Mount Vernon Cancer Centre Strategic Review

Patient and Public Engagement Report - Foreword

NHS England, working together with hospital trusts and local commissioners, has been leading a review of the services provided at the Mount Vernon Cancer Centre. We began the review to find a solution to the quality of the buildings as well as clinical challenges such as the limited hospital support there is for patients who are very unwell or have additional health needs.

The review has focused on the model of care provided at the centre. This includes the range of services provided, clinical leadership and operational management, and where and how patients can access them. The review is at an early stage and options for the future services will be developed from February 2020.

Above all, we want to build on the commitment and expertise of the staff team at Mount Vernon, which we know are well regarded, and to ensure that patients continue to receive high-quality care.

We know that there are pressures around the current buildings and premises, and that services must be developed in line with new treatments and approaches to delivering care for people living with cancer.

Central to all of this is hearing from patients and their carers – what creates an excellent patient experience, what aspects of the service are most valued by those who use them, and what they would like to see in cancer care developed.

To inform this thinking, a series of events and focus group meetings were held between July and September 2019. A survey was also carried out. This was not public consultation but some informal engagement with patients to listen to feedback on the existing service, test emerging thinking on how the services could develop, and identify priorities from the patient perspective.

This independent report was commissioned to record and summarise the views and ideas expressed at these meetings and through the survey. It forms an important part of the review process, and the Programme Board is now considering the findings and recommendations to ensure they influence the development of options, along with future opportunities for patient and public involvement, which will include public consultation on the options that are developed.

If you attended one of the events, thank you for the insight you have given us. For NHS staff and partners, I hope this report will provide a valuable resource and play an important role helping to shape services now and in the future.

If you would like to get involved in future events, or find out more about this review, please contact us england.eoesct-projects@nhs.net.

If you have questions or concerns about the current services or treatment you are receiving, please contact pals.enh-tr@nhs.net or 01438 285811.

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Engagement Support

Mount Vernon Cancer Centre

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CONTENTS

1. BACKGROUND

1.1 INTRODUCTION

The Mount Vernon Cancer Centre (MVCC) is run by East and North Hertfordshire NHS Trust (ENHT) and delivered from a site in North Middlesex owned by the Hillingdon Hospitals NHS Foundation Trust with clinical services provided by ENHT. It is a standalone, tertiary cancer centre and primarily serves a population of over two million people in Hertfordshire, south Bedfordshire, North West London and Berkshire. The patient pathways involve 16 other hospitals and service level arrangements with six other NHS trusts. There is an extremely small number of patients who use the service from other parts of the country.

Figure 1: Percentage of MVCC patients referred from each Trust by distance from the centre

(Source: Mount Vernon Cancer Centre Clinical Overview and the Case for Change, East and North Hertfordshire NHS Trust, May 2019)

The Centre provides outpatient chemotherapy, nuclear medicine, brachytherapy and haematology as well as radiotherapy for these populations. There are also inpatient and ambulatory wards.

NHS England and NHS Improvement through Specialised Commissioning are working to review the services at Mount Vernon Cancer Centre. The estate is not in a good state of repair, and a number of concerns have been raised in relation to the long-term clinical sustainability of the Cancer Centre. As well as ageing buildings, there are limited support facilities on site. For example, there are no high dependency or intensive care beds so patients who become very poorly are sent in an emergency ambulance, usually to Watford General Hospital. This limited support at the site creates challenges for the patient safety and patient experience. As cancer treatment becomes more advanced and as demand for cancer treatment grows, this is becoming increasingly important for patients and staff at Mount Vernon.

1.2 PREVIOUS ENGAGEMENT EXERCISES AND FEEDBACK ON MVCC

In considering the future of MVCC a review of previous engagement exercises relating to the services delivered on the MV site has been undertaken.

Over a number of years there have been mechanisms for gathering and reviewing the experiences of patients, patients' family and carers, staff and the wider community. A range of engagement exercise have been undertaken in the past, including engagement exercises, meetings, surveys. We provide a list, in Appendix 1, of some of the recent work done at MVCC to collect feedback. Overall care and staffing at MVCC are found to be very good, but there are concerns arising in the feedback about the physical environment at MVCC. We give an outline, below, of the feedback gathered recently.

Generally when patients have scored services at MVCC the results have been approximately at the national average, for instance, in the NHS Friends and Family Test, which asks patients whether they would recommend a service to their friends and family 96%-99% of in-patients and 95%-98% of out-patients said they would. Similarly, in the National Cancer Patient Survey (NCPES) of 2017 patients could score services on a scale of 0-10; the expected range, nationally, is 8.6 to 9.0 and MVCC scored 8.75.

Across the previous engagement exercises it has been usual for patients and others to praise the staff at MVCC, for example, a patient said of their care as an in-patient "*Always treated with respect and dignity by staff*".

Aspects of MVCC care which scored below average ratings in NCPES 2017 related to being able to discuss worries with staff and having sufficient support after treatment.

Areas of concern raised by NCPES 2017 were discussed at workshops held by ENHT in 2018. Patients were very positive about the level of care, kindness and compassion received during cancer treatment; however, areas for improvement were identified, including systems struggling to cope with the numbers of patients and service delivery which address individual needs within a very large patient group.

In June 2018 the poor state of buildings on the MV site led to the relocation of in-patient, palliative care services from the Michael Sobell Hospice on the MV site to MVCC[1]. Healthwatch Hillingdon conducted patient engagement interviews in October 2018 with eight patients and the family of an end-of-life patient to assess how the change might have affected the patients' experiences. The report described the environment in MVCC as being clean, spacious, respectful and bright. The patients were happy on the ward and were comfortable and receiving excellent care. One issue identified was that of patients being disturbed at night. Overall, whilst the environment and care were good, Healthwatch Hillingdon felt that the configuration of the ward made it difficult to create a homely environment, and suggested MVCC should work with the Michael Sobell Hospice Charity how best to offer patients a more personalised service, for example, by the charity offering things like ice cream, foam cushions and ear plugs for sleeping, which they felt would offer a more holistic service whilst efforts were being made to restore in-patient hospice services.

Work has started, through a committee which met for the first time in April 2019, to enhance the green space on the MV site. A team of thirteen volunteers working in wards and the chemotherapy area have had conversations with patients and carers and are driving the project forward. The project is led by the Centre for Sustainable Healthcare and NHS Forest, working with a specialist landscape designer.

A review of the patient pathway for oncology elective treatments began in January 2019. The review found that as treatments are changing MVCC is rapidly outgrowing its accommodation. The review went on to say that the main tasks for MVCC are to maximise its resources and to streamline processes to ensure the best patient care; further, the report said that MVCC should look at whether the accommodation and resource implications for the future are sustainable. To address these challenges ENHT and Bristol-Myers Squibb agreed a joint working project to develop service improvements for patients receiving cancer therapies. The six-month project aims to deliver four to six treatment efficiency proposals which will enable MVCC to maximise resource around the offering of I-O treatments and improve patient experience. Throughout the project the views of health care professionals (HCPs) through interviews and patients through surveys.

Sixteen patients at a melanoma clinic in May 2019 completed a survey about the information they received about their treatment. Whilst the comments were mainly positive, a small number of criticisms were made, including finding the information too much or feeling that different information had been given by different members of staff. Two patients felt that they were not adequately prepared for what their treatment would involve or what the side effects would be. Criticisms were made of waiting times, distances that patients needed to walk (from car parks and between departments within MVCC) and the waiting room environment. Suggestions for improvements at the site included: improvements to the waiting system and environment, and more convenient provision of services such as blood testing.

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[1] While comments relating to the Michael Sobell Hospice were recorded as part of the engagement exercise, please note that these services are outside the scope of the MVCC review.

A pilot of a Peer Evaluator Project was agreed by Macmillan and MVCC in December 2018. The scheme involves a person living with or beyond cancer carrying out interviews with their peers with the aim of carrying out peer evaluation to improve patients' experiences of services.

The Lynda Jackson Centre patient and carer advisory panel have discussed (May 2018 and March 2019) issues such as improvements to the signage at MVCC, car parking issues and improvements to the Transport Lounge.

The remainder of this report concentrates on a review process and pre-consultation engagement process relating to the future of MVCC.

1.3 REVIEW PROCESS

The purpose of the Review is to undertake a strategic assessment of the Mount Vernon Cancer Centre. Information is being considered from:

- Patients and public through a series of six public events and an online survey
- Clinical staff
- Data
- Independent review (Clinical Advisory Panel)
- A review of previous engagement exercises relating to cancer and adjunct services delivered on the MV site.

And there are 5 key lines of enquiry:

- Quality of Care
- Patient and Carer Experience
- A Sustainable Workforce
- Training and Education
- Research and Innovation.

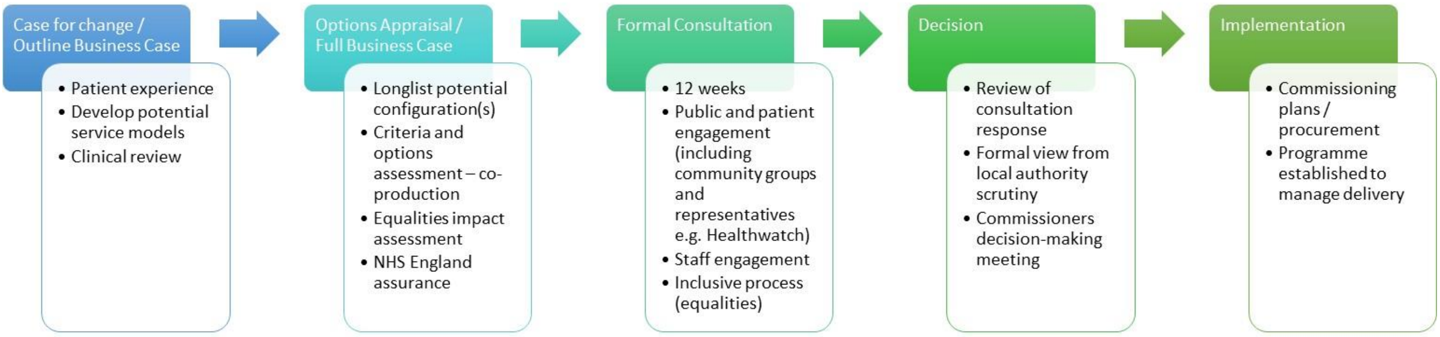

Figure 2: Overview of Review Process

1.4 PRE-CONSULTATION ENGAGEMENT PHASE

In this pre-consultation engagement phase, insight from local people (including patients, former patients and carers) alongside feedback from staff at Mount Vernon, input from other local hospitals and commissioners, and from the local Cancer Alliances was sought to help develop some potential models that best meet the needs of local people, and that will build on the services, research and patient experience the Centre already delivers. In particular the exercise sought general feedback on cancer services and people's priorities for service delivery in the future.

