

## Ten-year cancer strategy: Call for evidence by Department for Health and Social Care

### Written evidence submitted by Business Disability Forum

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#### About Business Disability Forum

1. Business Disability Forum (BDF) is a not-for-profit membership organisation which exists to transform the life chances of disabled people. Our policy and research projects work collaboratively with our members, disabled people, carers, and the Government to provide evidence-based solutions to improve disabled people's experiences in work, education, consumer settings, and public services.

#### About our response

2. We chose to respond to this consultation because we were concerned that a ten-year cancer strategy was based almost entirely on treatment and based solely within DHSC – i.e., a very medical focus. We know from our work with businesses and employers that people are also working with cancer, accessing insurance and private health products with cancer, and accessing benefits as they live with cancer and treatment. A ten-year cancer strategy therefore needs to reflect this.
3. Our submission therefore calls for **a cross-policy, whole-life approach to a ten-year cancer strategy** which is co-owned by multiple policy areas, and not seen entirely as a strategy for and based in DHSC.
4. To inform our views on the consultation, we carried out seven depth conversations with employees working within our member organisations who are living with cancer or who are close to someone living with cancer.

#### The language of the opening statement was not well-received

5. There were various concerns with the language used in the Secretary of State's words to introduce the consultation.<sup>1</sup> The choice of narrative and metaphors used in

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<sup>1</sup> The Secretary of State for Health and Social Care's words to introduce this consultation were as follows: "This country's fight against COVID-19 has shown just what we can do when we join forces against a

the in the introductory paragraphs were unfortunate and people we spoke to generally felt it set the wrong tone for what the next ten years of cancer care should look and feel like.

6. Firstly, the **“war” and “battle” analogies** were not well-received, and it was generally felt to be an unnecessary metaphor. Some women even said this was very “masculine” language that they did not recognise from their own experience of cancer, and it was a metaphor that they generally did not feel was appropriate for the future of cancer care either.
7. One person said cancer “doesn’t feel like a battle, because there is nothing you can do about it”, and others were more taken aback by the war-based imagery. In one person’s words, “Yes, it very much does need to be a **national** war, because the private sector and charities are carrying this [cancer care] at the moment”. Others commented that the “national war” narrative is ok if the Secretary of State is talking about the “momentum needed from the Government”, but this narrative is not ok if talking about individuals’ lives who are living with cancer, “then the war analogy becomes inappropriate”.
8. There is also a view – documented most articulately by the late John Diamond – that the narrative of ‘battling’ and ‘courage’ implies that those who survive (‘beat’ cancer) are those who ‘deserve’ to live and that those who do not survive (and die) have not ‘fought’ hard enough, and that is somehow their fault.
9. Secondly, the Secretary of State said, “now is the time” for cancer, “another common threat”, to receive the same “ingenuity and endeavour” that was given to responding to Covid. Individuals we spoke to wondered why the implication was that attention had not been on cancer before Covid. Cancer has been with us for a very long time. In their words:
  - “Covid is a “common threat” but it’s not the first. Cancer has always been here. Having cancer also doesn’t mean it will take [people’s] lives”.
  - “Why haven’t we used “ingenuity and endeavour” to put cancer on the back foot so far? “Now is the time?” Why hasn’t it been the time before?” The implication is that we have not been “trying” before, which clearly is not the case.
10. Similarly, others said cancer being a focus for the Government’s attention ‘only now’ “does NHS staff a disservice” to how hard the NHS’ oncology services work with the very limited resources they are given.

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common threat. During the pandemic we used this country’s ingenuity and endeavour to put the virus on the back foot, but now is the time to apply this same spirit and determination to another threat: cancer. It is time to declare a national war on cancer, which is the biggest cause of death from disease in this country. It is a menace that has taken far too many people before their time and caused grief and suffering on a massive scale”.

11. Thirdly, people responded to **how** cancer becomes “a threat”. In some people’s words:
  - “Cancer is only a ‘threat’ if people aren’t given the care and treatment that they need”.
  - “**This** is the war – training, resources and better investment”.
  - “‘Suffering’ comes from incompetence and lack of treatment”.
12. Fourthly, the sentence that said cancer is “a menace” was met with confusion. Someone commented that “a ‘menace’ is something ‘annoying’” and is therefore not appropriate to describe cancer. Another individual was unclear what the Government was trying to say with this, and they asked, “What is this trying to say? Am I ‘a menace’ to society because I have cancer?” Others agreed that this adjective to describe cancer had the effect of being a very “blaming” sentence on individuals living with cancer.
13. Ultimately, the narrative about cancer that introduced the whole consultation, in one person’s words, “makes cancer a dirty word”.

