

MUC2025-011 Dialysis Facility Discussion of Patient Life Goals Testing Update

Overview

To expand upon the patient level testing results provided in the original submission for MUC2025-011, UM-KECC conducted primary data collection to support facility level testing of the Discussion of Patient Life Goals Survey (D-PaLS). Survey data collection occurred in two phases beginning early February 2025. The survey is available in both English and Spanish.

For phase 1, UM worked directly with US Renal/Satellite Health which had agreed to have their dialysis unit staff distribute a flyer to patients at 369 of their facilities. The flyer included information about the study and a survey link/QR code for patients to complete the survey online through the secure REDCap portal. Patients were also provided with a phone number to request a paper survey or to complete the survey over the telephone with a trained UM-KECC staff member. Our goal for this phase of recruitment was to minimize facility burden while still reaching eligible patients.

Due to very low response rates and 70% of facilities not handing out recruitment information (phase 1), we developed a phase 2 plan which involved UM-KECC mailing surveys directly to patients at a subset of facilities from the phase 1 sample. In addition to increasing the response rate, use of these two modes provides initial information on implementation methods and potential barriers.

This document includes a summary of the preliminary patient and facility level analyses to date.

Summary of Preliminary Results

As of August 18, 2025 1,070 responses were received from both phase 1 and phase 2 recruitment efforts. After applying eligibility criteria and matching patients, there were 885 surveys eligible for analyses (Table 1). Among all 885 eligible responses, 247 were collected via REDCap; 2 via phone, and 636 via mail.

Table 1. Patient exclusions

Exclusion	Count
Age (%)	45 (21%)
Not on dialysis (%)	71 (34%)
No questions answered (%)	76 (41%)
Total	185

Note: Counts may not sum to the total since patients may be excluded for multiple reasons.

After omitting the 717 surveys that were returned to sender and never reached the potential respondent, 10,623 surveys were treated as the denominator for calculating the response rate, which was 8%. Three of the 109 facilities had response rates of 30% to 43%, and 6 had response rates between 20% and 26%. All other facilities had response rates under 20%. Most facilities had between 6 and 10 eligible responses (Table 2). Response rates by each participating facility in phase 2 are provided in Table 9 in Appendix 1.

Table 2. Facility distribution of responses (after exclusions)

Number of responses	Count (%)
1	2 (2%)
2-5	30 (28%)
6-10	48 (44%)
>10	29 (27%)
Total facilities with at least one eligible respondent	109

Overall, the average respondent age was 68 years; 58% were male; 82% were on in-center hemodialysis, and 22% were dual eligible. Full demographic results are in Table 3.

Table 3. Demographic Data for D-PaLS Study Participants

Variable	Count (N=880*)
Age (y)	
Mean (SD)	68 (16)
Sex (%)	
Female	372 (42%)
Male	508 (58%)
Ethnicity (%)	
Not Hispanic	651 (74%)
Hispanic	213 (24%)
Unknown	16 (2%)
Race (%)	
White	560 (64%)
Native Hawaiian or Pacific Islander	17 (2%)
Black or African American	163 (19%)
Asian	98 (11%)
American Indian/Alaska Native	33 (4%)
Multiracial	4 (0%)
Other/Unknown	5 (1%)
Education (%)	
Some high school	88 (10%)
High school graduate or equivalent	254 (29%)
Some college	282 (32%)

Variable	Count (N=880*)
College degree	126 (14%)
Master's degree or higher	75 (9%)
Do not wish to report	55 (6%)
Dialysis modality (%)	
In-center hemodialysis	719 (82%)
Peritoneal dialysis	140 (16%)
Home hemodialysis	21 (2%)
Dual Eligibility (%)	
Not Dual Eligible	690 (78%)
Dual Eligible	190 (22%)

Note: Entries in the Table represent N (%) of participants unless otherwise specified. Some percentages may not total to 100% because of rounding.

*N represents the number of patients for which matching allowed for identification of demographic characteristics.

Among all eligible surveys, over 60% of eligible respondents either agreed or strongly agreed with statements made about their life goals for Item 2a-2c (Table 4). For the questions related to the consistency of discussing life goals with the care team in items 3a-3c, 43%-61% of eligible respondents responded with “Usually” or “Always”. For Item 4, several different provider-types were represented as having talked with the patient about life goals; social workers, kidney doctors, and nurses were the most commonly endorsed providers for these types of discussion.

