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Abstract (249 words)

Background

The introduction of screening in the UK and other high-income countries led to a significant decrease in the incidence of cervical cancer and increase in survival rates. Minority ethnic groups are often underrepresented in screening participation for reasons that are poorly understood.

Objective

To explore experiences of cervical screening participation and non-participation of women from minority ethnic populations in Scotland and gain insights to support the development of interventions that could potentially support screening participation and thereby reduce inequalities.

Design

Qualitative comparison group study using in-depth, semi-structured individual interviews that were thematically analysed.

Setting and participants

This study took place in Scotland. Fifty women were purposively sampled from four ethnic minority groups: South Asian; East European; Chinese; and Black African or Caribbean. White Scottish women were also interviewed.

Results

Many experiences described were common regardless of ethnicity, such as difficulties managing competing priorities, including work and care responsibilities. However, important differences existed across the groups. These included going abroad for more frequent screening, delayed introduction to screening and not accessing primary care services, language difficulties in healthcare settings despite proficiency in English, and not being sexually active at screening commencement. Experiences of racism, ignorance, and feeling shamed were also reported.

Conclusions

Key differences exist in the experience of minority ethnic groups in Scotland. These offer potential opportunities to reduce disparity and support screening participation including maximising co-incidental interactions and developing outreach work.

Patient/Public Contribution

Patient/public contribution is planned for the translation of the findings into practice and policy.

Keywords

Cervical screening, cancer screening, ethnicity, minority populations, migrant populations, qualitative comparison groups.

1. Introduction

Cervical cancer is a leading cause of morbidity and mortality in women, with an estimated 570,000 new cases and 311,000 deaths worldwide in 2018.[1] However, cervical cancer is also one of the most successfully prevented and treated forms of cancer. Cervical screening aims to reduce cancer incidence through the early detection and treatment of precancerous changes and the introduction of screening in the UK and other high-income countries in the late 1980s led to a significant decrease in the incidence of cervical cancer and increase in the survival rate.[2-5]

However, the decrease in incidence in these countries has not been universal with minority ethnic groups under-represented in screening uptake and over-represented in cancer incidence compared to the majority White populations in some contexts.[6-9] In Canada, access of cancer screening is markedly lower among members of visible minority populations than the White population.[7] Similarly, studies in the USA report lower access to cervical screening in minority populations along with a higher incidence of cervical cancers and increased mortality rates compared to women from the majority White population[10]. While limited data exist for the UK as a whole, variation in cervical screening coverage by ethnicity has been reported at district level in England.[11]

While non-participation sometimes results from informed decision making,[12] studies including or focussing on minority populations suggest lower awareness of cervical screening[13] and attitudinal and emotional barriers[14] including fear, embarrassment, shame and absence of symptoms also contribute to the reduced uptake of screening among minority population in the UK. However, the relationship between non-attendance and such barriers is complex with the same barriers also reported among individuals who do regularly attend screening.[15, 16]

Reducing health inequalities, particularly in cancer, is a priority in the UK with screening and early diagnosis key foci.[17,18] Previous studies exploring barriers in cervical screening have been conducted with individual minority and ethnically diverse populations, however, limited comparisons can be made across the studies to understand how experiences of minority populations differ due to contextual differences. The use of comparison groups within qualitative studies (e.g. groups with differing social positions such as patients, relatives, and doctors,[19] or different lived experiences such as people with or without a condition[20]) can facilitate identification of the group idiosyncrasies and phenomenological differences that impact the experience of healthcare, which often remain obscured or presumed inherent when using non-comparative methods.[21,22] This study aimed to explore and compare the experience of cervical screening participation and non-participation of women from different minority ethnic populations in Scotland, as well as White Scottish women, using qualitative comparison groups. We aimed to gain insights to support the development of interventions to reduce potential inequalities and support screening participation in minority ethnic populations in this region.

2. Methods

2.1 Study design

This was an exploratory, descriptive study using qualitative comparison groups and individual, semi-structured interviews with women from four ethnic minority groups that represent the largest ethnic minority populations in Scotland[23]: South Asian; East European; Chinese; and Black African or Caribbean. White Scottish women were also interviewed for comparison. Participants self-defined their ethnicity and ethnic group.

2.2 Recruitment

Ten participants of each ethnicity were recruited through a specialist research recruitment company. Participants were recruited via an established database, social media, and snowball sampling using a purposive sampling approach. Participants received £40 for their participation. The sample size was determined to ensure a variety of experiences within and across the groups.

Women were eligible if they were: aged 30 – 65 years (inclusive); currently resident in Scotland; and self-identified as South Asian, East European, Chinese, Black African or Caribbean, or White Scottish. Participants were required to undertake the interview in English (with support of a friend/family if they wished). The exclusion criteria were: informed consent not provided; previous or current diagnosis of cervical cancer; or ineligible for cervical screening (e.g. not having a cervix due to surgery or other reasons).

2.3 Procedure

Recruitment and data collection took place between August and October 2019. Interviews were conducted in English, took place face-to-face in the participants' homes, and were audio-recorded. Participants lived around Edinburgh, Glasgow and Stirling, the most densely populated areas of Scotland. Interviews lasted between 30 – 100 minutes. Informed written consent was obtained prior to the interview. MN conducted all the interviews.

A topic guide, based on previous research in this area, was developed to facilitate participants' recall and description of their experiences of screening {supplementary file 2}. Each interview followed its own course; the interviewer free to pursue any line of conversation appearing to be of importance to that participant. However, as we intended to compare experiences between groups, the topic guide was also used to ensure that all core topics (Experience of participation; reasons for not participating; barriers/facilitators from their cultural perspective; views on acceptable approaches to women in their communities) were raised with every participant.

2.4 Data analysis

Interviews were transcribed verbatim using a professional service. Transcripts were read for accuracy by the interviewer (MN), pseudo-anonymised and uploaded to a qualitative data management software (QSR NVivo12).

We undertook thematic analysis.[24] Transcripts were first read for familiarity. Analysis involved a detailed examination of each transcript in turn, coding all the transcripts within one comparison group (defined by ethnicity) before moving on to the transcripts of the next group. As this study was designed with qualitative comparison groups, structural coding[21] was employed first, with the topic guide used to segment the data in line with the core topics. An open coding approach was then used, identifying common topics and patterns within responses in individual transcripts. Codes were then clustered into themes and individual transcripts were examined in relation to others within the group, flagging any responses that were noticeably different within a group or theme. Once analysis was complete within each group, comparative analysis across the groups commenced.

MN conducted the analysis in full and the research team (CC and AP) examined 30% of the transcripts (spread evenly over the comparison groups). The interpretations and thematic allocations made by MN were then discussed and reviewed during a series of team meetings over the course of the analytical process.

3. Results

Fifty women were interviewed aged 30-62 years (see Table 1 for demographic details). While each comparison group included participants with a range of demographic characteristics, none of the participants in the South

Asian group and all of the East European group had migrated to the UK as adults. A full list of themes and sub-themes with example quotes is provided in the supplementary material {supplementary file 1}.

