London Cancer
Annual Review 2013/14
Excellent care through partnership

LONDON CANCER
NORTH AND EAST
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London Cancer thanks the following organisations for their on-going support:

UCLPartners
NHS England
Macmillan Cancer Support
Camden Clinical Commissioning Group (CCG)
Our Partners

Information contained in this document is correct at the time of publishing (July 2014)
Established in 2012, London Cancer is the integrated cancer system for north central and north east London and west Essex. London Cancer is embedded within UCLPartners and the cancer programme of the Academic Health Science Network (AHSN), which extends to include mid and south Essex, west Hertfordshire and south Bedfordshire. UCLPartners’ overall purpose is to translate cutting-edge research and innovation into measureable health and wealth gains for patients and populations. For cancer patients, this means we aim to accelerate improvements in all aspects of a cancer patient’s care: from diagnostic pathways through reducing variation in access to ‘state of the art’ therapies and innovation, to streamlining research delivery so that more patients are offered access to and can participate in clinical trials.

We are a partnership between 12 NHS hospital trusts, and collaborate with a wider affiliation of Clinical Commissioning Groups (CCGs) and other NHS healthcare organisations, to improve cancer patient outcomes and experience by providing expert, compassionate care for every patient, every time.

Working in partnership as a healthcare system, rather than working at the individual hospital level, the clinical leadership that drives London Cancer can map out a comprehensive, seamless clinical pathway for every patient. By working together, patients, providers and commissioners – supported by the academic and scientific community, and the voluntary and community sector – we are able to implement improvements system-wide at greater scale and pace. This is what makes London Cancer a powerful broker for change.

Why we’re here
London Cancer is committed to saving lives, improving patient experience, and optimising the quality of life of people living with and beyond cancer. In addition, London Cancer is committed to giving patients a more powerful voice and active involvement in setting priorities for service improvement and in improving access to cutting edge diagnostics, innovative treatments and clinical trials.

This collaborative approach enables us to co-design and diffuse sustainable healthcare solutions. We lead through influence and support for new ways of working together, to facilitate and inspire, empowered by our shared goals.

Our objectives
This annual review provides a summary of London Cancer’s achievements over the past year. It is based around the organisation’s three overarching objectives, which are:

• To increase one year survival for patients in north central and north east London and west Essex by improving earlier diagnosis. To reduce deaths by 200 per year from 2015/16.
• To improve patient experience by delivering 90% positive level of response on 10 areas most important to patients on the National Cancer Patient Experience Survey in 2015, with annual improvement.
• To give patients access to innovation by increasing participation in clinical trials to one in three patients over three years.

For further general information about London Cancer and to read board papers, please visit the website at www.londoncancer.org.
Welcome from the Chair and Chief Medical Officer of London Cancer

Every hour, three more Londoners are diagnosed with cancer. On average, one of them will die within 12 months, one will live with their cancer for the rest of their life, and only one will beat it.

Despite all the advances in successfully treating the disease, we now need a step-change in the way we care for people living with cancer. London Cancer aims to save lives, improve patients’ experience of the care they receive and enhance the quality of life for people living with cancer.

Londoners living in our region still have a poorer chance of beating their cancer than elsewhere in the country and we need to close that gap. Tackling the reasons behind late diagnosis of cancer is key to making improvement, as well as addressing the unacceptable variations across the capital in screening rates and access to treatment.

We have worked in partnership to consider the full pathway of patient care, from diagnosis to living with and beyond cancer and, for some patients, end-of-life care. All colleagues – chief executives, medical directors, clinical leaders, cancer managers, nurses, GPs and other health professionals – are focused on addressing patients’ needs, enabling us to genuinely put patients at the heart of everything that we do.

In this annual review, we present the progress London Cancer has made in our second year of functioning as an integrated cancer system. These achievements are a testament to the people actively involved in our work without whom this change would not be possible. We wish to particularly acknowledge the essential contribution from Macmillan Cancer Support and our very constructive joint working with the London Cancer Alliance to tackle areas that require a co-ordinated effort across London.

Earlier diagnosis
In the past year, London Cancer has worked in partnership with Macmillan and many other organisations to improve earlier diagnosis of cancer. We have updated the processes GPs use to refer patients to hospitals and supported an innovative model at Barts Health NHS Trust that has streamlined the diagnostic pathway for GPs to refer patients with lower bowel symptoms for assessment.

Creating a patient-focused system
In conjunction with Macmillan and the London Cancer Alliance, we have delivered a number of projects to improve patient experience. All trusts worked in partnership in a pan-London analysis of the free text comments made by local patients in the National Cancer Patient Experience Survey. This has helped identify where improvement efforts should be focused within the system. We have worked with trusts to develop a learning community, particularly around using real-time feedback and quality improvement to effect change, and sharing best practice in good patient information.

Reducing variation and aiming for world-class care
During the past year, we have worked with London’s specialist commissioners to implement some of the key recommendations from London’s Model of Care for Cancer Services. The 12 hospital trusts have made significant progress in working in partnership...
to propose changes to five specialist cancer services. These proposals would create higher volume specialist teams, who by working together in a new way, could provide access to the same level of expertise seven days a week for all patients. By bringing all the experts together into one team, we are also improving training and accelerating research and access to new and cutting-edge treatment for patients, no matter where in the system they are first diagnosed.

