

Box S1

Cervical Screening Study Service-user Interview Guide

Understanding of cervical cancer and risk:

- What do you know about cervical cancer?
- Do you know anyone that's been diagnosed with cervical cancer [among family and friends, or in the media]? How has this changed your awareness of this type of cancer?
- What do you think puts a person at risk of developing cervical cancer? Do you worry about any of those things for your own health?
- What do you think might increase risk?
- Do you think there's anything anyone can do to lower their risk?
- Do you think the risk changes as you get older? Can you explain your thinking about this?

Experiences of Screening:

- Have you ever had a smear test?

IF YES...

- Please tell me what your experiences of cervical screening/smear tests have been like.
- When was the last time that you had a test?
- How old were you when you first attended?
- Where do you tend to go for the test? (GP/sexual health clinic etc)
- What makes you have the test?
- Have you ever talked about it with other people?

IF NO...

- Can you tell me about your reasons for not having the test?

AS APPROPRIATE...

- If you are overdue for a smear test or do not regularly attend, why is this?
- Have you ever booked an appointment but not attended it? What happened?
- What would help you to attend regularly?
- Does anyone try to persuade you to have screening? How do you feel about this?

Attitudes towards screening:

- Do you think that cervical screening (the smear test) is effective? Why/why not?
- Have you ever been given a leaflet about cervical cancer or screening? Did it explain things in a way that you understood?
- What do you think might encourage women to have a smear test? (within your age group/for women in general)
- Is there anything that I haven't asked you that you'd like to talk about?

Box S2

Cervical Screening Study Health Care Professional Interview Guide

Background:

- Can you tell me about your background as a practitioner and the involvement you have in cervical screening?
- Please tell me about your experiences of screening women over fifty. (Anything particularly memorable? Differences screening younger women and women over fifty?)
- Do you agree with the current NHS recommendations for cervical screening?
- Is there anything that could be improved?
- Do you think the risk of cervical cancer changes as women get older? Can you explain why? Do you think that some women are more at risk than others?
- What may increase risk?
- What can women do to lower their risk?
- Whose responsibility is it to encourage screening in older women?

Perceptions of service-users:

- Why do you think some women are more likely to avoid screening or be overdue?
- What, in your experience, may put women off from attending?
- What, in your experience, motivates women to attend for screening?
- What role do demographics play in screening, do you think? (age, ethnicity, sexuality, social class etc)
- Do you see differences in the attitudes/experiences of younger vs older women who attend for screening?

Your own practice:

- What do you think healthcare professionals can do to encourage uptake? (in women over fifty/in general)
- What information/tools do you currently use in your own practice to encourage screening? What would you like to see adapted/developed to encourage participation?
- Have you tried any special initiatives in your practice (e.g. drop in days, opportunistic screening)?
- What can we do to increase awareness about cervical screening among women over fifty?
- Is there anything else that you would like to say that hasn't already been covered?

