Overview & Scrutiny

Health in Hackney Scrutiny Commission

All Members of the Health in Scrutiny Commission are requested to attend the meeting of the Commission to be held as follows

Wednesday, 4th December, 2019

7.00 pm

Room 102, Hackney Town Hall, Mare Street, London E8 1EA

Contact:
Jarlath O'Connell

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Tim Shields
Chief Executive, London Borough of Hackney

Members: Cllr Ben Hayhurst (Chair), Cllr Peter Snell, Cllr Yvonne Maxwell (Vice-

Chair), Cllr Deniz Oguzkanli, Cllr Emma Plouviez, Cllr Patrick Spence and

CIIr Tom Rahilly

Agenda

ALL MEETINGS ARE OPEN TO THE PUBLIC

4 Minutes of the Previous Meeting (19.02)

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Access and Information

Getting to the Town Hall

For a map of how to find the Town Hall, please visit the council's website http://www.hackney.gov.uk/contact-us.htm or contact the Overview and Scrutiny Officer using the details provided on the front cover of this agenda.

Accessibility

There are public toilets available, with wheelchair access, on the ground floor of the Town Hall.

Induction loop facilities are available in the Assembly Halls and the Council Chamber. Access for people with mobility difficulties can be obtained through the ramp on the side to the main Town Hall entrance.

Further Information about the Commission

If you would like any more information about the Scrutiny Commission, including the membership details, meeting dates and previous reviews, please visit the website or use this QR Code (accessible via phone or tablet 'app') http://www.hackney.gov.uk/individual-scrutiny-commissions-health-in-hackney.htm



Public Involvement and Recording

Scrutiny meetings are held in public, rather than being public meetings. This means that whilst residents and press are welcome to attend, they can only ask questions at the discretion of the Chair. For further information relating to public access to information, please see Part 4 of the council's constitution, available at http://www.hackney.gov.uk/l-gm-constitution.htm or by contacting Governance Services (020 8356 3503)

Rights of Press and Public to Report on Meetings

Where a meeting of the Council and its committees are open to the public, the press and public are welcome to report on meetings of the Council and its committees, through any audio, visual or written methods and may use digital

and social media providing they do not disturb the conduct of the meeting and providing that the person reporting or providing the commentary is present at the meeting.

Those wishing to film, photograph or audio record a meeting are asked to notify the Council's Monitoring Officer by noon on the day of the meeting, if possible, or any time prior to the start of the meeting or notify the Chair at the start of the meeting.

The Monitoring Officer, or the Chair of the meeting, may designate a set area from which all recording must take place at a meeting.

The Council will endeavour to provide reasonable space and seating to view, hear and record the meeting. If those intending to record a meeting require any other reasonable facilities, notice should be given to the Monitoring Officer in advance of the meeting and will only be provided if practicable to do so.

The Chair shall have discretion to regulate the behaviour of all those present recording a meeting in the interests of the efficient conduct of the meeting. Anyone acting in a disruptive manner may be required by the Chair to cease recording or may be excluded from the meeting. Disruptive behaviour may include: moving from any designated recording area; causing excessive noise; intrusive lighting; interrupting the meeting; or filming members of the public who have asked not to be filmed.

All those visually recording a meeting are requested to only focus on recording councillors, officers and the public who are directly involved in the conduct of the meeting. The Chair of the meeting will ask any members of the public present if they have objections to being visually recorded. Those visually recording a meeting are asked to respect the wishes of those who do not wish to be filmed or photographed. Failure by someone recording a meeting to respect the wishes of those who do not wish to be filmed and photographed may result in the Chair instructing them to cease recording or in their exclusion from the meeting.

If a meeting passes a motion to exclude the press and public then in order to consider confidential or exempt information, all recording must cease and all recording equipment must be removed from the meeting room. The press and public are not permitted to use any means which might enable them to see or hear the proceedings whilst they are excluded from a meeting and confidential or exempt information is under consideration.

Providing oral commentary during a meeting is not permitted.



Agenda Item 4



Rt Hon Matt Hancock MP
Department of Health and Social Care
39 Victoria Street
London
SW1H 0EU
United Kingdom

Philip Glanville, Mayor Of Hackney Cllr Feryal Clark, Deputy Mayor and Cabinet Member for Health, Social Care, Leisure and Parks London Borough of Hackney Town Hall Mare Street London E8 1EA

philip.glanville@hackney.gov.uk feryal.clark@hackney.gov.uk

Tel: 0208 356 3373

28 October 2019

Emailed to: mb-sofs@dhsc.gov.uk

Dear Matt,

Rare and uncommon cancers

In October 2018, Hackney Council unanimously passed a <u>motion</u> 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 <u>GP training session</u>, 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.

Hackney

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,

Philip Glanville

Mayor of Hackney

Philip 6 laike

Cllr Feryal Clark

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