



An evaluation of the **Primary (early) breast cancer resource pack** (2008 edition)

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Background and introduction

It is well understood that high-quality information, available at the appropriate time and individually tailored, is essential for any cancer patient. In addition, empowering patients to understand their diagnosis and treatment, and make choices that will lead to the best possible outcomes, is central to government health strategies such as patient involvement in decision making and access to personalised information (DoH, 2007).

The **Primary (early) breast cancer resource pack** aims to provide patients with an individualised resource, at the time of diagnosis, which can be built up to become a useful tool throughout treatment and beyond. Inside an unbranded blue plastic folder, an A5 ringbound booklet contains several sections covering information on breast cancer, types of treatments, best treatment guidelines, contact details and further sources of support. Uniquely, every section suggests key questions patients might want to ask their healthcare providers and has space for them to make notes. Additionally packs have a pen and clear plastic wallet to store additional information such as appointment cards, letters, local details, other booklets and so on.

The pack allows people to collate all the information they gather in one place, so that it becomes a resource that can be added to according to each individual's needs.

The original edition of the **Primary (early) breast cancer resource pack** was designed with the intention to provide patients with tailored information enabling them to better understand their diagnosis and their disease, as well as their test results and treatment options, while storing local and personal information specific to their own situation. It was also intended to be a valuable resource for healthcare professionals, assisting multi-disciplinary teams to help patients understand primary breast cancer diagnosis, test results and treatment options and also to store local and personal information specific to each person.

Initial market research with patients, breast care nurses, oncologists and surgeons demonstrated significant demand for such a resource. Following this, the pack was piloted for four months in six hospitals across the UK from April to July 2006. The evaluation showed that the packs were very well received, with exceptionally high levels of satisfaction reported among patients and healthcare professionals. Subsequently these packs have been available free to patients and healthcare professionals since January 2007¹.

In order to monitor and evaluate the impact and effectiveness of services to both inform and develop both new and existing services, the Publications team requested the Research and Evaluation team undertake an evaluation of the usefulness and acceptability of this Primary Breast Cancer Resource Pack, among both patients and healthcare professionals.

The Primary (early) breast cancer resource pack

¹ Mags A., Emma P, Patient Resource Pack: an evaluation of the pilot project, Breast Cancer Care Sept 2006

The ringbound section of the resource pack is divided in six modules to include a range of information and/or space to allow participants to record personal details/information related to their care, tests and treatments, as well as anything they feel important to keep in writing:

- 'Personal details' provides space for participants to record their personal information around their medical care providers and any relevant personal data
- 'About breast cancer' gives a general introduction about breast cancer
- 'Deciding on treatment' explains how the treatment decisions are made, and how tests are being used to inform such a decision
- 'Treatment options' gives an introduction of current available treatments and how to keep well post-treatment
- 'Word list' provides a glossary of breast cancer terminology
- 'Finding out more' provides a useful list of further information and support
- 'Questions you want to ask' runs throughout the pack as an ensuing element to each of the modules, after key questions participants might want to ask their healthcare providers are suggested.

Methods

This evaluation used a mixed method approach, combining quantitative and qualitative data, with the aim of seeking the views of patients through a written questionnaire (included with each of the **Primary (early) breast cancer resource packs**) and semi-structured telephone interviews to a selected subsample. The initial methodology also included a further stage to conduct semi-structured telephone interviews with a range of healthcare professionals to include their perspective. This was not further pursued and reasons for this are explained later in the report.

The **Primary (early) breast cancer resource pack** questionnaire

Alongside the information leaflets and the ringbound booklet, the **Primary (early) breast cancer resource pack** included an evaluation questionnaire which patients could complete and post back to Breast Cancer Care. This questionnaire aimed to evaluate i) how and when the pack was received, ii) to what extent they felt that the pack was empowering and iii) how satisfied they were with the content. They were also asked whether they felt that anything was missing from the pack by writing additional comments in the blank space provided.

The patient telephone interviews

A subsample was recruited from those who had returned a completed questionnaire (n=172). All participants agreed to take part in up to four quarterly telephone interviews for a maximum period of 12 months. These telephone interviews further explored whether the pack had been used in the intervening period², when the pack was used and whether (or what) other resources had been used throughout this period.

² The first interview looked at the period from the moment they had received the pack, and subsequent interviews focussed on the period since the last meeting.

The profile questionnaire included questions related to socio-demographics data such as gender, home postcode, age, ethnic background, employment status and professional occupation as well as breast cancer diagnosis and disability (see 'Appendix three').

The interviews were conducted using a topic guide which sought to investigate patterns of use and the times at which the pack was used (for example at what stage and in which instances) and found most beneficial, as well as whether any other resources had been used in the intervening period.

The healthcare professional telephone interviews

A list of healthcare professionals who had ordered publications in the past was provided by the Breast Cancer Care Publications team. Healthcare professionals including nurses, oncologists and GPs were contacted with an invitation to take part in the study with the aim to find out the healthcare perspective on the adequacy and usefulness of the pack to their patients.

Sample

In total, 172 questionnaires were analysed over a six month period (December 2009 – May 2010). Out of these respondents, twenty participants (n=20) were recruited to take part in the telephone interviews.

Eligibility criteria for this subset of participants were as follows: participants within three months post diagnosis of primary breast cancer who had received the pack for the first time. Informed consent was obtained from all participants, and a further profile questionnaire was sent to them.

Although the initial plan was to interview participants four times over a period of 12 months to identify patterns of use (ongoing or discontinued), evaluating the 'non-use' of the pack proved challenging. All of the twenty recruited participants expressed the wish to withdraw after the second telephone interview. The majority of the participants gave reasons for withdrawal including (1) not wishing to talk further about their breast cancer for emotional reasons, (2) not having anything further to share due to no longer using the pack for some time (3) and the pack not meeting their needs because they had progressed through their treatment. As a result of this:

- five participants (n=5) were interviewed once
- fifteen of them took part in two telephone interviews over a period of eight months (n=15)
- none of the participants took part in telephone interviews beyond this period (n=0).

In total 86 healthcare professionals were emailed with an introduction to the study and an invitation to be contacted at a convenient time of their choosing. Despite numerous email contacts, the feasibility and practicalities of including a healthcare professional focussed evaluation proved unsuccessful, due to lack of response, out of date email addresses with staff no longer being employed at the contacted organisation and unanswered emails. Challenges were further compounded by a change of internal priorities within the Research and Evaluation team such that the team were unable to dedicate sufficient time to this aspect of the project. For these reasons, the decision was made to remove this element from the study design.

All quantitative data was analysed using SPSS 17.0, quantitative data analysis software. All additional comments were analysed using a content analysis approach. Qualitative semi-structured interviews were analysed using a thematic framework approach.

Findings

I – The Primary (early) breast cancer resource pack questionnaire

The questionnaire included a series of questions to find out the views of the resource pack users, and more particularly how they rated the content of the pack and whether this publication met its intended aims and objectives.