Table S1

Exploring the barriers
'Guiding light' experiences
<p><i>She said 'oh you're bleeding' and gave me, you know, a pack that would've sufficed for somebody that had, you know, that was haemorrhaging – I felt, hmm, I little bit undignified. It was a few spots of blood...it was like, you know, put this between your legs and you know [laughs] I kept saying somebody that might have been haemorrhaging would've been OK with that, so that was erm a bit unnecessary [laughs]... I just remember that time when 'oh dear, you're bleeding' you know, and I was given that. I'm not surprised, I feel as if you've nearly come up to my throat...You know, it was it was very very unpleasant. Well, it was painful never mind unpleasant. It was painful. And I kept thinking surely, if I'm bleeding now, will that sample be able to be properly checked? So there was that little bit of worry at the back of my mind. Attender [101]</i></p>
<p><i>...the gynaecologist lady, she, she was determined, she just sort of went [hand movement], you know, it was forced, rather than – you know, to get it, she really had to use force and it was, it was very painful...I've got quite a high pain threshold I think. But, erm, but I think it is, I mean it's, it's, it's a difficult area isn't it, to experience pain in, erm, is your vagina?...it's at your core I suppose, that's the, the word, it's so internal and in your core of your body and that sort of a pain is just, you know – although you're telling yourself that this is a, a medical examination, it's like being raped. I mean I did, I came out of the, I came out of the surgery, [laughs] and I, out of the hospital, I thought "Jesus, I feel as if I've been raped". I did, you know. Participant with a complex story [115]</i></p>
<p><i>The first horrid one I had [fifteen years ago]...when I was shaking, my legs were shaking and I thought, it was like torture, it felt like torture and this women who I didn't know, she was a nurse at the surgery but I didn't know her face, erm, she – in my mind, but she maybe didn't hear me, as I say – she had her back to me for a while, she'd left the thing [speculum] in, she was doing whatever, I don't know, for a short while, but to me it seemed like ages. And I said, "I'm shaking, I can't stop my legs shaking, it hurts like mad!" But I don't know if I shouted it long, loud enough, and it was as if she didn't hear me and she's carrying on, and to me it was like some torture chamber or other, and she was a horrid woman, do you know what I mean? And that's maybe in the back of my mind somewhere. Non-attender [137]</i></p>
<p><i>The plastic ones [speculums] are much better than the clanking of the metal and the cold. And I remember they used to keep them in a bucket, you know...after they'd used it, put it in a bucket. You felt a bit cattle like, I suppose I would say, in the past. Attender [105]</i></p>
<p><i>There'll be some people who'll come and say oh I'm having a smear done but they've just been to the beauticians and had a complete waxing or something like that...they all go seem to have that done, it's not a problem but having a smear and I've said to people well, you know, what do you, what difference? Oh it's just because you put that thing inside, [laughs] so it's mostly the actual penetration of this speculum that's the problem, not the actual embarrassment of having to get on a couch and things...they see that as completely different to having a smear. Practice Nurse [222]</i></p>
<p><i>You want to do a very good impression, you want to make them feel at ease, you don't want to rush somebody, because if they, it only takes one bad experience...she were thinking twice, because she'd had such a bad experience...you want them to come back. Practice Nurse [213]</i></p>

'Are you saying I'm past it?': Sexuality after fifty

I'm still having a sex life...I got a letter saying that they won't be giving me any more [cervical screening]. Well I think that's out of order, because all the time that I'm having, you know, indulging with my partner, then I feel that I could be possibly be at risk, so I think that I should have the option to still have them. Attender [140]

Why, at the magic age of fifty, does it then become unnecessary to do it three-yearly?...Do they assume that after that age you're less sexually active – is that what it is?...I mean, I don't know, sexuality has changed so much over the years, hasn't it?...It's the women over fifty that are more at risk than younger women because they're post-menopause and they don't feel they need to use condoms...I don't know, sexuality has changed so much over the years... ladies of a certain age, the older generation, perhaps never let their husbands see them naked let alone going to a male doctor. So once again it's this generational change to attitudes to bodies and sexuality I think changes things. Attender [138]

I think it's quite bad really, I mean, you know, you go all that time having smears and when you reach the age of, I'm not sixty five yet, I think yeah, it's sixty five then you're kind of cut off so it is pretty bad really because not everyone's sort of past their sell by date and finished with are they really? Attender [142]

You then stop having periods when you're fifty fifty-five, so that level of conversations about those kind of things sort of go away and we know that women are less likely to come about their gynae problems as they get older like incontinence and vaginal dryness and painful intercourse. It's harder for them to come and talk about that then it is about heavy periods. Heavy periods are OK, incontinence doesn't seem to be. And painful sex doesn't seem to be erm or not having sex doesn't seem to be, because of other reasons. So, they're less likely to come about those kind of things... And painful sex doesn't seem to be erm or not having sex doesn't seem to be, because of other reasons. So, they're less likely to come about those kind of things. GP [201]

...for older women as well, it's all about being erm your sexual health, so and with... especially with divorce becoming more prominent in older ladies, whereas maybe years ago it wasn't so common and older ladies getting new partners etcetera. It's trying to keep the message for them as well about their sexual health. Cause I know in south London, the cases of sexually transmitted diseases cases went up in the over sixties... You know, second marriages, third marriages and being exposed maybe to to sexually transmitted diseases, they're not necessarily as careful for their... with their sexual health. Practice Nurse [203]

Your last smear's going to be at sixty, if you have a new partner at sixty, by the time you're seventy, that's when you could be starting showing signs and when you're not screening. Hard one to call really, isn't it? Practice Nurse [220]

