ANTHONY NOLAN

Saving lives through stem cells

From referral to recovery: Improving the CAR-T patient experience

AN ANTHONY NOLAN REPORT

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Introduction

Over the last decade, chimeric antigen receptor T-cell (CAR-T) therapies have transformed the treatment of advanced blood cancers such as lymphoma and leukaemia. The number of patients treated with CAR-T on the National Health Service (NHS) is expected to rise significantly in the coming years. However, there is very little insight directly from patients and caregivers about their experiences of CAR-T.

Anthony Nolan is committed to supporting cell and gene therapy patients directly through our patient services and advocating for improved NHS services. To improve our collective understanding of patient experiences, unmet needs, and opportunities for improvement, we commissioned the first ever national qualitative research study exploring the experiences of CAR-T patients and carers.

With generous grant support from Gilead Sciences and Johnson & Johnson, we commissioned researchers from the Centre for Patient Reported Outcomes Research (CPROR) at the University of Birmingham to conduct qualitative interviews with CAR-T recipients and their caregivers recruited from four NHS CAR-T treatment centres located in Birmingham, Bristol, Cardiff and Glasgow. 26 patients and nine caregivers were interviewed for this study between May and December 2024. More detail on the methods and participant demographics is available in the Appendix .

The study aimed to address the following research questions:

- What are the unmet care and support needs and expectations of patients undergoing CAR-T therapies?
- What are patients' perceptions of CAR-T prior to treatment?
- What are patients' experiences at different points of the pathway?
- What support services are available to patients and family members/ caregivers pre- and post-treatment?

In this report, we describe the experiences of CAR-T recipients and caregivers of the treatment pathway in the UK; focus on specific needs and issues which may require intervention; and provide recommendations for policy.

The published study and full findings can be found **here**.

Key findings

Patients and carers were overall very satisfied with their experiences of CAR-T and were grateful to have been offered lifesaving treatment. However, we identified four key areas where patients and carers felt services could be improved:

1. **Access to more tailored information** about CAR-T, for example on treatment outcomes for younger patients or UK-specific information.
2. **Improved patient facilities** would help to improve treatment experience, for example having access to reliable WiFi, exercise equipment and better-quality food.
3. **Better financial support** is required for patients and their caregivers, who often must reduce their hours or even stop work completely to support their loved ones.
4. **Better mental health support** should be offered to patients throughout and following their treatment journey.

This report dives into areas across the CAR-T patient pathway, highlighting aspects that may require intervention. The insight from this study will inform the development of appropriate and targeted strategies to improve the care experiences of future patients and caregivers.