{Table 1}

3.1 Experiences of participating in screening

Screening was universally reported as being unpleasant, but important, and many of the experiences described were common regardless of ethnicity. Similarities and differences in themes at the group level are demonstrated in Table 2.

{Table 2}

3.1.1 Response to invitation letter

Many women across the groups described emotional responses to receiving the invitation letter relating to fear, dread or nervousness, recalling the physical or social discomfort experienced during previous examinations. Practical considerations were similarly common, including the need to plan round menstrual cycles, arrange childcare and/or time off work, or wear clothes that would make the process simpler.

> *Dread, to start with. It's like, oh, goodness. Oh, God. Like so I'm quite prudish so just the thought of having to be in that physical position of having it done. (South Asian participant)*

While those responses were frequent and common across the groups, a few participants described responses in keeping with avoidance, ranking screening as a low priority in their day-to-day life and perceiving themselves as low risk. These were only reported by women in the South Asian and East European groups but were unusual responses even within those groups reflecting individual differences rather than a common belief.

> *I was like, oh, I don't need it, I'm young, you know, I don't think it's necessary for me. Like I'm sure I'm going to have to check myself in a few years, not quite yet. (East European participant)*

3.1.2 Getting an appointment

Obtaining an appointment was typically considered quite simple because it was with the nurse, not the doctor. While flexible work hours, supportive work environments, and extended GP opening hours were described as helpful by some participants, others cited limited work flexibility, working in male dominant environments, and limited GP hours as problematic. Many participants commented that they needed to "wait a couple of weeks" for an appointment. While some used this as an example of their difficulties in getting an appointment, just as many used it as an example of the ease with which they obtained one. These experiences were, again, common across the comparison groups.

> *It's always been within a reasonable timeframe, week, two weeks, to get in with the nurse and get it done. (South Asian participant)*
>
> *Getting the appointment sometimes is very difficult because it takes two weeks. (Chinese participant)*

3.1.3 During the screening

Some participants, across all the groups except the Black African/Caribbean group, presented their experience of the examination itself in a neutral or positive way, often linked to the idea that it was quick. A few participants reflected on how their experience of the screening process had changed over the years. While one participant described becoming more self-conscious as her body had aged, others discussed feeling more socially and

physically comfortable with the process, often attributed to childbirth. Experiencing pain during screening was also common within and across the groups with participants describing it as *'very uncomfortable'*, *'always painful'* and *'really, really sore'.*

There were mixed views within and across the groups about the health practitioner's gender. Many women discussed how they preferred female practitioners and while some expressed this view as a relaxed preference, others were ardent about it. This was common across the groups. Some participants suggested that the practitioner's gender was unimportant; this was not however an experience expressed by any of the South Asian participants. Regardless of preference, the majority of participants across the groups assumed that the practitioner would be female and had only been screened by a female practitioner. Three participants discussed having had cervical screening performed by a man. These exceptions referred to screening undertaken 25-35 years ago (White Scottish group) or abroad in a country where screening is routinely performed by gynaecologists (East European group).

3.1.4 Talking and not talking about screening

There was a diverse range of experiences of both talking and not talking about cervical screening within and across the groups. Many participants across the groups believed that it was something that just wasn't talked about because the topic related to a sexualised body-part and was embarrassing. Participants in the South Asian and Black African and Caribbean groups indicated that there were also broader cultural influences hindering conversations.

> *It's not something that you like…see the older generation, they would never talk about stuff like that anyway, kind of thing, I think. They were quite prudish, for want of a better word, about all these kind of things. (South Asian participant)*

Participants suggested that there were some occasions where they did talk about screening including reminding female friends and family members that it was important to go, or to compare experiences or check something they were unsure about. However, limitations remained about the scope of the conversations and it was suggested that these were still not conversations to be had with men.

A few participants in the Black African and Caribbean, Chinese, and East European groups, reported having conversations with friends and family to obtain basic factual information and understand what cervical screening was after receiving their first invitation letter. These particular participants had migrated as adults and had not experienced screening before in their country of birth or in the UK.

> *I don't have any knowledge about it before. I don't know anything about it. You're seeing your name, date of birth…everything is correct. And cervical cancer screening…do I have a cancer? Oh my God, you know. It was, like…she is, like, my neighbour… I said, I don't know, I received a letter and said about cervical screening, ... she said, oh no, no, that's…they do it for women every day, every three years. (Black African/Caribbean participant)*

3.2 Experiences of not participating in screening

All the participants had attended cervical screening at some point in their lives and were still currently eligible. However, many women within and across the groups had experience of being out of date with their screening.

Delays ranged from months to years and several participants were more than a year overdue for their screening at the time of the interview.

Four themes were identified in the participants' experiences of delaying their cervical screening: competing demands; knowledge and risk perception; emotions; and system or process barriers. (Table 3).

{Table 3}

3.2.1 Competing demands

Participants across the groups discussed problems managing competing demands on their time, energy and attention. The welfare of dependants and work-related duties were discussed as being of greater importance than screening. This was portrayed not as a conscious decision to not screen, but as repeated short delays, where screening was perpetually planned but never top priority, or as an anticipated fixed-term delay while waiting for a dependant's acute needs to ease or a busy period at work to pass.

> *I didn't put it in a priority. Yeah, normally, just you care about your children more than yourself. So, you just think, maybe not, yeah, you put something lower in your schedule, yeah. (Chinese participant)*

Participants in the Black African/Caribbean, South Asian, and East European groups described delaying their screening due to their own competing health needs. This most often related to being or trying to become pregnant, although there were also instances where significant acute illness had left individuals feeling less resilient and unwilling to undertake screening at that time.

As well as these specific identifiable issues, participants across the groups also talked of non-specific competing demands with multiple pressures on their time and energy. Here, participants talked of simply forgetting or of deliberately delaying screening as a time management strategy, waiting to combine screening with other reasons for attending their GP practice.

> *And I remember delaying it, or not delaying it, just being so busy with everything else in life and putting it off. (Black African/Caribbean participant)*

3.2.2 Knowledge and risk perception

A small number of participants talked of delaying their screening as they believed their risks were low or viewed screening as a low priority generally, often linking this to the absence of symptoms. Although an identifiable theme within the study, it was unusual within each group and was not seen at all in the Black African/Caribbean group.

> *And then you think, I'm healthy, I will just, okay, I've got to get an appointment but not…it won't be that urgent. (Chinese participant)*

3.2.3 Emotions

Embarrassment and fear of the pain were themes that were, again, identifiable across the study but unusual in each group, and emotional experiences for delaying screening were not identified at all in the Chinese group. It is also of note that, while pain was a common theme when discussing the experience of screening, only a few participants attributed pain for their delay in obtaining screening.

