Piloting specialist care for people with radiation-related problems
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Executive Summary

The large majority of the 228 members of RAGE (Radiotherapy Action Group Exposure) have severe and complex conditions for which they are getting little or no clinical support and treatment.

Due to significant incapacity and usually extreme pain most of this group of people struggle to maintain their home and quality of life without physical and emotional help and support.

Many would be able to self-manage with financial support. This project has piloted a direct grant programme and we show in this report how a small self-managed grant can make a significant difference to the Well-being of people with severe and complex conditions.

People with complex radiation related damage require increased access to appropriate support and therapies and to be able to reconnect with specialist oncology and pain management services if and when required.

Not all of these people need intensive treatment. However, they need to be reassured that they are receiving appropriate care and, if they are not, their local health professionals need to be able to access information about what interventions or therapies are advisable.

This project set up 15 national pilot clinics to test whether a multi-disciplinary team of health professionals could assess the needs of those with this complex condition, produce a care plan and identify local support.

We have shown that it is possible for patients with complex injuries to self-assess and self-refer and that assessment and care planning can be carried out in regional centres.

Several of the pilot centres are keen to continue with this work and we have recommended a model of a specialist hub providing triage, multi-disciplinary assessment and intensive therapy. This hub centre would be able to refer to the local champions and act as an information centre for patients and health professionals.

The National Cancer Action Team are now leading on the further development of this recommended model and it is currently being considered by the Specialised Commissioning Team.
Introduction
Introduction

1.1 Background
During the late 1970s and early 1980s, several factors combined to result in an increase in severe radiation-induced injuries, particularly, radiation-induced brachial plexus nerve injuries (RIBP). People with this condition can suffer continuous pain and/or complete loss of arm movement, breathing difficulties and bone and soft tissue destruction. Many have lost their homes, their jobs and their self-confidence. As they get older their problems are deteriorating and complicating other chronic illnesses and they are increasingly fearful for the future. Their story has been recorded in ‘Yesterday’s Women’.1

In 1995, The Maher Committee (set up by the Department of Health and Royal College of Radiologists) proposed guidelines to provide affected women with the care they need including annual specialist assessment, pain management, aids for daily living and psychological support2. However, 12 years on, these guidelines are still to be implemented.

In 2007, as a result of a meeting at the Department of Health, Rosie Winterton MP instructed the Cancer Director Professor Mike Richards to explore more effective ways to meet the needs of these women through a partnership between the charity Macmillan Cancer Support and the Cancer Action Team. This was included in the Cancer Reform Strategy3.

This activity has been included in the NHS Improvement workstream of the National Cancer Survivorship Initiative jointly chaired by Ciaran Devane (CEO Macmillan Cancer Support) and Professor Mike Richards.

1.2 Aims of the project
In partnership with the Cancer Action team and RAGE (Radiotherapy Action Group Exposure), Macmillan set up a pilot project to look at how best to deliver cost effective integrated approaches to care for people living with the long term effects of radiotherapy treatment for breast cancer.

The project had two main aims:
1) To make available to RAGE members a one-off self managed well-being grant.
2) To set up multi-disciplinary pilot clinics offering RAGE members a one-off health assessment and care plan identifying local services and support.

In addition it wanted to raise awareness of health professional about the late effects of cancer treatment and to signpost RAGE members to other services they might find helpful.

1.3 Content of the report
This report looks at:
1) how the grants programme and specialist health clinics were planned, set up and executed.
2) how the grants were spent and the benefit to the recipients.
3) how the pilot clinics tested self-identification and referral, telephone triage by a non-professional and assessment/care planning by a range of different specialist teams.
4) the challenges faced by both the grants programme and the clinics.
5) the short-term results for the RAGE members.

Speech bubbles throughout the report contain quotations from telephone conversations, letters and interviews with participants and post clinic meetings and teleconferences with clinicians.

3 Cancer Reform Strategy (Page 80, 5.61)
1.4 Stakeholders

Project steering group:
- Jan Millington (RAGE)
- Lady Audrey Ironside (RAGE)
- Pam Pond (RAGE)
- Margaret Carling (RAGE)
- Helen Austin (RAGE)
- Bec Hanley (TwoCan Associates)
- Justine Palin (Cancer Action Team)
- Prof Jane Maher (Chief Medical Officer, Macmillan Cancer Support)
- Jane Gammage (Head of Lifecare, Macmillan Cancer Support)

Project workers:
- Jo Heath (Healthcare/clinics)
- Andrea Todd (Lifecare/grants)
'I have been so overwhelmed that someone has recognised our condition for which I am so grateful. 30 years is a long time to have to wait for an acknowledgement that there is such a thing as “late effects”. I think a grant is a way forward'.
2.

Well-being Grants
2.1 Setting up the grants programme
The project made available to RAGE members a one-off grant of £750. This was a self-managed grant, which was offered to help with daily living or personal care. The recipients were asked to participate in an evaluation process to identify how the money was spent and what difference it made to their Well-being.

All RAGE members living in the UK who had joined RAGE before 31st March 2008 were eligible for the grant. Applications needed to be received by end of February 2009 (15 weeks to apply).

2.1.1 Application process for the grant
228 RAGE members were sent:
1) An information sheet about the project
2) An application form asking:
   • What services they currently access
   • What they pay for these services
   • What services they need that are not currently available
   • If they would like to apply for a grant
   • What they anticipate spending the grant on
   • If they would like information about services or signposting
   • If they would like a specialist health check.
3) A form for their GP to sign confirming that they have been diagnosed with late effects of cancer treatment
4) A Well-being questionnaire to give baseline information about how they currently feel
5) A stamped addressed envelope

2.1.2 Uptake
A total of 163 grants were made. 16 RAGE members returned the forms but did not want the payment. Sadly, 5 RAGE members died during this time. 36 RAGE members did not respond at all.

We are not clear why some RAGE members did not apply for the grant. It may be that some women were reluctant to go to their GP or consultant to ask them to confirm that they were suffering from the long-term effects of radiotherapy treatment. Some told us that they did not need the money or felt that their late effects were not sufficiently severe to justify claiming it.

2.1.3 Challenges
Many participants had difficulty completing the forms due to physical disability and needed help to complete the forms over the telephone. Others just felt too unwell to face it. 73 reminders were sent out one month before the deadline to those who had not responded.

Several RAGE members had difficulty getting their GP to sign the form. Three GPs charged to sign the form (these costs were reimbursed by the project).

2.1.1 Application process for the grant diagram

Application form sent to RAGE members with questionnaires
Form returned with signed confirmation from GP or consultant
Grant paid
Data collected about how grant was spent. Well-being questionnaire resent

See Appendix A
The chart below shows the expected pathway of the RAGE member’s grant application in dark green. The chart shows some of the difficulties that were experienced and how they were overcome:

- **Interested in grant**
  - Feels not sufficiently disabled or deserving
  - Query about project/lost forms
  - Needs to tell story
  - Gets help from project worker
  - Reminder sent by project

- **Not interested in grant**
  - Does not apply

- **RAGE member receives project information**
  - Too ill or disabled to face paperwork
  - Completes application form
  - Goes to GP for signature on form
  - Completes Well-being questionnaire
  - Application form returned to Macmillan
  - Grant paid within one month of receipt at Macmillan

- **Query about project/lost forms**
  - Application form returned to Macmillan

- **Needs to tell story**
  - Application form returned to Macmillan

- **Feels not sufficiently disabled or deserving**
  - Application form returned to Macmillan

- **Too ill or disabled to face paperwork**
  - Application form returned to Macmillan

- **Remainder sent by project**
  - Application form returned to Macmillan

- **Does not apply**
  - Application form returned to Macmillan

- **GP won’t sign**
  - Application form returned to Macmillan

- **GP requires payment**
  - Application form returned to Macmillan

- **Macmillan arranges GP payment**
  - Application form returned to Macmillan

- **Not interested in grant**
  - Application form returned to Macmillan

- **GP doesn’t recognise condition**
  - Application form returned to Macmillan

- **Interested in grant**
  - Completes application form
  - Goes to GP for signature on form
  - Completes Well-being questionnaire
  - Application form returned to Macmillan
  - Grant paid within one month of receipt at Macmillan
2.2 How the grant was spent
A full analysis of what RAGE members intended to spend the money on and what they actually spent the money on is attached.

The main areas of financial need were:

Personal Care

- ‘I cannot lift my arm above my shoulder height so clean hair is impossible without help’.
- ‘I am unable to manage looking after my feet or hands’.
- ‘So nice to be able to go out once a week instead of once a month’.
- ‘I used to get my feet taken care of by the NHS but due to cutbacks I was taken off the lists’.

Complementary therapies

- ‘Regular treatments of homeopathy. It’s a great help but very costly’.
- ‘Acupuncture helps the pain but is not available on the NHS in my area’.
- ‘Sessions with a remedial therapist mean I can reduce my pain relief medication’.
- ‘I live by myself and at times get very low because of my disability so I am going to treat myself to a massage once a month’.

