



Public Health  
England

# National Cancer Intelligence Network Cancer Outcomes Conference 2014

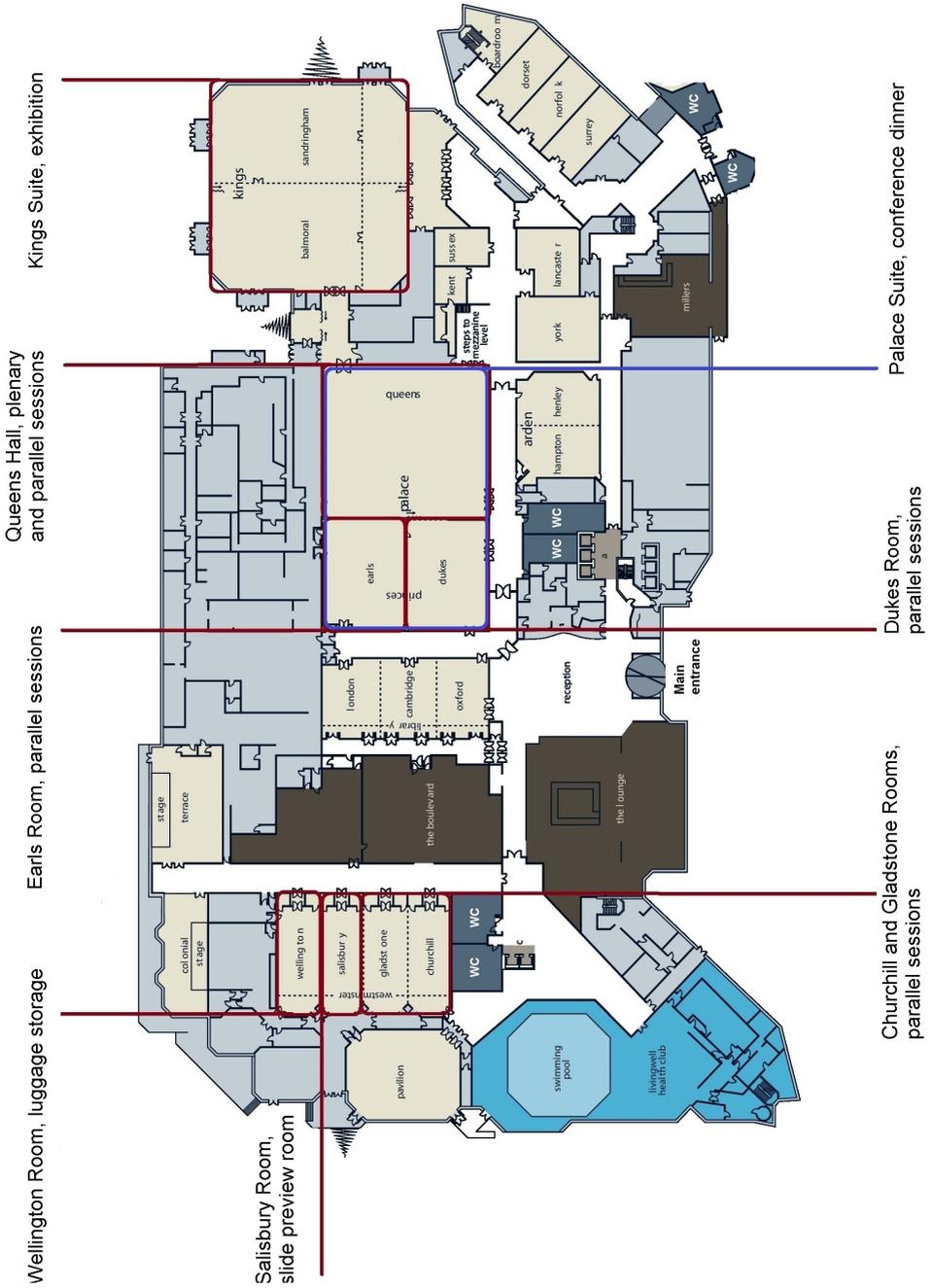
9-10 June, Hilton Birmingham Metropole



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# Venue Map



# Welcome to the conference

## Welcome to the Cancer Outcomes Conference 2014 – the power of information.

Data has been hitting the headlines. The uses of data, the value of data and most importantly, the need to engage patients and the public about what access to data means for the development and delivery of health and healthcare. The Cancer Outcomes Conference 2014 focuses on exactly that - the 'power of information' and its transformative relationship with the quality and outcomes of care.

The National Cancer Intelligence Network (NCIN) is one of five key health intelligence networks which are operated by Public Health England. Each network has the explicit role to service the information and intelligence requirements of the NHS and public health. For NCIN, this has been a year of evolution, with a particular focus on how we can make best use of the opportunities of being part of a new national body which spans activity across health prevention, awareness, screening and protection.

Whilst we have seen a significant change in the structures of the health system, the demand for real-world evidence has not wavered. One of the key roles of Public Health England's cancer programmes will be to ensure that clinicians, commissioners, patients and the public have information and intelligence at their fingertips. This means getting data out to the world-leading cancer researchers, and working with our third sector partners and PHE's Knowledge and Intelligence teams to translate information into impactful tools, accessible guidance and intelligence.

The Network, and its conference, have always brought together the views and expertise of its members, especially clinicians and patients, to understand and update on for the use and sharing of evidence to affect outcomes and inspire interventions that will make a difference to public health now and in the future.

Throughout the conference, you will hear from speakers that are often 'behind the headlines'. We welcome you to explore our exhibition and learn more about the incredible work being done throughout the UK, using information to improve outcomes.



**Chris Carrigan**  
Director, National Cancer  
Intelligence Network  
Public Health England



**Dr Mick Peake**  
Clinical Lead, National  
Cancer Intelligence Network  
Public Health England

# Sponsors

The National Cancer Intelligence Network would like to thank our conference sponsors for their continued commitment to the Cancer Outcomes Conference and for their financial support.



## Full conference, plenary and parallel session sponsor

Cancer Research UK is the world's leading cancer charity dedicated to saving lives through research. We fund over 4,000 scientists, doctors and nurses and work across all types of cancer. Our pioneering work into the prevention, diagnosis and treatment of cancer has helped save millions of lives. Cancer Research UK has been at the heart of the progress that has already seen survival rates in the UK double in the last forty years. Our vision is to bring forward the day when all cancers are cured.



## Full conference, plenary and parallel session sponsor

At Macmillan, we know a cancer diagnosis can affect everything in a person's life and we're here to support people throughout their cancer journey. We'll help people make the choices needed to take back control. To achieve this we do more research into the needs and experiences of people living with cancer and their carers than any other charity in the UK.

We believe all cancer patients should be treated with dignity and respect and that staff should be supported to deliver this. To enable this, we are working to develop services and policy solutions and building relationships with commissioners to drive change.

Macmillan's sponsorship of the health economics session reflects a commitment to understanding the cost of cancer in the broadest sense. Our Cancer Population Evidence Programme has identified health economics as a vital discipline for addressing challenges posed by a growing population of people affected by cancer.



## Parallel session sponsor

Pancreatic Cancer UK is the only national charity fighting pancreatic cancer on all fronts: Support, Information, Campaigning and Research. We provide an expert nurse-led support and information service for patients and their families and carers. We fund innovative research, focusing our resources in those areas where we believe we can make the most impact towards efforts to tackle the disease. Working closely with patients and their families and carers, clinicians and other healthcare professionals, researchers, politicians and policy makers we campaign to improve survival and pancreatic cancer patient experience.

# Programme Summary: Monday 9 June

09:30 - 10:55	<b>Registration</b> Registration desks, ground floor reception	
09:30 - 10:55	<b>Coffee and exhibition</b> Kings Suite	
10:00 - 10:45	<b>UKIACR Annual General Meeting (open meeting)</b> Churchill and Gladstone Rooms	
11:00 - 11:10	<b>Welcome address</b> Queens Hall	
11:10- 12:15	<b>Plenary 1</b> Harnessing the power of information to deliver quality and innovation in cancer surveillance, services and outcomes Queens Hall	
12:15 - 13:25	<b>Lunch, exhibition and poster viewing</b> Kings Suite	
13:30 - 14:25	<b>Parallel sessions 1</b> <b>Prevention, screening and early diagnosis</b> Queens Hall <b>Variation in treatment patterns and access to specialist care</b> Earls Room <b>Cancer intelligence to support local and national service provision</b> Dukes Room <b>Outcomes for young people with cancer - matching commissioning with the evidence</b> Churchill and Gladstone Rooms	  
14:30 - 15:25	<b>Parallel sessions 2</b> <b>Living with and beyond cancer</b> Queens Hall <b>Supporting clinical trials and observational research</b> Earls Room <b>Patient experience and reported outcomes</b> Dukes Room <b>Colorectal cancer outcomes and quality of care</b> Churchill and Gladstone Rooms	 

# Programme Summary: Monday 9 June

**15:30 - 15:55** Tea, exhibition and poster viewing

Kings Suite

**16:00 - 17:30** Plenary 2

**“Show me the data!” - information and intelligence for your  
ovarian cancer service**

Queens Hall

**18:45 - 19:25** Networking, exhibition and poster viewing

Kings Suite

**19:30** Conference dinner and poster prize awards

Palace Suite

# Programme Summary: Tuesday 10 June

08:00 - 08:55	Coffee, exhibition and poster viewing Kings Suite	
09:00 - 10:15	<b>Plenary 3 - The Brian Cottier Plenary</b> Global cancer surveillance: opportunities and challenges. Queens Hall	
10:15 - 10:40	Coffee, exhibition and poster viewing Kings Suite	
10:45 - 11:40	<b>Parallel sessions 3</b>  Epidemiology Queens Hall  Reducing health inequalities Earls Room  Health economics Dukes Room	  
11:45 - 12:45	<b>Workshops</b>  Systemic Anti Cancer Therapy (SACT) Queens Hall  Early career researcher showcase Earls Room  Preventing emergency presentations: the need for research Dukes Room	
12:45 - 13:40	Lunch, exhibition and poster viewing Kings Suite	
13:45 - 14:40	<b>Parallel sessions 4</b>  Data quality, governance and management Queens Hall  End of life and palliative care Earls Room  Less common cancers Dukes Room	  
14:45 - 16:15	<b>Plenary 4</b> Delivering outcomes that matter - panel debate and Q&A Queens Hall	
16:15 - 16:30	Close of conference	

# Conference Information

## Conference programme, abstracts, slides and posters

This booklet contains outline information about the conference programme and oral sessions.

To see the abstracts of the poster presentations please check the conference website: [www.phe-events.org.uk/ncin](http://www.phe-events.org.uk/ncin). Only the titles are included in this booklet.

Most slide presentations will be available in PDF format on the conference website after the event (subject to permission from the authors). PDFs of many of the posters will be added too.

## Registration and enquiries desk

To collect your badge and conference booklet, or to speak to a member of our conference team with any enquiries during the event, please visit our registration desk, which is situated in the hotel reception area.

## Accessibility

If you require assistance please visit the conference registration desk and we will be happy to help.

## Badges

Please make sure you wear your badge throughout the conference – without it you will not be able to get into the conference sessions and meals.

If you lose your badge, please visit the conference registration desk.

## Places in sessions

We have allocated sessions to rooms we hope will accommodate all those wishing to attend. Some sessions may become full and places in the sessions will be on a first-come, first-served basis.

Once capacity is reached, for health and safety reasons, we will not be able to allow additional people into the room so please arrive in good time before the start of the session.

Please help colleagues by avoiding sitting at the end of a row and leaving empty seats inaccessible.

For those arriving once the session has started, to avoid disrupting colleagues, and as a courtesy to speakers, kindly wait until the speaker has finished before taking a seat.

## Mobile devices

As a courtesy to speakers and colleagues, please remember to switch mobile phones off or to silent during sessions. If you are presenting please do not have a mobile or pager on you when you are near the microphones.

# Conference Information

## Wi-Fi

Wi-Fi is free in the public areas of the hotel but not in the conference rooms. If you would like to have access to Wi-Fi during the conference then please go to Wi-Fi networks on your mobile device and select BTOpenZone - you will be able to pay online (£14.99 for 24 hours). Alternatively please go to the hotel reception and pay for a code to access the Wi-Fi.

## Social media

The Twitter hashtag for the Cancer Outcomes Conference is **#NCIN2014**. We would be delighted to have a lively stream of tweets during the conference.

## Conference App

An App has been developed providing conference information on your mobile device. Follow these steps below to download the App:

1. Enter <http://bit.ly/ncin2014> into your device's browser, or scan the QR code with your device's QR code reader
2. Once loaded, follow your mobile device's on screen instructions to pin the web based App to your home screen
3. The App will now be located (pinned) on your mobile device's home screen allowing you to access it in future at the touch of a button



Please note the Conference App requires a 3G/internet connection.

## Poster exhibition

Posters are displayed in the Kings Suite and may be viewed at the following times:

<b>Monday 9 June</b>	<b>Tuesday 10 June</b>
12:15 -13:25	08:00-08:55
15:30 -15:55	10:15-10:40
18:45 -19:25	12:45-13:40

## Special dietary requirements (lunches)

If you informed us of special dietary requirements when you booked, your lunch will be ready for collection on both days - please ask a member of the catering staff. Vegetarian options will be provided as standard.

## Conference dinner and pre-dinner networking

For those staying at the venue, the conference dinner will take place on Monday 9 June at 19.30 in the Palace Suite. Prior to the conference dinner there will be an opportunity for networking in the Kings Suite where a bar will be set up (18.45 –19:25) - you will also be able to buy drinks for your meal.

# Conference Information

## Evaluation of the conference

We value your feedback about the Cancer Outcomes Conference 2014. Please complete the online evaluation which we will send to you after the conference.

## Photographs and filming

Public Health England staff will be taking photographs and filming during the conference. If you do not wish to be included in this, please see one of the camera operators.

## CPD/Certificates of attendance

If you would like to have a certificate of attendance for your records please send an email after the event to [events@phe.gov.uk](mailto:events@phe.gov.uk) with subject 'Certificate' and we will send one to you in PDF format.

The conference has been accredited for 11 CPD points by the Royal College of Physicians.

# Venue Information

## Accommodation

If you booked accommodation for the night of Monday 9 June, you will be required to give credit card details to hotel staff during the registration process on Monday morning to cover any incidentals and your room key will be available for collection from the conference registration desks from 15.00 onwards.

## Breakfast

Breakfast is available from 06.30 in the hotel restaurant.

## Check out

Please check out of your room prior to the start of the conference on Tuesday morning, hand your key card into the hotel reception, pay for any extras incurred and store your luggage in the Wellington Room.

## Luggage storage

Luggage can be stored after registration on Monday and after check out on Tuesday in the Wellington Room on the ground floor.

## Liability

Public Health England and the venue accept no liability for loss or damage to articles during the event.

## Car parking

If you purchased a pre-paid car parking ticket when you booked your place at the conference this will be given to you with your badge when you register for the conference.

If you did not pre-pay for a car parking ticket but will be parking at the hotel then you can pick up a special conference price car park ticket from the conference registration desk before you leave and pay at the machines.

Please note that parking at the hotel is subject to availability and if the hotel car park is full, a member of hotel security will direct you to alternative car parks in the surrounding area owned by the NEC and costing around £10.00 per day.

## Shuttle bus to and from the station

The Hilton shuttle bus departs from the bus/taxi area outside Birmingham International train station every 30 minutes. This is a 24-hour service.

Please note there may be a queue at peak times. It takes around 10 minutes to walk to the station so you may find it quicker and more convenient to walk.

## Sports facilities

A gym and swimming pool are available for hotel guests.

# Poster Information

## Putting posters up

All posters will be displayed in the Kings Suite. On arrival, all poster presenters should register and then put their poster up as soon as possible.

Poster numbers are given in this brochure.

Display boards in the Kings Suite are numbered and Velcro to attach your poster is available from conference staff.

## Poster viewings

All poster presenters are encouraged to stand by their poster during the breaks.

## Poster prizes

The National Cancer Intelligence Network is delighted to announce the introduction of four new poster prize categories at the Cancer Outcomes Conference 2014. The awards celebrate the outstanding creativity, vision and contribution of poster authors to the conference.

The awards are as follows:

- Transforming clinical practice and service delivery
- Delivering improved patient outcomes and experience (patient choice award)
- Understanding the patient pathway
- Early career investigator

## Patient choice award

Bursary holders are invited to select their favourite poster from a shortlist. Voting papers are available from the registration desk and should be returned to the NCIN stand in the Kings Suite by 17:00 on Monday.

## Announcement of winners

Award winners will be announced at the conference dinner on Monday by Chris Carrigan, Director, National Cancer Intelligence Network, Public Health England.

The National Cancer Intelligence Network would like to thank the contribution of the judging panel.

## Taking posters down

You may only take posters down on Tuesday 14.30-17.00 and strictly not before. Many delegates will only be attending on Tuesday and will want to have the opportunity to see the posters.

Please note that posters left after 17:00 will be recycled.

# Speaker Information

## To check your presentation

Please visit the slide preview room (Salisbury Room) as soon possible to allow a quick final check through your presentation with a technician.

The slide preview room will be open during the following times:

Monday 9 June	09:30 - 17:00
Tuesday 10 June	08:00 - 11:45

To facilitate sharing of knowledge and expertise, we hope you will be willing for a PDF of your presentation to go on the conference website. You will be asked to confirm this with the technician.

## In the session

Please check the time and venue of your session in the conference programme. Kindly arrive there in good time before your session is due to start to meet the session chair and technician. The technician and a member of the conference staff will be in the room throughout the session to make sure it runs smoothly.

The chair has been provided with your biography and your abstract to facilitate your introduction.

Please observe the time given for your presentation in email correspondence. You will not be permitted to speak for longer than this.

Q&A will be held at the end of the session.

# UKIACR Annual General Meeting

## UK and Ireland Association of Cancer Registries Annual General Meeting

The UK and Ireland Association of Cancer Registries (UKIACR) Annual General Meeting will take place on Monday 9 June, 10:00 - 10:45 in the Churchill and Gladstone Rooms.

### Overview

The UKIACR replaces the UK Association of Cancer Registries (UKACR) following the merging of the eight English regional cancer registries into the English National Cancer Registration Service (NCRS).

The historic UKACR Conference has, since 2008, been linked with the National Cancer Intelligence Network (NCIN) conference, which is a larger event with a focus on involving patients and policy makers. The UKIACR is also now linked with this in the same way as UKACR.

### Membership and structure of the UKIACR

Membership now includes the National Cancer Registry of Ireland (NCRI) as a full member (previously it had observer status), plus Scotland, Wales, N. Ireland, England and the Office for National Statistics.

Observer status remains with the National Cancer Intelligence Network (NCIN). There are also associate members, which include the major cancer charities and the London School of Hygiene and Tropical Medicine.

Professor Julia Verne (Public Health England) and Dr David Brewster (Scottish Cancer Registry) co-chair the UKIACR.

The subgroups of the former UKACR have been retained as their work is recognised as excellent for the standardisation and enhancement of cancer registration, and also the use of population based cancer registry data.

The chairs of these subgroups attend the UKIACR executive committee meetings.

# Programme: Monday 9 June

09:30 - 10:55	<b>Registration</b> Registration desks, ground floor reception	
09:30 - 10:55	<b>Coffee and exhibition</b> Kings Suite	
10:00 - 10:45	<b>UKIACR Annual General Meeting (open meeting)</b> Churchill and Gladstone Rooms	
11:00 - 11:10	<b>Welcome address</b> <b>Queens Hall</b> Chris Carrigan, Director, National Cancer Intelligence Network, Public Health England	
11:10 - 12:15	<b>Plenary 1</b> <b>Harnessing the power of information to deliver quality and innovation in cancer surveillance, services and outcomes</b> <b>Queens Hall</b> <i>During this plenary, speakers from NHS England and Public Health England will explore how both local and national level approaches are improving prospects of survival and quality of life for cancer sufferers. Speakers will also reflect on lessons from the past twelve months and how we can build on this experience.</i>	Sponsored by <b>WE ARE MACMILLAN.</b> CANCER SUPPORT
11:10 - 11:20	<b>Chair's welcome and introduction</b> Professor Brian Ferguson, Interim Director, Knowledge and Intelligence, Public Health England	
11:20 - 11:35	<b>Ensuring everyone stands the best chance of surviving breast cancer</b> Kris Hallenga, Founder, CoppaFeel!	
11:35 - 11:50	<b>Cancer - a public health perspective</b> Professor John Newton, Chief Knowledge Officer, Public Health England	
11:50 - 12:05	<b>Progress on the delivery of optimal care for cancer patients in the new NHS</b> Sean Duffy, National Clinical Director for Cancer , NHS England	
12:05 - 12:15	<b>Q&amp;A</b>	
12:15 - 13:25	<b>Lunch, exhibition and poster viewing</b> Kings Suite	

# Programme: Monday 9 June

## 13:30 - 14:25 Parallel sessions 1

### Session 1 Prevention, screening and early diagnosis

#### Queens Hall

Sponsored by



#### 13:30 - 13:45 Chair's introduction

Dr Yoryos Lyratzopoulos, University of Cambridge

#### 13:45 - 13:55 Improving early diagnosis of lung cancer - the impact of regional and national public awareness campaigns

Lucy Ironmonger, Cancer Research UK

#### 13:55 - 14:05 Assessing the impact of the national early diagnosis initiative in primary care using four early diagnosis metrics

Carolyn Gildea, Knowledge and Intelligence Team (East Midlands), Public Health England

#### 14:05 - 14:15 The primacy of early stage cancer survival statistics in reducing emotional barriers to help-seeking behaviour in lower socioeconomic status populations

Susan Cunningham-King, London Cancer

#### 14:15 - 14:25 Q&A

### Session 2 Variation in treatment patterns and access to specialist care

#### Earls Room

Sponsored by



#### 13:30 - 13:45 Chair's introduction

Dr Dyfed Huws, Director, Welsh Cancer Intelligence and Surveillance Unit

#### 13:45 - 13:55 Skin cancer care in England

Veronique Poirier, Knowledge and Intelligence Team (South West), Public Health England

#### 13:55 - 14:05 Resection rate, hospital procedure volume and mortality from pancreatic cancer: population-based study in England, 2005-2009

Victoria Coupland, Knowledge and Intelligence Team (London), Public Health England

#### 14:05 - 14:15 Trends in mortality after cystectomy for bladder cancer in England 1998-2010

Luke Hounsome, Knowledge and Intelligence Team (South West), Public Health England

#### 14:15 - 14:25 Q&A

# Programme: Monday 9 June

## Session 3 **Cancer intelligence to support local and national service provision**

### Dukes Room

Sponsored by



- 13:30 - 13:45 **Chair's introduction**  
Bob Park, Lay Representative
- 13:45 - 13:55 **Frequency and characterisation of outpatient attendances before and after cancer diagnoses**  
Sarah Miller, National Cancer Intelligence Network, Public Health England
- 13:55 - 14:05 **Reporting of recurrent and metastatic breast cancer on CWT varies by Trust**  
Catherine Lagord, Knowledge and Intelligence Team (West Midlands), Public Health England
- 14:05 - 14:15 **How often is colorectal cancer diagnosed within five years of a previous colonoscopy in the West Midlands?**  
Timothy Evans, Knowledge and Intelligence Team (West Midlands), Public Health England
- 14:15 - 14:25 **Q&A**

## Session 4 **Outcomes for young people with cancer - matching commissioning with the evidence**

### Churchill and Gladstone Rooms

- 13:30 - 13:35 **Chair's introduction**  
Dr Martin McCabe, Clinical Senior Lecturer in Paediatric Oncology, University of Manchester
- 13:35 - 13:45 **Paediatric clinical outcomes research - UK policy and the role of the European Network of Cancer Research in Children and Adolescents**  
Professor Kathy Pritchard-Jones, London Cancer
- 13:45 - 13:55 **Survival trends for young cancer patients in the UK - the good and the bad**  
Tony Moran, Knowledge and Intelligence Team (North West), Public Health England
- 13:55 - 14:05 **Referral to and from specialist centres - how widespread is the practice?**  
Catherine O'Hara, The Christie NHS Foundation Trust
- 14:05 - 14:15 **Clinical trial accrual rate in young cancer patients - a metric of short-term relevance?**  
Tony Moran, Knowledge and Intelligence Team (North West), Public Health England
- 14:15 - 14:25 **Q&A**

# Programme: Monday 9 June

## 14:30 - 15:25 Parallel sessions 2

### Session 1 Living with and beyond cancer

#### Queens Hall

- 14:30 - 14:45 **Chair's introduction**  
Heather Monteverde, General Manager for Northern Ireland,  
Macmillan Cancer Support
- 14:45 - 14:55 **Non-cancer cause-specific mortality among 219,901 survivors of teenage and young adult cancers - the Teenage and Young Adult Survivor Study (TYACSS)**  
Raoul Reulen, University of Birmingham
- 14:55 - 15:05 **A method of identifying stage IV cancer**  
Matthew Francis, Knowledge and Intelligence Team (West Midlands), Public Health England
- 15:05 - 15:15 **Using routine prescribing data to identify comorbidities in ovarian cancer patients**  
Christopher Brown, National Cancer Registry Ireland
- 15:15 - 15:25 **Q&A**

### Session 2 Supporting clinical trials and observational research

#### Earls Room

- 14:30 - 14:45 **Chair's introduction**  
Professor Judith Bliss, Institute of Cancer Research
- 14:45 - 14:55 **Improving the effectiveness of multidisciplinary team meetings: assessing the predictors of decision implementation**  
Caoimhe Nic a Bhaird, University College London
- 14:55 - 15:05 **BiobankLink - automating data exchange between the cancer registry and human biosample collections**  
Brian Shand, National Cancer Registration Service, Public Health England
- 15:05 - 15:15 **The feasibility of measuring recurrence free survival from routine data sources: an example for head and neck cancer**  
Matt Williams, Imperial College Healthcare NHS Trust
- 15:15 - 15:25 **Q&A**

Sponsored by



# Programme: Monday 9 June

## Session 3 Patient experience and reported outcomes

### Dukes Room

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MACMILLAN.**  
CANCER SUPPORT

- 14:30 – 14:45 **Chair's introduction**  
Professor Jane Wardle, Cancer Research UK Health Behaviour Centre
- 14:45 – 14:55 **Health-related quality of survival after cancer in England: a patient-reported outcomes study of 21,000 individuals diagnosed with colorectal cancer**  
Adam Glaser, University of Leeds
- 14:55 – 15:05 **Persistent physical side-effects following treatment for prostate cancer. Results from an all-Ireland population-based study of medium and long term survivors**  
Heather Kinnear, Queen's University Belfast
- 15:05 – 15:15 **How helpful is the National Cancer Patient Experience Survey (NCPES) in driving rapid service improvement?**  
Jo Marsden, King's College London
- 15:15 – 15:25 **Q&A**

## Session 4 Colorectal cancer outcomes and quality of care

### Churchill and Gladstone Rooms

- 14:30 – 14:45 **Chair's introduction**  
Professor Paul Finan, St James's University Hospital
- 14:45 – 14:55 **Population-based changes in treatment and overall survival for squamous cell cancer of the anus - evidence of impact of ACT1?**  
Amy Downing, University of Leeds
- 14:55 – 15:05 **Rates of post-colonoscopy colorectal cancer (PCCRC) are significantly affected by methodology but are nevertheless declining in the NHS**  
Eva Morris, University of Leeds
- 15:05 – 15:15 **Development of a composite indicator for the quality of colorectal cancer care delivered in NHS Trusts across England**  
Faye Samy, Knowledge and Intelligence Team (Northern and Yorkshire), Public Health England
- 15:15 – 15:25 **Q&A**

## 15:30 – 15:55 Tea, exhibition and poster viewing

### Kings Suite

# Programme: Monday 9 June

16:00 - 17:30

## Plenary 2

### **“Show me the data!” - information and intelligence for your ovarian cancer service**

**Queens Hall**

*The session will focus on the current issues affecting the delivery of ovarian cancer services and further explore the information, intelligence and research that enables service providers and practicing clinicians to provide high quality, patient-centred care to ovarian cancer patients.*

16:00 - 16:10

### **Chair's welcome and introduction**

Annwen Jones, Chief Executive, Target Ovarian Cancer

16:10 - 16:25

### **Ovarian cancer in the UK: the emerging picture**

Dr Andy Nordin, Chair, NCIN Gynaecological Cancers Site Specific Clinical Reference Group

16:25 - 16:40

### **Short-term ovarian cancer mortality in and across England**

Jason Poole, Associate Director, Knowledge and Intelligence Team (East Midlands), Public Health England

16:40 - 16:55

### **Improving cancer services by commissioning pathways – the increasing value of data**

Dr Rob Gornall, Clinical Director, Cancer Services, West Midlands Strategic Clinical Network

16:55 - 17:10

### **Robust data - the value to patients and patient organisations of the NCIN**

Louise Bayne, Chief Executive Officer, Ovacome

17:10 - 17:30

### **Q&A**

18:45 - 19:25

## **Networking, exhibition and poster viewing**

**Kings Suite**

19:30

## **Conference dinner and poster prize awards**

**Palace Suite**



# Plenary 1

**Harnessing the power of information to deliver quality and innovation in cancer surveillance, services and outcomes**

## **Ensuring everyone stands the best chance of surviving breast cancer**

### **Kris Hallenga**

Founder, CoppaFeel!

