

Minutes

All Party Parliamentary Group on Cancer

Stakeholder Group Meeting

Wednesday 6th July, 16:00-17:00pm, CPA Room, House of Commons
Chaired by Minesh Patel, Head of Policy, Macmillan Cancer Support (APPGC Secretariat)

Representatives from:

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| <p>Tonia Antoniazzi MP Office of Grahame Morris MP Office of Sharon Hodgson MP Abbvie Alcohol Health Alliance Anthony Nolan Blood Cancer UK Bowel Cancer UK Brain Tumour Charity Breast Cancer Now British Association of Surgical Oncology Cancer Research UK Less Survivable Cancers Taskforce</p> | <p>Less Survivable Cancers Taskforce Leukaemia Care Macmillan Cancer Support Maggie's Prostate Cancer Radiotherapy UK Roy Castle Trust Royal College of Pathologists Royal College of Radiologists Target Ovarian Cancer Teenage Cancer Trust Young Lives vs Cancer</p> |
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| <u>Proposed Timings</u> | <u>Item</u> |
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| 16:00 | Introductions – Chaired by Minesh Patel, Head of Policy, Macmillan Cancer Support |
| 16:03 | Early Diagnosis – ensure that every patient receives their diagnosis, treatment for their cancer, and treatment for their wider needs within national waiting time limits and in a way that works for them. |
| 16:15 | Personalised care – ensure that at every stage of their cancer journey, people understand the benefits of personalised care and support planning (PCSP) and can access tailored support for their holistic needs. |
| 16:25 | Workforce – Build the cancer workforce of the future by addressing current shortages, retaining expertise, and investing in innovative workforce planning models so that everyone with cancer has the dedicated support of a team of professionals? |
| 16:35 | Tackling inequalities – develop a robust understanding on inequalities across the cancer pathway to drive targeted interventions that improve access and experience for the most excluded groups. |
| 17:00 | Close |

Minutes

| <u>Summary</u> | <u>Four key themes for the Cancer Plan that it needs to include</u> |
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| 1. | Awareness and Education - Increasing and improving cancer awareness and education for both patients and clinicians. |
| 2 | Personalised Care – ensure shared decision making with access to a Cancer Nurse Specialist and supported by a Holistic Needs Assessment |
| 3 | Digitalisation - Improving leadership on digitisation and sharing patient data |
| 4 | Workforce - sufficient workforce planning and funding to ensure staff retention and fill the historical gaps in the cancer workforce |

1) Introductions

As Chair of the meeting, **Minesh Patel** introduced himself and colleagues from Macmillan Cancer that hold the secretariat for the APPC.

With new Secretary of State for Health and Social Care – it is still very unclear what this will mean for the cancer plan. Despite this uncertainty, this session will still be incredibly useful to help formulate our collective thoughts which will be written up and sent to the Department and NHSE for their information.

Tonia Antoniazzi MP, Chair of All Party Parliamentary Group on Cancer said that we must be relentlessly focussed on delivering for people living with cancer regardless of the political dramas with the resignations of the Prime Minister and Secretary of State for Health and Social Care. It's critical that we continue to hold Ministers to account and this is an important meeting in keeping up that momentum.

2) Item 1 – Early Diagnosis

Phillipa Anders – Patient representative - Brain Tumour Charity

Public awareness is critical. Husband died after only a very short time following diagnosis due to lack of awareness of professionals when presenting with symptoms. GPs need to be better trained on red flags on signs and symptoms of brain tumours. Early diagnosis and better public awareness is critical.

Corrie Drumm – Bowel Cancer UK

Large percentage of Bowel Cancer diagnosed in stage 4. Bowel Cancer is 4th largest cancer area but lack of symptom awareness hampers early diagnosis. Bowel screening is critical – requires targeted approach to screening in 10 Year Cancer Plan. Expanding/lowering the age categories for screening needs to be rolled out more quickly. Workforce pressures is key barrier in addressing the backlog of cases.

Judith Neptial– Patient representative - Macmillan Cancer Support

Communication with patients is fundamental. More funding being invested in diagnostic machines but little on symptom awareness. Diagnosis in minority ethnic groups needs to be improved as well as symptom awareness within the community. Significant lack of communication between different NHS departments resulting in poorer care and treatment. Workshops required on cancer symptom awareness in GPs including education/increasing awareness for all healthcare professionals of cultural differences and sensitives that drive patient interactions and behaviour. Important that patients have support from a human being like a Cancer Nurse Specialist (CNS) to help signpost/navigate through the often complicated and confusing health system.