We have also contributed to the creation of London’s five year cancer commissioning strategy that embraces innovations to diagnostic and treatment pathways and services for patients.

**Improving access to research**

At London Cancer, we are committed to supporting cancer research and improving patients’ access to clinical trials. This year saw success in immunotherapy trials, with clinicians in the region entering the first patient in a global clinical trial of a new type of treatment that is showing great promise in patients with advanced skin and lung cancer. We have also seen the impact that a system-wide approach can have in access to clinical trials, such as that demonstrated by our Teenager and Young Adult Pathway Board.

We have supported wider cancer research including research focused on healthy lifestyles and patient-led research. Clinicians were also successful in winning funding from Cancer Research UK for research into low dose CT scan screening of heavy smokers for earlier detection of lung cancer.

**Focus for the future**

With the blueprint for a world-class comprehensive cancer system in place, and the proposals for specialist hubs defined, we are now putting most of our effort into the common cancer pathways, to make the biggest difference for the largest number of patients. We are bringing UCLPartners’ expertise in quality improvement across pathways to support our partners in a co-ordinated manner, from diagnosis through informed treatment options and follow up as close to home as possible.

Connectivity of healthcare information is critical to ensure that cancer patients, and the staff who care for them, have the right information in the right place at the right time. We will therefore be working to implement and join up high quality, easy to use data systems that help navigate care along the patient journey and to understand the quality and outcomes of whole pathways of care.

London Cancer’s work is starting to make a real difference for cancer patients in North and East London and West Essex. With a continued focus on increasing early diagnosis, reducing variation and working in partnership with primary care and patients themselves, we are determined to support all those involved in the day to day care and treatment of cancer patients. Together, we can achieve the step change that is required to make sure that Londoners and patients across the entire six million population served by UCLPartners’s Academic Health Science Network will have outcomes and care that are the very best available in England and can match the best in any part of the world.

— Pelham Allen, Chair

Professor Kathy Pritchard-Jones, Chief Medical Officer
Objective 1:

To increase one year survival for patients by improving earlier diagnosis of cancer.

Despite overall improvements in cancer survival in the UK, patients in London still have poorer outcomes compared to the rest of the country. It is estimated that an extra 1,000 lives could be saved in London alone if international best practice could be matched. Improving early diagnosis of cancer, when treatments are more successful, is therefore a key focus of London Cancer.

In the past year, London Cancer has worked with a wide variety of organisations to increase the earlier diagnosis of cancer. From updating the processes GPs use to refer patients to hospitals, to improving the assessment of vague abdominal symptoms to catch cancer earlier and creating IT solutions to increase the speed of diagnostic services, we are tirelessly working to help our partners diagnose and treat cancer sooner.

Supporting professional development in primary care

As the majority of patient care takes place within primary care, we recognise the key role that GPs play in patient pathways and in increasing rates of early detection of cancer. We are committed to supporting GPs to improve how they spot the early signs and symptoms of various cancers and improving their knowledge of referral routes and diagnostics through our GP Educational Series, in partnership with Macmillan Cancer Support.

We have co-created educational events with local Macmillan GP cancer leads since November 2012, to ensure the content and delivery of events is matched to the identified learning needs of local GPs. Through interactive case study discussions with the local hospital staff who care for cancer patients, we are strengthening relationships that are vital for improvement work in diagnostic and follow up pathways.

“Co-producing educational events with London Cancer has allowed me as a local Macmillan GP Cancer Lead to bring clinical leaders to a local forum for innovative and system-changing dialogue. We have used innovative, inclusive approaches that reach out not only to GPs but also to their wider healthcare teams,” said Dr Clare Stephens, Primary Care Cancer Lead, Barnet CCG.

These educational events have been made possible by generous support from Macmillan Cancer Support and local CCGs. A total of 279 GPs and 86 practice staff have attended across the system with very positive feedback. A suite of educational films are available on the London Cancer website www.londoncancer.org/gps/educational-films/.

When asked how participation has changed their practice, GPs indicated several changes. At the events, some GPs were open about their hesitation to refer patients for certain diagnostic tests. Examples were given around sigmoidoscopy for suspected bowel cancer and tests for ovarian cancer in people in their 40s and 50s. However after attending the education events, and understanding the importance of the two-week referral process, GPs reported their willingness to refer patients and to provide the support and information needed to reassure people during the process.
Straight to test triage for colorectal cancer

*London Cancer* is working collaboratively to shorten the patient pathway to diagnosis. Dr Ed Seward at Barts Health NHS Trust has developed a new service at Whipps Cross Hospital that opens up the referral pathway for patients with lower gastrointestinal symptoms beyond the strict criteria for urgent referral of suspected colorectal cancer. GPs and patients receive a definitive diagnosis more efficiently through a ‘straight to test’ model whereby a trained specialist nurse assesses patients by telephone. This enables most patients to go directly to the appropriate endoscopic investigation, according to symptoms and age, rather than attending clinic first.

