CancerWatch

Punching below our weight

The cancer charity sector and cancer prevention

Executive Summary – Spring 2024

CancerWatch is a registered charity in England and Wales (1206140)

Introduction

CancerWatch exists to campaign for more and better action to prevent cancer. The UK is nowhere near to doing all it could on cancer prevention. Nearly 40% of cancer cases are preventable, and the biggest modifiable causes are lifestyle factors: smoking tobacco; diet, in relation to obesity, processed and red meat, and insufficient fibre; and drinking alcohol. The most preventable cancers are of the lung, bowel, skin (melanoma), breast, oesophagus, bladder, kidney, stomach and pancreas.

CancerWatch was founded in recognition of the lack of a charity dedicated solely to campaigning on cancer prevention, and an expectation that there could be a significant gap to fill. We want to identify how we can collaborate with existing organisations in the field, and to add our shoulder to the wheel in the most useful way possible, without duplicating or supplanting efforts already being made.

While numerous charities do much worthwhile work on cancer prevention, we believe that the sector as a whole punches below its weight on this hugely important issue. This report highlights the excellent work that is being done, and the many sound reasons why other priorities often prevail.

1. Methodology and approach

The report draws on responses made to a call for evidence issued in summer 2023, and desk research that reviewed the work of a range of cancer charities, as set out on their websites.

We reviewed the websites of 36 cancer charities, and 12 further health charities whose remit has some relevance to cancer. While an organisation's website may not always capture the full detail of its work the websites we reviewed contained a wealth of rich information, which we judged typically offer a fair indication of what they do.

The call for evidence was an online questionnaire, asking a range of multiple choice and open-ended questions. We approached 89 organisations directly, covering cancer charities, other health charities with remits in some way related to cancer, health think tanks, medical royal colleges, professional bodies, public health organisations and others.

We received 17 responses, which provided a valuable collection of expertise and insight, and we are grateful to everyone who took the time to respond. This input offers many useful signals and illuminating views, which are presented in the report below.

2. Approaches to "prevention"

The World Health Organisation utilises a distinction between primary and secondary prevention.[1] Primary prevention, "refers to actions aimed at avoiding the manifestation of a disease," and is targeted at people before they develop an illness.

Secondary prevention entails, "early detection when this improves the chances for positive health outcomes," and is targeted at people who are asymptomatic or appear generally healthy, but may be in the early stages of developing an illness, or developing a condition that will lead to an illness later.

This distinction is widely used. However, a further distinction can be made within the broad category of primary prevention that we believe is important. Primordial prevention entails,"risk factor reduction targeted towards an entire population through a focus on social and environmental conditions."[2] This can mean regulatory or other legal change to alter the environment people live in, as distinct from primary prevention which involves interventions targeted at the individual.

1. https://www.emro.who.int/about-who/public-health-functions/health-promotion-disease-prevention.html
2. Kisling LA, M Das J. Prevention Strategies. [Updated 2023 Aug 1]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing https://www.ncbi.nlm.nih.gov/books/NBK537222/

We argue that both the cancer charity sector and public policy as a whole have been much more strongly focused, over the long term, on the secondary or even tertiary (treatment to prevent cancer getting worse) end of the range rather than the primordial. When earlier prevention has been prioritised, it has typically been in the form of primary prevention aimed at the individual, not primordial prevention aimed at the population and society as a whole.

This approach is seen in the Government's proposed Major Conditions strategy for England, which proposes primary prevention measures such as more smoking cessation services, extra funding for drug and alcohol recovery treatment, and the introduction of new weight loss drugs. But it is silent on primordial prevention: it does not propose any new measures on reformulating products to reduce sugar, salt or calorie content, further restrictions on the sale or consumption of tobacco, (although recent intentions to prevent anybody born after 2009 from ever smoking are very welcome), minimum unit pricing for alcohol, or any greater regulation of the sale of unhealthy takeaway food. This exhibits continuity with long term policy approaches, particularly (but not exclusively) in England.

