

4. Findings

4.1 Quantitative statistical data for participants

111 subjects were contacted. 30 responded and of these 20 were able to be included in the study. The details of the responses are shown in table 2.

Table 2. Response rate

	Total
Targeted	111
Letters returned	(2)
Consent forms received, person contacted x 3 but no response	6
Interested in study, consent form not returned	1
Unable to take part	3
Interviewed	20
Response	30
Response rate %	27
Uptake %	18

4.1.1 Study Participants

Of the twenty women who participated in the study there were similar numbers of BRCA1 and BRCA2 carriers. The majority of participants were white British, there was no ethnic minority in the group. The age group from 50-60 years was the largest. The sample included a wide age range, from 25 to 76 years. The majority of the women were married or co-habiting (85%). 75% of participants were known to be educated up to or beyond secondary school. 65% had a BMI above the recommended healthy range. All except one woman were non smokers, this woman reported to be a social smoker. 95% attended regular breast cancer screening. 70% were post menopausal. See table 3.

Table 3. Demographic information of study participants

Demographics		Total
Gene status	BRCA 1	9
	BRCA 2	11
Age, years	18-35	4
	36-49	3
	50-60	9
	60+	4
Marital status	Married/co-habiting	17
	Single	3
Education	Secondary school	9
	Further education	6
	Unknown	5
Body mass index. kg/m²	≤25	7
	26-29	8
	≥30	5
Menopausal status	Pre-menopausal	6
	Post menopausal	14
Smoker	Smoker	1
	Ex smoker	11
	Non smoker	8
Breast screening	6 - 12 monthly	13
	18 months - 3 years	6
	Not started screening	1

9 participants carried or were at risk of carrying a BRCA1 mutation and 11 for BRCA2.

Table 4. Participant's genetic status

Participants:	BRCA 1	BRCA 2	Total
Treated for unilateral breast cancer	5	4	9
Not diagnosed with breast cancer	3	4	7
Unaffected 1 st degree relatives of BRCA 1 or 2 mutation carrier who have not had genetic testing who are at 50% risk of being a carrier.	1	3	4
Total	9	11	20

18 of the participants in the study had a high cancer burden, defined as having had breast or ovarian cancer themselves or having had a first degree relative who had breast or ovarian cancer. Of the two women classified as unaffected one had a mother who was affected with a different type of cancer.

Table 5. Cancer burden

Cancer burden table	BRCA 1	BRCA 2	Total (%)
Women with a first degree relative affected with breast or ovarian cancer	8	8	16 (80)
Women with > 1 first degree relative affected with breast and or ovarian cancer	3	4	7 (35)
Women with affected mother	7	7	14 (70)
Women with sister or mother who have died of breast or ovarian cancer	7	6	13 (65)
Participants affected with breast cancer	5	4	9 (45)
Women without an affected first degree relative and who are unaffected themselves	1	1	2 (10)

4.2 Qualitative Analysis of interview data

Having followed the methodology described to analyse the data that had been collected during the study five distinct themes emerged. These themes were;

1. Perceived causes of breast cancer
2. Perceived risk of breast cancer for the participant
3. Control of risk of developing breast cancer
4. Behaviour changes made or considered
5. Attitudes to entering future breast cancer trials

4.2.1 Theme 1. Perceived causes of breast cancer

The major and minor categories relating to the theme of causes of breast cancer were summarised into the table below. Themes emerging from the data were grouped into two major categories, controllable causes of breast cancer and causes which were uncontrollable. The major elements that were controllable gave rise to the sub categories of lifestyle, environmental and hormones. Conversely genetics and a fatalistic nature were all sub categories which contributed to uncontrollable causes.

Table 6. Perceived causes of breast cancer

Theme	Category	Sub category 1	Sub category 2
Causes of breast cancer	Controllable	Lifestyle	Diet
			Weight loss
			Alcohol
			Smoking
		Environmental	Chemicals
		Hormones	The pill
	Childbirth		
	Uncontrollable	Genetics	
		Fatalism	Pre-determined
			Nothing you can do about it
Triggers			

4.2.1.1 Uncontrollable

A strongly held view was that having the faulty BRCA gene was the main cause of breast cancer for this population group. This is illustrated by the quotations in table.

