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NAEDI Newsletter

National Awareness and Early Diagnosis Initiative

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Welcome to the second edition of the NAEDI newsletter. It's been a busy few months since the first issue back in July last year – not least because of the launch conference that took place in November. The day attracted around 300 delegates and was so popular that, reluctantly, we had to turn people away. Feedback from the event has been overwhelmingly positive – many thanks to all who gave their time to make the day such a success.

Following the conference, many delegates have requested copies of the slides as we had originally intended to make these available online. Since the event however, the Co-Chairs have decided that there's potential to publish some of the novel work that was presented in an academic journal, as much of this work is as yet unpublished. This means that we're not able to post the presentations online just yet. In the meantime, we hope you'll find this edition of the newsletter useful – it's almost entirely devoted to the conference with highlights from the presentations and breakout sessions.

If you have any particular questions about NAEDI or the launch presentations, you can email us at naedi@cancer.org.uk and we'll do our best to help.

The NAEDI Launch Conference

Overview of the National Awareness and Early Diagnosis Initiative

Professor Mike Richards, national cancer director, gave the opening and concluding presentations of the conference.

In his first, he spoke of the core hypothesis on which NAEDI is based – 'delays' can occur at different steps in the pathway to diagnosis. And because of delay, cancer in the UK is more often diagnosed at an advanced stage, contributing to poor survival rates and, ultimately, a significant number

of deaths that could be avoided. Professor Richards then briefly outlined each of the NAEDI work streams and updated on progress that's been made.

The seven work streams

- Awareness measurement
- Promoting earlier presentation
- Reducing primary care delay
- Key messages
- Review the evidence base
- International comparisons
- New research

New diagnostics work stream

The Cancer Reform Strategy identified improving primary care access to diagnostics as a priority. In recognition of its potential to improve early diagnosis of cancer, a new work stream looking specifically at cancer diagnostics has been added to the NAEDI programme. It will be led by Dr. Mick Peake, national lead for lung cancer, and will link with the wider work on diagnostics within the Department of Health.

Keynotes and plenaries

“Huge gains could be made if survival in the UK was brought into line with that in Europe.”

Keynote speech: Cancer Survival and ‘Avoidable Deaths’

Dr. Michel Coleman, professor of epidemiology and vital statistics at London School of Hygiene and Tropical Medicine, gave a thought-provoking keynote speech on the results of his work analysing how many cancer deaths could be avoided each year if our survival rates matched the best, or even the average, in Europe.

Professor Coleman’s work used data from 13 countries that took part in EURO CARE studies 2, 3 and 4, which compare cancer survival across Europe. By comparing five

year survival rates in Great Britain with those of the average in Europe, the team showed that, for people diagnosed between 1995 and 1999, there were over 6,000 avoidable cancer deaths in Great Britain each year. This figure increased to almost 11,000 avoidable cancer deaths per year when survival rates in Great Britain were compared to the best in Europe.

The work signals the huge gains that could be made if survival in the UK was brought into line with that in Europe.

The National Cancer Awareness Survey: Initial Baseline Results

Professor Jane Wardle, lead researcher on the CR-UK Cancer Awareness Measure (CAM), gave a fascinating presentation on the background to the CAM and the preliminary results of the National Cancer Awareness Survey through which it was used for the first time.

The CR-UK CAM is a validated set of questions designed to reliably assess cancer awareness nationally, regionally and, potentially, globally. This ability to compare different populations through a standardised measure is a first for this area.

The measure has several different sections and features questions on awareness, time to presentation, barriers to seeking medical advice,

risk factors for cancer, cancer incidence and national screening programmes.

The National Cancer Awareness Survey (using the CAM) was delivered as part of the ONS Omnibus Survey in September and October 2008, face-to-face in people’s homes. Approximately 2,000 people completed the measure. An ethnic boost survey was also conducted in October and November and involved more than 1,000 people.

The preliminary results from the first waves of the national survey were presented at the launch. These results supported previous reports of low awareness of cancer

symptoms other than a lump and generally lower levels of awareness in men compared to women. The team are currently analysing the full dataset for publication.

