

Written evidence submitted by Prostate Cancer (ESC0017)

Prostate Cancer UK Submission

Please note, the Health & Social Care Committee's Planning Grid has been used to structure and frame this response. As such the questions suggested have been included across each commitment and addressed where appropriate or possible. Additional points or questions have been introduced to ensure relevant details are covered.

Organisation

Prostate Cancer UK represents and advocates for the interests of those affected by prostate cancer, including those at risk of the disease, those suffering from it, and their families and loved ones. This consultation is a key opportunity to detail our assessment of the Government's commitments to cancer services and the causes of their being met or failed as they relate to prostate cancer. We also take this opportunity to highlight areas for change and improvement that would benefit those groups mentioned above.

Key Recommendations

- A centrally agreed table of Government commitments and strategies are held and published by the Department of Health & Social Care, the NHS, the Treasury and other key stakeholders. Targets and objectives are listed out and marked up when superseded or de-prioritised with the cause of the change explained.
- A national 'designated body' to regularly publish workforce projections.
- A duty on the Secretary of State for Health and Social Care to respond to workforce projections with a plan for what government will do.
- Funding for research into developing new prostate cancer screening programmes
- A shift away from symptoms awareness, which is reflective of later stage diagnosis to instead focussing on raising the awareness of a man's risk to prostate cancer, within primary care as well as with the public.
- A focus on reducing the number of late stage incurable diagnoses, to the more curable stages of diagnosis.
- A standardisation of national data collection that includes equipment and health inequalities.
- Government should provide information on the disbursement of prior spending promises including £70m on research into prostate cancer and £200m on diagnostic imaging equipment.
- Include molecular radiotherapy (a.k.a. radioligand therapy) in commitments on access to the latest radiotherapy technologies, and ensure readiness for the rollout of molecular radiotherapy technologies.

- Commit to the expansion of diagnostic imaging capacity called for in the Richards Review and the replacement of machines over ten years old.
- More needs to be done on personalised care to achieve the commitment made by the Government. There are likely to be very good examples of personalised care happening across England that can be utilised as a learning exercise. The Government should look to these models, understand the challenges and solutions and use that information to inform future commitments and investment in this area of cancer care to support NHS Trusts that are struggling.

1. Workforce

The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?
Was the commitment effectively funded (or resourced)?
Did the commitment achieve a positive impact for patients?
Was it an appropriate commitment?
Summary Response:
<p>Within the Cancer Workforce plan seven outcomes to be met by 2021 are clearly mapped out¹ according to the Five Year Forward View (FYFV), a nationally funded programme of transformation for the NHS, these were:</p> <ol style="list-style-type: none">1. Fewer people getting preventable cancers (fall in age-standardised incidence)2. More people surviving for longer after diagnosis (75% for at least one year)3. 62% of people diagnosed early stage4. More people having a positive experience of care and support5. More people having a better long-term quality of life6. Reduce unwarranted variation in outcomes (geographic & social)7. Meet cancer waiting time targets <p>Seven initial priority workforce areas were identified where national action is required to support the delivery of the FYFV² objectives by 2021, that of: Histopathology and health care scientists, Gastroenterology, Clinical Radiology, Diagnostic Radiography, Medical and Clinical Oncology, Therapeutic Radiography and Nursing (CNS).</p> <p>Actions to increase the net supply of staff and skills in the above initial priority workforce areas were outlined as:</p> <p>(1) Immediate/ongoing actions to make better use of existing supply (registered staff) through better deployment, retention, time to care, Return to Practice etc. (immediate and ongoing) with everyone supported to work at the top of their skills set.</p> <p>(2) Net expansion of skilled staff over 1-3 years to support growth and transformation, through providing more, faster and accessible Post Graduate training courses and other in-post learning and development opportunities at scale for clinicians to carry out new procedures or take on new roles, such as endoscopies, Advanced Clinical Practitioner (ACP) or CNSs (within one year)</p> <p>(3) Net expansion of skilled staff over 3-15 years to support growth and transformation – it takes three years to train a Registered Nurse but the majority go on to undertake a Masters and many undertake a Doctorate study which can equate to a Medical Consultant timescale, which takes between 12-15 years to train.</p> <p>The three class of actions outlined are all set within distinct time frames within an overall set of objectives to be met by 2021. Issues and actions are then identified against each of the seven priority workforce areas. For instance, regarding Cancer Clinical Nurse Specialists:</p>

“HEE will work with the Royal College of Nursing (RCN), Cancer Alliances, Charities, Nursing and Midwifery Council and other ALBs, building on existing competency frameworks and using any learning from the Macmillan Specialist Adult Cancer Nurse Census 2017 and agree the existing competences required of CNSs.”³

To our knowledge this has not occurred for Urological CNSs.