No decisions had been made at this stage, and the NHS was in 'listening mode'. In order to engage with public and patients, a series of engagement events were convened, with the following purposes:

1. To ensure that patients, carers and the public are well informed by explaining the programme and processes in presentations and discussions
2. To provide an opportunity to ask questions of the clinicians and managers leading development proposals
3. To listen to public opinions on services at MVCC and potential changes
4. To summarise the views of the public for the Programme Board, providers and commissioners to inform their decision making.

We understand from NHS England that people were invited to events by Healthwatch, in both Hertfordshire and Hillingdon, and through social media to ensure that there was broad participation by people with lived experience of cancer services at Mount Vernon Cancer Centre, or elsewhere.

In addition, some telephone interviews were carried out with people from three protected characteristic groups – BAME, LGBTQ+ and people with disabilities. These interviews were undertaken to get the views of seldom heard voices at an early stage of the process. The aim of the interviews was to give insight into any potential needs of the three groups, which might differ from the needs of the general population.

The feedback from the events and interviews will inform the next stages of work for the programme, which may include:

- Development of pre-consultation business case
- Information for patients and the public (e.g. a *Case for Change* summary)
- Model appraisal criteria and process (if consultation follows)
- Further engagement plans.

1.5 VERVE COMMUNICATIONS LTD

Verve Communications Ltd. (Verve) is an independent full-service agency specialising in supporting NHS organisations in delivering transformation and change. Over the past several years Verve has supported NHS service configurations, institutional and major programmes of clinical change and has helped NHS leaders to meet some of their most difficult transformational challenges.

Verve was commissioned by NHS England to conduct a series of engagement events and interviews with people from some protected characteristic groups and to write a report summarising the views of the public on the information given.

1.6 THIS REPORT

The rest of this report describes the approach taken to engage with people across the MVCC catchment area; it goes on to describe the views people expressed about the current situation at MVCC, their concerns about the review process and their views on two possible models for future cancer care arising from the Expert Clinical Review. The next section presents the criteria people thought were important when evaluating future proposals for change. The results of an online survey are given. There is then a brief description of interviews undertaken with people from some protected characteristic groups. Views from both participants at events and people interviewed are brought together to present views on what are important considerations when planning or building future services. The report ends with conclusions and recommendations.

2. PUBLIC AND PATIENT ENGAGEMENT EVENTS: APPROACH

Six engagement events were held in:
- Stevenage – July 10th 2019
- Uxbridge – July 16th 2019
- Luton – July 17th 2019
- Central London – July 23rd 2019
- Mount Vernon – August 14th 2019
- Watford – September 3rd 2019

The first four events were held from 12.30-15.30, the final two were held 18.00-20.30 and each event involved:
- A scene-setting presentation describing the current context and process for the MVCC review, including information on two models recommended by the Clinical Advisory Panel as a result of the Expert Clinical Review
- Table discussions, focusing on three aspects of the service (Estates, Dependencies and Patient Journey), to hear views and experiences from members of the public
- Generally, a final, plenary session discussed the possible criteria that could be used to evaluate future proposals for the delivery of cancer services.

Each event was chaired by a Verve staff member and each table of participants had a Verve facilitator to engage participants with the discussion topics and to record all questions, comments and discussions.

Those attending the events have included:
- Many of the participants had lived experience of cancer services at MVCC or elsewhere, as current or former patients and carers/family members of patients
- Current and former employees at MVCC
- Employees and volunteers working in cancer services with a connection to MVCC
- Healthwatch/other patient group representatives
- Residents from the MVCC catchment area.

Attendance varied across the sessions; in total approximately 75 people participated in the events.

3. VIEWS ON MVCC SERVICES

This chapter reports the positive and negative views people expressed at the events about the current situation at MVCC.

The events allowed people to discuss in detail their views about the services at MVCC.

There was high regard for the quality of care delivered at MVCC, and a great deal of attachment was evident for the MV site, however, people acknowledged that the buildings were not in a good state of repair, and that the site was difficult to access for some people.

3.1 POSITIVES

The quality of care at MVCC is very highly regarded and praised by those with experience of the services. It has a reputation that patients and residents want to see maintained and, particularly locally, there is a strong sense of pride in the MVCC name.

Staff at all levels – clinical, support and administrative staff – are widely praised. In the main, patients report being treated with respect and empathy, and note the pride in their job and sense of teamwork that they see among the MVCC staff.

Participants expressed a high degree of affection for the current site – the buildings and the physical environment, particularly the sense of space, the greenery and gardens and the opportunity to be outside. They feel these provide enormous benefits for cancer patients and their families/carers and contribute to making MVCC a special place.

"It's such a contrast to central London and that's what makes it unique… It always makes me smile when I know I'm coming to MV and I know I'm going to see all those trees." (Uxbridge)

"I like the old building. It used to be a TB hospital and they used to wheel the patients out on the veranda to look out over London, and I like seeing that in the building. I want to go somewhere that has character." (Luton)

"You want to be somewhere where it makes life feel worth living." (London)

There was strong local support Mount Vernon hospital in general and the Cancer Centre in particular, with local people mentioning contributing to collections for specific pieces of medical equipment.

"Northwood is Mount Vernon and Mount Vernon is Northwood" (Mount Vernon)

There is very strong appreciation for the services that are run alongside MVCC on the site – the Lynda Jackson Centre, the Paul Strickland Scanner Centre and Michael Sobell Hospice; the capacity to access these varied services on one site is felt to offer considerable patient benefits and there is concern about what will happen to these services if the main cancer services are relocated/the site is redeveloped.

"It's (Lynda Jackson) a calming place, somewhere you can get away from the main hospital area." (Uxbridge)

"They all contribute to the sense of it being a specialist cancer centre… It caters to all the needs of the patient. Just being on the same site makes it feel connected." (Luton)

3.2 NEGATIVES

Whilst the staff and the care patients received were highly praised, and there was great attachment to the MV site and buildings, especially by people most local to MVCC, there were some negative views expressed about the state of the buildings at MVCC and the long distance to travel for some people. Split site appointments were also a concern for some people.

3.2.1 BUILDINGS AND LAYOUT

There was widespread acknowledgement that the buildings at MVCC are beginning to feel tired, and that many of the waiting spaces are inadequate, with patients reporting cramped, uncomfortable environments.

"The service is marvellous; we want buildings that don't leak" (Mount Vernon)

"It's a traumatic time, you're so grateful someone's looking after you and yet you're in these dingy little grey rooms." (London)

"If we had brighter buildings that would be so much better" (Mount Vernon)

There was a strong feeling that lack of maintenance has led to the MVCC being in its current state, and that improving the buildings and making use of other buildings on the site could be a way of keeping MVCC in its current location.

"There needs to be a vision because everything looks bad now" (Mount Vernon)

The sprawling layout of the site is also regarded as problematic, especially for new patients, with a confusing number of car parks, multiple entrances and complicated routes to different departments/parts of the building.

"It's so easy to end up in the wrong place, there are so many different entrances." (Stevenage)

3.2.2 TRAVEL AND ACCESS

Unsurprisingly, the most concern about distance to travel were most strongly voiced in Stevenage and Watford, although it also came up during the discussion in Luton. MVCC feels remote and difficult to get to, with few public transport options, and hospital transport regarded as unreliable and inconvenient. For those living close to MVCC travel, whether by public transport or car were not problems.

For those undergoing treatment, the distance to clinics can be challenging and stressful, and means many must rely on a carer to bring them home afterwards. Stevenage based patients reported that visiting MVCC requires an entire day, allowing for the journey there, additional time in case of travel delays and time required for treatment.

There were members of staff present at the event in Watford who had experience working at the MVCC. They said that they found travelling to MVCC difficult at times and felt that it must be stressful for patients undertaking the same journey; they said that in planning for future provision any site chosen should be easy to get to and easy to find (they felt that MVCC was difficult to find for those who were not local).

Staff at the Watford event also said they often found parking at MVCC difficult, and that future models should consider how it could be improved.

3.2.3 CARE ACROSS DIFFERENT SITES

For patients whose care is split across different sites concerns were expressed about continuity of care, and anxiety and stress in navigating around different sites and remembering where appointments are going to be. For many patients in the north of the catchment area some appointments were at the Lister Hospital. Generally, people did not understand the rationale for why care was delivered across different sites, with a feeling that there was a lack of explanation about why this was necessary.

'Continuity of care' meant different things to different people. For some, having contact with the same set of health care professionals throughout their care was important.

"It's hard to keep track of where you're meant to be, when and for what." (Stevenage)

"Every new site that you have to go to is stressful." (Uxbridge)

"I don't want a bit here and a bit there, have it all in one site." (Luton)

Others felt this was less crucial as long as the quality of care was consistent and patient records could be shared or communicated properly. This latter point emerged as particularly key across all the sessions; in one location a family member reported an experience of particularly poor communication which nearly resulted in a drastically negative outcome for her relation. Across the board, people looked for reassurance that any future configuration of services would provide seamless access to patient information for anyone involved in their care.

"So that you've still got that team working with you, it's important to have familiar faces. It makes you feel more confident – they know me and know my treatment." (London)

People living very locally to MVCC reported fewer concerns about split site care; they were pragmatic about receiving care across several different London hospitals because local transport was good.

"We are so lucky that hospitals are close together" (Mount Vernon)

3.3 SUMMARY

Patients and staff, especially those who lived near MVCC expressed a deep affection for the buildings and the hospital site. There was acknowledgement, though, that the buildings were in a state of disrepair and that something needed to be done in the future.

The care offered at MVCC and the staff working there were highly regarded by patients.

