

The impact of screening on future health-promoting behaviours and health beliefs: a systematic review

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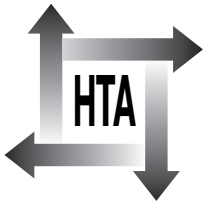
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**Health Technology Assessment
NHS R&D HTA Programme**





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The impact of screening on future health-promoting behaviours and health beliefs: a systematic review

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The NHS R&D Health Technology Assessment (HTA) Programme was set up in 1993 to ensure that high-quality research information on the costs, effectiveness and broader impact of health technologies is produced in the most efficient way for those who use, manage and provide care in the NHS.

Initially, six HTA panels (pharmaceuticals, acute sector, primary and community care, diagnostics and imaging, population screening, methodology) helped to set the research priorities for the HTA Programme. However, during the past few years there have been a number of changes in and around NHS R&D, such as the establishment of the National Institute for Clinical Excellence (NICE) and the creation of three new research programmes: Service Delivery and Organisation (SDO); New and Emerging Applications of Technology (NEAT); and the Methodology Programme.

This has meant that the HTA panels can now focus more explicitly on health technologies ('health technologies' are broadly defined to include all interventions used to promote health, prevent and treat disease, and improve rehabilitation and long-term care) rather than settings of care. Therefore the panel structure was replaced in 2000 by three new panels: Pharmaceuticals; Therapeutic Procedures (including devices and operations); and Diagnostic Technologies and Screening.

The HTA Programme will continue to commission both primary and secondary research. The HTA Commissioning Board, supported by the National Coordinating Centre for Health Technology Assessment (NCCHTA), will consider and advise the Programme Director on the best research projects to pursue in order to address the research priorities identified by the three HTA panels.

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Abstract

The impact of screening on future health-promoting behaviours and health beliefs: a systematic review

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Objectives: To carry out a systematic review to examine the effects of cholesterol, breast and cervical cancer screening on actual or intended health-promoting behaviours and health-related beliefs.

Data sources: Eleven electronic databases (between 1980 and 2000).

Review methods: All English language studies that investigated the impact of cholesterol, breast and cervical screening programmes on health-promoting behaviours and beliefs were assessed for inclusion. The data extraction form and quality assessment criteria were developed using the NHS Centre for Reviews and Dissemination guidelines. Data were extracted and a non-quantitative synthesis was conducted. Reviewers categorised the outcomes into those that could be considered beneficial or detrimental to health. This categorisation was based on a value judgement that considered both statistical and clinical significance.

Results: The cholesterol studies used prospective designs more frequently, possibly as many focused on observing changes in lifestyle following screening. Participants who went for breast or cervical screening were not offered advice on lifestyle changes and most of the research into cancer screening programmes investigated issues related to uptake of screening services, explanations of why people are or are not screened and interventions to improve uptake. All three screening programmes are associated with high levels of favourable health behaviours and beliefs that have been measured, although there is evidence that recommended follow-up after screening is often not adhered to. There was no literature on the cost-effectiveness regarding the wider implications of screening (only on reduction of disease-specific

mortality/morbidity), possibly due to the outcomes being very broad and not easily categorised and classified.

Conclusions: The studies reviewed suggest that cholesterol screening had a positive effect on health behaviours, although participation was voluntary and those screened were possibly more motivated to make changes. These results are therefore not generalisable to the entire population and other factors need to be taken into account. Reduction in blood cholesterol levels was reported in all but two of the studies that assessed this outcome, suggesting that successful lifestyle changes were made. However, as most of the studies only reported follow-up of those screened, some of the reduction can be attributable to regression to the mean. Whether breast and cervical screening affect future health behaviours and beliefs has not been directly measured in many studies and few studies have collected baseline measures. However, evidence suggests that women who attend breast and cervical screening once are likely to reattend and attendance is associated with several positive health behaviours, although it cannot be confirmed whether the associations observed were a result of screening or because these women have a certain set of health behaviours and beliefs irrespective of their experience of screening. Areas of further research include: measuring a much wider range of behaviours and beliefs before and after screening is accepted or declined, examining the subgroup of participants who receive 'desirable' results and the impact of this on health beliefs and health-promoting behaviour, and qualitative research into the experiences of screening and how this interacts with knowledge and beliefs about other aspects of health.



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List of abbreviations

AC	all-clear result	med	MEDLINE
ACS	American Cancer Society	NA	not applicable
ASCUS	atypical squamous cells of undetermined significance	NCEP	National Cholesterol Education Program (USA)
BCSP	breast cancer screening programme	NCI	National Cancer Institute (USA)
BMI	body mass index	NF	normal findings
BS	breast screening	NHIS-HPDP	National Health Interview Survey of Health Promotion and Disease Prevention
BSE	breast self-examination	NHSBSP	National Health Service Breast Screening Programme
CBE	clinical breast examination	NHSCSP	National Health Service Cervical Screening Programme
CHD	coronary heart disease	ns	not significant
cin	CINAHL	NSC	National Screening Committee
CI	confidence interval	NSF	National Service Framework
CIN	cervical intraepithelial neoplasia	ORadj	adjusted odds ratio
CRD	Centre for Reviews and Dissemination	OR	odds ratio
CVD	cardiovascular disease	Pap smear	Papanicolaou smear
DNA	did not attend (non-attender)	PCQ	Psychological Consequences of Screening Questionnaire
emb	EMBASE	PEP	Prevention for Elderly Persons
FNA	fine-needle aspiration	psy	PsychInfo
FNAC	fine-needle aspiration cytology	RCT	randomised controlled trial
FP	false-positive result	REF	referents
HBM	Health Belief Model	RR	relative risk (risk ratio)
HFF	high-frequency follow-up	SCI	Science Citation Index
HGSIL	high-grade squamous intraepithelial lesions	SCORE	screening, counselling and referral
HLC	Health Locus of Control	SD	standard deviation
HMO	Health Maintenance Organization (USA)	SE	standard error
HPV	human papillomavirus	SSCI	Social Science Citation Index
HRT	hormone replacement therapy	TRA	Theory of Reasoned Action
LFF	low-frequency follow-up	WHO	World Health Organization
LGSIL	low-grade squamous intraepithelial lesions		

All abbreviations that have been used in this report are listed here unless the abbreviation is well known (e.g. NHS), or it has been used only once, or it is a non-standard abbreviation used only in figures/tables/appendices in which case the abbreviation is defined in the figure legend or at the end of the table.



Executive summary

Background

The review focuses on two types of screening: risk factor screening (cholesterol) and screening for early disease (breast and cervical cancer). Risk factor screening involves a strategy for primary prevention, whereas early or preclinical disease screening is secondary prevention.

Screening can be delivered as a systematic programme, an 'opportunistic' programme or an 'open-access' programme. A systematic programme is provider led and will actively seek out the eligible population and invite them to participate in screening. Opportunistic screening occurs when a patient consults a health professional about an unrelated problem, and the opportunity is taken (by a healthcare provider) to offer and conduct the screening. Open-access screening is user led, where the screened population is self-selected.

Objectives

To carry out a systematic review to examine the effects of cholesterol, breast and cervical cancer screening on actual or intended health-promoting behaviours and health-related beliefs.

In particular, the review addressed the following questions:

- What are the effects of screening for hypercholesterolaemia, breast cancer and cervical cancer on future health beliefs and behaviours?
- What are the implications for the NHS?

Methods

Data sources

Systematic searches of 11 electronic databases (between 1980 and 2000) were conducted.

Study selection

All English language studies that investigated the impact of cholesterol, breast and cervical screening programmes on health-promoting behaviours and beliefs were assessed for inclusion.

Data extraction

The data extraction form and quality assessment criteria were developed using the NHS Centre for Reviews and Dissemination guidelines. Initially, two reviewers extracted data and disagreements were resolved by discussion with a third reviewer. This procedure was changed owing to the large number of papers involved, to data being extracted by one reviewer and checked by a second reviewer; any disagreements were resolved by discussion with a third reviewer.

Data synthesis

Data were extracted and a non-quantitative synthesis was conducted. Reviewers categorised the outcomes into those that could be considered beneficial or detrimental to health. This categorisation was based on a value judgement that considered both statistical and clinical significance.

Results

The study designs used in the three screening types differed. The cholesterol studies used prospective designs more frequently. This may be explained by differing research agendas as the majority of the cholesterol papers were interested in observing changes in lifestyle following screening. However, participants who went for breast or cervical screening were not offered advice on lifestyle changes and most of the research into cancer screening programmes investigated issues related to uptake of screening services, explanations of why people are or are not screened and interventions to improve uptake.

All three screening programmes are associated with high levels of favourable health behaviours and beliefs that have been measured, although there is evidence that recommended follow-up after screening is often not adhered to. However, most of the research has been restricted to outcomes related to the condition being screened for (e.g. cancer-related beliefs as related to cancer screening). To explore fully the effects of screening on future health behaviours and beliefs a much wider range of outcomes should be studied. There were very few qualitative studies that could have

provided a better understanding of how and why participants in screening are affected by the processes they have undergone.

There was no literature on the cost-effectiveness regarding the wider implications of screening (only on reduction of disease-specific mortality/morbidity). This is possibly due to the outcomes being very broad and not easily categorised and classified.

Conclusions

Cholesterol screening

The studies reviewed suggest that cholesterol screening had a positive effect on health behaviours. However, these positive findings need to be interpreted in the light of methodological issues. For example, participation was voluntary and those screened were possibly more motivated to make changes. These results are therefore not generalisable to the entire population. Other factors include the lack of reliability and validity of tools to measure changes in health behaviours, study attrition and uncertainty of self-reports. Furthermore, uncertainty of long-term changes, inaccurate risk assessment, perception of cholesterol testing in a non-medical environment, perception of seriousness of the risk status due to lack of symptoms, readiness to accept advice, and convenience and cost of follow-up should all be considered.

Reduction in blood cholesterol levels was reported in all but two of the studies that assessed this outcome, suggesting that successful lifestyle changes were made. However, as most of the studies only reported follow-up of those screened, some of the reduction can be attributable to regression to the mean.

Breast and cervical screening

Whether breast and cervical screening affect future health behaviours and beliefs has not been directly measured in many studies and few studies have collected baseline measures. Therefore, it is difficult to answer with certainty the question of what are the effects of these screening programmes on future health beliefs and behaviours. However, evidence suggests that women who attend breast and cervical screening once are likely to reattend and attendance is associated with several positive health behaviours. Many of these studies were cross-sectional or relied on retrospective data collection where the temporal relationship between screening and these behaviours cannot be assessed. Therefore, it cannot be confirmed whether the associations observed were a result of screening or because these women have a certain set of health behaviours and beliefs irrespective of their experience of screening.

Recommendations for research

To answer the question posed by the review, further research needs to be undertaken to include:

- measuring a much wider range of behaviours and beliefs (including long-term lifestyle changes) before and after screening is accepted or declined, to measure changes that could be attributed to screening
- specifically in cholesterol screening: the subgroup of participants who receive 'desirable' results and the impact of this on health beliefs and health-promoting behaviour
- qualitative research into the experiences of screening and how this interacts with knowledge and beliefs about other aspects of health, not simply those relating to the condition being screened for.

Chapter I

Introduction

Background

Screening has been defined as “a medical investigation which does not arise from a patient’s request for advice for a specific complaint”.¹ Screening programmes differ from other healthcare activities in that it is usually a health professional who initiates the encounter with an apparently healthy population. The aim of screening is to reduce mortality from the disease in question by detecting risk factors, early disease or a preclinical condition before symptoms occur, in order to prevent or reverse the disease process. This occurs in people who are often presumed and presume themselves to be healthy.² The value of screening depends on the success of the programme in attracting, identifying and treating those at risk of a particular disease, and the extent to which the associated costs are minimised (including unnecessarily interfering in the lives of the people screened who do not have the disease).

This review was commissioned with the aim of examining the impact of screening programmes on future health behaviours and beliefs. An initial broad search covering all types of screening was refined in collaboration with the NHS HTA commissioning body to focus on two types of screening: risk factor screening (cholesterol screening) and screening for early or preclinical disease (breast and cervical cancer screening). Risk factor screening involves a strategy for primary prevention of another disease [cardiovascular disease (CVD) in the case of cholesterol screening]. Where there is no strategy for primary prevention, the focus is on early detection in the form of either early or preclinical disease (breast and cervical screening).

These two areas were chosen to investigate any differences between health-promoting behaviour following screening for a potentially ‘modifiable’ risk factor and screening for a preclinical condition or early disease.

Screening can be delivered as a systematic programme, examples of which are the nationally coordinated NHS Breast or Cervical Screening Programmes (NHSBSP and NHSCSP). Such programmes are provider led and actively seek out

the eligible population to invite them to participate in screening. Screening can also be ‘opportunistic’. This occurs when a patient consults a health professional about an unrelated problem, and the opportunity is taken (by the healthcare provider) to offer and conduct the screening test. An example of this includes screening for high blood pressure or cholesterol. Another form of screening, sometimes termed ‘open access’, is screening offered at supermarkets, pharmacies, and so on. Often, cholesterol screening is conducted in this manner. This type of approach to screening is user led rather than provider led.

This review examines the effects of screening (delivered by any of the above three methods) for cholesterol, breast cancer and cervical cancer on actual or intended health-promoting behaviours and health-related beliefs.

Cholesterol screening

Cholesterol screening in the UK

This report assumes that cholesterol screening consists of a blood test accompanied by basic recommendations about lifestyle changes. For individuals with a high serum cholesterol measurement, it is assumed that advice to visit a doctor regarding their cholesterol levels is given.

High blood cholesterol is an important risk factor for CVD. It is known to contribute to atherosclerosis and subsequently to coronary heart disease (CHD). Total blood cholesterol levels in the UK are high by international standards, particularly in women. The prevalence of raised cholesterol increases with age in both men and women. It is estimated that 45% of deaths from CVD in men and 47% of deaths from CVD in women are due to a raised blood cholesterol level and that 10% of deaths from CVD in the UK could be avoided if everyone in the population had a blood cholesterol level of less than 6.5 mmol/l.³

Blood cholesterol can be assessed using a finger-prick or venous blood test. Results may be obtained immediately afterwards, from an instant reading by a Reflotron or other such instrument,

or later, after being analysed in a hospital laboratory.

The definition of desirable cholesterol levels has changed since the 1980s as further research on levels of risk has been conducted.

Different guidelines give slightly different advice for managing high levels of blood cholesterol. The National Service Framework (NSF) for CHD includes guidelines for the UK. The current recommendations for individuals found to have elevated levels of cholesterol are to make lifestyle changes, such as following a low-fat diet and increasing their level of exercise. Those with high cholesterol levels are advised to visit their GP, and if lifestyle change is not effective to take medication such as statins to reduce total cholesterol levels to below 5 mmol/l or by 30%, whichever is the greater.⁴

Cholesterol screening in other countries

In the USA, the National Cholesterol Education Program (NCEP) was initiated in November 1985. The goal of the NCEP is to reduce illness and death from CHD in the USA by reducing the proportion of the population with high blood cholesterol. The NCEP aims to raise awareness and understanding about high blood cholesterol as a risk factor for CHD and the benefits of lowering cholesterol levels as a means of preventing CHD through education of health professionals and the public.⁵

The National Institutes of Health recommends that all adults (aged 20 and over) should have a fasting lipoprotein profile (which includes cholesterol) taken every 5 years and that the total cholesterol measurement should be < 200 mg/dl (equivalent to < 5.17 mmol/l) (Table 1).⁶

TABLE 1 Cholesterol measurements and classification⁶

Total cholesterol blood test score	Cholesterol level classification
< 5.17 mmol/l (< 200 mg/dl)	Desirable
5.17–6.21 mmol/l (200–240 mg/dl)	Moderate/ borderline risk
> 6.21 mmol/l (> 240 mg/dl)	High risk

In the UK cholesterol is measured in mmol/l, whereas in the USA the commonly used units are mg/dl.

There is much debate over what constitutes a high cholesterol level. In the USA the NCEP guidelines are used, but there is controversy over whether these cut-off levels (high, borderline high and desirable) should be used. A raised blood cholesterol reading should not be interpreted in isolation using fixed cut-off points, as it may or may not indicate average coronary risk depending on other lifestyle factors present.⁷ The impact of cholesterol screening on an 'at-risk' status is therefore disputed. It is not just one factor that gives a participant an at-risk status, but multiplicative interaction with other risk factors. Those classified as low risk in cholesterol screening could in fact be at higher risk, yet lifestyle changes are not made.

Breast screening

This report assumes breast screening to be screening by mammography. Clinical breast examination (CBE) and breast self-examination (BSE) as screening techniques are excluded.

Breast screening in the UK

Breast cancer is the most common form of cancer in women in the UK, affecting one in nine women during their lifetime. Mortality rates from breast cancer in England and Wales are the highest in the world, and account for almost 12,000 deaths each year.⁸ The mortality rate has reduced by 14% from the late 1980s, when about 14,000 women were dying each year.⁹

The NHSBSP was introduced in 1988. Women aged 50–64 years are invited to attend breast screening every 3 years. Women aged over 64 may request mammography once every 3 years, but they are not routinely invited. Following relevant feasibility studies, routine screening will, in future, be offered to women up to the age of 70. Breast screening is free of charge to participants.

Women who receive a 'suspicious' result are asked to attend an assessment clinic approximately 2 weeks after the mammography appointment to undergo further investigations. Further investigation at the assessment clinic may include additional mammography, a CBE, ultrasound and, in some instances, fine-needle aspiration cytology (FNAC). If there is still a suspicion after the assessment results, a diagnostic biopsy may be performed or, if the degree of suspicion is low, the woman may be placed under surveillance and asked to come back for further investigation in 6–12 months' time (early recall).

For the screening programme to be cost-effective and result in projected reductions in mortality, it is vital that attendance rates are high for the first mammogram and remain high throughout subsequent screening rounds.¹⁰ It has been stated that the “uptake of mammography among the eligible population may be the single most important determinant if the programme is to be effective in its aim to reduce breast cancer mortality in the screened population”.¹¹

Breast screening in other countries

A survey of 22 countries (including the UK) in 1995 found that 21 of them were routinely offering mammography to women (women in Japan were screened using CBE and BSE only).¹² The lowest age at which women are initially offered mammography was 40 years, and the majority of countries continued screening until the age of 69, with the USA and Uruguay having no upper age limit. The most frequent recommended screening interval was 2 years.¹²

There are no national guidelines in the USA and several major organisations have issued their own recommendations. The American Cancer Society (ACS) advises that women aged 40 years and over should have annual mammograms, although before 1997 they were advising women aged 40–49 to have breast screening every 2 years. The US Preventative Task Force recommends that mammography should be undertaken every 1–2 years for women aged 50 and over.¹²

Cervical screening

This report assumes cervical screening to be screening by Papanicolaou smear (Pap Smear). Pelvic or abdominal examinations are excluded.

Cervical screening in the UK

In 1998, over 3000 new cases of invasive cervical cancer were registered in the UK, making it the 11th most common cancer in women,¹³ accounting for 2% of all cancers in women. Since 1988 the incidence of invasive disease has been steadily decreasing, from a standardised incidence rate of 16.9/100,000 women¹⁴ to 9.3/100,000 women in 1996.¹⁵ Mortality rates have also been declining and currently the reduction is around 7% per year, whereas previously the decline in mortality had been around 1% per year.

Cervical screening was introduced in the UK in the 1960s, mostly on an opportunistic basis in general practice, family planning and gynaecological clinics. The programme was not well organised and the proportion of women over the age of 40 who were not receiving screening was extremely high. In 1988 the NHSCSP was reorganised and a computerised call–recall system introduced. Following the reorganisation of the service, reductions in both incidence and mortality rates have been observed.¹⁶

In the UK, women aged 20–65 years are offered a cervical smear every 3–5 years, depending on where they live. Recall times vary from one area to another as there is still debate about the costs and benefits of 3-yearly screening. Cervical screening uses cytology to detect areas of nuclear abnormalities that are described as dyskaryotic. Dyskaryosis ranges from mild to severe. Depending on the severity of the dyskaryosis, women may undergo a further procedure called colposcopy to provide histological diagnosis of cervical intraepithelial neoplasia (CIN), or may undergo more frequent screening.

Cervical screening in other countries

Across the European Union the recommended age for commencing cervical screening ranges from 15 to 30 years, with the most common age being 25. The upper age limit is 64–65 in seven of 15 countries and 59–60 in five countries, and in Germany, Austria and Luxembourg there is no upper age limit.¹⁷ The screening interval ranges from 1 year to 5 years, with the majority of programmes conducting screening every 3 years.¹⁷

As for breast screening, there is no national consensus in the USA about who should have cervical screening or how frequently. The ACS has issued the following guidance: “screening should commence 3 years after initiation of vaginal intercourse and no later than age 21. Suggested frequency of screening ranges between 1 to 3 years based on screening method, age of woman, presence of risk factors and results of previous tests”.¹⁸

Health behaviours and beliefs

Although the explicit aim of screening is to reduce mortality from a specific disease, the implicit

assumption is usually made that it will improve health, attitudes towards health and health-related behaviours in general.¹⁹ Health beliefs and corresponding behaviours are important determinants of health, and have been considered to be a key component of most models of health promotion. However, screening can potentially also result in more negative health beliefs and health behaviours.

For the purpose of this review, health behaviour was defined as an activity likely to have an influence on health. It was expected that the following behaviours would be found in the literature, but no health-related behaviours were excluded from the review:

- health-related lifestyle changes, such as smoking cessation, exercise participation and dietary improvements
- uptake of preventive healthcare, such as immunisation and dental check-ups
- actual or intended reattendance at screening when next invited
- future use of other screening services
- appropriate use of health services in illness, including adherence to follow-up recommendations following screening.

Theoretical models of health beliefs

Health beliefs can be categorised in many ways, but the underlying assumption is that these beliefs drive corresponding behaviours. Several psychological models to predict health behaviours have been developed. These can be classified as those that:

- suggest a central role of beliefs (i.e. not necessarily rational)
- examine the cognitive (i.e. rational) predictors and precursors of behaviours
- include reference to why some individuals fail to maintain a behaviour that they are apparently committed to (i.e. rational but in a social context).

Central role of belief **Attribution Theory**

Attribution Theory is predicated on the assumption that individuals are motivated to understand the world as predictable and controllable, and therefore make attributions (explanations) about the causality of events.²⁰ In relation to health behaviours, attributions of personal responsibility for an illness have been found to predict subsequent treatment choice.

Health Locus of Control

Health Locus of Control (HLC) is closely related to Attribution Theory and describes the extent to which individuals differ in whether they regard events as controllable by them (internal locus of control) or by other agents (external).²¹ This is found to be related to whether individuals change their behaviour, and what kind of communication style they prefer from health professionals.

Transtheoretical Model of Behaviour Change (Stages of Change model)

The Transtheoretical Model of Behaviour Change describes the dynamic process of behaviour change, with five stages, although these need not necessarily occur in a linear fashion.²² The stages are:

- precontemplation (not intending to change)
- contemplation (considering change)
- preparation (initiating/preparing for change)
- action (actively changing behaviour)
- maintenance (sustaining this change).

This model has been applied to a broad range of health-related behaviours (e.g. smoking cessation and exercise uptake).

Unrealistic optimism

Unrealistic optimism, also referred to as optimistic bias, is the tendency to perceive one's circumstances as being more positive than those of individuals in a similar comparison group.²³ When a whole population of individuals perceives itself to be at lower risk than the average person in the same population, the group is demonstrating unrealistic optimism. It is not possible for everyone to be at less risk than average. There is evidence that people display unrealistic optimism in their assessment of personal risk of a variety of health outcomes.

Cognitive models

Health Belief Model

The Health Belief Model (HBM) was developed initially to predict preventive health behaviours,²⁴ but has more recently been extended to a variety of health-related behaviours. It assumes that behaviour results from a rational appraisal of the costs and benefits of a given behaviour. The HBM predicts that behaviour is a result of a set of core beliefs that have become defined (and redefined) over several years. These core beliefs relate to the individual's perception of:

- susceptibility to the disease
- seriousness of the disease

- benefits of a given behaviour (e.g. screening)
- cues to action
- barriers to action.

Protection Motivation Theory

Protection Motivation Theory is an extension of the Health Belief Model and suggests that behavioural intentions are the product of perceived severity of the disease, perceived vulnerability to the disease, perceived effectiveness of the behaviour change and self-efficacy beliefs related to the behaviour change.²⁵ It has also been suggested more recently that a fifth component, fear, should be incorporated into this model.

Models in social context

Theory of Reasoned Action

The Theory of Reasoned Action suggests that in addition to the individual's attitude towards the costs and benefits of a given health-related behaviour, there is an important role for subjective norms.²⁶ In other words, the perception of *others* of the behaviour will also predict that behaviour. This emphasised the social context within which any rational appraisal of behavioural change takes place.

Theory of Planned Behaviour

The Theory of Planned Behaviour extended the theory of reasoned action and placed an emphasis on behavioural *intention* as being the outcome of these beliefs.²⁷ However, intentions do not necessarily result in the corresponding behaviour, which depends in addition on the perceived behavioural control of the individual, based on an appraisal of internal control factors (e.g. ability to change one's behaviour) and external factors (e.g. obstacles to behaviour change). This is related to self-efficacy theory (described below).