A phase 1 update was published by HEE in 2019⁴. A Phase 2 update was deemed “out of date” and incorporated into new plans^{5, 6, 7} following a new five-year funding settlement announced by Prime Minister May in 2018. To unlock this funding, national NHS bodies were asked to develop a Long-Term Plan (LTP) for the service.^{8, 6}

HEE described these changes and their effects as: “The world has moved on since we produced the working paper on phase 2, much of the analysis is now out of date, but many of the questions it raises about long-term demand and supply and the impact of digital technologies remain pertinent.”⁵

In the last five years it seems as if three separate forces developed, occasionally met and diverged to affect cancer workforce planning within the NHS. Those of NHS or independent workforce strategies, government funding settlements and ministerial requests. The interplay of those forces caused plans to change, adjust and created an abstruse pathway to the point of determining what NHS Workforce plans could reasonably be aspired to, let alone what commitments were still relevant.

To ascertain then whether or not the then Government commitment to expand the capacity and skills of the cancer workforce by 2021 (from 2017) was successful a blunt methodology is suggested. That of, net workforce figures in 2017 compared to the latest available data in the key professions listed above and the provision of training programmes and development opportunities for existing staff in those professions compared between 2017 and the latest available data.

From the perspective of prostate cancer care and in line with the priority workforce areas, at this point it would be valuable to focus on Clinical Nurse Specialists, as they are a critical resource within the prostate cancer pathway and to the functioning of all the other professions highlighted.

However, given the lack of centralised and independent workforce data for the NHS this is almost impossible without a significant amount of research and hypothecation. Added to which there is no agreed comprehensive structure to nursing careers or education. According to the NHS’ own Getting it Right First Time report on Urology:

“Specialist nurses are crucial providers of urology care, particularly in outpatients’ settings, and yet, at present, there is little or no evidence of a systematic, proactive approach to the recruitment, training, development and retention of urology specialist nurses. There is no standard training curriculum for urology specialist nurses; training is typically provided in an ad hoc manner.”⁸

Bearing this in mind then, and even if the data were available, what those findings would not answer is whether or not overall workforce figures for urology CNSs meet the key metrics of meeting demand and improving patient outcomes.

If attained, the above metrics might demonstrate a plausible way of arguing that a government commitment made in 2017 was met despite it being superseded in 2018 and that latter

commitment having possibly failed. Whereby, in 2019 the LTP committed to a 25 per cent increase in nurse undergraduate placements, funding a 25 per cent increase in clinical nursing placements from 2019/20 and an increase of up to 50 per cent from 2020/21.⁹

To evaluate government commitments relating to a subject as expansive as the NHS workforce, it is recommended that a centrally agreed table of commitments and strategies are held and published by the Department of Health & Social Care, the NHS, the Treasury and other key stakeholders. Targets and objectives are listed out and marked up when superseded or de-prioritised with the cause of the change explained. As currently there is little transparency and accountability this would help improve general understanding, and the agreed metrics of success or failure, for stakeholders and the general-public.

As stated elsewhere, and by members of this committee, in order to evaluate whether workforce commitments have been met, we would call for legal duties to be introduced to ensure transparency and accountability on whether we are training enough people now to meet future demand.

As outlined by the Royal College of Physicians¹⁰ this would entail specifically:

- A national 'designated body' to regularly publish workforce projections.
- A duty on the secretary of state for health and social care to respond to projections with a plan for what government will do.

Without commitments such as these any statements regarding NHS workforce planning remain obfuscated and subject to misinterpretation.

References:

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10. The Royal College of Physicians. Strengthening workforce planning in the health and care bill: coalition principles. 2021. <https://www.rcplondon.ac.uk/guidelines-policy/strengthening-workforce-planning-health-and-care-bill-coalition-principles>

2. Diagnostics

A faster diagnosis standard from 2020 to ensure most patients receive a definitive diagnosis or ruling out of cancer within 28 days of referral from GP or from screening

By 2028 the proportion of cancers diagnosed at stages 1 and 2 will rise from around 50% now to 75% of cancer patients

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

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

The NHS Long Term plan, launched in January 2019, stipulated a standard that will ensure “patients will be diagnosed or have cancer ruled out within 28 days of being referred urgently by their GP for suspected cancer.”¹

The Long Term Plan also set an ambition that, by 2028, the proportion of cancers diagnosed at stages 1 and 2 will rise from 50% to 75% of cancer patients.

To achieve the goal set for 2028 would mean in real terms, 55,000 more people each year surviving their cancer for at least five years after diagnosis.

Prostate Cancer UK are concerned that for prostate cancer patients, if the focus shifts to increasing stage 1 and 2 diagnosis, it may result in more men being diagnosed with clinically insignificant cancers, which will not cause them any harm and instead would cause worry and anxiety. Prostate Cancer UK state that for improving outcomes for men with prostate cancer, the aim should be to reduce the number of late-stage diagnoses that are identified when they are not curable.

2. Are there any *mitigating factors or conflicting policy decisions* that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?

The PSA test is the first test that measures the prostate specific antigen (PSA) levels of a person with a prostate and, depending on the result, informs what action is taken. The National Screening Committee has consistently recommended against screening for prostate cancer due to the inadequate specificity and sensitivity of PSA testing. The test results in a high number of false positives, a large number of clinically insignificant cancers being diagnosed and many clinically significant cancers being missed. Although the pathway has improved in recent years with the introduction of pre-biopsy MRI and more consistent use of active surveillance, recent evidence reviews suggest that the 20% cause-specific mortality reduction seen in trials that use PSA to screen for prostate cancer comes at too high a cost in terms of overall harm and detriment to quality of life. This is a mitigating factor when considering a national screening programme.

