



Shaping the National Cancer Plan Hastings and Rother Cancer Support Network Consultation Workshop Report

Shaping the National Cancer Plan Workshop Report



Introduction

At the meeting of the Hastings and Rother Cancer Support Network (H&RCSN) on 5th March 2025 a workshop was proposed to bring together a response to the Department of Health and Social Care call for evidence to shape the national cancer plan.

The proposal was well received and so the HVA/Macmillan Cancer Champions project agreed to host a workshop, that was held on 1st April. Twelve attendees were present.

All members of the network were invited, with the aim to encourage people with lived experience and service providers to feed into a local response to the call for evidence. Volunteers from the Macmillan information and advice hub at the town hall were also invited.

The structure of the discussions broadly followed the key questions set out in the Call for Evidence.

<https://www.gov.uk/government/calls-for-evidence/shaping-the-national-cancer-plan/shaping-the-national-cancer-plan>

Context

Attendees acknowledged that within Hastings and Rother, we are relatively well served in terms of cancer support services. The H&R CSN brings together organisations and teams from across Hastings and Rother that are supporting people living with and affected by cancer to:

Improve joint working, integration and shared learning

Improve pathways to care and support activities

Increase awareness and ease of access in areas of high need

Reduce inequalities in support, care and access

Consultation Responses

Prevention and Awareness – Which three risk factors should the government focus on?

Rather than choosing three risk factors, we suggest that the government considers the wider social determinants of health and uses positive references to refer to possible preventative measures, using a trauma informed approach.

The group felt that the current list of risk factors, that includes alcohol, tobacco, obesity, physical activity, UV radiation and air pollution is unhelpful in isolation. It does not acknowledge factors such as stress, poverty, poor housing, health literacy and other variants that may influence individual engagement with these risk factors.

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For example, Sussex based organisation Adfam has found that excessive alcohol use is often linked to self-medication, mental health and other underlying issues. The best approach to tackling this is by de-stigmatising it, and encouraging people to come forward, not by labelling or implying it is a lifestyle choice.

In addition, the last risk mentioned, air pollution, is even less subject to choice, and more about where an individual lives and works. A focus on raising awareness and reducing health inequalities across the board would be more helpful.

Vaping was not mentioned in the list, and the group thought this should be included in factors to address.

Early diagnosis

Which three actions should be taken to help diagnose cancer at an earlier stage?

We discussed the emotions that come into play that create barriers to seeking help at an early stage, such as fear, stress, and shame, and feel that the focus should be on normalising the preventative processes such as screening.

Health professionals should adopt a whole person approach, be welcoming, and supportive when patients present with an early potential symptom and understand additional levels of stress that may be present when patients have a family history or a genetic predisposition to develop cancer.

Currently individuals reported needing inner resilience, determination and strength to gain access to screening when they do not meet the standard parameters for a screening programme (e.g. presenting at a younger age).

GP receptionists and other staff could have up to date guidance on what needs an in-person appointment, rather than a phone call. For example, if a lump has appeared it needs to be seen rather than discussed. If an individual recognises a common sign or symptom for cancer, outside of a regular screening programme, should be taken seriously and referred quickly for relevant tests.

Living with and Beyond Cancer

Improve support that people who are diagnosed with cancer, treated for cancer, and living with and beyond cancer receive.

The four most impactful actions:

- Increase the number and availability of cancer care coordinators, clinical nurse specialists, cancer support workers and other staff who support patients
- Increase support to Hospice services and charities that provide care, and support for patients.

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- Provide a more comprehensive, integrated and personalised support after an individual receives a cancer diagnosis and after treatment.
- Explore the emotional, mental health, practical support for patients, as well as partners, family members, children and carers

Attendees added that the cancer care coordinator role is proven to aid recovery, and access to support for patients. The role also assists with communications between primary and secondary care, linking patients to local services, and helps coordinate care between providers.

Participants were keen to emphasise the importance of taking a whole patient, and whole family approach, particularly addressing the psychological impacts. Emotional and practical support.

We discussed health inequalities here too, with a focus on targeting specific groups, and an appreciation of the breadth of services that hospices provide. The role of the local hospice, and the services provided by charities locally are seen to be very important, and inclusive.

It's also important to build employers' knowledge about supporting and managing staff who receive a diagnosis and enabling them to continue to work. This links with the current government strategy around enabling those with long term health conditions to remain working or re-enter employment where this is appropriate.

Treatment

What three actions should the government take to improve access to cancer services, and the quality of cancer treatment that patients receive?

The top three were:

- Increase treatment capacity, including workforce (5 votes)
- Improve communication with patients, so that they have the information that they need
- Review and update treatment and management guidelines to improve pathways, (processes of care) and efficiency

The group felt that the final point, 'Increasing genomic testing and other ways of supporting personalised treatment' was important, and might also be relevant under 'prevention, or early diagnosis' categories.

Research and Innovation

How can we maximise the impact of data, research and innovation regarding cancer and cancer services?

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The top three actions were:

- Improve patient access to clinical trials
- Increase research into early diagnosis
- Increase research into innovative treatments

However, there was only one vote difference for:

- Speed up adoption of innovative diagnostics and treatments into the NHS

We had a discussion around what these would actually mean in practice, and the group felt less able to prioritise these without some examples or further explanation.

For example, we discussed the MRI scan process – and the difference between AI-led and person-led approaches.

Inequalities

What three actions will have the most impact in reducing inequalities in incidence and outcomes of cancer?

The top three actions were:

- Raising awareness of the signs and symptoms of cancer, reducing barriers and supporting a timely response to symptoms.
- Improving and achieving a more consistent experience across cancer referral, diagnosis, treatment and beyond
- Improving earlier diagnosis of cancer across all groups

There was a lot of discussion around these points, and we noted the fact that some of these points were more than one action, for example the first bullet point above.

There was some overlap with some of the other areas already discussed.

Priorities for the National Cancer Plan

The three most important priorities for the National Cancer Plan to address are:

- Raising awareness of the signs and symptoms of cancer
- Improving patients' experience across cancer referral, diagnosis, treatment and beyond
- Improve outcomes for cancer patients

People with lived experience are reporting instances of receiving their initial diagnosis from a health professional that believed they had already been made aware, when in fact it was the first time that cancer had been confirmed.

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Patients experienced being told they are on a 'cancer pathway' and not understanding fully that this is a process to rule out cancer, rather than an actual diagnosis. This can have a huge emotional and practical impact on patients.

The news that cancer has been ruled out should be given in a telephone call rather than a letter. Acknowledging that prior to a diagnosis the patient is likely to be confused and frightened.

People used the words 'conveyor belt' to describe their pathway and emphasised that a whole person approach will improve cancer outcomes for patients.

Conclusion

There were 12 participants involved in the workshop from the following organisations:

Macmillan
Age UK East Sussex/Macmillan Advice Hub (volunteers)
Horizon Cancer Centre, Brighton
Adfam East Sussex
Active Hastings/20:20 Health
Sara Lee Trust
Hastings Macmillan Cancer Support Champions
1066 Pink Ladies
NHS Bexhill Primary Care Network

The notes were circulated to those present and then sent out to the wider Hastings and Rother Cancer Support Network for input.