

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:

1. Information: with little community awareness, most of the participants did not have an understanding hepatitis D when diagnosed and its relationship with other forms of hepatitis. There is a need for community information, and for better information to give newly diagnosed. In addition, information needs to be easy to understand and available in multiple languages

2. Support: support services, including peer support that are specific to hepatitis D and to the variety of people it affects (demographically) are needed.

3. Care coordination: there is a need for better access and coordination of healthcare services, better access to supportive GP, specialist nurses, allied health (This group had poor care coordination, low access to specialist nurses, low access to specialists, low access to allied health yet high levels of depression, anxiety and other comorbidities, and their physical health interfered with work and daily activities).

2023 PEEK study in hepatitis D

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 Hepatitis D 2023 Metrics

Measure	Detail	Mean	Median
Baseline health (SF36)	Physical functioning*	68.93	72.50
	Role functioning/physical	46.43	37.50
	Role functioning/emotional*	52.38	66.67
	Energy/Fatigue*	46.07	50.00
	Emotional well-being*	63.43	62.00
	Social functioning*	58.93	68.75
	Pain*	70.18	72.50
	General health*	52.50	55.00
Knowledge of condition and treatments (Partners in Health)	Health change	60.71	50.00
	Knowledge*	22.62	26.00
	Coping*	17.08	17.00
	Recognition and management of symptoms*	18.23	19.00
	Adherence to treatment*	10.85	11.00
Care coordination scale	Total score*	68.77	67.00
	Communication*	37.69	38.00
	Navigation*	24.23	24.00
	Total score*	61.92	65.00
	Care coordination global measure*	6.23	6.00
Fear of progression *	Quality of care global measure*	6.00	6.00
	Total Score	33.15	34.00
		Percent	
Participants that had discussions about biomarkers/genetic tests	-	42.85	-