Table 7. Quotations on the causes of breast cancer

Interviewee Number	Causes of breast cancer
#1	"For me it's hereditary."
#2	"Obviously in my case it's because of the gene."
#3	"Obviously with me genetic has been the main factor."
#4	"A gene or something."
#5	"You have more chance of getting breast cancer if you carry a gene."
#7	"I suppose I have to say they're genetic for me aren't they."
#8	"I think it probably more is genetics."
#9	"Well I know the genetics... the... I mean... Yes it is."
#10	"I got it because of my mother."
#11	"I think it must be a faulty gene."
#12	"Well for me I think it's genetic."
#14	"Hereditary, is I think the biggest one."
#15	"I feel obviously the gene is a major factor. I think the gene is the bottom line."
#17	"The gene is the cause."
#18	"Apart from thelike the gene in the family."

The link to genetics as a cause of breast cancer was in almost all cases the first response given, the most frequent reply and the strongest statement made. The nature of the comments and the phrases used were very consistent indicating that this is a clear and widely held belief amongst this group.

It should be noted that when asked about the causes of breast cancer virtually all the interviewees placed the question within the context of their own risk rather than considering it in terms of the abstract risk for the population in general.

When asked about the causes of breast cancer many of the women expressed a fatalistic view. Believing that there was nothing they could do themselves to prevent developing breast cancer feeling that there are uncontrolled triggers that cause the cancer to develop or that it is pre determined. This fatalistic thread is further analysed under the section relating to control of breast cancer.

4.2.1.2 Controllable

Initial responses focused strongly on the perceived uncontrollable nature of the causes of breast cancer. Further probing was used to explore whether the group believed that there were other elements which are causes of breast cancer.

4.2.1.2.1 Lifestyle

Lifestyle factors such as a diet, weight loss, alcohol and smoking were cited as causes of breast cancer. Opinions on the role of diet related to several elements ranging from specific foods which may cause breast cancer such as sugar, red meat, fats and processed foods, to dietary trends which may help protect against

the disease such as increasing vegetable intake and ‘healthy diet.’ There was no particular single element of diet which this group believed was more strongly associated with causing or protecting against breast cancer. Several of the individuals who were interviewed believed that overweight may play a role in causing breast cancer and some commented that there maybe a link between breast cancer and yo yo dieting.

#5 “ Because I looked at the ladies that I know that have got breast cancer or had breast cancer, are hefty.....so when you look at that you think well maybe there is something in it.”

Alcohol consumption was mentioned as a possible cause of breast cancer by a small number of the group. A larger number of the women believed that smoking is linked to developing cancer however this appears to be related to cancer in general rather than specifically to breast cancer.

#12 “Well smoking doesn’t help with a lot of cancers.”

4.2.1.2.2 Environmental

Some respondents believe that exposure to chemicals on food and in the environment are possible causes of breast cancer.

4.2.1.2.3 Hormones

Use of the contraceptive pill was believed to play a role in the cause of breast cancer. This was a strongly held view of one woman which was clearly related to her experience.

#3 “I personally think that the pill has a huge thing.....I personally think that that’s got a part, that played a big part really”

This woman recalled how her sister died young of breast cancer and was on the pill from a young age and on several different types.

Causes related to having had children or not was a rarely held view amongst the interviewees.

4.2.1.3 The relative strength of various causes

There is a clear difference in how strongly the interviewees link the different causes with the development of breast cancer. Whilst there is a very clear, strong and consistent belief that the uncontrollable factors described above are linked to the development of breast cancer, the number of different factors and the descriptions used for these many controllable factors imply a much weaker certainty in the beliefs of the group. This is illustrated by the language used in their responses as can be seen in table 8.

