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Factors influencing the decision to attend screening for cancer in the UK: a meta-ethnography of qualitative research

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ABSTRACT

Background This review aimed to better understand experiences of being invited to cancer screening and associated decision-making.

Methods Qualitative evidence explaining UK cancer screening attendance decisions was systematically identified. Data were extracted and meta-ethnography used to identify shared themes, synthesise findings and generate higher level interpretations.

Results Thirty four studies met inclusion criteria. They related to uptake of breast, cervical, colorectal, prostate, ovarian and lung cancer screening. Three primary themes emerged from the synthesis. *Relationships with the health service* shaped decisions, influenced by trust, compliance with power, resistance to control or surveillance, and perceived failures to meet cultural, religious and language needs. *Fear of cancer screening* was both a motivator and barrier in different ways and to varying degrees. Strategies to negotiate moderate fear levels were evident. *Experiences of risk* included the creation of alternative personal risk discourses and the use of screening as a coping strategy, influenced by disease beliefs and feelings of health and wellness.

Conclusions The findings highlight the importance of the provider-patient relationship in screening uptake and enrich our understanding of how fear and risk are experienced and negotiated. This knowledge can help promote uptake and improve the effectiveness of cancer screening.

Keywords Cancer screening, screening uptake, screening barriers, qualitative review, meta-synthesis, meta-ethnography, cancer fear, patient-practitioner relationship

Introduction

More than fifty per cent of people in the UK born after 1960 will be diagnosed with cancer in their lifetime.[1] In order for screening to be effective in reducing cancer mortality it is important that uptake is high. National Health Service (NHS) population screening tests for breast, cervical and colorectal cancer have uptake rates of 71%,[2] 73%[3] and 52%[4] respectively in England. Those who do not attend are more likely to be at higher risk; improving uptake is therefore a key public health strategy to reduce health inequalities in outcomes at every stage of the cancer patient pathway.[5] Ethnicity, social deprivation and gender are important determinants of cancer screening uptake.[6] Factors influencing screening uptake identified in quantitative research include practical barriers, such as difficulty making an appointment, forgetting to do so and dependency on others to carry out the activities of daily living.[7, 8] Psychosocial motivators and barriers, including embarrassment, worry, anxiety and self-efficacy have also been identified.[9, 10] Interventions to improve uptake targeting structural and system factors, such as invitation and reminder methods, and education have been demonstrated to be effective.[11-13]

Public debate about communication of the benefits and harms of screening has led to a shift from the objective of maximising uptake to the promotion of informed uptake.[14] A systematic review of interventions to promote informed choice about health screening found some evidence that greater informed choice does not reduce uptake but this was based on a limited number of studies.[15] A randomised controlled trial of information about overdetection in breast cancer screening found that greater knowledge about the potential harms of screening may reduce intentions to be screened.[16] Higher awareness of the risks of screening could contribute to a decline in the positive social attitudes to cancer screening which have generally been observed.[17, 18] This highlights the importance of using an exploratory approach to investigate thoughts and experiences of recipients of cancer screening invitations to better understand why a proportion of individuals do not attend when invited.

The aim of this meta-ethnography was to systematically identify and synthesise qualitative evidence which explains cancer screening attendance decisions in the UK.

Methods

Eligibility criteria

Studies were eligible for inclusion if they utilised qualitative methodology and included evidence of factors influencing decisions to attend screening for cancer. We limited our search to UK studies because there are international differences in the organisation and delivery of screening and a need for uptake strategies to consider health service context and cultural and societal norms.[6] At least one factor must have been described, either by a participant or the author, as having influenced the participant's prior real-life screening attendance decision.

Screening programmes eligible for inclusion were organised population screening and research trials of screening methods. Opportunistic screening, self-examination, second stage screening (e.g. a diagnostic test following an abnormal screen), genetic testing and family history counselling were all ineligible. Reports solely of the views of people other than the screening invitation recipient (e.g. health care practitioners) were ineligible. Research which reported screening attendance decisions exclusively in individuals with symptoms of the disease, a previous cancer diagnosis, physical or learning disabilities, or who had experienced sexual abuse were ineligible.

Several data sources were searched (see Supplementary data, Table 1), reference lists of included studies were searched for further relevant references and Web of Science was used to search for papers citing the included studies. Search results from each source were combined and duplicates removed. Titles and abstracts were screened for eligibility independently by BY and LB. A third researcher (RdN) was available to resolve any disagreements. Full text papers were retrieved and the eligibility of each paper for inclusion was assessed by BY and LB. Papers assessed as eligible were then classified independently by both BY and LB according to a typology of findings in qualitative research.[19] This addressed the problem that methodologies stated by qualitative study authors often do not accurately reflect those which are used. The typology outlines five categories which classify study findings as qualitative or not qualitative depending on the degree of data transformation (see Supplementary data, Table 2). Studies classified as 'qualitative findings' were included and others were excluded.

Study characteristics were extracted from included papers. Quotes and text from papers which met the criteria were extracted into a spreadsheet by BY, coded as first or second order constructs[20] and as primary or secondary data (Supplementary data, Figure 1).

Appraisal of included papers was conducted independently by both BY and LB using the Critical Appraisal Skills Programme (CASP) tool for qualitative research.[21] The tool has ten questions which assist in forming a judgement of the validity and value of reports. It was not used to numerically score papers on their quality. By taking into account the CASP tool, typology of findings, conceptual richness and relevance and contribution to the review question, papers were categorised as a key paper, satisfactory paper, or fatally flawed. Such an approach allows the value and importance of qualitative studies in answering a research question to be tempered by the validity of the findings.[22] This categorisation was used to guide the synthesis, allowing more emphasis to be placed on key papers.

The synthesis of findings involved interpretative analysis using meta-ethnography (Supplementary data, Figure 2).[23] Included papers were carefully read and the relationships between the concepts arising in the papers considered using a matrix of shared themes. Thematic coding was undertaken, firstly with data extracted from key papers and continued through all included studies. When a new theme was identified the other papers were reviewed to check for the presence of the theme, forming a cyclical process. Studies were compared and contrasted via an interpretative reading of meaning of conceptual data. Third order constructs[24] were developed by taking the first and second order constructs and analysing them thematically to form a new interpretation.

Results

Summary of included studies

Thirty six papers reporting 34 different studies were included in a 'reciprocal synthesis'[23] (Figure 1). The characteristics and relevant findings of included studies are shown in Table 1. Twenty one papers had cancer screening uptake as the main focus of the reports.[25-45] The primary focus of other reports included wider knowledge and attitudes to cancer and prevention,[46-52] responses to information about screening,[53-56] experiences of screening test results[57, 58] and risk management options which included screening.[59, 60] Cervical, breast and colorectal cancer accounted for 29 of the 34 studies. Two related to prostate cancer, two to ovarian and one to lung cancer. Five papers were categorised as key papers[32, 35, 36, 42, 53] and the rest as satisfactory.

Evidence synthesis

Three primary themes emerged from the analysis: First, screening attendance decisions were shaped by individuals' relationships with the health service. Second, fear was a dominant influence on both decisions to attend and to not attend. Third, experiences of risk were expressed throughout the data. Additionally, a range of other factors interacted with these primary themes as described below. The distribution of themes across the 36 papers is shown in the Supplementary data, Table 3. Illustrative quotes from study participants (P) and authors (A) are provided below and further supporting data excerpts are shown in the Supplementary data, Table 4. A diagram of third order constructs and their relationships is shown in Figure 2.

Relationship with health service

Responses to screening invitations were largely explained in terms of individuals' relationship with the health service. There was a wide range of levels of trust evident in the data, ranging from those who interpreted the invitation as a command to be obeyed, to those who perceived it as an attempt at control to be resisted. Between these two extremes individuals cited other aspects of the relationship which influenced their decision.

There was evidence that the NHS is seen as a higher power in the relationship: "Many interviewees referred to having a smear test as a 'correct' form of behaviour: as the right/correct/proper thing for women to do. Notions of deviance were associated with non-attendance.(A)"[48] Some felt obliged to comply with the 'system' in order that they are taken seriously when presenting with other health problems in the future.[41] In this sense they viewed trust as something to be demonstrated and maintained in both directions in the relationship. In contrast, others felt privileged to be invited to screening[56] and viewed it as the offer of a valuable service at no financial cost to them.[36]

Immigrant populations with limited experience of the NHS lacked trust in its services and employees, sometimes opting to be screened in their home country where a stronger relationship existed with the health care provider.[40] Language problems inhibited them from asking questions and forming a trusting relationship.[38] There were perceptions from ethnic minority groups that screening services did not (or would not) meet their cultural and religious needs. "They just make you feel uncomfortable [for requesting a female nurse]. So that is why I don't go, if I got the test I would say no I don't want to go because of this thing.(P)" [25] Associations of cervical screening with promiscuity raised concerns about confidentiality in women who did not trust clinicians and receptionists to meet these needs.[45] There was distrust of interpreters provided by the NHS who were described as unqualified to translate using medical terminology,[44] distrust of practitioners themselves, and of the wider motives of the health service.[49]

Another aspect of the relationship which influenced decisions was the communication flowing from the health service to the individual containing information about screening and the potential harms and benefits. Different levels of knowledge about screening resulted from this information, but in those who did not attend there was often a deficit in knowledge and understanding about screening, which they were not motivated to overcome: "Throughout the focus groups the women expressed a lack of awareness about the need for cervical screening, resulting in the women ignoring an invite for cervical screening.(A)"[33] "Expressions such as 'never knew anything about cancer before'; 'I never knew'; 'I didn't know what is cancer' were common.(A)"[50] There were expectations that screening should take place in a clinical setting and that patients are the passive receiver of care from the screening provider.[35] The receipt of home testing kits for colorectal cancer, for example, was interpreted as unusual and impersonal. The detachment of screening from clinical settings was linked to non-uptake: "Self-testing at home ... undermined the value and relevance of screening.(A)"[35] Invitations endorsed by general practitioners carried additional weight and were revered, especially in those holding a biomedical view of the health service relationship in which the medical profession were seen as the sole decision makers.[25]

For women, the relationship with the health service was sometimes not perceived to be strong enough to entertain the prospect of attending screening, during which they would be required to reveal private parts of their body to a stranger.[45] There was a theme of control and surveillance experienced by women, within a discourse from the provider of the female body being a site of risk in need of medical observation,[48] or feelings their bodies were being used to fulfil quotas[45] or achieve other objectives.[28]

Fear

Fears about cancer screening manifested as both a motivator and barrier to screening attendance. Four key sources of fear were screening invitations, the threat of cancer in the absence of screening, the threat of abnormal test results and screening methods.

