Specialist Cancer Charities Group

From Lived Experience to National Policy:

A citizens' jury approach to improving cancer care

This research was funded by Anthony Nolan, Blood Cancer UK, Bowel Cancer UK, Breast Cancer Now, Sarcoma UK and Young Lives vs Cancer.

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Contents

Executive summary

The Specialist Cancer Charities Group (SCCG) is a group of charities that support and advocate for the needs of people living with and affected by cancer. In order to help ensure that patient views are centred in cancer policy, the SCCG commissioned a citizens' jury to explore patients' priorities for cancer care in the UK.

This jury convened 17 members of the public who have received treatment for cancer in the past five years. Its aim was to develop priorities for the future of cancer care in the UK, and to inform recommendations for the UK Government and the devolved governments in Scotland, Wales and Northern Ireland.

Key findings

Experiences of receiving cancer care were overall very positive, and jurors were grateful to have received free lifesaving care at the point of need from the NHS.

However, there were some areas of concern for jurors around the state of cancer care in the UK. Based on their own and others' experiences, as well as the information they learnt, jurors raised concerns around:

- **Diagnosis:** Challenges with getting symptoms acknowledged and diagnosed, and failures in communication by healthcare professionals were seen as particularly difficult for people affected by cancer.
- **Access to clinical trials:** Few had heard of or been offered the option to take part in a clinical trial. Ensuring patients are offered the possibility of taking part in clinical trials and improving the diversity of the people involved in trials could improve outcomes.
- **Mental health and wellbeing:** Limited availability of resources impacted patients negatively, especially at diagnosis and after treatment. Support at all stages and ensuring supportive and empathetic interactions with healthcare professionals would help patients.

Jurors also worried about the impact of health inequalities and staffing issues across the NHS. While it was harder for jurors to personally acknowledge that they might have experienced inequalities (for example, as a result of their ethnicity, financial circumstances or level of confidence), jurors felt that inequalities in access to and experience of care are common and important to address.

At the end of the engagement, jurors identified four key priorities they want the UK Government and devolved governments to take forward, providing recommendations for action in each area:

1. **Diagnosis:** Ensure people are diagnosed as early as possible by investing in education, screening and primary care.
2. **Equal access to care:** There should be equitable cancer care for all – no matter who you are or where you live.
3. **Mental health support:** There should be mental health and wellbeing support for all patients, and their families or carers.
4. **Improving communication:** There should be better communication within the NHS and with cancer patients about their care.

Jurors then came up with actionable recommendations for each priority area, and these can be found in Priority 1 – Diagnosis: Ensure people are diagnosed as early as possible by investing in education, screening and primary care.

Foreword from the SCCG

Half of us will develop a form of cancer during our lifetimes. And all of us will be affected by cancer in some way – be it caring for a loved one, receiving treatment ourselves or sadly losing someone we love. Whilst there have been many incredible advances in cancer treatment and care, the UK still falls behind comparable countries when it comes to cancer outcomes including diagnosis and survival.

At the same time, 'patient involvement' and 'patient voice' have become buzz words across the health and care sector. From hospitals and GP surgeries to big pharmaceutical companies and indeed healthcare charities. But there's a concern about how meaningful patient involvement is. How do we hear from patients in a way that actually leads to change, rather than simply ticking a box?

These two broad challenges were what led the SCCG to embark on a new way to hear from cancer patients. The challenge we set Thinks Insight & Strategy was to facilitate a citizens' jury of cancer patients who should decide where the new government should focus its efforts, all in the context of the tight fiscal environment set out by the government. Importantly, we not only wanted to learn which areas cancer patients would prioritise for improvement, we also wanted to test how a citizens' jury approach could work in this context.

We're delighted with the results. It was a privilege to see the members of the jury shift from being people who have experience of cancer, to citizens who engaged with some of the most complex challenges facing our healthcare system. The process itself proved the value of taking the time to hear from patients in a different way. We might know that time to diagnosis is important, but only by hearing from patients do we understand the impact of having little or no information while waiting months for test results. We're focused on physical health, but the lack of good quality mental health support is desperate for many patients and their families.

Given the increasing pressures on the NHS, the wider health and care system and the increasing complexities and opportunities of new treatments, finding meaningful ways to listen to patients and act on their valuable insight is more important than ever. Through the findings of this Citizens' Jury, we hope to bridge the gap between policymakers, clinical practice and the lived experiences of those with cancer. As a model of engagement, the insights this Citizens' Jury has generated are profound, and we're thrilled with the engagement it has inspired so far. We look forward to continuing the conversation.

We'd like to give our heartfelt thanks to everyone involved in this project – the expert witnesses who shared their knowledge with the Jury; Thinks Insight and Strategy who led the process with aplomb, and most importantly the wonderful patients and their families who gave their time to provide such thoughtful insights and considerations.

Henny Braund MBE

Chair of the Specialist Cancer Charities Group

Overview of our approach

Introducing the research

The Specialist Cancer Charities Group (SCCG) is a coalition of leading cancer charities: Anthony Nolan, Blood Cancer UK, Bowel Cancer UK, Breast Cancer Now, Pancreatic Cancer UK, Prostate Cancer UK, Sarcoma UK, Shine Cancer Support, Teenage Cancer Trust and Young Lives vs Cancer. The group is dedicated to increasing patients' and healthcare professionals' involvement in services to improve cancer outcomes.

As part of this work, the SCCG commissioned Thinks Insight & Strategy to facilitate a citizens' jury with cancer patients on the topic of cancer care.

