

Section 12

Next steps

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At the end of each PEEK study, CCDR identifies three key areas that, if improved, would significantly increase the quality of life and/or the ability for individuals to better manage their own health.

In relation to this community, these three areas are:

Information

This is a cohort that accessed printed information from charities and from the hospital or clinic where they were being treated. They valued being able to talk to a healthcare professional as this gave them the opportunity to ask questions. It is important to this community to have up to date printed materials, relevant to their specific type of blood cancer. Question prompts in printed material may also be of value to increase conversations about all available treatments.

Managing side effects

This is a group where side effects were important in decision making, adherence, and minimising side effects was an important treatment goal. Side effects had a negative impact on quality of life, relationships and made people with blood cancer feel vulnerable. Support and information to help manage side effects and access to treatments with fewer side effects may have a positive impact on quality of life. This may be achieved by increased awareness and access to allied health professionals given this cohort, on average, accessed only one allied health service.

Impact on daily life

Participants in this study had to quit, reduce hours, or take leave from work. Carers and family took leave with and without pay. The loss of family income was an extremely significant burden. CAR-T treatable blood cancers are characterised by fatigue and exhaustion, with treatments taking up a significant amount of time for patients who may need to interrupt family life or stop work to accommodate this. This domain of a patient's life needs to be recognised and addressed through appropriate, practical support services.

2023 PEEK study in blood cancer

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2023 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 blood cancer 2021 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	68.68	72.50*
	Role functioning/physical	51.47	50.00*
	Role functioning/emotional	70.59	100.00*
	Energy/fatigue	52.50*	50.00
	Emotional well-being	76.24*	80.00
	Social functioning	73.90	75.00*
	Pain	69.56	72.50*
	General health	53.38*	55.00
	Health change	67.65	62.50*
Knowledge of condition and treatments (Partners in Health)	Knowledge	27.58	30.00*
	Coping	16.61*	18.00
	Recognition and management of symptoms	20.71	22.00*
	Adherence to treatment	15.16	16.00*
	Total score	80.06	85.00*
Care coordination scale	Communication	45.18*	47.00
	Navigation	27.09*	28.00
	Total score	72.27*	72.00
	Care coordination global measure	7.94	8.00*
	Quality of care global measure	8.85	9.00*
Fear of progression	Total Score	30.82	28.50*
		Percent	
Accessed My Health Record	-	51.52	-
Participants that had discussions about biomarkers/genetic tests	-	27.03	-

*Best measure of centrality