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NAEDI Newsletter

National Awareness and Early Diagnosis Initiative

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Welcome to the sixth edition of the NAEDI newsletter. It's been a busy few months with lots of activity, much of it driven by the announcement of funding for 59 local projects and two regional bowel cancer awareness pilots, and the International Cancer Benchmarking Partnership. This newsletter has more information on all of these and lots more.

If you have questions about NAEDI or any of its activity, please don't hesitate to get in touch by emailing naedi@cancer.org.uk or visit www.naedi.org.uk to find out more.

New Government cancer strategy

Improving Outcomes: A Strategy for Cancer was published on 12th January and sets out the Government's plans for cancer care in England. More than £750 million has been committed to the plans over four years, with over £450 million identified to increase earlier diagnosis of cancer. This includes funding for Public Health England to promote cancer screening and raise awareness of signs and symptoms, and for increased access for GPs to diagnostic tests.

The strategy document refers to several NAEDI-related activities which have been taking place since the Initiative was formally launched in November 2008, including the national audit of cancer diagnosis in primary care and the recently announced local projects on breast, bowel and

lung cancer. And it highlights the findings of the recent [Routes to Diagnosis](#) analysis, which indicated that a significant proportion of cancer patients are diagnosed following emergency presentation.

As well as plans related to earlier diagnosis of symptomatic cancer, the strategy updates on progress and outlines plans for cancer screening, and for areas across the cancer-related pathway.

The Department have also published a *Review of Cancer Waiting Times Standards* which confirms that the standards will be maintained without change.

Both the Strategy and the Review can be downloaded from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123371

First NAEDI research call

At the end of 2009, a research call was issued under the auspices of the National Cancer Research Institute (NCRI) for project grant applications on raising awareness and early detection of cancer. This was a broad-based call and applications were received from a cross-section of disciplines including health economics, social science, epidemiology, and health services research.

Overall, the majority of the proposals focused on developing interventions to promote symptoms awareness to patients/public or to primary care professionals. Only a small number of applications proposed to assess the effectiveness of certain interventions in reducing delay in specific parts of the diagnostic journey, to develop methodologies to measure key time points and intervals in early cancer diagnosis research or to assess the relationship between diagnostic delays and survival.

The call's Scientific Committee met over two days in September 2010 to consider a total of 49 project grant applications and recommended 10 applications for funding. This represents a 20% success rate, which is similar to that of Cancer Research UK's [Population Research Committee](#) and higher than that of other national and international funding bodies.

Subsequently, the call's Management Committee met to ratify these recommendations, and awards are currently being processed and ethics approvals sought. Full details of the successful projects will be released in due course, once all required documentation has been issued. But in the meantime we can share that four of the recommended projects focus on Health Services research with all of them proposing to design interventions to respond appropriately to symptoms as they present in primary care; two projects focus on screening uptake; two on raising public awareness and early presentation; one on high risk populations (low socioeconomic status and ethnic minorities); and one on methodology and evaluation of early detection and awareness interventions.

First NAEDI Research conference

The first NAEDI Research conference takes place 17th/18th February in London. It will feature presentations from leading researchers in the fields of cancer awareness, screening, epidemiology and early diagnosis and include updates from some of the projects funded through the first NAEDI call. A full report of the day will be made available at www.naedi.org.uk.

There are a few places remaining, so if you'd like to register interest in the event please email naedi@cancer.org.uk

New NAEDI research call

Following the response to the first call, the funding partners are delighted to have announced a further funding call at the end of 2010. The new call covers the same broad research areas as the first, reflecting the continuing need to advance understanding and develop this remit. In particular, the funders strongly encourage the submission of projects grant proposals on the development and evaluation of:

- Models, tools and approaches to improve cervical and bowel cancer screening uptake; and
- Integrated computer-based decision support systems.

For up-to-date information on the NAEDI Research Call, please visit [CR-UK's Funding and Research website](#).

Update on centrally-funded activity

In September 2010, Health Minister [Paul Burstow announced](#) that £9 million was to be invested in campaigns to promote earlier diagnosis of breast, bowel and lung cancer. Since the announcement, the 109 Primary Care Trusts (PCTs) that received the funding have been working incredibly hard to assess their local needs, engage with a wide range of health and community professionals and scope out the details of their activity in a changing landscape. The next few months will see the launch of many of these projects.

