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CANCER RESEARCH UK’s (CRUK) Fourth Biennial Early Diagnosis Research Conference took place on 23 and 24 February 2017 in London, attracting speakers and delegates from across the UK and internationally, who gathered to share, hear and debate the very latest developments in early diagnosis research.

This year’s conference, with the themes of investigating, implementing and innovating, covered the entire diagnostic pathway; from screening and public awareness of symptoms, through primary care factors, to obtaining a definitive cancer diagnosis in secondary care.

The programme featured keynotes from world-leading figures on the international stage, early career researchers emerging as thought-leaders in the field, and impactful reflections from our patient representatives. This year’s conference was our largest yet, seeing over 165 abstracts submitted for review by our scientific panel, with 25 selected for session talks and 102 selected for poster presentation. We were delighted to welcome in excess of 300 delegates across the two-day programme.

Really high calibre of speakers covering a lot of very relevant and interesting topics. – delegate, communications officer

A fantastic conference, well organised, stimulating and inspiring. – delegate, clinical lead
EARLY AND LATE CANCER DIAGNOSIS
STAGE OF CANCER WHEN DIAGNOSED, ENGLAND 2015

**ALL CANCERS**

- Early (Stage I + II): 54%
- Late (Stage III + IV): 46%

**Breast Cancer**

- Early (Stage I + II): 85%
- Late (Stage III + IV): 15%

**Bowel Cancer**

- Early (Stage I + II): 45%
- Late (Stage III + IV): 55%

**Lung Cancer**

- Early (Stage I + II): 26%
- Late (Stage III + IV): 74%

**Melanoma Skin Cancer**

- Early (Stage I + II): 91%
- Late (Stage III + IV): 9%

**Non-Hodgkin Lymphoma**

- Early (Stage I + II): 35%
- Late (Stage III + IV): 65%

**Ovarian Cancer**

- Early (Stage I + II): 41%
- Late (Stage III + IV): 59%

Source: Public Health England Stage breakdown by CCG 2015, NCRAS 2017
There remains an urgent need to diagnose cancers earlier, as substantial survival gains can be made by improving stage at diagnosis. This conference is all about the evidence base for achieving this.

CRUK works across the cancer pathway to secure better outcomes and experience for patients, and has made early diagnosis a strategic priority. The focus of this conference is on the role of screening and effective diagnosis of symptomatic patients to drive further improvements and reduce late diagnosis.

Bowel screening uptake is not where we’d like it to be, as we know that the risk of dying from bowel cancer is 25% lower in patients who are screened using guiac faecal occult blood testing (gFOBT) at least once. CRUK is supporting the introduction of the faecal immunochemical test (FIT) into the bowel screening programmes in England, Scotland and Wales, and are working to obtain similar commitment from Northern Ireland. In cervical screening, we’re supporting a move to testing for HPV as the primary test, and have had commitment from England and Wales so far. This test could save 150 women’s lives a year when fully rolled out, and could be cost saving for the NHS.

We’re getting better at capturing data on stage at diagnosis – Public Health England (PHE) now have data for 80%* of patients – which allows us to conduct local level analysis to drive improvements. There is significant variation in late diagnosis across the country, ranging from 39% to 55% across clinical commissioning groups (CCGs) in England. We know that this can be explained in part by regional differences in population demographics and cancer type, but this detailed analysis can be used to target interventions to specific local requirements.

We also have much better data on routes to diagnosis. We can see which cancers are more likely to be diagnosed as an emergency presentation, a route we know to be associated with poorer survival. We’re starting to see improvements in emergency presentation rates. In 2006, one in four cancers were diagnosed via emergency presentation, but this dropped to one in five in 2013 – however we must still work harder to reduce this proportion.

Thanks to data from the International Cancer Benchmarking Partnership (ICBP), we also know that UK GPs are less inclined to urgently refer for an investigation on the first or second presentation, compared with international counterparts. New National Institute for Health and Care Excellence (NICE) guidelines in 2015, which lowered the threshold for referral from GPs, have in part addressed this. CRUK translated the 100-page NICE document into a series of one-page infographics to help translate guidelines into practice at the local level.

As we cast the net wider for GP referrals, we must reduce capacity bottlenecks in diagnostic services. We fall behind many countries that we would choose to compare well with, whether we look at the equipment available to us, or the diagnostic workforce. ‘Achieving World Class Cancer Outcomes, A strategy for England, 2015-2020’ hones in on this as vital if we are to address cancer survival. CRUK has published several reports on endoscopy, imaging and pathology with recommendations on the need for improving diagnostic capacity.

There are also several research gaps we need to address. We need better bio-markers and tests for early stage cancer and, as we get better at early diagnosis, distinguishing the lethal from...
the non-lethal tumours will become even more important. Artificial intelligence and machine learning could hold the key to solving some of our workforce problems, or improve the accuracy of some diagnostic pathways.

Earlier diagnosis provides a transformational opportunity for improving cancer outcomes. I’m delighted to see the maturing research community and growing audiences at each successive conference, as well as the progress we’re making in this area of research.

*2015 data. 2014 data was presented at the conference but has since been updated.

https://youtu.be/pWpl01OmwTk

[Early diagnosis is] the most transformational opportunity we have to improve cancer outcomes. – Harpal Kumar

SURVIVAL BY STAGE AT DIAGNOSIS

MORE THAN 9 IN 10

BOWEL

AROUND 4 IN 10

LATEST STATS

= PEOPLE SURVIVING THEIR CANCER FOR ONE YEAR OR MORE

Data for people diagnosed in England in 2014
Source: ONS/PHE, Cancer survival by stage at diagnosis for England (experimental statistics)
CANCER SCREENING: INNOVATIONS TO IMPROVE UPTAKE

MAIN SESSION

Evidence to increase our understanding of the wider impacts and determinants of screening was a key topic of the Cancer Screening session.

The increase in detection of ductal carcinoma in situ (DCIS) through breast screening has contributed to the debate about the balance of benefit and harm in breast screening. Dr Amanda Dibden from Queen Mary University of London has published data showing an association between screen-detected DCIS and subsequent invasive breast cancer, indicating the detection and treatment of DCIS is worthwhile.

Longer term benefits of screening were highlighted by Dr Laura Woods from the London School of Hygiene and Tropical Medicine on the second day of the conference. She reported that while women still have a small, persistent increased risk of death 12 years after their breast cancer diagnosis compared with the wider population, survival rates in those detected by screening were much higher than those in the non-screened group.