Having studied a HND in travel and tourism, Kris's dreams of scaling the world looking for adventure started with a six month placement at a travel company in Beijing. Learning a new language, culture, meeting new faces, experiencing new places, did not prepare her for what was to be a far bigger challenge - a secondary breast cancer diagnosis.

Cast straight into the next chapter of her life, Kris entered a frightening territory that she knew nothing about. She went from believing she was a normal healthy 23 year old, to facing a boobless and hairless existence. But why was it that she got cancer? And why had she been so naive? Was she the only one? No.

Kris started her crusade to ensure that this wasn't to happen to any other young woman in Britain and just two months following her diagnosis; whilst she still underwent treatment, her charity CoppaFeel! was born.

Kris leads this unique breast cancer awareness charity with the aim to reduce the incidence of late detection or misdiagnosed breast cancer. Approaching its fifth birthday, Kris and CoppaFeel! have successfully reached out to millions of women in the UK and are beginning to save lives. Kris' recent BBC3 documentary told her incredible story and launched her drive to get cancer education into all schools as a statutory requirement.

After an incurable diagnosis, Kris is not cancer free – and never will be. But she's keeping as well as she can. And whenever she's not in the presence of doctors, she's pouring her heart, soul and a truckload of kick-ass into making a success of CoppaFeel!, not only refusing to let cancer wreck her party, but refusing to let it ruin yours too.

## **Cancer - a public health perspective**

### **Professor John Newton**

Chief Knowledge Officer, Public Health England

If we are to make a difference to outcomes we must prevent cancer, diagnose it earlier, or treat it better. Scientific advances are transforming the field of cancer diagnostics and therapy and we need to bring the same innovation and drive to prevention.

A third of the most common cancers in the UK could be prevented through improving diet, maintaining a healthy body weight and being physically active but of course smoking still tops the list as the most important preventable cause of cancer. The same risk factors that are linked to cancer also drive the UK's other major causes of death and disability.

We are lucky in this country to have high-quality cancer screening programmes for breast, cervical and bowel cancer – programmes that are continually enhanced to improve their impact. We also are beginning to see the impact of the 'Be Clear on Cancer' campaigns to raise public awareness of symptoms;

# Plenary 1

Cancer intelligence has made a real difference to improving cancer outcomes in this country. We already hold some of the best data in the world on cancer and the National Cancer Intelligence Network (NCIN), now operated by Public Health England, has made great strides in driving new insight out of this data. We have also established a single National Cancer Registration Service for England, which draws data from clinical and other services along the patient pathway. This allows the data from screening, diagnostic and treatment services to be linked with outcomes data – including outcomes as reported by patients.

There is a lot more to do for the future. For example, we must understand better, and help address, patient and clinical behaviours that have a direct impact on earlier diagnosis and prevention. By collecting data on cancer therapies received, in a new Systemic Anti-Cancer Therapy (SACT) data set, we are also providing an invaluable resource for the NHS and industry to assess how these expensive but powerful drugs are being used.

The NCIN will remain an extremely important function within Public Health England and will benefit from being part of a much larger public health organisation.

## Progress on the delivery of optimal care for cancer patients in the new NHS

### **Sean Duffy**

National Clinical Director for Cancer, NHS England

One year on from NHS transition, the National Clinical Director for Cancer, Dr Sean Duffy, will reflect upon how the new commissioning landscape aims to improve outcomes for all cancer patients and the progress made on the Cancer Reform Strategy's ambition to save an additional 5,000 lives every year by 2014/15.

The National Clinical Director for Cancer will focus on:

- Tackling advanced stage at diagnosis and delayed diagnosis;
- Variations in access to treatment;
- Measures of patient experience and of the quality of care.

# Parallel Sessions 1

## Prevention, screening and early diagnosis

### Improving early diagnosis of lung cancer - the impact of regional and national public awareness campaigns

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#### Background

Lung cancer is the most common cause of cancer death in the UK. The long-term survival of lung cancer has not improved greatly in recent years and rates in the UK are worse than many other countries.<sup>[1]</sup> The Department of Health (DH) funded the Be Clear on Cancer campaign aiming to raise public awareness of persistent cough as a lung cancer sign/symptom.

#### Method

The campaign ran nationally in England 8 May - 30 June 2012 following a regional pilot in 2011. Data were collected on a number of metrics including: public awareness of lung cancer symptoms; presentations of persistent cough to GPs; urgent GP referrals for suspected lung cancer; diagnosis, staging and treatment in secondary care; and one-year survival (regional pilot only). Differences between campaign months and a pre-campaign period were analysed and compared to a control when possible.

#### Results

Following both campaigns, public awareness of persistent cough as a sign/symptom of lung cancer increased, as did the number of: patients presenting to GPs with a persistent cough; urgent GP referrals for suspected lung cancer; and lung cancers diagnosed. Most encouragingly, for the national campaign there was a 3.6 percentage point increase ( $p < 0.001$ ) in the proportion of non-small cell lung cancers diagnosed at an early stage and a 2.3 percentage point increase ( $p < 0.001$ ) in the surgical resection rate for patients seen during campaign months in 2012 compared to the same months in 2011, with no evidence these proportions changed during the control period ( $p = 0.105$  and  $p = 0.425$ ).

#### Conclusions

The data are the first to show a shift in stage distribution at diagnosis following a public awareness campaign for any cancer. It is reasonable to expect that the increase in resection rate will lead to improved long-term lung cancer survival rates.

#### References

<sup>[1]</sup> Coleman MP, Forman D, Bryant H, et al. Cancer survival in Australia, Canada, Denmark, Norway, Sweden, and the UK, 1995-2007 (the International Cancer Benchmarking Partnership): an analysis of population-based cancer registry data. *Lancet*, 2011;377:127-138.

# Parallel Sessions 1

## Prevention, screening and early diagnosis

### Assessing the impact of a national early diagnosis initiative in primary care, using four early diagnosis metrics

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#### Background

The NAEDI/Cancer Networks Supporting Primary Care programme is a national initiative that, since 2010, has supported primary care with the aim of understanding and improving current referral practices for suspected cancer. The programme consists of a complex package of initiatives, with this analysis focusing on four activities hypothesised to have an early impact on referral practice: clinical audit, significant event analysis, development of practice plans and use of risk assessment tools.

#### Method

Practice level data on participation in NAEDI activities was collected and used with Cancer Waiting Times (CWT) data, to consider urgent GP referrals for suspected cancer (Two Week Wait – 2ww), and Hospital Episode Statistics (HES) data. Analysis considered changes, from 2009 to current, in four early diagnosis metrics: age-standardised referral rate, conversion rate (percentage of 2ww referrals subsequently diagnosed with cancer), detection rate (percentage of CWT recorded cancers diagnosed following a 2ww referral) and emergency presentation rate (percentage of HES identified cancers first presenting as an emergency).

#### Results

In the period under study, the all-England referral rate increased by 29%, the conversion rate fell by 1.3 percentage points to 10.2%, the detection rate rose 3.9 percentage points to 47.8% and emergency presentation rates fell 2.3 percentage points to 21.1%. Overall, 38% (2,495) of GP practices were involved in at least one of these four activities. Practices engaging in any of four activities had a significantly higher increase in referral rate, with reduced between-practice variation. These practices also had a greater, though not significant, increase in detection rate. There were no significant differences in conversion or emergency presentation rates.

#### Conclusions

Against a background change in referral practices for suspected cancer, we found that specific primary care initiatives promoted by NAEDI and Cancer Networks had an additional and positive impact on practice.

#### Acknowledgements

This analysis was funded by NCAT, as part of the University of Durham led evaluation of the Cancer Networks Supporting Primary Care programme.

# Parallel Sessions 1

## Prevention, screening and early diagnosis

### The primacy of early stage cancer survival statistics in reducing emotional barriers to help-seeking behaviour in lower socioeconomic status populations

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#### Background

Camden Clinical Commissioning Group has commissioned London Cancer (UCL Partners) to undertake a multidisciplinary intervention to reduce avoidable deaths resulting from the late diagnosis of cancer in the borough. The three-year integrated programme, commencing in April 2014, will use social marketing, primary care professional development and cancer pathway service improvements to address delays in cancer presentation, referral, diagnostic tests and treatment. London Cancer commissioned UCL/City University to undertake a six-month research programme, which included the identification of key messages most likely to overcome common perceived emotional barriers to early presentation within the lower SES population. This key target group is characterised by higher emotional barriers to early presentation, compared with the general population.

#### Method

The short-term impact of seven different message sets on emotional barriers to help-seeking were assessed in a lower SES (< degree-level education) sample of 49 people recruited from the London Borough of Camden. The messages related to fatalism, communication embarrassment, body embarrassment, consideration of loved ones, not wanting to waste the GP's time, fear of cancer and fear of cancer treatment. Emotional barriers that were measured included the two most significant (CAM National Baseline Report): 'being scared of what the doctor might find' and 'worries about wasting the GP's time'. Scores were measured before and after exposure to each message. Data were analysed using ANOVA to compare the pre and post-message scores.

#### Results

Comparing post-message scores with baseline scores, each message set lowered at least one of the emotional barriers. The message set with a large effect size on 'being scared of what the doctor might find' (power analysis:  $F(1,46)=8.68$ ,  $p=0.005$ ,  $\eta^2=0.159$ ) and 'worries about wasting the doctor's time' (power analysis:  $F(1,46)=6.66$ ,  $p=0.008$ ,  $\eta^2=0.143$ ) – was message set 6 (survival statistics for early stage cancers). The message set with a large effect size on 'being scared of what the doctor might find' (power analysis:  $F(1,45)=7.54$ ,  $p=0.009$ ,  $\eta^2=0.144$ ) was message set 1 (general early stage cancer survival message).

# Parallel Sessions 1

## Variation in treatment patterns and access to specialist care

### Skin cancer care in England

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#### Background

Skin cancers – Non Melanoma Skin Cancer (NMSC) and Malignant Melanoma (MM) are the most common cancers in England. The treatment and consequent cost related to NMSC is often considered insignificant compared to MM. We considered the trends in numbers of day case and inpatient treatments for skin cancer during a five year period in England, including procedures used, specialties involved and costs.

#### Method

Details of admissions between 2007 and 2011 for a diagnosis of skin cancer (ICD 10 code C43 or C44) were extracted from the inpatient hospital episode statistics (HES). We identified the procedures used and the specialties involved. Healthcare Resources Group (HRG) codes were used to estimate the costs involved. NMSC admissions were matched to the National Cancer Data Repository to determine their morphology: Squamous Cell Carcinoma (SCC) or Basal Cell Carcinoma (BCC).

#### Results

There has been a significant increase in hospital admissions between 2007 and 2011 for NMSC (76,528 vs. 109,333) and MM (11,157 vs. 14,475). The main procedures recorded in 2011 were surgical excisions both for NMSC (78%) and MM (71.5%). Mohs surgery was mainly undertaken for BCC. Over 16,000 flaps and grafts were undertaken for NMSC in 2011 compared to 1,766 for MM. There was some use of amputation for MM and SCC. Most day cases were managed by Dermatologists and Plastic Surgeons and the latter represented the main specialty involved with inpatient care. Dermatologists' involvement with day cases increased between 2007 and 2011 (3.9% for NMSC and 5.3% for MM) but decreased for Plastic Surgeons (-3.3% and -5.9%). The overall cost of inpatient treatment in England in 2011, based on our data, was £81,114,834 for NMSC and £14,355,797 for MM.

#### Conclusions

We have provided some evidence for the amount of surgery and consequent costs involved in the treatment of NMSC compared to MM. This is an under-estimate as treatment also takes place on an out-patient basis. Given the predicted increase in incidence of NMSC over the coming years in an ageing population, it is essential to improve assessment of the level of care and cost involved, as well as increase public awareness of the disease.

# Parallel Sessions 1

## Variation in treatment patterns and access to specialist care

### Resection rate, hospital procedure volume and mortality from pancreatic cancer - Population-based study in England, 2005-2009

**Victoria Coupland**<sup>1</sup>, Margreet Lüchtenborg<sup>1,2</sup>, Julie Konforton<sup>1</sup>, Ruth Jack<sup>1</sup>, Sharma Riaz<sup>1</sup>, Hemant Kocher<sup>3</sup>, William Allum<sup>4</sup>, Henrik Møller<sup>2</sup>

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#### Background

Our previous studies on oesophageal, gastric and lung cancer found lower mortality among patients resident in geographical areas with higher resection rates and lower mortality among patients resected in hospitals that carry out a greater number of operations per year. Centralisation of surgical services is thought to be particularly applicable to high-risk procedures such as pancreatic cancer surgery. This study aimed to assess the association between resection rates, hospital procedure volume and mortality rates in pancreatic cancer patients in England.

#### Method

Patients diagnosed with pancreatic cancer between 2005 and 2009 were identified from a national population-based cancer registration and Hospital Episode Statistics linked dataset. Cox regression analyses were used to assess all-cause mortality according to geographical resection quintile and hospital procedure volume, adjusting for sex, age, socioeconomic deprivation and Charlson comorbidity score.

#### Results

31,973 patients were diagnosed with pancreatic cancer, 2,580 (8.1%) of which underwent surgery. Increasing resection rates were associated with a lower mortality (p-trend<0.001), with a hazard ratio (HR) of 0.82 95%CI [0.79-0.85] in the highest compared with the lowest geographical resection quintile. Further adjustment for socioeconomic deprivation and comorbidity did not change this finding (p-trend<0.001, HR=0.82 95%CI [0.79-0.85]). There was a suggestion of lower postoperative mortality in patients operated in higher volume hospitals (p-trend=0.155, HR=0.92 95%CI [0.81-1.04] in hospitals carrying out 30+ compared with <15 operations a year, fully adjusted model).

#### Conclusions

Higher geographical resection rates were associated with lower mortality in pancreatic cancer patients. Pancreatic cancer survival could be increased if more patients underwent surgical resection, although further work needs to be done to assess the relationship between resection rate and survival. It is feasible that this study was underpowered to show a significant association between hospital procedure volume and postoperative mortality in pancreatic cancer patients due to the small number of patients that underwent surgery.

# Parallel Sessions 1

## Variation in treatment patterns and access to specialist care

### Trends in mortality after cystectomy for bladder cancer in England 1998-2010

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#### Background

Cystectomy is a major treatment for muscle-invasive bladder cancer, and its use has increased by 50% between 1998-2000 and 2008-10. In 2010 about 18% of bladder cancer patients had a cystectomy. One aim of bladder cancer service reorganisation was to improve outcomes of surgery, but there is little evidence as to whether there was any effect.

#### Method

All bladder cancer patients from the National Cancer Data Repository were selected and linked to Hospital Episode Statistics to identify cystectomies. Date of death was used to calculate crude and relative survival, and age at operation and place of death were extracted. Stage data was too incomplete to analyse. Trends in survival were tested using Joinpoint software. Data on cystectomies were available for 1998 to 2010.

#### Results

The number of radical cystectomies undertaken has increased by 50% in the last decade, yet there has been a linear and continuing reduction in short and medium-term mortality. 30 day mortality reduced from 5% to 2%, 90 day mortality from 10% to 5% and death without discharge from 4% to 2%. The effect has been particularly noticeable in the eldest patients, where 30 day mortality reduced from 11% to 3% in those aged 80 and over, and from 8% to 3% in those aged 70-79. All cause survival at 1 and 5 years improved by several percent, but bladder cancer specific survival did not. The number of trusts performing cystectomy has fallen by 40% with the mean number of procedures rising from 6 to 24.

#### Conclusions

The reduction in short-term and medium-term mortality seen over the last decade is good news for patients, especially given the increasing numbers of cystectomies being performed. Trend analysis does not indicate that service reorganisation caused a step-change in mortality reduction, but this could be due to a protracted period of reconfiguration. There have been a number of initiatives over the time period studied, including enhanced recovery, neo-adjuvant chemotherapy and fellowship training. These will have all contributed to the increased survival.

# Parallel Sessions 1

## Cancer intelligence to support the local and national service provision

### Frequency and characterisation of outpatient attendances before and after cancer diagnosis

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<sup>1</sup>National Cancer Intelligence Network, Public Health England

#### Background

In 2012/13 there were 15 million inpatient admissions to English NHS hospitals across all disease types. There were 76 million outpatient attendances. Data in the Hospital Episode Statistics (HES) system generated during in-patient admissions of cancer patients have been reasonably well explored in recent years and are widely reported. In contrast the frequency and nature of outpatient attendances for persons diagnosed with cancer is much less well known or understood. While diagnostic and procedural data in the outpatient HES dataset is largely incomplete there remain a number of data items containing useful information about cancer patient pathways.

#### Method

Cases of cancer in the National Cancer Data Repository diagnosed up to the end of 2010 have recently been linked to outpatient HES data using a standard algorithm. Outpatient records were examined for 473,718 residents of England diagnosed between 2008 and 2010 with cancer of the lung; colorectum; breast; ovary or prostate, or with melanoma. Outpatient attendance records were available for 2006 to 2012 and were characterised according to patient sex, age at diagnosis, cancer type, provider trust, first/followup attendance status, referral source, and consultant speciality.

#### Results

The patient cohort had 1.1 million attendances between one and two years prior to diagnosis, 6.2 million attendances in the year following diagnosis and 2.5 million attendances in the year after that (albeit in a smaller cohort due to patient mortality). The median patient age is 73 in the period prior to diagnosis and drops to 61 and 62 in the year following diagnosis and the one after that. The ratio of first attendances to follow up attendances was approximately 1:3 prior to diagnosis, 1:4 in the year after diagnosis, and 1:6 in the year following.

#### Conclusions

Demand for cancer services should be understood as an addition, though a significant one, to patients' pre-existing health needs. Linked data currently available on outpatient services at trust or CCG level has the potential to greatly improve the monitoring and commissioning of services and reveal a great deal about treatment pathways as they actually occur in patient care.

# Parallel Sessions 1

## Cancer intelligence to support the local and national service provision

### Reporting of recurrent and metastatic breast cancer on CWT varies by Trust

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#### Background

A joint pilot between Breast Cancer Care, the National cancer Intelligence Network and the Association of Breast Surgery to collect data on recurrent and metastatic breast cancer demonstrated that 81% of the patients identified by 15 Breast Multi-Disciplinary Teams were also flagged through the Cancer Waiting Times (CWT) process. Since April 2012, NHS Trusts have been required to submit information on patients diagnosed with a new recurrence or metastatic disease through the CWT process; the submission of this information has been monitored by the project team.

#### Method

CWT data submitted by West Midlands Trusts during Apr-Dec 2012 were compared with the data held by the region's cancer registration service, which records diagnosis and treatment events for the whole breast cancer pathway. England level figures were obtained by counting the number of patients flagged on CWT as diagnosed or treated for breast cancer recurrence during 2012/13. To estimate the likelihood that a Trust would come into contact with this cohort of patients, the number of recurrences on CWT in each Trust was compared with the number of primary breast cancers diagnosed annually by the Trust.

#### Results

West Midlands: 80% of patients identified by the registration service as having regional recurrence or metastatic breast disease had at least one CWT record within the same time frame, and 40% were on CWT with a diagnosis and/or treatment for recurrence. Agreement between registration and CWT data on the presence of secondary disease varied between Trusts from 2% to 67%, with some Trusts clearly failing to submit all of their recurrence and metastatic breast cancers through CWT. England: 7,176 patients were flagged on CWT as having been diagnosed or treated for breast cancer recurrence during 2012/13. Taking the 133 largest Trusts (100+ primaries/ year), the ratio "recurrences reported through CWT/number of primaries diagnosed" varied from 0.004 to 0.676, again suggesting that some Trusts have yet to implement complete recording of recurrences on CWT.

#### Conclusions

Some NHS Trusts appear not be submitting information on recurrence/metastatic disease through the CWT process. This failure to submit mandatory data should be followed up actively by NHS England Local Area Teams.

# Parallel Sessions 1

## Cancer intelligence to support the local and national service provision

### How often is colorectal cancer diagnosed within 5 years of a previous colonoscopy in the West Midlands?

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#### Background

Published literature suggests up to 9% of patients with colorectal cancer (CRC) are diagnosed within three years of having had a colonoscopy which did not detect cancer. We have investigated how often post colonoscopy colorectal cancer (PCCRC) occurs in the West Midlands and the associated risk factors.

#### Method

Computerised colonoscopy records from 10 Trusts up to the end of 2009 were retrieved and linked to cancer registration data held by the Public Health England Knowledge and Intelligence Team (West Midlands) in order to identify CRC registrations. Subjects undergoing colonoscopy 3 months to five years before diagnosis were identified as PCCRC cases and those with no colonoscopy 3 months to five years before diagnosis served as controls. Variations by age, gender, deprivation index, CRC site and stage at diagnosis on PCCRC were examined by logistic regression analysis.

#### Results

Over 200,000 records were submitted for matching with 4,115 records being identified in the cancer registration dataset as cancers diagnosed at or following endoscopy. Colon (63%) and rectal cancer (30%) accounted for the majority of cancers. Of the matched cases, 3,659 were used as controls with 456 cases being classed as possible missed cancers. Female (OR 1.26), right sided tumours (OR 1.54), unspecified/overlapping tumours (OR2.79), and the very elderly (OR 2.00) were associated with significantly higher likelihood of possible missed CRC diagnoses; deprivation and stage at diagnosis was not associated with missed cancer diagnoses.

#### Conclusions

Female and elderly patients are more likely to have incomplete colonoscopy procedures as they do not tolerate these investigations well. Further investigation needs to be undertaken to assess the impact of incomplete colonoscopy as well as general fitness of patients.

# Parallel Sessions 1

Outcomes for young people with cancer - matching commissioning guidance with the evidence

Paediatric clinical outcomes research - UK policy and the role of European Network of Cancer Research in children and adolescents

Kathy Pritchard-Jones<sup>1</sup>

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*Summary unavailable at the time of print.*

# Parallel Sessions 1

## Outcomes for young people with cancer - matching commissioning guidance with the evidence

### Survival trends for young cancer patients in the UK - the good and the bad

Charles Stiller<sup>1</sup>, Catherine O'Hara<sup>2</sup>, Nicole Diggins<sup>1</sup>, **Tony Moran<sup>3</sup>**

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#### Background

Recent studies show survival of young people with cancer to be worse in the UK than in neighbouring countries. We set out to put these findings in a historical context.

#### Method

Actuarial survival rates were calculated for children aged under 15 at diagnosis in the National Registry of Childhood Tumours, with follow-up to the end of October 2012. For all cancers combined and for the major disease groups the analyses were population-based for children in Great Britain diagnosed during 1971-2010. For more detailed diagnostic subgroups, the analyses refer to children diagnosed during 1978-2010 and registered from recognised principal treatment centres. For TYA patients aged 15 to 24 diagnosed between 1992 and 2006 and followed up to the end of December 2011, UK 5-year relative survival rates were estimated and compared between the five-year periods 1992-1996, 1997-2001 and 2002-2006. Survival was estimated for each cancer type and time period for the whole population and separately by gender.

#### Results

Five-year actuarial survival in Great Britain improved for all childhood cancers from 40% (1971-1975) to 82% (2006-2010) (Chi-square for trend 538.7,  $p < 0.001$ ). Most cancers showed improvements during the period, many continuing to improve in the most recent five-year period. However, in analyses by more detailed diagnostic subgroup, survival for some subgroups was static, notably high-grade astrocytomas and Ewing sarcoma. There was a similar overall upwards trend for TYA patients from 75.7% in 1992-96 to 82.2% in 2002-06. However, while the outcome of most cancers improved there were notable exceptions, with no improvement in survival for carcinomas or germ cell tumours of the ovary, and non-significant increases for several types of cancer including rhabdomyosarcoma and osteosarcoma. Several cancers showed gender-specific changes, with significant survival improvements in men but not women for Hodgkin's lymphoma, Ewing sarcoma and rhabdomyosarcoma and improvements in women but not men for soft tissue sarcoma.

