

## Supplementary 3. Participants' suggestions for supporting women making breast screening decisions in the future

What's needed?	Advice/recommendation - How to implement it	Illustrative quotes
Individual level		
Prioritise patient preferences	Medical preferences quiz elicited by nurses or clinicians and incorporated into decision making about screening, diagnosis, and treatment	<i>It would be good if there was some way one could try to ascertain which women would welcome more information and which would not... and one thing I remember saying was that, if someone had looked at my medical history and the choices I had taken earlier in my life, they would have figured out that I was a person who wanted to know and was a little bit skeptical...if there was some way of, doing a quiz with women, or something, about what choices they would make in a parallel situation to kind of gauge, I think that would be really good. (Participant 5)</i>
Communicate screening harms; don't downplay overdiagnosis	Clinician communication training  In surgical consultations, provide information about overdiagnosis and the harms of overdiagnosis including what that looks and feels like (Participant 6) – (e.g. having video testimonies of women, because 'people's risk perceptions are off')	<i>It's (overdiagnosis) a really difficult concept to get hold of actually...It's not intuitive...it is a difficult concept to explain...one part of me understands why the medical establishment doesn't want to complicate things...but at the same time...I think people should know (Participant 5)</i>  <i>They downplay overdiagnosis. They don't think it even exists. They say you can't measure it. Like it does, like my story and all the women that feel this way, like--- doesn't matter...you feel like you're...somewhat of a victim of our medical system, yet nobody's acknowledging that, except for a handful of people (Participant 6)</i>  <i>Quite a lot of that could be done through training doctors better, how they communicate (Participant 8)</i>  <i>I think that it's about managing expectations (Participant 4)</i>
Flexible care pathways, patient-preference-driven		<i>The other thing I think is absolutely crucial is that once you get the diagnosis there should not be an unambiguous set of steps that are always followed independent of the patient, what they want, and what matters to them at that time in their lives. (Participant 1)</i>
Medical profession / health system level		

Acknowledge limitations and uncertainty in current knowledge		<p><i>I think it's appropriate for people (medical professionals) to acknowledge what they know and acknowledge what they don't know (Participant 10)</i></p> <p><i>How do you talk to women that already – the problem for you is how do you say it in a way that doesn't offend all the women that went through all this crap including chemo and then you tell them it's for nothing. They're going to fight you (Participant 7)</i></p> <p><i>What's needed is a much clearer account of what the mammography screen, well any kind of screening, can and can't do. And also what the chances are that you'll get a really ambiguous outcome... like...a false positive...or DCIS (Participant 1)</i></p>
Opportunity for proper discussion before screening		<p><i>And I think... maybe it should be flagged up to women... that they can go and discuss screening with their GP before they go for it. That should be made more prominent. (Participant 5)</i></p>
Lower the anxiety dial	Build in more time between appointments, possibly with nurses	<p><i>If people just knew, something this size, this is probably taken 7 years to develop in you. Why can't we give you 30 days...Just to...make a decision? Why do we think that between finding it and doing something is going to like go poof, which it took 7 years to get to this tiny little spot. I hate that whole idea that we kind of assume, well now that you know, you have to do something. 'Cause otherwise you're being stupid...give them stuff to read ...this is not a medical emergency (Participant 3)</i></p> <p><i>Take more time and not panic...everyone just pause...when you make decisions out of fear it can be life changing and you can't go back... I mean I'd just feel awful if someone didn't find out... that there is a controversy and there is a potential overdiagnosis (Participant 6)</i></p> <p><i>In other words to say look even if they find a small lump actually to say your body can get rid of these things naturally, you have an element of choice. I think to sort of lower the level of anxiety basically about the disease. ..I think if you lower the dial, it allows women to make more informed choices about their treatment and not go for the just give me everything I want to get rid of this (Participant 8)</i></p>

Address external factors that pressure women into screening	Remove/address screening incentives, targets, automatic invitations	<p><i>The whole system is set up to disempower you (Participant 10)</i></p> <p><i>I tried to argue that one should make the invitation more neutral it shouldn't be you've been given an appointment or mammogram at this time, because that means if you don't want to go you have to do something (Participant 12)</i></p> <p><i>And I think that what they should not do is send you a screening invitation for breast cancer screening with a date and a time and a place on it, because that kind of almost preempts your decision. I think it's wrong because I think it steers women towards having screening without them thinking too much about it. (Participant 5)</i></p> <p><i>It's very hard when you're trying to go around whatever the system is set up to do (Participant 6)</i></p>
Culture / Society level		
A shift in thinking about and labelling cancer		<p><i>Our culture is teaching us to get rid of this, get help. You've got this whole cultural thing to deal with ...People want that from their Doctors, they want a take away and I think this is one of the reasons why people are perhaps over treated...I've got this, you told me I've got this and now I need something to deal with it. We've got to change a whole way of thinking which is not easy (Participant 9)</i></p> <p><i>You can see that people hate the idea of having a cancer. Oh my god, get rid of it. I can see that but that's because of the way we think of cancers... If the words around it, the language around it was gentler I think people wouldn't feel oh my god I've got to get rid of it. I think there is a lot of that...The whole cultural history of doing big things when it comes to breast cancer...I think that's something that perhaps lingers in people's minds...it's only really recently that we've been talking about quality of life (Participant 9)</i></p>

		<i>I still don't think this is a true cancer as we know cancer...it's a mindset that for me shifted pretty quickly ...The nature of DCIS, it's not a tumour, it's not like an invasive cancer. And this isn't really explained to women (Participant 6).</i>
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