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UNDERSTANDING AND ADDRESSING SOCIOECONOMIC INEQUALITIES IN ROUTINE CERVICAL SCREENING PARTICIPATION: DEVELOPMENT OF AN INTERVENTION STRATEGY USING THE BEHAVIOUR CHANGE WHEEL.

ANGELA WEARN

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UNDERSTANDING AND ADDRESSING SOCIOECONOMIC INEQUALITIES IN ROUTINE CERVICAL SCREENING PARTICIPATION: DEVELOPMENT OF AN INTERVENTION STRATEGY USING THE BEHAVIOUR CHANGE WHEEL.

ANGELA WEARN

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Abstract

From 1988, the National Health Service have offered all women, aged in between 25-64, routine cervical screening to detect precancerous abnormalities within the cervix. This screening programme is estimated to prevent around 5,000 cases of cervical cancer each year. Past research has highlighted socioeconomic inequalities in participation, whereby those living in the most deprived areas are least likely to attend in line with guidelines. However, the reasons behind these inequalities are not clear and existing interventions to increase uptake do not adequately take the socioeconomic context into account. As such, this thesis aimed to a) understand factors influencing participation for those living in areas of high relative deprivation and b) develop tailored intervention strategies to facilitate timely attendance within this group.

Following guidance from the Medical Research Council on developing complex interventions, a multimethod, qualitative programme of research was conducted to highlight the perspectives of women living in areas of high relative deprivation. A systematic review (Study1), one-on-one interviews (Study 2) and a qualitative online survey (Study 3) were conducted to provide in-depth insight into key factors influencing participation. Focus groups (Study 4a) with service users and interviews with health-related professionals (Study 4b) were then conducted to consider how these factors contribute to the observed socioeconomic inequalities in participation and consider ways in which any barriers might be best addressed. Findings across studies were then systematically combined with behavioural theory (Study 5) to develop an understanding of what needs to change for the target behaviour to occur and identify appropriate intervention components and strategies.

Findings suggested that cervical screening participation is determined by a complex accumulation of interrelating, multi-level factors. Application of the Theoretical Domains Framework suggested that *Social Influence*, *Environmental context and resources* and

Emotion were the top three areas of influence most often mentioned by participants. Application of the COM-B model suggested that, to encourage timely attendance, changes were needed at in terms of women’s capability, opportunity and motivation to screen. Using guidance from the Behaviour Change Wheel and the Behaviour Change Taxonomy v1, these findings were then linked with intervention options and components likely to influence change within the target population and several intervention strategies were recommended.

This research is the first to use the Behaviour Change Wheel to systematically combine behavioural theory and the perspectives of the community in understanding and addressing socioeconomic inequalities in routine cervical screening participation. These findings can be used to further test and develop a range of novel interventions, and/or refine existing interventions, which aim to increase cervical screening attendance within areas of high relative deprivation.

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I dedicate this work to my late grandmother, Peggy who always showed unwavering belief in me. I miss you every day.

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Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others.

Any ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the Faculty Ethics Committee on 05/01/17, 25/09/17, 08/03/18 and 20/07/18.

I declare that the Word Count of this Thesis is 58 908 words

Name: Angela Wearn

Signature:

Date:

1 General Introduction

1.1 Background

Cervical cancer is an often symptomless, uncontrolled multiplication of cells within the cervix which have the potential to spread to other parts of the body. There are around 3,200 new cases of cervical cancer each year (Cancer Research UK, 2017). Whilst cervical cancer mortality rates have decreased by a quarter over the past decade, there are still approximately 850 cervical cancer deaths annually (Cancer Research UK, 2017). These figures are of particular concern as cervical cancer is believed to be 99.8% preventable, predominately as a result of the national routine cervical screening programme available for all women aged 25-64 years, via the National Health Service (NHS, 2020a). Whilst all women should make an informed choice regarding cervical screening attendance (and thus are entitled to decline the service), there is a wealth of evidence to suggest the majority of non-participants are not actively declining the test, and instead are influenced by other factors (Marlow, Chorley, Haddrell, Ferrer, & Waller, 2017). The present chapter aims to provide an introduction to routine cervical screening in the UK, consider currently known factors that influence uptake and highlight the persistent socioeconomic inequalities in cervical screening participation. The approach to investigating and addressing these socioeconomic inequalities will be set out.

1.1.1 Routine Cervical Screening

Introduced in 1988, routine cervical screening detects cell abnormalities that can (if left untreated) develop into cervical cancer. This population level, preventative programme works on a call-recall basis; in that women are invited, or ‘called’, (via letter) to arrange a cervical screening appointment around the time of their 25th birthday. Following this, they are ‘recalled’, again via letter, to book another appointment every 3 years. The intervals between screening appointments increase to every 5 years when an individual reaches 50. Women are not invited for screening following their 64th birthday if their previous last 3 tests were normal (as cervical cancer is generally slow to develop, it is unlikely that women beyond this age, would develop the disease; Castañón, Landy, Cuzick, & Sasieni, 2014). Generally, individuals arrange their screening appointment via their local GP surgery, although some sexual health clinics also offer this service. During the appointment, a small sample of cells are collected from the cervix using a small, soft brush, which are then sent for testing. This process should only take approximately five minutes. Presently, samples are sent to a laboratory and tested for cell abnormalities (i.e. cervical cytology) which have the potential to develop into cervical cancer. Those with borderline or small cell abnormalities are also tested for Human Papillomavirus (HPV), a group of common sexually transmitted infections. There are over 100 different forms of HPV, and most cause no health problems. However, there are some high risk forms (particularly HPV16 and HPV18) which are likely to develop into cervical cancer (Li, Franceschi, Howell-Jones, Snijders, & Clifford, 2011). If high-grade cell abnormalities (or high-risk HPV) is found, then women are referred to their local hospital for a colposcopy appointment (this usually involves a small biopsy from the cervix and/or potentially removal of abnormal cells).

The NHS are currently in the process of making changes to the way cervical samples are tested and have been rolling out primary HPV testing across the UK from 2018-2020. Primary HPV testing involves an initial test for the presence of HPV; if high risk forms of HPV are not found, it is unlikely that cell abnormalities will be detected or develop. Thus, cervical cytology is not carried out. If a high-risk form of HPV is detected, then cytology is conducted. If no abnormalities are found, women are recalled in 1 year for further screening. If abnormalities are found, women are invited to attend a colposcopy.

As high-risk forms of HPV (and indeed cervical cancer) are often symptomless in the earlier stages, routine cervical screening is therefore believed to be the most effective way to prevent cervical cancer morbidity and mortality. Indeed, recent figures estimate that screening prevents around 5,000 cases of cervical cancer each year (Public Health England, 2016). Despite this, uptake of routine cervical screening consistently falls short of the national ‘acceptable’ target of 80%; of those who are invited to participate in routine cervical screening in England, actual attendance is currently 71.4% (NHS Digital & Office for National Statistics, 2018). As well as the clear health-related implications of low uptake (i.e. increased cervical cancer morbidity rates) there are also associated economic impacts that arise from poor participation in cervical screening. From an individual perspective, a cancer diagnosis can have a severe impact on an individual’s financial position and result in loss of income and other cancer-related costs (e.g. related to travel, household and childcare; see Macmillan Cancer Support, 2019). It is estimated that early diagnosis can significantly reduce cervical cancer related costs from approximately £1,102 to £360 per month, whereas early detection and treatment of cell abnormalities would have relatively minimal cost to the individual (Salter, 2014). There are also wider financial implications of low uptake; as of 2014, treatment of cervical cancer was estimated to cost the NHS around £21 million; if uptake rates continue to fall to 70% this cost is estimated to rise to approximately £27.6 million. Increasing uptake rates to 85% would have clear economic as well as public health benefits, reducing the costs of cervical cancer to around £17.7 million (a potential saving of almost £10 million per year; Salter, 2014). From both a public health and economic perspective, it is therefore vital to understand factors associated with cervical screening non-participation.

1.1.2 Determining factors which influence cervical screening participation

Psychological theory suggests preventative health behaviour is determined by complex combinations of determinants relating to the individual (Michie, van Stralen, & West, 2011). Considering determinants of screening uptake, within the context of psychological models of behaviour, helps to facilitate identification of meaningful factors which are likely to influence behavioural change (Michie, Atkins, & West, 2014). Predominately, researchers have applied social cognitive models of behaviour to understand cervical screening, suggesting that engagement in such behaviour is a result of the individual's perceptions about their social world (Connor & Norman, 2005). For example, the Theory of Planned Behaviour (Ajzen, 1985, 1991) would suggest that screening attendance is resultant of goal-directed plans and intentions to engage, these intentions being influenced by attitudes towards a behaviour (i.e. what does the individual think about cervical screening participation) subjective norms (i.e. what the individual believes others think of cervical screening participation) and perceived behavioural control (i.e. how much control an individual believes he/she has in regards to cervical screening participation). Similarly, The Health Belief Model (HBM; Janz & Becker, 1984; Rosenstock, 1974) was originally developed to predict preventative health behaviours and emphasises the importance of individual's health related beliefs in determining the likelihood of engaging within a given behaviour (see Abraham & Sheeran, 2005). In relation to routine screening participation the HBM proposes that engagement is dependent on 1) perceived personal susceptibility to cervical cancer 2) the perception that cervical cancer is a severe illness 3) perceived barriers to engaging in screening and 4) perceived benefits of engaging in screening and 5) perceived ability to overcome screening barriers (i.e. self-efficacy). This model also acknowledges the influence of additional factors that may influence these beliefs, accounting for the role of 'modifying factors' (e.g. age, class, ethnicity, education) and internal (e.g. concerning symptoms) or external (e.g. leaflets or invitation letters) 'cues to action' which prompt engagement in the relevant behaviour. Researchers have utilised TPB and HBM as frameworks to understand specific key determinants of screening behaviour (e.g. Cooke & French, 2008; Jirojwong, Maclennan, & Manderson, 2001; Julinawati, Cawley, Domegan, Brenner, & Rowan, 2013; Orbell, Crombie, & Johnston, 1996). As such, common cognitive barriers to engagement have been identified i.e. negative attitudes towards screening, low perceived risk of cervical cancer and low self-efficacy to overcome participation-related barriers have all been shown to hinder engagement with screening services (Eaker, Adami, & Sparén, 2001; Marlow, Wardle, & Waller, 2015; Tung, Lu, Granner, & Sohn, 2017). These socio-cognitive barriers are also often reported in line with informational based barriers, such as poor awareness and knowledge surrounding a) the purpose and benefits of the test, b) cervical cancer related symptoms and c) risk factors (Ekechi et al., 2014; Kwok, White, & Roydhouse, 2011; Lovell, Wetherell, & Shepherd, 2015; Tran et al., 2011; Walsh, 2006; Wong, Wong, Low, Khoo, & Shuib, 2008).

However, health psychologists have criticised the use of socio-cognitive theoretical frameworks as it can lead to an over-emphasis on rational, conscious processes, which in turn neglects the role of automatic, non-conscious drivers of health behaviour (Marteau, Hollands, & Fletcher, 2012; Sheeran, Gollwitzer, & Bargh, 2013; Sniehotta, Presseau, & Araújo-Soares, 2015). Within the current context, pro-screening beliefs, attitudes and intentions are clearly integral to determining engagement, however there is also a wealth of evidence that highlights the additionally important role emotional factors play in determining screening engagement; most commonly referring to embarrassment and fear (of both test and outcome) as important barriers to engaging with screening services (Marlow, Waller, & Wardle, 2015; Oscarsson, 2012).

In addition to these affective and non-conscious factors, a number of determinants external to the individual have also been identified. For example, challenges accessing suitable appointment times (Chorley, Marlow, Forster, Haddrell, & Waller, 2016; Ryan, Waller, & Marlow, 2019), accessing childcare to attend appointments (Olsson, Lau, Lifvergren, & Chakhunashvili, 2014; Waller, Jackowska, Marlow, & Wardle, 2012) and/or lack of available time (e.g., due to work commitments) (Marlow, Waller, et al., 2015; Oscarsson, Benzein, & Wijma, 2008) have been cited as additional barriers to participation.

Combined, existing evidence therefore suggests cervical screening participation is determined by a variety of cognitive, emotional, and environmental based factors (Bukowska-Durawa & Luszczynska, 2014; Chorley et al., 2016; Julinawati et al., 2013). It is therefore important that any interventions to increase cervical screening take these broad and complex range of determinants into account (Short & Mollborn, 2015).

1.1.3 Current interventions to increase cervical screening participation

There have been numerous attempts to increase routine cervical screening uptake within the UK. Perhaps most notably, media-based campaigns are often employed to provide information, encourage awareness and positive attitudes toward screening, and reduce any aversive emotional response to the procedure. Jo’s Cervical Trust charity run regular awareness campaigns, ‘Cervical Cancer Prevention Week’ and ‘Cervical Screening Awareness week’ in January and June each year. In addition, there are regular campaigns across Twitter (#SmearForSmear #EndSmearFear) encouraging women to get involved, share screening related facts, and ‘smear’ screening related myths and stigma (see https://www.jostrust.org.uk/get-involved/campaign). In 2019, Public Health England also launched their first national cervical screening campaign aiming to tackle the aforementioned barriers by reducing fear and embarrassment and increasing screening related knowledge. This campaign was run across TV advertisements, social media platforms and promoted across healthcare settings. Although early data from the months following the campaign launch were positive (i.e. over 100,000 more samples were recorded over the 3-month period following the launch; Stubbs & Pearmain, 2019), further evaluation and analysis are needed to determine the efficacy of this approach, particularly as such campaigns may present screening as an individualised, easy and logical choice, which in turn can further marginalise or stigmatise those who face significant structural and/or psychological barriers to attendance (McGeechan, James, & Burke, 2020).

Broadly, evidence of efficacy has been found for interventions within two categories; written or print materials (i.e. invitation/reminder letters) and self-sampling techniques, with letters being the most common intervention to encourage attendance (Albrow et al., 2014; Camilloni et al., 2013; Everett et al., 2011). Indeed, it is standard practice within the UK that women are sent invitation and reminder letters to prompt appointment booking, as well as a 16-page printed information leaflet ("NHS cervical screening: Helping you decide" see Public Health England, 2019b). Self-sampling techniques are a relatively newer approach; females are provided with a sampling kit to take their own sample at home and post back. A recent meta-analysis suggests that this technique may be an effective option for those who are embarrassed or face practical barriers (i.e. lack of free time) to attend scheduled appointments (Verdoodt et al., 2015).

However, there is evidence that these interventions are not suitable to increase uptake in certain sub-groups. For example, evidence has demonstrated that letters do not effectively increase screening attendance in young women (Albrow et al., 2014). Moreover, individuals living within deprived communities, and those in ethnic minority groups, are likely to have low levels of health literacy (i.e. the ability to read, understand and use health information; Public Health England, 2014b). Indeed cervical cancer information materials have been found to be inaccessible to those with poor levels of health literacy (Helitzer, Hollis, Cotner, & Oestreicher, 2009). Recent evidence from Okan, Petrova, Smith, Lesic and de Bruin (2019) also demonstrates this within a UK context, finding that although the NHS leaflet (received at invitation) was viewed positively overall, misinterpretations and poorer understanding were greater in groups with lower educational level, lower numeracy levels and non-white ethnicities. As such, current intervention letters/ printed materials do not appear to adequately target traditionally under-served groups (i.e. those who face healthcare related disadvantage, in this case those living in areas of socioeconomic deprivation and/or those of ethnic minority status) and may in some cases even exacerbate health inequalities (as the information provided may be inaccessible for portions of the female population).

Moreover, the acceptability and efficacy of self-sampling approaches are not yet fully understood. Although early evidence appears positive and suggests cervical self-sampling reduces feelings of embarrassment, women do appear to have concerns over the accuracy of the at-home test (Sultana et al., 2015). This concern is in line with already established self-sampling techniques such as colorectal screening whereby patients have suggested they would prefer trained professionals to carry out such procedures (Palmer, Thomas, von Wagner, & Raine, 2014). Moreover, whilst self-sampling clearly reduces embarrassment for many, there are other, common barriers to cervical screening neglected by this form of intervention. For example, as previously mentioned, Oscarsson et al. (2008) found that women often did not take part in cervical screening because they felt afraid of the outcome of the test. Self-sampling therefore does little to change fear of outcome that may be associated with a screening test of this nature (Palmer et al., 2014). In addition, this technique is not yet available via the National Health Service. Women are able to purchase the test from chemists, but it is possible that the associated cost and effort may deter many women from taking part in this alternative approach.

While current interventions to increase uptake have had some success, it is clear that they only partially address barriers to uptake. While there is much focus on addressing individual level factors such as poor knowledge, negative attitudes and aversive screening-related emotions, less focus is given to social and environmental based barriers to engaging in screening services. In this way, existing interventions place a responsibility onto the individual, to interpret sometimes complex health-related information and/or ‘change’ their thoughts, feelings and behaviours, which in turn may inadvertently increase challenges in service access for marginalised or under-served groups (Lorenc, Petticrew, Welch, & Tugwell, 2013; McGill et al., 2015; White, Adams, & Heywood, 2009). In fact, it is notable that there are indeed significant and persistent socioeconomic inequalities in cervical screening uptake (Douglas, Waller, Duffy, & Wardle, 2016; Public Health England, 2019d). It is therefore necessary to consider current inequalities in participation in more depth and determine how research can best highlight and address the determinants of screening non-participation for those who are least likely to attend.

1.1.4 Understanding and addressing socioeconomic inequalities in cervical screening participation

Socioeconomic inequalities in health are well established, whereby those of low socioeconomic status generally have lower life expectancy and poorer health outcomes (Marmot, 2020). These inequalities have been partially attributed to socioeconomic disparities in health behaviours (Sánchez-Santos et al., 2013; Stringhini et al., 2011); those of lower socioeconomic status are more likely to engage in risky health behaviours such as smoking (Hiscock, Bauld, Amos, Fidler, & Munafò, 2012) and excessive alcohol use (Collins, 2016), and less likely to engage in preventative or protective health behaviours such as regular physical activity (VanKim & Laska, 2012), healthy eating (Wardle & Steptoe, 2003) and even seatbelt use (Colgan et al., 2004). Similarly, there are socioeconomic disparities in cervical screening uptake, whereby the most deprived are least likely to attend routine screening in line with guidelines (Public Health England, 2019d).

Whilst socioeconomic status is often viewed at the individual level via measures such as household income, education level or occupation; considering area, or neighbourhood level deprivation can be particularly useful as it gives a more holistic view of an individual's social context and life experience, incorporating social and environmental factors that are not captured by individual level measures of deprivation alone (Lakshman et al., 2011; Pepper & Nettle, 2018). There is a growing body of evidence using area-level deprivation to understand disparities in health and health-promoting behaviours (Halonen et al., 2016; Keita et al., 2014; Lakshman et al., 2011;

Li, Sundquist, Calling, Zöller, & Sundquist, 2012; Sánchez-Santos et al., 2013; Vinther-Larsen, Huckle, You, & Casswell, 2013), with evidence that poor health behaviours may be associated with neighbourhood deprivation over and above individual socioeconomic status (Halonen et al., 2012).

Broadly, deprivation refers to the amount of resources an individual has access to (e.g. money, education, healthcare, adequate housing), and is measured in terms of being *absolute* or *relative.* Absolute deprivation (also referred to as absolute poverty) can be defined as not having the resources to meet basic standards of living (e.g. access to food, clean water and shelter) and is measured against a fixed standard of income (Chen, 2015). Relative deprivation can be defined as the amount of resources available *in relation to others in society.* Thus, basic standards of living may be exceeded, but still fall short of the standards that are deemed acceptable within that society. In high-income countries such as the United Kingdom, much evidence suggests that it is most useful to consider deprivation in the latter context; due to the high established levels of income disparity (see Wilkinson & Pickett, 2010). Relative deprivation refers to a lack of 'socially perceived necessities', or resources (such as adequate access to quality housing, education, diet and so on), in comparison to others (Smith et al., 2015; Townsend, 1987). Whilst many of these resources are closely linked to economic capital (e.g. household income), relative deprivation is multi-faceted and individuals who have higher levels of income in comparison to those who live in the direct vicinity, can still be classified as socially deprived due to factors such as external living environments and local crime rates etc. (Smith et al., 2015).

Within England, area-level relative deprivation is measurable by the Index of Multiple Deprivation (IMD; Ministry of Housing Communities and Local Government, 2015, 2019). The IMD is a governmental tool which ranks all of the neighbourhoods in the England from 1-10 (1=10% most deprived to 10 = 10% least deprived). As indicated above, relative deprivation is calculated not only in relation to household income within an area, but also incorporates levels of employment, health deprivation/disability, education skills and training, barriers to housing and services, crime levels and living environment (see Smith et al., 2015 for a more detailed breakdown on each of these domains). Whilst the measure is not without its limitations (it cannot be used to quantify how deprived an area is, for example) it is a valuable tool when seeking to identify areas of high relative deprivation at local levels.

In relation to cervical screening uptake, categorising individuals via area level deprivation is also in line with NHS coverage data, which is regularly measured at local/GP surgery level rather than grouped via income brackets. Indeed, women living within the highest levels of deprivation (as measured by the IMD 2015) are less likely to attend screening in comparison to their more affluent counterparts (Douglas et al., 2016; Public Health England, 2019d). These inequalities are particularly alarming given non-attendance at routine screening has been named as the biggest risk factor contributing to cervical cancer mortality (Dugué, Lynge, & Rebolj, 2014). Indeed, cervical cancer incidence rates are 72% higher for women living in the most deprived areas in England, in comparison to the least deprived. Moreover, women living in the most deprived areas in England are 148% more likely to die from cervical cancer in comparison to women living in the least deprived areas (Public Health England, 2014c). Area level deprivation has been shown to be associated with cervical cancer morbidity and mortality even after controlling for individual-level measures of socioeconomic status (Li, Sundquist, Calling, Zöller, & Sundquist, 2012).

Despite these stark area-level inequalities in uptake, cervical cancer morbidity and mortality, there is little focus within psychological literature on the determinants of cervical screening uptake in the context of area level deprivation. In fact, within countries that employ routine, population-wide cervical screening, existing reviews of determinants generalise the female population (see Chorley et al., 2016) and thus do not specify the most important factors for those least likely to attend, nor allow for an understanding of how factors hinder or facilitate screening behaviour within this specific population. Moreover, a generalised view of determinants leads to interventions that may neglect key barriers contributing to socioeconomic inequalities in uptake and as explored above, may therefore not be suitable for increasing uptake within under-served groups. The Medical Research Council (MRC; Craig et al., 2008) and the National Institute of Clinical Excellence (2014) advise that, to improve efficacy, interventions should be tailored to specific social contexts. A recent review identified a number of interventions tailored to increase cervical screening uptake in low socioeconomic groups, suggesting that the use of lay health advisors and HPV self-sampling may be useful (Rees, Jones, Chen, & Macleod, 2018). However, none of these interventions were situated within a UK healthcare context. Given the obvious challenges in extrapolating evidence across different healthcare systems, there is an urgent need to develop a more tailored understanding of the determinants of cervical screening uptake for those living in areas of socioeconomic deprivation within the UK, and in turn combine this in-depth knowledge with theoretical understanding of behaviour change, to develop intervention strategies that are suitable and appropriate within a UK healthcare context.

1.1.5 Developing complex interventions

The MRC (Craig et al., 2008) have provided comprehensive guidance on developing and evaluating complex interventions to improve health. Development of a complex intervention (i.e. that which has several interacting components) is a lengthy process that requires in-depth consideration at a number of different levels. Figure 1.1 outlines the iterative and systematic approach advocated by the MRC, the first stages of which breakdown the process of intervention development.

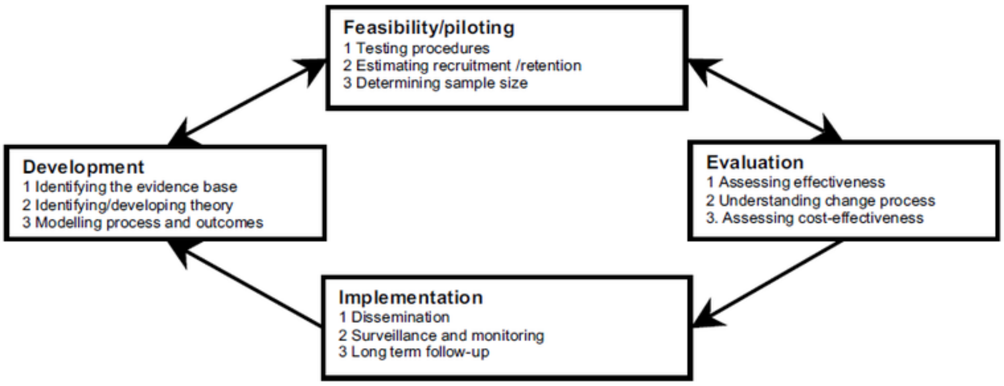

Figure 1.1 Guidance framework for Developing and Evaluating Complex Interventions (Taken from Craig et al., 2008)

The first step to developing an intervention is to *identify the current evidence base*; most often by conducting a systematic review of existing literature. Following this, it is important to *identify and develop appropriate theory* often by conducting additional primary research which can elucidate the process by which change is likely to occur. For example, qualitative approaches, which focus on rich and in-depth detail, may be particularly beneficial in developing an understanding of a complex behavioural issue such as engagement with screening services. The subsequent body of evidence can then be considered in line with appropriate theory to facilitate a tailored and specific understanding of the behaviour at hand. All considered, the second stage of intervention development may be particularly lengthy, dependant on the depth of primary evidence needed to adequately support the development of detailed theoretical understanding of the topic. The final stage of development refers to *modelling process and outcomes;* further primary research for example, feasibility studies and/or economic evaluation could be conducted to test, refine or develop intervention design and delivery prior to piloting and full evaluation. The MRC framework has been widely applied across the development of health-based interventions in a range of settings (Byrne et al., 2006; Eiser et al., 2013; e.g. McEvoy et al., 2018; Smits et al., 2018). Following MRC guidelines (Craig et al., 2008) would be therefore be a useful framework to guide tailored intervention development in relation to routine cervical screening participation within areas of high relative deprivation.

1.2 Rationale for the thesis approach

Given the persistence of socioeconomic inequalities in cervical screening uptake (Douglas et al., 2016) there is an urgent need to develop a richer understanding of factors which influence participation within areas of high relative deprivation. Whilst it is expected that common influential factors (e.g., fear, embarrassment, lack of knowledge) will be present across sociodemographic backgrounds, it is vital to identify which of these are most relevant to the target group. The identification of these relevant factors would therefore allow for the development of intervention strategies that are specifically tailored toward those who are least likely to attend. The MRC framework offers a tried and tested route to developing complex behavioural interventions, supporting the integration of evidence and established theory to result in greater likelihood of change. Following this approach within the current context would contribute to a) our understanding of socioeconomic inequalities in uptake and b) the development of tailored intervention strategies to increase uptake within areas of high relative deprivation.

1.3 Research Questions

The overarching aim of this thesis is to systematically combine evidence and behavioural theory to understand socioeconomic inequalities in cervical screening participation and develop intervention strategies that have the potential to increase uptake within areas of high relative deprivation. Two broad research questions investigated this aim, using a qualitative approach across five studies.

1) What are the factors influencing routine cervical screening participation in areas of high relative deprivation?

2) How can we best address the observed socioeconomic inequalities in cervical screening participation?

1.4 Research Objectives

In order to address these broad research questions, the objectives of this thesis were to:

- Identify existing literature which highlights the determinants of cervical screening from perspectives of under-served women (Chapter 2)
- Consider how to effectively access the perspectives of those living in areas of high relative deprivation (Chapters 3 and 4)
- Explore relevant factors influencing participation for those living in areas of high relative deprivation (Chapters 2, 3 and 4 and 5).
- Explore how these identified factors may contribute to socioeconomic inequalities in cervical screening participation (Chapter 5)
- Identify intervention characteristics, that are acceptable to stakeholders, to increase cervical screening participation in areas of high relative deprivation (Chapter 5)
- Develop a theoretical understanding of cervical screening participation in areas of high relative deprivation, and the likely process of change (Chapter 6)
- Develop suitable intervention components and strategies that have the potential to increase screening attendance in areas of high relative deprivation (Chapter 6).

1.5 Epistemological position

The current research is grounded in a contextual constructivist perspective, which aims to take into account the individualised and complex social worlds of participants. This approach proposes participants' reality is constructed from their social surroundings and as such, 'reality' may be described in different ways depending on this social context. The researcher is not viewed as a passive recipient of knowledge but instead is an active part of the research process and plays a role in ‘constructing’ the collated knowledge through social interaction (Madill, Jordan, & Shirley, 2000; Tolan & Grant, 2009; Willig, 2013). The present research is therefore underpinned by an appreciation that findings are interpreted from both participant’s and the researcher’s social context. For the purposes of transparency and clarity, the positionality statement in Appendix A gives further details on the researcher’s social context.

1.6 Research Context

The primary research included within this thesis recruited women living in areas of high relative deprivation and was situated within the North East of England. The North East has distinctly poorer health outcomes in comparison to other regions across the country, with the lowest average female life expectancy (81.6) and healthy life expectancy (60.1 years) in England (Public Health England, 2017). The region also has higher than average rates of cervical cancer incidence (ONS, 2019). Routine cervical screening uptake, across the region, is slightly above England’s average at 74.7%, but varies widely between local authorities, from 78.1% in Northumberland to a low of 68.3% in Newcastle Upon Tyne, where the majority of recruitment took place (NHS Digital & Office for National Statistics, 2018).

1.7 Thesis Approach

In line with guidance from the Medical Research Council Framework (MCRF; Craig et al., 2008) a broad, three stage approach will be taken to develop suitable intervention strategies that are likely to increase cervical screening uptake in areas of high relative deprivation. The thesis will mainly focus on stage 2 of the MRCF (identifying and developing theory) given this is an important but generally overlooked stage of intervention development. The broad stages taken here are shown in Figure 1.2.

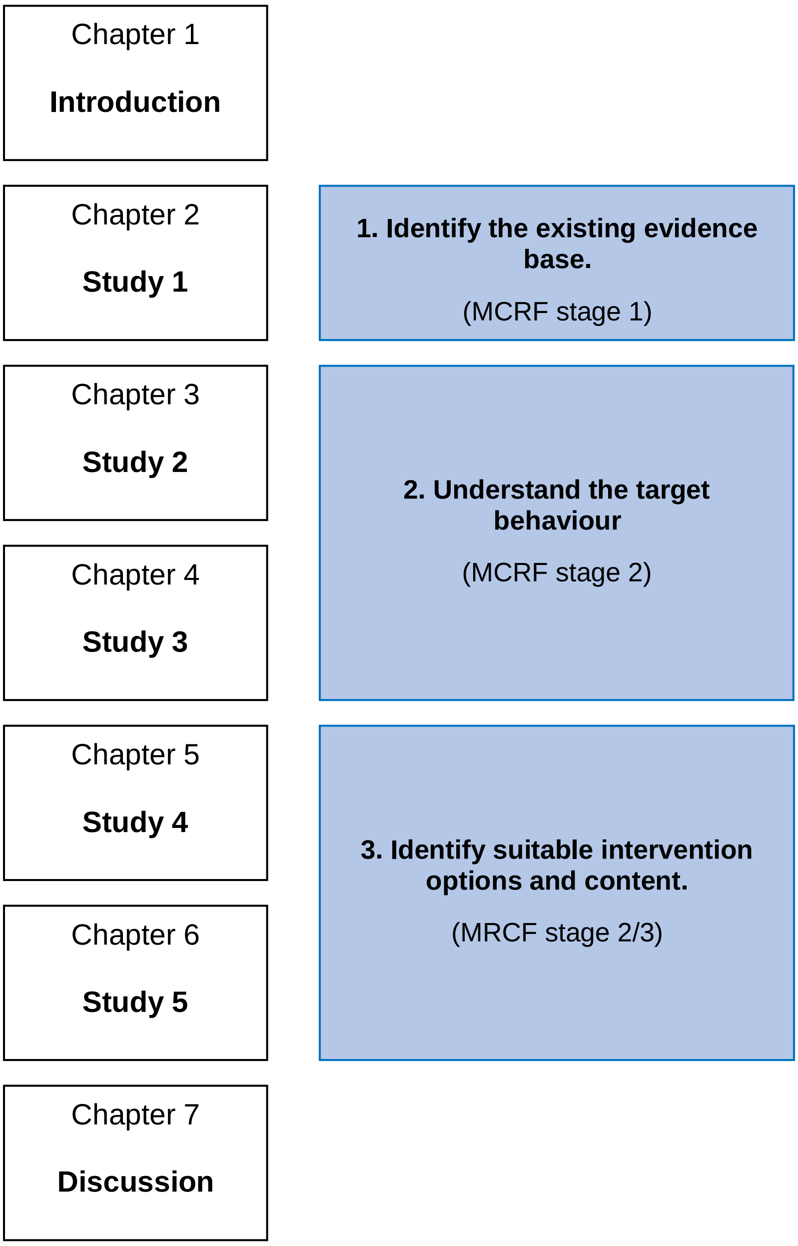

Figure 1.2. Thesis approach developing intervention strategies to increase cervical screening participation in areas of high relative deprivation.

1.8 Overview of Studies

1.8.1 Study 1 (Chapter 2)

Study 1 comprised of a large-scale qualitative literature review to establish potential determinants of cervical screening, within under-served women (i.e. ethnic minority women, and women of low socioeconomic status). Data was synthesized in line with Framework synthesis, an adaption of framework analysis originally used to synthesize primary qualitative data (see Dixon-Woods, 2011). Dahlgren & Whitehead's (1991) social model of health was used as a broad *a priori* coding framework to identify multi-level determinants, with appropriate amendments made throughout the coding process. Synthesis of 21 studies resulted in four broad layers of influence. Cervical screening participation in under-served women was influenced by 1) *the individual* 2) *social networks* 3) *the healthcare environment* and 4) *wider society*. The complex interrelationships identified between determinants suggest that barriers have a cumulative effect on screening participation. It is proposed that this accumulation of barriers increases difficulties in accessing screening services, and thus exacerbates currently observed inequalities in participation.

These findings support the view that social context is imperative to understand and address inequalities in cervical screening uptake. However, there was a distinct lack of qualitative literature in relation to the views and perspectives of those living within socioeconomically disadvantaged areas. This highlights the need for further qualitative work in the area; to further explore and understand influencing factors that are specific to this group.

1.8.2 Study 2 (Chapter 3)

Following on from the poor evidence base identified in Study 1, Study 2 took a qualitative approach to access and highlight the lived experiences of women living in areas of high relative deprivation, in relation to routine cervical screening. There were a number of difficulties in recruitment, with advertisement taking place via social media, personal connections of the researcher, and within the community to engage potential participants. Ultimately, 15 one-on-one interviews were carried out with a diverse sample of women living in areas of high relative deprivation (Department for Communities and Local Government, 2015).

Interviews were transcribed verbatim and Template Analysis (King, 2012) was used to analyse resultant data. Findings supported those within the previous systematic review and identified three important areas of influence specific to those living in areas of high relative deprivation: 1) *personal motivation* 2) *community* and 3) *the healthcare environment*. More specifically, whilst personal motivation to attend was a barrier to participation, positive interpersonal relationships within both the community and primary care were key and facilitated timely attendance. Given issues recruiting those from socioeconomically disadvantaged backgrounds, the present study also provides insight on suitable approaches in engaging traditionally marginalised groups in academic research. Working with/alongside community-based organisations (although time consuming) may be a suitable approach to engaging those living within areas of high relative deprivation (inclusive of ethnic minority and migrant groups).

1.8.3 Study 3 (Chapter 4)

In light of the aforementioned recruitment challenges, a brief, online qualitative survey was developed as an accessible and anonymous avenue for participants to provide their views towards routine cervical screening participation. Initially, a focused recruitment strategy was taken to engage those overdue screening, living in areas of high relative deprivation. However, this was unsuccessful in engaging these traditionally underrepresented groups, and so an inclusive approach to recruitment was taken. A total of 64 women aged 25-64 took part in the survey, across a broad range of socioeconomic backgrounds. Qualitative data was analysed using Template analysis (King, 2012). Analysis presented three over-arching themes which encapsulated current attitudes towards cervical screening participation; '*Screening is worthwhile'*, ‘*Screening can be difficult to access*’ and ‘*Past experiences are important’*. While the vast majority of participants believed screening to be a valuable procedure, it can be both psychologically and practically challenging to access, with distinct challenges in relation to appointment making. This approach also resulted in disclosure of particularly sensitive issues related to screening attendance, namely surrounding past trauma and negative experiences with healthcare staff. Overall, these findings include the perspectives of those living in areas of high relative deprivation, a generally under-represented group within academic research. However, only 11 participants lived within the most deprived areas within England, even after attempts to specifically target this group, suggesting that face-to-face recruitment may be preferable in future research. Nonetheless, the anonymous, online approach may allow women to more readily share sensitive experiences thus provoking important methodological considerations; online methods should therefore not be dismissed, but costs and benefits carefully considered in light of the research context.

1.8.4 Study 4 (Chapter 5)

Whilst Studies 1-3 focused on identifying and developing the evidence base, Study 4 aimed to explicitly discuss these findings with stakeholders and consider potential routes to increasing informed participation. This study was conducted in two stages.

Study 4a: Four focus groups (total N=29) were carried out within areas experiencing the highest levels of relative deprivation (i.e. 10% most deprived areas in England; Ministry of Housing Communities and Local Government, 2019) and lowest levels of screening uptake in the local area. Participants discussed previously identified factors, and their own thoughts in the context of their own communities, and then made intervention suggestions that they felt would be acceptable to increasing participation. Group discussions were transcribed verbatim and Template Analysis (King, 2012) was used to analyse transcripts. Preliminary analysis then took place, briefly outlining the community’s suggestions, to develop materials for Study 4b.

Study 4b: Five health related professionals (n=2 community sector, n=3 NHS health professionals) took part in one-on-one semi-structured interviews to discuss the preliminary findings of qualitative work detailed above. These interviews predominately focused on feasibility and acceptability of suggestions from the community from an organisational context. Interviews were transcribed verbatim and data was analysed alongside study 4b to gain a well-rounded view of stakeholder perspectives.

Participants' views broadly echoed those of previous qualitative work and gave additional insight into the connections between determinants. Key *external factors* (i.e. *Negative experiences of primary care*, *Competing demands* and *Social Influence*) and *internal factors (*i.e. *Screening-related knowledge, Prioritisation of screening and Emotional response to clinical care)* appeared to be inextricably linked. Postponement of cervical screening was discussed as a logical choice for those living in areas of high relative deprivation, who often had multiple challenges to engagement coupled with low resource availability. To address these challenges, it was suggested that interventions should *increase service accessibility* and prioritise *working in partnership to normalise screening*. Health-related professionals felt community suggestions may be valuable and acceptable to those tasked with delivering the intervention but could be challenging to implement depending on the availability of finance and other relevant resources.

1.8.5 Study 5 (Chapter 6)

Study 5 aimed to select and apply appropriate theory in order to clarify the likely process of change and develop tailored strategies suitable for increasing timely participation at routine cervical screening for those living in areas of high relative deprivation. Guidance from the Behaviour Change Wheel (Michie et al., 2014) was used to facilitate the development of intervention strategies which reflected both community perspectives and behaviour change theory. Previous qualitative findings were mapped to the COM-B model (Michie et al., 2011) and the Theoretical Domains framework (Cane, O'Connor, & Michie, 2012; Michie, Johnston, Hardeman, & Eccles,

2008) to enable a behavioural diagnosis (i.e. identification of what needs to change, in terms of capability, opportunity and motivation, for the target behaviour to occur). These targets of change were then linked to intervention functions (i.e. means by which behaviour may be changed), policy categories and behaviour change techniques that are likely to be effective within the target population. Overall, *Psychological Capability, Social and Physical Opportunity* and *Automatic and Reflective Motivation* were identified as important targets of behavioural change. Six intervention functions (*Education, Persuasion, Training, Environmental restructuring, Modelling and Enablement),* three policy categories (*Guidelines, Service Provision* and *Communication/Marketing*) and 16 BCTS were identified as appropriate ways in which to change the target behaviour. From this, a range of example strategies were developed.

2 Determinants of Routine Cervical Screening in Under-served Women: A Qualitative Systematic Review.

2.1 Chapter Synopsis

Given the persistent inequalities in routine cervical screening uptake introduced in Chapter 1, this chapter aims to bring together existing evidence which provides insight into the potential determinants of these inequalities. Specifically, this chapter aims to synthesise qualitative research which considers determinants of routine cervical screening uptake in under-served women. A detailed search strategy will be outlined. Relevant evidence will be considered within the context of Dahlgren and Whitehead's (1991) Social Model of Health to identify determinants of screening within the wider social context of under-served women's everyday lives. These determinants, and the relationships between determinants, will be considered and discussed in-depth. This study identifies the existing evidence-base as a foundation for future intervention development to increase cervical screening uptake in under-served groups.

2.2 Background

Routine cervical screening uptake is complex and dependent on multiple factors that are situated within psychological, socio-cultural and environmental contexts (Chorley et al., 2016; Sorensen et al., 2003). For example, negative attitudes and beliefs towards cervical screening, poor screening-related knowledge, fear and embarrassment surrounding the procedure, work commitments and childcare challenges have all been cited as common barriers to participation (e.g. Lovell et al., 2015; Marlow et al., 2015; Olsson et al., 2014; Oscarsson, 2012; Oscarsson, Wijma, et al., 2008; Tran et al., 2011; Tung et al., 2017; see section 1.1.2). Qualitative evidence can be particularly valuable when aiming to understand barriers and facilitators to screening engagement, as it provides in-depth exploration of participant perspectives, capturing their experience and perceptions of the world (Given, 2008). Moreover, synthesising bodies of qualitative evidence allows researchers to draw together detailed insight into a phenomena and, as such, encourages new understanding to develop and therefore potentially highlight previously unexplored pathways to behavioural change (Seers, 2012).

Previously, researchers have synthesised qualitative evidence to gain insight into determinants of engagement with cancer screening programmes. Young et al., (2018) reviewed qualitative literature in the U.K which focused on factors influencing the decision to attend for cancer screening. Although considering cancer screening broadly, this review highlighted the influence of patient-provider relationships, cancer-related fear and risk beliefs/discourses in contributing to decisions surrounding screening attendance. More specifically to cervical screening, Chorley et al., (2016) synthesised 39 studies that explored factors influencing cervical screening participation. This review emphasised screening as a behaviour that was consistently reassessed and revaluated over time, determined predominately by women's thoughts and perceptions of the test as they considered the relevance and value of screening in conjunction with their emotional responses towards (and previous experiences of) the procedure. To a lesser extent, extrinsic factors such as competing priorities and practical barriers, were also identified and discussed as factors that may influence screening participation.

Whilst these reviews provide detailed insight into screening participation, they present an overview of determinants in the context of a generalised female population and therefore do not adequately consider social context. Indeed, Young et al., (2018) acknowledge those who are least likely to engage in screening were potentially underrepresented within their review. Moreover, the majority of existing cervical screening literature tends to emphasise individual level factors (e.g. beliefs, attitudes, emotions). Again, situating these determinants within wider social, structural and cultural contexts would be valuable, particularly as doing so allows researchers to explore and understand how multi-level factors interact with one another to influence behaviour (see Marmot et al., 2010; Public Health England, 2017). This approach may also be useful in identifying specific factors that are modifiable by policy (Dahlgren & Whitehead, 2007). Thus, more work is needed to synthesise existing qualitative literature to develop an understanding of cervical screening determinants in the wider context, tailored to those who are least likely to attend.

Within the UK, those living in areas of high relative deprivation are least likely to attend routine cervical screening (Douglas et al., 2016; see section 1.1.4). Given those living in the highest levels of deprivation are predominately of ethnic minority status (Office for National Statistics, 2018), it is also important to ensure that efforts to understand socioeconomic inequalities include evidence which elucidates factors important to ethnic minority groups. This is particularly relevant in relation to cervical screening as those from ethnic minority groups are also often less likely to participate in routine screening in comparison to their White British counterparts (Lovell et al., 2015). Despite this, perspectives of ethnic minority and deprived communities tend to be largely absent from academic research (Bonevski et al., 2014) and as such, it is currently difficult to determine how generalised determinants of uptake are relevant to these under-served groups (i.e. those living in areas of socioeconomic deprivation and/or those of ethnic minority status). Indeed, it is entirely possible that the key determinants of screening participation may differ dependant on sociological context and/or have differing influences on behaviour. For example, cancer fear and fatalism were found to be more prevalent in women from ethnic minority groups, in comparison to White British women (Vrinten, Wardle, & Marlow, 2016). Furthermore, cancer fear was found to be a barrier to engagement with health services in women of low socio-economic status, whilst conversely encouraging engagement in those from more affluent backgrounds (Marcu, Black, Vedsted, Lyratzopoulos, & Whitaker, 2017). It is therefore imperative to synthesise the perspectives of under-served women to gain further understanding within this area.

Whilst reviews of the literature focusing solely on under-served populations are scarce, there are some examples of systematic reviews which have aimed to identify specific determinants of screening participation within those least likely to attend (e.g. Chan & So, 2017; Johnson, Mues, Mayne, & Kiblawi, 2008; Lee, 2015). However, these reviews consider participation across a variety of international screening services, many unlike the free screening programme available within the U.K. Due to these disparities, it remains important to consider specific determinants of cervical screening participation for under-served women, in the context of population wide call-recall programmes (i.e. whereby women are invited/recalled to participate at regular intervals). Drawing together detailed perspectives of those least likely to attend cervical screening would also facilitate the development of interventions to increase uptake and highlight where further research is needed (Craig et al., 2008; Michie et al., 2014). Indeed, synthesising existing literature in this way is directly in line with guidance from the Medical Research Council, who strongly recommend intervention development should begin with identification of the existing evidence base to draw together current knowledge on a given topic and aid in theory selection and development (Craig et al., 2008).

2.2.1 Rationale and Aims

Whilst previous reviews of the literature have identified determinants of cervical screening participation; there have been no reviews of literature which solely focus on the perspectives and experiences of under-served women. This is particularly important given evidence which suggests determinants may have differing effects and influences on health behaviour dependant on sociodemographic context. The present review therefore aims to systematically collate and synthesise qualitative literature which explores determinants of cervical screening participation within ethnic minority women and women of low socioeconomic status, in the context of a population wide, call-recall screening programme. In addition, this review will consider existing evidence in the wider context, mapping key themes to a suitable (and flexible) *a priori* framework to result in findings which are accessible and more easily translatable into policy and practice.

2.3 Method

2.3.1 Defining Terms

The present review uses the term ‘under-served women’ to collectively refer to a) women of ethnic minority status and b) those of low socioeconomic status. For the purposes of clarity, further defining details of these sub-groups are outlined below.

2.3.1.1 Ethnic Minority

Ethnic identity is generally believed to be subjective and multi-faceted. Within research, it is therefore difficult to ascribe objective descriptors to what it means to be an ‘ethnic minority’ (Schwartz et al., 2014). Bulmer (1996) states that an ethnic group can be classified as a sub-population that has *“real or putative common ancestry, memories of shared past and a cultural focus upon one or more symbolic elements which define the group’s identity, such as kinship, religion, language, shared territory, national or physical appearance”.* Therefore, a combination of different factors including (but not limited to) race, religious beliefs, country of origin may be used to determine one’s minority status. Alongside this, it may also be beneficial to consider the ethnic majority within the country or countries of interest and then consider sub-populations from this perspective (e.g. In the UK the ethnic majority would be White, British born and English speaking so any group outside of this would be classified as an ethnic minority; Office for National Statistics, 2019b). For the purposes of this review, an ethnic minority group was therefore classified as a sub-population that has different national or cultural traditions to that of the main population.

2.3.1.2 Low Socioeconomic Status

Socio-economic status may be measured via household income, levels of education, occupational status and/or area of residence amongst other metrics. As such, participants may be categorised as ‘low socioeconomic status’ differently across studies. Whilst this thesis is predominately interested in area-level deprivation (see section 1.1.4), other measures of socioeconomic status remain relevant to the present study’s aims (i.e., to explore determinants of screening in under-served women). Therefore, an inclusive approach was taken to consider both individual and area level measures of socioeconomic disadvantage during the literature search and data extraction.

2.3.2 Search Strategy

The present systematic review was carried out in line with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines (PRISMA; Liberati et al., 2009). A comprehensive search of Web of Science, Scopus, MEDLINE, CINAHL and PsycARTICLES databases were carried out in June 2018. Grey literature was searched via Proquest Dissertation and Theses. Reference lists from relevant articles were hand searched for additional references. Databases were searched with the following, broad search terms and Boolean connectors so as to minimise the risk of missing any potentially relevant studies ; (“Cervical screening “ OR “papanicolaou test” OR “pap smear” OR “cervical cancer screening” OR “vaginal smear” OR “smear test” OR “hpv test”) AND (Determinants OR barriers OR reasons OR facilitat* OR attitud* OR perception OR behaviou*) AND (Participation OR attendance OR nonattendance OR “non-attendance” OR nonparticipation OR “non-participation” OR uptake OR compliance) AND (“United Kingdom” OR “Great Britain” OR England OR Ireland OR Scotland OR Wales OR Australia OR Denmark OR Finland OR Iceland OR Korea OR Netherlands OR Norway OR Slovenia OR Sweden). The countries named within the search terms were included as these were the only countries that have well-established (i.e. 10 years+) free, call-recall cervical screening programmes. The reference lists of full text articles were hand searched for additional eligible literature. This search strategy was repeated in January 2021, to incorporate relevant literature published in between September 2018 and January 2021, in line with guidance from Cochrane on updating systematic reviews (see Cumpston & Chandler, 2020). All included articles were assessed via a set of strict eligibility criteria (see Table 2.1).

Table 2.1 Eligibility Criteria for included articles

Eligibility Criteria	Rationale
1. Must include women's, detailed, perspectives and/or experiences regarding participation (or non-participation) in routine cervical screening	To ensure the synthesized findings reflect the actual opinions of women in regard to routine cervical screening.
2. Study concerns a healthy sample of adult women, eligible for routine screening (in their country of residence) who, in addition, can be classified as belonging to an ethnic minority or low socioeconomic status group.	To minimise the risk of additional factors (e.g. ill health) as much as possible whilst including specific consideration of the population groups of interest.
3. Must include an analysis of primary data (e.g. no reviews).	To reduce the likelihood of repetitive information and findings.
4. Based in a country with a well-established (i.e. 10 years+) call-recall programme	To ensure the call-recall programme is a familiar, routine process at a societal level.
5. Articles must be published 10 years after commencement of routine screening in that country.	To ensure participants views are in reference to an already well-established routine screening programme (i.e. rather than something that was unfamiliar at a societal level).
6. Full-text available in English	To allow for full synthesis of the study's findings.

2.3.3 Data extraction

Identified records were initially stored on Endnote. Following the removal of duplications, AW screened title and abstracts for potential eligibility. At both the title/abstract screening, and full text screening stages, LS acted as an independent, second reviewer and screened 20% of the sample. Rates of concordance between the first and second reviewer were high (96% overall). Any disagreements were resolved via discussion.

2.3.4 Data synthesis

Data was synthesized in line with Framework synthesis, an adaption of framework analysis originally used to synthesize primary qualitative data (see Ritchie, Spencer, & O'Connor, 2003). Framework synthesis has been applied to a range of different research areas and allows researchers to systematically and transparently analyse diverse literature. This approach allows for the application of a broad *a priori* theoretical framework, whilst still being flexible enough for amendment, dependent on the concepts that emerge from the literature during the coding/analysis process. This approach therefore strikes a balance between overly data-driven methods (that may be difficult to apply to surrounding literature) and overly rigid theoretically based reviews (which may neglect new or unique concepts that emerge from the data in favour of well-established theoretical constructs; Dixon-Woods, 2011).

Thomas, O'Mara-Eves, Harden and Newman (2017) suggest the process of framework synthesis can described in two broad stages: *Developing or selecting an initial framework* and *Recognising patterns through aggregation*. These two stages were then broken down in line with previous literature (e.g. Lorenc, Brunton, Oliver, Oliver, & Oakley, 2008; Ritchie et al., 2003), specific stages of data synthesis for the current review are outlined below.

