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# NAEDI

## National Awareness and Early Diagnosis

### Inside this issue:

Welcome	1
Second NAEDI research call	1
Update on centrally funded activity	2
GP leads to promote early diagnosis in primary care	3
Safety netting recommendations are tested by GPs	3
Sharing learning about engaging primary care	4
The nature and duration of symptoms	4
Risk assessment tool and GP referrals	5
The International Cancer Benchmarking Project – Module 2	6
What's new on <a href="http://www.NAEDI.org.uk">www.NAEDI.org.uk</a> ?	6
The first National Audit of Cancer Diagnosis in Primary Care	7
Skin cancer early detection pilot in Dorset	8

Welcome to the seventh NAEDI newsletter.

Since January we have seen two bowel cancer awareness pilots in the East of England and the South West, 59 local projects have implemented an impressive range of activities to raise awareness and encourage early diagnosis of breast, bowel or lung cancer and the International Cancer Benchmarking Partnership continues to make great strides in building the evidence base. Read on to find out about all of these things and more.

If you have any feedback about the newsletter or any NAEDI related queries please get in touch by emailing [naedi@cancer.org.uk](mailto:naedi@cancer.org.uk).

### Second NAEDI Research call - update

The NAEDI Research Call funding partners announced the second NAEDI research call at the end of 2010. This call, which closed in April this year, covered the same broad areas as the first:

- Higher risk populations
- Raising public awareness and reasons for late presentation
- Health services
- Methodology for, and evaluation of, early detection and awareness research

In particular, the funders strongly encouraged the submission of proposals on the development and evaluation of:

- Computer-based decision support systems for following patients along the cancer diagnostic pathway; and
- Models, tools and approaches to improve cervical and bowel cancer screening uptake.

There has been a great response to the call, with applications received from across the UK. The majority of proposals target common cancers (e.g. bowel and lung cancer) and focus on participation in cancer screening and the development of decision support tools designed to improve the recognition of cancer symptoms.

Awards will take the form of project grants with a maximum duration of 3 years. Final funding decisions will be made by the Scientific and Management Committees in September 2011. Another NAEDI research call is likely, but the remit of this call and when it will be announced have not yet been decided.

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

## Update on centrally funded activity

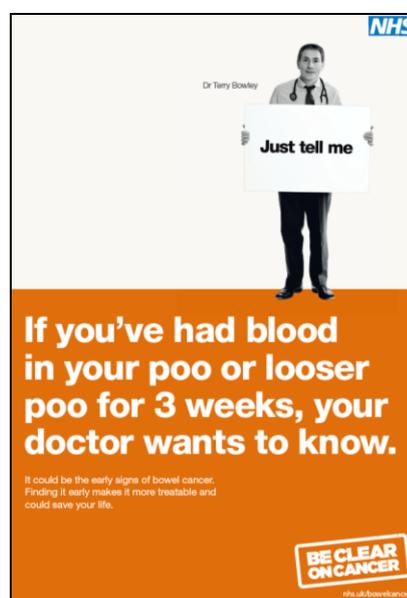
In January we reported on the 59 local projects that have been funded by the Department of Health and the National Cancer Action Team to focus on the signs and symptoms of breast, bowel and lung cancer.

Since January the projects have moved from planning to implementation phase and the activity across the country has been amazing. We have seen 109 Primary Care Trusts involved in a wealth of activities including: health promotions teams getting out into their communities, GPs talking on local TV and radio stations, an army of community champions signposting their neighbours and loved ones to places for further information, advertising at football grounds and local success stories told in their newspapers – all these activities have been spreading the good news that early diagnosis can save lives. For most projects, the communications and outreach work has been fully integrated with training and information briefings for a wide range of health professionals - from dentists to GPs.

Amanda Boughey, Cancer Research UK lead for the team who support the 59 projects recalls “I was listening to a drive time radio interview with a GP in the North West who was promoting the local lung cancer campaign. After the interview had finished and a few songs had played a local lady called in to tell her story about how early diagnosis of lung cancer had given her dad another 50 years. When you see and hear the local communities respond to planned activities in this way, it is just fantastic. This is just one little example of what we know has gone on around the country and it has only been possible through all the hard work, determination and passion that local NHS colleagues have invested into this programme of activities.”

The evaluation of the programme of work will start this summer and a report will be published at the end of the year.