Clothing

- ‘Zips in clothes are impossible. I have bought three items of clothing with large buttons’.
- ‘Shops do not cater for big arms. I have to buy specially tailored or altered clothes to fit me properly’.
- ‘Because of the radiotherapy I have different cup sizes. Because of the sores I need a soft material to stop the rubbing and this get me down. The quality of these new bra’s is incredible’.
- ‘Right arm lymphoedema and collapse of right rib cage means I have difficulty all of the time with clothes. I can only wear a certain kind of bra at £27 each’.

Transport

- ‘I will be using the mini cab more often. With my bad arm I cannot carry bags with any weight’.
- ‘I often use taxis to get about with shopping and hospital visits’.
- ‘I have to use wheelchair taxis and they are very expensive’.
- ‘I am unable to drive and unable to walk a distance because of breathing problems due to radiotherapy’.

See Appendix B
Late effects project

Cleaning/ironing/household maintenance/window cleaning

- ‘I cannot lift my arm above my shoulder height so cleaning windows is impossible without help’.
- ‘It is difficult to clean anything properly with one hand. Lots of breakages occur when dealing with one hand only’.
- ‘To do things I can no longer do myself e.g. wash kitchen floor, clean bath, shower and windows’.
- ‘My son visits every two months but small jobs cannot always wait that long’.

Gadgets/adaptions

- ‘I do not sleep well and spend time in bed especially when in pain. The new bed is so much more comfortable’.
- ‘New kitchen tap with accessible handle. Before I couldn’t even turn the tap on to fill a kettle’.
- ‘I could not use the tin opener – even the electric one. I now have ones that are hands free’.
- ‘I put half the grant towards buying a reclining chair. I suffer dreadfully from fatigue. To be able to have a sleep without pain in my shoulder will make a great difference’.

Gardening

- ‘I can look at a pleasanter view which helps keep my spirits up’.
- ‘I do what I can in the garden but am unable to cut the grass or do any digging’.
- ‘Window cleaning and gardening cause more pain in chest, shoulder and arm’.
- ‘This will enable me to remove my lawn and replace with stone and slabs as I have great difficulty keeping it under control’.

Chiro/physio/osteo/massage/MLD

- ‘I need MLD and bandaging. I have to pay £97 for a course of 6 treatments as there is nothing available on the NHS’.
- ‘I would like specialist exercise sessions to try to keep some mobility in my arm and shoulder’.
- ‘Physio provides me with some relief. The NHS is not able to offer the service I require to meet my needs’.
- ‘More frequent massages as my muscles/nerves have been affected, particularly over the last 5 or 6 years when my condition has been deteriorating very quickly’.
The overall response from the recipients was that this relatively small grant can make a huge difference to their personal care and environment. In many cases it was able to increase their independence and restore confidence and self-respect.

2.3 Well-being questionnaire

The Well-being questionnaire was sent out with the application form to all 228 RAGE members at the beginning of the project. 136 forms were completed and returned with the grant application forms.

The same form was sent out to the 136 initial respondents one month after the final grant was processed. 119 forms were completed and returned.

A comparative analysis of the data is attached. Clearly, this is a short-term evaluation and it is unrealistic to expect lasting changes in Well-being. However, one month after the grant provision a shift could be seen in the project participants’ feelings of:

- Autonomy – many more felt in control
- Fun and enjoyment – more feel their lives are less dull and boring
- Resilience – more can cope with problems
- Self-esteem – more feel positive about themselves
- Depression – many more are happier
- Social isolation – the feeling of isolation from family and friends has reduced. However, the local community is still not a particular source of comfort
- Social interaction – more feel able to go out and about and contribute to the lives of others
- Needs satisfaction – immediate needs have been met but long term financial aid is still a problem.

See Appendix C
2.4 Feedback from RAGE members

For many RAGE members this grant represented recognition of a long struggle to have their condition recognised and acknowledged.

- ‘I have been so overwhelmed that someone has recognised our condition for which I am so grateful. 30 years is a long time to have to wait for an acknowledgement that there is such a thing as “late effects”. I think a grant is a way forward’.

- ‘It was a wonderful surprise and so very welcome for it’s practical help and also for the acknowledgement of the pain and difficulties which many of us radiotherapy patients endure’.

- ‘Somehow this recognition by way of the cheque has gone a long way to healing old wounds’.

2.5 Additional services

146 RAGE members reported on the application for that they wanted information about services that might be helpful. Unfortunately, we were only able to do a limited amount of work on this in the time available. We were able to signpost enquiries to Macmillan services, such as Macmillan Helpline or a local Macmillan Support and Information Centre or Age Concern. We were able to encourage RAGE members to use services they already know about but were reluctant to call on – for example, the community nurse. We also helped some grant applicants to find information about the things they wanted to buy with their grant.

2.6 Learning

- Self-managed grants can make a significant difference to the well-being of those with severe and complex illnesses
- Financial support for maintenance and improvement of living environment (house and garden) can be as important to a person’s well-being as personal care and therapies.
- Many people with this condition need physical help and emotional support to complete the applications
- Many people with this condition have a need to tell their story and sufficient time needs to be allowed for this.
- Recognition of the condition has been an important part of the benefit felt by grant recipients
2.7 What next?
Information about the administration, findings and user feedback of this project has been reported to the Cancer Action Team and Department of Health to inform their current and future work on direct payments and self-managed grants.

The findings from this work will be fed into the evaluation of the financial support package that is being piloted by the Macmillan Solutions Project. Macmillan Solutions aims to meet the needs of people affected by cancer by providing financial, emotional and practical solutions. Macmillan will be using the data from this project to look at whether a one off grant as part of Macmillan Solutions suggests similar patterns of financial need.
Pilot multi-disciplinary clinics
3.1 Setting up clinics

3.1.1 What kind of clinic?
Multi-disciplinary clinics were to be set up to enable RAGE members to access advice about how best to deal with the impact of late effects, how particular conditions might progress and how these can be managed. Clinics are also meant to provide information and reassurance.7

A questionnaire was sent to all 228 RAGE members asking if they would like to apply for a one-off well-being grant and whether they would like access to a specialist health check. 127 returned the form to say they would like a specialist health check.

In order to ensure that the project was patient-led and providing a service that was really required by this group of people, those who requested a health check were each called by the project worker to find out what services they were currently accessing and what they would like to access. They were also asked how far they could travel to a clinic.

- 51% wanted help with pain management.
- 33% wanted to see someone who knew about their condition and had up-to-date information about treatments. In particular they wanted to know ‘what’s normal’ and what they could expect in the future i.e. a prognosis.
- 44% wanted some advice from an occupational therapist.
- 17% wanted to find out more about complementary therapies.
- 17% wanted to talk to an oncologist.
- 7% wanted to know about anything that could help.
- Other services that were requested included: orthopaedic specialist, physiotherapist, shoulder specialist, neurologist, advice about amputation, advice about fighting infection, advice about lymphoedema and counselling.

Most wanted recognition of their condition, advice about how best to deal with it and what to expect in the future as well as access to local services.

The Steering Group agreed that we would ask pilot centres to provide a multi-disciplinary clinic with a minimum of an oncologist, a pain or palliative care consultant and an occupational therapist.

3.1.1 What kind of clinic? process diagram

Questionnaire sent to RAGE members

Follow up telephone call to those requesting health checks to establish need

Agree clinic format

Intended outcomes included8:

- An opportunity for patients to be assessed by specialist services matched to their needs (identified through structured phone interviews).
- An opportunity to improve clinician's attitudes towards, and understanding of, late effects of cancer treatment (both professionals at the clinics and the GPs through communication from the clinics).
- Enhancing access to, and raising awareness of, appropriate and good quality services, which are local, convenient, joined-up, long-term and preventative in a way that is proportionate to the severity of the condition experienced.
- Improving the quality of life of those experiencing this complex condition.

3.1.2 Contacting Cancer Centres

A tender document9 was prepared and sent via the Cancer Action Team to the Cancer Networks. Only one cancer network (North East London) responded that they would like to work with us. This led to pilot clinics being set up at Barts and Queens Romford.

Due to the poor response to the tender we then made direct contact with consultants known to Dr Jane Maher to ask if they would be prepared to set up a one-off clinic. We also responded to recommendations from RAGE members of consultants who have shown an interest in this work.

The following chart (opposite) shows when an individual in each Cancer Centre first expressed interest in holding a clinic and the date of the actual clinic. The amount of emails exchanged with consultants or administrators has been included to give an idea of the work involved in setting these up.