Clear benefits for patients have already been seen from the first 125 cases, including: faster diagnosis, a reduction in missed appointments and unnecessary clinic visits and cost savings across the whole pathway, which could be redeployed for more early diagnosis. The project was recently shortlisted for a BMJ Award in 2014.

Tackling health inequalities and early diagnosis

*London Cancer* has been working to improve early diagnosis for groups experiencing health inequalities. In September, we participated in an event to mark the publication of ‘Hear Me Now’, a report highlighting the health inequalities for black African/Caribbean men with prostate cancer. We are now developing the first project to link promotion of prostate specific antigen (PSA) testing in high-risk communities to a cancer diagnostic and treatment options appraisal pathway. This will maximise choice of treatment and avoid overtreatment for patients with less aggressive disease. By improving earlier diagnosis of prostate cancer in these hard to reach high-risk patients, we aim to increase survival and minimise the risk of permanent side effects of treatment.

In partnership with Macmillan Cancer Support and Cancer Equality, we held an event in Hackney to raise awareness with local councillors and CCGs about the higher risk of prostate cancer and poorer outcomes amongst black and minority ethnic communities. Through local community workers, we have helped support people from these groups to get the most out of GP appointments.

“We are delighted with this innovation. For the first time, we are able to offer our patients a service that prioritises making a reliable diagnosis in days rather than weeks or months. The patient feedback is fantastic, it is truly patient-centred, and the service costs my commissioner colleagues less money. Everyone wins.”

Dr Munesh Mistry
GP in Waltham Forest
Community engagement with Tottenham Hotspur
Improving public understanding of cancer symptoms is critical to early detection. London Cancer partnered with Tottenham Hotspur Football Club, Haringey Council and NHS England (London) to launch the first ‘Get To Know Cancer’ drop-in clinic close to White Hart Lane football stadium.

The clinic, staffed by nurse specialists, was open to anyone who had questions or concerns about symptoms and crucially, no appointments were necessary. The goal was to reduce the fear or embarrassment associated with cancer and its symptoms that can stop people going to the GP when signs first appear. The drop-in clinic was mainly aimed at men who have a tendency not go to the doctor as regularly as women.

The clinic was open for a trial period of 21 sessions over six weeks, predominately outside GP hours. The launch received fantastic traction on social media having over 300 tweets that reached nearly six million followers.

Visitors were predominantly male and from the Tottenham area. Nurses saw 325 people in one-to-one consultations, discussing the most common symptoms of lumps, change in bowel or bladder habits and unexplained bleeding. John Hines, urological cancer surgeon and Pathway Director at London Cancer, also took to the pitch during half-time against Manchester United to encourage the tens of thousands of fans to visit their doctor if worried about symptoms.

The Tottenham Hotspur Foundation will continue to support the Get to Know Cancer campaign during the 2014/15 Premier League season.

Get to Know Cancer clinic in numbers
- 325 visitors during the 21 days
- 21% were referred to a follow up service (e.g. GP, stop smoking clinic)
- 11% referred to a GP
- 4.6% referred to a weight management programme
- 5.2% referred to stop smoking service
- Over 50% of fans said the knowledge gained had changed how long they would wait to get advice about unexplained changes in their health
- Cost per visit was nearly half that of a walk-in clinic or A&E attendance

“My wife nagged me for months to go to the doctor when I had symptoms. I was lucky they caught the cancer in time – she probably saved my life.”

Steve Brown, cancer survivor, speaking at the launch of the cancer drop-in clinics in Tottenham.
Earlier diagnosis of cancer in Camden
A new way of working in partnership

London Cancer and Camden CCG are collaborating with clinicians and partners to address the main causes of late diagnosis. The programme aims to increase population awareness of cancer, tackle health myths and misperceptions in specific community groups and encourage people to use the services of primary care.

The work is being delivered through a partnership approach, involving Macmillan Cancer Support, Cancer Research UK, BMJ Learning, local GP practices, community groups and NHS providers.

The overarching objectives of the project are to:
1. Improve one year survival rate
2. Increase uptake in screening programmes
3. Increase the number of cancer patients presenting at Stage 1 and 2
4. Increase knowledge and awareness of signs and symptoms of cancer.

- Over 50% of GP practices in Camden have been involved
- 60 volunteers have been trained to talk about cancer
- Through partnership with the Bengali Workers Association, we contacted 7,000 people from the Bangladeshi community
- We aim to reach over 10,000 people aged over 50 to raise awareness of bowel cancer through partnership with Arsenal in the Community and the Tottenham Hotspur Foundation

GP education and professional development in Camden
A bespoke primary care education programme was developed to improve GP referral of patients for investigation of cancer symptoms. This was in response to practitioner delays identified in the 2012 Camden Annual Health Report as one of the key drivers of late cancer diagnosis. Engagement with GPs has been very successful with over half of Camden GP practices having received a visit and two well attended educational events have been held.

