Accessing Screening Services: A Review of the Literature and Local Practice in the context of the Equality Delivery System

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Contents

Page

Equality Dimension

Barriers to Accessing Screening Services

Introduction

This literature review is part of the work undertaken by NHS Midlands and East SHA Cluster on behalf of the UK National Screening Committee with the aim of helping NHS Screening Programmes understand and meet the requirements of the Equality Delivery System as defined through the Equality Duty 2010. In order to help screening services identify where reasonable adjustments may be able to have an impact on screening uptake rates amongst equality groups (As defined in the Equality Duty and within society as a whole) a search of published literature was undertaken.

Aims

To identify the key barriers that the protected equality groups may face in accessing and utilising NHS screening services (screening services are those available nationally in England through the NHS, (see box 1). To help ensure that screening services enable equal access across the community, the majority of included studies and reports look to identify and help mitigate against barriers experienced by sections of the population, in order to give them the same opportunity as the wider population in accessing screening services. However this should not be confused with informed choice in decision making with regard to screening, as this is something which is beyond the scope of this project.

The Equality Duty

This literature review is undertaken in the context of the; Equality Duty (2010), which replaced thethree previous public sector equality duties for, race, disability and gender. The new Equality Duty covers the following protected characteristics:

- Age
- Disability
- Gender reassignment
- Pregnancy and maternity
- Race – this includes ethnic or national origins, colour or nationality
- Religion or belief – this includes lack of belief
- Sex
- Sexual orientation

It also applies to marriage and civil partnership, but only in respect of the requirement to have due regard to the need to eliminate discrimination (Government Equalities Office 2010).

The Equality Duty has three aims. It requires public bodies to have due regard to the need to (Government Equalities Office 2010):

- Eliminate unlawful discrimination, harassment, victimisation and any other conduct prohibited by the Act
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it
- Foster good relations between people who share a protected characteristic and people who do not share it

This literature review looks to take a pragmatic approach to the issue of equality in screening. It looks at inequality of access to screening over a greater number of equality groups than those set forward in the Equality Duty 2010.

Box 1 NHS Screening Programmes available in England.

NHS Screening Programmes

Antenatal and Newborn Screening

Down’s Syndrome

Fetal Anomaly Ultrasound Scan

Infectious Diseases in Pregnancy

Antenatal Sickle Cell and Thalassaemia

Newborn and Infant Physical Examination

Newborn blood spot

Newborn Hearing Screening

Adult

Abdominal Aortic Aneurysm Screening

Diabetic Eye Screening

Breast Cancer Screening

Cervical Cancer Screening

Bowel Cancer Screening

Methodology

Overview

The brief for this report was to identify the literature around barriers to access and uptake of screening services by each equality group as specified in the Equality Act 2010. The purpose of this was two-fold:

1). To inform a workshop (conducted in October 2012) attended by health professionals and service users to look at the barriers experienced by various equality groups (as identified in the literature and by the service users themselves) and how services may be able to make reasonable adjustments to encourage use of screening services.

2). To form part of a toolkit for staff working in or commissioning NHS screening programmes to access and utilise as a resource.

This literature review began with an initial scoping exercise, which found a report by Porter (2008) 'Interventions to reduce inequity and inequality in accessing national screening programmes' commissioned by the UK National Screening Committee. This report included a literature review, with a literature search strategy that covered Medline, Embase, and the Cochrane Library, for studies conducted from 2000 – 2008. The focus of this report was to look at interventions and examples of local practice that were shown to have an impact on inequalities in access to NHS screening services.

Literature Search

As the Porter (2008) report had already conducted a review of interventions to reduce inequity and inequality, this review will focus on identifying barriers specific to each equality group; it will also look to add to the information provided in the report by Porter (2008), with information from studies conducted after 2008.

This literature review is comprised of studies identified from the MEDLINE and EMBASE databases (An example of the search strategies employed are included in appendix 1), the search strategies were designed to identify systematic reviews and randomised controlled trials conducted between 2000 - 2012. Studies that looked at barriers to screening in specific population groups were included in the review. Once studies were included in the review any other relevant references were identified, if one of these identified studies covered a specific equality group it was also included in the review, some of these studies were not as robust a study design but they did focus on specific topics of interest. In order to gain a greater understanding of the barriers faced by equality groups including contextual information, qualitative studies were included in this review.

A search of the Cochrane Library was also undertaken to identify any further appropriate systematic reviews relating to barriers and inequality in screening uptake.

From this literature search a total of 41 studies were found to be relevant, studies were included if:

- They focused on barriers to screening attendance by any of the equality groups.
- They focused on interventions to increase attendance amongst equality groups and/or tackled specific barriers to attendance through the intervention.
- They focused on barriers to access specific to a screening programme (that is available through the NHS in England) regardless of equality group (these studies were included if the predictors to screening were identified as falling into an equality group e.g. ethnicity, sexuality).

The included studies consisted of, 10 systematic reviews, 7 randomised controlled trials (RCTs), 2 Cluster RCTs, 3 lower quality intervention studies, 2 cohort studies, 3 cross-sectional studies, and 15 other types of study design including qualitative studies. The majority of studies addressed the cancer screening programmes and were based in the United States.

Grey Literature and Examples of Local Practice

In keeping with the aim of the overall project to explore the barriers faced by equality groups in screening the inclusion of grey literature and evidence from meetings and correspondence with the equality groups was vital to give depth and context to the literature review.

All PCT screening leads in the NHS Midlands and East Cluster were contacted and asked for relevant information, examples of practice and reports that they had either undertaken or knew about that targeted specific equality groups in relation to accessing screening services. Over 30 documents were forwarded to the project team from this process. The documents included; evaluations of local projects, powerpoint slides from relevant presentations, health equity audits, health needs assessments and reports on specific local population groups that contained elements relevant to screening and equality.

A brief internet search (using a well-known search engine) was undertaken of organisations that represent certain equality groups i.e. the Royal National Institute of Blind People (RNIB) to identify any appropriate reports or research undertaken by the organisations that would be relevant to this literature review.

An internet search (using a well-known search engine) was also undertaken using the key word; screening followed by the name of each equality group e.g. Traveller populations. This search provided a further 20 documents that were found to be relevant to the literature review.

Equality leads and champions from PCT’s in the NHS Midlands and East Cluster were also contacted in order to gain information of community and voluntary sector organisations and groups who represent the equality groups. From the lists of groups and organisations providers, all were contacted and meetings were arranged with those who wished to be heavily involved in the project, while email and telephone contact was made with those who wanted to have input into the process but were unable to participate in focus groups and meetings.

Over 100 organisations and groups were contacted directly by email across the Midlands and East, these organisations and groups were asked to forward the email to other potentially relevant parties who may have been interested in the work being carried out. The project team had direct correspondence with approximately 60 organisations, with approximately 25 organisations/groups making direct contributions to this work either by email, telephone, letter and/or face to face meetings, which took the form of either interviews or focus groups.

Definition of terms Box 2.

Screening Coverage

Is defined as the percentage of the population eligible for screening at a given point in time who were screened adequately within a specified period. (NHS Information Centre, 2009)

For example for breast screening coverage would be:

Coverage of breast screening is the proportion of women resident in the screening target area (excluding those who are ineligible for screening, for example, those who have had a bilateral mastectomy) who have had a recorded test result at least once in the previous three years. (http://info.cancerresearchuk.org/cancerstats/types/breast/screening/definitions/breast-screening-definition-of-terms)

Screening Uptake

Refers to the proportion of persons eligible to be screened within a populationwho have been both invited for screening and have received an adequate screen during a specifiedperiod.(Jepson et al, 2000 p. 1)

For example breast screening uptake would be:

The proportion of women eligible for a mammogram who had attended for a mammogram and had a test result recorded, during a specified time period.

Grey Literature

In its broadest definition, grey literature is a body of materials that cannot be found easily through conventional channels such as publishers. It can include; government research, reports, and policies, non-profit reports, think tank assessments, reports from observations, and investigations. With the advent of the internet grey literature is now much more easily accessed. Grey literature is not peer reviewed and so care must be taken when interpreting findings from grey literature. However without including grey literature within a literature there is a danger of missing some vital data and information (Huffine, 2010).