At a time when breast cancer screening rates are in decline, Roberta Maroni presented data looking at whether second timed appointments would boost uptake. Currently, non-attenders either receive another letter with a date and time, or a letter with a number to rebook their appointment, depending on their screening site. In this randomised controlled study, second timed appointments appeared more effective: 22% of women attended screening within 90 days if sent a second timed appointment, compared with only 12% who received an open letter.

Bowel cancer screening uptake is significantly lower than uptake in breast and cervical screening programmes. Rosie Hinchcliffe from CRUK shared results from a pilot campaign in Wales where inclusion of a personalised Welsh and English language letter of endorsement from CRUK resulted in a 9.1% increase in uptake across all screening respondents. This study gives insight into the potential of targeted interventions for reaching specific groups, as some interventions were shown to have a significant effect in the most deprived groups.

Dr Christian von Wagner from University College London followed with results of the first randomised controlled trial looking at the effectiveness of text message reminders in bowel screening. They merged phone numbers from primary care records with information about non-responders to screening invitations, and then used targeted text messages once all usual reminders and invitations had been exhausted. There was no significant increase in uptake across all those who received the text messages, but they did see an improvement in uptake among first-time invitees. They are now investigating modifications to the text messaging programme to increase its efficacy.

https://youtu.be/vsHjsbE9zzY

Great conference which flowed really well.
– delegate, senior manager
Even where there is clear evidence that the benefits of cancer screening outweigh the harms, implementation of screening programmes remains a challenge.

In her Keynote, Dr Anne Mackie stressed the importance of the sometimes small but significant evidence-based interventions that can begin to tackle disengagement and inequalities in uptake and coverage. Small gains are being seen with these innovations, she said, and many of them are simple and cheap to implement.

Understanding the barriers to screening uptake remains a top priority, she argued, but we need to balance this with remembering that screening is still a choice. Existing IT systems and incomplete primary care data have hindered progress with implementing targeted interventions for different groups, but both are improving and there is appetite for change within the NHS, she said.

Dr Mackie stressed the importance of sharing of best practice across screening programmes. As she prepares to finalise service specifications for screening, she said these included many of the ideas and insights coming from the research community and presented during this session. She urged the audience to maintain an ongoing dialogue with the NHS and funders to set up and evaluate pilots so that new innovations can be tested and incorporated into future programmes.

https://youtu.be/6LldFuvh0rs
PATIENT FACTORS IN EARLY DIAGNOSIS

MAIN SESSION

Most cancers are diagnosed once a patient has decided to go to their doctor with a symptom. In setting the scene for the first two talks in this session, Dr Katriina Whitaker from the University of Surrey reminded the audience that while increasing symptom awareness is important, it is not a panacea for promoting timely help-seeking.

Moving to a different sociodemographic group, Dr Tanimola Martins from the University of Exeter presented a study looking at ethnic variation in the help-seeking behaviour of men with symptoms suggestive of prostate cancer, including time between symptom and presentation, and acceptance and performance of digital rectal exams. Contrary to evidence from interviews, preliminary results suggest no difference in the acceptance of tests by ethnic group, which indicates that delays in diagnosis may occur at points in the pathway after presentation of symptoms.

Evidence is mixed on whether presence of comorbidities promotes or delays help-seeking, and most studies have focused on the link with overall comorbidity. Dr Cristina Renzi presented initial data looking at the effect of specific comorbidities on help-seeking behaviour. There are likely to be complex interactions between specific types of morbidity and specific cancer symptoms, she argued, and these must be understood given their prevalence and potential consequences for early diagnosis.

During the cancer data session on the second day of the conference, Nicola Barnstaple, Lead of the Detect Cancer Early (DCE) programme, presented initial evaluation of targeted interventions implemented in Scotland to improve early diagnosis. The programme involves a number of workstreams, including screening uptake and public awareness. So far, the headline result of the campaign has been the reduction in inequalities relating to stage at diagnosis, with the largest stage shift achieved in the most deprived quintile. This programme of work is continuing, with a focus on a more local level approach for future interventions.

Teenagers and young adults (TYAs) are a challenging group for early cancer diagnosis, because of the rarity and non-specific symptoms of cancers in this patient population. Dr Rachel Dommett shared data from a review of TYA diagnostic pathways, where they found extreme variation between different cancer types and between patients with the same type of cancer. Most TYAs present to GPs initially, where there was marked variation in referral rates; however, the study showed that intervals in secondary care were just as important, re-adjusting their view of where the difficulties lie. Even lymphoma, the most common cancer in TYAs, was diagnosed through nine different routes. They are now looking at ways to streamline pathways, improve safety netting, and consider who might advocate for these patients as they navigate – often for the first time – a healthcare system predominantly designed for older patients.

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https://youtu.be/KDa_WQd8eLE
PROFESSOR SUE ZIEBLAND
THE GOOD CITIZEN WITH CANCER

Presenting in the International Perspectives session, Professor Ziebland introduced the concept of ‘the good citizen’, identified through in-depth analysis of help-seeking behaviour in the UK, Denmark and Sweden.

Reading accounts of people’s experience in the pre-diagnostic phase, they found they grouped into behaviours and characteristics that patients felt were ‘good, excusable and non-excusable’. The self-reported ‘good’ patient was someone who doesn’t self-diagnose, participates in screening, goes to the doctor promptly (but not ‘too soon’), and assesses what is worth mentioning.

Yet the good citizen has difficulty identifying the most appropriate level of help-seeking behaviour when it comes to cancer symptoms, particularly knowing whether to re-consult if symptoms persist. Professor Ziebland noted competing demands where patients tried to navigate what she described as the ‘Goldilocks zone’ – the level of help-seeking that was deemed by the patients as ‘just right’. Her research indicates that the Goldilocks zone is much narrower in the UK compared with other countries: patients in Sweden see their doctor less frequently than those in the UK, but spend longer with them each time and have a lower threshold for when to mention potential cancer symptoms.