The receipt of a cancer screening invitation was experienced as provoking varying levels of fear, often explaining avoidance or delay in participation. Non-attenders described being ‘terrified’ and ‘frightened to death’ by the invitation,[42] leading to a quick decision to not respond. Less extreme experiences of fear were carefully negotiated by talking to others and seeking more information about screening. An incentive to take up screening was anticipation that in doing so fear may be reduced. Fear of developing cancer in the absence of screening was a powerful motivator to attend which facilitated the overcoming of other perceived barriers to screening: “Fear appeared to be the main driving force behind the decision to have smear tests.(A)”[48]

Implications of an abnormal screening test result were a principal source of fear in the data. This was interpreted as ‘fear of the unknown’ and fear of an inability to cope with a diagnosis and ‘the word cancer’ itself.[42] Fears about screening methods were commonly cited, either from previous experience or from anecdotes heard from others. These were anticipated as leading to other negative emotions including pain, discomfort and embarrassment.

Other sources of fear were the potential social inadequacy in the performance of an unfamiliar event under professional scrutiny,[36] anticipation of having to wait for screening results, a general fear of hospitals and medical procedures[42] and stigma associated with cancer or cancer risk.[50]

Experiences of risk

Closely related to the first two themes was that of risk. Individuals were subject to external discourses of risk and also created their own ‘game of chance’.[36] The official discourse on screening from the health service was one which labels individuals as ‘at risk’, non-attenders as at even higher risk and attenders as at lower risk. There was, however, some resistance to this discourse, influenced by themes of beliefs about the disease and current health and wellness. For example, individuals who believed that an absence of symptoms and a feeling of wellness placed them at low risk cited this as a reason for either attending or not attending screening: “I'd almost be surprised if I did get it, I don't feel anything.(P)"[43] They felt they had either nothing to gain or nothing to lose by screening. Beliefs were expressed that risk of cancer was reduced by participation in screening. This may be a coping strategy to gain protection from the risk and uncertainty of the threat of cancer. Beliefs about cancer also influenced risk in minority ethnic groups, for example beliefs that talking about cancer or being in close proximity to someone with cancer can put one at risk.[50] This likely represents a culture in which cancer is a taboo subject and is avoided.

Discussion

Main findings of this study

This meta-ethnography provides an insight into the thoughts and experiences which explained participants’ screening attendance decisions. Three primary themes emerged from the synthesis.

Individuals’ relationship with the health service was the most important factor, influenced by underlying dynamics of trust, power, control and authority. Some were compliant with screening requests, particularly when received from a known source. For example, invitations received from general practitioners were more trusted than those received from screening hubs. This is consistent with experimental research demonstrating that general practitioner endorsement promotes higher uptake.[61] However, in a society where ever more areas of our lives are under routine surveillance, this synthesis found individuals can be sceptical of the requirement to adhere to a screening regime.[48] Their resistance is interpreted as an attempt to maintain control over their own bodies and their right to decide when they are unwell and need medical attention.[53] A general distrust of those in power is a social dynamic that can include the NHS, which is viewed by some as an extension of the Government.[36]

A further demonstration of the level of trust necessary in the relationship was the cultural and language needs which were seen as being unmet. Immigrant groups experience additional barriers due to a lack of familiarity with the NHS and limited knowledge of services. A fundamental aspect to the relationship with the screening provider is the information received and resulting knowledge and understanding. In screening, this communication typically occurs in writing and many of the nuances of communication that could contribute to a trusting relationship are lost. Home visits combined with an educational video have been shown to be particularly effective in promoting screening uptake in hard to reach groups, whilst written translated materials were ineffective.[62]

According to our analysis, ultimately it was the sender’s characteristics, rather than the content of the message itself, which were important. Interventions to modify invitation materials to address other barriers may therefore have limited potential to promote uptake beyond that which has already been achieved.[11, 12, 63] Improvements in uptake may be achieved by patient-oriented interventions targeting perceptions of the wider health service, rather than screening invitation materials or methods alone. For certain groups there may be a benefit in including key community figures (e.g., local religious leaders) in communicating the health agenda. An extension of general practitioner involvement in cancer screening could utilise an existing trusted relationship to promote uptake. For example, a banner on the invitation letter indicating endorsement from the patient’s GP practice has been shown to increase uptake of colorectal screening.[64] Such interventions could lead to other desirable outcomes as a result of increased levels of trust in the relationship.

There are consistencies with other qualitative syntheses, which report cervical screening as an emotional experience[65] and fear as a barrier in colorectal screening.[66] Our finding of experiences of fear from a number of sources in cancer screening is consistent with patients' reported experiences of seeking help for cancer symptoms.[67, 68] The role of fear and its link with cancer worry and perceived susceptibility in cancer screening uptake has received much attention. Fear of a number of aspects of screening, including the hospital setting, pain from screening procedures, test results and their consequences, was strongly associated with non-attendance in a survey.[69] In a colorectal screening trial desire for screening was higher in people who reported worrying about cancer, but individuals were less likely to attend if they had reported feeling uncomfortable at the thought of cancer.[70] It has been suggested that fear combined with high-efficacy messages promotes health behaviour change and fear with low-efficacy messages creates defensive responses.[71] The importance of response efficacy (the perception that a behaviour will alleviate a threat) in behaviour change has been demonstrated.[72] This relationship between fear and cancer screening attendance is complex and our findings provide an insight into the different ways fear is experienced and interpreted in this context. Specifically, the synthesis supports the theory that very high levels of fear about cancer screening, from sources including screening invitations, the perceived threat of cancer, abnormal test results, or the screening methods, can promote avoidance. Some overcame their fear having been persuaded by another person to attend. Increasing familiarity and trust in relation to the health service might have a similar effect in enabling individuals to negotiate moderate levels of fear in deciding to attend screening.

The analysis showed how the experience of being identified as ‘at risk’ by the health service led to some resistance and the creation of alternative explanations based on a range of beliefs about the disease. Evidence shows a moderate level of perceived risk optimises screening uptake, with high levels leading to avoidance and low levels a lack of motivation.[73] A meta-analysis of a range of behaviours suggests that this relationship between a threat and behaviour holds only when accompanied by high self- and response-efficacy.[74] Our study found individuals create their own perceptions of risk irrespective of the ‘official discourse’ and use screening as a coping strategy.

A better understanding of the complex determinants of uptake could lead to the identification of modifiable psychological variables as targets for intervention. Current screening invitation materials emphasise the recipient's choice in deciding whether or not to take part. To complement this, the perceived control an individual has over other aspects of the process could be promoted. Rather than screening being experienced as a mass surveillance programme in which people are systematically called and recalled by a computer, personalised aspects of screening could be enhanced and the element of individual control emphasised. The aims of ensuring that individuals have the knowledge to decide what they want to do and that they feel the communication is personalised could potentially be achieved in synergy. For example, interactive methods could be used in decision aids which address gaps in knowledge, tailored to individual levels of fear and perceived risk.

Our findings could also help in understanding why certain sociodemographic groups engage less with other health processes, as there may be common barriers generalisable beyond cancer screening. The findings could further contribute to understanding of delays in help-seeking when experiencing cancer symptoms.

What is already known on this topic

There is evidence that ethnic minorities, younger aged and economically deprived groups are less likely to attend cancer screening. Quantitative research has identified some practical and psychosocial factors influencing screening uptake but has not fully explained why a proportion of individuals do not attend. Qualitative studies have reported experiences of cancer screening uptake, focusing on specific groups and types of screening tests. Their findings have not been synthesised in a way that can be integrated with the existing hierarchy of evidence to inform future research, policy and practice.

What this study adds

A synthesis of evidence from a systematic review of qualitative studies has identified important themes which influence cancer screening uptake in the UK. A higher level interpretation of data demonstrated how an individual's relationship with the health service, their fear of cancer screening and their experiences of risk influence their response to a screening invitation. This review makes this important body of evidence more accessible to clinicians, policy makers and researchers.

Limitations of this study

Reasons for taking part or not taking part in a cancer screening research trial may differ to those for routine NHS screening. As an example, altruistic reasons for participation were particularly evident in trials of ovarian and lung screening methods.[43, 59] However, the majority of included studies related to NHS cervical, breast and colorectal screening. The studies were published over a wide timeframe (1994-2016) and therefore the experiences of participants may not all necessarily reflect the current state of screening in the UK. Recall bias could have influenced the data because participants reported past experiences. Those who are least likely to engage in screening were probably underrepresented in the data since they might be less likely to take part in a research study on the topic.

Conclusion

This synthesis highlights important factors which underpin the uptake of cancer screening. It emphasises the importance of the provider-patient relationship in promoting informed uptake and enriches our understanding of how fear and risk are experienced and negotiated in the screening attendance decision. Further research should use quantitative methods to explore in which groups the barriers identified are prevalent and the extent to which they are experienced. The qualitative literature could be examined further to draw out differences between screening programmes or population subgroups. Interventions could be piloted to promote a perception of personalised care, improved trust in the health service and prevent extreme levels of fear and perceived risk. As cancer screening invitations change in the future, due to the use of new screening methods and the growth in importance of concepts such as informed choice and risk stratification, there will be a continuing need to explore experiences of being invited to cancer screening.