Accessing the information

Participants received a list of options to tick as highlighted below. The majority of participants (88%) obtained their pack through a Breast Care Nurse, while the remaining received it from other NHS healthcare professionals, including oncologists (4%) and surgeons (2%) or ordered it directly through Breast Cancer Care. Under the category of 'Others', 4% of participants cited Macmillan Nurse (n=4) and friends (n=2).

Figure 1: How did you get your Primary (early) breast cancer resource pack?

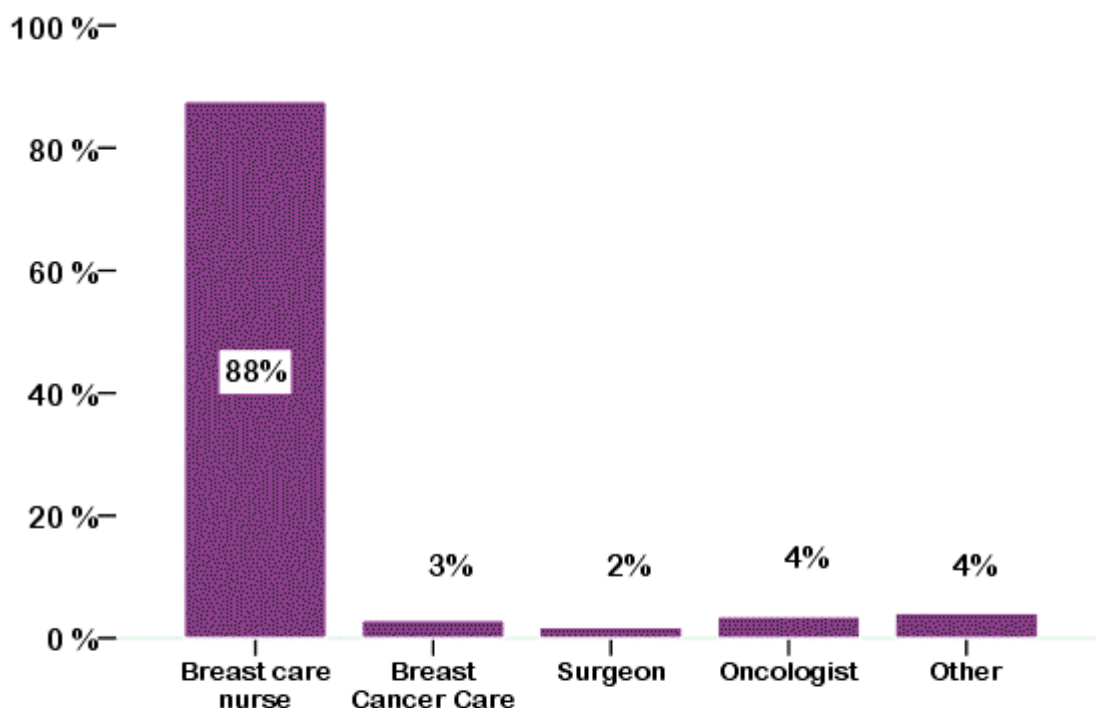
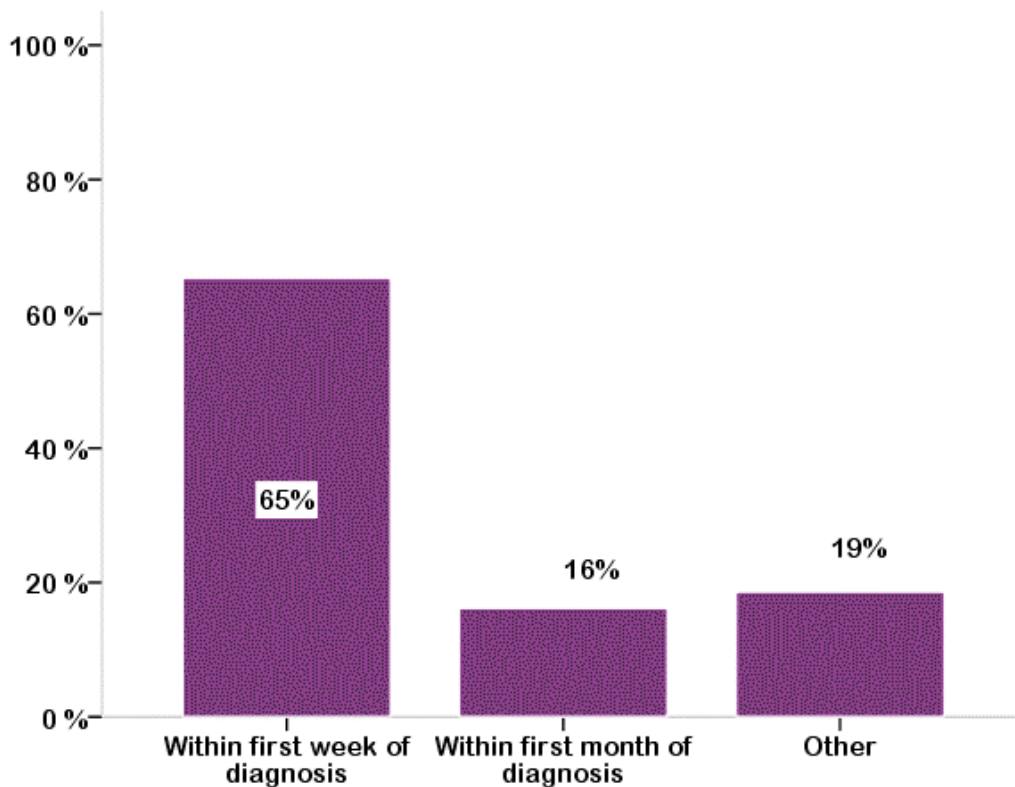


Figure 2: When did you get your pack?



