

<https://www.canceralliance.co.uk/>

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Welcome to the East of England Cancer Alliance newsletter where we intend to keep you updated about all the National, regional and local developments in cancer. We would like to utilise this opportunity to show case the work of the Sustainability and Transformation Partnerships (STP) and Integrated Care Systems (ICS) around the East of England.



If you have any suggested inclusions for the newsletter please contact us via: enquiries@canceralliance.co.uk

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Welcome from Rory Harvey, East of England Chair and Mary Emurla, East of England Director

It is our pleasure to welcome you to the East of England Cancer Alliance newsletter. Through our extensive partnership of patients, clinicians, NHS and non-NHS organisations everything we do is intended to improve the care, experience and outcomes of people with cancer and their families. We hope this newsletter helps you to find out more about all the great work that's happening across the Alliance to contribute to our goals. A big thank you to everyone who has contributed to this edition.



East of England Cancer Alliance Review

We recently wrote to our stakeholders to confirm that a decision has been made by NHS England and NHS Improvement to create two Cancer Alliances within the current geographical footprint of the East of England Cancer Alliance. The conclusion to reorganize flowed from a combination of last years' Cancer Alliance self assessments, and a recent independent review of Cancer Alliances in the former Midlands and East region of NHS England.

The aim is to align with national principles of no Alliance being larger than three Sustainability and Transformation Partnerships (the current Alliance has 6 STPs), ensuring that the Alliances have the authority and influence to provide clinical, operational and transformational leadership across their geography, and clearly defining the role of the Alliance in working with their STPs to lead the planning and delivery of local cancer strategy.

We see this an evolution of the current Cancer Alliance and a real opportunity to work more closely with our local health and care partners in

smaller geographical footprints. The aim now is to establish the two new Cancer Alliance geographies by end of July 2019, with interim management arrangements in place.

The two new Cancer Alliances will be:

East of England Cancer Alliance, North
Cambridgeshire and Peterborough STP
Norfolk & Waveney STP
Suffolk and North East Essex ICS
East of England Cancer Alliance, South
Mid and South Essex STP
Hertfordshire and West Essex STP
Bedfordshire, Luton and Milton Keynes ICS

We have a challenging program for the next year and these changes will bring Cancer Alliance support closer to our partner organisations to ensure that momentum for improvement in outcomes and patient experience is sustained.

As Executive Lead, Rory Harvey our Chair, will be leading and overseeing the transition process.



New Pathway for Patient-centred Follow-up for Patients with Early Breast Cancer

The NHS Long Term Plan vision is by 2021 where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and well-being information and support.

Under the NHS's long term plan, all Trusts that provide care for patients with breast cancer must have a person centred approach in place by the end of 2019 with the aim of transforming follow-up care so that individuals with breast cancer will receive follow-up care that best addresses their needs.

For Breast cancer this will mean that patients will be assigned a specialist nurse who they can contact for advice and support, meaning patients can have any concerns quickly addressed. The approach is set out in the regional guidance published by the East of England Cancer Alliance, which is made up of the NHS organisations responsible for providing cancer care across the

region.

Dr Christopher Scrase, Medical Director for the Cancer Alliance said: "We need to address the fact that across the east of England, there is currently variation in how follow-up care is provided to individuals who have completed their breast cancer treatment. Our new approach will mean patients are more in control of their follow-up treatment, better tailored to their own specific needs, with the necessary support in place from their hospital and wider support services".

"This patient centred approach is in line with NHS England's recently published Long Term Plan, which calls for a greater focus on promoting wellbeing, recovery and empowerment to provide Individuals with the information and confidence to have an active role in their care."

Tonia Dawson, clinical lead for the East of England Cancer Alliance said: "Happily, due to the effectiveness of treatment, more people are living longer after the completion of their treatment, and we have had to consider how best they can be supported. Our

new guidance puts a greater emphasis on helping patients to look after their own long term health and wellbeing, and knowing what to do if they have any concerns following their treatment. Having specialist breast care nurses available and in some areas community cancer nurses means patients can be reassured that an appropriately trained health professional is on hand to help them".



