

CROSS-PARTY GROUP ON CANCER INQUIRY REPORT

Priorities for the Future of Cancer Services, Support
and Research in Scotland

This report was written by Cancer Research UK in its capacity as secretariat to the Cross-Party Group (CPG) on Cancer. The views expressed in this report have been collated from survey submissions completed by organisations and individual members of the CPG and reflects discussions at recent CPG meetings.

Contents

3. FOREWORD

4. ABOUT THE CROSS-PARTY GROUP ON CANCER

5. INTRODUCTION

6. FINDINGS

12. RECCOMENDATIONS

13. APPENDIX 1: List of respondents to the Inquiry

14. REFERENCES

Foreword



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We are pleased to present this report of the Scottish Parliament Cross-Party Group (CPG) on Cancer's inquiry into the policy priorities for the future of cancer services in Scotland.

We are delighted with the number of individuals and organisations that provided written evidence to the inquiry, including patients, academics, clinicians and third sector representatives. These written responses were explored further in a productive discussion session at our September meeting.

We would like to thank all of our members who took part in the inquiry for their collaborative and positive approach to discussions.

This report provides a set of agreed priorities to progress cancer prevention, diagnosis, treatment, research and support to improve the survival of cancer in Scotland and the services for people affected by cancer.

The CPG on Cancer's report into the implementation of the current cancer strategyⁱ found that while progress is being made, investments are being undermined by the challenges facing Scotland's cancer workforce.

Again, this inquiry found that addressing Scotland's diagnostic workforce is a key priority to improve cancer outcomes across Scotland.

The inquiry also highlighted how unlocking the potential of patient data could have a transformative effect on cancer services. It is important that the Scottish Government and NHS Scotland

ensure that every tool possible is utilised to provide the best care to all cancer patients.

It is also crucial that the Scottish Government, NHS Scotland and everyone involved in cancer collaborate to tackle the health impacts associated with socio-economic inequalities. Socio-economic inequalities present a significant barrier to Scotland's cancer outcomes and put an unsustainable financial strain on the NHS and other services, and it is urgent that action is taken to address this.

The provision of holistic support services for every person affected by cancer was also highlighted as a key priority by our members. Projects are ongoing to address many of these issues, but it is crucial that every cancer patient receives the support they need throughout their cancer journey.

Scotland is making fantastic progress towards beating cancer. Recent statistics published by ISD have shown us that the overall risk of dying from cancer has fallen by 10% in the last ten yearsⁱⁱ. This report seeks to provide priorities to build on that progress.

We would like to conclude by again thanking all those who have contributed their expertise and time to this important inquiry, and we are pleased to herein publish the findings.

About the Cross-Party Group on Cancer

The Cross-Party Group (CPG) on Cancerⁱⁱⁱ has 76 member organisations and individuals from across cancer research, treatment, care and prevention, as well as cancer patient representatives. The group aims to look at key issues in cancer care in Scotland by bringing together the cancer community.

Purpose of the group:

- To act as a channel of communications between the Scottish Parliament and people and organisations working in cancer research, treatment, care and prevention.
- To identify areas where inequalities exist in the provision of cancer treatment and support and campaign for their improvement.
- To provide opportunities for MSPs to learn about the latest Scottish and international cancer research and to learn about cancer care needs and services, including the views of both patients and carers.

CPG on Cancer convenors and members

Anas Sarwar MSP

Co-Convenor

Miles Briggs MSP

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Brian Whittle MSP

Member

Finlay Carson MSP

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Jenny Marra MSP

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Introduction

At the meeting of the Scottish Parliament's Cross-Party Group (CPG) on Cancer in June 2019^{iv}, Cabinet Secretary for Health and Sport, Jeane Freeman MSP, responded to the CPG on Cancer's inquiry into the implementation of the cancer strategy, "Beating Cancer: Ambition and Action."

During the meeting, the Cabinet Secretary announced a 'pause' to the current Scottish Cancer Strategy. This is intended to allow for a review of the progress and relevance of the current strategy and the chance to explore new priorities. The CPG on Cancer has undertaken a short inquiry among its members in response to identify the priorities they wish the Scottish Government to consider as part of the pause/review, and to start to influence thinking for the next strategy.