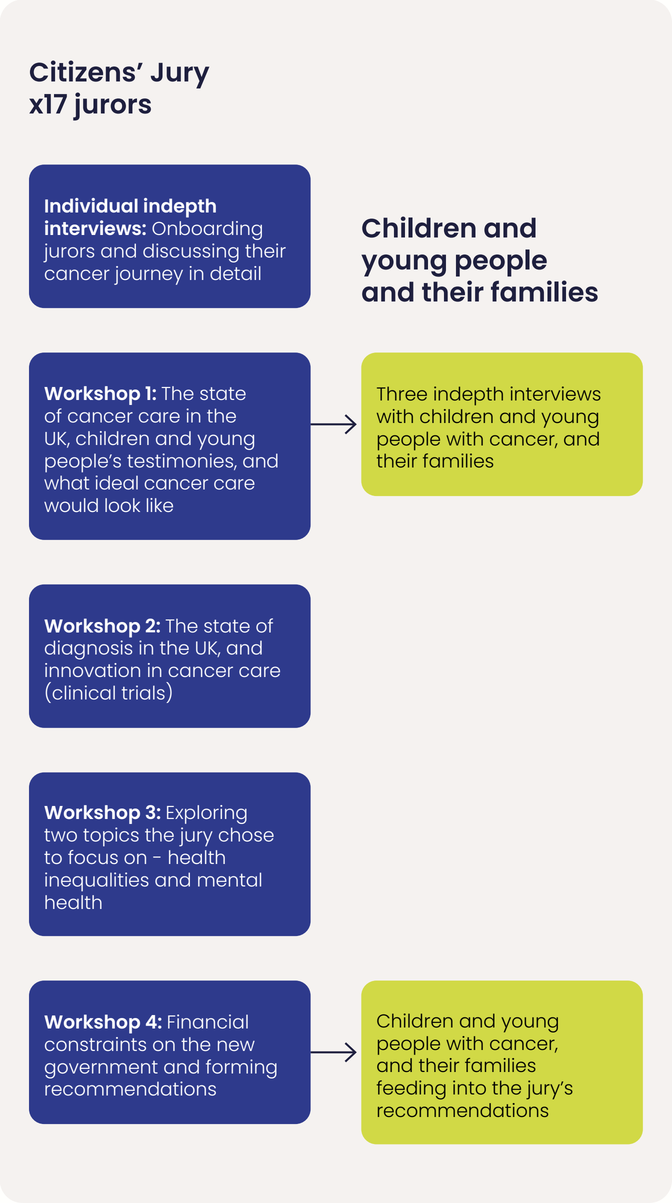
Aims and objectives

This citizens' jury aimed to develop insight for the new UK Government to guide policy prioritisation, acknowledging that this insight will also be pertinent to the devolved governments in Scotland, Wales and Northern Ireland. The objectives of this research were:

- For participants to develop an understanding of the current state of cancer care, along with the challenges and policy options for future care.
- To develop jury recommendations through group discussion that will be presented to the UK Government and devolved governments.
- To demonstrate that a citizens' jury is an effective method for engaging and involving cancer patients on policy relating to cancer care.

Methodology and approach

Outline of our approach



Citizens' Jury x17 jurors

Individual indepth interviews: Onboarding jurors and discussing their cancer journey in detail

Children and young people and their families

Workshop 1: The state of cancer care in the UK, children and young people's testimonies, and what ideal cancer care would look like → Three indepth interviews with children and young people with cancer, and their families

Workshop 2: The state of diagnosis in the UK, and innovation in cancer care (clinical trials)

Workshop 3: Exploring two topics the jury chose to focus on - health inequalities and mental health

Workshop 4: Financial constraints on the new government and forming recommendations → Children and young people with cancer, and their families feeding into the jury's recommendations

The citizens' jury was formed of 17 adults who had received treatment for cancer from the NHS in the past five years. This diverse sample comprised of individuals with experiences across various cancer types, representing a mix of ethnic backgrounds and socioeconomic grades. It also included interviews with three children and young people and their families.

Fieldwork included one-to-one interviews with each juror, to understand their individual experiences of cancer care in a private environment. This was followed by four online workshops totalling 11 hours of engagement throughout September 2024. Each workshop included plenary sessions for all participants to share information and opinions, as well as moderated discussions in smaller breakout groups.

In these workshops, jurors heard about different aspects of cancer care and potential policy proposals. These were presented by 'expert witnesses' – people who had spent time thinking about each topic area. Four areas of policy were explored in detail: two were chosen by the SCCG, and the other two were chosen by jurors in the first workshop. This allowed jurors to shape the discussion and ensure our conversations included the issues that mattered most to them.

More information about why we chose a citizens' jury and who we spoke to can be found in the appendix, as well as the content of each workshop and who was included as an expert witness.

Children and young people's role in this engagement

It was essential that children and young people and their parents had a voice in this research. However, it would not have been appropriate to engage this audience within the core jury, as children and young people would require extensive support to manage their feelings on this emotive topic in a group environment and to feel confident exploring these issues on equal footing with adults. We did not believe it was possible to provide the appropriate support within the project scope.

We therefore supported all three children and young people and their parents to develop testimonies of their experiences which they shared with the other jurors in the first workshop. In this way our citizens' jury was supported and enabled to include the experiences of children and young people in their thinking. The children and young people and their parents also reviewed the final recommendations developed by the jury to validate them and feed in any additional views.

Context for jurors' recommendations

Jurors' personal cancer experiences

Experiences of cancer care varied across the jury. Most described their overall experience as positive, but all experienced difficulties and had suggestions for where care could have been improved.

What went well

Generally, jurors entered this engagement with a positive outlook on their cancer journey. Jurors placed the greatest emphasis on the treatment stage when assessing their experience spontaneously, pointing to the fact that their treatment worked (or seemed to be working) and/or that their surgery went smoothly as evidence of success. All jurors repeatedly expressed their gratitude for having access to free at the point-of-need healthcare through the NHS. As a result, the quality of their experiences was initially assessed in the context of their treatment being free, rather than against the 'ideal' experience of cancer care.

> "I've got no complaints. I've got my money's worth from the NHS. My journey's been fantastic, and I've had no problems waiting for things to happen. It's been very good for me personally."
>
> **(50+, Scotland)**

There were also some more specific aspects of care that jurors pointed to as working well. Most jurors felt that their treatment post-diagnosis was a quick and relatively smooth process. They described feeling like part of a seemingly well-established system that efficiently pushes a patient along their treatment journey.

Jurors also highlighted the kindness of the staff they engaged with throughout their journey. Specifically, jurors overwhelmingly praised the work of nurses who they felt were patient, personable and knowledgeable, believing this had a big impact on their experience. Though less widespread, there was also admiration for oncologists and surgeons who jurors praised for their knowledge and kindness.

What could be improved

While jurors felt, overall, that they had a good experience of cancer care, they also highlighted aspects of their journey that were challenging:

- **Getting a cancer diagnosis:** many reported difficulties in getting diagnosed by a GP and the struggle of waiting for test results to diagnose cancer.
- **Impersonal treatment:** jurors appreciated that the treatment stage was quick and efficient, but felt care was rarely personalised. They described feeling like they were on a conveyor belt.
- **Poor communication:** many felt they didn't receive clear and consistent information, and struggled to find a centralised source of clear and reliable advice.
- **Pressure to advocate for themselves:** some felt they had to "kick up a fuss" to make sure they received the best possible care. Jurors worried this wasn't something that everyone would feel comfortable doing, causing concern that care was being delivered unequally based how vocal the patient was.
- **Mental health and wellbeing:** While the NHS took care of their physical health during their cancer journey, jurors argued it did far less to support their mental health and wellbeing.