Health Action Process approach

The Health Action Process approach incorporates a temporal element into the understanding of health-related beliefs and behaviour.²⁸ It distinguishes between making a decision to initiate behavioural change, and subsequently initiating and maintaining this change. The motivation stage is made up of self-efficacy beliefs, outcome expectancies (i.e. perceived benefits and the anticipated perceptions of others) and threat appraisal (i.e. perceived severity of and susceptibility to the disease). The action stage is composed of cognitive (e.g. plans for sustaining the change), situational (e.g. social support) and behavioural factors.

Other models

Another model not unique to health behaviours but potentially important as a moderator or mediator of the relationship between health beliefs and health behaviours is Bandura's Self-Efficacy Theory,²⁹ which is incorporated into some of the models described above.

The above models distinguish health beliefs in differing ways. Arguably the most commonly applied is the HBM.²²

Effect of screening on health beliefs and behaviours

Health beliefs may influence self-care motivation and could have an effect on health-promoting behaviour. Several studies have suggested that awareness of and involvement in screening programmes could have a positive or negative impact by influencing beliefs about the causes of illness, the effectiveness of healthcare and the acceptability of health services, and may be manifested in actual or intended behaviour change. While these various models may have some intuitive appeal, they suffer in many cases from being largely descriptive (e.g. HBM, Transtheoretical Model of Behaviour Change) or derived from a literature not primarily concerned with health-related beliefs and behaviours (e.g. Attribution Theory, Theory of Reasoned Action, Theory of Planned Behaviour). Those that have been developed specifically to understand health-related behaviours in general and screening behaviours in particular (e.g. HBM) are also rather circular in application and do not readily lend themselves to quantitative research, as there are few instruments with demonstrated reliability and validity for assessing the constituent constructs.

It has been suggested that the relationship between screening, health-promoting behaviour and health beliefs may be complex.³⁰⁻³³ Studies on different types of screening programme have given contradictory results.

Empowerment of participants

There is evidence to suggest that screening may have a positive impact on a range of health-related behaviours, including diet and exercise, and that it can lead to significant lifestyle changes and play an important part in the 'empowerment' of patients.³⁴⁻³⁶

Impact of normal screening results

There is also evidence to show that screening can inadvertently reassure patients about their lifestyle.

A true negative result such as a 'normal' cholesterol result may be misinterpreted as permitting unhealthy behaviour such as smoking.³⁷ Reassurance of people with negative results may make them more resistant to general health advice because they interpret the test result as showing that they are immune to the impact of unhealthy lifestyles. This phenomenon has been described under the heading 'certificate of health effect'.³⁸ A false-negative result may create a false sense of security and future symptoms may then be ignored.^{37,39,40}

Effect of increasing awareness

Raising awareness of a condition can have either positive or detrimental consequences on health-related behaviour. There is evidence to suggest that absenteeism from work increases after a diagnosis of hypertension following workplace screening.⁴¹ This increase in absenteeism bore a relationship to awareness of the diagnosis, but appeared to be unaffected by the institution of antihypertensive therapy or the degree of success in reducing blood pressure. However, it has also been proposed that an invitation for screening awakens curiosity about disease and its causes. This health awareness may encourage people to make health-enhancing changes to their lifestyle that could have a positive effect on public health. It can also be argued that the process of being screened makes people more disease aware and therefore could increase the chances of early presentation of disease between screening tests. It is likely that the magnitude and direction of these potential effects are dependent on prior psychological state and beliefs.

Personal control of health

Screening programmes may also imply that good health can be maintained by regular visits to the doctor for check-ups and that individual behaviour is less important.¹⁹ Evidence from the USA has shown that a reduced sense of personal control over health is associated with poorer self-rated health, more episodes of illness and less self-initiated preventive care.⁴²

Using Bandura's Self-Efficacy Theory²⁹ to investigate cancer prevention suggests relationships between self-efficacy and cancer prevention. Strong precepts of self-efficacy predict increased participation in screening programmes. Increased self-efficacy is associated with increased self-care behaviours and decreased psychological symptoms.²⁹ Using psychological models may, therefore, help to predict reactions to screening. This could be valuable in predicting any implications for preventive health behaviours.³⁸

Scope of the review

The review focuses on cholesterol screening and two cancer screening programmes (breast and cervical screening) to address the question of how screening impacts on future health behaviours (actual or intended) and health beliefs.

The literature identified often did not specifically state which theoretical models underpinned the studies. The most commonly used models were the HBM and the Health Locus of Control (HLC) model, but were often used to predict uptake of screening, not reactions to screening. This is unfortunate, in particular given the broad range of models described above that exist for predicting behaviour from a variety of theoretical perspectives. This review, therefore, does not explore the relationships between the different models and screening, but aims to document and quantify changes in health-related beliefs, attitudes and health-promoting behaviour that may be associated with the screening types included. It also aims to identify factors that could facilitate or inhibit health-related behavioural change as a response to screening. The findings should contribute to a more accurate assessment of the true costs and benefits of screening.

Cholesterol screening aims to identify those with an elevated cholesterol level, which is a risk factor for future development of CHD. Beliefs regarding cholesterol screening and the test result (e.g. perceived seriousness) play an important role in driving corresponding behaviours. As many of the risk factors are modifiable, it is expected that much research has focused on direct behavioural changes (such as increasing exercise or changing to a low-fat diet). However, cholesterol screening could also have an indirect impact on beliefs about vulnerability to illness in general and personal control over disease.

Breast and cervical screening aims to reduce mortality from these conditions. Breast screening detects very early stage breast cancer, whereas cervical screening can detect a precancerous lesion which, when treated, is very unlikely to develop into cervical carcinoma. As for cholesterol screening, beliefs regarding breast and/or cervical screening and the test result (such as perceived susceptibility and personal disease control) play an important role in driving corresponding behaviours. In contrast to cholesterol screening, there are few modifiable behavioural risk

factors for breast and cervical cancer. However, the effect of screening may be seen indirectly in other types of behaviour such as subsequent reattendance or adherence with follow-up recommendations.

To determine the effect of screening on health behaviours and health beliefs, the ideal situation would be to measure these outcomes before and after screening. This would enable a change after screening to be observed. However, in many papers (particularly breast and cervical screening) this has not been specifically examined. In studies of breast and cervical screening the emphasis has been on investigating determinants of uptake rather than the effects of screening. It would also be ideal to have a clear temporal relationship between screening and subsequent outcomes of interest. In reality, information about screening and health behaviours and beliefs were often measured and collected at the same time. This made it very difficult to determine whether beliefs and behaviours precede or follow screening.

Objectives

To carry out a systematic review to examine the effects of screening on actual or intended health-promoting behaviours and health-related beliefs.

In particular the review addressed the following questions:

- What are the effects on health behaviours and beliefs of the screening process for hypercholesterolaemia, which is a modifiable risk factor for CHD?
- What are the effects of screening for breast and cervical cancer on future health beliefs and behaviours?
- What are the implications for the NHS, including the impact on the cost-effectiveness of screening programmes?
- The review also aimed to identify gaps in the literature, make recommendations and describe a framework for further research on this topic, taking into account any important theoretical perspectives identified in the literature search.

Chapter 2

Methods

Development of the searches

Appendix 1 shows the search strategy used for the four main electronic databases (MEDLINE, PsychInfo, EMBASE and CINAHL). A combination of text terms and MeSH terms was used to maximise the literature retrieved. These search terms were developed to ensure that papers that were included in the authors' personal collections or had been identified by handsearching were retrieved by the search strategies.

Searches included all temporal relationships, but papers with the incorrect temporal relationship (e.g. beliefs preceding screening) were excluded.

The following journals were handsearched: *Journal of Medical Screening*, *Journal of Public Health Medicine*, *Health Education Journal* and NHS reports of recent literature.

Additional advice on the development of searches was sought from Ms Nicola Bexon, Librarian and Information Manager, Institute of Health Sciences, Oxford University, and Dr Jane Barlow, Sociologist, Health Services Research Unit, Oxford University.

Systematic searches of electronic databases

Systematic searches of electronic databases were conducted, including MEDLINE, PsychInfo, EMBASE, CINAHL, HealthStar, Science Citation Index (SCI), Social Science Citation Index (SSCI); FPHM database of Part 11 MFPHM theses, and University Databases of DPhil, PhD and MSc databases. The years included in the searches were 1980–2000 (see Chapter 3).

Continued handsearching of journals occurred until April 2002. Key papers found by this method are not included in the systematic review, but are discussed in the relevant sections.

Retrieved papers were downloaded into Reference Manager.

Guidance was provided by Ms Nicola Bexon, Librarian and Information Manager, Institute of

Health Sciences, Oxford University, and Dr Lindsay Stead, Cochrane Tobacco Addiction Group, University of Oxford.

Inclusion and exclusion criteria

Inclusions

- Health-promoting behaviours and beliefs that occur as a result of:
 - cholesterol screening
 - breast screening
 - cervical screening
- all study types.

Exclusions

Studies that looked at:

- anxiety caused by screening, unless the anxiety affects health-promoting behaviour or beliefs (e.g. effect on reattendance for screening)
- pain and discomfort, unless it affects health-promoting behaviour or beliefs (e.g. effect on reattendance for screening)
- studies focusing on improving uptake of screening as included in a previous HTA review⁴³
- longitudinal studies with the incorrect temporal relationship between screening and behaviours/beliefs (behaviours and/or beliefs measured before screening)
- children and screening
- effect on families (salient others) and social environment
- non-English language papers.

Data extraction and assessment of study validity

There were six stages to the review process.

Stage 1

Titles of papers were screened by two reviewers and papers were initially included or excluded where the reviewers agreed. Any disagreement was resolved by discussion.

Stage 2

Titles and abstracts of all remaining papers were read for relevance and coded according to the

TABLE 2 Details of the coding system

1	Include in data extraction	Include
2	Temporal relationship unclear	Include*
3	Not relevant	Exclude
4	Anxiety only	Exclude*
5	Report only (conference proceedings etc.)	Exclude
6	No abstract	Include
7	Letter	Include
8	Uptake of screening only	Exclude
9	Thesis – still under consideration	Include
10	Pain	Exclude*
*See Stage 3 of the review process.		

schedule shown in *Table 2*. This process was conducted by two reviewers for the 712 papers in the MEDLINE database. Agreement was good and improved over time. Owing to the vast numbers of papers it was decided that only one reviewer needed to conduct this process for the remaining databases as agreement was high on the largest database, MEDLINE.

Stage 3

Papers in the asterisked categories in *Table 2*, itemised in Stage 2, were examined twice. In the case of the temporal relationship papers this was

to check whether a decision regarding inclusion/exclusion could be made before data extraction. For the other two categories (anxiety and pain) the abstracts were re-read and if there was a mention of intention to attend for future screening or reattendance for screening these papers were fully data extracted.

Stage 4

Data were extracted from relevant studies (*Figure 1*) by two reviewers onto the data extraction form in Appendix 2. The data extraction form and quality assessment criteria were developed using the guidelines produced by the NHS Centre for Reviews and Dissemination (CRD)⁴⁴ (see Appendix 2). Quality assessment criteria were developed separately for each study design included in the review (Appendix 2).

Data extracted included identification of the study, study aims, setting, design, sample size and follow-up rates, study methods, including comparative groups, outcomes (divided into health-promoting behaviours and health beliefs), results (divided into health-promoting behaviours and beliefs), summary of results and quality scoring (see below). Any disagreements were resolved by discussion with a third reviewer. Midway through the project,

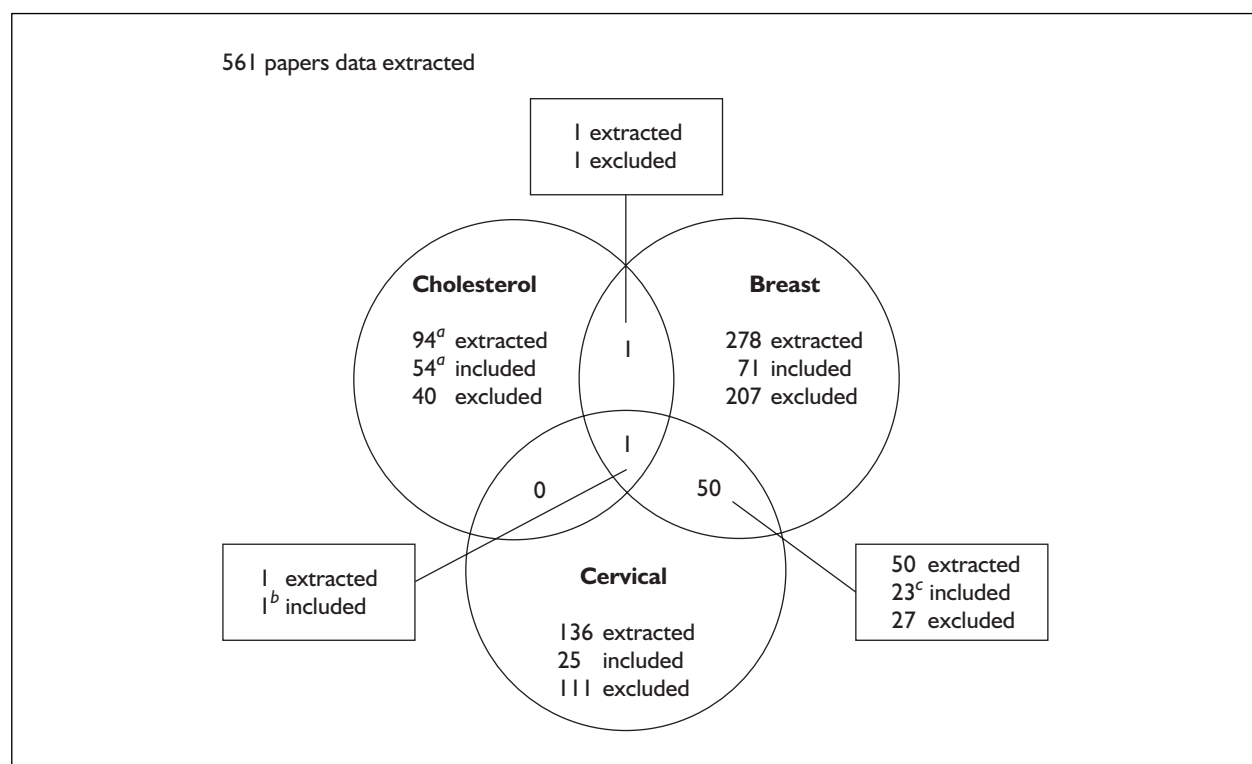


FIGURE 1 Distribution of papers by screening category. ^a One paper is presented as two studies in the results tables; therefore, the number of included studies in the table is 56 (55 + 1). ^b This paper is included in all three screening sections. ^c These papers were included in both the breast screening and cervical screening sections.

this procedure was changed owing to the large number of papers involved in the review, and one reviewer extracted data onto a copy of the final tables. This was then checked by a second reviewer. As before, any disagreements were resolved by discussion with a third reviewer.

Stage 5

Information was recorded relating to the methodological quality of the studies. Validity checklists as described in CRD Report Number 4⁴⁴ were modified for this review and are included in the data extraction form in Appendix 2. A score was given by rating each criterion under 'adequate' (3 points), 'partial' (2 points) or 'inadequate or not stated' (1 point). Any criteria that were not applicable were excluded from the total. The points were added up and a percentage score was calculated. Any paper scoring under 50% was excluded.

Stage 6

A non-quantitative synthesis was conducted of all papers that were extracted. At this point the reviewers categorised the outcomes into those that can be considered beneficial or detrimental to health. These are shown as (+) where the outcome has been judged to be a favourable outcome in health behaviour or belief terms and (-) where it could potentially be harmful. The symbol (ns), not significant, is used where the relationship has been explored, but no statistically significant relationship has been observed.

The categorisation as to whether a beneficial or detrimental effect was observed was based on a value judgement which considered both statistical and clinical significance. Therefore, where a large effect was observed that almost reached statistical significance (and it was shown that the study was underpowered) this is coded as either a beneficial or detrimental effect, rather than a non-significant association.

For descriptive data where an effect was judged to be important this was also coded as being either detrimental (-) or beneficial (+).

It could be argued that some outcomes that have been categorised as beneficial may not actually be so. For example, an increase in the use of GP services has been categorised as a beneficial outcome. This may be the case in cholesterol screening where the participant has consulted to obtain more advice about lifestyle modifications. However, an increase in GP usage after breast or cervical screening may be indicative of unnecessary visits owing to increased concern about their personal risk of developing cancer. This is discussed further in Chapter 7.

The results of the non-quantitative synthesis are presented in each screening section and a summary of the individual study results is presented in the appendices.

Chapter 3

Search results

Searching of the five main databases resulted in retrieval of 12,939 papers that were not immediately identified by Reference Manager as duplicates (during the download process). The breakdown of papers by databases is shown in *Table 3*.

After the titles had been scanned independently by two reviewers a total of 1172 papers remained for possible inclusion. Where available, the abstracts of these papers were read, again by two reviewers, and were coded according to the schedule outlined in *Table 2* (see Chapter 2). When abstracts were not available the papers were obtained and data extraction was conducted.

Using the codes described in Stage 2 of the review, a total of 561 of 1172 papers was selected and fully data extracted (4% of the total papers retrieved, 561/12,939).

These 561 papers were distributed among the three screening programmes as shown in *Figure 1*. The numbers of papers included in the review and the numbers excluded are also shown (see Chapter 2).

Cholesterol screening

After title selection, 95 papers relating to the impact of cholesterol screening on health beliefs and health behaviours were obtained. Of the 95 papers retrieved, 55 were included and 40 were excluded. One of the included papers is presented as two studies in the results table, giving a total of 56 studies.

The 40 papers were excluded because of inappropriate temporal relationship between screening and outcomes ('outcomes' measured before screening took place) ($N = 4$), no relevant outcomes (8), no relevant exposures (6), not relevant at all (1), no data given (2), other secondary reports (1), reviews (3), foreign language (1), poor quality (2), duplicates (3) and not available (9).

Breast screening

After the initial round of exclusions (title and abstract scanning), 330 papers remained that investigated the effects of breast screening (including 50 that are classed as breast and cervix, one that covered breast and cholesterol screening, and one that covered all three screening types). Of these papers, 95 were included in the review (71 from breast alone, 23 from breast and cervix, and the paper that included breast, cervical and cholesterol screening) and 235 were excluded.

The reasons for exclusion were: incorrect temporal relationship between screening and outcomes ($N = 52$), no relevant outcomes (44), no relevant exposures (43), not relevant at all (15), reviews (12), other secondary reports, including editorials, summaries and theses that were published as papers (15), contained no data (including letters) (9), foreign languages (8), theses that were not obtained (3), duplicate publications (15), not available (13), poor quality (5) and one paper that should have been excluded earlier as focusing on determinants of uptake.

TABLE 3 Papers retrieved from the main databases

Databases	Years searched	Total 'unique' retrieved	Papers entering Stage 2 of the review
MEDLINE	1980–2000	8071	757
EMBASE	1980–Jan 2001	2504	136
PsychInfo	1977–Nov 2000	608	140
CINAHL	1982–Nov 2000	1716	133
HealthStar	(searched 5 Mar 2001)	40	6
SCI and SSCI		1299 (not unique)	
		14,238 (12,939 not including SCI)	1172

Cervical screening

After the initial round of exclusions (title and abstract scanning), 187 papers remained investigating the effects of cervical screening (including 50 that are classed as breast and cervix and one that covered all three screening areas). Of these papers, 49 were included in the review (25 from cervix alone, 23 from breast and cervix, and one paper that included breast, cervical and cholesterol screening) and 138 were excluded.

The reasons for exclusion were: incorrect temporal relationship between screening and outcomes ($N = 20$), no relevant outcomes (22), no relevant exposures (11), not relevant at all (23), reviews

(11), other secondary reports, including editorials, summaries and theses that were published as papers (4), contained no data (including letters) (11), foreign languages (3), duplicate publications (2), poor quality (8), not obtained (17) and six papers that should have been excluded earlier as uptake only papers.

Health belief models

The literature identified often did not specifically state which theoretical models underpinned the studies. The most commonly used models were the HBM and the HLC model. However, these were often used to predict uptake of screening, not reactions to screening.

Chapter 4

Cholesterol screening

Introduction

All of the studies identified in this review classify cholesterol screening as a blood test with basic education on lifestyle changes for those who receive a raised blood cholesterol result. The education and counselling involved in the cholesterol screening programme are crucial because the onus is on the individual to make lifestyle changes to reduce their risk status.

Cholesterol screening is usually offered on an opportunistic or open-access basis. Studies reported screening in shopping centres, local pharmacies, worksites, colleges and the healthcare setting (e.g. general practice or hospital). Some studies were undertaken in people who had already been identified as being at high risk of CVD.

The following results report on studies that observe the subsequent behaviour of participants who receive a high or moderately high cholesterol result following blood cholesterol screening. No studies report solely on those who received a desirable result or on those who chose not to attend for cholesterol screening.

Description of included studies

A total of 55 papers reported the effects of cholesterol screening on health behaviour and health beliefs. Fifty-six studies are reported, as one paper reported two studies. The methods of this review and inclusion and exclusion criteria are detailed in Chapter 2. Overall results of the searches are presented in Chapter 3. The summary result tables are presented in Appendix 3 (description of studies) and Appendix 4 (summary of results).

The majority of studies were published after 1990, with 36 studies published between 1990 and 1994, and ten studies between 1995 and 2000. A further ten studies were published between 1985 and 1989. The timing of the majority of studies follows the introduction of the NCEP in the USA in 1985.

The review consists of studies carried out in eight different countries, with 35 studies conducted in the USA, seven from Canada, four from the UK,

four from Sweden, three in Australia, and one study from each of Germany, Norway and South Africa. In 23 of the studies, cholesterol screening was conducted in an open-access environment such as in a supermarket, at a health fair or at a pharmacy. Studies reporting on open-access cholesterol screening were from the USA, Canada or Australia. Fourteen studies were conducted in a workplace environment, two involved both open-access and workplace participants, 12 were conducted in a healthcare setting, two were conducted on college students, one surveyed a specific community and two did not report the cholesterol screening setting.

The majority of studies aimed to observe changes in health behaviours and health beliefs over time following screening. For this reason, 43 of the 55 studies used a cohort design. The results are therefore subject to a number of biases inherent in observational studies. This is discussed further in the discussion of the whole review (Chapter 7). A further eight studies used a randomised controlled trial (RCT) design and one study used a non-randomised intervention design. One study used a cross-sectional design and three used a qualitative design. Thirty-six studies had a follow-up rate of over 70%, 17 had a follow-up rate of below 70% and in three studies the follow-up rate is unclear. Thirty-six studies had a follow-up period of less than 1 year, 11 studies had a follow-up period of 1 year and six studies had a follow-up period of greater than 1 year. The remaining studies did not report a follow-up period.

The results reported may have been attributed to the self-selected nature of the screened population, who may be more motivated to change behaviour. In addition, the results may have been attributed to the heightened publicity of the risks of high blood cholesterol at the time the studies were conducted. Findings also need to be interpreted in light of the methodological limitations regarding the reliability of the tools used to measure health behaviours and health beliefs, uncertainty of self-reports, recall bias, regression to the mean and study attrition.

