**Title: FG2\_15.07.2022**

**Interviewee/s: GPR 2, GPR 3, GPR 4, GPR 5, GPR 6**

##### Interview Date: 15.07.2022

**Interviewer: Main interviewer (Q), Co-facilitator (V)**

Q: Okay. To help the transcriber distinguish between the voices, please can you each introduce yourselves, and if you feel comfortable sharing what your current profession is, and I’ll just start with GPR5 ‘cos you’re at the top of my screen, if that’s okay.

GPR5: So, my name is GPR5 and I’m a GP trainee.

Q: Thanks GPR5. GPR 6?

GPR6: Hi, I’m GPR 6 and I’m also a GP trainee.

Q: Thanks. GPR2?

GPR2: Hi, I’m GPR2 and I’m also a GP trainee.

Q: GPR3?

GPR3: Hi, I’m GPR3, and no surprises what I do, I’m also a GP trainee [laughter].

Q: And finally GPR4?

GPR4: I’m so glad to not be diverting. My name’s GPR4 and I’m also a GP trainee [laughter].

Q: Thank you. You’re all in good company [laughter]. Okay, so I’m just going to read some text here and then ask you a couple of questions. So, breast cancer becomes more common in women in their thirties, and it’s the most common cause of death in women aged thirty-five to fifty. Before the age of fifty years, at least sixty-five percent of women who develop breast cancer do not have a family history and are not currently identified as being at increased risk. This means there’s currently no defined systematic mechanism to identify this group of women. The introduction of breast cancer risk assessment for women aged thirty to thirty-nine years would allow women to find out their risk of developing breast cancer in the future. Women identified as being at increased risk could then be offered earlier breast screening, as well as methods to reduce breast cancer risk. One potential approach is for breast cancer risk assessment and some aspects of risk management to be conducted in primary care. What are your immediate thoughts and reactions to offering women the opportunity to find out their breast cancer risk estimate from the age of thirty years?

GPR3: I think it’s only helpful if that changes their access to clinics. So, for example, at the moment, you know, a woman with a breast lump under thirty or thirty-five is deemed as lower risk for it to be a concerning lump when they present to the GP. So, if a person has a higher breast cancer risk score, it’s only useful if they can directly self-present to a breast clinic, as opposed to – otherwise there’s no benefit. Otherwise it’s just more anxiety for them, waiting for the GP appointment and subsequent referral onwards.

GPR4: I’m not sure. I think it would be a very good idea, ‘cos like the NICE guidelines, as you said, GPR3, they kind of categorise women as higher or lower risk, but that wouldn’t stop me from referring a less than thirty year old woman to the two week breast clinic. I actually did it the other day. She’d had several mammograms and several cysts, and each time the breast clinic were happy to receive her, even though she was really young and deemed low risk. Yeah, I agree, it could increase anxiety, but I think it would be a good extra thing to have when you’re assessing a particularly young girl, and then you can obviously discuss it with the patient and see what they want to do, if they want to sit and wait for a few more weeks to see if the lump changes with their menstrual cycle, or whether they would prefer a referral straight away.

GPR2: I think as well – you know, I kind of agree with GPR3’s point about, you know, the access to the breast clinic. At the end of the day, if you’re concerned about a lump, you would refer them. It’s quite commonplace. But I think also, from what I read on the, you know, sort of synopsis on it, it’s also about trying to reduce future risk rather than like detection of an early breast cancer. So, a clinic can obviously check you out and see whether there’s any concerning lump now, but this is also about saying that a woman may be at higher risk of developing a cancer in the next few years, and then in that case for me it’s important that you are able to do something about it. Because like GPR3 says, there’s no point increasing anxiety about the future unless you can actually do something to influence it. So, for me, that was the bigger point is that we know that there’s certain risk factors there. Everyone knows about the BRCA genes, but obviously there’s other things, which can be, you know, coined together from lifestyle, the genetic markers and the sort of pre-mammogram, to combine that together. But that – for me, you’d have to be able to influence that path in some way, otherwise it just becomes something else to worry about.

GPR5: I think that’s a good point, GPR2, the fact that, you know, it’s not a diagnostic test that’s being proposed. It is a screening tool for future risk. And I think, as you were alluding to, you know, as a screening test or a potential screening tool, it needs to meet the set criteria, that it is, you know, a good – or that it will be a valid screening test, and one of them is, isn’t it, that, you know, there needs to be a point where you can intervene. So, there isn’t much point in telling people that they’ve got a heightened risk of something unless you’re able to change that course, and unless the screening as well is acceptable and accessible to the people that it's designed for.

GPR6: Yeah, I mean, I agree with everything that everyone’s said. I mean, one of the things that I would be concerned about is – I think, you know, as a female and around that age, I would say, oh yeah, it sounds like a great idea, but I think sometimes you think, well, who would actually make use of that screening. So, in more of an affluent, sort of health conscious population, you might have women of that age coming forward and wanting to know their risk. And obviously, a lot of the risk factors that you’ve mentioned, which obviously are correct, actually contribute to a lot of other conditions as well. And we know that, in more deprived areas, those risk factors are likely to be higher, you know, obesity and various other lifestyle factors, and that’s often when we find the uptake being quite a lot lower of screening, of engagement with sort of lifestyle factors. So, I just wonder, one, what would be the response to it, and then, two, what the practicalities of it would be. So, obviously, everyone’s mentioned what would actually happen if you identify as someone who’s having a higher risk, like where would you go from there, but then also is that going to be a yearly screen, is that going to be like a six monthly, or like what happens when they reach forty, would you just stop doing that screen then. So, I think it’s just more how would you actually incorporate that into general practice, and then where would you direct the patient when you identify, “Yes, actually, you are higher risk.” So, what are we going to do about it, and when are we going to check that risk again, you know, if you do lose weight or if you do stop smoking? Where are we going to go from here?”

GPR2: I think also, in that same line of thinking, GPR 6, when you said about, you know, if we do tell a patient, “You’re in a high risk category,” we also need to think about, if we tell someone they’re in the low risk category, it’s making sure that we balance that against giving sort of false reassurance that might dissuade someone from coming and seeing us if they do notice something, ‘cos they think, “Oh actually I’m low risk.” Is that going to influence behaviour and actually getting checked out if they do notice a change?

GPR6: Yeah, definitely, yeah.

GPR3: I think as well, sort of in parallel to what GPR 6 said about sort of those from lower socioeconomic backgrounds having lower turn up rates to screening, potentially, I guess, if you had people from those backgrounds knowing that they had a slightly higher risk, potentially that would increase their attendance to screening, or become more vigilant of their own health, but that’s probably a double-edged sword as well, so it’s difficult really.

GPR5: I think there’s the issue as well of kind of the test being this kind of triple pronged screening tool. So, there’s the risk factors assessment, then there’s the ultrasound, isn’t there, and also the genetic tests, and I think there’s maybe some consideration that needs to be given to kind of, I suppose, things like ultrasound scan, that as a resource. You might need specialised sonographers as well. My understanding, from being in a breast team as a foundation doctor several years ago, is that ultrasound isn’t as good a tool, you know, as women age as well. It’s difficult – they’ve got denser breasts when they’re younger. But I don’t know, is there a – should some women be better placed having mammograms. And the other thing is the genetic component of it as well, how much does that cost. I don’t know how much it would cost to do all of those genetic assays on ladies. But I suppose, from a resource point of view, is it quite an expensive screening test in relation to other screening tests that are offered.

GPR2: I think the suggestion was for it to be a mammogram rather than an ultrasound. So, rather than actually looking for a lump at that time, to actually grade the density of the breast tissue, I think with the idea being – I might have got this the wrong way round, but the idea being that the denser the breast, the higher the risk of cancer in the future. I think that’s the right way round, is it [laughter].