Table 8. Language used in response to the causes of breast cancer

Interviewee Number	Causes of breast cancer	Phrases used
#8	"It probably helps having your 5 portions of fruit of veg."	"Probably"
#14	"Be careful about red meats they say."	"They say"
#5	"It could be all the fats you eat."	"It could be"
#3	"I think it possibly does have some bearing on it [high fat]"	"It possibly does"
#7	"There maybe an issue with what's in processed foods."	"There maybe an issue"
#8	"To a certain extent maybe smoking, drinking, overweight and stress."	"To a certain extent maybe"
#15	"You can maybe help yourself by eating correctly and exercising."	"You can maybe help yourself"
#6	"Maybe the chemicals that are introduced now on food, on crops."	"Maybe the"
#15	"Maybe it's because you've been on the pill a long time."	"Maybe its because"

Analysing both the tone and the phrasing used during these responses it is clear that the interviewees do not fully own many of the statements made and they are not fully committed to them. In certain cases they may not even believe them to be true for example the word maybe is used in several cases. This contrasts strongly with the comments made by the group relating to hereditary risk.

4.2.2 Theme 2. Perceived risk of breast cancer for the participant

The major and minor categories relating to the theme perceived risk are summarised in the table below. Themes emerging from the data were grouped into two major categories: awareness of risk and coping with risk. The major elements of awareness of risk gave rise to the sub categories of clear awareness and unclear awareness. Conversely 'ignore', 'acceptance' and 'action' were all sub categories of coping with risk.

Table 9. Perceived risk of breast cancer for the participant

Theme	Category	Sub category 1	Sub category 2
Perceived risk	Awareness of risk	Clear	
		Unclear	
	Coping with risk	Ignore	
		Acceptance	
		Action	Risk reducing surgery

4.2.2.1 Awareness of risk

Majority of women in this study believed they were at risk of breast cancer. This was often related to and confirmed by having the faulty BRCA gene. Many women could describe in great detail their family history and some were able to report their percentage risk of developing breast and or ovarian cancer.

#9 “I know at this age, they've said it is 80% chance of having breast cancer, so there is 20% that don't. And I feel perhaps touch wood, luckily enough to have maybe the 20% that didn't. But I've still got a risk along with the general public.”

#3 “And explained that because... even though I'd had the breast cancer I was now at an 80% lifetime risk of developing ovarian cancer, which absolutely horrified me, because I know it's like a silent killer, isn't it, ovarian.”

#1 “Hysterectomy reduced the chance to about 27% from 85%.”

These phrases imply that the very specific numerical risk values have originated from a detailed source. It should be noted that all the women in this study have attended the family history clinic held at the Nightingale Centre. These clinics are targeted at women who may be at an increased risk of developing breast cancer due to a genetic predisposition. These clinics involve specialists from a number of related clinical areas; medical oncologists, geneticists, specialist research nurses and radiographers. Those attending the clinic are asked to provide information about family breast cancer history, childbirth patterns, and other details which relate to hormone exposure. This information is then used to

build up a comprehensive risk profile for each individual. Models such as Tyrer-Cuzick (Tyrer, Duffy, & Cuzick, 2004) are used to give detailed numerical risk information, this is then explained to the individual and a written summary is also sent to the patient.

Most women had a close family member, often first degree relatives who had been affected and in many cases had died due to breast cancer or ovarian cancer. One woman recalled how she was 11 when her mother died of breast cancer.

#17 “My mum and my grandma have had breast cancer. They're like the closest to me.....My mum died of breast cancer, yeah, in 1993. But she would have got it in about '89, I think she was diagnosed.....Obviously my mum died when I was 11.”

The awareness of increased risk is illustrated by the quotations in table 10.

Table 10. Quotations on awareness of risk

Interviewee Number	Clear awareness of risk – Do you think you’re at risk of breast cancer?
#1	"I know I am."
#3	“And the fact that, you know that's going to give me an 80% lifetime risk, then I have developed it. And I'm hoping that that's it now. But I'm not stupid and I realise that I am still at a quite a high risk.”
#6	"Hopefully not, but probably.....But obviously once you've had it once its higher isn't it."
#7	"Yes, but I don't think it goes away you know."
#8	"Just the increase risk of having the gene."
#10	"Well I must be at risk mustn't I, if I've got the gene."
#12	"Yes, yeah."
#14	"Yes. Possibly slightly more than another woman not with my circumstances."
#15	"Yeah, yeah. I don't feel 100% safe."
#16	"Well obviously I've got a higher risk because I've got the gene."
#18	"I do, yeah.....because it's gone down the family."