Methodology

To gather the views of the CPG on Cancer's 76 members, an online call for views was made, based around four questions:

- What one measure could the Scottish Government take that would most reduce Scotland's cancer incidence rates?
- What one measure could the Scottish Government take that would most improve Scotland's cancer survival rates?
- What one measure could the Scottish Government take that would most effectively tackle health inequalities?
- What one measure could the Scottish Government take that would most help people affected by cancer?

The survey received 67 responses including from people with lived experience of cancer, charities, the university sector, clinicians, cancer service managers and pharmaceutical companies. (A full list of the respondents can be found in Appendix 1).

Submissions to the survey were used to develop a short paper that was discussed at the CPG on Cancer meeting on 24 September 2019. This meeting further prioritised the issues raised in the survey.

Findings

The evidence presented in the short inquiry highlighted several policy recommendations, which are listed at the end of each section in this report. Amongst these recommendations, three key, over-arching and inter-related priorities were identified:

1. Urgently develop a national model of workforce planning, starting with cancer diagnostic staff, in order to address long-standing vacancies and align future training, recruitment, development and retention plans with projected patient need.
2. Unlock the potential benefits of linked patient data across Scotland to enable the data-led planning of cancer services. This data should be used to optimise cancer services, lead a conversation about the centralisation of treatment services and embed research at all levels of the NHS. It should also be used to tackle inequalities in outcome across Scotland, including a reaffirmed commitment from Scottish Government to tackle the health impacts associated with socio-economic inequalities in Scotland.
3. Deliver a step change in the provision of holistic cancer patient support services across Scotland for both the physical and emotional needs of cancer patients. This should support travel for all patients who require it and nationally supporting the development of local service directories.

1. Workforce

Diagnostics

In the CPG on Cancer's inquiry into the implementation of Beating Cancer: Ambition and Action, the biggest concern highlighted was gaps in, and the long-term unsustainability of Scotland's diagnostic workforce^{vi}.

The inquiry found that "actions in the Strategy aimed at building a sufficient and sustainable cancer diagnostic workforce were not being sufficiently funded, hindering efforts to increase diagnostic capacity."

In June 2019, more than 18% of patients had been waiting for more than the standard 6 weeks for key diagnostic tests^{vi}; a three-fold increase within three years^{vii}.

Currently, around 32,200 people in Scotland are diagnosed with cancer^{viii}. The demand for tests is only going to increase, due to a growing and aging population, and a welcome focus on early diagnosis and appropriate screening. By 2035, it has been estimated that this figure will increase to 40,000 per year^{ix}.

In this inquiry, the CPG on Cancer highlighted issues in this workforce as the greatest concern currently impacting cancer outcomes.

It is essential that the Scottish Government take urgent and sustained action to both address the current vacancies in the cancer diagnostic workforce and introduces a robust model of long-term workforce planning based around projected patient need.

Nursing

The inquiry also raised concerns around staffing levels in nursing, particularly highlighting the roles of Cancer Nurse Specialists (CNS) and research nurses as needing further support.

Cancer Nurse Specialists are a key point of contact and a crucial source of support for cancer patients. While the latest Scottish Cancer Patient Experience Survey^x (SCPES) highlighted that 86% of patients were provided with the name of a CNS, there is a need to

ensure that every patient has access to a CNS, as per the commitment in Beating Cancer: Ambition and Action.

Participation in research trials allows NHS patients to access promising new treatments sooner and often with a lower cost to the NHS. Our members also emphasised the benefits of research in training staff in new techniques earlier.

However, there are concerns about the number of staff and patients currently participating in clinical trials. The SCPES also showed that only 19% of respondents had a discussion with a research nurse or indeed any member of NHS staff about taking part in research. This is lower than the figures in Wales and England. Investing in more research nurses is key to increasing the number of patients who have access to clinical research.

Allied Health Professionals (AHPs)

The work of AHPs is vital to improving the mental and physical health of patients that has been shown to significantly increase overall outcomes.

Moreover, cancer patients are increasingly presenting with co-morbidities and there are ongoing projects that demonstrate the value of rehabilitation services in both preparing patients for treatment as well as helping them to recover from the side effects.

The cancer journey is often difficult for patients and their families. Psychologists and other support services assist patients throughout their treatment pathway and enhance both the patient experience and outcomes.

Recommendations

- The Scottish Government must take urgent action to address gaps in the diagnostic workforce in both the short and long term.
- The Scottish Government should also prioritise supporting workforce planning in the nursing and allied health professional workforce to ensure cancer patients receive the best quality holistic support.