#### Conclusions

The survival of childhood and young adult cancer patients in the UK has shown overall steady improvements in recent decades. However, for some cancers survival has remained static, both in short- and long-term survival.

# Parallel Sessions 1

## Outcomes for young people with cancer - matching commissioning guidance with the evidence

### Referral to and from specialist centres - how widespread is the practice and what is the outcome?

Tony Moran<sup>1</sup>, **Catherine O'Hara**<sup>2</sup>, Anita Bayne<sup>3</sup>, Charles Stiller<sup>3</sup>

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#### Background

Childhood cancer has been managed by specialist principal treatment centres (PTCs) for several decades. Variations have developed over time in the extent to which PTCs share care with local paediatric units. Referral of teenage and young adult (TYA) patients to regional TYAMDTs, although mandated by national guidance in 2005, is less established. We evaluated the relationships between levels of shared care and survival outcomes in children and determined the proportion of older patients referred to a specialist TYAMDT.

#### Method

Paediatric PTCs were assigned a level of shared care: 1) little or none, 2) moderate, 3) extensive. Survival was analysed by level of shared care. Referral to a TYA PTC was evaluated by submission of a TYAC enhanced cancer registration form, a proxy for discussion at a TYAMDT. Cancer registrations from the calendar years 2009-2010 were categorised by demographics and by presence of a matched TYAC notification. For registrations without a matching TYAC notification, place of treatment was determined from the Cancer Waits dataset.

#### Results

Eight paediatric PTCs practiced extensive shared care throughout the study period. For the remainder, there was a steady increase in the number of PTCs practising moderate shared care during the study period. Neither 1-year nor 5-year survival varied significantly by the level of shared care for all cancers combined, broad diagnostic group or prognostic group.

Referral to a TYA MDT varied significantly by age, tumour type and area of residence. Overall, 62% of 15 to 18 year olds and 34% of 19-24 year olds were referred to an age-specific MDT. Referral to a TYA MDT also varied significantly by cancer network. TYA patients not referred to a TYA PTC were treated by over 170 hospitals.

#### Conclusions

The current practice of management of children through shared care arrangements with local units has no measurable effect on survival outcomes. In contrast, despite NICE guidance that the management of TYA cancer patients should be either directed by or agreed with an age-specific MDT, only a minority of patients are currently referred. The prognostic impact of this finding is not yet known.

# Parallel Sessions 1

## Outcomes for young people with cancer - matching commissioning guidance with the evidence

### Clinical trial accrual rate in young cancer patients - a metric of short-term relevance?

**Tony Moran**<sup>1</sup>, Maria Khan<sup>1</sup>, Debasree Purkayastha<sup>1</sup>

<sup>1</sup>Knowledge and Intelligence Team (North West), Public Health England

#### Background

Approximately one in seven teenagers and young adults (TYA) with acute lymphoblastic leukaemia (ALL) in the UK dies within a year of diagnosis. Almost all patients with ALL are eligible for recruitment into the relevant clinical trial, which from 2003 to 2011 was UKALL2003. The maximum eligible age for this trial changed during 2006-2007, firstly from 17 to 19 years and then to 24 years. We explored the relationship between participation in this trial and short-term outcome.

#### Method

Patients on the UKALL2003 database were record-matched against the National Cancer Data Repository for England for 2003-2010. The percentage of patients taking part in the study was calculated. One-year relative survival with 95% confidence intervals (CI) and the number of deaths that occurred each month in the year following diagnosis were calculated for patients diagnosed in 2006-2010 who (a) participated and (b) did not participate in UKALL2003.

#### Results

65% of 15-19 year olds diagnosed during 2006-2010 were found to have participated in UKALL2003 compared with 43% of 20-24 year olds diagnosed in 2008-2010. One-year survival for those aged 15-24 years and diagnosed in 2006-2010 was 91.3% (95% CI: 86.2% - 94.6%) for the 184 patients in the trial and 79.4% (95% CI: 72.3% - 84.9%) for the 160 patients not in the trial. 33 (21%) patients not in the trial died in the first year compared with 16 (9%) in the trial. 19 (12%) not in the trial died in the first three months after diagnosis compared with only 5 (3%) in the trial.

#### Conclusions

One-year survival is considerably higher in young ALL patients recruited to UKALL2003 compared to those treated outside of the trial, with deaths in the three months following diagnosis being more common in those not in the trial. The reasons for this are being explored.

#### References

<sup>[1]</sup>T Moran, D Purkayastha, C O'Hara. Pattern of deaths in the year following diagnosis in cancer patients aged 15-24 years in England, NCIN April 2013

# Parallel Sessions 2

## Living with and beyond cancer

### Non-cancer cause-specific mortality among 219,901 survivors of teenage and young adult cancer - the teenage and young adult cancer survivor study (TYACSS)

Raoul Reulen<sup>1</sup>, David Winter<sup>1</sup>, Clare Frobisher<sup>1</sup>, Michael Hawkins<sup>1</sup>

<sup>1</sup>University of Birmingham

#### Background

Although five-year survival after cancer in teenage and young adulthood has improved substantially over the last few decades, there remains considerable uncertainty about the excess long-term cause-specific mortality among survivors of cancer in teenage and young adulthood.

#### Method

In this, to our knowledge, largest ever population-based cohort study of survivors of teenage and young adult cancer we quantified the non-cancer cause-specific mortality in 219,901 5-year survivors of cancer diagnosed age 15-39 years (1971-2006) in England and Wales. Standardised mortality ratios (SMRs) were calculated to investigate non-cancer cause-specific mortality by type of first primary cancer.

#### Results

Most common first primary cancers were: breast carcinoma (N=34,700), non-melanoma skin cancer (N=26,452), testicular cancer (N=23,682), melanoma (N=21,469), Hodgkin's Lymphoma (HL) (N=116,335) and Central Nervous System (CNS) tumours (N=15,200). Overall mortality due to non-cancer causes of death was substantial (SMR $\geq$ 2.5 & observed deaths $>$ 50) after HL (SMR=2.6, 95%CI: 2.4-2.7) and CNS tumour (SMR=2.6, 95%CI: 2.4-2.8) survivors. Excess mortality due to circulatory disease was substantial after HL (SMR=3.3, 95%CI: 3.1-3.7) and CNS tumour (SMR=2.5, 95%CI: 2.2-2.8). Substantial excesses in mortality due to respiratory disease were observed after leukaemia (SMR=6.5, 95%CI:4.6-9.1), lung carcinoma (SMR=4.2, 95%CI:2.8-6.5), CNS tumour (SMR=3.9, 95%CI: 3.2-4.7) and HL (SMR=3.6, 95%CI: 3.0-4.4). The SMR for endocrine disease was substantially increased for CNS survivors (SMR=3.7, 95%CI: 2.5-5.5). Deaths due to genitourinary disease were substantially increased after HL (SMR=4.1, 95%CI:2.4-7.1), CNS tumour (SMR=4.1, 95%CI:2.5-6.9), cervical cancer (SMR=4.4, 95%CI:3.2-6.2) and other genitourinary carcinoma (SMR=4.7; 95%CI:2.9-7.8) survivors. Mortality due to external causes was significantly elevated, although not substantial, for CNS tumour (SMR=1.5, 95%CI:1.2-1.9) survivors.

#### Conclusions

These preliminary results suggest that long-term survivors of CNS tumour and HL diagnosed in teenage and young adulthood experience the largest excess risk of dying of non-cancer related causes of death. This national resource will provide a basis for a spectrum of population-based research in relation to this, internationally acknowledged, insufficiently investigated group of cancer survivors.

# Parallel Sessions 2

## Living with and beyond cancer

### A method for identifying Stage IV cancer

**Matthew Francis**<sup>1</sup>, Nicola Dennis<sup>1</sup>, Gill Lawrence<sup>1</sup>

<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England

#### Background

Sarcomas are staged according to the UICC TNM tumour staging classification. Accurate staging requires information relating to size, lymph node involvement, metastases and grade. English registry sarcoma staging data are incomplete. A method for identifying stage IV sarcomas at diagnosis, utilising Hospital Episode Statistics (HES) and the National Cancer Data Repository (NCDR) datasets is described.

#### Method

The 2010 NCDR contains the details of all malignancy diagnosed between 1990 and 2010 in England. The HES dataset contains all inpatient and day case hospital activity, including diagnoses and dates of admission and discharge, for all cancer patients admitted between 1 April 1998 and 31 March 2012. Patients who were diagnosed with bone or soft tissue sarcoma between 2000 and 2010 in England were extracted from the NCDR and linked to the HES database. Corresponding HES records were examined to identify diagnoses relating to metastatic cancer (ICD-10 cancer sites C77-C79) within four months of their sarcoma diagnosis.

#### Results

There were 4,602 new cases of bone sarcoma and 27,913 new cases of soft tissue sarcoma in England between 2000 and 2010. 20% of bone sarcoma patients and 13% of soft tissue sarcoma patients had a metastatic cancer diagnosis in HES within four months of diagnosis. There were significant differences in five-year relative survival rates across the different groups. Patients with no metastatic disease had significantly higher five-year relative survival rates than patients with metastases in both the bone and soft tissue sarcoma patient groups (64% vs 19% and 62% vs 12% respectively, 2001-2005). Metastatic rates varied significantly with cancer site and histological diagnosis. Five-year relative survival rates for patients with metastases at diagnosis were consistent with results published by SEER where complete staging data are available.

#### Conclusions

It is possible to identify patients who were diagnosed with metastatic cancer utilising the NCDR and HES. These patients have significantly lower five-year relative survival rates than patients who do not have a record of metastatic cancer. The method described provides a good proxy to identify stage IV disease at diagnosis in the absence of detailed staging data, and can be applied across other cancer sites.

# Parallel Sessions 2

## Living with and beyond cancer

### Using routine prescribing data to identify comorbidities in ovarian cancer patients

**Christopher Brown**<sup>1</sup>, Thomas Barron<sup>2</sup>, Kathleen Bennett<sup>2</sup>, Linda Sharp<sup>1</sup>

<sup>1</sup>National Cancer Registry Ireland, <sup>2</sup>Trinity College, University of Dublin

#### Background

Although certain comorbid conditions may predict treatment receipt and survival in cancer patients, most cancer registries do not routinely collect data on comorbidities. Registries increasingly have access to community prescribing data. A number of algorithms exist for estimation of comorbidities based on prescription history, including RxRisk1 (the updated Chronic Disease Score) and the number of distinct prescription classes<sup>2</sup> (DMC). We evaluated the utility of using prescribing data to identify comorbidities in ovarian cancer patients in Ireland.

#### Method

Free healthcare within the Irish public healthcare system is restricted to holders of general medical services (GMS) cards, eligibility for which is based on means-test and age. Prescription records were linked, using probabilistic matching methods, to primary ovarian cancers (ICD10 C56) diagnosed 2001-2010. Degree of comorbidities was estimated, using RxRisk and DMC, based on prescriptions in the year prior to cancer diagnosis. The scores were evaluated for prognostic value on treatment (within 12m) and overall survival using logistic and Cox regression respectively.

#### Results

2,003 (65%) of the 3,097 incident ovarian cancers had GMS prescriptions in the year prior to diagnosis. Among these women, RxRisk comorbidities with highest prevalence were: gastric acid (57%), steroid dependent diseases (53%) and pain (45%). Other common categories (>20%) were: allergy, inflammatory pain, anxiety, hypertension, liver-related and depression. The median simultaneous comorbidity categories was 4 (range 0-14). The median number of DMCs was 14 (range 1-48). The number of conditions was associated with chemotherapy receipt (unadjusted OR=1.19, 95%CI 1.14-1.23), but not cancer-directed surgery (OR=1.0, 95%CI). DMC also predicted chemotherapy receipt. RxRisk predicted survival (HR=1.04, 95%CI 1.01, 1.08) but DMC did not. Among common comorbidities, allergy, hyperlipidaemia and osteoporosis adversely affected survival. Hypertension was associated with improved prognosis.

#### Conclusions

Comorbidities can be estimated from prescribing data and have prognostic value for predicting treatment and survival in ovarian cancer.

#### Acknowledgements

Health Research Board (HRA\_HSR/2012/30).

# Parallel Sessions 2

## Supporting clinical trials and observational research

### Improving the effectiveness of multidisciplinary team meetings - assessing the predictors of decision implementation

Rosalind Raine<sup>1</sup>, **Caoimhe Nic a Bhaird**<sup>1</sup>, Penny Xanthopoulou<sup>1</sup>, Isla Wallace<sup>1</sup>, Julie Barber<sup>1</sup>, Anne Lanceley<sup>1</sup>, Alex Clarke<sup>2</sup>, Gill Livingston<sup>1</sup>, Archie Prentice<sup>3</sup>, Dave Ardron<sup>4</sup>, Miriam Harris<sup>5</sup>, Michael King<sup>1</sup>, Susan Michie<sup>1</sup>, Jane Blazeby<sup>6</sup>, Simon Gibbs<sup>7</sup>

<sup>1</sup>UCL, <sup>2</sup>The Royal Free Hospital, <sup>3</sup>The Royal College of Pathologists, <sup>4</sup>Patient and Public Involvement Representative, North Trent Cancer Research Network, <sup>5</sup>Patient and Public Involvement Representative, <sup>6</sup>University of Bristol, <sup>7</sup>Imperial College London

#### Background

Multidisciplinary team (MDT) meetings are widely used for managing cancer and other chronic diseases. However, the evidence underpinning the development of MDTs is not strong and the degree to which they have been absorbed into clinical practice varies widely. There is, therefore, a need to identify factors that promote effective MDT decision-making in terms of implementation of MDT treatment plans.

#### Method

We undertook a prospective observational study of 12 MDTs (including gynaecological, skin and haematological cancers, mental health and heart failure). We used random-effects logistic regression models to investigate the influence of MDT and patient characteristics on treatment plan implementation. MDT characteristics examined were team climate, disease type, team skill-mix (Adjusted Teachman's Index and number of professional categories), and whether comorbidities and patient preferences were considered. Patient characteristics examined were age, gender and deprivation (measured using the Index of Multiple Deprivation score).

#### Results

We observed 370 MDT meetings during which 3184 patients were discussed. 2654 patients had a treatment plan. Overall 78% of plans were implemented. Implementation was highest in gynaecological cancer and lowest in mental health teams. There was a trend for non-implementation with increasing patient deprivation (OR comparing most versus least deprived 0.60, 95% confidence interval: 0.39 to 0.91) and more professional groups present (OR = 0.75, 95% CI = 0.66 to 0.87). Implementation was more likely in MDTs with a good team climate (OR 1.07 for a 0.1 unit increase in team climate score, 95% CI = 1.01 – 1.13).

#### Conclusions

Greater multidisciplinaryity is not necessarily associated with more effective decision making. Explicit goals and procedures are also crucial. Furthermore, decision implementation should be routinely monitored to ensure the equitable provision of care. As the largest study of its kind in this area, and the first to examine and compare MDTs for cancer and other chronic diseases, this study enables identification of factors associated with treatment plan implementation that are generalisable across healthcare.

# Parallel Sessions 2

## Supporting clinical trials and observational research

### **BiobankLink: automating data exchange between the cancer registry and human biosample collections**

**Brian Shand**<sup>1</sup>, David Neal<sup>2</sup>, Geraldine Thomas<sup>3</sup>, Christopher Tomlinson<sup>3</sup>, Sarah Thorpe<sup>1</sup>, Michael Chapman<sup>4</sup>, Jessica Farrimond<sup>5</sup>, Ekaterini Blaveri<sup>7</sup>, Jem Rashbass<sup>1</sup>

<sup>1</sup>National Cancer Registration Service, Public Health England, <sup>2</sup>University of Cambridge, <sup>3</sup>Imperial College London, <sup>4</sup>Cancer Research UK, <sup>5</sup>Health Data Insight, <sup>7</sup>National Cancer Intelligence Network, Public Health England

#### **Background**

Biobanks and clinical trial collections hold clinical samples from patients, but it is very costly, complicated and time consuming to obtain follow-up patient information, such as vital status, clinical indicators, previous medical history, treatment and outcome, all of which may be crucial to correctly interpret results for research studies using these samples. We describe a project which aims to deliver: (i) a sustainable service that links biosamples held in different collections to national cancer registration records and (ii) an associated web portal that will allow potential users to search this valuable resource.

#### **Method**

The portal developed to support this service is currently based on two portal servers, each running an HTTPS web service which responds with XML messages. The first allows collection holders to register samples and donor demographics, in exchange for a randomised identifier; for security, this server is available only on the NHS-wide N3 network. Each 77 character donor identifier embeds both a 128-bit universally unique identifier (UUID) and a 160-bit cryptographic key. The NCRS matches the sample details against the registry database, to populate the second, public server's database. Collection holders contact the public server to update NCRS with sample information, and receive updated vital status and cause of death data. The per-patient cryptographic key allows the public portal to hold data in encrypted form, and decrypt it only when biobanks update sample information.

#### **Results**

After specifying the data exchange protocol, and engaging in initial proof-of-concept exchanges, two servers have been set up, trialled by collection holders at the Cambridge Biomedical Campus and the Imperial College Healthcare Tissue Bank. Following these successful feasibility pilots, the service is now available for use by other sample collection holders.

#### **Conclusions**

Linking biosamples to cancer registration data through the BiobankLink service would provide valuable patient information to annotate these samples and a searchable cancer biosample directory with up-to-date sample availability.

# Parallel Sessions 2

## Supporting clinical trials and observational research

### The feasibility of measuring recurrence free survival from routine data sources: an example for head and neck cancer

**Matt Williams**<sup>1</sup>

<sup>1</sup>Imperial College Healthcare NHS Trust

National cancer registration, linked to national death registration, allows us to measure disease incidence and overall survival. However, for patients with many types of tumour, disease progression and recurrence are key outcome measures.

The national cancer audits rely on institutions manually submitting data. Detection of disease recurrence depends on interval data submission which is labour- intensive. At a national level, there are routine data sources for hospital admissions, surgery, radiotherapy and chemotherapy. The question is therefore whether we can use these data to detect disease recurrence, and the accuracy with which we can do this.

We have developed a technique to automate the interpretation of routine datasets, allowing us to derive patterns of treatment from routinely acquired data, from which we can detect disease recurrence. In this talk, I use head and neck cancer as an example to demonstrate the use of routine data to detect disease recurrence, and discuss the promises and problems of such approaches. Although our work has focused on head and neck cancer, such approaches have the potential to be applied at a national level, across many tumour types.

# Parallel Sessions 2

## Patient experience and reported outcomes

### Health-related quality of survival after cancer in England - a patient-reported outcomes study of 21,000 individuals diagnosed with colorectal cancer

Amy Downing<sup>1</sup>, Eva Morris<sup>1</sup>, Mike Richards<sup>2</sup>, Jessica Corner<sup>3</sup>, Penny Wright<sup>1</sup>, David Sebag-Montefiore<sup>1</sup>, Paul Finan<sup>4</sup>, Paul Kind<sup>1</sup>, Charlotte Wood<sup>5</sup>, Sarah Lawton<sup>5</sup>, Richard Feltbower<sup>1</sup>, Richard Wagland<sup>3</sup>, Sally Vernon<sup>5</sup>, James Thomas<sup>5</sup>, **Adam Glaser<sup>1</sup>**

<sup>1</sup>University of Leeds, <sup>2</sup>Care Quality Commission, <sup>3</sup>University of Southampton, <sup>4</sup>Leeds Teaching Hospitals NHS Trust, <sup>5</sup>National Cancer Registration Service, Public Health England

#### Background

Patient-reported experience measures (PREMs) of cancer services have been effectively used in England to inform service improvement and as a stimulus for change. To date, there are no routinely collected national data on cancer patient-reported outcome measures (PROMs). The primary objective of this study was to establish a methodology for the routine evaluation of patient-reported outcomes of cancer in England with reference to colorectal cancer survivors. The secondary objective was to identify factors associated with poor health outcomes in colorectal cancer to support enhanced, targeted aftercare.

#### Method

All individuals diagnosed with colorectal cancer in England in 2010 and 2011 alive 12-36 months after diagnosis were sent a postal questionnaire. This included questions related to treatment, disease status, long-term conditions (LTCs), generic HRQL (EQ-5D) and cancer-specific outcomes (FACT and Social Difficulties Inventory items). EQ-5D scores were categorised as 'perfect' (no problems on any of the five domains) or 'less than perfect' health.

#### Results

The response rate was 63.3% (21,802/34,467). Overall HRQL was reduced in cancer survivors compared to the general population. This was most marked in the younger ages <55years). Disease status (active or recurrent disease), the presence of other LTCs and a stoma were the strongest predictors of reduced HRQL. Additionally, living in a more deprived area and receiving radiotherapy and/or chemotherapy were predictive of lower HRQL. Of respondents without a stoma, 22.1% reported no/little bowel control. Reversal of a stoma resulted in similar levels of bowel control as those who had never had a stoma. A quarter of rectal cancer respondents reported difficulties with sexual matters (25.1% compared to 11.2% of colon cancer respondents).

#### Conclusions

Collection of patient-reported outcomes of malignant diseases without selection-bias by procedure, intervention or institution is possible in England and can provide a baseline against which improvement initiatives can be measured. Results identify those at highest risk of reduced HRQL and support the delivery of enhanced, targeted aftercare. Extending this process to all malignant diseases will, alongside already collected mortality statistics and patient experience data, generate a comprehensive "quality account" for cancer care.

# Parallel Sessions 2

## Patient experience and reported outcomes

### Persistent physical side-effects following treatment for prostate cancer. Results from an all-Ireland population-based study of medium and long-term survivors

**Heather Kinnear**<sup>1</sup>, Frances Drummond<sup>2</sup>, David Donnelly<sup>1</sup>  
<sup>1</sup>Queen's University Belfast, <sup>2</sup>National Cancer Ireland

#### Background

Prostate cancer (PCa) is the most common male cancer in Ireland, accounting for 23% of all malignancies. The number of men affected is increasing. Treatments may impact adversely on men's physical/psychological/social well-being. Physical side-effects include urinary/sexual/bowel/hormone-related functioning. Implementation of recommendations that men be involved in treatment decision-making requires high-quality, reliable treatment side-effects information. However, population-based data is limited. We investigated the persistent physical side-effects of treatment at population-level over 15 years, a longer period than has previously been reported.

#### Method

6,937 men diagnosed with primary, invasive PCa (ICD10-C61), identified through cancer registries Northern Ireland (NI)/Republic of Ireland (RoI), received a postal questionnaire during 2012. Men were asked about treatments received and side-effects experienced. Analyses relate to side-effects present at questionnaire completion.

#### Results

Response rate was 53.5%. Men more often received prostatectomy (RP) in RoI; hormone (HT) and radiotherapy (EBRT) in NI. 51% reported "ever" having urinary symptoms (including haematuria and pain); urinary incontinence was reported by 13% of RP patients diagnosed 2-5 years ago, 8% diagnosed 5-10 years ago and 7% diagnosed >10 years ago. For men treated with EBRT/HT 7% diagnosed 2-5 years ago, 4% diagnosed 5-10 years ago and 3% diagnosed >10 years ago reported ongoing urinary incontinence. 1 in 5 reported impotence before treatment, trebling post treatment to 1 in 2 (19% diagnosed 5-10 years ago, 12% diagnosed >10 years ago). Almost half reported ongoing loss of sexual desire post-treatment, an increase from 15% beforehand. One in 7 reported ongoing bowel problems. One in 3 reported ongoing fertility problems. Ongoing sweats/hot flushes and gynecomastia were more common following HT. When asked about expectation of side-effects 27% said they were same as expected, 19% were worse, 24% said they were not as bad and 18% reported having no side effects; this varied by treatment modality.

#### Conclusions

This study quantifies - for the first time - a population-based picture of men's perception of PCa treatment-related side-effects. Results suggest monitoring side-effects and appropriate management should be a priority and should be conducted throughout the survivorship continuum.

# Parallel Sessions 2

## Patient experience and reported outcomes

### How helpful is the National Cancer Patient Experience Survey (NCPES) in driving rapid service improvement?

**Jo Marsden<sup>1</sup>**

<sup>1</sup>King's College Hospital NHS Foundation Trust

#### Background

Since the inception of the NCPES, King's has scored poorly. Service issues highlighted fail to identify where in the treatment pathway attention can be targeted with realistic expectation of rapid outcomes improvement. This is due to the questionnaire design.

#### Method

The Department of Health granted permission to use the NCPES methodology in a cohort of breast cancer patients diagnosed consecutively at KBC (January 2012 to end August 2012). In contrast to the NCPES, treatments and their sequencing were recorded. It was hypothesised poorer experience would be associated with increasing treatment complexity and provide evidence for prioritising service improvement interventions.

#### Results

The response rate (61%, 60/98) was similar to the 2010-2013 NCPES Trust reports (i.e. 55% to 60%) as were patient demographics. Compared with the 2013 NCPES Trust report, the KBC cohort scored more positive and fewer less positive responses (63% vs 33% and 21% vs 40%). Requirement for radiotherapy +/- chemotherapy or in-patient reconstruction in addition to day surgery +/- endocrine therapy (i.e. the simplest treatment pathway) resulted in less positive responses (33% and 30% vs 22% respectively). Questions scoring poorly reflected perceptions of dignity, understanding, involvement in care (by all levels of hospital staff), pain control, ability to discuss concerns and treatment as a 'set of cancer symptoms'. These issues were not identified by the overall cohort. 'London Effect' questions also scored less positive responses for the same treatment groups.

Ninety percent of the KBC cohort had their first treatment within the previous year in contrast to the NCPES Trust reports (66%) and the KBC cohort scored better for questions influenced by recency (positive 52% vs 36%, 32%, 25%; less positive 21% vs 40%, 43%, 46%). Recency was also influenced by treatment complexity (less positive scores with chemotherapy 38%, reconstruction 42%, overall cohort 21%).

#### Conclusions

This study demonstrates reliance on overall NCPES findings only may not identify important modality-specific issues. Increasing treatment complexity is associated with poorer experience, impacts negatively on recall bias and may be a contributory factor towards the 'London Effect'. Unfocused service improvement measures are unlikely to result in better NCPES scores in the shorter term.

# Parallel Sessions 2

## Colorectal cancer outcomes and quality of care

### Population-based changes in treatment and overall survival for squamous cell cancer of the anus - evidence of impact of ACT1?