Nobody could make an unequivocal statement that they felt they were not at risk of breast cancer. Some compared their risk to the general population. This is illustrated in table 11.

Table 11. Quotations relating to uncertainty about cancer risk

Interviewee Number	Less clear about risk
#4	"I don't know. I suppose it could pop up. I don't know at my age now."
#5	"I don't know."
#9	"No. Not now I've got to this age. There's 20% that I don't. I feel perhaps to maybe the 20% that didn't.....still got a risk along with the general population."
#11	"I hope not, now that I've had a mastectomy, but I will always be a little cautious."

4.2.2.2 Coping with risk

4.2.2.2.1 Risk reducing surgery

Sense of risk was reduced for those who had surgery such as hysterectomy. In some this was as a preventative measure or as a result of having breast cancer.

#15 “Although, it doesn’t play on my mind as much as it used to before I had the hysterectomy. I feel a lot safer now.....I feel I’ve helped myself as much as I can, I could help myself further.....I’m not ready for that kind of surgery.

#1 “Hysterectomy has reduced the chance to 27% from 85%.”

#3 “Hysterectomy will lessen my risk of getting cancer in my other breast.”

Hysterectomy was the most cited surgery women had undergone. This seems to be thought of as more acceptable than having a mastectomy as a preventative measure in this population.

#9 “I’ve only had my ovaries removed. Oh yeah. I am quite happy with that. I mean I didn’t want the operations. Nobody wants an operation, but I am glad I did it. But the oddest thing is that I had a letter just before I went on holiday, about whether I wanted to reduce... Basically if I wanted to have. Reduce my chances even more and have a mastectomy. Now I don’t feel that way. I feel I need to have the appointment to ask them how much would I reduce it, you know percentage wise. Because it was 80% with the gene that you have getting breast cancer at an early age, and I’ve got to 58, so I still have a... the normal risk. I am not sure that I want to have a total mastectomy. To me to have your ovaries removed is really no big deal, once you are over the operation, it doesn’t affect you in anyway, but to have a mastectomy.”

#3 “Because we talked about the mastectomy and I really didn’t want to go down that route as well, at this present moment. “

The phrases used by these women relating to having a mastectomy suggest they regard this type of surgery as a bigger step to take in preventing breast cancer than a hysterectomy and require a lot of consideration. Investigation of the groups feelings about the acceptability and effectiveness of the various surgical options is not part of this study and therefore was not explored further.

4.2.2.2.2 Acceptance

Although the women in this study had a clear sense of risk it appears that different coping strategies were employed. Some who carried the gene or were at a 50% risk of having the gene accepted that they might develop breast cancer in the future and there was a sense that there was little they could do to control this due to carrying the BRCA gene. The sense of reduced control led to the views of “life is for living,” “if it happens it happens,” and one woman commented that she would “probably end up with breast cancer at some point in her life.” This fatalist view was strong during many of the interviews and is discussed further under the theme control.

#18 “At some point in my life I will, I will probably end up with breast cancer.....because it's gone down the line.”

4.2.2.2.3 Ignore

Another coping strategy employed by a small number of the women was to not think about it. This is illustrated with the quote below;

#8 “Some people would dwell on it, I don't tend to dwell.....I don't personally go round thinking oh I'm at risk. In all honesty I don't really think about it.....I don't sort of think.....I'm more at risk than the person stood next to me it's one of those things you know if you're going to get it you'll get it. Because you're in higher band it doesn't necessarily mean I might never get it, I hope I never do.”

#10 “I just think if I'm going to get it I'll get it. That's why I don't worry about it.”

4.2.3 Theme 3. Control of risk of developing breast cancer

Once analysis was carried out the major and minor categories relating to the theme of control were summarised into the table below. Themes emerging from the data were grouped into two major categories: those which increased control and those which reduced control. The major elements reducing control gave rise to the sub categories of genetic factors, barriers to control. Conversely monitoring, lifestyle and psychological elements were all sub categories which contributed to increased control.