Declaration of conflicting interests

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Supplementary data

Supplementary data are available online.

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Fig. 1 PRISMA flowchart.

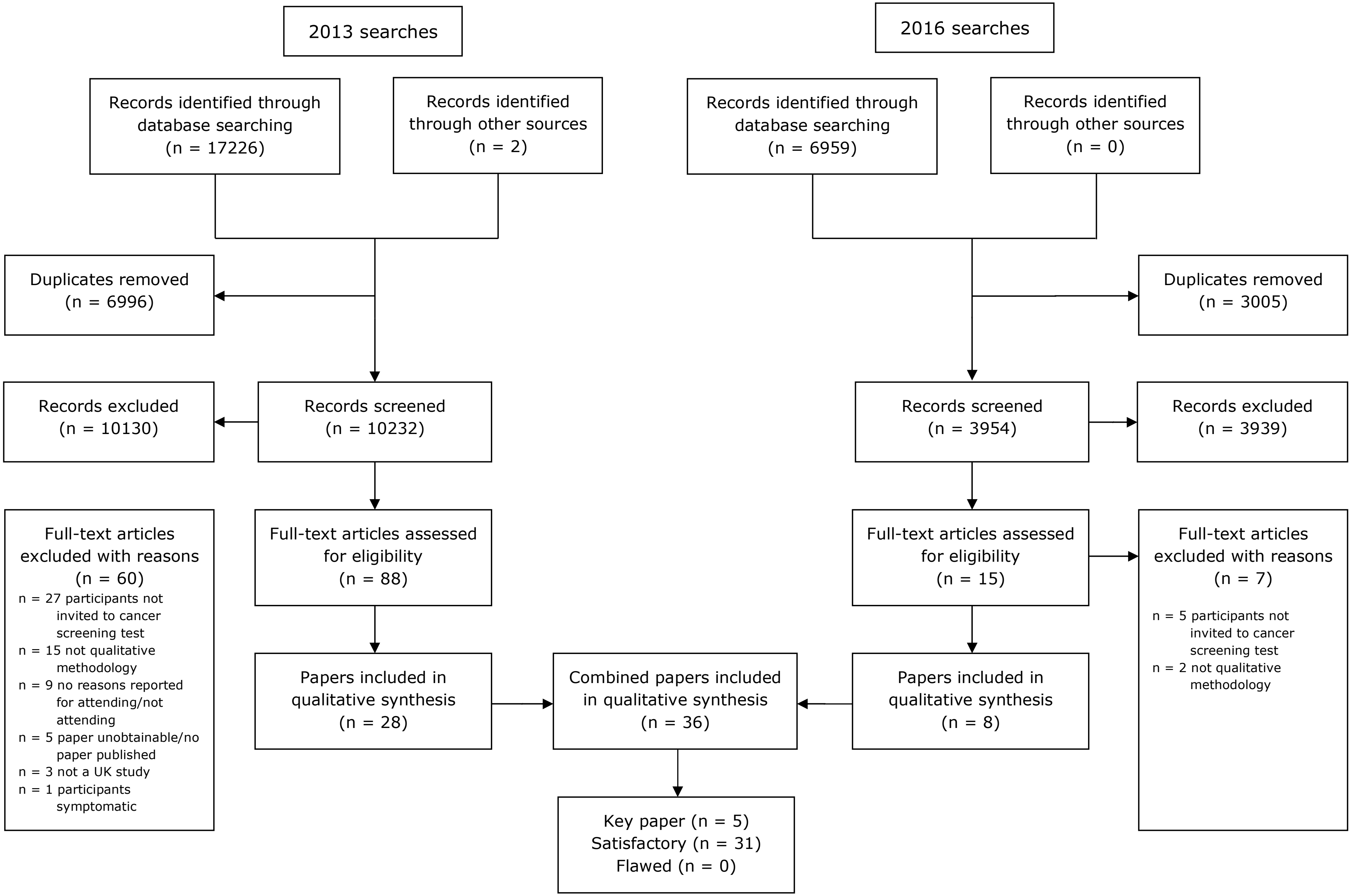

Figure 2 Diagram of primary third order constructs and their relationships

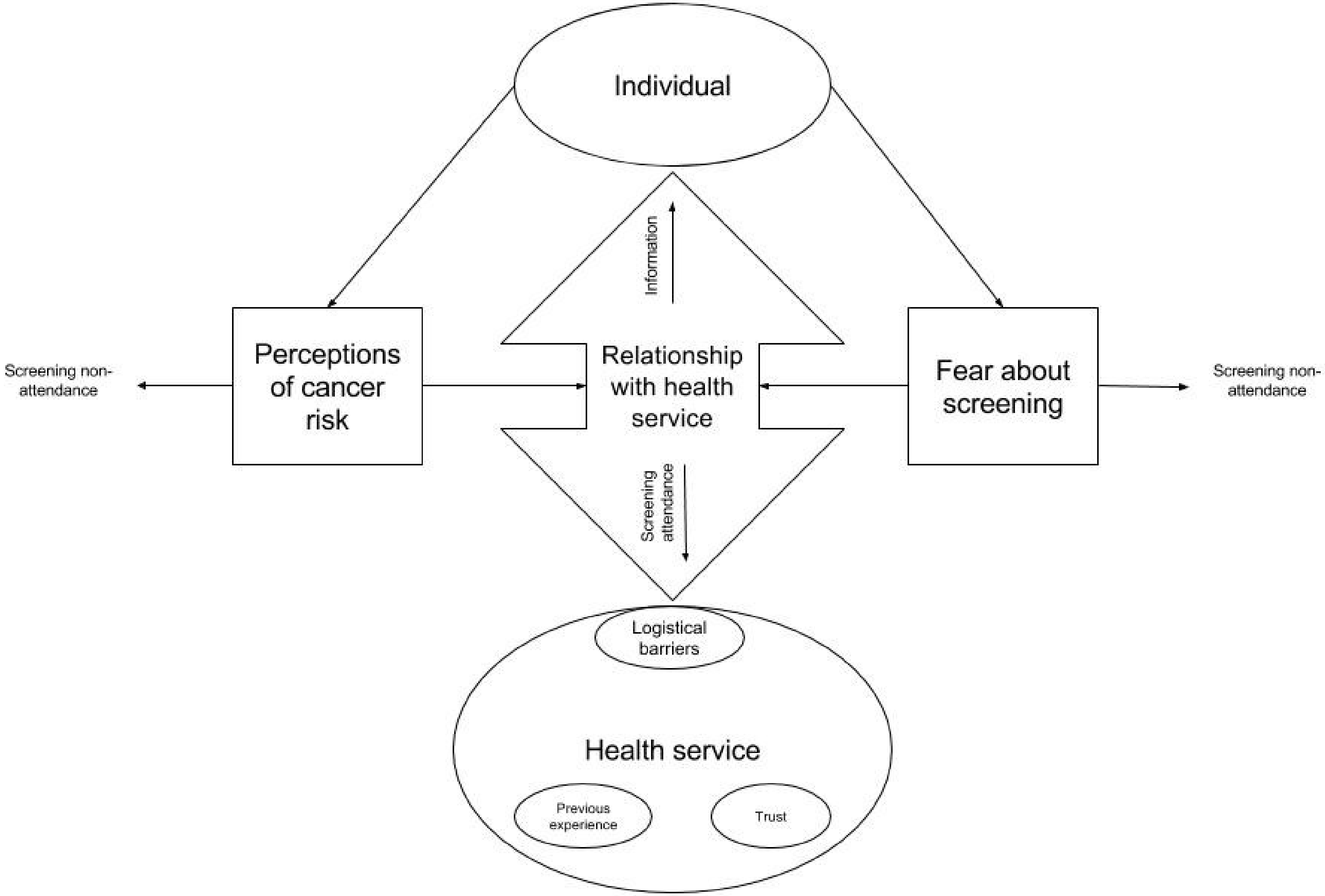

Table 1 Characteristics and relevant findings of included studies

Study Key paper/satisfactory paper/fatally flawed	**Aim/research question(s)**	**Screening** Disease Screening method Study context	**Participants** No. of participants Screened status Age; sex; ethnic group; location Sampling method	**Data** Collection method Analysis method (as described by authors)	**Themes and subthemes explicitly linked to screening attendance** **Theme** -Subtheme or *theme summary*	
Abdullahi et al. 2009 Satisfactory paper	Explore understanding of the purpose of cervical screening, risk factors for cervical cancer, opinions on barriers to screening and suggestions for overcoming those barriers	Cervical cancer Liquid-based cytology Community setting	n = 42 (focus groups), n = 8 (interviews) Never been screened = 19; Screened status not reported = 31 25–64 years; women; Somali; Camden, London Purposive sampling	Focus groups and interviews “Thematic analysis informed by an interpretivist approach”	**Barriers to uptake of screening** -Lack of knowledge -Language difficulties -Fear of the test -Embarrassment -Negative past experiences -Male practitioners -Practical difficulties	**Proposed solutions to the barriers** *Provision of education and information about cervical screening in Somali by Somali community workers; training for staff about Somali culture, particularly female circumcision; more proactive encouragement for Somali women to attend from GPs*
Archer & Hayter 2006 Satisfactory paper	Describe the experiences of men who received equivocal prostate-specific antigen test results	Prostate cancer Prostate-specific antigen test Prostate Testing for Cancer and Treatment (ProtecT) trial	n = 7 All received inconclusive screen and participating in ongoing monitoring of blood tests or biopsies or both 50-59 years; men; ethnic group not reported; all were from one general practice in the north of England Purposive sampling	Semi-structured interviews Phenomenological approach - seven stage reductive process	**Pre-conceptions** *Their beliefs about prostate cancer before screening* **Responsibility** *Their sense of obligation to their own health, to the future health of men generally and to their family*	
Armstrong 2005 Satisfactory paper	Explore ways that women think about and understand cervical cancer risk factors and how these are, or are not, relevant to them as individuals	Cervical cancer Papanicolaou test NHS Cervical Screening Programme	n = 35 All previously invited 1 never attended 26 regular attenders 20-64 years; women; white British, South Asian and African Caribbean; east midlands, England Quota sampling by age and ethnic group	Lightly structured interviews “Analysis of the material was approached inductively and explored the kinds of discourses and themes that women drew upon when talking about their views, understandings and experience.”	**Bodily risks** -Genetics -Menopause **Behavioural risks** -Sexual behaviour -General health status	
Armstrong 2007 [a] Key paper	Explore how women interpret, negotiate and make sense of the information material they receive when called to attend cervical screening in the context of their personal circumstances, experiences and characteristics; therefore producing alternative conceptualisations of, and discourses upon, cervical screening	As above	As above	In-depth interviews “Analysis of the material was approached inductively with emergent themes being identified from the interview transcripts and explored for the kinds of discourses and themes that women drew upon.”	**Emotional experiences** *Explanations of what it is about individuals that mean their experiences are more troublesome than others* **The changing body** *How changes in women’s bodies, e.g. the menopause, influenced thoughts about screening*	
Armstrong & Murphy 2008 [a] Satisfactory paper	Examine the complex interplay between lay and professional understandings of cervical cancer risk and causation	As above	As above	Semi-structured interviews Thematic analysis	**Childbirth: the extension of explanations based on trauma** *The role of childbirth in lay understandings of cervical screening*	
Austin et al. 2009 Satisfactory paper	Explore perceived barriers to flexible sigmoidoscopy screening among UK ethnic minority groups	Colorectal cancer Flexible sigmoidoscopy (FS)	n = 53 Screened status not reported 49-78 years; 20 men, 33 women; 18 Gujarati Indian, 14 Pakistani, 12 African Caribbean, 9 White British; London	Focus groups Framework analysis	**Lack of awareness about bowel cancer** *Lack of knowledge as a barrier to attending* **Perceived benefits of FS screening** - a ‘definitive’ test	**Recommendations to increase attendance to the FS test - Message dissemination and screening location** -General practitioner involvement -Group discussions within communities -Use ethnic community media

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		Community group	Opportunistic sampling		- peace of mind - reduction of invasive treatment **Perceived barriers to FS screening** -Procedural barriers ~ invasiveness of the test and the area of the body under investigation ~ bowel preparation (enema) at home -Psychosocial barriers ~ fear of test results ~ attitudes to cancer treatment -Lack of symptoms -Culturally influenced barriers ~ attitudes of staff to religious beliefs e.g. female endoscopist necessary ~ biomedical view of healthcare system ~ language difficulty ~ threat to masculinity -Gender -Lack of awareness about screening	-Use celebrities and community leaders as role models **Recommendations to increase attendance to the FS test - Message content** -Increase awareness -Emphasize severity -Emphasize preventive nature of the test
Avery et al. 2008 Satisfactory paper	Increase understanding of men's decision-making about prostate-specific antigen (PSA) testing and subsequent biopsy	Prostate cancer Prostate-specific antigen (PSA) test Prostate Testing for Cancer and Treatment (ProtecT) trial	n = 21 14 screened 7 unscreened 51-55 years; men; ethnic group not reported; screened participants were from Bristol, Newcastle, Sheffield, Birmingham, Cardiff, Edinburgh, Cambridge, Leicester and Leeds. Unscreened participants were from just one of these locations (unspecified) Purposive sampling	Semi-structured interviews Constant comparison methods derived from grounded theory	**Accepting PSA test** -Nothing to lose -Opportunity for reassurance -Lack of symptoms -Perceived good health	**Not responding to PSA test** -Belief that the PSA test is unwarranted due to: ~ Perceived low risk of prostate cancer ~ Lack of symptoms/perceived good health ~ Belief that prostate cancer is not severe/life-threatening ~ Advice of medical practitioner/other -Belief that the PSA test/result is inaccurate
Bond et al. 2015 Satisfactory paper	Understand what it is like to have a false-positive screening mammogram	Breast cancer Mammography NHS breast screening programme (participant recruitment via GP practices and university staff newsletter)	n = 21 All screened with a false positive result between 0.5-12 years ago, for 6 of whom it had been their first screen 42-69 years; women; ethnic group not reported; location not reported Purposive sampling	Semi-structured interviews Interpretive Phenomenological Analysis	**Believing in the healthy self** *Going for mammography every 3 years had become part of their health care routine, it was welcomed, and there was a sense of handing responsibility for their health, in some measure, over to the NHS; screening gave peace of mind*	
