Mitigating the impact of the pandemic:

A lens on kidney cancer patients and support groups

This report was initiated and funded by Bristol Myers Squibb in partnership with Action Kidney Cancer

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Executive Summary

The COVID-19 pandemic has redirected resources and exacerbated existing barriers across diagnosis, treatment and follow up for kidney cancer patients. This has affected the ability of the NHS to maintain the increased level of support required by patients. As a result, patients have been seeking support and information from other resources, such as the patient support group Action Kidney Cancer. Patient groups stepped up at a crucial time of need to support patients on behalf of the NHS and help prevent the ongoing capacity challenge becoming a crunch point.

Bristol Myers Squibb heard directly from kidney cancer patients and Action Kidney Cancer who shared their first-hand experience of the pandemic impact, which helped inform the development of this report and its recommendations.

Learnings from these insights suggest that a renewed focus on the collaboration between the NHS and patient groups who provide vital support to patients is needed to ensure the exchange of expertise, capacity and resource is more efficient and better serves patients. In line with this, kidney cancer patients should be provided with tailored information, their care adapted to a virtual environment and clinical guidance issued to reduce variation in kidney cancer service provision across England.

The hope is that this report will highlight the barriers to care and support for kidney cancer patients that have been exacerbated by the pandemic and ensure patient groups receive the resource they need to continue to fill the gap between what the NHS is able to provide and what patients need, minimising the impact on kidney cancer patients.

Introduction

In April 2020, four in ten people were too concerned with the burden on the NHS to seek help from their GP.[1] Many cancer patients also reported feeling anxious or hesitant to access care due to fear of contracting COVID-19.[2] Cancer Research UK suspect that a combination of these factors might be contributing to the reduction in urgent referrals of urological cancers overall and therefore impacting early diagnosis.[3]

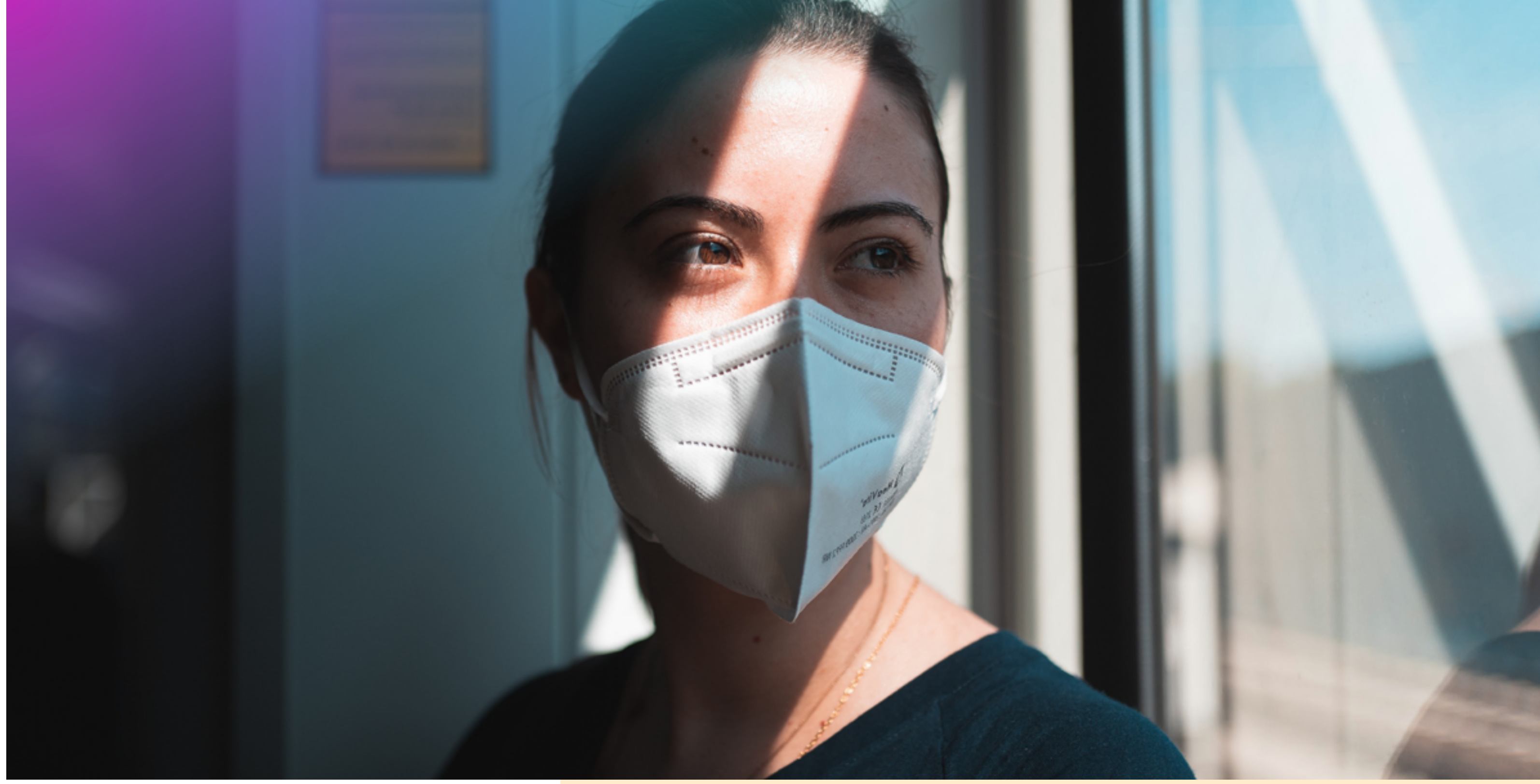
Although kidney cancer is the seventh most common cancer in the UK, patients experience challenges in terms of availability of appropriate healthcare professionals and clinical guidance.[4,5,6] Existing health inequalities, are thought to have been exacerbated by the pandemic and created new challenges for patients, which is likely to have impacted kidney cancer patients also.[7] There is now a concern that delays in diagnosis, reduced access to routine scans and changes to treatment will all have a knock on effect for kidney cancer patients and may affect survival rates.[8]