Table 12. Control of risk of developing breast cancer

Theme	Category	Sub category 1	Sub category 2	Sub category 3
Control	Reduced control	Genetics		
		Barriers to control	Information	Too much
				Too little
				Changing advice
				Confusion
	Practical			
	Increased control	Monitoring	Support	
			Health awareness	
			Screening	
		Psychological		
		Lifestyle	Exercise	
			Weight loss	
			Diet	Healthy eating
Sweets				
Vegetables				

When discussing control of their risk the majority of interviewees immediately made connections between developing breast cancer and the items that influenced what the outcome would be in such a situation. It was very clear that they do not think of the risk of developing breast cancer in isolation but think of the risk of developing breast cancer and the outcome of any cancer treatment they would receive as very much a single element.

4.2.3.1 Increased Control

4.2.3.1.1 Monitoring

Increased awareness of risk did result in all women ensuring they attended annual and in some cases twice yearly screening such as clinical breast examination and mammograms at the family history clinic or their local hospital. Some reported to perform regular self examinations.

#6 “I am paranoid. I keep checking all the time.....I’m checked up to twice a year.”

#4 “They check me because of my right breast.....so we keep an eye on it....I make sure there’s nothing there to report.”

Both these women have had breast cancer which may result in them checking more often and being extra vigilant.

#14 “At least I’ve got a really good team behind me. You know. I know that if I find anything wrong I could phone up today.....it would be actioned today.”

#9 “Being aware of your body wouldn’t reduce your risk of getting it but would detect it early enough.”

Regular screenings such as breast examinations and mammograms, as well as being body aware, seems to give the women some element of control, although many of the women recognised that this did not reduce their risk of breast cancer.

4.2.3.1.2 Psychological

A state of mind, a healthy mental approach, a positive attitude and mind over matter was quoted by some to help give them some control. This was not a strong viewpoint amongst the study population.

4.2.3.1.3 Lifestyle

The vast majority of respondents believed that lifestyle was related to control of their risk, however the positive benefits of controlling their lifestyle were seen as relating to their overall health and to the outcome of any instance of cancer that may occur. Almost all of those interviewed believed that they could control the state of their health, to some extent, through changing their lifestyle. There were several different positive benefits that were perceived to be gained through control of lifestyle. These included; being prepared to fight off any future cancer, feeling that they were doing everything that they could, generally feeling better about themselves physically and psychologically, helping to control other diseases or illnesses. Despite the overwhelming positive attitude towards a 'healthier lifestyle' it is very clear that those interviewed did not believe that lifestyle changes were able to provide a significant impact on their risk of breast cancer occurring.

#7 "I think I have a fairly healthy life I have a better chance of dealing with it."

#17 "But you know, the other parts of you thinks right, well you've got to do something to make yourself well, and make yourself like fit and strong or

whatever.....and now I feel like it may be a mind over matter sort of thing, but I feel like I really wanted to combat illness. So I've sort of tried to eat well, like not eat loads of crap or whatever because I feel better. And I don't know whether that has some kind of psychological sort of something.....its runs alongside knowing that if I could fight a common cold then I might have a little bit more of a chance of fighting a possible cancer somewhere down the road. So it's just a crazy thought.....I consider it to give me control over like how I'd cope if I was ill.”

Lifestyle changes were believed to provide benefits if the interviewee developed cancer in the future, this related to having a better chance to overcome the illness.

Even when individuals are not necessarily convinced of a causal link between lifestyle and developing breast cancer there appears to be some feeling of control and reassurance provided by following a healthy lifestyle.

#8 “You know just try and eat as healthy as you can and just generally try and keep as well as possible to try and eliminate any possible causes.”

#3 “Just so that I can say, right, well I’m trying my best. And I am trying my best, but I’m no saint.”

#16 I also believe in eating healthily and doing all the things that I should do to try and prevent it. So that's my philosophy on it.”

Lifestyle changes also appear to help with the control of outlook and to deal with the knowledge of an increased risk of developing breast cancer.