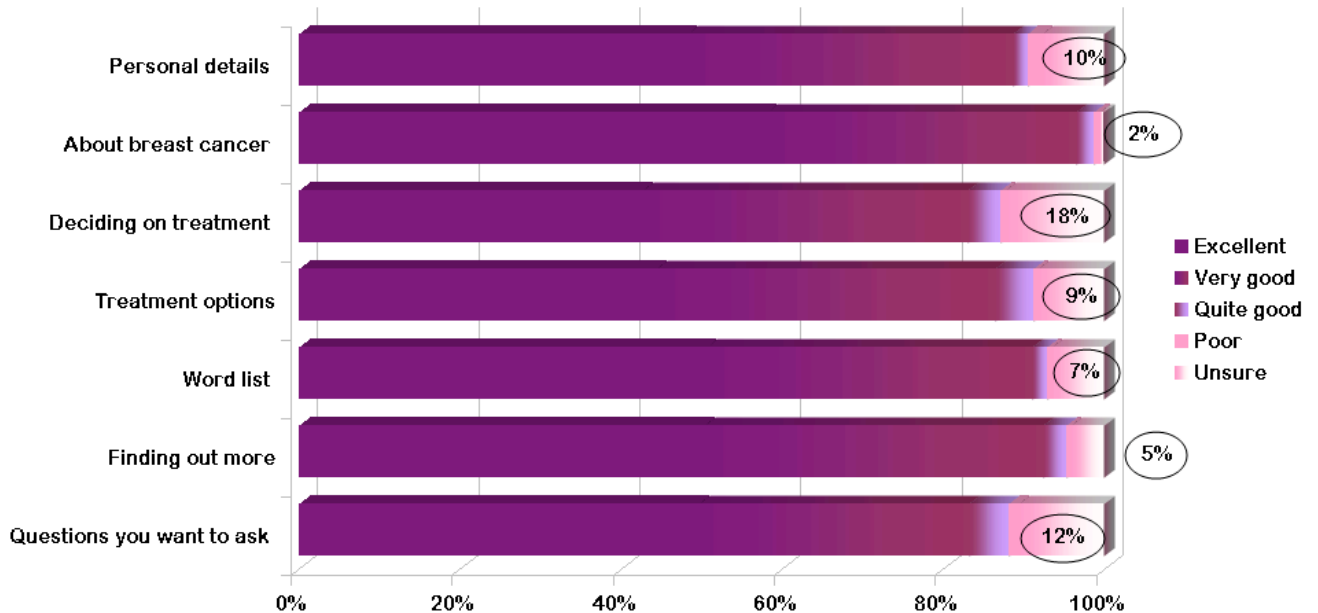
The majority of participants received their pack within the first week, while many others received it within a month (16%). For the 19% of participants who ticked the 'other' category, this varied up to a year post operation/diagnosis.

Not surprisingly, there is strong relationship between the person who provided the pack and when it was received. Correlation between these two variables ($r=.37$) indicates that participants who received their pack from a breast care nurse tended to receive their pack within the first week with some participants citing having received it as soon as they were diagnosed – reflecting the crucial role that breast care nurses play in providing patient information early in the care pathway.

Content

Participants were asked to rate each of the sections contained in the resource pack using a five-point descriptor scale ranging from excellent, very good, quite good, poor and unsure.

Figure 3: Please tell us what you think about the content of each section of the pack....



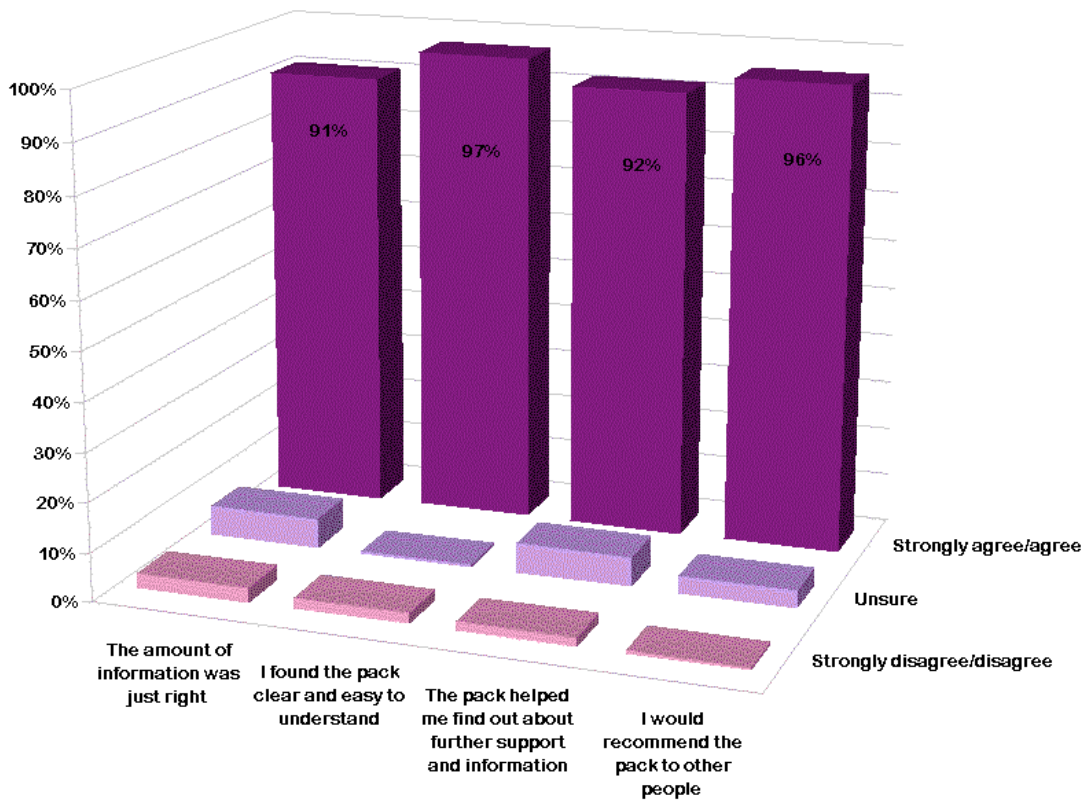
Each section achieved high levels of satisfaction from the respondents and all were mostly rated positively (excellent/very to quite good):

- 99% of respondents felt that the section ‘About breast cancer’ was excellent/very good to quite good
- 98% of respondents felt that the ‘Word list’ was excellent/very good to quite good
- 95% of respondents felt that the module ‘Finding out more’ was excellent/very good to quite good
- 91% of respondents felt that the sections ‘Treatment options’ and ‘Personal details’ were of high or good enough quality
- 88% of respondents felt that the sections titled ‘Questions you want to ask’ were excellent/very good to quite good
- 82% of respondents felt that the section ‘Deciding on treatment’ was excellent/very good to quite good.

While all of the listed modules and section rated very highly, levels of dissatisfaction/indecision about the quality or usefulness of the content of the pack were subject to more or less noticeable variations.