Children and young people's experiences

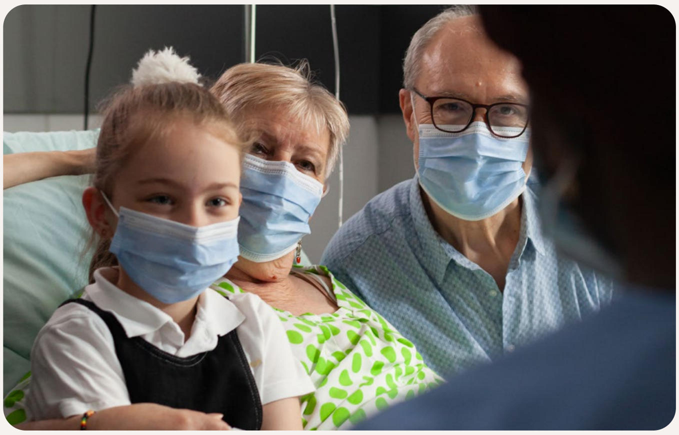
Much like adult jurors, the children and young people we heard from were initially very positive about their cancer care. However, as interviews progressed, they identified some key challenges they had experienced.

It is worth noting that, as we spoke to three children and young people and their families, their experiences will not be representative of all young people's experiences.

Overall assessment of care

The three families we spoke to felt that once they received a diagnosis, everything moved very quickly. They felt that symptoms were taken seriously from the start and escalated immediately, with specialist care being delivered in a timely manner. Families were immensely grateful that treatments were effective and that their child had been able to live happily and healthily since.

Young people and their families also praised the support work of specialist children and young people charities. Jurors appreciated the support offered in wards and signposting to mental health support. Two families also spoke positively of the kindness and care of staff, who were supportive of both children and parents. However, this experience was not universal, and one family felt that staff were often distant and difficult to access.



Challenges

Parents felt that at times communication was poor, with many feeling they had to conduct their own research and then push for their child to get the best possible care. For example, one family mentioned having to raise options for protecting their daughter's future fertility with specialists themselves. The young person, who was still a child at the time, had to insist on receiving a procedure that would support her to get pregnant as an adult. Both the parent and young person felt this important opportunity to live a full life after cancer would have been missed if they had not been as engaged and forthright as they were.

Children, young people and their parents highlighted the profound mental health and wellbeing impacts that arose from diagnosis and treatment. They struggled with the isolation of not being able to see friends or go to school due to their symptoms from cancer and treatment, or having to shield from Covid-19 or other illnesses. Families noticed a lack of formal mental health support both for the child and their parents. While they could rely on each other and people in their network, parents especially felt they could have benefitted from counselling to help them cope.

Some key elements of hospital stays also proved challenging. The children and young people we heard from all mentioned a struggle with food. Without access to appealing and high-quality food, one participant struggled to eat enough to maintain the necessary weight and not require a feeding tube.

Being on a children's ward with patients who were a wide range of ages was a positive experience for some, but one young person did feel it impacted his recovery. He said being surrounded by babies and young children who were making noise and crying made it difficult for him to get the rest he needed to recover. This family called for a teenage ward where young people would be closer in age.

Finally, the parents we spoke to mentioned financial concerns associated with supporting a child or young person with cancer. This was especially an issue for families where one parent had to give up work to care for their child. The families we heard from had to rely on support from family and friends but recognised that this would not be available for everyone.

Jurors' concerns about the state of cancer care in the UK

At the start of the jury, jurors used their own experiences as the lens through which they judged the state of cancer care in the UK. Sharing of experiences between jurors and information from expert witnesses helped the group to move past their own experiences to explore system-wide challenges.

The group identified three key areas of concern around cancer care: diagnosis, mental health support and innovation. They also identified two other areas of concern, which they saw as challenging to address: health inequalities and healthcare workforce challenges.

Jurors felt that many of the issues discussed were interconnected, drawing out instances where improvements in one area could lead to or require improvements in other areas.

Diagnosis

Improving diagnosis was a top issue for all jurors, as a poor diagnosis experience significantly impacted their care and overall experience. It also, in many cases, was seen to impact cancer survival and outcomes.

Diagnosis is the moment in the cancer journey where many jurors reported poorer experiences of care. They spoke about long waiting times, poor emotional support from healthcare professionals and inadequate information about their diagnosis. Some jurors also described problems with the delivery of their diagnosis, with news delivered in a robotic fashion, by non-specialist staff or given over the phone.

> "The GP was quite rushed at the time [of diagnosis]. He didn't really have much time to speak to me... he just wanted to move me onto the next stage. They don't have the time to sit with you and see how you're feeling."
>
> **(18-34, England)**

Many jurors had particular issues in relation to GP care. Some spoke of the struggle to get appointments or in-person consultations due to pressures on GP services. Others had negative experiences where GPs did not believe their symptoms, or did not take their concerns seriously, requiring multiple trips to the GP or seeking out a second opinion. Jurors from ethnic minority groups reported needing more GP visits before getting diagnosed with cancer than those from white backgrounds.

Some jurors were diagnosed in A&E or in emergency care, while others were diagnosed when doing routine tests, or when investigating other health issues. This led these jurors to feel that their cancer could have been diagnosed earlier if they had been given access to screening, or if they had known what symptoms to look out for.

Case study: Vikki*

Prior to her secondary cancer diagnosis, Vikki noticed changes to her body, but these were dismissed by the first GP she had an appointment with. She had to make another appointment with a different GP to get a diagnosis.

Following tests for secondary cancer, Vikki did not receive the results for a long period of time. When she was at her GP surgery for another health issue, she asked the GP if there had been an update. The GP looked it up on her computer and Vikki found out that she had secondary cancer by seeing it on the screen herself. This made the diagnosis very difficult to process mentally.

Vikki was frustrated by how much she had to advocate for herself to get a diagnosis. She says she would not be alive today if she had listened to the first GP she saw prior to her diagnosis of secondary cancer.

Vikki wants to see GPs take symptoms more seriously and listen to patients: they know their body better than anyone. She also wants GPs to be trained in how to deliver diagnoses, as the way this news is delivered can have a huge impact on patients' mental wellbeing.

"There was a really horrible bit where they misdiagnosed me. I still think to this day that something that they said wasn't cancer a year before was actually cancer, so I think I was late getting diagnosed with secondary. There was a lot of anger there."

(50+, Northern Ireland)

*Names have been changed to protect anonymity.

Access to clinical trials

Jurors felt that access to clinical trials was lacking. None of the jury members were offered the option to join a clinical trial when they were diagnosed and given treatment, although one of our children and young people cohort did take part in a clinical trial.

There were widespread misconceptions around clinical trials. Most jurors thought of them as risky, and mostly used by students to make quick cash, rather than formalised processes available to cancer patients. Those who had been aware of trials throughout their treatment thought that cancer clinical trials would not be available to people like them, so did not think to ask if there were any appropriate for them to participate in. The information on clinical trials provided by our expert witness made jurors excited and interested in them. They understood the real impact they could have on improving care, and wanted to see them offered to as many people as possible.