#12 “Well probably might make me personally feel better, psychologically. Whether it has a bearing on, you know the outcome, I don’t know.”

#11 “I feel my lifestyle..... I like to keep active and fit and healthy, and that helps me to just get through everything.....because it keeps your body healthier.”

There is also an underlying belief that a healthy lifestyle has positive benefits in relation to many other serious illnesses. Again there is a clear link here between lifestyle and control of both risk and outcome however for other illnesses it would seem the group believe there maybe a stronger link than for breast cancer.

#10 “I think it’s helped in other ways because the size of me, I haven’t had a heart attack.....I do think the healthy eating has definitely helped.”

#14 “18 months ago I was told I was borderline diabetic, and I was obese, and I smoked. And it was the biggest kick up the pants that anybody has ever given me in my life. And I worked so hard, and I lost four stone, and I gave up smoking, and I took up sport, and I've never felt better.”

Table 13 illustrates that the respondents believed lifestyle changes however beneficial could not necessarily be expected to have a significant effect on their chances of developing breast cancer. Although there are many positive comments about healthier lifestyle there is very little conviction about its ability to directly reduce risk. This is illustrated by the frequent use of phrases such as “maybe,” “don’t really know,” “not convinced.”

Table 13. Control and lifestyle factors

Interviewee Number	Control and lifestyle factors	Unconvinced
#6	“Well not necessarily, but maybe it has got something to do with it. I don’t really.....It's when they have a talk on like on programmes that I've seen of being healthy and not being too much overweight, and eating fruit and veg, that sort of thing. I don't really know whether it has got anything to do with it or not.....”	"but maybe it has" "I don't really know"
#7	“I think I’ve taken control. I’ve reduced it as far as I can. I sew, I exercise, I eat healthily, I’m not particularly stressed in my life I don’t think. You know I mean things that I think might help.....I think I have a fairly healthy life I have a better chance of dealing with it.....”	"things I think might help"
#8	“You know just try and eat as healthy as you can and just generally try and keep as well as possible to try and eliminate any possible causes.”	"to try to eliminate any possible causes"
#12	“Well probably might make me personally feel better, psychologically. Whether it has a bearing on, you know the outcome, I don’t know.”	"I don't know"
#3	“I think I know deep in my heart that yes, it probably does contribute, so I’m trying as much as I can to live the healthy lifestyle.....just so that I can say, right, well I’m trying my best.”	"it probably does contribute"
#10	”I think it’s helped in other ways because the size of me, I haven’t had a heart attack.....I do think the eating has definitely helped, but I don’t know whether it would help.....I'm not convinced it would stop me getting cancer if I get it. Not breast cancer anyway, you know.”	"I'm not convinced it would"
#5	"I mean we don't know, nobody can actually tell you whether or not whatever you're eating is going to give you cancer. You just don't know that at all. But if you can prevent it by not eating that kind of rubbish, then yeah, fine, you know.....I have to be careful with eggs, you know, because of my cholesterol."	"just don't know that at all"
#9	"If I thought it would I would stop it [alcohol]. I would reduce it. I think it is just that I feel I should reduce it.....for one thing I am putting on weight, I don't want to put on weight with it.....I don't think it would reduce my chances of breast cancer, because I think it is irrespective."	"I don't think "

This theme of the overriding significance of the genetic factors recurs in discussions of control of risk and causes of breast cancer. Despite this lifestyle is felt to afford the respondents a level of control over their situation. This is articulated here in relation to control of risk and is also a clear theme when they discuss behaviour changes. Most respondents have made or are looking to make lifestyle changes despite feeling that lifestyle factors are not the most significant causes of them developing breast cancer.

4.2.3.2 Reduced control

4.2.3.2.1 Genetics

A strongly held view was that the genetic element of their risk of developing breast cancer was by the most significant factor. This leads to a feeling that their ability to control their risk of developing breast cancer is greatly reduced because they cannot change their genetic makeup. This gives rise to many statements of a fatalistic nature. This is illustrated in the table below.

