A diagnosis of breast cancer following screening mammogram: the women’s experience

Breast Cancer Network Australia
Survey Report
October 2014
Executive Summary

Background and methodology

In September 2014, BCNA developed a survey to explore the experiences of women diagnosed with breast cancer in the past five years following a screening mammogram. In total, 1,012 members of BCNA’s Review & Survey Group were invited to participate, and 236 women completed the survey.

The majority of respondents were aged between 50 and 74 years, the new target age range of the BreastScreen Australia program. Ninety six per cent of women (178) were diagnosed between 2009 and 2014 (i.e. within the last five years).

Women had their mammograms in all states and territories, except the Northern Territory. The majority of respondents had their mammograms in New South Wales (30%), Queensland (26%) and Victoria (24%). Sixty-four per cent respondents had their mammograms in a metropolitan area and 36% in a regional, rural or remote area of Australia.

Only three women spoke a language other than English at home.

Key findings

Eighty per cent (189) of respondents were diagnosed following a BreastScreen mammogram and 18% (43) were diagnosed following a screening mammogram at a private imaging clinic. Two per cent (4) were diagnosed following a screening mammogram, but were unsure what type of service they attended.

The majority of respondents noted that they required additional scans following their mammogram. Ultrasound was the most common follow up scan (70%; 164).

Written and verbal information

The significant majority of women (198; 86%) understood either most or all of what they were told by health professionals about their diagnosis, and 90% of women (197) understood ‘most’ of the written information they were provided, or understood it ‘very well’. Seventy-six per cent women (176) also understood very well what would happen following their diagnosis (i.e. what the next steps would be).

However, 13% (29) indicated they understood only a ‘little bit’ of what they were told about their diagnosis. Thirteen per cent (31) reported being unsure about what to do following their diagnosis, and 4% (10) said they had no idea what would happen next or what to do when diagnosed.

A number of women (11, 5%) indicated they were told about their diagnosis over the phone. Of these, four were diagnosed through BreastScreen.
Given the importance of information in assisting women to make informed and empowered decisions about their treatment and care, there is a need to ensure that all women diagnosed receive high quality information and that they understand it.

**Health professionals**

Women reported that a wide range of health professionals are involved when they were told of their diagnosis, including surgeons, nurses, GPs, radiologists and counsellors. Surgeons and nurses were more likely to be present when women were diagnosed through BreastScreen (48% and 49% respectively) compared with private imaging clinics (21% and 5% respectively), while GPs were more likely to be present when women were diagnosed via private imaging clinics (47%) than through BreastScreen (22%). However, as the majority of respondents were diagnosed through BreastScreen (189) compared to private imaging (43), these findings are indicative only.

**Emotional support**

Throughout the survey, many women discussed the shock, disbelief and fear they experienced when diagnosed following a screening mammogram.

When asked about the emotional support they received from health professionals, 65% of the 225 women who responded to the question reported that they had received enough emotional support. Yet, one in five women indicated they would have liked to receive more emotional support from the health professionals involved in their diagnosis. Fifteen per cent of women reported they were not given any support when they were diagnosed.

Women also spoke of the value of having a support person present when undergoing tests and scans and when learning of their diagnosis. While 46% of respondents (108) indicated they had someone with them when diagnosed and 36% (84) said they did not mind not having anyone with them, almost one in five (18%) women would have liked to have someone with them to provide support. Some women said they were not told that they could have a support person present for the recall mammogram and tests, and other women spoke of distress when a partner or other support person was excluded from waiting rooms throughout the day.

**Consistency of recall processes**

As a follow up to unexpected findings that some respondents did not remember being told they could bring a support person with them and others feeling unprepared for the follow up scans and tests that were performed, BCNA staff contacted BreastScreen Victoria regarding their recall processes. Staff also examined the recall letter templates contained in BreastScreen Queensland’s *Quality Standards, Protocols and Procedures Manual*. Of concern was that services use different letters when recalling women for further tests. These letters differ in the tone and emphasis placed on the value of women bringing a support person with them and what women can expect to happen at the recall appointment, e.g. the range of scans and tests that may be performed.
Recommendations

1. Australian women being recalled following a BreastScreen screening mammogram should be provided with consistent standard written information about what may happen at the follow-up appointment, including possible tests and procedures, and that they can bring their partner or another support person to the appointment if they wish.

