Second NAEDI Research Conference

17th April 2013

Cambridge Research Institute

Contact: Please email MAEDIconference@cancer.org.uk if you would like more information about this conference or would like PDFs of the speaker presentations.



The National Awareness and Early Diagnosis Initiative (NAEDI) research conference was hosted by Cancer Research UK in collaboration with:

- Department of Health
- Economic & Social Research Council
- HSC Public Health Agency
- Chief Scientist Office
- Llywodraeth Cymru Welsh Government
- National Cancer Research Institute (NCRI)

Speakers presented on topics from across the NAEDI research landscape, with sessions focusing on screening uptake, help-seeking behaviour, data linkage and health economics. A key aim of the conference was to encourage communication and cross-speciality dialogue between researchers working in the early diagnosis and awareness field.

Conference programme

The conference programme is available as an appendix to this document

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Introduction

Dr. Harpal Kumar, Chief Executive Officer, Cancer Research UK

Introduction

The aim of the conference is to present findings from some of the latest NAEDI funded research, to meet and gain inspiration from speakers across the NAEDI research field, foster new potential research collaborations and to stimulate interest in future NAEDI research funding calls. There are multiple funders for research into awareness and early diagnosis, including Cancer Research UK who support programmes, projects and trials looking at diverse aspects of the awareness and early diagnosis field such as genetic predisposition, screening, behavioural research and decision support tools.

There have now been two <u>NAEDI Research calls</u> funded by a host of organisations including:

- Cancer Research UK
- Department of Health (England)
- Economic and Social Research Council
- Public Health Agency Northern Ireland
- National Institute for Social Care and Health Research Wales
- and the Scottish Government

These funders have already invested £7 million pounds into high quality research in the NAEDI field over the last five years —with the ultimate aim of improving cancer survival. Outcomes and progress of NAEDI-funded projects to date has been positive. One strength of the field is its multidisciplinary nature, driving stronger research proposals and outcomes. The quality of the projects funded through the first two rounds of funding has now led to the launch NAEDI Research Call 3 (hyperlink) at this conference.

The <u>International Cancer Benchmarking Partnership</u> (ICBP) is a programme closely linked to the NAEDI initiative. The partnership is seeking to understand how and why cancer survival varies between countries, and is focused on breast, colorectal, lung and ovarian cancers.

There are seven peer reviewed <u>publications</u> to date from the ICBP. Findings from the publications have filled in some gaps in our knowledge:

- The UK's 1 and 5 year survival has improved for all four cancers studied in the partnership, but it still trials behind those of several other developed nations.
- Factors which may influence lower UK cancer survival differ between cancer types but include later diagnosis of advanced stage cancers, issues with access treatment or inferior treatment and adverse stage distribution.
- The UK has the least complete set of stage data, there is a need to improve this to improve robustness of future international comparisons.
- People in the UK compared to other countries are as aware of cancer symptoms and generally have positive beliefs about cancer.

Findings from NAEDI research and the ICBP feed into a wider policy background, as outlined in the 'Improving Outcomes: A Strategy for Cancer (Jan 2011)' and 'Operating Framework for the NHS 2011/2012'.

The Be Clear on Cancer campaign falls under the 'Achieving early presentation' arm of NAEDI. The Be Clear on Cancer brand has been in use since January 2011 to promote awareness and early diagnosis of cancer at a local, regional and national level. Cancers targeted by the campaigns have included bowel, breast, lung, bladder and kidney, oesophago-gastric and ovarian cancers. A more generic cancer symptoms campaign called 'Know 4 Sure' has also been piloted. This campaign was developed to raise awareness of four symptoms that cover a wide range of cancers. Bowel cancer and lung cancer specific campaigns were rolled out nationally in 2012 and featured TV advertising. Results from

these campaigns have been promising and show statistically significant increases in GP attendance, spontaneous awareness of symptoms, referral rates and cancers diagnosed. There have also been promising signs of earlier diagnosis. Cancer Research UK is leading on the evaluation of these campaigns. You can learn more about Be Clear on Cancer campaign here.