The projects, funded by the Department of Health and National Cancer Action Team, are varied. Some will focus on one or two tumour types, whilst others will look at all three cancers; activities will run in rural, urban and inner city areas across England; some PCTs have opted to work on their own while others are in collaboration with neighbouring PCTs; the channels being used to communicate messages vary from teams of local volunteers to piggybacking existing health promotion and community engagement channels; and whilst some are building on existing work, others are trialling new and exciting ways to encourage easier and earlier diagnosis.

Matt Atherton, Communications and Marketing Manager for NHS Halton and St Helens explains the importance of the funding to their PCT. “Three years ago, with funding through the Healthy Communities Collaborative, we developed the Get Checked programme to raise awareness of breast, bowel and lung cancer and to encourage individuals to seek medical advice if they had a concern, and it achieved some good results.

However, receiving this new funding in September has been a fantastic boost to our work and it has provided us with a real opportunity to build on it and move the programme forward. Being a communications specialist, I know how important it is to build on the heritage of Get Checked, but also to keep the campaign fresh so that it stays at the front of people’s minds. We launched our refreshed activity on 17th January and will be closely monitoring and tracking our work so that we can contribute to the overall evaluation of this programme of activity”.

In addition to the 59 projects centrally-funded local projects, the Department of Health is piloting two regional bowel cancer campaigns in the East and the South West of England. This activity will include regional TV, press and radio advertising to raise awareness of early signs and symptoms and direct people to their GP. These regional pilots will be integrated with locally funded projects to ensure that the public and health professional colleagues receive consistent messages.

Sara Hiom, Director of Health Information and Cancer Data at Cancer Research UK said “2011 has the potential to be an exciting year for NAEDI. We have the opportunity through this local activity and the two regional pilots to not only raise awareness and prompt early presentation, but to contribute to the evidence base for the NAEDI programme of work. Robust evaluation of this programme of work is imperative so that it can help us shape the future agenda”.

“Receiving this new funding in September has been a fantastic boost to our work”

Lancashire and South Cumbria train frontline staff in cancer awareness

With health service budgets under pressure, the challenge is to find cost-effective ways of promoting public awareness of cancer.

Lancashire and South Cumbria Cancer Network (LSCCN) believes part of the answer lies with the large number of people who work with members of the public one to one. These people can be trained to have simple conversations about the symptoms of cancer and what to do if you spot them.

LSCCN service improvement facilitator Carol Grant-Pearce said the idea came from a member of the Cancer Partnership Group, which represents cancer patients and their families, friends and carers, who said that when people raise the issue of cancer, care assistants, health trainers or other frontline staff often don't know how to respond.

'Health and social care staff have a key role in cancer awareness but it is not being tackled at the moment,' she said.

Permission to talk about cancer

The group came up with the idea of developing training materials to equip the whole range of frontline workers with some basic knowledge, so they could respond appropriately if people wanted to talk about cancer.

The network applied for funding from the National Cancer Action Team to look initially at bowel and lung cancer. The first stage of the project was to survey a group of health and social care staff using the Cancer Research UK [cancer awareness measure](#) (CAM). This found that frontline staff had a better awareness of cancer than the general public but it wasn't as good as it would need to be if they were to be advisers to the public.

Nurses, dental and other staff with a clinical role had better knowledge than the rest so the project decided to focus on the non-clinical group of pharmacy, social care, admin and clerical staff and health trainers.

The training resource will suggest what to say and how to say it. Just as important is the work project manager Kate Simpson is doing to ensure that managers are supportive of their staff taking on this role.

Lancashire County Council and the two PCTs are part of the project board and Kate used her background in workforce development to get the support of the local Workforce Development Partnership, which has strong links with the voluntary and private sectors who employ many social care and other frontline staff. A local chemists chain, Rowlands Pharmacy, is supporting the project and is keen to train its counter staff.

