

# Punching below our weight

The cancer charity sector and cancer prevention

# Spring 2024



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# Introduction

CancerWatch exists to campaign for more and better action to prevent cancer. This isn't a contentious aim: there is no serious argument for better cancer prevention being anything other than a desirable thing. Yet the UK is nowhere near to doing all it could on cancer prevention.

The figure of around 40% of cancer cases being preventable is well established and widely cited.<sup>1</sup> The biggest 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.

We want to identify how we can work with existing organisations in the field in a collaborative way, and how we can add value to work that is already being done. We want to add our shoulder to the wheel in the most useful way possible, and to ensure that we do not risk duplicating or supplanting efforts already being made.

This report is therefore a natural starting point for CancerWatch's development. We set out to understand the existing cancer charity sector, and its work on prevention. This enables us to understand both what work is already well in hand, and what we might usefully step up and do ourselves. We will also use it to propose future action that can be taken in a collaborative way across the sector.

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. This report will argue that there is indeed such a gap: it is hard to demonstrate an absence or lack, but we believe we have identified one. 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 isn't a suggestion that any charity is doing a bad job or getting anything wrong. Rather, there appears to be a natural dynamic for many charities that draws them to focus, entirely rationally, on other priorities: their beneficiaries and supporters have overwhelmingly been affected by cancer already, and have strong interests in treatment and research; improving treatment and services is a more concrete and understandable campaigning call than improving prevention, which is a longerterm and highly challenging endeavour; and prevention can never have the motivating emotional pull for volunteers and donors of providing immediate help to patients through better treatment or new biomedical breakthroughs. Finding the time and energy to prioritise prevention in the face of such strong competing calls for resources will inevitably be a challenge.

And so it has proved. The cancer charity sector is not generating sustained pressure for major structural changes that would improve cancer prevention. That's not to say there is no such messaging or activity: there is indeed some, and it is highly welcome. But the scope for improvement in the UK's record on cancer prevention is colossal, as is the difficulty of achieving it. This is a challenge that the sector needs to rise to, both because it will be an effective way of meeting its aims in reducing the devastating impacts of many (though not all) forms of cancer, and because cancer's totemic status could greatly enhance calls for improved public health, if the two can be married up in the public discourse.

Cancer touches the lives of millions of people: it is a widely feared diagnosis; this fear and high level of awareness fuel the sense for many that things should be better. Yet the alarming spectre of cancer does not co-exist in public debate, or in many people's minds, with the need for healthier lifestyles, still less does it fuel demand for politicians and other decision-makers to act decisively on public health.



It is true that achieving this would require effort by more than just cancer charities, but it is equally true that the sector is not pushing hard for it as things stand.

This report explores the reasons why the push from the cancer charity sector for substantial improvements in cancer prevention is relatively modest. It will highlight the excellent work that is being done, and the many sound reasons why other priorities often prevail. These include that for many types of cancer, the question of whether they can be described as "preventable" is not clear-cut. It is also the case that there are different types of prevention, some easier to call for, and deliver, than others: charities can understandably home in on what they are most familiar with, or what seems most achievable; this can often mean interventions in the form of services, rather than structural changes to tackle problems at source.

We also set out suggestions for how the sector can do more and better in future. The challenge is considerable, but there certainly appears to be scope to galvanise the sector's work on prevention further, and focus it on key areas for change.

# 1. Methodology and approach

This 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.

#### i. Desk research

We reviewed the websites of 48 organisations: 36 cancer charities, and 12 further health charities whose remit has some relevance to cancer. (See Box 1 for a full list.)

Box 1: List of organisations whose websites were reviewed for work on cancer prevention

- Action Against Heartburn
- **Action Kidney Cancer**
- **Against Breast Cancer**
- Anthony Nolan
- Asthma + Lung UK
- Bloodwise / Blood Cancer UK
- **Bowel Cancer UK**
- **Brain Tumour Charity**
- Brain Tumour Research
- **Brains Trust**
- **Breast Cancer Now**
- **British Liver Trust**
- **British Nutrition Foundation**
- **British Skin Foundation**
- C3 Collaborating for Health
- Cancer Focus Northern Ireland
- Cancer Research UK

- Cancer Support UK
- Caribbean & African Health Network
- Coppafeel
- Eve Appeal
- Guts UK!
- Heartburn Cancer UK
- Institute for Cancer Vaccines and Immunotherapy
- Jo's Cervical Cancer Trust
- Leukaemia Care
- Lymphoma Action
- Macmillan Cancer Support
- Men's Health Forum
- Mesothelioma UK
- Myeloma UK
- **Oracle Cancer Trust**
- Ovacome

- Ovarian Cancer Action
- Pancreatic Cancer Action
- Pancreatic Cancer UK
- Prostate Cancer UK
- Roy Castle Lung Cancer Foundation
- Sarcoma UK
- Tackle Prostate Cancer
- Target Ovarian Cancer
- Teenage Cancer Trust
- Tenovus Cancer Care
- **Urology Foundation**
- Wellcome Trust
- World Cancer Research Fund
- Yorkshire Cancer Research
- Young Live Vs Cancer

Given the complexities involved in identifying whether some cancers can be regarded as meaningfully "preventable" or not (see chapter 3, below), no attempt was made to categorise the organisations as working on preventable or non-preventable cancers. Nonetheless, it will be the case that prevention is more directly pertinent to the work of some charities than to the work of others.

An organisation's website may not always capture the full detail of its work, and we recognise that this makes reviewing websites a somewhat crude method of assessing what an organisation does. Nonetheless, these organisations' websites between them contain a vast wealth of rich information about their work, and we judged it fair to assume that websites would typically offer a fair indication of the organisation's work, albeit sometimes at a high level rather than in granular detail. Findings are given in chapters 4 and 5, below.

#### ii. Call for evidence

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 (see Box 2 for the full list). All of the organisations whose websites were included in the desk review were approached to respond to the call for evidence.

