates compared to those published by BreastScreen Victoria.

The reasons for these geographic variations have not been clearly articulated. Akers *et al.* (2007) noted that, in terms of health system infrastructure, the availability of hospitals, primary care, sub-specialty providers and quality laboratory services is relatively limited in rural areas of the USA and this is likely to impact negatively on women's ability to obtain cervical cancer screening services.<sup>24</sup> Whilst this argument has face validity, the authors did not present any evidence to support their hypothesis.

The following analysis in relation to the uptake of screening mammography, Pap tests and FOBT concentrates on the impact of having, or not having, a regular source of care and, where data are available, the utilisation of a doctor's services.

- **Screening mammography**

Jepson *et al.* (2000) reviewed five studies of the association between the number of previous visits to a health care provider on uptake of screening mammography. The authors concluded that the majority of studies did not find a significant association between uptake and the number of visits women make to their health care provider.<sup>6</sup>

In a review of the uptake of screening mammography by Latin American women in the USA, Wells *et al.* (2007) found that:

- having a usual source of health care was strongly associated with the uptake of mammograms (adjusted ORs ranged from 1.24 to 3.4); 1 study investigated different types of usual care providers (primary care physicians, other physicians, other facilities and non-physician providers) and found that all were positively associated with screening uptake
- recently receiving health care from a doctor was associated with higher adjusted OR of receiving a screening mammogram (adjusted OR 1.15–1.47); 2 studies evaluated the type of recent visit and found that:
  - outpatient, office or primary care visits were associated with a higher odds of receiving screening mammography
  - visits to the emergency room were associated with lower or the same odds as not being seen in the emergency room
  - being hospitalised was associated with lower odds of receiving screening mammography.<sup>10</sup>

As shown in Table 40, Schueler *et al.* (2008) found that (i) not visiting a doctor within the past year, and (ii) not having a primary care doctor or usual source of care were associated with a reduction in the uptake of mammograms.<sup>26</sup>

**Table 40 Relationship between availability and the uptake of mammograms: Schueler *et al.* (2008) review**

	Number of studies	Adj OR	95% CI
No physician visit within year	17	0.34	0.25-0.47
No primary care physician/usual source of care	33	0.41	0.32-0.53

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

Adj OR: adjusted odds ratio; CI: Confidence interval

- **Pap tests**

Condron and Fernbach (2001) undertook an evaluation of the PapScreen Victoria Neighbourhood Grants Program to examine which steps in the process of getting a Pap test were most difficult for women. As shown in Table 41, compared to well-screened women, other women were more likely to find choosing a health care practitioner more difficult. However other steps such as making an appointment and turning up for it were not more difficult for the non well-screened women.<sup>86</sup>

**Table 41 Comparison of difficulty in the steps necessary to obtain a Pap test with well-screened women**

Decision point	Compared to well-screened women	
	OR	95% CI
Statistically significant difference		
Deciding to have a Pap test	0.24	0.11–0.53
Choosing a practitioner	0.29	0.13–0.61
No statistically significant difference		
Making an appointment	0.73	0.34–1.59
Turning up to the appointment	0.42	0.16–1.11

Source: Condron and Fernbach (2001)<sup>86</sup>

Notes:

OR: Odds ratio; CI: Confidence interval

Ackerson *et al.* (2007) found that lack of an established usual source of health care influenced Pap testing in 3 of 7 studies (43%). For example, women without a usual source of health care were not aware of the available services within their community to obtain low-cost Pap smears and were less likely to obtain regular cervical cancer screening. However, one study found that having a usual source of health care did not influence whether African-American women obtained Pap tests.<sup>27</sup>

- **Faecal occult blood testing**

The Jepson *et al.* (2000) review included one study that looked at the association between uptake of FOBT and having a regular source of care for older black Americans. In this study, having a regular source of care was found not to be a significant factor in the uptake of FOBT.<sup>6</sup>

In 2002, Petersen concluded that not having a doctor was associated with lower adherence to colorectal cancer screening in the USA.<sup>5</sup> The review by Guessous *et al.* (2010) reported that among people aged 65 years of age and older:

- 77% of studies (17 of 22) found that having a usual source of care/personal physician significantly improved the uptake of colorectal cancer screening
- 94% of studies (17 of 18) found that routine preventive care/primary care/doctor visits in the recent past significantly improved the uptake of colorectal cancer screening.<sup>3</sup>

## 8.2 Accessibility

- **Screening mammography**

In the Jepson *et al.* (2000) review, 50% of studies (2 of 4) found a positive association between uptake of mammograms and the recommendation of health care providers. The authors concluded that it was not clear whether recommendations from health care providers were associated significantly with uptake of screening mammography.