The first-time round they sent me the letter and I pretty much ignored it, I didn't want to go … it was painful, and it was difficult, and I was really embarrassed, and I didn't want to go back and go through that again. (Black African/Caribbean participant)

3.2.4 System and process barriers

Women in Scotland receive an open invitation to screening via the post. Many participants across the groups, except for the White Scottish group, cited difficulties in making that appointment as a reason for their delayed screening including a lack of available appointments at the GPs, problems matching appointment availability with their own availability, and difficulties in phoning to then book the appointment.

Other participants across the groups, except for participants in the South Asian group, discussed delays related to moving home. Participants had not received their screening invitation and while some suggested this was because they had not informed their GP of their new address, others were unsure why their letters had not arrived. A few participants talked of not registering or deliberately not updating their details with the GP as they were on short term lets and moved out of their GP's catchment area on multiple occasions.

So, since moving here, and moving to a new surgery, I thought I would get like a letter to remind me that it's approaching, and I know that it's probably due, or maybe even overdue, and I've not had any word about it. (Black African Caribbean participant)

3.3 Ending the delay

Participants who had experience of being out of date with their screening were asked to reflect on how their delay had ended. Four themes were identified: changing focus of fear; persuasion from friends and family; GP/system reminders; and community awareness. (Table 3)

3.3.1 Changing focus of fear

Some participants who had expressed concern over anticipated pain and embarrassment described how their focus changed over time with the attention shifting from the potential pain to the potential consequences of not being screened.

They're the things that make me feel like, oh, it's not going to be nice, but, no, an awareness of the importance of having it done for definite overrides the feeling of, oh, I don't want to get it done. (South Asian participant)

3.3.2 Persuasion from friends and family, and GP/system reminders.

Reminder letters and phone calls from the surgery were often talked of as providing the impetus to stop delaying. However, some participants talked of requiring several reminders before they took action. As well as letters and phone reminders, a few participants had been approached by their GP while consulting on a different matter. Such reminders and direct approaches were viewed positively by the participants in this study.

How did she say it? You've not had your smear test … I went, okay. I said, oh, I'll make it next time. No need to bother, I'll do it now. (South Asian participant)

3.4 Key differences in experiences

While many screening experiences were broadly similar across the groups, there were a few key areas that differed. These areas included going abroad for screening while living in the UK, routes to screening and

accessing primary health care services, language difficulties in healthcare settings despite proficiency in English, and not being sexually active by the age of screening commencement.

In addition to these group differences, several participants discussed experiences that had been particularly difficult. Although the particulars of each participant's experience were different, they each illustrated experiences of marginalisation. (Table 4)

{Table 4}

3.4.1 Screening abroad while living in Scotland

Among the East European participants, Polish women discussed travelling to Poland to access specialist doctors, to have a broader health check including screening, and to have screening on a yearly basis none of which was available in the UK. While some participants had spent many years only undertaking their screening in Poland, while living in Scotland, others described undertaking screening in both countries. All of the East European participants had migrated to Scotland as adults.

Chinese participants also described undertaking screening as part of a general health check when visiting China, with language barriers also suggested as a motivating factor in this group. It was noted that only women in the Chinese group who had migrated to the UK as adults talked of travelling abroad for screening.

> *In Poland it's usually once per year. So, then they check if everything is okay and do other tests, or just look inside and check if everything looks okay inside you. Well I never went here [Scotland] for years. So, I always went when I went to Poland. (East European participant)*

3.4.2 Routes to screening and accessing primary health care services

Many participants who migrated to the UK talked of not registering with a GP or accessing healthcare for several years after their arrival, despite their right to do so. Participants in the Black African/Caribbean group discussed being hesitant as they associated doctors with illness rather than preventative healthcare, and they were not ill. In these instances, the participants did not register with a GP until it was necessitated by illness or pregnancy, with screening introduced thereafter. Although accustomed to preventative healthcare, several participants in the East European group also talked of only registering with a GP when it was necessitated by illness, pregnancy or contraception.

> *When I got pregnant, then I had to go and register with a GP. …Because in Africa, you don't go to the hospital unless you are sick, you just have to treat yourself. … I'm like, oh…I go, how do I do it? She [close friend] said, no you have to register at the GP. I've been telling you to register, you said no. (Black African/Caribbean participant)*

In both groups, participants who had migrated discussed learning about Scottish primary healthcare services through their social networks, with partners and friends who were either born here or had lived in Scotland longer than they had guiding them in how to register with a GP. Chinese participants also talked of being informed by their work or university.

Migrant participants across the groups also discussed experiencing practical barriers to registering with a GP, and therefore to accessing screening. For some, this related to short-term occupancy of rental accommodation and the likelihood of moving out of a surgery catchment area multiple times. For others, the need to register in person and during working hours, to provide evidence of migration status, acted as a barrier.

When I come over here, obviously I had to go and register with the doctor. However, on the beginning, I was renting a house every six months, so that was quite difficult to do, so we were changing all the time. And eventually, when I moved to where I was living for a longer period of time, then obviously I went to a GP, and I registered myself. (East European participant)

3.4.3 Language difficulties in healthcare settings

Again, participants who had migrated to the UK described experiencing difficulties with language in healthcare setting despite being otherwise proficient in English. This also included participants in the Black African/Caribbean group who grew up in English speaking African countries. Difficulties arose around the difference between medical and social English, and the colloquial Scottish dialects and accents. These difficulties made some aspects of screening, such as phoning to make an appointment, more difficult.

I was very scared to phone, because I thought, what if I don't understand, and I felt embarrassed to ask three times, the same. (East European participant)

3.4.4 Not yet sexually active at 25 years old

Several Chinese participants talked about the fact that they were not yet sexually active when they received their first screening invitation. This experience was not identified in any of the other groups. While one participant had decided not to attend screening because of this, other participants had attended for their screening. The experience of those participants varied significantly. Although both identified their virginity to the practitioners, while one participant was advised to wait until she was sexually active the other participant described how she had been screened regardless, which left her feeling anxious and tense about subsequent screenings.

My first experience was I was at uni and I went to see the doctor and then she gave me a cervical screening…. I told her I wasn't sexually active or anything but she still went and did the screening, but I was quite sore, it wasn't something I anticipated at all….because of that soreness from the first… every time I go, I tense up, you know….I don't think the doctor believed until they did the smear and then she saw the blood. (Chinese participant)

3.4.5 Marginalisation

A number of particularly difficult experiences were raised by participants across the groups, with the exception of the East European group. Participants in the Chinese, South Asian and Black African/Caribbean groups talked of difficulties related to ignorance, racism, and the lack of representation in the training and experience of healthcare practitioners. The experiences described related to both clinical and non-clinical staff and while some experiences were described as *'not racist, just ignorant'* others were experienced as racism.