The call for evidence was circulated by email to named contacts in three mailings, on June 6th, June 27th and July 18th 2023. For the second mailing, we also sent it to generic contact addresses at the organisations ("information@" email addresses and similar). Additionally, it was circulated to the UK members of the All.Can alliance.2

Box 2: List of organisations that were directly approached to respond to the call for evidence

- Academy of Medical Royal Colleges
- Action Kidney Cancer
- Action on Smoking and Health (ASH)
- Action on Sugar
- Alcohol Change UK
- Anthony Nolan
- Association of Cancer **Physicians**
- Association of Directors of Public Health (UK)
- Association of Medical Research Charities
- Asthma + Lung UK
- Bloodwise
- **Bowel Cancer UK**
- **Brain Tumour Charity**
- Brain Tumour Research

- **Brains Trust**
- **Breast Cancer Now**
- **Breast Cancer Now**
- British Liver Trust
- **British Nutrition Foundation**
- British Skin Foundation
- C3 Collaborating for Health
- Cancer Focus Northern Ireland
- Cancer Research UK
- Cancer Support UK
- Cancer Support UK
- Caribbean & African Health Network
- Caroline Walker Trust
- Chartered Institute of **Environmental Health**
- City University Centre for

- Food Policy
- Coppafeel
- **Demos**
- Drinkaware
- **Fabian Society**
- Food Foundation
- Food Foundation
- General Dental Council
- General Medical Council
- Guts UK!
- Health Action Campaign
- Health and Care **Professions Council**
- Health and Care Professions Council
- Health Education Trust
- Health Foundation
- Heartburn Cancer UK

<sup>2.</sup> https://www.all-can.org/



- Institute for Cancer Vaccines and Immunotherapy
- Institute of Alcohol Studies
- Jo's Cervical Cancer Trust
- Leukaemia Care
- Local Government Association
- Lymphoma Action
- Medical Council on Alcohol
- Mesothelioma UK
- Myeloma UK
- **National Voices**
- Nesta
- New Local
- **Nuffield Trust**
- Nursing and Midwifery Council
- Obesity Health Alliance

- Obesity UK
- **Oracle Cancer Trust**
- Ovacome
- Ovarian Cancer Action
- Ovarian Cancer Action
- Pancreatic Cancer Action
- Pancreatic Cancer UK
- Professional Standards Authority
- Prostate Cancer UK
- Reform
- Roy Castle Lung Cancer Foundation
- Royal College of General **Practitioners**
- Royal College of Physicians
- Royal Society for Public Health
- Sarcoma UK

- Scottish Health Action on Alcohol Problems
- Sustain
- Tackle Prostate Cancer
- Target Ovarian Cancer
- Teenage Cancer Trust
- Tenovus Cancer Care
- The Eve Appeal
- The King's Fund
- the World Cancer Research Fund
- UK Public Health Association
- UK Public Health Association
- **Urology Foundation**
- Wellcome
- Yorkshire Cancer Research
- Young Live Vs Cancer

We received several responses, which provided a valuable collection of expertise and insight, and we are grateful to everyone who took the time to respond. Our invitations prompted further discussions with some organisations, which were also positive and helpful. This input overall offers many useful signals and illuminating views, which are presented in the report below.

This report does not list all the organisations who responded, as we do not wish to "name and shame" those who did not by implication. However, some comments reproduced below are ascribed to organisational respondents, when they gave us permission to present them in that way. The respondents can be broadly characterised as set out in Table 1.

Table 1: Respondents by organisation type

Cancer-focused charities	9
Cancer-focused organisation, not registered as a charity	1
Health / public-health focused charity	3
Alliance of health / public health-focused charities	2
Individual who was approached due to their role in a relevant organisation and answered personally	2

Inevitably, some email messages will have gone to spam, although we checked our email address's spam rating with an industry standard tool before sending, and it was rated excellent; we therefore do not expect this to have been a major problem. We received automated replies from many email accounts, particularly the generic contact addresses, indicating that our emails broadly got through. We recognise that many professionals regularly find requests to respond to questionnaires and surveys arriving in their inboxes: it is understandable that some people did not prioritise this one. We also know that numerous organisations looked through the call for evidence, but felt they were not well placed to respond; in a few cases, we know that resource pressures precluded a response. We are nonetheless grateful to everyone who took the time to consider the questions.

Ultimately though, however many mitigations we might identify, it is hard not to read at least a little into the relatively modest response rate. Presented with an initiative about cancer prevention, many invitees appear not to have prioritised it especially highly.

# 2. Approaches to "prevention"

#### Formal definitions of prevention

Reaching a shared understanding of what "prevention" means is surprisingly challenging. Some of the complexity involved in this gives rise directly to some issues identified later in this report, so it is important to define our terms clearly.

The World Health Organisation utilises a distinction between primary and secondary prevention.3 Primary prevention, "refers to actions aimed at avoiding the manifestation of a disease." These can include:

- actions to improve health through changing the impact of social and economic determinants on health
- the provision of information on behavioural and medical health risks
- measures to decrease health risks at the personal and community level
- nutritional and food supplementation
- oral and dental hygiene education
- and clinical preventive services such as immunisation, vaccination and post-exposure prophylaxis (for people exposed to a communicable disease).

Primary prevention is targeted at people before they develop an illness.

Secondary prevention entails, "early detection when this improves the chances for positive health outcomes." This can include:

- evidence-based screening programs for early detection of diseases or for prevention of congenital malformations
- preventive drug therapies administered at an early stage of the disease.

Secondary prevention 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. In the UK for instance, the Local Government Association works in terms of both primary and secondary prevention, plus tertiary prevention: "softening the impact of an ongoing illness or injury that has lasting effects, [by] helping people manage long-term, often-complex health problems and injuries (e.g. chronic diseases, permanent impairments) in order to improve as much as possible their ability to function, their quality of life and their life expectancy." This might be understood as straightforward care and treatment, with a view to preventing worse health in the future. Tertiary prevention is targeted at symptomatic patients.

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." 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.

<sup>3.</sup> https://www.emro.who.int/about-who/public-health-functions/health-promotion-disease-prevention.html

<sup>4.</sup> https://www.local.gov.uk/our-support/our-improvement-offer/care-and-health-improvement/integration-and-better-care-fund/better-care-fund/integration-resource-library/prevention

<sup>5.</sup> 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/

Table 2: Examples of primordial, primary, secondary and tertiary prevention

Primordial	<ul> <li>Regulating the sale of unhealthy products</li> <li>Banning smoking in indoor areas</li> <li>Improving public transport or walking infrastructure to reduce car reliance</li> </ul>
Primary	<ul> <li>Social prescribing (eg of exercise)</li> <li>Information and awareness to enable people to make healthier choices</li> <li>Immunisation and vaccination</li> <li>Food supplements</li> <li>Addiction / help-to-quit services</li> </ul>
Secondary	<ul><li>Screening</li><li>Preventive medication</li><li>Timely diagnosis</li></ul>
Tertiary	<ul> <li>Rehabilitation</li> <li>Walking aids to prevent falls</li> <li>Medication to manage symptoms or slow progression</li> </ul>

CancerWatch is concerned with all forms of prevention, and we will argue in this report that the wider cancer charity sector's focus on prevention gets stronger the further one looks down the hierarchy from primordial to tertiary, with many charities placing heavy emphasis on services but the emphasis on structural change being lighter and less common. The sector is not alone in this: public policy as a whole has been much more strongly focused, over the long term, on the tertiary end of the range rather than the primordial. And when prevention has been prioritised, it has typically been in the form of primary prevention aimed at the individual, not primordial prevention aimed at society as a whole.

