Welcome to the third edition of the newsletter for Cancer Services at The Pennine Acute Hospitals NHS Trust, providing news and an insight into Cancer Services delivered by the Trust.

**Acute Oncology Service (AOS) - Now Live**

A team of Macmillan Acute Oncology Nurses, supported by co-ordinators is now in place and delivering a Trust-wide service, to support urgent care teams to provide optimal care to patients who present with acute oncological problems.

This includes:

- Complications of cancer treatment e.g. neutropenic sepsis, severe mucositis or uncontrolled nausea and vomiting.
- Complications caused by the cancer e.g. metastatic spinal cord compression, hypercalcaemia or lymphangitis, specifically when a patient presents with urgent and acute problems.
- Patients who present with a cancer of unknown primary, where the original site of the cancer has not been identified.

The service, which is co-ordinated from the service office at The Royal Oldham Hospital where all referrals, alerts and telephone calls are managed, operates Monday to Friday during 08.30-16.30. It is currently operating with two nurses in post; Sharron Deane and Tracy Wild. A third nurse is joining the team early in the year.

Development of the service includes the introduction of a flagging system to alert staff to patients known to have a cancer diagnosis who present at the Trust, and to support early and appropriate intervention. The flagging will be placed on the records of all patients who have been diagnosed with cancer or a recurrence of cancer at the Trust in the previous 2 years. Patients will then need to be assessed to determine whether they are presenting because of an acute oncological problem, and the team has been training staff to help them identify patients who should be referred to the service. Patients diagnosed elsewhere, or who are existing in-patients who develop an acute oncological problem, will not be flagged and will need a specific referral to the team for assessment.

Development of the service is a mandatory requirement and has been funded by the Greater Manchester and Cheshire Cancer Network and Macmillan Cancer Support. The aim of acute oncology services is to promote optimal care of oncology patients with urgent care needs, and support reduced lengths of stay, improve patient outcomes and enhance experience, and potentially prevent avoidable admissions to hospital. Key Performance Indicators will be monitored to demonstrate the impact of the service.

To find out more about the Macmillan Acute Oncology Nursing Service or to discuss any issues relating to acute oncology or to access advice please phone 0161 627 8134.

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**Inside this issue:**

- Macmillan Cancer Support at Pennine
- National Cancer Patient Experience Survey
- Welcome to New Staff
- Macmillan Buddying Scheme
- Lymphoedema Drop-in
- Information Prescriptions Update
- Trust Meets Cancer Waits Challenge
- Farewell to Juliette Mottram
- New Website Puts Spotlight on Cancer
- The Liverpool Care Pathway
- Regional Vision for Cancer Services
- Cancer Team Contacts
- Getting in Print
Macmillan Cancer Support and Pennine Acute Hospitals NHS Trust

Macmillan Cancer Support is a national charity which provides practical, clinical and financial support for people affected by cancer, as well as campaigning for better cancer care. It has a long history of working with our Trust to help provide services not just for the person with cancer, but also those around them.

Treatment and care of people with cancer is a significant part of the workload at the Trust, with patients seen at all stages of the patient pathway from pre-diagnosis to end of life care. Macmillan has for many years invested in cancer services at the Pennine Acute Hospitals NHS Trust: did you know that there are currently over 70 professionals at the Trust who have the word Macmillan in their title? Have you ever wondered what that means? Although we’ve probably all heard of Macmillan nurses, they are only a small part of what Macmillan provides.

Why do people affected by cancer need additional support? ‘One in three of us will get cancer and it’s the toughest thing most of us will ever face. If you’ve been diagnosed with cancer, or a loved one has, you’ll want a team of people in your corner supporting you every step of the way’1. A cancer journey can be long and unpredictable, with lengthy periods of treatment and recovery which can affect the patient’s ability to return to normal activities. It can also make considerable demands on the patient’s family, both practically and emotionally.

