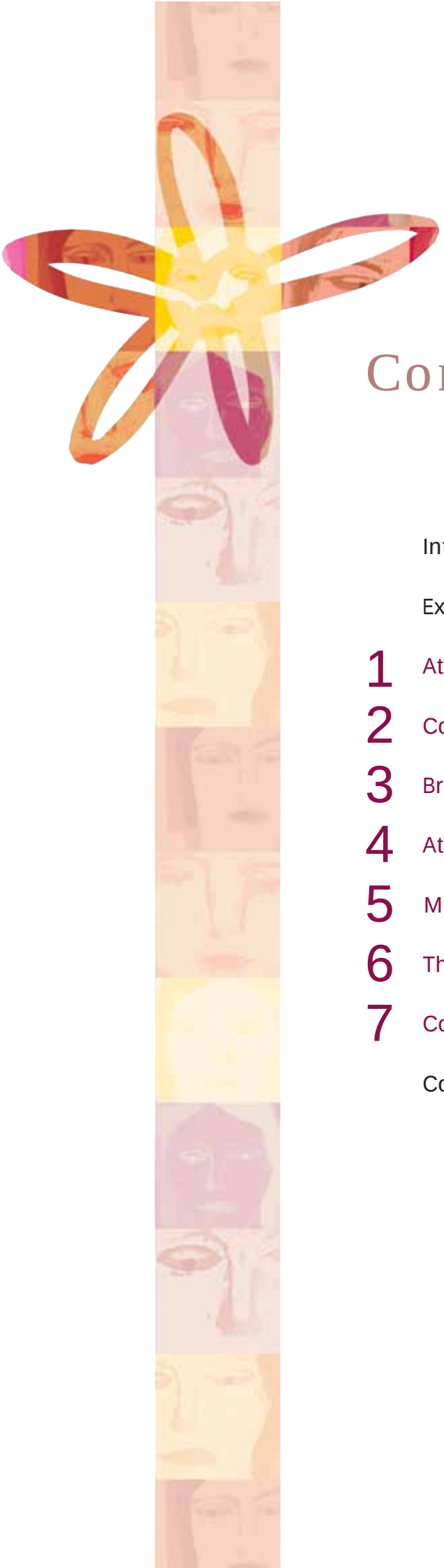

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Acknowledgements

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BreastCheck

BreastCheck, the National Breast Screening Programme, is a population based screening programme that aims to reduce mortality from breast cancer.
The programme offers a free breast x-ray (a mammogram) to women aged 50-64 every two years. The x-ray can detect early cancer which is highly treatable. The service is currently available in the East and Midlands and is being extended nationwide.

Public Communications Centre

Introduction

Background

In early 2004, BreastCheck (the National Breast Screening Programme) commissioned Public Communications Centre and Lansdowne Market Research to implement a research programme which would provide them with a better understanding of the women in BreastCheck's target age group and of their relationship with BreastCheck.

There were a number of information needs which prompted the decision to carry out the research. These could be broken down into a number of categories:

1. Information and communications:

- How successful has BreastCheck been at telling women about itself?
- Were women aware of BreastCheck?
- Did they understand what BreastCheck did?
- How did they hear about BreastCheck?
- Had they seen/heard the advertising and other communications?
- What did they think of the communications?

2. Attitudes & experience:

- What did women who had used the service think of it?
- What did they think of the follow-up?
- What did they think could be improved?

3. Motivations:

- What prompted women to attend or not attend?
- What were the barriers to attending?
- Who or what could persuade women to attend?
- What were their general attitudes to health, and to cancer in particular?

Given the range of information needs, a combination of both quantitative and qualitative research was used. This allowed us to gather statistically significant data on BreastCheck which could be used as a benchmark for future research and also to probe deeper and gain a better insight into women's relationships with BreastCheck.

Methodology

The research was carried out in two phases. Phase one was a nationally representative survey of 400 women aged 50–64, conducted by Lansdowne Market Research. The interviews were carried out in respondent's homes between the 19th and 30th April 2004. A quota sample was used to control for age, social class and geographic location.

Phase two involved qualitative research conducted by Public Communications Centre. Eight focus groups were conducted with women aged 50–64. The breakdown of the groups was as follows:

	Location	Social Group	Screened or not
1.	Blackrock	ABC1	Screened
2.	Finglas	C2DE	Screened
3.	Portmarnock	ABC1	Screened
4.	Dublin Inner City	C2DE	Non-screened
5.	Tullamore	BC1F	Screened
6.	Dundalk	C2DE	Non-screened
7.	Kilkenny	BC1C2	Non-screened
8.	Galway	C1C2D	Non-screened

Each group contained approximately 8 members. The groups were convened in July 2004.

Executive Summary

Key Indicators

Awareness of BreastCheck is very high amongst its target audience of women aged 50-64 and is almost universal in areas in which the service is available.

Nationally, 84% of women aged 50-64 have heard of BreastCheck, rising to 98% in Leinster and 100% in Dublin.

97% were aware that BreastCheck screened women for cancer.

The vast majority of women are very positive towards the service and those who have experienced it, rate it highly.

- 97% of those screened agree or strongly agree that the service is very professional
- 95% agree or strongly agree that the staff were very friendly
- 96% agree or strongly agree that they felt looked after
- 98% agree or strongly agree that the service was convenient
- 96% that it was efficient
- 90% of those screened said that they would be very likely to attend again.

Overall, women aged 50-64 believe that the service is vital and its rapid roll out is key.

Health

The respondents in the group discussions can be classified into a number of segments based on their attitude to health:

- complacent acceptors who have had a successful history of health and had to trust the medical profession
- fear avoiders who avoid health issues until they actually occur
- dismissive rejectors who believe that there is no way of knowing when ill-health might occur, so why worry about it now
- fatalists who have a fatalistic obsession with ill-health.

In general, the closer the experience of ill-health is to home, the great the awareness of and concern for personal health.

The research identifies two over-riding, top-of-mind health concerns: cancer and heart health. These are seen as the main causes of mortality in today's society.

Health checks tend to be ad-hoc rather than routine, and reactive rather than pro-active. There is some confusion about certain tests – such as cholesterol and the smear test – which tends to deter uptake.

There was spontaneous recall of mammograms in seven of the eight groups.

While almost all women had a family doctor, visits were typically infrequent and cost was cited as a deterrence. There is a high level of credibility in a doctor's advice.

Cancer & Heart Health

Cancer is a top-of-mind health concern. It is regarded as being more prevalent in recent times and a minority of the women exhibited a strong fear of the topic.

Breast cancer was the most commonly cited cancer that specifically affects women. Many women believe that it is hereditary.

Heart health is not as pressing an issue and appears to be a less emotive topic.

BreastCheck

There was a high level of awareness of BreastCheck in the national survey and spontaneous recall in all but one of the group discussions. In the areas where the service is offered, awareness of BreastCheck is close to universal.

The name is positively regarded, self-explanatory, relevant and credible.

The primary sources of awareness of BreastCheck are the media, GPs, word of mouth and in some cases, women first heard of BreastCheck on receiving their consent letter.

97% of the women in the national survey knew that BreastCheck screened women for cancer. However, large numbers also believed that BreastCheck campaigned for a better cancer service and ran the Pink Ribbon campaign – neither of which it does.

The age band for screening was a contentious issue. It is regarded as being too narrow. The greatest concern is with the upper age limit of 64.

95% of those surveyed in the national survey would like BreastCheck to be more available. Only 48% believed that it is reasonable to have a gradual roll-out rather than the immediate introduction across the country.

Attendance

Nationally, 31% of the women claim to have attended BreastCheck for screening. This rises to 67% of those living in Dublin.

The main reasons cited for non-attendance were ineligibility. Of the other reasons for non-attendance having had a recent mammogram elsewhere was the most common reason (15%). Smaller number of women cited fear (5%), inconvenience (2%) and lack of confidence in the service (3%).

The GP is regarded as the most likely encouragement to attend for screening, followed by more information about the procedure and encouragement from family and friends.

Fear of attending involves fear of the end result, fear of the mammogram and fear of coping, fear of dying and fear of mis-diagnosis.

Those who attend view the screening as a precautionary measure and have an optimism that cancer will not be detected. Having had a previous mammogram or having experience of breast cancer among family or friends have a positive influence on the decision to attend.

From the group discussions, attendees tend to be

- younger
- better educated
- have an active social life
- either have had experience of ill-health or are very healthy

Whereas, non-attendees tend to be

- older
- less well educated
- a less active social life
- have less experience of ill-health or a very strong negative experience of breast cancer.

Mammogram

There is a general understanding of what a mammogram involves. The top of mind association is that it is painful. While it would not deter those who had previously been screened it did act as a deterrence for those who had not attended in the past.

It is understood that a mammogram is used to detect cancer cells. It is assumed to detect all cancers and there is a preference to believe that it foolproof and has a 100% detection capability.

Few respondents physically examine their own breasts. Most were afraid of what they might find. There was some conflicting advice from GPs with some known to have told women to leave their breasts alone. There was a consensus amongst the women that they knew how to do a physical examination.

The Process

There is a general level of understanding of the need for BreastCheck to operate by appointment only. It is regarded as a necessary mechanism to cater for the numbers.

There was a high level of satisfaction with time keeping. 96% of those who attended said they were seen as promptly as possible. No-one in the group discussions complained about delays.

