WHERE NEXT FOR CANCER SERVICES IN SCOTLAND?

AN EVALUATION OF PRIORITIES TO IMPROVE CANCER OUTCOMES
EXECUTIVE SUMMARY

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

While valuable progress has been made in improving cancer outcomes, with around half of UK cancer patients now surviving for ten years or more, UK cancer survival remains lower than in Australia, Canada, and several comparable European countries.  

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 NHS 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 investigate the state of cancer services in Wales, Scotland and Northern Ireland. 

This report presents findings on Scotland and our ambition for the shape of cancer services in the future.

THE CANCER LANDSCAPE

Cancer incidence rates in Scotland have increased by 2% over the last decade (from 619 cases per 100,000 people between 2003-2005 to 632 cases per 100,000 people between 2012-2014). Over the same period the number of cases diagnosed has increased from around 27,500 to around 31,700. This incidence is expected to continue to rise and it is estimated that the number of new cases diagnosed in Scotland every year will increase by around a third by 2023-27. An ageing population is driving this in part, but preventable risk factors such as smoking are also contributing. 

Cancers of the lung, breast, prostate and bowel together represent just over half of all cancer diagnoses in 2014. They are also the most common cancers worldwide. 

Cancer incidence also varies between demographic groups in Scotland. There were around 33,000 cancer registrations in the most deprived quintile of Scotland’s population combined between 2009-2013, and more than 27,000 in the least deprived. 

Cancer survival in Scotland has been improving in Scotland for over 40 years. However, survival varies considerably by cancer type. In men, survival is lowest for lung, oesophageal and stomach cancers. In women, survival is poorest for pancreatic and lung cancers. Overall survival is poorer than many other comparable European countries.

Increasing cancer incidence will place additional demand on the NHS in Scotland. And as survival continues to improve, the NHS will need to be prepared to support more patients living with or beyond cancer.

NHS STRUCTURES, POLICIES AND LEADERSHIP

Spending plans set out in the Scottish Budget for 2015/16 show that £9.6 billion was allocated to the NHS and Special Health Boards. However, a breakdown of the
expenditure on cancer services in Scotland is not currently available.

The recent Scottish Government cancer strategy, Beating Cancer: Ambition and Action (‘Beating Cancer’), has committed an additional £100m to cancer over the next five years. This is a welcome development. While there is some indication of what this money will support, further clarity is needed on how spending on cancer is allocated.13

The NHS in Scotland is a devolved independent organisation, administered through 14 geographical Health Boards. A dedicated leadership structure is in place to oversee cancer services, split into two complementary pathways: a professional network that influences policy and practice and a managerial structure that is accountable for achieving targets set by the Scottish Government.

Overall, this structure was supported by stakeholders. Nonetheless, our research found that concerns exist about a perceived lack of clear leadership on some issues and lack of resources needed to implement some national policies.

RECOMMENDATIONS

1. The Scottish Government should publish a full implementation plan for the delivery of Beating Cancer. This should set out: the roles and responsibilities of cancer leadership bodies at national, regional and local levels, clear timings and how success will be measured. A national clinical lead for cancer to support this should also be considered.

2. The Scottish Government and the Information Service Division should consider reporting NHS spend by clinical speciality.

NHS PERFORMANCE ON CANCER

Performance data published by Information Services Division Scotland (ISD) shows that action is needed to improve some aspects of cancer services.

For example, the NHS in Scotland is consistently not meeting one of its waiting times targets – a clear indication that some aspects of the service are struggling to keep up with demand:

- The target for 95% of people with a suspicion of cancer referred via the urgent route to begin treatment within 62 days of receipt of referral has not been met since 2013. Performance in the first quarter of 2016 was 90.2%.14
- The target for 95% of all patients diagnosed with cancer to begin treatment within 31 days of decision to treat has performed better. It has been met since 2010, but the proportion of patients meeting the standard has been falling and this was missed in the most recent quarter. Performance in the first quarter of 2016 was 94.9%.15

The 31 day wait is holding up reasonably well, but does not capture the time it takes to diagnose patients. Poor and deteriorating performance in meeting the 62 day wait, compared to the 31 day wait, therefore indicates that patients are experiencing delays in being diagnosed. Concerns on this issue were also raised in the Early Diagnosis section.

Overall, stakeholders offered mixed views about the impacts of waiting time targets. Our research identified the contention they have a role in driving up standards, but can sometimes put adverse pressure on both clinicians and patients.

Nevertheless, it is clear that cancer services in Scotland, and most probably diagnostic services in particular, are struggling to cope with increased demand for their services as
cancer incidence rises, and that this should be addressed.

RECOMMENDATIONS

3. The Scottish Government should review capacity – both equipment and workforce – in diagnostic services with a view to providing additional resources to Health Boards to help them meet cancer waiting times.

4. Scottish Government’s review of waiting times should ensure cancer targets are defined in a way that optimises their intended impacts – while maintaining the 62 and 31 day standards as a minimum. It should also consider expanding waiting times targets to include all types of cancer.