That said, some structural change to achieve primordial prevention has been undertaken: the marketing, display and packaging of tobacco products have been progressively restricted; restrictions on how supermarkets promote unhealthy food items are arriving in the near future; the Soft Drinks Industry Levy prompted the reformulation of many products; and of course smoking was banned in workplaces and indoor public spaces in 2006 and 2007 (Scotland being the first of the home nations to introduce a ban, and England the last).

Nonetheless, the distinction between primary and primordial prevention illustrates a divide between forms of prevention that are relatively well recognised and promoted, and forms that are both harder and often not attempted.

3. The meaning of "preventable" cancer

The meaning and significance of "prevention" can vary hugely between different forms of cancer, and often it is not feasible to categorise a cancer straightforwardly as either preventable or not.

For some cancers, causal links are clearly identifiable, and prevention is therefore clearly possible by addressing modifiable lifestyle factors: this means smoking for lung cancer and others, diet for bowel cancer and others, and so on.

For some cancers, a proportion of cases are estimated to be preventable, but many are not. For example, 23% of breast cancer cases are estimated to be preventable through lifestyle choices.[3] In other cancers, lifestyle factors are associated with particular (usually more serious) forms of the disease: for example smoking is more strongly linked to mucinous ovarian cancer tumours than other types of ovarian cancer.[4]

This complexity in what can be considered a "preventable" cancer is important for understanding the work of the cancer charity sector on prevention: for many organisations, the extent to which prevention can be considered relevant to their mission is hard to quantify.

3. https://www.againstbreastcancer.org.uk/about-us/about-breast-cancer/breast-cancer-facts-statistics
4. https://targetovariancancer.org.uk/about-ovarian-cancer/risk

4. The sector's view of prevention

The respondents to our call for evidence provided valuable insight into the sector's understanding of prevention, views on it and preferred approaches.

We asked respondents to our call for evidence to rate the effectiveness of the current approach to prevention across the UK on a scale of one to ten. While the response rate to the questionnaire precludes statistically robust results, the results do suggest some strong signals – and in this case, a very downbeat one.

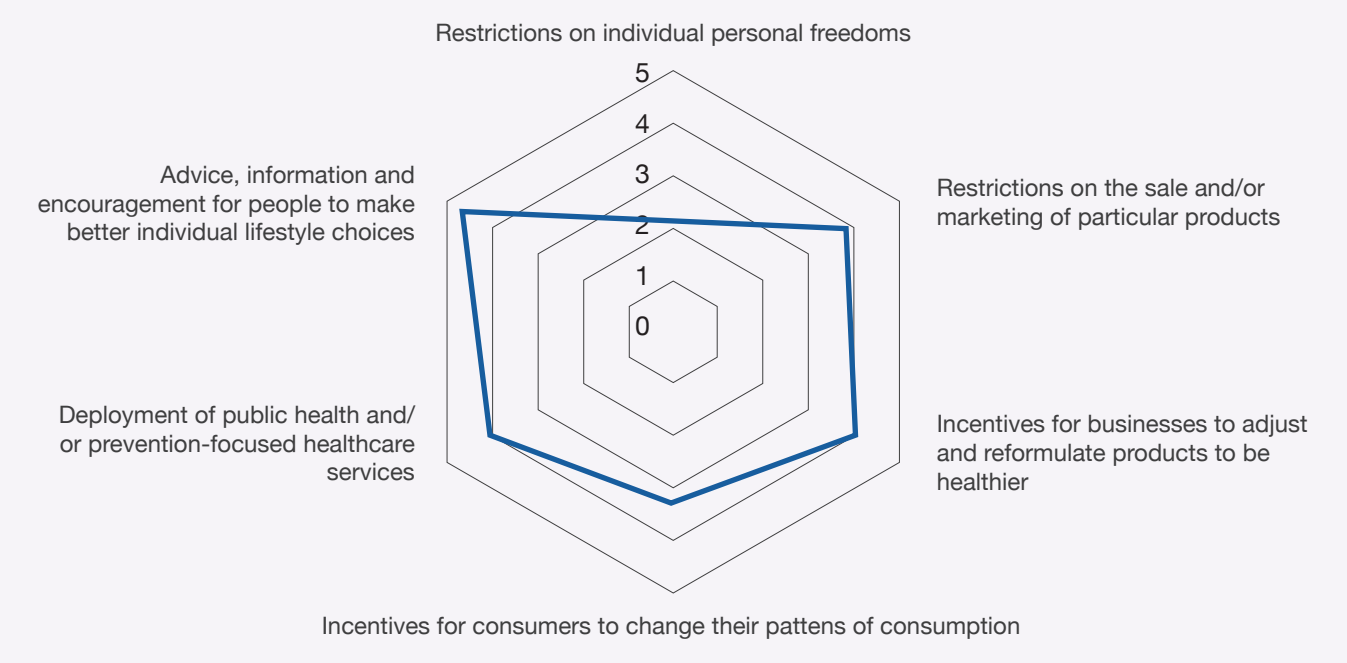
Table 1: Overall, how effective do you feel the current policy approaches to cancer prevention are in each of the following parts of the UK?