Box 1998 Satisfactory paper	Ascertain the views and knowledge of cervical cancer and the cervical screening programme held by black and minority ethnic women and by health advocates and facilitators	Cervical cancer Papanicolaou test 'ScanLink' - project to raise awareness and uptake of breast and cervical cancer among black and minority ethnic women in the North Thames	n = 17 eligible for meta-ethnography. Study also included ineligible interviews with facilitators of cancer awareness sessions and focus groups with health advocates Screened status unclear 16-46+ years; women; "Black and minority ethnic" speaking either Cantonese, English, Hindi, Gujerati, Punjabi, Somali, Tamil or Urdu; Newham, London Sampled from those completing a questionnaire evaluation form as part of a cancer awareness session, to represent the range of ethnic groups in the area	Interviews Method of analysis not reported	Themes may be derived partly from ineligible data from facilitators and health advocates or due to age of interviewee **Ethnicity** *Beliefs and attitudes thought to be culturally specific e.g. cervical cancer associated with promiscuity, inflicted as a punishment from God, a disease of the West, nothing could be done to avoid cervical cancer* **Racism and other problems** Being treated coldly because of race, being treated like a piece of meat, being too	**Language** *Failure of information to reach women, fears that they will be unable to communicate adequately, letters ignored or considered alien, irrelevant, or frightening* **Advocacy** *Women who had made use of advocates appeared to be better informed. Many were unaware that health advocates could be booked*

Study Key paper/satisfactory paper/fatally flawed	**Aim/research question(s)**	**Screening** Disease Screening method Study context	**Participants** No. of participants Screened status Age; sex; ethnic group; location Sampling method	**Data** Collection method Analysis method (as described by authors)	**Themes and subthemes explicitly linked to screening attendance** **Theme** -Subtheme or *theme summary*	
		region			intimidated to ask questions	
Bradley et al. 2015 Satisfactory paper	Identify the reasons why some people do not participate in bowel cancer screening so that steps can be taken to improve informed decision-making	Colorectal cancer Faecal occult blood test Northern Ireland Bowel Cancer Screening Programme	n = 28 All unscreened. 27 had received but not completed a screening kit and 1 had not yet received a screening kit Age not reported (60-71 years were eligible); 18 men, 10 women; White; Northern Ireland (focus groups conducted in Belfast and Armagh Purposive sampling	Focus groups Thematic analysis	**Fear of cancer** *Fear and anxiety provoked by different aspects of screening, especially among men. Responses to suddenly being considered 'old'* **The test procedure** *Repugnance at idea of having to handle own faeces, mixed views about how difficult the test was to use, e.g. having to take samples three times* **Social norms** *Test is embarrassing, encouraged to participate by others who had done so*	**Past experience of cancer and screening** *Knowing people who had cancer, futility of treatment, early treatment more successful* **Lack of knowledge or understanding about bowel cancer screening** *Surprise at receipt of test, difficult to distinguish from private advertising, misunderstanding of test instructions, lack of symptoms* **Resulting behaviour towards the test** *Test put aside then either left indefinitely or binned*
Brain et al. 2004 Satisfactory paper	Explore perceptions of ovarian cancer screening and prophylactic oophorectomy (PO) in women newly identified as being at increased risk of familial ovarian cancer	Ovarian cancer Ultrasound scan and blood test UK Familial Ovarian Cancer Screening Study	n = 10 Identified by screening as high-risk and facing a treatment decision (ongoing screening or prophylactic surgery) 27-62 years; women; ethnic group not reported; Wales Sampling method not reported	Semi-structured interviews Thematic analysis	**Reactions to ovarian cancer screening** *Expectations for the appointment, waiting for the scan, the experience of undergoing transvaginal ultrasound, the impact of screening results, attitudes to screening and the idea of benefiting others through screening*	**Reactions to the option of prophylactic oophorectomy** *Reactions to the option of undergoing prophylactic oophorectomy and factors that helped to decide whether to go ahead with surgery or remain on ovarian screening including the practicalities of surgery, issues regarding the onset of surgical menopause, views on surgery as a risk-reducing strategy and the uncertainties associated with screening and genetic testing*
Bush 2000 Satisfactory paper	Explore the importance of cervical screening discourses in framing women's perceptions of femininity	Cervical cancer Papanicolaou test Community setting	n = 35 Range of screening histories. All had been screened at least once 20-64 years; women; white; South Yorkshire Purposive sampling (cervical screening experiences, age and socioeconomic criteria)	Semi-structured interviews and open ended questions in a questionnaire "analytical process inscribing a movement from the particular to the general. Constant comparison of emergent conceptual categories"	**Smear tests are a normal part of being a woman** *Feelings of normalcy associated with having a smear test* **Deviance associated with not attending for a smear test** *Having a smear test as a 'correct' form of behaviour and notions of deviance associated with non-attendance*	**Regulatory discourses and cervical screening** -Regulatory discourses embedded within the call and re-call programme -Regulatory pressure exerted by opportunistic screening **Fear** *Fear was reflected in the interview transcripts in different ways*
Chapple et al. 2008 Satisfactory paper	Why some people decided to take part in screening while others felt reluctant to participate or declined to take part	Colorectal cancer Faecal occult blood test NHS Bowel Cancer Screening Programme & pilot	n = 44 Screened = 35 Screened after delay = 6 Invited but not screened = 3 58–64 years = 14, 65 years or over = 30; 22 men, 22 women; White British = 42, Black Caribbean = 2; location not reported Maximum variation sampling	Semi-structured interviews Thematic analysis with constant comparison	**Factors affecting the decision to accept screening** -Close relatives or friends had cancer -Past experience with other forms of screening -Convincing information in the leaflets -General practitioner involvement -A sense of obligation - a civic duty	**Factors that made people feel reluctant or decline to accept screening** -Perception of low risk -Busy lifestyle -A sense of denial and fear of unpleasant results -Dealing with faecal matter -Issues about confidentiality -Confused about the instructions -Fear of colonoscopy and scepticism about treatment for bowel cancer
Clements et al. 2008 Satisfactory paper	Explore the value that women at increased risk (with a family history of breast cancer) placed on screening, both pre- and post-cancer diagnosis and the impact of the diagnosis	Breast cancer Mammography PIMMS Study (evaluating the psychological impact of mammography	n = 12 All diagnosed with screen-detected breast cancer 37-50 years; women; ethnic group not reported; location not reported - from one of 21 centres in the UK 6 sampled from questionnaire study of 2321 women (sampling method not reported); 6 identified as eligible	Semi-structured interviews Framework approach	**Reasons for being on the early screening programme** -greater perceived chance of survival by early diagnosis -greater faith in mammography than self-examination	