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8 J Taylor and C H Sin (2009)
9 See Appendix D
<table>
<thead>
<tr>
<th>Cancer Centre</th>
<th>Initial Interest</th>
<th>Clinic Date</th>
<th>Number of patients seen</th>
<th>Exchange of emails</th>
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<tbody>
<tr>
<td>Royal Marsden</td>
<td>November 2008</td>
<td>7 March 2009</td>
<td>7</td>
<td>51</td>
</tr>
<tr>
<td>Barts 1</td>
<td>February 2009</td>
<td>31 March 2009</td>
<td>4</td>
<td>13</td>
</tr>
<tr>
<td>Mount Vernon</td>
<td>April 2009</td>
<td>27 May 2009</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>Christie</td>
<td>January 2009</td>
<td>10 June 2009</td>
<td>5</td>
<td>26</td>
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<tr>
<td>RD&amp;E</td>
<td>March 2009</td>
<td>12 June 2009</td>
<td>5</td>
<td>19</td>
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<tr>
<td>Barts 2</td>
<td>April 2009</td>
<td>16 June 2009</td>
<td>4</td>
<td>19</td>
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<tr>
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<td>March 2009</td>
<td>23 July 2009</td>
<td>6</td>
<td>38</td>
</tr>
<tr>
<td>Edinburgh</td>
<td>February 2009</td>
<td>4 September 2009</td>
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<td>41</td>
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<tr>
<td>Leeds 1</td>
<td>February 2009</td>
<td>15 September 2009</td>
<td>4</td>
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<td>Newcastle</td>
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<td>29</td>
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<td>Maidstone</td>
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<td>25 September 2009</td>
<td>6</td>
<td>38</td>
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<td>Bath</td>
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<td>47</td>
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<td>2 (1 DNA)</td>
<td>7</td>
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<tr>
<td>Sheffield</td>
<td>April 2009</td>
<td>Not able to arrange</td>
<td></td>
<td>8</td>
</tr>
<tr>
<td>Royal Surrey</td>
<td>April 2009</td>
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<tr>
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<td></td>
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<td>Cheltenham</td>
<td>April 2009</td>
<td>Not able to arrange</td>
<td></td>
<td>5</td>
</tr>
</tbody>
</table>
Reasons given for clinics not to be able to work with us on this pilot included:
• Lack of time
• Lack of space
• Lack of funding
• No access to appropriate specialists
• Lack of protocol/ethics approval
• Staffing problems
• Lack of NHS directive
• Restricted numbers would mean inequable service for existing patients
• Other priorities.

3.1.3 Booking appointments
Once the interested clinics had established how many patients they could see, the project worker called those living nearest to the centre and invited them to the clinic. They were asked again what their most important issues were, their expectations of the clinic, details of GP and any consultants and information about where they had their original radiotherapy treatment.

They were then sent an appointment letter with three different quality of life questionnaires (EQ5D, SF-36 and HeiQ). The purpose of using these questionnaires was to obtain a profile of those with radiation-induced brachial plexus neuropathy, which could be compared with other complex diseases and the treatments and therapies available to them.

Cancer Centres were then sent patient details, times of appointments and a clinic form with a brief summary of their condition and what they were hoping to get from the clinic.

3.1.3 Booking appointments diagram

3.1.4 Attendance
70 patients attended 15 different clinics at 13 regional centres. They completed feedback forms directly after the clinic and were reimbursed for their travel expenses. Clinics were asked to send a follow-up letter to GPs (copied to patient and Macmillan).

3.1.4 Attendance process diagram

10 See Appendix E
26 RAGE members, who requested a clinic, were not able to attend when offered an appointment

- Did not attend the day: 2
- Too ill to agree to appointment: 6
- Not convenient: 5
- No longer interested: 3
- Now getting the help they need: 4
- Will not travel: 3
- Caring responsibilities: 2
- Mental health issues: 1

31 RAGE members, who expressed interest in the clinics, were not offered a clinic space. This was because we were unable to find clinics in certain areas of the country (e.g. Sussex, Surrey, West Midlands, East Anglia) and also the number of patients at each clinic was limited to that which each clinic felt they could handle in one session.

The Christie (Manchester) and RD&E (Exeter) offered to hold another clinic but there were not sufficient RAGE members who could get to these centres to attend another clinic.

3.2 Profile of those attending clinics

The Project Worker spoke to all the patients before they attended the clinic.

70% reported problems with pain. For some this pain was very severe and constant. Some people commented that the pain treatment they had received either hadn’t worked, only helped slightly or that they found it intolerable.

46% reported paralysis of their arm or hand. Some could not use their arm at all. Others were finding it difficult to lift anything. A couple had found that physio had helped, but one person commented that it had been of no use. This symptom seems to show the most obvious signs of progression, as a number commented that the problem was moving from their arm to their shoulder, or that their arm or hand was getting progressively weaker.

Many reported problems with lymphoedema (39%). Some people said they had no access to treatment for this, or that they had to pay for manual lymphatic drainage.

A considerable number reported lung damage, breathing problems or chest infections (24%)

Other symptoms reported by a small number of people in each case included:
- Numbness/pins and needles (16%)
- Broken bones ribs/collar bone (10%)
- Shoulder damage (9%)
- Skin damage ulcers/burns (9%)
- Cancer from radiotherapy (skin, lung, chest wall or oesophagus) (7%)
- Fibrosis (7%)
- Osteoporosis (4%)
- Cellulitis (4%)
- Arthritis (4%)
- Anxiety/depression (3%)
- Fatigue (1%)
The majority of the people who attended the clinics had not been able to access this kind of help through their GP (63%). Only 11% said their GP had been able to help them. A small number accessed services via their hospital. Some people were still receiving annual check-ups from their oncologist. Others commented on a complete lack of support since they had been discharged from oncology services.

Before attending a clinic 68 patients completed EQ-5D, SF-36 and HeiQ quality of life questionnaires. The analysis of these questionnaires found that:

- The level of physical health was lower than mental wellbeing in all three questionnaires
- The scale measuring the role limitations due to physical health had the lowest score of 13.6 (on a scale of 0-100, where 100 represents the highest level of functioning)
- The results from EQ-5D and SF-36 showed that the majority of the respondents had high levels of pain. 44% reported to have extreme pain and 50.8% reported to have some pain
- The vast majority of respondents experienced some problems with mobility and usual activities
- EQ-5D showed that 63.1% of respondents had some problems with anxiety/depression
- However, HeiQ showed that most of the respondents tended to disagree that their health has a negative effect on their emotional well-being.

‘Clearly, these are not angry, dependent patients but strong resilient people looking for coping strategies under difficult circumstances.’

Clinical Oncologist

It is important to note here that the RAGE committee are concerned about the appropriateness of the quality of life questionnaires which:

‘...really do not help patients to expose their true feelings and serve to encourage a defensiveness which members say often emerges in their medical consultations. As many of us have served in jobs and professions which defined and distinguished us, we have to find ways to keep this thread in our lives so we can maintain a degree of self worth and self respect and indeed reality. People don’t often want to admit to despair and defeat but that doesn’t mean that they are not waging a daily battle. We are quite a competitive bunch and within our group we fight to keep the upper hand in coping with extreme suffering and stoicism’.

RAGE committee member

Follow-up questionnaires were sent to the patients some weeks after the clinic. These were analysed to evaluate if there was any measurable short-term improvement to the patients’ quality of life (See Short Term Outcomes).

11 Full analysis in Appendix F
3.3. Patient expectations

Before the clinics, patients were asked what their expectations of the clinic were.

10% of respondents said that they hoped to get a clearer prognosis and to find out what to expect in the future.

10% came with no expectations. Some said they were only taking part in the pilot to help other people.

Some people experiencing pain said they did not have any hopes of alleviation of their symptoms, as nothing they had tried had worked before.

Others had quite specific expectations including:
- Finding out about new treatments
- Getting helpful hints from an OT on coping with difficulties and useful gadgets
- Identification of a local source of help.

Most wanted recognition of their condition and reassurance that they were doing all they could.

‘I have had 10 years of trying things. I’m coming with an open mind. Not expecting too much – just someone who understands’.

RAGE member

3.4. Clinic environments

It was difficult for every centre to find a half day’s clinic space. Some managed to find space away from the Oncology Outpatients department; others were able to fit the clinics outside normal hospital hours (e.g. Saturday, Friday afternoon). Some centres were able to find separate areas where the RAGE members could sit together and gain benefit from talking together.

- The Royal Marsden held the clinic in the Oncology Outpatients Department on a Saturday as this was the only time available. It did mean, however, that the patients had a comfortable place to themselves and were able to sit together and get to know each other.
- In Bristol they took a team from Bristol University Hospital to the luxurious environment of the Penny Brohn Cancer Care Centre.
- At Mount Vernon they were able to hold the clinic in the Lynda Jackson Macmillan Centre.
- Southampton held the clinic in their Education Centre where the patients had their own waiting room where tea and coffee were served.
- At the Christie the clinic was held in their Clinical Trials department.
- At the Royal Devon & Exeter and at Queens Romford the clinic was held in the Oncology Centre Outpatients Department, but at a time when no other clinic was being held so again the patients were able to chat amongst themselves.
• In other places the clinic was held alongside other outpatient clinics and there was little opportunity for the patients to get to speak to each other.

