

Theme 4

Patient reported outcomes

A patient's view of their health status.

Patient reported outcomes are measures that ask patients about the limitations they experience as a result of their condition. Their answers are recorded without anyone else's interpretation. PROMs give patients a voice that is heard, quantified and compared to normative data in a large variety of domains such as physical function, pain, depression, anxiety and fatigue¹⁶.

Patients on chronic dialysis

The Short Form-36 Health Related Quality of Life survey (SF-36 HRQoL) is a PROM used to assess the physical, psychological and social functioning of chronic dialysis patients. The physical component measures the extent to which their health limits physical activities such as self-care, walking, and moderate and vigorous activities. The mental component measures depression, behavioural/emotional control, anxiety and feelings of belonging¹⁷.

National Renal Care outcomes

National Renal Care's results deteriorated slightly in 2019 but remain above the DOPPS benchmark¹⁸ for the physical component and on par with the benchmark for the mental component. In response, National Renal Care is conducting a 'what matters most to you' campaign, which will inform improvement strategies, and continues to explore new PROM methodologies to co-create a person-centred participative dialysis environment.

Chronic dialysis patient reported outcomes (higher score is better)	DOPPS	2019	2018
Physical component summary (% patients in the DOPPS recommended range)	51.5%	66.7%	67.9%
Mental component summary (% patients in the DOPPS recommended range)	89.7%	87.2%	88.2%

Measure definition: the percentage of patients who are in the DOPPS recommended range for the mental and physical composite scores calculated from the SF-36 HRQoL PROM.

16. Source: Baumhauer, J.F. et al. (2016). Value-based Healthcare: Patient-reported Outcomes in Clinical Decision Making. *Clinical Orthopaedics & Related Research*, 474(6), 1375-1378.

17. Source: Hays et al., 1995; Lopes et al., 2007; Nissenon and Fine, 2008; Fructuoso et al., 2011.

18. Website: www.dopps.org

Patients with mental disorders

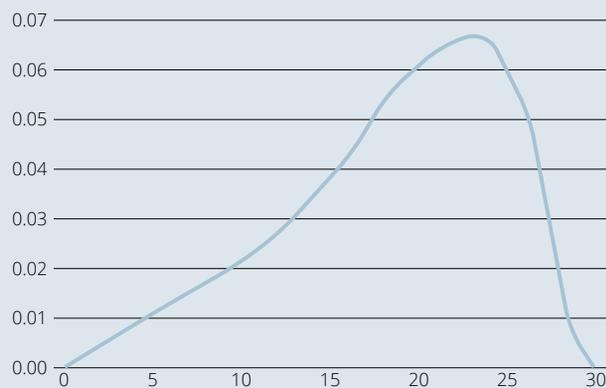
The majority of patients admitted to an Akeso Clinic suffer from some form of depressive mood disorder or condition. PROM questionnaires are completed on admission and discharge, and include:

- The Patient Health Questionnaire¹⁹ (PHQ-9) to measure the severity of depression.
- The DSM-5²⁰ Self-Rated Level 1 Cross-Cutting Symptom Measure²¹ to measure a patient's symptom burden.
- The WHO Disability Assessment Scale 2.0²² to measure the level of disability.

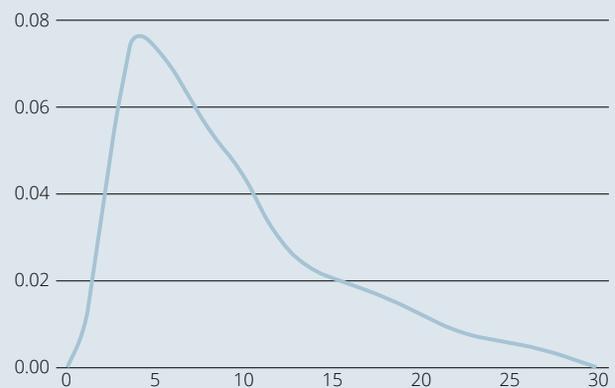
Akeso Clinics outcomes

The graphs below plot the distribution of the PHQ-9 score for 7 455 patients on their admission and discharge, with higher scores on the horizontal axes showing more severe depression. The graph on the right shows a marked shift to the left (or lower scores) for patients at discharge, indicating a significant improvement in the severity of their depression.

Admission



Discharge



Patients are admitted to Akeso Clinics because of the severity of their symptoms (symptom burden) and the impact of their mental illness on their level of functioning in their day-to-day lives (level of disability). Patient reported outcome measures (PROMs) are used to give these patients a voice that quantifies their symptom burden and level of disability and can be used by patient and clinician to track change over time. PROMs are completed on admission to quantify the severity of their symptoms and disability and are repeated on discharge to assess their progress towards recovery. Using the American Psychiatric Association publication guidelines, the table below shows the significance of the clinical improvement achieved and sustained by Akeso Clinics, namely reducing patient symptom severity and increasing level of functioning from admission to discharge.

Akeso Clinics admitted patient reported outcomes (higher score is better)	Large improvement threshold ²³	2019	2018
Symptom burden (A_w effect size)	0.71	0.875	0.867
Level of disability (A_w effect size)	0.71	0.737	0.724

Measure definition: the non-parametric common language estimator (A_w) for effect size²⁴ and Cliff's Confidence Intervals²⁵. An A_w effect size of greater than 0.71²⁶ indicates a large improvement.

19. Website: http://www.cqaimh.org/pdf/tool_phq9.pdf.

20. Source: American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. <https://doi.org/10.1176/appi.books.9780890425596>.

21. Website: <https://www.psychiatry.org/psychiatrists/practice/dsm/educational-resources/assessment-measures>.

22. Website: <https://www.who.int/classifications/icf/whodasii/en/index3.html>.

23. Source: Li, J. C. H. (2016). Effect size measures in a two-independent-samples case with nonnormal and nonhomogeneous data. *Behavioural Research Methods*, 48(4), 1560–1574.

24. Source: Li, J. C. H. (2016). Effect size measures in a two-independent-samples case with nonnormal and nonhomogeneous data. *Behavioural Research Methods*, 48(4), 1560–1574.

25. Source: American Psychiatric Association (2010). *Publication Manual of the American Psychological Association (6th ed.)*. Washington, DC.

26. Source: Li, J. C. H. (2016). Effect size measures in a two-independent-samples case with nonnormal and nonhomogeneous data. *Behavioural Research Methods*, 48(4), 1560–1574.