Few studies investigated the impact of cholesterol screening on those who received desirable blood

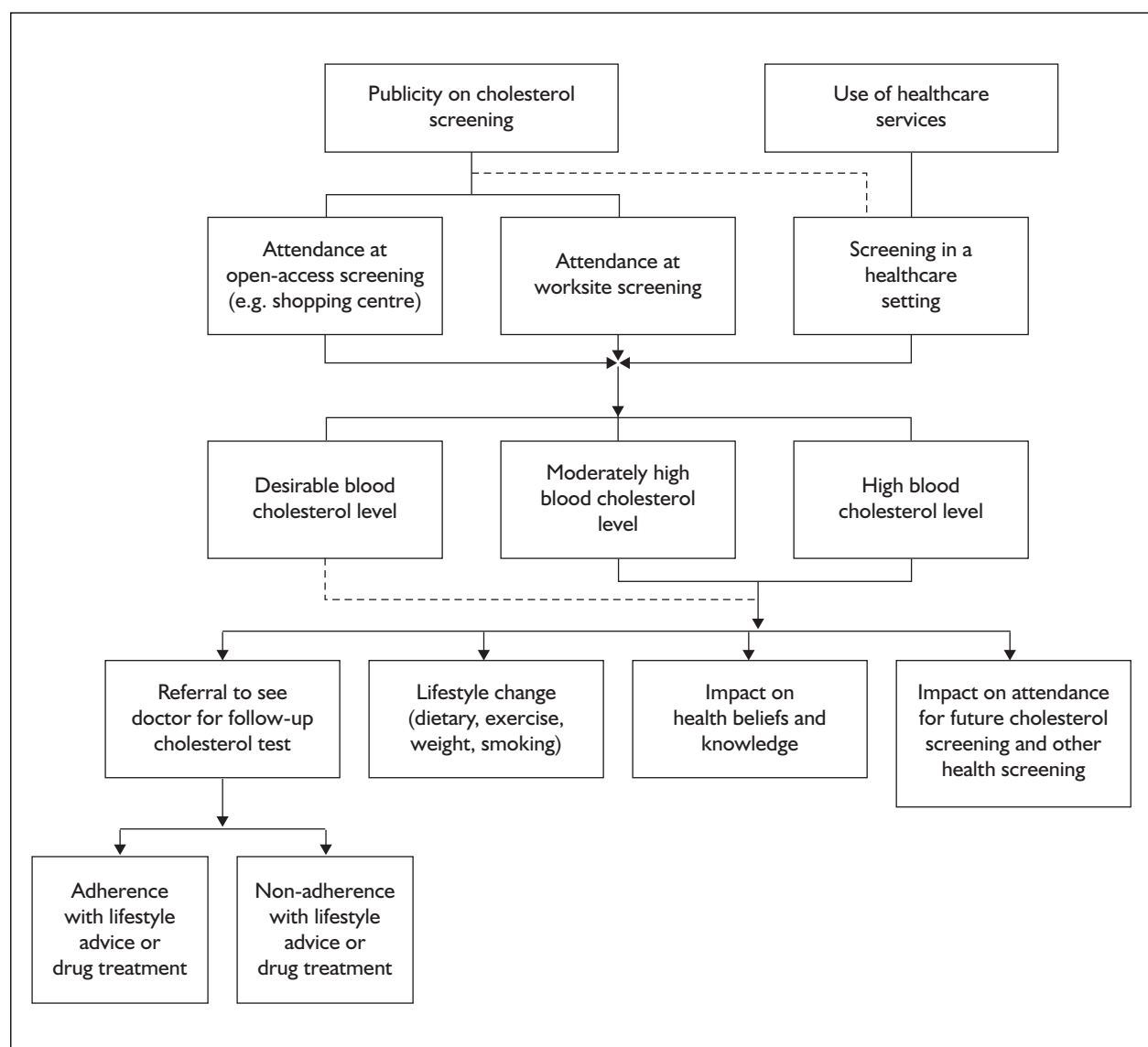


FIGURE 2 Cholesterol screening process

cholesterol results, such as the ‘certificate of health’ effect, and few studies investigated the long-term changes in health behaviours and health beliefs. Furthermore, the literature lacked appropriate qualitative studies that could assess the subtle impact on health beliefs, and lacked comparisons across cultural and socio-demographic groups.

The limitations of the literature and the gaps in the literature are discussed further in the discussion on cholesterol screening.

Figure 2 demonstrates the cholesterol screening process identified in the studies reported in this review. Table 4 reports the summary of outcomes for cholesterol screening.

Results

Changes in health behaviours following cholesterol screening

Dietary change

Dietary change was assessed in 30 studies.^{45–74}

Most of the tools used to measure dietary change were survey specific, reporting change by frequency of specific foods consumed,^{46,47,49,50,59,60,62,65,67,68,70–72} assessing mild, moderate or major improvements,^{51,69} or simply reporting improved diet with lower fat intake versus not improved diet.^{52–57,63,66} The validity and reliability of these measures were not discussed. Previously validated measures were used in eight studies, including the Block Fat Screener,⁴⁵

TABLE 4 Summary of outcomes associated with cholesterol screening in comparative papers

Outcome	Beneficial/detrimental to health ^a	Symbol in result tables	No. of studies	Comments
Health behaviours				
Dietary change	Beneficial (improvement in diet/adoption of low-fat diet)	(+)	28/30	
	Detrimental (no improvement in diet or adoption of low-fat diet)	(-)	2/30	
Exercise change	Beneficial (increased level of exercise: more often or for longer duration)	(+)	11/15	
	Detrimental (no change in level of exercise or exercise less)	(-)	4/15	
Weight change	Beneficial (weight reduction)	(+)	8/11	
	Detrimental (no change in weight or weight gain)	(-)	3/11	
Adherence with referral to see a doctor	Beneficial (good uptake to recommendation to see doctor after receiving a high cholesterol result, i.e. > 60% of high cholesterol participants)	(+)	8/24	
	Detrimental (poor uptake of recommendation to see doctor after receiving a high or moderately high cholesterol level, i.e. < 60% of high cholesterol participants)	(-)	16/24	
Adherence with drug treatment	Beneficial (good adherence to drug treatment)	(+)	3/5	
	Detrimental (poor adherence to drug treatment)	(-)	2/5	
Smoking cessation	Beneficial (stopped smoking or smoke less)	(+)	5/9	
	Detrimental (no change in smoking or smoke more)	(-)	4/9	
Impact of cholesterol screening on other preventive screening	Beneficial (increased use of other preventive screening)	(+)	3/3	
	Detrimental (no effect or decreased use of other preventive screening)	(-)	0/3	
Blood cholesterol change	Beneficial (blood cholesterol reduction)	(+)	19/21	
	Detrimental (no change in blood cholesterol or increase in blood cholesterol)	(-)	2/21	
Beliefs				
Labelling individuals with high cholesterol status	Beneficial (no adverse effects of labelling, i.e. no increase in sick days at work, no change in well-being, good intention to change lifestyle)	(+)	6/7	
	Detrimental (adverse effects of labelling, i.e. increase in sick days at work, adverse effects on well-being, little or no intention to change lifestyle)	(-)	1/7	
				<i>continued</i>

TABLE 4 Summary of outcomes associated with cholesterol screening in comparative papers (cont'd)

Outcome	Beneficial/detrimental to health ^a	Symbol in result tables	No. of studies	Comments
Acceptance of risk	Beneficial (coped well with new risk status, actively took steps to change lifestyle)	(+)	1/7	
	Detrimental (poor coping with new risk status, denial of risk status, threat minimisation, little or no active role in changing lifestyle)	(-)	6/7	
Recall of personal cholesterol risk	Beneficial (accurate knowledge of personal cholesterol risk)	(+)	6/9	
	Detrimental (poor knowledge of personal cholesterol risk)	(-)	3/9	
General knowledge of cholesterol issues	Beneficial (good general knowledge of cholesterol issues)	(+)	4/5	
	Detrimental (poor general knowledge of cholesterol issues)	(-)	1/5	
A positive relationship is a combination of statistical and/or clinical significance.				
^a Beneficial and detrimental defined for the purposes of this review.				

the Food Habits questionnaire,^{48,74} Rate Your Plate,^{58,73} the Burnette 21 Dietary Item questionnaire⁶¹ and the Sackett 10 Dietary Change questionnaire.⁶⁴

Twenty-eight of the 30 studies reported positive changes in diet following cholesterol screening, whereas two reported no change.^{48,56} A dose–response relationship between higher cholesterol levels and magnitude of dietary changes was looked for in seven of the studies.^{45,57,60–62,66,68} Of these, six reported that the higher the cholesterol levels, the greater the dietary changes that were made, and one reported no effect.⁶¹

Four RCTs assessed dietary change. Two RCTs assessed whether ‘knowing your high cholesterol result’ had a greater impact on dietary changes.^{45,73} One reported a greater impact on dietary change for those who knew their high cholesterol result,⁴⁵ while the other found no effect for those in the intervention group.⁷³ The latter study reported that both those in the intervention group and those in the non-intervention group reported dietary improvement.⁷³ The difference in results observed between these two studies may have been due to the different study settings. The former study was conducted in a healthcare setting, whereas the latter was conducted in a workplace setting. One RCT assessed the difference between participant-orientated goals and doctor reminder for dietary change,⁵⁸ while another assessed the difference between enhanced information and routine information giving following cholesterol screening.⁵⁷ In both of these studies the intervention had no effect, although positive dietary changes were observed in all groups. It is therefore possible that the dietary change in these studies was due to the effect of screening.

In five cohort studies^{46,59,69,71,74} and one non-randomised intervention study⁴⁸ an intervention (enhanced education either at screening or subsequently from the doctor) was used to improve dietary change. One of these cohort studies showed significant improvement over time in the intervention group compared with the control group, which showed no change,⁴⁶ and two studies showed significant improvement over time between baseline and follow-up.^{69,71}

Two cohort studies found that those who had previously been screened were more likely to adopt a low-fat diet than newly diagnosed people.^{50,65} Contrary to this, another study reported that participants who had been

previously screened with a high cholesterol result found it more difficult to make dietary changes than those who were newly detected with a high cholesterol level.⁶⁵ One study found that women were more likely than men to make dietary changes.⁵⁴

Exercise change

The impact of cholesterol screening on level of exercise was reported in 15 studies.^{46,47,50,51,53,57,59,60,63,66,68–70,74,75} Eight of the studies reported exercise improvement simply by asking the participants whether they had increased their level of exercise or not^{63,66,69,70,74,75} or reported changes in those who exercising regularly.^{50,57} Four studies reported exercise improvement over time using frequency of exercise per week,^{46,47,59,60} two studies assessed exercise using a Likert scale of minor, moderate and major improvements,^{51,68} and one study used descriptive methods.⁵³

An increase in exercise for those with high cholesterol levels was reported in 11 of the studies, three reported no change in exercise after screening,^{47,50,69} and a case study reported a negative outcome where the patient stopped exercising because he was worried it might lead to a heart attack.⁵³

A dose–response relationship between higher cholesterol levels and magnitude of exercise changes was reported in two of the studies.^{66,68}

An RCT assessed the difference on exercise levels between enhanced and routine information. The intervention was found to have no effect.⁵⁷ An intervention (enhanced education) was also used to try and increase the adoption of exercise in two cohort studies,^{59,74} but although exercise adoption increased overall in these studies, the enhanced education intervention was no more effective than routine care. One study compared prior screenees with new screenees, and found no difference in exercise adoption.⁵⁰

Weight change

Following cholesterol screening, weight change was investigated in 11 studies.^{46,47,54,57,59,63,69,70,74,76,77} Weight reduction was reported in eight of the studies, and three reported no change in weight.^{47,69,77} An intervention (enhanced education) was used in an RCT⁵⁷ and one in a cohort study⁷⁴ to try to improve weight reduction. Both studies found that although weight reduction was reported overall, this was not as a result of the intervention.

Adherence with referral to see a doctor

Twenty-four studies reported on adherence with referral to see a doctor for retesting of cholesterol levels following opportunistic screening.^{47,49,51,52,54,57,60,61,63–66,70,72,75,78–86}

An adherence rate of 30–60% was reported in 16 of the studies, seven reported an adherence rate of over 60%^{65,70,72,80–82,86} and one study reported over 60% compliance in the high blood cholesterol group, but under 60% compliance in the moderately high blood cholesterol group.⁶⁴

A positive dose–response relationship between higher cholesterol levels and greater adherence to referral was observed in five of the studies.^{52,60,66,78,79} One study observed a negative dose–response relationship between higher cholesterol levels and greater adherence, but this was probably due to the high cholesterol groups having to attend more follow-ups than the desirable cholesterol group (four versus one).⁸⁵

Two RCTs reported the effects of an intervention (reminder letter) to increase adherence to see a doctor regarding a high cholesterol result.^{57,84} One found this intervention to be successful,⁸⁴ whereas the other found the intervention to be ineffective at increasing adherence.⁵⁷

One study reported that those who had previously received a high cholesterol result were more likely to adhere to referral than new screenees.⁶⁵ Knowledge of prior cholesterol level was associated with a significantly greater adherence with referral to see a doctor.⁷⁹ Prior knowledge of cholesterol levels and actual cholesterol levels were independently associated with compliance to follow-up.⁶⁶ Increasing age⁶³ and being female^{52,82} were both shown to increase adherence to referral.

Adherence with drug treatment

Five studies reported adherence to drug treatments.^{51,53,56,83,86} Of these, two reported poor adherence to drug treatment.^{53,56} One found a dose response relationship where those taking drug treatment reported a greater reduction in cholesterol levels over the study period,⁸⁶ one reported that adherence to drug treatment increased over the study period,⁵¹ and one reported that a high proportion of those who took drug treatment for high cholesterol levels remained compliant for at least 6 months.⁸³

Smoking cessation

Smoking cessation or reduction in number of cigarettes smoked per day was assessed in nine

studies.^{47,50,57,59,63,66,69,70,74} Four of the studies measured change in smoking behaviour by reporting whether or not the participants had stopped smoking at follow-up,^{50,57,63,69} four studies reported the level of reduction in the number of cigarettes smoked by follow-up^{47,66,70,74} and one study reported smoking behaviour by frequency of cigarettes smoked per day.⁵⁹ An intervention (enhanced education) was used to encourage smoking cessation in two cohort studies^{69,74} and one RCT.⁵⁷

A reduction in or cessation of smoking was reported in five of the nine studies.^{57,59,63,70,74} Where an intervention was used to encourage smoking cessation no additional benefit was observed.^{47,50,57,59,63,66,69,70,74} One study reported an improvement in smoking cessation in both the control group and the intervention group.⁷⁴ One study observed previously screened participants to assess whether they would be more likely to reduce their smoking level than new screenees.⁵⁰ No difference was observed between the two groups.

Association with attendance for further screening

Three studies reported an association between cholesterol screening and further health screening. Stockbridge and colleagues reported that previous cholesterol screening was the motivation to attend for cholesterol screening again by just over half of all participants.⁷⁰ Wynder and colleagues reported that 11% of the participants went for cholesterol screening because of a previous high blood cholesterol result.⁸⁶

One cross-sectional study investigated the association between cholesterol screening and use of breast screening.⁸⁷ Previous cholesterol screening had a positive association with attendance for breast screening.

Blood cholesterol change

Blood cholesterol change following cholesterol screening was investigated in 21 studies.^{45–48,59,61,64,69,73,76,77,80,81,86,88–94} Nineteen of these studies reported a cholesterol reduction. Two of the studies reported no change in cholesterol level following screening.^{48,61} A dose–response relationship between higher cholesterol levels and greater reduction in cholesterol levels over time was observed in three studies.^{47,80,92}

Three RCTs reported blood cholesterol change. Two RCTs reported that ‘knowing your high cholesterol result’ resulted in greater cholesterol reduction.^{45,89} The blood cholesterol reductions

reported in these two studies were similar. One RCT reported that those who expected to be followed up after a health check had a greater reduction in blood cholesterol level than those who were not expecting to be followed up.⁹³ One non-randomised intervention study⁴⁸ and three cohort studies^{64,69,90} also used an intervention (enhanced education) to encourage cholesterol reduction. Cholesterol reduction was observed as a result of the intervention in three of these studies.^{64,69,90}

Some reduction in cholesterol levels would be expected because of regression to the mean (see discussion on cholesterol screening).

Changes in health beliefs following cholesterol screening

Effect of labelling on absenteeism from work, change in well-being and intention to change lifestyle behaviours

Seven studies reported on the impact of labelling people with high or borderline-high cholesterol levels on health beliefs as well as behaviours.^{45,53,67,78,89,95,96}

Only one qualitative case series reported a negative effect of labelling.⁵³ This study reported that labelling of individuals who were diagnosed with hypercholesterolaemia led to feelings of illness, anxiety and confusion.

The other six studies were quantitative studies and reported no effect of labelling. Two studies reported that having a high cholesterol result did not increase absenteeism from work.^{67,78} Rastam and colleagues reported an overall increase in sick days, but concluded this was due to the ageing population.⁶⁷ Fischer and colleagues reported that although participants reported distress immediately after screening, this did not affect absenteeism from work or perception of their health and well-being.⁷⁸

Havas and colleagues used the General Health Perceptions Questionnaire⁹⁷ to assess the impact of a high blood cholesterol result on general well-being.⁹⁶ It was concluded that labelling participants with high cholesterol levels did not result in negative beliefs about well-being, although the authors suggest that this may have been due to the positive way in which the participants were counselled after the screening test.

Elton and co-workers conducted an RCT and reported that those who are more informed about

their cholesterol risk made a greater effort to change their lifestyle in order to reduce their cholesterol levels.⁸⁹ Two further RCTs found that participants who knew that they had a high cholesterol result increased their intention to alter their lifestyles and to gain more information about the condition.^{45,95} However, this latter study was carried out on university students, and therefore is not generalisable to the general population at risk from a high level of cholesterol.

Acceptance of risk status

Seven studies (published in six papers) reported the impact of cholesterol screening on acceptance of risk after cholesterol screening.^{61,83,88,95,98,99}

Negative consequences caused by receipt of a high-risk result were reported in six of the seven studies. Two qualitative studies reported that people at high risk found it difficult to make sacrifices to reduce their cholesterol levels.^{88,99}

These studies reported that people resisted lifestyle changes as they felt it would impact on their quality of life. Clarke and colleagues reported that fatalism prevented people from taking an active role in changing their health behaviours to reduce their cholesterol levels.⁸⁸

One study, using the General Well-Being Schedule,¹⁰⁰ concluded that there were no adverse effects of accepting a risk status on general well-being.⁶¹

Four studies reported that people coped with their risk status by denial or threat minimisation.^{83,95,98,99}

Irvine and Logan⁹⁸ assessed life satisfaction of deniers and non-deniers using the Rand Corporation Mental Health Index,⁹⁷ Spielberger State-Trait Personality Inventory¹⁰¹ and Campbell's Life Satisfaction Index.¹⁰² They concluded that denial was a significant barrier to health behaviour change.⁹⁸ People did not perceive themselves as ill, which made it difficult for them to understand and accept their diagnosis and undertake lifestyle changes.⁹⁹ Croyle and colleagues,⁹⁵ using an RCT design, assessed threat minimisation of borderline-high blood cholesterol participants using Miller's Monitoring and Blunting questionnaire¹⁰³ and self-esteem using the Rosenberg's Self-Esteem questionnaire.¹⁰⁴ The study concluded that while people in this group were more willing to make lifestyle changes compared with the desirable cholesterol group, they were more likely to deny the seriousness of the raised cholesterol levels and to have lower self-esteem.

One study reported that those who had previously received a high cholesterol result and received a

second high cholesterol result were less likely to report threat minimisation.⁹⁵

Knowledge

Recall of cholesterol level

Recall of cholesterol levels after screening was reported in nine studies. Accurate recall of cholesterol levels was reported in six of these studies,^{49,60,68,71,75,78} whereas three reported poor recall.^{47,56,105}

Two of the above studies reported on whether socio-demographics had an impact on personal cholesterol knowledge levels, and found that older people, women and those with higher education were more likely to have a greater knowledge of cholesterol issues.^{56,105}

General cholesterol knowledge

Accurate recall of knowledge about cholesterol issues (e.g. national recommendations on healthy levels and association with other diseases such as CVD) at follow-up was reported in five studies,^{60,70–72,78} and one study reported poor recall of general information about cholesterol.⁶⁸

Summary

- Evidence suggests that cholesterol screening may have a positive impact on health behaviours. A majority of studies reported an adoption of healthier diets, increase in exercise, reduction in weight and reduction in cholesterol levels for those diagnosed with high or moderately high cholesterol levels. There was inconsistent evidence to suggest that screening had a positive impact on smoking cessation.

However, most of the studies were observational studies with inherent biases, and it is difficult to assess the extent to which changes in health behaviours were attributable to other influences such as heightened publicity about the risk of high cholesterol and the self-selected nature of the screened population. Furthermore, methodological limitations should be noted.

- Evidence suggests that follow-up among those identified as possibly having high blood cholesterol is often inadequate, although higher risk levels predict better referral adherence.
- Evidence from quantitative studies suggests that the impact of labelling the screened population with an at-risk status had little effect on absenteeism from work or negative perceptions of health. One qualitative study suggests that

some individuals did experience consequences of their new 'sick' label.

Furthermore, a small number of qualitative studies suggests that some participants experience psychological problems as a consequence of their newly identified at-risk status.

- Evidence suggests that participants of cholesterol screening have a good general knowledge of cholesterol issues, but there is inconsistent evidence for recall of personal cholesterol levels.
- Evidence suggests that previous cholesterol screening had a positive impact on health behaviours such as future cholesterol and breast screening, dietary change, smoking cessation and adherence to recommended follow-up. Those who had previously attended cholesterol screening also accepted their risk status better than newly screened participants.
- Evidence from RCTs suggests that randomising participants into knowing their high cholesterol status and not knowing their high cholesterol status resulted in an improvement in health behaviours, but had negative effects on health beliefs for those who were aware of their high-risk status.

There is inconsistent evidence from RCTs for the effectiveness of interventions (e.g. enhanced lifestyle education or reminder letters to increase referral rates) to improve health behaviours.

Discussion: cholesterol screening

Study design issues

Design type

A majority of the studies followed a cohort design, and the roles of chance, bias and confounding influence should therefore be considered (see Chapter 7).

A striking aspect in the literature reported is the contrast in findings between the small number of studies using a qualitative methodology and the larger number using a quantitative methodology. A negative impact on health beliefs and well-being was evident only in the qualitative studies. The quantitative studies did not report such effects, possibly because they were unable to detect such subtle outcomes. Although positive behavioural

changes are reported in the qualitative studies, significant negative consequences on health beliefs are also reported. More qualitative studies are needed to understand this issue.

Study groups

All the studies in the review focused on people who had been identified as having moderately high or high cholesterol levels. None aimed solely to examine the 'certificate of health effect' on people who were screened and found to have desirable cholesterol levels. The findings of this review therefore cannot comment on, or rule out, an adverse impact on the subsequent health beliefs or behaviours of those who were screened as normal.

Self-selection bias

There is concern that the voluntary screening programmes described in many of these studies may attract a more health-conscious population than the general population, who are more motivated to make lifestyle changes to improve their health.^{51,72,86} The inverse care law suggests that those who benefit most from voluntary cholesterol screening are the ones least likely to participate in such a public screening programme. These people may be less motivated to improve their health.

Opportunistic screening may also be used to monitor cholesterol levels over time.⁵¹ Those who are at high risk are more likely to be found in the healthcare setting.^{51,72,86}

Recall bias

Recall bias is a problem for the studies in this review, owing to the self-reported nature of behaviours and beliefs. Participants are more likely to report the behavioural change if they know that this is the relationship being investigated. Added to this is the problem of seasonal lifestyle changes that may have affected the study results.

Many of the studies in the USA may have had difficulties having matched controlled groups because of the great awareness and publicity of the cholesterol problem. This would particularly have influenced studies assessing the effectiveness of interventions to improve lifestyle behaviours.

Generalisability

As reported earlier, the majority of these studies were conducted in the USA, and cultural differences will affect the generalisability of the results in Britain. Caution should also be applied to the generalisability of studies with small sample

sizes, studies specific to certain small cultures and selection bias.

Impact of cholesterol screening on health behaviours

Diet, exercise, weight and smoking changes

The results reported for health behaviours are generally positive, with the majority of studies reporting change in a healthy direction for the outcomes diet, exercise and weight. There was inconsistent evidence for changes in smoking behaviour.

However, with methodological weaknesses, particularly in the measures used to assess changes, and the limitations of selection bias and attrition, interpretation should be treated with caution.

The simplicity and the lack of reliability and validity of tools used to measure behavioural changes should be noted. However, behavioural changes did reflect changes in cholesterol levels, so it is possible that the measures used are acceptable.⁵⁹ Accuracy may be improved by logging changes over time.⁵¹ However, with large samples and limited resources in many of these studies, it may not be feasible to record changes over time.⁴⁵

Many of the tools used to measure lifestyle change were based on self-report. These self-reports may have been exaggerated to reflect the heightened publicity and pressure to conform to changes in lifestyle to lower CVD risk.⁵¹ Changes in behaviour may also have been done just before follow-up appointment for study purposes only, and therefore participants may not have adopted long-term changes. The timing of the studies could have affected the behavioural changes too, owing to seasonal changes in lifestyle behaviours. Studies have proven that cholesterol levels may rise in the colder months.⁸⁹

It could be argued that those who volunteer for opportunistic cholesterol screening are more health conscious, and are therefore more motivated to make health-related changes.

Those with higher cholesterol levels may have been more likely to change their health behaviours owing to unhealthier lifestyles at baseline, and more likely to exaggerate the changes made because they knew the importance of change.⁵⁸ However, Klepp and colleagues found that those with the highest cholesterol levels were strongly motivated to change diet to a greater extent than

those with lower cholesterol levels because of the perceived seriousness of their condition.⁶²

Klepp also stated that confidence in a person's ability to change, and seeing the risk reduction were important in behavioural change.⁶² However, few studies in this review took an in-depth look at the motivation for and process of behavioural change.

Adherence with follow-up to see a doctor

The majority of studies that assessed adherence with follow-up to see a doctor showed a low adherence rate ($\leq 60\%$). This may have been due to the lack of perceived seriousness of the condition diagnosed in a non-medical environment. For some participants the initial test in a non-medical environment may have lessened the perceived seriousness of the test and therefore not motivated participants to seek the necessary retesting in a medical environment. Participants may have perceived themselves healthy with no obvious symptoms of cardiovascular disease, and therefore not understood the importance of having their high blood cholesterol result rechecked. Furthermore, many of the cholesterol screening programmes offered free cholesterol checks at convenient places, whereas follow-up with the doctor involved making an appointment, travelling to the clinic and often incurring medical fees.^{58,82}

Concern has been expressed that the community screening programmes may counteract the medical advice by arming subjects with strategies for attempting to reduce their cholesterol levels on their own, and therefore making them feel that visiting the doctor is unnecessary.⁸⁴

Other factors that may have contributed to poor adherence to follow-up are lack of time, procrastination and too short a length of follow-up.^{58,82} Ovved and colleagues argued that to achieve greater compliance to follow-up, reinvitation and tracking of patients who do not show up is necessary.⁸⁵ This would be hard to achieve in a community open-access cholesterol screening programme.