Originally set up over 100 years ago to provide support to people who were dying from cancer, Macmillan has evolved to meet the changing needs of cancer patients and their families, as more people live longer after a diagnosis of cancer. Although it is still very much involved in palliative and end of life care Macmillan is now working hard to change the perception that they are only concerned with death and dying, reflected in the change of name from Macmillan Cancer Relief, to Macmillan Cancer Support in 2006. This includes working to ensure that people are able to return to as normal a life as possible, through rehabilitation and survivorship initiatives aimed at helping people to adjust to living after a diagnosis and treatment.

Services or posts are either ‘pump-primed’ - funded by Macmillan from set-up with an expectation that after initial funding ends the host organisation will continue it, ‘adopted’, which means that an existing post can access the benefits provided by Macmillan, including Macmillan training courses, grants for education and equipment and other resources provided by Macmillan, or ‘project posts’ where the funding is provided to support a time-limited, defined piece of work. Macmillan does not therefore directly employ any of these posts, and post holders are employed by the Trust. Examples of the diverse posts and services Macmillan has funded or supported, which enhance the care provided at the Trust:

- Macmillan Cancer Information and Support Centre at North Manchester General Hospital (development of the centre and pump-priming of posts in the centre)
- Macmillan Oral Health Practitioner
- Macmillan Welfare Rights Adviser (based at North Manchester General Hospital, employed by Manchester City Council)
- Macmillan Clinical Nurse Specialists (including tumour specific e.g. breast, lung, etc and specialist palliative care
- Macmillan Speech and Language Therapist
- Macmillan Acute Oncology nurses
- Free booklets for people affected by cancer about their cancer, treatment and living with the effects of a cancer diagnosis
- Macmillan grants for people affected by cancer which has caused them financial hardship
- Music in Hospitals sessions for cancer patients, held on wards J5, NMGH and F11, ROH
- Grants and support to the Trust’s Cancer Patient User Partnership (PPUP) group.

Anyone can access free on-line training courses on Macmillan’s Learnzone website: http://learnzone.macmillan.org.uk

To find out more about Macmillan Cancer Support, visit their website www.macmillan.org.uk, or look out for details of a ‘meet Macmillan’ event to be held at the Trust in the next few months.

1. Source: www.macmillan.org.uk/aboutus
The results of the second National Cancer Patient Experience Survey were published in September 2012, following on from the 2010/11 survey which was reported in January 2011. The Trust was one of 160 NHS Trusts which participated in the survey.

The survey included all aged 16 and over with a primary diagnosis of cancer who had been admitted as a day case or in-patient, and had been discharged between 1st September and 30th November 2011. Patients with cancer were identified by the Trust and a postal questionnaire was sent to them at their home address by the National Cancer Action Team. Up to two reminders were sent to non-responders. A freepost envelope was included for replies and patients could also call a free telephone line to ask questions, complete the questionnaire verbally, or access an interpreting service.

A total of 113,808 patients, from 13 different cancer groups, who had received treatment for cancer from September to November 2011 were included in the national sample, of which 1057 were from Pennine Acute Hospitals NHS Trust. Of these 578 questionnaires were returned completed. This represents a response rate of 59% once deceased patients and questionnaires returned undelivered had been accounted for, and compared with a national response rate of 68% (71,793 respondents).

The questionnaire is made up of 64 questions in 15 sections ranging from ‘Seeing your GP’, ‘Support for people with cancer’ to ‘Your overall NHS care’. 8 new questions were introduced, including 3 around research. 1 question related to radiotherapy treatment which is not provided by the Trust; therefore the responses to 63 questions were reported, and comparisons with the previous year’s results was possible for 55 questions. In almost all Trusts, there were tumour groups where the number of respondents was less than 20, and this was particularly true for rarer cancers. Where numbers of respondents in a particular tumour group were less than 20 responses were not reported. Patients were asked to answer questions about treatment at this Trust, so where treatment was carried out at a different Trust as part of the patient’s treatment pathway (e.g. patients with prostate cancer attending MRI for surgery) patients only answered the questions relevant to their treatment here.

The Trust’s overall results showed:

- Scores for 32 questions improved, but not significantly
- 4 questions scored significantly higher than in the previous survey (information about financial help, free prescriptions, the patient’s condition and treatment, and emotional support given)
- Scores for 5 items were the same as last year
- 13 questions scored lower than in the previous survey, but not significantly
- 1 item scored significantly lower than the previous survey (waiting longer than 30 minutes in out-patients for the appointment to start).