To address this, we need to improve the diagnostic pathway and this will require large scale trials of promising new approaches to prostate cancer screening. Prostate Cancer UK is committed to funding those trials but will need support from funders including MRC and NIHR to fully fund and support those trials. We will be engaging potential funding partners over the next 12 months and hope that this review will highlight the importance of research in this area to relevant government departments and agencies.

We have not seen the roll out of a risk stratified screening approach, based on risk factors like the

lung screening pilots that are running in different parts of the country. Albeit, some Cancer Alliances are piloting a number of different approaches to adopting a risk stratified approach to screening by targeting men who are Black African, Caribbean, of a certain age and in South East London Alliance, have a family history of prostate cancer. However, more evidence is needed to understand how the risk of prostate cancer varies by specific characteristics.

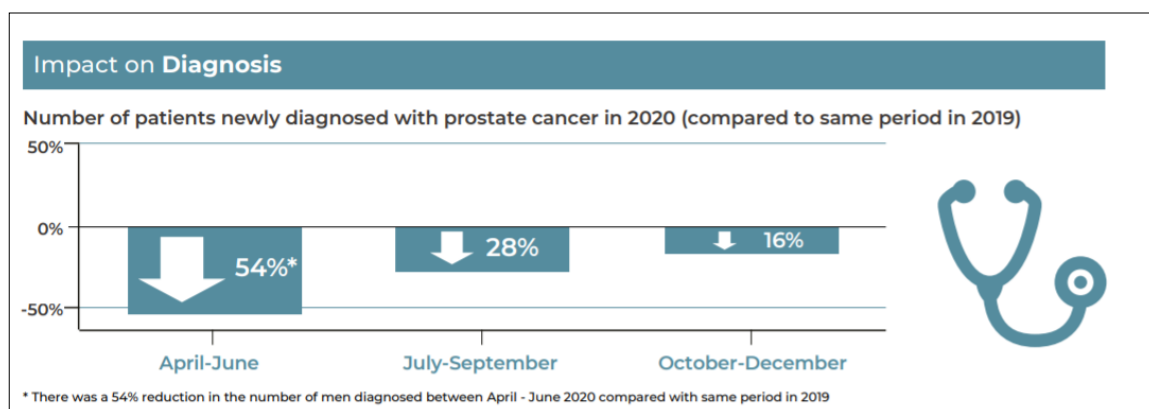
Although the PCRMP² identifies family history as being a risk factor for prostate cancer, the NICE³ prostate cancer referral guidance does not allow men to be referred into secondary care for further tests based upon having a family history of prostate cancer. Prostate Cancer UK are not aware of there being any targeted individual testing of family members of prostate cancer patients.

3. To what extent has the NHS's Covid-19 response affected progress on targets?

During the pandemic, there was a drop in urgent referrals⁴, with around 55,000 fewer referrals for urological cancers in England for April 2020 – April 2021 compared to the same period the previous year.

This has resulted in fewer men starting their first treatment for prostate cancer.

The below table provided by the National Prostate Cancer Audit⁵ demonstrates the drop in the number of men diagnosed in 2020 to those in 2019 and how this trend continued throughout the year, albeit reduced.



Prostate Cancer UK know that COVID-19 has also caused a drop in stage 1, 2, and 3 diagnoses but that stage 4 diagnoses remain as high as during the pre-pandemic period.⁶

Prostate Cancer UK are highly concerned that this drop in staging diagnosis will result in mortality and that 'too late' diagnoses in the advanced stages will be on the rise, as is being seen in Europe. The pandemic has affected access to GPs, diagnosis, treatment and care. This is expected to further contribute to delayed diagnoses, being diagnosed at a later stage and a marked increase in the numbers of avoidable cancer deaths. It should also be noted that this also results in more complex and costly care.

Indeed, this concern has recently been picked up by NHSE and we are working in conjunction with them to raise awareness of prostate cancer by promoting risk messaging and getting men to understand their risk factors of potentially being diagnosed with prostate cancer.

A national awareness raising campaign will launch on 17th February 2022.

There should be a sense of urgency for the Government to ensure that prostate cancer is prioritised at a national level and for urgent investment to be made to save men's lives. Unless we find these missing men quickly, this would translate into thousands being diagnosed late and less cancers being caught whilst they can be cured.

Regional variation

The ONS in their Cancer Registration Statistics of 2016⁷, found that the rate of prostate cancer incidence was generally highest in the south of England and lowest in the north of England; varying from 147.9 per 100,000 in the North East to 192.5 in the South East.

However Prostate Cancer UK expect the missing diagnoses to be spread out broadly throughout the country.

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

Rapid Diagnostic Centres

The rollout of Rapid Diagnostic Centres (RDCs) across England started in 2019 and is designed to speed up diagnosis of cancer and other serious conditions.

Vague, non-specific pathway

RDCs also introduced a new non-specific symptom pathway for patients who display symptoms that could indicate cancer that don't align to specific cancers. The new non-specific pathway complements current cancer diagnostic pathways, as well as providing elements that can be applied to existing pathways.

