



**Personalised
Medicine**
All-Party Parliamentary Group

MINUTES

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Jo Churchill, MP

Co-Chair:

The Rt Hon. the Lord
Warner

Vice Chairs:

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Secretariat

PHG Foundation
2 Worts Causeway
Cambridge
CB1 8RN

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Sanger Institute
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All-Party Parliamentary Group on Personalised Medicine Roundtable discussion

More personalised medicine for lung cancer: benefits & barriers

Venue and time

Location: House of Lords, Committee Room 4

Date: Tuesday 28 February 2017

Time: 9:00 – 11:00

Speakers

Ms Janette Rawlinson

Lung cancer patient, Roy Castle Lung Cancer Foundation

Dr Sanjay Popat

Consultant Thoracic Medical Oncologist, The Royal Marsden
Honorary Clinical Senior Lecturer, National Heart and Lung Institute (ICL)

Dr Robert Rintoul

Consultant Respiratory Physician
Lead Clinician for Cancer, Papworth Hospital Clinical Trials Unit Collaboration
Honorary Senior Visiting Fellow, University of Cambridge

Apologies

There were a number of apologies from parliamentarians.

Minutes

Jo Churchill welcomed attendees and gave a brief introduction to the challenge of lung cancer and the related vital role of more personalised medicine for lung cancer care.

Ms Janette Rawlinson, a lung cancer survivor, explained how diagnosis is overwhelming and puts people in a panic. She stressed there is a real need for access to reliable information and "*mechanisms to discern what is real and what is fake*". Patients need reality – not "*wishy washy*" diagnosis or platitudes but honesty and clarity. A better understanding of survivorship and the immune system (how the body responds to lung cancer) would help this.

Janette highlighted that patients want recognition. Only 5% of cancer research funds are spent on lung cancer and up to 20% of cases involve non-smokers. She argued that the stigma of a 'self-inflicted' disease should be lifted, adding that people can survive late stage diagnoses but research and treatments just haven't caught up yet.

Janette stressed patients must be seen as individuals in terms of heterogeneity and the causes of cancer. She added that patients are not interested at treatment at all costs, they just want to know whether they are going to live and what quality of life they can expect.



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Dr Sanjay Popat gave an explanation of the great potential for circulating tumour DNA testing to improve cancer care and patient outcomes.

Dr Popat acknowledged the progress made in lung cancer medicine, from the emergence of chemotherapy in the late 1990s when the survival rate was about 8 months, to the early 2000s when the human genome project improved outcomes through the measurement of abnormality in cancer genomes, to 2004 and the advent of tyrosine kinase inhibitors (TKIs) that were combined with genetic screening to 'switch off' the production of a particular cancer and radically shrink tumours. In 2016, a new generation of mutation-specific drugs greatly improved lung cancer care but required additional testing of tumours. Rather than repeated biopsies and wasted time, circulating DNA (ctDNA) testing facilitated the non-invasive measurement of small amounts of tumour cells travelling in the blood. This is easier for the patient, faster for clinicians and increasingly reliable as a test.

Dr Popat concluded by arguing that the question is now how to move forward and implement this kind of technology into practice, where it is commissioned into routine NHS care. Currently testing is being offered due to grants from industry but it should be supported further and encouraged as an additional tool in the clinician's toolkit.

Dr Robert Rintoul gave a presentation on the importance of earlier, non-invasive diagnosis to provide more personalised care for lung cancer.

Dr Rintoul explained that 75-80% of patients present at a late stage of cancer when little can be done, however 20-25% are diagnosed at an early stage when surgery and radiotherapy are still options. But even then, long term survival is reportedly 50-70% likely. This led him to stress the importance of early diagnosis and raise questions regarding screening strategies.

Stressing the challenges of screening, including the time and resource requirements, the complexities of differentiating between types of lung nodules and the implications of invasive procedures like biopsies and bronchoscopies, Dr Rintoul highlighted a need for better, more advanced, non-invasive tests. He gave his recent collaboration with Owlstone Medical and their Breath Biopsy, which measures traces of compounds in breath that indicate the presence of lung cancer, as a case study.

Drawing on the findings of the LUCID clinical trials, Dr Rintoul concluded that such medical technologies could be used within a screening programme built on non-invasive tests combined with the stratification of the population according to genetic risk of lung cancer.

Jo Churchill MP chaired the Q&A that followed where attendees posed questions to the speakers.