The pandemic has redirected resources and exacerbated existing barriers across diagnosis, treatment and follow up. This has affected the ability of the NHS to maintain the increased level of support required by patients. As a result, patients sought support and information from other resources, such as Action Kidney Cancer, which played a leading role in meeting this urgent need for support and guidance.

Action Kidney Cancer, much like other patient support organisations, were critical in alleviating pressure and absorbing demand on behalf of the NHS, before it became a crisis. They acted as a 'bridge' between the clinical team and the patient, providing support and information to patients.[9] A survey of 157 such organisations, representing advanced breast, bladder, lymphoma, ovarian and pancreatic cancer patient groups from 56 countries, found that 57 per cent experienced an average increase of 44 per cent in patient calls and emails[10]. This highlighted how the organisations have been an invaluable source of information and support for patients. However, Action Kidney Cancer found it difficult to access and navigate information to support patient welfare and there is substantive concern around the financial challenges faced by patient groups[9]. 45 per cent of patient groups report that their future viability might be under threat as a direct result of the pandemic.[10]

Action Kidney Cancer helped meet the increased demands from patients and carers during the pandemic and filled the need for the NHS to redeploy system resources. Whilst this ensured the NHS could continue to deliver critical clinical care, the role patient groups played has not received proportionate recognition, and financial aid is urgently needed to meet the new care needs of kidney cancer patients[9].

There is an urgent need to better understand the unique experience and challenges faced by kidney cancer patients during the pandemic, and to identify how new and additional barriers to care can be overcome. We must also consider the role played by patient groups to support patients during the pandemic, ensuring that appropriate resources are provided to these organisations in recognition of their services and support.



To understand and explore the true impact of the COVID-19 pandemic on kidney cancer patients, Bristol Myers Squibb hosted a patient workshop in partnership with Action Kidney Cancer. During the workshop, patients shared their experiences of how they had felt during the pandemic and how their cancer journey had been impacted. Action Kidney Cancer also shared how they had been impacted by the pandemic and detailed the services they provided to patients in their time of need. Participants highlighted the inequalities that may have been exacerbated in kidney cancer by the COVID-19 pandemic, while highlighting new and additional barriers to optimal care.

BMS has already undertaken work to raise awareness and support the system to tackle the inequalities faced by kidney cancer patients. In 2019, the company published the report, *Overcoming inequality: Achieving better outcomes for kidney cancer patients.*[11] Subsequently in 2020, BMS produced two resources highlighting gaps in the provision of clinical guidance for kidney cancer and the workforce challenges that have the greatest impact on patients at diagnosis and in ongoing care.[5,6]

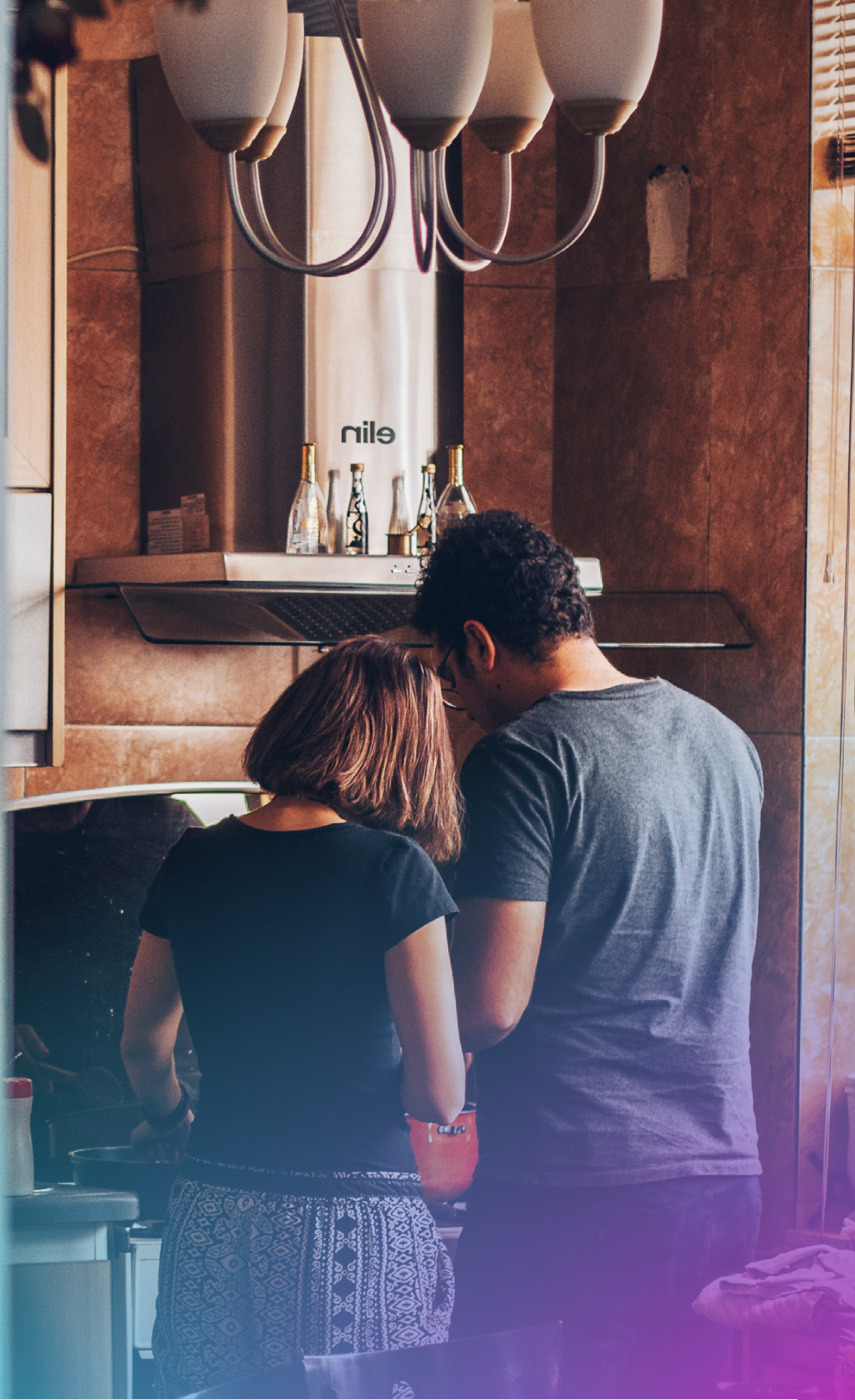
This report combines information gathered via this patient workshop with desk-based research to provide an insight into how the COVID-19 pandemic has impacted kidney cancer patients as well as the services and support provided by patient groups. We also set out some recommendations for improved collaboration between the NHS and patient groups, to help the system recover from the pandemic and ensure sustainable progress on patient outcomes for kidney cancer patients.