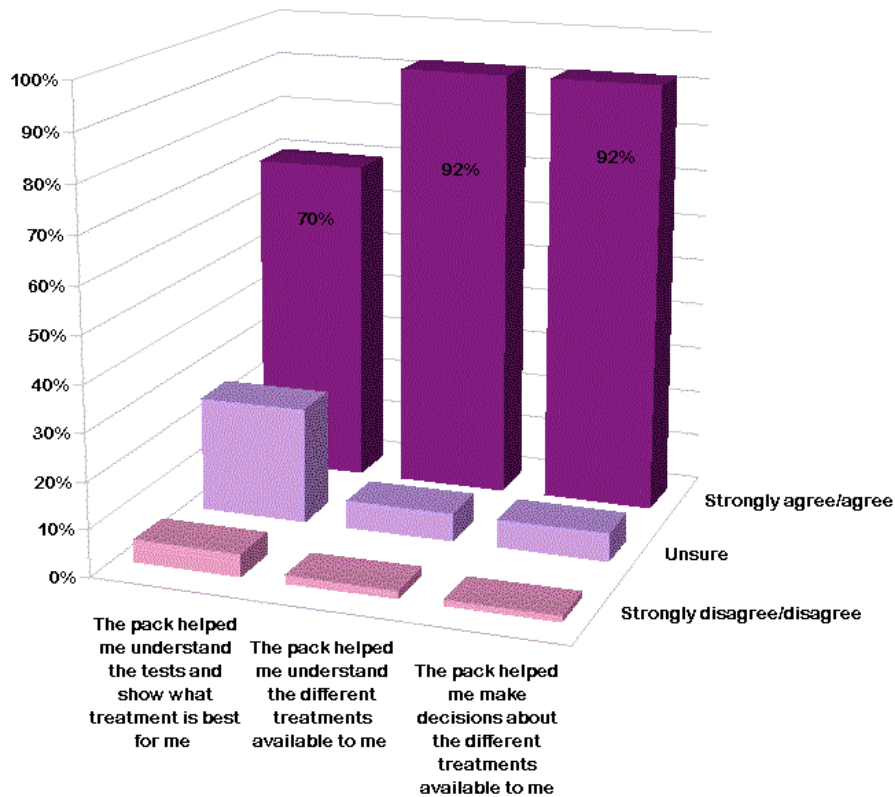
Satisfaction and Outcomes

Figure 4: Overall satisfaction



97% of respondents found that the pack was clear and easy to understand, 92% felt that the pack helped them find out where they could find further information and 91% felt that the pack provided just the right amount of information. Overall, 96% of respondents felt that they would recommend the pack to other people with breast cancer – confirming how well the **Primary (early) breast cancer resource pack** is received by participants and their high level of satisfaction, suggesting that the pack is meeting most of their needs in the early stages of diagnosis.

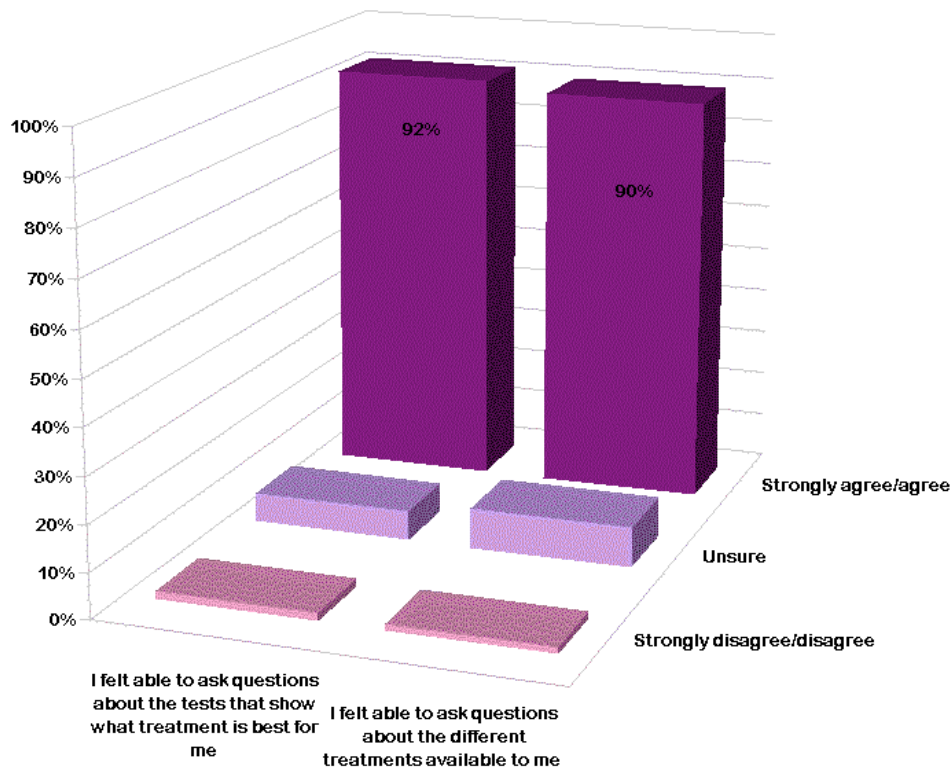
Figure 5: The pack helped me...



92% of respondents agreed that the pack generally helped them understand the tests and the different treatments available which may be best for them. However, figures showed slightly less consensus when asking specifically about whether the pack helped participants to make decisions about these different treatments available to them, with 69% of participants agreeing to this statement.

The above figures show that while the pack is helpful in promoting greater understanding of tests and treatments, there is a greater degree of uncertainty with regards to enabling decision making (25% of participants feeling unsure).

Figure 6: After reading the pack, I felt able to...

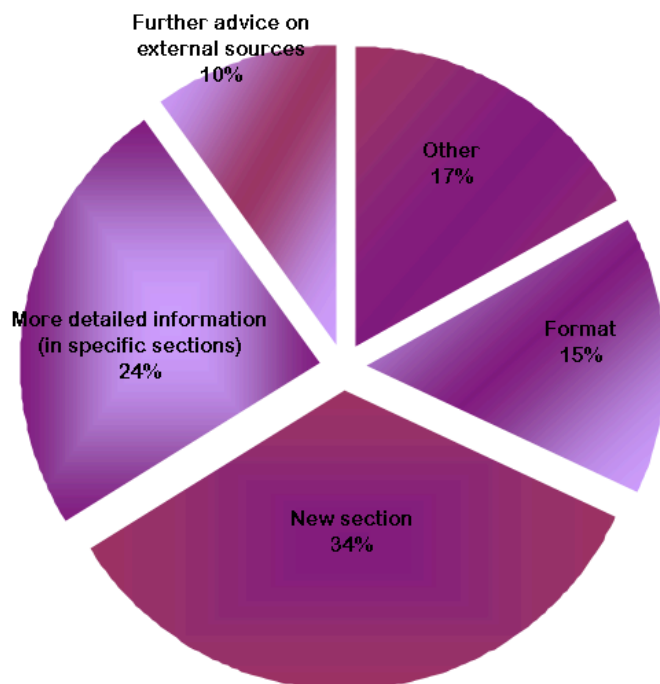


Respectively, 90% and 92% of respondents agreed or strongly agreed that the pack had enabled them to ask questions to their healthcare professionals about tests and understand the different treatments. This finding would suggest that a key outcome of the primary breast cancer resource pack is about enabling patients to make informed decisions.

Suggested improvements

41% (n=70) of respondents who responded to the questionnaire felt that the pack could be improved by including further information. A text box was provided to participants in order to suggest any content or format improvements they felt were useful.