She suggested that the UK might tackle this by looking at GP appointment frequency and length, and move towards active planning at the end of consultations to ensure safety-netting for patients.

https://youtu.be/z0zG7Mv4m2Q
KEYNOTE: PROFESSOR PETER JOHNSON – THE EPIC JOURNEY OF CANCER DIAGNOSIS

As a medical oncologist specialising in the treatment of lymphoma, Professor Peter Johnson acknowledged at the outset of his Keynote speech that he has the undoubted advantage of already knowing what the problem is when patients consult him. With his talk he hoped to offer useful observations and reflections looking back from the time a patient starts to receive treatment in his care.

Using the analogy of the Clerk from Canterbury Tales, Professor Johnson gave an example of one woman’s ‘epic journey’ to obtain a definitive diagnosis of her cancer. It’s true that the UK is referring more patients from primary care, and an additional £750 million has been invested in earlier cancer diagnosis, but the UK is still largely behind countries with comparable economies. The system doesn’t service the needs of the population nearly as well as it should, Professor Johnson argued. So why does the UK lag behind others?

One reason, explained Professor Johnson, is the paradox that we have a system of gatekeeping which is calibrated to keep people out of the healthcare system to constrain costs, and a population which has been calibrated to stay out. Data from the International Cancer Benchmarking Partnership (ICBP) has shown the correlation between cancer outcomes and the readiness and capacity of GPs to investigate symptoms indicative of cancer. Primary care clearly has a big part to play, said Professor Johnson, but an inability to fill vacant GP roles and heavy workload is creating strain and, according to the British Medical Association (BMA) GP survey, at times prevents quality and safe care.
That’s not the only problem. There is limited diagnostic capacity and workforce which has huge consequences on the delivery of the health service and its ability to get people through the system, Professor Johnson explained.

It’s not only routine service delivery either, he noted, but implementation of new interventions. One of the seminal results of early diagnosis research was evidence showing the benefit of the ‘bowel scope’ test for the prevention and detection of bowel cancer. Yet, implementation of this technique has been challenging even in the least deprived CCGs for a range of reasons, including availability of trained workforce.

The economic case for early intervention is clear, he said, highlighting that it costs an estimated £7,592 to treat a stage I lung cancer, and nearly twice as much – £13,078 – to treat at stage IV. But early cancer is probably not simpler from a biological perspective than late-stage cancer, he cautioned. Professor Johnson, like others, believes a multi-modal plan of action is needed: more sophisticated biological understanding, shared ownership of the problem – by patients, primary care and secondary care – radically different approaches to diagnostic services, such as multidisciplinary teams, and a proper plan for workforce development. The latter problem, in particular, needs to be addressed urgently, as the supply and demand numbers are going in the wrong direction. But Professor Johnson believes there’s enough optimism and expertise in the early diagnosis community to make it happen.

https://youtu.be/jR3ZB6pc3l0

Really enjoyable conference with excellent content.
– delegate, screening team leader
USING DATA WITH INTELLIGENCE

MAIN SESSION

We’re awash with cancer data, but we’re not always turning it into intelligence to improve outcomes, said Professor Aileen Keel, Director of the Innovative Healthcare Delivery Programme in Scotland, who chaired this session on the use of local cancer data.

The session highlighted the increasing opportunity to use local data to assess the need for early diagnosis activities and the evaluation of their impact, as well as the importance of revisiting methodology to ensure the validity of the evidence generated.

On this latter point, Matthew Barclay, from the University of Cambridge, presented an analysis of the current way we measure stage at diagnosis across different CCGs. Despite the quality and completeness of data now routinely collected by registries, missing stage information can bias comparisons between regions. The registry has other information about these patients that can be used to historically model a reasonable idea of their stage, and this was used by Mr Barclay as a ‘gold standard’ indicator to compare two different ways of handling missing stage data for real-time reporting: the ‘missing is late’ approach, and the ‘complete-case’ approach. Mr Barclay reported that the complete-case approach was much closer to the gold standard indicator, producing less bias. Discussing the putative use of the complete case indicator, Mr Barclay concluded that basing analysis on three years of data, rather than annual data, would improve reliability.

Presenting data for lung and colorectal cancer, Patrick Muller from the London School of Hygiene and Tropical Medicine reported on a comparison of three potential measures of early diagnosis in cancer: percentage of patients diagnosed at a late stage, those diagnosed through emergency presentation, or those who died within 30 days of diagnosis. Looking at geographical variation according to these measures, he found regional pockets of high or low rates of emergency presentation, but less marked variation in 30-day mortality, concluding that these proxy measures are not interchangeable. He also reported that the ‘missing is late’ assumption to complete missing stage data altered the geographical variation. An outlying CCG for one cancer type was more likely to be an outlier for another for the same measure – perhaps indicating common factors influencing the diagnostic pathways of different cancers in that location.

To help navigate the wealth of cancer metrics now available, PHE, in conjunction with the transforming cancer services team in London, have developed Practice Profiles Plus, which was demonstrated by Lucy Young. The interactive tool contains 19 cancer metrics searchable by different categories, with additional information including a practice index and executive summary. It was created as an all-encompassing tool for commissioners, health professionals and facilitators to support primary care providers in identifying inconsistencies between CCGs and promoting discussion of how services may be improved. PHE is working with clinicians at CCG level to look at the potential for a future dashboard that can measure CCG activity and correlate this with outcome, to help identify activities to stop, or those to prioritise further, Lucy explained. PHE is also working on a powerful new ‘pathway viewer’ tool for mapping individual patient pathways from presentation to outcome, which was introduced by Dr Jem Rashbass, National Director for Disease Registers and Cancer Analysis, who chaired the ‘Using Data with Intelligence’ session on the second day of the conference.

All session speakers highlighted that if you take data at face value it can be misleading – local context, the regional population, age, gender and cancer type all make a difference – and that there’s a need to keep revisiting the sources of metrics and measures.

https://youtu.be/GDI3_i_QtEo
KEYNOTE: PROFESSOR PATRICK BOSSUYT
FROM ACCURACY TO CONSEQUENCES

In his Keynote, Professor Patrick Bossuyt from the University of Amsterdam highlighted the requirement for data in a different context, as he argued for robust evaluation of new biomarkers and diagnostic tests.

Telling a story of a fictional diagnostic test salesman promoting a new diagnostic test to a hospital consultant, he illustrated how getting evidence of the clinical impact of diagnostic tests can be harder than obtaining evidence for a new treatment.

Evaluation of medical tests is changing, he said. It’s not enough to have an innovative test that is as good as the gold standard, and approved to be safe for clinical practice – it must have relevance to the current clinical pathway. This means demonstrating not just its reliable technical and analytical performance, but that it provides meaningful results – and most importantly, is helpful in changing clinical outcomes.