### The experience of diagnosis needs improvement

14. Some individuals we spoke to had gone to their GP because they were concerned about lumps they had found when examining themselves. In each situation, they had been told by their GP that the lumps were not cancer but “if you are worried, come back”. A few people said when they did go back, their GP requested a blood test. However, it generally took two weeks for those blood tests to be done and another two weeks to get the results. In three situations, during that time, individuals’ lumps had spread.
15. One employee said, “Even the slightest change in the body should start the [referral] process”. Another recalled that the way they examine themselves when looking for lumps was quite different to how their GP of the opposite sex examined them. This had meant the medical professional could not feel lumps where the individual could. This individual was therefore sent away because the GP could not feel any lumps. In the individual’s words, “They missed the opportunity to refer me. By the time I went back [the lumps] had spread”. This individual was also dismissed by their GP partly due to their age, as they were told “You are too young” to have this type of cancer.<sup>2</sup>

### The NHS lacks resources and does not have time

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<sup>2</sup> This section is not intended to undermine or criticise the GP profession or individual GPs at all. Individuals we spoke to recognised GPs are overwhelmed, significantly under-resourced, and were working with processes that were themselves lengthy, disjointed, and that relied on other outsourced services or procedures.

16. The 'privilege' of the region where individuals lived generally had an impact on a few areas of diagnosis, care, and access to treatment funding. One person said, "I was lucky to get cancer where I did, geographically... it was outstanding". In other areas of the UK, people commented that they needed "a loud voice" and "energy" to "chase appointments and results", particularly where "communication and paperwork isn't great" and because it is not often clear if people will be contacted about their results or if they need to follow up themselves. Cancer diagnosis and treatment must not be a postcode lottery and dependent on geography and the funding/approach of different NHS Trusts.
17. A common recollection among individuals we spoke to was that the NHS lacks resources, staff are overworked, and this then has an impact on the care people receive. "The NHS doesn't have time" was a common sentence during the conversations we had. The difference between NHS and services outsourced to charities (Macmillan and Maggie's came up a lot in discussions) was clear. Someone recalled that their NHS consultant would ask, "You ok?", whereas the Macmillan nurse would ask a more open question: "How are you coping?". Another recollection was that, in the NHS, appointments were sometimes "two minutes" long, and other times, they were twenty minutes long. Someone recalled how the length of time you had with an oncologist became the 'marker' for "how well you're doing". They continued, "If you're in there for two minutes, you're having a good day. If you are in there for twenty, well, it is not a good day".
18. The significant lack of resources in the NHS came up in many conversations. One individual recalled they received a letter about their NHS referral which said there was a "national shortage of staff" in the NHS, and their appointment may therefore have to take place across a "few separate appointments" instead of just this one upcoming appointment. When this individual eventually got an appointment, they felt "told off" by the clinician as they were told "Why didn't you come sooner?", even though it was due to delayed appointments and the aforementioned "national staff shortage" that caused the delay for this person. During this appointment, the clinician left the room after saying they were going to refer the individual for more tests. The individual asked the nurse who was still in the room, "Should I be worried?", and the nurse replied "Well, the doctor is worried". This individual described their experience of NHS staff in similar ways to other people living with cancer that we spoke to: NHS staff were "busy, rushed, and their bedside manner was 'off'". After this appointment this individual experienced more delays, which caused "extreme anxiety". She therefore contacted her employers' private health insurer, and she was seen "within days".

### **The pivotal role of employers' private health insurance**

19. Employees we spoke to who are working in the private sector, and who have access to private health insurance as part of their benefits package, said their

employers' private health insurance gave them quicker access to treatment in an environment that "had time" and was "well resourced". This was in comparison to NHS "scans and waiting times for results causing anxiety and are lengthy". Being able to combine private health insurance services and NHS care appeared to differ by region, though. Some NHS trusts allowed individuals to use their private health cover for some parts of their cancer care, and the NHS for other parts. In other regions, if an individual used some of their private health cover, their NHS trust would not let them use any of the NHS for treatment.