It could be argued that those who adhered to the recommendations for follow-up were more health conscious and more used to the culture of visiting health centres for health checks. The presence of other health problems (hypertension, diabetes) may have predicted greater follow-up to see the doctor as these individuals are already seeing their doctor regularly about other conditions and will

not incur extra time or cost by mentioning cholesterol levels.⁵⁸

Gordon and colleagues found that those who had high cholesterol levels were more likely to comply with follow-up to see their physician than those with borderline-high cholesterol levels. This could have been due to the greater perceived seriousness of the condition, but equally could have been due to the greater vigour with which the message to follow-up was delivered at screening for those with very high cholesterol levels.⁶⁰

Change in cholesterol levels

Changes in blood cholesterol levels were considered in the review as one potential measure of successful lifestyle change, and the evidence suggests that cholesterol reduction was achieved. However, although 19 studies showed a drop in cholesterol levels on follow-up after screening, only one study measured this in such a way as to rule out a regression to the mean effect (i.e. a greater reduction in cholesterol levels would be expected in participants with the highest cholesterol levels).⁸⁹ Regression to the mean is potentially a problem when interpreting the results owing to the large number of cohort rather than controlled designs. Regression to the mean may occur in both these study designs, but if the initial cholesterol levels are randomly distributed between intervention and control groups, then any differential effect is probably due to the intervention. It is therefore not possible to distinguish reduction in cholesterol levels attributable to regression to the mean from reduction attributable to screening.

All but one study that reported cholesterol change and behavioural change showed that cholesterol reduction was concomitant with behavioural improvements. This indicates that the decrease in cholesterol change is real and may be associated with improved lifestyle. However, because of the difficulty in measuring change in health behaviours, it would be difficult for any study to measure whether the magnitude of the cholesterol reduction was the same as the magnitude of behavioural change, and therefore does not completely rule out the effect of regression to the mean.

Cholesterol levels were measured using clinical assessment, which is a more accurate assessment than self-reported assessments used to measure other behaviours such as diet, exercise and smoking.

Effects of previous cholesterol screening on future screening and health behaviour

Those who went for cholesterol screening were more likely to return for future cholesterol screening and more likely to attend for other screening such as mammography. It could be argued that those who attend for opportunistic cholesterol screening are more health conscious and are therefore more motivated to attend for health screening.

Those who had a history of previous screening reported greater compliance to lifestyle changes. This may also have been due to these individuals having greater motivation and interest in their health⁵⁰ or may have been because they are more accustomed to their health status.

Impact of cholesterol screening on health beliefs

Effects of labelling screening participants with a 'sick' status and risk acceptance

The results with regard to health beliefs were less positive, with several studies reporting denial and harm minimisation and many also reporting that lack of engagement with the lifestyle change agenda was common. Only one qualitative study found a significant problem with labelling individuals with a 'sick' status, the other six quantitative studies found no effect of labelling. Caution should be noted regarding the self-reported measures used to assess health beliefs in such quantitative studies as they may under-report the negative beliefs and may not elicit subtle outcomes. Qualitative methods may provide a more in-depth description of the effects of labelling and acceptance of risk status.

Acceptance of an at-risk status was shown to cause stress in some people,⁵³ and coping mechanisms such as denial¹⁰⁶ and threat minimisation¹⁰⁷ were observed in some participants.^{83,95,98} The response to an at-risk status varied as these participants sought explanations for their new status and tried to identify the factors that might have caused it. Those who perceived that their personal circumstances or lifestyle were consistent with having a raised cholesterol level had fewer difficulties than those who defined themselves as being within the anomalous group (i.e. at risk according to the test but not appearing to have any of the risk factors).⁸⁸ Denial inhibits the appraisal of risk status and may prevent the adoption of appropriate behavioural actions.⁹⁸

Irvine and Logan argued that people who received a raised cholesterol level did not perceive the

seriousness of the disease because of the lack of symptoms and the opportunistic nature of screening.⁹⁸ Several studies report that good quality information and counselling can assist in overcoming the problem of acceptance of risk and denial.^{65,96} The SCORE (screening, counselling and referral) process in the USA aims to do this.¹⁰⁸

No research was identified on the negative effects of labelling participants with low cholesterol risk. Screening can falsely reassure people who receive a normal result and therefore no behavioural changes or detrimental behavioural changes are made.⁹¹ This is often referred to as the 'certificate of health' effect.

Knowledge about cholesterol screening

General knowledge about cholesterol issues was good, and in a majority of studies was associated with changes in behaviours. However, this may have been due to heightened publicity about cholesterol as a risk factor, and not as a direct result of cholesterol screening. There was inconsistent evidence regarding the level of recall of personal cholesterol risk levels. Poor recall of personal cholesterol levels could, again, reflect the lack of perceived seriousness of high cholesterol owing to the lack of symptoms and the non-medical environment in which screening is conducted.

Understanding the meaning of having a raised cholesterol level is crucial for behavioural changes to occur.⁹⁹ Feeling susceptible to the disease and knowing that the disease is severe facilitate patients to act.¹⁰⁹

Cultural and social differences

International differences

In this review a majority of the studies showed some improvements in health behaviours and health beliefs following cholesterol screening. However, the majority of these studies were conducted in the USA at a time when there was a great public interest in community cholesterol screening, and a culture of health check-ups. Few studies were conducted in Britain. There are certainly great differences to be noted between the USA and Britain. In Britain the health-check ritual is less well established and public interest does not appear to be high. It has been suggested that the impact of cholesterol screening is rather limited in the British population and adoption of lifestyle advice is poor.^{7,93,110} Such opportunistic screening at community centres may therefore not be so effective in changing the health behaviours

and health beliefs of the British population as it is in the USA and elsewhere. Cholesterol screening in Britain is currently mainly provided in a healthcare setting identifying and treating those at greatest risk.

The increased use of cholesterol screening in the USA may be reflected in the heightened publicity of the condition that could have equally influenced the changes in health behaviours and beliefs. Certainly, the literature has recognised that a single event such as cholesterol screening is unlikely to secure changes in ingrained lifestyle patterns.^{7,51,57,111}

Ethnic and social differences

Relatively few studies assessed the impact of cholesterol screening on cultural, gender, age and other socio-demographic groups. Cultural and social norms can affect the impact of screening on health beliefs and health behaviours. Brunt and Shields explain that the cultural norm for women to be 'Rubenesque' in the Hutterite culture makes weight loss particularly resistant to change. Studies indicated that women were more likely to make dietary changes,⁵⁴ more likely to adhere to referral to see a doctor,^{52,82} and had a greater general knowledge of cholesterol issues.⁵⁶

Brett reported that change in diet may not necessarily lower cholesterol. There may be a genetic determinant involved.⁵³

Study setting differences: community, workplace and healthcare settings

Although no studies directly compared across cholesterol settings, studies have suggested that workplace screening is more effective at encouraging lifestyle changes than community screening because there is more control over follow-up and more peer pressure to make changes to health behaviours.^{46,57,112} Studies report that workplace programmes allow continued individual and group monitoring, which are necessary components of any programme designed to elicit desirable changes to modify health behaviours and beliefs.⁴⁶ In a community open-access setting follow-up and continual support after cholesterol screening are harder to achieve.

Gemson and colleagues certainly found that those who were followed up more frequently showed greater reduction in cholesterol levels.⁵⁹ Strychar and co-workers concluded that if greater dietary changes were required, a more intensive follow-up programme may be appropriate.⁷³

Wang and colleagues argue that community open-access screening reaches risk groups who may not otherwise have used the healthcare system, but there is no evidence that these people will then comply to follow-up recommendations or make long-term lifestyle changes.⁷⁴ Strychar and colleagues commented that one of the major roles of community cholesterol screening was to raise awareness of the cholesterol problem, as it helps to facilitate changes in health behaviour and health beliefs.⁷²

The healthcare setting is the most controlled environment for cholesterol screening, but currently targets those who are at highest risk.

Summary

The questions this section of the review aimed to answer were:

1. What are the effects of opportunistic blood cholesterol screening on future health beliefs and behaviours?
2. What are the implications for the NHS, including their impact on the cost-effectiveness of screening programmes?
3. The review also aimed to identify gaps in the literature and make recommendations and describe a framework for further research on this topic, taking into account any important theoretical perspectives identified in the literature search.

1. The studies reviewed herein suggest that cholesterol screening had some positive effects on health behaviours. However, these positive findings need to be interpreted in the light of methodological issues. For example, participation was voluntary, and screened participants were possibly more motivated to make changes. These results are therefore not generalisable to the entire population. Caution should also be noted regarding the lack of reliability and validity of tools to measure changes in health behaviours, study attrition and uncertainty of self-reports. Furthermore, uncertainty of long-term changes, inaccurate risk assessment (additive rather than multiplicative), perception of cholesterol testing in non-medical environments, perception of seriousness of the risk status owing to lack of symptoms, readiness to accept advice, and convenience and cost of follow-up should all be considered.

Reduction in blood cholesterol levels was reported in all but two of the studies that assessed this outcome, suggesting that successful lifestyle

changes had been made. However, as most of the studies only reported follow-up of screened participants, some of the reduction will be attributable to regression to the mean.

Blood cholesterol screening had a less positive effect on health beliefs, with several qualitative studies reporting denial and threat minimisation leading to a lack of engagement in lifestyle changes. Quantitative studies concluded that the effect of labelling did not appear to have adverse effects on absenteeism from work or cause negative perceptions of health and well-being. However, one qualitative study did report negative effects of labelling. There are indications that

qualitative methods may be necessary to identify such effects.

2. When interpreting the results, there is little evidence about the effect of open-access cholesterol screening programmes on health behaviours and health beliefs in the UK. None of the papers provided cost-effectiveness data on cholesterol screening programmes. Research comparing the different cholesterol screening settings within the UK should be considered.

3. *Box 1* outlines the gaps in this review for the literature on cholesterol screening and makes recommendations for future research.

BOX 1 *Future directions in research*

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| <ul style="list-style-type: none"> • Assess the impact of cholesterol screening on people who have normal results. Is there a certificate of health effect? • A range of qualitative studies is required to assess the subtle impact of cholesterol screening on health beliefs, on the process of change and on the complexity of individual decisions to change behaviour. • Assess the long-term impact of screening on health behaviours and health beliefs. Most of the studies in this review only assessed short-term changes to health behaviours and health beliefs, and the conclusions cannot be extended to longer term changes. • Assess the elements of the multicomponent interventions, individually and in combination, which are most effective in motivating patients to make changes in their behaviour. | <ul style="list-style-type: none"> • Assess the differences between countries regarding the impact of cholesterol screening on health behaviours and health beliefs. • Assess the differences between cholesterol screening settings. Which cholesterol screening setting is the most effective at impacting on long-term changes in behaviours and beliefs in the UK? • Assess why people who attend for cholesterol screening do not make changes in health behaviours. • Assess the relative impact of cholesterol screening on various racial, ethnic and socio-demographic groups. Is there a need to develop and evaluate targeted recruitment strategies and more effective follow-up to overcome selection bias? |
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Chapter 5

Breast screening

Introduction

In this report, the term 'breast screening' refers to mammographic screening only. Studies concerning the effects of BSE or CBE (as an exposure) on subsequent health behaviours or beliefs are not included in this review. However, assessing whether or not a woman practises BSE following mammography is a legitimate health behaviour outcome and is therefore included as a review outcome.

The screening process has been considered to start with receipt of an invitation therefore, those who choose to not be screened still have an experience of screening, albeit significantly different from those who undergo the test and have therefore been included in this review, as shown in *Figure 3*.

Comparative studies have looked at the effects of screening as an exposure on attenders versus non-attenders, those who screen negative versus those who screen positive, and on those who adhere or do not adhere to recommended follow-up. Adherence to recommended further investigations can also be considered as a subsequent health behaviour and therefore has been included as an exposure and as an outcome where applicable. This is shown diagrammatically in *Figure 3*.

Papers focusing on anxiety, pain or discomfort were excluded unless the title or abstract indicated that they had subsequent effects on health-promoting behaviour or beliefs (e.g. effects on reattendance for screening). Interventions to improve uptake of screening were also excluded from this review.

Description of included papers

Ninety-five studies investigated the relationships between breast screening and subsequent health behaviours (including undergoing screening for other cancers) and health beliefs. Twenty-four of the papers also concerned the effects of cervical screening and these papers are marked with an asterisk (*) in Appendices 5 and 6 as the data will also contribute to the cervical screening chapter of this review.

Very few studies made any baseline measurements (measures of behaviours or beliefs before exposure

to breast screening) and therefore changes in behaviours or beliefs following screening were rarely reported. Only five papers presented some measures of reported change (measured at one time), changes in reported behaviour or beliefs (measured at two times), or observed changes. The direction of the relationship can be established with more certainty in these five studies. Papers that investigated reattendance or intention to attend or reattend also show a clear temporal relationship for these outcomes.

The review consists of studies conducted in 11 different countries. Of the 95 papers, 52 studies were carried out in the USA, 18 in the UK, six were from Australia, five from the Netherlands, four were conducted in Canada, three in New Zealand, two from Italy and Norway, and single studies from Finland, Northern Ireland and Spain.

In 54 of the 95 studies, breast screening was conducted in organised screening programmes, 17 papers reported data from population surveys, nine focused on health service users, four concerned worksite screening programmes, three studied women who had been invited to attend for breast screening, but it is not stated whether or not this was part of an organised programme, three studied other groups of women, two involved fee-for-service mammography, two reported data on women who were interested in breast screening (had requested information about a new breast screening programme) and one studied referring doctors.

All study designs were eligible to be included in the review. However, unlike the cholesterol screening studies, all the studies were observational, with no RCTs or qualitative research. Fifty-seven studies were cohort studies. Although these papers all presented data that were relevant to this review, the effect of screening on future health behaviours and beliefs was frequently not the main focus of the individual studies. It has not been stated in the review whether the cohort studies were prospective or retrospective, as frequently the data pertaining to the relationship between screening and other health behaviours or beliefs were not collected prospectively even if the study design for the

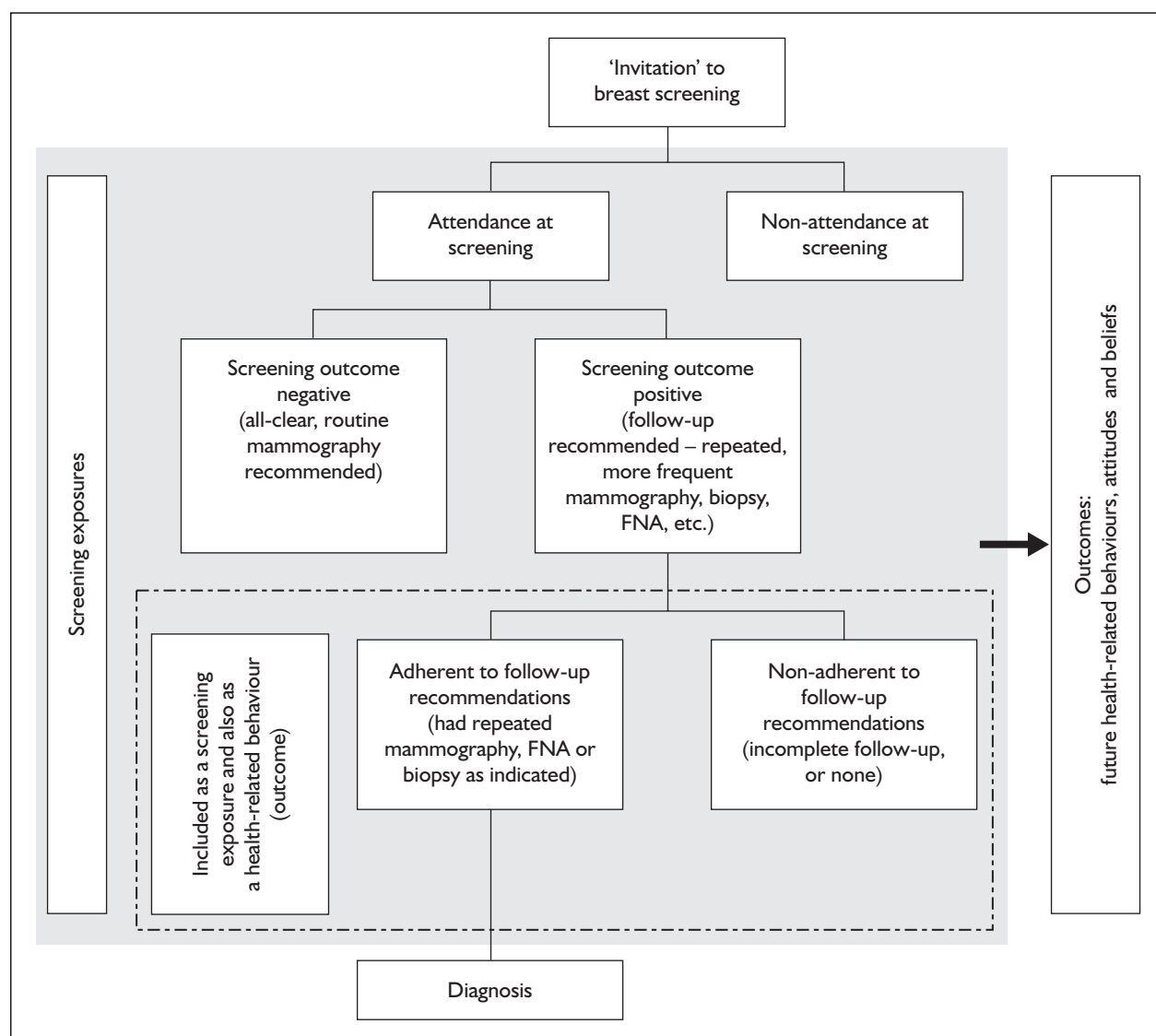


FIGURE 3 Breast screening process: exposures and outcomes. All groups in the shaded area are included in the review. FNA: fine-needle aspiration.

primary research question was prospective. Thirty-six papers reported results from cross-sectional studies and two used a case-control design.

Of the 95 breast screening papers, 15 did not include any comparison groups and were primarily descriptive in nature. Of the 80 comparative papers, only 24 looked at the possible effects of this screening programme on health-related behaviours other than screening visits. None looked at health beliefs that are not cancer related.

The majority of studies (83/95) were published after 1990, with only 12 studies being printed before 1990. This may reflect the increasing use of mammography in the late 1980s.

Results

Health behaviours reported in observational comparative reports

Intention to undergo mammography

Eighteen papers reported results on stated intention to be screened or rescreened, 11 compared breast screening attenders with non-attenders, one compared three groups of 'underusers' (recent adopters, previous users and never users), four compared women who received a false-positive result with those given a clear result and two papers investigated the effect of pain on intention to reattend.

Reported intentions were high in all studies, but nine of the 11 papers still showed a significantly

TABLE 5 Summary of health behaviours and beliefs associated with breast screening in comparative papers

Outcome	Beneficial/detrimental to health	Symbol in result tables	No. of studies ^a	Comments ^b
Health behaviours				
Intention to undergo future mammography	Beneficial (increased intention)	(+)	9/11	
	Detrimental	(-)	0/11	
Intention to undergo future mammography (comparison between false-positive/all clear)	Beneficial (increased intention)	(+)	2/4	
	Detrimental	(-)	0/4	
Attendance/reattendance at future mammography	Beneficial (increased attendance)	(+)	11/22	
	Detrimental	(-)	5/22	Decreased rate may be due to recent screen
Attendance/reattendance at future mammography (comparison between false-positive/all clear)	Beneficial (increased attendance)	(+)	1/6	
	Detrimental	(-)	2/6	Decreased rate may be due to recent follow-up
Adherence to follow-up recommendations after a positive screen (comparison between previously screened and not previously screened)	Beneficial	(+)	2/2	
	Detrimental	(-)	0/2	
Adherence to follow-up recommendations after a positive screen (early recall vs immediate follow-up)	Beneficial	(+)	0/3	
	Detrimental	(-)	1/3	Higher dropout with early recall
Attendance at cervical screening	Beneficial	(+)	10/12	
	Detrimental	(-)	0/12	
BSE	Beneficial (increase)	(+)	4/10	
	Detrimental (decrease)	(-)	0/10	Increased breast awareness is considered beneficial to health, whereas obsessive BSE is not (see discussion)
BSE (comparison between false-positive/all clear)	Beneficial (increase)	(+)	2/4	
	Detrimental (decrease)	(-)	0/4	Change in behaviour occurred after the screening result. This behaviour may not be beneficial to health (see discussion)

continued

TABLE 5 Summary of health behaviours and beliefs associated with breast screening in comparative papers (cont'd)

Outcome	Beneficial/detrimental to health	Symbol in result tables	No. of studies ^a	Comments ^b
Use of GP/health services	Beneficial (increased use)	(+)	1/2	The paper that showed no change had a clear temporal relationship
	Detrimental	(-)	0/2	
Other preventive health behaviours (dental check-ups, seatbelt use, diet, exercise, smoking, etc.)	Beneficial	(+)	10/13	
	Detrimental	(-)	0/13	
Health beliefs and attitudes				
Perceptions of breast cancer risk	Beneficial (no increased risk perception)	(+)	1/13	Increased risk perception may induce worry and anxiety
	Detrimental (increase in perception of risk)	(-)	8/13	
Perceptions of breast cancer risk (comparison between false-positive/all clear)	Beneficial (no increased risk perception)	(+)	0/2	Increased risk perception may induce worry and anxiety
	Detrimental (increase in perception of risk)	(-)	2/2	
Perceptions of breast cancer risk (before and after screening comparison)	Beneficial (no increased risk perception)	(+)	0/1	Temporal relationship clear: increased risk perception occurred after screening
	Detrimental (increase in perception of risk)	(-)	1/1	
Barriers to mammography	Beneficial (fewer reported barriers)	(+)	7/11	
	Detrimental	(-)	0/11	
Benefits of mammography	Beneficial (believe it to be beneficial)	(+)	5/5	
	Detrimental	(-)	0/5	
Benefits of mammography (comparison between false-positive/all clear)	Beneficial (believe it to be beneficial)	(+)	2/2	Less prone to selection bias
	Detrimental	(-)	0/2	
Efficacy of mammography	Beneficial (believe it to be useful)	(+)	8/9	
	Detrimental	(-)	0/9	
Efficacy of mammography (comparison between false-positive/all clear)	Beneficial (believe it to be useful)	(+)	2/2	Increasing confidence in mammography associated with increased intensity of further investigations
	Detrimental	(-)	0/2	

continued

TABLE 5 Summary of health behaviours and beliefs associated with breast screening in comparative papers (cont'd)

Outcome	Beneficial/detrimental to health	Symbol in result tables	No. of studies ^a	Comments ^b
Efficacy of early detection	Beneficial (believe it to be beneficial)	(+)	2/4	One study reported an increase in awareness since screening and that women felt this is beneficial More intrusive thinking, more stressful than other life events
	Detrimental	(-)	0/4	
Concerns about radiation	Beneficial (fewer concerns)	(+)	6/7	
	Detrimental	(-)	0/7	
Knowledge of screening and screening guidelines	Beneficial (increased knowledge)	(+)	6/10	
	Detrimental	(-)	0/10	
Knowledge of breast cancer	Beneficial	(+)	4/5	
	Detrimental	(-)	0/5	
Screening is needed even if asymptomatic	Beneficial (understanding this point)	(+)	6/7	
	Detrimental	(-)	0/7	
Fear of cancer	Beneficial (less fearful)	(+)	2/3	
	Detrimental	(-)	0/3	
Embarrassment about breast screening	Beneficial (less embarrassment)	(+)	4/6	
	Detrimental	(-)	0/6	
Health motivation	Beneficial (increase awareness of health)	(+)	1/3	
	Detrimental	(-)	0/3	
Other health beliefs (denial, reassurance, etc.)	Beneficial (less denial, more reassurance)	(+)	7/11	
	Detrimental	(-)	1/11	
Other health beliefs (denial, reassurance, etc.) (comparison between false-positive/all clear)	Beneficial (less denial, more reassurance)	(+)	0/2	
	Detrimental	(-)	2/2	

^a Non-significant effects are not shown in this table.
^b The temporal relationship is unclear in most studies unless otherwise stated.

increased intention in attenders compared with non-attenders.^{113–121} One of these papers investigated when the women intended to have a mammogram, and found that women who had previously had a mammogram were more likely to report that they would have a mammogram in the next 1–2 years, compared with previous non-attenders where a larger proportion would intend to have a mammogram when the physician recommended screening.¹¹⁸ One paper did not observe a difference between the groups¹²² and another did not undertake an analysis but stated that overall intention was very high.¹²³

Among women who were underusers of mammography, those who had recently attended for screening were more likely to intend to have another mammogram in the next 1–2 years. Women who had never had a mammogram were least likely to intend to be screened, despite ease of access (provided in the workplace).¹²⁴

Increased intentions to reattend were shown for women who had received a false-positive mammography result in two out of four studies,^{125,126} one study did not detect a statistically significant difference, perhaps due to the high intention levels in both groups¹²⁷ and one study only gave the proportion who intended to be rescreened for the whole cohort as 99%.¹²⁹

Papers that primarily investigated pain associated with mammography were excluded from the review. However, if the abstract of the paper indicated that the effect of pain on intention to reattend in the future was investigated then these papers were included. A total of two papers satisfied this criterion.^{130,131} Both of these papers found that pain experienced during mammography did not affect the women's intention to go again. Another paper examined the pain that reattenders and non reattenders experienced in their previous breast screening experiences. It also found that there were no significant differences in reported pain between women who had further mammography and women who decided not to undergo mammography subsequently.¹³²

Attendance/reattendance

Twenty-two papers compared breast screening behaviours in women who had or had not undergone mammography previously. Eleven showed a positive relationship indicating that women who undergo mammographic screening are significantly more likely to be screened again than women who have not been screened;^{133–143}

two of these papers were prospective.^{135,139} Six papers showed no significant differences in mammography use between attenders and non-attenders^{122,123,144–147} and five papers showed an association between lower rates of attendance and ever having a mammogram.^{120,148–151} The authors of the papers that showed a negative association hypothesised that this may be due to women having had a mammogram recently and therefore perceiving no need for another.