I kind of realised that when I came to this GP here that you're not…they've never had any Asians before. He was surprised that I spoke English. …. Just the comments that were made were I found quite demeaning. …But it wasn't…I would not…definitely not racist, just ignorant. (South Asian participant)

The receptionists at that practice were really horrible. That's why I changed GP. …One of them wouldn't talk to me when I approached them and went to the other receptionist "you need to deal with her." I was really, really down. …I think there was a racial thing going on there. Because it wasn't just me, it was any coloured person that went in. (Chinese participant)

Participants in the Black African/Caribbean group talked of a lack of representation in terms of a sparsity of healthcare practitioners in Scotland from minority ethnic populations, and in terms of practitioners' understanding of normal and abnormal physiology in Black and minority populations.

In addition, a small number of participants in the Black African/Caribbean group and the White Scottish group described experiences that left them feeling shamed by practitioners due to their physical difference. These differences related to cutting (female genital mutilation) and body size. While some of the difficulties related to thoughtless comments and inappropriately timed conversations, others involved looks, facial expressions, and poorly masked reactions. The participant discussing body size spoke of her own experience. However, the participant discussing cutting had not been cut herself and was discussing experiences shared by older women in her social network in Scotland.

> *They catch you in the cervical smear, and you're saying, here I am, everything is exposed, and you start talking about my weight. … You know, I mean, the whole thing it becomes unbelievably excruciating, talk about it when I've got high blood pressure testing, that's fine, that is an appropriate…not when my legs are in the air. (White Scottish participant)*

> *Being from Sierra Leone, one of the things, a stigma, is FGM. So, I've been in the room when other women, aunties, have been speaking about their experiences of giving birth, going for cervical screening, and receiving the reactions from nurses, that, "Oh my God, what's happened there?" and the shame that goes with it. (African/Caribbean participant)*

4. Discussion and Conclusion

This study examined experiences of participating and not participating in cervical screening in four minority ethnic populations and the majority ethnic population in Scotland. While many of the experiences participants discussed were common regardless of ethnicity, some key differences exist and offer insights to support the development of interventions to increase participation in screening among minority ethnic populations.

Pain and embarrassment were experiences seen across the groups in the anticipation of screening and in the recall of previous experiences of cervical screening and have been reported as potential barriers in other research studies with minority populations and in the general population.[25-27] However, they were rarely cited by participants in any group in this study as an actual barrier when reflecting on previous episodes of delayed cervical screening.

Competing demands and practical factors, in comparison, were commonly reported as barriers across the groups when reflecting on episodes of delayed screening. Practical barriers have been reported in ethnically diverse populations in England[13] with work pressure, childcare commitments, and limited GP opening hours being common themes. Our results additionally illustrated ways in which the postal system may act as a potential practical barrier to screening uptake in Scotland, with participants discussing deliberately and accidentally failing to update their postal address with their GP practice. Invitations have been identified as an effective method of improving uptake to cervical screening[28] and reminders from the practice, by letter, phone, and in person, were experienced by participants in our study as important factors in returning to cervical screening after a delay. A recent Scottish study explored the acceptability of different forms of communication for cervical screening[29] and the results suggested that broadening the options in communication methods beyond letters may help increase

screening participation in Scotland. However, although such measures may help increase screening across the population as a whole, it might not address inequity of access for minority ethnic populations.

Previous studies in the UK and other European countries have indicated a lower awareness of screening programs and lack of understanding of the benefits of screening among ethnic minority populations in comparison to the majority population.[13,27] However, research within Black African populations in the UK and USA has suggested that limited awareness amongst the recent migrants plays an important role in shaping the lower uptake in this population.[30,31] Risk perception and limited awareness of screening were unusual themes within each of our groups, however, it was the participants who had migrated as adults, especially from regions where screening programs are not routinely offered, who discussed being unaware of screening prior to the receipt of their first invitation letter.

It is also of note that many participants who had migrated did not register with a GP for several years after arriving in the UK, despite eligibility to do so. Cervical screening is predominately provided through GP services but is available to individuals not registered with a GP through sexual health and family planning services. Although this may be of limited benefit to a population with little awareness of screening, several of our participants indicated that their impetus to register, and their first screening opportunity arose through contraceptive need, pregnancy, or postnatal care. These results illustrate the value of maximising coincidental interactions to promote screening. Recent studies and reports in England and abroad, focussing on a range of health conditions as well as cervical screening, have demonstrated the feasibility and effectiveness of community based outreach programs in addressing inequalities and reaching underserved populations.[32-36] Strengthening efforts to engage with minority populations in the community, and in particular the migrant populations within them, may help address disparity in cervical screening participation in Scotland.

East European participants discussed travelling to Poland to access specialists for their screening, either instead or as well as screening in Scotland. This pattern has also been reported in England[37] and noted in relation to breast cancer screening in Scotland.[38] However, there were still instances where participants were not accessing screening in either country and it should not be assumed that non-attenders are obtaining healthcare elsewhere.

Participants reported experiences of racism, ignorance and feeling shamed. Previous research undertaken in the USA,[39,40] New Zealand[41] and Europe[42,43] have indicated that the experience of racial and religious discrimination in healthcare settings not only impacts trust and satisfaction with the healthcare services, but also acts as a barrier to accessing preventative care and leads to delayed help-seeking. The experience of enacted/felt stigma in relation to bodyweight[44,45] and cutting[46,47] have similarly been found to negatively impact healthcare use and help-seeking in the USA and UK. Addressing stigmatising beliefs and practices among healthcare professionals and supporting the development of culturally sensitive and knowledgeable practitioners may help to promote cervical screening participation in minority ethnic groups in Scotland.

4.1 Strengths and Limitations

We employed qualitative comparison groups. Although much work has been carried out with individual minority populations limited comparisons can be made across the studies due to contextual differences. To our knowledge, this is the first study to qualitatively compare cervical screening experiences across groups of women from different ethnicities in the same contextual setting.

We intended to obtain a mix of demographic characteristics within each group. However, all the participants in the South Asian group grew up in the UK. While we did achieve a mix of demographics overall and elucidated some of the experiences particular to individuals who migrated as adults, experiences of South Asian migrants have not been captured in this study. Our sample was purposive and we did not attempt to represent any particular screening groups (e.g. non-attenders/attenders). It is possible that those who participated in the interviews experienced fewer barriers to cervical screening and that both shared and ethnic group-specific problems were less common than in the wider population. For example, all participants spoke English. However, although the participant's current language ability enabled them to participate fully, this had not always been the case and participants were able to reflect on past experiences and describe the ways in which language had impacted their experience of screening.

One researcher undertook all the interviews in this study. While there are arguments for having multiple interviewers in some study designs, qualitative comparison group methodology requires minimal variation between groups beyond their focal difference.[21] Having one interviewer was, therefore, a strength in this particular study.

4.2 Conclusions

While many of the experiences reported were common regardless of ethnicity, key differences exist and offer potential opportunities to reduce disparity of access, including using alternative ways of identifying and communicating with women eligible for screening, maximising co-incidental interactions with individuals from minority and migrant populations, and developing outreach work with populations not otherwise accessing healthcare. While we found many examples of positive supportive practice there is also an ongoing need to address stigmatising beliefs and practices in healthcare staff and support the development of culturally sensitive and knowledgeable practitioners to support screening in Scotland.