Professor Wardle’s group will be working on developing and evaluating site-specific modules for the four most common cancers, breast, lung, bowel and prostate. They will also be working closely with a number of ‘early implementers’ who will be piloting the CR-UK CAM in their area. You’ll be able to find out more about this on the NAEDI webpage, www.naedi.org.uk, as the information becomes available.

Afternoon Plenary: Developing a Cancer Network Early Detection and Prevention Strategy

Pat Higgins, director of Merseyside and Cheshire Cancer Network, had been due to deliver the afternoon plenary but was unable to make it and so colleagues Jon Hayes, the Network’s deputy director, and Dan Seddon, public health consultant, stepped in at the last minute.

Their presentation introduced the Network’s strategy to reduce health inequalities through improved early detection and

prevention of cancer. The strategy is a vision for 2020 that identifies six priority cancers (bladder, breast, cervix, bowel, lung and skin) and has five themes (staging, early warnings, schools and young people, screening performance and social marketing). The success of the strategy will be measured through improved screening performance, greater recording and reporting of staging, improved stage at diagnosis and reduced exposure to cancer risk factors.

Especially for the conference, Merseyside and Cheshire Cancer Network compiled a toolkit to help others in developing a strategy.

There are a few hard copies of the toolkit and strategy left. If you’d like one, please send your name and address to naedi@cancer.org.uk. The documents can also be found at www.mccn.nhs.uk.

Keynote Speech: The 'Size of the Prize'

In his final presentation of the day, Professor Mike Richards took Professor Coleman's work a step further by asking what proportion of avoidable deaths can be attributed to later diagnosis? Essentially, what is the size of the prize for NAEDI?

Drawing on processes of elimination and extrapolation, Professor Richards presented his own personal view that advanced stage at diagnosis is likely to account for at least 50-75% of avoidable cancer deaths. Assuming that the number of avoidable deaths has actually improved over the last few years, this equates to something like 4,000-7,500 unnecessary deaths each year.

The work of NAEDI is therefore vital. To move things forward, Professor Richards made a number of calls to action to both national and local levels.

Nationally:

- Publish a summary of the current evidence on awareness and early diagnosis
- NCRI to support high quality research where gaps have been identified
- Pilot and evaluate new interventions

- Continue work with Royal College of General Practitioners to improve assessment, investigation and onward referral from primary care
- Develop a new work stream on diagnostics

Locally:

- Every PCT/Network should assess its own one year survival rates – unless these already match the best in Europe, action is required!
- Identify target groups/cancers
- Invest in pilots to increase awareness and promote early presentation (and evaluate)
- Consider investing in a 'locally enhanced service' to promote better referral by GPs

The presentation, and indeed the conference, ended with one powerful call to action – promoting earlier diagnosis could save over 5,000 lives each year without needing to wait for new discoveries or technological advances. Apart from reducing smoking prevalence, what else provides such a good opportunity? – “LET'S DO IT!”

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Breakout sessions

Research

Jane Cope, administrative director of NCRI, and Aoife Regan, of Cancer Research UK, led the research breakout sessions. Jane and Aoife were joined by Dr. Richard Neal in the first session, and Dr. Una Macleod, in the second. Both are senior lecturers in general practice; Richard at Cardiff University and Una at the University of Glasgow.

Sessions opened with a presentation outlining the findings of an analysis of NCRI partners' spending on research in cancer awareness, early detection and early diagnosis. The analysis shows that, in 2007, early detection and diagnosis research accounted for

12% of the annualised spend, compared to the 22% spent on treatment research and the 42% spent on basic biology.

When the spending was broken down into categories it was clear that the funding wasn't equally distributed with some areas, such as research into screening and diagnostic technologies, receiving a greater percentage of funding than those such as research into symptom awareness in the general public or GP delays and referral pathways.