I can't see why dropping the age level would actually get those, that group of people who don't prioritise their health to attend. GP [210]

When we were doing three [three-yearly screening] for everybody and now, when it was five...our target rate was probably better than it is now that we've moved it...So I just wonder if there is something. But then you have to think about the cost effectiveness of doing that, and whether that results in positive screens. GP [201]

More recently, I suppose people have had, it, it's more the norm not to, not to stay in a marriage then it, twenty years ago. People sort of stuck things out a bit more, even twenty, thirty years ago, but now people have a lot more partners I think and as they get older they're starting new relationships, I mean the whole population's getting older isn't it? So if you start a new relationship at sixty, is that putting you at risk again in your seventies, when we're not screening?...it's all, it's a totally different way of living than it was thirty years ago isn't it? So I think, I don't think any age group is particularly lower risk. Practice Nurse [220]

'Your view on life changes': The burden of staying healthy

It's always 'You make an appointment'. And the appointment is, it could be two days later, it could be a week later. And I can't guarantee that I'm going to feel healthy enough on that particular day to actually come in and actually have it [screening] done. Non-attender (with chronic illness) [136]

[patient with multiple sclerosis diagnosis just before 50 years old, previously very active] I've attended everything that I've been called for, erm and without a problem, and the feedback being positive, you know, results being positive, right the way through to probably starting with my MS. And erm I've been pushed and pulled and in and out of MRI scanners and you name it, there wasn't hospital I felt I hadn't attended, and I just got fed-up with being erm intru... erm having the intrusion. The physical intrusion. So I just let one go and then I thought well, you know, so what don't need it anymore because there's such an argument about money and the funding of the NHS and got two grand... well one grandchild by then, and I thought I'd rather have the money be spent on them than me so I'll just back out of all these silly tests that, you know, keep keep getting called for. And that was it really. Non-attender [108]

I tend to forget [screening appointments]... for a lot of years I had my parents to look after...you start to think at that point I can't fit anything else in...that'll have to wait...the time of life when you get in between this age group that you're talking about, fifty five to sixty four, you have got elderly parents...young children, maybe grandchildren, there's so many things to look after, so you don't tend to look after yourself...I tend to, I don't mean conveniently forget because I don't, I just forget, you know, because they usually say, you know, it's time for, you know, to make an appointment and then, you know, months later I'm going through the bottom of my bag [of letters to action] and thinking – ooh, what's this? Attender [117]

...some of the women haven't been because they've got a letter...they've put it in their pile of letters and the day's gone on and they've forgotten, or they've rung up and they couldn't get through to the GP surgery...if that happens it can go on and on for years. Practice Nurse [217]

A lot say, 'Oh I got the letter, but it was just not at the right time and then I forgot about it completely'. And it's so easy to put a letter to the back of your mind and not worry but I think if they've got that phone call, it tends to be a lot easier and they actually, they do seem to come a little bit more. Practice Nurse [219]

The role of relationships

'Older women need to be taken care of': Matching and networking

I think it's always a bit difficult, it would be different when you see somebody different...it shouldn't, it shouldn't be, but I just, you know...that sounds a bit daft really doesn't it? Because it shouldn't really matter who it is but I think a lot, for a lot of years the same person did do it for quite a while...you've just got, don't know, oh it's that time again and, you know, that sort of conversation and, and it, and I suppose then all the dynamics of a group practice change don't they and people do different roles and people move? And I think then you maybe don't see, not that it's a big problem. Attender [116]

I used to be really impressed with the practice but I'm not so much now, it's really hard to get appointments, think they've probably got a lot more patients on their books than they used to have, I don't know, but yeah, if you had a relationship with the nurse then I think you probably would do that more. ...Some men, I think deal with it better than others, but I think it, it can feel quite, erm, quite intimidating...I have in the past been raped, so whether impacts on it or not I don't know... I wouldn't like to go to one of the men, male doctors at my surgery. Participant with complex story [141]

...they can be any nurse practitioner really doing it. Erm some you like, some you don't. And it'd be nice to get to know one that did it regular, you know, from my point of view anyway. Attender [133]