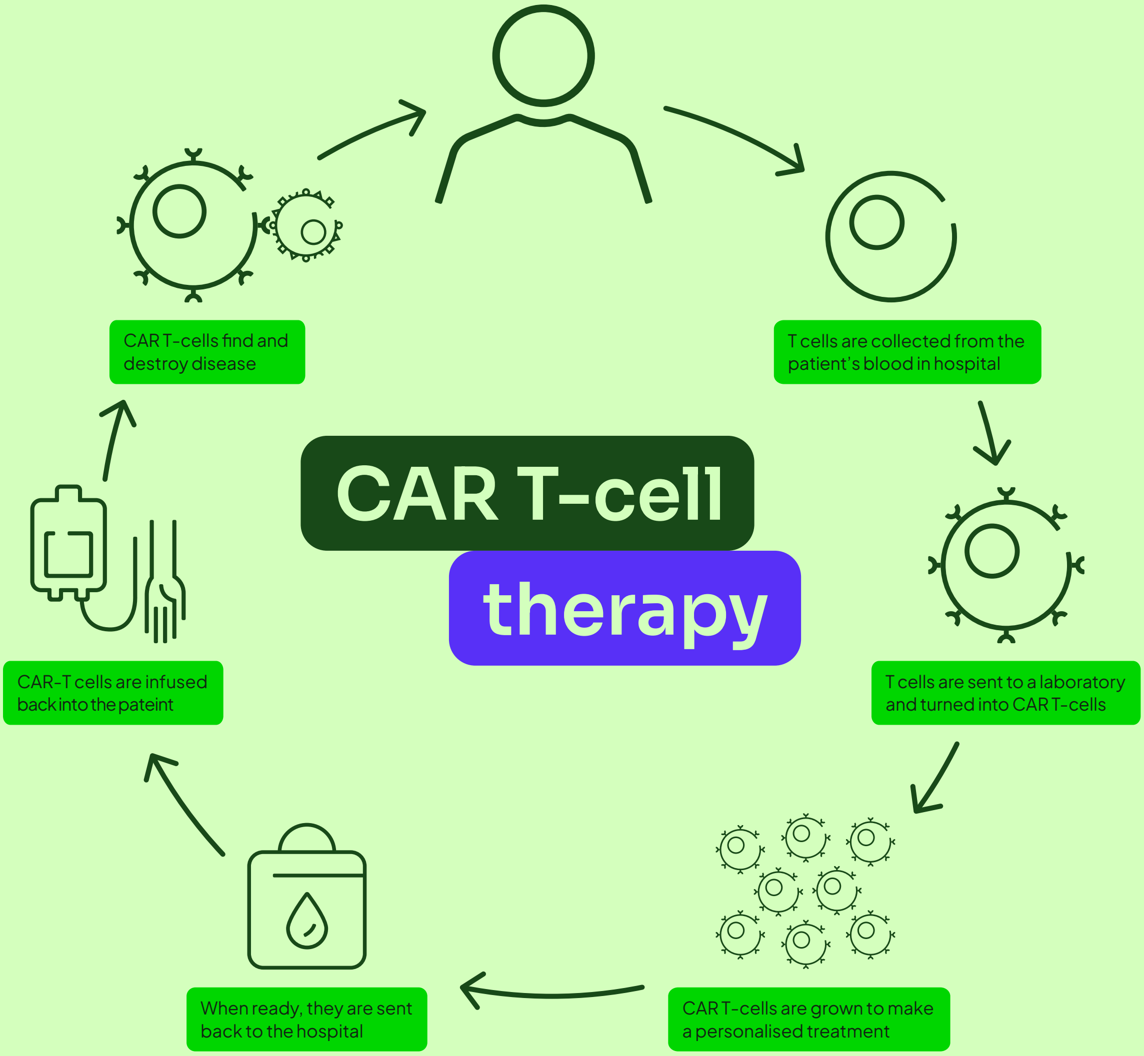
What is CAR-T therapy?

T cells are a type of white blood cell that form an important part of the immune system. They recognise abnormal cells, such as cancer cells, and destroy them using proteins on their surface called receptors. Sometimes, cancer cells survive by disguising themselves from being recognised by T cells.

T cells become **CAR T-cells** when they are genetically altered to make them produce a new type of receptor, called a Chimeric Antigen Receptor (CAR).

These CAR T-cells are more efficient at binding to and removing cancer cells. They also send out signals that attract other immune cells and cause them to rapidly reproduce near the cancer cells. This increases the chance of all the cancer cells being removed.

Treatment involves collecting a patient's T cells via their blood, genetically modifying them so they can fight the cancer, then infusing them back into the patient. The whole process is relatively complex and takes time, with treatment and recovery in general taking several months.



CAR T-cell therapy

T cells are collected from the patient's blood in hospital

T cells are sent to a laboratory and turned into CAR T-cells

CAR T-cells are grown to make a personalised treatment

When ready, they are sent back to the hospital

CAR-T cells are infused back into the pateint

CAR T-cells find and destroy disease

Who can have CAR-T therapy?

There is specific eligibility criteria for CAR-T, and it is currently only offered if other treatments have been unsuccessful.

At the time of writing, CAR-T has been approved in England, Wales and Scotland to treat:

- Children and adults with relapsed or refractory B cell acute lymphoblastic leukaemia (ALL)
- Adults with B cell lymphoma, specifically:
  - relapsed or refractory diffuse large B cell lymphoma (DLBCL)
  - relapsed or refractory primary mediastinal large B cell lymphoma (PMBCL) (only available in England and Wales)
  - follicular lymphoma (FL) grade 3B after one line of systemic therapy
  - relapsed or refractory mantle cell lymphoma (MCL)

The CAR-T treatment pathway

Referral for CAR-T treatment

Patients are referred by their local hospital to a CAR-T centre, once there is evidence that previous treatments have been unsuccessful. Once a patient decides to undergo CAR-T treatment, their doctor will discuss their case at one of the national CAR-T panels. These panels are made up of clinical experts who determine whether CAR-T is an appropriate treatment option for the patient.

↓

Preparation for CAR-T

Patient's T cells are collected, sent to a laboratory where they're genetically modified to make CAR-T cells. Meanwhile, patients are likely to require chemotherapy or radiotherapy to control their cancer until they receive their CAR-T infusion. In the days leading up to the infusion, patients receive lymphodepleting chemotherapy to prepare the body and create space for the CAR T-cells.