On similar lines, it was found that when a new breast screening programme was introduced in Spain, women who had previously had a mammogram were more likely to enrol in the organised programme than women who had never had a mammogram.¹⁴⁷

The effect of receiving a false-positive result and rescreening behaviour was investigated in six papers. Only one of these showed an association between experiencing a false-positive result and increased attendance,¹⁵² three showed no effect^{126,128,153} and two showed a tendency for less subsequent screening in women who had received a false-positive result.^{139,150} However, this may be due to the time taken for the clinical work-up and therefore, effectively, a shorter screening interval.

Adherence to recommended follow-up for further investigations

Two papers investigated the likelihood of adherence to further investigations following a suspicious mammogram, dependent on whether the participants had previously attended for breast screening. Both papers concluded that women who had previously attended for breast screening were more likely to comply with recommendations for further investigations than women with no previous history of breast screening.^{154,155} One of these papers showed the result to be statistically significant only in the group of women recommended to attend for 6-month early recall and not in women asked to attend for further investigations immediately.¹⁵⁴

The management of women with a suspicious mammogram depends on the degree of abnormality observed. Commonly used options are repeated, more frequent mammography (also known as early recall) for up to 3 years, or immediate investigation which may include ultrasound, FNA or biopsy. Three papers looked at women's attendance rates according to the management option offered. All of these papers showed a reduced non-attendance rate with immediate follow-up, but two of these studies

showed small differences that were not significant.^{156,157} The largest study showed a 30 percentage point difference in non-attendance, with higher non-adherence rates observed in the repeat mammography group.¹⁵⁴

One paper showed that women with mammograms with increasing levels of suspicion were statistically more likely to be adherent to recommended follow-up procedures.¹⁵⁵

Cervical screening practices

Twelve papers investigated the effects of breast screening on cervical screening. Ten of the papers showed a significant positive association between the two screening behaviours, such that those who have participated in breast screening are more likely also to attend for cervical screening,^{87,118,144,158–164} and the remaining two showed no association.^{123,136}

BSE behaviours

The use of BSE in relation to attendance or non-attendance for mammographic screening was examined in ten papers. Six of these did not show any association between these behaviours,^{119,136,146,165–167} although one paper showed that despite BSE practice and mammography not being associated, women who had mammographic screening were more likely to be knowledgeable about how to do BSE than non-screened women.¹⁶⁷ The remaining four all showed positive associations, so that women who had undergone breast screening were more likely to also practise BSE,^{115,161,168,169} and no papers showed a negative relationship.

One paper contacted women 6 months after they attended for screening. The screening appointment had also included instruction on BSE. At the 6-month follow-up 67% of women (88/132) reported that they were still conducting BSE, but only 23.5% at monthly intervals and 29% more often (including 20.5% who conducted BSE at least once a week).¹⁷⁰

Four papers looked at the relationship between breast screening and BSE between women with different screening results. Two of the papers showed that women who had further investigations following screening tended to perform BSE more frequently than before screening.^{127,171} Women who experienced increasing degrees of investigation tended with increasing frequency to perform BSE.¹⁷¹ One of these papers asked about the changes that women had experienced since screening and the other paper measured BSE

behaviours before screening; they found no significant differences, and therefore the temporal relationship is clear.^{127,171} The other two papers showed no association.^{125,129}

Use of GP/health services

One study showed that women who were screened went to the GP more than women who were not screened.¹²³ However, because there are no baseline measures this may simply be that women who undergo breast screening already use health services more than women who choose not to be screened.

The effect of a false-positive mammography result on the use of health services was examined in one of the few studies that measured a change after screening. It found that the number of GP appointments, outpatient visits and appointments with physiotherapists did not change after screening.¹²⁹

Other preventive health behaviours

Several papers investigated the association between breast screening and a range of other preventive health behaviours, such as regularity of dental check-ups, seatbelt use, (non-)smoking behaviours, diet, alcohol use and exercise patterns. Ten out of 12 papers found positive associations between mammography use and health prevention behaviours but, again, none of these studies had baseline measures so the direction of the association cannot be ascertained.^{87,118,133,146,158–161,164,172} Two studies reported no association.^{123,136}

One study found positive associations between mammography and tetanus immunisation, sigmoidoscopy screening and faecal occult blood testing, but no associations between breast screening and smoking behaviours, exercise, seatbelt use, aspirin or hormone replacement therapy (HRT) use.¹⁷³ They concluded that preventive services that require a clinician's intervention and no ongoing involvement (e.g. tetanus, colorectal screening) were associated with having ever had a mammogram, but not with undergoing regular breast screening. Preventive services that are patient initiated or require patients to take a more active role (e.g. current use of calcium supplementation, BSE, stool for occult blood) were associated with regular use of mammography.

Health beliefs reported in observational comparative papers

Women's perception of breast cancer risk

The issue of how women rate their risk of breast cancer was assessed in 16 studies: 13 compared

attenders with non-attenders, two studied women who had received a false-positive result, and one was a before and after study of screening attenders.

In the 13 papers comparing attenders with non-attenders, eight found that women who had undergone mammographic screening perceived themselves to be at a higher risk of breast cancer than women who had not undergone screening.^{126,174–180} Only one study found that women who had undergone breast screening felt that they were not at increased risk of breast cancer¹⁸¹ and the remaining four studies showed no association.^{146,165,182,183}

The two papers that investigated the perception of breast cancer risk in women who had received a false-positive result showed an increase in risk perception in women with false-positive results.^{127,128} One study showed that in addition to perceiving themselves to be at increased risk, the women had a lowered perception of healthy breasts.¹²⁷

One study reported the change in the proportion who said that they worried about developing breast cancer as a result of screening.¹⁷⁰ Ten women out of a sample of 132 reported that screening had made them more anxious about developing breast cancer 6 months after being screened. This represented 7.6% of the cohort [95% confidence interval (CI) 3.06 to 12.09%].

Barriers to mammography

Eleven papers looked at the proportions of attenders and non-attenders who report that they have barriers to mammography. Probably not surprising was the finding that seven of the 11 papers reported that attenders had significantly fewer barriers to mammography than non-attenders^{146,165,175,180,183–185} and the other four found no associations.^{143,181,182,186}

One paper asked women who had previously undergone mammography, but had not attended for their next routine screening appointment, for their reasons for not attending. Fear of mammography, the safety of the procedure and fear of what it might find (cancer) were all cited as reasons.¹⁸⁷

One paper investigated barriers to mammography in women who had previously had a false-positive result and in women with a normal result. Women with a false-positive result reported fewer barriers to mammography than women who received a clear result.¹²⁶

It appears that there is a high level of acceptance of false-positive results in breast screening from the general population, but also specifically from women who have experienced them.¹⁸⁸

Benefits of screening

All five studies in this area reported that attenders viewed mammographic breast screening as having greater benefits than did non-attenders.^{147,177,184,185,189}

Two studies compared women with false-positive results with those given a normal result and found that those who were recalled for further investigations, but then were given the all clear (false-positive results), reported greater benefits of screening than women who were immediately given a normal result.^{126,128} These studies have greater weight in assessing the beliefs of women as a result of screening because the differences observed are all within screened women, but the comparison is between groups with differing outcomes, over which the women had no control. In other words, this latter comparison is subject to less selection bias than the comparison between attenders and non-attenders.

Efficacy of mammography

Eight out of nine papers found a positive relationship between mammography use and the belief that it is efficacious,^{143,165,174,178,183,184,189,190} and one paper showed no association.¹³⁶ Once again, it cannot be discerned whether this belief was already held and influenced the decision to attend for breast screening, or whether the belief is a result of screening.

Two studies were conducted comparing women with false-positive results and women who were given the all clear. Both of these studies found that women who had received a false-positive result reported greater confidence in the ability of breast screening to detect cancer.^{126,171} One of these studies¹⁷¹ compared women with a normal result, women with a false-positive that was resolved after breast assessment and a group that had a biopsy (increasing levels of investigation), and found that women reported increasing confidence in the programme with increasing intensity of investigation.

Efficacy of early detection

Women who undergo screening were found to have greater beliefs in the efficacy of early detection in curing breast cancer than women who chose not to have breast screening in two out of four studies that examined this relationship.^{167,181}

The other two studies did not show any association.^{158,174}

Radiation concerns

From the research in this area, it would appear that women who attend breast screening have fewer concerns about the radiation involved in a mammogram than women who do not have mammograms, with six out of seven studies observing this result^{121,133,146,167,174,183} and one showing no association.¹⁸⁶

None of the studies examined this belief both before and after screening, so it cannot be assumed that this association is due to screening. It is possible that women are more likely to attend because they are not concerned about risks associated with radiation.

Knowledge of screening guidelines

Only four studies looked at women's knowledge about the screening guidelines (ages eligible and recommended screening intervals, etc.). Three of them found that women who have had breast screening were more knowledgeable in this aspect than women who have not had screening^{123,133,174} and the other study showed that increased knowledge of screening was associated with higher decisional balance scores, but independently of breast screening behaviour.¹⁹¹

Knowledge of screening

Several studies investigated the level of knowledge about cancer screening in women who chose to undergo screening and those who did not. Four (57%) of the studies found no difference in knowledge between the two groups^{123,136,143,158} and three observed increased knowledge in women who had had breast screening.^{147,178,185}

Understanding that screening is needed even if asymptomatic

The majority of studies (six out of seven) that investigated this belief found that screenees were significantly more likely to agree that screening is needed, even if you there are no symptoms, than women who did not attend for mammography,^{146,158,159,167,183,189} and one study found no association.¹⁴³

Knowledge of breast cancer

Women who went for breast screening were reported to be more knowledgeable about breast cancer than women who did not go for mammography in three out of four studies,^{165,177,192} and there was no effect in the fourth study.¹⁵⁸ Another paper reported that 38% of women who

had undergone breast screening said that they had an increased awareness of breast cancer since the screening appointment, and 93% of these women thought that this heightened awareness was a good thing.¹⁷⁰

Fear of cancer

Three studies looked at expressed fear of cancer between attenders and non-attenders; two found that attenders were significantly less fearful of cancer than non-attenders^{133,158} and one found no association,¹⁴³ although the temporal relationship is not clear. A further study asked about what were the important determinants of deciding to go for screening. It found that for participants, fear of cancer was reported more frequently as an influential factor than for non-attenders.¹³⁶ This appears to contradict the results from the two studies that found fear was less in attenders.

Another study found that attenders thought that thinking about cancer as a consequence of screening was more acceptable than did non-attenders.¹²¹

One study that asked women whether they worried about breast cancer before and after screening showed no difference between the two periods, with 40% reporting worry before screening and 39% after screening.¹⁷⁰

It has to be noted here that studies that investigated predictors of screening were excluded from the review unless they also looked at previous breast screening, cervical screening or cholesterol screening, and their influence on future screening. Papers that principally looked at anxiety and screening were also excluded unless they looked at the effect of anxiety on reattendance.

Embarrassment about mammography

Six studies reported results about embarrassment associated with breast screening. Four of the studies found that breast screening attenders reported fewer feelings of embarrassment.^{121,143,165,189} and two showed no difference.^{146,167} Owing to the lack of data before screening it cannot be determined whether this difference in reported embarrassment is an enabling factor for breast screening or whether, having gone for screening, those women feel less embarrassed than before they were screened.

Health motivation

One out of three papers showed that women participating in screening were more likely to report that they were aware of health issues than

women who did not participate in breast screening (as measured by the health motivation scale of the HBM)¹⁸⁴ and the other two papers showed no effect.^{147,176}

Other health beliefs

Other health beliefs that were investigated in a small number of papers were denial, where it was found that women who had undergone breast screening were less likely to report that 'they would rather not think about it' than non-attenders;¹⁴⁶ reassurance, where three papers found that screenees are reassured by breast screening;^{165,170,189} and intrusive thinking, where one study found that women who had had screening had less intrusive thoughts than women who did not go for screening.¹²¹ Two studies investigated women's opinions about the importance of breast screening, one of which found that attenders had a greater sense of the importance of BSE¹⁵⁹ and the other found no effect.¹³⁶ A further paper found that a greater proportion of breast screening attenders knew about BSE compared with non-attenders for breast screening.¹¹⁸

A detrimental association was found in a paper that reported that women who underwent breast screening perceived breast cancer as a more serious disease than women who did not have screening,¹⁷⁶ although another study showed no significant difference.¹⁸² A further paper found that women who had had breast screening were less confident in breast awareness techniques than women who had not had mammography.¹⁷⁶

There were no differences in the proportion of attenders and non-attenders who reported that they believed breast screening to be 'an intense process'.¹⁸⁶

Women who underwent further investigations after mammography to exclude the possibility of cancer reported more intrusive thinking about breast cancer than women who were given a clear result after screening,¹²⁷ a pattern that was not observed when comparing attenders with non-attenders.¹²¹

Women given false-positive results reported that the work-up period (during further investigations) was felt to be significantly more stressful than the following life events: headache, gastric flu, rain on holiday and suffering from a sprained ankle. After 18 months there was no difference in reported sense of well-being between the groups.¹²⁹

Health behaviours and health beliefs: descriptive data from non-comparative reports

Of the breast screening papers, 15 did not include any comparison groups. These papers described the health behaviours and beliefs of women who had recently undergone breast screening,^{193–200} those who had undergone screening and were recommended to have further follow-up investigations,^{201–204} women who had recently undergone further investigations, and were found not to have cancer,²⁰⁵ women who had previously received a false-positive screening result, necessitating a breast biopsy, and then were found to not have cancer,²⁰⁶ and women who had recently not reattended for routine breast screening.¹⁸⁷ An additional cross-sectional survey of a random population sample (not necessarily after screening) studied the level of opinion regarding the acceptability of false-positive results in mammography.¹⁸⁸ Data were described for the sample as a whole and then separately for women who had previously received a false-positive result. Only this latter set of data can be assumed to be derived from women who have been exposed to breast screening.

Women's intention to reattend for mammographic screening, when next invited, was examined in six of the eight papers that studied recent attenders.^{193–195,197–199} All of these papers reported a high proportion of women with positive intentions (89–99%). The descriptive study of women who had a recent false-positive result found the same result, with 96% of the women reporting that they would reattend for routine screening next time.²⁰⁵ Despite this high level of intention, one study of screening behaviour after a false-positive result showed that only 73% of women received another mammogram within 2 years, and 13% never had another mammogram.²⁰⁶ It would appear that intention to attend does not correlate precisely with actual behaviour, as the observed attendance rate is generally lower than stated intention. However, the same study²⁰⁶ also found that 77% of the respondents said they were more likely to obtain further mammograms as a result of their false-positive experience.

Intention to reattend for mammographic screening was found to be positively correlated with overall satisfaction with the screening process and negatively correlated with pain during mammography.¹⁹⁹ In women who reported a painful mammogram, a lower proportion of 75% intended to reattend.¹⁹⁷ However, in a cross-sectional study of recent attenders (31% of whom

experienced moderate or severe pain) only 2.6% (25/945) reported that pain might deter them in the future.¹⁹⁵ Among non-reattenders, the main reason women gave for not reattending was that they experienced pain during the last screen.¹⁸⁷

Four papers investigated adherence to follow-up recommendations in women who had a suspicious mammogram.^{201–204} In addition to these four papers, three comparative papers described the uptake rates in the population of women who were advised to undergo further investigations.^{154,156,157} Of these seven papers, five measured incomplete adherence (e.g. women who only attended one out of three repeated screenings).^{154,157,201,203,204} Four of these papers (80%) showed a sizeable proportion of women who do not adhere to the advice given after mammography, ranging from 16.5% of women having incomplete follow-up (although these women had all recently had an FNA) to 36.8% when the management option was repeated mammography (early recall),^{154,157,201} and between 7.2 and 13.5% when the chosen follow-up regimen was immediate investigations.^{154,157,203} The remaining two papers reported the proportions that did not have any follow-up. Between 12.5 and 21% of women did not attend for any further repeat mammography.^{156,202} Of the women who were recommended to have immediate investigations, 19.4% failed to attend.¹⁵⁶

Two papers found that screening can be a reassuring process for women, with 84% and 90% of the respondents reporting this as an effect of screening.^{193,200} The effects of reassurance are discussed further in the discussion of the breast screening results.

One paper described women's estimation of their lifetime risk of cancer and found that 67% correctly identified the 1 in 10 risk, 27% overestimated it and only 4% underestimated it.¹⁹⁶ The authors concluded that this sample of breast screening attenders believed themselves to be at moderate to high risk of cancer.

Papers that had a clear temporal relationship between screening and outcomes

This section reiterates the results of the few studies that clearly demonstrated that the reported health behaviours and beliefs occurred after contact with breast screening.

One study investigated the effect of a false-positive result on women's intention to obtain a further mammogram. It found that 77% of the respondents

said they were more likely to obtain further mammograms as a result of their false-positive experience.²⁰⁶

One paper measured BSE behaviours before and after screening, and found that women who received a false-positive result practised BSE more frequently after screening than women who received an all-clear result, when at baseline there was no difference in BSE behaviours.¹²⁷ Another paper specifically asked about changes in behaviour since receiving a false-positive result, and also found that women who had a false-positive result increased the frequency with which they conducted BSE significantly more than women who had an all-clear result. In addition, women who had more invasive investigations (biopsy) had the largest increase in BSE frequency.¹⁷¹ This study also showed increasing confidence in the screening programme following screening in false-positive women compared with those with normal results.

However, another study showed that there were no significant changes in BSE frequency as a result of a false-positive screening, although no data were given.¹²⁹ This study also showed that there were no changes in the number of GP appointments, outpatient visits and appointments with physiotherapists after receiving a false-positive result.¹²⁹

One study collected data before breast screening and 6 months later from a group of women who underwent breast screening and obtained a normal result.¹⁷⁰ This study showed that two-thirds of the women were still conducting BSE 6 months after screening, with 20% of the cohort examining their breasts more than once a week. This could be considered as inappropriate behaviour, although there is no comparison with women who have not been screened.

The same study reported that 86% of the women thought that breast screening provided reassurance, 38% thought it had raised their awareness of breast cancer and the majority of these women felt that it was a positive change. In another study, there was no overall change in the proportion of women who reported that they worried about breast cancer before screening and after screening (40% and 39%, respectively), although almost 8% (ten women) thought that screening had made them more anxious about breast cancer (95% CI 3.06 to 12.09%).¹⁷⁰

When breast screening reattenders and non-reattenders were asked to recall their experiences

at their previous breast screening appointment, reattenders were significantly less likely to have found the previous mammography embarrassing or distressing and were more likely to have felt that it was reassuring and worthwhile. In addition, more reattenders believed breast screening to be beneficial and effective.¹⁸⁹

Discussion: breast screening

Design issues

The studies included in this section of the review were subject to a number of biases inherent in observational studies. This is discussed further in the overall discussion of the whole review (Chapter 7). In addition, many of the papers did not specifically measure the effects of screening on future health behaviours and health-related beliefs prospectively, but often reported simple associations or correlations between breast screening and the outcomes presented here. Therefore, it was very difficult to answer the review question and further research is needed to fill the gaps.

There was a limited range of outcomes, with most studies focusing on breast cancer knowledge and attitudes and beliefs about breast cancer screening. Although several studies looked at the association between breast screening and other health behaviours they still did not aim to examine how these might have been changed as a consequence of screening. No studies looked at health beliefs in general, such as the 'certificate of health effect', and there were no qualitative studies that could identify some subtle (negative) effects.

What is shown by these studies

Overall, it appears that previous breast screening is positively associated with most of the limited number of beneficial health behaviours and positive beliefs reported, although the temporal relationship that exists between screening and health behaviours and beliefs is not clear.

Many of the studies included in the review are cross-sectional and therefore only provide evidence about associations or the coexistence of screening behaviours and other beliefs or behaviours. Of the studies that used a prospective approach, many of them did not collect information regarding behavioural patterns or health-related beliefs at baseline and therefore it cannot be determined whether the positive associations observed were because the types of women who engage in breast screening are the same women who already hold positive health

beliefs and behave in a 'health-inducing' manner. In other words, in many cases it was impossible to tell whether the observed traits were brought to screening, or resulted after screening.

The majority of studies showed that women who attend for breast screening are highly likely to reattend in the future. However, two out of five papers showed a significant decrease in reattendance in women who had previously been given a false-positive result compared with women who were given the all clear (of the other three papers, two showed no association and one showed an increase in attendance among recipients of false-positive results). It has been postulated by the authors of the papers showing a detrimental effect on future routine screening that this is due to a recent follow-up appointment and therefore the perception that there is no need for another routine screen.

Several papers measured women's intentions to reattend for screening when next invited. In all studies, the reported intention was high, with 89–99% of screened women reporting that they would go again and 96% of women who had been given a false-positive result saying that they would be rescreened.

There is a difference between intention to reattend and actual behaviour, with screening uptake falling short of that expected from the intended behaviour data. This is observed indirectly by comparing the paper that reported that 96% of women with false-positive results would reattend (and therefore 4% would not) and the paper that measured actual reattendance in another group of women with prior false-positive results which showed that 13% did not ever obtain another mammogram.²⁰⁶ This is a large increase compared with only 4% with such intentions. Further research should be conducted into the relationship between intended and actual behaviours to investigate the possible reasons for the disparity between the two measures.

Adherence to follow-up recommendations following a suspicious mammogram was quite low overall. Estimates of the proportion of women that received no follow-up at all ranged between 12.5 and 21%. The proportions of women who only received partial follow-up varied between 7 and 36%. If women are to obtain a benefit from undergoing screening, then it is important that they adhere to follow-up recommendations. Women who fail to attend for further investigations are likely to suffer adverse

psychological consequences and the possibility of harbouring undiagnosed disease remains. Therefore, these proportions of those defaulting were judged to be a detrimental consequence of screening.

The majority of studies that analysed the relationships between attendance at breast screening and attendance at cervical screening showed a positive association between the two cancer screening services. However, many of these studies were cross-sectional or collected the data retrospectively, and hence it cannot be ascertained whether breast screening behaviours lead to increased cervical screening attendance, or whether it is just that women who use one type of screening would tend to engage in another type of screening. A prospective study would be needed to measure the temporal relationship, or a study that obtained each woman's chronological screening history and its impact on subsequent health decisions.

Looking at the evidence from two separate studies may provide a clue as to whether screening affects health service use (including screening). One of these studies which measured change in accessing health services after receiving a false-positive breast screening result showed that there were no changes in the number of GP appointments, outpatient visits or appointments with physiotherapists.¹²⁹ However, another study that compared women who engaged in breast screening with those who did not showed that women who accepted invitations to breast screening visited the GP more than women who were not screened.¹²³ It seems possible that participation in screening does not change the utilisation of health services, but the women that accept breast screening use the health service more than women who choose not to go for screening.

A few papers measured the change in BSE behaviours following breast screening. These studies tended to show that breast screening, and especially a false-positive breast screening result, leads to increased BSE behaviour. There appeared to be a dose-response relationship, with women who had undergone more invasive further investigations exhibiting a significantly increased frequency of BSE. In *Table 5*, this type of behaviour has been labelled with a (+) sign, indicating that this is a beneficial effect of screening. However, it is arguable whether this type of behaviour is beneficial as there is no evidence to show that self-examination reduces

mortality from breast cancer, and there is good evidence that it may cause harm such as unnecessary biopsies, anxiety and worry.²⁰⁷ Some of the women in these studies reported that they conducted BSE at least once a week, which is certainly not a recommended practice.

Increased perception of susceptibility to breast cancer can probably be viewed as a negative effect, as it may induce worry and anxiety about cancer. None of these studies measured risk perception before screening, so it cannot be determined whether this effect is due to screening or whether it is the women who believe themselves to have a heightened risk who then attend screening. It was also difficult to ascertain from the papers whether the increase in risk perception was to a realistic level, as often risk was measured on a Likert scale (ranging from very low/small risk to very high risk) or on a continuous scale, but was not measured relative to actual risk. The few papers that asked about the population lifetime risk of being diagnosed with breast cancer found that the proportion of women who correctly identified the risk as 1 in 10 (as it was at the time of the research) ranged from 30 to 67%. One paper reported that 14% of regular screenees thought their personal risk was higher than population risk, compared with 8% of one-time screenees.

