

NAEDI

National Awareness
and Early Diagnosis
Initiative

November 2013 Issue: 10

Newsletter

A note from the editor:

2013 has been a busy year for NAEDI! This issue gives a flavour of the exciting events that have taken place, an update on research and campaign activities and the launch of a new Cancer Research UK (CRUK) early diagnosis committee. Please click on the underlined web links throughout the text for more information. We hope you like the NAEDI newsletter makeover! Please send any comments to [Anna Lawrence-Jones](mailto:anna.lawrence-jones@cancer.org.uk) at naedi@cancer.org.uk

2nd National Awareness and Early Diagnosis Initiative Research Conference 16th -17th April 2013

The NAEDI research funders hosted the event at the CRUK Cambridge Institute, which was oversubscribed with more than 200 delegates in attendance, showing the high level of engagement in the NAEDI field.

The event held a poster session to give delegates an additional opportunity to view research from the field and network with colleagues. An expert panel judged the extraordinary range of high calibre research posters and after much deliberation were pleased to award Dr Jo Waller, for her poster entitled "[Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study.](#)"

Catherine Thomson (CRUK) and David Meechan (Trent Cancer Registry) were also both highly commended for their posters.

16 speakers presented on a range of topics, with sessions focusing on screening uptake and screening programme insights, help-seeking behaviour, data linkage and health economics. The keynote speaker, Dr Christine Berg, gave the event an international flair by presenting on a fascinating lung cancer screening



Dr Jo Waller and Professor Sir Mike Richards

trial from the USA. Professor Sir Mike Richards (former National Cancer Director) rounded off the day by reflecting on the progress of the NAEDI work so far.

"Terrific initiative - extremely important and very useful work that will inform policy. Huge potential for improving services for patients. Great to experience cutting-edge healthcare research."

The fantastic feedback, the high attendance and the stimulating discussions between academics, clinicians, policymakers and charity workers, allowed us to conclude that the event achieved its aim of encouraging cross-specialty dialogue between the community.

For more details on the conference, talks and posters please visit the [website](http://tinyurl.com/cxhj2uf): <http://tinyurl.com/cxhj2uf>.

Look out for details of the 2015 3rd NAEDI research conference in future newsletters!

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Be Clear on Cancer

How evaluation is driving 2013/14 activity

Be Clear on Cancer aims to raise public awareness of cancer symptoms across England and encourage people with symptoms to see their GP earlier. Evaluation is a core part of the programme of work and we are now building up a strong base of data and evidence, which has informed 2013/14 activity.

Each campaign is tested locally and then regionally, with a view to finally rolling them out nationally if they prove effective. Since it began in 2011 there have been five national, four regional and 25 local campaigns across England.

The second national bowel cancer campaign showed that it was effective in further raising awareness of key symptoms, so this summer saw a lung cancer 'reminder' campaign seeking to build on the success of its first national outing. Another national campaign, 'blood in pee' as a

symptom of kidney and bladder cancers, was then launched in October. The decision to progress this campaign was based on encouraging findings from 2012 local pilots; and a regional pilot campaign in 2013, which saw a 28% increase in 2 Week Wait (2WW) referrals for suspected urological cancer (pathways cover several urological cancer types in addition to bladder and kidney cancer).



A new national 'breast cancer in women over 70' campaign will launch in February 2014. Local pilots in 2012 saw an 8% increase in 2WW referrals for both non-suspected and suspected breast cancer symptoms, compared with

5% increase in the control area. A 4% increase in the number of breast cancers diagnosed following a 2WW referral for non-suspected breast cancer symptoms was also seen in the local pilot area compared with a 2% increase in the control area. A regional pilot campaign earlier this year showed a significant increase in the belief that one in three women who get breast cancer are aged over 70, from 16% to 25%.

There will also be regional pilots of two other campaigns that have shown promise at a local level – ovarian and oesophageal-gastric cancer. The latter in particular having shown one of the strongest examples of Be Clear on Cancer's contribution in 2012, with a 20% increase in oesophageal cancers diagnosed following a 2WW referral for suspected upper GI cancer.

Visit the website for more information:

<http://tinyurl.com/mg38psu>.



Cancer Research UK's new Early Diagnosis Advisory Group

The Early Diagnosis Advisory Group (EDAG) is a new CRUK small grants funding, advisory and policy setting committee focusing on the early diagnosis of cancer (excluding biomedical research). It is a separate, but complementary, funding body to NAEDI and CRUK's Population Research Committee focusing on commissioning rapid pieces of self-contained research (e.g. systematic reviews and pilot studies) to add to the early diagnosis evidence base and inform policy. In its advisory capacity to CRUK, EDAG is looking at the broader issues and challenges for early diagnosis research and policy.