2.3.4.1 Stage One: Selecting an initial framework

As the present review considered cervical screening in the wider context, it was important to select a framework which incorporates a holistic view of determinants that may influence an individual’s health and/or health behaviours. Dahlgren and Whitehead’s (1991) Social Model of Health (see Figure 2.1) was deemed a suitably

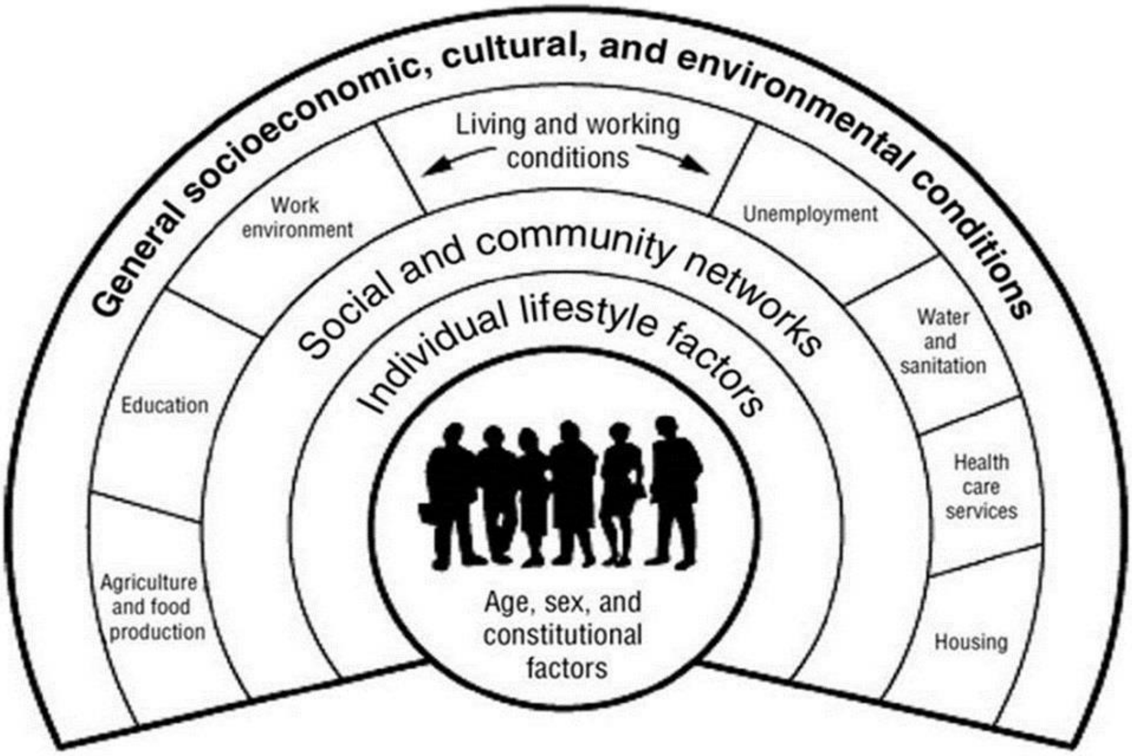

Figure 2.1 Dahlgren and Whitehead's (1991) Social Model of Health

2.3.4.2 Stage two: Recognising patterns through aggregation

As in Ritchie and Spencer (2003), the following stage can be broken down into three distinct phases 1) Indexing, 2) Charting and 3) Mapping and Interpretation. These stages, as they pertain to the current review, are outlined in more detail below

2.3.4.2.1 Indexing

Eligible literature was uploaded to NVivo version 12. Any text that referred to the findings of the included studies were coded and grouped thematically in line with the initial framework. The coded text included participant quotes and interpretive text from the author(s). Text excluded from coding is summarised in Table 2.2 below. During this stage, the initial framework was iteratively amended to incorporate any new codes/themes identified within the data during the coding process. Topics arising from the data were discussed between the first (AW) and second (LS) reviewer.

Table 2.2 Text excluded from coding, with rationale

Exclusion Criteria	**Rationale**
Text quoting/referring to the opinions of health professionals	To ensure derived themes are reflective of service user's own decisions and reasons for attendance/non-attendance.
Text quoting/ referring to participants who did not fit the eligibility criteria (i.e. comparison groups - such as women from countries that do not offer routine screening, or women who are not part of an ethnic minority/from a deprived community).	To ensure that derived themes are reflective of the perspectives of women within the previously outlined 'at-risk' groups.
Text referring to demographic data of the sample	This data is detailed within the summary tables in the results section.
Summary sentences describing multiple topics/themes.	Repetition of information e.g. conclusions which refers to/repeats information which has already been coded.

2.3.4.2.2 Charting

Data relating to each aspect of the finalised framework was extracted into tabular format. This format clearly highlights the differing types and levels of determinants of routine cervical screening, as expressed through the lived experiences and perspectives of under-served women.

2.3.4.2.3 Mapping and Interpretation

The data presented during the charting stage was again analysed in line with the overall aims of the review. The outlined determinants of screening were considered and explored in depth, considering sub-populations differences and how determinants related to one another. This approach also allowed for the development of multi-level recommendations/strategies to increase uptake. The studies contributing to each aspect of the framework were expressed in tabular format, to illustrate the robustness of the review and relative weight of each determinant/aspect.

2.3.4.3 Quality Assessment

The quality of included literature was assessed using the Critical Appraisal Skills Programme (CASP) checklist. This checklist guides systematic appraisal of studies on the basis of 10 areas; 1) clarity of aims, 2) appropriateness of qualitative methodology 3) appropriateness of research design to address aims, 4) appropriateness of recruitment strategy, 5) data collection methods, 6) consideration of the relationship between researcher and participants, 7) consideration of ethical issues, 8) rigour of data analysis, 9) clarity of findings and 10) overall value of the research. The first 9 areas/questions are answered via yes/no (or unsure) checkboxes and with the statement of value being made for the final question. Quality was assessed purely for guidance purposes, as poor reporting does not adequately justify excluding valuable participant data (Garside, 2014; Sandelowski, Docherty, & Emden, 1997). However, no studies were found to be of low quality (see Table 2.3)

Table 2.3 Quality assessment of reviewed studies

Study	Was there a clear statement of the aims?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researchers and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Abdullahi et al., (2009)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Addawe et al., (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Valuable
Anaman-Torgbor et al., (2017)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Valuable
Azerkan et al., (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Batarfi (2012)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Butler et al. (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Cadman et al., (2015)	Yes	Yes	Yes	Yes	Yes	No	Yes	Unsure	Yes	Valuable
Chiu et al., (1999)	Yes	Yes	Yes	Unsure	Yes	Yes	Unsure	Yes	Yes	Valuable
Gele et al., (2017)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Valuable

Study	Was there a clear statement of the aims?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researchers and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Idehen et al., (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Jackoswka et al., (2012)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Kwok et al. (2011)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Logan et al., (2011)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Marlow et al., (2015)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Valuable
Marlow et al., (2019)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Valuable
Ogunsiji et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Patel et al., (2019)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Unsure	Yes	Valuable
Peters (2010)	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Yes	Valuable
Salad et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

Study	Was there a clear statement of the aims?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researchers and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Szwarewski et al., (2009)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Valuable
Team et al. (2013)	Yes	Yes	Yes	Yes	Yes	Yes	Unsure	Yes	Yes	Valuable

2.4 Results

2.4.1 Literature search and summary of study characteristics.

Following the literature search (and after removal of duplications),551 articles were screened, with 512 being removed due to ineligibility. During the second (full-text) round of screening, 18 further articles were removed. Further details of this process can be found in Figure 2.2. Characteristics of the 21, included studies are summarised in Table 2.4 below. As highlighted within the inclusion criteria, all participants were residents of a country with a population-wide, routine, call-recall cervical screening programme. In addition, all participants were eligible to participate in their home country's routine screening programme. The vast majority of the studies (n=18) focused on the perspectives of ethnic minority women with 2 studies focused on the perspectives of women from deprived communities. One further study included the perspectives of both ethnic minority women and those of low socioeconomic status (i.e. two focus groups included those of low socioeconomic status and four focus groups included those of ethnic minority).

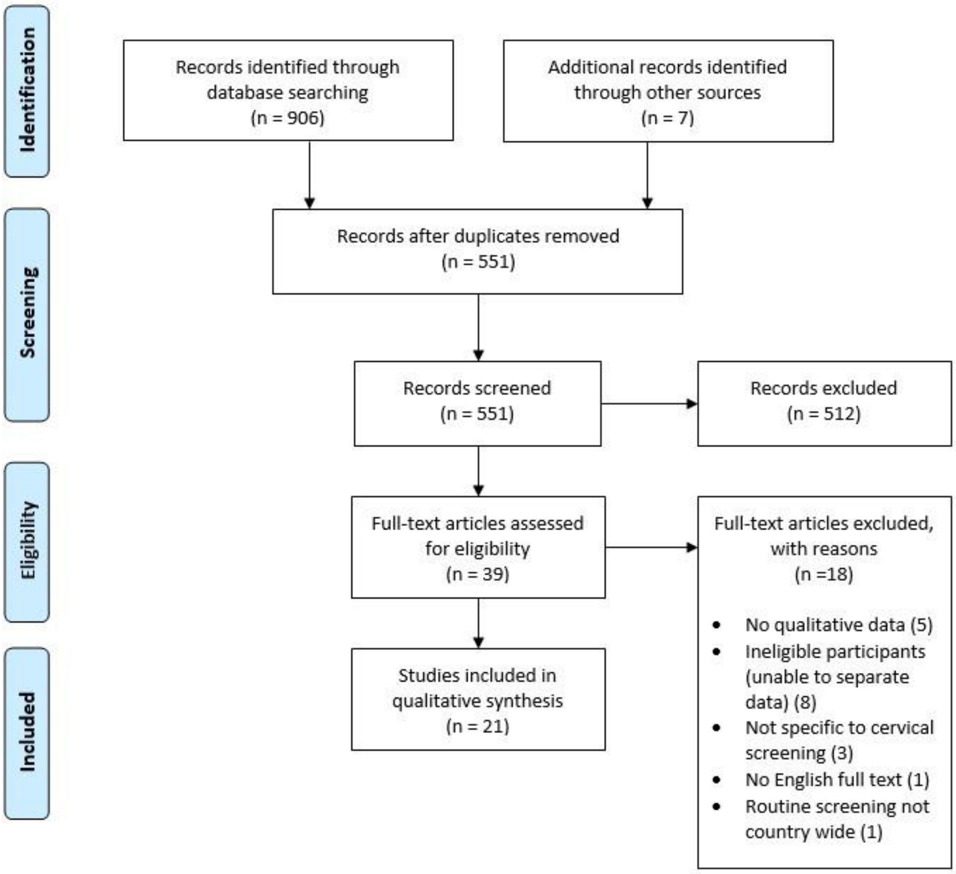

Figure 2.2. Study selection flowchart.

2.4.1.1 Ethnic minority women

Of the studies recruiting ethnic minority women, 9 were carried out in the United Kingdom, 5 carried out in Australia, 2 in Norway, one in Sweden, one in Finland and one in the Netherlands. The majority of studies (n=13) were focused upon migrant women. Two further studies grouped women as a minority based upon their religious beliefs, 3 studies classified participants as an ethnic minority if they self-defined as an ethnic group other than the country's majority population and a further described participants as an ethnic minority in relation to their language group (without reference to migrant status). In terms of data collection methods, 6 studies used one-to-one interview methods to collect participant perspectives, 8 studies used focus groups and 4 studies used a combination of both methods. One study used yarning, and indigenous, culturally appropriate qualitative method, to collect data (see Bessarab &

Ng'andu, 2010). There was more variability in analytic methods used with 7 studies using framework analysis, 6 using content analysis, 4 using thematic analysis, 1 using grounded theory and 1 using discursive strategy to analyse the resulting transcripts. There were variable descriptions of overall participant screening regularity. Across the 19 studies, 47 participants were described as never screened, with a further 11 suggesting they either had never been screened or did not know if they had been screened. Amongst those who have experience of screening (n= 311 in total), 147 participants were described as attenders, 159 participants were described as having been *screened at least once* with 29 of these currently overdue or *'intermittent attenders'.* A further 4 participants were described as being *'screened but no intention of return'* and 1 participant was described as an attender outside of their country of residence (i.e. they returned to their home country to participate in cervical screening). Six studies did not clearly refer to the screening regularity of participants (Addawe, Brux Mburu, & Madar, 2018; Batarfi, 2012; Gele, Qureshi, Kour, Kumar, & Diaz, 2017; Jackowska et al., 2012; Ogunsiji, Wilkes, Peters, & Jackson, 2013; Patel, Sherman, Tincello, & Moss, 2019)

2.4.1.2 Women of low socioeconomic status.

Of the studies specifically recruiting women of low socioeconomic status, 2 were carried out in the UK and collected data across 6 focus groups. One of these studies used content analysis, and the other used a framework approach to analyse the resulting transcripts. The remaining study was carried out in Australia and collected data via conversational interviews, using feminist approaches to analyse data. Two studies recruited women from areas of high deprivation. One study classified participants by their social grade i.e. including those who were from social grades C (lower middle class/skilled working class) through to E (non-working). All but 2 participants (i.e. across all 3 studies) had been screened at least once before.

Table 2.4 Study characteristics

Author/year	**Location**	**Participants**	**Years living in current country of residence**	**Data collection method(s)**	**Analytic method**	**Screening status of participants**
Abdullahi et al. (2009)	London, UK	50 Somali women	*1-10+ years*	Focus groups, in-depth interviews	Thematic analysis	N=19 never screened N=31 at least once
Addawe et al. (2017)	Norway	57 Somali migrant women	*2-25 years*	Interviews and Focus groups	Thematic content analysis	Not stated
Anaman-Torgbor et al., (2017)	Australia	19 African immigrants (10 refugee, 9 non-refugee)	*Not specified*	Semi-structured interviews	Interpretive content analysis	N=4 never screened N=15 at least once
Azerkan et al. (2015)	Sweden	40 Danish and Norwegian immigrant women	*<1-48 years*	Focus groups	Content analysis	N=1 never screened N=39 at least once
Batarfi (2012)	UK	14 Saudi migrant women	1 year +	Focus groups	Content analysis	Not stated
Butler et al., (2020)	Australia	50 Aboriginal and Torres-strait Islander women	NA	Yarning	Thematic analysis	N=50 screened within the last 5 years

Author/year	**Location**	**Participants**	**Years living in current country of residence**	**Data collection method(s)**	**Analytic method**	**Screening status of participants**
Cadman et al.(2015)	UK	23 Hindu women	*Mixed.* *N=4 Native, N=19 1-20+ years*	Focus groups	Framework analysis	N=3 never attended N =20 at least once (7 intermittent)
Chiu et al. (1999)	UK	27 Ethnic minority women	*Not specified*	Focus groups	Discursive strategy	N=1 never attended N= 26 attenders
Gele et al., (2017)	Norway	35 Migrant women (18 Pakistani, 17 Somali)	*1-35 years*	Focus groups	Thematic Framework analysis	Not stated
Idehen et al., (2020)	Finland	30 African migrant women	*1-12 years*	Focus groups	Inductive content analysis	N=19 regular participants N=11 non-attenders/unsure
Jackowska et al., (2012)	UK	32 Polish, Romanian and Slovak women	*1-20+ years*	Focus Groups and interviews	Framework analysis	Mixed/not clearly stated

Author/year	Location	Participants	Years living in current country of residence	Data collection method(s)	Analytic method	Screening status of participants
Kwok et al. (2011)	Australia	18 Chinese-Australian women	*3-16 years*	In-depth interviews	Content analysis	N=7 never screened N=4 screened once, no intention to return N=7 screened within last 2 years
Logan & McIlfatrick (2011)	UK	48 women of low SES	*NA*	Focus groups	Content analysis	Attenders (N=5 first time, N=13 within last 3-5 years, N=30 over 5 years)
Marlow et al. (2015)	UK	43 Ethnic minority women (and 11 white women)	*Not specified*	Interviews	Framework analysis	N=26 regular attenders N= 13 intermittent attenders N=1 attend (not in UK) N= 1 non attender

Author/year	**Location**	**Participants**	**Years living in current country of residence**	**Data collection method(s)**	**Analytic method**	**Screening status of participants**
Marlow et al., (2019)	UK	38 older women (50-64 years) from lower socio-economic and ethnic minority backgrounds	*Not specified*	N=4 focus groups w/ethnic minority women N=2 focus groups w/women from lower social grades	Framework approach	N=33 previously attended N=19 overdue N=4 never attended N=1 unknown
Ogunsiji et al. (2013)	Australia	21 West African migrant women	*1- >11 years (majority less than 10 years)*	In-depth interviews	Thematic analysis	Mixed/not clearly stated
Patel et al., (2019)	UK	26 Eastern European women (and 20 Native English women)	Not specified	Semi-structured interviews/ N=1 focus group	Inductive framework analysis	Not clearly stated
Peters (2010)	Australia	9 low SES women	NA	Conversational interviews	Feminist methods	N= 2 never N= 7 at least once

Author/year	Location	Participants	Years living in current country of residence	Data collection method(s)	Analytic method	Screening status of participants
Salad et al., (2015)	Netherlands	6 Somali mothers	*5-15 years*	Individual interviews	Thematic analysis	N=2 attenders N=3 intend but no prior attendance N=1 intend but no invitation
Szarewski et al., (2009)	UK	28 Muslim women	*Mixed (non-specific) residency status.*	Focus groups	Framework analysis	N=1 never screened N= 27 at least once
Team et al., (2013)	Australia	8 Russian-speaking immigrant women	*7-57 years.*	In-depth interviews	Grounded theory	N=1 regular attenders N=3 occasional attenders N=2 only once N=2 never attended

2.4.2 Data Synthesis

Literature was synthesized using Framework Synthesis, to determine multi-level factors that influence cervical screening uptake in under-served women. Four over-arching, inter-dependant levels of influence were developed: (1) The Individual (2) Social Networks (3) The Healthcare Environment and (4) Wider Society. All levels were influential across both ethnic minority women and women living in deprived areas, however the *type* of influence within each level (i.e. sub-themes) were often underpinned by sociodemographic context. Figure 2.3 outlines the major themes and sub-themes relevant to under-served women. A narrative outline of sub-themes are presented below, with accompanying illustrative quotes shown in Table 2.5.

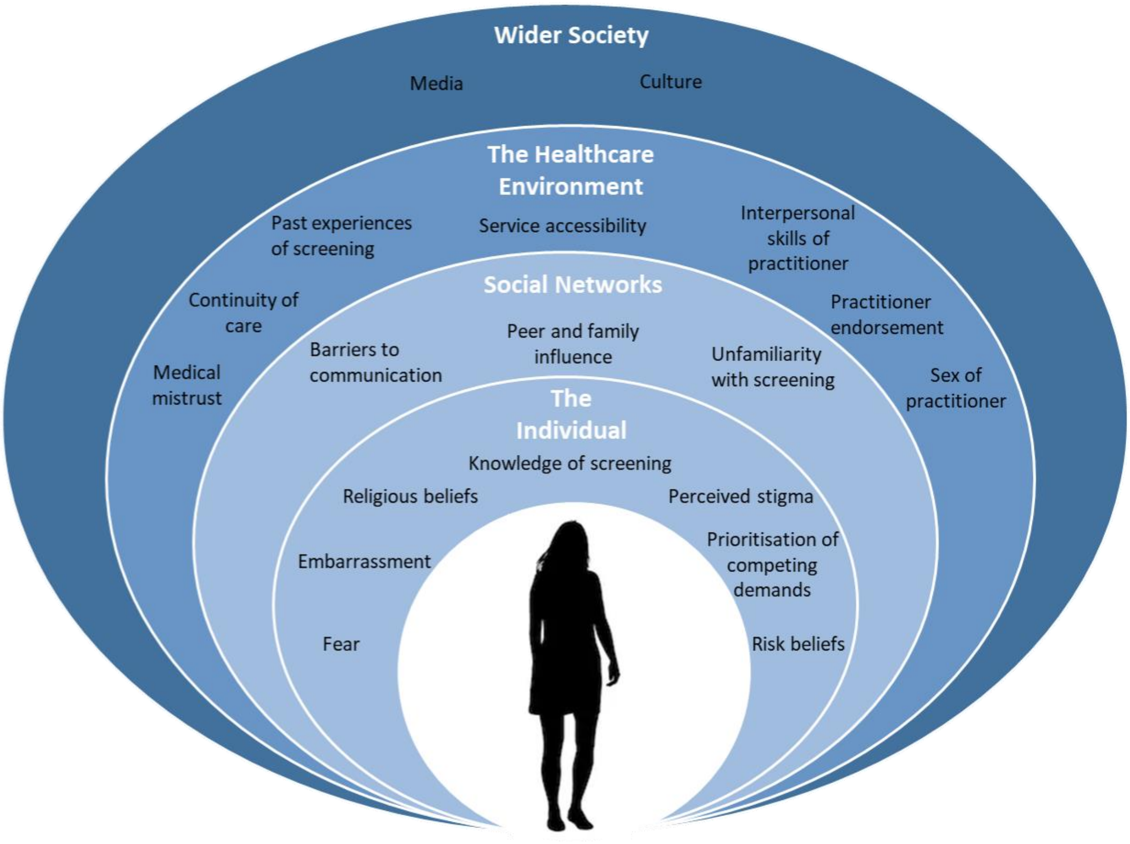

Figure 2.3 Determinants of routine cervical screening in under-served women.

2.4.2.1 Wider society

2.4.2.1.1 Culture

There were eleven studies that referred to factors influencing screening uptake at the level of the wider society (Addawe et al., 2018; Anaman-Torgbor, King, & Correa-Velez, 2017; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Gele et al., 2017; Idehen, Pietilä, & Kangasniemi, 2020; Jackowska et al., 2012; Marlow, Waller, et al., 2015; Ogunsiji et al., 2013; Salad, Verdonk, De Boer, & Abma, 2015). More specifically, nine studies (Addawe et al., 2018; Anaman-Torgbor et al., 2017; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Gele et al., 2017; Idehen et al., 2020; Ogunsiji et al., 2013; Salad et al., 2015) explicitly discussed the role of culture on migrant women’s thoughts, feelings and choices surrounding routine cervical screening. Women highlighted disparities between their own cultural background and that of the country they now resided in as a barrier to engagement in cervical screening. For example, African women felt there was stigma surrounding female circumcision and were apprehensive in attending cervical screening, where they felt they may be judged by health professionals (e.g. Anaman-Torgbor et al., 2017).

Women also mentioned religious or supernatural beliefs that were not in line with engagement in preventative health (as ‘searching’ for disease may ‘trigger’ ill health; e.g. Batarfi, 2012). In many cases, cervical screening was not discussed, particularly within non-western cultures in part due to the association with cervical cancer and partly due to the personal nature of the test. The silence surrounding cervical screening was thus a significant barrier to sourcing further information and also exacerbated feelings of fear and embarrassment surrounding the procedure.

2.4.2.1.2 Media

To a lesser extent, four studies briefly mentioned the influence of media on participation (Batarfi, 2012; Jackowska et al., 2012; Marlow, Wardle, et al., 2015; Ogunsiji et al., 2013). Participants felt cervical screening related campaigns in public places, and human-interest stories had a beneficial effect, raising awareness and encouraging women to participate in routine cervical screening. The media focus on Jade Goody, a celebrity who died from cervical cancer in 2009, was mentioned by both migrant and native women in two studies (Jackowska et al., 2012; Marlow, Wardle, et al., 2015); participants felt this highlighted both the importance of screening attendance and also the potential seriousness of cervical cancer if left undetected.

2.4.2.2 Healthcare Environment

2.4.2.2.1 Past experiences of screening and healthcare

Eight studies (Abdullahi, Copping, Kessel, Luck, & Bonell, 2009; Azerkan et al., 2015; Butler et al., 2020; Chiu, Heywood, Jordan, McKinney, & Dowell, 1999; Idehen et al., 2020; Kwok et al., 2011; Marlow, McBride, Varnes, & Waller, 2019; Marlow, Waller, et al., 2015; Peters, 2010) referred to participant's past healthcare experiences as a potential barrier to future engagement. Negative past experiences of the test (such as pain and/or bleeding) reduced the likelihood of future attendance. Moreover, migrant women described negative screening experiences that arose due to language barriers; for example one study included accounts of women participating in cervical screening without the procedure being explained to them (thus also highlighting a lack of informed consent; Chiu et al., 1999). The context in which women were screened also served as a potential barrier to screening engagement. Impersonal and 'clinical' environments and/or screening facilities (in one instance likened to 'herding cattle'; Azerkan et al., 2015) were off-putting to service users and increased barriers to future participation.

2.4.2.2.2 Continuity of care

Three studies (Batarfi, 2012; Butler et al., 2020; Peters, 2010) expressed the importance of a regular health-care practitioner and outlined women's desire to see a (preferably female) doctor who they had previously built a rapport with and who was already familiar with their medical history. This was deemed particularly important in relation to those who had suffered sexual abuse, so individuals were not required to repeatedly explain their background to various different members of staff. Poor continuity of care, or access to a familiar/trusted practitioner was therefore a barrier to screening for some service users.

2.4.2.2.3 Medical Mistrust

In addition to the above, participants across six studies (Addawe et al., 2018; Batarfi, 2012; Gele et al., 2017; Jackowska et al., 2012; Marlow et al., 2019; Patel et al., 2019) discussed the mis/trust they felt in relation to their healthcare providers. Migrant women in particular, expressed mistrust toward healthcare providers within the country they were currently residing in, referring to (their own or others') experiences of medical mistakes or inadequate healthcare as validation. These women often preferred to verify medical decisions and diagnoses with practitioners in their countries of birth. In some cases, participants also described travelling, or intending to travel, back to their country of birth for screening (e.g. Jackowska et al., 2012; Patel et al., 2019).

2.4.2.2.4 Sex of practitioner

Ten studies (Abdullahi et al., 2009; Addawe et al., 2018; Anaman-Torgbor et al., 2017; Batarfi, 2012; Butler et al., 2020; Gele et al., 2017; Kwok et al., 2011; Logan & McIlfatrick, 2011; Marlow, Waller, et al., 2015; Peters, 2010) emphasised that access to a female screen-taker was key to encouraging screening participation. The potential of a male screen-taker was off-putting to participants, resulting in feelings of embarrassment and indignity, and encouraged postponement. Female practitioners were believed to be more understanding and empathic; participants suggested they could be more open about their fears, questions and concerns if they were speaking to a professional who had also experienced the screening procedure.

2.4.2.2.5 Interpersonal skills of practitioners

Although female staff were preferred throughout, this alone was not enough for participants to feel at ease with the screening procedure. Twelve studies (Addawe et al., 2018; Anaman-Torgbor et al., 2017; Azerkan et al., 2015; Butler et al., 2020;

Cadman, Ashdown-Barr, Waller, & Szarewski, 2015; Gele et al., 2017; Idehen et al., 2020; Jackowska et al., 2012; Kwok et al., 2011; Logan & McIlfatrick, 2011; Marlow et al., 2019; Marlow, Waller, et al., 2015) outlined the influence of practitioners' general interpersonal skills. Women spoke favourably about healthcare staff who explained the procedure well and were friendly and approachable. They suggested such an approach prepared them for the screening test and encouraged a comfortable clinical environment. However, some participants described contrasting experiences; feeling misunderstood, unheard, 'shouted at' and/or rushed by healthcare staff which in turn, was a barrier to future participation. It was suggested that the overall experience of screening could be much improved if the staff member had strong interpersonal skills.

2.4.2.2.6 Practitioner Endorsement

Ten studies (Anaman-Torgbor et al., 2017; Batarfi, 2012; Gele et al., 2017; Idehen et al., 2020; Kwok et al., 2011; Marlow et al., 2019; Ogunsiji et al., 2013; Patel et al., 2019; Team, Manderson, & Markovic, 2013) suggested women were more likely to attend cervical screening if they felt attendance was endorsed by a known health professional. Participants discussed being reminded or encouraged to attend when visiting their GP surgery. Some also felt a personally addressed invitation letter was encouraging and also acted as a reminder to book their appointment. Reliance on GP encouragement was particularly strong within individuals who had migrated from a country with a more compliance-based healthcare system (e.g. Team et al., 2013).

2.4.2.2.7 Service Accessibility

Six studies (Abdullahi et al., 2009; Butler et al., 2020; Jackowska et al., 2012; Kwok et al., 2011; Logan & McIlfatrick, 2011; Marlow et al., 2019) referred to the difficulties under-served women experienced accessing screening services. Participants outlined practical factors such as lack of childcare, difficulties with travelling to screening locations and unsuitable appointment times that were barriers to participating in services. These practical difficulties decreased motivation to find solutions, particularly when perceived risk or beliefs around the importance of the test were low.

2.4.2.3 Social Networks

2.4.2.3.1 Barriers to communication

Ten studies (Abdullahi et al., 2009; Addawe et al., 2018; Anaman-Torgbor et al., 2017; Batarfi, 2012; Chiu et al., 1999; Gele et al., 2017; Idehen et al., 2020; Jackowska et al., 2012; Kwok et al., 2011; Patel et al., 2019) highlighted the impact of communication barriers, particularly amongst those who did not speak English as a first language. Participants described difficulties in reading and comprehending written information related to screening (thus not appreciating the importance of attendance) and in verbally communicating with health professionals. Some needed to attend their GP surgery with their husbands as they were not always aware that they could have access to a translator. Even those who could communicate well in English, outlined more nuanced difficulties in communication (e.g. expressing their thoughts and feelings clearly) during such a personal procedure, and experienced and/or expected negative attitudes or judgement from health professionals because of their ethnic status.

2.4.2.3.2 Unfamiliarity with screening

Eleven studies (Abdullahi et al., 2009; Addawe et al., 2018; Anaman-Torgbor et al., 2017; Azerkan et al., 2015; Batarfi, 2012; Cadman et al., 2015; Chiu et al., 1999; Idehen et al., 2020; Marlow et al., 2019; Ogunsiji et al., 2013; Team et al., 2013) referred to a lack of familiarity with cervical screening. As well as being exacerbated by the language barriers described above, migrant participants discussed the differences between healthcare in their home country and the country they were living in now; this being particularly problematic when individuals had migrated from countries with no formal screening programme. For example, those who had travelled to the United Kingdom from India indicated they had no knowledge or experience of participating in westernised style of healthcare and thus did not anticipate participating in population wide screening programmes (Cadman et al., 2015). For some however, this unfamiliarity was not necessarily with the concept of cervical screening in itself, but with the way that cervical screening was delivered. Team et al., (2013) described the disparities between healthcare in Russia (where women would be penalised if they did not participate in regular health checks) and the free choice that existed within the women’s new place of residence. Unfamiliarity with their new healthcare system thus resulted in perceptions that cervical screening was unimportant (i.e. as it would be compulsory if important to participate in).

2.4.2.3.3 Peer and family influence

Eight studies (Abdullahi et al., 2009; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Jackowska et al., 2012; Logan & McIlfatrick, 2011; Marlow, Waller, et al., 2015; Ogunsiji et al., 2013) outlined the importance of social networks in both deterring and facilitating cervical screening engagement. Strong social networks facilitated screening access, particularly for newly arrived women who found the process of settling into a new country, registering with numerous healthcare providers and services, overly complex. As such, a limited social network resulted in difficulties in accessing healthcare (and other) services in general.

Close family members were felt to be particularly influential in facilitating appointment making and encouraging attendance (e.g. Azerkan et al., 2015). Conversely, hearing negative stories and experiences from others, or even never having heard about female relatives attending screening could increase barriers to their own engagement. Husbands were particularly influential, especially for those who were reliant on their partners for translation services (as discussed in section 2.4.2.3.3 above). In some cases, participants would not, or could not, attend if their partner held negative views towards cervical screening. This negative influence was more pronounced for older women and/or more traditional marriages, with younger women suggesting they received encouragement and support from their respective partners.

2.4.2.4 The Individual

2.4.2.4.1 Embarrassment

Embarrassment was a prominent sub-factor associated with cervical screening, mentioned across thirteen studies (Abdullahi et al., 2009; Addawe et al., 2018; Anaman-Torgbor et al., 2017; Batarfi, 2012; Butler et al., 2020; Chiu et al., 1999; Gele et al., 2017; Kwok et al., 2011; Logan & McIlfatrick, 2011; Marlow et al., 2019; Marlow, Waller, et al., 2015; Patel et al., 2019; Szarewski, Cadman, Ashdown-barr, & Waller, 2009). The procedure itself was deemed to be both physically and emotionally invasive, and those with strong religious or cultural beliefs felt there was an aspect of shame associated with ‘exposing’ oneself, even to medical professionals. These feelings of embarrassment and shame decreased women’s motivation to make appointments and were a key barrier to attending routine cervical screening. Some who had experienced embarrassment during past experiences of screening said this was a significant barrier to them returning for future tests.

As well as personal feelings of embarrassment, women referred to others’ embarrassment surrounding the test and described difficulties in even talking about cervical screening or their own female body parts. Some described their inability to discuss screening in association with their culture, suggesting it was not usual for women to openly discuss such private matters.

2.4.2.4.2 Fear

Often in conjunction with feelings of embarrassment, participants in twelve studies (Abdullahi et al., 2009; Addawe et al., 2018; Anaman-Torgbor et al., 2017; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Cadman et al., 2015; Gele et al., 2017; Logan & McIlfatrick, 2011; Marlow et al., 2019; Marlow, Waller, et al., 2015; Ogunsiji et al., 2013) discussed feeling fear in relation to making, attending or even talking about a cervical screening appointment. This fear appeared to be related to two distinct aspects of the screening process; fear of the actual test, and fear of the potential outcome.

Seven studies (Abdullahi et al., 2009; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Gele et al., 2017; Marlow et al., 2019; Marlow, Waller, et al., 2015) detailed the perceived painful nature of the test deeming cervical screening to be an unpleasant procedure that women often preferred to postpone. In one study (Logan & McIlfatrick, 2011) a participant recalled visibly shaking with fear as she sat in the waiting room, only attending as she had been encouraged to go by others.

Participants in ten studies (Addawe et al., 2018; Anaman-Torgbor et al., 2017; Batarfi, 2012; Butler et al., 2020; Cadman et al., 2015; Gele et al., 2017; Logan & McIlfatrick, 2011; Marlow et al., 2019; Marlow, Waller, et al., 2015; Ogunsiji et al., 2013) also referred to their fear of a negative outcome, particularly the fear of being diagnosed with cervical cancer. Some suggested they could not emotionally cope with a diagnosis of cervical cancer and thus felt it was better to, instead, avoid the test. In the most extreme case some participants suggested they would prefer to die without knowing they had cancer than attend screening and find out in advance (see Gele et al., 2017). This fear was often linked to superstitious, religious and/or cultural beliefs (i.e., attempting to detect abnormalities would in itself cause disease). In two studies, women suggested that the anticipated relief of a receiving a positive outcome could overcome these fears, with the benefits of screening outweighing their own emotional response to the test (Butler et al., 2020; Marlow, Waller, et al., 2015).

2.4.2.4.3 Risk beliefs

Eleven studies (Abdullahi et al., 2009; Addawe et al., 2018; Azerkan et al., 2015; Butler et al., 2020; Gele et al., 2017; Idehen et al., 2020; Kwok et al., 2011; Marlow et al., 2019; Marlow, Waller, et al., 2015; Ogunsiji et al., 2013; Patel et al., 2019) outlined the influence of cervical cancer related risk beliefs on screening engagement. Women felt they were at low risk of developing cancer if they only had one sexual partner or were in a monogamous long-term relationship. Others felt that cervical cancer was linked to westernised cultures and thus those outside of those cultures were therefore not at risk of the disease. There were also some participants that felt that because they had no concerning symptoms, or were not worried about cervical cancer, they would not be at risk of developing the disease. All of these risk beliefs were a significant barrier to attending screening services, as women felt there was no urgent need to attend under these circumstances. In contrast, as cervical cancer was often symptomless in earlier stages, some felt it was possible to unknowingly develop the disease during the three-year period between screening appointments. This belief not only appeared to encourage intentions to screen but was also linked to the belief that women should be able to participate in screening on a more regular basis (Patel et al., 2019).

2.4.2.4.4 Religious Beliefs

Participants across six studies (Abdullahi et al., 2009; Addawe et al., 2018; Anaman-Torgbor et al., 2017; Cadman et al., 2015; Gele et al., 2017; Salad et al., 2015) also referred to their religious belief's surrounding sickness and disease, and suggested that praying to Allah or God would keep them safe from cervical cancer. Some believed the development of cervical cancer to be the result of a curse or engagement in negative behaviours or attitudes. Religious beliefs were often also tied to fatalistic attitudes towards cervical cancer, suggesting that it was 'God's will' or 'fate' if one developed, or indeed were cured of, this disease. This is turn suggested cervical screening was an unnecessary procedure, which could do little to alter the already inevitable.

2.4.2.4.5 Prioritising competing demands

Nine studies (Addawe et al., 2018; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Gele et al., 2017; Logan & McIlfatrick, 2011; Marlow, Waller, et al., 2015; Patel et al., 2019; Szarewski et al., 2009) directly referred to the competing responsibilities managed throughout individuals' everyday lives, and discussed how cervical screening was often prioritised last. Home life, work life and paying bills were deemed more urgent and more important than participating in cervical screening, with some suggesting that their own health in general was not a priority when they had so many different responsibilities to manage. Migrant participants also had increased demands and responsibilities such as finding employment, accommodation and schooling for children which similarly needed to take priority over and above arranging cervical screening appointments (e.g. Patel et al., 2019). Some participants suggested screening was often postponed or forgotten about due to these complex, competing demands.

2.4.2.4.6 Perceived stigma

Four studies (Anaman-Torgbor et al., 2017; Butler et al., 2020; Logan & McIlfatrick, 2011; Marlow et al., 2019) referred to perceptions of stigma surrounding participation in cervical screening. Women expressed a concern that they would be negatively judged, as screening attendance indicated to others that they were sexually active or had a ‘bad lifestyle’ (e.g. Marlow et al., 2019). This was also exacerbated by the belief that cervical cancer was caused by promiscuity, which was particularly problematic for those with strong religious networks.

2.4.2.4.7 Knowledge

There was a general lack of knowledge regarding the purpose of cervical screening, across fourteen studies (Addawe et al., 2018; Anaman-Torgbor et al., 2017; Azerkan et al., 2015; Batarfi, 2012; Butler et al., 2020; Chiu et al., 1999; Gele et al., 2017; Idehen et al., 2020; Jackowska et al., 2012; Kwok et al., 2011; Logan & McIlfatrick, 2011; Marlow et al., 2019; Patel et al., 2019; Team et al., 2013). Some participants did not associate screening with cervical cancer and in some cases believed the test was carried out to detect other diseases or infections (i.e. such as HIV or syphilis). Others held risk beliefs that were rooted within incorrect knowledge about cervical cancer (i.e. that a lack of symptoms meant that they did not need to attend cervical screening). This lack of knowledge contributed to a lack of a perceived importance in relation to screening and was a clear barrier to engagement, particularly for migrant women who were not familiar with the concept of screening and did not always have access to further information in their own language.

A lack of knowledge did not always lead to non-participation however, with some participants explaining that they had taken part in cervical screening simply because they had been told they should, or in one case feared punishment for non-attendance , with little knowledge or understanding of the benefits or costs of the test (see Chiu et al., 1999; Idehen et al., 2020; Kwok et al., 2011; Team et al., 2013).

Table 2.5 Reviewed literature as mapped to themes and sub-themes, with illustrative quotes

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
Wider Society	Culture		Addawe et al. (2018) Anaman-Torgbor et al. (2017) Azerkan et al.(2015) Batarfi et al., (2012) Butler (2020) Gele et al. (2017) Idehen et al., (2020) Ogunsiji et al., (2013) Salad et al., (2015)	*"I think it also has a bit to do with the mentality of the Danes. That you don't really have quite the same view on this, going for regular checks like the Swedes have. It's rare in Denmark that you have this approach with planned, like every six months or every other year or every year that you go in for some check. It isn't really in the same way in Denmark." (Azerkan et al., 2015)* *"Most of the Somalis that I talk to don't get themselves tested. They get the letters about testing, but they threw them in the trash. They hate the disease since it can be fatal. [Somali woman] stay silent about it, and it is hard to get them tested. I did not go since I hated cancer, and do not want to hear anything related to it" (Gele et al., 2017)* *"I think it has to do with my culture because my culture does not emphasise things like that…*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
				looking for damages and things like that" (Ogunsiji et al., 2013)
	Media		Batarfi et al (2012) Jacowska et al., (2012) Marlow et al., (2015) Ogunsiji et al., (2013)	*"Hearing about positive and happy endings for cancer survival encourages women to attend screening services...for example when Dr. Samia recounted her story on the TV...lots of women were talking about her survival...and attend screening services...especially because she was a gynaecologist" (Batarfi, 2012)*
The Healthcare Environment	Past experiences of screening	Peters (2010) Marlow et al., (2019)*	Abdullahi et al., (2009) Azerkan et al., (2015) Butler et al., (2020) Chiu et al., (1999) Idehen et al., (2020) Kwok et al., (2011) Marlow et al.,(2015) Marlow et al., (2019)*	*"There are lots of people who have said that we avoid getting [cervical screening] done because when they put that thing in us, it hurts so much, we bleed loads and for a while we can't face it again. We are too scared, afraid of it" (Abdullahi et al., 2009)* *"I had a friend who was, she only went once, but when you came to this clinic you went into this cubicle with curtains in front. Then you had to sit there and wait. In, up in the stirrups, out again. She says she's not going to do it again. It was*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
				like... .it was as she said, it was like herding cattle" (Azerkan et al., 2015) *". . . I think it was [hospital name], and they were the roughest they could be in there. They weren't gentle at all, especially having something like that done and they say, "Lay down," and wham, you know, they're in, and that, and it was awful. I said, no, that's it." (Butler et al., 2020)*
	Continuity of care	Peters (2010)	Batarfi (2012) Butler et al., (2020) Marlow et al., (2015)	*"I think women should stick to one doctor...to monitor any health problem. For example, my doctor in Saudi used to call me or send a text message to remind me that my check-up was due" (Batarfi, 2012)* *"I would like a female doctor that has experience dealing with someone who has been sexually abused so that they can explain every step that goes along the way. I don't want to have to tell my story to you and then to someone else to eventually get there. I just want to have to explain it once and have that knowledge that that person*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
				is understanding of what I've been through and how it affects me" (Peters, 2010)
	Sex of practitioner	Peters (2010) Logan et al., (2011)	Abdullahi et al., (2009) Addawe et al., (2018) Anaman-Torgbor et al., (2017), Batarfi (2012) Butler et al., (2020) Gele et al., (2017) Kwok et al., (2011) Marlow et al., (2015)	*"I can't see how I would have a Pap smear test done by male doctors. Although male doctors are doctors who should understand all health issues, I don't think they are as understanding and sensitive as female doctors to women's health needs and feelings" (Kwok et al., 2011)* *"I hate the idea of going to a man doctor. It's a lot of embarrassment for me. I'm not going back to him. Even though it lasts only a couple of minutes I think it's, it's very undignified. It's embarrassing" (Logan et al., 2011)*
	Interpersonal skills of practitioners	Logan et al., (2011) Marlow et al., (2019)*	Addawe et al., (2018) Anaman-Torgbor et al., (2017) Azerkan et al., (2015) Butler et al., (2020)	*"I am not at all satisfied with the Norwegian doctors. They do not listen, when I try to tell them about my health problems, they say just one thing at a time. They do not give me enough time" (Gele et al., 2017)* *"The nurse has always explained everything and showed me what she was going to do …so I*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
			Cadman et al., (2015) Gele et al., (2017) Idehen et al., (2020) Jackowska et al., (2012) Kwok et al., (2011) Marlow et al., (2015) Marlow et al., (2019)*	*always felt prepared for what was going to happen next" (Jackowska et al., 2012)* *"Mine was absolutely horrible and, erm, that's why I won't go again. It was … the first time I ever had it done it was okay but the second time I went, I don't know quite what happened and I thought I was gonna die from the pain from this woman and then … and I did cry. I mean, it hurt that much. And she shouted at me and called me a baby, err, which was just dreadful." (Marlow et al., 2019)*
	Medical Mistrust	Marlow et al., (2019)*	Addawe et al., (2018) Batarfi (2012) Gele et al., (2017) Jackowska et al., (2012) Marlow et al., (2019)* Patel at al., (2019)	*"There are many things that can cause doubt, for example, you can't tell whether the person examining you is helping you or deceiving you. Since an important organ is being tested, it can happen that you might not trust the person examining you." (Addawe et al., 2018)* *"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*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
				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" (Jackowska et al., 2012) *"Something else has bothered me as well, I think that … I don't know, like you call them instruments or whatever it is they use. I'm not always so sure they are as clean as what they say they are" (Marlow et al., 2019)*
	Practitioner Endorsement	Marlow et al., (2019)*	Anaman – Torgbor et al., (2017) Batarfi (2012) Idehen et al., (2019) Gele et al., (2017) Kwok et al., (2011) Marlow et al., (2019) Ogunsiji et al., (2013) Patel et al., (2019) Team et al., (2013)	*"My GP encouraged me, she asked me have you done Pap smear before and I said no and she said well it's important to do it then she explained why it's done then I accepted to do it because I have never done it before …"* (Anaman – Torgbor et al., 2017) *"I have never had my breasts examined, never attended [mammography screening], but Pap smear...That, yes. I was encouraged by my doctor, the GP, from the medical centre where I usually go. They remind me and invite me" (Team et al., 2013)*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
	Service Accessibility	Logan et al., (2011) Marlow et al., (2019)*	Abdullahi et al., (2009) Butler et al., (2020) Kwok et al., (2011) Marlow et al., (2019) Jackowska et al., (2012)	*“I have nowhere to put my children while I go for the test, which is why I haven’t had one since my oldest son came” (Kwok et al., 2011)* *“Whenever they send me an appointment it never suits me, and I can’t get time off work for that. Can you see me asking my boss for time off to go for that?” (Logan et al., 2011)*
Social Networks	Barriers to communication		Abdullahi et al., (2009) Addawe et al., (2018 Anaman-Torgbor et al., (2017) Batarfi (2012) Chiu et al., (1999) Gele et al., (2017) Idehen et al., (2020) Jackowska et al., (2012) Kwok et al., (2011) Patel et al., (2019)	*“I know many Somali women especially the older generation; I think they would not take such a test because there is a language barrier. When they come across a written document, they do not have the skills to understand the importance of it.” (Addawe et al., 2018)* *“I am motivated to go, but the language is a barrier. If the letter comes in Finnish, I will not read it, and I will throw it away because I do not understand.” (Idehen et al., 2020)* *“I don’t have difficulties communicating with doctors in English, but I still prefer having a Chinese speaking doctor for a Pap smear test*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
				because I feel best able to express myself and my feelings, particularly during a procedure where I feel very vulnerable already" (Kwok et al., 2011)
	Unfamiliarity with screening		Abdullahi, Copping et al., (2009) Addawe et al., (2018 Anaman-Torgbor et al., (2017) Azerkan et al., (2015) Batarfi (2012) Cadman et al. (2015) Chiu et al., (1999) Idehen et al., (2020) Marlow et al., (2019)* Ogunsiji et al., (2013) Team et al., (2013)	*"Firstly, if a person is new in this country, it's likely that they don't know the language. it may be that back in their country, they didn't know where to get a smear test done. so, when they receive their smear test invitation and it's explained to them. they may get shocked and say 'as if I can strip naked in front of strangers" (Abdullahi et al., 2009)* *"They're brought up in India, they hardly take orthodox medicines or hospitals and clinics … no awareness about their health, I'm sure they were not even educated they didn't go to schools … so nobody told them about all this" (Cadman et al., 2015)*
	Peer and Family Influence	Logan et al. (2011)	Abdullahi et al., (2009) Azerkan et al., (2015)	*"But it's also about networks. Because if you haven't built up a network in Sweden then, if you*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
			Batarfi (2012) Butler et al., (2020) Jackowska et al., (2012) Marlow et al.,(2015) Ogunsiji et al. (2013)	*move to Sweden, then you don't get any suggestions about gynaecologists, dentists...all these things you have to look up, and then it isn´t done, because searching eniro.se [online telephone directory], well...[covers her eyes with her hands]" (Azerkan et al., 2015)* *"Husbands are busy...and some of them prevent women from going [to cervical screening]...and others don't care" (Batarfi, 2012)*
The Individual	Embarrassment	Logan et al. (2011) Marlow et al., (2019)*	Abdullahi et al., (2009) Addawe et al., (2018 Anaman-Torgbor et al., (2017) Batarfi (2012) Butler et al., (2020) Chiu et al., (1999) Gele et al., (2017) Kwok et al., (2011) Marlow et al., (2015)	*"Since we have been circumcised, you'll be embarrassed to surprise them: 'What happened to her?'. There are many reasons you would avoid it, it's so embarrassing" (Abdullahi et al., 2009)* *"Every time I went to the Pap smear test, it was a big struggle. I found it really embarrassing and the embarrassing feelings persisted a few days after the test, so I decided not to have it anymore" (Kwok et al., 2011)* *"I remember, now it's a while ago, but I had to go for my six week check-up ...He says right, while*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
			Marlow et al., (2019)* Patel et al., (2019) Szwareski et al., (2009)	*you're here ...So it wasn't we'll send for you, but right we'll do it. You're here for your six-week check, it is being done. So, there was no option. I hadn't even my legs shaved or anything or time for a bath, I was mortified" (Logan et al., 2011*
	Fear	Logan et al., (2011) Marlow et al., (2019)*	Abdullahi et al., (2009) Addawe et al., (2018 Anaman-Torgbor et al., (2017) Azerkan et al., (2015) Batarfi (2012) Butler et al., (2019) Cadman et al., (2015) Gele et al., (2017) Marlow et al., (2015) Marlow et al., (2019)* Ogunsiji et al., (2013)	*"Most of the Somali women don't go for the screening because they fear the outcome. […]. Most of the women fear to be told that they have cervical cancer after the screening." (Addawe et al., 2018)* *"To be honest...I received the invitation letter...it explained everything about the process...this has stopped me from attending...it looks painful" (Batarfi, 2012)* *"I was shaking when I came in. . . . I was petrified and it was everybody in here that encouraged me to go and then when I went in, I was shaking like a leaf" (Logan et al., 2011)*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
	Risk beliefs	Marlow et al., (2019)*	Abdullahi et al., (2009) Addawe et al., (2018) Azerkan et al., (2015) Butler et al., (2020) Gele et al., (2017) Idehen et al., (2020) Kwok et al., (2011) Marlow et al., (2015) Marlow et al., (2019)* Ogunsiji et al., (2013) Patel et al., (2019)	*“‘I don’t believe I should be worried about things like that because it is only when you worry that you get what you are not supposed to get. Anyway, I just don’t believe that it will happen to me and it’s not of concern to me” (Ogunsiji et al., 2013)* *“I don’t think I need the Pap smear test as I have only one man, my husband, in my life. Thus, I am not at risk for cervical cancer” (Kwok et al., 2011)*
	Prioritisation of competing demands	Logan et al., (2011)	Addawe et al., (2018) Azerkan et al., (2015)	*“I think we do not prioritize our health. Paying the monthly bills are more important for us and that’s what we care about most” (Gele et al., 2017)*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
			Batarfi (2012) Butler et al., (2020) Gele et al., (2017) Marlow et al., (2015) Patel et al., (2019) Szwareski et al., (2009)	*Time wise it's difficult. When women don't have time so they just like shelve it for one reason or another. Or children come along.... and you put it on the back burner.* *"It wasn't that I didn't want to do it, um, I felt that it wasn't a great priority for me at that time, everything else was more important" (Marlow et al., 2015)*
	Religious beliefs		Abdullahi et al., (2009) Addawe et al., (2018 Anaman-Torgbor et al., (2017 Cadman et al., (2015) Salad et al., (2015) Gele et al., (2017)	*"Invitation letters are usually sent but some women are not interested in going for the test. They say it's through God's fate that one gets the disease and he is the one who cures it." (Addawe et al., 2018)* *"I know is that any kind of diseases like my Pastors told me, any kind of disease typically, cancer comes from bitterness or fear that manifest itself in the body. That is my Christian point of view [….] I would think people would generally think in the Shona culture if they were sick of cervical cancer it would have something to*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
				do with black magic or kind of black magic" (Anaman-Torgbor et al., 2017)
	Perceived stigma	Logan et al. (2011) Marlow et al., (2019)*	Anaman-Torgbor et al., (2017) Butler et al., (2020) Marlow et al., (2019)*	*"I just hate the idea of it. The stigma that's attached to it. Like people will see you go up for smear tests and they're . . . thinking the worst or you think that that will mark you out . . . that you know that you're sexually active yeah" (Logan et al., 2011)* *"The stigma, why I think, because people don't have much information about this problem, the most perception about cervical cancer within the community is that this disease is someone suffered from this disease having had bad lifestyle or bad things. So that's why." (Marlow et al., 2019)*
	Knowledge about screening	Logan et al. (2011) Marlow et al., (2019)*	Addawe et al., (2018 Anaman-Torgbor et al., (2017) Azerkan et al., (2015) Batarfi (2012)	*"Pap smear generally is a test that you go in to have a check-up they take fluid from the under part to test for diseases that is not seen it could be HIV, syphilis it could be anything. Once they take the fluid they check for all these things it tells*

Theme	Sub-Theme	Low SES Studies	EM Studies	Illustrative quotes
			Butler et al., (2020) Chiu et al., (1999) Gele et al., (2017) Idehen et al., (2020) Jackowska et al., (2012) Kwok et al., (2011) Marlow et al., (2019)* Patel et al., (2019) Team et al., (2013)	*them what you have" (Anaman-Torgbor et al., 2017).* *"I did not know that the Pap test is for cervical cancer, so there was no fear ofanything. I was not thinking about how good the test is to me at that moment, but I went because everybody was going. I was thinking I will be punished for not going." (Idehen et al., 2020).* *"I didn't know anything about cervical cancer and that I had to go for cervical screening.... I didn't go because I didn't know that it was important" (Logan et al., 2011).*

*- Where appropriate, Marlow et al., (2019) is included under both 'Low SES studies' and 'EM studies' as these findings include perspectives women from both lower socio-economic and ethnic minority backgrounds.

2.5 Discussion

Cervical screening participation is currently at a 20-year low in the United Kingdom, with women living in areas of high relative deprivation, and those from ethnic minority groups, less likely to participate. While existing reviews present an overview of screening determinants for the general female population, there is currently limited understanding of key factors that contribute to the low levels of uptake within the aforementioned groups. The present review aimed to systematically identify and synthesise qualitative research that outlined factors influencing routine cervical screening participation specifically within under-served women.

There was relatively minimal qualitative research identified which specifically focused on the views and perspectives of under-served women. Nineteen studies detailed factors influencing screening uptake for ethnic minorities, and only 3 considered the perspectives of those categorised as low socioeconomic status. As one of these studies classified participants on the basis on their individual occupational status, there were only 2 of the included studies that focused on cervical screening participation within areas of socioeconomic disadvantage. The lack of qualitative literature specifically focused on the views and experiences of those living in areas of socioeconomic disadvantage is particularly concerning given data which demonstrates this group are less likely to attend cervical screening (Douglas et al., 2016; Public Health England, 2019d), and have higher rates of cervical cancer morbidity and mortality (Public Health England, 2014c). It is imperative that, to address such inequalities, researchers prioritise and highlight the perspectives of this clearly seldom-heard group.