Eileen Murphy, Macmillan Survivorship/eHNA Lead (left) and Linda Kelly, Patient Representative (right) promoting the pathway at Woodlands Macmillan Centre, Hinchingbrooke Hospital

For more information please visit our website www.canceralliance.co.uk

Early Diagnosis Update

In 2018 the Prime Minister called for "A step change in how we diagnose cancer"; looking to improve the diagnosis of cancers at an early stage, the ambition being that 55,000 more people each year will survive cancer for five years by 2028. To achieve this, throughout last year the Cancer Alliance has worked with the STP/ICs and their constituent teams to implement the first wave of early diagnosis transformation programmes, in line with the national focus on Lung, Colorectal/FiT, Prostate and the MDC/Vague Symptoms pathways. Significant progress has been made, with the following having been achieved to date:

- FiT - testing for symptomatic patients has been rolled out in our STPs
- Colorectal - straight to test is in-place in 10 of our 18 Trusts
- Prostate pathway - MpMRI prior to biopsy has been implemented in 14 Trusts
- Lung pathway – Chest x-Ray before CT achieved in 14 Trusts
- MDC/ vague symptoms pathway - pilot sites actively informed National Guidance on RDCs

The coming year will see a further drive to fully implement the transformed pathways across the footprint, together with the introduction of the following:

- The work required to transform the oesophago-gastric pathway in all Trusts.
- Improving the uptake of screening for bowel, cervical and breast cancers
- Rapid Diagnostic centre models
- The lung health check programme
- A model that will oversee a more-streamlined and combined focus on longer-term transformation with the short-term aims of achieving and sustaining compliance with the 62-day standard ("sustainable operational performance")
- Implementation of the working practices at Trust-level to maximise the number of patients who receive a confirmed cancer diagnosis by latest day 28 on the pathway (to enable treatment to start earlier), or confirmation that cancer has been ruled out

The Lung Health Check Programme

10 Cancer Alliances will be piloting this lung screening programme across England. CCGs chosen to take part in the pilot study were ranked and selected based upon mortality from lung cancer and incidence of lung cancer in their 55-80 year-old population.

Luton and Thurrock have been selected as 2 pilot sites in the EoE Cancer Alliance as they were particularly challenged with a high number of lung cancer deaths.

Lung Health Checks will identify lung disease, specifically lung cancer, at an earlier and more treatable stage.

Any patient assessed as being at high risk of lung cancer will have an immediate low-dose CT scan; this will identify more cancers quickly but also pick up a range of other health conditions, including chronic obstructive pulmonary disease.

People will be invited to a lung health check by their GP if they are aged between 55 and 79 years and have 'ever' smoked.

At the Lung Health Check, the patient will have a breath test and a discussion to assess the patient's individual lung cancer risk. This will include questions about smoking habits and they will be offered smoking cessation advice and treatment if still smoking. Those at low risk do not require a CT scan. Any patient assessed, using a risk prediction model, as being at high risk of lung cancer will be invited to an immediate low-dose CT scan

Patient feedback from the first wave of pilot sites was very positive evidencing that patients attended the clinic because invite came from GP, they liked the fact that the clinic and the CT was in a community location with easy access and it made them feel less anxious.

There is the expectation that after this 4-year pilot the programme will be rolled out further. CADEAS will be working with the sites and evaluating nationally.

FiT Testing in Primary Care

FIT stands for Faecal Immunochemical Test. It is an antibody test for the presence of human globin in faeces. It is a highly sensitive, quantitative test and is performed on a single sample. GPs are able to offer FIT testing to those patients

whose symptoms may represent colorectal cancer but do not meet existing 2WW criteria. FIT in primary care is completely separate from the National Bowel Screening Programme, and a recent negative screening test does not preclude a primary care test if there is clinical concern.

In 2017, the Cancer Alliance committed

to rolling out access to FiT across the whole of the East of England. It is still early days with this project as some STPs have not offered FiT until very recently, so we will aim to provide more information on progress in a future newsletter update which hopefully include data on numbers of patients who have accessed the service.