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		screening in women with a family history of breast cancer)	by clinics in study			
Clifton et al. 2016 Satisfactory paper	Identify barriers and facilitators for breast, cervical and bowel cancer screening uptake by people with mental illness in order to inform interventions to promote equal access	Breast, cervical, and colorectal cancer Mammography, liquid-based cytology & faecal occult blood test NHS Breast, Bowel and Cervical Cancer Screening Programmes	n = 45 eligible for meta-ethnography. Study also included ineligible interviews with NHS professionals Some screened, some had missed, declined, ignored, or delayed screening, 1 not registered with a GP 26-73 years; 39 women, 6 men; 31 white, 5 black Caribbean, 4 mixed, 3 black African, 2 other; 29 London, 16 Dorset Purposive sampling	In-depth interview Framework analysis	**Knowledge of screening programmes and processes** -Barriers: Not knowing what to expect or what to do; unsure of need for screening; difficult to process information **-**Facilitators: Wanting to be informed; understanding the benefits of screening; feeling health conscious; encouragement **Knowledge of, and attitudes towards mental illness** -Barriers: Lack of understanding of mental illness in screening professionals; made to feel like a burden on health service; stigma of mental illness **-**Facilitators: Staff being understanding; staff knowledge of mental illness **Health service delivery factors** -Barriers: Screening environment aggravates mental health symptoms; staff can be rushed; staff can be rough; exclusion from GP registers **-**Facilitators: Continuity of care	**Beliefs and concerns** -Barriers: Additional burden; mental health symptoms reduce motivation for self-care; past negative experience; embarrassment; traumatising; fear of bad news; poor relationship with GP; diagnostic overshadowing **-**Facilitators: Feeling health conscious; being anxious to avoid further health problems; physical symptoms (e.g. finding a lump); past positive experience; good relationship with GP; good relationship with practice nurse **Practicalities** -Barriers: Appointment booking; transport difficulties; difficulty remembering appointments; difficulty leaving the house due to mental health problems; taking time off **-**Facilitators: Familiar location; reminders
Dharni et al. 2016 Satisfactory paper	Explore the factors affecting screening participation in an ethnically and socio-economically diverse inner city population	Colorectal cancer Faecal occult blood test NHS Bowel Cancer Screening Programme, recruitment and interviews done in GP practices	n = 50 19 not invited, 18 screened, 7 declined, 5 invited but not yet completed, 1 tested as part of medical investigation 55-74 years; 29 men, 21 women; 17 white British, 15 black Caribbean, 13 black African, 3 white other, 2 black other; London Purposive sampling	Semi-structured interviews Framework analysis	**Benefits of screening** -Helping oneself *Belief that taking part in screening is a way of protecting one's own interests and keeping healthy. Susceptibility due to age, belief that cancer is a hidden disease, that early detection would be beneficial and offers the opportunity for reassurance* -Helping others *Helping others intertwined with beliefs about the purpose of screening, e.g. that it is a form of medical research which benefits society* **Awareness of screening** *Knowing a close family member or friend who had died of cancer, feeling susceptible, surprise at screening invitation due to low awareness*	**Fear of cancer** *Fear of colorectal cancer, of the potential outcomes of screening, of stigma of cancer, lack of fear or embarrassment* **Religious faith** *Belief that God would help them, the word 'occult' having demonic connotations* **Civic duty** *Not participating would be a waste of NHS time and money* **Barriers to faecal occult blood test Completion** -Everyday pressures -Faecal sample -Misunderstanding of instructions -Planning test completion
Ekberg et al. 2014 Satisfactory paper	Identify and understand the factors that encourage or discourage individuals from participating in the Bowel Cancer Screening Programme	Colorectal cancer Faecal occult blood test NHS Bowel Cancer Screening Programme	n = 33 All eligible for screening 60-69 years; 15 men, 18 women; ethnic group not reported; 3 towns in the East Midlands of England	Focus groups Analysis method not reported	**Association of screening with entry into 'old age'** *Avoiding the association of older age with illness, turning 60 as a social stigma* **Exposure to health screening** *More frequent exposure likely to result in an increase in body awareness and greater acceptability of medical screening, women who have been through pregnancy and childbirth more likely to participate* **Significant others**	**Fear of cancer** *Fear of the result, fear of cancer* **Lack of symptoms** *Especially for older people familiar with consulting a doctor only when symptomatic* **Embarrassment** *Embarrassed to discuss with others, threats to dignity and privacy, decision to be screened becomes a very private and personal decision*

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					The presence or absence of support and encouragement from significant others **Perception of risk** *Subjective assessment of risk, influenced by unique biographical past*	**Paternalistic healthcare** *Resistance to paternalism, preventative healthcare and the 'nanny state', interpreted as being a threat to individual freedom and autonomy and as being overly broad and repetitive*
Hall et al. 2015 [b] Key paper	Explore the beliefs and experiences of individuals who had not responded either to their screening invitation or reminder to colorectal cancer screening	Colorectal cancer Faecal occult blood test NHS Bowel Cancer Screening Programme	n = 27 Non-responders to screening invitation 60-72 years; 13 men, 14 women; none from an ethnic minority group; north east England Purposive; maximum variation	In-depth interviews "Grounded theory approach, with an emphasis on the constant comparison method"	**Knowledge, beliefs and awareness** -Lack of awareness of others who have taken part (social norms difficult to assess) -Perceived low awareness of bowel cancer generally and screening programme specifically -Preference to go to GP with symptoms/belief that screening more necessary if symptoms apparent -Belief that treatment is likely to be unsuccessful or that bowel cancer is untreatable -Perception that screening is not personally needed (e.g. lack of symptoms, feeling well) -Unrealistic optimism/low perceptions of risk -Age-related beliefs (e.g. decreased ability to fight off illness with age) -Perception that it is better not to know (e.g. when there is no interest in receiving treatment) -Traditional male gender roles and beliefs regarding health care and related activities -Bowels are private and not discussed -Belief that rectal bleeding (haemorrhoids or IBD) will affect test results **Emotional reactions to invitation** -Disgust/distaste at dealing with faeces -Avoidance of decision making (put at back of mind or ignored) -Anxiety and fear about susceptibility, potential cancer diagnosis, further testing and hospitals -Unable to 'cope' with additional demands (e.g. due to depression, illness, stressful life events) -Embarrassment/difficult topic to discuss -Lack of need for reassurance	**Circumstances** -Other more pressing priorities, (stressful life events, health concerns and illness, caring for others) or not prioritising own health -Not wanting to waste resources by completing kit unnecessarily -Previous negative experiences of health care and health-care system **Recent GI medical intervention** -Recent colonoscopy or other surveillance procedure -Recent bowel cancer diagnosis -Ongoing monitoring or medical review for bowel condition (e.g. IBD) **Practicalities of completing kit** -Perceived complexity of sampling procedures -Disgust/distaste at dealing with faeces -Lack of understanding of information provided -Unfamiliarity of taking own samples -Inability to take sample due to disability -Need for contemplation, planning and organization -Lack of confidence in being able to carry out sampling procedures -Lack of understanding of whether/when screening is appropriate when under medical review, or recent endoscopy investigations taken place -Not having read the information thoroughly or at all -Practicalities associated with going to the toilet, for example where and when bowel movements take place, regularity of bowel movements -Test seen as unable to provide definitive answer re: cancer diagnosis -Concerns about hygiene (storage, disposal of equipment and posting)
Jackowska et al. 2012 Satisfactory paper	Identify patterns of screening attendance, awareness about, attitudes to, and barriers to participation in the NHS Cervical Screening Programme in migrant women from Central and Eastern Europe living in London	Cervical cancer Liquid-based cytology NHS Cervical Screening Programme	*Focus groups* n = 32 *Interviews* n = 20 Screened status not reported 20-53 years; women; country of origin *Focus groups* Poland = 18, Romania = 9, Slovakia = 5, *Interviews* Poland = 11, Romania = 2, Slovakia = 7; London Opportunistic sampling via local advertisements and snowballing	Focus groups and semi-structured interviews Framework analysis	**Language** *Ease of communication as a reason for not attending screening* **Negative attitudes to the NHS** *Lack of confidence in NHS health professionals*	**Lack of awareness of entitlements** *A belief that some migrant women might not know what their rights to health care in Britain are* **Time pressures** *Pragmatic reasons for not participating in screening*