When considering the merit of a medical test, you could take an essentialist or a consequentialist view, Professor Bossuyt asserted. The essentialist believes that the value of a test can be judged by the trueness of its results. A consequentialist believes a test should be judged by the value of the consequences. The moral of this story? When it comes to evaluating diagnostic tests, we all need to become consequentialists, not essentialists.

https://youtu.be/KKRAMqXfAYs
SPOTLIGHT WORKSHOP ON EARLY CAREER RESEARCHERS

Six up-and-coming researchers who were each awarded early career researcher bursaries got the opportunity to present their work during a lunchtime quick-fire ‘PechaKucha’ style workshop – with slides lasting 20 seconds each.

Elisavet Syriopoulou, University of Leicester, presented on the use of ‘loss in expectation of life’ as a measure to quantify the impact of a cancer diagnosis among different socioeconomic groups. In addition to age at diagnosis, which affects loss in expectation of life estimates, she reported that stage at diagnosis had the most profound effect. Loss in expectation of life could be more than 10 times higher for late-stage disease compared with early-stage, and in patients diagnosed at a late stage, sociodemographic inequalities had an even more pronounced effect, with differences of approximately three years observed between the most and least deprived groups.

Stephanie Smits, University of Cardiff, described feasibility testing of the ‘health check’ intervention – an interactive touchscreen questionnaire delivered by lay advisers to raise cancer awareness and encourage timely help-seeking among adults living in deprived communities. Preliminary evidence provided insight on participant recruitment, data collection methods, and reach to low socioeconomic groups. They found that events such as health awareness days yielded the highest recruitment, followed by community groups (e.g. sheltered housing) and one-to-one sessions (e.g. job clubs). This suggests that proactive recruitment of the target group in non-traditional community settings, although labour intensive, may yield better rates of engagement than in healthcare settings.

Elka Humphrys, University of Cambridge, presented findings from the Pathway to Oesophageal and STomach CAncer Diagnosis (POSTCARD) study, which aims to explore how health literacy and other patient factors influence diagnostic pathways for stomach or oesophageal cancer. The study found that many patients may not understand terms such as heartburn and, rather than look for information about their symptoms, participants tended to normalise them or make significant changes to their diet to accommodate them. Help-seeking was most often prompted by new symptoms or when coping strategies stopped working.

Continuing exploration of the patient interval, Annie Hendry, Bangor University, presented preliminary data on the LUCAS (LUng Cancer and Stigma) study, in which they used qualitative interviews to examine patient behaviour in 40 symptomatic lung cancer patients. Early analysis showed many participants did not recognise that their symptoms might indicate cancer, and were worried about bothering their doctor with symptoms that were ‘unimportant’. Many also had comorbidities such as chronic pulmonary obstructive disease and asthma, and attributed new symptoms to these pre-existing conditions. The analysis showed that patient intervals in lung cancer are complex and that each participant’s consulting decisions were influenced by a variety of factors.

Joseph Akanuwe, Lincoln University, presented results from a study exploring the perspectives of patients and primary care practitioners on the use of a cancer risk assessment tool, QCancer. Individual interviews and focus groups with patients, GPs and practice nurses highlighted potential benefits of the tool in supporting clinical decision making, and recalling individual patient’s risk over several years, but concerns included conflict with NICE guidelines, and potential for causing unnecessary worry or anxiety, and over-referrals.

Ethna McFerran, Queen’s University Belfast, presented data on the potential use of faecal immunochemical testing (FIT) for surveillance of patients at low risk of bowel cancer after polyp removal. Using data from observational and experimental studies she modelled 42 combinations of surveillance programme, each
set to simulate 10 million screening participants receiving either surveillance by colonoscopy at established intervals or FIT-based surveillance at time intervals varying from six months to three years depending on risk group. The model estimated that colonoscopy-based surveillance provided the greatest overall gain in quality-adjusted life-years (QALYs), suggesting that colonoscopy based surveillance was shown to be the optimal strategy. Stratifying risk groups by number of adenomas and offering either FIT or colonoscopy yielded greater QALYs outcome than those of FIT-based testing alone in all groups, she reported.

“
It was great to see many early career researchers talk about their work.
– delegate, epidemiologist”
The ACE programme is a unique early diagnosis initiative supported by NHS England, CRUK and Macmillan Cancer Support. Its aims are to develop a knowledge base on early diagnosis, to evaluate and spread good practice, and to drive changes that will result in earlier stage diagnosis, a decrease in emergency presentations, and improvements in patient experience.

Wave 1 of the ACE programme consists of 60 projects organised into eight areas of work, or ‘clusters’, which enables teams to share best practice on project implementation, collecting and sharing data and outputs as they become available.

This session, chaired by ACE Programme Lead Brian Knowles, provided an update on one of the ACE pilots in the Cancer Screening Uptake for Vulnerable Groups cluster, and lessons learned from evaluation of the programme.

JULIE TUCKER
REDUCING INEQUALITIES IN SCREENING

Working with the North East and Cumbria Learning Disability Network, this ACE project is looking at improving access to NHS cancer screening for people with learning disabilities. Uptake of screening is much lower in this group, particularly for bowel screening. The aim of this pilot is to reduce inequality and increase uptake of screening by embedding reasonable adjustments and best practice into screening pathways that already exist.
Since February 2016, the bowel cancer screening database has allowed flagging of additional care needs on patient records, and since May 2016 it has been possible to search these notes prior to screening invitation. Using this capability, the project team developed an information sharing pathway where the GP surgery flags people who might need additional support to consider whether to participate in screening. They are constantly trying to find better data, Ms Tucker said, and are working with local commissioning groups to get a learning disability dashboard into GP surgeries. Having local capability to flag people is important, she said, but we also need to look at how we could do that nationally.

They have also developed a cervical screening support pack aimed at primary care practitioners and sexual health screening services who frequently encounter patient populations that include people with learning disabilities. Like many great ideas, Ms Tucker said, it wasn’t theirs, but was shared by screening liaison nurses in Cornwall. Nine packs for different geographical areas are now in use and they intend to share what they’ve done more widely across the country.

