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NAEDI Newsletter

National Awareness and Early Diagnosis Initiative

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Welcome to the fifth edition of the NAEDI newsletter.

In the last newsletter, we mentioned plans to review the way the Initiative was organised and to think about how the areas of activity might be streamlined. This process has been completed, and NAEDI now has four work streams reflecting the different areas of activity:

- Achieving early presentation
- Optimising clinical practice and systems
- Improving GP access to diagnostics
- Research, evaluation and monitoring

The first three of the work streams are very much ‘outcome-focused’, while the fourth underpins and informs all NAEDI activity. For more information on the work streams, and for information about activities happening within them, visit www.naedi.org.uk

Audit of Cancer Diagnosis in Primary Care

With funding from the Department of Health/National Cancer Action Team, eighteen cancer networks undertook the cancer diagnosis audit in 2009/10, using the [Cancer Diagnosis Audit Tool](#).

Fifteen networks have either completed or are near to completing the audit. The audits have been driving service development locally – see the [audit ‘case study’](#) at www.naedi.org.uk – and efforts are underway to capture the impact and experience of doing the audit.

Networks are also making their data available for national analysis. The national analysis is being undertaken by NCIN. Encouragingly, the dataset is so far very complete – in excess of 95% for many of the fields and greater than 80% for staging information. Preliminary findings were presented at the NCIN conference in June, and a full report is expected in October.

There will be an update on the national analyses in the next issue of the NAEDI newsletter.

Cancer networks deliver the NAEDI agenda

Kathy Elliott, national lead for awareness and early diagnosis (NCAT) reflects on cancer networks' achievements in 2009/10.

Cancer networks have done a tremendous amount of work in the past year, taking hold of the awareness and early diagnosis (NAEDI) agenda and making it their own. Every one of the 28 networks now has a programme of work and has been involved in at least one of 61 separate DH/NCAT funded projects.

Most significantly, this surge of activity has led to increased engagement by PCTs, as evidenced by the fact that 140 out of 152 applied for Department of Health funding for NAEDI work in 2010/11. This provides a positive starting point for the next phase of the work.

I've been moved by the imaginative and dedicated way that so many individuals have responded to the challenge of saving lives by

speeding up the process of getting a diagnosis. I wish I had space to name all those outstanding professionals who have brought so much to the job.

I am hopeful that the networks will continue to prioritise awareness and early diagnosis, building on the foundations that the 2009/10 programme has put in place (see box below). And by offering a programme of shared learning, we hope that none of the hard-won experience from this year will be lost.

For details of the work so far see *Local Awareness and Early Diagnosis Initiatives 2009/2010 Programme Summary Report* and the local activity section on www.naedi.org.uk

For more information about the shared learning events contact Sally Williams, Frontline Consultants on 0207 404 7005 or at www.frontline-consultants.com

Highlights from the 2009/10 LAEDI programme

- * 25 networks have completed baseline assessments of local cancer data, which are being used by networks and PCTs to draw up strategies, shape commissioning and provide a benchmark to measure progress in bringing forward the diagnosis of cancer.
- * Networks have gained support for the NAEDI agenda from the key players – commissioners, public health specialists and especially GPs – leading to new services and service improvements. The RCGP/NCAT national audit of cancer diagnosis in primary care has caught the imagination of GPs. A total of 18 audits were conducted, leading in all areas to changes in procedures and greater awareness of cancer among GPs.
- * Most of the networks have sought to raise public awareness of cancer. The CRUK cancer awareness measure has been used by 22 projects to test existing awareness and to make the case for interventions. A number of social marketing projects were funded to inform people about spotting the signs of cancer and how to respond. The most successful of these worked simultaneously with primary and sometimes secondary care.
- * Other projects have used community partnerships to raise awareness and have provided training for NHS and other staff to build cancer awareness into their jobs.
- * Some networks have set up new structures to ensure that primary care and public health are represented at network level, to improve liaison with site specific groups and to oversee LAEDI work.
- * The funded work will be completed by July, and evaluations will be available as part of the shared learning.



Mapping project leads to better co-ordination and more strategic work

Greater Manchester and Cheshire Cancer Network (GMCCN) believes its cancer awareness and early detection work will be better co-ordinated, more strategic and more cost effective in future, thanks to a mapping project.

Although not designed as a recession-busting exercise, the initiative points to ways that those involved in cancer awareness and early detection can take forward their work in the face of budget cuts.

The network commissioned a social enterprise, Hope Street Centre, to interview people from health, local authority and community and third sector organisations to discover what work they were doing that was relevant to the national awareness and early diagnosis (NAEDI) agenda, and to test this work against published evidence of what is effective.