2. Partners/support people should be included in consultations if that is the woman’s wish.

3. Wherever possible, delivery of a diagnosis of breast cancer should be provided at a face to face appointment by a health professional who can clearly explain the diagnosis, the next steps in the process and answer any questions the woman or her partner/support person may have.

4. High quality written information should be provided to women at the time of diagnosis.

5. A study should be developed and conducted to measure women’s experience of being diagnosed with breast cancer through BreastScreen Australia services.
A diagnosis of breast cancer following screening mammogram: the women’s experience

Background
Breast cancer is the most common cancer affecting women. In Australia, it is estimated that 15,270 women will be diagnosed with breast cancer in 2014.

Women may be diagnosed with breast cancer in a number of ways. For women who are asymptomatic, this is often through a regular screening mammogram at BreastScreen Australia or a private imaging centre.

BreastScreen Australia is Australia’s national breast cancer screening program. It provides free screening mammograms every two years for women aged 40 and over, with the aim of reducing deaths from breast cancer through early detection. The BreastScreen program is targeted specifically at women aged 50 to 74, as evidence shows that screening has the greatest potential to prevent deaths from breast cancer in this group. Women aged 40 to 49 years and over 74 who have no symptoms or signs of breast cancer are also eligible for a free screening mammogram every two years.

The latest BreastScreen Australia monitoring report indicates that, in 2012, 4,738 women had an invasive breast cancer detected through BreastScreen and 1,199 women were diagnosed with ductal carcinoma in situ (DCIS) through BreastScreen.1 Of the estimated 14,600 women diagnosed with breast cancer in Australia in 2012,2 this data indicates that approximately 41% of women were diagnosed through BreastScreen.

Women may also be diagnosed with breast cancer through screening at private imaging clinics. While the proportion of breast cancers detected through these clinics is not known,3 it is clear that screening mammograms play a key role in the early detection of many women’s breast cancer in Australia.

Methods
In September 2014, BCNA invited women to participate in a survey developed by BCNA about their experience with breast screening. The survey was restricted to women whose breast cancer was detected in a regular screening mammogram, through either Breastscreen or a private imaging service, in the last five years.

The survey aimed to explore and provide a more detailed understanding of the experiences of women diagnosed with breast cancer through a screening mammogram.

3 Ibid.
In total, 1,012 members of the BCNA Review & Survey Group were invited to participate via email, of who 246 started the survey. Ten were ineligible because their cancers had not been detected through a screening mammogram and were exited from the survey, with the remaining 236 completing the survey.

Throughout the report, all quotes are from women diagnosed with breast cancer through a BreastScreen service unless otherwise noted.

Demographics

Age
The majority of women who responded to the survey were aged within the target BreastScreen age range of 50-74 years. This is a new target age range which the Australian Government implemented as part of the 2013-14 Budget. It follows recommendations contained in the 2009 BreastScreen Australia Evaluation Final Report.4

Sixteen per cent of respondents were under 50 years. This is broadly representative of the population of women who get breast cancer.

Location of respondents
Respondents had their mammograms performed in all states and territories, except the Northern Territory. The majority of respondents had their mammograms in New South Wales (30%), Queensland (26%) and Victoria (24%).

Women from metropolitan, regional and rural areas of Australia were represented in the survey. In total, 64% of respondents had their mammograms performed in a metropolitan area, while 36% had their mammograms performed in a regional, rural or remote area.

**State and Territory of Mammogram (n=231)**

- New South Wales: 30%
- Queensland: 26%
- Victoria: 24%
- Western Australia: 7%
- South Australia: 6%
- Australian Capital Territory: 4%
- Tasmania: 3%
- Northern Territory: 0%

**Year of diagnosis**
In total, 186 women (79%) nominated a year of diagnosis. Ninety-six per cent of these (178 women) were diagnosed within the past five years (i.e. from 2009 to 2014).

