An investigation into the provision, fitting and supply of external breast prostheses: A national study

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Contents

List of Tables

List of Figures

Glossary of Terms

A&EP	State Government's Aids and Equipment Program
ABC	Action Breast Cancer
ADP	Assistive Devices Program
BCN	Breast Care Nurse
EORTC	European Organization for Research and Treatment of Cancer
HIPE	Hospital InPatient Enquiry
HSE	Health Service Executive
NCRI	National Cancer Registry of Ireland
NHS	National Health Service
NMSC	Non-melanoma Skin Cancer
SPSS	Statistical Package for the Social Sciences
WHOQOL-BREF	World Health Organisation Quality of Life Questionnaire (Brief Version)

Executive Summary

Breast Cancer is one of the most common cancers affecting women in Ireland with approximately 1,726 women being registered with breast cancer each year (National Cancer Registry Ireland (NCRI), 2005). The majority of women with breast cancer have surgery as a form of treatment either on its own or in combination with radiotherapy, chemotherapy and/or hormone therapy (NCRI, 2005). An integral part of the recovery post surgery involves considering restorative options. For many women in Ireland this means being fitted with an external breast prosthesis. Currently, there are an estimated 16,000 women in Ireland who have undergone a mastectomy and require an external breast prosthesis. The overall purpose of this research is to gain an insight into women's experience of the provision, fitting, supply and use of external breast prostheses in Ireland.

Women have a right to be satisfied with their breast prosthesis, not least because in being supplied and fitted, they are recipients of a service, but also because it plays a role in terms of their psychosocial well-being. External breast prostheses are designed to restore the woman's self-confidence in her appearance, thus curtailing the impact of the disease on her psychological health (Shimozuma et al., 1999). The importance of a good-quality prosthesis and prosthesis-fitting service is paramount for body image, femininity, and psychosocial well-being following breast cancer surgery (Nissen et al., 2001; Mahon & Casey, 2003; Roberts et al., 2003; Murphy 2004; Breast Cancer Care, 2006).

Despite the importance of external breast prostheses, it is acknowledged by those working at both policy and practice level within the Irish context that there are potentially many inadequacies in the current system of care regarding breast prostheses. Indeed this research has arisen directly as a response to queries to Action Breast Cancer from members of the public who have found it hard to get information and good quality service in the provision of external prostheses following surgery. The potential shortcomings in the provision, fitting, and supply of external breast prostheses in this country are confounded by insufficient research. It is argued by Hart et al. (1997) that the provision of breast prostheses is an area of a woman's post-mastectomy treatment that has the least amount of objective information available and that has been subject to the least amount of scientific inquiry. According to Healey (2003), a rigorous, evidence-based approach to the evaluation of external breast prostheses would enhance both the development of the service, as well as the adjustment, well-being and quality of life of breast cancer survivors. It is within this context that this research sought to:

i. Assess factors and perceptions that impact on access, equity, quality, and affordability in relation to the needs of women requiring a breast prosthesis

ii. Assess the type, content, timing and mode of providing external breast prosthesis information to women and how this might impact on their experience of acquiring or replacing an external breast prosthesis

iii. Identify factors that promote quality in the supply, fitting and aftercare of all external breast prostheses and related products.

These objectives were achieved though a two-stage research project. The first part of the research employed focus group methodology to investigate women's personal and subjective experiences of the provision, fitting and supply of breast prostheses in Ireland. The second part of the research involved conducting a series of four concurrent national postal surveys directed at women with breast cancer and those involved in their care, notably breast care nurses, retail prosthesis fitters and bra fitters in department/lingerie stores.

PART 1 - FOCUS GROUP STUDY

The focus groups were undertaken to provide a detailed insight into the experiences of women in the provision, fitting and supply of external breast prostheses in Ireland. Their over-riding advantage was their capacity to provide women with the opportunity to share and recount their own experiences in their own words. Five focus groups with 6-12 participants in each were conducted. One group was run in each of the four new regional health authority areas in Ireland in 2005, except in Dublin where there were two groups. Forty-seven women in total participated in the five focus groups. The average age of participants in the focus groups was 57.8 years with a range of 38-80 years of age. The average length of time since being diagnosed with breast cancer was 8.1 years with a range of 1-32 years. The majority of women wore a single prosthesis.

With regard to the provision, fitting and supply of external breast prostheses, six main themes, each with their own sub themes, emerged (See Figure 1). These were:

1. *The fitting experience:* In particular, reference was made to the need for optimal fitting environments and suitable fitters.
2. *The prosthesis:* Most notably this pertained to patterns of use and its physical characteristics. Some women expressed satisfaction with the prosthesis. However, many women reported experiencing problems with the weight, temperature, durability, movement, shape, texture, comfort and style of prostheses.
3. *Bras/swimwear:* Similar to the prosthesis, women also mentioned the physical characteristics, for example, limitations in the style, choice, material and quality.
4. *Cost:* Women raised the issue of the cost of the prosthesis highlighting the burden of its expense and the lack of uniformity with regards to entitlements.

5. *Information:* Women described a general lack of information, for example, in accessing post-mastectomy products, entitlements, and types of prostheses, bras and swimwear available. Women made suggestions about the future sharing and receiving of such information.
6. *Personal implications:* The personal implications of wearing/requiring an external breast prosthesis highlighted by the women were collated under four headings: coping with a new image; adjustment; lifestyle considerations; and coping socially.

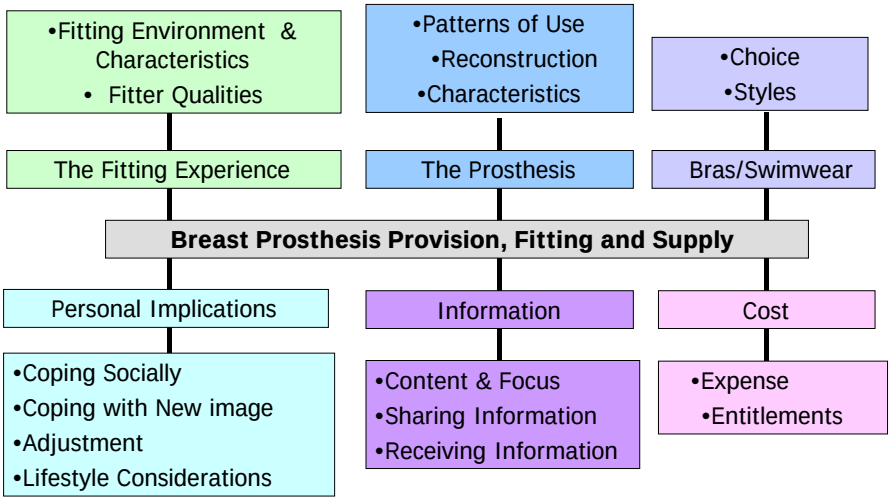

Figure 1: Summary of Focus Group Themes

PART 2 – NATIONAL SURVEYS

The second part of the study consisted of four concurrent national surveys. Survey 1 explored the experiences of women with breast cancer (n=527). Survey 2 investigated the views of breast care nurses (BCNs) (n=32). Survey 3 and Survey 4 documented the views of retail prosthesis fitters (n=12) and retail bra fitters respectively (n=6). The main findings from this part of the study are listed below.

Patterns of Prosthesis Use

- The majority of women reported using the full-weighted traditional silicone prosthesis (55.6%) or the light-weighted silicone prosthesis (21.6%) most regularly.
- 26.4% of women continue to use their temporary post-operative soft fibre filled prosthesis at least one year post surgery and 7.6% of women indicated that this was the type of external breast prosthesis that they used most regularly.
- 92.5% of women wear their external breast prosthesis all or most of the time.
- 61.8% and 62.2% of women perceived themselves to be limited in buying clothes and swimming because of the use of an external breast prosthesis.

- Almost half of the women considered that they were limited in sports and sexual activity because of their prosthesis and almost one-quarter of women perceived themselves to be limited in socialising.

Perceived Importance of and Satisfaction with External Breast Prosthesis

- Women, breast care nurses, commercial/retail prosthesis fitters and bra fitters perceived the external breast prosthesis to be important for balance, posture, shape, appearance to self, appearance to others, sense of well-being, self-confidence and femininity.
- The most important aspects of wearing an external breast prosthesis for women were shape (91%), self-confidence (90.9%) and appearance to self (90.4%).
- While women are generally satisfied with the external breast prosthesis that they wear most regularly, a sizeable proportion expressed dissatisfaction with various aspects of the prosthesis, in particular its weight (24.4%), comfort (17.3%) and movement with the body (14.3%).

Fitting

Temporary Soft Prosthesis

- 49.9% of women reported that they were fitted for their temporary soft prosthesis in a hospital ward. Some 41.7% reported that they were fitted in the breast care nurses' office.
- Women were generally satisfied with the environment within which they were fitted for their temporary soft prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (39.8%), display of products (35.4%), choice of products (35.8%) and time to look at products (30.3%). It is also important to note that one out of every five women expressed a level of overall dissatisfaction with the fitting environment for the temporary soft prosthesis.
- Women who were fitted in a breast care nurse's office were significantly more likely to rate the lighting, space, mirrors, privacy, display of products, choice of products, time to look at products, brochures and overall satisfaction with the fitting environment more positively than women who were fitted with their temporary soft prosthesis in a hospital ward.
- Women indicated that their preferred location for the fitting of the temporary soft prosthesis was the breast care nurses' office (71.8%). Similarly, 78.1% of breast care nurses pinpointed a 'specialised fitting room in breast care unit' as the location of choice for the fitting of the temporary prosthesis.

First Silicone Prosthesis

- 62.1% of women reported that they were fitted for their first silicone prosthesis in a hospital setting whereas 18.8% were fitted in a specialised prosthesis supplier.
- Women were generally satisfied with the environment within which they were fitted for their first silicone prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (32.5%), display of products (27.0%), choice of products (25.6%) and space (22.6%).

- Women fitted with their first silicone prosthesis in a hospital were more satisfied with the privacy of the fitting environment than women fitted in a specialised prosthesis supplier.
- 51.4% and 24.8% of women indicated their preferred location for the fitting of the first silicone prosthesis as being the hospital and a specialised prosthesis supplier, respectively. Some 77.4% of breast care nurses indicated that their preferred location for the fitting of the first silicone prosthesis was the hospital, whereas 25% of retail prosthesis fitters identified a specialised prosthesis supplier as their chosen location for the fitting of a first silicone prosthesis.

Replacement Prosthesis

- The most common fitting environments for replacement prostheses, as reported by the women, were the hospital (46.1%) and the specialised prosthesis supplier (32.0%).
- Women were generally satisfied with the environment within which they were fitted for their replacement prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (24.0%), display of products (22.4%), choice of products (23.0%) and time available (18.5%).
- At the fitting for a replacement prosthesis, women who were fitted by a specialised prosthesis supplier expressed greater satisfaction with space, display of products, choice of products and brochures than women who were fitted in the hospital environment for the replacement prosthesis.
- 37.6% and 31.6% of women identified the hospital and the specialised prosthesis supplier as their preferred locations for the fitting of the replacement prosthesis. Some 42.3% and 27.3% of breast care nurses and prosthesis fitters identified the specialised prosthesis supplier as their preferred location for the fitting of the replacement prosthesis.

Overall Comment on Fitting Environment

- Women were dissatisfied with the display of products, choice of products and brochure availability across all different stages of fitting. While the hospital is the preferred environment during the earlier stages of fitting, there is a shift towards an increased preference for and attendance at the specialised prosthesis supplier as the woman becomes more accustomed to wearing an external breast prosthesis and replacing her prostheses.

Characteristics of the Person Fitting the Prosthesis

Temporary Soft Prosthesis

- The majority of women (68.0%) were fitted with their temporary soft prosthesis by a breast care nurse.
- Women were consistently and significantly more satisfied with the characteristics of the person who fitted them with a temporary soft prosthesis if that person was a breast care nurse or trained fitter.
- The majority of both the women (71.8%) and breast care nurses (93.1%) indicated that their preferred person to fit the temporary soft prosthesis was the breast care nurse.

First Silicone Prosthesis

- 59.7% and 29.9% of women were fitted with their first silicone prosthesis by a breast care nurse and trained fitter, respectively.
- Overall women were satisfied with the characteristics of the person fitting their first silicone prosthesis. However, 10.3% and 10.5% of women indicated a level of dissatisfaction with the time available and emotional support given by the person fitting the first silicone prosthesis.
- 58.1% and 35.3% of women identified their *preferred person to fit the first silicone prosthesis* to be the breast care nurse and trained fitter respectively. Breast care nurses and commercial/retail fitters identified themselves as the ideal people to fit the first silicone prosthesis.

Replacement Prosthesis

- 42.5% and 41.0% of women were fitted with their replacement prosthesis by a trained fitter and breast care nurse, respectively.
- Overall women appeared satisfied with the characteristics of the person fitting their replacement prosthesis. However, women indicated a level of dissatisfaction with time available (10.5%) and emotional support (8.5%) given by the person fitting the replacement prosthesis.
- There were no significant differences in women's satisfaction with the characteristics of the person fitting the replacement prosthesis between women fitted by a breast care nurse and women fitted by a trained prosthesis fitter.
- The majority of women (52.1%), breast care nurses (53.5%) and prosthesis fitters (72.7%) identified a trained fitter as the ideal person to fit the replacement prosthesis.

Overall Comment on Fitter Characteristics

- Over all time periods, women expressed a consistent level of dissatisfaction with the emotional support given by the person fitting the prosthesis and the time available to the women. Furthermore over time, it is evident that an increasing number of women are fitted with their prostheses by a trained fitter and the gap in satisfaction ratings between the trained fitter and breast care nurse is reduced. In addition, while there is a clear desire to be fitted by a breast care nurse in the early stages, there is a clear preference for the replacement prostheses to be fitted by a trained fitter.

Mastectomy Bras

- The majority of women, who consider the purchase or availability of mastectomy bra products to be relevant to them, are dissatisfied with the availability of mastectomy bra products.
- 16.2% of women highlighted an overall dissatisfaction with mastectomy bras. In particular, dissatisfaction is expressed about the choice of bra styles (32.4%) and colour (32.7), value for money (22.4%) and appearance (20.0%).
- 41.8%, 22.4% and 18.2% of women were fitted for their bra in a hospital, lingerie shop/department store, and specialised prosthesis supplier, respectively.

- Women expressed a greater level of satisfaction with the characteristics of the person fitting the bra when fitted with either a breast care nurse and/or trained fitter than when fitted by a sales assistant.
- While the majority of women were satisfied with aspects of the environment where they were fitted for their mastectomy bras, approximately one in four women were dissatisfied with the availability of brochures, display of products and choice of products.

Other Fitting Issues

- Respondents to the breast care nurse questionnaire were particularly dissatisfied with the space (45.2%), display of products (36.7) and storage area for products (58.1%) in their fitting environment. This endorses the women's dissatisfaction with similar aspects of the fitting environment. However, while a sizable proportion of women (24%) indicated dissatisfaction with brochure availability, breast care nurses and prosthesis fitters did not.
- 75% of breast care nurses did not think that there were sufficient staff employed to meet the number of fittings required.
- 51.6%, 90.9% and 33.3% of breast care nurses, commercial/retail prosthesis fitters and bra fitters, respectively, consider that the *choice of products* available on the market satisfactorily meets the women's demands.
- 62.1%, 50% and 80% of breast care nurses, commercial/retail prosthesis fitters and bra fitters, respectively, reported that there were products not on the market that there was a demand for.
- When women were asked if they had a *choice of where to go* to get fitted for a prosthesis, 28.1% said they had, 36.0% said they had no choice, and 35.8% did not know. Despite only a minority indicating that they had a choice, 68.8% of women indicated that having a choice of fitting centres was important or extremely important.
- 26.4% of women indicated that *travel distance* to the fitting centre limited their ability to avail of replacing a prosthesis.

Waiting Times

- The average length of time between making the *appointment* and being fitted was 2.4 weeks (SD 2.6) (range 0.2-30 weeks)
- 72.4% of women indicated that their first silicone prosthesis was available on the day of fitting, 27.6% reported that it was not. For those women who did not receive it on the day of fitting, the average wait was 4.5 weeks (SD 4.2), range 0.5-25 weeks.
- 41.1% of women reported that their replacement prosthesis was not available on the day of fitting. For these women, the average wait was 22.3 days (SD 13.89), range 4-84 days.
- 80.1% of women indicated that they were fitted each time they got a new prosthesis; 53.8% and 81.8% of breast care nurses and commercial/retail prosthesis fitters, respectively, reported that in their experience women are always re-fitted prior to receiving replacement prostheses.

- 16.3% of women, who had not replaced a prosthesis, had had the same prosthesis for more than 4 years, despite recommendations that a replacement is advisable every 2 years. The average time specified for replacing the prosthesis was 2.3 years (SD 1.5) (range 0.5-12 years).
- 48.5% of women indicated that their bra was available on the day of fitting/purchase; 51.5% reported that the bra was not available on the day of fitting/purchase. For those women who indicated that the bra was not available, the average waiting time for receipt of the bra was 21.1 days (SD 13.3) with a range of 3-84 days.

Cost

- 35% of women who had replaced their prosthesis received it free of charge.
- 2.9% of women who receive their replacement free of charge do not have health insurance or a medical card. Conversely, there are approximately 16.3% of women who indicated that they have a medical card and do not get their replacement prosthesis free of charge.
- The average cost for each prosthesis bought was €125.4 (SD 53.4) (range €15-€300); 43.3% of women who were paying for their prosthesis indicated that the cost of the prosthesis influenced when they replaced it.
- The average cost of each bra bought was €38.6 (SD 15.8) (Range €5-150).
- 48.3% of women indicated that the cost of the mastectomy bra influenced when they replaced it.
- The average cost of a mastectomy-pocketed swimsuit was €77.4 (SD 27.49) (range €5-150).
- All commercial/retail fitters contract directly with the insurance companies; 91.7% (n=11) accept the medical card. Of these, 81.8% process the claim on the client's behalf. None of the bra fitters contract with the insurance companies nor do they accept the medical card.

Information Needs & Provision

- 46.0% of women indicated that they had not received information on prostheses and bras.
- One in three women was dissatisfied with the information they received on entitlements. Approximately one in four women was dissatisfied with the information they had received on cost of prostheses, types of bras, costs of bras, mastectomy swimwear, and location of fitters.
- The top three preferred ways of receiving information on prostheses and bras were (1) face-to-face meeting with breast care nurse; (2) information booklet; and (3) other women with experience of breast cancer or from the retail fitter, both of which had similar mean rankings.

Adjustment

- On average the cohort of women in this sample have good quality of life and a low number of arm and breast symptoms.
- Women who had replaced their prosthesis but did not receive it free of charge and who indicated that cost influenced when they replaced it had significantly lower scores in each of the quality of life domains than woman who said that cost did not influence when they replaced their prosthesis.

- Higher levels of satisfaction with aspects of the external breast prosthesis were associated with higher quality of life scores in each of the WHOQOLBREF domains (i.e. physical health, psychological, social relationships and environment) and fewer breast and arm symptoms.

Professional Development

- 69.0% of breast care nurses and 33% of commercial/retail prosthesis indicated that there was insufficient opportunity for professional development in the field of prosthesis fitting. Forty percent of bra fitters considered that there was insufficient opportunity for professional development in the field of mastectomy bra fitting.

Standards of Care

- The majority of services had a follow-up service for issues related to fitting and also a follow-up service for complaints. However, these were localised follow-up services.
- While nurses are bound by their professional code of conduct, there are no national or external service guidelines and protocols for commercial/retail prosthesis fitters or bra fitters.

RECOMMENDATIONS

Overall, this research provides a detailed picture of women's experiences in the provision, fitting, supply and use of external breast prostheses in Ireland and has informed the following recommendations.

1. Develop protocols, standards, and best practice guidelines in the provision, fitting, and supply of external breast prostheses for women in Ireland as a matter of expediency.
2. Make available professional development opportunities for those fitting external breast prostheses that augment existing expertise and where necessary, the capacity to provide emotional support.
3. Establish a standardised complaints/satisfaction procedure in order to further develop the service.
4. Provide optimal fitting environments that incorporate:
    - a display and choice of products, and brochures of same;
    - sufficient time to peruse and fit products;
    - adequate privacy and space;
    - good lighting and ventilation;
    - available mirrors.
5. Develop and expand fitting options in supportive environments in a range of geographical locations. Women need to be given a choice in where they are fitted with their prosthesis and by whom, recognising that breast care nurses may be the most appropriate in the early stages post-mastectomy with retail fitters becoming more so as time progresses.

6. Disseminate information on the types and costs of prostheses, locations of fitting centres, entitlements, and available supports using multiple formats including brochures, face-to-face meetings with breast care nurses and fitters, roadshows and mailshots, across multiple time periods including before and after surgery and at replacement prosthesis fitting. Readily available information stimulates self-help and informed choice. Women must be made aware of their entitlements and know how to access the services they require.
7. Develop a buyer's specification for the range of prostheses and post-mastectomy products that should be supplied.
8. Address equity in the provision of breast prosthesis services throughout the country. All suitable products should be available to all women in all parts of the country. Products should be available to all women in a timely fashion and there should be equitable costs and expenses nationwide.
9. Lobby the Irish Government to ensure financial protection in the purchase of breast prostheses and mastectomy bras.
10. Monitor and re-evaluate women's experiences as services develop and change.
11. Incorporate this research and its findings into future health policy and strategies at national, regional and local levels.

To conclude, it is imperative that the empirical evidence base and recommendations made are used by policy makers and practitioners to facilitate women's experiences in relation to external breast prostheses.

Chapter 1

Introduction

1.1: INTRODUCTION

In Ireland, an average of 1,726 women are registered with breast cancer each year (National Cancer Registry Ireland, 2005). Early screening and advances in treatments mean that more women are living with and recovering from breast cancer than ever before. An integral part of the recovery post surgery involves considering restorative options. For many women in Ireland this means being fitted with an external breast prosthesis, though for some it may mean reconstructive surgery and for others it may mean neither. Breast prostheses are designed to restore the woman's self-confidence in her appearance, thus curtailing the impact of the disease on her psychological health (Shimozuma et al., 1999). The importance of a good quality prosthesis and prosthesis-fitting service is paramount for body image, femininity, and psychosocial well-being following breast cancer surgery (Nissen et al., 2001; Mahon & Casey, 2003; Roberts et al., 2003; Murphy 2004; Breast Cancer Care, 2006c). Consequently, the fitting of a good-quality prosthesis is an essential aspect of post-mastectomy care and it is imperative that accessible services supplying breast prostheses are provided for women post surgery. In the absence of Irish literature and research in the area, the overall purpose of this research project is to gain an insight into women's experience of the provision, fitting, supply and use of breast prostheses in Ireland. The aim is to significantly involve women who require prostheses and the people who provide the service in research in order to affect the development of policy guidelines directly responding to identified need.

This research has arisen directly as a response to queries to Action Breast Cancer (ABC) from members of the public who have found it hard to get information and good-quality service in the provision of external prostheses following surgery. ABC is a national project established by the Irish Cancer Society to provide breast cancer information and support and to fund breast cancer research. Its services include a national freefone helpline staffed by specialist cancer nurses, information booklets, health promotion, a Reach to Recovery Programme, which offers one-to-one emotional support by former breast cancer patients, research and advocacy. According to ABC, there is a clear inequality in the provision of breast prosthesis services throughout the country. They maintain that there is insufficient accountability and a no complaints procedure in place. They have also noted that for some patients the purchase of their prostheses is a huge financial burden. There is no research base for this topic within an Irish context and no documented evidence of patient's experiences. There is no detailed information known about how women access information about breast prostheses, their pattern of prosthesis use, their satisfaction levels and how the prosthesis impacts on their quality of life. Consequently, a comprehensive research programme is required to inform best practice.

Recent policy and review documents published by the Department of Health and Children emphasise the importance of espousing patient-centredness. For example, national goal 3 of the 'Health Strategy – Quality and Fairness: A Health System for You' (2001) emphasises responsive and appropriate care delivery (Department of Health and Children, 2001). In achieving this goal, a patient-centred and responsive system is required that develops ways to engage with individuals and the wider community receiving services. In particular, collating structured feedback has been identified as an essential input to policy planning and routine patient satisfaction surveys have been recommended. With regard to cancer services, specific reference is made to developing, implementing and evaluating evidence-based practice guidelines and protocols that cover prevention, treatment, rehabilitation and palliative care in both community and institutional settings (p83).

This research will also build on earlier documents, which highlighted an ongoing requirement to review cancer services. According to 'An Evaluation of Cancer Services in Ireland: A National Strategy 1996', there was only a moderate level of satisfaction with cancer services in Ireland, with over a quarter of respondents indicating a level of dissatisfaction (Department of Health and Children, 2003). In April 1999, the Minister for Health and Children asked the National Cancer Forum to report and make recommendations on the development of breast services for symptomatic women. This report, entitled 'Development of Services for Symptomatic Breast Disease' aimed to develop a multidisciplinary service involving surgeons, radiologists, pathologists, medical oncologists, radiotherapists and others to bring expertise together to provide the best care for each patient (Department of Health and Children, 2000). There were only two brief references to breast prostheses in this 33,045 word document. Firstly, that the breast care nurse (BCN) should discuss with patients the fitting and supply of breast prostheses and plan a patient's discharge to ensure that the necessary support facilities are available and secondly that Breast Units should be able to offer specialist advice regarding 'the availability of wigs and prostheses and other supports…' According to the Department of Health and Children, there are many inadequacies in the current system of primary care. Such inadequacies mentioned include 'limited opportunities for user participation in service planning and delivery' and 'an emphasis on diagnosis and treatment with weak capacity for prevention and rehabilitation'.

The inadequacies in service provision in regard to breast prostheses in Ireland as recognised by those working at practice and policy level are confounded by insufficient research. Indeed, Hart et al. (1997) have argued that the provision of breast prostheses is an area of a woman's post-mastectomy treatment that has the least amount of objective information available and that has been subject to the least amount of scientific inquiry. According to Healey (2003), a rigorous, evidence-based approach to the evaluation of external breast prostheses would enhance both the development of the service, as well as the adjustment, well-being and quality of life of breast cancer survivors. It is within this context that this research will seek to:

i. Assess factors and perceptions that impact on access, equity, quality and affordability in relation to the needs of women requiring a breast prosthesis

ii. Assess the type, content, timing and mode of providing external breast prosthesis information to women and how this might impact on their experience of acquiring or replacing an external breast prosthesis

iii. Identify factors that promote quality in the supply, fitting and aftercare of all external breast prostheses and related products (e.g. mastectomy bras).

1.2: BREAST CANCER STATISTICS IN IRELAND

According to the most recently available cancer statistics from the National Cancer Registry Ireland (NCRI), with the exception of non-melanoma skin cancer (NMSC), breast cancer was the most common cancer in women (28% excluding NMSC) for the years 1994-2001 (NCRI, 2005). The annual average of women registered with breast cancer between 1994 and 2001 was 1726 cases with a significant annual percentage *increase* in breast cancer *incidence* for women (2.1%). Simultaneously, while breast cancer was the most common cause of cancer death in women in the same period (18% of all cancers), the annual average of women who died from breast cancer was 644 with the age-standardised *death rates* for breast cancer in women *decreasing* over the time period.

An earlier NCRI report documenting cancer statistics for the period 1994-2000, estimated that in 1997 there were 22,446 women alive with breast cancer at any one time, representing 1.2% of the female population (NCRI, 2004). In more recent correspondence with the NCRI in 2005, it has been estimated by the NCRI that this figure has increased to approximately 24,500 women alive with breast cancer in Ireland at present. However, it is important to note that this figure is an estimate. In conjunction with the increasing incidence and decreasing mortality since 1994, in February 2000, BreastCheck was developed in the eastern half of Ireland to provide free breast screening every two years to women aged between 50 and 64 years of age to reduce the number of deaths from breast cancer in Ireland amongst this age group. On 5 May 2005, the Tánaiste and Minister for Health and Children, Mary Harney T.D. issued approval for the national expansion of this service.

With regard to the treatment of breast cancer, over 80% of people with breast cancer had surgery as a form of treatment either on its own or in combination with radiotherapy, chemotherapy and/or hormone therapy between 1994 and 2001 (NCRI, 2005). The rate of surgery as a treatment modality fell with increasing age (NCRI, 2005). To further break down surgery as a treatment modality requires reviewing data from an earlier NCRI report covering the years 1994-1999 (NCRI, 2003). This report documents data from the Hospital InPatient Enquiry (HIPE) regarding type of surgery which indicated that just over half of the surgery for breast cancer in Ireland in 1999 consisted of a total mastectomy

and just under half consisted of partial mastectomy. The majority of total mastectomies were unilateral with less than 1% having a bilateral mastectomy.

1.3 POST SURGERY OPTIONS: EXTERNAL BREAST PROSTHESIS VS RECONSTRUCTION

It is important to note that not all women who have had a total or partial mastectomy will want or require an external breast prosthesis. There is a growing demand for breast reconstruction after breast surgery. According to Morrow et al. (2001), little is known about patterns of use of reconstruction, however, advances in surgical techniques and changes in our understanding of the biology of breast cancer have made immediate or early breast reconstruction a viable option for the majority of women with breast cancer. Callaghan et al. (2002) have noted the increasing popularity of breast reconstruction as safe reconstructive techniques have evolved, along with increased availability of surgical expertise. However, they found that surgeons performing in Ireland were significantly less likely than those in the UK to discuss breast reconstruction before the operation, to perform reconstructions themselves, to have patients who received immediate breast reconstruction or to have access to plastic surgery services. In spite of this, there has been increased interest in reconstructive procedures in more recent times, and Callaghan et al. have noted that the publication of the Irish National Cancer Forum suggests that these practices will change in Ireland in the future. Although there are no official Irish statistics available on rates of reconstruction surgery, according to the Comhairle na nOspidéal's report (2005) entitled 'Plastic Surgery Services', the need for reconstructive surgery following breast cancer within the general hospital framework is an area where demand exceeds supply.

Although reconstruction following breast surgery has become more common in recent times, there are still an estimated 16,000 women in Ireland who have undergone a mastectomy and potentially require a breast prosthesis. This figure is based on the annual number of women requiring breast surgery for cancer (an estimated average of 1,188 as per the National Cancer Registry, 1994-1999) and an estimate of the accumulative number of women from previous years. This figure was derived during consultation and correspondence with the National Cancer Registry Ireland but it is important to note that it is an estimate. For many reasons there will always be a need for the external prosthesis. Some women simply do not desire additional surgery or are anxious about having a foreign object in their body (Healey, 2003). In addition, many women have age-related issues and comorbidities that prevent them from having reconstructive surgery. Reaby (1998), in a survey of 64 women with an external breast prosthesis and 31 women who had had breast reconstruction, reported that the most frequent reasons for not having breast reconstruction in the prosthesis group were (1) not essential for physical well-being (2) not essential for emotional well-being (3) not having sufficient information about the procedure and (4) not wanting anything unnatural in the body. With regard to the group of women with a breast reconstruction, the most frequent reasons for having the reconstruction

included: (1) to get rid of the external breast prosthesis; (2) to be able to wear many different types of clothing; (3) to regain femininity; and (4) to feel whole again. There is much conflicting evidence regarding the debate between reconstruction and the external prostheses. According to Healey (2003), many studies have reported the large benefits from reconstructive surgery. Similarly, Rowland et al. (1993) have suggested a significant improvement in body image, sense of femininity and general psychological well-being compared to those who do not undergo reconstructive surgery. On the other hand, more recent research by the National Cancer Institute reported that women describe the same levels of satisfaction with their lives whether or not they undergo reconstruction (Zuckerman, 2002). Irwig and Bennetts (1997) noted that survival after breast conservation is similar to that after mastectomy; therefore, women should generally have a choice between treatments. In order to help practitioners provide accurate information, Irwig and Bennetts reviewed literature to find all randomised control trials comparing breast conservation to mastectomy with quality of life or psychological effects as an outcome. Their search identified six relevant, fully reported trials. Background characteristics, which might affect generalisability, were determined from the studies (e.g. women's age, other therapies given, etc.) and internal validity was determined based on standard criteria (e.g. blind assessment, similarity of quality of life measure, etc.). Irwig and Bennetts found no evidence for a difference in psychological health, sexual health, physical health, fear of the future and global quality of life between mastectomy and breast conservation. Many women have been found to choose reconstructive surgery in order to have a feeling of permanence and fewer physical reminders of losing a breast (Kiefer, 2001). However, a study by Nissen et al. (2001) suggested that women who had a mastectomy without reconstruction experienced greater feelings of well-being.

Despite the inconclusive nature of the relative advantages and disadvantages of the differing modes of breast restoration, it is clear that a non-surgical option is still a requirement. Furthermore, this option should be as individualised as a surgical option (Healey, 2003). The need for choice should extend to all aspects of cancer care including the type, supply, fitting and provision of external breast prostheses.

In summary, with increasing incidence of breast cancer, the earlier detection of breast cancer due to BreastCheck and the increasing number of women surviving breast cancer, the number of women requiring a breast prosthesis will likely increase further in future years. Although breast reconstructive surgery is on the increase, there are still many women who wear an external prosthesis either through choice or because age or the presence of comorbidities prohibits reconstructive surgery, and therefore their needs and experiences should be documented and met.

Chapter 2

External Breast Prostheses: Setting the Scene

2.1: DEFINITION OF EXTERNAL BREAST PROSTHESES

A breast prosthesis is an artificial breast form that fits into a bra in order to replace the natural breast. It is most often used after surgery for breast cancer, either after a mastectomy (removal of the breast) or a wide local excision (removal of a lump and some surrounding tissue) (Action Breast Cancer, 2004). A temporary prosthesis is fitted approximately one week following surgery and is worn until the wound has healed or sensitivity arising from further treatment such as radiotherapy has subsided. The permanent prosthesis is fitted approximately 6-8 weeks post-operatively (Murphy, 2004) and tends to require replacement every 2 to 5 years (BreastCare Victoria, 2003). As can be seen in Table 2.1, an external breast prosthesis can be full or partial/shell, standard or lightweight, and self-supporting or loose.

Table 2.1: Description of different types of prostheses

Type	Description
Standard prosthesis	The standard prosthesis is made from silicone gel moulded to form the natural shape of a woman's breast, sometimes including the nipple outline. It is made to weigh the same as the normal breast. It rests against the chest wall and is held in place by the bra.
Partial prosthesis	This is a shell-type prosthesis, which is hollow and fits over the remaining breast tissue, restoring the breast to its original shape. Alternatively it refers to a small, wedge-shaped prosthesis to fill out the bottom, top or side of the bra. This type of prosthesis is generally required following a wide local excision where much breast tissue may not have been lost but may result in a different breast shape.
Lightweight prosthesis	For women who find the standard prosthesis too heavy, the lightweight prosthesis is also made of silicone but weighs less than the standard prosthesis.
Self-supporting prosthesis	These prostheses stick directly to the skin by using adhesive strips that stick to the back of the prosthesis. They may feel more natural and secure than other types which simply fit into a bra cup. However, these prostheses still need the support of a well-fitting bra.
Foam/swimming prosthesis	This is a lightweight prosthesis made from foam or silicone and specially designed for swimming or sports.
Prosthetic nipple	These are artificial nipples in different sizes and skin colours that can be stuck onto the prosthesis or after breast reconstruction where there is no nipple.
Temporary prosthesis	This is a lightweight, fibre-filled prosthesis that can be worn immediately following surgery until the scar has fully healed. It is made of synthetic washable fibre inside a cotton cover.

Source: Based on information in the ABC Factsheet on Breast Prostheses

2.2: USE OF EXTERNAL BREAST PROSTHESES

Approximately 75% of participants in the BreastCare Victoria (2003) study reported wearing their prosthesis every day or most days. Reasons mentioned for wearing the prosthesis included a desire to achieve a natural look, to feel comfortable, to feel balanced and to get accustomed to using it. This pattern of usage is in contrast to many earlier studies. According to Feeley, Peel & Devlin (1982) many women wear the prosthesis only when they are outside the home and others continue to wear the temporary prosthesis years after surgery. This has been supported by Tanner et al. (1983) who discovered that 17% of women were still using temporary prosthesis six months and more after surgery. They also reported women filling the empty cup of the bra with cotton wool, an old sock, a discarded pair of tights or bird seed. Furthermore, they reported that 23% of the women wore their prosthesis only when going out; at home they chose not to wear it.

Although it is generally assumed that women who have undergone a mastectomy and have not obtained reconstruction will automatically wish to be fitted with a breast prosthesis, this is not always the case. According to Potts (2000), some patients believe that a prosthesis or reconstruction is an attempt at hiding the problem and perhaps sheltering people from the reality of the disease. Lorde (1980) has supported this claim by stating that false breasts represent the 'passive acceptance of false values'.

2.3: SATISFACTION WITH AND QUALITY OF EXTERNAL BREAST PROSTHESES

External breast prostheses can have a negative impact on femininity and body image, be expensive, be uncomfortable due to sweating caused by the heat of the prosthesis, be heavy, have an unpleasant texture, restrict choice in clothing, make noises or become displaced with movement (Smoot, Silverman & Cohen, 1979; Feeley, Peel & Devlin, 1982; Tanner et al., 1983; Reaby & Hort, 1994; Reaby 1998; Thijs-Boer & Van de Weil, 2001). However, a number of studies have also reported a reduction in the level of emotional distress and frustration with the practical problems of prosthesis use over time (Hart et al. 1997; Reaby & Hort, 1995; Roberts et al., 2003). Satisfaction with an external breast prosthesis has been linked to aspects of the fitting experience, characteristics of the fitter, and the provision of adequate support and information (Smoot et al., 1979; Lee, 1991; Tanner et al., 1983). More recently, Roberts et al. (2003) explored issues relating to quality of breast prostheses in focus group discussions with women, breast care nurses and fitters. Consumers, fitters and breast care nurses consistently reported that natural appearance and the shape of the prosthesis were features associated with the quality of the prosthesis. Other factors associated with quality prostheses were comfort when worn, durability, lightweight, value for money, easy care, feel real, movement with the body and finally that the prosthesis was produced by reputable manufacturers that provided a good service. In general, participants reported satisfaction with their prosthesis and with mastectomy bras. Roberts et al. (2003) identified the quality of the prosthesis as one of the most

important aspects considered when selecting a breast prosthesis. This was supported by BreastCare Victoria (2003) who identified that the most important feature considered when buying a prosthesis included shape that closely matches the other breast (63%), natural look (57%) and comfortable to wear (49%). Only 5% of women indicated price of prosthesis as a factor in selection. Quality remained a key factor in prosthesis selection over time with women rating lightweight, shape, size and natural appearance as important when choosing their replacement prosthesis.

Livingston et al. (2005) stated that it was unclear as to what constituted a quality prosthesis. Consequently, they undertook a study to determine what factors affected prosthesis satisfaction and what factors constituted a quality prosthesis. With regard to satisfaction, Livingston et al. (2005) found that at 1 week post fitting, a high level of satisfaction was associated with how well the prosthesis fitted the woman. At 3 months post fitting, satisfaction was best predicted by how well the prosthesis fitted the woman and by the level of comfort. At 6 months post fitting, appearance of the prosthesis when worn was the best predictor of satisfaction. With regard to ratings of the quality of the prosthesis, 43% of the women thought their prosthesis to be of excellent quality at 1 week post fitting, 38% at 3 months post fitting, and 39% at 6 months post fitting. A high quality rating at 1 week post fitting was predicted by how well the prosthesis fitted the woman and how natural it felt. At 3 months post fitting, an excellent quality rating was predicted by the weight of the prosthesis and how well it fitted the woman. Finally, an excellent quality rating was best predicted by appearance when worn and how natural it felt at 6 months post fitting.

Thijs-Boer et al. (2001) conducted a prospective randomised crossover study of 91 women undergoing one-sided mastectomy for breast cancer to compare the self-adhesive breast prosthesis with the traditional breast prosthesis. Some 59.3% preferred the self-adhesive breast prosthesis and this preference was independent of age, randomisation order or the possible use of adjuvant chemotherapy. Preference for this type of prosthesis was related to an increased perception of the prosthesis as a part of the body, whereas preference for the traditional prosthesis was related to ease of application and less local irritation of the skin. According to Healey (2003), women might be dissatisfied with aspects of the external breast prosthesis that could be altered. For example, difficulties with the weight and heat of prostheses, which results in perspiration in the chest and abdominal area, are frequently commented on by women. However, lighter weight prostheses have been found to ease this discomfort and also bras with fast-drying fabrics have been developed to improve the situation (Kiefer, 2001). Therefore, it is important that studies on the satisfaction levels of women who wear an external breast prosthesis define specific physical characteristics of the prosthesis. It is also important that research exploring the psychosocial and physical correlates of satisfaction with the external breast prosthesis is undertaken. For example, what relationship exists, if any, between quality of life and satisfaction with a prosthesis? Furthermore, what relationship exists, if any, between satisfaction with a breast prosthesis and such factors as age, length of time since first

using a breast prosthesis, or physical well-being? According to Gottrup et al. (2000), 75% of women with breast cancer may experience chronic pain, lymphoedema, post-irradiation neuropathy, phantom pain or sensory disturbances following treatment. As more women are surviving breast cancer due to progress in diagnosis and treatment, the population at risk for chronic pain can be expected to increase in coming years (Jung et al., 2003). It has been well documented that chronic pain can be a source of considerable disability and psychological distress (Jung et al., 2003). Women with post-mastectomy pain have reported a significantly poorer quality of life than breast cancer patients without pain (Carpenter et al., 1998). Due to this pain, some breast cancer patients must apply for disability benefits or reduce their work schedule to part time (Jung et al., 2003). Also, these sensations were noted as constantly reminding the women of their mastectomy experience (Bredin, 1998). Finally, Jung's research also notes that women with chronic pain and discomfort following a mastectomy are at greater risk for psychiatric morbidity including depression and anxiety. As a result, pain is a potential factor that may impact on a woman's experience of her breast prosthesis and is worthy of further consideration.