In the Government's announcement of its Major Conditions strategy for England there is a strong focus on primary prevention.<sup>6</sup> It proposes new measures to help people stop smoking, extra funding for drug and alcohol recovery treatment, the introduction of new weight loss drugs and an app-based incentives system for helping individuals to make healthier choices. These prevention measures are in the context of more extensive chapters on changes to the delivery of care and treatment.

But it is silent on primordial prevention: it does not propose any new measures on reformulating products to reduce sugar, salt or calorie content; it does not propose further restrictions on the sale or consumption of tobacco; it does not propose minimum unit pricing for alcohol; it does not propose any greater regulation of the sale of unhealthy takeaway food. What's more, it has been issued in place of a white paper on health inequalities, which would have been expected to home in on the underlying structural causes of health inequalities much more acutely.

This relatively weak approach to prevention, understanding it in terms of changing individual behaviour (primary prevention) but not attempting any structural change to tackle root causes (primordial prevention) exhibits continuity with long term policy approaches, particularly (but not exclusively) in England.

In respect of diet, this has been seen in the 2020 obesity strategy, with its 'Better Health' information campaign and NHS weight loss app. In respect of alcohol, the Government had announced plans in 2012 for a range of interventions, including minimum unit pricing, restrictions on promotion in shops

<sup>6.</sup> https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework/major-conditions-strategy-case-for-change-and-our-strategic-framework-2#chapter-2-keeping-people-healthy-through-primary-and-secondary-prevention

and new duties to consider public health in alcohol licensing decisions, but then quickly scrapped them all. No strategy on alcohol harm has been published in England since, and it has not followed Scotland, Wales and Northern Ireland in introducing minimum unit pricing. In respect of tobacco, the Government has largely declined to adopt the strong measures for structural change recommended by the Khan Review (indeed, the Major Conditions Strategy proposals do not even refer to it; even its focus on smoking cessation services is in the context of substantial prior funding cuts to services).8 However, recent Government intentions to prevent anybody born after 2009 from ever smoking are very welcome.

This is not to say that structural change to achieve primordial prevention has been entirely absent over recent decades: 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 (albeit after much delay); 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. This distinction will repeatedly become important in this report.

<sup>8.</sup> https://ash.org.uk/uploads/2019-LA-Survey-Report.pdf



<sup>7.</sup> https://reader.health.org.uk/addressing-leading-risk-factors/addressing-the-leading-risk-factors-for-ill-health-in-england-review-of-the-uk-government-s-policy-p#policy-to-addressharmful-alcohol-use

# 3. The meaning of "preventable" cancer

Just as defining "prevention" is not straightforward, its meaning and significance 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 good lifestyle choices on alcohol, diet and so on.9 For pancreatic cancer, obesity has been found to have increased risk in approximately 12% of cases. 10 In other cancers, lifestyle factors are associated with particular (usually more serious) forms of the disease: being overweight brings a greater risk of diagnosis with advanced prostate cancer;11 smoking is more strongly linked to mucinous ovarian cancer tumours than other types of ovarian cancer. 12 This picture of complex and incompletely understood causation is common to many cancers, but certainly contributes to the total of 38% of cancer cases being classed as preventable.13

Other cancers either are, or may be, preventable in other ways. Vaccination against HPV has been deployed since 2008 to prevent cervical cancer, with a 71% reduction in pre-cancerous cervical disease in young women already evident.14 Vaccine research is an active field, so other cancers may be preventable by vaccination in future, and vaccine technology may also offer effective forms of treatment for people who have been diagnosed with cancer. 15

Another subtly different scenario is where screening can prevent a cancer by detecting a precancerous condition. Cervical cancer offers the most clear-cut example. For other current screening programmes, breast and bowel, the aim is to detect cancer itself at an early stage. Both can be considered secondary prevention.

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 or even scientifically murky.

<sup>15.</sup> https://www.cancerresearchuk.org/about-cancer/treatment/immunotherapy/types/vaccines-to-treat-cancer/



https://www.againstbreastcancer.org.uk/about-us/about-breast-cancer/breast-cancer-facts-statistics

<sup>10.</sup> https://pancreaticcanceraction.org/about-pancreatic-cancer/risk-factors-of-pancreatic-cancer/

<sup>11.</sup> https://prostatecanceruk.org/prostate-information-and-support/risk-and-symptoms/can-i-reduce-my-risk

<sup>12.</sup> https://targetovariancancer.org.uk/about-ovarian-cancer/risk

<sup>13.</sup> https://www.cancerresearchuk.org/health-professional/cancer-statistics/risk/preventable-cancers

<sup>14.</sup> https://www.gov.uk/government/publications/hpv-vaccine-vaccination-guide-leaflet/information-on-hpv-vaccination

# 4. The sector's view of prevention

Before we consider the sector's work on prevention, we need to consider its understanding of prevention, views on it and preferred approaches. The respondents to our call for evidence provided valuable insight into this.

#### i. Views on the current state of prevention

Table 3: 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

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 precludes statistically robust results, the results do suggest a strong, and very downbeat, signal. Table 3 shows the mean average responses across all four of the home nations (with 14 responses in respect of England, 12 for Scotland, 11 for Wales and 10 for Northern Ireland). The median score for each was four, except for in Northern Ireland where it was three.

Table 4: In the event that a new UK government takes office in 2024, to what extent do you expect an improved approach to cancer prevention?