After the presentation, delegates formed small groups to consider how they would spend £10 million

on research if given the chance. Several key points came out of the ensuing discussions: the need for tools that allow research to happen, such as the National Cancer Intelligence Network (NCIN) and the General Practice Research Database (GPRD), the importance of identifying where there is the most to gain from research, the need for investment in evidence-based, properly evaluated, awareness campaigns and the need to better understand the symptoms (and symptom complexes) that people with cancer develop, the behaviour of people who develop symptoms and the pathways of patients in primary care.

“There was great interest in the Cancer Research UK Cancer Awareness Measure and its potential for standardising measurement of cancer awareness,”

Evaluation

Jane Wardle, lead researcher for the CR-UK Cancer Awareness Measure (CAM), Kathy Elliott, national lead for prevention, early diagnosis and inequalities, and Sara Hiom, director of health information at Cancer Research UK, led the evaluation breakout sessions.

The sessions started with an introduction to the CR-UK CAM and how it was developed. Then the delegates formed smaller groups to discuss issues around evaluation and use of evaluation at a local level. It was clear from the discussion that there's been minimal focus on, or specific expertise in, evaluation, either in PCTs, Networks or charities. There was debate about how evaluation differs from needs assessments and performance management as well as discussion about the need to have high-level buy-in and leadership in this area. On a positive note, there was great interest in the CR-UK CAM and its potential for standardising measurement of cancer awareness, with many of the delegates keen to use it in their area.

Improving Screening Uptake

Richard Winder, deputy director of NHS Cancer Screening Programmes, and Professor David Weller, leading screening researcher, led the improving screening uptake breakout sessions.

The sessions featured two presentations. The first, from Richard, highlighted the Cancer Reform Strategy pledges to reduce variation in cervical and breast cancer screening and gather information on the uptake of bowel screening. The second, from Professor Weller, looked at the factors that influence screening uptake, such as deprivation and ethnicity.

Much of the discussion that followed highlighted the need to collate the examples of interventions designed to increase screening uptake. This would help to share learning and, very importantly, could help to avoid unnecessary duplication. There was also much discussion about the use of incentives and informed choice in cancer screening, the accessibility of screening information, particularly in terms of literacy, and the need to embrace targeted interventions with a move away from a 'one size fits all' approach.

“We need to make use of a range of health care settings, draw on social marketing techniques and deliver messages in a clear and positive way.”

Patient Delay

The patient delay sessions were amongst the most well-attended and were led by Derek Stewart, patient representative, Professor Amanda Ramirez, director of the Cancer Research UK London psychosocial group, Dr. David Lyon, GP and clinical lead for the Healthy Communities Collaborative, and Paul Mackenzie, health inequalities manager at Merseyside and Cheshire Cancer Network.

Derek Stewart opened the sessions by emphasising the role that individuals play in achieving change and the need for all of us to be the individuals that make earlier diagnosis of cancer happen.

Professor Ramirez then began the presentations by giving an overview of the evidence for delay and clinical outcomes and her work to increase breast cancer awareness and earlier presentation of breast cancer in older women. Following that, Dr. Lyon spoke about the work of the Healthy Communities Collaborative in promoting the earlier presentation of lung, breast and bowel symptoms across 20 Spearhead PCTs. The last presentation was given by Paul Mackenzie on his work to reduce ‘delay’ in presentation among people with learning disabilities through

the development of an innovative ‘anticipatory care calendar’.

The floor was then opened up to discussion which fell into three main themes: what’s going on in PCTs and Networks, what NAEDI can do to support activity, and what research needs there are. Delegates spoke about interventions going on at local level and the need to make use of a range of health care settings, draw on social marketing techniques and deliver messages in a clear and positive way.

Delegates thought that NAEDI could support local activity by bringing about a mechanism to share good practice, what does as well as what doesn’t work, helping to develop mechanisms and processes for monitoring outcomes and developing key messages for cancers with non-specific symptoms.

In terms of research, delegates thought it vital that the evidence base on effectiveness and cost-effectiveness of interventions be developed, that symptom frequencies in different cancers be investigated and ways of de-stigmatising cancer be explored.