20. In addition, employers' private health insurance was rarely enough to cover individuals' cancer medication for the length of time they needed it. Individuals described time spent trying to confirm with the NHS that it would pick up the cost of medication when their employers' private health cover cap ran out (there is usually a cap, most commonly four years of cancer medication is provided). This was not always possible for individuals, and some ended up having to pay tens of thousands of pounds to buy their own cancer medication because of the 'gap' created between their employer's private health insurance policies and the NHS.
21. In comparison to the rushing and lack of time and resource that was evident when being treated in the NHS, people we spoke to said it's not just time in terms of waiting times where the private sector fares better; it is also the time the private sector has for people and the resources they have to provide care and wider support services. In one person's words about the private healthcare they received for their cancer:
  - "I don't care about a nicer sandwich. It's the time they have and the consistency they offer. They even have a support group [for people living with cancer]".

### **Lack of mental health support**

22. Almost everyone we spoke to mentioned the lack of access to mental health support during diagnosis, care, and treatment in the NHS. Referrals for mental health support or counselling are directed out of oncology and into the lengthy, backlogged mental health services referral process. In one person's words, when remembering when they were first told their diagnosis, "You can't be told news like that and be sent home".
23. People with access to an employer's private health insurance could get counselling via that policy, or their employers Employee Assistance Programme had a dedicated cancer counselling service.

### **Working flexibly, not just flexible working, is crucial**

24. Some people said they felt they should have left work to recover from lengthy and recurring treatment phrases properly, but they felt they needed to keep working to get access to the private health insurance that gave them speedy access to

appointments and treatment, plus their employer's Group Income Protection which relieved financial pressure. In one person's words:

- "If you have cancer, you have to keep working to access the thing that keeps you alive. The Government's narrative is if you can work, you can work... they don't understand there is an impact on your personal life and health if you keep working sometimes. People push themselves through".

25. Others said similar words. They felt they wanted to work even though they knew this was not the best thing for them:

- "I wanted to work... That was not the wisest thing because of infection risk, but it helped."

26. Generally, during treatment or when recovering from the most recent bout of treatment, people generally agreed the most helpful response from an employer was when they were allowed to **work more when they were well and less when they were unwell**. There was recognition though that this is "more doable" with the type of job they occupied and would be less reasonable with some other types of job. The role of flexible working reform and Good Work is pivotal here. Employers we work with are looking at reforming how they consider the future of job design in their organisations. Some employers have told us they will in future purposefully design jobs and workforce capacity with the assumption that people **will** need extended periods of leave while fulfilling jobs in their organisations, whether this is due to ill-health, acquired disability, or caring (for example).

27. Being well enough to work was not always a 'linear' experience for people we spoke to. Some people came out of work and into the benefits system for a period while they recover, and then went back into work again. One individual took ill health retirement but could (and wanted to) work again six years later. They found a suitable job and re-started a career where they still work now.

### Occupational health is helpful when used appropriately

28. Some people said if employers do not know what to do and the employee does not yet know the 'future' (of treatment or their condition) themselves, employers tend to refer to Occupational Health (OH). Someone described this as "You go through the motion of occupational health because that's the policy, but it's not helpful [at this stage]".

29. Many were referred to OH before they or their medical teams had a prognosis or knew how they would respond to treatment. Some people said that, depending on the stage they were at with their treatment or diagnosis, the best person to speak to about information was not always OH or their GP, but their oncology consultant. However, responding to questions and requests for fitness to work is not currently often part of an oncologists' 'billable hours' duties. This often means requests for information from employers and OH teams are rarely replied to.



30. While OH has a vital role in workplace health, some employees spoke about other interventions that they felt they needed when learning to live with “treatment fatigue” or re-learning skills now that their body has different limitations and capabilities, particularly before considering a return to work again. Some could not return to the job they were doing, and others needed to work with rehabilitation services who could support them to build up stamina to do work each day and regain skills that were ‘put in the background’ during a lengthy phase of being off work. The role of **access to vocational rehabilitation interventions and occupational therapy services** to help facilitate a comfortable and sustainable return to work **is currently missing**. This is urgent, not just for cancer care, but for very many other acquired injuries and conditions.