It was clear that, although a comfortable environment was much appreciated by the patients, the most important thing was the opportunity to meet other people in the same situation. Many of the patients said how comforting it was to share their experiences with others. Several will be keeping in contact with the people they met at the clinics and others said they would like to contact more RAGE members in their locality through the RAGE committee or newsletter.

3.5. Assessment/care plans
Clinics were asked to produce a one-off assessment and care plan to be sent to the patient’s GP and copied to the patient. They were asked to make recommendations for any treatment/therapy and, where possible, identify local support and care.

Some clinics (Christie, Exeter, Bath, Bristol, Barts 1) sent out their care plans within a week. Others had problems with co-ordination and administrative support and took up to 13 weeks to send out their letters. These delays meant that several patients, who had given positive feedback immediately after the clinic, phoned to complain about the lack of follow-up.

Clinicians have commented that it would have been more helpful to have more structured paperwork in advance of the clinic and a template for the care plan.

3.6. Clinic feedback

3.6.1 Feedback from patients
After the clinic the patients were asked for their feedback about the experience.

The majority of respondents reported that going to the clinic had been a very positive experience (81%).
20% commented that they found the pain specialist helpful. They particularly valued:

- Having more time than normal at the pain clinic
- Getting new and up-to-date advice
- Being able to talk to someone specifically about pain
- Repeat appointments or onward referrals.

19% mentioned that the Occupational Therapists had been very helpful in providing practical tips as well as general information, exercises and referral to local services.

A small number also mentioned finding the oncologist very helpful and reassuring. Some had not been examined by an oncologist for many years.

A small number (7%) said that they did not find the clinic useful, as they did not learn anything new.

Every respondent who commented on seeing a multi-disciplinary team (90%) said that they found it very valuable.
3.6.2 Feedback from clinicians

Teleconferences were held towards the end of the pilot with the oncologists, pain specialists and OT/Physiotherapists who had been involved in the clinics.

The main themes that came out were:
  - These patients are mainly strong and resilient and coping well with complex and profound problems
  - Difficulties for clinicians to identify local support
  - Clinic would be enhanced by a psychologist in the team
  - Enjoyable experience to work in a multi-disciplinary team
  - Importance of environment so patients can meet
  - Difficulties of working without notes – although some clinicians thought that it allowed the consultation to be more patient led and that with notes you can come with preconceptions
  - Importance of oncology input.

3.7. Short-term outcomes

3.7.1 Care plans

Some clinics were able to refer directly into hospital and local OT services. Others were not able to do this without a GP referral and were only able to make recommendations back to the GP. All clinics found it difficult to identify local services due to many patients living out of their area and the disparity in local provision.
All patients were given advice by the specialists at the clinic. A selection of patient care plans have been followed up to see what, if anything, happened after the clinic:

**Patient 1 – Marsden**

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>N/A</td>
<td>Trial of Level 3 Opiates</td>
<td>Nothing</td>
<td>Advised patient to discuss care plan with GP</td>
</tr>
<tr>
<td>N/A</td>
<td>Acupuncture, massage and reflexology</td>
<td>Patient not able to pay privately</td>
<td>–</td>
</tr>
<tr>
<td>N/A</td>
<td>MRI and orthopaedic opinion</td>
<td>Nothing</td>
<td>Advised patient to discuss care plan with GP</td>
</tr>
<tr>
<td>N/A</td>
<td>Anti-depressants to be monitored</td>
<td>–</td>
<td>–</td>
</tr>
</tbody>
</table>
### Patient 2 – Marsden

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient referred to Clinic</td>
<td>Trial of tricyclics and referral to rheumatologist</td>
<td>GP referred to pain clinic</td>
<td>Waiting for appointment</td>
</tr>
<tr>
<td>Local OT for assessment</td>
<td>CT scan for abdominal pain</td>
<td>GP referred to CT scan. Nothing serious detected</td>
<td></td>
</tr>
<tr>
<td>Local OT for assessment</td>
<td>Social Services OT rang and asked if patient could walk and shop. As she could, OT said there was no reason to visit</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Patient 3 – Barts

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient referred to Clinic</td>
<td>Physio for gait training</td>
<td>Physio assessed and gave walking stick and instructions on use</td>
<td></td>
</tr>
<tr>
<td>Local OT for assessment</td>
<td>Trial of shoulder support sling</td>
<td>OT assessed and supplied bath seat. Tried four slings but none were comfortable</td>
<td></td>
</tr>
</tbody>
</table>

### Patient 4 – Barts

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tried to refer to local OT service for new splint but does not exist</td>
<td>Wrote to patient and GP with details of recommended splint to buy privately</td>
<td>Patient has not done this</td>
<td></td>
</tr>
<tr>
<td>Local physio service</td>
<td>Physio has called once and is coming back next week</td>
<td>Under care of local physio team</td>
<td></td>
</tr>
<tr>
<td>Referral to neurologist for botox injections</td>
<td>GP has not mentioned</td>
<td>Advised to discuss care plan with GP</td>
<td></td>
</tr>
</tbody>
</table>
### Patient 5 – Barts

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative care team</td>
<td>Appointment at hospice within a week</td>
<td>Under care of palliative team</td>
<td></td>
</tr>
<tr>
<td>Local OT for assessment</td>
<td>Trial of shoulder support sling</td>
<td>Appointment with community OT within a week</td>
<td></td>
</tr>
</tbody>
</table>

### Patient 6 – Mount Vernon

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Consultant</td>
<td>Under care of Palliative Care Dept. Has enjoyed 6 week course of aromatherapy</td>
<td>Next appointment on 4/12/09. Patient happy under care of consultant</td>
<td></td>
</tr>
<tr>
<td>Trial of lignocaine patches at pain clinic</td>
<td>Patient says she already uses patches</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vigorous prophylaxis for osteoporosis</td>
<td>GP has not mentioned</td>
<td>Advised to discuss care plan with GP</td>
<td></td>
</tr>
<tr>
<td>OT assessment for home aids</td>
<td>GP has not mentioned</td>
<td>Advised to discuss care plan with GP</td>
<td></td>
</tr>
<tr>
<td>Local lymphoedema service</td>
<td>Nurse has not yet made referral</td>
<td>Reminded to make referral</td>
<td></td>
</tr>
<tr>
<td>Breathing management support</td>
<td>Now under care of Palliative Care services</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Patient 7 – Christie

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain management consultant</td>
<td>Patient has already been seen three times by consultant</td>
<td>Patient happy under care of consultant</td>
<td></td>
</tr>
<tr>
<td>Continue to monitor re osteomyelitis</td>
<td>Patient has since had emergency hip operation despite osteomyelitis in sternum</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Patient 8 – Exeter

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physio and lymphoedema service</td>
<td>Has new hand support and stockings for arm which are much more comfortable</td>
<td>Patient is happy with ongoing support</td>
<td></td>
</tr>
<tr>
<td>Increased use of versatis patches</td>
<td>Patches are really helpful</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Course of complementary therapy</td>
<td>Course was arranged. Found sessions very relaxing</td>
<td>Will continue sessions even though she now has to pay for them</td>
<td></td>
</tr>
</tbody>
</table>

### Patient 9 – Bristol

<table>
<thead>
<tr>
<th>Clinic referred to</th>
<th>Clinic recommended</th>
<th>What happened</th>
<th>What next</th>
</tr>
</thead>
<tbody>
<tr>
<td>Review of pain medication</td>
<td>Patient does not want to take stronger medication. GP has referred to Royal Nat. Hospital for Rheumatic Diseases in Bath</td>
<td></td>
<td>Waiting for appointment</td>
</tr>
<tr>
<td>Vascular surgeon re subclavian stenting</td>
<td>Has been seen and received treatment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local OT for assessment</td>
<td>OT has assessed and is coming back in two weeks</td>
<td>Now under care of Social Services OT Dept</td>
<td></td>
</tr>
</tbody>
</table>

From this it is clear that the referrals made directly by the clinic specialists were generally much more effective than the recommendations to GPs.

When recommendations were sent to GPs they were rarely acted upon without prompting either from the clinic team or the patient.

*I remain unconvinced that the recommendations to the GPs will be actioned*.

**Consultant Clinical Oncologist**
The diagram below shows the expected pathway (in dark green) from the RAGE member receiving information about the project to receiving appropriate care. It also shows some of the obstacles to this pathway.
3.7.2 Quality of life
It is perhaps unrealistic to expect an immediate improvement in quality of life following one clinic appointment and care plan. However, follow up questionnaires (EQ-5D, SF-36 and HeiQ) were sent to the first 31 patients who attended the early clinics. The results can be seen on page 43.