Overall, 21 studies were synthesised in line with the principles of Framework Synthesis (see Ritchie et al., 2003), Dahlgren and Whitehead’s (1991) social model of health was used as the initial conceptual framework for the analysis. Synthesis of existing literature resulted in four over-arching levels of influence, situating cervical screening participation within the wider context of participant's everyday lives. Whilst screening participation was unsurprisingly influenced by women's attitudes, beliefs and emotions, this review also demonstrates the social, cultural and environmental layers of influence that extend beyond the individual level. The sub-themes included within each 'layer' of influence further reflect the complexity of factors contributing to under-served women's engagement in routine cervical screening.

At the societal level, participants indicated that exposure to cervical screening related mass-media facilitated screening engagement, whilst cultural issues were discussed as a barrier to engagement. Related literature outlines the positive influence of media on cervical screening attendance (Anderson, Mullins, Siahpush, Spittal, & Wakefield, 2009; Morrell, Perez, Hardy, Cotter, & Bishop, 2010). It is believed that this positive influence can be particularly effective in reducing health related disparities when media-based messages contain personal narratives (Murphy, Frank, Chatterjee, & Baezconde-Garbanati, 2013). Indeed, Macarthur et al. (2011) demonstrated the rise in cervical screening coverage in 2008, following intense media coverage of a celebrity (Jade Goody) who developed, and subsequently died from cervical cancer. This effect was found to be more influential amongst younger women and those with no formal education; arguably as these sub-groups were able to identify with Jade Goody to greater degree than older and more affluent groups (Marlow, Sangha, Patnick, & Waller, 2012). Indeed, this celebrity death was directly referenced by women within two studies in the present review (Jackowska et al., 2012; Marlow, Waller, et al., 2015).

In contrast, cervical screening was often described as incompatible with non-western cultural backgrounds, mainly due to religious beliefs and perceived stigma (e.g. Anaman-Torgbor et al., 2017; Batarfi, 2012). This is in line with past research which highlights that UK health services often do not meet the needs of culturally diverse groups (George, Thornicroft, & Dogra, 2015; Salway et al., 2016). All considered, these findings suggest under-served women are more likely to engage with routine cervical screening if the service provided appears to be relevant and accessible to the sociodemographic groups that individuals identify with.

The healthcare environment was, unsurprisingly, a strong influence on women’s screening participation, with several barriers identified at this level including poor continuity of care, negative past experiences of screening, practical difficulties accessing services, increased levels of mistrust and impersonal patient-provider relationships. Whilst much literature focuses on individual level factors when seeking to increase screening uptake, these findings emphasise the prominent role of the healthcare system in ensuring under-served women feel safe, supported and able to participate in screening services. In particular, the availability of a female screen-taker greatly influenced participants’ willingness (or ability) to engage in cervical screening. It is already well-established that the potential of a male screen-taker increases cervical screening non-adherence (Leinonen et al., 2017). Whilst women have a right to request a female practitioner for any intimate or invasive procedure, this right may be difficult to exercise for under-served women who often have poor communication with healthcare providers (Moss, Gilkey, Rimer, & Brewer, 2016; Sheppard, Adams, Lamdan, & Taylor, 2011). The present findings therefore suggest that healthcare providers should not only have female screen-takers available as standard, they should also aim to increase awareness of female screen-takers for those who may be unfamiliar with standard practice (e.g. migrant populations).

Patient-provider relationships appeared to be particularly influential in determining screening participation and has been previously cited as one of the strongest modifiable factors to encourage cancer screening behaviour (see Peterson et al., 2016). Within the present review, a good rapport and feeling listened to during past appointments reduced anxiety surrounding the test, encouraging women to attend. Practitioner endorsement of screening also facilitated uptake, particularly within migrants who were used to practitioner-led healthcare within their home countries.

Conversely, those who had negative interpersonal experiences with healthcare staff were understandably reluctant to engage with future cervical screening. Increased patient-provider communication has previously been associated with greater levels of healthcare engagement and trust (Street, Makoul, Arora, & Epstein, 2009). However, more recent evidence suggests that it is not sufficient to simply increase patient-provider communication when attempting to encourage cancer screening participation; the quality of such interactions are key (Peterson et al., 2016). In line with this, the present review suggests that increasing relational quality and screening related conversations between patients and providers would positively influence engagement with cervical screening within under-served women.

The present review also detailed ways in which women’s social networks influenced their cervical screening participation. Factors at this level related to barriers to communication, unfamiliarity with screening and peer and family influence. Interestingly, participant’s social networks could have a strong facilitative impact on screening uptake and were a source of encouragement, reassurance and information for women. Without these supportive social networks, participants were often unfamiliar with the screening process, which in turn increased negative emotions and attitudes towards the test. Past literature has highlighted links between social support and engagement in screening behaviours (Gamarra, Paz, & Griep, 2009; Jensen, Pedersen, Andersen, & Vedsted, 2016; Seow, Huang, & Straughan, 2000). Moreover, there is evidence to suggest the association between social support and cervical screening uptake is more pronounced for those of low socio-economic status (Documet et al., 2015). However, evidence of this association within a UK based sample is limited. Given the findings of the present review, further exploration of pathways between social support and cervical screening within under-served women would be beneficial.

Whilst poor social networks had the potential to act as a barrier to screening across sub-populations, the potential impact of this was particularly significant for migrant and newly arrived participants. These participants faced additional obstacles to seeking appropriate social support due to language barriers and unfamiliarity with both screening services and the healthcare system in general (see also Kang, Tomkow, & Farrington, 2019; Piacenti, 2016). These barriers were particularly problematic within some non-western cultures, as inaccurate/negative screening related beliefs were prevalent, thus women were not able to access additional information or support outside of their immediate family members (with indications that some had been prevented from attending by their husbands). Increasing social integration and migrant support networks within the community would therefore likely increase information provision and engagement in screening services within these groups.

At the individual level, and in line with dual-process models of behaviour (e.g. Strack et al., 2004), participants across all reviewed studies discussed cervical screening participation as a result of conscious thought processes (i.e. beliefs and attitudes towards screening) and unconscious, automatic reactions to screening (i.e. affective reactions such as embarrassment and fear). These cognitive and emotion-based responses were often discussed in line with participant’s familiarity and knowledge of cervical screening i.e. participants who displayed increased awareness and knowledge of screening also often described feeling comfortable with attending their screening appointments. That being said, there was a general lack of screening related knowledge across participants. Poor cervical screening related knowledge was also often displayed in conjunction with low perceptions of cervical cancer risk, which in turn resulted in women postponing their appointments until an unspecified later date. The findings of the present review suggest increasing awareness/knowledge around both the purpose of cervical screening, and the actual process of the test has the potential to reduce inaccuracies surrounding risk beliefs and encourage women to prioritise their screening appointments.

However, it is of note that screening related information is already available to a generalised audience (e.g. in leaflet and online formats). Indeed, Naz et al., (2018) recently conducted a review of educational interventions to increase knowledge of cervical screening and found these effective in facilitating cervical screening within a generalised female population. The lack of knowledge observed within the current review suggests that existing approaches to information provision may not be suitable and/or appropriate for under-served groups. Given the low educational attainment often observed within disadvantaged groups (Thomson, 2018) and the language barriers observed within migrant populations, it is likely that this lack of screening-related knowledge is exacerbated by low health literacy levels (i.e. the ability to obtain, read and understand basic healthcare information; Berkman, Davis, & McCormack, 2010; Institute of Medicine, 2004). Indeed, von Wagner, Steptoe, Wolf & Wardle (2009) suggest that health knowledge mediates the pathway from health literacy to the uptake of services such as cancer screening, with other evidence suggesting a direct link between health literacy and, specifically, cervical screening attendance (Kim & Han, 2016). Thus poor levels of health literacy result in a lack of health related knowledge, which in turn results in a greater reliance on, often inaccurate, lay knowledge, deterring individuals from screening participation (Dolan et al., 2004). Healthcare providers and public health professionals must therefore develop and provide more accessible and acceptable forms of cervical screening related education, specifically in communities where uptake is low.

Affective responses to cervical screening (i.e. anticipated embarrassment, fear of test and/or outcome) were also pervasive across studies and participants, exacerbated not only by an individual’s knowledge of, and unfamiliarity with, screening, but also more distal factors; namely cultural disparities and poor patient-provider relationships. Whilst experiencing negative emotions towards screening was a clear barrier to further engagement, there was some evidence to suggest that anticipated positive emotion (in this case anticipated relief) could encourage attendance, and overcome any negative emotional responses to the test (see Marlow, Waller, et al., 2015). Anticipated relief has been found to promote other forms of health screening (Shepherd, Watt, & Lovell, 2017). However, this has yet to be explored in the context of cervical screening. As such, it may be useful to further investigate the potential of anticipated relief in facilitating cervical screening participation in under-served women.

The reviewed literature provides insight into the experiences and perspectives of under-served women, outlining key determinants of cervical screening participation. However, there were some general methodological limitations identified across studies during the review process. Firstly, the vast majority of participants had previously attended cervical screening. Whilst there are clear difficulties in recruiting participants who are completely disengaged or unaware of cervical screening, a lack of perspective from unscreened individuals may result in unidentified barriers or key targets for intervention. Whilst there is no reason to believe that the identified barriers would not also be relevant for unscreened individuals, it remains important for researchers to explore and identify the most important barriers for those who have never been screened.

Secondly, quality assessment (i.e. via the CASP checklist; see section 2.3.4.3) demonstrated that many of the included studies did not fully consider the relationship between the researcher and participant(s). Considering this relationship is an important part of researcher reflexivity (i.e. acknowledgement of the role of the researcher within the research context and process; Dodgson, 2019), as the knowledge constructed during qualitative research is heavily influenced by the relationship between researcher and participant(s) (Brinkman & Kvale, 2018). Researchers should reflect upon their position in relation to that of the researched, and consider how this position affects their relationship with participants and thus, the research findings (Berger, 2015). This may be particularly important when conducting research within under-served or marginalised populations, where there is clear power asymmetry between the researcher/research team and participant group (e.g. Ecker, 2017; Gamble, Grant, & Tsourtos, 2015; Ozano & Khatri, 2018). As the vast majority of included literature was taken from academic journals (thus adhering to strict word count guidelines) it is difficult to determine whether limited consideration of this relationship was due to poor reflexivity, or whether this aspect simply cut from the published manuscript (Mitchell, Boettcher-Sheard, Duque, & Lashewicz, 2018). Nonetheless, it is critical for researchers to explicitly outline their positionality in conjunction with their research population and the context in which the research takes place, so the reader can make an accurate evaluation of rigour (see Dodgson, 2019 for examples of how reflexivity can be incorporated into journal manuscripts).

2.5.1 Strengths and limitations

The present review is the first to synthesise qualitative literature which identifies determinants of routine, population-wide cervical screening participation within under-served women (specifically those from ethnic minority groups and those living within areas of high deprivation). This synthesis was conducted systematically, using the PRISMA guidance to aid study selection. Quality assessment was conducted to provide qualitative insight into the value of existing literature in the area, and as such has further highlighted general methodological limitations (i.e. related to reflexivity) which have the potential to increase the quality and rigour of future qualitative research in this area.

The findings of this review highlight not only the range of determinants that influence screening participation in under-served women, but importantly, situates these determinants within a well-established theoretical framework, which emphasises the complex relationships between factors. Whilst those from more affluent and/or privileged social positions may also experience barriers identified in the present review (e.g. unsupportive family members/friends, low perceived risk of cervical cancer or feelings of embarrassment), this synthesis highlights the additional structural and organisational barriers that are present for those in disadvantaged social positions. As such, non-participation within under-served women is most often a result of multiple barriers at a number of different levels; the likelihood of attendance being progressively reduced as barriers increase. The accumulation or 'clustering' of barriers within disadvantaged populations has been previously discussed as a mechanism by which social gradients in health occur (Dahlgren & Whitehead, 2007; Diderichsen, Evans, & Whitehead, 2001). However, this is the first study to the authors' knowledge which puts forward this argument to account for the persistent inequalities observed within cervical screening participation.

Despite the strengths discussed above, this review should be considered alongside its limitations. As indicated above, under-served populations are diverse. Whilst we present an overview of literature that is tailored toward the perspectives of those who traditionally experience difficulty accessing healthcare services, it is important to note that study samples include those from a variety of different cultural and social backgrounds (e.g. Somalian migrants, White British natives, Muslim women and so on). As such, some of the factors discussed may be more relevant to some groups than others. However, the present findings highlight key commonalities within traditionally under-served populations and therefore provide a foundation from which further insight can be developed. It is therefore recommended that the present findings are applied alongside an understanding of the specific population of interest. This approach would facilitate identification of key factors most likely to elicit change within a more specific target population (see Michie et al., 2011 for a more in-depth guidance identifying key targets of change).

As previously mentioned, it is also of note that the present findings synthesised very few studies, particularly in relation to area-level deprivation (n=2). Thus, the results reported here may not necessarily be fully representative of the wider population of under-served women. For example, although there is much literature to suggest that factors such as living and working conditions can encourage healthy behaviours (see Lovell & Bibby, 2018; Short & Mollborn, 2015)*,* these factors were relatively unexplored within the present review. In addition, the social context/demographic backgrounds of participants are often not fully described within published literature and as such, it is possible that some relevant studies were missed during the selection process. However, the lack of obviously relevant literature demonstrates the need for further qualitative work with those living in areas of high relative deprivation, to explore cervical screening participation from the experiences and perspectives of those who are least likely to access the service. Whilst reaching those who are traditionally disengaged from academic research is a challenge (Bonevski et al., 2014), doing so would ensure future interventions to increase cervical screening uptake are adequately tailored to, and suitable for, those who are in the need of most support.

2.5.2 Recommendations for future research

The current review presents a number of avenues for researchers to pursue. In the first instance, it is clear that there is a paucity of qualitative evidence exploring the experiences and perspectives of routine cervical screening participation, in relation to those living within areas of high relative deprivation. Developing this body of evidence would allow for further exploration of observed uptake inequalities and encourage identification of suitable targets for intervention. As socioeconomically disadvantaged groups are often described as ‘hard-to-reach’, it is also recommended that researchers develop acceptable strategies for engaging socioeconomically disadvantaged groups within screening related research (see Bonevski et al., 2014).

The present findings also indicate that cervical screening participation is a result of a wide range of influences, indicating that more distal factors such as social networks can indirectly increase likelihood of engagement. Whilst the importance of social determinants on health behaviours is widely known (Short & Mollborn, 2015), this is relatively unexplored in relation to cervical screening participation. As such, it is recommended that further inter-disciplinary research is conducted to explore individual’s social, economic and environmental contexts in conjunction with cancer screening behaviours. Understanding screening within this broader societal context would reduce further individualisation of screening behaviour (which is unhelpful to those who face increased structural barriers to engagement which they cannot control; Baum, 2007; Holman, Lynch, & Reeves, 2018) and facilitate the development of multi-level interventions. The complex interrelationships between determinants, described within this review, suggests that this approach is likely to be successful in increasing screening participation in under-served populations.

2.5.3 Conclusion

There are distinct and persistent inequalities in cervical screening participation. Women from ethnic minority backgrounds and/or those living in areas of high relative deprivation are currently ‘under-served’ and least likely to attend routine cervical screening. The present review aimed to systematically collate and synthesize qualitative literature which explored determinants of routine cervical screening uptake within under-served women, in the context of a population wide call-recall programme. Following systematic searching and screening of studies in line with PRISMA guidelines, 21 studies were synthesised in the context of Dahlgren and Whitehead’s (1991) Social Model of Health. Literature synthesis suggested that, for under-served women, screening participation was a result of multiple, interrelated determinants that spanned four levels of influence i.e. The Individual, Social Networks, The Healthcare Environment and Wider Society. Those from ethnic minority groups, particularly migrant participants, described distinct communication barriers and cultural disparities. Whilst the literature was sparser in relation to those of low socio-economic status, participant’s highlighted poor continuity in care, negative past experiences of screening and practical barriers to attending appointments as barriers to cervical screening attendance. Combined, these barriers impeded service access and encouraged negative attitudes, beliefs and emotive responses to the screening process. Overall, positive patient-provider relationships and strong, supportive social networks facilitated screening engagement. These findings suggest social context is key in understanding the low participation rates observed within ethnic minority and economically disadvantaged communities; in contrast to their more affluent or privileged counterparts, under-served women face increased structural barriers to accessing screening services, navigating healthcare systems and services that are not adequate for their, often complex, needs.

Synthesising existing literature within the aforementioned theoretical framework has also highlighted a number of recommendations for future research. In light of the current paucity of research in the area, researchers should refocus efforts to explore cervical screening participation from the perspectives of those living within socioeconomically disadvantaged communities. These individuals are most likely to experience structural and organisational barriers to screening thus may be most in need of intervention and support. The challenges in recruiting the most disadvantaged in society may also call for a greater focus on developing accessible data collection and recruitment methods. Overall, this review outlines the need to consider cervical screening participation in the wider context of participants' lives. Focusing on the social determinants of screening uptake may provide more effective avenues for intervention development, that are targeted to those most in need of support.

2.6 Chapter Summary

This chapter aimed to identify and synthesise existing qualitative literature that outlined determinants of cervical screening participation in under-served women. Synthesis across 21 studies demonstrated the complex, multi-level determinants that influence uptake within disadvantaged groups. This review highlighted that most of this research has been undertaken on ethnic minority groups and that there is a distinct lack of qualitative work exploring perspectives of those from socioeconomically disadvantaged communities. As individuals from these communities are more likely to develop, and die, from cervical cancer (Public Health England, 2014c) it is imperative to further explore factors that influence screening uptake within this group. The observed lack of available literature is likely to be a result of difficulties engaging and recruiting such individuals to participate in academic research (Bonevski et al., 2014). Thus, it is similarly important to consider the most suitable and appropriate recruitment strategies, to reach those whose experiences and perspectives are most often unheard. The following two chapters aim to address these recommendations, qualitatively exploring factors contributing to cervical screening participation, whilst implementing and reflecting upon data collection methods which increase accessibility for those from disadvantaged communities.

3 Understanding factors that influence cervical screening participation in areas of high relative deprivation.

3.1 Synopsis

The previous chapter reviewed existing qualitative literature to identify factors that influence routine cervical screening participation within under-served women (i.e. those within ethnic minority groups and those of low socioeconomic status). Findings suggested that under-served women faced multi-level barriers to engaging in cervical screening services which encouraged negative attitudes, beliefs and emotions towards participation. In addition, this review also highlighted a lack of research exploring the experiences of women who live within socioeconomically deprived areas, and recommended researchers develop suitable strategies to access the views of those traditionally marginalised from academic research. The present chapter presents a study which explores women's experiences related to cervical screening to develop a detailed understanding of factors that influence participation, specifically within areas of high relative deprivation. In line with previous concerns regarding engagement of traditionally marginalised groups in research, the challenges and successes of the recruitment process are also detailed and reflected upon.

3.2 Background

It is well established that health and psychology related research is predominately conducted on White, middle-class, highly educated individuals (Bonevski et al., 2014; Woolf & Hulsizer, 2011). This results in an evidence base that tells us much about those within a particular social context, and conversely little about others. Moreover, translating these findings to those in less privileged social contexts may be inappropriate and result in generic treatment and intervention options which neglect important social and/or structural barriers to improving health outcomes, thus widening health inequalities. For example, past evidence suggests that cancer-related fear can encourage health service engagement in high socioeconomic groups whilst conversely hindering health service engagement in low socioeconomic groups (Marcu et al., 2017) suggesting that interventions which encourage fear as a motivational tool may in fact further discourage attendance in those who are traditionally most in need of intervention and support. Indeed, policies devised from generalised determinants of health/health behaviours tend to be ineffective at reducing health related disparities (Dahlgren & Whitehead, 2007). A systematic review, reported in full in the previous Chapter, found only 2 studies exploring the experience of routine cervical screening for those living within areas of high relative deprivation within the U.K. This is concerning given this group are least likely to attend screening (Public Health England, 2019d). As past healthcare experience is known to influence future service access (e.g. Abdullahi et al., 2009; Thangarajah et al., 2016), it is likely that exploring this group's screening related experiences will facilitate identification of context-specific determinants of participation.

There are methodological factors to consider when attempting to access the perspectives and experiences of those living within areas of high relative deprivation. In the first instance, qualitative approaches offer a valuable route to accessing the level of detail and insight needed to develop a deeper understanding of screening related behaviours. However, there are known challenges to engaging marginalised groups in academic research (Bonevski et al., 2014) and so recruitment methods should be carefully considered to ensure they are accessible and acceptable to the population of interest (Sadler, Lee, Lim, & Fullerton, 2010; Valerio et al., 2016).

Community-based recruitment strategies are often cited as the most effective method of recruiting socioeconomically disadvantaged populations in regard to other health-related topics (Erves et al., 2017; Harkins et al., 2010). There is also evidence to suggest that such methods can be successful in engaging marginalised groups to discuss preventative health services. Rockliffe et al., (2018) recently published a reflective account of the challenges in recruiting those that do not access HPV vaccination and cervical screening. The authors provided detailed accounts of strategies used to recruit those who have never attended cervical screening services and found that community-based methods of recruitment were most effective. This success was believed to be due to the connections researchers had established with community leaders and thus demonstrates the importance of relationship building with ‘gatekeepers’ (i.e. trusted community leaders or organisations who can facilitate communication) and/or community members to recruit those from traditionally marginalised groups (Eide & Allen, 2005) . This approach is therefore likely to be an effective strategy to recruit both those within areas of high relative deprivation, and discuss sensitive topics related to cervical screening. Given the limited knowledge in this area, taking such an approach would be valuable in determining suitable routes to increasing the evidence base contributing to our understanding of socioeconomic inequalities in cervical screening.

3.2.1 Study rationale and aims

The previous chapter outlined and discussed determinants of screening in under-served women. However, the importance and relevance of specific determinants for those living in areas of high relative deprivation within the UK is unclear. Further qualitative exploration in this area would result in a greater understanding of routine screening services from the perspective of those within socioeconomically marginalised groups and facilitate the identification of factors that influence low rates of cervical screening participation within this group. Community-based engagement has previously been cited as an effective way to discuss cervical screening participation, mainly due to the opportunity for relationship and rapport building, which is known to facilitate engagement with traditionally marginalised groups, and the discussion of sensitive topics.

Based on this, the main aim of the present study was to explore the cervical screening related experiences of women who live in areas of high relative deprivation to identify context-specific factors that influence participation. The specific research question in this case is ‘What are the factors that influence routine cervical screening participation for those living within areas of high relative deprivation?

3.3 Method

3.3.1 Approach

This study took a qualitative approach to explore personal experiences and attitudes towards cervical screening. This approach was deemed appropriate for the present study as it allowed for rapport-building both prior to and during data collection (Lyons et al., 2013) and results in in-depth, detailed accounts which can facilitate identification of factors that influence participation in health programs. Interview-based data collection methods have previously been recommended as a naturalistic approach to understanding phenomena and increase opportunities to involve marginalised populations (Denzin & Lincoln, 2011; Woodley & Lockard, 2016). As such, one-to-one semi-structured interview methodology was employed to allow the researcher to gently guide conversational topics of interest while still allowing the participant freedom to elaborate on their own experiences and viewpoints. This approach was in line with a contextual constructivist stance as detailed in section 1.5, whereby knowledge surrounding screening participation was constructed and interpreted in light of the both the researcher’s and participants social context (See Appendix A for a researcher positionality statement). Template analysis (King, 2012) was used to analyse the resultant data.

This study is reported in line with guidance from the Standards for Reporting Qualitative Research (SRQR) checklist (O’Brien, Harris, Beckman, Reed, & Cook, 2014). A checklist is included in Appendix C.

3.3.2 Recruitment Methods

A variety of methods were enlisted, and conducted concurrently, between November 2017-July 2018, to recruit participants eligible for routine cervical screening, living in areas of high relative deprivation. In line with recommendations from Rockliffe et al. (2018), methods are presented in detail to demonstrate challenges and successes in recruitment and facilitate future research and engagement with socioeconomically disadvantaged groups. Figure 3.1 outlines the contribution of each method to the final sample. A financial incentive was offered across all methods of recruitment; individuals who participated received either a £5 Amazon or a £5 Love2Shop voucher.

3.3.2.1 Personal Connections/outreach

Personal outreach was used as the researcher is a member of, and has strong personal links to, socioeconomically deprived communities. This method of recruitment took the form of discussions (face-to-face and over email) regarding the purpose and the nature of the research, with personal contacts who lived within areas of high relative deprivation. Seven individuals initially showed interest in participation, although two declined to take part before the interviews took place. In total, five participants were recruited using this method.

3.3.2.2 Community groups/events

Following email communication with local charities and community groups, the researcher engaged in community outreach events from November 2017 – March 2018. Relationship-building involved delivery of a participatory workshop at a non-academic conference in November 2018 and attendance at two community-based charity events in December 2017 and March 2018, held within areas that were within 10% most deprived within the UK. During these events, the researcher discussed the research with residents, gave out recruitment flyers (See Appendix B) and exchanged contact details with any interested individuals. Three individuals showed interest in taking part, but later failed to respond to any further communication. However, attendance at these events led to further engagement with charities and community centres within the local areas. Following discussions with community centre staff, the researcher was invited to attend a pre-existing community group in July 2018, to build a rapport and discuss the present research with attendees. This method resulted in the recruitment of 8 participants.

3.3.2.3 Social Media

Given the low time and financial costs of online recruitment, advertisements were also posted on social media (i.e. Facebook and twitter; see Appendix B). Two individuals contacted the researcher to participate, although did not live in an area of high relative deprivation therefore were not eligible to take part. As such, no participants were recruited via Twitter advertisement.

Advertisements posted on Facebook were shared by 32 personal Facebook accounts, 1 local community centre (in an area that was 10% most deprived as per the IMD) and 1 charity who works alongside socioeconomically deprived women within the North East. Fifteen individuals showed interest in taking part however, nine participants failed to respond to further communication. Following further screening only four (out of the remaining six) individuals lived within areas of high relative deprivation. Two participants did not respond to requests to arrange an interview time/date, thus this approach ultimately resulted in the recruitment of 2 eligible participants.

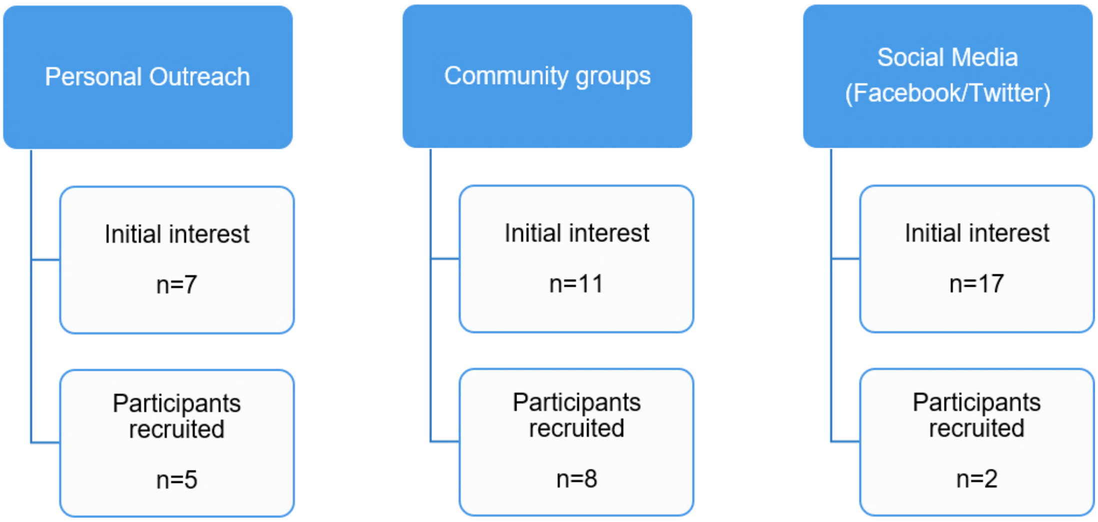

Figure 3.1 - Recruitment methods used, and associated participant interest, from November 2017 - July 2018.

3.3.3 Participant Sample

In total, 15 women, aged in between 25-62 years (M_{age} = 38.33, SD_{age}=10.77), took part in the present study. As we were looking for views towards cervical screening participation, those who are ineligible for screening (i.e. not between 25-64 years, do not participate in screening on medical grounds) were excluded from taking part in this study. All participants took part in one-to-one semi-structured interviews, apart from two participants who requested to be interviewed together. One interview took place over the telephone.

In line with previous research (Douglas et al., 2016; O'Carroll, Shepherd, Hayes, & Ferguson, 2016) area-level relative deprivation was used as a measure of socioeconomic status and determined by postcode via the English Index of Multiple Deprivation (IMD) 2015 (Ministry of Housing Communities and Local Government, 2015). Using this measure, participants place of residence is ranked between 1 (10% most deprived areas in England) to 10 (10% least deprived areas in England; see section 1.1.4 for more information on the use of the Index of Multiple Deprivation). All participants lived in areas classified as falling within the 30% most deprived areas in the country. However, the majority of participants (N=12) lived in areas that are known to be of particularly high relative deprivation (i.e. within the 20% most deprived areas in the country). Seven participants were native to the U.K, the remaining eight participants were migrants from the Irish Republic (N=1), Libya (N=3), Bangladesh (N=2), Pakistan (N=1) and Sudan (N=1). Prior to the interviews, all participants reported that they had previously attended, and were up to date with their routine cervical screening appointments. An overview of sample characteristics are presented in Table 3.1 below. As the demographic details provided are comprehensive, an overview by participant is not included to maintain anonymity.

Table 3.1 Characteristics of the sample (n=15)

Characteristic	**Total** ***n* (%)**
Age (Mean + SD)	38.33 (10.77)
Ethnicity	
White	7 (46.7%)
Asian	3 (20.0%)
Black	1 (6.7%)
Other	4 (26.7%)
Nationality	
U.K Native	7 (46.7%)
Non-Native	8 (53.3%)
Overall Deprivation Decile*	
1 – Most deprived in England	7 (46.7%)
2 – Second most deprived in England	5 (33.3%)
3 – Third most deprived in England	3 (20.0%)
Education (N=1 missing)	
Secondary School	4 (26.7%)
College	1 (6.7%)
University undergraduate	4 (26.7%)
University Postgraduate	5 (33.3%)
No Education	1 (6.7%)
Occupation	
Student	2 (13.3%)
Working full-time	2 (13.3%)
Working part-time	5 (33.3%)
Unemployed	3 (20.0%)
Other	3 (20.0%)
Previously attended	
Yes	15 (100%)
No	0 (0%)

3.3.4 Data collection

This study was granted ethical clearance through Northumbria University's Ethical Approval System (ref: 770). Further details on the setting and context of this study are available in section 1.6. Participants were given a copy of the participant information sheet to read prior to arranging the interview (see Appendix D for examples of ethical documents). On the day of the interview, participants were taken to a quiet room, and were given the opportunity to read the information sheet once again. Following this, they had the opportunity to ask any further questions, before reading and signing the consent form. The participant completed a brief demographic questionnaire and the interviewer then indicated the recording would begin. A digital voice recorder was used to record all interviews. One interview took place over the telephone, as per participant request. This participant received and completed ethical documentation and the associated questionnaire via email.

The interviewer used a semi-structured interview schedule to explore participant's experiences of, and views towards, routine cervical screening. The aim of this schedule was to guide conversation around relevant topics or issues related to screening attendance whilst still allowing participants to discuss or express factors that were particularly relevant to their circumstance. This schedule was loosely informed by the findings of a previous systematic literature review (see Chapter 2), touching upon the role of the individual (e.g. screening related knowledge: 'Can you tell me about the purpose of routine cervical screening?'), social networks ('How do your friends and family feel about cervical screening, in your opinion?'), the healthcare environment ('Do you feel comfortable with the health professionals carrying out the test?') and wider society ('How do you think the media portrays cervical screening?'). Public Health England (Public Health England, 2019d) state that screening related disparities can become apparent at various points throughout the screening pathway, thus the main body of questions were structured to explore the stages of participation (i.e. receiving the invitation letter, attending the appointment and after the appointment/waiting for results).

The schedule was refined after the first 4 interviews to facilitate natural conversational flow and remove repetitive questions. A full copy of the interview schedule is included in Appendix E. Interviews took in between 20 mins – 1 hour. When the interviews were completed the recording device was stopped, participants were thanked and debriefed.

3.3.5 Data analysis

Template Analysis (TA; King, 2012) was used to analyse the qualitative data. TA is aligned with a contextual constructivist stance and takes a thematic approach to organising qualitative data, attaching codes (i.e. meaningful labels) to the text, which in turn allow for the identification of recurrent themes across participant responses. These themes are organised into a hierarchical template which reflect the content of the qualitative data, and also the relationship between themes. To promote transparency and rigour, the analysis strategy for the present study was as follows:

Recorded interviews were transcribed and anonymised by giving each participant a number and removing any identifying information. Transcripts were then read through repeatedly so the researcher could further familiarise themselves with the data. Four broad *a priori* themes were defined (*The Individual, Social Networks, Healthcare Environment and Wider Society*), in keeping with the findings of the previous systematic review (as detailed in Chapter 2) and following initial familiarization with the recordings/transcripts. Beginning the analysis with relevant (and importantly, flexible) *a priori* themes is common in Template Analysis to support and build upon existing knowledge (Brooks et al., 2015). Relevant sections of the transcriptions were coded in NVivo v.12 and attached to the *a priori* themes. Example coding is included in Appendix F. From these themes, further hierarchical subsets of themes were developed to produce a thematic template. Following another reading of the data the initial template was again applied to the whole dataset. Two themes were renamed

(‘The Individual’ was renamed ‘Personal Motivation’ and ‘Social Networks’ was renamed ‘Community’) and one theme removed (‘Wider Society’) to ensure the template adequately fit the data. From this a final template of themes was produced (see Figure 3.2).

3.4 Results

This study aimed to explore cervical screening related experiences for those living in areas of high relative deprivation and identify factors that influence participation. All women reported that they were up to date with screening prior to taking part, however during the course of the interviews it became apparent that many had previously postponed appointments and did not attend in line with NHS guidelines, with one participant disclosing that she had left her only appointment without being screened. Three overarching themes were developed from the transcripts, highlighting *Personal Motivation*, *Community* and *The Healthcare Environment* as important factors that drove screening participation within women living in areas of high relative deprivation. There were strong links/interrelationships between themes (For example, *The Healthcare Environment* was often discussed in relation to participants’ emotional responses to screening, and thus was linked to *Personal Motivation* to attend). To accurately reflect participant’s everyday life, these links are referenced throughout the subsequent description of findings. Highlighting interrelationships in this way is important to demonstrate the complex multi-level nature of screening participation. The full thematic template is presented in Figure 3.2. All themes are described and discussed in further detail below. Quotes are presented alongside participants’ age and (self- identified) ethnic and migrant status to give as much context as possible without compromising anonymity.

1.0 Personal Motivation
- 1.1 Emotional responses to screening
  - 1.1.1 Embarrassment
  - 1.1.2 Fear
- 1.2 Screening related beliefs
  - 1.2.1 Importance of screening
  - 1.2.2 Personal risk of cervical cancer

2.0 Community
- 2.1 Social support
  - 2.1.1 Giving support
  - 2.1.2 Receiving support
- 2.2 The experiences of others

3.0 The Healthcare Environment
- 3.1 Relationships with staff
- 3.2 Women-centred care

Figure 3.2. Final thematic template outlining factors that influence routine cervical screening participation for women living in areas of high relative deprivation.

3.4.1 Personal Motivation

Emotional response to screening

Throughout the interviews, participants discussed aversive emotional responses they experienced in relation to screening participation.

Embarrassment

Feelings of embarrassment, related to the personal nature of the test, was a common barrier to participation. Screening was compared to childbirth, with the connotation that those who had children should not experience embarrassment related to the procedure, although this was not necessarily always the case.

> *"[The screen-taker] goes, 'Oh you know, you've had babies don't feel embarrassed', and I said 'Well I'm in pain then I want to get the baby out. Now*

> *I'm not in pain, I'm not comfortable and I'm embarrassed to just...you know, spread my legs and some woman do something there…..For me, it's just like embarrassment, just opening up the legs and letting somebody do it...I don't know it's just [laughs]. Having a baby, that's different."* -P9, Asian Native.

Fear

Participants indicated increased negative affect when there was little familiarity with the procedure; in particular, test related fear was exacerbated when participants had little or no prior knowledge of the screening procedure or environment.

> *"I think it's not knowing what it's going to be like 'cause I really didn't know what to expect. I hadn't been for any screening like that previously, so I really didn't know what to expect. I didn't know whether it was going to be with a female nurse, or a male doctor, or a female doctor. I didn't know who was doing the screening, or how many people were in the room, or even how it was done to be honest. I really had no clue. So, for me, it was just the anxious feeling of, 'Oh God, what's this going to be like? How long is it going to take?'."* – P3, White Native

Others had concerns about the potential negative outcome; one participant likened cervical screening to the NHS bowel screening programme and suggested that avoidance of screening services was common amongst her social network due to fear of a negative result.

> *"It's like the bowel screening isn't it. There's loads of people I know who've never done it…cause they don't want to do it. They're frightened to do it in case they've got bowel cancer."* – P1, White Native

Screening related beliefs

Importance of screening

All participants were keen to point out that they believed screening to be an important procedure that could potentially save lives and allowed women to better understand their own health status. Even when women were not fully aware of the purpose of the test, they believed it was important to participate.

> *"[Screening] is best way and best idea, after you sure you are healthy. Otherwise, if you no have the screening test then what happens inside, you don't know."* – P11, Asian Migrant.

> *'To be honest, I'm not sure exactly the medical…I can't remember the medical reason why it's done but I know it's important to be done.'* – P8 Arabic Migrant.

Personal risk of cervical cancer

Despite the general belief that it was an 'important' test, women expressed variable beliefs surrounding their own personal cervical cancer risk. For some, the belief that screening was important was underpinned by personal experiences of abnormal results.

> *'It's high on my...I definitely want to get it done. Mainly because of having the abnormal screen...I dunno know how I would feel if I hadn't had that in the past*.'
> - P2, White Native

Conversely, one participant described how she did not attend screening for many years as she felt that she was not at risk of developing cervical cancer;

> *"I wasn't interested, I said 'What the hell is that? Smear test? Cervical Cancer? No, it's not going to happen to me'"* – P9, Asian UK Native

However, she believed that her chance of developing cervical cancer had increased with age and thus felt she was more likely to attend in future as a result.

> *"…When next [screening appointment] comes, we'll see what happens. I think now I will get it done because I'm getting older and menopause and all these things coming up. You know, your body change so, there could be more risk or chance".* – P9, Asian UK Native.

3.4.2 Community

Social support

Receiving support

Social support appeared to be a factor which positively influenced engagement with routine cervical screening participation. This usually came in the form of a family member or friend who had encouraged the participant to attend or attempted to reduce their fears surrounding the test.

> *"I think I was at home when the letter came. I think my mum was there, so I said, 'Oh I've got the letter' and said I was nervous about it, and then she was saying, 'Oh don't be, it's over really fast"* –P6, White UK Native

Migrant women discussed the importance of spousal support, particularly in terms of translating letters and helping them to understand the aim of the programme that they were invited to attend. One participant, who had never been screened, expressed resentment that her husband had not discussed screening with her, in line with others in the community.

> *"…my husband, he should talk with me more to do it, more to do it, but he doesn't do that…. This is important, this is...you know I'm not happy about it. It is important that husband talk with wife about this."* – P13, Arabic Migrant.

Changes in support were able to motivate participants to attend even after many years of postponement. One participant described screening as something she would never have discussed with family during the earlier years of her life, however a family member suggesting they attend together, recently motivated the participant to participate.

> *“I didn't go for about two, three [appointments], about six years, and it was last year she said, 'Come on, let's both of us have it done'…I said, 'Ok then, both of us will go and have it done'. And I'm glad I did it actually.”* –P9, Asian, UK Native

Giving support

Those who attended promptly felt it was important to encourage others to participate in cervical screening and appeared to get altruistic benefits for doing so.

> *“I think everybody is got every opinion but when they talk to me, I said, 'Go. Do it. It's good for me, good for you and good for everyone.’ It's so important for us. I told them to do it.”* – P10, Arabic Migrant

> *“[Cervical Screening is] really, really important. It makes me feel really proud to know that other people care about those sorts of things! And also helps me to feel good for caring about it myself.”* -P4, White Migrant

In contrast, one participant who reported often postponing her appointments, suggested she did not discuss screening with others and did not think it was appropriate to encourage others to attend as it was personal decision.

> *“I wouldn't talk about my...myself going for smears. I don't think it concerns anybody but me. [I wouldn’t] …discuss it with anybody, no. It's up to them what they do. It's up to me what I do.”* – P1, White UK Native

The experiences of others

Participants also discussed stories they had heard or seen in the wider social context, relating to others’ experiences with screening and/or dealing with the outcome of screening. This usually referred to ‘scare’ stories in the media with some participants highlighting the Jade Goody story.

> *“One thing that stuck in my mind though, talking about stories in the media...remember when it was Jade Goody? When she was diagnosed and I think that was widely publicised and everyone saw how much she suffered towards the end, and how awful it was. So, I think that always sticks in my mind whenever I think, Ooh maybe feel a bit nervous going or when I put it off a bit.”* – P6, White, UK Native

Others mentioned stories from people they knew personally. In most cases these were stories of negative outcomes relating to cervical cancer, and often served to encourage women to attend. However, there was an awareness that such stories may also make some too frightened to participate.

> *“…say if I go and have my smear it's because I know people who haven't had them, so I know what's happened to them because they didn't have it. But that can have an opposite effect…If they know something's happened it's like, 'Oh, I don't wanna go and find [that] out myself'. So, just because it's worked out that way for me, it doesn't mean it's gonna work that way for everyone else.”* – P7, White UK Native

3.4.3 The Healthcare Environment

Relationships with staff

All participants referred to the relationships they had with staff, often independent of the actual screening test, and described some important qualities that appeared to positively shape participant’s experiences and perceptions relating to cervical screening participation. Those who attended regularly spoke about the friendly, open approach of staff that had helped to put them at ease and increase trust within the healthcare environment.

> *"The doctor that I seen, she was really kind, she was really nice, and she spoke to me about everything and she told me exactly what she was going to do so it put me at ease. You know, it was in and out within a couple of minutes, so it was fine."* – P5, White Native

One participant, who had postponed her first appointment, described her positive experience and reflected on the influence healthcare staff could have had on her feelings toward cervical screening.

> *"I think if I went in there and I had a different experience and I felt rushed, or they weren't very...if they didn't ask if I was OK, or if I needed any more information about [the procedure], I think I would have continued to feel dread, and I would've been tense and it wouldn't have been a very nice experience. So, I think the fact that they were patient, and happy to talk about it, really, really helped."* – P3, White Native

The majority of migrant women were keen to compare their experiences of healthcare within their home countries, to that which they received, and had access to, here. They discussed negative past experiences, and expressed gratitude for the services offered in the U.K.

> *"I'm so...so appreciative from this country because they knows what we need. Like, breast cancer, they check when you are age. So, in our country when you are not feeling [well], go and check, and get the money, lots of money cost, some people doesn't go because it cost lots. This country is so happy, we are so happy because they [healthcare practitioners] knows what we need."* - P10, Asian, Migrant.

In contrast, one participant said she was still undecided on when to return to screening as she was upset about losing a trusted doctor at her local practice and as a result did not feel she had anyone to discuss concerns with.

> *“I'm still thinking [about attending screening]. No, do you know why? Because a long time ago I was with my doctor...I'm upset about my doctor, she's gone. No, which doctor now? Which doctor? But I was very happy with that doctor and I miss her. I really miss her. I talk with her like my family, everything.” -P13, Arabic Migrant.*

Women-centred care

Participants mentioned the importance of women-centred care and how this increased positive feelings and experiences surrounding screening. It was suggested that the perception of care being generalised, rather than ‘*by women, for women’* may be problematic. For example, those who perceived male practitioners as a possibility, and in addition who did not have good levels of communication with their practice, may postpone or decline on this basis.

> *“Men don't have it, so why should they want to know about it? I know that's a really stupid thing, but they won't experience it, they won't know anything about it, so why would they want to go into that profession? And why would you want a man looking at it? I dunno, I'm a bit weird about it.”* – P5, White Native

> *“Maybe [Muslim women] are scared, do you know? Because we're all Muslim and there's specific things...that the nurse has to be woman, things like that...so maybe, some of them maybe receive this letter but they don't want to go...what if the nurse is a man?”* – P8, Arabic Migrant

One participant had attended a sexual health clinic, rather than her GP surgery and participated in screening at the same time as receiving contraception. She suggested this holistic form of female focused care made screening participation ‘easy’.

> *“[Accessing screening] was easy for me, because I was in...I had a consultation about contraceptives...So they were like, 'Do you want to do it?' and I was like, 'Yes', 'Cool, let's do it now’*– P4, White Migrant

3.5 Discussion

3.5.1 Principal findings

This study aimed to highlight experiences of routine cervical screening participation for those living in areas of high relative deprivation and identify specific factors that influence participation within this group. Analysis resulted in three broad determinants of participation: *Personal Motivation*, *Community* and *The Healthcare Environment*. Overall, *Personal Motivation* tended to be a barrier to screening attendance. Positive interpersonal connection within the *Community* and *The Healthcare Environment* facilitated attendance. There was also a suggestion that a lack of such connection, hearing negative experiences from others and/or overly clinical and impersonal healthcare settings had the potential to exacerbate motivational barriers, demonstrating the interactive nature of determinants.

All participants demonstrated an awareness of routine cervical screening programmes. In addition, all expressed beliefs that screening attendance had clear health benefits and as a result, held intentions to participate. Despite this, some described postponing or ‘putting off’ their actual attendance for months and, in some cases, years. Thus, awareness of the screening programme, and the associated health benefits, was not always enough to translate positive intentions into action. Although the literature on this topic is scant, intention-behaviour gaps have previously been evidenced in relation to cervical screening participation (Orbell & Sheeran, 1998; Sheeran, 2002). More recently, Marlow, Chorley, Haddrell, Ferrer, & Waller (2017) highlighted the large proportion of women who do not attend screening in line with guidelines, despite holding positive intentions to participate; demonstrating that this group accounts for the majority of cervical screening non-participants. Moreover, those from lower social grades were disproportionately likely to postpone attendance in this way. Within the present study, low personal motivation to screen appeared to directly exacerbate postponement. As in previous literature (Strack et al., 2004), motivation in this context refers to both cognitive (reflective) and emotional (automatic) processes. Feelings of embarrassment and/or fear, as well as low perceived risk of cervical cancer resulted in reduced motivation to attend promptly and led to participants ‘putting off’ screening rather than consciously declining to take part. The present findings therefore add to the current body of knowledge by providing insight into factors which may influence the cervical screening related intention-behaviour gap, within areas of high relative deprivation. Overall, these findings suggest that whilst awareness and knowledge of screening-related health benefits are critical to achieving informed decision making, actual screening attendance requires additional motivation. Interventions to increase pro-screening behaviour, for those living within areas of high relative deprivation, should therefore include techniques known to target motivational factors.

In addition to individual level thoughts and feelings toward participation, it appeared that positive interpersonal factors within both the community and the healthcare environment, buffered the effects of reduced personal motivation to engage in screening services. For example, participants who attended promptly still often expressed aversive emotional reactions to screening participation but attended following social support and/or because they had good relationships with their healthcare providers. Conversely, those with less social support or more clinical, impersonal perceptions of the healthcare environment expressed increased fear and/or embarrassment. Whilst cervical screening is often thought of as a personal, individualised procedure, these findings suggest interpersonal factors are an important factor in encouraging prompt engagement with screening services. These findings support those discussed earlier in this thesis and further highlight social support as a key factor in encouraging cervical screening participation within areas of high relative deprivation. Indeed, evidence has previously demonstrated the benefits of social support in relation to breast cancer screening (Jensen et al., 2016). Targeting social determinants of screening may increase personal motivation to attend in line with guidelines and could therefore also be valuable in reducing the aforementioned intention-behaviour gap. To this end, it may be beneficial to explore how aspects of social support can be modified within areas of high relative deprivation, particularly for migrant groups who may already experience reduced social networks and language barriers (Kang et al., 2019; Koelet & De Valk, 2016).

Alongside these interpersonal factors, the present findings also more generally highlight the importance of the healthcare environment. Participants indicated that they preferred women-centred settings and, although female screen-takers are extremely common, there were still some concerns about the possibility of a male practitioner being present at their screening appointment. These preferences and concerns have previously been raised as barriers to screening attendance for those within areas of socioeconomic disadvantage (Logan & McIlfatrick, 2011; Peters, 2010) and amongst ethnic minority groups (Abdullahi et al., 2009; Anaman-Torgbor et al., 2017). These findings support the view that screening attendance is not solely the responsibility of the individual; healthcare providers have an important role in creating a female focused healthcare environment that supports and encourages screening attendance. Thus, interventions to address socioeconomic based inequalities in cervical screening participation should take a multi-pronged approach and aim to tackle barriers at the individual, social and organisational level.

Overall, these findings reflect and support those in the systematic review detailed within the previous chapter and have highlighted determinants that are deemed important for those living in areas of high relative deprivation. They also add additional understanding in regard to the important influence of social factors. From the perspectives of those within the target population, social influence and support (from both family members/friends and healthcare professionals) appears to facilitate engagement with screening services and thus should be considered a key mechanism by which to encourage positive change in screening behaviours.

3.5.2 Strengths and limitations

This interview study provides important insight into routine cervical screening participation as experienced by those who are least likely to attend (i.e. those living in areas of high relative deprivation, inclusive of ethnic minority and migrant groups). There is currently limited qualitative data on the factors that influence cervical screening uptake within areas of socioeconomic disadvantage in the UK. Therefore, the present piece of research addresses an important gap in current literature, highlighting screening from the perspectives of those who are traditionally seldom heard. The diversity of the sample is also considered a strength of the study, addressing pervasive under-representation of ethnic minority groups in health research (Gill & Redwood, 2013). As such, findings reflect a range of experiences and perspectives within areas of socioeconomic disadvantage, and thus are not exclusively related to the views of native White women.

However, these findings should be considered in light with study limitations. Firstly, there were language barriers between the researcher and participants for whom English was not a first language. This at times, led to difficulty accessing detailed participant views. Some researchers advocate the use of interpretation services to allow participants to discuss topics in their own language, although this approach also comes with challenges and ethical considerations (Plumridge et al., 2012). Thus, researchers should carefully consider which approaches are most suitable for the topic at hand. As the present study was focused on sensitive personal experiences, and participants had no objections to discussing their views in English, it was felt an interpreter was not a requirement in this circumstance. Moreover, given the paucity and lack of diversity in qualitative research of this nature, it was important to include those for whom English was not a first language, particularly as language barriers are often cited as hindering engagement in screening services (e.g. Abdullahi et al., 2009; Addawe et al., 2018; Chiu et al., 1999; Gele et al., 2017). Excluding these participants would therefore have reduced the diversity of the sample and omitted important insights from those who have increased barriers to accessing screening services.

In addition, participants self-reported their screening status prior to the interviews, which should be interpreted with caution. Previous research suggests that participants may not accurately remember whether they are overdue screening appointments or not, particularly within low-income or minority groups (Anderson, Bourne, Peterson, & Mackey, 2019; Klungsøyr, Nygård, Skare, Eriksen, & Nygård, 2009). However, the design of the present research helped to both identify and address this limitation somewhat, as participants were given the opportunity to discuss previous screening experiences with a researcher in greater depth after completing the pre-interview questionnaire. This therefore highlighted potential disparities in screening status and allowed the researcher to gain more accurate insight into participant's screening related behaviour than from a questionnaire alone. Indeed, as mentioned in section 3.4, all participants reported that they had previously attended, and were up to date with screening, yet further discussion during the interviews revealed 5 participants had postponed or 'put-off' arranging their appointment at least once in the past, sometimes for a number of years. One participant also highlighted that she had changed her mind during her only screening appointment and left without the procedure being completed. It should also be noted that, in this case, the potential inaccuracy of self-reported current screening status does not detract from the main focus of the present research; identifying factors which influence screening participation.

Finally, it is of note that a large proportion of the participant sample (60%) reported they had a university level education. Given participation in higher education is generally around 19% within the most deprived areas of the UK (Wiseman et al., 2017) this sample was not fully representative of a typical socioeconomically disadvantaged population. Nonetheless, the perspectives and experiences of those living in areas of high relative deprivation should not be discounted simply because they are educated to a greater degree than is typical within their social context. Previous research demonstrates that area-level (i.e. postcode-based) deprivation predicts engagement in health behaviours even when controlling for individual measures of socioeconomic status (Halonen et al., 2012), which signifies the importance of neighbourhood characteristics, such as social and cultural norms, on health behaviours. Indeed, the present study highlights social influence (i.e., Community) as one of the most important determinants of cervical screening participation. As such, the perspectives detailed here remain valuable in understanding factors that influence cervical screening participation for those living within areas of high relative deprivation, but perhaps could be strengthened by additional complementary qualitative work with a broader range of educational backgrounds.

3.5.3 Recommendations for future research

These findings present a number of avenues for further research. The majority of participants were recruited via established community groups. While this was a valuable method of accessing participant views, there are many living within areas of socioeconomic disadvantage who do not readily access, or engage with, community group settings. Particularly in light of the sensitive nature of the present research, it may be useful to consider additional methods of data collection to complement the present findings and access perspectives of those who may not engage via community organisations. For example, the growing use of online survey methods (Terry & Braun, 2017) may offer a more easily accessible alternative for individuals to provide insight into their thoughts and opinions surrounding cervical screening participation. Researchers should further consider how these data collection methods may be of use when aiming to collate perspectives from marginalised groups.

It would also be valuable to discuss these findings with stakeholders to further ensure factors identified here accurately reflect the experiences and perspectives of socioeconomically deprived communities. When aiming to develop behaviour change interventions, it is also important to gain a sense of which strategies, techniques and modes of delivery are acceptable and feasible given the context in which they are to be delivered (Michie et al., 2014). Collaborative stakeholder discussions of this nature could help to develop this shared understanding and facilitate the identification of suitable intervention routes to increase cervical screening uptake in areas of high relative deprivation.