↓

CAR-T infusion and monitoring

Patients are admitted to the treatment centre to receive their CAR T-cells under close monitoring. Patients remain heavily immunocompromised for many months and even years after treatment, so contact with family and friends during this phase is limited.

↓

Discharge

Once patients have sufficiently recovered, usually around 10–14 days after infusion, they may be discharged to an ambulatory care setting if eligible, and if such a service is available at the CAR-T centre. Otherwise, they remain as inpatients for around one month after infusion before being discharged. Ambulatory care allows patients to receive specialist treatments without having to be admitted into hospital – instead, the hospital provides more comfortable accommodation nearby and ensures there is a pathway for out-of-hours support.


ANTHONY NOLAN saving the lives of people with blood cancer
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Study findings

This report is split into seven topic areas across the patient journey, based on the study findings:

Information provision

The need for peer support

Impact of travel and distance

Financial wellbeing and support

Mental health and support

Patient facilities

Experience of ambulatory care

The following pages dive into these areas of the CAR-T journey, outlining specific needs and issues, both from a patient and caregiver perspective.

Information provision

Clear, timely, and relevant information is essential to help CAR-T patients and their caregivers make informed decisions and feel confident about the treatment ahead. The journey starts with an initial consultation with the CAR-T delivery team – this is a key moment in the process, shaping expectations and providing a view of what's ahead.

The study found patients and their caregivers often come away from the initial consultation feeling reassured and positive about the treatment. Most participants felt they had access to the right level of information to support them with their decision-making.

However, there were still some areas for improvement identified:

- More tailored information, for instance on treatment outcomes for younger patients, and UK-specific information.
- Opportunities to access information from peers.
- Practical information on what to expect, for instance from Clinical Nurse Specialists (CNS) and other non-consultant staff.
- Provision of printed information to all patients and signposting to other reputable sources of information.
- Additional information on success and mortality rates for individuals interested in such statistics.

Some patients also noted they were given more verbal information than they could realistically process in a single appointment. Information overload caused by both the quantity of information and the way it was delivered, has been recognised as a potential issue patients may face during their treatment journey.[1,2] The issue is particularly relevant for CAR-T patients and their caregivers, who may already be physically and mentally overwhelmed by the rapid pace of the process and the numerous hospital appointments it entails. This study also found some centres gave out leaflets while others didn't. Due to the nature and intensity of the information received, having leaflets to refer to following the appointment is key.

> **"We had verbal stuff but nothing to take away, to go home and look at and get it clear in your mind."**

CAREGIVER

More tailored information about CAR-T

Some younger patients and their caregivers reported not receiving information and statistics relevant to their age group, and felt they received limited information about potential outcomes specific to their age.

> **"They couldn't give us information specific to her age because there wasn't a lot of data. It was more for the older generation, so we were going to a bit of the unknown."**

CAREGIVER

Roughly half of the patients and caregivers in this study felt as though they did not need to seek further information from other sources such as the internet – however, those that did expressed frustration that most information was for US patients, and did not apply to the UK context. Some also explained that information on the internet could be inaccurate. This further highlights the need for healthcare organisations and charities in the UK to continue to develop more guidance specific to CAR-T.

> **"When you can't find an answer, you go on social media. You go on there looking for information but there isn't any because the American medical system is completely different from ours."**

PATIENT

Access to information from peers

When searching for further information online, patients and caregivers were more interested in seeking the experiences of previous patients rather than scientific information provided by the NHS, charities and support groups. Read more about the need for peer support on page 14.

Practical information on what to expect

While patients and caregivers felt they received sufficient information about how CAR-T therapy works, the process involved and potential side effects, some expressed a desire for more practical information on what to expect throughout their treatment journey, from individuals such as their Clinical Nurse Specialist (CNS) or other non-consultant staff. For instance, information around the length of time required to collect T cells could help patients and caregivers better plan their travel arrangements.

