

SUMMARY OF CANCER52/PHE EVENT: DEVELOPMENT IN DATA FOR RARE AND LESS COMMON CANCERS

22nd May 2019

cancer52
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rare and less common cancers



Public Health
England

**Summary of Cancer52/PHE Event:
Development in Data for Rare and Less Common Cancers
Held 22nd May 2019**

Public Health England (PHE) and Cancer52 held a full day event on 22nd May 2019 to share and explore developments in data for rare and less common cancers.



The event was chaired by Lindsey Bennister, Trustee of Cancer52 and Chief Executive, Waldenstrom's Macroglobulinemia UK.

Representatives from PHE, NCRAS (National Cancer Registration and Analysis Service) and various charities presented at the event. The slides of the event are available [here](#) and a film of the event has also been produced and is available here.

Summary of Event

Welcome address

Jane Lyons, CEO, Cancer52

Jane Lyons introduced the event, reminding participants that more people die of rare and less common cancers each year in England than the four most common cancers.



Session 1: Setting the scene - NCRAS and data for rare and less common cancers

Dr Jem Rashbass, Director for Disease Registration and Cancer Analysis, PHE



Dr Jem Rashbass explained how there has been a big improvement in the collection and analysis of data for rare and less common cancers over the last 15 years.

It is now possible to track patients through the pathway in near real time.

Opportunities for the future include improving data collection and quality, linking data and helping clinicians use data via machine learning.

Session 2: Data collection - How NCRAS works to support the collection of data for rare and less common cancers

Karen Graham, Head of Data Improvement, NCRAS

Karen Graham explained how NCRAS has a network of regional cancer registry teams collect data by collating information from a wide range of sources and data sets so that NCRAS can get a complete picture of what happens to a patient, even if they have treatment outside a region. Data from 162 data providers and over 1700



MDTs coming from 12 different datasets feed into NCRAS. NCRAS works with trusts and MDTs to improve data collection. Trusts can see their data analysed via Cancer Stats. NCRAS's work is essential to ensure accurate statistics and to help identify areas for quality improvement.

Session 3: Development of the staging data indicator

Lucy Elliss-Brookes, Head of Cancer Analysis, NCRAS



Lucy Elliss-Brookes explained how she and her team are working on a methodology to produce a statistically robust early stage indicator to publish as an official statistic by 2020. This work will support the Government's ambition of diagnosing 75% of all cancers at stage 1 and 2 by 2028. The expert group leading the work have agreed to develop a case-mix adjusted indicator for 2018 diagnoses that includes cancers that have staging completeness of 70%; cancers that have at least 1,500 cancers diagnosed in England per year; a well-defined site.

This means 21 cancer sites will be included in the 2018 data, covering 84% of all cancers diagnosed.

Currently 54% of cancers are diagnosed at an early stage and this has been the case for roughly the last five years. Staging data is much better collected in recent years; however, stage cannot currently be recorded for 7% of cancers.

There has been consultation with stakeholders who represent cancer sites that will not initially be included in the case-mix adjusted metric as well as with potential data users.

Session 4: New methods of data collection - Retinoblastoma Register

Dr Helen Jenkinson, Consultant Paediatric Oncologist, Birmingham Children's Hospital
Paul Davies, Head of Registration, NCRAS

Dr Helen Jenkinson and Paul Davies described how they have developed a Retinoblastoma Register. Retinoblastoma is a rare childhood cancer, with a 99% successful treatment rate. It can be heritable so adult survivors want to know whether their children might also be affected. The register allows clinicians and patients to access information about their cancer and its treatment whenever they need to do so.

It is hoped that the register will help with:

- reporting into specialised commissioning
- improving outcomes by comparing treatment centres
- enriching patient experience through access, better long term follow up
- research into retinoblastoma nationally and internationally.



Session 5: Making data available - insights from the Get Data Out Programme

Dr Charlie Turner, Senior Cancer Data Analyst, PHE
Georgia Papacleovoulou, Senior Policy and Intelligence Manager, Pancreatic Cancer UK
Will Jones, Chief Executive, brainstrust

Rebecca Rennison, Director of Public Affairs and Services, Target Ovarian Cancer



Dr Charlie Turner explained how PHE has been working with patients, analysts and clinicians to ‘get data out’ for small groups and subtypes of cancer. So far, data has been released on brain, meningeal and other primary CNS tumours; ovary, fallopian tube and primary peritoneal carcinomas; pancreatic; and testicular tumours including postpubertal teratomas.

Data released includes incidence, routes to diagnosis, treatment and survival. Data on prostate and sarcoma is due soon.

Will Jones of brainstrust talked about how his charity has turned data into information and used it to raise the profile of benign brain tumours, which have an impact on people’s quality of life.

Georgia Papacleovoulou from Pancreatic Cancer UK shared findings from a review of pancreatic cancer, which showed differences in survival for different subtypes of pancreatic cancer. 7 in 10 people with pancreatic cancer do not receive any active treatment.