Limitations

This literature review was conducted by one individual and was limited primarily to two journal databases. Abstracts of all studies identified in the literature search were reviewed to determine if they were relevant to the literature review. Of those studies that were relevant to this literature review, the full text version of the article could not be acquired for all studies. Ideally the literature review would have been done by two or more individuals who could have assessed the relevance of the studies together. This would also have allowed a sample of the reviewed articles to be reviewed by a second individual to check that they were happy with the appraisal of the articles and allow a consensus to be formed for the overall review.

Due to the work involved in this overall project and the time limit imposed on this literature review (and the small size of the project team) the scope of the literature search had to be limited. An overarching aim of the project was also to identify good example of local practice, and using local data to help highlight possible gaps in screening services that would benefit from reasonable adjustments, and thus increasing participation in screening amongst equality groups. To this end a focus of this review was to gather information from various local projects and initiatives, this was considered to be a pragmatic approach to the area of equality and screening. However the inclusion of such examples of practical work, reduced the depth of the peer reviewed literature search, and meant that more local examples of work were reviewed. The hope is that this will provide an overall view that will be useful to both screening service commissioners and providers, and the equality groups.

The information from local services and equality groups was gathered from the Midlands and East and may not be representative of areas of the country. The documents found through the internet search are likely to be the tip of the iceberg in terms of relevant documents available.

The main focus at the project outset was identifying barriers specific to equality groups, therefore this should not be seen as an exhaustive list of studies looking at barriers to screening uptake and related interventions.

Equality Dimension – General **(Likely to cut across a number of inequality areas)**

A report conducted by Greater Manchester Public Health Practice Unit (Threlfall and Fazil, 2009), investigated various approaches (through the available literature, local data and local experience) to increasing attendance at breast and cervical cancer screening in Greater Manchester. They highlighted a number of reasons for not participating in cervical screening highlighted by some women:

- Unavailability of a female screener, a female screener was preferred by most users and non-users (i.e. women outside the age criteria but who will be eligible for screening in future, women who may consider attending for a cervical screen in future)
- Inconvenient clinic times
- Lack of awareness about the test
- Fear, embarrassment and previous negative experiences

From the literature and evidence reviewed within this report, these factors are likely to be even more of a barrier for women from some of the protected groups.

Pakistani groups in particular were found to have low screening rates; the reasons for this had not been explored by the Trelfall and Fazil report (2009) however number of studies, including those by, Thomas et al (2005), Hayden (2012), Applebee (2012), have identified the following factors, cultural beliefs and attitudes, language issues (particularly in the older population), lack of understanding of screening, as being important factors in determining screening uptake amongst the Pakistani community

These factors are also likely to be compounded by socio-demographic issues. Factors like; an individual's social influences and peer group are likely to further influence or compound behaviour, and act as a facilitator or a barrier to attendance of screening. This could equally apply to all screening programmes, and will interact with an individual's knowledge, behaviour and beliefs, which are influenced by a person's social surrounding and educational attainment.

A report by the North West London Cancer Screening Network, that looked at maximising screening attendance (Zelenyanszki, 2009) highlighted that there was; persistently low attendance to breast and cervical screening amongst:

- Women who have never been screened before

Macalister et al (2012) surveyed non-attenders for cervical screening (aged 25-34) in a sample of General Practices in the Shropshire County and Telford and Wrekin PCT areas. Although the response rate was low they found the most common reasons for non-attendance were cited as; lack of time and being too busy, and a belief that the screening test was painful.

The National Cancer Action Team (NCAT), have put together a document that gives an overview of patient experience across cancer services by equality group. Some of these experiences can be identified as barriers patients may face in accessing screening services and are highlighted in the underlined headings below:

Older people

- Less likely to be directed to sources of financial help and benefits, which may also apply to screening.

Costs in accessing screening (e.g. travel) can be an important barrier for some people. If older people are less likely to be provided with relevant information about support they may be entitled to, this could impact on the likelihood of them attending screening services.

Ethnicity

- Patients from black and minority ethnic (BME) groups are more likely to report a poorer experience of care.

Perception of treatment/actual treatment by health professionals has been highlighted as a barrier to screening participation by BME groups.

- BME patients are more likely to report not receiving understandable answers to their questions, and are less likely to receive written information on tests and procedures.

Understandable information and level of knowledge have been demonstrated as barriers to screening by the literature.

- BME patients have lower levels of confidence in their care and are less satisfied with communication about their care.

This links to the previous point of understandable information. The literature has highlighted that some BME groups have less confidence in screening than their white counterparts.

NCAT identified a number of barriers in relation to those with lower socioeconomic status accessing cancer care and treatment. The following barriers can be equally applied to screening services and are similar to those highlighted in the literature.

Deprivation

- The most deprived groups report delayed diagnosis, and are less likely to receive understandable information or explanations.

- The findings for the most deprived groups are similar to those reported by BME groups.

Sexual Orientation

- Lesbian, gay, and bisexual people find it hard to cope with clinical assumptions that they are heterosexual (e.g. assumptions made about friends and partners), and find it hard to tell clinicians about their sexual orientation.

- People whose sexual orientation is other than heterosexual report that they are less likely to be treated with dignity and respect.

- Less likely to be positive about their experience of communication.

Waller et al (2009) undertook a population based study to investigate barriers to cervical screening attendance in England. The study compared the barriers reported by women who were up to date with screening and compared them with women who were overdue for screening. The study used a stratified random probability method to recruit the sample of women aged 26 – 64 years (n=580), a face to face interview with each woman was used to gain the data included in the study.

The sample included 85% of women who were up-to-date with screening and 15% who were overdue. Four barriers showed significant independent associations with a woman being overdue for a cervical screen (Waller et al, 2009):

- Not getting round to going for screening straight away
- Finding it difficult to arrange a convenient appointment time
- Not trusting smear tests
- Not being sexually active

Equality Dimension – Age

Vedel et al (2011) conducted a systematic review which looked at the main barriers and facilitators to breast and colorectal cancer screening in older adults. The review included studies that looked at barriers and facilitators from both the primary care physician and patient viewpoint.

The review included studies from Europe and the United States, although the majority of studies were from the US. Most of the included studies used a cross-sectional study design which has inherent limitations and is one of the weaker forms of evidence. Although a cross-sectional design can be used to indicate an association between 2 variables if sufficient data is collected, it then needs to be investigated through a more rigorous study design. However it can be subject to a number of bias' including, recall bias and response bias. The main barrier identified by Vedel et al (2011) was; a lack of belief amongst physicians of the usefulness of cancer screening for older adults. This may be less of an issue in the UK due to the NHS recognised age criteria of the national screening programmes.

From the patients' perspective barriers identified were (Vedel et al, 2011):

- Embarrassment of having the test
- Discomfort of having the test
- Fear of having the screening test

Guessous et al (2010) undertook a systematic review to identify the most consistently mentioned barriers to, or facilitators of colorectal cancer screening in older people (classified as ≥65). There were 83 studies included in the review (taking place from 1995 – 2008). Included studies were concentrated within the US.

The main barriers identified by the Guessous et al (2010) review were:

- Low educational attainment
- African American Race
- Hispanic ethnicity
- Female gender
- Lack of insurance

However the extent to which these issues apply to a UK population and screening programme is questionable due to the substantial differences between the UK and US healthcare systems.

Waller et al (2012) undertook a qualitative study to explore the different barriers to attending cervical screening across different age groups. The authors interviewed 12 health professionals working in the screening 'field' for their views on the reasons for lower attendance at screening by younger females. The study then conducted four focus groups (n=27) and 19 interviews with women who under-attend screening.

The health professionals identified the following reasons/barriers:

- Service provision issues (e.g. time of clinics/convenience)
- Time pressures
- Risk perceptions
- Lack of knowledge
- Psychological barriers

Non-attendees were defined as falling into one of two groups:

- Those who made an active decision not to participate (who tended to be older)
- Those who intended to attend screening but did not end up attending (predominantly younger women).

Practical barriers were raised more often by younger women e.g.:

- Time pressures
- Location
- Whereas older women tended to have more negative attitudes towards screening in general

Equality Dimensions – Socioeconomic status, Ethnicity, Age, and Gender

Javanparast et al (2010) reviewed published literature relating to the equity of participation in colorectal cancer screening amongst different population subgroups in the US,63 studies were included in the review. To be included in the systematic review studies had to include faecal occult blood test (FOBT) as at least one of the screening tests. Javanparast et al (2010) found that the most important predictors of colorectal cancer screening were reported to be:

- Socioeconomic status - Lower socioeconomic status, less likely to attend screening
- Ethnicity – background other than white, less likely to attend screening
- Age – younger age less likely to undertake screening
- Gender – male gender less likely to undertake screening

The study found very few evidence based solutions to the problems of inequity in screening participation.