[0:10:10]

Q: Yeah, yeah, so it is a mammogram, but yeah, you’re completely right, it’s not being used for a diagnostic capacity. It’s being used to assess breast density.

GPR2: But along that though, you know, when younger women in that age group that we’re talking about – if they have had a previous experience of being referred to the breast clinic, they’ve probably had an ultrasound, so it’s a different type of scan, not something they’ve experienced. Ultrasound scan, it’s not particularly uncomfortable, but a mammogram, from what I’ve heard, it’s pretty uncomfortable, so you’ve got that – you know, again, going back to what someone said earlier about the acceptability of it. You know, when you look at young people with trying to get their cervical screening, you know, what’s a smear versus having your boobs squeezed in a machine [laughter]. So, there’s that as well. It’s not something young people are used to having done.

GPR6: So, would it be that we do a risk assessment and then refer to a specialist clinic? Is that what the proposal would be, would be extra clinics for those people identified as high risk?

Q: Yeah, so we’ll come onto it when we talk about the process in more detail, but yeah, it’s to understand, when I ask the questions, what you might be happy being involved in. So, at present, this service doesn’t exist. But yeah, the idea being that if we could identify them at increased risk, they would be offered those management strategies, but it’s basically up for discussion as to who’s best placed to discuss those strategies with women.

GPR6: Yeah, I think because it’s just – obviously, everything we do do in healthcare has got the patient at the focus of it, but at the same time, obviously primary care’s run as a business and they have to make sure that they’re showing, you know, that they can continue as a business. So, at the moment, obviously, a lot of them are paid by QOFs and outcomes. There would need to be a specific outcome, I suppose, that you’re trying to meet, to make this sort of, you know, tangible to be able to continue. So like for example, if you’ve got the QRISK, which you mentioned as an example, if you can show that you’re reducing QRISK and you’re reducing cholesterol then you get paid for that and therefore that would incentivise you – you can pay someone to do those reviews and go round – but if you don’t have a specific target for these people then I think that would be one thing that primary care would find difficult, to justify the time of doing those estimates, even if it – you know, that’s just the way it is, unfortunately. But [inaudible 0:12:34] to the patient, you would still have to pay that member of staff to sit there and go through that with the patient, and do the risk assessment, and then it would be how do you show that that’s actually improving health outcomes.

GPR2: Yeah, I think there’s also – you know, there are some programmes that are run like via primary care but are paid for externally. Like the smear programme, they don’t have to necessarily prove the outcomes, but that’s obviously a screening programme. This isn’t technically a screening. It’s a risk stratifying programme. But yeah, you still need to – you know, if it’s going to be something like a QOF outcome, like you said, it has to be something which they can prove over time there’s been a change or an intervention, whereas it could be something that’s still delivered in primary care but it’s funded externally, because it might just be that it’s most appropriate to deliver it in primary care. That’s one of those things where, like you say, you have to work out who’s going to pay for it for there to be an incentive.

GPR4: I also have a question about how we would reach out and engage with these women. ‘Cos like everything, especially in primary care, we’re at risk of exacerbating health inequalities. And so, are we opportunistically discussing it with young women that call us up or book an appointment for something else, or would we send out a blanket letter? And I think – was it GPR2 mentioned about considering the cervical screening plan and the uptake with that. And I mean, I’m generalising, but I think it’s probably fair to say that there’s less uptake in more deprived and isolated communities, and I wonder if this would be at risk of the same thing, or are we actively targeting every young woman on our list.

Q: Yeah, no, that leads me onto my next question, which is about primary care potentially identifying and inviting the women. So, what are your thoughts on what would be the best way? Or if you think primary care shouldn’t be responsible for inviting women?

GPR3: I’ve got just a thought on that. I think my concern is, this is sort of a triple approach risk assessment. If the GP practice invites the patient, who is answering the questions about the actual risk assessment? Is it a central group like yourselves or whoever it is? Is it the GP? Because my other question would be, what if people are happy to have the sort of polygenic – the risk score and the ultrasound, but not have the genetics. There are people who don’t want to have their genes tested for multiple reasons. Are they allowed to take two of those three to get an attempt at a score? Are they just not allowed at all, you know?

Q: Yes, that would be an important consideration.

GPR2: I guess like, if it was something where it was already pre-programmed, like a QRISK calculator, then if you don’t have one piece of data to put in, maybe it’ll have a way of sort of disregarding that, but with the sort of disclaimer that it’s reducing the accuracy of the prediction. That might be one way. But you’re going to have to back that up with a lot of data to be able to come up with an outcome risk, whether it’s just high risk or low risk, or whether it’s an actual, you know, nominal value, like the QRISK score, where, you know, you can say, “If we had a hundred of you, it’ll be this number,” or whether it is just a high risk, low risk, or high risk, medium risk, low risk, you know. I think that – it depends on I guess the strength of the algorithm. I think if it was something like that, where it’s pre-programmed and you just put the answers in and then discuss it, like, you know, “This is the best available prediction score we have and this is what you can do about it,” that’s something that I would feel comfortable delivering. But going back to what I said at the start, there would have to be sort of enough in it that could be influenced, otherwise it’s a bit like I suppose delivering bad news. I don’t know whether you’ve got a question leading onto this, so tell me if you do and I’ll save it, but something that crossed my mind was – obviously, you’ve got the lifestyle stuff that you mentioned, you know, weight, smoking, alcohol, that sort of stuff, and, you know, contraceptive choices and things, which influence risk, but when it said about – did it mention – was it medication or something? You know, the medications in that sort of group, in that sort of class that do reduce breast cancer risk, you’re targeting women in a time in their lives when they probably are family planning and thinking about the impact of that. So, maybe we’ll get onto that in a bit.

Q: Yeah, yeah, we will [laughter], but no, thanks good to bring it up now.

GPR3: Can I ask as well, obviously, this is something that would be available to all women with an age range similar to cervical and breast screening, I presume.

Q: Yes, yeah.

GPR3: I suppose one difficulty is how do you include transgender female to males. It’s hard enough locally for GPs to find suitable arrangements where you have a new patient record, where someone is a male but still having them invited for cervical screening if they haven’t had any bottom surgery sorted. And I suppose it’s sort of similar here, how do you make sure there’s no indirect, you know, discrimination then.

GPR5: I think that’s like an NHS-wide problem, GPR3, because a lot of patients, when they change their gender on EMIS, they’re often asked if they want a whole new health record, that’s my understanding, and some people just will have a new record with kind of most of their previous medical information gone, including risk factors and things. And I think that’s a bit of a blip at the moment on the system. I think there is an option to merge the records, but people don’t have to consent to that. That’s my understanding. I think it’s one of the downfalls of kind of the computer system as it’s set up at the minute. The other thing I was going to mention as well that GPR2 had picked up on with regards to, you know, people opting in and out of different aspects of the screening, is the weighting of each of those kind of tasks, I suppose. Because if one is significantly, you know, contributing to a risk – for example, if it’s the genetic screening then I suppose it almost makes the rest of the test, you know, unreliable. Or as GPR2 said, you’d have to have a very big dataset, wouldn’t you, to try and justify, you know, what the other risks were. But I don’t know how the algorithm works and exactly how much is weighted to each of the aspects of the test. Because I suppose, you know, if a lot of it's based on the mammogram as well, as GPR2 was alluding to with regards to the acceptability of that, then, you know, if we’re giving people a risk and if they’re making changes based on it, including if, you know, for example, prescribing Tamoxifen, etc, then we need to give them as accurate a risk as we can do.