"I didn't know much about [clinical] trials. I assumed they were only available to the sickest people when there is nothing else the NHS can do for them."

(18-34, Scotland)

Jurors also heard about inequalities in access to clinical trials. In response, jurors thought it was important that clinical trials were offered to everyone. They also recognised the importance of increasing the diversity of patients taking part in clinical trials, ensuring that new innovations will work for a wider pool of patients.

"How do you know treatments are working if you don't trial them on a whole spectrum of people?"

(35-49, England)

Although jurors felt that access to clinical trials needed improvement, their limited awareness of the topic made it challenging for them to develop specific recommendations in this area.

Mental health and wellbeing

Many jurors experienced mental health challenges as a consequence of their cancer diagnosis and treatment. Throughout their cancer journey and beyond, they worried about the future and struggled with changes to their body and relationships. Some also had financial concerns to manage and found these had a profound impact on their mental health.

The jury saw access to free mental health support through the NHS as essential to countering these challenges. However, this support was either unavailable or very challenging to access, often with long waiting lists. Those who did manage to access NHS mental health support found it was lacking. They generally found they were provided with too few sessions with a mental health professional and that by the time they reached the top of a waiting list it was too late in their cancer journey to make a difference.

"For me, mental health support has been terribly lacking, all the way through, from every angle."

(50+, England)

On the other hand, those who received mental health support through charities spoke positively about the support provided to them, and found this improved their mental health overall. These jurors were careful to acknowledge that they had to do their own research to identify these services, which they recognised would not be possible for everyone.

"I feel like I had to ask for it [mental health and wellbeing support]. I feel like if I didn't ask for extra support in terms of counselling and talking therapies, I don't believe I would've got it."

(18-34, England)

Finally, jurors identified a real lack of support for mental health post-treatment. They spoke positively about the care that was provided by most healthcare professionals as part of treatment. However, with reduced contact with healthcare professionals after treatment, this reassurance dropped off at a time when many still felt they needed help and support to stay mentally well.

Case study: Rohan*

Rohan was diagnosed with bowel cancer as a teenager. The diagnosis came as a massive shock.

Although Rohan had a lot of support from his family, he struggled mentally throughout his journey. He felt that his GP was very rushed when delivering his diagnosis and did not take the time to speak to him. During his treatment, Rohan's nurses were friendly, but he did not feel that they had the time to check how he was doing mentally.

Rohan found it hard to go out and do the things that he enjoyed doing before his diagnosis. This was both because of the tiredness caused by his treatment and because his cancer was always at the back of his mind when he did spend time with friends and family.

Rohan also found it hard to talk about his mental health. He felt that having support from other people with cancer – and in particular other young men with cancer – would have helped him discuss how he was feeling and made his journey easier. In addition, Rohan felt that being able to talk to other people with similar experiences would have helped him manage his anxiety by giving him a better idea of what to expect.

"It was really hard to deal with the after-effects after going through all of that. It feels like a part of you is stolen. Most of the support I got was from my family. The nurses were nice but didn't have the time to sit down with you and talk. I think it's an issue in the UK that people just don't have the time."

(18-34, England)

*Names have been changed to protect anonymity.

Addressing health inequalities

By comparing their experiences, jurors saw that care is not equivalent across the four nations of the UK. Jurors from Scotland and Northern Ireland felt that aspects of their care were worse due to issues within the health systems where they live (i.e. GP access and hospitals closing).

Multiple jurors from minority ethnic backgrounds described difficulties in accessing good quality care. For example, jurors from minority ethnic backgrounds were often said that they had struggled to get a diagnosis due to their symptoms being repeatedly ignored by GPs. However, none of these jurors explicitly related the problems in their cancer care to health inequalities, nor was this explicitly pointed to by other members of the jury.

Many jurors noted that they had had to advocate for themselves to receive a better standard of care. Jurors worried that not everyone would have the skills or confidence to do this, especially people who speak little English, or who are not able to spend the time learning more about cancer.

"Social inequality goes against what the NHS should be, which is having equal healthcare across the country."

(18-34, England)

Jurors also spoke about the challenge of being able to access treatment. They noted that patients need both access to transport to get to their treatments and the ability to pay for that transport. These expenses were especially challenging for those with fewer financial means. Patients living in rural areas were also felt to be particularly disadvantaged by the cost and time needed to get to treatment.

Case study: Emily*

Emily was diagnosed with two forms of cancer around the same time.

She had to stop working due to her illness. Her husband is on a low income, so money was tight, and they struggled while she was undergoing treatment. She was grateful for financial support from the charity Macmillan Cancer Support, but it only came at the start and quickly ran out.

Emily struggled with using hospital transport while she was going through radiation therapy for tongue cancer. She had to be ready for specific windows of time in the mornings, then wait after treatment to be dropped home. Emily found waiting for the transport especially difficult as she had to deal with fatigue and side-effects from her treatment. She considered staying in a flat near/in the hospital while undergoing treatment, but this was far too expensive.

Now, Emily still needs to regularly go to hospital for treatment for breast cancer, and for follow-up treatments and procedures to improve her quality of life following her tongue cancer. Each round trip costs her £30, accounting for trains and taxis.

> "Having no money makes everything much more difficult. I have no money… I have zero income, and my partner is on a low wage. We've really struggled […] There needs to be some sort of reform with payments… people really need help."
>
> **(50+, England)**

*Names have been changed to protect anonymity.

Addressing healthcare workforce challenges

Jurors had picked up on news of staff shortages within the NHS. They suspected that this problem was leading to a general decline in standards of care, as well as contributing to some of the challenges they had personally faced. They linked under-resourcing to instances where staff had been distant, negligent and/or rushed when dealing with them as patients. They also suspected that a shortage of time led to staff providing incomplete or unclear information. Staff shortages were also felt to be a probable explanation for experiences of slow processes, particularly at the beginning of a cancer journey. Many suspected that the delays for GP appointments and test results which they experienced might have been caused by staff shortages.

> "My breast cancer nurses were great. The only downside, which is more from an NHS perspective, is that they come back to you slowly because of the strain on resources."
>
> **(35-49, England)**

While staff shortages were not seen as the top issue throughout the workshops, jurors continued to see them as a probable contributor to the challenges they felt the system is facing. This was also an area where jurors struggled to see how matters could be improved, especially in the short term.

The jury's priorities

How the jury developed its recommendations

In the first three workshops, jurors spoke about how cancer care could be improved, exploring proposals from expert witnesses and suggesting their own. In the final workshop, they revisited all the proposals discussed so far to develop a set of recommendations that reflected their priorities.

