WHERE NEXT FOR CANCER SERVICES IN NORTHERN IRELAND?

AN EVALUATION OF PRIORITIES TO IMPROVE PATIENT CARE

CANCER RESEARCH UK

EXECUTIVE SUMMARY

Incidence of cancer is rising, with one in two people born after 1960 expected to be diagnosed with cancer in their lifetime.[1] This presents a huge challenge to the UK's health services.

While valuable progress has been made in improving cancer outcomes, around half of all UK cancer patients now survive for ten years or more, UK cancer survival remains lower than in Australia, Canada, and several comparable European countries. [2, 3,4]

Cancer Research UK believes that in the next 20 years, with the right approach, three in four people can survive their cancer for at least ten years. Having high quality cancer services across the UK is crucial if we are to reach this goal.

Cancer Research UK therefore commissioned the Institute of Health and Wellbeing at the University of Glasgow to explore the 'state' of cancer services in Wales, Scotland and Northern Ireland.

This report, which is based on publicly available data and interviews with expert stakeholders in the region, presents findings on Northern Ireland (NI), and our ambition for the shape of cancer services going forward.

We believe the recommendations below would improve outcomes for patients and should be taken forward – ideally as part of a comprehensive cancer strategy for NI.

THIS REPORT PRESENTS CANCER RESEARCH UK'S AMBITION FOR THE SHAPE OF CANCER SERVICES IN NORTHERN IRELAND

CURRENT LANDSCAPE

In 2014, over 8,900 people were diagnosed with cancer in NI.[5] This has risen from around 7,200 in 2004. Over the last decade incidence rates have increased by 7% from 554 cases per 100,000 people between 2003-2005 to 594 per 100,000 people between 2012-2014.

This upward trajectory is expected to continue in the coming years. By 2035, it is projected there will be over 14,000 cancer diagnoses each year – an increase of 65% among men and 63% among women.[6] This is being driven predominantly by an ageing population; but preventable risk factors, such as smoking, also contribute.[7] Cancer services will therefore need to cope with significant increases in demand for diagnostic and treatment services.

Breast, bowel, lung and prostate cancers are the most commonly occurring cancers. In 2013 they accounted for 54% of all cases.[8] These are also the most common cancers worldwide.[9]

Cancer incidence varies across NI. The incidence rate among the most deprived quintile of the population, for example, is 23% higher than among the least deprived.[10]

But cancer survival is improving. One-year net survival has reached 70%; and five-year

survival has reached 54%.[11] This, however, varies significantly by cancer type. Over 80% of females diagnosed with breast cancer and males diagnosed with testicular cancer between 2005-2009 survived their disease for at least five years.[12] In contrast, fewer than 6% of people diagnosed with pancreatic cancer survived their disease for at least five years.[13]

POLICY AND LEADERSHIP

In 2015-16, the NI Department of Health (formerly the Department of Health, Social Services and Public Safety) had a budget of approximately £4.7 billion – around 46% of total NI Executive spending.[14] In 2016-17 healthcare spending in NI is set to rise to slightly less than £4.9 billion.[15]

Publicly available information does not break down healthcare spending by disease area, so it is not possible to show how much is spent on cancer services specifically. We would welcome the NI Executive making this information available. This would enable the best use of resources to deliver outcomes for patients.

The healthcare system in NI is in transition. While full details of reforms to the way health services will be commissioned have not been confirmed, we expect the Health and Social Care Board to be abolished and responsibility for commissioning to move to the Department of Health. In addition, an independent expert panel has recently conducted a review to explore options for service reconfiguration.

The impact of these changes on cancer policy and leadership is not yet clear. However, we understand clinical leadership for cancer will remain through the Northern Ireland Cancer Network; and the Public Health Agency will retain its responsibility for cancer awareness and input to commissioning. It is important that strong clinical leadership for cancer services is maintained within the new structure.