[0:20:37]

GPR6: I think it’d be quite difficult to – you know you said about trying to reach out to the women and invite them in? I do think that’s going to be quite a challenging thing. Because with screening, obviously, it’s a national screening programme, and we’re involved in that but we’re not actually involved in sending out the letters. And I think it just comes back again to that sort of business model, like taking a step back and saying, well, who would be responsible for identifying the patients, and then who would be responsible for either sending out like text messages or letters, and then, you know, how are they going to sort of book those into clinics and how are they going to run it. So, I think it’s just understanding how it’s going to be structured. Because if it’s just an opt-in, opt-out situation then is it just going to be a one off invite, or is it going to be like a yearly invite that they can take up, or is it just going to be, “Here’s the information, come forward if you want to.” Or is it going to be something like a QOF and saying, “Well actually, you need to have asked these women in this decade,” and therefore the business might be more likely to take that up and say, “Yes, we have asked them all.” So, I don’t really know – if it’s just going to be, say, a north-west thing then that’s going to be quite tricky, because every practice will probably approach it in a different way, unless you can say, “This is what you gain and this is hopefully what you’re going to improve, and then this is how we recommend you approach it.” But I’m not quite sure – I think that might just not be a very good answer, but I’m not sure sort of how you would go about it in a standardised way.

Q: Well, on the back of that then, in an ideal world, how do you think it should be structured in terms of – should it be similar to the breast screening programme, where you don’t actually send out the letters, or should it be like a separate, centrally organised service? I wondered what your thoughts were on that.

GPR2: My thought on that is really the only element of it that I suppose can’t be done from a – you can send off a saliva sample and you can do your lifestyle bits and bobs, but the only thing you can’t do from the GP practice is do the mammogram itself, unless that’s something that’s like a – you know, you get your appointment and then you come back with all of the answers, and then it’s a consultation where you actually discuss the outcome of the risk assessment so I think that could be done from primary care. But obviously the infrastructure to have the mammograms done in a timely manner and then link that up with a sort of review appointment where you actually get your answers, that would have to be quite – it’s quite a logistical challenge to get that in place. Whereas if it was something that was sort of centrally organised and it was sort of like fed back to the practice to be on file, but run almost like a screening programme, then we could have sort of a one-stop – well, maybe not a one-stop clinic, ‘cos obviously the saliva sample – I imagine it takes time to get that analysed. I don’t know whether it’s something that can be done quickly, probably not. So, again, whether you could have a clinic or, you know, outreach – not outreach, a satellite clinic service, where they organise those things, and it’s just sort of – then the outcome score is sent to the GP practice so that it stays on file, so that if those women subsequently come in for contraception advice or they come in with a lump or anything else, then you already know, “Oh right, okay, you’re in a high risk group, therefore I might manage you differently for these other reviews.” So, I think it could work either way, but I think it all comes down to who’s funding it.

Q: Okay, yeah, thank you.

GPR5: I mean, do these women need contact with primary care services in the first instance? Because, you know, if it’s just for a saliva sample, that could just be a self-swab that was sent out in the post and returned, couldn’t it? That’s my understanding of kind of the analysis. And the other thing is, if you’re doing just a lifestyle risk factors assessment, again that could just be an online questionnaire. The mammogram could be at a – you know, even in almost like a remote – you know, like a remote screening centre or whatever. You know, sometimes you’ve got services in carparks or whatever, don’t you, you know. It could be outsourced to a different company. It doesn’t even necessarily have to be NHS mammogram services, does it? But the result would then come back to the GP, and I suppose it’s what would the GP do with it. As GPR2 says, would it be that if someone’s risk was above a certain percent, it warranted a telephone consultation to talk about lifestyle factors? Would it be something that, if it was below a certain percent, it would just be kept on file? Or would all women need counselling if they’d taken part in the screening? Or, you know, is written kind of information, if they’re low risk, adequate enough, from a central service? ‘Cos I suppose it depends on how many women you’re screening and the level of counselling you need, and what pressure that puts on GPs as well to do that counselling, if that’s who would be given that responsibility.

GPR4: That builds upon – I had a fleeting thought, does it have to be a GP, or could it be any allied health professional within the practice that actually initially collects the data. So, that takes it one step further and devolves it even further, which might actually work a bit better. I also wonder, there probably is some data on mammogram interaction and uptake, and the type of women that are more likely to engage, and the type of women that are not. I wonder – I mean, I’m sure you guys have done loads of research, but have you looked at potentially mirroring bits and bobs from that, or is that something that we can look at to ensure that a lot of women don’t get lost to whatever invites we send out.

Q: I’d just like to pick up on the point that you said there, GPR4, about other allied health professionals within your practice. Would you be able to say a bit more about who you think could be involved?

GPR4: Well, as GPR5 said, the questionnaire could be self-fill in, or I was initially thinking the HCAs or the physician associates. I mean, even the receptionists, the data’s all there within the notes, like we’ll know if they’re on the oral contraceptive pill. The only thing is I guess how old is the data. Sometimes, when I’m doing QRISK, I look and they haven’t had their blood pressure done since 2017, so I then contact them to bring them in to update it. So, I think that might be the only pitfall of the situation is how relevant the data is. And then I think it was mentioned previously, how often do we need to keep updating it and plugging in new parameters.

GPR2: I mean, now that GPR5’s said it, I’m just thinking, I can easily imagine a situation where a pack comes through the letterbox, you know, almost like a covid test kit, you know, one of those little parcels, where you’ve got your swab sample, your explanatory letter and then a little online – you know, unique identifier, online link, where you fill in your health questionnaire, you do your self-swab for the saliva, and you’ve already done two things out of the three. And also on that website link, the opportunity to see what centres are nearby to book your mammogram. Then you’ve done all those things off your own back, but with the sort of invitation that you can do a pre-counselling discussion at your practice if you wish, or are you just satisfied with the explanation in the invite. And then subsequently, once all of that information’s collated and it’s ready to be shared with you, then have the option of it being then either a GP or allied health professional to actually have that consultation with you. I think one group that we didn’t mention was nurse practitioners in GP practices, who deliver – you know, they do asthma review clinics and metabolic review clinics and stuff like that, where, you know, they’ve got the clinical acumen to be able to – you know, the experience of having those types of consultations, talking about risk and modifying things, whilst also giving the patient an opportunity to talk through the results, rather than say just being sent a result. But, you know, cervical screening manages on just having letters, and your only interaction is with the nurse when the sample’s being taken. But they manage to, you know, survive through letters of, “Oh, you’re low risk,” or, “Oh, you’ve got this, you’ll have recall in a year.” And I guess you only have that further interaction with a clinician if there’s a high risk and you’re being invited in.

[0:30:01]

GPR3: I wanted to ask as well, the only – I suppose there’s a lot of conversation around here as to whether the GP needs to get involved at all. There’s only one real true benefit I can see with getting the GP involved, which would be if there was a calculator that the GP could then amend with future relevant information. So, for example, with QCancer, where you can estimate the person’s cancer risk, you can use that to show a person, “Okay, if you lose three stone in weight and you stop smoking, this is how much your reduction to cancer goes by.” And the only benefit or a benefit I could see in general practice would be able to have that with this sort of triple risk assessment, to say, “You can’t modify your genes. You can’t really modify your breast density. What can you modify to reduce your breast cancer risk?” And then that will also be a positive financial incentive for GPs as well, because the healthier your patient population is, the more you get them off blood pressure medications, the more QOF points you get, etc.