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Jepson et al. 2007 Satisfactory paper	Explore what people know about cancer screening, the information they want to make an informed choice (as to whether or not to participate), and factors affecting the choices and decisions they made	Breast, cervical, and colorectal cancer Screening methods not reported NHS national cancer screening programmes	n = 68 Normal screen result = 30 Abnormal screen result = 29 Did not attend screen = 9 *Cervical* 19-55 years, *Breast* 50-65 years, *Colorectal* 50-60 years; 11 men, 57 women; ethnic group not reported; Tayside and Lothian Purposive sampling	Focus groups and semi-structured interviews Constant comparative method	**How information is used when making a decision about whether to be screened or not** *Whether information was used to make the decision depended on what the information wasrelated to (e.g. symptoms, risk factors or limitations)*	**Relationships between information provision and knowledge, choice and behaviour** *Whether they felt they had made an 'informed choice' to participate in screening or not and how concerned they were about this*
Karbani et al. 2011 Satisfactory paper	Explore attitudes, knowledge and understanding of breast cancer and preventive measures amongst South Asian breast cancer patients	Breast cancer Mammography Breast cancer units	n = 24 Screened status not reported 39-69 years; women; South Asian; West Yorkshire Purposively sampled breast cancer patients (but screening attendance decisions were pre-diagnosis) from three hospitals. Unclear how participants were sampled from this group	Interviews guided by topic list Framework analysis	**Awareness and knowledge of breast self-examination and breast screening**	**Cultural practices and beliefs about cancer** -Cancer was a taboo subject -Cancer was contagious -Cancer was a stigma -Cancer in the family had ramification on children's marriage prospects
Lifford et al. 2013 Satisfactory paper	Examine how women felt about screening and what contributed to these feelings	Ovarian cancer Ultrasound scan and blood test UK Familial Ovarian Cancer Screening Study	n = 48 24 undergoing screening, 24 screened but withdrawn from programme 38-76 years; women;	Semi-structured interviews Framework approach	**Positive experiences of ovarian cancer screening** -Benefit for self *Privilege to be able to be screened, peace of mind, reassurance, being proactive about their risk, taking responsibility for their health* -Benefit for research/others *Wanting to help the medical community deal with the disease*	**Negative experiences of ovarian cancer screening** *Inconvenience of having to be screened on particular days*
Logan et al. 2011 Satisfactory paper	Explore the experiences and perceptions of cervical screening among women from a socially deprived area	Cervical cancer Liquid-based cytology Community setting	n = 48 All attended a mobile cervical smear unit and had a cervical smear test taken within the last 12 months 35-55 years; women; ethnic group not reported; Northern Ireland Purposive sampling	Focus groups Thematic content analysis	**Women's perceptions of cervical cancer and screening** *knowledge and awareness of cervical cancer risk factors and the need for screening* **Women's experiences of cervical screening** *Negative attitudes and feelings of fear, embarrassment and stigma*	**Barriers to attending for cervical screening** *Practical factors: timing of appointments, issues of time and having to find child care* **Perceived solutions to barriers** -Flexibility of appointments -Use of peer support -Opportunistic screening -Education and empowerment
Marlow et al. 2015 Satisfactory paper	Explore self-perceived barriers to cervical screening attendance among ethnic minority women compared to white British women	Cervical cancer Liquid-based cytology Community setting	n = 54 35 regularly screened, 8 screened but had missed or delayed screening in the past, 6 screened but >3/5 years since last test, 1 regularly screened outside the UK, 1 never screened, 1 had a hysterectomy, 1 unknown 28-63 years; women; 24 Indian, 11 white British, 6 Caribbean/mixed white & black Caribbean, 4 black other, 3 white other, 2 Pakistani, 2 Bangladeshi 2 African; London boroughs of Brent, Barnet, Hounslow, Hillingdon, Newham, Lewisham and Camden	Semi-structured interviews Framework analysis	**Lack of knowledge or misunderstanding** *Misunderstandings in the ethnic minority sample about cervical cancer, its causes and screening* **The procedure** -The health professional -Location	**Emotional barriers** -Fear of pain -Embarrassment -Fear of cancer -Shame **Practical barriers** *Screening as an inconvenience* **Cognitive barriers** -Perceived risk -Absence of symptoms
McCaffery et al. 2001 Key paper	Explore and interpret the accounts given by people who declined FS screening	Colorectal cancer Flexible sigmoidoscopy Within a bowel	n = 60 non-responders = 20 'definitely not interested' = 20 'probably not interested' = 20 Age not reported - participants sampled from group aged	Semi-structured interviews (telephone) Method of analysis not named	**Reactions to the letter** *Little memory of the letter; negative feelings; neutral responses* **Social influences** *Whether they had discussed the test with anyone else and whether this had influenced*	**Avoidance - 'leave well alone'** - Avoid thinking about illness when well to prevent psychological harm - The sense that the test could cause physical harm **Emotional responses**

Study Key paper/satisfactory paper/fatally flawed	**Aim/research question(s)**	**Screening** Disease Screening method Study context	**Participants** No. of participants Screened status Age; sex; ethnic group; location Sampling method	**Data** Collection method Analysis method (as described by authors)	**Themes and subthemes explicitly linked to screening attendance** **Theme** -Subtheme or *theme summary*	
		cancer screening trial	55-64; 30 men, 30 women; ethnic group not reported; Leicester Purposive sampling		*their decision about screening* **Attitudes to screening** *Positive attitudes; few overtly negative attitudes* **Susceptibility** - Not necessary - Cancer: experience and attitudes	- Embarrassment - Pain and discomfort **Practical barriers** *Had little influence on decisions to decline screening*
Michie et al. 1996 Satisfactory paper	Describe how members of families affected by familial adenomatous polyposis perceive this health threat and how they perceive predictive genetic testing (and subsequent bowel screening)	Familial adenomatous polyposis which leads to colorectal cancer if untreated. Regular bowel screening from adolescence if at risk of inheriting gene Colonoscopy A single polyposis clinic	n = 20 All from families in which a predictive blood test had been offered or carried out Affected individuals = 6 High risk result on genetic test = 1 Low risk result on genetic test = 3 Waiting for genetic test result = 10 15-46 years; 12 women, 8 men; ethnic group not reported; location not reported Purposive sampling from the polyposis register of a specialist hospital	Semi-structured interviews Grounded theory approach	**Relief and the hospital visit** *The hospital visit is associated with relief from anxiety* **Social reinforcement and the hospital visit** *Further reinforcement may come from the social and emotional contact with the hospital staff*	**Bowel screening: a necessary evil** *Bowel screening is regarded as aversive* **Genetic testing: reluctance to relinquish bowel screening in the face of low risk** *A desire for bowel screening to continue, even when the result of genetic testing indicates very low risk results*
Palmer et al. 2014 Key paper	Explore reasons for non-uptake of bowel cancer screening, and examines reasons for subsequent uptake among participants who had initially not taken part in screening	Colorectal cancer Faecal occult blood test NHS Bowel Cancer Screening Programme	n = 128 Included those who had and had not attended screening. 100 participants (78%) reported non-uptake on at least one occasion Age not reported; 67 men, 61 women; two focus groups were specifically for people of African-Caribbean origin; London and South Yorkshire Purposive sampling for 16 focus groups; opportunistic sampling from community settings for 2 focus groups	Focus groups "Analysed inductively using techniques originating in grounded theory"	Themes common across non-professional and professional occupational groups: **Risks posed by faeces** *Aversion to complete a test kit by reference to the perceived risks that collecting, storing, and posting samples of faeces posed to hygiene* **Detachment from familiar health-care settings** *Discomfort with the detachment and a preference to attend a health setting* **Implications of knowing screening results** *Participants preferred not to be in possession of this information for several reasons*	**Judgements of good health and low relevance of screening** *Test was irrelevant because they were certain that they did not have and were unlikely to get bowel cancer* Professional occupational groups only: **Delaying uptake, leading to non-uptake** *Non-uptake in terms of delay, rather than outright rejection* **The power of talk: a key 'tipping point'** *Being influenced by discussions with family members, friends, and health professionals*
Patel et al. 2012 Satisfactory paper	1. Are the screening methods offered acceptable to patients? 2. Why do some people take part and others decline?	Lung cancer Sputum cytology Lung-SEARCH trial	n = 60 Screened = 16 Abnormal screen plus annual bronchoscopy and CT scanning = 20 Declined screening = 24 52-81 years; 29 men, 31 women; ethnic group not reported - "limited numbers of ethnic minority patients"; location not reported Purposive sampling	Interviews (24 face-to-face; 36 telephone) Thematic analysis	**Acceptability of the screening methods** -Providing sputum samples -Views of bronchoscopy -Experiences and perceptions of CT scans **Taking part** -Altruism -Personal benefit -Reassurance -Knowing other people with lung cancer	**Perception of risk of lung cancer** -Influence of family history on risk -Influence of current health and medical care on risk **Barriers to participation** -Travelling for screening tests -Bad experiences of hospitals and doctors -Perception of bronchoscopy
Pfeffer 2004 Key paper	Why do some women accept their invitation for free screening mammography and others do not?	Breast cancer Mammography Community setting	n = 70 (of eligible screening age) Screened status not reported 50-64 years; women; white = 12, white Jewish = 9, Gujarati speakers = 9, Punjabi speakers = 9, Black Afro-	Focus groups "The transcripts were analysed both deductively and inductively. They were	**Compliance** *How ideas of personal candidacy influence compliance*	