By the end of the engagement, jurors had developed a list of priorities for the Government, and recommendations for what a focus on this area could look like in practice.

Priority 1 – Diagnosis: Ensure people are diagnosed as early as possible by investing in education, screening and primary care

Why this was a priority

Jurors identified diagnosis as the aspect of their cancer journey where they had experienced the greatest problems in the quality of their care. They discussed how diagnosis is the time when many patients are at their most vulnerable, making it particularly important to get right. Hearing about each other's challenging experiences at diagnosis reinforced the jury's view that this should be an important area of focus for the UK Government.

> "As a nation we need to be more educated about cancer, we are so in the dark. We just bury our heads, because it's scary, until we have to take it on board."
>
> **(50+, England)**

In the second workshop, an expert witness provided more information on the state of diagnosis in the UK. Hearing about the incidence of late stage and emergency diagnosis and the impact this has on outcomes helped move the conversation on from the impact of poor diagnosis on their experience. The jury began to see this as a resourcing challenge with an impact on survival, and, more pragmatically, cost implications for the NHS. In their view, earlier diagnosis would improve patient experiences, cancer survival, and cost the NHS less money.

In the final workshop, the expert witness spoke about some challenges around access to equipment, including equipment used for

diagnosis. This solidified the view that diagnosis could be improved through better access to equipment and technology. Jurors also spoke about different types of screening they had been offered or had heard of. They spoke about family screening, BRCA testing, and other gene testing. While they did not go into detail about these technologies, they felt that these and similar tests could be rolled out on a larger scale since the technology is available.

The jury emphasised that improving the diagnosis process is vital to improving cancer care overall, because patients being diagnosed late, and/or in urgent and emergency settings, leads to more intensive and complex treatment and lower survival rates. This in turn puts pressure on the health service by increasing costs and requiring more or specialist staff time.

Jurors' recommendations for action

1. More should be done to educate the public about cancer symptoms

Jurors had personal experience of not recognising symptoms related to their cancer. With this in mind, they felt there should be investment into raising public awareness of key symptoms to look out for. They hoped that this would give people confidence to seek help early and, if needed, push their GP for tests.

Jurors identified two key channels for increasing knowledge of cancer symptoms:

- **Public awareness campaigns:** Jurors felt that campaigns to encourage checks for breast cancer were particularly effective and hoped to see something similar for other types of cancer. They noted social media as an important channel for spreading a message. Jurors also expressed gratitude to celebrities who have disclosed when they had a cancer diagnosis. They felt that this is a powerful way of raising awareness of symptoms.

- **More education about cancer symptoms in schools:** Younger jurors explained that they did not hear about cancer in school, but believed it should be covered in personal, social, health and economic education (PSHE) as part of the school curriculum.

2. Invest in increasing the number of GPs and improving their knowledge of cancer symptoms

Jurors said they wanted to see investment in increasing the number of GPs across the UK. In practice, they hoped this would mean:

- **Sufficient numbers of GPs across the country,** meaning it is easy to get a GP appointment, no matter where you live.

- **Easier access to face-to-face appointments and appointments with the same GP:** two things they felt are vital to spotting signs of cancer.

Jurors also wanted to see increased investment in training for GPs to spot cancer symptoms. This was especially important for jurors who had visited the GP multiple times and been dismissed before receiving their diagnosis, and those who had been diagnosed with rarer forms of cancer. A juror with a rare form of cancer pointed to work by the charity Myeloma UK to raise awareness of this form of cancer among GPs and felt the same should be done for other cancers.

> "Myeloma UK have developed a booklet that they were trying to distribute to all GPs. I think it's coming out more now and I've also seen it advertised on the TV. I'm sure GPs are well trained in spotting other cancers like breast cancer or prostate cancer, but they know less about rarer forms of cancer."
>
> **(50+, Scotland)**

3. Invest more in innovations around diagnosis

Jurors wanted the UK Government to focus on improving the equipment, infrastructure and IT used for cancer diagnosis. In particular, expert witness presentations demonstrating that the UK is behind other countries in terms of innovation inspired jurors to call for significant improvements in this area. Some also spoke about the use of the PSA (Prostate Specific Antigen) test to diagnose prostate cancer as an example of the potential to innovate better and faster ways to test for cancer.

> "One of the main things for diagnosis is research – prostate cancer is an example at the moment. Once the prostate cancer antigen test became available, it was accessible to everyone. So, diagnosis depends on research."
>
> **(50+, Scotland)**

Jurors strongly believed that investment in innovations at this stage would improve efficiency and reduce waiting times.

They also wanted to see increased access for cancer patients to clinical trials, and increased diversity in the people taking part in trials. They felt this would support the development of better innovation in treatments and diagnostic tools.

4. Screening for cancer should be made faster and easier

Jurors wanted to see improvements in the take up of cancer screening. In their view, increasing the number of people who are screened would help identify cancer earlier and in turn improve health outcomes.

They wanted to see more efforts made to highlight the importance of cancer screening to the public. In particular, they felt investment should be made into outreach efforts in local communities, like the use of mobile testing units and campaign communications in a variety of different languages.

Some jurors also wanted to see increased access to screening techniques and genetic tests such as those for breast or prostate cancer. They also wanted family screening to be more widely available.

Priority 2 – Equal Access to Care: There should be equal cancer care for all – no matter who you are or where you live

Why this was a priority

In the jury's view, providing equal care to all patients, regardless of where they live or their background, is an essential part of the NHS' ethos. From listening to expert presentations and sharing their own experiences, jurors became increasingly concerned that the quality of cancer care differs based on:

- Where you live.
- Ethnicity and cultural background.
- Income and financial situation.
- Ability to advocate for yourself.

For jurors, it was a fundamental principle that everyone getting treatment for cancer should be able to receive the same level of care. They wanted to see this be a key focus for the UK Government and the devolved governments in Scotland, Wales and Northern Ireland, and the NHS in the future.

> "You shouldn't be receiving worse or less treatment purely because you cannot afford to live in [an] area that others can."
>
> **(18-34, Scotland)**

However, jurors recognised that inequality is a problem across society and not just in healthcare. While they wanted the governments of the UK to focus on the challenge of health inequalities, it felt like a big problem related to other large structural challenges (employment, education, transport in rural areas, the position of people from ethnic minorities in society etc). They were therefore sceptical that significant changes could be made in the short term or by the NHS by itself.

Jurors' recommendations for action

1. There should be equitable access to care across all four nations of the UK

Jurors wanted to see the four nations work together to address challenges across cancer care.

They emphasised that funding for cancer care should be distributed 'equally' across the four nations, according to population. They believed this would help ensure that staffing levels are more equal across the four nations and that standards of care are equivalent.

