Turning data into action

UNDERSTANDING CANCER PATIENTS’ PREFERENCES FOR TREATMENT OUTCOMES

This report was initiated and funded by Bristol Myers Squibb in partnership with Action Kidney Cancer, Kidney Cancer UK, Melanoma Focus, Melanoma UK, Mouth Cancer Foundation, Shine Cancer Support, and The Swallows Head & Neck Cancer Support Charity.

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With an increased range of new cancer treatment options but unprecedented capacity constraints in the NHS, the system, patients and healthcare professionals are navigating a new normal in cancer treatment and care.1,2

Within this context, to ensure the delivery of improved patient outcomes and uptake of new cancer treatments at the point of clinician-patient decision making, patients should be encouraged to express their treatment preferences during conversations with their clinicians.3,4

The importance of patient preferences should be considered as equivalent to other system considerations, such as capacity or costs, and clinical expertise. Without these criteria being considered, there is a concern that patients’ preferences may not ultimately inform treatment decisions.

As a first step to demonstrate the value of patient preferences informing treatment decisions, Bristol Myers Squibb conducted an online survey of 881 UK cancer patients aged 18 years and over, who have received anti-cancer therapy (systemic cancer treatments, not inclusive of surgery – see Methodology section for full definition) between 22 September and 3 December 2021 and chose to take part in the research.

This was conducted in partnership with seven oncology patient advocacy groups and undertaken by Ipsos. This is one of the most recent UK surveys investigating cancer patient preferences for treatment outcomes. The survey specifically asked which factors were most important to patients when deciding the right treatment for their cancer and individual circumstances to build a better picture of what patients wanted from a treatment. The survey also explored whether these patients felt they were sufficiently involved in these treatment decisions and the benefit of tailored support.
The importance of patient preferences should be considered as equivalent to other system considerations, such as capacity, costs and clinical expertise.

### INTRODUCTION

Determining the right treatment for a patient’s cancer is unique to each individual, often requiring consideration of a number of factors. These can include the distance needed to travel to hospital, pre-existing comorbidities, and how it will impact their ability to carry out day to day tasks. The importance of these factors can be influenced by a clinician’s expertise, a patient’s preferences and system considerations such as workforce capacity and costs.

Macmillan Cancer Support has previously evidenced the influence of such criteria on treatment decisions. They reported that many older patients were not offered potentially beneficial treatment, which was due in part to system-wide assumptions about a patient’s ability to tolerate treatment, based on age rather than physical fitness. This suggests that, if patients are to access the right treatment for their circumstance, it is crucial that all criteria used to inform treatment decisions are considered equally.

Patient preferences are particularly important because when patients play an active role in their health care, there is evidence that they may feel greater ownership of their care. In turn, this can result in better outcomes for the patients, minimised escalation of clinical support, and reduced costs to the health system. When patients are faced with a decision about their cancer treatment, they may compare the benefits and drawbacks associated with their treatment against what matters most to them. In some instances, patients may be willing to accept drawbacks and compromise on elements of their care for their treatment to achieve its desired outcome.

Listening to such patient preferences for treatment is crucial to securing patient empowerment and therefore improved patient outcomes.

As investment in cancer and the therapeutic pipeline of treatments continues to grow, scientific advances are contributing to improved patient outcomes. Cancer survival rates have doubled over the last 40 years and, as of 2018, oncology treatments made up nearly 40 per cent of the global pharmaceutical industry clinical pipeline. A greater variety of treatment options presents the potential for different outcomes, and different drawbacks and benefits for patients to consider. This means the choices patients and clinicians have to make about treatment are likely to become more complex.
Moreover, there is growing consensus that patients’ preferences are not always considered and given equal weight to other treatment decision making criteria.15,16 This means that patients may have a preference for a certain cancer treatment, or the experience associated with it, which may not be echoed by their clinician. There is also uncertainty as to how and if patient preferences are communicated to clinicians during treatment decision conversations.17 If conversations about the difference in preferences for treatment do not take account of the evolving cancer treatment landscape, there is a risk patients may not be able to access the treatment, and therefore the outcome they want.

There is, therefore, an urgent need to better understand and demonstrate the importance of listening to patient preferences for treatment, particularly within the context of increasing access to innovative cancer treatments. Giving equal weight to patient preferences, clinical expertise and systems considerations, will help patients and clinicians navigate more complex treatment decisions in the future.