Workforce Project

After the Alliance was awarded funding to take forward strategic transformation of cancer services across the East of England, it was quickly acknowledged that this change needed to be supported by workforce transformation. During 2018, the Alliance, with support from HEE, commissioned an external company GE Healthcare to undertake workforce project across the whole of the Alliance footprint. The objective of the programme is to:

- Determine how the current workforce manages and delivers current cancer activity and care
- Model future scenarios for delivering cancer care for specified pathways
- Use the baseline and future view modelling to form a view of how new ways of working will impact activity and workforce in the future (five years) and inform a workforce plan

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Ultimately, this should enable us to deliver cancer care along best practice pathways in a sustainable and fit-for-purpose way – getting the most value from our greatest resource, our staff.

Although this project covers the whole of the East of England, the work is being delivered at an STP level. The outputs will inform a global East of England 'current' and 'future' view but most importantly each STP will an understanding of its own workforce challenges and its own potential solutions.

Each STP will be able to develop their own workforce strategy and have information to support the submission of business cases for new posts or staff training, that will deliver new models of care.

The project is in early stages with mobilisation having taken place in most areas, and moves towards extracting data slowly progressing, but it is hoped that this project will deliver its findings in early Summer.

Prostate Best Practice Pathway

One aspect of the Prostate programme this year is that the Cancer Alliance and Prostate Cancer UK (PCUK) have this year collaborated on a training programme

that will support and underpin the implementation of multi-parametric MRI (mpMRI) prior to biopsy. This new imaging technique offers men with suspected prostate cancer a more accurate and for some men, a less-invasive procedure. This requires Consultant Radiologists to become

experts in interpreting and reporting complex mpMRI scans, for which training is necessary. The first training programme of this kind in the UK, and in its first wave, has been designed to be undertaken locally within the region's expert centres.

A HUGE Congratulations...

'I was delighted to note that over last weekend a raft of inspirational individuals from across the East of England were recognised in the **Queen's Birthday Honours**, with over a dozen people awarded for services to healthcare. Our own **Tonia Dawson was awarded an OBE** for services to nursing and people affected by cancer. Tonia is the Macmillan Clinical Lead for the East of England Cancer Alliance and couldn't be more deserving. Congratulations Tonia, I hope you celebrated the accolade with friends, family and colleagues.' - A message from NHS England & Improvement Regional Director, Ann Radmore

Engaging a Footballer to Tackle Cancer in Men

Former Norwich City footballer Darren Eadie has been raising awareness of cancer as part of Norfolk County Council's MenKind campaign.

The campaign - targeted at men between the ages of 40-74 - focusses on a different health issue each month. Earlier this year, MenKind chose to highlight cancer awareness and prevention.

The Norfolk and Waveney STP cancer team worked in collaboration with the campaign providing information, statistics and arranging for three interviewees to take part in an Anglia News feature. Dr David Plume was

interviewed in his Norwich surgery; consultant urologist Mr Cristian Ilie participated in the studio interview and a Facebook live Q&A session about cancer symptoms and survival and prostate patient Roy Bullen gave a heartfelt interview about the importance of going to see a GP when symptoms first appear.

The Eastern Daily Press published Darren's cancer blog about cancer in the sports section the following Saturday. In the blog he talked of his father recently having surgery for cancer of the tongue.

Links to the Anglia footage and the EDP article were shared by Darren via his Twitter account that has 33k followers. There were a number of retweets so the reach was great.



Former Norwich City footballer Darren Eadie

in good health
The Norfolk and Waveney Health and Care Partnership

Learn more about the MenKind campaign:
[Men's health MenKind—Cancer](#)

Read Darren's blog here:
[Knowing the signs of the Big C could save your life](#)

Watch the full video here:
[ITV news—men's health](#)

Spotlight on Genomic Testing for Cancer

Building on the foundation of the [100,000 genomes project](#), the NHS is launching a new national [genomic medicine service](#). This was announced last September by Matt Hancock as part of a wider UK [genomics strategy](#).