Although travel could be difficult for some patients there was agreement across all events that travelling a significant distance was worth it to access quality care in a centre of excellence, but that adequate transport infrastructure (including looking at improved options for hospital transport) must be built into any future plans.

Receiving care across several sites tended to be seen as stressful. People desired continuity of care which they worried was less likely across different sites.

People were also interested in hearing about, and considering, how population density, demand for cancer services and journey times/accessibility intersect across the catchment area; the broader context for delivery of cancer services can also be of interest, with some participants enquiring where else they are delivered, and what the options would be if they chose not to travel to MVCC (or any future site). If services are relocated, this kind of information might aid understanding of how decisions have been arrived at to deliver benefits to the greatest number of patients.

4. VIEWS ON POTENTIAL MODELS OF SERVICE DELIVERY

The independent Clinical Review Panel, including Healthwatch, spoke to clinicians and patients about MVCC services, as a result of which they put forward two potential models for future service delivery. The two models were tested at the events with participants, who had the opportunity to discuss and give their views on them, and to put forward alternatives from a patient perspective.

The two models were:

> **Model 1**: a single site model with all MVCC services being moved to an acute hospital site
>
> **Model 2**: an "ambulatory hub and spoke" with some out-patient therapy services remaining at MVCC and other services moving to an acute hospital site.

Both models suggested that additional radiotherapy satellite provision in the north of the catchment area would be desirable, and that leadership of the cancer centre should be through an existing tertiary cancer centre.

People's views about possible future models for cancer services could be contradictory and inconsistent, compounded by the fact that the implications of the different models were not always clear to them, and terminology could be confusing and distracting. In particular, the terms 'mobile' and 'ambulatory' were not well understood; these words were frequently interpreted as referring to treatment which could be delivered in-home or through a mobile centre, akin to a mobile breast screening service. Other terms causing confusion included 'commissioning' and 'buying' services, which were interpreted by some as meaning that the NHS would be buying services from private providers, which was not well received.

4.1 DELIVERABILITY AND FUTURE-PROOFING

Participants sought reassurance that any models considered for formal consultation would be deliverable, and that there is a commitment to funding them. In the current NHS funding context, people were somewhat sceptical that sufficient funds would be available for the development of a new site/new services and they fear a compromise/short-term solution may be imposed because of financial restrictions. Not surprisingly, the discussions tended to prompt more general complaints about the underfunding of the NHS, and the perception that too great a proportion of the NHS budget is spent on 'management/bureaucracy' rather than frontline staff and services.

People were also curious to understand how the development of technology, as well as medical/ treatment advances might impact on the future delivery of services. There was some awareness of the new treatments that are becoming available, and of their implications for cancer service delivery, although more information around this would be welcomed. People felt hopeful that new technologies would allow for greater flexibility in how patients are seen and treated, with, they believed, opportunities for virtual consultations, virtual diagnosis and remote care/treatment. Again, reassurance was sought that the impact of new technology on how care is delivered would be taken into account in any future proposals.

"We're looking at something that will take ten years to put in place and it has to be relevant in 30 or 40 years' time." (Luton)

There was a perception that the Hillingdon area is experiencing fast population growth and people wanted to know that this is recognised by decision-makers and will also be taken into account when planning for the future.

At Mount Vernon participants expressed the view that any future service should have good research and trial facilities, which, they felt, would ensure that patients had access to innovative treatments, and would be likely to attract and keep staff.

Having a cancer centre which could deal with all types and forms of cancer on one site was thought to be important to ensure that future services were sustainable.

4.2 MODEL 1: RELOCATING ALL MVCC SERVICES TO AN ACUTE SITE

Patients, past patients and carers tended to find it difficult to understand the importance of having access to acute hospital services. Frequently people questioned how often transfer from MVCC to acute hospitals is needed, and how many people are affected. They were not necessarily convinced that the numbers involved justified relocating cancer services to an acute site and co-location of services were deemed to be less of a priority than other aspects of cancer care.

"It seems a shame to move all of Mount Vernon to an acute hospital, just for this. It feels like overkill." (Luton)

However, staff attending the events recognised the need for acute services, and at the Watford session said that co-location of services would save a lot of time and reduce risk to life in the time spent waiting for ambulances to transport patients to other hospitals. They noted that ambulances cannot always pick up patients who need to be transferred to ICU/HDU quickly. Further, the staff said that there was a wealth of knowledge amongst the current staff at MVCC which could be utilised when planning the future of the services, to help design an effective model of care.

It was a common for non-staff participants to suggest that the MV site itself should be redeveloped to offer wider hospital/emergency care services. It should be noted that people expressed doubts about the quality of care available at some of the current DGH Acute sites.

Once the drivers for a move to an acute site were explained in more detail (for example, by giving the numbers of patients affected and the impact of an ageing population and increasing co-morbidities, people were more be prepared to accept there is a need. It should be noted that there were no patients or past patients who had experienced the need to be transferred to HDU/ICU, nor were there any carers whose relatives had been transferred. One man had been transferred to another hospital by ambulance, but he said that was because he needed inpatient care – it was not an urgent or emergency transfer.

Concerns about relocation emerged, particularly from local participants in the Hillingdon and Mount Vernon areas. These concerns related to whether their access to cancer services would become more difficult, but also because many people appreciate the fact MVCC is not part of a large hospital site and has a different feel to it. It is described as 'homely', 'welcoming' and 'friendly', 'intimate' rather than clinical; this less intimidating environment is particularly welcomed by cancer patients. There was a worry this will be lost if cancer services are relocated to an acute site. Further, participants at Mount Vernon said that the hospital had close and long-standing ties with the local community which they would like to keep.

Concern was also expressed about losing the high standards of clinical care if services were to be relocated, not least because staff morale could be affected by any move. Several people asked, *"why fix something that isn't broken?"*

Patients would like to see the three 'companion services' (Lynda Jackson, Paul Strickland, Michael Sobell) maintained. If the cancer services were relocated, it was viewed as very important that these services, or something very similar, should be relocated alongside a new facility.

4.3 MODEL 2: AMBULATORY HUB AND SPOKE

For people who lived near MVCC Model 2 presented a way of keeping at least some services on a site they felt a great attachment to and viewed as having many benefits over a larger hospital, such as the outside spaces and the homely feel of MVCC. Indeed, when discussing Model 2, some people suggested that in-patients should be moved to an acute site, where they could access HDU/ICU if they needed them, but that outpatient treatments be kept at MV; Model 2, therefore, met this requirement.

For others, however, especially those living further away from MVCC, the problems of split services arose, with the expectation that some people might have to go to both sites at different times in their treatment. Concerns were raised about the ability to ensure continuity of care across two sites.

It was not completely clear to people whether services other than radiotherapy and chemotherapy clinics would be located at MVCC.

4.4 MODEL 1 VS MODEL 2

Most participants acknowledged that a large, specialist centre would offer better access to research and the latest developments in cancer care. They thought that such a centre would be likely to attract the best staff and retain them for prolonged periods. There was an expectation that patients would be able to access all services on one site, thus reducing anxiety and stress, reduce delays and offer better continuity of care.

Some people felt that it was important that operations which are part of the cancer pathway take place on the same site as other cancer services. It should be noted, however, that this was not a high priority for all.

While identifying the benefits of a large, specialist centre people across the catchment area said that they would like to be able to access some cancer services – particularly routine services, such as blood tests – more locally, either at GP surgeries or at local clinics.

"Could they be more flexible around the kind of treatment required? Perhaps grade the treatments in terms of intensity, there are some which need a lot of kit and medical back-up and others which I could go to my GP for, especially as I'm an old-timer." (Luton)

For those in the north of the catchment area, the option of accessing a fuller range of treatment services at their local hospital, was appealing. However, some concerns were raised around Model 2, including:

- Some people raised concerns about cancer services being delivered at district general hospitals and questioned whether this could be as good as delivery at a specialist centre such as MVCC, where services were very highly regarded. People had very good experiences with staff at MVCC, saying that they cared about their patients and had a lot of compassion, and some felt that this might not be replicable on other sites. Delivering services under the MV name (for example "Mount Vernon at…") was put forward by some patients as a way to mitigate these concerns.

- Questions were raised about whether an ambulatory hub model would be adequately funded to ensure that equipment and staff at the 'spokes' were fully resourced; in particular, concerns were expressed over whether specialist equipment, perhaps required for specific kinds of cancer, would be available.

- Some had concerns about how well communication between the different sites would work in order to ensure continuity of care, and high-quality care, for all patients.

4.5 TERTIARY LEADERSHIP

On the whole this was regarded as a positive move (once an explanation was given of what it means and how it might come about), although Hillingdon residents in particular expressed concern that they might lose something locally that is unique and special, and some sought reassurances that this would not mean that they had to travel into central London for treatment.

"The thought of travelling into town on a day-to-day basis fills me with horror." (Uxbridge)

In Watford the staff attending the session thought that the management structure of the service is important, but emphasis on ensuring the right front-line staff will also be key to getting the right results.

4.6 SUMMARY

On the whole people agreed that the priority must be expert care, whatever arrangements are made in the future for the location of premises.

People living closest to MVCC feared losing a connection to the site. As well as their attachment to the buildings local people feared a different location would give them a more complicated journey but acknowledged that this is currently the case for people living in other parts of the catchment area.

Model 1, an integrated single site, was understood by many to be a good model, especially if some services could be delivered nearer to home for people in the north of the catchment area. It was assumed that there would be advantages to having services on a single site, including continuity of care.

Model 2, which proposed keeping some clinics at MVCC, tended to be preferred by those who had a great affinity for the buildings and the site in general. This model, however, caused some concerns about split sites and whether continuity of care would be affected.

Some people, most usually those who lived near MVCC, proposed a third model, whereby the whole of the MV site was acquired in order to repair and renovate buildings, incorporating whatever was needed (including acute services) to have an integrated cancer centre on the Mount Vernon site.

5. CRITERIA FOR EVALUATING FUTURE PROPOSALS

Participants were asked to suggest and comment on criteria that might be used to evaluate future proposals for the configuration of cancer services. This was an iterative process across the engagement events, and at times required extrapolating from what was being said, to arrive at some potentially workable criteria.