2.4: ACCESS TO EXTERNAL BREAST PROSTHESES

In Ireland, there are currently 58 nurses from 28 hospitals working in breast care across 15 counties. Twenty-two of these hospitals fit the initial prosthesis/bra and 10 of these hospitals also have a refitting service (Cork-2, Donegal, Galway, Mayo, Portlaoise, Sligo, Kerry, Waterford and Wexford). There are 14 retail outlets supplying prostheses/bras at present in Ireland across 10 counties (Dublin-3, Cork-2, Galway-2, Carlow, Kilkenny, Limerick, Mayo, Monaghan, Waterford and Wexford). Two of these outlets (1 in Dublin, 1 in Cork) are general medical supply outlets and the others are mastectomy fitting centres. Medical card holders are restricted in where they can obtain their mastectomy products, for example, only one of the three retail fitters in Dublin are contracted to supply women on the medical card with prostheses and bras. To sum up, from the 26 counties in Ireland only 14 possess an outlet supplying replacement prostheses/bras and, of these, most only have one prosthesis fitting centre to supply the whole county. There are 17 retail outlets across six counties in Ireland that supply mastectomy bras without the prostheses (Dublin-7, Cork-4, Galway-3, Longford, Donegal and Waterford). With an estimated 16,000 women requiring a replacement prosthesis every 2 years, plus bras, swimsuits, etc., these resources are predictably stretched.

In Australia, BreastCare Victoria identified accessibility issues, which particularly affected rural women as opposed to women living in metropolitan areas. A lack of availability of different types of prostheses was identified, increased travel was noted in accessing fitters, concerns regarding confidentiality were expressed and finally, a possible inaccessibility to breast care nurses was mentioned (BreastCare Victoria, 2003).

2.5: FITTING OF EXTERNAL BREAST PROSTHESES

2.5.1: Breast care nurses / fitters

The provision of a well-fitting prosthesis and mastectomy bra is an essential aspect of the healing process and in improving quality of life post-mastectomy (Mahon & Casey, 2003; Roberts et al., 2003). Roberts et al. (2003), in their focus group study of the experiences and views of women with breast cancer, breast care nurses and prosthesis fitters, suggested that the characteristics of the fitters and the fitting experience and relationships with breast care nurses and prosthesis fitters were important to women's acceptance and satisfaction with their prosthesis. Furthermore, the study highlighted the significant role played by breast care nurses and the underestimation of the prosthesis fitter's role. Breast care nurses were identified as the main providers of support and information about breast prostheses and were critical in facilitating access to breast prosthesis services. Breast prosthesis fitters were recognised as important for the provision of information to women and for assistance with paperwork during the application. Mahon & Casey (2003) indicate that nurses play an important role in providing anticipatory guidance for the women so they will know what to expect during the fitting and how they can be prepared for it. Furthermore, they provide support and encouragement and facilitate adjustment during the initial and subsequent fittings. As a prosthesis fitting is an emotional experience, nurses play a role in ensuring that not only do the women receive a well-fitting prosthesis but that it is fitted in a caring and personal environment.

In addition to hospital clinics, prostheses are also available from retail outlets with retail staff specially trained by the breast prosthesis manufacturers (Livingston et al., 2000). Livingston et al. (2005) reported that fitters were generally held in high regard with 97% of fitters rated as either 'very good' or 'excellent'. This high rating of fitters was associated with two factors: knowledge and experience, and attitude towards the women. Indeed, attitude of the fitter has previously been identified as an important aspect in the acceptance of the fitting process and satisfaction with it (Smoot et al., 1979; Lee, 1991; Roberts et al., 2003). Fitters also seemed to have a strong influence on prosthesis selection as 98% of women stated that the fitters' opinions were important. Furthermore, fitters saw themselves as having an important role in supplying women with information and helping them to choose the appropriate product. Overall, fitters have been found to play a significant role by influencing the woman's use and adjustment to the prosthesis and also provide support and reassurance to the woman (Smoot et al, 1979; Lee 1991; Livingston et al., 2005). However, according to Livingston et al. (2000), they may not be sufficiently trained to deal with the psychological and emotional issues associated with this experience. In Ireland, the prosthetist as a profession is not recognised nor are there standards of competencies and behaviour for those who work as fitters in their role as fitters. Some may be registered as a nurse and subject to the statutory regulatory regime in that sphere. Those who act as fitters of bras are trained in the main by the suppliers and not subject to any external regulatory processes. In the UK, on the other hand, with the Health

Professions Council the prosthetist is fully registrable as a professional and under their statutory scheme of regulation there are legally enforceable standards of conduct, performance and ethics such that each prosthetist must protect the health and well-being of people who use or need their services in every circumstance. The British Association of Prosthetists and Orthotists has also produced guidelines for its members on a range of best practice issues. The actual impact that fitters have on women's overall satisfaction however remains unclear. The lack of a code of practice or regulatory framework for prosthesis fitters in the Irish context necessitates research into their role and its impact on the experience of women being fitted with or requiring an external breast prosthesis.

2.5.2: Fitting environment

Keeton and McAloon (2002) emphasise the importance of taking time to achieve a satisfactory fitting with Denton (1996), for example, recommending that at least 45 minutes should be given to each fitting. Ninety-six percent of participants in the Livingston et al. (2005) study rated their fitting experience as 'very good' or 'excellent'. High ratings were associated with number of styles of breast prosthesis shown and privacy. BreastCare Victoria (2003) highlighted the importance of discretion as concerns regarding confidentiality were expressed by women from small rural areas. Lee (1991) also noted the importance of privacy and the fitting being carried out by a woman. Further findings from Livingston et al. (2005) revealed that women from the intervention group with full subsidies were shown significantly more expensive prostheses than the control group. This may be because the fitters were sensitive to the fact that the cost was a more important factor for the control group and consequently showed them only the prostheses within their budget. However, whatever the reason, all women should be made aware of the full range of prostheses available to them.

2.5.3: Fitting guidelines

Keeton and McAloon (2002) noted the lack of a uniform approach to the fitting of prostheses and developed a 12-point plan for the supply and fitting of a temporary breast prosthesis, which they believe nurses and fitters should adhere to. Firstly, there are two points with regard to 'planning ahead' – discussing the use of the temporary breast form before surgery and secondly determining when the patient would like the prosthesis to be supplied (e.g. making the patient aware that the non-fitted prosthesis can be inserted into a gown immediately after surgery). The other 10 points relate to the actual fitting of the prosthesis. They note that a private room should be available with a full-length mirror, a skin tone breast should be provided and that sizes should be used as guides only, filler may need to be removed or added. They also suggested that a smaller breast size should be used with foam types (as they tend to look firmer and fuller), a minimum of two prostheses of the same size should be provided and washing instructions should be given. Security methods should be discussed with the patient (e.g. safety pins and stitching), the movement of the prosthesis should be checked and the patient should be encouraged to try on clothing to see her contour. Finally, the fitter should be patient and allow adequate time to ensure that the individual is satisfied with her

appearance. These guidelines have been used along with other literature to form the Irish breast care nurses Association's 'Guidelines for Practice' relating to the provision of a prosthesis (Murphy, 2004). There is a distinct lack of research into the fitting of temporary breast prostheses, which is a crucial aspect of post-mastectomy care. Keeton and McAloon (2002) recommend that this aspect of care should be evaluated as any other aspect of care would be, and that this could be enhanced by using anonymous satisfaction surveys.

In 2006, Breast Cancer Care in the UK developed and published '*Standards of Care for Prosthesis-Fitting Services'.* These standards emerged following the completion of a qualitative study, involving 38 telephone interviews with women, which explored people's experiences of accessing prosthesis-fitting services, identified unmet information and support needs and made recommendations on the essential features of a good-quality fitting service. These standards, which can be accessed in full at www.breastcancercare.org.uk, address the importance of women being fitted with an appropriate prosthesis, being seen by a female fitter, a fitting environment that is welcoming, accessible, private and comfortable, being able to see and try a range of prostheses, having well-trained and sensitive fitters, having sufficient time at a fitting appointment, knowing when the prosthesis will be available and how to care for the prosthesis, and having access to impartial information and guidelines for prosthesis replacement.

2.6: INFORMATION & ITS PROVISION

Women with breast cancer face many important decisions that require an informed decision, for example, whether to have reconstruction, to wear an external prosthesis or nothing at all. Reaby (1998) notes that women would benefit from information supplied by healthcare providers as to their options available for breast restoration including use of prosthesis and reconstructive surgery. Indeed, education about the various prosthetic options, both temporary and permanent can facilitate decision-making. Consequently, nurses and healthcare providers should be aware of the many different options that now exist for mastectomy patients and ensure that women are fully informed. Kiefer (2001) reports that women who feel that they have actively participated in their treatment decisions have a more positive adjustment to their surgical treatment. Overall, an informed decision is vital; Kraus (1999) has noted that women who are well informed adjust better to their treatment outcomes. Although the importance of information has been emphasised in the available literature, breast prosthetic science is not taught in medical or nursing education programmes and few articles exist on the subject (Kiefer, 2001). Breast prostheses are designed to outwardly restore the feminine shape, however, if women are to obtain the full psychological benefit of wearing a breast prosthesis, they need to be informed about the available breast forms and have an opportunity to choose between them and to be satisfied with the choice. In general, the responsibility of providing breast prosthesis information has fallen to the breast care nurse or to a volunteer from a breast cancer service,

providing that they have sufficient training and awareness. Available up-to-date evidence-based information provided by informed and unbiased individuals/professionals is important in dispelling myths and misinformation about external breast prostheses. According to Healey (2003), some fitters are retail staff who have been trained by the manufacturers and may not have had adequate education in healthcare or oncology and may not have the training to adequately deal with the psychological and emotional issues many women may experience. Manufacturers may also overstate the virtues and understate problems associated with their product. Even some websites, which provide general information on breast cancer, are maintained by external prosthesis manufacturers.

Tanner et al. (1983) carried out a study in order to investigate breast prosthesis services in Australia. This included an exploration of women's access to information regarding available breast prostheses. Although carried out in 1983, 50% of women received information about permanent breast prostheses from a health professional, and 25% had to seek their own information. Forty-five percent of women knew of prosthesis types other than the one they wore themselves. However, only 34% of women had been shown more than one type, so their choice had been limited. Roberts et al. (2003) indicated that the provision of adequate and timely information was important in facilitating women's acceptance of the breast prosthesis. They also highlighted the need for multiple sources of information and that information needed to be repeated by breast care nurses to the women. More recently, Livingston et al. (2005) reported that the majority of women considered that the information provided to them about breast prostheses was either very good or excellent. Furthermore, an excellent rating for the overall quality of information received was associated with the amount of information given and the accuracy of that information. Despite this high rating for information, the women identified that they would have liked additional information on the different types of prostheses, in particular additional information on the weights, styles, costs and expected lifespan of prostheses and financial assistance. Finally, in the UK, Breast Cancer Care (2006c), in their qualitative study, identified confusion and lack of information about entitlements, prosthesis products, caring for prostheses and clothing and swimwear.

2.7: FUNDING MECHANISMS

2.7.1: Irish service provision

In 2001, the Minister for Health and Children Micheál Martin T.D. stated that a total of €298,000 revenue was allocated to the health boards for the provision of prosthesis services to all breast cancer patients requiring such services. Accordingly, all post-operative patients requiring a breast prosthesis fitting are provided with their initial prosthesis and two bras free of charge, irrespective of their medical card status. Women who hold a medical card are entitled to two bras every year and a replacement breast prosthesis every two years, if required (Action Breast Cancer, 2004). In order to avail of this, medical cardholders must get a prescription from their GP and bring this prescription to

the local health centre in order to be processed. An official order form is then sent out to the medical cardholder, which can be used in some hospitals or retail suppliers (Action Breast Cancer, 2004). Women who do not hold a medical card may gain some reimbursement from insurance policies; some may cover a percentage of the cost while others have a minimum requirement, which must be met in order to make a claim (Action Breast Cancer, 2004).

2.7.2: International service provision

In the United Kingdom, NHS patients are entitled to the prosthesis of their choice free from the NHS (Breast Cancer Care, 2006b). They can receive a free replacement prosthesis every 2 years or when it shows signs of wear, is damaged, or if the individual gains or loses a lot of weight. Some hospitals recall the woman automatically for a replacement prosthesis. However, if the woman is no longer attending the hospital, her GP will need to write to her surgeon who will need to write 'prosthesis to suit' on the prescription. This prescription can then be taken to the breast care nurse or appliance officer (Breast Cancer Care, 2006b). Private patients buy their replacement prostheses from mail order suppliers or from certain high street shops and VAT is not payable if the person signs a form stating that they have had surgery from breast cancer (Breast Cancer Care, 2006b). Insurance policies differ in whether they cover the cost of the first and replacement prostheses.

Different policies apply across the United States and in general the provision of funding for replacement breast prostheses depends on the person's insurance. Medicare and Medicaid can be used to pay for some expenses if the person is eligible and if the prosthesis and/or mastectomy bras have been prescribed by a doctor. It is recommended that people requiring a prosthesis or mastectomy bra make contact with their insurance company to determine whether they are covered, the extent to which they are covered and whether certain procedures need to be followed to ensure they are covered. For example, in some instances, women must purchase the prosthesis and post-mastectomy bras themselves and submit the appropriate paperwork to their insurance providers to receive partial or total reimbursement. In other instances, the manufacturer or shop where the items are purchased will bill the patient's insurance company directly. Some insurance companies may require patients to order products from a specific manufacturer or shop (Imaginis–The Breast Health Resource, 2006). The American Cancer Society (2006) recommend that doctors are asked to write prescriptions for a prosthesis or special mastectomy bra. It is also important for the doctor to specify how many prostheses are necessary and how often they should be replaced. For example, Medicare will cover the cost of a new breast prosthesis every 2 years and two post-mastectomy bras every 6 months (Imaginis–The Breast Health Resource, 2006). Furthermore, bills and cheques for purchasing bras or prostheses should be marked as surgical as they may be tax deductible.

The funding provided also varies across the provinces in Canada. For example, in Ontario the Assistive Devices Program (ADP) governed by the Ministry of Health and Long-Term Care Ontario, Canada contributes to the cost of the breast prosthesis post surgery and towards a replacement prosthesis

once the prosthesis has not been lost, stolen or damaged due to misuse. The ADP does not fund bras, temporary breast prostheses, silicone nipples or breast implants. To access this funding the woman is required to complete an ADP Equipment/Supply Authorisation form. An examination by a medical doctor is also required and who writes the medical diagnosis and the need for a breast prosthesis on the form (Ontario Ministry of Health and Long-Term Care, 2004). In contrast in Manitoba, Manitoba Health will provide reimbursement to a maximum of CAN $153.50 per prosthesis. The programme also provides an allowance of up to CAN $12.30 per surgical bra. Women who have had a single mastectomy may claim two prostheses every 4 years and two surgical bras every year. Similarly, women who have had a double mastectomy may claim four prostheses every 4 years and two surgical bras every year. A receipt from the supplier and a medical practitioner's prescription and diagnosis is required for reimbursement (Manitoba Health, 2006).

The final example is Australia, where there is also variability in funding across the various states and there is no agreed standard throughout. For example in the state of Victoria subsidies are provided by the state government for both initial and replacement breast prostheses. These subsidies can be provided through the public hospitals or through the State Government's Aids and Equipment Program (A&EP). The A&EP is an administrative system for funding provision in Victoria. However, Livingstone et al. (2000) report that in Victoria, Western Australia and New South Wales, the rate of subsidy provided is at the discretion of the treating hospital. In Queensland, women with a pensioner or health care card receive initial and replacement breast prostheses free of charge; all other women incur costs. In South Australia, public hospitals provide the initial prosthesis free of charge and funding up to AUS $250 is available for women with a health care or concession card. Livingston et al. (2000) also report that in Tasmania, women are required to pay the first AUS $50 towards their prosthesis and then the rebate is means tested against income. If they are eligible for a health care card or concession card, then a maximum of AUS $160 is available through the State's Breast Prosthesis Scheme.

2.7.3: Impact of funding provision on the prosthesis experience

Research has shown that cheaper prostheses may be uncomfortable, cause shoulder, back or neck pain or may not give the desired natural look compared to the more expensive models (Kiefer, 2001). However, for many women, the cost of the prosthesis is a considerable financial burden when combined with other costs encountered with treatment for breast cancer (Livingston et al. 2003). Consequently, Livingston et al. (2003) undertook a study to assess 87 women's experiences with, and perceptions of, the provision of funding for breast prostheses through the Aids and Equipment Program (AEP) in Victoria, Australia. THE AEP provide funding subsidises up to AUS $300 where private insurance does not cover the initial prosthesis and for all women replacing their prosthesis. The findings revealed that on average, women received AUS $258 towards the cost of their first prosthesis and spent on average AUS $283. However, one-third of women reported an average

personal contribution of AUS $66. Women were significantly less satisfied with the amount of funding as the money they had to contribute increased. Although service providers indicated that clients were extremely satisfied with waiting periods up to 2 months, clients responded differently, with satisfaction decreasing significantly after a 30 day wait. There were also some problems identified with the AEP application process. Firstly, participants noticed there were delays due to the necessity of a doctor's referral; secondly, participants did not feel comfortable with the requirement to declare disability status and finally, an inflexibility and inequity of breast prosthesis subsidies was noted.

To date there has only been one study that has specifically explored the impact of variability in the availability of funding on the prosthesis experience. The aim of the Livingston et al. (2005) study was to evaluate women's experience regarding provision of their first prosthesis following a mastectomy and to investigate the impact of funding levels on women's ratings of satisfaction regarding their prostheses. The study compared responses from 30 women who received a usual level of subsidy for breast prostheses from their hospital (control group) with the responses of 51 women who were provided with full funding for their prosthesis of choice (intervention group). The level of funding had some impact on women's satisfaction with the quality of their prosthesis. One week post fitting, women in the intervention group who had received full funding for their prosthesis were more satisfied with their prostheses than women in the control group. However, over time ratings of the prosthesis fell to a similar level reported by women in the control group. It is likely that this relationship is to a certain extent a reflection of their satisfaction with the funding they received. Women's ratings of satisfaction in the control group remained relatively constant over time. Overall both groups reported being satisfied to extremely satisfied with their prostheses. Livingston et al. (2005) found that differences in subsidies awarded influenced prosthesis expenditure and choice: the intervention group spent an average of AUS $298 dollars on their prosthesis in comparison to the control group who spent an average of AUS $233. Cost was also an important factor in deciding on the prosthesis to buy in the control group. Interestingly, the choice of prosthesis was further influenced by the fact that the amount of funding available to the women impacted on the price range of prostheses shown to them. Women in the intervention group were shown more expensive prostheses than the women in the control group, which suggests that women with restricted funding were not given the opportunity to supplement the cost with their own money. It is important to note the small sample size in this study and Livingston et al. assert that further research should be conducted to understand the needs of women from diverse cultures.

2.8: IMPORTANCE OF AN EXTERNAL BREAST PROSTHESIS

2.8.1: Quality of life

As there is an increasing number of people surviving breast cancer, it is becoming increasingly important to evaluate women regain their quality of life and progress with their lives. There has been

very little research on external breast prostheses and their influence on a woman's quality of life after mastectomy (Healey, 2003). Nissen et al. (2001) compared the quality of life of women who had breast-sparing surgery, reconstruction, and mastectomy and found that women who had a mastectomy without reconstruction experienced greater feelings of well-being. The quality of life of the cancer patient can often be affected by issues related to surgery and body image. Indeed, adjusting to a new body image is a central component to the quality of life of people who have breast cancer. As such, Mahon and Casey (2003) state that prostheses and bras that fit properly can be very important in the recovery process and ultimately improve quality of life for cancer survivors. Furthermore, nurses who provide education and information about breast restoration, either through reconstructive surgery or the fitting of a prosthesis, can facilitate the improvement of quality of life of breast cancer survivors. Roberts et al. (2003) reported that the women in their focus group study initially viewed prosthesis use negatively but in time there was a perceived positive impact of prosthesis use with regard to body image, appearance, and sense of femininity. In addition, there was a greater integration of the prosthesis into their daily lives and the prosthesis was seen as something that could enhance their quality of life. Similarly, the qualitative study conducted by Breast Cancer Care (2006c) highlighted the positive psychosocial impact of the external breast prosthesis in promoting the woman's self-confidence and self-esteem.

2.8.2: Body image

Research suggests (Fallowfield et al., 1990) that the threat to the patient's life is a greater issue for breast cancer patients than the loss of femininity associated with losing a breast. Some research (Anderson, 1994) has reported that women who undergo a mastectomy recover well; this may result from the removal of the threat of cancer. However, Dixon and Sainsbury (1998) state that the breast is a symbol of femininity, sexuality and creativity, and losing such a symbol may result in greater distress than the acceptance of cancer. Yurek, Farrar and Andersen (2000) found that women who received breast reconstruction experienced disruption in their sexual behaviour and sexual responses significantly more than women who received lesser surgery or comparable surgery with no reconstruction. This finding should be viewed in light of previous research, which has found that overall 20% of women who had undergone either reconstruction or conservation reported poor adjustment on sexual satisfaction, psycho-social adjustment and body image (Bredin, 1998).

A substantial number of women have reported dissatisfaction with mastectomy scars and/or discontentment with their prosthesis (Maguire et al., 1983). Cancer and cancer treatments are by their very definition destructive and breast cancer can result in the loss of a body part, scarring, disfigurement and having to adjust to a prosthesis (White, 2000). External prostheses are worn in order to regain the contours of the woman's body, however, some studies have noted that the prosthesis is never incorporated in the women's actual image of her own body (Reaby, 1998). The

prosthesis is often seen as a foreign object and is associated with feelings of vulnerability (Bostwick, 1990). The concept of body image can be broken down into three areas: body reality, body ideal and body presentation (Price, 1998). Body reality refers to the way an individual looks without any cosmetic work. Body ideal refers to the way an individual would like to look. Finally, body presentation refers to the way an individual presents themselves to the world using clothes, make-up or other camouflage to achieve a desired appearance. A mastectomy can result in a considerable change to the body reality, most likely in the opposite direction of the body ideal. If there is a large discrepancy between the body reality and body ideal then clinically significant body image problems are more likely to exist (White, 2000). Women who either receive an external prosthesis or undergo reconstructive surgery often have to deal with the reality that they have not returned to their original image. Re-imagining of the self is necessary as a conclusive phase in order to accept the altered body reality (Kraus, 1999). Indeed, Keeton & McAloon (2003) conclude that effective re-imagining is best achieved either by the use of an external prosthesis or reconstructive surgery and therefore is an integral component of the rehabilitation process.

Bredin's 1998 study investigated the impact of a mastectomy from a woman's private perspective. He conducted two one-hour semi-structured interviews. With regard to the effects of breast loss on the self, Bredin found that women saw their breasts as deeply bound in their womanly image and saw the loss of the breast as the loss of a part of oneself. Women noted an effect of the mastectomy on their social identity reflected in concealment, withdrawal, concern about others noticing, self-consciousness and changed behaviour with family/partners. Unfortunately these finding cannot be generalised as the participants in the study were all having difficulty coming to terms with their changed body image. However, they do raise some important concerns regarding the experiences of post-mastectomy women. Instead of merely trying to replace the irreplaceable, Bredin asserts that a body-centered intervention may help to treat the distress after the mastectomy (Bredin, 1998).

Thomas-MacLean (2005) explored women's experiences of embodiment after breast cancer. Twelve women were interviewed on two occasions each and were asked to talk about changes to their bodies that occurred as a result of breast cancer. She identified three key themes: (1) how it feels (e.g. sensation and breast loss); (2) managing appearances (e.g. wearing prostheses); and (3) treatment without end (e.g. menopause). She concludes that women with breast cancer are a diverse group and that survivorship is a dynamic, lifelong process, which suggests that health professionals can play an important role in establishing interdisciplinary approaches to caring, beyond the conclusion of acute treatment. With regard to specific references to external breast prostheses in her study, wearing a prosthesis 'may be considered an act of restoration, an avoidance of stigmatization, attention to one's own physical comfort or a combination of these efforts. Critical considerations of breast prostheses then have many features. While some involve physical elements, others involve social considerations' (p205). This was consistent with Healey (2003) who asserted that the prosthesis is an important tool for interacting with the outside world. The women who have undergone a mastectomy may not want

to lose control and have people's attention diverted to their physical disfigurement. Therefore, a breast prosthesis can help a woman to regain her social credibility and sense of personal well-being. Roberts et al. (2003) support this hypothesis as the findings from their focus group study indicated that quite a few of the women wore their prosthesis more often going out as a means of maintaining a normal appearance.

Keeton and McAloon (2003) state that the clinical need for informed and effective prosthetic fitting can be better understood by exploring literature on the effect of altered body image on breast cancer patients and their families. Wearing an external breast prosthesis may assist women in improving body image and quality of life, and reducing emotional distress (Fallowfield et al., 1990; Livingston et al., 2000).

2.9: CONCLUSION & RESTATEMENT OF RESEARCH AIM

Breast cancer affects a growing number of women in Ireland annually and for a significant proportion of these women, part of the post-surgical experience and recovery involves an external breast prosthesis. Women have a right to be satisfied with their prosthesis, not least because in being supplied and fitted, they are recipients of a service, but also because it plays a role in terms of their psychosocial well-being. Internationally, research on the correlates of satisfaction such as the quality of the prosthesis and optimal aspects of the fitting environment is sparse and research on how this satisfaction impacts on psycho-social well-being and recovery post-mastectomy is limited. Despite this, the extant research has clearly identified the importance of an external breast prosthesis for the woman. Furthermore, previous research has found significant gaps in information, accessibility, equity, quality and financial resources relating to external breast prostheses. However, as a result of different policy and healthcare frameworks in different countries, the appropriateness and applicability of these research findings to the Irish experience is unknown. To date, there has been no research in Ireland that investigates women's experience of the provision, fitting, supply and use of external breast prostheses. Consequently, an objective and rigorous evidence base is crucial in influencing policy and developing services. The overall aim of this research is to gain an insight into women's experience of the provision, fitting, supply and use of breast prostheses in Ireland. The aim is to significantly involve women who require prostheses and the people who provide the service in research in order to influence the development of policy guidelines, directly responding to an identified need. Specific objectives include:

i. To assess factors and perceptions that impact on access, equity, quality and affordability in relation to the needs of women requiring a breast prosthesis

ii. To assess the type, content, timing and mode of providing external breast prosthesis information to women and how this might impact on their experience of acquiring or replacing an external breast prosthesis

iii. To identify factors that promote quality in the supply, fitting and aftercare of all external breast prostheses and related products (e.g. mastectomy bras).

The objectives of the research will be achieved through a two-stage research project. Having conducted a review of the literature to identify national and international research and policy in the area of external breast prostheses, the first part of the research will adopt focus group methodology to investigate women's personal and subjective experiences of the provision, fitting and supply of breast prostheses in Ireland. In part 2, national surveys will be conducted to attain the perspective of a wider group of people. There will be four concurrent surveys. Survey 1 will explore the experiences of women with breast cancer. Survey 2 will investigate the views of breast care nurses. Survey 3 will document the views of retail prosthesis fitters (i.e. prosthesis fitters primarily in retail/commercial outlets) and Survey 4 will target bra fitters in department/lingerie stores. As the people directly involved in the care of women with breast cancer, the views of breast care nurses and retail/commercial prosthesis and bra fitters will enhance our understanding of women's experiences of prosthesis provision, fitting, supply and use. Overall, this research will be a crucial step in the development of policy that will inform the appropriate provision, supply and fitting of external breast prostheses and in turn ensure the highest quality of care for women availing of this service.

Chapter 3

Focus Group Study

The first part of the research adopted focus group methodology to investigate women's personal and subjective experiences of the provision, fitting and supply of breast prostheses in Ireland. Krueger and Casey (2000) define a focus group as 'a carefully planned series of discussions designed to obtain perceptions of a defined area of interest in a permissive, non-threatening environment' (p5). Wilkinson (1998a) concludes that focus groups are an ideal method for gaining access to participants' own meanings. They have the capacity to exhibit a synergy and provide insights that cannot be achieved by individuals alone (Wyatt, Bogart & Ehrhardt, 1998). In particular, Stevens (1996) postulates that the sense of shared experience and security in the group can enhance the breadth and depth of discussion beyond what is possible in individual interviews. Furthermore, the discussions that ensue are considered to more closely approximate a 'normal' social context than do individual interviews (Weinberger et al., 1998). They enhance disclosure, provide access to participants' own language and concepts, enable participants to follow their own agendas, and encourage the production of elaborated accounts (Wilkinson, 1998a). According to Robinson (1999) the primary purpose of focus group discussions with a homogeneous group of people is to capture detailed data on a specific issue and within a social context where people consider their own views in relation to others.

A particular use of focus groups, *inter alia*, has been the assessment of health status and healthcare needs, improving practice and quality care through consumer input (Ivanoff et al., 1996; Makrides et al., 1997) understanding people's experience of a disease or condition (Gallagher and MacLachlan, 2001) and in identifying appropriate language and content for questionnaires for new populations (McKinley et al., 1997; Gallagher and MacLachlan, 2000). In particular, previous research has demonstrated that focus groups are suited to eliciting insights from consumers who have been underserved, unheard or overlooked in previous research (Stevens, 1996; Taylor & Dower, 1997; Koppelman & Bourjolly, 2001). Overall, the intent is not to generalise findings but to gain a more complete understanding of a particular topic (Krueger, 1997). As focus groups have also been previously used successfully with women with breast cancer (Wilkinson & Kitzinger, 1993; Ferrell et al., 1997; Lauzier et al., 2004; Tam Ashing-Giwa et al., 2004), it was agreed to conduct focus groups as a means of investigating women's personal and subjective experiences of the provision, fitting and supply of breast prostheses in Ireland.

3.1: SAMPLE

Five focus groups with 6-12 participants in each were conducted. This was in keeping with the recommendation of Stewart and Shamdasani (1990), Stevens (1996), Morgan (1997), and Krueger and Casey (2000). Côté-Arsenault and Morrison-Beedy (2005) also suggest that the optimum combination of homogeneity of interest and common ground with adequate diversity of experiences is critical for productive interaction in a group. Consequently, the women participating in the focus groups were wearing an external breast prosthesis. However, purposive sampling was used to ensure that focus groups reflected varying age range and length of time since first using a breast prosthesis. One group was run in each of the four new regional health authority areas in Ireland in 2005, except in Dublin where there were two groups. Women were recruited through a national cancer support/advocacy organisations independent of a prosthesis-fitting service (Action Breast Cancer and Reach to Recovery) and four Follow-up Breast Clinics throughout the country. These organisations were contacted and permission sought to purposively select volunteers to invite to focus group sessions held at a local venue.

All participants were female and over 18 years of age. The following inclusion criteria were applied:

- At least 1 year after the initial diagnosis
- Fitted with a breast prosthesis
- Currently not on radiotherapy or chemotherapy.

Forty-seven women in total participated in the five focus groups. The average age of participants in the focus groups was 57.8 years of age (range 38-80 years). The average length of time since being diagnosed with breast cancer was 8.1 years (range 1-32 years). The majority of women wore a single prosthesis with five women wearing double prostheses arising from bilateral mastectomies. See Appendix 1 for a table detailing the sample characteristics of focus group participants.

3.2: INTERVIEW/TOPIC GUIDE

In order to elicit information on the women's experiences, predetermined, open-ended questions were arranged into an interview guide. Question themes were derived from the literature review and in consultation with a group of healthcare professionals (e.g. breast care nurses, prosthesis fitters, clinicians, psychologists) and women who wear breast prostheses themselves. The main topics covered in the focus groups included: initial reaction to breast prosthesis; access to information about prostheses; the fitting experience – facilitators and barriers; pattern and impact of prosthesis use; importance of the relationship with breast care nurse and with prosthesis fitter. See Table 3.1 for examples of questions. These themes draw on the work of Roberts et al. (2003). The focus group guide was also piloted in the first focus group.

Table 3.1: Content of focus group topic guide

Question Theme	Example of Question/Probe
Initial reaction to the external breast prosthesis	What were your expectations about having a breast prosthesis? Were these expectations met? If so, in what way? If not, in what way? What was your initial reaction to your first permanent breast prosthesis? What do you remember from the initial fitting experience?
Current prosthesis	Are you satisfied with your breast prosthesis? Prompt: cost / weight / fit / comfort How often do you wear your breast prosthesis? Where do you not wear your breast prosthesis?
Fitting experiences	Are you satisfied with the fitting service? Prompt: travel and accessibility / waiting time for appointment / delivery time What would help improve the fitting experience?
Relationship with breast care nurse	Is your relationship with the breast care nurse important? If yes, why? If no, why not
Relationship with prosthesis fitter	Is your relationship with the prosthesis fitter important? If yes, why? If no, why not?
Personal impact of prosthesis	What are the most common issues, if any, that arise because of having a breast prosthesis? What do you find most difficult to deal with having a breast prosthesis? What kind of things did you need to adjust to? What made/makes this adjustment easier? What do you think could be done to help other people adjust?
Availability and accessibility of information	Do you feel that you have sufficient access to information about breast prostheses? In your opinion, what is the best way to make information available to women on external breast prostheses?

3.3: PROCEDURE

Having contacted, sought and received ethical approval from the participating organisations, potential participants were recruited through breast care nurses and staff from the cancer support/advocacy organisation and Follow-up Breast Clinics. The contact details of women who expressed an interest in and agreed to being contacted further about the focus group were given to an identified member of the research team. This member then made telephone contact to provide additional information, request participation and to make arrangements for attendance at the focus group. The women who agreed to participate were subsequently contacted by a letter, which provided written information about the study and an informed consent document. The women were asked to sign and return by FREEPOST the informed consent document indicating their agreement to participate and for the session to be audiotaped. The receipt of all signed informed consent documents was verified before commencing the focus group. The participants were informed that they could withdraw from the study at any time in the research process and that they would not be required to provide a reason to do so.

The focus groups took place in an environment that was geographically accessible, private and with no external distractions thereby facilitating uninterrupted discussion. Participants received travel

expenses and light refreshments. The setting was relatively informal and comfortable with members seated in a circle to facilitate participation. The facilitator/moderator of the focus groups was a trained oncology nurse familiar with the area and capable of dealing with any issues that might have arisen. The moderator played an important role in explaining the purpose of the group, putting people at their ease and facilitating and focusing the discussion. To avoid leading questions, the influence of dominant participants and pressure to conform within the group, the moderator was not only intimately familiar with the goals of the research study but also knowledgeable of the need to take an objective yet empathic stance, as recommended by Krueger (1997). Each focus group was audiotaped and notes taken by the note-taker. Participants were assured of confidentiality at all times. As data saturation was reached after the fifth group, no additional focus groups were held. Drawing on the work of Krueger (1997) and Morse & Field (1995), both respected experts in focus group methodology, it was anticipated that five focus groups would be sufficient to detect themes and patterns across the groups. Morse & Field (1995) has also argued that detailed descriptions are more important than the amount of data as excess groups do not enrich the results, they simply prolong the collection and analysis of the data.

3.4: ANALYSIS

The tapes of the discussions were transcribed verbatim. As the transcript does not reflect non-verbal communication, it was supplemented with some additional observational data obtained during the session. The goal of the analysis was to identify themes as described by the participants and to describe the range of issues and experiences within each theme. These themes were identified both through the analysis of individual narratives and through the analysis of the dynamic construction of social meaning that occurs in focus group interactions (See Wilkinson, 1998a, 1998b). Data were analysed line by line. To ensure consistency, two analysts coded the focus group transcripts independently for recurrent themes and coding categories. Once these coding categories were agreed upon and following the coding of all transcripts, 20% of the transcripts were double coded to assess inter-rater reliability.

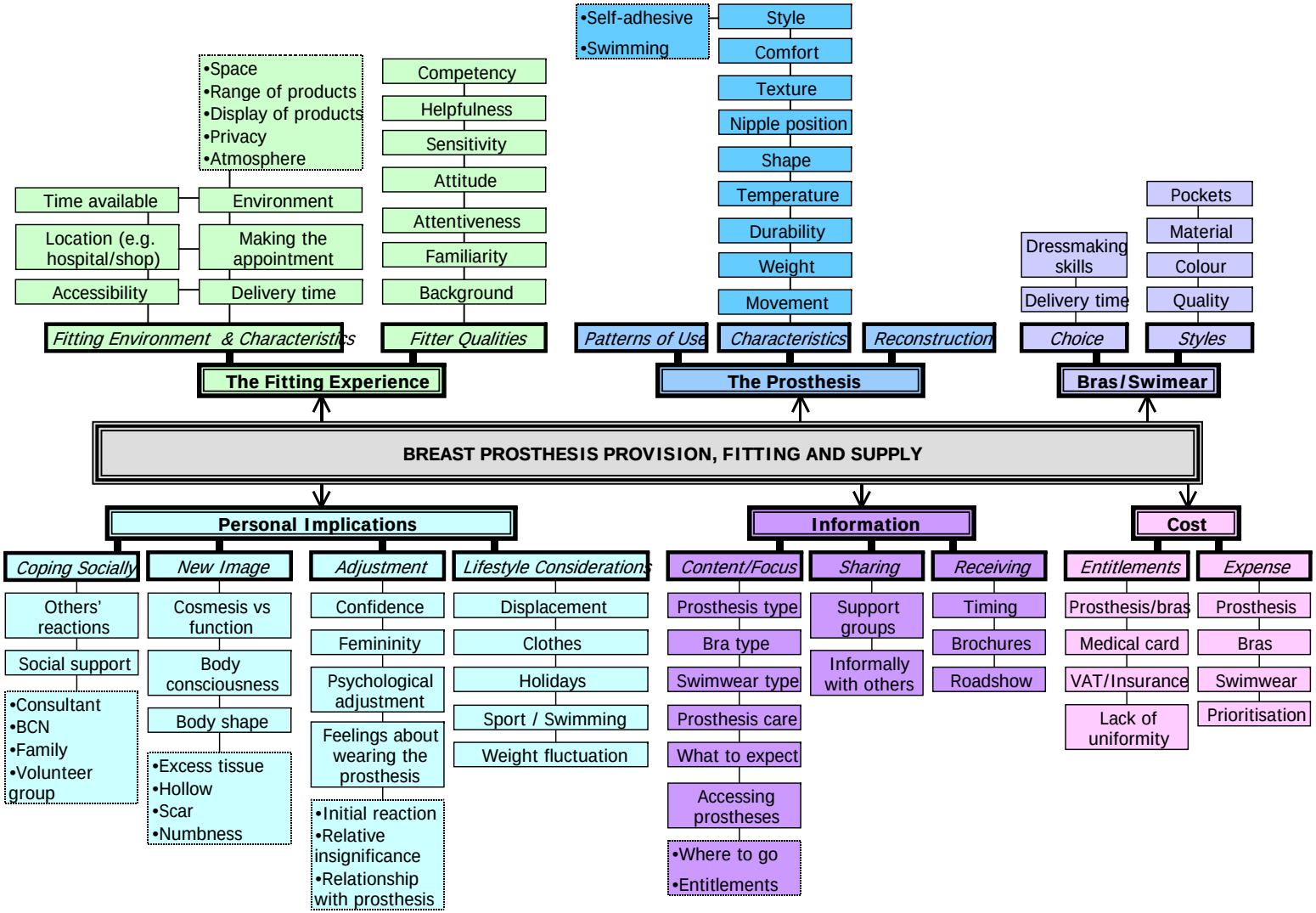

Figure 3.1: Graphical Illustration of Emerging Focus Group Themes

3.5: FINDINGS

Figure 3.1 depicts a graphical representation of the major themes that emerged throughout the focus groups. With regard to the provision, fitting and supply of external breast prostheses, six main themes, each with their own sub-themes, emerged. These were:

1. The fitting experience
2. The prosthesis
3. Bras/swimwear
4. Cost
5. Information
6. Personal implications

3.5.1: The fitting experience

One theme that women identified pertained to the fitting experience. In particular, reference was made to the need for optimal fitting environments and suitable fitters.

3.5.1.1: Qualities of the person fitting the prosthesis

The qualities of the person fitting the prosthesis were discussed in relation to the general fitting experience. The background of the fitter was brought up frequently as a point of importance for women. Overall, women remarked that they would prefer a trained, professional fitter with personal experience of wearing a prosthesis.

> >37: 'I would like a trained fitter, somebody with a personal touch.'
>
> >5: 'It'd be even better if it was somebody who had been through it themselves.'

There was some inconsistency of opinion over whether a clinically trained professional was deemed as preferable as a retail fitter.

> >11: 'Yes you do pay the same price but that's what I'm saying, why does it have to be professionals all the time when it can be somebody maybe, that's what I'm talking about, we could all get together maybe and say well if we're going to a person that's not a professional, it should be cheaper.'
> 1: 'Well I know price is important.'
> 11: 'It's very important when you're on a fixed income.'
> 1: 'Yeah but the most important thing I think is for the vulnerable patient or someone with hang-ups about being fitted anyway, we've had some horrific experiences with people who were fitted by shop assistants, people on job-sharing.'
> 11: 'Well I was fitted one time by a shop assistant and I have tell you she was better than any nurse.'
> 1: 'Well you were lucky, you were lucky.'
> 'It is a sensitive issue.'