The 'I statements' included in the report are not direct quotes from individual patients but are instead composite statements, which have been developed with Action Kidney Cancer to communicate the experiences of kidney cancer patients during the COVID-19 pandemic.

Impact of the pandemic on the kidney patient experience

Our workshop highlighted the variability in experiences of kidney cancer patients during the COVID-19 pandemic. When asking patients for three words to describe their experience during the pandemic, words used ranged from 'opportunity' to 'isolated' and from 'enlightening' to 'frustration', which is to be expected considering the different stages of disease experienced by patients attending the workshop.

> "I felt frustrated about the messaging around the need for kidney cancer patients to self-isolate and I was left feeling confused and faced with the worry of being told I was at significantly higher risk of contracting COVID-19. The ability to stay at home helped me deal with my situation, but this only made things worse when I 'put up' with side effects for too long."



Impact on access to consultations

Reducing the number of people entering the hospital environment was a key strategy to help control the number of COVID-19 infections and protect vulnerable patients. Prohibiting family or friends from attending hospital consultations with patients or from visiting loved ones undergoing treatment was also introduced to help reduce hospital footfall.[12] As a result of this reduced face-to-face interaction, the move to virtual and telephone consultations was critical to ensure that healthcare professionals could continue to provide care for kidney cancer patients.

Whilst these protective procedures were essential, the impact these changes had on kidney cancer patients' experiences when interacting with the system and their healthcare professionals was significant.

When addressing this topic during our workshop, most kidney cancer patients agreed that the move to virtual or telephone consultations was a positive change. Such consultations allowed patients to carry on working and easily fit appointments into their schedule, which may not have been possible before. They also enabled carers, partners, and family members to join the consultation, which was not allowed in a hospital setting. One patient at our workshop explained that the telephone consultations saved them a 40-mile round trip once a month, which had a serious impact on their physical health and finances. This also meant some of the more routine appointments, such as general check-ups, could be dealt with quickly and avoid the need for patients to take time out of their day.

Although virtual and telephone consultations appeared to be beneficial for many kidney cancer patients, patients stressed the importance of having face-to-face contact in certain situations.