According to Austin *et al.* (2002), recommendation by a doctor is one of the most important cues to cancer screening and is more important than the availability of services. However, this review only included studies undertaken in the USA and, as the authors point out, the majority of women in the USA who have mammograms are referred by their doctor.<sup>53</sup>

The Austin *et al.* (2002) review reported on 2 studies of Hispanic women in the USA in which close to 100% of the women had visited a doctor in the last year, over three-quarters of whom indicated that nobody had ever suggested getting a mammogram. The authors indicated that ‘respect for authority (respect) is an important characteristic of Hispanic culture. Latin Americans regard doctors as powerful authority figures and have a tendency to listen to what doctors say, but rarely show self-initiated health care behaviours’.<sup>53</sup>

Wu *et al.* (2005) reviewed the factors associated with breast screening practices among Chinese, Korean, Filipino, and Asian-Indian American women and concluded that a doctor’s recommendation influenced screening mammography participation.<sup>70</sup>

In the Australian context, BreastScreen Australia is a self-referral service. However, Blue Moon Research and Planning (2008) indicated in their review that:

‘Numerous studies point to the positive influence of a doctor’s recommendation or endorsement on breast cancer screening behaviour.<sup>13</sup> In particular, one article highlighted that studies have shown that between 68% and 91% of women will attend for screening after a recommendation from their GP. Another study indicated that there is a link between a doctor’s involvement and re-screening activity. While a doctor’s recommendation or referral seems to be influential across audiences, one study suggests this can be particularly beneficial among women from non-English speaking backgrounds.’<sup>71</sup>

In a review of 23 studies, Schueler *et al.* (2008) found that the lack of a doctor’s recommendation had a negative impact on the uptake of mammograms (Table 42).<sup>26</sup>

**Table 42 Relationship between accessibility factors and uptake of screening mammography: Schueler *et al.* (2008) review**

	Number of studies	Adj OR	95% CI
No physician recommendation	23	0.16	0.08-0.33
Poor healthcare access	6	0.76	Not available

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

Adj OR: Adjusted odds ratio; CI: Confidence interval

- **Pap tests**

In a review published in 2007, Ackerson *et al.* concluded that African-American and Hispanic women who did not receive a recommendation to obtain cervical screening from

<sup>13</sup> 11 references, see the Blue Moon report for the primary sources.

a health care provider were less likely to obtain Pap tests. One of the studies included in the review indicated that participation among Hispanic and African-American women who reported not receiving a recommendation for a Pap test was 24.3% compared to 75.7% among those who did report receiving a recommendation. However, none of the studies reported an actual chart audit to evaluate whether or not documented provider recommendations coincided with the participants' recollections.<sup>27</sup>

Ackers *et al.* (2007) have pointed out that transportation problems, such as large distances between women's residence and health facilities and the absence of mass transit systems, may also present barriers to regular screening in rural areas.<sup>24</sup>

- **Faecal occult blood testing**

In the Vernon *et al.* (1997) review, 75% of studies (3 of 4) showed a positive association between doctor advice/ability and FOBT and one (25%) found no association.<sup>2</sup>

The Jepson *et al.* (2000) review included 2 studies that examined the influence of health care professionals on the uptake of FOBT. In neither was there a statistically significant effect for the influence of health care professionals.<sup>6</sup>

Petersen (2002) concluded that: (i) absence of a doctor's recommendation; (ii) lack of information from health care providers; and (iii) distance or lack of transport to health care providers, were all associated with lower adherence to colorectal cancer screening.<sup>5</sup> The Guessous *et al.* (2010) review included 7 studies that considered the impact of a doctor's recommendation. All 7 studies found that lack of a recommendation was a significant barrier to the uptake of colorectal cancer screening in people aged 65 years and older.<sup>3</sup>

### 8.3 Affordability

In the literature, affordability has most often been operationalised as 'having health insurance'. As shown in Table 43, just over half of the studies included in the Jepson *et al.* (2000) review reported a significant positive association between having insurance and the uptake of screening mammography. However, few studies examined this association in relation to Pap tests and FOBT.<sup>6</sup>

**Table 43 Uptake of cancer screening tests and insurance status: Jepson *et al.* (2000) review**

	Screening mammograms	Pap tests	FOBT
Studies with statistically significant effects ( $p \leq 0.05$ )	7/12 (58%)	2/4 (50%)	One study found an association between the type of insurance and uptake
Authors' conclusions	The majority of studies found a significant association between uptake and insurance status. Those who had some form of insurance were, in general more likely to attend than those who did not	Unclear whether insurance status is associated with uptake	No conclusions reached

Source: Jepson *et al.* (2000)<sup>6</sup>

As shown in Table 44, monitoring data in the USA appear to indicate that having health insurance is associated with an increase in the uptake of screening mammography, Pap tests and FOBT in that country.<sup>8</sup>

**Table 44 Association between health insurance and the uptake of cancer screening in the USA (2005)**

	Mammogram past 2 years	Pap test past 3 years	FOBT within past year
Yes: Have insurance	69.8%	82.4%	12.7%
No: Do not have insurance	33.2%	61.4%	3.1%

