

What PROMs Reveal About Life on Dialysis

September 2025

For Malaysians living with end-stage kidney disease (ESKD), haemodialysis is often a lifeline. But while it replaces kidney function, the treatment itself is demanding and life-altering, affecting not only health but also day-to-day living. To better understand these experiences, the NKF undertook one of its largest patient-reported outcome measures (PROMs) surveys to date.

The Study at a Glance



As part of NKF's 2024 Annual Patient Review, **1,562 haemodialysis patients** across 29 NKF dialysis centres (including Sabah and Sarawak) completed the **SF-12 Health Survey Questionnaire**. The tool measures two components:

- **Physical health** (muscle strength, mobility, energy, and comfort)
- **Mental health** (emotional wellbeing, resilience, and coping ability)

Patients with cognitive impairment, those hospitalised, or too unwell to participate were excluded. The response rate was an impressive **89.5%**, ensuring the results provided a strong reflection of NKF's dialysis community.

Key Findings

Demographics

- 57% of participants were aged 60 and above
- 54% were male
- 60% were married
- 80% had independent functional status
- Mean dialysis duration was 73 months (about six years)

Physical Health

- **79% scored below 50** on the physical health index, showing reduced physical capacity.
- Many reported frailty, muscle wastage, and comorbidities such as diabetes and cardiovascular conditions.

Mental Health

- Only **18% scored below 42**, suggesting that most patients maintained relatively stable mental wellbeing despite the challenges of dialysis.
- Centres showed variation, with some reporting higher resilience and others highlighting areas of concern.

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Centre Variations

- The lowest mean physical score was **7 (NKF Permas Jaya, Johor)**, while the highest was **66 (NKF Kuching, Sarawak)**.
- For mental health, scores ranged from a low of **10 (NKF Kuching, Sarawak)** to a high of **77 (NKF Kulim, Kedah)**.

These results confirm that patients' experiences vary not only by health status but also across dialysis centres.

More Than Numbers: Patients' Daily Realities

Haemodialysis patients often experience fatigue, cramps, itching, thirst, and limited mobility. Alongside physical burdens, there are psychosocial struggles such as social isolation, hopelessness, and emotional sensitivity. Yet, the survey showed that many patients continue to cope well mentally, highlighting their resilience in the face of daily challenges.

By listening to patients' voices, we can tailor care that supports not just their treatment, but their dignity and quality of life

Why PROMs Matter

PROMs provide healthcare teams with a **direct line into patients' lived experiences**. They can inform individualised rehabilitation programmes, identify patients who need more physical or psychosocial support, and guide policy to raise the standard of dialysis care across Malaysia.

Moving Forward

This nationwide PROMs survey underscores the importance of a **patient-centred approach**. For NKF, it reaffirms that dialysis care is not only about keeping patients alive — it is about ensuring they live well.

Because when patients are heard, their care becomes truly holistic.

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PATIENT REPORTED OUTCOME MEASURES WITH END STAGE KIDNEY DISEASE PATIENTS UNDERGOING HAEMODIALYSIS IN THE NATIONAL KIDNEY FOUNDATION MALAYSIA

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ABSTRACT

Introduction:

Haemodialysis is one of the kidney replacement therapies for end-stage kidney disease, to replace kidney function. The experiences of haemodialysis patients and the quality of care are pertinent not only to the patients but to the National Kidney Foundation of Malaysia (NKF).

Objective:

We examined the patient-reported outcome measures (PROMs) of the patients undergoing haemodialysis in NKF Malaysia.

METHODS

Setting:

As part of the Annual Patient Review by the NKF Welfare Department, all patients were routinely screened on PROMs.

SF-12v2 was used with 1,562 patients from the 29 NKF Haemodialysis Centres in 2024 cohorts in NKF Malaysia, including in Sabah and Sarawak, except in Malacca and Negeri Sembilan where NKF does not have a dialysis centre.

Design:

A cross-sectional, multicenter annual routine screening conducted by the NKF Welfare Department for all patients undergoing dialysis at NKF Dialysis Centers.

Subjects:

Total 1,562 haemodialysis patient across all NKF HD Centres from the National Kidney Foundation of Malaysia. The total response rate was 89.5%.

Screening Criteria:

All patients are eligible except those with cognitive impairment, hospitalised, ill, or who refused to participate were excluded.

Screening Tool:

The SF-12v2 Health Survey Questionnaire was used in this survey to measure the physical and mental health components. A higher score indicates better self-reported physical and mental health status by the patient. The SF-12v2 validity and reliability have been well established.