**Amy Downing**<sup>1</sup>, Eva Morris<sup>1</sup>, Ariadni Aravani<sup>2</sup>, Paul Finan<sup>3</sup>, Sarah Lawton<sup>2</sup>, James Thomas<sup>2</sup>, David Sebag-Montefiore<sup>1</sup>

<sup>1</sup>University of Leeds, <sup>2</sup>National Cancer Registration Service, Public Health England, <sup>3</sup>Leeds Teaching Hospitals NHS Trust

#### Background

In the early 1980s, surgery was the standard treatment for squamous cell cancer (SCC) of the anus. Three randomised phase III trials (ACT1, EORTC and RTOG) between 1987 and 1994 showed chemo-radiotherapy (CRT) to be the superior treatment. Population-based changes in treatment and survival for anal cancer in England before, during and after the UK-based ACT1 trial were explored.

#### Method

Information was extracted from the National Cancer Data Repository (NCDR) on patients diagnosed with squamous cell anal cancer in England between 1981 and 2010. The data were divided into five-year periods due to the small case numbers each year. Three-year relative survival was calculated for each period. Robust treatment information is available from the Yorkshire region but not all of the cancer registries contributing data to the NCDR. Treatment patterns were analysed in seven year cohorts prior to, during and after the ACT1 trial.

#### Results

11,743 individuals were diagnosed with anal cancer in England. Overall three-year relative survival was 67.9% (95%CI 66.9-68.9). This improved from 59.2% (95%CI 55.7-62.5) in 1981-1985 to 75.8% (95%CI 73.9-77.7) in 2006-2010. 1,065 cases of anal cancer were diagnosed in the Yorkshire region. Survival in Yorkshire was comparable to that in England. In Yorkshire, the proportion of patients receiving surgery fell from 61.6% prior to, 29.8% during and 12.5% after ACT1; the proportion of patients receiving CRT rose from 6.5% prior to, 17.7% during and 58.8% after ACT1 and continued to rise to 70.3% in the subsequent period.

#### Conclusions

Population-based treatment for SCC of the anus changed dramatically during the study period. The predominant use of surgery prior to ACT1, a transition phase during the trial and a dramatic increase in the use of CRT after ACT1 provides strong indirect evidence of the impact of the trial. Survival has continued to increase during this period.

# Parallel Sessions 2

## Colorectal cancer outcomes and quality of care

### Rates of post-colonoscopy colorectal cancer (PCCRC) are significantly affected by methodology but are nevertheless declining in the NHS

**Eva Morris**<sup>1</sup>, Matt Rutter<sup>2</sup>, Paul Finan<sup>3</sup>, James Thomas<sup>4</sup>, Roland Valoni<sup>5</sup>

<sup>1</sup>University of Leeds, <sup>2</sup>University Hospital of North Tees, <sup>3</sup>Leeds Teaching Hospitals NHS Trust, <sup>4</sup>National Cancer Registration Service, Public Health, <sup>5</sup>Gloucestershire Hospitals

#### Background

It is recognised that post-colonoscopy colorectal cancer (PCCRC) can be due to missed cancer, or cancer arising from missed or incompletely removed polyps. Thus PCCRC rates have been suggested as a key quality indicator of colonoscopy. This study compares methods for defining PCCRC rates and explores rates over time.

#### Method

Information on all individuals with a primary colorectal cancer and prior colonoscopic investigations in England between 2001 and 2010 was extracted from the National Cancer Data Repository. Previously published methods (Bressler, Cooper, Singh and leClerc) for deriving PCCRC rates were applied to these data to investigate the effect on the rate. A new method, based on the year of the colonoscopy, not CRC diagnosis, is proposed.

#### Results

Of 297,956 individuals diagnosed with colorectal cancer in the study period a total of 94,648 underwent a colonoscopy in the three years prior to their diagnosis. Depending on the method and exclusion criteria applied PCCRC rates ranged from 2.4 to 7.8%. The PCCRC rate of 6.8% produced by the Singh method best fulfilled the proposed criteria for a quality indicator but was not suitable for annual reporting. Amending this method to look forward from the time of colonoscopy, rather than backward from the time of diagnosis of cancer, provides a rate relating to the year the procedure was actually performed. This new method demonstrates that PCCRC rates within three years of colonoscopy (without exclusions) decreased in the English NHS over seven years by 29%: from 10.2% to 7.2% for colonoscopies performed in 2001 and 2007 respectively. 25% (37/148 hospitals) achieved a PCCRC for the period of 4.0% or less.

#### Conclusions

PCCRC rates in England are improving over time and comparable to those in other countries. The method used to determine rates significantly affects findings, thus international benchmarking requires an agreed method for defining PCCRC. It is proposed that on the basis of current evidence, and improvements evident over time in this study, a reasonable target for a national rate of PCCRC up to three years following a colonoscopy should be less than 4%.

# Parallel Sessions 2

## Colorectal cancer outcomes and quality of care

### Development of a composite indicator for the quality of colorectal cancer care delivered in NHS Trusts across England

**Faye Samy**<sup>1</sup>, Eva Morris<sup>2</sup>, Katie Harris<sup>2</sup>, James Thomas<sup>1</sup>, Paul Finan<sup>3</sup>  
<sup>1</sup>Public Health England, <sup>2</sup>University of Leeds, <sup>3</sup>Leeds Teaching Hospitals NHS Trust

#### Background

Ensuring all individuals diagnosed with colorectal cancer receive the highest standard of care possible is a priority but there is growing evidence of significant variation in the quality of services offered by English NHS Trusts. There is currently strong emphasis on developing methods that robustly quantify the quality of care being delivered and so enable variation to be minimised. Individual indicators of care, such as 30-day post-operative mortality or long-term survival are useful but cancer management is complex and many other factors such as stoma formation, length of hospital stay and quality of life may also be relevant. This study aimed to develop methodology which robustly quantified a number of individual components of care and subsequently combined to generate an overall composite indicator that could be used to assess Trust performance.

#### Method

Population-based data were taken on all individuals diagnosed with colorectal cancer and treated in an English NHS Trust between 2007 and 2008 from the National Cancer Data Repository. Multilevel logistic regression models and funnel plots were used to identify Trusts with significantly outlying practice/outcomes for the indicators of one-year survival, major surgical resection rate, 30-day post-operative mortality, length of hospital stay, presence of a stoma at one year and use of abdominoperineal resection in rectal cancers. An overall composite score was then derived for each Trust.

#### Results

Significant variation was found across all individual indicators between Trusts. There were 59 trusts that had a composite score not equal to 0. Three trusts were identified as having the maximum composite score of 3, indicating significantly worse performance in three indicators than expected.

#### Conclusions

This composite indicator effectively identifies Trusts with outlying practice on multiple aspects of colorectal cancer care. Further work is required to incorporate other important aspects of care such as quality of life of survivors and patient experience.

# Plenary 2

## “Show me the data!” - information and intelligence for your ovarian cancer service

### Chair's welcome and introduction

#### **Annwen Jones**

Chief Executive, Target Ovarian Cancer

Ovarian cancer is the fourth most common cause of death from cancer in women in the UK. A third of women are diagnosed only following admission to A&E. The path to diagnosis is often not straightforward, with many factors contributing to delays. High quality, timely data is vital in unravelling these complexities.

The Target Ovarian Cancer Pathfinder Study provides a multidisciplinary approach to mapping the experiences of those living and working with ovarian cancer across the UK. It aims to identify clear gaps in knowledge, infrastructure, funding and need with regard to the care and treatment of women with ovarian cancer and to seek opportunities to improve outcomes not only in survival but also in quality of life and women's experiences of care.

Annwen Jones will discuss the importance of data for the development of ovarian cancer services from a political, charitable and patient perspective and will explore questions that have come out of the work of the Target Ovarian Cancer Pathfinder Study data.

### Ovarian cancer in the UK - the emerging picture

#### **Dr Andy Nordin**

Chair of NCIN Gynaecological Cancers Site Specific Clinical Reference Group

Diagnosing and treating ovarian cancer has historically proven to be a major challenge at all points in the patient care pathway - but how are the data, intelligence and research that are currently available changing outcomes for ovarian cancer patients in the UK and beyond?

Dr Nordin, Chair of the NCIN Gynaecological Site Specific Clinical Reference Group (SSCRG), will describe the most recent and compelling evidence from projects including; the International Cancer Benchmarking Programme (ICBP), Routes to Diagnosis, Major Resection and Centralisation of Surgery Analyses, Survival Data, MDT Service Profiles and United Kingdom Gynaecological Oncology Surgical Outcomes and Complications (UKGOSOC).

He will further explore how the emergence of new datasets, such as the Cancer Outcomes and Services Dataset (COSD) and the Systemic Anti-Cancer Therapy (SACT) dataset, have the potential to change what we know about the diagnosis, treatment and survival of gynaecological cancer patients.

### Short-term ovarian cancer mortality in and across England

#### **Jason Poole**

Associate Director, Knowledge and Intelligence Team (East Midlands) , Public Health England

Despite significant improvements over the last decade, ovarian cancer survival in England lags behind comparable countries. The International Cancer Benchmarking Programme (ICBP) identified that the UK had particularly high mortality in the first few weeks following diagnosis, but did not have an unfavourable stage distribution.

## Plenary 2

Jason Poole will present the current understanding of mortality in the first year following diagnosis in England and the case-mix effect of potential risk factors, including treatment, as well as possible regional variations.

### Improving cancer services by commissioning pathways - the increasing value of data

#### **Dr Rob Gornall**

Clinical Director, Cancer Services, West Midlands Strategic Clinical Network

*Summary unavailable at the time of print.*

### Robust data - the value to patients and patient organisations of the NCIN

#### **Louise Bayne**

Chief Executive Officer, Ovacom

To deliver the best possible experience for patients who use NHS services, high quality care should be clinically effective, safe and patient-centred. Understanding and improving patient experience of NHS services is essential to providing a service based on patients' needs.

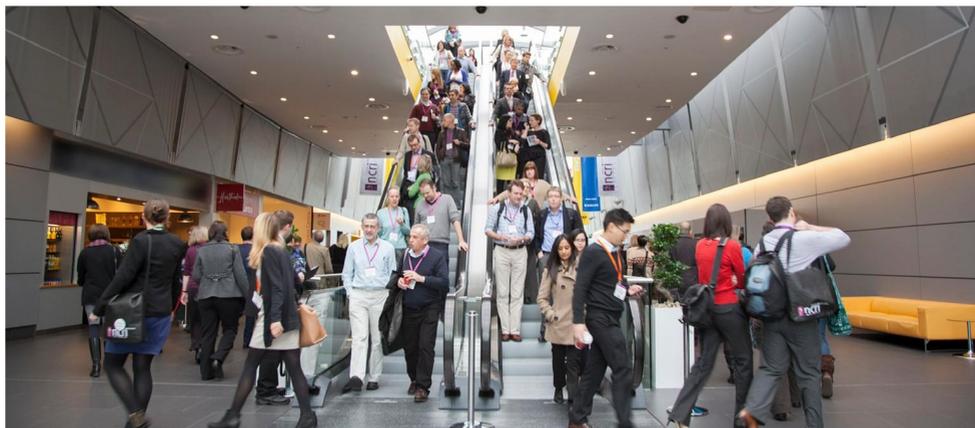
How can data and intelligence be used to support patient-centred services and to ensure cancer patients are able to make informed decisions about managing their own health and care? What are the strengths and weakness of the data available to patients and patient organisations?

Louise Bayne, Chief Executive Officer, Ovacom, will discuss current major issues in ovarian cancer from the perspective of patients and the charitable sector. Louise will discuss what she sees as the strengths and weaknesses in the data that are currently available, the priorities for future analyses and how the charitable sector are using data to drive service improvements.



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**Mr Sean Duffy,**  
**National Clinical Director for Cancer, NHS England**

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# Programme: Tuesday 10 June

08:00 - 08:55 **Coffee, exhibition and poster viewing**

Kings Suite

09:00 - 10:15 **Plenary 3 - The Brian Cottier Plenary**

**Global cancer surveillance: opportunities and challenges.**  
Queens Hall

*By 2030, the global cancer burden is expected to nearly double, growing to 21.4 million cases and 13.2 million deaths. This session will identify the opportunities and challenges in reducing the burden of cancer, both in the UK and on a global scale.*

09:00 - 09:10 **Chair's welcome - introduction to the session**

Professor Julia Verne, Director, Knowledge and Intelligence Team (South West), Public Health England

09:10 - 09:30 **World-wide cancer burden**

Dr Freddie Bray, International Agency for Research on Cancer (IARC)

09:30 - 09:50 **EUROCARE 5 - survival of cancer patients in Europe**

Dr Milena Sant, Istituto Tumori, Italy

09:50 - 10:10 **The impact of the International Cancer Benchmarking Partnership on policy and practice to date**

Sara Hiom, Director of Patient Engagement and Early Diagnosis, Cancer Research UK

10:10 - 10:15 **Q&A**

10:15 - 10:40 **Coffee, exhibition and poster viewing**

Kings Suite

10:45 - 11:40 **Parallel sessions 3**

**Session 1** **Epidemiology**

Queens Hall

Sponsored by

10:45 - 11:00 **Chair's introduction**

Dr Freddie Bray, International Agency for Research on Cancer (IARC)



11:00 - 11:10 **Epidemiology of cancer of unknown primary site in Scotland, 1961-2010**

David Brewster, NHS National Services Scotland

11:10 - 11:20 **Misrepresentation of the origins and composition of staging data and its impact on colorectal cancer survival**

Michael Eden, National Cancer Registration Service (Eastern Office), Public Health England

# Programme: Tuesday 10 June

11:20 - 11:30 **Do South Asians show differences in colorectal cancer survival and trends in survival compared to non-South Asians in England?**  
Camille Maringe, London School of Hygiene and Tropical Medicine

11:30 - 11:40 **Q&A**

## Session 2 **Reducing health inequalities**

**Earls Room**

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**WE ARE  
MACMILLAN.**  
CANCER SUPPORT

10:45 - 11:00 **Chair's introduction**  
Dr Tony Moran, Director of Research and Intelligence, Knowledge and Intelligence Team (North West), Public Health England

11:00 - 11:10 **Lifetime risk of being diagnosed with, or dying from, prostate cancer by major ethnic group in England 2008-2010**  
Therese Lloyd, Prostate Cancer UK

11:10 - 11:20 **A cohort study of mental disorders, stage of cancer at diagnosis and subsequent survival**  
Chin-Kuo Chang, King's College London

11:20 - 11:30 **Understanding deprivation inequalities using the loss in expectation of life due to a cancer diagnosis: an example using UK cancer registry data**  
Mark Rutherford, University of Leicester

11:30 - 11:40 **Q&A**

## Session 3 **Health economics**

**Dukes Room**

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MACMILLAN.**  
CANCER SUPPORT

10:45 - 11:00 **Chair's introduction**  
Professor Linda Sharp, National Cancer Registry Ireland

11:00 - 11:10 **A cost-effectiveness analysis of PSA testing for the secondary prevention of prostate cancer in the Republic of Ireland**  
Richéal Burns, Health Economics Research Centre, University of Oxford

11:10 - 11:20 **The management of head and neck non melanoma skin cancers in England in 2011**  
Tom Walker, University of Bristol

11:20 - 11:30 **Measuring societal burden of cancer - the cost of lost productivity due to premature cancer-related mortality in Europe**  
Paul Hanly, National College of Ireland

11:30 - 11:40 **Q&A**

# Programme: Tuesday 10 June

11:45 - 12:45 **Workshops**

**Workshop 1** **Systemic Anti - Cancer Therapy (SACT) Workshop**

**Queens Hall**

11:45 - 12:00 **Chair's introduction**

Professor David Dodwell, Chair, Chemotherapy Clinical Information Group

12:00 - 12:10 **Introducing the SACT data standard - where the SACT is today?**

Charles Wilson, Consultant Clinical Oncologist, Addenbrooke's Hospital

12:10 - 12:20 **Understanding the patterns of SACT chemotherapy - what have we learned?**

Mike Wallington, Knowledge and Intelligence Team (South East), Public Health England

12:20 - 12:30 **The future of SACT - what next?**

Professor David Dodwell, Chair, Chemotherapy Clinical Information Group

12:30 - 12:45 **Q&A**

**Workshop 2** **Early Career Researcher (ECR) Showcase**

**Earls Room**

11:45 - 11:55 **Chair's Introduction**

Professor Liam Murray, Queen's University Belfast

11:55 - 12:35 **ECR Presentations**

**A. Cause-specific mortality in five-year survivors of central nervous tumours in young adulthood - The Teenage and Young Adult Cancer Survivor Study (TYACSS)**

Chloe Bright, The University of Birmingham

**B. What factors predict non-surgical treatment of breast cancer in the elderly and does it affect survival? Initial findings from the Bridging the Age Gap study**

Paul Richards, The University of Sheffield

**C. Routes to diagnosis: does it matter when or how a cancer is diagnosed?**

Sam Johnson, National Cancer Intelligence Network, Public Health England

**D. Surgery and risk of venous thromboembolism in women with cancer - a UK-based prospective cohort study**

Sian Sweetland, University of Oxford

# Programme: Tuesday 10 June

## E. Variation in discussion about and participation in cancer research and its relationship with patient experience

Louise McGrath-Lone, Imperial College London

12:35 - 12:45 **Q&A**

### Workshop 3 **Preventing Emergency Presentations - the need for research**

#### Dukes Room

*This interactive workshop will discuss key questions relating to Emergency Presentations (EPs) and how best to improve our knowledge and research in this area. An information pack of what we know about EPs will be provided to aid the discussion.*

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11:45 - 11:55 **Chair's introduction**  
Professor Stephen Duffy, Wolfson institute

11:55 - 12:25 **Group discussions** (*small breakout groups*)

12:25 - 12:45 **Feedback and Q&A**

### 12:45 - 13:40 **Lunch, exhibition and poster viewing**

#### Kings Suite

### 13:45 - 14:40 **Parallel sessions 4**

#### Session 1 **Data quality, governance and management**

##### Queens Hall

Sponsored by

13:45 - 14:00 **Chair's introduction**  
Dr Jem Rashbass, National Director for Disease Registration,  
Public Health England



14:00 - 14:10 **Partnership working - the key to cancer data quality improvement**  
Hilary Wilderspin, London Cancer Alliance

14:10 - 14:20 **The challenges of coding cancer of unknown primary (CUP) - a survey of current registration and reporting practices in the UK, Republic of Ireland and Australia**  
Claudia Oehler, National Cancer Intelligence Network, Public Health England

14:20 - 14:30 **Colorectal cancer pathology reporting: a regional audit**  
Rebecca Birch, University of Leeds

14:30 - 14:40 **Q&A**

# Programme: Tuesday 10 June

## Session 2

### End of life and palliative care

#### Earls Room

Sponsored by



- 13:45 - 14:00 **Chair's introduction**  
Professor Julia Verne, Director, Knowledge and Intelligence Team (South West), Public Health England
- 14:00 - 14:10 **Use of hospital services among palliative oesophago-gastric cancer patients**  
Angelina Taylor, The Royal College of Surgeons of England
- 14:10 - 14:20 **Investigating end of life care across NHS Area Teams using the National Survey of Bereaved People**  
Helen Harris, Office for National Statistics
- 14:20 - 14:30 **Impact of electronic palliative care coordination systems on place of death**  
Andy Pring, Knowledge and Intelligence Team (South West), Public Health England
- 14:30 - 14:40 **Q&A**

## Session 3

### Less common cancers

#### Dukes Room

Sponsored by



- 13:45 - 13:50 **Chair's introduction**  
Jane Lyons, Chief Executive, Cancer 52
- 13:50 - 14:00 **Setting the scene for rare and less common cancers**  
Lucy Elliss-Brookes, National Cancer Intelligence Network, Public Health England
- 14:00 - 14:10 **Menopausal hormone therapy and risk of central nervous system tumours - a nested case - control study**  
Oskana Kirichek, University of Oxford
- 14:10 - 14:20 **Incidence, survival and treatment patterns for patients with head and neck sarcoma**  
Nicola Dennis, Knowledge and Intelligence Team (West Midlands), Public Health England
- 14:20 - 14:30 **Risk of adverse health and social outcomes up to 50 years after Wilms' tumour: the British Childhood Cancer Survivor Study**  
Kwok Wong, University of Birmingham
- 14:30 - 14:40 **Q&A**

# Programme: Tuesday 10 June

14:45 - 16:15 **Plenary 4**

## **Delivering outcomes that matter - panel debate and Q&A** **Queens Hall**

Sponsored by



*Timely, patient-level data linked across primary and secondary care is required by clinical organisations to inform their practice and implement long-term conditions' strategies.*

*The NCIN welcomes an expert panel to this interactive, 'Question Time' debate to discuss 'are we getting data into the right hands and delivering outcomes that matter?'*

14:45 - 15:00 **Chair's welcome & introduction to the debate**  
**Robert Peston**, Economics Editor, BBC

15:00 - 16:15 **Panel debate with Q&A to the panel:**

### **Ciarán Devane**

Chief Executive, Macmillan Cancer Support

### **Sean Duffy**

National Clinical Director for Cancer, NHS England

### **Professor Peter Johnson**

Chief Clinician, Cancer Research UK

### **Dr Jem Rashbass**

Director for Disease Registration, Public Health England

### **Andrew Wilson**

Chief Executive, Rarer Cancer Forum

16:15 - 16:30 **Close of conference and announcement of 2015 conference**



# Plenary 3

## The Brian Cottier Plenary: Global cancer surveillance: opportunities & challenges

### World-wide cancer burden

#### Dr Freddie Bray

International Agency for Research on Cancer (IARC)

Societal, economic and lifestyle changes in a rapidly globalising world are having profound effects on the scale and profile of cancer, and the need for tailored and effective strategies for cancer control and prevention. The presentation aims to link global cancer indicators to measures of social and economic progress. It will provide an overview of the key characteristics of the changing cancer burden and focus on the impact on countries under developmental transition, many of which are ill-equipped to deal with the escalating numbers of cancer patients expected over the next decades

### EUROCARE 5 - Survival of cancer patients in Europe

#### Dr Milena Sant

Istituto Tumori, Italy

*Summary unavailable at the time of print.*

### The impact of the International Cancer Benchmarking Partnership on policy and practice to date

#### Sara Hiom

Director of Patient Engagement and Early Diagnosis, Cancer Research UK

The International Cancer Benchmarking Partnership (ICBP) is a unique collaboration of clinicians, academics and policymakers, seeking to understand how and why survival varies between Australia, Canada, Denmark, Norway, Sweden and the UK, focusing on breast, colorectal, lung and ovarian cancer. The ICBP is funded by participating jurisdictions and is programme managed by Cancer Research UK.

The ICBP has provided the most up to date international survival comparisons, showing that while survival rates improved between 1995 and 2007 in all partner countries, they remained persistently higher in Australia, Canada, and Sweden, intermediate in Norway, and lower in Denmark and the UK. Further analysis revealed that while there are seemingly 'delays' in diagnosis in the UK, with the UK having a worse stage distribution in comparison to ICBP partner countries (for colorectal and lung cancer in particular), treatment differences do in fact play a more significant role than perhaps expected with survival within stage being variable too (particularly for breast and ovarian cancer). The ICBP has also shown that awareness of symptoms is high and that beliefs about cancer were generally positive in all partner countries, while highlighting that people in the UK are more worried and embarrassed about seeing their doctor with a symptom that might be serious than those in other countries, with worrying about wasting the doctor's time coming up as barrier.

Research currently underway in the ICBP is focusing on the important role of primary care in diagnosing cancer, looking at the impact of time spent on the cancer pathway from first symptom to treatment and differences in routes to diagnosis, and the impact of comorbidities on short term mortality. The findings from each of these studies will continue providing insights into why survival varies between partner countries and identify potential further areas for action to impact policy and practice, at home and abroad.

# Parallel Sessions 3

## Epidemiology

### Epidemiology of cancer of unknown primary site in Scotland, 1961-2010

David Brewster<sup>1</sup>, Jaroslaw Lang<sup>1</sup>, Lesley Bhatti<sup>1</sup>, Catherine Thomson<sup>1</sup>, Karin Oien<sup>2</sup>  
<sup>1</sup>NHS National Services Scotland, <sup>2</sup>University of Glasgow

#### Background

Cancers of unknown primary site (CUP) pose problems for diagnosis, treatment, and accurate prediction of prognosis. However, there are limited published data describing the epidemiology of this disease entity. Our aim was to describe the epidemiology of CUP in Scotland.

#### Method

Anonymised data, covering the period 1961-2010, were extracted from the Scottish Cancer Registry database, based on the following ICD-10 diagnostic codes: C26.0, C26.8, C26.9, C39, and C76–C80. Age-standardised incidence rates were calculated by direct standardisation to the World Standard Population. Estimates of observed survival were calculated by the Kaplan-Meier method.

#### Results

Between 1961 and 2010, there were 50,941 registrations of CUP, representing 3.9% of all registrations of invasive cancers. Age-standardised rates increased to a peak in the early to mid-1990s, followed by a steeper decrease in rates. During 2001-2010, age-standardised rates of CUP were higher in the most compared with the least deprived fifth of the population. Observed survival was marginally higher in patients diagnosed during 2001-2010 (median 5.6 weeks) compared with those diagnosed in the previous two decades. During the most recent decade, survival decreased with age at diagnosis, and was higher in patients with squamous cell carcinoma and lymph node metastases.

#### Conclusions

Patterns of CUP in Scotland are largely consistent with those reported from the few other countries that have published data. However, in comparing studies, it is important to note that there is heterogeneity in terms of definition of CUP, as well as calendar period of diagnosis or death. Variation in the definition of CUP between different epidemiological studies suggests that there would be merit in seeking international agreement on guidelines for the registration of CUP as well as a standard grouping of diagnostic codes for analysis.

# Parallel Sessions 3

## Epidemiology

### Misinterpretation of the origins and composition of staging data and its impact on colorectal cancer survival

Michael Eden<sup>1</sup>, Brian Rouse<sup>1</sup>, Jem Rashbass<sup>1</sup>

<sup>1</sup>National Cancer Registration Service, Public Health England

#### Background

Large international differences in colorectal cancer survival are known to exist and attempts have been made to investigate the extent to which stage at diagnosis explains these differences. The recently published study by Maringe et al. takes staging data between countries that use a variety of staging systems (TNM, Dukes', SEER and locally SEER based) and translates this data into one unified classification. Despite the obvious limitations of this methodology the authors have principally misinterpreted the origins and composition of the data used in their analysis.