Table 14. Reduced control of breast cancer risk

Interviewee Number	Reduced control – Do you think you have control over your risk of breast cancer?
#1	"Not over the hereditary bit, I know that I could not do anything about that."
#2	"Not really, no."
#4	"No I don't not with cancer, I don't think there is anything you can do not to get it."
#7	"If it's going to happen its going to happen."
#9	"No, not really If I found a lump I would think that's it."
#10	"No. No, I don't. No. Not with the genes one no. I just think if I'm going to get it I'll get it."
#11	"Not really."
#12	"No. I think my risk comes from the genetic side.....If it's in my genes it's going to happen."
#14	"It's a bit head in the sand isn't it. I'm a great fatalist that if it happens it happens."
#15	"I feel like it's a lottery if that disease is in the gene and ready to pounce then nothing is going to stop it."
#17	"No. I don't feel like I'm in control of it. I'm predisposed to it anyway and nothings going to make any difference."
#18	"If it happens it happens if it doesn't then you are one of the lucky ones."

4.2.3.2.2 Barriers to control

When discussing control of risk a small number of women brought up the issue of lack of information and conflicting lifestyle information. This variation in quality of information seemed to be a de-motivating factor when they were considering how lifestyle could affect risk levels. It did not seem to be related to general health but was more related to specific cancer risk.

#14 “It comes out every couple of years well don’t do this and don’t do that.....you hear it on the news researchers have found that such and such a thing is detrimental.”

#5 “Nobody can actually tell you whether or not whatever you are eating is going to give you cancer.”

In the rare case where practical difficulties of obtaining recommended exotic foods was mentioned this was not implied to be a strong barrier.

4.2.4 Theme 4. Behaviour changes made or considered

The major and minor categories relating to the theme behaviour changes made or considered were summarised in table 15. Themes emerging from the data were grouped into two major categories: long term behaviour changes and ongoing behaviour changes. The major elements of long term behaviour changes gave rise to the sub categories of no changes made and life choices. Conversely lifestyle and environmental factors were all sub categories which contributed to ongoing behaviour changes.

Table 15. Behaviour changes made or considered

Theme	Category	Sub-category 1	Sub-category 2	Sub-category 3	Sub-category 4		
Behaviour changes made or considered	Long term	No change	Already practising desired behaviour				
			Behaviour stays the same				
		Life choices	Have children early				
			Breast fed				
	Ongoing	Lifestyle	Exercise	Exercise			
				Weight loss			
				Alcohol			
			Diet	Increased	Fruit and vegetables		
					Fish		
					Fresh/organic food		
				Decreased	Saturated fat		
					Dairy products		
					Sugar		
			Environmental	Reduce stress	Red meat		
					Salt		
					Chemical exposure		

4.2.4.1 Long term

4.2.4.1.1 No change

When describing their general long term behaviour changes a significant number of the respondents felt that they hadn't made and weren't considering major changes. Within this view there were two clear categories with a similar number of comments in each category. Several felt that they were already practising what they considered to be the optimal behaviour that would reduce their risk.

#7 "I already eat healthily and exercise."

There were several responses which could be categorised as illustrating that the respondents did not feel that they would change their behaviour.

#18 "I've just carried on as normal."

#8 "It didn't sort of affect my life and think right I've got make really significant changes."

One respondent felt strongly that she had made a significant long term behaviour choice in that she had her children very soon after finding out that she had the gene. She also chose to breast feed because she felt that this would benefit her cancer risk.

#1 "I breast fed, which I didn't find easy, so I did struggle with that for 9 months but I thought no, I need to do this."

4.2.4.1.2 Ongoing

Many of the respondents have made lifestyle changes, three of the areas that were articulated are exercise, weight loss, and alcohol consumption. There was a range of commitment within these statements, some of the group talked forcefully about the changes that they had made to their weight and exercise level.

#16 “Exercise and I do a lot of that.”

#3 “I have definitely made conscious choices losing weight.”

Others talked of wanting to make changes rather than strongly insisting that they already had.

#1 “I’ve joined the gym to try to do more exercise.”

#15 “I started a weight loss programme.”

Some of the group had cut down their alcohol intake.