A proactive organisational culture and a commitment to quality improvement was evident in all sites considered, he said. Good leadership was also a key ingredient, especially the presence of dedicated clinical leadership. Project management was clearly important, with many stressing the critical role their dedicated project managers played, and lack of resource planning was the most common pitfall, Professor Rubin reported.

Communication and connection between organisations, clinical staff, patients and other stakeholders, and the ability to sell to others what you’re trying to do, was key. This was often a weakness, he said: it was striking that, with some exceptions, there was little in the way of considerable and meaningful patient involvement.

Ultimately, those that succeeded were well organised from the outset, had critical friends, such as public health doctors, who asked difficult questions, and strong leadership with an ambition to see new ways of working rolled out more widely. They used mechanisms such as insight work, clearly understood the source of their next funding, and approached their project in a systematic but adaptive way. The challenge now, he said, is to sustain this and go from a pilot to a way of working that can become embedded in the participating organisations.

**PROFESSOR GREG RUBIN**

**WHAT MAKES A SUCCESSFUL ACE PILOT?**

Professor Greg Rubin, Professor of General Practice at Durham University, was responsible for leading evaluation of the Wave 1 ACE pilots. It’s too early to look at outcomes yet, he said, but in terms of those that were successfully implemented, there were several common factors.

[There was a good] range, variety, topicality, expertise of speakers.

– delegate, research fellow
In 2015, NICE published updated referral guidelines for suspected cancer, replacing the 2005 version. The updated guidelines aimed to give GPs more flexibility to refer patients by reducing the symptom threshold for referrals, with recommendations for urgent referral for some symptoms where a patient should be seen within 48 hours.

Beginning a joint Keynote, Professor Willie Hamilton looked at how both the 2005 and 2015 guidelines have impacted primary care and cancer diagnosis. He reported that although GPs have been motivated to act more quickly in suspicion of a potential cancer, there’s also been a pull from specialists who are keen to see the ‘right’ patients, and from patients who want to have cancer identified or excluded early. As a GP, he acknowledged that guidance is not always welcomed, but said the 2015 recommendation was popular as it was based on primary care evidence and answered genuine questions that GPs were facing.

It is too early to tell if the latest 2015 guidance is working, he said. Early indications suggest that diagnostic intervals have decreased, but there is no evidence of acceleration of that fall. However, he reported a marked shift in the initial symptom of cancer that appears to prompt diagnosis, which reflects changes to the 2015 guidance. Moreover, in ovarian cancer, where referral recommendations based on additional symptoms were introduced in 2011, the diagnostic interval for cases diagnosed solely from these new symptoms has significantly reduced, suggesting that new symptoms are being recognised and acted on by GPs.

In conclusion, national guidance probably does expedite cancer diagnosis, said Professor Hamilton, and may work best if it is led by evidence from a GP source. However, a major limitation is the increased demand on diagnostic services and a new mechanism is needed to allow this cancer testing to occur. Although we now know ‘who’ should be investigated, we now need to work out ‘how’.

This is exactly what a new collaborative, CanTest, funded by CRUK’s first ever Catalyst Award, aims to do, as Professor Fiona Walter explained in the second half of this Keynote.

In its 2015 recommendations, England’s Cancer Taskforce set an ambition that by 2020, 95% of patients referred by a GP should be definitively diagnosed with cancer, or have cancer excluded, and the result communicated to the patient, within four weeks. This will require a significant increase in diagnostic capacity, explained Professor Walter.

The vision of CanTest is to support this ambition by transforming the GP office into a hub of diagnostic excellence for cancer and to offer the right patient the right test, at the right time, and in the right setting.

Struck by the lack of evidence for cancer testing in primary care, Professor Walter, Professor Hamilton and an international group of investigators aim to increase capacity and sustainability of research in this area. They plan to establish an International School for Cancer Detection Research in Primary Care, which will host residential meetings and provide bursaries for CanTest researchers to visit other institutions, supporting them to establish personal research programmes in the field.
In parallel, the initiative will identify existing and emerging tests and care models, and evaluate their potential for the UK. The team hope to address difficult-to-diagnose cancers and will focus initially on point-of-care tests – such as the tumour markers CA125 and CA19.9, and SNP panels – before looking at potential applications of new and existing imaging technology, such as teledermoscopy. To exemplify this, Professor Walter shared the example of a randomised controlled trial of a new technique, SIAscopy, to detect melanoma in primary care. It was shown to be too low in specificity and wasn’t recommended, but exemplifies the types of study they hope to do for other promising technology.

Sustainability of the initiative is key, Professor Walter argued: their hope is to leave a school that will continue to run, an evidence base that informs primary care and policy, and a thriving research community that will continue to drive improvements for patients for years to come.

https://youtu.be/yu-Vm7J-y0A
OPTIMISING CLINICAL PRACTICE AND SYSTEMS

MAIN SESSION

Detailed scrutiny of current diagnostic pathways can provide insights that are key to optimising early diagnosis in the future. This session, exploring examples from primary and secondary care, began with a presentation by Dr Gary Abel from the University of Exeter, who highlighted the opportunity to learn from different practice processes in cancer diagnosis.

Many factors can influence variation between practices – from the age of the GP to the type of patients. Dr Abel argued that using process indicators rather than outcome indicators can reveal more useful insights about how and why variation between practices occurs.

Using process data from PHE’s Fingertips website, and adding in GP-specific data and practice population characteristics, he reported trends such as lower urgent referral rates at practices with male, older GPs and in those with a high proportion of ethnic minorities, and much higher rates in larger, training practices. There could be many reasons for these trends, he said, but analyses like this could explain some of the variation and be used to target and tailor interventions to address referral rates.

Waiting time targets were introduced in 2005 to drive early diagnosis and act as an indicator of quality of care. Dr Chiara Di Girolamo presented data showing how well targets were met between 2009 and 2013, and whether they impacted one-year survival. Her results revealed a paradox: those waiting longer had higher survival. This probably reflected the less debilitated status of the patients and the time taken to accurately stage patients and plan curative treatment. Cancer waiting times do appear to reduce the time in waiting, she concluded, potentially reducing anxiety and stress among patients.

The predictive power of symptoms was a theme throughout the conference. Two speakers showed the value of looking back along the diagnostic pathway to learn how to better manage risk to patients in future.

Jeremy Brown from Imperial College London shared his unpublished data from the SOCCER study, looking at whether symptoms of bowel cancer can predict whether tumours form in the distal or proximal region of the bowel, and Tania Seale, from Bangor University, presented a moving account of diagnostic journeys in multiple myeloma.