Evaluation of the colorectal cancer screening pilot suggests that the following groups are likely to have low uptake of bowel cancer screening (UK CRC, 2003[1]):

- Men
- Younger people
- Those living in more deprived area
- Individuals of minority ethnic origin

They also identified that practical issues such as ease of completing the kit appeared to be an important determinant of uptake.

During the pilot phase of the bowel cancer screening programme a separate study considered potential issues around uptake amongst ethnic minority groups (UK CRC, 2003[2]). The report found low uptake in the Asian community which could not be explained by differences in other factors such as age, gender, date of screening invitation, or deprivation index. The report found that Asians:

- Had low levels of knowledge and awareness of bowel cancer and CRC screening
- Were less confident in colorectal cancer screening effectiveness than non-Asians
- Had low self-efficacy with regard to completing the kit

The report also noted that uptake rates were significantly lower for individuals (regardless of ethnicity) registered with an Asian GP (UK CRC, 2003[2]).

Wilf-Miron et al (2011) analysed the uptake of breast and colorectal cancer screening services in Israel. While the setting and healthcare system of Israel is not directly comparable to the UK, the study did find that individuals classed as lower socioeconomic status attended viewer screening services than those from higher socioeconomic groups. Those individuals in lower socioeconomic groups were also more likely to be immigrants.

Whitaker et al (2011) examined the role of time perspective in explaining inequalities in colorectal cancer screening attendance. They found that lower socioeconomic status was associated with:

- Lower consideration of future consequences of not attending screening
- Low perception of the benefits of screening
- Perception of higher barriers to screening than those individuals in higher socioeconomic groups

The study included 809 participants, and the colorectal screening test used was flexible sigmoidoscopy as part of the UK trial. However flexible sigmoidoscopy is not the screening test used in the UK, but colonoscopy is used following a positive FOBT and people's perception of sigmoidoscopy may be similar to that of colonoscopy when the test procedure is explained. There is no comparator group within the study with which to compare difference in screening uptake. However, socioeconomic differences in screening uptake have been established in a large number of studies.

NHS Nottingham City and Nottinghamshire County (Pearce, 2012) produced a Bowel Cancer Screening health equity audit. The analysis of the local data found associations between low uptake and:

- Being male
- Living in a deprived area
- Living in an urban area
- Attending a practice with a high proportion of patients who are non-white

Nnoaham et al (2010) found that age, gender, deprivation and geographical context can effectively explain variations in colorectal screening uptake.

Equality Dimension – Socioeconomic Status

McAlearney et al (2007) looked at cost as a barrier to mammography screening in the US. Study participants lived in rural areas and were classified as, low income, white, native American or African women. Cost was found to be the main barrier to mammography screening. Although women in the UK do not have to pay for screening, it was not just the cost of the screen that was the issue. It was also associated costs which included:

- Transport

- Childcare

- Loss of pay

Interestingly, the authors found that in women for who cost was an issue they tended to perceive the costs as being higher than they actually were, making the barrier even greater. This is similar to the point made in the Whitaker et al (2011) study, which found individuals in lower socioeconomic groups were more likely to perceive higher barriers in accessing screening.

Johns and Moss (2010), undertook a randomised trial to study the effect on breast cancer mortality of invitation to annual mammography from age 40/41 up to age 48. The study was conducted in 23 NHS breast screening units in; England, Wales and Scotland, between 1991 and 2004. The authors found that screening attendance was comparable to that of the national screening programme for women over 50. However there was an inverse relationship between screening attendance and deprivation. Using the Townsend score the first invitation to the routine trial screening was accepted by:

- 75.1% (10,152) of women in the least deprived quintile, with a further 10.9% (1,474) who refused the first offer but accepted a later offer of screening.

- In the most deprived quintile 55.5% (4,190) women attended in response to the first invitation and 17.6% (1,331) accepted subsequent invitations.

- In the least deprived quintile 56.2% (6,538) women attended all offers of routine screening, compared with 36.7% (2,025) in the most deprived group.

Initially this may seem irrelevant to the UK screening programme due to the age range being younger than the national programme. However the national breast screening programme is now being extended to cover the age range 47 – 73 by the year 2016 (http://www.cancerscreening.nhs.uk/breastscreen/under-50.html). Furthermore similar patterns of attendance by socioeconomic group are repeated in other screening programmes.

Peek and Hann (2004) conducted a study in the USA on mammography use. They found that women with the lowest income had the lowest rates of screening for breast cancer. The rate remained low even when adjusted for ethnicity, race and insurance status. The authors conclude that there are many reasons for this low level of uptake and they include:

- Inadequate cancer prevention knowledge and behaviours
- Lower educational attainment
- Poor access to healthcare than their more affluent counterparts (inverse care law)

Von Wagner et al (2009) reviewed FOBT screening for colorectal cancer uptake rates in London, in relation to socioeconomic deprivation over the first 30 months of the screening programme. Results showed a strong socioeconomic gradient in FOBT uptake, which declined from 49% in the least deprived quintile of postcodes to 38% in the middle quintile and 32% in the most deprived quintile. Variation in socioeconomic deprivation accounted for 63% of the variance in return rates, with little attenuation as a result of controlling for ethnic diversity, household mobility or health status.

A health equity audit undertaken by NHS Wirral Performance and Public Health Intelligence team found that the higher the General Practice deprivation score, the more uptake of diabetic eye screening decreased (NHS Wirral, 2009).

Millett and Dodhia (2006) found that attendance rates for diabetic eye screening in South East London were significantly lower in younger patients (aged 40 and under), in those with type 1 diabetes and in patients residing in areas with the highest deprivation. This was an equity audit using a cross-sectional study design, there are limitations with this type of study design (as stated previously), but the findings are in-line with other literature on screening uptake and socioeconomic inequalities.

Equality Dimensions – Age, socioeconomic status

A large systematic review was conducted in the year 2000 by Jepson et al. This review examined factors associated with screening uptake and the effectiveness of interventions to improve screening uptake.

The review by Jepson et al (2000), was thorough, detailed and covered a wide range of studies undertaken up to that point in time. The review covered 23 databases of both published and grey literature to find potentially relevant studies for inclusion in the systematic review. All published and unpublished studies were assessed for inclusion and there were no language restrictions. The size of this review means some elements are still applicable today.

Jepson et al (2000) assessed 65 studies (that met the inclusion criteria for the review), that appear to help determine if someone is likely to attend a screening programme or not. The main relevant points from the Jepson et al (2000) review are listed below:

Breast Screening – Mammography

- Women who had attended for a previous mammogram were more likely to attend for future mammograms.

Meaning – those women who do not attend are less likely to attend in future.

- Women who reported an intention to attend screening (i.e. they actively planned to attend mammography screening) were more likely to attend when the invitation arrived, than women who had no active plan to attend.

Meaning – those women who do not make active plans in advance are less likely to attend for a mammogram.

- Women who had health insurance (predominantly U.S. studies) were more likely to attend screening

Meaning – this is not likely to have a significant impact in England with screening being available free at the point of access for those people who meet the eligibility criteria through the NHS funded programme.

- Women who received a recommendation letter for screening from their General Practitioner were more likely to attend for screening.

Meaning – where current practice is not to use a General Practitioner signed letter some women may be less likely to attend screening.

Cervical Screening – Papanicolaou (Pap) smear

- Women who had health insurance (predominantly U.S. studies) were more likely to attend screening

Meaning – this is not likely to have a significant impact in England with screening being available free at the point of access for those people who meet the eligibility criteria through the NHS funded programme.

- Age was found to be a determinant for cervical screening, but from conflicting outcomes in the studies assessed by Jepson et al (2000) it was unclear whether older or younger women were more likely to attend.

Meaning – it is unclear the role in which age predicts attendance for a cervical screen in women.