These reforms, at a time of rising cancer incidence, provide a timely opportunity to take a fresh look at how cancer services should be delivered, and set new ambitions to improve outcomes for patients in NI. Clearly identifying priority areas and funding requirements would support annual planning and investment decisions.

While other countries across the UK set out new strategies with clear ambitions for improving cancer outcomes, it is clear that NI must now do the same. NI's most recent strategy for cancer, the 'Cancer Control Programme', was published in 2008 and has not been reviewed since. While the Service Framework for Cancer was published in 2011 and is being reviewed, it is not a comprehensive strategy.

RECOMMENDATIONS

1. **The NI Executive should develop a new comprehensive cancer strategy, which sets ambitious goals and allocates sufficient resource to ensure cancer services can improve outcomes, meet rising demand and reduce variation in care. The strategy should ensure strong clinical leadership for cancer services and clarify how these services will be commissioned within the reformed NI health service. It should also set measurable targets to reduce cancer incidence, improve survival and better support the growing number of patients living with cancer. Particular attention should be afforded to cancer types with poor outcomes and variation across**

demographic groups, including men. We suggest the following targets:

- **One-year survival should reach 75% by 2020.**
- **Five-year survival should reach 58% by 2020.**

HEALTH SERVICE PERFORMANCE

Performance on cancer is measured through standards of care set out in the Service Framework, monitoring of performance data by Trusts, the Regulation and Quality Improvement Agency, waiting time standards, clinical audit, peer review and patient experience.

NI maintains three operational waiting times standards for cancer. These standards are not currently being met which suggests the service is struggling to keep up with demand.

1. 95% of newly diagnosed cancer patients should start treatment within **62 days** of an urgent referral by a GP. This has not been met nationally since it was introduced in 2009. Since 2013, performance has deteriorated from around 83% to below 75%. In the first quarter of 2016 performance was 69.9%.[16]
2. 98% of patients should commence treatment within **31 days** of a cancer diagnosis. Performance against this standard is higher but still below the target. It was last met between October and December 2013; in the first quarter of 2016 performance was 95.5%.[17]
3. Thirdly, there is an operating standard that 100% of patients referred urgently with suspected breast cancer should be seen by a specialist within **14 days**. This target was last met in July – September 2012. In the first quarter of 2016 performance was 81.8%.[18]

While performance against the 31-day standard is holding up reasonably well, it does not capture the time it takes to diagnose patients. Therefore, significantly lower performance against the 62-day standard suggests patients are experiencing delays in being diagnosed.

NI is unusual in applying the 14-day operating standard only to breast cancer patients. This has implications for where resources are focused.

Our research found the ongoing peer review process was having a positive impact. The commitment to extend peer review to cover all the major cancer types is welcome.

In general, measures with potential to drive quality improvement seem to be in place. It is less clear, however, why these have not necessarily led to improvements in service delivery. Further work is therefore needed to understand why key targets such as waiting times are not being met.

On a positive note, the Northern Ireland Cancer Patient Experience Survey (CPES) showed that the majority of patients are pleased with the services they receive. 92% of respondents described their overall care as 'very good' or 'excellent'.[19] But in some areas performance is poor and must be improved. For example, only 18% of respondents reported being asked whether they would like to participate in clinical research.

RECOMMENDATIONS

2. **The Department of Health and Trusts should undertake work to clarify why operating standards for cancer are not being met. Based on that, the Department should provide**

investment to ensure they are met in the future. The Department should also consider broadening the 14-day operating standard to cover all cancer types.

3. **The Public Health Agency should fund and continue to undertake the CPES on a regular basis. Its findings should be used to support ongoing evaluation and improvement.**

EARLY DIAGNOSIS

Early diagnosis is crucial to improving survival in many cancer types.[20] For example, when bowel cancer is diagnosed at stage one around 95% of patients survive their disease for at least five years compared to less than 10% among those diagnosed at stage four.[21] But evidence strongly suggests that barriers to early presentation are contributing to the UK's cancer outcomes being below those of some other countries.