GPR4: I wonder if we’re at risk of contraceptive shaming women though. I feel like it’s so difficult to empower young girls and women to make contraceptive choices that are actually right for them and their lifestyles and their bodies, and what they want from it. And I guess we’re potentially at risk of kind of shutting off a whole avenue of combined pills or – yeah, I think that’s right. My brain is dead, sorry. Yeah, no, that’s basically all I needed to say [laughter].

GPR2: I kind of agree with you, GPR4, that it can already be a minefield as it is, trying to find – you know, when you’ve had issues with different types, or problems with like the acceptability of different types. Once someone’s happy with something, it can feel really difficult trying to say, “Actually, I don’t think that’s suitable for you anymore.” But by the same token, you know, when I was told to stop the combined pill when I developed migraines with auras, you know, I was grateful for that advice when I realised the health risks. And so, you know, I guess if you’re in the high risk category then is it better to know?

GPR5: I think as well, depending on how this was set up – let’s say for example – I really like the idea you said, GPR2, about, you know, it coming in a pack. You could even have an app to complete your lifestyle questionnaire on potentially. And, you know, where it tells you about your nearest mammogram centre. I wonder if there’s then the possibility that that could be utilised for education, and even possibly counselling for lower risk, you know, following the results as well. So, maybe some educational videos for women about their risk factors and kind of how they can reduce certain risk factors. Obviously, if someone’s high risk – and I know obviously there was, in the briefing, discussion about potentially Tamoxifen. That isn’t something that you could manage on an app. But I think, you know, as an intervention that would not take up, I suppose, you know, manpower, that is a possibility for low risk women. Because as you say, you know – for example, if someone’s had a cervical smear and they’re HPV positive, you know, you’re not going to see in person every lady that has got HPV on their smear. They’re going to go back into the system, but with an awareness that they need to be screened sooner than, you know, they would be routinely. And I suppose, you know, we’ve not come onto it yet, but how often would these screens be done? Because that would or could increase the demand on not just GPs but the other allied healthcare professionals, who, out of the pandemic, seem to be having increasing roles in catching up with or in, you know, enhancing services. So, it’s not just GPs that are under pressure, but allied health professionals too. So, I suppose we need to – if something was developed, it needs to be as streamlined as possible to ensure that, you know, we’re utilising all the technology that we’ve got, to make sure that we’re only really seeing the people that need to be seen.

GPR3: I think you made a very interesting point, GPR5, about an app. And I guess for myself, it raised a question. If this is an NHS based initiative and you’re collecting lifestyle data, and a person admits that they smoke, you sort of have an ethical duty to give them information to say, you know, “You probably should stop smoking,” or that sort of stuff. But that then puts people off, because people talk, and women of similar ages have friends of similar ages. I suppose if the GP is the one to collect the data, or people submit it straight to the GP record, it's totally appropriate for the GP to be saying, “You need to stop smoking,” and actually then the GP’s smoking data is up to date and, you know, the QOF points for referring to – you know, suggesting a cessation programme – I guess it’s just the ethical duties of responding to that lifestyle advice. Or, you know, if someone’s overweight, if someone’s got a BMI of fifty, you know, can you as an NHS service just sit by and say, “Yeah, okay, your BMI’s fifty, your breast cancer risk is x.” You probably do have to sort of attempt some form of signposting or something.

GPR4: This might be a very silly question, and I think it might be to do with radiation, but why couldn’t one of the outputs or recommendations be for high risk women, like the cervical screening, that they just have increased frequency of monitoring? Why would that not be acceptable, rather than starting someone on Tamoxifen or, you know, telling someone to stop smoking and it’s landing on deaf ears?

Q: Yeah, yeah, so no, that would be an option, to start monitoring earlier, to undergo breast screening earlier, but it’s just more like – obviously, that would only detect if – that would help with the early detection of breast cancer, whereas medication would help to reduce their risk overall.

GPR4: Oh okay, okay.

Q: Yeah, so the idea is that like moderate and high risk women would be offered like the opportunity to do both of those, but for moderate it might be more like it’s offered, whereas for high it would be like suggested that you have it. It’s a bit more strong if it’s high risk.

GPR4: Okay, cool.

Q: But yeah, that’s the kind of options. So yeah, it isn’t that everybody has to take the medication. It’s up to the women, ‘cos there will also be the monitoring.

GPR5: One of the other things I was just thinking of as well is, you know, if we are saying that these women are high risk, or there’s an increased risk, or assessing risk in general, I think there should be an element of education, which I know I’m banging back to. But even, you know, encouraging breast self-examination. And I sound like I’m really pushing for someone to develop this app [laughter], but certainly that is something that could be factored in as well, you know, those kind of – you know, education, where you can just have a video or someone explaining about things like that. So, there’s other smaller interventions, which might support the main aim, I think, that you can think about adding in.

Q: Okay. So, you’ve already mentioned like loads already, but I’m just going to drill down a bit into the different – you’ve already mentioned like the different measures that would be completed for the risk assessment. So, the risk of developing breast cancer is best calculated with a combination of three measures, and I think [name of co-facilitator]’s just going to share the diagram that was in the material, so that you can see it whilst I go through it.

[Sharing screen]

Q: Okay, so as we’ve discussed, first would be like a self-reported questionnaire, which would assess the information listed here, so height and weight, family history of breast and ovarian cancer, age at first period, age of first pregnancy, oral contraceptive history and alcohol consumption. And then secondly, the women would undergo a mammogram in order to assess breast density, which is a measure of the amount of non-fatty tissue compared to fatty tissue in the breast, with women with a higher proportion of non-fatty tissue being at increased risk of developing breast cancer. And then finally it would be a saliva sample to look at polygenic risk scores, which is a combination of multiple common genetic changes into a single score, whilst also looking for more of the mutations in the high risk genes that you’ve mentioned, like BRCA1 and BRCA2. So, I’m just wondering, what do you think about primary care collecting information from women about the list of breast cancer risk factors, so, underneath the first pillar there?

GPR4: It is actually so depressing, isn’t it? The only thing that we can alter are our oral contraceptives and our alcohol consumption – well, and our weight [laughter], but yeah.

GPR2: Yeah. I guess, going on from what GPR3 was saying earlier, you know, when I said about it being like an online link questionnaire, you know, from what I think GPR 6 said as well, I guess that misses out on the option of it being captured under the GP QOF system, unless those were linked up, which - judging by the state of how EMIS captures information at the moment, I can’t see that working very easily, unless the information was taken via the practice directly. So, I think it would be relatively easy to make a – what’s the word – a template in EMIS to capture all that information. That would be quite easy. But then, you know, going on from the last comment, you’ve really got to be able to actually change something for it to be helpful. Even with women who, you know, have that strong sort of BRCA history, it looks bleak, but then a lot of people choose to do it just so they can have that earlier screening or interventions, even though it might seem like there’s not too much they can do about it.

[0:41:00]

GPR5: I was just wondering, are you collecting any data on anything like breastfeeding or any other factors such as that? Does that factor into the risk assessment?

Q: Yeah, it’s not currently in the algorithm, no, but obviously that is protective –

GPR5: I was just wondering if there was any protective factors that you were going to be collecting data on as well.

Q: Do you think that would be useful? Obviously, this doesn’t exist, so yeah, we’re just wanting your thoughts on what data would be useful.