Those who attended commended the staff very highly. They also rated the experience as better than their most recent hospital visit.

BreastCheck is seen as delivering a high quality of service and the service is likened to that of a private clinic.

The radiographer is the main or only point of contact and plays a critical role in the delivery of the service and in the public image of BreastCheck. It is preferable that the radiographer is female.

The facilities are very positively regarded. 94% of those who attended rated them as pleasant and comfortable.

A repeat x-ray at the same appointment is neither expected nor appealing.

It is assumed that a repeat x-ray would be indicative of a problem in the breast rather than in the technology.

90% of those screened said they received their results within 3 weeks. 68% rate the follow-up process very good, and an additional 21% rate it as fairly good.

While the 3 week waiting time for results is almost acceptable, it is expected that one would hear earlier if there was a problem.

There is uncertainty as to who reads the x-ray – a team is preferred to one person – and uncertainty as to who sends out the results – BreastCheck or her GP.

There is a high level of awareness of the two year period between mammograms. There is uncertainty as to why the gap is two years.

There is a high expectation for repeat attendance. 97% said they would be very, or fairly likely, to attend again.

Communications

The women in the groups assumed that their name is taken from a database, but the exact source is unquestioned.

96% agreed that the letter of invitation was clear. It is seen as easy to read and understand.

There was limited recall of having received the appointment leaflet with the letter.

There is strong recall of advertising. 66% have seen or heard advertising for BreastCheck, rising to 87% in Dublin. There was spontaneous recall of the advertising in all the group discussions.

43% recalled the outdoor poster and 91% rated it as good or very good.

There is a strong empathy with the three women in the poster/leaflets. They are seen to humanise the service.

48% recalled the radio advertisement and 94% rated it as good or very good. It was primarily associated with local radio and there was strong recall and appeal for Marian Finucane. It is seen to play an informative role and is encouraging and reassuring.

There was low awareness of the helpline and only 4% claim to have called it.

Only 2% have ever visited the website. However there was limited usage of the Internet by the women in group discussions.

Although only 1 in 4 are aware of the women's charter, it is rated highly. 34% rated it as excellent, while 79% rated it above average.

The over-riding personality of BreastCheck is that of a *caring service*. It is associated with strong positive imagery which augers well for future.

1. Attitudes & Behaviour Towards Health

1.1. Range Of Responses Towards Health

Group Discussions

The qualitative research identifies a range of responses towards health – varying from mild to strong. This range can be segmented to produce the following categories of response:

- complacent acceptors:

• respondents who have had a successful history of health thus far – not suffering from ill-health at all or having recovered from an episode or episodes of ill-health; they tend to trust the medical profession and to lean on it for support and guidance; they demonstrate a complacent acceptance of coping with ill-health – currently or in the future.

- fear avoiders:

• avoidance of matters relating to health and of facing the prospect of developing ill health in the future; why worry about it until it happens, worrying about ill-health can become a problem in itself, no point in living in fear

- dismissive rejecters:

• recent epidemics of illness and/or death in the community defies theories on age related illness – even the young can be inflicted; there is no way of knowing if and when ill health might befall one; it may never happen so why give it time or thought; live one's life to the full and face the problem if and when it happens

- fatalists:

• fearful and/or fatalistic obsession with ill health; there are so many effects upon ill-health – even chemicals in detergents, etc.; it is out of our control and we have no hope

- scare mongerers:

• those who espouse the most negative of responses; who claim to base their knowledge on 'fact' and exude a responsibility to convey it publicly.

The group discussions mainly comprised of complacent rejecters and fear avoiders, followed by dismissive rejecters and fatalists. There were no scare mongerers in the groups.

This segmentation is reflective of a number of issues – as follows:

- experience of ill-health
- age related factors
- type of health issue – especially if it life-threatening
- personality – and coping mechanisms

1.2. Experience Of Ill-Health

Group Discussions

The closer the experience of ill-health is to home, the greater one's awareness of and concern for personal health.

Thus, those who demonstrate the greatest affinity to one's health are those who have been personally touched by ill-health themselves – either a scare or an actual illness. The next level of experience is having a health problem within one's own family – be it one's husband, child, parent or sibling. Following on from this, are those who have experienced ill-health outside the family – be it with a significant other such as a best friend or a known person in the neighbourhood.

1.3. Age Inspired Concern For Health

Group Discussions

Age also serves a role – whereby, the older one is, the more opportunities one may have encountered to have experienced ill-health – thus, more prompts to think about one's own mortality and more occasions to suffer from age-related health issues:

"when you reach a certain age, you have more time to think" (Screened: S)

"you are not as fit… your energy levels are lower" (S).

1.4. Two Main Health Concerns

Group Discussions

The research identifies two over-riding health concerns – cancer and heart health. These two are top-of-mind when discussing the topic of health or more specifically concerns about ill-health. They are regarded as the main causes of mortality in today's society – for both males and females alike.

The strength of the concern for these two issues among respondents relates to their occurrence in family history – they represent the main killers and/or life threatening illnesses experienced by respondents and/or their family members to date. They are both regarded as hereditary and are seen to have a salient impact upon one's prospects for a healthy life.

While the two concerns are top-of-mind, there is a tendency to treat them with deference rather than obsession. They are seriously feared as dreaded contenders for ill-health but there appears to be little action or thought around their avoidance.

1.5. Other Health Issues

Group Discussions

There are a range of other health issues which concern respondents – only if they are of personal significance to them. In the eight group discussions, a broad spectrum of health issues arose:

- those which are currently being managed by respondents:

- angina, asthma, bowel cancer, blood pressure, breast lumps, candida, cholesterol, diabetes, emphysema, multiple sclerosis, menopause, osteoporosis, polyps on legs, rheumatoid arthritis, sciatica

- those which have been experienced by respondents in the past:

- angiogram, broken bones and ribs, debilitating virus, hysterectomy.

Respondents tended to speak about their illnesses matter-of-factly – without looking for undue attention or sympathy. In fact, a couple of respondents did not share their illnesses with the groups and privately disclosed their fate to the interviewer/ researcher. Thus, were there more occurrences of ill-health than mentioned?

Respondents tend to manage their lifestyle around their health issue – with the main effect being tablet-taking. There has been some influence on diet and exercise – depending upon the nature of the illness. Any changes seem to have been accepted as par for the course.

1.6. Health Checks

Group Discussions

The seeking out of health checks tends to be ad-hoc rather than routine – unless the woman is suffering from an illness which necessitates frequent/routine visits to a medical professional.

Respondents tend to be reactive rather than proactive in availing of health check-ups. They claim to defer their intention to have a health check-up rather than dismiss it as being useful to them – they sweep it under the carpet rather than confront it because to date they have not been driven to consider their health more seriously:

"I don't really think of myself too much" (S)

"I just get on with it" (S).

Deference is also a function of a busy lifestyle and not being prepared to give time to one's health.

It is known that a variety of health checks are pertinent to women – and that they are available in GP surgeries as well as mobile units – although there appears to be limited uptake of the latter. The availing of these check-ups tends to be driven by convenience – whereby, typically it would be included as part of a routine check-up with one's GP.

There is some confusion and ignorance about certain tests – which in turn serves to deter uptake of them – notably:

- the preparation required – for example:
- fasting for a cholesterol test
- no smear test required if one has had a hysterectomy or is aged over 60 years

- and the negative press around the reliability of the tests
- inaccurate reading of cholesterol tests in the mobile unit
- inconclusive reading of smear tests.

The most common tests taken are for cholesterol, blood pressure and smear testing. Other tests are rarely taken: blood sugar/glucose test, calcium, bone density, diabetes, glaucoma, colostomy, etc. – unless symptoms present themselves.

There was some spontaneous mention of mammogram in seven of the eight groups – all but the inner city group. The attendance for such has been driven by both symptomatic (e.g. breast lumps) and non-symptomatic (e.g. BreastCheck) reasons.

1.7. Visiting Of Doctor

Group Discussions

Almost all respondents have a family doctor – regardless of how often they might visit him/her. Those who do not have such claim never to be sick and not to have had occasion to need one.

The incidence of attending doctors is typically infrequent – unless one is suffering from a long-term illness which involves regular check-ups, repeat prescriptions and such like:

"you only go the doctor when you have to" (Non-screened: N)

"only when you are sick" (N).

The visiting of doctors is deterred by cost and also by the service offered (see 1.8. 'Sources Of Knowledge On Health').

There is a high level of credibility in a doctor's advice. Rarely is a diagnosis or recommendation questioned or a second opinion sought – although it was clear from the group discussions that different doctors give different advice on the same topic. There is a sense of security required from dedicating time and money to the

seeking out of a professional's advice – the idea of one's own GP being unreliable is not easily entertained. It is a matter of convenience and peace of mind to have faith in one's own chosen medical professional.

1.8. Sources Of Knowledge On Health

Group Discussions

The pursuit of knowledge on health tends to be a casual interest rather than an avid pursuit. Respondents react to information and give it attention once it is presented to them in a convenient fashion.

The most common sources of knowledge on heath are fourfold:

- professional – GP, pharmacist, physiotherapist, chiropractor, acupuncturist, reflexologist…
- media – magazines, news articles on television and radio…
- in-store – reading packs on shelf, browsing in health shops…
- word-of-mouth – family and friends.

Respondents tend to avoid seeking out professional help – because of cost and service.