**Language**
Of the 246 respondents who participated in this survey, only three women speak a language other than English at home.
Survey Results

BreastScreen versus private imaging clinics
When asked where they were diagnosed, 80% of survey respondents (189 women) reported being diagnosed through BreastScreen. Eighteen percent (43) were diagnosed through a private imaging clinic, and the remaining 2% (4) said they were unsure where they were diagnosed, but were diagnosed after a screening mammogram.

Other imaging scans

We know that many women require additional scans to supplement mammography findings. 233 women responded to a question asking whether they had required additional scans prior to their diagnosis. Seventy per cent of those women (164) required an ultrasound in addition to a mammogram.

In addition to ultrasound, a small number of women indicated they had an MRI or PET scan as part of their pre-diagnosis imaging.
Of the 17 respondents who selected ‘other’, 12 women indicated they had a biopsy performed.

Health professionals
We asked women what health professionals were present when they were given their diagnosis. It is important to note that only 43 survey respondents were diagnosed through private imaging centres compared with 189 respondents who were diagnosed through BreastScreen. This must be taken into account in relation to any comparisons made.

In total, 233 women responded to this question. Women were able to select more than one response.
Responses from the four women who were unsure whether they were diagnosed through BreastScreen or private imaging were removed to show direct BreastScreen / Private imaging comparison.

Of the women diagnosed through BreastScreen, almost half reported a surgeon was present when they were told about their diagnosis (89 women; 48%). Nurses were also present in almost half of all cases (92 women; 49%). Approximately one in five women also reported having a General Practitioner (40 women; 22%) and/or counsellor present (37; 20%).

Thirteen of the women diagnosed through BreastScreen who selected ‘other’ said that a ‘doctor’ had been present. Open ended responses to this question included, ‘the Breast screening doctor,’ ‘a doctor that helps out at the breast screening unit’ or ‘a doctor of some sort - can’t remember’.

When the responses of women diagnosed through BreastScreen and private imaging were compared, respondents diagnosed through private imaging more commonly reported that GPs were present when they were diagnosed. While 22% of women diagnosed through BreastScreen indicated that a GP was present, 47% of women diagnosed through private imaging reported that a GP was present when they were diagnosed.

A lower proportion of respondents diagnosed through private imaging reported that a surgeon was present (21% compared with 48%).

A number of women (11, 5%) indicated they were told about their diagnosis over the phone. Of these, four were diagnosed through BreastScreen. All had their mammograms performed in regional areas, though in three different states (2x Queensland, 1x Western Australia, 1x New South Wales).
My GP phoned me, I was out having dinner with a girlfriend.

I was informed by phone by Breastscreen. I thought a phone call was rather a shock and would rather have been called in with my husband to discuss it

It was over the phone by a doctor though I had a good idea from the assessment done the previous day at [location removed].

Of the seven respondents diagnosed by phone through private imaging, six indicated they were diagnosed at a private imaging clinic in metropolitan Queensland, however there is not enough information in the survey to determine if they all attended the same imaging clinic.

It was by phone, although I was told it was likely [to be breast cancer] by the doctor at the clinic.
– Respondent diagnosed through private imaging clinic

Emotional support
We also asked women whether they felt they were given enough emotional support by their health professionals when they were first given their diagnosis.

Of the 225 women who responded to the question, 65% (146) indicated they were given enough emotional support by health professionals to meet their needs. A number of women described specific actions taken by various health professionals, which helped them feel they were emotionally supported.

The health care professionals were very supportive. When first diagnosed, I burst into tears and explained my only child (daughter) was getting married in four weeks. They immediately called for the counsellor to come into the room to comfort me.

Other women described the support they felt more generally, using a range of terms such as ‘caring’, ‘understanding’, ‘supportive’, and ‘compassionate’.

My GP told me of my initial diagnosis. He was extremely considerate, understanding and compassionate which helped me tremendously. – Respondent diagnosed through private imaging clinic

They were understanding, supportive and compassionate. I wasn’t treated like a number, they were willing to sit and talk to me, mainly the counsellor.