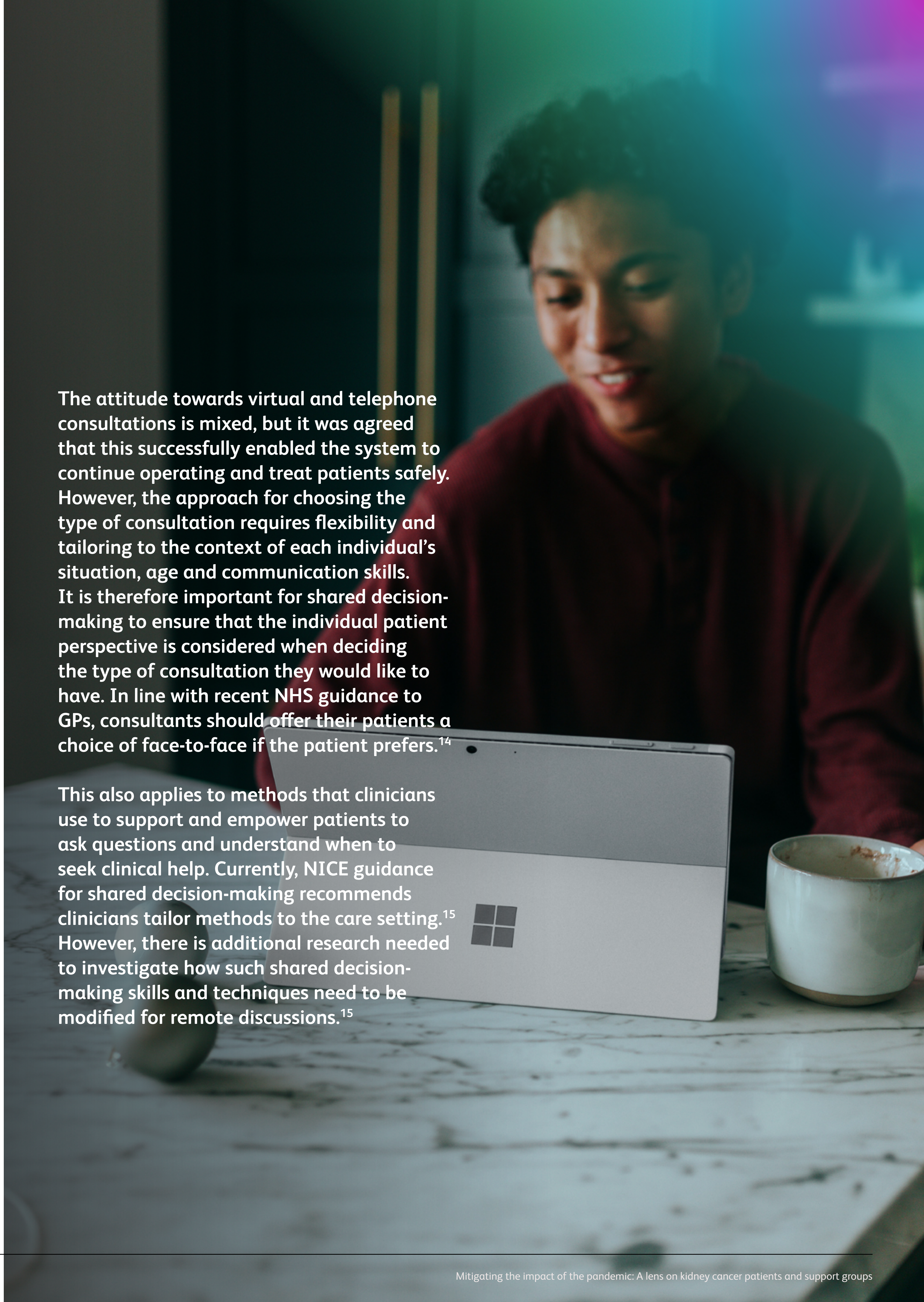
For example, the management of side effects in a virtual environment came with challenges.

Patients reported that they were more likely to endure more severe side effects when being cared for solely at home and they referred to cases where this resulted in hospitalisation. Considering the incidence rate of kidney cancer patients is highest in 85-89 year olds in the UK, not all patients may have the skills or find it easy to communicate via video or telephone, which further suggests that closer management for clinical escalation may be better managed face-to-face.[13]

However, this is heavily nuanced and, in some cases, kidney cancer patients explained that they benefited from reduced face-to-face appointments, making it easier to manage certain side effects, such as fatigue. In some cases, Action Kidney Cancer gave advice to help patients manage their care and treatment, including advice on the management of treatment side effects and kidney cancer symptoms. Given the complexity in symptom management, guidance to support kidney cancer patients to manage their condition in line with change of care format may be beneficial.

When face-to-face consultations have gone ahead, family and friends have not been able to accompany patients. Kidney cancer patients highlighted the difficulty in digesting information without support, with one patient describing the experience as 'soul destroying'. This mental health impact was echoed by carers, with carers, partners and family members experiencing a feeling of limbo and unable to support their loved ones.

Without close support during consultations, note-taking became more challenging. Patients told us that they were not provided with notes summarising their consultations and felt that this would have been valuable to help relay updates to family members. One patient explained that they actively requested that their carer joined their consultation, which allowed their relative to personally understand the complexity of their condition and treatment options discussed. It was suggested that this option should be pro-actively provided to patients, as some may not realise this is a choice.



The attitude towards virtual and telephone consultations is mixed, but it was agreed that this successfully enabled the system to continue operating and treat patients safely. However, the approach for choosing the type of consultation requires flexibility and tailoring to the context of each individual's situation, age and communication skills. It is therefore important for shared decision-making to ensure that the individual patient perspective is considered when deciding the type of consultation they would like to have. In line with recent NHS guidance to GPs, consultants should offer their patients a choice of face-to-face if the patient prefers.[14]

This also applies to methods that clinicians use to support and empower patients to ask questions and understand when to seek clinical help. Currently, NICE guidance for shared decision-making recommends clinicians tailor methods to the care setting.[15] However, there is additional research needed to investigate how such shared decision-making skills and techniques need to be modified for remote discussions.[15]

Impact on treatment

At the onset of the pandemic all elective surgery was halted to redeploy services and staff to deal with the COVID-19 surge.[16] Cancer Research UK reported that the pandemic disrupted treatment for almost 30 per cent of NHS cancer patients. This included having a test, procedure or appointment delayed, cancelled, or changed.[17]