Table 4. Summary of D-PaLS Survey Responses for Items 2, 3, and 4**Item 2: (Total N=885)**

	Strongly Disagree	Disagree	Neither Disagree/Agree	Agree	Strongly Agree
a. At least one member of my care team knows about my life goals. (N=874)	92 (11%)	99 (11%)	147 (17%)	321 (37%)	215 (25%)
b. I believe it is important at least one member of my care team talks with me about my life goals. (N=876)	55 (6%)	66 (8%)	150 (17%)	364 (42%)	241 (28%)
c. My treatment plan is consistent with my life goals. (N=864)	45 (5%)	67 (8%)	157 (18%)	389 (45%)	206 (24%)

Item 3: (Total N=885)

	Never	Rarely	Sometimes	Usually	Always
a. At least one member of my care team talks with me about my life goals. (N=879)	141 (16%)	133 (15%)	227 (26%)	192 (22%)	186 (21%)
b. I feel comfortable discussing changes in my life goals with at least one member of my care team. (N=876)	70 (8%)	90 (10%)	184 (21%)	228 (26%)	304 (35%)
c. At least one member of my care team helps me meet my life goals. (N=870)	155 (18%)	104 (12%)	168 (19%)	193 (22%)	250 (29%)

Note: Entries in the Table represent N (%) of participants. Some percentages for items 2 and 3 may not total to 100% because of rounding.

Item 4: My _____ has talked with me about my life goals (Check all that apply below) (Total N=870)

Care Team Member	Count
Nurse	394 (45%)
Kidney doctor	409 (46%)
Social worker	454 (51%)
Patient care technician	244 (28%)
Dietician	330 (37%)
No one on my care team	146 (17%)
Other	56 (6%)

Internal consistency reliability, t-score distributions and known-groups validity

We analyzed internal consistency reliability of the Likert based score; examined t-score distributions at the patient level and facility level; and known-groups validity comparing t-scores between in-center hemodialysis and home dialysis modalities.

Internal consistency reliability of the patient level data was very strong (Cronbach's alpha criterion of >0.70 , D-PaLS Cronbach's alpha = 0.89), and even slightly higher than what was observed with the development and validation samples. There was no evidence of floor or ceiling effects for the measure values for items 2a-2c and 3a-3c ($<1\%$ at the floor; 11% at the ceiling) (Table 5). These results provide further support for instrument reliability of the D-PaLS.

Table 5. Internal consistency reliability for D-PaLS Survey Responses

N	Internal consistency reliability	Raw score: M (SD)	% at Floor	% at Ceiling
834	0.89	21 (6)	0.90	11

Note: Abbreviations: M, mean; SD, standard deviation. N is restricted to participants that answered all 6 core items. Floor and ceiling represent the percentage of participants with the lowest and highest possible scores, respectively.

The average t-score across all patients was 50 (SD=10) (Table 6) which is very similar to the mean t-score for the prior development and validation samples from 2020 and 2022 indicating strong stability in the distribution of scores over repeated samples.

Table 6. Patient-level t-score distribution (deciles)

	All	Min	D1	D2	D3	D4	D5	D6	D7	D8	D9	D10	Max
Mean T-score	50	25	34	40	43	46	49	51	53	57	61	66	77
N	885	6	88	89	88	89	88	89	88	89	72	105	1

At the facility level the mean t-score ranged from a mean of 25 to 62, indicating as expected there is some variation in facility level t-scores across facilities, (M=50, SD=5) (Table 7).

Table 7. Facility-level mean t-score distribution (quintiles)

	Overall	Min	Q1	Q2	Q3	Q4	Q5	Max
Mean T-score	50	25	44	48	50	52	56	62
N	109	1	21	22	22	22	22	1

Known-groups validity was investigated in this testing sample and, as expected, patients on a home dialysis modality report greater life goals satisfaction than those on in-center dialysis, whereby patients on a home dialysis modality had higher (better) t-scores (M= 54, SD=8) compared to patients on in-

center hemodialysis (M=49, SD=10) (Table 8). This supports known-groups validity for this clinical factor. These results are also consistent with the results from the earlier patient level testing with the development and validation samples.

Table 8. Known-groups validity

Peritoneal and home hemodialysis patients (n=161)		In-center hemodialysis patients (n=725)		t	p
T-score: M (SD)	% of participants satisfied with discussion of life goals	T-score: M (SD)	% of participants satisfied with discussion of life goals		
54 (8)	96	49 (10)	81	6.7	<.0001

Note: Abbreviations: M, mean; SD, standard deviation. Participants satisfied with discussion of life goals defined as those with a t-score of >40.

Conclusion

Our overall facility level response rate for phase 1 and phase 2 was 8%. As shown in table 9 in appendix 1, no facility had a sufficient number of surveys to support reliability and validity testing of the facility level performance score. Based on the patient and facility level data collected to date we were able to perform internal consistency reliability and known groups validity on the patient level data. The results were strong and consistent with the prior results from the development and validation samples. We examined t-score distributions at both the patient level and facility level and observed a range of t-scores across observations at both levels of analysis, including a number of patient and facility level t-scores below 40 indicating some patients are reporting that discussion of life goals is unsatisfactory.

UM-KECC 's attempt to obtain facility level data for the D-PaLS Survey encountered several unexpected barriers. These included issues with motivation for both the patients and for facilities. We also identified concerns about the accuracy of patient residence addresses in the available data sources; this is also a concern for future mailing campaigns. In addition, phase 1 dialysis organizations engagement was extremely limited with only one of the national dialysis corporations agreeing to distribute survey recruitment information. Even in this single instance, only 30% of their facilities even distributed the recruitment flyer; 70% of their facilities did not participate. As a result, UM-KECC had to revise the recruitment plan, instead focusing on a direct-to-patient strategy. The response to this strategy was also inadequate; response rates were very low and did not support meaningful facility level analyses. However, the results did replicate previously reported patient-level results obtained from the two previous surveys (2020 and 2022).

