

2021 Cancer Strategy – RCGPNI response

Background

The Royal College of General Practitioners is the professional membership body for GPs in the UK. Our purpose is to encourage, foster and maintain the highest possible standards in general medical practice.

We support GPs through all stages of their career, from medical students considering general practice, through training, qualified years and into retirement. In addition, we set the standards for competency through our examination process.

In Northern Ireland, RCGPNI represents more than 1500 General Practitioners, more than 75% of the general practice workforce.

This strategy is one of many commissioned by the Department of Health (DoH) in Northern Ireland, the majority of which focus on Trust based services while necessitating significant workload and impact on general practice and primary care services.

These strategies do not adequately consider primary care resources or workload impact, with a resulting lack of necessary co-production and co-design when designing services.

We urge DoH to commission a review of all strategies and reviews since the Review of GP Led Primary Care Services in 2016ⁱ and introduce the necessary resources into primary care when cited in these reviews.

Introduction

We welcome the opportunity to respond to the consultation on the Draft Cancer Strategy 2021-2031 and the invitation to participate in the initial scoping workshop and working groups developing the strategy. Due to capacity restrictions, the College in Northern Ireland were only able to contribute to the initial scoping workshop and early diagnosis group.

We have concerns that the Strategy has no dedicated funding. We urge the DoH to act to ensure our population has the best cancer care, by taking necessary steps to avoid duplication of services and to consider when appropriate to reutilise and redesign services.

We respectfully suggest that in order to achieve its aims, the Strategy must place a greater emphasis on primary care.

We have three significant concerns about this Strategy.

- 1.) There is not enough focus in the Cancer Strategy on general practice and methods to support our ability to make an early diagnosis of cancer.
- 2.) We feel the fundamental concept of how general practice refers patients for specialist investigation or assessment is misunderstood. This has placed barriers in the implementation of NICE guideline 12 (NG12) by solely focusing on secondary care services.
- 3.) We feel that there is not enough robust use of data. There is insufficient mention of primary care data which has potential to improve our understanding of cancer through presentation, pathways, service design, user experience and community care.

1) Recognising and supporting general practice in the early diagnosis of cancer

We are disappointed that the importance of general practice in its role of making an early diagnosis of cancer does not have a more prominent role in this strategy. We feel an opportunity has been missed to enhance general practice services and direct access to diagnostics and specialist opinion which will benefit all patients through early diagnosis which will improve survival rates.

The earlier a cancer is diagnosed, the earlier its stage which will improve survival times and outcomes. For every week a cancer diagnosis is delayed, 10-year survival is reduced by 1%ⁱⁱ. We urge commissioners to focus on this aspect of cancer care and recognise the importance of good access to a community facing family doctor with relationship-based care at its core.ⁱⁱⁱ

Cancer is a very difficult disease to diagnose early. Many cancer symptoms are non-specific and require clinical skills, opportunities for review and subsequent further investigation. The significant primary care contribution to the common goal of early cancer detection must be viewed with respect by all aspects of the health service and facilitated in our common goal of early cancer detection. GPs have unique skills in diagnosing cancers which do not present with speciality specific symptoms and as such must be supported in a way that enhances early cancer detection.^{iv}

We feel the use of the National Cancer Diagnosis Audit (NCDA) is underutilised in Northern Ireland. Evidence supports its use, and it could be a valuable tool in service improvement in cancer diagnosis in general practice. Systemic use of NCDA could help general practice critically analyse and improve their service and should be considered by the Department of Health, as either part of revised general practice contracts.

The proposed increase in a more integrated approach to diagnostics is welcome but unfortunately lacks the detail required.

2) Fundamental concept of risk thresholds in general practice

GPs in Northern Ireland recognise the constraints on secondary care services and are committed to only referring patients for investigation or opinion when clinically necessary.

We are concerned that the Strategy does not recognise the difficulty in diagnosing cancer early in general practice where advanced imaging is unavailable. Current cancer referral guidance for Primary Care in NI as recommended by NI Cancer Network (NICaN)^v contains referral advice about symptoms which frequently represent a late stage of cancer presentation. A palpable mass, visible jaundice and the appearance of blood in sputum, vomit or faeces are frequently late presentation signs with associated poor outcomes.