Flexible training

The training resource is being developed to allow different employers to use it in ways that suit their training style and the skills, time and opportunities available to their staff. 'Health trainers are the gold standard as talking about health is part of their role. An admin person or receptionist might put up a poster but if someone says something to them they will know to direct them to their GP,' Carol says. Social care staff, for instance, are trained to refer difficult issues to their line managers so need permission and confidence to talk about cancer while pharmacy staff routinely get asked about symptoms.

Kate is currently trying to persuade the local QCS (formerly NVQ) providers to include cancer awareness in the health and well being modules for people studying social care. Beyond that there



are prison wardens, university and college teachers, youth workers... 'Any of these people might be the one person someone will link with – for instance someone delivering meals on wheels might be the only person you see all day.'

The project has been developed with consultancy Unique Improvements who used information from the CAM and other research to develop training materials that would work with different groups. The training resource has been extensively tested and will be available as an interactive pdf, DVD and on paper early in 2011.

Once the team are happy with it, other cancers may be added. So far there are no plans to make the training resource available beyond the region but, with enough interest, this may change.

Contact

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Lancashire and South Cumbria Cancer Network project manager Kate Simpson Kate.Simpson@lscn.nhs.uk

What's new on NAEDI.org.uk?

The NAEDI website goes from strength to strength, with useful and interesting content being added on a regular basis. Recent months have seen the addition of a number of [Cancer Network summaries](#), which highlight activities happening at a local level and signpost to useful reports and resources, and presentations from the first round of [Learning Sets](#) on sustainability, funded by the National Cancer Action Team. There's also a new article about engaging [public health leadership](#) in the awareness and early diagnosis agenda, and the showcasing of a number of [primary care-related interventions](#).

Risk assessment tool

Seven cancer networks are working on a project designed to assess the usability of a cancer risk assessment tool in primary care. Between them the cancer networks will ensure that around 200 GP practices use the tool during the first half of 2011 and provide data and feedback on its use. The risk assessment tool was based on work done by Professor Willie Hamilton in the [CAPER studies \(Cancer Prediction in Exeter\)](#), a series of case-control studies which both identified symptoms of common cancers that are presented to primary care and quantified the risk of cancer associated with them.

The tool acts as a reminder to GPs to consider the likelihood of an individual patient aged 40 or over having lung or bowel cancer given the symptom or combination of symptoms they present with. It is presented as 3 tables (colorectal cancer, lung cancer for non smokers and lung cancer for smokers) containing the risk values for each symptom in isolation or combination and is available as a mouse mat or a desk easel so as to be easy to hand.

The cancer networks participating in the project are currently recruiting and training GP practices in the use of the tool. GPs who sign up to the project will need to complete a quick tear off sheet (containing a handful of questions) each time they use the tool over the 6 month period of the project.

The overall aim of this work is to improve the early detection and diagnosis of lung and bowel cancer but more specifically it is looking to assess the overall acceptability of the presentation format of the tool and to see how it gets used in practice. The project will be evaluated both in terms of the impact of the tool usage and through a series of interviews, with the GPs who take part and with project managers at the cancer networks.

For more information about the project, please contact Claire.Morris@ncat.nhs.uk

Primary care is vital to the success of NAEDI

Primary care plays a hugely important role in the National Awareness and Early Diagnosis Initiative (NAEDI). People have to know the signs and symptoms and go to the GP as soon as they think something might be wrong. But what happens when they walk through the door of the GP surgery is equally crucial. The continuing success of NAEDI depends on GPs thinking about their consultations, about how practice systems work and how they make referrals.

A number of projects are in progress to support general practitioners in taking this work forward. Cancer Network GP leads are working with other general practice cancer leadership, including Macmillan GPs and cancer commissioning leads, to make sense of these opportunities in each local area.

Projects NCAT is supporting include:

- The RCGP/NCAT National Audit of Cancer Diagnosis in Primary Care. The results of the first round of audits have been analysed – see page 7
- The GP Leadership Project – 28 cancer network GP leads are supporting the distribution and use of GP practice profiles and the targeted use of the primary care audit
- The Cancer Primary Care Risk Assessment Tool is being tested by seven cancer networks – see page 5
- Applying Safety Netting to Cancer and Early Diagnosis
- Clinical engagement with the regional bowel cancer pilots in seven networks in East Anglia and the South West; and monitoring how many more people go to the GP as a result in three networks
- Learning sets focusing on primary care and GP engagement.