> **"I personally think I had enough information to make my decision, but what would I have welcomed? Maybe a talk with a specialist nurse would help more. People who've had their hands-on while giving the treatment."**

PATIENT

> **"I could get information from the doctors about how it works, but there's no practical information."**

PATIENT

Information on success and mortality rates

Most patients felt the verbal information they received from specialists at the CAR-T treatment centres was enough in terms of content and detail. However, some felt the provision of more statistical information around survival rates and treatment failures could be reassuring. These individuals acknowledged the fact that statistics, particularly on long-term outcomes of CAR-T therapy, may not be currently available. While some patients value information on prognosis to help with their decision-making and coping, others do not want such information and may find it distressing or difficult to comprehend.[3–5]

While there is scope for improvement in the provision of information, most patients in this study felt they had access to the right level of information to support decision-making. They consistently described their CAR-T consultant as extremely helpful in explaining the process, how CAR-T works, and what to expect. Participants also valued the use of lay terms when discussing complex technical aspects.

Information and support for patients and families

You can access Anthony Nolan's CAR-T patient information through our website **here**. We use the GTranslate tool on our website, which means our website can be translated into over 100 different languages. You can find the tool in the top left of all our webpages.

On our website there is a **guide to having CAR-T** leaflet, produced by Blood Cancer UK in partnership with Anthony Nolan. We also have a variety of other leaflets you can download or order – check these out **here**.

We also offer an **online forum** where patients and family members can connect with others facing similar circumstances and share their experiences.

Need to talk? Call our helpline on **0303 303 0303** for information and advice on CAR-T therapy or stem cell transplant.

The need for peer support

Studies have shown that peer support can strengthen patients' ability to cope with disease and the effects of treatment, while also improving health outcomes.[6,7] Peer support can take place on a one-to-one or group basis and may be in-person or online via chat rooms and social media message boards.

Patients and caregivers who accessed peer support shared that this helped them to prepare mentally for their treatment journey. They also viewed it as a valuable source of reassurance and practical, experienced-based advice, that healthcare professionals may not be able to offer.

> **"I know Mum goes online a lot. She would go online to chat rooms, and got a lot of information that way, and just got a little bit of reassurance from somebody else who's going through it... That really helped Mum, that sort of peer support network that she could talk to... I don't think there was the same support for the CAR-T, just because it was so new and rare."**

CAREGIVER

> **"There's not a lot of information about how other people have gone through it, and every time we looked for it, it would be in America."**

PATIENT

However, there are still some areas for improvement when it comes to offering peer support:

- Patients in the UK find most online forums are US-based and so the practical information shared by other patients relates to the American healthcare system and is not applicable to the UK context.
- There are concerns around the nature and content of peer-to-peer support, and the impact it will have on patients.

> “You can speak to your doctors, you can speak to the consultants and nursing staff but that’s not the same as speaking to someone that can say ‘when you go to hospital take this and this and this with you’.”

PATIENT

Some patients do not access peer support for several reasons

For some, the information from their medical team and the support from family and friends is enough. Others believe individuals cope differently with stressful situations, so the experiences of other patients may be of limited benefit to them.

Patients may also have concerns about the nature and content of peer-to-peer interactions. While the sharing of negative experiences can be seen as honest, it may also trigger or heighten anxiety in some patients. Interestingly, evidence suggests that patients at the end of their CAR-T treatment journey who had positive experiences may be more inclined to offer peer support to others.

There is also a view that the information shared should focus on non-medical advice and where possible, healthcare professionals should moderate discussions to ensure its accuracy and appropriateness.

Impact of travel and distance

The treatment journey involves arranging and attending several hospital appointments, which can be overwhelming for patients and caregivers. A typical CAR-T patient might attend two to three appointments a week in the lead up to admission, and similar following treatment. Once they are discharged back to the care of their local team, this may drop to one weekly appointment.

Patients tend to have their care managed by two, or in some cases, three hospitals, and often need to personally coordinate the appointments between these sites, as well as ensure they have someone to take them to the appointments. Some centres will have a CNS or a coordinator to arrange these appointments, but this isn't always the case. Patients and caregivers therefore experience substantial physical and mental burden from frequently scheduling and travelling for appointments. This is particularly burdensome and stressful for patients who live in rural and remote areas.

This study identified the following as key problem areas:

- Distance from referral and CAR-T centres.
- Frequent long-distance travel, with some patients suggesting virtual or telephone-based appointments could replace most in-person appointments following discharge.
- Often having to use public transport to travel to appointments and the increased risk of infection this poses.
- Limited availability of car parking spaces at hospitals and ambulatory care accommodation.

Distance from referral and CAR-T centres

At the time this study was carried out, there were around 20 CAR-T centres in the UK, the majority of which were in England. This means a substantial number of patients would not have a centre close to where they live. Clinical teams who analysed data from three CAR-T centres in England found 54% of patients had to travel over 50 km and 25% travelled over 100 km to their CAR-T centres.[8] Since this study, all allogenic transplant centres are now able to offer CAR-T, although for some patients, their closest centre will still be a considerable distance away from where they live. Additionally, there are currently only three centres in the UK that offer CAR-T to children.