Cancer accounts for 35% of premature deaths in Camden and the toll is disproportionately high among women and lower socioeconomic communities

The small ‘c’ campaign
The ‘small c’ awareness campaign is being used to support the work of community groups following its success in east London in 2009. The fear surrounding cancer can lead people to ignore important symptoms because they are afraid of cancer - the ‘Big C’ -, and this campaign wants to overcome the stigma and encourage people to seek help early. The aim is to highlight that in most cases, by participating in national screening programmes and recognising and acting on the early warning signs of cancer, people can turn the ‘Big C’ into a ‘small c’.

Peer education work in Camden began in April with volunteers completing Cancer Research UK’s ‘Talk Cancer’ programme, empowering them to build their knowledge, skills and confidence to talk about cancer.

“This is a truly exciting project that tackles one of our biggest health issues in Camden and typifies our CCG’s integrated approach. London Cancer has been instrumental in co-ordinating and leading this work to provide a focused approach to getting cancer diagnosed early whilst linking it in with other work streams across north and east London.”

Caz Sayer, Chair Camden CCG and local GP.
Understanding the reasons for late diagnosis of cancer

It is well known that the late diagnosis of cancer leads to poorer outcomes for patients. The London Cancer region has a particularly high number of people diagnosed with cancer after attending A&E (also known as an emergency presentation), rather than through traditional routes. Nearly a quarter of patients in our region are diagnosed this way – totalling approximately 3,000 patients each year.

The emergency presentation of cancer can be considered a failure of the healthcare system. London Cancer made it a priority to understand how and why so many patients are diagnosed via this route and undertook a system-wide evaluation across north east and central London and west Essex. In partnership with nine hospital trusts and GPs across the region, we aimed to understand the influences and drivers of emergency presentation that may be key to improving survival rates from cancer.

By analysing data in GP and hospital records, we were able to assess the whole diagnostic pathway. The project identified 963 patients in total. The commonest types of cancers identified by the emergency route were: lung (32%), colorectal (18%), upper gastrointestinal and hepatobiliary (12%) and haematology (8%).

The evaluation showed poor early outcomes as 10% of patients died within a month of diagnosis. Analysis of the primary care responses identified some emerging themes and areas for improvement, for example: faster access to diagnostic tests for GPs and better access in hospitals. This work also showed that A&E can be seen as a fast-track to definitive tests by both GPs and patients.

Most patients identified in the evaluation were known to their GP and reported a good relationship with them, despite so-called ‘stoic’ attitudes to help-seeking. People were put off seeking help for a second or third time if a medical practitioner had already given them a tentative diagnosis. Some did not have a GP or had not seen their GP in the last two years.

London Cancer is now actively working to address the concerns highlighted in the study.

We have standardised a measure to systematically collect an emergency presentations metric across trusts in London Cancer – approved by the Health and Social Care Information Centre (HSCIC).

London Cancer’s pathway boards are working to maximise understanding of the route to diagnosis for each type of cancer and to identify and prioritise possible interventions to diagnose cancers sooner.

We aim to deliver continued education to raise awareness with GPs and others in primary care of the signs and symptoms of cancer; how ‘red flag’ symptoms can be missed in patients with multiple problems; and the need for better pathways for patients who have ‘vague’ symptoms.

We are also working closely with primary and secondary care colleagues to redesign referral pathways and systems to ensure that patients who are diagnosed on a non-urgent route are transferred onto a time-dependent pathway and not delayed in the system.

Follow-up with primary care and interviews provided the following insights:

- 64% of patients went to A&E with symptoms lasting less than a month
- 63% of patients had seen their GP for the same problem prior to A&E and over half of these patients were waiting for tests organised by their GP
- The most common reason for delay was not thinking the problem was serious (53%)
- 7% of people delayed because they were worried about what would be found. This group waited the longest before seeking help.
Objective 2:

Improve patient experience by delivering 90% positive level of response on 10 areas most important to patients on the annual National Cancer Patient Experience Survey in 2015.

At London Cancer, we believe that patient experience and the patient voice is an under utilised resource for improving the health service. From the outset, we have co-designed our work in partnership with patients who are active participants in our pathway boards and expert reference groups. This year, we have even more patient and carer input into all areas of our work, with 65 people working directly with our team and clinical leaders and 16 newly joined in the past year.

We have seen improvements in five of the ten topics that matter to most to patients, however there is much work to be done. We remain committed to giving patients and carers a powerful voice and more active involvement in their care. This section provides an overview of our activities to improve patient experience.

We are grateful to Macmillan Cancer Support for their partnership in funding and mentoring our work in this important area.

Nikki Cannon, Senior Macmillan Development Manager comments: “Every person diagnosed with cancer should be treated with dignity and respect throughout their cancer journey and we are delighted to be working with London Cancer to improve patient experience. Great progress has been made in North and East London over the past 12 months and we look forward to continuing to work together on further improvements in this crucial area.”

Listening to patients and acting on their comments

Last year, with the agreement of all trusts in London, both integrated cancer systems in London worked together to perform a thematic analysis of over 15,600 free text comments submitted by cancer patients in the National Cancer Patient Experience Survey (NCPES).