However, 20% (45) of women indicated they would have liked to receive more emotional support. Thirty-three of these were diagnosed through BreastScreen.

As I was not expecting a [breast cancer] diagnosis, I was on my own when given the shocking news. Within 20 minutes I was in the street totally bewildered, sad and scared. A follow up phone call with more information would have been great.
Fifteen per cent of women (34) felt they were not given any emotional support by health professionals when they were first told they had breast cancer. Twenty-five of these were diagnosed through BreastScreen.

A number of women indicated being told in a way that was focused on the facts of their diagnosis, but did not meet their emotional needs.

*Emotion didn’t come into it. It was all very factual.* – Respondent unsure where diagnosed, but it was following a mammogram

*At the time I felt almost patronised, and just another number. I was too emotional to think clearly to ask relevant questions, and was soon back in the waiting room, without my partner. Horrible and lonely.*

*I was told matter-of-factly. I was very frightened and crying. The radiographer said I should get dressed, dry my tears and go to the waiting area. I remember asking her if I was going to be alright and she replied that she still sees patients who had breast cancer years ago and they are still fine. Would this be classified as emotional support? I was not given any written information. In shock I paid my bill, walked alone to the car park then went to pick my children up from school.* – Respondent diagnosed through private imaging clinic

Were you given enough emotional support by health professionals when you were first told you had breast cancer? (N=225)

- I was given enough emotional support by health professionals: 65%
- I was given some emotional support by health professionals, but I would have liked more: 20%
- I was not given any emotional support by health professionals: 15%
Throughout the survey, a number of women indicated that they found the process by which they were diagnosed to be an emotional and scary experience. This was particularly the case for women who were alone and for women who did not fully understand the various tests and scans involved in the diagnostic process.

*Being the last one left and then having to drive home wasn’t great. Nor was it great that I didn’t realise it would take all day. Otherwise, it was good that it was a one stop shop. The staff were pleasant and at least I knew [about my diagnosis] at the end of the day.*

I was totally unprepared for what happened for the rest of the day, with a repeat mammogram, an extremely painful biopsy, and various other procedures which were basically visited upon me with no explanation. The staff involved was kind and helpful but it all happened in a daze, without anyone really offering any specific support other than general kindness. At no stage did anyone suggest I might ask my partner or anyone else to come and join me.

The person doing the ultrasound said "It doesn't look good" or words to that effect and showed me on the screen what she was looking at. She repeated this several times. I was quite distraught by her response. I was visibly upset and she told me to wait outside. I said I didn’t think it was a good idea to go outside to the waiting area with other women. I was given a room to wait in on my own.

**Support people**

233 women responded to the question, ‘Was anyone with you when you were told about your diagnosis of breast cancer?’ In total, 54% (125) did not have a support person with them when they were told. Of those, 18% (41) said they would have liked to have someone there to support them.
When the responses of women diagnosed through BreastScreen versus private imaging were analysed, a slightly higher proportion of women diagnosed in private imaging said they would have liked to have a support person with them (24%) than women diagnosed through BreastScreen (16%).

*It would have been good to have my husband there for moral support. I regret getting that news on my own.*

*The doctor kept telling me to wait ... Another mammogram, then ultrasound, then wait to see the surgeon. I would have liked my husband there but I wasn't thinking straight and in denial.* – Respondent diagnosed through private imaging clinic

Some women expressed sadness and frustration at not having their partner present for the diagnosis.

*I was on my own, and had a four hour drive home.*

*Not sure if it was suggested to have someone with me, but it would have been nice to have husband there. ... I was traumatized.* – Respondent diagnosed through private imaging clinic

Other women told us that men were excluded from waiting rooms throughout the process, which they found distressing.

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*Responses from the 4 women who were unsure whether they were diagnosed through BreastScreen or private imaging were removed to show direct BreastScreen / Private imaging comparison.*
After being the last woman left on that day at the centre, I had already guessed, but had to wait for formal diagnosis in a couple of days with the counsellor. My issue was with that day at the centre. Men were excluded, and my husband was sitting outside and not allowed in even when it was obvious something was terribly wrong…I resorted to texting him so I could talk to someone.