2. Data

Unlocking Scotland's data

The CPG on Cancer strongly agreed that unlocking the use of patient data represented the biggest potential benefit to cancer outcomes in Scotland. The opportunity provided by Scotland's NHS infrastructure to link and centralise data collection and analysis, while affording all necessary protections, was repeatedly identified as a potential game-changer for patient outcomes, data-led service planning and resource optimisation in Scotland.

However, our respondents highlighted concerns that frustrate progress. These include:

- the red tape that characterises the current system of data governance across NHS Health Boards which delays the use of data for clinical, service planning and research purposes, and;
- the current quality and variation in IT systems across the NHS Health Boards which frustrates efforts to collect, link and compare data.

While Beating Cancer: Ambition and Action placed an emphasis on unlocking patient data, our members emphasised the need to now deliver tangible progress.

Inquiry submissions also highlighted that Patient Reported Outcome measures (PROMs) have the potential to provide clinicians with valuable information about the side effects of treatments, alerting them sooner to signs of recurrence and potentially reducing the number of appointments patients attend.

In addition to their benefits for the individual patient, PROMs benefit cancer services in general. The ability to routinely collect data from the outcomes and side effects of treatments could potentially allow Scotland to gain earlier access to medicines at a lower cost. Secondly, being able to accurately track the side effects of cancer treatments would allow for the development of NHS services that more effectively address the needs of patients.

Optimising national co-ordination and local planning of cancer services

The CPG on Cancer agreed that one of the key uses of patient data was in the planning cancer services. Concerns were raised in the inquiry about a lack of co-ordination of cancer services, which could be better coordinated at a national level.

Evidence demonstrates that the centralisation of many specialist cancer treatment services, particularly in surgery and radiotherapy, has potential to improve care provision and patient outcomes by increasing the likelihood of patients being treated in hospitals that have a full range of experienced specialists and equipment to support care provision. The size of Scotland's population means that, particularly in cases of rarer cancers, the patient population is not of a sufficient size to support optimal provision throughout Scotland. Some services, therefore, are best offered from centralised centres of excellence.

This potential of reconfiguring cancer services to improve outcomes is recognised in the Scottish Government's cancer strategy. The CPG on Cancer therefore emphasised the importance of continued focus on using of patient data to lead service planning at a national level focused on increasing patient outcomes.

Additionally, respondents raised the importance of providing other services locally, including patient and end of life support. Wherever possible, patient travel should be reduced, and support offered to volunteer-supported local patient-transport services. Investment in technology that supports remote consultations, PROMs, and improved data sharing between primary and secondary care can reduce un-necessary patient travel.

Preventing Cancer and Tackling Health Inequalities

Beating Cancer: Ambition and Action contained a strong and welcome focus on cancer prevention and there has been significant action aimed at reducing the 4 in 10 cancers caused by lifestyle factors. This includes the introduction of Minimum Unit Pricing on Alcohol and the commitment to introduce a bill to regulate the price promotion of unhealthy foods.

In addition to population-wide prevention initiatives, members highlighted the importance of engaging with the public at the point of contact with health services, taking advantage of so-called teachable moments. For example, some members highlighted the effectiveness of projects such as the Ottawa Model of smoking cessation.

The CPG on Cancer emphasised the need for continued focus on prevention, but with a redoubled focus on Scotland's most deprived areas.

For example, while overall smoking rates have reduced significantly in recent decades, the figures in Scotland's most deprived communities are more than three times higher than in the least deprived areas. A similar pattern is also seen across other cancer risk factors.

These risky behaviours are compounded by relatively low participation in screening programmes by people who live in poorer communities and a tendency to present later and consequently be diagnosed when cancers are at a more advanced stage when treatment outcomes are poorer.

The CPG on Cancer believes that socio-economic inequalities present a significant barrier to improving outcomes and put an unsustainable financial strain on the NHS and other services.

Reducing the inequality gap must, therefore, be emphasised in any future iterations of the Scottish Cancer Strategy.

While the causes of cancer health inequalities are complex, it is crucial urgent action is taken to address them. Where there are gaps in knowledge as to how best to tackle the issues involved, research should be commissioned as a matter of urgency, including evaluations of what innovative service interventions are most effective in Scotland's deprived areas. New ways of co-producing public health interventions should be resourced and actively promoted and what works elsewhere should be emulated.