Equality Dimension - Socioeconomic Status and ethnicity

Rowe et al (2004) undertook a systematic review to address the question of; whether there are social inequalities in either the offer or the uptake of prenatal screening in the UK. The review focused specifically on social class or ethnic origin, assessing the offer or uptake of prenatal screening or diagnosis, 20 papers met the inclusion criteria. Included studies covered screening and/or diagnosis for Down's syndrome, neural tube defects, haemoglobin disorders and HIV. Many of the studies were limited by small numbers or poor reporting of data and analysis. No study found any significant inequalities to screening and/or diagnosis related to social class.

Furthermore a small number of studies in the Rowe et al review suggested that women of South Asian origin may be less likely to receive screening for haemoglobin disorders and Down's syndrome. However these were small studies with some methodological flaws. A small number of studies also suggested that South Asian women may be less likely to be offered screening.

However as total population uptake of some antenatal and neonatal tests is close to a 100%, then all sizeable population sub-groups must also have uptake close to a 100%, meaning there is little value in relating screening uptake to equity variables (Allaby et al, 2009). Therefore it may be more useful to assess whether timeliness of uptake of the screening test is related any of the identified protected groups or other relevant equity variable.

Yu (2012) undertook a systematic review that aimed to identify issues around antenatal screening and prenatal diagnostic testing among women of Asian descent in western countries. The review included studies undertaken during the period of 1995 – 2010. Twenty-one studies met the inclusion criteria for the review. For the most part Asian women reported a poorer understanding of the tests than white women, and therefore felt less able to make an informed choice. The main issue here is most likely to be that of informed choice, and the way information is presented rather than screening uptake. The Yu (2012) review is predominantly based on studies conducted in the United States. The quality of the studies included was extremely variable, with the majority having a number of methodological flaws.

Brown et al (2011) investigated factors that predicted 'informed choice' by pregnant women with regard to the sickle cell and thalassaemia screening test. The study particularly investigated whether offering this screening test in primary care at the time of pregnancy confirmation compromises women making an informed choice. The study employed a partial factorial, cluster RCT design. The setting was 25 General Practices in two socially deprived areas of the UK. 464 women were randomised to one of three groups offered:

- Screening in primary care at time of pregnancy confirmation with parallel partner testing
- In primary care at time of pregnancy confirmation with sequential partner testing
- In secondary care by midwives, with sequential partner testing (usual care)

The study found that just over 30% of participants across each group made an informed choice:- there was also no statistically significant difference in informed choice between the groups. Across all 3 study groups, 91% of women underwent screening and 30.6% were considered to have made an informed choice as to whether or not be screened. Interestingly from the perspective of this literature, the majority of women did not feel they made an informed choice. Brown et al (2011) found that uninformed choices were generally due to a lack of knowledge (in 65% of those cases who felt their choice was not "informed").

Predictors of good knowledge were found to be (Brown et al, 2011):

- Older age
- More educational attainment

Indication of poor knowledge:

- Having to have the information translated

- Being from a high risk ethnic group

This indicates that participants whose first language was other than English were less likely to make an informed choice.

It should be noted that this was a relatively small study that relied on questionnaire response to determine level of knowledge, and may be open to bias in its findings. There was also an attrition rate of 32% in this study. The majority of confidence intervals although significant were very wide indicating a lack of precision in the findings due to the small sample size. However in relation to this the authors state:

> ‘Although it was not feasible to extend this study, we have no reason to expect that, were the sample size increased, primary care sequential testing would emerge as significantly worse for informed choice than either primary care parallel testing or secondary care sequential testing’ (Brown et al, 2011 p. 71).

Equality Dimension - Ethnicity

Thomas et al (2005) looked at barriers to breast and cervical screening in BME groups living in two areas on the outskirts of London in the UK. The study utilised a series of focus groups to elicit views from participants. The study included 135 people in total and looked to discover their perceptions of screening and barriers to taking up screening when invited.

Barriers classed as important were:

- Poor knowledge
- Underlying health and cultural beliefs – virginity screening – cervical screening taboo subject
- Attitudes
- Language
- Unhelpful attitudes of health professionals
- Need reassurance that a person of the same sex will be doing the test

Patnick (2007) reports that in the UK, the main reasons for low uptake of screening programmes by ethnic minority populations are consistently reported as being lack of knowledge and poor clinical communication.

Based on information provided from the Arden cancer network (which covers; Coventry, Warwickshire, Redditch and Bromsgrove), that the uptake of cancer screening by people from ethnic minorities locally was significantly lower than that of the white British population. Coventry LINK (2012) investigated the barriers to cancer screening attendance in these groups.

The information compiled in the Coventry LINK report was primarily gathered from:

- Informal and formal discussions on a one to one and group basis with people from BME communities
- Findings from the above discussions resulted in the production of a questionnaire which was disseminated around the BME community
- 2 single gender focus groups

The research captured information from a total of 282 people from BME communities within Coventry. Primary barriers identified were (Coventry LINK, 2012):

- Lack of knowledge of cancer and related services available
- Lack of access to relevant information
- Don’t understand the importance of screening
- Fear of cancer
- Logistical concerns – getting to the venue, organising childcare if necessary
- Embarrassment
- Fear of wasting Doctor’s time
- Fear of bad news
- Fear of causing stress to your family

Austin et al (2009) investigated perceived barriers to flexible sigmoidoscopy screening for colorectal cancer among UK ethnic minority groups. The study was a qualitative one, which utilised focus groups. Although flexible sigmoidoscopy is not the UK’s chosen option for colorectal screening, the FOBT and subsequent colonoscopy will likely raise similar issues with ethnic minority groups. Participants were from; African-Caribbean, Gujarati Indian, Pakistani and

White British Communities. The study used the Health Belief Model as a framework. The subjects highlighted the following issues/barriers to colorectal cancer screening:

- Limited awareness of bowel cancer
- Anxiety of the invasiveness of the test and bowel preparation
- Fear of a cancer diagnosis
- Language difficulties
- Failure to meet religious sensitivities
- Culturally influenced health beliefs

Equality Dimension – Learning Disability

The term learning disability is generally referred to as impairment in intellectual function (Defined as an IQ of less than 70, Emerson and Hatton, 2010). It is estimated that 1.2 million people in England have a learning disability (approximately 300,000 children and 900,000 adults) (Emerson et al, 2012).

The Department of Health’s Cancer Reform Strategy (2007) states there is a poor uptake of general cancer screening in people with learning disabilities. This is further highlighted by Read and Latham’s paper (2009), they highlight the poor uptake of people with learning disabilities across other screening programmes. Furthermore, research has highlighted that people with learning disabilities have more health problems than the general population, yet often experience poor access to health services (Disability Rights Commission 2006).

The Leicester, Leicestershire and Rutland Learning Disability Bowel Screening Working Group conducted some focus group discussions with a number of people (n=9) with learning disabilities. The group was aged between 53 and 64, there were both sexes represented in the group. The group itself was selected for their ability to take part in discussion (Finnamore, 2011). The session looked at issues related to bowel cancer screening, they identified the following:

- The group reported a low level of awareness in relation to cancers in general and to bowel cancer specifically.
- No individual within the group had any awareness of the bowel screening programme (there were 3 people in the group over 60, and thus will have/should have received the offer of a test.)
- The group reported:
    - Finding the screening invitation material difficult to understand.
    - Finding the lettering on the test kit too small and the words too complicated.
    - Finding the leaflet and test kit confusing.
    - Concerns over performing the test correctly, the manual dexterity involved, and the practicalities of doing the test if using a shared bathroom.

This is an unpublished piece of work based on a small focus group, of self-selected individuals, who were able to participate in discussion (It may be that other individuals with lesser communication skills may have more of an issue with accessing screening services). Nevertheless the themes here are similar to those raised in other studies and local practice.

It is not uncommon for women with a learning disability not to be offered routine cervical screening, on the assumption that they have never had sexual intercourse(NHS Cancer Screening Programmes, 2006). Likewise women with a physical disability should have the same access to cervical screening and assumptions should not be made regarding their sexual history. The main barriers from this report appear to be:

- Assumptions of healthcare staff

- Assumptions of support workers

Stokes and Clift (2012) highlight that approximately 50% of people with a learning disability will have some form of communication difficulty. They use examples from cancer diagnosis to identify various communication issues that can be accentuated in clinical settings, if:

- Consultations are rushed
- Limited appointment time
- Process not explained in clear understandable terms/inappropriate leaflet/literature available explaining the screening test

However, the examples given above can equally apply to screening, and were identified in some of the local work, as in the Leicester, Leicestershire and Rutland work for example.