Improvements in pathway

NHS England published four national best practice timed pathway handbooks in 2018/2019. The pathways aim to support improvements in operational performance and patient experience, as well as providing models to support sustainable improvement.

The four pathways are suspected lung, prostate, colorectal, and oesophago-gastric (OG) cancers. The features of faster timed pathways will be delivered as part of the rapid diagnostic centre programme.

As Integrated Care Systems (ICSs) become embedded post July 2022, we will be able to feed into how the new structure is working and its' effectiveness.

The Office of Health Improvements and Disparity was launched late 2021, with the aim of addressing health inequalities. We are yet to receive clarity and policy on how this will be achieved, how they will work cross departments and with ICSs.

Collaborative work

We are seeing pockets of work nationally, where Cancer Alliances are working in collaboration with local 3rd sector partners to help address health inequalities, develop innovations and models of good practice and will be able to provide examples of this at a future date and time if necessary.

5. Does data show achievement against the target (if applicable)?

Prostate cancer usually develops slowly, so there may be no signs for many years.

The statistics for 2018⁸ demonstrate that approximately:

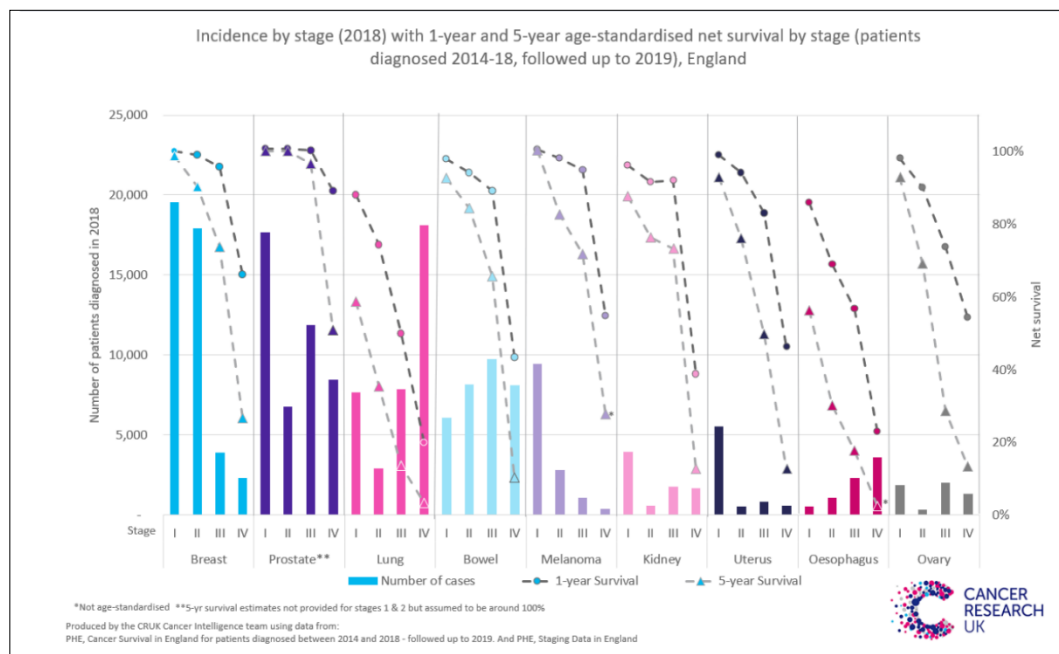
- Stage 1 and Stage 2: 49% of prostate cancers were diagnosed as localised.
- Stage 3: 27% were diagnosed as locally advanced
- Stage 4: 13% as metastatic.
- 11% of cancers were diagnosed at an unknown stage.

If we remove the cancers diagnosed at an unknown stage from the total, the proportion of men diagnosed with metastatic prostate cancer increases from: 13% to approximately 15%.

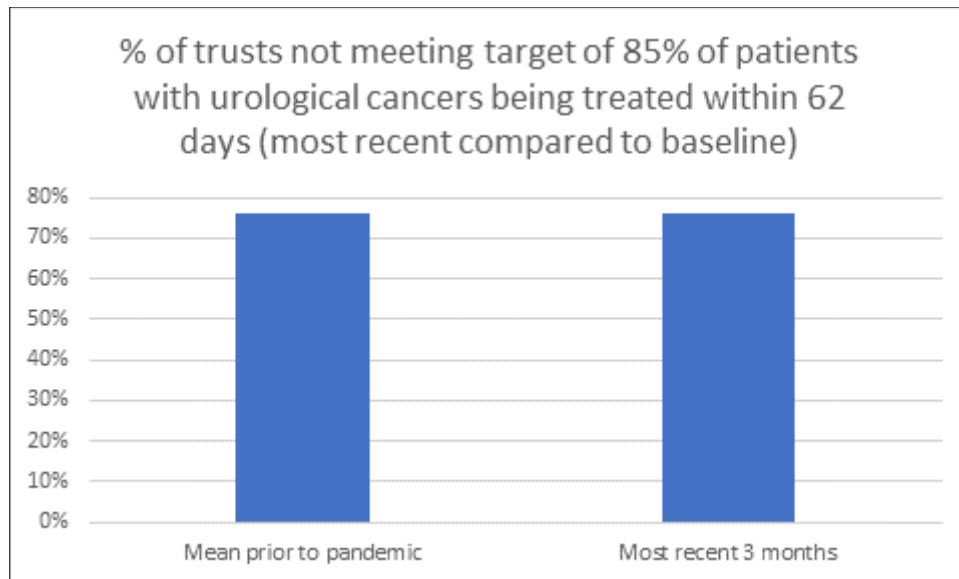
One of the reasons why the proportion of stage IV diagnoses is so high for prostate cancer is because it is rarely symptomatic until already metastasised. This limits the effectiveness of any awareness raising campaign based on “symptoms”.