To explore the value of patient preferences within treatment decisions, Bristol Myers Squibb, in collaboration with Ipsos and in partnership with seven patient groups, commissioned a UK wide survey of cancer patients who had received anti-cancer therapy. Throughout the survey, patients reflected on their experiences of decisions around their cancer treatment.

This report combines information from this survey with desk-based research to provide evidence supporting the integration of patient preferences in treatment decisions and delivery of care. The hope is that these survey data and insights can be turned into action, and be used pragmatically by NHS England (NHSE), Health Education England (HEE) and the National Institute for Health and Care Excellence (NICE) to ensure that uptake of innovative cancer treatment continues. It is also hoped that they will be used to ensure patient preferences are met as the cancer treatment landscape continues to change.
This survey demonstrates that the patients surveyed generally know which factors they are willing to compromise on to achieve their treatment goal. Yet these patients may not be involved in all treatment decisions as much as they would like, with 50 per cent of patients stating they were not fully satisfied with their level of involvement. Therefore, patients may not always be able to action preferences about their treatment.

In parallel, findings from the report indicate that tailored care and support would make a number of factors more manageable when considering anti-cancer therapy for cancer (only 23 per cent of patients surveyed said no other factor would be more manageable if it was possible to receive tailored care and support). This could help ensure that, in the future, the effects of treatments that patients are willing to compromise on to help their anti-cancer therapy achieve their desired outcome, are made more manageable.

This report provides evidence of the importance of routine integration of patient preferences in treatment decision making in an evolving treatment landscape. It also demonstrates the importance of giving appropriate weight to patient preferences, alongside clinical expertise and other system considerations. Recommendations to improve the integration of patient preferences in treatment decision making are outlined within this report.

1 EXPECTATIONS
Patients have expectations about anti-cancer treatment

- 61% of patients hoped their treatment would get rid of their cancer¹

- 24% of patients expectations of treatment were influenced by information they find online and 72% influenced by their clinician²

2 TREATMENT CONSIDERATIONS
There are various factors to consider when making treatment decisions and patients and clinicians value these differently

- 89% of patients experienced unpleasant side effects³
- 78% of patients felt the possibility of longer term side effects³
- 85% of patients felt the distance travelled to receive treatment³
- 57% of patients felt how quickly they could access treatment³

3 TREATMENT DECISIONS
Clinicians discuss treatments with patients

However...

- 50% of patients weren't involved in treatment decisions as much as they would have liked
- 28% of patients felt treatment decisions were made equally

4 IMPACT
Patient preferences may not be considered as much as other factors used by clinicians to make treatment decisions

¹ Patients surveyed were asked about the most important things they hoped their anti-cancer therapy would achieve.
² Patients surveyed who discussed anti-cancer therapy with their healthcare professional.
³ Patients surveyed who considered chosen factors to be important to them.
**METHODOLOGY**

**AIM AND RESEARCH OBJECTIVES**

Ipsos were commissioned by Bristol Myers Squibb to carry out a research study to understand the preferences and experiences of cancer patients in the UK, with the aim of establishing and championing patient-led insight on preferred treatments and outcomes. Specifically, it sought to establish:

1. Which factors, if any, are patients willing to compromise on to help their cancer treatment achieve their desired outcome?

2. Do the desired outcomes of cancer treatments differ between patients and healthcare professionals?

3. How involved do patients feel in decisions about their cancer treatment?

4. Could tailored care and support allow patients to better manage elements of their care?

To generate robust data that would reflect cancer patients’ preferences across the UK and for different tumour types, a large-scale quantitative study was required. A 20-minute survey was designed and was conducted online as the most cost- and time-effective way of rapidly undertaking large scale research.

A total of 881 participants aged 18 years and older completed the survey. Participation was open to those affected by cancer at any stage and status, provided they had received systemic anti-cancer therapy.

Patients were asked to specify the type of cancer they had experienced, from the following list: breast, lung, prostate, bowel, melanoma, lymphoma, kidney, brain, bladder, pancreatic, leukaemia, oesophageal, uterus, mouth, ovarian, stomach, myeloma, thyroid, and cervical.