Members also recognised that other sections of our community face significant barriers to accessing health services, for example people with disabilities. Any future Strategy should commit to tackling this by reforming mainstream services to make them as accessible as possible and innovating in partnership with patients and charities to develop best-practice.

Reducing the survival gap between cancer types

Concerns of the survival gap between the most and least survivable cancers also emerged as a theme during the inquiry. In the case of the least survivable cancers – such as pancreatic, brain, liver, stomach and oesophageal. The CPG on Cancer suggested that the areas where focus is needed include: increasing public awareness of symptoms; reviewing referral guidelines and service design; as well as supporting GP training and research into new treatments.

In addition to these measures, members emphasised the potential of lung cancer screening. Lung cancer is the biggest single cause of death in Scotland and survival rates remain poor, not least because of the high percentage of late-stage diagnosis. A lung screening programme could diagnose many patients earlier, thereby saving many lives and delivering a significant cost saving on expensive drugs for late-stage lung cancer treatment.

The CPG on Cancer therefore recommend that the Scottish Government should develop an implementation plan and provide funding for a pilot programme for lung cancer screening across Scotland. Targeting those most at risk of lung cancer will reduce health inequalities in the most deprived areas where smoking rates are highest. Smoking cessation services should be offered alongside lung cancer screening, which will be beneficial to those who do not normally present to these services. The Scottish Screening Committee could take a role in coordinating a pilot programme alongside the Scottish Lung Cancer Forum. This will help inform the UK Screening Committee (UKNSC) and provide a Scottish context as they review the evidence from the publication of the NELSON trial to decide whether there should be a national screening programme or a local targeted approach.

Recommendations

- The Scottish Government must prioritise unlocking NHS Data to inform service design, patient care and resource optimisation
- NHS Scotland's Health Boards and the Scottish Government should work collaboratively with people affected by cancer and the wider cancer community to achieve consensus around the data-led planning and delivery of centralised cancer services, while retaining localised provision in areas such as end of life and patient support.
- The Scottish Government must place greater emphasis on, and promote stretch targets to address inequity of outcomes, especially persistent disparities linked to socio-economic factors.
- The Scottish Government and NHS Boards should improve patient transport support for those making un-avoidable journeys for treatment. This should include evaluating and emulating volunteer-supported patient transport pilots.
- The Scottish Government should look to fund further pilots for lung cancer screening through the detect cancer early programme, which will help inform the UKNSC review. They should also act as quickly as possible to implement and optimise a lung cancer screening programme following a positive recommendation by the UKNSC.
- The Scottish Government and NHS Health Boards should place an emphasis on improved outcomes in cases of currently less survivable cancers.

3. Patient Support

Holistic Needs

Members recognised the quality of clinical service generally provided to cancer patients in Scotland; however, several concerns were raised about gaps in the holistic care received. The CPG on Cancer stressed the value of cancer nurse specialists and the work undertaken by Improving the Cancer Journey (ICJ) in providing patients with a link worker to undertake a Holistic Needs Assessment (HNA).

Following a HNA, it is crucial that the services which support patients needs, both physical and emotional, are sufficiently resourced. For example, there is an urgent need to further support the Allied Health Professional and Nursing workforce, as previously discussed.

In addition to these services, however, it is particularly crucial that greater funding is given to counselling services and the other services that support the mental health of cancer patients through their cancer journey. Several third sector organisations provide support services for cancer patients and the Scottish Government and NHS Scotland must work together with these organisations to ensure every cancer patient receives the emotional support they need.

The CPG on Cancer welcomes the £18 million recently committed to ensure everyone diagnosed with cancer has a dedicated support worker through the Transforming Cancer Care programme. It is important that this funding delivers the desired impact for cancer patients and that further funding for the support services to meet patient needs are prioritised.

Local Patient Service Co-ordination

There is a need for greater national co-ordination to raise awareness of the support services offered by the Health and Social care and third sectors. Members noted that some local directories exist and that work in this area is being undertaken by NHS 24.

It is crucial for patients that this directory is regularly updated and easily accessible – including to those who are not IT fluent.

Recommendations

- The Scottish Government must ensure the provision of holistic support assessments for all cancer patients across Scotland and that significant investment is put into services that support the wellbeing of people affected by cancer, working in partnership with the third sector organisations that provide this support.
- The Scottish Government and NHS Scotland should work with the third sector and patient groups to create and maintain a comprehensive and accessible up to date directory of local patient support and transport services.