Myeloma is a disease associated with multiple GP consultations, high levels of emergency presentation, and, consequently, complications and poorer outcomes associated with late diagnosis. The interval between a patient noticing symptoms and first presenting was five times greater in myeloma than in breast cancer, reported Ms Seale, and in some cases it took two years from first symptom to treatment. No single factor appears to influence intervals to diagnosis, but continuity of care is clearly important for this group of patients, she argued, as is the need to optimise the investigation of non-specific symptoms.

Dr Andrew Millar from North Middlesex Hospital explained how the proposed multidisciplinary diagnostic centres (MDCs) are intended to address the hospital ‘pinball machine’ of being bounced between secondary and primary care. As lead of the London pilot being conducted within the ACE programme, he’s been trialling a more streamlined diagnostic pathway in patients with abdominal symptoms. After entry via primary care or emergency, patients were assessed by the MDC and then triaged for onward referral. Despite seeing a lower number of cancer diagnoses than anticipated, patient experience was positive, and the programme is now being expanded as part of Wave 2 of the ACE programme.

https://youtu.be/czeeQBZi4lo
KEYNOTE:
MRS CELIA INGHAM-CLARK
PRIORITIES FOR THE NHS CANCER PROGRAMME IN ENGLAND

As sponsor of the early diagnosis workstream of the NHS England cancer programme, Mrs Celia Ingham Clark outlined three areas of priority: initiatives that increase screening; tools to help GPs improve appropriate referral; and actions to reduce inequity in patient groups – with specific focus on learning disabilities and deprived areas. Implementing the optimal diagnostic pathways for lung, colorectal and prostate cancer was also highlighted as a critical step towards meeting waiting time targets.

As she closed Day One of the conference, Mrs Ingham-Clark reflected on how much we had heard about variation in cancer outcomes and about where we stand nationally. Some CCGs are getting outcomes just as good as other countries, whereas in others, things are substantially worse.

Part of her job, she said, is to share examples of where people are doing this well, and she was excited by the insight and intelligence being shared that would facilitate these conversations. Some of the variation in outcomes, she acknowledged, is a result of extremely different patient groups across the country, but they are all patients who need our support, she argued. We must reduce unwarranted variation and bring all CCGs up to the strength of the others. CCGs will be measured on specific metrics, she said, and we must aspire to these.

https://youtu.be/YarJhF4fn0E

“It has been fantastic to hear what other people are working towards to improve early diagnosis of different cancers.”

– delegate, PhD student
KEYNOTE: PROFESSOR NIEK DE WIT

DIAGNOSING COLORECTAL CANCER IN PRIMARY CARE; CAN WE DO BETTER?

The Keynote speech from Professor Niek de Wit, from University Medical Centre Utrecht, was the first in a series of international perspectives on early diagnosis. His presentation focused on bowel cancer – the second most common cancer in The Netherlands – which despite high uptake of screening, is still diagnosed through symptoms 90% of the time, and 80% in general practice.

They’ve found extreme variation in the average time from GP consultation to referral, Professor de Wit reported, with a quarter of patients waiting 60 days and 10% as many as 219 days. There is considerable focus, therefore, on improving the quality of the GP consultation and moving towards more accurate personal risk assessment, he explained. They are proposing a diagnostic process that first considers baseline risk determined by gender, age, medical and family history, and then adds in the diagnostic value of symptoms and, where appropriate, tests, such as calprotectin and faecal immunochemical testing. Addition of these tests safely prevented colonoscopy referral in 30% of patients, according to results from one of their studies, the CEDAR trial. It’s a move towards shared decision making between patient and practitioner, Professor de Wit said, where the GP discusses the overall personalised risk, and it is the patient’s individual perception of this risk that determines if they are referred for endoscopy.

“It was great to find out about research outside of the UK – and possible collaboration.” – delegate, PhD student

https://youtu.be/Q1wRF4P6QYs
Professor Peter Vedsted from Aarhus University in Denmark shared some of the latest unpublished data from Module 4 of the first phase of the partnership, which is investigating whether there are differences between countries in time intervals from first symptom noticed to first presentation to a healthcare professional, and then to the start of treatment. Using surveys from 200 patients recruited for each cancer type – breast, colorectal, lung and ovarian – they have measured the healthcare interval for symptomatic patients. The data is soon to be published and will reveal both the value of identifying variation in diagnostic intervals both between cancer type and country, but also some of the challenges of comparing datasets from different healthcare systems and ensuring a comparison of like-for-like, Professor Vedsted said.

Dr Henry Jensen, also from Aarhus University, shared an analysis of new cancer patient pathways (CPPs) implemented in Denmark between 2008 and 2009, which include descriptions of selected symptoms, medical procedures for secondary care, and time frames for all phases. The CPPs have similar referral criteria to the UK, but are not as detailed and include more non-specific symptoms, he said. Initial findings suggest that the introduction of CPPs has had an impact on mortality, and the full results will reveal important insights for countries in the ICBP currently introducing, or reviewing, new diagnostic pathways.

In his Keynote presentation, Professor Jon Emery from the University of Melbourne shared an honest account of his experience running the Improving Rural Cancer Outcomes study, which tested the effectiveness of a community symptom awareness campaign and GP-led intervention in reducing time to diagnosis across a vast region of Western Australia.

Over two years, interviews and patient records from newly diagnosed cancer patients were used to calculate the total diagnostic interval. To their disappointment, they found no statistically significant difference between the interventions, which Professor Emery said emphasised the difficulty of trying to use ‘a blunt tool’ to alter GP behaviour in the context of cancer being a relatively rare event. Despite significant qualitative work about barriers and focus groups on mock campaign materials, he said they were aiming at a stoic population that may be resistant to the intervention. In conclusion, he couldn’t be sure if they had generated evidence that the approach doesn’t work, an effect had occurred that they hadn’t been able to detect, or just further evidence that awareness and engagement in this population is extraordinarily difficult.
A major challenge is to distinguish genuine lung cancer symptoms from symptoms of other comorbidities. Dr Lucy Brindle from the University of Southampton presented data from prospective studies which aim to identify the prevalence of potential symptoms of lung cancer in patients being seen in primary and secondary care. The trials use a questionnaire (IPCARD) developed with newly diagnosed lung patients, which records presence, severity, progression and chronicity of different generic symptoms. Symptoms that predict lung cancer in primary care, don’t predict the disease in secondary care, Lucy explained, because of the prevalence in secondary care of chronic lung diseases with similar symptoms. The Chest Study aimed to look for less obvious but distinguishing symptoms of lung cancer. But its early results suggest only the chronicity of symptoms is different, and this still did not strongly predict lung cancer.