(Where 0 = not at all effective, and 10 = as effective as possible.)

England	Scotland	Wales	Northern Ireland
3.9	4.3	3.8	3.0

Respondents to our call for evidence were asked to rank descriptions of five broad types of policy intervention for cancer prevention in terms of what they would prefer to see. Their answers are shown below, which gives average scores for each option out of a notional six points.

Respondents' preferred approaches to cancer prevention



Perhaps remarkably, the approach that is currently most heavily utilised – attempting to advise, inform and encourage people into making healthier choices – enjoyed the strongest support, despite the negative view respondents gave of how the status quo is delivering. However, the second most popular answer, deployment of public health and/or prevention-focused healthcare services, is not a prominent feature of the status quo: these services have been subject to significant cuts over the last decade or more. Also striking is the strong hesitation about restricting personal freedoms further.

Similar themes were apparent in open-ended responses. Taken together, these point towards a strong focus on primary prevention, and relatively little on primordial.

5. The sector's work on prevention

We reviewed the websites of 48 organisations: 36 charities dedicated to cancer, and 12 whose work is directly relevant to it. Of the 48 organisations, there were only nine whose websites contained no material at all (that we could identify) relating to prevention. Among the remaining 39 organisations, the nature and extent of the representation of prevention on their websites varies considerably.

We found 23 organisations that engage in campaigning work of some sort: of these, we identified only six websites that showed campaigning work on prevention (that is campaigning for change, as distinct from publicity-type campaigning to raise awareness).

By far the most common type of work relating to prevention that we found on the organisations' websites was providing information and materials to raise awareness and improve readers' knowledge of causes of cancer, or factors that contribute to causing cancer. Only 13 websites did not include material of this sort, while it was present on the other 35.

Some organisations campaign for improved healthcare services. We found 16 websites that featured positioning of some sort relating to screening, and nine organisations actively campaigned on it. Positioning on early diagnosis appeared to be even more common.

Another way in which cancer charities sometimes campaign on prevention is to call for improved public health services. Cancer Research UK's Smokefree UK campaign has been an example of this: its two calls are to "Stop the Start" (eliminate uptake of smoking among young people) and to "Start the Stop" (improved public health campaigns and cessation services to increase quit rates). Its current campaigning action focuses only on the latter: supporters are being asked to sign a petition calling for improved cessation services and health campaigns.[5]

Cancer Research UK's work on prevention deserves attention in its own right. They are by far the biggest and most active charity working on prevention: their research and policy development is sector-leading, and they provide the only substantial example of a cancer charity campaigning strongly on primordial prevention (although some alliances and coalitions do so as well).

Respondents provided insight into how their charities identify their campaigning priorities. This offers a plausible group of four factors to which the most weight is attached: assessment of priority issues; assessment of population needs; views of beneficiaries; and assessment of the needs of beneficiaries. The strong focus on beneficiaries is of course entirely correct for any charity.