GPR6: I think it would be really easy to get the data. I don’t really think that would be as much of an issue. I think it’s just how you would do it. Because I mean, obviously, for example, we’re thinking, well, we want it around the same time, don’t we, because we don’t want them having the mammogram in like December and then only getting the data in March, and then only having – you know, it all needs to be sort of timed at the right time, so that if you do have a high risk then someone can sit down with you and go through that risk. I mean, I don’t know what different practices are like, but the practice that I’m at at the moment have health improvement practitioners. So, if you’re identified as being high risk of cardiovascular disease or like, you know, various other things, then they actually send them a text. So, say the diabetes test was raised, they’ll send them a text saying, “You’re at risk of diabetes. If you want to book in with our health practitioner then please feel free to make an appointment.” But they do put the onus on the patient, and they sort of meet the QOF by saying, “Right, we’ve identified that you’re at risk. We’ve sent a text. Now it’s up to you,” sort of thing. So, I don’t know – you know, that’s sort of a separate issue, but it’s just trying to coordinate it, isn’t it? You can get that information quite easily from the patient, but it’s just when do we know – how do we know which patients are eligible at what time in the year, and when they’re going to have the mammogram. That’s the bit that’s more difficult, I think.

GPR3: I do want to ask as well – I know I touched upon it briefly before in terms of people not wanting, for example, to have their DNA tested, whether you can use it – but again, I think, you know, as we mentioned, these are three separate interventions that require three separate dates. People are bad enough – you know, if you look at say the uptake on say the faecal occult blood test that’s posted out to men over a certain age, whatever, the uptake on that’s really poor. So, how are you as a sort of system or whatever – how are you going to manage people who only do two out of the three or one out of the three? Because, you know, you’ll have a duty to tell them what their polygenic risk score is, even if you’ve got no idea about their lifestyle, because they leave it on the kitchen counter for three weeks or whatever. I just wondered what that was going to be like.

Q: Yeah, yeah, so I obviously don’t have the answers to your questions, ‘cos it’s not something that’s actually in place, but it’s really useful for us to understand what your considerations would be, so that’s definitely something that we’d need to bear in mind about, if they only answer one or two, what’s going to happen then. Do you think – ‘cos you’ve mentioned there about potentially it being like an online questionnaire or maybe sent over text. Do you think it’s appropriate to ask women to like enter their own data for the self-reported questionnaire?

GPR2: I think that’s fair enough.

GPR5: I would 100 percent think that’s absolutely fine. In primary care, I’m sure everyone would agree, at the moment like we use Accurx loads to communicate with our patients. We send them Floreys, so like asking them to complete, you know, home blood pressure monitoring, and return it on surveys. We send PDFs out to phones. You can send sicknotes as PDFs. So, I don’t know why you would use resources and clinic time to get someone to sit down and ask those – how many questions are the risk factors, [counting] – you’re going to use a ten minute appointment potentially, even if it’s not with a doctor and it’s with a healthcare assistant, to ask those questions. And I would just make it as easy and – you know, just something that they can just tap in on their phone, or even respond to, you know, via a text message on an online form. I think that would be a better use of resources for sure, in my opinion.

GPR2: I agree with you, GPR5, that with that demographic, you can probably capture most people in that way, ‘cos, you know, that’s the sort of demographic who will have a smart phone or be quite responsive to that, and it’d be quite easy and definitely the most straightforward way of getting that data. A consideration I just had when you said that was, you know, I recently did like a blood pressure, I suppose, screening thing at my practice, where I tried to capture the majority of the target through Accurx responses, but then for the ones who didn’t respond to the invite, didn’t really get around to the point of, well, what do you do with those people, what’s going to be the second line. Do you just assume that they’re not going to respond and that they’re excluded, or is there going to be an alternative method for the ones who don’t respond to that.

GPR4: Before starting this rotation, I would have completely agreed and said that thirty to thirty-nine all have smart phones, blah, blah, blah. But having done this GP rotation, I’ve spoken to a really surprising number of young women that don’t speak English strongly at all, or don’t have a mobile phone. And it’s still something that I reflect on a lot, and obviously it exacerbates, as I mentioned before, the health inequalities, and we’re just losing a whole demographic of women, potentially the ones that are at high risk, that don’t have healthy lifestyle choices anyway, maybe due to a combination of language and just not having much health awareness or education. So, I think if it’s completely online, we just cut out that massive subset of women. Obviously, [place] is very diverse and there are pockets of communities, and there are pockets of deprivation. So, I think that’s something that potentially we need to bear in mind if we’re completely going technological with it all.

GPR2: Yeah, I completely agree. There’s definitely going to be, you know, a percentage that either won’t be able to or just won’t respond to that, and they have to be captured, ‘cos like you say, it’s very, very closely related to, you know, I suppose, health economics and different socioeconomic groups, and also things like language barriers and things. It’s so closely linked to that that you can’t just assume it’s people not consenting to take part. Maybe they’ve just not had the opportunity to take part.

GPR3: I think on top of that as well, even just cost of equipment or travel can be a barrier to people. So, I work in a fairly impoverished area, and we find that – in my experience, probably about twenty percent of people I ask to do blood pressures at home say they can’t afford a blood pressure machine, and they end up walking to the practice ‘cos of their financial situation. So, you know, do people even have scales at home to be able to do their weight, or would that be at the practice, and how would they travel to the mammogram? Would it be, you know, a portable unit somewhere nearby? Would it be at the hospital? And these are all other considerations, I guess.

GPR5: I think, adding onto that, GPR3, probably kind of on the opposite side of things, you know, these are women aged in their thirties. A lot of these women are likely to be at work, you know. They probably struggle to sometimes justify going to the doctor for health complaints. They might sit on things that they probably think they should speak to the doctor about. If this is something that they have to physically book an appointment for, that might be to them, you know, overcomplicating it, having to try and, you know, move things at work or take time off or leave early. You know, they’ve already got to attend smear tests or whatever else or, you know, other commitments, so I think that could mean that this could possibly come down the pecking order for working women. And one of the things that GPR4 was saying obviously about women from, you know, diverse kind of ethnic backgrounds, I think if this was rolled out as a screening programme, you would definitely have to have champions in those areas. We know that women from BAME backgrounds are less likely to uptake screening. I think it’s something you’d have to have people that were – you know, people like local religious leaders encouraging women to come and engage. The other thing is the cultural acceptability of some of these tests. So, for example, mammograms, you know, that for some cultures is seen as quite an invasive and quite shameful thing to take part in. So, I think, you know, exploring the cultural barriers, as GPR4 was saying, is definitely something that, if this was a national screening tool, would need to be explored, and there’d definitely have to be champions or people that were able to really push and kind of emphasise the importance of this within those communities.

Q: Okay. I’m just going to stop the recording there.

[End of FG2\_15.07.2022\_part 1]

[Start of FG2\_15.07.2022\_part 2]

Q: So, that’s recording. So, you can stop sharing the screen now, [name of co-facilitator], thank you. So, building on what you’ve already previously said then, if we were thinking about this as like a complete model, so the three different components. So, one model of how breast cancer assessment could work in primary care is the development of a risk assessment tool, similar to QRISK. For example, scores for mammographic density and genetic risk could be fed into the tool, and a risk score generated once someone in primary care has entered family history, hormone and lifestyle factors. Primary care could then be responsible for communicating the risk score and making a management plan. What do you think about primary care coordinating the process of breast cancer risk assessment in this way?

GPR3: Why can’t the management plan be devised as a result of this risk score in the first place?

Q: Yeah, so is that something you’d want in the tool? Sorry, I’m just trying to put it back on you, ‘cos like I say, it’s not actually a real thing. So, if it’s an important consideration for you to have, is that what –

GPR3: Sorry, yeah, yeah. I mean, so it’s like the smear test. So, for example, you know, if HPV is detected, the GP does a smear test, they get paid for it and that’s it, whereas if this is an external thing, I don’t think the GP will get any financial incentive as a business to do this unless they’re paid per individual that they counsel. But even then, if you consider the current climate, when you have people with suspected cancer, you know, who are struggling to get appointments in some systems, how does one prioritise someone who’s basically just found out they’ve got an increased risk of cancer but asymptomatically. And again, I think you would, in an ideal model, link to – I think the first thing is, you know, what training are you going to have to give primary care practitioners? Are they going to want training? Is there even time – have they got the headspace for this training? It’s yet another thing that, if it’s done badly, people can bash GPs over, and I’m just a bit cautious about that.