Stokes and Clift (2012) also identified barriers to health appointments from a learning Disability perspective, again these are primarily related to cancer diagnosis, but the list below can apply equally to screening:

- Physical access
- Communication
- Values/Attitudes/prejudice
- Unfamiliar environments/people
- Waiting for & during appointment times
- Consent
- Limited understanding of own body
- Past experiences

Equality Dimension – Physical Disability

NHS Cancer Screening Programmes (2006) produced guidance to ensure that disabled women have the same rights of access to the NHS Breast Screening Programme and NHS Cervical Screening Programme as all other women.

Women in NHS residential care may not be registered individually with a General Practice. Therefore they are not routinely invited for screening. It is the responsibility of the breast screening unit to make contact with the NHS residential care unit and obtain a list of women who are eligible for invitation to breast screening.

In terms of cervical screening women in an NHS residential unit may not be registered individually with a General Practice. It is therefore the responsibility of the staff at the residential unit to consider which residents are eligible for cervical screening and to make appropriate arrangements for eligible individuals to be included on the Cervical Screening call and recall system

The Chief Executive of Hertfordshire Action on Disability made the following points, with regard to access of screening services by an individual with a disability.

Transport issues:

- Public transport routes not maintained
- Some vehicles not accessible for older/disabled people (bus companies have until the end of the vehicles working life before they have to upgrade to an accessible vehicle)
- Accessibility of the bus stop on the hospital site can be an issue (if the screening service is held at such a venue)
- Insufficient disabled parking bays
- Car park charging

Equality Dimension – Sensory Impairment, Ethnicity

The Royal National Institute of Blind People (RNIB) commissioned a number of studies that were completed in 2012, which looked at eye care services and barriers to attendance faced by some people in accessing these services. An element of some of these studies was to look at diabetic eye screening; this is the element of these studies that will be covered in this report.

The Applebee (2012) study involved qualitative work (focus groups and semi-structured interviews) with the Pakistani community of Bradford. The city of Bradford was chosen as the venue for the study, as available epidemiological data indicated an increased risk of diabetic retinopathy and suspected late presentation by the Pakistani community.

Applebee (2012) concludes from the engagement work undertaken that there is, limited awareness and understanding of eye health in the Pakistani community. There was low awareness of prevention of eye problems and the benefit of screening in this regard. The qualitative work revealed that within the Pakistani community in Bradford involved in this study, eye care is recognised almost exclusively in response to symptoms. This low level of awareness then acts as a barrier to the community undertaking preventative action (including screening).

Applebee (2012) found that most of the people interviewed with diabetes attended screening and eye examinations regularly when they knew and understood what the consequences of not attending might be. Knowing that diabetic retinopathy can lead to blindness was a huge motivator for screening attendance.

Barriers identified (Applebee, 2012):

- Lack of knowledge
- Reliance on relatives to make screening/healthcare appointments, for both translation and transportation purposes (sometimes relatives don’t understand importance of the screening test)
- Remembering all different appointments they need to attend
- Different appointment systems – confusing
- Lack of understanding of the difference between yearly eye exam and diabetic eye screening, some people didn’t realise you had to attend both.
- Location of services

Applebee (2012) suggested that the findings highlight that the local system would benefit from the recording of ethnicity. Currently ethnicity is very poorly recorded across eye health services, including Diabetic Eye Screening (Applebee, 2012). Contrary to other literature, language as a communication barrier was not identified as a major problem to accessing services.

As part of the overall RNIB work, Hurrell and Donohoe (2012) carried out a community engagement project investigating eye health and eye care in Glasgow, again with specific reference to the Pakistani community (aged 40 – 65).

The study utilised a similar methodology to the previously mentioned RNIB study in Bradford, using focus groups and semi-structured interviews.

There was one focus group and 26 semi-structured interviews that related specifically to Diabetic Eye Screening. These included people who have attended Diabetic Eye Screening appointments and people who have not attended one or more Diabetic Eye Screening appointments.

Similarly to the Bradford study, the authors found that there was little understanding of diabetic retinopathy or eye health and eye problems, so the focus is on symptom led seeking of care.

Main barriers identified were (Hurrell and Donohoe, 2012):

- Lack of knowledge/awareness of the condition and its potential serious consequences
- Lack symptoms = lack of attendance at screening services

- Bad experience with the service (e.g. rude staff) = non-attendance in future
- Location of services
- Organising work and childcare to be able to attend an appointment

Powell et al (2008) conducted a piece of research in the Cheshire and Merseyside area of the UK, the aim of the research was to investigate the experiences, perceptions and understandings of people with a sensory impairment of FOBT. The study was qualitative in design, using focus groups and interviews.

General barriers highlighted by the Powell et al (2008) study were:

- Level of knowledge
- Level of understanding with regard to the test/screening process
- Consequences of the test (i.e., a positive test associated with further invasive tests and extra worry)

Specific barriers highlighted by the Powell et al (2008) study were:

- Lack of disability specific knowledge amongst healthcare staff (can be a barrier or facilitator)
- Level of professionalism amongst healthcare staff (can be a barrier or facilitator)
- Nature of the FOBT
- Hygiene concerns
- Deaf participants had literary issues with the language used in the screening written materials
- Visually impaired people found the tone of the written material difficult
- Information on bowel screening was difficult to understand
    - Confused by terms such as:
        - Ulcerative colitis
        - Colonoscopy

Participants with more profound visual impairment anticipated substantial difficulty in completing the FOBT kit. They had particular issues with size and layout of the kit.

It should be noted that there were a number of conflicting views expressed by participants within this study; however there was a general consensus on the points raised above and this links with other research undertaken within this area of screening.

Equality Dimension – Learning Disabilities, Ethnic Minorities

This information was supplied via City, Sandwell and Walsall Health Promotion – Breast Screening Service, and is taken from powerpoint presentation slides.

Isaacs (2008) highlighted that although there are pictorial leaflets available (e.g. for use with people with learning disabilities), it is difficult to utilise them effectively to promote screening if you cannot identify women (in the case of breast screening) with learning disabilities because the data is not available in the system.

Isaacs (2008) also states that although there are breast screening leaflets in different languages it is difficult to utilise this information effectively as there is no ethnic monitoring within the "system". The point is also raised that a proportion of Asian women can only speak Urdu or Punjabi they cannot read it, meaning such translated leaflets have limited use.

Furthermore Isaacs (2008), has carried out work in the West Midlands over a number of years identifying barriers to screening and ways of addressing those barriers in various population sub-groups. A small research project undertaken by Isaacs found the following barriers identified by Urdu and Punjabi women in an area of the West Midlands:

Urdu/Punjabi women their main reasons for not attending breast screening were:

- Unable to read the screening leaflet information, as a large proportion of Urdu and Punjabi women can speak the language, but cannot read the language.
- Fear of finding cancer
- Language barrier
- Don't understand the need for it
- Embarrassed and frightened

Known barriers to women not attending breast screening from research focus groups are:-

- Poor knowledge
- Underlying health and cultural beliefs
- Language barrier
- Unhelpful attitudes of health professionals

It should be noted this work is based on a relatively small number of women's experiences, but the barriers identified are in the main consistent with those identified in both the published peer reviewed literature, grey literature and local examples of practice provided to NHS Midlands and East SHA cluster when compiling this report.

Equality Dimension – Transgender people

Ruby et al (2006) in a recorded presentation at the 2006 Public Health and Human Rights Exhibition presented findings from their study; which looked at the cervical cancer screening needs of female to male transgender persons.

Ruby et al (2006) highlighted that female to male transgender persons (FTMs) face unique barriers to cervical (pap smear) screening. A large proportion of FTMs, even those who have had surgery, retain their reproductive organs including the cervix. Therefore, the potential risk of cervical cancer remains and they should undergo routine screening. However,FTMs may not realise the potential risk of cervical cancer. Even if they do realise the risk they may not attend for a number of reasons including:

- Social stigma
- Psychological distress
- Fear of the perception of healthcare staff
- Limited amount of FTM specific health education material available

These barriers are in addition to the usual barriers that women state they have towards cervical screening e.g. fear, time pressures, embarrassment etc.

