
The CAR T-Cell Therapy Clinical Journey: A Guide for Patients and Carers

The Challenge

CAR-T cell therapy is an innovative new treatment with a highly complex patient journey. Patients eligible for a clinical trial with a CAR-T therapy will have already failed one or several courses of treatment, understandably heightening the emotions of the individual and their carers/family members. At this stage a large amount of information is then required to be presented and understood regarding CAR-T cell therapy in a short period of time. Not only does this present a challenge to the individual themselves, but also to the healthcare providers responsible for understanding and explaining each step of the complex treatment journey.

The Solution

To understand patients' and their carers' experience of this treatment, a CAR-T Cell Therapy Patient & Carers Advisory Board was organised by Autolus Therapeutics in 2019 for people who had previously received this therapy and their carers who had been intimately involved with the treatment journey. Workshops were held to share experiences and gather ideas for what would make the treatment journey easier. Feedback from the Board highlighted that information for both patients and their carers is scarce and was perceived as a significant gap by both parties. Autolus, in partnership with Northern Alliance Advance Therapies Treatment Centre, took these comments, as well as similar feedback from site staff from UK centres experienced in CAR-T delivery, to create a comprehensive and educational guide to help patients and carers through their journey as well as to inform those considering a CAR T-cell therapy clinical trial.

The results

The CAR T-Cell Therapy Clinical Trial Journey: A Guide for Patients and Carers, developed in hard copy and digital versions, was launched in September 2021. The Guide is intended for people who are considering either enrolling in, or are already enrolled in, a CAR T-cell therapy clinical trial. It provides patients and caregivers with support via education and advice throughout the whole treatment journey whilst also providing a teaching aid for clinical staff. This resource has bite-sized sections that helps readers assimilate the information at a level appropriate for their interest

Included within the guide in both written form and by illustration is:

Funded by

Coordinated by

- General information about CAR T-cell therapy clinical trials.
- An explanation of how CAR T-cell therapy works.
- What you can expect during each step of the treatment process, including long term post treatment (for both investigational and licenced products).
- Information about side effects.
- Information specifically for carers.
- Guidance on how and where to find emotional and financial support for the patient and caregiver.

The guide also provides more general information about the different phases of clinical trials.

This comprehensive educational resource can be accessed via
<https://www.theattcnetwork.co.uk/car-t-patient-guide>

Making further impact

Available online and as a physical copy, the guide will help the increasing numbers of CAR-T patients understand the treatment journey they will embark on if they chose to undertake that treatment option. In parallel, the guide will act as a training document for clinical staff delivering this treatment. Feedback has highlighted the impact which the guide is already making:

“Often clinical trials are daunting for patients, particularly when they involve new and innovative cellular therapies. This guide is an excellent resource that patients, and staff, can return to time and time again throughout the CAR-T journey to understand each step in the process from consent to infusion and beyond.”

Laura Rooney, Research Nurse Manager from NHS Greater Glasgow and Clyde

“There is a huge amount of information to take in at the start of the CAR-T treatment road and it can seem scary and overwhelming. I found this guide to be a huge help as it breaks each step down into clear sections which I could read at my leisure and it made understanding what was happening to me, and my cells, much easier for my family and I.”

James McCallum, CAR-T trial participant from Glasgow

In addition, Autolus Therapeutics designed this guide so it could be used as a template by other organisations looking to educate patients, healthcare professionals and such relevant parties about other advanced therapy medicinal products that present unique challenges in education. For example, gene therapies and tissue engineered products where there are numerous products in clinical development.

With thanks to contributing NA-ATTC partners, this work was led by Autolus.

Funded by



Coordinated by