The list below represents the final version that was arrived at once all the events had taken place:

The following four factors were mentioned by patients during discussion but did not always emerge as a high priority. After careful exploration of why this was the case, given how fundamental each of these are, it appears that patients largely take these elements as 'read'; i.e. they would assume that they would automatically be built into any proposal that is put forward. These factors are:

- Deliverable
- Efficient (value for money)
- Effective (clinical outcomes)
- Safe (high quality care)

In terms of patient experience, the following important considerations were then identified:

- **Accessibility:** ease and comfort of using the service, including reception; appointment times commensurate with travel distance; good and cheap parking available; use of different channels including remote/virtual etc.
- **The physical environment:** all patient areas, including waiting areas, should be comfortable and have a good ambience
- **Located close to home where possible:** co-located with support where necessary
- **Multidisciplinary / joined-up service:** supported by data-sharing and IT infrastructure, and including non-clinical support services such as the Lynda Jackson Centre and the Michael Sobell Hospice
- **Consistency of care:** seeing the same clinical staff at each appointment (consultants and other HCPs); streamlining record keeping so that there is seamless information-sharing
- **Understanding of needs:** dignity and respect; understanding of different patient groups' needs; availability of support and counselling
- **Patient empowerment:** participation in decisions over own care; being enabled to make choices
- **Access to research and trials:** to ensure the latest treatments are available to patients
- **Expert workforce:** recruitment, development and retention of staff; good governance and leadership
- **The track record of providers:** ensuring that new leadership has a good track record in the field; ensuring that acute hospitals involved in future can deliver the same quality of service as that currently available at MVCC.

6. VIEWS FROM SOME PROTECTED CHARACTERISTIC GROUPS

NHS England were keen to hear the views of people from some protected characteristic groups about the sort of things which need to be considered, from their perspectives, when planning services.

For the purposes of this work four of the nine protected characteristic groups[2] were engaged with:

- People with disabilities
- Black and Minority Ethnic groups (BAME)
- Gender reassignment
- Sexual orientation (LGBTQ+)

It should be noted that this was not an Equalities Impact Assessment, rather this element of the work was intended as a way to include seldom heard voices at the very earliest stages of the process to assess any likely requirements for a full Equalities Impact Assessment using all nine protected characteristic groups at a later stage of the process.

Eleven telephone interviews were undertaken, including three with Chaplains from the Trust (one Catholic, one Humanist and one Muslim – all minister to all faiths, and people of no faith). The chaplains were included as they see many patients and carers in hospital settings and were able to speak to needs which they identified or which patients had told them about. One person representing a refugee organisation gave feedback in an email.

It should be noted that there was intersectionality across several interviewees from the protected characteristic groups, for example, someone with a disability was Gay and belonged to a religious group with specific dietary needs.

Further, several interviewees were very involved in support groups, and were able to offer insight into the needs and views of other people.

People were recruited for the interviews by contacting support groups in Hertfordshire, Hillingdon and north London.

The telephone interviews lasted between 30 and 70 minutes and were recorded with the consent of the participants. The interviews were qualitative and semi-structured, that is, whilst there was a topic guide to act as an aide memoire for the researcher, there was no set order in which topics

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[2] Under the Equalities Act 2010 nine groups of people are specifically protected against discrimination because of characteristics they have: Age; Disability; Gender Reassignment; Marriage and Civil Partnership; Pregnancy and Maternity; Race; Religion or Belief; Sex; and Sexual Orientation.

were discussed, and participants were allowed to emphasise topics which were of importance to them.

The eleven interviewees had the following characteristics:

Interviewee number	**Protected characteristic**	**Other protected characteristics**	**Other**
1	Transgender	-	-
2	-	-	Chaplain, Humanist
3	-	-	Chaplain, Catholic
4	Disability	-	-
5	BAME	Religion (Hindu)	-
6	BAME	Religion (Sikh)	-
7	LGBTQ+	Religion (Orthodox Jewish) Disability	-
8	BAME	Muslim	Chaplain, Muslim
9	Disability	-	-
10	Disability	LGBTQ+	-
11	BAME representative		From a refugee organisation
Email input	BAME representative		From a refugee organisation

Whilst people with disabilities talked about physical aspects of hospital and clinic environments, all the interviewees expressed the view the most important thing of all was that staff were aware that people could have particular needs such as cultural needs relating to dietary requirements or end of life practices, physical needs for people with disabilities, the placement of transgender people on wards or how to communicate with people with little or no English. The overall view was that staff should be able to ask people in a considerate way what their needs were, and then have enough understanding to meet the needs, or find out how to get help in meeting the needs.

The findings from the interviews are incorporated into the section below "What Good Looks Like", including considerations to be taken into account when planning services.

7. WHAT GOOD LOOKS LIKE

This section includes findings both from the events and the interviews with people from some protected characteristic groups. At the events people were asked to identify what characterises a good service, regardless of where it might be delivered and how it might be configured; in the interviews people talked about their experiences, generally, in clinical settings, and they identified gaps in provision which could be rectified when planning new services or considering reconfiguring current services.

The following elements are thought to be necessary for good services.

7.1 EASING THE PATIENT PATHWAY

- Efficient, seamless sharing of patient information, to ensure continuity of care, quick, effective and safe communication between HCPs – although there should be assurances that data would not be shared with commercial organisations such as insurance companies. This would also involve IT systems to be able to speak to each other in different locations
- Continuity along the entire patient journey, from referral and throughout treatment, including end of life care. Continuity tended to mean seeing the same healthcare professionals wherever possible.
- Good patient information before and during treatment (with the aim of minimising anxiety), including:
  - Information about the site: where to park, where to go
  - What to expect during treatment, and clear explanation of what's happening and why (radiotherapy was given as an example of where good practice is already taking place)
  - *"It means that when you actually go in for treatment, there's no stress, you understand why things are happening in the way they are."* (Uxbridge)
  - Potentially some element of patient-held records, to give a sense of the treatment process, provide information about drugs, provide a diary/schedule (especially if care taking place across different sites), and to increase the sense of overall patient empowerment
- An 'intelligent' appointment system, which flexes around people's schedules, travel needs, high demand etc. including availability of evening and weekend appointments
- Staff knowing about how other departments offering care to cancer patients work, so that they can tell people what to expect.
- The ability to have telephone, Skype or video consultations
- Support, counselling and therapy services before, during and after treatment. Whilst some support and counselling is currently available at the Lynda Jackson Centre greater access was deemed to be important, formally from cancer nurses and informally from peers and volunteers, and offered through the mainstream clinical services.
- Volunteers could be available in treatment and clinic waiting rooms
- Support after treatment, for those living with cancer, was missing from current services.

  "People who've been through it and who are still alive and kicking, it's so reassuring, hearing the experiences of others." (Stevenage)

"6 months later, if someone had just rung me and seen how I was getting on that might have been nice. Unless you have a big problem, you don't like to ring and make a fuss, but just to say, 'is this normal' or 'I feel like this' would be nice." (Uxbridge)

7.2 PHYSICAL ENVIRONMENT

- A physical environment that is bright, airy, welcoming and that provides:
  - Access to outside space/gardens
  - A reception area/desk that is welcoming and fit for purpose
  - Sufficient waiting space for all patients; waiting areas that encourage interaction between patients (important for peer support); comfortable chairs and a temperate environment
  - A fresh, non-clinical atmosphere that helps to 'lift patient spirits'
  - Sufficient rooms available for private time/conversations, especially between HCPs and patients/family
  - Good access to refreshment facilities
  - A carers' hub that provides a comfortable space, including information about and access to support services for companions who might be waiting a long time
  - Be easily navigable, with clear signage (perhaps coloured routes) between different departments
  - Other minor comments around the physical environment include having: electronic doors; information in different languages; visual signposting; non-reflective floors and ensuring it is dementia-friendly
- A more 'user-friendly' waiting room system offering more information about delays, electronic tracking, use of pagers/apps to allow patients to leave the waiting room/visit the toilets etc. This is currently a commonly mentioned source of anxiety and frustration.

  "You daren't leave your seat, to go to the loo or get a cup of tea or make a phone call in case you miss being called." (Luton)

7.3 TRANSPORT AND ACCESS

- Parking provision in a single location that is, adequate, easy to navigate, reasonably priced, can be paid for in advance/remotely (rather than needing to have change to hand), and offering a 15 minute waiting area for patients to be dropped-off/picked-up by companions. £1 patient parking was deemed to be important, and something that should be kept wherever services are delivered
- Improved hospital transport (many feel that this would be key to overcoming problems with distance of services, or relocation to a less convenient site), including:
  - Offering transport by car, allowing for smaller numbers and therefore reduced waiting time
  - Improved, dedicated waiting areas
  - Using the journey time 'intelligently' e.g. to collect patient information, take blood pressure etc.
  - Allowing companions to travel as well
  - At the very least ensuring there is transport from the feeder hospitals to the central site

- Offering the option to travel to the site by public transport, but to return by hospital transport after treatment
- Providing B&B for those travelling for daily treatment from further away
- Further, for those not able to access hospital transport, it was felt to be very important that any new site should be well served by public transport from all catchment areas.

7.4 GOOD INTERACTIONS

- Interaction between staff and patients is currently generally well regarded, and patients would like to see this continue to ensure that staff treat patients with respect and empathy. Key aspects of positive patient-staff interaction were identified as follows:
    - Talking slowly, clearly and without using jargon; looking at you, the patient, as they talk
    - Allowing time for the patient to take notes, process what they're hearing, even being proactive in encouraging patients to record the conversation etc.
    - Not rushing the conversation, taking time to answer questions, listening carefully and addressing queries and concerns directly and honestly
    - Overall, a sense of knowing you as a person and recognising what's important to you. *"It was me being discussed, we focused on what might happen, without being fearmongering or gung ho. It was clear and clinical and then it was my decision to make."* (Uxbridge)
    - Being able to support people with little or no English. Translations services currently do not seem to be available to everybody at all appointments; if translation services are not available clear notes should be written for the patient to allow them to get them translated elsewhere
- Awareness of, and accommodating people's differing needs
    - Sensitivity to patients' cultural, ethnic and religious needs, for example, end of life practices of different religions. There is a booklet available on this which could be kept on wards[3]
    - Being aware of, and being able to provide for, different dietary requirements, including those relating to religion, such as Orthodox Judaism

7.5 TAKING ACCOUNT OF DIFFERENT NEEDS

- When planning future services account should be taken of any differential needs of people in protected characteristic groups, for example:
    - Ensuring lighting is at an optimal level for people with visual impairments
    - Having even floor surfaces with few or no steps
    - Having people available to accompany those who might need assistance navigating their way clinics (for example, people with disabilities)
    - Making sure that lavatories for people with disabilities have support handles on both sides
    - Staff training on how to ask people what their needs are, and how to accommodate the needs.

