Written evidence submitted by Cancer52 (ECS0008)

1. Workforce

No comment

2. Diagnostics - Faster Diagnosis Standard and Earlier Diagnosis Ambition

Section 1

1. **Does the commitment have a clear and fixed deadline for implementation?**

Yes, both have clear and fixed deadlines (2028).

2. **Are there any mitigating factors or conflicting policy decisions that may have led to the commitment being met or not being on track to be met?**

The Covid-19 pandemic affected delivery of measures to meet the early diagnosis target (for example some diagnostic services halted during the first wave) as well as hindered people from coming forward to be diagnosed. This means there will be some people who have cancer who will present with later stage cancer than they would otherwise have done.

We commend work by NHS England to encourage people to come forward for diagnosis and to raise awareness of the symptoms of cancer through the HelpUsHelpYou campaigns. We are also encouraged by NHSEngland plans which focus on improving earlier diagnosis through a number of measures. Cancer52 and its members are supporting this work.

However, staging data for 2020 and 2021 is still not available. 2019 data was only published in December 2021. This means we are unable at this time to properly understand the impact of the pandemic on the stage of diagnosis. Staging data must be published in a more timely and swift manner to allow the NHS to understand such impacts and react accordingly.

The faster diagnosis standard is in place but figures show that this standard is not yet being achieved.[1]

3. **To what extent has the NHS's Covid-1 response affected progress on targets?**

See above.

[1] https://www.england.nhs.uk/statistics/statistical-work-areas/cancer-waiting-times/quarterly-prov-cwt/2021-22-quarterly-provider-based-cancer-waiting-times-statistics/provider-based-cancer-waiting-times-for-q2-2021-22-provisional/

4. **Does data show achievement against the target?**

Staging data for 2019 shows that 54.5% (one year rolling average) of cancers were diagnosed at stage 1 or stage 2.[2] This is 20.5% behind the target. There has not been significant movement on this figure leading up to 2019. A significant effort is required if a 20.5% uplift is to be achieved by 2028. Cancer52 and its members are working with NHS England to help identify innovations and opportunities for speedier implementation that might improve earlier diagnosis.

Section 2

1. **Was any financial commitment a new resource stream?**

Financial commitments relating to these two ambitions are not readily available in the public domain. It would be helpful if funding commitments were more transparent. It is unclear how funding decisions are made and whether they are sufficient.

2. **Who was involved in funding arrangements?**

It is unclear how funding decisions are made and whether they are sufficient.

3. **What factors were considered when funding arrangements were being determined?**

It is unclear how funding decisions are made and whether they are sufficient.

4. **Do healthcare stakeholders view the funding as sufficient?**

The funding amount is unclear so it is not possible to comment on whether funding is sufficient or not.

5. **What factors were considered when funding arrangements were being determined?**

It is unclear how funding decisions are made.

Section 3

1. **What was the impact on equality of outcome for different groups?**

This is not clear as data is not available. We would be keen for this data to be collected and published including the disaggregation of data for different cancer types so that it is possible to understand progress made for different cancers. This is especially important as we know that some rare and less common cancers are diagnosed much later than others (for example pancreatic) and will require a much greater shift in order to raise the proportion of people diagnosed at stage 1 or 2 to 75%. Aggregating cancer data can lead to the masking of poorly performing cancers.

2. **Has there been a meaningful improvement in measurable outcomes, reasonably attributable to the commitment?**

It is not measured in detail.

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[2] https://www.cancerdata.nhs.uk/stage_at_diagnosis

3. **Has the commitment been met/is it on track to be met equally across England or are there regional variations?**

Not known.

Section 4

1. **Is the commitment likely to achieve meaningful improvement for service users, healthcare staff and or the healthcare system as a whole?**

Yes. Earlier diagnosis is known to improve outcomes for many cancers. However, earlier diagnosis must be supported by access to treatment if survival outcomes are to be improved.

2. **Is the commitment specific enough?**

Yes. However, not all cancers can be staged (eg certain blood cancers) and collection of staging is poor for many cancers. Proxy measures must be created to allow improvements in earlier diagnosis to be tracked for those cancers that can not be staged. There must be a concerted effort to improve the collection of stage data.

3. **Has the commitment had any unintended consequences?**

Not as far as we are aware. However, early diagnosis is only of benefit if a person with cancer is able to be treated. Greater investment in cancer research (especially for rare and less common cancers) is needed if we are to see an improvement in survival outcomes.

4. **Is the target contained in the commitment an effective measure of policy success?**

Yes.

5. **Was the commitment addressing an identified need and relevant to the problem?**

Yes.

3. Living well with cancer - access to personalised care

Section 1

1. **Does the commitment have a clear and fixed deadline for implementation?**

Yes, there are clear and fixed deadlines (2021).