The NHS Genomic Medicine Service will provide healthcare professionals with a [national directory](#) of available genetic and genomic tests for rare disease and cancer in a bid to speed up diagnosis and deliver more personalised medicine. The tests will be delivered by a network of Genomic Laboratory Hubs (GLHs) [announced last October](#) for the East Midlands and East of England, the GLH will be led from Cambridge, working together with laboratories in Leicester

and Nottingham.

What does this mean for cancer services? Over the next 18 months, molecular testing of tumours will be reorganized into a more regionally centralized model. We will work to disseminate information about changes as they occur. Please look out for information on our East Genomics website and sign up for our newsletter there to stay informed. As part of the NHS Genomic Medicine Service, whole genome sequencing (WGS) will be available as a clinical service for certain tumours from August 2019.

The WGS service will initially be available for acute leukaemias, paediatric cancers, and sarcomas. To order these tests, clinicians will need to familiarize themselves with the new national model of consent called Patient Choice. Under this model, all patients

receiving WGS will be eligible and should be offered the opportunity to participate in research. Information, education, and training on the Patient Choice model will be available through the Genomic Laboratory Hub.

For more information about the Genomic Medicine Service and to arrange training for your group, please contact: emee.glh@nhs.net

To learn about additional education and training opportunities to upskill in genomics, please see eastgenomics.org.uk or contact Education & Training Lead Gemma Chandratillake: glb28@medschl.cam.ac.uk

Informatics Update

Your newly formed Alliance Informatics Team members are Sarah Miller (Head of Information) based in Essex and Inderjit Patel (Information Manager) based in Cambridge. We have been busy getting to grips with the varied data and information needs you have. Highlights

and products from the past few months include: new monthly Cancer Waiting Times summaries, 6 STP intelligence reports, monthly screening data, CCG specific data packs, NCG specific data packs and providing data for [news stories](#).

To help us support you better, we have devised a new Information Request Service for which we now ask you to complete a form detailing your request, which we will log and work with you on. The process and details can be found [here](#). We look forward to working with you all, please get in touch with any data and information queries.

Cancer Research UK: The National Cancer Diagnosis Audit

The 2019 iteration of the National Cancer Diagnosis Audit (NCDA) is now fully open. The NCDA is a joint initiative between CRUK and Public Health England; with the support of NHSE, the RCGP and Macmillan and others across the cancer care community.

The NCDA aims to improve cancer outcomes by looking at patient pathways from first presentation to cancer diagnosis and is the only

large scale national audit to do so, providing a unique and rich data source. It examines the contribution of primary care to cancer diagnosis, to better understand the use of both open access diagnostics, straight to test and conventional referral pathways. It was last performed in 2014, so the 2019 audit is the first opportunity to robustly examine the impact of the NICE NG 12 guidance published in 2015 and should inform the revision expected in 2020.

Time per patient to complete the audit

Collecting data on a single patient took approximately 20 minutes. But this depends on patient complexity, clinical system navigation ease and internal support availability

Number of cases to Audit

A practice with list size 10,000 can expect approximately 5 patients per month, which will mean a time commitment of just under 2 hours per month. However, the number of patients records that need to be completed varies depending on practice size and patient population.

Flexibility with the audit

You can input data on patients as they come through, or you can submit data in instalments or all at once at the end of the data collection period.

The audit will look at information including:

- the place of first symptom presentation: in 2014 this was the GP surgery in nearly 70% of cases.
- the average time, the number of consultations and any diagnostic tests ordered from presentation to referral. In 2014, the average time delay was 5 days, but 35% of patients had more than three GP consultations prior to referral, although nearly 70% received an initial diagnostic test.

There is much current talk of “avoidable delays” in diagnosis, with approximately 45% being at primary care level; and although 70% first present to primary care, only 50% have cancer diagnosed by fast track referral. The new NCDA should help greatly to formulate practical steps to improve these figures.