Provider Delay

The provider delay breakout sessions were led by Dr. Willie Hamilton, Bristol based GP and primary care researcher; Professor Mayur Lakhani, chair of the National Patient Safety Agency (NPSA) early diagnosis in cancer project; and Professor Greg Rubin, professor of general practice and primary care at Durham.

The sessions began with speakers outlining their areas of expertise. Dr Hamilton spoke about some of the symptoms encountered by GPs in primary care, the risk of cancer they can be associated with and some of the difficulties of diagnosis and referral. Professor Lakhani outlined the NPSA project seeking to understand delay in cancer diagnosis through analysis of

patient safety incidents, workshops and a literature review, and Professor Rubin gave an overview of a planned national audit of cancer diagnosis in primary care, being led by the Royal College of General Practitioners.

There was much discussion in the sessions, with subject areas tending to fall under one of three main headings: evidence, the system and diagnostic tools. In terms of evidence, delegates thought it vital that a standard definition of delay be agreed upon so that comparisons could be made more easily between studies, that data be collected in a consistent manner, that the NICE referral guidelines be updated and that research be conducted into the development of

simple diagnostic tests.

Under the system heading, the delegates supported the offering of incentives for early diagnosis, such as through the Quality and Outcomes Framework (QOF) and in terms of diagnostic tools, delegates wanted greater access to diagnostics in primary care and clear diagnostic pathways and guidelines for processes following negative test results.

A number of other areas were flagged, for example how to empower patients to return to general practice if their symptoms persist, cancer awareness in young people as a driver for older people presenting and awareness of rarer cancers.

The wider picture

Compiling a picture of activity that everyone can learn from

In line with the calls made during the patient delay sessions, NAEDI is aiming to build up a picture of what people, networks and organisations across the country are doing to raise awareness of cancer, promote earlier presentation, or improve the uptake of cancer screening.

Lots of you have already helped us by telling us about the projects you're involved in but if you haven't, we'd love to hear from you. It doesn't matter what stage the project's at, just tell us as much as you can about the following things:

- Project title
- Organisations involved
- Region
- Description of the project
- What's being done to find out if the project is working/has been successful
- How NAEDI could support the project/future projects

Send this information, along with your contact details, to naedi@cancer.org.uk.

The information you give will go a long way to helping us understand what's going on out there. And we're in discussions about how this can be shared more widely in order to share best practice and learn about what does and does not work in this area. One idea is to establish a database where all the examples can be found. There'll be more information about this on our webpage, www.naedi.org.uk, in due course but if you have any comments in the meantime, please feel free to email in.

“Childhood cancer remains relatively rare and on average a GP will only encounter one case of cancer in children and young people in their career.”

Viewpoint: Childhood Cancer – a contribution from CLIC Sargent

My name is Charlotte and when I was 14 years old I was diagnosed with chondrosarcoma, a tumour in the post nasal space. It took almost a year from when I first went to the GP with nosebleeds to actually having the scan, the biopsy and being diagnosed.

Through my involvement with CLIC Sargent I soon found out I was not the only young person to experience delays in a cancer diagnosis. It is estimated that around half of children and young people with cancer visit their GP with symptoms four times before being referred to a specialist.

The GP treated me for all sorts of different things at first. Nobody took it particularly seriously until the blood started to go down my throat rather than my nose. The GP then referred me to an Ear Nose and Throat Specialist, but I had to wait a further four months for a scan.

Once the diagnosis had been made things all fell into place and moved extremely quickly but getting to that point was very difficult and frustrating.

Childhood cancer remains relatively rare and on average a GP will only encounter one case of cancer in children and young people in their career. GPs and other primary health professionals should have access to targeted information support tools to help them suspect a possible cancer diagnosis sooner. Medical training in paediatrics and cancer and better access to diagnostic services would also help to ensure that GPs are more vigilant of cancer in children and young people.

Charlotte Hails, CLIC Sargent

If you would like to contribute to a future NAEDI newsletter, please email naedi@cancer.org.uk