#### Method

We applied the methodology developed by Maringe et al. to colorectal carcinomas diagnosed between 1/1/2011 and 31/12/2011, and registered at the Eastern Office of the National Cancer Registration Service, Public Health England (formerly Eastern Cancer Registry and Information Centre). We compared the stage distribution of colorectal tumours obtained using pathological stage against the integrated stage for the same population of data.

#### Results

A total of 4880 cases were identified, of which 2406 had both a pathological stage and an integrated stage. The stage distribution determined by registry derived integrated staging showed a significant increase ( $p$ -value =  $<0.01$ ) in the proportion of Stage 4 (Dukes D) tumours and a significant decrease in the proportion of Stage 2 (Dukes B) and Stage 3 (Dukes C) tumours as compared to the stage distribution determined using the Maringe et al. methodology when only pathological stage is available. Stage 3 tumour 1 year overall survival increased from 85 to 90% and Stage 4 tumour 1 year overall survival increased from 33 to 63%.

#### Conclusions

Misinterpretation of the origins and composition of the data used in analysis has significant ramifications upon stage distribution and consequently on the one year overall survival, particularly for Stage 3 and Stage 4 tumours. Analysis of stage data, particularly when used in international comparisons must understand the source of the data if interpretation is to be meaningful.

# Parallel Sessions 3

## Epidemiology

### Do South Asians show differences in colorectal cancer survival and trends in survival compared to non-South Asians in England?

**Camille Maringe**<sup>1</sup>, Ruoran Li<sup>1</sup>, Bernard Rachet<sup>1</sup>

<sup>1</sup>London School of Hygiene and Tropical Medicine

#### Background

In England, people of Indian, Pakistani and Bangladeshi origin (South Asians, SA) compose the biggest ethnic minority group, representing 4% of the population. SA migrants show lower colorectal cancer incidence than non-SA in England.

#### Method

Due to their distinctive names, SA ethnicity could be flagged on national cancer registrations using SANGRA (South Asian Names and Group Recognition Algorithm), a validated algorithm. Analyses were restricted to the 997,104 patients eligible for analysis and aged 15-69 years at diagnosis; around 1% of which were of SA origin. We report one- and five-year net survival: survival from cancer in the hypothetical situation where patients cannot die from other causes of death. Population life tables specific to SA were constructed by deprivation and calendar year between 1991 and 2001 to adjust for background mortality. The effect of SA ethnicity, adjusted for age, deprivation and year of diagnosis was modelled on the excess mortality scale. We examine time trends, age and deprivation patterns in cancer survival in SA compared to non-SA between 1986 and 2004.

#### Results

In the period 1986-1995, SA had significantly higher age-standardised net survival for colorectal cancer in both men (54.7% vs. 43.5% at 5 years) and women (80.2% and 57.7% vs. 73.8% and 46.7% at one and five years respectively). Short-term excess hazard decreased faster in SA than non-SA between 1986 and 2004. This led to similar levels of one-year survival in both ethnic groups and sex by 2004. The excess hazards of deaths at one- and five- years were higher in non-SA than SA men at all ages. There were no varying effects of deprivation, age and year of diagnosis by ethnicity in women.

#### Conclusions

Steeper improvement in survival were observed in non-SA than in SA for whom survival only started to slightly improve from 1995. At a time when the bowel screening program me is being implemented, it is important to describe and understand the reason for varying trends in survival by ethnic group. It is crucial to make sure that SA benefit from recent gains in colorectal cancer survival as much as the rest of the population.

# Parallel Sessions 3

## Reducing health inequalities

### Lifetime risk of being diagnosed with, or dying from, prostate cancer by major ethnic group in England 2008-2010

**Therese Lloyd**<sup>1</sup>, Luke Hounsome<sup>2</sup>, Ali Cooper<sup>1</sup>

<sup>1</sup>Prostate Cancer UK, <sup>2</sup> Knowledge and Intelligence Team (South West), Public Health England

#### Background

The lifetime risk of being diagnosed with prostate cancer in the UK is <sup>[1]</sup>. However, this statistic is not broken down by ethnic group. The purpose of this study was to calculate both the lifetime risk of being diagnosed with, and dying from, prostate cancer by major ethnic group, as part of Prostate Cancer UK's ongoing work to help better inform men of their risks.

#### Method

The difficulty in calculating lifetime risk by ethnic group is a lack of data on ethnicity. Public Health England was able to provide incidence and mortality data by major ethnic group in England for 2008-2010, by linking a combination of hospital sources and death records. However, ethnic group data was incomplete and the total number of incidences and deaths did not match the overall numbers available through the Office of National Statistics. Therefore, we manipulated the data in various ways, including different methodologies to assign an ethnic group to the unknown cases, before calculating the lifetime risks using the 'Current Probability' method.

#### Results

The lifetime risk of being diagnosed with prostate cancer is approximately one in eight for White men, one in four for Black men and one in thirteen for Asian men. The lifetime risk of dying from prostate cancer is approximately one in twenty-four for White men, one in twelve for Black men and one in forty-four for Asian men.

#### Conclusions

This study has shown that Black men are at double the risk of being diagnosed with, and of dying from, prostate cancer compared to White men in England. Following a diagnosis of prostate cancer, Black men are no more likely than White men to die from prostate cancer. However, given the higher incidence rate, proportionally more Black men are dying from prostate cancer than White men which reinforces the importance of Prostate Cancer UK's work of reaching out to Black communities and informing these men of their increased risk. To improve future studies on ethnic differences, better collection of ethnicity data is required.

#### References

<sup>[1]</sup>Prostate cancer incidence statistics: Lifetime risk. Cancer Research UK. 2010.

# Parallel Sessions 3

## Reducing health inequalities

### A cohort study of mental disorders, stage of cancer at diagnosis and subsequent survival

Elizabeth Davies<sup>1</sup>, **Chin-Kuo Chang**<sup>2</sup>, Richard Hayes<sup>2</sup>, Matthew Broadbent<sup>3</sup>, Matthew Hotopf<sup>2</sup>, Elizabeth Davies<sup>4</sup>, Henrik Moller<sup>4</sup>, Robert Stewart<sup>2</sup>

<sup>1</sup>King's College London, <sup>2</sup>Institute of Psychiatry, King's College London, <sup>3</sup>South London and Maudsley NHS Foundation Trust, <sup>4</sup>Cancer Epidemiology and Population Health, King's College London

#### Background

Numerous studies have indicated a higher risk of all-cause mortality and shorter life expectancy for people with severe mental illness (SMI), including schizophrenia, bipolar disorder, schizoaffective disorder, and sometimes depressive disorders. However previous research has found mixed results for the risk of cancer mortality in patients with different mental disorders. This study aimed to assess the stage at cancer diagnosis and survival after diagnosis among people served by secondary mental health services, comparing to other local people.

#### Method

Using the anonymised linkage between a regional monopoly secondary mental health service provider in southeast London of four London boroughs, Croydon, Lambeth, Lewisham, and Southwark, and a population-based cancer register, a historical cohort study was constructed. A total of 28,477 cancer cases aged 15+ years old with stage of cancer recorded at diagnosis were identified. Among these, 2,206 subjects had been previously assessed or treated in secondary mental healthcare before their cancer diagnosis and 125 for severe mental illness (schizophrenia, schizoaffective, or bipolar disorders). Outcome measures investigated were stage when cancer was diagnosed and all-cause mortality after cancer diagnosis among cancer cases registered in the geographic area of southeast London. Comparisons between people with and without specific psychiatric diagnosis in the same residence area for risks of advanced stage of cancer at diagnosis and general survival after cancer diagnosed were analysed using logistic and Cox models.

#### Results

No associations were found between specific mental disorder diagnoses and beyond-local spread of cancer at presentation. However, people with severe mental disorders, depression, dementia, and substance use disorders had significantly worse survival after cancer diagnosis, independent of cancer stage at diagnosis and other potential confounders.

#### Conclusions

Previous findings of associations between mental disorders and cancer mortality are more likely to be accounted for by differences in survival after cancer diagnosis rather than by delayed diagnosis.

# Parallel Sessions 3

## Reducing health inequalities

### Understanding deprivation inequalities using the loss in expectation of life due to a cancer diagnosis: an example using UK cancer registry data

**Mark Rutherford**<sup>1</sup>, Therese Andersson<sup>2</sup>, Paul Lambert<sup>1,2</sup>

<sup>1</sup>University of Leicester, <sup>2</sup>Karolinska Institutet,

#### Background

There have been a number of previous publications investigating the effect of deprivation on cancer patient survival. Patients from more deprived areas have a lower relative survival than those from more affluent areas for many sites. However, there are of course also differences in other-cause mortality between deprivation groups. This means the loss in life expectancy may be a more informative way to explain the impact of a cancer diagnosis.

#### Method

We investigate the loss in expectation of life as a measure to report differences across deprivation groups in the UK. Loss in expectation of life is the difference between the expectation of life in the general population and the expectation of life in the cancer population. We use an approach developed by Andersson et al.<sup>1</sup> based on the flexible parametric excess mortality model. We apply the method to 10 cancer sites and report the findings by five deprivation groups (based on national quintiles of the income domain of the Index of Multiple Deprivation).

#### Results

The loss in expectation of life varies across cancer sites, depending on the severity of cancer mortality. Understandably, a diagnosis of lung or pancreatic cancer impacts more than a diagnosis of breast or colorectal cancer on a patient's life expectancy. There are also differences across cancer site in terms of the impact of deprivation. Because of the difference in background life expectancy, the impact of deprivation is not as great for the loss in expectation of life. For breast cancer, patients aged 60 lose around five years from their background life expectancy due to a cancer diagnosis irrespective of deprivation group.

#### Conclusions

The loss in expectation of life is a useful measure for reporting differences between population groups. It is easier to understand than other approaches and is influenced by both cancer and other-cause mortality; making it more informative to patients.

#### References

[<sup>1</sup>] TM-L Andersson, PW Dickman, S Eloranta, M Lambe, PC Lambert. "Estimating the loss in expectation of life due to cancer using flexible parametric survival models". *Stats in Med.* 2013; **32** (30): 5286–5300.

# Parallel Sessions 3

## Health economics

### **A cost-effectiveness analysis of PSA testing for the secondary prevention of prostate cancer in the Republic of Ireland.**

**Richeal Burns**<sup>1</sup>, Jose Leal<sup>1</sup>, Jane Wolstenholme<sup>1</sup>, Ciaran O'Neill<sup>2</sup>, Frank Sullivan<sup>3</sup>, Frances Drummond<sup>4</sup>, Linda Sharp<sup>4</sup>

<sup>1</sup>Health Economics Research Centre, University of Oxford, <sup>2</sup>Department of Economics, NUI Galway, <sup>3</sup>Prostate Cancer Institute, NUI Galway, <sup>4</sup>National Cancer Registry Ireland

#### **Background**

As in many developed countries, prostate cancer incidence has steadily increased over the last 20 years in the Republic of Ireland. A main driver of this trend is the widespread use of prostate specific antigen (PSA) testing as an ad hoc screening mechanism for prostate cancer; PSA use has increased five-fold since 1994. This work undertakes a cost-effectiveness analysis of PSA testing for the secondary prevention of prostate cancer which has not been previously evaluated in the Republic of Ireland.

#### **Method**

Incidence and clinical data from the National Cancer Register Ireland for men diagnosed with prostate cancer in 2009 was used. Unit costs were estimated using Irish reference costs, project-specific survey costs and costs reported in the literature. Both life years (LY) and quality adjusted life years (QALY) gained, compared to no PSA testing, were quantified. Utility data was collected from prostate cancer survivors and several utility measurement strategies were undertaken in scenario analysis to reflect the uncertainty around these estimates. Screening strategies were informed from the literature commencing at age 50.

#### **Results**

In the base case model with PSA cut-off of 3ng/ml, a once off PSA test at 50 years compared to no PSA test resulted in an incremental cost-effectiveness ratio (ICER) of €15,407 per LY and €19,189 per QALY gained. PSA testing every 10 years starting at age 50 resulted in an ICER of €30,612 per LY and €41,154 per QALY gained and every 5 years, €59,759 per LY and €79,957 per QALY gained. Estimates were sensitive to variation in effectiveness of screening parameters (as effectiveness decreased, ICERs increased) and in utility weights.

#### **Conclusions**

Depending on CE thresholds and the budgetary impact of the programme, PSA testing every 10 years commencing at age 50 could be deemed cost-effective compared to current practice. However, the scenario analysis indicated the sensitivity of the results to the values of key parameters. This analysis contributes to the ongoing international debate regarding PSA testing and can provide much needed support to reforming guidance within the Irish healthcare system.

# Parallel Sessions 3

## Health economics

### The management of head and neck non melanoma skin cancers in England in 2011.

**Tom Walker**<sup>1</sup>, Tim Jones<sup>2</sup>, Veronique Poirier<sup>2</sup>, Stephen Thomas<sup>1</sup>, Julia Verne<sup>2</sup>

<sup>1</sup>University of Bristol, <sup>2</sup>Knowledge and Intelligence Team (South West), Public Health England

#### Background

The incidence of NMSC has increased by over 30% in the last decade. They are the most common cancer in England accounting for a quarter of all recorded malignancies. Many authors have predicted an increased in incidence of NMSC. The burden of this disease entity is vastly underestimated. We have examined the management of head and neck NMSC manage in England by age, gender, deprivation, treating specialty, surgical procedure, cost and whether treated as an inpatient or day case. Identifying who is being affected by these conditions, as well as which practitioners are doing what, where and for how much can help improve services for patients and prepare us for the increased incidence of these conditions.

#### Method

In patient and day cases English hospital admission relating to a primary diagnosis of NMSC (ICD10 -C44.0-44.4) for anatomical site "head and neck" were extracted from inpatient hospital episode statistics. Office of Census and Surveys Classification of Interventions and Procedure's codes (OPCS-4) were used to identify hospital procedures. Healthcare resource group (HRG) codes associated with each hospital admission were linked to Payment by Results tariffs.

#### Results

The day case management of NMSC has risen by 169% whilst inpatient management has decreased. The majority of cases are in males over 60 years old (54%). 30% of NMSC treated was in the two most deprived quintiles. The majority of NMSC was treated in the East of England and day case vs inpatient admission rates vary across England. Dermatology and plastic surgeons each treat 35% of patients. 15% is treated by Oral and Maxillofacial Surgery. There is a range in the cost of treatment for day case (£639.57 – £1,018.74) and inpatient( £1,107.26 - £2,943.74). This varies by specialty.

#### Conclusions

Head and neck NMSC is major burden on the health services. Older males, from less deprived background are the most common person affected by these conditions. There is marked geographical variation in the specialty that manages this condition and inter-specialty variation in the cost of treatment. Service delivery (location and cost) needs to be borne in mind when planning NMSC services in England.

# Parallel Sessions 3

## Health economics

### Measuring the societal burden of cancer: the cost of lost productivity due to premature cancer-related mortality in Europe

Paul Hanly<sup>1</sup>, Isabelle Soerjomataram<sup>2</sup>, Linda Sharp<sup>3</sup>

<sup>1</sup>National College of Ireland, <sup>2</sup>International Agency for Research on Cancer, <sup>3</sup>National Cancer Registry, Ireland

#### Background

Every person absent from work due to cancer represents an economic loss to society. To inform priorities for cancer control, we estimated costs of lost productivity due to premature cancer-related mortality across Europe, for all cancers and by cancer site, region and country, and gender.

#### Method

Cancer deaths in 2008 were obtained from GLOBOCAN for 30 European countries across four regions. Years of potential productive life lost (YPPLL) were computed by multiplying deaths between 15-64 years by life expectancy. Costs were valued using the human capital approach and expressed in 2008€. YPPLL were multiplied by country-, age-, and gender-specific annual wages and adjusted for workforce participation and unemployment.

#### Results

Lost productivity costs due to premature cancer-related mortality in Europe in 2008 were €75 billion. Total costs were highest in Western Europe and the most populous countries. Male costs (€49 billion) were almost twice female costs (€26 billion); the male:female ratio was greatest in Southern Europe (2.5). The most costly sites were lung (€17 billion; 23% of total costs), breast (€7 billion, 9%) and colorectum (€6 billion, 8%). Stomach cancer (in Southern and Central-Eastern Europe) and pancreatic cancer (in Northern and Western Europe) were among the most costly sites. The average lost productivity cost per cancer death was €219,241 (males=€245,953; females=€182,131); this varied 12-fold across countries. For males and females combined, melanoma has the highest cost per death (€312,798), followed by Hodgkin disease (€306,628) and brain and CNS cancer (€288,850). Premature mortality costs were 0.58% of 2008 European gross domestic product, highest in Central-Eastern Europe (0.81%) and lowest in Northern Europe (0.51%).

#### Conclusions

Lost productivity costs due to premature cancer-related mortality in Europe are significant. These results provide an important new perspective on the societal cancer burden and may be used to inform priority setting for cancer control.

#### Acknowledgements

We appreciate the support of COST Action IS1211 CANWON.

# Workshops

## Systematic Anti-Cancer Therapy (SACT) Workshop

**Chair: Professor David Dodwell, Chair, Chemotherapy Clinical Information Group**

Cancer chemotherapy has been provided in the NHS for decades but no national recording of treatment has previously existed. Chemotherapy is increasingly successful as a treatment but is ever more expensive and complex. Accurate, timely and complete data collection is now seen as a priority and this is made feasible by the advent of electronic clinical data collection.

Attendees will hear about how the SACT dataset is changing what we know about this important treatment regimen and the potential of this data collection for research, audit and clinical practice.

## Early Cancer Researcher Showcase

**Chair: Professor Liam Murray, Queen's University Belfast**

The NCIN is delighted to announce the first electronic poster workshop. The workshop, hosted by Professor Liam Murray (Queen's University, Belfast), will showcase the work of early career researchers from diverse and complementary research backgrounds.

## Preventing Emergency Presentations - the need for research

**Chair: Professor Stephen Duffy, Wolfson Institute**

The overarching goal of the National Awareness and Early Diagnosis Initiative (NAEDI) is to promote early diagnosis of cancer and thereby improve survival rates and reduce cancer mortality. To help achieve this we need to better understand the different routes taken by patients to their cancer diagnoses, to examine what effect this has on overall outcomes.

This interactive workshop will discuss key questions relating to Emergency Presentations (EPs) and how best to improve our knowledge and research in this area.

An information pack of what we know about EPs will be provided to aid the discussion.

# Parallel Sessions 4

## Data quality, governance and management

### Partnership working; the key to cancer data quality improvement

Hilary Wilderspin<sup>1</sup>, **Karen Graham**<sup>2</sup>, Michael Sharpe<sup>2</sup>, Steve Raynor<sup>2</sup>, Barry Plewa<sup>2</sup>

<sup>1</sup>London Cancer Alliance, <sup>2</sup>National Cancer Registration Service, Public Health England

#### Background

In 2012 it became clear that the quality and timeliness of cancer data flows from the 16 London Cancer Alliance providers needed to be significantly improved. A partnership with the National Cancer Registration Service was created to address these deficiencies.

#### Method

The improvement methodology focused on people, processes and systems. There was not a “magic bullet”; it required a whole change management approach. The problems varied considerably Trust by Trust, between centres and units and by tumour type. The approach required:

- bespoke, tailored support from skilled individuals with a track record of delivering improvement.
- engagement with and building relationships between Trust teams and with NCRS.
- review of MDT systems and processes and finding solutions.
- staff training.
- action planning, monitoring and feedback to clinical teams
- support from LCA Clinical Board, including regular reporting and review of progress, distribution of performance via pathway group metrics and on the LCA cloud system.

#### Results

In 2011/12 the range of stage submission was 0% to 38%. Overall for the 16 trusts full stage was 18%, partial stage was 8%. Overall staging submissions were 26%. By the end of 2012/13 across the LCA - 56% of cases had a full stage, 9% had a partial stage with an overall submission of 65%. In Quarter 4 2013/14 performance was sustained despite the implementation of COSD. Monitoring has continued; for April-October 2013, 65% full stage, 6% partial stage and overall stage 71% has been achieved. The LCA and NCRS London office are now focusing on specific tumour types and individual MDTs to further improve staging data quality. MDTs that have already achieved high completeness and those who require further improvement have been highlighted to the individual tumour pathway chairs for action.

#### Conclusions

The improvement approach and partnership with NCRS has been the key to data quality improvement. Comparative reporting is now being used to improve SACT data quality and the LCA will adopt a similar approach to COSD conformance monitoring during 2014. Work will continue with the data improvement teams to sustain and further improve on the achievements to date.

# Parallel Sessions 4

## Data quality, governance and management

### The challenges of coding cancer of unknown primary (CUP) - a survey of current registration and reporting practices in the UK, Republic of Ireland and Australia

**Claudia Oehler**<sup>1</sup>, Claire Vajdic<sup>2</sup>, Nicola Cooper<sup>1</sup>, John Symons<sup>3</sup>

<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>University of New South Wales, Australia, <sup>3</sup>Cancer of Unknown Primary Foundation

#### Background

Cancer of unknown primary (CUP) is a malignancy without an identified primary site. Previous research indicated that the definitions of CUP used in existing publications, as well as the underlying data, are inconsistent. This impedes a precise assessment of the burden of CUP, both nationally and internationally. The aim of the study was to compare the current CUP registration and reporting practices in Australia, the Republic of Ireland and the countries of the UK, with a view to making recommendations for improving national and international standardisation.

#### Method

Directors of population-based cancer registries were asked to complete a survey concerning the guidelines and coding rules followed in the registration of CUP, and the reporting of CUP statistics. A total of 20 regional registries in Australia (n=8), the UK (n=11) and Ireland (n=1) were approached and agreed to participate. The survey data were analysed using descriptive statistics.

#### Results

The findings show no evidence of consistent national or international coding guidance for registering and reporting CUP, resulting in varied cancer registration practices. The variation in practice includes differing interpretations of ICDO3 and ICD10 codes, the investigation of death certificate only notifications, electronic notifications, consideration of prior registrations of site-specific cancers, and the types of notifiers approached for additional information. In addition, there is variation in coding practices for tumours with non-epithelial morphologies such as melanoma and sarcoma, and the use of ill-defined primary site codes such as 'gastrointestinal' cancer. Reporting practices also vary, with some registries using ICDO3 codes and others using different ICD10 codes to represent CUP.

#### Conclusions

Inconsistencies in the registration practices for CUP impact on CUP incidence reporting and hinder comparisons between jurisdictions. This obscures an accurate understanding of the burden of the disease which is important for its management. The survey results will be used to develop a better understanding of historic data issues whilst informing future national and international registration guidance.

#### Acknowledgements

The participation of the UK, Republic of Ireland, and Australian cancer registries is gratefully acknowledged. Additional thanks to Catherine Thomson, formerly of Cancer Research UK.

# Parallel Sessions 4

## Data quality, governance and management

### Colorectal cancer pathology reporting: a regional audit

**Rebecca Birch**<sup>1</sup>, Eva Morris<sup>1</sup>, Nick West<sup>1</sup>, Paul Finan<sup>2</sup>, Phil Quirke<sup>1</sup>

<sup>1</sup>University of Leeds, <sup>2</sup>Leeds Teaching Hospitals NHS Trust

#### Background

The Royal College of Pathologists recommends the completion of a histopathological minimum dataset to report resected colorectal cancers. This study aimed to audit the quality and completeness of these reports.

#### Method

All minimum datasets for resected colorectal tumours submitted to the Northern & Yorkshire Cancer Registry and Information Service (NYCRIS) between 1996 and 2010 were examined. Trends in the data were analysed by year, NHS Trust and overall.

#### Results

25,580 major resections for colorectal cancer occurred in the 11 submitting NHS Trusts over the study period and minimum datasets were available for 19,892 (78.7%) of the resected specimens. Of these, 11,720 (58.9%) were completed by the trust and 8,172 (41.1%) were completed using information obtained by the registry.

Circumferential margin status (CRM) was recorded in 82.1% of rectal cancer cases. Reporting of longitudinal margin status was variable, with the status of the proximal/distal margin being recorded in 92.1% of cases whilst the status of the doughnuts was recorded in just over half the population (50.6%). Local invasion and number of nodes examined contained the smallest amount of missing data (complete in 98.6% and 97.6% of cases).

Reporting varied by up to 60% between trusts. Completeness of differentiation by predominant area ranged from 10.8% to 42.7%, a similar pattern was seen in the recording of histological type and CRM. The number of lymph nodes identified improved with time, with the median yield increasing from 7 nodes in 1996 to 17 in 2010. An improvement was also seen in extramural vascular invasion with the completeness of this field increasing from 17.3% to 97.4%. Full staging information (I, II, III, IV) was recorded in 98.4% of cases.

#### Conclusions

This study demonstrates an improvement in pathology reporting, but, several important prognostic factors remain under reported.

# Parallel Sessions 4

## End of life and palliative care

### Use of hospital services among palliative oesophago-gastric cancer patients

Oliver Groene<sup>1,2</sup>, **Angelina Taylor**<sup>2</sup>, Richard Hardwick<sup>3</sup>, Stuart Riley<sup>4</sup>, Georgina Chadwick<sup>2</sup>, Tom Crosby<sup>5</sup>, Kimberley Greenaway<sup>6</sup>, David Cromwell<sup>1</sup>

<sup>1</sup>The Royal College of Surgeons of England, <sup>2</sup>London School of Hygiene and Tropical Medicine, <sup>3</sup>The Association of Upper GI Surgeons, <sup>4</sup>The British Society of Radiologists, <sup>5</sup>Royal College of Radiologists, <sup>6</sup>Health and Social Care Information Centre

#### Background

A high proportion of patients on a palliative care pathway continue to use hospital services or die in hospital, despite calls for increased care in the community. Further research is required to distinguish hospitalisation near end of life for specific disease pathways, since a wide range of factors influence service utilisation and place of death. For oesophago-gastric cancer patients with palliative treatment intent, three treatment options exist: palliative oncological treatment, endoscopic treatment, and best supportive care. This study sought to assess health service utilisation of patients diagnosed with oesophago-gastric cancer on a palliative care pathway.

#### Method

Patient data were obtained from the National Oesophago-gastric Cancer Audit and linked to the Hospital Episode Statistics (HES) dataset. For each patient, the method of hospital admission, date and mode of treatment intent was identified.

#### Results

8,499 palliative care patients were identified in the linked audit-HES dataset. 4,036 patients had an oncology treatment plan, 1,526 had endoscopic care, and 2,887 had best supportive care. 85.6% who received oncological care were re-admitted to hospital one or more times, in comparison to 76.3% and 50.7% who received endoscopic care and best supportive care respectively ( $p < 0.001$ ). Multivariate analysis suggests a six fold risk (OR 6.2; CI 95% 4.6-8.6) of hospital admissions for patients receiving oncological care, as compared to best supportive care. More than half (50.2%) of patients receiving palliative oncology experienced 4 or more emergency admissions before death.