There is a consensus that the cost of attending a medical professional is prohibitive – expensive consultation fees, prescription costs, additional and/or follow-up tests:

"you can't afford to get sick"(S).

In terms of service, there is a fear that the professional may not take the patient seriously or that he/she may initiate a series of tests which may warrant additional cost, time and worry:

"doctors don't give you time" (S)

"they only answer what you ask" (S)

"you need to have your questions written down" (N)

"they take phone calls and all when you are there" (N).

Thus, one typically seeks professional help in a selective manner:

"only when a problem arises" (S)

"you'd want to be dying first" (N)

"you'd want to be mad" (S).

1.9. A Healthy Lifestyle

Group Discussions

There was little mention of lifestyle patterns and habits being unhealthy. There seems to be a high level of satisfaction with the quality of life that one leads – its diet, exercise and general way of life.

Few have altered their diet to promote health. Any alterations have been reactive rather than proactive – whereby an illness has prompted a dietary change – e.g. diabetes, cholesterol. Any changes tend to be manageable – roughage for breakfast, less caffeine, less alcohol, more food supplements. Respondents claim to be confident in knowing what constitutes a good diet – and tend to be suspicious of

"going on diets"

"what was good for you is now bad for you" (S).

Exercise tends to be driven by social as well as health benefits. The most popular forms of exercise are walking, golf, and swimming. Physical ailments and injuries can deter exercise – especially broken/injured bones.

Any other hobbies tend to be mentally stimulating rather than physically challenging – reading, painting, crafts, travelling, cards, socialising. Thus, respondents tend to be socially active and open to pursuing interests outside of the home. This may be a reflection of the research method used in that group discussions tend to attract participants who are drawn to the sociable element of the event.

2. Concern For Cancer

2.1. Top-Of-Mind

Group Discussions

Cancer is a top of mind health concern:

> *"it's the first thing that comes into your mind" (N)*
>
> *"it's a big worry… every second person has it… you always hope you won't get it"(S).*

The concern for cancer has been prompted by a multiplicity of experiences over time. It is regarded as becoming more prevalent in recent times – it is so common, it is no longer an avoided word.

It is interesting to note that one group in particular demonstrated a strong fear of the topic and demonstrated difficulty in discussing it – i.e. the inner city group of non-screened, some of whom had refused a mammogram in the past. Strong negative feelings were expressed by these women. They explained they were *"afraid to mention it", "nobody likes to think of it"* – because suffering from cancer is *"a horrible way to be", "it is an awful state".*

The other seven groups were less threatened by the topic. They explained they try not to dwell on it and were more inclined to constructively assess the issue for the research.

2.2. A Silent Illness

Group Discussions

Cancer is regarded as an indiscriminate illness. It targets all ages and could happen to anyone. It is viewed as a silent illness – being difficult for one to determine whether one has it or will have it in the future.

It is not always a fatal illness "but you always think it is fatal" (S) – there are success stories and early detection is regarded as a necessity.

2.3. Multi-faceted

Group Discussions

Cancer is multi-faceted – it is known that there are many types of cancer and that it can affect many parts of the body.

2.4. Female Variants

Group Discussions

There are cancers that are particularly associated with the female body: breast, cervical, ovarian and womb.

2.5. Breast Cancer

Group Discussions

Breast cancer was the most commonly cited cancer that afflicts females. Yet, there was a general level of uncertainty about its cause and prevention:

"I have no idea" (N).

The most popular claim is that breast cancer is hereditary – it is the *"genes" (S,N)* – i.e. women with a family history of breast cancer are more susceptible to it than those who do not have such a legacy.

It is thought that other causes might include the following:

- stress – an excessively stressful lifestyle
- diet – *"what we eat" (S,N)*
- born with it – *"we are all born with a certain amount of cancer" (N)*
- motherhood – a woman's chances of getting breast cancer are understood to be reduced by having children and by breast-feeding
- smoking
- chemicals – e.g. chlorines in water, pesticides, in detergents, etc.

The research clearly indicates an educational role for BreastCheck to guide and direct women on the causes and prevention of breast cancer – especially in terms of diet and lifestyle.

2.6. Heart As A Health Concern

Group Discussions

Heart health is not as pressing an issue as cancer among respondents. While it is a top-of-mind source of concern for women, it appears to be less emotive a topic.

There is less claimed experience of heart problems among respondents.

It is viewed as an age-old killer which can affect the body in a variety of ways – aneurisms, blood pressure, emphysema, angina, strokes, palpitations.

It has no particular female association – inflicting men and women alike.

3. BreastCheck

3.1. The Name 'BreastCheck

National Survey

There was a high level of awareness of 'BreastCheck' in the national survey, and near universal awareness in areas in which screening has taken place.

- 84% claimed to have heard of it
- reaching 100% in 'Dublin', 98% in the 'Rest of Leinster including Dublin' and 70% in the 'Rest of Ireland'
- the results did not vary by age or by social class.

TABLE 1

Organisations Heard Of	Overall	Dublin	Rest of Leinster	Rest of Ireland
BreastCheck	84	100	98	70
Irish Blood Transfusion Service	96	95	96	96
Nat Treatment Purchase Fund	31	31	27	38

Group Discussions

There was spontaneous awareness of 'BreastCheck' in all of the group discussions except in Galway – where there was poor familiarity with the name and the screening programme.

The name 'BreastCheck' is more familiar to the screened than the non-screened – although there were some of the latter who claimed not to have heard of the name.

The most common sentiment among the non-screened is

"I know very little about it" (N).

The name is positively regarded. It is self-explanatory, relevant and credible in terms of what the service offers. It is distinctive and memorable – although there were screened respondents who did not recall the name.

There is no confusion in using the name – it was recited without error throughout the group discussions.

It is appealing because it is short and to the point – being more favourable as a name than 'The National Breast Screening Programme'.

3.2. Sources Of Awareness

Group Discussions

The media plays a critical role in informing on BreastCheck. There was recall of advertising in the form of radio, television and posters as well as news articles in press, radio and television.

Some of the screened respondents first heard of BreastCheck on receiving their consent letter. They would have had no prior knowledge of the service until then.

Others learned about it from their GP – when discussing a symptomatic problem.

Finally, word of mouth is a source of awareness and, more especially, a source of knowledge – whereby family and friends have discussed it among each other:

"everyone was talking about it" (N).

3.3. BreastCheck Associations

National Survey

In the national survey, the following associations were recorded:

- 97% agreed that BreastCheck screens women for cancer
- 95% agreed that BreastCheck provides information about breast cancer
- 91% agreed incorrectly that BreastCheck campaigns for a better cancer service
- while a lower figure of 69% agreed incorrectly that BreastCheck runs the Pink Ribbon campaign
- these associations were stronger in 'Dublin', followed by 'Rest of Leinster including Dublin', followed by 'Rest of Ireland'
- there were no age or social class differences.

Groups Discussions

In the group discussions, those who have been screened have more accurate knowledge on the service – although not in every case or about every association. The non-screened consistently demonstrated the weakest knowledge about BreastCheck.

The top-of-mind association with BreastCheck is that it is a government service that offers a free mammogram to women aged 50 to 60 plus.

It is generally well known that the service is offered bi-annually, that it has been around a long time (up to ten years); it is based in Dublin and operates from static as well as mobile units. There was much recall of Marian Finucane as an endorsee through advertising.

It is not as commonly known that the service is not nationally available, that there is a planned roll-out, and that it is run by the Department of Health.

There is some confusion with the Marie Keating Foundation. Some respondents wonder, while others are certain (incorrectly), that Ronan Keating's late mother is associated with BreastCheck – that she *"started this up"* (N) and runs the mobile clinic.

3.4. BreastCheck Service

Group Discussions

There is no confusion that BreastCheck offers a mammogram service only – that it is a screening service and not a treatment service. It specialises in the detection of breast cancer and refers any follow-up treatment to a hospital.

BreastCheck is known to be a clinic rather than a hospital service. It is likened to a private medical service whereby the clientele are treated in a special way.

3.5. Department Of Health

National Survey

There is general agreement that it is better for BreastCheck to continue to be offered as a stand-alone service, separate to health board services – 44% say it is 'a lot better' while an additional 21% say it is 'a little better' for this to remain so.

Group Discussions

It is assumed that BreastCheck has an association with the Department of Health. In addition, there was some expectation for the Eastern Health Board to be involved too.

There is a strong preference for the branding of the service to focus on BreastCheck and not on the Department Of Health. The former sounds more "personal" and the latter is more "anonymous".

3.6. Free Service

Group Discussions

The fact that the mammogram is a free service is critical. It is important because it implies that the Government cares about women:

> *"it is nice for the government to be thinking of us" (S).*

It is also seen to as a right for women – rather than a gift. Having paid taxes

> *"all of one's life, it is nice to get something at the end of the day" (S).*

The actual cost saving is regarded as substantial – it is known that a private mammogram can cost €100 or more. The price is also compared to attending a GP should you have symptomatic reason to seek medical advice:

> *"you wouldn't go to the doctor and pay €40 and say 'I think I need a mammogram'" (S).*

Thus, it is hoped by respondents that the free mammogram service will act as a preventative measure which is ultimately more cost effective for the Government than care.

3.7. Mobile Unit

Group Discussions

A mobile unit is a familiar concept in the medical service. It is generally acceptable that a mobile unit would be a relevant venue for a mammogram.