Figure 7: Suggested improvements (n=70)



New section/information

Another 24% of respondents (n=41) who made suggestions for improvements in the pack mentioned missing items. The following additions by way of new sections, inserts or additional information within existing modules were suggested:

- **A diary section** – This was the most common comment. Having a diary section at the end may be useful for participants who use it to write down their thoughts on, and experiences of, their journey through breast cancer. The note sections were generally found useful but too short. Also, some people reported the impracticalities of having to flick back and forth to find the information. Having an additional notes section at the end would allow people to use this section flexibly to record any information of their choosing (for example, absences from work, prescriptions, existing medical conditions and so on).
- **Testimonials** – participants felt that including views and quotes of ‘survivors’ who had undergone treatments would help to manage expectations, fears and convey messages of hope and positivity.
- **Practical and financial help during and after treatment** – more information around the financial implications of breast cancer treatment was requested (for example, travel expenses, car parking costs, and guidelines around free prescriptions and how to request them (via GP/HCP))
- **Further medical facts on cancer itself as a disease** – some participants felt that more was needed on cancer and its mechanism more generally (for example, what is known about it, more details about the way it spreads and so on).
- **Information on medication and other procedures used for better care management** – participants felt that treatment was one aspect of their care, but that they would also benefit to

know about the pros and cons of commonly prescribed medications and their side effects (one participant suggested Neulasta as an example), as well as generally recommended procedures (such as breast reduction).

More detailed information

More than a third of respondents (n=20) who felt that improvements were needed thought that while the information provided was excellent, they could benefit from receiving further details. The following suggestions were made.

- **After treatment and recovery** – in order to keep a sense of control, participants felt they needed more information about what happens during the recovery process. For example, how long it will take, what can happen, how poorly one can feel after treatment, whether help is needed and how to get assistance if needed, and what help and support is available, how long does it take before one can return to work?
- **More information on the different types of breast cancer** - even though the resource pack contains the section 'What is breast cancer?', some participants felt that more details on explaining the different types of diagnosis could be included.
- **More information about how to talk to children and family** – having to tell family and friends is also part of dealing with the diagnosis. Some participants felt that the information contained in the booklet **In it together** could be added to the pack.
- **Getting peer support in every way, not just via the internet** – Some participants felt that a lot of emphasis was put on signposting to peer support on the online forums – disregarding the fact that some people may not want to use computers. Including other ways of getting in touch with people with breast cancer face-to-face and by phone would be useful and more inclusive.

Format

A few comments (n=6) regarding the format of the pack were received. Most of them were about how to make it more user-friendly and practical to use.

- **Separation tabs** – some participants suggesting separation tabs in between the different modules for quicker access.
- **A zip up pouch rather than a folder** – this format was suggested as being more user-friendly and flexible, especially for people who find it hard to manipulate the folder.
- **Other languages and cultural awareness** – having a summary of each section in different languages would enable people whose first language is not English to better grasp the concepts and terminology. The glossary was suggested as an obvious resource to be translated.

Further advice on external sources

- **More local information** – some participants felt that the pack should contain more information on where to find details of local support groups and information centres.
- **Practical services addressing body image issues** – mirroring the request for more practical information, some participants would have wanted to find more details of which organisations to contact for help with maintaining their appearance during treatment (for example wigs, scarves, lingerie suppliers and so on).

II – The interviews

Participants' characteristics

Overall, 20 participants were interviewed over a period of eight months. The majority of them were interviewed twice at four monthly intervals. Five participants withdrew after the first interview and were therefore interviewed only once. All the participants were female; the majority were from White/White British background. Only two participants were of Asian or Mixed background. Two participants disclosed having long term disability (aside of breast cancer).

Table 1: Age range

Age		
	Number	%
20–30	1	5
41–50	4	20
51–60	11	55
61–70	4	20
Total	20	100

Most of the participants were employed either full time or part time (n=14) while four of them were not in current employment (unemployed, retired, homemaker, other). Two participants did not give information about their employment status. Table 2 shows a breakdown of the current or former occupation of participants.

Table 2: Occupation

Occupation		
	Number	%
Modern professional occupations	6	43
Clerical and intermediate occupations	2	14
Semi-routine manual and service occupations	2	14
Routine manual and service occupations	1	7.5
Middle or junior managers	2	14
Additional professional occupations	1	7.5
Unknown	6	
Total	20	

The selected subsample included a diversity of diagnosis and all major diagnostics of breast cancer were represented. Seven participants were diagnosed with invasive breast cancer (44%), four of them were diagnosed with ductal carcinoma in situ (DCIS) and four diagnosed with both DCIS and invasive breast cancer. One participant was diagnosed with lobular carcinoma in situ (LCIS), and four participants did not provide their diagnostic information.

Table 3: Breast cancer diagnosis

Breast cancer diagnosis		
	Number	%
DCIS	4	25
Invasive	7	44
DCIS and Invasive	4	25
LCIS	1	6
Unknown	4	
Total	20	

Content and breadth of information

The resource pack was seen as a lifeline, gently guiding the patient from the diagnosis through to the treatment trail. All the participants felt that the pack had been particularly successful in easing them progressively through these stages. Most commented on how the pack provided the right amount of information, at the right time (provided they had received the pack early on after their diagnosis) and how they had 'dipped in and out' of the pack.

Although the pack was seen as a very valuable resource, interviewees commented on the sense of information overload associated with receiving the primary breast cancer resource pack. Having numerous leaflets providing medical information (for example treatment, drugs and side effects) and general information (such as practical and emotional support) early on was felt to be daunting and, for some, triggered feelings of anxiety. Some participants found the content so overwhelming that they only 'skim read' to escape the information overload.

While acknowledging that the leaflets needed to provide more local information, there was a general feeling that the medical information could be – to a certain extent – included in the resource pack. Providing as many details as possible within the ringbound booklet would minimise the number of additional information leaflets included in the blue folder and would ensure that the most essential information was contained in one single resource. Some participants saw this as 'going one step further', an additional refinement on what most saw to be an already very successful information resource. In particular, further information was sought around:

- drugs commonly used during treatment
- the recovery process after treatment
- diet and exercise

- dealing with breast cancer at work
- financial and practical help.

Provided it remained within the current tone of the leaflet –described as ‘plain English’, ‘not overtly medical’, continuing participants felt that this additional type of information would help them pace themselves through their journey and retain some form of control by preparing (or getting a sense of) what was coming and finding reassurance in their acquired knowledge³.

Participants and the **Primary (early) breast cancer resource pack**: Patterns of use

It was apparent from the interviews that participants had stopped using the pack beyond the treatment stage despite wanting to know what could/would happen after treatment and how to manage the disease in the long-term very early on in their journey.

All of the women interviewed stopped using the pack immediately after the end of their treatment or considerably reduced their use of the resource pack as soon as they entered the treatment phase, usually being replaced by treatment specific leaflets provided by the healthcare team.