11: 'I know it's a very sensitive issue. I'm not saying it isn't, it's a very sensitive issue for me too but the girl in [NAME OF DEPARTMENT STORE], one of the assistants in [NAME OF DEPARTMENT STORE], fitted me one time and I have to say the experience I got off that lady was better, well it was as good as I got off a nurse.'
1: 'Well I know that for most patients, being fitted in the early stages, how they're handled is very important.'
11: 'In the early stages it's very important to get somebody that would be very professional. I'm not saying it isn't but as time goes on, years later on I mean you're very accustomed to your body being the way it is and wearing a prosthesis.'

>38: 'You don't really need somebody that's medically trained.'
47: 'Because you're' only getting fitted for a bra and prosthesis.'
'Yeah.'
38: 'There's no medical procedures.'
37: 'As long as they're aware of what it is we're looking for, something that's not too low and something that you're going to be comfortable in, how your clothes look.'
47: 'Someone that makes you feel comfortable.'

>29: 'At the start the breast care nurse and then I'd say at my stage I could be passed on because I'm taking up their time and there's so many other people that need their attention on the medical side.'
'Yes.'
'Initially you need the breast care nurse.'
29: 'Initially because you talk about other things that's bothering you more than the prosthesis, you know how you're feeling and all that. It's a consultation really. You know, that's at the earlier stages but now at this stage I feel...'
33:' I would agree with this lady, that at the initial stages you'd need the breast care nurse and after that then there should be somebody else to do it.'

>34: 'It's nicer if it's a medical person because you wouldn't be embarrassed then.....'

The attitude of the person fitting the prosthesis and their approach to prosthesis care was frequently referred to as an important contributor to the fitting experience.

>2: 'The attitude of the fitter, that they have an understanding. Really they need to be people who are emotionally tuned in to other people.'

One woman recounted her previous experiences of being a prosthesis fitter.

>30: 'Many a woman came in and I'd say how do you feel and when they say how do you feel, are you up to being fitted today? You know, have you accepted the fact that you need to have this done or want to have it done or you're supposed to have it done? Many a person came in crying and upset and they leave with a smile on their face and they say I don't believe I feel the way I feel and they feel whole again. A lot of it is to do with your own attitude as well, you know how you accepted it to start with.'

Women noted the value of an understanding fitter that succeeded in making them feel good about themselves. They wanted to feel like they were getting a fashion garment. However, some women had experienced intolerant, condescending fitters.

>'2: That service is so, I feel very strongly about it, [NAME OF SPECIALISED PROSTHESIS FITTER] and anyone working in that company, they make you feel as though you're getting a fashion garment and you feel good about yourself'

1: 'They work very hard at that service.'

2: 'That makes such a difference to how you perceive yourself, how you're actually prepared to hold your posture instead of being like this covering up. You're quite happy to be standing up straight because you feel I look good. You walk out of there feeling that you look good.'

>'It is & it isn't, it depends on how they perceive, how you perceive that they treat you.'

'It isn't that you have to build up a relationship with them, it's what you perceive they way they treat you. If you feel that they're condescending...'

On a similar note, the helpfulness of the fitter also arose as a factor relating to the fitting experience. Women noted the importance of a fitter that took the time to find the right product for each individual person.

>18: 'I think that all the people that have fitted mine from time to time have been absolutely excellent and they have spent so much time getting the right type of bra and the right type of prosthesis, you know, to suit, the best they can get to suit you. I don't have a problem as I said, apart from the hollow in the centre, with wearing a prosthesis or anything but I think they've taken so much time and they pull out every box there until they get the one and if they haven't got it, they'll send for it. I think the service is fantastic.'

Furthermore, the need for a confident and competent fitter was identified.

>10: 'I actually was em very upset and the person fitting them was a little bit eh upset too.'

2: 'Intimidated by having to do it, yeah.'

10: 'Because I was upset and I didn't think that she really, afterwards when I thought of it, that she understood, she got emotional about it because I was emotional and it was good for her and for me to be both emotional, but at the same time I needed somebody strong to encourage me and say this'll be grand, it'll be lovely.'

1: 'To normalise it for you, yeah'

10: 'It's just like you were saying there, if you know somebody, you get fitted by something you're familiar with or a place that you're familiar with, I think the option should be that we have choices of where you go. If you have the medical card you should have a choice of somewhere to go.'

In addition to these frequently mentioned factors, other points were mentioned in relation to the qualities of the prosthesis fitter. Women noted sometimes feeling like a burden to the fitter. They reported that the breast care nurses were often short staffed and regularly receiving phone calls or getting called away during the fitting, which resulted in them feeling that they were taking up too much of the nurse's time. As a result, it is important that the fitter has the capacity to be attentive and accommodating.

>13: 'I think that they really need to have a few more staff.'

That's the problem.'

17: 'They're stressed.'

21: 'The breast care nurses haven't enough time. They have too many other things. There are new patients coming in where they have to be there and there's always somebody ringing. Any time I came in there were phone calls. To [NAME OF BREAST CARE NURSE] I came, there were phone calls, you know for her. She can't get half an hour.'

12: 'You feel you're imposing on their time because you know that the people they're being called to are people who've been where you are some time ago so you feel a certain amount of guilt then for taking up their time.'

21: 'I never went back since the first day, like since the first day I got the prosthesis and the bras. I never went back, I bought them outside.'

12: 'I felt I'd be taking up their time.'

18: 'I would find now the opposite, I would find there's a sense of security going to people you know and I would feel awful branching out into another area, that there would be a fitter that I wouldn't be aware of.'

'Yeah.'

12: ' I'd love to come back to them but I feel I'm imposing on their time.'

Fitter sensitivity has been remarked as an important contributor to the fitting experience.

> 'I went up to the counter and said "I'm looking for someone to fit a mastectomy bra" and she shouts, I can't remember the name, 'Mary there's somebody here for a mastectomy fitting". I sort of slunk in amongst the rails of clothes and I disappeared and I thought oh my God never again. I stuck to the hospitals after that.'

Finally, familiarity between the woman and the fitter was mentioned by some as having an effect on the fitting experience. However, one woman argued that after the initial stages, familiarity with the fitter becomes less important.

>10: '[NAME OF BREAST CARE NURSE] and I haven't met that much, but I met [NAME OF BREAST CARE NURSE] a couple of, about 2 months ago at something outside and I was delighted to meet her and she was delighted to meet me and we had a grand little chat again, so obviously we bond, you bond with the person because you're vulnerable at that time and it's how the person treats you, that you bond with them and you know, you like to stick to that person if the person makes you feel comfortable.'

>46: 'Maybe in the first years but then after that I think, well I'm speaking for myself I suppose, but after the first years if you know that somebody, you know they're a trained fitter or whatever, after that no, it wouldn't be that important.'

Overall, the importance of a good fitting experience was exemplified in the following quote:

>2: 'Yeah, they tried a few to see what was the best to match and you're advised to bring something close fitting like a t-shirt, maybe if you weren't wearing a very close fitting one, so you could pull it across. You get a better view as to whether you're the same shape on each side and that's quite important because if you are wearing something loose it may just tip on the same spot but it may not have the same shape and they come in different shapes. Some have little bits that go under the arm if you've lost a lot of tissue there and that, to balance you out. It's quite important to be fitted for, not just the measurement but the shape, that the fitter knows that, because you don't know that yourself. You know nothing about it at first. I would know now what I want but it's years of experience and self denial as they say.'

3.5.1.2: Characteristics of the prosthesis-fitting environment

Participants repeatedly discussed the optimal location for fitting prostheses. Many of the women attending the focus groups desired a centre away from the hospital setting, in particular for replacing their prosthesis. Reasons for this included the advantages of not having to travel to the hospital, of being able to visit the shop at any time, and of having an identified individual specifically dealing with the provision of prostheses.

> >24: 'Yeah it's, I think, well for me anyway, there's something about hospital, a little bit scary and even though if I was only coming in to be fitted with a bra, it's just a different feeling, it's nicer going into somewhere that's more relaxing if you like.'

> >16: '...we shouldn't have to beg or appeal or you know. It shouldn't be a chore, it should just be a service that's there and I feel that maybe when you're down the road you'll still get your prosthesis but maybe it could be more em of a sort of an experience for buying nice lingerie rather than something clinical and, what's the word I would use, em you're still tied into an illness and being sick, and that it shouldn't be a sort of device that you're getting, you know that it should be a feminine experience.'

Conversely, some women did express a preference for the hospital so that both health appointments and prosthesis acquisition could be completed under one roof.

> >33: 'Every time you go for your check-up you should be able to go and have a look at those bras or prostheses, to have all that business done.'

> >12: 'I'd be happy with the hospital, but a nice room in the hospital.'
> 'Yeah.'
> 17: 'And a proper display of the bras.'
> 'That's right, models or something.'
> 17: 'Rather than pulling out boxes and drawers.'

> >34: 'Like as if you were in an ordinary shop that you'd go pulling out things yourself.'
> 33: 'Like an ordinary shop, yes. They're always busy. It could be part of the day as I said you go for your check-up, that the choice should be there rather than have to go into town and maybe somebody that's not living in Galway might have to travel 70 miles. Consider those people that are living 70 or maybe 80 miles away out the country. They're not going to be able to drive into Galway and if there's a nice shop there go in and look at their business. That would be my... whereas those people then they have to go for their check-up and they'd like to get finished and they can walk into this room or shop and the prostheses will be there and the bras and get all their business finished on the day.'
> 'There's be a lot for that alright.'
> 'That'd be a lovely idea.'
> 33: 'I think that in fairness that most people when they're finished with their check-ups or whatever, they don't want to go into town and start thinking about prostheses and bras.....'

Women reported restricted access to and choice of fitters throughout Ireland, especially for women outside Dublin and/or at a distance from a fitting centre and for women on the medical card.

>1: 'It's just how someone perceives the whole thing but my big hobby horse at the moment is the lack of choice for medical card patients because if you want to be fitted now for a prosthesis on your medical card, you have to go to a place in [NAME OF SPECIALISED PROSTHESIS SUPPLIER] that none of us know anything about. They've gotten the contract for the medical card patient and that shouldn't happen. It should be that you can buy your prosthesis anywhere, a recognised fitter obviously but you shouldn't be discriminated against because the State is paying for it. You should have the same choice as any other woman and that's not happening.'

>12: 'Everything should be sent out into the regions as well and not city based. I mean I have no problem, I haven't got a problem coming to Cork though it involves me taking a day off school. But you know, for, for, it's 60 miles for us to travel. And you know, it's a long long way.'

The issue of appointments was also frequently mentioned as impacting on the fitting experience. Although the women did see the logic of appointments, particularly with regard to retail prosthesis fitters, they were unhappy with always having to make appointments and with the length of time they may have had to wait (e.g. from 10 days to 3 to 4 weeks in some instances). While many of the breast care nurses in the hospitals would accommodate women when they were attending an appointment in the hospital, this became increasingly difficulty in rural areas where there may have only been one breast care nurse in situ or if breast care nurses were only available on particular days of the week and this did not suit because of the woman's work or childcare commitments.

>40: 'Yeah, you know if there was somewhere that, there was someone there say in a wee shop or that all the time that you could contact and go in and look at something new or something.'
47: 'It's usually when you're up for your appointment with the breast care doctor that [NAME OF BREAST CARE NURSE] is there and then you say well I need a bra and she'll say well go and have a coffee and come back up in 10 minutes and I'll see what I can do for you or come back next week.'
40: 'If there was somebody there say Monday, Tuesday, Wednesday that you could just go in.'
44: 'If they were there all the time that you knew you could go in just for your bra or your prosthesis.'
47: 'Even 3 days a week, even an afternoon for 2 hours, just Mon, Weds and Friday say, that you could just go and not bother anybody. The shop would be there and you could walk in and see what there was.'

The significance of making an appointment was exemplified in the following abstract.

>5: 'It's building up your confidence to try and go in, ye know what I mean, to go in'.
'It's your confidence to go in, exactly.'
5: 'It's not the person that's going to be treating you, it's yourself. If you're going in today you'd like to be seen today but you don't want to have to try and make an appointment. You just get up this morning, I feel good today, I'll go in today.'
'Yeah.'
11: 'You see you can't do that.'
'No.'
5: 'If you think you're going to go in a certain day you're going to get nervous about it, then you'll back out.'
11: 'Because you didn't know at the beginning that you had to make an appointment. Do you understand? They don't tell you that's what you have to do.'
2: 'I once in all those 30 years got seen without an appointment.'

Many aspects of the prosthesis-fitting environment were commented upon. Firstly, the women felt there was not sufficient space, referring to the fitting room within one hospital environment as a 'cupboard' and 'closet' in another, mentioning the tiny mirror, lack of fresh air and poor display of stock/products.

> '...And the other thing I would say, I would have worked within this hospital and I thought the fitting room here is appalling.'
'It is yeah.'
17: 'Appalling.'
'It's a cupboard.'
17: 'A cupboard, I said nobody but women would be expected to cope with it.'
'To put up with it.'
'Yeah'.
12: 'A dungeon.'
7: 'Oh, I couldn't, and I felt sorry for the girls because I know they were embarrassed about it and I would have had situations like that because I was a nurse. My career as a nurse we were embarrassed for the people you were trying to treat in a cupboard. That's all I have to say.'

>30: 'The other thing I found in [NAME OF LOCATION], now as I said I knew what I wanted and I said I want what size and whatever. I was very adamant in what I wanted. But I found when I walked in, No. 1 the fitting room in the [NAME OF HOSPITAL] is like a closet.'
33: 'That's right.'
'It's a cubby hole.'
30: 'It's total upheaval. There's bras hanging from the lights. There's bras hanging from the desk. There's bras under the desk. That's not a joke, they are, they're literally hanging. There's doors swinging open with bras hanging off them. You're thinking where the hell are the prostheses, do they have anything here and they're all under the desk. I mean it was, No. 1 it has to be more appealing when you walk in and more serene for somebody that's going through something so traumatic, if you could walk into a nice room, that's feminine and somebody comes in a professional manner.'

A spacious and air-conditioned room was considered important, particularly for women who may be experiencing hot flushes. One woman relayed the characteristics of a more positive experience:

>22: 'If I may say something about this extra area for fitting. They sell mastectomy swimsuits in [NAME OF DEPARTMENT STORE] and they sell beauties for 40 euros, very high neck and if you go in to fit them they have beautiful huge, as they have for all of them, air conditioned rooms. Now you can go in and you've 3 mirrors there each way, to look every way at yourself in privacy, take your prosthesis out and put it in and that I think is what as you say, the ladies there's so many women getting breast cancer, they should be able to have that and allow it, and it'd be wonderful if somewhere like [NAME OF DEPARTMENT STORE] or maybe one of our own Irish firms could take this on.'

The lack of privacy was also mentioned as impacting the women's fitting experience. It was generally established that having to undress in front of others was upsetting for the women.

>22: 'I don't know about any other ladies but there's a certain vulnerability there I think when you're standing like this, I've often heard will you pull up your other breast Mrs. X, please. You're standing there and you're really open.

They're looking at you front and back. There's a mirror behind somewhere, or there's one mirror somewhere. You know I find it really awful now to be honest with you.'

25: 'I don't think you ever get used to the fact that you're exposing yourself to somebody else, no matter how well you know, I mean I know [NAME OF BREAST PROSTHESIS FITTER] very very well now because she came out several times to the [NAME OF CANCER SUPPORT GROUP] to talk to us out there and to show all her wares you know, to show her, her swimming togs and bras and camisole tops and all that kind of thing, so I got to know her very well on a personal level but at the same time, the fact that she's there, you just don't get used to it even though I've got used to looking at myself.'

22: 'It's very difficult to get used to it.'

26: 'Your body is mutilated when you think about it, isn't it? When you think about it your body is mutilated.'

'Oh it is of course.'

26: 'When you're walking to the bathroom in the morning and on the way you pass a mirror and you go oh (laugh).'

25: 'I think it would be nice to have a, cubicle, to let her, if you say I'm wearing a 36B bra or whatever and let her pass in then what she thinks might be suitable for you to put on and then go to her wearing a bra. I think that would be nicer but for some reason or other it just doesn't seem to be happening.'

27: 'It doesn't work like that. You know what I mean, like if I went into [NAME OF DEPARTMENT STORE] to be fitted for a bra, they would fit me underneath my clothes and she's bring in 4 or 5 bras and I'd go in and fit each of them on. She'd come in if I had a bra on me and say well that one is too small because as you know all bras are all different sizes so from one to the other you can vary in size but it's..., I don't have to show off my body so why do I have to show off my body then when I have to have a prosthesis. You know the bra covers it, it'd be according to the bra nearly to what size I'd wear. I don't think I should have to stand there like half naked and show myself off to anybody and I don't want to do all these things.'

24: 'I suppose they're trying to get the best result for you.'

27: 'But I don't think, it is getting the best results for you because first of all I'm up to this, I'm sweating, I'm out of my mind because somebody is looking at me so I then don't care what she's giving me because what I want to do is get out of this environment as quickly as I possibly can and I just don't think it's the best for me in the end.'

22: 'Just put them in the bag and let me go, yeah.'

27: 'So what I do is I keep on wearing the one piece because the thoughts of going to get another one is just dreadful. So I just think it's not to our advantage to have this done to us. I just think it could be a little bit more better. We would be happier, they would be happier. They would sell more products because I would go back more often. And I just think, it would be, now this is only my opinion but I think it would be better for all concerned. That's all I think now.'

They described a more desirable fitting environment; feminine, airy and with air conditioning and also suggested giving the women the prostheses/bras to try on themselves so they were less exposed during the fitting.

>22: 'I would love to be in a cubicle, a prosthesis handed into me, you know fitted for my size and then the right bras and right prosthesis brought into me and me to go out and then for whoever is fitting me to make a judgement you know. I don't like baring myself no matter how well I know the people and that's just my personal opinion on the whole thing.'

The amount of <u>choice</u> and the <u>range of stock</u> that the fitting centre provided was frequently referred to by the women. Their experiences were varied. Although many women felt that they were not getting any choice of products, some women maintained that they had received a good choice in stock.

>29: 'The nurse picks out what she thinks will suit you. She gave you a bra and told you put it on and then she started putting this one in and taking that one out, that one is too big, this one is too small. That's the right one, how does that feel, grand.'
28: 'You don't know which is the right.'
32: 'You don't really know.'
31: 'I think as I said you're confused. You cannot make up your mind at that time. You had no choice. I had no choice.'

>25: 'I got another prosthesis there, I've had several because it's 14 years but last year I got another one over with [SPECIALISED PROSTHESIS SUPPLIER] and I found that she had several for me to choose from. There were ones that were quite concave and quite light and then others that fitted with a piece under the armpit and so on. And you know she let me put them into my bra and let me see for myself what I thought and then she said to me oh yes I think that one is better than this one and so on. In the end we were both kind of going for the same one and I must say now I find it very handy.'

Some participants stated that they did not receive an actual fitting when going to get a replacement prosthesis or bra.

>33: 'No and I understood that I'd get a bra every year as well and it's gone into 2½ years now and I had to phone up the hospital 3 weeks ago to apply for a new bra and I had to get the old one. She said, I said I'll have to go downstairs and bring it up. I said, I forget what brand it was and it was so faded but eventually we got through to it and she said you'll have one in about 6 or 8 weeks time.'
30: 'When you think about 8 weeks, 2 months to wait for a bra, it's ludicrous.'
29: 'And really you should have had another fitting.'
'You can either put on weight or lose weight.'

They also noted that there was not enough time available for the fitting. The women specified that they would like the time to browse and find out about all the different types of prosthesis without worrying about people waiting outside.

>22: 'Yeah the underwear, lots of little rooms for women that are sitting outside waiting when you're in there and you're conscious of maybe 2 or 3 waiting. Everybody seems to be fussed when I'm having my prosthesis fitted, there's always somebody has been waiting for half an hour, somebody from the country.'
27: 'No, I think it's just yourself though, you just hate going in for it.'
22: 'There's always somebody waiting and really you feel you deserve a little bit of time. It's ok if you're an easy going person, you'll go in and you'll keep that person waiting for as long as you feel like keeping her waiting and you'll try on as many prostheses as you feel like trying on, but if you're a little bit muddled like I am, most times I'd be conscious of these women outside. You're conscious of the heat of the room. I'm conscious of baring my breast that's gone you know and it becomes a nightmare. I think if I was able to go in, be measured, as I said I'm repeating myself now, be measured and be told listen these will suit you, take them in there Mrs. X, try them on, see how you feel, see how they look and I'd be a much happier person.'

There was a disparity in the length of time women were waiting for products to be delivered, some only waiting a few days while others reported waiting 6-8 weeks.

>47: ‘If [NAME OF DEPARTMENT STORE] hasn’t the bra you want and it’s there, they will order it and have it within 3 or 4 days.’
37: ‘And then they put the pocket into it for you, is that it?’
47: ‘Most of them have the pocket in. They order it on the internet and it’s there in 3 or 4 days.’

>I: ‘ARE THERE LONG DELAYS?’
35: ‘Well about 6 weeks.’
‘You’ll have forgotten about it when it comes.’
34: ‘Yeah it’ll come in the post but it could be 6 or 8 weeks.’
‘Yeah that’s right, it is.’
34: ‘It’s unforgivable really, I mean you wouldn’t be waiting that long for false teeth so why should you.’
30: ‘They should be all made up already and it’s the same with the bras.’
36: ‘They have a company and if they employed enough people they’d be able to deal with their orders on a daily basis. What’s 6 weeks, I mean, it comes out of a, a store room.’

3.5.2: The prosthesis

Another theme that emerged centred on the prosthesis itself notably *patterns of use* and although some women expressed satisfaction with the prosthesis, many concerns were raised surrounding the characteristics of the prosthesis.

3.5.2.1: Characteristics of the prosthesis

With regard to characteristics of the prosthesis, women mentioned the weight of the prosthesis most frequently. The prosthesis was found to be very heavy and as a result uncomfortable, so some women were still wearing the temporary prosthesis that they received immediately after surgery.

>:14: ‘You’d wonder why they are made so heavy.’
15: ‘I suppose they’re trying to compensate for the weight of the breast.’
13: ‘They try to match, yeah, but like that I found if you were bending down doing anything I felt I was keeling over. So I’ve just 3 weeks ago got one of the light ones and I don’t know myself really.’
14: ‘Is that silicone?’
13: ‘Yes.’
14: ‘It’s just a lighter silicone, is it?’
13: ‘It’s actually a different shape but when I was down with the nurses below, she actually rang up there and then to try and order one of these for me and she rang me then to say that the bras had arrived and that the prosthesis, you know, em you know to match the bras really basically, and I don’t know myself because em I had a bit of damage done to the ribs from the radium and the heaviness of the other prosthesis, it was just, I found it very, I was caught everywhere you know. If I was out gardening or anything I felt it was going to fall down with the weight of it, but I don’t know myself with this one.’
14: ‘I’m just wondering, I was at a wedding there now recently and for the first time ever I went back that day and wore the first thing we got in the hospital.’

I: 'THE TEMPORARY ONE?'

14: 'The temporary one, yeah. I must have known to myself, I must have been finding something wrong with it, finding it heavy or something because that day I wore that for the first time.'

21: 'But the problem with the temporary one is it moved everywhere. It kind of moves, there wasn't enough weight to keep it down.'

'And it loses its shape.'

The women expressed some dissatisfaction with the shape of the prosthesis. As the prosthesis didn't tend to fill the entire hollow in the chest wall, some women suggested a more specialised fitting, perhaps taking an impression of each individual woman's chest.

>18: '.....and I would love to think that somebody would take an impression of the area with this and actually just if you could even stick it onto the, we'll say you're a B cup or a C cup and if you could just fill the area because if I look down inside my t-shirt or anything, I can see, nobody else can see but I can see the hollow, I can see the thing and I'd love to have something filling the area that I have because the one with the adhesive is no good because it doesn't hit the chest wall. Most people I think, they don't have straightforward surgery. They don't have a straight chest wall, they have hollows or bumps or something.'

'Like a saucer.'

'Yeah.'

18: 'So it'd be lovely if you could get something, I suppose it's way off in the future but it would be the ideal really, something like that.'

12: 'That the back of the prosthesis wouldn't be straight, that it'd have a lump.'

18: 'To suit whatever you had, yeah.'

In relation to the shape of the prosthesis, the nipple on the prosthesis was criticised by some as being too prominent and situated in the wrong position.

>18: 'Can I mention something about the prostheses, maybe when you're in your 20s alright you're sort of eh, very upfront like that, but I noticed that the prosthesis that I've got at the moment has a very slight nipple on it which is about an inch higher than my original one, so if you go out in the cold, you have one down here and one sort of an inch up. Now it's only very slight, it's only a very slight one but you can still sort of see the form of it underneath the bra and I think you know get real, there's none of us have one up there at this stage of our lives. So em, maybe they should look at people's shapes and if they're going to put a nipple, put it in the right place.'

In addition, the women referred to the heat/temperature of the prosthesis. Many women found the silicone prostheses became very hot in warm environments, inducing excess sweating. Some women also noted that in the winter the silicone prosthesis could be colder than the natural breast to touch.

>44: 'If the bra could be sorted first. I find the prosthesis, well in warm weather if you're out at night you'd be sweating. I'm forever pulling the bra out, you know just the heat of them.'

37: 'I never noticed.'

44: 'Em, I do'.

41: 'I work at night; I'm a cook. I just have to change as soon as I get home; the water is dripping off me. New bra, everything. You end up the bra rots with the sweat. That's what I find.'

The durability of the prosthesis is an important factor. In general prostheses were found to last 2 years before they went out of shape or became worn. However, some women found that they lasted longer, for example, up to 7 years. Heat and flying were mentioned as shortening the life span of the prosthesis. Movement of the prosthesis was also found to be distressing for the women with the prosthesis moving around (temporary) or falling forward (silicone).

> >30: 'Do you know what I wore for my first few weeks? A bag of rice with cotton wool to give me shape and balance because I found with the softy they gave me, it was like up here and I thought what can I do to balance myself until I get the prosthesis and I thought, rice.'
> 'It probably sat down better, did it?'
> 30: 'I bought the boil in the bag rice and I flattened it down to the bottom of the bra and then I had cotton behind it and it worked perfect and nobody knew the difference (laugh). Boil in the bag came in very handy (laugh).'
> 34: 'I found the other ones up at my shoulder as well which like is really...'
> 30: 'That's upsetting.'
> 34: 'Absolutely terrible. That was just horrendous.'
> 28: 'I never knew how much stuff to put into them or how much stuff to take out of them. I was given this, I was given this one and a bag of wool with it and you didn't know whether you were meant to put more in or take less out. It's very hard, its very difficult.'

There was some discussion about specific styles/types of prosthesis, most notably a prosthesis designed specifically for swimming and a self-adhesive prosthesis. While some women indicated that they wore a padded swimsuit while swimming, others discussed the benefits of a swimming prosthesis.

> >30: 'There is a special swim prosthesis, and em I just received mine about 2 weeks ago. I went in on a Wednesday to [NAME OF BREAST CARE NURSE] is her name, she's a fantastic girl, she's a breast care nurse in [NAME OF HOSPITAL]. I order it on Wednesday and I had it Thursday afternoon. And the one that I got, it's like a hard sponge (yeah, I know it) and has a disc in the centre of it. I haven't actually used it yet. There's like a balancing thing in the centre so that you don't go lopsided and you don't go wibbly-wobbly in the water. But like I know from the States there is definitely several different types.'

The self-adhesive prosthesis received mixed appraisal; some women found it excellent while others could not wear it at all. Reasons for not wearing a self-adhesive prosthesis included having skin irritations, needing a large prosthesis, having a hollow in the chest wall and having a fear that the prosthesis would fall off.

> >46: 'Well I was telling them about the self stick-on prosthesis which I find are, is very good. I get on very well with it. I'm on my third one now.'
> 40: 'Oh I never heard tell of that, stick-on.'
> 46: '[NAME OF PARTICIPANT] didn't either.'
> 38: 'I got one but I was afraid to wear it. I was afraid that it wouldn't stay in place and that if I wore something like an ordinary bra that it'd slip out.'
> 'Where did you get that one?'
> 46: 'Oh it's [NAME OF SPECIALISED PROSTHESIS SUPPLIER], I went to now.'

'[NAME OF BREAST CARE NURSE] has them here.'

47: 'It doesn't suit everybody, it didn't suit me. My scar goes across like that and there was a hollow in my scar. It holds on with suction and every time I would go forward it'd fall off.'

>16: 'It adheres to your skin and it's very comfortable. I wear it sometimes when I'm wearing one of my bras, but you have to have a kind of skin regime but em I never had any problem with my skin and it's not going to fall off, I can tell you that. If you wanted to wear, I wouldn't be at this stage wearing a strapless top, but if you wanted to, it's, they are very comfortable and I got it from [NAME OF MANUFACTURER].'

3.5.2.2: Patterns of prosthesis use

With regard to patterns of external breast *prosthesis usage*, the majority of women reported wearing their prosthesis all the time, with some women not wearing it around the house, for example when doing housework. The main reason given for not wearing the prosthesis was increased comfort.

>40: 'Oh I always wear mine.'

47: 'I don't wear mine in the house.'

40: 'Do you not?'

47: 'No, if I'm up in the morning doing my housework. You know I have a big sloppy Joe t-shirt.'

46: 'Oh mine goes on, it's like the bra goes on, the thing goes on and that's it.'

38: 'I never leave the bedroom without it. It's the first thing I do, I'd be afraid one of the boys coming up, I'd be very aware of it.'

'Aye.'

41: 'I must admit I get up too and if I wasn't going to work and doing my housework I'd never put a bra on until I'm ready to go out.'

37: 'I'd be afraid then somebody would come in on me.'

38: 'Yeah somebody would come to the door or something.'

47: 'Everybody I know knows I've only got the one so it doesn't bother me.'

41: 'You should not worry about anybody else.'

42: 'I don't have that same confidence that you have.'

'No, neither do I.'

42: 'I'd just be conscious of it.'

The women also mentioned the issue of *reconstruction*. Some women were not offered reconstruction, others were content with the prosthesis and did not want reconstruction, it was not a viable option for some women, and others were anxious about the procedure.

3.5.3: Bras/Swimwear

Choice of mastectomy bra was a prominent topic referred to by the women. Although one or two women noted finding a good choice of mastectomy bra, the general view was that there is a poor selection available. Women noted finding it difficult to get larger sizes, to get a variety of colours and to find good quality bras including strapless, underwire and clear strap bras suitable for a prosthesis.

Women discussed the need to allow for delivery time and not, in all instances, being simply able to enter a store and get a bra of choice. They also mentioned having to order bras from the UK in order to get a good choice.

>38: '... I thought this is great because it's a black one. It's nearly impossible to get nice coloured ones. They're all white or cream but it had no pockets.'

>36: 'Strapless bras I found now if you wanted to wear for a wedding or something like that, there's no such thing as a strapless bra for people with prosthesis. All the strapless bras have underwiring and you can't wear, even the stick on.'

>30: 'I mean just because we have mastectomies doesn't mean we can't have nice underwear or clothes or whatever. I just thought they were an absolute disgrace. What I found, what I've ended up doing is I get old cotton t-shirts and my mother actually sews on a pocket in the bra for me because I like to wear underwire and that's another thing they hadn't heard of here. Well I mean they've heard of them but they're not of good quality.'

>13: 'I spotted the booklet now when I was being fitted for this prosthesis and you know the one thing that I thought, England are way ahead really because the swimwear now you have to send away for it, you can't get it here.'
21: 'That's right, I got a swimsuit from them as well and they've a pocket in it.'
13: 'Yeah, they have lovely stuff but it's awful to think you have to send to England for it.'

With regard to different *styles* of bra, the women tended to like the camisole bras with lace to cover the chest.

>11: 'I've a bra on me that has two pockets and it has the little frill across here and if I bend over they don't move. Well, I'll show yous because we're all women.'
'Oh very nice.'
'It's brilliant.'
5: 'That is a brilliant bra, yeah.'
11: 'That was what the nurse fitted me in [NAME OF SPECIALISED PROSTHESIS SUPPLIER].'
'That's terrific.'
'That's brilliant.'
5: 'They're 55 euro'
11: 'They're 55 euro the bra on its own.'
3: 'But it's worth it.'
11: 'I got 2, I took 2 the same because if I'm wearing a v neck, that's just like a little frill.'
'It's terrific, I'd love one of those.'
11: 'It's very, very eh dressy.'
1: 'But you could do that very simply if you were handy with a needle. Just get a bit of lace and sit it in.'
11: 'The lace is fitted and it's fitted kind of in and when you lean forward, nothing goes forward. They stay in the one position because normally with the prostheses, with the other bras without this across it, when you lean forward, everything leans forward, everything goes with you.'
1: 'Like you, I've a big dip so if I lean forward you've a big hollow.'
5: 'There is a hollow.'
11: 'But that's, that kind of bra, they're only new bras out.'

They found that if the bra was the same make as the prosthesis, it would fit more securely. However they found the styles of many mastectomy bras were heavy and unfeminine. In addition, the material of the bra was mentioned. Women seemed to like the cotton bras but found that many of the mastectomy bras are made from nylon, which was criticised as causing sweat and irritation. There was a contrast between women who preferred the security of mastectomy bras to those who preferred to buy regular bras.

>30: 'Yeah but part of it is nylon and I mean the thing, you're very limited when you have mastectomy bras because ok I have one now for everyday of the week because my mother is so good with her hands but for most people and to afford to buy them is the other thing. A lot of them have nylon and when you're wearing that with the silicone, I mean that causes a lot of sweat and irritation because there's so much moisture building up behind so you really need cotton between the chest wall.'
'It does make it very hot.'
32: 'I couldn't find them anywhere else only [NAME OF DEPARTMENT STORE].'
30: 'They're very limited there I find. If you're small good and well but.'
32: 'They do the one brand, it's [NAME OF BRAND], the one brand all the time.'

>47: 'You see what I find too, if you have an [NAME OF BRAND], I think that's what you call a prosthesis, and if you have an [NAME OF BRAND] bra, both will go together, where if you get an ordinary bra that prosthesis sits funny in it. You know the name of the bra and the name of the prosthesis always sits good but if you just get an ordinary, another name of a bra, that prosthesis doesn't sit as well. You know at the beginning when I had my operation it used to be [NAME OF BRAND] or something, them bras were terrible. It was like something my granny would have worn. It was way down here.'

In addition, dressmaking was referred to. Women mentioned regularly sewing pockets into the cup(s) of an ordinary bra or swimsuit. This was seen as a good substitute for the more expensive mastectomy products and it also helped them to acquire certain styles of bra which may be unavailable in mastectomy form. However, although one or two hospitals offer this service free of charge, many women had to alter the clothes themselves and this was found by some as quite unsatisfactory. Many women also found dressmaking necessary to alter the clothes that they buy. They noted the lack of suitable clothes for women who have had breast surgery, stating that clothes regularly have to be altered to cover scars, etc.

> 47: 'A cap sleeve too just because your scar is coming under your arm. You know the wee strap comes down here. I find I would sew up, you know, a lot of the tops another inch and have it right tight under here.'
37: 'Yeah I have to do that with all the tops, just take them up another bit.
Everything, nearly everything has to be altered in some way.'

>10: 'I sewed a little pocket…it's a great substitute rather than paying €50 or €80 for a swimsuit.'

>18: 'I also think maybe coming back to the bras, that it shouldn't be a chore to get a pocket in them. I think a lot of bras are given out now without pockets. I, I know in the [NAME OF HOSPITAL], the breast care nurse over there had a seamstress who used to do pockets. I might as well, you how she made the pockets, this was her own way of

doing it. She got the very light women's drawers, you know what I'm talking about, the cotton ones because that's very fine cotton and that's what she used for making pockets. That's what she still uses.'

12: 'You can buy the pockets.'

18: 'They're very cheap and easy to sew in.'

12: 'You can buy a pocket mail order.'

18: '5 euro for 2 I think and then you can sew them into whatever item of clothing you need.'

16: 'I think myself that maybe that could be a huge chore for some people.'

'True.'

'Absolutely true.'

16: 'Huge chore for some people to do it or to buy it. We can't assume all people can do that.'

3.5.4. Cost

3.5.4.1: Expense

The participants made many references to the general expense of prostheses. All women who were currently paying for their prostheses felt that they were too expensive with prices cited for a prosthesis ranging from €90 to €150.

>11: 'Well I just think they shouldn't be the price they are. They're too dear.'

Swimwear and bras were also deemed costly.

>37: 'I'm very small, I was always very small and I have to get bras that are very well padded and then they'll only last maybe 3 months and then I just have to throw them away because after so many washes and things like that, the, you know the fit of them and the feel of them, the look of them, it's no good to me. It actually costs me a lot of money.'

38: 'They are expensive to buy.'

37: 'They are expensive because I go through [NAME OF SPECIALISED PROSTHESIS SUPPLIER] in Dublin for them to order them for me and then to insert the pocket, 2 bras every time I think is around about, I can't remember now but I think it's about 106 euros so I'm talking about every 4 months on average.'

39: 'And the swimwear is very hard to get.'

37: 'The swimwear is very expensive.'

39: 'And it's very expensive, the Irish you know, they're double the price of the English crowd you know.'

As a result of these high costs, women reported not prioritising the prosthesis as an expense and having gone without a replacement prosthesis due to familial financial responsibilities (e.g. children).

>10: 'I'm wearing a prosthesis at the moment and it's too light for me, I know it is, but I keep saying I'll buy a new one, I'll buy a new one, but the thoughts of buying a new one, the thoughts of spending that money, I know it sounds terrible...'

1: 'No it doesn't sound terrible.'

10: 'It might sound terrible to somebody, you know but I mean, a lot of women will be thinking the same as me, again you get around to buying one of them, some other priority in the house and that's because you're sometimes

too …if you're a mother you think like that too you know. The mother bit is in you as well, you never lose that and with the result you think twice, but definitely saying there the proper balance, we, you don't have the proper balance'

3.5.4.2: Entitlements

The women generally expressed dissatisfaction with entitlements made available to them in relation to prosthesis provision. Although they did welcome the scheme, which gives them the first prosthesis and two bras free of charge, they also expressed a belief that the government should treat every person equally. They made particular reference to the fact that social welfare provides support for other medical requirements such as glasses and hearing aids but not breast prostheses.

>10: 'If you're paying PRSI, you get allowed for your glasses so you should have an allowance. The medical card is a separate issue to that but there is nothing for people that can't afford to buy them and if you're paying PRSI, like what [NAME OF PARTICIPANT] said there, she gets so much off her maintenance. We get nothing off our maintenance. I'm paying PRSI and I pay tax and we get nothing off our maintenance, yet we get, if I wanted my reading glasses renewed, I'd get them free because I, you get a price and if you want to go over that price you pay for it.'

'Yeah it's up to yourself.'

10: 'You can pay the extra.'

1: 'I think that would equalise things very much.'

11: 'We'd have to lobby kind of in a sense, if women wanted help from Social Welfare, ye know what I mean, or Social & Family whatever you call it. But em, there should be that kind of help. You've help with your glasses, I've help with my hearing aids. Now my hearing aids were 1,500 because I got them fitted and the SW paid half of that and I paid the other half. They gave me half of the money for the hearing aids. I don't see why it can't be the same for prostheses.'

>27: 'There should be something out there for us all, like you glasses or your teeth or whatever. You've worked, you should be able to put in this form and you should be able to get something in return, something in return.'

22: 'Yes.'

27: 'If you're not entitled to the medical card there should be something out there and you should get it. You shouldn't have to go through your life wondering, do you look alright, are you going to be alright. Do they not realise if they don't give younger women and especially women that can't afford it, it's going to be a mental health issue in the end because they are going to be mentally, apart from not looking properly you know what I mean, so they should be doing something for women like that that haven't got the medical card and can't afford to buy one. There should be something out there that they give you.'

The lack of uniformity in entitlements was mentioned. There was great disparity in the financial support that women received throughout different parts of the country.

>35: 'I'll just reiterate the idea of the information for every woman, the information and that things should be uniform throughout every health board. It's so confusing, different, eh things done in each health board. They should be all the same and it should be transparent.'

'In the eastern part of the country you can have a mammogram and you can't have it.'

35: 'Well you see there is no Ireland except on the east coast. I don't want to cause offence to anybody else but the rest of us are here too.'

39: 'Well I wasn't informed that you could get a free one every 2 years. I knew nothing about that until about 6 months ago.'

'I knew.'

46: 'You see it's not that while long in that we could get the free.'

40: 'It's in about 5 years anyway because I've been getting it and I was told that.'

41: 'I never had to pay for anything ever.'

39: 'I always had to pay for the bras, she sent out the bill like down to the person that does.'

46: 'So did I, I paid for my prosthesis and bra.'

I: 'YOU PAY FOR YOUR BRAS, DO YOU?'

39: 'Well not now, not the last time but every other time.'

44: 'It could come in the end that we would be paying for them like it's only…'

The accessibility of financial entitlements was also raised. Some women had very negative experiences when trying to apply for the medical card.

>30: 'I had a very positive attitude from the moment I got the phone call of diagnosis. I had a very positive attitude; I try to because I have 3 kids. She was the only one that made me feel that small and that was the Western Health Board out in Oughterard. What really got me as a woman to woman, that she could be so cold.'

'Exactly, I found that as well.'

30: 'It's a hard enough pill to swallow and it's not everybody likes going in the door of social welfare. You know what I mean.'