The Wales Abdominal Aortic Aneurysm (AAA) screening update gave details from a workshop that was held at a health summit in 2011 on the health of, lesbian, gay, bisexual and transgender people. The key barriers for transgender women (AAA Screening programme Wales, 2011) were identified as:

- Men who have undergone transgender surgery to become women may not identify themselves as at risk of AAA
- Potential negative staff attitudes towards “women” attending for “men’s” screening
- Communication of results to GP may act as a barrier to attendance, as transgender individuals often like to protect anonymity
- A belief that gay men may be less likely to access family support systems following positive diagnosis of a serious condition

Nottinghamshire County and Nottingham City PCT undertook an equality impact assessment (EIA) on the AAA screening programme. They also identified that transgender individuals who were born male but are registered with their GP as female at age 65 years will not be included, but may have a similar risk to males at age 65. The EIA included an estimation of the number of people with some gender variance who would qualify for the AAA screening. They concluded that specific identification of this population would not be justified as proportionate: however individuals within this population may self-refer at 65 years of age.

Equality Dimension – Lesbian, Gay, Bisexual women (LGB)

There is no accurate record of the LGB population in the UK, sexual orientation is not monitored on the UK Census, and this type of information is not routinely collected by health services. Hunt and Fish (2008) found that 20% of LBG women have been told by a health professional that they are not at risk of cervical cancer. Furthermore Hunt and Fish (2008)state that 2% of LBG women had been refused a cervical screening test based on their sexual orientation. This perpetuates the myth that LGB women do not require cervical screening, and makes them more apprehensive about attending screening in future. Only 10% of LGB women report having received information from health professionals that was appropriate to their sexual orientation (Hunt and Fish 2008).

Light & Ormandy (2011) conducted a research study in the North West of England that targeted LGB women who are less likely to access health services (the study focused particularly on cervical screening) than the general population of women. The study was part of a pilot project that included an awareness raising campaign; here the focus will be on the barriers to cervical screening in the LGB community that the study picked up on.

Participants were asked whether they thought LGB women required cervical screening, 609 LGB women responded to the survey, 91% agreed that LGB women need to have cervical screening tests, 4% did not know whether such a screening test was required, and 5% responded that screening was not necessary for LGB women.

Although the majority of women felt that LGB women should have cervical screening as they were at risk of cervical cancer. 77% considered LGB women to be at equal risk from cervical cancer compared to heterosexual women. Despite holding this belief, 36% had not responded to a screening invitation and 28% had been told a screening test was not necessary. From an eligible sample (for cervical screening according to England protocol) of 498 LGB women, 70.5% had accessed screening in the last five years. Only 48% of LGB women aged between 25 – 49 years had accessed a screen in the last three years, as recommended by the national screening programme and 73% of 50-64 years olds had accessed screening within the last 5 years as recommended.

Overall 51% of LGB women had either never had a test, or not had one within the recommended timescales.

General reasons for none response to cervical screening by LGB women given were:

- Not having time to book the test
- Fear of a painful procedure
- Embarrassment regarding the procedure

Reasons specific to sexual orientation:

- Previous negative experiences
- Fear of negative attitudes of health workers
- Misinformation – test not required due to not having sex with a man (told either by a health professional, family or friends.)
- Not aware that they required a cervical screen
- Inappropriate style of questioning from the health professional doing the test
- Discrimination and apprehension at being asked hetero-normative questions(hetero-normative - a viewpoint that expresses heterosexuality as a given instead of being one of many possibilities.)
- Feel the service is aimed at heterosexual women

Tracy et al (2010), conducted a study in the USA, which aimed to evaluate screening practices and barriers to screening in a sample of lesbians. The study was a cross-sectional survey completed online by 225 self-identified lesbians. The study was of a generally poor quality with large opportunity for bias. Although the study methodology was flawed, the barriers identified are similar to those found in other studies and local work that has been included within this review.

Barriers (Tracy et al, 2010):

- Discrimination – perceived in non- screeners
- Less knowledgeable – screening guidelines
- Perceived less benefits from screening

Fish (2009) undertook a review to identify gaps in the evidence relating to lesbian and bisexual women and cervical screening. The review covered a wide range of issues around cervical screening (including HPV transmission, prevalence rates and risk factors for cervical cancer) related to lesbian and bisexual women. A total 2290 papers were identified as being relevant to the review, these were then supplemented by grey literature. The area of the Fish (2009) review that is of interest here will be that relevant specifically to barriers in accessing cervical screening.

Participation rates in cervical screening increase with age among lesbian and bisexual women. Barriers to cervical screening identified from the literature included in the Fish (2009) review were:

- Cervical screening sometimes views as unnecessary for lesbian and bisexual women
- Perception of being at low risk of the disease
- Lesbian and bisexual women may be more likely to have adverse experiences of healthcare than their heterosexual counterparts
- Reluctance to “come out” to the health professional
- Heterosexual assumptions by healthcare professionals

Equality Dimension – Traveller/Gypsy community

Although not a specific equality group (as identified by the Equality Act, 2010) in their own right, the Gypsy/Traveller community would fall into the ethnic minority category. However due to their very specific cultural circumstances it was decided to look at the barriers to screening services amongst this group separately.

Van Cleemput et al (2004) undertook some qualitative work with the traveller community as part of a report for the Department of Health, they state:

> *'Travellers' health beliefs and attitudes to health services demonstrate a cultural pride in self-reliance. There is stoicism and tolerance of chronic ill health, with a deep-rooted fear of cancer or other diagnoses perceived as terminal and hence avoidance of screening.' (p. 7)*

Atterbury (2010) highlights a number of barriers faced by the Traveller and Gypsy community in accessing healthcare (including screening):

- Racism
- Cultural beliefs – both on the part of healthcare staff and the traveller community
- Inadequate health service provision
- Lack of a postal address

Work undertaken by NHS Doncaster identified the following barriers to Gypsy Travellers' in accessing healthcare services, including screening services:

- Widespread communication difficulties between health workers and Gypsy Travellers
- GPs are reluctant to register Gypsy Travellers or visit sites
- Practical problems of access whilst travelling

A meeting was held with the Gypsy Life group from Bircotes (near Doncaster) they made the following observations with regard to the barriers to accessing screening within the Gyspy Traveller community:

- Issues with communication on behalf of both the Traveller and Health Professional
- Lack of literacy – would not be able to understand standard appointment letter even if they had a home address
- Lack of understanding and knowledge with regard to healthcare services in general and screening services specifically
- Standard health messages do not resonate with the Gypsy Traveller community
- Cultural beliefs
- Believe that a woman may be screened (cervical and breast screening) by a man, this is totally unacceptable. Do not understand they can choose to be screened by a woman.
- No address, no way of receiving appointment letters
- Not being able to register with a General Practice

Interventions

This section of the literature review is focused on interventions designed to improve/ensure equality in utilisation of screening services, and the evidence base around such interventions. As there has already been a detailed report conducted in this area by Porter (2008) the focus here will be on studies conducted post 2008 to build on the information already available in the Porter (2008) report. Only where something seems particularly relevant will information from a study prior to 2008 be included. For a full overview of all studies from 2000 – 2012 please see the appropriate spread-sheet document that forms part of this overall screening and the equality delivery system toolkit on the UK National Screening Committee website.

Porter (2008) in his report focused on interventions to reduce inequity and inequality in access to screening programmes. He found that the evidence from the literature around the interventions to improve screening uptake was often contradictory. The report by Porter was in two main sections; the first being a literature review and the second highlighted examples of local practice. The examples of local practice were from Primary Care Trusts (PCTs) in the UK and Strategic Health Authorities (SHAs) in England, in all a total of 202 organisations were contacted with a response rate of 15.8% (32 out of 202 organisations responded). Although most organisations thought there was inequality in access to screening programmes, nearly half of these respondents did not have documented evidence of the inequities.

Porter (2008) found a discrepancy between the interventions which were supported by the literature, and those that were taking place locally in the UK. Porter (2008), gave the example, of most local initiatives being based on written information and media messages, which as Porter highlights even when culturally targeted have been found (at most) to have only a limited impact on screening rates.