Bespoke Trust level reports have been provided by the National Cancer Action Team, with results broken down by cancer type. Cancer teams at the Trust have produced action plans to address the results for their team, and progress will be monitored as part of the cancer peer review programme and the Trust’s audit monitoring processes. Where there were insufficient numbers of responses, local surveys of patient experience will be carried out. The national survey will be repeated annually and the next one will be carried out between January and July 2013, focusing on patients discharged between 1st September and 30th November 2012. The Trust will also be participating in a survey of patients undergoing chemotherapy treatment between 1st March and 31st August 2012 and is currently identifying patients who are eligible to take part.

For further information about the national cancer Patient Experience Survey go to www.dh.gov.uk, and enter ‘cancer survey’ in the search box.
Macmillan Buddying Scheme

An innovative approach to direct service delivery is being developed by Macmillan Cancer Support and the Pennine Cancer Patient User Partnership. The Buddying Scheme is designed to meet the increased need for practical and emotional support amongst people affected by cancer, by equipping and supporting volunteers to create local services that meet their communities’ needs.

The scheme has been developed following the success of a Macmillan pilot project, is designed to complement the work of Macmillan professionals, to offer a listening ear – little things that make a big difference to people affected by cancer. The first cohort of volunteers has been recruited and training has been provided by Macmillan.

The scheme has experienced some challenges, as outlined below:

- The scheme has taken longer to get off the ground than originally anticipated.
- The intensive level of input required from Macmillan and Trust staff in a variety of roles, supporting training and recruitment.
- Recruitment and implementation has been affected by availability of volunteers.
- The process of identifying a lead volunteer.
- Agreeing and arranging referral routes.
- Branding of the service.

These issues should be resolved in the next few months and active buddying of people affected by cancer should then commence.

For more information, contact Angela Wood on 0161 604 5880 (45880 internal).

Lymphoedema drop-in at the Macmillan Cancer Information & Support Centre at North Manchester General Hospital

Lymphoedema is a chronic condition which can arise as a result of cancer and its treatment as well as other causes. The symptoms, including swelling of the affected area, can be debilitating and although it cannot be cured the swelling and any infection present can be controlled. Education of people at risk of lymphoedema, alongside early detection and effective treatment can improve quality of life.

Helen Readdie, Macmillan Lymphoedema Specialist Nurse at the Trust held an awareness drop-in session at the Macmillan Cancer Information and Support Centre recently. Targeting patients, carers and health care professionals, the session aimed to heighten awareness of this condition and offer support and advice. It was also attended by a patient with lymphoedema who provided support to newly diagnosed patients and shared her own experiences, providing an insight into treatment and living with lymphoedema.

The session, which was very well received, was also supported by a manufacturer of lymphoedema support garments who demonstrated products to patients and provided refreshments. For more information about lymphoedema contact Helen Readdie 0161 778 5237 (75237 internal) or the Macmillan Information & Support Centre, 0161 604 5244 (45244 internal).
Trust Meets Challenge of Cancer Waiting Times

Getting cancer diagnosed as early as possible, and starting treatment quickly is key to improving survival for many cancers. Meeting national targets introduced to ensure timely diagnosis and treatment for patients with cancer can at times represent a challenge, for many different reasons.

The table below shows the trust’s performance for the last 4 quarters:

<table>
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<tr>
<th>Cancer Target</th>
<th>National Target</th>
<th>Pennine Performance (%)</th>
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<tr>
<td></td>
<td>Q3 11/12</td>
<td>Q4 11/12</td>
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<tr>
<td>Patients seen within 2 weeks of GP referring as suspected cancer</td>
<td>93%</td>
<td>97.2</td>
</tr>
<tr>
<td>Patients with any breast symptoms seen within 2 weeks of GP referral</td>
<td>93%</td>
<td>97.4</td>
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<tr>
<td>Patients starting first treatment within 31 days of the decision about treatment</td>
<td>96%</td>
<td>98.6</td>
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<tr>
<td>Patients starting subsequent drug treatment within 31 days of the decision about that treatment</td>
<td>98%</td>
<td>100</td>
</tr>
<tr>
<td>Patients having subsequent surgical treatment within 31 days of the decision about that treatment</td>
<td>94%</td>
<td>97.9</td>
</tr>
<tr>
<td>Patients with a confirmed cancer diagnosis starting first treatment with 62 days of urgent suspected cancer GP referral</td>
<td>85%</td>
<td>81.7</td>
</tr>
<tr>
<td>Patients starting treatment within 62 days after urgent referral as a result of attending screening (breast, bowel or cervical)</td>
<td>90%</td>
<td>58.8</td>
</tr>
<tr>
<td>Patients starting treatment within 62 days after non-urgent referral by GP when referral has been upgraded to suspected cancer by their consultant</td>
<td>85%</td>
<td>74.7</td>
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The 62 day targets were a particular challenge to the Trust but recovery plans and weekly monitoring have ensured that the Trust is meeting all targets. The Trust is fully engaged with the cancer network and other providers across the patient pathway to achieve the targets, which include the need for all patients referred to a treating tertiary centre to have been diagnosed and ready for onward transfer by day 42 of their pathway, to allow the tertiary centre time to assess and treat patients within the 62 day target. Cancer performance is managed via the Trust's Performance Management Group, the Trust Cancer Committee and weekly cancer performance meetings.

Information Prescriptions update

The Trust continues to work towards implementing information prescriptions for cancer patients. Alyson Brandom Macmillan Lead Information Prescription Facilitator from the National Cancer Action Team worked with the Trust up to the end of November 2012 to help support implementation, and together with the steering group has developed an action plan and exit strategy which will be available in early 2013. Achievements to date include:

120 staff have been trained in information prescription delivery, including use of the electronic information prescription system on NHS Choice (see www.nhs.uk/ips)

Debbie Clark, Macmillan Hepato-biliary Nurse Specialist and Annette German, Urology Lead Nurse, have worked with Alyson Brandom and Felicity Keeling, Macmillan Information Service Manager at the Trust, to develop paper information guides which can be used to prescribe information for patients. These will be implemented in early 2013.

A consent form has been developed for patients who agree to information being emailed to them via the Information Prescription Service on NHS Choice.

This important initiative, which the Trust hopes to extend to patients with other chronic conditions, will continue to be driven by the Information Prescriptions Steering Group chaired by Angela Wood, Patient Partnership Manager. For more information contact Felicity Keeling on 0161 604 5244 (45244 internal).
Farewell to Juliette Mottram, Lead Cancer Manager

After over 5 years at the Trust, Juliette Mottram, Lead Cancer Manager, has left to take up post as Lead Cancer Manager at East Lancashire Hospitals NHS Trust.

Said Juliette ‘I have really enjoyed working at the Trust, and particularly the challenges of working in a large Trust in one of the largest cancer networks in the country. I love working in cancer – my role has been one where I feel an administrative manager makes a real contribution to patient care. I am moving to a similar role at a Trust nearer to home, which will mean much less travel for me, but I will miss everyone, especially the staff who worked and reported directly to me.

My role involved working closely with many groups of staff, including cancer clinicians, directorate managers, divisional directors, heads of departments and numerous clerical support staff. In particular all members of the cancer multi-disciplinary teams helped me to fulfil my role, for which I am very grateful. The work also meant developing good relationships with staff in primary care involved in developing cancer services for our local community.

I was particularly impressed by the Trust’s Cancer Patient User Partnership (PPUP) group and have attended several of their meetings over the years – they do excellent work to support the Trust to develop cancer services across the Pennine footprint. Alison McCarthy, Macmillan Lead Nurse for Cancer and Palliative Care has also been a key source of support to me. I know I was always nagging people about cancer breaches, but it was always done in the interest of patient quality, and I will miss the interactions with the clinical teams that this brought.’

On behalf of the Trust Rob Gillies, the previous Lead Cancer Clinician said ‘Juliette is totally dedicated to improving the care of cancer patients and was an immensely valuable member and leader of the Pennine team. She played a key role in improving the quality of care delivered to our patients and leaves with our sincere thanks and best wishes for her new post’.