Examples of this include:

- Those with low internet accessibility are under-represented
- Those who are not motivated by the honoraria offered are under-represented
- Those who are regular participants in market research are over-represented

**Terminology**

- Anti-cancer therapy – any cancer treatment that uses drugs to kill or prevent the growth of cancer cells and can include chemotherapy, hormone therapy, targeted therapy, or immunotherapy
- Clinician – umbrella term used for the purposes of this report to describe oncologist, consultant or another healthcare professional, including nurses
- Side effects – this means any side effect that is categorised as unpleasant (e.g. tiredness, sickness, diarrhoea etc), pain associated with treatment, and the longer-term side effects of treatment

**LIMITATIONS**

Certain social groups are under- and over-represented on market research online access panels and charity networks. Incidence rates by cancer type are only available by gender but not by various other demographics.

Fieldwork took place between 22 September and 3 December 2021. A blended recruitment approach was used. Most of the sample was recruited from an online access panel (n=838) and to boost the sample for specific tumour types, more participants (n=43) were recruited from the following patient support charities/organisations networks: Action Kidney Cancer, Kidney Cancer UK, Melanoma Focus, Melanoma UK, Mouth Cancer Foundation, Shine Cancer Support, and The Swallows Head & Neck Cancer Support Charity. These organisations also contributed to the development and review of the survey and report.

No honoraria were offered to the patients from the patient support charities/organisations networks to participate in the survey.

Geographic quotas were also set to ensure all regions in the UK were represented, and proportionally reflected variation in cancers by location, as per national statistics.

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Patients surveyed usually expect a curative anti-cancer therapy and would be willing to compromise on some factors associated with anti-cancer therapy to achieve this goal—such as experiencing unpleasant side effects and the distance needed to travel to hospital. However, patients surveyed would be less willing to compromise on how quickly they could access treatment.

When patients are faced with the prospect of serious illness, such as cancer, a sense of fear and loss of control may be experienced, with an urgency to ensure that they receive the best treatment to increase their chance of survival. Patients inevitably have expectations about what cancer treatment will be able to do for them. This survey found that most participants desire a cure when they begin their anti-cancer therapy journey and for many, they have an expectation that this will be the outcome. When asked what were the most important things that they hoped their anti-cancer therapy would achieve, 61 per cent of patients surveyed ranked ‘it would get rid of my cancer’ first and 64 per cent ranked ‘it would prevent my cancer coming back’ as second most important.

89% of patients stated they were willing to compromise on experiencing unpleasant side effects (i.e. tiredness, sickness, diarrhoea etc) to help achieve what they wanted.

UNDERSTANDING PATIENTS’ PREFERENCES FOR CANCER TREATMENT
When patients are faced with a decision about their cancer treatment, they will want to make sure they are prescribed a treatment that meets their expectations. To ensure this, they may compare factors associated with their care against what matters most to them. In some instances, patients may be willing to compromise on elements of their care for their treatment to achieve its desired outcome.

**PATIENTS ARE WILLING TO COMPROMISE ON SIDE EFFECTS**

The consequences of cancer treatment can differ on a scale of severity, with the potential for long term impact. Among patients surveyed, 89 per cent reported that they were willing to compromise on experiencing unpleasant side effects (i.e. tiredness, sickness, diarrhoea etc) (Figure 1). This was the factor that received the highest proportion of patients that were willing to compromise.

Patients were also willing to compromise on other important factors. This included, the impact of more severe side effects that might lead to hospitalisation (80 per cent), the possibility of longer-term side effects (78 per cent) and pain associated with treatment (78 per cent). This demonstrates that most patients would be prepared to experience varying degrees of side effects if it meant their treatment would deliver their treatment goal.

**WHICH, IF ANY, OF THE FACTORS YOU MENTIONED WERE IMPORTANT TO YOU, WERE YOU WILLING TO COMPROMISE ON TO HELP YOUR ANTI-CANCER THERAPY ACHIEVE WHAT YOU WANTED?**