Information on stage at diagnosis is relatively good in NI; stage was recorded in 72% of cases during 2010-2014. However, too many patients are being diagnosed late. On average across 2010-2014, around 45% of patients with known stage were diagnosed at stage three or four.[22]

Public awareness campaigns are an important way to encourage people to see the doctor when they have concerns about their health. The *Be Cancer Aware* programme was adopted for NI in 2015 following a baseline study in 2014 to enable monitoring of the campaign's impact.[23] This should be continued and expanded to try and reach more disadvantaged groups.

GP direct access to diagnostic testing seems to be geographically variable – investigation is needed to understand how this can be addressed. In addition, the work being done to identify the resource implications of introducing the latest NICE referral guidelines must happen swiftly so that best practice can be implemented as soon as possible.

There are examples where new models of diagnostic services, such as a 'one-stop shop' for urology assessment, are operating in NI. It is important that these innovations are evaluated and rolled out where shown to be effective.

A clear area that is in need of further analysis is capacity in diagnostic services. The 2015/16 Commissioning Plan identified large numbers of vacant radiology posts and suggested a new regional service to ensure the service can meet demand.[24] Work is required to understand capacity needs in diagnostics to ensure the service can cope with increasing numbers of cancer referrals.

RECOMMENDATIONS

4. **The Public Health Agency should continue funding the *Be Cancer Aware* programme and look to expand it. The programme should be developed to target different types of cancer and hard to reach groups.**
5. **The Department of Health should undertake an urgent review of the state of direct access to diagnostic tests for GPs and capacity needs in diagnostic services. It should make the necessary investment to ensure diagnostic services can meet rising demand.**
6. **The Department of Health should explore the potential for new service models to support diagnosis, for example multi-disciplinary diagnostic centres to help diagnose cancer cases swiftly where symptoms may be vague.**

ACCESS TO TREATMENTS

Providing all patients with access to high-quality, evidence-based treatments is crucial to improve survival.

The Service Framework sets out a number of measurable standards for treatment services. However, a lack of publicly available data makes it difficult to assess whether patients are receiving the best treatments. For example, there is no data on access to modern radiotherapy techniques, like Intensity Modulated Radiotherapy, when clear access targets have been set in other countries.[25]

Peer review data is available on a group of cancer sites.[26] In places, these indicate a lack of progress in improving treatment services since 2010. While there has been some progress, such as increasing resection rates for lung cancer, other areas indicate variable access to treatments and long waiting times. The roll out of peer review to all cancer types will be crucial to get a better understanding of performance across the board.

Our research identified concerns that access to new cancer drugs was poorer in NI than in England but that the difference was diminishing in recent years. However, issues with swiftly adopting NICE guidance remain and must be resolved. Changes to the way NICE assesses cancer drugs following reform of the Cancer Drugs Fund in England demand attention as this will impact on drug approvals in NI.

The ongoing reforms to the Individual Funding Request (IFR) system, including the expected softening of the exceptionality criteria, are welcome.[27] We hope to see more data on IFR requests made available to ensure the system is working effectively.

As noted above, the CPES showed less than one-fifth of patients recall being asked to consider participating in clinical research.[28] Our research also identified concern about participation in clinical research going forward. This requires attention.

Shortages in oncology staff were also highlighted as an issue, exacerbated by the demands of the new acute oncology services. More work is required to understand where additional capacity is needed to ensure treatment services can cope with demand and consistently deliver the best treatments.

RECOMMENDATIONS

7. **The Department of Health should develop national datasets for chemotherapy and radiotherapy activity to help better understand access to these types of treatments. Further data on the success of IFR requests at the local level is required.**
8. **The Department of Health should set a clear ambition to increase the opportunities for patients to participate in clinical research. To support this, it should conduct a review to identify current barriers to setting up and running clinical trials.**
9. **The Department of Health should review workforce capacity in treatment services to understand where there are shortfalls in staff and set out how these will be addressed.**

www.cancerresearchuk.org/cancer-services-in-NI

For more information please contact policydepartment@cancer.org.uk

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