Alongside this local activity the Department of Health ran two regional pilots for bowel cancer in the South West and East of England. The ‘Be Clear on Cancer’ campaign started in January and ran for 7 weeks. This included TV, radio and newspaper advertising as well as events in key locations. At the launch, Care Services Minister Paul Burstow said: “Early diagnosis makes a huge difference to cancer survival rates and bowel cancer is one of the biggest killers. That’s why the ‘Be Clear on Cancer’ campaign uses simple messages to make people aware of the early signs of bowel cancer and to give them the confidence to talk to their GP about them.”



Although it is early days and evaluation data is still coming in, early indications are that ‘Be Clear on Cancer’ has been successful at raising awareness of the key signs and symptoms. A spokesperson for the Department of Health said “We are keen to understand the full picture, including the impact on services and the number of tumours diagnosed early, but due to the nature of this data it will take a few months to come through. In the meantime, we are looking at the feasibility of a national roll out of the bowel cancer campaign and will be working with local NHS teams in the coming months.”

## GP leads to promote early diagnosis in primary care

Cancer networks have been given the go-ahead to fund GP leads to work with primary care promoting awareness and early diagnosis of cancer in 2011/12. All of the 28 networks applied for funding and are waiting to hear feedback on their outline proposals.

NCAT project funding can be used to implement existing initiatives to support GPs in early diagnosis or new ideas. Existing projects include:

- dissemination and review of practice profiles, with targeted use of the RCGP/NCAT primary care audit
- support for GP education and training related to cancer and the contribution of awareness and early diagnosis to improving outcomes
- service improvement initiatives such as the North of England Cancer Network's work on the lung cancer pathway
- training for non-medical frontline staff and GP registrars.

New initiatives could include supporting GPs to prepare for patients coming to see them as a result of public awareness campaigns.

Networks will also be promoting clinical engagement in public awareness campaigns following the experience of the cancer networks involved in the pilot bowel awareness campaign run in East of England and the South West in 2010/11.

Kathy Elliott NCAT Lead Prevention, Early Diagnosis and Inequalities, said: "This is path breaking work. Support for primary care in cancer diagnosis has never been attempted on this scale before, anywhere. It will contribute to meeting the target of saving an additional 5,000 lives by 2014. Cancer networks, with their PCTS and primary and secondary care partners, are producing some excellent plans and I'm very grateful for their commitment."

"Support for primary care in cancer has never been attempted on this scale before, anywhere."

See the [NCAT website](#) for more details, or for more information about the 2011/12 programme contact Kathy Elliott [Kathy.Elliott@ncat.nhs.uk](mailto:Kathy.Elliott@ncat.nhs.uk)

## Safety netting recommendations are tested by GPs

A Department of Health funded project has produced a set of recommendations for how general practice can implement a safety net to ensure potential cancer patients collect test results or follow up on symptoms that haven't cleared up.

An initial long list of statements drawn from the research literature was whittled down and ranked according to their relevance by 40 GPs and others from local Cancer Networks. The resulting list was then developed again to ensure that it represented the consensus of what would be most helpful.

Dr Carl Heneghan, GP, Reader in evidence-based medicine at the Department of Primary Health Care at the University of Oxford and member of the research team, said: "Patients often present to primary care with vague symptoms and a low probability of cancer. The GP needs to be able to put a safety net in place and say to the patient, 'If certain symptoms persist, then I want you to re-present at a specified time and we will test you again'. If that safety net breaks down because of poor communication and poor practice systems, then you end up with patients presenting late and cancer diagnosed late."

The report will be published by the Department of Health, and a draft will be made available to support Cancer Network GP leads in their work on early diagnosis.

For more information about this project contact Ruth Davis: [Ruth.Davis@phc.ox.ac.uk](mailto:Ruth.Davis@phc.ox.ac.uk)

## Learning sets spread experience of involving GPs in awareness raising

The National Cancer Action Team (NCAT) has been running a programme of sharing and learning sets for Primary Care Trusts (PCTs) to help them engage GPs and primary care. The learning sets have given participants practical tips and the chance to share experiences and think more strategically about engaging with primary care.

NHS Bury Communities Against Cancer Project Manager, and learning set participant, Stephanie Mills said she had gained a number of practical ideas which she plans to use in her project including: making the first contact with practice managers, rather than GPs, who may not look at their email; and making presentations to GP learning sessions alongside a clinical colleague because GPs like to hear from their peers. She arranged for the Director of Public Health's regular bulletin to GPs to devote an issue to cancer. "I also found it useful hearing from people at the learning set who work at a strategic level as this gave me a greater sense of the wider debates around awareness raising and GP engagement."