Prostate Cancer UK are concerned that approximately 40% of men are diagnosed at later stages, where the prognosis is poorer and the chances of cures diminish significantly or disappear entirely. Since we are currently lacking a national screening programme we are unlikely to be able to dramatically drive down that number.

We can also see from the below chart⁹ that men who are diagnosed at stage 4, see their survival rates drop significantly after 1 and 5 years. We need to get more men diagnosed at an earlier stage to help improve outcomes for them, increase their treatment options and chances of survival.



The below graph demonstrates that the percentage of Trusts in England not meeting the target of 85% of patients being treated within 62 days between Feb-April 2021. It is apparent that the figure does not fluctuate and is the same as the monthly average prior to the pandemic (76%). We can infer from this that performance remains poor despite fewer referrals.



Urgent support needs to be provided to the Trusts identified by Prostate Cancer UK, to help improve performance and for them to reach their 62 day targets.

Was the commitment effectively funded (or resourced)?

4. Do healthcare stakeholders view the funding as sufficient?

We are aware that in the recent Spending Review (October 2021) the concept of Community Diagnostic Hubs was initiated. They are currently being developed and when they are rolled out, will take on board some scanning responsibility. We have spoken with a number of Cancer Alliances and the sentiment is that urologists want to keep their patients within their departments vs sending them to CDHCs.

A question was recently tabled for the Department of Health and Social Care¹⁰ about the number of MRI machines and how much money has been invested in the scanners.

The Department of Health and Social care noted that a total of 97 MRI machines were purchased through the £200 million equipment replacement programme to this specification from October 2019 to March 2021. Since the data is not held centrally, Prostate Cancer UK have in the past, submitted FOI requests to gather which Trusts have what machinery.

We note that the information requested on the number of multi-parametric magnetic resonance imaging (mpMRI) capable scanners and the investment in such scanners in the last three years is not held centrally. Thus making it a more onerous task to effectively audit scanners, the age of the scanner, and understand whether it is still fit for purpose etc.

We would recommend that this information is collected centrally, so that there is an increased accountability for machinery and Trusts. It would also become more apparent if the money that has been allocated for diagnostic equipment is adequate, below what is necessary or in fact too much.

Instead, accountability is given to the Trusts, with the Government stating that NHS trusts *are encouraged to adopt the national specification as a minimum requirement when purchasing new MRI equipment*. Since it is not a requirement, only an audit via a FOI request to all the Trusts, will give us this information as to whether scanners are out of date, appropriate, and whether they

provide the quality and improved experience a patient requires.

Health Inequality

There needs to be additional monies provided to address the widening health inequalities that have become more prevalent since the pandemic. Currently, there are no health inequality leads within Cancer Alliances to specifically address the inequity in the balance of access to care and treatment, including diagnoses. We urgently request that the inquiry looks into this matter and provides guidance and an allocated budget so that Cancer Alliances can begin to redress the balance.

Further investment would help improve diagnosis and get it to the current gold standard. However, this will not be enough to reduce the number of men being diagnosed late (Stage IV). Therefore, it's critical that prostate cancer diagnosis research is recognised as a priority and funded appropriately.

Did the commitment achieve a positive impact for patients?

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

It is difficult to answer this question as there is a lack of national and regional data measuring equity of outcome for different groups. Indeed, when looking at ethnicity capture for prostate cancer, 146,905 cases were identified; 37% had no known ethnicity.¹¹

There is good data regarding deprivation, which is summarised below.

- Prostate cancer incidence rates (European age-standardised (AS) rates) in England in males are 17% lower in the most deprived quintile compared with the least (2013-2017).¹¹
- It is estimated that there are around 3,100 fewer cases of prostate cancer each year in England than there would be if every deprivation quintile had the same age-specific crude incidence rates as the least deprived quintile.¹¹
- Prostate cancer is most common in Black males, then White males and least common in Asian males.¹¹

We need to improve data capture regionally as well as nationally. For us to be able to understand the impact of the prostate pathway for patients we need data for those within different age groups, ethnicity, learning disability and other protected characteristics.

We would recommend that this data capture should be standardised nationally, so that it is possible to cross compare regions and to measure the impact for different patient groups. Eg, ensuring that ethnicity capture is standardised and the use of READ CODES are universal.