Keynote

Dr. Christine Berg, National Lung Screening Trial Lead Investigator, formerly with the National Cancer Institute, USA

Risk-based Cancer Screening: Insights from the National Lung Screening Trial

Lung cancer is the leading cause of deaths worldwide. Since the US Surgeon General issues his first report on Smoking and Health tobacco control measures have resulted in an estimated lung cancer deaths being averted. However, more needs to be done and in addition to further preventative action an alternative method with the potential to reduce lung cancer mortality is lung cancer screening.

National Lung Screening Trial investigated the benefits and risks of low dose helical CT screening. Low-dose helical CT is an improvement on other screening techniques because it allows the entire chest to be surveyed in a single breath. This reduces the movement visible on the image making it easier to read.

It is well known that screening increases both lead and length time bias and therefore the only methodology that can truly measure the benefit of screening is a randomised control trial. The National Lung Screening Trial consisted of three annual screens in asymptomatic current/former smokers aged 55-74 with at least 30 pack year smoking history (former smokers must have given up within the last 15 years). The control arm consisted of Chest X Ray. The trial had a slightly younger population than the estimated at risk population, a smaller proportion of black people and a higher proportion of former smokers.

The results showed a reduction in lung cancer mortality in the CT arm of 20%. Across the three screens almost a quarter has of CT scans were positive for an abnormality compared with less than 10% for Chest X-ray. Of those with an abnormality 649 (3.5%) in the CT arm were diagnosed with lung cancer compared with 279 (5.5%) in the Chest X Ray arm. At the first round the CT arm had a higher sensitivity than chest X-ray (94% versus 74%) but the Chest X ray had higher specificity (91% versus 73%)

The benefit of low does CT scans is the reduction in radiation compared with standard CT scans. Despite this reduction in radiation, there is still an increased risk of cancer due to the radiation from CT scans. This along with the risk of over diagnosis means that lung cancer screening should only be carried out in high-risk groups where the benefit outweighs the harms. The next step is to use the data available to model which populations are at high risk and will benefit from lung cancer screening.

NAEDI-Funded Research

Chaired by Dr. Jane Cope

Dr Matthew Carr, University of Manchester

Cancer Screening Uptake in Patients with Type 2 Diabetes

In the UK, there are 2.8 million people with diabetes and 300,000 new cancers diagnosed each year. The two conditions share many common risk factors (for example, being overweight), but there is growing evidence that diabetes increases the risk of cancer itself. In addition, evidence from the USA has shown that diabetes patients may have lower uptake of cancer screening services. The aim of this study is to find out whether there are any differences in screening uptake between diabetic people and non-diabetic people in the UK, and identify possible reasons for any differences.

Dr Carr is using the CRPD (clinical practice research data link, formerly known as the GPRD) to compare screening uptake in diabetic and non-diabetic people. However, the CPRD is not designed to be a reliable indicator of cancer screening and there is striking under-reporting of screening events. The researchers assumed that diabetes diagnosis would not affect the chance of under-reporting of cancer screening. The first stage is to extract and clean the data from the CPRD. They then identify diabetes patients and the type of diabetes they have, as well as identifying cancer screening events among people who are eligible for NHS cancer screening.

Taking breast cancer as an example, the nationally reported uptake for the 2.7 million annual invitations is 73.6%, with a lower uptake rate in London (59%) compared to the rest of the UK. From the CPRD data, defining routine screening as mammograms happening in people without an identified higher risk, with no symptoms, with no screen in the previous 2 years, the uptake appeared to be 43%. This demonstrates the level of under-reporting in the CPRD. However, the patterns seen in the CPRD data were consistent with those seen in the national data including lower uptake in London (31%). To identify prevalent diabetes that was diagnosed over 2 years previously, Dr Carr used diagnostic codes in the CPRD as well as supporting evidence of diabetes (for example, drug prescribing history). To differentiate between type 1 and type 2 diabetes, drug history and other prescriptions were used.