Patient feedback was more positive in 2012/13 than in previous years, with over 65% of the comments submitted being positive about patient’s experience and less than 35% making suggestions for improvement, compared to 60% and 40% respectively in 2011/12. Positive comments were generally about the quality of care, specific services and teams, quality of professionals, speed and efficiency and support and attention.

Patients highlighted ten main areas of improvement: quality of care, quality of communication, waiting times in outpatient clinics, information, staffing levels, liaison between departments, the environment and hospital site, support, GP liaison, and delays. Improvement ideas have been shared with trusts and will be taken forward by the Patient Experience Learning Community (see below).

Establishing a community to improve patient experience

In March 2014, London Cancer launched the Patient Experience Learning Community to help drive improvement in patient experience. Its purpose is to enable sharing of best practice, reflect on less helpful practice and drive improvement through collaboration.

The community will have quarterly learning sets and an online platform to allow ongoing discussion between patient experience improvement managers, patients, and staff from the third sector. To date, five local improvement projects have been started as a response to our Learning Community launch. The work to assess and understand real-time feedback will be shared with the learning community as insights emerge.

Using real-time patient feedback to improve care

Over the past year, all 12 London Cancer trusts have developed their real-time patient feedback mechanisms, including electronic surveys, online feedback, kiosks, patient experience trackers, compliment and comment cards, and patient and staff stories. There are many similarities between the questions asked across the trusts, which include the Friends and Family Test, alongside bespoke surveys developed with patients, carers and external agencies to better understand and measure improvements made.

Improving the information patients receive about their care

London Cancer has worked with trusts and people to create an information standard across the integrated
cancer system. This involved identifying the principles of good patient information and agreeing a set of core information trusts should be providing to all cancer patients, drawing on the strength of organisations that are already showing best practice in this area.

A workshop, facilitated by Macmillan was held to:
- Identify the principles of good information
- Agree a set of core information—keeping it simple across tumour-types
- Get patient perspectives and advice on behaviour around provision and communication of information.

London Cancer’s pathway boards have also developed several projects to improve the quality of information that patients receive about their cancer diagnosis.

For example, the Teenager and Young Adults Pathway Board developed a new patient information pack to give young people with cancer and their families extra guidance and support; highlighting staff who are available to help, support services available and practical tips about finances, education and how to stay active during and after treatment. This will be issued to all young people aged 13-24 years in North London, Mount Vernon and Essex who are newly diagnosed with cancer.

Improving quality of life through community-based physical activity

The Aquaterra Cancer Survivorship Exercise Pilot supported by London Cancer won an award at the Quality in Care Excellence Awards 2013.

This pilot programme provides a community-based physical activity programme to promote the physical and psychological wellbeing of individuals living with or beyond cancer. Participants are offered a 12-week personalised course to increase their activity levels, with a strong emphasis on informed choice and empowerment. This support to adopt a healthier lifestyle may reduce the risk of cancer recurrence.

Results showed that physical activity levels increased by 100% and participants improved energy (71%); well-being (75%); and greater confidence (65%). 85% intended to continue with the lifestyle changes, and 91% took advantage of an Active Health discounted membership to continue using leisure facilities after the intervention.

If you are a patient or carer and would like to be involved in one of London Cancer’s groups or projects, please contact us at contact@londoncancer.org

“I am a senior citizen and was treated with the utmost care and respect. I received excellent service throughout. I would have liked sufficient opportunity to discuss options – not least the option to decline treatment and to understand the full consequences of that decision.”
Implementing the National Cancer Survivorship Initiative patient recovery package

With generous support from Macmillan Cancer Support, we are continuing our work to implement the National Cancer Survivorship Initiative (NCSI) recovery package for all individuals diagnosed with cancer. This package combines several interventions which, when delivered together, aim to improve care co-ordination, experience and outcomes for individuals.

The interventions are: holistic needs assessment (HNA), treatment summaries, cancer care reviews (conducted by GPs) and health and wellbeing events.

Treatment summaries
We have successfully agreed a standardised treatment summary template which outlines the details of the treatment received. It also includes possible treatment toxicities and/or late effects, symptoms that require referral back to a specialist team, an ongoing management plan, contact details for referral back into secondary care, and any recommended GP actions to monitor and support the individual once they have finished their treatment. This document is shared with both the individual and the GP.

Holistic needs assessment
We have worked jointly with the London Cancer Alliance to agree a standard pan-London HNA tool, which was launched in November 2013. Several trusts are also participating in the Macmillan Cancer Support e-HNA pilot project, which uses a touchscreen tablet for ease of completion of the holistic needs assessment and generates a personalised care plan.

“Whenever possible, we give patients the HNA in advance so they can think about any issues they wish to discuss. HNAs often prompt discussions in difficult areas for the patient and they bring emotions to the fore which need careful managing. However, this means these problems can be addressed with a care plan early on in treatment.” Janet Copp, Haematology Clinical Nurse Specialist (Barking, Havering and Redbridge University NHS Trust).

Since the beginning of the project, nine trusts have introduced holistic needs assessments, five have implemented treatment summaries and six host health and wellbeing events.
Clinicians across London Cancer have been working closely with NHS England and local CCG partners to ensure that we can achieve the best possible outcomes for every patient requiring a complex procedure for one of five cancers.