Q: Yeah, yeah, of course, thank you.

GPR6: I think the lifestyle side of things – I mean, we obviously already do that, don’t we, as part of our day job, but again it’s just trying to find the practicality of actually bringing someone in, or sharing that information and knowing that we’ve done that, and how we actually track that. But I think the suggestion that we sort of risk assess them and we stratify them, and then we decide whether maybe they might be suitable for something like Tamoxifen, seems like too much really. I think that’s beyond like the competency of primary care, if I’m honest. I think obviously, in [place], obviously the [name of Medicines Management Group], the guidelines for our prescribing, they always say that Tamoxifen would be started under specialist initiation, never in primary care. I don’t know if that’s something that they would review and deem a possibility, but at the moment it’s definitely not a thing that GPs would get involved in prescribing. And I’m not sure who mentioned it before, but someone mentioned obviously, at this stage, you know, between the ages of thirty and thirty-nine, a lot of women will be thinking about starting a family, and I think a lot of GPs would feel quite nervous about monitoring Tamoxifen and deciding whether or not someone should come off and on, you know, deciding on the risk. So, it’s that side of things that I think would be a struggle in primary care. I think it’s one thing to ask them to engage with the lifestyle data and recommend people go for scans, but it’s another thing I think to start doing the prescribing of specialist medications as well.

GPR4: Also, sorry, I’m a bit naïve to it, do we, as GP practices, get penalised for the amount of prescriptions that we do, or is that something that I dreamt up? Or is that just for antibiotics?

GPR3: It’s not the amount of prescriptions, but it’s the CCG or whatever it is, or [name of Medicines Management Group], tell us what we should and shouldn’t prescribe. But I would absolutely agree – I mean, my personal view is that if someone is deemed high risk, you know, if they’re that high risk – same with like – you know, you’ve got the polygenic risk score, taking into account BRCA. If someone has BRCA and has a high risk, they’re offered, for example, a mastectomy sometimes because of the high risk. So, why can’t those who are deemed high risk go straight to a breast clinic for discussion if required, for potential consideration Tamoxifen. It needs a breast surgeon or an oncologist really to make these decisions.

GPR2: I agree with you, GPR3, and my thought on that – and this might be a naïve view, because I’ve never worked in the breast department. I think someone said that they did, so maybe you could shed some light. But I’m aware that there’s like, you know, family history breast clinics for the ones where, you know, people are known to have so many relatives, and then they go to this clinic. As to what happens at that clinic, I don’t know the full extent of it, but maybe that’s an in for this, you know, that essentially that’s a risk stratification clinic, and maybe this could be another way into that sort of system, with that breast specialist supervision, but maybe being run by the breast specialist nurses. But I don’t know whether that’s something that’s feasible or practical.

GPR5: I think that’s a good point, GPR2. I was thinking, you know, the breast specialist nurses would probably be quite – you know, probably a good resource actually for the high risk women. And I don’t think it necessarily needs to be the breast surgeons that see these women themselves. I think, you know, if they were deemed high risk, I think that the breast service themselves could possibly just have a nurse run clinic. The only way that I would feel comfortable as a general practitioner really managing high risk women would be as a GPwSI in a breast clinic, or someone that was supported by the breast team. I also think that, if there was the hope to roll this out to general practice with GPs managing high risk women, as – I think it might have been GPR3 that maybe said about the amount of education that would be needed, or the teaching around this. I think it would have to be a huge teaching package. And I think that women are likely to have a lot of questions. I think this is the age where, you know, as we’ve said, women are sometimes thinking about extending their family and, you know, I can just think of the spectrum of questions that women are going to be asking about their risk, about different contraceptive choices, IVF, you know. They’re thinking about taking – you know, certain diets that they’re following. I can just imagine, a lot of the questions, we just might not have the answers to. And I think, when this was first rolled out, it would probably be – there’d be probably some quite tricky conversations to navigate until kind of the resources developed to try and catch up with the questions of the women that we were managing. But I think the breast specialist nurses are obviously fantastic at what they do, and I think they would be a really valuable resource in having maybe, you know, a high risk screening clinic, almost like a nurse colposcopist in the gynae department.

GPR2: Just to go back quickly to the thing about the Tamoxifen as well, I don’t know whether that is something that’s being like seriously considered or whether it was just sort of thrown in there as a possibility, or whether there was any other medications that were – I can’t think of one, but whether there’d be any other medications that were kind of – you know, that this was being sort of thought about. But, you know, in that age group where you’re at least – even if you’re not family planning, it’s being of child bearing potential and, just like with certain anti-epileptic drugs, you have to obviously be really careful, because it is a teratogenic medication. And so, you know, even to be able to safely prescribe that – I think if it’s going to be one of the core options and one of the core ways to modify your risk then - you know, it’s already difficult trying to get shared care protocols for prescribing and for having – you know, making sure you’re regularly reviewing someone being on highly effective contraception. So, that’s got to be a major consideration as well.

GPR3: I think that’s a really, really good point. One of the difficulties as a GP, when you’re relying on specialist advice, is you have no idea as to the appropriateness of the counselling, because ultimately, when you’re prescribing on specialist advice, it still comes down to you, especially if the person giving the advice isn’t a prescriber. And that would be my only concern about having a specialist nurse clinic. They might be fantastic, but you can’t guarantee the quality of the counselling given to that woman on Tamoxifen before you prescribe as a GP.

GPR5: I’m just wondering, are we also going to counsel them about the endometrial cancer risk with Tamoxifen, and how long are we thinking of putting them on it for. Because some of the risk factors for breast cancer are also risk factors for endometrial cancer. So, certainly elevated BMI is a big one. Obviously, women that have got high BMI, high risk of breast cancer, in combination with Tamoxifen and a high BMI, that would increase their endometrial cancer risk. And obviously – you know, I’m not saying they would be super high risk, but I think it’s a discussion that you would have to have with that woman. So then I suppose you’re saying, “You’ve got a risk of breast cancer that’s high. By taking this medication for x amount of years, it does slightly increase your risk of another cancer.” So, I think that’s the other thing. And they’re the conversations where, if you don’t feel confident and you’re not au fait with the literature or the research, they’re the times where I feel like, you know, in general practice, you’re likely to trip over yourself and maybe not communicate, you know, to your best ability what the knowledge is and what the evidence is around something. And then that’s when people are likely to disengage.

[0:11:13]

GPR4: Also, it’s so intense, isn’t it? Like the thought of – if I had to go on Tamoxifen now, like everything that you guys have been saying about fertility and lifelong risks, and the side effects as well – I’m basically going to become menopausal at like thirty-five. It’s just not something that I would ever have thought was a possibility. And obviously, I’m a doctor and I know about cancer risk and prevention, etc, and even I find it difficult to think of as a legitimate possibility. So, I think Tamoxifen’s probably quite well known as a breast cancer drug and for older women, so I think we’d be like fighting perception and the media and stuff as well to have – someone mentioned the Wilson and Junger criteria right at the beginning, and like an acceptable alternative. It’s all well and good if we can do all this stuff and identify the risk, but are women actually going to – are they going to engage with what we can offer them as risk reduction.