In comparison to a static unit in a hospital, the benefits of a mobile unit are deemed to be as follows:

- it offers the service in a more convenient location to a person's home – especially if it is located in a supermarket car park
- it is usually accompanied by easier parking facilities
- it inspires a sense of community in that it is in one's locality for the benefit of those who live there: a woman's service for local women – whereby one meets familiar faces in the same situation as oneself
- it can be more personal and friendly – although not necessarily more private
- it can be less clinical than a hospital – and, thus, less threatening
- it may be more efficient – with shorter waiting times
- it is practical in that it gets the job done
- it takes the pressure off hospitals.

The negative expectations for the mobile unit are:

- the service is on public view – labelling all who enter it as being over 50!
- the venue is small with less comfortable surroundings than a hospital facility
- one's privacy is not as assured – in light of one's conversations being overheard
- it can become busy and crowded.

3.8. Target Age Group

Group Discussions

The age band for service is a contentious issue. It is regarded as being too narrow and there is no obvious explanation to satisfy the concerns around it.

The greatest concern is for the upper age limit. It is seen to imply that those aged over 64 are not worthy of care – that they are "over the hill" (N). It is questionable as to how the upper age limit is set. Are older women less susceptible to breast cancer or is it that their medical card or old age pension entitles them to a free alternative in the hospital service? Respondents were looking for answers.

The lower age limit is also questioned. Again, it was asked do younger women have a lower chance of developing breast cancer. Although it is known that younger women are susceptible to such. It was recommended that younger women with a family history of breast cancer should be entitled to a free mammogram.

3.9. Roll-Out

National Survey

95% of the national sample would like BreastCheck to be more widely available.

53% are aware of the plan for a gradual roll-out of the service across the country.

Only one in two (48%) think that the gradual roll out, rather than an immediate introduction, is reasonable.

The reasons for thinking it is not reasonable are:

- it is urgently needed everywhere (56%)
- it favours some parts of the country (28%)
- some may never get it (23%)
- it takes too long (19%)
- it discriminates against some people (16%)
- it's not fair (15%).

Group Discussions

The staged roll-out of the programme is generally unknown. In fact, some were of the opinion that it had already happened. Those in the Dublin groups appear to be less sensitive to the roll-out in that they are secure in the knowledge that they are being included in the programme.

There is ignorance around the reason for a concentration of the service in Leinster to date. Is it due to finance or resources? Is there a higher incidence of cancer in the east? Is it for political reasons? Or is the east a pilot area?

Rather than feeling lucky, the sentiment of those screened was that the concentration is a *"disgrace" (S)*. However, they selfishly expressed a fear that a roll-out might affect their bi-annual entitlement to a free mammogram.

3.10. Smear Testing

Group Discussions

In discussing the BreastCheck service, comparisons were made with smear testing services. Both services are dedicated to women, are cancer related, are available in a mobile unit and can be embarrassing for a woman to have done.

But serious concerns were expressed about smear testing:

- **there has been negative press about the reliability of the test:**
  "usually told the result is atypical and you have to get it redone" (N)
  "it takes months… you would be dead before you get a result" (N)

- **there is conflicting doctor's advice about when and how often a woman should have a smear test:**
  "not when you are over 60" (N)
  "not after a hysterectomy" (S).

This confusion could have a possible negative reflection on the BreastCheck screening programme – in light of the perceived similarities in relation to the delivery of the service.

These comments are related to opportunistic smear testing and not to the pilot Irish Cervical Screening Programme in the mid-West.

4. Attendance

4.1. Invitation To Attend

National Survey

Less than one in three (30%) of the national sample claimed to have ever been invited by BreastCheck for a check-up. While 31% claimed to have attended.

The figures are higher for the middle age band i.e. 55-60 years:

- 41% claimed to have been invited and to have attended.

The figures are also higher for those living in the catchment areas:

- 67% of those living in 'Dublin' claimed to have received an invitation and 65% attended
- while 55% living in the 'Rest of Leinster including Dublin' said they were invited while 53% attended.

TABLE 2

Why Never Had a Check Up with BreastCheck

Not invited for Check-up	55
Not available in my area	37
Had recent mammogram elsewhere	15
Afraid it will be unpleasant/painful	5
No way of getting to an appointment	2
Inconvenient time	2
Breast screening not reliable	2
Breast screening not safe	1

4.2. Reasons For Non-Attendance

National Survey

The main reasons for not attending a BreastCheck check-up relate to ineligibility:

- 55% of those who never had a check-up said they were not invited
- 37% said it was not available in their area.
- 15% claimed to have had a recent mammogram elsewhere – especially those in the higher social class group – i.e. 22% of those belonging to the 'ABC1F50+' group.

All other stated reasons indicate a reluctance to attend based on:

- fear – 5% were afraid it would be unpleasant/painful
- inconvenience – no way of getting to an appointment (2%) and inconvenient time (2%)
- lack of confidence in the service – 'breast screening is not reliable (2%) and breast screening is not safe (1%).

Projecting to the future, those who had never attended a check-up were asked what might encourage them to have a check-up with BreastCheck. They were prompted with a list of possible encouragements:

- the main encouragement is advice and information:

- 56% said if they were encouraged by their GP
- 53% said more information about breast screening
- 53% asked for clear information about the procedure
- 43% said encouragement from friends and relatives
- and at a much lower level, 34% said encouragement from local community groups

- convenience is another issue:

- 56% want the service to be located near to their home
- 40% would like an evening/weekend appointment
- note that of those who did attend for a check-up, 98% said it was convenient for them

- media exposure is also important

- 46% would be encouraged by seeing/hearing advertisements
- 45% by media coverage per se

- finally, one in two (53%) of those who had never attended a BreastCheck screening said they would simply be encouraged if they were invited. At a later stage in the survey, 94% of the total sample agreed they would go if they were invited – 75% 'strongly agreed'.

Group Discussions

The responses to non-attendance in the group discussions were spontaneous – and while they mirrored the issues mentioned in the national survey, they add valuable depth and meaning to their significance.

The stated reasons for non-attendance focus on the woman herself – rather than on BreastCheck: *"it was my decision" (N).*

(a) Self-related reasons

The primary reason is fear – an overpowering, emotional fear of what is involved:

"I am so scared; I do not want to go there" (N).

- The fear is multi-faceted:

- of the process involved – it is a process which is initiated by the invitation and is not over until the result of the mammogram is received: *"I cannot handle the wait" (N)*
- of the mammogram itself – expecting it to be a painful experience and/or embarrassing – and/or the understanding that it is not fool-proof: *"there is no guarantee that the cancer will not show up three months later"* (N)
- the medical profession – fear of doctors and anything medical – inherent in this is the fear the screening be a stepping stone to a series or subsequent tests.

The fear results in deference. Women are prepared to wait for a symptomatic reason to have a mammogram done: *"never trouble trouble until trouble troubles you" (N).*

There is a sense that this deference is typical of Irish women – who *"put their own health on the back burner" (N).*

Another reason for non-attendance is the nature of one's experience of cancer. This can range from one extreme to the other. On one hand, a woman may have never been touched by someone with cancer and is, therefore, not driven to have her self checked.

On the other hand, she may have had a very strong negative experience of someone suffering from, or having died from, the disease and from breast cancer in particular: *"she was dying for eleven years", "she left nine children", "I only know of one woman who survived" (N).* Such experience seems to have added to the fear of cancer and to the attitude of deference in dealing with it.

Ignorance plays a critical role. Not knowing and/or having mis-information about breast cancer, and mammogram screening, also prohibits attendance. It was obvious from the group discussions, that the sharing of accurate and positive information shifted the opinions of some of those who had declined an invitation from BreastCheck. Such was the shift that they claimed they would seriously consider attending a future screening. There were others who demonstrated a stubbornness of mind and would not enter any negotiation about attending.

Being *"too busy to go"* or *"otherwise engaged"* was mentioned by some – but this appears to be a lame excuse as they did not rearrange to go.

Feeling that time is on their side is another reason. Being at the younger end of the target age band, it was acceptable to some to wait until a later time to have a mammogram done. In particular, there were incidences of women in the target age group not receiving an invitation from BreastCheck – and willing to accept that it was intentional on the part of the service because the older age groups were being dealt with first.

(b) BreastCheck-related reasons

The role of BreastCheck in affecting non-attendance is at a practical level.

Non-attendees attributed responsibility onto BreastCheck as follows:

- they had not received a consent letter from the service – and, thus, no contact had been initiated with them
- they received a consent letter and were still awaiting an invitation having done exactly what BreastCheck requested: wait to hear – some said they were waiting two years later.

The ease of non-attendance accommodates those who do not wish to go. There is *"no push to go"* or *"hassle"* from BreastCheck: *"I didn't feel pressure to go"(N).*

4.3. Non-Attendance – Contact With BreastCheck

Group Discussions

It is expected by both the screened and non-screened that approximately 25% of invited women do not attend for their mammogram. It is assumed that not all of this 25% would contact BreastCheck to cancel an appointment. This was the case in our groups – not all of those who had declined to attend had contacted BreastCheck. And some of those who had contacted BreastCheck to decline their first appointment, did not make any further contact with the service thereafter – i.e. in response to any subsequent invitations.