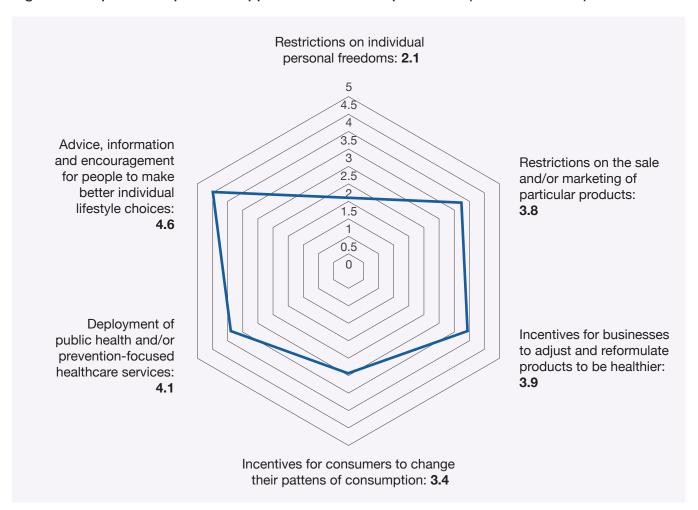
Not sure what to expect	4
Somewhat expect an improved approach	6
Strongly expect an improved approach	2
Somewhat expect no change	3
Strongly expect no change	2
Somewhat expect a worse approach	0
Strongly expect a worse approach	0

Respondents' pessimism about the current state of cancer prevention was underlined by none of them expressing an expectation that things would get any better under a future government. But beyond that there was no very clear signal, with respondents split roughly evenly between expecting improvement, expecting no change and not being sure what to expect.

#### ii. Preferred approaches to prevention

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 in Figure 1, (below) which gives average scores for each option out of a notional six points for a topranked preference.

Figure 1: Respondents' preferred approaches to cancer prevention (scores out of six)



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: while there may be much rhetorical acknowledgement of these services (not least in the announcement of the Major Conditions Strategy for England), they have in practice been subject to significant cuts over the last decade or more.

Also striking is the strong hesitation about restricting personal freedoms further: its average ranking placed it clearly at the bottom of the pile, and no respondent picked it as their top preference.

Although, as with the other data from the call for evidence, this cannot be taken as statistically robust, it is very consistent with replies given to the open-ended questions, and with how charities represent their work on their own websites.

We asked respondents to identify three policy interventions they would select to be implemented if given the chance. The responses were analysed by theme, and the results are set out in Table 5. Delineating the themes is not straightforward: as the extracts in Boxes 3-6 show, suggestions for awareness campaigning and education sometimes moved quickly into suggestions for expanded treatment services, while suggestions for market interventions sometimes moved quickly into the territory of direct prohibitions and stiff penalties.

Table 5: If it was in your power to decide, what three policy interventions would you select for national government (England / Scotland / Wales / NI, or UK-level – please indicate when answering, if needed) to implement as top priorities, in order to reduce the incidence of preventable cancers? Please describe each briefly on a separate line.

Theme	Frequency
Awareness campaigning / education / information	11
Strong legislation / regulation	7
Market interventions	7
Health interventions, eg cessation services	6
Address issues with the NHS, eg staffing, training	4
Addressing problems of socio-economic inequity	4
Improved healthcare treatment	3
Screening	3

Box 3: Suggestions from respondents relating to awareness campaigning / education / information

For preventable cancers, Westminster and the devolved governments need to focus on better awareness campaigns. Governments should be promoting healthy living - focus on keeping a healthy weight, avoiding tobacco, limiting the amount of alcohol - with better guidance issued.

#### - Brain Tumour Research

Less than half of young people aged 18-24 can identify any of the five most common signs of cancer: lumps, bumps and swellings; unexplained tiredness; mole changes; pain; and significant weight change. Four in five (82 percent) are unable to identify all five. UK Governments should work with the NHS to run an awareness campaign targeting young people in age-appropriate language and through the media most likely to reach them, such as social media.

#### - Teenage Cancer Trust

Better access and use of data to drive decision making and influence patient pathways and awareness campaigns.

#### - Oracle Cancer Trust

Campaign for smoking cessation (eg Stoptober) - increase length and reach of the campaign so that it runs not only for one month, but nationally throughout the year. [...] Campaign to combat obesity - again, this campaign needs to run throughout the year at a national level and people need a diet plan to help them lose weight and keep it off.

#### - Action Kidney Cancer

Taken together, these results point towards a strong focus on primary prevention, and relatively little on primordial prevention. In practical terms, this emerges as an emphasis on solutions that aim to prompt individuals to make healthier choices or that deliver direct support services, and less emphasis on, or even significant caution about, interventions that would bring about structural change at a societal level.

#### Box 4: Suggestions from respondents relating to market interventions

Effective measures to reduce harm from alcohol on marketing, price and availability

#### - Alcohol Change UK

Restrict unhealthy advertising (UK), extend levies to other unhealthy foods (UK), and remove industry from policy making (UK)

#### - An alliance of health / public health-focused charities

This summer, a coalition of UK charities called on the government to remove VAT from sunscreen. Melanoma skin cancer is the most fatal form of skin cancer, yet 86 percent of cases are preventable. It is the most common form of skin cancer in young people, and cases are rising.

#### - Teenage Cancer Trust

Use the successful model of the Soft Drinks Industry Levy to design further fiscal measures that incentivise the food industry to sell healthier food and drink options. [...] Bring in comprehensive restrictions on advertising and marketing of HFSS (high fat, salt, sugar) products.

#### Action on Sugar

Within primary prevention, as we have seen, some approaches have been heavily deployed in the UK (information and awareness in particular), while others have been under-deployed (public health services, addiction treatment services). Strong awareness of the weakness of the latter may explain respondents' focus on primary prevention.

#### Box 5: Suggestions from respondents relating to strong legislation / regulation

Make smoking illegal by passing legislation - about 25% of all cancers are caused by smoking. Implement a strategy of legislation and regulations to reduce being overweight and obese in the population as a whole - about 20% of all cancers are caused by being overweight.

#### - Action Against Heartburn

Raise age to legally buy tobacco to 25. Raise taxes on high-sugar and processed foods. Introduce minimum price-per-unit for alcohol nationwide.

#### - An expert respondent from a cancer-focused charity, responding personally

Introduce a new and improved Sugar Reduction Programme with mandatory, specific, and databacked upper limits for all contributing categories of sugar to the diet (including alcohol and infant food), imposing financial penalties for non-compliance.

#### - Action on Sugar

That said, it may be that the distinction between primary and primordial prevention, and the limitations of relying mainly on primary prevention, isn't as clearly in focus across the sector as it might be. Possibly some organisations are satisfied that primary and secondary prevention approaches adequately cover prevention as a whole. This is a tentative hypothesis, and would bear further investigation.