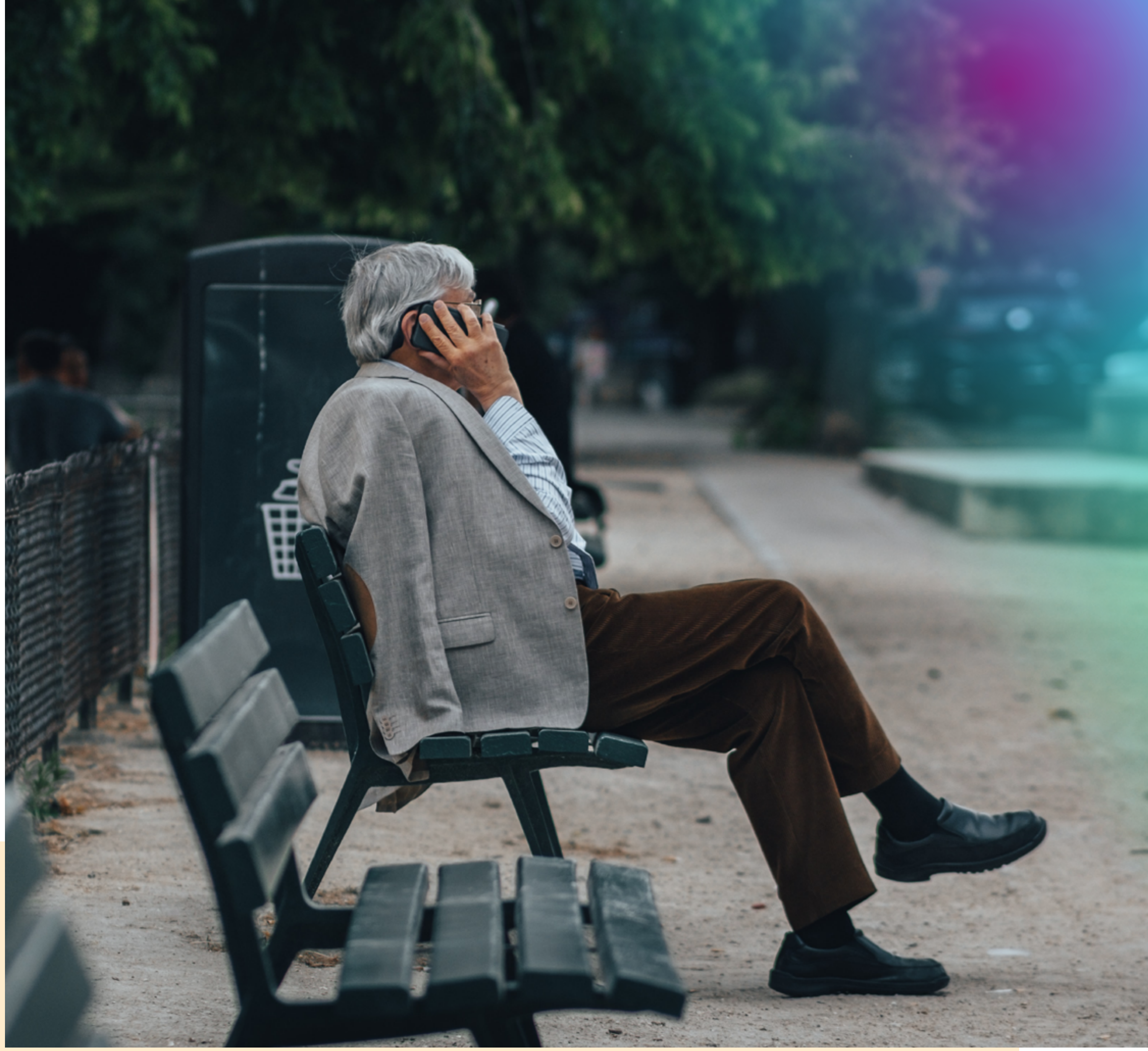
Although disruption to services had not impacted our workshop participants, it was something that affected members of the Action Kidney Cancer support group. However, one individual informed us that they had their treatment changed after receiving unexpected scan results, which created uncertainty and anxiety. Patients who are taken off a treatment they had previously been told was the best treatment for them, are likely to suffer psychologically.

During the pandemic, it remained unclear for some clinicians in the UK whether therapies for kidney cancer patients should be modified in response to the pandemic. An online survey of medical experts found that clinicians moved away from the use of immunotherapy and increased use of TKI monotherapy, but there was discordance among survey participants reasonings for making such decisions.[18] This study summarises that a careful decision-making process is required for each individual patient. The risk of the anti-cancer therapy increasing the chances of the patient contracting severe COVID-19 needs to be balanced with the long-term treatment outcomes.

To monitor kidney function, patients frequently receive routine blood tests. However, kidney cancer patients reported that during the pandemic this standard procedure was difficult to access. Information about the importance of maintaining testing was not effectively communicated to patients, resulting in some kidney cancer patients not having their kidney function monitored regularly if they were not actively coming forward to seek it.

One patient informed us of a blood testing 'drive through' initiative that had been introduced at a Park & Ride in Cambridge for Addenbrooke's Hospital. They found this service extremely convenient, and it enabled them to be tested without the concerns of attending the hospital. However, other patients communicated that they didn't have this service made available to them, highlighting the variation in service provision across the country.

Variation in provision of services and the delivery of care was highlighted by the patients during our workshop. There are currently no clinical practice guidelines available for the treatment and management of kidney cancer in England, which might be helpful in reducing variation across the country. This may be particularly helpful in assisting clinicians to make decisions around the specific risk vs benefit analysis associated with kidney cancer treatment. Transparency is also key to ensuring that patients understand any changes to their treatment or care. The continued implementation of the shared decision-making guidance, developed by NICE, will be helpful in supporting such conversations.