Breast screening uptake was seem to be higher in diabetic patients compared to non-diabetic patients, especially after 2005 (before this time, the rates had been the same regardless of diabetes diagnosis). These findings were not consistent with the hypothesis generated from the US data showing lower screening uptake in diabetic patients. Dr Carr concluded that there has been systematic under-reporting of breast screening in the CPRD, but that breast screening uptake was elevated in type 2 diabetes patients compared to the general population. Rates diverged around the time that the QOF (quality and outcomes framework) was introduced. The QOF may have been associated with positive side effects, for example on cancer screening, and more research is needed to fully understand this. In future, Dr Carr would like to link the national diabetes register and cancer screening data from the screening programmes.

Dr Melanie Morris, London School of Hygiene and Tropical Medicine

<u>Screening, timely diagnosis and inequalities in breast cancer survival - an investigation of differences by ethnicity and deprivation</u>

Melanie Morris from London School of Hygiene and Tropical Medicine presented methods for how she intends to measure the impact of breast screening on breast cancer survival in ethnic minority and deprived groups in England.

Using West Midlands cancer registry data, Hospital Episode Statistics and data from the breast screening service she has identified a cohort of 20,000 West Midlands women who turned 50 between 1989 and 2012. Combining data from Hospital Episode Statistics data and the breast screening service enabled her to identify the ethnicities for 90% of her cohort. She has attempted to ascertain the ethnicity of the last 10% using a name-identification programme. It works well for Asian names but cannot distinguish between black and white surnames. The next step in her study is to construct life tables specific to different ethnic groups in order to calculate net breast cancer survival.

Dr. Fiona Walter, University of Cambridge

Why do some patients present with thicker melanomas? A qualitative exploration of patients' symptom detection and help-seeking decisions

Malignant melanoma is the fifth most common cancer in the UK and incidence rates are rising rapidly – by around three-fold in men, and two-fold in women since 2000. Rising incidence is linked to increased UV exposure over previous decades (including holidays abroad becoming more popular, and the introduction of sunbeds to the UK). The main prognostic factors for melanoma are tumour thickness, plus ulceration and mitotic rate, and the UK has poorer outcomes for melanoma than comparable countries.

Recent research (Lyratzopoulos et al 2013) indicates that melanoma diagnosis in primary care in England is pretty timely, with a short primary care interval compared to many other cancer types. Most of the problems with time to diagnosis are probably at the patient level. Longer patient intervals for melanoma are commoner among older people, men, those with lower educational levels and in certain body locations (e.g. plantar, back). There is conflicting evidence around time to presentation and melanoma thickness at diagnosis. The aim of this research was to understand why some patients present with thicker melanomas, by exploring the ways patients appraise skin changes and the decisions they make to seek help in primary care. All those with thicker melanomas (≥2mm) were approached to take part in face-to-face interviews, as well as some with thinner (≤1mm) tumours.

A total of 121 people responded out of 241 approached. The first 17 participants formed a pilot study, followed by a further 63 people even spread across 'thin' and 'thick' melanomas. Mean age was 63 (range 29-93 years) with roughly half male. There were twice as many participants with no further education, as there were those who had further and higher education. Distribution by Fitzpatrick skin type scale was interesting, with a lower than expected proportion of cases categorised as Type I, (but this is a fairly small qualitative study).

The most common type of melanoma was superficial spreading (37 cases) and most participants had stage 1A or B tumours. A higher than expected proportion of cases reported a family history of melanoma (27%) and a significant number reported a previous melanoma. Interim analysis looked at the appraisal interval, help-seeking interval and disease factors (ie skin changes). In terms of the appraisal interval, pre-existing knowledge and awareness of melanoma doesn't seem to be affecting time to presentation. As people saw a change in their skin they sought to normalise it. There also appeared to be a mismatch with participants' mental image of melanoma/skin cancer, and what their own melanoma looked like. It didn't look like anything they'd seen in magazines etc. In terms of the help-seeking interval, competing responsibilities and priorities (not fear) seemed to be playing a significant role, with skin changes not frequently seen as a priority. There was evidence that sanctioning by others was important, with participants asking work colleagues, family etc for an opinion (and sometimes being falsely reassured). Participants described their skin changes in a range of ways, with some features on commonly used checklists (eg change in size, shape or colour) and some not on checklists (e.g. 'raised from skin', 'just a spot', 'spot on a mole'). These kinds of descriptions were used in both the 'thinner' and 'thicker' melanoma groups.