EDAG is chaired by Professor Peter Sasieni (Queen Mary University, London) and comprises a cross-cutting group of experts, relevant to the multifaceted challenge of early diagnosis, including primary and secondary care clinicians, health behaviour and cancer data experts, epidemiologists, biostatisticians and patient representatives. For information on future funding calls visit the [website](#) or email [Anna Lawrence-Jones](mailto:Anna.Lawrence-Jones@cancer.org.uk) on EDAG@cancer.org.uk

EDAG met for the first time in September 2013 and awarded funding, based on a closed call for proposals, to Professor Richard Neal at Bangor University, who is leading an international collaboration of experts from Aarhus (Denmark), Bangor, Cambridge, Durham, Edinburgh, Exeter and Perth (Australia) – the ABC-DEEP consortium – to complete three exciting and complementary projects on early diagnosis:

- 1) Updating the systematic review of evidence linking delays in symptomatic diagnosis to outcomes;
- 2) Creating a central resource of research into symptomatic early diagnosis of cancer;
- 3) Producing a 'league table' of expected survival benefits from the early symptomatic diagnosis for 22 cancer types.

We expect results from this project to be published in 2014, so look out for updates in future newsletters. EDAG will meet three times in 2014 and the committee is currently planning its first open funding call, with details being published on the website shortly.



NAEDI workshop

28th June 2013

CRUK, in collaboration with the other NAEDI Research funders, organised a full-day workshop in June 2013 for potential applicants to NAEDI Research Call 3. The aim was to provide an opportunity for interested members of the research community to find out more about what the funders were looking for in proposals, and to enhance their networks and collaborations.

Particular highlights were an overview of available data sources for research, provided by Dr Ekaterini Blaveri and Jon Shelton from the [National Cancer Intelligence Network \(NCIN\)](#), and Professor Sally Wyke's top tips for writing a successful grant application:

- Start early
- Get the right team
- Show clearly how the application builds on existing knowledge
- Spend time on the abstract
- Make every step of the methods 100% clear and don't skimp on the analysis section
- Tell a coherent, easily understood story
- Simple ideas appeal!

Participants were also introduced to the [NIHR's Research Design Service](#) – a free source of assistance for developing research proposals.

Dr Anne Helme, Research Funding Manager for NAEDI Research Call 3 commented

"I was pleased to see so many attendees had signed up to have 1:1 sessions with the funders to discuss their early diagnosis research ideas – we really encourage all applicants to talk to us before submitting their proposals."



Mr Tom Haswell

Mr Tom Haswell, who is the consumer representative on the NCRI Screening, Prevention and Early Diagnosis Advisory Group, provided a patient's perspective.

"I was pleased by the number of researchers who approached me asking about getting patients involved in their research proposals, bearing in mind funders are looking for patient involvement. We do have a lot to offer considering many of us have as patients participated in clinical trials and through our experiences we can improve the quality of research proposals leading to improved outcomes for patients."

This has been reflected in the increasing number of applications to NAEDI Research Call 3 that involve patient and consumer representatives in their planning stage, as well as in delivery.

The event received excellent feedback and we are therefore planning more events for 2014. If you have any ideas for what funders could do to support the NAEDI research community please send them to [Anna Lawrence-Jones](mailto:anna.lawrence-jones@naedi.org.uk) on naedi@cancer.org.uk.

NAEDI Research Call 3 Update

Earlier this year NAEDI opened its third research funding call, identifying five key areas in which proposals were encouraged:

- Investigating reasons for late presentation (to primary care or A&E) and low uptake of screening.
- Developing effective interventions to prompt change, at both individual and systemic levels, to reduce late presentation and low uptake of screening.
- Investigating reasons for delays occurring within primary care and onward referral.
- The significance of symptoms across different cancer types.
- Making use of available data.

The secretariat received lots of exciting applications from all over the country and was pleased to see a high level of collaboration between the NAEDI community. Topics represented include barriers to presentation, reasons for delay in primary care, screening uptake, inequalities, identifying risk factors and promoting public awareness. The proposals focused on a range of cancer sites with colorectal cancer being the most prevalent, followed by lung and breast cancer. The applications are currently being reviewed by external experts and funding decisions will be made in February 2014 by the NAEDI Scientific Committee. Look out for the funded projects in a future NAEDI newsletter.