Women who underwent screening reported fewer barriers to mammography than women who chose not to be screened. Perhaps more unexpected was the finding that women who received a false-positive result also reported fewer barriers to mammography than women who received a clear result.¹²⁶

Knowledge and beliefs about health and pre-existing psychological state may influence the magnitude and direction of the impact of screening although only one paper measured health beliefs before screening.¹⁷⁰ However, this study did not fully utilise these data and instead presented reported change in attitudes to breast screening.

Areas not covered comprehensively in this review

Uptake of screening services

As described in the Methods section (Chapter 2), it was originally planned to include papers that investigated ways of improving methods of uptake. The rationale behind this was that the interventions being tested may have differing effects in groups of women who had previously decided to go for screening or not. However, as the overall searches

retrieved almost 13,000 articles, it was decided to exclude papers that primarily focused on increasing attendance at screening. In addition, a recent HTA review of determinants of screening uptake and interventions to improve attendance had already been conducted.⁴³ That review looked at 20 papers that investigated previous mammography as a predictor of future screening behaviours. Eighteen of these 20 papers were retrieved by the search strategies used in this review.¹⁴⁸ The remaining two were not retrieved by the searches used in this review. Of the papers that were retrieved by the searches described in Appendix 1, 11 were excluded in Stage 2 of the review process (as described in Chapter 2) as they were primarily addressing strategies for improving uptake,^{208–218} and a further paper was excluded before data extraction because it also focused on increasing attendance.²¹⁹ The remaining six papers were included in the results of this review.^{122,135,148,151,153,220}

Knowledge about breast cancer, and knowledge about mammography and screening guidelines were found not to be predictive of screening uptake in the review of screening uptake.⁴³ whereas the present review found that women who had undergone screening were more likely to have greater levels of knowledge of screening and breast cancer (see breast screening results section). It would therefore appear that women who chose to be screened do not have greater knowledge before screening than women who chose not to be screened, but they do have greater knowledge afterwards. This would seem to be intuitively sensible, as one would expect knowledge about an experience to be higher in those who have experienced it than in those who have not.

Health belief models, primarily excluded for temporal reasons

A great many studies used psychological models, but they often examined predictors of uptake and therefore investigated the wrong temporal relationship for this review. As many papers were excluded for this reason it seems that it would be a misrepresentation of this body of literature if the role of health belief models were discussed in detail in this review. Therefore, it must be noted that this review does not fully represent the wider literature on health belief models and screening, but only contains those studies that also looked specifically at past screening as a predictor for future screening.

Influence of pain on mammography

The methods section (Chapter 2) explains that papers that investigated pain experienced during

or immediately after the mammographic process were excluded, unless the title or abstract specifically mentioned this experience as having an effect on actual future attendance or intended screening behaviours. Most papers in this review that investigated pain used it to explain reasons for non-attendance.^{187,195,197,199} Two papers examined pain experienced as a factor in affecting intention to reattend and found no difference in intention between women who reported painful mammograms and those who did not report pain.^{130,131} However, intention to attend may not be borne out by actual attendance behaviour. The only paper to have investigated previous pain experienced (measured after the initial mammogram) found that there were no significant differences in reported pain between women who had further mammography and women who decided to not undergo mammography subsequently.¹³²

Again, however, it must be emphasised that this is not a complete picture of the literature on pain and mammography, which is the focus of an additional review currently underway.

Anxiety associated with breast screening

Anxiety is neither a health behaviour nor a belief, but rather a health condition or psychological morbidity. Therefore, papers that focused principally on screening-induced anxiety were excluded from this review. The exception to this rule was where the title or abstract stated that intention to attend or actual attendance in the future was affected by previous anxiety experiences as a result of breast screening.

The body of literature on anxiety and screening processes is quite extensive and is being examined in a separate systematic review.

However, to exclude this outcome from the review does have limitations. Often psychological scales that measure anxiety contain aspects of self-care motivation, such as the Psychological Consequences of Screening Questionnaire (PCQ),²²¹ and these aspects are excluded from this review unless they were investigated as an individual variable in a paper that was not measuring anxiety as the primary outcome.

Effects on family/salient others

The impact of screening programmes may extend beyond the screened individual to other family members and could influence their health-related behaviours, such as health seeking. This is an important aspect of screening, but is not covered

in this review as the aim was to investigate the effects of screening on individuals who were exposed to the screening process, and not their wider social or familial contacts.

Papers published since the year 2000

The years that were included in the systematic search were 1980–2000 inclusive. However, handsearching continued until April 2002 and all relevant papers were examined and data extracted. These results are not included in the overall review as these papers were not systematically searched for. A summary of these papers is included in Appendix 7 and the results are discussed here in the context of this review.

During the period of handsearching after the systematic searches had been completed, six papers were identified that were of direct relevance to the breast screening aspect of this review. Four of these papers focused on the effects of screening in women who had received a false-positive result and the other two papers compared women who had recently received breast screening with those who had not attended.

Of these studies, three used a prospective design,^{222–224} with two of them also collecting baseline measures (prescreening).^{222,224} The studies that investigated the effects of screening on future outcomes reported that receiving a false-positive result increased perception of susceptibility to breast cancer and led to increased GP visits,²²² and that reattendance rates at the next routine breast screening appointment were lower in the women with false-positive results than in women who received a normal result.²²³ Reattendance at the next routine breast screening appointment was investigated in a further two papers, both focusing on women who received false-positive results. One of these papers showed no difference in reattendance rates between women with normal results and those who underwent further investigation.²²⁵ The other paper reported that 10% of women who had a benign biopsy following screening failed to reattend for their next breast screening result. However, those who did return for mammography came back sooner than women who had a normal breast screening (adjusted for recommendations for more frequent mammography).²²⁶ A further study showed that the following outcomes were not affected by breast screening (as measured before and after screening): intention to reattend, perception of susceptibility to breast cancer, perceived severity of breast cancer, knowledge about results and false reassurance after a normal result.²²⁴

Other associations reported in the papers published after 2000 were: cervical screening practices, which showed a positive correlation with breast screening behaviours,²²³ and other health behaviours (dental check-ups, colorectal screening) that were also positively associated with breast screening behaviour.^{223,227}

Summary

The questions that this section of the review aimed to answer were:

- What are the effects of systematic screening for breast cancer on future health beliefs and behaviours?
- What are the implications for the NHS, including their impact on the cost-effectiveness of screening programmes?
- The review also aimed to identify gaps in the literature and make recommendations and describe a framework for further research on this topic, taking into account any important theoretical perspectives identified in the literature search.

Whether breast screening affects future health behaviours and beliefs has not been directly measured in many studies, and very few studies have collected baseline measures (before screening). Therefore, it is difficult to answer with certainty the question ‘What are the effects of systematic breast screening on future health beliefs and behaviours.’

However, attending breast screening seems to be significantly and positively associated with previously attending breast screening, such that women who undergo breast screening once are extremely likely to reattend. It is also possible to conclude that attendance at breast screening is associated with several positive health behaviours, such as regular cervical screening, regularity of dental check-ups, seatbelt use, (non-)smoking behaviours, diet, alcohol use and exercise patterns. However, as many of these studies were cross-sectional or relied on retrospective data collection, the temporal relationship between breast screening and these behaviours cannot be firmly assessed. Therefore, it cannot be concluded whether the associations observed are as a result of screening or whether women who undergo breast screening have a certain set of health behaviours and beliefs irrespective of their experience of screening.

Taking the evidence from this review, which showed that knowledge was greater among women that

have been screened than women who have not, and the evidence from a previous review that looked at predictors of screening,⁴³ which showed that there were no differences in baseline knowledge between those who went for screening and those who did not, it can tentatively be concluded that attendance at breast screening increases an individual's knowledge about breast cancer and breast screening.

To answer the question posed by the review, further research needs to be undertaken which

would include measuring a wider range of behaviours and beliefs before screening and after screening has been accepted or declined, in order to measure changes that occur between the two periods. In addition, it would be of paramount interest to conduct qualitative research into women's understanding and knowledge of breast screening, how this interacts with knowledge and beliefs about other aspects of health, and how screening might influence the whole range of health behaviours. Suggested areas of future research are outlined in *Box 2*.

BOX 2 Future directions in research

- The nature of the methodology of the included studies meant that the studies could only demonstrate beliefs and behaviours associated with breast screening, rather than those that might have been caused by screening.
Very few studies included prescreening measures. The need for baseline measures is paramount to assess the influence of already held beliefs and behaviours, which currently cannot be accounted for.
Further research investigating the effects of breast screening on a full range of health beliefs and behaviours both before and after screening is needed. This needs to be included in evaluations of any screening programme (including emerging programmes such as screening for colorectal, ovarian and prostate cancer).
- Qualitative research should be conducted to investigate what people understand about health behaviours and beliefs.
- The differential effects on future behaviours and beliefs should be investigated in different screening outcomes groups (e.g. all clear, early recall, biopsy).
- Qualitative and quantitative research is needed to explore the relationship between intended behaviour and actual behaviour (e.g. attendance at breast screening) to explain the disparity between these outcomes.
This should examine the intention to attend during differing lengths of screening interval, including the effects in groups with differing screening outcomes.
- Qualitative research needs to be undertaken to understand why the attendance rate for follow-up investigations is not optimal.
This could ultimately lead to the development of appropriate interventions to minimise anxiety and uncertainty, and to optimise the benefits of early detection.
- BSE behaviour was reported in several studies. However, in the UK the emphasis is on breast awareness as a continual process of knowing what is normal for an individual, compared with a ritualistic examination for abnormalities in BSE.
Despite this shift in emphasis, there appears to be very little research on the prevalence of Breast Awareness. The impact of screening on Breast Awareness is understudied.
- Qualitative research is needed to explore understanding of screening, including reasons for screening, continuing awareness during the screening interval, the impact of screening interval and eligible age range on implicit risk perception and its impact on behaviours and beliefs.
- What is the influence of risk perception? Is it an enabling or a disabling factor?
- Research is needed to understand how people are currently using screening (confirmation of health or disease detection), reasons for misuse, why previous non-attenders decide to attend and reasons for possible declines in routine screening after a false-positive result.

Chapter 6

Cervical screening

Introduction

This aim of this chapter is to examine the effects of cervical screening on future health behaviours and health beliefs.

As described in Chapter 1, cervical screening uses cytology to detect abnormalities called dyskaryosis. This review does not include the role of human papillomavirus (HPV), as screening with this method is not widely available. The aim is to prevent cancer from developing, by detecting precancerous abnormalities. Potentially modifiable risk factors for cervical cancer include exposure to HPV and smoking.²²⁸ Other risk factors include oral contraceptive use and parity.²²⁸ Management of abnormal smears depends on the severity of cellular changes and may involve more frequent screening, colposcopy and removal of abnormal cells.

Figure 4 illustrates the exposures and outcomes of the cervical screening process. The start of the screening process has been defined as the receipt of an invitation; therefore, outcomes for women who chose not to be screened have been included. These women still have an experience of screening, even though it differs significantly from those who undergo the test. Outcomes for women with a negative (all-clear) and positive (abnormalities detected) smear test result have also been included. The early diagnosis of precancerous lesions that cervical screening may provide is only beneficial if follow-up recommendations are adhered to. Adherence/non-adherence to recommended follow-up has been included as both an exposure and an outcome. As there are few modifiable behavioural risk factors for cervical cancer, the effect of screening may be seen indirectly in other types of behaviour, such as subsequent reattendance or adherence with follow-up recommendations. Beliefs regarding cervical screening and the test result (i.e. perceived seriousness of a positive test result) play an important role in driving corresponding behaviours.

Description of the included papers

There are 49 papers included in this section of the review (25 from cervix alone, 23 from breast and

cervix, and one paper that included breast, cervical and cholesterol screening) that examine the effect of cervical screening on future health behaviours and health beliefs. Chapter 2 contains details on the methods used as well as the inclusion and exclusion criteria. For further details on the search results, refer to Chapter 3. The summary result tables are presented in Appendix 8 (description of studies) and Appendix 9 (summary of results).

It should be noted that many of the papers included in this section were based on studies of breast screening behaviour which included the influence of previous cervical screening. In these papers, the only relevant outcome for this section of the review was the effect of previous cervical screening on breast screening behaviour. Papers that are presented in both the cervical and the breast screening sections of the review are marked with an asterisk (*) in the summary tables (Appendices 8 and 9). The remaining studies focused on aspects of cervical screening. It is also important to note that although the data presented in this review are relevant to the examination of the effect of screening on future health behaviour or beliefs, very few of the studies focused primarily on this question.

Of the 49 included papers, 21 studies were conducted in the USA, 13 in the UK, three in Italy, two in Singapore, Canada and Australia, and one each in Denmark, Mexico, The Netherlands, New Zealand, Spain and Sweden. The majority of studies were published after 1990, with only four studies, based in the UK, published between 1980 and 1985.

A variety of settings was used in the papers, including cervical screening programmes in the USA, UK and Italy; GP practices or clinics; health districts, counties or neighbourhoods; university health clinics/teaching hospitals; hospitals, colposcopy clinics; population samples; breast screening programmes in Australia, The Netherlands, Scotland, Northern Ireland, the USA, Singapore, the UK, Spain and Sweden, and mobile breast screening units. Participants included a range of women, such as those invited for cervical or breast screening in a systematic

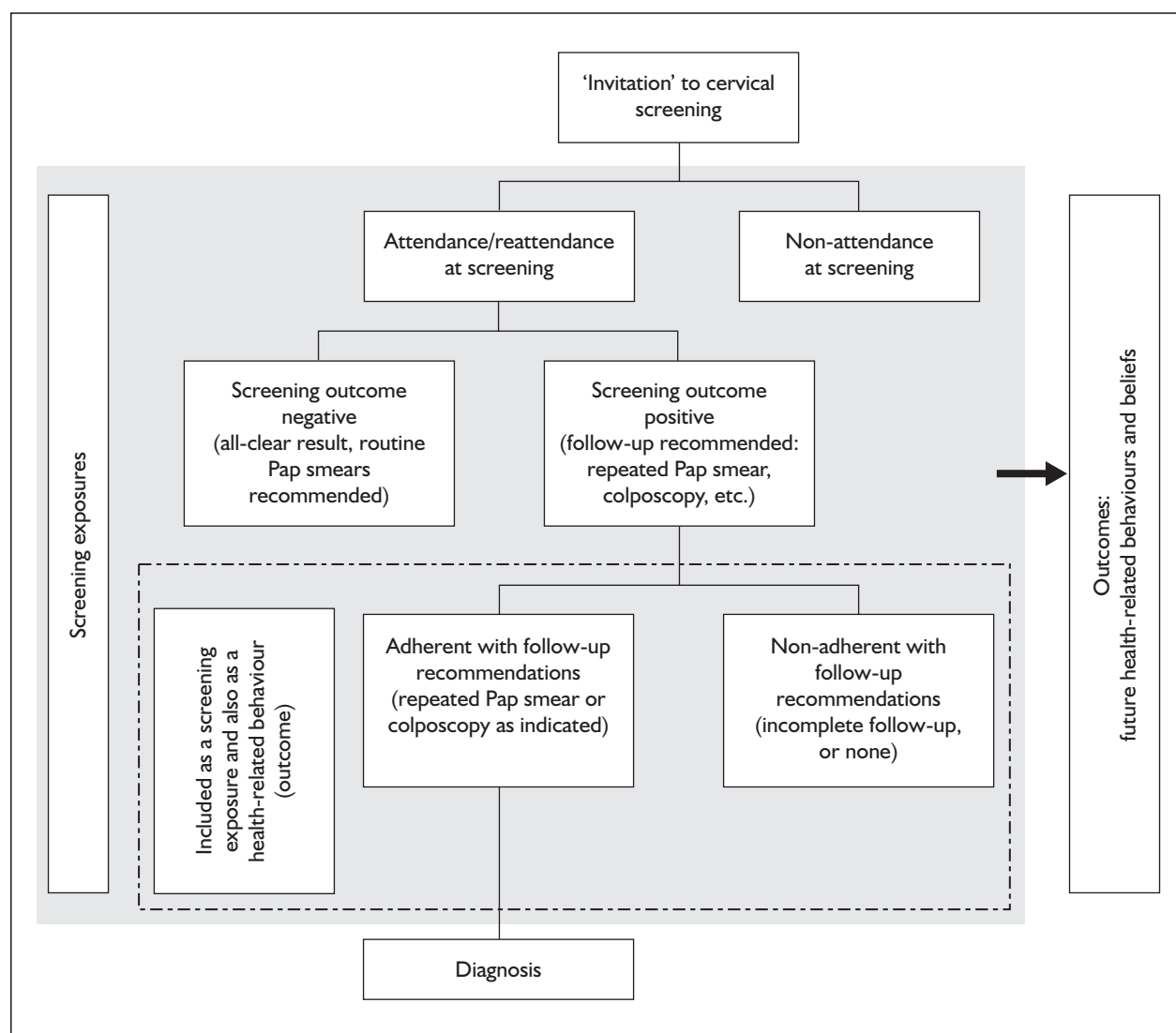


FIGURE 4 Cervical screening process: exposures and outcomes. All groups in the shaded area are included in the review.

population screening context or in an opportunistic context, or those who sought screening in a free-access context. Participant ages ranged from 18 to 74 years and included those with a positive Pap test result as well as the elderly, medically underserved, low income, underinsured, volunteers and various ethnic groups.

Two qualitative studies explored women's experiences of cervical screening. One examined older women's attitudes to cervical cancer and cervical screening.²²⁹ The other explored the experiences of women who had had an abnormal Pap smear and undergone colposcopy.²³⁰

Cervical screening behaviour was examined in five studies.^{231–235} Women's knowledge and attitudes to cervical screening were examined in five papers.^{236–240} Screening behaviour for both breast

and cervical screening in elderly, poor, black women was examined in one study.¹⁴⁵ Patterns of general preventive behaviour in women¹⁶⁴ and determinants of BSE¹⁶⁶ were also studied.

The effect of a positive smear test, adherence to recommended follow-up and health beliefs associated with this process were studied in five papers.^{241–245} In these studies, some of the self-selection biases that may be present in other studies are minimised, as the women did not choose whether or not to have a positive result.

Another study looked at the effect of cervical screening and a cancer screening education session on future preventive behaviour (cervical screening, BSE, mammography and regular healthcare provision) of women at high risk for cervical cancer.²⁴⁶ This study included a

baseline measure of preventive health behaviour and data at the 2-year follow-up. However, whether changes in preventive health behaviour were due to cervical screening, the cancer screening education session or a combination of both is not clear from the study. There was one randomised intervention trial in which women were randomised either to receive or not to receive a cervical screening invitation with their breast screening invitation.²⁴⁷ The women who did not receive the cervical screening invitation were invited for cervical screening when they attended their breast screening appointment.

Table 6 summarises the main outcomes found in the literature included in this section of the review. As discussed in Chapter 2, assumptions about whether or not the outcomes measured were beneficial to health were made. This is discussed in Chapter 7.

All study designs have been included in the review. However, the lack of RCTs and the observational nature of the studies resulted in the temporal relationship between cervical screening and the health behaviours and beliefs being problematic. Often, information about screening and subsequent health behaviour and beliefs was measured and collected at the same time. This made determining whether beliefs and behaviours precede or follow screening very difficult to ascertain. There was also a lack of studies that included baseline measures (i.e. prescreening) that would allow a direction of change to be ascertained. Because of the dearth of RCTs, it is important to note that one can only observe possible associations rather than causal relationships.

Results

Of the 49 papers in the cervical screening review, 40 included comparison groups. All of these studies were observational. Tables with the characteristics of the studies are found in Appendix 8 and the study results in Appendix 9. For more details on inclusion/exclusion criteria refer to Chapter 2.

Health behaviours: results from observational comparative papers *Intention to undergo cervical and/or breast screening*

Four papers compared attenders and non-attenders for cervical screening, and found a positive association between attending for cervical screening and intention to attend future

cervical screening.^{145,234,236,239} In one study, intention to attend cervical screening was reported as 99% in attenders, 92% in defaulters and 76% in non-attenders²³⁶ at cervical screening. Another study reported that cervical screening non-attenders were more likely to believe that embarrassment, anxiety and discovery of early changes would influence their intention to attend for cervical screening in a negative manner.²³⁴ One study that offered women cervical and breast screening found that women who intended to participate in screening were 2.7 times more likely to attend.¹⁴⁵

Four studies found that cervical screening was associated with an increased intention to attend future breast screening.^{114,119,145,161} One study found that women not intending to be screened were more likely to have had their last Pap smear more than 2 years ago.¹⁶¹

Attendance/reattendance at cervical screening

Three studies examined attendance at cervical screening. Two studies reported comparisons between attenders and non-attenders, and found no association with prior use of breast or cervical screening.^{145,231} These studies involved a pilot cervical screening programme and an opportunistic offer of breast and cervical screening to poor, minority women, as part of the study. One of the studies found that women who had previously been screened, but some time ago, were significantly more likely to be screened. Women who had been screened more recently (up to less than 3 months ago) were increasingly less likely to attend for cervical screening when invited.²³¹ This may be due to the perception that there is no need to repeat smears too often. A further study found that 2 years after attending an educational session and having a Pap smear, attendance at cervical screening improved from 40.2% to 60.3%.²⁴⁶ It is difficult to separate the effect of cervical screening from the cancer screening education session in this study.

Attendance/reattendance at recommended follow-up for a positive smear

Three studies examined adherence to follow-up recommendations (repeat Pap smear or colposcopy) for a positive Pap smear based on the severity of the lesion.²⁴¹⁻²⁴³ All of the studies found that women with high-grade lesions were more likely than those with low-grade lesions to attend colposcopy. One study found that 87% of women with high-grade lesions compared with 72% of women with low-grade lesions attended colposcopy, although this study was underpowered and only approached significance.²⁴¹

TABLE 6 Summary of health behaviour and belief outcomes associated with cervical screening in comparative papers

Outcome	Beneficial/detrimental to health ^a	Symbol in result tables	No. of studies ^b	Comments ^c
Health behaviours				
Intention to undergo future cervical screening	Beneficial (increased intention)	(+)	4/4	None of these studies compared intention to attend and actual attendance
	Detrimental	(-)	0/4	
Intention to undergo future breast screening	Beneficial (increased intention)	(+)	4/4	
	Detrimental	(-)	0/4	
Attendance/reattendance at future cervical screening	Beneficial (increase uptake)	(+)	1/3	Possible confounding with education session offered at initial cervical screening
	Detrimental	(-)	0/3	
Adherence to follow-up recommendation (comparison by severity of lesion)	Beneficial (increased adherence)	(+)	3/3	Overall adherence was low
	Detrimental	(-)	0/3	
Use of GP/health services	Beneficial (increased use)	(+)	3/3	In one study there is a possible confounding with education session offered at initial cervical screening
	Detrimental	(-)	0/3	
Attendance at future breast screening	Beneficial (increased uptake)	(+)	19/26	
	Detrimental	(-)	0/26	
Smoking	Beneficial (decreased smoking)	(+)	1/3	One study compared active, passive, never and ever attenders and found no significant differences in smoking status
	Detrimental	(-)	0/3	
BSE	Beneficial (increased examination)	(+)	2/4	In one study there is possible confounding with the education session offered at initial cervical screening
	Detrimental	(-)	0/4	
Other health behaviours (e.g. dental check-ups, dietary practice, exercise, use of safety belts)	Beneficial	(+)	1/1	
	Detrimental	(-)	1/1	
Health beliefs and attitudes				
Perceptions of cervical cancer risk (attenders/non-attenders)	Beneficial (no increased perception of risk)	(+)	0/3	
	Detrimental	(-)	1/3	

continued

TABLE 6 Summary of health behaviour and belief outcomes associated with cervical screening in comparative papers (cont'd)

Outcome	Beneficial/detrimental to health ^a	Symbol in result tables	No. of studies ^b	Comments ^c
Perceptions of cervical cancer risk (adherent/non-adherent for follow-up)	Beneficial (no increased perception of risk)	(+)	0/1	The temporal relationship was more clear in the two studies that showed no significant difference
	Detrimental	(-)	0/1	
Perceived barriers to cervical screening (adherent/non-adherent to follow-up)	Beneficial (decrease in barriers)	(+)	0/1	
	Detrimental	(-)	0/1	
Perceived benefits of cervical screening	Beneficial (increased belief in benefits of cervical screening)	(+)	0/1	
	Detrimental	(-)	0/1	
Perceived efficacy of cervical screening	Beneficial (increased belief in the usefulness of cervical screening)	(+)	1/1	
	Detrimental	(-)	0/1	
Perceived efficacy of early detection for cervical cancer	Beneficial (increase belief in the usefulness of early detection)	(+)	0/2	
	Detrimental	(-)	0/2	
Perceived efficacy of early detection for cervical cancer (adherent/non-adherent for follow-up)	Beneficial (increase belief in the usefulness of early detection)	(+)	0/1	
	Detrimental	(-)	0/1	
Knowledge of cervical cancer and cervical screening (attenders/non-attenders)	Beneficial (increased knowledge)	(+)	2/4	
	Detrimental	(-)	0/4	
Knowledge of cervical cancer and cervical screening (adherent/non-adherents to follow-up)	Beneficial (increased knowledge)	(+)	1/1	Knowledge was measured after the colposcopy appointment; therefore, it is possible that the appointment acted as a 'reminder'
	Detrimental	(-)	0/1	
Fear of cancer	Beneficial (decreased fear of cancer)	(+)	1/1	
	Detrimental	(-)	0/1	

continued

TABLE 6 Summary of health behaviour and belief outcomes associated with cervical screening in comparative papers (cont'd)

Outcome	Beneficial/detrimental to health ^a	Symbol in result tables	No. of studies ^b	Comments ^c
Fear of cancer (adherent/non-adherent for follow-up)	Beneficial (decreased fear of cancer)	(+)	0/1	
	Detrimental	(-)	0/1	
Embarrassment about cervical screening (attenders/non-attenders)	Beneficial (decreased embarrassment)	(+)	2/2	
	Detrimental	(-)	0/2	
Embarrassment about cervical screening (adherent/non-adherent to follow-up)	Beneficial (decreased embarrassment)	(+)	0/1	
	Detrimental	(-)	0/1	
Reassurance	Beneficial (increased reassurance)	(+)	2/2	
	Detrimental	(-)	0/2	

^a Outcome designation of beneficial/detrimental is explained in the discussion.
^b Non-significant effects are not shown in this table.
^c The temporal relationship is unclear in most studies, unless otherwise stated.