Juliette extends her thanks to everyone who came to wish her well, and for all the cards, flowers and presents she received.

New website puts spotlight on cancer services

The National Peer Review Team has launched a new website, www.mycancertreatment.nhs. The development of the site, which is in line with the NHS patient agenda of ‘no decision about me, without me’, has been driven by the National Cancer Peer Review (NCPR) user steering group. The group is made up of patients and carers who work closely with the NCPR team.

The site allows patients to see assessments of the quality of cancer services and locate and compare cancer services across the country. It aims to empower patients to be able to make informed decisions when they are choosing where to be treated. It is built on intelligence gathered from assessments of cancer teams carried out as part of the NCPR quality assurance programme, and includes detailed reports for thousands of clinical teams across England who specialise in the diagnosis and treatment of specific cancers.

Users of the site can access information about waiting times, compliance with peer review measures, comparisons of individual teams with median scores nationally, as well as performance in the National Cancer Patient Experience survey.

Details of teams providing services for brain and central nervous system, breast, colorectal, gynaecological, head and neck, lung, sarcoma, skin, upper gastro-intestinal, urological cancers as well as chemotherapy and radiotherapy are currently available. In the next stage of the website development Acute Oncology, Children’s, Teenage and Young Adults, Complementary Therapy, Psychology, Rehabilitation and Specialist Palliative Care services will also be included.
The Liverpool Care Pathway (LCP)

There has recently been much in the press about the Liverpool Care Pathway, with many questions and concerns being raised by both patients and relatives. The purpose of the pathway hasn’t always been clearly explained, so here are some facts and information about the pathway and its use.

What is it?
The LCP is a care plan devised to give guidance for staff to provide the best care at end of life which
• is based on the hospice model of care
• was developed by the Marie Curie Institute at Liverpool (hence the name)
• involves regular review and assessment
• ensures the patient is comfortable and all aspects of care are addressed
• encourages discussion with the patient, their family and carers
• neither hastens nor postpones dying
• does not rule out medical interventions.

If there is any improvement in the patient’s condition the patient can be taken off the pathway.

Research has shown that most people would prefer to die at home with their symptoms managed and family present, but only around 18% achieve this, with more than 58% dying in acute hospitals. The LCP aims to make sure people who are dying receive the most appropriate, best quality of care. It is recommended as a model of best practice by the Department of Health.

The human body is truly amazing! It copes with many changes through our lifetimes, from birth through puberty, pregnancy and menopause and old age; it also makes changes to cope with the dying process. As the body slows down the organs become less able to function, there is often a reduced need for food and drink in the last weeks, and the feeling of thirst is diminished. If fluids are given artificially at this time, it can often result in an overload of fluids causing difficulty in breathing as the organs are unable to process the fluids. The LCP recommends that patients are supported to drink for as long as possible, but if they are no longer able to do this then frequent mouth care is given.

Unfortunately this has been interpreted by some as starving people to death. But by this stage patients often don’t have the feeling of thirst, as when a wet swab is used to give mouth-care the patient rarely sucks on the swab. If they do show signs of thirst, then artificial fluids are considered.

How do we know when the LCP is appropriate?
Medical advancements in recent years have meant that many illnesses can be treated, but at some stage nature will take its course despite interventions. The decision to start the pathway is not taken lightly, and is made by the team, along with the family and patient. The doctors and nurses involved look at how progressed the disease is, what signs have been shown over the last weeks/days that the patient may be dying, and rule out any reversible causes, such as blood imbalances, that could be treated. By doing this and through discussions with the family/patient, the team can then assess if the patient is approaching end of life. The patient is continuously assessed, and if there are any improvements in condition then the pathway is stopped. In conclusion the LCP is designed to help staff manage symptoms, keep the patient comfortable and support the family at this difficult time. The LCP is used to provide a dignified death, with symptoms under control; when there has been a poor experience, it is usually because the pathway has been used inappropriately. If you have any questions please don’t hesitate to contact the Cancer Support Centre who will direct you to your local Macmillan team.