<table>
<thead>
<tr>
<th>Percentage</th>
<th>Factor</th>
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<tbody>
<tr>
<td>89%</td>
<td>Experiencing unpleasant side effects</td>
</tr>
<tr>
<td>86%</td>
<td>Whether I had to visit the hospital regularly</td>
</tr>
<tr>
<td>85%</td>
<td>Impact on my physical appearance</td>
</tr>
<tr>
<td>85%</td>
<td>The distance I had to travel to receive treatment</td>
</tr>
<tr>
<td>83%</td>
<td>Whether I would be able to continue my day to day tasks e.g. work</td>
</tr>
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<table>
<thead>
<tr>
<th>Percentage</th>
<th>Factor</th>
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</thead>
<tbody>
<tr>
<td>62%</td>
<td>Whether I would be able to access support from others who have the same condition as me</td>
</tr>
<tr>
<td>61%</td>
<td>Whether I felt comfortable with the healthcare professional who would be involved in my treatment</td>
</tr>
<tr>
<td>60%</td>
<td>How my treatment would affect my relationships with my family and/or partner</td>
</tr>
<tr>
<td>58%</td>
<td>Whether I would be able to share future experiences with my family/children/friends</td>
</tr>
<tr>
<td>57%</td>
<td>How quickly I could access my treatment</td>
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</tbody>
</table>

61% Whether I felt comfortable with the healthcare professional who would be involved in my treatment

60% How my treatment would affect my relationships with my family and/or partner

58% Whether I would be able to share future experiences with my family/children/friends

57% How quickly I could access my treatment

89% Experiencing unpleasant side effects

86% Whether I had to visit the hospital regularly

85% Impact on my physical appearance

85% The distance I had to travel to receive treatment

83% Whether I would be able to continue my day to day tasks e.g. work
“Every day, we hear from our patient community that they are willing to compromise on certain factors to increase their chances of being cured of their cancer or access the best treatment for them. However, we often hear that there is a disconnect between what patients want and are willing to compromise on, and what they are offered. For example, we often hear this regarding distance to travel and the assumption that patients would be unwilling to travel to access care. While this may be the case for some patients, many others may wish to make longer travels to ensure that they access the right care, and we need to make sure that they are not limited by assumptions. This survey provides important new insights on what UK cancer patients want from their treatment which should be used to re-think how we as a clinical and patient community approach treatment decision making.”

SHINE CANCER SUPPORT
THE EXTENT TO WHICH PATIENTS’ PREFERENCES ARE CONSIDERED WHEN MAKING TREATMENT DECISIONS

17% of patients did not discuss their preferences with their clinician during their first conversation about anti-cancer therapy.
Only half of patients surveyed were as involved in decisions about their anti-cancer therapy as much as they wanted to be, which means not all patients may be satisfied with their involvement. Patients reported that clinicians are their main influence when making decisions about treatment.

Ensuring patients and clinicians are equal partners in decision making has increasingly become a hallmark of care for cancer patients, which is seen as a key element to improving patient outcomes. Not only do patients have the right to be involved in decisions about their treatment and care, but patients should be supported to make informed decisions. This is of greater importance in the context of the evolving cancer treatment landscape, which offers more treatment choices with different downsides and benefits for each patient.

Within this survey, 28 per cent of patients felt that decisions were made equally with their clinician (Figure 3) and 50 per cent of cancer patients were not involved in all decisions about their anti-cancer therapy as much as they wanted to be (Figure 4). For kidney cancer patients (n=48), this level of dissatisfaction with involvement increased to 64 per cent, the highest of all cancers. While some patients may prefer their clinicians to make decisions about their treatment and care on their behalf, the survey suggests that this is a relatively small minority. Only 6 per cent of patients stated that they did not need to be involved in decisions about their anti-cancer therapy. This is likely because they felt comfortable with their clinician making decisions (Figure 4).
Patients should be satisfied with their involvement in decisions about their care and making decisions in equal partnership. Therefore, efforts should be prioritised to ensure that all patients are supported and empowered to be appropriately involved in decision making.

Patients’ perceptions can be shaped by how clinicians present and prioritise factors associated with treatment. This survey found that among participants who discussed anti-cancer therapy with their healthcare professional, 72 per cent of patients reported that their clinician influenced their expectations about their anti-cancer therapy telling them about the treatment and the cancer (Figure 6). This is important, as a patients’ understanding of, and therefore judgement on, what treatment would be suitable for them may be guided by their clinicians’ advice. This may then affect all subsequent conversations and treatment decisions that patients make with their clinician.
Patients believed that the factors they consider to be most important to them, including experiencing unpleasant side effects, tended to also be echoed by their clinician. However, the discussion of factors that can impact a treatment decision are not always consistent for patients. Among the patients surveyed for whom a healthcare professional offered more than one anti-cancer therapy option and explained why, only 15 per cent reported being informed about the impact of treatment on their mental health, while 60 per cent of participants reported being told about experiencing unpleasant side effects (i.e. tiredness, sickness, diarrhoea, etc.) (Figure 5). This variation suggests inconsistency in how conversations are held about cancer treatment and this may not be based on what matters most to patients.