Brouwers et al (2011) undertook a systematic review and found client reminders (defined as printed letter, postcard, or telephone communications that were tailored or untailored interventions and reminder or recall notifications, which could include one or more of; follow-up printed or telephone reminder; additional text or discussion with information about barriers to screening or appointment scheduling assistance) to be of benefit in increasing screening rates across all 3 cancer screening programmes. However Brouwers et al (2011) did highlight that not enough is known to determine the positive effective this intervention may have on population sub-groups (i.e. the equality groups). They also found the use of small media (this included videos or tailored/untailored printed materials e.g. letters, brochures, pamphlets, flyers or newsletters distributed by healthcare systems or community groups).

Furthermore Brouwers et al (2011) found that service provider audit and feedback helped improve screening uptake, this was defined as any intervention which; involved evaluation of provider performance in delivering or offering screening to clients (assessment) and presenting providers with information about their performance in providing screening services (feedback). Service provider audit and feedback could involve either group or individual practices, with possible comparison to a gold standard.

Brouwers et al (2011) stated that, one to one education proved effective for breast screening uptake but the evidence for bowel and cervical screening was less clear. One to one education was defined as; in-person or telephone, tailored or untailored communication delivered by healthcare professionals, lay health advisors, or volunteers in a variety of settings.

Brouwers et al (2011), also found that a reduction of structural barriers (defined as; Interventions that facilitate removal of non-economic barriers to accessing screening, for example by: reducing time or distance between screening location and target group; modifying hours of service; offering services in alternative settings (mammography vans); and eliminating/simplifying administrative process or other obstacles e.g. scheduling, transportation, translation services). These interventions could be combined with one or more secondary interventions: print/telephone reminders, cancer screening education, screening availability information. Again the impact of these interventions on bowel and cervical screening is not clear, but there is enough positive evidence of these interventions around breast screening.

Peterson et al (2012) undertook an RCT to assess the efficacy of an intervention to promote breast and cervical screening among women with mobility impairments. The intervention consisted of a small group participatory workshop, with 6 months of structured telephone support, based on the health belief model and social cognitive theory. This study found a significant increase in cervical screening uptake amongst the intervention group compared to control. However for breast screening there was no significant difference in screening uptake found between the control and intervention groups.

Makoul et al (2011), aimed to determine if print or multimedia messages were more effective in increasing screening behaviour and knowledge, while also looking at the impact literacy levels may have on the outcome. All participants were underserved patients who would benefit from colorectal cancer screening, according to national guidelines. This was an RCT, the authors concluded that although following he interventions participants in both the multimedia and the print group showed increased knowledge compared to control, actual screening rates did not increase significantly between the groups. Gimeno-Garcia (2009), found a video based educational intervention could significantly increase the return rates of FOBts for individuals eligible for colorectal cancer screening.

Ghevariya et al (2010), in a small pilot study found that the use of a patient navigator* significantly increased attendance at a colorectal screening clinic with colonoscopy. Lasser at al (2010), also investigated the effectiveness of patient navigators in improving colorectal cancer screening rates among ethnic minority populations (with a particular focus on none or limited English speaking immigrants), this was an RCT study design. The authors concluded that patient navigators significantly improved colorectal screening rates among ethnically and linguistically diverse patients. They did however have a word of caution; stating that whether healthcare systems can afford patient navigators is another matter.

Wang et al (2010) evaluated the effect of a community based pilot intervention that combined cervical cancer education with patient navigation on cervical cancer screening behaviours among Chinese American women. The intervention group showed a significant increase in screening rates compared to the control group. The intervention included education and navigation elements. It should be noted that this study had a number of methodological flaws.

Clark et al (2009), found a ‘case management’ system (which appeared to be similar to a patient navigator type intervention), appeared to have some effect on screening rates, although this was not clear-cut. The study was focused on improving screening rates for breast and cervical cancer among black women living in a deprived area of Boston (USA).

Stephens and Moore (2008) found an intervention designed to highlight individual risk of colorectal cancer to encourage screening amongst 1st degree relatives of a family member with a history of colorectal cancer, had no impact on screening uptake rates, amongst the intervention group compared to the control group.

Everett et al (2011) undertook a Cochrane Review assessing the effectiveness of interventions to increase uptake (including informed uptake) of cervical screening. This review did not look at a particular equality group but at all women eligible for the NHS Cervical Screening programme. They found invitations to be effective in increasing uptake, some limited evidence suggested telephone invitations increased uptake. There was also some evidence which suggested letters with fixed appointment times were more effective at increasing uptake than open appointment letters. This relates purely to the general population and gives no indication of what methods may increase uptake in specific population groups. Everett et al (2011), also found some evidence to (although limited) to support the use of educational interventions, however it was unclear as to what format is most effective.

Brown et al (2011) looked more specifically at informed choice in opting for antenatal sickle cell and thalassaemia screening pregnant women registered with 25 General Practices in two socially deprived areas of the UK. They looked to see if offering antenatal sickle cell and thalassaemia screening at the time of pregnancy confirmation in primary care. They found that rates of informed consent were low amongst all groups in the study regardless of which intervention they were randomised to.

**There is no one definition of a patient navigator, they are used most commonly in the United States and their basic function is to help patients and their families navigate through the screening and treatment pathway of a particular disease. This may include help with arranging transport, giving detail behind correspondence/helping the patient understand the information they are given, offering emotional support, helping the patient with payment methods, reminding the patient of appointments and rearranging them on the patients behalf if necessary. These are some but not all the roles a patient navigator may undertake.*

Summary

A lot of the information contained in the articles reviewed and the wider literature that was used throughout this project suggests that the general population does not fully grasp the concept of screening and there are many misconceptions about screening services. This is further compounded in equality groups who may not be able to understand the invitation to screening (e.g. people whose first language is not English, visually impaired individuals), or be able to physically access the venue in some cases (physical disabilities), or are given conflicting information by health professionals (lesbian, bisexual and transgender people), or be able to register with a primary care provider (Travellers). Although this is just a brief summary of some of the equality groups, it highlights the extra barriers faced by these populations beyond that of the general population, and it is therefore up to the services providing the screening test to ensure for each of these equality groups they have processes in place to help mitigate against these barriers.If the decision not to attend for screening was made as a result of informed decision making, then that is an individuals' choice and well within their rights. However it is apparent from the literature covered in this review that this is not the case, and it is on the whole these groups who are less likely to have the resources and information required to make an informed choice.

It is hoped that this literature review (along with the rest of the toolkit)will prove useful for screening services in helping them identify where certain client groups will need adaptations to be made to the screening process and how those adaptations may be made. While it may seem obvious which groups in society may be less likely to attend screening services the actual reasons for this under-representation at screening may be less obvious and it is important not to make assumptions about individuals or population groups.

Screening services are a unique aspect of the health service and play an important role in protecting the population's health. In addressing such issues as inequality of screening uptake and informed choice the services are performing a vital role in the protection of the populations health.

Recommendations

This literature review has been used to underpin the whole toolkit accessible through the equality portal of the UK National Screening Committee website. That is where you will find the recommendations resulting from this review, mainly in the 'top-tips' section of the portal.

**Please note that within the UK Screening Committee website equality portal there is a partner document to this literature review, which is a summary spread-sheet highlighting the relevant studies and grey literature reviewed in the course of this literature review and project as a whole.*

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Meetings

The Gypsy Life Group.**Meeting on 5/9/2012 to discuss Travellers experience with healthcare services and their perceptions of screening services**. Notes taken by: Dean Wallace and Carly Mellors (NHS East Midlands).

Email Correspondence Specific to the Literature Review

Waterfield, A. **(Chief Executive – Hertfordshire Action on Disability)** Specific email correspondence in October and November 2012, related to health care facilities and disabled clients.

Appendix 1 – Search Strategies

Search Strategy – Systematic Reviews and Meta-Analyses

1. EMBASE, MEDLINE; (mass AND screening OR neonatal AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 33906 results.

2. EMBASE, MEDLINE; Mammography.ti,ab [Limit to: Publication Year 2000-Current]; 20278 results.

3. EMBASE, MEDLINE; (cervical AND cancer AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 11087results.

4. EMBASE, MEDLINE; (prenatal OR antenatal AND screening).ti,ab [Limit to: Publication Year 2000-Current];11011 results.

5. EMBASE, MEDLINE; (abdominal AND aortic AND Aneurysm AND Screening).ti,ab [Limit to: Publication Year 2000-Current]; 1042 results.