Building on commissioners’ recommendations in 2010, clinicians came together to develop a Case for Change to drive improvements in the health outcomes and experience for cancer patients in our area. The Case for Change outlines proposals to consolidate some specialist cancer services into a partnership of world-class specialist centres in a new connected system of care – including local hospitals, primary and community care services – to provide consistently excellent services.

Clinicians believe the proposals would allow more rapid improvements in care, ensure every patient has access to the full range of treatment options and research opportunities and provide a consistent level of care no matter where a patient lives or first receives care. If agreed, the changes, along with improvements across the whole care pathway, could save over 200 lives a year.

NHS England has led the work to develop the proposals following feedback and input from patients, staff and stakeholders during an engagement exercise at the end of 2013. The proposals have received strong support from clinicians, clinical commissioning groups (CCGs) and the three joint health scrutiny committees for the area. It is expected that a final decision will be made by commissioners in summer 2014, following a second period of engagement on a detailed business case.

“Everyone who lives and works in our area deserves world-class care. Unfortunately the way that some specialist services are currently organised makes it impossible for our clinical teams to do their best for patients. This is frustrating for everyone; we are convinced by the evidence that consolidating complex and specialist cancer services into a small number of world-class specialist centres, where all the experts can work together in a new way around the patient pathway, is the best way to achieve this.”

Professor Kathy Pritchard-Jones, Chief Medical Officer of London Cancer.
Research studies and clinical trials allow patients to access the latest interventions not yet available as part of standard care, and help build the evidence base for changes in clinical practice that will improve outcomes for all patients. Our aim across London Cancer is for researchers at the cutting edge of discoveries to work with patients so that we can change lives, at a faster pace.

By working together as a co-ordinated system and linking up our clinical practice with leading medical research and innovation, we have a remarkable opportunity to give patients improved access to clinical trials. We are working closely with the newly formed NIHR Clinical Research Network North Thames to improve information for staff and patients and access to a full portfolio of studies for our population.

Novel immunotherapy approaches – a London Cancer first

Trials of an exciting new therapy that has shown dramatic responses in some patients in the advanced stages of skin cancer (malignant melanoma) and lung cancer have been supported by London Cancer this year. In September, a patient of Dr David Chao, London Cancer skin Pathway Director, became the first in the world to be enrolled in a global phase III skin cancer trial. With many lung cancers and malignant melanomas diagnosed at a late stage, this breakthrough could offer hope to patients in London and further afield.

Dr Chao leads two of the three trials taking place in the region and all studies are open to patients from any hospital across our academic health science partnership. “We want to ensure that as many patients as possible have access to these potentially curative or life-extending therapies,” says Dr Chao. “The idea is that UCLPartners functions as one virtual hospital for this and other leading clinical trials.”

As well as conducting the clinical trials, Dr Chao and his team across UCLPartners will also help enhance the understanding of the immune system by working with UCL Institute of Immunology and Transplantation based at the Royal Free Hospital. “We have world-class research laboratories focusing on the immune system and we are aiming to work collaboratively with pharmaceutical companies to develop better therapies for our patients.”

Currently, the cancers in which immunotherapies are showing the most promise are malignant melanoma, lung cancer, and kidney cancer. “It is hoped that these breakthroughs can eventually be extended to other types of cancers.” concludes Dr Chao.

Engaging with kidney cancer patients

The Royal Free Hospital and London Cancer hosted a renal cancer research day, an important part of the education and training plan for the planned Renal Cancer centre. The event focused on future treatment of renal cancer, particularly the research and clinical trials taking place. The meeting was attended by 120 delegates with international speakers from the Netherlands Cancer Institute, Harvard Medical School and the Cleveland Clinic and participation from clinicians, academics, third sector and patients.

Research into living with and beyond cancer

London Cancer is pleased to be working in collaboration with Professor Jane Wardle, Director of the Cancer Research UK Health Behaviour Research Centre at University College London (UCL). The aim is to explore the impact of healthy lifestyles on short and long-term outcomes in people living with and beyond cancer – focusing on breast, colorectal and prostate cancers.

National funding to support CT screening research for lung cancer

Lung cancer kills more people than any other cancer, largely because it is diagnosed late and standard chemotherapy is not very effective. In patients with early stage tumours, the disease is often found by accident. However, screening high-risk people (those who have smoked a pack of cigarettes every day for more than 30 years) using low-dose computed tomography (CT) has shown impressive results in early detection trials.
Dr Sam Janes, lung cancer Pathway Director, in conjunction with Professor Jane Wardle, has been successful in a bid to the National Awareness and Early Diagnosis Initiative (NAEDI) – funded by Cancer Research UK – to research the development and testing of targeted invitation materials for a pilot trial of lung cancer screening. The project will test the best way to invite people at high risk of lung cancer to have a screening CT scan. Those with the highest risk of lung cancer often come from the most deprived communities, which also have the lowest rates of uptake of other cancer screening programmes (breast, bowel and cervical cancers). This project will make an important contribution to addressing this inequality.