Research Ethics

Edinburgh University's Research Ethics Committee approval was obtained in August 2019 (study number: 1922 – Usher Institute).

Patient or Public Contribution

Patient and public contribution is planned for this research in the incorporation and translation of the findings into practice and policy. The patient and public involvement activity is anticipated for 2021 having been delayed from Autumn 2020 due to the COVID pandemic.

Data Sharing

Research data are not shared.

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Tables

Table 1. Participant demographics

	Black African or Caribbean n=10	South Asian n=10	Chinese n=10	East European n=10	White Scottish n=10
AGE (YRS)					
30-39	4	3	6	8	5
40-49	5	4	3	1	2
50-59	1	3		1	2
60+			1		1
MARITAL STATUS					
Single (never married)	4	2	2	5	3
Married	4	6	5	4	7
Separated	2	1	3		
Divorced		1		1	
EDUCATION					
Upper secondary education	1	1	1		
Post-secondary non tertiary education	2	4	4	2	3
1st stage tertiary education (under-grad)	3	4	2	5	4
2nd stage tertiary education (post-grad)	4	1	3	3	3
FIRST LANGUAGE					
Cantonese			2		
English	10	8	5		10
Mandarin			3		
Polish				9	
Punjabi		1			
Romanian				1	
Urdu		1			
RELIGION					
Agnostic					1
Buddhist	1		2		
Catholic	1			6	2

Christian	7		2	1	
Hindu	1	1			
Muslim		6		1	
Sikh		1			
Spiritualist		1			
No religion		1	6	2	7
TIME IN UK (YRS)					
5-9			2	3	
10-14	3			5	
15-19	1			1	
20+	1		3	1	
Life	5	10	5		10

Table 2. Experiences of participating in screening (● denotes presence of this theme in the group)

Section Code	Themes	Black African - Caribbean	South Asian	Chinese	East European	White Scottish
Response to letter	Emotions – Fear, Anxiety, Dread	●	●	●	●	●
	Practical considerations	●	●	●	●	●
	Engage	●	●	●	●	●
	Avoid		●		●	
Getting an appointment	Easy enough	●	●	●	●	●
	Issues and difficulties – GP related	●	●	●	●	●
	Issues and difficulties – workplace related	●	●		●	●
	Issues and difficulties – general	●	●			●
	Wait a couple of weeks – viewed as	●	●	●	●	●

	good					
	Wait a couple of weeks – viewed as bad	●	●	●	●	●
During screening	Neutral / Positive experiences		●	●	●	●
	Changing Experience	●		●		●
	Pain	●	●	●	●	●
	Practitioner's Gender	●	●	●	●	●
Talking about screening	That it is important	●	●	●	●	●
	Comparing experiences	●	●	●	●	●
	Up to a point	●	●			●
	To Understand	●		●	●	
Not talking about screening	We just don't talk about it	●	●	●	●	●
	Embarrassing - sexualised body part		●	●	●	●
	Cultural/Generational	●	●			
	Not with men	●				●

Table 3. Experiences of not participating in screening (● denotes presence of this theme in the group)

Section	Theme	Sub-themes	Black African - Caribbean	South Asian	Chinese	East European	White Scottish
Delayed screening	Competing demands	Looking after dependant	●	●	●		
		Competing health needs	●	●		●	
		Work	●	●	●	.	●
		Generally busy	●	●	●	●	●
	Knowledge and risk perception	Asymptomatic - why do it		●	●		
		It's screening not treatment				●	●
		Didn't realise importance				●	●
		Uncertain about what it was			●		
	Emotions	Embarrassment		●		●	●
		Pain	●	●		●	●
	System or process barriers	Couldn't get appointment			●		
		Problems making the phone call		●	●		
		Matching own/GP availability	●	●		●	
		Moving house / around country	●		●	●	●
Going in the end	Changing focus of fear	Importance overrides fear	●	●		●	●
	Persuasion from friends/family	Opportunistic approach by GP		●	●		
		Reminded by family/friend		●		●	
	GP/system reminders	Being chased up by practice	●	●	●		
		Reminder letters		●	●	●	

Table 4. Key differences in experience (● denotes presence of this theme in the group)

Section	Theme	Sub-themes	Black African - Caribbean	South Asian	Chinese	East European	White Scottish
Screening elsewhere	Screening abroad while living in Scotland	More frequent timeframe				●	
		Accessing a specialist				●	
		General or female health check			●	●	
		Easier to communicate - Language			●		
	Starting UK screening/Registering with GP	Not registering with a GP	●		●	●	
		Pregnancy/Post-natal check	●			●	
		Initiated by contraceptive need				●	
		Guided by partner / close friend	●			●	
		Directed by university			●	.	
Language	Difficulties	Difference medical - social English			●	●	
		Slang and accent	●				
		Telephone				●	
		Embarrassed to ask again	●			●	
Identified across multiple sections of the interview	Ignorance, racism and lack of representation	Experienced in Scottish NHS		●	●		
		Lack of representation in Scottish NHS	●				
	Feeling shamed	Weight					●
		Cutting	●				
	Not yet sexually active at 25 years old	Not going to be screened			●		
		Going, but not screened			●		
		Not being believed			●		