Adherence to follow-up with respect to different types of follow-up (repeated Pap smear, colposcopy) was examined and no significant differences were found.²⁴² In this study, 53% of women referred for a repeated Pap smear adhered to the recommendation and 61% of women referred for colposcopy adhered to the recommendation. This study also examined adherence to different types of follow-up in terms of the severity of the smear result. It was found that women with more severe test results were more likely to attend for repeated Pap smears than colposcopy. Women with abnormalities of undetermined significance were more likely to attend for colposcopy than repeated Pap smears. The authors state that this may be because women with abnormalities of undetermined significance may have already been for repeated Pap smears and therefore represent a group of more adherent women.

Effect of cervical screening on breast screening practices

Twenty-six of the 49 studies investigated the effect of cervical screening on subsequent breast screening practices. Of the 26 papers examining attendance at breast screening, 19 papers reported a positive association between attendance for cervical screening and attendance at future breast screening.^{87,116,118,120,132,138,144,151,158,161,162,164,173,191,247-251}

One paper, which examined stages of adoption of screening mammography, found that for the least committed group of women, having had a Pap smear in the past 2 years was associated with attending for breast screening.¹⁹¹ However, there was no association found for women who were either thinking about being screened or were inconsistently or routinely being screened. Another paper compared acceptors and rejecters of an invitation for breast screening with women who self-referred and found that acceptors were more likely to have had cervical screening than rejecters.²⁵⁰ This paper also found that the majority of women who self-referred for breast screening had prior cervical screening.

Eight of the 26 studies examined the effect of recency of the Pap test on mammography screening behaviour and found that women with more recent Pap smears were more likely to attend for breast screening.^{87,116,118,161,162,247,248,251} One study found that ever having had a Pap smear was associated with ever and current use of mammographic screening. However, there was no association between current mammography use and current Pap smear use.¹⁷³

Seven of the 26 studies reported no association between attendance for cervical screening and breast screening.^{122,123,133,136,145,147,153} Four of these studies involved free breast screening (Canada, UK, Australia and one US hospital in which care is provided regardless of ability to pay). The last study examined reduced cost mammography in a mobile setting. One study found no association with cervical screening and enrolment in a new breast screening programme in Spain.¹⁴⁷

Other health behaviours

Three studies examined the effect of undergoing cervical screening on subsequent use of GP/health services and found a positive association. Two studies, from Mexico and Denmark, found that attenders had more consultations than non-attenders.^{232,233} One of the studies did not find any difference between women who attended cervical screening following a screening programme invitation compared with women who were screened opportunistically.²³³ Another US study found a positive association with use of GP services for women who underwent cervical screening and were educated on the importance of obtaining regular cancer screening services.²⁴⁶ As this study recruited high-risk women (including those without a regular source of healthcare) and the education session discussed the importance of establishing a regular healthcare provider, it is difficult to separate the effect of the education programme from the effect of undergoing cervical screening.

Four studies examined aspects of BSE. Two cross-sectional studies reported no association between cervical screening and BSE behaviours.^{119,166} The other two studies both reported positive associations with women who have had cervical screening being more likely to engage in BSE behaviour.¹⁴⁴ In one study, women who attended a BSE class were more likely to have had cervical screening than non-attenders at the class.¹⁴⁴ The other study involved both cervical screening and an education session, and found a beneficial effect on BSE behaviour.²⁴⁶ However, the effect of the education session and the effect of undergoing cervical screening are difficult to separate in this study.

Three papers examined smoking behaviour and cervical screening. One cross-sectional study of preventive behaviour in women found a positive association, indicating that women who were screened were less likely to smoke.¹⁶⁴ The other two case-control studies reported no association

between smoking status and screening status.^{233,234} One of the papers compared passive, active, never and ever attenders at cervical screening, and found no significant differences in smoking status between these groups.²³³

One study examined various other preventive health behaviours. Positive associations were seen between cervical screening and dental check-ups, dietary practice, exercise and the use of seatbelts.¹⁶⁴

Health beliefs: results from observational comparative papers

Perceptions of cervical cancer risk

Three papers examined perceptions of cervical cancer risk. An age-matched (20–60 years) UK case-control study reported that screened women compared with non-screened women perceived themselves to be at greater risk of cervical cancer.²³⁴ The other two studies reported no association.^{145,235} One US study involved older black women (over 65 with an average age of 75 years) and no numerical data on this outcome were presented.¹⁴⁵ The other study involved lower income, predominantly black women aged over 20 years in the USA.²³⁵

One further study examined perceived susceptibility in women with a positive smear test who were adherent or non-adherent with recommended follow-up.²⁴⁵ This study found no difference between adherers and non-adherers for recommended follow-up with respect to perceived susceptibility.

Knowledge of cervical cancer and cervical screening

Four studies reported results on knowledge of cervical cancer and cervical screening. Two studies found a positive association between attendance at cervical screening and knowledge of cervical screening.^{232,236} One study found that 57% of cervical screening non-users knew of the Pap test, compared with 97% of users.²³² In another study, 47% of attenders, 26% of defaulters and 31% of non-attenders had good knowledge of the smear test.²³⁶ In two studies where the temporal relationship is more clear, there was no association between attenders and non-attenders with respect to knowledge of cervical screening.^{123,145} In one of the studies, the vast majority (99% of attenders, 100% of non-attenders and 95% of ambivalent attenders) knew what a Pap smear was.

One further study examined knowledge in adherers and non-adherers for colposcopy and

found that women who knew the result of their Pap smear were more like to adhere to colposcopy follow-up.²⁴¹ The study also found that women who reported their Pap smear results correctly were more likely to adhere. However, it is possible that attendance at colposcopy had a positive influence as an active or passive reminder of the result of the smear test.

Other health beliefs

One paper reported on perceived barriers to cervical screening. The study found no differences with respect to perceived barriers between women adherent or non-adherent with recommended follow-up.²⁴⁵

Three studies examined reported embarrassment about cervical screening. Two studies found a positive association with embarrassment and cervical screening. Women who were screened found it less embarrassing than those not screened or with fewer screens.^{234,235} One study of women with positive smear results referred for colposcopy found that there were no differences between adherent and non-adherent women regarding the belief that pelvic examinations are embarrassing.²⁴¹

Two studies reported a positive effect of cervical screening on fear of cancer. One study found that women who were screened in the past 3 years had less fear of cancer than those who had not been screened in the past 3 years.²³⁵ The other study of women with positive smear results referred for colposcopy found that there were no differences between adherent and non-adherent women regarding fear of cancer.²⁴¹

One study looked at women with a positive test result in terms of adherence with recommended follow-up, and found that adherent women were more likely to be able to cope with a positive test result than non-adherent women.²⁴⁵ This study also found that uncertainty about the test result was associated with adherence with follow-up recommendations.

Another study compared lower income black women with positive and negative cervical screening test results. At the 3-month follow-up, women with positive test results reported more worry about cervical cancer, impairment of daily activities, impairment of sexual interest and sleep disturbance than women with negative results.²⁴⁴ There were no differences reported in tension. This study then compared women with positive test results who were either adherent or non-

adherent with recommended follow-up, and found significant differences.²⁴⁴ Non-adherers were more likely to report worry, impairment of daily activities, negative mood, lowered sexual interest and sleep disturbance compared with adherent women, who only reported negative outcomes for sleep disturbance and impairment of daily activity. However, it is not possible to determine whether the distress pre-dates the result or is caused by the result, owing to the lack of baseline data.

One study reported on perceived benefits of cervical screening in users and misusers of cervical screening and found there was no significant difference between the misusers and adequate users in understanding the benefits of cervical screening.²³²

No differences in perceived benefits of cervical screening were observed in women with positive results who were either adherent or non-adherent with recommended follow-up.²⁴⁵

One study looked at perceived efficacy of cervical screening in women who had a cervical smear in the past 3 years compared with more than 3 years ago. The study found that women who were screened less than 3 years ago were more likely to believe screening to be effective.²³⁵

Three studies examined the perceived efficacy of early detection for cervical cancer. Two studies found no difference in perceived benefits of early detection based on attendance status.^{145,234} One study of women with positive smear results referred for colposcopy found that there were no differences between adherent and non-adherent women regarding perceived benefits of early detection.²⁴¹ The other study found that 80% of screened women and 74% of non-screened women believed that problems would be cured.²³⁴

One study found that women who were reassured by cancer screening were more likely to attend screening than women who were anxious about screening.²³¹ Another study found that women who were screened in the past 3 years were more likely to believe that screening was 'worth it to make sure nothing wrong' than women not screened in the past 3 years.²³⁵ Another study found that screening provided peace of mind and that there was no association between women screened and not screened on their perception of the likelihood of a positive result (21%).²³⁴

One study of women with positive smear results referred for colposcopy found that there were no

differences between adherent and non-adherent women in terms of their beliefs regarding the concepts 'staying healthy is matter of luck' and 'need follow-up only if sick'.²⁴¹

Health behaviours and beliefs: descriptive data from non-comparative reports

Of the 49 papers included in this section, nine studies did not contain comparison groups (although two studies had some comparative data).

Two qualitative studies explored women's attitudes to and beliefs regarding cervical cancer and cervical screening. The first study explored the attitudes to cervical screening and cervical cancer in a group of older women who had declined or delayed screening.²²⁹ This study found that the women had some misconceptions about cervical screening. Most women believed that by the time cancer was found it was terminal and all women presumed that cervical screening detected cervical cancer. Most women tended to be uncertain about the causes of cervical cancer, but thought that something might have aggravated it. There was uncertainty about risks for cervical cancer, but the idea that the cancer might already be present (hereditary), an active sexual life and smoking were all mentioned. Fear and devastation were used to describe how they thought they would feel if they were diagnosed with cervical cancer. Issues around whether or not to know that one has cancer, versus being pragmatic and doing all one can to help oneself, affected women's intention to have cervical screening. Most women described their pattern of health service use in terms of going to the doctor when something was wrong and did not think about going when all was well. In general, women seemed to feel that the embarrassment of having a smear was more distressing than the physical discomfort of the experience. Women thought that regular screening was important for younger women and also believed that since the guidelines for obtaining a smear test were 3-yearly, the test cannot be that important.

The second qualitative study explored women's attitudes and beliefs after being diagnosed with an abnormal Pap smear and attending colposcopy.²³⁰ The study found that women were unsure of the difference between a precancerous and a cancerous state and were therefore uncertain of their prospects. Women diagnosed with HPV infection were also uncertain of why and how they got it. Fear of cancer and the potential seriousness of the condition were also important aspects of the

experience. Some women actively sought knowledge about their diagnosis. Faith in medicine and a belief in doctors was also a component for some women, even if medicine had failed to explain how and why the abnormality had occurred.

Three studies examined the association between attending mammographic screening and prior cervical screening and found a positive association.^{238,252,253} Another study looked at predictors of mammography screening and found 79% of women had had prior cervical screening.²⁵³ The other study examined the demographics, risk profiles and health practices of women in a fee-for-service breast screening project and found a positive association between undergoing cervical screening and mammography screening.²⁵² Most mammography users had had previous cervical screening. Another study looked at attitudes to cervical screening in women who spontaneously presented themselves for screening.²³⁸ A positive association between previous smear testing and reattendance was seen, with 86% of women having had a prior test and most women having been tested within 3 years. This study found that 60% of women accepted the offer of breast examination/mammography at their Pap smear.

Two studies examined adherence to follow-up recommendations for colposcopy in women with positive smear results. These studies found that 77% and 75% of women attended colposcopy.^{241,243}

Two studies examined knowledge in women before their first colposcopy examination for a first time abnormal smear. One Canadian study from 1992 measured knowledge of reproductive anatomy, Pap tests and results, and colposcopy. Some details on the development of the questionnaire were provided.²³⁷ In this study, 40% of women did not know the location of the cervix, 52% had some understanding of an abnormal Pap result, 39% did not have a clear understanding of the meaning of an abnormal Pap result, 85% had no understanding of the relationship between an abnormal Pap result and disease of the cervix or vagina, and 32% had no knowledge, 40% had some knowledge and 27% had good knowledge of the main reason for colposcopy. A more recent UK study examined knowledge (using a multiple choice questionnaire) in women before their first colposcopy examination.²⁴⁰ This study found that women were very knowledgeable, with 96% understanding that a Pap smear detects early treatable abnormalities and 94% understanding that abnormal cells mean

that you may, but not necessarily, have cervical precancer or cancer. Details on the development of the questionnaire were not provided.

Discussion: cervical screening

Study design issues

It is important to note a number of study design issues, including the biases to which observational studies are subject. These will be further discussed in Chapter 7.

Owing to the observational designs of the studies in this section it was not possible to ascertain the temporal relationship between the exposure to cervical screening and health behaviour and belief outcomes. This, together with the fact that very few studies included pre- and post-screening data, made it possible to only report associations.

Response rates are an area of concern in many studies, particularly with non-attenders. It is possible that publication bias may have resulted in negative or non-significant results not being included in published studies. The accuracy of self-reports of past screening behaviour may have introduced bias into the data. The definition of screening status can be problematic and lead to the misclassification of participants. A variety of terms was used to define screening status, such as adequate users, misusers and non-users, attenders, defaulters and non-attenders, adherent and non-adherent, and ever and never users of cervical screening. Some studies used attenders and non-attenders. It is possible that 'non-attenders' may have been previously screened, but on this occasion were not screened within the specified period for the study. Therefore, the 'non-attenders' may have actually attended in the past, making the effect of screening difficult to ascertain.

There was also a wide range of cervical screening programmes. Some countries have a call and recall screening programme. Others rely on an opportunistic system to screen the population and may use the media to promote screening. These differences between programmes may also affect our understanding of outcome variables, such as the relationship between intention and actual behaviour due to the recommended length of time between smear tests.

In terms of outcomes studied, there were no studies of health beliefs other than those associated with cervical cancer.

What is shown by these studies

Overall, the associations between cervical screening and various health behaviours and beliefs that were examined were found to be beneficial. However, there are some caveats.

Not all effects of screening were beneficial. This particularly applies to women with positive Pap test results. The temporal relationship between the screening exposure and subsequent health behaviours and beliefs has been problematic. There were very few studies with the correct temporal relationship investigating outcomes of interest. Because of the absence of RCTs, it was possible to observe only associations, rather than causal relationships. This, coupled with the lack of baseline measures, has made ascertaining the effect of cervical screening on future health behaviours and belief difficult.

The outcomes present in the literature on the effect of cervical screening on health behaviours include intention to attend cervical or breast screening, attendance/reattendance at cervical screening and breast screening, adherence to follow-up for a positive smear test, and a few other behaviours such as use of GP/health services, BSE and smoking. Most of these health behaviour outcomes were positively associated with cervical screening. Only one cross-sectional study examined cervical screening in terms of general preventive health behaviours such as exercise, dietary practice and dental check-ups.

Intention to attend cervical screening and/or breast screening was high. However, none of the studies measured intention to attend and actual attendance in the same group of women, therefore, it is not known whether intention translated into actual behaviour. It was not possible to examine what effect the interval between screens may have on a person's intention to reattend.

Almost half the papers in this section were studies of breast screening that found that women who had prior cervical screening were more likely to attend for future breast screening. Women with more recent cervical screening were even more likely to attend breast screening. The effect of attendance at past cervical screening on attendance at future cervical screening was also examined and a beneficial association was found.

Adherence to follow-up recommendation after a positive smear test ranged from 53 to 75%. It is important that cervical screening should not have

a detrimental effect on adherence to follow-up recommendations and health beliefs in women with a positive smear test. Women who have undergone cervical screening and learned of a positive result, and who do not adhere to follow-up recommendations, lose out on the possible benefits of early diagnosis by not adhering to follow-up.²⁴² However, by this point, these women have experienced the advantages and disadvantages of the initial cervical screening event. The effect of screening on future health behaviour and beliefs is particularly important in this group of women.

The outcome use of GP/health services was classified as beneficial if an increase in use was observed. Based on the data presented in papers, it was not possible to judge whether or not the use of GP/health services was appropriate. However, the definition of 'appropriate' is difficult in itself. This was also the case for BSE, which was classified as a beneficial outcome. However, if the increase was beyond what would be classified as an appropriate level then this could be a negative outcome. Once again, for both outcomes, studies did not have baseline measures or reported changes that could help to determine the nature of the association.

Potentially, it could be anticipated that a woman who has undergone cervical screening to try to reduce the risk of developing cervical cancer, particularly if she has had a positive smear or been diagnosed with a minor abnormality, may alter her behaviour to reduce her level of risk. For example, the sort of behaviour change one might anticipate includes smoking cessation, reduction in the number of sexual partners or an increase in the use of condoms. However, smoking cessation is primarily associated with the desire to prevent lung cancer and CHD, and not with cervical cancer.²⁵⁴ In addition, screening programmes rarely publicise the risk attributable to smoking. A recent systematic review looking at interventions to reduce the risk of cervical cancer found no studies examining this issue.²⁵⁵ Although condoms may lower the risk of contracting HPV, in order to avoid stigma, cervical screening programmes rarely emphasise the fact that multiple sexual partners increase cervical cancer risk, so participants may remain unaware of this risk. It is therefore not surprising that no studies were found looking at this issue. However, this information is also necessary to enable women to make informed choices regarding potentially modifiable risk factors for cervical cancer.²⁵⁶

In terms of the effect of cervical screening on health beliefs, the outcomes found in the literature include perception of cervical cancer risk, knowledge of cervical cancer and cervical screening, barriers and benefits to cervical screening, and reassurance. Very few papers measured the same health belief outcomes in the same population in order for comparisons to be made. Also, most of the outcomes were measured in a small number of studies.

Cervical screening may be associated with a greater perception of risk of cervical cancer in women attending screening compared with non-attenders. For women with a positive Pap smear result there was no difference in risk perception between adherers and non-adherers. Perception of cervical cancer risk was classified as detrimental if an increase in perception of risk was reported. However, this may not be the case if the original perception of risk was too low, in which case it may have been brought up to a more reasonable level of risk. As the studies did not include baseline measures or reported changes in perception, the nature of the change in perception is not clearly understood. In many cases the temporal nature of this outcome was difficult to ascertain. It may be that screened women came to screening because of an increased perception of risk.

The effect of cervical screening on health knowledge is unclear. Not unexpectedly, most studies reported that attenders were more knowledgeable than non-attenders. However, most studies reported poor levels of knowledge even in screened women.

Women who attended cervical screening were less likely to be embarrassed than those who did not attend. There was no difference between women with a positive Pap test result for those adherent or non-adherent in terms of whether pelvic examinations were embarrassing.

Reassurance was classified as a beneficial effect of screening, although the effect of the reassurance on subsequent health behaviours and beliefs was not clear in the papers. The reassurance may be

beneficial by providing an 'all-clear' result. However, it may have a detrimental effect by providing false reassurance of a disease-free status and allowing symptoms to be ignored between cervical screens.

Cervical screening is targeted to women in a large age range. However, not all health behaviours will be applicable to all age groups (e.g. breast screening, which is targeted to women aged 50 years and over). The effect of age on health behaviours and health beliefs must be kept in mind in determining appropriate study outcomes.

Summary

In terms of the specific review questions, the effects of cervical screening on future health behaviour and beliefs have not been directly measured in many studies, so it is difficult to answer these questions. However, it appears that cervical screening has an overall positive association with health behaviour outcomes, such as intention to attend cervical and breast screening, actual attendance at cervical screening and breast screening, and use of GP/health services. The association between cervical screening and health beliefs is more complex. Relatively few papers examined the outcomes of interest, met the temporal requirements of the review and had a baseline measure, so the conclusions must be treated with caution.

Very little research focused on the questions posed by the review. Most of the data for this section of the review were from cross-sectional or cohort studies that lacked the temporal data needed to answer the question. Future research needs to be undertaken that prospectively measures change in a wide variety of health behaviours and beliefs before and after screening (*Box 3*). This will provide a better understanding of the role of pre-existing behaviour and beliefs, and how they may or may not be altered by screening. It is possible that women who attend cervical screening have a certain set of health behaviours and beliefs that are unconnected to their experience of cervical screening.

BOX 3 Future directions in research

- The impact of cervical screening on a full range of future behaviours and beliefs has not specifically been addressed in many studies.
- Prescreening measures are lacking. The need for baseline measures is paramount to assess the influence of already held beliefs and behaviours, which currently cannot be accounted for. This needs to be included in evaluations of any screening programme (including emerging programmes such as colorectal, ovarian and prostate cancer).
- Qualitative research should be conducted to investigate what people understand about health behaviours and beliefs in order to inform collection of appropriate outcome measures for future research. Particular emphasis should be on better understanding of age-specific behaviours and beliefs.
- The differential effects on future behaviours and beliefs should be investigated in different screening outcomes groups (e.g. all clear, positive).
- Qualitative and quantitative research is needed to explore the relationship between intended behaviour and actual behaviour (e.g. attendance at cervical screening) to explain the disparity between these outcomes. This should examine the intention to attend during differing lengths of screening interval, including the effects in groups with differing screening outcomes.
- Qualitative research is needed to understand why the attendance rates for colposcopy and repeated smears are not optimal. This could ultimately lead to the development of appropriate interventions to minimise anxiety and uncertainty, and to optimise the benefits of early detection.
- Exploration is required of women's perception of risk of cervical cancer and the role of personal risk factors and potential modification (e.g. smoking, HPV).
- Qualitative research is needed to explore understanding of screening, including reasons for screening, continuing awareness during the screening interval, the impact of screening interval and eligible age range on implicit risk perception, and its impact on behaviours and beliefs.
- What is the influence of risk perception? Is it an enabling or a disabling factor?
- Research is needed to understand how people are currently using screening (confirmation of health or disease detection), reasons for misuse, why previous non-attenders decide to attend and reasons for possible declines in routine screening after a false-positive result.

Chapter 7

Discussion

Review methods

Search terms

The scope of the review, particularly with respect to outcomes, was very broad. The searches were therefore developed to be inclusive. During their development it was ensured that papers that had been retrieved by handsearching or were in the personal collections of the authors were identified by the electronic search. This resulted in a search that was sensitive (identified relevant papers), but was not specific, as indicated by the proportion of the papers that were included in the review (4% were fully data extracted and only 174 of these were eligible to be included in the review, which represents just over 1% of all papers retrieved).

Many of the papers identified by the searches investigated participants' health behaviours and beliefs as predictors of screening. It was not possible to select out these studies at the search stage. Many of these papers were excluded in Stage 1 of the review (see Chapter 2).

Availability of evidence

A distinction should be made between the hierarchy of evidence and criteria for inclusion and exclusion. As there were very few RCTs in the literature all study designs were included in the review, resulting in a variety of levels of evidence being presented. This was especially so for the sections on breast and cervical screening, where there are well-established screening programmes and it would not be feasible or ethical to randomise participants into a screening group and a non-screening group, and therefore most comparisons were based on observational studies. It was also apparent from the cholesterol section that, although there were more RCTs available, it would not be possible to conduct some of them today for ethical reasons.⁹⁵

Restricting the review to studies that provide a high level of evidence (RCTs and to some extent prospective cohort studies) would have resulted in very few included papers. Although this would have been desirable, important messages from the rest of the literature would not have been found. Very few studies looked directly at this question,

and even where, for example, health beliefs were measured after screening, in very few cases were these beliefs also measured before screening. It could be argued that study types that provide low levels of evidence, such as cross-sectional studies, should have been excluded as they could not provide any information about future behaviour. However, if participants were asked what their future intentions are, conclusions can be drawn about the impact of screening on future behaviours and beliefs in studies of a lower order of hierarchy.

Studies from several countries were included to draw these conclusions, as it was felt that restricting the results to the very small number of methodologically robust UK studies was inappropriate, and lessons could be learnt from the experiences in other countries.