#### Conclusions

This study suggests that palliative treatment decisions for patients with oesophago-gastric cancer must be carefully made with hospital re-admission risk in mind.

#### Acknowledgements

The National Oesophago-Gastric Cancer Audit is commissioned and sponsored by the Healthcare Quality Improvement Partnership (HQIP).

# Parallel Sessions 4

## End of life and palliative care

### Investigating End of Life Care across NHS Area Teams using the National Survey of Bereaved People

Helen Harris<sup>1</sup>, Neil Bannister<sup>1</sup>, Emma Gordon<sup>1</sup>

<sup>1</sup>Office for National Statistics

#### Background

The National Survey of Bereaved People is an annual survey, run by the Office for National Statistics, that collects information on bereaved carers' views of the quality of care provided at the end of life across England. The survey utilises the Views of Informal Carers Evaluation of Services (VOICES s-f) questionnaire, developed by the University of Southampton to address a gap in knowledge of end of life care quality and provide a monitoring tool to inform the Government's End of Life Care Strategy for England. There are now two years of survey data, which have been combined and analysed at NHS Area Team level for the first time.

#### Method

Respondents are selected from people who have registered a death, whose details are recorded on the ONS Deaths Registration Database. In the period 2011 to 2012 a sample of 98,000 respondents were selected, based on the cause of death, place of death, age, sex and geographical area of the deceased. The VOICES questionnaire is mailed to the person who registered the death, requesting information on their perception of the quality of care provided to the deceased. The questionnaire collects data on quality of care across a number of themes such as dignity and respect, relief of pain and suffering, support for relatives, friends and carers and preferences and choices at the end of life. This data is then combined with the information from the death certificate for analysis.

#### Results

The analysis investigates quality of care by theme, reviewing how care varies across setting. For instance comparing the quality of care provided by out of hours services, hospitals and care homes and assessing the extent that this varies by NHS Area Team. Some aspects of health care vary widely by geographical area and care provider and this study investigates these patterns. Findings will be published on the ONS website in March 2014.

#### Acknowledgements

NHS England, Department of Health, National End of Life Care Intelligence Network, Public Health England and the University of Southampton.

# Parallel Sessions 4

## End of life and palliative care

### Impact of electronic palliative care coordination systems on place of death

Julian Abel<sup>1</sup>, **Andy Pring**<sup>2</sup>

<sup>1</sup>Weston Area Health Trust, <sup>2</sup>Knowledge and Intelligence Team (South West), Public Health England

#### Background

Between 50% and 90% of people would choose to die at home. EPaCCS (electronic palliative care coordination systems) have been in place in the south west for the last 3 years. They contain the wishes of where patients want to die. We report on a data set of 3171 people, 2022 of whom had a cancer diagnosis, whose wishes were placed on an EPaCCS. Place of death was determined using ONS mortality files.

#### Method

We combined the outputs from EPaCCS from 4 primary care trusts in the southwest who had been entering patient choices about place of death from March 2011 to February 2013. Recording of diagnosis was taken from the EPaCCS. This information was then matched with ONS mortality files, to determine diagnosis and place of death. All patients who were placed on the EPaCCS had given consent for information sharing.

#### Results

In total, 2022 patients with a diagnosis of cancer, who had information on an EPaCCS died during the study period. 386 (19%) died in a care home, 439 (22%) died in a hospice, 230 (11%) died in a hospital, 930 (46%) died in their own home and 37 (2%) died in other places. During the study period, there were a total of 21,936 cancer deaths. Of these 7,439 (33.9%) died in hospital. 9.2% of the cancer deaths were on EPaCCS.

#### Conclusions

The figure of a hospital death rate of 10% for cancer patients on EPaCCS is in keeping with previous study of the impact of advance care planning, in which 75% of patients died in their place of choice. The national mean percentage of cancer patients dying in hospital in 2012 was 37.5%. The process of asking people about their end of life preferences, placing these on an EPaCCS and providing care where patients choose is a highly effective intervention in allowing people to die in their place of choice.

#### Acknowledgements

Peter Lacey

#### References

[1]The impact of advance care planning on place of death. Abel J, Pring A, Rich A, Verne J. BMJ Support Palliat Care doi:10.1136/bmjspcare-2012-000327

# Parallel Sessions 4

## Less common cancers

### Setting the scene for rare and less common cancers

Lucy Elliss-Brookes<sup>1</sup>

<sup>1</sup>National Cancer Intelligence Network, Public Health England

Rare and less common cancers (cancers outside of the 'big four' of breast, prostate, lung and bowel) account for more than half of all cancer deaths in the UK. Using and understanding data is a key asset for charities and support groups in fundraising, awareness building work and patient support. For less common cancers it is especially important for organisations to work together to understand the common themes that the data are telling us.

The National Cancer Intelligence Network is committed to including rare and less common cancers in its core publications. Recent work on Routes to Diagnosis included results broken down into 57 cancer groupings. The updated deprivation report (incidence and mortality over a 15 year period), produced in partnership with Cancer Research UK, includes results broken down into 37 cancer groupings.

This presentation will provide a national overview of these data from a rare and less common cancer perspective.

# Parallel Sessions 4

## Less common cancers

### Menopausal hormone therapy and risk of central nervous system tumours: a nested case-control study

Victoria Benson<sup>1</sup>, Oksana Kirichek<sup>1</sup>, Valerie Beral<sup>1</sup>, Jane Green<sup>1</sup>

<sup>1</sup>University of Oxford

#### Background

Sex hormones may influence the risk of central nervous system (CNS) tumours, particularly meningiomas, but evidence is inconsistent.

#### Method

We conducted a nested case-control study within the UK General Practice Research Database (GPRD) cohort to examine the relation between prescription for hormone therapy (HT) for the menopause and the incidence of CNS tumours. Our study included women aged 50-79 years registered in the GPRD during 1987-2011. Controls were matched to cases in a ratio of 4:1 for year of birth, general practice and observation period. Relative risks (RRs) and 95% confidence intervals (CIs) were estimated using conditional logistic regression.

#### Results

During a mean observation period of 8.6 years, 3500 CNS tumours were recorded, of which 689 were glioma, 1197 meningioma, 439 acoustic neuroma, and 273 were pituitary tumours. Women prescribed HT had a significantly increased risk of any CNS tumour (RR for 1+ vs. no HT prescriptions = 1.2, 95%CI=1.1-1.3), and risk between tumour types did not differ for specified glioma, meningioma, acoustic neuroma, and pituitary tumours (heterogeneity-p = 0.6). In women with a current prescription for HT, the risks for all CNS tumours and for specified types were higher for oestrogen-only HT than for combined oestrogen-progestogen HT. Meningioma risk did not vary by type of HT.

#### Conclusions

Findings from the GPRD study suggest that HT for the menopause may increase the risk of CNS tumours, with the excess risk largely confined to oestrogen-only HT.

#### Acknowledgements

This study was funded by Cancer Research UK and the Medical Research Council.

# Parallel Sessions 4

## Less common cancers

### Incidence, survival and treatment patterns for patients with head and neck sarcoma

**Nicola Dennis**<sup>1</sup>, Matthew Francis<sup>1</sup>

<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England

#### Background

Bone and soft tissue sarcomas account for 1% of all malignancies diagnosed in England, and around 10% are diagnosed in the head and neck (H&N). Information on H&N sarcoma incidence, outcomes and treatment is limited. English cancer registration data can be used to establish incidence and survival rates, and treatment patterns.

#### Method

The 2010 National Cancer Data Repository (NCDR) includes all malignancies diagnosed in England between 1 January 1990 and 31 December 2010. The cancer analysis subset of the Hospital Episode Statistics (HES) dataset includes hospital inpatient and day case patients admitted between 1 April 1998 and 31 March 2010 with a record of cancer. Patients with a record of a H&N sarcoma diagnosed in England between 1990 and 2010 were extracted from the NCDR and linked to the HES database.

#### Results

Between 1990 and 2010 in England, 4,796 patients were diagnosed with H&N sarcoma, 793 in the bones and 4,003 in the connective or soft tissue. In 2010 age standardised incidence rates were 0.9 and 3.8 per million population for bone H&N sarcoma and soft tissue H&N sarcoma respectively. Both bone and soft tissue sarcomas were more common in older people. H&N sarcoma 5-year relative survival rates for patients diagnosed between 2001 and 2005 were higher than those for sarcomas in general: 73% for bone and 64% for soft tissue H&N patients, compared with overall survival of 56% and 54% respectively. 65% of H&N sarcoma patients diagnosed between 2000 and 2010 had at least one surgical HES record. The majority of patients were treated at a higher sarcoma surgical caseload centre although 81 different hospital Trusts surgically treated at least one bone sarcoma and 150 Trusts at least one soft tissue sarcoma between 2000 and 2010.

#### Conclusions

Bone and soft tissue sarcomas of the head and neck are very rare. Survival rates are slightly higher than those for all sarcomas. Surgical treatment has historically been carried out at a large number of NHS Trusts. The large number of hospital Trusts treating patients highlights the need for a more focussed management of patients with head and neck sarcomas.

# Parallel Sessions 4

## Less common cancers

### Risk of adverse health and social outcomes up to 50 Years after Wilms' tumour: The British Childhood Cancer Survivor Study

**Kwok Wong**<sup>1</sup>, Raoul Reulen<sup>1</sup>, David Winter<sup>1</sup>, Joyeeta Guha<sup>1</sup>, Miranda Fidler<sup>1</sup>, Julie Kelly<sup>1</sup>, Clare Frobisher<sup>1</sup>, Mike Hawkins<sup>1</sup>

<sup>1</sup>University of Birmingham

#### Background

Survival after Wilms' tumour (WT) has improved considerably over the last few decades, however, there is uncertainty regarding the magnitude of long-term adverse health and social outcomes. To investigate the risks of adverse health and social outcomes among five-year survivors of childhood Wilms' tumour with longer follow-up than available in previous studies.

#### Methods

The British Childhood Cancer Survivor Study (BCCSS) includes 1,478 five-year survivors of childhood WT. Cause-specific mortality and risk of developing subsequent primary neoplasms (SPNs) were investigated. Levels of smoking, drinking, educational attainment and health-related quality of life were investigated for survivors who completed the BCCSS questionnaire (n=971).

#### Results

Overall, 151 deaths were observed; almost six times the number expected (SMR=5.6;95%CI: 4.7,6.5). After recurrence the most frequent causes of death were SPNs (SMR=6.8; 95%CI: 4.9,9.2) and circulatory disease (SMR=5.3;95%CI: 3.3,8.2). The number of excess deaths due to all causes except recurrence increased 10-fold from the initial 25 years of follow-up to beyond 25 years where recurrence only accounted for 6% of the number of excess deaths, whilst deaths due to SPNs and circulatory disease together accounted for 66% of the total number of excess deaths. Cumulative mortality due to causes other than recurrence increased substantially from 2.8% at 25 years after diagnosis to 20.4% at 50 years – the majority of these deaths were attributable to SPNs and circulatory related diseases (62 of 106). Female survivors exposed to abdominal irradiation had a 2.4-fold odds ratio (OR) of delivering offspring with a low birth weight (95%CI: 1.5,4.8) and 3.1-fold OR of delivering preterm (95%CI: 2.1,4.7) compared to those who survived other cancers and did not receive abdominal irradiation. WT survivors rated their health as being much worse than expected, for example in answer to "I seem to get ill more easily than other people", 20% indicated agreement whilst 6% were expected from the general population.

#### Conclusions

WT survivors remain at a substantially increased risk of late mortality, specifically from SPNs and circulatory diseases beyond 25 years from diagnosis; this and other findings provides evidence for risk-based clinical follow-up, updated clinical follow-up guidelines and potential intervention studies.

# Plenary 4

Delivering outcomes that matter - panel debate and Q&A session

**Chair: Robert Peston, Economics Editor, BBC**

Robert Peston is the BBC's Economics Editor and founder of the education charity, Speakers for Schools. Before joining the BBC in early 2006, he was political editor and financial editor of the Financial Times, City Editor of the Sunday Telegraph and a columnist for the New Statesman and Sunday Times. Robert has published three books, "How Do We Fix This Mess", "Who Runs Britain?", and "Brown's Britain". He has won numerous awards for his journalism, including Journalist of the Year, Specialist Journalist of the Year and Scoop of the Year (twice) from the Royal Television Society, Performer of the Year from the Broadcasting Press Guild, Broadcaster of the Year and Journalist of the Year from the Wincott Foundation and Business Journalist of the Year from the London Press Club. The Global Lung Cancer Coalition named him Lung Cancer Journalist of the Year in 2014. You can follow Robert on twitter @peston



**Ciarán Devane, Chief Executive, Macmillan Cancer Support**

Ciarán Devane was educated at University College, Dublin where he gained first class honours in biochemical engineering. He also holds a masters degree in International Policy from George Washington University, Washington DC. He worked for ICI for 8 years before joining Gemini Consulting. Ciarán joined Macmillan Cancer Support as Chief Executive in May 2007. Ciarán co-chairs the National Cancer Survivorship Initiative and is a trustee of the National Council for Voluntary Organisation and the Makaton Charity. He is also on the advisory council of the Cicely Saunders Institute. In January 2012, Ciarán Devane was appointed as a Non-Executive Director of NHS England.



**Sean Duffy, National Clinical Director for Cancer, NHS England**

Sean Duffy is the National Clinical Director for Cancer. Mr Duffy is also a clinical academic gynaecologist based at the University of Leeds with his clinical practice at the city's St James's Hospital. His medical expertise is in endometrial cancer and he has an international reputation in the field of endoscopy surgery and training. He has had senior academic experience in laboratory and health services research and has had national and regional responsibilities for undergraduate and postgraduate education in obstetrics and gynaecology with senior roles in the Royal College of Obstetrics and Gynaecology and the University of Leeds. For the eight years before he was appointed national clinical director for cancer, he was leading the Yorkshire Cancer Network as medical director and over the last four as director as well.



## Plenary 4

### **Professor Peter Johnson, Chief Clinician, Cancer Research UK**

Professor Peter Johnson was appointed Chief Clinician for Cancer Research UK in 2008. He graduated from Cambridge University and St Thomas's Medical School. He trained in oncology at St Bartholomew's Hospital, where he was an Imperial Cancer Research Fund Clinical Research Fellow and completed his doctoral research on the Bcl-2 gene, its potential as a therapeutic target in lymphoma and the effects of CD40 ligation on the B-cell surface. He was subsequently a Senior Lecturer in Medical Oncology in the ICRF Cancer Medicine Research Unit, Leeds and took up the Chair of Medical Oncology in Southampton in 1998. He leads the Southampton Cancer Research UK Centre, responsible for bringing together a broad multidisciplinary group of basic, translational and clinical researchers, and linking the laboratory research to the extensive clinical practice in cancer treatment in the Southampton Cancer Centre.



### **Dr Jem Rashbass, Director for Disease Registration, Public Health England**

Jem Rashbass studied medicine at University College London, trained in diagnostic pathology, becoming a clinical academic dividing his time between clinical work and the creation of Clinical and Biomedical Computing Unit at Cambridge University. In 2003 he became head of the Eastern Cancer Registry and Information Centre, a post he held in conjunction with the leadership of the East of England Cancer Screening Quality Assurance Service. In 2011 he was appointed National Director for Cancer Registry Modernisation and in April 2013 he became National Director for Disease Registration in Public Health England. Previously Jem spent six years as a Non-executive Director and Vice Chairman of the NHS Information Authority and has acted as a special advisor to the Health Select Committee of the House of Commons.



### **Andrew Wilson, Chief Executive Officer, Rarer Cancers Forum**

Andrew Wilson was appointed Chief Executive in 2009. He works with parliamentarians, civil servants, clinicians, managers, patient groups, charities, researchers and industry to achieve the objectives of the charity which aims to achieve the best care and outcomes for patients with rare and less common cancers. Andrew was closely involved in the establishment of the Cancer Drugs Fund following the RCF report 'Exceptional England' mapping the unmet needs of cancer patients in the UK. Andrew has led many of the more recent campaigns for the charity and also takes the lead in policy matters.





# Understanding Cancer

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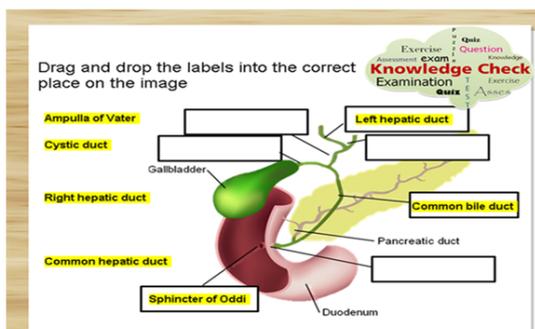
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## Who it is for and what you will learn

This e-learning tool is aimed primarily at Multi-disciplinary Team Co-ordinators and Cancer Registration staff who need to know:

- about cancer – medical terminology, diagnoses, tests and treatments
- how cancer services are organised in the NHS
- about cancer types – key risks, including causes, risk factors, signs and symptoms, anatomy and physiology

Other NHS and Public Health staff can also use the course to improve their understanding of cancer



# Posters

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Clinical audit	1-5
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Supporting commissioning	108-111
Survivorship	112-125
Treatment	126-132

# Posters

- 1. Are clinical guidelines governing the use of PET-CT scanners in congruence with clinical practice?**  
Damilola Agbato<sup>1</sup>, David Morrison<sup>1</sup>, Eileen Kesson<sup>2</sup>  
<sup>1</sup>University of Glasgow, <sup>2</sup>NHS Greater Glasgow and Clyde
- 2. Care of bladder cancer patients diagnosed in Northern Ireland 2010 & 2011**  
Finian Bannon<sup>1</sup>, Lisa Ranaghan<sup>1</sup>, Jackie Kelly<sup>1</sup>, Julie McConnell<sup>1</sup>, Bernadette Anderson<sup>1</sup>, Anna Gavin<sup>1</sup>  
<sup>1</sup>Queen's University Belfast
- 3. A multicentre audit of post gastroscopy upper gastrointestinal cancer**  
Timothy Evans<sup>1</sup>, Danny Cheung<sup>2</sup>, John Broggio<sup>1</sup>, Nigel Trudgill<sup>2</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England, <sup>2</sup>Sandwell and West Birmingham Hospitals NHS Trust
- 4. An audit to investigate whether second primary cancer waiting times in Leeds PCT comply with those outlined in the NHS Cancer Plan guidelines**  
Anna Rosiana<sup>1</sup>, Callum Booth<sup>1</sup>, Daniel Stark<sup>2</sup>, Martin Waugh<sup>2</sup>  
<sup>1</sup>University of Leeds, <sup>2</sup>Leeds Teaching Hospital NHS Trusts
- 5. How treatment varies by age in older women with breast cancer with no comorbid conditions**  
Saiqa Tabasum<sup>1</sup>, Tony Moran<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (North West), Public Health England
- 6. Characteristics and outcomes of patients with haematological malignancy admitted to intensive care units in the West of Scotland.**  
Philip McLoone<sup>1</sup>, David Morrison<sup>1</sup>, Kathryn Puxty<sup>1</sup>, Tara Quasim<sup>1</sup>, John Kinsella<sup>1</sup>  
<sup>1</sup>University of Glasgow
- 7. Comparison of cancer and non-cancer patients admitted to ICU with a non-surgical diagnosis**  
Kathryn Puxty<sup>1</sup>, John Kinsella<sup>1</sup>, Philip McLoone<sup>1</sup>, Tara Quasim<sup>1</sup>, David Morrison<sup>1</sup>  
<sup>1</sup>University of Glasgow
- 8. Emergency presentation of cancer: patients' journeys before arriving at A&E**  
Victoria Spencer-Hughes<sup>1</sup>, Melanie Ridge<sup>1</sup>, Lucia Grun<sup>1</sup>, Kathy Pritchard-Jones<sup>1</sup>  
<sup>1</sup>London Cancer
- 9. Cancer Diagnosis in the acute setting**  
Hilary Wilderspin<sup>1</sup>, Tom Newsom-Davis<sup>2</sup>, Cathy Hughes<sup>1</sup>  
<sup>1</sup>London Cancer Alliance, <sup>2</sup>Chelsea & Westminster NHS Trust
- 10. UK Biobank: A powerful new resource for cancer research**  
Daniel Wright<sup>1,2</sup>, Naomi Allen<sup>1,2</sup>, Cathie Sudlow<sup>1,3</sup>, Henrik Moller<sup>4</sup>, Michael Chapman<sup>5</sup>, Ekaterini Blaveri<sup>6</sup>, Rachael Brannan<sup>6</sup>  
<sup>1</sup>UK Biobank, <sup>2</sup>University of Oxford, <sup>3</sup>University of Edinburgh, <sup>4</sup>King's College London  
<sup>5</sup>Cancer Research UK, <sup>6</sup>National Cancer Intelligence Network, Public Health England

- 11. Empowering young people to participate in research: young people's views about research access and participation**  
Rachel Taylor<sup>1</sup>, Anita Solanki<sup>1</sup>, Natasha Aslam<sup>1</sup>, Jeremy Whelan<sup>1</sup>, Lorna Fern<sup>1</sup>  
<sup>1</sup>University College London Hospitals
- 12. Comorbidity and outcomes among cancer patients**  
Tom Liptrot<sup>1</sup>, Jacqueline Livsey<sup>1</sup>, Catherine O'Hara<sup>1</sup>, Ben Wilson<sup>1</sup>  
<sup>1</sup>The Christine NHS Foundation Trust
- 13. Effect of comorbidity on surgery and survival in lung cancer patients, England**  
Sharma Riaz<sup>1</sup>, Ruth Jack<sup>1</sup>, Michael Peake<sup>2</sup>, Mike Lind<sup>3</sup>, Henrik Møller<sup>4</sup>, Margreet Lüchtenborg<sup>1,5</sup>  
<sup>1</sup>Knowledge and Intelligence Team (London), Public Health England, <sup>2</sup>Department of Respiratory Medicine, Glenfield Hospital, <sup>3</sup>Queens Centre for Oncology and Haematology, Hull and East Yorkshire NHS Trust, <sup>4</sup>Cancer Epidemiology and Population Health, King's Health Partners Integrated Cancer Centre, <sup>5</sup>Department of Public Health and Research Centre for Cancer Diagnosis in Primary Care, Aarhus University
- 14. Comorbidities among critically ill cancer patients: a descriptive analysis of 7,434 intensive care unit patients**  
Alasdair Simpson<sup>1</sup>, Philip McLoone<sup>1</sup>, Billy Sloan<sup>1</sup>, David Morrison<sup>1</sup>  
<sup>1</sup>University of Glasgow
- 15. Using the Cancer e-Atlas in Scotland**  
Gwen Allardice<sup>1</sup>, Eileen Kesson<sup>2</sup>, David Morrison<sup>2</sup>  
<sup>1</sup>University of Glasgow, <sup>2</sup>West of Scotland Cancer Surveillance Unit
- 16. Managing disclosure in health statistics using statistical geographies**  
Diane Edwards<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England
- 17. Data to improve quality in end of life care: a new national information standard**  
Katie Lindsey<sup>1</sup>  
<sup>1</sup>End of Life Care Intelligence Network, Public Health England
- 18. The power of data captured by clinicians for clinicians**  
Jacqueline Livsey<sup>1</sup>, Rhidian Bramley<sup>1</sup>, Catherine O'Hara<sup>1</sup>, Ben Wilson<sup>1</sup>, Emma Blackwood<sup>1</sup>, Richard Clapham<sup>1</sup>  
<sup>1</sup>The Christine NHS Foundation Trust
- 19. The Online Cancer Staging Tool: calculating full, simplified or range of cancer staging with partial information**  
Giulio Napolitano<sup>1</sup>, Elizabeth Ranaghan<sup>2</sup>, James Brierley<sup>3</sup>, Morten Ervik<sup>4</sup>, Anna Gavin<sup>2</sup>  
<sup>1</sup>Queen's University Belfast, <sup>2</sup>Northern Ireland Cancer Registry, <sup>3</sup>Union for International Cancer Control and Princess Margaret Cancer Centre, Toronto, <sup>4</sup>International Agency for Research on Cancer
- 20. Validity and reliability of Thai version of the Missoula-Vitas Quality-of-Life Index**  
Piyawan Pokpalagon<sup>1</sup>, Somchit Hanucharunkul<sup>1</sup>  
<sup>1</sup>Faculty of Medicine Ramathibodi Hospital, Mahidol University

- 21. LCA Cancer Waiting Times analysis**  
Stephen Scott<sup>1</sup>, Hilary Wilderspin<sup>1</sup>  
<sup>1</sup>London Cancer Alliance
- 22. LCA Metrics**  
Stephen Scott<sup>1</sup>, Hilary Wilderspin<sup>1</sup>  
<sup>1</sup>London Cancer Alliance
- 23. Enhancing intelligence and research through improved data access**  
Jon Shelton<sup>1</sup>, Sally Vernon<sup>2</sup>, James Thomas<sup>2</sup>, Alan Macdonald<sup>2</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>National Cancer Registration Service, Public Health England
- 24. Exploring cancer statistics with maps**  
Alan Slater<sup>1</sup>, Ant Lewis<sup>1</sup>, Tori Howard<sup>1</sup>, Nick Ormiston-Smith<sup>1</sup>  
<sup>1</sup>Cancer Research UK
- 25. Cancers lost and found - what has changed about our understanding of cancer in England after the migration of the cancer registries?**  
Sally Vernon<sup>1</sup>, David Greenberg<sup>1</sup>, Christine Head<sup>1</sup>, Sean McPhail<sup>2</sup>, Brian Shand<sup>1</sup>, Jon Shelton<sup>2</sup>, James Thomas<sup>1</sup>, Jem Rashbass<sup>1</sup>  
<sup>1</sup>National Cancer Registration Service, Public Health England, <sup>2</sup>National Cancer Intelligence Network, Public Health England
- 26. Factors predicting the effectiveness of palliative care in patients with advanced cancer**  
Suchira Chaiviboontham<sup>1</sup>, Somchit Hanucharunkul<sup>1</sup>  
<sup>1</sup>Ramathibodi School of Nursing, Faculty of Medicine Ramathibodi Hospital, Mahidol University
- 27. QUALYCARE-NI Study: what enables cancer patients to die at home? A study of carers and bereaved relatives**  
Deirdre Fitzpatrick<sup>1</sup>, Anna Gavin<sup>2</sup>  
<sup>1</sup>Queen's University Belfast, <sup>2</sup>Northern Ireland Cancer Registry
- 28. Place of death in children and young people (CYP) with cancer: rural-urban differences and distance to usual residence**  
Wei Gao<sup>1</sup>, Julia Verne<sup>2</sup>, Joanna Davies<sup>1</sup>, Janet Peacock<sup>1</sup>, Emma Gordon<sup>3</sup>, Carolyn Morris<sup>4</sup>, Anne Greenough<sup>1</sup>, Irene Higginson<sup>1</sup>  
<sup>1</sup>King's College London, <sup>2</sup>Knowledge and Intelligence Team (South West), Public Health England, <sup>3</sup>Office for National Statistics, <sup>4</sup>National Cancer Research Institute
- 29. Using public health intelligence to improve end of life care**  
Kathryn Ingold<sup>1</sup>, Fiona Hicks<sup>1</sup>  
<sup>1</sup>Leeds Teaching Hospitals NHS Trust
- 30. Percentage of last 6 months of life spent at home or in a community setting**  
Andy Pring<sup>1</sup>, Julia Verne<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (South West), Public Health England
- 31. Locally advanced rectal cancer: a case of difficult pain control**  
Claire Rooney<sup>1</sup>, Amara Nwosu<sup>2</sup>, Leslie Allsopp<sup>2</sup>  
<sup>1</sup>The Christie Hospital, <sup>2</sup>Marie Curie Hospice, Liverpool