GPs do not refer patients they “know” have cancer – they refer patients “who might have cancer”. To improve our early diagnosis of cancer, high referral rates should not be viewed as a criticism but a necessity in improving survival outcomes.^{vi}

This is an important shift in ethos and values and consideration must be given to reducing our referral thresholds and consequent increased use of urgent referral for suspected cancer^{vii}. It should also be recognised that symptom complexes that suggest the need to rule out a cancer in a patient presenting in primary care may often not fit into those “typically seen and accepted within a referral pathway”. This lowering of threshold should reflect the need to include the atypical as well as the typical presentation.

The discussion of this issue in pages 38-40 of the strategy have all cited concerns about secondary care capacity. There is little evidence of new ways of working or involvement of primary care as true partners in the referral process.

The cited “Pathways to a Cancer Diagnosis” Report, mirrors data already published in British Journal of General Practice^{viii} that showed that around 1/3 of cancers diagnosed as an emergency had never presented to any healthcare professional. The NI study revealed 28% of emergency presentations are due to haematological cancers which are widely regarded as more difficult to diagnose in primary care. The 25% of head, neck, brain and eye cancers diagnosed in emergency departments frequently reflect patients with a first epileptic seizure which after imaging represents a brain tumour.

The proposed introduction of Rapid Diagnostic Centres (RDCs) needs more consideration. GPs would welcome a central “one stop shop” to enable quick diagnosis for patients with vague but worrying symptoms. With a population of 1.8 million and 5 different Health and Social Care Trusts, we have concerns that the risks of duplication of existing diagnostic services are too great. A regional approach should be used and close working with primary care will be essential. We urge commissioners to consider the work of

the No More Silos (NMS) network and the proposed Rapid Access Assessment Centres (RAAC). If implemented properly, we believe these structures could act as an RDC and would replace the entire red flag and urgent referral system completely. A quicker and more clinician to clinician-based service could perform the function of a RDC, ensuring earlier detection rates and supporting GPs as the primary risk holders in patient diagnosis. These must also have robust onward referral mechanisms when pathology identified.

We do note the initial promising results of the pilots of RDCs in Wales and Manchester and support the DoH undertaking analysis of these, to assess how it could be implemented in NI. We also highlight that RDCs are not used in Australia. This has been attributed to the fact that GPs in Australia have direct access to CT scans.

We look with interest at the proposed Community Diagnostic Hubs as proposed by Sir Mike Richards^{ix}. We particularly support his call for an increase in an integrated approach to improve access and availability.

3) Use of data

Despite the need for the use of data being strongly recommended at the initial stakeholder groups, it is not highlighted sufficiently in the strategy. In particular, general practice data is not mentioned. The Encompass project is not anticipated to be “live” regionally for another 5 years and is estimated to cost over £100m. We feel a fraction of this investment into general practice data could offer significant benefits to our entire population, help facilitate research and improve service design. Supercharging the General Practice Intelligence Platform (GPiP) could make a significant impact and preliminary work could be quickly adapted to ensure it was available for use.

Number 1 - Strategic priorities

Do you agree that the strategy has identified the correct strategic priorities?

We support the aims of the Cancer Strategy and agree that the strategic priorities have been correctly identified. However, we feel there must be more prominence given to the facilitation of early diagnosis of cancer. We feel this rests predominantly with general practice and it must be adequately supported to provide this. We are acutely aware that the Cancer Strategy is currently unfunded and there is no financial capacity in current budgets to meet the priorities. If the Cancer Strategy is to make difference to the lives of people living with cancer and the healthcare professionals who care for them, it must be funded fully and sustainably.

Yes

Do you have any further comments?

To reduce the number of people diagnosed with cancer, the Public Health Agency and relevant Government bodies must engage constructively with general practice. Government campaigns designed to reduce the rate of preventable cancers should aim to make it easier for populations to do the right thing for their health. Billboard campaigns must be evidence based and value for money.

Nicotine Replacement Therapy (NRT) has very strong evidence for its effectiveness in helping smokers stop smoking^x and its cost effectiveness^{xi}. We feel it should be made widely available and that the breadth of professionals able to refer to specialist smoking services should be expanded to reduce the workload burden on requiring an appointment with a GP.