33:' I tried that too, it was a man and he made me feel very very small and I had my letter from the consultant. I took them just in case. You know, to make sure I, and he said "I don't even want to see them" and he kept writing. I don't know what he was writing but I felt very small and I felt very hurt and I thought good grief I'm so sorry for ever entering that door. I didn't feel well after it, I felt very shook and I think that was his attitude towards a lot of people and I know people that really could do with a medical card and they felt the same.'

30: 'You have to fight for it.'

33: 'You do.'

30: 'You shouldn't have to.'

33: 'Your confidence isn't that strong, you're a bit low.'

30: 'You are of course.'

Finally, the issues of VAT and insurance were briefly mentioned by participants. It was thought that the women should not have to pay VAT on breast prostheses. In addition, some women found that having insurance was not beneficial as the quota which one needed to spend was too high.

>11: 'Another thing we didn't mention, hit on, that I'm only after thinking, the VAT, we should have to pay the VAT that we're paying for medical appliances because on all these things there's VAT and we're paying very heavy VAT for them. I think it's 21%, I'm not too sure.'

1: 'I think it's something like that.'

11: 'So, if you take 21% off 89 euro, it's a hell of a lot of money. Ye know so, that's another thing people should be lobbying about. We're paying the full amount plus VAT on top of that.'

1: 'And does that apply to bras as well?'

11: 'Oh yeah it does, applies, I'm not too sure whether it applies to the bra or not, but it does apply to the prostheses. I do know that. It's an appliance and that's what you pay. 'Cos I had to pay VAT on my hearing aids as well, so I do know that you have to pay VAT and I think it's very wrong that you have to pay VAT on what we need

to make ourselves comfortable. It's not for fashion or anything, I mean we want to have the weight so we can be balanced properly and walk properly because we can walk properly if we're not balanced right.'

The final extract in this theme highlights the far-reaching implications of cost particularly given the importance of the prosthesis for the woman.

>2: 'The people I feel sorry for are the ones who are just above the medical card limit. It's a huge amount of money to have to fork out to keep yourself looking good.'
11: 'Well reasonable and nice.'
2: 'Reasonable and self-confident.'
1: 'And healthy.'
2: 'And, because that affects your mental health.'
5: 'You need to feel feminine, you do need to feel feminine.'

3.5.5: Information

3.5.5.1: Content / Focus

Women described having a general lack of information regarding external breast prostheses. One main gap reported was where to access post-mastectomy products. In particular, this related to the replacement prosthesis and mastectomy bras and swimwear. For example, some women did not know whether they could go back to the hospital for a refitting. Furthermore, some of the women were not aware of the choice of fitters and outlets for accessing a prosthesis outside of the hospital setting.

>5: '...I have a prosthesis in now about a year and 2 months. And eh, I was fitted here by [NAME OF BREAST CARE NURSE] and the only complaint I have was that I hadn't got a clue where else to go for bras or another one or anything like that. I wasn't told, so it meant that I just had a soft one and a normal one that she fitted me with and eh, the rest I done was, thank God, I'm a good dressmaker so I made up all my own fitted bras and things and fitted swimsuits I fit them out myself. [NAME OF RETAIL OUTLET], as I said, I got one in which I had to go through a catalogue. So that's about it.'

>27: 'I think when you initially.., when you have your operation and they fit you in hospital, you come out of hospital then and you have to make a relationship with this "it" (laugh) as I said before, but when it comes to getting the next one, you're kind of in limbo. You're kind of saying well do I ring up and ask the hospital where do I go. You don't know what to do about going about the next one. Now I have to say I rang [NAME OF BREAST CARE NURSE] and they told me where to go and what to do and one thing and another. I think there should be something to tell you that if you didn't like the one you got in the hospital, you could go here and buy one for yourself. Or you can do this or...There is no information for you as regards that. I think there should be a little bit more information.'

Some women also mentioned the lack of information concerning the different types of prostheses and in some instances the care of their prosthesis. Indeed, some of the women did not know that there was more than the one type of prosthesis available. Many had not heard of the self-adhesive or swimming prosthesis. Few women recalled receiving brochures detailing the types of prostheses and

mastectomy bras and swimwear. They asserted that they should be kept up to date with current mastectomy products, particularly as they are constantly advancing.

> >40: 'It's good to know you can get different prostheses and it'd be nice if you were shown different ones when you go in because I didn't know. I thought they were all the same. There was just the one and that was it. And you know, grateful enough to get it right enough.'
> 37: 'I didn't know you got a prosthesis that went way back there.'
> 40: 'No I didn't either.'
> 37: 'Because you were seeing [NAME OFCONSULTANT], like [NAME OF CONSULTANT] when he does the operation he would take as much of the flesh and muscle, everything away, which means you were right in close to the ribs and you have nothing in under there and the wee prosthesis I have just sits there but there's nothing there.'

There was a contrast in the amount of information that women received prior to the operation regarding prostheses and what to expect. A small portion of women received booklets and/or were shown a prosthesis before the operation, either by the breast care nurse or a volunteer from a support group. However, many others indicated that they received no information or, at least acknowledging the trauma, shock and confusion that can often accompany the initial post-diagnosis period, that they had no recollection of receiving such information.

There was also much uncertainty over entitlements available. Entitlements differed from place to place and women were informed by a variety of sources such as nurses, GPs, pharmacies and friends. Although the Irish Government announced that for all women their initial silicone prosthesis and two bras were free of charge and that women who hold a medical card are entitled to two bras every year and a replacement breast prosthesis every two years, if required, many women indicated that they had discovered this by chance and had not been automatically informed of it. Furthermore, the women stated that there was no information available as to how they could access or avail of these entitlements.

> >1: '...The other thing that bothers me is the lack of information on how to access the prosthesis, the Minister announced, Michael Martin announced 2 years ago that the first bra and prosthesis was free to all women, irrespective of income, but nobody seems to know, including the professionals, how do you access that service. I mean those of us that, you were fitted in the hospital, a lot of women are not. They're just sent home. They don't know where to go.'

> >35: 'It would be nice if it was all uniform, not a whole lot of fragmentation all over the place. If every woman had the same choice of the product, not to have different things going on in different places and a complete lack of information really on what is on offer.'
> 28: 'Well that's how I would describe it too, no information whatsoever in that area, absolutely none. I didn't even have a clue that there was something different that you had a choice in. I think that day has well come that people should be informed.'
> 35: 'You almost felt grateful like that you got anything.'
> 28: 'That's right.'

3.5.5.2: Sharing information

The value of local and national support and advocacy groups was noted. Some participants were members and they found the support groups a valuable means of exchanging and receiving information. Furthermore, the usefulness of gaining information informally from others was exemplified in the focus groups themselves. For example, the women actively sought information from each other during the focus groups. They seemed to benefit greatly from simply talking to each other, discussing topics such as body numbness, prosthesis type (e.g. self-adhesive, lightweight or swimming prosthesis), prosthesis-fitting centres, and different types of mastectomy bras and swimwear.

> >44: 'It's amazing what you learn from talk, isn't it?'
>
> >39: 'And you get to speak to others too, you see. When you're making your appointment you're only going up on your own so you mightn't be asking all the questions, whereas if you're speaking to others, even today now we're hearing everyone's experience so you say god that might be ok, I'll try that.'

3.5.5.3: Receiving information

The women gave suggestions as to how they should be receiving information. With regard to this, the most frequently mentioned issue was the timing of the information given. The general consensus was that information should not be given too soon, or at least should be regularly repeated, and should be distributed by information pack in addition to being given verbally. This pack should include advice and information on what to expect, along with details of prosthesis types and fitters. It was suggested that information should be given in steps, gradually sent at different times throughout the whole process. In addition, a reminder letter was suggested to let women know when their prosthesis should be renewed. One woman likened this suggestion to getting reminders for eye tests every 2 years from the opticians. A further frequently mentioned suggestion for receiving information at a later stage post-mastectomy was through a brochure or magazine that was readily available and constantly updated.

> >17: 'The people who have been there you have to target and you have to do it step-by-step from the very minute they're diagnosed, what's going to happen to you, mammogram-wise, biopsy-wise, operation-wise, recovery in hospital, gradual information to be fed all the time as em the occasion arises, sort of thing, rather than as you say having a big litter of books going home and you just want to throw them away.'
>
> 15: 'Well, I think the breast care nurses are the best source of information and they're there at the breast care departments and most people visit them at some stage.'
>
> 12: 'Yes but I find now, you know I always like to talk to [NAME OF BREAST CARE NURSE] and [NAME OF BREAST CARE NURSE] because they're super but I find when I'm coming for my check-ups now, they see me, a big hello and that's it, because I'm not a priority anymore and that's absolutely fine with me.'
>
> 21: 'They're too busy.'
>
> 13: 'Yes but if every time you make your appointment for the next whatever that you are handed the updated newsletter, that it's automatic, when you make your next appointment over at the desk you're handed the next copy.'
>
> 17: 'That's right, in keeping with your time.'

12: 'Exactly, ok so you're a 6 month.'
'Yeah.'

>16: 'You shouldn't have to search for them. Could somebody like [NAME OF DEPARTMENT STORE], some of the underwear companies, could they sponsor a proper or even [NAME OF MANUFACTURER], and eh a proper brochure and maybe not just stick to the one brand. Kinda get, I suppose this is very idealistic.'

10: 'I was just going to say that, all the glass places, they send you out, most of them send you out information when you're due to get your glasses renewed. That would be, I mean 2 years could go by, 4 years could go by, somebody said 6 years there a minute ago, go by and you didn't think about, and for hygiene reasons as well you need to change your prosthesis.'

A roadshow event was also advocated as another way to ensure that women throughout the country were given the opportunity to receive sufficient information.

>18: 'It'd be nice if there was a day sort of thing, that if it was an organised day, that sort of people, advertise that people with breast care problems or who need a prosthesis, could all come and say right it's in Cork today, Tralee tomorrow, Limerick and have it well advertised.'
12: 'A roadshow.'
18: 'Because there's a little bit of anonymity about coming to a hospital, whereas if it was in a store I think an awful lot of people are very private about it and don't like mentioning it and they don't want to meet other people, of, that they might know.'
'Confidential to themselves.'
18: 'Yes, whereas if you go to a hospital I think.'
'If it was a room like this, with displays all around, have a cup of tea.'
18: 'It'd be lovely actually and you'd see what was available and if it was well advertised people would know about it.'

The general view was that information did exist but it was not getting to them.

>1: 'The sad thing for me in all this is that for years we've been advocating that breast cancer patients be given a little pack. The Irish Cancer Society would supply the pack and most of the hospitals now have breast care nurses who are doing a wonderful job, and add this little service to that service would take so much of this stuff out of it where you'd have the names and addresses of the fitters, and Reach to Recovery booklet has the fitters and the advice on what you need and little diagrams of what to expect when you go into the fitters. All that stuff is out there, it's not getting to the patient and it just seems so sad to me. I'm sure it does to you too because we put so much into trying to get that service.'

Conversely, there was also the recognition that receiving the diagnosis of cancer was preoccupying and at times all consuming, therefore the receipt of information could be forgotten and not prioritised at that point in time. This emphasises the importance of repeated information over a period of time and in various formats to ensure that it is there when the woman is prepared and willing to read, digest and act upon it.

>18: 'Maybe something they could read rather than somebody directly telling them, at this stage now especially.'

: ‘And also afterwards I think. You get all the information before when you’re in a complete traumatic state and there’s things said and it just goes in one ear and out the other and it’s afterwards, up to a year afterwards I think. You were just saying, how long is it now and you’re still recovering?’

14: ‘14 months later.’

12: ‘Even a year later, to sit down and talk about it and what’s available and where you can get this and what you can do.’

18: ‘You’re more acceptable to suggestions anyway at that stage.’

12: ‘Absolutely, you’ve recovered somewhat.’

18: ‘It’s not your priority like at the start.’

12: ‘Of course it isn’t your priority. Survival is your priority and your family and that everybody is ok. Definitely yeah.’

21: ‘You get all the information at the same time as you’ve just been told you’ve cancer and all you see is cancer and nothing else matters to you.’

‘You just can’t hack it.’

>12: ‘To be honest now, I mean now that you say it, I remember these booklets and things like that which were all part of a terribly big trauma which went straight to the back of the cupboard as soon as the trauma was over in my life anyway because it was all pushed away. But I think maybe it would have been nice to get a letter to say ok so many weeks are passed now and we’re onto the next step. This is what you’re going to be next, this is what’s available to you. You’re entitled to so many bras, you’re entitled to, it’s by pure accident that I think you find out about the... certainly that I found out that I was entitled to get 2 bras or where I would get them or whatever. Again like everybody says the two breast care nurses here are second to none. They’re just superb people and I couldn’t praise them or thank them enough but it’s a bit haphazard to be absolutely honest.’

>18: ‘I think we have to blame ourselves an awful lot too because an awful lot of people don’t ask. I know people that will go and I’ve said to them how did you get on with your results. I don’t know I didn’t bother ringing up about it, sure they’ll ring me if there’s anything in it. And I can’t understand that because I’ve got to find out everything. And I think if you enquire about things you will find them but I think an awful lot of people don’t. I think you have to blame yourself as well.’

3.5.6: Personal implications of an external breast prosthesis

Throughout the focus group discussions, women highlighted the many personal implications of wearing an external breast prosthesis. These implications were collated under four headings: coping with a new image; coping socially; lifestyle considerations; and adjustment.

3.5.6.1: Coping with a new image

Women’s body shape was brought up frequently. The women described having to cope with changes in their body shape such as having excess tissue, a hollow in the chest wall, scars and/or numbness in the area where the breast was removed.

>5: ‘Literally it’s peculiar looking now, I’m all funny on one side, completely missing where you know you come up here and you might be left with something there, I’m not, just a big dip. I make a few of my own clothes that’ll cover

me just comfortably but if I bend over that's it, it just looks peculiar. I have to be very very careful what I wear ye know, and I'm sure a lot of the ladies here are the same.'

>34: 'I think it's a very ugly scar as well and that nobody ever said that in the hospital at any time'

In tandem with body shape, body consciousness was discussed. Although some women were not at all worried about their image, others expressed a degree of self-consciousness. For example, some regularly check that their chest looked even, whereas others did not feel comfortable without their prosthesis and never left their bedroom without it. Although this sense of self-consciousness was potentially an ongoing feature post-mastectomy, it appeared to be most prevalent in the years directly after surgery.

>44: 'I know I was very self-conscious, you know very conscious of it at the beginning but you get used to it. I would never come down to the kitchen without my prosthesis in. I had 8 children at the time. My baby was only 9 months when I had mine and the eldest was 11. I was, I was always wild conscious. Even bending down I'd always have to keep my top up in case they'd be looking.'

>47: 'Yes, I keep looking down to see. I found that the first day too coming out of [NAME OF HOSPITAL] after my operation, I kept looking down to see if the two of them were exactly sitting properly.'
37: 'Well you're always looking down, you're always rearranging yourself. I'm always pulling it down.'
'You're always poking at the bra.'
47: 'Nobody notices but you, you know.'
'Yeah it's just yourself.'
47: 'And then the nipple, if it's a really hot day or something, you look down and god the nipple is sticking away out here and there's none here. I'd always put a t-shirt or something on.'
38: 'That's what I would find, you wouldn't wear tight t-shirts.'

A final issue raised in coping with a new physical image was a debate over whether a prosthesis was cosmetic or functional. Although recognising the cosmesis of the external breast prosthesis and its role in restoring the outward body shape, many of the women stressed the functional importance of the prosthesis, for example, with regard to balance. One exchange in the focus groups delineated the importance of emphasising the functional nature of a breast prosthesis and not solely classifying it as a cosmetic produce because it was felt that if prostheses were seen by many as solely cosmetic, it may diminish their importance vis-à-vis the loss of other parts of the body.

>10: 'I found for me there was a big lack of information and things maybe have improved in some areas an awful lot like treatments and that, but as regards things like cosmetic, because that's what it's looked at, prosthesis is cosmetic and regarding that end there isn't still isn't enough.'
2: 'It hasn't improved an awful lot since even since my day.'
10: 'If you have a mastectomy, it's a limb, no matter what way you look at it, you've lost something but in the world of em medicine, the consultant doesn't think about that, you know what I mean, he's not going around with no breasts. We are, the women are going around with no breasts.'
1: 'And it's not cosmetic because it does interfere with your carriage.'
'Your balance, yeah.'

1: 'You've carried around these x amount of pounds up until one is taken away so you're lopsided, so it's bound to interfere with your balance and you've all sorts of other problems so it's not cosmetic but it's treated as if it's cosmetic.'
10: 'And as you say, you can get round shoulders and all that.'
1: 'You get all sorts of back problems.'

3.5.6.2: Coping socially

The ability to cope socially was facilitated by the availability of social support; women noted the importance of volunteer groups. By seeing someone who had survived cancer, they felt reassured. The support of husband, family and friends was also of great significance to the women. The importance of support received from the breast care nurse was also noted as a key factor in helping to build the person back up after surgery. Finally, the consultants were mentioned as important for keeping the woman positive.

>27: 'I have to tell you the doctor might take the piece out but it's the nurse that builds you up. The breast care nurse takes you and puts you back together again because she has the sympathy, the time, the understanding. She has all the things for you that the surgeon hasn't got. The surgeon does his job, that's great, but the breast care nurse is the person who puts you back together again.'
25: 'And she's also the one you would ask.'
27: 'Any questions you want to ask she's there for.'

>5: 'My husband often says to me, I have to be honest, I forget which one is gone and I do say well thank God for that ye know. He's quite comfortable about it ye know? But eh.'
2: 'Not all women have that kind of support. They have to look good.'
'Yeah'
5: 'I am lucky, I'm very very lucky.'
11: 'My husband doesn't care what I look like (laugh). He's quite happy I'm alive.'
5: 'My husband is quite happy I'm alive too.'

It is important to note that other people's reactions can have an effect on the woman and that women are dealing with this in addition to their own feelings towards the prosthesis. Some women found that people looked straight at their chests rather than their faces after the operation, whereas others felt that shop assistants were dismissive of them. Furthermore, many of the women in the focus groups were wary of communal changing rooms in swimming pools and shops. Women could also be afraid of a family member or neighbour finding out about the surgery or seeing the prosthesis.

>18: 'I think people's attitude, I was so relieved to get the temporary one when I went home from hospital because automatically people know you've had a mastectomy and whether you like it or not, no matter who they are, they'll say how are you and the, the eyes drop.'

On the other hand, other people's reactions could have a positive effect, for example, one woman recounted being called 'sexy' by a passer-by, which gave her great confidence.

3.5.6.3: Lifestyle considerations

Overall, women did not think having a prosthesis restricted them hugely in their daily lives. The lifestyle change that was mentioned most frequently and that was seen as the biggest problem was clothes. Clothes that are clingy, v-neck, sleeveless, low at the front or back or anyway flimsy were not worn by most women in the focus group. The reasons given were that the large bra straps, the surgery scar or the nipple may be noticed. Many women found it most difficult when buying clothes for summer or for a special occasion. Some women found it distressing that they could not wear the variety of clothes that they used to wear. Furthermore, communal changing rooms made many of these women feel uncomfortable.

> >20: 'I was just making the same point about clothes, that it sometimes can get to you. It's just occasionally, it just depends how many times you've had to look at stuff and put it back or you see something and think that would be lovely or that would be nice. It brings the whole thing back to you again.'
> 'It does yeah.'
> 15: 'You think you've put the entire works behind you, you know and you're standing there in a shop and the next thing you realise that you're very close to tears, I can take very little more of this really.'
> 14: 'You'd be saying I could wear that 2 years ago but I can't wear it now.'
> 'But I can't wear it now, exactly or that would be lovely or sure I have to put it back because of, and it's not that, it's the little pink marks .. when you're above everything.'
> 13: 'Or especially too if you wanted to wear a sleeveless t-shirt, you have to get it tight enough under the arms not to show the scar.''
> 'Exactly, you've to look at all aspects of the neck and under the arms.'
> 16: 'And clothes are becoming so flimsy now anyway, I envy some of the girls, for instance the girls who present television programmes, my God and they're so glamorous and they've nothing here, oh I wish.'
> 20: 'It's funny you say that, I was just watching news announcers the other night and it was they who were in my mind, oh my God the glamour and the beauty and here we are just trying to cope.'
> 15: 'There seems like obstacles, you get over major ones but just now and again it gets to you.'
> 16: 'And if you're undressing in public, you know the em, there some fitting rooms that are, there are about a thousand people in there, you would be self-conscious. I wouldn't fit something on in a dressing room like that.'
> 'No I wouldn't'.

The prosthesis falling out and being displaced was a fear that many women had and that some women had even experienced. When this occurred they noted feeling embarrassed but tended to laugh it off. Other considerations referred to were sunbathing/holidays and weight fluctuation. If women put on weight their prosthesis needed to be changed so it looked the same size as the other breast. This was a problem for pregnant women and women taking certain medication.

> >2: 'As you get older you generally get a bit bigger, well I did (laugh), I shouldn't generalise, but a lot of people do get a bit bigger and have to get bigger prosthesis.'
> 5: 'The medication does ... so therefore you're left with one smaller than the other.'

3.5.6.4: Adjustment to the prosthesis

Women emphasised the difficulty in adjusting psychologically to the prosthesis while initially having to cope with being diagnosed with breast cancer and then having to undergo breast surgery.

> >35: 'I think at the very start, depending on, I was 31 and eh, I found it very difficult to accept that I could no longer wear the clothes that I was wearing at that time. You know I found it very difficult the first year to accept that this was me now and this was what I was going to be like in the future. Ye know, and maybe that was against, ye know I wasn't sort of, the prosthesis wasn't a vital thing for me, I was just so disappointed that I had got cancer and I was only 31 and that it was changing my life, which it did, but not so much for the worst as time went on, but at that particular moment in my life, no matter what the prosthesis person done, I don't think I would have been happy.'

> >22: 'But as regards the prosthesis and making women kind of feel a little bit better than they do, I think it would be a very very difficult task for anybody because a woman that's only after being diagnosed with breast cancer, there is so much going on in her head that I imagine the prosthesis is just absolutely secondary. I would say, but it would be great if they could be made feel better, but I really think it's a very hard task for anybody to make a woman that's just after having her breast removed feel good about any prosthesis, no matter how soft it is, how well it fits in the bra because like she's thinking about death and all these horrible things.'

For some women, the prosthesis was not seen as important. It was seen as relatively insignificant compared to the trauma of having a potentially fatal disease.

> >'I often think wearing those is very little to pay for being well and for your life I suppose'

Feelings towards wearing the prosthesis and the impact this had on adjustment varied across women. In particular, initial reactions to the prosthesis varied for the women. Some women were relieved to receive the silicone prosthesis. They were glad to have their body shape restored and were happy to wear the prosthesis on a day-to-day basis.

> >24: 'Em I hadn't thought too much about what it was actually going to look like. Initially I was fitted with a soft prosthesis which I would have had for about 4 or 5 weeks and then I made the appointment, went out to [NAME OF FITTING SERVICE] and eh I really didn't know what it was going to look like. And the first thing when I walked in there I thought there is life after this, because she had a whole range of beautiful coloured swimsuits and I thought gosh you could actually wear stuff like that and that was a big plus.'

However, some women experienced shock and distress when getting the prosthesis initially.

> >39: 'Horrible. Yeah'.
> 44: 'Embarrassed.'
> 39: 'Horrible looking, the feel of it. You just weren't, you weren't really ready for that you know.'
> 47: 'It's not real, it's just a dummy and that's it.'

> >17: '.... it's 3 years in April since I had my mastectomy. I got over that ok and I must say the support I got from the breast nurse was just fantastic from the point of view of education and what's to come. And that was ok until I was introduced to the silicone prosthesis. And the one, it had nothing to do with the person, she was fantastic but

when I saw it I said I will never, ever even look at it. I felt because it was so life-like that each time I touched it I feel it would remind me that it was a foreign body replacing my breast. So it was ordered for me and I said what'll I do if I can't wear it. I was aware of cost and this sort of thing and that is exactly how I reacted, I just would never ever wear it. Initially of course you're fitted with soft prosthesis and because that reminded me to an extent of a padded bra, not that I never needed to pad my bra, I was able to cope with it, so I've never worn silicone prostheses and I'm quite happy with the soft prosthesis. Nothing to do with any of the team, they were more than helpful.'

15: 'Was there not a cover on it?'

17: 'There was yeah but it was heavy, it was the feel of it when I felt it. I thought it was the hardest thing I had to cope with and therefore if I continued trying to wear it, I couldn't do it. And I always felt ashamed to say to anybody, I'm sure I'm the only one who doesn't wear a silicone prosthesis.'

>16: 'I'm going back 14 years when I got these 2 awful pink bras, she did not understand, and it was a nurse, and she was a stoma nurse, she could not understand why I was upset being presented with these 2 things.'

15: 'It's difficult even for the breast care nurses who haven't experienced it.'

'That's quite true.'

13: 'I remember the first bras that I got em, I don't know how it happened anyway but I got one white one and I got one of the knickery type. Jesus I'll never forget it, I thought it was disgusting.'

16: 'You understand what I'm talking about?'

13: 'I do exactly. That was only 5 years ago.'

14: 'Did you not pick them?'

16: 'I had no choice. It had the biggest effect on me and I've had several public forays over the years but that was the worst thing about my diagnosis.'

Some women felt that the prosthesis would serve as reminder for the rest of their lives; some found the feel and weight of the silicone prosthesis repulsive and others did not like the style of the mastectomy bras. Such women described the difficulty that they had establishing a relationship with the prosthesis and accepting the prosthesis as part of their life.

>27: 'I do, I have to say [NAME OF BREAST CARE NURSE] fitted me the first time and she was lovely. I thought it was the most dreadful thing that I'd ever seen in my life (laugh). It was actually worse than the operation. It was worse than being told I had cancer. I just thought it was absolutely dreadful and this was to be part of me. This was to become my friend because that's what it becomes to you. I mean it's part of you for the rest of your life and I just thought it was dreadful. I actually thought it was dreadful. I just couldn't look at my bra, I couldn't look at myself. It was all gone for me when I looked at this thing that had to be put next to my skin for the rest of my life. I thought it was dreadful. Now it was nothing to do with the person that fitted me, it was to do with me. I thought if I had seen them for a little while beforehand I might have got, I just thought it was terrible. You know I really did and it took me a long time to get used to this thing as I called it for a long time. "It", "it" was, "it" and I didn't get on for a long time but we had to make friends (laugh). It was something I had to make a friend with...'

>20: 'Like you I tried it but I just felt it was so repulsive, the weight of it, the feel of it, the texture. I just felt when you were bending over it was hanging out to go that way. I went back to my little satin one and kept topping it up with, it just felt so much lighter and I wasn't aware. I explained to [NAME OF BREAST CARE NURSE] why I wasn't wearing it so she said we have more updated ones, better ones, there's cream at the back of them and they're soft and what have you. I got one of those, I tell you I'm wearing it against my will. I think, I'm walking around thinking saying, oh my God I've just this lump of plastic stuck in front of me, I don't know what I'm thinking. I'm sorely tempted to revert back to my little satin one.'

Conversely, some women also mentioned briefly the importance of continuing life as before, for example, resuming activities such as swimming, for the adjustment process.

> >11: 'If you want to go on with an active ordinary [life], get back to normal or whatever normal is for you.'
> 2: 'You want to feel good doing what you always did and it's not always easy.'
> 11: 'You want to try and get back to what you always did in a sense.'
> 2: 'I suppose I was fortunate, I sort of went after it but I see a lot of people that it's not easy for them to do that which is a simple thing and it's part of the cure. I mean what's the good of giving you back half your life, you want to have the life you had before as much as possible. I think that's very important and it shouldn't be forgotten.'

Overall, the role of the prosthesis in preserving a sense of femininity was alluded to. Furthermore, while some women illustrated in general how confident they were in themselves by describing having sunbathed topless while on holiday, the importance of the prosthesis for building and restoring confidence was also highlighted.

> >13: 'I think basically any woman that has to go through this really, it's a matter of still trying to keep your femininity, isn't it, that you still feel well ok, I've had to have this done, it's a life saving operation and so be it if you have to have a prosthesis. It's just that you can still keep your femininity and not feel restricted.
> That it's not a product, I think it's very important that it's not a product, that it's something very very feminine, something very female still and it's not something hard and medical. Do you hear what I'm saying? I think that's really important and the underwear and the bras as well, everything that goes with it.'

> >25: '..... Unlike you I found I was so determined to be looking proper, that within a couple of weeks of getting my first prosthesis, I said I look every bit as good as anybody else and off I went. And I never, you know, I'd just pop it in and that was it and I've never looked back but em, certainly, I have found that these modern ones to be excellent but I also find I like to swim and I find the swimming prostheses that you can get now are marvellous.'

> >44: 'You get used to it and you get the confidence.'
> 47: 'You forget about it. As I say you get up, put your bra on and get on with life and that's it.'
> 41: 'I was even brave enough one night to model clothes for a fashion show. I strutted my stuff (laugh).'

> >39: 'I feel far more confident myself when I have the prosthesis and away I go.'

3.6: CONCLUSION

The focus groups were undertaken to provide a detailed insight into the experiences of women in the provision, fitting and supply of external breast prostheses in Ireland. Their over-riding advantage was their capacity to provide women with the opportunity to share and recount their own experiences in their own words. Good interaction and good detailed discussion was achieved throughout the focus groups. It appeared that participants became comfortable in the environment. The first questions were deliberately unobtrusive and appeared to put people at their ease. Women were generally quick to contribute their experiences and opinions. Interestingly, as the focus group progressed, women spontaneously asked questions of each other, shared common concerns, sought clarification and agreed/disagreed with each other. The focus groups inevitably went beyond their allotted time and women seemed to both enjoy and find the focus group useful and interesting. For each of the main themes that were identified, it is important to note that they emerged in each of the groups and were raised by a number of participants. They were raised spontaneously in addition to responding to questions posed by the facilitator.

Information emerging from the focus groups provides a strong foundation for developing standards of care in the provision, fitting and supply of external breast prostheses. In particular, several issues emerged in relation to the promotion of a positive fitting experience; these issues are relevant irrespective of the specific location of the fitting area, that is, hospital or retail prosthesis supplier. For example, the importance of a bright, well-lit, private, spacious, and feminine fitting environment with fitting rooms, air conditioning and full-length mirrors is paramount. In addition, having appropriate time available for each woman to try on different styles and types of prostheses and bras is also an integral element in promoting an optimal fitting environment. A waiting area away from the immediate fitting room area would also alleviate the concern that some women had about taking up too much time and being mindful of other people waiting outside which impinged on the time they allowed themselves to be fitted. The woman's privacy should be respected at all times. If she is more comfortable being measured without having to take off her bra and it is appropriate to so, this option should be offered to her. Furthermore, it is important that all women are measured and fitted when purchasing a replacement prosthesis and/or mastectomy bra and that the woman is given a choice of product and is aware of the different choices available to her. This is considered particularly pertinent as many women expressed dissatisfaction with aspects of their prosthesis that could be dealt with by using a different type of prosthesis. This was further compounded by a lack of information and knowledge on existing products. Indeed, it is recommended that not only should fitting areas keep brochures and information leaflets that women can take away with them, but that all products are on display for women to peruse. It is also important that at all times the woman is involved in the decision-making process and that her concerns and fears are listened to and taken into consideration when expressed. Finally, because of the identified importance of the prosthesis, procedures for

ensuring prompt appointments and minimum delay in supplying the products should be reviewed as a matter of urgency.

The person fitting the prosthesis plays a central role in the type of fitting experience that the woman encounters and in turn, promoting a positive sense of self and well-being in the woman. As evident in the focus groups, the importance of a sensitive and understanding female who is 'emotionally tuned into' the complexities and nuances of the breast cancer is advocated. There did not appear to be a consensus of opinion on the preferred background of the person fitting a replacement prosthesis, although the support and knowledge of the breast care nurse was appreciated and considered very important in the early stages of a diagnosis and for the first fitting of a silicone prosthesis. However, for the replacement prosthesis, some women acknowledged the busyness of the breast care nurse and appreciated their need to prioritise and be more concerned with women recently diagnosed as opposed to fitting women with a replacement prosthesis up to several years post surgery. Furthermore, irrespective of having a clinical/medical background, being trained in prosthesis fitting and being competent and knowledgeable are important traits in the person fitting the prosthesis.

With regard to the location of a fitting service, there was general agreement that this should be hospital based in the first incidence. However, opinions differed when discussing the provision of a replacement prosthesis. While the main arguments for maintaining a service within a hospital setting related to the ease of getting a prosthesis on the same day as a check-up, this may be facilitated by organising a fitting service either on the hospital campus but away from the breast care follow-up clinic or in a location close to the hospital setting. It is certainly an area worthy of further consideration. Indeed, this is an area to be explored as part of the national survey of women, breast care nurses and retail prosthesis fitters. It is also important to explore ways of making prosthesis-fitting services more accessible to women throughout the country and in particular to ensure that same options are available to all women irrespective of their medical card status.

The highest standards of practice should be in place at all times and in all settings. However, as each woman and her experience is different, standards of care should be applied but looked at in the context and experience of the woman being fitted. Overall, being fitted with a prosthesis can be a vulnerable experience for women and it is important that the person and setting are conducive to encouraging the woman to make contact with the service, putting her at her ease and to maximise the benefit of the fitting for the woman. This is particularly pertinent when the personal role of the prosthesis beyond the outward physical appearance that it restores is considered.

The identified lack of information experienced by many of the women may arise because of the perceived relative unimportance of the prosthesis in the greater scheme of having had and surviving or perhaps continuing to live with breast cancer. Consequently, the inconvenience or at times discomfort is considered a 'small price' to pay for being alive. Although acknowledging the support of clinical staff, many of the women self imposed a lower priority on their prosthesis requirements and

were less inclined to impinge on the breast care nurses' time in this regard. For some women, this was combined with insufficient information about alternatives. However, the importance of the prosthesis for the woman in terms of the contribution of a good-fitting prosthesis to body shape, a sense of femininity, confidence and well-being was evident throughout the focus group discussions. Furthermore, the desire and requirement for more information was clearly demonstrated in the focus groups themselves as many of the participants actively sought information from each other. In addition, specific requests for information were highlighted. It was a topic that was spontaneously discussed in each of the focus groups and was frequently revisited.

For many women, the impact of the prosthesis is almost intangible and predominantly a personal experience. The reaction and attitude towards the prosthesis is private and individual. Therefore, it is impossible to predict how a woman will react and adjust to wearing a prosthesis and the importance or not of it on their lives. Consequently, at the very least, it is important to be aware of the potential myriad experiences that a woman might have in relation to wearing and requiring an external breast prosthesis. The person's attitude towards and the meaning imbued by the prosthesis plays a central role in the adjustment process. For some women it is a constant reminder of the trauma of breast cancer and the accompanying loss; for others it is a small price to play for survival and ongoing enjoyment of life.

The findings arising from the focus groups are consistent with the extant international research. The need for privacy and awareness of product choice were two of the main elements in promoting an optimal fitting environment identified by this research. This accords with Livingston et al.'s (2005) observations that positive fitting experiences are associated with number of styles shown and privacy. Additionally, the finding that women highlight the importance of fitter sensitivity, understanding, support and knowledge corroborates with previous research suggesting that fitter attitude and characteristics (e.g. support, knowledge) are important to women's acceptance and satisfaction with the prosthesis (Roberts et al., 2003). Furthermore, in this present study, women expressed a clear desire and requirement for more information, something that has been highlighted repeatedly in previous research (Breast Cancer Care, 2006c; Roberts et al., 2003). Finally, consistent with Livingston et al. (2003), the issue of cost was raised by participants in this study in relation to the burden of the expense of the prosthesis and the lack of uniformity with regard to entitlements. Overall, these findings lend verification to the limited but growing international literature in this area. However, this research also expands the existing body of research with findings that offer new insights into the personal implications of wearing an external breast prosthesis, including women's own feelings towards the prosthesis, the importance of social support and the effect that other people's reactions can have. Equally as important, this research provides a basis for understanding the issues relevant to women's experiences regarding breast prostheses in the Irish context. Inherent in women's accounts are a number of suggestions regarding how their experiences in regard to their breast prosthesis could be facilitated, for example, being able to see all of the available products on

display, and having a waiting area away from the immediate fitting room. Suggestions such as these represent women's desires and need to be considered carefully in service planning and implementation.

As the focus groups were the first step in the two-stage research process, they played an important role in ensuring that the survey in the next stage of the research was valid and comprehensive. In keeping with Vogt et al. (2004) who conclude that focus groups hold promise for enhancing the content validity of instruments and ultimately the validity of research findings, they greatly facilitated the identification of key constructs and topics to be included in the survey.

Focus Group Summary

The focus groups were undertaken to provide a detailed insight into the experiences of women in the provision, fitting and supply of external breast prostheses in Ireland. Their over-riding advantage was their capacity to provide women with the opportunity to share and recount their own experiences in their own words.

Five focus groups with 6-12 participants in each were conducted. One group was run in each of the 4 new regional health authority areas in Ireland in 2005, except in Dublin where there were two groups. Forty-seven women in total participated in the five focus groups. The average age of participants in the focus groups was 57.8 years of age with a range of 38-80 years of age. The average length of time since being diagnosed with breast cancer was 8.1 years with a range of 1-32 years. The majority of women wore a single prosthesis.

The tapes of the discussions were transcribed verbatim. The goal of the analysis was to identify themes as described by the participants and to describe the range of issues and experiences within each theme.

With regard to the provision, fitting and supply of external breast prostheses, six main themes, each with their own sub-themes, emerged (see Figure 3.2 for graphical summary). These were:

1. *The fitting experience:* In particular, reference was made to the need for optimal fitting environments and suitable fitters.
2. *The prosthesis:* Most notably this pertained to patterns of use and its physical characteristics. Some women expressed satisfaction with the prosthesis. However, many women reported experiencing problems with the weight, temperature, durability, movement, shape, texture, comfort and style of prostheses.
3. *Bras/swimwear:* Similar to the prosthesis, women also mentioned the physical characteristics, for example, limitations in the style, choice, material and quality.
4. *Cost:* Women raised the issue of the cost of the prosthesis highlighting the burden of its expense and the lack of uniformity with regards to entitlements.
5. *Information:* Women described a general lack of information, for example, in accessing post-mastectomy products, entitlements, and types of prostheses, bras and swimwear available. Women made suggestions about the future sharing and receiving of such information.
6. *Personal implications:* The personal implications of wearing/requiring an external breast prosthesis highlighted by the women were collated under four headings: coping with a new image; adjustment; lifestyle considerations; and coping socially.

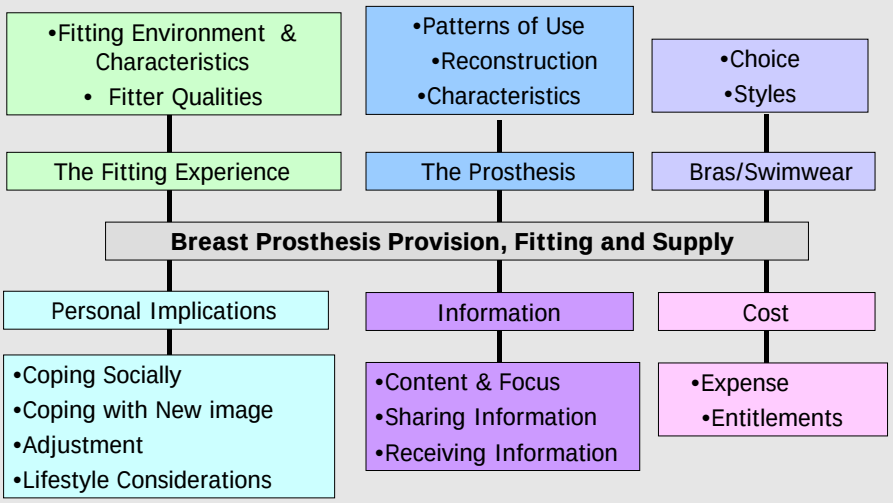

Figure 3.2: Summary of Focus Group Themes

Chapter 4

National Survey

The second part of the study consisted of a national postal survey. The findings of the literature review and the focus group study were used to inform the survey design, which was undertaken to attain the perspective of a wider group of people. There were four concurrent surveys. Survey 1 explored the experiences of women with breast cancer. Survey 2 investigated the views of breast care nurses. Survey 3 and Survey 4 documented the views of retail prosthesis fitters and retail bra fitters, respectively. As the people directly involved in the care of women with breast cancer, the views of breast care nurses, retail prosthesis fitters, and bra fitters would enhance our understanding of women's experiences of prosthesis provision, fitting, supply and use.

4.1: SAMPLE

Survey 1: All participants were female and over 18 years of age. The following inclusion criteria were applied:

- At least 1 year after the initial diagnosis
- Requiring a breast prosthesis.

Some 1,242 women wearing a prosthesis who met the above inclusion criteria were accessed through support organisations and breast cancer clinics.

- Women were accessed through seven Breast Care Clinics representing the East, South, West, Northwest and Midland of the country. Women were sent a cover letter, signed by the relevant breast care nurse(s), an information sheet and a survey on the supply, provision, use and experience of breast prostheses.
- Europa Donna is a support and advocacy organisation with a membership of approximately 300 people with an interest in breast cancer. All members were contacted by the Chair of Europa Donna Ireland to invite women meeting the above inclusion criteria to participate in the research. If women were willing to give their name and contact details to the research team for the sole purpose of being sent a questionnaire, they were asked to complete the slip at the end of the letter and return it in the enclosed FREEPOST envelope as soon as possible.
- Action Breast Cancer has a telephone helpline that receives approximately 300 calls per month with approximately 120 of these from women with breast cancer. Contact with the Irish Telephone Helplines Association, which sets quality standards for telephone helplines, indicated that it was appropriate at the end of a telephone conversation to inform people of a study taking place and if they agreed, information could be forwarded to them. Women meeting the above inclusion criteria were identified over a 4-month period.