- 32. Implementing the AMBER care bundle within cancer services**  
Robert Smith<sup>1</sup>, Irene Carey<sup>2</sup>, Adrian Hopper<sup>2</sup>, Susanna Shouls<sup>2</sup>, James Lapworth<sup>3</sup>  
<sup>1</sup>Derby Hospitals NHS Trust, Guy's and St Thomas' NHS Foundation Trust, <sup>3</sup>NHS Improving Quality
- 33. End of life care in head & neck cancers 2002-2011**  
Tom Walker<sup>1</sup>, Shivaun Fleming<sup>2</sup>, Andy Pring<sup>2</sup>, Julia Verne<sup>2</sup>  
<sup>1</sup>University Hospitals Bristol NHS Foundation Trust, <sup>2</sup>Knowledge and Intelligence Team (South West), Public Health England
- 34. Analysis of cancer deaths in hospital**  
Hilary Wilderspin<sup>1</sup>, Liz Chart<sup>1</sup>  
<sup>1</sup>London Cancer Alliance
- 35. Surveillance of non-melanoma skin cancer incidence rates in kidney transplant recipients in Ireland**  
Finian Bannon<sup>1</sup>, Jennifer McCaughan<sup>2</sup>, Carol Traynor<sup>3</sup>, Katie O'Brien<sup>4</sup>, Anna Gavin<sup>2</sup>, Alexander Maxwell<sup>2</sup>, Harry Comber<sup>4</sup>, Peter Conlon<sup>3</sup>  
<sup>1</sup>Queen's University Belfast, <sup>2</sup>Queen's University Belfast, <sup>3</sup>Beaumont Hospital, Dublin, <sup>4</sup>National Cancer Registry of Ireland
- 36. Agricultural land use and bone cancer: is there a link? Small-area analyses of osteosarcoma and Ewing sarcoma diagnosed in 0-49 year olds in Great Britain**  
Karen Blakey<sup>1</sup>, Richard Feltbower<sup>2</sup>, Peter James<sup>3</sup>, Charles Stiller<sup>4</sup>, Paul Norman<sup>5</sup>, Dave Garthwaite<sup>6</sup>, Jacqueline Hughes<sup>7</sup>, Craig Gerrand<sup>8</sup>, Richard Richard<sup>3</sup>  
<sup>1</sup>Newcastle University, <sup>2</sup>Paediatric Epidemiology Group, University of Leeds, <sup>3</sup>Institute of Health and Society, Newcastle University, <sup>4</sup>Childhood Cancer Research Group, Department of Paediatrics, University of Oxford, <sup>5</sup>School of Geography, University of Leeds, <sup>6</sup>Food and Environment Research Agency, <sup>7</sup>Science and Advice for Scottish Agriculture, <sup>8</sup>Northern Institute for Cancer Research (NICR), Newcastle University and North of England Bone and Soft Tissue Tumour Service,
- 37. Socio-economic patterning in early mortality of patients aged 0-49 years diagnosed with osteosarcoma or Ewing sarcoma in Great Britain, 1985-2009**  
Karen Blakey<sup>1</sup>, Richard Feltbower<sup>2</sup>, Peter James<sup>3</sup>, Charles Stiller<sup>4</sup>, Paul Norman<sup>5</sup>, Craig Gerrand<sup>6</sup>, Richard McNally<sup>3</sup>  
<sup>1</sup>Newcastle University, <sup>2</sup>Paediatric Epidemiology Group, University of Leeds, <sup>3</sup>Institute of Health and Society, Newcastle University, <sup>4</sup>Childhood Cancer Research Group, University of Oxford, <sup>5</sup>School of Geography, University of Leeds, <sup>6</sup>Northern Institute for Cancer Research (NICR), Newcastle University and North of England Bone and Soft Tissue Tumour Service
- 38. Cause-specific mortality in five-year survivors of central nervous tumours in young adulthood: The Teenage and Young Adult Cancer Survivor Study (TYACSS)**  
Chloe Bright<sup>1</sup>, Raoul Reulen<sup>1</sup>, David Winter<sup>1</sup>, Clare Frobisher<sup>1</sup>, Michael Hawkins<sup>1</sup>  
<sup>1</sup>University of Birmingham
- 39. The association of marital status with ovarian cancer stage, treatment and outcomes**  
Christopher Brown<sup>1</sup>, Harry Comber<sup>1</sup>, Linda Sharp<sup>1</sup>  
<sup>1</sup>National Cancer Registry Ireland

- 40. Cancer epidemiology: what's being studied – and how do we keep on top of it?**  
Casey Dunlop<sup>1</sup>, Katrina Brown<sup>1</sup>, Cheryl Livings<sup>1</sup>  
<sup>1</sup>Cancer Research UK
- 41. Measuring exposure to fluoridated drinking water for 1st Fluoride Monitoring Report (due to be published 31/03/14)**  
Diane Edwards<sup>1</sup>, Matthew Bull<sup>2</sup>, Nick Young<sup>3</sup>, John Morris<sup>4</sup>, Julia Verne<sup>3</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England, <sup>2</sup>Public Health England, <sup>3</sup>Knowledge and Intelligence Team (South West), Public Health England, <sup>4</sup>Public Health England, Operations (Midlands and East)
- 42. Long-term outcomes of paediatric bone sarcoma and its treatment using record linkage: a BCCSS study**  
Miranda Fidler<sup>1</sup>, Clare Frobisher<sup>2</sup>, Joyeeta Guha<sup>2</sup>, Kwok Wong<sup>2</sup>, Julie Kelly<sup>2</sup>, David Winter<sup>2</sup>, Raoul Reulen<sup>2</sup>, Mike Hawkins<sup>2</sup>  
<sup>1</sup>University of Birmingham, <sup>2</sup>Centre for Childhood Cancer Survivor Studies, University of Birmingham
- 43. Characteristics and outcomes of elective and emergency colorectal cancer patients managed within the English NHS**  
Gareth Hicks<sup>1</sup>, Eva Morris<sup>2</sup>, Dermot Burke<sup>3</sup>, Paul Finan<sup>1</sup>  
<sup>1</sup>St James' University Hospital, <sup>2</sup>Section of Epidemiology and Biostatistics, Leeds Institute of Cancer and Pathology, University of Leeds
- 44. Trends in survival from kidney cancer in England**  
Luke Hounsome<sup>1</sup>, Julia Verne<sup>1</sup>, Erik Mayer<sup>2</sup>, Roger Kockelbergh<sup>3</sup>  
<sup>1</sup>Knowledge and Intelligence Team (South West), Public Health England, <sup>2</sup>Department of Surgery & Cancer, Imperial College London, <sup>3</sup>University Hospitals of Leicester NHS Trust, Leicester
- 45. Cutaneous melanoma in older persons**  
Alexander Ives<sup>1</sup>, Julia Newton-Bishop<sup>2</sup>, Veronique Poirier<sup>1</sup>, Tim Jones<sup>1</sup>, Julia Verne<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (South West), Public Health England, <sup>2</sup>University of Leeds
- 46. Factors influencing survival from cutaneous melanoma in England, Northern Ireland, and Scotland**  
Tim Jones<sup>1</sup>, Alexander Ives<sup>1</sup>, Veronique Poirier<sup>1</sup>, Julia Newton-Bishop<sup>2</sup>, Julia Verne<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (South West), Public Health England, <sup>2</sup>University of Leeds
- 47. New female breast cancer patient incidence rates**  
Gill Lawrence<sup>1</sup>, Jackie Walton<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England
- 48. Incidence of central nervous system and intracranial tumours by ethnic group in England, 2001-2007**  
Edward Maile<sup>1</sup>, Isobel Barnes<sup>1</sup>, Alexander Finlayson<sup>1</sup>, Shameq Sayeed<sup>1</sup>, Raghieb Ali<sup>1</sup>  
<sup>1</sup>University of Oxford
- 49. Comparison of TYA cancer mortality rates in the UK with other countries**  
Debasree Purkayastha<sup>1</sup>, Sabrina Sandhu<sup>1</sup>, Tony Moran<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (North West), Public Health England

- 50. Do older people in the UK have higher cancer incidence than those in the Nordic countries?**  
Sabrina Sandhu<sup>1</sup>, Tony Moran<sup>1</sup>  
<sup>1</sup> Knowledge and Intelligence Team (North West), Public Health England
- 51. Smoking at diagnosis is an independent prognostic factor for survival in head and neck cancer: findings from a large, population-based study**  
Linda Sharp<sup>1</sup>, Joseph McDevitt<sup>1</sup>, Anne-Elie Carsin<sup>2</sup>, Christopher Brown<sup>1</sup>, Harry Comber<sup>1</sup>  
<sup>1</sup>National Cancer Registry Ireland, <sup>2</sup>Centre for Research in Environmental Epidemiology (CREAL)
- 52. Incidence of breast and gynaecological cancers by ethnic group in England, 2001-2007**  
Megan Shirley<sup>1</sup>, Isobel Barnes<sup>1</sup>, Raghieb Ali<sup>1</sup>  
<sup>1</sup>University of Oxford
- 53. The effect of emergency presentation on surgery and survival in lung cancer patients in England 2006-2008**  
Daniela Tataru<sup>1</sup>, Ruth Jack<sup>1</sup>, Henrik Møller<sup>2</sup>, Margreet Lüchtenborg<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (London), Public Health England, <sup>2</sup>King's College London
- 54. Surgery and risk of venous thromboembolism in women with cancer: a UK-based prospective cohort study**  
Sian Sweetland<sup>1</sup>, Angela Balkwill<sup>1</sup>, Valerie Beral<sup>1</sup>, Toral Gathani<sup>1,2</sup>, Jane Green<sup>1</sup>, Gillian Reeves<sup>1</sup>  
<sup>1</sup>University of Oxford, <sup>2</sup>Oxford University Hospitals NHS Trust
- 55. The burden of healthcare costs associated with prostate cancer in the Republic of Ireland**  
Richeal Burns<sup>1</sup>, Jose Leal<sup>1</sup>, Jane Wolstenholme<sup>1</sup>, Ciaran O'Neill<sup>2</sup>, Frank Sullivan<sup>3</sup>, Frances Drummond<sup>4</sup>, Linda Sharp<sup>4</sup>  
<sup>1</sup>Health Economics Research Centre (HERC), University of Oxford, <sup>2</sup>Department of Economics, NUI Galway, <sup>3</sup>Prostate Cancer Institute, NUI Galway, <sup>4</sup>National Cancer Registry Ireland
- 56. Factors affecting hospital length of stay (LOS) after surgery for head and neck cancer: a population based study**  
Joe McDevitt<sup>1</sup>, Joe McDevitt<sup>1</sup>, Marianna De Camargo-Cancela<sup>1</sup>, Harry Comber<sup>1</sup>, Linda Sharp<sup>1</sup>  
<sup>1</sup>National Cancer Registry Ireland
- 57. Productivity losses due to premature mortality and reduced workforce participation following head and neck cancer**  
Alison Pearce<sup>1</sup>, Aileen Timmons<sup>1</sup>, Paul Hanly<sup>2</sup>, Paul Walsh<sup>1</sup>, Ciaran O'Neill<sup>3</sup>, Linda Sharp<sup>1</sup>  
<sup>1</sup>National Cancer Registry Ireland, <sup>2</sup>National College of Ireland, <sup>3</sup>National University of Ireland, Galway

58. **Age inequalities in the surgical management of colorectal cancer across England: 1998 to 2008**  
Rebecca Birch<sup>1</sup>, Amy Downing<sup>1</sup>, Katie Harris<sup>1</sup>, James Thomas<sup>2</sup>, Phil Quirke<sup>1</sup>, Paul Finan<sup>3</sup>, Eva Morris<sup>1</sup>  
<sup>1</sup>University of Leeds, <sup>2</sup>National Cancer Registration Service, Public Health England, <sup>3</sup>Leeds Teaching Hospitals NHS Trust
59. **The impact of older people's social networks on cancer treatment outcomes in the UK**  
Patty Doran<sup>1</sup>  
<sup>1</sup>University of Manchester
60. **Tackling inequalities through cancer intelligence: key metrics to enable change**  
Lucy Elliss-Brookes<sup>1</sup>, Sam Johnson<sup>1</sup>, Jon Shelton<sup>1</sup>, Joanne Rule<sup>2</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>National Cancer Equality Initiative
61. **The Nepali settlement and cancer treatment – making it better**  
Mary Hayes<sup>1</sup>, Simon Gifford<sup>1</sup>, Kathryn Stuart<sup>2</sup>, Lauren Lakritz<sup>1</sup>, Deepa Doshi<sup>3</sup>  
<sup>1</sup>Frimley Park Hospital NHS Foundation Trust, <sup>2</sup>Rushmoor Healthy Living Trustee, <sup>3</sup>Macmillan Cancer Support
62. **Using local level data to influence politics, policy and service configuration**  
Rosie Hinchliffe<sup>1</sup>, Carina Crawford<sup>1</sup>, Tom Lee<sup>1</sup>  
<sup>1</sup>Cancer Research UK
63. **A comparison of depressive symptoms between British South Asian patients compared with British White patients with cancer? A cross-sectional survey**  
Karen Lord<sup>1</sup>, Paul Symonds<sup>2</sup>, Kausher Ibrahim<sup>2</sup>, Sawan Kumar<sup>2</sup>, Alex Mitchell<sup>3</sup>  
<sup>1</sup>University Hospitals of Leicester NHS Trust, <sup>2</sup>University Hospitals of Leicester, <sup>3</sup>Leicestershire Partnership NHS Trust
64. **Ethnic perceptions of cancer among British South Asian patients compared with British White patients**  
Karen Lord<sup>1</sup>, Harriet Walter<sup>1</sup>, Paul Symonds<sup>1</sup>  
<sup>1</sup>University Hospitals of Leicester NHS Trust
65. **A novel methodology for constructing ethnic majority life tables for England and Wales for use in net survival analysis**  
Melanie Morris<sup>1</sup>, Bernard Rachet<sup>1</sup>, Laura Woods<sup>1</sup>  
<sup>1</sup>London School of Hygiene and Tropical Medicine
66. **The NHS Bowel Cancer Screening Programme - a health equity audit**  
David Munday<sup>1</sup>, Jane Goodman-Brown<sup>2</sup>  
<sup>1</sup>Oxford University Hospitals NHS Trust, <sup>2</sup>Oxford Brookes University
67. **Variation in cancer incidence (1996-2010) and mortality (1997-2011) by deprivation quintile, in England**  
Claudia Oehler<sup>1</sup>, Jennifer Yiallourou<sup>1</sup>, Sean McPhail<sup>1</sup>, Lucy Elliss-Brookes<sup>1</sup>, Nick Ormiston-Smith<sup>2</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>Cancer Research UK

- 68. Identifying variation in cancer mortality in the elderly; not as easy as it sounds**  
Rachel White<sup>1</sup>  
<sup>1</sup>Macmillan Cancer Support
- 69. Can axillary nodal sampling after neoadjuvant chemotherapy for breast cancer safely allow more limited axillary surgery?**  
Georgina Devenish<sup>1</sup>, Philippa Young<sup>2</sup>  
<sup>1</sup>Cardiff and Vales UHB - Llandough Hospital, <sup>2</sup>Cardiff and Vale UHB
- 70. Can core biopsy of the tumour bed after neoadjuvant chemotherapy for breast cancer safely inform more limited surgical excision?**  
Georgina Devenish<sup>1</sup>, Philippa Young<sup>1</sup>  
<sup>1</sup>Cardiff and Vales UHB - Llandough Hospital
- 71. The survival of patients with high-grade glioma from different ethnic groups in South East England**  
Tarini Ratneswaren<sup>1</sup>, Ruth Jack<sup>1,2</sup>, Daniela Tataru<sup>1,2</sup>, Elizabeth Davies<sup>1,2</sup>  
<sup>1</sup>King's College London, <sup>2</sup>London & Knowledge and Intelligence Team (London), Public Health England
- 72. Survival in sarcoma patients with pulmonary metastases**  
Matthew Francis<sup>1</sup>, Nicola Dennis<sup>1</sup>, Gill Lawrence<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England
- 73. Extremity soft tissue sarcoma amputation rates in England**  
Matthew Francis<sup>1</sup>, Nicola Dennis<sup>1</sup>, Gill Lawrence<sup>1</sup>, Robert Grimer<sup>2</sup>, Robert Ashford<sup>3</sup>, Timothy Evans<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England <sup>2</sup>Royal Orthopaedic Hospital NHS Foundation Trust, <sup>3</sup>University Hospitals of Leicester NHS Trust
- 74. Adverse health and social outcomes of childhood central nervous system tumour survivors in The British Childhood Cancer Survivor Study**  
Joyeeta Guha<sup>1</sup>, Raoul Reulen<sup>2</sup>, Elaine Sugden<sup>2</sup>, Martin McCabe<sup>3</sup>, Kwok Wong<sup>2</sup>, Miranda Fidler<sup>2</sup>, David Winter<sup>2</sup>, Julie Kelly<sup>4</sup>, Clare Frobisher<sup>2</sup>, Michael Hawkins<sup>2</sup>  
<sup>1</sup>University of Birmingham, <sup>2</sup>Centre for Childhood Cancer Survivor Studies, University of Birmingham, <sup>3</sup>Institute of Cancer Sciences, University of Manchester, <sup>4</sup>Centre for Childhood Cancer Survivor Studies, University of Birmingham
- 75. Cardiac mortality among five-year survivors of cancer diagnosed in teenagers and young adults aged 15-39 years**  
Katherine E Henson<sup>1</sup>, Raoul Reulen<sup>2</sup>, David Winter<sup>2</sup>, Clare Frobisher<sup>2</sup>, David Cutter<sup>1</sup>, Sarah Darby<sup>1</sup>, Michael Hawkins<sup>2</sup>  
<sup>1</sup>Clinical Trial Service Unit (CTSUs), <sup>2</sup>Centre for Childhood Cancer Survivor Studies
- 76. Planning for the unknown - patterns of admission of patients with cancer of unknown primary in the West of Scotland**  
Will Jones<sup>1</sup>, Gwen Allardice<sup>2</sup>, David Morrison<sup>2</sup>  
<sup>1</sup>University of Glasgow, <sup>2</sup>West of Scotland Cancer Surveillance Unit

- 77. Understanding the variation in brain and central nervous system survivorship outcomes and morbidities**  
James Shield<sup>1</sup>, Julie Flynn<sup>1</sup>, Tom Welchman<sup>2</sup>, Edmund Drage<sup>2</sup>, Michael Gibbs<sup>2</sup>, Chris Edson<sup>2</sup>, Andrew Brodbelt<sup>3</sup>, Peter Collins<sup>4</sup>, David Greenberg<sup>5</sup>  
<sup>1</sup>Macmillan Cancer Support, <sup>2</sup>Monitor Deloitte, <sup>3</sup>The Walton Centre NHS Foundation Trust, <sup>4</sup>University of Cambridge, <sup>5</sup>National Cancer Registration Service, Public Health England
- 78. Incidence and survival from glioblastoma in England, 2007 - 2011**  
Matt Williams<sup>1</sup>, Tim Winters<sup>2</sup>, David Greenberg<sup>3</sup>, Sally Vernon<sup>3</sup>, Julian Flowers<sup>3</sup>, Peter Collins<sup>4</sup>  
<sup>1</sup>Imperial College Healthcare NHS Trust, <sup>2</sup>Knowledge and Intelligence Team (East), Public Health England, <sup>3</sup>National Cancer Registration Service, <sup>4</sup>Addenbrooke's Hospital
- 79. The Brain Tumour Information Portal: piloting patient access to cancer registry records**  
Michael Chapman<sup>1</sup>, Will Jones<sup>2</sup>, Sarah Stevens<sup>3</sup>, Sara Hion<sup>1</sup>, Jem Rashbass<sup>3</sup>  
<sup>1</sup>Cancer Research UK, <sup>2</sup>Brainstrust, <sup>3</sup>National Cancer Registration Service, Public Health England
- 80. Patient reported outcomes for women with vulval cancer**  
Susan Davidson<sup>1</sup>, Victoria Palmer<sup>1</sup>, Jacqueline Routledge<sup>1</sup>, Catherine O'Hara<sup>1</sup>, Jacqueline Livsey<sup>1</sup>  
<sup>1</sup>The Christie NHS Foundation Trust
- 81. Understanding the link between cancer patient experience and other outcomes**  
Arwenna Davis<sup>1</sup>  
<sup>1</sup>Macmillan Cancer Support
- 82. A patient and carer perspective on participation in brain tumour trials in the UK**  
Abigail Evans<sup>1</sup>, Helen Bulbeck<sup>2</sup>, Joanne Rickett<sup>1</sup>, Paul Smith<sup>1</sup>, Colin Watts<sup>3</sup>  
<sup>1</sup>University College London, <sup>2</sup>NCRI Brain Tumour Clinical Studies Group, <sup>3</sup>University of Cambridge
- 83. Lung cancer diagnostic pathway to empower patients, primary care and radiology departments**  
Ann-Marie Francis<sup>1</sup>, Martin Ledson<sup>1</sup>, Andrea McIver<sup>1</sup>, Colin Monaghan<sup>1</sup>, Matthew Wainman<sup>1</sup>  
<sup>1</sup>Liverpool Heart & Chest Hospital NHS Foundation Trust
- 84. Is the NCPES a useful outcome indicator for patient experience of same day discharge for non-reconstructive breast cancer surgery**  
Jo Marsden<sup>1</sup>, Terri Baxter<sup>2</sup>  
<sup>1</sup>King's College Hospital NHS Foundation Trust, <sup>2</sup>King's College Hospital
- 85. Developing a PREM to assess breast cancer patients' experience of reconstruction surgery**  
Jo Marsden<sup>1</sup>, Terri Baxter<sup>2</sup>  
<sup>1</sup>King's College Hospital NHS Foundation Trust, <sup>2</sup>King's College Hospital
- 86. Using PREMs to direct service improvement for breast cancer chemotherapy**  
Jo Marsden<sup>1</sup>, Terri Baxter<sup>2</sup>  
<sup>1</sup>King's College Hospital NHS Foundation Trust, <sup>2</sup>King's College Hospital

- 87. Variation in discussion about and participation in cancer research and its relationship with patient experience**  
Louise McGrath-Lone<sup>1</sup>, Sophie Day<sup>1</sup>, Helen Ward<sup>1</sup>  
<sup>1</sup>Imperial College London
- 88. Satisfied customers - how research participation associates with patient experience : findings from the 2013 National Cancer Patient Experience Survey**  
Carolyn Morris<sup>1</sup>, Matthew Baker<sup>2</sup>, Ekaterini Blaveri<sup>3</sup>, Rachael Brannan<sup>3</sup>, Sheila Fisher<sup>4</sup>, Sue Pavitt<sup>5</sup>, Richard Stephens<sup>2</sup>, Robert West<sup>6</sup>  
<sup>1</sup>Consumer Liaison Group, <sup>2</sup>National Cancer Research Institute Consumer Liaison Group, <sup>3</sup>National Cancer Intelligence Network, Public Health England, <sup>4</sup>NCRN, <sup>5</sup>Leeds Institute of Health Sciences, University of Leeds, <sup>6</sup>Leeds Institute of Health Sciences, University of Leeds
- 89. Who are the cancer patients not represented in patient surveys and does it matter for hospital performance comparisons?**  
Catherine Saunders<sup>1</sup>, Gary Abel<sup>1</sup>, Georgios Lyratzopoulos<sup>1</sup>  
<sup>1</sup>Cambridge Centre for Health Services Research
- 90. Measuring bothersome problems and service quality in ambulatory chemotherapy services: developing a Patient-Reported Outcome Measure (PROM)**  
Richard Wagland<sup>1</sup>, Peter Griffiths<sup>1</sup>, Alison Richardson<sup>1</sup>, Jo Armes<sup>2</sup>, Matthew Hankins<sup>1</sup>, Elaine Lennan<sup>3</sup>  
<sup>1</sup>University of Southampton, <sup>2</sup>King's College London, <sup>3</sup>University Hospital NHS Foundation Trust
- 91. Electronic Holistic Needs Assessment (eHNA) and care planning: identifying patients holistic needs to improve communications, information and patient outcomes.**  
Noeline Young<sup>1</sup>, Jackie Rowe<sup>1</sup>, Amanda Watson<sup>1</sup>  
<sup>1</sup>Macmillan Cancer Support
- 92. Using survey data to inform service improvements: analyses of National Cancer Patient Experience (2012-13)**  
Helen Ward<sup>1</sup>, Louise Mc Grath-Lone<sup>1</sup>, Sophie Day<sup>1</sup>  
<sup>1</sup>Imperial College London
- 93. Leading the information revolution in cancer intelligence: why the National Lung Cancer Audit is the key to transforming lung cancer outcomes**  
Jesme Fox<sup>1</sup>, Isabel Lawicka<sup>2</sup>  
<sup>1</sup>Roy Castle Lung Cancer Foundation, <sup>2</sup>MHP Health
- 94. Recommendations for improving the effectiveness of multidisciplinary team meetings**  
Rosalind Raine<sup>1</sup>, Caoimhe Nic a Bhaird<sup>1</sup>, Penny Xanthopoulou<sup>1</sup>, Isla Wallace<sup>1</sup>, Julie Barber<sup>1</sup>, Anne Lanceley<sup>1</sup>, Alex Clarke<sup>2</sup>, Gill Livingston<sup>1</sup>, Archie Prentice<sup>3</sup>, Dave Ardron<sup>4</sup>, Miriam Harris<sup>5</sup>, Michael King<sup>1</sup>, Susan Michie<sup>1</sup>, Jane Blazeby<sup>6</sup>, Simon Gibbs<sup>7</sup>  
<sup>1</sup>UCL, <sup>2</sup>The Royal Free Hospital, <sup>3</sup>The Royal College of Pathologists, <sup>4</sup>Patient and Public Involvement Representative, North Trent Cancer Research Network, <sup>5</sup>Patient and Public Involvement Representative, <sup>6</sup>University of Bristol, <sup>7</sup>Imperial College London
- 95. Accelerated Experience Based Co Design (AEB CD): using a National Archive of Patient Experience Narrative Interviews to Promote Rapid Patient Centred Service Imp**  
John Pearcey<sup>1</sup>  
<sup>1</sup>Royal Brompton and Harefield NHS Foundation Trust

