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Rt Hon Matt Hancock MP  
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28 October 2019

Dear Matt,

### Rare and uncommon cancers

In October 2018, Hackney Council unanimously passed a [motion](#) pledging to raise awareness of, and support training and research into, rare and uncommon cancers. It is thought to be the first motion of its kind in the country.

There are more than 200 different types of cancer, but cancer is considered rare if fewer than six in 100,000 people are diagnosed with it each year. People living with a rare or less common cancer often report difficulties in diagnosis, treatment and care.

The challenges for patients and the medical community include incorrect diagnoses, leading to delays. In the case of neuroendocrine tumours, diagnoses can take between 3 and 5 years, by which time, the disease has often metastasized to other organs. Even after a correct diagnosis has been confirmed, patients can be faced with, not only restricted access to appropriate clinical expertise and access to treatments, but also a lack of awareness and understanding of their rare cancer - especially as it follows non-traditional pathway biologically and therapeutically.

Given rare cancer incidence - research requires close collaboration nationally and internationally to promote and maintain scientific and clinically significant results. There are lessons to be learned from the rare/uncommon cancer community regarding personalised medicine, research and care - especially pertinent with the rising knowledge in genomics (cell type & genotype rather than site will determine cancer & cancer care evolution).



In 2017, 305,683 people were diagnosed with cancer in England of which 47% (144,642) were rare or less common cancer. In the same year, 135,885 people died of cancer in England. Of those, 55% (74,416) had a rare or less common cancer.

I'm writing to highlight these stark figures and to ask you for urgent action to:

- Improve diagnoses of all cancers at an early stage
- Urgently address the staffing crisis so that the current targets under the Long Term NHS Plan can deliver a better future for those living with rare and less common cancers
- Ensure a greater focus of attention is placed on research and high standards of medical care and support for patients
- Proportionally fund clinical studies of rare diseases and rare cancers - creating parity and improved equality
- Ensure the exchange of experience, information, data, collaborative research, and best practices on rare cancers is guaranteed, following Britain's exit from the European Union
- Call on pharmaceutical companies to prioritise development of medicines for rare cancers
- Improve education and on-going training for all healthcare professionals involved in the treatment and care of patients with rare cancers
- Commit to provide holistic care that addresses physical, mental health and wellbeing, social and everyday needs of patients
- Address the psychosocial burden of diagnosis - 1:4 people with rare disease/cancer presenting to healthcare were told their symptoms were anxiety or psychosomatic - this not only delays diagnosis but undermines individual sense of self, requiring great resilience to challenge this inaccurate labelling.

The Government has committed to diagnosing 75% of cancers at an early stage by 2028. This will save thousands of lives. However, this commitment cannot be met without diagnosing some rare and less common cancers earlier, and without delivering the medical staff to meet the needs of a growing population of patients with rare and less common cancers, some of whom live a long time after diagnosis.

Lack of cure and consequences of treatments are additional psychological burdens regardless of prognosis - living with cancer has its own issues similar but also separate to living beyond cancer. 25% of those seeking help in living with their cancer, have seriously considered or planned suicide - not at diagnosis but later when the inevitability of no cure becomes a reality.

Hackney Council recognises that, to address the current inequalities and improve outcomes for patients with these highly challenging diseases is to work in partnership with GPs, Clinical Commissioning Groups, (CCGs), cancer charities, cancer alliances, CCGs, specialised commissioning bodies, and the Government to change this.

This year, the council worked alongside health partners to design and host a GP training session, which over 60 GPs attended. The sessions was delivered alongside the NET patient foundation, Royal Free Hospital NET unit, UCL Cancer Institute ENETs Centre of Excellence, City and Hackney Clinical Commissioning Group, Royal London Hospital, Barts and the London Hepato-Pancreato-Biliary Unit, Royal Free Hospital, Royal National Orthopaedic Hospital and NHS London and South East Sarcoma Network.

Patients living with rare and less common cancers, need to hear a clear message that they matter too - and that this Government will commit to deliver improved access to diagnosis, expertise, therapeutics and research collaboration, across Europe following the outcome of Brexit. We also want to see rare and less common cancers, treated more equally when it comes to national campaigns and publicity around cancer, and how collectively we can better respond.

Yours sincerely,

A handwritten signature in blue ink that reads 'Philip Glanville'.

Philip Glanville  
Mayor of Hackney

A handwritten signature in black ink, appearing to be 'Feryal Clark'.

Cllr Feryal Clark  
Deputy Mayor and Cabinet Member for  
Health, Social Care, Leisure and Parks