Dietary changes were reported by many of the interviewees. There were a wide variety of changes to diet that the group felt would relate to their breast cancer risk. These were categorised into items of which consumption was increased, such as fruit and vegetables, fish, and fresh or organic food. There were a number of foods which had been cut out or reduced in the changes the group had made, these included dairy products and saturated fats, red meat, salt and sugar.

It is striking that not all the group are making specific dietary changes and that there are many different food related changes that are being made.

A few of the women made very strong statements about having changed their exposure level to certain chemicals. For these women this was one of their most important changes that had been made.

#16 “Wiped out everything under the cupboards, shampoo, bleaches, we have toothpaste that is not manmade. I use eco stuff. Using more natural products.”

#1 “Now I wear rubber gloves so that I don’t come into contact with them [chemicals].”

Changes to reduce stress were described by a few of the respondents however the statements made did not imply that this change was expected to make a significant difference for these individuals.

#3 “Being less stressed is hopefully going to help.”

4.2.5 Theme 5. Attitudes to future trials

The major and minor categories relating to the theme attitudes to future trials were summarised into the table below. Themes emerging from the data were grouped into two major categories: those which increased motivation and those which were barriers to involvement in future trials. The major motivating elements for diet and exercise trials were helping other people, losing weight and gaining control of the trial, the motivating element for drug trials was the possibility of getting better. The barriers to entering future trials were fears, attitudes and lack of information for drug trials and practical issues and unclear benefits for diet and exercise trials.

Table 16. Attitudes to future trials

Theme	Category	Sub category 1	Sub category 2	Sub category 3		
Attitudes to future trials	Motivations	Diet and exercise	Help other people			
			Lose weight			
			Control			
		Drug	Get better			
	Barriers	Diet and exercise		Fit in with life		
				benefits unclear		
		Drug trial		Fears	Hospital	
					Side effects	
					Needles	
					Feeling ill	
					Memories	
					Future	
Attitudes			Not natural			
			Don't take pills			
Information						

4.2.5.1 Motivations

For the majority of the interviewees the initial response when asked about entering a diet and exercise trial was that they would do this because they wanted to help others who may be in their situation in the future.

#15 “I feel that if there is anything that can be done to prevent the disease for the future then I’d be willing.”

#8 “Certainly if it was something that may help other people.”

Few of those in the study were also motivated because they felt that a diet and exercise trial would result in them losing weight.

#17 “If I could lose some weight that would be amazing.”

These women who acknowledged weight loss to be a motivation were young and had a BMI in the healthy range.

One perceived benefit of a diet and exercise trial when compared with a drug trial was that some respondents felt that they would have some level of control over the possible effects of the trial on them.

#14 “If it was a diet and lifestyle [trial] you’ve got more control than if it was a drug.”

The only positive response when asked about the possibility of entering a drug based trial was related to the possibility that there might be a direct benefit to their health.

4.2.5.2 Barriers

There were relatively few factors which the group felt would prevent them from entering a diet and exercise based trial. One respondent wanted to ensure that it would fit in with their day to day life, and a small number questioned whether such a trial would be likely to show any positive results.

There were a number of different categories of barrier that the group described which may make them feel less inclined to enter a drug based trial. Almost all respondents articulated significant concerns about the possibility of a negative outcome from drug based trial. These included worries about side effects, feeling ill, hospital environments and possible effects on their future.

#14 “I’m very scared of what side effects you can have.”

Several of the women also expressed concern that they would have little control of the effects of a drug based trial.

The group generally held a negative attitude to drug based intervention feeling that this is not natural and several describing themselves as a person who doesn’t take pills.

Several of the group were very clear that they would require a significant amount of detailed information before they would even consider a drug based trial.

#12 “I would have to know a lot more about it. I would have to read about it and be sure.”

The group display a very clear and consistent difference in attitude when considering entering a drug trial as opposed to a diet and exercise based trial. Although the likely effectiveness of a diet and exercise based trial was questioned by a small number of the group, there is very little resistant to entering such a trial. This contrasts strongly with the reaction when describing a drug based trial, in this case the group seemed much more reluctant and tended to place many more requirements on the trial before they would agree to join a drug trial.