

Picker's response to the 'Shaping the national cancer plan' call for evidence

About Picker

Picker is an independent health and social care charity based, with expertise in understanding, measuring, and improving people's experiences of care. We pioneered the [patient experience approach](#), now widely adopted around the world, and advocate for the delivery of the highest quality person centred care for all, always.

We work with policy makers, providers, professionals, and patients and the public to influence, inspire, and empower person centred care. We are commissioned by the Care Quality Commission (CQC) and NHS England (NHSE) to design, deliver and analyse the [NHS patient survey programme](#), the cancer patient experience surveys ([adult](#) and [under 16](#)), and the [NHS staff survey](#).

If you have any questions about this submission, please contact Olli Potter, senior policy officer (oliver.potter@pickereurope.ac.uk).

Note: Selections highlighted **yellow** denote our response to multiple choice questions.

Questions on the national cancer plan

Prevention and awareness

Which cancer risk factors should the government and the NHS focus on to improve prevention? (Select the 3 most important risk factors)

- Alcohol
- Tobacco
- Obesity
- Physical inactivity
- UV radiation
- Air pollution
- **I don't know**
- Other (please specify)

Please explain your answer.

Other organisations are better placed to answer this question on prevention and awareness.

Early diagnosis

What actions should the government and the NHS take to help diagnose cancer at an earlier stage? (Select the 3 actions that would have the most impact)

- Improve symptom awareness, address barriers to seeking help and encourage a timely response to symptoms
- Support timely and effective referrals from primary care (for example, GPs)
- Make improvements to existing cancer screening programmes, including increasing uptake
- Increase diagnostic test access and capacity
- Develop and expand interventions targeted at people most at risk of developing certain cancers
- Increase support for research and innovation
- I don't know
- Other (please specify)

Please explain your answer.

Picker is commissioned by NHS England to design, analyse and deliver the [National Cancer Patient Experience Survey \(NCPES\)](#) and the [Under 16 Cancer Patient Experience Survey \(U16 CPES\)](#). As results from both surveys highlight patient concerns about the timeliness of referrals and diagnostic testing capacity, we would support the prioritisation of increased testing capacity and timely referrals from primary care.

The most recent NCPES data, published in July 2024, shows a reduction in the number of patients reporting that the length of time they waited for diagnostic testing 'felt right' (77.6% compared to 81.9% in 2021). [Qualitative analysis](#) of survey responses shows that patients perceive there is a link between staffing levels and their waiting times, with lower staffing levels having a negative impact on both patients and staff. Other respondents noted long waits for the pharmacy to prepare their medication, which some believed caused delays to their treatment.

On waiting times, one respondent said:

"The length of time to wait for scans and results is appalling, I waited 7 weeks for the results of my last CT. I am also currently awaiting referral to another specialist which (unless there is a cancellation) will be 10 months from referral till appointment date. Cancer patients already have so much to deal with and this only makes things worse."

Another participant noted NICE guidelines in their response, stating:

"Very long waits – 3x longer than NICE guidelines – for test results, surgery, and chemo[therapy] start date. Also, up to 3.5 hours wait to see the doctor."

Of parents and carers responding to the U16 CPES, published in November 2024, 69.6% felt their child was seen in hospital as soon as they thought was necessary after being referred by their GP. [Analysis of the qualitative survey data](#) found evidence of delays in diagnosis and starting treatment, with some parents and carers reporting they did not feel listened to, or that they were being taken seriously, when they expressed concerns about their child's health. The length of time

to get a GP appointment was also mentioned by respondents as a contributing factor to delays in diagnosis.

These findings show that patients, their families and carers would like to see timelier and more effective referrals from primary to secondary care, and for diagnostic testing as part of cancer pathways. This aligns more broadly with results from the [2024 British Social Attitudes survey](#), which shows reducing waiting times is a top priority for the wider public.

We would also support the development and expansion of interventions targeted at people most of risk of developing certain cancers as this aligns closely with the government's proposed shift from 'sickness to prevention' while also supporting efforts to tackle wider health inequalities. Caution should, however, be taken in expanding existing cancer screening programmes, as [excess screening can cause harm](#) and lead to overdiagnosis.

Increasing uptake of existing screening programmes, however, should be prioritised, in co-production with communities to understand existing barriers to participation.