Source: Cokkinides *et al.* (2007)<sup>8</sup>

- **Screening mammograms**

In the Wu *et al.* (2005) review, 50% of studies (5 of 10) found that that lack of money and health insurance influenced mammography use in Chinese women. The review also found that a ‘significant correlate’ of Korean Americans having insurance coverage was an annual income greater than \$25,000.<sup>70</sup>

In the Wells *et al.* (2007) review of factors associated with the uptake of mammograms among Latin American women in the USA, 11 studies reported health insurance as a predictor of screening mammography in multiple logistic regression analysis. Adjusted ORs ranged from 1.7 to 8.5. Compared to having no insurance, both fee-for-service and Health Maintenance Organisation (HMO) insurance were associated with higher odds of obtaining a mammogram.<sup>10</sup>

Schueler *et al.* (2008) concluded that, although there was variability in the magnitude of the results, nearly all studies included in their review showed that having no insurance was a strong predictor of not undergoing screening mammography (Table 45). However, the impact varied across ethnic groups. The effect was stronger among white and Chinese women than among African-American and Latin American women ( $p < 0.001$ ).<sup>26</sup>

**Table 45 Relationship between financial factors and uptake of screening mammography: Schueler *et al.* (2008) review**

	Number of studies	Adj OR	95% CI
No insurance	40	0.47	0.39–0.57
Public vs private insurance	12	0.74	0.63–0.86

Source: Schueler *et al.* (2008)<sup>26</sup>

Notes:

Adj OR: Adjusted odds ratio; CI: Confidence interval

- **Pap tests**

In the Ackerson *et al.* (2007) review, out-of-pocket expenses were found to influence the uptake of Pap tests: women having to pay out-of-pocket costs were less likely to be screened. This included women with insurance plus a co-pay charge or the expense of an office visit or laboratory testing.<sup>27</sup>

The 2007 Akers *et al.* review indicated that having insurance increased the uptake of Pap tests, but they also concluded that the type of insurance had an impact. For example:

- in a study to evaluate a culturally appropriate cervical cancer intervention, women with private health insurance were more likely to be screened compared with those who were uninsured and those who were covered by the public Medicaid or Medicare insurance
- an evaluation of three interventions to increase cervical cancer screening rates in a multi-ethnic sample found that having private insurance was one of the strongest predictors of cervical cancer screening behaviour.<sup>24</sup>

However, Akers *et al.* (2007) point out that several studies have demonstrated that cervical cancer screening may not occur among insured women even when they have made multiple health care visits. They concluded that this indicates that insurance coverage alone does not ensure the uptake of Pap tests.<sup>24</sup>

- **Faecal occult blood testing**

Petersen (2002) concluded that a lack of health insurance is associated with lower adherence to colorectal cancer screening.<sup>5</sup> Guessous *et al.* (2010) reported that in 71% of studies (5 of 7), having private/supplemental insurance (including Medigap) was a significant facilitator of the uptake of colorectal cancer screening in people aged 65 years and over.<sup>3</sup>

In 2006, Wong *et al.* reported on a telephone survey in Hong Kong of attitudes towards colorectal cancer screening among 18–55 year olds in Hong Kong. As shown in Table 46, younger and older respondents were less likely to indicate a willingness to join a paid program than a free program.<sup>87</sup>

**Table 46 Effect of cost on willingness to join a colorectal cancer screening program in Hong Kong (young and old age groups only)**

Type of screening program	Willingness to join the program			
	Definitely	Probably	Undecided	Definitely not
Free	29.5%	23.9%	9.6%	37.0%
Paid	7.9%	21.7%	13.0%	57.4%

Source: Wong *et al.* (2006)<sup>87</sup>

### 8.3 Acceptability

According to the Federation of Ethnic Communities' Councils of Australia (2006), 'newly arrived migrants' lack of knowledge about existing health and social services, and lack of transportation may be compounded by services providers' inability or lack of interest in providing culturally sensitive services that address clients' needs'.<sup>37</sup> There is a paucity of data relating to the cultural safety of services and the cancer screening uptake. The issue most often discussed relates to the gender of the service provider in relation to mammograms and Pap tests.

- **Screening mammography**

The Jepson *et al.* (2000) review contained 3 studies that examined the influence of healthcare provider gender on uptake of screening mammography. Only one of the studies found a significant association.<sup>6</sup> One study in the Wu *et al.* (2005) review examined language concordance between doctors and Chinese women and found that women who had a female physician and Chinese language ‘concordance’ had the greatest likelihood of prior and recent screening.<sup>70</sup>

In the Australian context, qualitative research by Blue Moon Research and Planning (2008) indicated that:

‘Across non-English speaking audiences, there was an expectation that access to interpreters would be limited. Lapsed users in these groups confirmed this was their experience of using BreastScreen Australia services. Both lapsed and never participants felt that having access to either an interpreter or bilingual health worker would increase comfort levels and encourage them to screen regularly. Assistance of this kind was seen as particularly important during a first visit to help explain unknown factors and procedures. This issue was most crucial for recent arrivals to Australia.’<sup>71</sup>