For enquiries related to the NAEDI research funding calls please contact [Anna Lawrence-Jones](mailto:anna.lawrence-jones@naedi.org.uk) on naedir01@cancer.org.uk

NAEDI researchers may also be interested in the MRC's Public Health Intervention Development Scheme – deadline January 2014. Please visit the [website](#): <http://tinyurl.com/mrrpu7q>

International Cancer Benchmarking Partnership



Module 5

Module 5 will provide an opportunity to explore whether observed differences in outcomes between countries can be explained by 'early deaths' i.e. the number of patients that die within the first few months of diagnosis. Module 5 will also investigate suspected causes of short-term mortality.

Regular readers of the NAEDI newsletter will be familiar with the unique structure and purpose of the International Cancer Benchmarking Partnership (ICBP) and have so far been introduced to Modules 1-4. As a reminder, the ICBP is a partnership of clinicians, academics and policymakers across six countries to explore why cancer survival rates vary between countries. Module 1, the core benchmarking module of the ICBP, has reported significant international differences in lung, breast, colorectal and ovarian cancer survival, with England having some of the poorest outcomes. Module 1 also showed that differences in survival are greatest within the first year of diagnosis between ICBP countries and that stage at diagnosis correlates with an increase in excess mortality within the first month after diagnosis.

There are two proposed elements to Module 5:

1. Quality assurance: A qualitative investigation of cancer registry data and processes will be undertaken across participating countries. This qualitative work will inform the development of an electronic simulation tool that will enable comparisons of how and to what extent differences in key variables, such as data definitions and registration practices, have an impact on short term outcome measures including mortality.
2. International comparative analysis: This will focus on lung, colorectal and ovarian cancer. These cancers are affected by short term mortality and outcomes vary internationally. The team aims to analyse factors including routes to diagnosis, co-morbidities, treatment and characteristics, including age, sex and stage, of patients who die within a few months of diagnosis.

The electronic simulation tool and the methods from the international comparison study will provide a blueprint that can be adapted and used by other countries outside of the ICBP for future analyses on different cancers.

Module 5 is chaired by Dr Jem Rashbass, National Director for Disease Registration, Public Health England and supported by programme managers at CRUK. The central analytical team will include colleagues from the National Cancer Registration Service (NCRS) and the National Cancer Intelligence Network (NCIN).

For more information visit www.icbp.org.uk, or email [Sam Harrison](mailto:Sam.Harrison@icbp@cr.uk) on icbp@cr.uk.

Blogs that explore the ICBP findings in more depth can be accessed by clicking the links below:

Module 1:

- Core international cancer survival benchmarking: <http://tinyurl.com/mt2utkw>
- Ovarian cancer survival by stage at diagnosis: <http://tinyurl.com/mg99o4g>
- Lung cancer survival by stage at diagnosis: <http://tinyurl.com/lzeczss>
- Breast cancer survival by stage at diagnosis: <http://tinyurl.com/m9uh6uz>

Module 2:

- International differences in cancer awareness and beliefs: <http://tinyurl.com/l6z7rnu>

GP engagement

CRUK continues to test a new model of intensive support to primary care through the use of Primary Care Facilitators. The project, which began in October 2012, is currently operating in nine Clinical Commissioning Groups (CCGs) in Merseyside and Cheshire and three CCGs in London (Islington, Enfield and Waltham Forest).

Primary Care Facilitators provide practical and bespoke support to GP practices to help in the earlier diagnosis of cancer. The facilitators meet with individual practices to share data and encourage the GPs and practice staff to develop their own cancer action plans. The facilitators will then support the practice in implementing their plans and also act as a main point of contact for any cancer related matters within the practice. Since the project began CRUK's facilitators have worked with 88% of the 492 GP practices in the pilot areas and organised CCG cancer education events for 1000 clinical and non-clinical primary care staff.

Our facilitators also work closely with the CCGs in the pilot areas and have supported the development of cancer strategies in nine CCGs to include a focus on early diagnosis and cancer. The first interim evaluation report, by the University of Durham and CRUK will be available in June 2014. Later this year we will be recruiting three new facilitators to expand our work into Scotland, working in partnership with the Scottish Government's Detect Cancer Early Programme. We will also be working in partnership with the NHS in Thames Valley and North East London to provide additional facilitators in those areas. For more information please email [Tom Barber](mailto:Tom.Barber@primarycare@cr.uk) on primarycare@cr.uk