2. **Are there any mitigating factors or conflicting policy decisions that may have led to the commitment being met or not being on track to be met?**

The commitment has shifted to March 2022 for people with cancer other than breast, colorectal and prostate, when it was originally 2021. [3] [4] This decision was taken before the Covid-19 pandemic.[5] It is not

clear why the roll out of personalised care for people with lung cancer or rare and less common cancers was delayed.

3. **To what extent has the NHS's Covid-1 response affected progress on targets?**

The Covid-19 pandemic has affected delivery of personalised care. The NHS Cancer Programme Team in NHSEngland focused on responding to the pandemic as well as the immediate task of continuing cancer care. Providers and cancer alliances will also not have been able to focus on the delivery of personalised care. In our survey of people with rare and less common cancers undertaken in the summer of 2021, one in five told us that they had found it difficult to access support during the pandemic[6].

4. **How has this commitment been interpreted in practice at trust/patient level?**

Cancer52 does not have sufficient evidence to answer this question.

5. **Does data show achievement against the target?**

There is no reporting of data for this target. Reporting by NHS England suggests that this target has not been met.

Section 2

1. **Were specific funding arrangements made to support the implementation of the commitment?**

Financial commitments relating to this ambition are not readily available in the public domain. It would be helpful if funding commitments were more transparent. It is unclear how funding decisions are made and whether they are sufficient.

2. **Which relevant organisations responsible for the patients' care was involved in determining the funding arrangements?**

It is unclear how funding decisions are made.

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[3] https://www.england.nhs.uk/cancer/living/ *"The NHS Long Term Plan for Cancer states that "where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support. Cancer Alliances are working with trusts and primary care to offer these personalised care interventions to people with breast, colorectal and prostate cancer and for other cancers by March 2022. We estimate that around 80% of cancer multidisciplinary teams (MDTs) are now offering Personalised Care and Support Planning"*

[4] https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf. It contains the commitment for personalised care for all people with cancer by 2021.

[5] Cancer52, Getting a Better Deal for Rare and Less Common Cancers , 2020. https://docs.wixstatic.com/ugd/e22361_3419733e6074483aa7db8ddc841bd469.pdf Published before the pandemic, this notes that the commitment to deliver personalised care by 2021 has already slipped to 2022 for people with rare and less common cancers.

[6] https://www.cancer52.org.uk/single-post/2020/08/06/cancer52-publishes-england-results-of-its-patient-survey

3. **Do healthcare stakeholders view the funding as sufficient?**

The funding amount is unclear so it is not possible to comment on whether funding is sufficient or not.

4. **Was any financial commitment a new resource stream?**

This is unclear.

5. **What factors were considered when funding arrangements were being determined?**

Decision making in determining funding is not clear.

6. **Which relevant organisations/staff groups responsible for the patients' care made commissioning decisions?**

It is understood that cancer alliances have been involved in commissioning personalised care.

Section 3

1. **What was the impact on equality of outcome for different groups?**

Since the roll out of personalised care has been delayed for people with lung cancer and people with rare and less common cancers, it is likely that this has affected equality of outcomes. 47% of people who are diagnosed with cancer every year are diagnosed with a rare or less common cancer.

2. **Has this commitment led to improvement in the quality of life for service users/cancer patients? With respect to commitments which have yet to be completed, is there evidence that the quality of life of service users will improve as a result?**

A quality of life survey of people with cancer in England has recently begun but results are not yet available, so it is not possible to tell if this commitment has led to improvements yet. The quality of life survey is not appropriate for all cancers (for example those with a short prognosis) and an alternative will need to be found to measure the impact of improving care for these people.

3. **Was or is the commitment likely to achieve meaningful improvement for service users, healthcare staff and/or the healthcare system as a whole?**

People with rare and less common cancer can find it difficult to find information and support about their condition.[7] The rare nature of some cancers means there are fewer specialists and other people with the cancer with whom they can share support and information. Improving personalised care for these people so that they have information and support relevant to their condition and their needs will, we believe, improve both experience of care and quality of life. However, this is likely to require time and investment.

Section 4

[7] https://www.cancer52.org.uk/single-post/2019/07/10/-getting-a-better-deal-for-people-with-rare-and-less-common-cancers-what-we-can-learn-fro

1. **Is the commitment wide enough in scope?**
   Yes

2. **Is the commitment specific enough?**

Yes

3. **Was the level of the ambition as expressed by the commitment reasonable?**

Yes

4. **Is the target contained in the commitment an effective measure of policy success?**

Yes

5. **Was the commitment addressing an identified need and relevant to the problem?**

Yes - see previous.

6. **Did the system have the relevant tools to support the change?**

The fact that the deadline was delayed suggests not.

4. Innovation and technology

No comment.

About Cancer52

Cancer52 is a charity which represents over 100 charities working to support the 150,000 people diagnosed with rare and less common cancers every year. Cancer52 members represent over £220 million of charitable spend and range in size from tiny, volunteer run charities with incomes of only thousands, to large million-pound organisations, which invest heavily in research and support services.

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