#### Box 6: Suggestions from respondents relating to strong healthcare interventions

Systems to ensure the targeted and consistent use of IBAs [Identification and Brief Advice] can help to identify people drinking at high-risk levels, and provide them with individualised information on their risk and advice on strategies to reduce their alcohol consumption.

#### - Alcohol Change UK

Campaign to combat obesity - again, this campaign needs to run throughout the year at a national level and people need a diet plan to help them lose weight and keep it off.

#### - Action Kidney Cancer

Full implementation and dedicated funding to public health strategies eg Obesity Strategies in particular

- Tenovus Cancer Care

#### iii. Approaches to prevention: prioritisation

We also wanted to gain insight from respondents about how change should be prioritised. There is only ever so much time available in Parliament for legislation, and only so much capacity in government departments and agencies for developing and delivering new policies. The scale of policy change needed to improve cancer prevention is considerable, and while time is of the essence, realistically it can't all happen at once. So how should the priorities be identified?

Would it be best to focus on the things that will be hardest, and take the longest time, to achieve? The later we leave it to start, the longer we will continue living with the problems they are meant to address. Then again, can prioritisation be readily justified for something that won't show results soon over something that will? Would it be better to start with relatively quick and easy wins?

The question can be approached another way: what benefits should be prioritised? Should there be a focus on outright gains in terms of years of life, or of healthy years of life? Or should health inequalities be tackled first: this might mean rooting out the worst and least defensible inequities in society, but wouldn't automatically translate to the biggest aggregate gains.

Table 6: How should new cancer prevention measures be prioritised?

	Average score (out of 3)
Reducing disparities and inequalities in health outcomes	1.5
Reducing overall healthy years of life lost to cancer	1.2
Reducing overall years of life lost to cancer	0.9
Reducing future burdens on the NHS and other services	0.6
Preferences and wishes of people who have, or have had, cancer	0.3
Preferences and wishes of the public as a whole	0.1
Value for taxpayers' money	0.0

As shown in Table 6, with the usual caveat about sample size, respondents offer a strong steer to focus on disparities and inequalities in health outcomes. Years of healthy life are prioritised slightly above outright years of life, and respondents saw benefit to reducing burdens on the NHS and other services, albeit not as the over-riding priority. Other possible priorities scored notably less well.

A possible avenue for future research may be to ask a similar question to audiences of decisionmakers, such as MPs or senior government officials. It may be valuable to understand whether there is any mis-match between what cancer charities view as priorities and what decision-makers see as workable: understanding whether policy recommendations are likely to fall on stony or fertile ground could help to shape future campaigning.

## 5. The sector's work on prevention

Reviewing cancer charities' websites, we did not find it hard to identify charities attaching significance to prevention (when it's appropriate for their particular cancer, bearing in mind the complexity around this issue outlined in chapter three). Plenty of charities do so in their online materials, although the form this takes varies greatly.

We reviewed the websites of 48 organisations: 36 charities dedicated to cancer, and 12 whose work is directly relevant to it (all of whom were also invited to respond to the call for evidence - see Boxes 1 and 2). Of the 48, 23 engage in campaigning work of some sort: that is, work to bring about change in policy or practice. We evaluated their online material on prevention in several respects, and rated it on a simple scale:

- High, meaning prevention has a high or even dominant profile in the charity's work as depicted on their website
- Medium, meaning prevention is as prominent as at least some other issues or aspects of the charity's work
- Low, meaning prevention is not mentioned frequently, and/or is usually lumped in with other priorities or referenced only in passing.

Of the 48 organisations, there were only nine whose websites contained no material at all (that we could identify) relating to prevention. In many cases, this reflected the nature of the charity's focus, on cancers or aspects of cancer where prevention is not a relevant concept. Among the remaining 39 organisations, the nature and extent of the representation of prevention on their websites varies considerably.

This appears to illustrate variation in the strength and depth of charities' commitment to prevention. Sometimes it can be fairly nominal, and not translate into much, or any, of the work that the charity documents online. But very often there is indeed substantial work on prevention in evidence, albeit quite often as a somewhat secondary strand of the charity's activity. So, for example, 11 of the charities featured prevention on the front page of their website (we rated six of these mentions or references as medium and five as low, but none as high). Many more, however, featured work of various types elsewhere on their sites.

Commonly this involves one or both of information and awareness type work (primary prevention), or campaigning for one or both of improved awareness and improved healthcare services (either primary or secondary prevention). Primordial prevention is often an omission, however, with relatively little campaigning for structural change in evidence across the sector. The need for the structural change that is required for effective primordial prevention is sometimes acknowledged, but is less often incorporated into campaigning action: it often gets lost among other policy calls and campaigning initiatives.

In terms of campaigning overall, 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): we assessed four organisations as attaching a medium priority to this, two low, and none high. Fourteen organisations had positioning that in some way described change they would like to see relating to prevention (one high, five medium, eight low), although three of these were not campaigning organisations at all.

This chapter offers examples of these behaviours among cancer charities, and a possible rationale for why the sector attaches the priority it does to prevention. With one exception, it does not name

specific charities: our analysis is that there are understandable and justifiable reasons why individual charities make the choices they do, and our ultimate call will be for more work to fill the gap this leaves, not for charities to make major changes because they are in some sense doing something "wrong". We are not attempting to "name and shame" charities, and therefore will not specify them. The exception will be Cancer Research UK, whose work is sector-leading in many respects, and which merits discussion in its own right.

#### i. Nominal commitment

At the extremes, some charities offer a nominal commitment to prevention, but give no indication that this translates into any action. This may simply be because the charity is focused on care provision, although we did find at least one instance of a charity with this sort of focus but which is a campaigner and does mention prevention on its website; ultimately though, prevention does not feature in its campaigning work. In other cases, charities sometimes make reference to working with partners to bring about change, including on prevention: in practice this will often mean being part of a campaigning alliance or coalition, which is a valid and often effective way of supporting campaigning work without having to commit resources to it in-house.

#### ii. Reliance on awareness and changing individual behaviour

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.

The character of this material varied considerably. Some charities are able to point to modifiable risk factors that have a direct causal relationship with a particular type of cancer, such as smoking and lung cancer (among others).

For other organisations, where the same factors might be implicated as a contributing factor in causing cancer but the relationship is less clear-cut, general messaging encouraging a healthier lifestyle is often to be found on their website. Some feature it prominently, while others tuck it away as a point of detail, or mention it only in passing.