I've got one [patient] I can think in particular that was sexually abused as a child. So it, she's had the, she's gone through counselling and things, so she finds anything intimate of that nature quite uncomfy. So I've seen her twice. And I think she's sort of picked one person and sticks with that person to have the smears done. Practice Nurse [205]

A committed team I'd say is quite important. They've got to take it seriously – do they care?...your biggest driver to improve smear taking will be how much the practice want to get their figures good [for the Quality and Outcomes Framework]...If you've got a nursing team that feel strongly about it, or are they overworked? GP [214]

We've got a good mechanism between us and we would all look after each other's patients. But certainly one of these patients that's worried about her results I would ring...It is a lot about that history, that, that conversation. Erm, trying to work out with them who might be the best person to actually do that smear. Because we are all very different, and I think certainly if you've got another chronic illness you might want that smear to be done by somebody you already know or you might want it to be done by somebody you don't know... if they've said "Oh I've, I'm not having it done because last time I had it done the nurse couldn't find my cervix, it was really, really painful, it was terrible and then they sent me to somebody else...and they couldn't do it so I've said I'm never having one done again." So those people you think you need somebody that, with a lot of experience that can talk them through it and find their cervix. So they're the ones that would tend to come to me really. Erm, and all the other girls would signpost that – they'll say "Oh I, I know somebody who'll find your cervix"... We all work together as a team. Practice Nurse [217]

...we're very good at kind of keeping a track of, of who's not attending and who's DNA-ing, and between us all, I'm trying to think, there's quite a few of us now that take smears here as well. So between us all, there's sometimes we'll build up a rapport with the patient and we'll know them better than another nurse will know. So we'll notice that they've not attended for the appointment in that but if it's in with us they will turn up, so I think again, it's feeling comfortable with who's doing it as well. And sometimes I think because there's so many now of us that will do it here, it does, we do notice who will come, kind of specifically to, to one or another... as the team's got bigger, we've, it's just allowed that communication to, to kind of develop. Practice Nurse [219]

'It drags me down': Interactions between service-users and primary care

I think I like the doctors when you could just think oh I need to and you just went and queued up and you saw somebody. But when you've to think about making appointments and you know, whether you can get through and whether you're appointment's for a week or twos time and it all just seems a farce, so – I think oh by then I'll be feeling better anyway. Attender [114]

...sometimes when you ring the doctor's, it's so far in advance. Or it was the last time I did that, erm, you just think 'Ooh, I'll not bother'. Non-attender [111]

...it just, it seems every time I've gone to the doctors they've always found something wrong with me so if I don't go they can't find nowt. I only have to go when I have to go... if you have to ring up to get an appointment it's full...I don't really need to go to the doctor's because I'm not really a poorly person so, but if you need an appointment you just can't get one anyway. Non-attender [146]

I think, gone are the days where professionals are given the same respect as they used to be. Like I say, that doctor I had, I wouldn't dared have question him squeezing my breasts every time I went. Perhaps it's a good thing people are more questioning now under those circumstances but there was a time in years gone by I think when the doctor said 'jump' you'd jump. Whereas these days, "Oh I'll do what I like, I don't have to listen to them". So I think perhaps some... in some circumstances, advice isn't really adhered to. Attender [138]

I don't want to be part of letting the system down by none, not attending an appointment...it's not about me not knowing about cervical smears and stuff. It's about me physically getting my arse into gear one more, and maybe ringing up and saying is there any spaces for a smear, can I come in now? Rather than making an appointment and then getting up and thinking I'm not right to, to go in for a smear today and then having to cancel and take up that... Because I'm, I'm, I, I don't like, erm, abuse of the system. Non-attender [136]

I just let one go and then I thought well, you know, so what don't need it anymore because there's such an argument about money and the funding of the NHS and got two grand... well one grandchild by then, and I thought I'd rather have the money be spent on them than me so I'll just back out of all these silly tests that, you know, keep, keep getting called for. Non-attender [108]

You're sort of referred for a test and then you've got to wait for the test date and then you go and have your test and then you've got to wait while the results come, and they're you know [laughs], and it seems we go all around the house, whereas they just get on and do it and it's done and dealt with, and you know straight away what the problem is and you know what can be done about it. Attender [114]