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[3] https://www.gov.uk/government/publications/faith-at-end-of-life-public-health-approach-resource-for-professionals

8. ONLINE SURVEY

An online survey was available, advertised through service providers' communications networks, to be completed by anyone with an interest in MVCC. 190 people completed the survey.

This chapter gives an overview of the survey results. Full survey results are provided in Appendix 2

- 43% of the people who completed the survey had used services at MVCC, whilst 51% were a family member, a friend or a carer for a MVCC service user. 6% had not used services at MVCC
- Around 50% of those who had used MVCC themselves had done so in the last year
- Of those who had received treatment at MVCC 62% had had radiotherapy and 48% had had chemotherapy; 6% of people had received brachytherapy and 10% had received end of life care
- 80% of people had received some of their treatment at one or more other hospitals: 69% of people had received treatment at one other hospital, 9% at two other hospitals and 2% at more than two other hospitals
- Over 60% of people's nearest A&E departments were at Watford General Hospital or Lister Hospital (33% WGH, 29% LH). 13% lived nearest to Hillingdon Hospital, 11% nearest to Northwick Park Hospital, 7% nearest to Luton and Dunstable Hospital
- 90% of people answering the survey lived within a 30 mile radius of MVCC. Those living furthest away from MVCC were more likely to answer that the distance was too far to travel; however, many felt that travelling some distance was acceptable when getting specialist care
- When asked whether enough information was given when referred to MVCC 93% of patients said they had received enough information; the percentage of family, friends and carers who said they had received enough care was lower, at 67%, however, 23% of family, friends and carers said that they did not know, or could not remember, what information they had received
- Building renovation was thought to be the biggest change needed to improve experiences for future cancer patients (21%). Shorter waiting times (18%), more local services (18%) and expanding or improving facilities (16%) were also priorities. However, 18% of people thought that nothing needed to change.
- When asked what should stay the same with MVCC services staff quality was most highly rated (51%), followed by quality of care (22%) and quality of treatment (12%). 12% of people thought that everything should stay the same
- 16% of people said that they had been transferred to a different hospital to continue their treatment or for all of their treatment. For their patients the two things which could have made such a transfer easier were transport (27%) and communication between hospitals (23%)
- The idea of more community based or local delivering of cancer treatments was appealing to 57% of respondents; the biggest appeal was for those with longer distances to travel to MVCC
- People were asked to choose, from a list, the three things they felt were most important in a cancer treatment centre. 73% chose knowing their consultant and care team and having

them throughout their treatment. Also highly important was receiving the highest possible quality of care, even if that meant travelling further (52%). Being kept informed about treatment at all times (35%), care being provided locally (34%), knowing who to call for help or information if they become unwell at home (33%), receiving all cancer treatment at one hospital (31%) and getting the right help quickly if they become unwell, even if it is from a different team or hospital (19%) were also deemed to be important. The lowest score for the given options was for the buildings and environment where treatment is delivered being good (9%).

8.1 SUMMARY

This survey shows, as have other engagement exercises about MVCC services, that staff and quality of care are highly regarded. Whilst some people had to travel over twenty miles to receive treatment at MVCC many thought that this was worth it for the quality of care they received.

Renovation of buildings at MVCC was perceived as the biggest change needed to improve experiences for future patients, however, the building and environment being good was ranked as of lowest importance of things needed in a cancer treatment centre.

The three things people ranked as being of prime importance to them in a cancer treatment centre were: knowing their consultant and care team and having the same team throughout their treatment; having care of the highest possible quality, even if that means travelling further or having treatment in more than one place; and being kept informed at all times about treatment and what to expect.

9. CONCERNS ABOUT THE REVIEW PROCESS

During the events some people expressed concerns about the change process , with some, particularly at the Mount Vernon, Uxbridge and Central London events, sceptical about the motivations behind the review, the availability of funding and whether anything will really change (especially given the history of lack of investment in the MVCC site).

Participants raised questions, doubts and concerns along the following lines:

- Whether the site had been deliberately run down in order to justify moving cancer services and selling off the site for redevelopment.
  "I think the overall intention is to develop it for housing." (London)
  "Don't Hillingdon just want to sell off the land?" (Mount Vernon)

- If disagreements between the various Trusts involved in the site have been the reason for nothing happening in the past, how will these be resolved to ensure progress now?

- Why is money available now for a change, when it hasn't been available in the past to maintain the buildings in an adequate state of repair? Surely what's needed is simply investment in the site to bring the current facilities up to scratch (rather than wholesale change/relocation)?

- Could any changes be linked in with the current redevelopment plans for Hillingdon Hospital?

- Why has this situation arisen? Why are there two different Trusts involved with this site and how has ENHT 'ended up' running the cancer services? There was confusion about whether the Cancer Centre and Mount Vernon Hospital are different entities and what the relationship is between the two. An explanation that the situation has evolved in a piecemeal fashion over many years is both credible and welcomed.

- Concern was expressed by some participants that if cancer services were to be relocated, then the money that has been spent recently on renovating/updating some equipment and areas of the building at the MVCC site will have been be wasted.

- In Uxbridge a belief was expressed that the land and buildings have been covenanted for use as a hospital (possibly specifically a cancer hospital); whether or not this is the case should be clarified in any future communication.

- At Mount Vernon some people remembered a very similar review being undertaken ten years ago, and questioned why it was happening again, particularly as some of the recommendations in that report sounded similar to suggestions for future configurations of the service.

- The process of pre-consultation engagement and consultation were questioned, with some scepticism arising about whether people's views would really be considered when decisions were being made. There were questions about whether it was a 'tick box' exercise.

- People questioned why a review was needed at all, saying that if the NHS knew what was needed, they should just get on with things. There was a call for things to happen quickly, including taking a decision and moving forward from there. In general, perceptions of the review were more positive in Stevenage, where it is broadly welcomed, amid a sense that a discussion of the location of cancer services is long overdue; it should be noted that people in Stevenage and surrounding areas have a long distance to travel to MVCC and any new services which could be delivered nearer to them would be welcomed.

9.1 SUMMARY

There was a strongly held view that the ownership of the MV site with services being delivered at MVCC by another Trust was a reason that buildings had fallen into disrepair. There was also scepticism that moving MVCC services to another site was only necessary because the landlords wanted to sell the whole site for development. These views were most strongly expressed at events close to the MV site.

Given that there had been past reviews of MVCC, which had some similar recommendations, people questioned why the money to make changes was available now when it had not been in the past.

Some people viewed pre-consultation and consultation negatively, not believing that their views would be taken into consideration when decisions were being made. Others, however, felt that the NHS should decide what was needed and get on with delivering the best option quickly.

10. CONCLUSIONS

Generally, patients, past patients, carers and members of the public attending the events were of the opinion that the Mount Vernon site should be improved, and cancer services could remain in place there, either with in-patient services moving to an acute hospital or with acute services being built to serve the cancer services at MVCC. This was not one of the models considered at the events.

The service users and members of the public geographically closest to MVCC were most attached to the Mount Vernon site, citing it as an important part of their community. For those living in north Hertfordshire the attachment was less pronounced, and people were more open to change.

It should be noted that many of the staff attending the events were also attached to MVCC and the MV site, but they could see the need for change, and understood that this might involve moving services from MVCC in the future.

It was clear that patients, carers and the general public who attended the events did not understand some of the terminology commonly used to describe NHS structures and service change processes, nor the complex arrangements for commissioning and paying for care. In fact, the term ‘commissioning’ led people to think that the intent was to procure services from outside the NHS, that is, from private providers; there was a great deal of resistance to the idea of private provision in the NHS, and it would have been easy for the discussion to become derailed and for this to be the focus of discontent.

There were also concerns voiced that the pre-consultation stage, and anything which came after it, were tick box exercises and that decisions had already been made, or would be made, regardless of public opinion. This view was ameliorated to a large extent during the course of each event.

Two potential models for future provision, arising from the Expert Clinical Review, were considered at the events, where it was made clear that these were early thoughts, and other models could well arise as the process progressed. The first model was termed ‘full replacement’, which involved relocating all MVCC services to an acute site with additional radiotherapy satellite provision in the north of the catchment area and a networked chemotherapy service run from the cancer centre on acute district general hospital sites; the second model was termed ‘ambulatory hub spoke’ with a new build on an acute site with an ambulatory service for radiotherapy and chemotherapy remaining on the existing MVCC site, with additional radiotherapy satellite provision in the north of the catchment area and networked chemotherapy run from the cancer centre at other local hospitals and mobile chemotherapy if possible.

Past engagement exercises, the survey and events undertaken for this pre-consultation exercise all highly rate the standards of care at MVCC and a general concern raised by some event participants was that these standards might not be maintained if services moved, and there were particular concerns about any services delivered at non-specialist cancer centres, such as district general hospitals. A suggestion was made that services delivered outside the specialist centre could be badged as "MVCC at…" to ameliorate some concerns.

Patients, past patients, carers and members of the public tended to find it difficult to understand why cancer services needed to be co-located with acute services and why the need should result in a movement of services. They asked about numbers and patient outcomes when emergency ambulance transfer was needed – and they thought the numbers were relatively low; explanations about the likely future of cancer treatments and the likelihood of more patients needing HDU/ICU care, and the lack of it possibly meaning that some people might not be offered advanced cancer treatment, led to some people changing their minds.

When considering the single site model, concerns were expressed about losing the MVCC site, and there were calls for the 'companion services' (Lynda Jackson, Paul Strickland and Michael Sobell), or something very like them, to be relocated alongside a new facility.

Positive views of the single site model were that all services would be together, which people thought would lead to good continuity of care.

The hub-and-spoke model was particularly welcomed by those most local to MVCC as it was seen as a way of keeping some services on the MV site.