There are other organisations whose focus is a particular area of physiology and whose messaging applies to both cancer and other health conditions. So, for example, messaging about reducing alcohol intake might be promoted by organisations focused on liver health. (We have still counted this broad-based information / advice as material on cancer prevention.) Ultimately however, this approach relies on individuals making different choices, once either equipped with new information or motivated by convincing messages.

As an example, we found one organisation which focuses on an area of physiology, and describes its work under three headings, relating to prevention (listed first), treatment and cure. The work on prevention manifests as a focus on research, and also as information and awareness work: although the organisation is not a campaigning body, it expresses an aspiration for improved awareness in the future. However, this is the limit of its positioning on prevention: we did not identify an equivalent aspiration for, say, improved tobacco control or other similar structural change, even though at least some cancers covered by the organisation's work are unambiguously smoking-related.

#### iii. Calling for more healthcare services

Another somewhat common approach is to call for more or better healthcare services, including screening and improved (that is, earlier) diagnosis. We found 16 websites that featured positioning



of some sort relating to screening (three highly prioritised, six medium and seven low), and nine organisations actively campaigned on it (two as a high priority, six medium and one low).

Positioning on early diagnosis appeared to be even more common, although we have not counted this as relating straightforwardly to prevention: rather, it is an example of where a nominal focus on prevention is often really a focus on detection.

Among the campaigning examples we saw were a charity for a preventable cancer whose main campaigning action is a petition campaign where screening is the only respect in which prevention is mentioned, and the petition's calls otherwise relate entirely to treatment. This is by no means necessarily the wrong priority for that organisation, but does serve as an illustration of how prevention can very naturally take a lower priority in charities' campaigning.

#### iv. Calling for more public health services rather than structural change

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 guit 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. 16 However, the campaign is ongoing: Cancer Research UK will be developing new public-facing materials about it, and campaigning actions on the "Stop the Start" element could presumably still be introduced.<sup>17</sup>

#### v. Cancer Research UK

Cancer Research UK's work on prevention deserves attention in its own right, not just to provide an example as above. 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).

Of six campaigning successes they highlight, three relate directly to prevention. 18 Notably, all three involve restrictions on market behaviours (plain packaging for cigarettes; tobacco vending machines and open display; sunbed use by minors), and one involved restrictions on personal liberties (in respect of sunbeds). Cancer Research UK's campaigning success in advocating for the 2007 smoking ban also involved restricting personal liberties. 19

Prevention also features prominently on Cancer Research UK's website. In its extensive policy section we identified 28 pages containing material relevant to prevention, with a separate awareness and prevention section made up of a further 64 pages. On its webpage inviting supporters to campaign, it highlights the need to shape, "decisions on preventing, diagnosing and accessing cancer treatments," notably naming prevention first.20 The depth of its policy work is striking, going as far as providing analysis on tobacco tax and illicit trading for instance.<sup>21</sup> So while we may identify that it is not immune to the wider trends on prevention seen elsewhere in the sector, its status as the leading campaigning charity on cancer prevention is not in doubt.

<sup>21.</sup> https://www.cancerresearchuk.org/about-us/we-develop-policy/our-policy-on-preventing-cancer/our-policy-on-tobacco-control-and-cancer/tobacco-tax-and-illicit-trade



<sup>16.</sup> https://www.cancerresearchuk.org/get-involved/campaign-for-us/smokefreeuk

<sup>17.</sup> https://www.cancerresearchuk.org/get-involved/patient-involvement/patient-involvement-stories/smokefreeuk-campaign-update

<sup>18.</sup> https://www.cancerresearchuk.org/get-involved/campaign-for-us/our-campaigning-successes

<sup>19.</sup> https://www.cancerresearchuk.org/get-involved/campaign-for-us/our-campaigning-successes/smokefree-workplaces

<sup>20.</sup> https://www.cancerresearchuk.org/get-involved/campaign-for-us

#### vi. A natural dynamic: what charities are seeking to achieve, and what motivates their supporters and beneficiaries

In the discussion paper we issued alongside our call for evidence, we sketched out a hypothesis about the sector's behaviour and what drives it.

However, cancer charities' campaigning often focuses more on care and treatment, alongside research issues. This is not a criticism: there may be a very natural dynamic whereby members and supporters of charities are strongly supportive of those priorities. A focus on prevention might feel a bit beside the point to people whose lives have, very often, already been affected by cancer.

We were mindful that a more methodical review of the sector might prove this analysis wrong, in respect of the nature of the sector's work, the reasons for it, or both. However, our website review, and the responses to our call for evidence, appear to bear out our provisional view: cancer charities appear to be more at home calling for improved healthcare services, and more inclined to do so.

Of the ten respondents to the call for evidence who identified themselves as campaigning charities, three told us they do not campaign at all on prevention, one said it was their top priority, for three others it has equal priority with one or more other issue, with the rest prioritising it lower than some or all others. These responses appear broadly compatible with what we found out from charities' websites.

#### Table 7: How does your organisation decide on its campaigning priorities?

Please indicate how heavily you take each factor into account (0 = not at all; 10 = to the greatest possible extent). (Campaigning cancer charities only)

	Mean	Median
Assessment of priority issues	8.2	8
Assessment of population needs	8.1	8
Views of beneficiaries	7.9	8
Assessment of needs of beneficiaries	7.8	8
Views of members and/or supporters	6.6	7
Evaluation of available / expected technological developments (including medication)	5.3	5
Identification of funding that can be secured for work on a given issue	4.7	4

Respondents provided insight into how their charities identify their campaigning priorities (Table 7). While again this is subject to necessary caveats about the small sample size, it 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: as well as the factors that are explicitly about beneficiaries, it can be fairly assumed that the priority issues being assessed are those that affect beneficiaries, and the population whose needs are assessed is the largely (if not entirely) the beneficiary population.

Overwhelmingly, the beneficiaries of these charities will, by definition, be people who have been diagnosed with cancer. (Among the respondents to this question, only one organisation was researchfocused, and none exists wholly or mainly to serve other beneficiary groups such as carers of people with cancer.) The immediate need for care and treatment for people with cancer will be, and must be, of central importance to these charities' work. A focus on the needs of beneficiaries is not a problem or a failure: it is inevitable, necessary and correct.