Delivering a single intervention, such as a treatment decision aid, across the NHS (developed in collaboration with NICE and HEE) may be a suitable solution to support clinicians in delivering consistent treatment conversations. Such guidance needs to be designed through the lens of the benefits that could be afforded by listening to cancer patients. This will also ensure greater progress against national goals aimed at supporting patients to play a more active role in their care.

58% Some patients felt they weren’t involved in any decisions about anti-cancer therapy. Of these patients, 58 per cent wanted to be involved in discussions about the impact of treatment on their day-to-day life.

Figure 5: Factors communicated by clinicians

- 60% Experiencing unpleasant side effects (i.e. tiredness, sickness, diarrhoea, etc.)
- 50% How quickly I could access my treatment
- 50% Whether I had to visit the hospital regularly
- 41% How much support I would receive from my healthcare team during my treatment
- 40% Impact on my physical abilities/fitness
- 39% Impact on my physical appearance (i.e. loss of hair, skin inflammation, scarring, etc.)
- 31% The possibility of longer-term side effects
- 30% Impact on my overall wellbeing
- 30% Whether I would be able to continue my day-to-day tasks e.g. work
- 24% Impact of more severe side effects that might lead to hospitalisation
- 23% The distance I had to travel to receive treatment
- 22% Whether my treatment was completed in one visit to the hospital
- 21% Pain associated with my treatment
- 17% How my treatment would affect my relationships with my family/partner
- 15% Whether I felt comfortable with the healthcare professional who would be involved in my treatment
- 15% Impact on my mental health
- 13% Whether I would be able to access support from others who have the same condition as me
- 12% Whether transport was available for me to get to the hospital
- 11% Whether I would be able to continue with my caring responsibilities
- 7% Whether I would be able to share future experiences with my family/children/friends
- 4% None of these
- 1% Oncologist/consultant/other healthcare professional did not communicate any factors

WHEN EXPLAINING THE ANTI-CANCER THERAPY FOR YOUR CANCER DID YOUR ONCOLOGIST/CONSULTANT OR ANOTHER HEALTHCARE PROFESSIONAL COMMUNICATE ANY OF THE FOLLOWING FACTORS?
Today, patients’ expectations of their cancer treatment are influenced by more than their clinician and patients are potentially building their own picture of what to expect. With the evolving cancer landscape, more than one treatment option may be available to patients, so clinicians need be equipped with the right information and skills to meet rising, varied and changing patient expectations.

The availability of innovative treatments is growing. The continued success of the Cancer Drugs Fund, and other initiatives such as the Early Access to Medicines Scheme (EAMS), Accelerated Access Collaborative and Innovative Licensing and Access Pathway are all poised to fast track the number of innovative medicines available on the NHS. However, once medicines are available to the patient, updates to clinical guidance do not always include the more recent therapeutic options. This can result in possible clinician uncertainty on which treatment options to discuss with patients.
All appropriate treatment options should be explained, discussed and recommended to patients. 30 per cent of patients in this survey reported that they were offered more than one treatment option when they were first diagnosed, and of these patients 74 per cent reported that their clinician recommended an anti-cancer therapy and explained why. Not all patients will be suitable for more than one treatment option, but this could change as treatments become more advanced and more become available, so clinical conversations need to evolve with this new normal for cancer treatment.34

Increasingly, cancer patients are also exposed to the clinical potential of innovative treatments from a variety of sources, as evidenced by our survey. Patients are known to be driving conversations about access to new treatments as they are being exposed to information about treatment research and development.35 Most patients are influenced by their clinicians. 72 per cent of those who discussed anti-cancer therapy with their healthcare professional believed that their expectations were influenced by what their healthcare professional told them about the treatment and their cancer (Figure 6). However, the findings also identified that 24 per cent of those patients’ expectations of treatment had also been influenced by information they found online and 18 per cent had heard about recent or ongoing improvements in cancer treatment. As I understand, there have been no recent improvements in cancer treatment.35 Clinicians need to be equipped with the right information to be able to handle these patient preferences for treatment and ensure conversations about treatment decisions are as transparent as possible.