3.5.4 Conclusion

This study aimed to explore the factors influencing routine cervical screening uptake within areas of high relative deprivation. Through 15 semi-structured, one-on-one interviews, women living in areas of high relative deprivation discussed their thoughts, feelings and experiences surrounding cervical screening participation. Data analysis developed three, over-arching factors that were important in determining prompt participation within this group; *Personal Motivation, Community* and *The Healthcare Environment*. *Personal motivation* was generally described as a barrier to screening participation, sometimes resulting in participants postponing (rather than declining) their screening appointments, in some cases for months and/or years. However, positive interpersonal factors within an individual's *Community* and *Healthcare Environment* facilitated personal motivation to attend cervical screening in line with guidelines. Whilst individual level barriers are routinely reported in related literature, this study emphasises the facilitative nature of social connection and support in encouraging cervical screening uptake in areas of high relative deprivation. Moreover, these findings highlight that determinants of screening exist at multiple levels, thus attempts to address screening related inequalities should target individual, social and organisational level factors. Future research should aim to further explore these determinants with stakeholders, to identify acceptable and feasible routes to increasing uptake. From a methodological perspective, community-based recruitment was most useful in connecting with those from traditionally under-served populations. However, it is of note that there are many living within areas of socioeconomic disadvantage who do not readily access, or engage with, community group settings. Additional accessible methods of data collection should also be explored to maximise engagement with those who are seldom heard.

3.5.5 Chapter Summary

Guidance from the Medical Research Council Framework (for developing complex interventions; Craig et al., 2008) states that intervention developers should develop a detailed understanding of the target behaviour of interest, tailored to the relevant context. The present chapter aimed to develop a deeper understanding of routine cervical screening attendance within areas of high relative deprivation, and identify factors influencing participation. Via analysis of 15 semi-structured interviews with women living within areas of high relative deprivation, *Personal Motivation*, *Community* and *The Healthcare Environment* were identified as important factors that may be valuable to target for intervention. Taken together, these findings suggest a multi-level approach to increasing uptake is needed, with social determinants appearing particularly beneficial in increasing personal motivation to screen. Given the majority of participants were recruited via community groups, it would be useful to enlist complementary methods of collecting participant views, to ensure those not engaging in community services have an opportunity to be heard. The following chapter therefore aims to offer an alternative route for participants to share their views and experiences whilst also providing an opportunity to further reflect upon data collection methods that might best access the views of those from disadvantaged communities.

4 Understanding attitudes towards cervical screening participation.

4.1 Synopsis

The previous chapter explored cervical screening related experiences within areas of high relative deprivation and identified factors influencing participation. This chapter presents a study which uses online survey methods to a) further explore attitudes towards cervical screening participation and b) provide an alternative method of engaging those living in areas of high relative deprivation. Recruitment and data collection methods will be presented in-depth, as the challenges and successes of these methods will be reflected upon within the discussion section.

4.2 Background

The previous chapter demonstrated that, within areas of high relative deprivation, cervical screening participation is influenced by factors at the individual, social and organisational level. Broadly, negative thoughts and feelings towards cervical screening participation appeared to encourage intention-behaviour gaps in uptake, with participant's social networks, and their healthcare environments, having the potential to either exacerbate or alleviate these individual level, motivational barriers. This research fills an important gap in knowledge in providing specific insight into the factors influencing participation within areas of high relative deprivation in the UK. However, given the paucity of the current evidence base, it would be useful to conduct additional research in this area, to further understand current attitudes towards participation. Exploring supplementary methods of recruitment and data collection in this way would also be valuable in light of the difficulties faced in recruiting those living in areas of high relative deprivation (see section 3.3.2).

The challenges of recruiting socioeconomically disadvantaged populations are well-established within academic research (Bonevski et al., 2014; Stuber, Middel, Mackenbach, Beulens, & Lakerveld, 2020). Indeed, the term “hard to reach” is often used to refer to groups who have social and/or economic challenges in comparison to the general population and thus can be difficult to access. These “hard to reach” populations are diverse, and describe a number of, often intersecting, sub-populations within society e.g. ethnic minority groups, those living with a disability, those living in poverty and so on. As such, it is important for researchers to clearly define the specific population of interest when conducting any research of this nature. Within the present chapter, “hard to reach” populations refer to those who are least likely to access and engage in routine cervical screening; women living within areas of high relative deprivation, inclusive of ethnic minority and migrant groups. In light of the recruitment challenges faced in previous research, it is important to consider ways in which to best access the views and perspectives of this population, to increase the evidence base and support future research with socioeconomically disadvantaged groups.

4.2.1 Accessing “hard to reach” populations

A variety of psychosocial factors have been put forward to explain the lack of research engagement within hard-to-reach groups. In line with traditional psychological theory, such as the Theory of Planned Behaviour (Ajzen, 1991), poor engagement in academic research has been attributed to negative attitudes and beliefs toward academic research and researchers. For example, Bonesvki et al., (2014) reviewed literature which outlined barriers to engaging socially disadvantaged groups in health and medical research. This research found those within socially disadvantaged communities may experience high levels of mistrust toward research and researchers, perceive little personal or community benefit from their participation and/or believe research participation may increase poor treatment, stigma or exploitation towards them or others within their community. There is also the additional problem that individuals may simply be disinterested in engaging with research which focuses on health services they are often already disengaged from (Rockliffe et al., 2018).

However, whilst such evidence (and indeed the label of being “hard-to-reach”) infers these populations demonstrate a lack of interest or ability to engage in academic research, it can also be argued that academic research is designed and conducted in a way that is inaccessible for those who are unfamiliar with traditional academic and/or research process. In fact, recent evidence suggests that those from “hard to reach”, or more accurately, marginalised groups often do appreciate the value participating in health research, and are motivated to do so, yet lack awareness of actual research opportunities and/or feel these opportunities are communicated in a way that is not suitable for their needs or preferences (e.g. Erves et al., 2017; Sadler et al., 2010). In this way, the methods researchers use can also hinder recruitment of those traditionally underrepresented in health-related research. Rockliffe et al., (2018) argue that it is important for researchers to detail their (failed and successful) recruitment strategies to benefit the qualitative research community, and reduce spending unnecessary time and resources on approaches that are unlikely to engage, or be appropriate for, the specific population of interest. Despite this, reporting of, and reflection upon, such factors are currently lacking within published literature thus resulting in ambiguity in how best to design research studies which are acceptable and accessible for those in marginalised populations. More careful consideration of chosen approaches are therefore needed to encourage research which can effectively access the perspectives of those from socioeconomically disadvantaged groups.

4.2.2 Determining suitable methods of data collection and recruitment

When aiming to explore or uncover relatively unheard perspectives, the methods of recruitment and data collection should be carefully considered to ensure that chosen approaches do not exclude those that are traditionally marginalised (Harkins et al., 2010). Yet, as indicated above, there is limited discussion surrounding which methods are most suitable to engage those living in areas of high relative deprivation, particularly in the context of cervical screening participation. Qualitative approaches are often used to access and encourage detailed opinions and perspectives from those within traditionally marginalised groups (Arpey, Gaglioti, & Rosenbaum, 2017; Boland, Mattick, McRobbie, Siahpush, & Courtney, 2017; Curmi, Peters, & Salamonson, 2016; Mitra, Long-Bellil, Iezzoni, Smeltzer, & Smith, 2016). As outlined in Chapter 3, face-to-face community based methods can be useful in this respect (see also Erves et al., 2017; Harkins et al., 2010). However, traditional interview-based methods are resource intensive and direct contact with an relatively unknown researcher may be a barrier for some participants when discussing potentially sensitive or embarrassing topics, such as cervical screening (Davis, Bolding, Hart, Sherr, & Elford, 2004; Ellard-Gray, Jeffrey, Choubak, & Crann, 2015; Valerio et al., 2016). Devising complementary methods of data collection may help to address these limitations and increase participation for those who interview methods are not suitable.

Online methods of recruitment (and indeed data collection) are an increasingly used resource-light approach which allows for far-reaching recruitment of participants in a relatively short space of time (Braun & Clarke, 2013; Laws et al., 2016). Widely used social media sites such as Facebook for example, are now often used as a path to participant recruitment and have been shown to be an effective approach in engaging underrepresented groups in academic research. For example, Kayrouz, Dear, Karin and Titov (2016) demonstrated that Facebook recruitment was an effective and valuable recruitment method in accessing ethnic minority groups. Similarly, online qualitative surveys are being increasingly implemented to explore sensitive topics in-depth, without the need for direct contact with the researcher (see Terry & Braun, 2017). The anonymity of such methods may also lead to less inhibited responses (Jowett, Peel, & Shaw, 2011). These methods have been shown to be successful in recruiting hard to reach groups (Evans, Elford, & Wiggins, 2008; Horrell, Stephens, & Breheny, 2015; Levine et al., 2011), although the suitability of online methods in exploring screening participation, within those living in areas of high relative deprivation, is yet to be determined. As such, employing online methods in the present research may have benefits not only for further exploration of the topic at hand, but also be informative for researchers looking to reach and engage similar populations in discussing cancer screening participation.

4.2.3 Rationale and aims

Online methods of recruitment and data collection are believed to be useful in engaging those who are underrepresented in health-related research. It would therefore be useful to explore these methods of data collection and recruitment to determine whether they would be useful in engaging women living in areas of high relative deprivation. The present study had two aims 1) to explore attitudes towards routine cervical screening participation and 2) to explore whether an online qualitative survey is a useful approach to engage women living in areas of high relative deprivation. Recruitment methods will be fully described to allow for a reflection on the challenges (or successes) in engaging the target population. The main research question was, ‘What attitudes do women hold towards routine cervical screening participation?’. In light of the second aim we also asked, ‘Is an online qualitative survey a useful approach to engage women living in areas of high relative deprivation in discussing cervical screening participation?’.

4.3 Method

4.3.1 Approach

Study 3 took a predominately qualitative approach, using an online survey, as a brief, anonymous pathway to engage those living in areas of high relative deprivation and allow for exploration of respondent’s views towards routine cervical screening participation. This approach was chosen to enable the researcher to easily collect a wide range of data, whilst including open-ended questions to encourage participants to include information they feel is important and relevant to their own social contexts (Frith

& Gleeson, 2008; Terry & Braun, 2017).This is reflective of the contextual constructivist stance of the thesis which is presented in section 1.5, in that responses provided reflect the social context of participants and are also interpreted in light of the researcher's own background and experience (see Appendix A for a researcher positionality statement).

While this approach results in both qualitative and quantitative data, the textual responses are the primary focus of the study and will be analysed in line with the principles of Template Analysis (King, 2012). Quantitative data (in the form of frequency counts) will be collected to aid the interpretation of qualitative data and demographic background of the sample (Opperman, Braun, Clarke, & Rogers, 2014). As a predominately qualitative study, this research is reported in line with SRQR guidance (O'Brien et al., 2014). A checklist is included in Appendix C.

4.3.2 Recruitment Methods

Recruitment took the form of two social media-based advertisements as detailed below. Across both approaches, a financial incentive was offered to encourage participation (Kennedy & Ouimet, 2014). Financial incentives within research are often viewed as ethically contentious; some argue that offering monetary incentives constitute undue influence or coercion, particularly when the sample group includes those who are of low socioeconomic status (Grady, 2001; Largent, Grady, Miller, & Wertheimer, 2012). However, others have provided empirical evidence that payment for research participation does not unduly influence decision-making, and argues that withholding appropriate financial incentives due, for example, socioeconomic status raises significant ethical concerns in itself (see Resnik, 2019). In light of this, incentives were retained in line with departmental ethical guidance, in the form of an optional prize draw. As such, all participants who completed the survey in full were given the option to enter a prize draw for a £50 Love2Shop voucher.

4.3.2.1 Focused social media advertisement

Recruitment advertisements, aimed to specifically target those living in areas of high relative deprivation, were posted on social media from March-April 2018 (Twitter and Facebook). Given the large proportion of women who postpone screening (Marlow et al., 2017), we initially focused on recruiting individuals who were currently over-due, living within five local areas of high relative deprivation in the North East of England (see Appendix G).

This advertisement was seen a total of 2,492 times on Twitter, with 42 direct engagements (e.g. expanding the information within the tweet, clicking on media/links within the post). This recruitment advertisement was also ‘shared’ by three charities who work within/alongside socio-economically deprived communities within the North East of England. This method of recruitment did not result in any participants.

Although detailed viewing information was not available for the Facebook recruitment post, this was also shared by 7 personal Facebook users and also by a charity organisation which works with local women to tackle social and financial exclusion. Although it was not possible to determine how many individuals read this post; the aforementioned charity organisation has a following/community of 533 people. After almost two months of recruitment 7 participants accessed the survey with only 4 reaching completion.

4.3.2.2 Generalised social media advertisement

Following the lack of engagement from the focused advertisement, it was felt that naming specific areas and recruiting those as ‘overdue’ may have been overly restrictive (particularly as potential participants may not necessarily remember or identify with being overdue their screening appointments; Klungsøyr et al., 2009). As such, an inclusive approach was taken, and recruitment was widened to include any female who was eligible for cervical screening in the UK (i.e. aged in between 25-64 years and registered with a GP in the UK; see amended advertisement in Appendix G).

The demographic detail collected within the survey would still allow us to determine screening status and area-level relative deprivation (calculated by participant postcode). Given the researcher's socioeconomic background (See Appendix A), this amended recruitment advertisement was posted from April - May 2018, solely on the researcher's personal Facebook account, to increase the likelihood of recruiting participants from areas of high relative deprivation. This post was shared by 15 other personal Facebook accounts. This revised sampling strategy substantially increased recruitment with an additional 66 individuals accessing the survey.

4.3.3 Participant Sample

A total of 73 participants accessed the survey. Nine participants did not complete the survey and thus were removed prior to analysis.

The final sample consisted of 64 participants aged in between 25-64 years (M_{age}=34.73, SD_{age}= 8.48). Participants were predominately White (n=62), educated to degree level or above (n=53) and estimated their annual household income above 15,000 (n=54). Area-level relative deprivation was determined by postcode via the Index of Multiple Deprivation 2015 (Department for Communities and Local Government, 2015) The IMD assigns each postcode in England to a deprivation decile (1 = 10% most deprived to 10 = 10% least deprived). These deciles were then categorised into quintiles (as in Douglas et al., 2016) to facilitate exploration of any response patterns linked to area-level relative deprivation. Nine participants did not enter complete postcodes thus area-level relative deprivation could not be calculated for these participants. In line with the inclusive approach of the study, the responses of these participants were still included within the qualitative analysis as their views and experiences were still deemed valid to the main study aim (i.e. understanding views towards cervical screening participation). Overall, there was wide variation in area-level relative deprivation, with 11 participants (20% of the eligible sample) classified as living within the most deprived quintile. We calculated screening status (i.e. overdue or up to date) by participant age and last screening attendance. An overview of sample characteristics are presented in Table 4.1 below.

Table 4.1 - Demographics of the sample (n=64)

Characteristic	**Total** ***n* (%)**
Ethnicity	64 †
White	62 (96.9)
Black	1 (1.6)
Asian	-
Mixed Race	1 (1.6)
Other	-
Education	64 †
Secondary School	4 (6.3)
College	7 (10.9)
University undergraduate	20 (31.3)
University Postgraduate	33 (51.6)
Annual household income	63†
£15,000 or less	9 (14.3)
£15,001-19,999	8 (12.7)
£20,000-29,999	9 (14.3)
£30,000-39.999	13 (20.6)
£40,000 – 49,999	7 (11.1)
£50,000 – 59,999	5 (7.9)
£60,000 +	12 (19.0)
Deprivation quintile	55 †
Q1 (most deprived)	11 (20.0)
Q2	11 (20.0)
Q3	10 (18.2)
Q4	9 (27.3)
Q5 (least deprived)	7 (14.5)
Ever attended screening	64 †
Yes	58 (90.6)
No	6 (9.4)
Ever postponed screening	64 †
No	15 (23.4)
Once	15 (23.4)
Occasionally	24 (37.5)
Always	10 (15.6)

Characteristic	Total *n* (%)
Up to date with screening	64 †
Yes	45 (70.3)
No	15 (23.4)
Unsure	4 (6.3)

† - number of respondents.

4.3.4 Data Collection

This study was granted ethical clearance through Northumbria University's Ethical Approval System (ref: 7836). Data collection took place in between March – September 2018. Information, consent and debrief documents can be found in Appendix H. Interested individuals were required to click on a link to a Qualtrics survey accessible via any PC/Laptop or mobile phone in any location with internet access. After providing informed consent, participants were asked to complete demographic information (reported in Table 4.1) and an online 'interview schedule'.

This online interview schedule/survey was developed as a shortened version of the interview schedule within study 1 (see section 3.3.4). As qualitative surveys can be more cognitively and emotionally taxing than quantitative surveys included questions were short and clear whilst retaining the opportunity for elaboration (see Terry & Braun, 2017) The overall length of the survey was intentionally brief to reduce participant demand.

Specifically, nine multiple choice questions were included, accompanied by free text response boxes where the participant was prompted to expand further on their responses. Three of these multiple-choice questions related to participants past screening behaviour ('*Have you ever attended routine cervical screening?*', '*When did you last attend cervical screening appointment?*' and '*Have you ever postponed or 'put off' making your appointment?'*) Of the six remaining questions, one related to future screening intention ('*Are you likely to attend cervical screening when next invited?*'), two broadly captured attitudes towards screening participation (e.g. *'Do you feel there are any advantages to cervical screening participation? 'Do you feel there are any disadvantages to cervical screening participation?)* and three related to potentially influential factors of screening uptake; exposure to cervical screening related media (Macaarthur et al., 2011) (*'Have you noticed any cervical screening campaigns or information in the media; for example in newspapers, on TV/radio or on social media sites such as Facebook?'*), social influence (Azerkan et al., 2015) ('*Has a family member ever encouraged you to have cervical screening?*') or knowledge/awareness of the programme (Logan & McIlfatrick, 2011) (*'Are you aware of the routine cervical screening programme in the UK?'*). The full online survey can be found in Appendix I. Upon completion, participants were given the option to be redirected to separate survey whereby they provided an email address to enter a prize draw. The survey took approximately 10 minutes to complete.

4.3.5 Data Analysis

Data was exported from Qualtrics into SPSS v.25.and Nvivo v.12 to facilitate comprehensive analysis of participant responses. As detailed in section 3.3.5, Template Analysis (TA; King, 2012) was used to analyse qualitative data. One of the first steps of TA consists of developing an initial coding template. As we were initially interested in understanding the attitudes of women living in areas of high relative deprivation, responses from those living within the most deprived quintile (n=11) were extracted from the main sample, read and re-read and inductively coded to develop the initial coding template (see Appendix J). Following this, the researcher repeated this analysis procedure against the remaining dataset; firstly, reading and re-reading participant responses, and then coding qualitative survey responses in line with the initial template. An example of survey responses are provided in Appendix K. Whilst the initial coding template was a good fit for the remaining responses, there was increased elaboration regarding the '*Psychological barriers to attendance'* theme, thus further sub-themes were added. When all responses were coded, this 'final' template was applied again to the whole dataset, to ensure the themes were reflective of participant’s overall responses. The integrative theme ‘*Past experiences are important’* was added at this stage, as this aspect of the data permeated across all thematic clusters. The final thematic template is presented in Figure 4.1 below.

Frequency counts were calculated for quantitative data via SPSS v.25, to aid and contextualise interpretation of qualitative data (see Appendix L for an overview). As in other research using qualitative survey methods (e.g. Opperman et al., 2014), our focus was not on *comparison* or testing of group differences, but on understanding views toward cervical screening participation within a socioeconomically diverse sample.

4.4 Results

The present study asked, ‘What attitudes do women hold towards routine cervical screening participation?’. The final thematic template (Figure 4.1) consisted of two main themes; 1) *Screening is worthwhile* 2) *Screening can be difficult to access.* An integrative theme (see Brooks & King, 2014), *Past experiences are important,* was also developed to reflect the influential role of personal experience in determining attitudes towards, and future engagement in, cervical screening. Themes are discussed in more detail below with supporting quotes and frequency counts. Participant’s current screening status and deprivation quintile (Q) are presented alongside quotes (Q1 is highest deprivation and Q5 is lowest deprivation). For those who did not provide a valid postcode, the deprivation quintile is marked as unspecified.

1.0 Screening is worthwhile

2.0 Screening can be difficult to access

- **2.1** Appointment making
- **2.2** Practical access to services
- **2.3** Psychological access to services
    - 2.3.1 Expectations of screening appointments
    - 2.3.2 Emotional challenges of attendance

A1 Integrative theme - Past Experiences are important

Figure 4.1 - Final thematic template outlining participants' attitudes towards routine cervical screening participation.

4.4.1 Screening is worthwhile

Overall, respondents had a strong awareness of the preventative benefits of routine cervical screening; indeed 63 participants (98.4%) felt there were benefits to screening with 54 participants (84.4%) suggesting that they were likely to attend their next screening appointment. Participants described screening as a procedure that saved lives and allowed for the detection and early treatment of abnormalities.

> *'It is well known that cervical cancer is a 'silent killer' as there are little to no symptoms of having this. Having a routine smear test / screening is the best way to check you are healthy (down below!) And if anything further needs to be investigated.'* – P32, Up to date, *[Q unspecified]*

> *'It's quite good really that it's a pro-active test, that the NHS offers this routine test on such a wide scale. It's important in case you do have abnormal cells, to detect them early and stop their progression into something more serious or sinister down the line.'* – P37, Up to date, Q3.

Only one respondent said they were ‘unsure’ of whether there were any benefits to screening as they *‘didn’t know anything about it’* (P19, Unsure of last attendance, Q1). However, it is notable that some of the perceived benefits of screening were often rooted in incorrect beliefs i.e. that the purpose of the test was to detect cervical cancer and therefore could be treated in a timely manner.

> ‘…*regular screening means you are more likely to detect cancer sooner so making it more treatable*’. – P9, Never attended, *[Q unspecified].*
>
> *‘It will detect cervical cancer and therefore prevent women dying or undergoing unnecessary invasive treatment’* – P23, Overdue, Q4.

4.4.2 Screening can be difficult to access.

Whilst almost all respondents suggested screening participation was beneficial, the majority (n=49, 76.5%) reported postponing or ‘putting off’ screening at least once, with 10 participants (15.6%) reporting that they ‘always’ postponed their screening appointments. Participants often intended to participate in screening but practical difficulties making appointments and physically attending screening services facilitated postponement. Just under half of respondents (n=29, 45.3%) also felt there were disadvantages to participation; most of these related to the negative emotions and experience of participating in the test. Similarly, when asked whether they were likely to attend their next screening appointment 4 respondents selected ‘no’ and 6 selected ‘unsure’. These responses were often linked to a general sense that screening ‘feels inaccessible’ (P51, Unsure of last attendance, Q1). The different challenges to accessing screening are described in more detail within the sub-themes below.

4.4.2.1 Appointment making

Many participants referred to the difficulty of arranging a suitable appointment with their doctor’s surgery, citing this as a key reason for postponement. The current method of booking an appointment (i.e. by calling up the local GP surgery) appeared to be particularly off-putting. Some suggested that amendments to this current system, for example the option of online booking, would encourage attendance.

> *'I can't book an appointment online; I have to make a phone call which often involves sitting on hold for ages. If I could book online, I would probably procrastinate less.'* – P56, Overdue, Q3.

> *'Having to call up and make the appointment [is a disadvantage to screening], the appointment that I did attend was made in person when I was visiting the GP for another reason. Had the GP not booked me in then I wouldn't have got around to calling up myself.'* – P22, Up to date, Q5.

In addition to the above, participants also indicated that there were difficulties obtaining a suitable appointment when they did call the surgery. This often exacerbated negative feelings towards screening and thus was an additional reason for 'putting off' screening attendance, sometimes for years.

> *'It can be difficult to get an appointment within the timeframe needed to get the screening. Usually I call a couple of times and then will just put it off for a couple of years.'* – P59, Up to date, *[Q unspecified].*

> *'[I] have had three smears at the GP and hospital within a space of eight months and was due to go back every 6 months to the hospital as CIN 1 cells kept showing. But when trying to rebook there was no availability and the longer I left it the more scared I became.'* – P4, Up to date, Q1.

The combination of juggling personal and appointment availability meant accessing screening services was a challenge, and thus deemed a disadvantage to screening participation.

> *'[A disadvantage of screening is] having to work out when to book appointments for and call the doctors, only for them to have nothing available at the right times'.* – P2, Overdue, Q1.

4.4.2.2 Practical access to services

As an extension to difficulties arranging an appointment, some participants went on to indicate that there were also other practical barriers to engaging in screening services. These practical barriers mainly referred to ‘finding time’ to attend the appointment, especially alongside work commitments and childcare responsibilities. It was intimated that screening was an inconvenience which felt inaccessible for those who had complex responsibilities.

> ‘…*aside from giving up my job, friends and other commitment[s] there is no way for me to get more spare time to make appointments’.* – P9, Overdue, [Q unspecified].

> ‘*I have 3 children and a full-time job, trying to arrange an appointment without using holiday is difficult’* – P21, Overdue, Q2.

One participant suggested that it was easier to postpone screening than to search for a suitable time.

> *‘…there are always so many other things to fit into a busy life that it's easy to put screening off.’* – P61, Overdue, Q5.

The lack of alternative screening locations was also briefly mentioned as a barrier to engagement. Alternative settings in which to be screened gave women more choice and flexibility in regard to arranging/attending appointments.

> *‘Make it so there is a choice of place to be screened. [My local area] have stopped offering the service at sexual health clinics, therefore restricting women's choice and making it hard to attend an appointment’.* – P47, Up to date, Q1.

4.4.2.3 Psychological access to services

4.4.2.3.1 Expectations of screening appointments

Participants held a number of negative beliefs and expectations around the screening test and the appointment itself describing it as *'inconvenient'*, '*invasive*', *'painful'* and '*unpleasant*'. Some also suggested that the screening environment was too '*formal*', '*scary'* and '*clinical*' which in turn exacerbated the unpleasant nature of the test. In particular, there was some concern about the approach of the staff who carried out the tests.

> *'I already have an outstanding invitation which is over a year old. I must make an appointment but know as it contains a general health check that I will get a lecture about my weight and sedentary lifestyle (I am at the very top end of the healthy/normal BMI bracket). When I get my weight down, I will go. I hate being patronised'*– P61, Overdue, Q5.
>
> *'Make the staff nicer, less likely to judge you. To make horrible comments'* – P62, Up to date*, [Q Unspecified].*

4.4.2.3.2 Emotional challenges of attendance

Screening participation appeared to elicit strong, aversive emotions from participants. Participants described experiencing anxiety and fear in anticipation of the procedure and outcome, fear of experiencing pain, embarrassment and feelings of vulnerability.

> *'I think that the only time I would show my genitals to a nurse or doctor would be if I had a serious, painful issue, I don't think I could make myself go through it if I have an option'* – P19, Unsure of last attendance, Q1.
>
> *'[I am] too anxious to deal with any abnormal results.'* – P53, Overdue, *[Q unspecified].*

Whilst anticipated and/or experienced emotional challenges of attendance were clear barriers to engaging in screening services, some believed the health benefits and '*peace of mind'* outweighed negative screening related emotions.

> *'The 'embarrassment' of undertaking [cervical screening] is outweighed by how important it is to find any potential issues'* – P50, Up to date, Q5.

> *'It hurts (me at least), It's embarrassing. The advantages (i.e. knowing that your cervix seems healthy) far outweigh the disadvantages'* – P60, Up to date, Q4.

However, some women were concerned that screening attendance had the potential to reignite previous trauma and felt that screening services were ill-equipped to deal with these complex cases.

> *'I think there should maybe be something in place for people who have had traumatic experiences to encourage them into attending screenings if possible. Unsure what that might look like; however, we need to recognise that fear and trauma is a big part of why people may not attend'.* – P42, Up to date, Q4.

> *'I have Post Traumatic Stress Disorder caused by rape. I found it difficult to access a sympathetic GP to address my mental health needs. I also found it difficult to access services provided for physical health due to my condition. e.g. breast screening in a caravan - I can't do confined spaces, I don't like being physically touched. I cannot even begin to imagine what sort of conversations I would need to have to enable a cervical smear without fearing being re-traumatised. At no point has anyone asked me why I haven't attended, nor have I ever seen any sign of reassurance if (and there will be many other women) have suffered sexual violence'* – P51, Unsure of last attendance, Q1.

4.4.3 Past experiences are important

This final, integrative theme permeated all thematic clusters, highlighting the significance of screening related experiences in determining participant's attitudes, beliefs and emotions towards screening participation. Experiencing pain, particularly in conjunction with poor patient-provider relationships, gave participants a negative view of screening services and screen-takers, and was justification for postponing future attendance.

> *‘Nurses need to respect that women can know their own body and what they need. I have had a nurse insist on using a larger speculum than needed because she refused to believe that I knew from past experience what works for me’. – P52*, Up to date, Q4.

> *‘The appointments aren't the greatest. Depends on what nurse/doctor you get. Some are extremely rushed and rough. Puts you off going. When I went the nurse couldn't find my cervix as I'd had surgery that had meant it was the size of a pinhead. She proceeded to put bigger and bigger sizes of implements in without asking if I was ok until I finally screamed with the pain.’* – P39, Up to date, *[Q unspecified].*

Painful past experiences could be a significant barrier to re-engaging with the service even when participants were aware of the health risks associated with non-attendance.

> *‘I know that by not attending I may be putting myself at risk, but I simply cannot bear to go through that horrendous experience again.’* – P23, Overdue, Q5.

Previous abnormal results had a variable influence on participants. Overall, previous abnormalities highlighted the value of the test (as participants would not have been aware of these abnormalities had they not attended) and encouraged prompt future engagement.

> *‘After my very first screening I had to go to hospital for abnormal cells. Since then I've had routine screenings on a yearly basis and book them straight away to ensure everything is still okay.’* – P42, Up to date, Q4.

> *'[I] had a previous abnormal smear, so always keep up with the schedule.'*
> – P20, Up to date, Q4.

However, some experienced increased fear and anxiety following treatment for abnormal cells and were more hesitant to return as a result.

> *'After my first smear when I was 24, I received the abnormal results. I then attended a colposcopy clinic for further investigation, which showed high grade change/grade 3 cells. Over an entire year I received treatment...I put off my following smears only for maybe a few weeks, due to fear really. The fear of finding abnormal cells again and having to go through the painful treatment I had in the past.'* – P33, Up to date, Q1.

4.5 Discussion

The present study aimed to a) understand attitudes towards cervical screening participation and b) consider whether online methods are useful in engaging those living in areas of high relative deprivation. These aims will be discussed separately below.

4.5.1 Understanding attitudes towards cervical screening participation

The present research explored women's attitudes to routine cervical screening participation. Although there were initial challenges recruiting those who lived in areas of high relative deprivation; these findings give insight into widely held opinions on cervical screening participation, suggesting that screening is perceived as a valuable test, but often difficult to access due to multiple, complex practical and psychological factors.

Most predominantly, participants held the belief that screening was a psychologically and emotionally challenging procedure, expressing negative affective beliefs/expectations (i.e. that screening was and/or will be unpleasant and invasive) and anticipating strong aversive emotional challenges of participation (i.e.

embarrassment, fear and anxiety). Fear of pain, anxiety and embarrassment are routinely reported as barriers to screening attendance (Oscarsson, 2012) and have been discussed in-depth throughout the preceding chapters. The present findings add further complexity by outlining conflict between cognitive-based evaluations of screening participation (i.e. that it is important and has value) and affective evaluations of the test (i.e. that it is unpleasant, anxiety-inducing and so on).

Affect has been shown to influence health-based intention and behaviour beyond that of cognition when there is an internal attitude conflict (Lawton, Conner, & McEachan, 2009). Moreover, anticipated affective reactions have also been shown to predict a range of health behaviours (Connor, McEachan, Taylor, O'Hara, & Lawton, 2015). Although this is less explored in relation to cervical screening participation, the present findings support those in the previous chapter, suggesting that screening-related negative affect may encourage postponement even when individuals hold positive intentions to screen i.e. an intention-behaviour gap (Marlow et al., 2017; see Sheeran & Webb, 2016). The vast majority of respondents perceived value in the procedure (and intended to participate in future screening), but did not always promptly schedule screening appointments, with most reporting they had postponed more than once. Interestingly, some believed that feelings of relief or 'peace of mind' following the test, outweighed the aversive emotional aspects and promoted prompt participation. This supports the potentially facilitative role of anticipated relief in promoting cancer screening behaviour (Shepherd et al., 2017). It may therefore be useful to assess the predictive power of anticipated relief in the context of the cervical screening intention-behaviour gap.

Another key finding of the study was the influence of external factors on screening participation. In discussing the barriers to participation, respondents outlined difficulties in scheduling suitable cervical screening appointments; broadly related to appointment making and/or navigating complex lifestyle demands and priorities. Recent research demonstrates that the vast majority of women book their screening appointments via telephone, with the difficulty of getting through to the receptionist desk commonly cited as one of the most important barriers to participation (Ryan, Waller, et al., 2019). Online and text-message based reminders and appointment booking options increase the ease of accessing cervical screening services and show promise in encouraging uptake for those who wish to attend (Kitchener et al., 2018; Ryan, Marlow, Forster, Ruwende, & Waller, 2019). Indeed, the desire for online booking was highlighted within the present study, supporting the development and implementation of technology-based appointment systems. However, the present findings indicate that even when individuals access appointments, poor availability can be a challenge, particularly alongside busy work and home lives. While online appointment booking undoubtedly has benefits for both patients and healthcare providers (see Zhao, Yoo, Lavoie, Lavoie, & Simoes, 2017), there is currently unprecedented pressure on general practice, with many patients unable to access services when needed (Baird, Charles, Honeyman, Maguire, & Das, 2016; Swann et al., 2018; Wise, 2018). This reinforces the need for wider scale intervention beyond the individual level; focusing on service provision and commissioning of flexible appointment choices (Regan, Music, Martin-Hirsch, & Kasliwal, 2019).

As well as outlining both internal and external barriers to participation, the present findings demonstrate the underlying perception that healthcare providers are not able to adequately support women in managing the psychological impact of participation. This was particularly evident when participants referred to the role of past trauma (e.g. sexual abuse/violence) and anxieties around re-traumatisation. Participants felt the invasive nature of cervical screening could potentially trigger additional psychological trauma and it was believed healthcare providers were not equipped to support women with these increased psychological needs. This concern mirrors recent evidence whereby screen-takers have reported a lack of training and anxiety working with women who have experienced previous trauma (Walker & Allan, 2014). In addition, there is a growing body of literature which highlights high rates of non-attendance and increased psychological barriers to screening for those who have experienced past trauma (Cadman, Waller, Ashdown-Barr, & Szarewski, 2012). Although it is difficult to establish the percentage of the general female population who are affected by such issues, recent figures suggest more than 1 in 10 women have experienced sexual assault in childhood, and 1 in 5 women have experienced sexual assault since the age of 16 (although this percentage could be even higher, given that such figures rely on disclosure; Office for National Statistics, 2017). Again, this reflects the clear need for healthcare providers to promote a safe and supportive screening environment to all women to ensure those who do not wish to disclose or discuss previous trauma are unintentionally excluded from participating. Trauma-informed care and an increased focus on the psychological impact of screening should also be incorporated into existing training for screen-takers.

Participants also often referred to past screening related experiences to support and/or justify the perception that current screening services were unable to adequately meet the needs of service users. Those who had negative experiences with staff and/or painful screening procedures described increased negative affective beliefs and emotion-based barriers to re-attendance. In a minority of cases, participants felt their past experiences were so upsetting that they did not feel able to return. Previous experience of screening is an intuitively significant factor in future screening engagement and has been previously cited as a determinant of re-attendance (Abdullahi et al., 2009; Marlow, Waller, et al., 2015). Within both the present study and previous literature, patient-provider relationships were key in determining the quality of individuals experience; supportive, informative contact within the healthcare setting is likely to encourage future screening behaviour and also reassure individuals who have had previous abnormal results (Peterson et al., 2016; Thangarajah et al., 2016). Given that cervical screening is a repetitive health behaviour (albeit with 3-5-year intervals), it is critical to further explore provider-level determinants of screening uptake, to facilitate screening spaces where individuals feel safe and supported to return for future, as well as first-time, screening.

4.5.2 Accessing the perspectives of those within areas of high relative deprivation

The secondary aim of the current research was to determine whether online methods of recruitment and data collection were a useful approach to engage women living in areas of high relative deprivation.

The recruitment strategies implemented within the present study resulted in a total of 64 participants. Initially, we took a targeted approach to online recruitment, focusing the study advertisement toward those who were currently over-due screening living within specific areas of high relative deprivation. This purposive approach was used to directly promote opportunities for research participation towards seldom-heard groups, in line with previously documented concerns that marginalised groups are not informed of relevant opportunities to participate (Erves et al., 2017). However, this approach was not effective in recruiting the target population within a suitable time period. Indeed, only 4 participants completed the survey across March - April 2018, and only 11 participants within the final sample lived within the most deprived quintile (Ministry of Housing Communities and Local Government, 2015).

The poor uptake may have been for a number of reasons. Firstly, participants living within the specified areas simply may not have seen or been interested in participating within a cervical screening related online survey. Secondly, we particularly attempted to target those who were currently overdue their screening appointment. As highlighted above, women sometimes do not view themselves as non-attenders due to their intentions to participate and/or remember when they last attended screening (Azerkan et al., 2015; Klungsøyr et al., 2009; Marlow et al., 2017). Thus, upon reflection, the inclusion of this within the study advertisement may have been off-putting for potential participants.

Following the decision to take a more inclusive approach to recruitment, an amended form of snowball sampling methods was used; recruiting from the researchers personal (online) contacts, who in turn were able to share the survey with their own contacts, to increase the likelihood of engaging those from areas of high relative deprivation i.e., similar to the researchers own background. Snowball sampling methods have previously been recommended as an effective and acceptable supplement to purposive sampling methods (Atkinson & Flint, 2001; Valerio et al., 2016). While this method was useful in recruiting a larger number of participants, only 20% of those who provided an eligible postcode lived within the most deprived quintile. In addition to the potential reasons for low engagement explored above, the low proportion of participants living within the most deprived quintile may also be reflective of increased levels of digital poverty (i.e., lack of internet access, motivation to use the internet and/or digital skills; Watts, 2020), which have previously been observed within areas of high deprivation (Longley & Singleton, 2009; Yates et al., 2020). Whilst there is a growing recognition of the impact of digital poverty in relation to healthcare access and education, it may therefore be valuable to consider this aspect in greater depth in relation to community engagement and participation in research. In light of this, and to maximise participation in groups who are traditionally underrepresented, it may be useful to explore forms of recruitment that allow for greater face-to-face rapport building, especially given the aforementioned trust-based issues between marginalised groups and academic research (Ellard-Gray et al., 2015). Whilst there are potential issues with the resource and time intensive nature of community-based recruitment (e.g. Valerio et al., 2016), they allow for greater research-participant trust to be established and thus appear to be more suitable for recruiting those living within areas of high relative deprivation in comparison to online surveys (Rockliffe et al., 2018)

Nonetheless, the data collected via the online survey was valuable in accessing general attitudes towards cervical screening and provided insight into existing perceptions of healthcare services (which in turn were associated with screening participation). Although responses tended to be less detailed than traditional interview transcripts, participants referred to extremely sensitive aspects of screening participation that may not have been disclosed via face-to-face methods (i.e. the impact and role of past trauma and/or upsetting past experiences of screening). For these reasons, alongside the low-cost and potentially wide reach of online methods, it is important not to discount the value of online approaches but instead appreciate where they may (or may not) be most useful. The present study therefore suggests that online methods may be useful in accessing cervical screening related views and experiences but have less efficacy in accessing the specific perspectives of those living with areas of high relative deprivation.

4.5.3 Strengths and limitations

This study is the first to consider the value of an online qualitative survey in accessing attitudes towards cervical screening participation, within areas of high relative deprivation. Whilst there were challenges in recruiting those living in areas of high relative deprivation, the reflective detail presented within this chapter can contribute to an understanding of how online methods may be best used. In particular, the use of online methods resulted in a broad understanding of how cervical screening participation is presently viewed and demonstrated the conflict between cognitive and emotion-based evaluations of participating in this service. These findings also highlight the important role of provider level factors on individual level attitudes and emotions towards participation.

However, it is important to consider the value of this research alongside its limitations. As this was an anonymous, online survey, it was not possible for the researcher to clarify or expand upon participant responses, thus limiting opportunities for further contextualisation. Methods which incorporate more researcher-participant interaction may result in deeper exploration of thoughts and feelings and encourage shared understanding. Nonetheless, within the present study, it was not only important to access views towards cervical screening participation but also to explore the value of online methods in accessing traditionally hard-to-reach groups. Thus, it is argued that enlisting these methods resulted in valuable (i.e. methodological as well as topic-based) knowledge that offset the limitations of relatively brief qualitative responses. In future, the detail that may be lost by an absence of researcher-participant interaction should be carefully considered and balanced with the potential gains of employing online survey methods.

It is also notable that there was a lack of ethnic and educational diversity within the present sample, with the majority of participants indicating they were White and highly educated. It is likely that attitudes towards cervical screening and/or barriers to participation may differ in a more diverse sample (Marlow, Wardle, et al., 2015). Therefore, it is important to conduct further research which involves the perspectives of those from ethnic minority groups and/or those from more diverse educational backgrounds.

4.5.4 Recommendations for future research.

In line with the points raised above, it is recommended that researchers continue to explore acceptable and effective methods to engage socioeconomically disadvantaged groups in cervical screening related research. This is crucial in developing an understanding of factors that contribute to the social gradient in uptake. The present findings suggest it may be challenging to recruit this population via an online survey; methods which incorporate more focused rapport-building may be preferable. Thus, in line with related evidence, researchers should further explore the value of community-based methods in accessing views towards, and experiences of, cervical screening participation. To promote methodological advancements in engaging marginalised groups, it is also recommended that researchers continue to report detailed and reflective recruitment information, highlighting the challenges and successes of useful (and not so useful) approaches (see also Rockliffe et al., 2018). In this way, the research community can develop successful strategies for including the voices of those who are traditionally excluded from academic research.

The present findings also demonstrate the importance of provider-level factors in determining attitudes towards cervical screening participation. From a research perspective, it would therefore be valuable to explore experiences of cervical screening in greater depth, considering the psychosocial implications of women's interaction with healthcare providers and screening services. It remains important to explore this particularly within ethnic minority and socioeconomically disadvantaged groups, due to the increased patient-provider barriers reported within such populations (Arpey et al., 2017; Verlinde, De Laender, De Maesschalck, Deveugele, & Willems, 2012; Williams, Whitaker, Piano, & Marlow, 2019).

4.5.5 Conclusion

The present research aimed to explore two broad aims; to explore attitudes towards cervical screening participation and to determine whether a brief, anonymous online survey was a useful approach in engaging women living in areas of high relative deprivation. A total of 64 women completed the survey, from a broad range of socioeconomic backgrounds. Overall, findings suggested cervical screening participation is evaluated as a valuable, but psychologically challenging procedure. External factors such as patient-provider interactions and appointment accessibility and availability can increase psychological barriers to engagement and in turn hinder women from translating their intentions into action. From a methodological perspective, online qualitative survey methods were useful in accessing insight into the sensitive psychological side of cervical screening participation. However, these methods may not be appropriate in engaging the specific perspectives of socioeconomically disadvantaged and/or ethnic minority groups. These findings should therefore be complemented with face-to-face qualitative work, to access a range of detailed experiences and perspectives from those living in areas of high relative deprivation.

4.6 Chapter Summary

The present chapter aimed to explore attitudes toward cervical screening participation and determine whether online methods were a useful and acceptable approach to engaging women living within areas of high relative deprivation. Overall, this brief, online, qualitative survey highlighted conflicting attitudes towards cervical screening; whereby participation was deemed valuable but difficult to access from both a psychological and practical perspective. These findings therefore support those reported in the previous chapter, in that those who traditionally experience increased barriers to engaging in health services, may require multi-level intervention to reduce observed inequalities in cervical screening uptake. However, there were challenges recruiting women specifically living in areas of high deprivation. In line with previous evidence, approaches that incorporate the opportunity to develop researcher-participant rapport may be beneficial to explore in future studies. In conjunction with the previous chapters, these findings provide a good foundation for understanding factors that influence cervical screening participation. The following chapter aims to further examine these factors, specifying key targets likely to influence change and identifying acceptable and feasible routes to increase uptake.

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5 Addressing the barriers to cervical screening participation: a stakeholder perspective.

5.1 Synopsis

The previous chapters have identified determinants of routine cervical screening participation, relevant to those living in areas of high relative deprivation. The next stage is to specify which factors should be targeted, and link these to suitable strategies to increase uptake. To facilitate this next stage, the following chapter presents two studies which discuss the aforementioned findings with stakeholders, aiming to explore determinants in more detail with those living and working in areas of high relative deprivation, and identify acceptable and potentially feasible routes to intervention from both a community and professional perspective. Taking a community focused approach, focus groups were conducted within communities classified as being within the 10% most deprived areas in the UK, to further contextualise existing findings and develop a shared understanding of how best to address the barriers to screening participation. One-on-one interviews were then conducted with health-related professionals to give insight into the feasibility of the communities' suggestions. Alongside previous evidence, these findings will be taken forward and considered in line with established behaviour change theory to develop both community-informed and theoretically based intervention strategies.

5.2 Background

The previous chapters provide detailed qualitative evidence that socioeconomic inequalities in routine cervical screening attendance are a result of a variety of interacting, multi-level factors. Across studies, aversive attitudes and emotions towards participation, practical barriers to accessing screening appointments and a lack of interpersonal support have all been identified as potential barriers to engagement. It is well recognised that women's thoughts and feelings toward participation appear to have a direct influence on whether they attend their screening appointment promptly, or not. However, the aforementioned evidence demonstrates that these factors should not be considered in isolation; to adequately address inequalities in screening uptake it is imperative to consider screening participation within the wider context, and develop an understanding of how community, healthcare access and environment can shape and influence more proximal individualised determinants (Craig et al., 2018; Holman et al., 2018; Sorensen et al., 2003). Whilst the interviews and survey methods used in Chapters 3 and 4 have been valuable in gaining personalised accounts and perspectives in relation to cervical screening participation, further collaborative group-based discussion would be useful to validate determinants that have been highlighted as important throughout the previous qualitative work, help in fully embedding the identified determinants within the relevant social, economic and cultural context, and broaden understanding of how determinants act at both an individual and community level.

Focus group methodology is traditionally employed to encourage an exchange of ideas between participants, developing shared understanding and consensus which is not always possible during individual interviews or survey methods (Barbour, 2018). Employing this methodology within the present body of research would further involve communities and thus strengthen the ability to tailor any resultant intervention strategies to the context in which they are to be delivered (Ayala & Elder, 2011). As indicated above, this approach also has the added benefit of triangulating findings (i.e. collecting data from a variety of different methods, individuals and/or groups to increase depth of understanding and validity of findings; Carter, Bryant-Lukosius, Dicenso, Blythe, & Neville, 2014) and may help to iron out any existing misconceptions and misunderstandings on the part of the researcher, ensuring that research outcomes better reflect the priorities, needs and perspectives of the target population.

Gaining a more contextualised understanding of determinants is also critical when developing effective intervention strategies as it helps to avoid unintended adverse outcomes and identifies potential future implementation issues (Craig et al., 2018). However, such considerations can often be often-overlooked during intervention development, which can, in turn, risk misuse of time and resources (i.e. developing interventions that do not work in practice) and/or increase inequalities (McGill et al., 2015; White et al., 2009). For example, media campaigns which present screening as a ‘simple’ choice may increase barriers for those whom screening could trigger past trauma or those who experience increased practical barriers to uptake (Cadman et al., 2012; McGeechan et al., 2020). Involving community members to not only contextualise determinants, but also to make practical suggestions to address existing barriers and challenges may therefore be instrumental in gaining a formative understanding of acceptable approaches to reducing socioeconomic inequalities in participation.

Given that health-based interventions involve a wide range of stakeholders (i.e. those who would be interested in and/or affected by an intervention), community-based suggestions should also be considered in light of the organisational contexts in which they may be delivered, to determine whether they are practical, affordable and acceptable to any professionals involved in delivery or implementation. However, to ensure community groups are not inhibited in expressing their views towards healthcare providers and vice versa, it may be necessary to speak with community groups and healthcare professionals separately. Nonetheless, considering acceptability and feasibility related issues in the formative stages of intervention development, from both community and professional based perspectives, is likely to be a valuable step in facilitating efficient and effective intervention development (Ayala & Elder, 2011).

5.2.1 Rationale and aims

Previous research has identified a variety of factors which influence cervical screening participation in areas of high relative deprivation, at individual, social and organisational levels. Further group-based discussion with the target population encourages shared, in-depth, and contextualised understanding of inequalities in cervical screening participation. This approach also provides an opportunity to involve the community within the initial stages of intervention development and collaboratively consider acceptable routes to increasing participation within areas of high relative deprivation. Although it is important to prioritise the perspectives of the community (as they are traditionally seldom-heard in research of this nature; Bonevski et al., 2014), incorporating additional insight from health-related professionals would increase understanding of the feasibility of community-based suggestions and thus support future stages of intervention development.

To encourage community groups and health-related professionals to speak freely, both focus group and one-on-one interview methodology was employed across two stages. Firstly, community-based focus groups (Study 4a) were conducted to discuss determinants of screening participation in areas of high relative deprivation, and to consider acceptable ways in which to increase uptake. Following this, one-to-one, semi-structured collaborative interviews with health-related professionals (study 4b) were conducted, to discuss feasibility of community suggestions from a professional perspective. The findings from both Study 4a and study 4b will answer two broad research questions' 'Which factors influence cervical screening participation in areas of high relative deprivation?' and 'How might we best increase cervical screening participation in areas of high relative deprivation?'.

5.3 Method

5.3.1 Study 4a – Focus Groups

5.3.1.1 Approach

The present study took a qualitative approach to explore stakeholder views within the community. Focus group methodology was used to facilitate community-based consideration of the factors influencing cervical screening participation, and collaboratively explore acceptable approaches to increase uptake in areas of high relative deprivation. This approach therefore views knowledge surrounding the determinants of screening, and ways in which to increase uptake, as constructed and co-created between all participants (including the researcher) in light of their social contexts (see also section 1.5 for the overarching epistemological stance). A researcher positionality statement is included in Appendix A. Data was analysed using Template Analysis (King, 2012).

As in previous chapters, this research is reported in line with guidance from the Standards for Reporting Qualitative Research (SRQR) checklist (O'Brien et al., 2014). A checklist is included in Appendix C.

5.3.1.2 Participant Sample

A convenience sample of twenty-nine participants, aged in between 25-64 (M=40.86, SD=10.39), took part in the study across four focus groups. All focus groups took place within community venues that were situated within areas experiencing the highest levels of relative deprivation (i.e. 10% most deprived areas in England as identified by the IMD, 2015) and included one staff member who was already familiar to the participants and worked within the community organisation. The remaining focus group members were members of the local community who attended the community venue with varying regularity and had informally indicated that they were interested in taking part during the researcher's previous community engagement work. Overall, the majority of the sample were White British (37.9%), had a college education (44.8%), were currently unemployed (65.5%) and had an annual household income of £15,000 or less (75.0%). Most participants (82.8%) reported they had previously attended and were up to date with screening, with 3 reporting that they had never attended and a further 2 reporting that they were overdue. An overview of demographics by focus group is presented in Table 5.1 below.

Table 5.1 - Demographics of the sample, split by focus group.

n (%)	Group 1 (n=5)	Group 2 (n=14)	Group 3 (n=6)	Group 4 (n=4)	Total (n=29)
Mean age (age range)	38.80 (26-51)	43.21 (27-64)	42.33 (26-60)	33.00 (25-42)	40.86 (25-64)
Ethnicity					
White (British)	5 (100)	4 (28.6)	-	2 (50.0)	11 (37.9)
White (Other)	-	-	6 (100)	-	6 (20.7)
Black	-	1 (7.1)	-	1 (25.0)	2 (6.9)
Asian	-	7 (50.0)	-	-	7 (24.1)
Mixed Race	-	-	-	1 (25.0)	1 (3.4)
Other	-	2 (1.3)	-	-	2 (6.9)
Education					
Secondary School	1 (20.0)	5 (35.7)	4 (66.7))	-	10 (34.5)
College	4 (80.0)	6 (42.9)	1 (16.7)	2 (50.0)	13 (44.8)
University undergraduate	-	2 (14.3)	1(16.7)	2 (50.0)	5 (17.2)
University Postgraduate	-	-	-	-	-
No education	-	1 (7.1)	-	-	1 (3.4)
Occupational status					
Working full time	1 (20.0)	1 (7.1)	1 (16.7)	-	3 (10.3)
Working part time	2 (40.0)	-	2 (33.3)	1 (25.0)	5 (17.2)
Student	-	1 (7.1)	-	-	1 (3.4)
Retired	-	-	-	-	1 (3.4)
Unemployed	2 (40.0)	11 (78.6)	3 (50.0)	3 (75.0)	19 (65.5)
Annual household income	4[a]	10[a]			24[a]
£15,000 or less	2 (50.0)	9 (90.0)	5 (83.3)	2 (50.0)	18 (75.0)
£15,001-19,999	1 (25.0)	-	1 (16.7)	-	2 (8.3)
£20,000-29,999	1 (25.0)	-	-	2 (50.0)	3 (12.5)
£30,000-39.999	-	1 (10.0)	-	-	1 (4.2)
£40,000 +	-	-	-	-	-
Ever attended screening					
Yes	5 (100.0)	12 (85.7)	6 (100.0)	3 (75.0)	26 (89.7)
No	-	2 (14.3)	-	1 (25.0)	3 (10.3)

n (%)	Group 1 (n=5)	Group 2 (n=14)	Group 3 (n=6)	Group 4 (n=4)	Total (n=29)
Up-to-date with screening					
Yes	4 (80.0)	11 (78.6)	6 (100.0)	3 (75.0)	24 (82.8)
No	1 (20.0)	3 (21.4)	0 (0)	1 (25.0)	5 (17.2)

[a] – number of participants who completed this section

5.3.1.3 Data collection

This research was granted ethical clearance through Northumbria University's Ethical Approval System (ref: 770). Further details on the setting and context of the present research is available in section 1.6. Four focus groups (FG) discussions were conducted in between May and June 2018, within community venues with around 5 participants in each. This only differed in FG2 whereby 14 individuals participated, due to a larger number of individuals than expected arriving at the day and time of the focus group. Information was presented to participants both verbally and in paper format prior to participants signing consent forms and completing demographic questionnaires (See Appendix M for copies of ethical documents and Appendix N for additional study materials). Information was presented in English and verbally translated into participants' native language by a staff member, if requested. All focus groups were conducted in English, except FG3 which was conducted in Romanian at the request of the participants. This was assisted by one participant who had professional experience of acting as an interpreter. Focus groups were intended to be informal and flexible to increase engagement. However, discussions focused on two broad areas; discussing factors that influence screening participation within the community and considering ways in which to increase participation (See Appendix N). Focus groups lasted in between 1-2 hours.