Previous public health messaging campaigns have encouraged citizens to “go see your GP” with little GP engagement on workload impact, evidence basis of advice, robust outcome data or capacity within the general practice workforce. All future campaigns should constructively engage with primary care and co-design campaigns where possible. Hard objective metrics reflecting the capacity of general practice must be met prior to running campaigns which encourage increased use of our services. This should include consideration of numbers of practice consultations per week with a clear threshold value set (current consultation rates are unsustainable at over 200,00 per week), practice list size per general practice partner ratio and whether a practice has formally requested for emergency assistance from the HSCB in way of list closure or use of Federation based rescue teams.

Targeted public health intervention to improve early cancer diagnosis must be considered and learning from national studies and regional pilots gleaned. The NELSON study in 2020^{xii} highlighted improvements in lung cancer mortality as a result of targeted low dose CT screening. We encourage DoH to pilot targeted lung cancer screening in NI and urge DoH to work collaboratively with general practice which has invaluable patient data to improve our poor outcomes in lung cancer.

In 2021, a pilot in Southern Trust highlighted the benefit of guided GP access to red flag chest CT scanning. With careful criteria and procedures in place to monitor pulmonary nodules, after only 6 months, 6 lung cancers were diagnosed more quickly than would have on traditional pathways and 265 red flag referrals were not needed and able to be managed safely in the community by GPs. 93% of all referrals were deemed to have met the referral criteria dispelling previous myths that GPs would misuse advanced imaging service if granted appropriate access. The learning from this pilot should be quickly adopted regionally.

GPs do not want unfettered access to advanced diagnostics, but we urge the Department to consider how the above example shows that if services and protocols are commissioned correctly, outcome improvements are made.

We support the development of a regional approach to ensure patients receive equitable access to diagnostics, care, treatment, and support. When faced with early cancer diagnosis, we urge HSC Trusts to work collaboratively together so that services are not duplicated, and efficiencies are maximised. Consideration should be made for patients and practices who are located on the border between two or even three Health and Social Care Trusts and how seamless flows of information and care can be maintained.

Health inequalities must be addressed to tackle preventable cancers and address social deprivation. While policy responsibility sits with the Department of Health primarily, RCGPNI believes this matter is cross cutting and there must be a commitment from across the NI Executive, to improve cancer services for the people of Northern Ireland. A successful Cancer Strategy is a commitment for all of Government under New Decade, New Approach.

2) Do you agree that these recommendations will reduce the number of preventable cancers in NI?

Yes

Do you have any further comments?

RCGPNI is aware of the evidence that tells us the proportion of cancer incidence attributable to lifestyle and environmental factors is estimated to be between 30-40%. We also know the World Health Organisation (WHO) states that 30-50% of all cancers are preventable. We support a population health approach that, with appropriate policy measures and adequate resources, encourages and supports people to live healthier lives and reduces cancer risk factors. These include obesity, lack of physical activity, tobacco and alcohol consumption. We support action to improve health literacy and encourage people to be aware of potential symptoms. We recognise that while this sits primarily with the Department of Health, there are other relevant factors such as education and housing that must be taken into consideration. A cross Departmental and full societal approach must be taken to cancer prevention.

We support the recommendations contained within the draft Cancer Strategy and agree that these will be impactful in reducing the number of preventable cancers. It is appropriate that these recommendations focus on raising awareness, but we feel focusing on personal responsibility will not achieve the outcomes necessary. The onus on government must be to make it easier for citizens to do the "right thing" rather than public messaging campaigns which highlight information already known. If adequately supported and resourced general practice can play an important role in population health to achieve these aims. Full implementation of Multi-Disciplinary Teams with important first contact social workers could play an important proactive role with vital links to community and voluntary services. It is important to understand that primary care input into improving lifestyle and reducing risk is only one part of a multifaceted approach requiring input and collaboration from the wider health and social care providers as well the cross departmental and societal approach outlined above.

RCGPNI believes it is vital that we recognise the inequalities that exist with regards access to cancer treatment and wider access to health service. We must learn lessons from the Covid-19 pandemic and make a concerted effort to reach out to minority groups; including people with disabilities and the BAME community, to ensure equality of access to cancer services.

3) Do you agree that these recommendations will improve outcomes for people living with cancer?

Yes, but it is vital general practice is supported to improve early diagnosis of cancer.