Martin Grange – Roy Castle Lung Cancer Foundation

NHSE Lung cancer screening pilots in lower socio-economic areas seems to have some good initial results in early diagnosis. This includes 11% increase in smoking cessation projects. Long Term plan targets for all cancers diagnosed at stage 1 and 2 set at 75% by 2028 – long way to go for lung cancers with 40% currently diagnosed at stage 4. Screening is critical to finding lung cancer early so a full national lung cancer screening programme needs to be part of 10 Year Cancer Plan if we are to meet the ambitious targets set out in the Long-Term Plan. Access to the correct data incredibly important for full working on an multi-disciplinary team surrounding a patient.

Janice Aldridge - Royal College of Radiologists

A shortage of capital investment is harming the efforts to reduce the backlog with 32% of radiotherapy equipment needing to be replaced. Addressing diagnostic backlog and improving early diagnosis is being hampered by poor equipment. What we need is an

urgent audit of all existing equipment and a capital strategy to invest in replacing the outdated equipment.

Zaed Hamady – British Association of Surgical Oncology

Improving radiology is really important but we need to rethink how we are referring people under an outdated model. Currently a patient presents to their GP and then is referred into hospital for tests. But there is little/no direct access for GPs to CT scans or other diagnostic equipment. In international comparator countries, GPs have access to CT scans directly in community – speeds up process considerably.

Sarah Quinlan – Radiotherapy UK

Massive issues with treatment waits with 36% of patients waiting too long for radiotherapy. Concerns with diagnostic waits within the elective recovery plan are important but seems to be at the expense of treatment capacity which is on its knees and little/no strategy of increasing treatment supply. Need to increase treatment capacity when the backlog of patients present. Significant deficiency in usage of radiotherapy in the UK compared to international comparator countries where radiotherapy is used in 50% of patients compared to 27% in UK. Addressing funding gap and issues with tariffs in radiotherapy will be important along with workforce. The diagnosis backlog is increasingly prominent but the treatment backlogs have only just begun so we will see far greater treatment waits in future. Would like to see audit and analysis of what works internationally to form part of Ten Year Cancer Plan.

Andrew Seggie – Prostate Cancer UK

Some good success in increasing diagnosis rates with collaboration with NHSE on awareness campaign on prostate cancer. While other cancer campaigns focused on signs and symptoms, early prostate cancer does not have signs and symptoms, therefore the NHSE-Prostate Cancer UK awareness campaign has focused on risk factors of prostate cancer. Had 500,000 additional visits to websites with 80% found at being high risk of prostate cancer. There was a record referral for urological cancers following campaign.

Frankie Walker – Young Lives vs Cancer

From research at the charity, majority of staff would benefit from continual professional development to support diagnosis in young people due to low awareness. 52% of child patients went to GPs 3 times before they finally got a diagnosis.

Emma Stevenson – Teenage Cancer Trust

Young people present up to 5 times before receiving a diagnosis so can be traumatic to get a diagnosis. Need to create innovative ways to engage with young people on symptom awareness. Addressing the wellbeing of young people throughout cancer journey is imperative as often very significant impact on mental wellbeing.

Jess Potter – Target Ovarian Cancer

No screening currently on ovarian cancer with 21% of people diagnosed not aware of specific symptoms. Time to diagnosis should be shortened within 10 Year Cancer Plan with an increase in prominence of awareness campaigns.

3) Item 2 and 3 – Personalised Care and Workforce

Judith Neptial– Patient representative - Macmillan Cancer Support

The care that a lot of patients currently get, including myself in the past, is not person centred. My treatment choices did not seem to be respected and no alternatives were presented to her when she said no to chemo. Alternative methods were available and should have been offered. Ended up being clinically orphaned with no hospital for 8/9months whilst having no treatment. Treatment options should be collaborative

between clinicians and patient. Stated that her voice was not heard and feels that this was due to her ethnicity and being a black women.

Ella Guthrie – Leukaemia Care

Invaluable that patients have access to a CNS to provide holistic care. Some concerning postcode lotteries about access to a CNS. Vital psycho-social needs addressed by CNS and that all patients get access to a CNS. Still a bit of postcode lottery. Having good access to a CNS to provide holistic support for those with Leukaemia is absolutely vital as 52% of those diagnosed with Leukaemia are “watch and wait” – in limbo between diagnosis and treatment. Huge impact on mental wellbeing so access to psycho-social is a life-line in this uncertain time period.