It is easy for GP practices to sign up for the audit at <https://www.canceraudit.phe.nhs.uk> (requires a N3 connection) and can form part of their required **quality improvement activity**. They will receive their collated results from PHE, who will also provide data at CCG level and above.

In 2014, 35 GP practices took part and provided details of 1676 patients for the audit, numbers it is hoped will substantially increase for the 2019 version. Any activity that could increase awareness of the NCDA in your sphere of influence would be most welcome, and a short presentation is available in the primary care group page of the Alliance website.

Further information and support is available from the CRUK website and local facilitators please contact Donna Reeve Facilitator Manager East of England Email: Donna.reeve@cancer.org.uk Tel: 07979926403



Macmillan Electronic Holistic Needs Assessment

What is e-HNA?

The Macmillan Electronic Holistic Needs Assessment (e-HNA) is a web-based app that allows people affected by cancer to select their concerns and rate them on a scale of 1 to 10. It allows an assessment to be undertaken anywhere: clinic, ward or at home.

The assessment information is then encrypted and sent to a secure Care Planning website. Concerns are grouped under different domains: Physical, Practical, Emotional, Family Spiritual/Religious and Information needs. The eHNA responses will facilitate the conversation with the individual who completed the assessment. The actions and notes of the conversation can then be captured in the care plan.

The care plan will be saved and can be printed as a PDF. It can also be uploaded directly to an organisations electronic filing system, and shared with other services using the eHNA if required.

What are the benefits of e-HNA?

- Free to use and minimal training required.
- Micro or Macro data reporting via CSV files to support service planning and delivery
- The data gathered can help organisations understand where the demand for support is greatest.
- The assessment can be completed on any device with a browser.
- Supports personalisation as it is designed to be patient led.
- Concerns will be triaged highlighting priority concerns to be actioned.
- The data gathered can help organisations understand where the demand for support is greatest.

What steps need to be taken to engage with Macmillan to start the process?

You can register your interest in using the system on <https://signup.mycareplan.co.uk> or contact eHNA@macmillan.org.uk if you have any questions.

Cancer Care Reviews - Mid and South Essex STP Practice Nurse Course

Cancer Care Reviews (CCR) in primary care are an important part of the care of people living with cancer. The CCR provides the person living with cancer with an opportunity to think about their needs and, together with their Practice Nurse or GP, make a plan about how to best meet these needs.

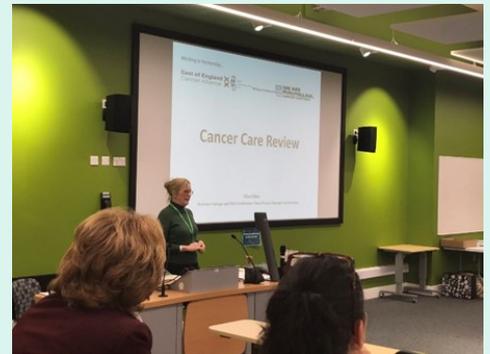
In early 2019, Practice Nurses working in Mid and South Essex STP were invited to attend one of 3 events that offered them the chance to increase their knowledge about cancer and upskill themselves for the role of undertaking CCRs. The courses were driven by Caroline Baya, Macmillan Recovery Package and Risk Stratification Clinical Lead at Mid and South Essex STP and the Essex Macmillan GPs, the sessions were fully funded by the STP, including the offer of backfill for staff who attended.

The events were planned and delivered by a variety of Macmillan Professionals and health colleagues. The first part of the morning session looked at the changing story of cancer and why,

because of improvements in early detection and treatments, cancer should now be seen as a long-term condition.

The afternoon session saw two actors taking the roles of a nurse and a patient at a Cancer Care Review. The audience were given an opportunity to suggest different communication styles that could improve the outcome and experience for the person affected by cancer.

There are now over 60 Practice Nurses in Mid and South Essex who are trained to complete effective CCRs, they represent GP practices from across the geography. The courses all received very positive evaluations and there are plans to roll out the courses across West Essex.