5.3.1.4 Preliminary Data Analysis

Audio recordings of focus group data were transcribed by the author and analysed in line with Template Analysis (King, 2012). Two broad *a priori* themes were developed to answer the research questions; *barriers to cervical screening* and *suggestions to improve participation.* Transcripts were read and re-read, and preliminary coding took place. Codes were considered alongside previous study findings and grouped into a hierarchical preliminary thematic template of key barriers and suggestions (See Appendix O). These preliminary themes were then used to develop materials for Study 5.

5.3.2 Study 4b – One-on-one interviews

5.3.2.1 Approach

Following the community-based focus groups and preliminary analysis of data, one-on-one interviews were conducted with health-related professionals to gain an initial understanding of the feasibility of communities' suggestions from a professional perspective. One-to-one interviews were selected to allow participants to freely describe their own thoughts and related experiences within an organisational context. In line with previous studies in this thesis, Template Analysis (King, 2012) was used to analyse participant responses.

5.3.2.2 Participant Sample

A purposeful sample of 5 health related professionals took part in semi-structured, one-on-one interviews. All interviews were conducted face to face apart from one which took place over the telephone, at the participant's request. To reflect the wide range of professional stakeholders associated with cervical screening uptake, participant's roles spanned research, practice and community-based organisations. All participants were female and reported that they had previously attended, and were up to date, with cervical screening themselves. Further details of participant's job roles and experience are outlined in Table 5.2.

Table 5.2 - Participant job roles and experience (n=5)

Participant	Job Role	Years in role	Relevant Experience
1	Project Manager for Health-based charity.	10 years	Conducted community-based research project on barriers to cervical screening engagement. Involved in projects which focus on inequalities in health.
2	Network Co-ordinator for health and race inequality focused community organisation.	1.5 years	Works with voluntary sector and advises health sector on health inequalities. Involvement in cancer screening boards.
3	Practice Nurse (NHS)	6 years	Community-based healthcare practitioner and screen-taker.
4	Trainee Health Psychologist (NHS)	3 years	Research experience in health service engagement, and patient-practitioner communication.
5	Cervical screening facilitator (NHS)	Not provided	Previous practice nurse experience. Training and assessment of screen-takers including offering support and guidance to those who carry out cervical screening. Involvement in initiatives to increase screening in marginalised groups.

5.3.2.3 Data Collection

This research was granted ethical clearance through Northumbria University's Ethical Approval System Interviews (ref: 9392). Participation was voluntary and all participants contacted the researcher to take part following advertisement flyers (See Appendix P) and word of mouth. Due to the nature of the recruitment, ethical approval from NHS Health Research Authority was not deemed necessary. One-on-one interviews were conducted between April and July 2019 in a mutually agreed upon, quiet location. Ethical documentation was completed prior to the interviews (See Appendix Q for copies of ethics documents). Four interviews were audio-recorded. One participant requested that their voice was not audio-recorded on the day of the interview, as they were concerned this would compromise their anonymity. Field notes during the interview were agreed upon between researcher and participant, as an alternative form of recording this participant's responses. The researcher began the interview with a brief, informal presentation of the barriers to screening engagement identified throughout previous qualitative work, and highlighted intervention suggestions from those living in areas of high relative deprivation (i.e., the results from Study 4a). This presentation included the participant's quotes to prompt focused discussion. A broad topic guide was also developed to loosely guide discussion around the feasibility of intervention suggestions (see Appendix R for study materials). Interviews ranged in length from 30-60 minutes.

5.3.2.4 Data Analysis

Audio-recorded data was transcribed, and responses were read and re-read to familiarise the researcher with the data. To link together both community and professional perspectives, and therefore gain a fuller understanding of stakeholder suggestions, all of the transcribed data from both Studies 4a and 4b were coded again in line with the principles of Template Analysis (King, 2012). The thematic template developed during preliminary analysis of focus group data was used as an initial *a priori* coding template. However, this remained flexible and open to amendments throughout the whole coding progress (see Appendix S for example coding). In-depth analysis resulted in refinements to the thematic template (e.g. one of the higher-level theme *Barriers to cervical screening* was renamed *Determinants of cervical screening*) to better reflect some facilitative factors discussed during the focus groups and interviews, and to include factors that could either help *or* hinder participation (e.g. the impact of social influence depends on whether this is positive or negative). Themes were also expanded upon and renamed to better express the overarching concepts discussed by participants. For example, *Practical difficulties in accessing services* was further specified, with data categorised under the theme titles *Competing demands* and *Prioritisation of screening*. This thematic template was applied again to the dataset to ensure it reflected participant responses (the final thematic template is presented in Figure 5.1. below).

5.4 Results

The present research took a community focused approach in answering two research questions, ‘Which factors influence cervical screening participation in areas of high relative deprivation?’ and ‘How can we best increase cervical screening participation in areas of high relative deprivation?’. Overall, participants suggested that *External factors* (e.g. *Negative experiences of primary care*, *Competing demands* and *Social influence)* were important determinants of uptake within disadvantaged communities, which in turn had an impact on *Internal factors* (e.g. individual’s *Screening-related knowledge*, *Emotional response to clinical care*, and *Prioritisation of screening*). As in previous qualitative chapters, there were strong interrelationships between themes. These interrelationships are cross-referenced throughout the presentation of findings below and demonstrate the complexity of increasing cervical screening participation within the target population. In light of this complexity, it was felt multiple, concurrent strategies were needed to tackle socioeconomic inequalities in participation. Overall, there were two overarching suggestions; these were to *Increase service accessibility* and to *Work in partnership to normalise screening*.

The final thematic template summarising these themes are presented in Figure 5.1. Findings are presented in further detail below. Focus group number, participant number and self-reported screening status are reported alongside illustrative quotes. In line with previous chapters, although self-reported screening status provides insight into participant’s engagement with cervical screening, there is the potential for inaccuracy and thus this should be interpreted with caution (see also Anderson et al., 2019; Klungsøyr et al., 2009).

1.0 Determinants of cervical screening

- 1.1 External factors
  - *1.1.1 Negative experiences of primary care*
  - *1.1.2 Competing demands*
  - *1.1.3 Social influence*
- 1.2 Internal factors
  - *1.2.1 Screening-related knowledge*
  - *1.2.2 Prioritisation of screening*
  - *1.2.3 Emotional responses to clinical care*

2.0 Suggestions to improve participation

- 2.1 Increase service accessibility
  - 2.1.1 *Introduce drop-in appointments*
  - 2.1.2 *Consider non-clinical environments*
  - 2.1.3 *Integrate with other gynaecological services*
- 2.2 Work in partnership to normalise screening
  - 2.2.1 *Introduce screening in adolescence*
  - 2.2.2 *Increase peer support in communities*
  - 2.2.3 *Develop co-created information*

Figure 5.1. Final thematic template outlining factors influencing cervical screening and ways in which to increase participation, in areas of high relative deprivation.

5.4.1 Determinants of cervical screening

5.4.1.1 External factors

5.4.1.1.1 Negative experiences of primary care

All focus group participants discussed past experiences of primary care and suggested that the quality of this care was variable depending on the local GP surgery. Although not all participants reported negative screening-related experiences, those who had suggested this was a barrier to future engagement.

> *“I think it sounds like [P4], you've got a female doctor that's got a skill. Cause some don't know what they are doing with the instruments and it gets quite painful whereas your doctor…you feel you've had a positive experience… see I didn't have...the nurse was kind of, OK, but it was really painful and that's kind of put me off”.* -FG2, P3, Overdue.

Negative experiences were not always specifically related to the screening test; participants shared broader, sometimes distressing incidents, which diminished trust between themselves and healthcare providers, and created anxiety.

> *“The day I met you here I actually got a thing from my nurse saying you have to come in and I still haven't made my appointment...you just do put it off... I think though that I’m at that age...I’m nearly 50..I can remember being quite young 14, 15 year old, and having a 'Was I pregnant' and stuff like that and having some really, really intrusive.. […]…even though I know the nurses are different and I know they are usually female, and I know you can request a female, I still have that little bit in my head that makes me feel...this is going to be awful, this is going to hurt, this is going to be some bloke who just.....You know this is what they used to do! Do you remember...? Too young. Honestly in the 80's it was really intrusive they used to put a glove on and do an internal, just for the hell of it kind of thing.”*- FG1, P1, Overdue

These experiences were shared within communities and due to the sensitive nature of the test, were believed to influence screening participation. This was a particular barrier within migrant communities, especially if individuals were unfamiliar with the UK healthcare system and did not understand the purpose of the test (See also 5.1.1.4 Screening-related knowledge).

> *“If one [woman] goes and says, 'I've been for a cervical test' and the others will go, 'Ok, so how it was?' and then the person says, 'Well, it was like this, and like this, but I wasn't so happy, it's not like Romania'. So then, by saying this, the*

> *other person will say, 'Oh, I'll not go' and obviously they don't understand the importance of the test."* -FG1, P1/Translator, Up to date.

> *"...you have services that aren't designed to be accessible by [marginalised groups]. So even if they did go along they would feel like, 'I don't feel this is inclusive for me, I'm going to tell my friends that it wasn't an experience I liked..."*- Interviews, P2, Network co-ordinator.

5.4.1.1.2 Competing demands

Those living in areas of high relative deprivation reported a number of competing demands which required constant focus and attention throughout daily life. This factor was commonly mentioned across all focus groups and interviews with professionals.

> *"In relation to disadvantaged groups, they have such complex lifestyles, with so many different pressures and things going on…"*- Interviews, P5, Cervical screening facilitator

In particular, childcare posed barriers to participation, making cervical screening difficult to access.

> *"A lot of people around here have got big families. It's not just saying, 'Can you look after her while I go to the doctors'. They might have 4 or 5 children and people just can't get them looked after."* – FG4, P4, Up to date.

Financial constraints also presented significant pressures and challenges in relation to accessing screening, as individuals had limited ability to access childcare, pay for bus fares or take paid leave from work.

> *"It's the bus fares, childcare, managing to feed yourself that morning."* – FG1, P1, Overdue.

> *"I definitely heard that particularly in really deprived communities, where women are working in pretty...not very nice working conditions. You know, maybe on minimum wage, maybe not even getting paid the living wage where actually some women didn't feel they had the confidence to a) say they needed to take the time off to have a smear test but also, what was so interesting was women saying, 'if I take time off work, I don't get paid'."* – Interviews, P1, Project manager.

5.4.1.1.3 Social Influence

Positive social influence was a key facilitator for engaging with screening across all focus groups. Participants referred to supportive family members or friends who informed them about the availability of screening, normalised attendance and encouraged them to participate.

> *"I think it has something to do with the influence you've had from your family as well. So, my mam's always been very, very open about things like that, and we've always spoke about anything to do with sex or health. And [cervical screening] was just one of them things, 'This is just what you do'*." – FG4, P1, Up to date.

> *"But my impression is for the local community is that there are quite strong networks of women who explain things to each other at home and that kind of has a positive side...I've had ladies who've said 'I've only come because my friend and my mam have said I've had to come'"* - Interviews, P3, Practice nurse

However, positive social influence may not always be available to all within the community dependent on parent's own thoughts and feelings surrounding the test.

> *"I have friends who parents weren't as open as my parents were. And I don't know if that's a sort of...not a shame thing, but an embarrassment thing for the parents."* – FG4, P4, Up to date.

> *“My mam put the fear of God into me about them, she did..[…]..you know when you've got to in [to see the doctor] when you find out you're pregnant? Well, you go and see your doctor and it's like, 'Right, get on the bed' and I said 'What for?'...'I'm going to do your smear'...I've never sh...myself so much in my life, I was ill. And you know what it is, when it was over, I was like, 'Is that it?'. I come out and said to my mam, 'You put the fear of God in me, and there's nothing to it!'*. – FG1, P2, Up to date.

5.4.1.2 Internal factors

5.4.1.2.1 Screening-related knowledge

Although the majority of participants expressed a good level of screening related knowledge, participants across focus groups and interviews did not believe this was the case for many within disadvantaged and/or migrant communities.

> *“…majority of the people here, they are not attending because of the lack of the information, because they don't know exactly what [screening] is, they don't know how it is with the procedure, they don't know what to expect.”* – FG3, P1/Translator, Up to date

Participants in two focus groups reflected on their own upbringing and suggested a lack of knowledge was due to screening not being discussed in the family home or in schools (See also *Social Influence*).

> *“Because it was never talked about in our house, I didn’t know what a smear was.”* - FG1, P5, Up to date

> *“See, it's like even at school, even in school we weren't taught about [cervical screening]….. I don't think things are taught in schools early enough. I think you take a lot from school*.” - FG4, P4, Up to date.

Migrant participants briefly discussed that language barriers made it difficult to access screening related information, and as such they were reliant on others to support them in translating information leaflets and letters.

> *“Another barrier, to say like this, could be English...like the language. […] So, when people, they don't understand, they don't have any idea what writing is there. When you see this letter, the first thing is, you know...'Oh my God I have cancer', or something. They get in this stress, they don't think, 'Ok, how do these people know I have cancer, maybe it's not true' and they go to a person who can read the letter.”* – FG3, P1/Translator, Up to date

Two healthcare-related professionals referred to the influence of health literacy and indicated that increasing knowledge was about more than information provision alone.

> *“There's that health literacy isn't there. Just...just understanding...just because you have information in front of you about health doesn't mean that you understand what it means.*” - Interviews, P2, Network co-ordinator

5.4.1.2.2 Prioritisation of screening

Participants across all focus groups referred to prioritisation of childcare, taking care of the family home and/or work commitments over the need to attend for routine cervical screening (See also *Competing demands*).

> *“Well, like you say people have children - they are busy with their childcare. They prioritize themselves last. They have families to look after, getting from A to B is a big thing. An appointment even for an hour for some people would be...just a massive issue wouldn't it*.” - FG2, P3, Overdue

> “[*P2] was saying the Romanian community are more concerned about...like, to have food in the house, to make it clean, to clean the house, to take care of the kids…”* -FG3, P1/Translator, Up to date.

The impact of poverty was also discussed across three focus groups and two interviews. It was suggested that it was not always realistic to expect cervical screening to be prioritised when financial resources for food, hot water and other basic necessities were in short supply.

> *"When people don't have money, when people don't have...the last thing they're going to do is manage to get off their arse and get down to the doctors and have screening***."** – FG1, P1, Overdue.

> *"I think my impression is probably particularly under the recent decade with austerity government, is that people are experiencing quite a lot of hardship and consequently they have different priorities".* -Interviews, P3, Practice nurse

Participants in two focus groups also referred to drug and alcohol use as being problematic in local areas and felt this contributed to the observed low uptake.

> *"I live in [local neighbourhood], there's a lack of information and...I don't mean to sound rude or anything but the people that live round there...they just can't...they're not bothered…A lot of them are alcohol or drug users so that's more important...that lifestyle, you know what I mean? That's what I think cause I'm from that area and I know that area".* -FG2, P1, Up to date.

5.4.1.2.3 Emotional response to clinical care

All focus groups and health-related professionals briefly detailed the negative emotional response individuals often experienced in relation to screening. Embarrassment, fear of pain and fear of screening outcome were considered key barriers to engaging with screening services, although it was indicated that social support could help with this (See also *Social influence*).

> *"I never used to get it done...because it was um…uncomfortable? Uncomfortable and embarrassment and thinking in back of my head that, 'No, I won't have it', you*

> *know? It's just about doctors, you know, they just want to do....it is about the fear as well…what if the worst comes”.* - FG2, P12, Up to date

> *“I think there are quite a lot of people who will come for very, very delayed screening. You know, up to ten years delayed, and they tend it say it’s because they feel it’s embarrassing, it makes them a little bit anxious or upset...those kinds of things. Often, they will say, 'I knew I was very late, and I haven't responded to the letters and I've only come because my friend or my neighbour said I ought to come'. And I think those... the anxiety and the embarrassment, and the fear of pain, are some of the key reasons people highlight”.* – Interviews, P3, Practice nurse.

These negative emotional responses were also discussed more broadly within two focus groups, one participant explained that she, and others she knew of, experienced fear even when attending the local GP surgery more generally, which in turn had an impact on her engagement with cervical screening.

> *“I just have a fear of going to the doctors. I just don't like going to the doctor’s full stop…That's what putting me off…. There are a few of my friends that haven't been for their [screening] for the same reason”.* -FG4, P3, Never attended.

5.4.2 Suggestions to increase participation

5.4.2.1 Increase service accessibility

5.4.2.1.1 Introduce drop-in appointments

Across focus groups the most prominent suggestion was to make attendance easier by increasing service access. Given the numerous competing demands for those living in areas of high relative deprivation (See *Competing demands*) screening services should offer increased choice and flexibility. Most commonly, drop-in clinics were suggested.

This would allow women to schedule screening at short notice, which wasn't always possible for booked appointments.

> *"There [would be] proper nurses there, and they're all women, and you can just go...like a pop in so whenever you've got time. Just say it's every once a month from say, 9 o'clock til 3 o' clock you can just pop in and have it done."* – FG2, P4, Up to date

Health-related professionals felt drop-ins could be a useful strategy, which would be supported by practitioners, but it may not be feasible given limited financial resources and uncertainties surrounding patient engagement.

> *"If you were always going to get [a good] response it would be great – but there are no guarantees so I would think there would be logistical and financial considerations that could cause problems. It wouldn't be so bad if it was out of usual hours but if not, you would be taking nurses from usual clinic time which may not make financial sense. GP surgeries are a business at the end of the day, and it has to make sense".* -Interviews, P5, Cervical screening facilitator.

Another participant suggested that this approach may have unintended consequences in potentially increasing postponement.

> *"There would be something there, I think, about the timing...because I don't know whether it might then been seen as something like...'I can't make this one, I'll go to the next one...I'll go to the next one' or whatever and the time gets longer."* – Interviews, P4, Trainee Health Psychologist.

5.4.2.1.2 Consider non-clinical environments

Participants across focus groups discussed the possibly of making screening available in non-clinical, 'safe' spaces such as community centres, where women may feel more comfortable (See *Emotional response to screening*).

> *"… this centre would do something like that. They do polling and stuff like that? So, I'm sure that [the centre owner] would organise it for women to feel comfortable to have [cervical screening] done here. And then a lot of the women here know each other, so if they came to that they would feel more comfortable about it. And obviously with us having this talk they would definitely be comfortable cause we've already talked about [screening]. I think that would work for me like*." -FG2, P1, Up to date

Although professionals felt this suggestion may increase engagement, feasibility would again be a challenge and require the development of a detailed business plan. Funding remained an issue, as well as challenges determining who would be responsible for the service.

> *"We always say don't organise a one-off isolated event or expect people to come to you. The best engagement you get will be if you have gone to them, in places that they are comfortable with"* – Interviews, P2, Network co-ordinator.
>
> *"I think these things are always a little bit political, because it's always about funding. Is that going to come under a GP service? Because GP services are paid by job, so if you ran a drop-in and sometimes it wasn't well attended, then they're not getting QOF [Quality and Outcome Framework] points for those attendances. So, I think that's going to be an issue. And if it's run under contraception/sexual health services would that funding then be available for that? Or could it be funded as a screening initiative under the health authority with funding just for that project. I think unfortunately, I've worked for so long in the health service, you can't just have ideas, you have to have a business plan for things".* – Interviews, P3, Practice nurse.

5.4.2.1.3 Integrate with other gynaecological services.

Participants across focus groups also indicated they would prefer women-only, 'one-stop shop' style clinics as a safe space to access a range of services related to gynaecological health.

> *"They said to ask you would you help them to open a clinic on [nearby location], a gynaecological clinic...once a week, not every week, or every two weeks or once a month, you can go there and not the same people, you can just go there and get...Yeah, everything all at once..."* -FG3, P1/translator, Up to date.

Although this again was deemed an acceptable strategy to increase uptake, healthcare-related professionals suggested this approach would require a significant amount of organisation and allocation of resources.

> *"I suppose it's...where would you do them? Would they be in the community centres? Having resources...women-only clinics...what are you actually...how many different services are you providing there? So how many staff do you need there, expertise and all of those. So, it's quite resource heavy, and needs a lot of organisation to make sure everyone is in the right place at the right time. And then you need to let people know about it...is it only a one-off every now and again? So that's almost slightly more of a project manager needed for that, so there's a lot of organisation to make that happen*. – Interviews, P2, Network co-ordinator.

5.4.2.2 Work in partnership to normalise screening

5.4.2.2.1 Introduce screening from adolescence

Participants across two focus groups felt that healthcare providers, sexual health services and community-based volunteers should work alongside schools to introduce screening-related knowledge to girls at a younger age. It was believed this approach would familiarise girls with screening and provide information that they may not always necessarily get from home (see also *Screening-related knowledge).*

> *"I still think they should educate [girls] a lot younger on it. Because when you're at that age, then if you got it drummed it into you at that age, when it does come to [being 25] it's nothing new to you. Yeah, it's something you've heard constantly...something you're a bit desensitised to. Like everything else, they're so desensitised now to all these different things and they just accept it, so why can't they just accept [cervical screening]? If they...desensitise them from being little."* – FG4, P4, up to date

There were mixed views from health-related professionals, two participants agreed that this would be a potentially valuable strategy to increasing familiarity with screening, with a recommendation that this could be introduced in more depth alongside HPV vaccinations.

> *"You can't get better than going right to the grassroots and yeah, [I] absolutely heard that. You know, I think, going into schools and speaking to young girls in schools and going with a speculum and talking about it. If that can become embedded in the schools [in the local area] that could be quite powerful I think*"
> - Interviews, P1, community-based researcher

> *"I also think that when girls are invited for their HPV vaccinations in schools, they should use one of their PSHE lessons to go through what's involved and introduce them to the idea of cervical screening at that time. […] I think it's important for them to make a link, at that age*. -Interviews, P3, practice nurse.

However, one participant questioned the potential efficacy of delivering information in schools, given the time to first invitation.

> *"I would say maybe the only issue with having it within a school is that you don't go to get your screening until you're in your mid-20's. So, the impact from that to [screening attendance] ...I don't know what that would be like.*"- Interviews, P4, Trainee health psychologist.

5.4.2.2.2 Increase peer support in communities

There was an underlying suggestion across focus groups that cervical screening related information was impersonal and/or delivered by those outside of their communities. One focus group discussed this more explicitly and suggested that peers (i.e. someone participants could identify with) should offer verbal support to others within the community.

> *"You tend to find the ones that are protesting and that and telling you to go and get your smears are the ones that have their cushy little jobs and that...lovely flash car that they can just jump in and dive down to the doctors"* – FG1, P2, Up to date.

> *"Maybe we need to hear from other women in the same social class as us and stuff like that."* -FG1, P1, Overdue

Those working within community-based organizations were particularly enthusiastic about this approach and felt peer education or health trainer style interventions would be useful in encouraging partnership working across healthcare providers, community organisations and community members.

> *"In terms of the volunteers and the peers [delivering support]. Completely...completely endorse that."* – Interviews, P1, Project manager.

> *"That idea of health volunteers. So that eventually...OK, this is something I would like to be able to do. The groups that you are working with, not only can they talk about their culture and help services understand what they need...but actually get to the point of...they actually start to know enough about the*

> *information that they can be that health trainer".* – Interviews, P2, Network co-ordinator.

Despite some enthusiasm for this approach, some participants felt difficulties surrounding funding and reach of information could be potential barriers to implementing peer support style interventions.

> *"If you are going to have a peer education type model it's about setting it up and then making sure it's sustained. And some money will be needed to do that you know, whenever there's money behind something you need to prove that it's going to be useful and you need to find a way of sustaining it after the money goes away so it's a harder one."* – Interviews, P1, Project manager

> *"…the people in the community...there are differences in how they are engaged within community activities you know, so, you might not necessarily be targeting the people that might benefit from it the most. So there might be people that are more isolated, or I don't know...it's dependent on different types of relationships where they might only go out with their husbands, and they might not get that opportunity to have those kind of discussions even when there are volunteers there. So, yeah. There's something about that which is a bit of a barrier really. It would be good to have that, but again you wonder whether you are going to be targeting the people that are [already] able to access that information anyway?"* – Interviews, P4, Trainee health psychologist.

5.4.2.2.3 Develop co-created information

Although verbal communication was preferred, one focus group referred to past instances of their community co-creating health related information with health practitioners and felt this would be a valuable approach to replicate in regard to cervical screening participation. For migrant communities, direct translation of English leaflets was not deemed suitable and instead required a deeper understanding of messaging which was appropriate within different cultures.

> *It’s not only [developing] a leaflet and translate it and say, 'OK now this is Romanian', because it will not be any help. It's actually... […]... thinking what is the best way to put it, how to write it in Romanian, how to put the message across for people…’* – FG2, P1, up to date.

Health-related professionals agreed that this was a useful and acceptable strategy to ensure information provision within typically marginalised communities. However, one participant was keen to point out that leaflets should be used as a tool, rather than a standalone intervention that could, or should, open up further conversation and interpersonal support (See also *Increase peer support into communities*) .

> *“[Leaflets are] just a tool. Yes, it's got all the information on but it's just a bit if paper. It's actually all the engagement work that then should happen as a result of that. That health practitioners should talk to people to provide them the right information. It's actually then the discussions they've had, the engagement and getting people interested in the issue by having the leaflet. Giving them the leaflet will make not a jot of difference. Here's your bit of paper, 'Oh brilliant. I'm not reading that'.”*- P2, Network co-ordinator

Two other participants had concerns about the time-consuming nature of the work and considered that this process would need to be repeated across a number of different sub-groups and cultures.

> *“The co-creation of information is…I would like to see more of that but again, I don't know whether it's financial or capacity but I don't know how feasible that is if it's done per community or...you know, where do you...not where do you draw the line, but how many different versions of the information do you need for different groups?”* – Interviews*, P*2, Trainee Health Psychologist

5.5 Discussion

5.5.1 Principal findings

The present research aimed to discuss factors influencing cervical screening participation within areas of high relative deprivation and from this, explore ways in which to best increase participation. Determinants were discussed with participants across two studies: focus groups with women living in areas of high relative deprivation and one-on-one interviews with health-related professionals. The resulting qualitative data resulted in in-depth insight into the complexities of addressing socioeconomic inequalities in cervical screening participation and highlighted key intervention characteristics that may facilitate uptake within areas of high relative deprivation. These findings are summarised below.

Determinants identified as important throughout the focus groups supported the findings from Chapters 2, 3 and 4 in suggesting that external factors have a psychological impact that may in turn influence cervical screening related behaviour. Individual's social, economic and cultural contexts (often termed the wider determinants of health) have repeatedly been linked to health outcomes and behaviours throughout past research (Dahlgren & Whitehead, 2007; Short & Mollborn, 2015; The King's Fund, 2016). There are therefore a wide variety of factors that may influence preventative health behaviours. However, the present findings add further understanding to cervical screening participation within the context of area-level deprivation and detail key external determinants (e.g. *Negative experiences of primary care*, *Competing demands* and *Social influence*), identified as important by community members. The key internal, psychological barriers to screening identified throughout the focus groups (i.e. *Screening-related knowledge*, *Prioritisation of screening* and *Emotional responses to clinical care*) have commonly been discussed throughout this thesis and in cervical screening related literature more broadly (e.g. Azerkan et al., 2015; Lovell et al., 2015; Marlow, Waller, et al., 2015). However, the present findings add additional insight into the challenges of prioritising screening within the context of deprivation, whereby postponing participation was described as a rational choice in light of more urgent competing demands and low resource availability (see Sheehy-Skeffington, 2019).

The suggestions put forward by the community reflected the key determinants of screening discussed above. *Increasing service accessibility* was the most prominent overarching recommendation. Introducing drop-in appointments, in both clinical and non-clinical environments and/or integrating screening into other gynaecological services would provide more options for engaging with screening and make it easier for those with numerous competing demands to attend. However, health-related professionals highlighted that, within an organisational context, service-level change would be resource-heavy, particularly challenging given the limited budgets available to healthcare providers (Robertson, Wenzel, Thompson, & Charles, 2017). Nonetheless, such interventions appeared to be acceptable to both community members, practitioners and community health organisations, with professionals stressing that (if resources were available) healthcare practitioners would likely engage with any attempt to encourage participation. Further discussion with policy makers and service commissioners may therefore be useful to highlight potential avenues for establishing more flexible screening services to meet the needs of those who are least likely, or able, to engage.

In addition, it was believed that interventions involving co-creation and *working in partnership* across communities, community organisations and health providers would be valuable in normalising cervical screening and thus increasing participation. These findings reflect the growing body of literature advocating community participation in improving health service access (National Institute for Health and Care Excellence., 2016; South, 2015). Although there are a range of ways to increase community participation and partnership working to reduce health-based inequalities, participants felt *introducing screening from adolescence* in schools*, increasing peer support in* *communities* and *developing co-created information* would have positive outcomes within their communities. Health-related professionals were enthusiastic about the possibilities of these strategies, however identified some key considerations again surrounding funding, time pressures and reach of information that would be important to address if taken forward for future intervention development.

5.5.2 Strengths and limitations

The present research echoes, and thus strengthens, the findings and conclusions of previous chapters, and further contextualises the determinants of cervical screening participation for those living in areas of high relative deprivation. Most notably, these findings provide detailed insight into the connections between determinants, highlighting how individual's external environment may influence screening related psychological responses. This research also goes beyond previous studies in highlighting acceptable routes to increasing cervical screening participation from the perspectives of those living in areas of high relative deprivation, as well as health-related professionals from research, practice and the community sector. Insight from professionals meant community-based suggestions could be considered from an organisational context, allowing for more informed feasibility-based judgements to take place in the latter stages of intervention development.

Despite these strengths, this research should be viewed in the context of its limitations. Although these findings touched upon perspectives from a range of lay and professional stakeholders, health professionals were challenging to access and as a result, views of health service decision-makers including those involved in commissioning screening services were not included in the present research. Accessing the views and experiences of such individuals would be valuable given their knowledge of finance and resource allocation, topics that were repeatedly referred to throughout the interviews and have a critical role in determining feasibility of intervention options. Nonetheless, feasibility-based considerations typically become of greater focus throughout the later stages of intervention development and refinement (Craig et al., 2008); as such, this research therefore helps to highlight targets for collaboration in future research.

Moreover, this research did not compare views of community members and health-related professionals. Thus, we cannot infer whether there are disparities in perceived determinants of screening between groups. Potential discordance may influence health-related professionals' beliefs about, and thus engagement with, intervention suggestions (e.g. professionals may not see value in drop-in clinics if they believe embarrassment and fear are the predominate barriers to screening participation) (Michie et al., 2005). This aspect may require additional focus during more in-depth feasibility work following refinement of intervention strategies. However, within the present research, it was important to prioritise community views and suggestions given those living in areas of high relative deprivation are seldom heard in existing cervical screening literature in the UK.

5.5.3 Recommendations for future research

These findings open up a number of avenues for further research. As indicated above, the insight and suggestions that are included within this research can be taken forward to inform tailored interventions to increase cervical screening participation in areas of high relative deprivation. To enhance the efficacy of any resultant intervention, researchers should aim to select appropriate behavioural theory to consider this evidence from a theoretical perspective and thus clarify the likely process of behaviour change at a community and/or individual level (Craig et al., 2008).

Further work should also focus on understanding preventative health decision-making in the context of relative deprivation. The themes discussed suggest that lack of engagement in cervical screening may be a logical response to challenging life circumstances and low availability of resources. This is relatively unexplored in relation to socioeconomic inequalities in cervical screening and may add valuable contributions to the growing body of research which suggests many non-participants describe themselves as postponing, rather than refusing, cervical screening. (Azerkan et al., 2015; Marlow et al., 2017; Marlow, Chorley, Rockliffe, & Waller, 2018). Given that socioeconomic disparities in uptake are also observed in other screening services (Blanks et al., 2015; Jacomelli, Summers, Stevenson, Lees, & Earnshaw, 2017; Kashim, Newton, & Ojo, 2018; D. Smith, Thomson, Bambra, & Todd, 2019), these findings may also have implications for preventative health screening engagement in the broader context.

5.5.4 Conclusion

Previous research has identified multi-level determinants of cervical screening in areas of high relative deprivation. The present research aimed to further explore these determinants with stakeholders and identify potential acceptable routes to increasing participation within the target population. These aims were achieved across two studies. First, focus groups were conducted at community organisations situated within 10% most deprived areas in England. Following this, individual interviews were conducted with health-related professionals from research, practice and community organisations.

Findings highlighted key external and internal determinants of participation and highlighted how these determinants interact to increase barriers to engaging in screening services. Broadly, screening participation was influenced by *negative experiences of primary care*, *competing demands* and *social influence* which in turn influence *screening related knowledge*, *prioritisation of screening* and *emotional response to clinical care.* Suggestions to increase screening participation were linked to these determinants; participants felt *drop-in appointments, non-clinical screening environments* and *integration with other gynaecological services* would *increase service accessibility* by providing more flexible appointments in more supportive environments. The need to *introduce screening from adolescence*, *increase peer* *support in the community* and *provide co-created information* was also suggested; these approaches focusing on communities, healthcare providers and community organisations *working in partnership to normalise screening* and increase both informational and emotional support.

These findings echo past research and add further contextualisation of screening participation in areas of high relative deprivation. The views of health-related professionals also add initial insight into the feasibility of community-based suggestions and identify potential issues with finance and resource availability that may hinder development and implementation of these suggestions from an organisational context. Future research should aim to consider this learning alongside behavioural theory to further understand the likely process of behaviour change needed to reduce observed socioeconomic inequalities in cervical screening participation.

5.6 Chapter Summary

The present chapter further contextualised the determinants of cervical screening with stakeholders and considered ways in which to increase participation in areas of high relative deprivation. The next stage of intervention development is to integrate findings presented throughout this thesis and, in line with MRC guidance (Craig et al., 2008), consider these in line with appropriate behavioural theory. The following chapter introduces a systematic approach to combining theory and evidence, and from this, further utilises these findings to develop specific intervention strategies likely to increase cervical screening participation in areas of high relative deprivation.

6 Selecting and applying appropriate theory: A behavioural analysis of cervical screening attendance using the behaviour change wheel.

6.1 Synopsis

In line with guidance from the Medical Research Council, the previous chapters have a) identified the existing relevant qualitative literature within the area and b) presented supplementary qualitative research conducted to gain a deeper understanding of the factors influencing cervical screening participation for those living in areas of high relative deprivation. Taking a systems approach throughout this process has allowed for a richer understanding of not only the determinants of screening participation, but the relationships *between* these determinants; a consideration which is key to understanding socioeconomic inequalities in uptake. The next stage of this process is to select and apply appropriate theory. The present chapter therefore presents and justifies the application of well-established theory of behavioural change; the COM-B model. Findings will be mapped to COM-B components to identify relevant targets of behavioural change. These targets of change will then be linked to intervention functions, policy categories and behaviour change techniques to result in a ‘toolkit’ of intervention components and strategies appropriate to encouraging cervical screening participation in areas of high relative deprivation.

6.2 Background

The selection of an appropriate theoretical basis in which to consider evidence is crucial in developing interventions which have the greatest chance of impact/efficacy (Craig et al., 2008). As explored in section 1.1.2, a number of theoretical frameworks, such as the Theory of Planned behaviour (Ajzen, 1985, 1991) and The Health Belief Model (Janz & Becker, 1984; Rosenstock, 1974) have been used to identify determinants of cervical screening, highlighting negative attitudes toward screening, low screening-related knowledge and low perceived risk of cervical cancer as some of the dominant barriers to participation (Eaker, Adami, & Sparén, 2001a; Ekechi et al., 2014; B. Lovell et al., 2015; Marlow, Wardle, et al., 2015) . In recent years, extended or amended versions of these socio-cognitive models of behaviour have been used to account for the commonly reported emotional processes involved in screening uptake (e.g. Sandberg & Conner, 2009), although there is debate surrounding the utility of continuously extending models of behaviour that are outdated in light of current knowledge (Sniehotta, Presseau, & Araújo-Soares, 2014; Sniehotta et al., 2015). Dual process models of behaviour (e.g. Strack et al., 2004) are valuable in this respect, as, at their core, they acknowledge that health behaviour is a result of both reflective (i.e. conscious, effortful) and automatic (i.e. non-conscious, impulsive) processes. However, even when employing such models, there has traditionally been a tendency within psychology to over-emphasise individual level factors and decision making, with lesser prioritisation given to social and environmental determinants of health behaviour (Short & Mollborn, 2015). Ongoing developments in health psychology and behavioural science suggest that both internal and external factors hold equal importance in understanding and determining health behaviour, and support the view that researchers should consider the interplay between multi-level factors to understand behaviour and behaviour change (Michie et al., 2011). In line with this, it is therefore important that determinants of screening are considered within theoretical frameworks which adequately acknowledge the social, environmental and individual level factors that drive health behaviour and health behaviour change. The qualitative findings across previous chapters support this viewpoint as participants have, across studies, outlined determinants of screening participation that go beyond the individual e.g. emphasising the role of their social networks and past experiences oh healthcare provision. A focus on cervical screening behaviour within this wider context would therefore contribute to our understanding of the pervasive inequalities in participation, particularly as those within socioeconomically disadvantaged groups are more likely to face external barriers to engaging with health services (Holman et al., 2018).

The COM-B model (Michie et al., 2011; see Figure 1.2) is a framework for understanding behaviour and behaviour change, which takes the wider determinants of health into account (i.e. accounting for individual, social and environmental factors). This model identifies Capability, Opportunity, and Motivation as broad interacting domains that influence behaviour and therefore provide useful targets for intervention. Capability reflects both the physical and psychological influences associated with an individual e.g., having the necessary physical capability, knowledge and skills to engage in a given behaviour. Motivation can be defined as the automatic and/or reflective drivers of behaviour e.g., habits, emotions (automatic motivation), beliefs and attitudes (reflective motivation). Opportunity can be defined as that which is outside of the individual and refers to both social and physical factors which may influence the uptake and/or maintenance of a particular behaviour (e.g., the physical environment). These domains interact as demonstrated in Figure 6.1. For example, Motivation can be influenced by Capability and Opportunity to engage with/in a behaviour. Similarly, engaging a given behaviour can reciprocally influence Capability, Motivation and Opportunity.

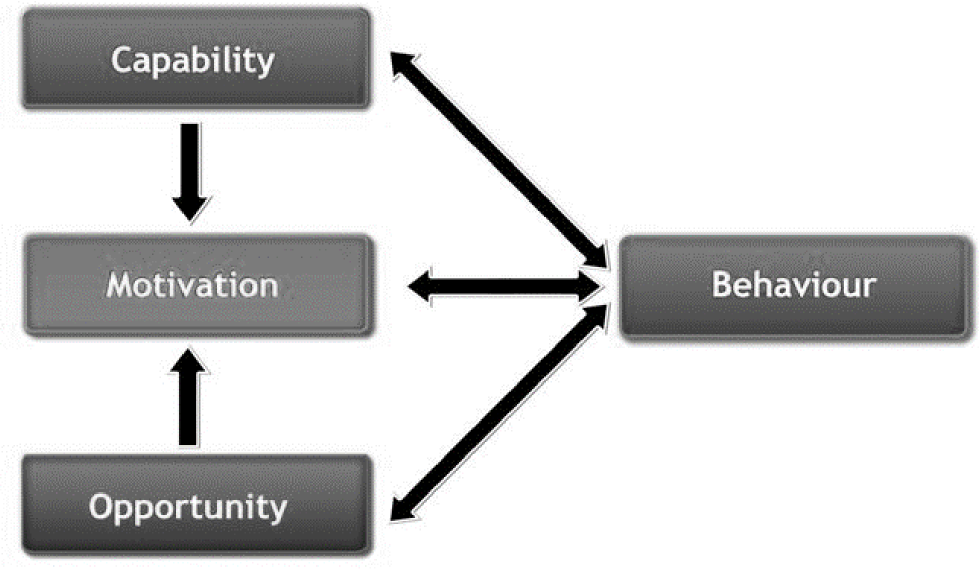

Figure 6.1. The COM-B model of behaviour (Michie et al., 2011)

The COM-B model has previously been employed to facilitate understanding of barriers and facilitators to cancer screening (e.g., Maramaldi et al., 2018; Oketch et al., 2019). However, as Michie et al. (2011) state, the COM-B model is particularly useful when used as a systematic basis for designing interventions aimed at behaviour change. The model itself suggests no particular emphasis on one domain or the other; all may be equally important in determining behaviour. However, the model can be used to determine which domains may be most useful in modifying behaviour in a specific context. Identifying the most useful/valuable domains to target can then facilitate the development of interventions which are likely to influence positive behaviour change. Supporting this process, the COM-B model is situated within the larger framework of the Behaviour Change Wheel (BCW; Michie et al., 2014); a systematic, theoretically grounded approach to intervention development developed from 19 frameworks of behaviour change.

The BCW has been successfully applied to develop and refine a wide range of tailored, behavioural interventions, such as childhood weight management (Curtis, Lahiri, &

Brown, 2015), hearing-aid use (Barker, Atkins, & de Lusignan, 2016), medication adherence (Jackson, Eliasson, Barber, & Weinman, 2014), cancer symptom presentation (Smits et al., 2018), and attendance at smoking cessation services (Fulton, Brown, Kwah, & Wild, 2016). This framework has also recently been used to advise UK government on potential strategies to increase social distancing and shielding during the current COVID-19 pandemic (Michie et al., 2020; West, Michie, Rubin, & Amlôt, 2020). The COM-B model has previously been applied to classify barriers to cervical screening (Oketch et al., 2019). However, this research was conducted in relation to self-sampling screening practices in Kenya, a low-income country without an established population-wide, call-recall screening service, and furthermore did not employ the broader systematic approach of the BCW to develop intervention strategies. As such, the systematic approach of the BCW framework has yet to be utilised to increase cervical screening participation within under-served groups, within the UK healthcare context. Adopting this well-established approach would therefore be useful in a number of ways. Firstly, it would allow for the development of a holistic and theoretically grounded understanding of inequalities in cervical screening uptake. Secondly, it would allow researchers to identify key targets of behaviour change, intervention functions, behaviour change techniques and policy categories that are relevant to increasing participation within those living in areas of high relative deprivation. The identification of intervention options/content appropriate within this context could also contribute to the development of novel interventions and/or the refinement of existing interventions. Finally, it would add to current literature in detailing a systematic approach to intervention development that is, importantly, translatable to UK policy and practice (Michie et al., 2014).

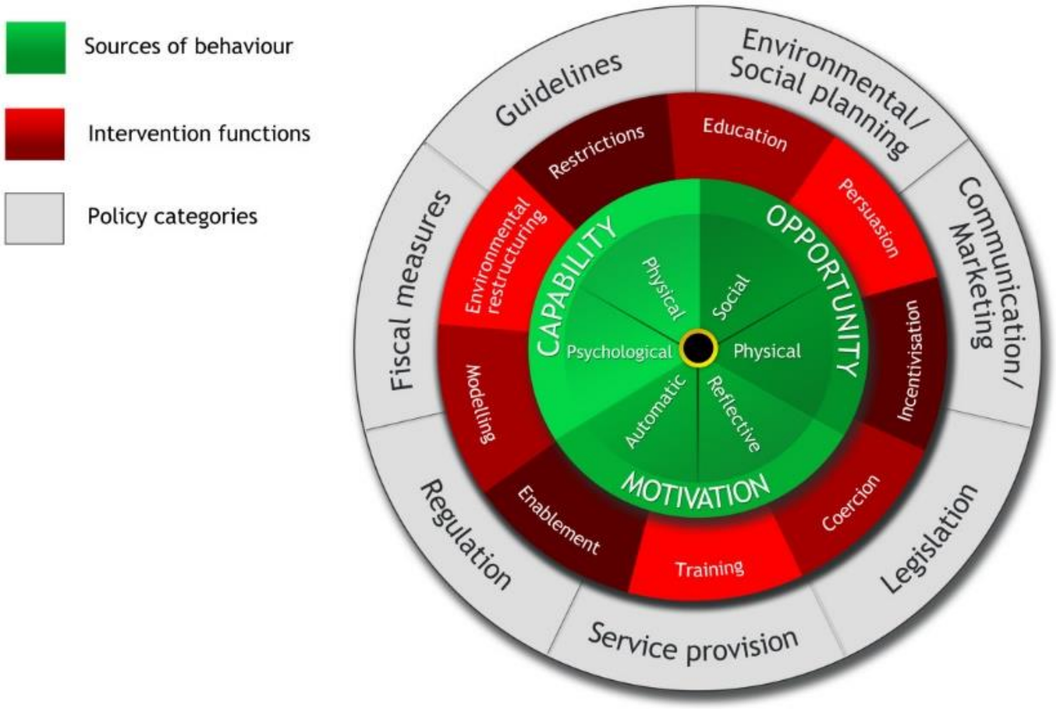

Figure 6.2. The Behaviour Change Wheel (Michie et al., 2014).

6.2.1 Applying the Behaviour Change Wheel

There are three main stages to the application of the BCW; the first of these consists of developing an in-depth understanding of the behaviour in question and utilising the COM-B framework to complete a ‘behavioural diagnosis’ of what is required for change to occur. This behavioural diagnosis can then be considered within the wider context of the framework, with guidance provided for identifying specific intervention approaches (stage 2) and techniques and modes of delivery (stage 3) that are most likely to be effective in eliciting change. For the purposes of clarity, the components and stages of the BCW are described in more detail below.

6.2.1.1 Stage I: Identifying and Understanding the Target Behaviour

There are three main steps involved in identifying and understanding behaviour. Firstly, the problem should be defined in behavioural terms. Secondly, the target behaviour should be selected and comprehensively defined (e.g. *Who needs to perform the behaviour? When and where will they do it? How often will they do it*?). Thirdly, potential processes of change should be identified. Michie et al., (2014) suggest that it is crucial to consider this step in-depth, as subsequent interventions are more likely to be a success if there has been detailed consideration of factors influencing the target behaviour and potential routes to eliciting positive behavioural change.

A range of evidence may be synthesised and/or generated to identify determinants of a behaviour, prior to a behavioural diagnosis taking place. Usually, this would involve a review of existing evidence, with additional primary research being conducted if deemed necessary. Mapping this evidence onto the domains of the COM-B then facilitates the ‘behavioural diagnosis’ (i.e., identification of what needs to change in order for the specified behaviour to occur). If a more granular level of detail and/or understanding of factors that influence behaviour is required, the COM-B domains can also be mapped on to the Theoretical Domains Framework (Cane et al., 2012; TDF; Francis, O’Connor, & Curran, 2012; Michie et al., 2005). The TDF is a synthesis of 128 constructs (across 33 theories) known to influence behaviour, and explains behaviour in relation to ‘knowledge’, ‘beliefs about consequences’, ‘beliefs about capabilities’, ‘skills’, ‘environmental context & resources’, ‘social influences’, ‘memory, attention & decision processes’, ‘behavioural regulation’, ‘emotion’, ‘social or professional role/identity’, ‘, ‘optimism’, ‘intentions’, ‘goals’ and ‘reinforcement’. The links between COM-B components and TDF domains are highlighted in Figure 6.3 below.

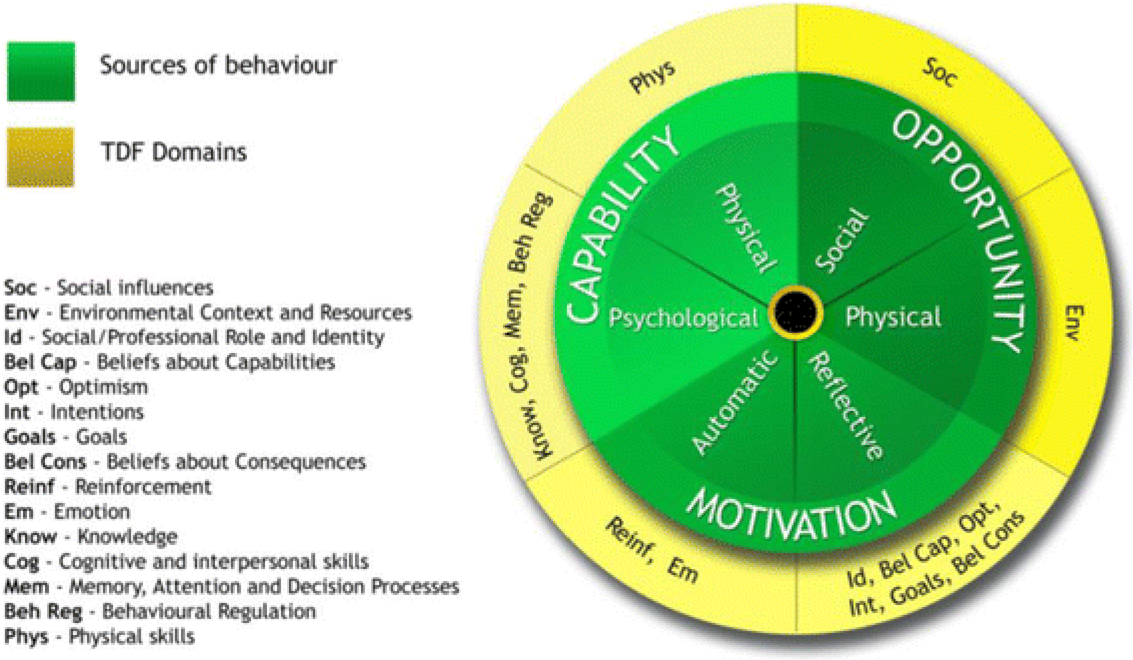

Figure 6.3. COM-B components with associated TDF domains, from Michie et al., (2014).

6.2.1.2 *Stage II: Identify Intervention Options*

Following the behavioural diagnosis, it is important to assess which approaches, or functions, may be most suitable to elicit behavioural change. From a systematic review synthesising 19 frameworks of behaviour change interventions (Michie et al., 2011), the BCW identifies nine intervention functions (or means by which behaviour can be changed). These functions are education, persuasion, incentivization, coercion, training, enablement, modelling, and environmental restructuring. It is important to note that an intervention can include more than one function; for example, the message ‘Please book your cervical screening appointment at your local GP surgery – this is a five-minute appointment that can save your life’ provides information on booking screening appointment (education) whilst also referring to aspects of screening participation that are known to invoke emotion and increase motivation to attend (e.g. ‘quick’, ‘life-saving’; persuasion).

Through an expert consensus exercise, Michie et al. (2014) provide guidance on the links between the COM-B/TDF domains and the aforementioned intervention functions.

The process of identifying relevant and useful intervention functions specific to the topic of interest requires intervention designers to use appropriate judgement and therefore have adequate background knowledge of the context in which the intervention is to be implemented. The APEASE criteria can facilitate such judgements by considering factors that influence the success of behavioural interventions. These criteria are Affordability, Practicability, Effectiveness and cost effectiveness, Acceptability, Side effects/safety and Equity (see Table 6.1). Thus, intervention developers should systematically consider each identified intervention function in turn in accordance with the APEASE criteria. This enables identification of intervention functions that are most likely to be of value.

Table 6.1 - APEASE criteria for evaluating interventions (taken from Michie et al., 2014).

Acceptability	How far is it acceptable to all key stakeholders?
Practicability	Can it be implemented as designed within the intended context, materials and human resources?
Effectiveness	How effective and cost-effective is it in achieving desired objectives in the target population?
Affordability	How far can it be afforded when delivered at the scale intended?
Side-effects	How far does it lead to unintended adverse or beneficial outcomes?
Equity	How far does it increase or decrease differences between advantaged and disadvantaged sectors of society?

If applicable, it is also possible to use the behaviour change wheel to identify policy categories that may support the delivery of intervention functions. The usefulness of this stage is dependent on the context in which the intervention designer is working. However, this stage may be particularly valuable when developing recommendations for policymakers and to increase potential research impact. Again, the APEASE criteria should be implemented when selecting specific policy categories.

6.2.1.3 Stage III: Identify Content and Implementation Options

Following the identification of suitable intervention functions and policy categories, the behaviour change wheel guidance (Michie et al., 2014) also supports intervention designers in selecting techniques and modes of delivery to develop more detailed intervention strategies. The behaviour change technique taxonomy (BCTTv1; Michie et al., 2013) specifies 93 techniques or ‘active ingredients’ used within behaviour change interventions. Whilst any behaviour change technique (BCT) could potentially be used within an intervention, the guidance highlights BCTs which are most likely to be effective in association with previously identified targets of behaviour change and intervention functions. The appropriateness of these BCT’s can then be considered in conjunction with the APEASE criteria and also in conjunction with the frequency in which the techniques have previously been used (Abraham et al., 2015).