96. **FFORESTS:First FORum and REGistration STUDy in Secondary Breast Cancer**  
Jacinta Abraham<sup>1</sup>, Emma Harrett<sup>1</sup>, Elizabeth Hodges<sup>1</sup>  
<sup>1</sup>Velindre NHS Trust
97. **Understanding the characteristics of patients diagnosed with metastatic breast cancer on presentation**  
James Shield<sup>1</sup>, Lynne Walker<sup>1</sup>, Julie Flynn<sup>1</sup>, Tom Welchman<sup>2</sup>, Edmund Drage<sup>2</sup>, Michael Gibbs<sup>2</sup>, Chris Edson<sup>2</sup>, Martin Lee<sup>3</sup>, Jane Maher<sup>1</sup>  
<sup>1</sup>Macmillan Cancer Support, <sup>2</sup>Monitor Deloitte, <sup>3</sup>NHS England
98. **Diagnostic imaging and cancer survival**  
Matthew Barclay<sup>1</sup>, Jason Poole<sup>1</sup>, Lucy Elliss-Brookes<sup>2</sup>  
<sup>1</sup>Knowledge and Intelligence Team (East Midlands), Public Health England, <sup>2</sup>National Cancer Intelligence Network, Public Health England
99. **Improving early diagnosis of bladder and kidney cancers; findings from the regional 'Blood in Pee' Be Clear on Cancer pilot**  
Abigail Bentley<sup>1</sup>, Monika Ciurej<sup>1</sup>, Ella Ohuma<sup>1</sup>, Lucy Ironmonger<sup>1</sup>, Nick Ormiston-Smith<sup>1</sup>  
<sup>1</sup>Cancer Research UK
100. **Self reported use of sunbeds by under 18 year olds has fallen following the introduction of legislation**  
Nicola Bowtell<sup>1</sup>, Mark Dancox<sup>1</sup>, Katie Collins<sup>2</sup>, Narges Dailami<sup>2</sup>, Julia Verne<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (South West), Public Health England, <sup>2</sup>University of West England
101. **Four "Be Clear on Cancer" pilot awareness campaigns - what impact did they have on urgent GP referrals for suspected cancer?**  
Carolynn Gildea<sup>1</sup>, Matthew Barclay<sup>1</sup>, Sue Wild<sup>1</sup>, Rebecca Elleray<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (East Midlands), Public Health England
102. **Routes to diagnosis: does it matter when or how a cancer is diagnosed?**  
Sam Johnson<sup>1</sup>, Jon Shelton<sup>1</sup>, Alex Ives<sup>2</sup>, Matt Greenslade<sup>2</sup>, Lucy Elliss-Brookes<sup>1</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>Knowledge and Intelligence Team (South West), Public Health England
103. **'One size doesn't fit all': Cancer Research UK supporting primary care to deliver the NAEDI agenda**  
Anna Murray<sup>1</sup>, Elizabeth Bates<sup>1</sup>, Rebecca Banks<sup>1</sup>  
<sup>1</sup>Cancer Research UK
104. **Awareness of cervical cancer risk factors and symptoms: a cross sectional community survey in rural Uganda**  
Amos Deogratus Mwaka<sup>1</sup>, Christopher Orach<sup>1</sup>, Georgios Lyratzopoulos<sup>2</sup>, Henry Wabinga<sup>1</sup>, Martin Roland<sup>2</sup>  
<sup>1</sup>Makerere University, <sup>2</sup>University of Cambridge
105. **Public awareness of cancer symptoms and barriers to early symptomatic presentation in England**  
Maja Niksic<sup>1</sup>, Dr Lindsay Forbes<sup>1</sup>, Prof Amanda-Jane Ramirez<sup>1</sup>, Dr Bernard Rachet<sup>2</sup>  
<sup>1</sup>King's College London, <sup>2</sup>London School of Hygiene and Tropical Medicine

# Posters

- 106. GP practice cancer screening uptake in the context of their patient population characteristics**  
Becky White<sup>1</sup>, Steven Prosser<sup>1</sup>, Nick Ormiston-Smith<sup>1</sup>  
<sup>1</sup>Cancer Research UK
- 107. Outcome following LLETZ treatment for women attending 10 year follow up**  
Simon Wrathall<sup>1</sup>, Sarah Flower<sup>1</sup>, Jullien Brady<sup>2</sup>  
<sup>1</sup>East of England QA Reference Centre, <sup>2</sup>Bedford Hospital
- 108. Using localised data to inform the planning and development of services to best support people living with cancer**  
Tanvi Barreto<sup>1</sup>  
<sup>1</sup>Macmillan Cancer Support
- 109. How NCIN supports commissioners and public through the Cancer Commissioning Toolkit**  
Carl Francis<sup>1</sup>, Kath Yates<sup>1</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England
- 110. Incidence projections for Upper GI Cancer in the East Midlands**  
Jennifer Lai<sup>1</sup>, Matthew Barclay<sup>1</sup>, Jason Poole<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (East Midlands), Public Health England
- 111. Prostate cancer services in London Cancer**  
Karen Linklater<sup>1</sup>  
<sup>1</sup>National Cancer Registration Service, Public Health England
- 112. Health behaviours in curative colorectal cancer patients: analysis of pre-operative assessments linked to cancer registrations**  
Dayna Alexander<sup>1</sup>, Philip McLoone<sup>1</sup>, Billy Sloan<sup>1</sup>, David Morrison<sup>1</sup>  
<sup>1</sup>University of Glasgow
- 113. Circulatory morbidity and mortality in the British Childhood Cancer Survivor Study (BCCSS)**  
David Cutter<sup>1</sup>, Sarah Darby<sup>1</sup>, Clare Frobisher<sup>2</sup>, Julie Kely<sup>2</sup>, Simon Read<sup>1</sup>, Raoul Reulen<sup>2</sup>, David Winter<sup>2</sup>, Michael Hawkins<sup>2</sup>  
<sup>1</sup>University of Oxford, <sup>2</sup>University of Birmingham
- 114. Risk of poor psychological wellbeing of medium and long-term prostate cancer survivors is associated with mode of presentation. Results from an all-Ireland survey**  
Frances Drummond<sup>1</sup>, Heather Kinneer<sup>2</sup>, Anna Gavin<sup>2</sup>, Eamonn O'Leary<sup>1</sup>, David Donnelly<sup>2</sup>, Linda Sharp<sup>1</sup>  
<sup>1</sup>National Cancer Registry Ireland, <sup>2</sup>Northern Ireland Cancer Registry

- 115. Risks associated with levels of care proposed by the National Cancer Survivorship Initiative (NCSI) for childhood cancer survivors**  
Clare Frobisher<sup>1</sup>, Adam Glaser<sup>2</sup>, Gill Levitt<sup>3</sup>, Emma Lancashire<sup>4</sup>, David Winter<sup>4</sup>, Kevin Oeffinger<sup>5</sup>, Joyeeta Guha<sup>4</sup>, Julie Kelly<sup>4</sup>, David Cutter<sup>6</sup>, Raoul Reulen<sup>4</sup>, Mike Hawkins<sup>4</sup>  
<sup>1</sup>British Childhood Cancer Survivor Study, <sup>2</sup>Paediatric Oncology and Haematology Department, Leeds General Infirmary, <sup>3</sup>Department of Haematology/Oncology, Great Ormond Street Hospital for Children NHS Trust, <sup>4</sup>British Childhood Cancer Survivor Study, University of Birmingham, <sup>5</sup>Memorial Sloan-Kettering Cancer Centre, <sup>6</sup>Clinical Trial Service Unit, University of Oxford
- 116. Using evidence to shape social, emotional and practical support for young people with cancer**  
Helen Gravestock<sup>1</sup>  
<sup>1</sup>CLIC Sargent
- 117. Primary and hospital care in the clinical follow-up of childhood cancer survivors**  
Joyeeta Guha<sup>1</sup>, Clare Frobisher<sup>2</sup>, Andrew Toogood<sup>3</sup>, Adam Glaser<sup>4</sup>, David Winter<sup>2</sup>, Emma Lancashire<sup>5</sup>, Julie Kelly<sup>2</sup>, Raoul Reulen<sup>6</sup>, Michael Hawkins<sup>7</sup>  
<sup>1</sup>University of Birmingham, <sup>2</sup>Centre for Childhood Cancer Survivor Studies, University of Birmingham, <sup>3</sup>University Hospitals Birmingham NHS Foundation Trust, <sup>4</sup>St James' University Hospital, <sup>5</sup>Public Health, Epidemiology and Biostatistics, University of Birmingham, <sup>6</sup>Centre for Childhood Cancer Survivor Studies, University of Birmingham, <sup>7</sup>Centre for Childhood Cancer Survivors Studies, University of Birmingham
- 118. Understanding the burden and characteristics of older people living with and beyond with cancer**  
Lucy Irvine<sup>1</sup>, Sarah Miller<sup>1</sup>, Hannah McConnell<sup>3</sup>, Luke Hounsome<sup>4</sup>, Sean McPhail<sup>1</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>Macmillan Cancer Support, <sup>4</sup>Knowledge and Intelligence Team (South West), Public Health England
- 119. Other cancers diagnosed in female breast cancer patients in England who died in 2008**  
Gill Lawrence<sup>1</sup>, Jackie Walton<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (West Midlands), Public Health England
- 120. Factors predicting quality of life among Thais with colorectal cancer and colostomies**  
Aporacha Lumdubwong<sup>1</sup>, Yupapin Sirapo-ngam<sup>1</sup>, Chukiat Viwatwongkasem<sup>2</sup>  
<sup>1</sup>Faculty of Medicine Ramathibodi Hospital, Mahidol University, <sup>2</sup>Faculty of Public Health, Mahidol University
- 121. Using routinely collected data to stratify prostate cancer patients into phases of care in the UK: implications for resource allocation and cancer survivorship**  
Hannah McConnell<sup>1</sup>, Roberto Alonzi<sup>2</sup>, Kent Yip<sup>3</sup>, Jane Maher<sup>4</sup>  
<sup>1</sup>Macmillan Cancer Support, <sup>2</sup>Mount Vernon Cancer Centre, <sup>3</sup>Norfolk and Norwich University Hospital, <sup>4</sup>Macmillan Cancer Support & Mount Vernon Cancer Centre

- 122. UK cancer survivorship: What the data tells us about the number of children, teenagers and young adults living with and beyond cancer**  
Sarah Miller<sup>1</sup>, Lucy Irvine<sup>1</sup>, Hannah McConnell<sup>2</sup>, Luke Hounsome<sup>3</sup>, Sean McPhail<sup>1</sup>, Antony Moran<sup>4</sup>, Martin McCabe<sup>5</sup>  
<sup>1</sup>National Cancer Intelligence Network, Public Health England, <sup>2</sup>Macmillan Cancer Support, <sup>3</sup>Knowledge and Intelligence Team (South West), Public Health England <sup>4</sup>Knowledge and Intelligence Team (North West), Public Health England, <sup>5</sup>School of Cancer and Enabling Sciences, University of Manchester
- 123. Survival in solid cancer patients following intensive care: a systematic review and meta-analysis**  
Kathryn Puxty<sup>1</sup>, Philip McLoone<sup>1</sup>, John Kinsella<sup>1</sup>, Tara Qasim<sup>1</sup>, David Morrison<sup>1</sup>  
<sup>1</sup>University of Glasgow
- 124. Patterns and predictors of workforce participation in cancer survivors 6-months and 12-months post-diagnosis**  
Linda Sharp<sup>1</sup>, Damian O'Driscoll<sup>1</sup>, Eamonn O'Leary<sup>1</sup>, Kate Higney<sup>1</sup>, Cathy Bradley<sup>2</sup>  
<sup>1</sup>National Cancer Registry Ireland, <sup>2</sup>Virginia Commonwealth University
- 125. Understanding the evolution of lung cancer survivorship over time and the resulting implications for care**  
Tom Welchman<sup>1</sup>, Edmund Drage<sup>2</sup>, Michael Gibbs<sup>2</sup>, Chris Edson<sup>2</sup>, Julie Flynn<sup>3</sup>, James Shield<sup>3</sup>, James Thomas<sup>4</sup>, Michael Lind<sup>5</sup>  
<sup>1</sup>Monitor Deloitte Europe, <sup>2</sup>Monitor Deloitte, <sup>3</sup>Macmillan Cancer Support, <sup>4</sup>National Cancer Intelligence Network, Public Health England, <sup>5</sup>University of Hull
- 126. Factors that affect who receives surgery for pancreatic cancer in England, 1998-2009**  
Julie Konfortion<sup>1</sup>, William Allum<sup>2</sup>, Hemant Kocher<sup>3</sup>, Elizabeth Davies<sup>1</sup>, Ruth Jack<sup>1</sup>, Victoria Coupland<sup>1</sup>  
<sup>1</sup>Knowledge and Intelligence Team (London), Public Health England, <sup>2</sup>Royal Marsden Hospital, <sup>3</sup>Barts Cancer Institute
- 127. Do trends in cancer patient ICU admissions reflect population trends in the incidence of cancer?**  
Philip McLoone<sup>1</sup>, Kathryn Puxty<sup>2</sup>, Tara Quasim<sup>2</sup>, David Morrison<sup>2</sup>, John Kinsella<sup>2</sup>  
<sup>1</sup>West of Scotland Cancer Surveillance Unit, <sup>2</sup>University of Glasgow
- 128. Systemic Anti-Cancer Therapy Data Set : a Trust's experience in testing the validity and usability of such information**  
Linda McNamara<sup>1</sup>, Ann Blake<sup>2</sup>  
<sup>1</sup>Roche Products Ltd., <sup>2</sup>East and North Hertfordshire NHS Trust
- 129. Factors associated with ICU mortality among critically ill patients with colorectal cancer**  
Kathryn Puxty<sup>1</sup>, David Morrison<sup>1</sup>, Tara Quasim<sup>1</sup>, John Kinsella<sup>1</sup>, Philip McLoone<sup>1</sup>  
<sup>1</sup>University of Glasgow

- 130. What factors predict non-surgical treatment of breast cancer in the elderly and does it affect survival? Initial findings from the Bridging the Age Gap study.**  
Paul Richards<sup>1</sup>, Paul Richards<sup>1</sup>, Sue Ward<sup>1</sup>, Jenna Morgan<sup>1</sup>, Gill Lawrence<sup>2</sup>, Catherine Lagord<sup>2</sup>, Matthew Francis<sup>2</sup>, Christopher Lawrence<sup>2</sup>, Sarah Lawton<sup>3</sup>, Lynda Wyld<sup>1</sup>  
<sup>1</sup>University of Sheffield, <sup>2</sup>Knowledge and Intelligence Team (West Midlands, Public Health England, <sup>3</sup> Knowledge and Intelligence Team (Northern and Yorkshire), Public Health England
- 131. Surgery rates in older lung cancer patients with low pre-diagnosis mortality risk**  
James Shield<sup>1</sup>, Julie Flynn<sup>1</sup>, Tom Welchman<sup>2</sup>, Edmund Drage<sup>2</sup>, Michael Gibbs<sup>2</sup>, Chris Edson<sup>2</sup>, Michael Lind<sup>3</sup>  
<sup>1</sup>Macmillan Cancer Support, <sup>2</sup>Monitor Deloitte, <sup>3</sup>Hull and East Yorkshire Hospitals NHS Trust
- 132. What factors affect access to surgery and chemotherapy for Welsh patients diagnosed with lung cancer?**  
Ceri White<sup>1</sup>, Rowena Bailey<sup>1</sup>, Rebecca Thomas<sup>1</sup>, Julie Howe<sup>1</sup>, Dyfed Huws<sup>1</sup>  
<sup>1</sup>Welsh Cancer Intelligence and Surveillance Unit

# Exhibition

The exhibition at the Cancer Outcomes Conference 2014 will run each day during the conference.



There are over 55,500 people living with a brain tumour in the UK. brainstrust is the charity and the community that's here to help these people and those that look after them, whoever they are and no matter where they are on their journey.

We know how lost you can feel when you are told you have a brain tumour.

We know that there are good days and bad days.

We know that it might get better. But we know that maybe it won't.

When you are diagnosed with a brain tumour sometimes all you need is someone who understands. We know.

Get to know us.



## The Brain Tumour Patient Information Portal

The Brain Tumour Patient Information Portal is an innovative joint project between the National Cancer Registration Service, brainstrust and Cancer Research UK to provide cancer patients with online access to their own records and other relevant information. It is the first portal of its kind to offer cancer patients access to their registry records. Following a successful pilot with brain tumour patients, we will test the portal with patients with other cancers and are seeking clinical teams who might be interested in participating.

Visit our exhibition stand in the Kings Suite exhibition hall to find out more!



## Cancer Research UK's Cancer Statistics

We provide cancer statistics for the UK and around the world, presented for all cancers combined and by type of cancer, for health professionals.

Our data covers:

- Incidence, survival and mortality stats
- Variation by age, ethnicity and socio-economic group
- Prevalence and lifetime risk estimates
- Risk factors evidence
- Diagnosis, treatment and screening stats
- Local and world stats

We have over 300 web pages which give top-line cancer stats or in-depth analyses and interpretation, including charts, tables, interactive data visualisations and reports, posters and key facts publications.

[www.cruk.org/cancerstats](http://www.cruk.org/cancerstats)  
[stats.team@cancer.org.uk](mailto:stats.team@cancer.org.uk)

# Exhibition

The exhibition at the Cancer Outcomes Conference 2014 will run each day during the conference.



## **Cancer52**

Cancer52 represents more than 75 predominantly small cancer charities united by their vision of seeing a better future for everyone affected by the rare and less common cancers, which account for more than half of all cancer deaths in the UK.

Our aim is to promote improved diagnosis, treatment and support for those affected by rare and less common cancers, leading to improved QOL and increased survival.

We work on matters that impact on the rare and less common cancer community – defined as all cancers outside the ‘big four’ of breast, prostate, lung and bowel.

Current data shows that 46% of cancers diagnosed are rare and less common cancers, yet they account for 54% of cancer deaths



## **Chameleon Information Management Services Ltd (CIMS)**

CIMS is an information company specialising in the implementation and support of InfoFlex software.

InfoFlex is used extensively across the NHS to support the national cancer reporting requirements as well as the day-to-day cancer patient management. InfoFlex supports all aspects of Cancer data collection and meets all national reporting requirements.

This includes the latest COSD data collection and XML reporting requirements, MacMillan Treatment Summaries, SACT, Holistic Needs Assessments, support of CNS and Remote Monitoring. InfoFlex provides a single fully integrated patient care-pathway solution that can be easily extended to cover other elements of the patient care-pathway and research.

Contact CIMS on 01923 896939 or [www.infoflex-cims.co.uk](http://www.infoflex-cims.co.uk)



## **Digital Spark**

We are Digital Spark. We collaborate with clinicians and informatics specialists to develop quality healthcare software. We are passionate about equipping and enabling clinicians with digital solutions that drive improvement in services and help keep patients safer.

With significant NHS and private sector experience across the Digital Spark team, we design, develop and implement innovative systems using our software platform that drive performance improvements across all care pathways.

# Exhibition

The exhibition at the Cancer Outcomes Conference 2014 will run each day during the conference.



## Independent Cancer Patients' Voice (ICPV)

Independent Cancer Patients Voice believes that patients should be active participants in cancer research and treatment rather than passive recipients of care.

ICPV provides education, mentoring and support for people who, having been treated for cancer, want to add an effective patient perspective to cancer research. Our new Science for Advocates five day course is a "global first" as it includes lab-based experience as well as lectures and discussion.

We can offer researchers access to advocates who are confident, informed and realistic lay partners in research offering constructive criticism and advice leading to improved recruitment



## InstantAtlas

InstantAtlas is already being used by cancer registries in the United States, the United Kingdom and Germany. It is an ideal software solution for presenting incidence, mortality data and trends in a spatial context to internal and external audiences.

With the inclusion of interactive charts, graphs, tables and maps together in a single view, InstantAtlas reports are particularly suited to presenting cancer statistics. Report authors can adapt layouts, content and annotations easily to suit their intended audience.

Learn more about InstantAtlas for cancer data reporting and visit our stand in the King's suite.



## Macmillan Cancer Support

Macmillan does more research into the needs and experiences of people living with cancer and their carers than any other charity in the UK. We produce robust evidence to better understand the issues facing those with cancer, to help us raise awareness of these issues among the general public, policy makers and opinion leaders, and to target our resources at the most effective solutions.

We fund a range of research projects and work in partnership with leading national research organisations and academics. Our research covers health and social care services, patient experience, cancer survivorship, the economics of cancer, the demographics of the cancer population and many more areas.

Talk to us at our exhibition stand in the Kings Suite Exhibition Hall to collaborate and to view examples of our research.

# Exhibition

The exhibition at the Cancer Outcomes Conference 2014 will run each day during the breaks.



Public Health  
England

## National Cancer Intelligence Network (NCIN)

Public Health England's National Cancer Intelligence Network (NCIN) is a UK-wide initiative, working to drive improvements in cancer awareness, prevention, diagnosis and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

The NCIN has strong links with patients, clinicians and charitable organisations with representation on all our decision making groups.

<http://www.ncin.org.uk/>



## National Cancer Research Institute (NCRI)

NCRI is a UK-wide partnership between government, charity and industry, which promotes cooperation in cancer research among its 22 member organisations.

Through our initiatives and the NCRI Cancer Conference, we encourage knowledge sharing and cross-disciplinary collaboration for the benefit of patients, the public and the research community.

Come and visit our exhibition stand to find out more about us and our work.

[www.ncri.org.uk](http://www.ncri.org.uk)



National Institute for  
Health Research

Clinical Research Network  
Cancer



## Consumer Liaison Group (CLG)

A key focus for patient and public involvement (PPI) across the National Institute for Health Research Clinical Research Network: Cancer (CRN Cancer) and the National Cancer Research Institute (NCRI) is the Consumer Liaison Group (CLG): a national network of cancer patients and carers working with research teams to help develop and deliver patient-focussed research studies.

The CLG works through various organisations to ensure information about research provided to patients and the public is easily understood and made widely available.

# Exhibition

The exhibition at the Cancer Outcomes Conference 2014 will run each day during the conference.



## **The National Institute for Health Research (NIHR) Clinical Research Network (CRN): Cancer**

NIHR CRN: Cancer provides researchers with the practical support they need to make clinical studies happen in the NHS, so that more research takes place across England, and more patients can take part.

We provide opportunities for healthcare professionals to become involved in research, and for existing researchers to access our research support services, and we aim to show that patients and the NHS benefit from our approach of delivering cancer research alongside cancer services.

Come and visit our exhibition in the Kings Suite for more information.



## **National Peer Review Programme**

The National Peer Review Programme is a quality assurance programme for NHS clinical services. The programme first started as a regional cancer programme in 2001, it was an integral part of the NHS Cancer Plan. Since then the programme has developed and now covers nearly all cancer services, as well as paediatric diabetes and major trauma centres in England. The programme is hosted by the Medical Directorate, NHS England.

The programme responded to the call for increased transparency to patients and enabled the assessments of cancer services to be easily accessible on a patient facing website. The unique website, My Cancer Treatment ([www.mycancertreatment.nhs.uk](http://www.mycancertreatment.nhs.uk)), is the only resource that provides details on the quality of individual clinical teams, including national benchmarking and comparison of up to three services at a time.

This website puts the patient at the centre and was designed with full inclusion of a group of patient and carer representatives. It aims to support not only transparency of information, but also patient choice and entitlements.



## **Pelvic Radiation Disease Association**

In 2008, a group of patients at London's Royal Marsden being treated for gastrointestinal problems following pelvic radiotherapy formed an informal support association.

A growing awareness of the fact that radiation-induced pelvic injury was a widespread and little recognized problem prompted the Association to become more structured and in 2012 the Pelvic Radiation Disease Association became a registered charity. It is now a significant voice within the cancer community, speaking at and attending major national and regional conferences, workshops and forums, providing help and support for a rapidly growing number of patients as well as providing information for health professionals.

# Exhibition

The exhibition at the Cancer Outcomes Conference 2014 will run each day during the conference.



Public Health England

## Public Health England

Public Health England's mission is to protect and improve the nation's health and to address inequalities through working with national and local government, the NHS, industry and the voluntary and community sector.

PHE is an operationally autonomous executive agency of the Department of Health.



## Quality in Care (QIC) Oncology

### 2014 is now open for entry

Now in its third year, QIC Oncology identifies and recognises work that has directly or indirectly improved patient care, and shares these examples across the health service so that more patients can benefit from enhanced care.

A Quality in Care award means that your initiative has been recognised by the NHS, patients, industry and charities as improving the quality of life for people living with cancer. Entry deadline is July 10, followed by judging on September 11 and our awards evening is being held alongside the Britain Against Cancer conference on December 9, 2014.

A full list of categories and criteria is available through our Quality in Care website [www.qualityincare.org](http://www.qualityincare.org). Visit our stand for more information.



## Understanding Cancer

Understanding Cancer is a professionally accredited online learning course primarily for non-clinical staff in the NHS and Public Health England. The course was launched in April 2012 and there are now around 40 modules available.

The course covers general information about cancer such as medical terminology, tests and treatments, cancer registration and MDTs as well as more detailed information on specific cancer types including incidence and survival figures, risk factors, signs and symptoms, anatomy, physiology and coding.

Understanding Cancer is free of charge to UK users and provides the flexibility to work at your own pace from work or home and includes a certificate of achievement for each successfully completed module.













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