Debs Roebuck – Abbvie

Offer shared decision making support and tools which are vital for patient centred care. Patient knowledge of NHS systems can be low – patients don’t know, what they don’t know. Patients often told to have a say in their care but this needs to be supported by training and awareness on patients’ rights and patient advocacy. Need to empower and train patients better.

Kate Roberts – Brain Tumour Charity

“Watch and wait” is common with brain tumours which is hugely anxiety inducing. Research by the charity showed that only 40% of brain tumour patients had a HNA and only 21% had a care plan. Within this 40% who had HNAs, this included significant variation and inequalities as CNS tend to be offered more in more affluent areas of the country.

Georgina Annan – Maggie’s

Maggie’s has 24 centres across the UK and is Scottish charity. Psychological support often completely missed from the care and support offered to cancer patients. Maggie’s supports mental wellbeing and holistic care through a partnership approach with the NHS.

Laura Challinor – Blood Cancer UK

Blood Cancer Patient’s used Maggie’s facilities near them. Charity has undertaken research with Oxford Brookes University on Psychological support. Because Blood Cancer doesn’t have staging and often has very long and complicated names that don’t sounds like cancer. Often patients not actually even told they have a form of cancer and hence they don’t access additional support for cancer patients.

Billie McPartlan - Patient representative – Anthony Nolan

Talked about how vital access to a CNS is for a patient. Critical that every patient has access to a CNS to support them. It meant so much to her to have good access to a CNS and wants this for all cancer patients.

Andrew Seggie – Prostate Cancer UK

Talked about how invaluable helplines from by Prostate Cancer UK staffed by nurses was for cancer patients. Gap in access for prostate patients in accessing a CNS and need to encourage more nurses to train as a cancer specialist. Huge caseloads for CNS so can’t always give the care and support they would like. A CNS may have up to 400 patients each which is not sustainable nor possible to provide personalised care.

Mike Grundy – Roy Castle Lung Cancer Foundation

Fantastic new genomics and genetic labs which are becoming more used needs to be full integrated into the cancer pathway. Always liked analogy of NHS and treatment like being a very long corridor – you need a CNS/person to have navigate it and help open the correct doors. CNSs are the backbone of cancer treatment and we just need more of them.

Phillipa Anders – Patient representative - Brain Tumour Charity

Unfortunately, her husband had no access to a CNS when undergoing treatment and care – having someone to support you to navigate the NHS system and support wellbeing would have made such a difference to her and her late husband. Really important not exclude family and particularly carers in collaborating and co-producing a care plan for patients.

Corrie Drumm – Bowel Cancer UK

Over half of bowel cancer patients don't have access to a Holistic Needs Assessment. They are not getting access to good patient advice and information early nor access to a HNA – creates poorer outcomes for cancer patients for years to come.

Mike Osborn – Royal College of Pathologists

Addressing the shortages of pathologists will be fundamental to improving cancer services and diagnosis in the future as only a pathologist can diagnose cancers. There is a shortfall of 20% within the workforce. Workforce is the backbone of all NHS and is the main cause of lack of performance within NHS. Need fundamental change in IT and data to ensure interconnectivity of IT programmes and data transfer. Need one connected NHS in a fully linked data system not 100 different systems that don't talk to each other.

Zaed Hamady – British Association of Surgical Oncology

Significant improvements need to be made on data interconnectivity between hospitals and within hospital departments themselves. Also require workforce retention and build plan to ensure we have the staff to support patients in the future.

Janice Aldridge - Royal College of Radiologists

Massive issues with systems and data. On workforce in future – mix of skills will be required including specialists and generalists to ensure we can do more in all areas as part of MDTs.

Judith Neptial– Patient representative - Macmillan Cancer Support

There is significant inequality of funding in some cancers – all deserve good care – but ensuring this happens shouldn't be at the expense of other cancers or condition areas.

6) Closing remarks

Minesh Patel thanked everyone for coming to this successful session and participating. Summarised discussion into four broad themes:

- **Awareness and Education** - Increasing and improving cancer awareness and education for both patients and clinicians.
 - **Personalised Care** – ensure shared decision making with access to a Cancer Nurse Specialist and supported by a Holistic Needs Assessment.
 - **Digitalisation** - Improving leadership on digitisation and sharing patient data
 - **Workforce** - sufficient workforce planning and funding to ensure staff retention and fill the historical gaps in the cancer workforce.
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