

# What Breast Cancer Patients Want From a World Class Radiotherapy Service

*“Rapid access, a personal touch - with clinical excellence that’s  
explained”*

(Breast Cancer Advocate, London focus group)

April 2005



## About the authors

**Breakthrough Breast Cancer** is a charity committed to fighting breast cancer through research and awareness and has established the UK's first dedicated breast cancer research centre, in partnership with the Institute of Cancer Research. Breakthrough promotes education and awareness of the issue among the public, policy makers, health professionals and the media.

Breakthrough's Campaigns and Advocacy Network (Breakthrough CAN) is a network of individuals with personal experience of breast cancer and organisations with a desire to improve breast cancer services for all people in the UK through patient advocacy. Breakthrough provides information, training and support to our Network members to enable them to campaign on issues of concern to them.

**Breast Cancer Care** is the UK's leading provider of information, practical assistance and emotional support for anyone affected by breast cancer. Every year we give direct support to over 22,000 people with breast cancer or breast health concerns through our helpline, peer support and other direct services. In addition, we respond to 2 million requests for support and information about breast cancer or breast health concerns through our publications, website and outreach work. All our services are free.

We are committed to campaigning for better treatment and support for people with breast cancer and their families.

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# **What Breast Cancer Patients Want From a World Class Radiotherapy Service**

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## 1. Executive Summary

### 1.1 Background:

*'The worst part about it is that patients don't always realise there is another way, a better way' (Breast Cancer Advocate, Essex).*

Breakthrough Breast Cancer and Breast Cancer Care work closely with breast cancer patients, many of whom have experienced problems with radiotherapy services across the UK. For many the main problems are delays in receiving treatment, which causes considerable stress and anxiety. However, there are also serious concerns about the way radiotherapy services are delivered and the lack of sufficient emotional and psychological support for patients and their carers.

### 1.2 Gathering the experiences of people using radiotherapy services:

When the National Radiotherapy Advisory Group was set up to advise on the development of high quality radiotherapy services, it was clear to patient groups that it would be important to feed into this process the detailed experiences of people who have actually used the service. In part this role is served by the inclusion of patient representatives on the Group. However, it is important for the Group to hear the experiences and thoughts of as wider range of people as possible. For this reason Breast Cancer Care and Breakthrough Breast Cancer decided to hold a series of focus groups and telephone interviews to gather the experiences of people affected by breast cancer who had used radiotherapy services.

In total 26 people participated in three focus groups, held in London and Sheffield and 22 people participated in telephone interviews. Participants were members of Breakthrough Breast Cancer's Campaigns and Advocacy Network (Breakthrough CAN), members of the Breast Cancer Care Campaign Panel and people that had contacted both organisations with concerns about the service.

The focus groups and telephone interviews focused on collecting information about the difficulties experienced with radiotherapy services, how this affected people and suggestions for improving services. Jane Whittome, National Programme Manager - Hospital Services at the National Cancer Action Team attended two of the focus group meetings to listen in person to people's experiences. Carolyn Morris, a member of the National Radiotherapy Advisory Group and Breakthrough CAN, was also in attendance at one of the London focus groups.

*Please note that the report often refers to "people using the service" as opposed to patients. This is because it is not only the person being treated who needs support and information during this time, but also carers who attend appointments along with the patient.*

### 1.3 Key recommendations for improving radiotherapy services:

Based on discussions with people who have used radiotherapy services, below are a set of key recommendations for improving the service. More detailed information about the suggestions for improvements is given in the main body of the report.

- **A greater emphasis on providing more “patient centred care” so that the whole person is treated not simply the disease**

Many people with personal experience of the service believe that it is often too clinically focused and does not always consider their other needs.

Staff should be trained and encouraged to improve their skills in communicating with patients, identifying individual needs, answering questions and empathising with patients’ fears and experiences.

There should be greater consideration of the dignity of people during treatment.

- **Improved communication with people using the service about all aspects of radiotherapy including waiting times and how to cope with side effects**

The provision of information about radiotherapy needs to be radically improved.

People using the service would welcome greater honesty and clear communication about how long they will have to wait before starting treatment and the reason for delays. They would also like reassurance about the impact of delays on treatment efficacy.

There should be more information about how radiotherapy works and potential side effects in both written and verbal forms. This information should be provided before the first treatment appointment to give people time to prepare for treatment and ask questions.