Supplementary material – additional illustrative quotes for themes

Experiences of participating in screening

Section Code	Themes	Illustrative quotes
Response to letter	Emotions – Fear, Anxiety, Dread	Dread, to start with. It's like, oh, goodness. Oh, god. Like so I'm quite prudish so just the thought of having to be in that physical position of having it done is…and then the build-up of this imaginary, oh my god, it's going to be agony, and it's never been agony. It's uncomfortable for a few seconds, but it's not agony. (South Asian participant)
	Practical considerations	Oh, not again. And then it means that I have to wear a skirt, 'cause I don't want to wear trousers. Because trousers are harder to remove than a skirt, a skirt, you can just remove your underwear, and then that's you sorted. (Black African/Caribbean participant)
	Engage	I just think it's routine, I'm like oh okay, book the doctors and get the smear test done. Just get it out the road. (Chinese participant)
	Avoid	It's not a priority, I'll be honest. And that sounds really bad but it's like, oh, right, okay, I need to make an appointment, I need to go through and get it done, and obviously because it's an invasive procedure, I think…well, I personally I tend to put it off so I have been quite bad in the sense that I usually end up waiting for a reminder to come through. (South Asian participant)
Getting an appointment	Easy enough	I just booked an appointment with the nurse as opposed to the doctor. So, it was fairly easy and fast from what I remember, because the nurses have quite a lot of appointments. (South Asian participant)
	Issues and difficulties – GP related	it's pretty bad considering how much they scare you into needing to get it done and when you try and book an appointment, they're like we're not taking an appointments actually until next month now, we've closed our books. (Chinese participant)
	Issues and difficulties – workplace related	My job is very much deadline, like deadline is an event so within certain times, especially like when the first letters came through, I probably had an event on. So then for the next month I was super-busy in the lead-up to it, so there was no way for me to take time away off work. (East European participant)
	Issues and difficulties – general	You can either get one within a week or sometimes it's within three weeks or four weeks that you can get something that suits, kind of thing. I have on occasion like I've said, many a time that I've realised, oh, my cervical smear, oh, goodness I'm on my period so I'll have to cancel it, and then once you've cancelled it you're looking again. (South Asian participant)
	Wait a couple of weeks – viewed as good	It was definitely easy. I just went to the reception and they checked the dates and it was pretty easy to get in. So I got it within the next two weeks. (East European participant)
	Wait a couple of weeks – viewed as bad	In Edinburgh, it's a bit tricky. So if I call my surgery, it usually takes about two weeks, so it's quite tricky. (East European participant)
During screening	Neutral / Positive experiences	I don't feel any way either way about it really. It's just something, as I said, something that you have to do. It's fine. (Chinese participant)
	Changing Experience	When I was really young, I remember there was something and I was quite…I wasn't bothered about it at all. I was quite comfortable. There was like five people at one point having a look. I think they were doing some kind of training where they had people and I was just a bit like…but now I wouldn't feel that comfortable. I would never be comfortable with that now. … I've put on loads of weight and I'm a bit more flabby and that doesn't look like…my vagina doesn't look like the way it used to look. (Black African/Caribbean participant)
	Pain	Someone has to look at your private parts and even worse it's sore as well and I couldn't get [relaxed], … so then it's taking longer and the nurse has to try a few times. It's very unpleasant. s(East European participant)

Continued…

	Practitioner's Gender	I've not had any guys. I think if it was a guy, I'd feel a bit awkward. …if I saw a guy I don't think I'd feel comfortable, I'd say I need to get a female, you'd just feel a bit awkward. …But then if I don't have a choice, then I'd be like okay, fine, but I think preferably I don't want a guy looking down there, preferably more a woman. (Prefer female/not to have male HCP – Chinese participant) No, I'd refuse. … I don't know, I don't know, I would feel uncomfortable. I don't really want anyone looking down there, who's not a lady, I have no idea why. (Prefer female HCP – White Scottish participant) I would prefer to have the female, and I would prefer to have the doctor who's seen everything, just because she's very thorough. But I don't really mind a male, because it's his job. (Doesn't really matter - Black African/Caribbean participant) My gynaecologist was a male, which again, I didn't mind, because that's what we always had. We were always being told that the male is more gentle than the woman. that was kind of, I don't know, a stigma, maybe not even a stigma, but that's what we'd been told, you go to a male, it's much more gentle, and it's better. The woman can be not as gentle, and can be, not as nice. So we always went to a male, and obviously, it was kind of

		embarrassing at the beginning. (Prefer male HCP – East European participant)
Talking about screening	That it is important	However, me, as me, I go, because I know it's important, and it's preventable. And even though sometimes I share on Facebook when it's, obviously, I think it's in June, the awareness. So I just usually send, even share this important, and even sometimes, I giving trouble to my friends if they don't want to go, I say, you have to go, that's it, you have to go. (East European participant)
	Comparing experiences	I was worried about, I've seen some blood on the sheet whenever she took out the tools, even though I wasn't on my period. So that's always quite worrying. I don't think that I've ever asked about it, but I...yes, I spoke to my sister about it. And she said she had that as well. (East European participant)
	Up to a point	You know, I wouldn't just text them and go, oh, have you been for your smear? It would be a conversation. What have you been up to today? Oh, well, I had to go for my smear. I'd go, ouch, how was that? Okay, fine and then we'd move on. (South Asian participant)
	To Understand	I don't have any knowledge about it before. I don't know anything about it. You're seeing your name, date of birth...everything is correct. And cervical cancer screening...do I have a cancer? Oh my God, you know. It was, like...she is, like, my neighbour... I said, I don't know, I received a letter and said about cervical screening, ... she said, oh no, no, that's...they do it for women every day, every three years that...just to, you know, check if there any abnormalities and everything. (Black African/Caribbean participant)
Not talking about screening	We just don't talk about it	Oh, my god. Never, we never talk about it. No, you just presume, because I'm going for mine and checking that I'm alright, that everyone else is doing it, you never think to ask. Wow, that's an eye opener. (Black African/Caribbean participant)
	Embarrassing - sexualised body part	I think it's that whole talking about your reproductive organs and, you know, that's a bit embarrassing. (South Asian participant)
	Cultural/Generational	It's not something that you like...see the older generation, they would never talk about stuff like that anyway, kind of thing, I think. They were quite prudish, for want of a better word, about all these kind of things. (South Asian participant)
	Not with men	No, I wouldn't openly talk about it. But equally, if I'm going for a smear test, I don't find that embarrassing to say, I'm going for a smear test. So I might not say it to a male boss, for example, but like, I wouldn't have any qualms saying to my mum or to sort of female colleagues at work, I've got my smear, kind of, a bit like that. (White Scottish participant)

Experiences of not participating in screening

Section	Theme	Sub-themes	Illustrative quotes
Delayed screening	Competing demands	Looking after dependant	I didn't put it in a priority. Yeah, normally, just you care about your children more than yourself. So, you just think, maybe not, yeah, you put something lower in your schedule, yeah. (Chinese participant)
		Competing health needs	I hadn't been well myself, so sometimes I just, and I think, okay, I'll just give it a miss, and go another time.... I had taken septicaemia. So I was in hospital with that. And then when I came back out of hospital, it was like, it took a lot out of me so I was really kind of drained out, so I just couldn't cope with having the smear test. (South Asian participant)
		Work	Because with [company name] I worked away a lot of the time for a... It was a different company so I could be away for four months at a time, so I think that's probably the only times but it's not intentional, like I've delayed it. I just haven't been able to get there. (White Scottish)
		Generally busy	And I remember delaying it, or not delaying it, just being so busy with everything else in life and putting it off and then eventually going and then being really relieved that it was fine. (Black African/Caribbean participant)
	Knowledge and risk perception	Asymptomatic - why do it	And then you think, I'm healthy, I will just, okay, I've got to get an appointment but not...it won't be that urgent. (Chinese participant)
		It's screening not treatment	I know that if lots of things like that is left to my devices, it's going to be postponed, unless it is something really, you know. You can argue, because it is important, it is very important, but because it is screening, it is not treatment, you feel like, oh okay, it doesn't matter. (East European participant)
		Didn't realise importance	I was in the army and it was never something that, sort of, crossed my mind. It wasn't really out there as, like, an urgent thing you had to get done, or anything. It was only really since having my son and the Jade Goody thing that, sort of, made me more aware sort of thing. (White Scottish)
		Uncertain about what it was	So I think I got about three letters by the time I went. I got that letter through after I registered with the GP and I didn't want to go for it. Because I wasn't sure what it was at that point, to be honest...I was postponing going for a long time. But I think one of the conversations