We welcome the recent announcement by the Director of Cancer Services at the recent Department of Health and Social Care inquiry (20/1/22) into cancer services, stating that Cancer Alliances are now beginning to collect data according to ethnicity and provide a breakdown of cancers according to ethnicity. It is unclear whether this data capture is standardised, allowing for cross comparison of regions and would recommend this as good practice.

Was it an appropriate commitment?

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

Patient awareness of prostate cancer

A large-scale study commissioned by Prostate Cancer UK in 2013, demonstrated that:

- 83% of UK men at higher than average risk of prostate cancer do not classify their own risk of being diagnosed with prostate cancer as 'higher than average'.
- When broken down, this is true of 83% of UK men aged 50 and over, 90% of UK Black men and 50% of UK men with a family history of prostate cancer in a father or brother.
- Furthermore, 75% of UK men at higher than average risk of prostate cancer told us that even if they were aware that they were at a higher than average risk of cancer, but didn't have any symptoms, they wouldn't speak to their GP about it. When broken down, this is true of 77% of UK men aged 50 and over, 69% of UK Black men and 65% of UK men with a family history of prostate cancer in a father or brother.

This data suggests that a considerable amount of national investment and work has to be done to raise awareness in men about their risk to prostate cancer, so that they are informed and can make better informed decisions about their health.

To go further and faster, we would advocate a focus at the beginning of the diagnostic pathway and where responsibility lies with the patient to speak to their GP. Increasing awareness of men's risk to prostate cancer needs to be made not only for the general public, but also for GPs in primary care.

When we polled GPs about what were the risk factors for prostate cancer, over 50% did not know that ethnicity was a risk factor. This is concerning and an improvement in GPs knowledge would help to address this.

Views of Patients

The Cancer Patient Experience Survey of 2020 was offered to Trusts on a voluntary basis. Reports for each of the 55 participating Trusts are available [here](#). These are designed to inform commissioners and providers about their patients' experiences and to identify areas for local improvement.

As there were no Cancer Alliances with full Trust participation, it was not possible to produce Cancer Alliance level reports. Therefore, the results from the Cancer Patient Experience Survey in 2020 cannot be used to make comparisons at a national or Cancer Alliance level with previous years"¹² As a consequence there is no up to date data to be able to provide on whether the commitments made have made a meaningful improvement for patients.

We would strongly advocate national data capture as it plays a vital part of being able to inform, develop strategy and provide targeted support to areas that need it.

2. Is the commitment specific enough?

"We will build on work to raise greater awareness of symptoms of cancer" is a commitment specified in the NHS Long Term Plan.¹³

Prostate Cancer UK would advocate that for prostate cancer, it is crucial that the awareness focuses on the risks of prostate cancer, not symptoms, as early prostate cancer often does not show symptoms and if patients wait for these before going to the GP it might result in a higher number of late-stage diagnoses.

To meet the ambitions of the plan, investment needs to be made into embedding changes in public behaviour regarding what they do when they are sick or ill. Barriers that have been evidenced via Cancer Awareness Measures (2018)¹⁴ demonstrated that for many, the availability and accessibility of certain GPs was a major barrier.

Many patients also state that they did not want to be seen to be a “fuss”, reinforcing that many will sit on their symptoms longer, thus delaying diagnosis and treatment. So, although the commitment to raise greater awareness of cancer symptoms is good, it should be noted that a one size fits all approach is not appropriate for all cancers and that risk awareness should be the focus for prostate cancer. Further systemic changes also need to be made to help change men’s attitudes towards healthcare nationally.

Use of personalised and risk stratified screening: See answer 2.

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3. Living well with and beyond cancer

By 2021 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

Summary Response:

The Government's commitment that by 2021 where appropriate every person diagnosed with cancer will have access to personalised care was ambitious but did address an area of cancer care and support widely accepted to need improvement across the cancer community.

Following the publication of the NHS Long-Term Plan¹, it's evident that a lot of work has been undertaken to put in place policy and guideline on the implementation of personalised care models across England. NHS England and local NHS provider guidelines (for example Cancer Alliances) have adopted the commitment and acknowledge the need for personalised care models. Local guidelines reflect the core policy ambition set out by the Government, which is positive and will hopefully reduce inequality in access to personalised care across England.

A range of data sources suggest personalised care models are being rolled out and patients are accessing them, however there's still a lot to do to achieve full roll-out across England. Prostate Cancer UK carried out a freedom of information request in 2020 which showed 41.5% of NHS Trusts said they had a prostate cancer PSFU protocol in place. NHS England reports - *"Good progress has been made, for example at the end of Quarter 3, 20/21, 87% of trusts have operational breast cancer PSFU protocols in place and 62% of trusts have operational PSFU protocols in place for Prostate and Colorectal patients."* The National Cancer Patient Experience survey also highlights there is still work to do with just 44% of prostate cancer patients saying they had been given a care plan (variation between 17%-67%). Variation also exists in the provision of information (27%-100%) and support (46%-100%) which should be addressed so that all men with a prostate cancer diagnosis get access to the right information and support to meet their needs.