During our desk research, we encountered many examples of messaging that charities use to encourage donations, volunteering, and other forms of support. With the above in mind it is notable, though perhaps only an incidental indication, that we could not find examples of prevention being featured in this messaging (with the exception of Cancer Research UK's appeal specifically for volunteers to take campaigning actions). It does not appear to motivate people – or at least, to be used to motivate people - to become involved with a charity. By contrast, examples of the support, treatment and research that can be secured with funds raised or donated are commonly given on charities' websites.

We might speculate that there are other drivers for a focus both on care and treatment services, and on forms of prevention that involve services or the provision of information. Charities that are set up primarily to meet the needs of people with cancer may naturally develop a cultural skew towards thinking and acting in terms of service provision, as that is what their beneficiaries primarily need. Such a bias may also arise if charities' workforces contain a substantial proportion of trained health and care professionals, as can often be the case: they are trained and experienced in delivering services, so may lean towards seeing services as a solution. It is probably also fair to say that improved or newly introduced services can be tangible and measurable results of campaigning action: this too may predispose charities towards focusing on them as a campaigning ask. However, these points are somewhat speculative: further research may shed light on the extent to which these possible drivers are in operation within cancer charities in the UK.

# 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. 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. Again, there are probably good reasons for these behaviours: particular forms of prevention might be especially relevant for certain cancers; and policy asks relating to primary or secondary prevention are easier to frame, easier to achieve, and easier to measure once implemented. However, the gap in charities' campaigning is especially marked in respect of primordial prevention and the structural change it requires.

This chapter considered what might be involved in filling this gap, and enabling the cancer charity sector to maximise its impact in this area.

#### i. What should charities be asking for?

Judging by the responses we received to our call for evidence, cancer charities are unimpressed by the current approach to prevention. A more effective public policy approach will inevitably have to be bolder; and charities' policy asks must therefore be bolder too.

The input we received, and our review of work across the sector, offers several important directives:

- 1) Structural change is the biggest gap to fill
  - This is evident from our review of charities' work, as they present it on their own websites
  - It also offers the biggest scope for improvements in population health
- Improved prevention services are also an important focus
  - Charities told us very clearly that they view this as a clear priority area for improvement
  - Coupling this with calls for structural change would represent a two-pronged approach akin to that of Cancer Research UK's twin Stop the Start / Start the Stop calls
- Restrictions and incentives on commercial practices should be prioritised over restrictions on personal liberties
  - Restricting personal liberties was clearly the approach that the sector felt least comfortable with, despite success stories such as the smoking ban
  - Changes focused at commercial practices may well be the most effective solution now in any case, as the case studies discussed below suggest.

It would support the implementation of the recommendations of the Khan Review, including substantially improving funding for smoking cessation services and imposing a levy on tobacco manufacturers (and would not entirely preclude other measures such as progressively raising the age of sale and restricting smoking outside restaurants, pubs and cafes, although these do involve restrictions on personal liberty).<sup>22</sup>

<sup>22.</sup> https://www.gov.uk/government/publications/the-khan-review-making-smoking-obsolete



Similarly, potential interventions in respect of food and diet have already been developed, for instance in Henry Dimbleby's report as part of the National Food Strategy, which recommended extending the approach of the Soft Drinks Industry Levy and introducing a £3/kg sugar tax and £6/kg salt tax on ingredients for processed food manufacturers, restaurants and catering businesses.<sup>23</sup> Tougher planning and licensing rules to promote the development of "healthy high streets" (with ready access to fresh food, and without proliferations of fast food outlets) would be another strong candidate for a structural intervention.<sup>24</sup>

As shown not least by our respondents' pessimism about the success of the current approach to cancer prevention, there is ample scope for improvement if a bolder policy approach is taken. The sector has a role in calling for it.

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

There is no doubt that cancer is a disease with a uniquely totemic status in our public discourse, and in the minds of many people. It is the biggest health fear for more the majority of people.<sup>25</sup> Its status as the most feared health condition is long standing over many years.<sup>26</sup>

Cancer's high, even totemic, profile has translated into political momentum to gear the NHS to put a strong focus on treating cancer, certainly in England. Currently there are targets of diagnosis within 28 days of referral, and of treatment starting within 62 days of referral and 31 days of agreeing a treatment plan with a doctor. While seeing that these targets are met in practice may be an ongoing battle, they are far beyond the prioritisation attached even to other 'big killer' disease areas such as respiratory illness, where no comparable pathways or targets have ever been established.

Indeed, politicians have recognised the usefulness of invoking cancer. In the 2019 general election, the successful Conservative Party manifesto, sometimes characterised as a "populist" platform, mentioned cancer five times in its 64 pages (offering little substantial commitment, but big ambitions, for instance to improve survival rates, and to improve early diagnosis across 78 hospital trusts). The Labour Party's manifesto, by contrast, mentioned cancer only twice in its 107 pages, and the Liberal Democrats mentioned it just once in their 100 page long manifesto. This is not to suggest that the parties' respective approaches to cancer wholly explain the outcome of the election, but it is striking that the most successful party homed in much more acutely on the grip held by cancer on the public imagination.

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. Such interventions would be beneficial across many other disease areas, not just cancer. Yet there is no widespread clamour to make these changes that is comparable with strong public support for improved cancer treatment. 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. Learning from past successes

In seeking an improved approach to cancer prevention, it is important to learn from past successes. Here we briefly consider key lessons that the sector would do well to consider when deciding on future action.

<sup>26.</sup> https://news.cancerresearchuk.org/2011/08/15/people-fear-cancer-more-than-other-serious-illness/



<sup>23.</sup> https://www.nationalfoodstrategy.org/the-report/

<sup>24.</sup> https://www.instituteofhealthequitv.org/resources-reports/marmot-review-10-years-on/the-marmot-review-10-years-on-full-report.pdf

<sup>25.</sup> https://www.england.nhs.uk/2022/03/nhs-chief-launches-new-campaign-to-combat-the-fear-of-cancer/

The first is the importance of external pressure for action, from multiple sources and of multiple kinds. For instance, in the early 2000s not only were Cancer Research UK campaigning for a ban on workplace smoking, but the British Medical Association had also made the call. At the same time, many hospitality venues and other workplaces had followed a long trend of firstly introducing smoking and non-smoking areas, and latterly banning smoking entirely (more in some types of venue, such as cinemas, than in others, such as pubs). These pressures and changes outside government, from multiple directions, helped to prompt the administration of the day towards stronger action in England than it had initially contemplated.<sup>27</sup> In respect of cancer prevention, this invites an uncomfortable question: where is the pressure for change coming from? There is some from charities, but there needs to be more.