> "Virtual and telephone consultations have made it easier for me to attend appointments, but I would like the option to have a face-to-face appointment. However, not allowing visitors can make this experience very difficult. I think a combined approach to consultations should be based on what patients want"

Impact on patient communication

The reaction from the NHS and Government in response to the arrival of the pandemic in the UK resulted in communication aimed at all patients, providing cautions of the severity of the COVID-19 disease. Those with pre-existing health conditions were told to stop all non-essential contact and travel. These messages were valuable in the initial stages of the pandemic; however, we have heard from kidney cancer patients that the communication shared by the NHS and the Government can be confusing and occasionally fear inducing.

Kidney cancer patients told us that they felt cancer had been framed as 'less important' than COVID-19, and the public should not disrupt GPs and other healthcare professionals who were focused on the pandemic response. Messages were ambiguous, which made their situation feel worse than it did before the pandemic. In this situation, patients sought guidance from patient groups to unpick the messaging and understand what it meant for them, which also led to variations in messaging being highlighted across the country. From our research, this placed significant pressure and reliance on patient groups to translate national and local guidance at speed.

The 'Help Us, Help You' campaign launched by the NHS was an example of the Government aiming to mitigate the fear that the media had generated, resulting in patients staying away from the health system. This campaign was targeted at people with suspected lung cancer initially and then expanded to abdominal and urological cancers, encouraging patients to come forward with signs and symptoms.[19,20] However, kidney cancer did not benefit from clear and specific messages within this campaign.

The overarching messaging also applied to guidance shared with cancer patients about whether they are considered clinically extremely vulnerable (CEV) and therefore would need to shield. From March 2020 letters were sent to CEV patients explaining that they would be at highest risk of severe illness if they contracted COVID-19 and, therefore, should not leave the house at any time for at least twelve weeks.[21]

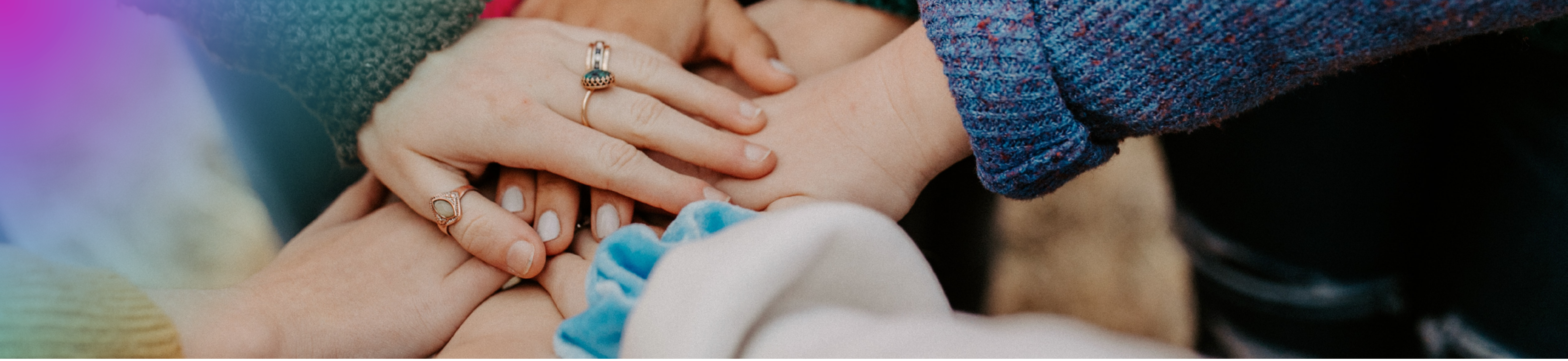
The initial shielding process identified over two million people as CEV patients via the Networked Data Lab (NDL) between March and April 2020.[22,23] It is not known how accurate this process was but hearing from kidney cancer patients confirmed that it was not obvious which patients were considered most at risk and therefore needed to isolate, creating confusion amongst patients and healthcare professionals alike. One patient told our group that despite not being on active treatment, they were informed to shield, but subsequently found out that this wasn't necessary.

The pandemic has placed renewed emphasis on the need for tailored communications for kidney cancer patients. Individualised care pathways are due to be introduced for every cancer type by 2023, presenting a significant opportunity to ensure kidney cancer patients receive accurate and tailored communications as routine.[24]

Impact on patient groups

The impact of the pandemic was felt acutely by kidney cancer patient groups, who stepped in to help support the healthcare system deal with a heightened demand for patient support. We heard from kidney cancer patients that patient groups, such as Action Kidney Cancer, became a valuable source of information and support throughout the pandemic and will continue to do so.

> “During the height of the pandemic, demand for the Action Kidney Cancer helpline and community forum services increased on average 30 per cent. The number and complexity of the issues that were presented with increased considerably, since patients were unable to contact their health care team and were understandably very anxious. The ambiguous nature of guidance from the Government also compunded issues for patients and patient groups alike.”



Capacity within the NHS kidney cancer services was already stretched before the pandemic, as evidenced by the smaller number of Urology Cancer Nurse Specialists (CNSs) available, who on average each manage 700 patients. This in comparison to breast cancer CNSs, who manage on average 160 patients, highlights the disparity in care provided to kidney cancer patients.[5] A survey of 157 patient organisations found that international cancer patient advocacy groups had an average increase in patient support calls and emails of 44 per cent.[10] This survey also identified a substantial need for psychosocial support and information from patient organisations, that had to adapt their service provision for evidence-based information.