Treatment

What actions should the government and the NHS take to improve access to cancer services and the quality of cancer treatment that patients receive? (Select the 3 actions that would have the most impact)

- **Increase treatment capacity (including workforce)**
- Review and update treatment and management guidelines to improve pathways (processes of care) and efficiency
- Improve the flow and use of data to identify and address inconsistencies in care
- **Improve treatment spaces and wards, including facilities available to carers**
- **Improve communication with patients, ensuring they have all the information they need**
- Increase the availability of physical and mental health interventions before and during cancer treatment
- Increase the use of genomic (genetic) testing and other ways of supporting personalised treatment
- I don't know
- Other (please specify)

Please explain your answer.

Based on responses to the NCPES and U16 CPES surveys – particularly the qualitative analysis that identifies concerns about waiting times and communications as key themes – our view is that increased treatment capacity alongside improvement to treatment spaces and wards, and improved communication with patients, would have the most impact in improving access to cancer treatment and services.

On communications, and ensuring patients have access to all the information they need in adult services, the picture is mixed. While 72.2% of respondents said that they 'definitely' had a discussion with a member of the team looking after them about their needs or concerns before

their treatment started, other questions in the 'care planning' section of the survey consistently score over 90%. Furthermore, 82.5% of patients reported that treatment options were explained in a way that they could 'completely understand'.

While 74.4% of respondents agreed possible side effects of treatment were 'definitely' explained in a way that they could understand, and 70.1% said they were 'always' offered practical advice on dealing with immediate side effects, scores were lower when participants were asked about 'definitely' receiving an explanation of possible long-term side effects of treatment (60.1%) and being able to discuss options to manage these (54.6%) with their clinician.

Concerns about communication are also evident in paediatric services. Only 47.1% of respondents to the U16 CPES reported that it was 'very easy' to contact the main person looking after their child and 72.8% of parents, carers and children said that the information provided at diagnosis was given in a way that they could understand. Patients said they value clear, proactive information, that is tailored to make it understandable and addressed to children as well as to their parent or carer. Only 64.3% of parents, carers and children felt they always knew what was happening with their or their child's care – with one parent saying that:

"During [our child's] surgery (9 hours!) there were no updates or reassurances that things were ok. We were frantic by the end. A quick phone call to the nurses' station from the theatre to reassure us would've saved us so much heartache."

In relation to improving treatment spaces and wards, respondents to the U16 CPES generally report low scores related to hospital facilities, particularly facilities for staying overnight (only 35.7% described these as 'very good') and the choice of food (only 37.8% said there was 'definitely' a suitable choice). One parent said:

"There are never any pillows for parents - they are like gold dust yet having to sleep there every night they are kind of essential given the sofa beds are so uncomfortable."

In relation to choice of food, respondents noted that the quality of food was often poor and lacking in nutritional value, while choices were limited.

Living with and beyond cancer

What can the government and the NHS do to improve the support that people diagnosed with cancer, treated for cancer, and living with and beyond cancer receive? (Select the 3 actions that would have the most impact)

- Provide more comprehensive, integrated and personalised support after an individual receives a cancer diagnosis and (if applicable) after treatment
- Improve the emotional, mental health and practical support for patients, as well as their partners, family members, children and carers
- Offer targeted support for specific groups, such as ethnic minority cancer patients, children and bereaved relatives
- Increase the number and availability of cancer co-ordinators, clinical nurse specialists and other staff who support patients

- Increase the support to hospice services and charities who provide care and support for patients
- Improve access to high-quality, supportive palliative and end-of-life care for patients with incurable cancer
- I don't know
- Other (please specify)

Please explain your answer.

The NCPES survey includes three questions related to living with and beyond cancer, looking at the emotional support offered to patients from community services, the information that is provided to patients after their final treatment and their follow up appointment, and whether they receive enough information about how to spot the signs of cancer returning or spreading. Patient experience is particularly poor related to the emotional support offered at home by community or voluntary services, with less than one in three (32.3%) saying they 'definitely' could get enough support.

It is concerning that only 63.8% of respondents felt they were given enough information about how to spot signs of cancer returning or spreading, with limited change over the last three years (62.5% in 2021). Patients were more positive about the information provided between their final treatment and their follow up appointment, with 79.3% saying they were offered the right amount of support.