For further information please contact Sheona Evangeli, Macmillan Partnership Manager (Essex) SEvangeli@macmillan.org.uk

Soul Searching, Not Box-Ticking

Shae Eccleston Patient Advisory Board Member shares her personal experiences as a cancer patient of an online research community



In 2014, I took part in an online community of cancer patients. The patients in the study were

from an ethnic minority background, or LGBT or aged 65 and over. I was not aware of it at the time, but that was because national survey evidence showed that cancer patients with these characteristics were less satisfied and had poorer outcomes in cancer services than other cancer patients. So, the aims of the project were to understand why this was the case and to learn how to improve services to reduce these inequalities.

I had taken part in many surveys before. In my mind, I knew what researchers wanted to hear: they would ask relatively standard questions about how I felt about my diagnosis, how it affected me, what changes had to be made in my everyday life and what I felt could have been better. I had made all of these assumptions before the project started.

I started answering questions in the online community by giving short, canned responses to deep questions. I wanted to contribute but I didn't want to hurt more than I already did, so I stayed in the safe area. However, as the study progressed, the researchers – who, to me, began to feel more like virtual support – found a way to convince me that they wanted to hear my real experience. They truly wanted to use what I would share to make a difference. They also seemed to care about me, and the other participants, as individuals.

I answered some 50 questions, over eight weeks, about most aspects of my experience as a cancer patient: from fighting to be taken seriously by my GP

to getting my devastating diagnosis; from struggling to navigate a complex health service to anxiety about how I would make ends meet financially; from undergoing treatment to learning to live with the long-term consequences.

The questions required soul-searching, not box-ticking. For instance, we were asked to write the diary entry we would have written on the day we received our diagnosis. We were also provided a virtual 'bin' and a 'gratitude box', which was liberating and uplifting. Another question required us to imagine having a leisurely cup of tea with our doctors and to rehearse what we would really want to tell or ask them. Where relevant, we were also invited to talk about preparing for the end of our life – an impossibly difficult topic. It might have been gruelling, but it felt only warm, supportive and important.

The answers poured out of me and the others. We had been gently coaxed into deeper and deeper disclosures. Those eight weeks went quickly and the format of the research – an online environment where we were given the time and space to answer questions when it was convenient – made taking part flexible, accessible and empowering.

At the end of the study, the researchers collated all our individual responses and send the data back to each one of us, for safekeeping. This act was to be something that would touch my life years later.

In 2017, I started working with the East of England Cancer Alliance as a member of the Patient Advisory Board. After some time, I realised that the one area that needed urgent attention was the patient experience. What patients valued and what clinicians felt patients valued and should value were vastly different.

It is not easy to bring the voice of patients to healthcare professionals. Not just because of some people's inability to truly listen, but because it is hard to convey how my diagnosis has changed my life: any contemporary account lacked the emotional rawness, the

confusion, the despair, the unmet needs as I experienced them four years ago.

This is where the file shared by the researchers proved so transformational. It provided vivid proof of what I had lived and felt. As I read through, I remembered every feeling, pain and struggle. I didn't have to use my memory; it had been recorded. I was also blown away by the skill and the kindness of the researchers.

Through sharing that data, others could now see the value of empathy and understanding. They could observe what 'listening' felt like and the impact this has on patients. They could see that although I didn't want to die back then, I did not have the tools to live the life I deserved. There was learning to be done and by capturing and sharing the snapshot of my life as they had, the researchers had impacted me in way I could never have imagined. Merely surviving was no longer enough.

The feedback received from those with whom I shared my answers to that online community has been astounding. It has helped people to understand the everyday reality of someone struggling through diagnosis, treatment and life post-trauma. The data was raw, real and very honest and, while I was somewhat on my guard initially, I am truly glad I let go of the defensiveness.

The research was funded by Macmillan Cancer Support, led by Dr Marie-Claude Gervais, co-founder and director at Versiti.

Click here to learn more about the [Patient Advisory Board](#)

We are always looking for people with experience of cancer – whether as a patient, carer or family member – to get involved with us.

If you are interested in joining our Patient Advisory group please contact our Patient and Public Involvement Lead jai.jayaraman.nhs.net