> **"I lived so remotely from the hospitals, it was a six-hour journey from where I live to see the consultant there."**
>
> PATIENT

Frequency of long-distance travel

Frequent long-distance travelling is also expensive and financially burdensome for patients and caregivers. Where possible, combining multiple appointments into a single visit would be more practical and convenient. This is already being done by many CNSs around the country – however, this study showed that this isn't every patient's experience. Patients in the study suggested virtual or telephone-based appointments could replace most of the in-person appointments with the CAR-T delivery teams after discharge, especially when there are no symptoms of side effects.

> **"The hospitals are so spread out and you've got appointments one day and another appointment the next day. It was physically exhausting… I was just crying because I was so tired, but you didn't want to miss any appointments because they were really important. So that was really stressful and also the expense was huge."**

PATIENT

Patient safety and practical issues with travel

All CAR-T recipients are advised to avoid public transport due to their suppressed immune system and the risks of infection. However, many patients have no option other than to use public transport to travel to and from appointments.

For those able to travel by car, the limited availability of parking spaces at the hospitals and ambulatory care accommodations is a frequent issue.

While these issues are not unique to CAR-T patients, such practical difficulties can heighten anxiety and add to the emotional burden and stress experienced during this period. Studies have shown hospital services and the physical environment can influence patients' care experiences, which in turn can affect their health outcomes.[9]

Financial wellbeing and support

The financial cost of treatment to patients and caregivers can be substantial. This includes the cost of travel and the loss of income for both patients and caregivers taking time off work, changing from full-time employment to part-time, or even stopping work. As many as 30% of people living with cancer experience a loss of income as a result of their diagnosis and 33% stop working either permanently or temporarily.[10]

> **"I had a job which I eventually had to give up. I just couldn't manage to do everything."**

CAREGIVER

> **"We have to spend extra money for emergencies. For example, sometimes we have to leave the kids somewhere because me and my husband need to be in hospital."**

PATIENT

In addition, our patient survey, conducted between February and March 2024 with CAR-T and stem cell transplant patients, revealed that **24% had at some point paid out of pocket for overnight accommodation** due to the distance from home. Furthermore, a staggering **89% of respondents had never heard of the Healthcare Travel Costs Scheme**, which can reimburse some travel expenses for patients receiving benefits, and only 7% had ever applied for the scheme.[11]

This study identified the following key problem areas:

- Some patients being unable to access financial support.
- Inconsistent information provision and signposting.

Anthony Nolan patient grants of up to £500 (split into two payments, six months apart) offer crucial relief for patients and their families, with travel costs consistently the most common request in grant applications, making up 33% of all grants provided in the 2024–25 financial year.[12]

Being unable to access financial support

This study found that some patients and caregivers in need of financial support were unable to access it due to reasons such as UK residency status, or eligibility thresholds for welfare support. Reduced income may force patients and their families to deplete their savings, and in some cases, end up in debt, further adding to an already extremely stressful and worrying time.[13]

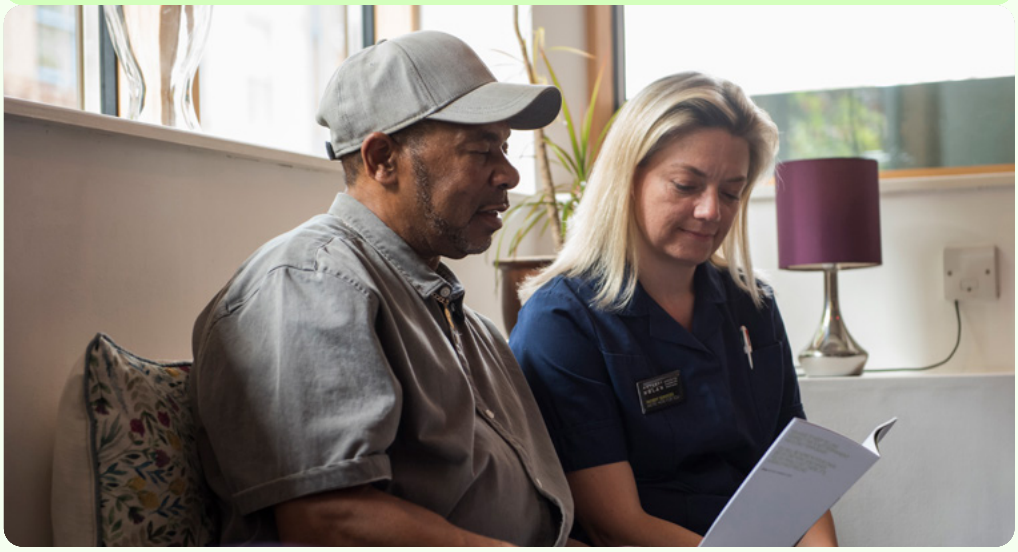
Inconsistent information provision and signposting