The survey also asked patients about the support they receive during treatment:

- Only 52.3% said they 'definitely' got enough support at home from community or voluntary services.
- When asked if they received the right amount of support from their GP practice during treatment, 46.4% agreed they had.
- Only 22.7% said they had a review of their cancer care by their GP practice while receiving treatment.

Having access to the right information is empowering, while opportunities to discuss concerns help alleviate patient anxiety. It is, therefore, concerning that there has been a reduction in the proportion of patients who feel that they were 'always' able to discuss their worries and fears with hospital staff (64.8% in 2024 compared to 66.8% in 2021). Only 61.6% of respondents felt that their care team gave family, or someone close to them, all the information they need to help care for them at home.

In paediatric services, only 61.7% of parents or carers felt they 'definitely' received enough ongoing support from the hospital after their child's treatment ended. Consistent information is important to reassure patients and their families, yet only 56.9% of parents, carers and children reported not being told different things by different members of staff that left them feeling confused. This has declined sharply from 61.7% in 2021.

These findings demonstrate the need for more comprehensive support after diagnosis and treatment, as well as a focus on emotional support, both for patients and their families and carers. Supporting hospices and charities who provide support in communities is also an important part of

strengthening this offer. Picker's [Principles of Person Centred Care](#), developed with patients, are clear about the importance of involving family and carers, as well as the importance of emotional support, empathy and respect in delivering holistic care.

Research and innovation

How can the government and the NHS maximise the impact of data, research and innovation regarding cancer and cancer services? (Select the 3 actions that would have the most impact)

- Improve the data available to conduct research
- Improve patient access to clinical trials
- Increase research into early diagnosis
- Increase research into innovative treatments
- Increase research on rarer and less common cancers
- Speed up the adoption of innovative diagnostics and treatments into the NHS
- I don't know
- Other (please specify)

Please explain your answer.

While other organisations are better placed to answer this question on research and innovation, the latest NCPES results show that only 44.7% of patients report research opportunities being discussed with them by their clinical team. This has seen little change over the last three years (44.1% in 2021). This indicates there is more to be done to improve patient access to, and knowledge of, clinical trials.

Inequalities

In which of these areas could the government have the most impact in reducing inequalities in incidence (cases of cancer diagnosed in a specific population) and outcomes of cancer across England? (Select the 3 actions that would have the most impact)

- Improving prevention and reducing the risk of cancer
- Raising awareness of the signs and symptoms of cancer, reducing barriers and supporting timely response to symptoms
- Reducing inequalities in cancer screening uptake
- Improving earlier diagnosis of cancers across all groups
- Improving the access to and quality of cancer treatment
- Improving and achieving a more consistent experience across cancer referral, diagnosis, treatment and beyond
- Improving the aftercare support for cancer patients
- I don't know
- Other (please specify)

Please explain your answer.

We support action to improve earlier diagnosis, to ensure consistency, and to improve aftercare support, as inequalities in cancer care are evident across all parts of the pathway.

NCPES subgroup analysis highlights that younger patients (aged between 25-34) were less happy with their care experience compared to older age groups, as were women and non-binary respondents, those whose gender is not the same as sex registered at birth, or bisexual respondents. Patients with mental health conditions, a learning disability, or autism were also less happy with their experience of care. White respondents reported better experiences of care compared to black, Asian, and respondents who identify as 'mixed' and 'other'.

The results can also be split by deprivation level, which highlights inequalities by Index of Multiple Deprivation (IMD) quintile. When asked about how long respondents waited before contacting their GP after they thought something might be wrong, 40.0% of respondents in IMD1 (most deprived) waited 'less than three months' compared to 46.5% of respondents in IMD5 (least deprived). Similarly, when asked if staff at their GP practice 'completely' explained why they were being referred for diagnostic testing in a way that they could understand, 60.7% of respondents in IMD1 said 'definitely' compared to 69.7% of respondents in IMD5. There are also gaps between the most and least deprived respondents when asked whether they received information on potential long-term side effects of their treatment and how to manage these; whether they received information on how to identify if cancer has returned or is spreading; and if they felt their diagnosis was shared in a sensitive way. Across these metrics, respondents in IMD1 were less likely to respond 'definitely' compared to respondents in IMD5.