It would seem from those that did contact BreastCheck that writing a letter is the most popular means of communicating a refusal. Those who used this method explained that they were directed by BreastCheck to do so in their letter of invitation. The researcher wondered is letter writing used as a means of avoiding personal contact with BreastCheck – whereby the use of the phone would mean talking to a BreastCheck staff member who might not understand the woman's reluctance to attend and might encourage her to change her mind.

The phone is more likely to be used to rearrange an appointment – being regarded as a convenient and hassle-free means of contacting BreastCheck. Such women are more confident about attending for a screening and do not avoid the personal contact with service. It also allows the woman and BreastCheck to discuss a time that suits both parties.

4.4. Reasons For Attendance

Group Discussions

The reasons for attending a BreastCheck screening are self-driven – primarily reflecting the personality and will of the woman rather than any other influence.

Attendees are almost self-righteous about their attendance: *"it is the sensible thing to do"; "anyone who turns their nose down at it needs their head examined" (S).* These women know that *"it has to be done" (S)* – ultimately for their own benefit.

The attendees view the screening as a precautionary measure. They are inspired by the fact that the screening is a routine examination rather than it being symptomatically driven: *"you are less worried as it is an invitation", "you are going of your own free will", "you'd be more worried if the doctor sent you" (S).*

There is optimism that cancer will not be detected – although, it is understood that it is a possibility, the attendees demonstrated less pessimism than the non-attendees.

The attendees tend to have confidence in the service – in that early detection works: *"if you get it in time, you have a better chance" (S).* There is little awareness of a mammogram not detecting all cancers.

Having had a previous mammogram assists the decision to attend. Some attendees have had multiple mammograms – either through BreastCheck or for symptomatic reasons. The experience did not deter attendance.

Having experience of breast cancer in the family or among one's friends encourages attendance – especially, if that experience is viewed constructively: *"all the more reason to go" (N).*

The fact that the mammogram is free is an incentive – in light of the knowledge that it could cost around €100 or more to have one done privately. For this reason alone, one woman waited to receive a BreastCheck appointment although she had been recommended to have a mammogram done earlier. (This is contrary to BreastCheck advice.)

The convenience of location is important. The easier it is for the woman to attend, the more attractive the prospect. The mobile unit delivers this convenience.

Being forewarned about the invitation also helps. Knowing that one is in the relevant target age group and that the service is in one's area prepares the woman for receiving an invitation – whereby she is mentally prepared to manage the process. This is a timing issue whereby the woman gathers knowledge and confidence about attending. Some women are quick to respond while others need time to eventually come around to the idea. In some cases, this may result in declining the first invitation but accepting the second: *"the first one I didn't go to" (S).*

Time renders acceptance. Previous mammogram recipients are much more aware of the process and more confident about it. Thus, there is a feeling that the longer the service exists and the more exposed women are to what it is about, the greater the likelihood of attendance: *"we are not into the habit of it " (S).*

Almost all of the respondents who had attended did so for themselves. Some were even driven to self-register to ensure that they did not miss out. But there were a few who had to be encouraged to attend: *"I went with a lot of coaxing… a gun put to my head… I didn't want to go at all… then I was told of others who had died… my daughter came up with me the first time" (S).*

4.5. Typical Profiles of Attendees & Non-Attendees

Group Discussions

In order to understand the different attitudes and behaviour of attendees (i.e. those who attended a screening) and of non-attendees (those who declined an invitation to do so), it is interesting to isolate the features that are common to each group. These features are those which arose in the group discussions and represent a generalisation rather than actual fact. They indicate a trend and demonstrate some influences upon their response to BreastCheck.

The attendees tend to be:

- younger in age
- being more liberal in their views

- better educated
- more likely to be lateral thinkers – to weigh up the pros and cons of having a mammogram

- have had experience of ill-health or are very healthy
- each of which impacts upon their acceptance of availing of a routine health procedure

- have an active social life
- which brings with it a source of learning on a mammogram and BreastCheck.

The non-attendees tend to be:

- older in age
- with a more conservative outlook

- less well educated
- demonstrating a more narrow-minded outlook on the topic of cancer and the issue of a mammogram

- have less experience of ill-health or a very strong negative experience of breast cancer
- each of which curtails their openness to personally pursuing a medical procedure

- have a less active social life
- with limited opportunities to expand their knowledge on matters relating to BreastCheck.

4.6. The Fear Factor

Group Discussions

The fear factor is held by all – by attendees and non-attendees, by the screened and non-screened. While it is a manageable for some, it is too strong for others.

The fear is multi-faceted – having occasion to arise at any stage of the process.

There is the ultimate fear of the end-result – of finding out whether one has cancer or not. It is recognised that by accepting a BreastCheck invitation, there will be a time period before one receives the answer to this – and, for some people, the wait is too difficult to handle:

"you do no good until you get the result" (S)

"until it is all over and then a weight is lifted off your mind" (S)

"fear of the unknown" (N)

"afraid of finding a lump" (N).

There is also the fear of the mammogram. There is a strong suspicion that it is a painful experience. In particular, this suspicion is being fed by word-of-mouth among those who have attended. This is off-putting for those who are considering whether to attend or not. But it is not as great a fear as the fear of the end-result.

There is the fear of coping. Some people question their ability to cope with a diagnosis of cancer, with the treatment involved, with the deterioration of one's health, with living in hospitals, with affecting one's family and loved ones, with coping with all of this for years:

"I'd rather get a gun and shoot myself" (N).

Then there is the fear of dying – and especially of leaving families and children behind:

"with cancer you die" (N).

For some people, there is the fear of mis-diagnosis. While there is little awareness of a mammogram not being able to detect all cancers, there are some who are aware of it:

"afraid it will find something and think there is something there and it mightn't be at all and a breast might be removed unnecessarily" (N)

"there is a lot diagnosed with cancer and a womb removed unnecessarily" (N)

"you are always worried about things when they come out first… things might be done wrong" (N).

These fears elicit different types of responses. Those who are more likely to manage their fear tend to:

- demonstrate a preference for knowing what lies ahead for them
- to have faith in a mammogram and its ability to provide early detection
- view the fear as a short-term pain for a long-term gain

"you need to brave" (N)

"you can't live your life contemplating something is wrong" (N)

"you wouldn't refuse to take an antibiotic if you had a cold" (N)

"the risk is too high to ignore" (S).

Those who are less able to manage the fear tend to:

- prefer not to know what lies ahead
- to have less self-confidence in their ability to handle the process from invitation to end-result
- to have low faith in early detection.

"terrified" (N)

"trembling thinking f it" (N)

"afraid of what I'd find out myself" (N).

4.7. Preparation For Attendance

Group Discussions

Typically, no preparation occurs. A few attendees discussed their appointment with another person – for example, their GP, husband, friend, children – but most attendees did not discuss it with anyone or to seek out information on what is involved. There may be a number of reasons for this.

The woman may feel adequately informed – which is possible from a number of sources:

- the BreastCheck advertising
- the BreastCheck documentation – the letters and leaflets received by the woman in the post
- word-of-mouth – there may be plenty of talk about it at the time by women in the locality.

It is also attributable to the emotional state of the woman as she awaits her appointment. She has accepted to go and has a fair understanding of what a mammogram involves. She may feel vulnerable and be reluctant to discuss it with anyone, or seek information on it, in case it prohibits her going ahead with it.

It is a personal and private matter and some attendees may not wish to share the fact that they were going with anyone else. Some respondents did not tell their husband or children.

Another reason for non-pursuit of information is that the woman may not know where to seek it. Some attendees explained that they knew of no-one else who had been for a BreastCheck mammogram and therefore felt they had no-one to ask.

There is a tendency to attend the appointment unaccompanied: “unless you are afraid you may get bad news” (S). Some attendees had been accompanied for this reason and some non-screened had accompanied others – for solace and support. It was suggested by some of those who had declined an appointment to be encouraged to seek out someone to accompany them in the future.

5. Mammogram

5.1. Understanding Of A Mammogram

Group Discussions

There is a general level of understanding of what a mammogram involves. It is obviously better known among those who have experience of one than those who have not – although, the former demonstrate mixed levels of understandings about it.

5.2. Pain and Discomfort

Group Discussions

The top of mind association with a mammogram is that it is painful – by both the screened and the non-screened. The screened acknowledge that it is not an easy procedure and described different levels of pain or discomfort involved. Pain would not deter their likelihood of attending another mammogram:

"you don't care so long as they say it is all ok"

"it takes so quick", "it is all over in a jif"

"just like getting a blood pressure test", "like a pinch" (S).

The non-screened talk about the pain quite graphically – explaining that they have learned about such from others who have had it done and from the media:

"it is really sore", "very severe"

"a friend came out crying", "breasts go black and blue"

"bruised and sore for a week afterwards"

"squeezes you to death" (N).

For reluctant attendees, this pain expectation deters their attendance.

The pain is attributed to the machine rather than to the radiographer. The machine is likened to a *"clamper"* and *"an electric chair".* It is known that the size of one's breasts can affect the level of pain/discomfort – in terms of the manoeuvrability of them onto the machine. It is hoped and expected that the radiographer would be as gentle as possible – although she is human and this may not always be the case.

5.3. The Procedure

Group Discussions

A 'mammogram' is a common term to most people – it was spontaneously mentioned as a form of medical check-up for women.

It is generally regarded as an expensive test if one is having it done privately – whereby one needs to be referred by a GP and/or specialist to have it done and to be prepared to wait for an appointment.