People should be given the opportunity to tour the radiotherapy service before they begin treatment to familiarise themselves with the service.

- **Improved psychological and emotional support before, during and after radiotherapy treatment.**

There needs to be significantly improved provision of emotional and psychological support during radiotherapy treatment.

Better information needs to be provided about the possible psychological impact of treatment to prepare and support patients, and to alert families/carers to psychological and support needs of people having treatment. There should be a designated member of staff within the radiotherapy unit tasked with answering questions, providing advice on concerns about treatment and helping with emotional issues that arise as people approach the end of active treatment. There is evidence that issues

of people feeling abandoned at the end of formal treatment are better understood now, but too often not dealt with.

Trained volunteers, who have experienced radiotherapy, should be encouraged to work within radiotherapy units. Their role is to help orientate people, listen and provide emotional as well as practical support.

- **Increased resources – both more staff and more modern machines**  
Radiographers should be awarded “key worker” status by Government and offered improved salaries, benefits, and career structure to encourage them to remain in the profession.

Public ignorance about the profession of radiographer needs to be addressed in order to improve recruitment.

- **Significantly reduced radiotherapy delays and adherence to national guidelines and standards of clinical excellence**

Everyone should begin treatment within the National Institute for Clinical Excellence recommended time of four weeks, unless there is a clinical reason for delay<sup>1</sup>. If a person has to wait more than four weeks, they should be offered the choice to travel elsewhere for radiotherapy treatment.

- **Improved accessibility to the service – including greater consideration given to how people can be supported in their travel arrangements to appointments; if possible more local venues for treatment and expansion of the flexibility in appointment times seen already in some centres**

Ideally, people with personal experience of the service would like more locally based radiotherapy services. However, people are willing to travel longer distances to treatment where this is necessary, particularly if this would mean a shorter waiting time to start treatment. There was a great deal of confusion about the ability to choose a treatment venue and this needs clarification.

Where this is not possible, greater flexibility in appointments is needed, both in choice of time and availability of appointments during evenings and weekends. This would help to avoid ‘rush hour’ if travelling long distances and make it easier to arrange work and other commitments. The practice of extending the hours of operation of radiotherapy services to include evenings and weekends should be encouraged.

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<sup>1</sup> Radiotherapy centres should have sufficient staff and capacity to guarantee access to radiotherapy within four weeks of identification of need. (*Guidance on Cancer Services: Improving Outcomes in Breast Cancer*, National Institute of Clinical Excellence, August 2002).

## 2. What are breast cancer patients' priorities for improving radiotherapy services?

It is important at the outset to highlight that not all the consultees' experience of the NHS radiotherapy service were negative. Indeed, some spoke about the kind and caring nature of the staff looking after them and about the speed at which they had started their treatment.

However, even amongst those women who had a largely positive experience, there were plenty of suggestions for how services could be further improved – these have been incorporated into this report.

The consultation began by asking past and present breast cancer patients to outline their priorities for improving radiotherapy services.

The priorities can be categorised into eight key areas.

- a) More patient centred holistic care so that the whole person is treated and not simply the disease - focusing on providing training for staff to improve their ability to communicate with the people using the service
- b) Improved communication to the people using the service about all aspects of the radiotherapy service, potential delays and how to cope with side effects
- c) Improved psychological and emotional care and support before, during and after radiotherapy treatment.
- d) Increased resources for both more staff and more modern machines
- e) Clinical excellence in the service and equal access to the best treatment throughout the UK
- f) Significantly reduced delays in starting treatment so that national guidelines are met<sup>2</sup>
- g) Greater consideration given to how people can be supported in their travel arrangements to appointments and if possible more local venues for treatment
- h) Expansion of the flexibility in appointment times seen already in some centres

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<sup>2</sup> Radiotherapy centres should have sufficient staff and capacity to guarantee access to radiotherapy within four weeks of identification of need. (*Guidance on Cancer Services: Improving Outcomes in Breast Cancer*, National Institute of Clinical Excellence, August 2002).

### 3. What difficulties have breast cancer patients experienced with radiotherapy services and how have these difficulties affected them?

During the consultation process, many of the women that had, or have, breast cancer talked about the difficulties they encountered during their treatment. For some, realisation that their treatment and care was not as good as it could have been only came after treatment was over, and they met and talked with other women about their experience. Understanding the current difficulties with the service is key to determining areas that require action to improve.