All this work is being captured through evaluation and feedback.

GP leadership project

The GP leadership project is moving into the implementation stage. The profiles show practice data compared to national and PCT figures for more than 20 indicators. More information is available, including a short flyer, on the [NCIN website](#).

Charles Buckley, primary care cancer lead for Gloucestershire and clinical lead for the project in 3 Counties Cancer Network would like to be able to fund some protected learning time for each practice so they can sit down and develop an individualised action plan using a ‘picking list’ of ideas. He is also intending to write to every practice which has ‘orange dots’ for two week waits and emergency referrals (meaning that they vary from the PCT average).

Primary care lead in Mount Vernon Cancer Network Philip Sawyer’s underlying aim is to get cancer onto the agenda of the new commissioning groups. In addition to the NCAT funding for GP leadership, a new Macmillan project will pay for an extra one or two sessions a week for four GPs across the network. These GPs will discuss the profiles with practices in their localities and the wider agenda around cancer in primary care.

Pawan Randev, who is the primary care lead for North West London Cancer Network, intends to encourage practices to engage with the project as part of their professional training. Carrying out the audit will provide a block of evidence for revalidation that can be used by all the GPs in a practice. Pawan will offer online training in consultation techniques for cancer or suspected cancer, through a [network-funded video developed for GP registrars](#), use of which would provide CME points.

Kathy Elliott National Lead for Prevention, Early Diagnosis and Inequalities, National Cancer Action Team

The full text of this article, describing learning from 13 of 28 GP Cancer Network Leads, can be found at:

<http://info.cancerresearchuk.org/spotcancerearly/naedi/local-activity/getting-results/clinical-leadership/gp-leadership/>

Findings from the National Audit of Cancer Diagnosis in Primary Care

The audit was developed to inform decisions about how best to provide more support to primary care professionals to ensure the early diagnosis of cancer.

Following the enthusiastic participation of cancer networks in primary care cancer audit in 2010, the task of aggregating that mass of data has made good progress in the hands of [NCIN](#).

18 networks contributed information on 18,113 patients with cancer. The quality and completeness of the data were outstanding, with close to or over 90% completeness for almost all fields including stage at diagnosis. The age/sex/cancer site profile of the audit dataset compares well with cancer registry data. Key elements of the audit were the time spent by patients being assessed in primary care and waiting to be seen by a specialist, the use of investigations by GPs, pathways to diagnosis and the effect of demographic factors on the time to specialist assessment.

The median time from first consultation to referral was 4 days, and from referral to being seen by a specialist 12 days. There were avoidable delays for 18% of all patients. A longer wait to see a specialist was associated with communication difficulty and non-white ethnic status.

Almost half of all the patients had an investigation prior to referral. In 6% of patients rapid access to investigations would have altered the patient's management, though this figure doubled for ovarian, pancreatic and renal cancers.

There is a wealth of data still to emerge from the analysis. The final report will be submitted in February.

A narrative synthesis of reports from Cancer Networks who participated in the audit is available at www.dur.ac.uk/school.health/erdu/cancer_audit/cancerdiagnosisaudittool/

Understanding cancer survival differences at home and abroad

To inform our continued understanding of international differences in cancer survival, Professor Sir Mike Richards established the International Cancer Benchmarking Partnership (ICBP) in 2009. The ICBP is an innovative global partnership of clinicians, researchers and policymakers. It is the first of its kind in closely examining the possible reasons as to *why* cancer survival varies between countries, as well as establishing the current extent of the differences. The partnership aims to generate insight and understanding that will help all partners improve their cancer outcomes and quality of care.

The research programme focuses on three common cancers, lung, colorectal and breast, and a less common cancer with a complex and challenging diagnostic pathway, ovarian.

The first outputs have recently been published in the *Lancet* ([vol 377: pp. 127-138](#)) showing that while survival improved over the study period in all jurisdictions, survival in England, Denmark, Northern Ireland and Wales remains lowest. Australia, Canada and Sweden show consistently higher survival while Norway has intermediate levels.