This could suggest that some patients are setting their own expectations outside of the clinical setting, which will influence the framework for any treatment decisions. With more cancer treatments providing different benefit and risk profiles, including primary treatment outcomes and quality of life, patients may consider the most suitable treatment for them and compare the benefits and drawbacks. With this, clinicians may need to change the way that patient preferences are incorporated into decision-making.

NHS treatment decision aids supporting consistent patient-clinician conversations should also emphasise how clinicians may need to change the way conversations are held. With increasing availability of treatment innovations, clinicians should be supporting and guiding patients to explore these options. Again, the associated patient preferences for these treatments should be given the same level of importance as clinical judgement.

WHAT FACTORS, IF ANY, DO YOU THINK INFLUENCED YOUR EXPECTATION FOR THIS ANTI-CANCER THERAPY?

Figure 6: Patient influences of expectations

<table>
<thead>
<tr>
<th>Factor</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>What my oncologist/consultant/another healthcare professional told me about the treatment and my cancer</td>
<td>72%</td>
</tr>
<tr>
<td>I understood the NHS to be the best/one of the best places to receive treatment for cancer</td>
<td>49%</td>
</tr>
<tr>
<td>Level of confidence in the abilities of my oncologist/consultant/healthcare professional</td>
<td>45%</td>
</tr>
<tr>
<td>Information I found online</td>
<td>24%</td>
</tr>
<tr>
<td>I have heard about recent or ongoing improvements in cancer treatment</td>
<td>18%</td>
</tr>
<tr>
<td>Experiences of other people living with the same cancer (positive or negative)</td>
<td>17%</td>
</tr>
<tr>
<td>Views of friends and family members (positive or negative)</td>
<td>13%</td>
</tr>
<tr>
<td>As I understand, there have been no recent improvements in cancer treatment</td>
<td>7%</td>
</tr>
<tr>
<td>I understood the NHS to not be the best/one of the best places to receive treatment for cancer</td>
<td>6%</td>
</tr>
<tr>
<td>No factors influenced my expectation</td>
<td>3%</td>
</tr>
</tbody>
</table>
Among the patients surveyed for whom a healthcare professional offered more than one anti-cancer therapy option and explained why, 60% reported that unpleasant side effects were communicated to them when explaining the anti-cancer therapy they would receive.
Some elements of treatment, such as experiencing side effects, could be better managed if patients were offered tailored care and support. The impact of treatment on a patient’s family and relationships became more important to a number of participants throughout treatment (among the patients surveyed who considered the factor ‘How my treatment would affect my relationships with my family and/or partner’ to be important, it became more important for 39 per cent of them), so patients should be supported to manage these in the early stages and throughout treatment.

Receiving appropriate patient support is an ongoing need of patients. In the 2019 National Cancer Patient Experience Survey, only 65 per cent of patients reported that they were offered comprehensive practical advice and support in dealing with the side effects of their treatment.36 Providing education, information and supported self-management tools on how to manage side effects, has previously been identified as necessary to help patients cope with the side effects of their cancer treatment.37 Patient support should be holistic incorporating psychosocial and clinical support to minimise the wide ranging impacts of cancer treatments.

Although 89 per cent of patients surveyed reported they would be willing to compromise on experiencing unpleasant side effects associated with their treatment (i.e. tiredness, sickness, diarrhoea etc.), this does not mean that managing side effects is always simple and bearable. Some side effects associated with anti-cancer therapies can be highly unpleasant and result in long term impact.38 When asked whether tailored care and support would help make certain factors more manageable, 1 in 4 patients (25 per cent) stated that overall wellbeing and unpleasant side effects could be made more manageable (Figure 7). Interestingly, a greater proportion of female patients stated that their overall wellbeing and side effects would be more manageable than males, if they received this support.

Some elements of treatment, such as experiencing side effects, could be better managed if patients were offered tailored care and support. The impact of treatment on a patient’s family and relationships became more important to a number of participants throughout treatment (among the patients surveyed who considered the factor ‘How my treatment would affect my relationships with my family and/or partner’ to be important, it became more important for 39 per cent of them), so patients should be supported to manage these in the early stages and throughout treatment.