Consultant in public health Rona Cruickshank said the nationally funded mapping exercise had revealed that a huge amount of work is going on, from large scale social marketing campaigns to primary care based awareness raising and community development projects. Imaginative and varied though the work is, the research found that it wasn't always as strategic or well co-ordinated as it could be and projects were often not well evaluated.

Sharing publicity materials

One of the first outcomes of the project will be an afternoon meeting of cancer commissioners and public health leads from the network's PCTs, where they will discuss the findings and decide on ways that they can work better together. Directors of Commissioning have already been presented with the report at the network's commissioners' board.

With virtually no money for new stand-alone projects, Rona believes it will be vital to share existing experience and materials. For instance, the network is using NAEDI money to develop cancer awareness materials for the South Asian community, which will be offered to other organisations in the network (and made available through www.naedi.org and the National Cancer Action Team).

Training for cancer awareness trainers

Another cost effective option is to add cancer awareness to the work of people already employed

or volunteering in communities, such as health trainers, neighbourhood teams and local community partnerships. Collaborating with Macmillan, the network is developing an accredited programme for training trainers, which any organisation in the network will be able to use. 'If we have these training tools, commissioners can build the use of them into their plans.'

Some of the changes that will flow from the mapping project could be quite basic, such as ensuring that any initiative that is commissioned has a budget, is evaluated and is targeted at the population groups which have been identified as priorities in the strategic plans for the North West region and for particular PCTs, Rona says.

Co-ordinating mobile team visits

Already a protocol has been agreed with Macmillan Cancer Support and Cancer Research UK to cover visits from their mobile teams and potentially those of other organisations. Locations will be agreed with PCTs and acute trusts to fit in with their priorities; local health trainers, smoking cessation advisors or other NHS staff will attend sessions; and local NHS bodies will be informed that the visit is taking place.

Alison Holbourn, who conducted the research, says, 'We got a very strong sense that people would like to collaborate and learn from each other and understand what works in other environments.'

While aware of the difficulties, participants were also keen to work more closely with primary care, as the evidence shows this is key to getting results.

GMCCN is publishing the report on its website, along with all the reports and evaluations uncovered in the course of the mapping, and is happy for other networks to use its findings. It will also be available on www.naedi.org.uk

Mapping Activity in Greater Manchester and Cheshire in the Promotion of Cancer Awareness and Early Detection by Greater Manchester and Cheshire Cancer Network is available on www.gmccn.nhs.uk

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Cancer Awareness Measures

Since the development of the generic Cancer Awareness Measure in 2008, it has been implemented across a number of Primary Care Trusts and Cancer Networks, as well as in a national baseline survey.

Several partners have been supporting the local implementation as part of the National Awareness and Early Diagnosis Initiative. As part of this we have collected feedback from CAM users, which has informed some improvements to the measure and the toolkit. These are minor changes and we have ensured that results from future CAM surveys will remain comparable with previous CAM surveys. The new CAM toolkit is available to download from www.naedi.org.uk

NCAT will be bringing together experience of using the CAM locally.

One of the biggest challenges we face this year is making sure we learn from CAM survey results and that they are used to inform strategies for improving awareness and early diagnosis.

An essential part of this process is ensuring that all CAM data are lodged in the UK Data Archive so that they are freely accessible to all. Guidance about how to access and upload data is available in the toolkit and on the [NAEDI website](http://www.naedi.org.uk). We would like to see everyone who has CAM survey results upload their data as soon as possible.

Over the past year several site specific CAMs have also been developed including Breast, Bowel, Cervical, Lung and Ovarian. These measures and associated toolkits are now available to download from the NAEDI website.

The Breast, Bowel and Lung CAMs were implemented in a national survey in March 2010, the results of which will be available in due course – look out for updates on the NAEDI website.

If you have any queries about the CAMs please get in touch via naedi@cancer.org.uk

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NCRI/NAEDI Research Call

Under the activities of NAEDI work stream 4 and the auspices of the National Cancer Research Institute, a call for expressions of interest in awareness and early detection of cancer was issued in December 2009.

A high number of proposals were received from across the UK, with the majority focusing on common cancers and developing interventions to raise awareness of symptoms, promoting early presentation by patients and helping GPs and other primary care practitioners to respond appropriately to symptoms as they present in primary care.

In March 2010, the NAEDI Research Call Management Committee, consisting of senior representatives from the funding partners, met together with the Chair and Deputy Chair of the Scientific Committee to triage the expressions of interest on the basis of fit with call. Shortlisted applications were invited to participate in the second phase by submitting Full Project Applications in April 2010.

This first call is now closed and final funding decisions will be made in October 2010. Awards will be in the form of project grants with a maximum duration of 3 years.

