

Section 12

Next steps

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At the end of each PEEK study, CCDR identifies 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:

1. Information: Many participants were unaware of the different types of breast cancer. Sometimes information given was misinterpreted as good news e.g. 'Your cancer is not fed by hormones' was interpreted as good, and not understood that this resulted in different treatment options and a different prognosis. Likewise, all participants knew that they are triple negative, but not aware that these are biomarkers or in-depth understanding of the implications of biomarkers. To this end, it is recommended that at diagnosis, triple negative breast cancer-specific information be discussed (not just provided in writing) and this could be done for example by a nurse educator via telehealth.

2. Cost: This is a group that have an aggressive cancer and are often motivated to opt for private surgery to get it done quickly. Out of pocket expenses from private treatment costs are often unexpectedly high and over time are very costly. Initiatives to educate women on the cost of treatment and likely trajectory of ongoing care would help them to plan ahead, anticipate costs and be able to make more informed decisions.

3. Support: As this is a type of cancer that typically affects younger women, we have seen through the study the impact on ability to work and also, impact on families, particularly those who have young children. Initiatives to support women and families to live with as little interruption to their everyday lives would likely increase quality of life, particularly during treatment. Given the demographic, this may also include additional support to women that are pregnant when diagnosed.

2021 PEEK study in Triple negative breast 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 2021 metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1 Triple negative breast cancer 2021 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning	71.36	77.50
	Role functioning/physical	55.11	75.00
	Role functioning/emotional	77.27	100.00
	Energy/fatigue	41.93*	45.00
	Emotional well-being	70.91	74.00
	Social functioning	69.60	75.00
	Pain	63.92	67.50
	General health	51.93*	55.00
Knowledge of condition and treatments (Partners in Health)	Health change	51.14	50.00
	Knowledge	25.98*	26.50
	Coping	16.18*	16.00
	Recognition and management of symptoms	19.61	20.00
	Adherence to treatment	14.45	15.00
	Total score	76.23*	76.00
Care coordination scale	Communication	44.64*	45.00
	Navigation	26.55*	27.00
	Total score	71.18*	72.00
	Care coordination global measure	7.66	8.00
	Quality of care global measure	8.45	9.00
Fear of progression	Total Score	35.89*	36.00
		Percent	
Accessed My Health Record	-	43.18	-
Participants that had discussions about biomarkers/genetic tests	-	72.34	-