I was angry that they did not invite my husband in to be with me when I was told. They were aware he was waiting outside. I felt totally overwhelmed and by then I was emotionally exhausted.

Some women told us they were not told that they could have a support person present for the recall mammogram and tests.

I was totally unprepared for what happened…, with a repeat mammogram, an extremely painful biopsy, and various other procedures which were basically visited upon me with no explanation…At no stage did anyone suggest I might ask my partner or anyone else to come and join me.

I think that, when women are called back for further testing, they should be urged to bring a member of their family or a close friend with them

Women who did have a support person with them emphasised the benefits, noting the emotional support they received and the value of having someone with them to help remember and digest information.

I was very grateful that my husband decided to accompany me the day of my call back, as I usually attend medical appointments on my own. It was very important that he was with me.

It is good to have someone else with you; because once you hear the word ‘cancer’ it is very hard to take much else in.

Understanding the diagnosis
The overwhelming majority of women (198; 86%) understood most or all of what they were told about their diagnosis.

The staff were very empathetic and understanding. They simply and clearly explained the situation to me.

However, 13% (29) indicated they understood only a ‘little bit’ of what they were told about their breast cancer diagnosis.

Looking back, I was quite shocked at the diagnosis so I didn't really take in a lot of information. I understood the basics but was too scared to take in any more details.
I think it was mainly because I was still in shock and couldn’t take it all in.

It must be noted that of the 246 respondents who participated in this survey, only three women speak a language other than English at home. This limitation means that we are unable to comment on the levels of understanding of women from culturally and linguistically diverse backgrounds.

Understanding what would happen next

When asked if they understood what would happen next following their diagnosis, 76% of women (176) said they understood very well what would happen next.

The staff were very empathetic and understanding, and simply and clearly explained the situation to me.

I remember that the medical staff were quite serious but they answered all my questions and prepared me well for what was to happen. Their support was (and still is) a major factor in my recovery.

Although most women had a clear understanding of what would happen next, some women told us that they had difficulty understanding some aspects of their diagnosis, and the scans and treatments to follow. Thirteen per cent (31) indicated they were unsure what to do or what would happen next, and 4% (10) said they had no idea what to do or what would happen next.

Even though I was told [I had breast cancer] after the ultrasound, I did not fully understand what they meant by a ‘core needle biopsy’. I had no idea that it would be so barbaric, painful and humiliating. I had all these tests on the one day.
Written Information

Of the 231 women who answered the question, ‘Were you given enough written information about breast cancer when you were told about your diagnosis’, 63% (145) said they were given the right amount of information.

*I felt very well informed with the information I was provided.*

*The booklets I was given were excellent. I was able to research and decide what I wanted to do given the type of cancer, the biopsy report and the odds of recurrence. No regrets with my choice.*

*The information I received was excellent, informative and very much appreciated. I still have most of the information, and do refer back to it sometimes.* – Respondent diagnosed through private imaging clinic

Thirteen per cent (29) of women told us they felt they received too much information. Of these, 12 spoke about being in ‘shock’ and feeling ‘overwhelmed’ when diagnosed, and discussed the difficulty digesting the information while coming to terms with their diagnosis.

*I was in shock, I was trying to understand what I was reading, so many thoughts were going through my head, I had just received my diagnosis which then I believed to be a "death sentence".*
Overload of info/booklets/brochures given. Whilst fairly easy to read, it was difficult to process whilst coming to terms with the diagnosis. – Respondent diagnosed through private imaging clinic

Similarly, women who felt they were given the right amount of information discussed this initial shock of their diagnosis. They talked about going back over the information at different points during their treatment, as well as being overwhelmed initially.

I think I was in shock and didn’t really take much in initially. Over the course of my treatment I would go back over the information I was given.

I felt overwhelmed by all the info I received and had to put it away and then read in dribs and drabs as the need/questions arose.

Many women were happy to receive a lot of information, even if they were unable to digest it immediately. They spoke about the importance and value of being able to take home information and read through it at their own pace.

I was given plenty of information but you wade through slowly and take notes for the next visit and with family because you do not take in all the information.