He [doctor] nags about it [making a cervical screening appointment], and I just put him off and say 'Yeah, when I'm ready'. And I know I'm not gonna do it so. Because he's such a nice man and I don't want to erm, you know... Non-attender [108]

A couple of times, I forgot to go. And was mortified, absolutely mortified that I'd done that. Just, just didn't, like today, just didn't see it in my diary. And, and was, yeah, must have been too busy. The first thing I did was rang and apologised. But I was mortified, yeah. Attender [135]

...it comes back to communication, if you're saying it in a way that's not, you know, you should be coming in, and. If you're just saying it as a, erm, as just simple terms and, and building that rapport then people are more likely to respond to you and at least be honest. You know, that's, that's better than saying 'Ooh yeah, I will book, I will book at some point'. And walking out and think well you won't. Practice Nurse [204]

'I don't discuss things like that': Who do women over fifty talk to about cervical screening?

Daughters... they have more information about that type of thing than when we had... I can ask them, you know...you can have a conversation about it but in depth.... When you're growing up in the seventies, you weren't taught anything like that. Attender [139]

My mum never talked about it with me and she never had a smear test... 'Oh, I don't do that, it's private'...I have a totally different relationship with my own daughter, completely the opposite...I felt quite ignorant about all sorts of female health complications. Attender [147]

Well my mother died when I was young, so I never, I have never had a mother to talk to about it. Non-attender [137]

We don't tend to talk about it...we don't often get a chance to just sit and talk...[my daughter's] got two extremely active young children and it's just kids, really!

Non-attender [143]

It's just something I've, we've never, I've never actually spoke about with friends. Like I say we talk about mammograms, but never, never smears. Non-attender [123]

A lot of ladies are quite happy with the, the breast issues. But not cytology. Maybe because it's hidden, they don't see it. It's not part of that bodily image is it? A woman's figure. Because at end of day they're sat there in front of you, you can't exactly miss them. Practice Nurse [205]

I don't know where women actually learn about cervical screening, thinking about it... Apart from their parents, from their mum, from their aunty. Practice Nurse [212]

More often than not...it's their daughters have pushed them into it...if they know their mum's out of date. Practice Nurse [219]

Her daughter had apparently turned around and said...'I'm not going for mine if you're not going for yours!' So that made her come. Practice Nurse [203]

What constitutes good practice?

'Ask the question': history-taking as the key to successful screening

Since I've changed doctors a few years ago, the nurses just sit with you and explain, you know, 'Any worries about it and we'll explain what happens', and just put me so much at ease, and I think that is a big thing. If you just went into a doctor's surgery knowing that you're going for a cervical smear, nobody talked to you what was gonna happen and, you know, then just did it. Attender [139]

No-one's ever asked me at the surgery at [town], where I was before, about why I didn't want to do anything...if you don't ask, you don't know where people come from, as in the background, and why they might be a bit hesitant. Non-attender [148]

I think nowadays they're kinder. Somehow it just seems to be more acceptable for them to have a – well it's not a bedside manner is it, but, you know what I mean by saying that? ... they're not as embarrassed about talking about certain things so they're able to put you put you at ease. Attender [105]

I purposely went to the, see this lady doctor at the time... she was understanding...I'd had a chat with her prior to that when I was there about something else and I said oh smear test's due, you know, and I told her about these problems I'd had in the past, so she just said well, you know, and she was real reassuring and understanding, it wasn't like a straightforward in there and out and that, and she explained things to me then and said well book a double appointment and we'll see if we can sort it ... she was really good, er, she, no, she was good, she, you know, did her best for me and then as I say she said well next time we could try this diazepam but, erm, no, it's the pain and then, and then once you've gone, once that's happened the next time you're expecting it aren't you I guess? ...Oh I know what it was also, she was understanding and that, and then when she started to perform the deed... I, I led, was led to believe it had all, like the walls had collapsed in or something [laughs] maybe. And, er, she could tell before we even started doing anything, she said oh yes, it is as if, as if yes, that is the reason why it's going to be a, or it has been a bit more difficult than it was when I was young. Non-attender [137]