London Cancer publications and presentations

The primacy of early stage cancer survival statistics in reducing emotional barriers to help-seeking behaviour in lower socioeconomic status populations S Cunnington-King, London Cancer, oral presentation, NCIN conference, 2014

Paediatric clinical outcomes research – UK policy and the role of the European Network for Cancer research in Children and Adolescents K Pritchard-Jones, oral presentation, NCIN conference 2014


London Cancer Chief Medical Officer, Prof K Pritchard-Jones gave a plenary lecture: “What can we learn from abroad?” at the World Cancer Day congress: Together against cancer – taking the next steps. Radboud University Medical Centre, Nijmegen, The Netherlands, February 2014

Straight to test colonoscopy – a viable means of shortening time to a definitive diagnosis P Andrews, H Watson, M Mistry, M Machesney, E Seward, poster presentation, British Society of Gastroenterology 2014

Straight to test colonoscopy – a viable means of shortening time to a definitive diagnosis L Steward, P Andrews, H Watson, M Mistry, M Machesney, E Seward, poster presentation, European Society of Coloproctology 2014

Pragmatic approach to quality metrics development in cancer D Chung, A Dwarakanath, C Williams, K Pritchard-Jones, J Mountford, A Mayer, poster presentation, ASCO Quality Care Symposium 2013
Supporting patient-led research in skin cancer

*London Cancer* is committed to engaging with patients in the development of our research strategy. Patients are at the heart of both study design and the oversight of clinical trials and recently we have introduced innovative models of patient-oriented research.

Chris Devereux, a patient representative on the *London Cancer* Skin Pathway Board, is undertaking a piece of patient-led research that complements the skin research portfolio. An avid cyclist, Chris was diagnosed in early 2012 with a basal cell carcinoma which was successfully removed by Mohs micrographic surgery; a surgical technique that is appropriate for some types of skin cancer. He is now conducting a study of patients’ perceptions of their own Mohs surgery with the intention that this will enable improvements in care through reciprocal understanding.

Drawing from behavioural sciences and learning theory, the qualitative study involves in-depth conversations with patients, discussing with them how they felt about the process they went through from start to finish – what they appreciated about it and what could be improved. The goal is to improve understanding between patients and those who work with them.

Research findings will be used to offer suggestions for tangible actions for improvement. Key themes emerging from his research show that patients’ experiences have been most influenced by their anxiety about the procedure and poor administrative procedures whilst they have been impressed by the technical expertise of the surgeon and the outcome of the surgery itself.

“*Working with patients like me on their experiences of Mohs surgery has enabled conversations that may not happen when talking to professionals. This study has given me the chance, through talking to fellow patients, to suggest low-cost ways in which some aspects of the patient experience could be made better.*”

Chris Devereux,
Patient representative on the *London Cancer* Skin Pathway Board
The NIHR Clinical Research Network North Thames

- The newly formed NIHR Clinical Research Network North Thames is a streamlined organisation whose geographical boundaries correlate with the UCLPartners Academic Health Science Network.
- It is the second largest Clinical Research Network by population; serving around six million people.
- Trusts in London Cancer are particularly strong in recruiting to interventional trials (studies that test a particular treatment), contributing 11.3% of the total cancer patients recruited nationally, with particular strength in gynaecological oncology, melanoma and upper gastro-intestinal cancers.
- London Cancer’s trusts have recruited 20% of the country’s Children’s Cancer & Leukaemia portfolio.
- To date, 70 Principal Investigators from London Cancer trusts have participated in 14 disease/cross-cutting areas.
Increasing participation by teenagers and young adults (TYA) in clinical trials

Following the establishment of the Teenager and Young Adult Cancer Network (TYA) in November 2012, we have seen a dramatic improvement in participation in research.

A particular success has been London Cancer’s work with acute lymphoblastic leukaemia TYA patients. Previously, these patients have had poorer survival compared to children, likely due to a combination of factors including more aggressive biology of disease, increased toxicity, poorer recruitment to clinical trials, poorer compliance and lack of unified protocol, with patients treated on either a paediatric or adult protocol based purely on local referral patterns.

The TYA Pathway Director, Dr Rachael Hough, was involved in a national working group which brought together paediatric and adult physicians to agree which protocols offer younger patients the best chance of survival. These were then rolled out across the system. Now patients up to 24 years of age are treated on the paediatric protocols and have a substantial improvement in event-free survival. This has also doubled recruitment to clinical trials as clinicians now know which trial is best for their patients and are more willing to refer.

In addition, this age group previously had poor clinical trials recruitment circa 40%. This has dramatically improved as clinicians now know which trial is best for their patients and are more willing to refer. This has doubled enrolment in clinical trials.
Transforming pathways of care

London Cancer currently hosts 11 cancer pathway boards, five specialist boards and six expert reference groups (ERGs). Last year, we hosted 15 educational events within these groups, bringing together multi-professional groups to better understand and treat cancer, leading to several joint initiatives, co-developed across the partnership.

Implementation of sub-cutaneous trastuzumab
The Chemotherapy ERG worked with the London Cancer Alliance and NHS England in the implementation of subcutaneous trastuzumab (Herceptin) across London. Sub-cutaneous injections are made just under the skin as opposed to the traditional intravenous (IV) route of administration which takes a long time to administer.