Combined, this process therefore results in the identification of intervention options and content appropriate to employ in relation to the specific topic of interest (in the present case, this would be cervical screening participation in areas of high relative deprivation). Through the policy categories previously outlined, potential intervention strategies can then be drafted. Specific modes of delivery (e.g. face-to-face or distance/individual, group or population level) may also be considered. Following the development of these strategies and recommendations, subsequent interventions can be refined and tested in line with guidance within the MRC framework and the context in which they are to be delivered, for example via collaborative stakeholder discussions and/or workshops (Craig et al., 2008).

6.2.2 Rationale and aims

The Behaviour Change Wheel is a systematic approach to developing behavioural interventions which have been widely applied to range of public health issues. However, this approach has, to current knowledge, not yet been applied to understand and/or address cervical screening uptake in areas of high relative deprivation. Utilizing this approach in the present context would therefore combine both community voice/insight and behavioural theory and strengthen the likelihood of successful intervention. The aim of this chapter is to therefore conduct a behavioural analysis to identify what needs to change in order to increase engagement with routine cervical screening services in areas of high relative deprivation. This, in turn, allows for the identification of intervention strategies, or recommendations, to address socioeconomic inequalities in cervical screening uptake.

The specific research questions addressed within this chapter are 1) What factors need to be changed, in terms of capability, opportunity and motivation, to encourage cervical screening uptake in areas of high relative deprivation? and 2) What intervention functions, behaviour change techniques and policies might be recommended to encourage cervical screening attendance in areas of high relative deprivation?

6.3 Method

Following guidance from Michie et al., (2014) appropriate intervention components and strategies were developed across three broad stages; Understand the target behaviour (steps 1-4), Identify intervention options (steps 5-6) and Identify content and implementation options (steps 7-8). The steps that compromise these broad stages are summarised in Figure 6.4 and described in more detail below. As in Ojo, Bailey, Brierley, Hewson and Chater (2019), the first three steps are presented to provide context, with the following steps (4-8) presented to provide further specific detail in the development of intervention strategies.

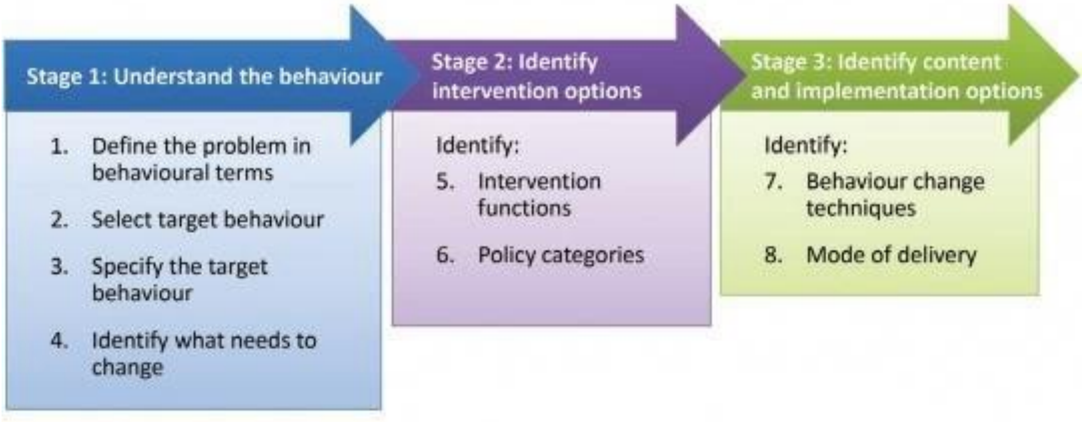

Figure 6.4. Behaviour change intervention development process, from Michie et al., (2014).

6.3.1 Step 1: define the problem in behavioural terms.

Cervical screening is available via the NHS for all females registered with a GP in the United Kingdom. Eligible individuals (i.e. those with a cervix) are invited to attend screening routinely; every three years for those aged 24-49 and every 5 years for those aged 50-64 (NHS, 2020b). Previous evidence has demonstrated socioeconomic inequalities in routine cervical screening participation, whereby those living in areas of high relative deprivation (classified by the Index of Multiple Deprivation; Department for Communities and Local Government, 2015) are least likely to attend in line with government guidance (Douglas et al., 2016; Public Health England, 2019d).

6.3.2 Step 2: select the target behaviour

Given the problem defined above, there is a need for intervention strategies which aim to increase participation in routine cervical screening appointments, tailored to those who live in areas of high relative deprivation. Like all behaviours, cervical screening participation exists as part of a system of competing and complementary behaviours, related to the individual themselves and other associated individuals/groups (Barker et al., 2016). For example, service-user behaviours associated with improving attendance could involve reading the invitation letter, reading information about the benefits/disadvantages of screening, discussing screening with others, identifying free time to attend an appointment, booking an appointment and attending an appointment. For the purposes of this research, we focus on timely attendance at a routine cervical screening appointment. As NHS statistics refer to adequate coverage as ‘less than 3.5 years since last test’ (NHS Digital & Office for National Statistics, 2018), ‘timely’ attendance within this context can be defined as attending within 6 months of invitation.

6.3.3 Step 3: specify the target behaviour(s)

The specific target behaviour of interest is described in further detail in Table 6.2 below.

Table 6.2. Specification of target behaviour.

Target behaviour	**Who** i.e. Who needs to perform the behaviour? With whom?	**What** What do they need to do differently?	**Where** Where will they do it?	**When** When will they do it? How often?
Attend a screening appointment	Service User With Screen-taker	Attend screening appointment within six months of invitation.	G.P. surgery (or sexual health clinic where/if applicable)	Any convenient time within six months of receiving an invitation letter (i.e. every 3-5 years depending on age).

6.3.4 Step 4: identify what needs to change

Findings from previous qualitative work (reported in full in Chapters 2-5), that related specifically to the perspectives of those living in socioeconomically disadvantaged areas, were included to inform this stage. This compromised of a data from a systematic review (Chapter 2; themes relating to those of low socioeconomic status only), one-on-one interviews (Chapter 3), an online survey (Chapter 4; themes from the initial coding template which were derived from the perspectives of those who lived in areas of high relative deprivation) and focus groups (Chapter 5; themes which related to section 5.4.1 *Determinants of cervical screening* only). As such, data from 120 individuals, living in areas of high relative deprivation, therefore informed the development process. The content of the extracted themes were read and re-read and then mapped to both the TDF (Cane et al., 2012) and COM-B model (Michie et al., 2011) to facilitate a detailed behavioural diagnosis of which areas of change are required to encourage the target behaviour.

To highlight which factors were most important to target from the perspectives of the target population, TDF domains were then ranked by frequency (number of studies in which the domain occurred) and elaboration (number of themes mapped to the domain).

6.3.5 Step 5 and 6: identify intervention options and policy categories

Using the pre-existing matrices available in the Behaviour Change Wheel guidance (Michie et al., 2014), the relevant COM-B domains were linked to intervention functions (i.e. means by which behaviour may be changed; pg. 116 of the guide). Each identified intervention function was then considered in light of the APEASE criteria to determine potential feasibility. These judgements were guided by stakeholder discussions throughout the research process; particularly, findings from focus groups and one-on-one professional interviews reported in Chapter 5 relating to section 5.4.2 *Suggestions to increase cervical screening participation.* Given the early stage of the development process, and the strong relevance of resource availability (which may differ across locations), it is important to note that further evaluation of APEASE criteria would be relevant/needed in the later stages of development and intervention refinement, particularly in regards to determining effectiveness/cost-effectiveness (see also Cadogan et al., 2016; Ojo et al., 2019). Again, pre-existing matrices were then consulted to link the identified intervention functions to relevant policy categories (pg. 138 of the guide) that might facilitate the delivery of subsequent interventions. Feasibility was again considered in light of APEASE criteria as detailed above.

6.3.6 Steps 7-8: Identify behaviour change techniques and modes of delivery.

The BCTTv1 (Michie et al., 2013) was reviewed to re-familiarise the researcher with the definition of each technique (as intervention designers should focus on the specific definition, rather than the title, of each BCT during the selection process; Michie et al., 2014). Relevant intervention functions, as identified in step 5, were then linked to individual behaviour change techniques (BCTs) (Michie et al., 2014). This guidance also informs researchers as to which techniques are most frequently used (Abraham et al., 2015), thus this aspect was also considered alongside APEASE criteria. Selected BCTs were also cross-checked via The Theory and Techniques tool (https://theoryandtechniquetool.humanbehaviourchange.org/) which uses data from literature synthesis, expert consensus and triangulation studies to inform researchers as to the strength of links between BCTs and TDF domains. This process resulted in the identification of BCTs which are appropriate to encouraging behaviour change within the current context.

Following the selection of BCTs, potential modes of delivery were considered, again in line with suggestions from the community (reported in full in 5.4.2 *Suggestions to increase cervical screening participation)*, and a summary of potential intervention strategies/modes of delivery were drafted.

6.3.7 Topic-specific knowledge

Throughout the stages described above, a significant amount of judgement on the part of the researcher is required, which should be underpinned by in-depth topic specific knowledge (Michie et al., 2014; Public Health England, 2019a). The principal researcher in the present study has conducted all of the qualitative research synthesised as part of this process. Importantly, the researcher is also a member of the target population (i.e., those eligible for routine cervical screening, living within an area of high relative deprivation) as well as consulting extensively with other members this population through community engagement work. Therefore, all judgements on content/option appropriateness were supported by in-depth knowledge of both routine cervical screening related behaviour and the target population.

6.4 Results

Timely attendance at routine cervical screening was specified in the section above as the target behaviour. The findings of steps 4-8 are presented in detail below.

6.4.1 Identifying and understanding the target behaviour.

Following the mapping exercise (see Appendix T) the following COM-B components (and TDF domains) were identified as relevant to routine cervical screening participation in the current context: Psychological capability (knowledge; memory, attention and decision processes; cognitive and interpersonal skills; behavioural regulation), Social opportunity (Social influence), Physical opportunity (environmental context and resources), Automatic motivation (emotions) and Reflective motivation (beliefs about consequences; intentions; beliefs about capabilities; optimism). The behavioural diagnosis (i.e., a summary of what is required for the target behaviour to occur) is presented in Table 6.3.

Table 6.3. Summary of what needs to change in order to increase attendance at routine cervical screening appointments in areas of high relative deprivation, as it relates to capability, opportunity and motivation.

COM-B component	What needs to happen for timely attendance to occur?	Is there a need for change?
Capability		
Physical capability	• Have the ability to physically attend an appointment.	No indication that change was needed within this domain.
Psychological capability	• Have the ability to read and understand cervical screening related information. • Know how to book an appointment. • Understand the purpose/benefits/disadvantages of screening. • Decision-making skills to help manage competing priorities. • Understand ways to cope with the psychological/emotional discomfort associated with cervical screening.	Change needed within this domain.
Opportunity		
Social Opportunity	• Acceptability and normalisation of screening attendance. • Opportunity to discuss screening with others. • Have access to a supportive and welcoming healthcare environment.	Change needed within this domain.
Physical Opportunity	• Have access to suitable appointments and screening locations. • Have (financial and time) resources to attend an appointment.	Change needed within this domain.
Motivation		
Automatic motivation	• Feel a need to attend routine cervical screening when invited, despite potentially strong emotional barriers to doing so.	Change needed within this domain.
Reflective Motivation	• Hold belief that screening is worthwhile and has health benefits. • Hold belief that health benefits outweigh feelings of discomfort.	Change needed within this domain.

COM-B component	What needs to happen for timely attendance to occur?	Is there a need for change?
	• Hold belief that one is at personal risk of developing cell abnormalities/cervical cancer. • Hold an intention to attend and prioritise prompt attendance. • Hold belief that one has the ability to attend despite a number of competing priorities. • Hold a belief that there will be a positive outcome as a result of attending screening.	
Behavioural diagnosis: Psychological capability, Social opportunity, Physical Opportunity, Automatic motivation, and reflective motivation need to change to encourage timely cervical screening participation in those who live within areas of high relative deprivation.		

To provide further insight into which factors were most important to target from the perspectives of participants, TDF domains were then ranked by frequency (number of studies in which the domain occurred) and elaboration (number of themes mapped to the domain). From the perspectives of those living in areas of high relative deprivation, the most important targets of change related to Social Influence (Social opportunity), Environmental context and resources (Physical Opportunity) and Emotions (Automatic motivation). This ranking is presented in full in Table 6.4.

Table 6.4. Key domains influencing timely routine cervical screening participation, ranked by frequency (number of studies in which the domain occurred) and elaboration (number of themes mapped to the domain).

Ranking	TDF Domain (COM-B)	Frequency (No. of sources identifying domain)	Elaboration (Number of themes mapped to TDF domain)
1	**Social Influences (social opportunity)**	4	14
2	**Environmental context and resources (physical opportunity)**	4	12
3	**Emotion (automatic motivation)**	4	11
4	**Beliefs about consequences (reflective motivation)**	4	8
5	**Cognitive and interpersonal skills (psychological capability)**	4	5
Joint 6th	**Knowledge (psychological capability)**	4	5
	Intentions (reflective motivation)	4	5
7	**Memory, attention, and decision Making (psychological capability)**	3	3
8	**Behavioural Regulation (psychological capability)**	2	3
Joint 9th	**Beliefs about capabilities (reflective motivation)**	2	2
	Optimism (reflective motivation)	2	2
Joint 10th	**Physical Skills (physical capability)**	0	0
	Professional role and identity (reflective motivation)	0	0
	Goals (reflective motivation)	0	0

6.4.2 Identify intervention options

6.4.2.1 Identify intervention functions

Relevant COM-B components were linked to intervention functions most likely to bring about change within that domain (See Appendix U). All intervention functions were identified as potentially relevant. Restriction (i.e. use of rules to reduce opportunity to engage in competing behaviours) and Coercion (i.e. create an expectation of punishment or cost for non-participation) were not deemed as acceptable within the context of attending an optional routine cervical screening appointment. During stakeholder interviews, it was also suggested that incentivisation would not be acceptable to health professionals and was not feasible at scale. Therefore, following application of the APEASE criteria, the intervention functions of Education, Persuasion, Training, Environmental restructuring, Modelling and Enablement were deemed appropriate means by which to bring about change. A summary of these intervention functions as applied to the current context are provided in Table 6.5 below.

Table 6.5. Intervention functions appropriate to increasing timely attendance at routine cervical screening appointments in areas of high relative deprivation.

Intervention function	**Definition of intervention function in the context of attending a cervical screening appointment.**	**Associated COM-B components**
Education	Increase knowledge or understanding surrounding cervical screening attendance.	Reflective motivation Psychological capability
Persuasion	Use communication to encourage positive feelings toward screening appointment attendance[a]	Automatic motivation Reflective motivation
Training	Impart skills to facilitate timely screening attendance.	Physical Opportunity Psychological Capability
Environmental restructuring	Change the physical or social context relating to cervical screening attendance.	Social Opportunity Physical Opportunity Psychological Capability
Modelling	Provide a positive example for people to aspire to or imitate e.g. Introduce peer support workers and/or screening related support and information from community members.	Social Opportunity Automatic motivation Reflective motivation Psychological Capability
Enablement	Increase means, or reduce barriers, to participate in screening to increase capability (beyond education and training) or opportunity (beyond environmental restructuring) e.g. social support	Social Opportunity Physical Opportunity Automatic motivation Psychological Capability

[a]- Persuasion could also relate to encouraging negative feelings towards non-participation. However, this aspect was deemed unacceptable in the current context, as it may increase inequalities for those who have increased competing priorities or demands.

6.4.2.2 Identify policy categories

The intervention functions identified above were then linked to relevant policy categories that may support intervention delivery via pre-established matrices (See Appendix U). Following consideration of APEASE criteria, fiscal measures (i.e. using the tax system to increase financial cost) and legislation (i.e. making or changing laws) were not deemed applicable in this context. Regulation (i.e. establishing rules of practice) and Environmental/social planning (i.e. designing and/or controlling the physical or social environment via e.g. urban planning) were deemed potentially useful but only in the longer term and thus were unlikely to be practical in the shorter term so were not included. The policy categories deemed most appropriate for supporting timely attendance at routine cervical screening were Guidelines and Service provision. Communication/marketing was also included given information accessibility was mentioned by some participants (as well as suggestions for co-created leaflets as a suitable intervention, as detailed in Chapter 5). Table 6.6 provides definitions of these policy categories and clarifies connections between relevant intervention functions and COM-B components.

Table 6.6. Potentially suitable policy categories to support delivery of interventions focused on increasing timely attendance at routine cervical screening appointments in areas of high relative deprivation.

Policy categories	Definition of policy category	Associated intervention functions	Associated COM-B components
Guidelines	The creation of documents that make recommendations for action or to direct practice. Related to all changes to service provision.	Education, Persuasion, Training, Environmental restructuring, Enablement	Physical opportunity Social opportunity Automatic motivation Reflective motivation Psychological capability
Service provision	Delivering a service, materials and/or social resources or aids.	Education, Persuasion, Training, Modelling, Enablement	Physical opportunity Social opportunity Automatic motivation Reflective motivation Psychological capability
Communication/ marketing	Use of media (i.e. print, electronic, telephonic or broadcast).	Education, Persuasion, Modelling	Social opportunity Automatic motivation Reflective motivation Psychological capability

6.4.3 Identify content and implementation options.

6.4.3.1 Identify behaviour change techniques

Following review of the BCTTv1 (Michie et al., 2013), the intervention functions of Education, Persuasion, Training, Environmental restructuring, Modelling and Enablement were linked to specific behaviour change techniques that may be useful in facilitating timely attendance of routine cervical screening in areas of high relative deprivation. Further consideration of APEASE criteria and cross-checking of links between BCTs and relevant TDF domains (as identified in section 6.4.1) resulted in 16

BCTs being identified as being potentially valuable in encouraging change. For the purposes of clarification these BCTs are specified and defined in the context of timely attendance at cervical screening participation in Table 6.7 below.

Table 6.7. Appropriate behaviour change techniques, taken from BCTTv1 (Michie et al., 2013), to encourage timely cervical screening attendance.

Selected behaviour change technique from BCTTv1	**Definition of technique in the context of timely attendance at routine cervical screening.**	**Frequently associated intervention functions**
1.2. Problem solving	Prompt the person to analyse what is stopping them from attending screening and generate or select strategies that enable them to overcome these barriers and/or increase facilitators of the behaviour.	Enablement
1.9. Commitment[a]	Ask the person to use/affirm statements which indicate a commitment to attending their screening appointment *(e.g., 'I will…or using words such as 'high priority').*	Enablement
3.2. Social support (practical)	Advise on, arrange, or provide practical help *(e.g., from friends, relatives, colleagues, healthcare professionals*) to help the person attend their screening appointment.	Enablement
3.3. Social support (emotional)[a]	Advise on, arrange, or provide emotional social support (*e.g., from friends, relatives, colleagues, healthcare professionals*) to encourage attendance.	Enablement
5.1. Information about health consequences	Provide written, verbal or visual information informing the person about the health consequences of screening attendance.	Education, Persuasion
5.5. Anticipated regret[a]	Induce or raise awareness that non-participation at cervical screening may result in future regret.	Enablement

Selected behaviour change technique from BCTTv1	Definition of technique in the context of timely attendance at routine cervical screening.	Frequently associated intervention functions
5.6. Information about emotional consequences[a]	Provide written, verbal or visual information about the emotional consequences of timely attendance.	Education, Persuasion
6.1. Demonstration of the behaviour	Provide an observable demonstration of screening attendance (e.g., via short film or pictures).	Training, Modelling
6.3. Information about others approval[a]	Provide information clarifying that others' within the person's community believe screening attendance is worthwhile/important.	Education, Persuasion
7.1. Prompts/ cues	Introduce environmental or social stimulus to prompt or cue individuals to book an appointment at the time or place it would usually occur.	Education, Environmental restructuring
9.3. Comparative imagining of future outcomes[a]	Prompt or advise the person to imagine/compare potential future outcomes of timely attendance versus non-timely attendance at cervical screening.	Enablement
11.2. Reduce negative emotions[a]	Advise on ways of reducing negative emotions related to cervical screening attendance.	Enablement
11.3. Conserve mental resources[a]	Advise how to minimise demands on mental resources to encourage screening attendance (e.g., advise that booking an appointment at the time of reading the invitation letter would reduce the need to rely on memory or decision-making processes at a later date).	Enablement
12.1. Restructuring the physical environment	Change, or advise to change the physical environment in order to encourage screening attendance or discourage non-	Environmental restructuring Enablement

Selected behaviour change technique from BCTTv1	Definition of technique in the context of timely attendance at routine cervical screening.	Frequently associated intervention functions
	attendance/postponement (other than prompts/cues, rewards and punishments).	
12.2. Restructuring the social environment[a]	Change the social environment in order to encourage screening attendance or discourage non-attendance/postponement (other than prompts/cues, rewards and punishments).	Environmental restructuring
13.2. Framing/ reframing[a]	Suggest that the person adopt a new perspective (e.g., to think of screening as a valuable health check with less focus on it being an ‘unpleasant’ procedure), so as to change thoughts and feelings about attendance.	Persuasion, Enablement

[a] – These BCTs are not classified as *frequently used techniques* in association with the intervention functions identified. However, they are included here as they have been judged to have particular relevance for the specific intervention aim of increasing timely attendance at cervical screening participation in areas of high relative deprivation.

6.4.3.2 Identify modes of delivery

Potential modes of delivery (i.e., ways in which intervention functions and behaviour change techniques might be delivered) broadly cover a range of face-to-face or distance methods and may target individuals, groups or populations. In the present context, face-to-face methods of engagement, at individual or group level were deemed most acceptable to targeting those living in areas of high relative deprivation. Given the suggestions for intervention from community members reported in Chapter 5, leaflets (i.e. a population focused mode of delivery) may also be an acceptable mode of delivery for the target population, but only if they are carefully tailored to the target population.

The identified targets of change, and associated intervention functions, policy categories, and BCTs presented above are summarised in Table 6.8, with examples of how these intervention options/content could be operationalised within the relevant context. It should be noted that any form of intervention would require further evaluation and refinement in line with guidance from the Medical Research Council (Craig et al., 2008). Therefore, the example content and delivery of interventions may be amended depending on available resources and the overall design of any subsequent interventions.

Table 6.8. Summary of relevant targets of change (with COM-B/TDF domains), associated intervention functions, policy categories and BCTs identified to encourage timely attendance at cervical screening attendance within areas of high relative deprivation.

Summary of what needs to change to encourage timely attendance within areas of high relative deprivation[a].	**TDF domain**	**Intervention functions**	**Policy categories**	**Behaviour Change Techniques**	**Examples of content**	**Example modes of delivery[b]**
Social Opportunity						
Wider acceptability and normalisation of screening attendance. Greater opportunities to	Social influence	Environmental restructuring Modelling Enablement	Guidelines Service Provision Communication / marketing	Restructuring the social environment	Promotion of peer support workers to discuss women's health/screening.	Face-to-face, community-based peer support. Group-based health promotion in
				Social support (practical)	Support women to arrange 'buddying' appointments so women can provide childcare	

discuss screening with others. Consistent access to supportive and welcoming healthcare provision/ professionals					for each other during their appointment.	schools during HPV vaccination
				Social support (emotional)	Advise individuals to take a friend/family member to an appointment.	
				Information about others approval	Advise that others’ in the community believe screening attendance to be a good idea.	
Physical opportunity						
Greater access to suitable/flexible appointments and screening locations.	Environmental context and resources	Training Environmental restructuring Enablement	Guidelines Service Provision	Restructuring the physical environment	Offer cervical screening at the same time as contraception checks/fittings. Out of normal hours screening appointments as standard.	Drop-in women’s health clinic. Healthcare provider – patient communication
				Restructuring the social environment	Providing a welcoming, informal environment.	

				Social support (practical)	Offer short notice, or drop-in appointments to increase access.	
				Conserving mental resources	Advise that screening and contraception can be done at the same time to reduce cognitive demand of remembering and identifying time to schedule two separate appointments.	
Psychological capability						
Wider understanding of the purpose, benefits and disadvantages of routine screening. Wider familiarity with the	Knowledge	Education	Guidelines Service Provision Communication / marketing	Information on health consequences	Inform individuals of the purpose of screening and introduce the benefits and disadvantages to attendance to ensure informed choice.	Face-to-face, community-based peer support. Group-based health promotion in schools during

screening process						HPV vaccination. Co-created leaflets
Wider ability to read and understand screening related information.	Cognitive and interpersonal skills	Training	Guidelines Service Provision	Demonstration of the behaviour	Provide visual information to facilitate understanding.	Co-created leaflets
Increased reminders (to plan and arrange attendance given several competing priorities).	Memory, attention, and decision processes	Training Environmental restructuring	Guidelines Service Provision	Commitment	Advise individual to make/affirm a commitment to attending screening when invited describing timely attendance as high priority.	Face-to-face, community-based peer support. Group-based health promotion in schools during HPV vaccination.
		Enablement		Conserving mental resources	Advise individual to book an appointment upon receiving an invitation letter to reduce reliance on memory at a later date.	

				Prompts/cues	Place posters/stickers in GP surgery waiting room to encourage individuals to arrange attendance.	Healthcare provider – patient communication
Greater understanding of ways to cope with the psychological/ emotional discomfort associated with cervical screening	Behavioural regulation	Education Training Modelling Enablement	Guidelines Service Provision Communication / marketing	Problem solving	Encourage individuals to identify barriers to making an appointment and identify solutions that could address these barriers.	Face-to-face, community-based peer support.
				Reduce negative emotions	Advise on ways of reducing negative emotions surrounding appointment making/primary care.	
Automatic motivation						
Individuals to feel a need to attend routine cervical screening despite potentially	Emotion	Persuasion Modelling Enablement	Guidelines Service Provision Communication / marketing	Reduce negative emotions	Advise on ways to reduce embarrassment and/or fear surrounding the screening test.	Face-to-face, community-based peer support. Healthcare provider -
				Social support (emotional)	Provide psychologically informed healthcare	

strong emotional barriers to doing so.					professionals to ensure individuals feel emotionally supported to attend.	patient communication
				Information about emotional consequences	Advise that attendance may result in individuals feeling relief.	
				Anticipated regret	Advise that non-attendance or postponement may result in feelings of regret.	
				Framing/reframing	Suggest cervical screening attendance should be viewed as a valuable health check, as opposed to embarrassing/scary/ unpleasant.	
Reflective motivation						
Individuals to believe that cervical	Beliefs about consequences	Education Persuasion	Guidelines	Information about emotional consequences	Inform individual that despite screening related discomfort,	Face-to-face, community-

screening is important and potentially lifesaving Individuals to challenge belief that cervical screening will be psychologically and physically unpleasant		Modelling	Service Provision Communication / marketing		they may experience relief following attendance.	based peer support. Healthcare provider – patient communication Co-created leaflet
				Information about health consequences	Inform individuals on the purpose of screening and introduce the benefits of disadvantages to attendance to ensure informed choice.	
				Anticipated regret	Advise that non-attendance or postponement may result in feelings of regret.	
				Comparative imaging of future outcomes	Prompt individual to imagine potential outcomes of timely attendance versus non-timely attendance.	
				Reduce negative emotions	Advise on ways to reduce embarrassment and/or fear surrounding the screening test.	
				Framing/reframing	Suggest cervical screening attendance should be viewed	

					as a valuable health check, as opposed to a focus on the test being embarrassing/ frightening /unpleasant.	
Individuals to hold an intention to attend promptly (rather than a general intention to attend).	Intentions	Education Persuasion Modelling	Guidelines Service Provision Communication / marketing	Information about health consequences	Inform participants on the purpose of screening and why timely attendance may be important.	Face-to-face, community-based peer support. Group-based health promotion in schools during HPV vaccination. Healthcare provider – patient communication Co-created leaflet
				Information about others approval	Suggest that others within the community believe timely attendance is important/worthwhile.	
				Commitment	Advise individual to make/affirm a commitment to attending screening when invited describing timely attendance as high priority.	
				Framing/reframing	Suggest individuals view screening as something to prioritise and participate in upon invitation, as opposed to	

					viewing as something that can be postponed indefinitely.	
Individuals to believe that they are able to attend, even in light of competing priorities/family life.	Beliefs about capabilities	Education Persuasion Modelling Enablement	Guidelines Service Provision Communication / marketing	Problem solving	Encourage individuals to identify barriers to making an appointment and identify solutions that could address these barriers.	Face-to-face, community-based peer support.
Individuals to believe that there will be a positive outcome as a result of attending screening.	Optimism	Education Persuasion Modelling Enablement	Guidelines Service Provision Communication / marketing	Framing/reframing	Suggest cervical screening attendance should be viewed as a valuable health check, as opposed to a focus on the test being embarrassing/ frightening /unpleasant.	Face-to-face, community-based peer support. Healthcare provider - patient communication Co-created leaflet
				Information about emotional consequences	Advise that attendance may result in individuals feeling relief.	

[a] – Refers to multi-level targets of change. For example, '*Wider acceptability of normalisation of screening'* refers to change needed at the community level, 'Individuals *to feel a need to attend routine cervical screening despite potentially strong emotional barriers to doing',* requires change needed at the individual level. [b]- Example modes of delivery are based on suggestions from those living in areas of high relative deprivation

6.5 Discussion

6.5.1 Principal findings

Following guidance from the Behaviour Change Wheel (Michie et al., 2014), this study combined qualitative evidence and theory to identify a) what needs to change in terms of capability, opportunity and motivation to encourage timely attendance at routine cervical screening appointments in areas of high relative deprivation and b) what intervention functions, behaviour change techniques and policy categories might be recommended to encourage timely attendance at routine cervical screening appointments in areas of high relative deprivation.

A behavioural diagnosis was conducted via a mapping exercise linking determinants of screening to COM-B components and, for a more granular level of detail, TDF domains. Findings suggested that, to encourage timely screening attendance within the relevant population, changes would be needed in relation to (social and physical) opportunity, (psychological) capability and (automatic and reflective) motivation. Broadly, this suggests intervention developers must employ multi-faceted intervention with the aim to make cervical screening both psychologically and physically easier to access. Ranking the associated TDF domains in terms of frequency (number of studies in which the domain occurred) and elaboration (number of themes linked to the domain) demonstrated targets of change that were most commonly mentioned by those living in areas of high relative deprivation. The top three most important domains being Social influence (social opportunity), Environmental context and resources (physical opportunity) and Emotion (automatic motivation) (See Table 6.4 for full ranking). As such, it may be appropriate to prioritise these factors in subsequent future intervention development, to ensure the views and priorities of the target population are addressed.

The present study also presented intervention options and content that are likely to be effective in increasing attendance within areas of high relative deprivation. Six intervention functions of Education, Persuasion, Training, Environmental restructuring, Modelling and Enablement were recommended as appropriate in achieving this aim. From this, 16 BCTs (see Table 6.7) were also identified as suitable content to encourage the specified behaviour change. Whilst this approach has been used widely in relation to a range of health-related behaviours (e.g. Barker et al., 2016; Cassidy, Steenbeek, Langille, Martin-Misener, & Curran, 2019; Fulton et al., 2016; West et al., 2020) this study is the first to use the Behaviour Change Wheel to identify specific intervention components/strategies appropriate for increasing cervical screening attendance in areas of high relative deprivation in the UK.

To further support delivery of this content, some potentially valuable policy categories (guidelines, service provision, communication/marketing) and modes of delivery (broadly face-to-face methods targeting individuals or groups, leaflets) were also identified. However, it is important to note that media based communication is already widely used/employed to encourage routine cervical screening attendance (e.g. Stubbs & Pearmain, 2019) and should be carefully considered throughout later stages of intervention development to ensure it does not encourage stigma towards those who do not, or cannot, participate (McGeechan et al., 2020; Wearn & Shepherd, 2020) . Leaflet based interventions should be also be developed with caution to ensure the information included is accessible for those with low levels of health literacy and/or language barriers (Helitzer et al., 2009). As such, it is suggested this approach should preferably be used *alongside*, not instead of, face-to-face methods and content must be tailored to the intended audience. It is also important to note that the practicality of policy categories and modes of delivery depends on the policy levers and resources researchers have access to, and therefore should be reviewed throughout subsequent intervention development, when implementation becomes of greater focus.

6.5.2 Strengths and limitations

The present study is the first, to the author's knowledge, to apply the Behaviour Change Wheel to community-identified determinants of routine cervical screening participation, within areas of high relative deprivation in the UK. This approach facilitates the identification of theoretically based targets of behaviour change and, importantly, identifies a package of intervention options and content appropriate for encouraging timely cervical screening attendance in areas of high relative deprivation. Whilst this study is the first to apply this method of intervention development to the present context, the systematic approach employed here, and the associated terminology used, is well-established in both academic research and public health (e.g. Public Health England, 2019a). Therefore, these findings are relevant and more easily translatable not only to future related research, but also to health policy and public health practice.

Despite these strengths, it is important to acknowledge the limitations of this work. As mentioned throughout, addressing socioeconomic and place-related barriers to timely attendance at a cervical screening appointment requires intervention beyond the individual. Given those living in areas of high relative deprivation often have significant external/environmental barriers to engaging with health services (Holman et al., 2018), it is therefore important to acknowledge that the specific intervention content recommended here would be most effective when employed alongside wider community and population level intervention to reduce health and social based inequalities (e.g. improving resource and healthcare access on a wider scale). Without this broader focus on reducing inequalities, it will be particularly difficult to address barriers related to individual's *environmental context and resources,* an area of influence that was commonly mentioned throughout the qualitative research synthesised within this study. Nonetheless, these intervention strategies take into account the social and environmental context of the target population and as such present a package of multi-faceted intervention components, to ensure that behaviour change is not solely the responsibility of the individual and can also be supported and encouraged through, for example, restructuring the social and physical environment.

It is also important to note that *physical capability* was not deemed a relevant target of change, as it was not brought up as an issue during the range of qualitative research synthesised within this study. However, the relevance of this particular component may increase for those with physical disabilities (Kilic, Tastan, Guvenc, & Akyuz, 2019). As such, it may be useful to seek the views and perspectives of those who experience capability-based barriers to ensure subsequent interventions fully consider the importance and influence of this domain.

6.5.3 Recommendations for future research

A number of intervention options and strategies are recommended in section 6.4.3, to increase cervical screening attendance in areas of high relative deprivation. These recommendations have been developed in light of qualitative evidence and a theoretical understanding of behaviour change. To support further development of these recommendations for piloting, it would be valuable to model potential outcomes related to the specific intervention components detailed here. For example, experimental studies could be conducted to investigate the influence of recommended BCTs (e.g., information about others' approval, information about emotional consequences of participation/non-participation, reframing cervical screening) on screening related thoughts, feelings and/or behaviour.

The intervention components outlined here may also inform the refinement/adaptation of existing interventions, which aim to increase cervical screening participation and/or increase access to preventative healthcare services. For example, these findings could be used to identify missed opportunities for improvement and/or inform intervention developers to tailor existing interventions to benefit those living in areas of relative deprivation. Given the challenges in sourcing additional resources in healthcare (Robertson et al., 2017), using these findings to inform and amend interventions already in-place may be a cost-effective approach of ensuring those living in areas of high relative deprivation are adequately supported to attend their routine screening appointments.

6.5.4 Conclusion

This study applied a systematic, theoretically based approach to developing intervention strategies appropriate for encouraging timely attendance at routine cervical screening for those living in areas of high relative deprivation. Specifically, this study aimed to understand what needs to change (in terms of capability, opportunity and motivation) in order for timely attendance to occur and in addition, identify intervention functions, behaviour change techniques and policy categories appropriate to encouraging behaviour change for those within the target population. A range of qualitative evidence, comprising of findings from a systematic review, one-on-one interviews, focus groups and an online survey were mapped to COM-B and TDF domains demonstrating that changes in Psychological capability, Social and Physical Opportunity and Automatic and Reflective motivation are relevant targets of change within this present context. In relation to the TDF domains, Social Influence, Environmental Context and Resources and Emotion appear to be the most important areas of influence when taking into account community perspectives. From this, 6 intervention functions, 16 BCTs and 3 policy categories were selected as intervention components appropriate for encouraging behaviour change within the target population. Recommendations for content and delivery were provided based upon these intervention components.

This study is the first to systematically apply the behaviour change wheel to understanding and addressing socioeconomic inequalities in UK routine cervical screening participation. These findings can be used to in inform both the development of novel interventions and the refinement of existing interventions to ensure the needs and priorities of those living in areas of high relative deprivation are being met. Future work should also aim to test the influence of BCTs on screening related thoughts, feelings and behaviours within the target population.

6.6 Chapter Summary

Following MRC guidance (Craig et al., 2008) the present chapter identified and developed a theory of behaviour change relevant to routine cervical screening. Viewing the qualitative findings presented throughout this thesis through the lens of the COM-B model facilitated a deeper understanding of the process of behaviour change needed to address existing socioeconomic inequalities in routine cervical screening participation. The application of the COM-B, and by extension the behaviour change wheel, also facilitated the development of tailored and theoretically based intervention options and strategies which have the potential to increase timely cervical screening attendance in areas of high relative deprivation. The following chapter aims to discuss the contribution of these findings in light of existing research and consider the implications of this research to future research, policy and practice.

7 General Discussion

7.1 Synopsis

The previous chapters have a) reported in-depth insight into the determinants of cervical screening participation within areas of high relative deprivation within the UK, b) conducted a behavioural diagnosis of the problem, and c) outlined intervention components and strategies that are likely to be suitable and acceptable in reducing the observed inequalities in participation. The present chapter provides an overview of the intended aims and research questions addressed within this thesis. Findings across studies will be summarised and, following this, the contribution of these findings are outlined and considered in relation to current literature. The implications of the current project are reviewed, and general strengths and limitations are discussed. Finally, suggestions for future recommendations are provided.

7.2 Overview of aims and research questions

The overarching aim of this thesis is to systematically combine evidence and behavioural theory to understand inequalities in cervical screening participation and develop intervention strategies that have the potential to increase uptake within areas of high relative deprivation. Two broad research questions investigated this aim:

1) What are the factors influencing routine cervical screening participation in areas of high relative deprivation?

2) How can we best address the observed socioeconomic inequalities in cervical screening participation?

7.2.1 Research Objectives

In order to address these two broad research questions, several specific research objectives were outlined. These were to:

- Identify existing literature which highlights the determinants of cervical screening from perspectives of under-served women (Chapter 2)
- Consider how to effectively access the perspectives of those living in areas of high relative deprivation (Chapters 3 and 4)
- Explore relevant factors influencing participation for those living in areas of high relative deprivation (Chapters 2, 3 and 4 and 5).
- Explore how identified factors may contribute to socioeconomic inequalities in cervical screening participation (Chapter 5)
- Identify intervention characteristics, that are acceptable to stakeholders, to increase cervical screening participation in areas of high relative deprivation (Chapter 5)
- Develop a theoretical understanding of cervical screening participation in areas of high relative deprivation, and the likely process of change (Chapter 6)
- Develop suitable intervention components and strategies that have the potential to increase screening attendance in areas of high relative deprivation (Chapter 6).

Both research questions were addressed in line with guidance from the Medical Research Council's Framework for developing complex interventions (Craig et al., 2008) using a multi-method approach across five studies. It was important to take a qualitative approach and access the perspectives of those least likely to attend routine cervical screening, as the views of those living in socioeconomically deprived areas are traditionally marginalised and thus largely missing from past academic research (Bonevski et al., 2014). A summary of study findings are presented below in the context of the relevant research question.

7.3 Summary of findings

7.3.1 What are the factors influencing routine cervical screening participation in under-served women?

To answer the first research question, it was necessary to 1) identify the existing evidence base and 2) understand the target behaviour in greater depth. To gain an over-arching understanding of the factors influencing routine cervical screening participation, the existing qualitative evidence base in the area was identified through a systematic review (Study 1, Chapter 2). This review synthesised the determinants of routine cervical screening from the perspectives of under-served women (i.e. those who face healthcare related disadvantage; in this case those of low socioeconomic status and ethnic minority women). Literature specifically relating to ethnic minority women was included to ensure an overview of potentially relevant factors across a culturally diverse group, given those living in socioeconomically deprived areas are predominately of ethnic minority status (see Office for National Statistics, 2019a). Whilst other systematic reviews have broadly considered determinants of cervical screening (e.g. Chorley et al., 2016), there was no review of qualitative evidence which specifically focused on determinants of cervical screening for under-served women, within the context of a population-wide, call-recall programme (i.e. reflective of the UK national cervical screening programme).

There were 21 studies identified and synthesised (n=18 focusing on the perspectives of ethnic minority women, n=2 focusing solely on the perspectives of those living in socioeconomically deprived areas and one study which focused on both of these populations). Using Dahlgren and Whitehead’s Social Model of Health (1991) as an *a priori* framework, previous literature was synthesised and the resulting themes were categorised at *The individual*, *Social network*, *The healthcare environment* and *Wider society* levels. Categorising determinants in this way highlighted that factors influencing screening participation operate at multiple levels. This synthesis outlined complex interrelationships between determinants, suggesting that under-served women often face an accumulation of barriers. Given only n=2 studies were identified which focused on those living in socioeconomically deprived areas, this review also highlighted the lack of existing research which takes into account the views and experiences of those least likely to attend. This led to further complementary qualitative research being conducted, aiming to access the views of those who lived in areas of high relative deprivation (as categorised by the Index of Multiple Deprivation 2015; Department for Communities and Local Government, 2015), through one-on-one interviews (Study 2, Chapter 3) and a qualitative online survey (Study 3, Chapter 4).

Study 2 consisted of 15, one-on-one interviews with those living in areas classified within the ≤30% most deprived neighbourhoods in England. All participants self-reported that they were up to date with their cervical screening appointments, believed screening was beneficial for health and intended to take up future invitations to attend. However, throughout the interviews some participants suggested they had previously ‘postponed’ attendance, in some cases for many years. Overall, it was suggested that factors influencing cervical screening participation related to participant’s *Personal motivation*, *Community* and *The healthcare environment*. Personal motivation to attend (compromising of both emotions towards screening, and screening-related beliefs) was generally discussed as a barrier to prompt engagement. In contrast, participant’s community and healthcare environment had the potential to facilitate screening attendance through positive interpersonal relationships and communication. Whilst supporting the outcomes of the previous systematic review, these findings highlighted key areas of influence for those living in areas of high relative deprivation and provide further important detail on the facilitative nature of social factors in encouraging prompt screening participation.

Study 3 was a qualitative online survey, aiming to provide an accessible and anonymous route for those living in areas of high relative deprivation to share their views towards cervical screening participation. This method posed unanticipated challenges engaging those living in areas of high relative deprivation, but nonetheless introduced valuable insight into some more sensitive topics surrounding cervical screening participation. Participants' views towards participation were expressed through 3 broad themes; *Screening is worthwhile*, *Screening can be difficult to access* and *Past experiences are important*. These over-arching themes emphasised the cognitive conflict often present in relation to cervical screening whereby participants felt attendance was worthwhile and had valuable health benefits, but in contrast was psychologically difficult to access due to expectations that the test would be both physically and emotionally unpleasant. This study also highlighted appointment-making, lack of time and lack of alternative screening location as barriers to participation. Whilst it is notable that this method was not successful in recruiting an ethnically diverse sample, it was beneficial in that it appeared to encourage disclosure of particularly sensitive topics influencing uptake, with participants also highlighting significant psychological barriers to participation posed by previous trauma and negative past experiences with healthcare staff.

Combined, this multi-method approach has resulted in a broad, in-depth understanding of factors that influence cervical screening participation for those living in areas of high relative deprivation. The systematic review identified an overview of relevant determinants, with the subsequent primary qualitative research providing additional depth of detail; demonstrating how factors can help or hinder engagement within the context of UK screening services.

Given the well-established challenges in accessing the perspectives of socioeconomically deprived groups (Bonevski et al., 2014; Erves et al., 2017; Rockliffe et al., 2018; Sadler et al., 2010), Studies 3 and 4 also reflected upon the value of face-to-face and online methods in discussing cervical screening participation within this group. Across both studies, recruitment of participants was particularly time-consuming. However, community-based face-to-face methods of recruitment offered a chance to build a rapport with individuals and communities, which in turn facilitated recruitment and detailed data collection. As indicated above, online methods of recruitment and data collection were less successful in engaging the target population, potentially hindered by the previously observed challenges surrounding internet use and access for those in areas of high relative deprivation (Longley & Singleton, 2009; Watts, 2020; Yates et al., 2020). However, online data collection does confer some benefits in that it appears to be an acceptable way for participants to disclose particularly sensitive and personal information. Overall, community-based, face-to-face methods appeared to be the most valuable in engaging participants from traditionally seldom-heard populations, but the costs and benefits of recruitment and data collection approaches must be carefully considered in line with the research aims and context.

7.3.2 How can we best address socioeconomic inequalities in cervical screening uptake?

In light of the findings detailed above, this research question aimed to broadly identify and explore appropriate intervention options and content. This was achieved through stakeholder discussion (Study 4a and 4b, Chapter 5) and the systematic application of behavioural theory (Study 5, Chapter 6).

Study 4 aimed to discuss previously identified factors from a community perspective and identify suitable ways in which to increase cervical screening participation within areas of high relative deprivation. These aims were explored in two stages. First, four focus groups were conducted at community venues situated within 10% most deprived areas in England (Study 4a). Groups were encouraged to give their views on previously identified barriers and discuss their own thoughts regarding factors that contributed to the low levels of uptake observed within their communities. Following this, the groups then considered acceptable ways to address any barriers to participation. Community-based suggestions for intervention were then taken forward and considered in one-on-one interviews with health-related professionals. These professionals spanned research, the community sector and healthcare to gain a sense of feasibility from an organisational perspective. Data from both stages were analysed together to ensure a well-rounded understanding of stakeholder perspectives. Findings re-examined determinants of screening within the social and economic context of disadvantaged communities, highlighting how factors contribute to the overarching socioeconomic inequalities in participation and emphasising the psychological impact of relative deprivation. *External factors* (i.e. *Negative experiences of primary care*, *Competing demands* and *Social Influence*) were felt to be important drivers of non-participation and postponement within socioeconomically deprived communities, these in turn linked to more individualised *Internal factors (*i.e. *Screening-related knowledge, Prioritisation of screening and Emotional response to clinical care)* that directly influenced participation. A key finding here was that postponement of screening was often framed as a logical choice in light of multiple competing demands and low resource availability.

From these discussions, participants suggested intervention characteristics that they felt would be acceptable to their communities. Broadly, interventions should aim to *Increase service accessibility* whilst also *Working in partnership to normalise screening.* In terms of increasing service accessibility, some specific recommendations were suggested, these related to *Introducing drop-in appointments*, *Considering non-clinical environments* for women to access screening (e.g. community venues) and *Integrating cervical screening with other gynaecological services*. In addition, participants made specific recommendations in regard to communities and healthcare providers working together to *Introduce screening from adolescence in schools*, *Increase peer support in communities* and *Develop co-created information*. These suggestions were deemed acceptable to the target population and thus provided a strong foundation from which to consider future intervention. Health-related professionals were broadly supportive of community suggestions although highlighted feasibility related concerns surrounding finance and resource availability, which have the potential to hinder the development and implementation of interventions even when deemed to be effective and/or acceptable to delivery staff.

Considering research evidence through the lens of behaviour change theory is strongly suggested to clarify the likely process of change (Craig et al., 2008). In light of this, Study 5 took a systematic approach to integrating participant insight and a theoretical understanding of behaviour change, using the Behaviour Change Wheel (BCW; Michie et al., 2014). Within this study, the previous study findings were mapped to the COM-B model (Michie et al., 2011) and the Theoretical Domains Framework (TDF; Cane et al., 2012; Michie et al., 2005) to facilitate a behavioural diagnosis of the problem and identify appropriate targets of change. A behavioural diagnosis highlighted *Psychological Capability, Social and Physical Opportunity* and *Automatic and Reflective Motivation* as important targets of behavioural change. Whilst highlighting key targets of change, the inclusion of the TDF during the mapping process also allowed for consideration of more granular areas of influence that were prioritised throughout the qualitative research. In order of frequency (number of studies in which the domain occurred) and elaboration (number of themes mapped to the domain), timely attendance at cervical screening was therefore found to be influenced by *Social influences*, *Environmental context and resources*, *Emotions*, *Beliefs about Consequences*, *Cognitive and interpersonal skills*, *Knowledge*, *Intentions*, *Memory, attention and decision-making processes*, *Behavioural regulation*, *Beliefs about capabilities* and *Optimism*.

Once targets of change were identified, these could be linked to specific intervention components and strategies likely to be effective in encouraging timely screening participation for those living within areas of high relative deprivation. Six intervention functions of *Education, Persuasion, Training, Environmental restructuring, Modelling and Enablement* were identified as appropriate ways in which to change the target behaviour. Moreover, 16 specific BCT’s and three policy categories were identified, which together formed a detailed list of tailored recommendations and strategies summarised in section 6.4.3.

7.4 Original contribution to knowledge

The findings summarised above have made some important contributions to current knowledge in the area. Firstly, to understand and adequately address socioeconomic inequalities in health behaviour, it is important to gain an understanding of contributing determinants, and how these impact upon individuals and communities. Whilst much cervical screening literature present generalised overviews of determinants (e.g. Bukowska-Durawa & Luszczynska, 2014; Chorley et al., 2016; Plourde, Brown, Vigod, & Cobigo, 2016), this programme of research has taken a multimethod, qualitative approach to understanding the factors relevant to those least likely to attend. Given the persistent disparities in uptake between the most and least deprived areas in the UK (Douglas et al., 2016; Public Health England, 2019d), cervical screening participation was viewed within the context of area-level deprivation. This measure of deprivation goes beyond commonly used individual measures (e.g. household income, education level or occupation) as it takes into account the social and environmental context in which individuals live (Lakshman et al., 2011; Pepper & Nettle, 2018). To the author’s knowledge, this was the first programme of research to focus on area-level socioeconomic inequalities in cervical screening participation within the North East of England, a region with high levels of health inequality (ONS, 2019; Public Health England, 2017) and wide variations in routine cervical screening uptake (NHS Digital & Office for National Statistics, 2018).

The methods taken here are also reflective of participatory approaches in tackling public health issues. Participatory research is a relatively new approach within health psychology literature (although used extensively in education and social work research; Stern, Townsend, Rauch, & Schuster, 2013) which offers varied opportunities for public and stakeholder involvement (Andrews, Allen, Sheppard, Baylis, & Wainwright, 2015;

Involve, 2012; Public Health England, 2014a). In short, participatory methods promote collaboration between professional researchers and communities throughout the research process (see Wright, Cook, Springett, & Roche, 2013). The studies detailed here, particularly the focus groups reported as part of study 4, enabled the direction of the research to be heavily influenced by the views and perspectives of a traditionally marginalised group, and more closely linked to the needs of the target population.

The resulting qualitative findings demonstrate the important influence of contextual factors in both facilitating and hindering engagement with cervical screening. Determinants of cervical screening are most commonly discussed in terms of individual level factors, such as embarrassment and fear, low perceived risk of cervical cancer and screening related knowledge (e.g. Eaker et al., 2001b; Ekechi et al., 2014; B. Lovell et al., 2015; Walsh, 2006). Whilst these determinants are clearly important to understanding cervical screening participation, gaining an understanding of these factors alongside broader contextual factors gives a stronger foundation to developing and targeting interventions to where they are most needed (Sorensen et al., 2003). Previously, Plourde et al. (2016) conducted a systematic review of contextual factors associated with breast and cervical screening and found that provider and structural-level factors were associated with participation. Although the application of these findings to a UK context is limited, as almost all the studies included within the review came from the USA (which does not have a free population-wide, call-recall approach to cervical screening). Moreover, contextual factors were not considered in conjunction with individuals’ socioeconomic background. Highlighting the contextual factors of cervical screening within area-level deprivation is important as, clearly, those living within socioeconomically deprived areas are more likely to face external barriers and challenges to accessing healthcare services (as discussed in Chapter 5). The present thesis identified and considered these broader contextual factors by employing Dahlgren and Whitehead’s Social Model of Health (1991) as an initial conceptual framework, situating identified determinants within this framework to demonstrate cervical screening participation within the broader context of individual's everyday lives. As a result, more distal layers of influence that impact upon participation were highlighted. For example, the quality of participants' social networks, general experiences of, and within, primary care and low resource availability to access health services, appeared to be important contextual factors specific to cervical screening participation within areas of high relative deprivation. Overall, these findings highlight the relevance of place-based approaches (i.e. acknowledging the wider conditions in which people are born, live and work) to understanding engagement with screening services (Public Health England, 2019c)

Viewing determinants through the lens of the Social Model of Health (Dahlgren & Whitehead, 1991), the COM-B model (Michie et al., 2011) and the TDF (Michie et al., 2008) also contributes to our understanding of socioeconomic inequalities in participation as it translates the often-marginalised perspectives of the target population into a 'shared language' of theoretical frameworks and concepts widely used in both research (Barker et al., 2016; Fulton et al., 2016; Lorencatto, West, & Michie, 2012; McEvoy et al., 2018; Smits et al., 2018) and public health (Health Education England, 2020; Public Health England, 2019a, 2019c). Moreover, the present thesis is the first, to systematically apply guidance from both the MRC (Craig et al., 2008) and the BCW (Michie et al., 2014) to understand and address socioeconomic inequalities in cervical screening participation. The MRC and BCW frameworks offer complementary, tried and tested routes to developing complex behavioural interventions (McEvoy et al., 2018), incorporating evidence and established theory to result in greater likelihood of change, in this case specifically related to increasing cervical screening participation in areas of high relative deprivation.

7.5 Implications for theory

The present thesis contributes to a theoretical understanding of socioeconomic inequalities in cervical screening participation and has moreover highlighted theoretically based connections and interrelationships between factors that reflect the real day-to-day life experiences of participants. To the authors knowledge, there is no existing theoretical model or framework that aims to specifically explain pathways to socioeconomic inequalities in cervical screening participation. However, von Wagner, Good, Whitaker and Wardle (2011) present a conceptual framework to explain socioeconomic differences in the psychosocial predictors of cancer screening. In short, this framework suggests that stressors and resources for change (e.g., levels of crime, unemployment, quality of housing and medical facilities), educational opportunities and illness experiences associated with low socioeconomic status influence perceived threat of cancer screening, self-efficacy to participate in screening and the perceived value of screening. This in turn influences decision-making and how individuals process cancer screening-related information.