I was given an armful of books and pamphlets. It seemed like a lot at the time but it was all really useful and informative. I knew very clearly what would happen and what different treatments meant. I was happy to read this information to confirm what the nurse had told me. I was really very impressed by the amount I was given - although it seemed a lot at that precise moment I was grateful to be able to read through it at home and share it with my husband. I would rather get everything up front and work my way through it than have to struggle to ask the right questions to find the information.

You need to be given the full 'load' of information, but as I did only a few would actually be able to take it all in at the time of diagnosis. You can refer to it all when you go home & sit down

Some women told us that often it is not the amount of information that concerns them, but the amount of information they are given that is not specific to their own individual needs.

Information good but needed to know more about the type of breast cancer I had to get the most out of it.

I would have liked more information on lobular cancer (but found the Mayo clinic website a good source for this). – Respondent diagnosed through private imaging clinic

Nine per cent (21) of respondents indicated they were not given any written information when diagnosed.
I was not given any written info when diagnosed. I was told to come back in a few days to see a specialist.

Written information was provided later.

When the responses of all survey responses (which included women diagnosed through private clinics) were compared with those of women diagnosed through BreastScreen, no significant differences were found.

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<th>All women (n=231)</th>
<th>BreastScreen (n=184)</th>
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<td>63% were given the right amount of information</td>
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<td>4% were unsure</td>
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Understanding of written information
When asked whether women understood the written information they were given, 90% (197) of the 220 women who answered the question said they understood most of the information, or understood the information ‘very well’.

All the information was very detailed and easy to understand. My surgeon described on the diagram of a breast exactly what I had.

The information I received was great, and enabled me to ask informed and intelligent questions of the surgeon and reconstruction surgeon and the oncologist. It also helped my husband to understand what was to be done, and why and how, and be involved in what was going on. – Respondent diagnosed through private imaging clinic

I had no real problem understanding the information given to me, it is really pretty self-explanatory. My GP also went over anything I questioned.
Additionally, many women highlighted BCNA’s *My Journey Kit* as a particularly useful written information resource.

*The information I was given was the BCNA Kit. I don’t know how I would have coped without this. It was like my Bible. I referred to it constantly when I was in doubt about my diagnosis. I still have occasion to refer to it at times today. It is the most comprehensive information I’ve ever had and I’ll never cease to be grateful to BCNA and its resources.*

*I understood the information but I did not retain it, and referred to it over and over. Best info came from BCNA.*

**Additional feedback**

When asked if they would like to share anything further about being told they had breast cancer, 118 women took the opportunity to provide us with a very detailed picture of the emotional impact the diagnosis had on them.

Significantly, many women gave feedback on how they were treated by the healthcare professionals who told them they had breast cancer.

*I found the whole system to be caring, informative and understanding. Breastscreen is a wonderful organisation which we are lucky to have.*

*I am extremely grateful that I was diagnosed in routine screening. I had a very high grade invasive tumour but it was caught very early. My GP insisted on annual not 2 year scans.*
surgeon says she saved my life. The private screening unit were fabulous - especially as I was out of town - from mammogram to biopsy results in 48 hours. – Respondent diagnosed through private imaging clinic

The nurse was extremely caring, understanding and provided us with all the information we required. She was wonderful.

My GP told me of my initial diagnosis. He was extremely considerate understanding and compassionate which helped me tremendously. – Respondent diagnosed through private imaging clinic

Following my diagnosis with the very caring staff at Breastscreen, my GP and Breast Surgeon also provided guidance and support.

A number of women reiterated the importance of screening services providing emotional support to women who are newly diagnosed due to the 'life changing moment' that a breast cancer diagnosis can be for many women.

It is a life changing moment. You are never the same again no matter the outcome. I had no idea when I went to my screening that I would come out needing to have a biopsy the next day as I had no feel-able lump or other visible indicator. I was externally calm - I didn't every cry - that's not me. I was on my own and away from home. I was moved several times over the next few days to make room for women who needed private spaces. Those of us who don't react by expressing our emotions externally are still experiencing them and need just as much care support and privacy. – Respondent diagnosed through private imaging clinic

Discussion
This survey explored the experiences of women whose breast cancer was detected following a regular screening mammogram. Of the 236 women who completed the survey, 80% were diagnosed through BreastScreen and 18% through private imaging clinics. Four women were unsure where they were diagnosed.