To join a learning set contact Sally Williams  
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For more information about the awareness projects contact Amanda Boughey or Caroline Philpott  
[Amanda.Boughey@cancer.org.uk](mailto:Amanda.Boughey@cancer.org.uk)  
[Caroline.Philpott@cancer.org.uk](mailto:Caroline.Philpott@cancer.org.uk)

Cancer Research UK has been supporting the 109 PCTs running cancer awareness projects funded by the Department of Health and NCAT in 2010/11. Caroline Philpott, Social Marketing Consultant at CR-UK said: "Primary care engagement is essential to the success of many of these projects and from the outset it was one of the areas where the projects wanted to learn from their peers and use examples of good practice from around the country. It has therefore been great to work with NCAT and Frontline over the last few months to extend the existing round of learning sets and open them up to the funded projects. The feedback has been great and people seem to have found the learning sets useful."

Sally Williams from consultants Frontline, who are running the learning sets, said she was most struck by the commitment and enthusiasm of participants, which was much greater than from other groups of NHS staff she has been working with. "The learning sets were not designed to provide all the answers but were very useful as a way of sharing experience, top tips and networking" she said. "One of the great advantages is the learning set gives people the time to think in advance about the best ways of engagement rather than having to do it on the hoof."

Reports and presentations from the learning sets will be available shortly on [NAEDI.org.uk](http://NAEDI.org.uk).

## The nature and duration of cancer symptoms

An exciting new project to examine the nature and duration of symptoms experienced by people with cancer before their diagnosis is under way. The Department of Health, the National Cancer Action Team, and Cancer Research UK are funding the project which will involve people who took part in the [Cancer Patient Experience Survey](#) in early 2010.

67,713 people with cancer took part in the Cancer Patient Experience Survey in 2010 and 53,104 said they were willing to be re-contacted to provide further information. Postal questionnaires will be sent to people who were diagnosed with one of 20-25 cancer types. The data provided in these questionnaires will help us to:

- describe the nature of symptoms that patients experienced before their cancer diagnosis
- measure the interval between the first onset of symptoms and first seeking medical advice
- describe the barriers to seeking medical advice

Professor Amanda Ramirez and Dr Lindsay Forbes are providing scientific leadership of the project, developing the sampling strategy, questionnaire, and carrying out the analysis. The survey fieldwork will be carried out by Quality Health, who conducted the 2010 Cancer Patient Experience Survey.

This project is a unique opportunity to add to the limited evidence base on the frequency and nature of symptoms experienced prior to a cancer diagnosis and the time interval between first noticing symptoms and presenting to the health service.

Please contact [Beth.Capper@dh.gsi.gov.uk](mailto:Beth.Capper@dh.gsi.gov.uk) at the Department of Health or Dr Reg Race at Quality Health [Reg.Race@quality-health.co.uk](mailto:Reg.Race@quality-health.co.uk) for more information about this project.

## Desktop 'Risk Assessment Tool' supports GP referrals

The first anecdotal evidence from NCAT's pilot lung and bowel cancer risk assessment tool (RAT) suggests GPs find it useful.

Designed as a mouse mat and desktop 'easel', the tool is being trialled in 131 general practices in seven cancer networks. Macmillan is working on a parallel project to incorporate the risk assessment tool into software used by GPs.

The tool, which was developed from Professor Willie Hamilton's CAPER studies (Cancer Prediction in Exeter), shows the risk for each symptom on its own and each combination of cancer symptoms in a useful grid. GPs taking part in the trial are asked to complete a six-question tear sheet each time they use the tool in a consultation.

North Trent Cancer Network GP Lead Dr Louise Merriman said the tool had been easy to sell to GPs as they felt it would "give them permission to refer at a time they are being increasingly pressured to cut costs by reducing inappropriate referrals". The at-a-glance format was "fantastic", she said. The amount of risk associated with different combinations of symptoms is difficult to remember, especially for GPs who only see an average of two potential cancer patients a month. And "Accessing the NICE guidelines for referral of cases of suspected cancer, is often impractical in a 10 minute consultation!" 187 tear sheets have been received so far in North Trent and indicate that the tool seems to be affecting GPs' behaviour. "A small but significant minority have referred a patient they say they would not have referred without the tool." Louise said.

Three Counties Cancer Network project manager Emma Walsh said she shared the impression that GPs found it useful. The network had paid for an initial training session for one GP and a practice manager from each participating practice but had not funded GPs to use the tool. Despite this, 64 GPs in Three Counties were taking part in the pilot, suggesting they were genuinely interested in using the tool.