Many people told the consultation that the difficulties they experienced had an enormous impact on them - emotionally, psychologically and economically. Some people stated that **they would refuse to have radiotherapy treatment again because they had found the experience too distressing**. One woman even revealed that she stopped treatment half way through because the process was so traumatic and the lack of support from staff so acute. Many women felt the experience had affected their ability to return to work and therefore had a significant economic impact.

Although this consultation focused on the experience of breast cancer patients, it is clear that many of these issues will not be unique to them and will be relevant to all people using radiotherapy services.

#### 3.1. Lack of patient centred care and humanity in the service

The consultation revealed that many people who have used the service encountered staff that were not aware of, and/or were ill equipped to deal with, their information and support needs. Common to consultees' experience were staff who did not empathise with people's fears and concerns and who were unable to treat them as individuals. Many commented that experiencing the service was like *"being on a conveyor belt"* and that not enough consideration was given to the dignity and privacy of patients. One woman commented;

*"I felt like a piece of meat on a slab when I wanted and needed to be seen as a person"* (Breast Cancer Advocate, London focus group)

another that,

*"there was no sense of any needs beyond the immediate physical needs I presented, I felt like a carcass"* (Breast Cancer Advocate, Essex).

*"I had to wait in a mixed waiting room with my hospital gown on – this was very embarrassing"* (Breast Cancer Advocate, Burton on Trent).

*"People were walking in and out of the room whilst I undressed and was being prepared for treatment"* (Breast Cancer Advocate, Salisbury).

Lack of contact time with staff often meant that the process of radiotherapy and related issues, such as potential side effects of the treatment, were not

adequately explained. In turn, many people found there was little time to ask questions, they felt rushed and that they would be viewed as “difficult” if they persisted in asking for information and explanations.

*“I asked a lot of questions and was branded neurotic and a difficult patient by staff”* (Breast Cancer Advocate, York).

The lack of choice around when you are treated (i.e. appointment times) or by whom (e.g. the gender of staff) contribute to the feeling that it is only the disease being treated, not the whole person, who has to fit treatment around the rest of their life, work and family. Many commented that they were made to feel lucky that they were being treated and they had no right to make “*extra demands*” of the service.

Many women thought that radiotherapy can feel like a separate service and that it needs to be better integrated into the rest of the breast cancer treatment system. This would help to keep a patient centred focus. Women were often surprised that the levels of support were significantly less than during other aspects of their treatment and care.

### **3.2. Lack of information and poor communication skills of staff**

A lack of information to explain and support all stages and aspects of treatment was an issue common to the majority of the women who took part in the consultation.

Women talked about the lack of both verbal and written information. Information that is provided is often not specific enough to the individual or to the hospital where the treatment is taking place. Information is often not presented in a clear format or available in different languages.

When there is no information about what to expect from the service people can feel anxious while waiting to start treatment. Difficulties are also caused by a lack of information on side effects. Without the provision of relevant information, many patients are left to seek out information for themselves from charities or the internet. People also need high quality information to be clear about what relevant questions they should be asking.

*“No information was provided, I had to do research alone. Clinicians were dismissive of my questions and I felt there was no one to turn to”* (Breast Cancer Advocate, Essex).

Despite the importance placed on information provision, the women we talked to made it clear that a person’s decision not to want detailed information must also be respected.

### **3.3. Lack of information about waiting times for radiotherapy treatment**

For many women, the lack of honest and open information about the cause of radiotherapy delays, and even the existence of a delay in the first place, were a major concern.

*“I was never told how long the treatment was going to be delayed by – they just kept saying probably a few weeks – it was very difficult to make plans with my family”* (Breast Cancer Advocate, Salisbury).

In addition, most women had no explanation about what impact, if any, possible delays might have on their treatment outcome. This creates enormous worry for the patient and their family. In some areas the delay in starting treatment is resulting in women having their treatment adapted. For example, they will receive larger fractions but every two days. Many were concerned about the clinical impact of such changes. Some women were recommended to have a mastectomy rather than wide local excision to remove the need for radiotherapy treatment because of delays.

The majority of people who took part in the consultation believed they should be offered the choice of referral to another centre if their wait to start treatment was longer than the recommended four weeks.