Some participants also reported that, having had the resource pack early on, they felt more confident and reassured about how things were progressing, and therefore concentrated on ‘getting through’ and ‘getting on with it’ – supported by their specialist team.

The pack was found to be most useful and beneficial at two main timepoints: at diagnosis and immediately before or after undergoing tests.

Receiving the resource pack at diagnosis was felt to be the most appropriate time at which it could be handed out to participants. In spite of the initial feeling of disappointment at needing an information pack after a diagnosis – due to the emotional impact of the news – most women nevertheless reported being grateful to having received the **Primary (early) breast cancer resource pack** at that stage. It was information that they were able to keep and refer to in their own time, in anticipation of subsequent appointments, tests and treatments.

‘Wish this had been handed to me at hospital following diagnosis. It feels like all the important information is in one place and this is vital in trying to retain some control over what is happening’

For many participants, the time period before or soon after tests was very important as it triggered questions about their forthcoming treatment. At this point, there was a greater need for understanding the terminology, the reports and the process behind decisions on the best treatment. For the participants who had received the pack much later than this point, there was a clear sense that their experience of breast cancer and the subsequent care pathway could have been improved if they had received the pack earlier.

³ Survey conducted before launch of the Breast Cancer Care Moving Forward Resource Pack in January 2011

While it did not diminish the quality and adequacy of the pack, the interviews revealed a pattern of use that did not extend beyond these two points. Further, we were unable to capture data beyond this time point due to participants dropping out of the research project.

The role of healthcare professionals

As mentioned earlier, the breadth and variety of information contained within the **Primary (early) breast cancer resource pack** folder was felt by some like an ‘avalanche of information’ during a very unsettled emotional time for most participants. Not surprisingly, the interviews revealed the central role of healthcare professionals and breast care nurses in managing and navigating this maze of information.

The more proactive the specialist team were in communicating and delivering this information to the participants, the better they felt equipped with all the information they needed as and when appropriate. In some cases, the healthcare team, and in particular the nursing teams were in fact encouraging the ‘step by step approach’ often mentioned by participants, pointing to the ringbound booklet and when to use the other leaflets. In these instances, the breast care nurse and specialist team provided, for example, instructions on how best to use the resource pack, would talk through the content of the booklet and leaflets, and supplement the pack with literature relevant to the patient’s circumstances (Example 1).

Example 1

Morgan (aged 41–50) was due for chemotherapy after having had lumpectomy and lymph nodes removed.

The breast care nurse gave her the pack on the day she was diagnosed with breast cancer. She gave her the basic information about going through surgery and what to expect. ‘She did not want to give me too much information as there is an awful lot to take in’. When Morgan asked about chemotherapy, the nurse replied ‘we’ll cross that bridge when we come to it.’

The breast care nurse gave Morgan enough information to get through her operation and a few weeks afterwards. She gave her the resource pack, and pointed out two booklets that would be of use in the first couple of weeks. These were **Your operation and recovery** (BCC151) and **In it together** (BCC120). Both were included in the blue folder with the ringbound booklet. She read all of these in the first couple of weeks after her diagnosis.

At first, when she sat down with the surgeon and breast care nurse on the day of her diagnosis, she was asked whether she had any questions but she did not know what to ask. However, after reading **Your operation and recovery** booklet, it prompted questions which she noted down in the ringbound booklet and asked at the following appointment.

Later on, the breast care nurse supplemented the blue folder with other leaflets as she progressed through her treatment. She was recommended to read the ‘Treatment options’ section and was given the **Treating breast cancer** (BCC74) and **Breast cancer and you** (BCC44) booklets nearer to her chemotherapy sessions. Right before she started her chemotherapy sessions, the breast care nurse gave her the **Breast cancer and hair loss** booklet (BCC54), recommended the section on health and wellbeing in the ringbound booklet and also gave her **Chemotherapy for breast cancer** (BCC16).

When she was first diagnosed, Morgan was jumping ahead, wanting to know about her prognosis and prospects. Her nurse helped her to take the information step by step and treat it like ‘homework for the weekend’. She was given the information only when it was appropriate.

By contrast, there were clear indicators of participants receiving the resource inappropriately. Either too much information, or information without instructions and explanations reflected low-level interaction of the specialist team with the patient. This resulted in participants feeling unsupported and confused by the overload of information (Example 2).

Example 2

Helen (aged 51–60) was diagnosed with invasive primary breast cancer, had radiotherapy and recently had her three-month follow up.

The blue folder was given to her at her first appointment when she found out she had breast cancer. It was given to her by the breast care nurse without any explanation. She remembers that the folder was bulging and was quite heavy.

The pack came with a lot of additional information. There was a leaflet about sentinel node biopsy, wide local excision, an 'inappropriate' leaflet about breast cancer for younger women as she doesn't consider herself as a young woman. There was a lot of mixed information from different sources: from the hospital, Breast Cancer Care and Macmillan.

She wished that the breast care nurse had not given her so much information. She felt she could have managed at first with just the **Primary (early) breast cancer resource pack** plus another couple of leaflets. She acknowledged that she needed some of the other information, like the booklet on surgery, but she felt that she could have been talked through which ones were appropriate or 'safe' to read at this stage

'The blue box was stuffed full and it was too much to be given at once'. She wishes that she had been given the leaflets separately 'If you could concentrate on that book (the ringbound booklet), I think it would be more useful than trying to get everything...just quite muddled'. She felt that she did not have a good look at the ringbound book initially and felt sidetracked by all of the other information.

She only started reading the resource pack when she knew she would be interviewed by a Breast Cancer Care researcher. She did not use it at the time when first diagnosed as she felt overloaded with so much information.

Tailoring and supplementing the pack

Additional Breast Cancer Care publications were listed as supplements to the pack. The most cited publication was **In it together** which was found very useful by participants for communicating with their families and friends. It was deemed as an essential leaflet for the resource pack. This led to most participants who had used this leaflet suggesting its inclusion to the ringbound book, rather than as a separate leaflet. Other information sources which were usually cited by participants were:

- **Cancerbackup DVDs** - now part of Macmillan Cancer Support's resources. DVDs around treatment were particularly found useful because they showed what would happen as well as the look of the machinery used. The level of medical details was particularly appreciated by participants who had used the Macmillan resources.
- **Macmillan written materials and website** – specifically around financial and practical help.
- **Breast Cancer Care resources and website** – as part of a conscious effort to keep referring to the same source of information either by the participants themselves or their healthcare provider. Some participants had used the online forums to read stories of people who had gone through the same type of treatments.
- **Internet** – in addition to the internet sources listed above, some participants had consulted other specialist websites for further information, mostly research specific, such as Cancer Research UK or The American Institute of Breast Cancer. Some other participants had used Google as a tool for finding further additional information even though they were aware of possible pitfalls in the quality or accuracy of the information provided.