Study Key paper/satisfactory paper/fatally flawed	**Aim/research question(s)**	**Screening** Disease Screening method Study context	**Participants** No. of participants Screened status Age; sex; ethnic group; location Sampling method	**Data** Collection method Analysis method (as described by authors)	**Themes and subthemes explicitly linked to screening attendance** **Theme** -Subtheme or *theme summary*	
			Caribbean = 5, Somali speakers = 9, Sylheti speakers = 8, Cantonese speakers = 5, Turkish speakers = 4; Hackney, London "Sampling sought to capture the diversity of Hackney women and the groups were organised around a mixture of language, faith, skin colour, and social status."	read and coded to test assumptions about compliance. The transcripts were then read for in vivo categories and coded accordingly. A notable theme emerging from the inductive analysis .. lead to a second reading…"		
Prinjha et al. 2006 Satisfactory paper	Explore the attitudes of women with screen-detected ductal carcinoma in situ (DCIS) towards information provision for mammographic screening	Breast cancer Mammography DIPEx project/NHS Breast Screening Programme	n = 10 All screened and diagnosed with DCIS 52-69 years; women; ethnic group not reported; locations throughout the UK Maximum variation sampling to include younger and older women from various social backgrounds	Semi-structured interviews Framework analysis	**Women's knowledge of mammographic screening and DCIS before diagnosis** *Reasons for attending screening* **Information about screening mammograms after diagnosis** *Women searched for information at different stages and from various sources*	**Screening mammography and informed choice** *Women now felt more able to make an informed choice about whether to have mammograms in future.*
Shang et al. 2015 Satisfactory paper	Explore views on breast cancer and breast health among Chinese women in the UK and the potential influence of social and cultural context on views and screening behaviour	Breast cancer	n = 22 18 regular attenders, 1 irregular attender, 3 did not attend when invited 50-70 years; women; Chinese; Manchester and Liverpool Purposive sampling	Semi-structured interviews Grounded Theory approach	**Breast screening practice** *Belief that screening is effective and beneficial, time constraints and distance to screening centre, invitation letter key to encouraging attendance, some view screening as mandatory*	
Szarewski et al. 2009 Satisfactory paper	1. Identify barriers to attendance at conventional cervical screening among Muslim women 2. Assess the acceptability of self-sampling for HPV using a new cervico-vaginal lavage self-sampling device (the Pantarhei Sampler) and to compare attitudes to this new device with women's feelings about the Qiagen kit	Cervical cancer Liquid-based cytology Community setting	n = 28 Screened status not reported. "Only one woman in the screening age range reported never having had a smear test" 21-65 years; women; Pakistani = 15, Indian = 9, not reported = 4; Leyton, north-east London Purposive sampling	Focus groups Thematic analysis/ framework analysis	**Barriers to attendance for screening** -Embarrassment	
Thomas et al. 2005 Satisfactory paper	Describe some of the factors that act as barriers to effective uptake of breast and cervical cancer screening services among black minority ethnic groups living in Brent and Harrow	Cancer screening in general but predominantly breast and cervical cancer Mammography and Papanicolaou test Community setting	n = 135 Screened status 20-75 years; 85 women, 50 men; Indian = 26, Pakistani = 16, Blind Asian group (largely from Indian subcontinent) = 9, West African = 22, African Caribbean = 26, Arabic = 14, Greek = 20; Brent and Harrow, London Purposive sampling	Focus groups and 'a few' telephone interviews Content analysis and a coding method based on frequency of ideas	**Accessing the screening services** *Knowledge and uptake of screening with reasons for not attending* **Barriers to screening services** - Language barrier - Cultural beliefs - Lack of confidence in screening and outcome - Relationship with health professionals - Religious beliefs **Improving uptake of screening** *Strategies included community-based cancer awareness education*	**Inclined abstainers** (believing in the importance of screening but not translating positive screening intentions into action) -Service provision issues -The test itself -Apathy -Competing time demands -Low-risk perceptions **Uncertainty about reasons for nonattendance** *Identification of barriers without being sure whether they really played a role* **Age differences** *Age-related trends in responses*

Study Key paper/satisfactory paper/fatally flawed	**Aim/research question(s)**	**Screening** Disease Screening method Study context	**Participants** No. of participants Screened status Age; sex; ethnic group; location Sampling method	**Data** Collection method Analysis method (as described by authors)	**Themes and subthemes explicitly linked to screening attendance** **Theme** -Subtheme or *theme summary*	
Waller et al. 2012 Satisfactory paper	Explore differences in barriers to attendance at cervical screening across age groups	Cervical cancer Liquid-based cytology Participants recruited via a market research company - context appears to be NHS Cervical Screening Programme	n = 27 (focus groups) n = 19 (interviews) Never screened = 26 Currently overdue = 17 Up to date but has delayed in the past = 3 25–50+ years; women; white = 29, Asian/Asian British = 7, black/black British = 5, mixed race = 3, Chinese = 1, unknown = 1; London Purposive sampling	Focus groups and interviews (face-to-face and telephone) Framework analysis	**Disinclined abstainers** (making an active decision not to attend)	
Waller et al. 2013 Satisfactory paper	Explore the influence of overdiagnosis information on women's decisions about mammography	Breast cancer Mammography NHS Breast Screening Programme (participant recruitment via an agency and other methods)	n = 40 Time since last mammogram <=3 years = 29, 4–9 years = 4, >=10 years = 3, screened but time missing = 2, never screened = 2 50-71 years; women; white = 27, black = 6, Asian = 5, mixed = 1, other = 1; London Purposive sampling	Focus groups Thematic analysis	**Making sense of the concept of overdiagnosis** *In a few cases … women were put off by the information*	**Implications of overdiagnosis information** -Erring on the side of caution -Impact on screening decisions
Woodrow et al. 2008 Satisfactory paper	Explore public perceptions regarding the communication of information designed to facilitate informed choice in relation to the new NHS Bowel Cancer Screening Programme	Colorectal cancer Faecal occult blood test NHS Bowel Screening Programme pilot	n = 86 Screened = 38, lives outside screening area = 48 60-69 years; 42 women, 44 men ; 83 white British, 2 Asian origin, 1 European origin; screened participants from Coventry and Rugby, unscreened participants from other unspecified locations Random sample stratified by screening result	Focus groups Transcripts were coded within a framework developed by the authors	**General perceptions of screening and information provision** *Positive and negative views about bowel screening*	

[a] Same study as Armstrong 2005

Supplementary Figure 1 Categories of relevant data extracted from included studies

	First order construct[20]	**Second order construct**[20]
Primary data	Direct participant quote Described by a participant or the study author as having influenced the participant's screening attendance decision	Study author commentary Described by the study author as having influenced a participant's screening attendance decision
Secondary data	Direct participant quote Not primary data but interpreted by the current authors as having potentially influenced a participant's screening attendance decision	Study author commentary Not primary data but interpreted by the current authors as having potentially influenced a participant's screening attendance decision

Supplementary Figure 2 Seven phases of Noblit & Hare's meta-ethnography[23]

1. Getting started
2. Deciding what is relevant to the initial interest
3. Reading the studies
4. Determining how the studies are related
5. Translating the studies into one another
6. Synthesising translations
7. Expressing the synthesis

Supplementary Table 1 Search strategy

Sources searched

Databases searched from date of inception to September 2013 and updated with searches from 2013 to October 2016

MEDLINE

Embase

CINAHL

PsycINFO

ASSIA

Web of Science

Journals handsearched	***Period searched***
Social Science & Medicine	1982 - Oct 2016
Journal of Medical Screening	1994 – Oct 2016

Online sources

Cancer Research UK

National Cancer Research Institute

International Cancer Research Partnership Database

NHS Cancer Screening Literature Database

HealthTalkOnline

Search strategy for MEDLINE (adapted for other databases)

1 exp qualitative research/
2 exp interview/
3 exp focus groups/
4 (qualitative or interview$ or focus group$).tw.
5 (themes or thematic or content analys$ or framework analys$ or template analys$ or IPA or grounded theory or discourse analys$ or phenomenolog$ or $ethnograph$ or interpre??tiv$ or inductiv$ or reflexiv$ or triangulat$).tw.
6 or/1-5
7 (cancer$ or sigmoidoscopy or colonoscopy or faecal occult blood test or bowel or colorectal or PSA or digital rectal examination or prostate$ or pap$ or smear or liquid based cytology or cervical or mammogra$ or breast or sputum or bronchoscopy or chest radiography or chest x-ray or computed tomography or CT or lung).tw.
8 exp Mass Screening/ut [Utilization]
9 screening.tw.
10 8 or 9
11 (uptake or utili#ation or participat$ or $respond$ or respons$ or experience$ or decision$ or choice$ or decline$ or $attend$ or factor$ or motivat$ or predictor$ or reason$ or influence$ or barrier$ or acceptability).tw.
12 6 and 7 and 10 and 11

Supplementary Table 2 Sandelowski and Barroso's typology of findings in qualitative research[19]

Category	Degree of transformation of data	Defining feature	Action for this review
1. No finding	**Lowest**	Presentation of data as if they were the findings	**Exclude study - not qualitative findings**
2. Topical survey		Reduction of data to nominal or categorical data, or lists and inventories of topics	
3. Thematic survey	↕	Data more transformed than 2, e.g., a move toward describing themes or patterned responses, but less transformed than 4 or 5	**Include study - qualitative findings**
4. Conceptual/thematic description		A move beyond surveying the topical or thematic landscape of events, phenomena, or cases toward interpretively integrating portions of data	
5. Interpretive explanation	**Highest**	Transformation of data to produce grounded theories, ethnographies, or otherwise fully integrated explanations of a phenomenon, event, or case	

Supplementary Table 3 Types of cancer screening studied and identification of themes from extracted data