Another lesson is that commercial behaviour can be shaped successfully. The Soft Drinks Industry Levy aimed to reduce calorie intake primarily by prompting manufacturers to reformulate their products. Changes in consumer behaviour (buying less sugary and therefore cheaper drinks) was intended as a secondary effect. And so it proved: the total sugar sold in soft drinks fell by 35% from 2015 to 2019, with 83% of the reduction attributable to recipe reformulation. 28 This is an approach that cancer charities could be pushing for much more strongly.

Thirdly, past successes show that process matters. Future campaigning should consider matters of process carefully, and use them to target campaigning actions and recommendations precisely. For example, the Soft Drinks Industry Levy was introduced as part of a Finance Bill, which introduced the primary legislation that was the basis for the eventual regulations. This by-passed the "write-round" process that would usually be used to seek collective agreement among ministers, which would have been hard to obtain for this (at the time) contentious measure. Another example would be the powerful inquiry by the Health Select Committee ahead of the introduction of the smoking ban: this was influential in shaping the debate among MPs, ahead of a free vote in the House of Commons. The appointment as the Committee's chair of Kevin Barron MP, a long-term advocate of greater curbs on tobacco use, acted as a signal (intentionally or not) that the Committee should investigate the issue. Charities would do well to identify and encourage parliamentary champions for bold measures on cancer prevention, and to include procedural advice as part of their recommendations.

A final lesson from previous policy successes, albeit away from cancer prevention, could be that progress is not inevitable, and gains are not guaranteed to be secure. Both public policy and public attitudes on drink driving have been transformed since the first public information film on the subject was launched in 1964. In 1979, nearly two thirds of young male drivers admitted to drink driving regularly, but modern day research shows that over 90% of people now agree it is unacceptable and would feel ashamed if they were caught doing it.29 However, the blood alcohol content limit in the UK remains higher, at 80 milligrams of alcohol per 100 millilitres of blood, than the continental standard of 50: 2% of driver breath tests following a collision produce results in the range between the two, and reducing the UK limit to 50 has been estimated to be capable of saving 64 lives per year. However, not only has the drink drive limit not been strengthened, but the enforcement of breath testing has also declined in recent years.<sup>30</sup> Cancer charities may wish to draw conclusions from this about the ongoing need to maintain campaigning pressure over time.

#### iv. Organisational considerations

Cancer charities are not the only game in town when it comes to campaigning for prevention. Perhaps the most high profile campaigner on food and diet in recent years has been the celebrity chef Jamie Oliver, whose current focus is with the Bite Back 2030 campaign, focusing on nutrition for young

- 27. https://www.instituteforgovernment.org.uk/sites/default/files/smoking\_in\_public\_places.pdf
- 28. https://www.instituteforgovernment.org.uk/article/explainer/sugar-tax
- 29. https://www.lookers.co.uk/blog/drink-driving---how-attitudes-have-changed-over-the-last-50-years
- 30. https://www.ias.org.uk/wp-content/uploads/2020/12/A-brief-history-of-drink-driving-policy.pdf
- 31. https://www.biteback2030.com/



people, and apparently mostly funded by government contracts.31 Oliver has previously campaigned for a sugar tax and other measures relating to sugar and junk food advertising, advancing positions not unlike Cancer Research UK's positioning at around the same point in the mid-2010s.32 It may be that other campaigners will emerge in the future who will similarly be able to promote complementary messages about cancer prevention. Alternatively, it could be that those campaigners will advance more quickly, and leave the cancer charity sector behind. Cancer charities can claim to have been on the leading edge of change with the smoking ban; would a similar claim be tenable if further significant changes were introduced in the next few years?

While it may be obviously desirable to fill the gap in cancer prevention campaigning in the charity sector, it is much more challenging to identify how this should be done, from an organisational perspective. We hope this discussion will stimulate thinking and conversations, but we do not pretend to have a complete answer.

Clearly it would be unrealistic and unreasonable to expect a large number of charities to sign over a chunk of their resources and rip up a chunk of their existing campaigning priorities. However, could a small pooling of resource around a joint campaign or campaigning structure provide a way forward?

This model is already in use to a large extent, of course. One respondent to our call for evidence gave a frank and highly useful summary of their approach:

"We do not prioritise prevention due to limited resources and instead add value to other organisations who lead on these initiatives, eg ASH Wales, the Obesity Alliance, Public Health Wales campaigns etc. Our main focus is on influencing cancer systems to improve diagnostics and outcomes once people are diagnosed with cancer. Given limited resources, this has been a strategic decision based on insight from our partners, beneficiaries and other stakeholders."

As well as those named above, examples of collaborative or coalition-based working include initiatives ranging from the One Cancer Voice petition organised by Cancer Research UK33 to formal alliances such as Cancer52.34 Other coalitions are focused on themes other than cancer of itself, such as the Smokefree Action Coalition, which is co-ordinated by Action on Smoking and Health (ASH), the preeminent tobacco control campaign charity.35

Alliances of this sort are common across multiple sectors and causes, and can range from formally constituted charities in their own right, such as the Association of Medical Research Charities, to looser working alliances operated by secretariats of either dedicated staff hosted in a member charity (such as the Care and Support Alliance) or staff who incorporate the work into their wider duties (such as the Prescription Charges Coalition).36

A clear voice on prevention from the cancer charity sector is lacking: could a grouping or alliance along these lines be a workable solution? While it could offer a route for small charities to add to the campaign on prevention without overburdening their own resources, the 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 would therefore be to provide leadership, and assist member charities with, for instance, compelling messaging on prevention that provides an appropriate degree of consistency across the sector. This could include both ensuring that all visitors to a cancer charity website have sight of a message about prevention, and spreading information and insight within the sector about the different forms of prevention, and the importance of structural change for primordial prevention.

<sup>36.</sup> https://www.amrc.org.uk/, https://careandsupportalliance.com/, http://www.prescriptionchargescoalition.org.uk/



<sup>32.</sup> https://www.cancerresearchuk.org/about-us/we-develop-policy/our-policy-on-preventing-cancer/our-policy-on-obesity-and-diet-1

<sup>33.</sup> https://news.cancerresearchuk.org/2023/03/29/one-cancer-voice-for-cancer-patients/

<sup>34.</sup> https://www.cancer52.org.uk/

<sup>35.</sup> https://ash.org.uk/about/who-we-work-with/smokefree-action-coalition

#### 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.