Next steps include a complete analysis of comparisons between thicker and thinner tumours, and an in-depth exploration of descriptions. It is hoped that this research will have implications for both community awareness (e.g. in terms of effective language and images used to describe skin changes in campaigns, and to further understand prompts to encourage timely help-seeking) and GPs (to aid appropriate and timely referrals and reinforce importance of monitoring and safety-netting).

Dr Richard Wagland, University of Southampton

Symptom prevalence and help seeking among patients at risk of lung cancer: an exploratory feasibility study in a primary care population

Dr Richard Wagland, from Southampton University, gave the final presentation of the session. He's working with Professor Jessica Corner to assess the feasibility whether a simple questionnaire, sent to people at high-risk of lung cancer (e.g. > 50 year old smokers), could spot people with early symptoms of the disease. They also want to find out how people with such symptoms seek medical advice.

Their initial target was to get 600 questionnaires back from high-risk people from 8 GP surgeries – but they've hugely exceeded that target: a 26% response rate meant they've had 1210 responses, giving them a far richer data set than anticipated – this will allow them to do additional future analysis.

To date, analysis of the results has shown: that fatigue, breathing problems and chest pain are the most common symptoms among respondents; that 20% of respondents reported three or more symptoms, and that a similar number had been to see the GP five or more times. They also discovered that about 11% of respondents had not been to see a GP, despite their symptoms. They're now going to hold a series of focus groups, first with participants - to explore attitudes to and experience of seeking help for their symptoms – and then with GPs to identify thresholds for symptoms identified by the questionnaire that need GP review.

Launch of NAEDI Research Call 3

Launch of NAEDI Research Call 3

Sara Hiom, Director of Patient Engagement and Early Diagnosis at Cancer Research UK, launched NAEDI Research Call 3, and provided an overview of the timeline, remit, and target areas for the new call. For more information about the Research Call and an accompanying workshop for potential applicants, please see visit the NAEDI Research Call page.

The Wider NAEDI Landscape

Co-chaired by Professor Sir Bruce Ponder and Sara Hiom

Dr Yoryos Lyratzopoulos, University of Cambridge

Stratifying early diagnosis initiatives and research

Dr Lyratazopoulos's talk focused on how looking at data variations from the perspective of cancer type, GP performance or patient factors can help us make decisions about targeting early diagnosis interventions. He argued that there are only really two important decisions when it comes to early diagnosis – helping patients make the right decisions about seeing their doctors, and helping doctors make the right decisions about referring their patients for further investigation. The proportion of patients with cancer referred at their first presentation to a GP can be considered the 'sensitivity' of GP. (82% of cancers are referred in 1 or 2 consultations.)

He notes there is huge variation by cancer type in the number of times cancer patients see their GPs before a diagnosis. Over 30% of multiple myeloma, pancreatic, stomach and lung cancer patients see their GP more three times or more, whilst for breast, endometrial cancers and malignant melanoma fewer than 10% of patients see their GP more than 3 times before a diagnosis. It's likely that this can at least partly be explained by the symptom signature of these cancers – the breast cancer, melanoma, testicular cancer symptom signature is well-understood (Dr Lyratzopoulos refers to these cancers as 'easy to spot'), while myeloma, pancreatic and stomach cancer signature is less clear and symptoms may be harder to identify.