Dr Suzy Lisham raised the issue of pathology and the need for additional investment in and more attention to such crucial services in the NHS.

Baroness Masham questioned the state of lung cancer diagnosis in primary care outside of hospitals and whether there is enough information available to encourage the public to get checked.

Dr Rintoul cited the success of informational campaigns for GP attendance.

Janette Rawlinson noted that often, the symptoms of lung cancer go unnoticed, even as particular patients present over and over.



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Dr Mick Peake reiterated the success of lung cancer campaigns and added that GPs have also been made more aware of lung cancer symptoms as well. He added that personalised medicine means getting things right every step of the way, which requires feeding back data and sharing information to improve outcomes.

Lord Warner pointed out that there is a lot of system variation around the country and a lottery in terms of the health system capabilities. Scientific knowledge is being ignored in places, financial pressures mean rationing and GPs have become gatekeepers in terms of access to diagnostics. Science is driving new advances but a lot of this system failure is about behaviour.

Jo Churchill acknowledged that evidence suggests there is a postcode lottery, where the health services you are offered and can access are dependent on where in the UK you happen to live. This is a political issue and the question is how to make the best services routine business.

Dr Popat observed that, in terms of personalised medicine, the notion of access is linked to certain drugs. These are innovative and expensive and need to be considered by NICE committees. Furthermore, there is a cost for gene testing and a budget for drugs but it is difficult to tease out who is paying for what. The gene testing department needs a budget and clear commissioning laws – who is commissioning which gene test.

Prof Gary Middleton acknowledged the postcode lottery and noted that clinicians and clinics are overwhelmed; many oncologists can't keep up with meetings, readings, etc. And if you are a couple years behind, you are miles behind. Oncologists should perhaps focus on and test for what they know about their subject. Ability counts and it is driving this to a great extent.

Jo Churchill asked attendees about specialties and what the profession is doing to ensure politicians are aware of what specialists need to know and that they have access to that knowledge.

Dr Rintoul said GPs will see one case of lung cancer per year but will see many more people with symptoms and a wide range of other conditions. If specialists are having problems, imagine how GPs are doing.

Janette Rawlinson argued that, as a member of many closed internet forums for patients, there is a lot of misinformation out there and while lung cancer groups are becoming more vocal, both advice (legal and not) and information are circulating. There is a need for a better dissemination route for research – perhaps through training modules or general media – so research is put out there and translated.

Clive Morris asked how to develop a system that can harness the great strides being made in science and biotech. He argued we need better ways of working and publicising, and we need to profile what is ripe for implementation today.

Jo Churchill provided an example that the Royal Colleges should be encouraged to work together more closely. There are barriers that don't need to be there.

Karen Livingstone highlighted the work of SBRI and suggested that culture changes make implementation harder.

Professor Sam Janes observed that palliative treatment is improving – we can extend life. But clinicians are desperate for early diagnosis. In fact, he said if high risk groups were CT scanned, we could save 2000 to 3000 lives per year. This has been



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proven, it just requires resources and funding. There is a need for a centralised effort to save lung cancer lives.

Rob Hastings highlighted that we have a poorly digitised health system. There are big advantages to technology, particularly in linking up personalised care. We need a digitised and 'skilled up' system to achieve these advantages.

Jo Churchill pointed to her Health and Social Care (National Data Guardian) Bill currently going through parliament as an effort to improve the system more broadly.

Janette Rawlinson pointed to larger systemic problems, including a lack of joined up care between public health and primary care, and incomplete data sharing. She said patients would benefit from lung cancer data sharing and more advanced resources in surgery and treatment.

Prof Middleton added that many patients with cancer get no treatment at all. He stated that more research is needed on the very poorly patient and better palliation; opening up of therapies to the very ill.

Lord Warner stressed that the NHS is in dire straits and it is crucial for clinicians to push for the changes they think are necessary. More innovative clinicians need to state what needs to be done and drive the conversations with the General Medical Council.

Dr Rintoul concluded by stressing that detection can and will save more lives in the future. There are new technologies on the horizon – some will work and some will fail. But we could implement ctDNA testing at the moment. This is the place to start.

Jo Churchill concluded the Q&A session by reiterating that improving patient care and cancer outcomes is clearly at the heart of everything this group and all these attendees do. There is a dire need to do something to improve the current state of affairs, from systemic issues through to support systems for science and staff.

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