Do you have any further comments?

We are supportive of the need to improve haematological cancer diagnosis and treatment. We note that on page 45, whole body MRI is recommended for suspected myeloma. It is disappointing there is no reference to general practice and our role in highlighting these patients.

Page 47 highlights advanced surgical techniques. These will be wasted if our theatre capacity is not optimised. Rehabilitation (Page 50) has a good evidence base, but we suggest that due consideration for general practice and limited resource is considered before moving this work into the community.

Metastatic Spinal Cord Compression is an oncology emergency, and its presentation can be vague and difficult to diagnose. We urge commissioners to implement primary care facing pathways and guidance which are easy to access with good links to oncology specialist colleagues.

The focus on page 64 for care of patients with learning difficulties with cancer is welcome. Consideration should be made to support GPs who have good relationship-based care with this cohort of patients and other GPs with specialist interest in this area.

We support the facilitation of clinical trials (page 76) and urge Department of Health to enable GPs to fully participate in clinical trials. General Practice Speciality Training is shorter than many hospital specialities at 3 years and we urge policymakers to provide support for GPs to develop research skills particularly in cancer.

We understand that early diagnosis of cancer significantly reduces mortality. GPs and practice teams are prepared to be a key part of efforts to improve survival rates, but it is vital that the current difficulties in general practice are recognised. While we recognise the effectiveness of public awareness campaigns in other parts of the UK, we are concerned about how primary care would cope in the present climate. We are worried this would lead to an increase level of demand on our already overwhelmed general practice surgeries. . Indeed, the long waiting lists and backlog in secondary care means that diagnostic services would also be unlikely to cope. It is essential that significant resource into general practice must follow a public awareness campaign, to allow GPs and practice staff to cope with the potential increased volume of contact. We also support the comment about co-designing these awareness campaigns in partnership with GPs and we would welcome the opportunity to engage with this work.

RCGPNI supports investing in targeted screening programmes to improve outcomes for patients. We are aware that Northern Ireland is behind the curve in adopting the UK National Screening Committee recommendations and we support this being rectified urgently. However, we agree that screening is only effective in improving outcomes if there is timely access to diagnostic and cancer treatment services. There has been no significant improvement in cancer waiting times over the last number of years. On many occasions, GPs refer their patients for diagnostic tests in the knowledge they will have to wait far longer than they should. A new approach is required if we are to improve the effectiveness of cancer treatment and survival.

We welcome the acknowledgement of a need to improve pathways for patients with vague but worrying symptoms. There is an absence in referral pathways in many HSC Trusts to be able to see a secondary care generalist and referrals tend to need to be speciality specific. This leads to a reduction in capacity and capability to be able to refer such patients for a generalist opinion and diagnosis? as well as a dilemma for

the referring clinician as to which pathway to follow - particularly in the current climate when waiting times are so long. Choosing the wrong speciality could have catastrophic consequences for the patient.

When a patient presents with symptoms that are vague but of concern, GPs in Northern Ireland currently have no clear guidance on where to refer this patient. In many cases, they are referred for numerous tests and this increases the workload in our health service but crucially, is a distressing time for the patient. We support the development of diagnostic hubs. Diagnostic hubs, along with clear guidance for general practitioners, will go some way to address current difficulties but we have concerns about duplication of existing services. This would allow earlier diagnosis and ultimately improved patient experience and outcomes.

GPs in Northern Ireland are strongly supportive of the introduction of Faecal Immunochemical Testing (FIT) to help the early diagnosis of bowel cancer. This is used now as a screening test or as a test available to GPs for patients with symptoms. We commend the working group from NICaN and colo-rectal surgical colleagues who have implemented qFIT (Quantitative Immunochemical Testing) in Northern Ireland. They used a true co-production model with frequent opportunities for both primary and secondary care to meet, engage and design this service together. GP concerns about having rigid referral rules have been listened to and assurances of support for unusual presentation symptoms have been offered.

In Northern Ireland the value of FIT for population screening is set at 150ng/ml – the same level as Thailand^{xiii}. England has a level of 120 ng/ml and some studies feel even this lower threshold may miss up to 50% of potential cancers. We urge the Department of Health to review the level of FIT set at 150ng/ml and consider lowering it.