III – Summary and recommendations

In many ways, the interviews replicated and therefore validated some of the findings generated by the analysis of the quantitative data. In turn, the qualitative data provided a more detailed and layered perspective on: patients' patterns of usage, how the pack was delivered and factors influencing information provision, and potential areas for improving the pack.

The majority of participants described the pack as useful, well designed, clear, informative and reassuring. In particular, the plain English approach to the pack was especially praised.

Although participants interviewed recognised that it would be difficult to provide a ‘one for all’ solution, they felt that the content of the resource pack could be improved so as to avoid the risk of conflicting information originating from different sources. They commonly used the pack as their point of reference from diagnosis to treatment, and therefore felt that it should be more explicit about the different aspects of the care pathway (diagnosis, treatment, recovery and living with breast cancer after treatment) and the signposting to further sources of information – with particular reference to local supporting networks and practical services addressing body image and appearance issues.

Participants also commented on the importance of language and communication skills in explaining the content of the pack. In particular, the section titled ‘Deciding on treatment’ encountered a higher level of hesitancy in comparison to other sections. This highlighted a discrepancy between patients’ expectations, brought by the title, and the actual content of this section: participants may have expected to be able to make a decision regarding their treatment whereas the section only provides guidelines and explains how decisions about treatments are being made by healthcare providers for individual participants. This raises the question over whether the **Primary (early) breast cancer resource pack** is actually seen as a decision making tool by patients, even though it is intended to be an information resource.

Not surprisingly, breast care nurses were identified by patients as key to providing adequate information and support in both content and (particularly) volume, as this was felt to have an influence on how patients felt subsequently about their treatment.

Recommendations

The table below summarises the findings from both the quantitative and qualitative data. Following actions are suggested as potential ways towards improving the information provision of the primary breast cancer resource pack:

Findings	Suggested actions
Improving the format of the Primary (early) breast cancer resource pack	<ul style="list-style-type: none"> ▪ Include separation tabs ▪ extend aspects (listed below) of the resource pack to enable participants to access information from the same resource ▪ retitle the section ‘Deciding on treatment’ to reflect that it only provides information on how treatment decisions are made by healthcare professionals.
Including further information and signposting on.....	<ul style="list-style-type: none"> ▪ treatment and recovery ▪ talking to family and children (replicating the information included in In it together) ▪ practical and financial help.
Personalising the content of the pack	<ul style="list-style-type: none"> ▪ Include a further diary/note section at the end of the pack or provide advice on ways to diarise the breast cancer experience ▪ signpost to the Breast Cancer Care services map and/or recommend to call the Helpline

	<ul style="list-style-type: none"> ▪ signpost to Breast Cancer Care peer support service.
Facilitating understanding of people whose first language is not English	<ul style="list-style-type: none"> ▪ Provide the glossary in different languages , enabling explanation of most common breast cancer terms used by healthcare professionals to minimise costs .
Supporting healthcare professionals in providing appropriate information	<ul style="list-style-type: none"> ▪ Provide guidance to healthcare professionals, in particular nurses, around when to provide the breast cancer resource pack, what to include (list suggested leaflets and when they are most appropriate), and so on ▪ utilise existing Breast Cancer Care healthcare professional networks to this effect.

Limitations and suggestions for further exploration

Healthcare professionals

Due to the difficulty in recruiting healthcare professionals to take part in the study, the design was altered to solely include patients' views. Our study's findings provide valuable feedback to healthcare professionals in using and disseminating the primary breast cancer resource pack. We recommend that further investigation is carried out to engage healthcare professionals and examine how Breast Cancer Care can promote good practice in information provision to breast cancer patients.

Equality and Diversity

Additionally, the evaluation was unsuccessful in recruiting Black and Minority Ethnic (BME) participants. The case study in [Appendix One](#) does reflect a very extreme case of one of the few BME participant recruited in the study. Although it cannot be generalised, it does echo finding from previous studies carried out at Breast Cancer Care. In particular, one of the recommendations made following the Better Access Better Services project (Breast Cancer Care, 2009) highlighted the need for improved cultural and diversity awareness and communication skills by healthcare professionals. Investigating how best to support healthcare professionals in this area through perhaps educational materials, e-learning platforms or by providing examples of Best Practice case studies might be an appropriate way to support this particular area of work. Further research is required in this area.

Further research

This study has raised the question of whether the **Primary (early) breast cancer resource pack** could be further developed into a decision-aid tool for patients. Effective decision aids which supplement healthcare professionals' practice have been shown to increase positive mental, health and well-being outcomes by preparing patients for the physical and emotional impact of diagnosis and treatment

through a patient participatory approach to the care pathway (Cochrane Review of Randomised Controlled Studies, 2009, Issue 3). We would recommend that this is discussed by the Research Committee, the Research and Evaluation and the Clinical teams at Breast Cancer Care.

Appendix One – An extreme case study: the experience of an Asian woman

Example 3: the experience of an Asian woman

Adhira (aged 51–60) was diagnosed with breast cancer and was scheduled for radiotherapy followed by hormone therapy, after having had a lumpectomy.

Adhira received her breast cancer resource pack from her breast care nurse within the first week she found out she had breast cancer. At first, she did not know what it was nor did the nurse explain what it was: 'She just told me to go home and read it'.

She only received the basic pack and did not have any additional information. The pack was very good for her because she got all her information from it. She had lots of questions to ask, but she felt that 'they [the healthcare professionals] were always "clock-watching" so I gave up in the end'.

She was given the pack a second time by the oncologist, along with a publication on radiotherapy, but here again no explanation on what to expect. She had to ask for more information from a relative who had been diagnosed with breast cancer in the past.

She felt that the pack was easy to understand and the medical terms were well explained. However, when she gave the pack to one of her friends (who is also Asian) who had been diagnosed with breast cancer and had not received any kind of information, she had had to translate and explain some of the terms in Gujarati. She felt it was sometimes difficult to understand the content of the pack for people whose first language is not English. She ended up giving the pack to another friend who has been recently diagnosed as she feels she needs it more than her.

Appendix Two – Patient Information Sheet

Breast Cancer Care Patient Resource Pack

Information Sheet

Explanation of study

The Breast Cancer Care Resource Pack aims to provide participants with an individualised resource at the time of diagnosis, which can be used throughout treatment and beyond. The Resource Pack allows people to collate all the information they gather in one place, so that it becomes a resource that will grow according to each individual's needs.

Breast Cancer Care is undertaking a small study exploring how the Resource Pack is used by patients over the course of a year. We are carrying out telephone interviews with 20 people to find out (a) whether the Resource Pack has been used (b) how the Resource Pack is being used, how helpful and at what times has it been most helpful (c) whether/what other information resources have been used. The findings of the evaluation will help to inform the redevelopment of the resource pack and increase the accessibility and effectiveness of our information provision.

Criteria

We are looking for people who have been diagnosed within the last 3 months as we are particularly interesting in following individuals through their treatment cycle.

What is involved?