Quality scoring

Each paper that was data extracted was given a quality score using a modified version of the checklists developed by the CRD in York (see Chapter 2 and Appendix 2). After excluding papers that had a low quality score (< 50%) it was hoped to examine the results from all included papers and then a subgroup of high-quality papers. However, it was felt that the quality scores obtained from these measures did not represent the general quality of the papers, and although 'low'-quality papers were excluded, an analysis of only 'high'-quality papers was not conducted. Some papers were rated with quite a high score, when the reviewers felt that the paper was not of good quality. This has two implications: first, the quality scores were not used beyond excluding the poor-quality papers (the question could be asked as to whether these papers should have been excluded on the basis of a 'substandard' measure); and second, there is a need to develop a scoring scheme that will adequately capture the methodological and reporting rigour of each type of study design. Whether a quantitative measure, such as a checklist, can ever answer an essentially qualitative question needs to be explored. Further research into this area is needed if the methodology of epidemiological systematic reviews is to be developed.

Temporal relationship between screening and outcomes

The majority of papers looking at the effects of cholesterol screening were prospective and followed participants after screening to investigate whether lifestyle changes were made and how screening affected their beliefs. However, for breast and cervical screening many of the studies measured and collected information about screening and health behaviours at the same time. This made determining whether beliefs and behaviours precede or follow screening difficult to ascertain. Of the studies that used a prospective approach, many did not collect information regarding behavioural patterns or health-related beliefs at baseline and therefore it is impossible to tell whether the positive associations observed were because the types of women who engage in screening are the same women who already hold positive health beliefs and behave in a 'health-inducing' manner. In other words, in many cases it was impossible to tell whether the observed traits were brought to screening or resulted after screening.

Classification of beneficial or detrimental health outcomes

In the results tables the outcomes were categorised into those that could be considered beneficial or detrimental to health. These were shown as (+) where it was judged to be a favourable outcome in health behaviour or belief terms and (-) where the outcome could potentially be harmful.

There may be argument over whether some of the outcomes that have been categorised as beneficial may be so. Outcomes such as smoking cessation or improvement in diet are unquestionably beneficial to health, but for other outcomes the relationship is less clear. For example, an increase in the use of GP services has been categorised as a beneficial outcome in all three screening outcomes. This may be the case in cholesterol screening where the participant has consulted the GP to obtain more advice about lifestyle modifications. However, an increase in GP usage after breast or cervical screening may be indicative of unnecessary visits due to increased concern about the personal risk of developing cancer.

Another example of a behaviour that may be beneficial, but could also be deleterious to health, is the practice of BSE. Historically, BSE was promoted as a screening technique for breast cancer, but there is no evidence to suggest that it is effective and it may even increase anxiety in women. Several studies investigated the relationship

between breast screening (including the effects of false-positive results) and BSE behaviours. An increase in BSE behaviours was coded as beneficial (+) as the authors of the papers seem to view this as a favourable practice. However, recently, the emphasis in health promotion has shifted from a ritualistic examination of the breasts to a more general awareness of healthy breasts. In time this will be reflected by a more sceptical view of BSE in emerging papers.

Methodological issues of studies

Selection (response) bias

In some papers the response rates between the comparison groups were vastly different, with the lowest response rates often occurring in non-attenders at screening. A particular problem that affected breast and cervical screening studies was that many of the studies were cross-sectional, and although overall response rates to the surveys were given it is not known what proportion of the non-responders were those who accepted or declined screening.

A similar issue was observed in the cohort studies. Several of the studies looked at predictors of screening in attenders and non-attenders, and often one of those exposures was past breast or cervical screening collected retrospectively. Hence, the response rates in the comparison groups of interest cannot be ascertained as those data were not available for non-responders. Infrequently, routine data sources were used to collect such information, but the investigators did not present this information for non-responders.

In some studies, sociodemographic data on the participants were not presented. This does not allow an understanding of the participants and limits the generalisability of the study. Cervical screening is targeted to women in a large age range, from 20 years and older. However, not all health behaviours will be applicable to all age groups; for example, breast screening is targeted to women aged 50 years and over. The effect of age on health behaviour and health beliefs must be kept in mind.

Ascertainment bias

The definition of screening status can be problematic and lead to the misclassification of participants. A variety of terms was used to define screening status, such as adequate users, misusers and non-users, attenders, defaulters and non-attenders, adherent and non-adherent, and ever and never users of screening. The term non-

attenders does not necessarily imply that they have never undergone screening, but means that they have not attended for the latest screening appointment.

Most studies used the same methods for collecting information from exposed and unexposed populations (e.g. screened and not screened). Where a study collected data using different techniques for the comparison groups (e.g. direct data collection from one group and routine data sources for another), this is noted in the 'notes' column of the results tables.

Recall bias

The accuracy of self-reports of past screening behaviour may introduce recall bias to the data. Some studies tried to validate this information by asking for information on where the test was performed, how the results were obtained and whether or not the screening was undertaken following a recommendation by a doctor. Other studies used medical records to obtain data on past screening history. It is very difficult to study beliefs retrospectively owing to the difficulty in accurately recalling previous beliefs and the possible effect of bias from current beliefs.

Recall bias can also occur as exposed subjects are more likely to report the outcome of interest if they know the relationship that is being investigated. However, in many of these studies the effects of screening on future behaviours and beliefs were not the primary relationships studied and therefore the respondents are likely to be blinded to that hypothesis. However, conversely, as these data were not collected specifically to address these questions, the quality of the data may be questionable.

Publication bias

In epidemiological studies a great deal of information is collected about a wide range of variables. It is possible that variables that showed negative or non-significant results were not included in published studies. Studies with overall negative or non-significant results may also have not been written up or were turned down for publication.²⁵⁷ These would not be included in this review.

Other reviewers have contacted authors for unpublished data, but these have frequently been of RCTs which tend to collect data on fewer variables. The search criteria went back to papers published in 1980 and the data from these papers will probably not be available now.

Health belief models

Although some studies made reference to models of health beliefs and subsequent health behaviours, this tended to be largely atheoretical. The various models of health behaviour share the common theme that beliefs about the disease, the impact of one's actions, and so on, will influence behaviour. To this extent, some measurement of these beliefs is appropriate as it may be hypothesised that a change in these beliefs will be a predictor of subsequent behavioural change.

However, where models were used (most frequently the HBM and the HLC model), they were often used to predict uptake of screening, not reactions to screening. This is unfortunate, in particular given the broad range of models that exist for predicting behaviour from a variety of theoretical perspectives.

However, it is also the case that the nature of the relationship between these beliefs and corresponding behaviours varies across different models, depending also on the role of various moderating variables, such as self-efficacy beliefs. It would be desirable for studies that attempt to assess the role of health beliefs to state explicitly the model of health behaviour that is being adopted, as this will influence the measures taken.

Results of the review

The study designs used in the three screening types differed. The studies that focused on cholesterol screening used prospective designs much more frequently to investigate the effects of screening than those that studied breast or cervical cancer screening. This may be explained by differing research agendas. The majority of the cholesterol papers were interested in observing changes in lifestyle behaviour following screening, as participants who were given a high blood cholesterol reading following cholesterol screening were able (and recommended) to make beneficial lifestyle changes to reduce their risk. However, participants who went for breast or cervical screening were not offered advice on lifestyle changes to reduce their health risk, and therefore studies tended to report associations between screening and behaviours/beliefs, owing to cholesterol screening being a primary prevention approach with accompanying lifestyle advice to reduce cholesterol levels where needed.

Most of the research into cancer screening programmes has investigated issues related to

uptake of screening services, explanations of why people are or are not screened and interventions to improve uptake. Less research has been conducted on the effects of screening. Those that have investigated the consequences of screening have largely concentrated on cancer-related outcomes, such as further screening behaviours, perceived susceptibility and severity of cancer, and have not looked at the wider issues. *Table 7* summarises the outcomes measured in the included studies.

Across all three screening types there were very few qualitative studies that could have provided a better understanding of how and why participants in screening are affected by the processes that they have undergone. The small number of qualitative studies in the cholesterol screening section elicited some negative effects of screening on health beliefs which were not identified by the quantitative studies that measured these types of outcome. It is possible that the quantitative methods are not sensitive enough to detect such subtle changes in beliefs. Qualitative research could explore how screening experiences have altered the participants' beliefs and whether this change in belief has affected, is affecting or will affect their behaviour regarding health-promoting activity.

Comparison between systematic, opportunistic and open access screening

Screening may be offered as a systematic programme, opportunistically in health service settings or as open access in drop-in clinics. The patient–doctor role is reversed in organised screening programmes, as professionals approach the public who may perceive themselves to be healthy and may never have considered the condition to be screened for as a problem. This is also the case in opportunistic screening, as the doctor introduces the subject to the patient. In contrast, open-access screening is participant led and therefore the dynamics are different.

The studies of cholesterol screening included all three methods of provision, whereas studies of breast screening were mainly of systematically organised programmes and those of cervical screening were conducted using either a call and recall system (systematic) or opportunistic approaches. None of the studies compared the three approaches to screening provision, so it cannot be concluded which method is best in terms of impact on health behaviours and beliefs.

Comparisons with other reviews

Most of the reviews identified by the searches were non-systematic and those that were systematic focused on psychological effects of screening (not included in this review) or on predictors of screening. As stated elsewhere, the only relevant predictors of screening that are included in this review are measures of previous attendance at cholesterol, breast or cervical screening, and in these cases the relevant primary papers were included in this review. However, the reviews of predictors of screening also concluded that previous attenders were more likely to continue screening than those who have never been screened.

National Screening Criteria

The National Screening Committee (NSC) has produced a modified version of the World Health Organization (WHO) screening criteria to take into account the more rigorous standards of evidence and also to increase the weight given to the potential negative effects of screening.²⁵⁸ The committee states that all the criteria below should be satisfied before a screening programme is introduced.

This systematic review has focused on one condition for which there is no organised, systematic screening and relies purely on opportunistic screening or open screening (cholesterol screening) and on two systematic programmes, namely breast and cervical cancer screening.

The NSC criteria are outlined below and are discussed with reference to the three screening types.

The condition

1.1 *The condition should be an important health problem.*

As mentioned in the Introduction, hypercholesterolaemia has been estimated to contribute to over 40% of CVD deaths in the UK, and breast cancer is the most common form of cancer in women, with one in nine women in the UK being affected during their lifetime, and these are therefore clearly important health problems. Cervical cancer currently accounts for 2% of cancers in women in the UK. Cervical screening has contributed to this low figure as it screens for a precancerous lesion which, if treated, prevents the development of invasive cervical cancer. Since 1988 the incidence of invasive disease has almost halved and therefore the burden of this disease has declined.²⁵⁹

TABLE 7 Comparison of the number of studies examining relevant outcomes in the three screening types

Outcomes	Exposures		
	Cholesterol screening	Breast screening	Cervical screening
Health screening behaviours			
Adherence to follow-up recommendations after a positive screen (still part of the current screening process)	24 studies	3 studies (comparing early recall vs immediate follow-up) 2 studies (comparing adherence in previously screened vs not previously screened)	3 studies (comparison by severity of lesion): overall adherence low, but showed increasing adherence with increasing severity of lesion
Intended future screening (same type)	No studies	10 studies	4 studies
Intended future screening (same type) (comparison between false-positive/all clear)	No studies	5 studies	No studies
Actual future screening (same type of screening)	2 studies	21 studies	3 studies
Actual future screening (same type) (comparison between false-positive/all clear)	No studies	5 studies	No studies
Intention to use other preventive screening	No studies	No studies	Breast screening 4 studies
Intention to use other preventive screening (comparison between false-positive/all clear)	No studies	No studies	No studies
Actual use of other preventive screening	1 study (breast screening)	Cervical screening 12 studies Cholesterol screening 1 study Faecal occult blood test 1 study	Breast screening 26 studies
Actual use of other preventative screening (comparison between false-positive/all clear)	No studies	No studies	No studies
Health service usage			
Use of GP services	No studies	2 studies	3 studies
Other health service use	No studies	Dental check-ups 4 studies Immunisation 2 studies	Dental check-ups 1 study
Adherence with drug treatment	5 studies	No studies	No studies
Healthy lifestyle behaviours			
Dietary change	30 studies	3 studies	1 study
Exercise change	15 studies	6 studies	1 study
Blood cholesterol change	21 studies	No studies	No studies

continued

TABLE 7 Comparison of the number of studies examining relevant outcomes in the three screening types (cont'd)

Outcomes	Exposures		
	Cholesterol screening	Breast screening	Cervical screening
Weight change	11 studies	No studies	No studies
Smoking cessation	9 studies	9 studies	3 studies
BSE	No studies	10 studies	4 studies
BSE (comparison between false-positive/all clear)	No studies	4 studies	No studies
Other preventive health behaviours	No studies	Seatbelt use 5 studies Alcohol use 2 studies	Seatbelt use 1 study
Health beliefs^a and attitudes			
Susceptibility to the disease	Accurate recall of personal risk (beneficial effect) 9 studies	19 studies	4 studies
Seriousness of the disease	'Labelling effects' 7 studies	7 studies	2 studies
Benefits of screening	No studies	21 studies	7 studies
Barriers to action	Denial of risk status, etc. 7 studies	23 studies	4 studies
Knowledge regarding disease	5 studies	15 studies	5 studies

^a Health beliefs have been presented according to the major constructs of the HBM. 'Cues to action' have not been included as they are not beliefs, more a trigger that together with the beliefs initiates an action.¹⁷⁶ Cues may be internal, such as symptoms of disease, or external, such as GP recommendation to undergo screening or having experience of salient others with the disease, and are therefore not useful outcomes in this respect. Factors that could be considered to be cues to action have been included more usefully in the other domains of the HBM. For example, symptoms would be included as a susceptibility item, recommendation to go for screening could be classified as believing it to be beneficial; and personal or family experience of the disease could be classed as seriousness of the disease.

- 1.2 *The epidemiology and natural history of the condition, including development from latent to declared diseases, should be adequately understood and there should be a detectable risk factor, or disease marker and a latent period or early symptomatic stage.*

The natural history of CVD (and its relationship to cholesterol as a risk factor), breast cancer and cervical cancer is reasonably well understood.

- 1.3 *All the cost-effective primary prevention interventions should have been implemented as far as practicable.*

Primary prevention, such as modification of risk factors, can only be achieved once the presence of a risk factor has been identified. Cholesterol screening identifies such a factor for CVD and it has been assumed throughout this report that cholesterol screening consists of a blood test and at least simple lifestyle recommendations to reduce cholesterol levels. Currently, there are no well-defined modifiable risk factors for breast cancer and therefore screening remains the most effective method of disease control. At the moment, screening for cervical cancer remains the most viable method of reducing incidence and mortality of the disease, although research is ongoing into HPV as a necessary cause of cervical cancer²⁶⁰ and ways to reduce infection rates among the population.^{261,262}

The test

- 1.4 *There should be a simple, safe, precise and validated screening test.*

For all three types of screening included in this report there are established screening tests that fulfil the above criterion.

- 1.5 *The distribution of test values in the target population should be known and a suitable cut-off level defined and agreed.*

As stated in the Introduction, there is wide debate about the cut-off value that identifies a 'high' cholesterol level. What is deemed to be an acceptable level also depends on other coexisting CVD risk factors such as activity levels and smoking status. An agreed cut-off point, possibly dependent on age and other risk factors, should be decided before the introduction of a systematic programme in the UK. For both breast and cervical screening there are well-defined quality assurance standards to which the programmes adhere.

- 1.6 *The test should be acceptable to the population.*

Cholesterol screening may be undertaken using either a finger-prick or a venous sample of blood, and results may be obtained a few days later or instantaneously. This report has not investigated the impact of these variables on the population and these options should be evaluated before the organisation of a systematic programme.

Women undergoing breast and cervical screening may experience embarrassment, pain or discomfort and anxiety while waiting for test results. There is a large body of research regarding these outcomes and methods to minimise their impact. This evidence has not been synthesised in this report, but where such outcomes have been shown to affect future screening use or affect other health behaviours or beliefs they have been included in the report as described in the relevant Methods sections.

- 1.7 *There should be an agreed policy on the further diagnostic investigation of individuals with a positive test result and on the choices available to those individuals.*

Where there are systematic screening programmes, such as those for breast and cervical screening, there are established protocols for further diagnostic work-up and follow-up.^{263,264} However, in opportunistic or open screening such as cholesterol screening, there are no failsafe procedures to ensure that those at increased risk obtain appropriate investigations or care. There is, however, quite a large body of literature (24 studies) looking at whether participants in cholesterol screening who are found to have a high cholesterol level adhere to recommendations to seek medical advice, and the majority of these studies showed that adherence rates were below 60% (see cholesterol section, Chapter 4).

In breast screening, following a suspicious mammogram, some women are offered further investigations immediately and others are invited to attend for a repeat mammogram after 6 or 12 months, which is called early recall. From this report it would appear that there is higher attendance at the immediate follow-up type of appointment rather than being placed on early recall.

The studies that investigated adherence with follow-up recommendations in cervical screening found that the overall attendance rates were low, but increased with worsening severity of lesion observed on screening. Women with moderate dyskaryosis or worse are referred for colposcopy immediately, whereas women with mild dyskaryosis are invited for a repeat smear after 6 months, which is a similar situation to the early recall procedures in breast screening. Similarly to breast screening, a pattern of lower adherence with increasing time between screening and follow-up was observed.

The treatment

- 1.8 *There should be an effective treatment or intervention for patients identified through early detection, with evidence of early treatment leading to better outcomes than later treatment.*
- 1.9 *There should be agreed evidence-based policies covering which individuals should be offered treatment and the appropriate treatment to be offered.*
- 1.10 *Clinical management of the condition and patient outcomes should be optimised by all healthcare providers prior to participation in a screening programme.*

There are established effective treatments for the three types of condition included in this review, such as statins and lifestyle modifications to lower cholesterol levels, surgery with or without radiotherapy for breast cancer, and excision of affected areas of the cervix to prevent cervical cancer, but this area is not relevant to this review. However, for any intervention to be effective, there must be high levels of adherence to treatment and this may be influenced by experiences of screening. Following cholesterol screening, five studies investigated compliance with drug treatment, three of which reported positive outcomes such as good adherence to treatment regimes and decreasing cholesterol levels. No studies of breast or cervical screening reported compliance with treatment recommendations.

The screening programme

- 1.11 *There must be evidence from high-quality randomised controlled trials that the screening programme is cost-effective in reducing mortality or morbidity.*
This is not relevant to this review.

- 1.12 *There should be evidence that the complete screening programme (test, diagnostic procedures, treatment/intervention) is clinically, socially and ethically acceptable to health professionals and the public.*

This review has attempted to collate the evidence regarding the impact of screening on those members of the public who have been exposed to the three types of screening included.

There was a much larger literature base investigating adherence to diagnostic procedures for cholesterol screening than either breast or cervical screening (24, five and three publications, respectively). The results of these studies have been discussed under section 1.7 of the NSC criteria.

- 1.13 *The benefit from the screening programme should outweigh the physical and psychological harm (caused by the test, diagnostic procedures and treatment).*
Physical harm is not included in the scope of this review as it is not a behaviour or a belief. There is a large body of evidence regarding the psychological effects of screening, including some systematic reviews. For this reason, anxiety caused by screening was excluded from this review unless its effects on health behaviours or beliefs were measured. However, this is an important effect of screening and methods to minimise and accurately measure such outcomes should continue to be the focus of research.
- 1.14 *The opportunity cost of the screening programme (including testing, diagnosis, treatment, administration, training and quality assurance) should be economically balanced in relation to expenditure on medical care as a whole (i.e. value for money).*
- 1.15 *There must be a plan for managing and monitoring the screening programme and an agreed set of quality assurance standards.*
- 1.16 *Adequate staffing and facilities for testing, diagnosis, treatment and programme management should be made available prior to the commencement of the screening programme.*
- 1.17 *All other options for managing the condition should have been considered (e.g. improving treatment, providing other services), to ensure that no more cost effective intervention could be introduced or current interventions increased within the resources available.*

- 1.18 *Evidence-based information, explaining the consequences of testing, investigation and treatment, should be made available to potential participants to assist them in making an informed choice.*
- 1.19 *Public pressure for widening the eligibility criteria, for reducing the screening interval, and for increasing the sensitivity of the testing process, should be anticipated. Decisions about these parameters should be scientifically justifiable to the public.*

The above criteria are not discussed further as they do not have a direct relevance to this review, except that in the UK, where there are established breast and cervical cancer screening programmes, the above criteria are met. However, in the case of cholesterol screening which is available opportunistically and via open-access routes there is not the organisation of an established programme and consequently these criteria are not fulfilled.

Limitations of the review

The literature searches produced an overwhelming number of papers. Reviewing the literature was regarded as a higher priority than writing to those active in the field to enquire about studies in progress. In addition, the exclusion of articles published in foreign languages may introduce bias into the review.²⁵⁷ However, as only 1% of the total papers retrieved were included and the vast majority did not meet the inclusion criteria the effects of these approaches may be small.

An original question to be addressed by the review was: What are the implications for the NHS, including their impact on the cost-effectiveness of screening programmes? However, there was no literature on the cost-effectiveness regarding the wider implications of screening (only on reduction of disease-specific mortality/morbidity). This is possibly due to the outcomes being very broad and not easily categorised or classified.

Summary

The literature was limited to a small number of potentially relevant outcomes, such as follow-up after screening, future screening and cancer-related health beliefs, which were directly related to cancer screening and were derived mainly from observational studies. Given the limited nature of the data, the evidence seems to suggest that all three screening types (cholesterol, breast cancer

and cervical cancer screening) are associated with high levels of favourable health behaviours and beliefs that have been measured, although there is evidence that recommended follow-up after screening is often not adhered to. This is summarised below. However, in order to explore fully the effects of screening on future health behaviours and beliefs a much wider range of outcomes should be studied, as most of the previous research has been restricted to outcomes related to the condition being screened for.

- Evidence suggests that cholesterol screening may have a positive impact on health behaviours. The majority of studies reported an adoption of healthier diets, increase in exercise, reduction in weight and reduction in cholesterol levels for those diagnosed with high or moderately high cholesterol levels. There was inconsistent evidence to suggest that screening had a positive impact on smoking cessation.
- Follow-up among those identified as possibly having high blood cholesterol is often inadequate, although higher risk levels predict better adherence to referral.
- Evidence from quantitative studies suggests that cholesterol screening has no effect on labelling, with no increased absenteeism from work or negative perceptions of health. However, qualitative studies identified problems with participants accepting their new risk status.
- Participants in cholesterol screening have a good general knowledge of cholesterol issues, but there is inconsistent evidence for recall of personal cholesterol levels.
- Evidence suggests that previous cholesterol screening had a positive impact on health behaviours such as future cholesterol and breast screening, dietary change, smoking cessation and adherence to recommended follow-up. Those who had previously attended cholesterol screening also accepted their risk status better than newly screened participants.
- Results from intervention studies suggest that knowledge of high cholesterol status resulted in improvement in health behaviours, but had negative effects on health beliefs for those who were aware of their high-risk status.
- Breast screening participation appears to be positively associated with previous breast screening attendance.
- It is also positively associated with several favourable 'passive' health behaviours, such as regular cervical screening, regularity of dental check-ups and seatbelt use, and, to a lesser extent, 'active' health behaviours such as (non-)smoking, diet, alcohol use and exercise patterns.

- The temporal relationship between breast screening and these behaviours cannot be firmly assessed owing to the study designs used.
- Knowledge was greater among women who had been screened than among women who had not.
- Cervical screening is positively associated with intention to attend cervical and breast screening, actual attendance at cervical screening and breast screening, and use of GP/health services.
- The association between cervical screening and health beliefs was more complex.

To answer the question posed by the review, further research needs to be undertaken which would include measuring a wider range of behaviours and beliefs before screening and after

screening has been accepted or declined to measure changes that occur between the two periods. Those with normal results need to be studied, as well as those with abnormal results. Qualitative research into the experience of screening and how this interacts with knowledge and beliefs about other aspects of health, not simply those relating to the condition being screened for, is needed. Methods of quantifying the quality of epidemiological studies need to be further developed and improved. See *Box 4* for the recommended prioritised research topics.

Areas for future research for each of the three screening types in this review are outlined in Chapters 4–6.

BOX 4 Summary of recommended research topics

- | | |
|---|---|
| <ul style="list-style-type: none">• Research is needed on the effects of screening on a wide range of health beliefs and behaviours, both before and after screening. This needs to be included in evaluations of any screening programme (including emerging programmes such as colorectal, ovarian and prostate cancer, and for new technologies such as HPV testing and liquid-based cytology).• Research is needed on the differential effects on future behaviours and beliefs in different screening result groups (normal, increased risk, false positive, etc.). | <ul style="list-style-type: none">• Studies are needed to assess the long-term impact of screening on health behaviours and health beliefs.• Qualitative studies are needed to assess the impact of screening on health beliefs, as well as the process of change, and to look at the complexity of individual decisions to change behaviours.• Investigation of elements of multicomponent interventions, individually and in combination, are most effective in motivating patients to make changes in their behaviour. |
|---|---|



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