Although there is much enthusiasm for the PaLS survey in the dialysis community, that enthusiasm has not translated to enthusiasm from the large corporate dialysis providers nor has it translated to the patients that were the focus of our direct-to-patient recruitment efforts.

Future attempts at implementing this survey for facility-level testing must consider the dialysis community's reluctance to support external primary data collection for development and testing and

therefore focus on strategies to incentivize facility participation. The apparent reluctance of dialysis organizations to support patient reported survey data is not limited to PaLS. As an example, despite use of third-party survey organizations and significant effort to educate and encourage patient participation, response rates for the mandated ICH-CAHPS survey have been historically low and declined in recent years, dropping to the high 20% range. In addition, there was a relatively high percentage of unusable addresses resulting in return to sender failures. Future work is needed to identify a more accurate source for these mailings in order to support more complete data collection.

UM-KECC will continue to enter data as surveys are returned and will update analyses as needed.

Appendix 1

Table 9. Facility-level response rates

CCN	# of Patient Surveys Received	# of Active Patients	State	Response Rate
322550	1	51	NM	2%
122521	9	365	HI	2%
672740	3	102	TX	3%
552714	4	131	CA	3%
742510	4	102	TX	4%
672856	5	124	TX	4%
452895	2	49	TX	4%
022509	6	144	AK	4%
442665	2	47	TN	4%
742580	4	92	TX	4%
452788	5	111	TX	5%
552652	6	128	CA	5%
552555	2	42	CA	5%
552575	7	146	CA	5%
332633	10	199	NY	5%
552629	7	139	CA	5%
452840	3	58	TX	5%
452890	8	152	TX	5%
672502	8	144	TX	6%
672557	3	54	TX	6%
052630	14	242	CA	6%
032596	6	100	AZ	6%
052888	10	166	CA	6%
112524	11	180	GA	6%
052887	4	65	CA	6%
672705	8	129	TX	6%
052629	10	159	CA	6%
452820	14	220	TX	6%
052531	8	125	CA	6%
672577	3	46	TX	7%
672589	10	153	TX	7%
552704	11	160	CA	7%
342591	9	129	NC	7%
052819	13	186	CA	7%
742549	8	114	TX	7%
262645	6	84	MO	7%
382511	7	97	OR	7%
422673	7	97	SC	7%

CCN	# of Patient Surveys Received	# of Active Patients	State	Response Rate
112754	7	95	GA	7%
142787	2	27	IL	7%
742586	6	81	TX	7%
052572	16	215	CA	7%
552752	4	53	CA	8%
052600	9	118	CA	8%
552739	11	144	CA	8%
022506	12	157	AK	8%
052514	12	155	CA	8%
332687	5	63	NY	8%
362782	4	50	OH	8%
552730	8	100	CA	8%
322535	9	112	NM	8%
322534	15	186	NM	8%
552600	6	74	CA	8%
142834	7	86	IL	8%
042564	12	146	AR	8%
072532	7	83	CT	8%
552653	14	165	CA	8%
672700	4	47	TX	9%
672510	8	92	TX	9%
122509	29	331	HI	9%
362654	5	57	OH	9%
392707	7	79	PA	9%
452799	14	157	TX	9%
742581	8	89	TX	9%
052751	16	177	CA	9%
452797	11	121	TX	9%
112708	8	87	GA	9%
452896	12	128	TX	9%
552550	7	73	CA	10%
552827	10	104	CA	10%
672656	10	103	TX	10%
552754	18	183	CA	10%
312665	8	81	NJ	10%
362798	6	60	OH	10%
052891	9	89	CA	10%
152635	8	79	IN	10%
742574	13	128	TX	10%
222589	10	96	MA	10%
112700	11	105	GA	10%
362641	7	66	OH	11%

CCN	# of Patient Surveys Received	# of Active Patients	State	Response Rate
052609	8	75	CA	11%
552863	8	75	CA	11%
442730	19	178	TN	11%
422541	14	131	SC	11%
052647	14	129	CA	11%
112707	8	72	GA	11%
122534	8	70	HI	11%
422646	12	105	SC	11%
102596	14	118	FL	12%
232740	12	101	MI	12%
262621	6	48	MO	13%
442764	5	40	TN	13%
392829	6	47	PA	13%
232309	5	35	MI	14%
082524	7	43	DE	16%
552560	8	48	CA	17%
672718	14	80	TX	18%
243540	2	11	MN	18%
552720	18	97	CA	19%
742577	12	62	TX	19%
742534	10	51	TX	20%
552725	7	34	CA	21%
362893	6	29	OH	21%
152595	13	58	IN	22%
152673	14	58	IN	24%
322559	19	72	NM	26%
232671	19	62	MI	31%
243541	5	14	MN	36%
353506	10	23	ND	43%