In conclusion, more needs to be done in this area of cancer care to achieve the commitment made by the Government. There are likely to be very good examples of personalised care happening across England that can be utilised as a learning exercise. The Government should look to these models, understand the challenges and solutions and use that information to inform future commitments and investment in this area of cancer care to support NHS Trusts that are struggling.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

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

Yes, the Government set out a clear and fixed implementation deadline in their commitment – **"By 2021, 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."**¹

2. Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?

The Covid-19 pandemic could have potentially delayed the implementation of this commitment. Although we believe the opposite occurred as national guidance was published encouraging

providers to implement aspect of personalised care, including digital remote follow-up systems to ease the burden on NHS services during the pandemic.

3. To what extent has the NHS's Covid-19 response affected progress on targets?

We believe the Covid-19 response has had a positive impact and accelerated the implementation of PSFU and Patient Initiated Follow Up (PIFU) systems, however there is still work to do to achieve the full commitment. This follows NHSE guidance on *'Implementing phase 3 of the NHS response to the COVID-19 pandemic (August 2020).'*²

Implementation of PIFU and PSFU were encouraged as a way to support the NHS in recovering from the pandemic, enabling cancer patients to continue with some aspects of their care remotely, where appropriate.

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

NHS England and NHS Improvement published – ['Implementing Personalised Stratified Follow Up Pathways'](#) (March 2020). The handbook outlines the case for change, benefits of PSFU, and requirement for implementation. Prostate cancer, alongside breast and colorectal, were identified as priorities for implementing PSFU. The handbook sets out requirements for Cancer Alliances to work with local systems to ensure that every patient has access to personalised care interventions from diagnosis by 2021. Interventions include: *"Personalised Care and Support Planning based on Holistic Needs Assessments, Health and Wellbeing Information and Support, and End of Treatment Summaries (collectively formerly known as a 'recovery package')."*³

There are good examples where Trusts have developed checklists, principles, and resources for the implementation of PSFU and related interventions. For example, the Healthy London collaborative (North Central London / North East London / South East London 'RM Partners (South West and North West London) issued Personalised Stratified Follow-Up guidance in October 2020.⁴

This guidance was issued alongside a set of Key Performance Indicators (KPIs) to help measure success in implementation of PSFU.⁵

All Cancer Alliances in England have identified Personalised Care as a priority area within their area, with most having a published plan on implementation which aligns to the national plans referenced above.

5. Does data show achievement against the target (if applicable)?

Prostate Cancer UK submitted a Freedom of Information request to NHS hospital trusts (October 2020) to understand the uptake of Personalised Stratified Follow Up (PSFU) for men living with and beyond a prostate cancer diagnosis.

- 41.5% of NHS Trusts said they had a prostate cancer PSFU protocol in place.
- 16.8% said they did not have a prostate cancer PSFU protocol in place.
- 41.5% said they were in the process of developing PSFU protocols.

Of the NHS Trusts that responded (101), 51% said they did not have an IT solution in place to manage follow up, but 48% said they planned to implement soon. 85% of NHS Trusts said that men had access to a Support Worker who was acting as a key worker for the duration of the man's care. Only 18% of Trusts said that men had access to an online system allowing access to results, needs

assessments, patient information and direct messaging with their clinical team. 26% of Trusts were offering men a PSFU workshop and 39% said they were able to prevent men having to attend clinic unless tests or other issues required it.

[NHS oversight metrics 2021-22 \(June 2021\)](#)⁶: include the metric ‘Number of personalised care interventions’ against the NHS LTP headline area – ‘People will get more control over their own health by rolling out NHS personalised care model across the country’. We cannot find data on this metric.

[NHS England](#) report that “Good progress has been made, for example at the end of Quarter 3, 20/21, 87% of trusts have operational breast cancer PSFU protocols in place and 62% of trusts have operational PSFU protocols in place for Prostate and Colorectal patients.”⁷

[National Cancer Patient Experience Survey \(NCPES\)](#)⁸, Prostate cancer unadjusted scores from 2020:

- Have you been given a care plan?
 - National average: 44%
 - Range: 17% - 67%

- Questions in relation to support (self-help groups, access to a CNS, practical advice, etc.)
 - National average: 83%
 - Range: 46% - 100%

- Questions in relation to the provision of information:
 - National average: 84%
 - Range: 27% - 100%

In summary, the NCPES shows variation and poor levels of access to care plans. Health and wellbeing information and support for men diagnosed with prostate cancer rates highly but, again, there is huge variation in what men experience. More could be done to ensure all men have a high-quality experience beyond their diagnosis.

Was the commitment effectively funded (or resourced)?

Did the commitment achieve a positive impact for patients?

Was it an appropriate commitment?

1. Is the commitment wide enough in scope?

The original commitment was wide enough in scope – “*where appropriate every person diagnosed with cancer will have access to personalised care*”. However, the [‘Implementing Personalised Stratified Follow Up Pathways’](#) (March 2020)³ handbook identifies prostate cancer, alongside breast and colorectal cancers, as priorities for implementing PSFU. Therefore, other cancers may have missed out because of providers focusing attention on the roll-out for prostate, breast and colorectal.