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### IF IT WAS POSSIBLE TO RECEIVE TAILORED CARE AND SUPPORT (I.E. PHYSICAL, MENTAL, EMOTIONAL, SOCIAL, FINANCIAL, ETC.), WOULD THIS MAKE ANY OF THE FOLLOWING FACTORS MORE MANAGEABLE WHEN CONSIDERING ANTI-CANCER THERAPY FOR YOUR CANCER?

- **Impact on my overall wellbeing**: 27%
- **Experiencing unpleasant side effects**: 25%
- **Impact on my physical abilities/fitness**: 24%
- **How quickly I could access my treatment**: 24%
- **No factors would be more manageable**: 23%
- **How much support I would receive from my healthcare team during my treatment**: 22%
In line with the NHS Long Term Plan for Cancer to deliver personalised care and support interventions, patients’ needs should be identified and inform tailored care and support programmes that will assist them during their treatment. As evidenced by this survey, patients value support to help manage the impacts of treatment, therefore, it is important that patients are aware of the support available to them when making decisions about their treatment. This will help to ensure that anticipations or concerns about a lack of support do not act as a barrier when considering treatment options.

To optimise care, compromises may need to be made by the patient but corresponding tailored care and support should meet patients’ holistic care needs to ensure treatment is made more manageable. Targeted interventions should be made widely available to patients to ensure that patients do not feel they need to sacrifice elements of their care or quality of life.

“Kidney cancer patients are usually cared for as urology patients, resulting in patients not always being provided with support and care that is specific to them. Sometimes, management of their treatment side effects can be difficult, which increases complexity of care. Action Kidney Cancer provides patient-led support throughout a patient’s cancer journey. These findings suggest more personalised and specific support is required, as well as greater awareness of existing services to enable patients to better manage their health.”

ACTION KIDNEY CANCER
RECOMMENDATIONS

Routine integration of patients’ preferences, on an equal footing with clinical expertise and system considerations, is essential to ensuring patients can access the cancer treatments best suited to them.

This survey and report set out to build a better understanding of cancer patients’ preferences – what they wanted from their treatment and which factors mattered most to them as they make decisions about their treatment. The hope is this will demonstrate the importance of listening to patients’ preferences for treatment, within the context of increasing access to innovative cancer treatments.

This survey provides evidence that cancer patients have clear expectations about what they want their cancer treatment to achieve. Patients also hold unique preferences for treatment, valuing factors associated with treatment differently. Some patients would be willing to compromise on experiencing unpleasant side effects and the distance they had to travel to receive treatment to meet their treatment goals. Yet there is evidence to suggest that patient preferences and values may not be consistently driving treatment decisions for all patients. Only half of patients were involved as much as they wanted to be at all times when making decisions about their anti-cancer therapy. This would suggest that further action needs to be taken to ensure that patient preferences are considered as a core pillar within treatment decision making.
In parallel, the survey emphasises the critical role of tailored care and support for cancer patients to manage the impacts of their treatment. It is therefore vital that there is clear communication of support services, so that patients are aware of the help available to them and can make informed choices.

Through improved integration of patient preferences in treatment decisions, patients may become more empowered and therefore more likely to achieve their treatment goals. By ensuring the importance of patient preferences is acknowledged and given the same weight as system considerations and clinical expertise, there is potential for downstream economic benefits for the system and improved patient outcomes.

To support this ambition, there are some practical solutions that could be used by NHSE, HEE and NICE. These include:

**Recommendation 1**
NHSE should conduct further research to quantify the importance of listening to patient preferences during treatment decision making. This includes understanding both the patient benefits as well as the economic and system/service level benefits.

**Recommendation 2**
NHSE, NICE and HEE should implement guidance to support clinicians to routinely integrate patient preferences and changing how they deliver high-quality conversations in the context of an evolving cancer treatment landscape.

**Recommendation 3**
NHSE should foster increased availability, communication and awareness of tailored care and support for cancer patients, in line with the ambitions set out by the NHS personalised care model.

Figure 8: Visual showing the ambition for equal footing of clinical expertise, system considerations and preferences in all treatment decision making conversations.
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