In September 2012 The National Council for Palliative Care was among a range of leading health and social care organisations who published a consensus statement on the LCP. The charity supports the appropriate use of the LCP and makes clear that it is not in any way about ending life, but rather about supporting the delivery of excellent end of life care. However, it must be used correctly and proper training and education are vital for it to be successful. For more information, go to www.dyingmatters.org.uk. For details of training provided by the Trust see the Professional and Learning Development Plan Bulletin on the Trust’s Intranet, in the Training and Development section.

If you have any further questions please contact the Macmillan Cancer Information and Support Centre (0161 604 5244) and staff will signpost you to the most appropriate person.
New Regional Vision for Cancer Services

At an event held on 24th and 25th September, attended by patients and stakeholders in cancer services across the region as well as national ‘Cancer Tsar’ Mike Richards, the NHS Greater Manchester & Cheshire Vision for Cancer Services was produced. The document is part of a set of vision documents for the Healthier Together programme for health services generally across the area. It provides a clear mandate for the development of a radically new cancer system, cancer leadership and model of care.

The vision for cancer includes:

- More robust commissioning of cancer services
- The development of world class cancer services, with no waiting times
- Prioritisation of prevention and detection with a commitment to public health and awareness campaigns
- Specialist surgery developed beyond national standards
- Increased focus on survivorship
- Fully integrated IT systems
- New governance arrangements

Work is now underway to develop and implement new models of care which reflect the aspirations included in the vision. This includes the establishment of a new Greater Manchester & Cheshire Cancer Provider Board, and a unified cancer commissioning structure to be defined and implemented from April 1st 2013 when the current Greater Manchester and Cheshire Cancer Network ceases to exist.

Discussions are underway to finalise specialist cancer surgical services for gynaecology, hepatopancreato-biliary, upper gastro-intestinal and urological cancers. NHS GM is also working with local CCG commissioners, NCAT and other national bodies to define service specifications for cancer surgery which will go beyond minimum, national IOG standards. Work will be carried out by NHS Greater Manchester to ensure that Acute Oncology Services are available at all Trusts providing Urgent Care and Accident and Emergency services, by 1st April 2013.

NHS Greater Manchester is also working to secure a potential £2 million investment from Macmillan Cancer Support to support the development and re-design of cancer pathways in Manchester to enhance primary care, community care and survivorship, which will enhance help to facilitate the vision.

A copy of the report ‘A Greater Manchester and Cheshire Vision for Cancer Services’ can be downloaded from the Greater Manchester and Cheshire Cancer Network website, www.gmccn.nhs.uk

Cancer Team Contacts (internal numbers in brackets)

<table>
<thead>
<tr>
<th>Name</th>
<th>Phone Number</th>
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<tbody>
<tr>
<td>Christina Kenny, Lead Cancer Clinician</td>
<td>0161 604 5454 (45454)</td>
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<tr>
<td>Vacant, Lead Cancer Manager</td>
<td>0161 918 4331 (44331)</td>
</tr>
<tr>
<td>Alison McCarthy, Macmillan Lead Cancer and Palliative Care Nurse</td>
<td>0161 627 8699 (78699)</td>
</tr>
<tr>
<td>Alice Davies, Macmillan Associate Lead Cancer and Palliative Care Nurse</td>
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<tr>
<td>Catherine Sharp, Macmillan PA / Specialist Palliative Care Admin Team Leader</td>
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<td>Lindsey Newton, Macmillan Lead Chemotherapy Nurse</td>
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<td>Felicity Keeling, Macmillan Information Service Manager</td>
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<td>Liz Barwick, Cancer Support Manager</td>
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<td>Hazel Nangle, Cancer Clinical Data Analyst</td>
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<td>Sandra Wood, Cancer Performance Manager</td>
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<tr>
<td>Heather Kilpatrick, Cancer Tracker Supervisor</td>
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<tr>
<td>Christine Noble, Peer Review Co-ordinator and Cancer Team Support</td>
<td>0161 918 4461 (44461)</td>
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This newsletter will be published quarterly. If you have anything you would like to include in a future edition please contact Felicity Keeling on 0161-604-5244 or e-mail felicity.keeling@pat.nhs.uk. Deadlines for future editions are: April 30th; July 1st; October 7th 2013