Dr Lyratzopoulos argues that this has implications for the decisions that we should be making about early diagnosis interventions. He argues that we should primarily focus our efforts particularly on harder-to-spot cancers but we should also take a different approach depending on the cancer type. For difficult to spot cancers we need new screening and diagnostic tests. For intermediate cancers (those that are neither very easy, nor very difficult to spot) we need better decision support tools for primary care and new diagnostic tests would also help. For 'easy to spot' cancers, maybe delays should be considered safety breaches. But patient factors also play a role - e.g. female bladder cancer patients see GP more times than males before a diagnosis, even if they have macroscopic haematuria. He also emphasised that staging data can give us important insights. Take the example of the association between stage at diagnosis and age. For bladder, lung and kidney cancers older people are less likely to be diagnosed at a late stage, whereas for breast, prostate, endometrial cancers and melanoma, older people are more likely to be diagnosed in advanced stages. This suggests it isn't ageism in the NHS that's causing these differences in survival. Instead to address inequalities we need to target interventions for 'easy to spot' cancers to high risk groups (such as Be Clear on Cancer breast cancer symptom campaign targeting women over 70). But we do also need to help doctors to refer better. There is a huge variation in conversion rates (i.e. proportion of urgent suspected cancer referrals that turn out to be cancer) by GP practice.

Dr Sophie Whyte, University of Sheffield

Effectiveness and cost effectiveness of an awareness campaign for colorectal cancer: A mathematical modelling study

In January 2011, a colorectal cancer awareness campaign was piloted in two regions of England (East of England and South West). The objective of this study was to use data from this campaign to estimate the effectiveness and cost effectiveness of an early awareness campaign from an NHS perspective. An existing mathematical model was adapted and used to predict the long term impact of the campaign at a national (England) level. The model included data on the direct costs of running the campaign, costs of any additional GP attendances or referrals and any change in incidence or screening uptake.

Results showed that the campaign caused an increase in Dukes' stage A-C presenting symptomatically and a decrease in stage D presenting symptomatically. Screen detected colorectal cancers and colorectal cancer specific deaths decreased, and Quality Adjusted Life Years (QALYs) increased. Overall the campaign led to an increase in NHS costs, due to the campaign running costs, costs associated with increased GP attendances and referrals, and increases in treatment costs (due to people presenting at younger ages and the shift of cases from Dukes stage D to Dukes stage C). However, there was a decrease in screening costs.

Overall, the model estimated that for an awareness campaign resulting in a 10% increase in presentation rates for one month, it would cost £5.5 million, prevent 66 deaths and gain 404 QALYs. The Incremental cost-effectiveness ratio (ICER) compared to no campaign, was £13,496 per QALY. This is less than the £20,000 per QALY considered to be cost-effective by NICE, suggesting that a national awareness campaign could potentially be cost effective. Sensitivity analyses indicated that results were highly sensitive to the magnitude, duration and stage distribution of the immediate increase in incidence due to the campaign. Future cost-effectiveness evaluations would benefit from more data, including items such as emergency presentation rates, effect of the campaign by age, and rate of diagnosis of other lower GI conditions with similar symptoms to colorectal cancer.

Sebastian Hinde, University of York

Modelling the cost-effectiveness of early awareness interventions for the early detection of lung cancer

Between October and November 2011, a lung cancer pilot campaign ran in the Midlands and aimed to improve awareness of the signs and symptoms of lung cancer. This study uses modelling methods to estimate the cost-effectiveness of an awareness campaign at a national level.

A natural history model was developed which simulated the experience of patients with Non Small Cell Lung Cancer (NSCLC) from disease onset through to pre- and post- diagnosis stages. Actual lung cancer incidence data collected from the National Lung Cancer Audit was also included in the model. The model estimated that there were 79,238 underlying undiagnosed cases of NSCLC in England, 93% of which are at an early stage. Whilst the probability of moving from the early pre-clinically diagnosed NSCLC to a more severe disease state is low, the progression from early stage NSCLC to a severe stage is rapid.