Both models recommended that leadership should be through an existing tertiary cancer centre. Not all participants understood the meaning of this, but once it was explained it was thought to be a positive move although there were discussions about whether this could mean losing local services, with Hillingdon residents in particular voicing concerns about having to travel into central London for treatments.

People were asked to consider the types of criteria which might be used for evaluating future proposals. Whilst four factors were sometimes mentioned by participants (plans should be: deliverable, give good value for money, give good clinical outcomes and have high quality care), for others there was an assumption that these would always be at the forefront of planners' minds. Ten important considerations were identified in terms of patient experience: accessibility; the physical environment; location close to home where possible; multidisciplinary/joined up services, including non-clinical services; consistency of care; understanding needs; patient empowerment; access to research and trials; an expert workforce; and the track record of providers.

The survey revealed that the three most important things when receiving care at a cancer treatment centre were: knowing their consultant and care team, and seeing the same team throughout treatment; receiving care of the highest possible quality, even if that means travelling some distance; and always being kept informed about treatments and what to expect.

People from the protected characteristic groups made suggestions about what people with disabilities, people from LGBTQ+ community and those of various ethnic backgrounds and faiths would like to be considered if new services were being planned. Some of the suggestions involved the physical aspects of buildings – for example adequate lighting and even floor surfaces, but predominately the message from the interviewees was about staff in hospital and clinical environments being aware of people's individual needs, by asking in an appropriate manner what the needs were and being able to facilitate the needs being met.

Event participants and people from protected characteristic groups identified various aspects of health care provision which encapsulate 'what good looks like' including efficient, seamless sharing of patient information to ensure quick and effective communication between health care professionals. There were suggestions of what a good physical environment would look like, how parking should be organised, what information needs patients have, how appointments systems should work etc. Plans which accommodated some or all of the aspects of perceptions of good provision could help to mitigate various concerns people had about plans for the future, for example, if it could be explained that a new service would have brighter and better buildings with good, reasonably priced, parking nearby, some barriers to change could be overcome.

Overall, whilst there was resistance to the idea of moving any services away from the MV site, especially by those living closest to it. There was, however, an acknowledgement that there could be advantages to a single site model, with continuity and consistency of care being the most important, for example, seeing the same consultant and care team at every appointment. It was important to people that there should be a streamlined system of record keeping to allow seamless information sharing and that non-clinical services such as the Lynda Jackson Centre and the Michael Sobell Hospice should be co-located with any future cancer centre. Being able to access some services closer to home, as outlined in both models, was attractive to people, especially those living furthest from MVCC.

11. RECOMMENDATIONS

In order for patients, past patients, carers and the public to see reconfiguration as an opportunity to improve some of the current processes and administrative procedures in the cancer care currently offered at MVCC a strong, clear case needs to be formulated. Above all, transparency of how the process is running is crucially important, including the stage the process has reached at any point in time, in order to encourage public confidence.

We offer the following recommendations to give a foundation for putting forward such a case.

11.1 CONSIDERATIONS WHEN PLANNING FUTURE SERVICES

Participants at the events and people interviewed from protected characteristic groups made recommendations they considered to be important if planning a service from scratch or updating or moving an existing service.

The following were common themes:

- **Accessibility**
  - Services should be as easy to reach as possible, with good public transport links
  - Where possible services should be close to home
  - Parking, especially for patients, should be adequate and reasonably priced
  - Floor surfaces in hospital environments should be level and step free
  - External and internal signage should be easy to read and understand, and kept up to date
  - Lighting should be adequate
  - There should be a staffed reception area and, when needed, there should be someone who could accompany people to the room or clinic they need (for example, people with visual impairments).

- **Communication**
  - All communications should be clear and simple, for example, letters written to patients
  - Different channels of communication should be considered, for example, remote/virtual appointments
  - For people with little or no English an appropriate interpreter should be available wherever possible; if it is not possible to have interpretation at appointments key information should be clearly written for the patient to take away to enable them to seek help later.
  - People should be able to participate in decisions about their own care and be made aware of choices.

- **Environment**
  - There should be adequate waiting areas which are comfortable for patients and carers. Enough seats should be available for all who need them.
  - Care should be taken to ensure that the needs of people with disabilities can be met, for example, by having assistance handles on both sides of lavatories.

- **Continuity and consistency of services**
  - Patient care should be consistent across all sites.
  - There should be continuity in care wherever possible, for example, seeing the same healthcare professionals.

- **Quality of service**
  - People should be treated with dignity, which includes staff understanding any particular or special needs they might have and accommodating them wherever possible.
  - Understanding people's cultural needs is important and easily accessible information should be available to help staff.
  - Adequate counselling services should be available for those who need them.

11.2 HAVING A ROBUST SYSTEM OF ENGAGEMENT/CONSULTATION

For the public and staff to understand and believe that engagement and consultation really does want to hear their views, and that the views will be considered when making decisions, several things need to happen:

- There should be a clear timetable showing when the touchpoints with the public will be, alongside key decision-points and milestones.
- The timetable should be published in places where it might be expected to be found – for example, on Healthwatch websites, hospital websites, in any newsletters sent out and in the local press and through support groups. The catchment area of MVCC should be considered, with notifications covering the whole patch.
- It should be clear to the public how and where they can make their views heard, by all methods, such as in writing, by email, in surveys and at events where they can attend in person. If there are any other public meetings where people can either listen to views or take part these should be publicised too.
- Events should be run throughout the catchment area and should be publicised for several weeks before they run. Local support groups should be alerted to the events, and advertising in local newspapers and on local radio should be considered. It should be clear to people that the events are a chance for them to make their voices heard, not just listen to a panel of experts.
- Information of all descriptions, including that given at events, should be clear and accessible – see recommendations below.
- The tone of the events should be informative and inclusive, so that people feel they have had a chance to put their views forward.
- At the events information should be available about how people can find out about next steps, including which websites they can visit.
- After each event a summary should be available on easily found websites.
- Information should be regularly updated, and, where possible, archives should be available for searching.
- At the end of the engagement/consultation process a clear report should be available summarising the process, the views expressed, what can and cannot realistically be accommodated and what the next steps are.

11.2.1 CLARITY IN LANGUAGE

The general public do not always understand NHS terminology and acronyms. When putting a case forward it is vital that people do not get overwhelmed by detail, such as the complex organisational structure of the NHS, or allow misunderstanding of words or concepts to cloud their understanding of the overall message.

We suggest that terms such as ‘commissioning’ and ‘buying services’ are carefully considered, as there were instances when people thought this meant buying from private providers.

At MVCC there is a need for people to understand that the site is owned by one trust and the service run by another – indeed many people knew this already. However, there was sometimes confusion about who NHS England were and what their role was in the process.

Our general advice is to keep things as simple as possible and deliver information with as much clarity as possible in language people can readily understand.
The following should be considered:

- If complex organisational structures are to be included adequate time to fully explain them should be allowed, however, we would suggest that for simplicity’s sake this should be kept to a minimum.
- When talking about staff roles, departments or services, do not use acronyms, but give the full title each time it is used.
- Terms such as ‘commissioning’ and ‘buying’ services should not be used, as people do not understand the internal financial arrangements of the NHS.

11.2.2 TRANSPARENCY OF INFORMATION

When giving information to the public it should be clear, using the recommendations above as a guide, but it should also be transparent and honest. There tends to be a level of cynicism amongst the general public about engagement and consultation exercises, with some people believing that decisions have already been made and engagement and consultation are expensive box-ticking exercises which make no difference to the end decision. It is therefore crucial that when decisions are made along the way people are kept informed and up to date information is always available for people.

We suggest the following be considered to ensure transparency:

- It should be clear to people what any decision-making process is, and who makes decisions.
- At events, keynote information should be presented by senior relevant clinicians, who are best placed to set out the case for change, represent the vision and explain models, and they should be on hand to answer patients’ questions and clarify where there may be misunderstanding.
- Costs of models should be clear, including where cost is a factor in decision making.
- If plans change during the process the most up to date information should be available for the public and be given in presentations, including why the changes have occurred.
- Sources of information should be clear for those who might want to follow up and read further about the process, for example, hyperlinks to reports which have informed the plans.

- If any information is too sensitive to share with the public there should be clarity about why it cannot be shared, for example if a report is commercially sensitive reference could be made to it with an explanation of why it is not in the public domain.

There should be a presumption to share information fully unless there are compelling reasons not to do so, in the spirit of the Freedom of Information Act and NHS England guidance on engagement, including being clear about challenges and trade-offs within models.

11.3 PATIENTS' AND STAKEHOLDERS' VIEWS IN DEVELOPING MODELS

We recommend additional engagement as models are developed further and during the options appraisal process should the programme proceed to this stage.
This should:

- Be focused on the considering the trade-offs within and between different models
- Aim to separate and identify benefits and concerns to enable clear criteria which can be applied during decision-making
- Patient and public priorities should be considered alongside clinical and financial criteria within a structured process for options appraisal, and representatives of patients should be formally involved in weighting and ranking options

Patient priorities and concerns should be specifically considered during future planning, including mitigations which could be delivered on implementation of preferred models and decisions.