EQ-5D showed a slight increase in problems with mobility, self-care and usual activities. However, the percentage of respondents experiencing extreme pain had decreased by nearly 14% and the percentage of respondents experiencing ‘no problems’ with anxiety/depression had increased by 22%

SF-36 and HeiQ showed very little change in the average scores.

3.7.3 Learning from the pilot clinics
We have learned that
• It is possible for patients with complex injuries to self-assess and self-refer
• A non-clinical telephone triage service can identify the needs of this group
• Assessment and care planning can be carried out in regional centres
• It is possible to assemble a multi-disciplinary team and generate a care plan for local support
• Care plans need a structured pro forma and need to be sent out promptly
• A successful clinic requires a ‘champion’ who can not only co-ordinate the clinic and send out a care plan but also ensure that the recommended follow up takes place
• Clinics need to take place in a comfortable environment where patients can talk together and be mutually supportive
• People with this condition need to be able to re-contact appropriate clinical support if their condition changes in the future
• Not all those who attended clinics (and found them helpful) felt the need for a regular clinic as long as they had access to expertise if required in the future, as the condition deteriorated
• Direct referrals from specialist clinics are more effective in getting local help set up than recommendations sent to the GP.

The challenges are:
• Clinicians finding the time and appropriate space for the clinic
• Identifying and securing local champions
• Clinicians working without a full clinical history
• Working without GP referral. GP must play a role in taking forward aspects of the care plan generated by the clinics.
• Disparity of local service provision.
• Not all patients with this condition are able or willing to travel to a specialist centre
• Making direct referrals out of PCT area and without further GP referral
• Care plans have been of variable quality and there needs to be a commitment to follow up
• Sufficient administrative support needs to be in place after the clinic to ensure the paperwork goes out promptly
• Implementing care plans – there is a disparity of local services available and lack of co-ordination once recommendations made.
3.8 What next?

3.8.1 Clinicians interest

The clinicians that took part in the teleconferences were keen to stay involved with this work and were asked about their thoughts for the future:

"Short-term we have enabled patients to tell their story. Long-term providing ongoing co-ordinated care is a problem. It has a place in the NHS. I hope it's not a one-off."

Consultant Anaesthetist

"I feel that this is the tip of the iceberg. We have seen patients with years with problems that have not been addressed. It's not difficult to make their quality of life much better. I would be keen to take this forward as I think we can make a significant impact in their quality of life."

Consultant Anaesthetist

"If you do a yearly follow-up call then there has to be a capacity to refer people to something more comprehensive like a clinic. I would not want to be uncovering some significant problems and not having anywhere to send them. You need a screening process where some of them are directed into clinics, whereas others wouldn't need it."

Occupational Therapist

"To take this forward it has to involve a group of people with understanding of the problems that can develop a network and then signpost people relevantly. It's key to get the GPs involved."

Clinical Oncologist
3.8.2 Informing other work
The findings from these pilot clinics will be fed back to the Department of Health and the National Cancer Action Team. The work will also inform Macmillan’s work on the National Cancer Survivorship Clinics.

3.8.3 Proposed model
The Steering Group considered the different models trialled and felt that any future commissioned service should consist of a specialist hub centre with a care tracker role to ensure that patients get access to the recommended services.

This centre could provide multi-disciplinary assessment and specialist intensive therapies for those that require it but it could also triage patients on the telephone and refer on to regional specialists, who have already been identified by this project. It could act as a ‘virtual’ clinic for those who are unable to travel.

Ideally, this centre would be able to act as a specialist information centre for patients and health professionals. Potentially it could become a centre of research and training for specialists in this field across the UK.

The Royal National Hospital for Rheumatic Diseases (RNHRD) in Bath, which ran a successful pilot clinic and already runs assessment clinics and residential intensive therapy courses for people with chronic pain syndrome, is interested in taking this work forward with a view to becoming the specialist hub.

This project has identified several clinicians who, after the care tracker assessment, might be willing to act as local champions, assessing people who do not wish or are unable to travel to Bath.

Stephen Parsons from the National Cancer Action Team is now leading on the further development of this model. He is working with RNHRD to define the structure of the new model and the care tracker role.

The Cancer Action Team have worked closely with RAGE to produce a submission to the Specialised Commissioning Team, which was submitted on 18th December 2009 and has passed the first stage of the assessment process.

3.8.3 Proposed model process diagram

1st tier
- Information
- Triage
- Referral to local champions

2nd tier
- MDT assessment

3rd tier
- Intensive therapy
‘I’d like to think we could improve patients’ quality of life, whether it be improved pain control or easier access to occupational therapy’

Clinical Oncologist
Thank you
Thank you

Kristina Staley and Bec Hanley (TwoCan Associates), Chih Hoong Sin and Jean Taylor (Office for Public Management) and Kavita Rainova (Macmillan) for their input to this report and data analysis.

The RAGE/LATE EFFECTS Steering Group and Andrea Todd and Jo Heath, Project Workers

All those who took part in the pilot clinics and those who helped make them happen:

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(Divisional Director of Cancer Services)
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(Occupational Therapist)
Elaine Melcome  
(Lymphoedema CNS)
Judy Young (Counsellor)
Rosemary Lucey  
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Christine Brannan (PA to Jane Maher)

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(Occupational Therapist)
Michael Connors  
(Head of In House Services, Penny Brohn Centre)
Anne Currie  
(PA to Karen Forbes)
Edinburgh
Prof Ian Kunkler  
(Consultant Clinical Oncologist)
Prof Marie Fallon  
(Consultant Palliative Care)
Barbara Lyle  
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Gillian Murdoch  
(Senior Occupational Therapist)
Elizabeth Preston  
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Patricia Simpson  
(PA to Prof Kunkler)

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Dr Louise Lynch  
(Consultant Anaesthetist)
Kathy Thompson  
(Macmillan Occupational Therapist)
Janice Martin  
(Physiotherapy Team Leader)
Sue Chadwick  
(Senior Sister)
Angie Craig  
(Acting Cancer Lead Manager/Strategic Lead for RT)
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Odeth Richardson  
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Anne Ewing  
(Occupational Therapist)
Clare Doney  (Sister)

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Dr Rema Jyothirmayi  
(Consultant Clinical Oncologist)
Dr Jon Norman  
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Mumtaz Parkar  
(Radiographer)
Amanda Allen  
(Occupational Therapist)
Melanie Winmill  
(Occupational Therapist)
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(Physiotherapist)
Abigail Hill  
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Sheila Wood  
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Dr David Breen (Neurologist)
Linda Park (Breastcare CNS)
Pat Fisk (Pain Management Nurse)
Jo Griffith (Occupational Therapist)
Paula Henderson
(Occupational Therapist –
Lymphoedema)
Rachel DiCaprio (Physiotherapist)
Beverley Wilson (Tissue Viability Nurse)
Michelle Campbell (Skin Care Nurse)
Nana Ababio
(Service Improvement Facilitator)
Lucy Gladman
(General Manager – Oncology)
Donna Hurley (Patient Information)
Paul Trevatt – Macmillan Network
Nurse Director – North East London
Cancer Network

Thank you
Appendix
Appendix A:  
Well-being Questionnaire

Well-Being Questionnaire

In order to find out if an individual budget could improve the lives and well-being of people affected by cancer, we are asking a series of questions about how you feel now. We will ask again at the end of the study. You do not have to complete this questionnaire but we appreciate you taking the time if you do. Whatever you tell us is confidential and we will use general information anonymously. If there is a need to give more detail then we will seek your permission, but will always maintain confidentiality.

Name:

Please read each statement and tick one box to indicate how you feel now

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Neither Agree Nor Disagree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
<th>No answer/alternative answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am free to decide for myself how to live my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My life is dull and boring</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I do not let problems get on top of me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel positive about myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel unhappy and depressed</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am lonely as I have few friends or relations with whom to share concerns</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My local community is a source of comfort</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I keep to myself and have few social contacts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I help others as much as they help me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have enough money to meet my needs</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Additional Comment

If you prefer, you can ring the Project Worker and talk through your answers and she will complete the form with you.