The shift in stage at diagnosis observed in the regional campaign was applied to the natural history model. Overall the model estimated the additional cost to the NHS (including direct costs of the campaign, along with diagnosis and treatment costs) to be £3.9 million,

generating 325 quality-adjusted life years (QALYs). The Incremental Cost-Effectiveness Ratio (ICER) compared to no campaign was £12,192 per QALY. This is less than the £20,000 per QALY considered to be cost effective by NICE, suggesting a national campaign to increase awareness of the signs and symptoms of lung cancer could be potentially cost-effective. However, a number of major evidential uncertainties remain including the costs incurred by the NHS in treating a patient with NSCLC.

Professor Willie Hamilton, Exeter Medical School

<u>Update on DISCOVERY programme</u>

The DISCOVERY programme aims to develop knowledge about symptomatic early diagnosis (and not screening) through 15 projects in three major themes.

Theme 1 – SYMPTOM study.

This study looks into factors influencing patient appraisal of symptoms and decisions to consult medical care. There are cohorts for three cancer sites – lung, bowel and pancreas – and participants are asked in surveys what their symptoms were before they consulted a doctor (prompted and unprompted), as well as what their barriers and facilitators were to seeking help. The lung and bowel cohorts are finished but they have not recruited enough participants for the pancreatic cohort yet. There is also a nested qualitative study within this cohort looking at what factors are relevant when deciding whether to have cancer diagnostic tests or not.

Theme 2 - quantifying cancer risk depending on which symptoms patients have This aims to find out what leads patients down the wrong diagnostic route, for example patients with anaemia due to bowel cancer being referred to a haematologist. Professor Hamilton is doing a case-control study within the CPRD (formerly GPRD) about clinical features of oesophagogastric (OG) cancer in primary care. The aim is to identify all features of presentations with OG cancers and identify symptoms we may not have thought of before. Using the NICE referral guideline will only pick up 40% of OG cancer patients, as only the most common and most predictive symptoms are included (dysphagia and weight loss with nausea/vomiting). These two symptoms have positive predictive values of 4.8% and 2.8% respectively for OG cancer. If one were to investigate all people with all the less predictive symptoms of OG cancers, more cases would be found. But there is a need to balance the level of investigations (and associated cost) with the likelihood of symptoms indicating cancer.

Theme 3 - consumer values in design of cancer investigation services

The PIVOT study aims to find out a threshold at which people want to be tested/investigated for cancer. It is a vignette study describing a symptom or combination of symptoms, the possible diagnosis, the treatment and prognosis, the % risk that it is cancer, and a description of the diagnostic test. At the end of the vignettes, the participant is asked whether they would choose to be investigated and when. There are 3469 participants in the study and 6930 responses overall. 92% of people wanted lung cancer testing with a chest x-ray, which didn't really vary if the risk level was set at 1%, 2%, 5% or 10%. 91% of people wanted a CT for pancreatic cancer, again with little variation by risk level. 85% of people wanted a colonoscopy for bowel cancer, but this did vary by risk level. At a 1% risk level, 80% of people wanted to have the test, but at a 10% risk level, 90% of people did. The reasons people gave for wanting to be tested included peace of mind, early diagnosis and family history. Reasons people gave for not wanting to be tested included low risk of cancer, rather not know, unpleasant or harmful test (especially colonoscopy), or that early diagnosis would not help (for pancreatic cancer). Older people were less likely to want to be tested compared to younger people (81% for 70+ age group compared to 90% for 40-59s).

So far, the DISCO programme has helped us understand more about:

- Barriers and facilitators to seeking help
- Pathways patients take to diagnosis by symptom type
- Positive predictive values for OG, pancreas, kidney and bladder cancer symptoms
- What patients want to know before testing for cancer
- That most patients do want to be tested

In future, DISCO will help us understand more about:

- Which pathways are clinically and economically optimal
- Which pathways are logistically acceptable in the NHS setting.