6. EMBASE, MEDLINE; (Bowel AND Cancer AND Screening OR colorectal AND cancer AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 15038 results.

7. EMBASE, MEDLINE; (diabetic AND eye AND screening OR diabetic AND retinopathy AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 1883 results.

8. EMBASE, MEDLINE; (newborn OR sickle AND cell OR thalassemia OR down AND syndrome OR cystic AND fibrosis OR fetal AND anomaly OR foetal AND anomaly OR phenylketonuria OR medium-chain AND acyl-CoA AND dehydrogenase AND deficiency OR congenital AND hypothyroidism).ti,ab [Limit to: Publication Year 2000-Current]; 2944 results.

9. EMBASE, MEDLINE; 8 and screening [Limit to: Publication Year 2000-Current]; 1354 results.

10. EMBASE, MEDLINE; (infectious AND diseases AND in AND pregnancy AND screening).ti,ab [Limit to:Publication Year 2000-Current]; 100 results.

11. EMBASE, MEDLINE; (newborn AND hearing AND screening).ti,ab [Limit to: Publication Year 2000-Current];1595 results.

12. EMBASE, MEDLINE; (breast AND cancer AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 20592 results.

13. EMBASE, MEDLINE; 1 AND 2 AND 3 AND 4 AND 5 AND 6 AND 7 AND 8 AND 9 AND 10 AND 11 AND 12 [Limit to: Publication Year 2000-Current]; 0 results.

14. EMBASE, MEDLINE; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 [Limit to: Publication Year 2000-Current]; 103550 results.

15. EMBASE, MEDLINE; (screening AND uptake OR coverage).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 87442 results.

16. EMBASE, MEDLINE; (health AND services AND access OR accessibility OR healthcare AND access OR disparities).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 61819 results.

17. EMBASE, MEDLINE; (Inequity OR inequality OR barrier).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 128417 results.

18. EMBASE, MEDLINE; 15 OR 16 OR 17 [Limit to: English Language and Publication Year 2000-Current]; 270696 results.

19. EMBASE, MEDLINE; (age OR gender OR sex).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 1907188 results.

20. EMBASE, MEDLINE; (Disability OR physical AND disability OR learning AND disability OR mental AND illness OR dementia).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 108765 results.

21. EMBASE, MEDLINE; (Gender AND reassignment OR sexual AND orientation).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 3794 results.

22. EMBASE, MEDLINE; (Ethnicity OR ethnic AND origin OR race).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 91166 results.

23. EMBASE, MEDLINE; (religion OR belief OR religious AND belief).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 24323 results.

24. EMBASE, MEDLINE; (deprivation OR socioeconomic AND status OR socio-economic AND status OR poor).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 437047 results.

25. EMBASE, MEDLINE; (hearing AND impairment OR visual AND impairment OR sight AND impairment).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 25015 results.

26. EMBASE, MEDLINE; (offenders OR prisoners).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 12216 results.

27. EMBASE, MEDLINE; (travellers OR gypsies).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 3021 results.

28. EMBASE, MEDLINE; Homeless.ti,ab [Limit to: English Language and Publication Year 2000-Current]; 5291 results.

29. EMBASE, MEDLINE; (asylum AND seekers).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 960 results]

30. EMBASE, MEDLINE; (sex AND workers).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 7619 results.

31. EMBASE, MEDLINE; 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 [Limit to: English Language and Publication Year 2000-Current]; 2384314 results.

32. EMBASE, MEDLINE; 14 AND 18 AND 31 [Limit to: Publication Year 2000-Current and English Language]; 2847 results.

33. EMBASE, MEDLINE; (meta AND analysis OR systematic AND review).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 95829 results.

34. EMBASE, MEDLINE; 32 AND 33 [Limit to: Publication Year 2000-Current and English Language]; 35 results.

Search Strategy – Comparative and Intervention Studies

1. EMBASE, MEDLINE; (mass AND screening OR neonatal AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 33906 results.

2. EMBASE, MEDLINE; Mammography.ti,ab [Limit to: Publication Year 2000-Current]; 20278 results.

3. EMBASE, MEDLINE; (cervical AND cancer AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 11087 results.

4. EMBASE, MEDLINE; (prenatal OR antenatal AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 11011 results.

5. EMBASE, MEDLINE; (abdominal AND aortic AND Aneurysm AND Screening).ti,ab [Limit to: Publication Year 2000-Current]; 1042 results.

6. EMBASE, MEDLINE; (Bowel AND Cancer AND Screening OR colorectal AND cancer AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 15038 results.

7. EMBASE, MEDLINE; (diabetic AND eye AND screening OR diabetic AND retinopathy AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 1883 results.

8. EMBASE, MEDLINE; (newborn OR sickle AND cell OR thalassemia OR down AND syndrome OR cystic AND fibrosis OR fetal AND anomaly OR foetal AND anomaly OR phenylketonuria OR medium-chain AND acyl-CoA AND dehydrogenase AND deficiency OR congenital AND hypothyroidism).ti,ab [Limit to: Publication Year 2000-Current]; 2944 results.

9. EMBASE, MEDLINE; 8 and screening [Limit to: Publication Year 2000-Current]; 1354 results.

10. EMBASE, MEDLINE; (infectious AND diseases AND in AND pregnancy AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 100 results.

11. EMBASE, MEDLINE; (newborn AND hearing AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 1595 results.

12. EMBASE, MEDLINE; (breast AND cancer AND screening).ti,ab [Limit to: Publication Year 2000-Current]; 20592 results.

13. EMBASE, MEDLINE; 1 AND 2 AND 3 AND 4 AND 5 AND 6 AND 7 AND 8 AND 9 AND 10 AND 11 AND 12 [Limit to: Publication Year 2000-Current]; 0 results.

14. EMBASE, MEDLINE; 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 [Limit to: Publication Year 2000-Current]; 103550 results.

15. EMBASE, MEDLINE; (screening AND uptake OR coverage).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 87442 results.

16. EMBASE, MEDLINE; (health AND services AND access OR accessibility OR healthcare AND access OR disparities).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 61819 results.

17. EMBASE, MEDLINE; (Inequity OR inequality OR barrier).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 128417 results.

18. EMBASE, MEDLINE; 15 OR 16 OR 17 [Limit to: English Language and Publication Year 2000-Current]; 270696 results.

19. EMBASE, MEDLINE; (age OR gender OR sex).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 1907188 results.

20. EMBASE, MEDLINE; (Disability OR physical AND disability OR learning AND disability OR mental AND illness OR dementia).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 108765 results.

21. EMBASE, MEDLINE; (Gender AND reassignment OR sexual AND orientation).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 3794 results.

22. EMBASE, MEDLINE; (Ethnicity OR ethnic AND origin OR race).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 91166 results.

23. EMBASE, MEDLINE; (religion OR belief OR religious AND belief).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 24323 results.

24. EMBASE, MEDLINE; (deprivation OR socioeconomic AND status OR socio-economic AND status OR poor).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 437047 results.

25. EMBASE, MEDLINE; (hearing AND impairment OR visual AND impairment OR sight AND impairment).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 25015 results.

26. EMBASE, MEDLINE; (offenders OR prisoners).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 12216 results.

27. EMBASE, MEDLINE; (travellers OR gypsies).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 3021 results.

28. EMBASE, MEDLINE; Homeless.ti,ab [Limit to: English Language and Publication Year 2000-Current]; 5291 results.

29. EMBASE, MEDLINE; (asylum AND seekers).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 960 results.

30. EMBASE, MEDLINE; (sex AND workers).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 7619 results.

31. EMBASE, MEDLINE; 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 [Limit to: English Language and Publication Year 2000-Current]; 2384314 results.

32. EMBASE, MEDLINE; 14 AND 18 AND 31 [Limit to: Publication Year 2000-Current and English Language]; 2847 results.

33. EMBASE, MEDLINE; (meta AND analysis OR systematic AND review).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 95829 results.

34. EMBASE, MEDLINE; 32 AND 33 [Limit to: Publication Year 2000-Current and English Language]; 35 results.

35. EMBASE, MEDLINE; (intervention AND study OR comparative AND study).ti,ab [Limit to: English Language and Publication Year 2000-Current]; 326310 results.

36. EMBASE, MEDLINE; 32 AND 35 [Limit to: Publication Year 2000-Current and English Language]; 191 results.