To investigate possible reasons for these differences, the ICBP is now looking at various aspects that could affect cancer survival. These include the role of population awareness and beliefs; the role of behaviours and systems in primary care as well as the impact of delays in diagnosis and treatment. In addition, a high resolution study is looking at the impact of stage, treatment and co-morbidities on cancer outcomes. Cancer Research UK is providing programme management for these studies.

The ICBP involves 12 jurisdictions in 6 countries across 3 continents: Australia (New South Wales, Victoria), Canada (Alberta, British Columbia, Manitoba, Ontario), Denmark, Norway, Sweden, United Kingdom (England, Northern Ireland, Wales).

For more information about the ICBP modules of research and for an opportunity to share your views, please visit www.icbp.org.uk or email icbp@cancer.org.uk

Viewpoints

The Myeloma Diagnosis Pathway: Making a difference with a rare cancer

We have come an incredibly long way in developing effective treatments for myeloma and in 2011 the prospects for long-term survival are better than ever before.

However, despite an impressive tripling of long-term survival rates since the 1970s, 20% of myeloma patients still die within 60 days of being diagnosed and we have seen only very modest improvements in one-year survival rates over the last 30 years.

Early diagnosis is vital to ensure patients can benefit from effective treatments and to prevent the onset of complications that can have a major impact on their quality of life.

But this is a particularly enormous challenge. A typical GP will only come across one or two cases of myeloma in their whole career. On top of this, many of the signs and symptoms of myeloma share features with other less serious causes common to an older population e.g. fatigue, back pain and recurring infection.

The statistics are clear that diagnosis remains a critical challenge for myeloma, as it is with many other cancers in the UK. However, the nature of the myeloma diagnosis challenge presents a need - and an opportunity - to develop a proactive and focused approach to improving early diagnosis.

By identifying what the barriers to early diagnosis are and working with GPs and the myeloma medical community to develop a strategy for removing them, Myeloma UK hopes to make a difference for the 4,000 people diagnosed with myeloma in the UK every year.

With the help of our GP advisors we have developed the Myeloma Diagnosis Pathway, a simple 2-sided reference algorithm of the signs and symptoms of myeloma and the tests to take if myeloma is suspected. It aims to supplement national referral guidelines and provide relevant information to support appropriate and timely referral decisions.

Myeloma UK has received excellent and positive reviews of the Myeloma Diagnosis Pathway. We hope that the short-term awareness efforts we are making today will be reflected in statistics and patient experience over the long-term.

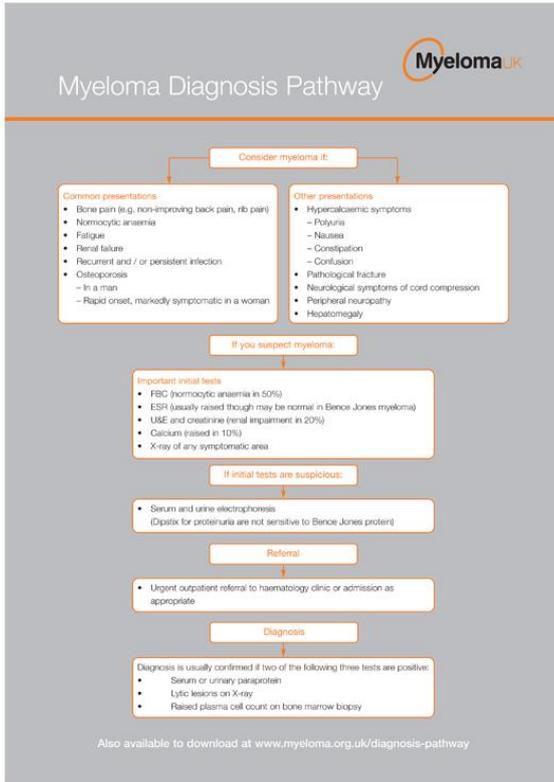
GPs can download their free copy of the Myeloma Diagnosis Pathway from www.myeloma.org.uk/diagnosis-pathway

For more information please contact the Myeloma UK team on 0131 557 3332.

Eric Low
Myeloma UK Chief Executive
www.myeloma.org.uk

Eric Low is the Founder and Chief Executive of Myeloma UK.