- Reach to Recovery is a supportive programme for women who have had, or are about to have treatment for breast cancer. The programme operates by encouraging and fostering personal contact between newly diagnosed patients with cancer and a Reach to Recovery volunteer who themselves have been successfully treated for breast cancer. Reach to Recovery has over 70 volunteers countrywide, who were contacted.
- Cancer support groups around the country were contacted and were asked to inform women, who may be attending support group meetings, of the research. They were asked to distribute a letter to the women asking them if they would be willing to forward their name and contact details to the research team so that they could be sent a questionnaire in September. Women who were willing to take part completed the slip at the end of the letter and returned it in the FREEPOST envelope to the research team.
- Posters advertising the survey were sent to support groups and prosthesis fitting clinics and retail outlets.
- The survey was also advertised in relevant support group newsletters so that people who were not in direct contact with these organisations but who may like to participate could be sent a copy of the questionnaire for inclusion. An article was also included in the 'Think Pink' supplement in the October issue of the *RTÉ Guide* and *Irish Daily Star* Newsletter during Breast Awareness month in October 2005.

Survey 2: All nurses holding positions in hospitals as breast care nurses or equivalent were sent a copy of the questionnaire designed for breast care nurses (n=59).

Survey 3: All prosthesis fitters in Ireland who are not breast care nurses and are mostly located in retail outlets were contacted (n=18 approximately).

Survey 4: Mastectomy bra fitters in Ireland who work in retail department stores were contacted (n=11) and sent a questionnaire designed for this group.

4.2: SURVEY INSTRUMENTS

4.2.1: Design of questionnaires

As a means of avoiding false or irrelevant structures and ensuring the full range of possible responses, questionnaire content and subsequent item selection were developed through three processes: the review of the literature, expert opinion (e.g. breast care nurses, prosthesis fitters, psychologists and women with a breast prosthesis), and the themes arising from the focus groups that have revealed issues requiring further exploration. These insights were used to develop question themes and wordings. Each questionnaire was piloted with a small number of members of the target group before

the main administration. In particular, this allowed for completion and comprehension difficulties to be identified. The content of each of the final questionnaires is summarised below.

Table 4.1: Content of surveys

Survey 1 – Women wearing breast prostheses	**Survey 2 – Breast care nurses**
▪ General information o Type of prosthesis o Importance of prosthesis for women o Satisfaction with the prosthesis ▪ Temporary soft prosthesis o Timing o Location o Fitter o Characteristics of person fitting temporary soft prosthesis o Characteristics of fitting environment ▪ First silicone prosthesis fitting o Timing o Location o Fitter o Characteristics of person fitting the first silicone prosthesis o Characteristics of fitting environment ▪ Replacement prosthesis fitting o Location o Fitter o Characteristics of person fitting the replacement prosthesis o Characteristics of fitting environment o Appointment o Travel distance ▪ Mastectomy bras and swimsuits o Type o Location o Fitting o Characteristics of person fitting the bra o Characteristics of the fitting environment o Satisfaction with bras o Product availability ▪ Cost of prosthesis and bras ▪ Information needs o Type and format of information given to women o Satisfaction with information ▪ Adjustment process[1]	▪ General information o Importance of prosthesis for women ▪ Type and format of information given to women ▪ Fitting of temporary soft prosthesis o Timing o Location o Fitter o Characteristics of person fitting temporary soft prosthesis ▪ First silicone prosthesis fitting o Timing o Location o Fitter o Characteristics of person fitting the first silicone prosthesis ▪ Replacement prosthesis fitting o Location o Fitter o Characteristics of person fitting the replacement prosthesis o Cost ▪ Product availability o Extent to which women are satisfied with prosthesis/bras o Products in demand o Available products o Delivery of products ▪ General fitting issues o Satisfactions with aspects of their fitting environment o Appointments o Competency ▪ Professional development o Training ▪ Service standards o Standard of care o Follow-up service

[1] *EORTC Breast Cancer Module: Arm Symptom and Breast Symptom subscales:*

The breast cancer module is meant for use among patients varying in disease stage and treatment modality. Validation studies have been completed and it has been field tested in a large cross-cultural study involving 12 countries (EORTC Protocol 15931). While there are five scales assessing systemic therapy side-effects, arm symptoms, breast symptoms, body image and sexual functioning, the survey included the Arm Symptom and Breast Symptom subscales.

World Health Organisation Quality of Life Questionnaire (Brief Version) (WHOQOL-BREF) (WHOQOL Group 1998). This instrument sees QoL as a broad ranging concept affected in a complex way by the person's physical health, psychological state, social relationships and relationship to salient features of the environment. Therefore, it produces scores for four domains related to quality of life: *Physical Health, Psychological, Social Relationships* and *Environment*. The instrument consists of 28 items with five-point Likert scales for all items. The WHOQOL-BREF domain scores demonstrate good discriminant validity, content validity, internal consistency and test-retest reliability. The WHOQOL group (1998) envisaged the WHOQOL-BREF to be of use in studies that require a brief assessment of quality of life and to health professionals in the assessment and evaluation of treatment efficacy. The WHOQOL-BREF places primary importance on the perception of the individual. By focusing on individuals' own views of their well-being, the instruments enquire not only about the functioning of people with certain diseases/disorders but also how satisfied the patients are with their functioning and with effects of treatment.

Survey 3 – Retail prosthesis fitters:	Survey 4 – Retail bra fitters:
▪ General information o Importance of prosthesis for women ▪ First silicone prosthesis fitting o Timing o Location o Fitter o Characteristics of person fitting the first silicone prosthesis ▪ Replacement prosthesis fitting o Location o Fitter o Characteristics of person fitting the replacement prosthesis o Cost ▪ Product availability o Extent to which women are satisfied with prosthesis / bras o Products in demand o Available products o Delivery of products ▪ General fitting issues o Satisfaction with aspects of their fitting environment o Appointments o Type and format of information ▪ Professional development o Training o Perceived competency ▪ Service standards o Standard of care o Follow-up service	▪ General information o Importance of a well-fitting bra for women ▪ Product availability o Extent to which women are satisfied with their bras o Products in demand o Available products o Delivery of products ▪ General fitting issues o Satisfaction with aspects of their fitting environment o Importance of characteristics in the person fitting the bra o Appointments o Provision of information ▪ Professional development o Training ▪ Service standards o Standard of care o Follow-up service

4.3: PROCEDURE

A cover letter, the questionnaire, and a stamped-addressed envelope were sent to each participant. The cover letter and information sheet clearly stated that participation was on a voluntary basis and that the women were under no obligation to take part in the research study. Questionnaires were anonymous and confidential. Names could not be associated with the respondents' replies. Furthermore, as this was an anonymous questionnaire, the person was deemed to have given consent by virtue of returning a completed questionnaire.

4.4: ANALYSIS

Data was analysed using SPSS 13 (statistical package of the social sciences). Descriptive statistics (e.g. frequency analysis, measures of central tendency) were employed to identify, *inter alia*, sample characteristics, information provision, fitter and fitting environment characteristics, and prosthesis and mastectomy bra features, cost, supply, provision and use. Chi-square statistics were employed, for example, to investigate differences in satisfaction with fitting-environment characteristics and location of fitting. Chi-square statistics were also employed to investigate differences in satisfaction with characteristics of the person fitting the prosthesis and the type of fitter. Thematic analysis was used to identify the themes emerging from the open-ended questions.

All the respondents did not necessarily answer all of the questions. Consequently, percentage results presented throughout the findings from the surveys are based on the total number of people who responded to that particular question and not out of the total sample.

4.5: FINDINGS

4.5.1: Sample characteristics

4.5.1.1: Survey 1: Women

Some 1,242 women were sent a questionnaire specifically designed for this group. Of these, 97 were returned as either deceased, not meeting the inclusion criteria, or non-deliverable. Out of the remaining 1,143 eligible participants, 527 women returned questionnaires that were included in the survey (46% response rate). The average age of participants in the survey was 58.6 years of age (SD 11.5) with a range of 27-90 years of age. The average length of time since being diagnosed with breast cancer was 6.7 years (SD 6.7) with a range of 1-44.5 years.

4.5.1.2: Survey 2: Breast Care Nurses/Hospital Based Fitters

Fifty-nine breast care nurses/hospital based fitters were sent a questionnaire specifically designed for this group. There were 32 returned questionnaires that were included in the survey (54.2% response rate). Table 4.2 documents the positions held by the 32 respondents. All worked in the area of breast care with the majority holding the position of breast care nurse. The average length of time working in this field of nursing was 101.6 months (SD 74.7) with a range of 6-360 months. Furthermore, the average length of time working in their current breast care department was 61.3 months (SD 46.7) with a range of 6-216 months. For the purposes of expedient reporting, the respondents to this questionnaire will be referred to as breast care nurses.

Table 4.2: Position held by respondents to breast care nurse/hospital based fitter questionnaire

	N	%
Breast care nurse	25	78.1
Breast care manager	1	3.1
Breast care nurse &/or hospital based fitter	2	6.3
Clinical nurse specialist	2	6.2
Advanced nurse practitioner	1	3.1
Staff nurse	1	3.1
Total	32	100.0

4.5.1.3: Survey 3: Commercial/Retail Prosthesis Fitters

Eighteen commercial/retail prosthesis fitters were sent a questionnaire specifically designed for this group. There were 12 returned questionnaires that were included in the survey (66.6% response rate). Table 4.3 documents the type of outlet in which these fitters work. Fifty percent of the fitters worked in specialised prosthesis suppliers dealing in mastectomy care products only. The average length of time working as a fitter was 145.4 months (SD 112.2) with a range of 12-324 months.

Furthermore, the average length of time working in their current centre was 126.7 months (SD 111.1) with a range of 12-372 months.

Table 4.3: Description of retail prosthesis fitting centre		
	N	%
Mastectomy care only	6	50.0
General medical supplies	4	33.3
Lingerie fitters	1	8.3
Department store	1	8.3
Total	12	100.0

4.5.1.4: Survey 4: Mastectomy Bra Fitters

Eleven centres that fit bras, including mastectomy bras but not prostheses, were sent a questionnaire specifically designed for this group. There were six returned questionnaires that were included in the survey (54.5% response rate). As documented in Table 4.4, the majority of fitters of mastectomy bras are located in department stores. The average length of time working as a fitter was 98.2 months (SD 112.4) with a range of 3-312 months. Furthermore, the average length of time working in their current centre was 98.3 months (SD 110.1) with a range of 3-306 months.

Table 4.4: Description of bra fitting centre		
	N	%
Lingerie store	2	33.3
Department store	4	66.6
Total	6	100.0

4.5.2: Patterns of prosthesis use

Tables 4.5, 4.6 and 4.7 report on the different types of external breast prostheses used, the types of external breast prostheses used most regularly and the frequency of external breast prosthesis use. As expected, the majority of women (55.6%) use the full-weighted traditional silicone prosthesis or the light-weighted silicone prosthesis (21.6%) most regularly. Considerably fewer people use an external breast prosthesis that is self-adhesive. Interestingly, 26.4% of women continue to use their temporary post-operative soft fibre filled prosthesis at least 1 year post surgery and 7.6% of women indicated that this was the type of external breast prosthesis that they used most regularly. When asked if they ever wore something other than a prosthesis, 43 (8.2%) women indicated that they did. As an alternative to a prosthesis, these women tended to wear either a padded bra or a homemade prosthesis of cotton wool, rice, shoulder pad or sponge.

Table 4.5: Use of different types of external breast prostheses		
Do you use a...	Yes N	Yes %
Post-operative soft fibre filled prosthesis	139	26.4
Full-weighted traditional silicone prosthesis	347	65.8
Full-weighted self-adhesive silicone prosthesis	26	4.9
Light-weighted silicone prosthesis	129	24.5
Light-weighted self-adhesive prosthesis	13	2.5
Leisure/swimming prosthesis	98	18.6
Prosthetic stick on nipple	5	0.9
Shell prosthesis	22	4.2
Lumpectomy prosthesis	16	3.0
Lumpectomy self-adhesive prosthesis	5	0.9

Table 4.6: Type of external breast prosthesis worn most regularly		
	N	%
Full-weighted traditional silicone prosthesis	278	55.6
Light-weighted silicone prosthesis	108	21.6
Post-operative soft fibre filled prosthesis	40	8.0
Shell prosthesis	15	3.0
Lumpectomy prosthesis	13	2.6
Full-weighted self-adhesive silicone prosthesis	8	1.6
Leisure/swimming prosthesis	6	1.2
Light-weighted self-adhesive prosthesis	4	0.8
Lumpectomy self-adhesive prosthesis	1	0.2
Indicated more than one prosthesis	27	5.4
Total	500	100.0

Table 4.7: Frequency of prosthesis use		
	N	%
All of the time	46	8.9
Most of the time	434	83.6
Some of the time	21	4.0
Rarely	9	1.7
None of the time	9	1.7
Total	519	100.0

As documented in Table 4.8, where women considered a specific daily activity to be relevant to them, the majority of women wore their external breast prosthesis. In particular, 95.4% of women indicated that they wore their external breast prosthesis when engaging in social activities. With regard to whether women felt limited in any relevant activities because of their external breast prosthesis, sunbathing, buying clothes and swimming were the activities where levels of activity limitation were

experienced by the women (see Table 4.9). However, it is also important to note that almost half of the women considered that they were limited in sports and sexual activity because of their prosthesis and almost one-quarter of women perceived themselves limited in socialising.

Table 4.8: External breast prosthesis use and daily activities

	Yes %	No %	Total relevant % (N)
Sporting activities	80.1	19.9	100.0 (286)
Social activities	95.4	4.6	100.0 (457)
Daily household chores	89.9	10.1	100.0 (476)
Daily outdoor chores	93.7	6.3	100.0 (461)
Employment/occupation	89.7	10.3	100.0 (320)
Taking care of children	86.5	13.5	100.0 (304)

Table 4.9: External breast prosthesis use and activity limitation

	Yes, limited a lot %	Yes, limited a little %	No, not limited at all %	Total relevant % (N)
Buying clothes	20.8	41.0	38.1	100.0 (485)
Socialising	5.2	19.8	75.0	100.0 (444)
Sports	17.3	32.7	50.0	100.0 (260)
Swimming	31.1	31.1	37.8	100.0 (315)
Daily activities	1.1	13.3	85.5	100.0 (435)
Work/employment	1.7	9.3	89.0	100.0 (290)
Sunbathing	37.3	31.2	31.5	100.0 (330)
Sexual activity	19.5	27.5	53.0	100.0 (313)

4.5.3 Perceived importance of and satisfaction with external breast prosthesis

Women, breast care nurses, commercial/retail prosthesis fitters and bra fitters were asked to specify how important they perceived an external breast prosthesis to be for each of the aspects listed in Table 4.10. All groups perceived the external breast prosthesis to be important for balance, posture, shape, appearance to self, appearance to others, sense of well-being, self-confidence and femininity. This is a statement of the perceived importance of an external breast prosthesis in the post-surgical care of women with breast cancer. In particular, the aspects deemed to be of most importance for women were shape, self-confidence and appearance to self, which were endorsed as important by 91.0%, 90.9% and 90.4% women, respectively.

Table 4.10: Perceived importance of wearing an external breast prosthesis*					
		Not at all important / Unimportant %	Neither important nor unimportant %	Extremely important / Important %	Total % (N)
Balance	Women	15.8	10.5	73.6	100.0 (474)
	Breast care nurse	3.1	6.3	90.7	100.0 (32)
	Prosthesis fitter	8.3	8.3	83.3	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Posture	Women	10.7	9.0	80.3	100.0 (477)
	Breast care nurse	0	6.3	93.8	100.0 (32)
	Prosthesis fitter	0	16.7	83.3	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Shape	Women	4.5	4.5	91.0	100.0 (492)
	Breast care nurse	0	3.1	96.9	100.0 (32)
	Prosthesis fitter	0	0	100.0	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Appearance to self	Women	6.0	3.6	90.4	100.0 (497)
	Breast care nurse	0	0	100.0	100.0 (32)
	Prosthesis fitter	0	0	100.0	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Appearance to others	Women	7.1	6.9	86.1	100.0 (480)
	Breast care nurse	3.1	3.1	93.7	100.0 (32)
	Prosthesis fitter	8.3	8.3	83.3	100.0 (12)
	Bra fitter	0	16.7	83.3	100.0 (6)
Sense of well-being	Women	7.1	4.8	88.2	100.0 (483)
	Breast care nurse	0	0	100.0	100.0 (32)
	Prosthesis fitter	8.3	0	91.6	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Self-confidence	Women	5.7	3.4	90.9	100.0 (493)
	Breast care nurse	0	0	100.0	100.0 (32)
	Prosthesis fitter	0	0	100.0	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Femininity	Women	7.0	4.1	89.0	100.0 (487)
	Breast care nurse	0	0	100.0	100.0 (32)
	Prosthesis fitter	8.3	0	91.6	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
* Bra fitters were asked about the importance of wearing a breast prosthesis in a properly fitting mastectomy bra					

While Table 4.11 highlights that women are generally satisfied with the external breast prosthesis that they wear most regularly, a sizeable proportion expressed dissatisfaction with various aspects of the prosthesis, in particular its weight (24.4%), comfort (17.3%) and movement with the body (14.3%). breast care nurses and prosthesis fitters were less likely to perceive that women were very dissatisfied / dissatisfied with the comfort of the prosthesis than the women themselves. Conversely, breast care nurses were more inclined to indicate that women were very dissatisfied/dissatisfied with the 'value for money' aspect of the prosthesis (30%) than the women (13.2%). Both breast care nurses and prosthesis fitters perceived none or minimal dissatisfaction with the colour, shape, appearance when

worn, fit, texture, temperature, quality and overall satisfaction with the prosthesis as compared to 6.8%, 11.0%, 10.6%, 13.8%, 8.7%, 11.1%, 6.6% and 11.4% of women, respectively.

Table 4.11: Satisfaction with the external breast prosthesis*

		Very dissatisfied / Dissatisfied %	Neither satisfied nor dissatisfied %	Very satisfied / Satisfied %	Total % (N)
Colour	Women	6.8	11.0	82.2	100.0 (489)
	Breast care nurse	0	19.4	80.6	100.0 (31)
	Prosthesis fitter	0	16.7	83.4	100.0 (12)
Shape	Women	11.0	9.6	79.3	100.0 (491)
	Breast care nurse	0	3.3	96.6	100.0 (30)
	Prosthesis fitter	0	0	100.0	100.0 (12)
Appearance when worn	Women	10.6	7.7	81.7	100.0 (492)
	Breast care nurse	0	0	100.0	100.0 (29)
	Prosthesis fitter	0	0	100.0	100.0 (12)
Weight	Women	24.4	13.0	62.7	100.0 (485)
	Breast care nurse	23.3	36.7	40.0	100.0 (30)
	Prosthesis fitter	16.6	0	83.4	100.0 (12)
Comfort	Women	17.3	11.2	71.5	100.0 (491)
	Breast care nurse	3.2	9.7	77.4	100.0 (31)
	Prosthesis fitter	8.3	0	16.7	100.0 (12)
Fit	Women	13.8	16.0	70.2	100.0 (493)
	Breast care nurse	3.2	6.5	90.4	100.0 (31)
	Prosthesis fitter	0	8.3	91.7	100.0 (12)
Movement with the body	Women	14.3	17.6	68.2	100.0 (484)
	Breast care nurse	10.0	40.0	50.0	100.0 (30)
	Prosthesis fitter	0	8.3	91.7	100.0 (12)
Texture	Women	8.9	12.9	78.2	100.0 (473)
	Breast care nurse	3.3	26.7	70.0	100.0 (30)
	Prosthesis fitter	0	8.3	91.7	100.0 (12)
Temperature	Women	11.2	16.9	71.9	100.0 (474)
	Breast care nurse	0	40.0	60.0	100.0 (30)
	Prosthesis fitter	0	0	100.0	100.0 (12)
Durability	Women	8.7	14.6	76.6	100.0 (467)
	Breast care nurse	0	35.5	64.5	100.0 (31)
	Prosthesis fitter	0	0	100.0	100.0 (12)
Quality	Women	6.6	14.3	79.0	100.0 (467)
	Breast care nurse	0	19.4	80.6	100.0 (31)
	Prosthesis fitter	0	0	100.0	100.0 (12)
Value for money	Women	13.2	16.9	70.0	100.0 (427)
	Breast care nurse	30.0	30.0	40.0	100.0 (30)
	Prosthesis fitter	8.3	8.3	83.3	100.0 (12)
Overall satisfaction	Women	11.5	10.2	78.4	100.0 (480)
	Breast care nurse	0	19.4	80.6	100.0 (31)
	Prosthesis fitter	0	0	100.0	100.0 (12)

*For women this refers to the prosthesis that they wear most regularly. For breast care nurses and fitters this data relates to how satisfied they consider women to be with the various aspects of an external breast prosthesis.

4.5.4: Temporary soft prosthesis – Post-operative soft fibre filled prosthesis

Four hundred and twenty women (84.8% of women who responded to the question) indicated that they were fitted with a post-operative soft fibre filled prosthesis following their operation, whereas 75 women (15.2%) indicated that they had not been fitted with such a prosthesis. Consequently, the women's survey responses in this section are out of a potential maximum of 420. There was a significant difference ($t=-5.4$, $df=484$, $p<0.0001$) in the length of time requiring a prosthesis between women who had been fitted with a temporary soft prosthesis (mean = 6.0 years, SD 5.8) and women who had not been fitted (mean = 10.5 years, SD 9.7), that is, women who had been fitted with a post-operative soft fibre filled prosthesis were likely to have had their surgery more recently than women who had not been fitted.

The average length of time after surgery that the woman was fitted with a temporary prosthesis was 12.9 days (SD 17.0) with a range of 1-156 days. There was a significant positive correlation between length of time requiring a prosthesis and how long after surgery the women were fitted with a temporary prosthesis ($r=0.114$, $p<0.05$), indicating that the longer it has been since the woman has had surgery, the longer she had to wait at the time to be fitted post surgery with a temporary breast prosthesis. Some 90.2% of women (n=370) indicated that the timing of this fitting was 'just right'. In contrast, breast care nurses reported that the average length of time taken to fit a temporary soft prosthesis was 5.3 days post surgery (SD 1.5) (range 2-7 days) with 96.8% of nurses indicating that the time taken was 'just right'. This difference probably arises because breast care nurses are reporting on their current situation whereas the women are reflecting on their own experiences, which span over the last 40 years.

Table 4.12 documents the women's satisfaction with the temporary soft prosthesis. While overall it is apparent that women were satisfied with their temporary soft prosthesis, it is noteworthy that just over 20% of women expressed a level of dissatisfaction with their temporary soft prosthesis.

Table 4.12: Women's satisfaction with their temporary soft prosthesis

	N	%
Very dissatisfied	48	11.5
Dissatisfied	41	9.9
Neither dissatisfied nor satisfied	105	25.2
Satisfied	159	38.2
Very satisfied	63	15.1
Total	416	100.0

4.5.4.1: Location of fitting of temporary soft prosthesis

While 49.9% of women (n=207) reported that they were fitted for their temporary soft prosthesis in a hospital ward, 41.7% (n=173) reported that they were fitted in the breast care nurses' office and 8.3% (n=35) indicated other locations including other rooms in the hospital, hospital toilet, specialised prosthesis supplier and home. This was supported by the breast care nurses' responses where it was also indicated that the most common location for the fitting of the temporary soft prosthesis was the hospital ward (see Table 4.13).

Table 4.13: Hospital location for fitting by breast care nurse of temporary soft prosthesis

	N	%
Hospital ward	15	48.8
Breast care nurses' office	9	29.0
Specialised fitting room in breast care unit	5	16.1
Room in a different part of the hospital	2	6.5
Total	31	100.0

While Table 4.14 highlights that women were generally satisfied with the environment within which they were fitted for their temporary soft prosthesis, a sizeable proportion expressed dissatisfaction with the availability of brochures (39.8%), display of products (35.4%), choice of products (35.8%) and time to look at products (30.3%). It is also important to note that one out of every five women expressed a level of overall dissatisfaction with the fitting environment for the temporary soft prosthesis (See Table 4.14).

Table 4.14: Women's satisfaction with the aspects of the environment where fitted for temporary soft prosthesis

	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Lighting	11.4	22.7	65.9	100.0 (396)
Ventilation	12.1	25.5	62.4	100.0 (388)
Space	21.3	21.9	56.8	100.0 (389)
Mirrors	24.9	22.3	52.9	100.0 (382)
Privacy	17.8	12.2	70.0	100.0 (393)
Display of products	35.4	26.3	38.3	100.0 (373)
Choice of products	35.8	26.8	37.4	100.0 (377)
Time to look at products	30.3	23.0	46.7	100.0 (379)
Brochures	39.8	20.7	39.5	100.0 (357)
Overall satisfaction	20.2	19.7	60.1	100.0 (381)

Furthermore, when satisfaction with the fitting environment of the temporary soft prosthesis was explored in terms of where the women were fitted and in particular only looking at the two most common locations (hospital ward and breast care nurses' office), the only aspect of the environment where there was not a significant difference in women's satisfaction rating between women fitted in the hospital ward and those fitted in a breast care nurses' office was ventilation. As can be seen in Table 4.15, women who were fitted in a breast care nurses' office were significantly more likely to rate the lighting, space, mirrors, privacy, display of products, choice of products, time to look at products, brochures and overall satisfaction more positively than women who were fitted with their temporary soft prosthesis in a hospital ward.

Table 4.15: Women's satisfaction with temporary soft prosthesis fitting environment by fitting location

	Location of fitting…	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Lighting	Hospital ward	12.6	29.3	58.1	100.0 (191)	X^2=10.5, df=2, p<0.005
	Breast care nurses' office	9.5	16.6	74.0	100.0 (169)	
Space	Hospital ward	19.3	28.3	52.4	100.0 (187)	X^2=8.3, df=2, p<0.05
	Breast care nurses' office	22.8	15.6	61.7	100.0 (167)	
Mirrors	Hospital ward	28.4	29.5	42.1	100.0 (183)	X^2=16.3, df=2, p<0.0001
	Breast care nurses' office	20.5	16.3	63.3	100.0 (166)	
Privacy	Hospital ward	22.4	17.2	60.4	100.0 (192)	X^2=16.7, df=2, p<0.0001
	Breast care nurses' office	12.7	7.2	80.1	100.0 (166)	
Display of products	Hospital ward	39.8	32.6	27.6	100.0 (181)	X^2=22.6, df=2, p<0.0001
	Breast care nurses' office	29.8	18.0	52.2	100.0 (161)	
Choice of products	Hospital ward	41.4	31.5	27.1	100.0 (181)	X^2=20.8, df=2, p<0.0001
	Breast care nurses' office	29.1	20.0	50.9	100.0 (165)	
Time to look at products	Hospital ward	37.9	27.5	34.6	100.0 (182)	X^2=25.5, df=2, p<0.0001
	Breast care nurses' office	20.7	17.7	61.6	100.0 (164)	
Brochures	Hospital ward	43.6	25.0	31.4	100.0 (172)	X^2=13.1, df=2, p<0.001
	Breast care nurses' office	34.0	15.4	50.6	100.0 (156)	
Overall satisfaction	Hospital ward	24.2	25.3	50.5	100.0 (182)	X^2=11.6, df=2, p<0.003
	Breast care nurses' office	16.4	15.2	68.5	100.0 (165)	

Women indicated that their *preferred location for the fitting of the temporary soft prosthesis* was the breast care nurses' office (71.8%) (See Table 4.16). Those who specified 'other' were referring to special fitting rooms.

Table 4.16: Women's preferred location for fitting of temporary soft prosthesis

	N	%
Hospital ward	69	17.3
Breast care nurses' office	287	71.8
Other	44	11.1
Total	400	100.0

Respondents were asked to explain their stated preference and of the *women* that chose the 'hospital ward' as their preferred location for fitting the temporary soft prosthesis, the majority commented on the importance of privacy. In addition, the convenience of the hospital ward was mentioned in order to avoid the inconvenience of travelling to another part of the hospital so soon post-surgery. The importance of being fitted in familiar surroundings and receiving ample time for questions were two further issues identified by the women. Furthermore, the relative unimportance of the location for fitting the temporary prosthesis was also mentioned by women, for example, one woman was too shocked to even notice and another did not mind as long as the fitting was carried out correctly.

A large number of participants (n=129) mentioned privacy as a reason for choosing the breast care nurses' office. Privacy was noted as important so others would not know the fitting was taking place and so the woman could ask questions and take time to deal with the situation. The appropriateness of the breast care nurses' office was noted because it is quieter, contains all the stock and is convenient within the hospital. Another relatively large group chose the breast care nurses' office because it is preferable to other alternatives such as semi-private wards and ward toilets. In addition, respondents recorded the choice of products; along with time and attention received, as reasons for choosing the breast care nurses' office. Some women liked the breast care nurses' as it was familiar to them. The general positive experiences that women had in this fitting environment were mentioned along with the importance of the relationship they had with the nurse.

Some participants ticked 'other' when asked where the temporary soft prosthesis should be fitted. The most frequently recorded reason for their choice was also to have the fitting somewhere private. A special room dedicated to fitting prostheses and mastectomy products was called for by other respondents, with good lighting, mirrors, space and privacy.

With regard to the stated preference of respondents to the breast care nurse questionnaire in relation to the ideal fitting environment for the temporary soft prosthesis, 78.1% pinpointed a 'specialised fitting room in breast care unit' as the location of choice (See Table 4.17).

Table 4.17: Breast care nurse preferred location for the fitting of the temporary soft prosthesis

	N	%
Hospital ward	3	9.4
Breast care nurses' office	3	9.4
Specialised fitting room in breast care unit	25	78.1
Room in a different part of the hospital	0	0
Other	1	3.1
Total	32	100.0

Breast care nurses who chose the hospital ward did so on the condition that it was private. They also remarked on the convenience of being fitted on the ward. Those that chose the breast care nurses'

office did so for its privacy. However, the specialised fitting room was chosen due to a preference for a relaxing atmosphere free from interruptions that may arise on the ward, a preference for privacy and a desire to have space in which to display and store mastectomy products. In addition, it was acknowledged that this initial fitting is an emotional and sensitive time for the woman. Furthermore, given the prominence of body image issues at this stage, it is important that the woman is fitted in a private and sensitive environment.

4.5.4.2: The person fitting the temporary soft prosthesis

The majority of women were fitted with their temporary soft prosthesis by a breast care nurse (see Table 4.18). The 'other' people referred to as fitting the temporary soft prosthesis included self-fitting, support group volunteers and GPs.

Table 4.18: Person fitting temporary soft prosthesis

	N	%
Breast care nurse	280	68.0
Nurse	59	14.3
Consultant	2	0.5
Trained fitter	34	8.3
Unsure	19	4.6
Other	18	4.4
Total	412	100.0

Table 4.19 provides a picture of women's satisfaction with the characteristics of the person fitting their temporary soft prosthesis. Although overall women appeared satisfied, areas to be reviewed are familiarity with stock/products, time available and emotional support given by the person fitting the temporary soft prosthesis as 13.8%, 11.4% and 10.5% of women indicated a level of dissatisfaction with this characteristic. In addition, just over 1 in every 10 women expressed a level of dissatisfaction in the 'overall satisfaction' with the characteristics of the person fitting their temporary soft prosthesis. Furthermore, when satisfaction with the person fitting the temporary soft prosthesis was explored in terms of type of person fitting the prosthesis and in particular looking at the breast care nurse, nurse and trained fitter, women were consistently and significantly more satisfied with the characteristics of the person who fitted them with a prosthesis if that person was a breast care nurse or trained fitter (see Table 4.20). Indeed, the only characteristic of the person fitting the prosthesis which did not elicit significant satisfaction differences between the three different fitters was discretion. Overall, this highlights the importance of a trained individual, knowledgeable and experienced in breast care, undertaking the fitting of the temporary soft prosthesis.

Table 4.19: Women's satisfaction with characteristics of person fitting their temporary soft prosthesis				
	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Knowledge	6.8	10.2	83.0	100.0 (382)
Competency	7.8	9.1	83.1	100.0 (373)
Experience	8.3	8.8	82.8	100.0 (373)
Training/qualifications	8.2	10.9	81.0	100.0 (368)
Attitude	7.2	4.5	88.2	100.0 (374)
Practical support	9.5	7.7	82.8	100.0 (378)
Emotional support given	10.5	9.2	80.3	100.0 (371)
Familiarity with stock/products	13.8	15.7	70.5	100.0 (370)
Confidence	7.3	8.4	84.4	100.0 (394)
Sensitivity	7.1	7.4	85.4	100.0 (378)
Discretion	7.0	6.4	86.6	100.0 (373)
Friendliness	4.2	5.3	90.5	100.0 (380)
Time available to you	11.4	10.1	78.6	100.0 (378)
Overall satisfaction	10.9	7.4	81.6	100.0 (376)

Table 4.20: Women's satisfaction with characteristics of person fitting temporary soft prosthesis by type of fitter						
	Fitter.....	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Knowledge	Breast care nurse	4.5	5.6	90.0	100.0 (269)	X^2=35.5, df=4, p<0.0001
	Nurse	16.4	23.6	60.0	100.0 (55)	
	Trained fitter	0	14.7	85.3	100.0 (34)	
Competency	Breast care nurse	5.0	5.0	90.1	100.0 (262)	X^2=32.2, df=4, p<0.0001
	Nurse	18.9	20.8	60.4	100.0 (53)	
	Trained fitter	2.9	11.8	85.3	100.0 (34)	
Experience	Breast care nurse	5.7	4.6	89.7	100.0 (262)	X^2=34.9, df=4, p<0.0001
	Nurse	18.9	22.6	58.5	100.0 (53)	
	Trained fitter	3.0	9.1	87.9	100.0 (33)	
Training/ qualifications	Breast care nurse	5.4	5.8	88.8	100.0 (260)	X^2=40.7, df=4, p<0.0001
	Nurse	22.0	22.0	56.0	100.0 (50)	
	Trained fitter	0	21.2	78.8	100.0 (33)	
Attitude	Breast care nurse	5.7	1.5	92.7	100.0 (262)	X^2=16.9, df=4, p<0.002
	Nurse	9.6	11.5	78.8	100.0 (52)	
	Trained fitter	2.9	8.8	88.2	100.0 (34)	
Practical support given	Breast care nurse	7.5	4.5	88.0	100.0 (266)	X^2=14.3, df=4, p<0.006
	Nurse	13.5	17.3	69.2	100.0 (52)	
	Trained fitter	8.8	8.8	82.4	100.0 (34)	
Emotional support given	Breast care nurse	7.3	6.2	86.5	100.0 (260)	X^2=17.8, df=4, p<0.001
	Nurse	19.2	11.5	69.2	100.0 (52)	
	Trained fitter	6.1	21.2	72.7	100.0 (33)	
Familiarity with stock/ products	Breast care nurse	9.6	12.3	78.2	100.0 (261)	X^2=31.4, df=4, p<0.0001
	Nurse	33.3	19.6	47.1	100.0 (51)	
	Trained fitter	6.1	27.3	66.7	100.0 (33)	

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Table 4.20: Women's satisfaction with characteristics of person fitting temporary soft prosthesis by type of fitter						
	Fitter.....	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Confidence	Breast care nurse	5.4	4.2	90.4	100.0 (261)	X^2=27.0, df=4, p<0.0001
	Nurse	17.3	17.3	65.4	100.0 (52)	
	Trained fitter	0	12.1	87.9	100.0 (33)	
Sensitivity	Breast care nurse	4.9	4.2	90.9	100.0 (265)	X^2=17.4, df=4, p<0.002
	Nurse	15.1	11.3	73.6	100.0 (53)	
	Trained fitter	0	11.8	88.2	100.0 (34)	
Friendliness	Breast care nurse	3.4	2.6	94.0	100.0 (266)	X^2=12.7, df=4, p<0.05
	Nurse	7.7	11.5	80.8	100.0 (52)	
	Trained fitter	0	5.9	94.1	100.0 (34)	
Time available to deal with woman	Breast care nurse	8.6	7.5	83.9	100.0 (267)	X^2=19.0, df=4, p<0.001
	Nurse	25.5	15.7	58.8	100.0 (51)	
	Trained fitter	5.9	11.8	82.4	100.0 (34)	
Overall satisfaction	Breast care nurse	7.6	4.6	87.8	100.0 (263)	X^2=24.8, df=4, p<0.0001
	Nurse	21.2	17.3	61.5	100.0 (52)	
	Trained fitter	2.9	11.8	85.3	100.0 (34)	

As revealed by Table 4.21, knowledge, competency, experience, training/qualifications, attitude, practical support, emotional support, familiarity with stock/products, confidence, sensitivity, discretion, friendliness, and time given to the women were perceived by all respondents to the breast care nurse questionnaire to be important or extremely important. Consequently, it is incumbent upon them to review and address those areas where women expressed a level of dissatisfaction.

Table 4.21: Breast care nurses' perceived importance of characteristics of person fitting temporary soft prosthesis				
	Not at all important / Unimportant %	Neither important nor unimportant %	Extremely important /Important %	Total % (N)
Knowledge	0	0	100.0	100.0 (32)
Competency	0	0	100.0	100.0 (32)
Experience	0	0	100.0	100.0 (32)
Training/qualifications	0	0	100.0	100.0 (32)
Attitude	0	0	100.0	100.0 (32)
Practical support	0	0	100.0	100.0 (32)
Emotional support given	0	0	100.0	100.0 (32)
Familiarity with stock/products	0	0	100.0	100.0 (32)
Confidence	0	0	100.0	100.0 (32)
Sensitivity	0	0	100.0	100.0 (32)
Discretion	0	0	100.0	100.0 (32)
Friendliness	0	0	100.0	100.0 (32)
Time available to you	0	0	100.0	100.0 (32)

The majority of both the women and the breast care nurses indicated that their preferred person to fit the temporary soft prosthesis was the breast care nurse (See Table 4.22). Indeed, 90.6% of the breast care nurses indicated that they generally fit temporary prostheses, which is in keeping with the stated preference of women for the preferred person to fit the temporary prosthesis.

Table 4.22: Preferred person to fit the temporary soft prosthesis

	Women (n=412) %	Breast care nurse (n=29) %
Breast care nurse	71.8	93.1
Staff nurse	3.6	0
Consultant	0.5	0
Trained fitter	21.4	3.4
Other	2.7	3.4
Total	100.0	100.0

Respondents to both questionnaires were asked to explain their preference. *Women* who chose the 'Breast care nurse' as their preferred person to fit the temporary soft prosthesis simply expressed a general preference for the breast care nurse; many noted previous positive experiences with the breast care nurse. Familiarity with the fitter was also noted by women as influencing their choice of person to fit the temporary soft prosthesis. A small number of women expressed a preference for the breast care nurse because of negative experiences they had had with other personnel fitting the temporary prosthesis. Similarly, women who chose 'trained fitter' mentioned other negative experiences, thereby emphasising the importance of being trained in fitting prostheses.

Of the respondents to the *Breast Care Nurse* questionnaire who chose 'breast care nurse' as the ideal person to fit the temporary soft prosthesis, the most frequently mentioned reason was the importance of the relationship between the woman and the breast care nurse. In addition the training and experience of the breast care nurse was also mentioned. Some respondents chose the breast care nurse as it gave the opportunity to assess how the woman was coping and to answer questions that she might have. One respondent chose the hospital based prosthesis fitter and noted that any person with experience would suffice.

4.5.4.3: Suggestions for improving the experience of being fitted with a temporary soft prosthesis

Twenty-four breast care nurses provided information in response to the open-ended question concerning the improvement of the experience of getting the temporary soft prosthesis for women. The breast care nurses highlighted the need for a specialised fitting environment and an improved range of products. Other themes that emerged related to the time that was needed to support each woman during their fitting, the importance of privacy and showing the woman the temporary prosthesis prior to surgery, and encouraging women to bring a partner/friend to the fitting.

Many of these themes were also raised by the 330 women who took the opportunity to respond to this open-ended question. In particular, women wanted more information in general but specifically information prior to fitting (e.g. shown samples of prostheses, given brochure, and opportunity to talk with nurse over options). The need for privacy, as a means of improving the fitting of the temporary soft prosthesis, was also discussed by the women. Many also expressed a desire for more time with the nurse in the fitting room so that they had time to try on prostheses and find the correct fit without feeling rushed. Many also wanted time to talk with the nurse about their feelings and to build up a relationship with her. The attitude of the person fitting the prosthesis was identified by many as an important issue; sensitive, caring and/or supportive attributes were the most sought after. In addition, women remarked on the need to improve the fitting environment. Lack of space and mirrors were the most frequent complaints. Women also desired a specialised room exclusively for fitting and the availability of more brochures. A larger choice of prostheses was identified as having an important role in improving this fitting experience. The timing of the fitting also emerged as a salient issue. While many women believed that the temporary prosthesis should be fitted prior to discharge, others felt that it should be dependent on the woman; some women are not ready to be fitted so soon after surgery. Finally, women expressed a desire for contact with women in the same situation or with women who have survived the experience. They noted the desire for a fitter with personal experience also.