Risk assessment tool project manager Claire Morris said the trial would end at the beginning of August and evaluation results were expected in November when the decision will be taken whether to make the materials available to all GPs. The tear sheets will be analysed to provide quantitative evidence about how the tool has been used and Professor Una McLeod of the Hull and York Medical School has been interviewing GPs and others involved to gather qualitative evidence as part of the evaluation.

Initial findings show that one of the main challenges was keeping the tool in GPs' minds. Most cancer networks sent out regular newsletters to remind people about the tool and contacted practices that had not sent in tear sheets. One of the benefits of the tool is that it can aid the discussion of risk with patients, and in making a referral, can help them understand that they were being referred for a possible cancer, which in turn makes it more likely they will attend their subsequent appointment.

For more information about the risk assessment tool contact [Claire.Morris@ncat.nhs.uk](mailto:Claire.Morris@ncat.nhs.uk)

## The role of population awareness and beliefs in cancer survival outcomes: The International Cancer Benchmarking Project (ICBP) - Module 2

The ICBP is a unique and innovative global partnership of clinicians, researchers and policymakers. It is the first of its kind to closely examine the possible reasons as to *why* cancer survival varies between countries, as well as establishing the current extent of the differences. Module 2 is looking at the role of population awareness and beliefs in cancer survival outcomes.

Amanda Ramirez, co-chair of Module 2 said: “One possible explanation for the major international differences in cancer survival identified by the ICBP<sup>1</sup> is that people in the UK and Denmark have lower cancer awareness and more negative beliefs about cancer, leading to delayed presentation and worse survival. Module 2 of the ICBP will provide the first robust international comparison of population awareness and beliefs in cancer across the participating countries. The results will indicate if we should be focussing resource on interventions to improve cancer awareness and address negative beliefs in England.”

Module 2 chairs Amanda Ramirez (King’s College London) and Jane Wardle (University College London), have, in partnership with an international collaboration of scientists from each ICBP jurisdiction, developed the ‘Awareness and Beliefs about Cancer measure’ (ABC). This measure is being used in population-based surveys in each jurisdiction.

The core ABC questions include:

- awareness of symptoms and the increase in risk of cancer with age
- physical and emotional barriers to symptomatic presentation
- beliefs that could lead to delayed presentation of symptoms, such as fear and fatalism

Some jurisdictions will collect additional data using one or more of the three optional ABC modules (awareness of cancer risk factors; awareness and beliefs about cancer screening; awareness and beliefs about ovarian cancer).

The fieldwork was carried out by global market research provider Ipsos MORI, who have surveyed nearly 16,000 men and women aged 50+ in Canada, Australia (Victoria and New South Wales), Denmark and the UK (England, Northern Ireland and Wales). Fieldwork in Sweden and Norway will start after the Scandinavian holiday season.

You can find more information about the partnership and Module 2 in the ICBP summer newsletter, available for download from [www.icbp.org.uk](http://www.icbp.org.uk) or email [icbp@cancer.org.uk](mailto:icbp@cancer.org.uk)

<sup>1</sup>Coleman MP, Forman D, Bryant H *et al.* Cancer survival in Australia, Canada, Denmark, Norway, Sweden and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *The Lancet* 2011, 377: 127-138

### What’s new on [NAEDI.org.uk](http://NAEDI.org.uk)?

The NAEDI website continues to be a great source of useful information for people working in the early diagnosis field. In the last few months a new page dedicated to the first [NAEDI Research conference](#), held in February, has been added to the site with pdfs of speakers' slides, as well as synopses of their presentations. Results from the [Derby bowel cancer awareness project](#) funded by Cancer Research UK are also now available.

Look out for new content on the second round of [learning sets](#) funded by the National Cancer Action Team that focused on general practice and primary care - coming soon.

## First national primary care audit due to be published

The results of the first national audit of cancer diagnoses in primary care are due to be published shortly.

Commissioned by the Department of Health and the National Cancer Action Team (NCAT), the audit was undertaken by the Royal College of General Practice, working with 20 cancer networks, in 2009/10. The aim was to improve understanding of the causes of later diagnosis of cancer and to help identify ways of addressing any delays.

One in seven (1,170) general practices in England took part, recording data from around 18,879 patients diagnosed with cancer. The audit was supported by GP leads, working for the cancer networks, who validated the practice returns.

The data were collated and analysed by the National Cancer Intelligence Network Coordinating Team.