Information about financial support is inconsistently provided to patients during their treatment journey. For instance, information concerning assistance with transportation may be provided in appointment letters for some patients, but not others. The topic of financial support may be raised infrequently by healthcare or social care professionals, and often patients and caregivers are reluctant to bring it up due to embarrassment.

Grants for CAR-T patients

For information on Anthony Nolan's patient grants and eligibility, check out our **webpage**.

Leukaemia Care also offer a financial grant to support with travel and food costs as well as hotel accommodation to support leukaemia patients undergoing CAR T-cell therapy. More information about the CAR-T Away From Home Service, can be found on their **webpage**.



Mental health and support

The emotional impact of a blood cancer diagnosis and treatment can be significant for both patients and caregivers.

In the period between panel approval and CAR-T infusion, numerous appointments and tests take place, requiring patients and caregivers to absorb large amounts of information and make important decisions within a short timeframe.

Many experience varying degrees of anxiety during this stage, not only due to concerns about the CAR-T therapy itself, but also the risk of cancer progression while waiting for treatment, and the possibility of treatment failure which is often heightened given their experiences with previous therapies. Patients often feel their caregivers and family members experience greater anxiety than they do throughout the treatment journey.

> **"… I think it's harder for them looking on and seeing what you're going through. And they feel that there's nothing they can do."**

PATIENT

Patients generally do not discuss these concerns with their medical teams. Some take a philosophical attitude, or some cope by not dwelling on their situation, focusing instead on the treatment. The intensity of medical tests and procedures before CAR-T infusion might facilitate this avoidant strategy, providing distraction for many.

> **"I really felt alone. I was always the youngest there. I've really struggled with that."**

PATIENT

After infusion, some patients may experience some degree of depression when they are discharged back to their referral team. At this stage, the medical procedures reduce significantly, leaving less distraction from self-reflection or intrusive thoughts.

This study identified two key problem areas:

- Uncertainty among patients and caregivers on what psychological support is available.
- Variations in the availability, consistency and approach to psychological support across the treatment pathway and between CAR-T centres.

Uncertainty on what psychological support is available

Patients and caregivers are generally unclear about the availability of psychological support post-discharge and which of the hospitals involved in their care should provide it. Due to limited resource, an 'on-demand' approach to the provision of psychological support may be adopted by care providers – however, patients with the greatest need may be reluctant to make such requests, and struggle with recovery and the return to usual activities. Patients in this study indicated they would be more likely to engage with psychological support if it was proactively offered.

> **"I think people will be reluctant to ask for mental health help but if somebody comes and speaks to you and says, oh I'm a psychologist, then you're more likely to open up if they're actually there in front of you."**

PATIENT

> **"It might have been my own fault that I never reached out to one of my consultants and said to them, 'Look, I'm suffering a wee bit here'. But at the same time, you were never really asked. And your consultant maybe only has 10 or 15 minutes with you."**

PATIENT

Variations in the approach to psychological support

Patients are offered psychological support during the treatment journey – however, there are variations in how this support is offered and provided. Some CAR-T centres consistently and proactively offer psychological support throughout patients' treatment, while others appear to take an 'on-demand' approach. Several patients reported receiving a visit from a psychologist during their admission at the CAR-T centre, but it remains unclear whether all patients are referred to a clinical psychologist at the very beginning of their treatment journey.

It's important to note that the level of support needed will vary among patients. Patients with a history of mental health issues will likely require more support, while those with close family, a strong network of friends and no history of mental illness may have less need for psychological support from NHS services.

Quality of psychological support

When psychological support was available, it was sometimes not as helpful as it could have been. A patient in this study with a history of mental health issues felt the interactions with the psychologist at the CAR-T centre were inadequate in terms of frequency and duration, making it difficult to build a relationship and open up.