4.5.5: First silicone prosthesis fitting

Some 91.7% of women (n=472) were fitted with a first silicone prosthesis, whereas 8.3% (n=43) indicated that they had not been fitted with a first silicone prosthesis. Consequently, the women's survey responses in this section are out of a potential maximum of 472. There was no significant difference in the length of time that a woman required an external breast prosthesis between those who were fitted and were not fitted with a first silicone prosthesis.

The average length of time after surgery that the woman was fitted with a first silicone prosthesis was 9.6 weeks (SD 9.6) with a range of 1-104 weeks. There was a significant positive correlation between length of time requiring a prosthesis and how long after surgery the woman was fitted with a first silicone prosthesis ($r=0.11$, $p<0.05$), indicating that the longer it has been since the woman has had surgery necessitating an external breast prosthesis, the longer was the period post surgery before being fitted with a first silicone prosthesis. Some 88.6% of women (n=389) indicated that the timing was just right, whereas 2.3% (n=10) reported the timing as being too soon and 9.1% (n=40) as too late.

The majority of respondents to the breast care nurse questionnaire (86.2%, n=25) indicated that they fit the first silicone prosthesis and 13.8% (n=4) indicated that they did not. They reported that the average length of time from surgery that the woman is fitted with their first silicone prosthesis is 5.9

weeks (SD 1.54) with a range of 2.5-10 weeks. With regard to the timing of this fitting, 83.3% (n=25), 10.0 (n=3) and 6.3 (n=2) of breast care nurses indicated that it was 'just right', 'too soon' and 'too late', respectively. Similarly, commercial/retail prosthesis fitters reported that the average length of time from surgery that women came to be fitted for their first silicone prosthesis was 6.2 weeks (SD 1.55) with a range of 3-8 weeks and 90.9% (n=10) reported that the timing of this fitting was 'just right'. It is likely that fitting times from surgery as reported by the respondents to the breast care nurse questionnaire and commercial/retail prosthesis fitters are less than the women because they reflect current practice, whereas the women are reporting retrospectively over many years.

Eighteen percent of women (n=82) who were fitted with a first silicone prosthesis paid for their prosthesis; 82.0% (n=374) did not. However, there was a significant difference (t=10.7, df=443, p<0.0001) in the length of time since surgery necessitated an external breast prosthesis between women who paid for their first silicone prosthesis (mean=12.6 years, SD 8.4) and those who did not (mean=5.1 years, SD 4.9). This is in keeping with the introduction by the Minister for Health and Children in 2001 that all women would require their first prosthesis for free irrespective of medical card status.

With regard to the first silicone prosthesis being available on the day of fitting, 72.4% of women (n=326) indicated that it was, 27.6% (n=124) reported that it was not. For those women who did not receive it on the day of fitting, the average wait was 4.5 weeks (SD 4.2), range 0.5-25 weeks. There was no correlation between waiting time for first silicone prosthesis to be delivered and time since surgery.

Table 4.23 documents the women's satisfaction with the first silicone prosthesis. While overall women were satisfied with their first silicone prosthesis, it is noteworthy that just over 17% of women expressed a level of dissatisfaction with their first silicone prosthesis.

Table 4.23: Women's satisfaction with first silicone prosthesis

	N	%
Very dissatisfied	43	9.3
Dissatisfied	37	8.0
Neither dissatisfied nor satisfied	69	15.0
Satisfied	175	38.0
Very satisfied	136	29.6
Total	460	100.0

4.5.5.1: Location of fitting of first silicone prosthesis

Some 62.1% of women reported that they were fitted for their first silicone prosthesis in a hospital, whereas 18.8% were fitted in a specialised prosthesis supplier. As can also be seen in Table 4.24, 7.3% specified 'other', and when asked to specify, 9 people indicated a combination of locations.

When breast care nurses were asked where they fit the first silicone prosthesis, 3.4% (n=1) indicated the hospital ward, 48.3% (n=14) indicated their office, 37.9% (n=11) a specialised fitting room in the breast care unit, 3.4% (n=1) a room in a different part of the hospital, and 6.9% (n=2) specified 'other'.

Table 4.24: Location for fitting of first silicone prosthesis

	N	%
Hospital	287	62.1
Visiting fitting service	17	3.7
GP	2	0.4
Pharmacy	9	1.9
Cancer support centre	9	1.9
Specialised prosthesis supplier	87	18.8
General medical supplier	15	3.2
Lingerie shop / department store	2	0.4
Other	34	7.3
Total	462	100.0

While Table 4.25 highlights that women were generally satisfied with the environment within which they were fitted for their first silicone prosthesis, a sizeable proportion expressed dissatisfaction with the availability of brochures (32.5%), display of products (27.0%), choice of products (25.6%) and space (22.6%).

Table 4.25: Women's satisfaction with the environment where fitted for first silicone prosthesis

	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Lighting	12.1	17.2	70.8	100.0 (431)
Ventilation	13.1	19.0	67.8	100.0 (426)
Space	22.6	17.7	59.8	100.0 (430)
Mirrors	19.1	14.2	66.7	100.0 (423)
Privacy	14.5	9.8	75.7	100.0 (428)
Display of products	27.0	20.3	52.7	100.0 (423)
Choice of products	25.6	20.7	53.6	100.0 (425)
Time to look at products	20.1	17.0	62.9	100.0 (423)
Brochures	32.5	18.3	49.3	100.0 (400)
Overall satisfaction	16.2	16.0	67.8	100.0 (432)

When satisfaction with the environment was looked at in terms of where the women were fitted and only looking at the two most common locations (hospital and specialised prosthesis supplier), there were only significant differences in satisfaction with mirrors and privacy (See Table 4.26). Women fitted with their first silicone prosthesis in a hospital expressed greater dissatisfaction with the mirrors

in the fitting environment than women fitted in a specialised prosthesis supplier. Conversely, women fitted in a hospital were more satisfied with the privacy of the fitting environment than women fitted in a specialised prosthesis supplier. Differences in overall satisfaction were approaching significance.

Table 4.26: Women's satisfaction with first silicone prosthesis fitting environment by fitting location

	Location of fitting…	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Mirrors	Hospital	21.1	10.7	68.2	100.0 (261)	X^2=10.6, df=2, p<0.005
	Specialised prosthesis supplier	11.1	23.5	65.4	100.0 (81)	
Privacy	Hospital	11.7	7.5	80.8	100.0 (265)	X^2=8.5, df=2, p<0.05
	Specialised prosthesis supplier	16.0	17.3	66.7	100.0 (81)	
Overall satisfaction	Hospital	13.2	13.6	73.2	100.0 (265)	X^2=5.6, df=2, p<0.06
	Specialised prosthesis supplier	18.3	22.0	59.8	100.0 (81)	

Women's, breast care nurses and commercial/retail prosthesis fitters' *preferred location for the fitting of the first silicone prosthesis* are documented in Table 4.27.

Table 4.27: Preferred location for the fitting of the first silicone prosthesis

	Women %	Breast Care Nurse %	Prosthesis Fitters %
Hospital	51.4	77.4	8.3
Visiting fitting service	7.4	0	0
GP	0	0	0
Pharmacy	0.2	0	8.3
Cancer support centre	8.8	9.7	0
Specialised prosthesis supplier	24.8	6.5	25.0
General medical supplier	0.2	0	8.3
Lingerie shop/ department store	0.9	0	25.0
Other, please specify	6.3	6.4	25.0
Total	100.0 (n=444)	100.0 (n=31)	100.0 (n=12)

The majority of *women* chose the hospital due to its familiarity, which they found more comforting. A number of women also chose the hospital in order to have the breast care nurse carry out the fitting. Other women mentioned the great care and support they had received in the hospital. Participants also noted the safe, relaxed atmosphere in the hospital and expressed a desire for more specialised rooms. The presence of experienced, knowledgeable and trained staff in the hospital was another important factor mentioned. The convenience of the hospital was noted as the ladies could get fitted on the same day as their check-up. Also, some women liked to have the first silicone fitting in the

hospital so if they had any medical questions, the staff and facilities were there on the premises to help. Some participants found it more discreet and private in the hospital. In addition, some women just expressed a general preference for the hospital, others had had previous positive experiences in the hospital and another group of women had no other choice than to use the hospital.

Of those women that chose the visiting fitting service, some women liked the fact that it was away from the hospital environment and not associated with the medical aspects. They also noted the privacy and comfort of being fitted at home. Again the importance of experience and training was a prominent factor. Some women believed this to be more convenient as it involved less travel. One woman noted the importance of a good supportive attitude and another noted the importance of time dedicated to the fitting. Women selected the cancer support centre due to the caring attitude of the fitters. They were given information, counselling and support. The importance of experienced fitters and of a private environment was mentioned. The also noted a more relaxed atmosphere when out of the hospital environment. Finally, women, who stated a preference for the first silicone prosthesis fitting to take place at a specialised prosthesis supplier, noted the importance of a comfortable and private environment and expressed a preference for a fitting service away from the hospital environment. In addition, some women believed that the specialised prosthesis suppliers would have more time available for the customer than the nurses.

With regard to the preferred location as specified by the respondents to the breast care nurse questionnaire, those that chose the hospital noted the importance of aftercare, of assessing the woman's wound along with her coping and body image. In addition, the relationship between the breast care nurse and the woman was again mentioned along with the importance of having a safe, familiar environment for the woman. The cancer support centre was chosen due to it being an environment away from the hospital. Similarly, the specialised prosthesis supplier was selected due to their training and the fact that the environment would be away from the hospital.

One *commercial/retail prosthesis fitter* who chose 'hospital' noted the convenience of this location. Another participant who chose pharmacy did so for privacy and due to the fact that it is away from the hospital environment. Similarly, the lingerie shop/ department store was selected as it is away from the hospital environment. The specialised prosthesis supplier was selected, noting the importance of time given to the woman in this environment.

4.5.5.2: The person fitting the first silicone prosthesis

The majority of women were fitted with their first silicone by a breast care nurse (see Table 4.28). Table 4.29 provides a picture of women's satisfaction with the characteristics of the person fitting their first silicone prosthesis. Although overall women appeared satisfied, areas to be reviewed are time available and emotional support given by the person fitting the first silicone prosthesis as 10.3% and 10.5% of women, respectively, indicate a level of dissatisfaction with these characteristics. Furthermore, when satisfaction with the person fitting the first silicone prosthesis was explored in terms of type of person fitting the prosthesis and in particular looking at the breast care nurse and trained fitter, women were consistently and significantly more satisfied with the characteristics of the person who fitted them with a prosthesis if that person was a breast care nurse (see Table 4.30). There were no statistically significant differences in familiarity with stock/products, confidence, friendliness, time available and overall satisfaction between women fitted with their first silicone prosthesis by a breast care nurse and women fitted by a trained fitter.

Table 4.28: Person fitting the first silicone prosthesis

	N	%
Breast care nurse	276	59.7
Nurse	25	5.4
Consultant	2	0.4
GP	2	0.4
Trained fitter	138	29.9
Sales assistant	8	1.7
Unsure	8	1.7
Other	3	0.6
Not specified	462	100.0

Table 4.29: Women's satisfaction with characteristics of person fitting the first silicone prosthesis

	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Knowledge	4.8	9.7	85.5	100.0 (435)
Competency	4.9	8.6	86.5	100.0 (429)
Experience	4.2	10.5	85.3	100.0 (428)
Training/qualifications	4.0	13.3	82.6	100.0 (420)
Attitude	6.3	5.8	87.9	100.0 (428)
Practical support	8.4	11.2	80.4	100.0 (428)
Emotional support given	10.5	13.1	76.5	100.0 (429)
Familiarity with stock/products	7.4	10.2	82.4	100.0 (420)
Confidence	4.9	9.3	85.7	100.0 (428)
Sensitivity	7.3	8.7	84.0	100.0 (426)
Discretion	5.9	8.7	85.4	100.0 (425)
Friendliness	6.0	4.8	89.2	100.0 (434)
Time available to you	10.3	7.9	81.8	100.0 (428)
Overall satisfaction	8.2	8.7	83.1	100.0 (437)

Table 4.30: Women's satisfaction with the characteristics of the person fitting the first silicone prosthesis by background of person fitting the prosthesis

	Fitter.....	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Knowledge	Breast care nurse	3.8	6.1	90.0	100.0 (261)	X^2=6.4, df=2, p<0.05
	Trained fitter	3.8	13.7	82.4	100.0 (131)	
Competency	Breast care nurse	3.5	5.0	91.5	100.0 (258)	X^2=9.4, df=2, p<0.01
	Trained fitter	3.9	14.0	82.2	100.0 (129)	
Experience	Breast care nurse	3.9	6.2	89.9	100.0 (257)	X^2=7.4, df=2, p<0.05
	Trained fitter	3.1	14.6	82.3	100.0 (130)	
Training/qualifications	Breast care nurse	3.1	9.4	87.5	100.0 (255)	X^2=6.4, df=2, p<0.05
	Trained fitter	4.0	18.3	77.8	100.0 (126)	
Attitude	Breast care nurse	4.7	2.3	93.0	100.0 (256)	X^2=11.8, df=2, p<0.005
	Trained fitter	6.9	9.9	83.2	100.0 (131)	
Practical support	Breast care nurse	5.0	6.2	88.8	100.0 (258)	X^2=19.6, df=2, p<0.0001
	Trained fitter	13.1	16.2	70.8	100.0 (130)	
Emotional support given	Breast care nurse	6.6	7.8	85.6	100.0 (257)	X^2=22.8, df=2, p<0.0001
	Trained fitter	14.6	20.8	64.6	100.0 (130)	
Sensitivity	Breast care nurse	4.7	4.7	90.6	100.0 (256)	X^2=15.2, df=2, p<0.001
	Trained fitter	10.9	13.2	76.0	100.0 (129)	
Discretion	Breast care nurse	3.9	5.4	90.7	100.0 (258)	X^2=11.2, df=2, p<0.005
	Trained fitter	8.0	13.6	78.4	100.0 (125)	

As revealed by Table 4.31, competency, experience, familiarity with stock/products, confidence, sensitivity, and discretion were perceived by all respondents to the breast care nurse and commercial/retail prosthesis fitter questionnaires to be important or extremely important characteristics of the person fitting the first silicone prosthesis. While still retaining a high satisfaction rating, breast care nurses bestowed a greater importance on knowledge, competency, training/qualifications, attitude practical support, emotional support, friendliness, and time given to the women than commercial/retail prosthesis fitters.

Table 4.31: Breast care nurse and retail prosthesis fitter perceived importance of characteristics of person fitting the first silicone prosthesis.					
		Not at all important / Unimportant %	Neither important nor unimportant %	Extremely important /Important %	Total % (N)
Knowledge	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	8.3	91.3	100.0 (12)
Competency	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	0	100.0	100.0 (12)
Experience	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	0	100.0	100.0 (12)
Training/qualifications	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	16.7	83.3	100.0 (12)
Attitude	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	8.3	0	91.3	100.0 (12)
Practical support	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	16.7	83.3	100.0 (12)
Emotional support given	Breast care nurse	0	3.1	96.9	100.0 (32)
	Retail fitter	0	25.0	75.0	100.0 (12)
Familiarity with stock/ products	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	0	100.0	100.0 (12)
Confidence	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	0	100.0	100.0 (12)
Sensitivity	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	0	100.0	100.0 (12)
Discretion	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	0	100.0	100.0 (12)
Friendliness	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	8.3	91.7	100.0 (12)
Time given to the woman	Breast care nurse	0	0	100.0	100.0 (32)
	Retail fitter	0	8.3	91.7	100.0 (12)

In terms of their *preferred person to fit the first silicone prosthesis,* 58.1% of women identified the breast care nurse, whereas 35.3% of women identified their preference to be a trained fitter. Interestingly, and perhaps expectedly, breast care nurses and commercial/retail fitters identified themselves as the ideal people to fit the first silicone prosthesis (See Table 4.32).

Table 4.32: Preferred person to fit the first silicone prosthesis			
	Women %	Breast care nurse %	Prosthesis fitters %
Breast care nurse	58.1	93.7	16.7
Nurse	1.3	0	0
Consultant	0.7	0	8.3
GP	0	0	0
Trained fitter	35.3	6.2	66.7
Sales assistant	0	0	0
Other	4.6	0	8.3
Total	100.0 (n=456)	100.0 (n=32)	100.0 (n=12)

Respondents to each questionnaire were asked to explain their preference. *Women* who chose the 'Breast care nurse' as their preferred person to fit the first silicone prosthesis discussed her training, experience, knowledge and awareness of the woman's needs. Another major theme emerging was the importance of the relationship that had developed with the breast care nurse. Women overall found the first silicone fitting more comfortable and less embarrassing with someone that they knew well. The breast care nurse's attitude was mentioned as important when choosing the person to fit the first silicone prosthesis. Caring, sensitive, sympathetic, supportive and understanding nurses were preferred by women. In addition, women chose the breast care nurse because they had had previous positive experiences with them. Some women noted the importance of trained fitters along with the breast care nurse. They also stated the need for a comfortable, spacious and private fitting environment. Similarly, some women who expressed their preference for a breast care nurse to fit the first silicone prosthesis reported a preference for receiving the fitting within the hospital environment.

Women who expressed a preference for a 'trained fitter' as the person to fit the first silicone prosthesis mentioned the importance of the fitter having experience and training. Other women noted the importance of a good choice of products and a good knowledge of mastectomy products in order to receive the best possible fit. Time available was a prominent factor; some women believed that the trained fitter would have more time to spare than a breast care nurse in the hospital. The attitude of the fitter was also noted as important. Caring, supportive, sensitive and familiar fitters were preferred. Another reason mentioned for choosing the trained fitter was that the fitting environment would be away from the hospital and more like a positive shopping experience.

Respondents to the *breast care nurse* questionnaire identified the relationship between the breast care nurse and the woman as the main reason for choosing the 'breast care nurse' to fit the first silicone prosthesis. Furthermore having the opportunity to assess the woman's body image, coping and wounds during the fitting was mentioned. Finally, their knowledge and training was raised as a justification for the breast care nurse to be the preferred person to fit the first silicone prosthesis. The commercial prosthesis fitter was chosen due to a greater choice of products and a more skilled fitting.

Commercial/retail prosthesis fitters who chose the trained fitter as the ideal person to fit the first silicone prosthesis noted the convenience of this choice, fitter experience, training and confidence, the time available, and range of stock. Similarly, those who selected the breast care nurse mentioned the importance of training as well as having an understanding fitter.

4.5.5.3: Suggestions for improving the experience of women being fitted with a first silicone prosthesis

Three hundred and forty *women* took the opportunity to answer the open-ended question concerning suggestions for improving the fitting of the first silicone prosthesis for women. While many women were happy with the service they had received, choice was the most frequently mentioned issue in relation to improving this fitting experience for women. Women wanted more stock available in their fitting centre; they also wanted more styles manufactured for women who have undergone a mastectomy. Furthermore, they wanted to be informed of their choices during the fitting rather than being 'just handed one (prosthesis)'. Similarly, women wanted more time in general at the fittings to look at and try on mastectomy products, but also time to talk to the nurse about any issues that they may have. Women suggested that the provision of more information would help improve this fitting for women. Information both prior to fitting and prior to discharge was desired. A video was suggested as a good means of presenting the information. More practical advice was also deemed as necessary. Fitter knowledge, efficiency, training and experience should improve the fitting, and privacy was again a prominent factor. Indeed, a fitter attitude that is sympathetic, friendly, supportive and positive was thought by many participants to have an impact on the first silicone fitting for women. The importance of familiarity with the fitter was noted. An enhanced environment was deemed important to improve the fitting experience. Women noted a need for more space, ventilation and mirrors. Some women expressed a preference for a non-clinical and relaxed environment. However, overall there was a difference of opinion over whether the fitting should be in or away from the hospital. Finally, a number of women agreed that there should be more contact with women in the same situation and with women who have survived the disease.

Twenty nine respondents to the *breast care nurse* questionnaire provided additional information on what they considered would improve the fitting experience of the first silicone prosthesis for women. The importance of the environment was mentioned by many respondents. A quiet, relaxing area was desired with mirrors and a choice of products. Privacy and a desire for a larger stock were also noted. The importance of giving time to the patient was stressed. In addition, some breast care nurses suggested having a partner/friend present at fitting, having products available at time of fitting and showing the clients the prosthesis prior to the fitting.

Finally, 10 of the *commercial/retail prosthesis fitters* responded to this open-ended question. Similar issues raised by the women and breast care nurses also emerged in this group, for example, additional time and information, a relaxed environment, and a confident, supportive fitter with adequate training.

4.5.6: Replacement prosthesis fitting

Some 73.5% of women (n=371) indicated that they received/bought another prosthesis since the first silicone prosthesis, whereas 26.5% (n=134) indicated that they had not replaced their prosthesis. As expected there was a significant difference (t=7.3, df=492, p<0.0001) in the length of time that a woman required an external breast prosthesis between those who had (mean 7.9 years, SD 7.0) and had not replaced their first silicone prosthesis (mean 3.1 years, SD 4.1). However, it is useful to note that 16.3% of women, who had not replaced a prosthesis, had had the same prosthesis for more than 4 years. The average time specified for replacing the prosthesis was 2.3 years (SD 1.5) (range 0.5-12 years).

Table 4.33 documents the locations where women generally *get* their replacement prosthesis (not necessarily fitted). Most women get their replacement prostheses in a hospital (40.7%) or a specialised prosthesis supplier (34.4%). When asked to specify 'other', 14 people indicated a combination of the options in the table.

Table 4.33: Location for *getting* replacement prostheses

	N	%
Hospital	149	40.7
Visiting fitting service	18	4.9
GP	2	0.5
Pharmacy	11	3.0
Cancer support centre	13	3.6
Specialised prosthesis supplier	126	34.4
General medical supplier	7	1.9
Lingerie shop / department store	7	1.9
Mail order catalogue	10	2.7
Internet	1	0.3
Other, please specify	22	6.1
Total	366	100.0

Some 80.1% of women (n=278) indicated that they do get fitted each time they get a new prosthesis. However, 19.9% (n=69) do not get fitted. Similarly, while 53.8% and 81.8% of breast care nurses and commercial/retail prosthesis fitters, respectively, reported that in their experience women are always re-fitted prior to receiving replacement prostheses, 46.2% and 18.2% of breast care nurses and commercial/retail prosthesis fitters, respectively, reported that women were only sometimes refitted prior to receiving their replacement prosthesis. For 56.7% of women (n=203) the replacement prosthesis was available on the day of fitting; 41.1% (n=147) reported that it was not. One hundred percent (n=12) and 70% (n=21) of commercial/retail prosthesis fitters and breast care nurses, respectively, indicated that prostheses were generally available on the day of the fitting. For breast care nurses, the main reasons given for lack of same day availability was due to lack of storage space

to hold stock. Two respondents reported never having products available on the day; the women are always fitted and then products are ordered and sent on later. For those women who did not receive it on the day of fitting, the average wait was 22.3 days (SD 13.89), range 4-84 days. The average length of time since the last prosthesis fitting was 19.3 months (SD 19.6), range 0.25-132 months. When asked if this fitting was their first silicone prosthesis fitting, 16.3% (n=51) indicated that it was and 83.7% (n=261) that it was not.

4.5.6.1: Location of fitting of replacement prosthesis

Looking at the people who had had a replacement prosthesis fitted (potential maximum of 261 women), Table 4.34 lists the locations for this fitting experience, where it can be seen that the hospital (46.1%) and the specialised prosthesis supplier (32.0%) were the most common fitting environments for replacement prostheses.

4.34: Location for fitting replacement prostheses

	N	%
Hospital	118	46.1
Visiting fitting service	13	5.1
GP	1	0.4
Pharmacy	9	3.5
Cancer support centre	11	4.3
Specialised prosthesis supplier	82	32.0
General medical supplier	9	3.5
Lingerie shop / department store	2	0.8
Other	11	4.3
Not specified	256	100.0

While Table 4.35 highlights that women were generally satisfied with the environment within which they were fitted for their replacement prosthesis, a sizeable proportion expressed dissatisfaction with the availability of brochures (24.0%), display of products (22.4%), choice of products (23.0%) and time available (18.5%).

Table 4.35: Women's satisfaction with the environment where fitted for their replacement prosthesis

	Very dissatisfied / Dissatisfied	Neither dissatisfied nor satisfied	Very satisfied / Satisfied	Total % (N)
Lighting	8.6	9.9	81.5	100.0 (243)
Ventilation	9.1	10.8	80.0	100.0 (241)
Space	16.7	12.1	71.3	100.0 (240)
Mirrors	11.3	14.2	74.6	100.0 (240)
Privacy	8.6	8.6	82.7	100.0 (243)
Display of products	22.4	14.3	63.3	100.0 (237)
Choice of products	23.0	15.9	61.1	100.0 (239)
Time to look at products	18.5	13.0	68.5	100.0 (238)
Brochures available	24.0	14.2	61.8	100.0 (233)
Overall satisfaction	14.2	10.9	74.9	100.0 (239)

When satisfaction with the environment was looked at in terms of where the women were fitted and only looking at the two most common locations (hospital and specialised prosthesis supplier), there were statistically significant differences in satisfaction with space, display of products, choice of products and brochures depending on the location of the fitting (See Table 4.36). At the fitting for a replacement prosthesis, women who were fitted in a specialised prosthesis supplier expressed greater satisfaction with space, display of products, choice of products and brochures than women who were fitted in the hospital environment for the replacement prosthesis.

Table 4.36: Women's satisfaction with replacement prosthesis fitting environment by fitting location

	Location of fitting…	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Space	Hospital	22.0	15.6	62.4	100.0 (109)	X^2=6.4, df=2, p<0.05
	Specialised prosthesis supplier	9.3	12.0	78.7	100.0 (75)	
Display of products	Hospital	29.9	14.0	56.1	100.0 (107)	X^2=6.8, df=2, p<0.05
	Specialised prosthesis supplier	13.5	14.9	71.6	100.0 (74)	
Choice of products	Hospital	30.6	15.7	53.7	100.0 (108)	X^2=6.5, df=2, p<0.05
	Specialised prosthesis supplier	14.7	16.0	69.3	100.0 (75)	
Brochures	Hospital	33.7	13.5	52.9	100.0 (104)	X^2=9.3, df=2, p<0.01
	Specialised prosthesis supplier	13.5	17.6	68.9	100.0 (74)	

Women's, breast care nurse's and commercial/retail prosthesis fitters' *preferred location for the fitting of the replacement prosthesis* are documented in Table 4.37. 'Other, please specify' in women is predominantly a combination of the options. In relation to breast care nurse respondents, while their 'othe,r please specify' also consisted of a combination, none of these included the hospital as a preferred location.

Table 4.37: Preferred location for the fitting of the replacement prosthesis

	Women %	Breast care nurse %	Prosthesis fitters %
Hospital	37.6	15.4	0
Visiting fitting service	6.0	7.7	0
GP	0.4	0	0
Pharmacy	0.4	0	9.1
Cancer support centre	11.5	7.7	0
Specialised prosthesis supplier	31.6	42.3	27.3
General medical supplier	1.3	0	9.1
Lingerie shop/ department store	4.9	7.7	18.2
Other	6.1	19.2	36.4
Total	100.0 (n=452)	100.0 (n=26)	100.0 (n=11)

A large number of *women* who chose 'hospital' as the ideal place to locate fitting centres for replacing prostheses did so due to the familiarity of the environment. A related theme was its convenience as they were attending for medical check-ups and could get fitted on the same day. The importance of having trained and experienced fitters was another factor. A relatively large number of women chose the hospital in order to get fitted by the breast care nurse. Other women mentioned feeling comfortable with the fitters due to their supportive and understanding attitude. A number of respondents had no experience of being fitted anywhere else other than the hospital. Some chose the hospital as they had previous positive experiences there while others chose it due to privacy. A smaller number of women noted the importance of a continuation of care from the hospital where the surgery was performed. Women mentioned the importance of location and of having a good selection of products. Finally, some women chose the hospital as the next best option from their ideal, which for one woman was a support centre with breast care nurses and for another, it was direct access to the manufacturer.

The most frequently mentioned reason for choosing the visiting fitting centre was privacy. The support received and the experience of the fitters were also identified as important. Finally, the convenience of the visiting fitting centre and the importance of receiving a fitting away from the hospital were noted by a small number of respondents. The most frequently reported reason for choosing the cancer support centre was the atmosphere, which was seen as comfortable, caring and relaxing. It was also important that the environment did not have a commercial feel. Understanding, supportive and experienced fitters were noted. Meeting similar people who had experienced cancer was a key reason given by participants for choosing the cancer support centre. In addition, privacy was noted as important and women also recounted previous negative experiences in other fitting centres (e.g. nurse too busy in hospital).

Experience and training were mentioned as prominent factors when choosing the specialised prosthesis supplier as the ideal place to locate fitting centres for replacing prostheses. A good supply of products was another reason frequently mentioned by participants. Again, the importance of privacy was noted. A factor relating to the replacement prosthesis was the view that women have more need for a correct fitting (and less need for emotional support) at this time so the specialised supplier was seen as more suitable. An understanding, familiar environment was also desired. There was a contrast in opinions over whether the hospital or an external environment would be more preferable; in general however, people who chose specialised prosthesis supplier would prefer to be fitted outside the hospital environment. Women who chose the general medical supplier noted the importance of a private, relaxing environment. Those that chose lingerie shop &/or department store did so due to a desire to see mastectomy products available and on display like any other underwear garment. In addition, they mentioned the convenience of these outlets

With regard to further explanations for the choice of *breast care nurses,* respondents to the breast care nurse questionnaire who chose the hospital noted the importance of aftercare for women to ensure that they receive mastectomy products and that any issues that have arisen can be dealt with. The visiting fitting service was chosen due to its range of stock. The cancer support centre was selected as it offers therapies and support to cancer patients. Respondents who chose the specialised prosthesis supplier mentioned the importance of normalising the fitting experience and consequently chose an environment away from the hospital. They also noted the good choice of products in these outlets. Participants who chose the lingerie store stressed the importance of having experienced fitters and of normalising the situation; they also mentioned the convenience of the lingerie store.

Commercial/retail prosthesis fitters that chose pharmacy as the ideal location for fitting replacement prostheses noted the importance of having the replacement prosthesis fitting away from the hospital. In addition, the importance of privacy was also noted. Privacy was also relevant in the choice of hospital. The importance of a positive fitter attitude was mentioned by those who chose the lingerie shop/ department store. Privacy and range of stock were identified as important by those who ticked 'other'.

4.5.6.2: Person fitting the replacement prosthesis

Some 42.5% and 41% of women were fitted with their replacement prosthesis by a trained fitter and breast care nurse, respectively (See Table 4.38).

Table 4.38: Person fitting the replacement prosthesis

	N	%
Breast care nurse	107	41.0
Nurse	16	6.1
GP	3	1.1
Trained fitter	111	42.5
Sales assistant	9	3.4
Unsure	6	2.3
Other	3	1.1
Not specified	6	2.3

Table 4.39 provides a picture of women's satisfaction with the characteristics of the person fitting their replacement prosthesis. Although overall women appeared satisfied, areas to be reviewed are time available and emotional support given by the person fitting the replacement prosthesis, as 10.5% and 8.5% of women respectively indicate a level of dissatisfaction with these characteristics. Furthermore, when satisfaction with the characteristics was broken down into the most common type of person fitting the prosthesis, that is, the breast care nurse and trained fitter, there were no statistically significant differences in the women's satisfaction with either. As there are no significant differences between women's satisfaction with the characteristics of the person fitting the replacement prosthesis

between women fitted by a breast care nurse and women fitted by a trained prosthesis fitter, it supports the possibility of a potentially wider selection of trained fitters being available at this stage.

Table 4.39: Satisfaction with the characteristics of the person who fitted the replacement silicone prosthesis

	Very dissatisfied / Dissatisfied	Neither dissatisfied nor satisfied	Very satisfied / Satisfied	Total % (N)
Knowledge	8.0	7.5	84.5	100.0 (252)
Competency	8.0	8.0	84.0	100.0 (250)
Experience	6.4	8.0	85.5	100.0 (249)
Training/qualifications	6.8	10.4	82.7	100.0 (249)
Attitude	6.4	7.6	85.9	100.0 (249)
Practical support	8.0	11.6	80.3	100.0 (249)
Emotional support given	8.5	15.0	76.5	100.0 (247)
Familiarity with stock/products	6.8	10.8	82.3	100.0 (250)
Confidence	6.8	10.8	82.3	100.0 (249)
Sensitivity	5.3	9.0	85.8	100.0 (245)
Discretion	4.8	7.7	87.4	100.0 (246)
Friendliness	3.6	7.3	89.0	100.0 (246)
Time available to you	10.5	9.3	80.2	100.0 (247)
Overall satisfaction	5.2	10.5	84.4	100.0 (247)

As revealed by Table 4.40, attitude, confidence, sensitivity, and discretion were perceived by all respondents to the breast care nurse and commercial/retail prosthesis fitter questionnaires to be important or extremely important characteristics of the person fitting the replacement prosthesis. While still retaining a high satisfaction rating, breast care nurses bestowed a greater importance on knowledge, competency, experience, training/qualifications, practical support, emotional support, familiarity with products, friendliness, and time given to the women, than commercial/retail prosthesis fitters.

Table 4.40: Breast care nurse and retail prosthesis fitter perceived importance of characteristics of person fitting the replacement prosthesis

		Not at all important / Unimportant %	Neither important nor unimportant %	Extremely important /Important %	Total % (N)
Knowledge	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	8.3	91.7	100.0 (12)
Competency	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	9.1	90.9	100.0 (11)
Experience	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	8.3	91.7	100.0 (12)
Training/qualifications	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	16.7	83.3	100.0 (12)
Attitude	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	0	100.0	100.0 (12)

→

Table 4.40: Breast care nurse and retail prosthesis fitter perceived importance of characteristics of person fitting the replacement prosthesis					
		Not at all important / Unimportant %	Neither important nor unimportant %	Extremely important /Important %	Total % (N)
Practical support	Breast care nurse	3.2	3.2	93.6	100.0 (31)
	Retail fitter	0	16.7	83.3	100.0 (12)
Emotional support given	Breast care nurse	0	16.1	83.9	100.0 (31)
	Retail fitter	0	25.0	75.0	100.0 (12)
Familiarity with stock/ products	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	8.3	91.7	100.0 (12)
Confidence	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	0	100.0	100.0 (12)
Sensitivity	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	0	100.0	100.0 (12)
Discretion	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	0	100.0	100.0 (12)
Friendliness	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	8.3	91.7	100.0 (12)
Time given to the woman	Breast care nurse	0	0	100.0	100.0 (31)
	Retail fitter	0	8.3	91.7	100.0 (12)

As documented in Table 4.41, women (52.1%), breast care nurses (53.5%) and prosthesis fitters (72.7%) identified the trained fitters as the ideal person to fit the replacement prosthesis.

Table 4.41: Preferred person to fit the replacement prosthesis			
	Women %	Breast care nurses %	Prosthesis fitters %
Breast care nurse	38.8	35.7	9.1
Nurse	1.5	0	0
Consultant	0	0	0
GP	0.2	0	0
Trained fitter	52.1	53.5	72.7
Sales assistant	0.2	0	9.1
Other	7.1	10.7	9.1
Total	100.0 (n=459)	100.0 (n=28)	100.0 (n=12)
*Out of 16 of the 32 breast care nurses who indicated a trained fitter, 2 specified a hospital-based fitter and 14 a commercial prosthesis fitter. **Out of 8 of the 12 prosthesis fitters who indicated a trained fitter, all 8 specified a commercial prosthesis fitter and did not refer to hospital-based fitters in this count.			

Of the *women* who selected the breast care nurse as the ideal person to fit the replacement prosthesis, experience and training were the most frequently reported reasons. The significance of the woman's relationship and familiarity with the breast care nurse were other prominent factors

mentioned. The caring, understanding and sensitive attitude of the breast care nurse helped women feel more comfortable and less embarrassed. An important issue for some women was that they did not feel like a commercial concern with the breast care nurse. The information provided by the breast care nurse was also mentioned by respondents. The nurse was chosen due to her medical affiliation, positive attitude and to the fact that women had previous positive experiences with her. The trained fitter was selected by a large amount of women. The most frequently reported reason for choosing the trained fitter was training and experience. On a similar note, many women noted the importance of the fitting expertise of the trained fitter in order to attain a perfect fit. Another reason given by respondents was that the trained fitter would have more time available than the breast care nurse. The importance of information provision was also noted. Some respondents mentioned choosing the trained fitter as they felt they did not have the same need for medical staff. In addition, product availability was mentioned and women told of previous positive experiences, which affected their decision. An understanding attitude and privacy were also noted as significant factors. Some women wanted the fitting to be away from the hospital environment and others noted the importance of convenience of location.

Of the *breast care nurse* respondents that chose the breast care nurse, the importance of aftercare was mentioned along with the importance of training. The hospital-based fitter was selected based on the fact that the breast care nurse was in the vicinity should there be any concerns. The commercial prosthesis fitter was chosen for her training and experience, the fact that she would carry a larger choice of products and that the fitting centre would be situated away from the hospital environment.

Commercial/retail prosthesis fitters who selected the specialised prosthesis fitter noted the importance of specialised training, of having the fitting away from the hospital environment and of having ample time available to fit. The fitter's attitude was identified as important by a participant who chose the breast care nurse and/or nurse. She noted the importance of an understanding, supportive fitter.

4.5.6.3: Suggestions for improving the experience of women being fitted with a replacement prosthesis

Two hundred and seventy six *women* availed of the opportunity to document their suggestions for improving the experience of women being fitted with a replacement prosthesis. A greater choice was the most frequently mentioned factor, which might improve the experience of the fitting of the replacement prosthesis. This choice referred to both choice of styles manufactured and choice of products stocked within the individual fitting centres. Attitude was also repeatedly mentioned, in particular relating to sensitive, friendly, sympathetic and caring fitters. Women wanted more time to carry out the fitting, to look and try on the mastectomy products and to talk to the fitter. Fitter knowledge, training and experience were noted in relation to improving the replacement prosthesis-fitting experience, however, many women did state that they were happy with the service they had received to date. Information was again a prominent factor, mainly with regard to knowledge of fitting centres and types of products on the market. Brochures were also desired. More privacy and an

improved environment were both deemed likely to improve the fitting experience. Aspects of the environment noted in particular included ventilation, mirrors and display of products. More fitting centres that were easily accessible were considered a necessary improvement by many women. In addition, familiarity with the fitting centre and/or fitter was noted as important. Respondents would have liked more contact with women in the same situation and if possible a fitter with personal experience. More improved prosthesis designs were desired by women. Finally, a greater number of fitters and the provision of counselling for women were also suggested as possible factors which could improve the fitting experience.

Of the 20 *breast care nurses* who expanded on how they considered the experience of women being fitted with a replacement prosthesis could be improved, they stated that providing a large choice of continuously updated products would improve the fitting experience for women. The importance of the environment was mentioned and a non-hospital based service was preferred by one respondent. The personal characteristics of the fitter were also deemed as important along with the presence of highly trained staff. Participants noted that there should be more fitting centres located across Ireland. Finally, the importance of privacy was mentioned.

Nine of the *commercial/retail prosthesis fitters* provided additional information on improving the experience of women being fitted with a replacement prosthesis. One frequently mentioned improvement was the need for enhanced information provision on products, entitlements and fitting services. A fitting centre with a non-clinical environment and a large range of stock, and a fitter with personal experience of breast cancer were suggested as factors that might improve the replacement fitting for women. Finally, retail fitters mentioned the importance of a fitter that the client has confidence in and also the importance of a fitting centre that is within easy access for women.

4.5.7: Mastectomy bras and swimwear

As expected the majority of women wear mastectomy bras (see Table 4.42). The majority of women get these bras either in the hospital (36.3%), specialised prosthesis supplier (23.1%), or a lingerie shop/department store (12.5%) (See Table 4.43).

Table 4.42: Type of bra worn

	N	%
Mastectomy bra	389	76.7
Ordinary bra	26	5.1
Ordinary bra	39	7.7
Mastectomy bra &/or ordinary bra with pocket	23	4.5
Mastectomy bra &/or ordinary bra	25	4.9
Ordinary bra with pocket &/or ordinary bra	2	0.4
All three	3	0.6
Total	507	100.0

Table 4.43: Location for *getting* bras		
	N	%
Hospital	183	36.3
Visiting fitting service	22	4.4
GP	1	0.2
Pharmacy	15	3.0
Cancer support centre	15	3.0
Specialised prosthesis supplier	116	23.1
General medical supplier	18	3.6
Lingerie shop/department store	63	12.5
Mail order catalogue	11	2.2
Internet	4	0.8
Other	56	11.1
Total	504	100.0

In Table 4.43, 50 out of the 56 cases of 'other, please specify' were combinations of the options above. Within this, an additional 16 people (3.2%) specified 'mail order catalogue' in addition to another option. Furthermore, 24 (4.8%) women indicated that they usually got their bras from a 'lingerie shop/department store' alongside other options.

Some 48.5% of women (n=231) indicated that their bra was available on the day of fitting/purchase; 51.5% (n=245) reported that the bra was not available on the day of fitting/purchase. For those women who indicated that the bra was not available, the average waiting time for receipt of the bra was 21.1 days (SD 13.3) with a range of 3-84 days. Seventy percent of the respondents to the breast care nurse questionnaire (N=21), 100% of the commercial/retail prosthesis fitters (n=12) and 100% of bra fitters (n=6) indicated that bras were generally available on the day of fitting; 30% (n=9) of breast care nurses indicated that they were not generally available.