According to the authors, Professor Greg Rubin, Sean McPhail and Kathy Elliott, the audit has raised GPs awareness of their contribution to timely diagnosis of cancer and has stimulated professional and practice development. Many individual practices have expressed their intention to use the audit tool to regularly monitor their performance for the future.

Cancer networks have used their involvement as a springboard for wider engagement with primary care, taking advantage of the other quality improvement approaches that have been developed alongside this audit.

The audit template is available from: [www.durham.ac.uk/school.health/erdu/cancer\\_audit/](http://www.durham.ac.uk/school.health/erdu/cancer_audit/)

For more information about the report contact:

Greg Rubin [G.P.Rubin@durham.ac.uk](mailto:G.P.Rubin@durham.ac.uk)  
Kathy Elliott [Kathy.Elliott@ncat.nhs.uk](mailto:Kathy.Elliott@ncat.nhs.uk)

The audit showed considerable variation by cancer site in the time taken to make the diagnosis and in how the patient presented.

For instance, of the patients audited, 39.3% of brain cancers were diagnosed after an emergency presentation compared to 3.7% of breast cancers. The average across all cancers was 12.9% which is worrying because outcomes are usually worse for patients diagnosed after an emergency presentation.

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*“This is the largest and most comprehensive study to date of the primary care pathway to cancer diagnosis. It provides detailed insights into current clinical practice that can direct initiatives to reduce the time to diagnosis for cancer, as well as raising important questions for future research.”*

Kathy Elliot, NCAT Lead  
Prevention, Early Diagnosis and Inequalities

GPs believed that better access to investigations would have reduced delays in diagnosis in 6% of cases, though the figures were higher for brain, ovary, pancreas and kidney cancer.

The audit template, which has been slightly modified in the light of the analysis of the results, is being promoted by cancer network GP leads in 2010/11.

## Skin cancer early detection pilot in Dorset

Building on previous campaign work with the Merseyside and Cheshire Cancer Network, Cancer Research UK's SunSmart campaign was funded by the Department of Health's third Sector Investment Programme to run a skin cancer early detection pilot campaign in Dorset working in partnership with Dorset Cancer Network. The pilot aimed to assess which communication channels are most effective in encouraging men over 50 to report symptoms of skin cancer to their GP.

### Key messages

- If you notice any unusual changes to a mole or patch of skin, get it checked by your GP as soon as possible
- Skin cancer kills more men than women
- If skin cancer is found early, it is easier to treat successfully

Three marketing approaches were compared:

- hit squads focussing on community engagement (Christchurch)
- a direct mail shot including a letter, flyer and a leaflet (North Dorset)
- a mobile information unit providing advice and information about skin cancer and an opportunity to speak to a Health Care Professional (Weymouth & Portland).

Advans were used with the hit squads in Christchurch



Surveys were carried out with over 860 people from all the campaign areas, plus a control area (Purbeck), 2 weeks following campaign activity, to assess awareness of the campaign and key messages. Presentations to the GP and GP referrals were tracked by GP Practices.

### Survey data

- 14% or more of respondents surveyed said they were aware of the campaign activity in their area (highest in North Dorset 21%)
- Across all areas, respondents who were aware of the campaign activities showed higher knowledge of symptoms, greater confidence in noticing changes and were more likely to say they checked their skin regularly or would go to the GP if they noticed anything unusual, than those who were not aware of the campaign.

GP data collection is still underway so the following figures should be interpreted with caution.

- GP referrals directly following the campaign activities (May & April 2011) were higher in all the campaign areas compared to the same period last year, with Christchurch seeing the biggest impact (+62%), followed by Weymouth and Portland (+28%) and North Dorset (+25%)
- Average referrals per GP practice were significantly higher across the intervention areas (21-43 referrals) compared with the control area (7 referrals)

### Summary of results

	Hit squads	Direct Mail	Mobile unit	Control
No. of interactions	2,550	10,000	1,499	-
Prompted recall of campaign	14%	21%	20%	15%
Average no. of presentations per GP practice	12	13	15	11
Average no. of referrals per GP practice	43 (215/5)	21 (214/10)	22 (89/4)	7 (33/5)

Contrary to expectations, the data collected so far indicate that across all the measures of interest, direct mail provides the most effective approach - and at a significantly lower financial and resource cost than the other approaches. These results are encouraging, but further work is being done to gather essential information on conversion rates which will be crucial in understanding the impact on earlier diagnosis of skin cancer.

For more information about this pilot please contact Caroline Cerny [Caroline.Cerny@cancer.org.uk](mailto:Caroline.Cerny@cancer.org.uk)