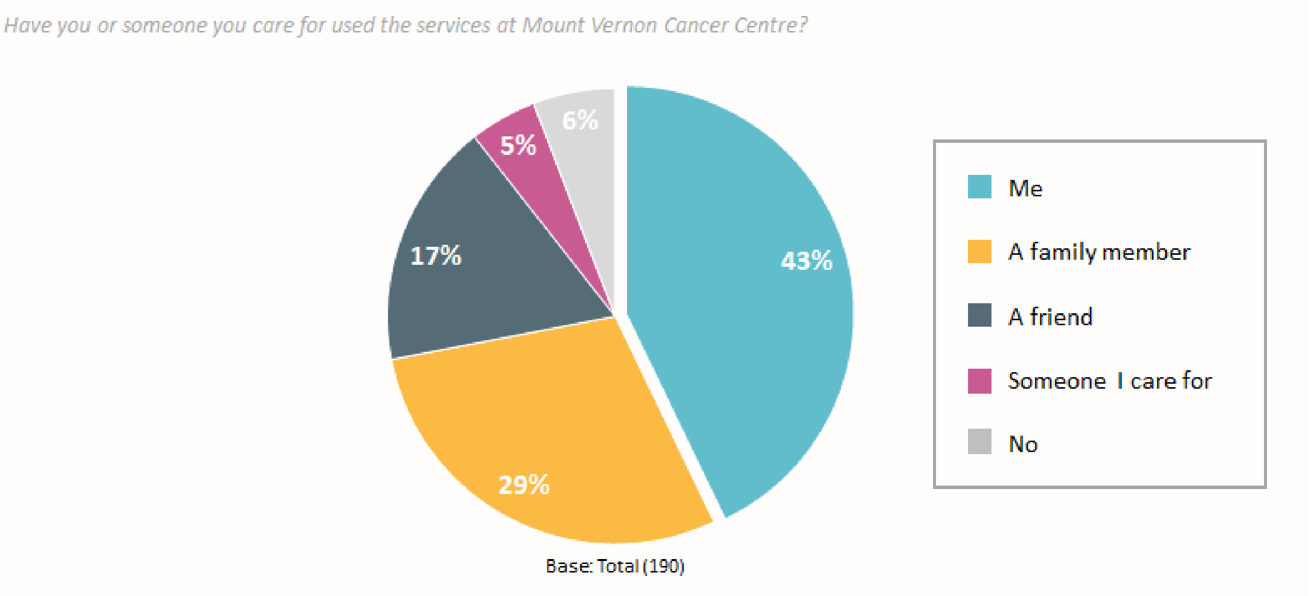
12. APPENDIX 1

Section 1.2 outlines recent engagement and feedback exercises relating to MVCC. The list below shows the documents consulted in writing section1.2

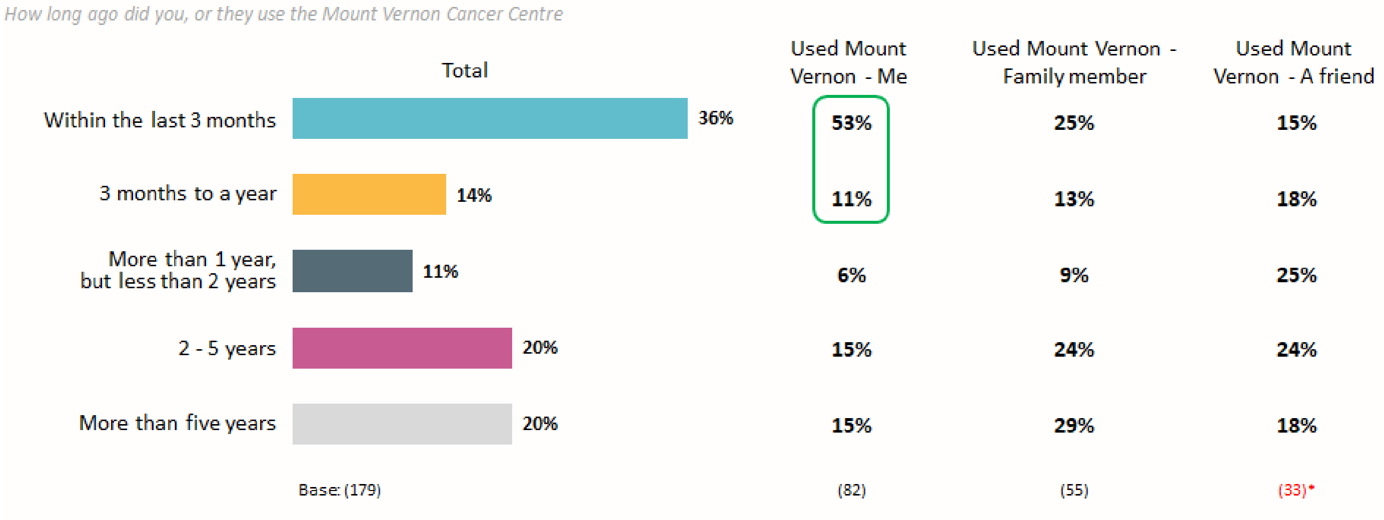
- Friends and Family Tests
  https://www.nhs.uk/Services/clinics/Overview/DefaultView.aspx?id=34923
- National Cancer Patient Experience Survey (2017)
  http://www.ncpes.co.uk/index.php/reports/2017-reports
- Evaluation Report on NCPES Cancer Patient and Carer Engagement Events May & June 2018 (East and North Herts NHS Trust and Herts and West Essex, Strategic Transformation Partnership, Cancer Locality Group)
- Healthwatch Hillingdon Patient Engagement Report Oct 2018
  https://healthwatchhillingdon.org.uk/?page_id=50&download-info=mount-vernon-cancer-centre-engagement-report-october-2018
- Patient Advisory Group Minutes May 2019 re NHS Forest Project; Development of Outdoor Space for Health and Wellbeing
- Summary Letter to Heathrow Communities Fund MVCC Evidence of Consultation Jan19
- Mount Vernon Green Space Steering Group 1 Agenda
- Clinical Governance - Consultant & Department Heads Oversight Agenda
- Hillingdon Hospital NHS Trust Health and Wellbeing Committee Agenda
- Immuno-Oncology Pathway at Mount Vernon ONC UK 1900114-01 Mount Vernon PID - Jan 2019 - New JG
- MVCC Patient Survey March 2019 - Presentation
- Correspondence with Macmillan about the Peer Evaluator scheme
- Peer Evaluator Information Sheet 'FAQ's Peer Evaluator'
- Patient Advisory Committee Minutes March 2019 and Anonymised Agenda May 2019.

13. APPENDIX 2

This appendix gives the full set of survey results referred to in section 8.

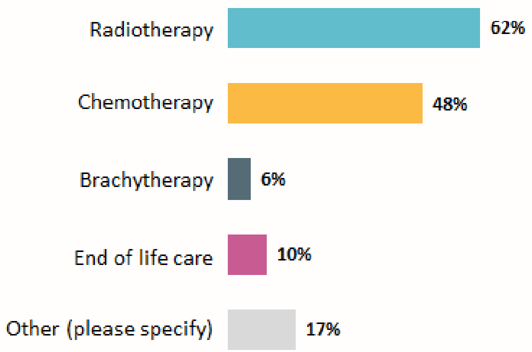

Have you or someone you care for used the services at Mount Vernon Cancer Centre?

Base: Total (190)


How long ago did you, or they use the Mount Vernon Cancer Centre

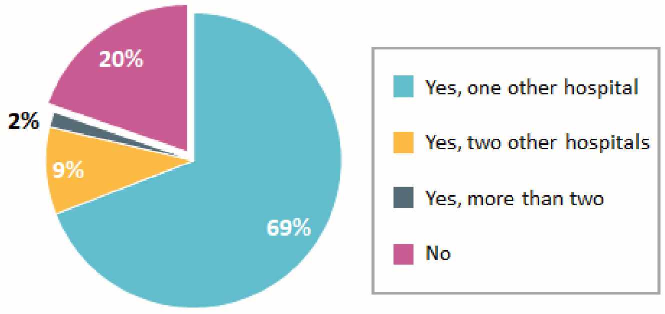
	Total	Used Mount Vernon - Me	Used Mount Vernon - Family member	Used Mount Vernon - A friend
Within the last 3 months	36%	**53%**	**25%**	**15%**
3 months to a year	14%	**11%**	**13%**	**18%**
More than 1 year, but less than 2 years	11%	**6%**	**9%**	**25%**
2 - 5 years	20%	**15%**	**24%**	**24%**
More than five years	20%	**15%**	**29%**	**18%**
	Base: (179)	(82)	(55)	(33)*

What treatment did you or they receive?



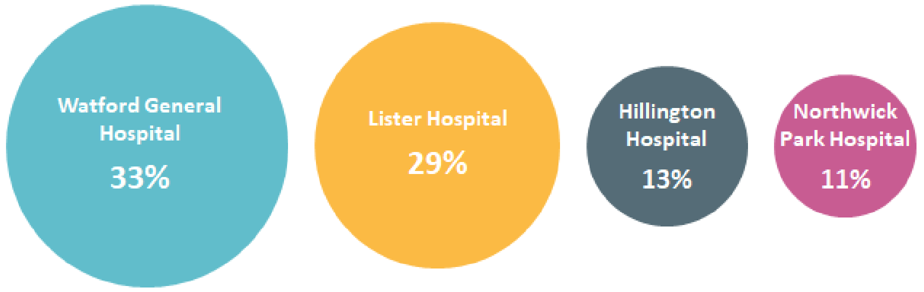
Base: Total (179)

Was any of the treatment at another hospital?



Base: Total (179)

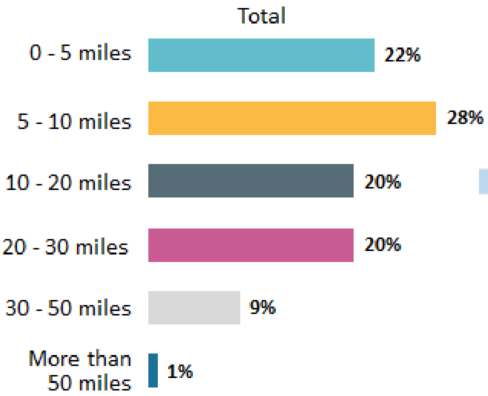
Which is your nearest A&E department



Luton and Dunstable Hospital	7%
Wrexham Park Hospital	1%
Ealing Hospital	1%
Barnet Hospital	1%
Royal Free Hospital	1%
University College London	1%
Bedford Hospital	0%
West Middlesex UH	0%
St Mary's Hospital	0%
The Whittington Hospital	0%
Other (please specify)	4%

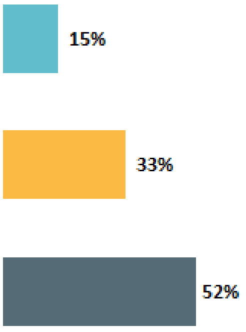
Base: Total (179)