Some of the non-screened were not as familiar with it and one referred to it as a 'monogram'. It is basically associated with the breasts – an examination of some sort. The non-screened were less consistent in their description of what a mammogram involves:

- while most were aware that it involved an x-ray of the breasts whereby one's breasts were put onto a machine while the woman remained in standing position
- others were less accurate in their description: *"a scan", "things put on your chest", "cream applied to your breasts" (N)*

Despite their inaccuracies, the non-screened did not demonstrate an eagerness to learn more detail on the procedure. Their basic concern was the level of pain involved in having it done.

5.4. Level Of Detection

Group Discussions

It is understood that a mammogram detects cancer cells – even at an early stage of development: *"it can pick up a pinhead" (S).*

Having subsequent mammograms allows comparisons to be made over time – i.e. changes in cells and/or changes in breast tissue. It is expected that BreastCheck do such comparative tests on subsequent mammograms.

A mammogram is generally accepted as a foolproof test. It is assumed to detect all cancers – there is little knowledge that it does not. It is expected that a service run by professionals, such as BreastCheck, is capable of delivering a fool-proof guarantee.

This high expectation for a fool-proof detection was even expressed by the screened – which is interesting in that they did not appear to have learned from their experience with BreastCheck that a mammogram does not detect all cancers, even though this is clearly stated in BreastCheck's materials. On learning such in the group discussions, respondents were disappointed:

"very shocking" (S)

"why bother?", "what's the point?" (N).

There is a preference to believe in a 100% detection capability. Such a 'guarantee' serves as a coping mechanism for attendance. It is a crutch for reluctance attendees.

There were a few respondents who were aware that a mammogram does not detect all cancers. Some were aware that *"a few slip the net"(S).* In such cases, the greatest fear is that a mis-diagnosis would occur. It is hoped that additional forms of detections would safeguard the woman – i.e. a physical examination or a scan.

It is regarded as inexplicable that a mammogram does not detect all cancers. Some assumptions and queries were made:

- there a variety of cancers which could appear in the breast, some of which are not detectable
- but what types of cancer are not detectable – i.e. perhaps it is the non-malignant cancers which are not detectable?
- perhaps the non-detection is attributable to the reader of the x-ray – it could be a human error.

As a result of the discussion on the limited detection capability of a mammogram, it was requested by respondents that BreastCheck promote physical checks – and possibly perform such for women after the x-ray has taken place.

5.5. Physical Checks

Group Discussions

Few respondents physically examine their own breasts. There was the occasional woman who does it on a regular basis. There were a few who asked their GP to do it for them.

Most others explained that they had good intentions but tended not to complete the task: *"I start and don't keep going"(S), "I might do a wee bit and then stop" (N).* Others excused themselves by explaining that *"I'm lumpy anyway".*

Most were afraid of what they might find and did not trust their own ability to be able to cope with that. This fear rendered them incapable of doing the examination:

> *"in case you might find a lump… God bless us" (N)*
>
> *"you'd be so afraid" (N).*

Furthermore, there was experience of conflicting advice from different GPs. While it is assumed that most doctors would recommend physical checks, it has been known that some doctors tell women to leave their breasts alone.

There was a consensus among the women that they know how to do a physical examination. Yet their descriptions of what they understood to be involved demonstrated evidence to the contrary. There was a high level of accuracy in terms of what to look for but there was confusion over what position one should

be in – lying down, in front of a mirror with arm lifted behind one's head, or in the shower. There was no mention of what stage of one's period cycle one should do it.

This level of confusion identifies a potentially critical role for BreastCheck in promoting physical checks and to convey personal responsibility for examining one's own breasts – as part of one's overall breast health. This could be done by means of:

- supplementing the mammogram with a physical check during one's appointment – by way of educating the woman as well as examining her
- to provide more detail in the literature – especially in terms of how to do an examination
- to develop an easy step-by-step guide which would guide the woman so that she could complete her examination in a quick and efficient manner.

5.6. Physical Check Vs. A Mammogram

Group Discussions

While both a physical check and a mammogram are recognised as being important to one's breast health, they are understood to serve different functions. One does not substitute the other and both have distinctive roles to serve.

In comparison to a physical check, a mammogram is seen to be:

- more thorough in that it is diagnostic
- more reassuring
- delivered as a professional service
- but it can only be done every two years, is painful and does not detect all cancers.

In comparison to a mammogram, a physical check is seen to be:

- a continuous check
- painless
- but requires mental stamina to complete it oneself, if one knows how to do it correctly, and is only indicative of a problem rather than being diagnostic.

6. The Process

6.1. By Appointment Only

Group Discussions

There is a general level of understanding of the need for BreastCheck to run screenings by appointment only.

It is regarded as a necessary mechanism to cater for numbers – i.e. of the population of women in the target age group in any given area. It ensures the time management of appointment duration and daily schedules of the BreastCheck service.

Another critical benefit is that appointment set-up is seen to mastermind attendance:

"they contact you… you would put it on the long finger otherwise" (N)

"when you have to make it (the appointment) yourself, it won't happen" (S)

"it is a great opportunity if you get a letter – you mightn't think of it otherwise" (S).

On the other hand, offering a screening by appointment only results in a wait for the woman which may deter those who are nervous about coping with the process (from consent letter to end-result). It removes personal control from the woman and does not cater for those who might respond to a more spontaneous approach – i.e. drop-in facility, whereby:

"you don't think about it, you just go in" (S)

"spur of the moment" (S).

A drop-in facility is associated with mobile units anyway – i.e. blood testing, cholesterol testing, etc. There was mention by attendees of having dropped into a BreastCheck mobile unit to avail of a screening, even though this is not a feature of the service.

6.2. Appointment Set-Up

Group Discussions

The policy of waiting to hear from BreastCheck is clearly understood and acceptable to most. It allows for rearrangement and, therefore, is seen to be flexible if required. Flexibility is required – to cater for those who cannot make the assigned appointment.

Apart from waiting to hear from BreastCheck, it is expected that one could contact BreastCheck oneself to self-register and to arrange an appointment.

There ware a few cases in the research whereby it was thought that a GP had set up the appointment with BreastCheck.
The idea of setting up one's own appointment is appealing to those who fear the service. It imposes the onus on the woman to seek her own appointment which, it is thought, may generate a greater responsibility on her to attend.

6.3. Appointment Notification

National Survey

Of those who attended BreastCheck for a screening, almost all (95%) said they received at least seven days notice of their appointment.

Group Discussions

A minimum of seven days notice is required – and possibly no more than fourteen days – any longer would lengthen the waiting period. This time span would allow for rearranging other commitments where necessary and for contacting BreastCheck should one need to make a more suitable appointment while the screening is happening in one's area.

6.4. Appointment Duration

National Survey

There is a high level of satisfaction with time keeping: 96% of those who attended a screening said they were seen as promptly as possible to the appointment time.

Furthermore, 79% said they were kept informed of unavoidable delays.

Group Discussions

There was positive comment on the appointment time keeping and duration.
No respondent complained about delays.

It is acceptable for the screening appointment to last half an hour. The screened found this satisfactory and no-one had any bad experience to recount. The appointments took between twenty to forty minutes – depending upon the numbers there at the time.

The description of the appointment duration in the BreastCheck literature as being thirty minutes is accurate. Any longer might deter attendance, any shorter may seem unrealistic.

6.5. Consent Form

Group Discussions

There was little spontaneous mention of the consent form that the woman signs at the screening. It did not appear to be an issue with attendees. In fact, not all attendees remembered filling it out.

There was little understanding of the reasons for signing such a form – it was assumed that the form is necessary in the event of an operation being required.

The information requested on the form is acceptable. It is assumed that BreastCheck would handle the information with confidentiality: *"BreastCheck is a professional organisation" (S).* Respondents claimed not to be bothered about the dissemination of information to other third parties: *"If I had cancer, I would just want to get treated" (S).* Only one person requested a tick box for each third party.

6.6. Staff

National Survey

Those who had attended a screening were highly commendable of the service they received from the staff:

- 97% rated it as very professional
- 96% rated it as very discreet
- 96% as 'you felt looked after'
- 96% as efficient
- 95% said the staff were very friendly.

TABLE 3

Attitudes of Those Availing of the Service	Strongly Agree	Agree
It's Very Professional	85	12
The Staff are very Friendly	83	12
It was very discreet	83	12
You felt looked after	85	11
It was convenient	84	14
Service was efficient	86	10

In comparison to one's most recent hospital visit, the BreastCheck experience is more positive:

- 35% rate it as 'a lot better'
- 14% as 'somewhat better'
- while 29% rate it as 'no difference'.

TABLE 3

Reasons for rating Breastheck better than hospital visit	
Staff very friendly/professional	35
Small queues/less waiting	25
Very good/efficient service	23
All health services are much the same	14
More personal	8
More private	8

The BreastCheck experience is better than a hospital visit because of the following:

- staff are very friendly and professional (35%)
- small queues, less waiting (25%)
- very good/efficient service (23%)
- all health services are much the same (14%)
- more personal (8%)
- more private (8%).

These findings are in keeping with those found in the group discussions.

Group Discussions

BreastCheck delivers a high quality of service – which is in keeping with what is expected of it. There were no bad experiences encountered by the attendees.

The service is likened to that of a private clinic:

"more like a visit to a private clinic than to A&E" (S)

"they treat you more special… like when you are pregnant" (S)

"nice atmosphere" (S)

"like you could go down and have a cup of coffee" (S)

"they make you feel very much at ease" (S)

"great… they explain it to you" (S).