Another call for proposals is very likely, the remit and time of which have not been decided at this stage. For up-to-date information on the NAEDI Research Call, please visit [CR-UK's Funding and Research website](http://www.cancer.org.uk).

NPSA Delayed diagnosis of cancer: Thematic review

A report from the NPSA following a project to explore issues of patient safety around delayed diagnosis of cancer is now available. The project, which included a literature review, a review of incidents reported to the NPSA's Reporting and Learning System, and a consultation with stakeholders, led to five broad recommendations for promoting earlier diagnosis of cancer:

1. Development of an accessible diagnostic tool for use in primary care.
2. Identify, review and disseminate good practice in the process of ordering, managing and tracking tests and test results.

3. Review and develop methods for empowering patients who may be on a cancer diagnostic pathway.
4. Develop a model for stronger leadership and improved patient safety reporting and learning, including Significant Event Audit (SEA), at a local and national level.
5. Develop indicators of delayed diagnosis for routine monitoring

The report is available to download from the NPSA website -

<http://www.nrls.npsa.nhs.uk/resources/type/data-reports/?entryid45=69894>

International Cancer Benchmarking Partnership

The Department of Health and the National Cancer Action Team have established an International Cancer Benchmarking Partnership, with the overarching aim of identifying specific causes of survival differences across partners with high quality cancer data and generating insights to improve cancer survival outcomes.

The Partnership is made up of 12 areas: New South Wales and Victoria in Australia, Sweden, Denmark, Norway, England, Northern Ireland, Wales and Alberta, British Columbia, Manitoba and Ontario in Canada. They all have high quality cancer registries, covering comprehensive populations and can therefore contribute to the in-depth analysis of causes of survival differences.

The scope of the work focuses on four cancers: breast, lung, colorectal and ovarian. Breast, lung and colorectal cancer were chosen because they contribute a large share of the burden of cancer, and ovarian cancer has been included as an example of a less common cancer with large variations in survival across countries.

The programme has 5 modules of work planned

to explore the underlying reasons for the delays in diagnosis and treatment and differences in the quality of treatment across the partnership:

Module 1: comparing updated, routinely available data from cancer registries and clinical databases relating to cancer across the partnership

Module 2: exploring differences in population awareness, attitudes and beliefs about cancer

Module 3: exploring differences in primary care systems, the interface with secondary care, and general practitioner awareness and behaviours

Module 4: exploring relative contributions of different factors to diagnostic delays

Module 5: exploring reasons for survival differences based on data from module 1 and the extent to which variation in the application of evidence-based treatments influence survival rate differences

Module 1 is currently underway and is due to be completed by the end of 2010, whilst development work for the other modules is being progressed.



Viewpoints

“Pancreatic cancer is the 5th commonest cause of cancer death in the UK, there are 7800 new cases per year and 20 people a day die.”

Pancreatic Cancer Awareness Week

Last year (2009) saw the inaugural Pancreatic Cancer Awareness Week in the UK, the first ever collaboration of its kind in the pancreatic cancer community.

There is an awful lot that is not publicly known about pancreatic cancer and much is misunderstood and/or misrepresented -so we have a lot to communicate. Virtually every statistic used to measure pancreatic cancer is dismal but there is one that just sticks in the throat: 5 year survival rates for pancreatic cancer (<3%) have NOT improved over the past 40 years. ‘Changing the numbers’ for pancreatic cancer is our mantra and probably will be for years to come.

Pancreatic cancer is the 5th commonest cause of cancer death in the UK, there are 7800 new cases per year and 20 people a day die. Pancreatic cancer can remain undetected until it is too late with the majority of patients being diagnosed with metastatic disease. And herein lies the problem - how do we diagnose patients in time for surgery (as only 10% are currently) which is the only potential option for a cure?

Our progress with awareness to date has been modest, but we did achieve unprecedented media exposure in local and national print media alongside some local broadcast media throughout the Awareness Week. Consistency of message across all of this was in fact the biggest plus and this could not have been managed without the communication, dialogue and the sharing of information between the organisations and individuals involved.

We are learning, evolving and embracing new technologies. There is agreement again this year of our key messages and the awareness colour purple has been adopted. The Awareness Week runs again this year from 22nd-28th November. We want as many people as possible to get involved and help “change the numbers” for pancreatic cancer. See www.pancreaticcancerawareness.org for information.

Ali Stunt
Founder
Pancreatic Cancer Action
www.pancreaticcanceraction.org

Ali Stunt is a rare survivor of the disease and was instrumental in setting up the very first Pancreatic Cancer Awareness Week last year. She has gone on to found Pancreatic Cancer Action, a charity whose mission it is to raise awareness of the disease in order to increase the numbers of people presenting to their doctors in time for surgery to be an option.