- **Pap tests**

According to Ackerson *et al.* (2007), the gender of the doctor providing screening services is correlated with the provision of cervical cancer screening, with female doctors ‘consistently noted’ to screen more women than male doctors.<sup>24</sup>

It has been hypothesised that ethnic minorities often prefer to have a physician of the same ethnicity to minimise cultural and linguistic barriers to care. However, Ackerson reported ‘several’ studies which noted that having a physician of the same ethnicity may be associated with lower rates of cervical cancer screening. Unfortunately, none of the studies examined other doctor characteristics (e.g. gender, physician type, or being trained outside the USA), so it is not clear whether the findings are mediated by other factors.<sup>24</sup>

## Summary

- **Availability**

Monitoring data provide clear evidence of geographic differences in uptake of screening. This was also apparent in the most recent literature review relating to the uptake of screening mammography. There is less evidence in the literature relating to Pap tests and FOBT. Reasons for geographic differences in uptake have been proposed but have not been examined in the literature.

Evidence indicates that people with a ‘usual source of care’ are more likely to be screened (especially for breast and colorectal cancer) and that recent visits to a health care provider are associated with higher screening rates. However, the results for uptake of screening mammography indicate that the type of health care provider has an influence; the association does not appear to hold for visits to emergency rooms or being

hospitalised. There is little evidence that the number of visits during a particular time period impacts on the uptake of screening.

- **Accessibility**

The major issue discussed in the literature in relation to accessibility is a recommendation for screening by a doctor. Recent evidence indicates that recommendation by a doctor is associated with uptake of breast and colorectal cancer screening. For mammograms, this result appears to be pertinent even in Australia where BreastScreen Australia is a self-referral service. It is also consistently pointed out that this factor may have particular relevance for people from some ethnic groups.

- **Affordability**

In the USA, having health insurance lowers the cost of screening services and having insurance has been associated with an increase in uptake of screening mammography, Pap tests and colorectal cancer screening including, but not limited to, FOBT. Having health insurance is likely to be of little relevance in those health systems that provide cancer screening services free of charge to eligible individuals within the target population.

- **Acceptability**

There is some evidence that female health care providers are associated with the greater uptake of breast and cervical cancer screening. It also appears that, in Australia at least, the provision of interpreters may increase the uptake of mammograms by NESB women.

## 9. DISCUSSION AND IMPLICATIONS

### 9.1 Discussion

Literature on screening adherence has moved away from a reliance on demographic and structural variables as sole predictors of adherence to include cognitive and, more recently, emotional variables as well as health and lifestyle factors.<sup>55</sup> It is clear that numerous, interacting factors are associated with screening uptake; 27 such factors have been examined in this review.

Before presenting a summary of the evidence in relation to these factors, a number of caveats need to be outlined.

- The data used in relation to associations between demographic variables and uptake of screening tests came primarily from two sources: (i) monitoring data for population-based screening programs from various countries; and (ii) reviews of factors associated with screening contained in peer-reviewed literature. In many instances there are discrepancies between these two sets of data, due in part to the fact that the conclusions in literature reviews were often based on multivariate analyses that controlled for other variables, whereas the monitoring data were not.
- Even within the literature reviews, there were differences of opinion, with earlier conclusions being contradicted in more recent reviews. These differences may be due in part to: (i) the inclusion of a larger number of studies in the later reviews; (ii) differences in review methodologies; and (iii) differences in the populations included in the reviews.
- Because of the lack of evidence in relation to FOBT screening, the reviews by Petersen (2002) and Guessous *et al.* (2010) were included. These reviews examined factors related to the uptake of colorectal cancer screening and did not focus specifically on FOBT.
- The analysis for each of the factors is based primarily on literature reviews in both the peer-reviewed and grey literature. The amount of evidence for each factor was dependent on the evidence contained in those reviews. In some instances, there is inadequate evidence on which to base firm conclusions. Stronger conclusions may have been reached if a review of primary sources had been conducted for each factor. This was, however, precluded by resources and time constraints.
- Most of the evidence in this volume relates to breast cancer screening. It cannot be, and has not been, automatically assumed that the results for screening mammography will generalise to other cancer screening tests.

Bearing these caveats in mind, a brief summary of the results for each factor is shown in Table 47.