The radiographer is regarded as the main or only point of contact. She plays a critical role in the delivery of service and in the public image of BreastCheck. It is essential that she is gentle in the physical handling of the breasts. While most people referred to her as the radiographer, some used other terms: *'radiologist', 'technician', 'nurse'.*

It is preferable that the radiographer is female – in light of the screening being such a personal experience. It is expected that a female would be more helpful, gentle and understanding:

"allows you to keep your dignity" (N)

"more comfortable with a female" (S)

"you don't mind a woman's hand all over you, fixing you, shoving you…" (S).

It is not uncommon among respondents to seek female professionals for female problems. Few claimed to like the idea of a male radiographer for BreastCheck.

6.7. Equipment

Group Discussions

It is assumed that the technology used by BreastCheck is of a good quality. There are more pressing issues in terms of one's emotional orientation towards having a mammogram done and the prospect of the end-result.

6.8. Facilities

National Survey

94% of those who attended a screening rated the surroundings as both pleasant and comfortable.

Group Discussions

The facilities provided by BreastCheck were also rated as commendable. There was no negative comment made.

The surroundings in both the static unit and the mobile unit are comfortable, clean and complete. The static unit is more salubrious but is less convenient in terms of location than the mobile unit. Thus, respondents were prepared to forego the extra space and comfort in the static unit for the practicality and convenience of the mobile unit.

There was one negative comment – about the prospect of having one's belongings stolen if they were left in the changing room – which did not happen as attendees brought their belongings into the x-ray room.

6.9. Undressing

Group Discussions

It is assumed and acceptable that a woman has to undress for the procedure. While it may be embarrassing, it has to be done. It is regarded as being less embarrassing than a smear test and to giving birth to children:

"if that is how it is has to be done" (N)

"it doesn't matter… it is private" (S)

"undressing from the waist up is better than undressing from the waist down" (N).

There were no bad experiences claimed by the screened.

6.10. Repeat X-Ray

Group Discussions

A repeat x-ray at the same appointment is neither expected nor appealing: it would be an additional trauma to deal with. Being told not to get dressed after the initial x-ray, and to wait to see if there is a necessity to do a repeat x-ray, brings attention to the possibility of a problem. It is frightening.

It is assumed that an invitation to have a repeat x-ray done would be indicative of a problem in the breast rather than in the technology:

"nothing good would come into your head… you would panic" (N)

"you would die… you would be convinced you had cancer… I couldn't cope with it" (N)

"I was worried that there was a problem" (S)

"your heart goes down to your boots" (S).

6.11. The End-Result

National Survey

90% of screened said they received their results within three weeks of their appointment.

There is a positive rating of the follow-up process from BreastCheck: 68% rate it as 'very good' while an additional 21% rate it as 'fairly good'. The latter may be due to the waiting period of three weeks or the nature of response, which among other issues are illuminated in the group discussions.

Group Discussions

The three week waiting time between appointment and result is almost acceptable.

It is expected, and hoped, that one would hear earlier if there was a problem – from BreastCheck and/or one's GP. The longer the wait the better the implication: *"if anything is wrong you would get the result sooner" (S).*

The non-screened regard the waiting as the *"agonising"* part of the process. They would like to hear before leaving the screening – although they do not expect that this could be the case. Thus, they would like to hear within 48 hours – even by phone: *"three weeks is too long if you had a lump" (N).*

There is uncertainty as to who reads the x-ray. It is expected that women would like to be reassured that the x-ray is read by a team. This would convey confidence in the results and explain the waiting period of three weeks:

"does just one person look at it or is it looked at by a team?"(N)

"you would like to know" (S).

It is uncertain as to who sends out the result to the woman – is it BreastCheck or the GP? The non-screened expected it might be one's GP or that one might not hear at all – in light of the fact that such happens with a smear test in that one only hears if there is a problem. Others thought that one would hear from the radiographer on the day if she was confident that there was no problem:

"told that everything is fine and that you would hear from your doctor" (S)

"you could nearly tell in her voice" (S).

Some non-screened respondents assumed that one would be *"kept back"* if a lump was found.

A result which conveys the all-clear is interpreted as *"nothing found"* and *"free of cancer"*. It is generally assumed that the good news applies for two years – i.e. until one is called for a subsequent mammogram. It is viewed as a transitory period in which:

"you are free for the present" (S)

"your mind is at rest for the moment"(S)

"you are free of the worry for a while" (S)

"I thought you were free for a couple of years" (S.)

It is regarded as a credible result – not requiring a second opinion. There is such a relief in receiving a good outcome:

"someone in the profession has done it" (S)

"it is like passing your driving test" (S).

6.12. Recall Appointment

Group Discussions

In the event of the result requiring a recall appointment, it is expected that the woman would receive a number of tests:

- a repeat mammogram
- a scan
- a physical check
- and a biopsy.

It would be a more frightening experience than the initial mammogram – because the reasoning behind it would be symptomatic.

On reading the leaflet about the appointment, respondents were perturbed by:

- its duration – half a day *"sounds serious" (S)*
- advising one to be accompanied – *"it sounds frightening", "your heart would go into overdrive" (S).*

It is expected that BreastCheck would make the appointment as comfortable as possible for the woman and than any concern would relate to one's emotional state rather than the service from BreastCheck.

6.13. Two Year Cycle

Group Discussions

There is a high level of awareness of a two year period between BreastCheck mammograms. It is perceived as in keeping with other cancer screening tests – for example, a smear test.

There is uncertainty as to why the period is two years in duration. A number of reasons were proffered:

- resources – is the target group too large in number to cater for each individual more frequently?
- cancer cell development – does it take two years for a cancer cell to develop and/or for a lump to appear?
- precautionary measure – would a shorter gap between mammograms be dangerous for one's body, what is the permissible amount of radiation in the body, could the x-ray bring on cancer?
- necessity – is two years the acceptable time to re-check that one has not got cancer in the breasts and, if so, why?

It would be important for BreastCheck to inform women about the rationale behind the two-year cycle.

6.14. Likelihood Of Attending Again

National Survey

There is a high expectation for a repeat attendance. 90% of those who have been screened by BreastCheck already claim they would be 'very likely' to attend again. An additional 7% said they would be 'fairly likely'.

Group Discussions

It is assumed that the screened would be willing to attend another mammogram with BreastCheck after the two year interim period. Having done it before, the experience would be less daunting. While they explained they would be less fearsome, they still might not look forward to the occasion – because of having to cope with the uncertainty of the end result.

7. Communication

7.1. Database

Group Discussions

It is assumed that one's name is taken from a database of some sort. There is no issue with it at all: *"don't worry about it" (N), "don't even think about it" (S).*

The exact source of the database is unquestioned. Respondents wondered would it be Government records, the electoral register or the census. They were surprised, but not perturbed, to hear it was from a combination of sources – including VHI and BUPA. Even the screened were not knowledgeable on this – although they would have been informed by BreastCheck in their correspondence.

It is not uncommon to expect that the database may not be complete. Therefore, it is understandable as to why BreastCheck would canvass for self-registration. Some respondents did self-register– some of whom received an appointment and others were told to wait until the next screening occurs in their area. The process of self-registration is regarded as easy – typically by telephone.

7.2. Letters

National Survey

The original invitation letter received by those who had attended the screening was positively deemed to be clear as to what it was inviting the woman for:

- 96% said 'yes' it was clear
- regardless of age or social class.

Group Discussions

The correspondence from BreastCheck by letter is expected and commendable. How else could BreastCheck initiate contact with their target group?

The consent letter sets the process in motion – it establishes the initial contact and involves a response, be it acceptance or rejection. The invitation letter follows-up on one's willingness to take part by offering an appointment.

The commendable elements of the letters are:

- the question and answer style: easy to read and digest
- the language: easy to understand and self-explanatory
- the facts: about early detection and the most common cause of death
- the basic premise: a free breast x-ray in your area for 50-64 year olds every 2 years
- how to avail of an appointment: do nothing
- how to cancel: easy to understand options

- the length of the appointment: half an hour
- signature: there was no spontaneous reference to the signatory and it went unnoticed that the consent letter and the invitation letter were signed by two different persons - it is not expected that one will meet him/her at the appointment
- the volume of information: adequate.

The questionable elements of the letter which require reviewing are summarised as follows:

- early detection: focus on 'finding' rather than 'treating' cancer
- free health service: the mention of it implies the service is run by the Department of Health
- cancellation: describe it in a separate sub-section rather than embedding it in a section on other topics
- non-100% detectable: reassurance is required on this
- other countries: what about Ireland?
- emphasis on 'death': rather than treatment
- preparation checklist: include family history of breast cancer.

The letters play an important role. Even the non-attendees would like to receive a letter again in the future: *"it is nice to know they are not forgetting you" (N).* It is thought that repeat letters may eventually initiate a response among the non-attendees – although there is no guarantee that this will happen.

Some would say that the letters are an easy tool for refusal – in that one can just cast them aside. Others would say that no matter what type of correspondence one receives from BreastCheck, there is no guarantee that one will attend for screening.

Despite the emblazoned BreastCheck logo/masthead on the notepaper, some respondents failed to recall the organisation name. It was assumed the letter came from the Department of Health.

