Northern Ireland Affairs Committee
Committee Office House of Commons London SW1A 0AA
Tel 020 7219 2173 Email northircom@parliament.uk Website www.parliament.uk

Richard Pengelly
Permanent Secretary, Department of Health
Castle Buildings
Stormont
BT4 3SQ

24 October 2018

Dear Mr Pengelly,

We would like to thank the Department for giving the Committee advanced notice of its proposed changes to the Individual Funding Request (IFR) process and welcome the greater access to innovative new medicines that patients in Northern Ireland will now benefit from in line with their counterparts elsewhere in the United Kingdom.

The Department has estimated that these new arrangements will cost between £2 million and £2.5 million per year.[1] The Committee has heard consistently over the course of its inquiry that long-term transformation of the Northern Ireland health service in line with the recommendations of the Bengoa report is urgently needed if Northern Ireland is to meet increasing demands from an aging population. It has also heard how budgets for health and social care are set on a year-by-year basis which has impeded long-term financial planning,[2] meaning that current financial commitments can not necessarily be projected into the future.

The Committee therefore requests clarification on where funding for these new arrangements has come from and whether cuts to transformational projects were made to make this funding available. The Committee also seeks clarification on when patients can expect to benefit from these changes and how the Department plans to fund these new arrangements beyond the current financial year.

In our recent session with cancer charities there were unanimous calls for the development of a comprehensive Northern Ireland cancer strategy. Northern Ireland's current cancer strategy is the *Regional Cancer Framework* which was published in 2008 and sought to:

> Make detailed recommendations for a programme of action for cancer services up to 2008; outline recommendations for the development of cancer services up to 2015; and for the strategic direction of cancer services up to 2024.[3]

This is now clearly out-of-date. Furthermore, the Northern Ireland Assembly Research and Information Service found that the Department of Health's progression against its 55

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[1] Department Announces Improved Access to New Drugs, Department of Health, accessed 25 September 2018
[2] Oral evidence taken on 5 September 2018, HC (2017-19) 1447, Q45
[3] Regional Cancer Framework: A Cancer Control Programme for Northern Ireland, page 52

recommendations could not be assessed due to a lack of publicly available supporting documents – including a target-based action plan and formal review.[4]

Cancer Focus NI told us that:

> Northern Ireland's cancer strategy is 10 years old and the world has changed so much in 10 years. We know from our Cancer Registry that by 2035 incidences will go up 65%. [...] We barely can deal with the patients we have now; how will we cope with a 65% increase?[5]

The lack of a comprehensive cancer strategy was also raised by Prostate Cancer UK, which cited comparatively poorer outcomes in Northern Ireland when compared with England, Scotland and Wales where cancer strategies are in place:

> Without a cancer strategy and that top-down direction, things are moving at a much slower pace. That is why things are falling behind in Northern Ireland. Wales, Scotland and England have cancer strategies and, while they are not perfect, they do offer the strategic direction that is needed to focus on survival rates and much better outcomes for cancer survival. Without that in Northern Ireland I think that we are going to continue to see things fall behind.[6]

The World Health Organization has recommended that 'no matter what resource constraints a country faces, when well-conceived and well-managed, a [national cancer strategy] helps reduce the cancer burden and improve services for cancer patients and their families.[7] Yet Northern Ireland is unique in the United Kingdom in not having a comprehensive and up-to-date cancer strategy in place.

The Committee therefore asks what decision-making processes are available to the Department in the absence of a Minister that would lead to the development of a comprehensive cancer strategy for Northern Ireland?

We heard that Northern Ireland is also lagging behind elsewhere in the United Kingdom with respect to its population screening programmes. The UK National Screening Committee has recommended FIT (faecal immunochemical testing) offered to men and women aged 50 to 74 years to screen for bowel cancer[8] and tests for Human Papillomavirus (HPV) as the primary test in cervical screening.[9]

Northern Ireland is alone in the United Kingdom in not committing to adopt these recommendations, offering instead the less cost-effective[10] FOBT (faecal occult blood test) to men and women aged 60 to 74 years[11] and routine smear tests as the primary test in cervical screening.[12]

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[4] Northern Ireland Assembly, Research and Information Service, Cancer: Northern Ireland, pp. 7-
[5] Oral evidence taken on 12 September 2018, HC (2017-19) 1447, Q71
[6] Oral evidence taken on 12 September 2018, HC (2017-19) 1447, Q73
[7] World Health Organization, National Cancer Control Programmes (NCCP), accessed 27 September 2018
[8] Public Health England, Current UK NSC recommendations, Bowel Cancer, accessed 27 September 2018
[9] Public Health England, Current UK NSC recommendations, Cervical Cancer, accessed 27 September 2018
[10] Public Health Agency, The UK NSC recommendation on Bowel Cancer screening in adults, Last evidence review summary, point 7, accessed 27 September 2018
[11] Public Health Agency, Overview of the NI Bowel Cancer Screening Programme, accessed 27 September 2018
[12] Public Health Agency, Overview of Cervical Screening Programme, accessed 27 September 2018