**Table 47 Summary of the evidence**

Domain	Factor	Association with screening uptake
Demographic	Age	<ul style="list-style-type: none"> <li>For screening mammography and Pap tests, participation appears to be lower in groups at the younger end of the target age for population-based screening programs.</li> <li>For Pap tests, there appears to be a decline in participation as women move towards the upper limits of the target age.</li> <li>For FOBT, it appears that participation is likely to increase up to about 70 years of age when it will decline.</li> </ul>
	Gender	<ul style="list-style-type: none"> <li>On balance, the evidence suggests that uptake of FOBT will be higher among women than men, although gender differences may be smaller in older age groups.</li> </ul>
	Ethnicity	<ul style="list-style-type: none"> <li>Monitoring data indicate lower participation among ethnic and Indigenous groups.</li> <li>It appears that ethnicity may not be a significant factor in the uptake of screening once other factors have been controlled for (e.g. socioeconomic status).</li> </ul>
	Socioeconomic status	<ul style="list-style-type: none"> <li>There is some evidence that low income may be associated with lower screening rates; however, the latest colorectal cancer review indicated that this association may not hold among older people (<math>\geq 65</math> years).</li> <li>No evidence was found to suggest that employment status has an impact on screening participation.</li> <li>There is some evidence to suggest that the association of lower screening uptake with low socioeconomic status may not be due to a lack of money but rather a result of the pressures of everyday life, which work against the uptake of screening.</li> </ul>
	Education	<ul style="list-style-type: none"> <li>On balance, evidence indicates that low levels of education are associated with a lower uptake of screening mammography, Pap tests and FOBT.</li> </ul>
	Literacy	<ul style="list-style-type: none"> <li>Australian literature suggests that literacy levels are lower among groups for whom English is not the first language.</li> <li>There is insufficient evidence to draw conclusions about the impact of low literacy levels on the uptake of screening mammography, Pap tests and FOBT.</li> </ul>
	Health literacy (HL)	<ul style="list-style-type: none"> <li>HL is related to, but not synonymous with, literacy.</li> <li>There is some evidence that HL is lower among the elderly, ethnic minorities, immigrants, non-active English speakers, those with limited education and low incomes.</li> <li>There is some evidence that lower HL is associated with: <ul style="list-style-type: none"> <li>a lower uptake of Pap tests (this association holds for within ethnic-group analyses)</li> <li>lower scores on proximal measures of participation in colorectal cancer screening (e.g. knowledge, comprehension, information seeking), negative attitudes towards colorectal cancer screening and an increased refusal to participate in FOBT screening</li> <li>a reduced willingness to seek out and engage with health-related information.</li> </ul> </li> </ul>

Domain	Factor	Association with screening uptake
	Cancer-related knowledge	<ul style="list-style-type: none"> <li>• There is some evidence that poor knowledge of screening, the belief that mammograms are harmful and the belief that mammograms are not needed in the absence of symptoms is associated with lower screening mammography rates.</li> <li>• There is insufficient evidence to draw any conclusions in relation to Pap tests.</li> <li>• There is some evidence that poorer knowledge of colorectal cancer may be associated with lower levels of colorectal cancer screening.</li> <li>• There is some evidence that colorectal cancer knowledge is lower in some ethnic groups.</li> </ul>
	Perceived risk	<ul style="list-style-type: none"> <li>• Evidence indicates that perceiving oneself to be at a heightened risk of breast cancer is associated with an increase in uptake of screening mammography, but the effect is small.</li> <li>• There is little evidence of an association between perceived risk and uptake of screening in relation to Pap tests and FOBT.</li> </ul>
	Perceived ambiguity	<ul style="list-style-type: none"> <li>• A small amount of evidence suggests that higher levels of perceived ambiguity (e.g. in relation to cancer screening) are associated with lower uptake of screening mammography.</li> <li>• There is no evidence about the association between perceived ambiguity and uptake of Pap tests and FOBT.</li> </ul>
Psycho-social	Fear/anxiety/worry	<ul style="list-style-type: none"> <li>• There is relatively strong evidence to suggest that: <ul style="list-style-type: none"> <li>(i) fear of screening decreases screening participation,</li> <li>(ii) cancer worry increases screening participation, and</li> <li>(iii) fear of the screening outcome has mixed effects on participation.</li> </ul> </li> </ul>
	Coping style	<ul style="list-style-type: none"> <li>• Little research has been conducted into the impact of coping styles on participation in screening.</li> <li>• There is a small amount of evidence to indicate that denial is associated with an uptake in screening and repression with a decrease in screening.</li> </ul>
	Social networks	<ul style="list-style-type: none"> <li>• There is some evidence that family and friends may have an influence on the uptake of screening, especially among ethnic groups.</li> <li>• There is evidence to suggest that being single, widowed or divorced may be associated with a decrease in the uptake of mammograms.</li> <li>• There is little evidence about the impact of different types of social support (emotional, tangible, informative) on screening uptake.</li> </ul>
Health and lifestyle	Physical/mental Health	<ul style="list-style-type: none"> <li>• The notion that people living with physical and mental health problems or disabilities would be less likely to participate in screening seems reasonable. However the evidence is not strong. In part this is due to: <ul style="list-style-type: none"> <li>(i) the fact that the issue has not received much attention in the literature reviews</li> <li>(ii) the broad range of physical and mental health problems that could be included in this research that makes it difficult to generalise</li> </ul> </li> <li>• The most compelling (but not strong) evidence concerns the uptake of FOBT; evidence indicates that increased uptake is associated with: <ul style="list-style-type: none"> <li>(i) the ability to perform ADL</li> <li>(ii) having a chronic/co-morbid condition.</li> </ul>           Australian monitoring data indicates increase in FOBT uptake by people with severe or profound physical limitation. </li> </ul>