Delays are not just an issue when starting treatment. It is common for there to be long delays when attending appointments and last minute cancellations when appointments are eventually secured.

### **3.4. Staff shortages**

Although many people taking part in the consultation had ideas about how staff could improve their communication skills and attitudes to patients, most were very sympathetic to the fact that this can be due to staff being overworked and not having the support they themselves need.

Women taking part in the consultation identified that a lack of staff often resulted in equipment being left idle, vulnerability of appointments to late cancellation, low morale amongst staff that impacts on patients and lack of continuity for patients.

One woman commented that she had had no real problems, but that the radiotherapy unit was *“slightly chaotic”* because the staff were overloaded with work and that this could cause anxiety for patients. (Breast Cancer Advocate, Whitley Bay)

### **3.5. Travel problems and lack of choice of treatment venue**

Arranging travel can be stressful during treatment for breast cancer and travelling long distances is tiring as well as expensive. The experience of most women is that relying on hospital transport means spending the whole day at hospital, so most patients rely on friends and family.

Many patients would like greater choice and flexibility over where they are treated, so, for example, they can stay with friends or family who can help them with travel. Most said that if they could get an appointment quicker they would be prepared to travel longer distances. There was a great deal of confusion about whether or not people currently have a choice of where to go for their treatment.

#### 4. What do patients want from a world class service?

Women taking part in the consultation were very clear about what needs to happen and change for the service to improve. The eight priorities they identified are outlined in Section Two.

Not all priorities were discussed in great detail, below are some of the key priorities listed for improving services with some suggestions of ways to achieve them.

##### 4.1. More “patient centred care” so that the whole person is treated and not simply the disease:

- **Provide training for radiotherapy staff to develop their communicating and listening skills** to better support the emotional and psychological needs of people using the service. These skills should be a core part of training for new staff and the need to use such skills should be integral to all staff’s job descriptions. A world class service should provide staff with continuous professional development to support the growth of these key skills; *“Take care of me the patient, not just the disease”* (Breast Cancer Advocate, London focus group)
- **Treat patients with dignity and respect.** This can be done by small, but significant changes to working practices, for example at the Royal Surrey Hospital, if there is a delay during treatment and the person is left naked on the machines, they are provided with a blanket; *“You shouldn’t have to ask for things that should be offered, for example gowns”* (Breast Cancer Advocate, London focus group). Other women commented that providing a curtain or a screen in the treatment room behind which they could get undressed would have made a great deal of difference.
- **Only allow radiographers who are administering treatment into the treatment room**
- **Encourage innovative ways in which the patient can remain an individual;** *“I have heard that some people have been invited to bring their own music to play when they are receiving their radiotherapy – this would have helped me”* (Breast Cancer Advocate, Newcastle)
- **Ensure permission is received before tattooing patients**

##### 4.2. Improved communication to the people using the service about all aspects of the radiotherapy service including waiting times and how to cope with side effects:

- **Provide clear, concise written information** at each radiotherapy unit about the services in their centre. Written information to take away is important *“Something written down about the service – the basic do’s and don’ts and what to expect – is vital as your mind isn’t really receptive at that point”* (Breast Cancer Advocate, Whitley Bay)

- **Provide written information** that includes; what radiotherapy is, what to expect at treatment sessions, possible side effects, coping with side effects and practical elements of treatment such as parking permits and car park charges. The information produced should encourage people to ask questions and suggest the type of questions it would be useful to ask
- **Produce information in a range of different languages and formats** as is appropriate for that geographical area
- **Use websites** to their full potential by providing a virtual tour of the equipment
- **Encourage the production of information that is presented from the patient point of view.** *“The local patient group did a booklet on past experiences which was really helpful”* (Breast Cancer Advocate, Burton on Trent)
- **Provide written and verbal information before treatment starts**
- **Provide patients with choice about the level of information they want to receive**
- **Promote the practice of giving a tour of the radiotherapy unit** to patients before they begin treatment to familiarise themselves with the service and to meet staff. This could be run by volunteers and happen while patients wait to start treatment. One woman commented that before she started treatment the staff took her into the treatment room to show her the equipment *“This made me much less frightened”* (Breast Cancer Advocate, Crawley)
- **Improve contact with patients on the day of appointment** - if appointment times are slipping, patients should be contacted to warn them about the delay
- **Improve the co-ordination of the service with Breast Care Nurses** to help with sense of a continuity of service and support
- **Provide better signposting** by staff to information produced by the voluntary sector on radiotherapy
- **Provide more information on grants that are available for financial help**
- **Provide an honest explanation about the reason for delays;** *“Explain how long I have to wait for treatment to start – and why”* (Breast Cancer Advocate, Sheffield focus group)
- **If a person has to wait more than four weeks, they should be offered the choice to travel elsewhere for radiotherapy treatment**