> "A lot of people have to travel to Belfast to get checked up. Staff are drawn to the bigger cities where there's more investment. Attracting consultants to other areas might balance some of the inequalities that we are seeing"
>
> **(35-49, Northern Ireland)**

2. The NHS should make more efforts to reach out to those who might find it difficult to engage with the healthcare system

Jurors wanted to see the NHS make more of an effort to reach out to and engage with people who might be less likely to seek support if they notice potential cancer symptoms. They suspected this could be people for whom English is not their first language, know little about the NHS, or do not feel confident seeking help.

They suggested that more materials should be available in languages other than English and that healthcare workers should go out into the community (via community groups) to educate people about the symptoms they should look out for and the care they should receive. They believed this would encourage people to come forward for help if they need it.

3. There should be support in place for people on low incomes including support accessing treatment

Jurors felt that people on low incomes receiving cancer care should be entitled to specific financial support or benefits. In particular, they wanted to see travel funds available to those on low incomes or those who need to travel very long distances e.g. those living in remote or rural areas.

They said this would help patients manage their symptoms and treatment, while also protecting their mental health and wellbeing by reducing the mental burden of worry about the financial impact of their illness. Protecting patients' mental health was seen as absolutely vital to their recovery.

> "Having no money makes things even more difficult. Charities have helped support me but going to the hospital is still expensive. There needs to be a reform with payments – people need help."
>
> **(50+, England)**

4. Care should be patient-centred and focused on what is right for the individual

Jurors wanted healthcare staff to advocate for patients to receive the best possible care, so patients would not have to do this themselves. In practice, this meant listening to and believing patients when they first disclose symptoms and suggesting where patients might benefit from taking part in a clinical trial or from alternative treatments.

Jurors felt this would help counter inequalities that some groups experience, and that it would also make patients feel more supported.

Priority 3 – Mental Health: There should be mental health and wellbeing support for all patients, and their families or carers

Why this was a priority

Jurors felt strongly about the need to improve mental health and wellbeing support for cancer patients.

Jurors' own experiences highlighted the difficulties in accessing mental health support via the NHS. They also agreed that signposting to mental health and wellbeing support was particularly poor when waiting for a formal diagnosis, and in the post-treatment and recovery phase.

There were concerns about experiences with busy, unempathetic or apparently poorly trained healthcare professionals, which all jurors agreed could have a significant impact on wellbeing and mental health at diagnosis and during treatment.

Jurors saw protecting patients' mental health and wellbeing as vital to their recovery, both in the short and long term. They believed investment in mental health and wellbeing would help produce better treatment and survival outcomes across the UK. Some even argued it would support those who are post-treatment re-enter the workforce and contribute to the economy.

Children and their parents spoke about the impact of their cancer experiences on their mental health and reflected on the lack of support they had received. This resonated with the jurors, who felt that younger people may struggle to talk about their mental health and find it difficult to know when and how to ask for help.

Jurors' recommendations for action

1. Patients should be given specific high-quality mental health and wellbeing support when waiting for and upon receiving a diagnosis

Jurors emphasised that all staff interacting with patients where cancer is suspected should be supportive and empathetic. They especially wanted GPs and staff delivering the news of a diagnosis to have the time and training to be able to communicate the news sensitively and answer important questions.

> "When it came to my appointments, that part of it [mental health support] was disregarded... There should be training for doctors who deal with any diseases regarding mental health so patients get initial heart-to-heart support."
>
> **(18-34, England)**

Jurors suggested a role for a specific 'friendly face' for every potential or recently diagnosed cancer patient. They wanted this person to provide support, reassurance and to answer questions in the period between being informed that investigations are taking place and a meeting with a specialist.

2. Mental health and wellbeing support should be available from diagnosis to post-treatment

The wide range of experiences shared throughout the workshops highlighted to jurors the importance of making mental health support available at all points in the journey, reflecting the variable nature of individual experiences. Jurors warned against considering the end of treatment as the last point at which someone might need mental health support. They wanted to ensure regular post-treatment signposting to formal support.

> "There was nothing beyond treatment. You feel left. You could really benefit from mental health support [following treatment]... There should be mental health support at all stages."
>
> **(35-49, Scotland)**

Jurors wanted to ensure it was easier to access free mental health and wellbeing support. They wanted to see a reduction in waiting times to access NHS support and some flexibility for patients with regard to appointment times. Among those who had accessed it, mental health and wellbeing support from charities was seen as valuable. They wanted to see better signposting to those resources from healthcare professionals, and more financial support to make sure these organisations have the capacity to deal with patients' mental health needs.

3. There should be an emphasis on bespoke and high-quality support for children and young people and their families

Jurors felt it is particularly important for children and young people to have access to mental health and wellbeing support, as they recognised they would be facing unique challenges.

Jurors felt children and teenagers should be given access to free mental health and wellbeing support as standard. They also wanted to see support offered to family members of children and young people with cancer. Jurors, especially those with children, discussed how difficult it must be for a parent to process their own emotions while supporting their child, making mental health support for the whole family feel especially important.

Priority 4 – Improving Communications: There should be better communication within the NHS and with cancer patients about their care

Why this was a priority

Jurors identified key moments where poor communication or an absence of communication could have a negative impact on a patient's care at diagnosis and during treatment. This included issues around:

- Having little to no information about cancer before being diagnosed, then having to process a lot of information very quickly as soon as they were diagnosed.
- Having to rely on incomplete or imperfect information about their treatment, delivered by healthcare professionals who were very busy.
- Not hearing about alternative treatment options or clinical trials.

Not having access to clear, high quality and complete information made jurors feel they could not make fully informed choices about their care, or that they might have missed an important option that would have made the process easier or more effective. Jurors also were keen to note that feeling 'in the dark' at key moments in their journey significantly increased their anxiety and contributed to poor mental health.

In addition to these problems communicating with patients, jurors also pointed to communications issues within the healthcare system. They said that information was not always easily shared between the healthcare professionals they saw. Many said they had to repeat their "story" in every appointment, or make sure that key information about their health was taken into account. They also worried that different NHS Trusts and devolved nations were competing to reach their own targets rather than collaborating. From their experience and from information presented in expert presentations, they concluded that this leads to long waiting times, issues getting referred, and information about patients not flowing smoothly from one part of the service to another.

> "You're given little information and have to fill in the blanks yourselves… There's not enough communication between departments and it doesn't flow. I had to chase things up myself."
>
> **(35-49, Northern Ireland)**

Jurors' recommendations for action

1. Information should be clear, high quality and complete, especially immediately after diagnosis

Jurors wanted to see better processes for delivering information at diagnosis. This included training to ensure information is delivered sensitively and appropriately, and the provision of written information that can be taken away and reflected on once the shock of a diagnosis has subsided.