Domain	Factor	Association with screening uptake
	Drug and alcohol use	<ul style="list-style-type: none"> <li>The most recent evidence indicates an association between smoking and a reduction in uptake of screening mammography and between alcohol consumption and an increase in uptake of screening mammography.</li> <li>No evidence was found in relation to the relationship between drug and alcohol use and uptake of Pap tests and FOBT.</li> </ul>
	Screening participation	<ul style="list-style-type: none"> <li>There is evidence that people who participate in: <ul style="list-style-type: none"> <li>(i) an earlier screening round are more likely to respond to future invitations to participate</li> <li>(ii) one type of screening are more likely to participate in a different type.</li> </ul> </li> </ul>
Cultural	Acculturation	<ul style="list-style-type: none"> <li>Acculturation has generally been measured as 'length of residence in the host country' and/or 'ability to speak English'.</li> <li>The strongest evidence was for the association between recent arrival in the host country and lower uptake of mammograms and Pap tests.</li> <li>There is some evidence that lower English language skills are associated with a lower uptake of Pap tests.</li> </ul>
	Fatalism	<ul style="list-style-type: none"> <li>Fatalism has been defined as either the belief that events are beyond the control of the individual and/or the belief that death is inevitable when cancer is detected.</li> <li>There is little quantitative research relating to the relationship between fatalism and screening uptake.</li> <li>Available evidence indicates that higher levels of fatalism are associated with lower levels of uptake of screening mammography and FOBT.</li> <li>No evidence was found in relation to the relationship between fatalism and uptake of Pap tests .</li> </ul>
	Modesty/embarrassment/shame	<ul style="list-style-type: none"> <li>On balance, the evidence indicates that modesty, embarrassment and shame inhibits breast and cervical cancer screening among ethnic and Indigenous groups.</li> </ul>
	Medical mistrust	<ul style="list-style-type: none"> <li>One review concluded that medical mistrust has a negative impact on the uptake of mammograms. (Note: There is some evidence that medical mistrust/scepticism is not confined to ethnic and Indigenous groups but was associated with a refusal to screen among well-educated Australian Caucasian women).</li> </ul>
	Collectivism/communalism	<ul style="list-style-type: none"> <li>There is some indication that collectivism/communalism has a negative impact on screening uptake, but there was little research was that examined these factors specifically.</li> </ul>
	Spirituality/religiosity	<ul style="list-style-type: none"> <li>Evidence around an association between spirituality/religiosity and uptake of screening mammography is inconclusive.</li> <li>No evidence was identified in relation to the effect of spirituality/religiosity and uptake of Pap tests or FOBT.</li> </ul>
Health system	Availability	<ul style="list-style-type: none"> <li>Monitoring data provide clear evidence of geographic differences in screening uptake.</li> <li>The literature provides some hypotheses as to why this may be (e.g. lack of services) but evidence is not definitive.</li> <li>There is evidence to suggest that people with a 'usual source of care' are more likely to be screened (especially for breast and colorectal cancer).</li> <li>There is evidence that recent visits to a health care provider are associated with higher screening rates; however, this association does not appear to hold for visits to an emergency room or admittance to hospital.</li> </ul>

Domain	Factor	Association with screening uptake
	Accessibility	<ul style="list-style-type: none"> <li>• There is strong evidence of a positive association between recommendation by a doctor and uptake of screening mammography and colorectal cancer screening.</li> <li>• The literature consistently suggests the relevance of accessibility for people from some, but not all ethnic groups (see also medical mistrust).</li> <li>• The association between a doctor’s recommendation and screening uptake is evident in Australia, where BreastScreen Australia is a self-referral service</li> </ul>
	Affordability	<ul style="list-style-type: none"> <li>• There is strong evidence of a positive association between having insurance and increased uptake of screening in the USA.</li> <li>• The issue of affordability may be of little relevance in health systems that provide free screening to the target group.</li> </ul>
	Acceptability	<ul style="list-style-type: none"> <li>• There is some evidence that female health care providers are associated with increased uptake of breast and cervical cancer screening.</li> <li>• There is some evidence that, in Australia at least, provision of interpreters may increase the uptake of screening mammography among NESB women.</li> </ul>

## 9.2 Implications

The implications of the findings from this review for population-based screening programs in Victoria are outlined below.