**Andrea Todd**
Late Effects Project Worker
Macmillan Cancer Support

Direct line 020 7091 2043
Tuesday & Wednesday

Please return this form with the Application Form in the envelope provided. Thank you for helping.
Appendix B: Analysis of Late Effects Well-being Grants Spend

- Personal Care
- Pedicure/Chiropody/Manicure
- Hairdressing/Beauty Treatment
- Arm Support
- Bath Aids
- Clothes/Special Clothes
- Transport/Taxis/Car adaptations
- Complementary Therapies
- Chiropractor/Physio/Osteo
- Massage
- MLD
- Counselling
- Pain Relief/Management
- Private Medicine
- Beds/Mattress
- Bills – inc Heating
- Cleaner
- Household Appliances
- Garden Care
- Housework
- Home Help
- Sewing/Ironing/Laundry
- Shopping
- Pet Care
- Specialist/Dietary Supplements/Convenience Foods
- Window Cleaner
- Exercise/Gym/Swim
- Telephone SOS
- Stair Lift
- Riser/Recliner chairs
- Gadgets
- Electric Wheelchair/Scooter
- Holiday
- Outings
- Paris (Dr. Delanian)
- Computer
- DIY/Renovation/Maintenance
- Other

% replies intention to spend vs % of replies actually spending.
### Appendix C: Analysis of Late Effects Well-being Questionnaire

#### Results Before and After the Grant

1. **Autonomy – I am free to decide for myself how to live my life**

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2. **Fun & Enjoyment – My life is dull and boring**

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3. **Resilience – I do not let problems get on top of me**

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Late effects project

4. Self Esteem – I feel positive about myself

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5. Depression – I feel unhappy and depressed

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During the project a shift can be seen in the project participants feelings of:

1. Autonomy – many more feel in control.
2. Fun & Enjoyment – more feel their lives are less dull and boring.
3. Resilience – more can cope with problems.
4. Self Esteem – more feel positive about themselves.
5. Depression – many more are happier.
6. Social Isolation – I am lonely as I have few friends or relations with whom to share concerns

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7. Social Isolation – My local community is a source of comfort

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Total: 137 100% 122 100%

8. Social Interaction – I keep to myself and have few social contacts

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9. Social Interaction – I help others as much as they help me

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10. Needs Satisfaction – I have enough money to meet my needs

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During the project a shift can be seen in the project participants feelings towards:

6&7 Social Isolation – the feeling of isolation from family and friends has reduced. However, the local community is still not a particular source of comfort.

8&9 Social Interaction – more feel able to go out and about and contribute to the lives of others.

10 Needs Satisfaction – immediate needs have been met, but long term financial aid is still a problem.
Appendix D: Invitation to Tender

Dear Colleague

People living with complex late effects of cancer treatment.

During the late 1970s and early 1980s several factors combined to result in an increase in severe radiation-induced injuries, particularly radiation-induced brachial plexus nerve injuries (RIBP), for a group of women with breast cancer. People with this condition can suffer continuous pain and/or complete loss of arm movement, breathing difficulties and bone and soft tissue destruction.

A committee (set up by the Department of Health and Royal College of Radiologists) proposed guidelines to provide those affected with the care they need including annual specialist assessment, pain management, aids for daily living and psychological support.

Macmillan Cancer Support and the National Cancer Action Team in collaboration with the Department of Health have set up a pilot project to support those living with late effects of radiotherapy (initially Radiotherapy Action Group Exposure (RAGE) members living with the late effects of radiotherapy for breast cancer) and to look at the best ways of implementing the guidelines from the Department of Health/Royal College of Radiologists Committee.

We are interested in establishing a small number of pilot clinics to undertake an annual health check for this cohort of patients and are seeking expressions of interest from cancer centres. Attached to this letter is a map profiling the geographical location of RAGE members living with late effects of radiotherapy. Also attached is document detailing the tendering process and further information.

Further information about the project can be sought from the Macmillan Late Effects Project Workers (Jo Heath or Andrea Todd) on 020 7091 2043 or email jheath@macmillan.org.uk.

Expressions of interest need to be returned to myself Justine.palin@gstt.nhs.uk by the 28th February 2009.

Yours faithfully

Justine Palin
Associate Director, Supportive and Palliative Care – CAT
Health check for those living with the long-term effects of radiotherapy treatment for breast cancer

Purpose
This briefing document has been produced to outline the criteria and requirements for cancer centres which intend to apply to pilot the use of an annual health check for a group of women who are living with the long-term effects of radiotherapy treatment for breast cancer and is in addition to the invitation to tender that has already been distributed to cancer networks.

Background
This brief has been produced to seek invitations and provide guidance for cancer centres considering submitting an Expression of Interest to establish a pilot clinic for the delivery of an annual health check to a group of women who are living with the long-term effects of radiotherapy treatment for breast cancer.

During the late 1970s and early 1980s, several factors combined to result in an increase in severe radiation-induced injuries, particularly, radiation-induced brachial plexus nerve injuries (RIBP) women with this condition can suffer continuous pain and/or complete loss of arm movement, breathing difficulties and bone and soft tissue destruction. Many have lost their homes, their jobs and their self confidence. As they get older their problems are deteriorating and complicating other chronic illnesses and they are increasingly fearful for the future. Their story has been recorded in ‘Yesterday’s Women’ – see http://www.macmillan.org.uk/Get_Involved/Campaigns/Latest_news/Campaigns_Update.aspx.

In 1995, The Maher Committee (set up by the Department of Health and Royal College of Radiologists) proposed guidelines to provide affected women with the care they need including annual specialist assessment, pain management, aids for daily living and psychological support. However, twelve years on, these guidelines are still to be implemented.

In 2007, as a result of a meeting at the Department of Health, Rosie Winterton MP instructed the Cancer Director Professor Mike Richards to explore more effective ways to meet the needs of these women through a partnership between the charity Macmillan Cancer Support and the Cancer Action Team. This was included in the Cancer Reform Strategy (Page 80, 5.61).

We are seeking expressions of interest to look specifically at the long term effects of radiotherapy treatment for breast cancer. A vignette of typical symptoms is on page 51.

We will be looking for organisations to establish a pilot clinic to test three specific elements;

- Giving advice and support to people about services that might be helpful.
- Raising awareness of health professionals about late effects of cancer.
- Access to a structured health check.

All patients identified as experiencing the late effects of treatment with radiotherapy for breast cancer
(see vignette Appendix A) will be offered an interview and examination by at least a clinical oncologist, an occupational therapist and a pain specialist. Each patient will have a structured assessment and a care plan sent to their GP. This will include recommendations for medication and regular diagnostic tests where appropriate.

**Project Proposal**

**Aim:**
To begin to determine how best to deliver cost effective integrated approaches to care for people living with the long-term effects of cancer, by providing a health check and advice and support to women living with the long-term effects of radiotherapy treatment for breast cancer.

**Project Objectives:**
- To plan and deliver an annual health check clinic to those who are living with the long term effects of radiotherapy treatment for breast cancer.
- To develop a framework with examples of practice to establish local services where appropriate.
- To share experience of setting up an annual health check with colleagues in other cancer centres.
- To provide information on the health checks undertaken and the long-term effects experienced by these women, whilst at the same time respecting their need for privacy and dignity.
- To contribute to an evaluation.

**Key Deliverables:**
The specific deliverables associated with this project are:

- Provision of an interview and examination for an agreed number of women living with the long term effects of radiotherapy treatment for breast cancer. This to be undertaken as a minimum by a clinical oncologist, an occupational therapist and a pain specialist, and should include pain assessment, neurological assessment, occupational therapy assessment, malignancy check, check for necrosis and/or skin breakdown.
- Development of a template to be used for assessing people living with the long-term effects of cancer treatment. This template will be developed in partnership with the cancer centres appointed to provide a health check. We anticipate that there may be two or three of these, so successful bidders will be expected to work in partnership with other centres to develop and review the template.
- Collection of information, health conditions and needs of women who have the health check.
- Provision of a report detailing services provided and the learning from the project.
- Invitation for cancer centres to tender to run a health-check clinic.
- Cancer centres are invited to tender to run a pilot health check clinic to the targeted group of women.
- Cancer centre selection criteria.

Centres seeking will therefore need to be able to demonstrate they have:

- The capability and commitment to deliver an annual health check, involving as a minimum a clinical oncologist, occupational therapist and pain specialist.
- Commitment to providing care to people living with the long term effects of cancer treatment.
- Ability to initiate, run and review a health check without causing major disruption to the delivery of other services.
- Commitment to support implementation of this new approach to care, if the pilot proves successful.
- Commitment to providing data which will contribute to the evaluation and impact of the clinics.
• Commitment to providing a final report.
• The endorsement of the cancer centre manager/clinical director to run the clinic
• Commitment to assess 5-20 patients in 2009
• It may well be that the clinic will have to be set up to run on a Saturday, or added onto an additional existing clinic.

**Pilot Evaluation Methodology**

An evaluation of the project is being commissioned and it is expected that successful bidders to undertake health checks will be expected to share data with any external evaluation where appropriate.

We hope that this project will:

• Demonstrate that regular monitoring by an oncologist, occupational therapist and pain specialist at a few selected centres is a more effective and sustainable approach to assessment than a multidisciplinary team offering this service at every centre, as originally proposed in the 1995 Royal College of Radiologists guidelines.
• Demonstrate approaches resulting in earlier identification of new problems, effective medication review & OT support together with access to helpful medical interventions and new research where appropriate.
• Demonstrate that providing women with severe progressive radiation related disabilities with additional services not currently provided by statutory services will enhance their capacity to live meaningful lives, in spite of their progressive disabilities.
• Develop elements of a new model looking at both health and social care needs which will be applicable to the management of other severe late effects.