Professor Stephen Duffy, Queen Mary University

<u>Update on the Policy Research Unit in Cancer Awareness, Screening and Early</u> Diagnosis

Professor Duffy explained that the Policy Research Unit is dedicated to research on cancer screening, symptom awareness and early diagnosis, with the aim of undertaking research to underpin earlier diagnosis of cancers, so enabling more successful treatments and ensuring better survival rates. Overviews were given on each of the topics the unit focuses on.

Cancer awareness: multiple studies have been funded and are ongoing looking at awareness, inequalities, survival and mortality from various cancers also looking at symptom prevalence in different populations and further analysis on the ICBP data. **Cancer screening:** studies are about to start or are ongoing on the impact and certain aspects of the breast screening and bowel screening programmes. There is also an evaluation of policy interventions looking at ways to improve screening availability and convenience.

Early diagnosis: studies are about to start or are ongoing on GP response to symptoms, by patient's ethnicity, socioeconomic status, age and sex at an advanced age, studies on biomarkers for early cancer, studies on biomarkers for early cancer and qualitative research on use of decision aid tools in primary care.

Professor Mahesh Parmar, MRC CTU

<u>Introduction to the NRCI Screening, Prevention and Early Diagnosis Advisory Group</u> (SPED)

The Chair of the NRCI Screening, Prevention and Early Diagnosis Advisory Group (SPED), Professor Max Parmar from the MRC Clinical Trials Unit, presented an overview of SPED, including the aims and remit of the group. Key activities of the group to date and plans for future work were outlined. These include assisting with the NAEDI applicant workshop on 28 June, and reviewing applications to NAEDI Research Call 3. Professor Parmar highlighted that SPED welcomed approaches from NAEDI applicants for comment/input from the group.

Poster Awards



If you would like to see copies of the abstracts of the posters presented at the conference please email NAEDIconference@cancer.org.uk

Congratulations to Dr Jo Waller, the winner of the NAEDI poster competition for her poster entitled "Women's responses to information about overdiagnosis in the UK breast cancer screening programme: a qualitative study", and to Catherine Thomson and David Meechan who were both highly commended for their posters "Assessing the impact of stage shift and treatment on survival improvements; a comparison of female breast and colorectal cancers in East Anglia using stage specific survival" and "Variation in use of the 2-week referral pathway for suspected cancer" respectively.

Reflection on Progress of NAEDI

Professor Sir Mike Richards, NHS England

Reflections on Progress of NAEDI

The National Awareness and Early Diagnosis Initiative in now entering its fifth year, Professor Richards reflected in the progress of this initiative and where gaps still remain. Brief overviews were given of established and emerging topics that are being targeted and investigated in NAEDI research and fieldwork.

Survival: Internationally and within the UK

Survival is improving for most cancers, but the UK still lags behind other developed countries on survival for most cancers. The survival gap appears soon after diagnosis (Coleman et al, Lancet 2011). Survival is the UK is associated with a number of factors such as age, stage at diagnosis, level of deprivation and emergency presentation etc.. Professor Richards noted the difficultly is nailing down why survival is poorer in the UK and acknowledged that it is likely down to a number of factors including late presentation, late investigation and suboptimal treatment.

Patient/GP Delay

Delays occur in presentation and referral. Most patients present to their GP quickly with symptoms but 25% of all cancer patients present as an emergencies to A&E in England. These patients are more likely to be older, more deprived and diagnosed at a later stage. Patients who do delay report that they are unaware of symptoms that could be serious.

Most patients referred promptly by GPs, but some are referred after multiple visits. There are large variations in use of diagnostic tests and urgent referral routes.

Rubin et al, should that there was a significant relationship between 2 week wait referral conversion rate and detection rate that can be interpreted as representing quality of clinical practice. Professor Richards notes that these findings offer a possible measure of quality of care in cancer diagnosis.

Diagnostic Services

We do not yet have international comparisons of usage of diagnostic services and procedures, but we do know that England and Wales have very low rates of colonoscopy.