- **Provide reassurance about impact of delays on treatment outcome**
- **Provide training and support for staff** in order for them to facilitate all of the above suggestions

#### 4.3. Improved psychological and emotional support

- **Provide information about the possible emotional and psychological impact of treatment** as well as side effects
- **Encourage staff to talk to people about concerns** they have about treatment; *"A smile or a touch can make all the difference to your treatment experience"* (Breast Cancer Advocate, Sheffield focus group)
- **Provide a named key contact within the radiotherapy unit to all patients** so that they know who to direct questions to. If patients are not always treated by the same radiographer this will provide greater continuity
- **Encourage the development of peer matching with ex-patients** so that women can talk through their treatment with someone who knows the process. The idea of a "volunteer councillor" was one that appealed to many women; *"Having a mentor figure when you arrive, to show you where to wait, where the toilet is, someone who is there for you and can answer some of the more personal questions you might have about treatment would be fantastic"* (Breast Cancer Advocate, Essex)
- **Provide better signposting from radiotherapy to support services and support groups.** Radiotherapy is often the last treatment given before a patient finishes treatment - many people experience difficulties about six weeks after treatment ends. There should be clear explanations and information about support services.
- **Offer, or provide information about, complementary therapy** to help people cope with the stress of radiotherapy and travel

#### 4.4. Increased resources- both more staff and more modern machines:

- **Give key worker status to radiographers**
- **Extend the practice of providing existing staff with more/new skills**
- **Improve their package of benefits** including a "Golden Hello" in the manner of the teaching profession; *"I sometimes felt that although the equipment was there, the staff were too stretched to use it"* (Breast Cancer Advocate, Birmingham)
- **Consider having spare machines available in case of breakdown** of equipment and promote better internal hospital communication to ensure that machines are serviced. One example was given of a Trust

that carries out all servicing of machinery out of working hours so as not to reduce time available for appointments.

**4.5. Significantly reduced radiotherapy delays and adherence to national guidelines and standards of clinical excellence:**

- **Extend good practice of increasing the working hours of radiotherapy units** into early mornings, evening and weekends
- **Improve internal communications within hospital** and Multi-Disciplinary Teams so that advanced bookings can be made
- **Improve communication between units to share best practice**
- **Press Primary Care Trusts to prioritise radiotherapy** and increase funding provision.
- **Consider allowing Cancer Networks to hold funding for radiotherapy services**

**4.6. Improve accessibility to the service** – including greater consideration given to how people can be supported in their travel arrangements to appointments; if possible more local venues for treatment and expansion of the flexibility in appointment times seen already in some centres

- **Ensure the opportunity to choose an appointment time that is flexible**
- **Co-ordinate appointments with other hospital appointments**
- **Facilitate greater choice over treatment venue**

## **5. Conclusion**

The key finding from discussions with people using radiotherapy services is that while delays in starting radiotherapy are a major issue, people also have other serious concerns about the care of the whole patient that need to be addressed.

Many improvements have been made to radiotherapy services in the UK and initiatives are being introduced to reduce delays in starting treatment. However, there is still a long way to go before the UK has achieved 'A World Class Radiotherapy Service'. The overriding issues of importance to those with personal experience of the service are the need to ensure that the service is "patient centred"; that information and communication is improved, and that the psychological and emotional needs of people are better understood and better supported.

This report has set out a number of key recommendations for improving radiotherapy services from people who have experienced radiotherapy treatment. Breast Cancer Care and Breakthrough Breast Cancer hope that the National Radiotherapy Advisory Group will consider and address the important issues raised in this report and take appropriate action. Breast Cancer Care and Breakthrough Breast Cancer would be very happy to work with the Advisory Group in finding ways to deliver on these patient concerns in the future.

**15<sup>th</sup> April 2005**