Many women described the significant shock, disbelief and fear they experienced when they were told they had breast cancer following their screening mammogram. The responses indicate that this can be an emotional, confusing and frightening time, and a time in which women have significant needs for information and emotional support.

Many women also emphasised the importance of having their partners or another support person with them at their recall appointment, and particularly when being told of their diagnosis. Eighteen per cent of women indicated that they did not have a loved one with them, but would have liked someone there to provide support.

Some women said they were not told that a support person could accompany them for the recall appointment. Others spoke of partners being unable to accompany them into waiting rooms.
The majority of women indicated that they understood either all or most of what they were told about their diagnosis and all or most of the written information they were provided. Approximately three quarters had a clear idea of what would happen next following their diagnosis.

However, 13% (29) understood only a little bit of what they were told, and 8% understood very little of the written information they received. Thirteen per cent also indicated they were unsure what to do next following their diagnosis and 4% said they had no idea what to do or what would happen next.

Throughout the survey, many women emphasised their ‘shock’ at being diagnosed and subsequent difficulty absorbing information at their appointment. However, many women reiterated the importance of being given verbal and written information, noting that it helped them understand more about their diagnosis as well as make treatment decisions. Women also emphasised the importance of being able to take information home to share and discuss with family, friends and others in their lives, or to read the materials at a time when the initial shock had lessened somewhat. The high information needs of women must be taken into account by screening services when developing processes around the provision of information, both verbal information at the time of diagnosis and written information to take home with them.

The survey also indicates a variety of health professionals are involved when women are told of their diagnosis. Health professionals play a key role in providing women with emotional support when they are first diagnosed. Sixty-five per cent of women spoke positively about the support they received, discussing particular actions, such as arranging for a woman to be driven home, that helped them cope with the shock and fear of being diagnosed. Other respondents shared their appreciation for the care, concern and kindness displayed by various health professionals when discussing the diagnosis with them.

Of importance are the differences women reported about their experiences of being recalled and diagnosed with breast cancer, even among women who were diagnosed through BreastScreen services. Four women diagnosed through BreastScreen were told of their breast cancer diagnosis over the phone. Women also reported differences in the types of health professionals that were present and in the information provided to them. Some women also indicated their partners were unable to remain in the waiting areas with them, while others said they were unaware that they could bring a support person with them.

As a follow up to these unexpected findings, BCNA staff contacted BreastScreen Victoria regarding their recall processes. Staff also examined the recall letter templates contained in BreastScreen Queensland’s *Quality Standards, Protocols and Procedures Manual.* Of concern was that services use different letters when recalling women for further tests. These letters differ in the tone and emphasis placed on the value of women bringing a support person with them.

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and what women can expect to happen at the recall appointment, e.g. the range of scans and tests that may be performed.

Given the emotional and information needs of women when they are diagnosed with breast cancer, these findings highlight the importance of a consistent approach by BreastScreen services, both in terms of what women are told about the recall process and how women are told of their diagnosis. Further research into the experiences of women diagnosed through BreastScreen services throughout Australia is needed to gain a more in depth understanding of differences in approach and women’s experiences.

Recommendations
1. Australian women being recalled following a BreastScreen screening mammogram should be provided with consistent standard written information about what may happen at the follow-up appointment, including possible tests and procedures, and that they can bring their partner or another support person to the appointment if they wish.

2. Partners/support people should be included in consultations if that is the woman’s wish.

3. Wherever possible, delivery of a diagnosis of breast cancer should be provided at a face to face appointment by a health professional who can clearly explain the diagnosis, the next steps in the process and answer any questions the woman or her partner/support person may have.

4. High quality written information should be provided to women at the time of diagnosis.

5. A study should be developed and conducted to measure women’s experience of being diagnosed with breast cancer through BreastScreen Australia services.