Interventions to promote earlier diagnosis

The Be Clear on Cancer campaign provide the best available evidence of the effectiveness of early diagnosis interventions. Many regional Be Clear on Cancer campaign pilots have now been completed. They have shown that the campaign raises awareness of symptoms, increases GP attendance rates with relevant symptoms, increases diagnostic activity and increase urgent referral rates. The campaigns also appear to be cost effective and may reduce emergency presentations.

Professor Richards laid out some priorities for the future:

- Further research update international comparisons, understand more about emergency presentations and evaluate GP decision support tools
- Better measurement ensuring improvements in stage data collection, routine recording
 of frailty and develop prevention and early diagnosis profiles at GP practice level
- Further campaigns if results from the regional campaigns continue to be positive, more cancer types and sub-groups of the population should be targeted
- Incentivise earlier diagnosis provide additional support for practices that are struggling and pay secondary care by outcomes, incentivising them to work more closely with primary care on earlier diagnosis

Professor Richards concluded that we know a lot more than we did at the start of NAEDI, but with more answers have come more questions and so there is a great deal more to learn.

Contact

Please email <u>NAEDIconference@cancer.org.uk</u> if you would like more information about this conference or would like PDFs of the speaker presentations.

Second NAEDI Research Conference Programme

Times	Session	Speakers
09:00	Registration & Refreshments	
09.30	Welcome & Introduction	
09:30	Welcome from Cambridge and the CRI	Professor Simon Tavaré, Cancer Research UK Cambridge Institute
09:35	Introduction	Dr. Harpal Kumar, Cancer Research UK
09:50	Awareness and Early Diagnosis: International Perspectives	
09:50	Risk-based cancer screening: Insights from the National Lung Screening Trial	Dr Christine Berg, National Lung Screening Trial Lead Investigator, formerly with the National Cancer Institute, USA
10:35	Q & A Session	
10.45	Refreshment Break	
11:00	Selection of NAEDI Funded Research: Chaired by Dr Jane Cope, Director, NCRI	
11:00	Cancer screening uptake in patients with type 2 diabetes	Dr Matthew Carr, University of Manchester
11:15	Screening, timely diagnosis and inequalities in breast cancer survival – an investigation of differences by ethnicity and deprivation	Dr Melanie Morris, London School of Hygiene and Tropical Medicine
11:30	Why do some patients present with thicker melanomas? A qualitative exploration of patients' symptom detection and help-seeking decisions.	Dr Fiona Walter, University of Cambridge
11:45	Symptom prevalence and help seeking among patients at risk of lung cancer: an exploratory feasibility study in a primary care population	Professor Jessica Corner & Dr Richard Wagland, University of Southampton
12:00	Q + A Panel Session	
12:15	Launch of NAEDI Research Call 3	Sara Hiom, Cancer Research UK
12:25	Lunch, Poster Viewing/Judging, Networking	
13:50	The Wider NAEDI Landscape: Chaired by Professor Sir Bruce Ponder, Emeritus Professor of Oncology at Cambridge University, Co-Director, Hutchison/MRC Research Centre and Sara Hiom, Director, Early Diagnosis & Patient Engagement, CR-UK	
13.50	Show me the data!	Dr Jem Rashbass, Public Health England
14:10	Stratifying early diagnosis initiatives and research: Evidence from new measures and datasets	Dr Yoryos Lyratzopoulos, University of Cambridge
14:30	The cost effectiveness of early awareness initiatives in lung and colorectal cancer	Sebastian Hinde, University of York and Dr. Sophie Whyte, University of Sheffield
14:50	Update on the DISCOVERY programme	Professor Willie Hamilton, University of Exeter
15:10	A patient's perspective	Eileen Condon, Cancer Research UK
15:30	Q & A Panel Session	
15:50	Update on the Policy Research Unit in Cancer Awareness, Screening and Early Diagnosis	Professor Stephen Duffy, Queen Mary University London
	Introduction to new NCRI Screening, Prevention and Early	Professor Mahesh Parmar (SPED Chair),
16:00	Diagnosis Advisory Group	MRC CTU
16:00 16:10	•	MRC CTU Professor Sir Mike Richards, NHS England