Myeloma UK is the only UK organisation dealing exclusively with myeloma and its related disorders. It provides a broad range of services covering every aspect of myeloma from information and support, to improving standards of treatment and care through education, research, campaigning and raising awareness. Today, Myeloma UK reaches over 12,000 people affected by myeloma and many of the healthcare professionals involved in their care.



Is myeloma on your radar?

About the Myeloma Diagnosis Pathway

Myeloma UK has developed the Myeloma Diagnosis Pathway to assist GPs in recognising the signs and symptoms of myeloma. The diagnosis of myeloma (also known as multiple myeloma) can be challenging due to the nature of the common signs and symptoms and its relative rarity. Approximately 4,000 patients are diagnosed each year in the UK and a GP may only encounter a few patients during their career.

About myeloma

- Myeloma is a B-cell malignancy characterised by an abnormal expansion of plasma cells in the bone marrow and less commonly in extramedullary sites. It is defined by an overproduction of monoclonal proteins. It is almost always preceded by Monoclonal Gammopathy of Undetermined Significance (MGUS).
- There is currently no cure, however myeloma and its complications can be managed and treated.
- Myeloma has seen the greatest improvement in long-term survival over the last 30 years than almost all other cancer types in the UK. This is due to a number of factors, including the availability of new effective treatments.
- Treatment for myeloma may consist of chemotherapy, radiotherapy, targeted novel therapy and stem cell transplantation depending on age and other myeloma patient factors.
- Myeloma patients will often undergo a number of lines of treatment and experience variable periods of remission. The aim of treatment is to prolong life, manage complications and improve quality of life.
- An early diagnosis of myeloma can prevent and slow down the development of complications and give a greater likelihood of long-term survival.
- A common issue that can occur in suspecting myeloma is related to musculoskeletal symptoms. For example, myeloma bone pain is sometimes initially suspected to be arthritis or sciatica.

Myeloma diagnostic criteria

The International Myeloma Working Group has developed the criteria below to classify MGUS and myeloma

MGUS	Asymptomatic myeloma	Symptomatic myeloma
Serum M protein < 30 g/l	Serum M protein > 30 g/l	M protein in the serum or urine
< 10% clonal plasma cells	> 10% clonal plasma cells	> 10% clonal plasma cells
No related organ and tissue impairment	No related organ and tissue impairment	Related organ and tissue impairment*
No other B cell lymphoproliferative disorder	-	-
No treatment - monitor	No treatment - monitor	Treatment required

*The four criteria commonly used to define myeloma (and therefore the requirement for treatment) can be grouped by the mnemonic 'CRAB', which stands for:
 1. HyperCalcaemia: elevated serum calcium
 2. Renal dysfunction: abnormal serum calcium
 3. Anaemia: haemoglobin 20 g/l below lower limit of normal
 4. Lytic Bone lesions

About Myeloma UK

Myeloma UK informs and supports people affected by myeloma, and helps improve treatment and standards of care through research, education, campaigning and raising awareness. Myeloma UK is the only organisation dealing exclusively with myeloma and its related disorders in the UK.

For more information about our patient services and resources for healthcare professionals visit www.myeloma.org.uk

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The Pathway is available for download at www.myeloma.org.uk/diagnosis-pathway

Pilot cancer awareness and early detection training for community staff

Cancer Research UK is working in partnership with Sandwell PCT to deliver cancer awareness training workshops targeted at community staff. The pilot programme, consisting of nine workshops, is running across Birmingham until March 2011.

The need for training was identified by community teams at the PCT and aims to equip staff with the confidence and skills necessary to deliver key cancer awareness messages in their daily encounters with the public. The training is for health trainers, healthy lifestyle teams and volunteers, amongst others.

The one-day workshop covers the following topics:

- What is cancer?
- The impact on public health - how cancer affects socially disadvantaged groups
- Signs and symptoms and early detection
- The importance of screening and cancer prevention
- How to use the key messages
- Best practice, signposting and boundaries

The pilot is being fully evaluated and results will be available from July 2011. These will inform future training development at Cancer Research UK. If you would like further information please contact Dr Alexis Macherianakis at alexis.macherianakis@sandwell-pct.nhs.uk or Helen Rendell at helen.rendell@cancer.org.uk.