- **Demographic factors**

Where monitoring data for population-based screening programs include reliable demographic data, they can be used to identify, in broad terms, groups who are non-adherent to screening guidelines, thereby identifying where efforts to increase screening participation should be focused. However, monitoring data offer little information about underlying reasons for non-adherence. The factors underlying some participation differences require further exploration. For example, evidence suggests that lower screening rates among low socioeconomic status groups may be related to lack of income or money worries as well as a focus on present and competing priorities.

The review also indicates that identified groups (e.g. men, older, rural, ethnic, Indigenous, recent immigrant) are likely to be heterogeneous and that within-group differences are likely to affect screening uptake. These differences need to be considered when designing strategies to improve screening uptake.

- **Cognitive factors**

A major finding of this review of factors influencing cancer screening participation is the importance of the way in which information is presented to target populations. There is evidence that literacy is likely to be low among some non-adherent groups. Literacy is related to, but not entirely synonymous with, HL. Even those with good literacy skills may have reduced HL levels because of the specialised nature of health-related information. There is evidence that individuals with reduced HL are less likely to seek out and/or engage with health-related literature and information. In such instances, improving cancer-related knowledge about screening, cancer and risk as a way of increasing screening participation rates will prove challenging.

- **Psychosocial factors**

It is likely that addressing issues of fear/worry/anxiety that reduce people's generalised cancer worries as well as fear of the screening process itself would have a positive impact on screening uptake. However, strategies for achieving this will need to take account of cognitive and cultural factors that may impact on these feelings.

Evidence of a relationship between coping style and screening uptake was not strong and the implication for population-based screening programs is unclear. Similarly, there is limited evidence in relation to social networks. If family and friends are able to influence the uptake of screening, they can presumably do so for better or for worse. Programs would need to ensure that family and friends have 'good' experiences and positive attitudes if they are to exert a positive pressure on individuals who are reluctant to participate in screening programs.

- **Health and lifestyle factors**

Little evidence was found of a relationship between physical and mental health and screening uptake. The issue here is the lack of evidence in the database to underpin common sense notions. This lack of evidence does not mean that physical health and mental health are not important factors in the uptake of screening. Screening programs should be cognisant of the difficulties people with physical and mental issues face when undergoing screening and make efforts to accommodate them.

Concordance between people who have been screened previously and those who will participate in future screening or take part in other screening programs is not definitive. However, the implication is that engaging people at the time of the first screen and ensuring that they have a positive experience is likely to enhance repeat screening within programs and screening across programs.

- **Cultural factors**

Some evidence suggests that recent immigrants are less likely to participate in screening mammography and Pap tests. This suggests that screening programs should consider how to engage this group in culturally appropriate ways. If this could be achieved, it may have positive implications for later screening and participation in other screening programs. Engagement would need to address the issues of fatalism, modesty/embarrassment/shame and medical mistrust.

- **Health system factors**

Monitoring data highlight geographic differences in screening participation rates but the reasons underlying these differences have not been explored in detail. Clear associations were apparent between:

- having a usual source of care and increased screening uptake
- recent visits to an outpatient or primary care doctor and screening uptake
- recommendations by a doctor and screening uptake
- female health care providers and increased uptake
- provision of interpreters at screening facilities and increased uptake.

These findings point to the importance of doctors and other health professionals being involved in the promotion of screening programs to their patients. Whilst it will not be practicable to increase the number of female doctors, the results imply that other female health practitioners could be used to improve screening rates. The evidence also implies that screening programs need to ensure that their facilities can respond to the needs of non-English speaking participants.

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## APPENDIX: CANCER SCREENING LITERATURE REVIEWS

Reference	Type of cancer	Number of studies included	Publication years	Countries in which studies located	Types of studies
1. Ackerson <i>et al.</i> (2007) <sup>27</sup>	Cervical	17	1999–2005	USA	All types of empirical studies with at least 10% of study participants African American and/or Hispanic women
2. Ackerson <i>et al.</i> (2009) <sup>88</sup>	Breast, Cervical	19	1994–2008	English language, worldwide	Qualitative analysis of quantitative studies related to decision, choice and framing of screening decisions
3. Austin <i>et al.</i> , (2002) <sup>53</sup>	Breast, Cervical	Unclear but <30	1966–2001	USA	Studies that used the Health Belief Model to examine factors influencing screening in Hispanic women
4. Bankhead <i>et al.</i> (2003) <sup>76</sup>	Breast, Cervical	Breast only: 71 Cervical only: 25 Breast & Cervical: 24	1988–2000	English language, worldwide	All study designs relating to the impact of breast and cervical screening on future health-promoting behaviours and beliefs
5. Blue Moon Research and Planning (2008) <sup>71</sup>	Breast	76	2000–2007	English language, worldwide	All study designs; included peer-reviewed and grey literature in relation to perceptions, knowledge and beliefs about breast cancer screening
6. Consedine <i>et al.</i> (2004) <sup>1</sup>	Breast	22	1987–2003	Appears to be: English language, worldwide	Studies examining the role of anxiety, fear, and worry as related to breast cancer screening behaviour
7. Deshpande (2009) <sup>29</sup>	Breast, Cervical, Colorectal	35	1990–2006	USA	All types of empirical studies
8. Guessous <i>et al.</i> , (2010) <sup>3</sup>	Colorectal	83 (59 (71%) reported on FOBT alone or in combination with other screening tests)	1995–2008	English language, worldwide	Full-length, peer-reviewed studies relating to colorectal cancer screening in people aged 65 years and older
9. Hay <i>et al.</i> (2005) <sup>60</sup>	Breast, Cervical, Colorectal	Mammograms Cervical 3 Breast & Cervical Colorectal 10	1872–2003	English language, worldwide	Studies with empirical findings about cancer worry as a correlate of cancer screening
10. Hay <i>et al.</i> (2006) <sup>65</sup>	Breast	12	1872–2006	English language,	Prospective studies involving a breast cancer