> **"She said he didn't have the bedside manner, and he was like 'what's up with you today then?'... there wasn't much sympathy so she stopped because she said it was making her worse rather than better."**

CAREGIVER

Lack of support following discharge

What is clear is that psychological support is not consistently offered after CAR-T infusion, during ambulatory care or post-discharge follow up. According to patients and caregivers, these are the stages where psychological support is most needed to help patients come to terms with their experience.

Despite these challenges, patients in this study who accessed psychological support through the NHS at some point in their journey (over half of participants) reported the service was valuable to them. The key challenge moving forward is to ensure every patient is consistently offered the same high-quality level of psychological care and support throughout their treatment journey.

Patient facilities

Before being discharged to ambulatory care, patients typically spend around 10–14 days in protective isolation, although this can go up to 28 days or longer in some cases. Most patients find this period challenging and stressful. For some, inadequate facilities at their CAR-T centre contributed to their feelings of despondency.

Issues identified by the patients and carers in our study included poor WiFi, which made remote interactions with family members difficult; lack of televisions; absence of air conditioning during summer; and even a broken shower.

> **“… but the food was just appalling… The other problem was there wasn’t any WiFi and there wasn’t a TV. So communication with the rest of his family – or generally the outside world – was very, very difficult.”**

CAREGIVER

Suggestions to improve the patient experience include:

- Access to another room which may have entertainment, such as a television, exercise equipment, or video games.
- Access to a safe garden space.
- Reliable WiFi and functioning air conditioning.
- Better-quality food.

> **“The fact that I couldn’t leave that room… I was just sat in that room and I was going crazy… I took books in with me, but because of the way that I felt, I couldn’t concentrate to read. I knew I had to be isolated because of the risk of infection, you just have to accept it to a certain degree. It’s very difficult when you’re going through it, but on reflection, it will be the best thing that I’ve done because it saved my life.”**

PATIENT

Experience of ambulatory care

When it is assessed as safe, usually around 10–14 days after infusion, patients may be discharged to an ambulatory care setting if eligible, and if such a service is available at the CAR-T centre. Otherwise, they remain as in-patients for around one month after infusion, before being discharged back to the care of the referring team.

Patients can go directly home if they live within one to two hours' drive of the CAR-T centre, depending on the specific rules at their centre. During this typically two-week period, patients are closely monitored by their medical team in case of any serious side effects of CAR-T treatment.

Although patients must still limit their interactions with others, particularly in confined spaces, discharge to ambulatory care offers greater freedom and is often seen as an important first step towards returning to normal life. Patients who stay at accommodation close to their CAR-T centre generally find it a pleasant experience.

However, there are still some areas for improvement, with this study identifying the following key challenges:

- Practical barriers, such as unsuitable facilities for individuals with disabilities and noise pollution from nearby construction.
- High cost of ambulatory care accommodation (patients are reimbursed, but often not immediately).
- Insufficient information provided following discharge.

Practical barriers

Accommodation is often designed and furnished with the assumption the caregiver will be the patient's partner or spouse. For instance, providing a single double bed in the bedroom. This might be an issue in situations where the caregiver is a friend or another relative, requiring patients to seek alternative, and often more expensive, accommodation.

Patients are required to have someone with them around the clock to monitor and provide practical assistance during recovery. This can be particularly challenging for caregivers in full-time employment as many are likely to have exhausted their leave entitlement at this stage. As a result, some patients are unable to find someone to stay with them constantly during this period and must remain at their CAR-T centre until they are discharged back to the care of their referring team. This often adds to the emotional burden, particularly on patients who struggle to cope with the isolation.

> **“I’ve had to take a lot of annual leave for appointments. And both my teenage girls had to leave their part-time jobs, because I couldn’t physically get them to work, and take my mum to appointments, and get myself to work…**
> **It just kind of takes over your life.”**

CAREGIVER

Cost of ambulatory care accommodation

While some centres arrange accommodation for patients, others require patients to arrange and pay for it themselves, with reimbursement provided afterwards. Even though costs are eventually covered, the upfront spending and reimbursement process can still create financial strain.

> **“It’s a long time, sometimes, waiting for that money to come back into her account, and I knew that was a worry for her, that she maybe doesn’t share that kind of worry, she doesn’t like people knowing her finances.”**

CAREGIVER

Information provided following discharge

Patients and caregivers generally feel adequately prepared for discharge, receiving verbal and, in some cases, written guidance on diet, medication, exercise, and sleep. However, caregivers expressed a desire for more detailed information on monitoring and supporting patients during recovery. There also appears to be some variation between treatment centres in both how patients are prepared for discharge and what information is provided.