The line 'Your best protection' appears to have gone unnoticed. When it was brought to their attention, it was agreed that one would like to think that the statement is true – but that confidence in it is overshadowed by the learning that a mammogram does not detect all cancers.

7.3. Appointment Leaflet

National Survey

85% claimed to have received information from BreastCheck about the screening before their appointment – the source of information is not specified – it may have been by letter and/or leaflet. It is an interesting figure to note in light of the finding from the group discussions.

Group Discussions

There was limited recall among the screened of having received the appointment leaflet with their letter.

It is expected that one would read the leaflet on receiving it. The screened who had received it claimed they had read it yet they were unaware of certain details.

The commendable features of the leaflet are:

- the question and answer style
- the emphasis on treatment rather than death
- the description of what an appointment involves
- the description of the mammogram as being 'like getting your blood pressure checked'
- the helpful hints section
- the image of the three ladies.

It was suggested that the leaflet should review the following:
the reference to 'plates' and 'pressure' when describing the mammogram
provision of more detail on the procedure for a physical check.

All in all, the leaflet is appealing and serves an important role.

7.4. Recall Of Advertising

National Survey

There is a relatively high level of recall of advertising for BreastCheck. Two thirds (66%) of the relevant target age group have seen/heard such advertising. The figure is higher (71%) for the middle age band: 55-60 years of age and for those living in screened areas: 'Dublin' (87%) and 'Rest of Leinster including Dublin' (85%).

Despite this relatively high level, four fifths (80%) say that BreastCheck is not publicised enough. This is in keeping with the apparent dearth of information on the service and its procedure – which is mentioned elsewhere in the report.

Group Discussions

There was some spontaneous recall of advertising for BreastCheck in all of the groups – especially of radio and poster, to a limited extent. There was much less mention of a television advertisement.

7.5. Outdoor Poster

National Survey

Less than half (43%) of the national sample claimed to have seen the poster advertisement.

Of those who had seen it, 55% rated it as 'very good' while an additional 36% rated it as 'fairly good' – which represents quite a positive response overall.

Group Discussions

There was limited recall of the outdoor poster in the group discussions – spontaneous or promoted – and there was limited discussion on it.

It was assumed that the poster serves a practical role in that it aims to promote the presence of screening in one's area. Again the image of the three ladies is particularly eye-catching.

7.6. Image Of The 3 Ladies

Group Discussions

It would appear from the assessment of the leaflets and the poster, that the image of the three ladies plays a critical role.

The image is a main focus of discussion – catching interest and focusing attention. The ladies exude an empathy with women – in particular the relevant target age group.

They have a high recognition factor: they look familiar and are expected to be known.

They reinforce the sense of community – of being part of a group of like-minded women – all of whom have something in common.

In essence they humanise the service. There is a human interest in their circumstances: have they all had cancer, are they friends, are they related or are they just models? It is assumed that they are real rather than acting – because cancer can touch anyone.

7.7. Radio Advertising

National Survey

Half of the sample (48%) of the national sample recalled hearing the radio advertisement – which is 5% more than the poster.

Those who had heard the radio advertisement, rated it highly – 58% rated it as 'very good' while an additional 36% rated it as 'fairly good'.

Despite the fact that the service is not available nationwide, 87% of the national sample think it is ok for BreastCheck to advertise on national radio. This is in keeping with the survey's identification of the request for the organisation to publicise itself more (see 7.4. 'Recall Of Advertising').

Group Discussions

In the group discussions, radio advertising was primarily associated with local radio.

The main details recalled were Marian Finucane (almost all remembered her) and the encouraging sentiment: *"don't be afraid".*

On playing the radio advertisement in the groups, it elicited a high level of familiarity.

There is a high level of appeal for Marian Finucane: she is a well-known personality,

with a distinctive voice, is in the relevant age group and has a positive attitude. She endorses the service. It was suggested that possible alternatives to her would be Ann Doyle or Mary Kennedy – although they may not match Marian Finucane's style.

The advertisement is seen to play an informative role – telling local women that the service is in their area, they should get it done, it is very treatable, wait to be called, target age group, freephone number, if they missed their appointment what they should do:

"it gives you the facts" (N)

"tells you to be sensible" (S).

There was an incorrect message taken from the advertisement in the Galway group whereby it was assumed that "you seek an appointment" rather than wait to be contacted.

The mood of the radio advertisement is encouraging and reassuring. It was thought that there is an opportunity for a pushier style – to more strongly impress upon the reluctant to attend.

It is expected that the campaign would be on local radio – in light of the service not yet being available on a national basis.

7.8. Helpline

National Survey

Only 4% of the national sample claimed to have ever called the BreastCheck Helpline. They, in turn, rated the helpline service as 'very good' (63%) or 'fairly good' (19%).

Group Discussions

There was low awareness of a BreastCheck Helpline. There was limited expectation for it. On hearing about it in the groups, it was thought that women might use it in the event of self-detecting a lump.

The freephone number was noticed and remembered from the advertising and the letters. It has been mainly used for the rearrangement of an appointment. The service has been commendable to date.

Those who have not used the freephone service are concerned that it may be impersonal – that they may be answered by a pre-recorded message, left holding for assistance, with music playing in the background. It is hoped that the service would be more personal and comforting.

There is concern that the reading out of the number on the radio advertisement may be too fast to catch – although there were some who did recall it accurately.

7.9. Website

National Survey

Only 2% of the national sample has ever visited the BreastCheck website. Of those who visited it, the website was rated positively – 33% rated it as 'very good' and an additional 44% as 'fairly -good'.

Group Discussions

The Internet is not a top-of-mind source of information among the women researched.

There is limited usage of the Internet by them and they do not expect they would access BreastCheck there. In fact, they expressed a reluctance to gather too much information on the service: "you do not want to know too much" (S). This is in keeping with their basic preparation for an appointment whereby they tend not to seek advice or guidance from any source prior to attending.

On learning about the video message on the website, respondents expressed an interest in it. In particular, they are attracted to the idea of hearing about the experiences of other women who have gone through the process. Perhaps the anonymity and privacy of accessing this information on the Internet, in one's own home, is what is so appealing about it.

7.10. BreastCheck Personality

National Survey

94% of the total sample is in agreement that BreastCheck is a vital service – 75% 'strongly agree'.

Group Discussions

The over-riding personality trait of BreastCheck is that it is a caring professional – which is a view held by both the screened and the non-screened.

In essence, the main characteristic features of BreastCheck are regarded as follows:

- caring: "it's nice to think someone is looking out for you" (S)
- professional: authorative and credible in what it does
- life savers: "they have saved a lot of people" (S)
- appeasing: "makes you feel very much at ease" (S)
- feminine: empathetic with women, organised by women for women
- part of the community: delivering a local service to local women

- encouraging but not hard sell: gentle not pushy
- flexible: accommodates change of appointment
- not institutionalised: removed from typical hospital associations.

This is strong positive imagery which augers well for the future development of the service. The research did not identify any negative imagery at all.

7.11. Women's Charter

National Survey

One fifth (19%) of the national sample claim to have heard of the BreastCheck Women's Charter.

The Women's Charter is rated highly – one in three (34%) rated it as 'excellent' while 79% rated it as above average – i.e. a rating of between 5 and 7 on a scale of 1 to 7 where 7 is 'excellent'.

Group Discussions

There was no awareness of the Women's Charter in the group discussions.

On been given the chance to acquaint themselves with it in the research, respondents complimented the concept. They deemed it to be a *"good idea" (S,N).*

It is not necessarily expected of BreastCheck to have such a Charter – yet, it is not unexpected either.

It was given attention in the group discussions for the sake of research – it was thought that few people would read it otherwise. Prior to reading it, respondents said they did not expect to learn anything new from it and that was the case – its content was as expected.

It's purpose was unclear. It was assumed to have an informative role:

"it might make people go or would it" (N)

"to educate people… especially those who won't go" (S)

"others might be interested in it but it has no effect on me" (S).

Conclusions

1. BreastCheck is well known, relatively well understood and positively regarded by women in the 50-64 age group. In areas in which BreastCheck is currently operating, awareness is close to universal.

2. The positive attitude generates demand from regions who have yet to receive the service. There is a strong preference that the service should immediately be available across the country, rather than rolling out gradually.

3. Women's experience of BreatCheck's service is very positive and it is more positively viewed than recent hospital visits. This positive experience should be maintained and it may be appropriate to minimise perceptions of the hospital connection, especially with the static units.

4. The women surveyed were health aware, but not health focused. The attitude to health is a function of their experience – the closer that experience is to home, the greater the concern. Health checks are driven by need and convenience and the general approach is reactive.

   An opportunity exists to inspire and encourage pro-active measures around health.

5. Women are not breast aware. Few do physical checks and few do them regularly. There is a low recall of information received from BreastCheck on breast health.

   There is a need to further educate women in this age group about good breast health.

6. Although there is strong awareness of BreastCheck, there is considerable ignorance about mammograms and breast screening. This exists among screened and non-screened women. There does not appear to be a great desire to learn more about this and it seems unlikely that greater knowledge would drive greater attendance.

7. However there are some areas where more information could encourage attendance such as that the mammogram is not too painful, who conducts the screening, how the x-ray is interpreted and by whom, and the reasons for the two year gap between tests.

8. Older and less educated women appear to be less likely to attend for screening. Those who attend tend to be younger, better educated, have an active social life and either have experience of ill-health or be very healthy.