The Committee therefore requests that the Department commit, in line with UK National Screening Committee recommendations, to adopting FIT (faecal immunochemical testing) offered to men and women aged 50 to 74 years to screen for bowel cancer and tests for Human Papillomavirus (HPV) as the primary test in cervical screening.

Alongside this, cancer service waiting times in Northern Ireland continue to exceed Ministerial targets. The 2017/18 Ministerial target relating to cancer services stated that by March 2018 at least 95% of patients should begin their first treatment for cancer within 62 days following an urgent GP referral for suspect cancer; at least 98% of patients diagnosed with cancer should receive their first definitive treatment within 31 days of a decision to treat; and all urgent breast cancer referrals should be seen within 14 days.

All but the last of these targets were not met. The statistics note that 75.4% of patients commenced their first treatment for cancer within 62 days of an urgent GP referral for suspect cancer; 96.7% of patients were treated within 31 days; and all breast cancer referrals were seen within 14 days.[13]

We have heard that these targets are not being met due to chronic shortages in the HSC workforce. Northern Ireland has the highest number of unfilled consultant radiologist posts in the United Kingdom, with 18.4% of posts unfilled,[14] leading to diagnostic delays for patients. According to the British Medical Association, Northern Ireland also has the lowest number of GPs per head in the United Kingdom at just 6.10 per 10,000.[15] Given that GPs play a vital role in cancer screening and diagnosis and are the first point of contact for the majority of people in relation to cancer care these shortages have implications for timely diagnosis and treatment. The Northern Ireland Cancer Registry showed that between 2011-2015, 45% of cancer patients were diagnosed at stage three or four, when cancer is far more difficult to treat.[16]

The Committee requests clarification on what steps are being taken by the Department to improve waiting time performance. The Committee also requests that the Department conduct an exercise to identify gaps in the HSC workforce and develop a comprehensive strategy for addressing these gaps via an appropriate funding settlement.

In addition to these delays we have heard that some patients are having to travel long distances to receive treatment, particularly patients based in parts of Fermanagh. While radiotherapy treatment is available at both Altnagelvin Hospital in Londonderry and Belfast City Hospital many patients still face journeys upwards of 65 miles to receive their treatment. In cases where very specialised care is required treatment is only available in Belfast – consequently some patients face even greater journey distances.[17]

There are many cases where patients must travel even further – to the rest of the United Kingdom to receive their treatment. Prostate Cancer UK found that of those patients referred to Belfast City Hospital for radical prostatectomy treatment all were subsequently referred for treatment in England[18] as 'access to prostate surgery is non-existent in Northern Ireland' – specifically Addenbrooke's Hospital in Cambridge or Guy's Hospital in London, for which

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[13] Northern Ireland Waiting Time Statistics: Cancer Waiting Times (January – March 2018), pp. 3-5
[14] The Royal College of Radiologists, Clinical radiology UK workforce census 2017 report, page 12
[15] British Medical Association, General Practice in Crisis – a report on primary care in Northern Ireland, page 3
[16] Northern Ireland Assembly, Research and Information Service, Cancer: Northern Ireland, page 13
[17] Northern Ireland Assembly, Research and Information Service, Cancer: Northern Ireland, page 20
[18] Written evidence received from Prostate Cancer UK, HC (2017-19) 1447

they had to pay for their own flights and accommodation before claiming back the expense. In one case, a patient had to 'travel over four times before actually having his surgery.'[19]

Aside from the detrimental impact on these patients of having to travel such long distances, for patients on low incomes there is the added worry of having to fund the initial outlay of their treatment. The Department is then financially burdened with the additional cost of having to fly patients out of Northern Ireland.

The Committee therefore requests that the Department examine whether providing specialist care locally would be a more cost-effective approach for the treatment of certain cancers and how investment could be directed to overcome the geographical distances between patients and providers.

We thank you for your consideration of our recommendations and we look forward to receiving your response.

Yours sincerely

Andrew Murrison.

Dr Andrew Murrison MP
Chair, Northern Ireland Affairs Committee

[19] Oral evidence taken on 12 September 2018, HC (2017-19) 1447, Q67-68