Reference	Type of cancer	Number of studies included	Publication years	Countries in which studies located	Types of studies
				worldwide	screening measure and measures of worry or anxiety about cancer
11. Jepson <i>et al.</i> (2000) <sup>6</sup>	Breast, Cervical, Colorectal	Unclear but <65 relating to breast, cervical and colorectal cancer	1966–1985	English language, worldwide 82% located in USA or Canada	Studies using some form of multivariate analysis. These included: randomised controlled trials (RCTs); quasi-RCTs; cohort studies; case control studies with a prospective time barrier between collecting information and uptake of screening
12. Katapodi <i>et al.</i> (2004) <sup>35</sup>	Breast	Primary Studies: Lit Reviews: 1	1985–approx. 2003	English language worldwide	Studies which examined the relationship between breast cancer perceived risk and breast cancer screening
13. Magai <i>et al.</i> (2007) <sup>55</sup>	Breast	71	1980–2005	Unstated, written in English was the only criterion	Studies of the psychosocial and cognitive variables associated with screening
14. McCaul <i>et al.</i> (1996) <sup>4</sup>	Breast	Unstated but quoted in Katapodi <i>et al.</i> (2004) <sup>35</sup>			
15. Petersen (2002) <sup>5</sup>	Colorectal	Not Stated	Not Stated	Not Stated	Not Stated
16. Purc-Stephenson, and Gorey (2008) <sup>19</sup>	Breast	33	1975–2006	USA, Canada	Empirical studies which included a white non-Hispanic comparison group focused on women aged 50 years and who did not have a history of breast cancer and which included findings with sufficient detail to calculate effect sizes
17. Powe and Finnie (2003) <sup>82</sup>	Breast, Cervical, Colorectal	Breast 4 Cervical 1 Colorectal 3	1996–2003	USA	Empirical studies on the phenomenon of fatalism and its association with cancer screening
18. Sadler and Fullerton (2001) <sup>20</sup>	Breast	Unclear but <80	Appears to be 1995–2000	Unclear	Unclear
19. Schueler <i>et al.</i> (2008) <sup>26</sup>	Breast	221	1988–2007	USA	Studies were included if they reported original data on factors related to mammography use and provided quantitative results in a form from which contingency tables and ORs or a percentage

Reference	Type of cancer	Number of studies included	Publication years	Countries in which studies located	Types of studies
					could be derived
20. Vernon (1997) <sup>2</sup>	Colorectal	Factors 36 Reasons 15	1973–1996	US, Canada, Europe, Other Countries (percentages not stated)	All types of empiric studies addressing the: (i) correlates and predictors of adherence to FOBT; and (ii) reasons for non-adherence. Published between
21. Vernon (1999) <sup>54</sup>	Breast, Colorectal No studies were located for the correlates of perceived risk of cervical cancer	Breast 9 Colorectal 2	1996–1998	English language, worldwide	Empirical studies relating to risk perception and cancer screening
22. Watts <i>et al.</i> (2004) <sup>89</sup>	Breast	Unclear but authors indicated it was a ‘small number’	1996–2002	English language, worldwide Predominantly North American	Studies relating to the breast health information needs of women from minority ethnic groups
23. Wells and Roetzheim (2007) <sup>10</sup>	Breast	15	1997–2007	USA	Empirical studies with population-based samples of participants that used multiple logistic regression analysis that addressed the association between Hispanic ethnicity and receipt of screening mammography and which reported adjusted ORs
24. Weller <i>et al.</i> , (2009) <sup>90</sup>	Cancer	Unclear	Appears to be 2000–2008	English language, worldwide	Unclear
25. Wolff <i>et al.</i> (2003) <sup>30</sup>	Cancer	25	Appears to be 1991–2000	USA	Unclear
26. Wu <i>et al.</i> (2005) <sup>70</sup>	Breast	23	1990–2003	USA	Survey research (mailed and face-to-face) focusing on Chinese Korean, Filipino and Asian Indian American women