- The evaluation will be conducted in the form of a telephone interview once every 4 months (this will mean a total of 4 interviews over the course of a year).
- Each interview should take a maximum of 20 minutes.
- All interviews will be recorded and transcribed. If you would like a copy of the transcript we are happy to send this to you.

- No personal information will be shared with any third party; however the anonymous content of the interviews and findings from the overall evaluation study may form the content of both internal and external publications.

What happens next?

If you are still interested in taking part please complete and return the monitoring and consent forms attached. Once this documentation has been received Dalila Ahamed (Research and Evaluation Coordinator) will be in touch to arrange a convenient time to arrange the 1st telephone interview.

Appendix Three – Monitoring Form

PARTICIPANT MONITORING FORM

For monitoring and analysis purposes it would be useful if you could tell us a little bit about yourself.

Please note in accordance with the Data Protection Act any personal information you provide will remain confidential. Breast Cancer Care will not share this information with any third party, and will only use it for internal monitoring and research purposes and assisting us with planning and improving our services.

Gender Female Male

Age: 20 -30 31 – 40 41 – 50 51 – 60
 61 -70 70+

What is your home postcode? _____

What is your ethnic origin?

White	Asian or Asian British	Black or Black British	Other ethnic group	Mixed
British <input type="checkbox"/>	Indian <input type="checkbox"/>	Caribbean <input type="checkbox"/>	Chinese <input type="checkbox"/>	White and Black Caribbean <input type="checkbox"/>
Irish <input type="checkbox"/>	Pakistani <input type="checkbox"/>	African <input type="checkbox"/>	Other <input type="checkbox"/>	White and Black African <input type="checkbox"/>
Other <input type="checkbox"/>	Bangladeshi <input type="checkbox"/>	Other <input type="checkbox"/>		White and Asian <input type="checkbox"/>
	Other <input type="checkbox"/>			Other <input type="checkbox"/>

Such as: secretary, personal assistant, clerical worker, office clerk, call centre agent, nursing auxiliary, nursery nurse.

(c) **Senior managers or administrators**

Such as: finance manager, chief executive. NB usually responsible for planning, organising and co-ordinating work and for finance.

(d) **Technical and craft occupations**

Such as: motor mechanic, fitter, inspector, plumber, printer, tool maker, electrician, gardener, train driver.

(e) **Semi-routine manual and service occupations**

Such as: postal worker, machine operative, security guard, caretaker, farm worker, catering assistant, receptionist, sales assistant.

(f) **Routine manual and service occupations**

Such as: HGV driver, van driver, cleaner, porter, packer sewing machinist, messenger, labourer, waiter / waitress, bar staff.

(g) **Middle or junior managers**

Such as: office manager, retail manager, bank manager, restaurant manager, warehouse manager and publican.

(h) **Additional professional occupations**

Such as: accountant, solicitor, medical practitioner and scientist.

Please return your completed form along with your signed consent form using the prepaid envelope enclosed or send to: **Dalila Ahamed, FREEPOST RRRKZ – ARZY – YCKG, Breast Cancer Care, 5-13 Great Suffolk Street, London, SE1 0NS.**

Appendix Four – Patient Consent Form

TELEPHONE INTERVIEW CONSENT FORM

Please read the following statements carefully. If you do not understand any of them please contact Dalila Ahamed, Monitoring and Evaluation Coordinator on 0207 960 3486 or email her at dalila.ahamed@breastcancercare.org.uk.

Once you have read and understood the following statements please tick the boxes next to all of those you agree with.

- I have had time to read and understand the information sheet.

- I have had an opportunity to ask questions about Breast Cancer Cares' Resource Pack evaluation study.

- I understand that my participation in Breast Cancer Cares' Resource Pack evaluation study is voluntary and that I can withdraw from at any time, without giving reason.

- I understand that my telephone interview will be recorded and that extracts of this may be used in written reports and articles, however all my comments will remain anonymous.

- I understand that all the information I give will be kept strictly confidential.

I agree to take part in up to 4 telephone interviews for this study.

Name	Date	Signature
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You must return ONE consent form to us and we advise you to keep ONE for your own records.

Appendix Five – Patient Interview Schedule

Patient Resource Pack

Interview Schedule (Patients)

Introduction: My name is Dalila Ahamed. I am the the Research and Evaluation Coordinator at Breast Cancer Care.

Purpose: I would like to ask you some questions about the cancer related information resources you have used over the last 4 months.

Motivation:

- Please note the objective of the interview is to gather data on the information you have used in the past 4 months.
- Please remember there are no right or wrong answers and we are interested in your thoughts whether you have used the resource pack or not
- The interview should take a maximum of 20 minutes
- Please note all questions relate to the previous 4 months (so from XX to XX)

- All interviews will be recorded and transcribed. If you would like a copy of the transcript we are happy to send this to you.
- No personal information will be shared with any third party; however the anonymised content of the interviews and findings from the overall evaluation study may form the content of both internal and external publications.

1. Please can you give me a brief update on the treatment you have undertaken in the last 4 months (i.e. since XX)

2. Please can you describe who gave you the Breast Cancer Care Patient Resource Pack and how it was delivered? (Interview One only)

[Provide examples e.g. was it delivered with an explanation, was it delivered on its own or with other information]

3. Have you used the Breast Cancer Care Patient Resource Pack within the past 4 months?

If **YES** → Can you tell me a little about how/when you've used the pack?
What has been most useful aspect?
Anything else?

[Provide examples of use e.g. used for reference phone numbers, taken to appointments, lent to family friends]

If **NO** → Can you explain why you've not used the pack?

[Provide examples e.g. avoided it, not felt like it, information wanted not included in pack, another source provided comprehensive information]

(IF NOT USED, GO TO QUESTION 6)

4. What have you liked or found useful about the resource pack in the last 4 months?

[E.g. size, colour, pictures, detail of information – too much/too little]

5. What haven't like about the resource pack? (If anything)

[E.g. size, colour, pictures, detail of information – too much/too little]

Have you found anything about the resource pack difficult to understand or use?

6. What other information would it have been useful to include in the resource pack? (If anything)

[Provide examples e.g. specific telephone numbers, localised information, information about other drugs or treatments]

7. Can you tell me about any other information you have used within the last 4 months?

[Provide examples e.g. other organisations, healthcare professionals, peers, internet]

Which of these sources did you find most useful? Is there a format you prefer?

Were you able to access the information you wanted/needed?

8. Do you have anything else you'd like to add about the resource pack or any other information resources you have used in the past 4 months?

9. Do you have any suggestions for how we could improve the Breast Cancer Care Patient Resource Pack?

End of interview

Thanks: Many thanks for agreeing to take part in the interview today. We really appreciate your time and all the information you have provided us with.

Next steps: The next interview is due to take place in 4 months time (i.e. XXXXX). We will be in touch to pre-arrange a convenient day and time in due course.