EARLY DIAGNOSIS

Early diagnosis is critical to improving cancer outcomes. For example, when bowel cancer is diagnosed at stage one around 90% of patients survive ten years compared to just 5% for those diagnosed at stage four. Efforts to improve early diagnosis of cancer have tended to focus on a small number of cancer types that comprise the majority of cases – and indeed staging data is only publically available for these specific cancers. The focus of the Detect Cancer Early (DCE) programme for instance, has been breast, colorectal and lung. The DCE programme comprises both national publicity and Board-level initiatives to promote earlier detection and aimed to achieve a 25% increase in the proportion of stage 1 breast, colorectal and lung cancers between 2012 and 2015. However, progress has been mixed.

Overall, the data shows that in the four years the DCE programme has been running there has been significant improvement in the early detection of lung cancer, static performance in breast cancer, while early detection of colorectal cancer has been falling, in spite of increased screening uptake. This is a concerning finding, and one in need of further investigation. Further evaluation is needed to understand the impact of elements of the programme, and its ability to impact harder to reach communities.

Primary care plays a critical role in the early detection of cancers. Yet while a number of initiatives, both national and local, have been developed to support and encourage primary care in the areas of recognising symptoms and making appropriate referrals, further clarity on how to deal with cases where vague symptoms present remains an issue.

While views about one of these initiatives - direct GP access to diagnostic testing - were mixed, the overall decline in the 62 day waiting time standard indicates serious capacity issues with diagnostic services.

Other indicators reinforce this: in 2009, the Scottish Government set a national standard that patients should not wait any longer than six weeks to receive one of the eight key diagnostic tests and investigations. That targets has not yet been met and in 2015, around 67,200 patients waited longer than 6 weeks for a diagnostic test. Beating Cancer commits to an additional £2 million per annum Diagnostic Fund for the next five year, the Scottish Government should ensure this funding alleviates pressure on diagnostics services swiftly and sustainably.

RECOMMENDATIONS

5. The Scottish Government and the Information Services Division should collect and publish staging data on all cancer types.
6. The DCE programme should publish a clear evaluation of public awareness campaigns to understand their impact. As outlined in Beating Cancer, DCE should publish plans on how they will reach deprived, harder to reach communities where early detection of cancer remains poor.

7. The Scottish Government should explore best practice pathways for referral of patients with vague or non-specific symptoms, such as the Borders model, and consider whether national guidance should be updated to ensure consistent pathways for referral.

ACCESS TO EFFECTIVE TREATMENT

Once a diagnosis is made, offering all patients timely access to high-quality, evidence-based treatments is crucial to improve survival.

Cancer drugs, radiotherapy and surgery are the three main types of treatment. Our research revealed areas for improvement in each category, as well as some themes across treatment types.

However, there is a lack of data on treatment activity in Scotland, specifically for cancer drugs and radiotherapy, making it difficult to assess progress. High-quality data is critical to evaluate performance and improvements.

The major questions in surgery centred on achieving a balance between local access to treatment versus the benefits of centralising smaller-volume surgery.

Views about the provision of radiotherapy were positive with regards equipment infrastructure. However, concerns were raised about whether this equipment was being used to its full potential to provide patients with the best treatments in all parts of the country. This is potentially due to workforce shortages.

We also heard doubts about the effectiveness of national radiotherapy leadership structures. The new National Cancer Clinical Steering Group (NSSCG) and its Radiotherapy Sub Group were created to provide a national lead on radiotherapy, and it will be important that they allocate the £50 million committed in Beating Cancer effectively.

The Scottish Medicines Consortium (SMC) evaluates new medicines and decides whether they will be made routinely available on the NHS. Stakeholders reported variations in access to approved medicines throughout Scotland, while regional differences in relation to individual patient treatment requests (IPTRs) were also a concern.

Due to the geography of Scotland, concerns were raised about barriers to access for patients living at a distance from treatment centres. Some stakeholders felt that such patients sometimes choose, or are given, treatment modes which are less than optimal to avoid travelling. Long travel times and variable support were also thought to delay some patients from starting treatment.

It’s therefore important that these factors should be prominent in the planning of cancer services and accommodation provision and new ways of working explored.

Finally, recruitment and retention of specialist staff formed a major theme of stakeholder concerns across treatment types.

RECOMMENDATIONS

8. The Scottish Government should ensure the NCCSG Radiotherapy Sub Group has the resources it needs to provide strong leadership in taking forward the commitments made in
Beating Cancer to address inequality of access to modern radiotherapy. A national radiotherapy lead should be appointed to support this. Developing and reporting annually on a national dataset for radiotherapy should be a priority for this group.

9. The Scottish Government and SMC should ensure equal access to new drugs across the country by considering mandating that Health Boards fund them once approved. A national approach should also be taken to IPTRS to ensure consistent decisions for all patients in Scotland. A national dataset for chemotherapy should be developed to help understand outcomes and assess progress.

10. The NSSCG should work to clearly define workforce capacity shortages in radiotherapy (via the Sub Group) and chemotherapy services, and identify mechanisms to address this to ensure adequate resource is in place to provide access to the best, evidence-based treatments.
12 ibid
15 ibid
19 8 Key Diagnostic Tests and Investigations which are classified as: all endoscopy tests (Upper endoscopy, lower endoscopy, colonoscopy, cystoscopy) and all radiology tests (CT scan, MRI scan, barium studies, non-obstetric ultrasound)