6. Vision for a stronger sector approach on prevention

We believe we have identified that there is a structural weakness in the cancer charity sector that needs to be addressed. Prevention is often out-competed in charities' priorities, particularly by care and treatment issues that can be more immediately relevant to beneficiaries. And from the perspective of individual charities, this is entirely correct: it is a feature, not a bug.

When charities do campaign on prevention, often this work skews towards primary prevention in the form of information and awareness-raising work to shape people's individual choices, or campaigning for improved public health services or detection of cancer. Primordial prevention, which requires structural change at a societal level, is a markedly less common feature of charity campaigning.

6. https://www.instituteofhealthequity.org/resources-reports/marmot-review-10-years-on/the-marmot-review-10-years-on-full-report.pdf

i. What should charities be asking for?

The input we received, and our review of work across the sector, offers several strong steers for future policy asks:

1. Structural change is the biggest gap to fill
2. Improved prevention services are also an important focus
3. Restrictions and incentives on commercial practices should be prioritised over restrictions on personal liberties

These point towards supporting the implementation of the recommendations of the Khan Review, and Henry Dimbleby's report as part of the National Food Strategy, which recommended a sugar and salt tax on ingredients for processed food manufacturers, restaurants and catering businesses. Tougher planning and licensing rules to promote the development of "healthy high streets" would be another strong candidate for a structural intervention.

ii. Harnessing the totemic power of cancer to wider public health messaging

There is no doubt that cancer is a disease with a unique status in our public discourse. It is the biggest health fear for more the majority of people.

Cancer's high, even totemic, profile has translated into political momentum to gear the NHS to put a stronger focus on treating it, certainly in England than even other 'big killer' disease areas such as respiratory illness.

If the totemic nature of cancer could be harnessed in respect of public health messaging, how far could it open the door to major structural change? It could be a way to secure support for potentially contentious interventions relating to food and diet, alcohol and even tobacco. One possible goal for the cancer charity sector, and wider public health sector, could be to bring the power of popular feeling about cancer to bear on public health interventions, and gather momentum for change.

iii. Organisational considerations

Clearly it would be unrealistic and unreasonable to expect a large number of charities to sign over significant resources and rip up their existing campaigning priorities. However, could a small pooling of resource around a joint campaign or campaigning structure provide a way forward? Alliances are common across multiple sectors and causes, and can range from formally constituted charities in their own right to looser working alliances operated by secretariats hosted in a member charity.

A down-side of this approach could be charities feeling that the box has been ticked and switching off from prevention. A challenge for any such grouping or alliance would therefore be to provide leadership and to assist member charities with, for instance, compelling messaging on prevention that provides an appropriate degree of consistency across the sector.

7. https://www.england.nhs.uk/03/2022/nhs-chief-launches-new-campaign-to-combat-the-fear-of-cancer/

7. Call to action

In this report we have shown that a widespread commitment to prevention exists among cancer charities, taking into account complex issues such as the extent to which some cancers can be understood as "preventable".

However, we have also shown that the sector can't always translate this commitment into high priority action, not least in its campaigning. This is not a fault or error, but the result of understandable dynamics within individual charities and the sector as a whole.

And finally, we have seen that approaches to prevention vary considerably, with much stronger priority attached to some forms of prevention than others – again, often for understandable reasons.

The challenge to strengthen the sector's campaigning on prevention is therefore a considerable one, and we call for an approach that involves:

1. Leadership to assist the sector in this work
2. An approach that harnesses the totemic nature of cancer to create demand for change within the public discourse
3. More unified messaging about prevention across cancer charities
4. Further pooling of resources across the sector
5. Sustained effort over the long term.

We propose three core elements for the sector's policy approach:

1. Stronger emphasis on primordial prevention
2. Continued emphasis on the need for improved public health and prevention services
3. Particular focus on solutions that will modify commercial behaviours.

We want to catalyse this renewed approach to prevention, and also play our part in delivering it. We want to work with all charities and other organisations who may have an interest in it. So as our next step, we invite as many organisations as possible to engage in an open and full conversation about how we can all work together to achieve it.