Statistical Analysis:

Statistical analysis was performed using SPSS, applying both univariate and bivariate analyses.

RESULTS

There was a distinct difference in physical health scores <50, cut-off score, among patients and different dialysis centres in NKF Malaysia. On an individual level, it ranged from a low mean score of 7 in NKF Permas Jaya, Johor, to a high mean score of 66 in NKF Kuching, Sarawak. For the dialysis centres, NKF Kepong has 100% of patients <50 mean score in physical health vs NKF Kulim, Kedah, with 44%, signifying poor physical health status.

Similarly, mental health scores <42, cut-off point, ranged from a low of 10 at NKF Kuching, Sarawak, to a high of 77 at NKF Kulim, Kedah. The NKF Centre with the highest percentage of a <42 mental health score was NKF Petaling Jaya with 77% and the lowest was NKF Kangar, Perlis with 0%.

The results showed there was a mix of patients with poor and good physical and mental health among the dialysis patients in NKF Malaysia.

Table 1. Summary of Patient-Reported Outcome Measure 2024 at 29 NKF Dialysis Centres

NKF Dialysis Centres in 2024	n	SF12v2 - Physical Component Summary Score					SF12v2 - Mental Component Summary Score				
		Mean	±SD	Min	Max	Range	Mean	±SD	Min	Max	Range
YTSP, Kangar	32	44	11	18	58	40	56	59	6	44	72
Lions, Alor Setar	37	44	6	33	59	26	84	47	7	33	63
Superkids Trinity	33	43	9	18	58	41	79	49	6	39	63
Kulim	50	46	13	15	59	44	44	62	7	43	77
FOY11	49	38	11	15	55	40	88	53	9	28	65
FOY12	59	41	10	19	55	36	80	51	8	33	66
Ipo	64	43	6	30	56	26	83	50	10	22	67
Taiping	48	39	9	22	55	33	85	51	7	33	65
Setapak	33	33	11	16	58	42	94	45	8	26	60
Charis	93	43	7	28	60	31	83	52	10	15	67
Kepong	65	30	6	15	39	24	100	49	6	35	61
Good Health	59	41	7	28	59	31	71	46	7	30	62
Calvary	20	38	10	24	57	33	90	52	10	36	65
Petaling Jaya	64	30	9	13	50	36	98	42	8	27	62
Selayang	64	44	13	14	57	43	55	62	4	45	69
Bakti, Klang	46	46	11	19	57	38	48	63	10	15	75
Kelab Apex, Klang	49	40	11	11	57	46	80	47	13	16	67
Chempaka	24	40	6	30	51	20	96	49	9	32	68
CLK, Klang	104	35	11	11	55	44	80	50	9	32	70
Permas Jaya, JB	53	35	12	7	55	48	85	53	12	19	71
Kota Bharu	61	46	8	28	62	34	61	52	11	15	65
Kota Sarawak	63	36	9	14	54	39	86	54	11	15	69
Kemaman	48	40	10	19	58	39	85	54	7	38	71
Kuantan	32	37	10	18	54	36	91	56	7	43	67
Sang Riang	57	35	10	12	53	41	95	55	9	35	72
Kuching	102	44	10	10	66	55	75	52	10	10	73
Kota Samarahan	54	42	11	14	55	41	70	52	10	27	69
Santien	33	48	8	23	57	34	48	52	8	28	64
MUIS, KK	66	40	12	15	60	45	76	51	10	32	70
Total / mean score / %	1562	39.9	10.7	7	66	59	79%	52.0	10.1	10	77

PCS, (F2-38) = 12.7, p=0.001; MCS, (F2-38) = 15.8, p=0.001

Haemodialysis treatment itself is extremely demanding and potentially restrictive, and requires lifestyle changes (Mohd Shahrin, Omar, Mat Daud, & Zakaria, 2019). Patients undergoing Haemodialysis are exposed to multiple challenges and stressors that may impact their PROMs even though Haemodialysis is one of the factors for the patients to improve their health-related quality of life. For example, patients experience physical discomforts such as immobility, pain, cramps, fatigue, itching, thirst, and psycho-spiritual discomforts such as hopelessness, sensitivity, and social isolation (Freire, S. de M., et al., 2020).

CONCLUSIONS

Most patients with poor physical health were frail, encountered muscle wastage, and had co-morbidities limiting physical functioning. Similarly, most patients had stable mental health and coped with their experiences on haemodialysis. The patients' assessment and experiences of PROMs may change. However, it is still beneficial to guide an individualised approach to haemodialysis rehabilitation with the results and formulate a policy to improve the quality standard of care and well-being.

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