They also thought that every patient should be given a clear account of all the treatment options available to them and be pointed to clinical trials appropriate to their circumstances.

> "Make the information you get at diagnosis clear, concise and show the options available for you. Information out there is so vague – there needs to be more pathway-type guides with what to expect next."
>
> **(35-49, England)**

As mentioned above, jurors also wanted to see more consistent and effective signposting to mental health support services throughout a patient's cancer journey, including those offered by charities.

2. There should be better information sharing between different healthcare services

Jurors wanted to see more information being shared between different services – for example, more information shared between cancer services and mental health services - to ensure that patients are getting better and more joined-up care.

Jurors also thought that better information sharing within the NHS would improve the quality of information that patients receive. They felt it would make the cancer journey smoother for patients and avoid them feeling 'lost' in the system between referrals and while waiting for appointments and results.

They also suspected that sharing information more readily would make it easier for patients to access a second opinion, especially if they are having issues around getting diagnosed.

3. There should be more effective collaboration between different hospitals and NHS Trusts

Jurors wanted to know that different services were working together to ensure that patients are receiving the best possible care.

Practically, this means making sure patients are referred to the best services for them, rather than what is closest or available in the same NHS Trust. Jurors believed that collaboration and information sharing would allow patients to have more choices and flexibility when it comes to their care, so they can decide what is best for them. They also hoped it would result in the sharing of expertise and knowledge which could result in better outcomes for patients.

Using a citizens' jury to inform policy making

Learnings from the citizens' jury: overall reflections

The citizens' jury method we used in this engagement was effective in helping to identify patients' priorities for cancer care across the UK. The time it allowed for learning, discussion and deliberation enabled participants to develop focused, actionable recommendations. Hearing the experiences of other patients and information from expert presenters enabled jurors to adopt a 'citizen mindset', considering system changes rather than simply identifying how their own experience could have been better.

Jurors' perceptions of the current state of cancer care did not always align with the data provided by experts and stories in the media, underlining the importance of understanding patient experiences qualitatively. Jurors' views also changed throughout the jury as they learnt more about cancer care in the UK; this demonstrated the importance of hearing the reflective, informed views of patients.

Jurors' priorities and the elements of care that they felt were important differed slightly from the experts' interpretations. Although the policy proposals outlined by experts were considered by jurors, their recommendations did not always align.

To encourage others to use this methodology to hear from cancer patients directly, we have shared some reflections on the process and recommendations for how to build on this approach in the future.

Learnings from the citizens' jury: What went well

Encouraging jurors to adopt a citizen mindset: We anticipated that jurors would initially be focused on their own experience, and not the experiences of cancer patients as a whole. To help jurors see the big picture, we:

- Asked jurors outright to focus on the experiences of different types of cancer patients, thinking about people on low incomes, from ethnic minority backgrounds or living in rural areas.
- Introduced testimony from children and young people and spoke about impacts on this group throughout the workshops.
- Encouraged jurors to think about what should change through activities like mapping out the 'ideal cancer journey'.

Ensuring jurors felt heard: This was key to ensuring that everyone felt comfortable and confident in contributing to group discussion. We did this by:

- Keeping jurors in the same breakout groups for each workshop, to help build rapport and the confidence to share their views and deliberate.
- Highlighting the potential for jurors' contributions to influence policy throughout the process, with support from representatives from the SCCG.
- Enabling jurors to shape the design of the process, by selecting topics to discuss in Workshop 3. This allowed jurors to be active participants in the direction of the jury.

Keeping jurors engaged: We recognised that the process was a big commitment, especially given that some jurors were receiving treatment for cancer. We helped participants to stay involved throughout by building in breaks, and sharing presentations after each workshop so jurors could revisit content at their own pace. We also took a flexible approach to participation, offering catch-up sessions and separate interviews for those struggling with balancing their cancer treatment with group workshops.

Making information digestible: We ensured that information shared with jurors was accessible by avoiding jargon and specialist concepts. We also provided short summaries which were revisited throughout the process.

Learnings from the citizens' jury: Lessons for future engagements with cancer patients

Drawing out inequalities: While jurors recognised differing experiences of care, those who received poor care did not link the issue of health inequalities to the failures they personally experienced. To gain a more nuanced and complete exploration of the issue, future engagements could include expert testimony from patients affected by health inequalities. It could also provide private forums to enable participants, who might have received worse care as a result of health inequalities, to analyse their own experiences in the context of the information they have learned.

Discussing more policy areas in detail: A limitation of this engagement was that we only had time to discuss four policy areas in detail. It is likely that this will have had some impact upon jurors' final priorities. Future research may want to consider longer engagement, or the use of tools like online engagement platforms to explore a range of policy areas between sessions.

Engagement between sessions: Jurors fed back that they sometimes struggled to express everything they wanted to say on a topic 'in the moment'. If budget is available, future engagement could offer an incentive to share further thoughts. While we asked jurors to follow up, there was no incentive for this which meant take-up was low. Offering the option to check in between session throughout an online engagement platform or interviews may help address this.

Supporting people currently going through treatment: We noticed that taking part in online workshops was a challenge for this group. While we offered options for these jurors to engage with the process outside of the sessions, these adaptations might be challenging to deliver at scale. Future engagement could offer alternative ways of taking part in the engagement via an online engagement platform or paper tasks.

Appendix

Our approach

Why a citizens' jury?

A citizens' jury is a type of engagement where a group of people from different backgrounds come together to have an informed discussion about an issue that matters to them. It is a deliberative method that is well suited to reaching a consensus on sensitive and complex policy areas like the provision of cancer care.

Deliberative engagement is an important tool for meaningfully involving the public in decision-making as it goes beyond surface level insights. It equips participants with the information they need to be able to meaningfully comment on the issues at hand, associated trade-offs, and to provide informed recommendations.

It places a strong emphasis on considered judgement, based on good evidence, and free and fair collective discussion. While we collected insight on patients' spontaneous views, we also gathered insight into their informed opinions. The recommendations in this report are based on those informed opinions.

Key features of deliberative engagement are:

- Input from expert witnesses to give participants the information they need to reach an informed opinion.
- Structured, facilitated, and inclusive discussion and deliberation between participants, giving them the space to reflect on the issue at hand.
- Participants coming to considered judgements, linked to a goal or purpose. In this engagement, participants identified priorities and developed 'recommendations' for government policy on cancer care to ensure it works in the public interest.
- Different life experiences and circumstances are represented in a deliberative process, to ensure participants hear from and consider perspectives outside of their own and adopt a 'citizen mindset'. This means they can consider where they consider and advise on system changes that would benefit everyone, rather than simply identifying how their own experience could have been better.