Action Kidney Cancer supported the NHS to manage the new and additional needs of patients, bolstering capacity before it became a crisis. Action Kidney Cancer played a crucial role in the delivery of psychosocial support and helped in deciphering COVID-19 guidance and other messaging about isolation for kidney cancer patients, at the time when it was needed most.

Action Kidney Cancer introduced a COVID-19 question and answer page on their website, which was updated daily to adapt to the fast-changing rules and guidance issued by the Government.[25] They adopted new ways of working to help tackle the increase in demand for support. For example, Action Kidney Cancer introduced the 'Click & Chat' service to provide psychosocial support to patients.[26] This was a regular virtual meeting with small groups of patients and carers organised by the Action Kidney Cancer Community Development Officer (a kidney cancer patient). Sessions were very informal and available to all kidney cancer patients, family, and friends. They were a great way to feel less isolated and lonely during the pandemic. Patients also shared that the reduced face time with consultants meant that support was needed from elsewhere and were therefore incredibly grateful for the services that Action Kidney Cancer provided.

Whilst patient groups, such as Action Kidney Cancer, were providing valuable services to cancer patients throughout the pandemic on a larger scale than ever before, this was not met with increased funding. Fundraising activities were cancelled during the pandemic resulting in loss of income.[9] Action Kidney Cancer's net income from donations and fundraising activities declined by almost 40 per cent.[27] This situation is slowly starting to improve with the introduction of virtual fundraising activities, but the group have relied heavily on industry grants to cope with the increased demand for their services from the patient community.[28] This wasn't just experienced by Action Kidney Cancer though, with a survey reporting 45 per cent of the European patient organisations facing financial burden that threatens the future of their work.[10]

However, it is important to recognise that because patient groups stepped up to bridge the gap between the patient and their healthcare team during the pandemic in terms of patient support, the need for the NHS to commission and redirect capacity to deal with patient support may not have been recognised. As a result, the efforts of patient groups may have slipped under the radar. We must ensure that the role patient groups played during the pandemic is further unpicked and documented. We recommend that this is undertaken as part of a formal consultation led by Government. This will help Government better understand the unmet needs of cancer patients managed by patient groups throughout the pandemic. The hope is that this will result in increased resourcing and improved ways of working with patient groups to meet the elevated care demands.

The workshop highlighted that there is variation in signposting to kidney cancer patient group services by the NHS. Similarly, this was the case between cancer types with the National Cancer Patient Experience Survey 2019, reporting that only 52 per cent of respondents with a urological cancer said they were given information about support or self-help groups by hospital staff.[29] This compares to 83 per cent for patients with brain cancer and 81 per cent for those with breast cancer.[29]

Taken together, this underscores the need for vital patient engagement strategies to be introduced to ensure that all patients, not only those more engaged, are made aware of external support. As we move towards greater formalisation of partnerships with local authorities and external organisations such as patient groups, there is an opportunity to standardise patient information signposting – and this should be prioritised as we look to address the cancer backlog.

There is an opportunity for kidney cancer patient groups and the NHS to work more collaboratively and assess the supply and demand on both parties more effectively. With Integrated Care Systems gaining greater statutory footing and collaborating with a wider range of partners, Action Kidney Cancer can play a role in alleviating capacity and meeting the needs of the local population. Care needs should be evaluated together with patient groups, and then a decision made on who is best suited to deliver a solution. This will ensure that demand and capacity to deliver support to kidney cancer patients is better managed at a more acute level and patient groups are provided with the recognition for the delivery of their services.

What the system needs to do to move forward

Post-COVID recovery of the healthcare system has been at the top of the Government and NHS agenda, with the 'building back better' and 'levelling up' initiatives working to take lessons from the pandemic.[30,31] These aim to not just maintain the status quo but seek to improve service provision that was delivered pre-pandemic.

We asked kidney cancer patients and Action Kidney Cancer directly what they believe the system should learn from the pandemic; what solutions have been successful or not; and how these can be optimised and extrapolated across the country without variation in implementation.