In paediatric cancer care, only 66.4% of parents or carers felt they had enough information about financial support or benefits that they could access, down from 69.1% in 2021. When broken down by ethnicity, the results show that white respondents are more likely to report having enough information (67.9%) compared to black respondents (60.7%) or respondents who selected 'mixed' as their ethnicity (57.7%).

Asian respondents were significantly less likely to report they had been seen as soon as they thought was necessary (55.0%) than white respondents (73.1%), while black respondents were less likely to report they were told about their child's cancer sensitively (54.6% answered 'definitely') compared to 70.7% of white respondents and 72.7% of Asian respondents. Conversely, when asked about being provided with the clear information about treatment, black respondents were more likely to say they had 'definitely' received clear information (89.3%) than white respondents (81.8%).

Respondents in IMD1 were less likely to report being told about their child's cancer in a way they understood (64.9% answered 'definitely') than respondents in the least deprived quintile (76.1%). Similarly, parents or carers in the most deprived quintile were less likely to report being told about charities that could support them (78.5% answered 'definitely') than respondents in IMD quintile 5 (81.6%).

Priorities for the national cancer plan

What are the most important priorities that the national cancer plan should address? (Select the 3 most important priorities)

- Prevention and reducing the risk of cancer
 - Raising awareness of the signs and symptoms of cancer
 - Earlier diagnosis of cancer
- Improving the access to and quality of cancer treatment, including meeting the cancer waiting time standards
- Improving patient experience across cancer referral, diagnosis, treatment and beyond
 - Improving the aftercare support for cancer patients
 - Reducing inequalities in cancer incidence, diagnosis and treatment
 - Other (please specify)

Please explain your answer.

It is our view that improving patient experience and access to cancer treatment, alongside interventions to prevent and reduce the risk of cancer, should be prioritised in the national cancer plan. Large-scale national patient experience surveys, commissioned by NHS England and delivered by Picker, already provide robust evidence as to where patients feel there is room for improvement in cancer care, as well as where they think person centred care is already being delivered. Both the NCPES and U16 CPES surveys highlight the need to improve the patient experience across all parts of the pathway from referral to treatment and beyond.

Improving access to care is a concern for patients across adult and paediatric pathways, with diagnosis and waiting times identified as key themes in qualitative analysis of the NCPES results, and access to care identified as a key theme in qualitative analysis of the U16 CPES results. As demonstrated in the recent [British Social Attitudes survey results](#), concerns about access to care are also identified by the public as their number one concern related to NHS services. Efforts to improve access to care and patient experience must also consider how to tackle existing inequalities identified across care pathways, while also ensuring that future interventions are co-designed with diverse communities to ensure they do not exacerbate inequalities.

Plans to improve access and care quality, as well as patient experience, must be co-designed with diverse patient voices and should be designed in accordance with Picker's [Principles of Person Centred Care](#), which were developed with patients to identify the key facets that are important to patients, their families and carers across care pathways.

Previous winners and finalists at the [Picker Experience Network Awards](#) provide examples of good practice in delivering person centred cancer care. For example, West Yorkshire and Harrogate Cancer Alliance won the 'Cancer Experience of Care Award' in 2024 with their ['Remove the Doubt' campaign](#), designed with the LGBTIQ+ cancer charity [OUTpatients](#) to increase awareness of the signs and symptoms of cervical cancer and the importance of screening attendance among the LGBTIQ+ community. South Tyneside and Sunderland NHS Foundation Trust were runners up in this category with their ['Personalised Cancer Care'](#) initiative. This initiative was co-designed with patients and harnessed the skills of stakeholders across the local health care system.

In line with the government's stated aim to shift from 'sickness to prevention', we support prevention and reducing the risk of cancer being prioritised in the national plan. This will take longer to achieve, and therefore, should be accompanied by efforts to raise awareness of

symptoms and ensure early diagnosis of cancer, particularly in the shorter term. As outlined in our [response to the Change NHS consultation](#), for this shift to be successful, plans must recognise the wider determinants of health and provide support to help people live healthier lives. This needs to be a cross-departmental approach in central government, in collaboration with local partners who have strong working relationships with their local communities.