Who we spoke to

Jurors were recruited to ensure diversity across the four nations of the UK, rural, urban and suburban locations, areas of more/less deprivation, age, age at diagnosis, gender, ethnicity, socio-economic group and sexuality. We initially began the process with 19 jurors, but two dropped out during the jury due to illness and other commitments.

We made the decision to focus the conversation on patients, as opposed to bereaved family members and partners, so they could reflect on their own experience of going through the cancer journey.

To capture a range of cancer experiences, we ensured that jurors were at different stages of the cancer journey and that they had been diagnosed across all four stages of cancer (if applicable). We also ensured that a range of different types of cancer were represented.

A total of 17 participants across the UK

5 aged 18-34
3 aged 35-49
9 aged 50+
1 received treatment before turning 18

9 male
8 female
2 identify as lesbian, gay or bisexual

11 in socio-economic* grade ABC1
6 in socio-economic grade C2DE

6 from a minority ethnicity background

7 living in the 20% most deprived areas according to the Index of Multiple Deprivation**

7 living in England
4 living in Scotland
3 living in Wales
3 living Northern Ireland

5 diagnosed with Stage 1
6 diagnosed with Stages 2-3
2 diagnosed with Stage 4

5 currently at diagnosis and treatment
4 finishing treatment and recovery
8 living with and beyond cancer

5 diagnosed with breast cancer
3 diagnosed with bowel cancer
3 diagnosed with prostate cancer
2 diagnosed with blood cancer (1 acute myeloid leukemia (AML) and 1 chronic lymphocyticleukemia (CLL))

2 diagnosed with brain cancer
1 diagnosed with sarcoma
1 diagnosed with another cancer

*Social Grade is a socio-economic classification. This is a way of grouping people by type, which is mainly based on their social and financial situation. 'A' is the highest grade and 'E' is the lowest. (Office for National Statistics).
**The Index of Multiple Deprivation (IMD) datasets are small area measures of relative deprivation across each of the constituent nations of the United Kingdom. Areas are ranked from the most deprived area (rank 1) to the least deprived area (rank 10) (Consumer Data Research Centre).

Participants were recruited through free-find market research recruitment. This involved our in-house fieldwork team partnering with specialist research recruiters across the country to identify potential participants. Recruiters used traditional methods, primarily the use of social media ads and database recruitment, topped up with recruitment via local community groups and snowballing to meet specific quotas.

We chose this approach to ensure that we could reach people who were not already within cancer charity networks and who were less likely to have engaged in other research on the topic.

Details on how we supported jurors throughout the process can be found in [Using a citizens' jury to inform policy making.]

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[2] Staging is a way of describing the size of a cancer and how far it has grown, ranging from stage 1 (early-stage cancer) to stage 4 (secondary or metastatic cancer).

Workshop content

The workshops covered the following themes:

- **Workshop 1: The current state of cancer care and children and young people's testimonies.** This explored the current state of cancer care in the UK and jurors' views of the ideal cancer journey. Then the children and young people cohort, consisting of three children and their parents, shared testimony of their experience. Finally, jurors selected two topics they were most interested in exploring in more detail in Workshop 3.
- **Workshop 2: Diagnosis and innovation.** This workshop explored the state of diagnosis in the UK, as well as innovation and access to clinical trials more specifically.
- **Workshop 3: Health inequalities and mental health.** This workshop explored the impact of health inequalities on cancer care, as well as the state of mental health support for cancer patients in the UK.
- **Workshop 4: Constraints on the new UK Government and final recommendations.** Jurors heard about financial constraints on cancer care and policy, identified priority areas and developed recommendations.

Expert Witnesses

Workshop 2

Our first expert witness was a Senior Fellow from The Nuffield Trust, who covered the current state of cancer diagnosis in the UK and the implications for policy. Key points covered included:

- There were over 2.89 million urgent suspected cancer referrals in 2022/23, but most of these referrals did not result in a cancer diagnosis.
- Current NHS policy is focused on diagnosing cancer at an earlier stage and improving the speed with which patients receive a definitive diagnosis.
- However, our current course shows that we are seriously off NHS targets.
- A large number of cancer cases are still being diagnosed through emergency routes which are less effective at early diagnosis.
- There will need to be sustained investment to close the gap between demand for cancer diagnostics and what services can deliver.

Our second expert witness, a Medical Director with expertise in medical oncology and clinical drug development, covered innovation and clinical trials. Key points covered included:

- Clinical trials aim to either develop new and better treatments or improve understanding of existing treatments.
- They can provide patients with early access to new, innovative treatments that can improve health outcomes, but there may be unexpected and/or serious side effects.
- Research suggests that while many cancer patients would consider treatment as part of a clinical trial, a much smaller number heard about trials during their treatment.
- At present, patients who join clinical trials are not representative of patient populations overall. This means many patients are missing out on the opportunity to take part, and the evidence from trials may not include all groups.
- We can improve access to clinical trials by increasing the public's awareness, encouraging trials in more locations and setting targets to improve diversity.

Workshop 3

The Chair of the Association of Cancer Physicians (ACP) discussed health inequalities. Key points covered included:

- Health inequalities impact people in many ways across different aspects of their life. Places where there are higher levels of deprivation and ethnic diversity are more likely to report poorer levels of care.
- There are barriers for people who live in more deprived areas – it can be hard to travel to hospital for treatment, or they may not be familiar with NHS systems.
- Having different NHS Trusts can mean it's hard for professionals to refer patients outside of the Trust – even if this would be better for the patient.

Workshop 4

A Senior Research Economist from The Institute for Fiscal Studies (IFS) discussed financial constraints on the new UK Government. Key points included:

- The UK Government has a large amount of money at its disposal but won't have the money to do everything, so some tough choices are coming – how much to spend on the NHS, and how to spend that money within the NHS.
- Based on the Labour party's manifesto, the UK Government will likely focus on reducing waiting lists, diagnostics and modernisation.

Remaining presentations on the state of cancer care in the UK (Workshop 1), and mental health (Workshop 3) were presented by member of the Thinks Insight & Strategy team. These presentations were developed with support from members of the SCCG.

We would like to extend our thanks to the members of the jury and the expert witnesses, who contributed their time, expertise and energy to this project, providing a wealth of insight and a clear vision for the future of cancer care.

The **Specialist Cancer Charities Group (SCCG)** is a coalition of charities dedicated to increasing patient and healthcare professional involvement in services to improve cancer outcomes. The SCCG aims to create an engaged patient and clinical community to drive necessary changes to improve cancer outcomes in line with comparable other countries.

The coalition includes prominent charities including Anthony Nolan, Blood Cancer UK, Bowel Cancer UK, Breast Cancer Now, Pancreatic Cancer UK, Prostate Cancer UK, Sarcoma UK, Shine Cancer Support, Teenage Cancer Trust, and Young Lives vs Cancer.