Conclusion and recommendations

CAR-T therapy has transformed treatment for certain advanced blood cancers, offering hope where other therapies have failed. It is still a relatively new type of therapy, with evolving evidence and opportunities to further improve patient access, long-term outcomes and experience of treatment.

Although participants of this study generally reported positive experiences of their treatment journey, as outlined in this report there are opportunities to further improve the patient experience. The priority areas where there is the greatest unmet need from a patient and carer perspective are around the provision of psychological, financial and peer support for both patients and their caregivers.

The recommendations outlined in this report present an opportunity to enhance the treatment journey for CAR-T patients and their caregivers, ensuring they are more supported, informed, and at the centre of care.

- Providing more **tailored information**, whether specific to younger patients, UK-based contexts, or peer experiences, will empower individuals to make informed decisions and feel more prepared.
- **Enhancing patient facilities** can help make the challenging CAR-T treatment process more manageable, offering comfort through improvements such as safe outdoor spaces, reliable WiFi, exercise equipment, air conditioning, and better-quality food.
- **Strengthening financial support** for patients and caregivers will ease the significant economic pressures that often arise when work must be reduced or stopped entirely.
- Finally, **expanding access to mental health support**, both during and after treatment, is essential to help patients and their families navigate the emotional and psychological challenges that accompany their journey.

With the number of patients treated with CAR-T expected to increase significantly in the coming years, it is vital that organisations and charities, such as Anthony Nolan, use these findings to advocate for change to enhance the experiences of care for future CAR-T patients and their caregivers, and ensure they have the support they need to survive and thrive.

Appendix: Methods

Ethical approval for this study was granted by the West Midlands Edgbaston Research Ethics Committee (Reference: 23/SC/0385). The study also received Health Research Authority (HRA) approval prior to commencement.

Participant recruitment

Twenty six CAR-T patients were recruited between May and December 2024 from four CAR-T treatment centres, namely: University Hospital Bristol and Weston NHS Foundation Trust, NHS Greater Glasgow and Clyde, University Hospitals Birmingham NHS Foundation Trust, and Cardiff and Vale University Health Board. At each site, a member of the medical team screened potential participants and invited eligible patients to participate in the study during telephone calls, face-to-face meetings and in emails. The contact details of patients were then passed on to the research team if they agreed to be contacted. Members of the research team provided participant information sheets and explained the purpose of the study to potential participants. Nine caregivers were recruited through the CAR-T patients who agreed to be interviewed for the study. Table 1 shows the enrolled patient characteristics.

Table 1. Patient characteristics (n = 26)

Variable	n (%)
Age (years)	
<50	6 (23%)
≥50	20 (77%)
Gender	
Female	13 (50%)
Male	13 (50%)
Ethnicity	
Minority ethnicities	3 (12%)
White	19 (73%)
Unknown	4 (15%)
Indication for CAR-T therapy	
Lymphoma	24 (92%)
Leukaemia	2 (8%)
Position of CAR-T in patients' treatment history	
2nd line	7 (27%)
3rd line	18 (69%)
5th line	1 (4%)
Time from CAR-T treatment to interview in 2024	
< 1 year*	7 (27%)
1 year	10 (38%)
2 years	7 (27%)
> 3 years	2 (8%)

Eligibility criteria

The patient participants interviewed were individuals previously diagnosed with blood cancer who received their CAR-T treatment via established NHS CAR-T services. Individuals who received CAR-T therapy via clinical trials were excluded. In addition, patient participants needed to be adults over 18 years old, at least one-month post-treatment, have the capacity to consent and the ability to speak/read English. Caregivers needed to be adults with the capacity to consent and the ability to speak/read English.

Data collection

This study was underpinned by phenomenological theory which explores individual lived experiences and perspectives.[14] Participants had the option of one-to-one semi-structured interviews or dyadic interviews (patient and an adult caregiver). Consent was obtained from participants prior to the interviews. The interviewers were healthcare researchers with qualitative experience based at the University of Birmingham. The interviews were conducted using the online video conferencing platform Zoom, or by telephone when preferred by the participant. The option of in-person interviews was given but not requested by any participant. All interviews were audio-recorded using the record function on Zoom and lasted up to 60 minutes. Semi-structured topic guides were used to ensure consistent coverage of key issues. They were developed with input from two patient partners who reviewed the initial drafts and provided feedback on relevance and scope.

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