

Section 12 Next steps

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At the end of each PEEK study, CCDD 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 the AD community, these three areas are:

- Treatments that offer a more holistic approach, that are safe and are not detrimental to long-term health.
- Interventions to address the psychological impact of AD, including patients experiencing embarrassment due to their appearance, reduction in social interaction and increased alienation from society.
- Initiatives that encourage coordinated and multidisciplinary care, including more follow-up and care planning to empower patients to proactively manage their condition.

2017 CHF Metrics

Data collected in this PEEK study also provides a basis on which future interventions and public health initiatives can be based. Some of the 2018 AD metrics that the sector can work together to improve upon are provided in Table 12.1

Table 12.1: AD 2018 Metrics

Area of evaluation	2018 data	
Baseline health	Mean	Median
Physical functioning	83.70	95.00
Role limitations due to physical health	64.00	100.00
Role limitations due to emotional problems	62.00	66.70
Energy/fatigue	42.00*	40.00
Emotional well-being	65.36	68.00
Social functioning	65.38	62.50
Pain	64.18	67.50
General health	64.18	60.00
Health change	58.40	50.00
Percentage of participants that have accessed My Health Record	16.00%	
Percentage of participants that have heard of AD at diagnosis	55.00%	
Percentage of participants that have a discussion about biomarkers/genetic tests	4.00%	
Percentage of participants where a clinical trial is discussed	5.00%	
Knowledge of condition and treatments (Partners in Health)	Mean	Median
Knowledge	24.42	25.00
Adherence to treatment	12.62*	14.00
Management of symptoms	19.49*	20.00
Coping	16.96	17.00
Total score	73.49	76.00
Care Coordination and care received	Mean	Median
Care coordination (sub-score)	64.06*	65.50
Communication	38.06*	39.00
Navigation	26.00	26.00
Care received	5.21	5.00
Total score	5.89	6.00
Fear of progression	Mean	Median
Total Score		28.00

*Normal distribution, use mean as measure of central tendency