The average length of time since being fitted for a bra was 16.6 months (SD 21.0) with a range of 0.25-240 months. Table 4.44 outlines whether breast care nurses, commercial/retail prosthesis fitters and bra fitters considered that women are generally refitted prior to receiving replacement bras.

Table 4.44: Breast care nurse, retail prosthesis fitter and bra fitter extent of refitting of bras				
	Always %	Sometimes %	Never %	Total % (N)
Breast care nurse	42.6	50.0	7.4	100.0 (26)
Retail fitter	66.7	33.3	0	100.0 (12)
Bra fitter	40.0	60.0	0	100.0 (5)

Some 37.3% of women (n=173) reported that their last fitting was not at the same time as the last prosthesis fitting; 62.7% (n=291) indicated that their last fitting was when they were fitted with a prosthesis. Where the last bra fitting was not the same as the last prosthesis fitting, these women were subsequently asked to indicate where this fitting took place (Table 4.45), who fitted the bra

(Table 4.46), and how satisfied they were with the characteristics of the person fitting the bra (Table 4.47) and the fitting environment (Table 4.49). Table 4.45 highlights that 41.8%, 22.4% and 18.2% of women were fitted for their bra in a hospital, lingerie shop/department store, and specialised prosthesis supplier, respectively. As evident in Table 4.47, women are satisfied with the characteristics of the person fitting the bra.

Table 4.45: Location for *fitting* of bra

	N	%
Hospital	71	41.8
Visiting fitting service	8	4.7
GP	0	0
Pharmacy	4	2.4
Cancer support centre	10	5.9
Specialised prosthesis supplier	31	18.2
General medical supplier	5	2.9
Lingerie shop/department store	38	22.4
Other	3	1.8
Total	170	100.0

Table 4.46: Person fitting the bra

	N	%
Breast care nurse	67	39.4
Nurse	7	4.1
GP	1	0.6
Trained fitter	55	32.4
Sales assistant	30	17.6
Unsure	3	1.8
Other	7	4.2
Total	170	100.0

Table 4.47: Satisfaction with the characteristics of the person who fitted the bra

	Very Dissatisfied / dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Knowledge	3.2	7.1	89.6	100.0 (154)
Competency	4.0	8.0	88.0	100.0 (150)
Experience	4.0	9.3	86.7	100.0 (150)
Training/qualifications	3.3	15.3	81.3	100.0 (150)
Attitude	3.9	9.2	86.9	100.0 (153)
Practical support	6.0	10.5	83.5	100.0 (152)
Emotional support given	8.8	16.9	74.3	100.0 (148)
Familiarity with stock/products	5.3	9.3	85.4	100.0 (151)
Confidence	5.9	6.5	87.6	100.0 (153)
Sensitivity	5.3	7.9	86.8	100.0 (152)
Discretion	3.9	7.8	88.2	100.0 (153)
Friendliness	2.0	6.5	91.5	100.0 (153)
Time available to you	9.1	5.8	85.1	100.0 (154)
Overall satisfaction	7.1	9.7	83.3	100.0 (155)

On investigating women's satisfaction with the characteristics of the person fitting the bra, there were significant differences in women's satisfaction with knowledge, competency, experience, training qualifications, attitude, practical support given, emotional support given, time available to deal with the women and overall satisfaction between women fitted by a breast care nurse, trained fitter or sales assistant. (See Table 4.48). Women expressed a greater level of satisfaction with the breast care nurse and/or trained fitter than a sales assistant. Satisfaction did not significantly vary with familiarity with stock/products, confidence, sensitivity, discretion and friendliness.

Table 4.48: Women's satisfaction with characteristics of person fitting bra by type of fitter

	Type of Fitter.....	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Knowledge	Breast care nurse	3.2	4.8	91.9	100.0 (62)	X^2=13.3, df=4, p<0.01
	Trained fitter	0	3.8	96.2	100.0 (53)	
	Sales assistant	10.7	17.9	71.4	100.0 (28)	
Competency	Breast care nurse	4.9	6.6	88.5	100.0 (61)	X^2=10.1, df=4, p<0.05
	Trained fitter	0	3.9	96.1	100.0 (51)	
	Sales assistant	10.7	17.9	71.4	100.0 (28)	
Experience	Breast care nurse	3.2	9.7	87.1	100.0 (62)	X^2=12.4, df=4, p<0.05
	Trained fitter	2.0	2.0	96.0	100.0 (50)	
	Sales assistant	10.7	21.4	67.9	100.0 (28)	
Training/ qualifications	Breast care nurse	1.6	11.5	86.9	100.0 (61)	X^2=14.7, df=4, p<0.005
	Trained fitter	1.9	9.6	88.5	100.0 (52)	
	Sales assistant	10.7	32.1	57.1	100.0 (28)	
Attitude	Breast care nurse	4.8	0	95.2	100.0 (63)	X^2=16.8, df=4, p<0.002
	Trained fitter	1.9	11.5	86.5	100.0 (52)	
	Sales assistant	7.1	25.0	67.9	100.0 (28)	
Practical support given	Breast care nurse	4.8	4.8	90.3	100.0 (62)	X^2=16.0, df=4, p<0.003
	Trained fitter	7.7	7.7	84.6	100.0 (52)	
	Sales assistant	3.6	32.1	64.3	100.0 (28)	
Emotional support given	Breast care nurse	4.9	9.8	85.2	100.0 (61)	X^2=16.1, df=4, p<0.003
	Trained fitter	10.2	14.3	75.5	100.0 (49)	
	Sales assistant	14.3	39.3	46.4	100.0 (28)	
Time available to deal with woman	Breast care nurse	6.3	1.6	92.1	100.0 (63)	X^2=11.6, df=4, p<0.05
	Trained fitter	5.7	5.7	88.7	100.0 (53)	
	Sales assistant	25.0	7.1	67.9	100.0 (28)	
Overall satisfaction	Breast care nurse	4.7	4.7	90.6	100.0 (64)	X^2=13.4, df=4, p<0.01
	Trained fitter	5.8	5.8	88.5	100.0 (52)	
	Sales assistant	17.2	20.7	62.1	100.0 (29)	

While the majority of women were satisfied with aspects of the environment where they were fitted for their mastectomy bras, approximately one in four women were dissatisfied with the availability of brochures, display of products and choice of products (see Table 4.49). When satisfaction with aspects of the fitting environment was investigated in terms of the fitting location (in particular hospital, specialised prosthesis supplier and lingerie/department store), the only significant difference emerging related to the availability of brochures with women who were fitted in a specialised prosthesis supplier being significantly more satisfied than women who were fitted in either the hospital or lingerie/department store (see Table 4.50).

Table 4.49: Satisfaction with aspects of the environment where bras fitted

	Very dissatisfied / Dissatisfied	Neither dissatisfied nor satisfied	Very satisfied / Satisfied	Total % (N)
Lighting	8.9	11.4	79.8	100.0 (158)
Ventilation	11.0	11.0	78.0	100.0 (154)
Space	14.8	14.2	71.0	100.0 (155)
Mirrors	12.3	9.1	78.6	100.0 (154)
Privacy	9.7	9.1	81.2	100.0 (154)
Display of products	25.3	13.6	61.0	100.0 (154)
Choice of products	26.1	13.1	60.8	100.0 (153)
Time to look at products	15.9	11.3	72.8	100.0 (151)
Brochures available	25.8	16.3	57.8	100.0 (147)
Overall satisfaction	12.9	16.8	70.3	100.0 (155)

Table 4.50: Women's satisfaction with bra-fitting environment by fitting location

	Location of fitting…	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)	Significance
Brochures available	Hospital	34.4	16.4	49.2	100.0 (61)	X^2=11.1, df=4, p<0.05
	Specialised prosthesis supplier	3.4	20.7	75.9	100.0 (29)	
	Lingerie/department store	34.4	18.8	46.9	100.0 (32)	

The majority of women, who consider the purchase or availability of mastectomy bra products to be relevant to them, are dissatisfied with the availability of mastectomy bra products (see Table 4.51). Furthermore, 16.2% of women are very dissatisfied or dissatisfied with mastectomy bras. In particular, dissatisfaction is expressed about the choice of bra styles (32.4%) and colour (32.7%), value for money (22.4%) and appearance (20.0%). Commercial/retail prosthesis fitters appeared to consistently consider that women were more satisfied with mastectomy products than the women expressed themselves (See Table 4.52).

Table 4.51: Satisfaction with the availability of mastectomy bra products						
	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Not relevant %	Did not know available %	Total % (N)
Underwired mastectomy bras	26.8	11.9	8.9	51.5	1.0	100.0 (404)
Camisole mastectomy bras	29.7	13.2	11.7	44.1	1.2	100.0 (408)
Strapless mastectomy bras	32.7	13.0	7.1	46.2	1.0	100.0 (407)
Clear strap mastectomy bras	31.2	10.7	15.7	41.4	1.0	100.0 (413)
Matching underwear set (with mastectomy bra)	31.3	11.8	9.8	46.3	1.0	100.0 (404)
Mastectomy bikinis	28.7	11.8	8.4	49.5	1.5	100.0 (390)
Mastectomy swimsuit	27.5	9.8	26.7	34.6	1.4	100.0 (419)
Matching sarong for mastectomy swimsuit/bikini	23.4	14.3	14.6	46.2	1.5	100.0 (398)

Table 4.52: Satisfaction with aspects of mastectomy bras					
		Very dissatisfied / Dissatisfied	Neither dissatisfied nor satisfied	Very satisfied / Satisfied	Total % (N)
Choice of styles	Women	32.4	9.2	58.3	100.0 (475)
	Breast care nurse	24.1	17.2	58.6	100.0 (29)
	Fitters	0	25.0	75.0	100.0 (12)
	Bra fitter	33.4	16.7	50.0	100.0 (6)
Choice of colours	Women	32.7	12.4	54.9	100.0 (459)
	Breast care nurse	26.6	26.7	46.7	100.0 (30)
	Fitters	8.3	33.3	58.3	100.0 (12)
	Bra fitter	66.7	0	33.3	100.0 (6)
Available sizes	Women	13.5	11.2	75.2	100.0 (464)
	Breast care nurse	16.1	25.8	58.1	100.0 (31)
	Fitters	0	8.3	91.6	100.0 (12)
	Bra fitter	16.7	16.7	66.6	100.0 (6)
Comfort	Women	13.0	11.1	75.8	100.0 (467)
	Breast care nurse	0	9.7	90.3	100.0 (31)
	Fitters	0	0	100.0	100.0 (12)
	Bra fitter	33.4	16.7	50.0	100.0 (6)
Security	Women	10.5	11.1	78.4	100.0 (458)
	Breast care nurse	9.7	6.5	83.9	100.0 (31)
	Fitters	0	8.3	91.6	100.0 (12)
	Bra fitter	16.7	33.3	50.0	100.0 (6)
Material	Women	13.0	12.8	74.1	100.0 (461)
	Breast care nurse	6.5	19.4	74.2	100.0 (31)
	Fitters	0	0	100.0	100.0 (12)
	Bra fitter	16.7	33.3	50.0	100.0 (6)
Appearance	Women	20.0	12.4	67.5	100.0 (465)
	Breast care nurse	6.5	12.9	80.6	100.0 (31)
	Fitters	0	0	100.0	100.0 (12)
	Bra fitter	20.0	20.0	60.0	100.0 (5)
Fit	Women	11.7	12.3	75.9	100.0 (461)
	Breast care nurse	0	6.5	93.5	100.0 (31)
	Fitters	0	0	100.0	100.0 (12)
	Bra fitter	50.0	0	50.0	100.0 (4)

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Table 4.52: Satisfaction with aspects of mastectomy bras					
		Very dissatisfied / Dissatisfied	Neither dissatisfied nor satisfied	Very satisfied / Satisfied	Total % (N)
Value for money	Women	22.4	18.6	58.9	100.0 (433)
	Breast care nurse	20.0	40.0	40.0	100.0 (30)
	Fitters	0	16.7	83.3	100.0 (12)
	Bra fitter	16.7	33.3	50.1	100.0 (6)
Quality	Women	9.1	14.4	76.5	100.0 (463)
	Breast care nurse	3.2	32.3	64.6	100.0 (31)
	Fitters	0	0	100.0	100.0 (12)
	Bra fitter	33.4	0	66.6	100.0 (6)
Overall satisfaction	Women	16.2	14.4	69.5	100.0 (465)
	Breast care nurse	0	0	100.0	100.0 (12)
	Fitters	0	29.0	71.0	100.0 (31)
	Bra fitter	16.7	33.3	50.0	100.0 (6)

4.5.7.1: Mastectomy swimwear

For those women who required a swimsuit (n=292), the mean time for replacing the swimsuit was 24.1 months (SD 23.6) with a range from 3-180 months. Where women got their swimsuits is listed in Table 4.54. The places in which mastectomy swimwear were most likely to be bought included the specialised prosthesis supplier (29.1%) and the lingerie shop/department store (34.6%). Fifteen (4.9%) of the other specified were combinations of the options included in the table. The majority of women wore a mastectomy-pocketed swimsuit (40.8%), with 57 (12.7%) wearing an ordinary swimsuit and 40(8.9%) wearing an ordinary swimsuit with a pocket sewn in (See Table 4.53).

Table 4.53: Type of swimsuit worn		
	N	%
Mastectomy-pocketed swimsuit	183	40.8
Ordinary swimsuit with pocket that you have sewn in	40	8.9
Ordinary swimsuit	57	12.7
Combination	12	2.7
Do not require swimsuit	157	3.8
Total	449	100.0

Table 4.54: Location for getting swimsuits		
	N	%
Hospital	7	2.4
Visiting fitting service	6	2.1
GP	2	0.7
Pharmacy	3	1.0
Cancer support centre	2	0.7
Specialised prosthesis supplier	85	29.1
General medical supplier	19	6.5
Lingerie shop/department store	101	34.6
Mail order catalogue	27	9.2
Internet	5	1.7
Other	25	8.6
Total	292	100.0

4.5.8: Breast care nurse and prosthesis fitter satisfaction with their fitting environment

Some 67.7% of respondents to the breast/hospital fitter questionnaire indicated that the breast care department in which they work provide a fitting service for replacement prostheses and mastectomy bras. Fifty percent indicated that the fitting room was located in the breast care nurse's office, 28.1% in a specialised fitting room in the breast care unit, 12.5% in a room in a different part of the hospital and 9.4% specified other. As can be seen in Table 4.55, respondents to the breast care nurse questionnaire were particularly dissatisfied with the space, display of products and storage area for products.

Table 4.55: Breast care nurse, retail prosthesis fitter and bra fitter satisfaction with aspects of their fitting environment

		Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Lighting	Breast care nurse	19.4	3.2	77.4	100.0 (31)
	Retail fitter	16.6	0	83.3	100.0 (12)
	Bra fitter	0	0	100.0	100.0 (6)
Ventilation	Breast care nurse	22.6	6.5	71.0	100.0 (31)
	Retail fitter	18.2	0	81.9	100.0 (11)
	Bra fitter	33.3	0	66.7	100.0 (6)
Space	Breast care nurse	45.2	0	54.9	100.0 (31)
	Retail fitter	9.1	0	91.0	100.0 (11)
	Bra fitter	0	0	100.0	100.0 (6)
Mirrors	Breast care nurse	12.9	3.2	83.9	100.0 (31)
	Retail fitter	9.1	0	90.9	100.0 (11)
	Bra fitter	0	0	100.0	100.0 (6)
Privacy	Breast care nurse	6.5	6.5	87.1	100.0 (31)
	Retail fitter	9.1	0	90.9	100.0 (11)
	Bra fitter	0	0	100.0	100.0 (6)
Display of products	Breast care nurse	36.7	30.0	33.4	100.0 (30)
	Retail fitter	9.1	18.2	72.8	100.0 (11)
	Bra fitter	0	16.7	83.3	100.0 (6)
Choice of products	Breast care nurse	20.0	16.7	63.3	100.0 (30)
	Retail fitter	9.1	9.1	81.9	100.0 (11)
	Bra fitter	16.7	16.7	66.6	100.0 (6)
Storage area for stock	Breast care nurse	58.1	9.7	32.3	100.0 (31)
	Retail fitter	9.1	9.1	81.9	100.0 (11)
	Bra fitter	0	0	100.0	100.0 (6)
Time given to women to look at products	Breast care nurse	3.2	12.9	83.9	100.0 (31)
	Retail fitter	9.1	0	90.9	100.0 (11)
	Bra fitter	0	0	100.0	100.0 (6)
Brochures available	Breast care nurse	0	6.5	93.5	100.0 (31)
	Retail fitter	9.1	27.3	63.7	100.0 (11)
	Bra fitter	33.3	0	66.7	100.0 (6)
Overall satisfaction	Breast care nurse	26.6	6.7	66.6	100.0 (30)
	Retail fitter	9.1	0	91.0	100.0 (11)
	Bra fitter	0	16.7	83.3	100.0 (6)

When asked how their fitting area could be improved, the main improvement identified by breast care nurses was increased space. They expressed a need for a larger room with plenty of storage, and space to display products and brochures. In addition, a specialised fitting room was identified as important. They also noted that the environment should not be clinical and should not hold any painful memories for the client. Commercial/retail prosthesis fitters mentioned the importance of sufficient space, appropriate lighting, ventilation and neatness.

4.5.9: Product availability

While all sources of external breast prostheses and mastectomy bras do not keep a complete stock of available mastectomy products (see Table 4.56), 77.8% (n=21), 100% (n=12) and 100% (n=6) of breast care nurses, commercial/retail prosthesis fitters and bra fitters respectively indicated that it was easy to obtain products from the supplier. Although 51.6% (n=16), 90.9% (n=10) and 33.3% (n=2) of breast care nurses, commercial/retail prosthesis fitters and bra fitters respectively consider that the choice of products available on the market satisfactorily meets the women's demands, 62.1% (n=18), 50% (n=5) and 80% (n=4) of breast care nurses, commercial/retail prosthesis fitters and bra fitters respectively reported that there were products not on the market that there was a demand for. Breast care nurses highlighted the need for a greater selection of styles and colour of bras (including front-fastening bras), greater availability of lightweight prosthesis products and more realistic texture in prostheses. The products identified by commercial/retail prosthesis fitters to be in demand but not on the market included more stylish bras, less expensive swimwear, tops with pockets for prostheses, nightwear and lighter strong support bras. Bra fitters also highlighted the need for a better selection of underwire and strapless bras, more bras with built in pockets or 'pockets which can be purchased by cup size and placed inside regular bras, held in place with Velcro.'

Table 4.56: Percentage of breast care nurses and retail prosthesis fitters whose department/centre supply different types of external breast prostheses and mastectomy bras and swimsuits

Post-operative soft fibre filled prosthesis	Retail prosthesis fitter (n=12)	91.7
	Breast care nurse (n=30)	100.0
Full-weighted/traditional silicone prosthesis	Retail prosthesis fitter (n=12)	100.0
	Breast care nurse (n=29)	86.2
Full-weighted self-adhesive silicone prosthesis	Retail prosthesis fitter (n=12)	41.7
	Breast care nurse (n=30)	66.7
Light-weighted silicone prosthesis	Retail prosthesis fitter (n=12)	91.7
	Breast care nurse (n=30)	93.3
Light-weighted self-adhesive silicone prosthesis	Retail prosthesis fitter (n=12)	33.3
	Breast care nurse (n=30)	63.3
Leisure/swimming prosthesis	Retail prosthesis fitter (n=12)	75.0
	Breast care nurse (n=30)	30.0
Prosthetic stick on nipple	Retail prosthesis fitter (n=12)	41.7
	Breast care nurse (n=30)	76.7

Table 4.56: Percentage of breast care nurses and retail prosthesis fitters whose department/centre supply different types of external breast prostheses and mastectomy bras and swimsuits		
Shell prosthesis	Retail prosthesis fitter (n=12)	75.0
	Breast care nurse (n=30)	90.0
Lumpectomy prosthesis	Retail prosthesis fitter (n=12)	83.3
	Breast care nurse (n=30)	90.0
Lumpectomy self-adhesive (stick-on) prosthesis	Retail prosthesis fitter (n=12)	25.0
	Breast care nurse (n=29)	31.0
Tinted prostheses	Retail prosthesis fitter (n=12)	50.0
	Breast care nurse (n=29)	37.9
Mastectomy bras	Retail prosthesis fitter (n=12)	100.0
	Breast care nurse (n=30)	96.7
	Bra fitter (n=6)	83.3
Underwire mastectomy bras	Retail prosthesis fitter (n=12)	58.3
	Breast care nurse (n=30)	46.7
	Bra fitter (n=6)	16.7
Camisole mastectomy bras	Retail prosthesis fitter (n=12)	83.3
	Breast care nurse (n=30)	70.0
	Bra fitter (n=6)	33.3
Strapless mastectomy bras	Retail prosthesis fitter (n=11)	27.3
	Breast care nurse (n=30)	10.0
	Bra fitter (n=6)	0
Clear strap mastectomy bras	Retail prosthesis fitter (n=11)	90.9
	Breast care nurse (n=30)	50.0
	Bra fitter (n=6)	33.3
Matching underwear set (with mastectomy bra)	Retail prosthesis fitter (n=11)	81.8
	Breast care nurse (n=30)	20.0
	Bra fitter (n=5)	40.0
Mastectomy bikinis	Retail prosthesis fitter (n=11)	100.0
	Breast care nurse (n=30)	13.3
	Bra fitter (n=5)	60.0
Mastectomy swimsuit	Retail prosthesis fitter (n=11)	100.0
	Breast care nurse (n=30)	20.0
	Bra fitter (n=6)	66.7
Mastectomy sarong for mastectomy swimsuit/bikini	Retail prosthesis fitter (n=11)	90.9
	Breast care nurse (n=30)	16.7
	Bra fitter (n=6)	66.7

4.5.10: Choice, travel distance and appointments

When women were asked if they had a choice of where to go to get fitted for a prosthesis, 28.1% (n=138) said they had, 36.0% (n=177) said they had no choice, and 35.8% (n=176) didn't know. Despite only a minority indicating that they had a choice, 68.8% of women (n=319) indicated that having a choice of fitting centres was important or extremely important. Furthermore, 62.0% of women (n=279) reported that having a choice of fitters within each centre was important or extremely important.

With regard to travel distance, 26.4% (n=128) of women indicated that it limited their ability to avail of replacing a prosthesis, whereas travel distance did not limit 73.6% (n=357) of women. The average travel distance to the nearest fitting centre was 34.5 kilometres (SD 43.2) with a range of 0.5–360 kilometres.

Out of the 392 women who answered the question 'do you need to make an appointment to go for a fitting', 86.0% indicated that an appointment was necessary, 7.6% said that they did not need to make an appointment and 5.4% did not know. The average length of time between making the appointment and being fitted was 2.4 weeks (SD 2.6) (range 0.2-30 weeks). Subsequently, the appointment lasted an average of 30.6 minutes (SD 15.0) (range 5-120 minutes). Eighty-four percent of women who had had an appointment to replace their prosthesis thought that the length of the appointment allowed their needs to be adequately dealt with, whereas 16.0% of women did not feel that their needs were adequately dealt with in their appointment.

Some 96.6% of respondents to the breast care nurse questionnaire (n=28) indicated that it was generally necessary to make an appointment in order to obtain a fitting. With regard to fittings in the home, 10.3% specified that arrangements could be made for this. While 19.2% (n=5) indicate a waiting time of 1-2 days and 7.7% (n=2) as soon as suits the clients, the average waiting period for the remaining was 1.5 weeks (SD 1.1) (range 1-5). The average length of time an individual prosthesis session would last was 48.6 minutes (SD 11.1) (range 1-10) and 93.1% (n=27) considered that this was sufficient time to meet the needs of the women. However, 75% (n=21) of breast care nurses did not think that there were sufficient staff employed to meet the number of fittings required.

Fifty percent (n=6) of commercial/retail fitters indicated that it was generally necessary to make an appointment in order to obtain a fitting and 50% also indicated that arrangements could be made for fittings to take place in the home. The average waiting time for an appointment with a commercial/retail fitter was 3.5 days (SD 3.6) (range 1-12 days). The average length of time an individual prosthesis session would last was 36.6 minutes (SD 15.66) (range 10-60 minutes) and 100% of commercial/retail fitters (n=12) felt that they had sufficient time for their clients' needs in this time. Furthermore, 100% (n=10) considered that there were sufficient staff employed to meet the number of fittings required in their service.

With regard to bra fitters, appointments were not necessary. One service (16.7%) indicated that a home fitting could be arranged. The average length of a fitting session was 20.6 minutes (SD 6.7) and 100% of bra fitters considered this sufficient time to meet the needs of their clients.

Finally, only one respondent to the breast care nurse questionnaire (4.2%) definitively stated that women receive reminders when they are due for their next fitting. Two respondents to the commercial/retail fitter questionnaire (16.7%) reported that women receive reminders when they are due for their next fitting.

4.5.11: Cost of prostheses, bras and swimwear

When asked if they received a replacement prosthesis free of charge, 65.0% of women (n=206) who had replaced their prosthesis and answered the question indicated that they had received their replacement prosthesis free of charge; 35% (n=111) did not. Table 4.57 points out that 2.9% of women who receive their replacement free of charge do not have health insurance or a medical card. Conversely, there are 4.5% of women who do not get their replacement prosthesis free of charge and yet have a medical card. Furthermore, there are 11.8% of women who did not get their replacement free of charge and they have indicated that they have both a medical card and health insurance.

Table 4.57: Cost of replacement prosthesis and funding source

Replacement prosthesis free of charge....?	Health insurance only %	Medical card only %	Has neither health insurance nor medical card %	Has both medical card and health insurance %	Total % (N)	Significance
Yes	17.2	47.1	2.9	32.8	100.0 (204)	X^2=120.8, df=3, p<0.0001
No	73.6	4.5	10.0	11.8	100.0 (110)	

Out of the women who indicated that they did not get a prosthesis free of charge, 14 women (15.4%) indicated that they paid a combined price for prosthesis and bra; 84.6% (n=77) did not get a prosthesis at a combined price. The average combined charge was €80.0 (SD 53.4) (range 30-180) (note median was €50 with 5 out of 9 instances of women paying €50) whereas the average cost for each prosthesis bought was €125.4 (SD 53.4) (range €15-300). Although 56.7% of women (n=59) said the replacement of their prosthesis was not influenced by cost, 43.3% (n=45) of women who were paying for their prosthesis indicated that the cost of the prosthesis influenced when they replaced it.

The average number of bras required in a year was specified as 3.6 (SD 3.0) (range 0-50). The average number of bras received free of charge was 1.23 (SD 3.1) (range 0-9) and the average number of bras bought by women in a year was 2.5 (SD 2.1) (range 0-10). The average cost of each bra bought was €38.6 (SD 15.8) (range €5-150). Some 48.3% of women who responded to the question 'does the cost of the mastectomy bra influence when you replace it' indicated that they were influenced by cost; 51.7% were not influenced by cost. Finally, the average cost of a mastectomy-pocketed swimsuit was €77.4 (SD 27.49) (range €5-150).

All commercial/retail fitters contract directly with the insurance companies and 91.7% (n=11) accept the medical card. Of these, 81.8% process the claim on the client's behalf. None of the bra fitters contract with the insurance companies nor do they accept the medical card.

4.5.12: Information needs and provision

Fifty-four percent of women indicated that they had received information on breast prostheses and bras; 46.0% (n=204) indicated that they had not. Table 4.58 reports on whether the women who received information did so from a number of different sources. Women were most likely to have received information from a face-to-face meeting with the breast care nurse (69.9%) or from an information booklet (53.3%). Table 4.59 depicts how more than one in three women were dissatisfied with the information they received on entitlements. Approximately one in four women were dissatisfied with the information they had received on cost of prostheses, types of bras, costs of bras, mastectomy swimwear, and location of fitters.

Table 4.58: Source of information on prostheses and bras

	Yes %	No %	Total % (n)
Face-to-face meeting with breast care nurse	72.0	28.0	100.0 (232)
Face-to-face meeting with consultant	11.0	89.0	100.0 (227)
Retail fitter	29.4	70.6	100.0 (228)
Family/friends	10.8	89.2	100.0 (222)
Other women with experience of breast cancer	24.0	76.0	100.0 (225)
Information booklet	53.3	46.7	100.0 (227)
Roadshow	5.9	94.1	100.0 (222)
TV/Radio slots	2.2	97.8	100.0 (223)
Magazines	22.0	78.0	100.0 (223)
Video	0.4	99.6	100.0 (223)
Website	11.7	88.3	100.0 (223)
ABC Freefone Helpline	2.3	97.7	100.0 (222)

Table 4.59: Women's satisfaction with information received on prostheses and bras

	Very dissatisfied / Dissatisfied %	Neither dissatisfied nor satisfied %	Very satisfied / Satisfied %	Total % (N)
Type of prostheses	18.3	14.7	67.0	100.0 (224)
Cost of prostheses	23.8	28.2	48.0	100.0 (202)
Type of bras	23.9	14.6	61.5	100.0 (226)
Cost of bras	28.1	26.7	45.3	100.0 (210)
Mastectomy swimwear	27.5	28.0	44.6	100.0 (193)
Entitlements	35.1	16.4	48.4	100.0 (219)
The fitting experience	9.1	17.8	73.0	100.0 (219)
Location of fitters	22.7	19.1	58.1	100.0 (220)
Contacting fitters	16.1	22.6	61.3	100.0 (217)
Taking care of the prosthesis	12.2	17.6	70.2	100.0 (222)
Adjusting to the prosthesis	15.2	22.3	62.5	100.0 (224)

Eleven out of the 12 retail/commercial prosthesis fitters (91.7%) indicated that they provided information on prostheses and bras to women. All breast care nurses indicated that they provided information. Table 4.60 documents the type of information that was provided by breast care nurses and commercial/retail prosthesis fitters. Table 4.61 documents the way in which the breast care nurses and commercial/retail prosthesis fitters provided this information to women.

Table 4.60: Type of information provided by breast care nurse, commercial/retail prosthesis fitter and bra fitter

		Yes %	No %	Total %(N)
Types of prostheses	Breast care nurse	93.8	6.3	100.0 (32)
	Retail fitter	90.9	9.1	100.0 (11)
	Bra fitter	Not relevant	Not relevant	Not relevant
Costs of prostheses	Breast care nurse	62.5	37.5	100.0 (32)
	Retail fitter	100.0	0	100.0 (11)
	Bra fitter	Not relevant	Not relevant	Not relevant
Types of bra	Breast care nurse	96.9	3.1	100.0 (32)
	Retail fitter	90.9	9.1	100.0 (11)
	Bra fitter	100.0	0	100.0 (5)
Costs of bras	Breast care nurse	68.8	31.3	100.0 (32)
	Retail fitter	100.0	0	100.0 (11)
	Bra fitter	60.0	40.0	100.0 (5)
Mastectomy swimwear	Breast care nurse	90.6	9.4	100.0 (32)
	Retail fitter	90.9	9.1	100.0 (11)
	Bra fitter	40.0	60.0	100.0 (5)
Entitlements	Breast care nurse	90.6	9.4	100.0 (32)
	Retail fitter	72.7	27.3	100.0 (11)
	Bra fitter	40.0	60.0	100.0 (5)
Replacing the prosthesis	Breast care nurse	87.5	12.5	100.0 (32)
	Retail fitter	90.9	9.1	100.0 (11)
	Bra fitter	Not relevant	Not relevant	Not relevant
The fitting experience	Breast care nurse	68.8	31.3	100.0 (32)
	Retail fitter	72.7	27.3	100.0 (11)
	Bra fitter	80.0	20.0	100.0 (5)
Location of fitters	Breast care nurse	87.5	12.5	100.0 (32)
	Retail fitter	72.7	27.3	100.0 (11)
	Bra fitter	60.0	40.0	100.0 (5)
Contacting fittings	Breast care nurse	78.1	21.9	100.0 (32)
	Retail fitter	45.5	54.5	100.0 (11)
	Bra fitter	40.0	60.0	100.0 (5)
Taking care of the prosthesis	Breast care nurse	96.1	3.1	100.0 (32)
	Retail fitter	100.0	0	100.0 (11)
	Bra fitter	40.0	60.0	100.0 (5)
Adjusting to the prosthesis	Breast care nurse	71.9	28.1	100.0 (32)
	Retail fitter	54.5	45.5	100.0 (11)
	Bra fitter	Not relevant	Not relevant	Not relevant

Table 4.61: Format of information provision				
		Yes %	No %	Total %(N)
Face-to-face meeting with breast care nurse, retail fitter or bra fitter	Breast care nurse	96.9	3.1	100.0 (32)
	Retail fitter	100.0	0	100.0 (11)
	Bra fitter	100.0	0	100.0 (5)
Face-to-face meeting with consultant	Breast care nurse	6.5	93.5	100.0 (31)
	Retail fitter	Not relevant	Not relevant	Not relevant
	Bra fitter	Not relevant	Not relevant	Not relevant
Information booklet developed by hospital	Breast care nurse	9.4	90.6	100.0 (32)
	Retail fitter	Not relevant	Not relevant	100.0 (10)
	Bra fitter	Not relevant	Not relevant	Not relevant
Information booklet developed by prosthesis/bra manufacturer	Breast care nurse	71.9	28.2	100.0 (32)
	Retail fitter	80.0	20.0	100.0 (10)
	Bra fitter	20.0	80.0	100.0 (5)
ABC information booklet	Breast care nurse	68.8	31.2	100.0 (32)
	Retail fitter	10.0	90.0	100.0 (10)
	Bra fitter	20.0	80.0	100.0 (5)
Video	Breast care nurse	7.1	92.9	100.0 (28)
	Retail fitter	10.0	90.0	100.0 (10)
	Bra fitter	Not relevant	Not relevant	Not relevant
Website address	Breast care nurse	45.2	54.8	100.0 (31)
	Retail fitter	40.0	60.0	100.0 (10)
	Bra fitter	20.0	80.0	100.0 (5)

Women were asked to rank in order of their personal preference the top three ways to receive information on prostheses and bras. It can be seen from the mean ranks listed in Table 4.62 that the top three preferred ways of receiving information on prostheses and bras are (1) face-to-face meeting with breast care nurse; (2) information booklet; and (3) other women with experience of breast cancer and the retail fitter, both of which have similar mean rankings.

Table 4.62: Ranking of preferred ways to receive information on prostheses and bras							
	1 %	2 %	3 %	Not ranked %	Marked but not ranked %	Total % (N)	Mean rank
Face-to-face meeting with breast care nurse	58.9	7.6	4.9	15.7	12.9	100.0 (489)	1.74
Face-to-face meeting with consultant	2.9	9.8	4.3	80.0	3.1	100.0 (489)	3.66
Retail fitter	4.7	18.8	11.0	59.0	6.5	100.0 (490)	3.33
Family/friends	0	1.8	4.1	91.6	2.4	100.0 (490)	3.92
Other women with experience of breast cancer	4.5	17.3	15.3	56.9	5.9	100.0 (490)	3.33
Information booklet	6.9	14.3	17.8	49.4	11.6	100.0 (490)	3.24
Roadshow	0.4	0.4	0.8	95.9	2.4	100.0 (490)	3.97
TV/Radio slots	0	0.4	1.2	95.3	3.1	100.0 (490)	3.98
Magazines	0.6	3.1	5.9	84.5	5.9	100.0 (490)	3.85
Video	0	0.6	2.7	93.9	2.9	100.0 (490)	3.96
Website	0.4	1.8	4.7	90.4	2.7	100.0 (490)	3.90
ABC Freephone Helpline	0.2	1.6	2.4	92.7	3.1	100.0 (490)	3.93

4.5.13: Adjustment

Table 4.63 depicts the number of arm and breast symptoms that this cohort of women were experiencing. Using the Physical Health, Psychological, Social Relationships and Environment subscales of the WHOQOLBREF and the Arm and Breast Symptom Subscales from the EORTC Breast Care Module, Table 4.64 indicates that on average the cohort of women in this sample have good quality of life and a low number of arm and breast symptoms.

Table 4.63: Arm and breast symptoms (EORTC)					
During the past week...	Not at all	A little	Quite a bit	Very much	Total
Did you have any pain in your arm or shoulder?	52.8	30.6	11.1	5.6	100.0 (468)
Did you have a swollen arm or hand?	70.6	16.7	7.3	5.4	100.0 (479)
Was it difficult to raise your arm or to move it sideways?	66.0	18.8	9.6	5.6	100.0 (479)
Have you had any pain in the area of your affected breast?	52.1	34.4	8.3	5.2	100.0 (480)
Was the area of your affected breast swollen?	84.5	11.0	3.0	1.5	100.0 (472)
Was the area of your affected breast oversensitive?	48.9	33.7	9.7	7.6	100.0 (472)
Have you had skin problems on or in the area of your affected breast (e.g. itchy, dry, flaky)?	74.6	16.3	5.6	3.5	100.0 (480)
Have you had any pain in the area of the breast that was removed?	54.3	34.2	6.1	5.4	100.0 (468)

Table 4.64: Descriptive statistics for the WHOQOLBREF subscales and arm and breast symptom subscales					
	Mean	Std. deviation	Minimum	Maximum	N
Physical health (QoL)	15.8	2.9	5.1	20.0	478
Psychological (QoL)	15.5	2.7	6.7	20.0	485
Social relationships (QoL)	16.0	3.3	5.3	20.0	482
Environment (QoL)	16.0	2.6	7.0	20.0	498
Arm symptoms (EORTC)	18.5	23.1	0.0	100.0	454
Breast symptoms (EORTC)	16.2	19.4	0.0	100.0	453

Although the women display good quality of life and low arm and breast symptoms overall, correlations indicate that the longer the woman required a breast prosthesis, the higher her scores on the physical health and psychological domain of the WHOQOLBREF, and the fewer arm and breast symptoms experienced (See Table 4.65). Furthermore, women who had replaced their prosthesis but did not receive it free of charge and who indicated that cost influenced when they replaced it had significantly lower scores in the physical health ($t=-2.2$, $df=110$, $p<.05$), psychological ($t=-3.0$, $df=110$, $p<.005$), social relationships ($t=-2.3$, $df=107$, $p<.05$), and environment ($t=-3.7$, $df=110$, $p<.0001$) domains of quality of life than woman who said that cost did not influence when they replaced their prosthesis.

Table 4.65: Relationships between general information, quality of life and arm/breast symptoms							
		Physical health (QoL)	Psychological (QoL)	Social relationships (QoL)	Environment (QoL)	Arm symptoms (EORTC)	Breast symptoms (EORTC)
How long have you required a breast prosthesis (full, partial, shell)?	r	0.100	0.110			-0.139	-0.156
	Significance	<0.05	<0.05	ns	ns	<0.005	<0.001
	N	467	474			447	446

ns: Not significant

Interestingly, except for satisfaction with the colour of the prosthesis, higher levels of satisfaction with the shape, appearance when worn, weight, comfort, fit, movement with the body, texture, durability, quality, value for money and overall satisfaction with the external breast prosthesis were associated with higher quality of life in each of the WHOQOLBREF domains (i.e. physical health, psychological, social relationships and environment) (See Table 4.66). Higher levels of satisfaction with the temperature of the prosthesis were associated with higher quality of life in the physical, psychological and environment domains. Higher levels of arm symptoms were associated with lower levels of satisfaction with the shape, appearance when worn, weight, comfort, fit, movement with the body, value for money and overall satisfaction with the prosthesis. Finally, higher levels of breast symptoms were associated with lower levels of satisfaction with all aspects of the external breast prosthesis.

Table 4.66: Relationships between satisfaction with the prosthesis worn most regularly, quality of life and arm/breast symptoms.

		Physical health (QoL)	Psychological (QoL)	Social relationships (QoL)	Environment (QoL)	Arm symptoms (EORTC)	Breast symptoms (EORTC)
Colour	r						-0.114
	Significance	ns	ns	ns	ns	ns	<0.05
	N						432
Shape	r	0.151	0.156	0.145	0.136	-0.179	-0.227
	Significance	<0.001	<0.001	<0.005	<0.005	<0.0001	<0.0001
	N	456	464	461	475	439	437
Appearance when worn	r	0.132	0.178	0.172	0.189	-0.126	-0.194
	Significance	<0.005	<0.0001	<0.0001	<0.0001	<0.01	<0.0001
	N	459	465	459	472	438	434
Weight	r	0.223	0.160	0.185	0.141	-0.191	-0.264
	Significance	<0.0001	<0.001	<0.0001	<0.005	<0.0001	<0.0001
	N	454	459	455	468	434	432
Comfort	r	0.220	0.179	0.173	0.182	-0.211	-0.293
	Significance	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001
	N	457	462	459	472	435	434
Fit	r	0.212	0.207	0.154	0.164	-0.187	-0.293
	Significance	<0.0001	<0.0001	<0.001	<0.0001	<0.0001	<0.0001
	N	461	467	465	476	442	439
Movement with the body	r	0.164	0.189	0.159	0.193	-0.118	-0.242
	Significance	<0.0001	<0.0001	<0.001	<0.0001	<0.05	<0.0001
	N	453	460	456	469	435	432
Texture	r	0.174	0.145	0.123	0.138		-0.152
	Significance	<0.0001	<0.005	<0.01	<0.005	ns	<0.005
	N	445	452	447	457		425
Temperature	r	0.152	0.117		0.132		-0.171
	Significance	<0.001	<0.05	ns	<0.005	ns	<0.0001
	N	447	454		459		427
Durability	r	0.134	0.145	0.172	0.136		-0.179
	Significance	<0.005	<0.005	<0.0001	<0.005	ns	<0.0001
	N	441	449	441	453		425
Quality	r	0.125	0.112	0.162	0.132		-0.151
	Significance	<0.01	<0.05	<0.001	<0.005	ns	<0.005
	N	439	445	441	451		422
Value for money	r	0.122	0.118	0.190	0.141	-0.171	-0.208
	Significance	<0.05	<0.05	<0.0001	<0.005	<0.001	<0.0001
	N	406	412	406	417	395	389
Overall satisfaction	r	0.201	0.181	0.183	0.195	-0.187	-0.229
	Significance	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001	<0.0001
	N	446	454	449	463	433	430

Higher levels of satisfaction with the choice of styles, choice of colours, available sizes, comfort, security, material, appearance, fit, value for money, quality and overall satisfaction with the mastectomy bras were associated with higher quality of life in each of the WHOQOLBREF domains

(i.e. physical health, psychological, social relationships and environment) (See Table 4.67). Higher levels of arm symptoms were associated with lower levels of satisfaction with the choice of styles, choice of colours, comfort, security, fit and overall satisfaction with mastectomy bras. Higher levels of breast symptoms were associated with lower levels of satisfaction with all aspects of mastectomy bras.