This detailed framework outlines components that are reflective of the determinants discussed throughout this thesis. However, cervical screening was associated with a significant negative emotional response for many women, which is not captured within this explanatory framework. Moreover, practical access to screening services (e.g. availability of suitable appointments) was discussed as a key barrier to engagement within the present research yet this was also not adequately reflected in von Wagner et al's (2011) framework. As such, these findings support the development of a more comprehensive and definitive theoretical understanding of socioeconomic inequalities in cervical screening participation, which may also have implications for cancer screening behaviours more broadly. The learning presented here could also be used to inform future research. For example, researchers could build on this work by quantitatively testing the conceptual links discussed throughout the thesis, and thus further develop our theoretical understanding of this topic.

Across studies, women commonly referred to postponement of screening, either currently or in the past, and differentiated this from ‘non-participation’. i.e. an individual may not have responded to a screening invitation, but they *intended* to at some undefined future point and so did not readily describe this as non-participation. As discussed earlier within the thesis, there is a growing body of literature suggesting the majority of non-attenders hold positive intentions to screen (Marlow et al., 2017). In light of participants’ responses, the factors discussed throughout this thesis may inform our understanding of the cervical screening related intention-behaviour gap in the context of relative deprivation. Postponement of screening may arguably be viewed as faulty decision-making, given the associated health risks of non-timely participation. However, findings within Chapter 5 suggested postponement was viewed as a sensible, logical choice given the amount of pressing demands that community members often faced. These findings link to recent theoretical developments which consider an adaptive ‘psychological shift’ in decision-making that occurs as a result of experiencing low socioeconomic status (Sheehy-Skeffington, 2019), whereby individuals’ focus on present needs even when this may be risky or counter-effective in relation to long-term goals (Sheehy-Skeffington, 2020). The present thesis therefore presents preliminary qualitative evidence which reflects this present-orientated focus in relation to inequalities in preventative health behaviour and suggests that this may contribute to an intention-behaviour gap within the target population. As outlined in Chapter 6, within the current context, interventions should therefore aim for *timely* participation (or at the very least a reframing of intentions, to attend within a specified time period). Interventions which aim to increase a general intention to screen are unlikely to be effective for a large proportion of women living within areas of high relative deprivation. Given the scarcity of research and current understanding within this area, this would be an important and interesting avenue to explore further.

7.6 Practical implications

The knowledge developed throughout this thesis has several practical implications. The findings throughout Chapters 1-5 demonstrate that to change screening related thoughts, feelings and behaviours, intervention is needed on a broader scale. Individuals, particularly those who experience social disadvantage, require support to enact health behaviours at social, organisational and environmental levels. The present thesis suggests that developing interventions that encompass positive social influence and support may be particularly beneficial as, throughout studies, these were key facilitators of attendance. Social support may refer to, or be inclusive of, informational, emotional and/or practical support, all of which appear to have clear benefits in encouraging participation within for those living in areas of high relative deprivation. Past literature suggests social connection and support is strongly associated with positive health outcomes and can positively influence engagement in a range of health behaviours (Cacioppo & Cacioppo, 2014; Cohen, 2004; Umberson & Karas Montez, 2010). Indeed, previous research has demonstrated an association between social support and cancer screening uptake (Documet et al., 2015; Gamarra et al., 2009; Jensen et al., 2016; Seow et al., 2000), although this evidence is mixed (Allen, Stoddard, & Sorensen, 2008; Kang, Bloom, & Romano, 1994; Suarez et al., 2000). Through Chapter 5, participants suggested that receiving information from peers was an acceptable way to learn about, and normalise, routine cervical screening. This is reflective of previous evidence which suggests lay health advisors may be a useful way of delivering health-related information and support to those within low socioeconomic groups (Rees et al., 2018; Smith et al., 2018). The present findings also support past evidence which suggests those in low socioeconomic groups perceive others within the same social group as a trusted source of information and advice (i.e. in relation to those outside of their own social class) (Navarro-Carrillo, Valor-Segura, & Moya, 2018). The intervention components presented in section 6.4.3, demonstrate a number of ways in which informational, emotional and practical social support could therefore be offered through peer-led interventions to encourage timely participation within areas of high relative deprivation in the UK.

Although participants suggested support from those within their own communities was a facilitator of participation, social support and connection did not only refer to family, friends and peers. Participants across studies indicated that it was important for women to feel safe and supported when attending cervical screening, and as such, positive patient-practitioner relationships were an integral aspect facilitating this. These findings are consistent with a wealth of previous literature which has found an association between health-care relationships and adherence to cancer screening programmes in other countries (Kindratt, Atem, Dallo, Allicock, & Balasubramanian, 2020; Matejic, Vukovic, Pekmezovic, Kesic, & Markovic, 2011; O'Connor, Murphy, Martin, O'Leary, & Sharp, 2014; O'Malley, Forrest, & Mandelblatt, 2002; Peterson et al., 2016; Sheppard et al., 2008). There is minimal evidence exploring this factor in relation to UK based socioeconomic inequalities in cervical screening participation, although a recently published study highlighted that empathy from screen-takers, and the ability to build a rapport with patients was an important influence within a culturally diverse sample of older women, categorised as low socioeconomic status by social class (Marlow et al., 2019). Within the present thesis, participants own experiences within primary care appeared to be variable, with an overarching view that quality healthcare provision was dependent upon the GP surgery participants were registered with. Indeed, participant's reticence to attend screening was often related to wider healthcare experiences and relationships, not only those with screen-takers. Given the procedure can be significantly psychologically challenging for some women (as highlighted particularly through Chapter 4), uncertainties around, or expectations of, poor healthcare relationships (informed by personal past experiences or the experiences of others) are not conducive to encouraging participation. It is important for healthcare providers to ensure that service provision is both psychologically and practically accessible to those living in areas of high relative deprivation.

The primary qualitative research conducted throughout this thesis has also provided important methodological insight into suitable ways in which to access the perspectives of those living in areas of high relative deprivation. Those living in socioeconomically deprived areas are often described as a hard-to-reach group. However, the terms 'seldom-heard' or 'marginalised' better represent this target population, who often do want to contribute to research but find doing so inaccessible (Erves et al., 2017; Sadler et al., 2010). In light of this, researchers should aim to amend traditional recruitment and data collection strategies to those which are most likely to be acceptable to those living in areas of high relative deprivation. The present programme of research suggests that a significant amount of time should be committed, where possible, to rapport-building with communities before data collection takes place. This will likely improve research engagement and increase knowledge sharing, although this potentially may be a challenge for programmes of research with considerable time pressures.

Rapport-building in this instance was facilitated by the researcher being a member of the target population, as it was easier to find 'common ground' with participants. The use of 'insider' researchers (i.e. those who are part of the target population) may be particularly useful when aiming to recruit marginalised groups and also offer additional benefits in terms of understanding more nuanced experiences relative to the group (Berger, 2015). However, it should be noted that insider status exists on a spectrum and, for example, researcher affiliation with universities and/or cultural differences may move the researcher further towards 'outsider' status even if some characteristics are shared (Breen, 2007). In the current research, establishing relationships with community health organisations, and community centres provided an additional bridge between academia and socioeconomically disadvantaged groups. This was integral to the progress of the present research, particularly in regard to accessing the perspectives of ethnic minority and migrant groups.

Overall, this thesis supports previous related research (e.g. Rockliffe et al., 2018) in suggesting community-based, face-to-face methods are generally most beneficial in engaging those within areas of high relative deprivation. This learning may also be useful in terms of intervention development, in light of the indication that face-to-face methods appeared to be preferable to the target population. There was less success when attempting to engage via online methods, particularly in terms of accessing perspectives of non-white women (see section 4.3.3). However, this particular aspect was potentially exacerbated by the amended snowball-sampling approach which can result in participants sharing similar demographic characteristics (e.g. in this case White, with a high-level of education) (Sadler et al., 2010; Woodley & Lockard, 2016). The increased disclosure of particularly difficult topics surrounding past trauma and negative experiences with healthcare staff detailed in Chapter 4 suggest that anonymous surveys may still be a potentially valuable and complementary approach when aiming to understand sensitive phenomena and thus should not yet be discounted when aiming to access marginalised groups. However, the impact of digital poverty and exclusion within research participation warrants further consideration to fully understand the potential value and use of online methods in relation to socioeconomically disadvantaged groups.

7.7 Limitations

The limitations of the studies discussed above have been considered in previous chapters (See sections 2.5.1, 3.5.2, 4.5.3, 5.5.2, 6.5.2). However, there are some general limitations to reflect upon. Similar to previous research, there were indications that self-reported screening status was not always accurate and there may have been more women who were overdue or never attended than reported within the demographic questionnaires. For example, two participants in the second focus group initially reported they were up to date with screening, yet explicitly mentioned that they were overdue during later discussion with the researcher. Determining accurate screening status remains challenging without objective medical records, and whilst self-reported status may be a useful indicator, should be viewed with potential inaccuracy in mind. The focus of this research was to understand and contextualise determinants of participation in areas of high relative deprivation. As such, the value of qualitative data reported here is not impaired by potential inaccuracies in self-reported screening status. Instead, self-reported screening status should be viewed as an approximation of actual engagement. If attendance accuracy is critical to the research question, then future research should consider the potential of more objective measures.

In addition, we viewed non-participation broadly and did not separate dependent on decisional stage. Some recent research from Marlow et al., (2017) has outlined different ‘types’ of non-participant based on the Precaution Adoption Process Model (Weinstein, 1988) (E.g. those who are *unaware*, *unengaged*, *undecided*, *intending to be screened* or *decided not to be screened*) and suggested that the salience of determinants can differ dependant on an individual’s specific decisional stage (For example, practical barriers appear to be more relevant for intenders, whilst negative past experiences appear to be more relevant for decliners; Marlow et al., 2018). Given the majority of participants self-reported themselves as attenders, it was difficult to consider the salience of determinants by decisional stage. However, tailoring interventions to specific decisional stages can be problematic as it is possible that women move back and forth between stages across time (Marlow et al., 2018). Instead, the present thesis focused on developing strategies to encourage timely cervical screening participation that may be relevant *across* decisional stages (e.g. peer support interventions which could simultaneously increase awareness for those who were not familiar with screening, and also provide support for intenders or those who were undecided).

Finally, this thesis views those living in areas of high relative deprivation as a culturally and ethnically diverse group, and as such aimed to consider factors that may influence the target population across a broad cultural spectrum. As with any diverse population, there are invariably several smaller sub-populations that make up this group. Most notably, it is important reiterate that ‘ethnic minority groups’, are not homogenous. The term ‘ethnic minority groups’ is used throughout this thesis to reflect the inclusion of non-White British groups within the overall participant sample, which is important as it is reflective of communities within areas of high relative deprivation (Office for National Statistics, 2019a). Those of ethnic minority status may belong to wide variety of cultures and backgrounds and face their own specific challenges in accessing health services. Due to the diverse ethnic backgrounds within the present research (and inclusive of migrants from Romania, Libya, Bangladesh, Pakistan, Sudan, Irish Republic and America) it was difficult to specify individual minority groups, therefore the findings presented here provide an overview of factors influencing a number of traditionally marginalised sub-populations. Further tailoring of interventions and co-created research is recommended if attempting to target specific ethnicities or cultural groups. The findings of the systematic review in Chapter 2 provide a foundation from which to work from in this respect (i.e. as findings detail a broad range of determinants relevant to ethnic minority and migrant groups) but was beyond the scope of the present research which focuses primarily on socioeconomic-based inequalities.

7.8 Future recommendations

The present thesis presents an in-depth focus on the early stages of intervention development; identifying existing evidence in the area, conducting additional primary research to gain a detailed, context-specific, understanding of the target behaviour and identifying appropriate intervention options and content. As a result, this provides a strong foundation for the next stages of development. It is recommended that researchers turn greater attention to modelling potential outcomes and assessing feasibility of intervention components in greater depth (see Craig et al., 2008). This could involve consideration of the recommended strategies in light of localised knowledge, with further attention given to the source of the intervention (i.e. *who* specifically would be delivering the intervention) and the schedule of the interventions (i.e. *when* would the intervention be delivered) (Public Health England, 2019a). In terms of the source of the intervention; those living in areas of high relative deprivation suggested a preference for receiving information from individuals who they could identify with and trust, and this did not always fall in line with what others' may consider a 'credible source' (e.g. health professional or something else with authority) As discussed above, peer-led interventions in this respect would be useful and it is recommended that the feasibility of this mode of delivery be assessed further. In terms of the schedule of the intervention; this may relate to when, and how frequently, to deliver an intervention (e.g., should an intervention be delivered around the time the behaviour is expected to occur and/or prior to the behaviour occurring?). Given participants expressed lack of familiarity with screening as a barrier to engagement, and suggested screening related information should be presented to girls during their school years, the feasibility of this mode of delivery may also be relevant to explore further.

Ideally, it is recommended that future work should take a participatory approach wherever possible, to ensure intervention acceptability and the voice of the target population is maintained throughout future stages of the development process. In terms of cervical screening, research from Sweden and the USA have shown participatory approaches to be successful in increasing screening uptake in ethnic minority and immigrant women (Nguyen, Belgrave, & Sholley, 2011; Olsson et al., 2014), the latter resulting in a 42% increase of uptake within foreign born women living in Sweden. A fully participatory approach (i.e., whereby the community and researchers aim for equal status and ownership of the research), was not practical within the present thesis given time and resource constraints of the research programme. Nonetheless, as mentioned above, the strategies developed throughout this thesis are rooted within the perspectives of those who any intervention would be targeted towards. Increasing involvement of the public and other stakeholders is also reflective of stakeholder preference detailed in Chapter 5, whereby participants expressed a view that interventions should be developed (and in some cases delivered) through collaboration across groups and sectors.

The health-related professionals interviewed in Study 4b outlined that even if intervention(s) are likely to be effective and acceptable to stakeholders, the limited availability of resources within primary care and the community sector may obstruct progress and implementation. This is a significant challenge given the need for increased flexibility and accessibility in service provision (both in terms of actual screening services, and support to access screening). A potential way in which to tackle this problem is to amend or refine already funded and resourced interventions and services (as mentioned in Chapter 6) to incorporate the intervention components outlined in section 6.4.3. In practice this could mean, for example, refining the content of existing training for screen-takers and other healthcare professionals and/or conducting a behavioural evaluation on existing local efforts to increase screening using the current findings to inform this process. In addition, an asset-based approach to increasing cervical screening participation could be explored further. Community asset-based approaches are increasingly used in public health to tackle health inequality and refer to the identification of (e.g. social, financial, place-based) existing resources within the community which can be mobilised to promote positive health (see Public Health England, 2018). The current research process highlighted a number of potential assets within areas of high relative deprivation, such as existing voluntary organisations and facilities and community cohesion that could be utilised to support timely cervical screening participation.

Finally, it is of note that this research was conducted prior to the COVID-19 pandemic. COVID-19 has resulted in significant changes to healthcare provision (NHS England and NHS Improvement, 2020) inclusive of cancer screening services (Cancer Research UK, 2020) and has widened health inequality on a number of levels (Public Health England, 2020). Moreover, a recent survey conducted by Jo's cervical cancer trust found that fears surrounding COVID-19 were discouraging many women from attending their screening appointments (Jones-Berry, 2020). As such, it may also be useful for future research to consider the present findings in light of the changing healthcare environment and determine which strategies would be best placed to explore and/or refine in light of existing restrictions to face-to-face communication and healthcare access.

7.9 Final conclusion

This thesis aimed to understand and address socioeconomic inequalities in routine cervical screening participation. In line with a growing body of literature (e.g. Halonen et al., 2016; Keita et al., 2014; Lakshman et al., 2011), socioeconomic status was considered at the area-level, using the Index of Multiple Deprivation (Department for Communities and Local Government, 2015) to highlight factors that influence cervical screening participation for those living in areas of high relative deprivation. Throughout this programme of research, it was also important to reflect the culturally diverse nature of socioeconomically deprived communities, and to take an approach whereby the views, experiences and perspectives of the target population were placed centre stage throughout the research. Via a systematic review of existing evidence, and primary qualitative research, cervical screening participation was found to be determined by a wealth of interrelated factors at the individual, social, organisational and environmental levels. These broad determinants suggest that non-participation is related to an accumulation of factors that are challenging to address with typically limited resources, which may often lead to individuals ‘postponing’, rather than declining, attendance. The integration of qualitative findings and behavioural theory demonstrated that change is needed at multiple levels to encourage timely attendance at screening appointments. As such, researchers and healthcare professionals have a responsibility to support those living in areas of high relative deprivation in accessing screening services by employing interventions that go beyond individual factors and create environments where screening is both practically and psychologically easier to access.

The aforementioned findings were systematically combined with behavioural theory via the Behaviour Change Wheel (Michie et al., 2014) to develop tailored intervention options and strategies which take social context into account and thus are likely to be effective in addressing socioeconomic inequalities in participation. These findings can be used as a ‘toolbox’ to construct novel interventions in keeping with local needs and preferences, and/or also to refine and strengthen existing interventions. As research and intervention development continue to emphasise tailored and co-created approaches, this thesis demonstrates valuable methodological and topic-related knowledge that can inform future research, policy and practice to address the persistent socioeconomic inequalities in routine cervical screening participation.

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9 Appendices

Appendix A. Researcher positionality statement

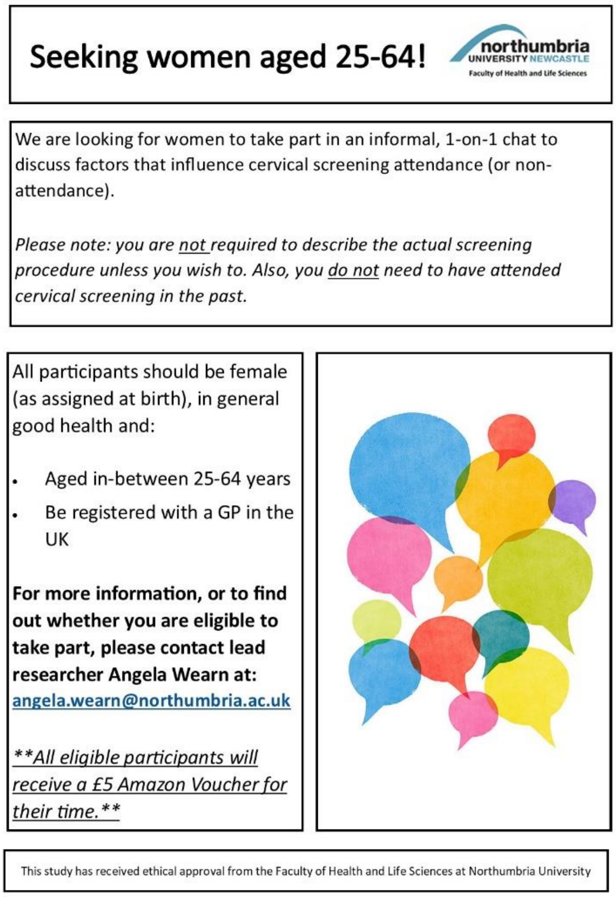
The research presented throughout this thesis is grounded in a contextual constructivist approach (e.g. that knowledge is constructed from within a cultural context, through interaction with participants/participant data, rather than ‘transmitted’ to a passive researcher). To promote transparency and clarity, I include a statement below providing some detail on my own past experience and cultural position, in relation to the research I have conducted.

I am a white, working class, female currently living in an area which is classified by the IMD (2019) as an area of high relative deprivation. Growing up in an area of high socioeconomic disadvantage, many challenges that are associated with deprivation were normalised from a young age; high levels of crime, drug use, domestic violence, neglected and overcrowded living environments and widespread poverty. However, although I regularly observed these issues in the environment around me, I feel I was well sheltered from them within my own home. As such, I believe this has led me to take a place-based approach to understanding inequalities, as the influence of socioeconomic disadvantage goes beyond individualised economic and educational contexts. In my experience, the social, particularly interpersonal, environment also plays an important role in how individuals perceive and engage with the world around them, throughout the lifespan. Given the increasing focus on place-based approaches in Public Health, I felt my own perspective was therefore a strength in developing a programme of research that aimed to consider cervical screening participation in the wider context.

Having lived in communities with high economic deprivation my whole life, I initially took the stance of an ‘insider researcher’ in that I feel I am part of the target population I aim to recruit and focus on within this doctoral research project. I initially felt strongly that I was a full ‘insider’; a member of the community I aimed to explore, with in-depth knowledge of ‘working class culture’ and the impact of poverty and socioeconomic disadvantage on health and wellbeing. However, I became aware throughout this process that, due to my education and status as ‘researcher’, others did not always perceive me this way. My professional context results in additional power and privilege that I appreciate could have influenced researcher-participant trust and the information participants were willing to share. However, this has also resulted in a drive to use this privilege to provide a platform for others to voices their opinions and experiences. In addition, I believe my educational background has resulted in the relatively unique position of being able to describe and understand inequalities in cervical screening participation from both a community-based and academic perspective, bridging two often disparate ‘worlds’. I am very keen to use my experience communicating with different audiences to increase interaction between academia and the community. This has therefore directly influenced the qualitative direction of the research, with the emphasis heavily weighted on combining the voice of the community with academic theory - to produce findings that are easily translatable to researchers, practitioners and the public.

I feel it is also important to note, that given the ethnic and cultural diversity within my overall sample, my positionality was not fixed throughout the present research and moved on a continuum depending on the individuals I was speaking with at the time. I always briefly discussed my background with members of the community during outreach events and also with participants prior to data collection taking place. I found this facilitated researcher-participant rapport-building (the only exceptions to this being Study 2 whereby the online nature of the research resulted in lack of researcher-participant relationship).

Appendix B. Recruitment advertisement (Study 2)



Seeking women aged 25-64!

northumbria
UNIVERSITY NEWCASTLE
Faculty of Health and Life Sciences

We are looking for women to take part in an informal, 1-on-1 chat to discuss factors that influence cervical screening attendance (or non-attendance).

Please note: you are *<u>not</u>* *required to describe the actual screening procedure unless you wish to. Also, you* *<u>do not</u>* *need to have attended cervical screening in the past.*

All participants should be female (as assigned at birth), in general good health and:

- Aged in-between 25-64 years
- Be registered with a GP in the UK

For more information, or to find out whether you are eligible to take part, please contact lead researcher Angela Wearn at:
angela.wearn@northumbria.ac.uk

All eligible participants will receive a £5 Amazon Voucher for their time.

This study has received ethical approval from the Faculty of Health and Life Sciences at Northumbria University

Appendix C. SRQR Checklist (Studies 2-4)

Table C1. Standards for Reporting Qualitative Research (SRQR) checklist. Each Domain is linked to each of the reported studies by page number. Some domains are not applicable due to incorporation of the study into a thesis, rather than a journal article

	Page number		
SRQR Topic	**Study 2 - Interviews**	**Study 3 - Online survey**	**Study 4 - Focus Groups/Prof Interviews**
Title and abstract			
S1 Title	84	112	142
S2 Abstract	i	i	i
Introduction			
S3 Problem formulation	86	116	145
S4 Purpose or research question	87	116	145
Methods			
S5 Qualitative approach and research paradigm	87	116	146/150
S6 Researcher characteristics and reflexivity	87/282	117/282	146/282
S7 Context	16	16	16
S8 Sampling strategy	90	117	146/150
S9 Ethical issues pertaining to human subjects	93	122	149/151
S10 Data collection methods	93	122	149/151
S11 Data collection instruments and technologies	93	122	149/152
S12 Units of study	92	121	140/143
S13 Data processing	94	123	141/144
S14 Data analysis	94	123	142/144
S15 Techniques to enhance trustworthiness	94	123	144
Results/Findings			
S16 Synthesis and interpretation	95	124	153
S17 Links to empirical data	96	125	153
Discussion			
S18 Integration with prior work, implications, transferability, and contribution(s) to the field	104	132	169

	Page number		
SRQR Topic	Study 2 - Interviews	Study 3 - Online survey	Study 4 - Focus Groups/Prof Interviews
S19 Limitations	107	138	213
Other			
S20 Conflicts of interest	NA	NA	NA
S21 Funding	NA	NA	NA

Appendix D. Ethics documents (Study 2)

Northumbria University
NEWCASTLE
Faculty of Health & Life Sciences

Participant Information

Project Title: Determinants of routine cervical screening

Principal Researcher: Angela Wearn

The purpose of this information sheet is to provide you with enough information so that you can give your informed consent. It is important that you read this document carefully, and raise any issues that you do not understand with the researcher.

What is the purpose of the study?

We know that many women do not attend routine cervical screening. Some areas have particularly low levels of attendance, although it is not entirely clear why this is.

We would like to discuss how women think and feel about cervical screening. It does not matter whether you have taken part in screening before or not.

Why have I been invited?

You have been invited to take part in this study as you are

- a woman aged 25-64 years old
- registered with a GP in the United Kingdom

Do I have to take part?

No, you do not need to take part and do not need to provide any reason for declining to take part. However, if you have any questions or concerns then please discuss these with Angela.

What will happen if I take part?

After reading this, you will be asked to sign a consent form (which lets us know you are happy to take part). You will then be asked to fill out a short questionnaire (e.g. your age, ethnicity and so on) so we can understand the general background of the women we speak to.

After this, you will be taken to a quiet area, to have a chat with Angela. We might talk about e.g. your thoughts and feelings surrounding cervical screening and reasons for attending (or not attending) in the past. You only need discuss things that you feel comfortable with. This chat will be recorded, however, any identifying names or information will be removed during analysis.

Will my taking part in this study be kept confidential and anonymous?

If you decide to take part in this study, you will be given a participant number. Your name will not be associated with any of your responses during this study. Anonymous quotes may be used in a research report, but any identifying information/names etc. that you may have used during your interview will be removed.

Signed consent forms will be kept in a locked cabinet, separately from all other documents related to this research.

How will my data be stored?

All electronic data will be stored on a password protected computer and any paper based information will be stored separately in a locked drawer on university premises (only accessible by Angela).

Contact for further information:

Principal Researcher: angela.wearn@northumbria.ac.uk

Please always contact the principal researcher for any queries directly related to this research. However, it may also be useful for you have these additional contacts:

Supervisor of Principal Researcher: lee.shepherd@northumbria.ac.uk
Ethics co-ordinator (Health and Life Sciences): nick.neave@northumbria.ac.uk

Northumbria
University
NEWCASTLE

Faculty of Health & Life Sciences

INFORMED CONSENT FORM

Project Title: Determinants of routine cervical screening

Principal Researcher: Angela Wearn

please tick or initial
where applicable

I have read and understood the Information Sheet and had the opportunity to ask questions	
I give consent for voice recordings to be made of my responses during the discussion.	
I understand that anonymous quotes from this discussion may be published in an academic journal/textbook or on an appropriate Northumbria University webpage, and therefore may potentially be available worldwide. **My name or other personal information will never be associated with this research.**	
I understand I can withdraw from this research at any time before publication, without having to give a reason for withdrawing, and without prejudice.	

Signature of participant.. Date.....………………..

(NAME IN BLOCK LETTERS)...…………………………………………….

Signature of principal researcher.. Date.....………………

(NAME IN BLOCK LETTERS)...…………………………………………….

Debrief Sheet

Project Title: Determinants of Routine Cervical Screening.

Principal Researcher: Angela Wearn

What was the purpose of the study?

We know that many women do not attend routine cervical screening in line with NHS guidelines. Research has also shown that certain areas have lower cervical screening uptake than others. We met today to gain a greater understanding of why this might be, by listening to the perspectives and experiences of those living within areas that often have low cervical screening uptake.

How will I find out about the results?

If you wish to receive a summary of the results, then please provide an email or postal address to Angela and this will be sent to you when the study is completed.

If I have any further questions, or wish to withdraw my data, who should I contact?

If you have any questions regarding, or related to, this research project then please contact Angela at angela.wearn@northumbria.ac.uk. If you wish to withdraw your data, please email Angela within 1 month of taking part, and quote the participant number that was allocated to you (this can be found at the top of this sheet). After one month, it may not be possible to withdraw your data as it may already have been analysed.

The data collected in this study may also be published or presented at conferences. Should the research be presented or published, all data will be anonymous (i.e. your personal information or data will not be identifiable).

All information and data gathered during this research will be stored in line with the Data Protection Act and will be destroyed 6 months following the conclusion of the study. If the research is published it may be kept for longer before being destroyed. At no point will your personal information or data be revealed.

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: nick.neave@northumbria.ac.uk), stating the title of the research project and the name of the researcher.

Appendix E. Interview Schedule (Study 2)

Individual interviews - Topic guide

Throughout this interview we will explore what you know about screening and your experiences of being to invited to and attending screening.. Remember you can give as much or as little detail as you like, you don't need to detail the screening procedure itself (unless you wanted to), or say anything that makes you feel uncomfortable. We might also focus on other things, surrounding your day to day life, that may guide or influence your decisions. There are no right or wrong answers – we are more interested in your thoughts and feelings.

Determinants of screening

- Are you aware of the routine cervical screening programme in the UK?
- Can you tell me about the purpose of routine cervical screening?
- Where did you first hear about this programme?
- Who do you think this screening programme is aimed at?
- Do you feel there are benefits to screening? Could you tell me about these benefits?
- Do you feel there are disadvantages to screening? Could you tell me about these disadvantages?
- How do your friends and family feel about cervical screening, in your opinion?
- Have you heard others discussing any positive/negative experiences of screening?
- How do you think the media (i.e. TV, newspapers, social media) portrays cervical screening?
    - Expand here – awareness

Experiences of screening

Invitation letter

- Can you tell me about the first time you received this letter? How did you feel?
- Did you notice/read the additional leaflet(s) that come with the letter?
- What do you think about this letter?

- Did/do you make the appointment immediately after receiving the letter?
    - If not, why not?
    - If so, have there been any occasions where you have not made the app. immediately?

Attendance

- Can you tell me how you feel on the day of your screening appointment?
- Have you ever missed or cancelled a screening appointment for any reason?
    - If so, explore the reasons for this and whether there is underlying feelings around this
- How do you find the experience?
- Do you feel comfortable with the health professional that is carrying out the test?
- Do you feel able to ask questions prior to/after the test?
- Who do you feel is in control of what is happening during your screening appointment?
- What qualities do you think a health professional should have (in this instance)?
- Do you feel the practitioner understands what you are thinking and feeling when you attend your screening appointment?
- How do you feel after your screening appointment?

After the appointment

- How do you feel waiting for your results?
    - Expand here on the experience of receiving results letter
- Do you feel fully informed as to what the results may be/mean?
- Are you likely to attend screening appointments in the future?
- Is there anything that would encourage, or make it easier, for you to attend future appointments?

<u>Throughout the interview</u>

- Have you discussed this with friends/family?
    - If not, why not?

<u>Summary</u>

- We have discussed a lot today - are there any other relevant factors that we have not covered here, that you would like to discuss?

Appendix F. Example coding (Study 2)

Table F1. Example coding from participant transcripts.

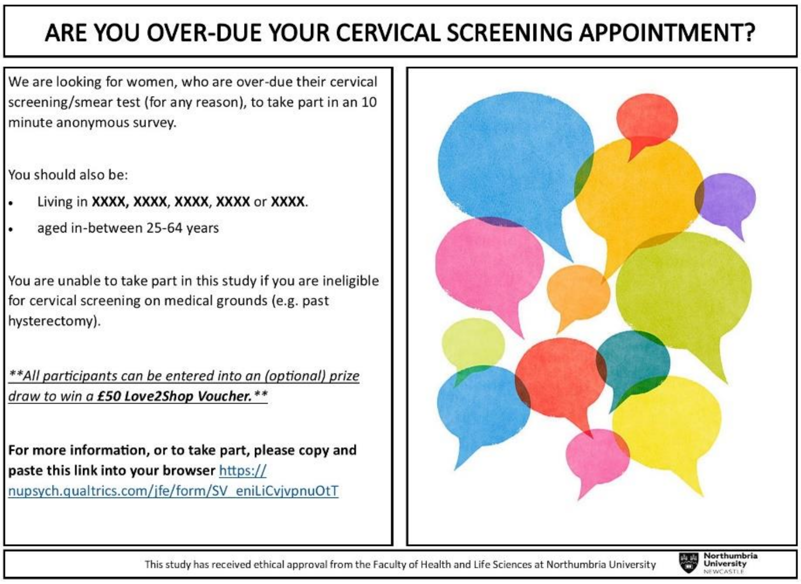
Participant 3				
Theme	**Sub-theme**	**Barrier/ Facilitator/ Mix**	**Notes/Summary of theme**	**Example excerpts from transcript**
Community	Giving and receiving support	M	There were challenges in accessing screening information related support and information from friends, however encouragement from family facilitated engagement. After attendance, it was easier to talk about screening with friends, which in turn made participant feel more comfortable.	Before I went I only spoke to my mum about it, and she said that she had abnormal cells come back beforehand, so she was saying how really important it is that you go and keep going to them. A lot of my friends hadn't been to theirs, so when I mentioned it they said, 'Oh yeah, I got the letter but I've ignored it'. I didn't actually find any friends that had actually been. So, I found it quite difficult to know who to speak to about it. So, really yeah, only my mum was the person before I went. After I went, I spoke to my friends and said, 'Make sure you go because it really isn't bad'. And now they've been, and we've actually spoke about it since, but beforehand I didn't really know who to talk to My mum kept reminding me and she was saying, 'You know, you really need to make that appointment. do you want me to ring for you?'. And I said, 'No, I'm going to do it!' [laughs] 'I just need time to ring up'. But it did take me a while to actually ring and make the appointment. But after my group of close friends had all been, we talked about it quite a lot and they're like, 'Oh God, this is what it was like when I went', and 'This is what it was like when I went' and we all discussed it and it made me feel a lot better about it. But before that, we didn't really discuss it at all, apart from saying 'I haven't been' or 'Oh God, I've got my letter' but we didn't really discuss the reasons why we hadn't been, and I don't think anybody really had a valid reason of why they hadn't been...apart from they don't want to go [laughs].
	The experiences of others	M	Hearing negative stories had the potential to increase perceived risk of cervical cancer but it could be a challenge to understand why others were not attending which appeared to increase fear surrounding participation. Hearing more people discussing participation recently over social media has resulted	I think, the more stories I hear on Facebook the more that makes me think, 'Ah God, I really do need to go'. Cause sometimes you think, 'Everything's going to be fine, it's never going to happen to me' and then when you see [those stories], actually there are young girls as well, that are 26, 27 [that have been diagnosed with cervical cancer] and I think, 'Oh God, they're my age...it can actually happen at my age I think now that I keep seeing more on Facebook, and people seem to be more open to talk about it recently, and a lot of my friends have posted their experience of it that's made me feel a lot better as well. So, I think just hearing that other people are going...and that it's not something that people don't go to...it's something people do go [to]...I think just in

			in participant feeling more reassured and positive towards participation.	general that makes me feel a lot better about it. when I was thinking about going, I kept asking my friends if they had been, and they said, 'Oh no, I haven't been'. And I was like, 'Why haven't you been?', and they'd say, 'Oh I dunno, I just haven't, I'm nervous about it'. I think it was quite hard to discuss with them why they hadn't been. Cause I was like, 'God, should I go? Shouldn't I?'. I wasn't really hearing people's reasons why they weren't going, apart from the fact they were feeling really nervous.
The Healthcare Environment	Relationships with staff	F	Positive experience with healthcare staff reassured and relaxed participant and facilitated positive views towards participation. Reflection on the impact that screen takers can have on how participants view screening.	It was really fine once I'd got there. The nurse was lovely. We sat down first, and she asked whether it was the first time I'd been for a screening, and whether I'd had any other similar ones done. Then she explained exactly what she was going to be doing and she showed me, whatever it's called, the [speculum]… She showed me that, and showed me what was going to happen, and that she would leave the room, close the curtain and just to let her know when I am ready. And I just remember feeling really calm because she was really nice about it. She was really patient and I think as soon as I went in there, and just how calm...and the fact that she explained it all first, it wasn't just sort of like, 'Just lie down, this is going to happen' [laughs]. It was really nice. I think, just instantly I thought, 'Ah this isn't as bad as I thought it was going to be, she's really nice, this is going to be fine'. I think if I went in there and I had a different experience and I felt rushed, or they weren't very...if they didn't ask if I was OK, or if I needed any more information about [the procedure], I think I would have continued to feel dread, and I would've been tense and it wouldn't have been a very nice experience. So, I think the fact that they were patient, and happy to talk about it, really, really helped.
Personal Motivation	Emotional responses to screening	**B**	Screening participation is associated with aversive emotions which pose a barrier to attendance. Fear surrounding unknowns of the test dominated as it was the participants first screening appointment. Fear of outcome came later on in the process but participant also reports feeling relief following attendance.	I felt dread. As soon as I got [the first invitation letter], it was the first feeling. I was like, 'Oh God, I'm not looking forward to this.' I thought as well, that you'd get it after your 25th birthday and it was 6 months before that, I thought, 'Oh God, this is too early, I'm not ready to get this done until next year, I'm not ready for this!'. And I did just feel really nervous about it. I thought, 'Oh, I don't want to go.' And it was a quite early appointment, cause I remember trying to get early appointment cause I thought, 'Oh, I don't want to worry about this all day'. I felt a mix of relief that it was done, and that it wasn't as bad as I thought it was gonna be, and also dread about getting the results back. Before I went to the appointment all I was thinking about was, 'What's going to happen at this appointment?'. I wasn't thinking about what's going to happen after, or the results or...I was just thinking, 'Oh God, this is going to be an uncomfortable, horrible experience'. But I think it's cause after [the test] we spoke

				about it and she said, 'This is how long it's going to take to get your results, and it comes in a letter form' and all of a sudden it hit me. I was like, 'Oh God, this is why I've come! It's about getting the results!' It is something I thought about pretty much daily afterwards.
	Screening related beliefs	F	Importance beliefs facilitated intentions to screen but notable that this was not enough to turn intentions into action (i.e. booking the appointment).	I just kept saying...it was strange [to postpone] because I knew it was important, and in my head, I knew I should do this.

Appendix G. Social media advertisements (Study 3)

Focused advertisement



ARE YOU OVER-DUE YOUR CERVICAL SCREENING APPOINTMENT?

We are looking for women, who are over-due their cervical screening/smear test (for any reason), to take part in an 10 minute anonymous survey.

You should also be:

- Living in **XXXX, XXXX**, **XXXX**, **XXXX** or **XXXX**.
- aged in-between 25-64 years

You are unable to take part in this study if you are ineligible for cervical screening on medical grounds (e.g. past hysterectomy).

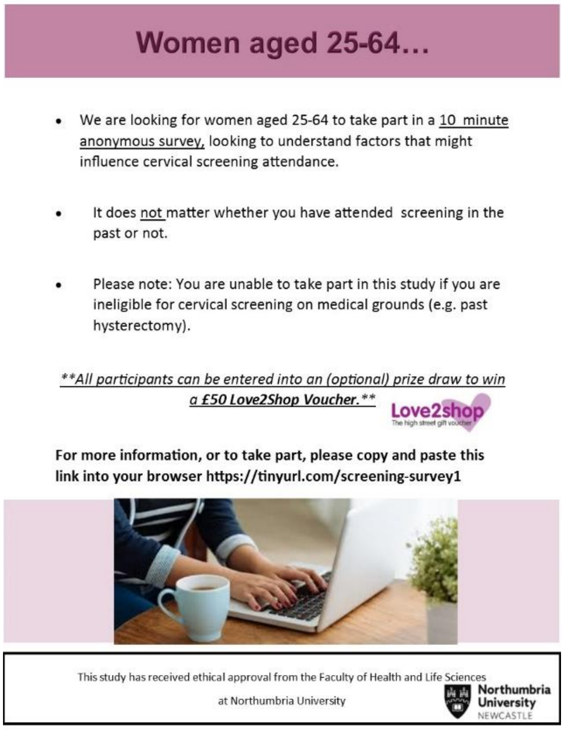
All participants can be entered into an (optional) prize draw to win a **£50 Love2Shop Voucher.**

For more information, or to take part, please copy and paste this link into your browser https://nupsych.qualtrics.com/jfe/form/SV_eniLiCvjvpnuOtT

This study has received ethical approval from the Faculty of Health and Life Sciences at Northumbria University

Northumbria University NEWCASTLE

Inclusive advertisement



Women aged 25-64…

- We are looking for women aged 25-64 to take part in a 10 minute anonymous survey, looking to understand factors that might influence cervical screening attendance.
- It does not matter whether you have attended screening in the past or not.
- Please note: You are unable to take part in this study if you are ineligible for cervical screening on medical grounds (e.g. past hysterectomy).

All participants can be entered into an (optional) prize draw to win a **£50 Love2Shop Voucher.**

Love2shop
The high street gift voucher

For more information, or to take part, please copy and paste this link into your browser https://tinyurl.com/screening-survey1

This study has received ethical approval from the Faculty of Health and Life Sciences at Northumbria University

Northumbria University NEWCASTLE

Appendix H. Information, Consent and Debrief information (Study 3)

Study Information

Principal Researcher: **Angela Wearn**

Project Title: **Understanding Routine Cervical Screening Participation.**

What is the purpose of the study?

The NHS suggest women should attend cervical screening appointments every few years. However, many women do not attend these appointments.

We would like to hear from women in these areas to understand why some women do (and some don't) attend their screening appointments in line with guidelines.

Why have I been invited?

You have been invited to take part in this study as you are:

- a woman aged in between 25-64 years old
- registered with a GP in the United Kingdom.

You are unable to take part in this study if you are ineligible for cervical screening on medical grounds (e.g. hysterectomy).

Do I have to take part?

No, you do not need to take part and do not need to provide any reason for declining to take part. You can stop the survey at any point by closing the browser window. However, if you have any questions or concerns then please discuss these with Angela.

What will happen if I take part?

If you decide you would like to take part, you will be asked to provide a code word. This code word will allow us to identify your data should you want to withdraw it at a later date.

Following this, you will be asked some demographic questions (i.e. age, ethnicity and so on). This is so we can fully understand the background of women who take part in this research. Then we will ask you some questions about cervical screening (e.g. whether you have heard of and/or attended screening in the past and so on). Some questions ask you to type answers in your own words. The answers to these questions are very important to us, however, you are free to give as much or as little detail as you like. There are no right or wrong answers.

Once the survey is complete, you will be asked to enter an email address so you can be entered into a prize draw to win a £50 Love2Shop voucher. The email address you provide for the prize draw is not associated with the answers you give in the survey.

Will my taking part in this study be kept confidential and anonymous?

If you decide to take part in this study, you will provide a code word only known by you. We do not collect any identifiable information (e.g. your name) as a result you will not be associated with the data in any way. However, at the end of the study you will be asked whether you would like to take part in a one-to-one chat at a later date. If you would like to take part in a one-to-one chat you will be asked to provide an email address, which would be linked to your previous responses. If you prefer to remain anonymous, simply leave the box blank.

How will my data be stored?

All data will be stored on a password protected computer. Findings will be presented as part of a PhD thesis and may be published in relevant scientific journals, at conferences or to community groups. Collected data may be made publicly available at the time of publication, but it will not be possible to identify any individual from this information.

Contact for further information:

Principal Researcher: angela.wearn@northumbria.ac.uk

Please always contact the principal researcher for any questions directly related to this research. However, it may also be useful for you have these additional contacts:

Supervisor of Principal Researcher: lee.shepherd@northumbria.ac.uk

Ethics co-ordinator (Health and Life Sciences): nick.neave@northumbria.ac.uk

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Informed consent

Please read the statements below and indicate whether you agree.

- I have carefully read and understood the Information Sheet.
- I have had an opportunity to ask questions and have received satisfactory answers.
- I understand I am free to withdraw from the study at any time, without having to give a reason for withdrawing, and without prejudice.

I agree and I am happy to continue

Thank you for agreeing to take part in this research. Please provide an anonymous (but memorable) code word in the box below. This word will be used to identify your data should you wish to withdraw at a later date. Please avoid choosing obvious phrases (e.g. 'code word') or phrases that may compromise the anonymity of the data (e.g. your name).

Debrief

What is the purpose of this research?

Despite saving an estimated 2000 lives per year, uptake for routine cervical screening is at a 20-year low. Researchers would like to understand the barriers to routine screening. Recent research also suggests that many women intend to take part in screening but postpone or ‘put off’ making their appointment. However, it is not always clear why this is.

As such, this study aims to understand, in more detail, why some women do (and some don’t) attend screening in line with guidelines. It is hoped that these findings can be taken forward to address some of the barriers that women face.

How can I find out about the results?

If you wish to receive a summary of the results, then please provide an email or postal address to Angela and this will be sent to you when the study is completed (around September 2018). You can also contact the researcher at any time to request feedback at angela.wearn@northumbria.ac.uk

How can I find out more about cervical screening?

If you wish to find out more about cervical screening, you can access information online via the NHS: https://www.nhs.uk/conditions/cervical-screening/when-its-offered/ and/or via Jo’s Cervical Cancer Trust: https://www.jostrust.org.uk/about-cervical-cancer/cervical-screening-smear-test-and-abnormal-cells

If I change my mind and wish to withdraw the information I have provided, how do I do this?

If you wish to withdraw your data, please contact Angela within 1 month of taking part, and quote the code word that you included at the beginning of the survey. After one month, it might not be possible to withdraw your data as it may already have been analyzed.

The data collected in this study may also be published or presented at conferences. Information and data gathered during this research study will only be available to the research team named in the information sheet. Should the research be presented or published, all data will be anonymous (i.e. your personal information or data will not be identifiable).

All information and data gathered during this research will be stored in line with the Data Protection Act and will be destroyed 6 months following the conclusion of the study. If the research is published

it may be kept. At no point will your personal information or data be revealed.

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: nick.neave@northumbria.ac.uk), stating the title of the research project and the name of the researcher.

Appendix I. Online survey (Study 3)

Demographic Questionnaire

Please provide the following information:

1. How old are you?

2. **Are you registered with a GP in the United Kingdom?**

Yes ☐

No ☐

3. **What is your ethnicity?**

White

Black

Asian

Mixed race

Other

If 'mixed race' or 'other' please state …………………………………………..

4. **What is your postcode?**

5. **What is your highest level of education?**

Secondary school

College

University undergraduate

University postgraduate

7. What is your estimated household income per year?

70,000+

60,000-69,999

50,000 – 59,999

40,000 – 49,999

30,000-39.999

20,000-29,999

15,000-19,999

15,000 or less

Screening Survey

7. Are you aware of the routine cervical screening programme (i.e. smear tests) in the UK?

Yes

No

Unsure

8. Have you ever attended routine cervical screening?

Yes (Survey will go directly to Q9)

No (Survey will go directly to Q8a)

8a. What are the main reason(s) for this? (survey will go directly to 11)

9. When did you last attend a cervical screening appointment?

Within the last year

Within the last three years

Within the last five years

Over five years ago

Not sure

10. Have you ever postponed or 'put off' making your appointment (for any reason)?

Yes, once

Yes, occassionally

Yes, always

No, I make the appointment immediately.

10a. What were the main reason(s) for this?

11. In your opinion, what is the purpose of routine cervical screening?

12. Do you feel there are benefits to cervical screening?

Yes

No

Not sure

12a. Please explain further

13. Do you feel there are disadvantages to cervical screening?

Yes

No

Not sure

13a. Please explain further

14. Are you likely to attend cervical screening when next invited?

Yes

No (survey will go directly to Q14a)

Unsure (survey will go directly to Q14a)

Not thought about it

14a. Please explain further

15. Has a friend or family member ever encouraged you to have a cervical screening/smear test?

Yes

No

Not sure

16. Have you noticed any cervical screening campaigns or information in the media (for example in newspapers, on TV/radio, on social media sites such as Facebook).

Yes

No

17. How do you feel when you notice cervical screening in the media?

18. Is there anything that would encourage, or make it easier, for you to attend future appointments?

19. Is there anything else that you would like to mention about routine cervical screening?

Appendix J. Initial thematic template (Study 3)

1.0 Screening is worthwhile

2.0 Screening can be difficult to access

  - **2.1** Appointment making
  - **2.2** Practical access to services
  - **2.3** Psychological access to services

Note: Following analysis of the full data set this template was iteratively amended as presented in section 4.4. Core themes were retained, however due to breadth of data relating to *'Psychological access to services'* this theme was expanded to included two additional sub-themes (i.e. *'Beliefs about the test'* and '*Emotional challenges of attendance'*.). As described in section 4.3.5, the integrative theme *'Past Experiences are important'* was also added when the amended template was applied to the whole dataset

Appendix K. Example survey responses (Study 3)

Table K1. – Examples of survey responses, detailing reasons for postponement.

Participant	Have you ever postponed or 'put off' making your appointment (for any reason)?	What were the main reasons for this?
1*	Yes, once	I am disabled and I don’t think I’ve had a reminder ??
2*	Yes, always	Awkwardness/difficulty of arranging an appointment. Plus, anxiety issues.
3*	Yes, occasionally	Having to wait 4 to 6 weeks for appointment with nurse by which time either forget about appointment or I’m in the middle of menstrual cycle
4*	Yes, always	Have had 3 smears at GP and hospital within a space of 8 months and was due to go back every 6 months to hospital as have and CIN 1 cells kept showing but when trying to rebook there was no availability and the longer I left it there more scared I became
5	Yes, once	Anxiety/ fear
6	Yes, always	Fear, inconvenience
7	Yes, once	Ease of making an appointment at a time convenient to attend/predictability of period (I have just changed my implant which screws everything up)
8	No, I always make the appointment immediately	History of cancer in family
9	Yes, once	Having other commitments that get in the way and as it is supposed to be an unpleasant experience
10*	Yes, occasionally	Putting it off and not wanting to use phone to book appointment (I'm hard of hearing) so having to go into surgery to book in person.
11	Yes, occasionally	Anxiety. I work in a surgery too, so I have developed a subtle way of informing ladies of their smear being due little piece of paper I try to persuade the reluctant ones
12	Yes, occasionally	I often need to attend more than once due to bleeding during the swab, and I don't always have time to attend.
13	Yes, occasionally	1. Busy/can't get an appointment at a convenient time. 2. Bad experiences at previous tests, e.g. Bleeding, insensitive approach by nurse.

14	Yes, occasionally	Period due Couldn't get out of work
15*	Yes, occasionally	Time to phone GP surgery and make appointment. Having free time to attend appointment.
16	No, I always make the appointment immediately	I know that it is important, and my Mother has had abnormal cells and treatment
17	Yes, occasionally	Forget to make appt Difficulty getting suitable appt
18	Yes, always	Put off and forget to make appointment
19*	Yes, always	unwilling to be embarrassed/uncomfortable
20	No, I always make the appointment immediately	Had a previous abnormal smear so always keep up with schedule
21	Yes, occasionally	Time, I have 3 children and a full-time job, trying to arrange an appointment without using holiday is difficult

* Responses contributing to the initial coding template; participants living within the most deprived quinti

Appendix L. Demographics and responses by deprivation quintile (Study3)

Table L1. Participant demographic information split by deprivation quintile.

	Quintile 1 **N=11**	**Quintile 2** **N=11**	**Quintile 3** **N=10**	**Quintile 4** **N=15**	**Quintile 5** **N=8**	**Unspecified**[a] **N=9**	**Total** **N=64**
Age Mean (SD)	41.36 (12.56)	35.09 (6.17)	32.50 (5.44)	33.53 (3.94)	34.75 (13.29)	30.67 (4.24)	34.73 (8.48)
Ethnicity							
White	11 (100.0)	11 (100.0)	10 (100.0)	15 (100.0)	8 (100.0)	7 (77.8)	62 (96.9)
Black	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (11.1)	1 (1.6)
Asian	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (11.1)	0 (0)
Mixed Race	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1.6)
Other	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Education							
Secondary School	2 (18.2)	1 (9.1)	0 (0)	0 (0)	0 (0)	1 (12.5)	4 (6.3)
College	2 (18.2)	0 (0)	1 (11.1)	2 (20.0)	2 (13.3)	0 (0)	7 (10.9)
University undergraduate	4 (36.4)	3 (27.3)	6 (66.7)	1 (10.0)	4 (26.7)	2 (25.0)	20 (31.3)
University Postgraduate	3 (27.3)	7 (63.6)	2 (22.2)	7 (70.0)	9 (60.0)	5 (62.5)	33 (51.6)
Annual household income						8†	63†
£15,000 or less	5 (45.5)	1 (9.1)	1 (10.0)	0 (0)	2 (25.0)	0 (0)	9 (14.3)
£15,001-19,999	2 (18.2)	0 (0)	3 (30.0)	1 (6.7)	0 (0)	2 (25.0)	8 (12.7)

	Quintile 1 N=11	**Quintile 2 N=11**	**Quintile 3 N=10**	**Quintile 4 N=15**	**Quintile 5 N=8**	**Unspecified[a] N=9**	**Total N=64**
£20,000-29,999	0 (0)	1 (9.1)	3 (30.0)	2 (13.3)	0 (0)	3 (37.5)	9 (14.3)
£30,000-39.999	3 (27.3)	3 (27.3)	1 (10.0)	3 (20.0)	2 (25.0)	1 (12.5)	13 (20.6)
£40,000 – 49,999	0 (0)	1 (9.1)	0 (0)	4 (26.7)	2 (25.0)	0 (0)	7 (11.1)
£50,000 – 59,999	0 (0)	1 (9.1)	1 (10.0)	1 (6.7)	2 (25.0)	0 (0)	5 (7.9)
£60,000 +	1 (9.1)	4 (36.4)	1 (10.0)	4 (26.7)	0 (0)	2 (25.0)	12 (19.0)

[a] -Unspecified refers to the nine participants who did not submit a valid postcode. [†] -One participant did not submit a figure for household income.