So how do we get to the optimal pre-diagnostic pathway for people at risk of lung cancer? Clare Pearson reported on another ACE project in lung cancer – the Lung Cancer Pathways project. She discussed how they have studied linked national-level datasets for lung cancer patients diagnosed in 2013/14 to look at where there may be delays in pathways, particularly in the order and timing of diagnostic tests. They compared this with the newly endorsed National Optimal Lung Clinical Pathway (NOLCP), and looked at the variation in diagnostic intervals across England. The data will be used as a benchmark to measure progress after introduction of NOLCP, and the hope is that it will provide specific insights into variation between CCGs that will help improve diagnostic performance across England.

A theme from this spotlight session, and echoed throughout the conference, is the complexity of the challenge faced in lung cancer – from understanding early symptom patterns, to reaching those at highest risk.
This was brought to life by Tom Haswell, a patient advocate who was diagnosed with lung cancer in 1993. Mr Haswell shared his experience of being diagnosed through a routine medical assessment, and how shocked he was, as someone who felt ‘perfectly healthy and had no signs’.

Tom argued that despite much progress being made in early diagnosis, lung cancer is still an outlier and he believes the public need to be better educated on the difference early diagnosis makes to treatment and outcome.

https://youtu.be/ed2P-3IfKaE

We also heard inspiring patient insight from Richard Stephens, who, having initially had his Hodgkin’s Lymphoma symptoms identified by a dentist, reflected on different routes to diagnosis, and the importance of engaging all health professionals in expediting diagnosis.

He also discussed the importance of patient involvement in research, and the vast contribution that patient data makes to advancing our knowledge in the early diagnosis field.

https://youtu.be/_LjoPe8SuJ4
KEYNOTE: DR GEORGIOS LYRATZOPoulos
THE EPIDEMIOLOGY OF CANCER DIAGNOSIS – CURRENT PROBLEMS AND FUTURE DIRECTIONS

Improving cancer diagnosis is a complex problem, with components distributed in space and time, and with multiple players and socio-technical aspects, said Professor Georgios Lyratzopoulos in his Keynote lecture. The benefits that earlier diagnosis can deliver – of improving both cancer outcomes and the cost-effectiveness of healthcare – will come from a multidisciplinary effort of which epidemiology is an important part, but will not deliver on its own. Its role, he argued, is to identify who is at greater or lower risk of untimely diagnosis, which is essential for identifying problems along the pathway and targeting interventions and evaluation.

Epidemiology of diagnosis is a relatively new discipline, but there are now many studies providing evidence and insights into cancer awareness in populations, understanding diagnostic routes and patient-reported delays, and the first UK audits in primary care. None of this would be possible without a high-quality cancer registration system and the data linkages it now enables, he argued, citing the importance of bodies such as PHE and the National Cancer Registration and Analysis Service, and their equivalents in the devolved nations.

Echoing Professor Peter Johnson’s comments, he reminded the audience that timely diagnosis matters beyond improving survival and that patient experience is now considered as important as clinical effectiveness and safety. Here, being able to combine data on a patient’s diagnostic pathway with qualitative information on their experience, can be powerful. Such studies have shown that patients with more than three pre-referral consultations are more likely to report negative experience of subsequent cancer care, compared with those who only had 1–2 consultations; and those who were diagnosed through emergency presentation were more likely to report a negative experience of subsequent cancer care compared with those referred through the 2-week wait (2WW) pathway.

Moving on to identifying problems along the pathway, Professor Lyratzopoulos outlined three types of measure used in early diagnosis epidemiology and shared recent research examples of each.

Activity measures such as number of referrals were used to identify a problem with reaching specific demographics – where it was observed that 2WW referrals were less likely in low cancer incidence groups, highlighting that the guidelines only work for a proportion of patients and complementary approaches are needed.

Several studies have used surrogate measures, such as emergency presentation, and revealed important insights into diagnostic routes. For example, one-third of patients presenting to their emergency department did not see a GP with their symptoms, and closer analysis of these patients revealed trends by cancer type and deprivation (with the most deprived groups less likely to have consulted their GP). Emergency presentations have decreased since 2006 – but deprivation group inequalities are practically unchanged, he explained. If this gap were to be removed, it would bring the 2013 rate of emergency presentation down to 17% rather than 20%, equating to ~7,000 fewer emergency diagnoses.
Finally, Dr Lyratzopoulos showed how direct measures of diagnosis such as the patient interval have shed light on our understanding of variations in symptom reporting that could help to target awareness in patient populations.

Looking to the future, the key research priorities for epidemiologists in early diagnosis can be split into two areas of opportunity – before and after presentation. Before presentation, the examination of under-studied risk modifiers (symptom burden in the community, co-morbidities and false reassurance from prior ‘all clear’) is a window for significant potential impact, but requires the development of more efficient methods for measuring these in the population. After presentation, we need to better understand pre-diagnostic events, he argued, and look at the pattern of consultations, investigations, prescriptions and symptoms to determine whether referral or surveillance is appropriate based on an integrated risk threshold.

Lessons could also be learned from the many other diseases where diagnosis is a challenge, he said, because a wide range of initial symptoms are presented. Whereas cancer treatment is a cancer problem, he argued, cancer diagnosis is a medical problem.

https://youtu.be/nILmr0BtmxU

Great organisation, great venue, great programme, keep up the good work! – delegate
More than 100 posters attracted lively discussion at this year’s conference. They were judged by both a scientific panel and a patient panel, who all agreed that there was an impressive array of posters on display, with wonderful ideas, methodological rigour, generating huddles of people deep in conversation.

In addition to looking for good concepts, new ideas and studies that were novel or quirky, the panel wanted to see robust methods and rigour, outcomes and impact, and also considered presentation of the poster – the graphics and the level of information. Each panel awarded a prize of £100 to its winner, and £50 each to two runners up.