Table 4.67: Relationships between satisfaction with mastectomy bras, quality of life and arm / breast symptoms

		Physical health (QoL)	Psychological (QoL)	Social relationships (QoL)	Environment (QoL)	Arm symptoms (EORTC)	Breast symptoms (EORTC)
Choice of styles	r	0.171	0.206	0.223	0.128	-0.099	-0.210
	Significance	<0.0001	<0.0001	<0.0001	<0.01	<0.05	<0.0001
	N	447	450	442	459	431	429
Choice of colours	r	0.160	0.194	0.234	0.132	-0.111	-0.187
	Significance	<0.001	<0.0001	<0.0001	<0.005	<0.05	<0.0001
	N	436	440	433	446	422	419
Available sizes	r	0.145	0.193	0.182	0.127		-0.189
	Significance	<0.005	<0.0001	<0.0001	<0.01	ns	<0.0001
	N	438	441	433	450		422
Comfort	r	0.220	0.181	0.136	0.184	-0.137	-0.238
	Significance	<0.0001	<0.0001	<0.005	<0.0001	<0.005	<0.0001
	N	441	444	436	453	426	425
Security	r	0.273	0.249	0.190	0.236	-0.166	-0.296
	Significance	<0.0001	<0.0001	<0.0001	<0.0001	<0.001	<0.0001
	N	436	438	431	445	423	418
Material	r	0.189	0.197	0.199	0.152		-0.185
	Significance	<0.0001	<0.0001	<0.0001	<0.001	ns	<0.0001
	N	435	438	432	446		419
Appearance	r	0.148	0.188	0.188	0.128		-0.178
	Significance	<0.005	<0.0001	<0.0001	<0.01	ns	<0.0001
	N	440	443	435	451		424
Fit	r	0.242	0.223	0.160	0.212	-0.123	-0.158
	Significance	<0.0001	<0.0001	<0.001	<0.0001	<0.05	<0.001
	N	437	440	432	447	422	419
Value for money	r	0.152	0.205	0.228	0.163		-0.159
	Significance	<0.005	<0.0001	<0.0001	<0.001	ns	<0.005
	N	409	413	406	419		397
Quality	r	0.197	0.218	0.206	0.180		-0.137
	Significance	<0.0001	<0.0001	<0.0001	<0.0001	ns	<0.005
	N	440	443	433	450		424
Overall satisfaction	r	0.196	0.240	0.269	0.201	-0.119	-0.235
	Significance	<0.0001	<0.0001	<0.0001	<0.0001	<0.05	<0.0001
	N	438	442	433	449	423	420

4.5.14: Professional Development

In addition to having their professional nursing qualification, the majority of breast care nurse respondents had also undertaken a higher diploma in oncology with breast care specialist focus or a post-registration equivalent. Some 48.4% of nurses (n=15) responded that the training provided in attaining their qualifications was sufficient to enable them to fit prostheses and bras; 51.6% (n=16) did not share this viewpoint. Fifty percent of nurses indicated that they had also completed training courses specific to fitting prostheses and bras. Of these, the majority indicated that they had attended a course by a supplier of mastectomy products or were trained by a more experienced colleague. Thirteen percent of breast care nurses (n=4) did not consider length of training to be important in being a confident fitter. The average length of time specified by the remainder to be necessary to be a confident fitter was 4.96 months (SD 4.0) (range 0.25-14 months). Furthermore, the average number of weekly fittings deemed necessary to maintain a level of expertise as a fitter was 3.7 (SD 1.9) (range 1-10).

While five of the commercial/retail prosthesis fitters had a clinical/professional qualification, the remainder were trained via courses offered through manufacturing companies and experience. Overall, 90.9% (n=10) considered that their training was sufficient to enable them to fit external breast prostheses and mastectomy bras. All commercial/retail prosthesis fitters had attended training courses specific to the fitting of prostheses and bras. The response to the question about the length of time needed to be training as a fitter elicited varying answers ranging from 3 hours and a practical to months. Furthermore, commercial/retail prosthesis fitters considered that the average number of fittings needed in a week to maintain a level of expertise was 5.2 (SD 3.11).

Sixty-nine percent of breast care nurses (n=20) indicated there was insufficient opportunity for professional development in the field of prosthesis fitting; 31.0% (n=9) considered that there was sufficient opportunity for professional development in the field of prosthesis fitting. One third of commercial/retail prosthesis fitters did not think that there was sufficient opportunity for professional development in the field of prosthesis fitting. Most of the breast care nurses, prosthesis fitters and bra fitters engaged in self-learning (see Table 4.68).

Each of the bra fitter respondents were completing the questionnaire on behalf of their service. Out of the 39 fitters identified across five services, 32 had completed training courses specific to fitting a mastectomy bra. Sixty percent of bra-fitter respondents thought that there was sufficient opportunity for professional development in the field of mastectomy bra fitting.

Table 4.68: Methods of keeping up-to-date with advances in mastectomy products				
		Yes %	No %	Total %(N)
Reading a relevant journal	Bra fitter	20.0	80.0	100.0 (5)
	Breast care nurse	80.0	20.0	100.0 (30)
	Prosthesis fitter	91.7	8.3	100.0 (12)
Reading a relevant magazine	Bra fitter	60.0	40.0	100.0 (5)
	Breast care nurse	93.3	6.7	100.0 (30)
	Prosthesis fitter	75.0	25.0	100.0 (12)
Attending conferences	Bra fitter	20.0	80.0	100.0 (5)
	Breast care nurse	93.5	6.4	100.0 (30)
	Prosthesis fitter	66.7	33.3	100.0 (12)
Attending lectures/meetings	Bra fitter	20.0	80.0	100.0 (5)
	Breast care nurse	90.3	9.7	100.0 (31)
	Prosthesis fitter	58.3	41.7	100.0 (12)
Liaising with prosthetic company representatives	Bra fitter	60.0	40.0	100.0 (5)
	Breast care nurse	93.5	6.4	100.0 (31)
	Prosthesis fitter	91.7	8.3	100.0 (12)

When asked to describe training needs to be addressed, breast care nurses identified the need for more regular meetings and workshops. Regular updates on products and workshops were also desired. Some breast care nurses noted that the training should be of a higher standard and new fitters should be supervised. In addition, more information on prostheses types and more training relating to difficult fittings was required. One respondent noted that training sessions should be run independently from manufacturers, so companies do not have the ulterior motive of promoting their own products. To address these needs, breast care nurses requested additional training days, study days and fitting courses in general. The important of utilising the IBCNA (Irish Breast Care Nurses Association) was also mentioned. The breast care nurses stressed the importance of sales representatives visiting hospitals with new products and also noted the value of practical experience in addition to training courses. It was suggested that proficiency testing should be introduced. Indeed, one respondent suggested that the Irish Cancer Society run biannual training days for update and evaluation of competencies. Commercial/retail prosthesis fitters identified similar training needs and in addition specifically mentioned training courses on interacting with the clients. One prosthesis fitter notes that there should be a regulation of fitting services.

4.5.15: Standards of care

The majority of breast care nurses, prosthesis fitters and bra fitters are satisfied with the standard of care in relation to prosthesis/bra provision (See Table 4.69).

Table 4.69: Perceived standard of care in relation to prosthesis/bra provision

	Very low standard of care %	Low standard of care %	Neither high nor low standard of care %	High standard of care %	Very high standard of care %	Total % (N)
Breast care nurse	0	6.5	29.0	61.3	3.2	100.0 (31)
Prosthesis fitter	0	0	50.0	25.0	25.0	100.0 (12)
Bra fitters	0	40.0	20.0	20.0	20.0	100.0 (5)

The majority of services had a follow-up service for issues related to fitting (see Table 4.70) and also a follow-up service for complaints (see Table 4.71).

Table 4.70: Availability of a follow-up service for women to gain information on issues that may arise later on in relation to fitting

	Yes %	No %	Don't know %	Total % (N)
Breast care nurse	84.4	12.5	3.1	100.0 (32)
Prosthesis fitter	83.3	16.7	0	100.0 (12)
Bra fitters	60.0	40.0	0	100.0 (5)

Table 4.71: Availability of a follow-up service for women to issue complaints to

	Yes %	No %	Don't know %	Total % (N)
Breast care nurse	84.4	12.5	3.1	100.0 (32)
Prosthesis fitter	80.0	10.0	10.0	100.0 (10)
Bra fitters	75.0	25.0	0	100.0 (4)

When asked to provide additional information on this follow-up service, the main route for issuing a complaint, identified by the breast care nurses, appeared to be through the breast care nurse herself. Women were advised to contact the breast care nurse should they have any problems with their prosthesis. A smaller number of respondents mentioned that women could go through a complaints procedure in the hospital. Some noted that there was no formal complaints procedure in their place of work and others reported that they liaise with the supplier when complaints are received. With regard to commercial/retail prosthesis fitters, the majority of fitters inform their clients to contact them should any problems arise and they deal with the complaint from there. Other commercial/retail prosthesis fitters noted that the client would contact the supplier herself should they have any complaints. Finally, one commercial/retail prosthesis fitter mentioned a support group as a means of issuing complaints. The complaints procedure for bra fitters was mentioned in the context of the place of purchase, that is, similar to other products in the shop; if the item is faulty, it will be replaced or

monies reimbursed. Similarly, women can bring a complaint to the manager of a shop who will talk with the company representative.

Table 4.72: Awareness of service guidelines

	Yes %	No %	Total % (N)
Breast care nurse*	N/A	N/A	N/A
Prosthesis fitter	45.5	54.5	100.0 (11)
Bra fitter	50.0	50.0	100.0 (4)

*Not applicable because registered nurses are bound by their professional code of conduct as stipulated by An Bord Altranais

When asked to provide additional information on the service guidelines identified in Table 4.72, some of the commercial/retail prosthesis fitters stated that they adhere to the same guidelines as any other health professional (e.g. confidentiality etc). Another respondent noted the importance of common sense and kindness. Similarly, the additional responses from the bra fitters related to general rules of thumb when fitting rather than specific service guidelines.

4.6 CONCLUSION

The survey findings provide a clear statement of the importance that women bestow upon the external breast prosthesis in terms of its contribution to her shape, appearance to others, appearance to self, femininity, self-confidence, balance and posture. Furthermore, despite a degree of dissatisfaction with elements of the prosthesis, 92.5% of women continue to wear their prosthesis most or all of the time and in activities that they consider relevant to them, both inside and outside of the home environment. Given the clear importance of the prosthesis and the integral role it plays in the life of women post-mastectomy, it appears not only inequitable but undeserved that almost half of the women indicated that the cost of the prosthesis and mastectomy bra influenced when they replaced them. In addition, while it is likely that the ordering of external breast prostheses and mastectomy bras are subject to external constraints beyond the control of the breast care nurse or retail fitter, it is unacceptable that a woman may have to wait for 3 weeks for replacement prostheses and mastectomy bras; items that are integral to her comfort and well-being and that play a key role in the external presentation to others and also to oneself. A more equitable service provision is also required to ensure that centres are within accessible distances for women attending them. Currently, just over one in four women indicated that travel distance to the fitting centre limited their ability to avail of replacing a prosthesis.

The continued use of the temporary post operative soft fibre filled prosthesis by just over a quarter of women at least one year post surgery, the fact that 7.6% reported using it most regularly as the prosthesis of choice, and the fact that 8.2% of women sometimes wear something other than a

prosthesis is indicative of a degree of dissatisfaction with available products. This is further supported by a degree of reported dissatisfaction with the weight and comfort of the external breast prosthesis and its movement with the body. In addition, an element of dissatisfaction was expressed with the choice of mastectomy bra styles and colour, value for money and appearance. This dissatisfaction may exist, however, because of a lack of information on the existing mastectomy products that are available for women; a finding that emerged in the focus group study. Furthermore, in the national survey, 40% of women indicated that they had not received information on prostheses and bras. Therefore, although there are different types of prostheses that can be matched to the woman's needs, if she is not in possession of the appropriate information, it is difficult for the woman to make an informed choice concerning the most suitable products. This, in turn, may lead to a restriction in activities. For example, at least half of the women indicated that they felt limited in swimming and in participating in sport because of their external breast prosthesis. This finding raises concerns given the importance of such activity in the rehabilitation and well-being of women post-mastectomy. However, if a woman is unaware of the availability of a leisure/swimming prosthesis, as was explicitly identified in the focus groups and suggested in the surveys given the fact that less than one in five women used such a prosthesis, this may contribute to them feeling restricted because of the inappropriateness of using a traditional weighted prosthesis for such activities. Furthermore, as one in three women were dissatisfied with the information that they received on entitlements, it is possible that the 16% of women, who indicated that they had a medical card and yet were paying for their replacement prosthesis, were not aware of the scheme introduced by the Government in 2001 whereby women on the medical card were entitled to two free bras every year and a replacement prosthesis every 2 years.

The survey findings also provided an opportunity to investigate in detail what aspects of the prosthesis, environment or person fitting the prosthesis were important for the women's experience and contributed to her degree of satisfaction. Furthermore, given the potential variability in experiences at the various fittings and the different stages of the breast cancer trajectory that a woman is likely to be at for each of the temporary, first silicone and replacement prosthesis fitting, it was considered important to look at each of these fitting experiences separately. Indeed it became apparent across the three different fitting stages that women's needs and satisfaction ratings with various elements changed. For example, while a significant proportion of women were dissatisfied with the display of products, choice of products and brochure availability across all the different stages of fitting, dissatisfaction with the time given to look at products at the temporary prosthesis fitting, space at the first silicone prosthesis fitting, and time available for the woman at the replacement prosthesis fitting were also highlighted. In addition, while the hospital was the preferred environment during the earlier stages of fitting, there was a shift towards an increased preference for and attendance at the specialised prosthesis supplier as the woman became more accustomed to wearing an external breast prosthesis and replacing her prosthesis. In addition, women fitted with a replacement prosthesis in a specialised prosthesis supplier expressed greater satisfaction with the

space, display of products, choice of products and brochures than women who were fitted in the hospital environment. The preferred location for the fitting of the replacement prostheses was endorsed by the breast care nurses and commercial/retail fitters who similarly advocated the specialised prosthesis supplier as the location of choice for the fitting of the replacement prosthesis. With regard to the person fitting the prosthesis, over all time periods, women expressed a degree of dissatisfaction with the emotional support given by the person fitting the prosthesis and the time available to them. It is important that women not only receive well-fitting prosthesis but that it is fitted in a caring and personal environment. Furthermore as the woman progressed from the temporary and first silicone prosthesis fitting to the fitting of a replacement prosthesis, it was evident that an increasing number of women were fitted with their prostheses by a trained fitter and the gap in satisfaction ratings between the breast care nurse and trained fitter were reduced to comparable levels at the fitting of a replacement prosthesis. In addition, while there was a clear desire to be fitted by a breast care nurse in the early stages, there was a clear preference for the replacement prostheses to be fitted by a trained fitter.

Women who were fitted with their temporary prosthesis in the breast care nurses' office were significantly more likely to rate the lighting, space, mirrors, privacy, display of products, choice of products, time to look at products, brochures and overall satisfaction with the fitting environment more positively than women who were fitted with their temporary soft prosthesis in a hospital ward. Consequently, it is recommended that where possible, women be fitted with their temporary prosthesis in a private room away from the hospital ward. Respondents to the breast care nurse questionnaire were particularly dissatisfied with the space, display of products and storage area for products in their own fitting areas. This is an endorsement of the women's dissatisfaction with similar aspects of the fitting environment. However, there appears to be a discrepancy in satisfaction with the availability of brochures, that is, a significant proportion of women were dissatisfied with brochure availability but breast care nurses and prosthesis fitters were not.

The findings from the survey provide an evidence base upon which to develop prosthesis and mastectomy bra-fitting services. Some of the findings pinpoint relatively minor changes that could potentially elicit significant improvements in satisfaction ratings, for example, making information booklets and brochures on products available in prosthesis-fitting centres and in breast care units nationwide. Such information booklets already exist, for example, Action Breast Cancer have an information booklet on breast prostheses which contains much of the information that is being sought by women – contact details for prosthesis fitters, websites of manufacturers, a description of the fitting experience, entitlements, etc. This is an important resource that is regularly updated and its use and availability should be capitalised upon wherever possible. Furthermore, the use of support groups such as Reach to Recovery and local cancer support centres and the outreach and peer support facility that they provide should be continued to be used by clinical staff. For many this contact is neither sought nor wanted but for others, it was a welcome relief and a source of reassurance. As also

indicated in the focus groups, information is given but it is a traumatic time and is it possible that the woman cannot register the information that she is receiving or hearing. Consequently, information should be made available on a number of occasions.

Overall the findings arising from the survey data are consistent with the existing international research. An element of dissatisfaction with choice of product was expressed by women in the fitting of the temporary soft prosthesis, first silicone prosthesis and replacement prosthesis, and this issue was also highlighted in the open-ended questions as having an important role in improving the fitting experience. This finding corresponds to observations from Livingston et al. (2005), who found that positive fitting experiences were associated with number of styles shown, and Breast Cancer Care (2006) who reported that a quarter of participants felt the choice in prostheses offered to them was limited. Women expressed an element of dissatisfaction with privacy and noted its relevance for an improved fitting experience, which is again consistent with results from Livingston et al. (2005). It emerged from this research that just over a quarter of participants were still wearing their temporary post-operative prosthesis at least 1 year after surgery. This accords with Tanner et al.'s (1983) observations that a sizeable proportion of participants were still wearing a temporary prosthesis. Over 40% of women indicated that the cost of the prosthesis influenced when they replaced it. This supports previous research by BreastCare Victoria (2003) that over a quarter of women reported costs influenced their choice of breast prosthesis. Previous research by Healey (2003) and Livingston (2003) also supports the finding that a sizeable proportion of dissatisfaction was expressed by women with regard to weight and comfort of the breast prosthesis. Furthermore, a desire and need for improved information provision was expressed which corroborates with similar findings from previous research (Breast Cancer Care, 2006c; Roberts et al., 2003). Finally, consistent with Roberts et al. (2003), the attitude of the fitter and the relationship with the fitter were both identified as important issues relating to the improvement of the fitting experience. This is also in keeping with Livingstone et al. who reported that the high rating of fitters was associated with two factors: knowledge and experience and attitude towards the women.

These findings play an important role in substantiating and developing the limited but growing international literature in this area. Furthermore, these findings contribute new insights that take account of the temporary, first silicone, and replacement prosthesis fitting needs. The empirical data on the temporary prosthesis fitting is particularly noteworthy. Furthermore, this is the only research, which has specifically looked at the relationship between satisfaction with aspects of the external breast prosthesis and quality of life. The external breast prosthesis is important not only because women perceive that it plays an integral role in their appearance, self-confidence and shape, but that satisfaction with aspects of the external breast prosthesis is related to higher quality of life and fewer arms and breast symptoms. While, the direction of this relationship is unknown, that is, we cannot say whether satisfaction with the external breast prosthesis precedes a good quality of life or vice versa, at the very least, it highlights the need to explore this relationship further. Most importantly, the

survey findings provide a detailed and comprehensive picture of the provision, fitting and supply of external breast prostheses in Ireland. Of particular relevance to the Irish context is the identified need for professional development opportunities in the field of prosthesis fitting. In addition, although the majority of services had a follow-up service for issues related to fitting and also a follow-up service for complaints, these were ad hoc localised follow-up services. While nurses are bound by their professional code of conduct and subject to the statutory regulatory regime in that sphere, there are no national or external service guidelines and protocols for commercial/retail prosthesis fitters or bra fitters. In Ireland, the prosthetist as a profession is not recognised nor are there standards of competencies and behaviour for those who work as fitters in their role as fitters. However, as the fitting of an external breast prosthesis is a private, sensitive and vulnerable time for women, it is a service that should be subject to the highest of standards and guidelines.

SUMMARY: NATIONAL SURVEYS

The second part of the study consisted of four concurrent national surveys. Survey 1 explored the experiences of women with breast cancer (n=527). Survey 2 investigated the views of breast care nurses (n=32). Survey 3 and Survey 4 documented the views of retail prosthesis fitters (n=12) and retail bra fitters (n=6), respectively. The main findings from this part of the study are listed below.

Patterns of Prosthesis Use

- The majority of women reported using the full-weighted traditional silicone prosthesis (55.6%) or the light-weighted silicone prosthesis (21.6%) most regularly.
- 26.4% of women continue to use their temporary post-operative soft fibre filled prosthesis at least 1 year post surgery and 7.6% of women indicated that this was the type of external breast prosthesis that they used *most regularly*.
- 92.5% of women wear their external breast prosthesis all or most of the time.
- 61.8% and 62.2% of women perceived themselves to be limited in buying clothes and swimming because of the use of an external breast prosthesis.
- Almost half of the women considered that they were limited in sports and sexual activity because of their prosthesis and almost one-quarter of women perceived themselves to be limited in socialising.

PERCEIVED IMPORTANCE OF AND SATISFACTION WITH EXTERNAL BREAST PROSTHESIS

- Women, breast care nurses, commercial/retail prosthesis fitters and bra fitters perceived the external breast prosthesis to be important for balance, posture, shape, appearance to self, appearance to others, sense of well-being, self-confidence and femininity.
- The most important aspects of wearing an external breast prosthesis for women were shape (91%), self-confidence (90.9%) and appearance to self (90.4%).
- While women are generally satisfied with the external breast prosthesis that they wear most regularly, a sizeable proportion expressed dissatisfaction with various aspects of the prosthesis, in particular its weight (24.4%), comfort (17.3%) and movement with the body (14.3%).

FITTING

Temporary Soft Prosthesis

- 49.9% of women reported that they were fitted for their temporary soft prosthesis in a hospital ward. 41.7% reported that they were fitted in the breast care nurses' office.
- Women were generally satisfied with the environment within which they were fitted for their temporary soft prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (39.8%), display of products (35.4%), choice of products (35.8%) and time to look at products (30.3%). It is also important to note that one out of every five women

expressed a level of overall dissatisfaction with the fitting environment for the temporary soft prosthesis.

- Women who were fitted in a breast care nurses' office were significantly more likely to rate the lighting, space, mirrors, privacy, display of products, choice of products, time to look at products, brochures and overall satisfaction with the fitting environment more positively than women who were fitted with their temporary soft prosthesis in a hospital ward.
- Women indicated that their preferred location for the fitting of the temporary soft prosthesis was the breast care nurses' office (71.8%). Similarly, 78.1% of breast care nurses pinpointed a 'specialised fitting room in breast care unit' as the location of choice for the fitting of the temporary prosthesis.

First Silicone Prosthesis

- 62.1% of women reported that they were fitted for their first silicone prosthesis in a hospital setting, whereas 18.8% were fitted in a specialised prosthesis supplier.
- Women were generally satisfied with the environment within which they were fitted for their first silicone prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (32.5%), display of products (27.0%), choice of products (25.6%) and space (22.6%).
- Women fitted with their first silicone prosthesis in a hospital were more satisfied with the privacy of the fitting environment than women fitted in a specialised prosthesis supplier.
- 51.4% and 24.8% of women indicated their preferred location for the fitting of the first silicone prosthesis as being the hospital and a specialised prosthesis supplier, respectively. Some 77.4% of breast care nurses indicated that their preferred location for the fitting of the first silicone prosthesis was the hospital whereas 25% of retail prosthesis fitters identified a specialised prosthesis supplier as their chosen location for the fitting of a first silicone prosthesis.

Replacement Prosthesis

- The most common fitting environments for replacement prostheses, as reported by the women, were the hospital (46.1%) and the specialised prosthesis supplier (32.0%).
- Women were generally satisfied with the environment within which they were fitted for their replacement prosthesis. However, a sizeable proportion expressed dissatisfaction with the availability of brochures (24.0%), display of products (22.4%), choice of products (23.0%) and time available (18.5%).
- At the fitting for a replacement prosthesis, women who were fitted in a specialised prosthesis supplier expressed greater satisfaction with space, display of products, choice of products and brochures than women who were fitted in the hospital environment for the replacement prosthesis.
- 37.6% and 31.6% of women identified the hospital and the specialised prosthesis supplier as their preferred locations for the fitting of the replacement prosthesis. Some 42.3% and 27.3% of breast care nurses and prosthesis fitters identified the specialised prosthesis supplier as their preferred location for the fitting of the replacement prosthesis.

Overall Comment on Fitting Environment

- Women were dissatisfied with the display of products, choice of products and brochure availability across all different stages of fitting. While the hospital is the preferred environment during the earlier stages of fitting, there is a shift towards an increased preference for and attendance at the specialised prosthesis supplier as the woman becomes more accustomed to wearing an external breast prosthesis and replacing her prostheses.

CHARACTERISTICS OF THE PERSON FITTING THE PROSTHESIS

Temporary Soft Prosthesis

- The majority of women (68.0%) were fitted with their temporary soft prosthesis by a breast care nurse.
- Women were consistently and significantly more satisfied with the characteristics of the person who fitted them with a temporary soft prosthesis if that person was a breast care nurse or trained fitter.
- The majority of both the women (71.8%) and breast care nurses (93.1%) indicated that their preferred person to fit the temporary soft prosthesis was the breast care nurse.

First Silicone Prosthesis

- 59.7% and 29.9% of women were fitted with their first silicone prosthesis by a breast care nurse and trained fitter, respectively.
- Overall women were satisfied with the characteristics of the person fitting their first silicone prosthesis. However, 10.3% and 10.5% of women indicated a level of dissatisfaction with the time available and emotional support given by the person fitting the first silicone prosthesis.
- 58.1% and 35.3% of women identified their *preferred person to fit the first silicone prosthesis* to be the breast care nurse and trained fitter respectively. Breast care nurses and commercial/retail fitters identified themselves as the ideal people to fit the first silicone prosthesis.

Replacement Prosthesis

- 42.5% and 41.0% of women were fitted with their replacement prosthesis by a trained fitter and breast care nurse, respectively.
- Overall women appeared satisfied with the characteristics of the person fitting their replacement prosthesis. However, women indicated a level of dissatisfaction with time available (10.5%) and emotional support (8.5%) given by the person fitting the replacement prosthesis.
- There were no significant differences in women's satisfaction with the characteristics of the person fitting the replacement prosthesis between women fitted by a breast care nurse and women fitted by a trained prosthesis fitter.
- The majority of women (52.1%), breast care nurses (53.5%) and prosthesis fitters (72.7%) identified a trained fitter as the ideal person to fit the replacement prosthesis.

Overall Comment on Fitter Characteristics

- Over all time periods, women expressed a consistent level of dissatisfaction with the emotional support given by the person fitting the prosthesis and the time available to the women. Furthermore over time, it is evident that an increasing number of women are fitted with their prostheses by a trained fitter and the gap in satisfaction ratings between the trained fitter and breast care nurse is reduced. In addition, while there is a clear desire to be fitted by a breast care nurse in the early stages, there is a clear preference for the replacement prostheses to be fitted by a trained fitter.

Mastectomy Bras

- The majority of women, who consider the purchase or availability of mastectomy bra products to be relevant to them, are dissatisfied with the availability of mastectomy bra products.
- 16.2% of women highlighted an overall dissatisfaction with mastectomy bras. In particular, dissatisfaction is expressed about the choice of bra styles (32.4%) and colour (32.7), value for money (22.4%) and appearance (20.0%).
- 41.8%, 22.4% and 18.2% of women were fitted for their bra in a hospital, lingerie shop/department store, and specialised prosthesis supplier, respectively.
- Women expressed a greater level of satisfaction with the characteristics of the person fitting the bra when fitted by either a breast care nurse and/or trained fitter than when fitted by a sales assistant.
- While the majority of women were satisfied with aspects of the environment where they were fitted for their mastectomy bras, approximately one in four women were dissatisfied with the availability of brochures, display of products and choice of products.

Other Fitting Issues

- Respondents to the breast care nurse questionnaire were particularly dissatisfied with the space (45.2%), display of products (36.7) and storage area for products (58.1%) in their fitting environment. This endorses the women's dissatisfaction with similar aspects of the fitting environment. However, while a sizable proportion of women (24%) indicated dissatisfaction with brochure availability, breast care nurses and prosthesis fitters did not.
- 75% of breast care nurses did not think that there were sufficient staff employed to meet the number of fittings required.
- 51.6%, 90.9% and 33.3% of breast care nurses, commercial/retail prosthesis fitters and bra fitters respectively consider that the *choice of products* available on the market satisfactorily meets the women's demands.
- 62.1%, 50% and 80% of breast care nurses, commercial/retail prosthesis fitters and bra fitters respectively reported that there were products not on the market that there was a demand for.
- When women were asked if they had a *choice of where to go* to get fitted for a prosthesis, 28.1% said they had, 36.0% said they had no choice, and 35.8% did not know. Despite only a minority

indicating that they had a choice, 68.8% of women indicated that having a choice of fitting centres was important or extremely important.

- 26.4% of women indicated that *travel distance* to the fitting centre limited their ability to avail of replacing a prosthesis.

Waiting Times

- The average length of time between making the *appointment* and being fitted was 2.4 weeks (SD 2.6) (range 0.2-30 weeks)
- 72.4% of women indicated that their first silicone prosthesis was available on the day of fitting, 27.6% reported that it was not. For those women who did not receive it on the day of fitting, the average wait was 4.5 weeks (SD 4.2), range 0.5-25 weeks.
- 41.1% of women reported that their replacement prosthesis was not available on the day of fitting. For these women, the average wait was 22.3 days (SD 13.89), range 4-84 days.
- 80.1% of women indicate that they get fitted each time they get a new prosthesis. Some 53.8% and 81.8% of breast care nurses and commercial/retail prosthesis fitters respectively report that in their experience women are always refitted prior to receiving replacement prostheses.
- 16.3% of women, who had not replaced a prosthesis, had had the same prosthesis for more than 4 years, despite recommendations that a replacement is advisable every 2 years. The average time specified for replacing the prosthesis was 2.3 years (SD 1.5) (Range 0.5-12 years).
- 48.5% of women indicated that their bra was available on the day of fitting/purchase; 51.5% reported that the bra was not available on the day of fitting/purchase. For those women who indicated that the bra was not available, the average waiting time for receipt of the bra was 21.1 days (SD 13.3) with a range of 3-84 days.

Cost

- 35% of women who had replaced their prosthesis received it free of charge.
- 2.9% of women who receive their replacement free of charge do not have health insurance or a medical card. Conversely, there are approximately 16.3% of women who indicated that they have a medical card and do not get their replacement prosthesis free of charge.
- The average cost for each prosthesis bought was €125.4 (SD 53.4) (range €15-€300). Some 43.3% of women who were paying for their prosthesis indicated that the cost of the prosthesis influenced when they replaced it.
- The average cost of each bra bought was €38.6 (SD 15.8) (Range €5-150).
- 48.3% of women indicated that the cost of the mastectomy bra influenced when they replaced it.
- The average cost of a mastectomy-pocketed swimsuit was €77.4 (SD 27.49) (range €5-150).
- All commercial/retail fitters contract directly with the insurance companies; 91.7% (n=11) accept the medical card. Of these, 81.8% process the claim on the client's behalf. None of the bra fitters contract with the insurance companies nor do they accept the medical card.

Information Needs & Provision

- 46.0% of women indicated that they had not received information on prostheses and bras.
- One in three women were dissatisfied with the information they received on entitlements. Approximately one in four women were dissatisfied with the information they had received on cost of prostheses, types of bras, costs of bras, mastectomy swimwear, and location of fitters.
- The top three preferred ways of receiving information on prostheses and bras are (1) face-to-face meeting with breast care nurse; (2) information booklet; and (3) other women with experience of breast cancer or from the retail fitter, both of which had similar mean rankings.

Adjustment

- On average the cohort of women in this sample have good quality of life and a low number of arm and breast symptoms.
- Women who had replaced their prosthesis but did not receive it free of charge and who indicated that cost influenced when they replaced it had significantly lower scores in each of the quality of life domains than woman who said that cost did not influence when they replaced their prosthesis.
- Higher levels of satisfaction with aspects of the external breast prosthesis were associated with higher quality of life scores in each of the WHOQOLBREF domains (i.e. physical health, psychological, social relationships and environment) and fewer breast and arm symptoms.

Professional Development

- 69% of breast care nurses and 33% of commercial/retail prosthesis indicated that there was insufficient opportunity for professional development in the field of prosthesis fitting. Forty percent of bra fitters considered that there was insufficient opportunity for professional development in the field of mastectomy bra fitting.

Standards of Care

- The majority of services had a follow-up service for issues related to fitting and also a follow-up service for complaints. However, these were localised follow-up services.
- While nurses are bound by their professional code of conduct, there are no national or external service guidelines and protocols for commercial/retail prosthesis fitters or bra fitters.

Chapter 5

Conclusions & Recommendations

This research set out to investigate the provision, fitting, supply and use of external breast prostheses in Ireland. In so doing, it involved asking women about this aspect of their post-mastectomy care using both focus groups and survey methods. In order to incorporate service providers' perspectives, the perceptions of breast care nurses, retail fitters and bra fitters were also elicited using survey methods. The findings yielded a rich tapestry of information concerning patterns of prosthesis use, perceptions of the importance of the prosthesis, levels of satisfaction with the prosthesis and mastectomy bras, and quality of life issues. In addition, it provided a valuable insight into the fitting of temporary, first silicone, and replacement prostheses including product availability, choice, cost, and waiting times. The importance of the characteristics of the person fitting the prosthesis was also identified. Furthermore, this research was instrumental in highlighting women's information needs regarding external breast prostheses and the preferred channels for the communication of this information. At a broader level, the need for professional development, notably training opportunities, for those involved in the provision, fitting and supply of breast prostheses and mastectomy bras was emphasised. Finally, the absence of national or service guidelines and protocols for commercial/retail fitters was noted.

This research builds upon the limited but growing extant international literature on women's experiences of external breast prostheses. The findings coincide with the existing research, in particular, reports of dissatisfaction with the weight of external breast prostheses, the importance of fitter characteristics, for example, attitude and training, and the importance of choice, cost and adequate and appropriately timed information. This suggests that internationally there are similar issues for women with regard to external breast prostheses. Furthermore, this research contributes new insights that take account of the temporary, first silicone, and replacement prosthesis fitting needs. In addition, it explicitly addresses quality of life issues, a relatively unexplored area in the literature to date.

Most importantly, this research and its associated findings are pioneering in the Irish context. While anecdotal evidence of women's experiences of breast prostheses existed, the present study marks the first formal investigation and report and provides a rigorous evidence base and empirical insight into the experiences of women in Ireland with an external breast prosthesis. This research contributes to a person-centred and responsive system as outlined in the Health Strategy (2001). In particular, it recognised that women are experts on their own experiences of the provision, fitting, supply and use of external breast prostheses and the fact that women's views are strongly represented along with the other principal stakeholders, notably breast care nurses, retail fitters and bra fitters, enhances the

validity and breadth of the research. Moreover, this ensures that the findings are well placed to make meaningful recommendations for policy and practice. There are currently positive aspects in women's experiences in the provision, supply and fitting of breast prostheses, with many women giving favourable reports of the fitting environment and their relationship with the person fitting the prosthesis. However, there are also clear inadequacies and it is these that have informed the following recommendations.

1. Develop protocols, standards, and best practice guidelines in the provision, fitting, and supply of external breast prostheses for women in Ireland as a matter of expediency.
2. Make available professional development opportunities for those fitting external breast prostheses that augment existing expertise and where necessary, the capacity to provide emotional support.
3. Establish a standardised complaints/satisfaction procedure in order to further develop the service.
4. Provide optimal fitting environments that incorporate:
    - a display and choice of products, and brochures of same;
    - sufficient time to peruse and fit products;
    - adequate privacy and space;
    - good lighting and ventilation;
    - available mirrors.
5. Develop and expand fitting options in supportive environments in a range of geographical locations. Women need to be given a choice in where they are fitted with their prosthesis and by whom, recognising that breast care nurses may be the most appropriate in the early stages post-mastectomy with retail fitters becoming more so as time progresses.
6. Disseminate information on the types and costs of prostheses, locations of fitting centres, entitlements, and available supports using multiple formats including brochures, face-to-face meetings with breast care nurses and fitters, roadshows and mailshots, across multiple time periods including before and after surgery and at replacement prosthesis fitting. Readily available information stimulates self-help and informed choice. Women must be made aware of their entitlements and know how to access the services they require.
7. Develop a buyer's specification for the range of prostheses and post-mastectomy products that should be supplied.
8. Address equity in the provision of breast prosthesis services throughout the country. All suitable products should be available to all women in all parts of the country. Products should be available to all women in a timely fashion and there should be equitable costs and expenses nationwide.

9. Lobby the Government to ensure financial protection in the purchase of breast prostheses and mastectomy bras.
10. Monitor and re-evaluate women's experiences as services develop and change.
11. Incorporate this research and its findings into future health policy and strategies at national, regional and local levels.

To conclude, it is imperative that the empirical evidence base and recommendations made are used by policy makers and practitioners to facilitate women's experiences in relation to external breast prostheses.

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Appendix

Sample Characteristics of Focus Group Participants					
I.D.	**County**	**Age**	**Type of prosthesis**	**Years diagnosed**	**Source**
FG1 (n=10)					
1	Dublin	66	Single	20	Support/advocacy organisation
2	Dublin	75	Single	32	Follow-up Breast Clinic
3	Dublin	52	ns	1.5	Follow-up Breast Clinic
4	Dublin	74	ns	1	Follow-up Breast Clinic
5	Dublin	52	Single	1.2	Follow-up Breast Clinic
7	Dublin	76	Single	1.5	Follow-up Breast Clinic
8	Kildare	43	Single	2	Follow-up Breast Clinic
9	Kildare	80	ns	1	Follow-up Breast Clinic
10	Dublin	ns	Single (L) + reconstruction(R)	15	Support/advocacy organisation
11	Dublin	60	Double	15	Support/advocacy organisation
FG2 (n=10)					
12	Cork	49	Single	3	Follow-up Breast Clinic
13	Cork	53	Single	5	Follow-up Breast Clinic
14	Cork	55	Single	1	Follow-up Breast Clinic
15	Cork	68	Single	27	Follow-up Breast Clinic
16	Cork	62	ns	15	Support/advocacy organisation
17	Cork	66	ns	3	Follow-up Breast Clinic
18	Kerry	57	Single	3	Follow-up Breast Clinic
19	Cork	56	Single	2	Follow-up Breast Clinic
20	Cork	55	Single	4	Follow-up Breast Clinic
21	Cork	67	Single	2	Follow-up Breast Clinic
FG3 (n=6)					
22	Dublin	ns	Single	11	Support/advocacy organisation
23	Dublin	53	Single	2	Follow-up Breast Clinic
24	Dublin	58	Single	9	Support/advocacy organisation
25	Wicklow	63	Single	14	Support/advocacy organisation
26	Dublin	ns	Single	4.5	Support/advocacy organisation
27	Dublin	ns	Single	4.5	Support/advocacy organisation
FG4 (n=9)					
28	Clare	49	Single	2	Follow-up Breast Clinic
29	Galway	ns	Single	5	Follow-up Breast Clinic
30	Galway	41	Single	1	Follow-up Breast Clinic
31	Mayo	ns	Single	3	Follow-up Breast Clinic
32	Galway	64	ns	3	Follow-up Breast Clinic
33	Galway	55	Single	2.5	Follow-up Breast Clinic
34	Clare	ns	Double	20 (1 yr 2nd)	Follow-up Breast Clinic
35	Galway	59	Single	18	Support/advocacy organisation
36	Galway	45	Single	9	Support/advocacy organisation
FG5 (n=12)					
37	Donegal	42	Single	7	Follow-up Breast Clinic
38	Donegal	38	Single	9	Follow-up Breast Clinic
39	Donegal	50	Single	17	Follow-up Breast Clinic
40	Donegal	61	Single	5.5	Follow-up Breast Clinic
41	Donegal	64	Single	20	Follow-up Breast Clinic
42	Donegal	42	Single	5	Follow-up Breast Clinic
43	Donegal	ns	Single	7	Support/advocacy organisation
44	Donegal	57	Double	7	Follow-up Breast Clinic
45	Donegal	76	Single	6	Follow-up Breast Clinic
46	Donegal	64	Single	15	Follow-up Breast Clinic
47	Donegal	45	Single	8	Follow-up Breast Clinic
48	Donegal	64	Double	10	Follow-up Breast Clinic

*ns = not specified