Table L2. Participant's responses to the online screening survey, split by deprivation quintile, n(%)

	Quintile 1 **N=11**	**Quintile 2** **N=11**	**Quintile 3** **N=10**	**Quintile 4** **N=15**	**Quintile 5** **N=8**	**Unspecified[a]** **N=9**	**Total** **N=64**
Aware of routine cervical screening programme?							
Yes	11 (100.0)	11 (100.0)	10 (100.0)	15 (100.0)	8 (100.0)	9 (100.0)	64 (100.0)
No	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Unsure	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Ever attended screening?							
Yes	9 (81.8)	11 (100.0)	10 (100.0)	14 (93.3)	7 (87.5)	7 (77.8)	58 (90.6)
No	2 (15.4)	0 (0)	0 (0)	1 (6.7)	1 (12.5)	2 (22.2)	6 (9.4)
Ever postponed screening?							
No	0 (0)	4 (36.4)	3 (30.0)	5 (33.3)	3 (37.5)	0 (0)	15 (23.4)
Once	3 (27.3)	2 (18.2)	1 (10.0)	5 (33.3)	2 (25.0)	2 (22.2)	15 (23.4)
Occasionally	4 (36.4)	5 (45.5)	6 (60.0)	3 (20.0)	1 (12.5)	5 (55.6)	24 (37.5)
Always	4 (36.4)	0 (0)	0 (0)	2 (13.3)	2 (9.5)	2 (22.2)	10 (15.6)
Up-to-date with screening?							
Yes	5 (45.5)	10 (90.9)	8 (80.0)	12 (80.0)	5 (62.5)	5 (55.6)	45 (70.3)

	Quintile 1 N=11	**Quintile 2 N=11**	**Quintile 3 N=10**	**Quintile 4 N=15**	**Quintile 5 N=8**	**Unspecified^a N=9**	**Total N=64**
No	4 (36.4)	1 (9.1)	2 (20.0)	3 (20.0)	3 (37.5)	2 (22.2)	15 (23.4)
Unsure	2 (18.2)	0 (0)	0 (0)	0 (0)	0 (0)	2 (22.2)	4 (6.3)
Benefits to cervical screening?							
Yes	10 (90.9)	11 (100.0)	10 (100.0)	15 (100.0)	8 (100.0)	9 (100.0)	63 (98.4
No	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Unsure	1 (9.1)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1.6)
Disadvantages to cervical screening?							
Yes	5 (45.5)	4 (36.4)	6 (60.0)	9 (60.0)	2 (25.0)	3 (33.3)	29 (45.3
No	4 (36.4)	6 (54.5)	3 (30.0)	5 (33.3)	5 (62.5)	5 (55.6)	28 (43.8
Unsure	2 (18.2)	1 (9.1)	1 (10.0)	1 (6.7)	1 (12.5)	1 (11.1)	7 (10.9)
Likely to attend next appointment?							
Yes	7 (63.6)	11 (100.0)	9 (90.0)	13 (86.7)	7 (87.5)	7 (77.8)	54 (84.4
No	2 (18.2)	0 (0)	0 (0)	1 (6.7)	0 (2.4)	1 (11.1)	4 (6.3)
Unsure	2 (18.2)	0 (0)	1 (10.0)	1 (6.7)	1 (12.5)	1 (11.1)	6 (9.4)
Discussed with family member/friend?							
Yes	5 (45.5)	8 (72.7)	7 (70.0)	10 (66.7)	6 (75.0)	4 (44.4)	40 (62.5)

	Quintile 1 **N=11**	**Quintile 2** **N=11**	**Quintile 3** **N=10**	**Quintile 4** **N=15**	**Quintile 5** **N=8**	**Unspecified[a]** **N=9**	**Total** **N=64**
No	5 (45.5)	3 (27.3)	2 (20.0)	5 (33.3)	2 (25.0)	2 (22.2)	19 (29.7)
Unsure	1 (9.1)	0 (0)	1 (10.0)	0 (0)	0 (0)	3 (33.3)	5 (7.8)
Noticed any media campaigns?							
Yes	7 (63.6)	6 (54.5)	5 (50.0)	12 (80.0)	6 (75.0)	2 (22.2)	38 (59.4
No	4 (36.4)	5 (45.5)	5 (50.0)	3 (20.0)	2 (25.0)	7 (77.8)	26 (40.6
Unsure	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)

[a] – Unspecified refers to the nine participants who did not submit a valid postcode.

Appendix M: Ethics documents (Study 4a)

Northumbria University
NEWCASTLE
Faculty of Health & Life Sciences

Participant Information

Project Title: Determinants of routine cervical screening

Principal Researcher: Angela Wearn

The purpose of this information sheet is to provide you with enough information so that you can give your informed consent. It is important that you read this document carefully and raise any issues that you do not understand with the researcher.

What is the purpose of the study?

We know that many women do not attend routine cervical screening. Some areas in XXX have particularly low levels of attendance (e.g. XXXX) although it is not clear why this is.

We would like to discuss why women might not attend their cervical screening appointment and think about ways we can address any issues raised.

Why have I been invited?

You have been invited to take part in this study as you are eligible to participate in routine cervical screening i.e.:

- a woman aged 25-64 years old
- registered with a GP in the United Kingdom
- You should also be currently living in one of the areas mentioned above.

Do I have to take part?

No, you do not need to take part and do not need to provide any reason for declining to take part. However, if you have any questions or concerns then please discuss these with Angela.

What will happen if I take part?

After reading this, you will be asked to sign a consent form (which lets us know you are happy to take part). You will then be asked to fill out a short questionnaire (e.g. your age, ethnicity and so on) so we can understand the general background of the women we speak to.

After this, we will have a group chat about e.g. women’s thoughts and feelings surrounding cervical screening and reasons for attending (or not attending). We might also talk about ways to help women attend their appointments in the future. You only need discuss things that you feel comfortable with and do not need to disclose any personal experiences about the screening procedure, unless you wish to. This group chat will be recorded, however, any identifying names or information will be removed during analysis.

Will my taking part in this study be kept confidential and anonymous?

If you decide to take part in this study, you will be given a participant number. Your name will not be associated with any of your responses during this study. Anonymous quotes may be used in a research report, but any identifying information/names etc. that you may have used during your interview will be removed.

Signed consent forms will be kept in a locked cabinet, separately from all other documents related to this research.

How will my data be stored?

All electronic data will be stored on a password protected computer and any paper based information will be stored separately in a locked drawer on university premises (only accessible by Angela).

Contact for further information:

Principal Researcher: angela.wearn@northumbria.ac.uk

Please always contact the principal researcher for any queries directly related to this research. However, it may also be useful for you have these additional contacts:

Supervisor of Principal Researcher: lee.shepherd@northumbria.ac.uk
Ethics co-ordinator (Health and Life Sciences): nick.neave@northumbria.ac.uk

Northumbria University
NEWCASTLE

Faculty of Health & Life Sciences

INFORMED CONSENT FORM

Project Title: Determinants of routine cervical screening

Principal Researcher: Angela Wearn

please tick or initial where applicable

I have read and understood the Information Sheet and had the opportunity to ask questions	☐
I give consent for voice recordings to be made of my responses during the discussion.	☐
I understand that anonymous quotes from this discussion may be published in an academic journal/textbook or on an appropriate Northumbria University webpage, and therefore may potentially be available worldwide. **My name or other personal information will never be associated with this research.**	☐
I understand I can withdraw from this research at any time before publication, without having to give a reason for withdrawing, and without prejudice.	☐

Signature of participant...
Date....………………..

(NAME IN BLOCK LETTERS)...……………………………………………

Signature of principal researcher...
Date....…………………

(NAME IN BLOCK LETTERS)...……………………………………………

Northumbria
University
NEWCASTLE

Faculty of Health & Life Sciences

Debrief Sheet

Project Title: Determinants of Routine Cervical Screening.

Principal Researcher: Angela Wearn

What was the purpose of the study?

We know that many women do not attend routine cervical screening in line with NHS guidelines. Research has also shown that certain areas have lower cervical screening uptake than others. We met today to gain a greater understanding of why this might be, by listening to the perspectives and experiences of those living within areas that are known to have low cervical screening uptake.

How will I find out about the results?

If you wish to receive a summary of the results, then please provide an email or postal address to Angela and this will be sent to you when the study is completed.

If I have any further questions, or wish to withdraw my data, who should I contact?

If you have any questions regarding, or related to, this research project then please contact Angela at angela.wearn@northumbria.ac.uk. If you wish to withdraw your data, please email Angela within 1 month of taking part, and quote the participant number that was allocated to you (this can be found at the top of this sheet). After one month, it may not be possible to withdraw your data as it may already have been analysed.

The data collected in this study may also be published or presented at conferences. Should the research be presented or published, all data will be anonymous (i.e. your personal information or data will not be identifiable).

All information and data gathered during this research will be stored in line with the Data Protection Act and will be destroyed 6 months following the conclusion of the study. If the research is published it may be kept for longer before being destroyed. At no point will your personal information or data be revealed.

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: nick.neave@northumbria.ac.uk), stating the title of the research project and the name of the researcher.

Appendix N: Additional study materials (Study 4a)

Demographic Questionnaire

Why are we asking for this information? We are collecting this information because it is important to understand the background of the women we speak to. All of your responses are anonymous and strictly confidential.

Please provide the following information:

1. How old are you? ☐

2. Are you registered with a GP in the United Kingdom?

Yes ☐
No ☐

3. What is your ethnicity?

White

Black

Asian

Mixed race

Other

If 'mixed race' or 'other' please state …………………………………………..

4. What is your postcode? ………………………………………….

5. What is your highest level of education?

Secondary school

College

University undergraduate

University postgraduate

6. What is your occupational status?

Student

Working full-time

Working part-time

Retired

Unemployed

Other

If ‘other’ please state …………………………………………..

7. What is your monthly household income? ***(this does not have to exact)***

…………………………………………

8. Have you ever been invited to take part in routine cervical screening? ***(this is usually via a letter sent to your home address)***

Yes ☐
No ☐

9. Have you ever attended routine cervical screening?

Yes ☐
No ☐

10. When did you last attend a cervical screening appointment?

Within the last year ☐
Within the last three years ☐
Within the last five years ☐
Over five years ago ☐
Not sure ☐
Never attended ☐

Focus Group – Expected Schedule

As these focus groups are intended to be informal and flexible, this schedule is intended to be a loose guide to facilitate the focus group/group discussion.

Introduction

Purpose of the focus group – Researcher introduces the research topic (i.e. routine cervical screening to the group, highlighting that attendance rates are currently falling. This background will lead on to the current research (i.e. the systematic review and qualitative research) that has recently taken place. Verbal presentation of information sheet/ethics info.

Break (5-10 mins) – Researcher to answer any individual questions before signing of consent forms and then demographic questionnaires.

Part One – Understanding factors that influence participation

Group discussion – Researcher begins group discussion by asking what participants feel influences cervical screening participation and introducing the different factors/themes that were found in previous research. Topics will broadly relate to **psychological factors** (e.g. embarrassment, fear, screening related beliefs) **social factors** (e.g. social support) and **the healthcare context** (e.g. relationships with practitioners). The group will discuss these factors in the context of their own communities and be encouraged to introduce other barriers or facilitators to participation as they feel necessary.

Part Two – Addressing barriers to screening

Group Discussion – Reflecting on the barriers and facilitators that have been discussed, consider as a group how we might best increase cervical screening uptake/increase participation in areas of high relative deprivation.

Debrief.

Appendix O: Preliminary thematic template (Study 4a)

3.0 Barriers to cervical screening

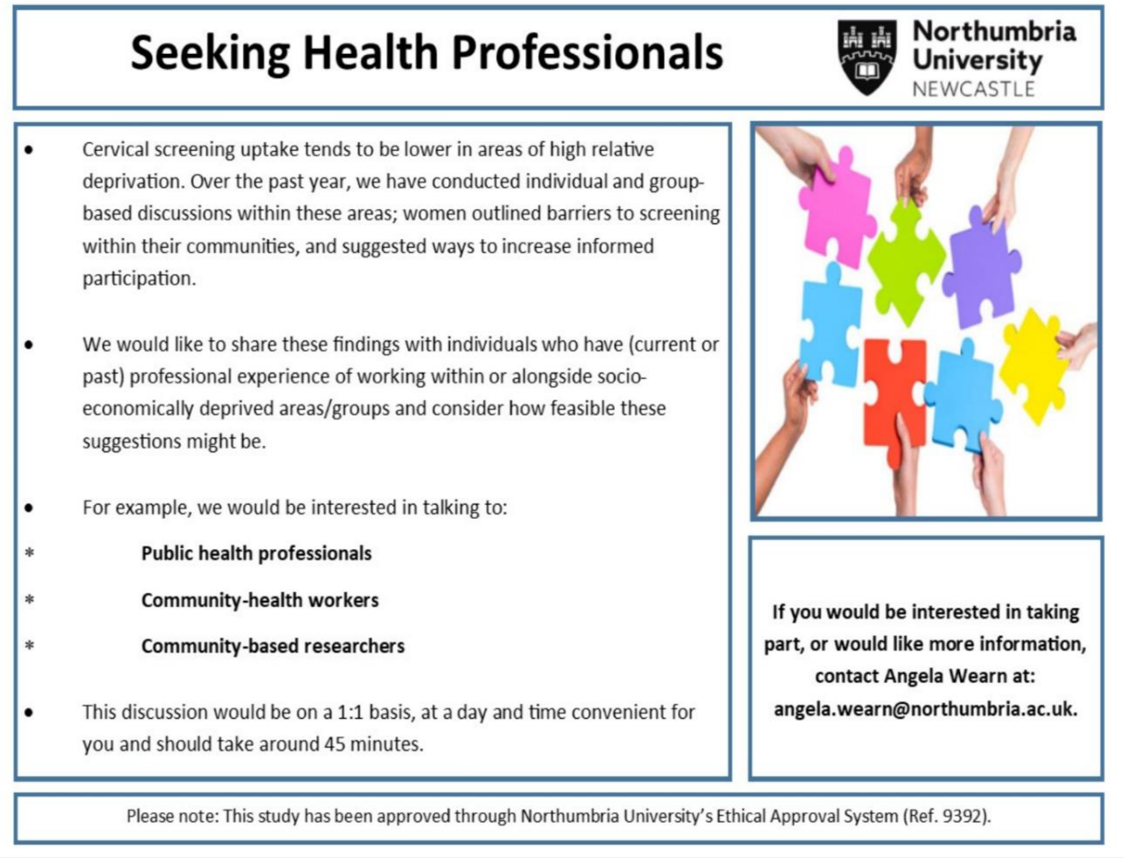
- 3.1 Social support
  - *3.1.1 Emotional support*
  - *3.1.2 Educational support*
- 3.2 Service access
  - *3.2.1 Practical difficulties in accessing services*
  - *3.2.2 Psychological difficulties in accessing services*

4.0 Suggestions to improve participation

- 4.1 Increase access to screening services
  - 4.1.1 *Drop-in appointments*
  - 4.1.2 *Consider non-clinical environments*
  - 4.1.3 *Women-only clinics*
- 4.2 Increase support in the community
  - 4.2.1 *Encourage conversation in non-clinical settings*
  - 4.2.2 *Verbal peer support*
  - 4.2.3 *Provide co-created information*

Figure O1. Preliminary thematic template outlining factors influencing cervical screening and ways in which to increase participation, in areas of high relative deprivation.

Appendix P: Recruitment Flyer (Study 4b)



Seeking Health Professionals

Northumbria University
NEWCASTLE

- Cervical screening uptake tends to be lower in areas of high relative deprivation. Over the past year, we have conducted individual and group-based discussions within these areas; women outlined barriers to screening within their communities, and suggested ways to increase informed participation.

- We would like to share these findings with individuals who have (current or past) professional experience of working within or alongside socio-economically deprived areas/groups and consider how feasible these suggestions might be.

- For example, we would be interested in talking to:

* **Public health professionals**

* **Community-health workers**

* **Community-based researchers**

- This discussion would be on a 1:1 basis, at a day and time convenient for you and should take around 45 minutes.

If you would be interested in taking part, or would like more information, contact Angela Wearn at: angela.wearn@northumbria.ac.uk.

Please note: This study has been approved through Northumbria University's Ethical Approval System (Ref. 9392).

Appendix Q: Ethics Documents (Study 4b)

Northumbria University
NEWCASTLE

Faculty of Health & Life Sciences

Participant Information

Project Title: Addressing barriers to routine cervical screening: views from stakeholders

Principal Researcher: Angela Wearn (angela.wearn@northumbria.ac.uk)

The purpose of this information sheet is to provide you with enough information so that you can give your informed consent. It is important that you read this document carefully, and raise any issues that you do not understand with the researcher.

What is the purpose of the study?

We know that many women do not attend routine cervical screening. Some areas in Newcastle have particularly low levels of attendance (e.g. XXXX) although it is not clear why this is.

We would like to discuss why women might not attend their cervical screening appointment, and think about ways we can address any issues raised.

Why have I been invited?

You have been invited to take part in this study as you are over 18 years of age and have professional experience working in or alongside low-income/deprived communities.

Do I have to take part?

No, you do not need to take part and do not need to provide any reason for declining to take part. However, if you have any questions or concerns then please discuss these with Angela.

What will happen if I take part?

You will be asked to take part in an informal, one-on-one interview at a date/time convenient to you.

On the day of the interview, Angela will firstly ask you to fill in a short anonymous questionnaire outlining your own past screening behaviour (3 questions; i.e. ‘Have you ever taken part in cervical screening?’.). We do this because we know an individual’s opinions surrounding cervical screening may be related to their own screening behaviour. Following this, Angela will highlight some barriers to cervical screening, and potential ways to address these barriers, as suggested from women living in low-income communities. Throughout this, you will have the opportunity to contribute your own thoughts and opinions on these findings and suggestions, given your familiarity with low-income communities. You only need discuss things that you feel comfortable with and there is no need to disclose any personal experiences regarding cervical screening, unless you wish to. It is important to note that we are interested in your own personal opinion, and do not require you to comment on any current policies or procedures of any organization that you are affiliated with.

This interview will be recorded, however, any identifying names or information will be removed during analysis.

Will my taking part in this study be kept confidential and anonymous?

Yes. We have a number of procedures to ensure the data you provide remains confidential and anonymous. If you decide to take part in this study, you will be given a participant number. Your name, or any other personally identifiable information, will not be associated with any of your responses during this study. In addition, whilst we are interested in speaking to individuals that work within health and/or community-based settings, we are only interested in your personal opinions. As such, the organization you work for will not be recorded or associated with your interview in any way. Anonymous quotes may be used in a research report, but any identifying information/names etc. that you may have used during your interview will be removed.

Signed consent forms will be kept in a locked cabinet, separately from all other documents related to this research.

How will my data be stored?

All paper data, including questionnaires, typed up transcripts from your interview and consent forms will be kept in locked storage. All electronic data; including the recordings from your interview, will be stored on the University U drive, which is password protected. In accordance with University guidelines, all data will be retained for 3 years following completion of the study and after this point will be destroyed. Data will be stored in line with the Data Protection Act (2018) and GDPR (2018).

What is the legal basis for processing personal data?

The legal basis for processing the personal data required is that the research is being conducted in the public interest.

Who is organizing and funding the study?

The data controller (Northumbria University) has organised and funded this research. Before this study could begin, ethical clearance was granted from Northumbria University's Health and Life Science Faculty Ethics Committee.

Contact for further information:

Principal Researcher: angela.wearn@northumbria.ac.uk

Please always contact the principal researcher for any queries directly related to this research. However, it may also be useful for you have these additional contacts:

Supervisor of Principal Researcher: lee.shepherd@northumbria.ac.uk
Ethics co-ordinator (Health and Life Sciences): nick.neave@northumbria.ac.uk
Data Protection Officer (Duncan James): dp.officer@northumbria.ac.uk

Northumbria University NEWCASTLE

Faculty of Health & Life Sciences

INFORMED CONSENT FORM

Project Title: Addressing barriers to cervical screening: views from stakeholde

Principal Researcher: Angela Wearn

please tick or initial where applicable

I have read and understood the Information Sheet and had the opportunity to ask questions	☐
I give consent for voice recordings to be made of my responses during the discussion/interview	☐
I understand that anonymous quotes may be published in an academic journal/textbook or on an appropriate Northumbria University webpage, and therefore may potentially be available worldwide. **My name or other personal information will never be associated with the recording.**	☐
I understand I can withdraw from this research at any time before publication, without having to give a reason for withdrawing, and without prejudice.	☐
I consent to the retention of this data under the condition that any subsequent use also be restricted to research projects that have gained ethical approval from Northumbria University.	☐

Signature of participant..
Date.....……………….

(NAME IN BLOCK LETTERS)..…………………………………………

Signature of principal researcher...
Date....…………………

(NAME IN BLOCK LETTERS)..…………………………………………

Northumbria
University
NEWCASTLE
Faculty of Health & Life Sciences

Debrief Sheet

Project Title: Addressing barriers to cervical screening: views from stakeholders.

Principal Researcher: Angela Wearn

What was the purpose of the study?

We know that many women do not attend routine cervical screening in line with NHS guidelines. Research has also shown that low-income communities often have lower cervical screening uptake in comparison to more affluent communities, although it is not entirely clear why this is. We have recently discussed cervical screening with women from low-income communities, with these discussions highlighting a number of barriers, and potential ways in which these barriers could be addressed.

We met today to discuss barriers and suggestions regarding routine cervical screening participation as highlighted in this previous research, given your familiarity with low-income communities. We are particularly interested in understanding how acceptable and feasible these suggestions may be to those who work within a health and/or community-based capacity. These findings will be considered alongside previous research and incorporated into a PhD thesis, which aims to understand and address inequalities in cervical screening participation.

What will happens to the results of the study and how can I find out more?

The general findings from this research might be reported in a scientific journal or presented at a research conference and/or shared with other organizations that have shown interest in this research, however the data will be anonymized and you will not be personally identifiable. If you wish to receive a summary of the results, then please provide an email or postal address to Angela and this will be sent to you when the study is completed.

If I have any further questions, or wish to withdraw my data, who should I contact?

If you have any questions regarding, or related to, this research project then please contact Angela at angela.wearn@northumbria.ac.uk. If you wish to withdraw your data, please email Angela within 1 month of taking part, and quote the participant number that was allocated to you (this can be found at the top of this sheet). After one month, it may not be possible to withdraw your data as it may already have been analysed.

The data collected in this study may also be published or presented at conferences. Should the research be presented or published, all data will be anonymous (i.e. your personal information or data will not be identifiable).

All information and data gathered during this research will be stored in line with the Data Protection Act (2018) and GDPR (2018) and will be destroyed 3 years following the conclusion of the study. If the research is published it may be kept for longer before being destroyed. At no point will your personal information or data be revealed.

This study and its protocol have received full ethical approval from Faculty of Health and Life Sciences Research Ethics Committee. If you require confirmation of this, or if you have any concerns or worries concerning this research, or if you wish to register a complaint, please contact the Chair of this Committee (Dr Nick Neave: nick.neave@northumbria.ac.uk), stating the title of the research project and the name of the researcher.

Appendix R: Additional study materials (Study 4b)

Past Screening Behaviour - Questionnaire

Why are we asking for this information? We are collecting this information because we know that people's thoughts and opinions surrounding routine cervical screening may be associated with their past screening behaviour. As stated on the information sheet, all collected data will be anonymous and strictly confidential. If you have any concerns about the information you are being asked to provide then please feel free to speak to the researcher.

Please provide the following information:

1. Have you ever attended routine cervical screening?

Yes
No

2. When did you last attend a cervical screening appointment?

Within the last year
Within the last three years
Within the last five years
Over five years ago
Not sure
Never attended

3. Have you ever postponed or 'put off' making your appointment (for any reason other than pregnancy)?

Yes, once
Yes, occassionally
Yes, always
No, I make the appointment immediately.

Interview Schedule.

Stakeholder consultations – Health/community workers.

We have been working with members of local communities to understand factors that may contribute to the low rates of cervical screening participation in these areas. Today I will briefly go through what we have found so far, and some of the suggestions that have been put forward by the women, to potentially increase screening participation. While I am doing this we will have a chat, regarding your own thoughts and opinions, as someone who is familiar with and/or works alongside low SES communities. We will also discuss how acceptable or feasible you feel these attempts to increase participation would be.

Part One – Understanding barriers to screening

- ❖ Brief introduction to screening inequalities in low SES areas.

- **Before I go into the findings of our research, I wondered if you had any thoughts regarding why screening participation tends to be lower in the areas I've just mentioned?**

- ❖ Loose discussion surrounding stakeholder's personal opinion on low screening uptake.

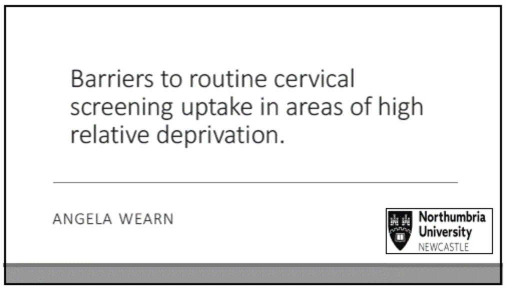
- *Determinants of screening participation in areas of high relative deprivation:* brief presentation of the different factors/themes that were found in previous research. *[Give participant opportunity to give thoughts/opinions on these themes throughout]*

Part Two – Addressing barriers to screening

- *Which of these issues were most important to our communities?* - Short introduction to the key factors that arose from the focus groups and associated recommendations that women felt would increase screening uptake.

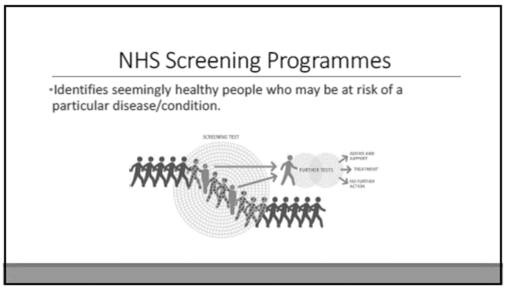
- **Could you tell me your thoughts on these/this recommendation?**
- **In your opinion, is this something that you feel would benefit the wider community?**
- **Do you feel health professionals/community organisations would engage with this type of intervention?**
- **How do you think this intervention would work?**
- **Can you foresee any problems with this type of intervention?**

Interview slides (study 4b)



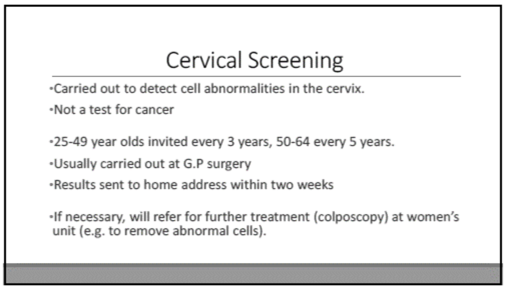
Barriers to routine cervical screening uptake in areas of high relative deprivation.

ANGELA WEARN



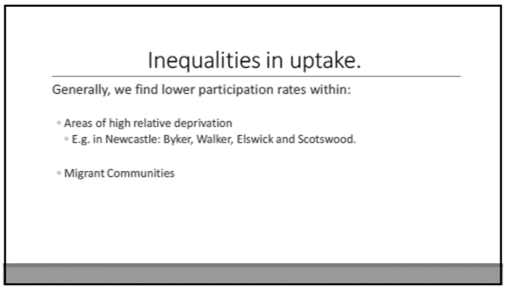
NHS Screening Programmes

- Identifies seemingly healthy people who may be at risk of a particular disease/condition.



Cervical Screening

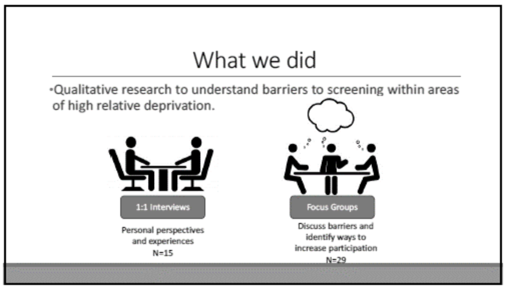
- Carried out to detect cell abnormalities in the cervix.
- Not a test for cancer
- 25-49 year olds invited every 3 years, 50-64 every 5 years.
- Usually carried out at G.P surgery
- Results sent to home address within two weeks
- If necessary, will refer for further treatment (colposcopy) at women's unit (e.g. to remove abnormal cells).



Inequalities in uptake.

Generally, we find lower participation rates within:

- Areas of high relative deprivation
  - E.g. in Newcastle: Byker, Walker, Elswick and Scotswood.
- Migrant Communities



What we did

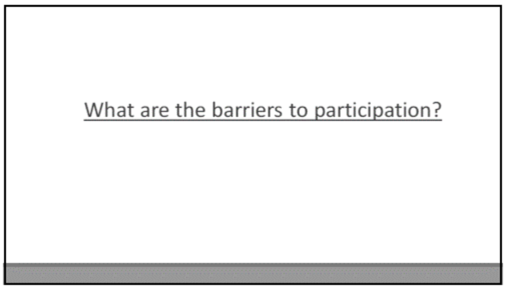
- Qualitative research to understand barriers to screening within areas of high relative deprivation.

1:1 Interviews

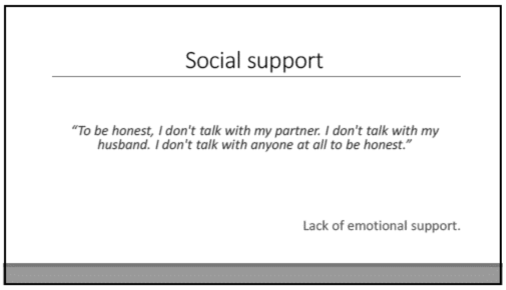
Personal perspectives and experiences
N=15

Focus Groups

Discuss barriers and identify ways to increase participation
N=29



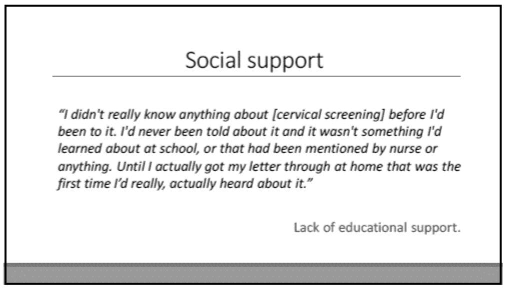
What are the barriers to participation?



Social support

"To be honest, I don't talk with my partner. I don't talk with my husband. I don't talk with anyone at all to be honest."

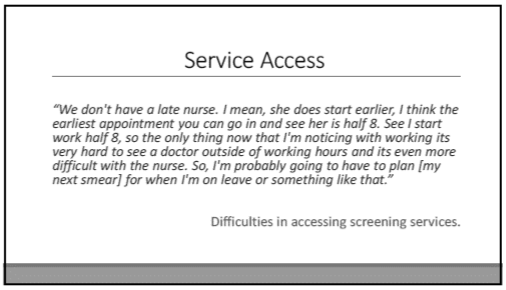
Lack of emotional support.



Social support

"I didn't really know anything about [cervical screening] before I'd been to it. I'd never been told about it and it wasn't something I'd learned about at school, or that had been mentioned by nurse or anything. Until I actually got my letter through at home that was the first time I'd really, actually heard about it."

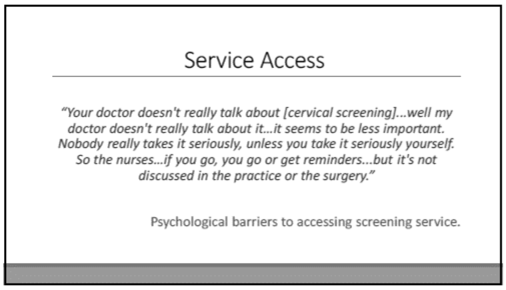
Lack of educational support.



Service Access

"We don't have a late nurse. I mean, she does start earlier, I think the earliest appointment you can go in and see her is half 8. See I start work half 8, so the only thing now that I'm noticing with working its very hard to see a doctor outside of working hours and its even more difficult with the nurse. So, I'm probably going to have to plan [my next smear] for when I'm on leave or something like that."

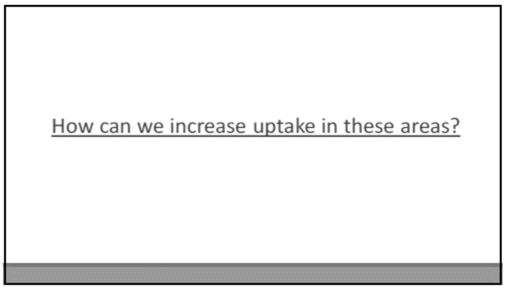
Difficulties in accessing screening services.



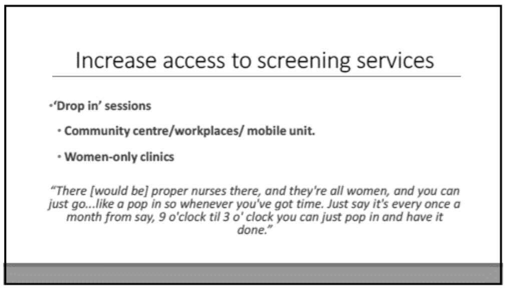
Service Access

"Your doctor doesn't really talk about [cervical screening]...well my doctor doesn't really talk about it...it seems to be less important. Nobody really takes it seriously, unless you take it seriously yourself. So the nurses...if you go, you go or get reminders...but it's not discussed in the practice or the surgery."

Psychological barriers to accessing screening service.



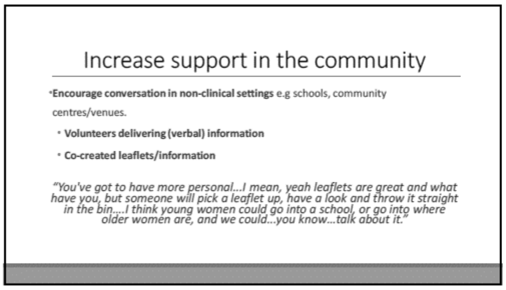
How can we increase uptake in these areas?



Increase access to screening services

- **'Drop in' sessions**
  - **Community centre/workplaces/ mobile unit.**
  - **Women-only clinics**

"There [would be] proper nurses there, and they're all women, and you can just go...like a pop in so whenever you've got time. Just say it's every once a month from say, 9 o'clock til 3 o' clock you can just pop in and have it done."



Increase support in the community

- **Encourage conversation in non-clinical settings** e.g schools, community centres/venues.
  - **Volunteers delivering (verbal) information**
  - **Co-created leaflets/information**

"You've got to have more personal...I mean, yeah leaflets are great and what have you, but someone will pick a leaflet up, have a look and throw it straight in the bin....I think young women could go into a school, or go into where older women are, and we could...you know...talk about it."

Appendix S: Example coding (Study 4b)

Table S1. Example coding from participant transcripts, relating to determinants of cervical screening.

Determinants of cervical screening			
Theme	**Sub-theme**	**Notes/Summary of theme**	**Example excerpts from transcripts**
External factors	Negative experiences of primary care	There are variable experiences of primary care (related and unrelated to screening) which can influence willingness to engage with future screening. If negative, these experiences can discourage women from attending. This may be an issue even when hearing other's general experiences of primary care (sharing experiences appears common in the community).	*"I think it sounds like [P4], you've got a female doctor that's got a skill. Cause some don't know what they are doing with the instruments and it gets quite painful whereas your doctor…you feel you've had a positive experience… see I didn't have...the nurse was kind of, OK, but it was really painful and that's kind of put me off".* -FG2, P3, Overdue. *"If one [woman] goes and says, 'I've been for a cervical test' and the others will go, 'Ok, so how it was?' and then the person says, 'Well, it was like this, and like this, but I wasn't so happy, it's not like Romania'. So then, by saying this, the other person will say, 'Oh, I'll not go' and obviously they don't understand the importance of the test."* -FG1, P1/Translator, Up to date. *"...you have services that aren't designed to be accessible by [marginalised groups]. So even if they did go along they would feel like, 'I don't feel this is inclusive for me, I'm going to tell my friends that it wasn't an experience I liked..."*- Interviews, P2, Network co-ordinator.
	Competing demands	Those living in areas of high relative deprivation often have complex everyday challenges and demands, often with significant childcare financial worries and pressures.	*"It's the bus fares, childcare, managing to feed yourself that morning."* – FG1, P1, Overdue. *"A lot of people around here have got big families. It's not just saying, 'Can you look after her while I go to the doctors'. They might have 4 or 5 children and people just can't get them looked after." – FG4, P4, Up to date.* *"I definitely heard that particularly in really deprived communities, where women are working in pretty...not very nice working conditions. You know, maybe on minimum wage, maybe not even getting paid the living wage where actually some women didn't feel they had the confidence to a) say they needed to take the time off to have a smear test but also, what was so interesting was women saying, 'if I take time off work, I don't get paid'."* – Interviews, P1, Project manager. *"In relation to disadvantaged groups, they have such complex lifestyles, with so many different pressures and things going on…"*- Interviews, P5, Cervical screening facilitator
	Social influence	Individuals often make decisions around screening depending on the people around them. This can be friends/peers within the community or family members. If individuals have family members who are not 'open' with them from a young age they may not be familiar with screening. Communities typically have social networks which offer support to one another.	*P1- So what she's saying, [P2]; She knew about papanic...sorry that's Romanian. She knew about cervical screening from Romania, but she never had it done in Romania. But when she come to UK she got the letter through the post and she ask the daughter of [another lady], who was working in the NHS, and then she advised her this is a good thing that you need to go to, and she went to the test. So, she knew before but she never had it, then in UK she had it done. She asks if it was important or not and then the person said yes, it is really important.* *I - So, it was talking it through with somebody else...and it was important..* *P1 - Yes, because she wanted to not give importance to that letter, she didn't know exactly what it was about so that's why she ask for advice and the*

			person said, 'It's OK, it's very important', and she went' -FG2 *"I think it has something to do with the influence you've had from your family as well. So, my mam's always been very, very open about things like that, and we've always spoke about anything to do with sex or health. And [cervical screening] was just one of them things, 'This is just what you do'*." – FG4, P1, Up to date. *"I have friends who parents weren't as open as my parents were. And I don't know if that's a sort of...not a shame thing, but an embarrassment thing for the parents."* – FG4, P4, Up to date. *"But my impression is for the local community is that there are quite strong networks of women who explain things to each other at home and that kind of has a positive side...I've had ladies who've said 'I've only come because my friend and my mam have said I've had to come'"* -Interviews, P3, Practice nurse
Internal factors	Screening-related knowledge	Individuals might not know what screening is, particularly in terms of what to expect in an appointment. This is exacerbated if women come from cultures or families where screening is not discussed. Typically low levels of health literacy may mean individuals cannot always access existing information themselves.	*"…majority of the people here, they are not attending because of the lack of the information, because they don't know exactly what [screening] is, they don't know how it is with the procedure, they don't know what to expect."* – FG3, P1/Translator, Up to date *"Because it was never talked about in our house, I didn't know what a smear was."* - FG1, P5, Up to date *"See, it's like even at school, even in school we weren't taught about [cervical screening]….. I don't think things are taught in schools early enough. I think you take a lot from school*." - FG4, P4, Up to date. *"There's that health literacy isn't there. Just...just understanding...just because you have information in front of you about health doesn't mean that you understand what it means.*" -Interviews, P2, Network co-ordinator
	Prioritisation of screening	Timely screening is often not viewed as a priority. This is because people often have needs and demands that are genuinely pressing and urgent to tackle i.e. childcare/finance and so on. Postponement of screening is therefore a sensible choice if individuals feel they are struggling to meet basic needs.	*"Well, like you say people have children - they are busy with their childcare. They prioritize themselves last. They have families to look after, getting from A to B is a big thing. An appointment even for an hour for some people would be...just a massive issue wouldn't it*." - FG2, P3, Overdue "[*P2] was saying the Romanian community are more concerned about...like, to have food in the house, to make it clean, to clean the house, to take care of the kids…"* -FG3, P1/Translator, Up to date. *"When people don't have money, when people don't have...the last thing they're going to do is manage to get off their arse and get down to the doctors and have screening*.**" –** FG1, P1, Overdue. *"I think my impression is probably particularly under the recent decade with austerity government, is that people are experiencing quite a lot of hardship and consequently they have different priorities"*. -Interviews, P3, Practice nurse
	Emotional responses to clinical care	General engagement with primary care may elicit negative/aversive emotions (e.g. fear and anxiety and mistrust). In addition (and perhaps even more commonly) there are strong negative emotional responses to screening attendance. In general aversive emotional responses to	*"I never used to get it done...because it was um…uncomfortable? Uncomfortable and embarrassment and thinking in back of my head that, 'No, I won't have it', you know? It's just about doctors, you know, they just want to do....it is about the fear as well…what if the worst comes"*. -FG2, P12, Up to date *'Some women are shy, some women are like....you know what I mean...might have had a bad experience with men'* – FG1, P2, Up-to-date *"I think there are quite a lot of people who will come for very, very delayed screening. You know, up to ten*

		the thought of clinical care is a strong barrier to engagement.	*years delayed, and they tend it say it's because they feel it's embarrassing, it makes them a little bit anxious or upset...those kinds of things. Often, they will say, 'I knew I was very late, and I haven't responded to the letters and I've only come because my friend or my neighbour said I ought to come'. And I think those... the anxiety and the embarrassment, and the fear of pain, are some of the key reasons people highlight".* – Interviews, P3, Practice nurse.

Table S2. Example coding from participant transcripts, relating to suggestions to improve cervical screening participation.

Suggestions to improve participation (with comments on feasibility from health-related professionals)			
Theme	**Sub-theme**	**Notes/Summary of theme**	**Excerpts from transcripts**
Increase service accessibility	Introduce drop-in appointments	Drop-in appointments would offer more flexibility for those with various competing demands and challenges. Would reduce the need to think about/make appointments (which has previously been discussed as a barrier). May pose challenges in terms of finance and staffing resources.	*"There [would be] proper nurses there, and they're all women, and you can just go...like a pop in so whenever you've got time. Just say it's every once a month from say, 9 o'clock til 3 o' clock you can just pop in and have it done."* – FG2, P4, Up to date *'I think [to P1] your idea of a drop-in centre would be absolutely ideal'* -FG3, P4, Up-to-date *"There would be something there, I think, about the timing...because I don't know whether it might then been seen as something like...'I can't make this one, I'll go to the next one...I'll go to the next one' or whatever or the time gets longer."* – Interviews, P4, Trainee Health Psychologist. *"If you were always going to get [a good] response it would be great – but there are no guarantees so I would think there would be logistical and financial considerations that could cause problems. It wouldn't be so bad if it was out of usual hours but if not, you would be taking nurses from usual clinic time which may not make financial sense. GP surgeries are a business at the end of the day, and it has to make sense".* -Interviews, P5, Cervical screening facilitator.
	Consider non-clinical environments	To reduce aversive emotions towards clinical care, it may be useful to offer screening in non-clinical locations, so	*"… this centre would do something like that. They do polling and stuff like that? So, I'm sure that [the centre owner] would organise it for women to feel comfortable to have [cervical screening] done here. And then a lot of the women here know each other, so if they came to that they would feel more*

		women feel more supported and in more familiar surroundings. Acceptable to engaging the target population but again may pose challenges in terms of resource availability/funding and determining who would be responsible for the service.	*comfortable about it. And obviously with us having this talk they would definitely be comfortable cause we've already talked about [screening]. I think that would work for me like*." -FG2, P1, Up to date *'Could they do smear drop ins in workplaces or something? Just rock up and say, 'Come on ladies!' …'Cause I think if they were literally there and they were like, 'Right, it's in the other room' and everyone would encourage you, 'Oh go on, go on!'. Instead of you having to physically go, I think that would be a good idea*.' – FG4, P1, Up-to-date *"We always say don't organise a one-off isolated event or expect people to come to you. The best engagement you get will be if you have gone to them, in places that they are comfortable with"* – Interviews, P2, Network co-ordinator. *"I think these things are always a little bit political, because it's always about funding. Is that going to come under a GP service? Because GP services are paid by job, so if you ran a drop-in and sometimes it wasn't well attended, then they're not getting QOF [Quality and Outcome Framework] points for those attendances. So, I think that's going to be an issue. And if it's run under contraception/sexual health services would that funding then be available for that? Or could it be funded as a screening initiative under the health authority with funding just for that project. I think unfortunately, I've worked for so long in the health service, you can't just have ideas, you have to have a business plan for things".* – Interviews, P3, Practice nurse
	Integrate with other gynaecological services	Integration with other services would allow women to attend for multiple appointments in one, therefore saving time in light of their busy lives. Also, the having female staff could also be more explicitly highlighted to those who were worried about sex of practitioner. Location and regularity of services would need to be	*"They said to ask you would you help them to open a clinic on [nearby location], a gynaecological clinic...once a week, not every week, or every two weeks or once a month, you can go there and not the same people, you can just go there and get...Yeah, everything all at once..."* -FG3, P1/translator, Up to date. *"I suppose it's...where would you do them? Would they be in the community centres? Having resources...women-only clinics...what are you actually...how many different services are you providing there? So how many staff do you need there, expertise and all of those. So, it's quite resource heavy, and needs a lot of organisation to make sure everyone is in the right place at the right time. And then you need to let people know about it...is it only a one-off every now and again?*

		refined which then poses similar challenges to those outlined above.	*So that's almost slightly more of a project manager needed for that, so there's a lot of organisation to make that happen*. – Interviews, P2, Network co-ordinator.
Work in partnership to normalise screening	Introduce screening in adolescence	Speaking to girls from a young age would familiarise them with screening and potentially reduce fears surrounding the test. Also could be beneficial if they did not have this support from home. Suggestion that talks could be delivered from peers. Possible issues with age gap between introduction to screening and time of first invite that may need to be explored further to encourage buy-in from healthcare staff.	*"I still think they should educate [girls] a lot younger on it. Because when you're at that age, then if you got it drummed it into you at that age, when it does come to [being 25] it's nothing new to you. Yeah, it's something you've heard constantly...something you're a bit desensitised to. Like everything else, they're so desensitised now to all these different things and they just accept it, so why can't they just accept [cervical screening]? If they...desensitise them from being little."* – FG4, P4, up to date *"You can't get better than going right to the grassroots and yeah, [I] absolutely heard that. You know, I think, going into schools and speaking to young girls in schools and going with a speculum and talking about it. If that can become embedded in the schools [in the local area] that could be quite powerful I think*" - Interviews, P1, community-based researcher *"I also think that when girls are invited for their HPV vaccinations in schools, they should use one of their PSHE lessons to go through what's involved and introduce them to the idea of cervical screening at that time. […] I think it's important for them to make a link, at that age*. -Interviews, P3, practice nurse. *"I would say maybe the only issue with having it within a school is that you don't go to get your screening until you're in your mid-20's. So, the impact from that to [screening attendance] ...I don't know what that would be like.*"- Interviews, P4, Trainee health psychologist.
	Increase peer support in communities	Provide screening related information from people that those in the community can identify with – can often seem as though individuals are being 'told' what to do when coming from an outsider. This is a popular idea but can have a	*"You tend to find the ones that are protesting and that and telling you to go and get your smears are the ones that have their cushy little jobs and that...lovely flash car that they can just jump in and dive down to the doctors"* – FG1, P2, Up to date. *"Maybe we need to hear from other women in the same social class as us and stuff like that."* -FG1, P1, Overdue *"If you are going to have a peer education type model it's about setting it up and then making sure it's sustained. And some money will be needed to do that you know, whenever there's money behind*

		number of challenges funding a service, training those in the community and then maintaining this long-term. Concerns that it may not reach everyone who needs support, as only some of these people would engage with community services.	*something you need to prove that it's going to be useful and you need to find a way of sustaining it after the money goes away so it's a harder one."* – Interviews, P1, Project manager *"…the people in the community...there are differences in how they are engaged within community activities you know, so, you might not necessarily be targeting the people that might benefit from it the most. So there might be people that are more isolated, or I don't know...it's dependent on different types of relationships where they might only go out with their husbands, and they might not get that opportunity to have those kind of discussions even when there are volunteers there. So, yeah. There's something about that which is a bit of a barrier really. It would be good to have that, but again you wonder whether you are going to be targeting the people that are [already] able to access that information anyway?"* – Interviews, P4, Trainee health psychologist.
	Develop co-created information	Written information should be developed in partnership with community members and healthcare staff – to ensure the information is suitable and appropriately worded (and thus accessible) to the target audience. Requires real partnership working, which involves listening on both sides. Can be very time-consuming though, particularly when considering different sub-populations. Also important that leaflets are used as a tool, not as a replacement for support.	*It's not only [developing] the leaflet and translate it and say, 'OK now this is Romanian', because it will not be any help. It's actually, we sat down like we spent like 3 hours in the session with health professionals around the table from [local] medical centre and thinking what is the best way to put it, how to write it in Romanian, how to put the message across for people…'* – FG2, P1 *"{Leaflets are] just a tool. Yes, it's got all the information on but it's just a bit if paper. It's actually all the engagement work that then should happen as a result of that. That health practitioners should talk to people to provide them the right information. It's actually then the discussions they've had, the engagement and getting people interested in the issue by having the leaflet. Giving them the leaflet will make not a jot of difference. Here's your bit of paper, 'Oh brilliant. I'm not reading that'."*- P2, Network co-ordinator *I've got queues of health services wanting to talk to communities, BAME communities, but they...if they went and talked to them, they wouldn't know anything about that communities culture...what they need from [the community's] perspective. So they're delivering to, rather than first of all finding out, 'Well you tell me what your needs are, tell me how you want to hear about this and then I'll work*

			with that and make sure you get the right information'. -P2, Network co-ordinator *"The co-creation of information is…I would like to see more of that but again, I don't know whether it's financial or capacity but I don't know how feasible that is if it's done per community or...you know, where do you...not where do you draw the line, but how many different versions of the information do you need for different groups?"* – Interviews, P2, Trainee Health Psychologist

Appendix T: Matrix of themes mapped to COM-B components/TDF domains (Study 5)

Table T1. Factors influencing cervical screening participation from the perspectives of those living in areas of high relative deprivation, as reported through study 1 (systematic review), study 2 (one-on-one interviews), study 3 (online survey) and study 4 (focus groups), mapped to COM-B components and TDF domains[a]

			Capability					Opportunity		Motivation							
			Physical	Psychological				Social	Physical	Reflective						Automatic	
Source of data	**Identified factor/theme**	**Sub-theme**	**Physical Skills**	**Knowledge**	**Cognitive and interpersonal skills**	**Memory, attention and decision processes**	**Behavioural regulation**	**Social influence**	**Environmental context and resources**	**Professional role and identity**	**Belief about capabilities**	**Intentions**	**Optimism**	**Goals**	**Belief about consequences**	**Reinforcement**	**Emotion**
Systematic review	The Healthcare environment	Past experiences of screening						▨	▨								
		Continuity of care							▨								
		Sex of practitioner						▨									▨
		Practitioner endorsement						▨									
		Interpersonal skills of practitioner			▨			▨									
		Medical mistrust													▨		▨
		Service accessibility							▨								
	Social Networks	Peer and family influence						▨									
	The Individual	Embarrassment													▨		▨
		Fear													▨		▨
		Prioritisation of competing demands				▨			▨		▨	▨					
		Risk beliefs		▨								▨					
		Perceived stigma															▨
		Knowledge about screening		▨													
One-on-one interviews	The Healthcare environment	Relationships with staff			▨			▨	▨								
		Women-centered care							▨								
	Community	Social support			▨			▨									
		The experiences of others						▨							▨		
	Personal Motivation	Emotional responses to screening													▨		▨
		Screening-related beliefs		▨								▨	▨		▨		
Online survey	Screening is worthwhile			▨								▨	▨		▨		
	Screening can be difficult to access	Appointment making			▨	▨	▨		▨								
		Practical access to services							▨								
		Psychological access to services					▨	▨									▨
		Past experiences are important					▨	▨	▨								▨
Focus groups	External factors	Negative experiences of primary care						▨	▨						▨		▨
		Competing demands							▨								
		Social influence						▨									▨
	Internal factors	Screening-related knowledge		▨	▨			▨									
		Prioritisation of screening				▨			▨		▨	▨					
		Emotional responses to clinical care.						▨									▨

[a]-some themes reported across studies have similar titles but have been mapped differently due to the specific content within that theme. For example, *Knowledge about screening* in study 1 was mapped to the TDF domain of ‘knowledge’. In study 4a, *Screening-related knowledge* was also mapped to the TDF domain ‘knowledge’ but additionally to ‘cognitive and interpersonal skills’ and ‘social influence’ as participants explicitly discussed how screening-related knowledge was related to individuals ability to read/understand written information they received and social factors.

Appendix U: Behavioural analysis

Table U1. Matrix of links between identified COM-B components and associated intervention functions, from Michie et al. (2014)[a].

	Intervention functions								
COM-B components	**Education**	**Persuasion**	**Incentivisation**	**Coercion**	**Training**	**Restriction**	**Environmental restructuring**	**Modelling**	**Enablement**
Social Opportunity						▨	▨	▨	▨
Physical Opportunity					▨	▨	▨		▨
Automatic motivation		▨	▨	▨				▨	▨
Reflective Motivation	▨	▨	▨	▨				▨	
Psychological capability	▨				▨		▨	▨	▨

[a] - grey cells indicate pairing between COM-B components and intervention functions. White cells indicate these components/functions are not paired

Table U2. Matrix of links between selected intervention functions and associated policy categories, from Michie et al., (2014)[a].

	Intervention functions					
Policy categories	**Education**	**Persuasion**	**Training**	**Environmental restructuring**	**Modelling**	**Enablement**
Communication/marketing	▨	▨			▨	
Guidelines	▨	▨	▨	▨		▨
Fiscal measures			▨			▨
Regulation	▨	▨	▨	▨		▨
Legislation	▨	▨	▨	▨		▨
Environmental/Social planning				▨		▨
Service Provision	▨	▨	▨		▨	▨

[a] - grey cells indicate pairing between COM-B components and intervention functions. White cells indicate these components/functions are not paired