			with my sister when she got a letter as well, she was like, no, you need to go, you need to check yourself, it's important. So then I started to go. (East European participant)
	Emotions	Embarrassment	I would get the letter and I was delaying that as long as possible... I think, first of all, it's shame and, well, you have to get naked there. Someone has to look at your private parts and even worse it's sore as well. (East European participant)
		Pain	The first-time round they sent me the letter and I pretty much ignored it, I didn't want to go ... it was painful, and it was difficult, and I was really embarrassed, and I didn't want to go back and go through that again. (Black African/Caribbean participant)
	System or process barriers	Couldn't get appointment	Last time I phoned for an appointment. I phoned up, I got through, I wanted to get an appointment, I couldn't book it, they had it on their diaries, and then I was on holiday for a month. So, by the time I finally got booked in it was probably three months after I got the letter. (Chinese participant)
		Problems making the phone call	For my practice anyway I have to phone up at eight o'clock in the morning and even if I've been on the phone at the dot of eight o'clock or even a minute beforehand it will either be engaged or you just...I kid you not, you know when you keep pressing the number, it can be up to 30 times before you've got through. (South Asian participant)
		Matching own/GP availability	I put it off a little bit but I do get it. Well there is just, yeah childcare and then booking time off work, so it is just whatever day that I can get off work. I work until half five, the doctors is only open until six, ... you have to take a flexi half day. (South Asian participant)
		Moving house / around country	So, since moving here, and moving to a new surgery, I thought I would get like a letter to remind me that it's approaching, and I know that it's probably due, or maybe even overdue, and I've not had any word about it. (Black African Caribbean participant)
Going in the end	Changing focus of fear	Importance overrides fear	They're the things that make me feel like, oh, it's not going to be nice, but, no, an awareness of the importance of having it done for definite overrides the feeling of, oh, I don't want to get it done. (South Asian participant)
	Persuasion from friends/family	Opportunistic approach by GP	How did she say it? You've not had your smear test or something and I went, okay. I said, oh, I'll make it next time. No need to bother, I'll do it now. (South Asian participant)
		Reminded by family/friend	It was actually my husband who prompted me because you know when you have that list to do or papers et cetera. He was going through them and he was like, you've still not made that appointment, have you? I was like, oh, no. He was like, you'd better make it, and I'm like, yes, I know, I know, I know. (South Asian participant)
	GP/system reminders	Being chased up by practice	The first time round they sent me the letter and I pretty much ignored it, I didn't want to and the practice manager knows our family pretty well, ... and she was like, yeah [Name], you haven't responded – 'cause I don't want to go, last time it was really difficult'. ... And I didn't want to go back and go through that again. They were like, well why didn't you say, you can tell us. ... So they did the right thing in chasing me up and I went there ...and I was really lucky because, yeah I would have happily ignored that phone call or the letters and just put my head down. (Black African Caribbean participant)
		Reminder letters	I think, another letter, I think it said, I'm overdue, and I need to register. So I go, I just come to the GP. The appointment system was easy, so you'd go early in the morning, I think, and book on the day. And then I did it, and then, yeah, it's okay. (Chinese participant)

Key differences in experience

Section	Theme	Sub-themes	Illustrative quotes
Screening elsewhere	Screening abroad while living in Scotland	More frequent timeframe	In Poland it's usually once per year. So smearing is once per year but you can go more often. So, then they check if everything is okay and do other tests, or just look inside and check if everything looks okay inside you. Well I never went here [Scotland] for years. So, I always went when I went to Poland. Yes. So, when I went on holiday every year, I tried to go to the gynaecology and go there for the check-up. And then yeah, this... The first time here, in this year, in April this

			year, so I decided like oh, I'm living here, I need to start going here. (East European participant)
		Accessing a specialist	When I go to Poland, I always go check myself, anyway. So, it's like kind of, extra, even though I'm attending the smear test here, but when I've got opportunity to go to Poland, I always make a point of the gynaecologist. I pay my share, what I have to pay, but I always check with the smear test, and I also check my breasts, and ovaries, everything, so I've got a scan. And this is kind of like, that's what we do. (East European participant)
		General or female health check	NHS is my main doctor here. I can't really go back China every time, every year, I can't afford it. So, I normally maybe go every maybe three years, so that's the time I go for my whole health check. (Chinese participant)
		Easier to communicate - Language	Well, my mum did…she's got health problems so she does go privately and all that sort of thing, she goes to Hong Kong for private screening and all that sort of thing. Yeah, and sometimes…she had one here for the BUPA, sort of thing but…'cause she can't really communicate so she'll do it in Hong Kong when she's there for a visit. (Chinese participant)
	Starting UK screening/Registering with GP	Not registering with a GP	When I come over here, obviously I had to go and register with the doctor. However, on the beginning, I was renting a house every six months, so that was quite difficult to do, so we were changing all the time. And eventually, when I moved to where I was living for a longer period of time, then obviously I went to a GP, and I registered myself. (East European participant)
		Pregnancy/Post-natal check	Well when I came here, I came with my first born. I had her in Nigeria. And the second one, I think…when I got pregnant, then I had to go and register with a GP. Because I'm like, oh I missed my period and I don't know, maybe stress of being in another country, 'cause of that. Because in Africa, you don't go to the hospital unless you are sick, you just have to treat yourself. When you know that it is getting worse, that's when you go to the hospital. So when I noticed that, oh this is unlike me, maybe it's the weather, this and that, then…so it's now over a month…two months, I'm like, oh…I go, how do I do it? She [close friend] said, no you have to register at the GP. I've been telling you to register, you said no. (Black African Caribbean participant)
		Initiated by contraceptive need	I came to Glasgow, first of all. And I needed contraceptive pills, so I think this was the first time I went to a GP to sign up. And I think, just the letters started coming. So I didn't know about it, but the letters would usually inform me. (East European participant)
		Guided by partner / close friend	Well, we were going to travel and my husband, when I first came, he said, oh, you have to register with a GP to get your shots to go travelling. …He is British … so he told me what to do because I would not have known what you have to do and all that so he said, oh, you register. … When it [THE INVITATION LETTER] first came, I went on the internet as well and looked at it so I knew, I had an idea what it was because I know over here there is so much more they do, like the screenings and all of that. You get all that and you get these letters sent out. I thought, well, I'd better go and do it. (Black African Caribbean participant)
		Directed by university	I was registered with a GP automatically when I started studying here but at that time, yes, you're young, you don't really care and yes you don't think it's necessary to have a GP, you have one but you just don't need it. (Chinese participant)
Language	Difficulties	Difference medical - social English	At that time, my vocabulary was not very enough, especially for the kind of special medical terms. Sometimes you don't get what they're for. But generally, I can understand most of the words. (Chinese participant)
		Slang and accent	It's just sometimes they would speak fast and I couldn't understand like some of the accents but now I can. (Black African Caribbean participant)
		Telephone	I think I went over, I didn't, I was very scared to phone, because I thought, what if I don't understand, and I felt embarrassed to ask three times, the same. So I used to go, and actually was face to face, and I prefer actually going and saying, right, that I would like to make an appointment. But then, obviously, when my English became better, then I was more brave to actually speak on the phone. (East European participant)