Study	Breast cancer screening	Cervical cancer screening	Colorectal cancer screening	Prostate cancer screening	Ovarian cancer screening	Lung cancer screening	Relationship w. health service	Fear of cancer screening	Risk/uncertainty	Beliefs about early detection	Beliefs about the disease	Other emotions e.g. embarrassment	Individual responsibility	Privacy/taboo/disgust	Information/knowledge (or lack of)	Social influences	Moral/altruism	Surveillance/control/regulation esp. of	Specific population needs	Gender	Life-cycle needs	Avoidance	Current health/wellness	Previous experiences of screening (or	Experiences of cancer e.g. family	Practical factors	Screening invitation/materials
Bond et al. 2015	✓						✓	✓		✓		✓	✓			✓		✓					✓	✓	✓		✓
Clements et al. 2008	✓						✓	✓		✓		✓							✓					✓		✓	
Karbani et al. 2011	✓										✓			✓	✓	✓			✓	✓		✓		✓			
Pfeffer 2004	✓						✓	✓		✓	✓	✓		✓		✓			✓	✓				✓	✓	✓	
Prinjha et al. 2006	✓						✓		✓	✓		✓	✓		✓									✓			✓
Shang et al. 2015	✓						✓			✓																✓	✓
Waller et al. 2013	✓						✓			✓		✓			✓												✓
Clifton et al. 2016	✓	✓	✓				✓	✓		✓	✓	✓	✓		✓	✓			✓					✓		✓	
Jepson et al. 2007	✓	✓	✓				✓	✓	✓			✓			✓												
Thomas et al. 2005	✓	✓					✓		✓		✓				✓				✓	✓	✓			✓			
Abdullahi et al. 2009		✓					✓	✓	✓		✓	✓			✓	✓			✓	✓				✓		✓	✓
Armstrong 2005		✓							✓				✓				✓	✓	✓		✓			✓			
Armstrong 2007		✓									✓	✓		✓				✓			✓			✓			
Armstrong & Murphy 2008		✓									✓							✓			✓						
Box 1998		✓					✓	✓	✓			✓			✓				✓								
Bush 2000		✓					✓	✓					✓	✓		✓		✓		✓							
Jackowska et al. 2012		✓					✓												✓							✓	
Logan et al. 2011		✓					✓	✓				✓			✓					✓						✓	
Marlow et al. 2015		✓					✓	✓	✓	✓	✓	✓		✓	✓					✓			✓	✓		✓	
Szarewski et al. 2009		✓						✓				✓							✓	✓							
Waller et al. 2012		✓							✓	✓					✓						✓					✓	

Study	Breast cancer screening	Cervical cancer screening	Colorectal cancer screening	Prostate cancer screening	Ovarian cancer screening	Lung cancer screening	Relationship w. health service	Fear of cancer screening	Risk/uncertainty	Beliefs about early detection	Beliefs about the disease	Other emotions e.g. embarrassment	Individual responsibility	Privacy/taboo/disgust	Information/knowledge (or lack of)	Social influences	Moral/altruism	Surveillance/control/regulation esp. of	Specific population needs	Gender	Life-cycle needs	Avoidance	Current health/wellness	Previous experiences of screening (or	Experiences of cancer e.g. family	Practical factors	Screening invitation/materials
Austin et al. 2009			✓				✓	✓	✓	✓	✓	✓		✓	✓				✓	✓							
Bradley et al. 2015			✓				✓	✓				✓		✓	✓	✓				✓	✓	✓	✓	✓	✓	✓	✓
Chapple et al. 2008			✓				✓	✓	✓	✓				✓			✓							✓	✓	✓	✓
Dharni et al. 2016			✓					✓	✓	✓	✓	✓		✓	✓		✓				✓		✓		✓		
Ekberg et al. 2014			✓				✓	✓	✓			✓				✓					✓		✓	✓			
Hall et al. 2015			✓					✓		✓		✓				✓	✓					✓	✓		✓	✓	✓
McCaffery et al. 2001			✓					✓		✓						✓						✓	✓		✓	✓	
Michie et al. 1996			✓				✓			✓		✓				✓											
Palmer et al. 2014			✓				✓	✓				✓		✓		✓						✓	✓	✓		✓	✓
Woodrow et al. 2008			✓					✓		✓		✓			✓	✓								✓			✓
Archer & Hayter 2006				✓			✓		✓	✓	✓	✓	✓		✓	✓	✓							✓			
Avery et al. 2008				✓			✓	✓	✓	✓	✓			✓									✓			✓	✓
Brain et al. 2004					✓				✓	✓																	✓
Lifford et al. 2013					✓					✓		✓	✓				✓									✓	
Patel et al. 2012						✓			✓	✓		✓		✓			✓						✓	✓	✓	✓	

Supplementary Table 4 Selected data excerpts from included studies

Theme: Relationship with health service
First order constructs (direct participant quotes)
“…they did send me an invitation to go which I didn't, an appointment which I didn't keep, but they did send me another one. They sent a follow up letter. So I thought well, you know, I'd better behave myself and go.” (Bush - cervical screening) “The person translating should have knowledge on it. and work with doctors.. should be female and pass on accurate information.” (Abdullahi - cervical screening) “It’s just something that I just hate, I think it’s, you know I don’t know what it is, and I know to the nurse it’s nothing but I think it’s just, perhaps because I’m such a private person.” (Armstrong 2005 - cervical screening) "I have a lot of colleagues who aren't at all registered with a GP here because they … work all the time and say they prefer to go to Poland once a year, when during 1 week they do all the medical tests with all the doctors. They just don't trust the British health care. There is a language barrier or they don't have time to go , or even think they don't need to." (Jakowska - cervical screening) "I go to the GP surgery and all he wants to do is to write a prescription, so now I don't bother because what is the point of going." (Thomas - breast and cervical screening)
Second order constructs (author commentary)

The letter of invitation can be understood as conveying a non-medical message. A Sylheti-speaker had gone along to the screening unit because she understood her letter of invitation, emblazoned with official logos, as a command, not a request. Her response suggests the NHS is sometimes indistinguishable from government departments which have considerable power over people's lives… (Pfeffer - breast screening)

… resistances were made to the regulatory nature of the call and re-call system. Some women felt that the invitations were too forceful: like demands and orders rather than invitations. (Bush - cervical screening)

Going to the doctor's is not a routine occurrence for Julia; it is an unusual and unwelcome event and, as such, is something of an ordeal for her. She does not regard herself as the type of person who regularly visits the doctor; indeed, elsewhere in the interview she stressed her very good general health and her reluctance to rely on doctors to resolve minor health complaints. Julia therefore resists attempts within the official discourse to construct screening as routine and stress its role in maintaining good health, by associating it clearly with illness and literally with 'feeling sick' at the prospect of submitting herself to the medical gaze. (Armstrong 2005 - cervical screening)

The Pakistani group held a very biomedical view of the health-care system, refusing to attend the test unless told to go by the general practitioner. (Austin - colorectal screening)

Many women of all three nationalities lacked trust in the NHS, often citing poor hygiene and a perceived tendency to treat every illness with paracetamol. In many cases, women's negative opinions regarding the NHS were based on stories that they heard from other people rather than their own experiences. (Jackowska - cervical screening)

Generally, a sense of feeling coerced was not a major issue for people invited for breast and colorectal screening. As people received invitations at home, most saw it as their choice whether they went or not. (Jepson - breast, cervical & colorectal screening)

It appeared that the detachment from clinical settings and professional roles may have reduced the perceived importance of the offer of screening. The prospect of self-testing at home therefore inhibited rather than facilitated uptake. (Palmer - colorectal screening)

Zoe believed that attending screening will protect her from breast cancer. There is a passivity about her response 'I go when I'm called', the responsibility for this aspect of her health lies elsewhere, and she was responsive not active. (Bond – breast screening)

Some participants suggested that the implementation of the new preventative approach to healthcare, where people are encouraged to recognize early symptoms and take measures to prevent illness, tends to alienate or dehumanize their engagement with the health system. Some of our participants associated the messages of preventative healthcare with the 'nanny state', which they interpreted as being a threat to individual freedom and autonomy and as being overly broad and repetitive. (Ekberg – colorectal screening)

Theme: Fear of cancer screening

First order constructs (direct participant quotes)

"I just have never done anything like that so I would be frightened of it getting lost up there or something." (Austin - colorectal screening)

"I think the word cancer frightens most people ... I lost my mother with it." (McCaffery -

colorectal screening) “It [receipt of first test kit] was a shock, I wasn’t expecting it and you get it as soon as you’re sixty. Like now I’m sixty they expect me to get everything.” (Bradley – colorectal screening) “It could be embarrassing.” “If there were men, it would be disastrous.” (Pfeffer – breast screening)
Second order constructs (author commentary)
Others cited embarrassment and fear of pain, sometimes resulting from previous experiences. Their beliefs often seemed entrenched and they rarely stated any intention to attend in the future. (Waller 2012 - cervical screening) Fear of the test results was also thought to prevent some women from coming forward for screening. (Abdullahi - cervical screening) The breast was seen by all participants as a symbol of femininity and feminine beauty. Therefore, for most participants, breast cancer was a doubly fearful disease: It not only was associated with death but also threatened physical attractiveness and psychological well-being. (Shang – breast screening) Julia very rarely visits the doctor and so the presentation of the cervical smear test as a simple and routine test does little to allay her fear and anxiety. ... Julia therefore resists attempts within the official discourse to construct screening as routine and stress its role in maintaining good health, by associating it clearly with illness and literally with ‘feeling sick’ at the prospect of submitting herself to the medical gaze. (Armstrong 2007 – cervical screening)
Theme: Experiences of risk
First order constructs (direct participant quotes)
"I’m healthy enough and I feel that any mucking about ... will disturb something that you’ve no need to disturb." (McCaffery - colorectal screening) “I’m not like other ladies and going with other men, I stick with one man, I’ve been twice and there is nothing there and now I have no husband because he has died so I have no sexual relation with anyone so after going twice I don’t need them now.” (Armstrong 2005 - cervical screening)
Second order constructs (author commentary)
The interviewees varied on who they felt was `at risk' from cervical cancer. Some drew on the traditional association between cervical cancer and promiscuity. Others felt that all women were at risk, even those who aren't sexually active. (Bush - cervical screening) This man … felt fit, believed he ate well and found it hard to imagine that anything was wrong. He did not feel susceptible to cancer. Even though his children had noticed that he looked less healthy than usual he assumed this was due to ageing. (Chapple - colorectal screening) Some respondents considered their risk of lung cancer in relation to their current health status, with absence of symptoms interpreted as indicating a low risk of cancer. (Patel - lung screening) There were also instances of women incorporating compliance with the NHSBSP into a game of chance with the disease. However, women interpret the rules of this game differently. Sometimes compliance may load the dice in a woman’s favour. (Pfeffer -

breast screening)