The sub-cutaneous trastuzumab has benefits in cost, efficiency and improved patient experience compared to IV therapy. London Cancer, in conjunction with London Cancer Alliance, developed a comprehensive package for hospitals to allow the easy adoption of this treatment with the aim of reducing the time required for implementation. This package includes risk assessments, guidelines, a patient information leaflet, e-prescribing advice, and a nursing administration procedure.

To date, four trusts have implemented subcutaneous Herceptin and the Chemotherapy ERG is working with the remaining trusts to drive adoption across the system.

Single integrated radiotherapy service
The London Cancer Radiotherapy Expert Reference Group (ERG) has been conducting an options appraisal into the feasibility of a single integrated radiotherapy service working across the integrated cancer system. The vision is to provide a high quality radiotherapy service to any patient within London Cancer as close to home as is possible; facilitating swift access to specialist and innovative treatments, pooling expertise and sharing the resource required to lead, manage and maintain a high quality service. The report will be completed by August 2014.

Online integrated renal pathway
We were successful in securing funds from the NHS England Safer Hospitals, Safer Wards Technology Fund to integrate data within existing healthcare IT systems in order to provide a renal cancer pathway overview. This will show the number of patients at different stages of the pathway with the ability to drill down to an individual patient level. This is an innovative project with an industry partner based in Scotland, and hosted at the Royal Free London NHS Foundation Trust.

Using information to improve the patient pathway
This past year London Cancer signed an information sharing agreement with trusts in our area to set out how we will share information. We have started modelling and developing scorecards for each of the pathways. For more information on London Cancer scorecards go to http://meetinglibrary.asco.org/content/120394-140. We will continue to develop our scorecards in 2014/15, with the support of our partner trusts, to present data that drives improvements across the patient pathway.

Pan-London five year strategy plan to transform cancer services
London Cancer, in conjunction with London Cancer Alliance, participated in the development of NHS England’s (London) five year plan to transform cancer services, leading on the reducing variation and patient experience work streams. The strategy sets out key recommendations for health services. We continue to work closely with commissioners, NHS England, Public Health England and charity partners to ensure the implementation of this work.

Directory of services
In order to assist our clinical staff to signpost individuals to relevant services during or after treatment, London Cancer carried out a system-wide scoping exercise to identify local resources to support individuals close to home. A directory of these services has been created and will be uploaded to the London Cancer website.
**London Cancer Board and Clinical Leadership**

**London Cancer Board**

*London Cancer* is led by an independent, skills-based and clinically-led board that sets the overall strategy, considers recommendations from cancer pathway directors and makes specific recommendations to commissioners on potential changes to cancer services and pathways.

The London Cancer board is made up of the following members:

**Chair** - Pelham Allen

**Chief Medical Officer** - Professor Kathy Pritchard-Jones

**Executive Director** – Mairéad Lyons

**Non-Executive Directors**: Elizabeth Benns, Dr Tony Brzezicki, Dr David Colin-Thomé, Dr Nigel Marchbank, Professor Emma Ream, Dr Timothy Walls

**Clinical Leadership of London Cancer**

*London Cancer* pathway directors provide clinical expertise and leadership to cancer pathway boards and expert reference groups helping to drive excellence in care and research and inspire improvement.

**Acute Oncology Expert Reference Group** – Dr Ian Grant and Dr Ekateria Boleti

**Brain and Spine Pathway Board** – Dr Jeremy Rees and Mr Andrew Elsmore

**Breast Pathway Board** – Dr Rebecca Roylance

**Chemotherapy Expert Reference Group** – Dr Chris Gallagher

**Colorectal Pathway Board** – Mr Michael Machesney

**Gynaecology Pathway Board** – Dr Rebecca Roylance

**Haematology Pathway Board** – Professor Ronjon Chakraverty

**Head and Neck Pathway Board** – Mr Simon Whitley

**Living with and Beyond Cancer Board** – Sharon Cavanagh

**London and South East Sarcoma Network Sarcoma Advisory Group** – Professor Jeremy Whelan and Mr Andrew Hayes

**Lung Pathway Board** – Professor Sam Janes

**North Thames Children’s Cancer Network Coordinating Group** – Dr Darren Hargrave

**North Thames Teenager and Young Adult’s Cancer Network Coordinating Group** – Dr Rachael Hough

**Nursing Expert Reference Group** – Alison Hill (interim)

**Palliative care (PallE8)** – Dr Adrian Tookman and Clare Philips

**Psychosocial Support Expert Reference Group** – Dr Mark Barrington

**Radiotherapy Expert Reference Group** – Dr Katharine Pigott and Dr Seeni Naidu

**Rehabilitation Expert Reference Group** – Sharon Cavanagh

**Skin Pathway Board** – Dr David Chao

**Upper GI (Oesopho-gastric) Pathway Board** – Professor Muntzer Mughal

**Upper GI (Hepatic Pancreatic and Biliary) Pathway Board** – Dr Andrew Millar

**Urology Pathway Board** – Mr John Hines