PATIENT PANEL WINNERS
PRESENTED BY RICHARD STEPHENS, CHAIR OF THE PATIENT PANEL

Winner: Grace McCutcheon – Development of a lung cancer awareness intervention targeted at socioeconomically deprived communities

Grace’s poster described a community-based educational intervention to increase lung cancer symptom knowledge, modify negative beliefs and encourage timely symptom presentation in deprived groups by exploiting strong social networks in the community. They found that group-based education was an acceptable mode of intervention delivery among people in deprived communities, and warrants further feasibility and pilot testing, providing important evidence into effectiveness of methods to engage harder to reach groups in lung cancer early diagnosis. The patient panel described it as a great example of going out into a community and working with them and getting people to talk to each other.

RUNNERS UP

Emma Thorpe, whose poster describes the systematic set-up of the National Institute for Health Research Manchester Biomedical Research Centre (BRC) Cancer Prevention and Early Detection Theme, and opportunities for synergy across domains. There will be three programmes of research: developing and improving models for risk stratification; obesity-related cancers; developing new imaging and molecular bio-markers.

Sam Brown presented data from the East of England Cancer Diagnosis in an Acute Setting Study, an observational, prospective case controlled study of the organisational, clinical and patient factors in patients with lung and colorectal cancers who are diagnosed through emergency routes. Data from patients, primary and secondary care was collated and analysed to create a rich picture of the factors for delay.
SCIENTIFIC PANEL WINNERS
PRESENTED BY DAVID WELLER,
UNIVERSITY OF EDINBURGH

Winner: Julie Walabyeki – Fatalistic attitudes, ‘lived experiences’ and help-seeking behaviour for potential cancer symptoms in older people: a qualitative interview study

Julie’s poster described a qualitative study of in-depth interviews with people aged over 60 years, exploring issues around fatalism using the Powe Fatalism Inventory and how presence or absence of fatalistic beliefs might influence help-seeking behaviour and responses to awareness-raising initiatives. Their findings suggest that an individual’s ‘lived experiences’, such as having symptoms that interfere with daily living, or a previous experience of cancer, influenced participants’ fatalistic attitude, which in turn influenced their help-seeking behaviour. The scientific panel praised this group for tackling a tricky topic of lung cancer and fatalistic attitudes, doing so in a novel way and presenting their findings with lovely graphics, photos and clear messages.

RUNNERS UP

Staying with the theme of lung cancer, David Kennedy’s poster described an elegant study that linked diagnostic imaging data with cancer registration data for more than 50,000 patients, and reveals sociodemographic variation in the use of GP direct access X-rays for the diagnosis of lung cancer.

Christian Von Wagner shared results of a randomised controlled trial investigating annual reminders to encourage bowel scope screening non-participants to self-refer. This improved uptake and increased the number of precancerous lesions detected by the bowel scope programme. The panel agreed that this poster was visually stunning, and presented a large amount of information very clearly.
In recent years, we have seen tremendous growth in the attention cancer diagnosis receives in policy, practice and research, and the calibre and variety of presentations and posters highlighted in this report is testament to that progress. A heartfelt thank you to all who attended and enthusiastically participated in the lively discussion and debate.

What underpins this progress is the increasing availability and completeness of data helping us to understand all the elements that create an earlier diagnosis and improve the pathway to survival. It’s easy to forget that we didn’t have ‘emergency presentations’, or ‘survival by stage’, as part of our cancer vocabulary 10 years ago, such has been the improvement of staging data in England, and our ability to link this data with records from primary and secondary care. The topic of translating data into intelligence was a key theme at this year’s conference, as we continue to discuss what is important to measure, which intervals we need to be looking at and where we need to focus for best impact.

We also heard a lot about the importance of diagnostics – a fundamental bottleneck in the pathway in terms of workforce capacity and availability of imaging equipment. Primary care services are also struggling due to workforce issues, which must be dealt with before we can realistically consider the potential of increasing consultation time to allow GPs to fully explore symptoms in the context of comorbidities and family history.

A clear take out we were left to reflect on was the concept of the ‘good citizen’ outlined in Professor Sue Ziebland’s talk (page 11) and whether we can really shift the paradigm such that the patient and the clinician have a shared responsibility, and are in partnership along the diagnostic process. We heard from Fiona Walter and Willie Hamilton about the new CanTest programme, and are delighted to be investing in such an exciting initiative through CRUK’s new Catalyst Award, helping to address the gap in innovations available to diagnose patients more effectively in primary care.

Our understanding of what underpins the differences in survival between the UK and other countries has grown considerably since we led publication of the early diagnosis (NAEDI) supplement in 2009, and I genuinely believe and hope that when we see the next international survival figures we’ll see we’re closing that gap. We have come a long way. However, there is still more to do in terms of translating our understanding into practice. By the next Early Diagnosis Research Conference, I am looking forward to reflecting upon even greater progress achieved.
EARLY DIAGNOSIS AT CRUK: WEBPAGES, NEWSLETTERS AND RESEARCH FUNDING

CONFERENCE RESOURCES
Conference videos, slides, posters and other resources can be accessed at: http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities/early-diagnosis-initiative/early-diagnosis-research-conferences/2017-conference-programme-and-materials

EARLY DIAGNOSIS WEBPAGES
Further information on CRUK’s early diagnosis work can be found at: http://www.cancerresearchuk.org/early-diagnosis http://www.cancerresearchuk.org/health-professional/early-diagnosis-activities

For regular updates on our activities, sign up for the early diagnosis newsletter at: http://www.cancerresearchuk.org/health-professional/newsletters

RESEARCH FUNDING

EARLY DETECTION:
New funding schemes for early detection research are opening for applications in July 2017. More information is available at: http://www.cancerresearchuk.org/earlydetection

POPULATION RESEARCH COMMITTEE (PRC):
PRC supports clinical and public health epidemiology and educational and behavioural research on cancer prevention, screening and early diagnosis. More information is available at: http://www.cancerresearchuk.org/funding-for-researchers/applying-for-funding/funding-committees/population-research-committee

EARLY DIAGNOSIS ADVISORY GROUP (EDAG):
EDAG is a policy-focused funding and advisory committee responsible for the oversight, development, review and management of a portfolio of research that aims to significantly add to the evidence base that will impact on policy and practice for earlier cancer diagnosis. http://www.cancerresearchuk.org/funding-for-researchers/applying-for-funding/funding-committees/early-diagnosis-advisory-group-edag