...there's a lot in smear taking, a lot of psychological stuff. A lot of emotional stuff and it really... if you if you are sensitive to it, it allows women to come out with stuff that they've kept locked inside for years. And it can be... it can be quite emotional, but it can be very healing as well. And I know we're not there as psychologists [laughs], but we

can gate-keep. You know, we can we can signpost to somewhere else and and help. Really, you know, do the job that you're there for, not just for this task, which is like very task orientated in in general practice. I think that sort of space, it's a...it can be very an intense sort of space at times – not always, I mean, some women just wanna get it over with and that's fine and off you go you know and that's all they want. But for some women it's a really hard business to come and get it sorted out and get it done. Non-attender (ex-Practice Nurse) [102]

The difficulty is dis, is uncovering that hidden reason as to why they're not engaging with the process... there's something else going on in the background and it's whether that physician's, is really ready to tackle all of the other bits that a patient's not come in with. GP [209]

...postmenopausal ladies I always use a small a speculum as I can. Erm, and again it's, it's down to history taking, erm. And if we find that we can't use the speculum then I'd, we'd get some hormone cream, erm, they'd use that for six weeks or so, so they're much more comfortable and then wait another four to six weeks and then we would do the smear, so that would be a, you know, over a period of time. But again you've, you've built up a good rapport with that lady and she's got confidence with you. Practice Nurse [217]

'Learn the tricks': Practical solutions

I've ended up with a prolapse...it was either a ridge or a drop or something, so I have to like bring my hips up and it just aligns it and as I say, like when they're removing the contraption, obviously it's got a straighter run. Attender [140]

My hip locks...I can't expand my legs...they pulled me right down to the edge, had like one of the nurses there and I had to put my feet on her...it was painful but I needed to get it done. Attender (with hip replacement) [142]

[patient with arthritis and respiratory problems] I just think I don't want to go for that. Er, partly because I struggle to get in any position that would be, [laughs] erm, and I, I don't know, just don't fancy the idea anymore to be quite honest with you. Erm, both I would say, the, the physical problem of it and also I just. Crackers isn't it when you go for breast screening and do your bowel screening test? Non-attender [143]

You can maybe try taking a smear when they're on their, their left side...or maybe sitting more towards the end of the bed rather than, you know, having their legs up... Or if it was really difficult we could always refer them elsewhere to get the screening done. Practice Nurse [215]

The ones I suppose that are quite difficult are the ones that have got really atrophic changes. And they're really quite sore. So we can't put the lube on the end of the speculum, so we always do wet it and warm it and I tend to put it further up the shaft. I tend, I tend to use – I generally find out if they've had children, erm – if they've not had no children at all then I tend to use a small speculum. If they have had children then I tend to use the, it's a long thin one. Because it's, it tends to go higher but it's still on the thin side. It's all about making it as comfortable as possible. Practice Nurse [205]

I had a lady who'd had a stroke but she's only in her forties...she is crude, she's terrible. [laughs] I've done swabs and smears on her and she's just...she'll make anybody blush...she's kind of had to position herself, you know, because I couldn't visualise her cervix and she was just so matter of fact about it. She's got her legs in all kinds of positions and I had to giggle at her because she's saying "Could you imagine what people are thinking if they could hear us in this room?" [laughs] I said "Dread to think!". But she was very comfortable with everything. I'd be very different with somebody who'd had a stroke was much, you know, more embarrassed. Practice Nurse [207]

If I speak to women who have menopausal problems or pain with sex, which often you see people, erm, and anyone who's menopausal to be honest. I, if, if they're coming to talk to me about the menopause, I will raise that and say actually use the oestrogen cream and lots of moisturiser, that's what we should be telling everybody, and I, that's, that is following a recent meeting I went to, erm, can't remember when, when, when that was very much the message that we should be encouraging any women, over fifty to, to treat that as essential part of their healthy life. GP [214]

...she has MS and was in a wheelchair so one of went there and did it. But then you've got erm no torch [laughs] you know, lamps – speculums are easy, so we can take a speculum out and you can take the gear out but, you know, it was like “OK so I'm gonna need a torch, I'm gonna need somebody holding the torch”. [laughs] Yeah, but you know, what I didn't want her to do was... we did it because actually we said we don't want her to get the message that because she's got MS and in a nursing home that if she feels it's important that she shouldn't have it. And I think that's what you've got to be careful of giving the message that because you've got X thing than I'll, you know, we're not bothered about you having your your smear, 'cause you still need to be. GP [201]