How far away from you is the Mount Vernon Cancer centre



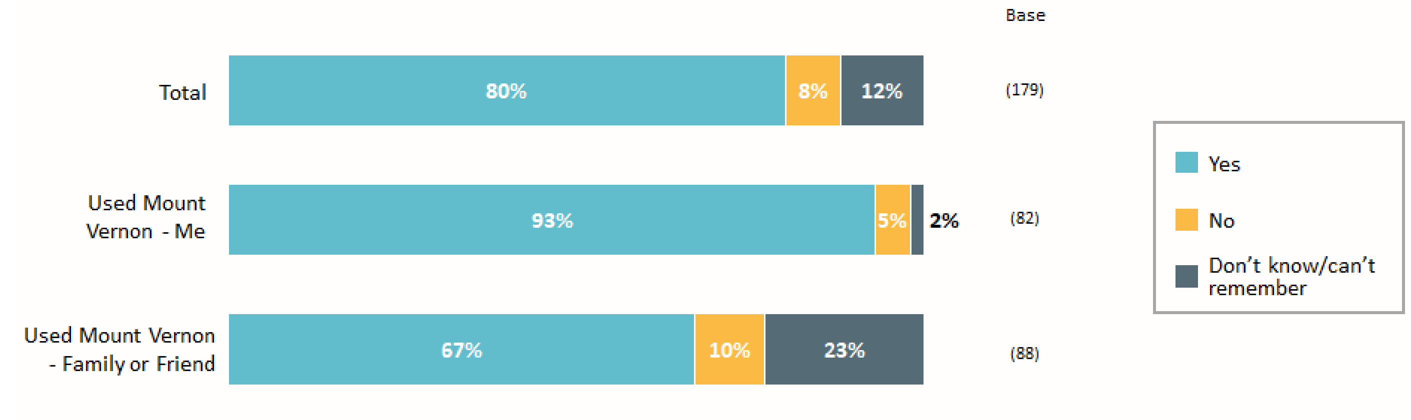
Base: (179)

How did you feel about travelling this distance for specialist cancer treatment?

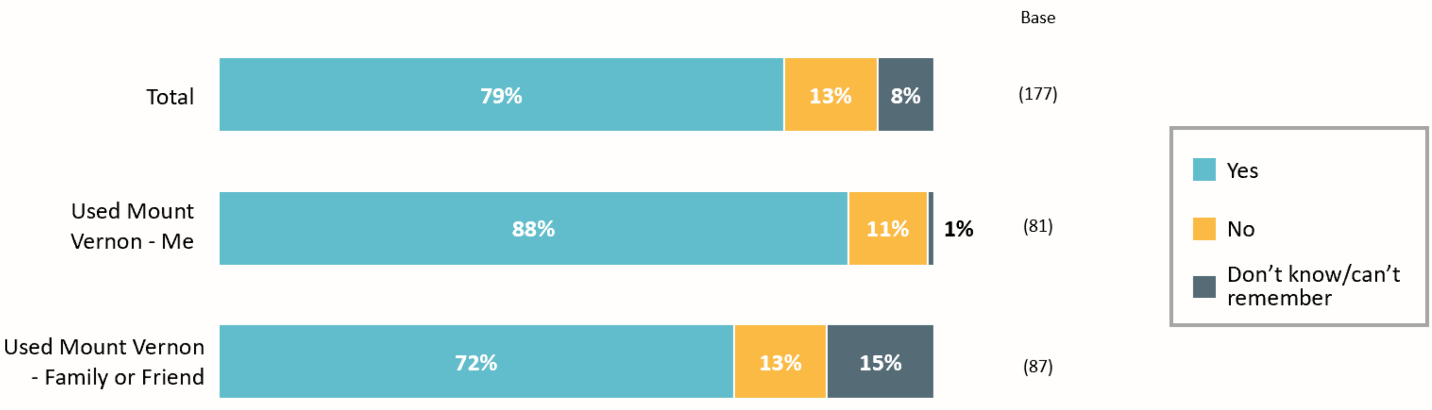


	Total	0 - 10 miles	10 - 30 miles	30 miles or more
It was too far	15%	4%	22%	38%
It was a long way but acceptable for specialist care	33%	7%	61%	56%
It was about right	52%	89%	17%	6%
	(179)	(90)	(70)	(18)*

Do you feel you received all the information you needed when you were referred to Mount Vernon Cancer Centre



Do you understand where you should go if you became ill during your treatment?



What would you change to improve the experience of cancer services for future patients?

Building renovation	21%
Shorter waiting times	18%
More local to me	18%
Nothing	18%
Expand/improve facilities	16%
Improvements to patient information	9%
More Staff	8%
Improve parking	5%
More patient/family support	5%
Organised transport	4%
Flexible treatment	3%
Improve Pharmacy	1%
Point of contact	1%
Close it	1%
Disabled access	1%
DK	1%

The building is very old and past it's sell by date. Treatment areas are too small and cramped. Too far away from north Hertfordshire.

Upgrade the buildings. Provide Emergency beds

Waiting times for treatment

Waiting times varied quite a bit for treatment. This was due to the distance travelled by so many people

Build newer and more modern buildings and give people a better option of not having to travel as far it is not easy for elderly who are under going treatment to always travel long distances

Base: All answered (141)

What would you keep the same?

Staff Quality	51%
Quality of care	22%
All of it	12%
Quality of treatment	12%
Location	6%
Specific Depts.	6%
Nothing	6%
Culture/Atmosphere	5%
Buildings and Facilities	4%
Garden/outside space	3%
Free/Cheap Parking	2%
Speed of treatment	1%

The level of care and the skill of staff and volunteers.

Brilliant staff and care

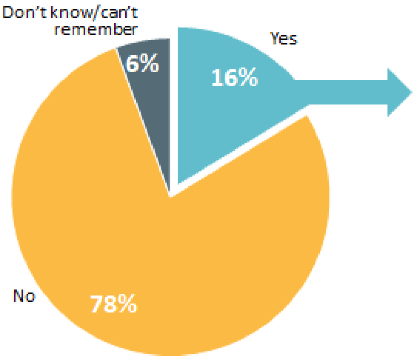
The staff as they are so friendly compassionate and helpful

The care and expertise of the wonderful oncologists, and nursing staff, the family feel if the hospital

The nursing staff, particular the radiotherapy department. They are all a credit to Mount Vernon.

Base: All answered (137)

Were you ever transferred to a different hospital to continue some, or all your treatment?



Base: Total (179)

Co-ordination between hospitals, more information

Edgware general at the time, too far by public transport

If yes, is there anything that could have made that as easy as possible to manage for you?

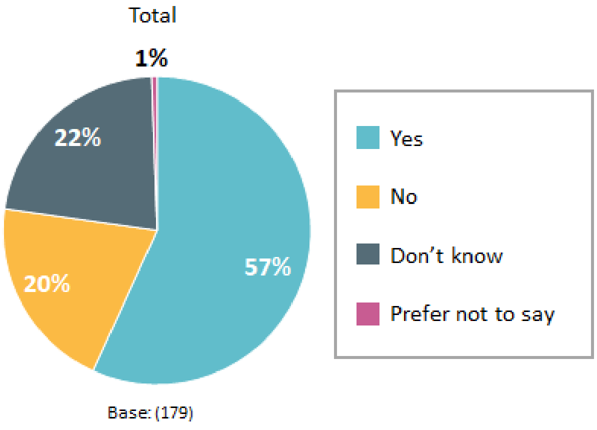
Transport	27%
Communication between hospitals	23%
Distance to travel	5%
Quality of emergency care	5%
More/better Information	9%
Parking	5%
Treatment received	5%
Preferred MV	5%
Don't know	5%

Yes information and transport

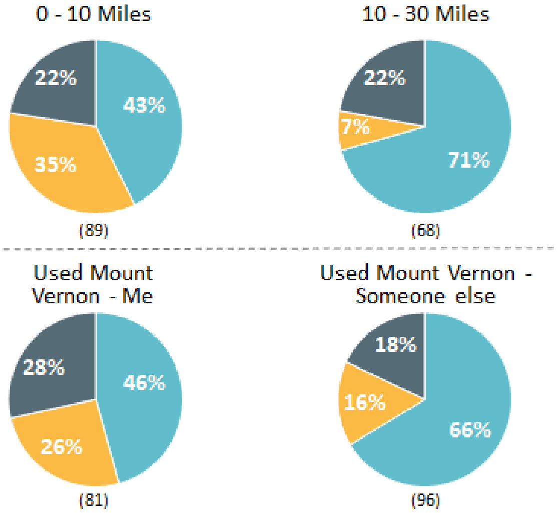
The two hospitals don't appear to really talk to each other or share notes in a timely manner…

Base: Had been transferred (22)*

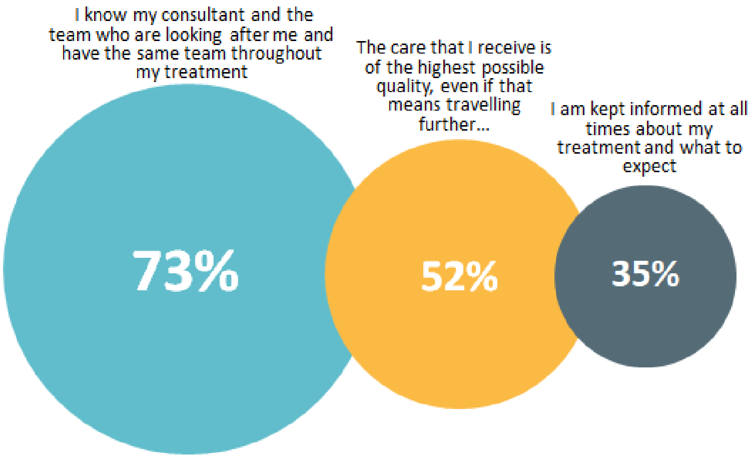
If we could provide services, such as chemotherapy, through a combination of at home/community units and/or mobile service options, or in a local hospital, is this something you would consider?



Base: (179)



*From the list below, please tick the **three** most important things to you in a cancer treatment centre*



Care is provided locally	34%
I know who to call for help or information if I become unwell at home	33%
I can receive all my cancer treatment at one hospital	31%
I can get the right help quickly if I become unwell, even if this is from a different team or hospital	27%
My relative or a friend can attend with me for support when I access my treatment	19%
There is adequate parking available	15%
I am given clear information, including on travel and parking	11%
The doctors and nurses caring for me have good links with my local hospital	10%
The building and environment where I have my treatment is good	9%
Other (please specify)	6%

Base: Total (179)