Evaluation will be based on these and other indicators relating to other aspects of the project as a whole.

**Pilot Management and Reporting Arrangements**

The national team that is running the project will work with you to support the establishment of the clinic, specifically by providing direct liaison with the patients that need to be assessed and arranging for them to get to the clinic. The logistics of setting up an additional clinic will need to be addressed by the cancer centre and endorsed by the centre manager/clinical director.

The national team will also support you in evaluating the clinic and will provide templates to do this.

**Expression of Interest Submission Deadline**

The Expression of Interest should be submitted to Justine.palin@gstt.nhs.uk by 28th February 2009. A copy of the proforma for completion can be located on page 52.

Please note: Appointed cancer centres will need to have arrangements in place to begin seeing patients by April 2009.

For further information about the project please contact Jo Heath or Andrea Todd on 020 7091 2043 or email jheath@macmillan.org.uk.
Vignette – women living with the late effects of radiotherapy treatment for breast cancer

We know that there is a sizeable group of women who are living with the long term effects of radiotherapy treatment for breast cancer. Although the severity of their symptoms varies, the group of women we are interested in supporting in the Macmillan/Department of Health pilot study are likely to:

• Be in their late 60’s or 70’s
• Have been treated for breast cancer in the 1980’s
• Have been treated with radiotherapy.

These women are likely to have developed symptoms within five years of treatment. These symptoms vary, but usually involve several or all of the following:

• Fibrosis in any of the irradiated tissue
• Pain in the irradiated area
• Pain in the hand and or arm on the side of the body that was treated
• Breathing problems
• Bone fractures in the collarbone, ribs and or arm
• Severe lymphoedema.

Without early intervention, over the years these symptoms will have progressed to include:

• Paralysis in the shoulder, hand and/or arm
• Non-healing ulcers
• Tissue necrosis
• Severe lung problems
• Bone necrosis
• On occasions, heart problems.

They will be known to the NHS but may have been discharged by their oncologist. They may be using palliative care services, but are likely to be struggling to find any service that can help them within the NHS.
Expressions of Interest to run a pilot health check clinic

Name of Cancer Centre;

Please provide a brief outline of the pilot health check clinic you are able to run (how the clinic will be set up ie new or added onto an existing clinic session; how many patients are able to be seen, timescale for running the clinic) Maximum 250 words.

Please outline the specific services you will offer as part of the health check.

What support/ resources will you require to conduct the health check?
Please give the names and a 100 word profile of the clinical oncologist, occupational therapist and pain specialist who will be involved in the annual health check. Add any others who will be part of the assessment.

Please provide the contact details of the key individuals who will be involved in delivering the health check.

<table>
<thead>
<tr>
<th>Named Lead</th>
<th>Telephone Number</th>
<th>Email</th>
</tr>
</thead>
<tbody>
<tr>
<td>Key contact for queries</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical Oncologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain specialist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health check clinic co-ordinator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(link person with the national team)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any other key staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>involved in the proposed annual health check</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The tender submission approved by the Cancer Centre Manager/Clinical Director:

Name:                                   Signature:  

Please return your completed Expression of Interest Proforma to:  Justine.palin@gstt.nhs.uk by February 28 2009
Appendix E:
Late Effects Clinic Form
(RAGE Members Pilot)

<table>
<thead>
<tr>
<th>Name:</th>
<th>GP:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address:</td>
<td></td>
</tr>
<tr>
<td>Tel:</td>
<td>Consultant:</td>
</tr>
<tr>
<td>Date of birth:</td>
<td></td>
</tr>
<tr>
<td>NHS Number:</td>
<td></td>
</tr>
</tbody>
</table>

| Hospital where radiotherapy received: |

| Date of radiotherapy: |

| Details of surgery: |

| Details of radiotherapy: |

| Details of chemotherapy: |

Patient Summary
ONCOLOGY:  

Patient Name:

☐ Any evidence of new primary (lung, sarcoma, opposite breast, in field BCC/SCC)

☐ Chest wall skin viability

☐ Bone fractures  
  Clavicular fracture – if present, any inflammation or threat of tissue breakdown and rib fractures

☐ Signs of osteoporosis  
  Are they on prophylaxis for osteoporosis – vitamin D or Bi phosphonates

☐ Signs of hypothyroidism

☐ Significant lymphoedema (may need access to lymphoedema services e.g. at local hospice)

☐ Any cardiac problems (at risk of heart problems)

☐ Consideration of who might act as local champion /advocate to ensure long term access to specialist expertise

---

ONCOLOGY:  

Patient Name:

AREA OF DISABILITY

☐ Shoulder Right/Left

☐ Arm Right/Left

☐ Hand Right/Left

☐ Chest

☐ Breathlessness

☐ Other
**LYMPHOEDEMA**

- Lymphatic drainage
- Massage
- Physiotherapy
- Bandaging
- Other

**PERSONAL CARE**

**DOMESTIC TASKS**

**WORK**

**LEISURE**

**SOCIAL ISSUES/RELATIONSHIPS**

**OTHER**
<table>
<thead>
<tr>
<th>PAIN:</th>
<th>Patient Name:</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>AREA OF PAIN</strong></td>
<td></td>
</tr>
<tr>
<td>☐ Shoulder Right/Left</td>
<td></td>
</tr>
<tr>
<td>☐ Arm Right/Left</td>
<td></td>
</tr>
<tr>
<td>☐ Hand Right/Left</td>
<td></td>
</tr>
<tr>
<td>☐ Chest</td>
<td></td>
</tr>
<tr>
<td>☐ Back</td>
<td></td>
</tr>
<tr>
<td>☐ Other</td>
<td></td>
</tr>
<tr>
<td><strong>TYPE OF PAIN</strong></td>
<td></td>
</tr>
<tr>
<td>☐ Mechanical</td>
<td></td>
</tr>
<tr>
<td>☐ Neuropathic</td>
<td></td>
</tr>
<tr>
<td>☐ Other</td>
<td></td>
</tr>
<tr>
<td><strong>TREATMENT RECEIVED</strong></td>
<td></td>
</tr>
<tr>
<td>☐ Medication</td>
<td></td>
</tr>
<tr>
<td>☐ Tens Machine</td>
<td></td>
</tr>
<tr>
<td>☐ Surgery</td>
<td></td>
</tr>
<tr>
<td>☐ Other</td>
<td></td>
</tr>
<tr>
<td><strong>PSYCHOLOGY</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EXPECTATIONS</strong></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OTHER</strong></td>
<td></td>
</tr>
</tbody>
</table>
EMOTIONAL SUPPORT

BODY IMAGE

LYMPHOEDEMA NEEDS/REFERRAL FOR SEVERE LYMPHOEDEMA CARE
# RECOMMENDED CARE PLAN

<table>
<thead>
<tr>
<th>Oncology</th>
<th>Local Provision</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapy</td>
<td></td>
</tr>
<tr>
<td>Pain</td>
<td></td>
</tr>
<tr>
<td>Referrals</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Different Clinic Formats

The clinics were asked to provide a one-off multi-disciplinary clinic with a minimum of an oncologist, a pain specialist and an occupational therapist. They did this in many different ways and were able to see between four and seven patients in one session.

**ROYAL MARSDEN**

Seven patients seen in Outpatients Dept on a Saturday. Appointments took between 15-35 mins. Patients were seen as and when the specialist became available.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology</th>
<th>Chronic Pain</th>
<th>Acupuncture</th>
<th>OT</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.00</td>
<td>Patient 1</td>
<td>Patient 2</td>
<td>Patient 3</td>
<td>Patient 4</td>
</tr>
<tr>
<td></td>
<td>Patient 4</td>
<td>Patient 1</td>
<td>Patient 4</td>
<td>Patient 1</td>
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<tr>
<td></td>
<td>Patient 3</td>
<td>Patient 3</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td>13.00</td>
<td>Patient 2</td>
<td>Patient 4</td>
<td>Patient 2</td>
<td>Patient 3</td>
</tr>
<tr>
<td></td>
<td>Patient 5</td>
<td>Patient 6</td>
<td>Patient 6</td>
<td>Patient 7</td>
</tr>
<tr>
<td></td>
<td>Patient 7</td>
<td>Patient 7</td>
<td>Patient 5</td>
<td>Patient 6</td>
</tr>
<tr>
<td></td>
<td>Patient 6</td>
<td>Patient 5</td>
<td>Patient 7</td>
<td>Patient 5</td>
</tr>
</tbody>
</table>