GPR2: Yeah, and I think with that – you know, I think it said in the prereading, was it something like, you know, it could reduce the risk by fifty percent or something like that, but, you know, it’s thinking about – you’ve really got to set out what the relative risks are when you’re talking about, “Well, if you do take this, it could actually lead to this.” Those relative risks are so important, aren’t they, in deciding whether it outweighs any future risk or risk now, and, you know, that reducing the risk of cancer by fifty percent sounds fantastic, but is it that, you know, your risk goes from one in a thousand to one in two thousand. That’s still, you know, a fifty percent risk reduction, but is it worth all of the downsides. And I don’t know what the data and the facts are on that, but that would be – if someone was counselling me about it, that’s what - I would have to understand the relative risks and have a good like basic grasp on it.

GPR3: I think it was a really excellent point about the risks of Tamoxifen as well like the endometrial cancer. You know, being a man, obviously, I’m clueless in certain regards, but, you know, at least with the risk of breast cancer, you can have the mammograms, you can self-examine, whereas endometrial cancer, you really can’t do anything to check things out, reduce that risk, apart from start smoking, which obviously is not a good idea and not a good suggestion to give people to try and counteract the balance. It’s very difficult. You are giving a drug to reduce the risk of something, and how do you know – you know, like it was mentioned, a fifty percent reduction, but what is the actual absolute risk of increasing the endometrial cancer? Is it just a pointless exercise in some regards?

Q: Okay, so if we go back to the idea of it being like a risk assessment tool similar to QRISK, how do people feel about that, that it might be similar to that in terms of – that you plug in numbers and you from that get like an output of the tool that would include recommendations for management of increased risk?

GPR2: I mean, the nice thing about QRISK is that, aside from it being quite a visual tool, there’s plenty of modifiable risk factors, and you can modify them and sort of see what the outcome may be. So, you can almost like predict the effect of your intervention. And there are quite a few things that you can influence, and they can pretty much all be done from primary care. So, I would say for me, I think they’re the main positives of a QRISK type tool.

GPR5: With the QRISK calculator as well, I actually include it in the consultation. So, I will say – you know, for example, if someone’s got a high QRISK, they’ve got an elevated cholesterol, BP’s up, they’re a smoker, I will do it with the patient and go, “Right, this is your current risk. Let’s have a look at what your risk will be if you were to stop smoking. So, let’s look at an ex-smoker.” And the patient can then see themselves the impact of that intervention. So, I feel like it’s a really useful consultation tool as well.

GPR3: And adding to that, I think, as GPR5 said, in terms of relaying the information to the patient, it’s very easy to translate QRISK into case plots and use that visual, you know, representation of risk reduction, for maybe people who struggle with numbers. That might be the average person as well.

GPR2: I think also you might get some easier wins as well with that. Because, you know, everyone knows that being overweight increases your risk for a hundred different things, but I think, if someone’s told, “Actually, you’re at pretty high risk, but if your BMI was this instead of this then look at what that does to your risk,” people might be pleasantly surprised by that, and it gives them a bit of ownership, you know, to motivate themselves. So, I think a lot of women would be surprised to learn the link between BMI and breast cancer. I don’t think it’s very well known about.

GPR5: The alcohol risk is huge as well, and that’s something that most women have no idea about.

GPR2: And that too, which is one of those things, isn’t it, where – yeah, for some people, it’s really, really tough, but that could be a great motivator in a QRISK tool type way.

GPR6: I think QRISK – like the template style is a good idea, because it is easy to input. And then also on EMIS, you do tend to get alerts when the QRISK is high or, you know, if they’ve not had a QRISK, and that could be something that is easily put into the system. You know, if someone’s due to have their breast cancer risk score calculated then you could actually incorporate that into the system. I suppose I’m just not quite sure how it would fit in with the other factors of the risk. But from the lifestyle data collection point of view, it is an easy tool to have.

GPR2: I mean, with the mammogram, it’s the idea being that, because it’s just to identify, are you a woman who has pretty dense breast tissue or are you a woman who has pretty fatty breast tissue – and that’s something I already talk about in my consultations with women who come in with, you know, breast lumps. And if it’s just that then really that’s sort of a one-off scan, isn’t it? It’s not like a screening test where you’re having to repeatedly – you’re not looking for a lump. You’re actually just saying, “Do you have fatty breasts or do you have dense breasts?” And so if that’s sort of a one off then you can keep updating the QRISK thing over time, as long as they’ve had that initial mammogram to say how dense their breasts are, because it’s not something that’s going to change very much in that time period, I presume.

GPR3: I think what’s helpful as well is that, if you just get a low risk or high risk, that might go to the GP in a simple letter that is then coded, but as the patient moves between GP surgeries or areas of the country, that can get lost quite easily. Whereas if you have an inbuilt scoring system like QRISK that is inbuilt into EMIS, SystmOne, Vision, whatever, every GP surgery – if a patient moves over and they know they’ve had it done before but they can’t remember what their risk was, it’s very easy to grab that information from the records, you know, so you get sort of the continuity that follows the patient round easier in that way.

Q: So, if we were to create a risk assessment tool similar to that, who would you envisage taking on that role at your practice to fill it in? Would it need to be a GP or is there scope for any allied health professional involvement in that?

GPR3: You could have it as an HCA appointment, to be honest, especially the information. And then if the person has an increased risk then, you know, they can go beyond. But I mean, HCAs do all the smoking stuff, all the alcohol stuff. They do all the healthy lifestyle stuff, and this is basically – it’s a form filling exercise, isn’t it, really.

GPR6: Yeah, I think general practice has changed quite a bit really in terms of like how they structure their appointments. So, I think realistically that that data and assessment would come from either – like maybe a HCA or – like I said, in our practice, there’s health improvement practitioners. Sometimes the pharmacies have clinics and they do risk assessments as well. So, it just depends on how your practice is run. But I think, if it was just a data collection exercise in that sense, and it wasn’t more about advice, then it probably wouldn’t be – you wouldn’t require a GP appointment for that necessarily.

[0:20:13]

GPR4: I guess potentially that we do need to have some criteria though, ‘cos then these practices that aren’t as well equipped as yours or – at mine, we have social prescribers – then it might fall to the HCAs, who are also doing the bloods. It might fall to the GPs, who are super pressed for time. So, whilst it is very good to have this flexibility and we can devolve it to a lot of people working in the practice, for those small practices that don’t have that luxury, I think – I mean, potentially, are they going to be in the more deprived areas anyway with less resources, and then there’s isolated women in an isolated practice. So, is it the Swiss cheese model of rubbishness.

GPR5: One suggestion I’ve got, but I don’t think it’s a particularly good suggestion [laughter], is, you know, using – when a woman comes for a cervical smear in her thirties, using that as an opportunity, you know, to gather that data, and approach it as almost like a well woman or well women kind of screening session. The downside to that is that I suppose you’re piggybacking onto the back of an existing screening programme that’s not directly linked to this. And the other thing is that some women might feel overwhelmed if they’re already anxious about coming to a screening appointment for cervical cancer, that they’re then having a chat about breast cancer. I think for us as clinicians, we’re quite used to kind of forgetting that people can be a little bit anxious, a little bit scared. And the other thing is, for a lot of women, you know, having a cervical smear isn’t the most pleasant experience, or it’s certainly something that can sometimes build up a lot of anxiety and kind of fear around. So, I think it might not be the best place to do that. But I think from a timing point of view and an opportunistic point of view, I think there are some strengths in that argument, but my only fear is that I suppose if it wasn’t kind of set up as almost like a joint kind of screening appointment, that it could maybe for some people feel a bit overwhelming.

