



CENTRE FOR COMMUNITY-DRIVEN RESEARCH

personal experience, expectations & knowledge

DECISION-MAKER BRIEF

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CAR-T treatable blood cancers

Brief for decision-makers considering treatments and services for people diagnosed with CAR-T treatable blood cancers

Purpose: When making decisions about the type of treatment and services people diagnosed with CAR-T treatable blood cancers can access, decision-makers need to understand the context in which their decisions are being made, what characterises the patient population, and ensure assumptions are not being made on behalf of this patient population.

This brief provides this context and information about the experience and expectations of people diagnosed with CAR-T treatable blood cancers, based on the knowledge of 37 people diagnosed with the condition as experts with lived experience.

Introduction: Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by the Centre for Community-Driven Research (CCDR). PEEK studies give us a clear picture of what it is like to be a patient at a given point in time. PEEK studies give us a way forward to support patients and their families with treatments, information and care. There are very few studies that report the personal experience, expectations, and knowledge of people with CAR-T treatable blood cancers. The data presented from the PEEK study in CAR-T treatable blood cancers is available at www.ccdr.org/2023aucrt

Background: Blood cancers accounted for approximately 12% of all cancers cases in Australia 2023. In 2019, 17,705 people were diagnosed with a blood cancer, a rate of 57.7 per 100,000¹. Blood cancer was diagnosed more often in men, with 9687 males diagnosed in 2019 compared to 7348 females¹. The most common type of blood cancer in Australia is non-Hodgkin lymphoma followed by multiple myeloma and chronic lymphocytic leukaemia¹, with those treatable with CAR-T therapy including B-cell acute lymphoblastic leukaemia (B-ALL), Diffuse Large B-Cell Lymphoma (DLBCL) and multiple myeloma.

Baseline health: The Short Form Health Survey 36 (SF36) measures baseline health, or the general health of an individual²². The SF36 comprises nine scales: physical functioning, role functioning/physical, role functioning/emotional, energy and fatigue, emotional well-being, social function, pain, general health, and health change from one year ago. The scale ranges from 0 to 100, a higher score denotes better health or function. SF36 General health scale measures perception of health. The overall scores for the cohort were in the middle quintile for SF36 Role functioning/physical (median=50.00, IQR=100.00), SF36 Energy/Fatigue (mean=52.50, SD=18.96), SF36 General health (mean=53.38, SD=24.70), indicating moderate physical role functioning, moderate energy, moderate general health.

Understanding of prognosis: Participants were asked in the structured interview to describe what their current understanding of their prognosis was. For those that did not consider themselves in remission, the most common understanding of their clinical outlook was that they had specific medical interventions they need to manage their condition (30.30%), that they were monitoring their condition until there is an exacerbation or progression (18.18%), that they would likely have a recurrence, or were in a cycle of recurrence (18.18%).

It catches up on you and you think you get a bit despondent if it's going the right direction it would give me hope and excitement and it'd be you know it may give you or may give me a reprieve from having it constantly in the back of your mind every minute of every day. You know you all cancer patients are the same and that you know we all get about laughing, get on with it. But it's just there in the back that you know that 1% or half percent in the back of your head. Be nice to be able to remove that one or half a percent in the back of your head....you know, it's tick, tick, tick, tick sort of thing, that's all. Participant 019_2023AUCRT

Decisions about treatment: Participants were asked in the structured interview what they considered when making decisions about treatment. The most common responses were advice of their clinician (45.45%), side effects (39.39%), and efficacy (24.24 %).

Goals of treatment: Participants were asked what their own personal goals of treatment or care were. The most common responses were to be cancer free, avoid recurrence, increase longevity (45.45%) and to have quality of life/return to normality (27.27%)

I think that probably. CAR-T should be offered before your half dead from chemo. I had to fail three courses of chemo to qualify for CAR-T and by the time I got to CAR-T. I was running very low on reserves.

Participant 009_2023AUCRT

Current understanding of condition: The Partners in health: total score measures the overall knowledge, coping and confidence for managing their own health. The overall scores for the cohort were in the highest quintile for Partners in health: Knowledge (median=30.00, IQR=4.00), Partners in health: Recognition and management of symptoms (median=22.00, IQR=5.50), Partners in health: Adherence to treatment (median=16.00, IQR=1.00), Partners in health: Total score (median=85.00, IQR=12.50) indicating very good knowledge, very good recognition and management of symptoms, very good adherence to treatment, very good overall ability to manage their health.

Care and support: The Care coordination: Quality of care global measure scale measures the participants overall rating of the quality of their care. The overall scores for the cohort were in the highest quintile for Care coordination: Quality of care global measure (median=9.00, IQR=2.00) indicating very good quality of care. In the structured interview, participants were asked what care and support they had received since their diagnosis. This question aims to investigate what services patients consider to be support and care services. The most common responses were that they found support and care from charities (45.45%) or the hospital or clinical setting (30.30%).

Leukemia Foundation would be the key one. I had some legal advice through the Cancer Council to sort out my will. The Cancer Council...Leukemia Foundation, were amazing. They provided accommodation for NAME and I, when we had to be in LOCATION, I would have backed out of my transplant because I got so scared without their counsellors. The counsellors were amazing and their ongoing social support post-transplant has been great. I came across your study through them. 016_2023AUCRT

Quality of life and vulnerability: In the structured interview, participants were asked whether they felt that their condition had affected their quality of life. Most commonly, the descriptions suggested that there was an overall negative impact on quality of life (57.58%), and a mix of positive and negative impact on quality of life (33.33%). In the structured interview, participants were asked if there had been times that they felt vulnerable. Participants reported that they felt vulnerable during/after treatments (36.36%), and experiencing side effects from treatment or symptoms from condition (15.15%).

Most of the time was undergoing for chemotherapy because it's just the unknown of what's going to be happening next week or the next month or how you're feeling. Because when you're if you're getting basically smashed by all these drugs so you don't know how quickly like if you have a cold, you can say oh we're going to recover in a week. But when you're having this chemo for three years, you go, well, how long is this going to affect me for? So it's just the unknown place that's the bit that you're frightened of. Well, not frightened, but you just wanna know more information than no one can really tell you. Participant 024_2023AUCRT

Message to decision-makers: Participants were asked, "If you were standing in front of the health minister, what would your message be in relation to your condition?" The most common messages to the health minister were that they were grateful for the healthcare system and the treatment that they received (30.30%), the need for more clinical trials and/or new treatments (27.27%), and to invest in research (including to find new treatments) (27.27%). Other themes included that treatments need to be affordable (21.21%).

As it started with that you know chemotherapy, they explained to me that they started with that baseline the very first, you know medication. Then they monitored, then I said okay, this one was not really effective. We are adding something stronger, then again something stronger and then they said they have exhausted all options and nothing it's working. So that's why they had to go away from therapy to CAR-T and even as I speak you know to you I, I have no, I have no words to express my gratitude that that did have a chance to have that treatment you know, literally to save my life and for long. So I'm just you know so grateful I know there is new treatment and so on and that that I have been you know qualified you know for this one...that's why I so willingly participate in absolutely every clinical trial for whenever I was approached I said yes, you know for we have to support that medical advancement and because I know how it was close call for me. Participant 034_2023AUCRT

References

1. Australian Institute of Health and Welfare. (2023). Cancer data in Australia. Retrieved from <https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia>.