Recommendations

1. The Scottish Government must take urgent action to address gaps in the diagnostic workforce in both the short and long term.
2. The Scottish Government should also prioritise supporting workforce planning in the nursing and allied health professional workforce to ensure cancer patients receive the best quality holistic support.
3. The Scottish Government must prioritise unlocking NHS Data to inform service design, patient care and resource optimisation
4. NHS Scotland's Health Boards and the Scottish Government should work collaboratively with people affected by cancer and the wider cancer community to achieve consensus around the data-led planning and delivery of centralised cancer services, while retaining localised provision in areas such as end of life and patient support.
5. The Scottish Government must place greater emphasis on, and promote stretch targets to address inequity of outcomes, especially persistent disparities linked to socio-economic factors.
6. The Scottish Government and NHS Boards should improve patient transport support for those making un-avoidable journeys for treatment. This should include evaluating and emulating volunteer-supported patient transport pilots
7. The Scottish Government should look to fund further pilots for lung cancer screening through the detect cancer early programme, which will help inform the UKNSC review. They should also act as quickly as possible to implement and optimise a lung cancer screening programme following a positive recommendation by the UKNSC.
8. The Scottish Government and NHS Health Boards should place an emphasis on improved outcomes in cases of less survivable cancers.
9. The Scottish Government must ensure the provision of holistic support assessments for all cancer patients across Scotland and that significant investment is put into services that support the wellbeing of people affected by cancer, working in partnership with the third sector organisations that provide this support.
10. The Scottish Government and NHS Scotland should work with the third sector and patient groups to create and maintain a comprehensive and accessible up to date directory of local patient support and transport services.

APPENDIX 1: List of respondents to the Inquiry

We received 67 responses from 31 organisations and 6 people with lived experience of cancer.

- Anthony Nolan
- AstraZeneca
- Beatson West of Scotland Cancer Centre
- Bowel Cancer UK
- Brain Tumour Action
- Brain Tumour Research
- Breast Cancer Prevention Scotland
- Blood Cancer Alliance
- Cochrane Collaboration
- Cancer Support Scotland
- Cancer Research UK
- Kidney Cancer Scotland
- Lilly
- MASScot
- Macmillan Cancer Support
- NHS Fife
- NHS GG&C
- NHS Lothian
- NHS Research Scotland
- Novartis
- OCHRE
- Pancreatic Cancer UK
- Pfizer
- Roche Products Ltd
- Roy Castle Lung Cancer
- Sarcoma UK
- South East Scotland Cancer Network
- Scottish Cancer Prevention Network
- SHAAP
- University of Edinburgh
- University of Dundee
- Womb Cancer Support UK

References

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- ⁱ <http://anassarwar.co.uk/wp-content/uploads/2019/01/Cross-Party-Group-on-Cancer-report-cancer-strategy-inquiry.pdf>
- ⁱⁱ <https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-10-29/2019-10-29-Cancer-Mortality-Report.pdf?>
- ⁱⁱⁱ Scottish Parliament. Cross Party Group on Cancer ([link](#))
- ^{iv} https://www.parliament.scot/CrossPartyGroups/Session5CrossPartyGroup/Minutes/CPG_Minutes_12_Jun.pdf
- ^v <http://anassarwar.co.uk/wp-content/uploads/2019/01/Cross-Party-Group-on-Cancer-report-cancer-strategy-inquiry.pdf>
- ^{vi} <https://www.isdscotland.org/Health-Topics/Waiting-Times/Publications/2019-08-27/2019-08-27-WT-Diagnostic-Report.pdf?>
- ^{vii} <https://www.isdscotland.org/Health-Topics/Waiting-Times/Publications/2016-08-30/2016-08-30-WT-Diagnostic-Report.pdf?>
- ^{viii} <https://www.isdscotland.org/Health-Topics/Cancer/Publications/2019-04-30/2019-04-30-Cancer-Incidence-Report.pdf?>
- ^{ix} Smittenaar CR, Petersen KA, Stewart K, Moitt N. Cancer Incidence and Mortality Projections in the UK Until 2035. Brit J Cancer 2016
- ^x <https://www.gov.scot/publications/scottish-cancer-patient-experience-survey-2018-national-report/>