2. Is the commitment specific enough?

The commitment mentions ‘where appropriate’ but does not provide details on which situations and patient circumstances are considered as appropriate or not appropriate. This could be left open

to local interpretation and create variation in access to personalised care.

The commitment could go into more detail on the point relating to *'health and wellbeing information and support'*. We know that prostate cancer patients are often overwhelmed with information during the initial diagnosis and treatment offer stages. Information and support should be in proportion, relevant to the cancer diagnosis and severity of the cancer and should be tailored to the patient's needs considering inclusion, equality and diversity.

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

The level of ambition was reasonable. For prostate cancer, we know that men with low-risk, localised prostate cancer and those men who have received curative treatment and are on a PSA monitoring pathway will benefit greatly. The NHS system also benefits as these men require less visits to hospital outpatient departments and can easily contact their clinical team if needed.

4. Is the target contained in the commitment an effective measure of policy success (if applicable)?

The target was set out as *"where appropriate every person diagnosed with cancer will have access to personalised care"*. This feels like an appropriate target

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

Yes. The need for survivorship and self-management models of care were highlighted by the Movember TrueNTH Supported Self Management programme in 2016.⁹

The programme outlined the rapidly increasing numbers of new cancer diagnoses and the growing number of cancer survivors, and the need for a new model of survivorship care to address the holistic needs of survivors. They went on to say "Prostate cancer survivorship in the UK is lagging behind".

The TrueNTH initiative, launched by the Movember Foundation, set out to markedly change the survivorship outcomes of men with prostate cancer and make a big impact on their lives. Their supported self-management model aimed to provide a better standard of care and deliver significant savings to the NHS that can be used for other cancer management programmes.

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4. Innovation and technology

Safer and more precise treatments including advanced radiotherapy techniques and immunotherapies will continue to support improvements in survival rates.

Summary Response:

Government has made commitments on access to the latest radiotherapy techniques and equipment. The Five Year Forward View (2014) stated that “by October 2018, patients will have access to sustainable high-quality, modern radiotherapy treatments wherever they live.”¹

The latest radiotherapy technique for prostate cancer is hypofractionated radiotherapy (60 Gy in 20 fractions) for radical treatment of localised prostate cancer. The National Prostate Cancer Audit of 2019 “report[ed] its use at 91% in intermediate-risk cases and 59% in high-risk/locally advanced cases, with substantial national variation in the latter.”²

The latest (2021) National Prostate Audit report shows that this had increased to 85% of patients receiving radiotherapy undergoing a hypofractionated regime.³ This increase is positive, and may be due to the adoption of hypofractionated radiotherapy by NICE guidelines in 2019.⁴ However, this does leave some patients still not receiving the most up-to-date treatment regime, and thus being exposed to potentially greater side effects and a more onerous treatment plan.

The NHS Long Term Plan (2019) stated that “Faster, smarter and effective radiotherapy, supported by greater networking of specialised expertise, will mean more patients are offered curative treatment, with fewer side effects and shorter treatment times.”⁵

Using the last year for which figures are available, the National Prostate Cancer Audit (2020) shows that 29% of men with high-risk localised or locally advanced prostate cancer did not have radical treatment, and were thus denied a potential cure.⁶

Commitments on radiotherapy have not included molecular radiotherapy technologies (also known as radioligand therapy). The 2021 Royal College of Radiologists report *Review of Molecular Radiotherapy Services in the UK* concluded that there is no clear “ownership” of molecular radiotherapy, with responsibility lying with clinicians in various roles.⁷ This lack of a consistent approach means molecular radiotherapy is lacking the vision and joined-up approach of external beam radiotherapy. NICE is currently appraising Lu-PSMA-617, a molecular radiotherapy treatment for advanced prostate cancer. If this is approved the demand for this service is likely to far outstrip current capacity. Molecular radiotherapy must be included in future government assessments of radiotherapy technology and availability.

The NHS Long Term Plan also described the commissioning of Sir Mike Richards’ Review into diagnostic technology and capacity. The report, released in 2020, called for diagnostic capacity, most importantly for prostate cancer including MRI and PET-CT should, as a minimum, be expanded in line with growth rates prior to the pandemic and all imaging equipment older than 10 years should be replaced.⁸

While we welcome the subsequent commitment of £200m for the replacement and expansion of imaging equipment, this sum will likely not go far enough to meet the suggested capacity increases of the Richards Review. In particular, MRI and PET-CT demand are both increasing, with changes to the prostate cancer pathway requiring greater use of both imaging modalities.

If Lu-PSMA-617 is approved by NICE, the need for PET-CT as the companion diagnostic will rise

immediately.

Research is currently ongoing investigating the use of MRI as a screening tool for prostate cancer (such as the recent PROSTAGRAM study⁹). If this proves successful, the demand for prostate MRIs will also rise significantly. Further commitments are needed for long-term support to increase the capacity of medical imaging technologies on a rolling basis in line with demand. A detailed audit of the dispersal and effectiveness of the £200m already committed would be instructive on how best to continue to increase imaging capacity.

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

Was the commitment effectively funded (or resourced)?

Did the commitment achieve a positive impact for patients?

Was it an appropriate commitment?

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