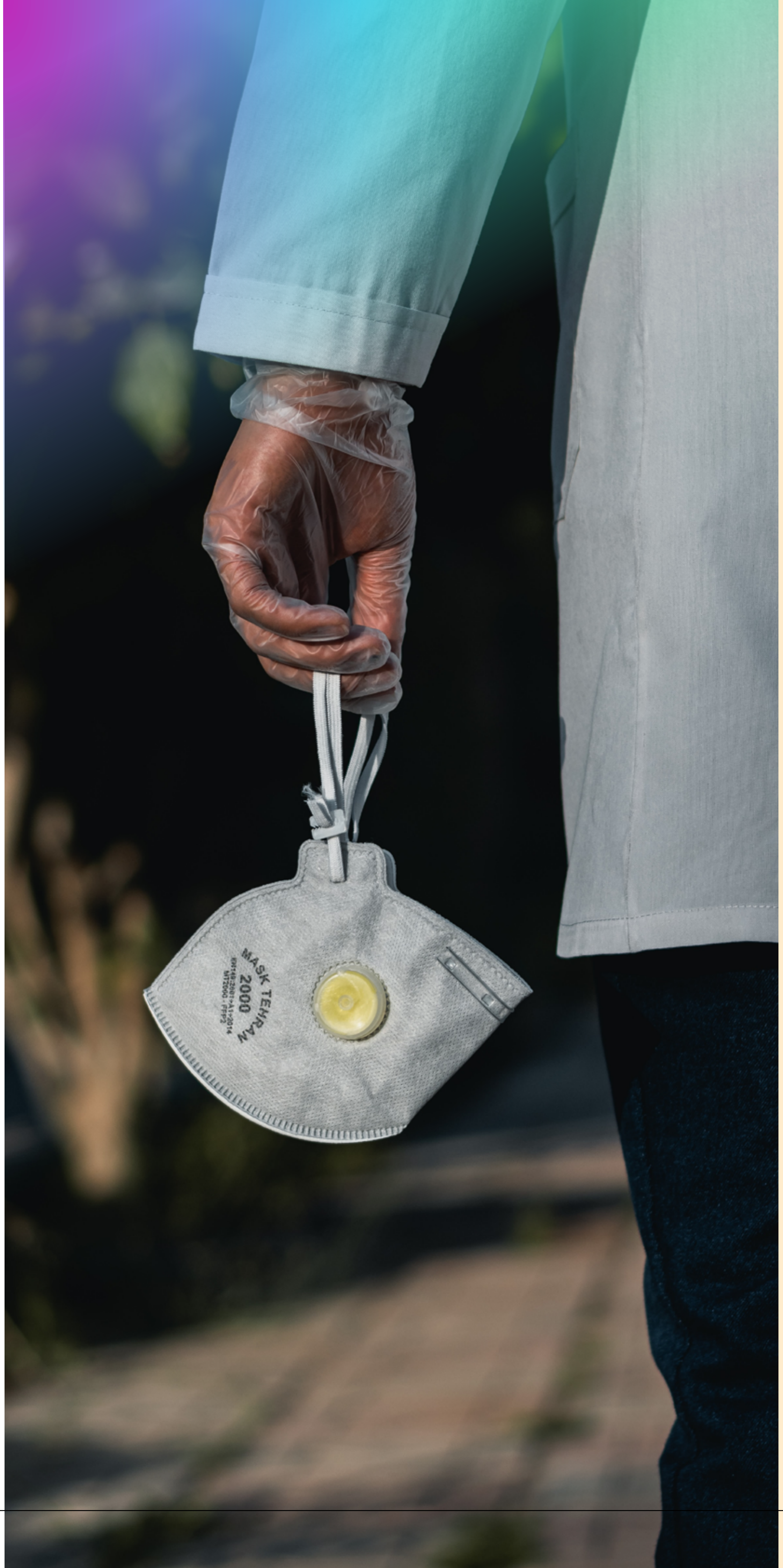
Patients agreed that the NHS has achieved a great deal and very quickly, which deserves credit. They hoped that virtual consultations would remain but acknowledged that an individualised approach is key for this to be appropriate for all patients. This also applied to the communications that were received by this group, and that tailored information is needed to provide confidence in the applicability of such advice. There also appeared to be a common theme of the need for shared decision-making practices to ensure patients are well informed and involved with changes to their treatment and their care.

Variation and inconsistency in service delivery across the country was also acknowledged by the group. The group agreed that there is an urgent need to reduce the variation that kidney cancer patients experience and ensure that all can receive the same services regardless of their postcode.

The role that patient groups played was also communicated as an area that required additional support from the Government. This is in recognition of the critical role they performed in supporting patients throughout the pandemic. They stepped in at a time of need to support patients on behalf of the NHS and help prevent the ongoing capacity challenge becoming a crunch point.

The group identified some tangible solutions that could be implemented to help patients and patient groups as we continue to navigate the pandemic. Whilst these are recommendations for improvement, it is also important to note that patients expressed their gratitude for the services that the NHS did continue to deliver under immense pressure.

By listening to the experiences faced by patients throughout the COVID-19 pandemic, BMS and Action Kidney Cancer look to support the NHS to address the additional barriers that may have materialised throughout the pandemic. The ultimate aim is to continue minimising the inequality gap experienced by kidney cancer patients and ensure patient groups receive the resource they need to deliver support.



Recommendations

- The role that patient groups, such as Action Kidney Cancer, played during the pandemic should be evaluated via a formal consultation led by Government to ensure appropriate resource and support is delivered to patient groups going forward. This review should acknowledge the evolving care needs of cancer patients due to the pandemic, such as the increased need for psychological support
- The NHS should collaborate with kidney cancer patient groups to co-develop a patient engagement strategy addressing the cancer backlog and evolving changes in care and treatment. The strategy should be tailored towards kidney cancer patients to ensure that ongoing messaging is understood by patient groups and communicated confidently across all patient networks
- Integrated care systems should routinely engage with patient groups to agree the support needed at a local level to help alleviate capacity issues in the short-term and determine care needs in the longer-term
- In line with the capacity pinch points that will be alleviated and awareness campaigns developed by patient groups, the Government should support these efforts with financial aid
- The NHS should encourage clinicians to accommodate kidney cancer patient preferences further to determine the best consultation method (virtual vs face-to-face) for each patient. Further research should be conducted to understand the impact of virtual care on patient experience and outcomes
- The NHS should work with NICE and patient groups to research and develop shared decision-making guidance that can help clinicians better support kidney cancer patients to manage their cancer in a new virtual environment, including side effects. Importantly, this will help improve patient outcomes and reduce frequent exacerbations of care that can arise when patients may feel disconnected from their specialists
- The NHS must ensure that variations in the delivery of care for kidney cancer are addressed, which could be achieved through the sharing of best practice initiatives and working with NICE to update national guidance for urological cancers, which was last reviewed in 2002.[32]

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