**MOUNT VERNON**

Five patients seen in Lynda Jackson Macmillan Centre Patients. Appointments were staggered by 20 mins and they were given appointments as and when the clinicians became available.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology + Palliative Care</th>
<th>OT &amp; Complementary Therapist</th>
<th>Lymphoedema Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.30</td>
<td>Patient 1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1.50</td>
<td>Patient 2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.10</td>
<td>Patient 3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.30</td>
<td>Patient 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.50</td>
<td>Patient 5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
BRISTOL
Six patients were seen in Penny Brohn Cancer Centre. Each had a 30 minute appointment with each specialist.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology</th>
<th>Palliative Care</th>
<th>OT</th>
</tr>
</thead>
<tbody>
<tr>
<td>12.30</td>
<td>Patient 1</td>
<td>Patient 2</td>
<td>Patient 3</td>
</tr>
<tr>
<td>13.00</td>
<td>Patient 2</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td>13.30</td>
<td>Patient 3</td>
<td>Patient 3</td>
<td>Patient 1</td>
</tr>
<tr>
<td>14.00</td>
<td>Clinicians meeting and feedback to patients</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.45</td>
<td>Patient 4</td>
<td>Patient 5</td>
<td>Patient 6</td>
</tr>
<tr>
<td>15.15</td>
<td>Patient 6</td>
<td>Patient 4</td>
<td>Patient 5</td>
</tr>
<tr>
<td>15.45</td>
<td>Patient 5</td>
<td>Patient 6</td>
<td>Patient 4</td>
</tr>
</tbody>
</table>

RD&E EXETER
Five patients seen in Exeter Oncology Centre. All came together and were seen individually by the oncologist who assessed their need and introduced them to the relevant specialists.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology</th>
<th>Chronic Pain</th>
<th>Physio</th>
<th>Breastcare Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>14.15</td>
<td>Patient 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient 3</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Patient 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient 5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

CHRISTIE MANCHESTER
Five patients seen in Derek Crowthers (Clinical Trials) Unit. They had two appointments of approx 30 mins with the doctors and OTs

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology + Chronic Pain</th>
<th>OT x2</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.30</td>
<td>Patient 1</td>
<td>Patient 4</td>
</tr>
<tr>
<td>1.50</td>
<td>Patient 2</td>
<td>Patient 1</td>
</tr>
<tr>
<td>2.10</td>
<td>Patient 3</td>
<td>Patient 2</td>
</tr>
<tr>
<td>2.50</td>
<td>Patient 4</td>
<td>Patient 3</td>
</tr>
</tbody>
</table>
**BARTS 1 & 2**

Four patients seen in Outpatients Dept. Appointments were approx 20 mins with all specialists but 45 mins with the OT

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology</th>
<th>Chronic Pain</th>
<th>OT</th>
<th>Breastcare Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.00</td>
<td>Patient 1</td>
<td>Patient 2</td>
<td>Patient 3</td>
<td>Patient 4</td>
</tr>
<tr>
<td></td>
<td>Patient 4</td>
<td>Patient 1</td>
<td>Patient 2</td>
<td>Patient 3</td>
</tr>
<tr>
<td></td>
<td>Patient 3</td>
<td>Patient 4</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td></td>
<td>Patient 2</td>
<td>Patient 3</td>
<td>Patient 4</td>
<td>Patient 1</td>
</tr>
</tbody>
</table>

**NEWCASTLE**

Six patients were seen in Haematology/Oncology Outpatients Dept. Patients had 30 minute appointments with 3 specialists

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology</th>
<th>Palliative Care</th>
<th>OT x 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.00</td>
<td>Patient 1</td>
<td>Patient 2</td>
<td>Patient 3</td>
</tr>
<tr>
<td>13.30</td>
<td>Patient 3</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td>14.00</td>
<td>Patient 2</td>
<td>Patient 3</td>
<td>Patient 1</td>
</tr>
<tr>
<td>14.30</td>
<td>Patient 4</td>
<td>Patient 5</td>
<td>Patient 6</td>
</tr>
<tr>
<td>15.00</td>
<td>Patient 6</td>
<td>Patient 4</td>
<td>Patient 5</td>
</tr>
<tr>
<td>15.30</td>
<td>Patient 5</td>
<td>Patient 6</td>
<td>Patient 4</td>
</tr>
</tbody>
</table>

**BATH**

Four patients were seen in the Royal National Hospital for Rheumatic Diseases with Oncologist from Royal Hospital Bath. Patients had two x one hours appointments with two teams of specialists

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncologist + Rheumatologist</th>
<th>OT + Consultant Nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.15</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td>10.15</td>
<td>Patient 2</td>
<td>Patient 1</td>
</tr>
<tr>
<td>11.15</td>
<td>Patient 3</td>
<td>Patient 4</td>
</tr>
<tr>
<td>12.15</td>
<td>Patient 4</td>
<td>Patient 3</td>
</tr>
</tbody>
</table>
### SOUTHAMPTON

Four patients were seen in Moorgreen Hospital (Education Centre). Appointments were 40 mins with each team.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology + Palliative Care</th>
<th>OT</th>
</tr>
</thead>
<tbody>
<tr>
<td>14.00</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td>14.40</td>
<td>Patient 2</td>
<td>Patient 1</td>
</tr>
<tr>
<td>15.20</td>
<td>Clinicians meeting and feedback to patients</td>
<td></td>
</tr>
<tr>
<td>15.50</td>
<td>Patient 3</td>
<td>Patient 4</td>
</tr>
<tr>
<td>16.30</td>
<td>Patient 4</td>
<td>Patient 3</td>
</tr>
<tr>
<td>17.10</td>
<td>Clinicians meeting and feedback to patients</td>
<td></td>
</tr>
</tbody>
</table>

### EDINBURGH

Three patients seen in Edinburgh Cancer Centre (one patient DNA). All came together. Oncologist was unexpectedly unable to attend two teams of specialists.

<table>
<thead>
<tr>
<th>Time</th>
<th>Palliative Care</th>
<th>OT &amp; Physio</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.30</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td></td>
<td>Patient 2</td>
<td>Patient 1</td>
</tr>
<tr>
<td></td>
<td>Patient 3</td>
<td>Patient 3</td>
</tr>
</tbody>
</table>

### ST JAMES’ LEEDS x 2

Four patients were seen in Oncology Outpatients Suite. Patients had 40 minute appointments with two teams of specialists.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology + Chronic Pain + Nurse</th>
<th>OT &amp; Physio</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.30</td>
<td>Patient 1</td>
<td></td>
</tr>
<tr>
<td>10.10</td>
<td>Patient 2</td>
<td>Patient 2</td>
</tr>
<tr>
<td>10.50</td>
<td>Patient 3</td>
<td>Patient 1</td>
</tr>
<tr>
<td>11.30</td>
<td>Patient 4</td>
<td>Patient 4</td>
</tr>
<tr>
<td>12.10</td>
<td></td>
<td>Patient 3</td>
</tr>
</tbody>
</table>
**MAIDSTONE**

Six patients were seen in Kent Oncology Centre. They each had 30 min appointments with 3 teams of specialists.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology + radiographer</th>
<th>Chronic Pain</th>
<th>OT + Physio</th>
</tr>
</thead>
<tbody>
<tr>
<td>14.00</td>
<td>Patient 1</td>
<td>Patient 2</td>
<td>Patient 3</td>
</tr>
<tr>
<td>14.30</td>
<td>Patient 3</td>
<td>Patient 1</td>
<td>Patient 2</td>
</tr>
<tr>
<td>15.00</td>
<td>Patient 2</td>
<td>Patient 3</td>
<td>Patient 1</td>
</tr>
<tr>
<td>15.30</td>
<td>Clinicians meeting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.00</td>
<td>Patient 4</td>
<td>Patient 5</td>
<td>Patient 6</td>
</tr>
<tr>
<td>16.30</td>
<td>Patient 6</td>
<td>Patient 4</td>
<td>Patient 5</td>
</tr>
<tr>
<td>17.00</td>
<td>Patient 5</td>
<td>Patient 6</td>
<td>Patient 4</td>
</tr>
</tbody>
</table>

**QUEENS ROMFORD**

Five patients were seen in the Oncology Outpatients Dept. All came together. Patients had appointments for approx 20 min with whichever specialist was appropriate.

<table>
<thead>
<tr>
<th>Time</th>
<th>Oncology x 2</th>
<th>Pain nurse + neurologist</th>
<th>OT &amp; Physio nurse</th>
<th>Breastcare nurse</th>
<th>Skin + tissue viability nurse</th>
</tr>
</thead>
<tbody>
<tr>
<td>15.00</td>
<td>Patient 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient 2</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient 3</td>
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If you have any questions about cancer, ask Macmillan. If you need support, ask Macmillan. Or if you just want someone to talk to, ask Macmillan.

Our cancer support specialists are here for everyone affected by cancer, whatever your need.

Call free on 0808 808 00 00, Monday to Friday, 9am to 8pm

www.macmillan.org.uk

We have an interpretation service in over 200 languages. Just state, in English, the language you wish to use when you call.

If you are deaf or hard of hearing, you can use our textphone service on 0808 808 0121, or the Text Relay system.