4) Do you agree that these recommendations will deliver person centred care?

Yes

Do you have any further comments?

The recommendations do not have enough emphasis in strengthening primary care and general practice which is key to improving person centred care. With over 95% of a citizens health care being delivered in primary care over their lifetime, we feel that in order to enable GPs to deliver a more person-centred care, investment is needed in our practice teams.

Page 77-79 highlights the need for best palliative and supportive care. This is welcome, but there is a significant role for general practice as patient advocate and expert generalist here. With rising multi-morbidity, many patients will have significant concomitant diseases. Some pre-existing conditions, for example heart failure, may pose more of a risk than cancer, re-enforcing the need of GP input to coordinate their care.

The cited report: 1 Northern Ireland Cancer Patient Experience Survey 2018 All Trusts Report showed that 71% of practice staff did everything they could to support their treatment. While significantly above England (60%) we are concerned that no active support has been offered to improve the fall in this from 2015 figure (77%). Work must commence to enhance practice offering to support patients who have incurable and terminal disease. Support to perform in practice cancer care reviews by specialist nursing could help

Page 81: GPs must be properly supported to provide a treatment summary record (TSR) and cancer care review (CCR) Simply delegating this to already overstretched general practice teams will not achieve the intended outcomes.

Page 91: Supporting people to live well: Cardiovascular, lymphoedema and community support are all within the remit of GPs. This highlights the need for Multidisciplinary Teams (MDTs) in our community, particularly social workers and to enhance the link with community, charity and voluntary sectors.

Page 102: We will deliver integrated, coordinated and personalised palliative and end of life care to people with non-curative cancer when and where they need it. Unfortunately, no mention of vital role of GPs as trusted health care professionals.

Page 106 Advance Care Planning: We support the implementation of the ReSPECT2 document which will replace all Do Not Resuscitate (DNR) documents. This document can be used seamlessly across all Trust and primary care services and only needs amended if there is a change in patients' clinical condition. In time it can be completed by a range of healthcare professionals, thus making these conversations more "normal" and reducing the workload burden.

Page 112: The mentioned workforce plan must be amended to reflect the impact and importance of general practice and be cognisant that 26% of our GPs are over the age of 55 years.

5) Do you agree that these recommendations will enable delivery of the 10 year strategy?

Yes

Do you have any further comments?

The Royal College of General Practitioners in Northern Ireland are supportive of the ambitious recommendations contained in the Cancer Strategy. However, we are deeply concerned that the Strategy is yet to be allocated any funding. If the Strategy is to be successful, it requires significant and recurrent funding to be allocated as a matter of urgency. We would urge political leaders to find the necessary funding to allow this Strategy to transform the lives of people with cancer.

While we are supportive of action to improve cancer outcomes in Northern Ireland, it is important to be clear about the current pressures within general practice. The workload for GPs in Northern Ireland is frankly unmanageable and decades of underfunding in general practice is taking its toll. While we recognise the effectiveness of public awareness campaigns, the increase in workload this will bring for GPs and their practices must be matched by resource otherwise practices will not cope with the regrettable negative impact on patient access and outcomes.

ⁱ <https://www.health-ni.gov.uk/sites/default/files/publications/dhssps/review-gp-led-primary-care-services.pdf>

ⁱⁱ <https://www.bmj.com/content/371/bmj.m4087>

ⁱⁱⁱ <https://www.rcgp.org.uk/policy/general-practice-covid-19-power-of-relationships.aspx>

^{iv} <https://bjgp.org/content/71/706/e356>

^v https://nican.hscni.net/wpfd_file/nican-gp-referral-guidance-2019

^{vi} <https://bjgp.org/content/70/695/e389>

^{vii} <https://bjgp.org/content/71/712/e826>

^{viii} <https://doi.org/10.3399/bjgp17X690869>

^{ix} <https://www.england.nhs.uk/wp-content/uploads/2020/11/diagnostics-recovery-and-renewal-independent-review-of-diagnostic-services-for-nhs-england-2.pdf>

^x <https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD000146.pub5/full>

^{xi} <https://www.sciencedirect.com/science/article/pii/S1098301521000541>

^{xii} <https://www.nejm.org/doi/full/10.1056/nejmoa1911793>

^{xiii} <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5454735/>