Rebecca Rennison from Target Ovarian Cancer explained how better data collection means they now have treatment data and incidence, survival and treatment data by tumour type as well as incidence, survival data and stage data by CCG, Routes to Diagnosis data and survival data by stage. This has allowed Target Ovarian Cancer to learn new information, such as 94 per cent of women with stage I disease have either just surgery or surgery and chemotherapy, and that this falls to just 39 per cent of women with stage IV disease.

Better data helps Target Ovarian Cancer to drive change in the NHS, research and charity services. There are still issues with data, for example, data fragmentation and differences in methodologies but the picture is better than it used to be.

Session 6: Analysis of data for rare and less common cancers

Clare Pearson, Senior Cancer Analyst, CRUK-PHE Partnership and ACE Programme
Tracey Genus, AMMF Partnership Analyst, NCRAS

Clare Pearson presented work undertaken to inform the development of multi-disciplinary diagnostic centres (MDCS) as part of the ACE programme.



MDCs will focus on patients with non-specific but concerning symptoms. Analysis of people presenting with vague symptoms showed that they tend to present late, are more likely to be an emergency presentation and take longer to diagnose.

Tracey Genus reported on an analysis of neuroendocrine neoplasms, conducted to inform commissioning. The analysis found that incidence is going up.

Session 7: Using NCRSAS data to understand sarcoma services and impact outcomes

Dr Sandra Strauss, Medical Oncologist, London Sarcoma Service and NCRAS Clinical Lead

Dr Sandra Strauss reported on an audit of sarcoma using data. Sarcoma is a rare cancer and there are more than 70 different types. Amongst other findings, the audit showed that outcomes are poorer for people not treated in specialist centres.

The use of national data is fundamental to assess the quality of sarcoma patient care and to impact outcomes. However, data collection is not always as complete as it could be.



Session 8: Analysis of care for rare and less common cancers

Dr Susan Harden, Lead Clinician, National Mesothelioma Audit/Clinical Oncologist/ NCRAS Clinical Lead

Prof Eila Watson, Professor of Supportive Cancer Care, Oxford Brookes University

Alice Turnbull, Programme Manager, Systemic Anti-Cancer Therapy, NCRAS

Dr Kwok Wong, Senior Cancer Analyst, NCRAS



Dr Susan Harden shared findings from an audit of Mesothelioma cancer, funded by Mesothelioma UK.

The audit uses data from COSD (Cancer Survival and Outcomes Data) and other sources, including HES (Hospital Episode Statistics), the National Radiotherapy Dataset and the Systemic Anti Cancer Dataset (SACT).

The data shows differences in incidence between trusts, a higher prevalence in men and survival differences between subtypes.

Prof Eila Watson presented the results of a survey of 274 pancreatic cancer patients regarding their experiences of treatment and care.

The survey found that patients have unmet information and support needs, including psychological support and access to a dietician.



Alice Turnbull explained how the SACT (Systemic Anti-Cancer Therapy) Dataset works. It collects data on chemotherapy treatments across England.

43 data items are collected to populate this database, including information about the patient, the hospital, the tumour and the treatment regime.

Analysis of SACT helps to give a national perspective and can help identify whether some patient groups are missing out on trials.

Dr Kwok Wong talked about how an analysis of sarcoma data has helped to develop information on sarcoma incidence and survival by morphological subtypes.

It has also informed the development of a Sarcoma Service Specification which sets out the standards of care expected from organisations funded by NHS England to provide specialist care.

It has also provided current, relevant Information for patients and charities, particularly Sarcoma UK.



Session 9: How synthetic data can help us understand more about rare and less common cancers

Sophie Morris, Engagement and Awareness Manager, National Disease Registration, PHE



Sophie Morris demonstrated the Simulacrum, a tool researchers can use to help inform their research questions.

The Simulacrum is populated with artificial data based on real cancer data and is a very accurate simulation.

Once researchers have developed their research questions using the Simulacrum, they can ask NCRAS to run their questions on actual data, as long as it will not identify patients.

<https://simulacrum.healthdatainsight.org.uk/>

Session 10: Question and answer panel: “The role of data in supporting the implementation, monitoring and evaluation of the NHS Long-Term Plan, in particular, for rare and less common cancers”

Lucy Elliss-Brookes, Head of Cancer Analysis, NCRAS

Mr Andy Nordin, Consultant Gynaecological Oncologist, East Kent Gynaecological Oncology Centre/ NCRAS Clinical Lead

Amy Lee, Cancer Alliance Data, Evidence and Analysis Service Lead, NHS Cancer Programme

Rebecca Rennison, Director of Public Affairs and Services, Target Ovarian Cancer/ Cancer52 trustee

Susan Oliver, Chair and Trustee, Pseudomyxoma Survivor

The final session before wrapping up was a question and answer session.

Questions included whether there would be interim measures developed for the NHS Long Term Plan and about the development of quality of life metrics.

A monitoring and evaluation framework is being developed to monitor progress against the Long Term Plan and quality of life metrics are also in development.



Session 11: Wrap up and close

Sarah McDonald, Director of Research and Policy, Sarcoma UK, Cancer52 Access to Data Working Group



Sarah McDonald thanked presenters and participants. She shared her takeaway from the event: the importance of collaboration between PHE, NCRAS, charities and others, to help get data out and use it to inform improvements in practice.

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