GPR2: Also a potential barrier with that is – I don’t know what the funding structure is like, but if those appointments for the smears are being funded by the National Screening Programme then there could be a conflict there in – you know, if the appointment time needs to be extended by five minutes to do that questionnaire then is there going to be a logistical issue with funding that if it’s being funded externally.

Q: Okay. I’m just conscious of time, so I’ll just move on a little bit. So, in terms of – you’ve already discussed like the two strategies that have proven benefit in reducing breast cancer risk are maintaining a healthy weight through diet and exercise, and limiting alcohol intake. And you’ve already had quite a lengthy discussion about Tamoxifen, so I probably won’t speak about that again. But it’s just to ask, what do you think about primary care providing lifestyle advice about reducing breast cancer risk?

GPR3: It’s the thing we’re best at, probably.

GPR2: Yeah, it’s the bread and butter, and it can be provided by all sorts of allied health professionals.

Q: Okay, that’s pretty straightforward then [laughter], if no one’s got anything else to say. Did anyone want to add anything about what you think about primary care discussing and prescribing risk reducing medication, such as Tamoxifen, other than what you’ve already said? [Pause] No? Okay, cool. So, overall then, do you think setting up a pathway for breast cancer risk assessment and management activities in primary care is a worthwhile idea?

GPR2: Shall we all chip into this one? I actually – I was quite excited by the idea when I saw the study. Unfortunately, our health service I think is far too reactionary rather than preventative, and so I think it’s a positive step forward. But it is still the NHS and there’s a massive pressure on resources, and I think a lot of the downside of the discussion has been about issues with resources and funding, and time. So I think it’s a really positive idea, but I think they’re the main barriers that need thinking through really carefully.

GPR4: I agree with GPR2. I’m less certain now than I was before we started this focus group, of how incredible it will be, and discussing the logistics and things, there’s a lot to consider. So, I actually think I’m a question mark to that answer [laughter] rather than a straight forward yes or no.

Q: No, no, I don’t mean that you have to answer it with yes or no [laughter].

GPR6: Yeah, I think like more needs to be done, doesn’t it, in terms of preventative work, but I think it’s just at the moment the NHS just seems so stretched all the time. But maybe a pathway that’s slightly adjusted, so maybe if we were able to do risk assessments with women in terms of lifestyle factors and it does identify if someone’s high risk, maybe they would then progress to a breast clinic that’s specifically set up for those women, and perhaps we don’t get involved after that. They’re then passed onto that clinic. But we can provide the lifestyle advice at the baseline level, you know. So, if someone’s intermediate risk then we advise what they can change, and then we see them again in a year’s time. But I think it’s still again how do you actually invite those women, how do you know if you’ve missed women, you know, who’s going to be paying for those resources. So, there’s still a question mark there. But I do think there’s something – you know, we should be trying to prevent conditions, which we do with a lot of other conditions, you know. We do try to prevent like smoking related diseases and cardiovascular disease. But I think we just often jump in too late, unfortunately. Like we often pick people up in the sort of fifth or sixth decades of life when we should have tried to do something sooner. But how we actually go about that, I’m not entirely sure. I do think it’s a good idea.

Q: Thank you.

GPR3: I think it’s a really good idea, but I’ve become convinced that I don’t think it’s appropriate for primary care to be involved in it. And I think it should be a totally separate entity, like – well, not like cervical screening, but similar to breast screening. I think it should be part and parcel of that sort of approach, even from the basic counselling of the scope of it to the host - you know, to the post risk assessment management of women are in the high risk category. I think the only way GPs could get involved in it would be in possible data collection, or helping get people involved. But I would be very hesitant – and I think, you know, with the crisis in general practice and everything else, where people are quitting, GPs are not going to get on board probably with this. They’ll just see it as another thing for us to be bad at and for the media to bash us, and then we’ll be giving out medications that cause endometrial cancer and all that sort of stuff. But I don’t mean to be cynical, sorry.

Q: No, no, no, honestly [laughter], like I say, it’s not something that is definitely going to happen. This is why we’re doing this, you know, to see what the potential is in the future. But that’s completely fine. I had a question here about should it be primary care’s responsibility, and it’s completely fine to say that you don’t think it should be. So no, thank you for sharing that.

GPR5: I think there’s definitely a place to try and prevent breast cancer in this cohort of women, you know. Unfortunately, women are still dying of a very treatable cancer, you know. Survival rates are massive, and it’s very sad to think that women, at the prime of their life, are still dying of breast cancer. And I think that if we can screen and try and reduce those numbers then that’s a fantastic thing. I think the problem, as GPR2 was saying, is a lot related to the lack of resources. So, my advice would be, if this was going to come to primary care, to just think about what is it that a general practitioner needs to be involved in? What is it that the practice need to be involved in? And if it is that the practice need to be involved in counselling or – not necessarily starting treatment in high risk women, but explaining to these women that they’re going to be passed onto another service, or, you know, giving them information with regards to the next step, I think that’s understandable. I think to manage all women, so to speak to the women that haven’t got an increased risk, and to be inputting data, wouldn’t be the best use of resources. So, I do think there is a possible scope, you know, for it to be supported by primary care, and it might even be that, you know, primary care is almost like stage two. If you’re unable to get women to engage, is it that they get a phone call, or is it, you know, that they get a subtle reminder from their general practitioner. You know, that doesn’t need to be a GP necessarily that rings them and says, “Are you aware that you’ve not attended for this? These are the benefits,” etc. But I think it would need to be massively streamlined, just because, you know, breast cancer – although, as I’ve alluded to, you know, it is a very treatable condition, there are lots of other conditions that we’re managing and screening as well, and a lot of other people that are worried about various things. So, it’s making sure that everything’s got its own allocation of resource and time, really.

[0:30:44]

Q: Okay, great, thank you. So, that’s all the questions I had, so I’m just going to hand over to [name of co-facilitator], who’s just going to provide like a very brief summary of everything. You’ve discussed so much [laughter].

V: You have discussed a lot, so I don’t even think I’ll go through the notes ‘cos they’re four pages long [laughter]. So, your main concerns are where is primary care going to be sitting in this pathway, how much should they be involved, especially when we’re talking about prescribing Tamoxifen, and is it appropriate that high risk women stay within primary care or should they be diverted to another service. There is also issues with how much is the woman able to be involved in that, should she answer all the questions, turn up to the mammogram and, you know, do her saliva sample all off her own back, and whether that’s appropriate, and whether that would be exacerbating some inequalities that we already have in healthcare. Also, if it was to run through primary care, it’s like what are the incentives for primary care to be doing that and to still be run as a viable business, and what are the health outcomes, in that, you know, what would be the output from this. It would be good if it ran a little bit like QRISK, so you’d be able to see everything on the screen, and you’d also be able to go through that with the patient, so you would help them to reduce their risk. The main thing that you think primary care would be good at is the lifestyle advice, and you’d be well placed to give that there, ‘cos obviously lifestyle also links to other diseases. What else? And then there was issues about whether you’d be shaming people with contraceptive advice, and also the thought about putting people on Tamoxifen when they might be thinking about families, and also it increases other risks of cancers. I think that’s the main things, except you were all a little bit mixed on whether you think it’s a good idea or not, and how much primary care should be involved, mainly due to resources, ‘cos the NHS is so limited on resources, and how expensive it would be. I don’t know whether anyone would like to add anything else or you think I’ve missed anything. [Pause] No? Great.

GPR4: That was a very good summary [laughter].

V: You said a lot more than that. I’ve just cherry picked.

V: Great, thanks [name of main interviewer].

Q: Okay, thank you. I’ll stop the recording there.

[End of Transcript]