		Embarrassed to ask again	Yeah, it's very difficult, because I knew…I think I was a little bit embarrassed as well, that I had to ask twice. And sometimes when I had to ask three times, I just nod. And then, obviously, my friend and my husband, they knew I didn't have a clue, that I was nodding because I didn't want to be rude. (East European participant)
Identified across multiple sections of the interview	Ignorance, racism and lack of representation	Experienced in Scottish NHS	The receptionists at that practice were really horrible. That's why I changed GP. …One of them wouldn't talk to me when I approached them and went to the other receptionist "you need to deal with her." And I wasn't doing anything. I was really, really down. To the point where I actually went into the GP and I burst out crying. …I think there was a racial thing going on there. Because it wasn't just me, it was any coloured person that went in. But the doctors were lovely. The nurses were lovely. But reception… And I observed it when I was sitting there waiting for the doctor to come out. "You can't do that", you know, that's the way she would talk to some people. Then a non-coloured person would go up and it was all, "hello, how are you, blah, blah, yes, thank you". But then to a coloured person [tutting], oh. (Chinese participant)
		Lack of representation in Scottish NHS	A lot of the African women that I work with, or used to work with, they would have preferred to have an African doctor, or whatever. But those are not the options that you have with the NHS in Scotland, you know. You might have come across one, but highly unlikely, and even less likely with a female doctor, you know. In fact, I don't think I've ever had a woman of colour as a nurse. No, I haven't, I definitely haven't. (Black African Caribbean participant)
	Feeling shamed	Weight	With being large you always hit the, kind of, oh you're making a fuss 'cause you're large, that sort of…It's automatic, so people have an automatic thing against large people. Particularly in the medical profession, you know, first of all it's, you know, you're in with the flu and they'll go, and what about your weight, and you feel like saying, I don't give an f'ing stuff about my weight. I've got…I am ill. You know, this is not the right moment to catch me, actually. Or they catch you in the cervical smear, and you're saying, here I am, everything is exposed, and you start talking about my weight. … You know, I mean, the whole thing it becomes unbelievably excruciating, talk about it when I've got high blood pressure testing, that's fine, that is an appropriate…not when my legs are in the air. And I might be a nice jolly friendly person, but I also have feelings. (White Scottish participant)
		Cutting	Being from Sierra Leone, one of the things, a stigma, is FGM, you know, genital mutilation. And thankfully my mum never took me to Freetown to do anything like that, so I'm really, really happy for that.. So, I've been in the room when other women, aunties, have been speaking about their experiences of giving birth, going for cervical screening, and receiving the reactions from nurses, that, oh my God, what's happened there? That type of thing. And the shame that goes with it. … One thing that remains quite clear was about the reaction and the face of the person when you spread your legs. I think that also needs to be really worked into and just understood, …, like hearing it from individuals' own mouths as to how that face, that stare, the questions, or maybe even how they were treated afterwards, makes them feel. (Black African Caribbean participant)
	Not yet sexually active at 25 years old	Not going to be screened	Some people said, some people said, it's not good, if you are still a virgin. They said, it's just, it will hurt you, or it will break the film. So that's why, that's the only, I think that's the reason why I didn't go for it in the beginning. I thought, I haven't had any experience, so I'm at little risk I have a problem with this. So, I think, I'll just avoid until maybe I'm more mature. (Chinese participant)
		Going, but not screened	I just booked an appointment with a nurse, with my local GP in London, my first job was in London and then I went there and then before nobody told me you had to be sexually active, so I didn't know that. It was just, okay over 25, I'll just go to it and then the nurse told me you had to be sexually active, to do that. So, then I didn't do it when I was just 25 and then I met my husband in London as well and after a while, I became sexually active. So, I went to do the screen. (Chinese participant)
		Not being believed	My first experience was I was at uni and I went to see the doctor and then she gave me a cervical screening. And at that time, I told her I wasn't sexually active or anything but she still went and did the screening, but I was quite sore, it wasn't something I anticipated at all….because of that soreness from the first… every time I go, I tense

	up, you know, I just have to relax or something, you know. ... I don't think the doctor believed until they did the smear and then she saw the blood and everything and then she realised that she...just because university students are sexually active, but I wasn't, yeah. (Chinese participant)

SCREEN Scottish Cervical Screening and Ethnicity

INTERVIEW GUIDE

Check if there are any outstanding questions, ensure consent form is signed, demographics sheet is completed, and recorder is on.

Knowledge of cervical cancer and cervical screening

- Is cancer of the cervix a type of cancer you've heard much / know much about? probe…
- What about cervical screening? Do the women in your family or social circle speak about it? probe…
- What different names/ terms used for cervical screening in your community?

Experience of participation or reasons for not participating as appropriate

- Do you remember receiving an invitation for cervical screening? (will have examples of invitation letters to act as trigger http://www.healthscotland.com/documents/24327.aspx)
- As best you can remember, when invitation letter arrived in the post what did you think and how did you feel?
- How did you decide what to do next? (e.g. Knew right away what you'd do/thought it over/don't know/remember)
- Did other things happening in life at the time influence decision? Was this time different from other times? Is this how you have reacted in the past? How did you find it? (probes .. who did the smear, nurse or GP, how well explained, any concerns)
- If not, please tell me why not? What influenced your decision not to take part?
- Ask about if have attended screening in another country (e.g. for eastern European women in Poland), and ask about experience there, and any differences they have seen.
- Have you taken in either breast screening or colorectal screening either here or in any country? If you, ask about any differences they've seen.

Barriers and facilitators from their cultural or religious perspective

- In your community, what sorts of things might put people off having cervical screening?
- Are there differing views among younger and older women?

Views on acceptable approaches to women in their communities in relation to cervical screening

- Ask about proximity of their general practice, whether language is an issue…
- Are there other health facilities you would be willing to go to for a smear?
- Community support / other women being available…

General understanding of HPV, HPV vaccination and cervical cancer

- What do you understand about HPV? and HPV vaccination?
- What do you understand about how HPV and the vaccine are related to cervical cancer?
- Ask about HPV self-sampling
    - In the future, it may be possible for women to do the cervical screening test themselves at home, using a vaginal swab (similar to a cotton bud). Would this be of interest to you? why or why not?

Closing

- Are there any other issues about cancer in general or about cancer screening that we've not covered that you would like to raise?

Thank participant for taking part; ask about results summary; ensure recorder is off, etc.

Snowballing

You are welcome to pass on the email/Facebook message you received about the study to anyone (women) you think might be interested in taking part. Or they can contact TM directly to find out about this study and see if they are eligible to take part.