### Carers and partners are ‘forgotten’

31. A common recollection was that all the support currently tended to be for the individual with the diagnosis, and partners or carers were usually “left in the cold”. People recalled their partners and carers being unwell because they were so “run down”; they were referred to as “the forgotten people”. In some instances, someone had stopped working because of their cancer, and their partner had stopped working as well due to being so run down. This of course had a financial impact on their household.
32. The policy backdrop is BEIS’ plans on carers leave. Five days unpaid leave per year would not have helped anyone I spoke to in their situations – mentally, physically, or financially. The thing that helped was (a) having a job where work could be done as and when the person (either the person with cancer or the partner or carer) felt they could work, and (b) having a line manager who allowed the employer to work in this way.
33. Flexible working reform therefore needs to advocate working flexibly in the most flexible, widest, agile, non-structured way as reasonably possible, not just changing the way statutory request can be made. Carers and partners do not have time to go through the current ‘admin heavy’ statutory process to request flexible working. We would like to see flexible working genuinely becoming the default, with the onus on employers to prove if it is not possible (if that is the case) in individuals’ situations, rather than employees having to prove that it is, rather than the other way round. The National Disability Strategy implied that the consultation would be a move toward this.

### A note on benefits

34. Almost every individual mentioned they had to rely on benefits at some point during their treatment or recovery, or they had applied for Personal Independence Payments (PIP).

35. The benefits system must ensure that people who need it can access it. For some, they were advised to apply for benefits – ESA or PIP – at a time when they were unwell or at their ‘weakest’. During these periods, the benefits system is tiring, lengthy, and feels difficult to progress through. One individual commented that help to apply for benefits was only through Maggie’s, where they had time to explain the process and the type of financial support that the benefits process might be able to offer people living with cancer.

### **Life during NED and/or beyond treatment**

36. The impact of ‘comorbidities’ came up a lot in our discussions. This has an impact on ‘joined up’ NHS services and employers supporting individuals with adjustments in the workplace. For example, some people we spoke to said that, although they had been told there is No Evidence of Disease (NED) in relation to cancer, they had acquired other health conditions as a result of their cancer or treatment, such as high blood pressure. This meant that, for some, they were being seen by multiple different clinics across multiple hospitals, and each time they had to tell each clinic that they have or have had cancer.

37. Some people had been disabled by their cancer or cancer treatment (for example, in terms of physical mobility, mental health, or brain injury, but because the ‘primary’ concern was the cancer itself, oncology services was the dominant clinic organising their care. Another common theme came up here: people who experience cognitive and social disabilities caused by their cancer and cancer treatment lacked social interaction, needed daily care to carry out ‘daily living activities’ (such as taking medication or encouragement to get dressed and eat), and had very little access to support services or respite for the person looking after them (usually a parent).

38. We were also concerned by the lack of questions in the consultation about life beyond treatment. There was no attempt to ask about what people living with cancer or living close to some with cancer wants for their life as they live with or beyond cancer or treatment. People had rarely had discussions with their clinical teams about what they wanted to do in their lives. In one person’s words: “There is not a lot of understanding about what people’s wishes are”. Without knowing this, we cannot be clear about the health outcomes we are trying to achieve.

### **Policy recommendations**

39. Ultimately, the future of cancer care needs a cross-policy, whole-life focus from health, social care, welfare and benefits, employment policy, BEIS, and employers. It is not enough for DHSC to be holding this consultation in isolation or without other ministerial departments having policy input into what their role in the next ten years of cancer care is. A cross-policy response must include paying attention to the following:



- a. The **language and narrative** around this strategy and about cancer in public health policy should be considerably rethought. The “war” and “battle” analogies, terms such as “menace” and “threat” and considering cancer with the backdrop of Covid is unhelpful and inappropriate, both for policy positioning and for individuals living with cancer and people close to them.
- b. Flexible working and carers leave policy are both being worked on in BEIS at the moment. Policy development on these two issues is central to a cancer strategy of the next ten years. **BEIS should be involved in the strategy** and should be informing elements of support for both people with cancer or who have had cancer, and for people living close to someone with cancer, particularly in light of the Government’s ambition to keep people in work wherever possible and appropriate.
- c. BEIS’ **Good Work strategy** must also account for working flexibly, not just flexible working. This must facilitate and advocate working structures where people with conditions and carers can work more when they are well and less when they are unwell.
- d. **Fit notes** are rarely completed by GPs fully or accurately, and many employers tell us that they write to medical teams requesting information that will help them make more informed decisions about the type of work employees can do and what a return to work should look like for individuals. Employers tell us they rarely hear back from medical professionals. Responding to employers and working with OH professionals should be part of GPs and medical professionals’ billable time; currently it is not, and this often means these tasks are not carried out.
- e. The ten-year strategy needs to ensure that holistic, cross-policy informed cancer care for both the individual with cancer and their loved ones around them **does not rely on the private sector or charities** to be delivered. This creates a fragmented process, and it also makes parts of cancer treatment confusing when elements of the process come in and out of the NHS. In one individual’s words, “If we want to provide better life choices [for people with cancer], we need investment”.
- f. Mental health support for people with cancer should be an integral part of cancer care, not a process which refers people outside of cancer care and into the mental health services process.
- g. An **overreliance on OH** is unhelpful. It means that for those who could not return to work, they were left with no one to help them regain work, home, or personal care skills which could possibly have enabled them to return to work in another job or a different type of role. OH is important; but people tell us that other, different types of interventions are needed before they are ready to see OH. The NHS therefore needs to invest in greater access to vocational rehabilitation, occupational therapies, and other rehabilitation

services that help people learn and re-gain skills for the next stage of their lives after hospital or treatment, whether this is living at home independently, returning to education, or returning to work. Examples of what rehabilitation services and therapies should seek to address are skills such as coping with fatigue, pain management, regaining muscle and dexterity stamina, learning to type, or being taught how to use other assistive technologies.

- h. We also noted a huge difference in access to speedy support (emotional, health and financial) **depending on the sector individuals worked in**. Each individual working in the private sector who we spoke to had access to private health insurance cover; those working for the Government and other public sector organisations did not. This meant public sector workers and civil servants (and those working for private sector organisations who do not offer this benefit, or whose roles do not “qualify”) had to rely on NHS services for their cancer care which, in turn, meant access to treatment for them was generally longer, they had greater risk of poorer prognosis due to these delays, and they were at greater risk of financial disadvantage by the lack of pay protection options, such as Group Income Protection or enhanced sick pay provided by the employer. For some working in the public sector, financial worries meant they returned to work sooner than they should have. In one person’s words: “There is the pressure of who is going to pay the bills. When you take out a mortgage, you don’t expect to get cancer”. We therefore want the Government to consider this point and act to ensure its own people are not disadvantaged by overwhelmed and under-resourced public health services.
- i. Everyone should be able to get high quality, timely and joined-up support on the NHS and not have to rely on private sector or charity provision for support. This is very important both ethically and practically, when you consider that public sector and voluntary sector workers and indeed many private sector employers are very unlikely to have access to private health that is funded by their employer. However, we recognise that the NHS is in crisis and that there is a severe lack of funding and capacity for many support services. Therefore, in the interim, the NHS should work with the private sector to ‘join up the dots’ where there is not funding available and ensure that how this works is not dependent on geography (a ‘postcode lottery’). Individuals who are able to use private funding and support to supplement or ‘join the dots’ in NHS provision must not be, effectively, “penalised” for this and should still be able to access NHS support.
- j. More policy attention needs to be given to understanding **Stage 4 cancer**, which is currently most often seen as ‘end of life’. Most research funding and policy attention is given to diagnosis and ‘earlier stages’ of cancer. However, a few people we spoke to are living and working with stage 4 cancer, and

stage 4 generally felt “forgotten” inters of resourcing, funding, and research attention.

- k. The provision of post-treatment support for people living with the impact of cancer and treatment and those close to them should be actively considered. This includes access to ongoing social care support for individuals living with the effects of cancer or treatment and access to day centres to provide parents and carers with respite each week. This prevents parents and carers becoming overwhelmed and ‘burning out’ and it allows them to work, and it also provides structure, and the opportunity to improve cognitive skills and social interaction for individuals living with the long-term impact of cancer or cancer treatment.

Ends.